

Partnering with Patient Organizations to Address the Unmet Needs of Patient Communities in the Asia Pacific Region and Beyond

Whitepaper

Published by the Asia Pacific Patient Innovation Summit (APPIS) 2021 Steering Committee:

Dr. Ratna Devi, Board Chair of the International Alliance of Patients' Organizations (IAPO)

Richard Vines, Rare Cancers Australia (RCA)

Anubha Taneja-Mukherjee, Thalassaemia Patients Advocacy Group (TPAG)

Paul Mendoza, International Federation of Psoriasis Associations (IFPA)

KP Tsang, Asia Pacific Alliance of Rare Disease Organizations (APARDO)

Ruth Kuguru, Head of Patient Engagement and Communications for Novartis Asia Pacific, Middle East and Africa (APMEA)

Noha Abdelbaky, Novartis APMEA Regional Patient Engagement Director



ASIA PACIFIC PATIENT
INNOVATION SUMMIT



Content

Foreword	1
Executive summary	2
Part 1 - The increasingly influential patient voice in an evolving healthcare landscape	
Empowered patient organizations in the region	4
• The role of patient organizations	4
• Success stories of patient organizations in the region	5
The growing importance of the patient voice in Asia Pacific	7
Part 2 - Addressing the critical unmet needs of Patient Organizations	
Critical unmet needs of Patient Organizations – Key results from the APPIS Survey 2021	8
Recommendation I: Build sustainable funding models	
• Maximize key channels of funding	10
• Use technology to reach new audiences	11
Recommendation II: Embrace digitalization and social media to raise disease awareness and improve access to health news and information	
• Enhance use of social media and social media channels	13
Recommendation III: Build strong relationships through partnerships and collaboration	
• Conduct regular stakeholder mapping exercises	14
Part 3 - Strengthening partnership for greater success	
How and why various stakeholders should support Patient Organizations	15
Appendix 1 - APPIS Survey 2021: Profiling of respondents	16
Appendix 2 - Survey findings	17
Appendix 3 - References	18

Foreword

Healthcare in the Asia Pacific region is changing rapidly, with healthcare spending increasing exponentially, a rapidly aging population, and a mindset shift among healthcare consumers. The patient community is now shouldering greater responsibilities, and this calls for the development of greater capabilities to continue improving outcomes for patients, particularly in this pandemic-stricken world.

The Asia Pacific Patient Innovation Summit (APPIS) Initiative 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 sustained improvements and changes in healthcare systems in this part of the world.

Funded by Novartis and led by patient organizations, the APPIS Initiative was launched with a region-wide summit in March 2021 and

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).

This whitepaper aims to review current knowledge and learnings from patient organizations in the region, the gaps that remain and the potential actions that can be taken to address these gaps. We hope that this whitepaper will provide a greater understanding and recognition of the seminal role of patient organizations and the patient voice in shaping the future of healthcare. Ultimately, this whitepaper can act as a starting point for conversations that will eventually lead to changes in practice and/or policy to give patients a bigger voice at the table in healthcare discussions.

The APPIS 2021 Steering Committee



Dr. Ratna Devi
International Alliance of
Patients' Organizations (IAPO)



Richard Vines
Rare Cancers
Australia (RCA)



Anubha Taneja-Mukherjee
Thalassemia Patients
Advocacy Group (TPAG)



Paul Mendoza
International Federation
of Psoriasis Associations (IFPA)



KP Tsang
Asia Pacific Alliance of
Rare Disease Organizations
(APARDO)



Ruth Kuguru
Head of Patient Engagement
and Communications for
Novartis Asia Pacific,
Middle East and Africa (APMEA)



Noha Abdelbaky
Novartis APMEA Regional
Patient Engagement Director

The Asia Pacific region is home to over half of the world's population^[1].

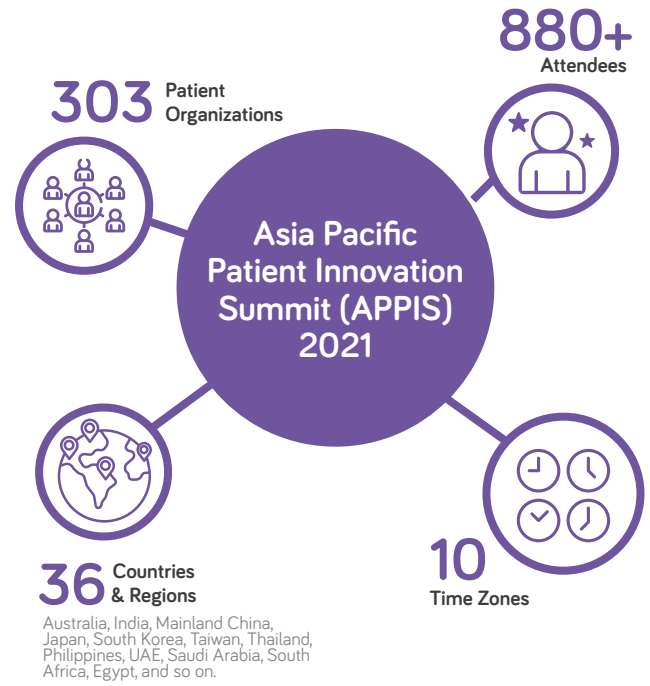
The diversity of disease types, patient profiles, presentation and management approaches tend to differ significantly between these countries based on:



>40% The region's healthcare landscape will represent more than **40% of growth in global healthcare spending** over the next decade—expanding at a rate almost double that of the rest of the world^[3].

Healthcare consumers and patient communities are demanding more control over their healthcare.

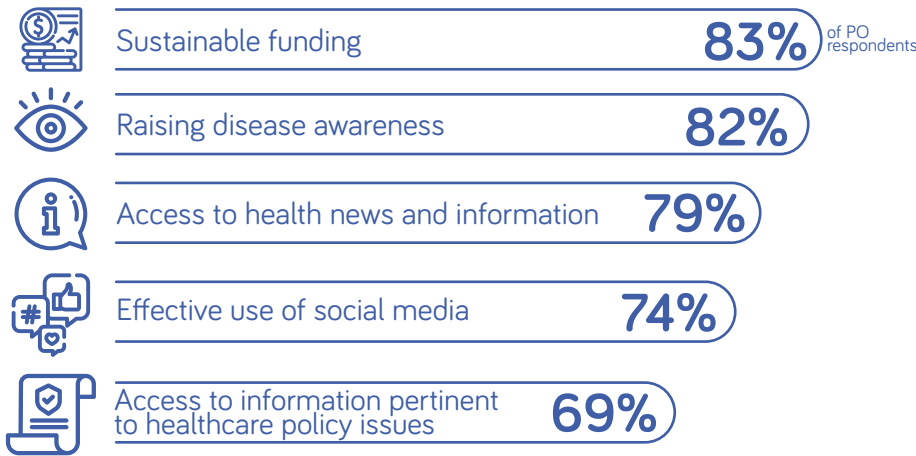
Patient organizations amplify the voices of patients and help them become active participants in the healthcare system, essentially providing patients a "seat at the table".



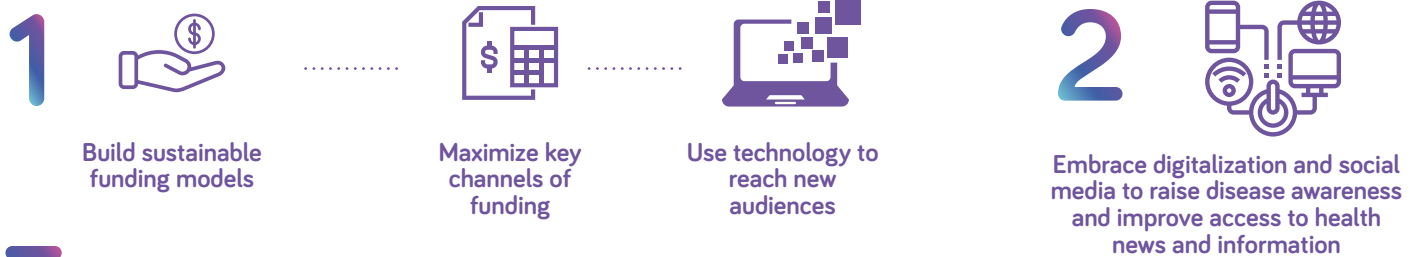
Understanding the needs of Patient Organizations (PO) in the Asia Pacific region

The APPIS Survey identified the following primary challenges and developmental areas:

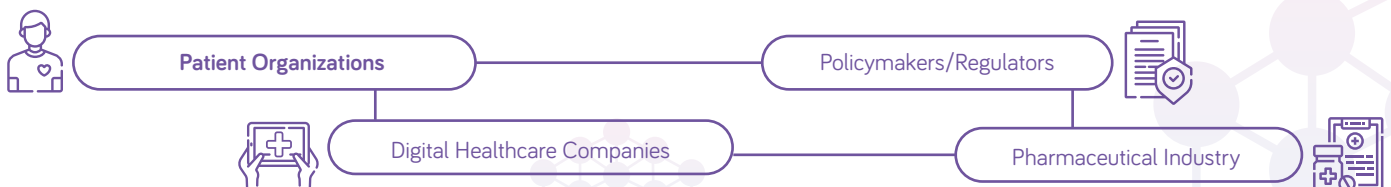
Skills and expertise POs are interested in sharing with other POs:



Recommendations for Patient Organizations



3 Build strong relationships through partnerships and collaboration



The increasingly influential patient voice in an evolving healthcare landscape

The Asia Pacific region is home to over half of the world's population^[1], and includes the most populous countries around the globe. The diversity of disease types, patient profiles, presentation and management approaches tend to differ significantly between these countries based on their gross domestic product (GDP), scale of economic development and resources. Healthcare systems in the Asia Pacific region are faced with a rapidly aging population while certain countries have some of the world's lowest percentages of GDP allocated to healthcare expenditure. Additionally, the COVID-19 pandemic has brought about unique challenges and exposed or intensified existing healthcare shortcomings which had previously either gone unnoticed or unaddressed in many countries, such as the availability of adequate hospital beds, staffing, and the lack of existing contact-tracing mechanisms, to name a few.

Recognizing the challenges ahead, governments in many countries have introduced or pledged additional resources as well as reforms to their healthcare systems^[2]. Healthcare spending in the Asia Pacific region has increased exponentially. It is estimated that the region's healthcare landscape will represent more than 40% of the growth in global healthcare spending over the next decade – expanding at a rate of almost double that of the rest of the world^[3]. This fast-changing healthcare landscape will bring with it opportunities for growth in key areas including patient engagement.

Patients today want greater ownership of their care. Many physicians and patients agree that healthcare systems must undergo transformational change, with at least 50% indicating they would be willing to embrace digitalization for better delivery of care^[3]. More than ever, it is patients and patient communities who are playing increasingly important roles in the frontline of healthcare delivery and demanding for more control over their healthcare.

This is where patient organizations (POs), an important stakeholder of patient communities, have an important role to play in realizing these changes.

Healthcare consumers and patient communities are demanding more control over their healthcare.

Empowered patient organizations (PO) in the region

The role of patient organizations

POs are non-profit groups that represent patients or families affected by a significant medical condition or disease, by amplifying their collective voices, and helping them to become active participants in the healthcare system^[4]. POs range from individuals or volunteers working in their spare time, to large non-governmental organizations (NGOs) that rival multinational corporations in size and scope^[5]. In addition to providing patient-friendly disease awareness, education, and support, some POs are also actively involved in the healthcare process and engage in drug development and health technology assessment^[6]. Ultimately, POs give patients a “seat at the table” where key healthcare decisions are made.

The role of POs is particularly significant when it comes to policymaking, which, in most countries, is essentially a consultative process that includes all concerned with the subject of the policy under contemplation. POs are on the frontline of the healthcare challenge that is the subject of such policy. They deal with the situation on an ongoing basis and thus occupy a unique vantage point of view.

These bodies are also well entrenched into the stakeholder landscape due to their familiarity with the subject in discussion. Moreover, POs often comprise qualified professionals as their patient

members and/or members thereby offering a rare blend of experience of the condition along with the wherewithal to devise solutions to deal with the same. It is, therefore, in the interest of any committee or consultative body tasked with the formulation or implementation of a policy impacting a certain health condition to include expert POs in any meaningful policy making.

It is, therefore, in the interest of any committee or consultative body tasked with the formulation or implementation of a policy impacting a certain health condition to include expert POs for any meaningful policy making.

The following are several case studies to illustrate where POs have made a significant impact on patient outcomes.

Success stories of patient organizations in the region

Case study 1

Heart-to-Heart Foundation Thailand: Providing a capacity building framework within communities

Heart-to-Heart Foundation (HHF) Thailand is an example of a PO that drives community participation and provides a framework for capacity building within communities. This helps patients manage their own conditions and also supports communities within the healthcare infrastructure of Thailand. This is done via the establishment of support centers across the country that provide basic primary healthcare (e.g. nurse-led healthcare drives) as well as patient information. To date, up to 17 Friendship Support Centers run by cancer patients have been established in health service units; and more than 500 Centers have been established nationwide for patients suffering from chronic

heart diseases.

To maintain interest and participation, HHF provides awards to outstanding Friendship Support implementers or volunteers. It also undertakes philanthropic activities via collaboration with individuals and organizations with public benefits such as the National Health Security Office and the National Health Commission Office. To ensure continuous improvement of their services to the community, HHF also established matrixes to assess the work of their volunteers and continuously identify areas for improvement^[7].



Up to 17 Friendship Support Centers run by cancer patients have been established in health service units.



More than 500 Centers have been established nationwide for patients suffering from chronic heart diseases.

Case study 2

Thalassemia Patients Advocacy Group (TPAG), India: Driving advocacy through strategic partnerships for resource optimization

TPAG India is an example of a PO that is delivering its mission of “protecting the overall interests of thalassemics in India and preventing thalassemia” by driving advocacy through strategic partnerships. These partnerships particularly helped TPAG during the pandemic that saw the outflow of a large amount of corporate and government resources towards COVID-19 related initiatives. To help thalassemics, who need regular blood transfusion

for survival, TPAG partners with other non-governmental organizations for donor searches. TPAG also utilizes social media platforms like Facebook in the form of ad credits and piggy-backs on ongoing media advocacy of corporates for voluntary blood donation drives. To cater to its larger objective of Safe Blood for All, TPAG carries out continuous engagement with industry bodies and corporates interested in the subject.

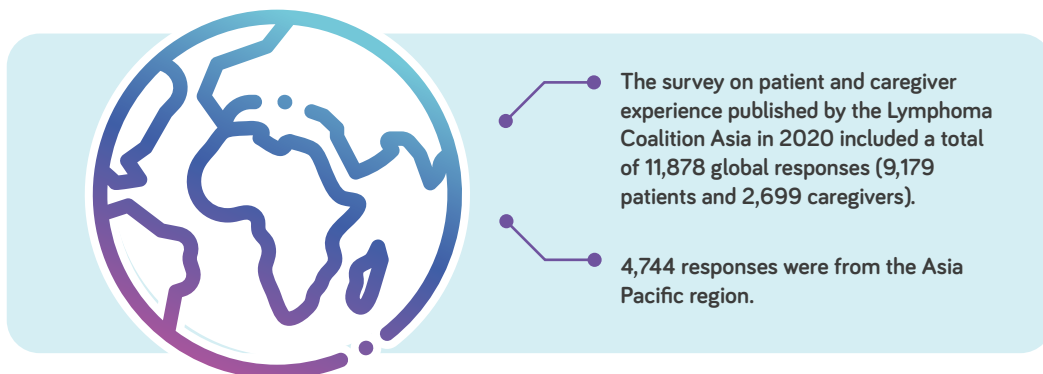
Case study 3

The Lymphoma Coalition Asia Pacific: Use of data to drive advocacy

The Lymphoma Coalition Asia Pacific is an initiative of the Lymphoma Coalition, a worldwide network of patient groups with a full or partial focus on providing support to patients with lymphoma. The organization was formed in 2002 and incorporated as a not-for-profit organization in 2010. The Lymphoma Coalition represents more than 80 member organizations from over 50 countries.

The Lymphoma Coalition Asia Pacific publishes a biannual global survey on patient and caregiver experience which, in 2020, included a total of

11,878 global responses (9,179 patients and 2,699 caregivers, of which 4,744 responses were from the Asia Pacific region). The results of this large survey are used by POs in Asia to understand gaps in services, inform healthcare professionals and policymakers, and contribute to health technology assessment discussions. The report on the exploration of disparities in lymphoma care in the region also aimed to highlight patient care issues across Asia Pacific, and determine where those issues could be addressed with common solutions and support.



The growing importance of the patient voice in Asia Pacific

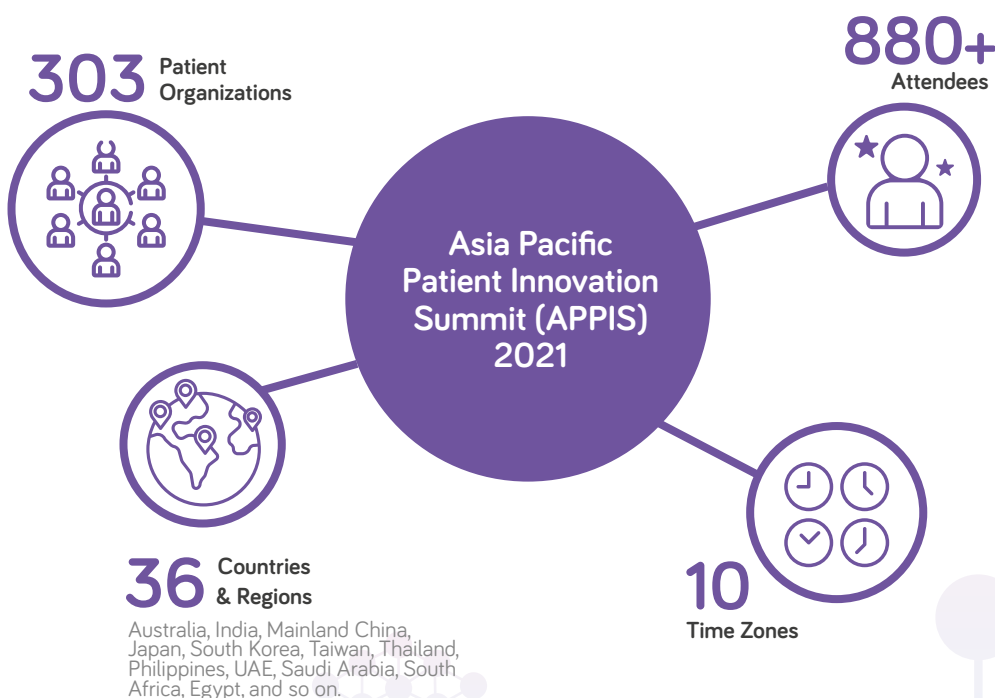
In the Asia Pacific region, patient group mobilization and interaction with governments, regulators and companies is in a relatively nascent stage, but at a ripe point for expanding the visibility and role of patients^[6]. Increasing recognition of the concept of “patient-centricity” in the last decade has led to pharmaceutical companies introducing roles that focus on understanding and communicating patient views at the highest organizational level, such as Patient Engagement and Communications roles at Novartis, Patient Affairs roles at Pfizer and the Diversity and Patient Engagement Group at Bristol Myers Squibb (BMS), to name a few^[5].

The growing number of POs in the region signifies a shift in patient expectations. A new type of consumer is emerging – one who is more interested in overall wellness and more informed about medical conditions and treatment options^[3]. Over the next decade and beyond, the patient voice will be pivotal in transforming healthcare in the region with the growing influence of patient

advocacy boards led by patients; the emphasis on real world versus clinical trial outcomes; and the importance of quality-of-life metrics versus clinical metrics^[8].

Healthcare systems are complex ecosystems that include multiple stakeholders and providers where the only consistent factor is patients. Not only are patients the experts on their own illness, patients are also potential leaders, innovators, entrepreneurs and communicators – all valuable skillsets and resources for any healthcare system^[6].

Realizing the unmet needs of POs in the region, **the Asia Pacific Patient Innovation Summit (APPIS) Initiative** was established to partner with patient organizations to drive patient-centric improvement and change in healthcare across the region. The inaugural Summit brought together 880+ attendees representing 303 patient organizations across 36 countries and territories.



Addressing the critical unmet needs of Patient Organizations

Critical unmet needs of POs – Key results from the APPIS Survey 2021

In order to better understand the needs of POs in the Asia Pacific region, APPIS conducted a survey^[9] between November 2020 and March 2021 with a focus on the capacity and capability building needs of POs. About 65% of POs surveyed have more than 10 years of experience and are predominantly country-focused with the majority of their workforces made up of volunteers. Additionally, a large number of the POs are either NGOs or have some kind of legal entity, with a considerable number of registered members and members who represent them.



147 respondents



8 survey languages
(English, Chinese, Japanese, Korean, Thai, Malay, Vietnamese and Tagalog)



36 countries and territories in Asia Pacific, Middle East and Africa



Respondents: Board members, the leadership team, key staff of POs

The key focus area for the majority of POs surveyed is oncology (68%), followed by immunology, hepatology and dermatology (IHD) (41%), and cardiology (16%) (Appendix 1). The survey has identified the following primary challenges and developmental areas:



Sustainable funding

83% of POs surveyed note that sustainable funding is a challenge.



Raising disease awareness

82% cite raising awareness of disease and related issues as a challenge.



Access to health news and information

79% cite access to health news and disease information as a challenge.

The POs also acknowledge that they lack merit in effective use of:



Social media (74%)



Information pertinent to healthcare policy issues (69%)

Approximately 65% of POs are interested in sharing skills and expertise in communications (with a focus on disease awareness and social media), 61% in patient and caregiver psychosocial support programs, and 55% in partnerships and collaboration (Appendix 2).

Recommendation I: Build sustainable funding models

According to the APPIS 2021 Survey, the issue of sustainable funding is the most commonly faced challenge by POs in the region, with 83% of respondents highlighting this as a challenge. It is therefore important that POs review their funding models and cashflow management strategies to ensure longevity of available finances.

There are several challenges in designing a framework or model for non-profit funding; and the funding paths that each non-profit takes will vary. When deciding on funding model(s), set realistic and known targets at the outset, and consider diversifying risk by having multiple funders or funding sources. Fundraising aside, it is the management of costs and budget over the fiscal year that will determine financial sustainability, particularly for NGOs and POs where funding can change very quickly^[1].

Rare Cancers Australia (RCA) recommends investing in a good fundraising strategy, paying for expertise, or assigning a dedicated team member to develop and implement a fundraising strategy. It lists the following tips for good cashflow management in their RCA Pinnacle Program Playbook.



Implement and adhere to an agreed process for budgeting and monthly forecasting.



Set aside at least 6-12 months of operating costs as reserve for times when less funding is received.



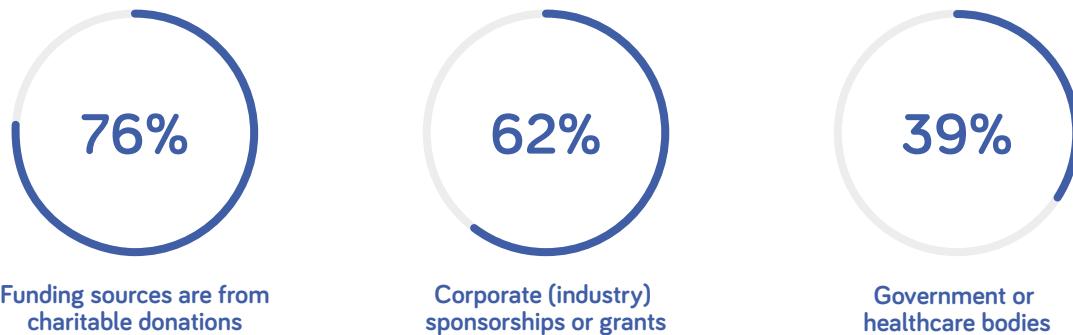
Prepare a contingency plan for downsizing operating costs when needed.



Allow for long processing times for donations and funding from corporate bodies.

Maximize key channels of funding

The following section provides an overview of some key channels of funding as well as suggested strategies to maximize them.



Public donations are a key source of funding for most POs and can be initiated in a variety of ways from simple street collections, via social media or third party organizations. Fundraising events are an important channel as they play a role in raising awareness and the profile of a PO. With both public donations and fundraising events, it is important to pay attention to the following elements^[1]:

- Convenient and attention-grabbing
- Transparency
- The donor experience
- Social media

An example on an annual fundraising event from Rare Cancers Australia (RCA):

The Kosi Challenge

RCA holds three events annually including the Mount Kosciuszko Challenge, Halloween Ball, and Halloween Scare4rare community campaign that have gained increasing traction over the years. In the Kosciuszko Challenge, participants raise money from family and friends for climbing to the summit of the highest mountain in Australia. Lessons learned from the Kosi Challenge include:

- Memorable and positive donor experience
- Participation from various age groups
- Participants gain sense of achievement, time spent with family/friends

Industry grants and sponsorships

Pharmaceutical companies invest globally to support and help POs as part of their Corporate Social Responsibility programs and under strict regulations. When engaging with industry, it is important that all parties operate with integrity and full transparency. Some key challenges with regards to industry grants and sponsorships include:

- Strict processes, tight regulation, and long processing times make applications and contracting processes difficult and time-consuming
- Stakeholders who wish to distant themselves from the pharmaceutical industry
- Proof of completion required by certain grantees

Despite these challenges, industry grants are valuable assets in ensuring long-term sustainability of a PO. Additionally, POs can also take advantage of the good relationships or links some companies have with global experts, stakeholders and market access teams. The RCA Pinnacle Program Playbook lists the following principles to keep in mind when working with industry:

- Be clear and transparent of mission(s) and objectives
- Approach companies as an equal and a provider of community value
- Understand what is beneficial to the industry and help them justify support for your cause

Use technology to reach new audiences

It is important to make use of technology to reach out to new audiences and to stay relevant in a community and among funders. This is especially important during the COVID-19 era where face-to-face communication is not always possible. Use low-cost social media outlets such as Twitter, Facebook, LinkedIn, Weibo or even WhatsApp to communicate up-to-date information without incurring significant financial or technical resources.

When incorporating social media into your outreach and/or funding plan, advertise the availability of these social media outlets to increase the number of followers and gain impact. Ensure blogs or websites are up-to-date and that it is easy for your audience to get in touch with you directly if they have any questions^[12].

Recommendation II: Embrace digitalization and social media to raise disease awareness and improve access to health news and information



Raising disease awareness

82% of PO respondents of the APPIS Survey 2021 cite raising awareness of disease and related issues as a challenge



Access to health news and information

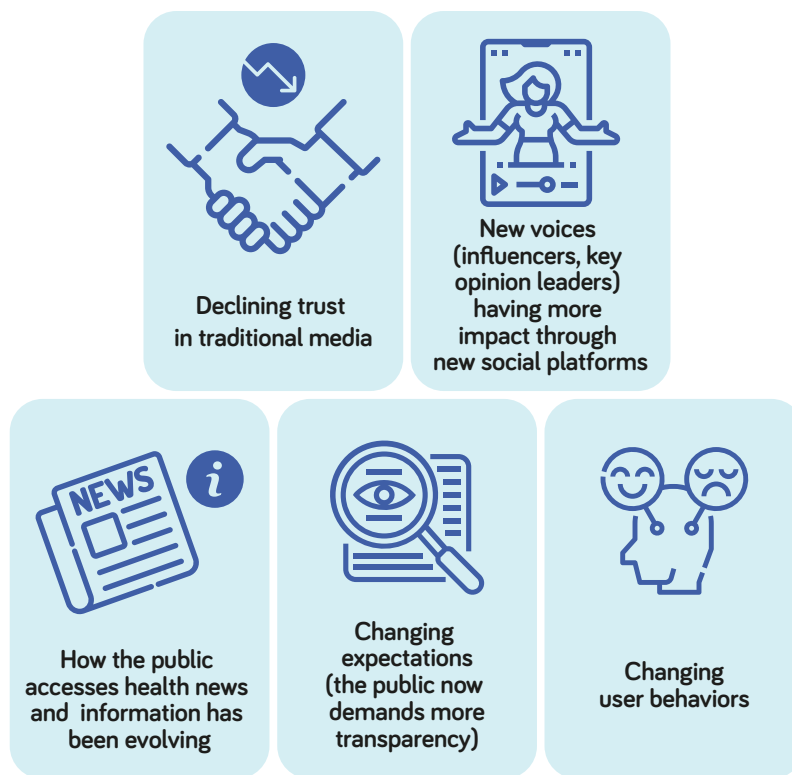
79% cite access to health news and disease information as a challenge

Patients are the most important end-users in any healthcare ecosystem. Strategic and consistent engagement with patients and POs are a critical success factor in end-to-end portfolio development, life cycle management and achieving meaningful health outcomes. Digitalization is pivotal in expanding outreach via a targeted social media strategy and providing patient as well physician information in simple yet compelling formats^[15]. Within any PO, digitalization in the COVID-19 era also enables a seamless remote working environment and the ability to hold multi-lingual workshops, podcasts and vlogs, among other digital offerings.

There is a need to increase knowledge of digitalization in healthcare in order to effectively contribute to digital health solutions development. According to the European Patient Innovation Summit (EPIS) 2019 Call-to-Action Report, patient advocates should actively seek out opportunities with all stakeholders in the digital ecosystem to enable earlier and more systematic engagement with patients in the development of digital health solutions^[16].

Enhance use of social media and social media channels

The APPIS Survey 2021 highlighted that 74% of POs regard effective use of social media as a challenge. It is important the POs enhance the use of social media and social media channels as the way patients receive and consume information is changing, moving away from traditional media sources to social and digital media. The following are reasons to consider using social and digital media to convey/enhance key messages^[1]:



There are various forms of social and digital media that can be leveraged, and these vary from country-to-country. RCA notes that social media has been critical in their communication strategies for all their projects and activities; but caution that there need to be plans in place to manage the pitfalls of social media (e.g. social media trolls)^[1].

Recommendation III: Build strong relationships through partnerships and collaboration

According to the APPIS 2021 Survey, 71% of POs surveyed believe themselves to be champions or experienced in collaboration with other stakeholders beyond patients or PO members. Many are keen to share skills and expertise via partnerships and collaboration^[9]. POs can and should engage regularly and build trust with key stakeholders such as government, pharmaceutical industry, clinicians, other POs, volunteers, and corporate funders.

Conduct regular stakeholder mapping exercises

It is advised that POs conduct regular stakeholder mapping exercises to continuously assess current partnerships, how to work together effectively, and how to build new partnerships. If your PO spans several countries, detailed mapping and assessment of current policies and systems in each member country is important to identify and fill current gaps in knowledge^[13]. Ensure that your partnerships contribute to the goals and objectives of your PO, while maintaining respectful long-term relationships with all partners. The following table are some suggested points to keep in mind in potential partnerships and collaboration^{[13], [11]}:



Government

Engagement with government can potentially influence policy decisions, lead to public funding, and lend credibility to the PO. Be cautious and mindful of local regulations and develop clear messaging and recommendations. Emphasize patient experience and stories to create trust and impact. Engage with all levels of government.



Other POs and civil society

Collaboration with other POs and civil society ensures there is trust and knowledge-sharing with your counterparts. Understand that, ultimately, you share the same goals – a better healthcare system and putting the patient voice first.



Pharmaceutical industry

Take into consideration industry's interests in your engagement plan. Be proactive, sophisticated and up-to-date with key trends and research to maintain interest. Bear in mind that industry partners will also open doors to other valuable stakeholders such as health economists, public relations agencies, clinicians, recruitment companies and other corporations – this increases exposure.



Clinicians

Clinicians play a pivotal role in drug access. Establish clinical advisory boards, if possible, to build reputation and trust. (Note: Multi-stakeholder country-level or regional advisory boards of influential clinical and patient leaders can lead to valuable knowledge-sharing and collaborations).

How and why various stakeholders should support POs^[18]



Policymakers /Regulators

How can POs help here?

- POs can help policymakers understand patient priorities and experiences of living with a disease/condition
- Provide end-user perspective in health services design
- Channel the voice of a community of patients by representing their interests in a united, coherent and consistent way
- Align with larger national agenda
- Provide user experience to identify and address gaps in system delivery
- Provide insights into what is important from the perspectives of the patient to better design policies
- Hold policymakers accountable

How can policymakers/regulators contribute?

- Provide policy input (direction, evidence, implications) and offer amendments to policy proposals through advisory groups and expert panels
- Advise on how to establish a framework and mandate for involving patients (how much to involve them, at what stage and outline patient roles); provide examples/guidelines of best practices and set expectations for patient engagement
- Involve patient representatives actively and equitably from inception to delivery



Digital healthcare companies (Digital startups)

How can POs help here?

- Encourage or provide avenues to encourage digital health literacy
- Provide sustainable and affordable sources of digital health information
- Aid patients in reviewing and determining credible sources of information

How can digital healthcare companies contribute?

- Provide patient-centric digital solutions to seamlessly connect patients with physicians, clinical care teams and research teams
- Expand patient communities on digital platforms
- Assess and recognize that different patients (or patient segments) have different attitudes towards digital tools
- Involve patients from the beginning to the end of the development of digital health solutions; and ensure that issues with accessibility or understanding are taken into consideration early in digital health solution development^[16]
- Provide tools that can be used pre-treatment, during treatment (monitoring) and post-treatment (post-discharge) to better understand the patient journey^[17]



Pharmaceutical Industry

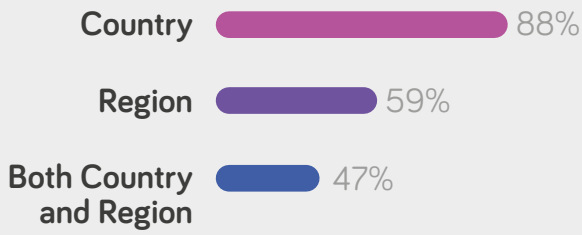
How can POs help here?

- Encourage greater involvement of patients in the early stages of research, including the development of pharmaceuticals and devices
- Educate and enable patients to understand and use digital tools
- Share and align common objectives that are for the greater good of the greater number

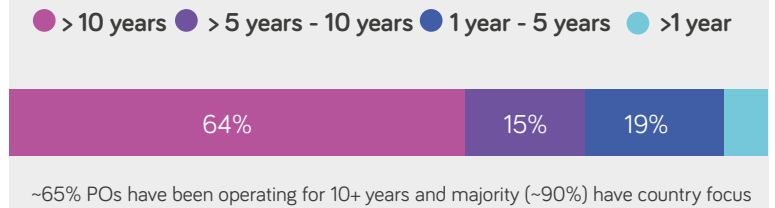
How can pharmaceutical industry contribute?

- Provide evidence on the benefits of patient engagement and how POs can add value in their engagement with pharmaceutical companies
- Drive cultural change within the industry as well as leadership to drive patient engagement for better patient-focused drug development. There needs to be better understanding of the value of patients in drug development
- Educate researchers on how to work with patients
- Help patients understand and navigate the complexities of the regulatory process
- Support POs in capability and capacity building and include patients in media and policy campaigns

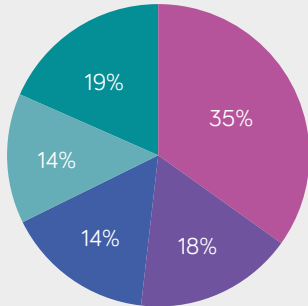
Organizational Focus



Tenure



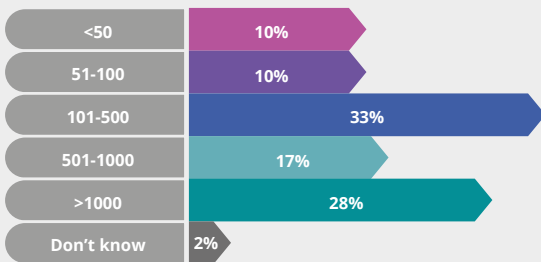
Legal Status



- **NGO**
- **Legal entity**
- **Open collaboration**
- **Foundation**
- **Others**
Others include patient association, voluntary organization, nonprofit organization, corporates etc

~50% POs are either NGOs or have some kind legal entity with majority of their staff being volunteers

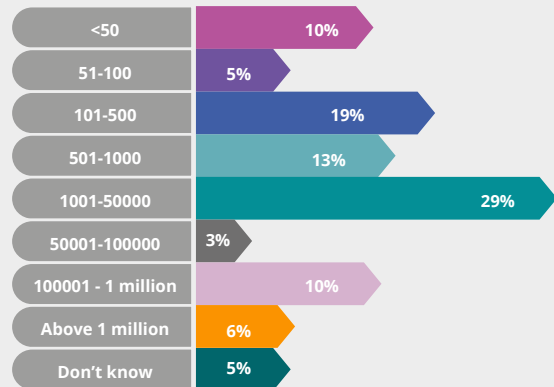
Registered Members



~40% POs have registered members anywhere between 100 - 500

Note: Registered members include patients and non-patients

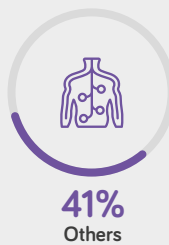
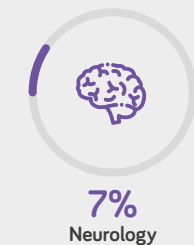
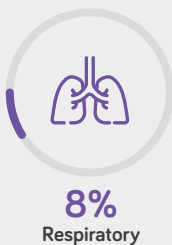
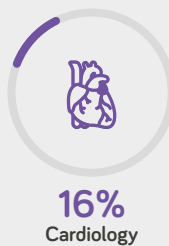
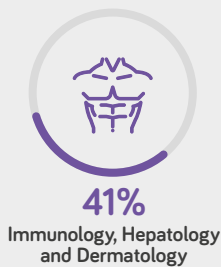
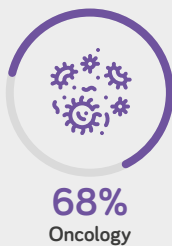
Total Members Represented



~30% POs represent 1000 - 50000 members including patients/caregivers

Note: Total members include patients and caregivers who are not formal members of the organization

Disease Area Focus

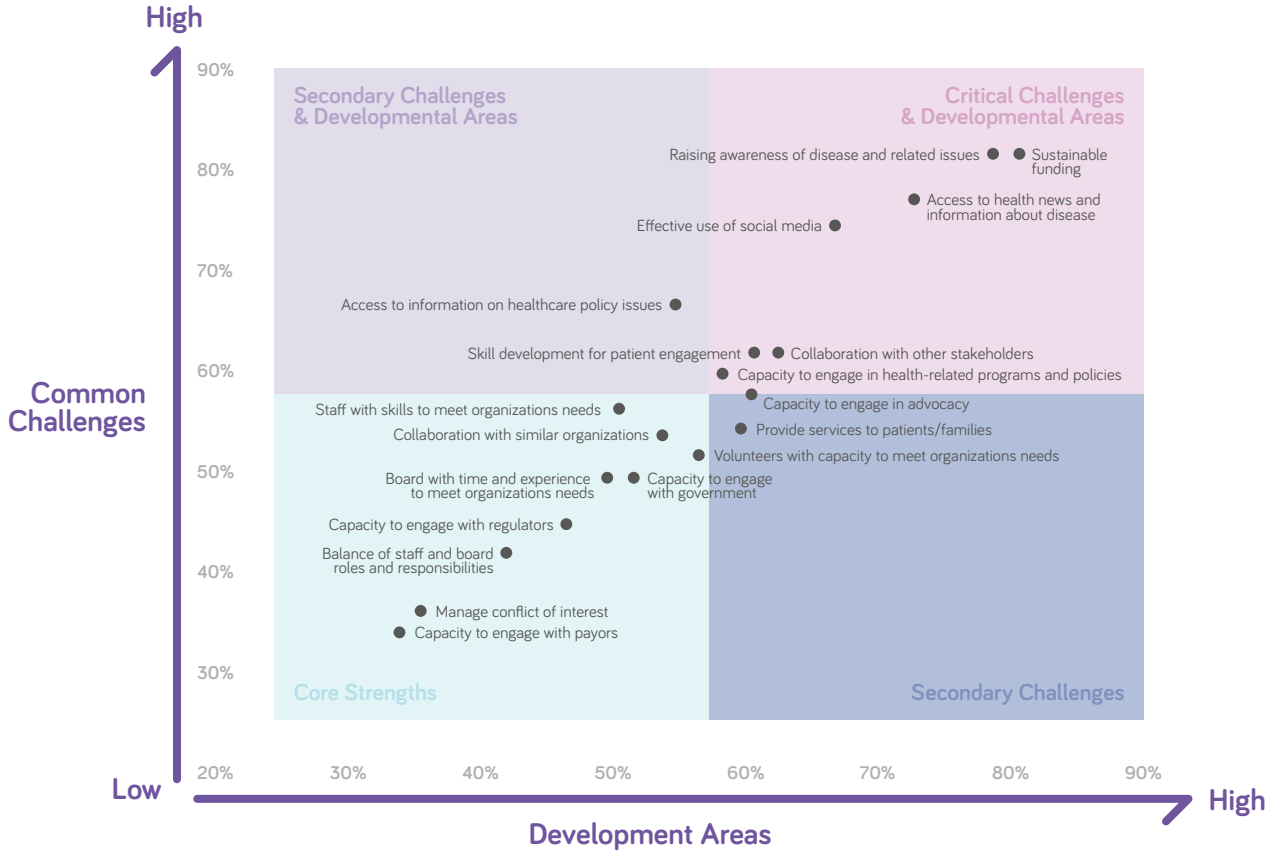


Top to bottom in the order of mentions

- Rare diseases
- Cross diseases areas
- Ophthalmology

Some of the POs also represented disease agnostic umbrella organization

Common challenges and developmental areas



Interest in sharing skills and expertise with other POs



- [1] "UNFPA Asia and the Pacific. Population Trends," [Online]. Available: <https://asiapacific.unfpa.org/en/node/15207>
- [2] "Health at a Glance: Asia/Pacific 2020: Measuring Progress Towards Universal Health Coverage. Chapter 2. The Impact of the Covid 19 outbreak on Asia Pacific health systems," [Online]. Available: <https://www.oecd-ilibrary.org/sites/aaa5448f-en/index.html?itemId=/content/component/aaa5448f-en>.
- [3] "Asia Pacific Front Line of Healthcare Report 2020 Heeding the call to reinvent healthcare delivery," Bain & Company.
- [4] K. PP and S. RR, "The role of patient advocacy organizations in shaping genomic science," *Annu Rev Genomics Hum Genet*, vol. 14, pp. 579 595, 2013.
- [5] DKI Health, "The Growing Role of Patient Advocates".
- [6] CoRE at Duke NUS Medical School Singapore , "Inaugural Roundtable Summit Report Integrating Patient Engagement into Healthcare and Access to Medicines in the Asia Pacific Region," 2019.
- [7] R. Devi, "APPIS 2021 Opening address," in Asia Pacific Patient Innovation Summit, 2021.
- [8] A. Shah, "Patient organizations in the future of healthcare: An outside in perspective," in Asia Pacific Patient Innovation Summit, 2021.
- [9] CONEXTS Market Research, "Asia Pacific Patient Innovation Summit Survey 2021 Quantitative Report," 2021.
- [10] W. L. Foster, P. Kim and B. Christiansen, "Ten nonprofit funding models," *Stanford Social Innovation Review*, Spring 2009.
- [11] Rare Cancers Australia (RCA), "RCA Summit Program Playbook Building stronger patient organisations together," 2018.
- [12] L. M. Sontag Padilla, L. Staplefoote and K. G. Morganti, "Financial Sustainability for Nonprofit Organizations," RAND Corporation, 2012.
- [13] M. Parker, "Case study RCA's digital transformation journey," in Asia Pacific Patient Innovation Summit, 2021.
- [14] T. E. P. I. S. (. 2019, "Patients in the Digital World: the EPIS Call to Action," 2019.
- [15] Lymphoma Coalition, "Lymphoma Care in Asia Pacific Exploration in disparities in care," 2020.
- [16] Healthcare IT News, "65% of hospitals in APAC are increasing spending on digitalisation, says report," [Online]. Available: [https://www.healthcareitnews.com/news/apac/65 hospitals apac are increasing spending digitalisation says report](https://www.healthcareitnews.com/news/apac/65-hospitals-apac-are-increasing-spending-digitalisation-says-report).
- [17] P. Chatterjee, "10 Emerging Startups Innovating Patient Engagement in 2019," [Online]. Available: <https://www.linkedin.com/pulse/10-emerging-startups-innovating-patient-engagement-2019-chatterjee/>.
- [18] M. Boudes , P. Robinson, N. Bertelsen , N. Brooke, A. Hoos , M. Boutin, J. Geissler and I. Sargeant , "What do stakeholders expect from patient engagement: Are these expectations being met?," *Health Expectations*, vol. 21, no. 6, pp. 1035 1045, 2018.
- [19] "UNFPA Asia and the Pacific. Ageing," [Online]. Available: [https://asiapacific.unfpa.org/en/node/15208#:~:text=The%20number%20of%20older%20people,be%20over%2060%20years%](https://asiapacific.unfpa.org/en/node/15208#:~:text=The%20number%20of%20older%20people,be%20over%2060%20years%20)
- [20] T. Victor, A. Stankus and S. Li, "The expanding role of the patient voice In medical decision making," *Value in Health*, vol. 17, pp. A719 A813, 2014.
- [21] Wellthy Therapeutics, "How a digital therapeutics platform helps pharmaceutical partners tap into remote patients across India," [Online]. Available: <https://www.wellthytherapeutics.com/how-a-digital-therapeutics-platform-helps-pharmaceutical-partners-to-tap-into-remote-patients-across-india/>.
- [22] D. Sienkiewicz and C. van Lingen, "The added value of patient organisations," *European Patients Forum*, 2017.
- [23] Reuters Events Pharma, "Successful relationships with patient groups," 1 July 2015. [Online]. Available: <https://www.reutersevents.com/pharma/commercial/successful-relationships-patient-groups>.
- [24] GoodUnited , "How the American Cancer Society Broke Fundraising Records During the 2020 Pandemic," [Online]. Available: <https://www.goodunited.io/successstories/acs>.