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# OVERVIEW OF CANCERPEDIA

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## A. INTRODUCTION

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Cancerpedia is a cohesive framework for a comprehensive cancer centre or program that provides the full spectrum of cancer care, serves as a hub for education and research, and is integrated into broader cancer control and health systems. It can serve as a checklist for healthcare professionals looking to develop, scale up or evaluate a cancer centre or program.

This framework is as relevant to high-income countries as it is to middle- and low-income countries. The latter will have fewer resources to address their needs for cancer control, and may only be able to support a subset of activities as funding and capacity are built incrementally; regardless, the framework provides a necessary reference point from which to structure a plan of growth. Given that different areas of the world are at different stages of development, each jurisdiction must assess its cancer burden, existing capacity and resources, and the opportunities provided by the health system and professional or volunteer cancer advocates and practitioners to support comprehensive cancer centre functions.

To build and strengthen systems of cancer control and care delivery, it must be recognized that the cancer system is not an island unto itself; rather, it is an integral part of the larger health system. An effective cancer system is only possible within the context of an effective health system. Also, cancer control systems include functions, components and multiple delivery agents, all of which must be well-developed for a robust cancer control enterprise. Finally, regardless of a country's resource level, the cancer centre – one important delivery agent – can play a critical role in advancing cancer control and health systems.

## B. THE HEALTH SYSTEM

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The health system is “all organizations, people and actions whose primary intent is to promote, restore or maintain health”.<sup>3</sup> The requirements for an effective health system are widely recognized and include six essential, interdependent building blocks that improve health outcomes.<sup>3</sup>

**Good health services** that deliver effective, safe, quality personal and non-personal health interventions to those who need them, when and where needed, with a minimum waste of resources.

A **well-performing health workforce** that works in responsive, fair and efficient ways to achieve the best health outcomes possible, given available resources and circumstances (i.e., sufficient staff who are fairly distributed, competent, responsive and productive).

A **well-functioning health information system** that ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health system performance and health status.

Equitable access to essential **medical products, vaccines and technologies** that are characterized by quality, safety, efficacy and cost-effectiveness, and whose use is scientifically sound.

A **health financing** system that raises adequate funds for health, to ensure that people can use needed services and are protected from financial catastrophe or impoverishment associated with payment. The health financing system provides incentives for providers and users to be efficient.

**Leadership and governance (stewardship)** that ensures strategic policy frameworks are used and combined with effective oversight, coalition-building, regulation, attention to system design and accountability.

Governments are responsible for designing, planning and overseeing health systems that involve multiple players and factors, which can include publicly-owned facilities, families and friends who care for sick loved ones, private providers, education programs to change unhealthy behaviours, disease control campaigns, health insurance organizations, health and safety legislation, healthy public policy and programs that address the determinants of health.<sup>3</sup> In addition, it is the government's responsibility to co-ordinate effective population-based healthcare programs.

## C. THE CANCER CONTROL AND CARE DELIVERY SYSTEM

The cancer control and care delivery system includes functions, components and multiple delivery agents.

### 1. FUNCTIONS

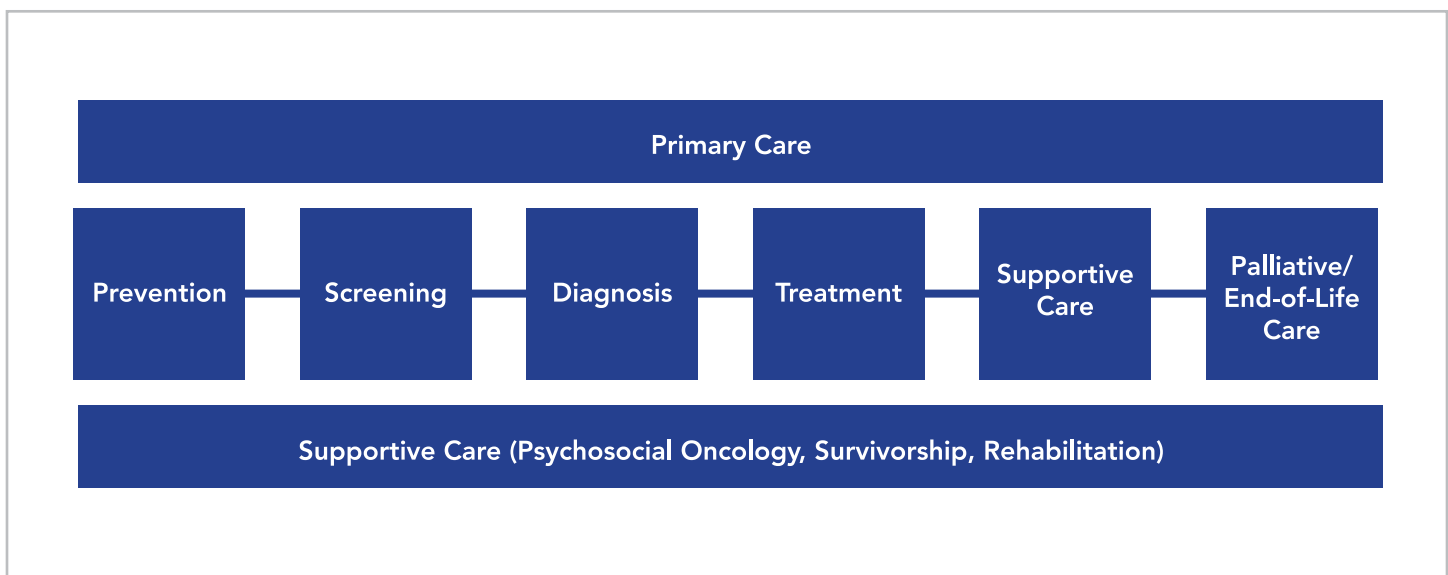
Functions are similar to the building blocks of the health system and are evident at multiple levels. Functions include financing (i.e., budgeting and allocating resources), service delivery, resource generation and the stewardship of health systems.<sup>4</sup> The latter involves developing national or population-based cancer strategies based on a jurisdiction's cancer burden, the prevalence of cancer risk factors, the skills and infrastructure available to implement plans, and the healthcare system and socio-economic environment.<sup>5</sup> Cancer strategies should include clear directions and priorities, service delivery and resource plans, policies, and provisions for advocacy efforts, information systems and funding. Other stewardship responsibilities include population-based prevention and screening programs, cancer registries, practice and operating standards and regulations, compliance systems, research, healthcare education and system performance. See the *Cancerpedia: Cancer Control Oversight and Policy* chapter for more information about developing and implementing a national cancer control strategy.

Since the cancer control system must be integrated with the larger health system, there are opportunities for synergies between functions and multiple disease programs.<sup>4</sup> A diagonal approach recognizes the value of targeted action for individual diseases, such as cancer, as well as collaborative action where interrelationships exist between cancer and other diseases in the health system.

### 2. COMPONENTS

The components of the cancer control and care delivery system are depicted in Figure 1. Patients do not necessarily use the components in a unidirectional manner. For example, patients who receive treatment may need ongoing screening and diagnostic services, followed by additional treatments. As well, many patients do not experience all of the components. For example, many individuals in low- and middle-income countries present with advanced or metastatic disease, and may receive only palliative and end-of-life care.<sup>6</sup>

Figure 1: Components of a Cancer Control and Care Delivery System<sup>1</sup>



The components are interdependent. Not only does each component have unique resource requirements, but resources are also needed to integrate the components and respond to the changing needs of patients. For example, screening will only help reduce mortality from cancer if there is effective diagnostic follow-up and treatment.

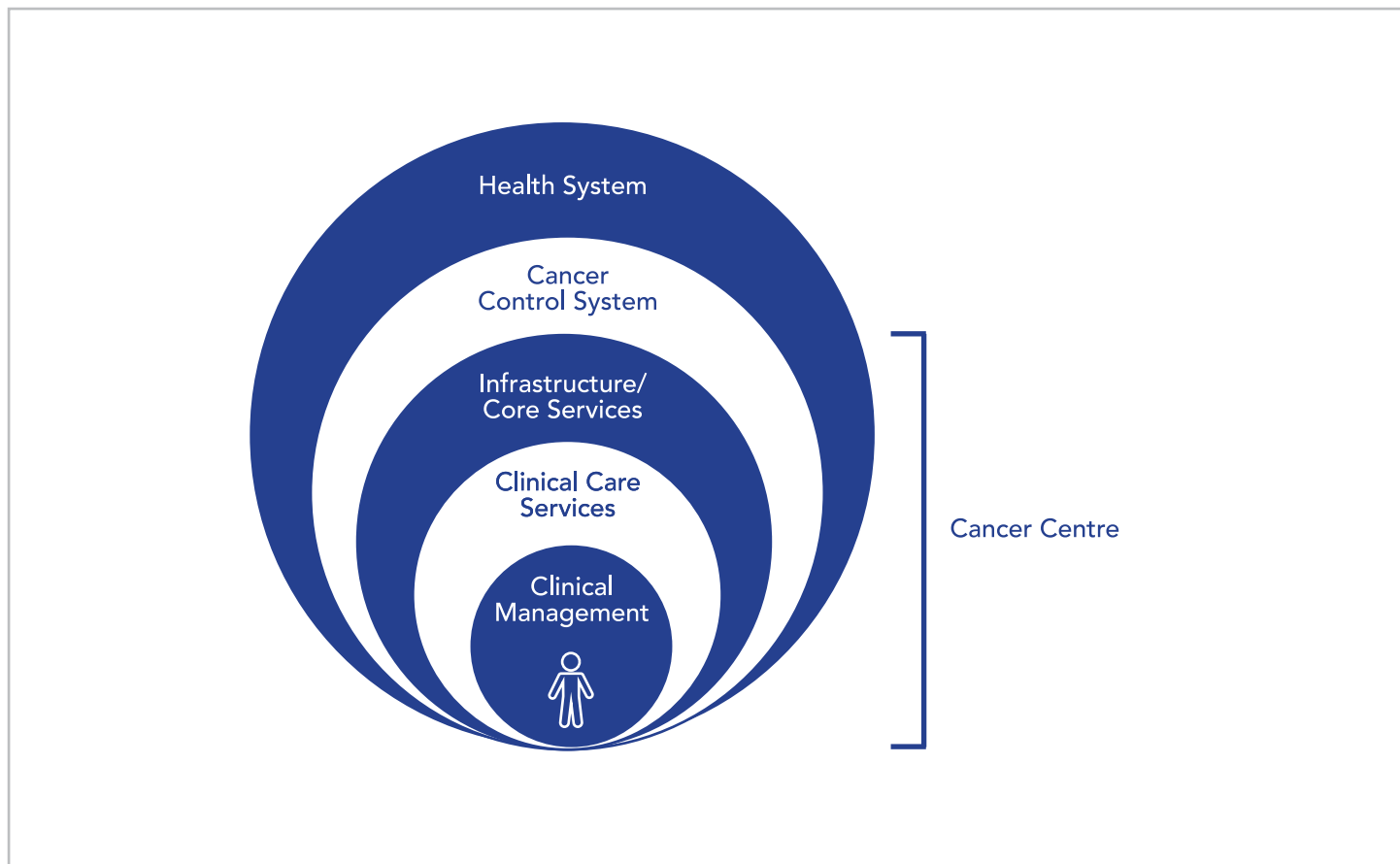
### 3. DELIVERY AGENTS

Delivery agents in cancer control and care delivery include multiple organizations and individuals who play different roles. Some influence and facilitate the provision of cancer control, such as governments, funders, advisory bodies, professional standards-setting organizations, regulatory bodies, advocacy groups, educators, researchers and developers, suppliers and managers. Others directly deliver cancer care, such as cancer centres, community hospitals, primary care providers, community-based and home care providers, public health and unpaid healthcare providers (e.g., family, friends, volunteers and other caregivers). See the *Cancerpedia: Integrating Hospital and Community* chapter for additional information about the range of delivery agents and their roles.

### 4. THE CANCER CONTROL AND CARE DELIVERY SYSTEM FRAMEWORK

Although the cancer centre may operate as an independent entity, it should ideally be integrated into a broader system of healthcare and cancer control. This allows for a number of synergies and opportunities to enhance care delivery at an individual and population level. For example, effective primary prevention and early detection and screening programs can result in earlier diagnoses and improved treatment outcomes, while national regulations and accreditation standards can impact the safe delivery of cancer services. Cancer centres are able to participate in shaping the development of regional cancer systems and influence decisions that affect national cancer control priorities.

Figure 2: The Cancer Control and Care Delivery System Framework<sup>2</sup>



## D. CANCERPEDIA

*Cancerpedia* contains 39 chapters that address cancer control within and beyond the cancer centre. As a framework, we have segmented the *Cancerpedia* into interrelated sections, while ensuring that each chapter is able to stand alone.

The *Cancerpedia* framework was constructed around the needs of patients with suspected or diagnosed cancer, as illustrated in Figure 2, and provides a system-level perspective as well as a granular view of the fundamental resources and structures needed for a cancer centre or program. At the core of cancer care, we describe the criteria and the principles of clinical management, the roles and responsibilities of the healthcare team, and strategies to engage patients in their care. The execution of clinical care plans requires the availability of the full spectrum of clinical services to deliver diagnostics, including medical imaging and laboratory and pathology services, as well as cancer treatment, including surgery, radiotherapy, chemotherapy and palliative care. Supportive care, pharmacy and emergency care help round out the full spectrum of cancer care. Supporting these are a wide range of core services and infrastructure, including infection prevention and control, physical facilities and support services, equipment and technology, health records, human resources and others services that allow the cancer centre to operate safely and effectively. The framework also presents guidelines for governance that ensure oversight and quality, describes the critical need for integrated education and research, presents best practices for engaging in philanthropy and outlines the need for integration with community care.

### The Cancer Centre

- **Clinical Management, the Healthcare Team and Patients:** Clinical management, the healthcare team and patients are three important topics that are relevant to all areas of cancer care, but that warrant individual discussion. Clinical management is focused on identifying evidence-based resources that inform a consistent approach to clinical decision-making. The complexity of cancer requires multi-professional and multi-disciplinary input. We describe the essential cancer team members and detail roles and professions specific to various clinical services. Patients – who are at the centre of the cancer control and care delivery system – have many needs. To provide optimal care, cancer centres must develop strategies for patient information, navigation, education, empowerment and engagement. Such strategies improve the patient experience, the quality and safety of care, and health outcomes.
- **Clinical Services:** Clinical services are essential elements of the cancer centre that deliver diagnostic, treatment and supportive care services. They include a wide range of services that must be effectively integrated to provide co-ordinated, efficient care. This section is comprised of a series of chapters dedicated to each of the following:

Medical Imaging	Radiotherapy	Ambulatory/Outpatient Care
Laboratory Medicine and Pathology	Supportive Care	Emergency Care
Surgery	Palliative Care	Pharmacy
Chemotherapy	Inpatient Care	

For each service, we have applied a standard approach to describe the goals and scope, physical facilities, equipment, human resource and information management needs, management and quality considerations, best practices, guidelines and future trends. While inpatient and outpatient/ambulatory care do not reflect clinical services, they are important care delivery settings that must be considered in relation to the clinical services offered. In some settings, pharmacy and emergency care could be considered core services; however, we have opted to include them as clinical services because they include direct patient care.

- **Core Services/ Infrastructure:** The delivery of cancer care is contingent upon a number of core services and infrastructure that enable the cancer center to function efficiently and effectively. Many of these services may be invisible to patients, but are important for the delivery of care. If the cancer centre or program is part of a larger organization, these core services and infrastructure maybe shared beyond the cancer patient population. This section is comprised of a series of chapters dedicated to each of the following:

Infection Prevention and Control	Health Records	Human Resources
Physical Facilities and Support Services	Hospital Registry	Communication
Equipment and Technology		

For each of these services, we describe key activities, resource requirements, processes and structures.

- **Governance and Quality:** Governance and administration are crucial to ensuring the effective operation of a cancer centre or program. Although each clinical and core service requires unique management and quality considerations, comprehensive cancer centres or programs also require overarching formal and informal leadership structures that enable planning, decision-making processes, financial management, risk management, effective co-ordination and efficient operations. This global oversight of the cancer centre is critical to ensuring harmonized services that are effectively integrated, and to assessing capacity needs across a number of interdependent services.

A robust organizational approach to quality is a vital responsibility of leadership. This includes fostering a culture of quality and implementing a plan to define and enforce quality standards, monitor performance and employ strategies to prevent, analyze and learn from safety incidents.

- **Research:** The continuous cycle of generating and transferring new knowledge to improve patient outcomes is typically integral to the vision and priorities of the cancer centre, making it an ideal place to advance cancer research, and especially to conduct clinical trials. The concentration of expertise within cancer centres can facilitate collaborative research that generates new knowledge and accelerates the validation of research in local environments. A successful program of research not only includes independent and internally-generated discovery, but also strategic local, national and international collaborations. This chapter presents an overview of the requirements for building a robust research program.
- **Education:** Progress in cancer care can advance at a rapid rate, and cancer centres or programs require well-established education programs to stay abreast of and implement advances into practice. Cancer centres should strive to support and facilitate lifelong learning to advance the skills and competencies of current professionals. The cancer centre is also an ideal setting for training the cancer professionals of the future. Students and trainees gain valuable tacit and practical skills through exposure to clinical settings. Beyond formal student programs, health professional education can be delivered using a variety of tools tailored to the busy healthcare provider, to support maintenance of competence, continuing education and professional development. This chapter details requirements for establishing a robust education program, and describes the multimodal educational strategies that meet the needs of learners at different training and career stages.
- **Philanthropy:** Many cancer centres seek and receive philanthropic support. Philanthropy has the potential to make a transformational impact on the future of cancer care, and cancer centres or programs can benefit from developing avenues for generating philanthropic support. This chapter presents how the centre or program can work together with donors and/or foundations to generate funds for strategic investments, through effective and ethical fundraising strategies that ensure appropriate stewardship and allocation of funds.
- **Integration with the Community:** Patients with cancer have health-related needs that must be addressed by a wide range of health services. A lack of integrated health services can result in siloed and episodic care, poor access, the potential for poor outcomes, risks to safety and significant health system inefficiencies. Integrated health services require a variety of providers, organizations and community programs to address the whole spectrum of cancer control. This chapter details how the cancer centre can operate as part of an integrated health services system that includes a comprehensive scope of clinical and health-related services working together to provide patients with timely access to co-ordinated and high-quality care.

## Beyond the Cancer Centre

- **Cancer control:** Primary prevention, early detection and screening programs reduce the burden of cancer and optimize outcomes by enabling earlier diagnoses and improved treatment outcomes. Some of these services can be provided by the cancer centre or primary care. Planning and providing effective and efficient cancer control services requires a thorough understanding of a population's current and predicted future burden of cancer. This section presents population-based strategies for primary cancer prevention that aim to address major lifestyle-associated risks for cancer as well as population-based screening programs and the development of cancer registries.



- **Policy and regulation:** National and regional strategies for cancer control can have an effect on the delivery of cancer care services. This includes the implementation of national cancer control strategies as well as licensing requirements, regulations and accreditation standards that govern cancer control activities. This section details examples of national cancer control strategies and presents an overview of licensing, regulation and accreditation bodies related to cancer control and cancer care services.

## 5. SCOPE AND LIMITATIONS

We constructed this framework within a number of parameters and restrictions. First, *Cancerpedia* is not a guide on how to deliver cancer care. This information can be found in many standard cancer and specific disease management, diagnostic modality or treatment modality textbooks.

Second, although the framework is comprehensive, it is not intended to be exhaustive. Due to its breadth, we focused on essential information, while linking readers to a wide range of vetted publications that detail additional standards, guidelines and best practices. The references provide reliable examples, but do not capture a complete, systematic literature review.

Third, although *Cancerpedia* is designed for global consumption, it does reflect a North American, European and Australian bias. This mirrors the disproportionate resources, research funding and information produced by these jurisdictions, as well as our need to review of resources available in English.

Lastly, we recognize that comprehensive cancer centres or programs exist as part of complex adaptive systems, whereby a wide array of interrelated factors and relationships inevitably influence the ability and capacity to implement cancer control measures. Although the framework does not address the complex nature of cultural, political, economic and geographic influences on healthcare, it provides a comprehensive summary of essential elements that can be adapted to local contexts.

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