



**ALLIANCE OF
PATIENTS'
ORGANIZATIONS
SINGAPORE**

Patients Co-creating Healthcare

Executive Summary

The Alliance of Patients' Organizations Singapore (APOS) is a transformative platform that envisions **patients-as-partners** in the Singapore healthcare system. Our mission is to enhance patient-centred healthcare in Singapore by actively collaborating with patients' organizations, advocating for patient-centric policies, promoting patient engagement, and providing accessible education to patients.

APOS will work closely with other stakeholders, namely the healthcare providers, research organizations, industry partners, philanthropic organizations, Ministry of Health (MOH), Centre of Regulatory Excellence (CoRE), Agency for Care Effectiveness (ACE), and the World Health Organization (WHO). By actively exchanging ideas and participating in collaborative projects, patients will be co-creating healthcare of the future in Singapore.

Through these strategic partnerships and educational programs, APOS aims to empower patients to actively participate in their healthcare journey by contributing ideas for improved patient outcomes, better technologies, as well as higher quality of care. In doing these patients will co-create a truly patient-centred healthcare system.

Background

Patient Engagement by the different healthcare organizations is gaining importance across Asia. At the global level, Patient Public Partnership has existed for more than 40 years. Patients and their carers have been invited to participate in hospital service quality improvement projects, Pharmaceutical and MedTech companies' R&D advisory councils, and Health Technology Assessment (HTA) committees to name a few.

A significant shift was seen when WHO launched its Global Patient Safety Action Plan 2021-30. One of their recommended strategies is for all stakeholders in the healthcare ecosystem to include the patient perspective. From policymaking, research objectives and prioritizing outcomes, to patientcare delivery in institutions, and innovative technology development, including the patient perspective will lead to improved quality of care, and better patient reported outcomes.

Traditionally, each healthcare organization works in their own silos. To bring all stakeholders together, to exchange ideas, identify and prioritize patients' preferences, to facilitate collaboration with each other for improved outcomes, we have established the Alliance of Patients' Organizations Singapore (APOS).

Through multistakeholder collaboration, patients can co-create healthcare of the future which will also be aligned with WHO Global Patient Safety Action Plan 2021-30 recommendations. Singapore will emerge as a Regional Leader in Patient Engagement.

Needs of Patients' Organizations

Patient Advocacy is minimal in Singapore although there are 100 Patients Organizations registered under the Ministry of Health (MOH). Each of them focuses on a specific disease area. There are also an unknown number of online support groups, as well as support groups within hospitals that are not a registered entity under MOH. All the above are led by compassionate individuals and are helping patients.

APOS aims to engage with all the above and provide a platform to exchange ideas for a brighter future. The needs of patients, support groups and patient organizations, are multifaceted and APOS could play a bridging role in alleviating at least a few listed below:

1. **ESTABLISHING SUPPORT GROUPS** Guidance on creating specialized support networks for patients facing specific health conditions, fostering a sense of community, and understanding among participants is limited. Getting a group registered as a society or charity could also be a helpful tool that is needed.

2. **FOSTERING NETWORK CONNECTIONS** Encouraging collaboration with similar organizations to exchange resources and knowledge, facilitating collective efforts to address common healthcare challenges could be improved.
3. **ADDRESSING UNMET PATIENT NEEDS** Equipping Board Members and Management of Patient Organizations with methods for identifying and tackling unmet patient needs in healthcare contexts is vital to ensure that all aspects of patient care are considered and addressed.
4. **NAVIGATING HEALTH TECHNOLOGY ASSESSMENT (HTA)** Education is minimal on health technologies assessment process. Barring a few top management or Board of Directors, patients are unaware of steps needed to participate in the HTA process, or informed decision-making and access to effective treatments.
5. **CONDUCTING BURDEN OF DISEASE STUDIES** There is an acute shortage in capacity, capability, funding, and guidance on designing studies to showcase the impact of a disease on the patients' life or family caring for them.
6. **PROMOTING PATIENT EMPOWERMENT** There is a lack of resources to empower patients in Singapore to actively participate in their own healthcare decisions and to effectively share their lived experience. Many skilled patients are unaware of opportunities of Patient Engagement.
7. **PREPPING FOR STAKEHOLDER ENGAGEMENT** For patients to effectively engage with other healthcare stakeholders is a relatively new concept in Singapore. A mindset shift is needed within patient organizations: at the i) Board and Management Level, ii) patients and their caregivers.

Singapore Patient Academy

In alignment with our mission to *advance healthcare and prioritize patient engagement*, the Alliance of Patients' Organizations Singapore (APOS) will establish the **Singapore Patient Academy**. This initiative aims to train and empower patients and their caregivers, enabling them to actively engage with various healthcare stakeholders.

The Patient Academy will focus on equipping participants with the knowledge, skills, and confidence necessary to co-create a patient-centered healthcare system in Singapore. Through comprehensive training modules, individuals will learn about their responsibilities & rights as patients, how to advocate for themselves and others, and how to effectively communicate 'lived experiences' with healthcare professionals and other stakeholders.

Key components of the Singapore Patient Academy curriculum will include:

1. **UNDERSTANDING THE HEALTHCARE LANDSCAPE** Participants will gain insights into the structure of the healthcare system in Singapore, including the roles of different stakeholders and avenues for improving care.
2. **PATIENT-CENTERED CARE** The academy will emphasize the importance of patient-centred care, teaching participants how to actively participate in treatment decisions and collaborate with healthcare providers to achieve optimal health outcomes.
3. **ADVOCACY AND ENGAGEMENT** Participants will learn advocacy strategies and communication techniques to effectively engage with healthcare policymakers, industry representatives, hospitals, clinics, and institutional care providers, researchers, and other stakeholders to influence positive change in healthcare policies and practices.
4. **HEALTH LITERACY AND EMPOWERMENT** The academy will focus on enhancing participants' health literacy, equipping them with the knowledge and skills to make informed decisions about their health and well-being. Moreover, how they could help co-create patient friendly brochures, information sheets and reports.
5. **PRACTICAL SKILLS DEVELOPMENT** Participants will have the opportunity to develop practical skills, such as communication and public speaking skills, sharing lived-experiences, importance of Patient Experience Data, importance of Real-World Evidence, and others.

Through the establishment of the Patient Academy, APOS seeks to empower patients and their caregivers to play an active role in their healthcare journey, driving positive change and improving healthcare outcomes for all. Educational materials using multimedia will be needed to meet the needs of different learning preferences of patients and their caregivers.

Patient Engagement

Instead of working in silos, APOS hopes to facilitate collaborative projects between patients' organizations and various healthcare stakeholders. The Alliance of Patients' Organizations Singapore (APOS) is dedicated to advancing healthcare through Patient Engagement by all stakeholders.

To foster collaborative projects going forward, workshops and seminars will be organized by APOS throughout the year using a comprehensive framework encompassing **five core pillars**:

1. **ENGAGEMENT WITH PHARMA AND MEDTECH INDUSTRY** we will actively collaborate with pharmaceutical and medical technology companies to ensure patient-centric approaches in product development, accessibility, safety, and affordability.

2. **PROMOTION OF PHARMACOVIGILANCE** we emphasize the importance of pharmacovigilance systems to monitor and evaluate the safety of medications, early and accurate diagnosis, advocating for robust mechanisms to include patient voice in all phases of clinical trials, patient experience data and real-world evidence to ensure patient well-being.
3. **ADVOCACY FOR QUALITY HEALTHCARE SERVICES** we will work towards enhancing the quality of care provided in public hospitals, clinics, residential institutions, and in the community, advocating for patient-centred practices, improved service delivery, and accessibility to healthcare across the spectrum of care.
4. **INFLUENCE ON NATIONAL AND INTERNATIONAL HEALTHCARE POLICY** we will engage with policymakers at both national and international levels to advocate for policies that prioritize patient needs, foster healthcare innovation, and improve access to quality care for all.
5. **INTEGRATION OF BEHAVIOURAL SCIENCE AND RESEARCH METHODOLOGIES** we will promote the integration of behavioural science principles with both, qualitative as well as quantitative research methodologies in healthcare initiatives. By leveraging insights from these disciplines, APOS aims to enhance patient engagement, improve healthcare outcomes, and drive evidence-based decision-making.

Through these pillars of focus, APOS endeavours to drive positive change in healthcare systems, championing the patient preferences, unmet needs, and well-being of patients across diverse healthcare settings in Singapore.

Each year, APOS will organize workshops, seminars, and a multistakeholder conference thereby creating opportunities for different stakeholders to exchange ideas on patient engagement and to co-create change.