

Asia Pacific Patient Innovation Summit examines capability building gaps of Patient Organizations

The Asia Pacific Patient Innovation Summit publishes a whitepaper, which serves as a blueprint to help patient organizations improve their approach to sustainable funding, digitalization, and multi-stakeholder partnerships.

Aug 06, 2021

The Asia Pacific Patient Innovation Summit (APPIS) has published its first whitepaper that examines the regional landscape for patient organizations and explores existing capability building gaps. The patient community-led report, 'Partnering with patient organizations to address the unmet needs of patient communities in the Asia Pacific region and beyond', aims to enable a greater understanding and recognition of the seminal role of patient organizations and the patient voice in shaping the future of healthcare, while providing a series of recommendations for patient groups:

- **Build sustainable funding models, maximize key channels of funding, and use technology to reach new audiences**, given that 83% of patient organizations surveyed noted that sustainable funding was a challenge.
- **Embrace digitalization and social media** to raise disease awareness (as reported by 82% of patient organizations) and improve access to health news and information (79%).
- **Build strong relationships with key stakeholders** through partnerships and collaboration.

Co-created by the APPIS Steering Committee, representing leading regional patient organizations and Novartis, the whitepaper leverages the results of a survey conducted to better understand the needs and capabilities of patient groups in the region. The survey captures the perspectives of 147 interviewees from patient organizations' Boards and leadership teams, across 12 countries and territories in the Asia Pacific region and beyond.



Dr Ratna Devi, Board Chair of the International Alliance of Patients' Organisations and APPIS 2021 Steering Committee Chair commented, "This is an important initiative for patient organizations in the region. I hope that the whitepaper will provide a greater understanding and recognition of the seminal role of patient organizations. We want to start conversations that will eventually lead to changes in practice and policy to give patients a bigger voice at the table in healthcare discussions."

"We aim to bring our Commitment to Patients and Caregivers to life in this part of the world by strengthening our partnerships with the patient community. Only by working together can we extend and improve people's lives by continuing to improve the standards of healthcare and elevating the patient experience", said Ruth Kuguru, Head of Patient Engagement and Communications for Asia Pacific, Middle East and Africa of Novartis and member of the APPIS 2021 Steering Committee.

APPIS: An initiative led by patient organizations for patient organizations

APPIS is a unique collaborative partnership between Novartis and the patient community that aims to address the evolving capability needs of patient organizations and to drive changes in healthcare systems in Asia Pacific and beyond. Held in March 2021, the inaugural region-wide Summit saw over 880 participants throughout the three-day event, representing more than 300 patient organizations across 36 countries and territories, including Australia, India, mainland China, Japan, South Korea, Taiwan, Thailand, Philippines, UAE, South Africa, Egypt, Saudi Arabia, and so on.

Funded by Novartis and led by patient organizations, the APPIS Initiative is continuing to engage the patient community via ongoing capability modules offered by APPIS partners – Rare Cancers Australia (RCA) and the European Patients' Academy on Therapeutic Innovation (EUPATI).

Additional Resources

[APPIS 2021 Whitepaper \(PDF 3.0 MB\)](#)

Source URL: *<https://prod1.novartis.com/news/asia-pacific-patient-innovation-summit-examines-capability-building-gaps-patient-organizations>*

List of links present in page

1. <https://prod1.novartis.com/news/asia-pacific-patient-innovation-summit-examines-capability-building-gaps-patient-organizations>
2. https://prod1.novartis.com/sites/novartis_com/files/asia-pacific-patient-innovation-summit-whitepaper.pdf