



IKCC Roundtable: Focus on Asia

29 November 2021

Welcome

IKCC Chair: [Dr Rachel Giles](#) (NL)

Dr Giles opened the virtual roundtable discussion by thanking everyone for attending and sharing their experiences. The aim of these discussions is to share best practices, learn from experiences, and formulate actions going forward. This is just the beginning of the conversation with the Asian patient organisations. It is an ideal opportunity to get to know each other and strengthen the IKCC Asian network for the future.

Session 1: Highlights ESMO Asia 2021

Speaker: [Dr Ravindran Kanesvaran](#) (SG)

Moderator: [Dr Eric Jonasch](#) (USA)

Dr Kanesvaran, head of medical oncology at the National Cancer Center in Singapore, summarised the highlights from the ESMO Asia Virtual Oncology Week 2021 in November. In most Asian countries (except Japan), there is a low incidence of kidney cancer due to limited testing and no screening. The mortality to incidence ratio is high. However, management of kidney cancer has recently moved on due to increased use of CT scans resulting in incidental detection, and adjuvant treatment.

Pembrolizumab as an adjuvant therapy

Nephrectomy is the standard of care for kidney cancer; however, the cancer can come back after surgery. Dr Kanesvaran described the results from the presentation about adjuvant therapy; treatment that is given after surgery to try to prevent the cancer from coming back.

The phase 3 KEYNOTE-564 trial looked at the use of pembrolizumab as an adjuvant therapy for patients with clear cell renal cell carcinoma (RCC) after nephrectomy. High risk previously untreated patients were randomly allocated to be given either pembrolizumab or placebo for one year and monitored for return of their cancer. Patients on pembrolizumab had longer disease-free survival compared to those on placebo by about 22%. More follow up is required to make any definitive conclusions about overall survival. This trial is practice changing, and pembrolizumab has just been approved in the USA by the Food and Drug Administration (FDA). However, it is not available in most Asian countries yet.

ESMO Asia RCC Guidelines

Guidelines for the treatment of kidney cancer exist in North America (American Society of Clinical Oncology (ASCO) and National Comprehensive Cancer Network (NCCN)) and Europe (European Society for Medical Oncology (ESMO)); however, currently there are no guidelines used widely in Asia. Most data for systemic treatments comes from western countries (although there were some clinical trial sites in Asia). These guidelines need to be adapted for an Asian population to achieve a more standardised approach to treatment of kidney cancer and help with the registration of new evidence-based medicines.

Dr Kanesvaran chairs a committee for the modification of the ESMO guidelines for Asian patients. The committee is made up from members of seven Asian oncology societies, as well as members from ESMO. The committee had their first meeting earlier this year. The guidelines cover diagnosis, pathology, staging, risk

assessment, biomarkers, treatment of localised and metastatic disease, treatment of non-clear cell RCC and follow-up. They surveyed experts in Asia for acceptability of the guidelines based on scientific evidence and applicability of standards of care for Asian patients. Applicability varied from country to country, e.g., local constraints such as availability of medicines, reimbursement etc. However, the guidelines were acceptable across Asia and will be published online next week. They will be updated regularly to keep up to date with the latest developments in the field.

There were some discrepancies regarding diagnosis and pathology/molecular biology, since not all tests are required in every Asian country, and differences in the local management of the disease, e.g., the use of biopsies in Japan. This resulted in modifications to the guidelines to reflect local practice. The recommendations in the guidelines could be used to lobby local government to improve the management of kidney cancer.

Discussion

Discussant: [Prof. Craig Gedye](#) (AU)

The data on adjuvant pembrolizumab treatment will change practice in Asia, but it will be dependent upon reimbursement of pembrolizumab by local healthcare systems. The drugs might be approved by the Asian regulatory bodies, but widespread use of the drugs will be restricted by cost. Adjuvant treatment could be de-escalated, i.e., the use of less doses to reduce overall cost; however, this will be driven by biomarkers to identify the patients who will benefit the most. Biomarkers to predict response to immunotherapy have not yet been identified.

Pan-Asian adaptation of the guidelines has identified some differences of opinion between countries. This presents an opportunity for researching these differences using real world data. For example, Chinese patients respond differently to TKIs with more side effects, and TKIs are not used as frequently in China. Funding for epidemiological studies is limited in Asia. It was suggested a consortium of countries come together to collect real world data to help with the development of kidney cancer guidelines.

Recommendation: IKCC to help build a consortium of patient organisations and local expert clinicians to collect and collate data to investigate heterogeneity in kidney cancer treatment within Asian countries. Dr Kanesvaran offered his assistance.

In Asia, the patient voice is not heard as it is in the West. The ESMO Asia RCC guidelines were developed without patient input. Patients need support to enable them to contribute. The patient voice is an important factor that is missing from the Asian guidelines.

Recommendation: IKCC to support patient groups through the translation and distribution of the ESMO Asia guidelines in local language.

Session 2: Asian perspective on patient engagement

Keynote speaker: [Lorna Warwick](#), [CEO Lymphoma Coalition](#)

Moderator: [Dr Michael Jewett](#) (CA)

Lessons learnt in Asia-Pacific lymphoma care

The Lymphoma Coalition consists of 83 patient organisations worldwide. Their vision is equity in lymphoma outcomes across borders, including the Asian countries. The Asia-Pacific region is made up of a collection of countries located in or near the Western Pacific Ocean. The population is immense, with over 60% of the global population living in Asia alone. Even within Asia, China and India remain the two largest countries in the world with roughly 37% of the world's people. There is diversity in socioeconomics, healthcare systems, beliefs, cultural practices, and how cancer is perceived and addressed.

For people with lymphomas specifically, all these factors contribute to wide-ranging availability and patterns of care. Barriers to care in lymphoma are varied and numerous and have huge impacts on patient experience and

outcomes. Best practices from the rest of the world do not always translate effectively in the Asia-Pacific region.

The Lymphoma Coalition commissioned a report on lymphoma care in the Asia-Pacific region. They analysed data from a global patient survey and outside sources, including interviews with patient organisations in Asia-Pacific countries.

The report highlighted differences in healthcare infrastructure between Asian countries, such as universal health coverage, national cancer control planning, health technology assessment and patient involvement in health technology appraisal. They discovered that universal health coverage means different things in different countries (e.g., private versus public healthcare systems). However, there is opportunity to improve equitable healthcare services in Asia.

Most countries have national cancer control plans and health technology assessment, but none allow patient input to the health technology appraisal process. All countries can make improvement in health technology assessment and access to medicines. There is inequity of access to treatments across Asia, for example India does not have access to modern lymphoma treatments. There is also little transparency regarding access to treatments, for example both the Philippines and Hong Kong do not publish health technology assessments.

The Lymphoma Coalition runs a global patient survey every 2 years. The 2020 survey had over 4,000 responses from Asian countries and 12,000 globally, dominated by China with the largest population. Adequate information about cancer is a key aspect of the patient experience. The top 3 sources of information were similar for Asian countries and the rest of the world, with 70-73% receiving information from their doctor, 64-66% from websites, and 36-39% from patient groups. China was slightly different, with more reliance on patient groups for information (51%) and less reliance on doctors (60%). Good communication with the healthcare team results in less psychosocial issues.

Around half of the patients in the rest of the world felt adequately informed about their cancer, 29% in Asia, and only 17% in China. This might result from the fact that in Asian countries patients are less likely to talk about psychosocial or emotional concerns with their doctor or healthcare team. Doctors do not encourage patients to talk about these issues in about two thirds of cases.

Less than half of patients in Asia reported being given the right information/diagnosis compared to 70% in the rest of the world. Most patients wanted more information about their treatment options, diagnosis, and side effects of treatment. Only a small number of patients had no psychosocial issues and psychosocial issues were reported at a higher rate than in Europe. This indicates the need for more support in these areas, particularly since patients do not discuss psychosocial issues with their doctors.

Half of the Asian patients reported at least one barrier to care, compared to 12% in Europe. The top three barriers to care were financial (82% from China, 31% from rest of Asia, 3% in Europe), treatment waiting times, and access to treatment. This creates high stress and financial toxicity.

Patient advocacy barriers include stigma of cancer, capacity of organisations, limited funding, and lack of data (especially clinical trials). This makes it difficult for patient groups to understand disease burden or advocate for better care. The value of the patient voice is an issue. Doctors are held in high esteem and their opinions are valued, while the patient voice is not. There is an absence of national and regional platforms since healthcare systems don't engage patients because it is seen as not culturally appropriate.

Recommended actions from the report included:

- Advocacy skill building – capacity building and training local patient organisations
 - Conduct detailed assessment of current policies and systems in each member country to fill current knowledge gaps
 - Audit each patient group to assess their ability to undertake meaningful advocacy and create a customised plan for how to address advocacy issues
 - Provide training and ongoing mentoring to members to enable them to build and action their advocacy plans
- Evidence-based advocacy – global patient surveys to guide advocacy work and projects

- Prepare reports using evidenced-based data to compare with global patient experience data
- Train patient advocates on how to use patient experience data effectively to improve patient advocacy
- Information – toolkits and customised data for local organisations to improve health literacy
 - Provide a platform for sharing best practices among member organisations and to learn from each other to extend and improve local capacity
 - Work with patient groups to develop medically validated materials and toolkits on key issues raised by patients and caregivers
- Collaboration – involving patient groups and patients with regional stakeholders, such as ESMO Asia
 - Identify regional stakeholders who are relevant and willing to partner with patient organisations
 - Establish a regional multi-stakeholder medical/clinical advisory board of influential clinical, patient, and academic leaders who are prepared to share ideas and knowledge and collaborate
 - Work with the pharmaceutical industry to highlight the importance of investing in this region and building capacity for patient groups.

From the report, there were several opportunities identified, such as:

- Using the patient advocacy gaps identified, working together to build strong patient advocacy skills
- There are a lot of programmes and models to learn from, but these need to be customised to Asia
- Patient engagement must be built into health technology, digital systems, clinical trials, guidelines, frameworks and structure, and the pivotal role of patient organisations must be recognised
- Building advocacy and engagement capability - all aspects of healthcare and delivery should include the patient voice
- Capacity building within patient organisations.

Discussion

The healthcare differences between Asia and the rest of the world seem to impact on patient outcomes/survival and toxicities of treatments. Higher rates of side effects were seen in Asian countries than other parts of the world. People experience more difficulty accessing care and treatment, and cancer diagnosis was delayed during the pandemic.

Session 3: Patient group experiences/challenges

Moderator: [Bryan Lewis](#) (USA)

Asia accounts for a third of the patient community worldwide. In this session, Asian patient organisations discuss their experiences and challenges.

India: [Vandana Gupta](#), [V Care Foundation](#)

The V Care Foundation's motto is "Together we can and together we will" for cancer patients. V Care helps cancer patients in whichever way they can. Their focus is on childcare support, nutritional support, supportive care, palliative care, emotional support, information booklets, patient assistance programmes to access medicines (supported by the pharmaceutical industry), and an information helpline.

One of the biggest challenges in India is funding for treatment. Patients don't want to admit they have cancer because of the additional costs for the family. Patient literacy is also an issue due to multiple languages, particularly in rural areas. Also, during the pandemic they were not able to do patient surveys and data analysis. Availability of patient advocates/volunteers has reduced their capacity to reach out to patients during the pandemic.

South Korea: [Jin Young Paik](#), [Korean Kidney Cancer Association](#)

The Korean Kidney Cancer Association (KKCA) started as an online 'café' in 2004 and became a non-profit corporation in 2020. They are the only kidney cancer patient organisation in Korea, and support 14,000

patients and carers. Korea has National Health Insurance Support where patients pay 5% of the total cost of treatment for their cancer and the government funds the remaining costs for 5 years.

KKCA is involved in disease education from experts and patients, counselling, and patient group meetings to provide information and support treatment. They also provide psychological care, such as art therapy and individual counselling, to improve the mental stability of patients, partnering with other cancer patient groups/committees to improve the treatment environment, policy improvements initiatives (especially related to funding), and collaborations with the pharmaceutical industry.

Malaysia: [Mei Ching Ong, The Max Foundation \(Max\)](#)

The mission of The Max Foundation is to accelerate health equity. Many cancer treatments are not available locally. All patients should be able to face their cancer with dignity and hope. The Max Foundation brings treatment to the patient, no matter where they live and at no cost. Currently, they support 30,000 patients.

The Max Foundation access solutions model (known as Max Access Solutions) include patient services, a network of doctors, donated medicines, and shipping and logistics at no cost to the patients wherever they live in the world. Many new treatments are not available in many countries around the world because of the view that cancer cannot be treated in the developing world. This is a broadly accepted belief that needs changing; it is no longer acceptable to leave these patients behind. Geography should not dictate a patient's destiny and we can prevent unnecessary suffering: 'Because we can, we must'.

Australia: [Belinda Jago, Bec's Troops](#)

Bec's Troops is a fundraising organisation for cancer clinical trials/research, cancer support, and improvement of services specifically for adolescent cancers. There is a specific emphasis on kidney cancer. In Australia, there is an advisory panel including the patient voice for new research ideas and trials. Bec's Troops also provide grants for small kidney cancer research projects/clinical trials.

The key challenge is fundraising. Ten years on from the inception of Bec's Troops, their fundraising circle has shrunk, and they are unable to keep asking the same donors. There is no formal kidney cancer organisation to support patients and families in Australia, only Facebook groups, and no government funding for these groups. Only the common cancers receive funding because of the large numbers of patients with these cancers. Pharmaceutical industry funding is not looked upon positively in Australia and can only be used for educational purposes. Australia has a good healthcare system, but limited access to new medicines because of the approval system. There is supportive care for serious diseases but there is still a long way to go. Limited funding is a big barrier for support organisations.

Japan: [Hiro Fukuda, AVEC and Nozomi Nonaka, JAMT](#)

In Japan, patient groups are very small. Advocacy activities include mostly peer support e.g., counselling, seminars and enlightenment activities, patient surveys and educational activities. Activities related to drug approval and development, government policy proposals, international relationships, and medical research are weak. In 2006 the Japanese Cancer Control Act was established to provide a cancer information service, and in 2011 the patient advocacy programme was started at a scientific meeting.

The key challenge for AVEC is financial. AVEC is not a charity, just a group: There are no membership fees, no dedicated staff, and they don't have a budget. Treatment costs are high, and the Japanese health insurance will pay 70%. However, patients pay about 30% out of their own pocket, which many can't afford. Also, there is a premium for health insurance dependent upon how much a person earns. There is also private health insurance. Japanese approved drugs are about 2-3 years behind US.

Philippines: [Fatima Garcia-Lorenzo, Philippine Alliance of Patient Organizations](#)

The Philippine Alliance of Patient Organizations is a coalition of disease specific organisations advocating for universal access to healthcare. They aim to empower Pilipino patients through education, networking, policy advocacy and capacity building. They advocate for reform in 3 fundamental areas: respect for patient's rights, universal access to healthcare, and patient participation in health policymaking to improve quality of healthcare. Their key activities are capacity building in healthcare and health technology assessment; participation in the Department of Health technical working groups; and they advocate for meaningful patient engagement.

Key challenges are fundraising, communication with patient leaders (limited technical knowledge for website and social media), public speaking to engage health leaders and government, and data gathering and research.

Bangladesh: [Dr Habibullah Talukder](#), [Bangladesh Community Oncology Trust](#)

The Bangladesh Community Oncology Trust is a non-profit, voluntary organisation dedicated to upholding the concept of community oncology for effective control of cancer. Activities include mass awareness for the prevention and early detection of cancer; community-based screening for certain cancers; promoting community participation in cancer care; and using online tools to provide cancer care to marginalised people using satellite community oncology clinics. They also have a support helpline for cancer patients and survivors, network with local, national, and international organisations, and get involved with national awareness campaigns for breast and cervical cancer.

Key challenges include a lack of national cancer control strategy/programme; only one hospital with a population-based cancer registry; no organised community-based national cancer screening programme; highly centralised cancer treatment facilities in the capital city; and a lack of health insurance (60% paid for by the patient).

Discussion

Several issues were highlighted during these presentations, such as limited funding, awareness through education and information, lack of data, access to treatments and the stigma of cancer.

The stigma of being a cancer patient in many Asian countries, especially India, can be an issue. In India, cancer patients are left in hospital because the family don't want them home or don't want others to know they have cancer. A diagnosis of cancer can lead to job loss and lack of marriage prospects. In the last couple of years there has been a change in attitudes, especially in urban areas; however, more needs to be done to address this. In Korea, the stigma of cancer patients is being addressed through social cooperation and the use of social media and regular meetings with cancer patients.

Lack of a patient voice is an issue in many low-income countries where cancer care is not well established and there are limited cancer guidelines. There needs to be a platform to bring patient voices together. As the ESMO Asia guidelines are rolled out, more countries will be keen to be involved and the patient voice will slowly grow. Currently there is no platform for patients in many of these countries, and some patients probably don't even know they have cancer.

Perception of cancer is changing as patient organisations grow and build awareness of cancer through campaigns. Patients need to understand that having cancer does not mean the end of their life.

Fundraising is a challenge for all Asia-Pacific countries, including medium-high income countries like Australia. Patient organisations need to reach out to the medical community and spread the word about access to new treatments. However, there are many small organisations that pop up but don't have the means to fundraise.

Kidney cancer research ignores many things that are important to patients, resulting in unmet care needs for patients, such as active surveillance for small renal masses. Researchers need to listen to patient advocates and develop research around those needs.

Data gathering from hundreds of islands and rural communities in the Philippines can be an issue due to the geography of the region. Researchers need to work with patient advocates and use technology to reach patient groups in other regions/islands.

Improved patient engagement improves outcomes. Physicians/clinicians have different approaches in different countries, and some don't understand patient engagement. Patients often have limited time with the doctor and need to be empowered to ask questions. This is happening in India, where patient advocates provide lists of questions that patients might want to ask their doctor. The doctor needs to use patient-friendly language to enable patients to engage with their own healthcare.

Online communication technology/tools can improve communication between doctor and patient and make it easier for the patient to ask about their treatment and care.

End of Meeting

IKCC Chair: [Dr Rachel Giles](#) (NL)

This is just the beginning of the conversation with the Asian patient groups. The IKCC would like to hear from these groups to learn from their experiences and address their needs. This has been a wonderful meeting to strengthen the Asia-Pacific network and we look forward to working together in the future.

Recommended actions for the IKCC

1. Help build a consortium of patient organisations and local expert clinicians to collect and collate data to investigate heterogeneity in kidney cancer treatment within Asian countries. Dr Kanesvaran offered his assistance with this project
2. Support patient groups through the translation and distribution of the ESMO Asia guidelines in local language
3. Survey Asian patients to identify the differences in healthcare systems, access to treatments, and funding of healthcare to guide advocacy work and future projects
4. Prepare information toolkits and materials customised (and translated) for local patient organisations to improve health literacy and share best practices
5. Training of local patient organisations to undertake meaningful advocacy and create a customised plan for how to address local advocacy issues and strengthen the patient voice
6. Assist local patient organisations to build collaborations with regional stakeholders, such as ESMO Asia and the pharmaceutical industry, to strengthen the patient voice in the development of guidelines and clinical trials.