



Towards country-observatories for vaccination promotion: the role of civic and patient organisations

EU workshop

Brussels, 26 June 2024 | 9:00 – 12:00

PARTICIPANTS' LIST

Vida Augustiniene, Council Of Representatives Of Patient Organisations Of Lithuania, Lithuania



Vida is a Civil Engineer and she's currently the President of the Lithuanian Diabetes Association (www.dia.lt), the Editor – in – chief of the Magazine "Diabetes" and the Chair of the Council of Representatives of Patients Organisations of Lithuania (www.pacienturyba.lt). Her daily activities include managing the day-to-day association operations, patient advocacy, participating and presenting in international and organizing national conferences, events, working groups, collaborating with Parliament, Ministry of Health, medical specialists to address Diabetes and other patient interests and care.

Christine Baluci, Malta Health Network, Malta



Christine served on the board of administrators of the Malta Health Network (MHN) since 2015, nominated by the executive board of the Malta Association for Public Health Medicine (MAPHM). She is a medical doctor with a specialisation in Public Health Medicine currently working in environmental health and tobacco related issues. She

also is a patient suffering from a chronic disease and a carer of elderly parents. She uses both her personal experience and her professional experience in various domains of public health practice including the development of public health legislation, policies and strategies at national and EU levels to advocate for public health through MHN.

Andreas Christodoulou, Cyprus Federation of Patients' Associations (CyFPA), Cyprus



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. He has been elected as a Board Member in EPF's Board of Directors in the Annual General Meeting 2023. As an expert patient advocate and a patient himself, Andreas has been actively involved in the fight to control cancer. He strongly advocates for the need for a Holistic Patient Care and for a Universal Healthcare Coverage. His field of expertise is patient advocacy, Digital Health, Innovation solutions, ICT and administrative support. He holds a Bachelor and Master degree in Computer Science and Master in Global Ethics & Human Values from King's College London.

Timo Clemens, Maastricht University, The Netherlands



Timo Clemens, PhD is a public health researcher. His focus of work is on supporting better decision making at the EU-Member States nexus for health policy. His interest is on European (Union) perspectives on the organisation and governance of health systems and policies – understanding, on the one hand, the process and effects of EU law, EU collaboration and integration in domestic health policy making. On the other hand, he focusses on the role of evidence in policy-making and how science advice (tools) are used within the EU (and beyond). Moreover, comparing the use and effect of governance approaches within health systems and policy making in Europe such as arrangements for transparency, participation or capacity building. Methodologically, this involves comparative and vertical (top-down) analyses of laws (mapping of laws) and policies (policy analysis) which are complemented by literature reviews and qualitative interview studies to assess the effects in practice. His scholarly work has covered so far cross-border care arrangements, hospital services, rare diseases, health workforce and patients' rights/patient information, health data governance and Health in All Policies. His experience includes involvement in EU funded research projects on comparative health service research questions including vaccination promotion (cooperator, HaDEA), use of real world data (Tender, EU DG RTD), patient rights (Tender Pre-MAX, EU-DG SANTE), rare diseases, (EMRaDi, INTERREG) and small states healthcare systems (SMSHealth.eu, EU-ERASMUS+). Currently, dr. Clemens is working as an associate professor at the Department of International Health, Faculty of Health, Medicine and Life Sciences at Maastricht University.

Bianca Ferraiolo, Cittadinanzattiva-Active Citizenship Network, Belgium



Bianca Ferraiolo is the Head of the Representative Office to the EU of Cittadinanzattiva - Active Citizenship Network since its opening in March 2015 and works as Senior Manager European Affairs.

She is involved in many activities at European level with a special focus on health and patient advocacy issues, liaising with all the relevant stakeholders as umbrella and national patient associations, private companies and the European Institutions and representing Cittadinanzattiva - Active Citizenship Network in several multi-stakeholder initiatives. She was responsible for the establishment and the secretariat of the Members of the European Parliament Interest Group “European Patients’ Rights & Cross-Border Healthcare” (2015) and of the Inter-Institutional Group “SDGs for well-being and consumers’ protection” (2021).

She is also actively involved in European project management, the organization and realization of important European initiatives as the “European Patients’ Rights Day”.

She is a certified Pharmacist, holds a Master’s Degree in Chemistry and a post-graduate Diploma in Marketing and Communications.

Dubravka Finka, ZD Patient- Zadarski pacijent, Croatia



Dr. Dubravka Finka, MD, has worked as GP since 1980. for seven years, then has been working at the Oncology Department in Zadar County Hospital and Clinical Hospital Center Zagreb. Since 1995. she was working in Croatian Institute for Health Insurance, participated in various international health educational projects, (Motovun Summer School of Health Promotion, 2nd Dubrovnik Summer School –Health Insurance in Transition, Reforms and New Priorities in Health Care Systems, The Healthy Cities Process and Outcomes, London School of Economics-Managing Organisational Changes. In 2003 she was appointed President of Croatian Association for Patients’ Rights-Zadar, member of Consumer Association Zadar, (participated in about 40 projects for patient rights in Croatia, international conferences etc.). In 2018 she became the President of the Association for Patients’ Rights - Zadar Patient (Zadarski pacijent). She also attended International Shiatsu School , Macrobiotic Health School, enjoying Tai chi and feng shui.

Christine Frühling, Lower Austrian Patient and Nursing Advocacy, Austria



Christine is, since February 2024, an associate of the Lower Austrian Patient and Nursing Advocacy. She works focusing on patient rights, advice on and establishment of patient decrees, advice on and establishment of death

decrees, out-of-court settlement negotiations, patient representation at the arbitration board of the medical association.

Sorin Gradinaru, My Child-My Heart Association (ACMIM) - Coalition of Chronic Diseases Patients Organizations (COPAC), Romania



Sorin Gradinaru is the Vice president of "My child-My heart Association" (ACMIM), the association for children with heart defects. He's also managing director for Romania at the Austrian advertising agency, Sery, and project coordinator for the project "Everything for your heart!", a screening program for identifying patients with cardiovascular risk factors. He is a board member of the Coalition of Chronic Diseases Patients Organizations (COPAC) and coordinator of the health information center in Iasi, infoSAN.

Reneta Ilieva, Bulgarian Association for Patients' Defense (BAPD), Bulgaria



She has been in the team of BAPD for 6 years as an associate lawyer and projects' coordinator. She has a number of international participation in health forums and conferences in the EU. Until now she implemented several international projects in a consortium with the European Public Health Alliance (EPHA) on air pollution: "Diesel and Health"; "Clean cities and clean air"; "Clean Transport". Provides legal advice on claiming responsibility from individual providers of medical services related to illegal actions to deprive patients of treatment in medical facilities, drug deprivation, delayed treatment, injuries and infections, medical incidents, refusal to pay for medical services rendered, clinical pathways, services and more. She is fluent in English and Spanish language, with a Masters degree in Law.

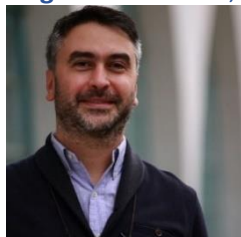
Jasna Karačić Zanetti, Croatian Association for the Promotion of patient rights, Croatia



Jasna Karačić Zanetti is the president of the Croatian Association for the Promotion of patients' rights. She has a Ph.D. in health diplomacy and she is also the Head of the Health Diplomacy Unit and director of Department of Health Diplomacy and Patient Rights at International chair in bioethics (Former UNESCO chair). She has an active mandate as an ombudsman at the International Council of the Patient Ombudsman. She is an associate lecturer at the diplomatic academy and medical law. She served as a diplomat during the Croatian Presidency of the Council

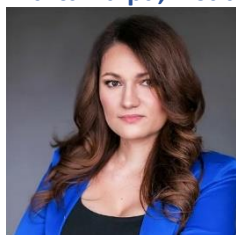
of the European Union 2020, delegated from the Ministry of Health. As a responsible person for patient rights, she holds consultative status with the United Nations. She got the Rector's Award for Achievements at the UNESCO level for human rights in medicine and the National Geographic Award for Justice in sustainable development goals. She was assigned "Young Leader" for health crisis management in 2021. She is EU Commission expert and associate editor for PLOS ONE journal.

Angelos Kassianos, Cyprus University of Technology, Cyprus



Angelos Kassianos holds the position of Lecturer in Health Psychology at the Department of Nursing of the Cyprus University of Technology since January 2022. He holds a degree in Psychology (BSc, Panteion University of Social and Political Sciences, Athens, 2007) with postgraduate and doctoral studies in Health Psychology at the University of Surrey in the UK (2013). In his doctoral dissertation, he studied the relationship between quality of life and behavioral changes in patients with prostate cancer. In addition to his Ph.D, he did the Stage 2 training in Health Psychology Practice and is registered as a Health Psychologist with the UK Health and Care Professions' Council (HCPC) since 2017. During his PhD, he also worked for 3 months in 2012 as an Intern at the World Health Organization (WHO) in Geneva.

Marta Kulpa, Institute for Patients' Rights and Health Education, Poland



Since 2009, she has been implementing training, education and community health projects at the Institute for Patients' Rights and Health Education (Instytut Praw Pacjenta i Edukacji Zdrowotnej, IPPEZ). She organizes trainings for representatives of patient organizations nationwide, and coordinates the work of the Patient Organizations' Support Centre at IPPEZ. Since June 2024, she has coordinated the work of the Alliance for Combating Infectious Respiratory Diseases. Poland Breathes Healthily.

Ioanna Liatsou, Hellenic Liver Patients Association "Prometheus", Greece



Ioanna Liatsou is a Sociologist with a master degree in Addiction Prevention & Treatment - Addictology, currently serving as the Programs Manager at The Hellenic Liver Patient Association "Prometheus" since February 2022. In this role, she oversees program design, implementation, and evaluation, manages financial expenditures, and coordinates communication with external partners. Ioanna's responsibilities also include organizing field activities,

conducting medical examinations and maintaining positive community relations. Ioanna excels in organizational culture management, efficient time management, and making informed decisions under pressure. Her strengths lie in critical thinking, problem-solving, and effective multitasking within collaborative settings. She also demonstrates strong communication skills. Additionally, Ioanna is actively engaged as a member of the Hellenic Scientific Society for AIDS, Sexually Transmitted, and Emerging Diseases Research, contributing to scientific committees and national conferences.

Stephen McMahon, Irish Patients Association, Ireland



Stephen McMahon is cofounder of the Irish Patients Association. He has been instrumental in coordinating a Patient-Centered Advocacy group. Its primary focus is to support patients and their families who have had negative experiences within the healthcare system. We advocate for their rights, improved patient safety, and accountability within the Health Care System. His experience encompasses various domains such as Patient Advocacy, Communications, Policymaking, Standard-setting, Regulation, Education, and Research. Some of his specialties include Individual and Collective Patient Advocacy, Patient Safety, Health Care Regulatory Experience, Crisis Management - Patients/Public Interests, Serious Incident Review, Board Room Conflict Resolution, Non-Government Organisations. He is a founding signatory on behalf of the IPA to ACN's European Charter of Patients' Rights.

Diane-Estelle Ngatchou-Djomo, LUSS, Belgium



Diane-Estelle Ngatchou-Djomo is a dedicated Pharmaceutical Policy Manager at the Ligue des Usagers des Services de Santé (LUSS), where she focuses on critical issues related to medications and medical devices. In her role, Diane-Estelle advocates for patients' interests, ensuring accessibility, availability, quality, and health literacy in healthcare services.

In addition to her work at LUSS, Diane-Estelle is a PhD fellow at the United Nations University. Her research delves into the socio-demographic, economic, and political factors associated with medicine quality, aiming to enhance understanding and policy-making in this vital area.

Through her professional and academic endeavours, Diane-Estelle is committed to improving healthcare systems and outcomes for patient.

Marleen Struss, EPECS & euPrevent, the Netherlands



Marleen Struss is an advisor for the board of EPECS, a foundation that aims at improving the quality and accessibility of (cross-border) healthcare, and strengthening transparency and the exchange of information, for and with citizens.

Furthermore, she works at euPrevent, a cross-border network of organizations committed to enhancing the quality of life for citizens living in the border area between the Netherlands, Germany, and Belgium.

Her line of work lies within the promotion and execution of cross-border initiatives, projects and activities that support public health and citizen participation.

Mariano Votta, Cittadinanzattiva-Active Citizenship Network, Italy



Mariano Votta is graduated in Political Science at University of Rome. He has a Master in European Public Relations and a Master in Corporate Social Responsibility.

Last July 2013 he was nominated Responsible of EU Affairs at Cittadinanzattiva and Director of Active Citizenship Network, the European interface of the Italian civic organization Cittadinanzattiva, responsible for the international relations with public and private stakeholders such as the European Commission, EU Parliament, EESC, companies. He is a freelance journalist and programme manager too, with more than 10 years working in the field of citizens' rights, civic information, evaluation of quality standards in services provided by Public Administration and public companies. Between 2011 and 2012 he worked as consultant for the United Nations Development Programme in Colombia, to assert a new governance in the managing of Public Services and Health. In that Country, Cittadinanzattiva opened several Citizen Advisory Centre on Public Services and Health.

In 2015 he took the initiative to encourage and promote the MEPs Interest Group focused on patients' rights called "European Patients' Rights and Cross-border Healthcare" inside the EU Parliament.

Hui Wang, euPrevent, Netherlands



euPrevent project worker; Ph.D in law, working in public health since March 2020.



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