



Data
Saves
Lives

Data Saves Lives 5th Year Anniversary

“It’s all about DATA”



26-27 November 2024
Double Tree by Hilton Brussels City Hotel, Brussels

DAY 1

Opening Ceremony



Gözde Susuzlu Briggs

Gözde joined EPF in March 2019 as the Coordinator of the ‘Data Saves Lives’ initiative, and is currently Senior Programme Manager at EPF. She formulates and implements EPF’s contribution to projects and handles technical and progress reports related to projects.



Nicola Bedlington

Nicola Bedlington has been EPF’s Special Advisor since late April 2019. She used to be Secretary General of EPF, and was previously the Executive Director since the setting up of the EPF Secretariat in June 2006.

Nicola Bedlington (British, born in Scotland) studied business and HR management in the UK and France. Nicola Bedlington is EPF’s Secretary General since September 2014 and was previously the Executive Director since the setting up of the EPF Secretariat in June 2006.

From 2004 to 2006, she worked for the Swiss Government, leading the Environment and Schools Initiatives Secretariat, an international government-based network set up by OECD focussing on innovation, action research and policy development in the field of Education for Sustainable Development. She worked as an external expert for the European Commission on disability policy and NGO cooperation and during the 90s was the first Director of the European Disability Forum, an umbrella organisation uniting over 70 European NGOs and National Councils of Disabled People to advocate for the human rights and inclusion of disabled citizens in Europe.



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Plenary Session 1: The digitalisation of health and care systems: what way forward and which role for patients?



Moderated by Claudia Louati

Claudia joined EPF as Head of Policy in May 2023. She leads EPF's policy and advocacy work and steers EPF's engagement with EU and international stakeholders on key policy issues. Before joining EPF, she worked for almost seven years at the Europe Office of the U.S. Food and Drug Administration, based at the U.S. Mission to the EU in Brussels, where she promoted EU-U.S. regulatory collaboration on medical products.

She started her career as a Communications and Public Affairs Consultant in Brussels. Claudia holds two master's degrees in European Affairs from SciencesPo Paris and the London School of Economics.



Keynote Presentation by Terje Peetso

Dr Terje Peetso is a Chief Medical Innovation Officer at the North Estonia Medical Centre in Tallinn. Among other tasks she is also responsible for the cooperation with other hospitals and clinical partners in Estonia and abroad.

Dr Peetso worked from 2003 – 2018 in the European Commission on digital health, tobacco control and risk assessment. Before joining the North Estonia Medical Centre, Peetso was the Head of Sector on eHealth and Ageing Policy in the European Commission's DG CONNECT. In 2014, she was the EU Fellow in the University of Southern California, USA, where her research focus was on the obstacles that hinder the introduction of eHealth in healthcare systems. 2018 – 2023 Dr Peetso was a member of the management board of the NEMC being responsible for R&D, training, client service and quality control. Dr Peetso holds a diploma in medicine from the University of Tartu, Estonia.



Fulvia Raffaelli

Fulvia joined the European Commission in 2002. Since September 2022 she is working at the Director-General for Health and Food Safety (DG SANTE) where she is Head of the Digital Health Unit.



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Andreas Christodoulou

Andreas is the Director of Operations of the Cyprus Federation of Patients' Associations (CyFPA), an EPF member whose mission is to ensure that patients in Cyprus have access to holistic, patient-centered, equitable and social healthcare.

As an expert patient advocate and a patient himself, Andreas has been actively involved in the fight to control cancer through the promotion of prevention and early detection of cancer in the general public and the improvement of quality of life of all cancer patients and their relatives. He strongly advocates of the need for a Holistic Patient Care and for a Universal Healthcare Coverage.

Andreas has served as the President of EPF's Youth Group from 2017-2019 and currently he serves as an advisor/patient expert and as the main representative of the Cypriot Federation of Patients' associations. He has been elected as a Board Member in EPF's Board of Directors in the Annual General Meeting which was held in late April 2023.



Katherine Polin

Katherine has been a Research Fellow with the Technical University of Berlin's Department of Health Care Management since February 2018 and a member of the Observatory's Berlin hub since February 2019.

She supports a variety of Observatory projects, including the State of Health in the EU programme, the COVID-19 Health System Response Monitor and serves as an editor for Health System Reviews (HiTs) on Slovenia and Ghana. Katherine's focus areas include quality and transparency in health care, health and health care policy reform approaches, and questions around digital data and data accessibility.

Katherine holds a Master's in Population Health from Columbia University and previously worked as a Consultant for SEEK Development, a strategic and organizational consultancy in global health and development, and at the Robert Koch Institute. She was a Robert Bosch Transatlantic Fellow for 2014-2015.



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Plenary Session 2: The importance of key stakeholders' dialogue in building trust



Gözde Susuzlu Briggs

Gözde joined EPF in March 2019 as the Coordinator of the 'Data Saves Lives' initiative, and is currently Senior Programme Manager at EPF. She formulates and implements EPF's contribution to projects and handles technical and progress reports related to projects.



Keynote Presentation by Marco Marsella

Marco is Director for Digital, EU4Health and Health systems modernisation at the European Commission's Directorate General for Health and Food Safety (DG SANTE). Previously, he was Head of Unit for eHealth, Well-Being, Ageing and Deputy Director for Digital Society, Trust & Cybersecurity at the European Commission's Directorate General for Communications Networks, Content and Technology (DG CONNECT).

Notable initiatives that he had a leading role in include the EU COVID Certificate, contact tracing apps, and research and innovation endeavours related to digital innovations during the COVID-19 pandemic. Moreover, he supervised the 1 Million Genomes Initiative and the European Cancer Images Initiative. Prior to his current position, Marco has held various other roles within the European Commission, including Head of Unit for Learning, Multilingualism, Accessibility responsible for the Web Accessibility Directive, for digital language technologies, and Safer Internet for Children.



Pedro Carrascal

Pedro is the Executive Director of the Patient Organizations Platform (POP) since October 2022. POP is an umbrella of the main national patients organisations born 10 years ago to serve them in advocacy, awareness, patient based research and patient organisation empowerment.

He has a degree in Law and a Master's degree in business management and direction (MBA). He has been linked to the movement of people with multiple sclerosis since he was 8 years old and his mother was diagnosed with the disease, at which time she and others created the Multiple Sclerosis Association of Bizkaia. He has been the director of ADEMBI for 25 years (until 2022), as well as Esclerosis Múltiple Euskadi and Esclerosis Múltiple España, positions that he has held simultaneously during those years.

He has been Board member of the Multiple Sclerosis International Federation (MSIF), where he has contributed for 15 years. He has also been actively involved in EMSP (European Multiple Sclerosis Platform) for 10 years, being its president between 2018 and 2022. During all this time he has been able to engage in many different ways with EPF. He's been member of the EPF Ethics Committee in 2023 and Board member of EPF since April 2024.



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Wannes Van Hoof

Wannes studied philosophy and anthropology at KU Leuven. He obtained his PhD in philosophy in 2014 from the Bioethics Institute Ghent. He worked as a postdoc at Ghent University and Ghent University Hospital. He currently works at Sciensano, the Belgian Institute of Public Health. There, he leads a team working on patient/citizen engagement and the ethical aspects of the secondary use of health data, innovative cancer therapies and the implementation of genomic technologies in healthcare.



Sara Roda

Sara is a Senior Policy Adviser at CPME (Standing Committee of European Doctors) responsible for the digital health file, working on the European Health Data Space, AI, data protection, among others. She is a Portuguese lawyer and a PhD candidate at the VUB - Vrije Universiteit Brussel. Her research interests are on health data sharing and access, medical confidentiality, privacy and data protection, innovation/experimentation in law and ethics. She holds a DES in public and administrative law from ULB (2006) and an LLM in International and European Law from VUB/IES (2018).



Verena Thaler

Verena has been working at MedTech Europe as Manager for Data Governance since 2022, where she focuses on supporting the development of a robust European health data ecosystem, particularly in the areas of data governance, interoperability, and the European Health Data Space.

Her background combines experience in healthcare policy and clinical IT systems, with previous roles in Brussels at APCO Worldwide's health practice and the European Society of Radiology. Verena began her career in Austria as a healthcare professional and IT specialist, where she coordinated health information system projects. She later completed a master's degree in Healthcare Policy, Innovation & Management at Maastricht University.

Verena is dedicated to helping improve healthcare through better use of digital tools and data, and she is committed to fostering collaboration across the health sector.



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Workshop Series - Parallel Sessions

Workshop 1 : Crafting impactful narratives: A hands-on workshop on communicating the European Health Data Space to empower and educate



Milana Trucl

Milana joined EPF in July 2022. As Policy Officer, Milana guides EPF's policy and advocacy work in digital health and coordinates 'Data Saves Lives' initiative. She is in charge of monitoring policy developments, drafting position papers, conducting background research, chairing EPF's Digital Health Working Group and engaging with external stakeholders and members on digital health issues.

Prior to joining EPF, Milana's work focused on monitoring and analysing EU health and social policies. She holds an MA degree in European Studies obtained at the University of Trento, Italy.

Workshop 2: Protecting patient data: What has changed in the last 5 years? Where were we, where are we going to?



Nienke Shutte

Nienke (PhD behavioural genetics) leads the Innovation in Health Information Systems unit at Sciensano. Her research focuses on facilitating health information exchange across Europe and strengthening health information systems, taking into account the FAIR principles (findable, accessible, interoperable, reusable data).

She plays an active role in European health information research projects (HORIZON, EU4HEALTH, Digital Europe) to support health research and evidence-based policy-making, such as the HealthData@EU pilot study, PHIRI-a sustainable pan-European population research infrastructure, and the Joint Action Towards the European Health Data Space: TEHDAS2



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DAY 2

Plenary Session 3: Data Savvy Patients: Empowerment through AI Literacy in Healthcare



Moderated by Anca Toma

Anca joined EPF as Executive Director in March 2022. Her career started in the Romanian EU accession negotiations team, continued as a consultant in a public affairs and communications agency in Brussels, followed by ten years in Smoke Free Partnership, a European coalition of NGOs working to advance tobacco control for cancer and NCD prevention.

Anca has over 15 years of experience in European health policy working in policy advocacy, strategic communications, developing and coordinating successful pan-European advocacy campaigns, and leading her team and organisation. Anca is a political science graduate of the University of Bucharest and holds a masters in European politics and administration from the College of Europe.



Keynote Presentation by Ildikó Vajda

Ildikó holds a PhD in neurophysiology and has worked for more than eight years in the field of fundamental scientific research. She then transitioned to applied research, where she modeled biological knowledge to be reasoned with by AI agents. Since 2011, she has been collaborating with patient organizations, healthcare professionals, and IT experts to make healthcare more patient-centric, especially in the digital era.

Since 2020, she has been working at the Dutch umbrella organization of patient organizations, the Netherlands Patients' Federation. There, she focuses on topics related to AI, secondary use of data, and ethics—all in relation to digital health from both national and European health policy perspectives. Her expertise lies at the intersection of digital health innovations, co-creation methods, AI ethics, and health policy. Ildikó has contributed to the development of the Dutch Integral Care Agreement and participates in various steering committees and advisory boards on privacy, ethics, and AI.



Eric Sutherland

Eric is a Senior Health Economist leading the OECD's work in Digital Health, bringing together policy guidance for digital tools, integrated data, and responsible analytics including artificial intelligence. In that role, he is accountable for measuring and evolving the OECD's Recommendation on Health Data Governance (2016) and supporting digital health policy that provides data protection (e.g. security and privacy) and timely access to quality data to optimize the use of data for information, insights, and impact among individuals, health workers, policy makers, researchers, and innovators.

Eric's work has led to publications on the use of Artificial Intelligence in Health, the state of Digital Security in Health across the OECD, and a thematic chapter on digital health in the OECD's flagship Health-at-a-Glance 2023 report.



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Lars Münter

Lars is a Founder and International Director at Nordic Wellbeing Academy. He is dedicated champion for self-care, empowerment and health literacy focusing on bottom-up, social movements and community health approaches. He works both with design of digital health solutions, health data frameworks, and in various NCD and mental health projects.



Stefan Phillips

Stefan is a seasoned professional with over 25 years of experience in Healthcare IT, including more than a decade focused on AI applications in healthcare. His extensive career spans leadership roles at prominent healthcare technology companies, showcasing his expertise in driving innovation and strategic growth.

As a former senior manager, Stefan has held key positions at industry-leading organizations such as Agfa Healthcare, TeraRecon, and McKesson (formerly Celesio). His diverse background encompasses both established corporations and entrepreneurial ventures, providing him with a unique perspective on the healthcare technology landscape.

Currently, Stefan serves as the CEO and founder of OneVision Healthcare, a startup that leverages a wealth of experience to address contemporary challenges in the healthcare sector. His entrepreneurial spirit, combined with his deep understanding of healthcare IT and AI, positions him as a valuable contributor to discussions on patient empowerment through technological advancements.



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Workshop Series - Parallel Sessions

Workshop 3 : Patient Registries: Enhancing Data for Better Healthcare



Petra Wilson

Petra is co-founder and managing director of Health Connect Partners, a boutique consultancy which focusses primarily on helping clients understand the European health policy environment. Current projects being undertaken by Health Connect Partners include the review of cross-border patient mobility for the European Commission, leading the development of an eHealth Governance Strategy for the Ministry of Health in Algeria, and the development of a new code of conduct for gene banking for the national gene bank in Spain. In addition, Petra is engaged as EU Programme Director for the Personal Connected Health Alliance (a HIMSS innovation company), and also acts a senior advisor on health and life sciences at FTI Consulting.

Petra's past experience includes eight years in the European Commission, where she focused particularly on the use of information society technologies in healthcare; seven years as Senior Director of Connected Health at Cisco, where Petra's team supported clients in making best use of new communications technologies to drive safer and more efficient access to healthcare. Petra also has deep experience of the health services sector, having worked on both the patient and provider side as CEO of the International Diabetes Federation. Petra holds a Doctorate in Public Health Law from Oxford University, she has British and Belgian nationality, has lived in Brussels for over 20 years and works in English, German and French.

Workshop 4: The importance of education in enhancing trust



Lars Münter

Lars is a Founder and International Director at Nordic Wellbeing Academy. He is dedicated champion for self-care, empowerment and health literacy focusing on bottom-up, social movements and community health approaches. He works both with design of digital health solutions, health data frameworks, and in various NCD and mental health projects.



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Plenary Session 4: From Data to Decisions: How HTA Shapes the Future of Patient-Centred Care



Moderated by Valentina Strammiello

Valentina Strammiello works as Director of Strategic Initiatives and oversees the EPF project portfolio. She represents EPF in HTA-related activities and in the European Health Parliament initiative.

Before joining EPF, Valentina has had a long collaboration with the CIPI Network and has worked as freelance OSINT analyst on Security and Energy issues. Self-trained in website management and web 2.0 applications, she is among the founders of ecpa2.0 (European Center for Public Affairs 2.0), a forum of young professionals. She holds a BA in International Relations and a Master's Degree in European Studies.



Keynote Presentation by Niklas Hedberg

Niklas is the Chief Pharmacist at the Swedish national governmental authority, the Dental and Pharmaceuticals Benefits Agency (TLV). Niklas is the Co-Chair of the HTAR Coordination Group with special expertise in pharmaceuticals. He was the Chair of the Consortium Executive Board for EUnetHTA21 (2021-2023) as well as the Chair of the EUnetHTA JA 3, Executive Board between 2018 and 2021.

Niklas has been working with pricing and reimbursement since 2001. He has held positions as medical assessor, project leader, Head of the Department for New Submissions (between 2009 and 2014) and he is now the Chief Pharmacist.

Niklas has a broad experience of different aspects of value based evaluation and over time has seen the increasing importance for health technology assessment (HTA) both across health care systems and on local level to prepare accurate decision making.

Among Niklas special interests have been the early development of joint scientific advice in 2009 and onwards (pilots both nationally with MPA and on European level with EMA) and strategic discussions about RWD.



Julien Delaye

Julien Delaye joined EURORDIS in September 2019 as an intern and moved to the position of Public Affairs Assistant on the Rare 2030 project. He then became Public Health Policy Junior Manager and now holds the position of Patient Engagement Manager in HTA. Working closely with the Director of Information & Access to Therapies & Health Policy Advisor, Julien is responsible for organizing the participation (awareness, training, monitoring) of people living with a rare disease and their representatives in the European Cooperation on HTA and in national HTA procedures, as well as participating in research activities in the HTA field where EURORDIS is invited to take a role.

He is the project coordinator of EUCAPA, a training programme on HTA for patient representatives. Prior to EURORDIS, Julien worked as an event coordinator for European Calcified Tissue Society (ECTS), was a volunteer for Osteogenesis Imperfecta Federation Europe (OIFE) and was a marketing intern at Sanofi – Copenhagen.



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Kaisa Immonen

Kaisa joined the Stakeholders and Public engagement team of the European Medicines Agency (EMA) in 2023. She supports interactions with patients, consumers and healthcare professionals and their organisations. Kaisa holds a Master's in Health Policy, Management and Innovation from Maastricht University and a Master's in International Relations.

She has extensive experience of EU health policy and patient advocacy: she was Director of Policy at the European Patients' Forum in 2010-2013 and co-chaired the EMA Patients and Consumers Working Party 2016-2022. She also contributed to OECD work on quality and safety of healthcare, the OECD PaRIS surveys, WHO Europe's work on people-centred health systems, as well as numerous European projects, working groups and networks on health policy.



Entela Xoxi

Entela is a Pharmacologist with Pharmaceutical policy, Health Technology Assessment (HTA)/Payer and Real-World Data (RWD) expertise. Ten-years at Italian Medicines Agency (AIFA) (04/2007-01/2017) coordinating the AIFA registries 2 (01/2014-01/2017) specialized in product-based registries (particular focus on cancer area & rare disease³) and managed entry agreement (MEA) implementation (performance-based risk sharing and financial-based).

Currently, Entela is a lecturer with Collaboration Agreement for Research Projects at Università Cattolica del Sacro Cuore Rome Italy - School of Health Economics and Management (ALTEMS⁴): Partner of More-EUROPA, Member of Steering Scientific Committee of RWE4Decision, Member of working group on international Early Access ISPOR Italy Rome-Chapter.

She participated in the EUnetHTA JA3 WP5b Lifecycle Approach to Improve Evidence Generation (PLEG⁸) project. Additionally, she served as a member of the Commission Expert Group on Safe and Timely Access to Medicines for Patients (STAMP⁹) and contributed as a member of the IMI ROADMAP Regulatory-HTA-Payer Expert Advisory Group (EXAG¹⁰). She also collaborated with the IMPACT HTA WP1011 Appraisal of Orphan Medicinal Products (OMPs) initiative.

She has extensive experience as a lecturer and speaker, delivering training sessions and presentations at national and international courses, master's degree programs, and conferences/congresses focused on drug regulation, health technology assessment (HTA), and topics related to pricing and reimbursement. Moreover, she has provided consultancy services to various pharmaceutical companies, leveraging her expertise in these fields.