Alliance & Partnerships for Patient Innovation & Solutions
APPIS 2022
Asia Pacific, Middle East, and Africa

TOWARD COLLABORATIVE PATIENT-CENTRIC DIGITAL HEALTH SOLUTIONS

A HANDOUT FOR PATIENT ORGANIZATIONS

This handout is part of the Alliance and Partnerships for Patient Innovation and Solutions (APPIS) 2022 initiative.

Organized and funded by Novartis, APPIS 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.

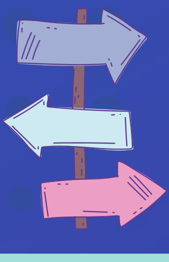
Digital Health and Communication was identified as one of the themes, given the real-world needs for patient-centric digital health solutions and the gaps in involving patients and organizations in the development processes.

The handout is intended to be used by patient organization leaders and representatives to be more involved in design, development, and adoption of digital health and communication tools.

Visit www.appisinitiative.com to learn more about APPIS and download the full version of the Guidance Report on Digital Health and Communication.

Three Principles to build Patient-centric Digital Tools

1. Engage with patients and doctors at the relevant level of the digital tool design process.
2. Incorporate meaningful communication and collaboration with each stakeholder. This can include research for peer-reviewed journals, participation in conferences, or outreach to patients.



ENGAGEMENT & COMMUNICATION

INTERACTION & ASSESSMENT

3. Practice active empathy while organizing virtual or in-person activities for patients, such as checking in on state of mind before starting and developing skills in using virtual platforms.
4. Remember the tool's core objective and gauge the positive impact of the tool on the patient, journey, experience, and health outcome.

5. Develop user skills and capacities, empower patients, build trust through the use of digital tools and improve digital health literacy outcomes.
6. Incorporate social elements and local context for user experience, expand delivery channels and include support features over these channels.

EXPERIENCE & LEARNING

Framework

Challenges	Focus Areas	Solutions
Lack of patient participation in framing of policies and guidelines	**Policy & partnerships**	Regulation for patient engagement Support groups to widen the network and increase impact
Lack of effective communication channels Mismatch between patients and doctors in usage and adoption of digital health	**Education & communication**	Platforms for networking and cross learning Stakeholder interaction for collaboration and sharing of journeys and ideas
Lack of processes for collection of data and inputs from patients Lack of representative patients' voices (e.g., those without internet)	**Data collection**	Build patient database and registries Resolve gaps in data collection and analysis Create feedback channels (e.g., patient and clinician knights)
Lack of indicators and frameworks for inclusion of patients to measure impact	**Demonstrate value & impact**	Implement two-way communication feedback Data capture and analysis using patient registries

PRODUCT CYCLE

STAGE I: IDEATION AND DESIGN

STAGE II: TESTING AND REFINEMENT

STAGE III: ADOPTION OF DIGITAL TOOLS

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STAKEHOLDER MAPPING AND ENGAGEMENT

IN SIX EASY STEPS

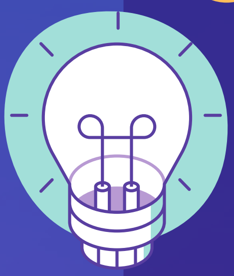
STAKEHOLDER MAPPING

1 Observe and Identify Members

Look for who is a champion, is influential, who can make an impact and who is already involved or associate with contributing to the digital health development process?

Prioritize, Research and Shortlist 2

- Plot your stakeholders to help identify who is most influential and interested in listening and engaging with the organizations.
- Seek input from sources such as research, media documents, conferences, white papers, healthcare organizations, and online platforms.



3 Brainstorm and Co-Create

- Think about the perspectives of your stakeholders on factors that can influence the behaviour and use of the digital tools.
- Involve the stakeholders in the design phase of digital health tools. Engage the doctors to account for information foreseen for patients.

For example, patients and doctors can be engaged to design tools that reduce the patient's pain and address side effects proactively. Engaging doctors would help account for side effects information onto the digital tool before they are reported by the patients.

Connect and Understand 4

Study the digital health developers’ and digital health industry values, goals, experiences and needs and understand the ‘people’ beyond the industry.

5 Define, Design, and Test

- Define the role and responsibilities for each of the stakeholders identified.
- Establish the formal, structured, sustainable channels to communicate with the stakeholders.
- Create a process to engage the stakeholders in the design of digital tools.

STAKEHOLDER ENGAGEMENT

6

- Maintain a unified voice and priorities with all.
- Develop a strong case in front of the developers, digital sandboxes and regulatory bodies for digital tools.
- Use networking platforms to co-create solutions and guidelines for usage and periodic feedback discussions.
- Organise roundtable discussions with the stakeholders.
- Co-host theme based educational sessions with digital health developers, hospitals, pharma industry and patients
- Publish and disseminate a white paper on the roles and responsibilities of patient organizations for digital health.

STAKEHOLDER ENGAGEMENT AND MAPPING TEMPLATE

POTENTIAL STAKEHOLDERS INCLUDE BUT NOT LIMITED TO

- Healthcare Organizations
- Research and Academic Institutions
- Digital Health Developers
- Government representatives
- Industry Experts
- Not-for-Profit and NGOs
- Unions, Associations, and representatives from groups such as:
  - Doctors and nurses
  - Patients and advocates

- Specialists and Supportive Stakeholders such as:
  - Journalists from print and digital media
  - Communication experts
  - Experts in specific disease area
  - Public health experts

QUESTIONS TO HELP WHEN USING THE TEMPLATE

- How much will the stakeholder impact in contributing to Digital Health solution design and development?
- How much influence will the stakeholder have in the process of engaging with Patients and Patient Organizations?
- What are some organizations and stakeholders (including healthcare providers) supporting patient-centric digital health solution design?
- What are the important priorities of the stakeholder?
- How could the stakeholder contribute to the process of engaging patient organizations in the health policy shaping process?
- What are the values and factors important to the stakeholder?
- How can the stakeholder hinder the process of engaging patient organizations in the digital health solution design?
- What is the strategy to engage the stakeholder?

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SAMPLE TEMPLATE - STAKEHOLDER MAPPING & ENGAGEMENT

Stakeholder Name	How much will the stakeholder impact in contributing to Digital Health Solution Design, Development, and Adoption?	How much influence will the stakeholder have over the process of engagement with Digital Health Solution Design, Development, and Adoption?	What is important to the stakeholder?	How could the stakeholder contribute to the process of engagement with Design, Development, and Adoption?	How can the stakeholder hinder the process of engagement with Design, Development, and Adoption?	Strategy to engage the stakeholder
(Examples) Nurses' Union	High	**Medium**	Support follow-up and treatment protocol for patients	Agree for union members to implement new reforms	Going on strike	Round-table discussions
Patient Group X	High	High	Maximising quality of care for patients	Communicate with other stakeholders to express their support for reforms	Making complaints about quality of service after the reports	Information and feedback meetings every 6 months Networking forums, webinars, cross-learning discussions, policy advocacy meetings

Steps to use the template:

- Refer to the snapshot of the stakeholder template on the left.
- Click on the pink box below to access the fully filled sample template and an empty template for your use.
- Download the document or take a print out for further usage.

Click here to download the Stakeholder Mapping and Engagement template

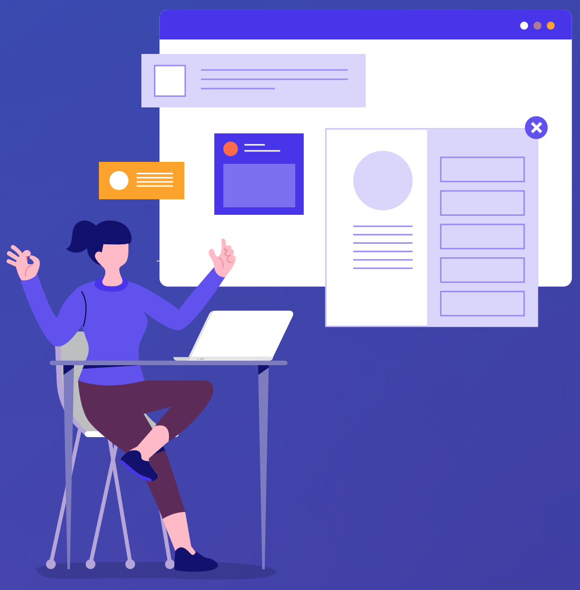
USING NETWORKING PLATFORMS AND FORUMS

THREE STEPS TO ENGAGE, COLLABORATE, AND ADVOCATE

1) Gather Information

- Identify and list the networking forums and platforms for a specific disease area
- These are usually organised by patient groups, healthcare organizations, non-profits, and academia.
- Find patient engagement platforms through the existing regional and global knowledge hubs
- Here are some examples: *WHO, the International Alliance of Patient Organizations, and country-specific events*

- Stay informed about the events organized by digital health experts and developers.
- Identify the champions in the digital health ecosystem.
- Find out the specific disease areas or healthcare areas that they are working on.
- Learn about the objectives and goals of the listed networking forums, cross-learning platforms, and experts.



Questions to help patient organizations:

- What are the active patient groups and healthcare organizations in your geography?
- What are some of the relevant and upcoming events and initiatives on their website or social media?
- What are these stakeholders trying to achieve? And would you benefit or be able to help?

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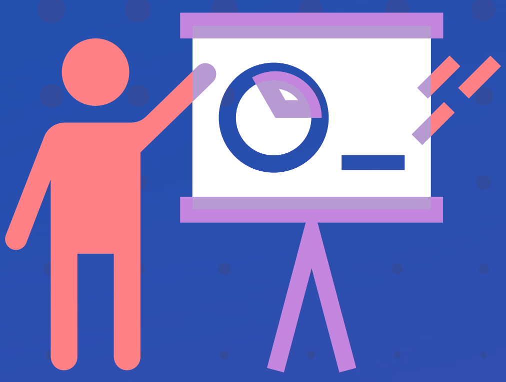
2) Identify Resources

- Explore the required resources to use networking forums and platforms.
- These resources can include but are not limited to:
  - Patient champions
  - Subject matter experts
  - Content writers
  - Funding
  - Knowledge products such as tools, guidelines, manuals, publications, newsletters, discussion forums, and others.

Questions to help patient organisations:

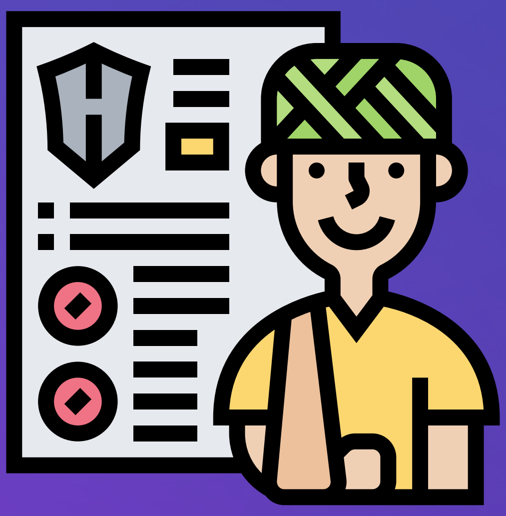
- Who are the champions and interested members in your networks who would like to use these platforms to learn more?
- Can these members help others learn and use these platforms themselves?
- Which of the above-mentioned resources does your network or organization already possess?
- Which members possess the expertise to consolidate the resources if unavailable?

3) Train, Build Capacity, and Advocate



- Understand the training needs and identify areas of interest for patients and developers to encourage patient-centric digital solution design
- Shortlist thematic areas of interest for doctors, developers, and experts on patient-centric care
- Look for training, capacity-building, and advocacy events organized by identified networks and forums in the shortlisted areas
- Co-host capacity-building workshops and virtual webinars at the networking forums and regional knowledge hubs with key stakeholders

- Propose the identified platforms and forums to organize thematic multi-stakeholder discussion forums on patient-centric digital health solutions
- Promote the design and adoption of digital health tools and solutions as a priority agenda on the platforms and forums
- Customize regional knowledge hubs to include disease-specific thematic areas for digital health solution design, such as *non-communicable diseases, breast cancer, leukemia, etc.*



- Advocate for creation of a process to engage patients in:
    - Policy-shaping process for digital health
    - Creation of laws and rights around data protection and privacy of medical and health data
    - Decision-making processes for adoption of digital health tools and communication solutions.

Questions to help patient organizations:

- What are the available entry points for your organization or patient group to engage based on this landscape?
- Does your organization have enough resources or expertise to gather further resources?
- How would you define the roles and responsibilities of the involved and potential stakeholders?
- What are some of the digital communication platforms/forums to participate in?
- Can you create new ones? What are the required resources and partnerships you need?

DIGITAL HEALTH AND COMMUNICATIONS HANDOUT

CHECKLIST - USE OF NETWORKING PLATFORMS AND FORUMS

Gather Information

Checklist	Notes
Leadership support. Use the stakeholder mapping template to identify patient organisations in the same disease area and other relevant stakeholders whom you need to look to secure leadership support	
Identify specific disease area and locate vulnerable patient population and develop clear definitions for the full range of functional needs of the populations with digital usage • Patients and caregivers with communication barriers • Patients and caregivers who need training on using digital tools • Patients and caregivers who do not have access to smartphone but can use text messages.	

Build Leadership Team

Checklist	Notes
Plan the first meeting with identified stakeholders. (The purpose of this meeting will be to share the gaps with engaging patients in health policy decision making process. The meeting will also serve to brainstorm an approach to engage in shortlisted networking forums, cross learning platforms, discuss channels to communicate the message with identified stakeholders on a regular basis.	

Create Communication Channels

Checklist	
Determine how to share information about the needs and purpose of engaging patients in digital health solutions development and use • Discussion forums • Advocacy	

Sustain Engagement

Checklist	Notes
Update the master list of network members and update them at regular interval	
Identify gaps in patient population represented in or reached out to and engage new partners yearly.	

Click here to download the checklist to engage with stakeholders and utilise networks

Steps to use the checklist:

- Refer to the snapshot of the checklist on the top.
- Click on the blue box on the left to access the complete checklist.
- Download the document or take a print out for further usage.

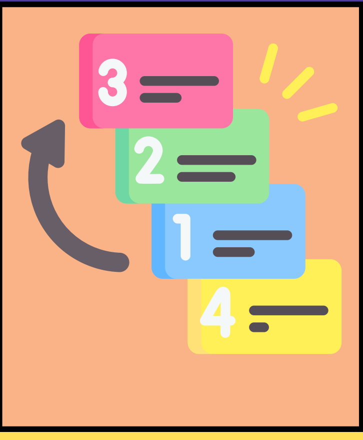
BUILD PATIENT REGISTRIES FOR EVIDENCE-BASED PATIENT ENGAGEMENT

1) Landscaping Exercise

- Scope out and understand the existing patient registries in specific disease area
- Identify linkages between the digital health solution developers and the patient registries if there are any
- Look for opportunities to integrate the developers with existing registries if not done already

Questions to help patient organizations:
- Does the existing registry gather the right patient data that aligns with the requirements of digital tools?
- Does the data help to evaluate patient experience with respect to patient treatment, outcome, and patient journey?

2) Planning



- Analyze and articulate purpose of the registry.
- Determine if a registry is an appropriate means to achieve the purpose.
- Determine the permissions and provide the required and agreed to user access to patients, caregivers, and clinicians to enter and use the data on the registry.

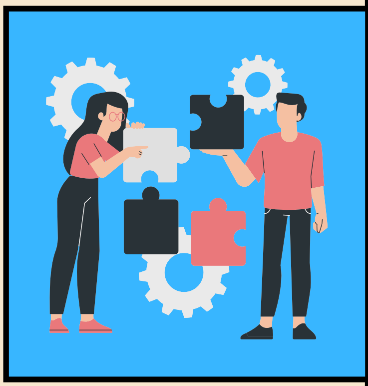
- Use existing or co-create a structured manual on patient data gaps and processes.
- Identify the stakeholders and define the user access management provisions for different stakeholders.
- Gather sources of data and determine the guidelines to use the data for analysis

Questions to help patient organizations:
- Why do you want to develop a patient registry?
- What problem in your organization does the patient registry solve?
- What are the different kinds of data access that the stakeholders (digital health developers, clinicians, and patients) have requested?
- Do the stakeholders in your networks or through networking forums and platforms possess an existing manual on common data gaps in patient data and processes to fill them?
- What are the broad buckets in which the data access requested by different stakeholders be segregated? (e.g., only data view; data entry and view; data entry, view, and edit; data organizing and analysis, etc.)
- What are the dos and don'ts of using these registries for all the stakeholders?

3) Resourcing and Organizing

BUILD A TEAM

- Project management
- Patient representatives
- Database management
- Registry manager
- Registry experts
- Legal personnel
- Quality assurance
- Study lead
- Marketing
- Communications



ESTABLISH GOVERNANCE AND OVERSIGHT

- Advisory board
- Executive or Steering Committee
- Scientific Committee
- Liaison Committee/Individual
- Data Access, Use, and Publications Committee
- Institutional Review Board for ethical study conduct

DEFINE THE DATASET, SOURCES, PATIENT OUTCOMES, AND TARGET POPULATION.

- Data element domains: Personal, exposure, and outcomes
- Data sources: Patient identifier, patient selection criteria, treatments and tests, confounders, cost/resource utilization, disease or condition data, treatment or therapy data, laboratory data, health care provider data, insurance data

4) Launching

CHECKLIST OF PLANS

- Timeline and Schedule Management Plan
- Cost Management Plan
- Risk Management Plan
- Scope & Quality Management Plan
- Communication Plan
- Procurement Plan

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REFERENCE GUIDE - BUILD A PATIENT REGISTRY FOR EVIDENCE-BASED PATIENT ENGAGEMENT

Areas	Purpose/Principle	Examples/ Context	Notes
Identify registry's aim and objectives	This information will guide the selection of data elements you will seek to collect.	Improve diagnosis (Examine effectiveness of screening)Treatment and prevention (identifying patients for clinical trials, real world evidence of treatment)Patient safety (monitoring safety of vaccines, devices).	
Define registry dataset	The selection of registry data should be confined to routinely recorded, reproducible, objective data. Select defined health outcomes that are systematically measured which are standardized at predefined intervals. Registry data should adequately describe the patient's condition & major co-morbidities, using clinical outcome measures captured by healthcare professionals.	Patients with certain chronic conditions, may require annual assessment, which provides an opportunity to capture variables at yearly intervals.	

Steps to use the template:
- Refer to the snapshot of the reference guide on the left.
- Click on the yellow box below to access the complete reference guide.
- Download the document or take a print out for further usage.

Click here to download the reference guide to build your own patient registry

ACKNOWLEDGEMENTS

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