



Uniting for change: Transforming healthcare together

IEEPO 2021 Kick-off event

22nd – 23rd March 2021

Meeting report

IEEPO 2021 meeting opening:

This year's IEEPO themed as 'Uniting for Change: Transforming Healthcare Together', was opened by Sanja Njegic, Global Head of Patient Partnership at Roche, who welcomed over 570 patient group representatives to the event.

Raquel Peck, the IEEPO 2021 programme chair and former CEO of the World Hepatitis Alliance proceeded to kick off the two-day virtual event series on 22nd and 23rd March with an introduction of the evolution of the IEEPO programme, and introduced this year's IEEPO theme and why it is so important to the community.

Divided into four distinct domains, [IEEPO](#) aims to deliver a programme of ongoing touchpoints that:

- Help to **increase knowledge, inspire** patient communities and provide **learning opportunities**
- Provide a broad forum for **experience exchange** among patient groups
- **Empower** patients and carers to work together with other stakeholders to be equal partners in shaping healthcare ecosystems

[IEEPO 2021 External Advisory Committee](#) members lead each of the four domains. Those leaders gave a snapshot of what each domain aims to achieve.

THINK

"The THINK domain aims to inspire us to be bold and visionary and think beyond the struggles of today to ready ourselves for the challenges of tomorrow."

"We want to look at emerging health trends and examine some of the most pressing health care challenges for our community, and we want to provide inspiration and how we can work together on some of these issues."



Domain leader: Bastian Hauck
Founder, #dedoc° Diabetes Online Community, Germany

LEARN

"LEARN will give you easy online access to existing tools, guidance, and resources that have been produced by and for the patient community. Having access to this LEARN library means that you'll be able to save precious time by adapting resources and materials that already exist without having to reinvent these yourself."



Domain leader: Alastair Kent
Former Executive Director, Genetic Alliance, UK

CHANGE

"The CHANGE domain will be focusing very much on policy; it will be a practical clinic looking at how to enhance the understanding of what's happening at a global level, looking at global health policy trends in a national and local setting and vice versa."

"We want to support our participants to use this knowledge in their local and national advocacy work, and we will be linking up with all of the other domains."



Domain leader: Nicola Bedlington
Special Advisor, European Patients' Forum, Austria

MAKE

"IEEPO is all about serving the patient community, and co-creation with the community. The MAKE domain focuses on creating a material that will inspire and support patient voices in many countries, and that's why we want to hear your voice."



Domain leader: Maira Caleffi
Founder and President, FEMAMA and IMAMA, Brazil

THINK panel webinar:

Tomorrow today: Preparing for our future together

Click here to listen to watch the entire session:

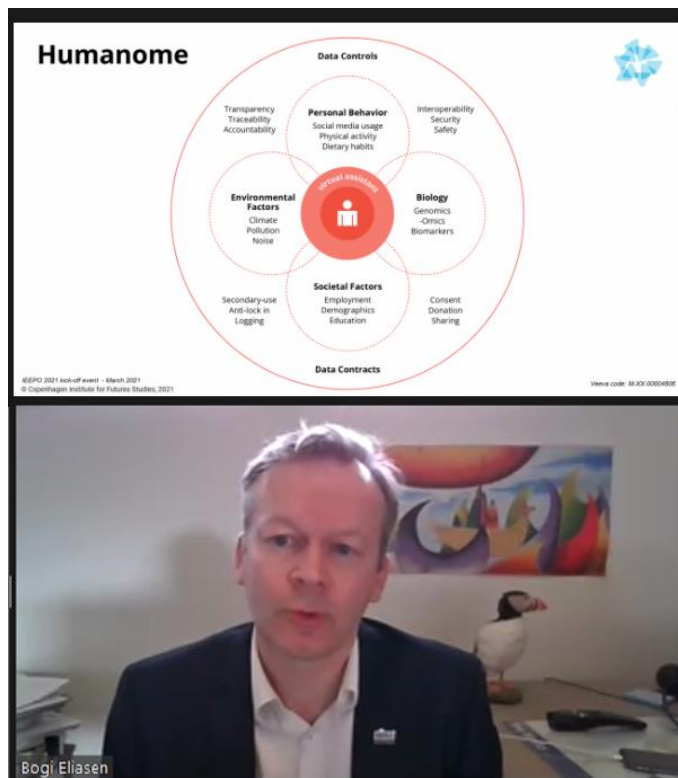
<https://www.ieepo.com/en/useful-resources/ieepo-resources.html>

Keynote speech: Digital health and future approaches to healthcare

Bogi Eliassen, Director of Health at the Copenhagen Institute for Futures Studies

With a background in political science and international law, and experience working with both the public and private sectors, Bogi Eliassen is now a pioneer of what he describes as 'the great alignment' between personal health and public health. This thought-leadership session highlighted some of the key emerging trends in shaping the future of this holistic view and some of the opportunities presented by the global pandemic that cannot be missed.

Mr. Eliassen's opening started with the concept that we cannot go back to normal; we must have a 'leap forward'. For him, the biggest disappointment during the current crisis has been the failure of countries to deal successfully with the pandemic. However, in his view, it opened a door of opportunity for patient organisations, highlighting the need for a global network to work together to take on these challenges.



The 'great alignment' between personalised health and public health

Mr. Eliassen is quite clear that the question is not whether there should be more emphasis on public or personalised health. Instead we need to work out how to merge these two paradigms – a challenge that he puts to the IEEPO community. He reiterated that the pandemic had shown us that we could do tests and get answers in places worldwide, which we couldn't do just over a year ago. Most of all it has shown us that we need to work with a global mindset.

Taking a global mindset with the 10-90 approach

The 10-90 approach, a concept that Mr. Eliassen and his Institute have been working on, examines how we can create health equity by examining factors such as the social determinants of health and use technology to not only focus on the 10% of the wealthiest countries, but also look at the other 90% of the world. It's not enough to say let's adapt products or services already available; with these needs built in from the outset.

He called on the IEEPO community to continue building a 'global co-operative of health' that includes perspectives from the 'bottom-up, not just top-down'. We must resist going back to the way we did things before the Covid-19 pandemic, and the progress and learnings made so far need to be harvested – but Mr. Eliassen is conscious that this does not come without challenges.

Tech we have, decisions we need

Mr. Eliassen's opinion is that we should not have the main focus on more tech; we don't need more tech; we need knowledge and decisions to use the technology more effectively, that he already presents. He was not too fast to criticize the current 'one size fits all' concept – it has given us a standardised way to deliver health – but we need to improve on it.

What should the focus be? His view is that we need to shift the focus from health inputs and outputs to health outcomes and quality of life and well-being as the output of care. Health is more than just providing the promise that you can open the door to a clinic.

Mr. Eliassen also discusses the need to get new players in. We already see this happening in the digital space, but we also need new players in the financial planning and the funding phases, such as pension funds and insurance companies. He highlights that companies will soon be able to produce and gather data on genomic sequencing, patient behaviour, and environmental data very cost-effectively. The question will be how best to use this data and integrate it into patient care.



The 50/50 aspiration

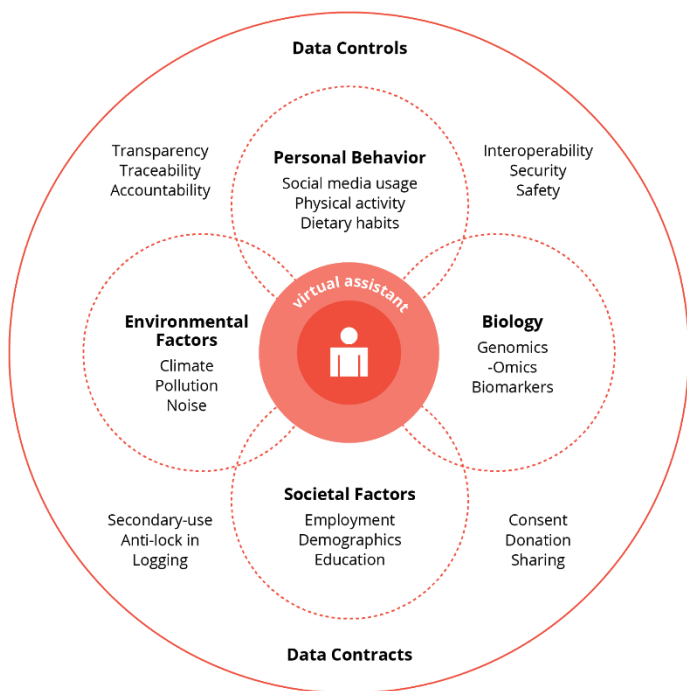
What happens when we think about health as investments rather than health costs and lifespans rather than budgetary years?

Mr. Eliassen outlined another concept he has been working on in this vein – the 50/50 aspiration – that half of the health budgets should be invested in prevention. Not just health promotion and primary prevention, but also in secondary prevention, in the diagnosis of diseases, and tertiary prevention to improve quality of life and reduce disease symptoms. The design of 50/50 is to help push the mindset of investment and not just the cost.

He highlighted that several of the technologies we have would not pay off if we look at them in a year's budget and make a massive difference if we look at them through a life span.

Personalised health is not just about precision medicine, Mr. Eliassen says it is also about doing screenings, early detection, and early intervention. Prevention will also be crucial, especially in a world where we get more and more comorbidities.

The humanome model

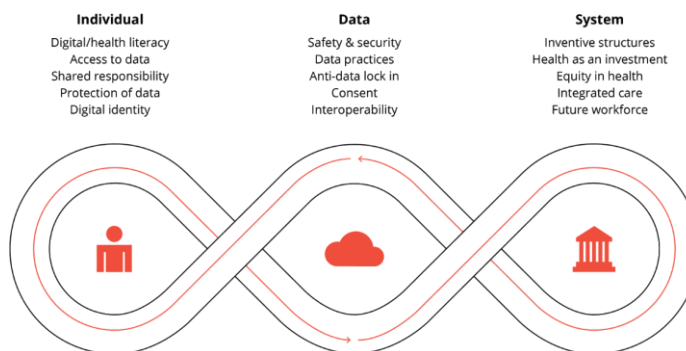


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Mr. Eliassen talked through his 'humanome' model, which looks at the concept of the individual becoming their own 'bio bank.' and 'data repository'. You are in the center, assisted by artificial intelligence (AI), and you have access to your data, and you can share and use it. He suggests that the focus should not be on who owns the data but provides advice and evidence on how data is beneficial for us and the health system.

He explained that here we would need to work with a new concept of transparency, traceability, and company accountability so data could not be detrimental to us in the future, and look at the interoperability of how it can work across systems.

The sustainable health model



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According to Mr. Eliassen, the health system has asked for the data in most countries but has not given anything back to the person. Working with a sustainable health model like this ensures that both the health system and the people in the system are learning, with qualified data being given back to the individual to act on it, helping them in daily life.

Sustainable health needs to act as a loop – not just a one-way system – but also a reciprocal interaction. Through the pandemic, decision-makers have gained some understanding that we need to work with data in a - practical way that is accessible for more people. There is a need for real-time data – and not just from the individual – but aggregated data so we can look for patterns and gain greater understanding.

What is Bogi Eliassen asking the worldwide patient community? There is no doubt in his mind that health is the most important pillar for a more stable world. There is also a huge opportunity to substantially change the underprivileged parts of the world through this model, especially where country systems are not so ingrained.

Bogi concludes with a call to action for the patient community to: "be the bridge builders across disease areas and countries and work together with companies and with public institutions, and more importantly, to do this with dignity and respect to achieve the best quality of life for patients that depend on this across the world."

IEEPO THINK Panel

Click here to listen to watch the entire session:

<https://www.ieepo.com/en/useful-resources/ieepo-resources.html>

With a panel representing patient group leaders from different geographies and specialities, Bastian Hauck moderated a discussion around some of the key themes from Bogi Eliassen's talk and how they were relevant for patient groups and communities today.



Working together in low and middle-income countries

[Ranjit Kaur](#), from Malaysia, representing patients from low and middle-income countries, highlighted that everyone is still working very much in silos, which is true of several patient organisations, but is also the case amongst healthcare providers and government authorities. It is timely to look at where the common issues exist and bring everyone together to move things forward, as there is not enough strength in one particular group to do that alone. She echoed Mr. Eliassen's point that countries with newly established governments may be able to make change much more quickly than those deeply entrenched in certain traditions and systems.

Ranjit Kaur added that "for patients who live in rural areas, who are unable to reach the bigger cities where the services are available, all you need is one mobile phone in that family, and they can connect to the health care provider."

Patients as active players in the future of data sharing

[Nicola Bedlington](#), a special advisor to the European Patients Forum, made the point that "patients are not passive recipients of health, they are active players" and described the importance of responsible data sharing and the intrinsic role of patients here. Nicola emphasises the fundamental lack of knowledge, awareness, and confidence around responsible data sharing. She highlighted the platform, [Data Saves Lives](#) which aims to address this issue by providing easy-to-understand examples and information. Improving digital health literacy is imperative, in her opinion, so that communities can feel in charge, but that they need ongoing support and resources to achieve that.

[Durhane Wong-Rieger](#), CEO of the Canadian Organization for Rare Disorders, highlighted that many patient organisations have limited capabilities and resources to be involved in these activities. Excited by the opportunities of data sharing and digital health, she advised that we still have a lot of work to bridge the understanding of the importance of these models. The question she posed was, how patient organisations can help meet the patients and families' needs around data?

Pivoting views on prevention and health expenditure as an investment

[Mary Baker](#), former President of the European Brain Council, discussed how the concept of looking at health prevention in terms of investment rather than cost resonated with her: "Health is wealth, a wealthy nation is a healthy nation". In her view, whatever the disease, whatever pathway we're on, so much is so similar for all of us, and we should be sharing that – which can be a real challenge for society.

Ranjit Kaur agreed that we generally use the phrase 'health expenditure' when we need to think about health investment and have dignity and respect for patients. Nicola Bedlington also raised the point that there is an incredibly large amount of waste in health systems – [equating to around 25% of investment](#) - and more to be done with working with patients and their organizations to involve them in health system design services that can help tackle this problem.

Closing remarks

Bogi Eliassen's final thoughts centred around the idea that we need a refocus on not getting as old as possible but living as well as possible in our lifetime. As Mary Baker alluded to, it's the human behaviour change that we need to focus on to do this. Durhane Wong-Rieger added that the one key point she will take out of the discussion is that we need to do much more of this, and we need to continuously challenge and think about how we bring it to a practical level.



IEEPO: In Conversation with Severin Schwan, Roche CEO

Click here to listen to watch the entire session:

<https://www.ieepo.com/en/useful-resources/ieepo-resources.html>

Day two of IEEPO 2021 saw Severin Schwan, Roche CEO, take to the stage to deliver an inspiring address to the patient community, followed by an in-depth interview with Raquel Peck that spanned thought-provoking issues, from how the notion of patient-centricity has changed to the pressing issues of diversity and inclusion, and the opportunities afforded to the community by advances in digital health.



A word from Severin Schwan

“If we are to be at the forefront of breakthrough medicines and diagnostics for patients, we have to be willing to take risks”, states Severin Schwan. “Trying and failing is not a reason to give up; on the contrary, we should celebrate failure and see it is a reason to continue to explore new ways to make a difference”.

This statement resonates with the overarching [vision of IEEPO](#) and the patient-first values it stands for; improving patients’ lives is at the forefront of our shared mission and is central to Roche’s purpose of driving bold scientific innovation.

Severin Schwan aptly commented that “nobody in the world knows a disease better than a patient,” which points to the role of the patient community as vital partners in helping industry and other stakeholders better understand the patient experience and unmet needs, and ultimately work in partnership to make medicines and solutions available for patients around the world.

Building on the discussions around patient data from Bogi Eliassen’s keynote, Severin Schwan emphasised the importance of real-world patient data and the unlocking numerous possibilities if data from clinical settings could be digitised and aggregated to garner new insights that could accelerate clinical trials, and ultimately allow treatments and care to be developed faster.

Key themes from Raquel Peck’s conversation with Dr Severin Schwan

Visit www.ieepo.com to watch the full video interview.

The changing nature of patient engagement

Patient engagement has changed significantly in the last 13 years since the founding of IEEPO. Patient engagement has broadened from focusing on patient access to medicines specifically to a more holistic way of working with patient communities with opportunities across the entire value chain.

One example of this is working more closely with patient communities to design clinical trials better, and importantly, defining clinical trial endpoints that are reflective of the patient experience, for example, measuring endpoints such as surviving mortality or quality of life measures.

In the last few years, rare diseases have become more of a focus. Whereas previously it may have been that a drug is repurposed to treat a rare disease, we are now engaging much more purposefully with the patient community to understand the biology of rare diseases and ensure the community knows that a rare disease trial is running to recruit enough patients for it.

As relationships with patients have become more complex, with multiple touch-points across the value chain, Roche has simplified and streamlined this way of working, so that patient groups have clear counterparts within the one Roche Patient Partnership team to make it easier to work together.



Roche's perspective on diversity, equity, and inclusion

We believe that innovation happens when you actively embrace a diverse range of perspectives and different or even conflicting viewpoints because this is what drives people to search for new and surprising solutions.

Roche has made a concerted effort to increase the diversity among our workforce, looking at gender diversity, religious and sexual orientation, and representative of ethnic minorities. We are now taking diversity and inclusion beyond our company borders and examining how we can integrate this into our patients' interactions. A recent example of this is a Covid-19 clinical trial we implemented that explicitly focused on the impact of the disease on US minority groups disproportionately affected by Covid-19.

Utilising patient data and digital health to make a difference

Using patient data in medical research is an age-old concept, evidenced for over 125 years by clinical trials. While clinical trials are valuable in studying a specific question. The trial is limited to a specific number of patients. On the other hand, capturing real-world patient data will allow us to see trends in diagnosis, treatments, and patient outcomes on a larger scale, analysing thousands or even millions of patients over time. The Covid-19 pandemic has only accelerated the opportunities we have to capture and share this data, which has added tremendous value to academics, researchers, and the industry to develop better medicines faster.

Severin Schwan answers questions from the IEEPO Global community

Visit www.ieepo.com to watch the recordings of the Q&A sessions.

Opportunities for the future of healthcare - Covid-19 learnings

Covid-19 has led to unprecedented collaboration and ways of working between pharma companies and regulators. Traditionally, pharma companies would conduct a clinical trial and pull together a data dossier to submit for regulatory approval at the very end of the process. What we have seen with Covid-19 is a 'rolling filing' process, whereby we share clinical data with health authorities from the very beginning and continue sharing this on an ongoing basis, making the approval possible for a new medicine in weeks rather than years, without loss of quality.

The pandemic has made it difficult or, in some cases, impossible for patients to access face-to-face healthcare, and so telemedicine has become more commonplace whereby patients consult with healthcare professionals via video conferencing. Before Covid-19, there had been hesitation among institutions to embrace telemedicine, and health authorities were behind the curve when it

comes to the digitalisation of data and using this to face challenges such as Covid-19. We have seen how much better we could have handled the pandemic through the digitalisation of data, and I hope that this will encourage governments and health authorities to embrace this going forward.

Working with healthcare stakeholders to use data effectively

Roche's core competency is collecting granular data for clinical trials to develop medicines. We can apply this expertise by actively working with healthcare institutions, academics, and physicians to record and curate the correct patient data and convert this data from analogue to digital formats to make this usable. The ultimate owner of the data is the patient, and so we work with institutions and patients to build trust and transparency, making sure that patients understand how their data is being used and ensuring that this becomes a two-way feedback loop back to the patient community. Roche takes this approach in a clinical trial setting with an ambition to transfer this approach to a real-world environment.

Making innovative treatments accessible to all patients

Access to innovative medicines relies heavily on the infrastructure in place within a country to enable access to medicine; this could be factors such as hospital infrastructure, trained personnel, sophisticated laboratories for analysis, or equipment needed to administer treatment. A lack of infrastructure makes it challenging to provide access to medicines sustainably and holistically; that is why we are working with governments on programs to look at all the factors that affect healthcare access.

Roche takes the pricing of our medicines very seriously and focuses on providing innovative medicines for challenging disease areas with high unmet need. Severin provided insight into how life-changing innovation in medicine is only meaningful if it reaches those who need it. Roche has looked deeply into the root causes that prevent access and have developed a comprehensive strategy to tackle them. Working in partnership to establish tailored access solutions that create rapid, broad, and sustainable access.

A call to action for the patient community

"Patient organisations must have a seat at the table so that they can build trustful relationships and take an active role in the decision-making process," urges Severin Schwan. He goes on to conclude that "patient organisations can credibly communicate the burden and impact of disease to stakeholders and decision-makers in a more impactful way than the pharma industry. Even though stakeholders will have differing priorities, if we can build trustful relationships, we can work together to find good solutions."



Transforming healthcare together: Insights from the IEEPO 2021 regional workshops

The mission of the IEEPO programme is to foster experience exchange and learning amongst the patient community, bringing together community examples and insights regardless of geography.

The IEEPO 2021 kick-off event saw 40 breakout workshops spanning five regions of the globe; participating patient group representatives discussed specific topics that were identified through a pre-event community survey that informed the programme and discussion.

Key topic 1: Patient-led evidence and patient data:

Generating patient-led evidence and data is one of the central topics at the heart of how healthcare systems can improve the quality of care for the future for patients around the world. While harnessing patient data is valuable - in developing new treatments, helping us advance clinical trial reporting, and deepening our understanding of disease pathology and management – using patient data must be rooted in a trust system.

Patient communities need to feel empowered and educated about the value of sharing their data, and transparency about how the data is used is absolute; for example, patient data can help physicians, the pharmaceutical industry, and other stakeholders such as health insurers improve care and make treatments available.

There is work to be done in determining the type of data that would be useful to collect and how this can be managed; for example, psycho-social or qualitative patient data can feed insights back into healthcare systems. The insights, in turn, can inform what funding and operational work required to establish a central regional patient data registry. Can digital apps and social media channels be vehicles by which to collect patient data compliantly?

Regional Workshop Group Reports – Summary of Discussions

APAC

- Consider creating a Patient Academy for the APAC region, similar to the one that exists in Europe. This could help to empower and educate patients to be in control of their data and understand the value of different types of data and how this data is captured
- Establishing a ‘friendship support centre’ would help to coordinate data between nurses, hospitals and patient groups

US & Canada

- Consider more passive data collection methods that minimise the onus on patients
- Finding a way to capture immediate feelings and psycho-social elements of living with a chronic disease could be helpful

- It can be hard for patient organisations to relay the patient lived experiences to other stakeholders, such as government bodies and regulators

Europe

- There was a significant focus on data and digitalisation, as well as data sharing across countries
- Could there be a central database to collect and analyse patient data across Europe, as this would make it easier to share data across regions, therapy areas of medicine, etc? There were some concerns that the infrastructure to collect patient data is not always available in all areas of Europe
- It was considered important that patients wanted/ needed to know where and how their data is used

LATAM

- Real-world data would improve all elements of healthcare and health policy. It can be used to foresee public health issues, help understand individual patient experiences, monitor drug and resource availability
- Without patient data and patient-led evidence, public health policies cannot be challenged. Change starts from the bottom up, with the collection of patient-led evidence at the core
- The COVID-19 pandemic has created an opportunity to build networks that are able to reach more patients within the community to collect their data and evidence.
- An alliance of patient organisations has a more significant impact when influencing health policies at a national and regional level
- There is a lack of solid data and evidence that captures the real patient need. The lack of adequate attention and resources given to patient groups makes it challenging to empower the patient community to find ways to work with healthcare systems

Middle East and Africa:

- The need to create an environment where patient-led evidence is recognised and embraced -is a massive challenge across Africa. A national registry of patient data would allow for greater collaboration, however, to create this would need access to funding which is not currently available
- Patients are currently unaware of how their data and experiences can contribute to change. The lack of awareness leads to a reluctance from the patient community to offer provided data



Key Topic 2: Digital health:

Undeniably, the COVID-19 pandemic has accelerated opportunities for telemedicine and has forced healthcare systems to build new ways to deliver patient care remotely. Healthcare systems and stakeholders will need to continue embracing digital tools and building on the learning opportunity that the pandemic has provided for the future of healthcare delivery.

In considering the future of digital healthcare tools and telehealth, patient communities and broader stakeholders recognise the global disparities in access to resources such as a reliable internet connection and access to technology, particularly for rural communities. While telehealth and digital tools provide significant benefits to society at large, some groups in society, such as elderly patients, may find it challenging to use these services.

The patient communities highlighted that the key to building a sustainable approach to digital healthcare is through collaboration and sharing of best practice also across disease areas. Only by creating partnerships between patient organisations, healthcare professionals, and other stakeholders, can we successfully drive innovation and uptake of digital tools.

Regional Workshop Group Reports – Summary of Discussions

APAC

- For patient organisations in APAC, digital health means that ‘wherever the patient is, we can connect with them, their communities, and with local healthcare professionals’
- There is a potential to harness the power of mobile phones more i.e., using apps to communicate with the health care team and other professionals, send alerts for assessments, remind them to manage their health and create reward systems for better compliance

US & Canada

- Patient organisations are advancing well with digital health tools
- Higher-income countries should ally with lower-income countries to further their digital capabilities
- Examples of digital advancements in the US & Canada include, for example, online financial tools to support patients with the financial management of living with breast cancer; and daily symptom tracker would be beneficial in generating real-world data

Europe

- Patient organisations recognise high costs associated with sustaining digital tools,
- There is potential to decentralise health systems through digital health tools which would create a more holistic care service for patients
- Patient organisations recognised that there is a need to develop material for health literacy. Digital tools could be used to simplify health education for patients by using creative methods such as animations and apps.

LATAM

- In LATAM patient organisations recognize the value of digital health tools, however there is a lack of investment and engagement with technology by government authorities
- In some regions, electronic prescriptions are being implemented, but this system is not yet finalised
- In some cases their health literacy must be strengthened, as currently there is a resistance by healthcare professionals when it comes to applying data to improve healthcare delivery
- Some patient organisations in the LATAM regions have developed an app where the patient can directly link to their treatment center and healthcare professional, e.g., this works via an alarm system that connects to a blood centre to notify them of a serious problem. Patients can also already use digital tools to highlight issues to their healthcare professional by submitting a photo, or voice / video message

Middle East and Africa:

- In the Middle East and Africa patient groups have not advanced much with digital health tools



Key Topic 3: Health Policy:

The economic pressures of the pandemic have undoubtedly affected the attention and resources given to rare diseases by policymakers. Across different regions, patient communities can see the reduced levels of investment by health authorities, e.g., timely disease diagnosis, delays in regulatory approvals, and product reimbursement lead to reduced access to medicines for patient populations with the greatest need.

Patient communities must forge alliances that cut across country borders and disease areas to highlight issues that affect all patients and ensure these are moved up the political agenda. Generating patient data and evidence will be key to building an economic case to encourage policymakers to see health budgets as investments into society instead of expenditures.

Regional Workshop Group Reports – Summary of Discussions

APAC

- An alliance of patient organisations is more powerful to approach policy makers, and this also helps smaller patient organisations have a voice
- Potential to unify health policies/guidance to encourage greater equality across countries e.g. resources, access, treatments

US and Canada

- Patient organisations recognised issues regarding the funding and reimbursement of medication, especially in rare disease areas where fewer of the population are affected. This can mean that sometimes rare diseases do not get access to necessary funding which inevitably has an impact on resources, treatments, research, access

Europe

- Some patient groups within the wider population (e.g. older groups, those in rural areas, those without access) can have technical barriers to accessing online policy resources
- The patient community should be involved more in the decision-making process, with better access to policymaking at a national and regional level
- Multi- stakeholder partnering, as well as patient groups partnering across cultures/regions/borders

LATAM

- There is a lack of interest and funding by policymakers in research and better health resources. This must be addressed for patient organisations to have a voice
- An alliance between countries could improve visibility of issues and of disease areas

Middle East and Africa

- Opportunity to twin organisations in higher-income countries such as in Europe/US with low-income countries to share best practice
- Regional political instability is a challenge for patient groups – there is no one to turn to. There needs to be better education on knowing who else to contact for health policy implementation and change
- Lack of funding into research and treatments, especially in rare diseases
- There was discussion around the importance of the European Medicine Agency's (EMA) role in fostering the engagement between patient organisations and the pharma industry (e.g. clinical trials created with patient insights)
- To take tools and digital resources from the regional and country-level, and use these to better educate and implement change at the local level



Key Topic 4: Capability building & tools:

Capability building is vital for patient organisations to affect political and systemic change for their communities and improve the patient experience, regardless of disease area. The need for more effective multi-stakeholder collaboration between patient groups, national health authorities, and the public and private sector emerged as an important topic and the need for more cohesive working among these different groups to find a common goal that serves patients across many disease areas.

Patient groups are uniquely placed to gather real-world patient evidence and tell the story of living with a disease to educate other stakeholders of the wider impact this has on society. They also play a vital role in educating and empowering patients to be more actively involved in managing their disease to improve the quality of care.

The growing possibilities for digital and online tools can be harnessed to co-create tools for the community to meet these goals, potentially in partnership with multidisciplinary stakeholders. However, it is important to bear in mind that the availability and utilisation of digital tools vary between developed and middle- to low-income countries, and so an argument can be made for simplifying tools and resources here for maximum uptake and local impact.

Regional Workshop Group Reports – Summary of Discussions

APAC

- The need to share data and resources across therapy areas encourages the exchange of experiences by both the patient and healthcare professional communities. Need to promote sharing of information/data between hospitals, as hospitals may be likely to have greater digitalisation and resource access than the patient community

US & Canada

- Roche has helped pioneer digital tools in some patient communities in the US & Canada. More pharmaceutical companies should assist in the creation of resources and learning tools to assist the patient community

Europe

- Patient representatives emphasised the importance of best practice sharing across disease areas, to achieve wider education, build on the strengths, and experiences between regions and groups

LATAM

- In the LATAM region there is a greater need for multidisciplinary teams in the states and municipalities to adequately treat patients and improve the quality of care for patients
- Patient organisations recognise the value in educating patients to be co-participants in their treatment, there is a need to share information among patient groups
- Patient organisations have few people trained with regards to digital health tools literacy and this is a challenge.

Middle East and Africa

- Lack of reliable data, digital tools, and digital resources
- Patient organisations recognise the importance of capability building between patient organisations, i.e. patients teaching other patients



Feedback from the IEEPO global community

We are continuously engaging with the patient community to provide ongoing feedback to use these insights to inform future IEEPO events and make them as relevant and engaging as possible for the community.

At the time of writing, we have received over 160 responses from the patient community about the IEEPO kick-off events and THINK series. Key feedback includes:

- 98% of respondents rated the THINK panel webinar, 'Tomorrow today: Preparing for our future together' as 'good', 'very good' or 'excellent' and 90% of people rated the topics that were discussed as 'relevant' or 'very relevant' to their advocacy work.

- 98% of the community rated the 'In Conversation with Severin Schwan' session as 'good', 'very good' or 'excellent'.

"Severin Schwan has such a personality, simple and at the height of all, that it is very charming. Since IEEPO began, his assessments about patients and orgs related as important and valuable partnerships and collaborations encourage the community to make a difference in the patients' lives."



Patient organisation representative from Mexico

"What was discussed is very relevant to the work I do. The correct use of data is very important, in addition to being very rich to evaluate real life data that can impact the development of health improvements. So we have to find a balance and ensure the security of this data."



Patient organisation representative from Brazil

"Mr Schwan had a great appreciation for the bread and butter issues that affect patient organisations. Most important was his understanding that there is no one size fits all."



Patient organisation representative from Barbados

"The IEEPO Kick-off THINK event was an engaging and informative session which enabled patient advocates the opportunity to not only hear from Severin Schwan but to discuss relevant aspects of healthcare pertaining to individual countries and the role patient advocates play in improving outcomes."



Patient organisation representative from Australia

"This is one of the highlights of the year. It's amazing to hear what knowledge he possesses. It does not matter what question he gets, he can answer. He also does it professionally, objectively and calmly so that everyone can take part in his answers and understand."



Patient organisation representative from Sweden

"It was a deeply insightful talk because it showed that there is room for change. We are all conditioned by tradition and long-standing values, but I think that patient organisations can really work towards changing the vision of what healthcare is and should be in the future."



Patient organisation representative from Italy

- 72% of people rated the IEEPO Regional Workshops as 'good', 'very good' or 'excellent'.

Your chance to engage with the global IEEPO community

We would like to extend our thanks to the IEEPO External Advisory Committee and all the speakers who took part in IEEPO 2021 for their valuable insights and the patient community for their active contributions in making IEEPO 2021 a success.

At its heart, IEEPO is a global platform for community experience exchange, and we are proud to continue building this with you. Staying true to this mission, we invite you to engage with IEEPO in the following ways:

- Visit www.ieepo.com to watch the videos from the kick-off event.

- Shape the CHANGE domain by submitting a best practice poster to highlight initiatives that you have worked on in health policy.
- Please share with the community links and suggestions for the most valuable resources for patient communities that you have come across. We'll use this to create an easy-to-access library of materials that will be launched later this year under the LEARN domain.