# Submission to the Parliamentary Joint Committee on Human Rights' Inquiry into Australia's Human Rights Framework

**Cancer Council Australia and**
**McCabe Centre for Law and Cancer**

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This submission has been prepared by Cancer Council Australia and the McCabe Centre for Law and Cancer.

Cancer Council Australia is Australia's peak national non-government cancer control organisation and advises the Australian Government and other bodies on evidence-based practices and policies to help prevent, detect and treat cancer.

The McCabe Centre for Law and Cancer is working for a world free from preventable cancers and in which all people affected by cancer have equitable access to safe, effective, and affordable treatment and care. The McCabe Centre is a Melbourne-based joint initiative of Cancer Council Victoria, the Union for Cancer Control and Cancer Council Australia. The McCabe Centre conducts world-leading legal research, policy development, and capacity building programs to promote the use of law as an essential tool in the prevention and control of cancer in Australia and overseas.

As organisations dedicated to reducing the impact of cancer on the community, Cancer Council Australia and the McCabe Centre believe that the human rights of all people should be respected, protected and fulfilled, and that laws and policies should be non-discriminatory.

Cancer Council Australia and the McCabe Centre therefore welcomes the Parliamentary Joint Committee on Human Rights' Inquiry into Australia's human rights framework. Our submission focuses on why a new National Human Rights Framework and National Human Rights Act is needed for people affected by cancer. The submission responds to the following consultation questions:

- Whether a National Human Rights Framework should be re-established
- Whether the Australian Parliament should enact a federal Human Rights Act and the elements it should include
- Whether existing mechanisms to protect human rights in the federal context are adequate
- The effectiveness of existing state/territory human rights acts
- Any other matters.

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This submission may be published. There is no need to anonymise this submission.

Cancer Council Australia and the McCabe Centre for Law and Cancer would like to thank and gratefully acknowledge community members for their contributions to this submission.

Cancer Council Australia and the McCabe Centre acknowledge the traditional custodians of the lands on which we live and work. We pay respect to Aboriginal and Torres Strait Islander elders past, present and emerging and extend that respect to all other Aboriginal and Torres Strait Islander people.

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## Executive Summary

All aspects of cancer prevention, control and care are matters of human rights. Advancing human rights is key to addressing the underlying social determinants of health that lead to the inequities we see reflected in the unequal burden of cancer in Australia. Our current patchwork of human rights provisions results in significant gaps in protection, diminishing the ability of people affected by cancer to have their human rights, including their right to health, upheld.

A National Human Rights Act should cover the human rights Australia has voluntarily committed to uphold under international law and other international agreements. This includes the right to health and other economic, social and cultural rights that relate to the social determinants of health, as well as civil and political rights, the right to a healthy environment, and the rights of children and people with disabilities. Acknowledging the importance of and actively promoting all human rights is critical to improving the lives and wellbeing of all Australians affected by cancer and to ensuring a future free from preventable cancers.

A new National Human Rights Framework centred around a National Human Rights Act would improve the lives of the one in two Australian men and women who will be diagnosed with cancer by the age of 85, their families, carers, and communities by:

- Ensuring federal government and government bodies consider the human rights of people affected by cancer when creating new laws and policies and delivering services.
- Listing rights and freedoms in one place so that all people in Australia affected by cancer as well as government and government bodies clearly know their rights, freedoms, and responsibilities.
- Enabling people affected by cancer to take action and seek justice if their rights are violated.

Our views relate to the human rights of natural persons and do not relate to the rights of legal persons that are corporate entities. We do not consider that human rights apply or should apply to corporate entities.

The successful promotion of human rights in Australia to prevent and control cancer through a National Human Rights Framework and National Human Rights Act will rely on an effective whole-of-government and whole-of-society response. Educational campaigns, reform of federal discrimination laws, and federal government leadership will be integral to creating a strong culture of human rights. This includes fostering a regulatory environment in which corporate entities respect and protect human rights.

Cancer Council Australia and the McCabe Centre fully endorse the Australian Human Rights Commission's (AHRC) submission to the Inquiry and its Position Papers: *Free and Equal*: *A Human Rights Act for Australia* (2022) and *Free and Equal: A Reform Agenda for Federal Discrimination Laws* (2021). Cancer Council Australia and the McCabe Centre recommend:

**Recommendation 1:** The Australian Government develop a new National Human Rights Framework consistent with the recommendations of the AHRC centred around a new National Human Rights Act.

**Recommendation 2:** The Australian Government introduce a National Human Rights Act based on the AHRC's model that includes the right to health and other rights related to the social determinants of health.

**Recommendation 3:** The Australian Government reform federal discrimination laws to better protect people affected by cancer by adopting the AHRC's discrimination law reform recommendations, banning genetic discrimination in life insurance and by including socio-economic disadvantage as a protected attribute under federal discrimination law.

## People affected by cancer need a new National Human Rights Framework and a National Human Rights Act

Every person in Australia deserves to live a life of dignity, respect, compassion, freedom, and equal opportunity. Indeed, these are the values that Australia chooses to define itself by and uphold.[1] Upholding human rights is important in ensuring this vision of Australia is a reality. Australia has a strong and proud record on human rights, having played a key role in the development of human rights standards. Australia has also committed itself to respect, protect and fulfil human rights by ratifying legally binding human rights treaties, endorsing non-binding human rights instruments and participating in United Nations human rights monitoring processes.[2] Despite this, human rights are not well protected in Australian laws. So while many people living in Australia enjoy a range of freedoms and can live in a peaceful and stable society where human rights are respected, this freedom is not fully extended to all and some groups are especially vulnerable to human rights violations.[3] This includes people affected by cancer, particularly communities who bear a disproportionate burden of cancer including Aboriginal and Torres Strait Islander people, refugee and migrant communities, LGBTIQ+ communities, people with disabilities, and those living in regional and remote areas of Australia.

### Cancer is a human rights issue

Human rights are a fundamental and important part of each of our lives, so much so that we often take them for granted. But a cancer diagnosis brings human rights close to home, including for family, carers and colleagues of a person diagnosed with cancer. This could include the need to access lifesaving treatment and essential support services, the need for income support and flexible working arrangements, concerns about discrimination at work, school, in health services and in access to travel and life insurance as well as access to transport and nutritious food and water. Beyond a cancer diagnosis, human rights are engaged in accessing appropriate screening services to help prevent cancer or detect it early, and preventive health measures ensure that people live in an environment that promotes their right to health and to have the information they need to make informed decisions about their health.

Cancer is the leading cause of disease burden in Australia,[4] and accounts for about 3 out of every 10 deaths in Australia.[5] Over one million Australians currently live with or have cancer and it is estimated that between 2022 and 2031, a total of 1.7 million new cases of cancer will be diagnosed.[6] The number of cancer cases is expected to increase both as Australia's population grows and ages,[7] and as cancer survival rates increase.[8] A cancer diagnosis is often a life-changing experience for a person with cancer, their family and carers. People affected by cancer face a range of psychological, emotional, social, financial, practical and other issues.[9] Yet many cancers are preventable, with almost half of the cancer burden attributable to modifiable risk factors.[10]

All aspects of cancer prevention and control[i] are matters of human rights. Advancing human rights is imperative to addressing the underlying social determinants of health that contribute to the significant burden of cancer in Australia. Human rights are engaged for a person affected by cancer in terms of their treatment, employment protections, access to social security, and in a range of areas as illustrated in Table 1 below. It is important to note that as human rights are interdependent, interrelated and

[i] We use the word 'control' to cover research and information, screening, detection, diagnosis, treatment and care as per *Cancer Prevention and Control in the Context of an Integrated Approach*: WHA Res 70.12, 70th sess, 10th plen mtg, Agenda Item 15.6, WHO Doc A/70/VR/10 (31 May 2017).

indivisible,[11] issues relating to cancer prevention and control may involve multiple human rights considerations, as illustrated in Table 2.

**Table 1: Human rights and cancer: Examples of human rights that are engaged in the prevention and control of cancer**

| Human right[12] | Relevance to cancer context |
|---|---|
| Right to life | All persons have the right to life, including the prevention of threats to the enjoyment of life with dignity. The prevention of cancer is critical to achieve the right to life. |
| Right to highest attainable standard of mental and physical health (right to health) | All persons have a right to the highest attainable standard of health, including access to cancer prevention, treatment and palliative care services, access to healthy food and environment. All health facilities, goods and services, including those related to the social determinants of health must be available, accessible, acceptable and of good quality.<br><br>All persons have the right to credible information to make informed decisions about their health, including through effective food labelling to ensure people can make informed decisions about what they eat, the labelling of tobacco, e-cigarettes, alcohol and unhealthy diet products linked to cancer, as well as accurate information about the costs of care upon diagnosis. |
| Right to equality before the law and freedom from discrimination | People affected by cancer should not face discrimination because they have or have had cancer, have a genetic predisposition to cancer or because they are caring for someone affected by cancer. |
| Protection from torture and cruel, inhuman or degrading treatment | People affected by cancer should not be subject to medical treatment or scientific experimentation without their consent. |
| Rights of the child | Children have a right to be protected from exposure to cancer risk factors such as tobacco, e-cigarettes, alcohol, and unhealthy foods and protection from economic exploitation such as the marketing of sugary drinks and unhealthy food to children. |
| Right to an adequate standard of living | People affected by cancer and their families have rights to adequate food, clothing and housing (and other social determinants of health), and to the continuous improvement of living conditions. |
| Right to privacy | People affected by cancer have a right to healthcare that respects confidentiality and privacy. |
| Right to culture | Aboriginal and Torres Strait Islander People and people from other linguistically and ethnically diverse communities have a right to respect for their culture including their language, and a right to enjoy the benefits of scientific progress in cancer and its applications. |
| Right to social security | People affected by cancer have a right to social security including access to income support payments, the right to paid leave, and unemployment benefits if they are unable to work due to cancer. |
| Right to a healthy environment | All persons should have access to safe and nutritious food, clean air and water and be protected from exposure to cancer causing agents. |
| Right to work and other work-related rights | All people have a right to work in a safe environment, including environments that are free of or mitigate the risk of exposure to carcinogenic agents such as tobacco, silica, asbestos and radiation. |

## Human rights and the unequal burden of cancer

Thanks to investments in addressing cancer from federal and state/territory governments, today almost seven in 10 Australians will survive for at least five years after a cancer diagnosis.[13] But the burden of cancer in Australia is unequal, impacting the full enjoyment of human rights for many people living in Australia.

People experiencing socio-economic disadvantage,[14] Aboriginal and Torres Strait Islander communities,[15] culturally and linguistically diverse (CALD) communities,[16] people with pre-existing disabilities,[17] those who live in regional and rural areas of Australia,[18] and LGBTIQ+ communities[19] tend to have higher rates of some cancers and face disadvantage in cancer outcomes. This is influenced by social determinants of health including lower employment rates, homelessness, mental ill health, higher smoking rates, lower health literacy, and poor access to health services. For example:

- People living in remote areas of Australia often experience disadvantage in accessing primary healthcare services, education, employment and income. They are also more likely to have higher rates of cancer risk factors including smoking rates and through the harmful use of alcohol.[20]
- Among Aboriginal and Torres Strait Islander peoples, tobacco smoking is directly responsible for a third of cancer cases and is the most preventable cause of ill health and early death.[21] 37% of Aboriginal and Torres Strait Islander people aged 15 and over were daily smokers in 2018-19[22] and adjusting for age, were 2.5 times as likely as non-Indigenous Australians to smoke daily in 2019.[23]
- Tobacco use is prevalent amongst LGBTIQ+ communities who are 1.5 times as likely to smoke daily compared to those who identify as heterosexual.[24] LGBTIQ+ communities have unique needs that are not yet being met by the healthcare system.[25]
- The health of people experiencing homelessness tends to be worse than that of the general population and there is a strong link between alcohol use, tobacco smoking and experiences of homelessness.[26]
- Adults who reported being diagnosed or treated for mental illness in the past year were almost twice as likely to be a current smoker than those who had not.[27]
- Some CALD communities experience higher incidences of cancer than the general population. This is related to a higher prevalence of cancer-related risk factors (such as tobacco and alcohol use), lower use of screening or cancer support services and varying levels of health literacy. For example, in New South Wales, rates of smoking amongst Chinese, Vietnamese and Lebanese born men are much higher than the State's population more generally.[28]

There is a need to ensure that all those affected by cancer can access suitable treatment services and to reduce these health inequities. Additionally, as the number of cancer survivors continues to grow,[29] equitable access to ongoing support services is essential.

*"Treatment is a postcode lottery. If you are not in the right postcode, you won't get the same care"*
*— Cancer clinician consultation with Cancer Council Victoria, August 2019.*[30]

*"The inequity of what is provided to people who attend (a metropolitan treatment centre) compared to what we can offer people up here (in a regional hospital) is extreme."*
*— Regional clinician consultation with Cancer Council Victoria, September 2019.*[31]

Preventing cancer is essential to reducing the burden of cancer. All individuals living in Australia should be able to live in an environment which helps reduce their cancer risk, and have access to credible information, programs and preventive health services to help them do this. Yet inequities exist. For example, Aboriginal and Torres Strait Islander people have lower participation in the National Bowel Cancer Screening Program compared to non-Indigenous Australians; LGBTIQ+ communities have lower cancer screening rates than the general population, particularly for cervical screening; and migrant

communities also have lower rates of participation in national breast, bowel and cervical screening programs.[32] Research also shows more needs to be done to meet the health information needs of Aboriginal and Torres Strait Islander peoples and CALD communities.[33]

Table 2 provides some examples of current limitations in fulfilling the human rights of people affected by cancer in Australia. This demonstrates there is a clear need for a more effective system to protect, respect and fulfil the human rights in Australia to reduce the burden of cancer and to improve the health and wellbeing of all people living here.

**Table 2: Limitations in fulfilling the human rights of people affected by cancer in Australia**

| **Pressure points and human rights impacted** |
|---|
| **Access to healthcare** *(rights to life, health, freedom of movement, protection of families, rights of the child)* |
| • Access to healthcare is delayed or forgone due to its costs impacting quality of life and cancer outcomes.[34]<br>• People in rural/remote areas have less access to cancer services.[35]<br>• Access to cancer screening, treatment and support services were disrupted during the COVID-19 pandemic with ongoing impacts including missed diagnoses, late-stage presentation.[36]<br>• During the COVID-19 pandemic, Australians were unable or found it very difficult to return home to access healthcare, support ill family members, including those with cancer and those facing end of life.[37]<br>• People with cancer and other disabilities have difficulty accessing the National Disability Insurance Scheme (NDIS).[38] |
| **Costs of cancer** *(rights to life, health, an adequate standard of living, social security)* |
| • Those living in the most disadvantaged socio-economic areas have higher incidence and mortality for all cancers compared to people living in the least disadvantaged areas.[39] Survival rates also decrease as socioeconomic disadvantage increases.[40]<br>• Many people affected by cancer are forced into financial hardship and are at risk of poverty due to direct (e.g. treatment) and indirect (e.g. hospital parking) out-of-pocket costs related to cancer care.[41]<br>• Current income support pensions and supports (Disability Support Pension, JobSeeker, NDIS) do not meet the needs of people unable to work due to cancer.[42]<br>• Due to the gendered burden of care,[43] women (and their families) face increased risk of poverty.[44] |
| **Cultural rights** *(rights to health, self-determination, culture, participate in and benefit from scientific progress and its applications)* |
| • Aboriginal and Torres Strait Islander people have higher rates of cancer incidence and mortality than non-Indigenous people,[45] but Aboriginal led initiatives are successful in reducing these inequities.[46]<br>• People from CALD communities with low English proficiency are less able to participate in and reap the benefits of cancer clinical trials.[47] |
| **Workplace issues** *(rights to health, work and work rights, non-discrimination, social security, privacy)* |
| • People affected by cancer report concerns about discrimination in the workplace.[48]<br>• Carers of people affected by cancer need better workplace protections to fulfil their caring responsibilities and maintain employment.[49]<br>• Access to paid sick/carer's leave is limited to non-casual employees and is unavailable to many people affected by cancer whose work arrangements fall outside this employer-employee relationship.[50] |
| **Discrimination** *(rights to health, non-discrimination, privacy)* |
| • People affected by cancer report difficulties in accessing travel and life insurance, including those who have taken risk-reducing measures and/or years after successful cancer treatment.[51]<br>• Around half of all older people have experienced ageism by health professionals,[52] particularly in the context of cancer care.[53]<br>• LGBTIQ+ people with cancer report high levels of dissatisfaction with cancer healthcare including experiencing overt hostility and discrimination from healthcare professionals.[54]<br>• Women experience inequities in cancer care, outcomes, research, support, particularly when other factors such as socio-economic disadvantage intersect.[55] |
| **Children's health** *(rights to life, health, information, rights of the child)* |
| • Australian children are targeted by harmful digital marketing of unhealthy products that increase the risk of cancer including alcohol and unhealthy food impacting their habits and health.[56] |
| **Cancer and environmental factors** *(rights to life, health, healthy environment)* |
| • Air pollution is a cancer risk factor, yet Australia has not adopted the WHO's 2021 Air Quality Guidelines to reduce air pollution,[57] which contributes to more than 11,000 premature deaths in Australia yearly.[58]<br>• Ninety per cent of polluting facilities are in postcodes with an average weekly income in the bottom 60% of all households whereas only 0.1% of polluting facilities are in the postcodes with an average weekly income in the top 20%.[59] |

# What a National Framework and National Human Rights Act should look like

## A new National Human Rights Framework centred around a National Human Rights Act

### Recommendation 1: Adopt a new National Human Rights Framework consistent with the Australian Human Rights Commission's proposals

The unequal burden of cancer in Australia outlined above is exacerbated by the lack of cohesive human rights protections in Australia. As noted by the AHRC, there is a general lack of federal constitutional protection of human rights in Australia,[60] and while Australia has ratified key international human rights law treaties, these are not all automatically enforceable in Australian courts as neither the Commonwealth nor States and Territories have legislation that systematically implements international human rights treaties into domestic law. Yet, by entering into these treaties, Australia has voluntarily committed to comply with their provisions in good faith and to take the necessary steps to give effect to those treaties under domestic law.[61]

Currently, human rights are protected in a patchy, complex, and piecemeal way incorporating the Constitution, judge-made law (the common law which Parliament can override at any time), and across various pieces of legislation resulting in an incomplete National Human Rights Framework. For example, only some international human rights obligations have been directly incorporated into domestic legislation, such as employment entitlements to paid sick and carer's leave for some workers under the *Fair Work Act 2009* (Cth), and the *Social Security Act 1991* (Cth).

While the *Human Rights (Parliamentary Scrutiny) Act 2011* (Cth) requires all bills and legislative instruments, including the budget, to be examined by the Parliamentary Joint Committee on Human Rights ('**PJCHR**') for human rights impact through preparation of a 'Statement of Compatibility', such scrutiny only applies to new bills and legislative instruments. Additionally, concerns have been raised that the PJCHR's recommendations are not fully considered by legislators.[62] Moreover, as the AHRC has noted, in the absence of enforceable legal protections for human rights breaches, scrutiny by the PJCHR is "without consequence".[63]

The gaps in our existing human rights framework means that federal decision-makers are not required to consider and act in accordance with human rights. This is particularly relevant for people affected by cancer given federal parliament has the legislative power to make laws regarding many issues that impact on the lives of people affected by cancer including the provision of pharmaceutical, sickness and hospital benefits and medical services,[64] as well as the regulation of the private healthcare system,[65] cancer screening programs (shared with states),[66] vaccination,[67] disability and aged care services,[68], rural health programs,[69] social security (e.g. sickness benefits),[70] anti-discrimination,[71] and workplace relations (e.g. sick/carer's leave entitlements).[72] Where protections are in place, different protections have different levels of enforceability and opportunities for redress that are not easily accessible to all people in Australia.[73] Australia's complex federal anti-discrimination laws are a prime illustration of this.[74]

The consequences of Australia's lack of legal human rights protections are felt most acutely by the most vulnerable people, including people affected by cancer who may also experience other disadvantage, marginalisation and discrimination, as highlighted in Table 2.

Experience in Australian jurisdictions with legislated human rights acts/charters, namely Victoria, the Australian Capital Territory and Queensland demonstrate that human rights acts are **effective in improving people's lives**, particularly in the promotion of healthcare and addressing social determinants of health, such as homelessness.[75] Additionally, research shows that the **biggest impact of human rights legislation in these jurisdictions is in improving law and policy development**

**and service delivery**.[76] Therefore, human rights-focused decisions help build trust in government and confidence in the integrity of government actions.

Similar experiences are found internationally in comparable common law countries with nationally legislated human rights law, including the United Kingdom[77] and Canada.[78] A new National Human Rights Act is therefore not a radical proposal — as Australia's stated values reflect human rights. Rather, a National Human Rights Act is the necessary logical step to fully articulate and embrace these values. Research shows Australians support a National Human Rights Act.[79]

At present, a person's access to human rights protections in Australia unfairly depends on where they live. Australia can no longer afford to be the country to remain an outlier amongst other liberal democracies with no overarching National Human Rights Framework and no overarching national human rights law that protects **all** people in Australia. A new National Human Rights Framework in Australia centred around a new National Human Rights Act, as proposed by the AHRC, is needed to close the gaps in our existing system and to ensure an effective system of human rights protection for 21st Century Australia.

We endorse the AHRC's recommendations that a National Human Rights Act should:[80]

- Protect human rights: Laws should respect human rights. Any limitations on these rights must be for a legitimate purpose, proportional, least restrictive, of limited duration and subject to review.
- Prevent violations of human rights: Human rights should be considered by decision-makers.
- Provide effective relief for breaches of human rights: Remedies should be available where human rights have not been considered or have been breached without justification.
- Apply to all Federal public authorities including organisations undertaking work outsourced by the Federal Government.

Cancer Council Australia and the McCabe Centre recommend the Australian Government adopt the AHRC's proposed parliamentary, dialogued-based model of a National Human Rights Act. This would preserve parliamentary sovereignty while also being participatory and enhancing the rule of law.

A National Human Rights Act that does this would improve the lives of people affected by cancer by:

- Helping Parliament and decision-makers to consider and respect the rights of people affected by cancer when creating new laws and policies and when delivering services. For example, this could lead to accelerating the introduction of preventative public health measures and promotion strategies that reduce exposure to modifiable cancer risks factors, such as tobacco and alcohol consumption, unhealthy diets, and physical inactivity,[81] and lead to improvements in healthcare experiences and with services used by people affected by cancer, such as Medicare and Centrelink.
- Ensure that if their human rights are violated, people affected by cancer can seek redress.
- List all our rights and freedoms in one place so everyone can learn and understand our rights and responsibilities.

## Rights that should be included in a National Human Rights Act

### Recommendation 2: Introduce a National Human Rights Act based on the Australian Human Rights Commission's proposed model that includes the right to health and other human rights that relate to the social determinants of health

Human rights are interdependent, interrelated, and indivisible. They encompass civil, political, economic, social and cultural rights.[82] The denial of economic, social and cultural rights can have a widespread impact on a significant proportion of the population. Further, denial of those rights can lead to the denial of civil and political rights and vice versa. For example, a lack of education and work or poor health can make it harder for individuals to exercise their freedom of expression.[83] Similarly, lack of access to adequate food can result in malnutrition which has a clear impact on the right to health.[84] **All** human rights are therefore important and should be protected and advanced in Australia, due to their indivisibility.

Accordingly, a National Human Rights Act should cover the human rights Australia has **already voluntarily committed to uphold** under international law, including civil, political, economic, social and cultural rights under the *International Covenant of Civil and Political Rights*,[85] the *International Covenant of Economic, Social and Cultural Rights*,[86] as well as the rights of women, children and people with a disability under the *Convention on the Elimination of All Forms of Discrimination against Women*,[87] the *Convention on the Rights of the Child*,[88] and the *Convention on the Rights of Persons with Disabilities*.[89] Additionally, the Act should cover obligations Australia has committed to under other international agreements, most notably, the United Nations (UN) Declaration on the Rights of Indigenous Peoples,[90] the UN General Assembly Resolution on the Human Right to a Clean, Healthy and Sustainable Environment,[91] and the UN Political Declarations on Universal Health Coverage,[92] and Non-Communicable Diseases,[93] and the 2030 Agenda on Sustainable Development.[94]

### The importance of including the right to health and rights relevant to the social determinants of health in a National Human Rights Act

It is essential that a new National Human Rights Act include the right to health and rights related to the social determinants of health — the non-medical factors that influence health and health outcomes.[95] This is critical not only for people affected by cancer but for the health and wellbeing of all people in Australia so that they can live productive and meaningful lives. Although the right to health is central to the lives of people affected by cancer, attaining the right to health is essential to and dependent upon, the realisation of other fundamental human rights (as Table 2 illustrates).

Under human rights law, the right to health is broadly conceived and contains both freedoms and entitlements. For example, freedoms include the right to bodily autonomy and to be free from non-consensual medical treatment and experimentation. Entitlements include the right to timely and appropriate healthcare that is available, accessible, acceptable and of good quality; and rights that address the underlying social determinants of health for people to enjoy the **highest attainable standard of health**.[96] Therefore, although the right to health does not mean that the state has to guarantee each individual good health, the right to health cannot be fully realised unless the rights to the underlying social determinants of health are also protected.[97] The right to health and the social determinants of health such as education, the workplace, social security, family life, participation in cultural life, freedom from discrimination, and access to housing, food and water are considered as 'economic, social and cultural rights' under international human rights law. [98]

Australia, like other countries, is obliged to progressively realise such rights through 'all appropriate means, particularly the adoption of legislative measures'.[99] The requirement to progressively realise these rights reflects the understanding that countries have resource constraints and that it can take time to implement human rights treaty obligations. But countries must show that they are making every

possible effort, within available resources, to better protect and promote economic, social and cultural rights.[100]

It is crucial that a new National Human Rights Act cover these economic, social and cultural rights because these rights are not currently well protected in Australia. Although the concept that human rights are interdependent, interrelated, and indivisible is often repeated, in practice these rights have received differential treatment.[101] Economic, social and cultural rights which are inextricably linked to health and the social determinants of health have historically not received as much protection as civil and political rights in Australia.[102] This is despite the **right to health being considered the most important right to Australians**,[103] and other economic, social and cultural rights related to the social determinants of health being some of the most valued rights in Australia, such as work rights and anti-discrimination protections.[104]

*"With cancer things are unpredictable….from an employee perspective, I think that it is essential that people in this position, and it's not just carers of people with cancer, it's any carer role, have access to paid and unpaid leave." — Jenna*, carer* (note name has been changed for privacy)

This lack of protection for economic, social and cultural rights has been explored in detail elsewhere, so we briefly note the following examples which illustrate this:

- The few rights which are expressly or impliedly protected under the *Australian Constitution* are limited to civil and political rights, such as the right to freedom of and from religion, and the implied right to freedom of political communication.[105] In contrast, despite ratifying the *International Covenant on Economic, Social and Cultural Rights*,[106] ('**ICESCR**') and other treaties that contain ICESCR rights, Australia has not implemented the ICESCR and other relevant treaties into domestic law as constitutional rights at either the federal or state level, meaning they cannot be considered by domestic courts.[107]
- Successive Australian Governments have chosen to promote economic, social and cultural rights indirectly through policies, programmes and legislation, and through less formal processes such as inquiry, conciliation and reporting. This contrasts with the treatment of civil and political rights which are usually legally enforceable and therefore subject to judicial processes and remedies.[108]

  While we do not wish to diminish the positive impact that some of these indirect measures may have had in promoting economic, social and cultural rights, we note that the United Nations Committee on Economic, Social and Cultural Rights has affirmed that aspects of all rights in the ICESCR are capable of judicial enforcement.[109] In its most recent review of Australia, the Committee recommended Australia take 'immediate steps to incorporate fully the Covenant provisions into [Australia's] legal order so as to render them justiciable in domestic courts'.[110]
- Some aspects (or sub-rights) of economic, social and cultural rights enshrined in international human rights law have been legislatively enacted via a patchwork of laws. For example, there is protection of some work rights through industrial relations laws.[111] Additionally, there are some laws that provide a range of social security benefits for certain groups of people but fall short of providing an express right to an adequate standard of living.[112] Federal laws establishing Medicare and the Pharmaceutical Benefits Scheme, as well as tobacco and alcohol control laws, address some aspects of the right to health — despite it not being enshrined in legislation.[113] However, persistent forms of economic, social and cultural disadvantage in Australia[114] suggests that the sum of these sub-rights do not constitute or fulfil the comprehensive regime of rights provided under instruments such as the ICESCR.[115]
- Unlike the *International Covenant on Civil and Political Rights*, the ICESCR is not included as a Schedule to the *Australian Human Rights Commission Act 1986* (Cth) or designated a 'relevant international instrument' under the Act.[116] The economic, social and cultural rights under the ICESCR are therefore not considered 'human rights' for the purposes of the Act. The effect of this

exclusion for the Australian public is that rights under the ICESCR cannot be the subject of a complaint or self-initiated inquiry or examination of enactment conducted by the Commission, except to the extent those rights are incorporated into other treaties within the Commission's statutory mandate.[117] Additionally, the Commission's other functions including human rights promotion and research are similarly limited for ICESCR rights.[118]

- Many economic, social and cultural rights, such as the right to health, are reflected in the provision of public services, yet such services cannot be claimed as a right and can be withdrawn at any time.[119] There is limited protection of these rights in Australian state/territory human rights acts.[120]
- The Australian Charter of Healthcare Rights is not legally enforceable, and Queensland is the only jurisdiction which recognises the right to health services.[121]

The right to health and other rights related to the social determinants of health will remain legally unenforceable across most of Australia in the absence of a National Human Rights Act. Yet both domestic and international examples demonstrate how making these rights legally enforceable in a human rights law benefits people and societies:

- The Victorian Charter of Human Rights and Responsibilities was used to successfully ensure a woman denied immediate medical assistance to treat contractures in her hand due to her being over 50 years of age could receive urgent medical treatment she required and the funding for it.[122]
- The Queensland Human Rights Act was used to help a man with a disability experiencing mental health issues avoid eviction.[123]
- An Indian Court ordered that citizens should be protected from exposure to second-hand smoke through the constitutional right to life and personal liberty. Consequently in 2003, laws were passed prohibiting smoking in various public places.[124]
- The Ugandan High Court ruled that public smoking violated the constitutional right to life and the right to a healthy and clean environment. As a result, in 2004, the National Environment Management Authority issued regulations banning smoking in several public places.[125]
- The Constitutional Court of Columbia affirmed that freedom of information under the Constitution includes the right to receive facts, idea and opinion through the media, including information about health effects of sugary drinks.[126]
- In South Africa, civil society organisations successfully litigated for the lifting of restrictions on access to nevirapine, a medicine that prevents mother-to-child HIV transmission, under the South African Bill of Rights which recognises a right to access health-care services. The treatment was only available at certain public hospital sites with no timeframe on expansion of access across the country. The Constitutional Court held that the treatment was cheap, safe and effective and that the country had the available resources to increase access to the treatment at more public hospitals to achieve the progressive realisation of the right to health.[127]

In assessing whether countries are implementing their human rights obligations relating to economic, social and cultural rights, resource availability (financial and other resources) and a country's development context will be considered by courts and human rights monitoring bodies.[128]

Progressively advancing the protection of economic, social and cultural rights is essential to the strengthening of **all** recognised human rights, due to their interrelated and indivisible nature.[129] Failure to do so leaves individuals and groups, such as people affected by cancer, vulnerable to human rights violations, with limited means of redress.

Accordingly, Cancer Council Australia and the McCabe Centre recommend that the Australian Government include the right to health and all other rights related to the social determinants of health in a National Human Rights Act, as articulated by the AHRC in its proposed model of a National Human Rights Act.

## Strengthening existing federal mechanisms to protect human rights: Reform Australia's federal discrimination laws

**Recommendation 3: The Australian Government reform federal discrimination laws to better protect people affected by cancer.**

The right to a life free from discrimination and equality before the law is central to full realisation of all human rights and a life lived with dignity. For example, the right to health requires that it be implemented in a manner that ensures non-discrimination and equal treatment to all.[130] Discrimination and equal opportunity laws are an example of Australia partly implementing key aspects of international human rights treaties it has ratified.[131] Federal discrimination law has a key role to play in meeting Australia's obligations to respect, protect and fulfil human rights. However, extensive research and analysis shows Australia's federal discrimination laws are clearly not fit for purpose and require reform.[132]

Reform of federal discrimination law is important for people affected by cancer for whom discrimination is a very real concern. People affected by cancer can experience various forms of discrimination and often in compounding, intersectional ways, as highlighted in Table 2: Several research and anecdotal reports demonstrate that people affected by cancer (including those living with cancer, cancer survivors and carers of people with cancer) are concerned about or have experienced discrimination in various aspects of public life (such as work) and in access to goods and services (such as healthcare and risk-rated insurance).

*"I travelled overseas recently and wanted medical insurance for when I was away. I couldn't get any because of my previous diagnosis." — Anonymous*[133]

Despite experiencing discrimination, people affected by cancer report not making complaints regarding workplace (or risk-rated insurance) for various reasons, including because they do not know how to and/or do not have the energy to navigate the 'hassle' of complaints processes while managing their cancer treatment and recovery process.[134] In part, this is because federal disability discrimination law places the evidentiary burden and an onus on individuals to prove direct disability discrimination, rather than placing a positive duty on workplaces and goods and service providers to prevent such discrimination.[135]

Alongside a National Human Rights Act that contains an enforceable right to freedom from discrimination, Australia's federal discrimination laws need to work better for people affected by cancer. Below, we outline further considerations for reform of Australia's discrimination laws.

### Workplace discrimination and cancer

*"My experience has shown me that once people find out I've had and again have cancer I'm definitely treated differently. Generally ignored and colleagues kept their distance. My last employer just stopped talking to me." — Anonymous*[136]

*"Promotional opportunities or opportunities to travel or work harder are assumed to be out of reach for a person with cancer – unproven of course."— Anonymous*[137]

Research conducted by the McCabe Centre and Cancer Council Victoria found that almost half (48%) of 40 survey respondents questioned about workplace discrimination believed there needed to be changes to the laws and complaints processes relating to unfair treatment at work, to make it easier for people to make complaints, including longer timeframes within which to make complaints were needed.

*"[It's] difficult to make a complaint and cover all aspects of the issues when unwell...most of your energy is spent just trying to get better and resume your normal/usual lifestyle." — Anonymous*[138]

Additionally, 70% of the survey respondents questioned about workplace discrimination reported taking action to avoid being treated unfairly at work, including minimal disclosure of cancer diagnoses and treatment and pressure to minimal time off, often to their detriment:[139]

*"Once diagnosed with breast cancer, I took three weeks off work to have breast cancer surgery and recover. I felt if I was away any longer, I wouldn't have a job to go back to!"— Anonymous*

*"Went back to work after surgery too soon." — Anonymous*

*"Minimal time off, but struggled to get through some days." — Anonymous*

Carers of people with cancer also experience discrimination and challenges at work:

*"My husband at the time was treated harshly by his employers when he asked for reduced hours during the months that I had active treatment. Asking for time off being so hard, that he felt he had no choice but to stop working and become my full time carer. He has since found it hard to find work, as he had been honest in his interviews that he may require time off occasionally as he was my carer" — Anonymous*[140]

*"I had to deliver my projects and I had specific deadlines. I can't say that my employers were that receptive or understanding of my caring responsibilities." — Jenna*, carer*
(note name has been changed for privacy)

Carers of people affected by cancer are further disadvantaged by gaps in coverage for carer responsibilities under federal discrimination laws (the *Sex Discrimination Act 1984* (Cth) and *Disability Discrimination Act 1992* (Cth)). These gaps are compounded by inconsistencies with protections under the *Fair Work Act 2009* (Cth) and also state/territory discrimination and equal opportunity acts,[141] some of which provide a broader definition of 'carers' to address varied domestic relationships and cultural understandings of kinship.[142] A consistent definition of carers should be applied across all federal and state/territory discrimination law across all areas of public life, including the workplace, as proposed by the AHRC.[143]

**Genetic discrimination and cancer**

Due to an exception under the *Disability Discrimination Act 1992* (Cth), it is legal for insurance companies in Australia to look at genetic test results as part of life insurance applications.[144] This means they can lawfully discriminate against people with a family history of cancer by denying life insurance, changing insurance coverage or increasing the cost of insurance premiums because of genetic cancer risk. This needs to be supported by statistical evidence that a person's genetic test results and family history mean they are at greater risk of developing cancer. In some insurance companies' decisions, this evidence is lacking, unclear or inconclusive. However, it is very difficult for people to challenge or overturn those decisions because there is no legislation in Australia to ban this kind of genetic discrimination in life insurance. While there is currently a moratorium on using genetic test results in insurance risk assessments for policies worth up to certain financial limits, it is self-regulatory with no government or independent oversight. Research shows the financial limits are also too low to offer meaningful protection.[145]

People affected by cancer are disproportionately impacted by genetic discrimination in life insurance applications because it is not uncommon for more than one family member to have had cancer.[146] Additionally, the genetic basis for common cancers such as breast, ovarian, colorectal and endometrial cancers have been identified and genetic testing for these cancers is available.[147] Research has repeatedly shown that people affected by cancer experience challenges in accessing life insurance due

to genetic discrimination, even with the current moratorium.[148] Furthermore, fears of genetic discrimination in life insurance deter some Australians from undergoing potentially lifesaving genetic testing and participating in important genetic research that could advance progress in cancer prevention and treatment.[149]

By relying on industry self-regulation, Australia is lagging behind other countries in dealing with genetic discrimination. Countries in Europe as well as Canada and the United Kingdom have already banned or restricted life insurance companies from using genetic test results.[150] A similar law reforming the *Disability Discrimination Act 1992* (Cth) would strengthen the rights of people affected by cancer in Australia.

**Better protecting people affected by cancer living in poverty**

There is a clear link between poverty and cancer.[151] Discrimination, marginalisation and exclusion are also major drivers of poverty.[152] Australia is a party to several international human rights treaties that impose obligations related to eradicating poverty including the right to social security and the right to health.[153] It has also made several commitments to reducing poverty and the social inequalities of health, including job and income security, by advancing universal health coverage and other Sustainable Development Goals.[154] As per the recommendations of the UN Special Rapporteur on extreme poverty and human rights, Australia's discrimination laws should be amended to include a prohibition of discrimination on grounds of socio-economic disadvantage as a key tool towards eradicating poverty.[155] This would benefit all Australians living in poverty, including people affected by cancer.

**Discrimination law reform summary**

Given the significant need to better address discrimination faced by people affected by cancer, Cancer Council Australia and the McCabe Centre endorse the AHRC's recommendations for reform of Australia's discrimination law system, as set out in the AHRC's Position Paper[156] and in its submission to this Inquiry. The AHRC's reform proposals which focus on preventing discrimination occurring and recognising intersectional impacts of discrimination; modernising the regulatory framework to shift to a more effective compliance model; enhancing access to justice; and improving the practical operation of federal discrimination laws will have a significant positive impact on the lives of people affected by cancer.

Cancer Council Australia and the McCabe Centre recommends the Australian Government reform federal discrimination laws to better protect people affected by cancer in the following ways:

1. Adopting the AHRC's recommendations regarding reform of federal discrimination law.
2. Amending the *Disability Discrimination Act 1992* (Cth) to ban the use of genetic testing in life insurance applications to prevent genetic discrimination.
3. Expanding protected attributes under federal discrimination law to include socio-economic disadvantage.

Cancer Council Australia and the McCabe Centre for Law and Cancer thank you for consideration of this submission.

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