



**International Experience Exchange
with Patient Organisations**

**IEEPO 2021 ‘Think Global,
Act Local’, Transforming
Healthcare Together Event –
Regional Workshop Insights**



In keeping with IEEPO's mission to bring together the patient community for international best practice sharing and experience exchange, the IEEPO 2021 'Think Global, Act Local' event saw 25 regional breakout sessions spanning six regions of the globe in early November 2021.

Participating patient group representatives discussed key topics from the IEEPO position paper with the aim of diving deeper into the paper for localised insight.

The insights from those conversations are captured within this document. Click on the name of the region below to view the regions specific insights from the IEEPO 'Think Global, Act Local' regional workshops.

- [Asia Pacific](#)
- [Europe](#)
- [Latin America – Spanish Group](#)
- [Latin America – Portuguese Group](#)
- [Middle East and Africa](#)
- [United States and Canada](#)

Asia Pacific

- Date of workshops – 09th November 2021
- Number of regional workshop breakout groups: 4
- Patient group attendees: 40

This region particularly focused on the need for improved education and communication among key stakeholder involved in policy change. Other key takeaways include:

- The need to improve the communication skills, empathy and sensitivity to language barriers from healthcare professionals.
- Helping patients to navigate the healthcare systems through greater multidisciplinary team collaboration and improving the health literacy of patients.
- The important role of nurse and peer navigators in health literacy and the need for health literacy to be taught in schools.
- Leveraging mobile solutions and digital channels to communicate and gather data to improve patient care.

Key insights from the jamboard include:

Important Stakeholders

- Ministry of Health
- Nurse and peer navigators and carers
- Patients and patient organisations

Opportunities

- Health and digital literacy - Health literacy beings in schools
- Sharing of best practise from across the APAC region
- Language used by medical professional needs to be tailored to patients to help overcome fear and improve understanding

Challenges

- Health literacy gap and lack of disease awareness
- Not all patients belong to society
- Privacy issues around collection of data and hesitancy to share from some NGOs

Strengths and Resources

- Training and capacity building of patient advocates and sharing of existing resources
- Greater awareness using popular social media platforms and encouraging patients to be more comfortable with zoom

Europe

- Date of workshops – 08th November 2021
- Number of regional workshop breakout groups: 7
- Patient group attendees: 45

This region particularly focused on the digital revolution; namely the importance of building digital solutions around the needs of patients and ensuring the digitisation of healthcare improved quality of life. Other key takeaways include:

- The increasingly important role of patient organisations to 1) help ensure digital tools and services don't 'lose' people in the system and 2) bridge the gap on language and digital literacy.
- Managed properly, digitisation should enable improved disease monitoring and communication with healthcare professionals.
- Barriers to the effective use of patient data need to be overcome for the digitisation of healthcare to realise its full, patient-focused potential.

Key insights from the jamboard include:

Important Stakeholders

- Media, journalists
- healthcare professionals
- Policy makers

Opportunities

- Patient organisations can help train patients on healthcare professionals' communications and be part of healthcare consultations
- Patient organisations to lead in how data should be used to humanise healthcare and act as role models and influencers/showcase best practise
- Universal screening for early detection and prevention

Challenges

- There are numerous challenges that are currently forming a barrier to the effective use of patient data - e.g., regulations, data governance, mindset around patient involvement and patient organisation registries
- Erase disease stigmas / Break taboos to allow data and empowerment to be truly unleashed and people to share data without concern of repercussions (at home, work, insurance, etc.)
- Healthcare professionals often don't have time or opportunity to access the right digital tools (apps) and can be overwhelmed with information

Strengths and Resources

- Federated systems: sometimes easier to work at a national level
- Think Global: Act Local: Adapt Position Paper for local use
- Patient networks and registries

Latin America – Spanish Group

- Date of workshops – 08th November 2021
- Number of regional workshop breakout groups: 4
- Patient group attendees: 35

This region particularly focused on the importance of health literacy as key, not only for its important impact on patient empowerment but also as an urgent need to demonstrate the impact that an educated and empowered patient can have on health system sustainability. Other key takeaways include:

- The subject of expanding stakeholder involvement/partnerships and the importance of getting not only health decision makers involved but also health professionals, industry, technology and information companies, and others.
- The importance of health literacy among the public and involving key stakeholders to correctly educate the public.
- Increased communication between organisations so that knowledge, resources, and experiences can be shared more effectively, with the exchange of success stories was also prioritised.

Key insights from the jamboard include:

Important Stakeholders

- Health decision makers
- Health professionals
- Industry, technology, and information companies
- Ministry of Education

Opportunities

- Work with the Ministry of Education to include trainings about disease prevention and promotion of health from school. A well-informed patient will save money to the health-care system money.
- Share and review existing resources to professionalise and develop a shared library of professional courses that can be shared across the educational system
- Technological access to democratise health

Challenges

- Health literacy - not only for its important impact on patient empowerment but also as an urgent need to show the impact that an educated and empowered patient can have on health systems and their sustainability.
- Lack of legislation on Patient's rights.; administrative burden; discrimination and harassment to some patients.

Strengths and Resources

- Digital health files that patients can get access to
- Exchange of knowledge sources, successful case studies and collaborative work

Latin America – Portuguese Group

- Date of workshops – 08th November 2021
- Number of regional workshop breakout groups: 3
- Patient group attendees: 29

This region particularly focused on the learnings from the COVID-19 pandemic (especially with low resources) around bringing high quality medical information, supported by healthcare professionals, to society. Other key takeaways include:

- Need to ensure that information reaches patients despite many not having access to digital channels and developing trusting relationships in a culture of fake news.
- Empowerment of patients was seen as the most significant factor in driving personal health, with the combination of patient, family, and healthcare professionals as the ultimate recipe for a humanised health process

Key insights from the jamboard include:

Important Stakeholders

- Patients
- Healthcare professionals
- Patient organisations

Opportunities

- Explore the COVID learnings (especially with low resources) in how to bring high quality information to the people, supported by healthcare professionals.
- Patients need to become the drivers of their own health
- Humanised technology solutions that help patients navigate healthcare systems

Challenges

- Ensuring information reaches patients
- Developing trusting relationships between healthcare professionals and patients in a culture of fake news
- Lack of access to digital channels - only 30% of the population has access to digital channels

Strengths and Resources

- Patient advocate mindset is strength
- Empowered patients

Middle East and Africa

- Date of workshops – 08th November 2021
- Number of regional workshop breakout groups: 5
- Patient group attendees: 29

This region particularly focused on patient empowerment and the role of patient organisations. Other key takeaways include:

- Despite legal and process difficulties in establishing patient organisations in the region, the need to advocate for patients to be better informed and better able to make joint decisions about their care is vital.
- The need to amplify the patient voice and ensure it is heard across multiple stakeholders with different levels of engagement, for example with government, policy makers, healthcare professionals, non-governmental organisations as well as community and religious groups.

Key insights from the jamboard include:

Important Stakeholders

- Imams and faith groups
- Tribal and certified Sangoma Healers
- Primary Healthcare investment: screening service managers

Opportunities

- Helping local patient communities to develop their health literacy
- Patient empowerment through focusing on education and awareness
- Create opportunities to amplify the patient voice at different levels of engagement and with different stakeholders

Challenges

- Difficulty to establish patient organisations in the region from legal and process perspective
- Patient empowered is extremely important, despite doctors thinking otherwise sometimes
- Equitable access to healthcare for all regardless of location, gender, ethnicity, or social status
- Dealing with drugs sold on the black market

Strengths and Resources

- Real life stories and storytelling for greater impact
- Social media platforms and the opportunity to educate social media influencers
- Our inspiration to change!

United States and Canada

- Date of workshops – 08th November 2021
- Number of regional workshop breakout groups: 2
- Patient group attendees: 15

This region particularly focused on the digitisation of healthcare systems and the utilisation of data. Other key takeaways include:

- The challenge of no global definition of the components of data which would enable the creation of an ecosystem.
- Meaningful data needs to be collected systematically in order to really leverage the power of data. Therefore, before any progress can be made, we need to narrow down and define the components of data.
- Only once this has been achieved can we move forward towards a meaningful harmonisation of data collection and data quality in a centralised way.

Key insights from the jamboard include:

Important Stakeholders

- Patient community
- Everyone across the ecosystem of health digital data
- Tech audience

Opportunities

- Generate data to understand the drivers of disparity
- Increase diversity across the medical workforce and clinical trial managers to help decrease inequality
- Patient organisations to be the stewards of patient data management

Challenges

- Losing private cover has exacerbated access issues
- Social-economic status resulting in inequity in care
- Some healthcare problems stigmatised, and research focused on high functioning people
- Data governance and hospital infrastructure

Strengths and Resources

- Sharing of recourses and research between US and Canada
- Working together to raise awareness of issues
- Electronic health data normal across US and Canada – but is its quality data and does it really reflect patient needs

With special thanks to the IEEPO External Advisory Committee members, and IEEPO Programme Chair Raquel Peck for their continued support in leading and co-creating the IEEPO annual programme throughout 2021. IEEPO is sponsored by Roche and organised in partnership with an independent Chair and an External Advisory Committee of global leaders in patient advocacy.

