2022 EPF Congress

Continuing the *conversation* on digital transformation

Summary report

Key statistics – EPF Congress 2022

150
PARTICIPANTS ONSITE

#2

#2 TWITTER TRENDING TOPIC IN BELGIUM

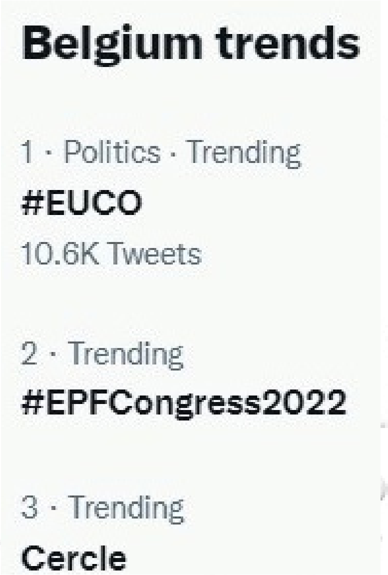
325

REGISTRANTS

2 EXCITING DAYS

40

SPEAKERS



Belgium trends

1 · Politics · Trending
#EUCO
10.6K Tweets

2 · Trending
#EPFCongress2022

3 · Trending
Cercle

Stella Kyriakides | @SKyriakidesEU
Twitter · 35 minutes ago · in English · Brussels, Belgium

Pleased to address #EPFCongress2022 today.

➡️🇪🇺 health policy is first and foremost about listening to patients and putting their needs first.

The building blocks of a strong #HealthUnion such as the European #HealthData Space will help to make this a reality.

Reflections on congresses past: the journey so far

Since EPF's first European Congress, held in 2019, a lot of things have changed. While the discussions in 2019 focused around patient centricity in the healthcare process, the 2021 debate moved into the digital realm, as the COVID-19 emphasised multiple vulnerabilities in the healthcare ecosystem.

Before diving deep into the 2022 Congress, let's have a look at the key takeaways from the previous Congress editions.

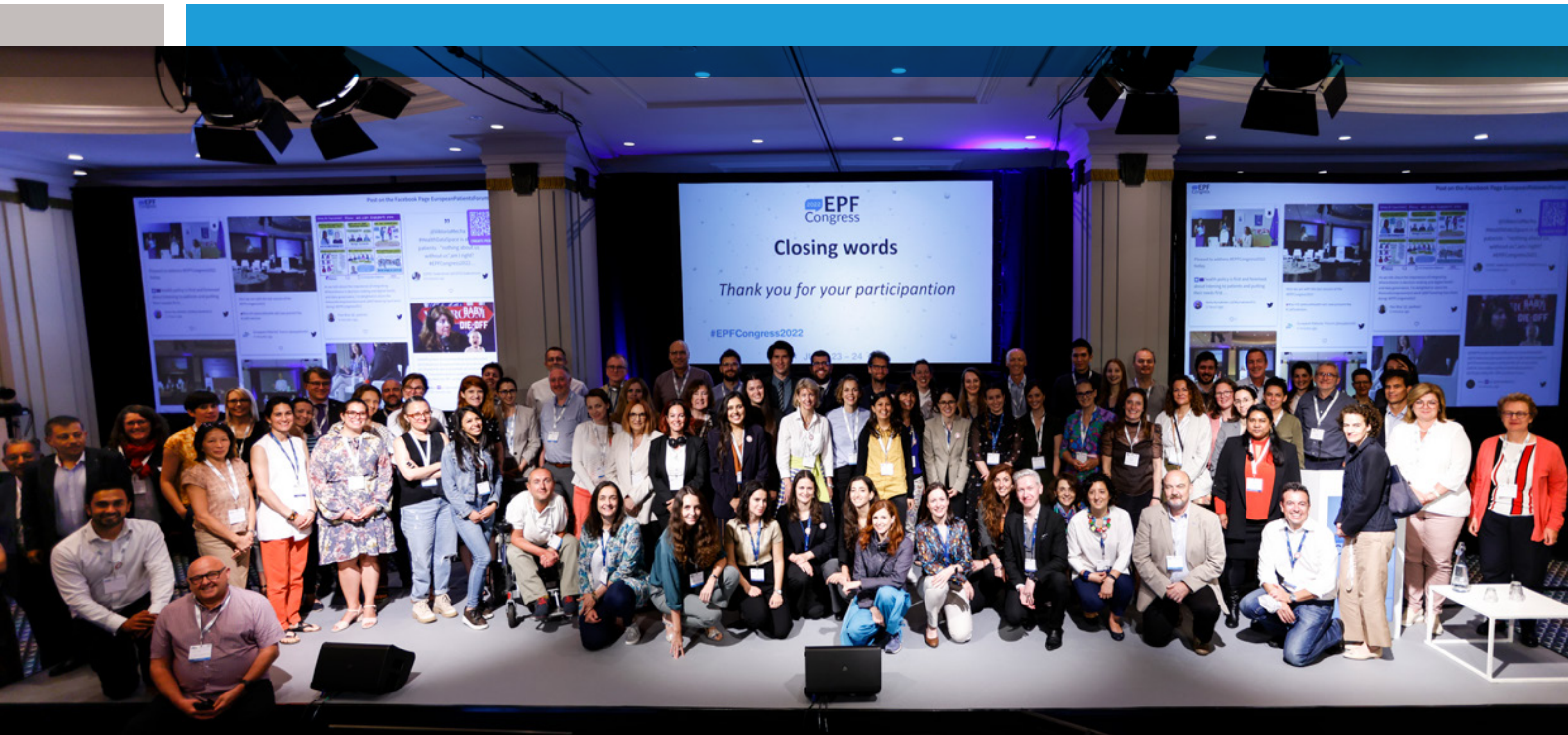
2019	2021
The evolution from 'chronic disease management' to 'participatory patient management' rightly puts the patient at the core	Education is essential to empowering patients and stakeholders
Patients are meaningful partners in knowledge	Co-creation with patients can completely change digital health
Shared decision making is the way to maximise value in healthcare	Trust is essential when working with patients

KEY TAKEAWAYS OVER THE YEARS:

2019:
Partnership

2021:
Education

2022:
Trust



Patients as partners in knowledge: the narrative shift

As the European Patients' Forum is approaching its 20th anniversary, we inevitably look back at how far we have come. What initially started as a 13 member organisation has become today an European umbrella organisation, gathering 78 members, from all disease areas.

Our growth has been steady and, throughout our journey so far, we have tried to observe, to learn, and to empower our members. Meeting representatives of member organisations was always inspirational and fruitful, in terms of actually understanding the needs of patients, regarding matters of healthcare policy.

That is why, in 2019, we decided to organise EPF's first ever European Congress. It created an unprecedented space for dialogue and growth, putting the patients in their rightful place – at the centre of the healthcare ecosystem. One of the key ideas that came to life following the 2019 Congress was that patients are (and should be treated as) partners in knowledge – for physicians and political factors alike.

Our plans for organising another in person Congress edition were detoured, when the COVID-19 pandemic struck in 2020. Therefore, in 2021 we held a full online Congress edition, and having in mind to organise a face-to-face follow-up event. The online edition of the Congress brought forth a paradigm shift. Patients had moved from passive recipients of treatment to partners in knowledge and, as we saw in 2021, they became more and more involved in the decision-making process for matters that concern them: health data sharing, equal access to medical services, and shaping the healthcare system future generations need.

Today, we set our attention towards creating a call for action on patient-driven digital health, compiling all the knowledge, insight, and experience we gather from the patients, experts and the many more who attended the two congress editions.

We envision a Europe where patient organisations are valued partners in creating equitable, person-centred, accessible, and sustainable healthcare systems, based on patients' unique expertise. Thank you to all of those who support our vision!

Grand opening

Co-hosts **Ivett Jakub**, former president of the EPF Youth Group, and **Tjasa Zajc**, podcaster at the Faces of Digital Health, welcomed delegates to the in-person and virtual EPF Congress 2022, acknowledging how special it was for everyone to be back together in person. They outlined how successful digital transformation of healthcare requires everyone involved in and around healthcare to open their minds and change their perspectives and day-to-day habits. Tjasa and Ivett concluded by emphasising the need for all stakeholders to join together to drive crucial but potentially challenging conversations.


Ivett Jakab


Tjasa Zajc


Radu Ganescu

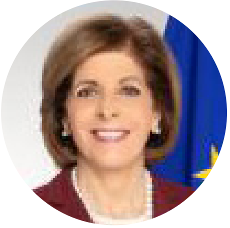
Radu Gănescu, EPF Treasurer, continued this theme in his welcoming address, acknowledging the challenges in coming together over the past two years. Following a quick recap on the four-day virtual event of 2021, he described how EPF aimed to take conversations about making digital health a central and integrated part of the healthcare system to a deeper and more actionable level over the next two days. As highlighted during the EPF Congress in October 2021, the digitalisation of healthcare can bring tremendous benefits for patients, but it also has its share of challenges – exacerbating inequalities, straining the traditional doctor-patient relationship, and raising concerns about consent and ethics. The 2022 Congress promised to continue these conversations to ensure that the digital transformation of healthcare works for patients.

Keynote address

Stella Kyriakides, European Commissioner for Health and Food Safety and a long-time advocate of the patient and caregiver community, began her keynote address by reinforcing the importance of involving patients in discussions and decisions regarding the future of healthcare: specifically in conversations about how industry should unleash the potential of healthcare data.

> **"To fundamentally improve health outcomes and the sustainability of local healthcare systems, patients must be at the centre of health data conversations. We need to empower people to take ownership of both their data and their care."**
> *Stella Kyriakides*

Against this background, the European Health Data Space (EHDS) was established to increase data availability, provide continuity of care across borders, and create a single European market for data. As a health-specific ecosystem comprised of rules, common standards and practices, infrastructures and a governance framework, the EHDS aims to establish the right for patients not only to have digital access to their health data, but to control how it is used. It also aims to provide patients with insight into which elements of their health data are shared and who accesses them as well as help to correct any inaccuracies.


Stella Kyriakides

Central to the EHDS proposal is the data protection by design principle. Data are provided in an anonymised format and can only be accessed and processed in closed and secure environments with the highest levels of cyber security. While it is an ambitious proposal, EHDS has the potential to create large pools of high-quality, interoperable data that could transform the development of registries and medicines – particularly for rare diseases, where data access is limited.

Stella Kyriakides closed her keynote address by describing the creation of a new EHDS board, where multi-stakeholders – including patients – collaborate to drive a healthier, more equal, and resilient society, where all EU citizens can benefit regardless of where they live. Its direct impact on patients means that representative organisations will have a significant role in educating patients and caregivers about the new EHDS and how to use it.

Paving the way for a healthier Europe

The EPF Strategic Plan, set up in 2021, will guide our work for the upcoming years, up to 2026. It brings a renewed approach towards advocacy, research participation, fundraising, a more vibrant communication plan, and an enhanced project engagement strategy. Amidst the ongoing COVID-19 pandemic, patients and the patient community are, more than ever before, key actors and contributors in creating equitable, person-centred, accessible, and sustainable healthcare systems in Europe.

We believe that both EPF's 2022 Congress and the two previous editions are important milestones in achieving our strategic goals, fully contributing to a safe space for dialogue that accommodates various perspectives and stakeholders.

For this report, we've gathered the different sessions, spread across the two exciting days of Congress, and listed them, and the discussions they generated under four of our five major strategic goals. With this approach we aim to offer our readers a better understanding of will offer readers a better understanding of the steps EPF is undertaking in order to reach our goals.

Strategic Goal #1:	Shaping A New European Agenda For Patients
Strategic Goal #2:	Meaningful patient involvement in co-creating better health policy, practice, research and education
Strategic Goal #3:	Digital Transformation That Delivers For Patients
Strategic Goal #4:	Accessing The Healthcare We Need With No Discrimination
Strategic Goal # 5:	Strengthening Patient Communities Across Europe

Watch the session video here

Strategic goal:
Shaping a new European agenda for patients
#1

THE EUROPEAN HEALTH DATA SPACE

Moderated by **Kaisa Immonen**, EPF Director of Policy, the first plenary panel session focused on the potential of the EHDS from different perspectives: **Peter Kapitein**, Patient Advocate and Founder of Inspire2Live shared his thoughts from a patient perspective, **Dr Melodie Bernaux** of the French Ministry of Health provided a national health authority perspective, and **David Novillo Ortiz**, Programme Manager, Digital Health, presented the view of the World Health Organization (WHO). They were also joined by **Martin Dorazil**, Deputy Head of Unit, DG Sante, to explain the key elements of the EHDS.


Peter Kapitein

First to present was **Peter Kapitein**, who believes that patients are willing to share their health data, but effective and responsible sharing is being limited by industry stakeholders. He invited the audience to look at examples from other industries, such as banking, for existing processes that enable the highly secure transfer and use of personal data and to apply the same principles to data sharing. To conclude, he asked delegates to make it their duty to facilitate health data infrastructure and the responsible sharing of health data.

> **"Doing nothing is not without consequences; there are always hidden costs of saying no."**
> *Peter Kapitein*

In her opening statement, **Dr Melodie Bernaux** explained how the French Ministry helped to pave the way for the EHDS. Following a study on digital health implementation in Europe, the French Ministry proposed 16 principles across four dimensions of digital health:


Dr Melodie Bernaux

- Placing digital health within a framework of humanist values.
- Enabling people to manage their own health data digitally.
- Developing inclusive digital health.
- Implementing eco-friendly digital health.

These European ethical principles were adopted with rapid consensus and will be used to facilitate discussions on the future European regulation on the European Health Data Space.

> **"The French Presidency was voted in under three principles: relaunch, strength and sense of belonging. These translate to the digital health space."**
> *Dr Melodie Bernaux*


David Novillo Ortiz

Dr Melodie Bernaux gave way to **David Novillo Ortiz**, who highlighted the importance of real-time data for guiding effective, timely and targeted decision-making during the COVID-19 pandemic and how we learned that health data interoperability is crucial to enable its effective use. Consequently, the WHO has issued a call to action on 'Better Data for Better Heath' in order to:

- Establish a national data coordination mechanism and implement a data governance framework.
- Invest in data and digital technology that can be useful for policymaking.
- Empower citizens to control the data they produce and develop their data skill sets.

David Novillo Ortiz explained that a regional digital health action plan to make patient involvement a reality is currently under review for the WHO European Region 2023–2030 and emphasised the importance of input from patient organisations.


Martin Dorazil

Martin Dorazil completed the panel presentations by providing an opening statement on the European Commission (EC) adoption of a proposal for the regulation of the EHDS in May 2022, aiming to:

- Empower individuals to access and control their personal health data.
- Unleash the data economy by fostering a genuine, single market for digital health services and products.
- Ensure a consistent framework for the reuse of health data for research innovation, policymaking and regulatory activities.

To conclude, he acknowledged the wide scope of the tasks ahead to implement the EHDS and the importance of trust in enabling its success.

> **"Infrastructure is one of the most important elements to get 'right' for this to work, for patients to be able to access their data in real-time, in a secure environment, in whatever country they are in."**
> *Martin Dorazil*

The second part of the session featured a panel discussion on how to build patient trust in the EHDS.

The panellists emphasised the importance of transparent and regular communication surrounding the use of health data for individual and societal benefit, but also the need of informing citizens about 'who' will be using their data is the most important factor in making patients feel comfortable about sharing their data. The conversation then turned to policymaking and the need to incorporate the patient voice when shaping solutions.

As the discussion concluded, panellists underlined the vast potential of health data and the importance of working together to not only unlock that potential but also to build trust, all the while keeping the end goal – improving citizens' and patients' quality of life – firmly in mind.

Watch the session video here

ETHICS AND ARTIFICIAL INTELLIGENCE

Fittingly, the concluding plenary session of the first day, was an interview-style debate with **Victoria Prantauer**, Patient Advocate and Co-Founder of Hippo AI Foundation, and **Dimitrios Athanasiou**, Board member of the EPF and the World Duchenne Organization, on the ethical implications of AI and data in health. The lively discussion explored themes such as how data should be valued, whether all patient data are of equal value, how bias can be moderated in AI, and what constitutes 'good quality' data.

Victoria Prantauer

The discussion began by the two participants exploring the value and monetisation of health data. To truly benefit patients and build their trust in data sharing, data should not be monetised or 'hoarded' in data siloes, it should be available for all and used for the common good. After this, the debate moved towards exploring the value of data and how open access to data could be a way to reduce inequality. Data sharing, both speakers concluded, is about building pathways to access new treatments and improving the management of diseases and quality of life.

Dimitrios Athanasiou

The conversation then turned to bias in AI, a technology that is only good as the data set on which it relies. The session concluded on two final points: the need to close the vast gap between the possibilities offered by existing AI technology and what's used in healthcare systems and the need for a data intermediary, a regulatory body charged with the standardisation, centralisation, and value of data that includes the patient perspective ensures that AI systems continue to contribute to the 'common good'.

Watch the session
video here

Strategic goal:
Meaningful patient involvement
in co-creating better health policy,
practice, research and education

#2

DIGITAL HEALTH GOVERNANCE

The final plenary session of the Congress saw **Elisabeth Kasillingam**, EPF Board Member and Secretary General, European Multiple Sclerosis Platform , moderating a panel discussion on digital health governance. Elisabeth Kasillingam was joined by **Isabel Proaño**, EPF Board Member, Director of Policy and Communications at the European Federation of Allergies and Airways Diseases (EFA), **Professor Dipak Kalra**, President of The European Institute for Innovation through Health Data, and **Victoria Prantauer**, Patient Advocate and Co-Founder of Hippo AI Foundation.


Elisabeth Kasillingam

To open the discussion, Isabel Proaño called for more inclusive governance that allows all healthcare stakeholders to be represented equally:

> **“The unique experience that patients can bring to inform health policy making is fundamental to human rights. There is a lot of real life in digital data.”**
> *Isabel Proaño*

While the EHDS is transformative in its ambitions, its governance must be robust and clear, and demands the creation of an EHDS board. As an EPF Board Member, Isabel Proaño shared the EPF’s concerns that patients will be excluded from the Data Board as the current regulation does not include permanent or mandatory inclusion of patients in EU-level and member-state level Data Boards.

Inclusivity proved a useful starting point for the panel discussion. Victoria Prantauer suggested introducing new terms such as ‘data justice’, defined as recognition of when injustice is happening, and ‘data solidarity’, an ongoing process of recognition and empowerment – to continually ask if we are truly being inclusive, whether we’re forgetting anyone in the data, who benefits from the data and who doesn’t.


Isabel Proaño


Dipak Kalra

Considering the EHDS, Dipak Kalra believes that the primary and secondary division of data is of critical importance. From the perspective of safe, quality care, he shared his excitement about mandating data interoperability and emphasising the importance of complete and accurate data. Patients must have easy, readable, friendly, free access to their data without delay and the ability to enter data into their health records. On the secondary use side, there is a strong proposal on behalf of society to advance care, but it’s limited by understanding how patient involvement can shape its use. However, this could be overcome by collaborating with PAGs.

Improving transparency and helping everyone understand how the data will serve individuals and society is fundamental.

> **“Regulators could take patients and patient representatives as the compass for legislation. Our role there, besides participating and actively shaping what is going to be there for us, is to be a watchdog for what happens.”**
> *Isabel Proaño*

To conclude, panellists agreed that the healthcare delivery system and the healthcare research system must take a multistakeholder approach to development. The patient voice has generally remained underrepresented (despite shining best-practice examples of patient involvement) so now governance should overcompensate for the historical failures to restore balance and build trust. Input is needed across all parties, including healthcare professionals, academics, industry partners, and governors.

Strategic goal:
Digital transformation that delivers for patients

#3

ELECTRONIC PRODUCT INFORMATION – HOW PATIENTS BENEFIT FROM A DIGITAL VERSION OF MEDICINE LEAFLETS

Hannes Jarke, Project Coordinator at EPF, moderated the first parallel session of the day, which focused on the multiple ways that patients could benefit from Electronic Product Information (ePI) – a digital version of medicine leaflets. ePI is authorised, statutory product information for human medicines (i.e. the summary of product characteristics, package leaflet and labelling) in a semi-structured format created using a common EU electronic standard.

Studies in Sweden (2014) and Finland (2020) report positive attitudes towards using an electronic form of PIL (41% and 63% respectively)


Juan Garcia Burgos

Juan Garcia Burgos, Head of Public and Stakeholders Engagement Department of the European Medicines Agency (EMA), began the discussion by explaining the regulatory environment for patient information. He emphasised that information about medicines is critical for citizens and patients. The way people consume this information should reflect the predominantly electronic nature of modern consumer behaviours. The EMA considers ePI essential to expanding public access and dissemination of unbiased, up-to-date, regulator-approved PI for all medicines in the EU, facilitating access to PI data across different regulatory procedures and tackling the increasing administrative burden of maintaining and updating traditional paper formats. However, to address access challenges and personal preferences, any proposed ePI should complement the paper leaflet, not replace it. It must also be multilingual, open access, and interoperable with ongoing EU eHealth initiatives.

His presentation gave way to **Ken Thursby** of MSD and also representing PharmaLedger, who presented an ePI demo to congress delegates.

> **"We think it starts with understanding the patient journey and realising that technology is not a silver bullet to solve all problems."**
> *Ken Thursby*


Ken Thursby

Demonstrating what a 'good' ePI looks like, Ken Thursby discussed the importance of engaging citizens in the prototype development process. PharmaLedger created a patient advisory group of eight chronic disease patients to understand what patients see as the most important product information. Over a series of interactive workshops, the group generated a list of ideas that patients would value over and above the paper PI.

The final speaker was **Jonila Gabrani**, Faculty of Medicine, University of Basel, Switzerland, and part of Gravitate Health, User Advisory Group. Jonila Gabrani presented healthcare provider views of ePI based on her research to identify motivators and barriers to implementing an ePI system. Overall, her study demonstrated general readiness among pharmacists to switch from paper to electronic formats.


Jonila Gabrani

90% of pharmacists in Belgium and Luxembourg agree to a complete switch from paper to electronic

However, her research identified some barriers to ePI implementation. These included accommodating the variation in patient (and provider) digital literacy, the slow adoption of new technology, the accessibility of smart devices, and the potential for hacking.


Steve Bourke

For the last part of the parallel session, the speakers were invited back for a panel discussion, with the addition of a new panellist, **Steve Bourke** of PersonalPulse. He had been involved in the PharmaLedger project and was able to represent the patient perspective. He began by describing how exhausting it can be for patients to navigate the complexities of their patient journey. Patients have no real involvement in their medication prescriptions, they are simply told what they will receive and the PIL comes with it.

> **"Patients should be able to access the information they need, at the time they want it, in a way that is accessible."**
> *Steve Bourke*

The panel members were asked to consider how people with low digital literacy could benefit from ePI. Ken Thursby began by making a case for the need for testing, a process where people are asked about their preference for paper or digital for specific projects. Jonila Gabrani clarified that we should examine how digital literacy and health literacy intersect. For example, a patient may have a high digital literacy (e.g., for online banking) but be poorly informed in health, or vice versa.

As opposed to just moving the paper content to digital, the group was challenged on the usability of the content itself. The panel members responded by saying that a digital tool would enable the industry to easily evolve the content and simplify the language over time, agreeing that this should be in the future scope of improvements to patient information. The panel also highlighted how digital formats could be used to promote a feedback loop from patients on the accessibility and comprehensibility of the language and content, as well as to report adverse events (AEs).

DSL TOOLKIT – HOW CAN WE SUPPORT THE PATIENT DATA JOURNEY THROUGHOUT THE HEALTHCARE SYSTEM TO BUILD PUBLIC TRUST?

Jessica Pacey, CEO of 67health and communications representative from the Data Saves Lives (DSL) team, opened up the session by introducing the DSL initiative. She went on to explain the purpose of this 90-minute session, namely, to explore how use of the Data Saves Lives toolkit can support the patient data journey throughout the healthcare system and build public trust. A key aim for the session was for PAG representative to gain a better understanding of what health data comprise and help them to communicate with confidence.


Jessica Pacey

This brief introduction was followed by an explanation of the key areas of the DSL toolkit. An interactive online poll gauged delegates' current attitudes to communicating about health data, their familiarity with the DSL initiative and the likelihood of their needing to communicate about health data now or in the future. The results were mixed: few delegates were very or somewhat familiar and many felt that they were not at all confident.

The delegates were then split into three different breakout sessions to examine a different challenge and area of the toolkit.

In group one, led by **Estefania Cordero**, Communications and Outreach Officer for Data Saves Lives, the discussion focused on how the community can feel more confident about engaging with digital tools. The group highlighted distrust and lack of transparency as key barriers to engaging in data driven initiatives, with some expressing concerns over not knowing how or where their data are being used. The group went on to examine the importance of co-creation and the need for patients to be central to and part of the data journey in order to build trust. Finally, the group came up with solutions on how to build public trust, with suggestions such as development of a code of conduct and sharing best practice.

Group two was led by **Lars Münter**, Head of International Projects Unit at the Danish Committee for Health Education. In this session, Lars Münter facilitated a discussion on the importance of communicating effectively with communities. This was demonstrated through an activity where the group brainstormed ideas on how best to communicate a health app to two different audiences: patients and HCPs. The group explored how the key messages and criteria differed for both audiences. Lars Münter closed the session by reinforcing that clear communication is vital to convince patients.


Lars Münter

Angela Bradshaw, Project Officer at Alzheimer's Europe, facilitated group three, which explored how PAGs can engage in potential opportunities and how the resulting partnerships can impact and reflect on an organisation. Using the DSL risk assessment tool, each member assessed different engagement opportunity scenarios for suitability for their organisation. Throughout the session, the group discussed the importance of trust and due diligence between groups and companies, core elements that need to be considered when making decisions. Finally, the group examined the unfair burden placed on PAGs to be fluent in technical jargon, and the requirement for researchers to understand and value the needs and experiences of the end user – the patient.


Angela Bradshaw

PARALLEL SESSION: ARTIFICIAL INTELLIGENCE IN A SERIOUS GAME

During the third parallel session that took place on the first day, **Stefan Phillips**, CEO of OneVision, led an interactive 90-minute workshop in which delegates took part in an educational game called 'AI-Hospital'. The session was designed to help delegates simulate and learn about the implementation of artificial intelligence (AI) technologies along patients' journeys, encouraging them to imagine themselves in various scenarios and decide for or against the use of AI solutions for patients at each step.

Stefan Phillips

This parallel session aligns with our capacity building work on AI, as part of the 'Understanding AI' webinar series. EPF aims to present complex technical content in an understandable and engaging way to equip the European patient community with the necessary know-how to shape and present the patient perspective on the new and increasingly important AI policy topics that are becoming an important field of policy discussions, both at European and national level.

The project has been supported by the European AI Fund, a collaborative initiative of the Network of European Foundations (NEF). The sole responsibility for the project lies with the organiser(s) and the content may not necessarily reflect the positions of European AI Fund, NEF or European AI Fund's Partner Foundations'.

THE PATIENTS' DATA JOURNEY


Cristian Andriciuc

Health data and health data sharing were certainly some of the most intensely debated topics at this year's Congress. This parallel session, presided over by Professor Dipak Kalra, the president of The European Institute for Innovation through Health Data (www.i-hd.eu). Together with panellists **Cristian Andriciuc** (Executive Coordinator for the Romanian Federation of Diabetes Associations), **Meni Styliadou** (VP Public Policy and Government Affairs – Takeda and Founder and Project Leader of the H2O), and **Maria Christofidou** (Researcher, i-HD; Ghent University) Dipak Kalra brought forth some very pressing questions regarding data sharing.


Meni Styliadou

The attendees were asked whether people should have absolute control over their data. People from the audience submitted their individual responses and the results were unsurprising: the majority of the people attending the session felt unsure over the absolute control over health data.

Starting from this in-house statistic, the panellists explored the EU regulations that define the ground rules for health data use: Data Protection (GDPR), Data Altruism, and European Health Data Space. The discussions were focused mainly on the practical implications of data ownership and what control would look like in practice. For example, patients might have to deal with several inquiries on their data privacy per day, each containing extensive information about what their data would be used for.


Maria Christofidou

Before concluding the session, the attendees were asked whether they had reconsidered their initial opinion on health data sharing. After briefly exploring the practical implications data ownership would have on patients, most of the people in the session had indeed changed their minds and considered that if data would be properly anonymised, approved bodies should be free to determine how the data can be used, without further interaction with the patients themselves.

While the session indicated that there are still a lot of questions pending over health data sharing and ownership, the panellist concluded that, in essence, having the exclusive right to control one's health data can in time become burdensome to patients.

Strategic goal:

Accessing the healthcare we need with no discrimination

#4

IMPACT OF DIGITALISATION ON THE HEALTHCARE PROFESSIONAL/ PATIENT RELATIONSHIP

David Somekh, Network Director at the European Health Futures Forum (EHFF), moderated an interactive workshop exploring the audience’s views on the use of digital tools and the impact on the power dynamic and role of healthcare professionals (HCPs) and patients.

David Somekh

In his opening speech, David Somekh introduced digital as an "enabler of change" in the industry. Patients expect digitalisation to lead to better outcomes and improved quality of life through self-management of chronic diseases, person-centred care, and empowerment and involvement in the care process as equal partners with HCPs. On the other hand, the health workforce is in transition, and countries will need to plan for new skills and roles such as coaching, shared decision-making, and advocacy to better address the needs of patients with chronic conditions. Naturally, these transformations will impact the existing patient/HCP relationship.

Papatya Alkan-Genca

Delegates were then introduced to two session co-hosts, **Papatya Alkan-Genca**, patient representative and Board member of the Turkish Spina Bifida Association and the International Federation for Spina Bifida and Hydrocephalus, and **Dr Ray Walley**, General practitioner and Vice-President of the Standing Committee of European Doctors (CPME). Their introductory remarks set the scene for the rest of the workshop, touching on the key concerns raised within the field of digital health. Namely, ethical issues surrounding the use of digital health data, patient and HCP willingness and motivation to use digital technologies, digital literacy, connecting patient data across borders, and wider security and legal risks.

Dr Ray Walley

Delegates were then split into different groups and asked to respond to a number of questions about digital health and identify any actions that could enhance patient/HCP relationships and collaboration. When asked about **digital health being an enabler in the patient/ HCP relationship** delegates responded with comments focused on the need for choice, balance and the need to make sure that no one is left behind.

In response to the question on whether the **use of digital tools makes collaboration more difficult**, delegates highlighted the need for education, continuity of care, and honesty in what digital health can provide.

DIGITAL HEALTH TECHNOLOGIES TO ADDRESS HEALTH INEQUALITIES – SOLUTIONS FOR LOWER-INCOME COUNTRIES & MARGINALISED GROUPS' INVOLVEMENT?

Kaisa Immonen, Director of Policy at EPF, moderated this parallel session, which explored how digital technologies can be used to reduce health inequalities in lower-income countries and marginalised groups. She outlined how health inequalities are often observed along a social gradient. These health inequalities are then compounded by disparities in access to healthcare, leading to the inverse care law:

> **"Those people who tend to need the most care will, in practice, receive the least care."**
> *Kaisa Immonen*

Ending her introductory speech, Kaisa Immonen highlighted the need for a patient-centred health data revolution.

Two further co-moderators were also introduced: **Ingrid Stegeman**, Programme Manager at EuroHealthNet, and **Natalia Maeva**, Chairman of the Board, Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH), who shared their introductory remarks, setting the scene for the rest of the parallel session.


Ingrid Stegeman

Ingrid Stegeman first introduced the work that EuroHealthNet does to promote health and health equity between and within European countries. She emphasised its focus on addressing the social determinants of health i.e., the conditions in which we are born, grow, work, live, age, and, more recently, how we access digital technologies. Digital technologies can reduce health inequalities if they are designed and applied to meet the needs of different population groups facing vulnerability, i.e., those who have the most to gain from their use.


Natalia Maeva

Delegates then heard from Natalia Maeva, who began by discussing Bulgaria's journey in developing a healthcare ecosystem that is open for private entrepreneurs and organisations and able to provide the technological and innovative tools and resources to create a value impact.

> **"70% of patients search online for health-related information before meeting their healthcare professional."**
> *Natalia Maeva*

Delegates were then split into two different groups to explore whether digital healthcare can impact vulnerable populations and whether digital health tools could diminish health inequities.

Group one began by defining the terms 'vulnerable' and 'digital health', while the second group explored whether digital tools are more of a barrier than an opportunity to healthcare access and whether we, as an industry, have asked vulnerable patients what they truly need. A representative from each group then presented the outcomes of the group discussions.

Watch the session video here

Strategic goal:
Strengthening patient communities across Europe

#5

PATIENTS ORGANISATIONS' ROLE IN DRIVING THE WORK ON REAL-WORLD DATA (RWD) AND REAL-WORLD EVIDENCE (RWE)

Co-hosts Ivett Jakub and Tjasa Zajc opened the second day of congress by introducing **Valentina Strammiello**, Head of Programmes at EPF, who facilitated a panel discussion between **Kristof Vanfraechem**, Founder and CEO of Data for Patients, **Elisabeth Kasillingam**, EPF Board member and Secretary General, EMSP, **Xavier Kurz, Head** of Data Analytics at EMA, and **Emile Schokker**, Head of Real-World Solutions EMEA at IQVIA.

Kristof Vanfraechem kicked off the panel discussion by directly addressing the patient organisation representatives in attendance:

Kristof Vanfraechem

> "You've been fighting for decades to have a seat at the table; your time is now - start loving the data topic, or you will hate it forever."
> *Kristof Vanfraechem*

Presenting an overview of how various stakeholders in healthcare systems have changed in response to hybrid and digital health solutions, Kristof Vanfraechem highlighted the importance of building patient trust in remote care systems to make them comfortable when sharing their data in new ways. PAGs have a fundamental role in supporting patients and providing insights into patient care at home versus at the clinic.

This set the scene for a lively debate on how the value of patient-generated data can be better recognised in regulatory settings, what is meant by 'patient involvement in research', and whether the volunteer and charity model structures of most patient organisations need to be revisited if these organisations become increasingly involved in leading the health data economy. According to Emile Schokker:

> "Patients bring dedication and commitment. Patient organisations bundle this energy and build infrastructure to channel it into something productive."

Elisabeth Kasillingam called for greater clarity and structure for patient organisations' involvement in research and care. Although there is acceptance that patient organisations should have a seat at the table, work is still needed to make them an equal partner in discussions.

Elisabeth Kasillingam

Panellists agreed that the industry is missing an appropriate framework to empower patients and caregivers to share RWD

Xavier Kurz

> **“In the healthcare ecosystem, the siloes do not have much practice in collaborating and partnering for the sake of patients – but patients themselves work across the ecosystem. They have to. All their organs are in one body.”**
> *Xavier Kurz*

effectively – a greater focus on harmonising interoperable data to answer scientific questions is needed. As highlighted by Xavier Kurz, regulators also need comparable data to make fair assessments of new healthcare innovations.

There was also universal agreement that patient organisations have a crucial role in supporting collaboration and partnerships between siloes in the healthcare system, but lack of resources and competing priorities means they cannot achieve this alone. Therefore, proposals need to be co-financed by profit-making organisations. If patient organisations are expected to play a greater leadership role in the health data economy, then we may need to revisit how groups are organised.


Emile Schokker

Emile Schokker closed the discussion by suggesting that the potential need to adjust the boundaries regarding ‘acceptable’ data to become more inclusive of the wealth of data, such as that gathered by IQVIA, available across different settings. At the same time, patient organisations have an important role in advising the EMA on the feasibility of data collection and guide it on the sensitivities and patient-reported outcomes that are achievable.

Concluding reflections and next steps

A**nca Toma**, EPF Executive Director, closed the Congress by commenting that trust, collaboration, and sharing were recurrent themes across the two days and emphasised that digital transformation will not happen without involving the patient community. She thanked everyone who had travelled to Brussels and thanked all those involved in making the event possible.

She closed with a final teaser – highlighting that next year, the EPF is turning 20. As such, the EPF plans to host a policy event to celebrate its 20th anniversary year.

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