

ESMO PATIENT ENGAGEMENT SUMMIT

An ESMO Meeting

Advancing cancer care in the Asia-Pacific region





The ESMO Patient Engagement Summit (PES)

This groundbreaking event will bring together patient representatives, policy makers, thought leaders, healthcare professionals, and corporate partners to identify the opportunities and challenges facing patients with cancer across the Asia-Pacific region.

6th-8th December, Suntec Singapore.

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Access to diagnosis and treatment

1. Access to diagnosis and treatment: Opportunities

Question 1: Top five themes covering opportunities in the region for patients with cancer in terms of access to diagnosis and treatment

1. Government Initiatives and Policy Reforms

Many countries are seeing the implementation or strengthening of national cancer control policies and healthcare reforms. Examples include:

- National Lung Cancer Screening Program in Taiwan and the Myanmar National Cancer Control Strategic Action Plan (2023-2027).
- Philippines' National Integrated Cancer Control Act (NICCA) and Vietnam's cancer screening initiatives.

2. Expansion of Healthcare Infrastructure

Several countries are expanding the number of specialised cancer treatment centres, improving geographic access for patients. Examples include:

- Vietnam's growing cancer treatment centers and Pakistan's specialised cancer hospitals.
- Australia's cancer nursing initiatives to provide more access to specialised support.

3. Health Insurance and Financial Support

Increasing coverage through national health insurance systems and financial support programs helps reduce the financial burden of cancer treatment:

- South Korea has seen expanded health insurance coverage for diagnostic tests and treatments.
- Pakistan's free and subsidised healthcare programmes

4. Advances in Science and Technology

There is a growing focus on personalised medicine, genomic profiling, and international collaborations that offer access to advanced treatments:

- Australia's investment in personalised medicine
- Digital health advancements, like telemedicine, are enhancing care for rural patients.

5. Awareness and Early Detection Campaigns

Efforts to increase public awareness and early detection are significant opportunities for improving outcomes:

- Breast and cervical cancer awareness campaigns in Vietnam and Pakistan.
- National screening programs in several countries are making early detection more accessible.

These themes reflect the growing opportunities for cancer patients in terms of improved infrastructure, financial access, advanced treatments, and early detection programmes.

2. Access to diagnosis and treatment: Challenges

Question 2: Top five themes covering challenges in the region for patients with cancer in terms of access to diagnosis and treatment

1. Geographic Disparities and Rural Access

The difficulty patients in rural or remote areas face in accessing specialised cancer care. Challenges include long travel distances, high travel costs, and the concentration of medical resources in urban areas:

- Vietnam, Philippines, and Australia face significant geographic barriers where advanced cancer centers are primarily located in cities.
- Patients in rural areas often experience delays in diagnosis and treatment due to these challenges.

2. High Cost of Treatment and Financial Toxicity

The high costs of cancer treatment, particularly for advanced therapies, continue to be a significant burden, even when national insurance programmes exist.

- Pakistan, Vietnam, South Korea, and others mention the prohibitive costs of treatments like chemotherapy, targeted therapies, and immunotherapies, often requiring out-of-pocket payments that many cannot afford.
- Limited health insurance coverage or lack of access to financial aid exacerbates the financial strain for families.

3. Shortage of Oncologists and Healthcare Workforce

There is a shortage of trained oncologists, specialised nurses, and other cancer care professionals in many regions, leading to overburdened healthcare systems and long waiting times:

- Many countries are affected by a lack of oncologists, especially in rural areas, resulting in delays in diagnosis and treatment.

4. Late Diagnosis and Low Awareness

Late cancer diagnosis remains a major issue due to limited awareness about cancer symptoms, lack of comprehensive screening programmes, and delays in seeking medical attention:

- Vietnam and South Korea report low early detection rates for certain cancers like lung cancer.
- Stigma surrounding cancer, lack of education, and limited awareness campaigns prevent people from seeking timely care, especially in LMICs & among marginalised populations.

5. Overburdened and Inequitable Healthcare Systems

Many countries experience inequities in care and overburdened healthcare systems that struggle to meet the needs of all patients with cancer:

- Overcrowded cancer centers in urban areas and long waiting times for treatment create delays.
- Inequity in care is also notable for populations in rural and remote areas, indigenous communities, and marginalised groups, particularly in Australia and Japan.

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Prevention

Question 3: Top five themes covering opportunities in the region for patients with cancer in terms of prevention

1. Government-Supported Screening Programmes

Expanding access to cancer screening is a key opportunity. Several countries have implemented or are enhancing screening programmes for various cancers, aiming to improve early detection rates:

- Taiwan offers free screening for five types of cancer, and Vietnam and Pakistan have implemented screening programmes for cervical, breast, and colorectal cancers.
- These initiatives provide an opportunity to reduce late-stage cancer diagnoses and improve outcomes through early intervention.

2. Vaccination Programmes

Vaccination programmes, particularly for HPV and hepatitis B, present a significant opportunity for cancer prevention by addressing preventable cancers:

- Vietnam, Pakistan, and other countries are increasing access to HPV vaccines to prevent cervical cancer, and hepatitis B vaccinations to reduce liver cancer risk.
- These programmes are effective preventive measures that can reduce the incidence of two of the most common cancers.

3. Public Awareness Campaigns and Health Education

Public health campaigns focusing on lifestyle changes, cancer risks, and early detection are expanding in several regions. These campaigns aim to educate the public on the importance of prevention:

- Vietnam, Australia, and Pakistan have rising national awareness initiatives around cancer prevention, smoking cessation, and early detection through lifestyle changes and self-examinations.
- Increased awareness and public education offer opportunities to reduce cancer risks and encourage proactive health behaviours.

4. Tobacco Control and Lifestyle Interventions

Tobacco control measures, such as smoking cessation programmes, anti-smoking campaigns, and stricter regulations, present a key opportunity to reduce cancer risk:

- National Tobacco Strategies in countries like Australia focus on reducing smoking rates, while Vietnam has laws focused on tobacco harm prevention.
- Promotion of healthy lifestyles, including nutrition, physical activity, and reduced alcohol consumption, can further reduce cancer risks in the population.

5. Telemedicine and Technological Advancements

The expansion of telemedicine and technology-driven cancer care opens up opportunities for broader prevention and early detection, especially in rural areas:

- Telemedicine has been identified as an opportunity to improve access to preventive services, particularly in countries like Australia and Myanmar.
- Technology can help bridge gaps in healthcare access and encourage regular screenings and follow-up care for early cancer detection.

Question 4: Top five themes covering challenges in the region for patients with cancer in terms of prevention

1. Limited Access to Preventive Services in Rural Areas

Access to cancer prevention services remains a significant challenge in rural and underserved regions:

- Geographic barriers, infrastructure gaps, and lack of transportation prevent rural populations from accessing screenings and early detection services.
- Countries like India, Vietnam, and Pakistan struggle with ensuring equitable access to cancer prevention measures in these areas, leading to delayed diagnoses and poorer outcomes.

2. Low Health Literacy and Awareness

A widespread lack of knowledge about cancer prevention and risk factors hinders effective prevention:

- Health literacy remains low in many regions, with populations not fully understanding the importance of screenings, vaccinations, or lifestyle changes in reducing cancer risks.
- Cultural beliefs, stigma, & misconceptions about cancer, particularly in rural areas of Vietnam, Pakistan, & the Philippines, further complicate efforts to promote early detection & preventive care.

3. Cultural and Social Stigma

Cultural barriers and stigma surrounding cancer, particularly breast, cervical, and lung cancers, pose significant challenges:

- In countries like Pakistan and Vietnam, social taboos around discussing cancer prevent many individuals, especially women, from seeking preventive care or participating in screenings.
- Traditional beliefs may also lead people to rely on alternative remedies, delaying medical care and worsening outcomes.

4. Lack of Comprehensive Screening and Preventive Programmes

Certain countries face challenges with insufficient or poorly-distributed cancer screening programmes:

- Screening services are often concentrated in urban centres, leaving rural populations underserved.
- In countries like Taiwan and Vietnam, the inconsistent availability of screenings for high-incidence cancers like lung and breast cancer prevents timely detection and intervention.

5. Financial Barriers

Financial constraints, both for individuals and healthcare systems, limit the effectiveness of cancer prevention efforts:

- Cost issues related to screenings, health exams, and preventive care deter many from participating, especially in low-income populations.
- Even in regions with national health systems, such as the Philippines, insufficient financial support for preventive programmes and logistical issues like healthcare provider accreditation create barriers to wider implementation of cancer prevention initiatives.

These themes highlight the need for addressing infrastructure gaps, improving health literacy, overcoming cultural barriers, and providing financial support to enhance cancer prevention efforts in the region.

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Survivorship

Question 5: Top five themes covering opportunities in the region for patients with cancer in terms of survivorship

1. Expanding Cancer Survivorship Support Networks

There is a growing network of organisations and support groups focused on helping cancer survivors:

- These groups provide crucial emotional, psychological, and peer support to survivors.
- Many countries have national programmes, such as the Cancer Resource Centres in Taiwan, which act as hubs between hospitals and communities, offering continuous care and resources after treatment.

2. Improved Access to Follow-Up and Rehabilitation Care

Healthcare systems are increasingly focusing on post-treatment care, ensuring that cancer survivors receive comprehensive follow-up services:

- In Vietnam, specialised oncology centres are integrating survivorship care plans into routine practice, providing regular follow-up, recurrence monitoring, and management of long-term side effects.
- Pakistan and Australia are also enhancing rehabilitation services to help survivors regain their quality of life through physical recovery, psychological support, and social reintegration.

3. Growing Awareness of Holistic and Psychosocial Care

There is an increasing focus on holistic care for cancer survivors, which goes beyond medical treatment to include physical, mental, and social support:

- Certain countries are embracing holistic care models, offering workshops on nutrition, physical rehabilitation, and mental health.
- Psychosocial support groups are also gaining prominence, with peer-to-peer programmes in places like Myanmar, where trained cancer survivors offer emotional support to newly diagnosed patients.

4. Technological Advancements in Survivorship Care

Telemedicine and digital health platforms are emerging as critical tools in providing follow-up care for cancer survivors, especially in rural and underserved areas:

- In Vietnam, the use of mobile health apps and digital health records is making it easier for survivors to track their healthcare needs and access remote consultations.
- These technological advancements reduce the need for long-distance travel, enabling better continuity of care and timely medical intervention.

5. Supportive Workplace Policies for Cancer Survivors

Companies in some regions are implementing cancer survivor-friendly workplace policies:

- In Vietnam, there is a growing number of companies offering flexible working hours, phased return-to-work programmes, and extended sick leave to help cancer survivors transition back to the workforce.
- Some employers are also providing access to occupational therapy, counselling services, and onsite healthcare, which supports survivors' reintegration into society and helps them regain financial stability.

Question 6: Top five themes covering challenges in the region for patients with cancer in terms of survivorship

1. Limited Access to Survivorship Care, Especially in Rural Areas

Access to comprehensive survivorship care remains uneven, with significant disparities between urban and rural areas:

- In Vietnam and Pakistan, rural regions lack healthcare infrastructure and specialised medical staff, limiting survivors' ability to access follow-up care, rehabilitation, or monitoring for recurrence.
- Survivorship care is often available in major urban centres, leaving those in more remote areas without adequate support.

2. Financial Burden and Economic Challenges

Cancer survivors face significant financial challenges, with ongoing medical costs being a major concern:

- The economic burden of long-term care, medications, and rehabilitation often leaves survivors in debt or without resources to continue necessary care.
- In many countries public health insurance does not fully cover long-term survivorship needs, leading to high out-of-pocket costs that can hinder recovery.

3. Psychological and Mental Health Challenges

Mental health support for cancer survivors is often inadequate, leaving many struggling with issues such as fear of recurrence, depression, and anxiety:

- Survivors in Vietnam and Australia face long waitlists for psychological support, while in other regions, such as Pakistan, mental health issues remain stigmatised, preventing survivors from seeking help.
- The emotional strain of dealing with cancer, compounded by societal stigma, leads to feelings of isolation and, in some cases, a high suicide rate among survivors.

4. Lack of Comprehensive and Coordinated Care

Survivorship care often remains fragmented or insufficiently integrated into the overall cancer care pathway:

- Many countries have focused on cancer screening, treatment, and palliative care, but have neglected to provide adequate post-treatment services such as mental health, physical rehabilitation, and fertility support.
- There is also a lack of formalised survivorship care guidelines, especially in countries like Pakistan and Myanmar, leading to inconsistent follow-up care.

5. Social Stigma and Reintegration Difficulties

Cancer survivors face significant challenges in reintegrating into society due to social stigma, lack of support, and employment difficulties:

- In Vietnam and Pakistan, survivors often encounter stigma that labels cancer as a "death sentence," leading to discrimination, isolation, and difficulty in finding or maintaining employment.
- Returning to work can be especially challenging for survivors who suffer from physical or cognitive limitations due to treatment, and misconceptions about survivors' health can prevent them from being rehired or supported in their workplaces.

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Living with cancer (supportive care/QoL)

7. Living with cancer (supportive care/QoL) : Opportunities

Question 7: Top five themes covering opportunities in the region for patients with cancer in terms of living with cancer (supportive care/QoL)

1. Growing Access to Palliative and Supportive Care

- Many countries are expanding palliative care services to improve the quality of life for cancer patients, particularly those in advanced stages.
- Vietnam and Australia have made strides in integrating palliative care into hospitals, focusing on pain management, emotional support, and overall symptom control, significantly enhancing patient well-being.

2. Peer Support and Community-Based Networks

- Peer support groups, where cancer survivors share their experiences and offer emotional support to current patients, are gaining traction across multiple regions.
- In Vietnam and Myanmar, these groups are becoming more available, creating safe spaces for patients to discuss their experiences and cope with the challenges of living with cancer.
- Philippine initiatives such as Compassionate Communities foster a supportive environment for patients through local government partnerships.

3. Rising Awareness and Advocacy for Supportive Care

- Increased public awareness and advocacy by NGOs and healthcare bodies are driving greater recognition of the importance of QoL alongside traditional cancer treatments.
- Advocacy groups across regions are encouraging discussions around supportive care, leading to improved services and government backing for patient-centred care, as seen in Australia and Philippines.

4. Telemedicine and Digital Health Solutions

- Digital health technologies, such as telemedicine and online support groups, are opening new avenues for supportive care, particularly for patients in rural or underserved areas.
- Australia and Vietnam are leveraging these tools to provide remote consultations, psychological support, and access to information, making healthcare more accessible and reducing hospital strain.

5. Improved Access to Medicines and Financial Support

- Several countries are making progress in increasing access to medications and financial support for patients with cancer.
- In China, patients now have access to a broader range of medications, and new health policies are improving reimbursement limits for severe illnesses. This alleviates some of the financial burdens associated with living with cancer, offering better QoL for patients.

These themes highlight key advancements in supportive care, with growing efforts towards palliative services, peer networks, and telemedicine playing significant roles in enhancing the overall quality of life for cancer patients.

8. Living with cancer (supportive care/QoL) : Challenges

Question 8: Top five themes covering challenges in the region for patients with cancer in terms of living with cancer (supportive care/QoL)

1. Limited Access to Comprehensive Supportive Care

- Many patients struggle with accessing adequate supportive care services, especially in rural areas. While urban centres may offer some support, comprehensive services—including psychological counselling and rehabilitation—are often lacking, leading to unaddressed emotional distress and pain.

2. Cultural Stigma and Misunderstanding of Palliative Care

- A pervasive stigma surrounding cancer often leads patients to feel isolated and ashamed, discouraging them from seeking timely treatment. Furthermore, misconceptions equate palliative care solely with end-of-life scenarios, preventing patients from accessing crucial support throughout their treatment journey.

3. Financial Burdens and High Costs of Treatment

- The high cost of cancer treatment, including medications and supportive services, creates significant financial strain for patients. Inadequate insurance coverage often exacerbates these issues, leaving many to shoulder the financial burden themselves, which negatively impacts their quality of life.

4. Overburdened Healthcare System

- Overcrowding in cancer treatment centres leads to long waiting times and insufficient attention to supportive care needs. Healthcare providers often prioritise curative treatments due to their overwhelming workloads, sidelining the emotional and psychological aspects of patient care.

5. Misinformation and Limited Education about Cancer Care

- Patients frequently encounter misinformation regarding treatment options, leading them to explore unverified or alternative therapies that may not be effective. This is compounded by a lack of education among both patients and healthcare providers, which limits the understanding of supportive care's role in enhancing QoL.

These themes highlight critical obstacles that need to be addressed to improve the living conditions and overall quality of life for cancer patients in the region.

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Patient participation in research/innovation

9. Patient participation in research/innovation: Opportunities

Question 9: Top five themes covering opportunities in the region for patients with cancer in terms of patient participation in research/innovation

1. Growing Research Infrastructure

- Many countries in the region are expanding their clinical research infrastructures, particularly for cancer treatment. This includes increasing numbers of clinical trials and partnerships with international research organisations, providing patients with enhanced opportunities to participate in innovative cancer research.

2. Patient Engagement and Empowerment

- There is a rising recognition of the importance of patient engagement groups, which are actively working to engage patients in research and innovation. These organisations educate patients about the benefits of participation, empowering them to contribute to the development of cancer treatments and care protocols.

3. Government and Policy Support

- Several governments are beginning to prioritise health innovation and research funding. New policies, such as those encouraging patient engagement in drug development, demonstrate a commitment to incorporating patient voices into the research process, creating avenues for patients to contribute to clinical trials and treatment design.

4. Increased Awareness and Interest in Clinical Trials

- There is a growing interest among patients in participating in clinical trials, driven by better access to information about these opportunities. Increased transparency regarding clinical trial availability enables patients to seek out and consider participation more actively.

5. Emergence of Precision Medicine

- The shift towards precision medicine, which tailors treatments based on individual genetic profiles, is opening new doors for patient involvement in research. This trend allows patients to engage in studies that explore personalised treatment options, enhancing the relevance and effectiveness of cancer therapies.

These themes highlight significant opportunities for enhancing patient participation in research and innovation, ultimately improving cancer care and patient outcomes in the region.

10. Patient participation in research/innovation: Challenges

Question 10: Top five themes covering challenges in the region for patients with cancer in terms of patient participation in research/innovation

1. Limited Awareness and Education

- A significant barrier to patient participation in research is the lack of awareness and understanding of clinical trials and their importance. Many patients and their families are not informed about ongoing research opportunities or the potential benefits of participation, leading to hesitancy and misconceptions.

2. Cultural Barriers and Mistrust

- Cultural factors contribute to reluctance in participating in research. Mistrust of medical experiments and fears of being treated as "test subjects" can prevent patients from considering involvement in clinical trials. This is compounded by misconceptions regarding the safety and efficacy of research initiatives.

3. Geographical and Access Barriers

- Access to clinical trials is often limited to urban centres, leaving patients in rural or remote areas with fewer opportunities to participate. The concentration of research facilities in major cities creates geographical disparities that can hinder involvement in potentially beneficial studies.

4. Financial and Logistical Constraints

- Many patients face financial barriers, including the costs associated with travel to clinical trial sites and the need for time away from work. Additionally, logistical issues, such as transportation to research facilities, pose significant challenges for patients trying to engage in research initiatives.

5. Healthcare System Overload and Lack of Resources

- The healthcare system in many regions is overloaded, which can impede the recruitment of patients for clinical trials. Limited resources and time constraints for healthcare providers can lead to prioritising routine care over research activities, further reducing opportunities for patient participation.

These themes highlight key challenges that need to be addressed to enhance patient involvement in cancer research and innovation across the region.

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Other

Question 10: Other opportunities

1. Education and Capacity Building

- Training and Partnerships: Countries are forming international collaborations for training healthcare professionals, enhancing local expertise in oncology and palliative care.
- Public Awareness Campaigns: Increased focus on cancer awareness, driven by both government and civil society, including campaigns that promote screening and early detection.

2. Insurance and Financial Support

- Medical Insurance Reforms: Revisions in medical insurance policies to include more cancer treatments, improve reimbursement rates, and expand coverage for innovative drugs.
- Financial Aid Programmes: The establishment of cancer assistance funds and initiatives aimed at reducing the financial burden on patients through subsidised treatments.

3. Social Attitudes and Cultural Shifts

- Changing Perspectives: There is a notable shift in societal attitudes towards cancer, moving from fear to acceptance and coexistence, influencing public health strategies and personal coping mechanisms.
- Community Engagement: The role of local governments and cancer coalitions in advocating for patients and creating supportive environments.

Question 10: Other challenges

1. Healthcare Resource Limitations

- Funding and Infrastructure: Many countries face inadequate funding for healthcare, reflected in low GDP expenditure on health and insufficient research facilities. This limits the ability to conduct large-scale clinical trials and impacts the availability of advanced treatments.

2. Policy and Governance Issues

- Government Accountability: The effectiveness of health programmes, including those for cancer care, is undermined by poor governance, inefficiency, and a lack of accountability. This results in wasted resources and unmet healthcare needs.
- Lack of Universal Health Reform: Calls for comprehensive healthcare reform reflect the necessity for systemic changes to improve access and quality of care. Without significant policy shifts, equitable access remains an elusive goal.

3. Mental Health

- Many patients lack adequate mental health services and end-of-life care, leading to unnecessary suffering and emotional distress.

4. Environmental Factors

- Environmental Risks: Increasing exposure to environmental pollutants and carcinogens poses significant health risks, particularly in urban and industrial areas. This highlights the need for improved regulations and safety measures to protect public health.