



Alliance &
Partnerships for
Patient
Innovation &
Solutions

APPIS 2022
Asia Pacific, Middle East, and Africa

SHAPING HEALTH POLICY WITH COLLABORATIVE PATIENT ENGAGEMENT

Guidance Document For Patient Organizations

www.appisinitiative.com

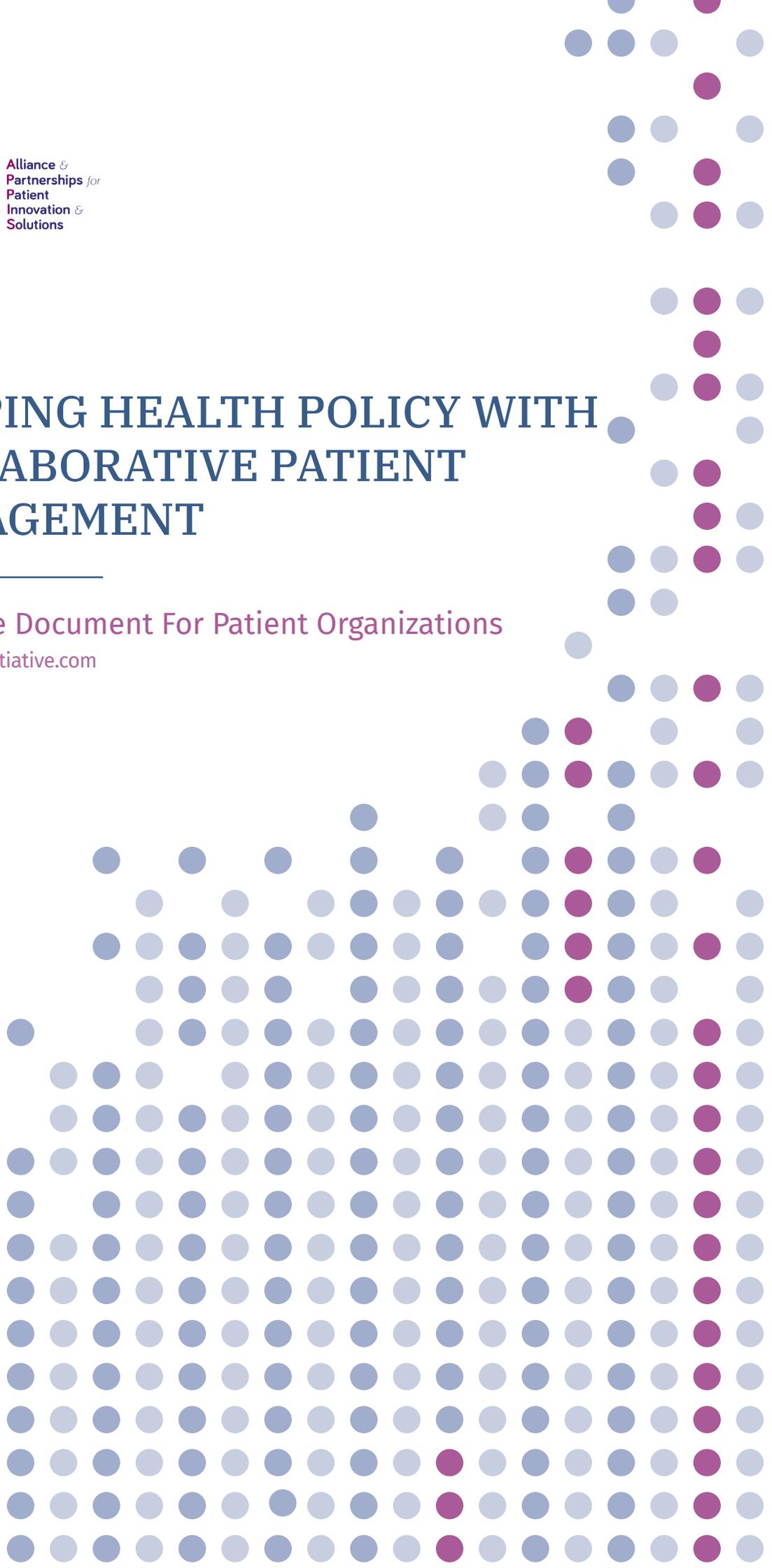


TABLE OF CONTENTS

Acknowledgment	3
Executive Summary.....	4
Section I: Introduction.....	6
Purpose	6
Background	7
Health Policy and Patient Engagement.....	7
Role of Patient Organizations.....	8
Health Technology Assessments	9
Section II: Challenges to Patient Engagement in Health Policy Shaping.....	10
Section III: Roadmap to Improve Patient Engagement in Shaping Health Policy.....	12
Action Item 1: Stakeholder Mapping and Engagement.....	14
Action Item 2: Participate in Networking Forums and Cross-Learning Platforms.....	17
Action Item 3: Standardize Data with Patient Registries.....	19
Action Item 4: Legislative Advocacy Campaign.....	21
Overarching Recommendations.....	23

ACKNOWLEDGMENT

This guidance document is an outcome of the **Alliance and Partnerships for Patient Innovation and Solutions (APPIS) Initiative in 2022**.

This has been possible with the pioneering leadership and continued intellectual support given by APPIS 2022 partners, who contributed to the content of this guidance document and reviewed, and provided valuable feedback on this document.

- **Carmen Auste**, Vice President, Co-Founder, Cancer Coalition Philippines; and CEO, Co-Founder, Cancer Warriors Foundation;
- **Reynaldo Abacan**, President, Dialysis Philippines;
- **Tanya Hall**, CEO and Founder, Hearts 4 Heart Australia;
- **Josef de Guzman**, Founding President and Executive Director, Psoriasis Philippines;
- **Sungki Kim**, President, Korea Psoriasis Association;
- **Paul Mendoza**, President, Psoriasis Philippines and Psoriasis Asia;
- **Derrick Mitchell**, CEO, Irish Platform for Patient Organizations, Science and Industry (IPPOSI);
- **Rod Padua**, President at Touched By Max Inc. Philippines;
- **Renuka Prasad**, Secretary (Hon), Indian Cancer Society, India;
- **Andrian Rakhmatsyah**, Secretary-General, ELGEKA Indonesia;
- **Prasanna Shirol**, Co-founder & Executive Director of Organization for Rare Diseases (ORDI), India;
- **YaHsin Wang**, Secretary General, Psoriasis Association Taiwan;
- **Jeff Weisel**, Policy Leader and Managing Director, APAC, PRMA Consulting, Singapore;
- **Sejal Mistry**, Regional Director, ACCESS Health International Southeast Asia;
- **Sireesha Perabathina**, Senior Consultant, ACCESS Health International Southeast Asia;
- **Abhishek Sudke**, Junior Consultant, ACCESS Health International Southeast Asia;
- **Aldina Aljukic**, Director, Public Affairs, APMA (Asia Pacific, Middle East, and Africa), Novartis;
- **Dipen Ankleshwaria**, Head, Emerging Markets CoE, Novartis;
- **Reem ElAdl**, Patient Engagement Director, APMA (Asia Pacific, Middle East, and Africa), Novartis;
- **Nidhi Dani**, Worldwide Access Product Lead, Novartis;
- **Vaishali Iyer**, Country Head, Communications, Patient Engagement, and CSR, India, Novartis;
- **Ruth Kuguru**, Communications and Engagement Executive Director, APMA (Asia Pacific, Middle East, and Africa), Novartis;
- **Maryline Marquet**, Patient Engagement Director, Asia Pacific, Middle East, and Africa, (APMA) Novartis;
- **Joy Ong**, Patient Engagement Director, APMA (Asia Pacific, Middle East, and Africa), Novartis;
- **Duo Xu**, Communications and Engagement Manager, APMA (Asia Pacific, Middle East, and Africa), Novartis;

and other international partners.

Visit www.appisinitiative.com to learn more about APPIS.

EXECUTIVE SUMMARY

Background & Purpose

This guidance document is part of the **Alliance and Partnerships for Patient Innovation and Solutions (APPIS) 2022** initiative, funded and organized by Novartis, and aims to enable the **convergence of perspectives between patient communities and key stakeholders in the healthcare ecosystem**, such as policymakers, payers, physicians, members of academia, research institutes, and regulatory bodies, to improve health outcomes in the **Asia Pacific, Middle East, and Africa region**.

Health policy shaping was selected as a theme of the APPIS initiative in 2022, given the real-world need for patient-centric health policy interventions and the limited involvement of patients and patient organizations in related decision-making processes.

This document is intended as a guidance note for **patient organizations** that wish to become more involved in the health policy decision-making process and ultimately contribute to improving health outcomes.

Content Overview

The **first section** introduces the APPIS initiative on health policy shaping and elaborates on the purpose and potential use of this document. This section introduces the role of patient engagement in shaping health policy and why it is important, highlighting several areas where patients can collaborate in the health policy decision-making process, including Health Technology Assessments (HTAs). HTAs are key decision-making policy tools that are frequently used to engage patients in the development and review of health policies.



The **second section** highlights the barriers standing in the way of involving patient organizations and sustaining their participation in the health policy-shaping process. These challenges mainly stem from patient organizations having limited recognition, capacity, and with little guidance on the right way to approach and engage with healthcare systems. It also highlights some systemic challenges, such as the lack of the right communication channels and engagement methods, the lack of government responsiveness, the use of inconsistent terminologies by patient organizations, the limited use of evidence-based engagement from patient organizations, and the lack of a legal mandate to engage patient groups in the health policy-shaping process.

The **last section** provides a strategic approach to overcoming the identified gaps through four main action items:



Conducting a stakeholder mapping and engagement exercise to identify key stakeholders in the health policy-shaping process and the proper channels to engage with them, such as through Health Technology Assessments (HTAs).



Using and/or creating networking and cross-learning forums.



Support setting up patient registries and using datasets to strengthen the voices of patient organizations.



Executing a legislative advocacy campaign that will help patient organizations raise the issue of engaging patients and carers in the health policy-shaping process



The section concludes with a comprehensive strategy for patient organizations to convene an in-country consultation and act on the suggested action items listed above.

Patient organizations can use this document as a jumping-off point to work with stakeholders and customize plans to improve patient engagement in health policy shaping.

SECTION I: Introduction

Purpose

Engaging patients in health policy decision-making helps to ensure that policies reflect patient and caregiver needs, preferences, and capabilities, making it an appropriate and cost-effective way to address the needs of the growing number of people with chronic conditions. However, the lack of appropriate channels has prevented patient organizations from participating in the health policy-shaping process. Even if a system is already in place, patients face issues in assuring that the processes are efficient and effective.

This guidance document is the output of consultations at the virtual APPIS workshops

conducted in February and March 2022. Thought leaders from patient organizations, academia, and the healthcare industry, from various countries shared their perspectives on patient involvement in health policy shaping, identified the challenges faced by patient organizations, and shared some solutions.

This document is for patient organizations who want to make a difference in the healthcare experience of patients and caregivers either at a national or a federal level, and can help them by:



Reinforcing why patient organizations are critical contributors to the health policy-shaping process.



Providing guidance on how patient organizations can use some of the existing channels and processes to be more participatory in the health policy decision-making process at both the local and national levels.



Enumerating how to initiate an in-country dialogue for countries to take suggested recommendations forward by adapting the recommendations to their local needs and requirements.

Background

Health Policy and Patient Engagement

Health policy is defined as the laws, regulations, actions, and decisions implemented within society to promote wellness and ensure that specific health goals are met.

Health policies bring the theory and research of public health into practice to solve identified problems. They can range from formal legislation to community partnerships with patient groups and other CSOs who play a critical role in creating solutions that close the gaps in healthcare systems. Several factors influence health policy decisions, such as: market forces, economic climate, fiscal pressures, research, and perspectives of patients. Each of these factors interacts with and influences the other in different ways. However, patient experiences and perspectives are seldom included in the health policy decision-making process. Research shows that a partnership between patient organizations and the healthcare system is linked to enhanced quality of healthcare services, elevated effectiveness and efficiency of health systems, and improved patient satisfaction and population health outcomes.

This partnership, termed “patient engagement,” refers to the involvement of patients in every step of the planning, development, and implementation of healthcare programs, interventions, and services.



Patient Engagement: “An active process of ensuring that patients’ experience, wisdom, and insight are infused into individual care and the design and refinement of any healthcare system.” (Caplan W, 2014)

Involving patient organizations is the key to improving patient engagement in health policy development. By unifying patients’ voices, patient organizations can build effective health policies and more robust healthcare systems by:

- Contributing patients’ experience and perspective as key participants in the healthcare system.
- Identifying gaps and challenges in existing policies.
- Providing patient data and information that enables data-powered decision-making on health policies.
- Contributing to the implementation of policies and monitoring their impact.



“Patients, caregivers, and patient organizations bring so much expertise from their experience of conditions and the challenges they face, as well as the ability to create solutions. Involvement of patient voices in meaningful health policy shaping is therefore so critical and invaluable.”

Iris Zenzoum, President, APMA (Asia Pacific, Middle East, and Africa) Innovative Medicines, Novartis, APPIS 2022



Role of Patient Organizations

Patients and patient organizations need to have standard channels to engage in the decision-making process. Further, for patients to engage with the healthcare system, they must build their capacities to:

- Identify stakeholders who are key decision-makers in health policy and the right channels to engage with them;
- Increase their understanding of the healthcare decision-making process; and
- Build their capacities to contribute to the decision-making process.

Several areas are relevant for patients and patient organizations to engage in the health policy decision-making process. Some of the key areas are:

1. **Research and Clinical Trials** – Manufacturers and developers should work towards incorporating patients' voices in crafting their research and clinical trial protocols. Participation from various patient groups and ethnicities must be encouraged. Patient groups must strengthen dialogue with clinicians and investigators.
2. **Digital Health and Innovations** – Patients need to provide feedback and user experience and input to digital innovators.
3. **Public Health Programs** – Patients to engage in surveys on the use and experience of certain preventive and promotive public health activities. Healthcare policy and clinical participation decision governance centered on medical staff and the government needs to be created with patients and consumers actively participating.
4. **Health Technology Assessments** – Patients can engage in a structured assessment process to provide their health technology inputs to decision-makers such as payers and regulatory bodies that manage the affordability, entry, and use of pharmaceuticals, medical devices, and other technologies within health systems. Some of the data which needs to be looked at can be lived patient experience, quality of life, burden of disease, etc.

Health Technology Assessments

Health Technology Assessments are a standard evaluation tool and one of the main areas for patient engagement in the decision-making process that significantly impacts patients' lives. Examples of health technologies include medicinal products, medical equipment for diagnostic and treatment, and prevention methods. Health Technology Assessments (HTAs) aim to inform decision-makers about what is known and what is not known about technology, to create policies that get the proper treatment to the right patient at the right time and at the right cost, given the trade-offs.¹

Health product makers, regulators, clinicians, patients, hospital managers, payers, government leaders, and others are increasingly in need of information that supports their decisions about whether or how to develop technology, allow it on the market, acquire it, use it, pay for its use, ensure its appropriate use, and more.

HTA can provide information to support decisions about priorities in healthcare, for example:

- Healthcare payers deciding which technologies (e.g., procedures, drugs, etc.) should be paid for.
- Healthcare organizations deciding whether to exclude or implement new technologies (e.g., modern types of radiotherapy).
- Healthcare companies producing new products and pilots (e.g., to demonstrate a level of benefit for the product that justifies the cost).
- Healthcare organizations setting clinical standards and protocols for certain procedures to standardize care, improve quality, and reduce fraud in the healthcare system (e.g., Clinical Pathways and Standard Treatment Guidelines for Breast Cancer).
- Some elements of HTA reports can also be used by individuals, including: patients and caregivers deciding which of the available treatment options best meet their needs.
- Health authorities thinking of putting screening programs in place.

¹ https://www.euro.who.int/_data/assets/pdf_file/0003/90426/E91922.pdf

SECTION II: Challenges to Patient Engagement in Health Policy Shaping

Patients are important stakeholders in the health policy decision-making process. There is a very real need to include, if not amplify, the patient's voice in the policymaking processes. Patient engagement in the region requires further development and policies that can support the inclusion of patient voices.

Many agencies have certain mechanisms in place to engage patients in their processes (e.g., HTAs), but there is great variability among these mechanisms and an absence of comprehensive, robust practices for involvement.² While many patient organizations continue to be involved in the APMA region, meaningful and systemic involvement of patients is still not the norm. HTAs should have actual involvement of patients; i.e. getting inputs from patients. Participation of patients should be multi-faceted, not only to provide input on the treatment of the condition but also to provide opinions on related aspects such as the impact on quality of life. Patients can also provide feedback on the HTA report. At present, most HTA institutions do not have established mechanisms for enabling two-way feedback with patient groups.

Patient organizations at APPIS identified the following main challenges in the health policy decision-making process:

1 Lack of knowledge and capacity

Without the knowledge and capability to identify the right stakeholders to involve in developing their communications, it is difficult for patient organizations to communicate with and receive favorable responses from policymakers.³ Knowledge and competencies of patients and patient groups need to be built not only through coursework but also through actual participation in policy meetings.

2 Lack of appropriate channels for communication

Patient organizations lack the information and understanding of where to start the journey to engage with policymakers. Understanding the relevant areas of patient engagement, the process of engagement, and the right time to do so are equally important.

3 Lack of consistent and structured forums to involve patients

Patient organizations lack the understanding of making their voices heard on an ongoing basis. There is a lack of structured interactive forums between patient organizations and policymakers. Patient organizations need to be persuasive and engage with policymakers at regular intervals. Training patient groups on how to organize roundtable discussions and to build their capacities to network is imperative.

4 Use of inconsistent terminology

Patient organizations may not have the awareness needed to use the right terminologies, such as medical, legal, regulation, health systems, etc., while

² https://www.researchgate.net/publication/348256282_Patients_and_public_are_important_stakeholders_in_health_technology_assessment_but_the_level_of_involvement_is_low_-_a_call_to_action

³ <https://implementationscience.biomedcentral.com/articles/10.1186/s13012-018-0784-z>

engaging with policymakers and are often inconsistent with the terminology they use. Standard and consistent terminology is needed to package the messaging for policymakers.

5 Lack of standardized patient data

The lack of patient-centric data impacts the development of evidence-based approaches that patient organizations can use to support the acceptance of their recommendations.

Challenges to Patient Engagement in the Health Policy Decision-Making Process



SECTION III: Roadmap to Improve Patient Engagement in Shaping Health Policy



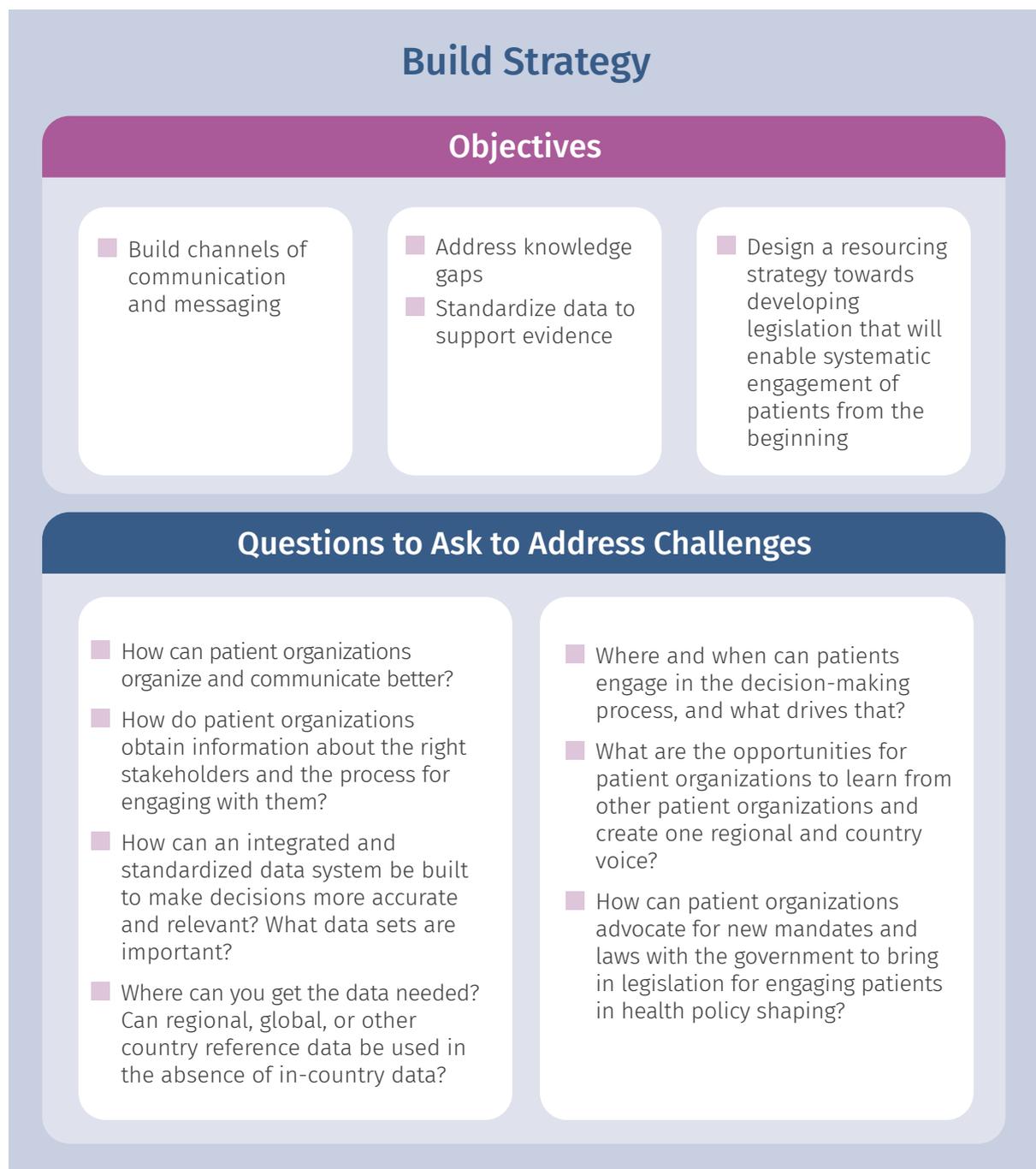
The APPIS pre-summit workshop and summit deliberations highlighted some priority areas. Patient organizations are urged to make efforts in these prioritized challenge areas that can help them move from the current level of engagement to the next in a more participatory and collaborative way. During APPIS 2022, one such example shared by Carmen Auste, Vice President, Co-Founder, Cancer Coalition Philippines; and CEO, Co-Founder, Cancer Warriors Foundation was the [National Integrated Cancer Control Act](#), which came into force in February 2019 in the Philippines. The objective of this Act is to strengthen cancer control in the country, increase cancer survivorship, and reduce the burden on families and cancer patients. This was the result of cancer patients, survivors, and families coming together to lobby for the act to be legislated and was based on the local values of strong kinship.

There is a need to bring all stakeholders together in a unified voice to raise an issue by talking around a roundtable and discussing the problem statement.



During APPIS 2022, Tanya Hall, CEO and Founder, Hearts 4 Heart Australia, shared an example on how a whitepaper was created as an opportunity to bring together the Cardiac Society, the Heart Foundation, Stroke Foundation of Australia, general practitioners, primary care bodies, and industry in a round table discussion to convey that atrial fibrillation is a growing epidemic in Australia.

The framework below suggests objectives and addresses the challenges for patient engagement in health policy shaping. It further breaks down the challenges in the form of questions and provides a step-wise guide to help patients and patient organizations build an effective engagement strategy. The patient organizations may use the questions below to brainstorm and prioritize the suggested strategy.



4 <https://www.ahajournals.org/doi/10.1161/CIRCULATIONAHA.108.821306>

Strategy for patient organizations to address identified challenge areas:

It is suggested that the patient organization in the country convene an in-country consultation to prioritize and plan the following action items as per need and urgency:

Action Item 1: Stakeholder Mapping and Engagement



Patient organizations must have a strong understanding of the stakeholders in the health policy decision-making process – their roles, objectives, needs, and channels to reach them. Patient organizations need to identify key contacts from the government who might be interested in a dialogue. They also need to look for people who are willing to be the voice and share their patients' lived experiences. These are the people who are potential champions for the cause – to spotlight compelling narratives and amplify the patient voice. Keep an eye out for unusual or unconventional stakeholders. A real-world example is the sickle cell disease community in India that found an unlikely ally in the [Ministry of Tribal Affairs](#) as an unusual and unconventional stakeholder to engage with.

However, for patient organizations to collaborate with other stakeholders, there is a need for adequate resourcing and planning. For organizations that start with little to no information, one way to approach this problem is to look for potential mobilizers or actors who might be motivated to help in both material and social forms, using their access to funding, resources, skills, or other stakeholders to build a larger group. To do this, one can look for conferences, publications, or even social media to identify stakeholders with shared interests. Patient groups may also look for alliances or build a network with different patient groups and CSOs who share a common goal in promoting health agendas.

If one has adequate resources and information to get started with engaging with stakeholders, then it might be necessary to carry out capacity-building exercises for each stakeholder involved, not just for communicating messages and using the existing means and channels but also for effective comprehension, integration, and implementation of external preferences into the internal agenda and actionable initiatives.

The following steps should be taken to carry out a stakeholder assessment:

1. Stakeholder Mapping Exercise

This exercise aims to identify stakeholders and select the best-suited ones to engage with. This will require understanding the landscape of health policy and the decision-making process in the specific disease area and/or geography. Look at key influencers, including but not limited to health product makers, regulators, clinicians, patients, hospital managers, payers, government leaders, health technology assessment bodies, industry, medical societies, development partners, government entities, research and academia on health policy, and digital health solution developers. It is important to also identify patients with compelling stories. Patients' voices and narratives can talk straight to the hearts and sensibilities of anyone willing to help with advocacy.

There can be different sources to identify the stakeholders, such as research through the review of medical literature, articles, conferences, white papers, healthcare organizations, online government, health technology assessment bodies, regulatory bodies, research, and academic institution websites. Here is a brief overview of the steps involved in carrying out stakeholder mapping:

Step
01

Study the country's health policy and decision-making process; assess the priorities of different stakeholders to contribute to the health policy decisions, their objectives, experiences, and how it all fits into the needs of the 'patients' beyond the industry and government priorities. Linking the patient organizations priorities with the country's health priority will give advocacy the slight advantage to push for the agenda.

Step
02

Once the key stakeholders are listed, they need to be plotted against their areas of interest through surveys and interviews to best fit their core area of expertise and the impact they can bring.

Step
03

Define the role and responsibilities of each of the stakeholders identified, establish channels, and create a process to engage them.

2. Stakeholder Engagement Process

A unified voice with all stakeholders will help make a strong case to involve patients and caregivers in the health policy decision-making process. Involve all relevant and shortlisted stakeholders from the mapping exercise in this process. Patient organizations must carry out the following steps to formalize and develop stakeholder engagement:



Step
01

Establish formal, structured, and sustainable channels of communication between patient organizations and policymakers, such as: platform for co-creation of guidelines, collaborative initiatives with other patient organizations, periodic roundtable discussions with government and other relevant stakeholders, and seek education and training support from medical societies and the pharma industry.

Step
02

Publish and disseminate a multi-stakeholder white paper through a multi-stakeholder platform or forum on the importance of patient engagement in the health policy-shaping process and how patient organization perspectives' are important for consideration in policy decisions.



A detailed handout to design and implement stakeholder mapping and engagement can be viewed [HERE](#). Or, refer to pages 2-5 of the handout.

Action Item 2: Participate in Networking Forums and Cross-Learning Platforms



The patient engagement landscape is still fragmented, and each stakeholder might not be able to effectively engage with patient organizations. To accelerate patient engagement, multi-stakeholder platforms and discussion forums need to be explored and created. There is a need to spread the use of multi-stakeholder platforms in more countries and contexts for greater joint learning and capacity building for every stakeholder.

Networking forums and cross-learning platforms or spaces for engagement, especially if there are no platforms for dialogue or open discussion, are the doorways to collaboration and partnership. These can allow policymakers to be comfortable while speaking and engaging with other stakeholders on health policy. These spaces might be necessary to defuse possible negative connotations with lobbying.

Setting up networking forums and learning platforms must be a partnership recognizing each stakeholder as a unique person with unique objectives and experiences. As described earlier, it is not just the patients that need capacity-building, but the entire healthcare sector, so as to facilitate collaboration that achieves multiple objectives at once. The integration of other stakeholders' perspectives is also critical to success. While there is a shared purpose, identifying and valuing each organization's objectives and mission is still important. It would be important to also look at new trends of communication, culture and languages used by the new generation patient groups. For example, Derrick Mitchell, CEO, [Irish Platform for Patient Organizations, Science and Industry, \(IPPOSI\)](#) at the APPIS 2022 summit, shared that the IPPOSI was set up by patient groups to provide neutral spaces for multiple stakeholders, especially policymakers, to comfortably join and speak openly.

The purpose of the networking forums and cross-learning platforms will be to engage identified stakeholders, collaborate with partners, learn, co-create, communicate, build capacities, and advocate as one voice. Patient advocates must have the mindset to be in the policy conversation and network at all costs. The following is an overview of the steps involved in the process:

Step
01

Plan and prepare: In preparation for setting up or using existing networking forums and cross-learning platforms, patient organizations will have to identify and list the forums that are already available for a specific disease area. Patient organizations must have a clear understanding of the objectives and goals of such networking forums and cross-learning platforms.

Step
02

Identify resources required: Patient organizations will have to look at what resources will be needed to set up or use already available forums and platforms. Examples include the European Patients Forum Event, EUPATI platform, Forum for Health Policy, the International Alliance of Patient Organizations, patient engagement forums, and country-specific events organized by patient organizations. The National Integrated Cancer Control Act in the Philippines was passed because of the WHO's resolution to transform global commitments to local action. Based on the list of potentially existing networks, identify the champions in the health policy ecosystem. Identify the main events organized by and for policymakers and patient organizations. Look at what disease areas they are working on and if that is something the patient organizations want to pursue.

Step
03

Build capacity of stakeholders: Identify platforms available for training, capacity building, and advocacy events. Alongside, look at thematic areas of interest for specialist doctors, health policy experts, and experts on patient-centric care and organize capacity-building workshops at the patient networking forums and regional knowledge hubs. Review, refer to, and use existing regional and global knowledge hubs such as Lion Bridge and HTAasialink for patient engagement and customization.

Step
04

Develop an advocacy strategy: Contribute to the process of engaging patients in the policy-shaping process, laws, and rights around data protection and privacy. Advocate for regulations on patient engagement as a law. Plan a strategy to advocate for the inclusion of patients in health policy decision-making processes.



A detailed checklist to use networking forums and platforms can be viewed [HERE](#). Or, refer to pages 6-11 of the [handout](#).

Action Item 3: Standardize Data with Patient Registries

There is a need for evidence and credibility to be built into patients' inputs on health policy. This can be done through using standardized patient data as the evidence base. It is imperative to provide insights on patient outcomes, perspectives, and disease management and treatment preferences and build the enabling infrastructure to process and synchronize data. Currently, there is a lack of patient registries and local data. Additionally, limited or no sharing of data between private and government departments through a structured framework or integrated data sharing system limits the real-time evidence to represent patient experience, preference, and outcome information.

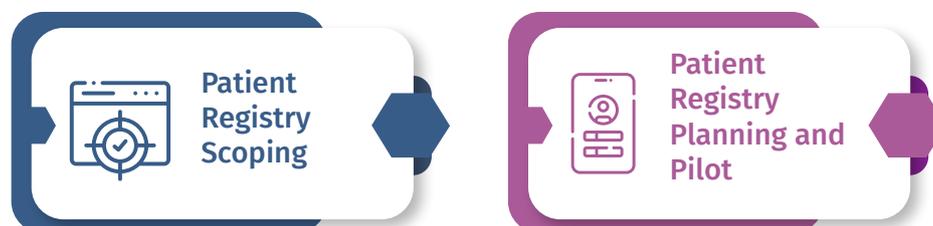


There is need for live patient data and not the data led by medical staff. Patient participation in Artificial Intelligence (AI) platforms, Information, Communication and Technology (ICT), Information and Communications and Media Technology (ICMT), and blockchain-based information protection technologies is critical and there is need to start small and build on it. Instead of facility-centric data, which the ministries might collect from hospitals or other facilities, what is needed are patient-centric datasets to get a holistic picture of the patient experience and the patient's condition.

The rights of patient organizations to access health information are often restricted, misunderstood, and poorly communicated. Sharing of personal information in a private, secure environment in which data is shared only with the knowledge and consent of patient organizations can be achieved through policy changes and patient registries. Networking platforms need to consider the privacy and data security aspects of patients and their caregivers when developing these registries.

Building a Patient Registry:

The following steps describe the process of supporting the development of patient registries:



1. Patient Registry Scoping

Patient organizations will need to conduct a scoping exercise to understand the landscape of patient registries in their geographies in different disease areas. Identify relevant linkages between the health policy priorities and the patient health outcomes from the registries, if there are any. They must look for opportunities to integrate with existing registries, if they are not already integrated. The registries must be inclusive.

Patient data must be aligned with the requirements of policymakers so that policymakers can use the data to evaluate the patient experience with respect to patient treatment, outcome, and their patient journey.

2. Patient Registry Planning and Pilot



Patient organizations will need to engage key stakeholders to support the creation of patient registries for a specific disease area if it does not exist. The government is the primary stakeholder usually responsible for creating and funding patient registries. Supporting a patient registry will need to be aligned with the larger goal of ensuring patient-centric data usage while integrating data privacy and protection elements. The intent will be to allow policymakers to understand patient needs and for policymakers and regulatory bodies to learn about the patient experience and address their most pressing needs. Governments must work with patient organizations to develop patient registries.

A patient registry would require resources and information from various aspects, including but not limited to an advisory board to steer the goals of the registry, human resources for operations and to pilot and test a patient registry study, funding, marketing and communications, contacts with the Institutional Review Board, which would approve the study, data collection, analysis, and monitoring processes and outcome measures articulated for different stakeholders, including digital health solution developers.

Currently, data protection policies lag far behind the technical capacity of patient organizations to share and use electronic information without appropriate permissions. Individuals' rights to access their own health information are often restricted unnecessarily, poorly understood, and poorly communicated. Sharing of personal information in a private, secure environment in which data is shared only with individuals' knowledge and consent can be achieved through policy change. Understanding and knowing the data privacy act in the local context is important. It is not only important to gather data but also to safeguard it. Partnerships with IT solutions providers can help in ensuring data privacy.



A detailed reference guide to designing and building a patient registry can be viewed [HERE](#). Or, refer to pages 12-15 of the handout.

Action Item 4: Legislative Advocacy Campaign

Advocacy is simply the process of influencing people to create change. Its lifeblood is good strategic communications – educating people about a need and mobilizing them to meet it. Patient organizations can organize an advocacy campaign to gain support for their cause as outlined below. Patient organizations can convene a disease-specific in-country patient organization consultation and execute a legislative health policy advocacy campaign through the following steps:

- 

1 Define the situation: Outline the case for a review of health policy and back it up with research and planning in terms of supporting data, time, and money. Research is the basis of communication, and getting the right data and advocates is the key. Patient organizations must start with the basic questions of who needs to be engaged, what the goals and objectives are, and how will the campaign be designed and implemented.
- 

2 Define the goal: The goals of the campaign need to be clear, measurable, doable, and unambiguous. The long-term goal will be to raise the issue of engaging patients and carers in the health policy decision-making process.
- 

3 Identify and engage the target audience: For an advocacy campaign to be effective, your messages must reach the right people. Ask the right questions to help patient organizations map the target audience.
- 

4 Map and engage stakeholders: Create a list of stakeholders best placed to engage in the campaign. Design the roles for stakeholders to bring clarity to the engagements and discussions to be held with each stakeholder. Choose the right person—authentic, credible, and knowledgeable—to deliver the message. Identify stakeholders and people who can influence the kind of change that is required. These include donors, policymakers, clinicians, regulatory bodies, payers, research and academia, media, bloggers, celebrities, social influencers, citizens, and community groups, among others. Communication with each stakeholder type must be led by a distinct team.
- 

5 Articulate the message: The messages must be simple and designed to achieve a specific goal. A successful advocacy campaign will most certainly involve simple messages that resonate with stakeholders and garner support for the campaign. This does not mean restating the goals – it simply means building a compelling case with the target audience. Highlight individual stories with compassion.
- 

6 Identify communication channels for targeted activities and opportunities: Lobbying, formal meetings, informal corridors, networking during events, public campaigns, online campaigns, street action, media interviews, and press conferences can be some of the ways to communicate and engage stakeholders in the campaign activities. Communication channels should provide credible and empathetic messages and must influence the target audience. Engage medical community members, journalists, celebrities, scientific experts, and other influential stakeholders, create lists for email advocacy and build a coalition of like-minded people.
- 

7 Monitor and evaluate success: Ask questions to review progress: What worked, and how well? What did not work, and why not? What could be improved, and how? How and where have partners and stakeholders been helpful? What messages have resonated, and have they helped to achieve the campaign objectives? What were the barriers to success (external and internal)? What facilitated success, including scenarios which were not anticipated?



A detailed handout for guidance on developing a legislative advocacy campaign can be viewed [HERE](#). Or, refer to pages 16-18 of the handout.

Strategy for Patient Organizations to engage in the health policy-shaping process



Overarching Recommendations

Finally, health policy-shaping initiatives must be engaged with all the identified stakeholders in the health ecosystem. In other words, they must be rooted in multi-stakeholder engagement for their success. For improved stakeholder engagement—necessary for gathering input on health outcomes and strategies—one of the main considerations for engaging stakeholders is to keep cultural considerations in mind: Language, demographic and local contexts must be considered when understanding and adapting healthcare systems.

Designing health infrastructure in line with patients’ inputs would not only enhance the performance of healthcare systems but also foster patients’ trust in the healthcare being provided to them. Patient organizations must push for this by mapping the right people, their interests, and the right channels and approaching them at the right time.

Patient organizations may also turn to media outlets as a way to inform the public and also to vocalize important messages about specific patient goals and disease areas. Data-centric and evidence-based approaches have been emphasized as a

useful language to convince policymakers. At the same time, appealing to emotion, such as through the personal stories of the policymakers and backgrounds, can also help provide that last push for a policy to be passed.

The goals of patient engagement should be pre-specified, explicit, and measurable, with consensus among stakeholders on defining success. In addition, feedback should be taken from all involved, patients, patient organizations, decision-makers, advisory groups, and committees, to continuously improve patient input practices and evaluate its impact. It is recommended to have close cooperation and partnerships between the various stakeholders, including healthcare professionals’ organizations, contract research organizations, patients and consumer organizations, academia, regulatory authorities and HTA bodies, and the pharmaceutical industry. The impact of patient input is not necessarily explicit to completely change health policies but provides context, reassurance, and new information for the decision-making process.

”

“It will not be an easy journey. Persistence, motivation, and courage will be needed to commit through the challenges of advocating for systemic change, especially when working against taboos or stigmas. However, if one holds onto the mantra that nothing is impossible, as long as one believes in the change that one can aspire to and asks for what is deserved, then it is possible to land lower than expected and still achieve the systemic change that is needed.”

Carmen Auste, Vice President, Co-Founder, Cancer Coalition Philippines; and CEO, Co-Founder, Cancer Warriors Foundation, APPIS 2022



**Alliance &
Partnerships for
Patient
Innovation &
Solutions**

APPIS 2022
Asia Pacific, Middle East, and Africa

www.appisinitiative.com

Organized and funded by:

