# CANCER PEDIA

INTEGRATION

# INTEGRATING HOSPITAL AND COMMUNITY

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# INTEGRATING HOSPITAL AND COMMUNITY CARE

## A. INTRODUCTION

According to the World Health Organization, good health services are an essential building block to improve health outcomes.[1] Health services may include a variety of providers, organizations and community programs that address the whole spectrum of cancer control, including prevention, screening, diagnosis, treatment, recovery/survivorship and end-of life care supported by primary, psychosocial and palliative care. Without the integration of providers, organizations and community services, the patient and family may experience fragmented care, poor access, the potential for poor outcomes, risks to safety and significant health system inefficiencies. Integration is, therefore, essential to providing safe, high-quality, accessible patient- and family-centred care.

Integration is not a single definitional term. The World Health Organization has identified a variety of perspectives on integration, as outlined in Table 1.[2]

Table 1: Perspectives on Integration

| Group | Perspective |
|---|---|
| Users (patients/clients) | Healthcare is seamless, smooth, easy to navigate and offers continuity of care across providers and facilities over time |
| Providers | Separate technical services are provided, managed, financed and evaluated together or in a co-ordinated way |
| Senior managers / policy-makers | Decisions on policies, financing, regulation or delivery are not inappropriately compartmentalized |
| Organizations | Mergers, contracts or strategic alliances exist between different institutions |
| Professionals | Different health professions or specialties truly work together to provide services |

Shaw et al. also delineated types of integration, each of which has a role to play in supporting an integrated care system.[3]

- **Systemic integration**: co-ordinating and aligning policies, rules and regulatory frameworks
- **Normative integration**: developing a shared vision, culture and values across organizations, professional groups and individuals
- **Organizational integration**: co-ordinating structures (e.g., contracts, co-operative arrangements), governance systems and relationships across organizations
- **Administrative integration**: aligning back-office functions, budgets and financial systems across integrating units
- **Clinical integration**: co-ordinating information and services, and integrating patient care within a single process

Integration is only possible when professionals and organizations – or "providers" – work together to provide care with the appropriate tools and resources. This chapter discusses the co-ordination of cancer services provided by a cancer centre and other essential parts of the healthcare system, with attention to the user perspective.

## B. INTEGRATED HEALTH SERVICES SYSTEM

An integrated health services system must include a comprehensive scope of clinical and health-related services that work together to provide a patient with timely access to co-ordinated and high-quality care, as depicted in Figure 1.[4]

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Figure 1: Integrated Health Services System
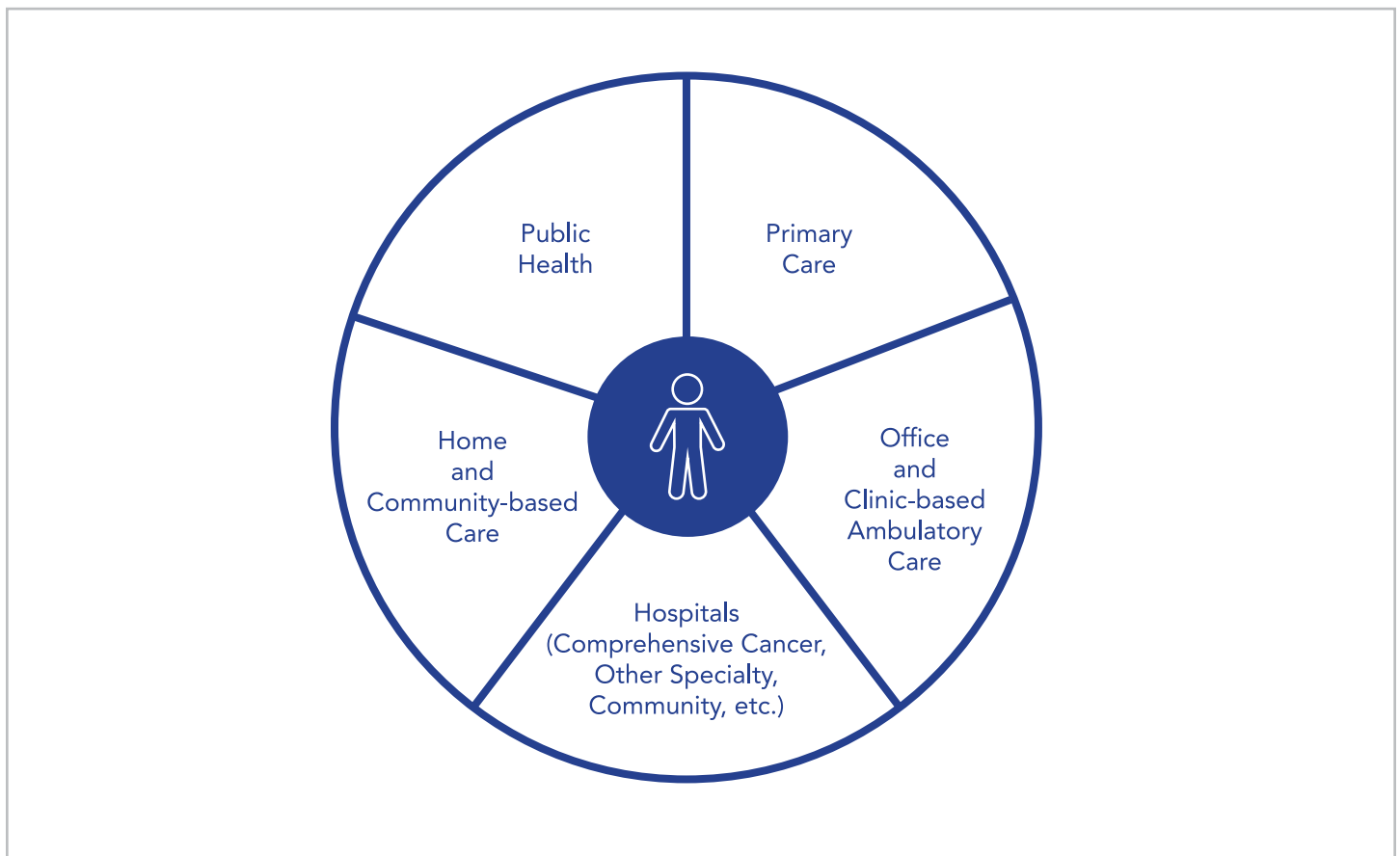


Integration between the hospital, primary care and other community partners are all important in achieving continuity of care, as well as smooth transitions in and out of the cancer system and between providers. With each additional care provider and/or sector, successful patient care and transitions become more challenging, and more streamlined processes and systems are needed. Pathways and guidelines are important to ensuring that all providers involved in the care of a cancer patient are co-ordinated, and to reduce the risk of errors and omissions. System efficiencies and efficacies increase with integration, benefiting patients and the sector as a whole.

## 1. PUBLIC HEALTH

Public health has a wide focus that includes promoting health, preventing and controlling infectious and chronic diseases and injuries, and responding to public health emergencies.  Typically, programmatic decisions are based on empirical analyses of population-based registry data, which identifies cancer-related trends and issues. For more information, see the *Cancerpedia: Population-Based Cancer Registries and Risk Factor Surveillance* chapter.

From the perspective of individuals at risk for or diagnosed with cancer, public health supports health education about prevention and screening, treatment impacts, available supports, and palliative or end-of-life care.  Efforts should be made to reach individuals who are vulnerable or who may experience language or other barriers to entry into the system.  These populations may include those who are impoverished, homeless/underhoused, Indigenous, immigrants or refugees, or LGBTQ (i.e., lesbian, gay, bisexual, transgender and queer).

For public health to be successful, linkages to other parts of the system are vital.  For example, public education (e.g. regarding healthy lifestyle choices, immunizations, public screening programs, supports during treatment or end-of-life, etc.) should be up-to-date, consistent across sectors and credible. To achieve

To achieve this goal, various health sectors must ensure harmonized messaging. Public health teams should also be integrated with downstream services, such as screening centres or organizations able to facilitate access when an eligible person is identified for screening, to improve compliance, access, the patient experience and the sustainability of the system. Additionally, alignment with hospital services for diagnostics is required to ensure timely and co-ordinated access when cancer screening reveals that additional testing is required.

## 2. PRIMARY CARE

The World Health Organization defines primary care as, "first-contact, accessible, continued, comprehensive and coordinated care".[5]  Primary care supports a person's ongoing care and long-term health. It provides a wide range of services, including directly addressing the common health problems of a respective population and co-ordinating specialist care and other supportive care, as required.[5] Depending on the jurisdiction, primary care may be provided by family physicians, general internists, nurse practitioners, registered nurses, physician assistants, pharmacists or other clinicians. Cancer care provision by primary care varies by jurisdiction and provider skill/knowledge, and may include: prevention and screening; identification and diagnosis; helping with treatment decisions; providing psychological support; treating intercurrent disease; recognizing and managing or co-managing the complications of cancer and cancer therapies; and supporting or providing palliative or end-of-life care.

The Lancet Oncology Commission on *The Expanding Role of Primary Care in Cancer Control* noted that the strengths of primary care – continuous, comprehensive and co-ordinated care – are particularly evident in cancer prevention, timely diagnosis, shared follow-up and survivorship care, and end-of-life care.[6] Primary care's role in integrating care throughout a patient's cancer experience is significant; a patient may enter and exit different care sectors, organizations and clinician teams throughout their journey, making primary care essential in longitudinal co-ordination, advocacy and continuous support. The importance of primary care's role in pre-cancer care is demonstrated by the fact that approximately 90 per cent of adult cancer patients present first in primary care.[6] Pre-cancer care activities may include: prevention education and intervention, including harm-reduction strategies (e.g. smoking cessation, dealing with harmful alcohol use, weight loss, vaccination, and physical activity); promotion of help-seeking and screening; and ensuring follow-up with individuals who receive a positive screening result or present with signs or symptoms suggestive of cancer. See the *Cancerpedia: Primary Prevention* and *Cancerpedia: Early Detection and Screening* chapters for more information. Integration with diagnostic centres or programs can decrease the risk of delays or loss to follow-up issues. Methods of integration may include co-ordinated appointment systems, shared electronic records, alert or reminder systems, or programs that have medical directives allowing additional testing and/ or referrals, when required. In the instance of medical directives, processes should ensure that the primary care provider is notified at each step in the process.

The end of the early diagnostic phase is a key intersection point between primary care and cancer treatment teams in hospitals. It requires a co-ordinated and responsive system for patient entry, whether facilitated through primary care or direct from diagnostic centres or programs.  For the primary care provider with few patients requiring cancer system access, this entry point can be complicated and unfamiliar; therefore, an important goal of integration is a streamlined, timely system of access to specialized cancer care.

Excellent models exist to integrate screening and entry to the cancer system for expedited cancer diagnostics, most including a single point of access, and some with navigational and psychosocial support. Examples include diagnostic assessment programs in Ontario, Canada and Croydon Health Services and Rivers Hospital in the United Kingdom.[7-9] In the absence of expedited cancer diagnostic programs with defined, integrative models, tools such as evidence-based, investigative algorithms or diagnostic pathways can support best practice investigations, standards of care including timelines, and clarity on roles and responsibilities.  Diagnostic pathways are successful when all providers and organizations use them consistently, good communication exists, and standards, roles and responsibilities, and appropriate responses and timelines are agreed upon and ensured. The enhancement of diagnostic pathways can include flow mapping to further delineate roles, responsibilities, timelines and communication pathways, to ensure a seamless experience for the patient. For more information, see the *Cancerpedia: Clinical Management* chapter.

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Once a patient enters a cancer facility, the primary care provider should continue to support the patient in making treatment decisions, provide psychological support, treat intercurrent disease, and help recognize and manage the complications of cancer and cancer treatment. In addition, primary care providers act as advocates, connecting patients with other community supports, as required. An integrated, shared-care model during treatment for cancer between the oncologist and a primary care provider has challenges, including the episodic nature of cancer treatment, multiple-provider involvement, and the primary care provider's incomplete understanding of cancer, its treatment and its sequelae.[10] The fundamental component to ensuring the success of this model is communication between healthcare providers by whatever mode makes sense for the environment, including email, phone, fax or other methods. With its holistic approach, primary care can also play a clearly-defined and extended role in cancer survivor support, including mitigating the physical and psychological impacts of cancer, either in a shared-care model or post-discharge from an oncologist's care. The ability to effectively support these activities depends on the capacity of primary care in the use of guidelines, educational support (i.e., building of knowledge and skills), clear lines of communication between healthcare providers, easy re-entry to the treatment environment (i.e., hospital) and adequate resources.

Primary care and palliative care share several common approaches: treating the whole person and their immediate family, applying best practices, and considering physical, psychosocial, practical and spiritual issues.[11] Palliative care can, depending on the jurisdiction, be provided by a variety of clinicians in a collaborative way, including oncologists, palliative care specialists, home or community care and primary care. Co-ordination of care is extremely important and must be supported by clear and comprehensive communication, documentation of advanced care planning, and clear roles and responsibilities.

Primary care has significant potential in the cancer system to act as a bridge and provide continuity during an often difficult period of time in a person's life. Rubin et al. notes that the integration of primary and specialist care can optimize quality and outcomes, but not without enablers.[11] As generalists, primary care providers need support, training and adequate resources to be successful. They also require clearly-defined roles, care pathways, effective lines of communication, cross-sectoral education (e.g., on clinical content, care pathways, systems, quality improvement), and evidence-based models and tools.

**Care Guidelines**

Care guidelines are evidence-based or evidence-informed recommendations that cover the continuum of care, from prevention and screening to end-of-life care. Many organizations and programs develop care guidelines that can be adopted and/or adapted for a local context. Some examples of care guideline development programs include the National Institute for Health and Care Excellence, Cancer Care Ontario's Program in Evidence-Based Care and Cancer Council Australia.[12-14] Care guidelines alone are not sufficient in integrating care. Additional supports and investments are required to bring care guidelines to practice as well as processes to select guidelines and address conflicting guidelines. Knowledge translation and exchange is critical, as is the development of pathways and systems to support the collaboration of the relevant providers and systems in streamlining care and meeting recommended standards. Work may also be required to ensure resources and access to services are developed. For more information, see the *Cancerpedia: Clinical Management* chapter.

**Primary Care Engagement and Empowerment**

Townsend's report on Kaiser Permanente – a non-profit insurance and management model – notes extensive investment in the development of a fully-integrated system of care centered on the patient's perspective.[15] The Kaiser Permanente model encompasses everything from preventative care to the personalization of healthcare goods and services. Central to the model is the empowerment of primary care providers to be proactive and take overall responsibility for care of the patient. Primary care providers also have a central role in facilitating overall population care, developing new services and managing health resources. In support of this model, Kaiser Permanente has invested in: a single, patient-accessible health record; access to online and/or video consultations; home-based models of care; and a clinical and administrative environment that is easy to navigate, with support for patients as they transition between clinics, hospitals, laboratories and pharmacies. The team also uses physical and virtual methods to connect primary, secondary and specialty structures. The resultant system is a successful model of integration, with primary care playing a central role in co-ordinating and personalizing the patient care experience.

In systems where only modest or limited infrastructure or funding are in place, such as in low- and some middle-income countries, healthcare may be organized by specific health problem or specialization.[16] In these instances, primary care can be empowered to play an even greater role in knitting the various parts of the system together for patients.  Innovation may assist in addressing some gaps and barriers, which may be as simple as using text messaging when cell phones are easily accessible.

## 3.  HOSPITALS

Hospitals are the primary setting for diagnostics, treatment and care for people who are sick or injured. Hospitals provide different levels of care, from basic to quaternary care.[17,18] Hospitals providing basic care are staffed by general practitioners and a few medical specialties (e.g. internal medicine, obstetrics and gynecology, paediatrics). They may offer general surgery and have general laboratory services. Tertiary and quaternary care facilities are focused on more complex clinical conditions, are staffed by highly-specialized and subspecialized providers with expertise in specific body systems or diseases, have highly-specialized technical equipment and laboratory services, provide health professional education to trainees, and usually conduct research.  Quaternary care facilities also support treatments or procedures that are uncommon, experimental or leading edge.  Specialty hospitals, such as cancer centres, generally provide tertiary or quaternary care. Because hospitals provide different levels of care due to various reasons (e.g., the size or type of population they serve, resources and skills sets available, the need to centralize key services for volume and quality advantages) patients may need to travel to receive specialty care or portions of their cancer care not accommodated at their local facility.  In order to support comprehensive cancer care as close to home as possible, hospitals and community partners must work together to develop systems and processes that support integration.  Hospital system integration models serve to optimize the use of cancer resources – such as specialized skills, equipment, advanced technologies and techniques – to ensure individuals have timely and equitable access to the diagnostic services and cancer care they need.

**Geographic Integration Model**

Systems to promote integration may be facilitated through a defined geographic area, such as a region, province or state, or nation.  A region may be defined by political boundaries (e.g., regional health authority), by a population's catchment area, by existing cancer expertise and referral patterns, or by other means. Jurisdictions may organize and integrate cancer services in different ways, depending on the focus of and need of the population. Cancer Care Ontario established regional cancer programs (RCPs) as a model of partnership and responsibility for the care of patients in a defined region.[19] RCPs are formal networks of stakeholders, healthcare professionals and organizations involved in cancer prevention, screening and care within each of the province's health regions, supported by administrative and clinical leadership. Each RCP contains at least one regional cancer centre, which provides a wide range of advanced diagnostics and cancer treatments.  In addition, each RCP contains defined partner hospitals that offer selected cancer services – usually for more common cancers – and refer patients to the regional cancer centre for radiotherapy or treatment of more complex or uncommon cancers. All RCPs must implement provincial standards and programs, and meet requirements and performance targets set out by Cancer Care Ontario across the cancer care continuum. Leadership of the programs is instrumental in bringing quality basic care to the patient and bringing the patient to quality quaternary, specialized or rare cancer care.

**Hub and Spoke Model**

A hub and spoke model includes a host site – or hub – that typically provides a full spectrum of specialized services, sophisticated treatments, and diagnosis and treatment relating to rare cancers.  The hub may also provide services that require volume or special infrastructure to meet standards of quality care. The hub is usually a cancer centre or tertiary/quaternary care centre. Partner sites – or spokes – provide a subset of clinical services, including varying levels of diagnosis, treatment and/or supportive services for a particular cancer, depending on their size and the availability of resources and expertise.  Partner sites refer patients to the hub for more specialized care, as appropriate.[20] Many examples of this models exist, although the impetus for the model may differ.  Some countries benefit from the hub and spoke model due to a lack of resources in providing specialized, multidisciplinary management of cancers; for example, in sub-Saharan Africa, India and Sri Lanka.[21,22] In these examples, cancer centres are established in highly-populated regions, incorporating a hub and spoke model to serve areas peripheral and more distant to the urban or regional

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centre.  Other examples act to address volume or quality issues, resulting in an ability to provide a critical mass of highly-specialized expertise; for example, provincial sarcoma services in Ontario, Canada and surgical lung cancer services in England.[23,24]

Tools and processes should be in place to support the transition of patients back and forth between the hub and spokes, to ensure co-ordinated, streamlined and safe care.  Some of these tools and processes may include formalized agreements between centres, a clearly outlined scope of practice at each site and formalized clinical discussion forums to support integrated care, such as multidisciplinary cancer conferences.[23,25] Process maps that clearly outline the intersection points and responsibilities between centres are also integral to an integrated approach. Telecommunications is essential for e-medicine, telemedicine, e-reporting (i.e., pathology and medical imaging) as well as integrated multidisciplinary meetings.  Enhanced telecommunications are now available in many low- and middle-income countries, making e-medicine or telemedicine a real possibility.[21]

**Organizational Standards Model**

In the province of Ontario, Canada, the development of standards for the organization and delivery of chemotherapy was undertaken to ensure the quality and co-ordination of care as close to home as possible, irrespective of the level of hospital.[26] Organizations were asked to align to one of four levels of care (i.e., I – IV).  Level I facilities include tertiary centres with a full spectrum of care, including radiotherapy, while level III and level IV facilities include community hospitals and satellite centres, respectively. All facilities are expected to meet standards for human resource practices, clinical care, performance monitoring and funding, designed to ensure high-quality and safe care for all patients in Ontario. Additionally, all facilities are expected to participate in a formalized partnership with a level I facility and an RCP. These partnerships support systems thinking, planning and knowledge exchange, and facilitate a formal avenue for engagement in ongoing quality improvement activities.

## 4. OFFICE AND CLINIC-BASED OUTPATIENT CARE

Office and clinic-based outpatient (or ambulatory) care may overlap with primary care and hospital care. Depending on the jurisdiction, scope and resources available, primary care may perform some cancer-related outpatient care/procedures and not others.  Similarly, a formal hospital setting may not provide some cancer-related outpatient care procedures or may locate them in a separate, purpose-built outpatient care space. Office and clinic-based outpatient care settings may conduct clinical interviews, physical examinations for malignancies, screening activities and/or procedures such as blood tests, Pap smears or endoscopies.  As discussed above, office and clinic-based outpatient care facilities must be integrated with other clinical services, so that the needs of patients are met in a seamless and timely fashion.

## 5. HOME AND COMMUNITY-BASED CARE

Home and community-based care is provided to people in their homes and in designated locations in the communities where they live. The range of home and community-based care services vary by jurisdiction and, depending on the service, may be provided by regulated healthcare professionals, non-regulated providers, volunteers, or caregivers who are friends or family. The services provided by home and community-based care meet a number of needs, which may include: basic clinical and supportive care for patients undergoing treatment and experiencing side-effects or mobility impairments; services to maintain or improve the patient's health status and quality of life; or support for families who are coping with a family member's cancer diagnosis, treatment or outcomes.

## C.  ENABLERS

The successful integration of sectors, inter-sectoral organizations and clinicians requires enablers and supports. As presented in the introduction, Shaw et. al. outlined five categories of integration.[3] The normative, organizational and clinical categories are key to integrating hospital and community care.  Below we will discuss the tools and resources necessary to develop appropriate integration both between sectors and within sectors.

Table 2: Enablers of Integration Between Hospital and Community Care

| Type of Integration | Description | Description |
|---|---|---|
| Normative | Developing a shared vision, culture and values across organizations, professional groups and individuals | Influential leadership<br>Communities of practice |
| Organizational | Co-ordinating structures (e.g., contracts, co-operative arrangements), governance systems and relationships across organizations | Formal agreements<br>Guidelines and/or care pathways<br>Standardized tools<br>Standardized policies and procedures |
| Clinical | Co-ordinating information and services, and integrating patient care within a single process | Record sharing<br>Information technology-enabled tools and processes<br>Navigation support |

Successful integration of clinical care requires the development of a shared vision, culture and values across organizations, professional groups and/or individuals.[3] This normative integration may be facilitated by influential leadership or champions, as well as communities of practice (CoP).  CoPs can take many forms, from ongoing interactions to time-limited, targeted interactions. They may involve the whole continuum of care, or a more limited set of partners and clinicians. The benefit of the CoP, no matter the model, is supporting collaboration in the achievement of a specified goal. Bringing people together for a common cause allows for new and unique pairings, ideas and interactions to flourish. CoPs also support the development of shared values, culture and vision, enhance co-operation across sectors and professions, and are influential in enabling organizational integration from the perspective of patient care.

Organizational integration can manifest as formalized agreements, guidelines and care pathways, or standardized tools, policies and procedures.  Formalized agreements between centres identify the key elements of a relationship, roles and responsibilities, as well as the way in which the institutions will interact. They are powerful in providing clarity about how members will co-operate and support the integration of defined systems or services for patient care.  Guidelines and care pathways outline when and what steps or procedures should occur, and how they should be provided appropriately and safely by trained staff.[27] Additionally they articulate best practice care for the patient and support the team in providing a cohesive and consistent care plan, irrespective of the sector providing care. Standardized tools and/or policies and procedures further clarify the intersection points between organizations and providers, hand offs, and roles and responsibilities, and may include patient education materials, standardized referral forms, checklists and other elements that facilitate integration.

Clinical integration includes record sharing, information technology-enabled pathways and patient navigation. Ideally, record sharing includes a fully-integrated patient health record that is accessible inter-organizationally, inter-sectorally, and to the patient (i.e., via a patient portal).  Information technology has been leveraged to support electronic care pathways with: embedded patient education and clinician materials; electronic referral forms or systems; tracking and follow-up documentation; remote health monitoring; online or distance consultations; and other functions.  Use of these tools has had various levels of success due to poor design, lack of common standards, fear of diminished privacy, inadequate training and incentives for providers to participate, and ineffective leadership. Patient portals support integrated care by allowing the sharing of information managed by the patient, and can be instrumental in empowering and activating patients in their care. As with other record sharing, portals provide the best functionality to patients when inputs from multiple sources are enabled, producing a single health record.[28]  Finally, patient navigators, who provide assistance in navigating complex health systems, have been shown to improve the patient experience of co-ordinated care, among other measures.[29] In a complex system, the better the integration of information related to patient care, the more likely it is that high-quality, safe and supportive care and improved patient satisfaction and outcomes are achieved.

## D. THE FUTURE

Technology continues to advance. Healthcare must embrace and expand its thinking about the use of technology to improve care integration, leapfrog over limitations, and look for new, and sometimes simple, solutions to providing more co-ordinated and comprehensive care.

Areas of innovation that continue to mature include patient portals, virtual care and telemedicine. While patient portals have the potential to enhance the continuity of care and patient participation, they also require self-motivated patients who have access to technology.[30] Virtual care and telemedicine offer remote and lower-income jurisdictions access to specialized care, decrease the need for travel for the management of more complex and/or rare conditions, and facilitate the management of less technical and less costly activities closer to home. They can also help to keep healthcare providers informed and involved as partners in care, facilitate learning in a shared-care model, and enhance opportunities for multidisciplinary meetings at a distance. All of these technical opportunities reduce the impact of distance and cost related to care for patients, and facilitate national and international consultation and learning.

Artificial intelligence (AI) is a new opportunity in healthcare. AI's processing speeds and ability to enhance the throughput of data is already decreasing costs. Future developments may support modelling activities for planning, the management of referrals and patient flow, clinical decision-making and safety alerts, to name a few.

Innovation does not always entail new or more advanced technologies. Systems or process innovations can also be effective in addressing barriers to integration. For example, an innovative solution to integration can be as simple as using text messaging in jurisdictions where cell phones are more accessible and reliable than electricity, the Internet or a computer. In some low- and middle- income countries, where the health system is fragmented due to targeted funding (e.g., cervical screening occurs at one centre, while prevention and education occur at another), people must visit separate and specialized clinics for their various health problems. This results in inefficiencies and duplications, and a less than ideal experience for patients.[16] Integrated services, packaged together, could lead to better health overall, with improved convenience and satisfaction for users.

Some of the most widely identified risks to patients include transitions in care, or when multiple providers, in multiple systems are engaged in caring for a patient. Integrated systems, despite outcomes not being fully demonstrated, are widely considered to provide superior performance in terms of quality and safety as a result of effective communication and standardized protocols. Integration from the patient perspective should be experienced as a seamless and cohesive system of care that includes a comprehensive scope of services. Sectors of care have interdependencies that require enablers, such as shared values, culture and vision, committed relationships, tools, co-ordinating structures and information systems. If systems, processes or tools are not supporting the system, however, seamless, safe, high-quality care will remain elusive. This highlights the need for a continued engagement of all players and a continued, collective investment in innovation.

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