

CANCER PREPAREDNESS AROUND THE WORLD

National readiness
for a global epidemic



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About this report

Cancer preparedness around the world: National readiness for a global epidemic is a report written by The Economist Intelligence Unit and sponsored by the biopharmaceutical companies Novartis, Pfizer and Roche. The content of this report is solely the responsibility of The Economist Intelligence Unit and the views expressed are not necessarily those of any of the sponsors.

The report looks at the diversity of the cancer challenge worldwide, as well as the current extent of efforts to address the disease and the essential elements to building enhanced preparedness. The report is based on several strands of research, as follows.

It introduces the Index of Cancer Preparedness (ICP), which looks at a wide range of elements that are relevant to cancer control. Created by EIU Healthcare, the ICP combines findings from around 45 separate data points to provide a comprehensive overview of how well the 28 included countries are doing in the key areas of this challenge.

Throughout the project, The Economist Intelligence Unit has benefitted from the input of an advisory board of experts from patient groups, think-tanks and academia, which convened in London in September 2018. Their advice has shaped the priorities of the study, as well as the content of the scorecard.

In addition to these advisers, we conducted 12 interviews with senior health-system officials, clinicians, cancer-control experts and patient-group leaders to obtain a more in-depth view of the issues involved.

Finally, supporting the research, and feeding into this publication, has been substantial desk research, including a wide-ranging literature review by EIU Healthcare in preparation for the advisory board meeting and further detailed study of specific topics that the ICP and interviews raised.

Our thanks are due to the following for their time and insight (listed alphabetically):

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- Lydia Makaroff, CEO, Fight Bladder Cancer UK, and former director, European Cancer Patient Coalition
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March 2019

Executive summary

Cancer is the world's second biggest killer, responsible for 9.6m deaths in 2018—roughly one out of six across the globe—and the leading or second largest cause of mortality before the age of 70 in over half the world's countries. The best, if imprecise, estimates are that its direct and indirect economic costs already exceed US\$1trn per year. Its incidence looks certain to increase markedly: the International Agency for Research on Cancer projects that demographic change alone, particularly population ageing, will lead to a 63% rise between 2018 and 2040.

This Economist Intelligence Unit report, sponsored by Novartis, Pfizer and Roche, looks at the complexities of this growing menace and at whether the world is ready to face it. In so doing, the study introduces The Economist Intelligence Unit's Index of Cancer Preparedness (ICP). It draws on a wide range of data relevant to cancer policy and control from 28 countries. The aims of the ICP are to allow benchmarking of national efforts and, even more, to initiate discussion on best practice in addressing the cancer challenge. In addition, the report draws on insights from both a high-level advisory panel and a series of expert interviews, as well as substantial desk research by The Economist Intelligence Unit.

The report's key findings include:

Cancer is a challenge as multifaceted as humanity. Cancer is a family of many diseases with distinct characteristics. They have in common, generally speaking, biological changes that favour the survival of specific cells, usually growing in tumours, to the detriment of the body as a whole. Carcinogens take many forms, including communicable diseases, genetic abnormalities, naturally

occurring agents (both internal and external to the body), manufactured chemicals, and environmental stress. This diversity of causes combines with the almost infinite variety of the human condition to turn the global epidemic of cancer into a kaleidoscope of national, or even local, ones. For example, in Mozambique, AIDS-driven Kaposi sarcoma is the leading cancer among men; in Mongolia, hepatitis-induced liver cancer; and in Montenegro, tobacco-caused lung cancer.

High-income countries currently have different and more cancers per person than middle- and low-income ones.

GDP and cancer have a complex relationship. Overall rates of incidence today mirror income status. As always with cancer, though, the picture is more complex. The main carcinogens, and the specific cancers arising, also tend to differ with income. In low-income areas, for example, communicable diseases are a common carcinogen, but much less so in most highly developed ones. On the other hand, lifestyle choices made possible by economic development, along with longer life expectancies, make certain cancers bigger problems where GDP is high. The best example of the split is that between the two most common cancers in women. Global heatmaps of breast-cancer incidence and measures of economic development resemble photos of the same scene, while one of cervical cancer could serve as a negative for either.

Middle- and low-income countries will suffer the largest increase in cancer incidence.

Already, despite their relatively lower per-head incidence rates, the greater populations in middle- and lower-income countries mean that 59% of cancer cases occur there. Looking ahead, the factors that

have muted incidence rates in these countries are set to diminish: much faster ageing and economic growth in emerging economies will drive a change in the number and type of cases to more closely resemble those in high-income states. Unfortunately, experience shows that cancers associated with wealth appear more quickly than those of poverty decline.

Middle- and low-income countries' health systems are struggling with today's cancer load, let alone tomorrow's greater one. The mortality-incidence (M:I) ratio (or the number dying in a given period divided by the number of new cases) is a rough measure of health-system success against cancer. It correlates closely, and negatively, with GDP. As a result, although 59% of cases are in middle- and low-income countries, they see 71% of deaths. The poorer performance compared with high-income countries reflects in part a different mix of cancers in the overall disease burden. The much bigger issue, though, is that these health systems are far less successful in finding and treating curable cancers.

The huge diversity of the cancer challenge across countries and levels of development calls for distinct local, multi-pronged responses. Cancer, with its wide range of potential causes, attendant variety in the forms it takes, and socio-economic drivers of risk is not a straightforward health challenge. Instead, effective cancer control includes a range of co-ordinated efforts in fields that include prevention, early diagnosis, treatment, palliative care and survivor support. Any given cancer may be best addressed by a different kind of intervention, and any given optimal national cancer strategy will therefore include a distinct mix of actions. As Princess Dina Mired, president of the Union for International Cancer Control, puts it "each country has its own cancer profile so the best solutions in each case are a combination of global and national practice. Success is really

all about which countries are better prepared to defeat cancer along the continuum of care."

The Economist Intelligence Unit's ICP is a useful benchmarking tool of overall cancer preparedness. The index covers 28 countries at various levels of economic development. In order to capture the breadth of factors that go into effective cancer control, the ICP presents data on 45 indicators relevant to specific parts of the prevention and care continuum as well as to the wider context in which such efforts occur. The sub-indicators accordingly range from matters as separate as the cost of cigarettes, through the number of oncologists, to perceptions of corruption. After each indicator is scored, they are aggregated using weight averages into sub-domains, domains, and eventually a single score. These numbers give an indication of how well countries are doing in the broad fields related to cancer preparedness. Although any such exercise has challenges and weaknesses, the overall scores do correlate with national M:I figures, indicating a robust relationship between our model (including its proxy measures) and wider cancer control reality.

We have identified the four essentials of cancer preparedness. The ICP provides a rich trove of comparable data across countries, and we encourage interested stakeholders to delve into them. Individual reports on all 28 countries would be far beyond the scope of this publication. Instead, the rest of the report considers the four essential elements of cancer preparedness that apply across countries and levels of economic development.

- **Essential investment:** the index results indicate that the link between higher GDP and better cancer outcomes probably reflects variations in the extent of investment in cancer control and healthcare more generally. Certain very effective, low-cost interventions exist, notably in

tobacco control. In aggregate, though, cancer preparedness is expensive. Spending on treatment in particular is typically associated with high costs. Meaningful investment is nevertheless unavoidable here, albeit national economic situations inevitably pose constraints. Lack of effective treatment undermines other elements of cancer control including those that can reduce costs and improve outcomes such as early detection and screening. Worse still, it leads to higher rates of catastrophic spending by patients and families seeking care. Finally, it makes cancer fatalism much more likely, thereby further corroding the impact of early detection efforts and even undermining prevention messages.

- **Essential roadmap:** The panoply of potential interventions and necessary actors in any given country's cancer-control efforts, as well as the value of co-ordination of initiatives, make national cancer control plans (NCCPs) a necessary part of preparedness. A comparison between cancer planning in Romania and Thailand suggests that effectiveness here saves lives. That said, while most countries now have NCCPs, too often they describe more aspirations than operational activities. Only 29% of index countries gain full marks in the NCCP sub-domain. More widely, a recent academic study of 150 plans indicates that many fall short in a range of basic areas. The nature and contents of an NCCP inevitably vary by country, but three necessary elements universally contribute to success: the plans must focus on interventions that address the specific needs of the population that the plan covers; they have to provide the necessary resources (and realism about what is available here should therefore shape the chosen interventions); and they have to be the collective efforts of all relevant actors. Underlying all three is an understanding that an NCCP is both a planning vehicle to allocate limited resources most effectively and a political

consensus-building exercise that brings together stakeholders.

- **Essential foundation:** Cancer control cannot occur in isolation; it must be embedded in an accessible, general health system. The ICP data reinforce this same message. Of our three domains, Health System and Governance scores have the closest correlation with national M:I ratios. The challenges for achieving the necessary integration vary with overall health system resources. Generally, in wealthier countries accessible care exists but links between oncology and other parts of the health system, notably primary care, frequently require improvement. In lower-income countries, the bigger issue is access to healthcare in the first place. In the latter case, rather than trying to build vertically integrated facilities, the best route to preparedness is to strengthen cancer control and health systems simultaneously. Rwanda provides a good example of what this can look like in practice.
- **Essential intelligence:** Cancer preparedness requires an understanding of the nature of the challenge as well as an indication of how well interventions are working. Accordingly, population-based cancer registries (PBCRs), which provide an overview of all cancer across a given group of people, are a core element of cancer control. This is yet another area that sets apart higher- and lower-income countries. A 2015 study, for example, reported that PBCRs covered 95% of North America's population, but only 1.9% of Africa's. Individual countries, notably China, have been rapidly broadening and strengthening their registry networks, and international efforts to bolster registration in low-income countries have existed for several years. It will take time for the results to show. The primary importance of PBCRs should not detract from the utility of other information sources. Mortality data are

crucial to understanding the cancer burden but too often need further strengthening. Large databases from payers—whether government health systems or private insurers—hold out substantial promise, especially as more countries seek to provide universal healthcare. As Colombia’s case shows, even where these cannot act as proxy PBCRs, they are able to provide key insights into the state of cancer treatment.

These four essentials are far from the complete solution to cancer preparedness: they are foundation stones that countries cannot afford to ignore. And the thinking behind them is not revolutionary. Cancer-control advocates have long understood their importance. The missing ingredient to achieving them within the cancer burden and socio-economic contexts of each country is not a lack of theoretical knowledge but of political will. It is time to act.

Key takeaways

Throughout this report are boxes that highlight the key points that policymakers and other stakeholders will find useful as they read through the next section of the text. We combine them here in a single box.

Chapter I: The scope of the challenge

- Cancer incidence is growing rapidly worldwide and, without action, so will cancer mortality.
- If it ever were a disease of the developed world, this is no longer the case. Incidence remains higher in wealthier countries, but all signs are that lower-income ones will close the gap. Moreover, because of poor cancer control, overall cancer mortality is already about the same in rich and poor states. The expected rise in incidence in the less developed states in particular will, without action, lead to substantial unnecessary death.
- Cancer is a family of diseases and national cancer burdens vary markedly because of the specific carcinogens that most affect populations. Local understanding and solutions are as important as global ones.

Chapter II: Introducing The Economist Intelligence Unit’s Index of Cancer Preparedness

- The Economist Intelligence Unit Index of Cancer Preparedness compares 28 countries across a range of areas relevant to cancer control.
- Its detailed data are publicly available and can help policymakers and other stakeholders to benchmark where their countries stand compared with global leaders and peer states as they shape appropriate national policies.

Chapter III: The four essentials of cancer preparedness

1. Essential investment: A closer look at the money-cancer control relationship

- Low-cost interventions to reduce the cancer burden certainly exist, but effective cancer control also requires investment, especially in the infrastructure, tools and personnel needed to treat the disease.
- The extent and nature of that investment is a political choice, and will vary by country, but, without effective treatment facilities, other cost-saving interventions, such as those around early detection, lose their value.
- An effective treatment capacity is also essential to address cancer fatalism, which undermines efforts across the entire cancer control continuum.

II. Essential roadmap: The national cancer control plan

- Effective cancer control planning saves lives.
- Ideally, every country should have a national cancer control plan (NCCP) in order to deploy its cancer control resources most effectively against the specific cancer burden it faces.
- A cancer element in a non-communicable diseases plan, although better than nothing, is a second best.
- NCCPs too often are more aspirational statements than operational documents. To be effective, they must focus on the specific cancer needs of the population covered, have realistic goals and budgets, and be drafted jointly with all relevant stakeholders.

III. Essential foundation: Integration with effective, accessible general health provision

- Cancer control should occur within the context of accessible general healthcare.
- In high-resource health systems, the most frequent issue in this area is the need for better integration of specialised cancer treatment with other medical provision, notably primary care. Ideally, patient-centred care should also involve any necessary social assistance.
- In low-resource systems, cancer control should be built into efforts to expand universal healthcare rather than happening in parallel.

IV. Essential Intelligence: Cancer registration and other data

- Where they do not exist, or cover only an unrepresentative part of the country, population-based cancer registries need to be strengthened. Without such information, cancer planning cannot focus narrowly on the specific needs of the country.
- Good mortality data are also essential to cancer control, and in too many cases worldwide this falls short.
- Policymakers should also make opportunistic use of other potentially valuable datasets, such as hospital cancer registries, patient-group-driven registries or information gathered by health systems. The last of these may grow in importance in low- and middle-income countries as universal healthcare becomes more common.

Chapter I: The scope of the challenge

Key takeaways

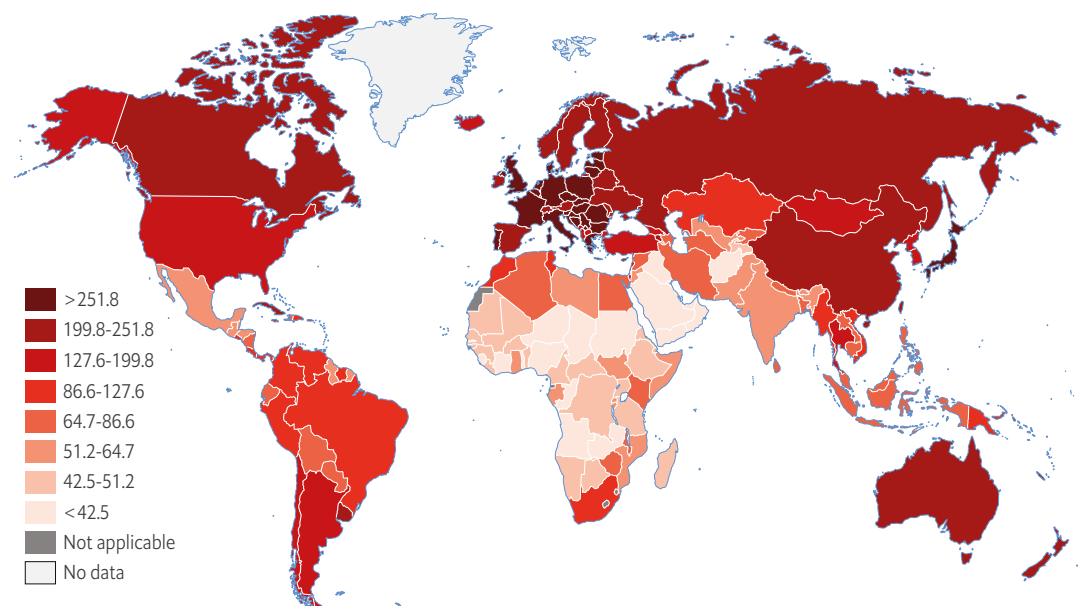
- Cancer incidence is growing rapidly worldwide and, without action, so will cancer mortality.
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- Cancer is a family of diseases and national cancer burdens vary markedly because of the specific carcinogens that most affect populations. Local understanding and solutions are as important as global ones.

A challenge of huge—if imprecise—proportions

Cancer ranks among the world's leading public health challenges. In 2018 malignant

neoplasms lay behind roughly one in six of all deaths globally, second only to cardiovascular disease.¹ Cancer was the leading or second biggest cause of death before age 70 in 91 of 172 countries in 2015.²

Estimated crude mortality rates in 2018, all cancers, both sexes, all ages



Source: World Health Organisation.

¹ Global Burden of Disease Data, Institute for Health Metrics and Evaluation, "GBD Compare Data Visualization" [Hereafter referred to as GBD Data].

² Freddie Bray et al., "Global Cancer Statistics 2018", *CA: A Cancer Journal for Clinicians*, 2018.

This big picture is clear; the exact numbers less so. The International Agency for Research on Cancer (IARC)—a part of the World Health Organisation (WHO)—estimates that in 2018 18.1m people developed cancer worldwide and 9.6m died from it.³ But estimates for 2017 from the Global Burden of Disease study—a highly respected international collaboration that uses a wider range of data than the IARC but with less robust exclusion criteria⁴—put incidence about a third higher, at 24.3m, although the number of deaths is only 1% above the IARC’s 2018 figure.⁵

Like global incidence and mortality, cancer trends also combine clarity about the overall direction with some uncertainty over details. As Rengaswamy Sankaranarayanan, senior visiting scientist to the Office of the Director at the IARC, says, “Everyone realises that the absolute number of cancers is increasing in all countries.” Two key drivers are population growth, around 1% per year worldwide, and—a bigger contributor—ageing populations

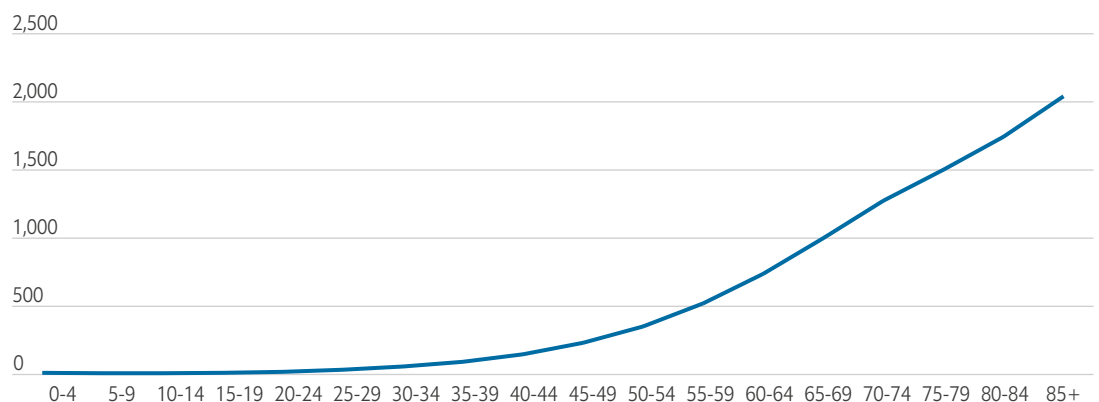
(see chart 1); in general, age correlates closely with cancer risk, although childhood cancers such as leukaemia are an important paediatric health issue.

It is difficult to quantify how much cancer incidence has been growing. Changes in the quality of data collection and the estimation methodology make direct comparison of IARC data over time problematic, but the difference between today’s global incidence and mortality figures compared with those issued for 2012—14m and 8.2m respectively⁶—at least illustrate how quickly the challenge that health authorities perceive has been expanding.

Looking ahead, the potential impact of ageing and population growth is huge: the IARC projects, in the absence of better cancer control, that these demographic shifts will lead to 63% more cancer cases per year by 2040, or 29.5m.⁷ As a result, according to a 2018 study, the disease “is expected to rank as

All cancers 2018 estimated global age-specific incidence rates per 100,000 population

Age range



Source: The Economist Intelligence Unit.

³Ibid.

⁴ See discussion of GBD cancer data in supplement of Global Burden of Disease Cancer Collaboration, “The Global Burden of Cancer 2013,” *JAMA*, 2015.

⁵ GBD Data.

⁶ Bernard Stewart and Christopher Wild, eds., *World Cancer Report 2014*, 2014.

⁷ J Ferlay et al., “Global Cancer Observatory: Cancer Tomorrow”.

the leading cause of death and the single most important barrier to increasing life expectancy in every country of the world in the 21st century.”⁸

However important, ageing and population growth are not the full picture. Other factors, discussed below, play a huge role, but how they may evolve over time is difficult to generalise. Changes in published IARC age-standardised rates (ASRs) of incidence—which eliminate the effect of population growth and ageing from the underlying figures—are suggestive of the overall direction of travel. Notwithstanding differences in data quality and methodology, the IARC’s global ASR figure in 2018 (197.9 per 100,000) is 9% higher than that of 2012.⁹ It may be unsafe to read much into this: according to Global Burden of Disease data, over the longer term, ASR incidence for cancer has remained consistent.¹⁰ At the very least, though, current trends suggest that, without better prevention, overall shifts in these various risk factors are unlikely to reduce the coming demographically driven surge in cancer.

Like the human toll, cancer’s economic burden is large and difficult to quantify. A frequently cited WHO figure, from 2010, is US\$1.16trn in annual direct and indirect costs or roughly 2% of that year’s global GDP. The authors’ laudable transparency about how they reached this number, though, shows that even by the standards of back-of-the-envelope calculations, the figure is better at

illustrating the likely order of magnitude than serving as a reliable estimate.¹¹ The problem is that it is currently the best guess available. However, the 2018 estimate of IQVIA, a consultancy, that global annual spending on cancer and supportive therapy drugs had reached US\$133bn,¹² makes an overall figure encompassing everything from medical costs to lost productivity of around US\$1trn a reasonable supposition.

In short, cancer is an already substantial problem that will only increase in size in the years ahead. This “growing burden has certainly attracted policymaker attention,” notes Dr Sankaranarayanan. This is not only because of aggregate statistics. Indeed, the experience of Lydia Makaroff, CEO of Fight Bladder Cancer, a UK-based advocacy group, and former director of the European Cancer Patient Coalition, in dealing with members of EU institutions is probably true of leaders in most developed and many developing countries: “a lot of parliamentarians are either cancer survivors themselves or have family or staff members who have experienced the disease. Cancer touches most families and is of personal importance to most people in the European Parliament and European Commission.” Such a degree of concern may at least provide the focus needed to address an issue which, it turns out, is not only huge but also complicated—both in the nature of the disease and in its causation (see *What is cancer?: Between a concept and a condition*).

⁸ Freddie Bray et al., “Global Cancer Statistics 2018”, *CA: A Cancer Journal for Clinicians*, 2018.

⁹ Bernard Stewart and Christopher Wild, eds., *World Cancer Report 2014*, 2014; Freddie Bray et al., “Global Cancer Statistics 2018”, *CA: A Cancer Journal for Clinicians*, 2018.

¹⁰ GBD Data.

¹¹ Bernard Stewart and Christopher Wild, eds., *World Cancer Report 2014*, 2014.

¹² *Global Oncology Trends 2018*, 2018.

What is cancer?: Between a concept and a condition

The closer one looks at cancer, the more complex a challenge it becomes. Even a definition is far from simple because it is not one disease, but a family of them.

The US National Cancer Institute defines the word as a term for “diseases in which abnormal cells divide without control and can invade nearby tissues [or]...spread to other parts of the body through the blood and lymph systems.”¹³

How to define the nature of that abnormality, though, remains a matter of debate, as is how cellular DNA goes rogue in the first place.¹⁴ One recent study nevertheless gives a useful list of cancer cell characteristics:

- genetic changes that provide growth and proliferation advantages over other cells;
- altered responses to cell stresses that favour overall survival of cancerous ones;
- creation of additional blood flow to cancer cells through some means;
- invasion of other areas of the body by these cells to form new tumours;
- metabolic rewiring, or changes in how and the extent to which cells use nutrients;
- the existence of a micro-environment of otherwise normal cells around the tumour which abet its growth; and
- modulation to the immune system to allow these cells to escape detection and destruction.¹⁵

Any such conceptual generalisation of cancer, though, belies a vast diversity within this family of diseases. To begin with, the kind of cell where the cancer first develops shapes its form. Carcinomas, for example, start in the skin or tissues that line or cover internal organs; sarcomas in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue; and lymphomas in the immune system.¹⁶ The forms these take can be quite different. For example, leukaemia, which affects blood cell production, does not even produce tumours, the most characteristic of cancer symptoms.

Meanwhile, the nature and challenge of cancer also varies according to the specific organ where it initially appears. The top six locations—lung, breast, colorectum, prostate, stomach and liver—made up 51% of all incidence worldwide in 2018, as well as 54% of mortality.¹⁷ Beyond these, the diversity of cancer sites is daunting: the IARC has data on 64 more. Many sites are in turn broken into sub-locations. Lip cancer, for example, has ten such secondary categories.¹⁸

¹³ National Cancer Institute, “NCI Dictionary of Cancer Terms: Cancer”.

¹⁴ Douglas Hanahan and Robert Weinberg, “Hallmarks of Cancer: The Next Generation,” *Cell*, 2011; Carlos Sonnenschein and Ana M. Soto, “The aging of the 2000 and 2011 Hallmarks of Cancer reviews: A critique,” *Journal of Biosciences*, 2014; Simon Rosenfeld, “Are the Somatic Mutation and Tissue Organization Field Theories of Carcinogenesis Incompatible?,” *Cancer Informatics*, 2013.

¹⁵ Yousef Fouad and Carmen Aanei, “Revisiting the hallmarks of cancer,” *American Journal of Cancer Research*, 2017.

¹⁶ National Cancer Institute, “NCI Dictionary of Cancer Terms: Cancer”.

¹⁷ Freddie Bray et al., “Global Cancer Statistics 2018,” *CA: A Cancer Journal for Clinicians*, 2018.

¹⁸ IARC, “International Classification of Diseases for Oncology, third edition, Topographical codes”.

The traditional classification of cancer types is based on the kinds of cells and organs in which the disease first develops. Genetics complicates this understanding, and also the nature of the challenge that cancer represents. A 2014 study looked at the genetics of thousands of cancers from the 14 most common sites. Of these, in 57% the tumour's genes most closely resembled those of other cancers affecting the same organ, but 43% of the time their DNA was closer to cancers that typically affect other organs.¹⁹ In other words, in this sample, a bit under half of the disease burden seems to come from cancers that might just as easily have started in any one of several organs, while slightly over half instead seem location-specific.

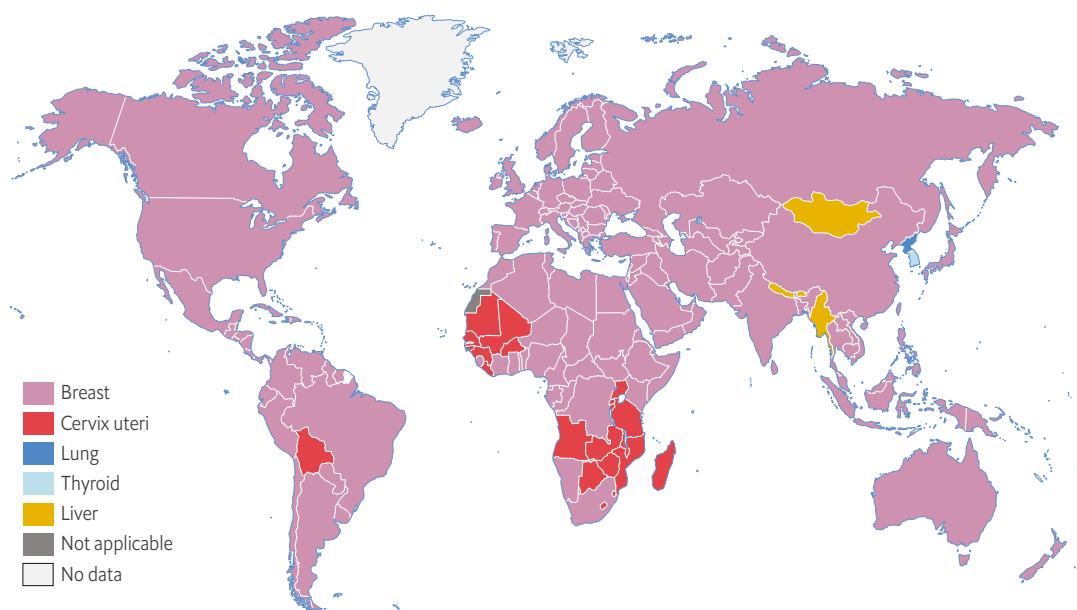
This genetic understanding of cancer may shift the definition of cancer. In 2017 the US Food and Drug Administration for the first time approved a drug for use on any tumour with a particular genetic mutation wherever it appears in the body. Organs and types of cells, though, are likely still to matter. Certain drugs that work on BRAF mutations in skin melanoma, for example, have little effect on tumours with this genetic trait elsewhere in the body.²⁰

Causes as diverse as ourselves

More complex than the disease itself are the factors that can bring one or more of its various forms. Cancer is a disease of the human condition—how it manifests itself reflects who we are biologically as well as how and where we live.

Indeed, even something as basic as gender shapes an individual's cancer risk. In 182 of 185 jurisdictions for which the IARC has 2018 estimates, the highest-incidence cancers among women are those of the breast or cervix. Similarly, in 55% of countries prostate is the most common malignant neoplasm

Top cancer per country, estimated crude incidence rates in 2018, females, all ages

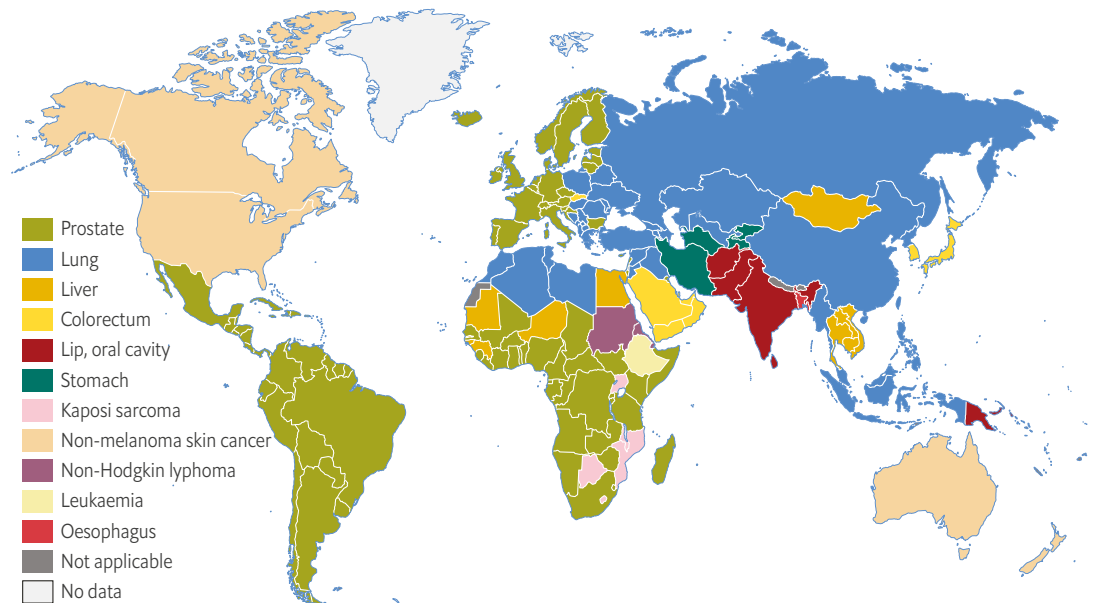


Source: World Health Organisation.

¹⁹ D Heim et al., "Cancer beyond organ and tissue specificity: Next-generation-sequencing gene mutation data reveal complex genetic similarities across major cancers," *International Journal of Cancer*, 135, 2362–2369 (2014).

²⁰ Lisa Jarvis, "Cancer, redefined," *Chemical & Engineering News*, July 3rd 2017.

Top cancer per country, estimated crude incidence rates in 2018, males, all ages



Source: World Health Organisation.

for men. By contrast, even where the other gender has a broadly equivalent potential cancer site—the male breast and the female skene gland—incidence rates for these are extremely low.

Our genders do not, of themselves, cause cancer but our genes may sometimes betray us. For example, roughly 100 known genetic variations are linked to colon cancer risk and a similar number for breast cancer (although up to 1,000 may actually exist for the latter).²¹ The overall burden of cancer arising from inherited genetic faults is relatively low: estimates fall between 5% and 10%.²² This figure can, though, run much higher in specific populations for particular cancers. For example, mutations to BRCA1 and BRCA2 genes that affect 2.5% of Ashkenazi Jewish women are responsible for between 29% and 41% of ovarian cancer in this group. This is

three to four times the rate for women as a whole.²³

In practice most cancers arise when accumulated damage to DNA—sometimes over many years—reaches a point where the body's own repair mechanisms can no longer prevent the now dangerous cells from reproducing uncontrollably. To generalise, such damage results from the body's exposure to any of a diverse range of chemical or biological agents or of environmental stresses.

Beyond that, the biology for specific carcinogens and types of cancer are far too diverse—and sometimes still too poorly understood—to detail here. The number of carcinogens is certainly large. The IARC currently identifies 200 agents as definite (120) or probable (82) causes of at least one type of cancer.²⁴ And this list is not exhaustive. Over

²¹ Jeroen R. Huyghe et al., "Discovery of common and rare genetic risk variants for colorectal cancer", *Nature Genetics*, 2019; Claire Hian et al., "Identification of Novel Breast Cancer Risk Loci", *Cancer Research*, 2017.

²² National Cancer Institute, "The Genetics of Cancer", October 12th 2017.

²³ Luis Robles-Díaz et al., "Hereditary ovarian cancer in Ashkenazi Jews", *Familial Cancer*, 2004.

²⁴ IARC, "Agents Classified [by degree of carcinogenicity] by the IARC Monographs, Volumes 1–123", updated November 2018.

the past few decades, on average researchers have added a little more than two new agents per year to the list of definite carcinogens. Nevertheless, even for some common cancers—notably that of the prostate—insufficient evidence exists to class any agent as a certain, rather than a suspected, cause.²⁵

Some carcinogens arise naturally within the body: cumulative exposure to oestrogen, the primary female sex hormone, correlates with higher rates of breast cancer, although the mechanism through which the two are linked remains unclear.²⁶ Others are external. These may also be entirely natural—such as ultraviolet rays from the sun, which are a leading cause of melanoma worldwide²⁷—or the result of human activity, like industrial pollutants or tobacco smoking, the second of which, even after years of decline, still causes 30% of US cancer deaths.²⁸

The overall effect of these carcinogens on specific populations and individuals to a great extent reflect where and how people live. The importance of location comes through especially in the extent to which carcinogenic infectious diseases or parasites may be common in a particular place. Among the best known of these are: human papilloma virus (HPV), a cause of nearly all of the world's cervical and anal cancers, which has a prevalence among women of over 30%

in East Africa and the Caribbean compared with a figure in North America of just 1.7%;²⁹ hepatitis B and C, responsible for around three-quarters of liver cancer globally, which has a particular effect in Mongolia, South-east Asia and West Africa but relatively little impact in Canada or Scandinavia;³⁰ and *Helicobacter pylori*, the leading identified cause of stomach cancer, which has a low prevalence in North America and Australia but an elevated one in Japan and South Korea.³¹

Many more such diseases exist. A recent study listed 24 viruses and bacteria, along with seven kinds of parasites that have been implicated in carcinogenesis. Of these, the IARC says sufficient evidence exists to classify 11 as definite causes of cancer and three more as probable ones.³² Collectively, all pathogens account for 15% of cancer worldwide.³³ In that sense, although cancer is a non-communicable disease, efforts to address it need to consider its origin as partly communicable.

An even bigger factor in the interaction between carcinogens and human beings than where we live is how. This includes employment. The Global Burden of Disease figures indicate that 3% of cancer mortality comes from known workplace carcinogens, such as asbestos, arsenic, benzene and at least 44 others.³⁴

²⁵ Vincent Cogliano et al., "Preventable Exposures Associated With Human Cancers", *Journal of the National Cancer Institute*, 2011; data in Cogliano updated in IARC, "List of Classifications by cancer sites with sufficient or limited evidence in humans, Volumes 1 to 123", November 2018.

²⁶ The Economist Intelligence Unit, *Breast Cancer in Asia: The challenge and response*, 2016.

²⁷ BK Armstrong, "How much melanoma is caused by sun exposure?", *Melanoma Research*, 1993.

²⁸ CDC, "Cancer and tobacco use", *Vital Signs*, 2016.

²⁹ Martyn Plummer et al., "Global burden of cancers attributable to infections in 2012: a synthetic analysis", *The Lancet Global Health*, 2016; Laia Bruni et al., "Cervical Human Papillomavirus Prevalence in 5 Continents: Meta-Analysis of 1 Million Women with Normal Cytological Findings", *The Journal of Infectious Diseases*, 2010.

³⁰ Delphine Maucourt-Boulch et al., "Fraction and incidence of liver cancer attributable to hepatitis B and C viruses worldwide", *International Journal of Cancer*, 2018.

³¹ Manami Inoue, "Changing epidemiology of *Helicobacter pylori* in Japan," *Gastric Cancer*, 2017; James K.Y. Hooi et al., "Global Prevalence of *Helicobacter pylori* Infection: Systematic Review and Meta-Analysis," *Gastroenterology*, 2017.

³² S de Flora and S La Maestra, "Epidemiology of cancers of infectious origin and prevention strategies," *Journal of Preventative Medicine and Hygiene*, 2015.

³³ Martyn Plummer et al., "Global burden of cancers attributable to infections in 2012: a synthetic analysis," *The Lancet Global Health*, 2016.

³⁴ Economist Intelligence Unit calculations based on GBD Data; Dana Loomis et al., "Identifying occupational carcinogens: an update from the IARC Monographs", *Occupational & Environmental Medicine*, 2018.

Far more important, though, are lifestyle choices. Global Burden of Disease estimates collectively attribute 51% of cancer deaths to the following modifiable behavioural risks, in reverse order of impact: low physical activity, drug abuse, unsafe sex, having a high body-mass index, alcohol consumption, unhealthy diet and tobacco consumption (which on its own accounts for about half of the known behavioural risk burden).³⁵ Worse still, notes Josep Taberner, president of the European Society for Medical Oncology, in many ways “lifestyles, globally speaking, are getting worse. We still don’t in many cases have very good prevention policies.” Although tobacco use has been dropping in all but a handful of countries, one in five adults still smoke. Moreover, the decline in usage is not currently fast enough to meet the WHO goal of a 30% reduction between 2010 and 2030.³⁶ Meanwhile obesity—a useful proxy measure for poor diet and low physical activity—steadily increased between 1990 and 2015 in almost every country in the world and doubled or grew faster in 73 of them.³⁷

Genes, communicable disease loads and lifestyles obviously differ across the world. A glance at the map (produced on page 15) of the most common cancers among men by country shows how these diverse drivers of the disease create a wide variety of unique local features amid the general challenge. As noted earlier, in a majority of countries prostate cancer is the most prevalent form.

The likely reasons seem to vary. The prime suspect in Europe and much of Latin America is population ageing, which is a leading correlation of this disease. In sub-Saharan Africa, though, according to UN Population Division figures, life expectancy is more than two decades shorter for men than in Western Europe. In the younger continent, genetics seems to play a larger role in the prostate-cancer burden, which also helps to explain higher rates of the disease among African-Americans compared with fellow nationals.³⁸

Looking at other countries, certain communicable diseases affect the cancer burden. The high incidence of Kaposi sarcoma in southern Africa and Uganda stem from the elevated prevalence of HIV/AIDS,³⁹ while liver cancer is often present in Egypt and Mongolia as a result of notoriously high rates of hepatitis C, as well as hepatitis B in the latter country.⁴⁰ Lifestyle choices also reveal themselves on the map. Heavy tobacco smoking among men in parts of Asia and Eastern Europe⁴¹ explains the swathes of countries where lung cancer is the leading issue, while the oral cavity and oesophageal cancer so common in South Asia arise from the widespread habit in this region of chewing tobacco.⁴² Meanwhile, a love of the sun in Australasia—where ultraviolet rays account for roughly one in ten of all cancers—brings about high melanoma incidence.⁴³ Finally, risk factors can work together: South-east Asia’s liver cancer comes from both an elevated hepatitis burden and a common

³⁵ Economist Intelligence Unit calculations based on GBD Data.

³⁶ WHO *global report on trends in prevalence of tobacco smoking 2000–2025*, 2nd ed., 2018.

³⁷ GBD 2015 Obesity Collaborators, “Health Effects of Overweight and Obesity in 195 Countries over 25 Years”, *New England Journal of Medicine*, 2017.

³⁸ Vanessa Hayes and M Bornman, “Prostate Cancer in Southern Africa: Does Africa Hold Untapped Potential to Add Value to the Current Understanding of a Common Disease?”, *Journal of Global Oncology*, 2017.

³⁹ Susan Krown, “Treatment strategies for Kaposi sarcoma in Sub-Saharan Africa: Challenges and Opportunities”, *Current Opinion in Oncology*, 2011.

⁴⁰ Ahmed Elgharably et al., “Hepatitis C in Egypt – past, present, and future”, *International Journal of General Medicine*, 2016; Oidov Baatarkhuu et al., “Viral Hepatitis and Liver Diseases in Mongolia”, *Euroasian Journal of Hepatogastroenterology*, 2017.

⁴¹ 21 of the 30 countries with the highest male smoking rates are from East Asia or Eastern Europe and Central (WHO *global report on trends in prevalence of tobacco smoking 2000–2025*, 2nd ed., 2018.)

⁴² Zohaib Khan et al., “Smokeless Tobacco and Oral Cancer in South Asia: A Systematic Review with Meta-Analysis”, *Journal of Cancer Epidemiology*,

⁴³ IARC, “Cancers attributable to UV Radiation”, Cancer Australia, *Position Statement – Lifestyle risk factors and the primary prevention of cancer*, 2015.

affection for uncooked or pickled cyprinid fish in diets. The latter can infect the person eating them with a kind of carcinogenic liver fluke.⁴⁴

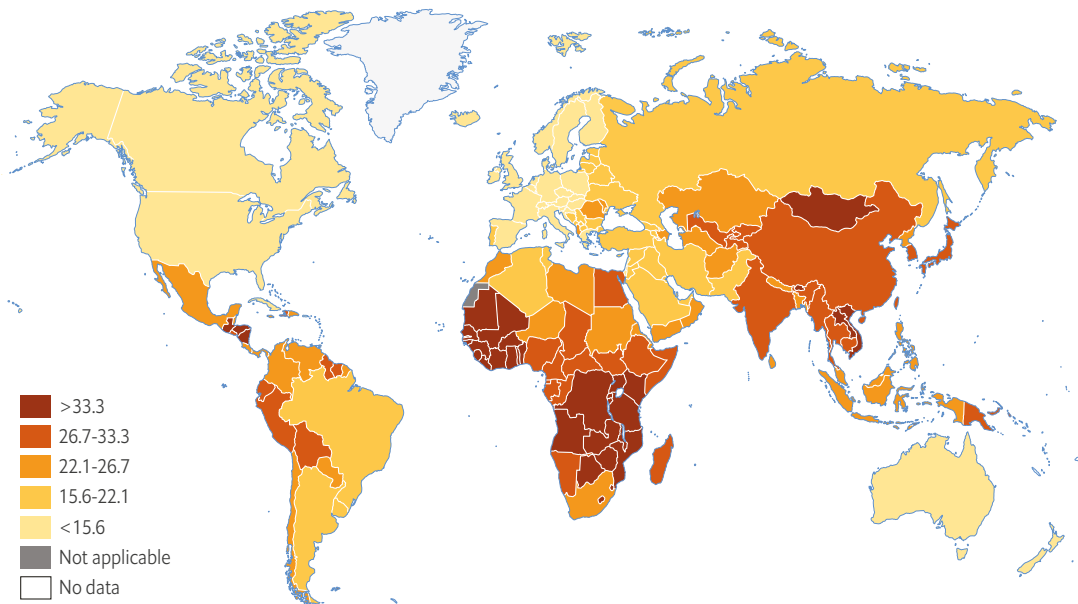
In short, addressing cancer across the globe has to begin with local awareness of who people are and how they live.

Cancer and GDP (I): Overlapping patterns of incidence

Another key consideration in understanding the cancer challenge is that, beneath the diversity in incidence worldwide, levels of economic development coincide with certain important similarities.

First, cancer risk varies by national income.⁴⁵ In general, as states develop economically, they experience an epidemiologic transition. As increasing wealth allows greater absolute public and private spending on health, the burden of communicable disease tends to drop. This has implications for cancer because the decline of carcinogenic infections mirrors that of others. Accordingly, in the world's less developed regions, 23% of cancer results from a disease or parasite—31% in sub-Saharan Africa—while in more developed regions this falls to 10% or less.⁴⁶

Proportion (%) (worldwide) of all cancer cases among both sexes in 2012 attributable to infections (all infectious agents), by country



Source: World Health Organisation.

⁴⁴ François Chassagne et al., "A 13-Year Retrospective Study on Primary Liver Cancer in Cambodia", *Oncology*, 2016; Thomas Hughes et al. "Opisthorchiasis and cholangiocarcinoma in Southeast Asia: an unresolved problem", *International Journal of General Medicine*, 2017.

⁴⁵ This discussion is based on the best available internationally comparable data and expert estimates. It is possible that some of the lower incidence figures in low-income countries reflect poor case-finding and data collection, but lower risk levels in many of these countries make the expert assessments credible.

⁴⁶ Martyn Plummer et al., "Global burden of cancers attributable to infections in 2012: a synthetic analysis", *The Lancet Global Health*, 2016.

Conversely, lifestyle-related risks tend to be higher in more economically advanced countries—if for no other reason than greater average disposable income permits worse health choices, such as more calorific diets or lifestyles involving less physical activity. Again, weight is a useful proxy: with the exception of the very richest people in individual societies, an increase in national income correlates closely with a rise in average body mass index.⁴⁷

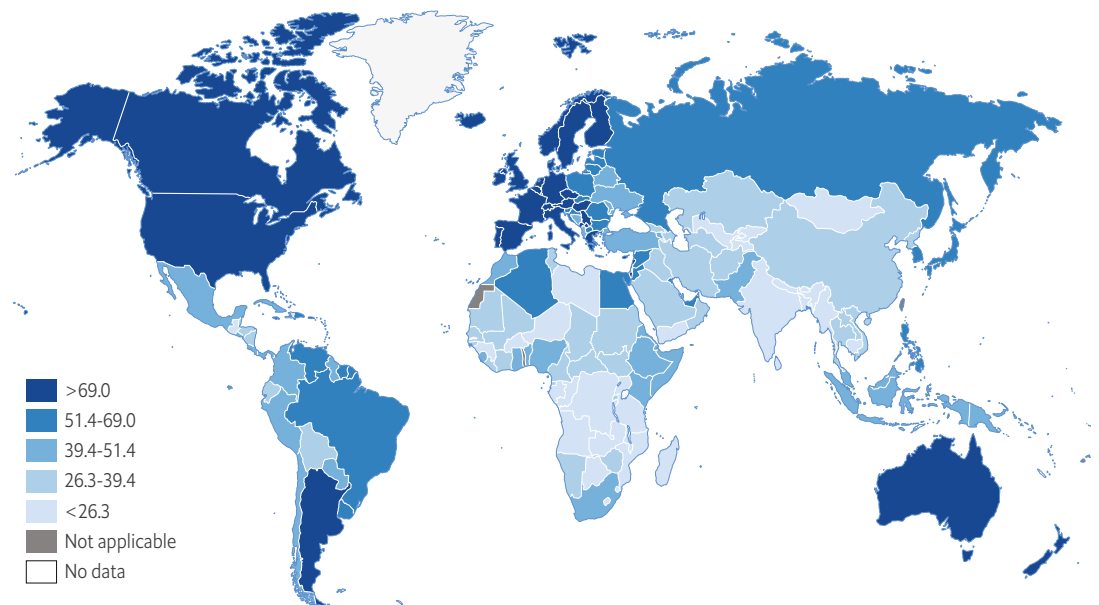
The result is visible in the cancer burdens at different levels of development. Several kinds tend to be more common in poorer states, such as liver or gastric cancer, while others, for instance colorectal cancers, have a greater incidence in wealthier ones. The clearest example of this difference, though, comes from the two most common cancers in women: those of the breast and cervix. The following three world maps show the

national age-standardised incidence for both cancers as well as scores from the Human Development Index (HDI)—a UN measure of national income and broader development indicators. Although the matches are not exact, the degree of overlap in the first two is clear, as is the extent to which the last one tends to be a mirror image of the others.

Turning from particular types of cancer to the aggregate burden, GDP also seems to matter, with better-off countries having a far greater total incidence. According to IARC data, crude rates in high-income countries dwarf those in lower-income ones. Much of this disparity reflects greater average ages in wealthier countries, but even ASRs rise substantially with income (see table).

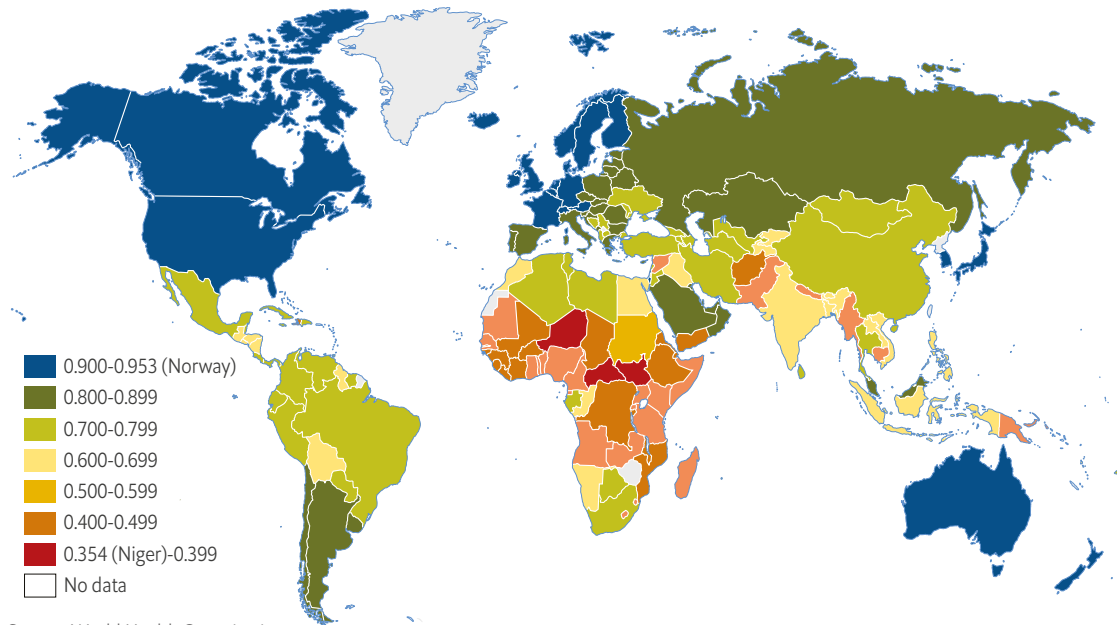
This does not mean, however, that cancer is simply a disease of the richest. The proportion of the world's cancer cases found in upper-

Estimated age-standardised incidence rates (world) in 2018, breast, all ages



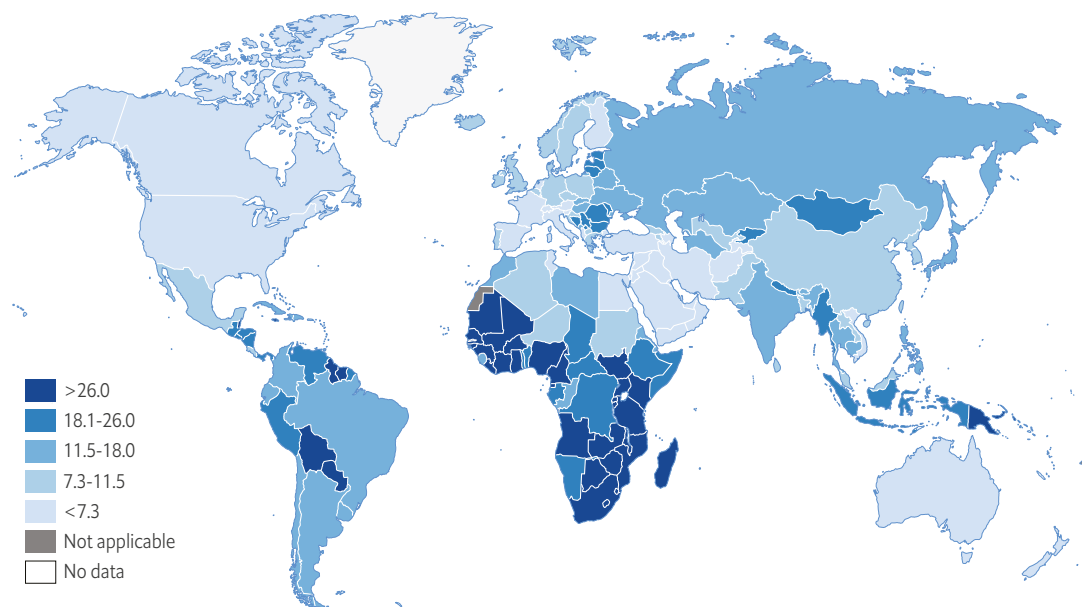
⁴⁷ Mohd Masood and Daniel Reidpath, "Effect of national wealth on BMI: An analysis of 206,266 individuals in 70 low-, middle- and high-income countries", *PLoS One*, 2017.

Top cancer per country, estimated crude incidence rates in 2018, females, all ages



Source: World Health Organisation.

Estimated age-standardised incidence rates (world) in 2018, cervix uteri, all ages



Source: World Health Organisation.

middle-income countries already exceeds their share of the global population overall. Moreover, although wealthier countries

have higher incidence rates, the weight of population numbers means the developing world already sees 59% of global cancer cases.

TABLE 1

Estimated number of new cases in 2018, all cancers, both sexes, all ages

	Number of cases	Crude rate per 100,000	ASR (world) per 100,000
High income	7,350,239	604.0	304.7
Upper middle income	7,019,867	267.4	197.4
Low middle income	3,023,894	100.4	112.6
Low income	552,762	73.6	121.1

Source: Cancer Today 2018

Cancer and GDP (II): Convergence around an unhealthy mean

Looking ahead, the age advantage of low- and middle-income countries looks set to diminish, giving them higher crude incidence at the very least. Between 2000 and 2015 average population ageing in richer countries was already markedly slower than that in less developed ones. Looking ahead those rates will diverge further.

Meanwhile, population growth is also set to remain far higher in countries with lower income, driving a greater absolute number of cases. Although high-income and upper-middle-income countries are expected to converge in this regard over the next ten years, rates in the poorest countries will be about eight times those in the wealthiest.

Finally, to the extent that economic development continues in emerging and frontier markets, the cancer challenge will become more complicated. Greater wealth, and attendant dietary and lifestyle changes, can drive rapid increases in cancers more

TABLE 2

Actual and projected increase in population over age 60

	2000-15	2015-30
High income	34.2%	32.0%
Upper middle income	64.0%	70.2%
Low middle income	48.8%	65.9%
Low income	56.2%	63.0%

Source: UN Population Division, *World Population Ageing*, 2015.

TABLE 3

Projected annual rate of population growth

	2015-20	2025-30
High income	0.46%	0.31%
Upper middle income	0.62%	0.29%
Low middle income	1.38%	1.15%
Low income	2.63%	2.40%

Source: UN Population Division, *World Population Prospects: The 2017 Revision*, 2017.

associated with richer countries. To cite just two examples, this is almost certainly behind the ongoing rise in breast-cancer incidence in much of Asia⁴⁸ and the rapid increase in colorectal cancer in parts of the Middle East.⁴⁹

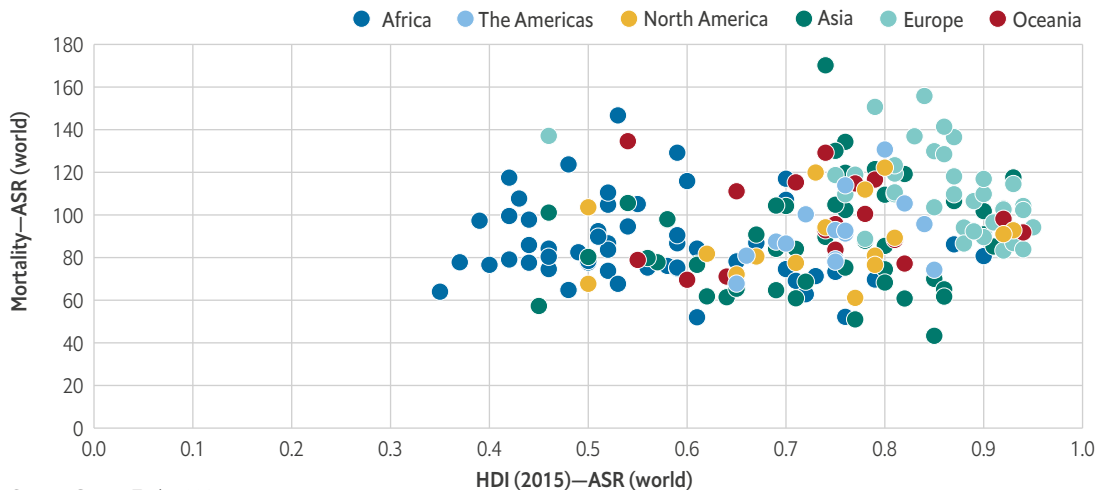
Meanwhile, other cancers will not necessarily diminish rapidly. The IARC reports that South Korea and Japan have the first- and third-highest age-standardised incidences of stomach cancer, a disease usually associated with less developed countries. The reason is that declines in *Helicobacter pylori* prevalence take time. Although this is happening steadily in both countries, each began with very high levels, with the bacterium infecting up to 80-90% of the Japanese population at one time.⁵⁰

Elsewhere, the problem of lingering incidence is more extensive. Prebo Barango, medical officer,

Non-Communicable Diseases, on the WHO's Inter-Country Support Team for Eastern and Southern Africa, notes that: "One of the key reasons for the increase in cancer in Africa is the partial epidemiological transition." He explains that while people are living longer and starting to face increased risk of lifestyle-related cancers, "Africa still has a huge burden of some cancers that are related to infections, which other developing places have got a grip on."

In short, although wealthy countries currently have a higher relative cancer burden than less developed ones, the latter look set to bear the brunt of the rapid expected increase in the coming years. Worse still, even as cancers associated with economic development become more common, those linked to poverty may disappear only slowly.

Mortality—ASR (world) versus HDI (2015)—ASR (world), all cancers, in 2018, both sexes, all ages



Source: Cancer Today 2018.

⁴⁸ The Economist Intelligence Unit, *Breast Cancer in Asia: The challenge and response*, 2016.

⁴⁹ Mostafa A Arafa and Karim Farhat, "Colorectal Cancer in the Arab World - Screening Practices and Future Prospects", *Asian Pacific Journal of Cancer Prevention*, 2015; Nasser Alsanea et al., "Colorectal cancer in Saudi Arabia: incidence, survival, demographics and implications for national policies", *Annals of Saudi Medicine*, 2015; Faraz Bishehsar et al., "Epidemiological transition of colorectal cancer in developing countries", *World Journal of Gastroenterology*, 2014.

⁵⁰ Jeong Hoon Lee et al., "Seroprevalence of *Helicobacter pylori* in Korea", *Helicobacter*, 2018; Manami Inoue, "Changing epidemiology of *Helicobacter pylori* in Japan", *Gastric Cancer*, 2017; James Hooi et al., "Global Prevalence of *Helicobacter pylori* Infection", *Gastroenterology*, 2017.

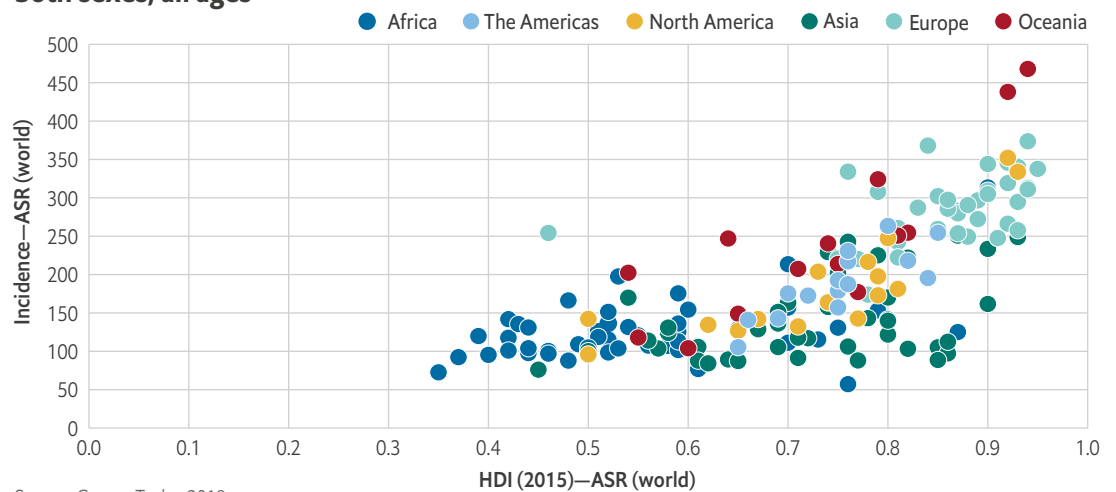
Cancer and GDP (III): Overlapping patterns of mortality

If cancer is currently a disease more common among the rich than the poor, it is already an egalitarian killer. Three charts illustrate the problem. The first compares national ASRs of mortality to HDI scores. The scattered result

could serve as an example from a statistics textbook of an uncorrelated data set.

This hodgepodge, though, arises not from randomness but from two drivers working at cross purposes. The first, discussed above and shown in the next chart is the easily discernible link between total incidence and HDI.

Incidence—ASR (world) versus HDI (2015)—ASR (world), all cancers, in 2018, both sexes, all ages

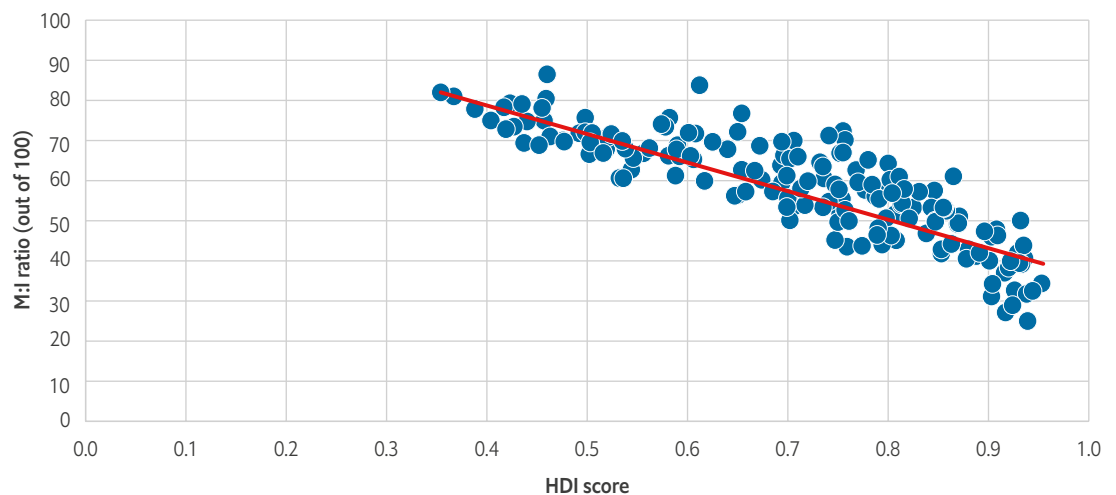


Source: Cancer Today 2018.

More worrying is the final chart. It compares HDI to the national mortality-incidence (M:I) ratios—found by dividing the number of

deaths in a given year by the number of new cases (and in this publication multiplied by 100 to create a percentage). This metric provides

HDI versus M:I ratio



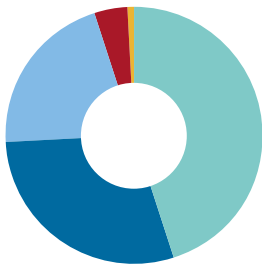
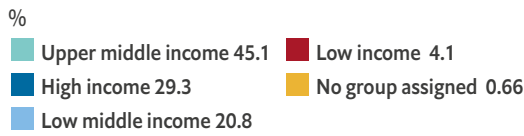
Source: UNDP.

a rough measure of how well countries are doing at finding and treating the disease, two key elements of cancer control. The lower the ratio the better. As the chart shows, however, low economic development and high death rates go hand in hand: at an extreme, in

Australia there is only one death for every four new cases of cancer in a given year; in Gambia five die for every six cases.⁵¹

As a result, although middle- and low-income countries have 59% of cancer cases, they have 71% of deaths.

Estimated number of deaths in 2018, all cancers, both sexes, all ages

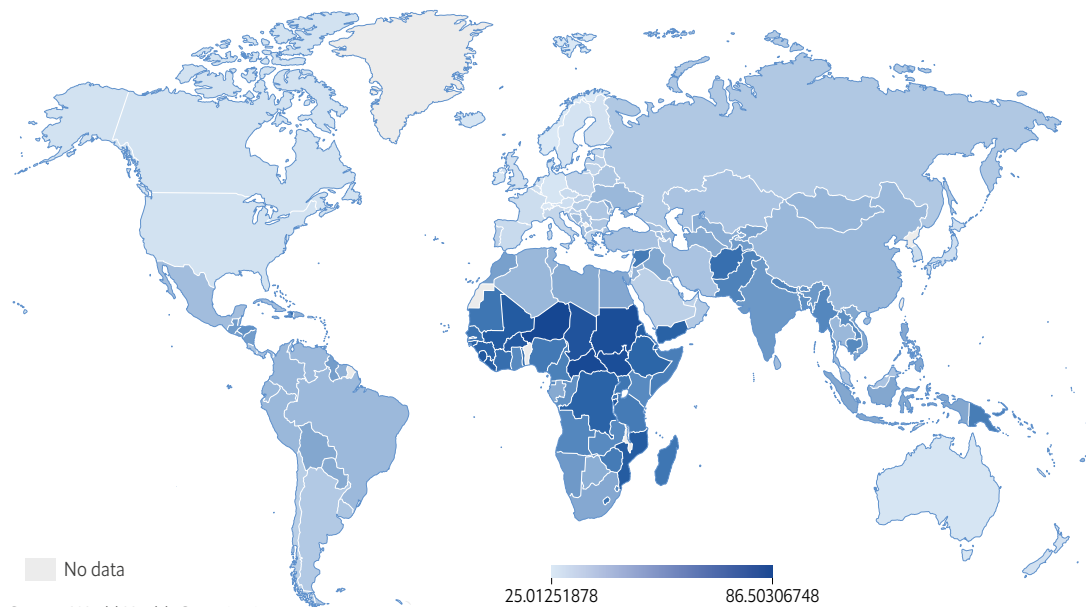


Source: Cancer Today 2018.

This link between lower levels of wealth and higher M:I ratios is notable even within groups of high-income countries. Dr Tabernero explains that in Europe, although incidence is higher in western countries, mortality is higher in eastern ones, which have lower average GDP. “This [elevated death rate] is a major challenge in all these countries,” he adds.

Worse still, people in less economically advanced countries are already dying faster from cancer when young. As the map indicates, among those below retirement age (65), the hotspots of mortality are not high-income countries but Africa, South-east Asia, Central Asia, and Eastern Europe. Cancer-

M:I ratio all cancers 2018



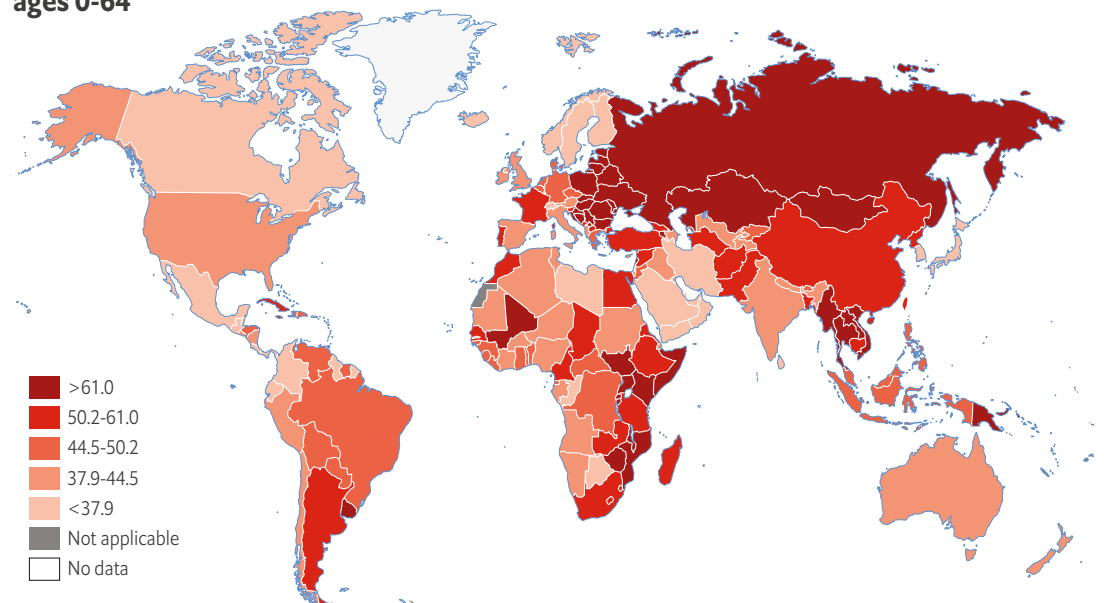
Source: World Health Organisation.

⁵¹ Economist Intelligence Unit calculations based on data from Freddie Bray et al., “Global Cancer Statistics 2018”, *CA: A Cancer Journal for Clinicians*, 2018.

control systems in these countries are unlikely to cope well with the increased incidence from population ageing. At the very least, already cancer is likely to be exacting a higher

proportional economic toll—usually measured in lost GDP from early death and disability—in relatively low-incidence, low-income countries than in high-incidence, high-income ones.

Estimated age-standardised mortality rates (world) in 2018, all cancers, both sexes, ages 0-64

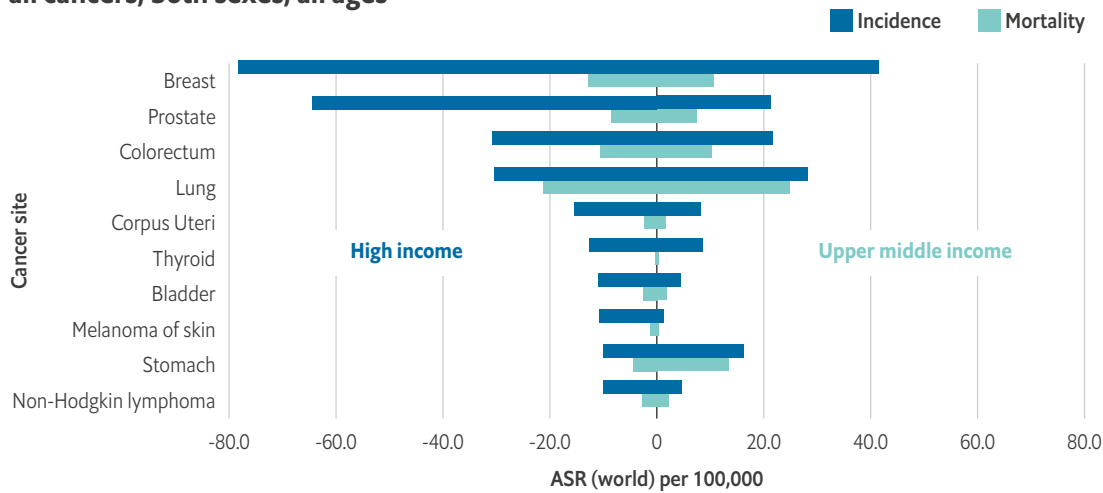


Source: World Health Organisation.

The income-correlated differences in mortality across the globe and within regions reflect, in part, some differences in the kind of cancers that countries face. According to the IARC, for example, liver cancer makes up 2% of total incidence in high-income countries, but 6% elsewhere. No health system has much success against it. That said, the bigger difference arises from how health systems are able to cope with cancers more likely to be treatable. The chart on the next page, for example, compares age-standardised mortality rates from leading cancers in high-income and upper-middle-income countries. Immediately striking is how, for most of these, incidence rates are much greater in high-income countries, but mortality rates are roughly equal in both.

This shows the importance of differences in cancer control. As incidence rises in states with lower incomes, current deficiencies in this field—absent action—will unnecessarily cost lives. Recent trends give cause for concern. Alejandro Mohar, head of Mexico's Co-ordinating Commission of National Institutes of Health, explains that middle-income countries as a whole have seen "a steady increase in incidence but a slow response from health systems". Princess Dina Mired, president of the Union for International Cancer Control (UICC) accordingly expresses "great concern that the upward trend in cancer incidence will continue unless governments take action across the cancer-control continuum".

Estimated age-standardised incidence and mortality rates (world) in 2018, all cancers, both sexes, all ages



Source: Cancer Today 2018.

Meanwhile, even success in addressing cancer brings challenges. Given the disparity in cancer incidence and mortality rates, the number of cancer survivors is already markedly higher in developed countries and this group is growing quickly in size. As Ms Makaroff points out, while this is a positive development, “it is raising many issues”, in terms of both health and social, with little support.

Cancer, then, is already a major killer across much of the world. Unless addressed better, rising incidence will mean a still greater human and economic toll. The rest of this study will accordingly look at how well countries are preparing for this challenge and, through this, consider the four universally applicable essentials needed for health systems to both diminish and cope with the wave of cancer facing the world in the coming decades.

Chapter II: Introducing The Economist Intelligence Unit's Index of Cancer Preparedness

Key takeaways

- The Economist Intelligence Unit Index of Cancer Preparedness compares 28 countries across a range of areas relevant to cancer control.
- Its detailed data are publicly available and can help policymakers and other stakeholders to benchmark where their countries stand compared with global leaders and peer states as they shape appropriate national policies.

The shape of cancer preparedness

What does cancer preparedness require?

The disparity between M:I ratios among countries at different levels of development strongly suggests that wealth has a role. There is far more to it than that, though: as Lisa Stevens, deputy director of the Center for Global Health within the US National Cancer Institute, puts it: “Money can be misspent. Success [against cancer] can’t be attributed solely to GDP. It is really about focused policies.”

Indeed, policy weakness in just one area, even amid an otherwise strong cancer control effort, can cause substantial problems. To cite a small but telling example, South Korea, with a well-regarded anti-cancer regime, has one of the world’s lowest M:I ratios. The country’s age-standardised incidence of thyroid cancer, though, is roughly nine times the world’s figure and triple that of the nearest country. This is an unintended artefact of policy. An unplanned consequence of the country’s successful screening programme is to encourage private testing for thyroid cancer. This identifies many tumours, but the majority would almost certainly never present a health risk to the patient. The resultant, substantial

overdiagnosis leads to much unnecessary medical intervention.⁵²

Flaws are easy to criticise but creating robust policies to address the complex challenge of cancer is far from straightforward. Magic bullets simply do not exist for such a multi-faceted, complex challenge. Dr Sankaranarayanan explains that the “many diseases [under the label of cancer] require different types of intervention. Some are predominantly amenable to prevention; some require intensive treatment; some require early detection and treatment. There is increasing awareness of the need for a multi-pronged approach.” Such a strategy integrates action across a wide number of areas including prevention, early diagnosis, treatment, survivor support and palliative care.

Adding to the complexity, a good, integrated policy for one country might be inappropriate in another. At a basic level, explains Sanchia Aranda, CEO of Cancer Council Australia, “the biggest issue for policymakers is making decisions that deliver the most value in terms of outcomes for the population they serve.” To do this, a high-income country might use sophisticated measures of life-years per unit of expenditure. Health systems with

⁵² Hyeong Sik Ahn et al., “Korea’s Thyroid-Cancer ‘Epidemic’ – Screening and Overdiagnosis”, *New England Journal of Medicine*, 2014.

fewer resources might instead focus on the WHO's so-called best buys—its most cost-effective public health interventions—and on investments that save rather than simply prolong lives.

As well as varying resource bases, adds Princess Dina, “each country has its own cancer profile,” with specific risk and incidence issues. As a result, she says, the best solutions in each case are a combination of global and national practice. “Success is really all about which countries are better prepared to defeat cancer along the continuum of care.” Such national peculiarities also make gathering data about, and researching issues specifically related to, the local and national cancer burden fundamental to good cancer control. Effective national planning requires accurate national information.

The index

How well prepared countries are to deal with cancer amid these challenges, notes Dr Sankaranarayanan, “is highly variable”. To assess the strengths and weakness of this response in 28 major countries across the globe and at different levels of economic development, The Economist Intelligence Unit has created the ICP.

The ICP draws on data collected from every country for a total of 45 different areas, known as indicators. These were selected in consultation with an expert advisory board (see About this report) supported by an extensive literature review. Each indicator benchmarks not only how well index countries are doing in specific fields relevant to cancer control, they frequently also act as proxies for wider efforts that are harder to measure.

Each indicator is scored out of 100 points. These results are then aggregated using weighted averages into 13 broader areas, called sub-domains, to show how well

countries are doing on a broader set of cancer preparedness issues, and the sub-domains in turn are combined into three relevant domains—Policy and Planning; Care Delivery; and Health System and Governance. Finally, everything is brought together into a single, overall score for general cancer preparedness.

The ICP is broad as well as detailed. It looks at all of the elements of good cancer policy discussed in the preceding paragraphs, with indicators ranging from the existence of policies to encourage physical activity to the extent of palliative care provision in the public health system. It also seeks to set these efforts within the broader health system and political contexts surrounding cancer control, with other indicators looking at issues as various as the size of the healthcare workforce and the prevalence of corruption. (For a detailed description of the methodology and information on specific indicators, scoring and weighting, see Appendix.)

The results are as follows:

The strong correlation between outcomes and the overall score indicates that the ICP more or less gets things right (see chart).

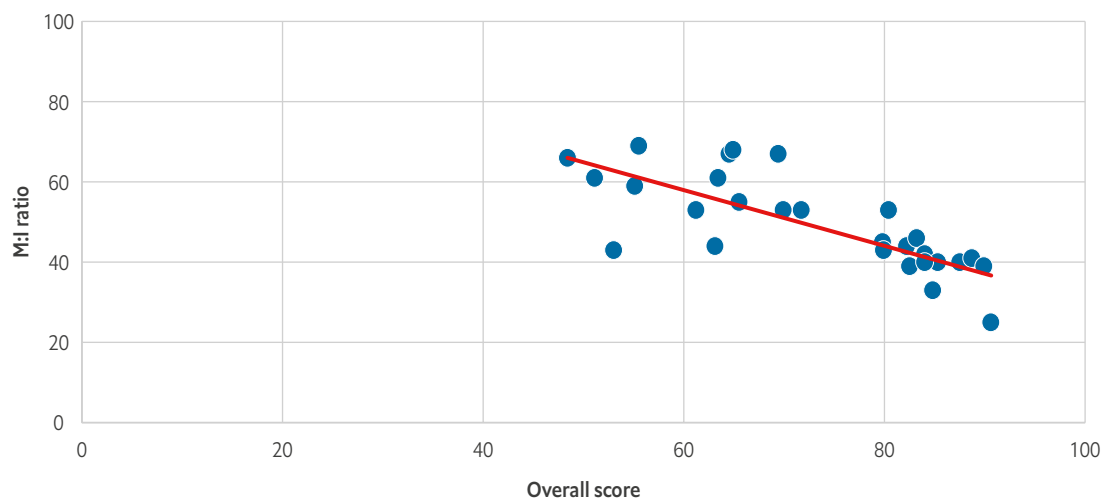
In other words, the ICP is a useful benchmarking tool for mapping cancer control. The purpose of this exercise is not to see which country is able to outscore another here or there—leading to demands for video instant replays from different angles. Instead, we hope to begin a discussion of what goes into good cancer control and where countries might usefully improve—something every state in the ICP can find room to do. As Dr Aranda says of first place Australia, “we are doing really well at cancer control, but that should not create complacency around what we are not doing well.” However, it is important to highlight some inevitable issues with the index.

■ High (85.1 - 100) ■ Moderate (70.1 - 85) ■ Low (50.1 - 70) ■ Very low (0 - 50)

OVERALL SCORE	1) POLICY & PLANNING	2) CARE DELIVERY	3) HEALTH SYSTEM & GOVERNANCE
1 Australia 90.6	1 Australia 98.0	1 Japan 96.6	1 Sweden 86.7
2 Netherlands 89.9	2 UK 96.3	2 Netherlands 92.1	2 Netherlands 77.1
3 Germany 88.7	3 Brazil 94.4	3 Germany 91.8	3 Australia 76.9
4 France 87.5	=4 Canada 94.0	4 Australia 90.0	4 Germany 76.3
5 UK 85.3	=4 Netherlands 94.0	5 Spain 89.2	5 France 76.1
6 Canada 84.8	6 France 93.8	6 France 86.9	6 US 75.7
=7 Spain 84.0	7 Colombia 92.1	7 Sweden 85.6	7 UK 74.0
=7 US 84.0	8 Germany 91.8	8 Italy 84.7	8 Canada 71.5
9 Japan 83.2	9 Spain 89.7	9 US 84.2	9 South Korea 68.5
10 Sweden 82.5	10 US 88.0	10 Brazil 84.1	10 Spain 62.1
11 Brazil 82.2	11 Turkey 87.4	11 Colombia 83.6	11 Italy 58.1
12 South Korea 80.4	12 South Korea 86.7	12 Canada 82.2	12 Japan 56.7
13 Italy 79.9	13 Thailand 86.4	13 Chile 80.7	13 Chile 56.6
14 Colombia 79.8	14 Italy 85.9	=14 South Korea 80.0	AVERAGE 55.5
AVERAGE 72.8	15 Argentina 83.4	=14 UK 80.0	14 Brazil 54.1
15 Argentina 71.7	16 Japan 83.1	16 Argentina 73.7	15 China 53.7
16 Chile 69.9	AVERAGE 81.3	AVERAGE 73.0	16 South Africa 48.2
17 Thailand 69.4	17 India 80.8	17 Russia 72.9	17 Colombia 47.5
18 Turkey 65.5	18 Kenya 77.6	18 Thailand 64.4	18 Turkey 47.4
19 India 64.9	19 Sweden 77.3	19 Mexico 61.9	19 Romania 46.5
20 China 64.5	20 Mexico 73.2	=20 China 61.3	20 Thailand 45.4
21 Russia 63.4	21 China 73.1	=20 India 61.3	21 Mexico 45.2
22 Mexico 63.1	22 South Africa 72.2	22 South Africa 56.7	22 Argentina 44.1
23 South Africa 61.2	23 Egypt 66.2	23 Indonesia 56.6	23 Indonesia 43.6
24 Kenya 55.5	24 Chile 65.8	24 Saudi Arabia 54.0	24 Russia 41.1
25 Indonesia 55.1	25 Russia 64.9	25 Turkey 52.6	25 India 40.3
26 Saudi Arabia 53.0	26 Saudi Arabia 62.6	26 Kenya 46.5	26 Saudi Arabia 32.0
27 Romania 51.1	=27 Indonesia 59.4	27 Egypt 45.1	27 Kenya 29.2
28 Egypt 48.4	=27 Romania 59.4	28 Romania 45.0	28 Egypt 19.7

Note. Normalised scores 0-100, where 100=most prepared.
Source: ICP.

National index scores versus M:I ratios (2018)



Source: ICP.

A few caveats

To understand the value of the ICP requires transparency about its limitations, an unavoidable issue in any scheme that models a very complex reality.

First, we could include only indicators that drew on broadly comparable data available across all 28 countries. This constrained the choices. For example, reporting on cancer control spending is not publicly available in all of the index countries.

Similarly, in such an exercise, various index elements reflect underlying information gathered by respected organisations, but that may have its own quirks. An indicator looking at the existence of national non-communicable disease (NCD) guidelines or protocols having a primary care focus, for example, drew on a WHO survey of national health officials. In several countries, these officials reported in 2013 and 2015 that such documents existed, but in 2017 replied that they did not. It is unlikely, albeit possible, that an existing guideline would be quashed without replacement; far more probable is that relevant Ministry of Health officials in any given year, and perhaps in different countries, understood the question differently.⁵³

Moreover, such surveys by other organisations can be skewed by errors from respondents. In another WHO survey we used, the assertion by a health official in Brazil that home-based or community palliative care is generally available in the public health system is inconsistent with the best information

from that country.⁵⁴ Reviewing and revising individual results in such cases, though, would undermine the ICP's transparency and consistency.

Next, on any individual indicator, the need for consistency in measuring results for 28 countries can sometimes throw up anomalous scores. Canada, for example, does badly on infant hepatitis B vaccination (69 out of 100) because only 69% of those under one-year old receive the intervention. Here, the reason is that health systems in six of the country's provinces—including the most populous, Ontario—give the vaccine when children are around ages 10 to 12. Though not best practice internationally, inoculation at this age still occurs before almost any high-risk behaviour associated with the disease is likely to take place. In total, 88% of children are, eventually, protected. Moreover, Canada has a low prevalence of the disease.⁵⁵ Indonesia, which has only 79% infant coverage with no programme for later vaccination, and a moderate overall prevalence,⁵⁶ still scores ten more points than Canada on this metric because granting exceptions for special cases across multiple indicators would make the ICP too complex to be of general utility.

Finally, although a large number of indicators measure health system inputs, policy has a strong weighting in the ICP score. This includes not just the Policy and Planning domain but indicators from other parts of the ICP, so that more than half of the overall country score reflects the existence or nature of specific policy.

⁵³ "NCD guidelines: Data by country", WHO Global Health Observatory database.

⁵⁴ "Palliative care in the public health system: Response by country", WHO Global Health Observatory database; Santiago Corrêa et al., "Brazil: time for palliative care in the community!", *European Journal of Palliative Care*, 2016; Economist Intelligence Unit, *The 2015 Quality of Death Index*, 2015.

⁵⁵ Government of Canada, *Canadian Immunization Guide: Part 4 - Active Vaccines*, 2017; Carla Osiowy, "Ordering and interpreting hepatitis B serology", *BMJ*, 2014; Public Health Agency of Canada, *Vaccine Coverage in Canadian Children*, 2016.

⁵⁶ David Muljono, "Epidemiology of Hepatitis B and C in Republic of Indonesia", *Euroasian Journal of Hepato-Gastroenterology*, 2017.

This can lead to results that are inconsistent with current outcomes in specific areas. In tobacco control, for example, Spain—tied for first—earned two and a half times the points of the US—tied for last. This was the case even though a quarter of Spanish adults—more than the global average of 21%—smoke, compared with just 18% of Americans. Moreover, while the US rate is dropping, Spain's is rising.⁵⁷

Any disconnect between policy and outcome may have a positive or a negative explanation. The former is simply that the ICP attempts to measure how strong policies are, not how long-standing. In some cases, they may not have had time to have an impact. Turkey's third place finish in tobacco control, for example, has much to do with policies introduced in the last few years arising from president Recep Erdoğan's public, personal hostility to smoking. They have had little time to affect behaviour. In that sense, as befits an index on preparedness, it points to likely future results rather than current ones.

The more problematic issue, though, is that lack of data across every country makes it possible for the ICP to measure implementation to only a limited degree. Following through on policy statements is far from given, and it is probably no accident that the average score for the Policy and Planning domain is far higher than for the other two.

The quality of implementation can matter greatly. Every country, for example, gets full marks for having a cervical cancer screening

programme. However, according to the latest OECD data, Mexico's efforts in this area reach just 16% of the target population, while in Japan it is 42% and Germany 80%. Similar national disparities are visible on breast cancer screening.⁵⁸ In the same way, while over half of index countries score all possible points for the existence of relevant NCD and cancer treatment guidelines, as Dr Cazap notes, the extent to which clinicians follow these "is not so clear".



A national plan without a budget is not a plan, but paper.”

Eduardo Cazap, founder and first president, Latin American and Caribbean Society of Medical Oncology

At an extreme, some national policies are little more than unfunded aspirations. But, Dr Cazap explains, "a national plan without a budget is not a plan, but paper". In line with this, Dr Barango adds that "if you have a good document, but 90% is not implemented, you do not really have a good document". To be prepared to the extent that the ICP scores suggest, countries will have to deliver on their promises.

While looking at each health system in detail would be far beyond the scope of this publication, the following section distils four essential, generally applicable insights about cancer preparedness.

⁵⁷ WHO, *WHO Report on the Global Tobacco Epidemic, 2017*, 2017; "Number of smokers in Spain reaches pre-smoking ban levels", *El Pais*, December 11th 2018; US Center for Disease Control, "Cigarette Smoking Among U.S. Adults Lowest Ever Recorded: 14% in 2017", press release November 11th 2018.

⁵⁸ "Health Care Utilisation: Screening", OECD.Stat database.

Chapter III: The four essentials of cancer preparedness

I. Essential investment: A closer look at the money-cancer control relationship

Key takeaways

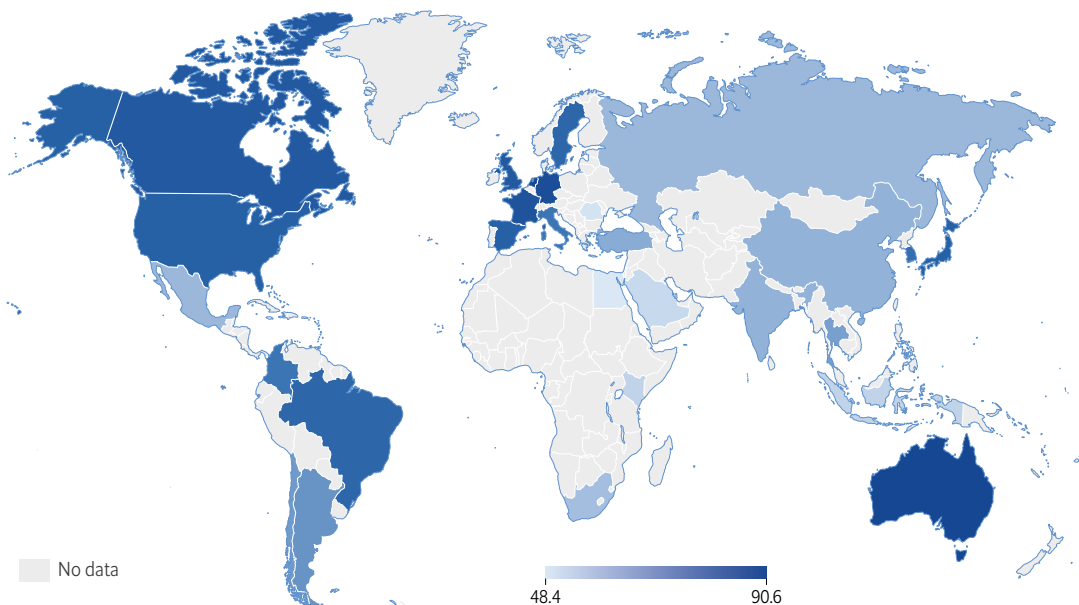
- Low-cost interventions to reduce the cancer burden certainly exist, but effective cancer control also requires investment, especially in the infrastructure, tools and personnel needed to treat the disease.
- The extent and nature of that investment is a political choice, and will vary by country, but, without effective treatment facilities, other cost-saving interventions, such as those around early detection, lose their value.
- An effective treatment capacity is also essential to address cancer fatalism, which undermines efforts across the entire cancer control continuum.

Cancer preparedness requires resources

Money matters. This merely restates in a simpler way what has already been discussed: a good HDI result and a good outcome in the ICP both correlate with lower M:I ratios.

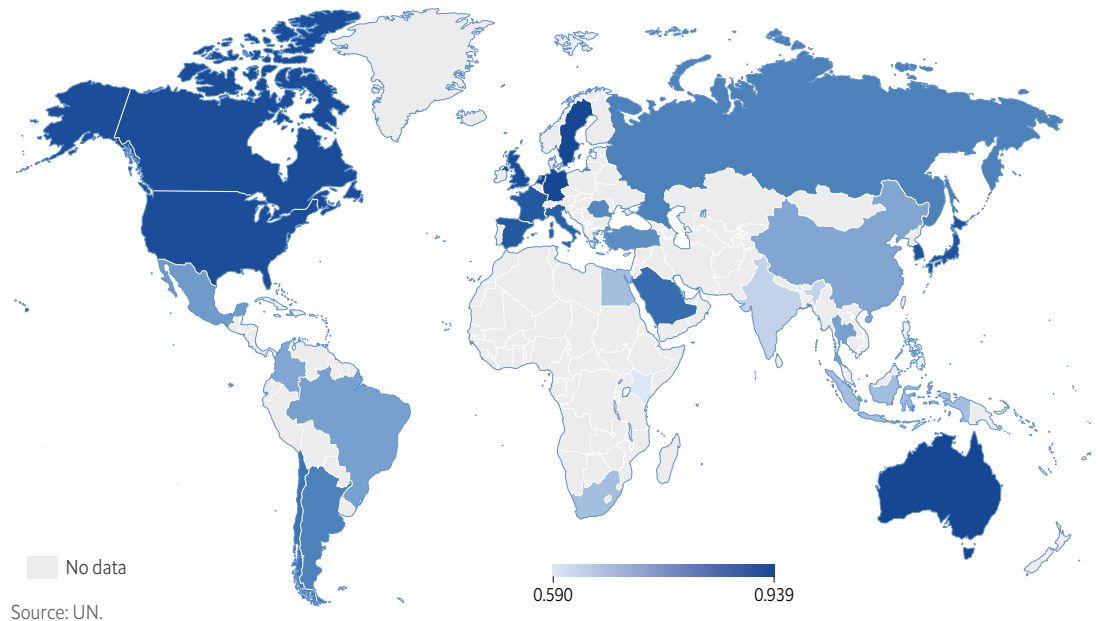
More striking is the extent of the link between wealth and preparedness. With few exceptions, a higher HDI score means a better overall result in the ICP. Two heatmaps—one illustrating each index—are surprisingly interchangeable beyond a handful of exceptions such as Saudi Arabia, India and Brazil.

Index score, 2019



Source: ICP.

Human Development Index, 2017



A closer look at the ICP shows that it is not wealth per se, but the ability it gives to invest that matters in cancer control. Two of the three index indicators with the closest correlation—an inverse one—to M:I ratios are those most directly concerned with spending, either on specialist cancer facilities (“service availability and workforce”, which is the most correlated) or on the health system in general (“infrastructure”, third). Moreover, health spending per head—not an index indicator, but gathered for background information—is as correlated with M:I ratios, as is the overall score.

The ICP captures a point in time, but research into trends over some years also finds this link between resources and cancer control. A 2014 study looking at 16 well-off countries between 1995 and 2007 found that not only did those spending more on cancer care have better mortality outcomes during that period, but those that increased spending most over the 12 years also saw a faster decrease in mortality.⁵⁹

Such data come as no surprise to Dr Sankaranarayanan. “Cancer is expensive,” he explains. Accordingly, he adds, key to preparedness for the disease is the extent of a country’s healthcare infrastructure development. “The single most important policy for cancer control is to increase the proportion of GDP invested in health,” he believes. Otherwise, “services for chronic and expensive diseases like cancer cannot be satisfactorily met.”

The strong link between investments and results presents a particular challenge in developing countries. Relatively well-off health systems, even if unable to afford immediate adoption of every advance in cancer care, can pay for important infrastructure. On the other hand, notes Dr Aranda, policymakers “in low resource environments often see the cancer problem as expensive and insurmountable. They may have no idea where they start.”

⁵⁹ Warren Stevens et al., “Cancer Mortality Reductions Were Greatest Among Countries Where Cancer Care Spending Rose the Most, 1995-2007”, *Health Affairs*, 2015.

Certainly, potential useful anti-cancer interventions are numerous and some require little, if any, funding. The WHO best buys, for example, include not just HPV vaccination and cervical cancer screening but various taxes and regulations around tobacco, alcohol and unhealthy foods, some of which are revenue generating.⁶⁰

Gains from such interventions can be huge. Rich Wender, chief cancer control officer of the American Cancer Society, says that “far and away, the number one contributor [to the 27% drop in US cancer mortality over the past 25 years] has been the decline in tobacco use.”

Without minimising the contributions of such low-cost interventions, in many areas implementing cancer control requires substantial investment.

Investment in treatment: A foundational pillar of cancer control

Treatment constitutes the most expensive part of cancer control: facilities, expert personnel, specialised equipment, and therapies all contribute to the substantial costs discussed earlier. Conversely, the selling points of prevention and screening programmes typically include an ability to cut treatment spending.⁶¹

Of course, balance is necessary. Too great an emphasis on the latest cures and technology can possibly distract from less expensive, potentially more cost-effective interventions, says Dr Cazap. As with cancer control as a whole, some containment of treatment costs is possible. He notes that “for many people, the latest technique may not be the best” and, in some health systems, drugs that extend life for a few months rather than cure may not be worth the price.

Nevertheless, good cancer care requires non-trivial treatment resources. Princess Dina, who was instrumental in reforming cancer care in Jordan, highlights that, regardless of a country’s economic status, some complex and large investments in cancer care are both unavoidable and critical. For example, “you cannot have just a normal nurse trained in basic nursing, or a basic laboratory. You need an oncology nurse and a more sophisticated lab. That is the nature of the disease.”

Such investment is ultimately unavoidable for several reasons. To begin with, effective cancer control involves integrated, mutually re-enforcing capacities, one of which is the ability to treat. Other elements either rely on it and cannot, on their own, replace it. For example, prevention alone, however necessary, is insufficient. As noted earlier, modifiable risk factors lay behind around half of incidence currently. Even if every cancer arising in this way disappeared tomorrow, that would leave health systems with roughly half of cases to address—a high burden in many countries and a still growing one almost everywhere.

Worse still, because of the latency period for many carcinogens, some of the near future’s cancer burden has already been shaped, however lifestyles may improve. It takes peaks in smoking rates, for example, a couple of decades to translate into peaks in lung cancer incidence.⁶² Dr Mohar adds that other cancers follow a similar pattern: “countries where we see a slightly declining incidence of lung cancer and other smoking related cancers are those where strong measures against tobacco were implemented more than ten years ago. It will be the same with colorectal cancer.”

⁶⁰ WHO, *Tackling NCDs: “Best buys” and other recommended interventions for the prevention and control of noncommunicable diseases*, 2017.

⁶¹ For a good example, see WHO, “Early cancer diagnosis saves lives, cuts treatment costs”, press release, February 3rd 2017.

⁶² Danny Youlden et al., “The International Epidemiology of Lung Cancer Geographical Distribution and Secular Trends”, *Journal of Thoracic Oncology*, 2008; and Tim Adair et al., “Reconstruction of long-term tobacco consumption trends in Australia and their relationship to lung cancer mortality”, *Cancer Causes & Control*, 2011.



To have a successful screening programme, you need a matching treatment programme.”

Prebo Barango, medical officer, Non-Communicable Diseases, World Health Organisation’s Inter-Country Support Team for Eastern and Southern Africa

Meanwhile, efforts to downstage tumour presentation, whether through screening or early diagnosis, make little sense on their own. As Dr Barango puts it, “to have a successful screening programme, you need a matching treatment programme.” This is why one-stop examination and care for cervical cancer lesions makes so much sense in low resource environments. Ms Stevens agrees: “Screening is part of a process, not a test. You have to make sure there is follow up and people can get treated” or access palliative care if the intervention finds untreatable, late-stage cancers. Dr Wender adds that this is more than a logical necessity: “screening in the absence of treatment is a tragedy. To find cancer that could be treated in a different setting, but that you don’t have the capacity to actually provide is a problem we all have to overcome.”

The result is that those countries that have made an investment are the ones capable of realising the savings from downstaging. A recent analysis of national cancer plans worldwide found that those from high-income countries were twice as likely to mention early detection as those from low-income ones.⁶³

The route to meaningful access

Another compelling reason for cancer investment even in low- and middle-income states is that, without accessible treatment capacity, patients and families will try to find funds to cover the costs. But the results are often as debilitating to finances as the disease can be to the body.

A few examples suffice to paint the broader picture. In China, even after insurance pay-outs, cancer poses “an unmanageable financial burden” for 78% of families; in Vietnam, more than half of patients need to use up half of total household income to fund treatment; in India, 40% of patients have to borrow or sell assets to afford care.⁶⁴

Personal resources and borrowing are often not enough. In the years after the worldwide economic downturn of 2008, especially in countries without universal healthcare, increases in unemployment—and therefore individual financial resources—are significantly associated with higher mortality rates for treatable cancers. In OECD countries, where healthcare is often easily accessible, a recent study estimated that job losses led to 260,000 extra cancer deaths over two years.⁶⁵ In lower-income countries the problem does not require an economic crisis to manifest itself. Indeed, Princess Dina blames at least part of the growth in cancer mortality rates worldwide on an inability of many to get care in the developing world. “Having no access to early detection means that patients present too late to achieve a cure and certainly having no access to quality treatment, or any treatment for that matter, confirms the fear of many that ‘cancer means death’”

The cure for fatalism?

Every element of cancer control is ultimately

⁶³ Yannick Romero et al., “National cancer control plans: a global analysis”, *Lancet Oncology*, 2018.

⁶⁴ Hui-Yao Huang et al., “Expenditure and financial burden for common cancers in China: a hospital-based multicentre cross-sectional study”, *Lancet*, 2016; Van Minh Hoang et al., “Household Financial Burden and Poverty Impacts of Cancer Treatment in Vietnam”, *BioMed Research International*, 2017; Sunil Rajpal et al., “Economic burden of cancer in India: Evidence from cross-sectional nationally representative household survey, 2014”, *PLoS One*, 2018.

⁶⁵ Mahiben Maruthappu et al., “Economic downturns, universal health coverage, and cancer mortality in high-income and middle-income countries, 1990–2010”, *Lancet*, 2016.

indispensable. Nevertheless, as Princess Dina's comment indicates, in one key respect investment in treatment capacity, however expensive, is the essential first step: the credibility it gives to other efforts. She is the former director-general of the King Hussein Cancer Foundation, and recalls that the management team of the foundation began the reform of cancer control in Jordan by transforming the King Hussein Centre, a hospital, into a high-quality specialist cancer facility. She describes this as one of the team's great successes in part because "once we fixed the treatment side, it made people more likely to listen to preventative and early detection awareness messages because they saw 'we can actually survive cancer'."

This credibility is particularly important in addressing cancer fatalism, or beliefs that little or nothing can be done to prevent or treat cancer. A widespread problem in much of the developing world, and not absent from the developed, a large body of research shows that it undermines every element of cancer control, not just willingness to report symptoms, but also to participate in screening, and even to respond to cancer prevention messages.

The resultant vicious circle is, literally, lethal. What Dr Barango says of his region could apply in any number of regions: "cancer is seen as a death sentence in most African settings. Most people don't know it can be survived. Because of fear and misconceptions about the cause, the patient does not seek treatment in time. The results are therefore bad, so people think nothing can be done. It is a chicken and egg problem."

The key to understanding fatalism is not to focus on the erroneous beliefs that undergird



We need to change the narrative so that cancer is not seen as a death sentence."

Prebo Barango, medical officer, Non-Communicable Diseases, World Health Organisation's Inter-Country Support Team for Eastern and Southern Africa

it, or to see it as culturally determined, says Princess Dina, but to understand that it is a perfectly rational response to life experience in too many countries. "It does not come out of nowhere," she says. "People are smart. The reason they are fatalistic is that they have never seen survivors. When people come out of cancer centres only when they are dead, of course people around them will be fatalistic."

Accordingly, to address fatalism, says Dr Barango, "we need to change the narrative so that cancer is not seen as a death sentence." Cancer survivors are essential to this shift. To cite just one of many examples in developed countries, within the past couple of decades, the stories of survivors have helped transform Australian attitudes toward the disease from a feared, taboo topic to a treatable, if serious, health problem.⁶⁶

Such a shift, like meaningful early detection and a broader openness to prevention, requires effective treatment facilities. Accordingly, what Dr Barango says about African countries that have made progress on cancer preparedness applies globally: "they have gone beyond the rhetoric of saying 'we will do something' and put real resources into the problem."

⁶⁶ The Economist Intelligence Unit, *Breast Cancer in Asia: The challenge and response*, 2016.

II. Essential roadmap: The national cancer control plan

Key takeaways

- Effective cancer control planning saves lives.
- Ideally, every country should have a national cancer control plan (NCCP) in order to deploy its cancer control resources most effectively against the specific cancer burden it faces.
- A cancer element in a non-communicable diseases plan, although better than nothing, is a second best.
- NCCPs too often are more aspirational statements than operational documents. To be effective, they must focus on the specific cancer needs of the population covered, have realistic goals and budgets, and be drafted jointly with all relevant stakeholders.

A recognised necessity

Cancer is a complex challenge varying across time and geography. Accordingly, it requires a comprehensive, multi-pronged response from a broad array of health system and other actors. Such a combination rarely arises spontaneously. Unplanned efforts instead far too readily turn out futile—in the case of cancer control with the added danger of wasting much of the money invested.

Accordingly, since the early 1980s the WHO has actively promoted the development of national cancer control plans (NCCPs). It defines them as public health programmes “designed to reduce the number of cancer cases and deaths and improve quality of life of cancer patients, through the systematic and equitable implementation of evidence-based strategies.”⁶⁷ This involves co-ordinating and integrating efforts across a wide range of fields including—following a recent European best practice guide—primary prevention and health promotion; cancer screening and early detection; diagnosis and treatment; psychosocial oncology care; survivorship and rehabilitation; palliative and end-of-life care;

governance and financing; cancer resources; cancer data and information; and cancer research.⁶⁸

The substantial value of NCCPs is now widely accepted, not least by the experts interviewed for this study. Princess Dina notes that “We know that these plans work. They are so important for all countries, but especially developing ones, which don’t have the luxury of wasting a penny.” Dr Tabernero agrees: “we definitely need policies tackling several aspects of cancer control, although some are more relevant to certain countries and regions. The important thing is to have a plan. We need all countries to have national cancer plans.”

This does not apply solely to country-level authorities. Ms Stevens says that in the US state cancer control plans have played an important role in addressing the disease. The UICC, meanwhile, has launched an initiative aimed at another level of government. C/Can 2025, the City Cancer Challenge, is a multi-sectoral initiative helping various cities with a population of over 1m people to design, plan and implement cancer treatment solutions.

⁶⁷ WHO, *National cancer control programmes: policies and managerial guidelines*, 2nd ed., 2002.

⁶⁸ Tit Albrecht et al. eds., *European Guide for Quality National Cancer Control Programmes*, 2015.

Diverse potential benefits

This enthusiasm for NCCPs arises from various potential attractions if well executed. At the strategic level, planning allows health systems to consider and integrate a selection of possible interventions, choosing the final combined programme based on how best to minimise cancer's overall burden. Just as beneficial is the chance to allocate resources coherently in order to maximise value for money. In the absence of a plan, health system biases can skew budget choices. For example, in Dr Tabernero's experience in Europe, officials are often willing to spend on anti-cancer therapies rather than funding prevention strategies. In Latin America, Dr Cazap explains, preferences in this area depends on whether one's job is focused on cancer care or is a more general, higher-level one in the Ministry of Health. Both experts agree that a strategic plan ensures that available funds are more likely to be split in the most effective manner.



If you have a real NCCP in place and operational, it is easier because usually you can address political hurdles."

Eduardo Cazap, founder and first president, Latin American and Caribbean Society of Medical Oncology

Tactical benefits can also arise from NCCPs, such as the chance to overcome the barriers that organisational silos too often raise. Dr Barango explains that, "Across the spectrum of plan implementation, there are multiple stakeholders which are traditionally in

different sectors. Vaccination, for example, is typically under a different government programme from cancer. The NCCP makes sure that all the sectors that have an influence are on board." Similarly, notes Dr Cazap, an agreed country-wide plan can diminish those frictions between different levels of government so common in federal systems. "If you have a real NCCP in place and operational, it is easier because usually you can address political hurdles," between different levels of government, he says. "You then don't need to go through the same amount of bureaucracy."

The ultimate measure of utility, though, is the extent to which NCCPs yield better cancer outcomes. Hard quantitative assessments do not exist to prove this definitively. On the other hand, two findings of this study suggest that good cancer planning's ability to save lives—an intuitively likely proposition—is in fact a reality. The first is a comparison of the efforts and outcomes of Thai and Romanian cancer control, which indicates that the former's better planning is able to make up for the advantage that greater resources give to Romanian healthcare (see *How valuable can an NCCP be? A tale of two cancer control efforts*). The second sign of value comes from the ICP itself. Its national cancer control programme indicator correlates with better M:I ratios across the 28 index countries, although the data are too few to say with certainty that this is a robust relationship.

The disconnect between NCCP aspiration and reality

The search for such possible gains is widespread: a substantial and rapidly growing number of NCCPs now exist. In 2017 79% of countries that replied to a WHO survey reported having operational cancer policies, strategies or action plans, up from 64% only four years earlier.⁶⁹ This is consistent with a

⁶⁹ Economist Intelligence Unit calculations based on "Policies, strategies and action plans: Data by country," WHO Global Health Observatory data repository.

2018 review of NCCPs in the *Lancet*, which found that 82% of WHO member states had either such a plan or at least a strategy for NCDs that contained a cancer element.⁷⁰ In the ICP, where more than half the countries are high-income, the figures are even better. All have some form of plan, although in three this is part of a wider NCD strategy rather than a specific NCCP.

The problem is not the quantity of these documents but their quality. Among index countries, just eight (29%) get full marks for the comprehensiveness, implementation framework, and monitoring and evaluation mechanisms of their NCCPs. The *Lancet* review cited previously, after looking at more than 150 national plans, found that these sorts of shortcomings are a common problem worldwide. In many cases, it says, NCCPs fell short in areas as diverse and basic as “setting of realistic priorities, specification of programmes for cancer management, allocation of appropriate budgets, monitoring and evaluation of plan implementation, promotion of research, and strengthening of information systems.”

Too often the flaws arise even though planners know that some given action is important. They simply are not clear about how to carry it out. For example, 79% of NCCPs worldwide mention, correctly, the necessity of leadership for successful implementation, but only 7% provide details on who should be in charge of this area. Similarly, 56% noted the need to budget for cancer-related activity, but just 10% explained how the plan itself would be costed or budgeted.⁷¹ These discrepancies have real-world consequences. Dr Taberero observes ruefully, for example, “All the NCCPs I know of promote a multi-disciplinary approach to

cancer care. Whether they actually achieve this on the ground is quite another thing.”

The right focus, the right resources, and the right actors

The history of NCCPs helps explain their current, equivocal state in many countries. Although the idea’s roots go back over 30 years, conventional wisdom about what plans should include has changed over time and even now no standard exists. In 2001, for example, the WHO reported that 48% of countries, including 62% in Europe, had a cancer control plan.⁷² Looking back from 2015, though, researchers found only a handful of European policies that looked like what would now be considered NCCPs.⁷³ Two pioneers from the region, Italy and Ireland, introduced their first plans only near the end of the 1990s. Similarly, as late as 1994-2004, Japan’s “comprehensive” anti-cancer strategy dealt, to a great degree, with insuring that research funding was spread across the cancer control spectrum rather than excessively concentrated.⁷⁴

This evolution continues. Lisa Lacasse, president of the American Cancer Society Cancer Action Network notes that in their plans, “more states, tribes, territories and Pacific Island jurisdictions are shifting away from cancer control and prevention efforts focused on specific programmes and are increasingly focusing on policy, early detection, survivorship, prevention, health equity (social inequities), financial burden and health systems change that will reduce their cancer burden.”

Thus, although a much more expansive and detailed concept of NCCPs is now well understood, this is relatively recent. Accordingly, expertise in the use of such plans

⁷⁰ Yannick Romero et al., “National cancer control plans: a global analysis,” *Lancet Oncology*, 2018.

⁷¹ *Ibid.*

⁷² WHO, Assessment of National Capacity for Noncommunicable Disease Prevention and Control: The Report of a Global Survey, 2001.

⁷³ Tit Albrecht et al. eds., *European Guide for Quality National Cancer Control Programmes*, 2015.

⁷⁴ James Bennett et al., *Cancer Control Strategies in Eleven OECD Countries*, 1999; Malcolm Moore and Tomotaka Sobue, “Cancer Research and Control Activities in Japan – Contributions to International Efforts,” *Asian Pacific Cancer Review*, 2009.

has taken time to bed in across health systems worldwide.

For countries looking to improve NCCPs, useful advice abounds. The WHO has written several detailed guides over the years, as have the US Centers for Disease Control and Prevention and the EU's recently completed Cancon project.

These cover far too much ground to address in this study. Worth noting here, though, are that interviewee comments point to three foundational requirements for effective plans without which other efforts will probably yield little.

The first is a tight, defined focus. This begins with concentrating as closely as possible on the particular needs of the place that the plan covers. Dr Cazap explains that "there are rules about cancer planning that can be applied in a general way, but ultimately it is something specific for each particular country."

To this, Dr Sankaranarayanan adds that, ideally, a narrow cancer-only policy is more effective than a broader NCD one. He says that relying solely on the latter means leaves certain specific elements of cancer control, such as the need to address the link between incidence and infection, liable to being overlooked. The data bear him out: the *Lancet* analysis of NCCPs repeatedly found that NCD plans fell short of those dedicated specifically to cancer on a range of measures, including comprehensiveness, coherence and consistency.⁷⁵ In other words, although including cancer in a general NCD plan is better than nothing, it is no substitute for a properly worked out NCCP.

The second basic requirement for success is to provide adequate resources to carry out the plan—seemingly obvious but too often absent, especially in low-income countries. The key here is, says Dr Barango, when drafting

strategy, to replace vaulting ambition with sober realism about potentially available tools. "An NCCP is as good as the resources that you put in to implement it," he says. "But, if a country that has very few oncologists and no radiotherapy machines puts into its NCCP that it will provide radiotherapy for all detected cancers, that sounds good on paper but won't happen." Planners should instead define and implement achievable goals.



Focus is important: don't have a sophisticated plan on paper which is so overwhelming it sits on a shelf."

Princess Dina Mired, president, UICC

This does not mean that lower-income countries will inevitably have inferior plans. Although the *Lancet* analysis discussed above did not publish country NCCP scores, Princess Dina has seen the underlying research and reports that some low- and middle-income countries achieved among the best results. This ranking came because they "tallied their priorities with their limited resources. They did not just have a fancy plan. Focus is important: don't have a sophisticated plan on paper which is so overwhelming it sits on a shelf."

Finally, an NCCP from development through implementation has to bring together the key actors in cancer control. This starts with leading government officials. Dr Cazap advises that "National Cancer Plans should be done at the highest level," ideally led by a cabinet minister, in order to give necessary impetus to the programme and its execution. It is more than a simple top down process, though. This is not just a health system activity. Ms Lacasse says of the many state and other sub-national

⁷⁵ Yannick Romero et al., "National cancer control plans: a global analysis", *Lancet Oncology*, 2018.

American plans, for example, those directly involved in cancer “are integrating their work with other divisions within departments of health, such as immunisation and tobacco control, as well as other agencies, such as Medicaid or the Department of Education, to more effectively and efficiently increase access to care and focus on the factors that contribute to cancer incidence and high mortality rates.”

Accordingly, Dr Barango repeats what the WHO has been suggesting as best practice since at least 1995:⁷⁶ “During the development of an NCCP, all stakeholders should be brought on board.” In this sense, an NCCP is best understood not as a technical document but as the outcome of a political process, which not only identifies the best cancer control strategy but also builds and gives direction to the coalition necessary to carry it out.

How valuable can an NCCP be? A tale of two cancer control efforts

How Thailand and Romania address their respective cancer burdens, and the results they achieve, illustrate the marked impact of effective national cancer control planning.

Of the two, Romania’s superiority in health systems assets, according to the data collected for our ICP, means it should be doing far better.

Comparison of key health system metrics (all per 1,000 population)

	Romania	Thailand	Ratio Romania:Thailand
Surgeons	460	60	7.7
Clinical oncologists	18.8	3.2	5.9
Radiation oncologists	4.1	1.1	3.7
Skilled health professionals	91,000	28,000	3.25

Source: ICP

Even after considering Romania’s higher cancer incidence—its crude rate is about 175% of Thailand’s—it still deploys a much larger workforce per patient.⁷⁷

Surprising, then, is the similarity between cancer outcomes in the two countries. Romania’s mortality-incidence ratio (M:I) ratio for cancer is 61%; Thailand’s is not far behind at 67%.⁷⁸ Looking more closely, though, the latter’s higher M:I figure reflects a significantly greater percentage of cancers within its overall burden, which neither country is particularly good at addressing, such as those of the liver. In other words, the differing nature of the cancer burden is skewing the results to Romania’s benefit. Taking the specific M:I ratios for every cancer in each country and then applying these to the same cancer burden—in this case one based on global incidence figures—puts both on a level playing field. Here, Thailand does slightly better than Romania although, after rounding, both have an adjusted M:I of 62%. In other words, the two countries arguably are doing nearly as well at cancer control.

Thailand’s ability to achieve just as much with fewer resources almost certainly comes down to its superior record of cancer planning over the years.

⁷⁶ WHO, National Cancer Control Programmes: Policies and managerial guidelines, 1995.

⁷⁷ Economist Intelligence Unit calculations based on data from J Ferlay et al., Global Cancer Observatory: Cancer Today.

⁷⁸ All figures in this paragraph from Economist Intelligence Unit calculations based on data from J Ferlay et al., Global Cancer Observatory: Cancer Today.

From 2001 onward, Romania had a national programme for cancer. This focused for the most part on treatment with little or no attention to prevention, data gathering, research, survivorship issues or palliative care. One academic analysis found, over this period, “an erratic vision underpinning the cancer programme and a complete lack of objective measures of the...results.”⁷⁹

After years of consultation with foreign experts, in April 2016 the Romanian Ministry of Health issued a detailed proposal for a high-quality national cancer control plan (NCCP). It had high-level political support—the minister was the former head of an oncological institute—and was expected to become formal policy in June 2016.⁸⁰ In May of that year, though, the minister lost his cabinet post and the policy sank without a trace. Indeed, because it was neither adopted nor rejected, several years later even Romanian MPs remain confused as to its status.⁸¹ General public health policies contain some cancer-related goals to improve cervical and breast cancer screening,⁸² but no coherent cancer strategy exists.

The health system’s response to cervical cancer illustrates how these problems play out in practice. Romania has the second-highest crude incidence rate of the disease in Europe and the seventh-highest age-standardised incidence on the continent, yet by far the highest mortality using either rate measurement.⁸³ Nevertheless, it abandoned its human papilloma virus (HPV) vaccination programme after two years, in 2010, because of low uptake and its poorly run cervical cancer screening programme has attracted only a small minority of its target population.⁸⁴ Even those women who have used it faced poor integration between screening and treatment and some from minority groups have been charged by general practitioners for what should have been a free service.⁸⁵

Thailand could not be more different. It has had an NCCP since 1998 with strong support from the top: the then prime minister drove adoption of the first plan and succeeding governments have retained cancer as a priority. The quality of these plans has also been high and their execution thorough. Rengaswamy Sankaranarayanan, senior visiting scientist at the International Agency for Research on Cancer (IARC), explains that the country is “an excellent example of taking a wider focus on all elements of cancer control. These are well thought-out and implemented in a balanced way.”

For example, the country has looked at all aspects of prevention. As the index research shows, relevant efforts include internationally common interventions, such as implementation of Framework Convention on Tobacco Control commitments, a high rate of infant hepatitis B vaccination (99% currently), and the ongoing roll-out of nationwide HPV vaccination. It has also not ignored prevention issues related to the local cancer burden.

⁷⁹ Adela Popa, “The national cancer programme in Romania: Challenges in a low-resource healthcare system”, *Journal of Cancer Policy*, 2017.

⁸⁰ Cancer Control Joint Action, “The first Integrated Multi-Annual National Cancer Control Plan in Romania for 2016-2020, submitted by the Ministry of Health”, press release, April 13th 2016; “Patriciu Achimaş: ‘Planul comprehensiv de cancer, soluția pentru controlul cancerului în România’”, *Ziar Medical*, February 5th 2018.

⁸¹ “Cancerului de sân prinde din nou România fără programe de preveniție”, *Jurnalul de Brăila*, October 1st 2018.

⁸² Ordinance 377/2017, March 30th 2017, *Monitorul Oficial al României*, Part I, number 223.

⁸³ J Ferlay et al., *Global Cancer Observatory: Cancer Today*.

⁸⁴ WHO Europe, “Group of experts assess prevention and treatment of cervical cancer in Romania”, press release, November 24th 2017.

⁸⁵ *Ibid.*, Trude Andreassen et al., “Controversies about cervical cancer screening: A qualitative study of Roma women’s (non)participation in cervical cancer screening in Romania”, *Social Science and Medicine*, 2017.

Since the late 1980s the government has tried various programmes to reduce infection by carcinogenic liver fluke and, despite a degree of success, is looking at ways to drive the still too high prevalence down.⁸⁶

Decisions on these efforts, like Thailand's NCCP as a whole, are firmly evidence based. In-country pilot projects to measure cost versus benefit informed the choice to begin HPV vaccination.⁸⁷ This approach carries over to screening, with such research preceding the recent change in the method of cervical cancer screening to a blood test that detects HPV DNA, and the roll-out of colorectal cancer screening country-wide.⁸⁸ A substantial literature review also informed the decision not to fund widespread mammography screening.⁸⁹

Consistent with this emphasis on evidence, cancer data are another strength of the system. The country's first population-based cancer registry dates back to 1986,⁹⁰ and, says Dr Sankaranarayanan, despite quality issues in some institutions, today's network as a whole provides "a valuable handle on the cancer pattern".

As the index data cited above suggests, Thai cancer control's biggest problem is a lack of specialised manpower.⁹¹ Nevertheless, it uses what it has effectively. Dr Sankaranarayanan notes that the Thais "have developed a network of seven regional treatment services with an apex centre in Bangkok, along with tertiary care in major hospitals and universities." Where care is available, it is also free under the country's universal health system.

Cancer control in Thailand, of course, has weakness beyond workforce issues. Lack of access to care in rural areas remains an important difficulty, as does palliative care, which is still basic.⁹²

That said, the country's more effective cancer planning than Romania's reveals itself in any number of ways. In Romania, cervical cancer screening uptake is only around 10%; in Thailand it is 70%.⁹³ While no Romanian population-based registries were of sufficient quality to merit inclusion in the IARC's 2017 *Cancer Incidence in Five Continents* study, Thailand had seven that covered in aggregate more than a third of the population.⁹⁴ Even in palliative care, Thailand comes out markedly ahead, scoring 40.2 out of 100 in The Economist Intelligence Unit's 2015 Quality of Death Index, more than 40% higher than Romania's 28.3.⁹⁵

The differences between these two countries, then, make all too clear that, while resources are essential for good cancer control, effective planning in their use saves lives.

⁸⁶ Narong Khuntikeo et al., "A Comprehensive Public Health Conceptual Framework and Strategy to Effectively Combat Cholangiocarcinoma in Thailand", *PLoS Neglected Tropical Diseases*, 2016; Tomás León, "Modeling liver fluke transmission in northeast Thailand: Impacts of development, hydrology, and control", *Acta Tropica*, 2018; Banchob Sripana and Pierre Echaubard, "Prospects and Challenges towards Sustainable Liver Fluke Control", *Trends in Parasitology*, 2017.

⁸⁷ Wichai Termrungruanglert et al., "Cost-effectiveness analysis study of HPV testing as a primary cervical cancer screening in Thailand", *Gynecologic Oncology Reports*, 2017.

⁸⁸ Worrawan Klinsupa, "HPV Vaccination Introduction in Thailand", slide presentation, 2015; Thiravud Khuhaprema et al., "Organised colorectal cancer screening in Lampang Province, Thailand: preliminary results from a pilot implementation programme", *BMJ Open*, 2014; Chomnapas Wangein "คัดกรองมะเร็งลำไส้ใหญ่ 'ตรวจพบเร็ว รักษาทัน'", June 22nd 2018, Thai Health web page.

⁸⁹ Yot Teerawattananon et al., "Development of a Health Screening Package Under the Universal Health Coverage: The Role of Health Technology Assessment", *Health Economics*, 2016.

⁹⁰ S Deerasamee et al., "Cancer Registration in Thailand", *Asian Pacific Journal of Cancer Prevention*, 2001.

⁹¹ The Economist Intelligence Unit, *Controlling cancer: The state of national cancer control plans in Asia*, 2015.

⁹² The Economist Intelligence Unit, *Breast cancer in Asia: The challenge and response*, 2016; Economist Intelligence Unit, *Controlling cancer: The state of national cancer control plans in Asia*, 2015.

⁹³ WHO Europe, "Group of experts assess prevention and treatment of cervical cancer in Romania," press release, November 24th 2017; communication from Thai National Cancer Institute to The Economist Intelligence Unit.

⁹⁴ Economist Intelligence Unit calculations based on data in F Bray et al., eds. *Cancer Incidence in Five Continents*, Vol. XI, 2017.

⁹⁵ The Economist Intelligence Unit, *The 2015 Quality of Death Index*, 2015.

III. Essential foundation: Integration with effective, accessible general health provision

Key takeaways

- Cancer control should occur within the context of accessible general healthcare.
- In high-resource health systems, the most frequent issue in this area is the need for better integration of specialised cancer treatment with other medical provision, notably primary care. Ideally, patient-centred care should also involve any necessary social assistance.
- In low-resource systems, cancer control should be built into efforts to expand universal healthcare rather than happening in parallel.

Part of a bigger whole

“Cancer control should not be done in isolation,” says Dr Barango, “but within the context of universal healthcare.” Dr Aranda agrees: “Many of its aspects require integration. Surgery and pathology, for example, are features of a broad, strong health system. Specialisation sits on top of that.”

The ICP data give the same message. Of our three domains, Health System and Governance scores have the closest correlation with national M:I ratios. Good cancer care requires good healthcare.

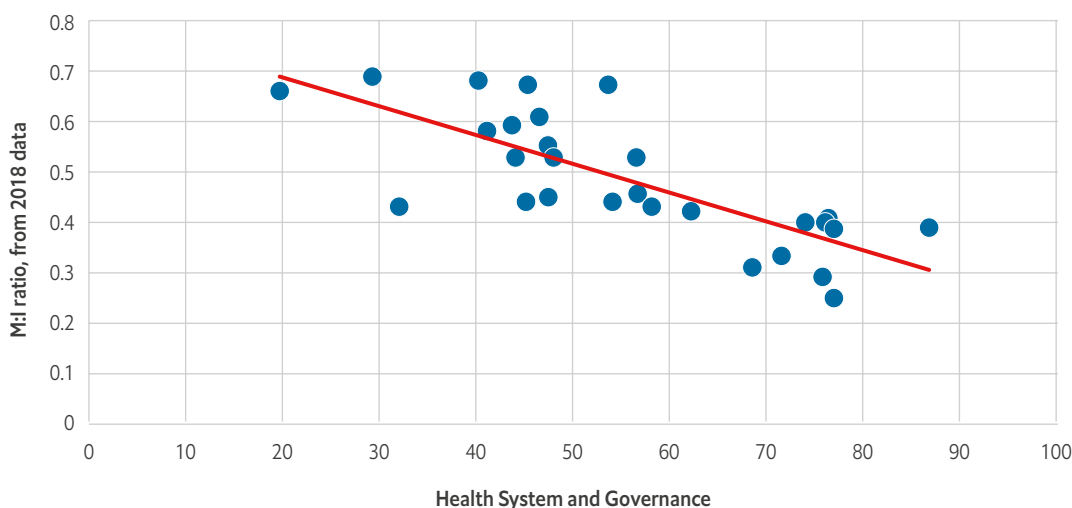
Two issues are salient here: the degree to which people have access to good general healthcare in the first place and the extent to which cancer control is integrated into that health system.

Care in higher-income states: Accessible (usually) but not as integrated as it could be

In the developed world, access is the less pressing issue. The ten index countries with full marks for universal healthcare are all high income.

That said, even in wealthier states the ability to get basic care can affect cancer outcomes.

Correlation between Health System and Governance scores and national M:I ratios



Source: ICP.

In the US, for example, explains Dr Wender, “we have a persistent problem with people without health insurance [currently 9% of the population⁹⁶] and a substantial number who are under-insured. They are less likely to get any preventative care or screening, and more likely to present with an advanced-stage cancer.”

Moreover, having a health system that ostensibly does cover the entire population does not guarantee high-quality access for all. For example, the UK’s ongoing problem with poor general practice provisioning in economically deprived areas still reflects, nearly 50 years on, one researcher’s “inverse care law”—that “the provision of good medical care tends to vary inversely with the need for it in the population served.”⁹⁷ Other high-income countries, such as Australia, have longstanding problems in attracting doctors to rural areas and attendant worse health outcomes there.⁹⁸

These geographic and socio-economic related differences almost certainly affect cancer control. A lack of gynaecologists, for example, particularly in rural areas, helps explain Japan’s poor cervical cancer screening rates.⁹⁹ Meanwhile, Dr Aranda reports that in Australia age-standardised cancer mortality rates are 30% higher in the lowest economic quintile than in the highest one. Differences in health literacy and lifestyle-related risk do explain some of this, “but we are trying to see if there are differences in system failure and speed” between the care received by this group and other Australians.

That said, the more common issue in the relationship between cancer control and

health systems in wealthier countries is integration.



People diagnosed with cancer often find themselves—especially if they get care through a traditional fee-for-service model—left to navigate that system on their own.”

Lisa Lacasse, president, American Cancer Society Cancer Action Network

The best example is the contrast in how primary care and oncology should and do interact. As Ms Lacasse says of the US, even after progress in increasing access, “we still have a way to go in terms of ensuring that this care is seamless. People diagnosed with cancer often find themselves—especially if they get care through a traditional fee-for-service model—left to navigate that system on their own. They face myriad challenges as they move from primary care into oncology and eventually back into primary care. These challenges include a lack of care co-ordination, no one to monitor the long-term implications of their cancer treatment, and lack of critical survivorship follow-up care.”

Although not their specialty, those in primary care inevitably play an important role at various points along the cancer control spectrum. In high-income countries, for example, studies indicate that support from primary care providers improves the effectiveness of cancer prevention messages and raises screening

⁹⁶ US CDC National Center for Health Statistics, “Health Insurance Coverage: Early Release of Estimates From the National Health Interview Survey, January-June 2018”, press release, November 2018.

⁹⁷ Julian Tudor Hart, “The Inverse Care Law”, *Lancet*, 1971; Centre for Workforce Intelligence, *In-depth review of the general practitioner workforce*, 2014.

⁹⁸ Australian Medical Association, “Rural Workforce Initiatives 2017”, Position statement, 2017.

⁹⁹ Hiroshi Sano et al, “Does lack of resources impair access to breast and cervical cancer screening in Japan?”, *PLoS One*, 2017.

uptake. Similarly, general practitioners (GPs) are the first impacted by new awareness campaigns: a UK media blitz encouraging people to consult about coughs lasting longer than three weeks led to a rise of 67% in the number of people at GP offices with a cough.¹⁰⁰

Cancer detection is also largely in the hands of primary care providers: around 85% of cases are found as a result of a patient visit to this kind of clinician.¹⁰¹ Even during acute cancer treatment—when oncologists would presumably dominate—a review of 35 distinct studies from across 11 developed countries found that 45% of GPs play some part.¹⁰² A strong primary care role alongside oncologists in survivorship treatment, meanwhile, leads to higher patient satisfaction along with medical outcomes that are at least as good as—in some studies better than—oncologist-only provision.¹⁰³

Co-ordinated interaction between specialists and primary care, whether seamless referrals back and forth or active co-operation at relevant times, is therefore integral to good cancer control. Moreover, according to the review cited above, roughly 95% of primary care doctors want a greater role in comprehensive cancer care.¹⁰⁴

In some cases, primary care physicians need better training or information to take a fuller role in cancer control: common cancers, for example, are usually suspected after the first patient visit, but with rarer ones this can take several appointments. Similarly, about half of GPs believe they need more information on managing long-term side effects of treatment.¹⁰⁵

Training could address this need. The far bigger problem for integration of cancer care is the often poor, fragmented relationship between primary and oncological clinicians.¹⁰⁶

Lack of clarity about respective roles is a common complaint, with the two sides not always agreeing on who ideally should be doing what.¹⁰⁷ Moreover, poor communication undermines the co-ordinated effort. As one study summed up it, “Primary care physicians report being isolated from the cancer care system and, therefore, less effective in helping patients cope with their diagnosis and treatments.”¹⁰⁸ Indeed, research in Canada, the US and the UK has found that it is not unusual for GPs to receive no information at all from oncologists on shared patients’ treatment.¹⁰⁹ More generally, in surveys 85% to 99% of primary care providers have indicated

¹⁰⁰ Greg Rubin et al., “The expanding role of primary care in cancer control”, *Lancet*, 2015.

¹⁰¹ Ibid.

¹⁰² Renae Lawrence et al., “Primary Care Physicians’ Perspectives of Their Role in Cancer Care: A Systematic Review”, *Journal of General Internal Medicine*, 2016.

¹⁰³ Greg Rubin et al., “The expanding role of primary care in cancer control”, *Lancet*, 2015; Renae Lawrence et al., “Primary Care Physicians’ Perspectives of Their Role in Cancer Care: A Systematic Review”, *Journal of General Internal Medicine*, 2016.

¹⁰⁴ Renae Lawrence et al., “Primary Care Physicians’ Perspectives of Their Role in Cancer Care: A Systematic Review”, *Journal of General Internal Medicine*, 2016.

¹⁰⁵ Greg Rubin et al., “The expanding role of primary care in cancer control”, *Lancet*, 2015; Renae Lawrence et al., “Primary Care Physicians’ Perspectives of Their Role in Cancer Care: A Systematic Review”, *Journal of General Internal Medicine*, 2016.

¹⁰⁶ “Integrated Cancer Care: Bringing Primary Care and Secondary Care Together”, 2017; See Greg Rubin et al., “The expanding role of primary care in cancer control”, *Lancet*, 2015; articles in “Toward Improving the Quality of Cancer Care: Addressing the Interfaces of Primary and Oncology Related Subspecialty Care”, special volume of *JNCI Monographs*, 2010; Dominique Tremblay et al., “Improving the Transition From Oncology to Primary Care Teams: A Case for Shared Leadership”, *Journal of Oncology Practice*, 2016.

¹⁰⁷ Jonathan Sussman, “Towards Integrating Primary Care with Cancer Care: A Regional Study of Current Gaps and Opportunities in Canada”, *Health Policy*, 2017; Michèle Aubin et al., “Patient, Primary Care Physician and Specialist Expectations of Primary Care Physician Involvement in Cancer Care”, *Journal of General Internal Medicine*, 2016.

¹⁰⁸ Jonathan Sussman, “Towards Integrating Primary Care with Cancer Care: A Regional Study of Current Gaps and Opportunities in Canada”, *Health Policy*, 2017.

¹⁰⁹ Renae Lawrence et al., “Primary Care Physicians’ Perspectives of Their Role in Cancer Care: A Systematic Review”, *Journal of General Internal Medicine*, 2016; Jonathan Sussman and Laura-Mae Baldwin, “The Interface of Primary and Oncology Specialty Care: From Diagnosis Through Primary Treatment”, *JNCI Monographs*, 2010.

that when they share patients they would like more details from the oncologist about basic matters such as the specifics of the treatment along with potential short- and long-term side effects; findings of investigations and likely prognosis; and the oncologist's follow-up plan.¹¹⁰



In many countries, cancer survivors are not well looked after or given a support structure after the acute phase of treatment.”

Lydia Makaroff, CEO, Fight Bladder Cancer UK, and former director, European Cancer Patient Coalition

The lack of integration between cancer control and primary care reflects a broader lack of engagement of cancer control services with not only other parts of medicine but also the fields of social and employment assistance. Ms Makaroff says of Europe, “In many countries, cancer survivors are not well looked after or given a support structure after the acute phase of treatment. Cancer survivors often struggle with financial debt, problems returning to work, stigma, fatigue, and mental health issues. They face a lot of challenges with insufficient support.”

Efforts to overcome the effect of such fragmentation on patients are widespread but may not be doing as much as their popularity

suggests. Nurse and other patient navigation programmes have become common in developed countries, and certainly help to increase screening rates and overall patient satisfaction. Nevertheless, the best research shows that, in general, they have only a limited effect on process, clinical and quality of life outcomes.¹¹¹ Tailored cancer plans for individuals are another promising route, but little consensus exists on what these should entail. Moreover, to a large extent, the plans focus on particular stages of treatment, such as surgery or survivorship, rather than integrating cancer care into seamless patient progress through all needed interventions.¹¹²

Wealthier countries, then, typically have a solid healthcare—and even social care—foundation on which to embed cancer control, but are not making as good a use of it as they could.

Care in lower-income states: A weak foundation undermines cancer control

Instead of integration, in developing countries the dominant issues in cancer control's relationship with the general healthcare system revolve around the nature, or lack, of access to such systems.

Important organisational barriers to receiving treatment can remain even in countries that have made substantial progress toward universal healthcare. In 2009 the Mexican government introduced *Seguro Popular*, a subsidised state health insurance and care system with premiums based on the ability to pay. The goal was to decrease the

¹¹⁰ Renae Lawrence et al., “Primary Care Physicians' Perspectives of Their Role in Cancer Care: A Systematic Review”, *Journal of General Internal Medicine*, 2016.

¹¹¹ Sobia Ali-Faisal et al., “Patient Navigation Effectiveness on Improving Cancer Screening Rates: A Meta-Analysis of Randomized Controlled Trials”, *Journal of Oncology Navigation and Survivorship*, 2017; Poh Tho and Emily Ang, “The effectiveness of patient navigation programs for adult cancer patients undergoing treatment: a systematic review”, *JBI Database of Systematic Reviews and Implementation Reports*, 2016; Karen Freund et al., “Impact of Patient Navigation on Timely Cancer Care”, *Journal of the National Cancer Institute*, 2014; Mark Bensink et al., “Costs and Outcomes Evaluation of Patient Navigation Following Abnormal Cancer Screening”, *Cancer*, 2014.

¹¹² Anum Khan et al., “Integrated Care Planning for Cancer Patients: A Scoping Review”, *International Journal of Integrated Care*, 2017.

large proportion of uninsured within the population. This has worked: 2012 figures, the latest available, show that 79% of Mexicans have health cover, up from 52% before the programme. Cost would not prevent even the poorest in the remaining 21% from joining.¹¹³

Nevertheless, as with much of Latin America, healthcare provision in the country is highly fragmented.¹¹⁴ Dr Mohar reports that six major national systems and over 30 state-based ones provide vertically integrated services. As elsewhere in the region, the quality of care one receives depends entirely on the system to which one belongs. *Seguro Popular*, for example, pays for the costs of treatment for many, but not all, cancers, although the list of those covered has lengthened steadily.

In Mexico, notes Dr Mohar, health system fragmentation not only affects care but has significantly impeded cancer planning, so that despite more than a decade of concerted effort the country still lacks an NCCP. Now, he says, “our new president wants to work to create one unique health system. Then we can set up national cancer, diabetes and other plans. Otherwise, we would have a plan without operational activities.”

A more fundamental problem exists when access to any reasonable-quality healthcare itself is difficult. Dr Sankaranarayanan notes that “more and more people in cancer control have realised the importance of, and recognised the need for, developing health service infrastructure. Without this, you won’t be able to provide services.” This is now so



More and more people in cancer control have realised the importance of, and recognised the need for, developing health service infrastructure.”

Rengaswamy Sankaranarayanan, senior visiting scientist to the Office of the Director, International Agency for Research on Cancer, and senior medical adviser, Research Triangle Institute International, New Delhi, India

widely accepted that in 2017 the World Health Assembly passed a resolution encouraging member states to adopt cancer control that integrates with basic healthcare.¹¹⁵

The difficult question in low-income countries is where to focus limited resources. The reluctance of the international donors to give money for NCD care¹¹⁶ makes it all the more important for health systems in these countries to choose wisely. The experience of efforts against HIV in Africa has done much to shape thinking. In the early years, vertically integrated, often foreign-subsidised, services formed the core of the response to that plague. Experience showed, however, that a more sustainable approach with better outcomes is to integrate HIV diagnosis and care within a wider health system.¹¹⁷

Thus, the answer to whether a country should invest in cancer control or general healthcare is, says Dr Barango, “both”. Health systems

¹¹³ Mercedes Juan López et al., “Reforming the Mexican Health System to Achieve Effective Health Care Coverage”, *Health Systems and Reform*, 2015; OECD, *Reviews of Health Systems: Mexico*, 2016.

¹¹⁴ The Economist Intelligence Unit, *Cancer Control, Access and Inequality in Latin America: A tale of light and shadow*, 2017.

¹¹⁵ “Cancer prevention and control in the context of an integrated approach”, WHA 70.12, May 2017.

¹¹⁶ WHO, *Public Spending on Health: A Closer Look at Global Trends*, [2018].

¹¹⁷ Susannah Mayhew et al., “Building integrated health systems: lessons from HIV, sexual and reproductive health integration”, *Health Policy and Planning*, 2017.

require specialised treatment services, but they also “need to strengthen [the] capacity of lower level healthcare facilities, their ability [to] diagnose cancer, and the mechanisms for referral back and forth to higher and lower levels.” Dr Aranda agrees: “You should invest in cancer control in a way to strengthen the overall health system,” pointing to data presented at the 2017 UICC annual conference—with particular reference to tuberculosis—which showed that countries that have the highest expenditure in vertically

integrated cancer care systems have the poorest outcomes. It is not simply a matter of cancer control building on basic healthcare: some elements of cancer control are basic healthcare. In measuring the extent of universal healthcare, one WHO metric is the extent of cervical cancer screening.¹¹⁸

This “both-and” approach may seem like a counsel of perfection, but Rwanda shows what carrying it out can look like in practice (see the box out on the next page).

Rwanda: Integrated cancer care in a low-resource health system

In many ways, Rwanda is an interesting exemplar of cancer control, lacking both a national cancer control plan (NCCP) and a registry. Instead, its attraction is a coherent medical system strategy.

Beginning with the need to rebuild healthcare from scratch after the civil war in the mid-1990s, officials eschewed short-term solutions to particular problems. Instead, they built up an integrated, multi-tiered system that provides free services to the over 95% of the country with government or other insurance. This was the only way to make the most effective use of resources that are very limited.¹¹⁹ For example, despite a rapid increase in number, as at 2016 Rwanda still had only one doctor per 12,000 population.¹²⁰

The first point of contact for a Rwandan with healthcare is typically one of the country’s 60,000 Community Health Workers. Each village now elects four and they perform a range of basic services such as antenatal, mother and child care—including assisting with childbirth; providing basic general medical advice; screening for tuberculosis (TB) and malaria; treating the latter as well as diarrhoea and malnutrition; monitoring those with TB and HIV; and acting as health system sentinels through regular reports to officials on village conditions. They can also refer patients, or people can go directly, to sector clinics, which are largely nurse-led. These clinics can refer more serious cases to doctors in district general hospitals, who in turn have the option of referral to one of a handful of specialist hospitals.

Cancer control occurs within this framework and ethos. The health system engages in appropriate interventions against a range of cancer where possible—such as hepatitis B vaccination—but focuses on where the need is most immediate. Accordingly, the government, despite its lack of an NCCP, has specific plans for addressing the country’s two most common cancers—those of the cervix and breast.

¹¹⁸ Daniel Hogan et al., “Monitoring universal health coverage within the Sustainable Development Goals: development and baseline data for an index of essential health services”, *Lancet Global Health*, 2017.

¹¹⁹ For a description of the development of Rwanda’s health system and its basic structure, see Economist Intelligence Unit, *Sub-Saharan African Healthcare: The User Experience*, 2014.

¹²⁰ “Rwanda in Need of More Doctors”, *The East African*, September 3rd 2016.

In its efforts, it makes maximum use of existing system resources. On prevention, hepatitis B and human papilloma virus (HPV) vaccinations were rolled into the existing national vaccination programmes rather than part of new, standalone ones. They have reached nearly all of the target populations (98% and 97% respectively).¹²¹

Meanwhile, Community Health Workers have been used as much as possible, playing a key role in promoting HPV vaccination and alerting village residents when mobile cervical cancer test and treat services would be visiting the area.¹²² Most health centres and hospitals also offer cervical cancer screening and treatment for women over 30 years old.¹²³

The nation's breast cancer programme is also creating a tiered approach to diagnosis and treatment. After research showed that poor awareness of this disease and its symptoms was causing very high levels of late-stage presentation, the Ministry of Health and its foreign partners launched a pilot project to address the problem. This involved educating over 1,000 Community Health Workers in breast awareness and encouraging them to refer women with worrying symptoms to district health centres. They sent 10 to 20 women per week overall. Clinic nurses, with training in clinical breast examination, examined them and sent on those with suspicious symptoms to regional hospitals. There, a team of nine general practitioners and nurses were equipped to perform ultrasound tests, which assessed suspect lumps and then referred on those where cancer could not be ruled out. The apex institutions already had the capacity for mammography and treatment. The project was sufficiently successful that the Ministry of Health will be rolling it out nationwide.¹²⁴

Rwanda has several specialist hospitals that can provide cancer treatment services. These too fit into the ethos of Rwandan healthcare. The most prominent, Butaro Cancer Centre of Excellence, was built in a rural area rather than the capital—already served by other institutions—in order to increase accessibility to treatment. It is part of a wider system, providing cancer pathology services for general hospitals and, where it cannot provide certain kinds of treatment, notably radiography, outsourcing those to providers in neighbouring countries. Finally, Butaro is largely funded by US organisations, which also provide some of the staff. The health ministry therefore taps into this expertise to train a cadre of local oncologists.¹²⁵

Rwanda's is not a comprehensive cancer control programme and late-stage presentation remains all too common.¹²⁶ And data do not exist to show what impact current efforts are having overall. Nevertheless, as Dr Barango points out, "Rwanda has high population coverage across all health issues, including cancer. People with early signs can approach [the] health system and be properly referred from primary to specialist facilities" without having to pay. In other words, its efforts show that a low-income country can pursue enhanced cancer control within the context of a broader health system expansion, to the presumed furtherance of both objectives.

¹²¹ WHO, "Rwanda: WHO and UNICEF estimates of immunization coverage: 2017 revision," 2017; Timothy Walker and Emmanuel Musabeyezu, "Hepatitis B in Rwanda: Closing the gaps to end an epidemic," *Rwanda Journal Series F: Medicine and Health Sciences*, 2015; Agnes Binagwaho et al., "Integration of comprehensive women's health programmes into health systems: cervical cancer prevention, care and control in Rwanda," *Bulletin of the World Health Organisation*, 2013.

¹²² Agnes Binagwaho et al., "Integration of comprehensive women's health programmes into health systems: cervical cancer prevention, care and control in Rwanda," *Bulletin of the World Health Organisation*, 2013.

¹²³ "Rwanda's move to control cancer, another milestone in the country's health sector's progress", government of Rwanda press release, October 22nd 2018.

¹²⁴ Jean Marie Dusengimana et al., "Integrating Breast Cancer Early Detection Services Into the Rwandan Health Care System", *Journal of Global Oncology*, 2018; Lydia Pace et al., "Early Clinical Impact of Diagnostic Breast Ultrasound Performed by General Practitioners and Nurses in Rwanda," *Journal of Global Oncology*, 2018; "Faster, Better Care for Breast Cancer in Rwanda," Partners in Health blog, February 5th 2016; Shilpa Murthy et al., "A national framework for breast cancer control: A report on Rwanda's inaugural symposium on the management of breast cancer," *Journal of Cancer Policy*, 2015; Lydia Pace et al. "Benign and Malignant Breast Disease at Rwanda's First Public Cancer Referral Center," *The Oncologist*, 2016.

¹²⁵ Tharcisse Mpunga et al., "Diagnosis of Cancer in Rural Rwanda: Early Outcomes of a Phased Approach to Implement Anatomic Pathology Services in Resource-Limited Settings", *American Journal of Clinical Pathology*, 2017; Clare Neal et al., "Cost of Providing Quality Cancer Care at the Butaro Cancer Center of Excellence in Rwanda", *Journal of Global Oncology*, 2017.

¹²⁶ George Ruzigana et al., "Cervical cancer screening at a tertiary care center in Rwanda", *Gynecologic Oncology Reports*, 2017.

IV. Essential Intelligence: Cancer registration and other data

Key takeaways

- Where they do not exist, or cover only an unrepresentative part of the country, population-based cancer registries need to be strengthened. Without such information, cancer planning cannot focus narrowly on the specific needs of the country.
- Good mortality data are also essential to cancer control, and in too many cases worldwide this falls short.
- Policymakers should also make opportunistic use of other potentially valuable datasets, such as hospital cancer registries, patient-group-driven registries or information gathered by health systems. The last of these may grow in importance in low- and middle-income countries as universal healthcare becomes more common.

The importance of knowing the enemy

“In my experience,” says Princess Dina, “countries that have done better on cancer control have in place population-based registries able to size and monitor the cancer burden.” Wanqing Chen, deputy director of China’s National Office for Cancer Prevention and Control, adds that all governments need to be aware of the value of registries. “You have to know the cancer burden and difference between areas and groups,” to respond effectively, he continues. These experts are far from alone. The WHO and IARC call registries a “core” component of cancer control.¹²⁷

An outside observer might miss why, and to what extent, these institutions are so crucial to cancer control. After all, they deliver neither prevention nor treatment. In an influential 1992 article, which helped move registries beyond the role of “back room” incidence tallying shops, distinguished Australian epidemiologist Bruce Armstrong posited a schema to cover cancer control’s many facets.

He divided the field into six key domains and nine essential activities common to each (see table). Of the resultant 54 elements, Dr Armstrong argued that registries played a central role in 34 and a supporting one in a further nine. In other words, roughly 80% of cancer control is impossible or very difficult to do effectively without good registration.¹²⁸

TABLE 4

Armstrong’s cancer control taxonomy

Domains	Activities
Primary prevention	Basic research
Screening	Situation analysis
Early diagnosis	Intervention
Treatment	development
Survivor issues	Evaluation of
Palliative care	intervention
	Awareness raising
	Programme planning
	Programme
	implementation
	Programme monitoring
	Future planning

¹²⁷ Freddie Bray et al., *Planning and Developing Population-Based Cancer Registration in Low- and Middle-Income Settings*, 2014.

¹²⁸ “The role of the cancer registry in cancer control”, *Cancer Causes and Control*, 1992.

Dr Cazap explains the nature of these links relative to another basic necessity of cancer control: planning. “Both it and data are not only fundamental, they should work in co-ordination,” he says. “Data are the basis of the planning, and planning also involves monitoring, follow up and having the results to evaluate whether an approach is correct or if you should make adaptations.” Dr Barango agrees: “to understand cancer, we need data, and, for that, we need cancer registries. We should base our healthcare priorities in the short and long term on the needs,” which registry data reveal.



Data are the basis of the planning, and planning also involves monitoring, follow up and having the results to evaluate whether an approach is correct or if you should make adaptations.”

Eduardo Cazap, founder and first president, Latin American and Caribbean Society of Medical Oncology

Population-based cancer registries

The simplest type of registry is the hospital-based one. These record details of the cases treated at a given healthcare institution or institutions. The strength of such information in aggregate has traditionally been the clinical detail it can provide on specific tumours, interventions and resultant outcomes. In short, hospital registries can help show which treatments work in which circumstances.

Another, less-common type of registry, called special registries in the US, focuses on specific forms of cancer or risk factors. An example is the Family Ovarian Cancer Registry, which maintains a collection of genetic data and family history profiles for families affected by that form of the disease.

The expert praise for registries described above, though, refers to population-based ones (PBCRs). These, as the name suggests, use both active and passive case findings to collect data on all cancers that occur in a specific population. This kind of coverage—where it extends across an entire population or a representative sample—can provide a clear picture of the national or regional cancer burden. This makes PBCR data useful in public health planning, research, monitoring and policymaking in a way that information from other sources cannot match.¹²⁹

Going beyond this generalisation, though, is difficult. As an IARC guidebook explains, it would be difficult to imagine a registry that did not gather at least very basic information on the patient and the tumour.¹³⁰ Most collect far more. Although certain key data are common across geography and time, the specific items included vary between country and by era.

Indeed, one constant of PBCRs’ history since the first one appeared in Hamburg in 1927, has been a widening of focus. The initial interest in incidence and trends soon grew to include survival rates as well as the outcomes of clinical and public health interventions.¹³¹ The evolution has continued. By one estimate, the number of standard data points per patient collected by US registries

¹²⁹ For a general description of cancer registration, see National Cancer Institute, “Cancer Registration”, *NCI SEER Training Modules*, last updated 2018; Rodolfo Saracci and Christopher Wild, “Cancer Registration: A worldwide endeavour,” Chapter 4 in *International Agency for Research on Cancer: The first 50 years, 1965-2015*, 2015.

¹³⁰ Freddie Bray et al., *Planning and Developing Population-Based Cancer Registration in Low- and Middle-Income Settings*, 2014.

¹³¹ Donald Parkin, “The evolution of the population-based cancer registry”, *Nature Reviews*, 2006.

rose from around 25 to 200 between 1995 and 2015.¹³² Experiments with collecting risk data—more difficult to assess than simple descriptive statistics—have also occurred: to cite one example, ten US registries recently studied the effectiveness of including smoking history among other patient information.¹³³ Now a given PBCR might, depending on the country and individual registry, record items as diverse as in-depth patient demographic, socio-economic and certain risk data; a range of tumour information, from location, through staging, to the presence of genetic markers; details of how and when diagnosis occurred; treatment interventions; outcomes, including side effects and survival; and measures arising from long-term patient follow up.¹³⁴

More important than differences in the range of information that registries collect is the quality of their work, especially on the most basic matters such as incidence. For such a diverse set of organisations, no standard international evaluation tool exists.¹³⁵ Instead, the most convenient and widely recognised yardstick of quality is whether or not the IARC includes a registry's data in its periodic *Cancer Incidence in Five Continents* (CI5) reports. The so-called high-quality registries that make the cut need to meet a range of qualitative and quantitative measures to show comparability with good practice internationally, completeness of coverage, and the likely validity of the result.¹³⁶ The standard is challenging but achievable, and the failure to meet it should raise concerns. As Princess Dina puts it “‘high-quality registration’ is the polite way of saying ‘accurate registration.’”

By this measure, many PBCRs still have work to do. For the most recent CI5 (volume XI), 483 registries submitted information, of which 343 merited inclusion.¹³⁷ Presumably others did not even send results.

Another wealth-related divide: Quality in cancer registration

Issues with registries can appear anywhere. In Australia, for example, lack of integration between state-level registries means, according to Dr Aranda, that “We have little capacity to look at how well we are doing,” at a national level in areas such as unwarranted variation in treatment.

That said, in general, GDP and registry quality go hand in hand. Of the 343 institutions included in the latest CI5, 213 are in North America, Western and Central Europe, Australia, New Zealand, Japan, and South Korea. Aggregate figures for population coverage have yet to be published but, for the registries included in volume X, Scandinavian ones covered all residents and those in North America 95%. In Africa, the equivalent figure was just 1.9%.¹³⁸

Even in the relative wealthy subset of the world that make up our index countries, three do not yet have high-quality PBCRs and most of the rest have incomplete coverage. For some, this is sufficiently representative of the overall situation to have an accurate national overview, but in others that picture is far from complete. For example, South Africa's one high-quality PBCR covers about 2% of the country's population.¹³⁹

¹³² Iris Zachary, “Information Management in Cancer Registries: Evaluating the Needs for Cancer Data Collection and Cancer Research”, *Online Journal of Public Health Information*, 2015.

¹³³ David Siegel, “Capture of tobacco use among population-based registries: Findings from 10 National Program of Cancer Registries”, *Cancer*, 2018.

¹³⁴ For general overviews, see Christine Bouchardy et al., “Cancer registries can provide evidence-based data to improve quality of care and prevent cancer deaths”, *ecancermedicalscience*, 2014; Donald Parkin, “The evolution of the population-based cancer registry”, *Nature Reviews*, 2006.

¹³⁵ Abbas Sheikhtaheri et al., “Development of a tool for comprehensive evaluation of population-based cancer registries”, *International Journal of Medical Informatics*, 2018.

¹³⁶ “Data Processing”, chapter 6 of Freddie Bray et al. eds., *Cancer Incidence in Five Continents*, Vol. XI (electronic version) [2017]

¹³⁷ Economist Intelligence Unit calculation based on data in Freddie Bray et al. eds., *Cancer Incidence in Five Continents*, Vol. XI (electronic version) [2017].

¹³⁸ Freddie Bray, “Cancer Incidence in Five Continents: Inclusion criteria, highlights from Volume X and the global status of cancer registration”, *International Journal of Cancer*, 2015; Marion Piñeros et al., “A Global Cancer Surveillance Framework Within Noncommunicable Disease Surveillance: Making the Case for Population-Based Cancer Registries”, *Epidemiologic Reviews*, 2017.

¹³⁹ Economist Intelligence Unit calculation based on data in Freddie Bray et al. eds., *Cancer Incidence in Five Continents*, Vol. XI (electronic version) [2017].

To an extent, weakness in cancer registration is not a standalone issue, but reflects problems in overall governance and issues with cancer care.¹⁴⁰ That has not stopped a few individual countries taking significant steps to strengthen their institutions. Dr Mohar reports a “big improvement” in Mexico, which now has a cancer registry law and funding for a network of population-based cancer registries located in seven cities across the country. “We have just finished our first year of data collection and hopefully can publish soon,” he says. India is also seeing a slow but discernible improvement in the number, quality and geographic spread of its registries.

By far, the most impressive recent effort, though, is in China. Dr Chen says, with understatement, “We’ve done well in the last ten years.” The government made registration a cancer control priority. As a result, the number of the country’s registries has jumped from 43 in 2008 to more than 300 now, covering over a fifth of the entire population. High quality is far from universal. The latest CI5 volume included data from only 35 of these, but this was still a substantial increase from the 13 that made the grade for volume X three years earlier.¹⁴¹

And officials are not standing still. Dr Chen reports that the Ministry of Health has invested heavily in an automated system for the National Cancer Centre, which collects data from all cancer hospitals and important general hospitals. The centre has also been experimenting with artificial intelligence to improve the speed and accuracy of cancer coding in this information.

Where individual countries lack the resources, international actors have tried to bridge registration’s wealth divide. In 2011 the WHO, IARC, agencies for several national governments, and a group of NGOs created the Global Initiative for Cancer Registry (GICR) Development. It has been working through six regional hubs, which bring together expertise in the area as well as acting as a conduit for extra-regional help. These hubs can provide needs assessment, knowledge, support and technical assistance for cancer registration programmes in low- and middle-income countries.¹⁴²



Some welcome developments have certainly helped improve estimation of the cancer burden.”

Rengaswamy Sankaranarayanan, senior visiting scientist to the Office of the Director, International Agency for Research on Cancer, and senior medical adviser, Research Triangle Institute International, New Delhi, India

Beyond a few bright spots, though, the results of all this effort, so far, have been slow to manifest. This is in part because cancer data typically appear years after the cases it records. The latest CI5 study, for example, although published in 2017, used data up to only 2012. On the one hand, volume XI saw a marked increase in the number of high-quality registries included—from 290 to 343—but the number of countries represented stayed

¹⁴⁰ Maria Curado, “Cancer registration data and quality indicators in low and middle income countries,” *Cancer Causes and Control*, 2009.

¹⁴¹ Economist Intelligence Unit calculation based on data in Freddie Bray et al. eds., *Cancer Incidence in Five Continents*, Vol. XI (electronic version) [2017]; David Forman et al., *Cancer Incidence in Five Continents*, Vol. X, 2014. Hong Kong registry not included in calculations.

¹⁴² For details, see <http://gicr.iarc.fr/en/>

¹⁴³ Economist Intelligence Unit calculation based on data in Freddie Bray et al. eds., *Cancer Incidence in Five Continents*, Vol. XI (electronic version) [2017]; David Forman et al., *Cancer Incidence in Five Continents*, Vol. X, 2014.

¹⁴⁴ Donald Parkin et al. eds., *Cancer in Sub-Saharan Africa*, 2018.

the same at 65. This suggests a deepening of registration in specific countries rather than a broadening across the global population: indeed, 42% of the newly included registries were in China.¹⁴³

Dr Sankaranarayanan also sees a mixed picture. “Some welcome developments have certainly helped improve estimation of the cancer burden” in specific countries, he says. Even in sub-Saharan Africa, high-quality registration is starting to grow slowly as a result of a thriving GICR hub. The IARC recently issued a special publication with data from 25 African registries. It noted that, although not all currently meet the criteria for inclusion in CI5, the information still gave a “reasonable” picture of the sub-Saharan cancer burden.¹⁴⁴ Despite these signs of progress, Dr Sankaranarayanan adds, “there is still substantial scope for improvement.” Much of the world, especially in developing countries, continues to lack the high-quality PBCRs so necessary for cancer control.

Other data sources old and new

PBCRs should not obscure the importance of other valuable information. Official mortality data have always been essential in accurately measuring the cancer burden. Here, too, Dr Sankaranarayanan sees “tremendous room for improvement”. Globally, from 2000 through 2012 government-collected vital statistics services covered only between 35% and 38% of deaths, with more than a third of these recorded in poor-quality systems. Issues with such data are not limited to developing countries: in France, for example, only a little over 80% of death records are usable for healthcare studies. For the most part, though, this is another area where low quality and low

GDP carry on their usual partnership.¹⁴⁵

On the positive side, other kinds of data are becoming increasingly available. Ms Makaroff notes that this includes patients getting involved in special registries. “The groups are starting to measure outcomes of interest to patients themselves,” she adds.

An early example of this trend dates back 12 years. Hong Kong has had high-quality cancer incidence and mortality data for decades. In 2007 the Hong Kong Breast Cancer Foundation wanted to enhance the kind of information collected and established the Hong Kong Breast Cancer Registry. Data submission is voluntary, but during most years from 2006 to 2015 enrolment represented between 40% and 50% of cases recorded by the government registry.¹⁴⁶ This has allowed the foundation to issue regular, evidence-based reports covering issues of cancer risk, treatment impact and the influence of socio-economic factors, including disparities in access and outcomes between patients in public and private healthcare.¹⁴⁷

A more recent initiative is the Lung Cancer Registry in the US, which straddles the line between a collector of data and provider of advice. Founded by patient groups, individuals with the condition are encouraged to join, contribute information on their case, and look for relevant clinical trials if desired. The hoped-for outcomes include not just better overall understanding of risks and outcomes, but individual patient assessment “to help determine the best line(s) of treatment”.¹⁴⁸

Yet another innovative source of cancer insight is payer data. Where it is of sufficient quality, consistency and cleanliness to aggregate, this kind of information holds out

¹⁴⁵ Lene Mikkelsen et al., “A global assessment of civil registration and vital statistics systems: Monitoring data quality and progress”, *Lancet*, 2015; Gretchen Stevens, “WHO assessment of CRVS quality for use in Global Health Estimates”, slide presentation, November 2016.

¹⁴⁶ Hong Kong Breast Cancer Registry, *Hong Kong Breast Cancer Registry Report No. 10*, 2018.

¹⁴⁷ For list of publications, see https://www.hkbcf.org/en/our_research/main/424/

¹⁴⁸ Lung Cancer Foundation, “Let’s Save Lives: Registry for the Most Common Cancer Launches During November Lung Cancer Awareness Month”, press release, November 4th 2016; see also <https://www.lungcancerregistry.org/>

the potential to provide the same type of insight as hospital registries, but backed by a far more extensive number of records. The case study on Colombia's National Administrative Cancer Registry discusses the strengths and weakness of one effort to harness this kind of information.

Ultimately, these cannot replace PBCRs. Cancer control efforts in many countries will suffer until these improve. At the same time, officials should be looking to draw insight from wherever they can get it rather than rely exclusively on one data source.

Cancer information: Going beyond the usual sources

Eduardo Cazap, founder and first president of the Latin American and Caribbean Society of Medical Oncology, says that “real, high-quality data generated by local resources is fundamental for improvement at the country level.” The international Globocan estimates from the International Agency for Research on Cancer (IARC) have value in the absence of better information, he adds, but without context are of limited use.

The keystone of good national data needs to be high-quality, population-based cancer registries. Now, though, Dr Cazap, sees “a growing interest in how to obtain good data from other sources—and not the usual ones.” In particular, aggregate data from some of Latin America's very large social insurance programmes could provide “incredible information”. He cites Argentina's Programa de Asistencia Médica Integral, which provides health coverage for seniors and military veterans—in total over 10% of the population—and has recently begun to create disease databases.

A side effect of the expansion of universal healthcare globally will be a greater availability of such large-scale health system or payer data in middle- and low-income countries, where cancer registration of sufficient quality is still too often lacking. Studies in high-income countries with well-run health payer institutions and registries show that, if necessary, insurance data might act as a surrogate population-based registry,¹⁴⁹ although best practice is to use multiple sources for a population-based cancer registry.

A look at recent efforts in Colombia, though, indicates both the limits and the uses of cancer data from a large insurer database.

The country has long been a Latin American leader in population-based cancer registration: the region's oldest registry, in Cali, has collected data continuously since 1962. A traditional registry covering the entire country would be prohibitively expensive. Instead, Colombia now has eight regional institutions, although only four—including Cali's—are of sufficient quality to merit inclusion in the latest CI5 volume.¹⁵⁰ These four better registries cover 9% of the population and one is present in each of the country's major regions.¹⁵¹

Meanwhile, Colombia has very good mortality data—far from given in the region—with a recent study finding that 93% of death certificates listing cancer as the cause of mortality were properly completed. Most of the rest were vague on the specifics but still accurately noted that a cancer was involved.¹⁵²

¹⁴⁹ Hee Jung Seo et al., “A Comparison of the Cancer Incidence Rates between the National Cancer Registry and Insurance Claims Data in Korea”, *Asian Pacific Journal of Cancer Prevention*, 2012; Aurore Palmaro et al., “Identifying multiple myeloma patients using data from the French health insurance databases: Validation using a cancer registry”, *Medicine*, 2017.

¹⁵⁰ Carolina Wiesner, “Public health and epidemiology of cancer in Colombia”, *Colombia Médica*, 2018; Freddie Bray et al. eds., *Cancer Incidence in Five Continents*, Vol. XI (electronic version), 2017

¹⁵¹ Economist Intelligence Unit calculation based on data in Freddie Bray et al. eds., *Cancer Incidence in Five Continents*, Vol. XI (electronic version), 2017.

¹⁵² Ricardo Cendales and Constanza Pardo, “Quality of death certification in Colombia”, *Colombia Médica*, 2018.

Recently, a completely different source—the country’s Cuenta de Alto Costo (CAC), or High Cost Account—has published data. The CAC is a state fund that covers all the treatment expenses of, among other diseases, cancer. In theory, as such care is free to the user and the country’s many private providers need to report on instances of treatment in order to get paid, the CAC should have data on every case of cancer in the country.¹⁵³

The CAC national totals, however, differ markedly from the IARC estimates extrapolated from registry data.

Incidence and mortality from cancer in Colombia (estimated number of cases among population 15 years or older)

	IARC Globocan		CAC	
	2012	2018	2015	2016
Incidence	71,442	100,265	30,675	31,238
Mortality	37,894	45,525	15,715	17,359

Sources: Constanza Pardo and Ricardo Cendales, Incidencia, mortalidad y prevalencia de cáncer en Colombia, 2007-2011, 2015; J Ferlay et al., Global Cancer Observatory: Cancer Today web site; Fondo Colombiano de Enfermedades de Alto Costo, Situación del cáncer en la población atendida en el SGSSS de Colombia, 2016; Fondo Colombiano de Enfermedades de Alto Costo, Situación del cáncer en la población adulta atendida en el SGSSS de Colombia 2016, 2017.

Although based on the partial information available, the IARC figures are almost certainly more accurate. The Colombian vital statistics office (DANE) report deaths among those over 15 years old from cancer in 2015 and 2016 as 42,006 and 43,534 respectively.¹⁵⁴ The similarity with the IARC figures are not coincidental: that organisation uses the DANE numbers as a starting point for its Colombian estimates.

That the CAC incidence figures do not even reach government-reported ones for mortality has raised eyebrows. The reasons are a matter of debate. An article by members of the CAC team suggests the IARC figures are overestimates.¹⁵⁵ One by the director of the Cali registry instead blamed flaws in case finding and other practices within the CAC process.¹⁵⁶

A worrying alternative possibility is that both are right but that the disparity reflects significant undertreatment of cancer within the country. If the registries are accurately counting cancer incidence across the population, and the CAC has the right number of cases within the health system, some of the worryingly large gap may be made up of people not accessing any meaningful care.

¹⁵³ Omaira Valencia et al., “Incidence and Prevalence of Cancer in Colombia: The Methodology Used Matters”, *Journal of Global Oncology*, 2017.

¹⁵⁴ Economist Intelligence Unit calculations based on DANE, “Defunciones no fatales 2015: Cuadro 11. Defunciones por grupo de edad y sexo, según departamentos de ocurrencia y grupos de causas de defunción”; “Defunciones no fatales 2016: Cuadro 11. Defunciones por grupo de edad y sexo, según departamentos de ocurrencia y grupos de causas de defunción” DANE database.

¹⁵⁵ Omaira Valencia et al., “Incidence and Prevalence of Cancer in Colombia: The Methodology Used Matters”, *Journal of Global Oncology*, 2017.

¹⁵⁶ Luis Bravo, “Estimating the incidence and mortality of cancer in Colombia: What are the best data for public policies?”, *Colombia Médica*, 2016.

A few things point in this direction. To begin with, the CAC figures do not seem to include people who died from cancer before accessing treatment.¹⁵⁷ Moreover, the CAC data appear to include a disproportionate number of early-stage cases. Studies of various cancers in Colombia indicate that the majority of patients present with advanced tumours (stages III or IV).¹⁵⁸ Although most of the CAC figures do not include staging data, for those that do a slight majority (51%) are early stage.¹⁵⁹ Some of those with cancer may simply not be seeking treatment. Moreover, especially for difficult to treat cancers such as those of the lung, general practitioners in Latin America sometimes share in the cancer fatalism of the general population. In such cases, they may not recommend treatment beyond palliation.¹⁶⁰

Given the disparity in mortality figures if nothing else, the CAC figures are, as the director of Colombia's National Cancer Institute wrote, "not useful to evaluate the population risk [of cancer]" and so cannot act as a proxy population-based registry.¹⁶¹ Accordingly, in a 2018 analysis of cancer epidemiology in the country, experts from that institute look only at the regional population-based registries.¹⁶²

Nevertheless, it would be foolhardy to ignore the great potential value of the CAC figures for Colombian cancer control. They provide data on a large proportion of cases in the country overall—as well as the vast majority that the health system is treating—extensive details on the specific tumours, complications, demographic data of the patient, treatment efforts and follow up. This gives health system officials a far better understanding of the state of anti-cancer interventions.

Already, this information is being used to shape practice. For breast, prostate, cervical, stomach, colorectal and lung cancer, the CAC has, after consultation with relevant experts, devised detailed, quantitative targets for appropriate care by providers. It is now collecting information in order to monitor attainment of these goals.¹⁶³ Researchers are also using it to determine whether appropriate health delivery is taking place beyond these indicators.¹⁶⁴ Even the aggregate figures could, potentially, play an important role: if nothing else, they should cause concern that many cases may be falling through health system cracks, either at the treatment or reporting stage.

¹⁵⁷ Esther de Vries et al., "Discrepancias en manejo de cifras de cáncer en Colombia", *Revista Colombiana de Cancerología*, 2016.

¹⁵⁸ Constanza Pardo and Esther de Vries, "Breast and cervical cancer survival at Instituto Nacional de Cancerología, Colombia", *Colombia Médica*, 2018; Mabel Bohorquez et al., "Clinical manifestations of colorectal cancer patients from a large multicenter study in Colombia", *Medicine*, 2016; Juan Combariza et al., "General features and epidemiology of lymphoma in Colombia. A multicentric study", *Annals of Hematology*, 2015.

¹⁵⁹ Economist Intelligence Unit calculations based on Fondo Colombiano de Enfermedades de Alto Costo, *Situación del cáncer en la población atendida en el SGSSS de Colombia*, 2016.

¹⁶⁰ The Economist Intelligence Unit, *Lung Cancer in Latin America: Time to stop looking away*, 2018.

¹⁶¹ Carolina Wiesner, "Public health and epidemiology of cancer in Colombia", *Colombia Médica*, 2018.

¹⁶² See editorial and articles in *Colombia Cancer Epidemiology*, dedicated edition of *Colombia Médica*, 2018.

¹⁶³ Paula Ramírez-Barbosa and Lizbeth Acuña Merchán, "Cancer risk management in Colombia, 2016", *Colombia Médica*, 2018; Fondo Colombiano de Enfermedades de Alto Costo, *Indicadores de gestión del riesgo en pacientes con cáncer de pulmón en Colombia*, 2018.

¹⁶⁴ R. Hsu et al., "A Review of Colombian National Administrative Cancer Registry (NACR) Data to Evaluate Healthcare Delivery and Biologics Use," *Journal of Thoracic Oncology*, 2018.

More important, the CAC figures are only the beginning. Since 2012 the government has been building a National Cancer Information System. It is meant to draw on these data, along with others from various health-sector information systems—such as departments covering immunisation and reporting of notifiable diseases—as well as occasional special reports. These are fed into a unified database, which will generate a National Administrative Cancer Registry with information from across government to allow analyses that consider a vast number of factors. This registry, in turn, is to provide data to a National Cancer Observatory, which that institution will combine with regional registry information to produce relevant reports.¹⁶⁵ So far, the observatory has published little¹⁶⁶ and the CAC reports are the most visible sign of activity. If, though, Colombian health officials have the creativity to use such rich seams of national data, it will substantially enhance national cancer control efforts.

¹⁶⁵ Colombian Ministry of Health, *Observatorio Nacional de Cáncer: Guía Metodológica*, 2018.

¹⁶⁶ See its web page: <http://www.sispro.gov.co/Pages/Observatorios/cancer.aspx>

Conclusion: The essentials and the will to carry them out

No health system, no government, no society can afford a lukewarm response to cancer.

This group of diseases is already in aggregate the world's second biggest killer and costs the global economy upwards of US\$1trn per year. Looking ahead, population ageing alone will drive risk levels substantially higher.

Indeed, no one can pretend that their society is exempt. Cancer is already the leading or second biggest cause of death in over half the world's countries, and during this century will be an important drag on possible improvements in life expectancy everywhere. For the moment, wealthier countries have higher incidence rates, but per-head mortality is similar across the world because of weak cancer control in developing states. Worse still, the latter will bear the brunt of the coming increase in the cancer incidence and are currently, as a group, the least prepared.

Any effort to deal with today's, let alone the future's, cancer burden is bedevilled by the complexity of the challenge. A successful response must be as multi-faceted as the disease, with possible interventions ranging from primary school anti-smoking lessons all the way to advanced experimental therapies and procedures. Moreover, what works in one country might fail in another, as the cancer burden, and therefore the best combination of interventions with which to fight it, are highly dependent on local circumstances.

For those stakeholders seeking insight into how to proceed, this study introduces a tool to assess national readiness in the face of the disease: the Index of Cancer Preparedness. It covers, for 28 countries, the breadth of cancer control and its necessary context. At the same time, the 45 specific areas measured are relevant to high- and low-income countries

alike. The ICP data contain a wealth of information on individual states, which, in turn, provide a way to compare with, and possibly learn from, the performance of others—that of both countries overall and those with similar levels of economic development or cancer burdens. We encourage interested readers to delve into that rich detail.

This study, though, is too short to do more than take a global overview and offer a few key, wide-applicable lessons that arise from the ICP, expert interviewee insight and desk research. These four “essentials” are:

Essential investment: some cancer-control initiatives are low cost, or even income generating. In aggregate, though, cancer control requires substantial investment across health systems. This is especially true with respect to treatment capacity. Although each country must decide what it can afford here, without this capability cancer control systems are not only missing a fundamental element, but they will also lack the credibility to overcome the cancer fatalism that undermines efforts in too much of the world.

Essential planning: good NCCPs are necessary: the foe is too complex, the necessary investment too high, and the potential human cost far too great to hope unco-ordinated cancer control will work out. National plans allow health systems to be sure that they use the best collection of interventions, make coherent funding choices, and draw all relevant stakeholders into the effort, all while doing so equitably.

Essential foundation: effective cancer control happens within the context of good, ideally universal, healthcare. Cancer planning and investment, rather than promoting silos, need

to build up, where possible, general resources and embed prevention, diagnosis, treatment and post-treatment interventions within wider primary, secondary and tertiary care. This will create better cancer control and institutions more able to address national disease burdens as a whole.

Essential intelligence: effective investment, planning and integration with health systems rely on knowing the nature and extent of the local cancer challenge and what works in fighting it. The most important tool is the high-quality PBCR, without which cancer planning would be like a general basing local strategy entirely on intelligence reports from another theatre of operations. Creative use of a growing number of additional data sources should also provide invaluable further insight.

The most difficult part of preparing this report, to those producing it at any rate, is our inability to address myriad issues that good cancer control must consider: the balance between education and regulation in effective prevention; how to make screening choices when for certain common cancers, such as those of the breast and lung, equally reputable scientists produce research with sharply dissonant conclusions; how to avoid delays, or the complete loss, of patients between diagnosis and the start of treatment; how best to create integrated, multi-disciplinary, person-centred care; how not only to provide enough palliative care but to also make it part of treatment from day one; how to address not just the medical sequelae that affect cancer survivors, but also their psychological, social and employment challenges; how to harness big data and artificial intelligence tools to make the most of cancer data, including not just issues of data organisation, but also winning and retaining patient willingness to share information about them; how to ensure that academic research aligns with the actual

cancer burden; how to support the informal carers, frequently family members, who are the volunteer bedrock of much cancer care; how to overcome the stigma still attached to the disease in too many parts of the world, both developing and developed; and, perhaps most important of all, the role of the patient as a key participant in, and organisational focus of, cancer control.

Every one of these could have, indeed has had, their own detailed studies and, even then, the list but scratches the surface. Our own resource constraints of time and word space meant that we had to pare back to the most essential issues underlying cancer preparedness overall.

One last issue, however, requires mention here, because without it none of the four essentials above is possible: political will. As Dr Sankaranarayanan explains of the variations in cancer outcomes between similar countries or even between regions within them, “ultimately, this all has to [do] with policies and investment.”

The ICP measure of political will is imperfect because its indicators, for lack of any alternative, focus on healthcare as a whole rather than on cancer in particular. Nevertheless, higher scores here still correlate closely with lower M:I ratios.

Building cancer-specific political will can be a challenge in a world with multiple, entirely legitimate, competing priorities for resources facing societies and their leaders. The size of the cancer threat will do part of the work. Dr Mohar says of Mexico, for example, “the political will is there because it [is] so obvious that it is unacceptable to continue with the current situation. Our president is conscious of the level and magnitude of the change needed.” Indeed, the ICP political will scores do correlate with cancer incidence rates.

The self-evident need for action, though, will not work on its own. Interviewees point to various crucial levers for changing attitudes and, through them, policies. Cancer survivors and their stories are absolutely essential in the process, as are enlightened clinical leaders within cancer control institutions who see the big picture, and studies that combine cancer data with economics to drive home the true costs and benefits of interventions on a small and grand scale.

Ultimately, though, health officials and politicians find within themselves the determination and courage to act vigorously. Princess Dina explains, “many countries have



Now it is up to governments to start implementing on the ground.”

Princess Dina Mired, president, UICC

not done so. We are all frustrated in the global health community that all the advice and guidelines have not translated on the ground. We have done all we can to bring attention to the issue. Now it is up to governments to start implementing on the ground.”

Appendix: Methodology

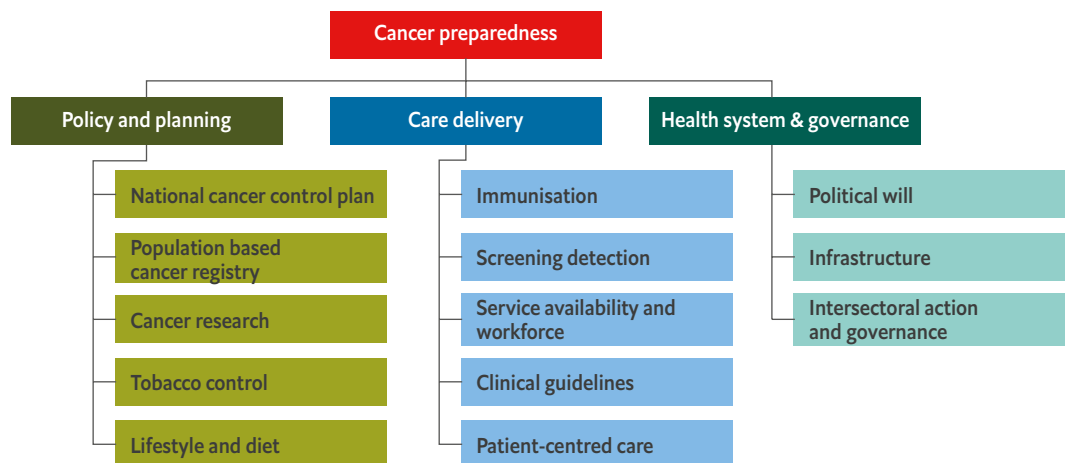
The Index of Cancer Preparedness (ICP) measures how ready healthcare systems are for the challenge of cancer across 28 countries. It seeks to answer the question: how well prepared are countries to achieve major reductions in premature deaths from cancer, increase cancer survival rates, and improve quality of life for cancer patients and survivors?

The ICP explores the issue of cancer preparedness through three broad domains: 1) policy and planning; 2) care delivery; and 3) health systems and governance. The first domain on policy and planning focuses

on levers that are mostly in the hands of policymakers. The second domain looks at the delivery of cancer-specific activities within health systems themselves, while the final domain acknowledges that cancer cannot be defeated by cancer-focused activities alone.

The three domains are broken down into 13 sub-domains and 45 indicators. Scores are weighted and normalised, so that the final score for each country ranges from 0 to 100, with 100 being the highest possible score, representing complete alignment with best practice.

The three domains and 13 sub-domains of the ICP



Source: ICP.

The design of the ICP was driven by the creation of a theoretical framework: the curation of a collection of indicators that measure elements of cancer preparedness that are inherently desirable. We therefore hope that the ICP can offer value beyond simply the final composite score, and be used to drive discussion based around action at the

domain, sub-domain and indicator level.

In addition to the ICP we have also collected data for 21 background indicators to support correlation analysis. These indicators provide context but are not computed in the index scores; they include indicators of healthcare spend, health outcomes and risk factors.

The ICP was built following a literature review and an expert panel meeting. It covers a total of 28 countries from across five geographic regions: Africa/Middle East, Latin America,

North America, Asia-Pacific and Europe; and three World Bank income groups: lower-middle, upper-middle and high. A full index methodology report is also available.¹⁶⁷

¹⁶⁷ The Economist Intelligence Unit, Index of Cancer Preparedness, Methodology report, <http://worldcancerinitiative.economist.com/index-of-cancer-preparedness/ICPMethodology.pdf>

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