

# Leadership in Action

## Asia Pacific region



A MEMBERSHIP ORGANISATION  
FIGHTING CANCER TOGETHER

## An initiative of the UICC CEO Programme

**27 March 2019, Singapore**

Launched in 2017, the Leadership in Action series are the regional expressions of the CEO Programme, UICC's flagship leadership development initiative providing a suite of tailored platforms and activities to CEOs and equivalent senior executives of cancer organisations from the UICC membership.

The second Leadership in Action meeting for the Asia-Pacific region took place on 27th March 2019 in the One Farrer Hotel, Singapore. Hosted by the Singapore Cancer Society, this exclusive meeting saw the participation of 42 CEOs, Directors, and senior executives from 40 different cancer organisations representing 19 countries in the Asia-Pacific region.

Building on the success from the first 'Leadership in Action meeting: Cancer Control in the Asia-Pacific region' in June 2017 in Seoul, Republic of Korea, and the following Regional Meeting during the World Cancer Congress 2018 in Kuala Lumpur, Malaysia, this second edition focused on key themes for the cancer community in the region such as Universal Health Coverage (UHC) and civil society mobilisation, alongside key interactive sessions such as the Expertise Marketplace, and the Public Private Dialogue, structured to further support the sharing of experiences and perspectives between participants and build networks.



### Sessions and speakers

#### Welcome address

- **Albert Ching** (CEO, Singapore Cancer Society)

#### Universal Health Coverage (UHC) sessions

- **Saunthari Somasundaram** (UICC Board Member and President, National Cancer Society Malaysia)
- **Sejal Mistry** (Senior Consultant, Access Health International)

#### Mobilising the community: the power of patient groups and volunteers

- **Jeff Dunn** (UICC Board Member and CEO, Prostate Cancer Foundation of Australia)
- **Ranjit Kaur Pritam Singh** (President, Breast Cancer Welfare Association Malaysia)
- **Ellil Mathiyan Lakshmanan** (Patient Ambassador, Singapore Cancer Society)

#### Expertise Marketplace – Sharing strengths and challenges on key organisational themes

- Breakout groups work

#### Public Private Dialogue - How can the patient become a real partner in shaping cancer care in the region?

- **Sheila Nair** (Director, Tata Trust)
- **Carlo Nalin** (Executive Director, Novartis)
- **Mary Wong-Hemrajani** (Chairperson, Global Chinese Breast Cancer Organizations Alliance)
- **Wang Ying-Wei** (Director General, Health Promotion Administration, Ministry of Health and Welfare - Taiwan)
- **Clarito Cairo Jr** (Programme Manager, Philippine Cancer Prevention and Control, Department of Health)

## Key learnings from

## presentations and discussions



The meeting started with an inspirational opening address from UICC's Board Member and President of the National Cancer Society Malaysia, Saunthari Somasundaram with a call to participants to work together to build a resilient regional cancer community, followed by a warm welcome message from Albert Ching, CEO of the Singapore Cancer Society and host organisation, sharing the impressive work of the Society in the Singaporean context and highlighting from his experience the value of the CEO programme in encouraging dialogue and support amongst leaders of cancer organisations.

### Setting the basis of Universal Health Coverage for Cancer Control - focus on innovative health financing

Sejal Mistry, Senior Consultant at Access Health International, opened the meeting by taking delegates through an introduction to UHC: why it matters; the position in the international development agenda; as well as the status in the Asia Pacific region.

In her presentation she elaborated on the importance of understanding how cancer fits in the UHC discussion, and the need for funding for cancer care to be embedded within a broader health system financing approach. She stressed how innovative financing initiatives can help improve the cancer response, and gave an overview of some innovative financing practices being introduced across the region.

“We need to advocate for increases in health financing – this will support cancer care and cancer financing” Sejal Mistry

The session also included case studies from the Philippines, with Maria Fatima Garcia Lorenzo, Kythe Foundation's CEO, sharing the journey of civil society in the lead up to the recently approved UHC bill, and from Mongolia, where Tsetsegsaikhan Batmunkh, CEO of the National Cancer Council of Mongolia, touched upon some of the challenges the country faces in terms of disparities in coverage of the population despite having a relatively well covered system.

### The role of civil society in achieving UHC in the Asia-Pacific region

Saunthari joined the conversation to put the focus on the role of civil society in the UHC discussion and the existing engagement mechanisms. She explored the three dimensions to be considered in order to advance towards UHC - the population (who is covered), services (which healthcare services are being covered), and direct costs (the proportion of costs covered) – and suggested some of the ways to approach them.

Evidence-based advocacy; engagement in decision-making; use of key opportunities for raising public awareness; patient support and counselling; and monitoring and accountability of coverage plans' implementation, were some of the key elements highlighted as means to influence UHC discussions at different levels.

“Advocacy is not about who can shout the loudest – it's how effective the message is that you want shared. The message can only be effective if it resonates with political leaders. And it will only resonate if it will impact them personally, or what they do.”  
Saunthari Somasundaram

The views of participants on UHC in their countries and the role of civil society organisations (CSOs) were gathered through a survey conducted by UICC prior to the meeting and complemented through a live consultation. Live poll questions prompted group discussions around two topics: the main barriers for CSOs to effectively impact on UHC, and the coordination (or lack thereof) of CSO's actions in their respective countries.

On the former, delegates identified credibility, perceived lack of professionalism, as well as shortages in funding and expertise, as some of the main drawbacks for civil society. On the latter, most participants acknowledged that CSOs were not well-coordinated, but discussions highlighted a growing willingness to act together, along with examples from participants where coordination mechanisms were proving effective.



## Mobilising the community, the power of patient groups and volunteers

Ranjit Kaur Pritam Singh, President, Breast Cancer Welfare Association Malaysia, provided an overview of the importance of volunteers/survivors for peer-to-peer support in the region, as well as related training requirements. She talked about the value of peer support for patients, the different ways this can be delivered, the limits that should be respected, and highlighted how an individual can train and become a volunteer for peer support.

“Well managed peer support groups have a positive impact on the quality of life of individuals affected by cancer.” **Ranjit Kaur Pritam Singh**

Echoing Ranjit, Ellil Mathiyen Lakshmanan, Patient Ambassador from the Singapore Cancer Society, gave an inspiring testimony of how patient support groups bring value in a variety of ways - increasing quality of life, not only of patients, but also caregivers, as well as inspiring communities and mobilising resources.

Finally, Jeff Dunn, UICC Board Member and CEO, Prostate Cancer Foundation of Australia, explored how civil society can mobilise the community, differing from the means used by government and private sector. The key to success, he noted, lies in focusing on three areas: strategic perspective (understand the environment and seek collaborations), develop capacities in terms of engaging volunteers, and scale-up activities through a clear mission and well-communicated messaging.

“We can't force society mobilisation. People come to us (civil society) because of a shared passion, values and mission” **Jeff Dunn**

To conclude, Jeff engaged with delegates to highlight, all together, priorities to consider when it comes to mobilise communities, namely: asking 'why' we seek to engage, providing a sense of inclusion and ownership, engaging communities as stakeholders, educating and creating awareness, ensuring proper communication, sharing and consolidating information, and collaborating with the private sector to increase the reach.

## Expertise marketplace: sharing expertise, strengthening collaborations among UICC members

The objective of this structured session was to provide a concrete and supportive opportunity for participants to engage in proactively exchanging and sharing knowledge and best practices, and through this, strengthen collaborations and networks in the region.

Participants were encouraged to identify their main challenges and expertise around six different topics: raising funds, managing people, engaging with policy-makers, managing projects and programmes, supporting patients and survivors, and leading and governing organisations, and participated in focused and facilitated small group discussions on these topics.

These conversations provided practical examples from other organisations or countries, showcased participants' experiences and challenges from their countries, and connected individuals. In order to support participants' continued engagement and collaboration following the event, an overview of opportunities available through UICC were presented including UICC fellowships, Young Leaders' programme and the Leadership Development Grants as part of the CEO programme.





## Public Private Dialogue - How can the patient become a real partner in shaping cancer care in the region?

### Background

UICC's Public Private Dialogue (PPD) series provides unique opportunities for UICC members and partners and other key stakeholders to engage in dialogue on key issues in cancer control and care and explore solutions and concrete areas for collaboration. Building on previous consultations with our members and partners and increased interest at our convening events, the PPD in Singapore addressed **how can patients become a real partner in shaping cancer care in the region**. With the global call for universal access to essential quality cancer care, there is a new imperative to put the patient at the centre of the cancer care continuum.

### Panel discussions: Multi-stakeholder perspectives

#### Evolution of the role of patients

The panel discussion kick started with Mary Wong-Hemrajani from the Global Chinese Breast Cancer Organizations Alliance which has an international reach, highlighting the importance of the cultural understanding and stressing the importance of having a shared, collective voice for the Chinese breast cancer community to improve patient care.

Carlo Nalin, Executive Director from Novartis shared a private sector perspective on how the industry has evolved from a physician and private sector focus towards a patient-centric approach, which prioritises patients in policy and develops a better understanding of their needs.

Furthermore, representatives from the public sector shared best practices from Taiwan and the Philippines. Wang Ying-Wei from the Health Promotion Administration, Ministry of Health and Welfare from Taiwan shared their focus on Engagement, Empowerment and Environment. Patients benefit from a national literacy plan through access to a platform for guidance and empowers them in decision-making. There has been a shift in the mindsets, with physicians and patients going through a shared decision process. The Ministry also supports the family and social environment of patients. Similarly, the Philippines is currently going through an impressive process following the adoption of the National Integrated Cancer Control Act on 14 February 2019.

Clarito Cairo Jr. from the Department of Health shared initiatives to involve patient groups together with other stakeholders to reach their shared vision of comprehensive cancer care and optimise cancer survival by 2025. For example, he shared that for the implementation of the National Integrated Cancer Control Act in the Philippines, a council of 11 members will include 3 civil society representatives involved in the decision making.

Sheila Nair from the Tata Trusts shared their work on improving basic infrastructure and the health economics situation in the country and on a recently setup section on cancer prevention and control. Patient groups are being set up in hospitals as a first step. She emphasized the need to train patients to contribute effectively in a patient advisory role to shape policy.

The role of technology and data to develop patient centric approach was emphasized.



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## Key finding from table discussions

### Main stakeholders

Governments were highlighted as a key stakeholder in raising the patient's voice. The private sector, insurance companies, civil society and patient groups also play an important role. The influencers also include the oncologists and the media who have a clear link with the legislators.

“All sectors need to have a deeper purpose – the private sector can't be just about making money”  
Mark Middleton, ICON

### Key barriers

The fragmentation of patient groups and CSOs and their different messaging was a key finding from all table discussions. When there are numerous civil society groups, competing with each other rather than working collaboratively, it can become a challenge for the Government to engage. The lack of advocacy capabilities negatively impacts on their credibility as a real partner. The lack of good data and use of evidence for patients' perspective was also mentioned as a barrier. There is also a lack of patient representation in the decision-making process. Furthermore, there is no solid consultative process where patient groups and private sector engage in dialogue.

### Actions to raise the patient voice

The importance of multisectoral partnerships to drive healthcare was discussed, as well as the need for a consultative process in all different stages including R&D. In Thailand, the government created an annual patient conference to input on concrete actions to improve the healthcare system.

It was also highlighted that stakeholders have different level of access to policy discussions, and it varies from countries to countries. Therefore, building multi-stakeholder coalitions or processes including the patients and patient advocacy groups, and leveraging on each other's strengths and knowledge was discussed as one of the next steps.

Additionally, given the many civil society groups, it was clear that more leadership in the patient advocacy space is needed to lead on the agenda and facilitate engagement with the government. It is also important to empower patient groups with the right information and tools, as well as professional advocacy capacity building to strengthen the effectiveness of their participation in policy discussions.

“Everything comes down to respect for the patient voice and anything we can do to make that possible in the future for better healthcare for patients” Carlo Nalin, Novartis

The potential for using big data to show evidence that would support the patient's voice was also an outcome of most discussions. It was suggested to develop a scorecard in hospitals to assess patient centricity that could also contribute in measuring progress and comparing different countries.

With the lack of adequate government funding on cancer, it was recommended that UICC play a key role in creating a common messaging to advocate and push governments to increase their healthcare budget. Treatment for All is one of UICC's initiatives that aims to build the professional advocacy capacity of civil societies. It seeks to build coalitions and equip UICC members with the right tools in countries, which was highlighted as a prerequisite to effectively advocate as a unified voice for cancer.



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## Summary and Next Steps



At the end of the meeting, it was noticeable across the participants that the discussions had provided a valuable first step in addressing some of the gaps for the cancer community in the region: support local leadership capacities with regionally relevant tools and connections, inspire organisations in engaging with a variety of stakeholders (patients, governments, private sector, as well as other CSOs), and provide platforms to address the willingness to coordinate CSOs both at the national and the regional level for common and concrete causes.

Positive feedback from participants showed a willingness to repeat regional gatherings, where the format and structure of the meeting allowed for relevant interactions and fruitful connections among members and partners.

Through its CEO Programme and other capacity building activities, UICC endeavours to continue providing the cancer community with the skills, knowledge, and networks to advance cancer control in their region. Please have a look at [our website](#) for the latest opportunities.

For further information about the Leadership in Action meetings, please contact the UICC Capacity Building regional team at [regionalcbb@uicc.org](mailto:regionalcbb@uicc.org)

If you are a UICC member, and are interested in hosting a Leadership in Action meeting in your region, please contact the UICC Members and Partners team at [hentsch@uicc.org](mailto:hentsch@uicc.org)

CC

*"I appreciate the wisdom of collective sharing and the networking between like-minded leaders from other countries. This facilitates future collaboration for common causes in the region"*

Melissa Lim, Brain Tumour Society – Singapore



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## List of participants



**Albert Ching**, Singapore Cancer Society, Singapore

**Angela Giselsvania**, National Cancer Control Committee of Indonesia, Indonesia

**Aru Sudoyo**, Indonesian Cancer Foundation, Indonesia

**Aryanthi Baramuli Putri**, Indonesian Cancer Information & Support Center Association (CISC), Indonesia

**Aung Naing Soe**, City Cancer Challenge, Myanmar

**Boon Lui Sew**, Society for Cancer Advocacy and Awareness Kuching (SCAN), Malaysia

**Camilo Cupitre**, MAKNA (Majlis Kanser Nasional), Malaysia

**Carlo Nalin**, Novartis, USA

**Carmen Auste**, Cancer Warriors Foundation, Philippines

**Cynthia Goh**, Asia Pacific Hospice Palliative Care Network, Singapore

**Fatima Lorenzo**, Kythe Foundation, Philippines

**Gautami Tadimalla**, Life Again Foundation, India

**Hongfei Gu**, House086, China

**Iris Leung**, The Hong Kong Anti-Cancer Society, Hong Kong

**Jorg Kreuzer**, Boehringer Ingelheim, Singapore

**Issarang Nuchprayoon**, Wishing Well Foundation, Thailand

**Jenny Zhang**, House086, China

**Juwairiya Saeed**, Cancer Society of Maldives, Maldives

**Karma Yangdon**, Tibetan Cancer Society, India

**Khin Thiri**, Pun Yaung Hnin Si (Pink Rose) Breast Cancer Patients Support Group, Myanmar

**Lena Abdullah**, National Cancer Society of Malaysia, Malaysia

**Maria Imaculada Guterres**, Alola Foundation, Timor Leste

**Mark Lin**, Singapore Cancer Society, Singapore

**Mark Middleton**, ICON, Australia

**Mary Wong-Hemrajani**, Global Chinese Breast Cancer Organizations Alliance, Hong Kong

**Mathilde Poiraudreau**, Sanofi, Singapore

**Matin Mellor Abdullah**, Malaysian Oncological Society, Malaysia

**Melissa Lim**, Brain Tumour Society, Singapore

**Mihir Shah**, MSD, Singapore

**Minying Zheng**, Shanghai Roots & Shoots, China

**Mohammed Zainul Abedin**, Aparajita Society Against Cancer, Bangladesh

**Murti Andriastuti**, Faculty of Medicine Universitas Indonesia, Indonesia

**Neil Wildman**, Pfizer, Australia

**Nur Aishah Mohd Taib**, University of Malaya, Malaysia

**Prashanth Bagali**, Diaceutics, India

**Preeti Manandhar**, Nepal Cancer Relief Society, Nepal

**Priscillar Napoleon**, Papua New Guinea Cancer Foundation, Papua New Guinea

**Ranjit Kaur Pritam Singh**, Breast Cancer Welfare Association Malaysia, Malaysia

**Rebecca Northridge**, Takeda, Singapore

**Rhys Fitzgerald**, ICON, Australia

**Sarbani Chakraborty**, Roche, Switzerland

**Sheila Nair**, Tata Trusts, India

**Shejila Chillakunnel Hussain Rawther**, Mims College of Nursing, India

**Siti Farida Shahar**, Yayasan Kanser Kanak-Kanak Brunei, Brunei

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**Tashi Dendup Wangdi**, Bhutan Cancer Society, Bhutan

**Thao Vu**, Bright Future Fund Vietnam, Vietnam

**Ti Hwei How**, AstraZeneca, Singapore

**Tingting Xu**, China Anti-Cancer Association, China

**Tom Fussaro**, Astellas, USA

**Tsetsegsaikhan Batmunkh**, National Cancer Council of Mongolia, Mongolia

**William Hwang**, National Cancer Centre Singapore, Singapore

**Wonyoung Jang**, Korea Blood Disease & Cancer Association, South Korea

**Yin Yin Htun**, Shwe Yaung Hnin Si Cancer Foundation Myanmar, Myanmar

## Sponsors



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