

Programme

EPF Congress 2021

26 – 29 October 2021
Virtual Event


Day One: 26 October

13:00 – 13:15 CET	<p>Grand Opening of the EPF Congress 2021</p> <p>EPF is pleased to launch its EPF Congress 2021 on the digital transformation of healthcare with a short opening session.</p> <p>Welcoming Address</p> <ul style="list-style-type: none"> • <i>Marco Greco, President, European Patients' Forum (EPF)</i> <p>Followed by a short introduction of our Congress co-hosts:</p> <ul style="list-style-type: none"> • <i>Ivett Jakab, President, EPF Youth Group</i> • <i>Tjasa Zajc, Podcaster, Faces of Digital Health</i>
13:15 – 14:15 CET	<p>PLENARY: The digitalisation of health and care systems in light of COVID-19: what way forward and which role for patients?</p> <p>Opening Address by <i>Dr Hans Kluge, Regional Director, WHO Europe</i></p> <p>Keynote Speech: Are our health systems ready for patient-centred digital health?</p> <ul style="list-style-type: none"> • <i>Dana Lewis, Founder, OpenAPS</i> <p>Panel Discussion: Different Perspectives – One Vision Moderated by <i>Tjasa Zajc, Podcaster, Faces of Digital Health</i></p> <ul style="list-style-type: none"> • <i>Dana Lewis, Founder, OpenAPS</i> • <i>Michelangelo Canzoneri, Global Head of Digital and Data, Healthcare, Merck</i> • <i>Clayton Hamilton, Regional Adviser, Digital Health Flagship, World Health Organization Regional Office</i> <p>Followed by an interactive discussion with the audience</p> <p>Session wrap up by <i>Tjasa Zajc</i>.</p>
14:15 – 14:45 CET	<p><i>Coffee Break & Exhibition Booths</i></p>

14:45 – 15:45 CET	<p>Special Session: Patients' health data sharing: perspectives, risks and key concepts</p> <p>This session will explore the best ways to keep data donors adequately informed of the risks and benefits before and after they share their data. It will also highlight the importance of finding the right balance between striving for excellent data protection and enabling the benefits from data to be realised. Lastly, it will also review the current state of data protection, and will focus on the implementation challenges (e.g. GDPR), the potential impact on patients' lives, and how to improve it at both the policy and implementation level.</p> <p>Panel Discussion: Trust, Transparency and the Current State of Data Protection Moderated by <i>Dipak Kalra, President, The European Institute for Innovation through Health Data (i~HD)</i></p> <ul style="list-style-type: none"> • <i>Petra Wilson, Managing Director, HealthConnect Partners</i> • <i>Kees van Bochove, Founder, The Hyve</i> • <i>Patrik Puljić, Young people's representative, European Multiple Sclerosis Platform (EMSP)</i> <p>Followed by an interactive discussion with the audience</p> <p>Session wrap up by Dipak Kalra.</p>
15:45 – 16:00 CET	<p><i>Coffee Break & Exhibition Booths</i></p>
16:00 – 17:00 CET	<p>Special Session: Our Health in our Hands: the role of mobile health (and digital therapeutics) to improve patients' control of their healthcare</p> <p>mHealth apps are playing an increasingly role in the digital health panorama but how can we ensure that patients access to the right applications and know more about benefits and risks? This session will help participants understand the role of mHealth as a tool to empower and involve patients and provide some recommendations for policy making.</p> <p>Panel Discussion: Empowering patients through mHealth Moderated by <i>Lyudmil Ninov, Senior Programme Officer, EPF</i></p> <ul style="list-style-type: none"> • <i>Petra Hoogendoorn, Strategic digital transformation of health and care entrepreneur, Leiden University Medical Center</i> • <i>Angel Martin, Senior Director Digital Health & Taxation Advocacy EMEA, Johnson & Johnson</i> • <i>Antanas Montvila, Vice President, European Junior Doctors Association</i> <p>Followed by an interactive discussion with the audience</p> <p>Session wrap up by Lyudmil Ninov</p>
17:00 – 17:30 CET	<p>Projects/Initiatives Video Presentations</p> <p>Flash presentations by our projects and sponsors (initiatives) Videos will also be available on the virtual exhibition booths.</p>
17:30 – 17:45 CET	<p>Day One – Closing Discussion</p> <p>Discuss and recap in the key outcomes of the day with a Congress guest.</p>
17:45 – 18:15 CET	<p>Virtual Concert</p> <p>Italian band <i>Malazùr</i> will play a live set of Gypsy Jazz to end the first day and offer a smooth and relaxing start to the evening.</p>

Day Two: 27 October



<p>10:00 – 10:15 CET</p>	<p>Day Two: Opening Address</p> <p>Opening address by our Congress co-hosts:</p> <ul style="list-style-type: none"> • <i>Ivett Jakab, President, EPF Youth Group</i> • <i>Tjasa Zajc, Podcaster, Faces of Digital Health</i>
<p>10:15 – 11:15 CET</p>	<p>Special Session: Patients and healthcare professionals: a partnership for and through digital health</p> <p>Digital Health has transformed healthcare provision in ways that were unthinkable just twenty years ago. From telemedicine to self-management, using apps and monitoring health data, developments have taken a massive leap – but what does this mean for patients? While the possibilities are vast, patients must understand the tools they have available and the benefits and risks that come with them. This session will give an overview of recent developments in digital health and, the benefits for patients, and will explore what that means for the interaction between healthcare providers and patients. It will conclude with recommendations for the use of digital health with a patient perspective in mind.</p> <p>Panel Discussion: Guiding Patients through the digital River Styx Moderated by Prof. <i>Nick Guldemon, Senior Researcher, Leiden University Medical Center</i></p> <ul style="list-style-type: none"> • <i>Danielle Drachmann, Executive Director, Ketotic Hypoglycemia International</i> • <i>Annabel Seebohm, Secretary General, General Committee of European Doctors (CPME)</i> • <i>Chloe Leebos, Vice Chair, European Affairs, EPSA</i> <p>Followed by an interactive discussion with the audience</p> <p>Session wrap up by Prof Nick Guldemon</p>
<p>11:15 – 11:45 CET</p>	<p><i>Coffee Break & Exhibition Booths</i></p>
<p>11:45 – 12:45 CET</p>	<p>Special Session: Accessing digital health: from reimbursement to the digital divide</p> <p>While digital health can offer new opportunities to patients, access to digital health is still fragmented and affected by different factors, from prices to usability to even basic digital barriers such as literacy or lack of infrastructure. This session will explore the factors that contribute to creating or exacerbating the access gap, including skills to assess digital health technologies, reimbursement methodologies and provide examples of good practices to address these issues.</p> <p>Keynote Speech</p> <ul style="list-style-type: none"> • <i>Corinna Hartrampf, Senior Policy Officer, International Association of Mutual Benefit Societies (AIM)</i> <p>Panel Discussion: Bridging the Digital Gap Moderated by <i>Neil Bertelsen, Past Chair, HTAi Patient and Citizen Involvement Interest Group</i></p>

	<ul style="list-style-type: none"> • <i>Bleddyn Rees, Chair, The Digital Health Society</i> • <i>Paola Kruger, Patient Advocate, EUPATI</i> • <i>Ana Toledo-Chávarri, Coordinator for the Patient Involvement Strategy, Spanish Network of Agencies for Assessing National Health System Technologies and Performance (RedETS)</i> • <i>Corinna Hartrampf, Senior Policy Officer, International Association of Mutual Benefit Societies (AIM)</i> <p>Followed by an interactive discussion with the audience</p> <p>Session wrap up by Neil Bertelsen</p>
12:45 - 13:00 CET	Coffee Break & Exhibition Booths
13:00 - 14:00 CET	<p>PLENARY - Discussing Health Data between access, control and ownership</p> <p> Co-led with the BMJ</p> <p>Patients' Access, control and ownership of health data remains key topics to address to harness health data for better patients' care. This plenary session will focus on discussing these three topics in terms of pros, cons, challenges and impact on patients' lives .</p> <p>Keynote Speech on EU/global progress towards providing patients with access to, ownership of and control of their full EHRs</p> <ul style="list-style-type: none"> • <i>Maria Hägglund, senior lecturer in Implementation Science at Uppsala MedTech Science & Innovation, and Keane OpenNotes Scholar and lecturer on Medicine at Harvard Medical School.</i> <p>Panel Discussion: Command and Control of Health Data Moderated by <i>Henry Scowcroft, Patient Editor, BMJ</i></p> <ul style="list-style-type: none"> • <i>Maria Hägglund, senior lecturer in Implementation Science at Uppsala MedTech Science & Innovation, and Keane OpenNotes Scholar and lecturer on Medicine at Harvard Medical School.</i> • <i>Tessa Richards, Senior Editor, Patient partnerships, BMJ</i> • <i>Angela Coulter, Freelance researcher and member of BMJ patient advisory panel</i> • <i>Emma Doble, Patient Editor, BMJ</i> <p>Followed by an interactive discussion with the audience</p> <p>Session wrap up by Henry Scowcroft</p>
14:00 - 14:30 CET	<p>Projects/Initiatives Video Presentations</p> <p>Flash presentations by our projects and sponsors (initiatives) Videos will also be available on the virtual exhibition booths.</p>
14:30 - 14:45 CET	<p>Day Two - Closing Discussion</p> <p>Discuss and recap in the key outcomes of the day with a Congress guest.</p>

<p>15:00 – 16:30 CET</p>	<p>Virtual Hangout with the EPF Youth Group on Zoom</p> <p>Congress participants are invited to join the EPF Youth Group for a separate networking session on Zoom to unwind, have fun and discuss some of the Congress themes.</p> <p>Register here: https://us06web.zoom.us/meeting/register/tZEuf-CprT8tHNNg_TczR3zehmh1fOTsiYD8</p>
<p>19:15 – 20:30 CET</p>	<p>STYPA x EPF Youth Group Night Session <i>How and why to engage young patients in patient organisations in a digital era.</i></p> <p>Keynote Speeches:</p> <ul style="list-style-type: none"> • <i>Ivett Jakab, President, EPF Youth Group</i> • <i>Nathalie Bere, Patient Engagement, European Medicines Agency (EMA)</i> <p>Breakout Sessions & Interactive Discussions</p> <ul style="list-style-type: none"> • Hosted by <i>STYPA team leaders and YG members</i> • <i>All participants</i> <p>Register here: https://us06web.zoom.us/meeting/register/tZ0ocQsrszosHNTujEjKUZfgri222MXWywkR</p>


Day Three – 28 October

<p>14:30 – 14:45 CET</p>	<p>Day Three Opening Announcements</p> <p>A short introduction from our Congress co-hosts:</p> <ul style="list-style-type: none"> • <i>Ivett Jakab, President, EPF Youth Group</i> • <i>Tjasa Zajc, Podcaster, Faces of Digital Health</i>
<p>14:45 – 15:45 CET</p>	<p>Special Session: Improving medicine innovation through better use of health data: Big Data and real-world evidence</p> <p>Using health data more effectively can play a crucial role in medicine innovation to develop safer and better medicines that target patients' unmet needs in a more efficient way. In this session we will look at developments in this fast-evolving area, with a spotlight on the role of patients. The session will look at the promises and challenges of big data and real-world data/evidence in the innovation chain, including perspectives from patients, medicines regulators, national policymakers, and industry.</p> <p>Panel Discussion: Trust, Transparency and the Current State of Data Protection Moderated by <i>Kaisa Immonen, Director of Policy, EPF</i></p> <ul style="list-style-type: none"> • <i>Elisabeth Vroom, Founder, Duchenne Parent Project</i> • <i>Peter Arlett, Head of Data Analytics and Methods Taskforce, European Medicine Agency</i> • <i>Martina von Meyenn, Global Medical Chapter Lead, Real World Evidence, Roche</i> <p>Followed by an interactive discussion with the audience</p>

	<p>Session wrap up by Kaisa Immonen</p>
15:45 - 16:00 CET	Coffee Break & Exhibition Booths
16:00 - 17:00 CET	<p>Special Session: Artificial Intelligence in Healthcare</p> <p>Artificial Intelligence (AI) has enormous potential for strengthening the delivery of healthcare and medicines and helping the world to achieve better healthcare, but AI comes with risks and challenges. In this session we will build on EPF's work on AI, through the AI NEF Fund, to explore current state of play, assess risk, ethical challenges and look at the patients' perspective and needs on the role of AI in healthcare.</p> <p>Panel Discussion: Ethics and governance implications of AI in healthcare Moderated by <i>Anca Petre, CEO, 23 Consulting</i></p> <ul style="list-style-type: none"> • <i>Janek Kapper, Founder, Estonian Inflammatory Bowel Disease Society</i> • <i>Sameer Pujari, Acting Head of the Unit, WHO's Department of Digital Health and Innovation</i> • <i>Rintje Agricola, Orthopaedic Surgeon, Department of Orthopaedic Surgery, Anna Ziekenhuis, Geldrop/Eindhoven, the Netherlands</i> <p>Followed by an interactive discussion with the audience</p> <p>Session wrap up by Anca Petre</p>
17:00 - 18:05 CET	<p>PLENARY: Patients as co-designers and co-innovators: between theory and practice</p>   <p>Co-led with EIT Health</p> <p>Patients play a crucial role in the development of digital health solutions. Without their involvement, innovative solutions might not address true unmet needs and may potentially remain unused or even harm patients.</p> <p>This session will look at the role of patients as innovators and co-innovators, with best practice examples + gaps and opportunities. It will consider how policy can facilitate and incentivise co-ideation and co-design. Lastly, it will discuss the acceleration of health digitalisation during the COVID-19 pandemic, what can be learnt from this and what the future should look like (à Future of Europe).</p> <p>Live Poll & Pitch Session: Patients as co-innovators Moderated by <i>Nicola Bedlington, Special Adviser, EPF</i></p> <ul style="list-style-type: none"> • <i>Jaume Puig, Co-founder & CEO, Biel Glasses</i> • <i>Dr Esther Murphy, Research Fellow, School of Nursing & Midwifery, Trinity College Dublin</i> <p>Panel Discussion: Challenges of Co-Creation in Digital Health Moderated by <i>Nicola Bedlington, Special Adviser, EPF</i></p> <ul style="list-style-type: none"> • <i>Jan-Philipp Beck, CEO EIT Health</i> • <i>Signe Ratso, Deputy DG for Open Innovation, European Commission</i> • <i>Jaume Puig, Co-founder & CEO - Father of Biel, Biel Glasses</i> • <i>Dr Esther Murphy, Research Fellow, School of Nursing & Midwifery, Trinity College Dublin</i>

	<ul style="list-style-type: none"> • <i>Mei Lin Yap, Digi-ID Citizen Advisory Panelist, Trinity Centre for Ageing & Intellectual Disability Ambassador Liaison Officer</i> <p>Followed by an interactive discussion with the audience</p> <p>Plenary wrap-up by Nicola Bedlington</p>
18:05 - 18:20 CET	<p>Day Three - Closing Discussion</p> <p>Discuss and recap in the key outcomes of the day with a Congress guest.</p>
18:20 - 18:50 CET	<p>Virtual Concert</p> <p>Italian band <i>I SHOTA MAN</i> plays a live set of blues and folk music to ease guests into the evening.</p>

Day Four: 29 October

10:00 - 10:15 CET	<p>Day Four: Opening Announcements</p> <p>A short introduction from our Congress co-hosts:</p> <ul style="list-style-type: none"> • <i>Ivett Jakab, President, EPF Youth Group</i> • <i>Tjasa Zajc, Podcaster, Faces of Digital Health</i>
10:15 - 11:15 CET	<p>Special Session: The road to patient empowerment - Data & Digital health literacy</p>  <p>Through describing the objectives and strategy of Data Saves Lives, the session will highlight how we can improve digital health data literacy in collaboration with patient organizations, healthcare professionals and policy-makers, addressing the different needs of such groups and the best practices through which these should be addressed. By doing so, it seeks to underscore and spread awareness of how improved health outcomes and healthier populations can be attained from the processes of safe health data-sharing</p> <p>Presentations</p> <ul style="list-style-type: none"> • <i>Data Saves Lives Video introduction</i> • <i>Kristine Sørensen, Founder, Global Health Literacy Academy</i> • <i>Birgit Bauer, Digital Health Consultant, Manufaktur für Antworten</i> <p>Panel Discussion: Harnessing the Power and Potential of Health Data Moderated by <i>Jessica Pacey, CEO, 67 Health</i></p> <ul style="list-style-type: none"> • <i>Nick Schneider, Head of Division 511, Ministry of Health Germany</i> • <i>Borislava Ananieva, European Patients Forum</i> • <i>Sheila Khawaja, Principal, Ripple Effects Communications</i> • <i>Ales Bourek, CEO, Masaryk University Faculty of Medicine</i> • <i>Angela Bradshaw, Project Officer, Alzheimer Europe</i> <p>Followed by an interactive discussion with the audience</p>

	Session wrap up by Jessica Pacey
11:15 – 11:45 CET	Coffee Break & Exhibition Booths
11:45 – 12:45 CET	<p>Special Session: Safer digital health: how to ensure it at European level</p> <p>Digital health products must be easy to use, accessible and most of all safe. In this section we should look at how to ensure that commercialised products are assessed and tested to avoid possible harm, what role can patients have in this. Furthermore, in case of harm, how can we look at liability in the context of Digital health? Can the Medical Devices Regulation contribute to inform HTA? What role for EU level HTA?</p> <p>Keynote Speech</p> <ul style="list-style-type: none"> • <i>Rosanna Tarricone, Associate Dean, SDA Bocconi School of Management</i> <p>Panel Discussion: Understanding the State of Play Moderated by <i>Valentina Strammiello, Head of Programmes, EPF</i></p> <ul style="list-style-type: none"> • <i>Papatya Alkan Genka, Board Member, International Federation for Spina Bifida and Hydrocephalus</i> • <i>Oliver Bisazza, Director General, Industrial Policies, MedTech Europe</i> • <i>Flora Giorgio, Deputy Head of Unit, European Commission</i> • <i>Rosanna Tarricone, Associate Dean, SDA Bocconi School of Management</i> <p>Followed by an interactive discussion with the audience</p> <p>Session wrap up by Valentina Strammiello</p>
12:45 – 13:00 CET	Coffee Break & Exhibition Booths
13:00 – 14:00 CET	<p>PLENARY – Shaping A European Health Data Space With And For Patients</p> <p>The European Health Data Space can represent a key milestone for health data and digital health policy at EU level. It is therefore a unique opportunity to build it with the patients and keeping all patients needs in mind. In this session, we will look at the EHDS development state of play and discuss how to shape it in partnership with patients, also building on the key learnings from the EPF Congress debates.</p> <p>Panel Discussion: Contributing to the success of the EHDS Moderated by <i>Petra Wilson, Managing Director, HealthConnect Partners</i></p> <ul style="list-style-type: none"> • <i>Toni Andreu, Scientific Director, EATRIS</i> • <i>Cecilia Bonefeld-Dahl, Director General, DIGITALEUROPE</i> • <i>Ioana-Maria Gligor, Head of Unit, European Commission</i> <p>Followed by an interactive discussion with the audience</p> <p>Session wrap up by Petra Wilson</p>
14:00 – 14:30 CET	<p>EPF Congress 2021 Closing Address</p> <p>EPF President Marco Greco will close the Congress with a recap of the key takeaways from the previous four days and announce the follow-up, in-person Congress from 21-22 April 2022 in Brussels, Belgium.</p>

Thanks for joining the EPF Congress 2021!