

## Programme EPF Congress

12-14 November 2019

Crowne Plaza Le Palace, Place Rogier, Brussels

Day 1: 12 November

8:30 - 12:30	<p><b>Hackathon – Enabling Patient Involvement while managing interests and relationships with multiple stakeholders</b></p> <p>EPF is pleased to be featuring a hackathon as an integral part of our Congress programme. The hackathon will focus on the problem of enabling meaningful patient involvement, whilst managing differing and sometimes diverging interests of health stakeholders. It will involve multi-disciplinary teams, led by patient representatives. Participants will be selected according to criteria agreed by the Advisory Board.</p> <p>By the end of the hackathon, participants will have better understanding of potential conflict of interest issues from a multi-stakeholder perspective and having engaged in the process hackathon participants will:</p> <ul style="list-style-type: none"> <li>▪ Understand the dynamics of trust building between actors;</li> <li>▪ Develop collaborative solutions to drive and nurture meaningful patient involvement, manage interests and avoid conflicts of interest.</li> </ul> <p>Participants will be evaluated by a jury comprising <i>Adrian van den Hoven (Director General, Medicines for Europe)</i>, <i>Susanna Palkonen (Chair, European Patient Access Partnership - PACT, and Executive Director, European Federation Allergy and Airways Diseases Associations)</i> and <i>Dr Miklós Szócska (Former Minister of State for Health in Hungary, Director of The Health Services Management Training Centre of the Semmelweis University)</i>.</p> <p>The announcement of Hackathon winners will be made at the end of today's final plenary.</p>
13:00 - 14:00	<b>Welcoming lunch and Registration</b>
14:00 - 15:30	<p><b>Grand Opening Plenary Session</b></p> <p>Our first plenary session will set the tone for the Congress. Following formal introductions initiated by our two Masters of Ceremonies <i>Albert Zoltán Aszalos (Project Manager, Semmelweis University, Hungary)</i> and <i>Mair Elliott (Young Patient</i></p>

	<p>Activist), we turn our attention to two keynote presentations, which will set out the case for patient involvement. Our two guest speakers will draw upon their own significant personal experience to set out the journey they have taken to becoming patient advocates and the value that the patient voice can add to all aspects of modern-day healthcare.</p> <p>Welcoming address</p> <ul style="list-style-type: none"> <li>▪ Marco Greco, President, EPF</li> </ul> <p>Welcome from the European Commission</p> <ul style="list-style-type: none"> <li>▪ Anne Bucher, Director-General for Health and Food Safety, European Commission</li> </ul> <p>Welcome from the European Parliament</p> <ul style="list-style-type: none"> <li>▪ David Lega, Member of the European Parliament</li> </ul> <p><b>Keynote Presentation: Why patient involvement?</b></p> <ul style="list-style-type: none"> <li>▪ Cees Smit, Patient Advocate, Dutch Patient Alliance for Rare and Genetic Diseases</li> <li>▪ Sara Riggare, Patient Advocate, Karolinska Institute, Sweden</li> </ul>
15:30 - 16:00	Coffee break
16:00 - 18:00	<p><b>Keynote Presentation: Patient involvement - presenting the evidence</b></p> <p>EPF is honoured to have Professor <i>Alf Collins, NHS England's Clinical Director, Personalised Care Group</i> to give the second keynote address of the day. As a doctor, commissioner, researcher and national policy advisor in person-centred care, Alf has researched and published widely on self-management support, shared decision making, care planning, co-production, patient activation and patient engagement. In his presentation Alf will set the scene of how the patient movement has developed and assess its impact and relevance for European health systems today.</p> <p><b>Panel discussion: Different Perspectives – One Vision</b></p> <p>Our final session of the first day which will be moderated by <i>Usman Khan (Executive Director, EPF)</i>, brings together a diverse panel of experts to reflect on the first day of our Congress and to consider how patients, policy makers, providers, academics and industry can unite around a single vision for patient empowerment.</p> <ul style="list-style-type: none"> <li>▪ Hans Henri Kluge, Regional Director nominee for Europe, World Health Organization (WHO)</li> <li>▪ Elena Petelos, Advisory Board Member, European Forum for Primary Care (EFPC)</li> <li>▪ Jean-Christophe Tellier, President, European Federation of Pharmaceutical Industries and Associations (EFPIA)</li> <li>▪ Cees Smit, Patient Advocate, Dutch Patient Alliance for Rare and Genetic Diseases</li> <li>▪ Sara Riggare, Patient Advocate, Karolinska Institute</li> <li>▪ Alf Collins, Clinical Director for Personalised Care, NHS England</li> <li>▪ Jan-Philipp Beck, CEO, EIT Health</li> </ul> <p>Interactive discussion with the audience</p> <p>Session wrap up by <i>Albert Zoltán Aszalos, Mair Elliott and Dr Usman Khan</i> and announcement of Hackathon winners</p>
19:00 - 21:00	Networking Reception

## Day 2: 13 November

09:30 - 10:45	<p><b>Keynote Presentation: Ensuring equity, inclusivity and diversity of the patients' voice</b></p> <p>Day Two begins with an address by <i>Professor Jan De Maeseneer, Professor Emeritus, Ghent University</i>. He will stress to Congress delegates the importance of taking a structured and systematic approach supporting patient advocates and patient advocacy organisations. In a wide ranging presentation Professor De Maeseneer will set out a range of approaches to provide for an independent, empowered and diverse patient voice is able to play a central role in health policy and practice.</p> <p>Panel discussion moderated by <i>Nicola Bedlington, Special Advisor, EPF</i></p> <ul style="list-style-type: none"> <li>▪ <i>Christopher Roberts, Vice-Chair of the European Working Group of People with Dementia, Alzheimer Europe</i></li> <li>▪ <i>Freek Spinnewijn, Director, European Federation of National Organisations Working with the Homeless (FEANTSA)</i></li> <li>▪ <i>Alyna Smith, Advocacy Officer, Platform for International Cooperation on Undocumented Migrants (PICUM)</i></li> <li>▪ <i>Tamás Bereczky, EUPATI Director of Communications and Course Design</i></li> <li>▪ <i>Alain Cornet, Patient Representative (ePAG), ReCONNECT</i></li> </ul> <p>Introduction to parallel working sessions by <i>Albert Zoltán Aszalos and Mair Elliott</i>.</p>
10:45 - 11:15	Coffee break
11:15 - 13:15	<p><b>Parallel working sessions</b></p> <p>These six thematic parallel working sessions will explore the “how-to” and the “building blocks” of patient involvement within different health settings. Each session will feature innovative case studies, selected interventions and discussions exploring how to scale-up and move beyond isolated examples of good practice so as to ensure patient involvement becomes the new normal.</p>
13:15 - 14:30	Networking lunch
14.30 - 16:00	<p><b>Parallel sessions continued</b></p> <p>Each parallel session has been designed in a manner to develop a critical narrative, and each will be facilitated and documented with the aim to provide participants with inspiration and ideas, and to set an agenda for future activities.</p> <p><i>A full description of the topics of the parallel sessions is set out on page 5.</i></p>
16.00 - 16:30	Coffee break
16.30 - 17:30	<p><b>Keynote: Culture change and leadership</b></p> <p>Following a wrap-up of the parallel sessions, EPF is very proud to welcome <i>Marc Boutin, Chief Executive Officer, National Health Council (United States)</i> for our final keynote of the day. Marc has been a leading voice for greater patient involvement at every stage of the health care continuum and in his keynote presentation will focus on the role of culture and leadership in ensuring that the patient perspective can effectively be brought into health policy and practice, with the voice of the patient at the heart of that process.</p> <p>Wrap-up of the session by <i>Albert Zoltán Aszalos, Mair Elliott and Usman Khan</i>.</p>
19:30 - 21:30	Congress Gala Dinner

## Day 3: 14 November

09:30 - 11:00	<p><b>Plenary session: Patients as teachers – what can patients teach professionals?</b></p> <p>How can and should patients’ involvement shape the education and the continuous professional development of our future healthcare professionals, and what can other professional groups learn from patients?</p> <p>This session will kick off with an overview of patients’ involvement in professional education and bring in the perspectives of a variety of stakeholders.</p> <p>Moderated by <i>Kaisa Immonen, Director of Policy, EPF</i></p> <p>Keynote: Towards working with patients as teachers rather than subjects in undergraduate medical education – where are we today?</p> <ul style="list-style-type: none"> <li>▪ <i>Stijntje Dijk, Medical Student, Erasmus University of Rotterdam</i></li> </ul> <p>Medical journals as trailblazers for promoting patient involvement in medical education, clinical care, research and policy making</p> <ul style="list-style-type: none"> <li>▪ <i>Tessa Richards, BMJ Senior Editor Patient Partnership</i></li> </ul> <p>Reflections on the presentations from different professional perspectives:</p> <ul style="list-style-type: none"> <li>▪ <i>Michel Ballieu, Executive Director, BioMed Alliance</i></li> <li>▪ <i>Nathalie Bere, Patient Engagement Liaison, European Medicines Agency (EMA)</i></li> <li>▪ <i>Katherine Capperella, Global Head, Patient Engagement Leader, Janssen</i></li> <li>▪ <i>Alice Casagrande, Director, Fédération des Etablissements Hospitaliers et d’Aide à la Personne, Privés Non Lucratifs (FEHAP)</i></li> </ul> <p>Followed by discussion with the audience: How to create a movement and make real progress on patients’ involvement in professional education?</p>
11.00 - 11:30	Coffee break
11:30 - 13:15	<p><b>Closing Plenary: Why health systems must start delivering for and with patients</b></p> <p>In a change to the traditional format our closing plenary, moderated by <i>Albert Zoltán Aszalos, Mair Elliott</i>, will feature <i>Mark Pearson, Deputy Director, Employment, Labour and Social Affairs, OECD</i> in conversation with <i>Susanna Palkonen, President, Patient Access Partnership</i>.</p> <p><b>Closing Remarks:</b> <i>Albert Zoltán Aszalos, Mair Elliott, and Usman Khan</i></p> <p><b>A step into the future of patient involvement: What will be yours?</b></p> <ul style="list-style-type: none"> <li>▪ <i>Elisabeth Kasilingam, Board Member, EPF</i></li> <li>▪ <i>Borislava Ananieva, President, EPF Youth Group</i></li> </ul> <p><b>Closing of the Congress</b></p> <ul style="list-style-type: none"> <li>▪ <i>Marco Greco, President, EPF</i></li> </ul>
13.15 -14:30	<b>Lunch and departure</b>

## Parallel Sessions

### Measuring the impact of patient involvement

The principle of patient involvement in areas of healthcare ranging from service design to research and development has become increasingly accepted within European health systems. The level and form of involvement varies as does the support that is provided to support the exercise of patient voice. The focus for this Parallel Session is a related and currently underdeveloped area which relates to measurement of the impact and value of patient involvement.

Our starting point is that value and value for money relating to the engagement of patients can and should be measured and that the act of providing such an accurate value assessment can be considered itself as a value of patient involvement. Yet, despite the identified need for evaluation of the impact of patient involvement, patient involvement is neither tracked nor evaluated in a systematic or in a standardised manner.

Having established the case for change the session we go onto untangle the knots that currently obstruct the systematic evaluation of patient involvement. We will explore studies and experiences from Health Technology Assessment, and other fields to show the potential of patient involvement in contributing to accurate value assessment.

Session moderators: *Nicola Bedlington and Valentina Strammiello, European Patients' Forum*

Panellists:

- *Nathalie Bere, Patient Engagement Liaison, European Medicines Agency (EMA)*
- *Irina Cleemput, Senior Health Economist, Belgian Healthcare Knowledge Centre*
- *Anke-Peggy Holtorf, Project Coordinator, HTAi Patient and Citizen Involvement Interest Group*
- *Paul Robinson, EU Patient Engagement Lead, Merck Sharp & Dohme (MSD)*
- *Donna Walsh, Executive Director, European Federation of Neurological Associations (EFNA)*
- *Elena Petelos, Advisory Board Member, European Forum for Primary Care*
- *Dimitra Lingri, Head of Legal Department, Greek National Organization for the Provision of Health Services*
- *Guendalina Graffigna, Director, EngageMinds-Hub*

### How the patient perspective can improve healthcare performance assessment

Health systems' performance can be assessed by evaluating the extent to which they deliver the outcomes and experiences that matter most to patients. Patients have specific expertise and knowledge derived from lived experience; only patients – and, often, their families – see the “whole journey.” Patients can identify gaps in services, risks, superfluous services, and priorities, helping make healthcare both more effective and efficient.

This session takes a health systems' perspective based on EPF's work with patients on defining “quality” in healthcare, and links this to current initiatives on developing patient-centred healthcare quality indicators.

Participants will understand the value of looking at healthcare through the patient's eyes when shaping healthcare quality improvement policies and actions at different levels; the importance of meaningful patient involvement; and develop an understanding as to the barriers that patients face in this area, as well as identifying solutions proposals to overcome these.

Session moderator: *Josep Figueras, Director, European Observatory on Health Policy and Systems*

Setting the scene: EPF's work with patients on defining “good quality” healthcare

- *Representative tbc, EPF*

The experience and perspective of a patient advocate on quality improvement

- *Cristin Lind, Patient Advocate and partnership facilitator, Sweden*

What the OECD PaRIS survey can contribute to improving patient-centredness

- *Katherine de Bienassis, Health Policy Analyst, OECD*

Perspective on health systems and value-based healthcare

- *Thomas Allvin, Executive Director Strategy and Healthcare Systems, EFPIA*

European patient survey – what quality indicators matter most to patients when choosing a medical provider?

- *Gregory Katz, Executive Manager and Professor, University of Paris*

### **Patients as partners in research: making co-production “the new normal“**

Patients are increasingly becoming not only research subjects but also co-researchers, and even drivers of the research agenda. Research with patients, driven by patients’ real-life unmet needs and priorities, can deliver high-value, sustainable solutions. This session will explore the opportunities of doing research “with” as well as “for” patients, looking at innovative examples from therapeutic research and development, but also at the wider context of health and the role of patients in setting research priorities. Participants will then contribute to the development of a patient-led framework on Meaningful Patients Involvement in Health Systems.

The morning will be spent with the speakers introducing how patient involvement is currently practiced by different stakeholders and how it is envisioned for the future, followed by small group discussions to frame the afternoon’s work. In the afternoon participants will co-develop a patient-led framework on meaningful patient engagement, leveraging the discussions and presentations from the morning, as well as building on existing insights of different patient engagement frameworks.

This session has been co-developed between EPF and VU-Athena.

Session moderators:

- *Matthew May, Programme Coordinator, European Patients’ Academy (EUPATI), EPF*
- *Mathieu Boudes, IMI-PARADIGM Coordinator, EPF*
- *Jacqueline Broerse, Professor Innovation and Communication in health and life sciences, VU Athena*
- *Carina Pittens, Assistant Professor of Patient involvement in health research, policy-making and care practice, VU-Athena*

Speakers:

- *Tamara Hussong Milagre, President, EVITA, European Reference Network GENTURIS*
- *Tessa Richards, Senior Editor Patient Partnership, BMJ*
- *Anne-Charlotte Fauvel, Head of EU Affairs, European Infrastructure for Translational Medicine (EATRIS)*
- *Camilla Krogh Lauritzen, Chief Patient Officer, Leo Pharma*

### **Designing better healthcare services with patients**

This session will look at inspiring and educational case studies, exploring the process, principles, benefits and pitfalls of co-designing healthcare services locally with those who use it. You will have an opportunity to learn from the perspective of the patients and healthcare users, as well as healthcare professionals and healthcare managers. Two case studies will be discussed:

- How the inspiration of a patient led a Danish university psychiatric hospital to transform the way it works with patients;
- How Slovenia is aiming to move towards person-centred, integrated care.

Building on a framed contribution from the EPF Youth Group and building upon a number of brief interventions, the session will bring together a range of perspectives so as to enrich the discussion that we will engage in.

In summary, the session aims to: identify gaps in the healthcare services; provide solutions by showcasing enablers that can improve the healthcare services by involving patients and patient

representatives in their design and leave the audience with concrete solutions that can be scaled up at a national level.

Session moderator: *Dr Miklós Szócska.*

**Panellists:**

- *Jan Mainz, Clinical Professor and Director, Aalborg University Hospital, Denmark*
- *Line Myrup Gregersen, Patient Representative at the Unit for Co-Creation, Aalborg University Hospital, Denmark*
- *Dušan Jukić, Patient Representative for the Diabetes local organization in Novo Mesto, Slovenia*
- *Jelka Zaletel, MD, PhD, co-chair of National Diabetes Programme Coordination Group, Ministry of Health in Slovenia*

**How to ensure digital health brings real-life benefits for patients**

Digitalisation in healthcare has the potential to transform patient-centred care. This session on digital health has two main objectives. On the one hand, we will explore the different ways in which “digital” can improve the care of patients - at a systemic as well as an individual level - as well as considering how this can be scaled up. At the same time, we will examine how patient involvement can be embedded in digital health as a driver for change, with the intention of harnessing digital technologies for the benefit of patients and society.

Our premise is that all developments should start from the needs of healthcare users and be co-created with users. This would ensure that technology actually facilitates participatory, person-centred healthcare and leads to better outcomes for patients and better value for society.

This very lively session will include interactive polls to get a better understanding of audience’s perspectives, short presentations to kick-start a discussion with all participants, and an exciting youthful surprise. The goal of the session will be to provide ideas and input for the participants to develop guidelines on how patient involvement can be advanced.

Session moderator: *Diane Whitehouse, Principal eHealth Policy Analyst, European Health Telematics Association*

**Panellists:**

- *Ana Cariazo, Senior Advisor, Junta de Andalucía*
- *Brian West, Chair of the Board of Directors, European Aids Treatment Group (EATG)*
- *Dipak Kalra, President, European Institute for Innovation through Health Data, i~HD*
- *Jo Van der Auwera, Co-Founder of FibriCheck, EIT health*

**Patient safety – how can patients and families help improve it?**

Patients and patient organisations play a key role in advocating for safer care, which should be promoted through empowerment and participation at all levels. Research suggests that “lay expertise” could be the backbone of patient safety, including in acute illness, but there are barriers – such as patients’ concerns not being taken seriously, persistent hierarchical culture, and the disempowering nature of many healthcare settings.

The session will start with a patient testimonial of one family’s experience, showing the rationale for patient and family involvement in improving safety. We will then hear examples of what is happening at international level, as well as being able to draw on national and local initiatives. Together with the audience, we will discuss the drivers and the resisters in the way of patient empowerment and consider how to achieve cultural change – moving from hierarchical and paternalistic to collaborative, open and participatory ways on engaging with the subject of patient safety.

Session moderator: *Tamsin Rose, Senior Fellow, Friends of Europe*

Keynote presentation: In safe hands? Maintaining the patient-caregiver relationship when harm has occurred

- *Roisin and Mark Molloy, Patient Advocates & Healthcare Reform Advisers*

Patients advocating for patient safety – how patients and families can help

- *EPF representative*

How measuring patient-reported safety incidents can contribute to a patient safety culture

- *Rie Fujisawa, Health Policy Analyst, OECD*

Applying PRIMs and a “patient partner” approach in Belgian hospitals

- *Laure Istas and Quentin Schoonvaere, Platform for Continuous Improvement of Quality of Care and Patient Safety, (PAQS), Belgium*

How to start changing culture through bringing together patients and healthcare managers

- *Jim Phillips, Executive Director, Centre for Empowering Patients and Communities*