Developing a rights-based approach to cancer control advocacy

Key messages

- Despite a growing recognition of health as a human right, cancer and other non-communicable diseases receive very little mention in the United Nations framework for human rights
- Cancer is both a public health and human rights issue, considering the challenges of disproportionate access to essential prevention, treatment and care, and discrimination toward vulnerable populations
- There is a critical opportunity for the cancer community to strengthen its advocacy efforts by combining a public health and rights-based approach to raise cancer issues through international human rights treaty bodies and mechanisms. This approach supports cancer advocacy in three ways: standard setting, awareness raising and holding UN Member States to account.

Background

Since the adoption of the WHO Constitution in 1948, the right to health has been embedded in the Universal Declaration of Human Rights (1948) and six other international human rights treaties, including the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW, 1979) and the Convention on the Rights of the Child (CRC, 1990). The recognition of health as a human right has gained traction in certain areas and, in some cases, fostered a strong rights-based approach to advocacy and programming, such as in sexual and reproductive health and HIV/AIDS. Yet, there remains a critical gap in the human rights discourse around cancer control and non-communicable disease (NCDs), despite the fact that NCDs are the leading cause of death and disability worldwide.

Recognising this disconnect, in January 2016, UICC commissioned a comprehensive assessment of the presence of cancer and NCDs across the spectrum of UN human rights mechanisms and bodies based on a review of the main outputs of these entities, including thematic or country reports and recommendations to Member States. Based on these findings, the opportunities and added value for UICC members and partners to engage with human rights bodies was explored. This briefing paper provides a summary of the findings and next steps for considering a rights-based approach to cancer advocacy.

“The enjoyment of the highest attainable standard of [physical and mental] health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.”¹
Understanding the UN human rights system

The UN human rights system is composed of several charter and treaty-based bodies. Non-state actors, including NGOs such as UICC, can be involved in the work of all the bodies and mechanisms below to varying degrees, including advocating for report themes or issues to be raised with Member States, taking part in expert meetings (including as panellists), submitting information, and influencing the drafting of resolutions, reports and recommendations.

1. **The Human Rights Council (HRC)** - This is the main UN inter-governmental body responsible for human rights. It is composed of 47 Member States and is responsible for strengthening the promotion and protection of human rights and addressing or making recommendations on violations. It covers both thematic issues and country situations.

2. **The HRC’s Special Procedures** - These independent human rights experts are mandated to report and advise on human rights from a thematic or country-specific perspective. Their main activities are: conducting country visits, acting on cases of alleged violations by sending communications to Member States, developing human rights standards and guidelines, convening expert consultations, advocating and raising awareness of issues, and providing advice for technical cooperation.

3. **Treaty bodies** - All the core international human rights treaties (see footnote 2) have established a mechanism to monitor Member States’ progress in implementing their treaty obligations. Collectively called ‘treaty bodies’, they consist of independent experts who have been nominated and elected by States parties. In accordance with the treaties they have ratified, Member States are obliged to report to these treaty bodies on a periodic basis and receive country specific recommendations. They also interpret certain articles of the treaties and hold expert discussions on key issues.

4. **Universal Periodic Review** - This is a process whereby all UN Member States have their human rights record examined by their peers. All Member States have to prepare a report of the actions they have taken to improve their human rights situations and fulfil their treaty obligations. They receive recommendations on measures they must take from other States and the accepted recommendations have to be implemented in time for the next review four-and-a-half years later.

How well is cancer represented in the UN human rights system?

A review of the recommendations of UN human rights treaty mechanisms and bodies established a clear gap in the human rights discourse around cancer control and NCDs. Cancer-related subjects remained under-recognised, either only mentioned in passing or never explicitly mentioned at all. The treaty body that acknowledges cancer the most is CEDAW, as it often makes multiple reference to cervical and breast cancer. Under the CRC, cancer was raised only with regards to Chernobyl, depleted uranium and other toxic waste or pollution.

It should also be noted that, across the various human right mechanisms and bodies, there is no systematic approach to raising issues relevant to health, including cancer. This omission is symptomatic of the general lack of knowledge, information and advocacy surrounding these issues within the human rights system.

The number of references to issues relevant to cancer and NCDs by the treaty bodies
A closer look at the Universal Periodic Review (UPR)

Generally, recommendations on health are raised and accepted in the Universal Periodic Review (UPR). However, there is a lack of recommendations on cancer control and other NCDs.

UPR Recommendations

Despite this, the UPR could serve as a useful body for future engagement in that it applies to all Member States, considers human rights, is publicly available, and includes opportunity for civil society engagement. NGOs can submit information, e.g. regarding access to and availability of key cancer services, that can be referred to by any of the Member States taking part in the interactive discussion during the review.

More information is available on the countries to be considered at the next UPR sessions in May and September 2017.
Cancer and the right to health

This approach emphasises human dignity, the rights and needs of key and vulnerable populations and universal access to health systems. It requires removing all forms of discrimination, building capacity and accountability between state duty and patients’ rights, and bolstering awareness and empowerment around the rights of all in cancer control.

There are five key aspects to the right to health, all of which are relevant to cancer and other NCDs. These are:

1. An inclusive right: This not only covers access to healthcare and the development of infrastructure, but also factors that contribute to leading healthier lives. These are called ‘underlying determinants of health’. Differences in occupation, gender, ethnicity and education are linked to common cancer risk factors, including nutrition, tobacco use and alcohol consumption. As an example, age, gender and socioeconomic status are a few factors that make a person more vulnerable to developing alcohol problems, and, where there is risk for alcohol problems there is also higher risk for other risk factors, like tobacco use or limited physical activity.

2. Freedoms: These include being free from non-consensual medical treatment or free from torture and other cruel, inhuman or degrading treatment or punishment. For instance, withholding pain treatment can be considered a form of torture.

3. Entitlements: These include the right to a system of health protection (equal opportunity for everyone), which in the case of cancer would include the right to prevention, treatment and care covering access to essential medicines, equal and timely access to basic health services, as well as health-related education and information.

4. Non-discrimination: Health services, goods and facilities must be provided to persons without discrimination of any kind. For instance, in the United Kingdom, efforts have been made to recognise cancer as a disability so that patients and survivors are covered under the Equality Act, formerly known as the Disability Discrimination Act. This Act is to protect against discrimination in the workplace and in education.

5. All services, goods and facilities must be available, accessible, acceptable and of good quality: These include functioning health facilities as well as goods and services in sufficient quantity, that respect medical ethics are gender sensitive, and that are accessible physically, financially and on the basis of non-discrimination. In cancer, the disparities in access to quality, diagnosis, treatment and care, both within and between countries, are stark. Patients in high-income countries, which account for only 17% of the global population, consume 92% of global medical morphine (UNODC 2014). Furthermore, 80% of cancer patients in low- and middle-income countries have access to only 5% of the world’s radiotherapy.

“A human rights-based approach (HRBA) aims to support better and more sustainable development outcomes by analysing and addressing the inequalities, discriminatory practices (de jure and de facto) and unjust power relations which are often at the heart of development problems.”

Developing a rights-based approach to cancer control advocacy
The added value of a human rights-based approach to cancer advocacy

Cancer is both a public health and a human rights concern. As a combined approach, there is potential to address structural barriers, raise awareness and foster political will to better prevent, detect, diagnose, treat and palliate, while simultaneously producing improvements in service delivery, equity and equality, and service availability to key and vulnerable populations.

The UN human rights system could be used to support cancer control advocacy in three key ways:

1. **Standard setting:** Ensure that any interpretations of States’ obligations on the right to health (e.g. general comments/recommendations or technical guidance) cover issues relevant to cancer control.

2. **Awareness raising:** Ensure that the human rights dimension of cancer control is understood by relevant stakeholders, including treaty bodies and diplomats involved in the HRC and UPR.

3. **Holding Member States to account:** Ensure that Member States receive recommendations from human rights mechanism and bodies on the measures they should take to address cancer from a rights-based approach and that they implement these recommendations.

We have already seen some success in using a HRBA, including in the palliative care space. A HRBA approach was applied to expanding access to pain medicines in India, Kenya and Ukraine13, focusing on four strategies:

1. **Making the voices of those affected heard** through testimony used to humanise the issue first-hand.

2. **Identifying and analysing the structural barriers** that prevent people from accessing palliative care or pain relief.

3. **Clarifying a government’s core obligations** to make the link between their responsibility to health and human rights clearer.

4. **Advocating for change at different levels** to introduce pressure through direct engagement with government officials and by creating public pressure through media.

Through these efforts, further civil society engagement was stimulated, in addition to more high-level political leadership that fostered the implementation of human rights-based palliative care programmes. For example, in Ukraine, a 2011 report found that, while hundreds of thousands of Ukrainians needed palliative care, few had access, and just as few medical students and physicians were trained in the basic principles of pain management. Advocacy and awareness allowed Ukraine to improve access to morphine and, in 2013, oral morphine was registered as an approved medicine. Palliative care was integrated into national HIV, TB and cancer control programmes and a national pain treatment protocol was disseminated.

Emerging opportunities for a rights-based approach to cancer advocacy

In addition to the opportunities outlined above, such as the Universal Periodic Review and the treaty bodies reporting processes, over the last two years, we have seen the emergence of new opportunities to strengthen the link between a public health and rights-based approach to cancer, including the establishment of the **UN Interagency Task Force on the Prevention and Control of NCDs**, whose membership includes the Office of the High Commission on Human Rights (OHCHR). The framework for monitoring the Sustainable Development Goals (SDGs) also creates a new route to explore how UN human rights bodies and mechanisms can monitor state implementation of human rights obligations, which is linked to the goal of promoting healthy lives and wellbeing for all.

In light of these new mechanisms and the growing recognition of health as a human rights issue that is central to the post-2015 development agenda, the cancer community has a unique opportunity to begin developing a stronger human rights approach that can bolster advocacy actions at global and national levels.
If you are already using a rights-based approach to advocacy in your work, or would like to learn more, we would like to hear from you.

Please contact UICC’s advocacy team: advocacy@uicc.org

Here are some useful questions to consider when exploring the development of a rights-based approach to your advocacy:

1. Are other advocacy strategies working or would a rights-based approach contribute to addressing some of the biggest barriers?
2. Which advocacy objectives would benefit from using a rights-based approach and why?
3. Should a rights-based approach be used at national level, international level or both?
4. What is the added value of focusing on more political mechanisms (HRC and UPR) or treaty-based ones (treaty bodies) or other independent experts (special procedures)?
5. Financial and human resources:
   a. What is the most effective way of using the resources to achieve the advocacy objectives?
   b. Which are the most relevant bodies or mechanisms with which to engage to achieve these objectives?
   c. How can your members or partners be involved?

1. World Health Organization Constitution (1948)
4. The communications provide a way for victims of alleged violations to bring their cases to international level when they cannot get redress in their country.
6. See the concluding observations for Iraq (CRC/C/IRQ/CO/2-4) and Turkmenistan (CRC/C/TKM/CO/2-4)
7. OHCHR. Study on the impact of the world drug problem on the enjoyment of human rights