

EPF Congress 2022: *Continuing the Conversation on Digital Transformation*

The European Patients' Forum (EPF) held its second in-person European Congress. The event took place at the DoubleTree by Hilton Hotel, in Brussels (Belgium), between the 23rd and 24th of June, 2022. For those who wished to join remotely, the option of joining the live stream was available.

Having in mind the experience and lessons learned from the 2021 online Congress, this year's event included a wide audience of patient representatives, policymakers, health systems experts, healthcare profession representatives, academics, and industry representatives, from Europe and beyond.

The 2022 Congress was dedicated to exchanging ideas and good practices in patient empowerment and involvement, moving forward on the much-needed policy commitments in this area, gaining a greater and genuine understanding of the wealth of experiential knowledge and expertise that patients bring to health systems' design and strengthening, and much more.

After Radu Gănescu, EPF Treasurer, opened the Congress by outlining, in his opening address, how successful digital transformation of healthcare requires everyone involved in and around healthcare to change day-to-day habits, we welcomed the first keynote speech given by Stella Kyriakides, European Commissioner for Health and Food Safety, who was livestreamed virtually into the Congress. Stella Kyriakides established the context for and introduced the principles of European Health Data Space (EHDS), which aims to establish the right for patients not only to have digital access to their own health data, but to control how it is used, which parts are shared, see who has accessed their health data and help correct any inaccuracies.

Brief Sessions' Overview

The two-day event fostered meaningful dialogue and explored answers to some of the most burning questions, in terms of digital healthcare transformation.

Day 1, Thursday 23 June 2022

Plenary 1: European Health Data Space (23 June 2022; 13:30-14:45 CET)

How can the EHDS be designed and implemented in a patient-centred way?

During this plenary session, EPF's Director of Policy, Kaisa Immonen, together with speakers Peter Kapiten (Patient Advocate and Executive Board member of Inspire2Live), Dr. Mélodie Bernaux (French Ministry of Health), Martin Dorazil (Deputy Head of Unit, DG SANTE), and David Novillo Ortiz (WHO Regional Office for Europe) explored a wide range of perspectives from patients, the European Commission, and regulatory bodies. Key themes included what we can learn from best practice already in existence in EU

member states (e.g. France); how we can effectively use health data without compromising security of data and high standards of privacy in both primary and secondary use settings; the central importance of transparency and accessible communication to address health inequality and the 'hidden cost of no' – why we simply must share our data if we want to see improvements in quality of life.

Parallel Session 1: Artificial Intelligence in a “Serious Game” (23 June 2022; 15:15 – 16:45 CET)

Have you ever considered using Artificial Intelligence (AI) for medical purposes? What benefits and challenges could AI bring to patients?

By playing a Serious Game „AI-Hospital“, participants to this session simulated and learned about the implementation of AI technologies along patients’ journeys. The experiential session allowed delegates to imagine themselves in a variety of different scenarios and decide for or against the use of AI solutions, for/by patients, at each step.

Parallel Session 2: Electronic Product Information: How patients benefit from a digital version of medicine leaflets (23 June 2022; 15:15-16:45 CET)

What are the recent developments of Electronic Product Information (ePI)? What are ePI’s advantages and limitations?

In the second of the afternoon parallel sessions, Hannes Jarke, EPF, invited attendees to imagine a future where patient information could be electronic. Representatives from the European Medicines Agency (EMA), industry, academic and the patient community explored the multitude of ways that patients could benefit from a digital version of medicine leaflets and presented a prototype that should become a reality in early 2023 through a series of pilot projects. As citizens increasingly consume information about products in other areas of life online and digitally, the pressing need to provide electronic patient information is a priority for the EMA, with support from the multistakeholder initiative, PharmaLedger, paving the way for the industry.

Parallel Session 3: The Impact Of Digitalisation on Healthcare Professional/ Patient Relationship (23 June 2022; 15:15-16:45 CET)

Is digital health an enabler in the healthcare professional/patient relationship? Does the use of digital tools make collaboration more difficult?

This session explored the impact of digitalisation on the patient/healthcare professional environment. Throughout the discussion, many agreed that digitalisation is an enabler of change, but there are many challenges that we need to address for this to be truly transformative. From a healthcare professional perspective, data can be burdensome and ‘dehumanise’ the profession. For patients, health education and improving health literacy is important to enable improved joint-decision making, but many factors including socio-economic status and location make this challenging. Disconnection between digital health solutions and patients’ needs was a recurrent theme, highlighting the value and importance of co-creation between patient groups and health technology companies to deliver value-based tools to patients.

Plenary 2: Ethics and Artificial Intelligence (23 June 2022, 17:15 - 18:00 CET)

What are the ethical challenges that arise from data sharing, availability and volume of data needed to train AI tools?

In the closing plenary session of the day, EPF Executive Director, Anca Toma, interviewed speakers Victoria Prantauer, Patient Advocate and Co-Founder of Hippo AI Foundation and Dimitrios Athanasiou, EPF Board member and Board member of the World Duchenne Organization about the ethics of Artificial Intelligence (AI). Key themes of the lively discussion included how data should be valued and whether all patient data is of equal value, how bias can be moderated in AI and what constitutes 'good quality' data.

Day 2, Friday 24 June 2022

Plenary 3: Patients organizations' role in driving the work on Real World Data (RWD) and Real-World Evidence (RWE) (24 June 2022; 9.00-9.45 CET)

How can patient organisations contribute in driving the work on RWD and RWE?

The second day was kicked off with a plenary panel session on patient organisations' role in driving the work on Real-World Data (RWD) and Real-World Evidence (RWE) moderated by Valentina Strammiello, Head of Programs at EPF. Kristof Vanfraechem, founder and CEO of Data for Patients opened by addressing the patient organisation representatives in the room: *'You've been fighting for decades to have a seat at the table, your time is now – start loving the data topic now or you will hate it forever'*. This set the scene for a lively debate on how the value of patient-generated data can be better recognised in regulatory settings, how what is meant by 'patient involvement in research' can be clarified, and whether the volunteer and charity models upon which most patient organisations are structured needs to be revisited if patient organisations are expected to take an increasing leadership role in driving the health data economy.

Parallel Session 1: The Patients' Data Journey (24 June 2022; 10:00-11:30 CET)

Should patients always be given the choice and control over how their health data is used? Is it reasonable and acceptable that these uses are broadly permitted, with accountability, so that everyone can benefit from better health care?

Health data is useful for many different purposes. Some of these are directly related to patient care, such as continuity of care, monitoring health outcomes and safety. Other uses are made by healthcare organisations, public health agencies, health ministries and a wide range of academic and industry research organisations to uncover new knowledge or to develop innovative diagnostics and treatments. This panel session explored the dilemmas posed in the plenary session, with the increasing availability of electronic health data, complex data use regulation and a growing focus on citizen involvement in healthcare decision-making.

Parallel Session 2: Digital health technologies to address health inequalities – solutions for lower-income countries & marginalised groups' involvement? (24 June 2022; 10:00-11:30 CET)

Could we improve health equality by reducing inequalities in terms of digital technology access?

Health inequalities in lower-income countries, and more concretely in marginalised groups, happen due to a variety of socio-economic reasons, many of which are defined at the national and/or regional levels. In addition, groups who are already subject to disadvantages and worse health outcomes are also subject to digital exclusion. For that reason, this session discussed possible solutions to involve lower-income countries and marginalised groups in decisions about their care to address health inequalities.

Parallel Session 3: Data Saves Lives Toolkit- How can we support the patient data journey throughout the healthcare system to build public trust? (24 June 2022; 10:00-11:30 CET)

It is no exaggeration to say that wealth of health data has already transformed public health in some areas and has phenomenal potential. It could be used to help prevent illness, improve treatments and access to them, as well as reduce unnecessary deaths. There are already numerous examples of situations in which this has happened. This is just the start and the possibilities are infinite. To truly harness the power of health data, it needs to be safely stored, shared and used effectively. This session aimed to equip patient groups with the information and materials they need to become more confident in communicating about health data and to empower their members. The test and trial tools from the Data Saves Lives initiative Toolkit helped the participants to better understand how patient organisations can better communicate on digital health topics and exchanged ideas for an upcoming training Bootcamp to take place in October 2022.

Plenary 4: Digital Health Governance (24 June 2022; 12:00-12:45 CET)

Is data governance the key challenge in ensuring a digital transformation of healthcare that delivers for patients?

The final plenary session of the Congress saw Elizabeth Kasilingam, EPF Board member and Secretary General, EMSP, return to the stage to moderate a panel discussion on digital health governance. She was joined by Isabel Proano, EPF Board Member, Director of Policy and Communications at the European Federation of Allergies and Airways Diseases (EFA), Dipak Kalra, President of i-HD, and Victoria Prantauer, Patient Advocate and Co-Founder of Hippo AI Foundation. It was acknowledged the EHDS is transformative in its ambitions and its governance therefore needs to be robust and clear. This involves the establishment of an EHDS Board. The EPF is concerned that patients are not foreseen as a part of that Data Board and their involvement would be limited to topics where their input is seen as particularly of value. The panel explored how patients can be successfully integrated into the plans and by extension, with the rightful involvement of patient groups as core stakeholders, trust can be built in the new proposed systems.

Closing remarks

EPF hopes that the dialogue initiated during the 2022 Congress helped bring coherence to the concept of patient involvement in digital health, while extensively exploring patients' needs in terms of medical data sharing and security, data-driven personalised healthcare, AI usage in healthcare, and the role of new technologies in health literacy.

