

PART 2.

MECHANISMS AND CONTEXT UNDERLYING SOCIAL INEQUALITIES IN CANCER

CHAPTER 12.

The role of law in reducing global cancer inequalities

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Introduction

This IARC Scientific Publication shows that large social inequalities in cancer exist both within and between countries, and that social determinants have an impact across all stages of the cancer continuum. This publication also identifies effective actions necessary for cancer prevention and control generally, and for reducing social inequalities in cancer specifically. As the individual chapters of this book illustrate, law occupies a central place in the prevention and control of cancer, and in the reduction of social inequalities in cancer. The importance of law is evident in each of the major agreed international frameworks for sustainable development, health, noncommunicable disease preven-

tion and control, and cancer prevention and control, including the United Nations Sustainable Development Goals (UN, 2015), the global noncommunicable diseases agenda (WHO, 2018), the World Health Organization Framework Convention on Tobacco Control (WHO, 2003), and the World Health Assembly resolution on cancer prevention and control (WHO, 2017). In each of these instruments, states commit to implementing interventions that can be achieved only through the use of law.

Law is critical both within (at national and subnational levels) and between countries (in the form of international law) to address the shared concerns and activities that cross national borders. Law is sometimes thought of in a narrow way, either at

the domestic level as legislation or in international law as treaties. However, law comes in many shapes and forms, including constitutions, regulations, decrees, ordinances, by-laws, decisions of courts and tribunals, enforcement practices, agreements by states (which are not themselves binding in the manner that treaties are, but may have legal significance) (Zhou and Liberman, 2018), and mechanisms to monitor or enforce compliance with international obligations. This variety and breadth of what represents law highlight both its capacity to affect cancer prevention and control in multiple ways and at multiple levels, and the range of actors it involves.

Law has a particularly powerful role to play in addressing social

inequalities, because of its ability to regulate the environments in which we live; law can modify the structural determinants of social inequalities (“the causes of the causes”; see Chapter 14), both domestically and internationally. However, law is only one of a range of tools that may be used to further the goals of cancer prevention and control, and of reducing inequalities, and is usually used most effectively in coordination with other measures. These may include education and support programmes,

medical interventions, financial incentives, professional training and supervision programmes, or non-legally binding forms of international cooperation.

Law in cancer prevention and control

Table 12.1 presents examples of the ways in which law can be used in the areas of cancer prevention and control addressed in this book, and in which social inequalities are identified. Although this chapter focuses on

the positive role that law can play, it is important to acknowledge that law can also hinder cancer prevention and control. Law can also exacerbate social inequalities, as demonstrated by: laws that regulate the availability of morphine as a controlled drug in a manner that impedes its availability for palliative care (WHO, 2011); laws that are designed to protect the privacy of personal health information but unreasonably constrain the conduct of essential public health research (Lieberman, 2014); protections of

Table 12.1. Examples of the use of law to advance cancer prevention and control

Area of cancer prevention and control	Examples of the use of law
Tobacco use, alcohol consumption, and unhealthy diet	Bans or restrictions on product or company advertising, promotion, and/or sponsorship; regulation of product packaging, including mandatory health warnings, product information, or plain or standardized packaging in the case of tobacco products; bans on smoking in workplaces, in public places, and on public transportation; excise taxes on unhealthy products or other regulations to affect product price, such as minimum pricing; restrictions on when and where products can be sold; and regulation of product content or portion size
Occupational and environmental cancers	Bans on the use of asbestos; various forms of chemical regulation; occupational health and safety law; environmental law; requirements that protective equipment be worn by workers exposed to hazardous materials; protection against sun exposure in the workplace; smoke-free workplaces; housing regulation and building codes; regulation of fuel content; vehicle emissions or efficiency standards; regulation of agricultural practices including burning; and regulation of waste management, including disposal and recycling of end-of-life electrical and electronic equipment (e-waste)
Screening, diagnosis, treatment, and/or care	Regulation of the safety, quality, and efficacy of cancer screening, diagnostics, treatments, and services; measures to increase the availability and affordability of screening, diagnostics, treatments, and services; regulation, qualification, and education of health practitioners, including task-shifting and task-sharing, and prevention of overscreening and overtreatment; responsibilities of health-care professionals to provide meaningful information on treatment options and their implications, including financial; measures to provide or strengthen support for patient and/or family decision-making about treatment; protection of patient privacy and confidentiality; regulation of health insurance, including its coverage; preventing or reducing corruption in the health system; regulation of direct-to-consumer advertising; and regulation of corporate engagement with the clinical community
Life after a cancer diagnosis	Measures to promote the well-being of people who have been diagnosed with cancer throughout their post-diagnosis lives, and to avoid potential negative consequences of having or having had cancer, including protection against discrimination or stigmatization; income protection; protection against misuse of personal health information; protection in employment, including appropriately flexible working arrangements and support; and access to insurance (including health, life, and travel), superannuation/pension funds, and loans
Cancer registries and other collection and maintenance of health information	Providing appropriate legal underpinnings for cancer registries and other relevant data collection and information systems, including notification of individual cases, and specification of details to be provided; providing for sharing of information to enable maintenance of records and to facilitate research; providing for individuals to have appropriate access to their personal health information; and balancing individual rights to privacy (including through protection against inappropriate sharing of information and security breaches, and through de-identification of data) and the need for population-level research

freedom of speech that are extended to corporate expression, limiting the restriction of harmful commercial marketing practices, which are often targeted at less advantaged groups (see Chapter 7); and litigation against health practitioners, which can lead to the practice of “defensive medicine” (O’Dowd, 2015), contributing to problems of overscreening, overdiagnosis, and overtreatment, imposing unnecessary burdens on individuals, families, and already stretched health systems (see Chapter 19).

A matter of human rights

All aspects of cancer prevention and control, including reducing inequalities, are matters of human rights. The right to health is recognized in several international agreements, including the International Covenant on Economic, Social and Cultural Rights (UN, 1966), the Convention on the Rights of the Child (UN, 1989), the International Convention on the Elimination of All Forms of Racial Discrimination (UN, 1965), the Convention on the Elimination of All Forms of Discrimination against Women (UN, 1979), and the United Nations Declaration on the Rights of Indigenous Peoples (UN, 2007). The constitution of the World Health Organization recognizes that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being” (International Health Conference, 1946).

The right to “the highest attainable standard of physical and mental health” enshrined in the International Covenant on Economic, Social and Cultural Rights is a right of everyone (UN, 1966). The right – and the corresponding obligations of governments – can only be understood and enjoyed in a social and economic context. The right includes “the right

to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable standard of health”. The right applies both to “timely and appropriate health care” and to “the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information” (CESCR, 2000). Steps that must be taken by states to achieve the full realization of the right to health include provision for the healthy development of children; the improvement of all aspects of environmental and industrial hygiene; the prevention, treatment, and control of epidemic, endemic, occupational, and other diseases; and the creation of conditions that would ensure medical service and attention in the event of sickness. The right demands “equality of access to health care and health services” (CESCR, 2000).

The right to health includes the four “interrelated and essential elements” of availability, accessibility, acceptability, and quality, as described in Table 12.2 (CESCR, 2000).

Impacts of non-health areas of law and governance

Many areas of law and governance, both domestic and international, have a range of impacts across the spectrum of cancer prevention and control (Lieberman, 2017) in terms of the potential both to improve overall cancer outcomes and reduce inequalities, and to worsen outcomes and increase inequalities. These areas of law and governance may pursue worthy goals and objectives and may explicitly provide scope for taking health into account; howev-

er, health goals and objectives may not be prioritized in their design and implementation, and their key actors and stakeholders may overlook or undervalue the health implications of their decisions and actions. For example, although intellectual property laws may be designed to encourage and reward innovation, including in medical products, technologies, and devices, they may in practice make medical treatment unaffordable (WHO, WIPO, and WTO, 2013), particularly for less advantaged groups. Although international trade law and international investment law may be designed to improve economic growth, development, and, in the long run, overall living standards, they inevitably create both winners and losers (Shea et al., 2007). The standards that such laws set for the cross-border flow of goods and services, and the protection of foreign investments, may impose conditions on the regulation of trade in products that cause harm. Trade and investment agreements generally do provide space for bona fide public health regulation, as seen in the comprehensive victories by the governments of Australia (WTO, 2018) and Uruguay (ITALAW, 2016) in defending international trade and investment litigation against their tobacco packaging laws. However, these agreements generally require a range of procedures that may be difficult for some governments to navigate, particularly lower-resourced countries. They may also introduce complexities and constraints in how governments regulate heterogeneous unhealthy products. For example, taxes on unhealthy products (see Chapter 11) such as sugar-sweetened beverages (SSBs), of which there are many kinds (e.g. carbonates, fruit drinks, sports drinks, energy and

Table 12.2. Essential elements of the right to health as relevant to social inequalities in cancer

Essential elements of the right to health ^a	Examples of application to social inequalities in cancer
<p>Availability: functioning public health and health-care facilities, goods, services, and programmes should be available in sufficient quantity within a country</p>	<p>There are enormous disparities in the availability of facilities, goods, services, and programmes across countries. For example, people living in low- and middle-income countries have little or no access to pain relief or palliative care. Of the 298.5 metric tonnes of morphine-equivalent opioids distributed in the world each year, 287.7 metric tonnes (96.4%) are distributed to high-income countries and only 0.1 metric tonnes (0.03%) are distributed to low-income countries (Knaul et al., 2018). Although one radiotherapy unit on average is available for every 120 000 inhabitants in high-income countries, one radiotherapy unit is available for every 1 million individuals in middle-income countries, and 51 countries or independent territories or islands have no radiotherapy services at all (Chapter 7). Less than 25% of the global population has access to basic, high-quality cancer surgery. Many settings have low-quality services, which can be attributed to human resource shortages, poorly trained or low-volume providers, inadequate drug supply, and lack of equipment (see Chapter 10).</p>
<p>Accessibility: health facilities, goods, and services should be accessible to all, “especially the most vulnerable or marginalized sections of the population”. This requires: non-discrimination; that facilities, goods, and services be “within safe physical reach for all sections of the population, especially vulnerable or marginalized groups”; affordability, including for socially disadvantaged groups; and the accessibility of information</p>	<p>Individuals with a low income, ethnic minorities, Indigenous populations, and other socioeconomically disadvantaged groups face considerable barriers to accessing needed cancer services in both low- and middle-income countries and high-income countries. This applies throughout the care continuum, from symptom awareness to accessing treatment and receiving palliative care (see Chapter 10). Early diagnosis of cancer requires access to screening and diagnostic services. Individuals in groups of low socioeconomic status and underserved populations may be less likely to recognize the importance of cancer symptoms (see Chapter 7).</p> <p>Geographical accessibility is particularly relevant in cancer care. Generally, the further a patient lives from a cancer treatment centre, the greater the delay and/or the more advanced the stage of the disease upon presentation (see Chapter 10).</p> <p>Across the globe, Indigenous populations experience significant disparities relative to the local non-Indigenous populations, across the cancer continuum. Addressing this excess burden requires culturally appropriate interventions that are developed, implemented, and evaluated in partnership with Indigenous communities, including the development of a culturally competent health-care workforce, and culturally appropriate systems, services, and programmes (see Focus 5).</p> <p>The costs of cancer care can push individuals into poverty or force them to make difficult decisions about their treatment (so-called financial toxicity). These barriers to effective, acceptable, and timely cancer care result in poorer survival outcomes and quality of life, with the most vulnerable individuals disproportionately affected. Without health insurance, the poor are left to fund health care through out-of-pocket expenditure (see Chapter 7). Out-of-pocket payments are twice as high in low-income countries as in high-income countries. The few who are able to receive cancer care in low- and middle-income countries are typically from the most privileged subpopulations (see Chapter 10).</p>
<p>Acceptability: health facilities, goods, and services should be respectful of medical ethics, culturally appropriate (including respectful of the culture of individuals, minorities, people and communities, and sensitive to gender), and designed to respect confidentiality</p>	<p>In most settings, cancer treatment is not sufficiently focused on the individual patient. Decisions are not sufficiently informed by user preferences or oriented around the person. This is particularly important in cancer management, because of the complexity of decisions about risks, benefits, and uncertainties of treatment, and because of the implications of the general fear and anxiety that accompany a cancer diagnosis (see Chapter 10).</p>
<p>Quality: health facilities, goods, and services should be scientifically and medically appropriate, of good quality, and delivered by skilled medical personnel</p>	<p>It has been estimated that improving the quality of existing health services, essential for improving cancer outcomes, can reduce the number of lives lost to cancer by millions. Poor cancer care results in worse overall outcomes for those affected, subjecting vulnerable subpopulations to the costs and harms of cancer care without the benefits (see Chapter 10). In high-income countries, there is compelling evidence that individuals in less privileged groups receive lower-quality treatment for cancer than those in more privileged groups (Chapter 7).</p>

^a Source: CESCR (2000).

vitamin water drinks, sweetened iced tea, and lemonade) (WHO, 2016), must be designed to ensure that they do not unjustifiably discriminate between products (George, 2019). Discrimination between imported and domestic products (whether explicit in law or evident in its practical impacts) that cannot be sufficiently justified on health grounds is likely to breach the obligations that states have undertaken under international trade agreements. This highlights the need to understand and prioritize health and social inequality in “non-health” forums, and to understand “non-health” legal and governance frameworks within health research and practice.

The assertion of rights to health care

As noted above, the right to health includes the right to timely and appropriate health care that meets the requirements of availability, accessibility, acceptability, and quality. States are obliged to take steps to achieve the full realization of the right to health, and are to be held accountable for failing to do so. Methods of accountability may include scrutiny by international human rights bodies, domestic or international criticism, and domestic litigation to enforce compliance. In practice, more advantaged groups will be in better positions to enforce such rights, whether in a formal legal sense through court action or through less formal expectations, requests, or demands that they be provided what they believe they are legally entitled to. This may be because of higher literacy (both health literacy and legal literacy), greater knowledge and access to information, participation in networks of influence, personal or professional connections, greater experience and

confidence in pursuing their rights, or the financial capacity to use legal processes to assert rights and to hold others accountable for failures to provide what is demanded. Creating, clarifying, or strengthening rights and expectations – all of which are generally to be encouraged for improvements in health outcomes – will have the effect of increasing inequalities if only privileged groups are able to do so. For example, if an individual can successfully take a government to court for failure to provide or subsidise a particular treatment for them, their legal action may deliver access to treatment for them that is not available to those who are not in a position to pursue such claims. These are increasing risks (and realities) as we continue to move to more tailored, targeted, and expensive cancer treatments. Chapter 18 describes the ever-increasing research focus on expensive medicines for wealthy patients in wealthy countries and, in emerging economies, the displacement of domestic, affordable innovations by high-end expensive technology. Although commercial interests are driving many of the developments towards so-called precision medicine (Saracci, 2018), the resultant inequalities can be exacerbated by allowing rights to be claimed as legal entitlements in overly individualistic contexts.

Litigation by corporate actors against public health regulation

Table 12.1 includes the kinds of legal interventions that governments can use to regulate exposure to the cancer risk factors of tobacco use, alcohol consumption, and unhealthy diet. All of the interventions listed involve regulation of the behaviour of commercial actors, and inevitably affect

the commercial interests of these actors. Corporate actors whose interests are negatively affected by government regulation may resort to litigation to oppose such regulation, whether under domestic law or regional or international agreements. Such litigation has become common for tobacco control measures over the past decade (e.g. against tobacco plain packaging, graphic health warnings, advertising bans, smoke-free places, product regulation; Zhou et al., 2019), and has also occurred with respect to alcohol (e.g. minimum unit pricing; Scotch Whisky Association, 2017) and diet (SSBs) (Matter of New York Statewide Coalition of Hispanic Chambers of Commerce, 2014). Corporate actors may have various aims in pursuing such litigation, including having laws struck down or amended, receiving compensation, delaying the implementation of laws, tying up government resources and increasing the implementation costs of interventions that may otherwise be inexpensive, or dissuading the litigated-against government from further regulating its behaviour or governments of other countries from doing so (Zhou et al., 2019). Defending litigation of this nature by, or funded by, large multinational companies can be extremely resource-intensive (Crosbie et al., 2018) and may be beyond the capacity of some governments. Such strategic use of litigation by corporate actors can potentially lead to different tiers of regulation, in which higher-resourced governments are able to implement more effective laws than lower-resourced governments because the higher-resourced governments are better able to withstand litigation or legal threats. The more this is the case, the greater the incentive for the corporate actors to dedicate resources to these

less-regulated markets. The implication is that populations in lower-resourced countries face greater exposure to cancer risk factors than populations in higher-resourced countries.

Collaboration in research and the use of evidence in the development and implementation of laws

Across the spectrum of cancer prevention and control, laws (as for all interventions) should be soundly based on evidence, and subject to regular monitoring, evaluation, and improvement. However, the capacity to conduct research varies across countries. Efforts to ensure that the development and implementation of laws are based on evidence should not impose requirements to conduct local research, including duplicating research conducted elsewhere, that are beyond the capacity of lower-resourced governments. Although evidence gathered in one setting should not be unthinkingly applied to

other settings, researchers and policy-makers could usefully engage in international collaborations to develop practical guidance on both what kinds of evidence might be usable across settings and on how to reliably extrapolate research findings across settings. Australia – the first country in the world to introduce tobacco plain packaging – has conducted an enormous volume of both pre-implementation research, on which the laws were based, and post-implementation evaluations, to assess their impacts in practice (Cancer Council Victoria, 2018). It would be wholly unreasonable to expect low-resource countries with less capacity, both in government and in the research community, to do the same as Australia, particularly because there is now a valuable body of implementation evidence that can be examined and used by others. The content of such guidance would vary according to subject matter; for example, guidance on how to use implementation research on tobacco control measures (e.g. tobacco plain packaging, graph-

ic health warnings) or dietary measures (e.g. nutrition labelling, taxes on SSBs) across settings would be different from guidance on how to use research on different approaches to health workforce regulation, effective ways to engage patients and families in decision-making, or addressing concerns about the collection and use of personal health information.

Conclusions

Law has a vital role to play in reducing social inequalities in cancer, both within and between countries. To maximize its impact, by harnessing the enormous positive effect it can have and by ameliorating its negative effects, legal expertise must be integrated as an essential component of the cancer prevention and control workforce. Interdisciplinary collaborations across all aspects of cancer prevention and control research and practice, across the entire cancer continuum, must be built, nurtured, and maintained.

Key points

- Law occupies a central place in cancer prevention and control generally, and in addressing social inequalities in cancer specifically, including: addressing risk factors (tobacco use, alcohol consumption, unhealthy diet, and occupational and environmental exposures); screening, diagnosis, treatment, and care; life after a cancer diagnosis; and the collection and maintenance of health information.
- All aspects of cancer prevention and control, including reducing inequalities, are matters of human rights. Although creating, clarifying, and strengthening rights related to health are to be encouraged, action is required to ensure that these rights can be availed of in practice by all groups, not only the most advantaged.
- It is essential to understand and manage non-health areas of law and governance, such as international intellectual property, trade and investment regimes, and the strategic use of litigation by corporate actors to resist regulation of their behaviour.
- There is a need for greater international collaboration to establish practical guidance on the use of evidence for the development and implementation of law across settings, particularly to support countries with limited local research capacity.

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