



International Experience Exchange
with Patient Organisations

IEEPO 2021 'Think Global, Act Local', Transforming Healthcare Together Event Highlights Report

Entitled 'Think Global, Act Local: Uniting for Change, Transforming Healthcare Together', the IEEPO event focused on uniting and strengthening the voice of patients, who are advocating for healthcare system changes, how patients can have a 'seat at the table' in healthcare decision-making processes locally utilizing the global policy recommendations and call to actions of the IEEPO Position Paper to humanise healthcare.



IEEPO in Numbers

8th – 9th November 2021



274

Patient Group
Representatives

66

Countries
represented

43

Disease areas
represented

2

Panel
sessions

1 purpose: Unite to “Think Global, Act Local”
for transformational change

25

Regional break
out groups

Introduction

From the United States to Singapore, Germany to Australia, India to Brazil, patient organisations gathered from around the world to represent the views of the IEEPO patient community on how we can transform healthcare systems and launch the IEEPO Position Paper, *Humanising Healthcare: A call for transformational change*.

The event kicked off with a welcome and introduction from the event moderator, Bastian Hauck, Founder, #dedoc° Diabetes Online Community. This was promptly followed by a reflection of IEEPO's 2021 achievements, presented by former CEO of World Hepatitis Alliance and IEEPO Programme Chair, Raquel Peck. Finally, Roche CEO, Severin Schwan took

to the stage to thank patient communities for their long and constant partnership over the past 13 years of IEEPO. To meet the speakers from the ‘Think Global, Act Local’ event, visit [IEEPO.com](https://www.ieepo.com)

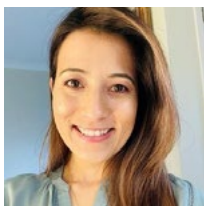


“As we celebrate our 125th year anniversary this year, IEEPO reminds us of what it is all about, it’s all about translating and turning cutting edge science technologies into benefits for patients.”

Severin Schwan, CEO, Roche



Bastian Hauck



Raquel Peck



Severin Schwan

Humanising Healthcare: A call for transformational change from the patient community

Introducing the IEEPO 2021 Position Paper

To translate vision into action and reality, the IEEPO External Advisory Committee (EAC) and the community co-created a [Position Paper](#) to agree how to credibly address (re)building trust in healthcare systems and humanising healthcare for all. The Paper contains an analysis of certain areas that the IEEPO community and the contributors see as pressing and in need for change. Most importantly, the Position Paper contains specific calls to action that sit within the following five chapters:



1 Putting people at the heart of healthcare



2 Humanising health literacy



3 Humanising digital healthcare to build capacity by harnessing the power of patient data



4 Humanising healthcare to focus on prevention and cure with a new 50:50 model



5 Prioritising diversity, equity and inclusion to humanise approaches to healthcare

The 'Think Global, Act Local' event welcomed Maira Caleffi, Founder and President of FEMAMA and IMAMA and member of IEEPO's External Advisory Committee (EAC) and Tamás Berczky, co-author of the IEEPO Position Paper, HIV Patient Advocate, Mental Health and Independent researcher, to share background and key outtakes from the Position Paper.

The IEEPO Position Paper was developed based on feedback and outcomes of a global patient survey conducted by IEEPO in 2021, plus additional content from individual contributors and expertise drawn from the IEEPO External Advisory Committee. During the session, Tamas highlighted three focus areas from the paper:



1

Humanised healthcare means putting people and patients at the heart of healthcare



2

Broader cooperation across patient groups, across stakeholder groups and the world is essential



3

The digital and data revolution in healthcare brings challenges and great opportunities for patients; new patterns of knowledge production and involvement emerging with patients in the driving seat.

What's next?

“The next step would be implementation of the calls to action and use feedback from the regional workshops to formulate your local action plan. We also hope to publish this in a scientific journal in 2022.”

Tamás Berczky

You can now read the full IEEPO 2021 Position Paper on ieepo.com and we encourage you to share the Paper within your own communities. The executive summary of the Position Paper is now available in the following languages: English, Simplified Chinese, Spanish, Portuguese, German, French, Italian. The translations for the full IEEPO Position Paper will be available at ieepo.com soon.

You can watch the IEEPO Position Paper discussion with Maira Caleffi & Tamás Berczky on demand on ieepo.com!

Humanising Healthcare: The Policy Perspective

In the policy panels moderated by Bastian Hauck, expert global speakers met to discuss and debate the key findings of the IEEPO Position Paper and how they could help change the health policy landscape at a global and local level, drawing on their own experiences.

The first debate focused on the humanisation and digitisation of healthcare with attendees highlighting in the event chat that accessibility to digital solutions needs to be solved in and across local healthcare realities.

Dykki Settle summarised findings from the **The Lancet and Financial Times Commission** which states that COVID-19 has fundamentally changed our relationship with digital forever, “Digital has become a new determinant of health that fundamentally impacts our human rights”. However, for digital to enable meaningful outcomes for patients, access to digital technology as well as broad systematic use and improved digital literacy must be prioritized.

Linked to digital, and putting patients at the heart of healthcare, the second panel discussed the need for enhanced trust, diversity and inclusion at all levels, as well as the importance of “meeting patients where they are” – geographically, culturally and linguistically. All panelists agreed that greater investment in a 50:50 healthcare funding model is essential. A greater focus should lie on prevention, better balanced investments in primary and secondary healthcare, underpinned by improved health literacy and HCP communication skills to help empower patients and improve self-care.

Want to know more about the 50:50 funding model? Read chapter 4 of the IEEPO Position Paper and listen to expert Bogi Eliason's keynote speech from the IEEPO THINK 'Kick off' event.



Bastian Hauck
Founder, #dedoc° and
IEEPO EAC member



Dykki Settle
Chief Digital Officer, PATH



Michael Oberreiter
Head of Global Access,
Roche



Niti Pall
President, International
Diabetes Federation



Ranjit Kaur
President, Breast Cancer
Welfare Association,
Malaysia and IEEPO
EAC member



Samuel Wiafe
Founder and Executive
Director, Rare Disease
Ghana Initiative



Maira Caleffi
Founder and President
of FEMAMA and IMAMA,
and IEEPO EAC member



Emilia Arrighi
Patient Advocacy and Health
Literacy expert, and Director
of La Universidad del Paciente
y la Familia (UPF)

Key highlights from the panel debate included the following statements and calls to action:



The **digital divide** should not worsen inequality, it must be utilised carefully to democratise and enhance healthcare via access and health literacy - Dykki Settle



Expert patient programmes whereby **patients train other patients** to help them self manage their conditions and improve self-care is an effective way to bridge language and trust barriers - Emilia Arrighi



Restructure financial models to reflect the 50:50 model, thus transforming primary and secondary healthcare in order to help provide the care where people need it most with a focus on prevention - Maira Caleffi



Patient organisations, often urban-based, need to go into outreach work, to get into rural areas to help with these challenges and act as a go between. Simple devices such as mobile phones are a very powerful tool in rural communities - Samuel Wiafe



Four things matter to consumers of healthcare, **“trust, empathy, expertise and information”** - Niti Pall



The existing 3P collaboration of **Public Private Partnerships** must be expanded to include **Patients** at the centre, therefore becoming the **4Ps**. The only way to ensure that healthcare Systems become more **diverse, inclusive and equitable** is by including Patients in the design and delivery of healthcare. *“Roche can be a catalyst for scalable solutions.”* - Michael Oberreiter.



We need language that patients speak, and others understand - if this is achieved, patients will then feel respected and able to trust. Geographical disparities and marginalised populations require different immersion techniques; “efforts should be made to respect different cultures.” - Ranjit Kaur

In conclusion, It was agreed that the patient community has an important role to play in every aspect of the decision making ecosystem, not only in helping to bridge the gap between patients and HCPs. Putting patients at the heart of healthcare means patients play an important

role in the transformation of healthcare systems. Underpinning this is access to healthcare both geographically as well via understandable language and collaborations with multiple stakeholders across the healthcare ecosystem.

“Humanising healthcare is a way to go. Doctors need to start speaking patients’ languages, the government must also play a role in helping NGOs with awareness advocacy and health care education.”

attendee joining from South Africa

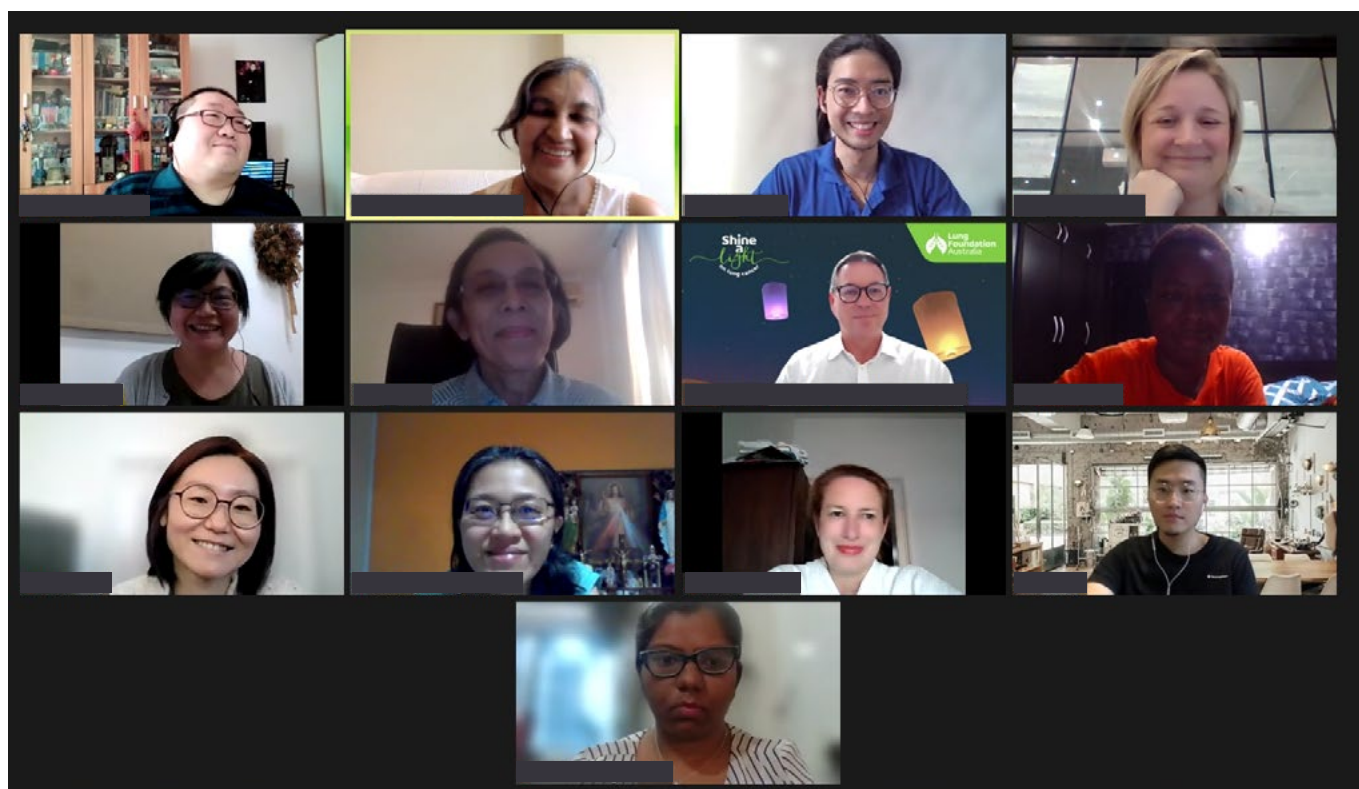
You can watch both Policy Panel sessions on demand on ieepo.com - here!

Humanising Healthcare: Insights from the IEEPO 2021 'Think Global, Act Local' Regional Workshops

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.

Participating patient group representatives discussed key topics from the IEEPO position paper with the aim of diving deeper into the paper for localised insight. Furthermore, the participants exchanged forward thinking practical approaches on how to leverage the position paper to engage in their local policy discussions.

More on the key insights from the different regional workshops to be found on ieepo.com through the IEEPO LEARN Library/Regional Insights document.



Echoing the panel debate, further key insights from across all regions are:



Collaboration is key: Leveraging the first chapter of the Position Paper, Putting people at the heart of healthcare, regions agreed that industry, policy and patient groups require stronger collaboration. They should leverage the collaborations to gain a seat at the table where decisions are made and be/become a convener for multi-stakeholder exchange and partnerships.

***For example:** Including patients in the development of clinical trials*



Exchange and Empowerment of patient organisations: Educate patient communities to enable greater understanding of scientific and digital/tech language and the policy landscape. Additional capacity and resource building is needed to help more patient communities become skilled and equal partners in co-creation processes, initiatives and decision making alongside all stakeholders.

***For example:** Educational and ambassadors/mentoring programs, more platforms for communication online like IEEPO, patient groups invited to scientific congresses and to be part of the research and solution development processes and their implementation*



Accessibility: It's imperative to translate scientific language into lay language, as well as utilising digital capabilities to make data accessible to all communities.

***For example:** Creating a glossary of terms, leverage mobile solutions, translating scientific language into secondary and tertiary native languages*

“Change won't happen overnight but if we unite for change, we will be able to transform our healthcare systems, together”

IEEPO External Advisory Committee (EAC)

Humanising Healthcare: Our goal is action!

We need to bridge the gap between global vision and grassroots action. The IEEPO Position Paper provides a global call to action for change within its recommendations, but it is up to local advocates to fight for that change locally. We have begun to 'Think Global', now we must 'Act Local'.



Useful resources:

IEEPO
Changemaker
video series &
how-to guides

IEEPO
poster
gallery

IEEPO
LEARN library

Personalised
Healthcare
Toolkit for
the Patient
Community

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.

