CANCER PEDIA

POLICY AND REGULATION

CANCER CONTROL OVERSIGHT AND POLICY

Contributors: Nelson Shen, Amanda Chudak, Joann Trypuc, Terrence Sullivan

UHN
Princess
Margaret
Cancer Centre

CANCER CONTROL OVERSIGHT AND POLICY

CANCER
PEDIA

A. INTRODUCTION

Several countries have developed and implemented a national cancer control strategy (NCCS) to reduce the burden of cancer in the population.[1] Each country has a unique mix of socio-cultural, political, financial and technological factors that can be enablers or barriers to achieving specific cancer control goals. Countries must leverage their enablers, address their barriers, and maximize the use of existing resources to meet the needs of their populations.

This chapter presents a detailed analysis of the experiences of five countries that established an NCCS: Australia, Canada, England, New Zealand and the United States. There are commonalities and differences in the systems of oversight, government and organizational structures, policies, and financing arrangements that each country used to support its NCCS. It is recognized that the five countries reflect an Anglophonic and North American bias. There was limited access to detailed cancer control literature, government documents, reports, subsidiary documents and online artifacts from Europe, Asia and Africa. The experiences of the five countries presented here, however, provide valuable background to inform the development and strengthening of an NCCS in other jurisdictions.

B. HEALTHCARE AND CANCER CARE SYSTEMS

1. FINANCING AND DELIVERING HEALTHCARE

Financing is often used as a factor to classify healthcare systems. The three traditional models of healthcare financing – Beveridge (public), Bismarck (mixed) and Private Insurance (market and out-of-pocket) – are based on sources of funding.[2] Sources may include taxation, social insurance contributions, private insurance, and/or out-of-pocket contributions. Although a country's financing system may include a mix of the three models, healthcare systems often demonstrate a predominant leaning towards one model.[3,4]

The *Beveridge model* is a public model in which governments finance and provide healthcare through taxation, and services are mainly delivered through public providers. For example, the National Health Service in England is a publicly-financed and delivered system. The government owns the majority of hospitals and clinics, in which physicians are government employees; some physicians work privately and are reimbursed under the system. Australia, Canada and New Zealand also have Beveridge financing models, since their healthcare financing comes principally, but not exclusively, from public sources.[2]

The *Bismarck model* is a mixed model that is mainly financed jointly by employers and employees through payroll for socially mandatory insurance premiums.[2] Although all the model's components are privatized, government regulates and maintains both for-profit and not-for-profit health insurance plans, while guaranteeing eligibility of the whole population. None of the five countries analyzed have Bismarck model financing. Examples where it exists include the Netherlands, Germany, France, and Switzerland.[5]

The *Private Insurance model* is a market or out-of-pocket model that is non-compulsory and mainly funded through insurance premiums paid to private insurance companies by individuals, or subsidized by employers. The Private Insurance model is the prevailing model found in the world and is often used in low-income or disorganized countries, where the provision of national-level healthcare is currently untenable.[5] The model's purest form is in the United States, where individual states regulate private insurance and insurance companies have wide discretion in developing insurance benefit policies.[2] The funding and delivery of healthcare are mainly private, with the exception of public insurance for veterans, low-income persons (Medicaid), and older persons (Medicare). Publicly-funded healthcare accounts for approximately 27 per cent of the population.[6]

Table 1 depicts a classification of the five healthcare systems, examined by funding model. Regardless of the variations in their financing models, the five countries share a common NCCS goal: to reduce the number of people underserved by the healthcare system and thereby reduce inequalities in cancer care.

CANCER PEDIA

Table 1: Financing, Organization and Delivery of Healthcare Systems in Canada, England, Australia, New Zealand and the United States[6]

Area	Canada	England	Australia	New Zealand	United States
Financing Model	Beveridge	Beveridge	Beveridge	Beveridge	Private Insurance
Government Funding Source	Federal and provincial tax revenue	General tax revenue	General tax revenue and earmarked income tax	General tax revenue	Payroll tax, premiums, federal tax revenue, state tax Public funding accounts for approximately 27 per cent of population covered via Medicare and Medicaid
Private Insurance	Extended coverage for extra benefits not covered by Medicare	Option for private coverage and facilities	Coverage for access to private facilities and extra benefits	Coverage for cost sharing, access to specialists, and elective surgery in private hospitals	Private insurance accounts for 56 per cent of the population
Cost Sharing	Varies based on public programs and private insurance	Pharmaceuticals and dental	Reimbursement of 85 to 100 per cent of ambulatory service costs and 75 per cent of in-hospital services	Co-payments required for primary care health services, with subsidies based on income and health needs	Varies based on type of insurance
Coverage	Universal coverage of medically necessary physician and hospital services	Universal coverage	Universal coverage	Universal coverage	Varies based on insurance plans; Veterans Health Administration for veterans, Medicare for the elderly, Medicaid for low income
Funding Mechanism	Block transfer of cash/tax mix to provinces and territories	National Health Service administered through 10 regional strategic health authorities	Funding provided to eight states and territories	Funding distributed to the district health boards based on a weighted population-based formula	Centres of Medicare and Medicaid administer Medicare and federal portion of Medicaid Medicaid primarily administered at the state level
Administration	Decentralized to provinces and territories	Centralized within the National Health Service	Decentralized to states and territories	Centralized within the National Health Service	Medicare – federal Medicaid – state
Delivery	Private	Mixed	Private	Private	Private
Primary Care	Private	Mixed	Private	Private	Private
Hospitals	Private, non-profit	Mostly public, some private	Mix of public and private	Mostly public, some private	Mix of non-profit, for-profit and public
Preventative / Public Health	Shared responsibility between the federal and provincial governments	Local Authorities responsible for public health programs, but funded by the National Health Service	Preventative subsidized by the federal government	Public health, preventive and public services covered by the commonwealth	Private insurance companies required to cover certain preventative services

The majority of the countries studied currently have, or are approaching, some form of universal coverage. **Universal coverage** is a critical component in narrowing the cancer divide and should be a core activity of an NCCS.[7]

Universal coverage is not coverage for everything; rather, it is an arrangement that ensures barriers do not prevent people from using the services they need.[8] The economic imperative of universal coverage is that people do not suffer severe financial repercussions in seeking care. In contrast, the public health concept of universal coverage is the principle of comprehensive, population-based coverage, where all people can access appropriate health services across the care spectrum. The public health concept also seeks to reduce the fragmentation associated with providing appropriate levels of care to those who require it.[9]

Universal coverage requires well-functioning health and financing systems that protect a country's constituents.[8] These systems should include sufficient financial resources, and planning and operational efficiencies. The World Health Organization identifies three dimensions to consider in expanding or maintaining coverage:

• Who is covered by pooled funds?
• What services are covered?
• What proportion of the costs are covered?

This approach requires that policy-makers understand the needs of the population, available resources, and the organization of cancer care delivery systems and programs when assessing how to allocate and administer healthcare.[10]

2. ORGANIZING AND DELIVERING CANCER CARE

All five countries analyzed in this chapter have subsidiary/regional bodies in charge of cancer delivery (i.e., district health boards; provincial cancer agencies; regional cancer networks; state health departments; state and territorial councils). The level of decision-making authority varies at the regional level. For example, in Australia, the state and territorial council has autonomy over how health services are administered, but is subject to federal funding agreements. In England and New Zealand, decision-making is centralized at the National Health Service. Its respective subsidiary bodies – regional cancer networks and district health boards – are authorized to implement and manage national decisions.[11]

The delivery of cancer services varies across the five countries. Although there are efforts to deliver integrated, population-based care through regional cancer networks, there are many instances in which the efforts are insular, unco-ordinated and distributed.[12] This difference is best exemplified in the mix of delivery models in the United States, which include "focus factory" and "centre of excellence" models.

Focus factories are high-volume settings that perform single specialty procedures. Although this model can achieve volume efficiencies, it may not be effective for chronic conditions that need integrated care across the full continuum of services.[13]

In contrast, **centres of excellence** usually reflect a hub-and-spoke system that enables a patient's usual source of care to be within an arm's-length referral link to their cancer centre. The centre of excellence model has many benefits, which include the following:

• Provides integrated care, especially for patients with multiple conditions requiring interprofessional/multidisciplinary care that is co-ordinated with community care and family supports.
• Integrates rural and underserved communities, and thereby helps address geographic disparities.[13]
• Addresses healthcare gaps due to increasing population needs, the complexity of cancer care, and funding constraints that can lead to deficiencies in clinical human resources and insufficient funding for positions and reporting.
• Provides opportunities to conduct population-based research to improve quality, performance and education, and guide the development of evidence-based practices and treatments, which are integral to safe regional cancer care.[14]

CANCER PEDIA

Many jurisdictions in Canada have implemented the centre of excellence model and have become a reference point for countries such as Australia and New Zealand.[15,16] The model has also been adopted as part of the National Comprehensive Cancer Community Program in the United States. Through this program various local and extra-local cancer care entities are linked to other hospitals, community-based organizations, national comprehensive cancer centres (i.e., as designated by the National Cancer Institute), and state and national bodies. The national comprehensive cancer centres form the crux of these networks and have a mandate that includes: addressing health disparities and improved access to evidence-based cancer care for underserved populations; supporting community-based research through increased participation in clinical trials; and encouraging the adoption and use of electronic medical records.[17]

Currently, there are 27 designated national comprehensive cancer centres in the United States, which cover only a proportion of Americans.[18] Furthermore, barriers, such as little or no insurance coverage, prevent individuals from accessing cancer care and participating in therapeutic clinical trials. These discrepancies introduce biases into the research mandate of the national comprehensive cancer centres.[19]

C. NATIONAL CANCER CONTROL STRATEGY

3. DEVELOPMENT

Two key elements for launching the development of an NCCS appear to be: (1) a national government report making cancer a priority, and (2) stakeholder engagement.

National Government Report Making Cancer a Priority

Each of the five countries took a unique journey to arrive at their respective NCCS. A common thread in all five countries was a high-profile, government-commissioned national report that initiated dialogue on national cancer control. These landmark reports highlighted the increasing burden of cancer and the urgent need to develop a national reform strategy to address the issue. The reports put the impetus on each national government to initiate discussions about a cancer control plan, and galvanized key actors to advocate for making cancer a priority on the national healthcare agenda.

In four countries – Australia, England, New Zealand and the United States – the NCCS was developed using a top-down approach, which began with a federal mandate to engage stakeholders (e.g., government officials, policy-makers, researchers, patients, experts) to build a winning coalition and begin the development process.[20]

For example, the United States Department of Health and Human Services supported the development of *Cancer Control Objectives for the Nation: 1985-2000*, which was produced through the Healthy People initiative.[21,22] The report brought together experts from many areas and resulted in an aggressive goal to decrease cancer mortality by 50 per cent by the year 2000. It eventually became apparent that significant investments in cancer control were not achieving the desired result.[23] The National Cancer Institute commissioned a Cancer Control Program Review that emphasized the importance of societal trends when setting research priorities. As a result, cancer control took on a broader focus to include cyclical investments in population-based research and the application of evidence.[24] This led to the development of a more robust National Cancer Institute cancer control research framework, adapted from the National Cancer Institute of Canada framework, and the institutionalization of the National Comprehensive Cancer Control Program.[24,25]

In England, the Calman-Hine report called for a fundamental restructuring of services in response to the EUROCARE study, which found that England's survivorship outcomes were the worst in most cancers, as compared to other European countries.[26-28] As a result, the national government called the Downing Street Cancer Summit to discuss how England could accelerate reform by creating an NCCS as a core element of the National Health Service Cancer Plan.[11]

In contrast to the four countries noted above, Canada is a unique case study, since the development of its national strategy was driven from the bottom up.[29] Although the need for a cancer control strategy was identified in the 1992 report, *Cancer 2000*, it took a long process of voluntary collaboration from over 700 Canadian stakeholders (including more than 250 cancer survivors) to establish the Canadian Strategy for

Cancer Control (CSCC) a decade later in 2002.[30] Despite consensus to develop the CSCC, the federal government did not provide dedicated and sustained funding and allocated $60,000 to support the extensive work of eight action groups focused on the CSCC priority areas.[31,32] The vast majority of effort developing the strategy came from the in-kind contributions of the participants, in the form of time and travel.[33] Their work remained largely invisible to the general public and the cancer care community. This spurred the development of the Campaign to Control Cancer, which publicly advocated for system change to improve cancer care.[31] Through an aggressive marketing and media campaign, the work gained public attention and was on the political agenda during the federal election.[31] In 2006, the newly-elected government committed $260 million over five years to implement the CSCC, to be overseen by a new arms-length, non-profit organization, the Canadian Partnership Against Cancer.[34]

Stakeholder Engagement

Stakeholder engagement is essential to ensure that a cancer control plan is acceptable and relevant to the people for whom it is intended. Each stakeholder comes with different knowledge and networks, which provide a plurality of perspectives to inform the cancer plan.[29] Having a widespread mix of stakeholder involvement is vital to the success of an NCCS; one study found that a lack of broad stakeholder representation resulted in the failure of the NCCS or a re-evaluation of the strategy in some countries.[35]

All five countries engaged stakeholders from across the cancer control continuum in the development of their NCCS, including health professionals, cancer experts, other service workers, patient groups, representatives from other sectors, governmental and non-governmental leaders in the cancer field, and the public.[36] Engagement began early in the planning process, but varied by country in its degree of participation and inclusivity. Inclusivity was a key factor in Canada's experience, which coalesced fragmented efforts and mobilized a vision for a national strategy.[37]

Non-government organizations (NGOs) play a critical role in bringing together the necessary stakeholders, co-ordinating initial efforts in the early phases of NCCS development, and advocating for the cause. An NCCS can only be realized through a co-ordinated effort between the government and NGOs at the national and regional levels.[35]

4. IMPLEMENTATION

The successful implementation of an NCCS requires an organizational entity to build on the work that led to the government's commitment to cancer control. The entity can be within the federal health department or stand as an independent body charged with overseeing the development and implementation of the NCCS.[11] For example, the organizational entities in the United States and England – the National Comprehensive Cancer Control Program and the National Cancer Director/Taskforce, respectively – are national/federal agencies in the department of health. Canada, Australia and New Zealand have independent bodies: the Canadian Partnership Against Cancer, the National Cancer Control Initiative and the New Zealand Cancer Control Trust.[34,38,39]

To a certain degree, the governance structure for implementing an NCCS mirrors the organizational structures used to deliver cancer services. As federations, Australia, Canada and the United States have both a decentralized delivery of healthcare services and decentralized bodies overseeing the implementation of the NCCS. Australia's National Cancer Control Initiative is funded by government, but acts as an independent body operated and supported by Cancer Council Australia and Cancer Council Victoria.[39] It bridges government and NGOs in developing and executing cancer control initiatives through its basic operating budget.[40] The Canadian Partnership Against Cancer functions in the same way as Australia's National Cancer Control Initiative.[34] The United States' National Comprehensive Cancer Control Program encourages each state to develop its own comprehensive cancer control plan in partnership with the comprehensive cancer control coalitions, and provides seed funding to develop infrastructure and engage stakeholders in developing state cancer control strategies.[25] While stipends are provided from the national level, the bulk of implementation costs are absorbed by the subsidiary government and NGOs.[25]

CANCER PEDIA

In a decentralized healthcare governance model, provinces, states and territories allocate the global budgets they receive from their national/federal government to implement the strategy in their jurisdictions.[11] Implementation budgets can be significant. For example, the annual budgets of the provincial cancer agency, Cancer Care Ontario, versus the national Canadian Partnership Against Cancer reflects an 18:1 ratio. The Canadian Partnership Against Cancer's national contribution is critical for uniting stakeholders and providing the infrastructure to leverage the total spend on cancer services in Canada, which is $6 billion. It has also demonstrated the value of the Canadian Strategy for Cancer Control, and its funding has been renewed.[34]

In contrast, New Zealand and England are unitary states with a highly-centralized approach, which concentrates the majority of the governance function – including setting goals and indicators, allocating resources, monitoring implementation, managing programs, organizing services and evaluating performance – in the administration at the national level.[11] Although Cancer Control New Zealand is an independent body appointed to oversee the strategy, its role is primarily advisory.[41] Much of the authority and leadership remain within the Ministry of Health, which establishes and delegates responsibilities to various groups internally.[38,42] In England, a similar system exists, where the National Cancer Action Team and Taskforce are departments within the National Health Service charged with implementing ministry decisions.[11]

D. KEY ACTORS

5. THE STATE

The state includes the national/federal government, and regional/state/provincial governments.

National/Federal Government

In all five countries, commitment from the national or federal government was vital, and accelerated the development and implementation of the NCCS. Similar to the Canadian experience noted earlier, the New Zealand Cancer Control Strategy did not gain traction until the national government changed.[11] When it recognized cancer control as a top priority, government became the impetus that drove key actors to begin a dialogue and build the nascent cancer control infrastructure.[43] This led to establishing and funding government organizations (e.g., departments, steering committees, advisory groups, task forces) to oversee, steer and implement the NCCS. In addition, NGOs were contracted to co-ordinate and represent the non-government cancer sector in the strategy development process (e.g., New Zealand Cancer Control Trust).

National governments can also play a critical role in funding research to improve cancer services and control. This can take the form of a government research institute (e.g., United States National Cancer Institute; Australian Health and Medical Research Council) or a partnership with an NGO (e.g., England's National Cancer Research Institute; the Canadian Cancer Research Alliance).

Regional/State/Provincial Governments

Similar to national governments, subnational governments face many political pressures, financial constraints and competing interests. This is definitely the case in countries where the healthcare system is decentralized and decision-making responsibilities are delegated to the state, territory or province. For example, in the United States, implementation of state cancer control plans is contingent upon supplementary investments from the state.[25] In contrast, countries with centralized decision-making, such as England and New Zealand, implement strategies from the national level, with cancer-governing entities managing the funds they are allocated, including implementing decisions from the parent ministry or department of health, co-ordinating actors to develop current and new initiatives, and monitoring progress.[11]

The analysis of five countries found that regardless of where decision-making authority was situated, each country's subnational governments participated in developing national and regional cancer control strategies. This ensured that the interests of the regions were represented, that the strategies were population-based, and that priorities were focused on interventions or programs that would effectively impact the greatest proportion of the population, given the resources available.[44] Subnational involvement also provided opportunities for knowledge exchange and collaboration at a national level.[37] Finally, regional governments' recognition of cancer control as a national priority may also be a prerequisite to begin cancer control activities at the regional level.

6. NON-GOVERNMENT ORGANIZATIONS

NGOs often serve as the catalyst for a national conversation regarding the need for cancer control. When policy discussions are dominated by policy elites, NGOs bring an outside voice to broad policy discussions and the policy environment.[45] Although this chapter has identified a dichotomy of top-down versus bottom-up approaches to developing an NCCS, a bottom-up approach was part of the process in all five countries. By supporting and rallying key stakeholders to create coalitions, NGOs raised the awareness of cancer control and the importance of cancer control in the healthcare agenda at all government levels.[35]

The essential role of NGOs includes engaging and mobilizing stakeholders. Advocacy and leadership training help to create champions for the cause. In Canada, the National Cancer Leadership Forum was created to bring together cancer stakeholders and create a unified voice for change in cancer care. More than 40 organizations participated in the forum, which resulted in the Campaign to Control Cancer marketing strategy. The forum also provided training workshops to groups across Canada as a way to expand the network, engage government officials and raise awareness of the need for cancer control in the public eye.[31]

NGOs also play an important role funding cancer research and disseminating research results. Various cancer societies around the world serve as charities that fundraise for research. The former Australian Cancer Society (now Cancer Council Australia) produced multiple reports emphasizing the importance of cancer control, and provided the foundation for the development of the National Cancer Control Initiative.[39] The Canadian Cancer Society housed the former National Cancer Institute of Canada (now the Canadian Cancer Society Research Institute) and has cumulatively funded over $1 billion of cancer research.[46] Moreover, the organization was a major funder of the early efforts of the Canadian Strategy for Cancer Control, matching the federal government's investment, which resulted in $650,000 to begin the work.[37] Cancer societies also provide free or highly-subsidized support to patients and families, public education and public health promotion.[47]

Once an NCCS is initialized, the role of the lead NGO changes. The national government takes on the onus and leadership for implementing the strategy, whereas the NGO takes on an advisory role.[35] This occurred in New Zealand and Australia, where the New Zealand Cancer Control Trust and Cancer Council Australia, respectively, were contracted to be advisors and a voice for the non-government cancer sector in strategy development.[42]

7. PATIENTS AND THE PUBLIC

The World Health Organization has declared that cancer control planning should involve the general public and civic leaders, whose knowledge and awareness can be a driver in persuading political leaders to commit to the cause.[36] Their perspectives can help promote efficient and effective service provision at the local level.[48]

In the five countries reviewed, public engagement was a common element in the cancer strategy planning process:

- In New Zealand, there is a statutory requirement for public consultation on major policy changes.[42]
- In Australia, patients and consumers were consulted about setting priorities in the inaugural five-year plan of the National Cancer Control Initiative, and have been similarly involved in all successive iterations.[39,40]
- In England, the National Health Service has a long-standing history of engaging and promoting the involvement of the public to inform policies and healthcare improvements. The rationale is that the public are funders and users of healthcare services, whose perspectives are often overlooked and who may be useful to improving the quality of services and accountability.[49] Patient involvement legitimizes the need for improved and new services, validates the appropriateness of services and gains political support.[44]
- In Canada, a core element in the Canadian Strategy for Cancer Control is the Canadian Cancer Action Network. This organization co-ordinates patient advocacy groups across Canada through the establishment of patient and community networks. The Canadian Cancer Action Network's main goal is to ensure that patient interests remain a key priority on the national cancer agenda, and to unite all cancer-site patient organizations so that all voices can participate in the development of the network.[50]

CANCER PEDIA

The examples from England and Canada illustrate how patients can participate in the development of an NCCS through their governments and NGOs. Individuals and groups of patients also have a role to play in cancer advocacy. The Movember Foundation is a powerful example of a viral movement started by a small group of individuals. The foundation raises awareness and funds for men's health – in particular, testicular and prostate cancer – and has funded more than 1,200 projects in 20 countries.[51] High-profile patients, such as Katie Couric, have been strong advocates for cancer patients by sharing their experiences and fundraising. Couric began advocating for colon cancer prevention after her husband passed away from the condition. Her efforts included a week-long public awareness series on her television show and fundraising to finance a public awareness campaign for more colon cancer research.[52]

8. PROFESSIONAL SECTOR

The professional sector primarily provides leadership and technical expertise in the development of an NCCS. By serving on various cancer control committees, professionals are involved in all aspects of cancer control, including planning, implementing, delivering care and evaluating impacts. Some tasks performed by the professional sector include, but are not limited to: reviewing evidence; summarizing progress; estimating costs and cost-benefits; establishing links with other strategies and sub-strategies; identifying opportunities and constraints; and identifying database requirements.[43] The professional sector can also champion the cancer control movement and the essential elements for effective cancer care (e.g., interdisciplinary collaboration, integrated care, patient-centred care) by engaging peers, mentoring colleagues and disseminating findings.[44]

9. INDUSTRY

Industry plays a role in the research and development of therapeutics, diagnostic equipment, information systems and preventative products used for cancer control and care. Industry's involvement in the cancer control dialogue is critical, given that product prices directly impact the delivery of, and access to, care. For example, between 1991 and 2002 spending for lung, colorectal and breast cancer increased substantially in the United States due to the increased use and costs of chemotherapy and radiation therapy. Similarly, imaging technologies, such as PET and MRI, are being used more frequently and are becoming more expensive.[53]

Industry contributes to cancer control by collaborating with researchers in clinical trials and financing the evaluation and assessment of new products. For example, in the United States, the National Comprehensive Cancer Control Program's public-private partnerships are designed to bring state of the art care to all cancer patients in a community through National Cancer Institute-sponsored research programs.[17]

The private sector also collaborates with public organizations and NGOs on shared cancer prevention goals.[54] Examples include sponsorships, cause-related marketing, event engagement, corporate donations, in-kind donations such as pro bono services or goods, the volunteerism of staff, and funding patient advocacy groups initiatives.[55] There are debates about the appropriateness of industry financial support, given that it may undermine the independence of advocacy groups and label them as allies in advocating for the consumption of certain brands or products.[56]

E. ENABLERS AND BARRIERS

The analysis of the five countries also identified enablers and barriers to developing, implementing and delivering an NCCS.

10. ENABLERS

Policy Coalitions

NGOs play an important role in engaging stakeholders across the cancer control continuum. Policy coalitions help to establish a leadership core that can begin planning and developing infrastructure in preparation for the national government's commitment to implement an NCCS.

Timing of the Political Cycle

New Zealand cancer control did not become a priority until the incumbent government was replaced.[11] In Canada, the Campaign to Control Cancer's marketing and lobbying efforts raised public awareness of cancer control and pushed the issue on the political platform during the federal election.[31] Although the timing of the political cycle is not under the control of policy coalitions, it is an important consideration in cancer planning and advocacy efforts.

Public Reporting

Public reporting is an enabler in three ways. One, it can play a significant role in highlighting the need for reform at the national level, and provide a rallying point for coalitions to engage other stakeholders and government in cancer control. Two, public reporting provides a critical review of the effectiveness of current strategies and policies, and gives a base upon which to leverage successes, and identify gaps and areas for improvement. Three, public reporting ensures public accountability and transparency on how resources are used and their impact. Although public reporting does not appear to dramatically affect patient behaviour, many studies have shown that clearly linking strategy with improvements can positively impact behaviours in various groups in healthcare, such as administrators and clinicians.[57]

Health Information Technology

Adopting and using health information technology makes it possible to monitor and improve cancer control through surveillance, system planning, program management, budgeting, and clinical and system quality improvement efforts.[58] Health information technology enables the development of comprehensive patient records and more informed patient care decisions. Registry information can be used to generate evidence and support decision-making in areas such as health services, public health, epidemiology, biomedicine, policy research and advocacy. Comprehensive information also allows policy-makers to assess the effectiveness and efficiency of their policies.[59]

Health information technology can also provide a platform for knowledge exchange, collaboration and decision-making. For example, the knowledge management platform adopted by the Canadian Partnership Against Cancer – cancerview.ca – provides stakeholders with resources, evidence and information to support the implementation of the Canadian Strategy for Cancer Control.[60] In addition, it offers an avenue for virtual collaboration, knowledge exchange and co-ordination of efforts, along with tools that support the projection and modelling of potential cancer control decisions and their impacts.[34] Other information technology innovations, such as telehealth, have the potential to increase access to health information and healthcare by overcoming geographical barriers to provide care for underserved and remote populations.[61]

International Collaboration

The five countries collaborated to varying degrees with international organizations in developing and supporting their NCCS. For example, the Canadian Cancer Society/National Cancer Institute of Canada and the United States National Cancer Institute cross-fertilized their efforts by iteratively building on each other's work to develop their respective cancer control frameworks.[24] The New Zealand Cancer Control Trust included members from the United Kingdom, Canada and Australia, who served as peer reviewers in developing New Zealand's cancer control strategy.[42]

From a research perspective, international studies such as EUROCARE and CONCORD provide comparisons of cancer survivorship to inform care benchmarks. Not only do these studies allow countries to rank the effectiveness of their cancer programs comparatively, they also provide a baseline to assess the effects of cancer control initiatives in subsequent studies.[62] The first EUROCARE report was instrumental in advancing cancer care reform in England.[11] EUROCARE was a product of the International Agency for Research on Cancer (IARC), which is a World Health Organization subsidiary responsible for co-ordinating interdisciplinary international research and collaboration.[63]

CANCER PEDIA

11. BARRIERS

Fiscal Challenges

Irrespective of voluntary and in-kind contributions from NGOs, industry and other stakeholders, governments must provide sustainable funding to develop and implement an NCCS. The current economic climate could be a barrier if funds are reallocated from the NCCS to other government priorities, although this has not been the case in the United States.

Long-term financial support from government enables governing bodies to focus on planning and evaluating the strategy, rather than securing funding. It gives a sufficient time frame to evaluate the impact of the strategy and its initiatives. Financial support also signals to potential collaborators that the endeavour is valid, which may incent them to participate in the process.[64]

Timing of the Political Cycle

Identified earlier as an enabler, the timing of the political cycle can also be a barrier. Governments are transient and may change depending on their re-election success. A new, incoming government with a different ideology may influence policy in an opposing direction and make other issues a priority.[64]

Competing Priorities Within Healthcare

Other healthcare issues – such as diabetes or heart disease – may be as important as cancer in the public eye and the political arena. This means that multiple important causes must compete for finite resources. Although it is essential to advocate for and educate policy-makers on cancer control as a top healthcare priority, efforts must also go into collaborating with other groups to address mutual interests, such as targeting similar risk factors for disease.[65]

Non-Cancer Control Specific Policies

Policies may not sufficiently support the development, implementation and delivery of a cancer control strategy. For example, some governments have legislation to protect patient confidentiality and prevent the abuse of individual information. Stringent privacy policies to govern the use of, and access to, personal health information in cancer registries may impede surveillance efforts, cancer registration and research.[66] Policies such as informed consent protect patient autonomy and privacy; however, the cost of obtaining consent on a large scale can be burdensome and hinder the development of evidence. Balancing patient confidentiality with the social benefits of conducting research using registry data requires appropriate policies, proper safeguards and social trust.[67]

Another example of a policy as barrier is the remuneration structure for providers. There are debates about how certain funding structures – such as fee-for-service – can suppress collaboration, while creating perverse incentives to use resources inefficiently and ineffectively; this can cause resistance to change.[68] High-level policies must be developed to support the cultural shift from a procedural-focused to a quality-focused approach.[68] Policies for public reporting can help provide accountability for quality. For example, performance reports have not only been used to restrict the privileges of lower-quality clinicians, their public release has played an important role in mobilizing physicians and hospitals to improve their practices.[69]

Fragmentation of Stakeholders

The success of an NCCS depends on its ability to co-ordinate and integrate multiple disciplines. The fragmentation of stakeholders may be due to logistical and financial barriers. To address these barriers, efforts are needed to strengthen linkages and the use of health information technology.[70]

Categorical funding – where funds are allocated to separate categories – has been identified as a significant impediment to cancer control. This funding approach restricts how federal funding is used, limits flexibility in how stakeholders work within their distinct environments, and creates many cultural issues that may hinder cancer control programming and collaboration. Stakeholders may fear losing their categorical funding to a block grant allocated to a competing interest in cancer care or cancer control. As well, successful programs

that have large categorical funding may not want to "fix something that is not perceived to be broken" or collaborate, due to a sense of self-sufficiency. In this instance, engaging multiple disciplines and using organizational behaviour and change management expertise is useful.[64]

Population Inequities

A lack of universal coverage can create health disparities and underserved populations that have higher levels of cancer, including incidence, prevalence, mortality, survivorship issues, co-morbidities and overall burden. Although disparities have been linked to age, gender, ethnicity/race and geography, the most common contributing factors are limited insurance, limited access to care and socio-economic status. These factors are barriers to effective cancer control, especially since underserved populations have a higher probability of late-stage cancer, which leads to higher treatment costs and more deaths. These consequences can be mitigated with better access to primary and secondary prevention measures.[71]

A population-based approach is necessary to understand the needs of communities. This requires capturing data that spans the cancer continuum, including primary prevention (i.e., risks and health behaviours in the healthy populations), secondary prevention (i.e., screening and diagnosis), and tertiary prevention (i.e., treatment, survival, quality of life, and palliative care). While national cancer registries capture those diagnosed with cancer, the data captured outside of these registries are usually collected in a discrete manner and only include those who have interacted with the healthcare system. This underlines the need to improve the content and quality of cancer surveillance, with a focus on disparities in health and access to high-quality care.[72]

Earlier, this chapter reviewed the potential of a hub-and-spoke model to address issues of inequity. Although some communities may not have enough people to achieve efficiencies of scale and experience across all diagnoses and forms of care, it has been demonstrated that population density is not a prerequisite for the successful implementation of this model.[13] A careful analysis of the appropriateness of the model is, however, needed before decisions are made about its implementation; the availability of resources and cancer control priorities must be considered.[16] Failure to perform a thorough analysis may result in opportunity costs related to other potentially disruptive innovations in cancer care, defined as "cheaper, simpler, more convenient products or services that start by meeting the needs of less-demanding customers".[73]

Cultural and Religious Barriers

Culture significantly shapes a person's perceptions of health and health-related behaviors, which can have a significant impact on, and present barriers to, the effective delivery of cancer care. The New Zealand Cancer Control Strategy observed inequalities in cancer care leading to poorer health status, regardless of socio-economic status, in the Māori population.[74] The Māori have a holistic philosophy of health, which includes interrelated spiritual, mental, physical and family dimensions as the foundation of good health. Healing is rooted in traditional invocations, counselling by tribal elders, cultural assessment, plant and berry remedies, the use of language and traditional healers. A failure to appreciate the impact of cultural beliefs on clinical realities has often resulted in misdiagnosis and mismanagement of the population, and created a greater divide between traditional Māori treatments and the western clinical model of care; a balance between the two – rooted in a commitment to understanding and cultural sensitivity when delivering healthcare – has been critical in responding to the needs of the Māori.[75,76]

Gender is another factor that may present barriers to effective cancer control. Different body parts potentially generate more stigma than others, especially with gynecologic, prostate and breast cancers. In some cultures, these body parts are taboo. Women with potential gynecological or breast cancer symptoms may be hesitant to talk to their physicians. They may be less willing to undergo necessary physical examinations to assess the causes of the symptoms.[77] This is further exacerbated in male-dominated cultures, where women are dependent on the male in the household. In these societies, a scarcity of female practitioners may inhibit the early diagnosis of breast cancer, as husbands often bar their wives from having breast examinations from male doctors.[78]

Patient perceptions of their physicians may also impact the delivery of cancer care. In some cultures, physicians are viewed as the epitome of expertise and are unquestioned.[79] In others cultures, greater physician interaction with patients, such as the number of questions asked, implies a poorer and lower

CANCER PEDIA

quality of healthcare.[80]   A deference to physicians can compromise the quality of cancer care, especially if the clinical decision-making process is financially incentivized, rather than based on best cancer control practices.[68] The rise of health consumerism may curb this barrier through better informed and engaged patients. It may also have unintended consequences, such as elevated patient expectations and demands.

In some cultures, having newer, innovative treatments or having more procedures is equated with receiving better quality of care, whereas older treatments are often associated with deprivation. This attitude can result in a vulnerability to industry marketing that drives an increasing demand for newer and more costly medications.[68] It has been argued that industry funding for patient groups has the same effect.[81] Physicians may be susceptible to physician-directed industry marketing that selectively features favourable data about effectiveness.[68] This underscores the importance of embedding focused research, health technology assessment and dissemination within the NCCS.[82]

F. THE FUTURE

There will continue to be pluralism in the field of cancer control oversight and policy, as the field is embedded in local culture and fiscal capacity. Happily, there are multiple ways in which jurisdictions can systemically tackle the development of comprehensive cancer control strategies. Many low- and middle-income countries have adopted a basic package of approaches and are on the road to better cancer control. Global efforts are required to advance basic prevention, treatment and palliative care services for cancer patients, recognizing the real challenges of fiscal capacity to delivery comprehensive services.[83]

G. REFERENCES

1. Ngoma T. World Health Organization cancer priorities in developing countries. Annals of Oncology. 2006;17:viii9-viii14.
2. Lameire N. Healthcare systems - an international review: an overview. Nephrology Dialysis Transplantation. 1999;14:3-9.
3. Kutzin J. A descriptive framework for country-level analysis of health care financing arrangements. Health Policy. 2001;56(3):171-204.
4. Wendt C, Frisina L, Rothgang H. Healthcare system types: a conceptual framework for comparison. Social Policy & Administration. 2009;43(1):70-90.
5. Reid TR. The healing of America: a global quest for better, cheaper, and fairer health care. New York: Penguin Press; 2009.
6. Thomson S, Osborn R, Squires D, Reed S. International profiles of health care systems, 2011. New York: The Commonwealth Fund; 2011.
7. Knaul F, Frenk J, Shulman L. Closing the cancer divide: a blueprint to expand access in low and middle income countries. Boston, MA; 2011.
8. World Health Organization. Health systems financing: the path to universal health coverage plan of action health. Geneva, Switzerland: World Health Organization 2012.
9. Towards universal coverage: concepts, lessons, and public policy challenges. WHO/World Bank ministerial-level meeting on universal health coverage 2013 February 18-19; Geneva: World Health Organization & The World Bank.
10. The World Health report: health systems financing: the path to universal coverage. Geneva, Switzerland: World Health Organization; 2010.
11. Caron L. Organizational structures for cancer control. In: Elwood SBSMJ, editor. Cancer Control. 1 ed. New York: Oxford University Press; 2010. p. 317-39.
12. Donaldson MS. Engineering tools and methods in the delivery of cancer care services. In: P.P. Reid WDCHJ, editor. Building a better delivery system: a new engineering/health care partnership. Washington, DC: National Academies Press; 2005. p. 177-82.
13. Robinson JC. Managed consumerism in health care. Health Affairs. 2005;24(6):1478-89.
14. Vandenberg T, Coakley N, Naylor J, DeGrasse C, Green E, Mackay JA, et al. A framework for the organization and delivery of systemic treatment. Current Oncology. 2009;16(1).
15. Adams P, Hardwick J, Embree V, Sinclair S, Conn B, Bishop J. Literature review: models of cancer services for rural and remote communities. Sydney, Australia: Cancer Institute NSW; 2009.
16. Cranleigh H. Report to the ministry of health new models of care for medical oncology. Aukland, New Zealand; 2011.

17. Clauser SB, Johnson MR, O'Brien DM, Beveridge JM, Fennell ML, Kaluzny AD. Improving clinical research and cancer care delivery in community settings: evaluating the NCI community cancer centers program. Implementation Science. 2009;4(1).
18. What makes an NCCN cancer centre? : National Comprehensive Cancer Network; 2018 [cited 2018 March 13]. Available from: https://www.nccn.org/patients/about/member_institutions/qualities.aspx.
19. Klamerus JF, Bruinooge SS, Ye X, Klamerus ML, Damron D, Lansey D, et al. The impact of insurance on access to cancer clinical trials at a comprehensive cancer center. Clinical Cancer Research. 2010;16(24):5997-6003.
20. Sabatier PA. Top-down and bottom-up approaches to implementation research: a critical analysis and suggested synthesis. Journal of Public Policy. 1986;6(01):21.
21. Greenwald P, Sondik EJ. Cancer control objectives for the nation: 1985-2000. Washington, DC; 1986.
22. Given LS, Black B, Lowry G, Huang P, Kerner JF. Collaborating to conquer cancer: a comprehensive approach to cancer control. Cancer Causes & Control. 2005;16(S1):3-14.
23. Friedman C. The promise of comprehensive cancer control. Preventing Chronic Disease. 2009;6(4):A111.
24. Best A, Hiatt RA, Cameron R, Rimer BK, Abrams DB. The evolution of cancer control research: an international perspective from Canada and the United States. Cancer Epidemiology, Biomarkers & Prevention. 2003;12:705-12.
25. Steger C, Daniel K, Gurian GL, Petherick JT, Stockmyer C, David AM, et al. Public policy action and CCC implementation: benefits and hurdles. Cancer Causes & Control. 2010;21(12):2041-8.
26. Calman KC, Hine D. A policy framework for commissioning cancer services: a report by the expert advisory group on cancer to the chief medical officers of England and Whales. London, England; 1995.
27. Berinno F, Sant M, Verdecchia A, Capocaccia R, Hakulinen T, Esteve J. Survival of cancer patients in Europe: the EUROCARE study. Lyon, France: IARC; 1995.
28. Haward RA. The Calman–Hine report: a personal retrospective on the UK's first comprehensive policy on cancer services. The Lancet Oncology. 2006;7(4):336-46.
29. Cancer control: knowledge into action. WHO guide for effective programmes: prevention (second). Geneva, Switzerland: World Health Organization; 2002a.
30. Cancer 2000: strategies for cancer control in Canada. The proceedings of cancer 2000. Toronto, ON: Cancer 2000 Task Force; 1992.
31. Green E, Kapusta B, Kelly P. Advocacy to advance cancer care policy. Oncology Exchange. 2007;6(1):53-5.
32. Michael J Prince. A cancer control strategy and deliberative federalism: modernizing health care and democratizing intergovernmental relations. Canadian Public Administration/Administration publique du Canada. 2006;49(4):468-85.
33. Canada - World Health Organization; 2006; Teleconference: World Health Organization.
34. Fairclough L, Hill J, Bryant H, Kitchen-Clarke L. Accelerating knowledge to action: the pan-Canadian cancer control strategy. Current Oncology. 2012;19(2).
35. Bennett JA, Brewer C, Beyko S, Bennett SAL. Cancer control strategies in eleven OECD countries. 1999.
36. National cancer control programmes: policies & managerial guidelines. Geneva, Switzerland: World Health Organization; 2002b.
37. Canadian strategy for cancer control. World Health Organization; 2006.
38. Minister of Health. The New Zealand cancer control strategy. Wellington, New Zealand: Ministry of Health and the New Zealand Cancer Control Trust; 2003.
39. Anderiesz C, Elwood M, Hill DJ. Cancer control policy in Australia. Australia and New Zealand Health Policy; 2006.
40. National cancer control initiative 1997-2002 report. Melbourne, Australia: National Cancer Control Initiative; 2003. Contract No.: 1-82.
41. Welcome. Cancer Control New Zealand; [cited 2013 April 27]. Available from: http://www.cancercontrolnz.govt.nz/.
42. New Zealand WHO Interview. World Health Organization; 2011.
43. Gavin J, Marshall B, Cox B. Progress towards a New Zealand cancer control strategy Aukland, New Zealand New Zealand Cancer Control Trust 2001.
44. Otter R, Qiao YL, Burton R, Samiei M, Parkin M, Trapido E, et al. Organization of population-based cancer control programs: Europe and the World. Tumori Journal. 2009;95(5):623-36.
45. Klugman BB. The role of NGOs as agents for change. Development Dialogue; 2000.
46. Canadian Cancer Society Research Institute. Canadian Cancer Society; 2013.
47. Burton RC. Cancer control in Australia: into the 21st Century. Japanese Journal of Clinical Oncology. 2002;32:S3-S9.

CANCER PEDIA

48. Tritter JQ, Barley V, Daykin N, Evans S, McNeill J, Rimmer J, et al. Divided care and the third way: user involvement in statutory and voluntary sector cancer services. Sociology of Health & Illness. 2003;25(5):429-56.
49. Health Commitee. Health committee patient and public involvement in the NHS. 2007.
50. Canadian Cancer Action Network. Canadian Cancer Action Network; [cited. Available from: http://www.ccanceraction.ca/about.
51. Movember Foundation. [cited 2018 April 3]. Available from: https://www.movember.com/?reset=1.
52. Gorman C. Katie's crusade. TIME. 2000.
53. Sullivan R, Peppercorn J, Sikora K, Zalcberg J, Meropol NJ, Amir E, et al. Delivering affordable cancer care in high-income countries. The Lancet Oncology. 2011;12(10):933-80.
54. Stories of success: national comprehensive cancer control in action. Atlanta, GA: Centers for Disease Control and Prevention.; 2012.
55. Cancer Council Australia. How you can work with us. Cancer Council Australia; 2012 [cited 2013 April 27]. Available from: http://www.cancer.org.au/get-involved/corporate-partnerships/how-you-can-work-with-us/.
56. Mintzes Barbara. Should patient groups accept money from drug companies? No. BMJ. 2007;334(7600):935-.
57. Sullivan T, Huynh T, Aprikian A, Batist G, Lynch A. The Rossy Cancer Network: A philanthropy-driven quality program. Oncology Exchange. 2013;12(1):25-8.
58. Chafe R, Spencer P, Hudson M, Milnes K, Sullivan T. Exploiting the secondary use of health data for effective cancer control: opportunities and risks. In: CM F, editor. Data data everywhere - access and accountability. Kingston, ON: McGill-Queen's University Press; 2011. p. 151-70.
59. Flood CM, Thomas B. Searching for a sweet spot: how do we trade off research benefits with health information privacy concerns? In: CM F, editor. Data data everywhere - access and accountability Kingston, On: McGill-Queen's University Press; 2011.
60. Canadian Strategy for Cancer Control Governing Council. Canadian strategy for cancer control: a cancer plan for Canada. 2006 [cited 2013 April 27]. Available from.
61. Doorenbos AZ, Demiris G, Towle C, Kundu A, Revels L, Colven R, et al. Developing the Native People for Cancer Control Telehealth Network. Telemedicine and e-Health. 2011;17(1):30-4.
62. Coleman MP, Quaresma M, Berrino F, JM Lutz, De Angelis R, Capocaccia R, et al. Cancer survival in five continents: a worldwide population-based study (CONCORD). The Lancet Oncology. 2008;9(8):730-56.
63. About IARC. IARC: 2013 [cited. Available from: http://www.iarc.fr/en/about/index.php.
64. Abed J, Reilley B, Butler MO, Kean T, Wong F, Hohman K. Comprehensive cancer control initiative of the centers for disease control and prevention: an example of participatory innovation diffusion. Journal of Public Health Management and Practice. 2000;6(2):79-92.
65. Trapido EJ, Borras JM, Burton R, Samiei M, Elwood M. Critical factors influencing the establishment, maintenance and sustainability of population-based cancer control programs. Tumori Journal. 2009;95(5):637-45.
66. Coleman MP, Muir CS, Ménégoz F. Confidentiality in the cancer registry. British Journal of Cancer. 1992;66(6):1138-49.
67. Upshur RE, Morin B, Goel V. The privacy paradox: laying Orwell's ghost to rest. Canadian Medical Association Journal. 2001;165(3):307-9.
68. Emanuel EJ, Fuchs VR. The perfect storm of overutilization of health care. Journal of American Medical Association. 2013;299(23):2789-91.
69. Chassin MR, Hannan EL, DeBuono BA. Benefits and hazards of reporting medical outcomes publicly. New England Journal of Medicine. 1996;334(6):394-8.
70. Marchibroda JM. The impact of health information technology on collaborative chronic care management. Journal of Managed Care Pharmacy 2008;14(2):S3-11.
71. Cancer health disparities. National Cancer Institute; 2008 [cited 2013 April 27]. Available from: http://www.cancer.gov/cancertopics/factsheet/disparities/cancer-health-disparities.
72. Wingo PA, Howe HL, Thu MJ, Ballard-Barbash R, Ward E, Brown ML, et al. A national framework for cancer surveillance in the United States. Cancer Causes & Control. 2005;16(2):151-70.
73. Christensen CM, Bohmer R, Kenagy J. Will disruptive innovations cure health care? Harvard Business Review. 2000;78(5):105-12, 99.
74. The New Zealand cancer control strategy action plan 2005 – 2010. Wellington, New Zealand: Ministry of Health; 2005.
75. Durie M. The dynamics of Māori health. Auckland, New Zealand: Oxford University Press; 2001.

76. Durie MH. Maori cultural identity and its implications for mental health services. International Journal of Mental Health. 1997;26(3):23-5.
77. Daher M. Cultural beliefs and values in cancer patients. Annals of Oncology. 2012;23:66-9.
78. Ersin F, Bahar Z. Inhibiting and facilitating factors concerning breast cancer early diagnosis behavior in Turkish women: a qualitative study according to the health belief and health development models. Asian Pacific Journal of Cancer Prevention. 2001;12(7):1849-54.
79. Die-Trill. The patient from a different culture. Psycho-oncology. New York: Oxford University Press; 1998. p. 857-66.
80. Meleis A, Jonsen A. Ethical crises and cultural differences Western Journal of Medicine. 1983;138(6):889-93.
81. Alastair K, Mintzes B. Should patient groups accept money from drug companies? BMJ. 2007;334(7600):934-5.
82. Vinson C, Porta ML, Todd W, Palafox NA, Wilson KM, Fairley T. Research and comprehensive cancer control coalitions. Cancer Causes & Control. 2010;21(12):2033-40.
83. Gelband H, Sankaranarayanan R, Gauvreau CL, Horton S, Anderson BO, Bray F, et al. Costs, affordability, and feasibility of an essential package of cancer control interventions in low-income and middle-income countries: key messages from disease control priorities, 3rd edition. The Lancet. 2016;387(10033):2133-44.