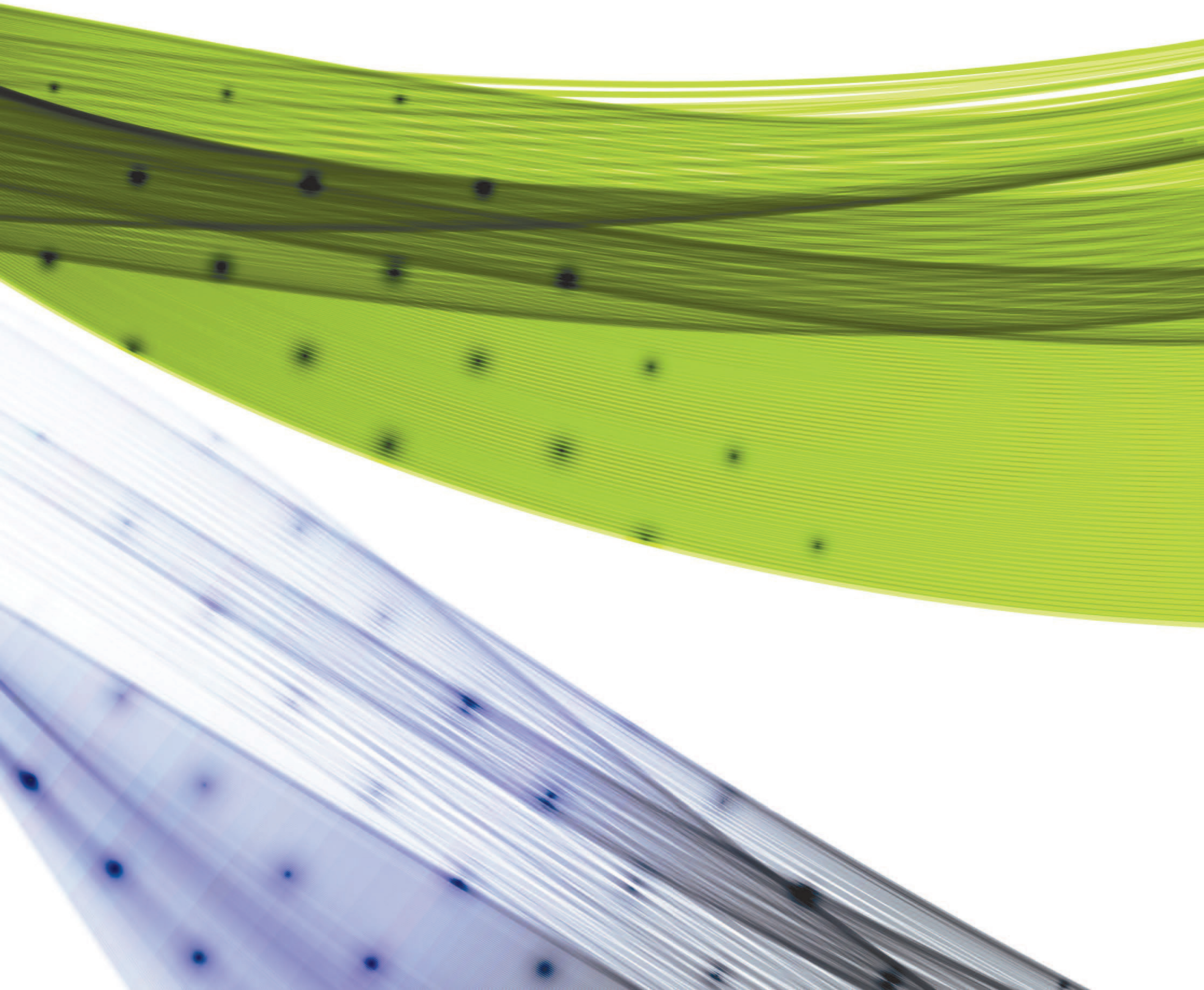
CANCER PATIENT ORGANIZATIONS IN ASIA

Report of findings from a regional survey



Foreword

The conduct of this survey can be seen as the beginning of a process not as a self-contained project. In all societies the people who pay for the health services we use are either tax payers, policy holders or payers in their own right. They are also the patients who use these services and benefit or suffer subject to their efficiency or otherwise. It is, therefore, logical that their voice should be heard and heeded when government and service providers are making decisions that will directly impact patient health outcomes.

As the countries that make up Asia develop and become increasingly prosperous, it is critical that there is a strong representative patient voice providing constructive input into the shape and priorities of health services provided. When we at Rare Cancers Australia (RCA) considered how we might assist in strengthening the patient voice, we established two clear objectives.

The first was to understand as clearly as possible the current capabilities of patient organizations and identify opportunities for improvement. This survey was considered an essential step in that process. From the 180 full and partial responses we are able to see areas of need and potential collaboration, and topics where intense training would be beneficial. In short, we have a starting point with identified areas of need and a comprehensive register of patient organizations within the region.

The second was to identify how RCA and other mature patient organizations can assist by working on a peer to peer basis. Whilst there are differing cultural sensitivities across the region which demand respect, there are also many basic principles that apply to any patient group. As an example, the first and most obvious of these is financial stability, and it is no surprise that fundraising rated uniformly as the most difficult challenge. By establishing an ongoing process where knowledge can be shared across the region we aim to build stronger, more capable organizations that will serve their communities and patients well.

Importantly, strong, stable, capable patient organizations can provide a voice for those who both pay for the health system and rely on it. RCA is committed to the development of these organizations.

Our thanks to AMICULUM®, the sponsors and those patient organizations who responded to the survey. These results are a great beginning.

Richard Vines
Chief Executive
Rare Cancers Australia

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Executive summary

With the projected increase in prosperity and life expectancy in Asia over the next 20 years, the number of patients with cancer in the region is expected to grow, presenting a range of challenges for patients, caregivers, healthcare professionals, governments and the pharmaceutical industry. As the number of patients with cancer increases, it will be important that supporting structures are in place to support patients and their families, and to ensure that they have access to information and guidance on diagnosis, treatments and supportive care.

Rare Cancers Australia (RCA) is a non-profit organization that is committed to improving the lives of patients with rare and less common cancers by promoting the importance of early diagnosis and increasing access to improved treatment options in Australia. The group is also actively involved in advocacy initiatives in the Asia-Pacific region and further afield. These are designed to enhance collaboration and share best practice between advocacy groups in order to optimize the support and information that these organizations provide to their members and the general public.

In order to understand the current activities, reach, and unmet needs of patient organizations from countries across the Asia-Pacific region, in 2016 RCA conducted a survey among advocacy groups and healthcare professionals involved in caring for patients with cancer. The aim was to learn about the current characteristics and aspirations of patient groups in the region as the first step to building a community of organizations who can learn from each other. This report presents the findings of the survey.

The results indicate that there is already a substantial network of organizations within the region and considerable advocacy experience. Many organizations have been established for over 20 years and assist over 1,000 new patients each year. The majority of groups have some paid staff, although there is considerable reliance on volunteers.

About half of the organizations who responded to the survey are focused on providing support to patients with specific malignancies, and the majority already collaborate with other patient groups and healthcare professionals, although they would welcome opportunities to extend collaboration and share experience.

While some organizations are working successfully with government bodies on initiatives to support patients with cancer, in general experience with and confidence in engaging with government bodies is limited. Respondents also reported barriers to engaging with pharmaceutical and medical device companies. This is partly due to a lack of understanding about how industry engages with groups and whom to contact.

Many organizations rely on charitable donations to fund their activities. Fundraising is a consistent challenge for the groups (regardless of the age or size of the organizations and the healthcare expenditure status of their countries) and was identified as the greatest training need. Provision of training programs for organizations in this area may help to increase groups' effectiveness in supporting patients with access to diagnosis, screening and treatment.

Survey background and objectives

Over the next 20 years, prosperity in Asia is predicted to increase dramatically. Consequently, people will live longer and be increasingly vulnerable to a range of cancers, both common and rare. This will present a significant challenge to governments, physicians, patient advocates, healthcare providers and the pharmaceutical industry. To address this challenge and ensure that patients receive the support and guidance they need, RCA believes that it will be critical for patient organizations to work together to share experience and expertise with each other, as well as with other stakeholders in their community.

The aim of this survey was to gather information regarding the current set-up, activities, successes and potential challenges of patient organizations in the region, and to start to build a community of groups that could work together to the benefit of patients and communities. The survey set out to investigate the number and geographical distribution of patient organizations, how they are set up and coordinated, what services they provide, their achievements to-date, and their relationships with each other, national governments and the pharmaceutical and medical device industries. It also sought to gain insight into the barriers to further development, and information and training needs.

The RCA hopes that the organizations that have contributed to this survey will have the opportunity to meet, share ideas and knowledge, attend regional training sessions, and help each other fulfill their potential for the benefit of patients and members involved.

Survey methodology

The survey was developed, conducted and analyzed with support from AMICULUM®, a healthcare consulting and communications agency, in consultation with RCA. Funding for conduct of the survey was provided in the form of unconditional grants from Amgen, Baxalta, Bristol-Myers Squibb, Janssen, MSD, Novartis, Pfizer and Roche. Sponsors of the survey were given an opportunity to review and make suggestions on an advanced draft of the questionnaire, but RCA was responsible for the final content of the survey.

Patient organizations and healthcare professionals engaged in treating or managing patients with cancer across 18 countries in the Asia-Pacific region were approached and invited to participate in the survey (Figure 1). Organizations and individuals were identified via searches of public domain sources, in addition to recommendations provided by RCA, AMICULUM® and the survey sponsors.

The final version of the questionnaire was translated into seven languages (Chinese, English, Indonesian, Japanese, Korean, Thai and Vietnamese) by third-party, professional translators and made available in online and paper versions to potential respondents via email. A copy of the survey questionnaire can be found in Appendix B.

The survey was launched in May 2016 and the questionnaire was available until August 2016. Regular email reminders were sent to invited organizations and groups were also asked to promote the survey within their own networks. During July and August, a telephone follow-up campaign was conducted to encourage participation.

The survey was closed at the end of August and findings were collated for analysis. Answers submitted in languages other than English were translated to English by the professional translators.

Responses in which no questions were answered were excluded from the analysis. Suspected duplicate entries (those with identical IP addresses and answers) were also removed.

For some questions, respondents were asked to choose answers from a number of options and then rank their choices. For these questions, a scoring method was applied, whereby the highest ranked answer received the most points and unselected answers received no points. This approach was adopted in order to reflect the rank given to each answer in addition to the frequency with which an answer was selected. This methodology is explained further in Appendix A.

During analysis of the findings, data were also further stratified according to the age of the responding organizations and the healthcare expenditure per capita of the countries where the organizations are based. For the latter stratification, the organizations were divided into two groups for comparison: those from countries with national healthcare expenditure per capita over and under USD 1,000. These were also compared with organizations from Australia (healthcare expenditure per capita USD 6,258[1]).

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1. World Health Organization, Global Health Observatory, accessed November 2016: http://apps.who.int/gho/data/view.main.HEALTHEXPCAPAUS?lang=en

Survey results

The survey was distributed to 18 countries (Figure 1), and responses were received from 17 of these. Almost half of the responses were from patient organizations in Australia, Vietnam and India. A total of 183 responses were received (77 full, 106 partially completed).

		Number of respondents
■	Australia	38
■	Vietnam	28
■	India	21
■	Philippines	12
■	Hong Kong	11
■	China	10
■	Japan	10
■	Taiwan	10
■	New Zealand	9
■	Singapore	8
■	Malaysia	6
■	Pakistan	6
■	South Korea	5
■	Thailand	4
■	Indonesia	3
■	Cambodia	1
■	Myanmar	1
■	Laos	0

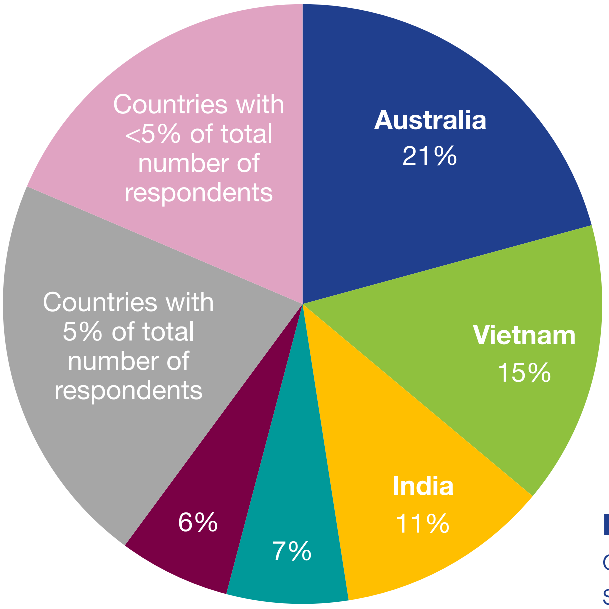


Figure 1. Number of organizations who responded, stratified by country.

Each question in the survey was analyzed according to the number of respondents who answered that question, and not the total number of respondents for the questionnaire overall. As a result, the numbers used for individual question analyses vary.

Profiles of the patient organizations

Many of the groups who responded are well established.

The majority of organizations were set up at least 10 years ago and 28% have been established for over 20 years (Figure 2). This shows there is considerable advocacy experience within region.

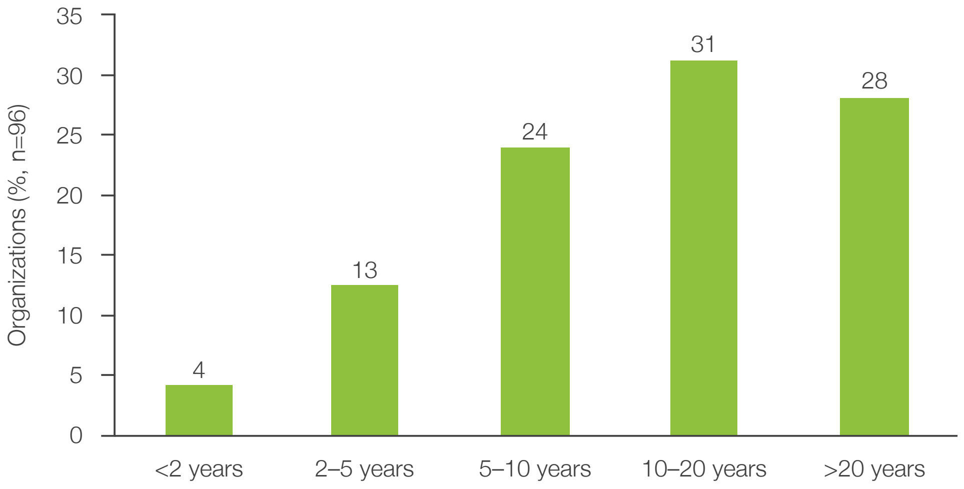


Figure 2. Age of patient organizations.

Over half (54%) of the organizations who responded specialize in supporting patients with a specific type or categories of cancers. These included organizations that focus on breast, gynecological, digestive tract, lung and brain cancers, as well as hematological and pediatric malignancies.

The majority of organizations (72%) have paid members of staff, with 65% having full-time paid members (Table 1). However, the number of full- and part-time staff in individual organizations tended to be low (a median of 6 and 4, respectively), especially in comparison to the number of volunteers (a median of 30). Organizations were composed of a diverse range of individuals from different backgrounds, including healthcare professionals, researchers, counselors, cancer patients and cancer survivors.

	Number of organizations with staff (%)	Median (range) number of staff per organization
Full-time paid staff	62 (65)	6 (0–250)
Part-time paid staff	47 (49)	4 (0–20)

Table 1. Full-time and part-time staffing within patient organizations (n=96).

There was a large range in the number of new patients the organizations support each year. 32% of organizations assist over 500 new patients annually, whereas 34% are helping fewer than 100 new patients each year (Figure 3).

Organizations that have been established for less than 10 years tend to work with a smaller number of patients, with only 41% providing support to over 100 patients per year. In contrast, organizations that have been established for more than 10 years assist more patients, with 70% helping over 100 patients per year. This suggests that it may take time or is challenging for organizations to extend their support to larger numbers of patients. Organizations that specialized in supporting patients with a particular type or group of malignancies tended to support fewer new patients per year than organizations without a specific focus (Supplementary Figure 1).

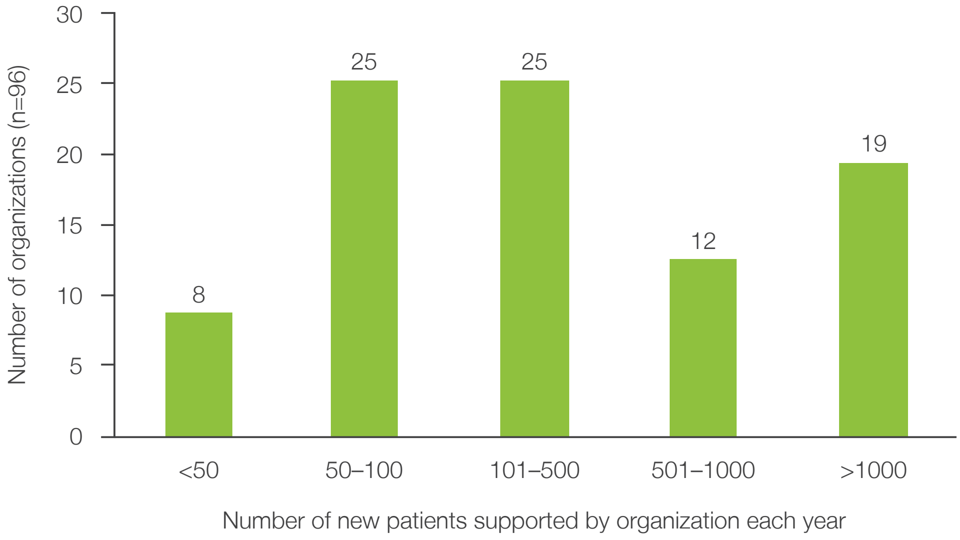


Figure 3. Number of new patients with cancer supported by organization each year.

Seven respondents (7%) answered this question stating they did not know the number of new patients their organization supported each year.

The greatest proportion of patient organizations' funding is from charitable donations.

When asked about their main sources of funding: 83% of organizations stated charitable donations, 53% cited corporate sponsorship and 35% listed funding from the state, government or healthcare bodies (Figure 4). Some organizations stated that they did not accept funding from industry or government due to concerns that this could compromise the independence of their activities. For the organizations that selected "Other" as a main source of funding, some responses could also be considered donations or grants, e.g. "Donation boxes and events" (India), "[From] people abroad" (India), "The hospital's fund and charity funds" (Vietnam), "Voluntary contributions from patients" (Vietnam) and "[From the] Victorian government" (Australia).

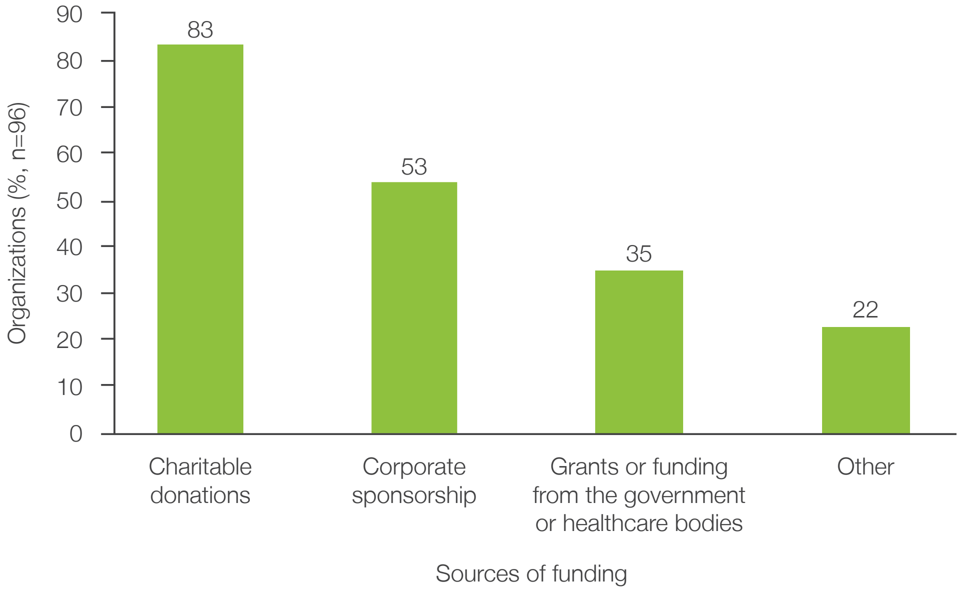


Figure 4. Key sources of funding for patient organizations.

Additional information provided by respondents*

“I am a cancer survivor of 13 years. I formed this foundation in 2003 as a non-governmental organization to support cancer patients, especially children. Currently, I am the Managing Trustee” (India)

“I am a cancer survivor and motivational speaker” (India)

“All our members are volunteers; including medical doctors, education counselors, families of cancer patients and cancer survivors” (Philippines)

“We also rely on thousands of volunteers” (New Zealand)

“It is difficult to state volunteer numbers, as they are on an as-needed basis. There is no formal registration” (Malaysia)

“I am the founder and president of this organization. We have no paid staff. All members are volunteers” (Myanmar)

“We do not accept government or corporate funding to ensure the independence of our advocacy voice” (Australia)

**Responses have been copy edited*

Organizations' approaches to communications and alliances

Digital channels are frequently used by patient organizations to communicate with members and the public.

Over 60 organizations engage with members and the public by means of Facebook at least once a week, and often these are daily communications (Figures 5 and 6). Organization websites were also frequently updated, and most organizations contacted their members via email at least once a month. Of those organizations using Twitter, Instagram, WhatsApp or WeChat, the majority used these media at least once a week.

While digital communications are the main method for regular correspondence with members and the public, meetings and forums remain an important channel. Over half of the organizations who responded engage with members via a meeting or forum at least once a month. Similarly, of those organizations that communicate with the public through meetings or forums, 70% do so at least every quarter.

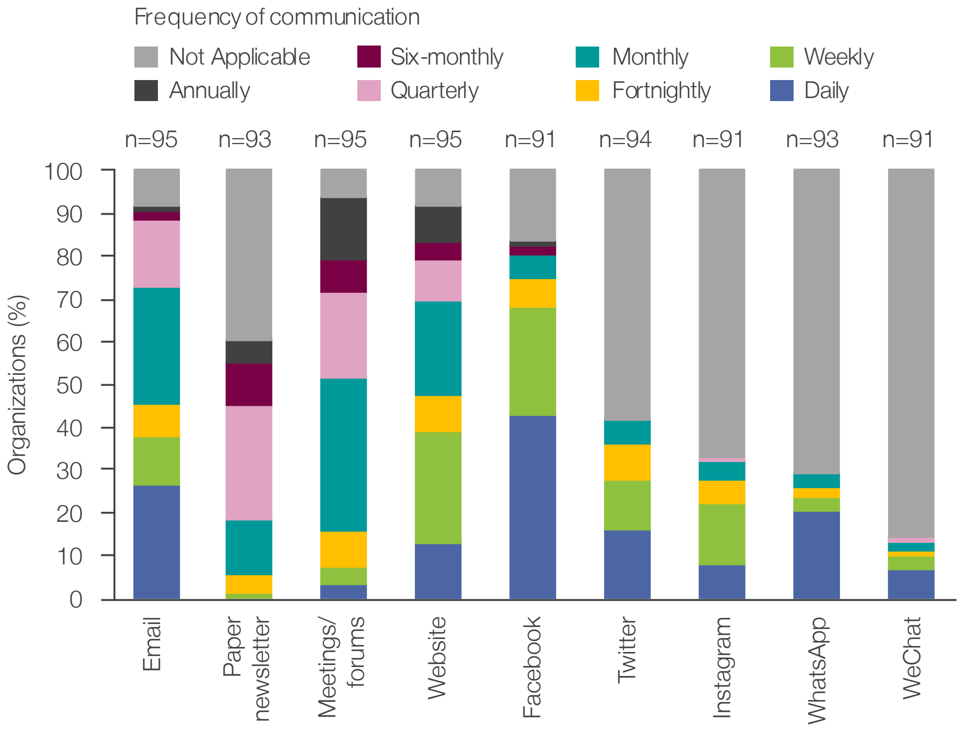


Figure 5. Methods and frequency of communications between patient organizations and their members.

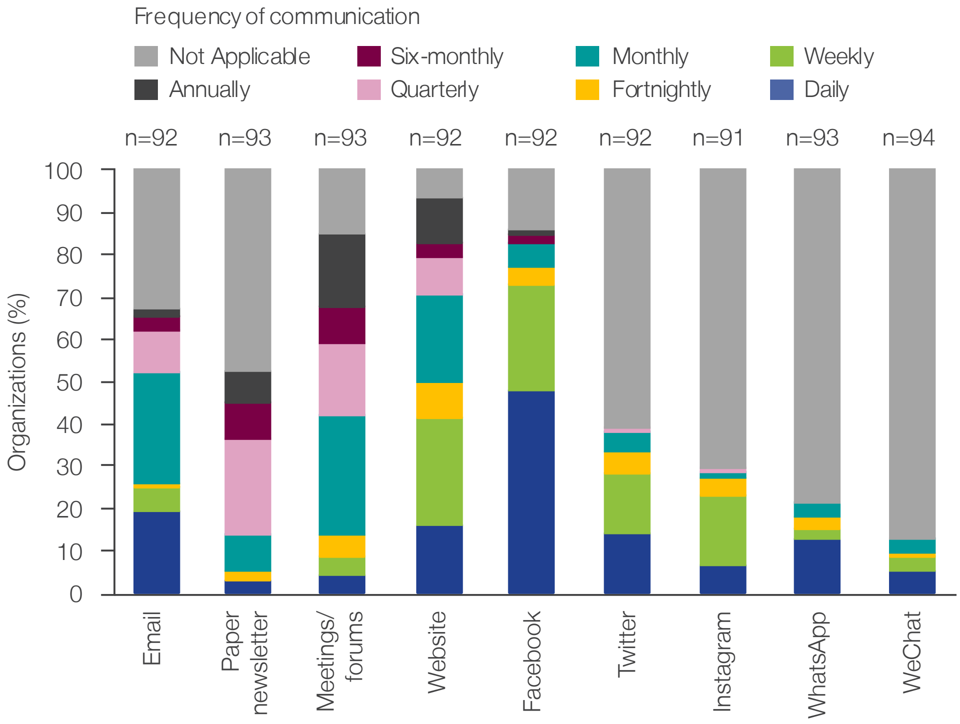


Figure 6. Methods and frequency of communications between patient organizations and the public.

The majority of the patient organizations have alliances of some kind with other patient groups and healthcare professionals.

Of the organizations that responded to the survey, 73% stated they allied with other patient groups, and 65% ally with healthcare professionals (Figure 7). Almost half (46%) work with pharmaceutical or medical device companies, whereas 38% have connections with government stakeholders. A few organizations (8%) stated they did not ally with any other groups.

In general, organizations that have been established for more than 10 years were more likely to ally or communicate with external partners compared with those established for less than 10 years (Supplementary Figure 2). With regard to alliances with pharmaceutical companies, however, the pattern is different. Here, 50% of organizations established for less than 10 years allied with industry versus 44% of longer established organizations.

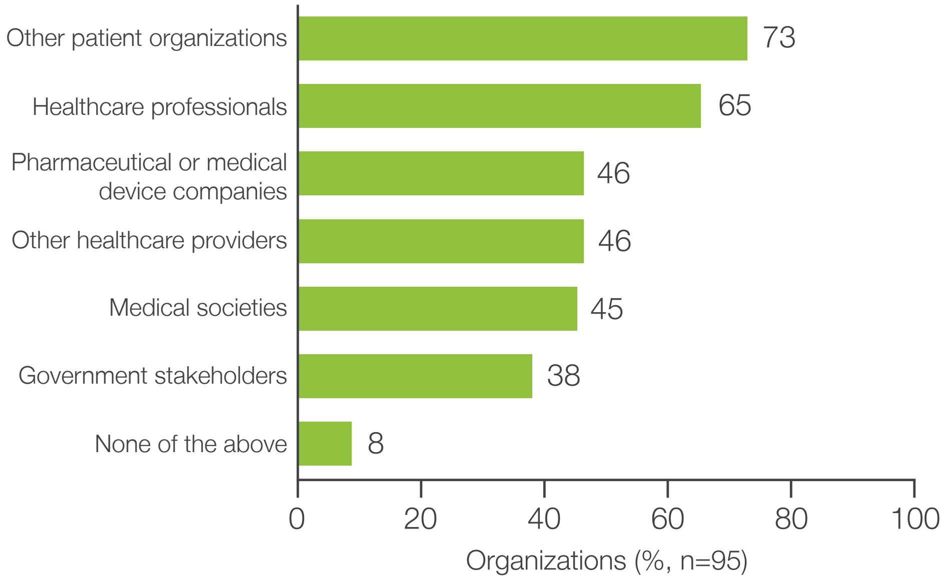


Figure 7. Alliances between patient organizations and other groups.

Additional information provided by respondents*

“We are an umbrella organization with alliances with those providing support for patients with brain tumors. This includes formal alliances with other patient organizations, and less formally with many other organizations including medical and other peer-to-peer support groups. Alliances include some big Pharma, but also some small scale” (Australia)

“We guard our independence but cooperate with some other bodies on either an ad-hoc or regular basis. We have a clear policy not to accept funding from commercial Pharma companies” (Australia)

“We work closely with the Hospital Authority medical personnel and in some hospitals as part of their team. We do purchase medical equipment for hospitals from medical device companies. And we collaborate with other non-government organizations” (Hong Kong)

“We seek to work with and influence the above stakeholders/ decision-makers [referring to the groups listed in Figure 7] in the interests of people affected by cancer; i.e. not formal alliances per se, but good working partnerships” (Australia)

“We receive referrals through local hospitals and allied health agencies, also through other patients, not-for-profits organizations, etc.” (Australia)

“We have worked and partnered with other communities such as artists, magicians, and storytellers in organizing events to entertain the patients” (Indonesia)

“We engage with medical societies to educate health professionals, and also with pharmaceutical companies who provide acknowledged sponsorship of specific activities/events” (Australia)

“Our main aim is to share the knowledge from engineers and medical professionals with pharmaceutical industries to produce cost-effective diagnostic tools for cancer patients. The economic burden of cancer care is one of the major road blocks” (China)

**Responses have been copy edited*

Organizations' activities, successes and future projects

Raising public awareness and providing information and support for patients are the most common activities for the patient organizations.

Over 80% of organizations devote time to raising public awareness of the needs of cancer patients and to supporting patients as well as their families and caregivers (Table 2). Only a minority of organizations actively raise funds for cancer screening and diagnosis or research.

Over half (54%) of patient organizations stated they engage with government decision-makers; this is a greater number than those who stated they allied with government agencies (38%, Figure 7), perhaps indicating that some organizations see their relationship with government agencies not as an alliance, but as a working relationship to ensure patients' voices are heard.

Activity	Organizations (%, n=96)
Providing information and support for patients with cancer	88
Raising public awareness of the needs of patients with cancer	85
Providing information and support for patients' families and caregivers	85
Engaging with government decision-makers and departments to ensure the patients' voice is represented	54
Raising funds for treatment for patients	45
Engaging with pharmaceutical and/or medical device companies	40
Engaging with medical societies	31
Raising funds for cancer screening and diagnosis	30
Raising funds for cancer research	25

Table 2. Proportion of organizations that engage in the described activities. Respondents were asked to select which activities their patient organization supported.

The most commonly undertaken activities are also those where the patient organizations feel they have been most successful.

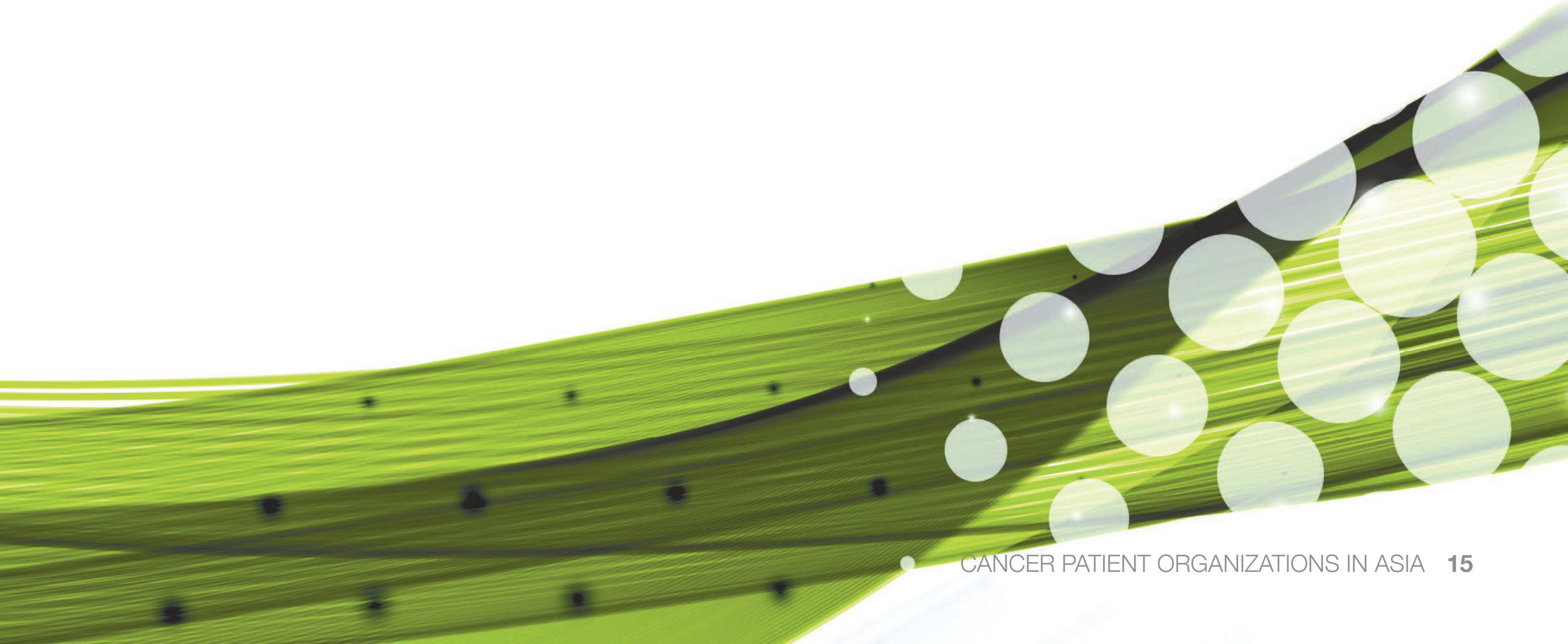
When rating their execution of initiatives and activities, organizations were most satisfied with their ability to provide patients and their families with information and support (Supplementary Table 1). Organizations were least satisfied with their effectiveness at raising funds for cancer research, treatment or diagnosis, and in engaging with government bodies.

In terms of future activities, patient organizations are mostly looking to continue their work in raising public awareness and providing support and information for patients, families and caregivers (Table 3).

Two thirds of organizations plan to engage with government in the future compared with 54% who currently have activities in this area. Approximately one third (36%) of groups intend to engage with pharmaceutical or medical device companies in the future. Only a minority of patient organizations listed fundraising for cancer treatment, diagnosis and research as predicted future initiatives.

Activity	Organizations (%, n=94)
Raising public awareness of the needs of patients with cancer	78
Providing information and support for patients’ families and caregivers	75
Providing information and support for patients with cancer	73
Engaging with government decision-makers and departments to ensure the patients’ voice is represented	66
Engaging with medical societies	43
Raising funds for treatment for patients	37
Engaging with pharmaceutical and/or medical device companies	36
Raising funds for cancer screening and diagnosis	32
Raising funds for cancer research	32

Table 3. Proportion of patient organizations planning to engage in the described activities in the future. Respondents were asked to select which activities their patient organization planned to support in the future.



Additional information provided by respondents*

Initiatives that organizations were most proud of include:

"Youth smoking prevention awareness programs" (Philippines)

"Instituting an award for doctors in the area of cancer care for the rural poor" (China)

"Fundraising for free mammogram screenings for the underprivileged" (India)

"A toll-free national helpline, available all day, 365 days of the year" (New Zealand)

"Our Resource and Wellness Center for the survivors and their caregivers with art classes, with their first exhibition this year" (Malaysia)

"Cervical cancer screening for underprivileged women" (India)

"Provision of consultations, diagnostic services and cancer treatments at subsidized rates for general public" (Pakistan)

"Lung cancer nursing roles and telephone support groups" (Australia)

"I believe we were the first organization to actually offer financial help for patients with gastrointestinal cancers to pay for their treatment" (Australia)

"Peer counseling, concert fundraising, and Christmas caroling for patients" (Philippines)

"Being the pioneer in the field of preventative screening for over 33 years" (India)

"We have senior nurses in disease-streamed care coordinator positions to assist patients navigate the process of diagnosis, treatment and follow-up of their blood cancer" (Australia)

"We provide camps for children with cancer. In these camps, we integrate parent support groups in concurrence with children's activities" (Australia)

"Providing home-based palliative care to patients with advanced disease" (India)

**Responses have been copy edited*

Engagement with government

Approximately half of the patient organizations (54%) engage with government stakeholders to raise awareness of cancer patients' perspectives and contribute to policy development.

Examples of successful government engagement initiatives conducted by the organizations included:

- Awareness campaigns
    - Cooperation with the Department of Education (Philippines)
    - Holding events at parliament houses in capital cities (Australia)
    - Launch of a report on rare cancers (Australia)
- Networking initiatives
    - Orchestrating meetings between cancer patient groups (Philippines)
    - Hosting symposia in government institutions (Philippines)
    - Assisting patients in writing letters to their local government (China)
- Prevention and screening initiatives
    - Involvement in skin cancer prevention awareness (Australia)
    - Cervical and oral cancer campaigns in regions where these diseases cause significant mortality (India)
    - Tobacco-cessation advocacy programs (Australia, Malaysia)
- Facilitating access to treatment
    - Encouraging prosthesis subsidies for patients with breast cancer (Malaysia)
    - Abolition of government sales tax on cancer drugs (Malaysia)
    - Assisting in provision of free medicines for patients with chronic myeloid leukemia and myelofibrosis (Pakistan).

A lack of expertise in government health policy or relations is the most common barrier for organizations when engaging with government. Of the patient organizations that responded, 28% cited this lack of expertise as their biggest challenge in working with government. 21% of groups stated that their greatest challenge was their government's reluctance to engage with advocacy groups, while 13% felt their biggest hurdle was that they did not have sufficient data or evidence to support discussions with government.

Three general themes emerged when organizations discussed the requirements they needed to enhance their ability to engage with government:

- Skills and knowledge:
    - Negotiations skills (Singapore)
    - Economic and statistical modeling capabilities (Australia)
    - Knowledge of how to collect robust data and evidence to support policy changes (Philippines)
    - Training to develop more patient advocates (Malaysia)
- Access to government:
    - Identifying and contacting individuals or departments in government who can support advocacy groups (Philippines)
    - Inclusion in discussions regarding policy issues (Malaysia)
- Resources: People, time, and money:
    - *"We have the knowledge and skill, and increased funding would help us disseminate the research findings and information" (Australia)*
    - *"Time: we are often so focused, tied up with service delivery, it can be difficult to re-focus onto government engagement" (Australia).*

Additional information provided by respondents*

“A challenge we face is convincing government officials that palliative care is a human rights issue” (India)

“A challenge we face is the government’s lack of knowledge about what we do” (Australia)

“We do not want our organization to be mixed up in politics” (Philippines)

“We are invited to sit down in the Department of Health’s National Cancer Control and Prevention Council” (Philippines)

“Childhood cancer treatment has been supported well by our government healthcare system” (Thailand)

“Due to efforts initiated by our department and negotiations with government and pharmaceutical companies, thousands of patients suffering from Chronic Myeloid Leukemia are being provided free medicines” (Pakistan)

“We are involved as one of the stakeholders in drawing a national, budgeted, cancer control plan in 2016” (Myanmar)

“We provide input to advisory committees and engage with health ministers” (Australia)

“There are plans set in motion to engage with government to increase health coverage for cancer patients, and institute reforms that would grant patients discounts on medications, etc.” (Philippines)

“We advocate on behalf of women diagnosed for better treatment options and access to clinical trials” (Australia)

“We are invited by the government to give our opinion on various cancer control measures” (India)

“Our organization is wary of becoming too politicized and negating our image of being impartial” (Philippines)

“We have engaged in the past, but no longer have the people or time to make this happen” (New Zealand)

“We have organized 4 large round tables for health policy makers to make them aware of the relevance of HPV vaccine in our country, so that it can be included in the country’s national immunization program” (India)

“We give training to government employees” (India)

“We engage in dialogue with the Minister of Health, engage social media communication with the Minister of Finance, engage employees in the social security sector to promote funding for cancer care, and engage with the insurance sector to create better insurance packages for the public” (Malaysia)

**Responses have been copy edited*

Engagement with pharmaceutical and medical device companies

Over two thirds (68%) of patient organizations reported that they were willing to engage with pharmaceutical companies. However, 43% of these would only do so with conditions in place.

Around a third (32%) of organizations do not currently engage with pharmaceutical or medical device companies.

41% of organizations received financial or other support for specific activities, and 18% received help from industry for their operations (Figure 8). Patient organizations also frequently partner with pharmaceutical companies for awareness activities.

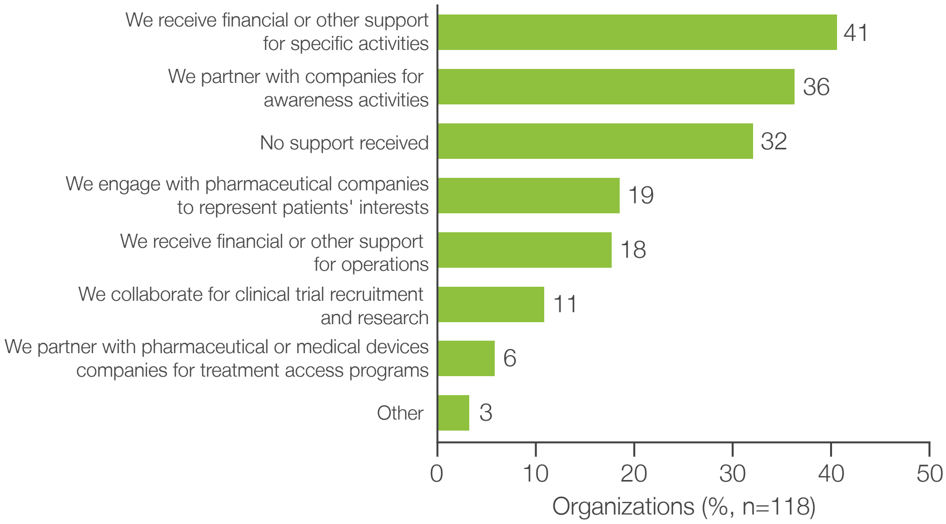


Figure 8. Engagement between pharmaceutical and medical device companies and patient organizations.

Patient organizations face various challenges in engaging with the pharmaceutical industry:

- 20% of organizations felt they did not understand how pharmaceutical or medical device companies engage with patient organizations
- 12% said a lack of data or evidence to support discussions with the pharmaceutical or medical device industry was a barrier they faced
- 17% felt they did not know how to go about contacting pharmaceutical or medical device companies.

Some patient organizations referred to ‘questionable ethics’ and ‘conflicts of interest or priorities’ as barriers for engaging with the pharmaceutical industry, although this issue was not cited frequently.

Additional information provided by respondents*

"While we are happy with our Pharma partners, we wish there were more" (Philippines)

"Pharmaceutical firms refrain from providing financial support or sponsorships during our fundraisers" (Philippines)

"We partnered with a Pharma firm to help set up our website. This made a big difference to us" (Australia)

"We engaged with industry in a presentation to Parliamentarians about blood cancers and the impact it has on patients and families" (Australia)

"We have negotiated better compassionate access for specific patients in need" (Australia)

"Our Volunteer Program in hospitals has provided opportunities for members of the Pharma industry to share their time and talent with the pediatric patients" (Philippines)

"We guard our independence" (Philippines)

"Our primary goal is to provide peer support to women from a positive personal perspective and we do not give medical advice. We would need to tread carefully if seeking engagement with industry" (New Zealand)

"Pharma companies are highly regulated in terms of the support they can provide patient support groups" (Philippines)

"The cumbersome grant application process is a barrier to engaging with industry" (Australia)

"Industry support has been valuable in providing educational forums for the public" (Australia)

"As a consumer-based organization, we have always committed to complete independence and never promoting particular brands, etc. We see our role as informing women about what is available and promoting freedom of choice" (Australia)

"Our focus is psychosocial and palliative care, likely not of pharmaceutical company interest" (Thailand)

"We engaged with industry to help deliver the launch of HPV vaccination programs" (Australia)

"We are not sure what we can offer and how partnership [with industry] would work" (New Zealand)

**Responses have been copy edited*

Challenges faced by patient organizations and patients

Perceptions of success

Patient organizations were hesitant to say they were “very successful”.

When asked to rate the success of organizations in their country on a scale of 1 to 4, where 1 is ‘not successful’ and 4 is ‘very successful’, the average score across all responding patient organizations was 2.29. This may be an indicative of high standards and ambitions of the organizations, rather than a true reflection of their performance and achievements.

Challenges

Overall, patient organizations view fundraising as their biggest challenge.

Patient organizations were asked to select and rank the 5 biggest challenges they faced from a list of 12 options. Fundraising was considered the greatest barrier overall (Table 4), with 36% of organizations selecting this as their number one challenge. Communication with the public, availability of volunteers and engaging with government were also highlighted.

Overall ranking	Challenge
1	Fundraising
2	Engaging effectively with government bodies and stakeholders
3	Availability of volunteers
3	Communication with the general public
5	Communication with members
5	Engaging with the media
5	Engaging with healthcare professionals
8	Retention of volunteers
9	Interaction and knowledge sharing with other patient organizations
10	Engaging effectively with the pharmaceutical and medical device industry
11	Engaging with medical societies

Table 4. Ranking of challenges faced by patient organizations (n=96). Respondents were asked to choose and rank the top 5 challenges from the list of 12 options above.

Organizations that have been established for more than 10 years ranked key challenges differently from the organizations that are less than 10 years old (Supplementary Tables 2 and 3). Both groups ranked fundraising as their biggest challenge, but longer established organizations regarded engaging with the government as a bigger challenge than organizations established for less than 10 years.

Training and unmet needs of patients

The survey also asked patient organizations to rank training requirements and patient needs from a list of options. The full results are in Appendix A (Supplementary Tables 4 and 5).

Patient organizations listed fundraising as their biggest area of training need. Social media platforms, public awareness campaigns and patient rights were also highlighted as areas where training is required.

Patient organizations ranked support for daily living and other practical matters as the biggest unmet need for patients. The following were also highlighted:

- Access to clinical trials
- Access to medication and other treatment (e.g. surgery, radiotherapy)
- Government policy supporting development and approval of new cancer treatments

A number of organizations commented that all the options presented in the questionnaire were unmet needs (Supplementary Table 5), and that it was difficult to rank the options presented.

Overall, patient organizations consider fundraising as their greatest challenge, regard their performance in this area as poor, and identify this as their most pressing training need. However, only a minority of organizations participate in fundraising and few plan to embark on this in the future, which could be due to limited success to-date. If patient organizations had better training and more positive experience to build on, more organizations may be inclined to actively engage in fundraising activities in the future.

Additional information provided by respondents*

"Most support groups are not active as they lack funding and are mainly volunteer-based" (Malaysia)

"The main challenge is lack of coordination among all the stakeholders and finding space for new research or technology in media so that proper dialogue could be initiated" (India)

"The avenues for communication with government, pharmaceutical, medical societies, etc., exist yet it is an issue of capacity. Our primary focus is the needs of the patients and this takes priority in the allocation of our very limited resources, nominal volunteers (i.e. patients/caregivers who are healthy to participate in a meaningful way as opposed to needing the services themselves) and budget constraints. There is also a competitive environment between like-minded charities and organizations – also seeking funding and a limited mindset of collaboration – which is unfortunate as it is our belief the patient must come first and not charity/organizational politics" (Australia)

"Advocacy for diseases affecting very small numbers of young patients often drowns out attempted advocacy on behalf of a much greater number of older patients due to differences in ability to utilize social media and inherent community bias to sympathize with children/younger people" (Australia)

"A key challenge is engaging government on the importance of patient representation on bodies that deal with patient issues" (Philippines)

"We need more collaboration on policy matters both between patient groups and with the broader cancer community" (Australia)

"We do not have any information or evidence to support the necessary discussion" (Vietnam)

"One challenge is the willingness of the patients themselves to come out and participate in the support program" (Malaysia)

"From the point of view of awareness, one challenge is the social stigma and the feeling that 'it won't happen to me'" (India)

"We need a democratic platform, completely independent of the pharmaceutical sector, to provide a unified voice with common key messages to government, industry and healthcare professionals" (Australia)

"There is a need for more cooperation, a willingness by the more successful groups to teach and mentor the younger or smaller ones, to unite and have clout when dealing with the government or pharmaceutical companies" (Philippines)

**Responses have been copy edited*

Analyzing organizations' responses according to the healthcare expenditure of their countries

Using 2013 data from the Global Health Observatory data repository and other sources[1–3], we stratified the results of the survey by the healthcare expenditure per capita (HEpc) of the country in which each organization is based. The breakdown of countries by their healthcare expenditure can be found in Supplementary Table 6.

The HEpc ranged from USD 18 (Myanmar) to USD 6,258 (Australia). In eleven of the countries included in the survey, the HEpc is less than USD 1,000, and there were 92 (50%) responses from organizations in these countries. There were 53 (29%) organizations from the remaining six countries with an HEpc over USD 1,000, excluding Australia (n=38). We used this stratification to further analyze the data in order to determine if there were differences in the profiles of patient organizations in Australia compared with other countries with a 'higher' HEpc and those with a 'lower' HEpc.

Profiles of organizations

Overall, organizations from countries with a lower HEpc were longer established than those from countries with an HEpc ≥USD 1,000 (Figure 9).

In total, 64% of organizations from countries with a lower HEpc have been established for over 10 years, and 33% over 20 years old. In contrast, 52% of organizations from countries with a higher HEpc have been established for over 10 years, with only 19% over 20 years old. 58% of organizations from Australia have been established over 10 years. It is interesting to observe that the lower HEpc status of some countries has not influenced the establishment and endurance of patient organizations.

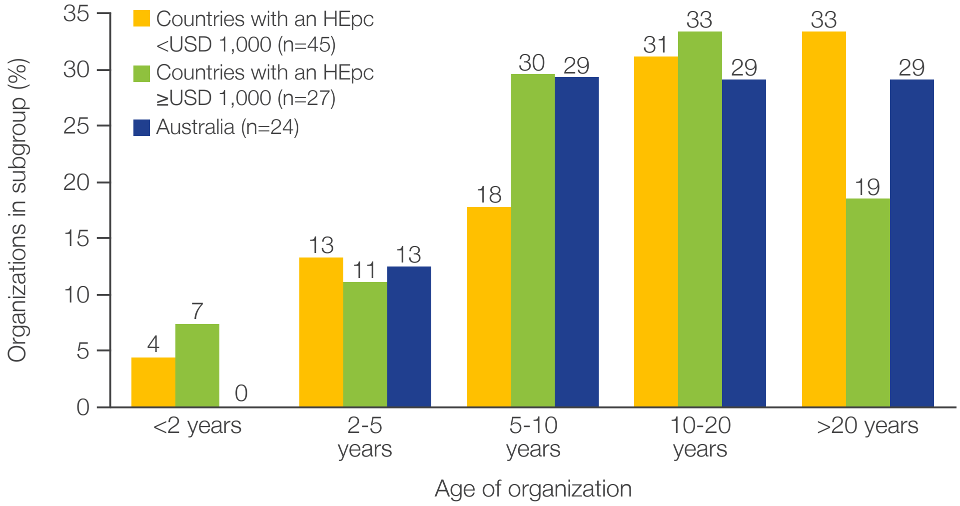


Figure 9. The age of patient organizations stratified by the healthcare expenditure per capita of their country.

Organizations from countries with an HEpc ≥USD 1,000 support fewer new patients per year than those from Australia and countries with a lower HEpc (Figure 10).

Only 23% of patient groups from countries with a higher HEpc supported over 500 new patients per year, compared with 36% of organizations from countries with a lower HEpc and 39% of Australian organizations. These data suggest the organizations from countries with a lower HEpc are not inhibited from supporting a large number of new patients each year. Overall, organizations from Australia supported the greatest number of previously unseen patients, with only 22% of respondents stating their organization supported fewer than 100 new patients per year.

1. World Health Organization, Global Health Observatory, accessed November 2016: http://apps.who.int/gho/data/view.main.HEALTHEXPCAPAUS?lang=en
2. Hong Kong Food and Health Bureau, accessed November 2016: http://www.fhb.gov.hk/statistics/cn/dha/dha_summary_report.htm
3. Taiwan Ministry of Health and Welfare, accessed November 2016: http://www.mohw.gov.tw/CHT/DOS/DM1_P.aspx?f_list_no=557&fod_list_no=365&doc_no=48453&rn=85043734

However, the number of organizations who responded stating they did not know the number of new patients that were seen each year varied between the three groups, and this must be considered when drawing firm conclusions on these data.

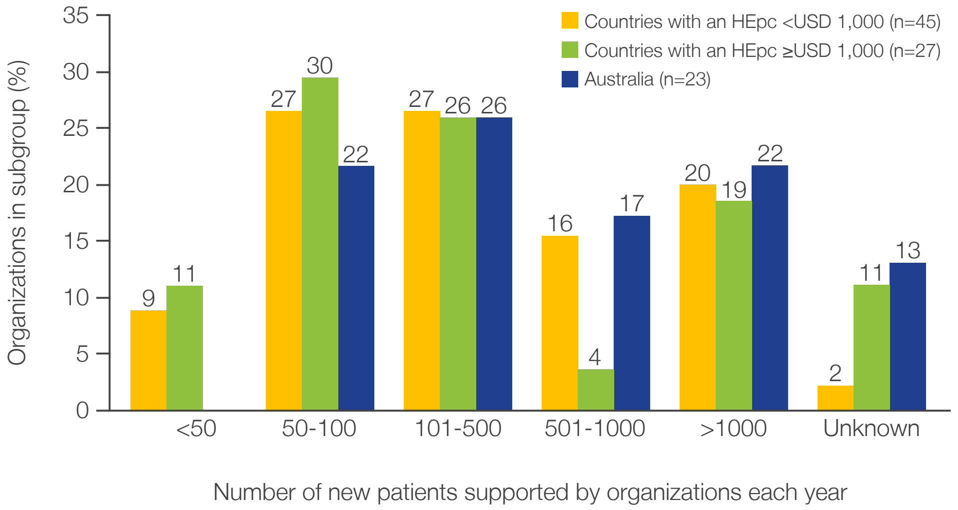


Figure 10. The number of new patients that patient organizations support each year, stratified by the healthcare expenditure per capita of the organizations' country.

Funding

Sources of funding differ between Australia and organizations from other countries with an HEpc over USD 1,000 (Figure 11).

Only a third (33%) of organizations from Australia reported receiving corporate sponsorship, which is a lower proportion compared with that of other countries with an HEpc ≥USD 1,000 and that of lower HEpc counties (59% and 60%, respectively). Fewer groups from countries with a lower HEpc receive monetary funding from government.

For all groups, the most commonly reported source of funding was charitable donations.

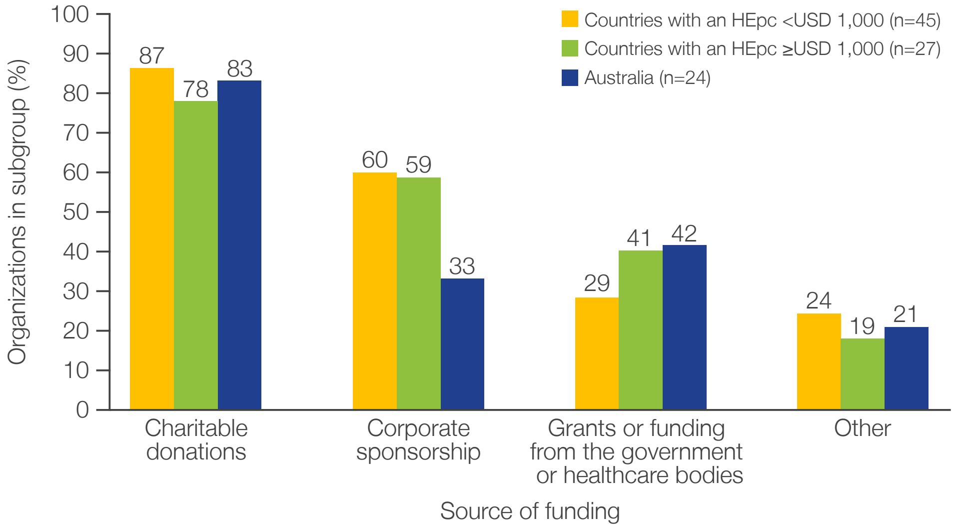


Figure 11. Main sources of funding for patient organizations, stratified by healthcare expenditure per capita.

Activities

Organizations from Australia and from higher and lower HEpc countries are active in different ways.

For all three groups, the activities most frequently undertaken by patient organizations were providing information and support for patients and their families and caregivers, and raising public awareness of the needs of patients with cancer (Table 5).

A far greater proportion of organizations from Australia engage with government decision-makers compared with organizations from other countries. This is also true for the proportion of organizations that raise funds for cancer research, and that engage with industry and medical societies.

A greater proportion of organizations from countries with a lower HEpc raise funds for treatment of cancer patients, and for screening and diagnosis of cancer, compared with countries with an HEpc ≥USD 1,000 and compared with Australia.

Activity	**Proportion of organizations supporting each activity (%)**		
	Organizations from countries with HEpc <USD 1,000 (n=44)	**Organizations from countries with HEpc ≥USD 1,000 (n=27)**	**Australia (n=24)**
Providing information and support for patients with cancer	95	81	83
Providing information and support for patients' families and caregivers	82	93	88
Raising public awareness of the needs of patients with cancer	89	85	83
Engaging with government decision-makers and departments to ensure the patient voice is represented	43	44	88
Engaging with pharmaceutical and/or medical device companies	39	22	63
Engaging with medical societies	30	22	46
Raising funds for cancer research	16	15	54
Raising funds for cancer screening and diagnosis	52	7	17
Raising funds for treatment for patients	73	22	21
Other	14	7	25

Table 5. Proportion of patient organizations from Australia and countries with higher and lower healthcare expenditure per capita that support various activities.

Engaging with government and industry

Compared with organizations from other countries, a greater proportion of patient organizations from Australia are in alliances with government stakeholders and with pharmaceutical companies (Figure 12).

About a third of organizations from Australia collaborate with industry for clinical trial research (29%) and to represent patients' interests (32%), which was greater than organizations from the other HEpc groups (Supplementary Figure 3). A greater proportion of groups from Australia also receive financial or other support from pharmaceutical firms for specific activities, but a much smaller proportion receive support for organizational operations.

Overall, compared with Australia and countries with an HEpc ≥USD 1,000, organizations from countries with a lower HEpc found it more challenging to engage with government and industry (Supplementary Figures 4 and 5). A greater proportion of these organizations felt that government authorities do not readily engage with patient groups. Concerning engagement with industry, 25% of groups from countries with lower HEpc stated they did not know who to contact, and 30% did not understand how a relationship with industry could work.

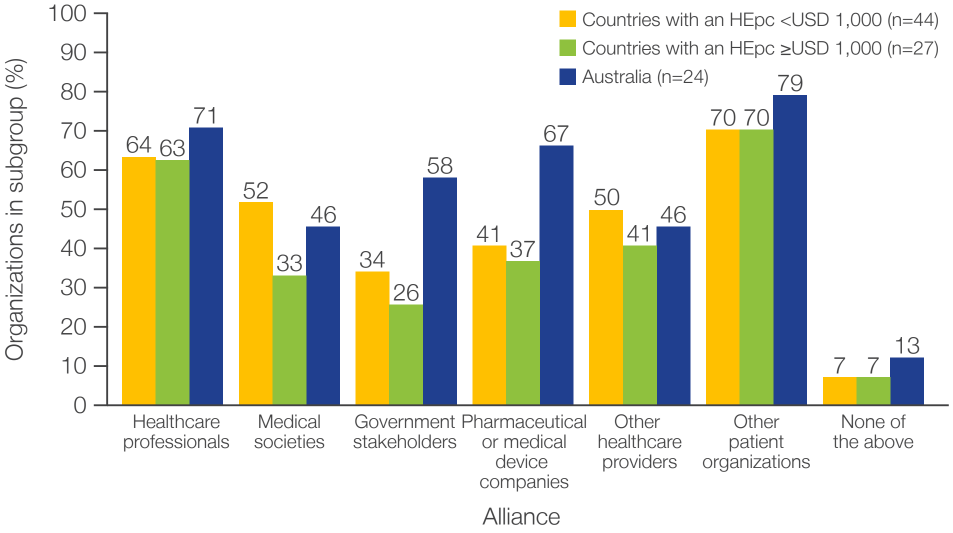


Figure 12. Patient organization alliances, stratified by healthcare expenditure per capita.

7% of organizations from countries with an HEpc ≥USD 1,000 responded that they did not know the alliances of their organization.

Perceptions of success

When asked to rate the success of organizations in their country on a scale of 1 to 4, where 1 is 'not successful' and 4 is 'very successful', the average score for patient organizations from Australia was 2.65. This average rating was higher than for groups from other countries with an HEpc ≥USD 1,000 (2.15) and those from countries with an HEpc <USD 1,000 (2.19).

Challenges

Fundraising was the biggest challenge for organizations regardless of HEpc status, but the other key challenges faced by organizations varied between countries with higher and lower HEpc and Australia (Table 6).

Australian organizations deemed communication with the members as their second biggest barrier; organizations from countries with an HEpc <USD 1,000 cited communicating with the general public as particularly challenging; and organizations from countries with a higher HEpc listed the availability of volunteers as a significant challenge. Organizations from all three groups cited engaging with government as one of their biggest barriers.

Organizations from countries with HEpc <USD 1000 (n=44)		Organizations from countries with HEpc ≥USD 1000 (n=27)		Australia (n=24)	
Challenge	**Average score**	**Challenge**	**Average score**	**Challenge**	**Average score**
Fundraising	5.04	Fundraising	4.64	Fundraising	3.89
Communication with the general public	2.58	Availability of volunteers	2.84	Communication with members	2.56
Engaging with the media	2.33	Engaging effectively with government bodies and stakeholders	2.50	Engaging effectively with government bodies and stakeholders	2.26
Engaging effectively with government bodies and stakeholders	2.21	Engaging with healthcare professionals	1.57	Engaging with healthcare professionals	2.22
Availability of volunteers	2.08	Retention of volunteers	1.55	Engaging with the media	1.48

Table 6. Rank of challenges perceived by organizations from countries with higher and lower healthcare expenditure per capita and Australia.

Respondents were asked to select and rank their top 5 challenges from a list of options (see below). Their choices were scored, with 1st choice given 8 points, 2nd 6 points, 3rd 4 points, 4th 2 points and 5th 1 point. If an option was not selected, that option scored 0 points. The cumulative total of their scores was then averaged to give an order of rankings.

The table above shows the top 5 ranked choices for each group. The full list of challenges the respondents were able to choose from is as follows: communication with members; communication with the general public; fundraising; availability of volunteers; retention of volunteers; engaging effectively with the pharmaceutical and medical device industry; engaging effectively with government bodies and stakeholders; engaging with healthcare professionals; engaging with medical societies; engaging with the media; and interaction and knowledge sharing with other patient organizations.

Conclusion

Survey responses from countries in the Asia-Pacific region have revealed both commonalities and differences across patient organizations.

The majority of organizations focus on patients with a specific malignancy, and many organizations have been established for over 20 years. The number of new patients that organizations support on an annual basis ranges from <50 to >1,000, and the majority of organizations have some paid staff, although many are reliant on volunteers.

Most patient groups interact with healthcare professionals and other organizations. This pattern of cooperation suggests that groups would be open to further sharing of experience, information and perhaps resources.

Alliances with pharmaceutical agencies or government stakeholders are less frequent, however. While organizations listed many successful activities as a result of collaborations with their governments, a proportion felt they lacked the experience to engage with government or that government authorities did not readily interact with advocacy groups. There is a need to build organizations' skills and confidence to increase the effectiveness of government engagement activities, and perhaps to raise awareness within government bodies of the contribution of advocacy groups in improving outcomes for patients.

While there were examples of organizations partnering with pharmaceutical companies for various initiatives, it was acknowledged that there are barriers to engaging with industry. A lack of understanding about how the different parties could cooperate, how industry engages with groups and who to contact in pharmaceutical companies were the most commonly listed challenges. Some organizations intentionally avoided engaging with industry to protect their independence.

Over 80% of all organizations listed raising public awareness, and supporting and providing information for patients with cancer, their families and caregivers as active initiatives. They highlighted a wide variety of successful projects and ambitions for future programs, but overall were modest in assessments of their successes, which may be a reflection of the high standards and ambitions of these organizations.

Fundraising was a consistent challenge for all organizations, regardless of their age or the HEpc of their country. Organizations cited fundraising as their biggest training need, and overall were unsatisfied with their approaches to-date. The limited number of groups actively participating in raising funds for patients' diagnosis and treatment may be due to the lack of previous success with these activities. Assistance with fundraising approaches is a clear need for all organizations.

The survey revealed differences in the characteristics and activities of organizations from countries with a healthcare expenditure per capita <USD 1,000 and ≥USD 1,000, and those from Australia. The majority of organizations from countries with a lower HEpc partake in fundraising for cancer screening and diagnosis or for patient treatment, compared with less than a quarter of organizations from countries with a higher HEpc, including Australia. It may be that the lack of funding for healthcare (be that private or from the government) drives the need for organizations in lower HEpc countries to seek funds for patients' medical care. In contrast, a far greater proportion of organizations from Australia partake in fundraising for cancer research than groups from other countries.

The majority of Australian organizations engage with government and the pharmaceutical industry. These engagements are not solely for fundraising; in fact fewer patient groups from Australia reported receiving funding from pharmaceutical companies compared with organizations from other countries. Clinical trial recruitment and research, and collaborations to represent patients' interests and to support specific activities were three areas where Australian organizations engaged with industry to a greater degree than those from other countries. The survey results suggest that there is a clear drive for organizations from Australia to engage patients in clinical trials through fundraising and engagement with the pharmaceutical industry, which is largely absent in organizations from other countries.

Australian organizations also stood apart from those of other countries with an HEpc ≥1,000, as a greater proportion were longer established and they supported more new patients each year. Interestingly, organizations from countries with a lower HEpc were similar to Australia in these areas. This implies the longevity and reach of organizations is not inhibited by the healthcare economic status of their country. The survey suggested a correlation between an organization's age and its capacity, and groups from higher HEpc countries may benefit from the experience of groups from lower HEpc countries, as well as Australia.

The survey has revealed that patient organizations across the Asia-Pacific region differ in their age, size, reach and specialization. The organizations have highlighted experience in a diverse range of activities, but also many ongoing challenges. Although the survey revealed that most patient organizations already engage with other groups, some respondents spoke of a need for better collaboration between organizations. It may be valuable to explore ways to promote dialogue and cooperation between organizations, and how the wealth and variety of experience within the region could be leveraged to improve the success and effectiveness of these groups in supporting patients with cancer. Given the success that organizations from Australia have in recruiting large numbers of new patients and engaging with government and industry, patient groups from other countries may benefit from this experience should international support systems for patient groups become more strongly established.

Appendix A: Analysis of ranking questions

For the questions regarding the challenges facing organizations, the organizations' training needs and the unmet needs of patients, respondents were asked to select answers from a list of options and rank these answers in order of the greatest challenge/need.

In order to generate a list of answers that incorporated the number of times an answer was selected in addition to the ranking it was given, a scoring system was devised:

- For the questions regarding challenges facing organizations and the organizations' training needs, respondents were asked to choose 5 options and rank these:
    - First choices scored 8 points, 2nd choices 6 points, 3rd 4 points, 4th 2 points and 5th 1 point
    - Options not selected scored zero points
    - If a respondent chose fewer than 5 options, the scoring system applied as normal to those options selected
- For the question regarding the unmet needs of patients, respondents were asked to select a maximum of 8 options and rank these:
    - First choices scored 18 points, 2nd 15 points, 3rd 12 points, 4th 10 points, 5th 7 points, 6th 4 points, 7th 2 points, 8th 1 point
    - Options not selected scored zero points
    - If a respondent chose fewer than 8 options, the scoring system applied as normal to those options selected.

Educational initiative	Average score
Providing information and support for patients with cancer	3.37
Providing information and support for patients' families and caregivers	3.14
Engaging with pharmaceutical and/or medical device companies	2.85
Raising public awareness of the needs of patients with cancer	2.84
Engaging with medical societies	2.63
Raising funds for cancer research	2.59
Raising funds for treatment for patients	2.53
Raising funds for cancer screening and diagnosis	2.27
Engaging with government decision-makers and departments to ensure the patient voice is represented	2.26

Supplementary Table 1. Satisfaction with execution of patient organizations' activities (n=87). Respondents were asked to score their execution of the above activities from 1 to 4, with 1 being 'Not satisfied at all' and 4 being 'Very satisfied'.

Challenge (n=38)	Average score
Fundraising	4.13
Communication with the general public	2.38
Communication with members	2.00
Availability of volunteers	1.95
Retention of volunteers	1.82
Engaging effectively with government bodies and stakeholders	1.51
Interaction and knowledge sharing with other patient organizations	1.49
Engaging with healthcare professionals	1.18
Engaging with the media	1.08
Engaging effectively with the pharmaceutical and medical device industry	0.92
Engaging with medical societies	0.49

Supplementary Table 2. Ranking of challenges faced by patient organizations established for less than 10 years. Respondents were asked to choose and rank the top 5 challenges from the list of above options. Their choices were scored, with 1st choice given 8 points, 2nd 6 points, 3rd 4 points, 4th 2 points and 5th 1 point. If an option was not selected, that option scored 0 points. The cumulative total of their scores was then averaged to give an order of rankings.

Challenge (n=57)	Average score
Fundraising	4.80
Engaging effectively with government bodies and stakeholders	2.95
Availability of volunteers	2.29
Engaging with the media	1.96
Communication with the general public	1.77
Engaging with healthcare professionals	1.77
Communication with members	1.46
Retention of volunteers	1.07
Engaging effectively with the pharmaceutical and medical device industry	0.93
Engaging with medical societies	0.82
Interaction and knowledge sharing with other patient organizations	0.79

Supplementary Table 3. Ranking of challenges faced by patient organizations established for more than 10 years. Respondents were asked to choose and rank the top 5 challenges from the list of above options. Their choices were scored, with 1st choice given 8 points, 2nd 6 points, 3rd 4 points, 4th 2 points and 5th 1 point. If an option was not selected, that option scored 0 points. The cumulative total of their scores was then averaged to give an order of rankings.

Overall ranking	Area of training need
1	Fundraising
2	Public awareness activities and media campaigns
3	Social media platforms
4	Patient rights
5	Identifying and approaching key stakeholders
5	Decision-making and processes in the healthcare system
7	Sourcing and providing authoritative medical information for patients
8	Operations/administration
9	Finance and accounting

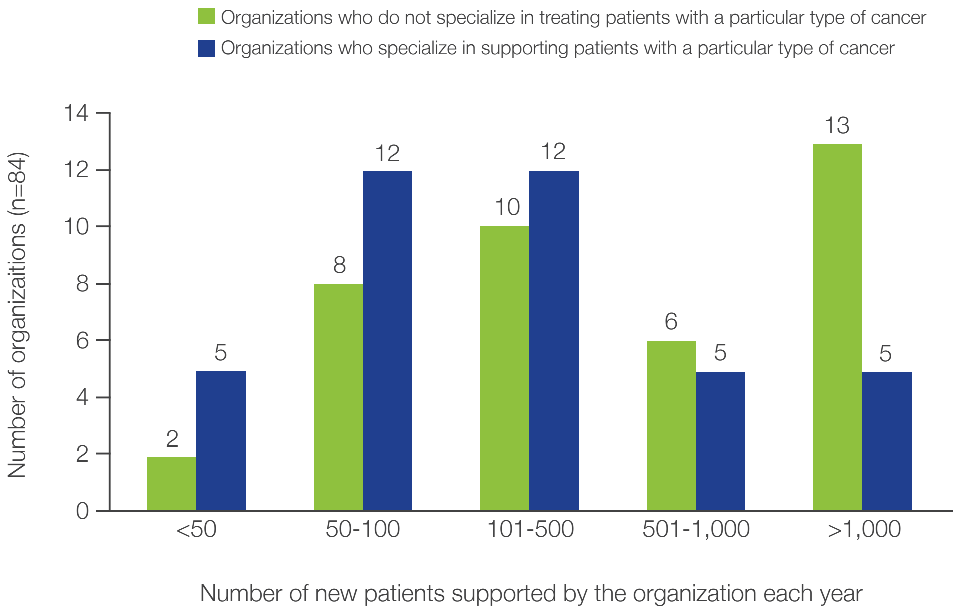
Supplementary Table 4. Ranking of training needs by patient organizations (n=118). Respondents were asked to choose and rank the top 5 challenges from the list of above options.

Overall ranking	Need for patients with cancer
1	Support for daily living and other practical matters for patients
2	Access to clinical trials
3	Access to medication and other treatment (e.g. surgery, radiotherapy)
4	Government policy supporting development and approval of new cancer treatments
5	Cancer screening, and timely and accurate diagnosis
5	Guidance and support for patients regarding consultations and discussions with healthcare professionals
5	Psychological counseling services for patients
8	Availability of palliative care
8	Wellness support (e.g. diet, exercise, managing side effects)
8	Availability of patient support networks
11	Awareness of needs and challenges of cancer patients among the general public
12	Access to specialists
13	Availability of budget for cancer diagnosis and treatment
14	Access to ongoing support following treatment
15	Provision of disease information for patients
16	Inter-department communication within hospitals

Supplementary Table 5. Ranking of unmet needs for patients with cancer by patient organizations (n=102). From a list of potential unmet needs, respondents were asked to select those that applied and rank those chosen.

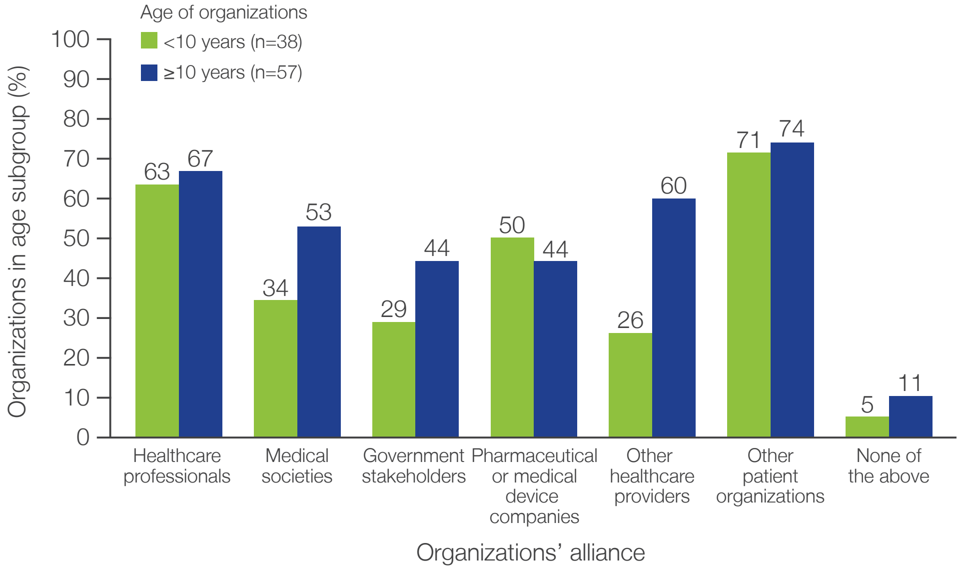
Country	Total HEpc in 2013 (USD)	Number of organizations	
Myanmar	17.93	1	Total number of responding organizations in countries whose HEpc <USD 1,000 = 92
Laos	32.70	0	
Pakistan	33.64	6	
Cambodia	60.44	1	
India	68.53	21	
Indonesia	106.02	3	
Philippines	127.09	12	
Vietnam	134.26	28	
Thailand	354.53	4	
China	375.14	10	
Malaysia	427.05	6	
Taiwan	1381.61	10	Total number of responding organizations in countries whose HEpc ≥USD 1,000, excluding Australia = 53
South Korea	1870.13	5	
Hong Kong	2049.44	11	
Singapore	2531.50	8	
Japan	3960.20	10	
New Zealand	4661.80	9	
Australia	6258.47	38	Number of responding organizations in Australia = 38

Supplementary Table 6. HEpc by country.



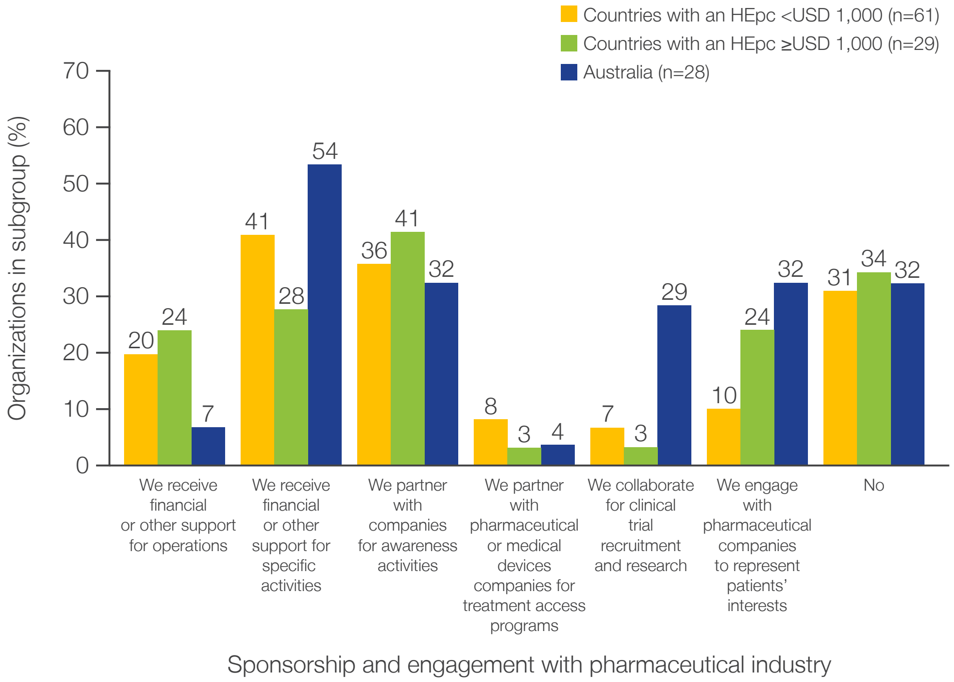
Supplementary Figure 1. Number of new patients supported by organizations annually, stratified by whether the organization specializes in a particular cancer or group of cancers.

Six respondents (7%) stated they did not know how many patients their organization supported each year.



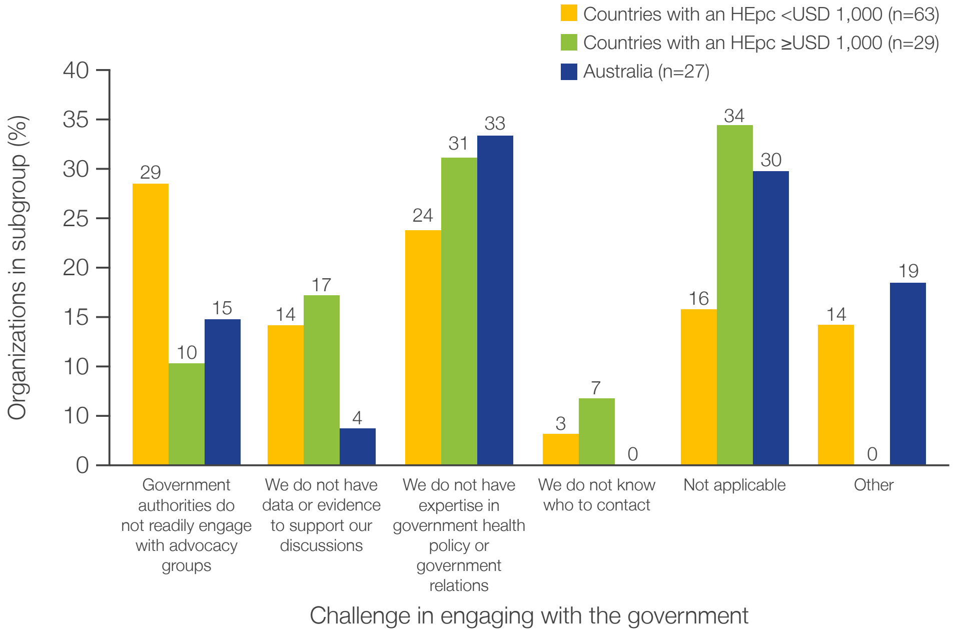
Supplementary Figure 2. Patient organizations' alliances stratified by age of organization.

5% of organizations established for less than 10 years stated they did not know who their organizations engaged with.

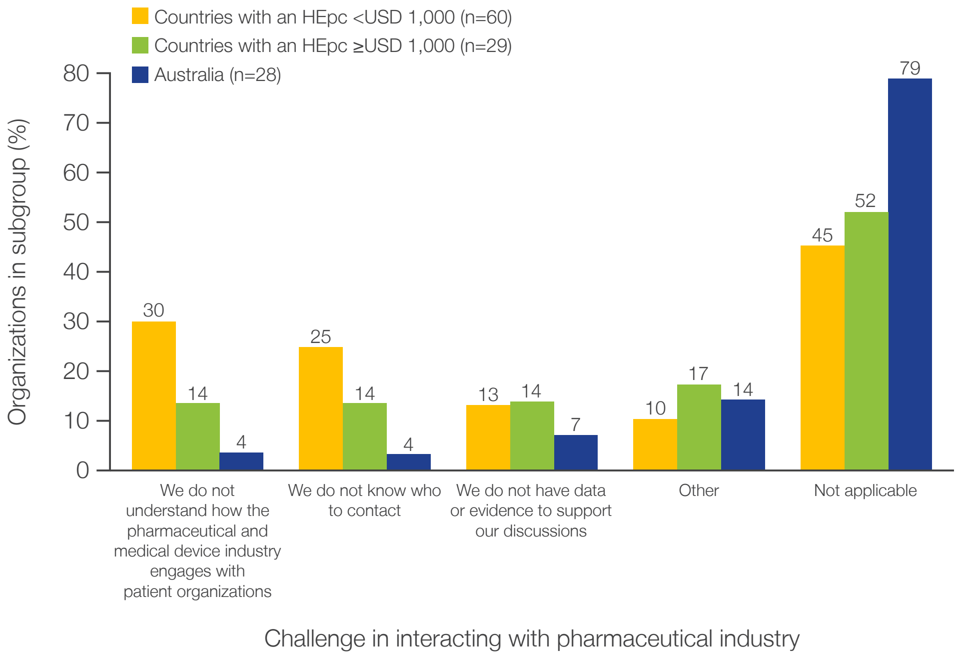


Supplementary Figure 3. Patient organizations' engagement with the pharmaceutical and medical device industry, stratified by healthcare expenditure per capita.

When asked the question, "Does the organization currently receive sponsorship from or engage with pharmaceutical and/or medical device companies?", respondents were asked to select all options that applied.



Supplementary Figure 4. Challenges patient organizations face in engaging with government, stratified by healthcare expenditure per capita.



Supplementary Figure 5. Challenges patient organizations face in engaging with the pharmaceutical and medical device industry, stratified by healthcare expenditure per capita.

Appendix B: Survey questions

Note: For the purpose of this survey, “Patient organization” is defined as an organization that provides any of the following services for patients with **any type of cancer**:

- Funding for cancer research
- Patient education
- Physician education
- General disease awareness for cancer
- Advocacy targeted at government, industry or institutions engaged in cancer awareness, diagnosis and treatment
- Cancer prevention initiatives
- Patient support (including medical, social, emotional, financial)

1. In which country are you based?	☐ Australia ☐ Hong Kong ☐ India ☐ Indonesia ☐ Japan ☐ Malaysia ☐ New Zealand ☐ Pakistan ☐ Philippines ☐ Singapore ☐ South Korea ☐ Taiwan ☐ Thailand ☐ Vietnam ☐ Other (please specify) ______________
2. Please select your role. *Please check all that apply.*	☐ Healthcare professional *(if yes, please answer questions 3–5 and 33–36)* ☐ Previously worked with a cancer patient organization *(if yes, please answer questions 6–36)* ☐ Currently working with a cancer patient organization *(if yes, please answer questions 7–36)* ☐ Other (please specify) ______________________________ *(if yes, please answer questions 33–36)*
If you are a healthcare professional (questions 3–5):	
3. Please select your role in the healthcare profession:	☐ Physician *(please indicate your specialty)* ☐ *Dermatology* ☐ *Endocrinology* ☐ *Gastroenterology* ☐ *Gynecology* ☐ *Hematology* ☐ *Hepatology* ☐ *Pulmonary medicine* ☐ *Nephrology* ☐ *Neurology* ☐ *Stomatology* ☐ *Genito-urinary medicine* ☐ *Other (please specify)* ☐ Surgeon ☐ Nurse ☐ Pharmacist ☐ Radiologist ☐ Medical social worker ☐ Other *(please specify)* ______________________________

4. What is the name of your hospital or institution? *(This question is to identify multiple responses from one organization for analytical purposes and will not be published in any form.)*	
5. Do you currently work with cancer patient organizations?	☐ Yes ☐ No
If you ***previously worked*** *with a cancer patient organization please answer question 6:*	
6. Is the organization you previously worked with still operating?	☐ Yes ☐ No
If you ***previously worked*** *or* ***currently work*** *with a cancer patient organization (questions 7–32):*	
7. What is the name of the organization? *(This question is to identify multiple responses from one organization for analytical purposes and will not be published in any form.)*	
8. Does the organization specialize in a particular type of cancer?	☐ No ☐ Yes *(please specify)* ______________________________
9. How long has the organization existed?	☐ <2 years ☐ 2–5 years ☐ 5–10 years ☐ 10–20 years ☐ >20 years ☐ I don't know
10. Approximately how many new patients with cancer does your organization help every year?	☐ <50 ☐ 50–100 ☐ 101–500 ☐ 501–1000 ☐ >1000 ☐ I don't know
11. What form does the organization take? Is it:	☐ A local charity that operates informally ☐ A local charity that is registered with the government ☐ A national charity that is registered with the government ☐ A professional medical association ☐ Other *(please specify)* ______________________________
12. Does the organization have any staff?	☐ Yes ☐ No If yes, how many? # full-time paid: __________ # part-time paid: __________ # volunteer __________
13. What is your role within the organization? *Please select all that apply.*	☐ Patient ☐ Medical advisor ☐ Patient counselor ☐ Advocate with the government ☐ Advocate with the pharmaceutical industry ☐ Founder or Chief Executive ☐ Member of the board of directors or trustees ☐ Event/campaign organizer ☐ Administrator (operations) ☐ Fundraiser ☐ Other *(please specify)* ______________________________

14. What are the main sources of funding for your organization? *Please select all that apply.*	☐ Charitable donations ☐ Corporate sponsorship	☐ Grants or funding from the government or healthcare bodies ☐ Other *(please specify)* __________________________

15. How does the organization communicate and interact with its **members**?
How frequent are the communications/activities?

	Daily	Weekly	Fortnightly	Monthly	Quarterly	Six-monthly	Annually	Not applicable
Email								
Paper newsletter								
Meetings/forums								
Website *(please indicate how often it is updated)*								
Facebook								
Twitter								
Instagram								
WhatsApp								
WeChat								
Other *(please specify)* ________________								
Other (please specify) ________________								

16. How does the organization communicate with the **general public**? How frequent are the communications/activities?								
	Daily	Weekly	Fortnightly	Monthly	Quarterly	Six-monthly	Annually	Not applicable
Email								
Paper newsletter								
Meetings/forums								
Website *(please indicate how often it is updated)*								
Facebook								
Twitter								
Instagram								
WhatsApp								
WeChat								
Other *(please specify)* ________________								
Other (please specify) ________________								

17. Does your organization have any alliances with any of the following groups? *Please select all that apply, and please indicate the nature of the alliance and whether these are local, regional, national or international.*	☐ Healthcare professionals ☐ Medical societies ☐ Government stakeholders ☐ Pharmaceutical or medical device companies	☐ Other healthcare providers ☐ Other patient organizations ☐ None of the above ☐ I don’t know
Comments		
18. Which of the following activities does your organization **currently** support? *Please select all that apply.*	☐ Raising funds for cancer research ☐ Raising funds for cancer screening and diagnosis ☐ Raising funds for treatment for patients ☐ Providing information and support for patients with cancer ☐ Providing information and support for patients’ families and caregivers ☐ Engaging with government decision makers and departments to ensure the patient’s voice is represented	☐ Engaging with pharmaceutical and/or medical device companies. *Please explain the focus of your engagement in the comment box below.* ☐ Engaging with medical societies. *Please explain the focus of your engagement in the comment box below.* ☐ Raising public awareness of the needs of patients with cancer ☐ Other *(please specify)* ____________________ ☐ None of the above
Comments		
19. Which of the following activities does your organization **plan to support in the future**? *Please select all that apply.*	☐ Raising funds for cancer research ☐ Raising funds for cancer screening and diagnosis ☐ Raising funds for treatment for patients ☐ Providing information and support for patients with cancer ☐ Providing information and support for patients’ families and caregivers ☐ Engaging with government decision makers and departments to ensure the patient’s voice is represented	☐ Engaging with pharmaceutical and/or medical device companies. *Please explain the focus of your engagement in the comment box below.* ☐ Engaging with medical societies. *Please explain the focus of your engagement in the comment box below.* ☐ Raising public awareness of the needs of patients with cancer ☐ Other *(please specify)* ____________________ ☐ None of the above
Comments		

20. What are your organization’s key challenges? *Please choose and rank the top 5 challenges.*	___ Communication with members ___ Communication with the general public ___ Fundraising ___ Availability of volunteers ___ Retention of volunteers ___ Engaging effectively with the pharmaceutical and medical device industry ___ Engaging effectively with government bodies and stakeholders ___ Engaging with healthcare professionals ___ Engaging with medical societies ___ Engaging with the media ___ Interaction and knowledge sharing with other patient organizations ___ Other (please comment)
Comments	

Your organization’s achievements, challenges and development needs

21. How satisfied are you with your organization’s execution of the following activities?
Please indicate on a scale of 1–4 where 1 is Not satisfied at all and 4 is Very satisfied.

	1	2	3	4	N/A
Raising funds for cancer research					
Raising funds for cancer screening and diagnosis					
Raising funds for treatment for patients					
Providing information and support for patients with cancer					
Providing information and support for patients’ families and caregivers					
Engaging with government decision makers and departments to ensure the patient’s voice is represented					
Engaging with pharmaceutical and/or medical device companies. Please explain the focus of your engagement in the comment box below.					
Engaging with medical societies. Please explain the focus of your engagement in the comment box below.					
Raising public awareness of the needs of patients with cancer					
Other *(please specify)* ____________________					
None of the above					
Comments					

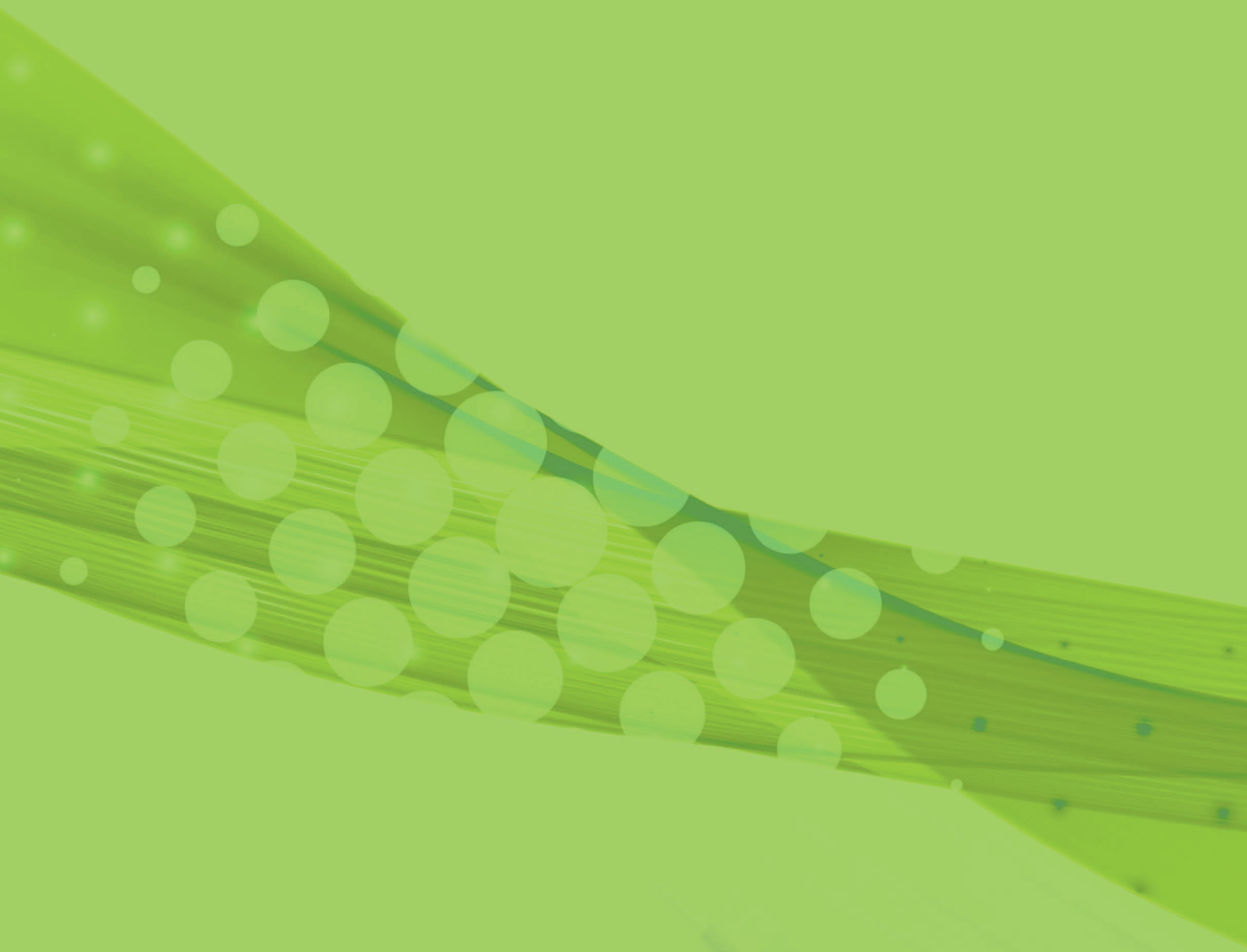
22. Which initiatives organized by your organization are you most proud of?	
23. What resources or skills does your organization need to enhance the support it is currently providing?	
24. Does your organization engage with government stakeholders to raise awareness of cancer patients’ perspectives and to contribute to policy development? *Please provide any additional information about your focus and approach in engaging with government stakeholders in the comment space below.*	☐ No ☐ Yes *(please explain)* Comments

25. Which government engagement initiatives organized by your organization are you most proud of?	
26. What are the challenges/barriers you face in engaging with government?	☐ We do not know whom to contact ☐ We do not have data or evidence to support our discussions ☐ We do not have expertise in government health policy or government relations ☐ Government authorities do not readily engage with advocacy groups ☐ Other (please specify) ____________ ☐ Not applicable
27. What resources or skills does your organization need to enhance its government engagement activities?	
28. Does the organization currently receive sponsorship from or engage with pharmaceutical and/or medical device companies? *Please check all that apply*	☐ We receive financial or other support for operations ☐ We receive financial or other support for specific activities ☐ We partner with companies for awareness activities ☐ We partner with pharmaceutical or medical devices companies for treatment access programs (please specify): ____________ ☐ We collaborate for clinical trial recruitment and research ☐ We engage with pharmaceutical companies to represent patients' interests ☐ Other (please specify) ____________ ☐ No
29. Which pharmaceutical or medical device industry engagement initiatives organized by your organization are you most proud of? *If not applicable, type N/A.*	
30. What challenges or barriers does your organization face in its interactions with the pharmaceutical and/or medical device industry? *Please select all that apply.*	☐ We do not understand how the pharmaceutical and medical device industry engages with patient organizations ☐ We do not know whom to contact ☐ We do not have data or evidence to support our discussions ☐ Other *(please specify)* ____________ ☐ Not applicable
31. Is your organization willing to consider engaging with the pharmaceutical and medical device companies?	☐ Yes ☐ Yes, with reservations/conditions *(please explain)* ☐ No *(please explain)*
Comments	

32. Do you have training needs in any of these areas? Please choose and rank the top 5	___ Fundraising ___ Finance and accounting ___ Operations/administration ___ Public awareness activities and media campaigns ___ Social media platforms ___ Sourcing and providing authoritative medical information for patients	___ Identifying and approaching key stakeholders ___ Decision-making and processes in the healthcare system ___ Patient rights ___ Other *(please specify below)*
Comments		

The patient voice in Asia

33. Please highlight areas of unmet need for patients with cancer in your country. *Please check all that apply and rank according to areas of greatest need. Please use the comment box to explain any special circumstances (eg if one point is an unmet need only for certain types of cancer or in certain regions).*	___ Cancer screening, and timely and accurate diagnosis ___ Access to specialists ___ Inter-department communication within hospitals ___ Access to medication and other treatment (eg surgery, radiotherapy) ___ Availability of budget for cancer diagnosis and treatment ___ Access to clinical trials ___ Access to ongoing support following treatment ___ Availability of palliative care ___ Provision of disease information for patients	___ Availability of patient support networks ___ Guidance and support for patients regarding consultations and discussions with healthcare professionals ___ Psychological counseling services for patients ___ Wellness support (eg diet, exercise, managing side effects) ___ Support for daily living and other practical matters for patients ___ Awareness of needs and challenges of cancer patients among the general public ___ Government policy supporting development and approval of new cancer treatments
Comments		
34. By which of the following groups do you feel the patient's voice is not being heard with regard to decisions about cancer treatment? *Please select all that apply.*	☐ Clinicians ☐ General public/in the wider community ☐ Industry ☐ Government	☐ Other *(please specify)* ____________________ ☐ None of the above (the patient voice is heard by everyone)
35. How do you rate the success of patient advocacy organizations in general in your country? *Please indicate on a scale of 1–4 where 1 is Not successful at all and 4 is Very successful*	☐ 1 ☐ 2 ☐ 3 ☐ 4	
36. What do you think is needed to advance the effectiveness of patient advocacy organizations and advocacy initiatives in your country?		



ABOUT RCA

Rare Cancers Australia Ltd (RCA) is a charity whose purpose is to improve awareness, support and treatment of Australians with rare and less common (RLC) cancers. Every year there are over 44,000 diagnoses of RLC cancers and around 24,000 deaths.

As distinct from common cancers (breast, prostate, bowel, lung and melanoma) there is very little patient support offered to RLC cancer patients. RCA works tirelessly to ensure that these cancers that impact so many lives will never be forgotten or ignored again.

Rare Cancers Australia Ltd is governed by a Board of Directors and is classified as a Health Promotion Charity by the Federal Government. All contributions are fully tax deductible. For more information, please visit www.rarecancers.org.au

RARE CANCERS AUSTRALIA
Postal Address: PO Box 440, Bowral NSW 2576, Australia
Phone/Fax: (02) 4862 2768
Email: contact@rarecancers.org.au

www.rarecancers.org.au

ABN: 24 159 196 997