

Towards Collaborative Patient-centric Digital Health Solutions

A Guidance Document For Patient Organizations



APPIS 2022
Asia Pacific, Middle East, and Africa

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

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EXECUTIVE SUMMARY



BACKGROUND

This guidance document is part of the Alliance and Partnerships for Patient Innovation and Solutions (APPIS) 2022 initiative, which is 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 and digital innovators, to improve health outcomes in the Asia Pacific, Middle East, and Africa.

The APPIS initiative identified digital health and communications as one of its themes in 2022, along with health literacy and health policy shaping, given the real-world needs for patient-centric digital health solutions and the gaps in involving patients and organizations in the development processes.

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PURPOSE

This document, together with the identified problem statement, challenges, guiding principles, and action items, is developed for patient organizations that wish to become more involved in the design, development, and adoption of digital health and communication tools for patients and caregivers.



CONTENT OVERVIEW

The **first part** of the guidance document introduces digital health tools to provide a better understanding of the types of solutions available, the potential impact of engaging in the development process and levels of the product life cycle patient organizations can engage in. This understanding will help them broaden access to healthcare solutions and enable improvements by providing their input and feedback.

The **second part** of the guidance document showcases the gaps and challenges in engaging patient organizations in the design and use of digital health and communication tools. Patient personas are used to present the hurdles that patients experience, their key priorities, and the impact of digital health solutions on a patient's healthcare journey. It also underscores the four focus areas where most barriers exist to get involved in the digital health solutions: 1) Policy and Partnerships; 2) Education and Communication; 3) Data Collection, and 4) Demonstrating Value and Impact. The document goes on to identify the key engagement points for patient organizations.

The **third part** of the guidance document lays down the path to engage patients in the digital health product life cycle from ideation to testing and adoption. It also provides guiding principles to design a patient-centric solution. This part also provides a framework to address the barriers through solutions in four identified focus areas.

The **last part** of the guidance document suggests a way forward through elaboration of three action items: 1) Stakeholder Mapping and Engagement; 2) Leveraging Networking and Cross-Learning Platforms and 3) Standardizing Data with Patient Registries. This part of the document also provides guidance to patient organizations to contribute to the design and development of digital tools constructively and lays down the action items for large-scale and structured patient engagement.

PART I INTRODUCTION

SUMMARY

Patient engagement is vital to enhancing a patient's ability to fully participate in their own healthcare, including the use of digital health tools.

By using this guidance document, patients, advocacy groups, and other stakeholders will be able to:

- o Understand the various digital health solutions with the required technologies and the impact they have on health;*
- o Identify their own pain points;*
- o Understand the partners in the ecosystem and who they should be talking to;*
- o Use this document as a jumping off point to work with stakeholders on customized plans to improve patient engagement in the digital health development process in their own countries and regions.*

Alliance and Partnerships for Patient Innovation and Solutions (APPIS) is a platform that enables the convergence of perspectives between patient communities and key stakeholders. The purpose of the platform is to drive alignment amongst key stakeholders, including policymakers, payers, physicians, members of academia, and digital innovators, on key challenges and prioritize actions towards better patient outcomes in the Asia Pacific, Middle East, and Africa.

Council members of APPIS 2022 recognized that digital health solutions often fail to achieve impact because patients and health providers perceive a disparity between the promised benefits of digital tools and the health outcomes of the patients and health providers. This gap leads to poor uptake of the solution and poor usage. In addition, healthcare providers are also often disenchanted with digital health solutions as they hear from their patients that the tool does not address their needs, and they cannot see the benefit of the tool to themselves. This led to the adoption of Digital Health and Communications as one of the key focus areas for APPIS 2022.

Patient Usage of Digital Health Tools: Despite being appreciated and used by many, there has been limited patient engagement in the designing and updating of digital health tools.

Patient Usage

27-30%
of 90-day user retention

50%
of the applications have less than 500 downloads

90%
of patients are interested in a technology-based solution for health

Digital Health Tool development

Developers' lack of understanding of the interdependencies between technology, human characteristics, and the socioeconomic environment for patients and providers

Source: [Patient engagement and the design of digital health](#)

DIGITAL HEALTH SOLUTIONS

Patient-centric digital health solutions are targeted to improve health outcomes by providing patients the ability to engage in self-care, access information, and seek support from peers at the touch of a smartphone or a wearable device. These solutions function through various foundational technologies and platforms such as the internet, smartphones, wearable devices such as smartwatches and health bands, social media, and machines.

| DIGITAL HEALTH SOLUTIONS | | HEALTH IMPACT AREAS |
|---|---|--|
| <p>Foundational Technologies</p> <ul style="list-style-type: none"> ○ Internet ○ Data <ul style="list-style-type: none"> • Electronic Health Records • Personal Health Records ○ Smart devices ○ Remote monitoring ○ Robotics <p>Interactive Technologies</p> <ul style="list-style-type: none"> ○ Tele-Health ○ Online health portals and community websites ○ Patient engagement chatbots ○ Social networking platforms ○ mHealth ○ Gamification and virtual reality health solutions <p>Self-care Technologies</p> <ul style="list-style-type: none"> ○ Informational websites ○ Wearable health devices ○ Medication support applications ○ Online health education programs |  <p>Impact of patient-centric digital health solutions to improve various health areas</p> | <ul style="list-style-type: none"> ○ Chronic disease management ○ Health information sharing ○ Long-term care ○ Mental and social wellness ○ Preventive health ○ Tools that assist with self-management ○ Medical records that involve the practitioner and patient ○ Side- and adverse- effects management ○ Prevention of some complications (related to infection/sepsis, for example) |

DEVELOPING A PATIENT-CENTRIC DIGITAL HEALTH TOOL

APPIS partners agree that the goal of a patient-centric digital health tool should be to place the patient at the center of their own care. This alongside ensuring that the tool will not increase the workload of clinical teams. Some of the aspects to consider in the development of a digital health tool are as follows:

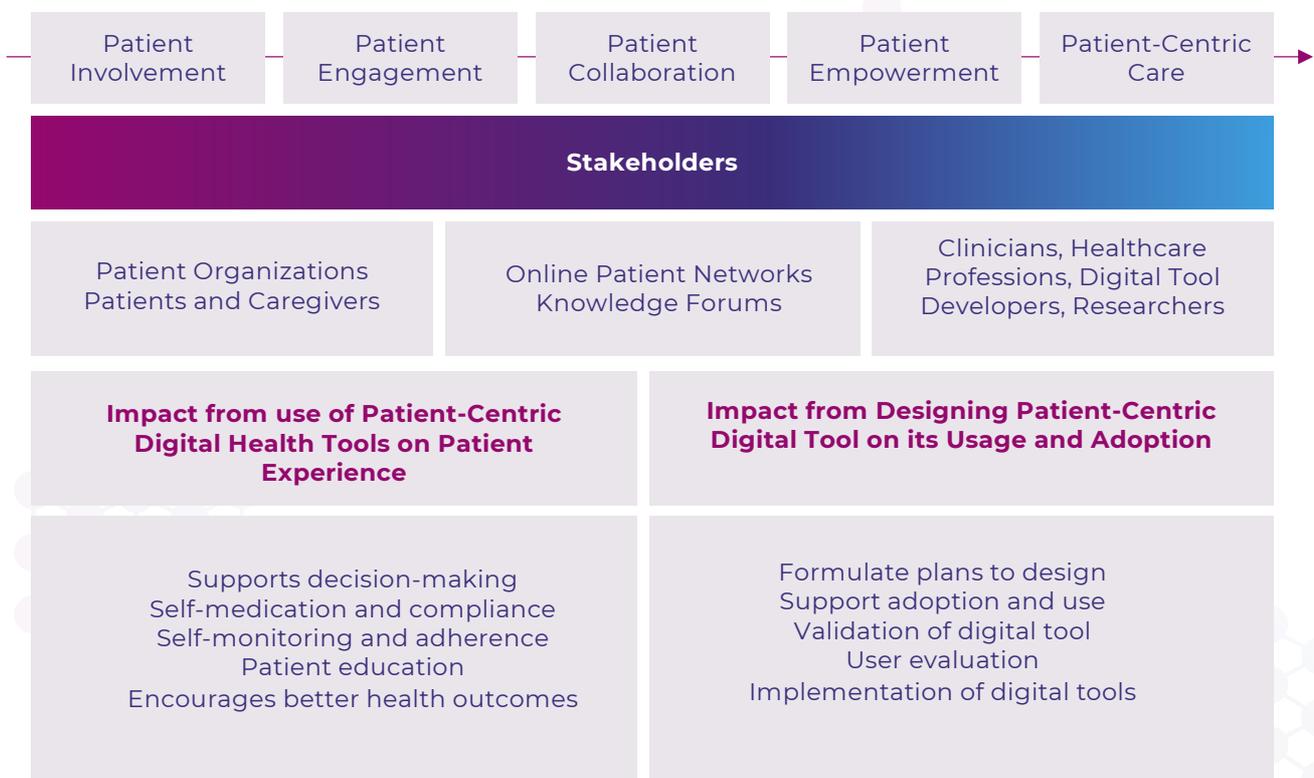
1. Understand the social dynamics and significance of technology
2. Determine the digital health solutions' actual potential to improve healthcare
3. Clarify the delivery of healthcare services during the design and development process
4. Involve all the stakeholders impacted by the digital health solution in the process
5. Identify and clarify the financing and payment means for the healthcare services
6. Highlight the interdependencies between technology, people, providers, and sociocultural environment and the infrastructural organization of healthcare
7. Identify how the tool will integrate into the care pathway

With the advent of the new normal brought about by the COVID-19 pandemic, it has become clear that the use of digital tools is integral to the sustainable development of patient organizations, whether it be for funding, collaboration, communication, or even data gathering and analysis. Physical divides from current health-seeking approaches have been bridged by new technologies such as Zoom, Google Meet and Teams, etc. These technologies allow the scaling of health initiatives through improved reach. Digital tools could be and have been instrumental in reducing the burden of healthcare systems around the world, broadening access to healthcare solutions, and enabling improvements in patient-centricity.

“At DXY, digital empathy is professional, continuous, and thoughtful. Professional development of content and tools is through peer reviewed evidence-based knowledge. An integrated model is used to treat people as a whole through delivery of content and consultation in a continuous manner. There’s emphasis on inclusion of thoughtful practises in the doctor’s treatment by training them to provide detailed answers in 300-500 words to the patients in order to make patient experience more empathetic.”

Stanley Li, DXY, Founder and Chairman, APPIS 2022

EMPOWER PATIENTS IN DIGITAL TOOLS DEVELOPMENT TOWARDS PATIENT-CENTRIC CARE



PART II

GAPS AND CHALLENGES TO ENGAGE PATIENT PERSPECTIVE AND EXPERIENCE IN DIGITAL HEALTH SOLUTIONS

SUMMARY

- Participants at APPIS working at all levels of health and digital technology ecosystems identified gaps and challenges in involving patients and patient organizations in the development of digital health solutions.
- Based on those discussions, this section identifies the barriers arising from the patient, digital innovator, policymaker, and healthcare provider points of view.
- The gaps are further categorized in four focus areas: policy and partnership, education and communication, data collection, and demonstrative value and impact.
- The gaps presented in this section show the hurdles patients are experiencing, their key priorities and wants in a digital health tool, and paint a picture of how a tool impacts patients' healthcare through four patient journeys of individuals hailing from different geographies, demographics, and facing varied issues.

The discussions held at the APPIS 2022 workshops and summit identified some critical challenges that require immediate action to be taken by all the stakeholders involved to facilitate better patient engagement. There is a lack of robust and structured practice to involve patients' voices in the development of digital health solutions.

“The biggest challenge in the development of a patient-centric application is having all stakeholders involved and clearly understanding one another with minimal miscommunication, especially about the feasibility, limitations and difficulties faced by the stakeholders.”

Adam Chee, National University of Singapore. WHO Digital Health Expert, APPIS 2022



The table below identifies the key areas where barriers exist to engaging patients in digital health.



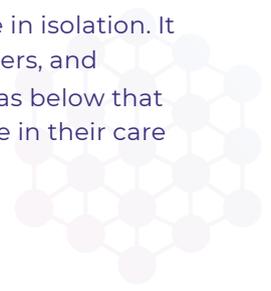
| | |
|------------------------------|---|
| Policy & Partnership | Lack of patient participation in framing of policies and guidelines for partnerships, development, regulation, and implementation |
| Education, Communication | Lack of effective communication channels between patients, developers and other stakeholders in the digital health ecosystem Mismatch between patients and specialist doctors (e.g., oncologists) in terms of what to expect, address, manage, or benefit from the ultimate use of digital health. |
| Data Collection | Lack of processes and mechanisms to ensure seamless collection of data and inputs from the patients to develop impactful solutions Lack of representative patients' voices - for e.g., those without access to internet and smart phones or devices. |
| Demonstrative Value & Impact | Lack of indicators, parameters, and frameworks for inclusion of patients and patient organizations to measure the impact of the digital health tools |

The following patient journeys illustrate the barriers that patients and caregivers face in engaging with digital health stakeholders and with their doctors. Patient organizations can play an important role in bridging the gaps between patients, digital health developers, and specialist doctors.



Patient organizations can support patients and their caretakers by channeling them to the right digital health and communication tools for use. They can also provide feedback and communicate patient needs and expectations to digital health developers in designing relevant solutions and bridging the communication gap between patients and doctors.

Integrating patient needs and expectations from the digital tool cannot be done in isolation. It is imperative to integrate the three: patient organizations, digital health developers, and providers to enhance communication among all of them. Here are a few personas below that walk you through various patient experiences and the different barriers they face in their care journey.



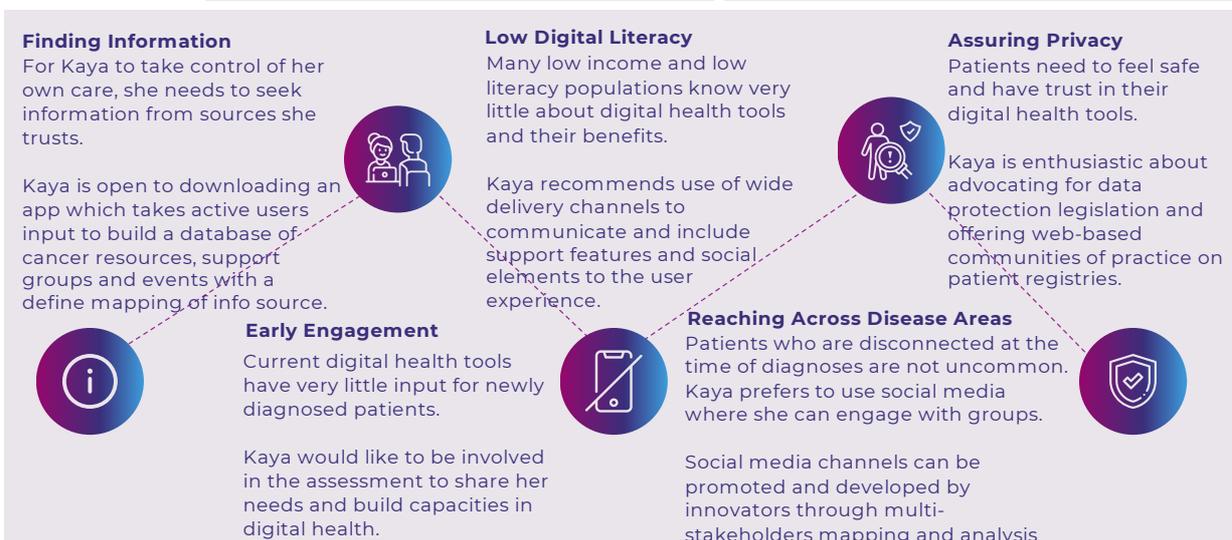
PATIENT JOURNEY 1 – KAYA FROM CAPE TOWN

Kaya, a 42-year-old working mother from Cape Town, and a newly diagnosed cancer patient, encounters challenges due to a lack of relevant information available through trusted sources. Given that she describes herself as “not tech-savvy”, she lacks the support and guidance on where she can seek the right information that is easy to understand. She doesn't feel safe or comfortable sharing her data and wishes there were web-based communities of practice on patient registries.



Kaya is a 42 years old working mother from Cape Town. She was recently diagnosed with breast cancer and knows very little about the disease or its progression. She feels disconnected from her healthcare providers and is uncertain and anxious about her treatment plan. She is also described “people person” who takes comfort in and learns best through hearing other peoples' stories and experiences.

Diagnosis: Stage 2 HR+ /HER-2 Breast Cancer
Family: Husband, two teenage daughters
Community Connectedness: Not introduced to any support groups upon diagnosis; engages with mom friends through mobile chat apps face-to-face
Digital literacy: No social media accounts; describes herself as “not tech-savvy” but feels she is capable enough to learn; willing to use digital health tools s it will help her connect more with her providers.



How can patient organizations help Kaya with her challenges?

The challenges Kaya is facing need to be tackled by multiple stakeholders within the digital health system. Kaya is facing challenges with two of the identified focus areas in the previous section – Education & Communication and Data Collection. To help Kaya overcome these challenges, patient organizations may carry out a stakeholder mapping and engagement exercise that can help patient organizations identify the relevant digital solution developers and healthcare providers and subsequently educate and inform them.

Engaging various stakeholders for digital solution design and adoption will include the co-creation and dissemination of knowledge products and guidance for digital solutions. To further improve stakeholder engagement, a feedback system for patient-centric design and adoption of digital solutions and keeping the patients engaged in the process from the beginning would be important. Finally, stakeholder engagement can be strengthened through actions that ensure data privacy and protection, such as advocacy and web-based communities of practice. To learn more about how stakeholder mapping and engagement can be useful, please refer to Action Item 1 in Part IV.

PATIENT JOURNEY 2 – NGOC FROM HANOI

Ngoc, a 32-year-old caregiver to an aunt suffering from cancer, has been unable to find support within the community or from other caregivers to cancer patients. The lack of networking platforms is hindering her from seeking guidance and support while she cares for a family member. Ngoc is looking to engage in policy-shaping channels for digital solutions where she can give inputs to digital health developers through a regulatory perspective and engage in networking platforms to share data and make an impact on the usage of digital solutions. After directly providing feedback to the developers, Ngoc finds that her feedback hasn't been incorporated. This could be due to the unstructured and direct channel of feedback utilized by Ngoc.



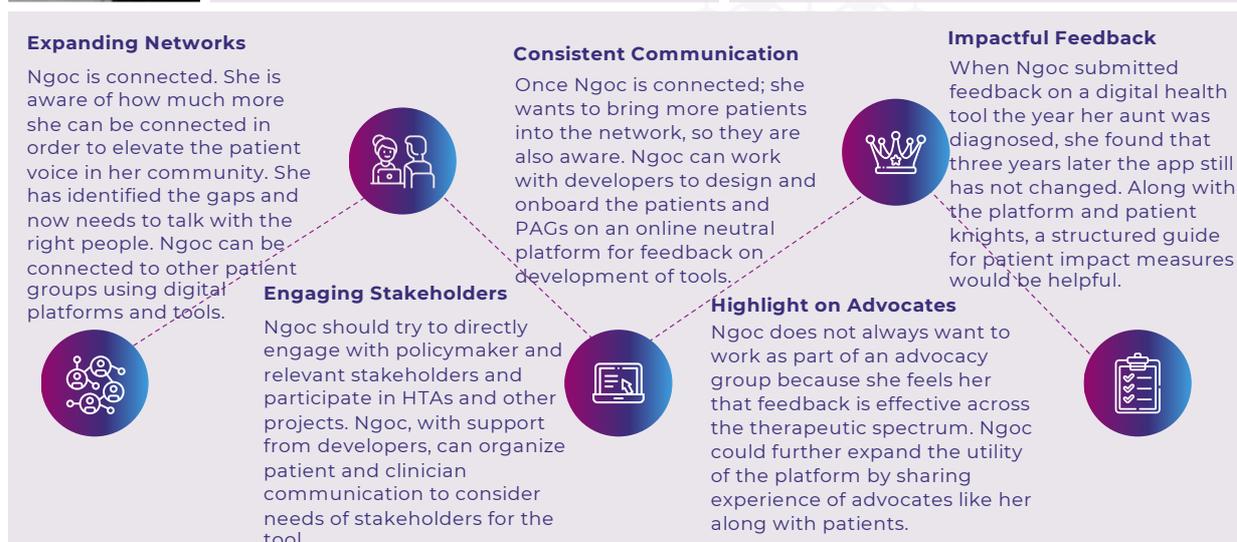
Ngoc is a 32-year-old caregiver for her aunt who was diagnosed with a rare but serious form of cancer three years ago. Ngoc plays a key role in the care coordination for her aunt and has used multiple digital health tools during this journey. She is connected to a cancer-focused PAG; however, though she feels she has important feedback, she does not feel she has access to digital innovators in order to elevate the patient voice in the design of these tools.

Diagnosis: Caregiver to a family member with a rare form of cancer

Family: Unmarried; lives with extended family

Community Connectedness: Well-connected though still uncertain of all of her options for engagement; would like to engage entities outside of traditional advocacy groups in a consistent, structured way

Digital literacy: High



How can patient organizations help Ngoc with her challenges?

Ngoc is facing challenges with two of the identified focus areas in the previous section – Policy & Partnerships and Data Collection.

To help Ngoc with the barriers that she is facing, patient organizations can build or use existing networking forums and cross-learning to engage relevant digital solution developers, patients, healthcare providers, and policymakers that will help provide formal and more structured feedback, aligning inputs from all stakeholders. To learn more about how networking forums and cross-learning platforms can be useful, please refer to Action Item 2 in Part IV.

PATIENT JOURNEY 3 – AHMED FROM ANKARA

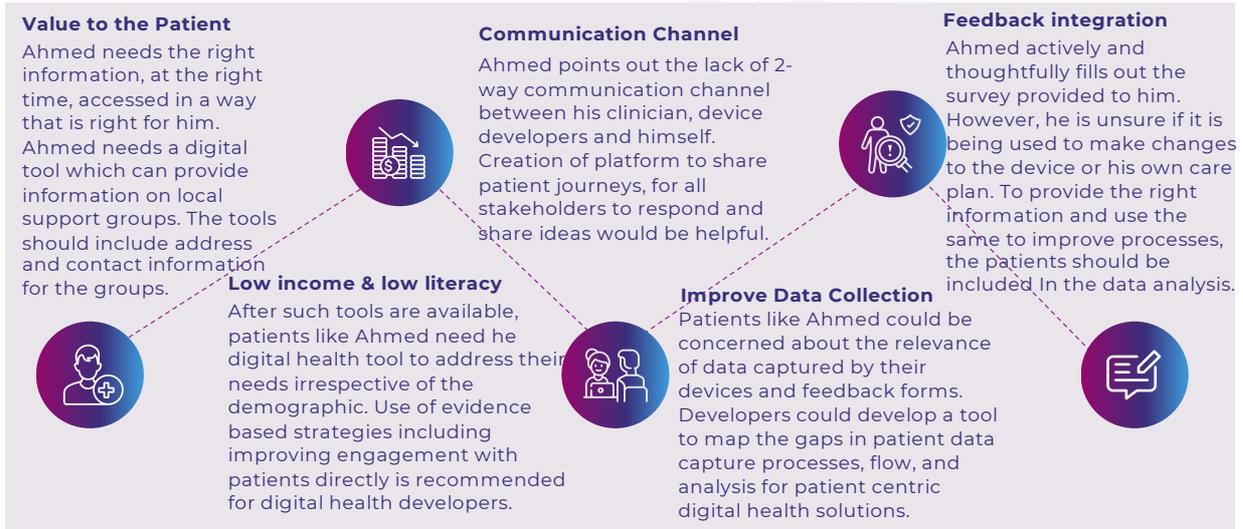
Ahmed is finding difficulty in identifying the right channels of education and communication to learn more about how to use digital health solutions. He is also concerned about the privacy of his health data and wants to share his ideas on improving the usage of the app, data privacy and safety, and how his input can upgrade a digital health solution to improve usage. With the increase in data from digital tools, it is important to ensure the use of the data while ensuring patient confidentiality and privacy. There is not only a need to emphasize the patient voice in developing digital materials but also to allow the developer's concerns to be heard back by the patient so that each party's limitations and desires are understood by others.



Ahmed is a 63 years old day laborer from Ankara who lives with his wife, son, and elderly mother-in-law. Last year, Ahmed experienced a heart attack and is now on medication and has made lifestyle changes to prevent another attack. He uses a remote heart monitoring device to avoid travelling for check-up and receives feedback from a physician. Ahmed feels discourage when he is unable to discuss his treatment and emotional issues.

Diagnosis: Cardiovascular disease; symptomatic heart palpitations
Family: Wife, son, elderly mother-in-law

Community Connectedness: Concerned about the use of his feedback to be incorporated into the quality improvement of the device for the community's use of such a device.
Digital literacy: Low



How can patient organizations help Ahmed with his challenges?

Ahmed is facing challenges in two of the identified focus areas in the previous section – Education & Communication and Data Collection.

To help Ahmed with the barriers that he is facing, patient organizations can help identify relevant digital solution developers and their tools for specific disease areas, provider networks, and local support groups available for patients to be guided toward for more directed information he may need. Patient organizations may use various channels to share information about relevant digital health tools for patients in specific disease areas and ensure ways to connect with patients in hard-to-reach underrepresented groups; build and enable a feedback system from patients to the digital solution developers from the beginning of the patient journey; and enable dialogue, exchange of ideas, patient experience, and their journeys through online networking platforms, focused group discussions and patient surveys. To learn more about how to map and engage stakeholders and to use networking forums and cross-learning platforms, please refer to Action Items 1 and 2 in Part IV.

PATIENT JOURNEY 4 – MEI FROM TAIPEI

Mei is blindly reliant on the internet and finds it difficult to find verified information for her symptoms. Easy access to unverified information can misguide patients. Mei thinks she can search through her mobile about anything and gather inaccurate, if not totally irrelevant, information. This information creates stressful conversations and miscommunications with her doctor, who tries to counter her mistaken diagnoses



Mei is a computer programmer from Taipei. Sometime ago, she was experiencing constant tiredness and exhaustion. She concluded that she has silent brain mass after surfing online for symptoms. She got an appointment with a doctor and went in for the visit with a list of scans and blood tests. Despite the doctor's advice against these expensive tests she got them. The results concluded that she was slightly anemic, which could have been detected without all of expensive tests.

Diagnosis: Anemic

Family: Husband, Son

Community Connectedness: Well-connected among the women in the community and has high regard for advice available on the internet

Digital literacy: High

Easy Information Access

Mei needs access to verified and validated information and easily available online platforms. Mei and other patients like her find it easy to receive online information about their illness by providing their symptoms.



Disclaimers & Advice

The internet hosts many websites and platforms that can be used by patient such as Mei to receive information on their illness. The websites need to advise and give information to patients about getting a doctor's appointment to seek more information on their illness.

Information Verified

Mei's case demonstrates the need to have robust information verification and flagging of misinformation provided online. Information indicating serious diseases will require more comprehensive verification.



Communication Channel

Patients like Mei who have strong beliefs on internet advice need to be informed through these websites on importance of the medical practitioner's opinion on the patient's health condition and the required next steps.

Symptom Definition

Patients many not be able to articulate their symptoms in an appropriate and optimum manner resulting in extreme results from websites. Patients need to be informed on ways to understand and explain their symptoms without exaggerating them.



How can patient organizations help Mei with her challenges?

The advancement of digital media has led to a rapid increase in false or inaccurate health information, with both patients and caregivers finding it difficult to evaluate information found online. Mei is facing challenges with two of the identified focus areas in the previous section – Education & Communication and Demonstrating Value & Impact.

To help Mei with the barriers that she is facing, patient organizations and stakeholders can build or use existing networking forums and cross-learning platforms for identified organizations that share and publish disease-specific content on their websites and advocate for disclaimers on the content shared in the public domain for patients who self-assess their symptoms. Use well-built networking forums and cross-learning platforms to give patients the opportunity to understand the symptoms and situations of other patients through a validated source. To learn more about how networking forums and cross-learning platforms can be useful, please refer to Action Item 2 in Part IV.

PART III

RULES OF ENGAGEMENT FOR PATIENT ORGANIZATIONS

SUMMARY

APPIS participants for Asia Pacific, Middle East, and Africa regions identified three stages where patients and patient organizations can have a higher impact on the development of patient-centered digital health solutions: 1) Ideation and Design; 2) Testing and Refinement; and 3) Adoption of Digital tools.

This section sets out guiding principles for patient engagement and uses a framework to analyze the challenges in patient engagement, recommends solutions to overcome these gaps and sets out an implementation pathway for patient organizations that is detailed further in the upcoming section.

APPIS partners were nearly unanimous that the key to improving patient engagement in digital health processes is to improve digital literacy, education, and communication between patients and healthcare organizations. In the new normal brought about by COVID-19, patient engagement with the virtual world remains vital. Understanding a product life cycle is critical to engaging stakeholders, who must contribute to its every stage and make the solution useful for patients.

STAGES OF ENGAGEMENT FOR PATIENT ORGANIZATIONS WITH DIGITAL HEALTH TOOLS



Stage I Ideation and Design

The following are some ways patient organizations can participate in the ideation and design stage:

- Engage with digital health developers to define the scope and focus of the digital health project. Digital solutions for specific diseases need to be determined through consultations.
- Provide and support timely patient feedback to digital health tool developers. Patient interaction sessions can be used to modify the design and content of a tool.

Example

During APPIS 2022, participants quoted examples where numerous investigators within emergency medicine obtained grants from organizations such as Patient-Centric Outcomes Research Institute ([PCORI](#)) and the [National Institutes of Health to use patient-centric design methods](#) where the patients are involved in the entire design process. A growing number of clinicians are also partnering with businesses, ranging from start-up companies to technology giants, to facilitate the creation of patient-centric digital health tools.



Stage II Testing and Refinement

During this stage, patient organizations can lead the provision of continuous feedback and input to digital health tool developers during the prototyping and testing stage. Digital health tool developers need to set and standardize evaluation protocols to gather feedback from patients regularly through the use of existing patient organizations and networking platforms while ensuring that new needs are addressed on a sustainable basis.

Example

The [‘Together for Her,’ a quality Improvement tool for Pregnancy Care](#) app, is an example of a patient-centric digital health solution developed by Avegen. The digital health tool team engaged a panel of patients, using rigorous qualitative methods, in the development and refinement of both the content and the day-to-day structure of text-messaging interventions and apps.

“Evaluating the impact of the Avegen’s Together for Her tool on clinical outcomes among mothers using the app is being done by constructing a virtuous loop, where we receive the ideas, we validate these ideas, and then undertake analysis to understand user behavior. The team uses this analysis to undertake interviews and discussions with the mothers to generate ideas and take them forward.”

Nayan Kalnad, Avegen, Co-Founder and CEO, APPIS 2022



Stage III Adoption of Digital Tools

Once a solution has gathered a stable user base, patient organizations can play an important role in helping digital health tool developers and other stakeholders interpret patient usage data while ensuring the protection of patients’ rights. Product usage data captured from the patients can be used to identify the patterns that structurally collate patient opinions and help developers contextualize the behavior of the users. These patterns help develop hypotheses for assessing digital tool adoption, and doctors and nurses can further validate these hypotheses.

GUIDING PRINCIPLES FOR PATIENT-CENTRIC DIGITAL SOLUTIONS

Patient organizations have a defined role and responsibility in the entire life cycle of a digital health product. The following are the guiding principles for a participatory and patient-centric approach to digital health solutions, irrespective of the stage a digital health solution is in.

- Engage patients and specialist doctors at the relevant stage of digital health solution design and implementation.
- Engagement will depend on the specific disease area chosen, available channels, and the subsequent nature of engagement between the patient organizations, digital health tool developers, and doctors.
- The purpose of the digital health tool is to be an enabler to care access and information and not a destination in itself.
- Practice active empathy when engaging patients through a digital platform. (Examples such as checking in on each patients'/participants' state of mind before starting a virtual session, developing skills in using virtual platforms such as Zoom, Google Meet, and others, targeting each activity towards specific subgroups of the patient population as well as using other public domains, such as newspapers, to disseminate information throughout the country or region.)
- Effectively gauge whether patients have had a positive impact using the digital tools they use. For example, a cancer organization might desire to focus on improvements in patient quality of life as a success factor and emphasize wellbeing and happiness over a complete cure for the patient.

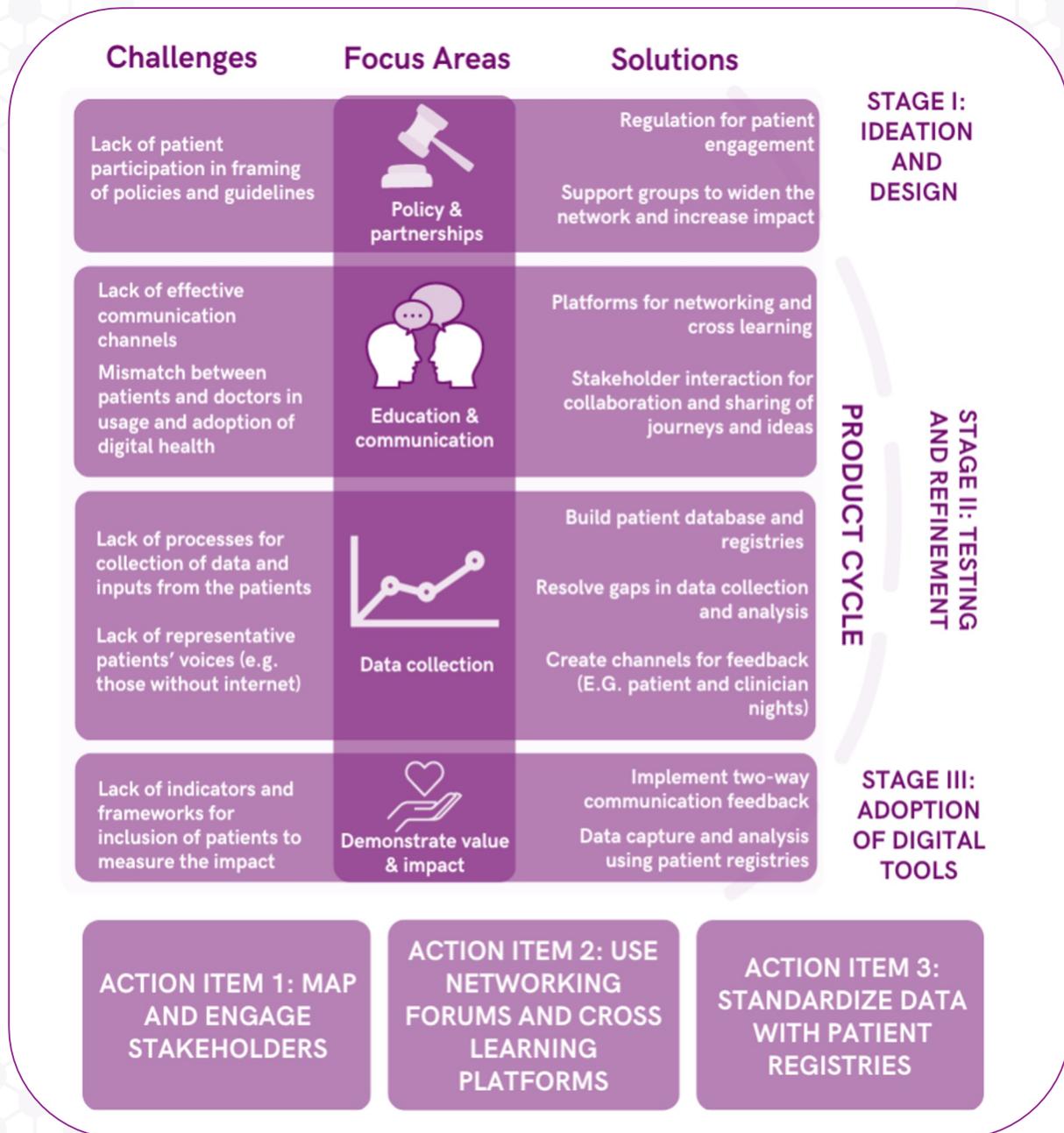
ANALYZING BARRIERS TO PATIENT ENGAGEMENT IN DIGITAL HEALTH

The below framework encapsulates all three stages of a digital health product life cycle, from ideation and design; to testing and refinement; to adoption of a digital health tool by patients and caregivers. It showcases solutions in four focus areas and three broad, comprehensive action items for patient organizations to address the identified gaps and barriers as a whole.

A patient-centric and participatory process of designing, testing, evaluating and implementing digital health products results in higher quality and adaptable digital tools as compared to not involving the patients or caregivers in the process. Patient organizations can engage with digital health tool developers and innovators at various stages to provide input and ensure that the tools developed and adopted are centered around patients.

Application and background to support the framework has been outlined in the APPIS 2022 handout.

DIGITAL HEALTH COMMUNICATION FRAMEWORK



<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4674428/>

[Click here to download the APPIS 2022 handout for Patient Organizations](#)

PART IV

ACTION ITEMS TO UNDERTAKE PATIENT-CENTRIC INTERVENTIONS FOR DIGITAL HEALTH

SUMMARY

This section outlines practical steps and action items highlighting the way forward for patients, advocacy groups, and other stakeholders to better engage in designing, developing and implementing digital health solutions.

Each of the action items and recommended suggestions are further complemented by a series of quick guides that includes mapping tools, checklists, and guides to help patient organizations.

APPIS 2022 witnessed the presentation of multiple patient-centric digital health solutions built with input from patient engagement.

Channels of collaboration need to be in place for patient organizations and stakeholders in order to contribute to the design, testing, evaluation, implementation, and use of digital health tools to improve health outcomes and encourage patient-centric care. In the next section please find three action items for patient organizations to review and identify which one would be the best fit and is the main priority, given their digital health landscape and healthcare ecosystem.

[Click here to download the APPIS 2022 handout for Patient Organizations](#)



Convene a patient organization consultation to prioritize and plan the action items



ACTION ITEM 1 MAP AND ENGAGE STAKEHOLDERS

The stakeholder landscape should be done primarily to identify mobilizers and facilitators who share common interests with patients, patient organizations, doctors, and developers. Stakeholder mapping will help patient organizations engage with the right people at the right time to communicate patient priorities and collaborate with stakeholders to share resources, experience, and guidance.

Approximately **75%** of the APPIS 2022 participants agreed **stakeholder mapping** as one of the best ways to understand the landscape to improve digital health education and communication.

This action item has two parts, first, mapping the stakeholders and second, engaging them to improve patient engagement.

Stakeholder Mapping Exercise

The aim of this exercise is to identify stakeholders, which requires understanding the landscape of digital health solution developers in the specific disease area and geography. Look at key influencers, including but not limited to, digital health developers, healthcare organizations, health technology assessment bodies, regulatory bodies, industry, medical societies, development partners, government entities, and digital sandboxes.

There can be different sources to identify the stakeholders, such as carrying out research through the review of medical literature, articles, conferences, white papers, healthcare organizations, and online digital health company platforms.

Here is a brief overview of the steps involved:

1. Study the digital health developers' and digital health industry values, goals, experiences, and needs and understand the 'people' beyond the industry.
2. 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.
3. Define the role and responsibilities of each of the stakeholders identified, establish channels and create a process to engage them.

Stakeholder Engagement Process

A unified voice with all stakeholders will help in making a strong case to engage digital health developers, industry, government, and regulatory bodies.

Involve influential digital health developers and active representatives from the digital health sandboxes, government, and regulatory bodies in this process. This can be done using the mapping exercise described above. Establish structured and sustainable channels of communication between patient organizations, digital health product developers and specialist doctors, and industry and regulatory bodies. Publish and disseminate a multi-stakeholder white paper through a multi-stakeholder platform/forum on the role and responsibilities of patient organizations in enabling patient-centric digital health product development.

[Click here to download the APPIS 2022 handout which includes template to support in stakeholder mapping and engagement on pages 2-4](#)



ACTION ITEM 2

USE NETWORKING FORUMS AND CROSS-LEARNING PLATFORMS

Patients and patient organizations need to upskill themselves in the design and development processes of digital health solutions through available and new channels of communication, capability-building training, and networking. Increased collaboration between patients and healthcare system stakeholders is the most essential step to bringing them together and speaking as one voice.

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.

“To create sustained and two-way communication channels, the creation of a platform for stakeholder engagement is recommended, whether this be interactive or online, what is important is there is a channel to share the patient and developer journey for other stakeholders to respond. Patient organizations have voiced their willingness to participate in such a neutral online platform for their feedback and active participation.”

Jan Geissler, Founder and CEO, Advocates, APPIS 2022

50% of the respondents at the APPIS 2022 think that local patient organizations can provide information on useful digital health tools for patients and about patients; and **73% of the APPIS 2022 participants** think that an online patient platform can be a good channel of communication with the patients and the digital health tool developers.

The following is an overview of the steps involved in the process:



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.



Identify resources

Patient organizations will have to look at what resources will be needed to set up or use already available forums and platforms. Examples include Healthcare Information and Management Systems Society ([HIMSS 22](#)), a not-for-profit organization, [Digital Health Live by Waracle](#), [Digital Health Reuters 2023 Event](#), and the [European Patients Forum Event](#). Based on the list of potentially existing networks, identify the champions in the digital health ecosystem. Identify the main events organized by and for digital health professionals. Look at what disease areas they are working on and if that is something the patient organizations want to pursue.



Build capacity on patient-centric care

Identify platforms available for training, capacity building, and advocacy events. Alongside this, look at thematic areas of interest for specialist doctors, digital health developers, and experts on patient-centric care and organize capacity-building workshops at the patient networking forums and regional knowledge hubs.



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 decision-making processes for digital health tools and communication solutions.

[Click here to download the APPIS 2022 handout which includes checklist to engage with stakeholders and utilize networks on pages 5-7](#)



ACTION ITEM 3

STANDARDIZE DATA WITH PATIENT REGISTRIES

Patient data stored in patient registries is a critical tool in building evidence-based digital health solutions and policies. Patient registries house the required patients' health data for developers, protected by the relevant protocols. Digital health developers can seamlessly use the required data to design patient-centric tools and solutions through patient registries. Data in the patient registries should comprise real-life patient stories along with structured patient data. Patient organizations must collaborate with developers to create structured data sets, data safety, and privacy protocols.

"It's important to make and share patient-centric datasets public and develop strong frameworks to guide data privacy and maintain confidentiality."

Kawal dip Sehmi, CEO, International Alliance of Patients' Organizations, APPIS 2022

The following is an overview of the steps to build a patient registry:



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 established between the digital health developers and these registries, if there are any. Look for opportunities to integrate with existing registries if not integrated already.

Patient data may not be aligned with the requirements of digital tool developers. If aligned, patient data can help evaluate the patient experience with respect to patient treatment, outcome, and also their patient journey.



Patient Registry Planning and Pilot

Patient organizations will have to plan to create a patient registry for a specific disease area if there isn't one already. Creating a patient registry will need to be with the larger goal of ensuring patient-centric data usage while integrating data privacy and protection elements. The intent will not only be to allow digital health developers to understand patient needs but also for policymakers and regulatory bodies to learn about the patient experience and address the most pressing needs.

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, engagement with Institutional Review Board, data collection, analysis, and monitoring processes and outcome measures articulated for different stakeholders including digital health solution developers.

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.

[Click here to download the APPIS 2022 handout which includes the reference guide to build your own patient registry on pages 8-10](#)

OVERARCHING RECOMMENDATIONS

Irrespective of the suggested action items, where there is any intervention to engage with digital health solution developer, to scale digital health tools by patients in low-middle-income countries, patient organizations will need to facilitate:

1. Developing user capacities and skills, which may be done through workshops or training material development. Digital health innovators may empower and encourage patients through their tools, as well as build trust to improve literacy outcomes. Engaging doctors in the capacity building of patients would be equally important.
2. Widening delivery channels used, from video to voice and even text.
3. Including support features over these channels, whether online, over phone, or over video chat.
4. Including social elements which are empathetic to the user experience, as well as customized local information, text, and language.



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