Global surveillance of cancer survival: the impact of real-world data on cancer control









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This booklet provides information about the survival of people who are diagnosed with cancer, and how that information can be used to improve cancer outcomes.

- Section 1 shows that world-wide trends and international comparisons of cancer survival from the CONCORD programme are valuable instruments to monitor how effectively national health systems are at diagnosing and treating everyone who is diagnosed with cancer.
- Section 2 highlights the importance of providing reliable information to support patients with cancer and their families and care-givers, especially in low-income and middle-income countries. The information needs to be adapted to the local culture, in the local language, and to address prevalent myths and fears about cancer.
- Section 3 shows how trends in cancer survival from the CONCORD programme are already being used to evaluate and improve national strategies for cancer control in member countries of the Organisation for Economic Co-operation and Development around the world.
- Section 4 sets out why the economic resources required to manage the growing cancer burden must be deployed in imaginative and cost-effective ways, because the cancer burden in low-income and middle-income countries, especially, will have to be managed efficiently with limited resources for the foreseeable future.
- Section 5 sets out the rights to health under the UN Declaration on Human Rights and other international treaties.

Published by the Cancer Survival Group, LSHTM, Keppel Street, London WC1E 7HT, UK. t: +44 20 7927 2551, e: <u>concord@lshtm.ac.uk</u>, w: <u>csg.lshtm.ac.uk</u>

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Trends and inequalities in cancer survival world-wide

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Claudia Allemani trained in applied mathematics, epidemiology, medical statistics, public health and education, in Turin, Milan and Pavia (Italy). She is an Honorary Member of the UK Faculty of Public Health (2014), She was awarded the Faculty's inaugural Global Public Health award in 2016. She has worked at the University of Pavia (1998–2001) and the Istituto Nazionale Tumori in Milan (2001–2011). She joined the Cancer Survival Group at the London School of Hygiene and Tropical Medicine in 2011. Her research is focused on international cancer survival comparisons and their impact on cancer policy. She is co-Principal Investigator of the CONCORD programme, and Principal Investigator of VENUSCANCER, a world-wide study on inequalities in survival from breast, cervix and ovarian cancers, supported by a European Research Council Consolidator grant.



The survival of all patients diagnosed with cancer in a country or region – *population-based survival* – is a key measure of the overall effectiveness of the national or regional health system in managing cancer.

Clinical trials test the **efficacy of a new treatment** – whether it is better than the current standard treatment. The patients recruited to trials are randomised to receive either the new or the standard treatment, but they are not representative of all cancer patients. They are usually selected on age, stage of disease and lack of other serious diseases (co-morbidity), and they are treated with close adherence to protocol in specialised cancer units by the most research-active physicians. Typically, fewer than 5% of all adult cancer patients are treated in clinical trials,¹ although in developed countries, the proportion for children may be 70% or more.

By contrast, population-based cancer survival reflects the overall **effectiveness of the health system** in dealing with cancer, including early diagnosis, screening, investigation and treatment, as well as the availability of human and financial resources, and the organisation of healthcare delivery.² It is an overall measure of the survival achieved by *all cancer patients*, young and old, rich and poor, with and without comorbidity, and whether the disease is early or advanced when diagnosed.

Population-based survival is estimated from data provided by populationbased cancer registries. These registries routinely collect a simple data set on every person diagnosed with cancer in a defined population, typically all residents of a country, or a defined area such as a province or state. In a clinical trial, differences in survival between patient groups can easily be interpreted as due to differences in the efficacy of the treatments being compared, as well as to the skill of the medical staff who designed the trial, and the rigour with which they applied the study protocol.

By contrast, survival estimates from population-based studies are very often misinterpreted. Differences in population-based cancer survival are often criticised by doctors in the country or region with lower survival, on grounds such as bad data, biased or incompetent analyses, or simply dismissed as flawed or unacceptable. The unspoken fear behind these criticisms is the implication that the doctors in the country with lower survival are somehow being judged as less competent.

However, no oncologist, surgeon or radiotherapist sees a representative sample of *all* cancer patients. Survival of the cancer patients seen by a single doctor, cancer team or hospital will rarely reflect the overall national picture ("referral bias"). Thus, patients whose disease is too advanced for surgery when diagnosed may be referred for radiotherapy. Also, for all except the most common cancers in the largest hospitals, survival estimates derived from a single hospital are also affected by statistical variability, or "noise".³

In short, population-based cancer survival estimates differ in purpose and scope from the survival estimates derived from trials, or for individual clinicians, clinical teams, or hospitals.

Population-based survival estimates are designed for public health surveillance, and to inform strategic policy-making on how to improve cancer management.

Global surveillance of cancer survival – the CONCORD programme

CONCORD is the research programme for the surveillance of populationbased cancer survival trends and inequalities world-wide. It currently involves almost 600 collaborators.

The first CONCORD study produced five-year survival estimates for two million patients who were diagnosed with breast, colorectal or prostate cancer during 1990-1994 and followed up to 1999.⁴ The data were provided by 101 cancer registries in 31 countries. In 16 countries, the cancer patient data provided coverage of the entire national population.

In 2015, the CONCORD-2 study established long-term surveillance of world-wide trends in cancer survival for the first time, covering the 15-year period from 1995 to 2009.⁵ It was the largest cancer survival study ever published, with data for 25,676,887 patients diagnosed with one of 10 common cancers. Together, these cancers represented 63% of the global cancer burden in 2009. The data were provided by 279 population-based cancer registries, covering a total population of 896 million people in 67 countries. In 40 countries, the data provided 100% national coverage.

Health ministers in 67 countries, home to two-thirds (4.8 billion) of the world's population, now had access for the first time to methodologically rigorous and internationally comparable cancer survival estimates, to help them formulate cancer control strategies.⁶ For some countries, this was the first time that cancer survival data had been available.

The CONCORD-2 article was covered by TV, radio, press and wire services around the world. The *Altmetric* score^a of social media impact is 787, in the top 0.04% of almost 12 million articles evaluated to date. The article has been cited more than 1,100 times in the scientific literature. The results have also been incorporated into the American Cancer Society's *Cancer Atlas*.^b

The US Centers for Disease Control (CDC) described CONCORD-2 as the start of global surveillance of cancer survival,^c with survival estimates *"that can be compared, so scientists can begin to determine why survival differs among countries. This could lead to improvements in cancer control programs."*



In 2015, the Programme for Action on Cancer Therapy (PACT) at the International Atomic Energy Agency used CONCORD-2 results to launch an ambitious worldwide campaign to highlight the global divide in survival, and to raise awareness of persistent inequalities in access to lifesaving cancer services.

^a <u>https://elsevier.altmetric.com/details/2924704#score</u>

^b http://canceratlas.cancer.org/data/

^c <u>https://www.cdc.gov/cancer/dcpc/research/articles/CONCORD-2.htm</u>

In March 2018, the summary article from the third cycle of the programme (CONCORD-3) was published in *The Lancet*,⁷ one of the world's most widely read medical journals. CONCORD-3 updates the world-wide surveillance of trends in 5-year survival to include data for over **37.5 million** patients who were diagnosed with cancer between 2000 and 2014, and who were followed up to 31 December 2014.



These patients were diagnosed with one of 18 cancers: oesophagus, stomach, colon, rectum, liver, pancreas, lung, melanoma, breast (women), cervix, ovary and prostate in adults (15-99 years), and brain tumours, lymphomas and leukaemias in both adults and children (0-14 years). Taken together, these cancers represent about 75% of all cancers diagnosed world-wide today. The 322 participating cancer registries cover a total population of almost 1 billion (14% of the world population). We examined variation in cancer survival trends between 71 countries and territories, 47 of which provided data with national coverage.

CONCORD-3 showed that survival trends were generally increasing for most cancers between 1995 and 2014. However, the world-wide differences seen in the first (1990-94) and second (1995-2009) cycles of the CONCORD programme were still evident in 2010-2014, both for cancers with a good prognosis (breast cancer) and for those with a moderate prognosis (colon cancer), and even for potentially curable cancers such as acute lymphoblastic leukaemia (ALL), the commonest childhood cancer (see Figure below).



Age-standardised 5-year net survival (%) for adults (15–99 years) diagnosed during 2010–14 with colon cancer, or breast cancer (women), and children (0–14 years) diagnosed with acute lymphoblastic leukaemia. Survival estimates for each country are ranked from highest to lowest within each continent. *Data with 100% coverage of the national population. †National estimate not age-standardised. §National estimate flagged as less reliable because the only available estimates are from a registry or registries in this category. See Allemani *et al.*, 2018 for details.⁷

CONCORD-3 has already had a substantial impact on the public, in the media and in the scientific and public health community. The *Altmetric*^d score of social media impact is 1,285, in the top 0.01% of almost 12 million articles evaluated to date.

From 2017, the Organisation for Economic Co-operation and Development has included survival estimates from the CONCORD programme for 48 countries in its "*Health at a Glance*" publications.⁸ The estimates will now become the *de facto* standard for international cancer survival comparisons, crucial for the comparative evaluation of health systems performance in all OECD Member States. This provides formal recognition by an international agency of the global coverage, methodological rigour and international comparability of the CONCORD survival estimates. The survival estimates are also being used in the

^d <u>https://www.altmetric.com/details/32453691?src=bookmarklet#score</u>

Country Health Profiles for European Union countries, as part of its initiative on the *State of Health in the EU*.^e

The results of the CONCORD programme are thus helping to monitor progress toward the overarching goal of the 2013 World Cancer Declaration, to achieve major improvements in cancer survival by 2020.

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^e <u>https://ec.europa.eu/health/state/country_profiles_en; https://ec.europa.eu/health/state/summary_en</u>

Information for cancer patients, their families and caregivers: improving outcomes in low- and middle-income countries

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Sally Cowal leads the American Cancer Society's efforts to share its experience in effective cancer prevention; strategies to provide access to screening, cancer treatment and pain relief, and patient services; and organisational development for non-profits. She coordinates advocacy efforts to raise awareness of the global cancer burden and to secure adequate funding for cancer prevention and control in low- and middleincome countries.





A cancer diagnosis usually raises significant questions, concerns, fears and uncertainties for the patient and their family. Providing useful support for cancer patients includes being able to answer these questions and to provide other information. The American Cancer Society has compiled a wide range of such information for cancer patients, their families, and caregivers.

This information can provide much-needed comfort, support, and clinical assistance for patients and caregivers. The materials are high-quality and extensive, but they are written by American public health professionals for an American audience, and they are not relevant for many communities around the globe, where access to cancer treatment and understanding of cancer may be more limited.

It is estimated that some 18 million people around the world will be diagnosed with cancer in 2018, and that there will be 9.5 million deaths from cancer.⁹

Nearly 60% of the world's cancer patients live in low- and middle-income countries,^f and about 70% of deaths from cancer occur in those countries.^g

By 2030, it is expected that the number of cancer patients diagnosed each year will reach 21.6 million, with 13.0 million cancer deaths, largely due to growth and ageing of the world's population.

Providing support for this rapidly growing number of patients requires extensive adaptation of existing materials to increase public awareness about cancer. and to address local concerns and the realities of cancer care in both low-income and middle-income countries.



To meet this need more effectively, the American Cancer Society has consulted with health professionals, non-government organisations and government officials in many countries to find out what resources were available, how current materials could fit into this landscape, and to understand the scope of the problem and the current cultural environment surrounding cancer education.

The results showed that many of our materials contained too much text, were too complicated, or too American. They did not reflect local realities, and they did not address common fears and misconceptions about cancer.



We used a step-by-step process to design, implement, monitor, and evaluate communication strategies and materials to create a design that would be culturally relevant and could help to change health behaviour concerning cancer. We engaged health providers, ministry-level officials, patient

f http://gco.iarc.fr/today/fact-sheets-cancers?cancer=29&type=0&sex=0

^g http://www.who.int/news-room/fact-sheets/detail/cancer

support organisations, and the patients who would benefit from more effective materials.

The materials must enable patients to understand and accept the disease and their diagnosis; to follow medical advice for treatment or a suitable alternative, and to take care of themselves physically, but also to help them re-integrate into society, at the same time as addressing local stigmas and myths about cancer.



The materials must also provide information for caregivers, to support family members or others who have been diagnosed with cancer.

Finally, the materials must also provide a simple and visually captivating connection for these different audiences. The materials also needed to be

translated into local languages, and training and communication leaflets must be prepared, with tips for healthcare providers.

Distribution of the materials is equally important. The target audiences must be defined. A plan for the distribution of the materials must be developed, to ensure that they reach their intended audience. We must monitor whether the materials are well received and fully understood.

The materials must also be evaluated and updated, to ensure that they continue to meet the needs of patients and caregivers, and that they give health providers an effective tool to help change the perception of cancer in this global landscape.



Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 2018; doi:10.3322/caac.21492.

Cancer survival comparisons as a tool to improve the quality of health care: experience from OECD

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Niek Klazinga has been convener of the Health Care Quality Indicator programme at OECD (Paris) since 2006. He is also Professor of Social Medicine in the Academic Medical Centre at the University of Amsterdam. He has been involved in health services research and policy debates on the quality of care for over 30 years. He has published around 200 peer-reviewed articles and supervised 35 PhD students. He is also a visiting professor at Corvinus University (Budapest) and the University of Toronto, advisor to WHO/EURO (Copenhagen) and to the Canadian Institute for Health Informatics (Toronto), and a trustee of the Isala Clinics (Zwolle, a large teaching



hospital in The Netherlands) and the Quality Council of the Dutch Health Care Institute (ZiN).

The Organisation for Economic Co-operation and Development (OECD) has been running a programme on Health Care Quality Indicators since 2005. Information on cancer survival in OECD member states has been part of this programme from the very beginning.

OECD's biennial flagship publication *Health at a Glance* provides international comparative data on cancer mortality, screening and 5-year survival. The focus so far has been on cancers of the breast in women, cancers of the large bowel (colorectal cancer) and cancers of the neck of the womb (uterine cervix).



For the latest publications in this series, the world-wide CONCORD programme has now become the source of information on cancer survival. This decision reflects the methodological rigour and global scope of the study, and the international comparability of the survival estimates.

Health at a Glance 2017 includes, for the first time, trends in 5-year survival for childhood leukaemia (acute lymphoblastic leukaemia), the commonest malignant disease in children.⁸ OECD data are widely used and quoted by governments of member states when they compare the performance of their health services, and when planning new policies to improve them.



The graphics below show how the data are presented:

The data on cancer survival are part of an overall set of data that helps policy-makers to monitor progress in the effectiveness of our systems and providing diagnosis and treatment of cancer. The overall trends in 5-year survival show gradual but steady improvement in many countries, however, delays in progress in some countries have been identified in the past as a reason to put more emphasis on health policies related to cancer. This has happened in Denmark and the UK, for example.



Source: CONCORD programme, London School of Hygiene and Tropical Medicine.

StatLink 📷 http://dx.doi.org/10.1787/888933604020

In 2013, OECD published a special report entitled: *"Cancer care: assuring quality to improve survival"*.¹⁰ This report showed that the speed of progress in cancer survival in OECD member states is related to the health policies they have in place.

The report also signalled a huge potential for improvement in cancer survival. It discussed implementation of a wide range of policies, including the existence of national cancer control programmes, the size and training of the professional cancer workforce and the availability and quality of radiotherapy facilities.

The report covered the speed of uptake of new cancer medications, the extent of patient involvement in health systems, and national standards and guidelines for cancer care, notably the existence of "volume norms" – these are guidelines that set the minimum number of cancer patients receiving a specific surgical procedure each year for a hospital to be recognised as a centre where that procedure can be safely performed.

OECD is actively involved in discussions about cancer care in member countries, both through regular reporting of data and based on the policy report issued in 2013. These discussions are sometimes specific to one country, but they also take place with the European Union, the European Parliament and cancer patient organisations (e.g. on colorectal cancer).

Because the data on survival are presented in the broader context of the health system infrastructure, the professional workforce, healthcare facilities and the costs of providing health care, they are increasingly considered by policy-makers as a valuable outcome measure for health care.



Current debates focus on the reimbursement of new medications for cancer and the concentration of cancer services based on volume norms.

A ministerial conference of the 35 OECD member countries in 2017 concluded that monitoring the added value of health care should continue to be a major focus. For cancer, survival data are an important outcome, but it was also decided to expand the metrics that OECD provides to include patient-reported outcome measures (PROMS).¹¹

OECD has therefore launched the PaRIS programme: Patient-Reported Indicator Surveys.¹² As part of this new programme, work has started on PROMS for breast cancer. Building on the standards developed by the International Consortium for Health Outcomes Measurement (<u>www.ichom.org</u>), OECD is now working with experts from national breast cancer registries towards international comparisons for performance, based on a standardised set of patient-reported outcome measures.

Cancer survival measures are increasingly used by OECD to monitor and improve the quality of care for cancer across countries. Cancer care is one of the areas where, based on robust and comparable data that are now available for a growing number of OECD countries, we can start closing the loop between health policies, health care delivery and the outcomes for cancer patients.



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Delivering affordable cancer care in developing and developed countries

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Richard Sullivan studies health systems, particularly health policy on noncommunicable diseases, and the impact of conflict on health. He qualified in medicine and trained in surgery (urology), gaining his PhD from University College London. He was Clinical Director of Cancer Research UK between 1999 and 2008. He is Professor of Cancer and Global Health at King's College London, Director of the Institute of Cancer Policy, and co-Director of the Conflict and Health Research Group.



One of the most profound challenges facing health systems around the world today is how to achieve good-quality, affordable and equitable cancer care that delivers meaningful improvements in the outcomes for cancer patients.¹³

The issue of affordability has become a critical policy and regulatory issue. It includes the need for affordable preventive and public health measures, the need for patients and their families to have access to affordable care, and the need for national health care provision to be economically affordable within constrained national budgets.

The classical challenges for affordability – especially ageing populations and increasing co-morbidity – are well known.¹⁴ More fundamentally, the challenge for cancer has been the need to deliver ever-increasing human resources at the same time as introducing more technological innovation.¹⁵



The Baumol effect,¹⁶ under which healthcare costs are not amenable to enhanced productivity, is a major new economic challenge for cancer. technology New for cancer generally increases healthcare costs, rather than supplanting the cost of human resources.

As cancer care has become more complicated, we have also seen greater policy and regulatory failures on both the supply and demand sides of "onco-economics" – the economic aspects of providing cancer care. In other words, the major increases in direct healthcare expenditure for cancer have not been matched by the outcomes delivered for cancer patients at the population level.¹⁷ This steep decline in the overall value of health care provided for cancer patients has been mirrored by the decline in value (in its strict economic sense, as the relationship between cost and outcome) for many individual technological 'innovations', be they pharmaceuticals, surgical procedures or radiation therapy.^{18,19}

The problems arising from the affordability of cancer care have also exposed deep fault-lines between the needs of society and the 'rights' of individuals. In many countries, the failure to address the issue of affordability is now creating even greater disparities in cancer outcomes for population groups defined by socio-economic class, gender or ethnicity, and among vulnerable populations such as refugees.²⁰

Given the widening global inequalities described by Thomas Piketty in *Capital in the 21st Century*, it is hard to be optimistic that emerging economies will be able to deliver affordable public cancer care for all their citizens. This will be required if they are to meet the targets set under the Sustainable Development Goals and the Universal Health Coverage agenda, but it will be particularly challenging in the light of the economic and structural deficits in the political, social and economic determinants of health.²¹

Even in rich countries, however, it is a myth that the development and delivery of affordable cancer care is simply a one-way process, without problems. There is concrete evidence that expensive new technologies are already creating unaffordable ecosystems. One example is in immunotherapy for cancer, in which cells from the patient's own immune system are extracted, modified and then re-infused into the patient to attack their cancer, such as CAR-T therapy. Another is the introduction of expensive robotic surgery instruments, such as the Da Vinci system for prostate cancer.²²

Our analyses of the research on system changes to global cancer care over the last 15 years all agree that the increasing problems of the affordability of cancer care arise from the convergence of several developments. These include the arrival of creative new solutions that can improve cancer care (a good thing), alongside an inefficient process for setting a price to be paid for those innovations that bears little relation to the research and development costs for the new technology, or to its impact on outcomes for cancer patients (a bad, but unsurprising thing). This is compounded by a failure to link policies to control supply and demand to regulations that can deliver end-to-end solutions for publicly funded healthcare systems – from basic price control to ensuring the delivery of care with appropriate quality care, and mechanisms that ensure all cancer patients are immunised against catastrophic personal expenditure arising from their disease.

The successes and failures of high-income countries in addressing the affordability of cancer care offer a rich mine of information from which emerging economies could learn. These include the success of price control using Health Technology Assessment (HTA) to set thresholds for the willingness of governments to pay; but also the failure of HTA when the mechanisms for access to treatment become distorted, as with the UK's Cancer Drugs Fund. They also include the adoption of real-world data collection systems, such as cancer registries and national clinical audits. Intelligent deployment of the data from these systems can help to ensure the quality of care and to inform policy for pricing and the reimbursement of the costs of treatment.

Unfortunately, the mechanisms for supporting and disseminating this type of research are woefully under-developed. It is a complex field, spanning cancer research, political economy and health policy.

Cancer intelligence for policy-makers in emerging economies has improved over the last decade, with greater insight on economics and outcomes, e.g. the ASEAN ACTION study.²³ However, most countries are still deeply under-prepared, with an almost complete lack of intelligence that could usefully guide health policy and regulation to improve the affordability of care for the growing number of cancer patients.

The fault lies partly with the market-focused nature of cancer control. It is a fundamentally flawed system that only drives up costs and drives down outcomes. Many countries and regions do not have a sufficiently welltrained workforce for cancer control policy. Only a few programmes, such as Research for Health in Conflict (r4hc-mena.org), are addressing this.

Techno-centric research in translational cancer medicine has grown rapidly in the last ten years. By 2020, it is expected that 80% of research publications in cancer will be focused on technology, including new medicines, surgical procedures and modalities for delivering radiotherapy.



Catastrophic expenditure or financial distress are already major issues for the affordability of cancer care, in both the public and private sectors. For example, between 40% and 55% of women with breast cancer in India experience financial distress because of their diagnosis, irrespective of their wealth quintile.²⁴

Finding solutions to the growing problem of the affordability of cancer care will require more interrogation of the evidence in this complex area. It will require specific cancer control hubs, dedicated to research into the political economy and systems of cancer care. Even these will be insufficient without committed and well-informed political leadership, that can emphasise public over private provision of services, structural and organisational reforms to the financing and delivery of health care, and the will to stand up to vested interests that favour inertia or the status quo. Such leadership could come from civil society or the clinical community.

There is currently no model for progressive universalism in health care that could deliver affordable cancer control, especially in countries with limited resources. The inefficient Western medical tradition is not a good example. Only the emerging powers themselves can deliver a new conceptual model: one that encapsulates their unique trajectories in the cancer burden, the health care system and the economy.

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The right to health

- The right to health is a human right, enshrined in Article 25 of the Universal Declaration of Human Rights of 1948.²⁵ This right is protected by international treaties.
- 168 States have signed or ratified the International Covenant on Economic, Social and Cultural Rights,²⁶ which is legally binding. The Covenant affirms that everyone has the right to the highest attainable standard of health (Article 12). It also states:
 - The right to health cannot be realised overnight, therefore States must take steps towards a progressive realisation, using the maximum of their available resources and through international assistance and cooperation (Article 2.1);
 - This provision is not an excuse to delay action but rather an obligation to continuous progress. There are core minimum obligations that need to be fulfilled, such as adopting a national public health strategy or providing essential drugs listed on the latest WHO Model List of Essential Medicines²⁷ (General Comment 14).
- The right to health is explained further in the Covenant:
 - Access to information is an important component of the right to health. More specifically, everyone has the right to seek, receive and impart information regarding health issues (General Comment 14, paragraph 12[b]). Most importantly, access to reliable information will help fulfil the right for everyone to control one's health and body (paragraph 8).
 - The right to health includes the right to prevention, treatment and control of diseases. More specifically, States have the responsibility of using and improving epidemiological surveillance and data collection on a disaggregated basis (paragraph 16).
 - Every State has a margin of discretion in assessing policies to ensure that everyone has access to health facilities, goods and services. However, in doing so, States must identify the resources available and use them in a cost-effective way (paragraph 53).

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