



ASIA PACIFIC  
PATIENT  
INNOVATION  
SUMMIT  
2021

# Outcomes Report

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# Executive Summary

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The Asia Pacific Patient Innovation Summit (APPIS) is a 3-day virtual summit that was attended by more than 500 registrants composing of 377 patient leaders from almost 300 different patient organizations held last March 2-4 2021. The virtual summit aimed to gather representatives from different patient communities to discuss common concerns of patient organizations while also focusing on generating solutions and capability-building in order to address various needs and challenges as they continue to advocate for better healthcare outcomes that improve and help the lives of patients across the world.

This report focuses on the 2-day Philippine breakout sessions held over the course of the virtual summit and attended by a total of 96 participants - which focused on effective establishment and governance of Patient Advocacy Groups held by Speaker Paul Perez for the Day 1 Breakout Session, and a discussion on the role of Patient Organizations in supporting patients and clinical trials conducted by speaker Carmen Auste for the Day 2 Breakout Session.

Day 1 focused more on how to effectively establish and govern Patient Advocacy Groups (PAGs). Speaker Paul Perez, chairman of the Cancer Coalition of the Philippines had placed heavy emphasis on striving for creating lasting impact among PAGs. Although many patient groups today have struggled to consistently engage and maintain their volunteers as well as gain adequate funding to support patients, there is an opportunity for these challenges to be resolved if PAGs can reach the right people who can provide the support and resources that they need. This entails creating strategic campaigns that communicate their message to the right audiences while also creating a ripple effect wherein a small change can yield bigger outcomes in terms of impact. Strategic communications campaigns are founded on a clear purpose and vision that PAGs must establish early on. This can help them lobby for effective solutions that can be backed by influential people such as policy makers, or help connect with like-minded individuals willing to help their cause – ultimately supporting them as they look towards providing better support for the patients.

Meanwhile, Day 2 tackled the crucial role of Patient Organizations in promoting participation for clinical trials which was headed by Speaker Carmen Auste, Chair of the Philippine Health Research Ethics Board Committee on Patient Family and Stakeholder Management. It is evident that the low patient participation in clinical trials is primarily due to the lack of proper access to information. This makes patient organizations all the more essential with their connections to the patient community to promote the importance of clinical trials and the various regulatory mechanisms put in place to ensure clinical trials follow necessary health research standards. Similarly, patient organizations should also champion the rights of patients to ensure that they are protected and receive adequate care all throughout the entire process. More than that, support should also come from other institutions such as government and healthcare bodies to create a more holistic system of support that will help clinical trials to run more efficiently with adequate information dissemination.



# Introduction

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More than 500 patient leaders and advocates across 298 patient organizations from multiple countries gathered together last March 2-4, 2021 for the annual **Asia Pacific Patient Innovation Summit (APPIS)**, an initiative that focuses on partnering with the patient community to address common challenges encountered by various patient organizations, while also paving the way for deep-dive discussions as an effort to address evolving capability needs of different groups across the Asia Pacific region and beyond.

The key focus of the APPIS initiative is to improve the learning and tools of patient communities amidst their increasingly important role in healthcare systems, in order to enable them to further champion the improvement of outcomes and addressing real-world needs among patients.

A 3-day virtual summit for patient communities across Asia Pacific, India, and Australia was organized and funded by **Novartis**, in recognition of their mandate to work with the patient community through understanding their perspectives and experiences, in order to co-create and bring true value to patients by discovering new ways to improve and extend people's lives.

The 3-day summit hosted various hubs among seven different countries in the Asia Pacific region, namely: Korea, Thailand, Taiwan, Japan, Australia, UAE/Middle East, and the Philippines. The purpose of this white paper is to bring to light key insights

during the 2-day breakout sessions hosted within the Philippines Hub.

The Philippines hub, which housed a total of 96 participants, chaired by APPIS Steering Committee member Paul Mendoza, and organized by Novartis, in partnership with Ipsos Philippines aimed to: (1) elevate the patient voice in disease management and health policy; (2) shorten the patient journey for sustainable access; and (3) generate insights and develop a policy paper. Speakers and moderators were invited to hold two breakout session topics:

## **Day 1 (March 2) – Breakout Session: Establishment and Governance of a Patient Advocacy Groups (PAG)**

- *Speaker:* Mr. Paul Perez (Chair of the Cancer Coalition of the Philippines)
- *Moderator:* Dr. Gia Sison
- *Objective:* To better understand gaps/barriers and success factors for the effective governance, adaptive leadership, and strategic management of PAGs

## **Day 2 (March 3) – Breakout Session: Building Capability in Clinical Trials**

- *Speaker:* Ms. Carmen Auste (Chair of the Philippine Health Research Ethics Board Sub-committee on Patient Family and Stakeholder Management)
- *Moderator:* Ms. Christine Fajardo
- *Objective:* To understand the different types of clinical trials and the role of PAGs and patients/caregivers before, during and after the clinical trial

# Insights from the Pre-event and Mentimeter Flash Survey

Pre-event survey questionnaires were released to invited participants ahead of the Asia Pacific Patient Innovation Summit. The survey was aimed at getting a baseline look at current needs and concerns of patient organizations ahead of the Philippine breakout sessions to be held over the course of the summit, particularly on the matters of governance among patient advocacy groups and participation in clinical trials.

On the other hand, Mentimeter Flash Surveys were also administered as the Philippine breakout sessions were occurring in order to provide an avenue for participants to share their thoughts and concerns during the sessions themselves.

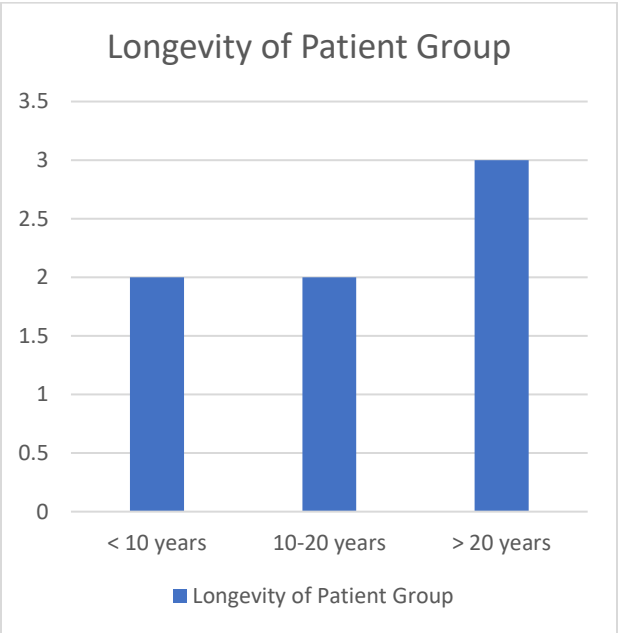


Fig A. Longevity of Patient Advocacy Groups (N=7 PH respondents)

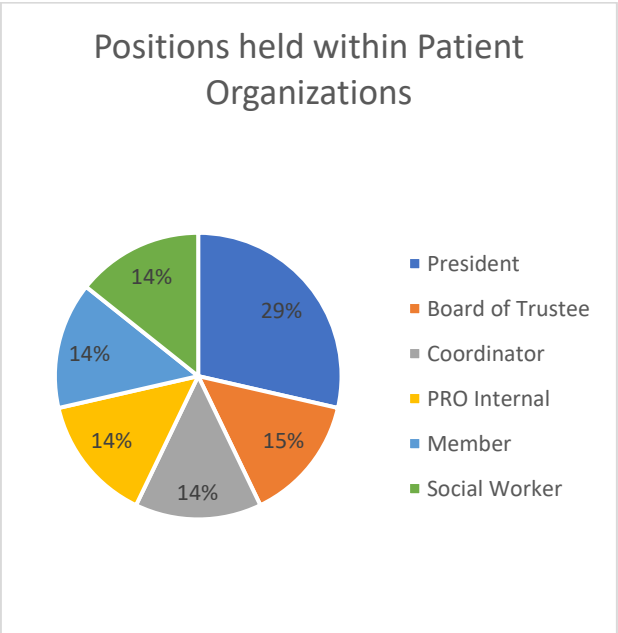


Fig B. Positions held within Patient Organizations (N=7 PH respondents)

Participants who answered the pre-event survey were mostly from Philippine patient advocacy groups (PAGs) and organizations that have existed for numerous years. Although the numbers vary in terms of longevity - as data show participants from PAGs that were formed as early as three years ago up to 26 years ago. (Fig A.) Furthermore, participants who answered the survey represent various positions within patient groups - from members and social workers, to presidents and founders of their respective patient organizations. (Fig B.)

## On Focus Areas of Patient Advocacy Groups and Organizations

Disease Areas of Patient Advocacy Organizations
• Neuroscience/Neurodevelopmental
• HIV
• Hematology (Chronic Myeloid Leukemia)
• Chronic Illnesses
• Non-communicable diseases
• Diabetology/Endocrinology

Fig C. Disease Areas of Participating PAGs (N=7 Respondents)

Areas of focus for these patient groups range across a variety of diseases. (Fig C.) However, despite the variety of disease areas among patient organizations, key similarities in functions and focus areas of importance surface across all patient groups.

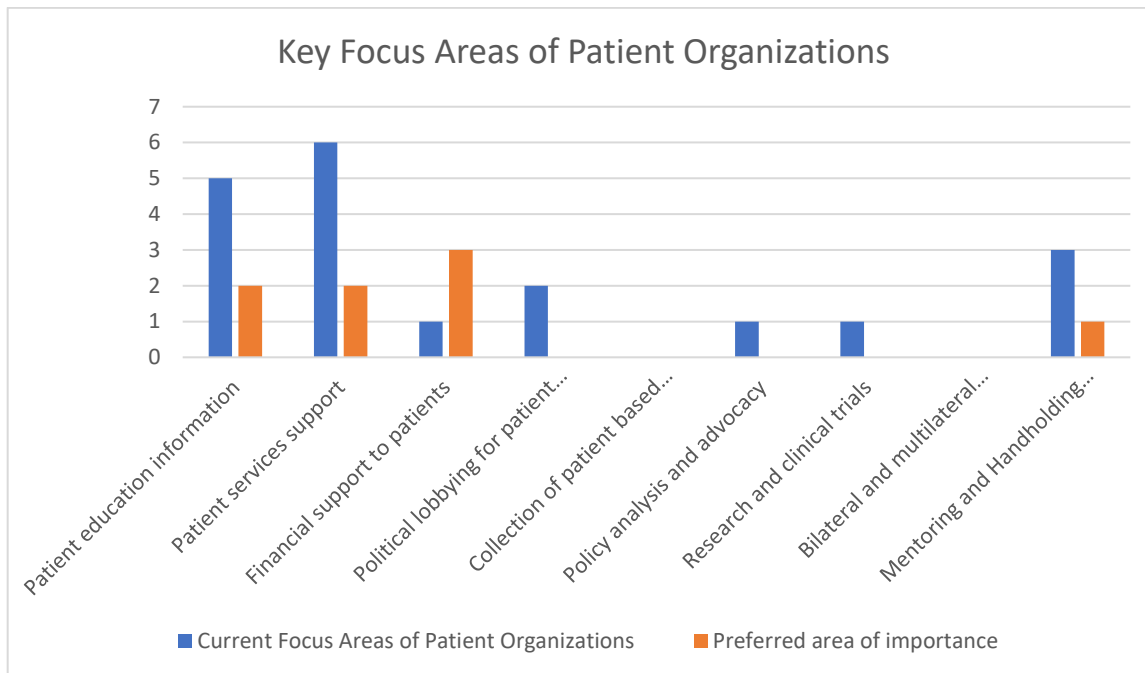
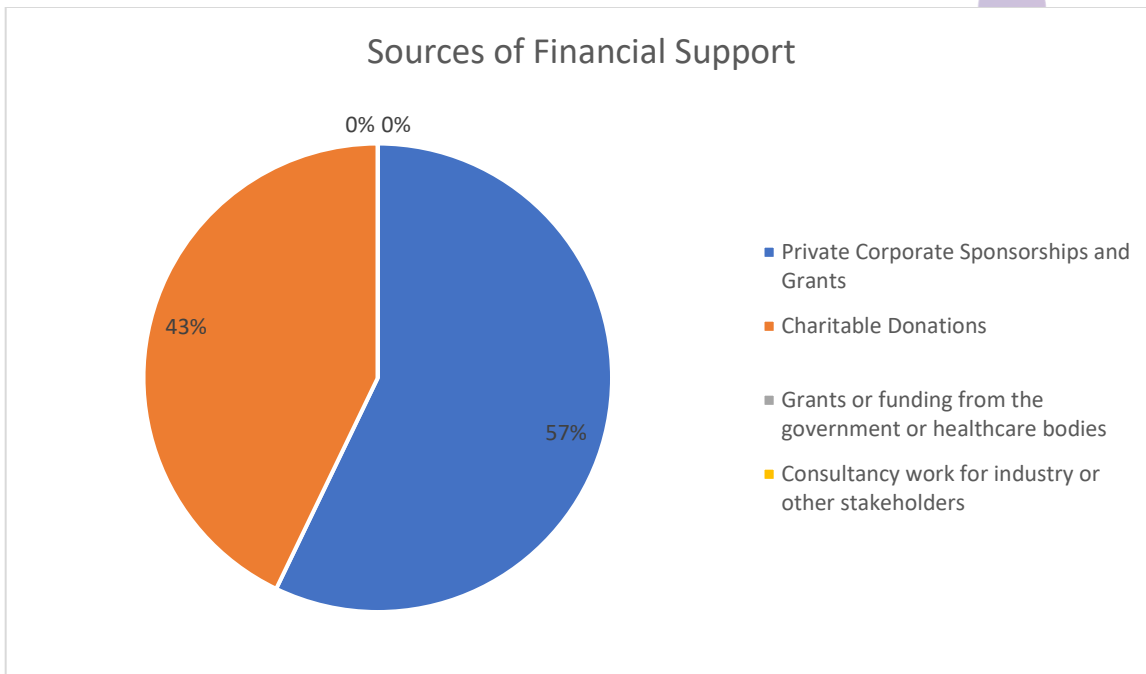


Fig D. Current Focus Areas of Patient Organizations against their preferred focus area (N=7 Respondents)

Providing Patient Services Support as well as ample Patient Education are the most common key focus areas of Patient Organizations. While a few also focus on other areas such as seeking financial support, political lobbying, policy analysis, and providing support for clinical trials. However, when asked what is the single most important key function of a Patient organization, many admit that it mostly revolves around providing financial support for patients as well as providing much needed services and educational information in order for patients to yield a better life.



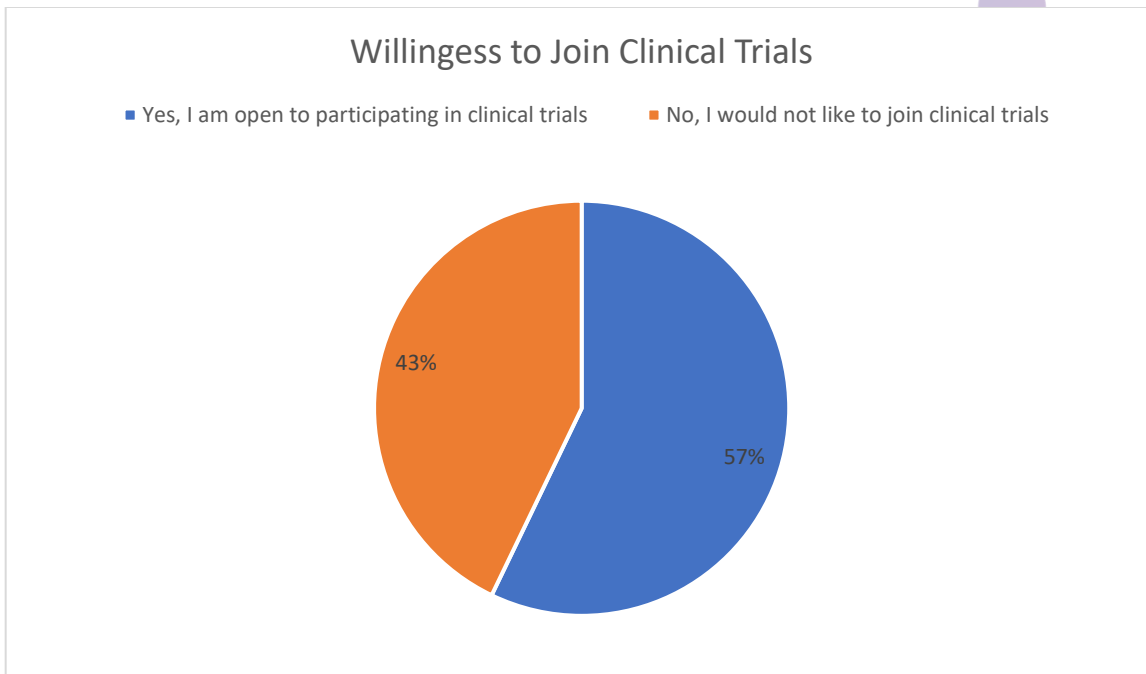
*Fig E. Sources of Income among Patient Advocacy Groups (N=7 Respondents)*

What is interesting to note is that patient organizations aim for providing financial support to patients as a key area of focus. However, they are not currently doing so. This could mean that patient groups currently lack the resources needed in order to sustainably provide financial support to patients. This is echoed by the Day 1 Mentimeter Flash survey, which show that PAGs are currently struggling with sustaining both funding and volunteers within their organizations. (See Appendix B. Figure 5). Data from the pre-event survey show that funding mostly comes from private corporate sponsorships and charitable donations. Funding from healthcare institutions and government bodies are notably absent. (Fig E.)

In fact, many of the breakout session participants wish that they had known how to get more funding and properly engage with government institutions in order to accumulate necessary resources to provide adequate yet better support to their patients. (See Appendix B. Fig 6.1-6.2)

### **On Participation in Clinical Trials**

When it comes to patient participation on clinical trials – which is the key topic of the Day 2 PH breakout session, the pre-event survey results show that 7/7 participants **have not participated in any clinical trial** in the past. (See Appendix A Fig. 2)



*Fig F. Willingness to Join Clinical Trials (N=7 Respondents)*

On the contrary, data also shows that some participants are open to joining clinical trials. (Fig. F). This is in recognition that participation in clinical trials are crucial in the potential development of more effective or alternative treatments plans for patients in the future.

*“We are deeply grateful for all those who participated in previous clinical trials. This is the reason why we have effective medicines today.” – Pre-event survey participant*

*“To be able to assist people with diabetes and to be updated to the new modalities of treatment – Pre-event survey participant”*

However, those who were willing to participate in clinical trials were only willing to participate if and when the treatment or medication has reached Phase IV, or the post-launch monitoring of trial medication for adverse effects - wherein it has already undergone majority of the standard testing required by healthcare bodies. None of the willing participants are open to joining clinical trials earlier in the process. (See Appendix A. Figure 2)

Meanwhile, those who were unwilling to participate in clinical trials choose to do so because of lack of information about clinical trials and lack of credibility on the safety of these trials. This was echoed by the Mentimeter Flash Survey conducted during the second day of the PH breakout sessions, wherein transparency and proper information dissemination were provided regarding clinical trials. Effective post-care plans should also be in place in case of adverse effects among patients to manage the perceived risk of joining. (See Appendix C, Fig. 9.1-9.2)

*“Explain properly about the trials and how it will benefit the people. – Mentimeter Flash survey participant*





*“Company should shoulder all medical costs in case of side effects – Mentimeter Flash survey participant”*

It is clear that lack of substantive information on clinical trials and the perceived risk of adverse effects are the primary reasons behind the lack of willingness to join clinical trials. Furthermore, pre-event survey results show that none of the participants, including those who are open to participating, are familiar with the processes or stages of clinical trials. (See Appendix A. Fig. 2) This simply emphasizes the lack of overall information on clinical trials themselves.



# Insights from Breakout Sessions – Day 1



## Asia Pacific Patient Innovation Summit PHILIPPINES 2 March 2021

*Day 1 of the APPIS Breakout Sessions for the Philippines which focuses on the Establishment and Governance of Patient Advocacy Groups.*

### **“Establishment and Governance of a Patient Advocacy Groups (PAGs)”**

*Presented by:*

- Mr. Peter Paul Perez (Chair of the Cancer Coalition of the Philippines)

*Facilitated by:*

- Dr. Gia Sison

The Day 1 breakout session for the APPIS PH Hub revolved around the establishment and governance of Patient Advocacy Groups. Based on participants’ responses from the pre-event survey questionnaire, most PAG representatives face a variety of challenges in relation to their patient organizations. Many are looking to focus more on providing patient services support, while others are keen on gaining financial support or patient education for patients. (See Fig. 1)

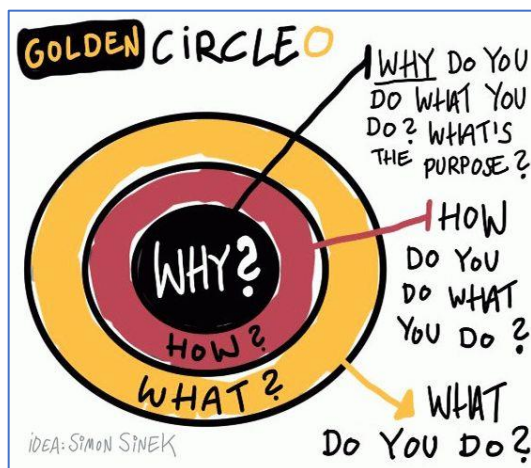


*Speaker Paul Perez*

In his talk, Mr. Perez emphasized that PAGs indeed strive to focus on multiple areas and services in general. Passion drives PAGs to focus on a diverse set of issues and it is very much common for different organizations

to focus on multiple things all at once. Spontaneous responses on the Mentimeter flash survey questions revealed that patient leaders find it challenging to sustain both volunteers and funding for their organizations. Others wish they had known how difficult it was to establish a PAG, engage more with volunteers, secure more funding, or properly communicate with government institutions. (See Fig 5-6.2)

However, the speaker emphasized that there is also merit in aiming to focus on one key area despite this. In fact, it is essential for all Patient Groups to start with a “Why?”



*The Golden Circle by Simon Sinek*

According to him, it is crucial for Patient Groups to figure out their main focus and purpose prior to establishing a community or collective. People normally do not engage in products, services, and movements until it is clear why they should do so. Patient leaders are invited to go beyond asking the “What’s” and the “How’s” and primarily ask: **Why is there a Patient Advocacy Group? Why do we do what we do?**

Asking “why” allows patient advocates to see things with new lenses, looking beyond

what is already known so that they can recognize gaps and barriers in the healthcare system.

Speaker Paul Perez recounted that his first “why” in establishing the Cancer Coalition of the Philippines, despite multiple existing cancer patient groups, is to create urgency in what they are advocating and bring the spotlight on the urgency of issues with a laser focus on their main advocacy initiatives.

Cancer is a leading cause of mortality with approximately 110,000 new cases of cancer in the Philippines and more than 66,000 deaths each year. Every hour 11 will be stricken with cancer and, at the same time, 7 will not make it – given this data, there is a need to allow cancer movements to be included in the agenda of different institutional discussions in order to bring a face to the numbers and make the data real. He believes that there is a need for real-life patient stories to be shared, no matter how difficult it is.



*Cancer Coalition of the Philippines*

Having a clear understanding of the organization’s purpose allows a patient group to ask the next essential question: “How?”

Knowing the “why” behind an advocacy initiative leads to the thought process of figuring out how a patient group can

prepare to make their advocacy initiatives happen.

Asking “How can we be ready?” enables a patient group to build a vision and strategy for execution. Mr. Paul Perez emphasized the importance of consistently being ready for a patient advocacy group so that they can strike when key opportunities arise. Recalling his journey with the Cancer Coalition of the Philippines, he mentioned that being prepared led them to be able to effectively communicate with government legislators who reached out to them once their initiative gained traction. He said that their coalition was confident to discuss with policy makers the different issues and lobby for solutions that can guide future policy-making because they had already established their vision, strategy, and clear advocacy as a patient organization.

With a clear strategy in mind, the next major step for patient organizations is to take action and find ways to turn their vision and advocacy into reality.

**Communication** is one of the key ways to take action. Making sure to tap all available communication channels will ensure that a patient group’s vision will reach the right people. With proper communication, advocacies can reach like-minded groups and **empower them** to create their own group activities and take action as well.

With collective action, short-term wins can be achieved and it is important to **celebrate these milestones**, no matter how small, because it can ripple into bigger changes. Even without significant results, Mr. Paul Perez calls on patient groups to show consistency when things slowed down. Continuous call for action cannot be ignored and, eventually, their voices will be heard. Patient groups will need to apply these

principles in their group activities in order to achieve greater impact.



*December 12, 2018:  
the national integrated cancer control law was approved by congress.*

On the other hand, group activities could potentially go to waste if it only creates fleeting impact. Therefore, patient groups must also work on making their advocacies “stick”. In order for long-term change to occur, any group must strive to revise existing norms and cultures by reinforcing new behaviors until it becomes the new norm – this principle also applies for patient groups. As simple as a lasting change in mindset can lead to better policies and outcomes for patients in the long run. On the part patient organizations, consistently evaluating current strategies and refreshing them to keep updated with the current landscape can help their advocacies adapt to a changing environment and remain relevant for a long period of time.



In the case of the Cancer Coalition of the Philippines, Mr. Paul Perez recalled that they had to carefully consider the timing of each campaign in order to maximize its impact.

His patient organization launched a “Freedom from Cancer Campaign” strategically on the date of the Philippine Independence Day for example. Furthermore, they made sure that their presence was evident not just offline, but also on various social media platforms – which helped gain the attention of legislators who are now ever-connected to the online world. Online presence also helped communicate their message to like-minded people in the academe, medical societies, and other patient advocacy groups.

Overall, Mr. Paul Perez emphasized that every change in the world came to be when certain individuals, may it be a person or a small group, committed to creating a difference.

For patient advocacy groups, it is not really about sustaining a large group of like-minded individuals or creating multiple campaigns, but rather more about putting forth strategic campaigns that focus on generating great impact.



#### KEY ELEMENTS IN PAG

- **MAKE IT ESSENTIAL**
  - Focus on absolutely necessary or extremely important to create urgency
- **MAKE IT REAL**
  - Focus on human stories
- **MAKE IT READY**
  - Focus on solutions
- **MAKE IT HAPPEN**
  - Produce short term wins, celebrate milestones and empower others to act.
- **MAKE IT STICK**
  - Create a new culture
- **MAKE IT COUNT**
  - Focus for impact

#### *Key elements in a patient advocacy group*

In order to establish and maintain an effective patient advocacy group, all organizations must:

1. **Make it Essential** – Focus on the “Why?” Bring to light what is extremely important and create urgency.
2. **Make it Real** – Recount the human experience, bring to life their stories, and bring a face to the data.
3. **Make it Ready** – Use your vision, strategy, and advocacy to lobby for solutions.
4. **Make it Happen** – Communicate, Empower, and be consistent in order to product short term wins and milestones.
5. **Make it Stick** – Create a new norm and aim for lasting change by consistently re-evaluating and refreshing tactics.
6. **Make it Count** – Aim for greater impact and let a small ripple cascade into bigger change.



# Insights from Breakout Sessions – Day 2



ASIA PACIFIC  
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**Asia Pacific Patient Innovation Summit  
PHILIPPINES**  
3 March 2021



## “The Role of Patient Organizations in Supporting Patients and Clinical Trials”

### *Presented by:*

- Ms. Menchie Carmen Auste (Chair Philippine Health Research Ethics Board Committee on Patient Family and Stakeholder Management)
- Vice-President and Co-founder of the Cancer Coalition of the Philippines

### *Facilitated by:*

- Ms. Christine Fajardo

On the second day of the Asia Pacific Patient Innovation Summit, a breakout session on Clinical Trials was held for the Philippines’ Hub. A spontaneous Mentimeter Survey was conducted among the breakout session participants which

revealed that the primary apprehension among patients in participating in Clinical Trials is the fear that they will be treated like Guinea Pigs. (See Fig. 8)

Furthermore, APPIS PH breakout participants have highlighted that transparency is key in encouraging more to participate, as well as providing adequate post-trial support, such as a post-care plan or an allowance to shoulder medical costs in case of consequent adverse effects. (See Fig. 9.1-9.2)





Speaker Carmen Auste

Speaker Carmen Auste fully acknowledged patient concerns such as these in clinical trials, but further emphasizes the need for information dissemination and patient assistance to encourage more patients to join in key roles, which patient organizations are in the best position to fulfill.

Apprehensions and concerns regarding clinical trials have always been rooted in the myths and misconceptions that many have towards them. The fact is, clinical trials can provide significant benefits to a patient as these can:

1. Provide hope in coming up with better treatment solutions.
2. Help patients to connect with a community, thus, building their confidence and washing away the feeling of being alone.
3. Offering access to treatment and medication for those in lower socio-economic classes.

Furthermore, there is a paradigm-shift present in clinical studies and trials wherein patients begin to take on more pro-active roles during the course of the entire process.

Patients are no longer passive research subjects, and are increasingly integrated into the research teams. First-hand experiences make for patients who are experts that should be consulted regarding the disease.

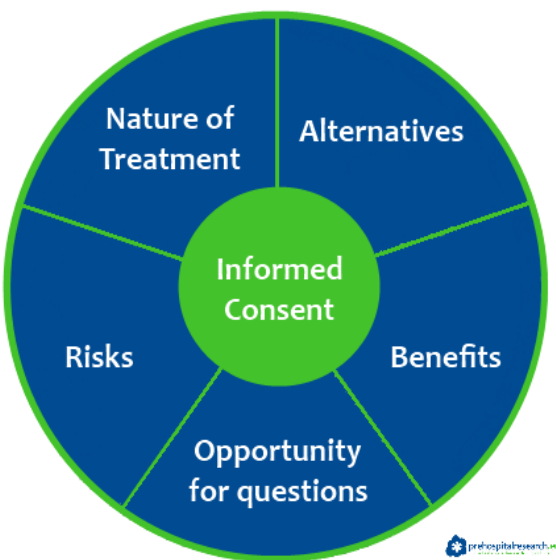
**CLINICAL RESEARCH** may be right for you if you want to:

- Help others, including future family members, who may be at risk for certain diseases
- Receive regular monitoring by medical professionals
- Test new disease treatments that may work better than others

*Benefits of Clinical Research*

Given the importance of patient participation in clinical trials, speaker Carmen Auste underlines the existence of robust mechanisms in place to ensure that patients remain protected throughout. Every clinical trial has protocols and guidelines that are carefully reviewed and accredited by existing ethical review boards with safety as their number one priority. Furthermore, patients are required to provide informed consent before participating in clinical trials.

Informed consent entails acknowledgement of the nature of treatment and its risks, alternative solutions, benefits, and an opportunity for patients to freely ask questions all throughout the study - with recognition that they have the right to withdraw consent at any moment.



*Different Facets of Informed Patient Consent*

Patient Advocacy Organizations carry strong connections with patient communities which is why they are very critical to aiding clinical trials. Patient organizations also carry the trust of their constituencies along with knowledge of real-life patient concerns and first-hand experiences with disease management. Therefore, they are invited to be committed and active partners in clinical trials while encouraging and, at the same time, representing patients over the course of these researches.

APPIS PH Hub Breakout participants have agreed that lack of knowledge and understanding leads to apprehension towards participation. This stresses the crucial role patient advocacy groups and organizations have in providing help among

patients by assisting in the navigation of the entire clinical research process - enhancing patient understanding by guiding them through the different phases of clinical trials as well as their rights and obligations, advising patients in weighing the benefits and risks of participation, and maintaining dialogues with the patient community to ensure that they have continuous access to information on availability of clinical trials.

At the same time, PAGs should also coordinate with appropriate sectors to connect qualified patients to clinical trials and various health researches, communicate the perspectives of participants, and champion their rights/voices while identifying gaps for improvement in the entire process and discussing these with relevant governing bodies. Post-trial support can also be provided for patients by aiding them in reporting any adverse effects.

In the end, clinical trials provide us with robust scientific data not limited to medication/vaccination efficacy testing, but also on how certain behaviors can affect health or treatment. Clinical trials enable the health sector to create better medical interventions that yield more promising patient outcomes alongside better preventive care.

The role of PAGs is two-fold – it advises patients and assists them throughout the process, while also representing them and articulating their perspectives and needs to research bodies in order to build better research practices and increase patient participation. The breadth of functions PAGs can undertake makes them pivotal partners for health research.





# Summary and Recommendations

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## Establishment and Governance of Patient Advocacy Groups (PAGs)

The first Philippine breakout session in the Asia Pacific Patient Innovation Summit (APPIS) focused on the key aspects that PAGs need to structure themselves on in order to create an impactful and purposeful organization.

Establishing and maintaining an effective Patient Advocacy Group mainly revolves around finding out why there is a need to establish one's own patient advocacy organization. A clear goal and focus will help a Patient Advocacy Group build a strong mission and vision for their organization. Having a strong vision then enables advocacy groups to strategically craft and advocate for better healthcare outcomes that can then be lobbied to policy makers and relevant bodies or institutions.

Being strategic in communicating advocacies are key to a sustainable and impactful Patient Advocacy Group. A central goal of patient advocacy groups should be to make a relevant and lasting impact on people in order to create change. Communicating messaging that sticks is more important than organizing grand movements. This, then, entails that PAGs should remain strategic in their advocacy campaigns, with proper consideration for the timing and communication platforms they will use in order to effectively establish their advocacies to the right people.

However, looking at the pre-event survey and mentimeter data, PAGs are generally more focused on two (2) key areas:

1. Providing support to patients
  - a. Providing adequate education information for patients in order to mentor and help them cope with their disease.
  - b. Strengthening different services to provide support to patients who need it.
2. Finding ways to gain funding and help.
  - a. Sustaining volunteers within their patient organization
  - b. Finding ways to get funding and grants from private institutions and, most importantly, government and healthcare bodies.

Given this information, it is clear that PAGs are turning their attention and resources towards building a sustainable source of support for patients, and are often challenged by the need to maintain engagement of their volunteers and getting adequate funding. Less attention is allocated to lobbying for solutions to different healthcare concerns, or communicating with the right people in order to create lasting impact.

Although providing support to patients is innate and a pillar of patient organizations, speaker Paul Perez emphasizes that many of the challenges PAGs face with regards to building their



volunteers or maintaining sustainable incoming have the opportunity to be resolved if they create strategic communications that reach relevant people who can offer them the help they need.

Bringing attention and raising awareness to different healthcare issues and proposing solutions, if executed properly, will reach people who are eventually willing to help and may bring the necessary volunteers and funding that they need. Therefore, what is needed is to boost the capability and learning of Patient Advocacy Groups when it comes to creating impactful ways to communicate their message and advocacy, target the right people, and efficiently leverage both online and offline platforms in order to create successful campaigns.

### **The Role of Patient Organizations in Supporting Patients and Clinical Trials**

The second Philippine breakout session was headed by Speaker Menchie Carmen Auste and talks about the importance of patient participation in clinical trials and the crucial role of patient organizations in supporting both clinical trials and participant patients.

Pre-event survey data and Mentimeter flash survey results show that common myths and misconceptions about clinical trials still predominantly exist in the country today. Common myths such as being an experimental Guinea Pig during the clinical trial and being left alone post-trial even with the risk of adverse effects greatly hamper the willingness to participate among patients in clinical trials.

However, speaker Carmen Auste emphasizes that clinical trials are essential in providing robust scientific data on various medical treatments for different diseases and can provide hope to patients who are looking for future medication and treatment plans. Patients are also crucial in clinical trials because of their lived experiences with the disease, making them more knowledgeable “patient experts” that can contribute to the success of health studies.

More than that, clinical trials are required to secure an informed consent from patients prior to joining which can be withheld at any time a patient decides to do so. Different health research boards and experts also ensure that clinical trials are regulated and safely conducted in accordance with established health and research standards. Therefore, clinical trials are carefully conducted with appropriate regulations to ensure safety and care for patient participants.

However, lack of information simply leads to low participation. The prevalence of myths and misconceptions stand evidence to the lack of proper information dissemination among patient communities regarding clinical trials – which needs to be enhanced. Patients also call for post-trial plans that effectively cover medical costs in the case of adverse effects to mitigate the risk and fears of participation.





Given the need to educate patients, different patient organizations have the opportunity to play a crucial role in utilizing their vast connections with the patient community in order to bridge them to different health research institutions through proper patient education on clinical trials in order to promote participation.

Furthermore, PAGs also play another crucial role in championing the rights and opinions of patients to health research institutions in order to improve clinical trials and health research in general. PAGs can serve as a two-way bridge of communication between patient experts and clinical research boards in order to create effective and safe clinical trials that lead to advancements in medical treatment for different diseases in the future.

Lastly, although it is clear that PAGs play a huge role in proper and adequate information dissemination, there is also a need for other influential institutions to play a role in promoting clinical trials. Patients call for the active participation of both the Philippine government and health bodies to make information more accessible to patients and reach a wider array of audiences to eliminate the fears brought about by the myths and misconceptions that surround clinical trials.

Patients recognize that other countries such as Singapore dedicate stand-alone government institutions for clinical trials that recruit directly from hospitals. While in Japan, pharma companies also have the opportunity to provide accessible information on clinical trials in working closely with patient organizations.

A more holistic structure similar to that of other countries wherein multiple stakeholders support the clinical trial process can certainly yield better outcomes for clinical trials, the patient participants, and the healthcare system as a whole.



# Appendix A – Pre-Event Survey Results

Figure 1. Patient Organizational Information and Key Focus


QUESTIONS							
1. In which countries/regions is your patient organization present?	Philippines	Philippines	Philippines - Region 3	Philippines - Region IV-A	Philippines	Philippines - region 3 bulacan	Philippines
2. How long has your patient organization existed?	Since 2000 (21 years)	16 years	Since 2017 (4 years)	26 years	15 years	6 years	20 years
3. What is your role in your patient organization?	Coordinator	President	President	Social Worker	Member	Pro internal	Board of Trustee
4. What are the current focus areas of your organization?	Patient Education Information Patient Services Support Political Lobbying for Patient Interests Policy Analysis and Advocacy	Focusing on HIV patient on Treatment Care and Support	Patient Education Information Political Lobbying for Patient Interests Research and Clinical Trials Mentoring and handholding for patients and caregivers Encouragement and support specially for newly diagnosed patients	Patient Education Information Patient Services Support Mentoring and handholding for patients and caregivers	Patient Education Information Patient Services Support	Patient Services Support Financial Support to Patients	Patient Education Information Patient Services Support Mentoring and handholding for patients and caregivers
5. If your patient organization can have one single focus, what do you think should it be?	Patient Services Support	Patient Services Support	Mentoring and handholding for patients and caregivers	Financial Support to Patients	Patient Education Information	Financial Support to Patients	Patient Education Information
6. What are the disease areas that your patient organization focuses on?	Neuroscience Neurodevelopmental	HIV	Hematology Chronic Myeloid Leukemia (CML)	Chronic Illnesses	Non-communicable Diseases	Non-communicable Diseases	Diabetology/Endocrinology
7. What are the main sources of funding for your organization?	Corporate (Sponsorship) or grants Through Membership and sponsorship	Corporate (Sponsorship) or grants	None at the moment	Charitable Donations	Charitable Donations	Corporate (Sponsorship) or grants	Corporate (Sponsorship) or grants
8. What channels do you usually use to communicate with your members?	Social Media (e.g. Facebook) Instant-messaging (e.g. Viber, Whatsapp, Messenger, etc.) Emails (e.g. direct or group mail subscriptions), Landline (i.e. Telephone, Mobile) Virtual Meetings (e.g. Zoom, MS Teams, Google Meet, etc.) Face-to-face discussions	Social Media (e.g. Facebook) Instant-messaging (e.g. Viber, Whatsapp, Messenger, etc.) Emails (e.g. direct or group mail subscriptions), Landline (i.e. Telephone, Mobile) Virtual Meetings (e.g. Zoom, MS Teams, Google Meet, etc.) Face-to-face discussions	Social Media (e.g. Facebook) Instant-messaging (e.g. Viber, Whatsapp, Messenger, etc.) Emails (e.g. direct or group mail subscriptions) Landline (i.e. Telephone, Mobile) Virtual Meetings (e.g. Zoom, MS Teams, Google Meet, etc.) Face-to-face discussions	Social Media (e.g. Facebook) Instant-messaging (e.g. Viber, Whatsapp, Messenger, etc.) Emails (e.g. direct or group mail subscriptions) Landline (i.e. Telephone, Mobile) Virtual Meetings (e.g. Zoom, MS Teams, Google Meet, etc.) Face-to-face discussions	Social Media (e.g. Facebook) Instant-messaging (e.g. Viber, Whatsapp, Messenger, etc.) Emails (e.g. direct or group mail subscriptions), Landline (i.e. Telephone, Mobile) Virtual Meetings (e.g. Zoom, MS Teams, Google Meet, etc.) Face-to-face discussions	Social Media (e.g. Facebook) Instant-messaging (e.g. Viber, Whatsapp, Messenger, etc.) Emails (e.g. direct or group mail subscriptions), Landline (i.e. Telephone, Mobile) Virtual Meetings (e.g. Zoom, MS Teams, Google Meet, etc.) Face-to-face discussions	Social Media (e.g. Facebook) Instant-messaging (e.g. Viber, Whatsapp, Messenger, etc.) Emails (e.g. direct or group mail subscriptions), Landline (i.e. Telephone, Mobile) Virtual Meetings (e.g. Zoom, MS Teams, Google Meet, etc.) Face-to-face discussions

Figure 2. Pre-event Survey on Clinical Trials

9. Have you participated in a clinical trial in the past?	No	No	No	No	No	No	No
9.1 May we know what clinical trials have you previously participated in?	N/A	N/A	N/A	N/A	N/A	N/A	N/A
10. Would you be interested in participating in a clinical trial?	No	Yes	Yes	No	No	Yes	Yes
10.1 If yes, why are you willing to participate?	N/A	Trying to educate after submitting myself first	We are deeply grateful for all those who participated in previous clinical trials. This is the reason why we have effective medicines today	N/A	N/A	It can be effective the result if I try to participate	To be able to assist people with diabetes and to be updated to the new modalities of treatment
10.1 If no, may we know if you have any issues/concerns with clinical trials?	This need a Board's approval	N/A	N/A	None	It might not work with my skin	N/A	N/A
10.2 What would motivate you to participate in a clinical trial?	Clear information on the said medication	N/A	N/A	None	Credibility	N/A	N/A
11. Are you familiar with the process or the steps you have to take in order to participate?	No	No	No	No	No	No	No
12. Up to what stage in a clinical trial are you comfortable with participating in?	Not open to participating in a clinical trial	Not open to participating in a clinical trial	Phase IV - after receiving approval for release to the market. Monitoring adverse effects post-launch to the general public.	Not open to participating in a clinical trial	Not open to participating in a clinical trial	Phase IV - after receiving approval for release to the market. Monitoring adverse effects post-launch to the general public.	Phase IV - after receiving approval for release to the market. Monitoring adverse effects post-launch to the general public.
13. Can you explain the reason behind your answer to the previous question?	N/A	N/A	Since we have comorbidities and have a higher risk than the general population, I think I am more comfortable with phase 4 trials	N/A	N/A	To know how much affective the medicine when we go to a trial and what are the indications	To be able to assist in explaining to people the effect of the clinical trial in layman terms

# Appendix B – Day 1 Mentimeter Results

Figure 3. Day 1 Mood Meter

How are you feeling today? Please write down 3 to 5 words or phrases to describe how you are feeling. 

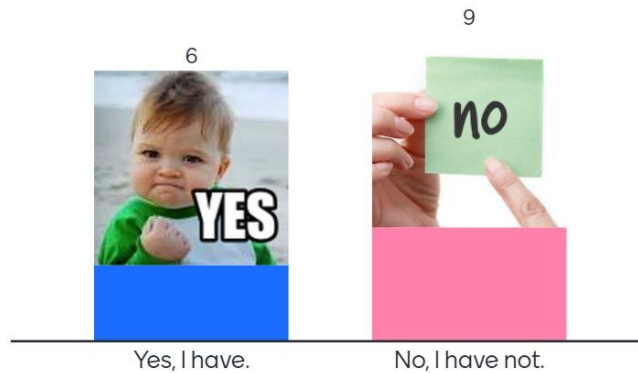


Press S to show image



Figure 4. 2019 APIS Participation

Did you participate in the 1st APIS in 2019? 



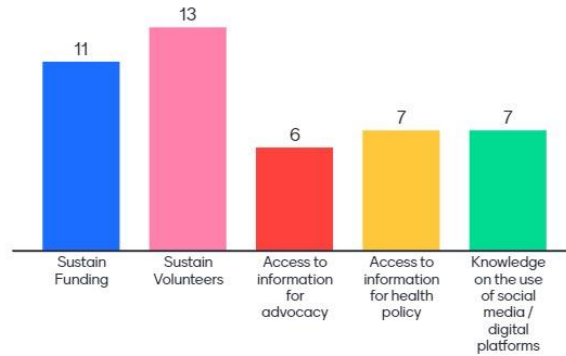
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Figure 5. Challenges faced by Patient Advocacy Groups

## What are the challenges that your Patient Advocacy Group (PAG) are encountering?

Mentimeter



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14

Figure 6.1. Things to know before starting a Patient Advocacy Group (1/2)

## What is it that you know now that you wish you had known before starting a Patient Advocacy Group (PAG)?

Mentimeter



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13

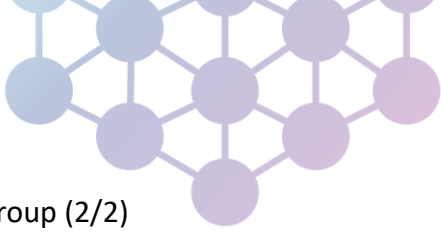


Figure 6.2. Things to know before starting a Patient Advocacy Group (2/2)

# What is it that you know now that you wish you had known before starting a Patient Advocacy Group (PAG)?



the support of the people and its before i got down with my condition

Engage with members and government

How to get help from government

What is the benefit of joining advocacy grp

how to get grants and funding

I think i just want more about lupus and how can i handle it to be back to my normal life because im a lupus patient and i cant handle it the way i know

I think by participatient this group will help me to cope with my illness and help me

Press S to show image



# Appendix C – Day 2 Mentimeter Results

Figure 7. Day 2 Moodmeter



How are you feeling today? Please write down 3 to 5 words or phrases to describe how you are feeling. 



Figure 8. Common Myths and Misconceptions on clinical trials

What are the common misconceptions or myths that people have when it comes to clinical trials? 

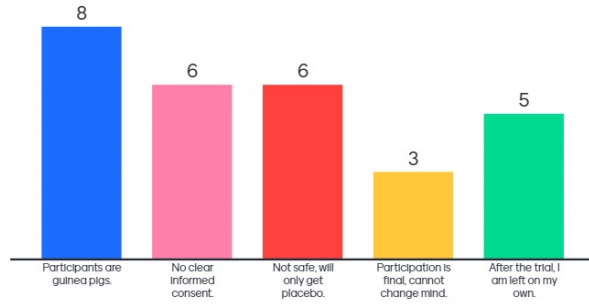




Figure 9.1. Ideas to encourage participation in clinical trials (1/2)



Figure 9.2. Ideas to encourage participation in clinical trials (2/2)

