

cancer control stories

from UICC members



## **About UICC**

The Union for International Cancer Control (UICC) is the largest global membership organisation dedicated to taking action against cancer. Founded in 1933 and based in Geneva, UICC has over 1200 member organisations in 172 countries and territories. UICC's mission is to unite and support the cancer community to reduce the global cancer burden, to promote greater equity in cancer control and to ensure that cancer continues to be a priority in the world health and development agenda.

## **Cancer control**

## advocacy

In line with its mission, UICC is committed to working with the cancer community around the world to advocate and influence the global agenda, ensuring that cancer control receives the necessary attention and is addressed in the relevant declarations and meetings at the highest political levels. Concurrently, UICC supports its members to advocate for the implementation and adoption of international commitments and targets at the national level, providing tools and guidance to support member organisations to shape their own national advocacy efforts.

Although there is no single correct way to perform advocacy, there are common principles and strategies that underpin successful advocacy efforts. The following stories from UICC members and cancer advocates, whilst specific to particular countries and areas of cancer control, illustrate how these common principles can be applied across different contexts.



## **UICC Cancer**

## **Advocates programme**

UICC's Cancer Advocates programme provides an opportunity for civil society organisations (CSOs) from low- and middle-income countries to gain the skills and knowledge to engage in national advocacy efforts for improved cancer control. Supported by an Advisory Group of internationally renowned experts, UICC member organisations benefit from technical and skills-based training, access to a multidisciplinary pool of mentors, and peer-to-peer learning opportunities in English, French and Spanish.

A pre-requisite for application to the Cancer Advocates programme is completion of the Master course 'Advocacy for improved cancer control', part of UICC's online learning offer. The course provides foundational knowledge on building effective networks and coalitions, engaging key decision-makers in effective advocacy, securing financial resources and reviewing and monitoring progress, using comprehensive toolkits to guide users through a 10-point action plan to drive change.

The one-year programme supports organisations to:



Activate networks and build national coalitions to support a shared advocacy goal.



Advocate for improved cancer control, including the ability to frame advocacy efforts in the broader health system context.



Address health and social inequities through engagement of key decision makers, including national governments

## The 10-point action plan

Aligned with the framework of the Cancer Advocates programme toolkits, the plan outlined below is designed to help support organisations to develop advocacy efforts, and guide the strategic process of influencing governments, decision makers and other key stakeholders to create the commitments, policies, resources and frameworks needed to create change.

The foundation of successful advocacy is a clear and comprehensive strategy. The following steps do not have to be addressed in a specific order but it is important to thoroughly understand them in order to identify the most pertinent objectives and effective actions.



1 Form a coalition 2 Identify the advocacy issue 3 Develop the advocacy goal 4 Set the advocacy objectives 5 Map decision makers and influencers 6 Craft compelling messages 7 Determine the activities and milestones 8 Analyse resource needs 9 Develop a fundraising strategy

Apply a monitoring, evaluation and learning (MEL) framework

10

### **Success stories**



The following stories share real-life examples of advocacy in action, profiling UICC members who have enhanced their skills and knowledge through the Cancer Advocates programme.

### **Tajikistan**

Advocating for the rights of older patients in accessing quality palliative care



### Fiji

Enhancing tobacco cessation services in support of the WHO Framework Convention on Tobacco Control



#### Lebanon

Laying the foundation for a National Childhood Cancer Control Strategy



### **Costa Rica**

Patient support services to national breast cancer advocacy: expanding influence and impact



### Senegal

Uniting as a coalition to influence national cancer control policies







Tajikistan

# Advocating for the rights of older patients in accessing quality palliative care

Access to diagnosis, treatment, and care services tailored to the needs of older adults is marked by significant inequities within and between countries. The geographical location of Tajikistan and its severe climatic conditions limit the population's ability to access information and vital services, and adhere to treatment regimens.

Key barriers to providing palliative care to the ageing population in Tajikistan is the lack of information available to primary health care providers regarding international standards, and of local legal frameworks supporting the provision of home-based palliative care for cancer patients. These barriers, coupled with the high costs of treatment and care relative to the senior citizen's pension benefit, contribute to the violation of patients' rights in accessing quality, affordable palliative care and essential medicines, including for elderly patients with NCDs and cancer patients.

NGO Avesto, a UICC member organisation, identified the need to advocate for the rights of patients over 65 years of age to access quality palliative care at home. Their objectives included addressing the economic accessibility of treatment and care for older people, strengthening muti-disciplinary collaboration with the inclusion of patient voices, and the provision of quality palliative care in the country's primary healthcare institutions.

To align interests and foster collaborative relationships, NGO Avesto gathered Ministries, members of Parliament, patient groups and public organisations for a roundtable discussion to discuss palliative care access issues for the ageing population. The multi-disciplinary group of stakeholders were also engaged in drafting the *Recommendations for organising palliative care at the primary healthcare level*, which were subsequently developed and approved by the Ministry of Health and Social Protection Republic of Tajikistan.



The advocacy work of NGO Avesto resulted in an increased allocation in the 2022 health budget for cancer treatment for patients over 65 years and other low-income segments of the population. They credit the power of patient voices in influencing the Ministry of Finance, as they were included in working meetings with key stakeholders in line with WHO's Nothing for Us, Without Us report.

To build capacity of the primary healthcare institutions, training was organised for family doctors and managers in the provision of quality palliative care.

Palliative care training, including for the ageing population, is now incorporated into the State Medical University's curriculum, and is a compulsory subject at all eleven nursing schools and four medical colleges in the country.

As evidenced, a key element of their advocacy strategy was developing a partnership with patient groups and empowering their voices as influencers. Through meetings with patient groups, NGO Avesto reached 2,500 and up to an additional six million through awareness campaigns disseminated through the state TV channel.



### Map decision makers and influencers

Consider which policy making body or organisation has decision making power to implement the desired change and map out stakeholders who are able to influence the success of the advocacy strategy. Consider cross-sectoral players, working in education, finance or other health areas. NGO Avesto strategically engaged the Ministries of Health, Education and Finance in their advocacy, and the National Parliament, Women and Family Affairs Committee and patient groups.

### Determine the activities and milestones

A well-designed plan of activities that leverages key advocacy moments will support the dissemination of advocacy messages and engagement of key stakeholders to achieve the objectives. NGO Avesto were methodical in creating a timeline of activities that leveraged key decision-making milestones that proved vital in achieving these advocacy wins.





## Enhancing tobacco cessation services and implementing the WHO Framework Convention on Tobacco Control

The World Health Organization (WHO) Framework Convention on Tobacco Control (WHO FCTC) was developed in response to the globalisation of the tobacco epidemic with the aim to reduce tobacco use in all forms worldwide. Despite the commitment of Pacific island countries to implement tobacco control measures in line with the objectives of the Convention, tobacco use remained the leading preventable cause of non-communicable diseases in the region in 2018, when the Fiji Cancer Society began working on tobacco control.

Fiji Cancer Society was invited by the WHO Division of Pacific Technical Support to complete the Tobacco Industry Interference Index, a tool for governments and nongovernmental organisations to monitor the types and extent of industry interference in their countries and strengthen their ability to protect public health interests. Through this work and their collaboration with WHO, Fiji Cancer Society identified the need to strengthen tobacco control, incorporating the development of a strategic plan, as a new focus of their advocacy goals.

As tobacco control was a new area of work for Fiji Cancer Society, they identified several gaps in their resources, such as relationships, evidence and knowledge of tobacco, which were needed to advance their advocacy strategy. In response, they created a partnership with the Hope Clinic Fiji, received technical support from the WHO, and attended tobacco control workshops and conferences to better understand the landscape and how Fiji's response to tobacco control compared to others in the region.

A key element of Fiji Cancer Society's advocacy work was conducting carbon monoxide breath tests for smokers and tobacco cessation campaigns during their outreach programmes.



At the time of initiation, there were no cessation services available so the partnership with Hope Clinic Fiji was vital in pooling resources to provide healthcare workers and establish follow-up cessation services and counselling.

Through individual interviews, Fiji Cancer Society strengthened their relationship with the government, and specifically with the Ministry of Health's Tobacco Control Unit. They supported the need for investments in health to prevent economic loss, through the protection of livelihoods, food sources, shelter and disease prevention. CSOs are recognised in Fiji as integral to the health and

humanitarian agendas, and as a result of their positive impact and influence, Fiji Cancer Society was invited to develop the National Tobacco Control Strategic Plan, currently in its final draft, together with other key stakeholders.

In 2022, four years after including tobacco control in their advocacy work, the Fiji Cancer Society and Hope Clinic Fiji jointly received the World No Tobacco Day award. The WHO award recognises individuals or organisations who have made an outstanding contribution to the advancement of tobacco policies and measures.



### Develop the advocacy goal

Prioritise one specific goal that would benefit from advocacy and can realistically be achieved. The goal should align with broader organisational commitments and include targets and timelines. Recognising the impact of tobacco use, and in line with the WHO Framework Convention on Tobacco Control, Fiji Cancer Society identified the goal of advocating for a National Tobacco Control Strategic Plan.

### Analyse resource needs

Identify potential operational, political or technical risks to mitigate their impact. Gaps in resource needs may include evidence, relationships, policy materials or practical resources. Fiji Cancer Society recognised their lack of technical and human resources in tobacco control and leveraged partnerships and learning opportunities to strengthen their advocacy work.



Lebanon

# Laying the foundation for a National Childhood Cancer Control Strategy

In September 2018, WHO announced a new effort – the WHO Global Initiative for Childhood Cancer – with the goal of increasing the survival rate of children with cancer globally to at least 60% by 2030, thereby saving an additional one million lives. The objectives of the initiative focus on increased capacity of countries to provide quality services for children with cancer, and increased prioritisation of childhood cancer at the global, regional, and national levels. With that initiative in mind, the Children's Cancer Center of Lebanon (CCCL) identified the need to advocate for the development of a National Childhood Cancer Control Strategy and an associated three year National Plan.

CCCL initiated planning for their advocacy strategy by mapping key stakeholders, including the Ministries of Public Health and Finance, WHO, paediatric oncologists and healthcare workers, hospitals and medical centres, other civil society organisations, community leaders, childhood cancer survivors and their parents. They were successful in receiving confirmation from the Ministry of Public Health to develop the National Childhood Cancer Control Strategy, starting with the development of a childhood cancer registry, however economic crises and a revolution delayed their plans.

Advocacy is often not a linear path however progress can still be made towards the goal; during this period, CCCL continued to engage the stakeholders identified to highlight gaps in national childhood cancer control and raise awareness amongst influential leaders through annual meetings, a series of social media campaigns, World Cancer Day activities, and the creation of 'The Champions Circle', a community of childhood cancer patients and survivors.

The Champions Circle engages patients in advocacy activities through the power of storytelling. CCCL supports and empowers patients and their families by providing psychosocial support, training in soft skills, such as public speaking, and a platform for them to share their voices.





CCCL's fundraising strategy uses a variety of innovative methods, including a concept called Gift for Life, which channels the creativity and emotions of patients into artwork that can be bought or gifted as a donation. They also include more traditional methods in their fundraising strategy, such as gala dinners and networking events, which provide another platform for members of The Champions Circle to share their voices.

CCCL ensured they remained present and visible at the national level throughout the challenging political and economic landscape by engaging in the annual National Health Sector Meetings organised by WHO.

At the international level, they participated in the World Cancer Congress through the presentation of abstracts and organisation of a session focused on childhood cancer in Lebanon and how to reposition advocacy efforts in a post-pandemic health landscape.

By maintaining focus on their advocacy objectives, CCCL successfully retained relationships with key stakeholders and laid the foundation for the development of a National Childhood Cancer Control Strategy once the Ministry of Public Health reaffirms its approval.



### Set the advocacy objectives

Create specific, measurable, attainable, realistic and time-bound (SMART) objectives that support the overarching goal. Objectives may be long-term and focused on policy change or short-term, focused on interim steps. In Lebanon, the advocacy objectives set by CCCL served as a guide for their advocacy work amidst political and economic challenges in the country. Advocacy is often not a linear path, but CCCL has consistently achieved incremental steps towards their advocacy goal through continued alignment with their objectives.

### Develop a fundraising strategy

Fundraising is key to the success of a national advocacy strategy and the implementation of its activities. Fundraising refers not only to the money an organisation or coalition brings in, but also to the strategic relationships established to support a sustainable and impactful national advocacy strategy. CCCL, through its proactive and innovative fundraising strategy, invites diverse streams of financial support, from small individual donations to larger corporate sponsorship opportunities.



Costa Rica

# Patient support services to national breast cancer advocacy: Expanding influence and impact

Breast cancer is the most frequent cancer among women in Costa Rica. A breast cancer diagnosis is often accompanied by a series of challenges including changes to family dynamics, complications in the workplace and poor or non-existent social interactions, which can increase the vulnerability and affect the self-esteem of the individual diagnosed. These challenges are often intensified when breast cancer is metastatic, due to a lack of knowledge or understanding of such a diagnosis.

Unidos contra el Cáncer, formerly known as Tour Rosa, is a civil society organisation run by female cancer survivors and volunteers with the support of oncologists. Founded in 2012, their mission was to advocate for early diagnosis of breast cancer and provide a support network for women diagnosed with cancer, aimed at improving their quality of life and defending their rights.

Since then, Unidos contra el Cáncer has leveraged a number of opportunities to enhance their organisational capacity and impact. In 2018, the founder and President was awarded a UICC grant to visit Instituto Desiderata, a Brazilian advocacy NGO focused on strengthening the public health system to support early diagnosis and treatment for children and adolescents with cancer. The objective of the visit was to learn from them and apply best practices to the work of Unidos contra el Cáncer's to maximise the organisation's ability to influence public policy in Costa Rica in line with their mission to advocate for early diagnosis of breast cancer.

In 2019, Unidos contra el Cáncer were awarded a project grant by UICC's Seeding Progress and Resources for the Cancer Community (SPARC) MBC Challenge initiative for their project "Más Vida". The project responded to the organisation's goal to improve survival rates by enhancing psychosocial and psycho-oncological support to metastatic breast cancer patients by creating a 'Community of Women' support group. They strategically partnered with Hospital México in San José to recruit patients to attend the biweekly meetings and benefit from individualised support across an array of topic areas, including sexuality, nutrition, physiotherapy, treatment, alternative therapies, and psycho-oncology.

The COVID-19 pandemic and related economic instability created an urgent need to address new challenges posed by the pandemic for cancer patients, specifically access to treatment and transport services. Unidos contra el Cáncer adapted the planned activities of the Más Vida project to provide transportation, food assistance and hygiene products to patients, and transitioned to a virtual model for the support groups via an online community. The programme received recognition from the Government of Costa Rica for its important role in supporting patients and the model has been shared as a best practice example with the Latin America and Caribbean region to train other organisations in facilitating virtual support groups.

As a result of their growing influence and recognition of their contribution to reducing the burden of metastatic breast cancer, Unidos contra el Cáncer formed new relationships and avenues to advocate at the national level. In October 2022, they achieved a new advocacy win when the President of the Republic of Costa Rica signed a decree that requires mammographies on the waiting list to be performed within one month, and the screening age was reduced to women over 40 years old. Alexandra Nuñez, founder and President of Unidos contra el Cáncer, was also elected to sit on the National Council for Cancer and act as a patient representative in meetings with the Ministry of Health.





### Identify your advocacy issue

Conduct a situational analysis of the national context to identify the advocacy issue and the desired change. In Costa Rica, the data were clear that breast cancer is the most frequent cancer among women and the health system was not optimised to diagnose early-stage breast cancer patients. By reducing the screening age and ensuring timely diagnosis, in line with the second pillar of the WHO Global Breast Cancer Initiative, breast cancer mortality rates are expected to decline as breast cancer cases are increasingly diagnosed at an early stage.

### Apply a monitoring, evaluation and learning (MEL) framework

A well-designed MEL framework is critical in generating timely and reliable data on the implementation status of an advocacy strategy and its impact, providing the opportunity to review progress and apply learnings. In Costa Rica, Unidos contra el Cáncer reviewed their approach and ensured continued impact through the COVID-19 pandemic by reallocating resources to improve treatment access and services.



Senegal

# Uniting as a coalition to influence national cancer control policies

The Ministry of Health and Social Action of the Republic of Senegal estimate that cancer is one of the highest causes of death in the country with an annual mortality rate of approximately 70% amongst cancer patients. The most common cancers are women's cancers. The Senegalese League Against Cancer (LISCA), created in 1985, is a coalition of organisations working in the cancer field and other health areas in Senegal uniquely positioned to advocate for improved cancer control in the country.

Coalitions, as groups of people or organisations working together to achieve a common goal, can be a powerful conduit for driving change. The LISCA coalition includes cancer associations and organisations, associations of health professionals, women's health specialists, state nurses and other generalist associations with a vocation linked to cancer control. They have created an established relationship of trust with the Ministry of Health and work in collaboration with healthcare workers, social workers, academics, and organisations from other areas of health and the community.

In recent years, LISCA has conducted regular assessments to identify the strengths and areas for development for the coalition, including through specific UICC programmes and support, resulting in improved organisational capacity, and a refined strategy and advocacy goals. By evolving as a coalition, they have been able to expand their reach at the community level, implement large-scale, innovative projects, and access more resources.

In the long term, LISCA's advocacy work is focused on achieving free treatment for all cancers in Senegal. In recent years, they have focused on the early detection and prevention of women's cancers. As a coalition, LISCA has a powerful united voice and can adapt their advocacy messages to their audiences by drawing on their resources and influential representatives from across the network.





As a result of their collective advocacy, the Ministry of Health and Social Action introduced a policy in 2019 to provide free chemotherapy for breast and cervical cancers, and a 70% cost reduction in the cost of chemotherapy for other cancers. In 2020, breast and cervical cancer were made a public health priority, with a focus on prevention and screening.

In addition to its advocacy efforts, LISCA supports prevention and screening programmes. LISCA has trained more than 1,600 midwives in screening techniques for cervical and breast cancer across Senegal, with the aim to integrate screening for women's cancers within family planning services. In 2020, LISCA leveraged Pink October for an awareness raising campaign

on breast cancer prevention, which resulted in 6,180 women screened. In 2020, free cervical cancer screening was also provided to over 1,800 women, with follow-up of treatment for precancerous lesions.

More broadly, LISCA's advocacy work and collaboration with the Ministry of Health has resulted in the National Cancer Institute in Senegal, the Joliot-Curie Institute, tripling its capacity following the construction of a chemotherapy room and renovation of the hospital rooms. As a result of their remarkable work, LISCA was also announced as the recipient of a donation for oncology medicines, worth almost 850,000 USD in 2021.



### Form a coalition

Coalitions can be a vehicle for mobilising collective action and creating a strong movement. LISCA recognises the importance of assessing the individual strengths of coalition members, and leveraging this to shape its shared agenda, unique identity and value-add.

### Craft compelling messages

Advocacy should use convincing, clear and consistent messages grounded in evidence-based advocacy and adapted to the intended audience. The core messages should outline the problem, the solution, the course of action and why it is needed. Supporting messages can include economic arguments, success stories, and local context. LISCA utilises its resources and voice as a coalition to adapt the delivery of their messages by leveraging influential representatives and relationships within the coalition



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