

Driving Equitable Access to Cancer Services Through the Engagement of People Living With Cancer: Regional Perspectives

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The participation of patients in all health-related decision making at the community, national, and international levels¹ is increasingly recognized around the world, particularly with the current codevelopment by WHO of a Framework for Meaningful Engagement of People Living with noncommunicable diseases and Mental Health Conditions. This shift in the last decades from the traditional understanding of patients as merely recipients of health care services to their conceptualization as active participants in all aspects of their health is critical to ensure equitable access to cancer care as part of the right to health.² Despite its central importance in the design and implementation of cancer policies and services, the participation of patients and their representatives in cancer policies is still nonexistent or nascent in many low- and middle-income countries (LMICs).³ There is insufficient literature addressing the level of involvement of cancer patient organizations (CPOs) in national cancer policies and challenges and opportunities to improve the representation of those organizations in policy dialogues in LMICs.

We explore some of these questions building on the experience and insights of participants in a capacity building program for CPOs from Asia-Pacific and Eastern Mediterranean supported by the Union for International Cancer Control (UICC). This commentary is primarily based on an annual survey with two cohorts of CPOs from these regions (n = 29), qualitative interviews with a subset of representatives of those cohorts (n = 7), and a dedicated analysis of national cancer control plans. In light of these data, we call for further investment in evidence-based capacity building to ensure that the voice of people living with cancers is sustainably considered through CPOs as a key criterion for the assessment of equitable access to cancer care in LMICs.

Engagement of Patient Organizations in Cancer Policies

In the annual survey that UICC conducted to measure the engagement with the CPOs participating in the Patient Group Mentoring Program (PGMP) from 21 countries in the Asia-Pacific and the Eastern Mediterranean regions, about 67% of respondents (n = 17)

reported that they took part in national policy dialogues. However, there are important variations for levels of engagement reported by CPOs, ranging from an absence of engagement to a strong legal recognition of CPOs as stakeholders in cancer policies. Although the practice suggests that CPOs engage with and have an influence on cancer policies, there is a low level of institutionalization of this engagement. About half of the interviewees reported that institutionalization of CPO engagement is absent or very low. Most national frameworks do not appear to include participatory approaches and such engagements seem to remain informal. For example, in Indonesia, a study mentions the informal participation of CPOs in the decision making processes for health technology assessments and their indirect influence on the listing of the national health formulary for new and high-cost medicines such as trastuzumab for breast cancer through collaboration with medical associations.⁴

A number of barriers hinder the meaningful participation of CPOs in the design and implementation of cancer policies. In many LMICs, CPOs might not be registered as independent legal entities or might face many hurdles in setting up and running local associations. According to one of the respondents, “without a clear normative framework for patient groups and no specific recognition of our public mission and representativeness, it is difficult to access funding and meaningfully participate in policies.”

Owing to their focus and priority in addressing key challenges in access to care, CPOs tend to have little time and resources to engage in policies in fragile or conflict settings. An example is the situation in the Palestinian territories where patients with cancer in Gaza face restrictions and blockades imposed by Israel. To leave the Gaza Strip, patients and companions need a permit and the whole process of application and waiting causes severe anxiety, with many unable to access critical, sometimes life-saving treatments.⁵ Support groups for Palestinians are few and far between whether in the Gaza Strip or the West Bank. They are all grassroots

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organizations and suffer from a lack of finances, human resources, and strategic planning.

Another reported critical barrier is the lack of health literacy and knowledge about policies. This leads to a lack of confidence, which is sometimes linked with the cultural reluctance to challenge medical or technical aspects of cancer control, which in turn hinders participation or advocacy. As one respondent highlighted, “patients don’t consider themselves as experts, so it is easy to not be considered in the conversations.” According to other respondents, “patients’ attitude is not to raise their voice to be perceived as complaining.” As CPOs are led by patients, this lack of confidence or perceived credibility constitutes a critical barrier to engagement. Another important perceived barrier is the alleged reluctance of policymakers to include CPOs representation or to consult them in decision-making processes. As one respondent observed, “patients are not culturally considered as competent in health issues, they might be invited sometimes but their voice is not heard.” Another respondent pointed out that “they don’t listen to the patient voice, they just decide on the basis of professional views.”

The absence or weaknesses of cancer policies in LMICs are often due to wider systemic barriers. Without an overarching framework for cancer control, such as a national strategy, there is limited room for the institutionalization of participation.

Toward Further Recognition in National Cancer Control Plans

The recognition of the role of patients’ representatives within national strategic public health instruments, such as national cancer or noncommunicable diseases control plans, is a critical step toward the institutionalization of the inclusion of the voice of people living with cancer in policymaking.

According to the global review of a data set of 159 national cancer control plans conducted in the context of the International Cancer Control Partnership (ICCP),⁶ there is a high proportion (77%) of national plans that recognize the empowerment of individuals, families, and communities as part of national strategies. However, despite this general recognition, there are very few plans that concretely institutionalize CPOs participation.

The National Integrated Cancer Control Act (NICCA) in The Philippines represents a major step toward institutionalized CPO engagement. The NICCA established “mechanisms and platforms for patient, family, and community engagement, especially on protection and promotion of the rights of patients, survivors, and their families and their active involvement in multidisciplinary patient care, patient navigation, and survivor’s follow-up care.”⁷ The cancer committee, in charge of the implementation of NICCA, also includes the representation of patient groups. CPOs continue to advocate for further implementation of this recognition.⁸

Although the specific health strategies do not include a reference to patient participation in some countries, such as Indonesia or Algeria, CPOs use the opportunity recognized in broader national legislation on public engagement to provide input regarding the development of cancer prevention and control policies, particularly through public hearings in Parliaments and broader legislations on public participation in decision-making processes.⁹

Investing in Capacity Building for Meaningful Involvement

Capacity building in health literacy, research processes, and policy-related topics has significant potential for the improvement of patient engagement. As one of the respondents stressed, “it is of utmost importance that patient groups empower themselves to be considered as an expert voice and gain credibility with policymakers.” The development of models that are culturally appropriate and adaptable to local needs, such as guidelines or step-by-step methods for engagement that could be replicated at the national or local levels and codesigned with CPOs and policymakers, could significantly help with the process of institutionalization of CPO engagement in LMICs.

Several dedicated capacity-building initiatives exist for patient groups to consolidate organizational competencies and build research and development literacy. Academic initiatives have developed curricula to train and offer credentials to expert patients engaged in patient groups, strengthening their knowledge, skills, and confidence. A systematic mapping of these initiatives, including through train the trainer approaches, available to CPOs and other stakeholders would facilitate access to such opportunities and maximize their impact.

One of the most frequently mentioned themes by CPOs leaders is the importance of data for patient engagement. Specifically, CPOs are increasingly willing to engage in conducting research themselves, to collect, analyze, and share evidence on the needs of patients, communities, and populations that they represent. In contexts where data on cancer services are scarce, CPOs have the opportunity to position themselves as experts, gaining credibility to inform the development and implementation of cancer policies. As knowledge producers, CPOs can play “an important role in opening the route to the policymaking table, especially but not exclusively in countries where the participation of patients, users, and consumers to the governance of health issues has not been much institutionalized.”¹⁰

Finally, academic initiatives such as the Health Democracy Index¹¹ developed primarily in the European context to measure patient engagement in policies could be used in LMICs to help inform the development of capacity building programs. Lessons learnt from other disease areas, such as HIV/AIDS, can also provide the cancer community with inspiration, and working models to build capacity in participatory approaches to cancer policies. As sustainable funding

for CPOs also constitutes a key barrier for their engagement, a mapping of good practices implemented by countries to support CPOs might be a useful contribution.

The current momentum at the global level offers a unique opportunity to further encourage CPOs engagement in

LMICs. It is critical to further invest in nationally led and evidence-based capacity-building activities to ensure that CPOs are recognized as a critical voice in national cancer policies in LMICs as part of the right to health but also as a prerequisite to quality cancer policies.

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