

Event summary report



The High-Level Policy Event "Towards a patient-centred EU mandate: Health policy with and for patients" took place on October 16th, 2024, in Brussels, Belgium. The event marked a step towards enhancing patient representation in healthcare policymaking, reaffirming the commitment to prioritise the voices of patients in every aspect of health policy development.



The voice of patients must be heard if we are to build the resilient, people-centred healthcare systems we seek.

Stella Kyriakides, European Commissioner for Health and Food Safety

• Some highlights



140
On-site participants



22
Guest speakers



2.5M
Social media impressions

• Programme overview

The High Level Policy Event concluded EPF's [#Vote4Patients](#) EU elections campaign by bringing together elected MEPs, EU policy-makers, health stakeholders, and patient organisations in a conversation about how to consolidate patient involvement in policy in the new EU mandate.

Building on the [EPF Patient Organisations' Manifesto](#) adopted at EPF's 20th anniversary celebration in 2023, this event took stock of progress in putting systemic patient involvement on the policy agenda and celebrated commitments made by EU elections candidates to support it during their mandate.

This event aimed to provide a greater understanding of the importance and added value of patient organisations' involvement in health policy and practice, as well as actionable proposals towards a more patient-inclusive EU mandate.

Moderated by Katrina Sichel

TIME	SESSION	SPEAKERS
12:00 13:00	Registration and networking lunch	
13:00 13:30	Opening remarks	<ul style="list-style-type: none"> Welcome by Marco Greco, President, European Patients' Forum Online intervention by Stella Kyriakides, Commissioner for Health and Food Safety, European Commission Video Message by Hans Kluge, Regional Director for Europe, World Health Organization Regional Office for Europe
13:30 14:30	Session 1: Patient involvement across the healthcare continuum Moderated by Anca Toma , Executive Director, European Patients' Forum	<ul style="list-style-type: none"> Melanie Carr, Head of Stakeholders and Communications Division, European Medicines Agency Marko Korenjak, President, European Liver Patients' Association Maya Matthews, Head of Unit, State of Health, European Semester, Health Technology Assessment, DG SANTE, European Commission Frederico Guanais, Deputy Head of the Health Division, Organisation for Economic Cooperation and Development Nathalie Moll, Director General, European Federation of Pharmaceutical Industries and Associations
14:30 15:00	Fireside chats	<ul style="list-style-type: none"> MEP Adam Jarubas (European People's Party, Poland) MEP András Tivadar Kulja (European People's Party, Hungary) MEP Ondřej Dostál (Non-attached, Czechia)
15:00 15:30	Coffee break	
15:30 16:30	Session 2: Supporting an effective patient movement: challenges and opportunities Moderated by Elisabeth Kasilingam , Vice-President, European Patients' Forum & CEO, European Multiple Sclerosis Platform	<ul style="list-style-type: none"> Baiba Ziemele, Board Chair, Latvian Network of Patient Organisations Martin Danner, Secretary General, BAG Selbsthilfe Germany Konstantina Boumaki, Board member & Youth Group member, European Patients' Forum Ildiko Vajda, Senior Advisor Digital Healthcare, Dutch Patients Federation
16:30 17:15	Fireside chats	<ul style="list-style-type: none"> MEP Tilly Metz (Greens, Luxembourg) MEP Vytenis Povilas Andriukaitis (Socialists & Democrats, Lithuania) MEP Kateřina Konečná (Non-attached, Czechia) MEP Stine Bosse (Renew, Denmark)
17:15 17:45	Closing remarks	<ul style="list-style-type: none"> Natasha Azzopardi-Muscat, Director, Division of Country Health Policies and Systems, World Health Organization Regional Office for Europe Anca Toma, Executive Director, European Patients' Forum
17:45	Cocktail and walking dinner	

- **Opening session**

The event began with introductory words from **Marco Greco**, President of the European Patients' Forum (EPF), who outlined the goals of the [#Vote4Patients](#) election campaign. He highlighted the limited understanding of what patient organisations are and do, and **the need for a definition** based on the European Medicines Agency's [definition](#), reflecting the values of transparency, legitimacy, democracy, representativeness, accountability, and consultation that form the basis of good governance.

Stella Kyriakides, European Commissioner for Health and Food Safety, praised the patient community for their input and advocacy. Patient contributions shaped the Commission's priorities as it started building the European Health Union "with patients at the centre", from the pharmaceutical legislation to the European Health Data Space. Collaboration with patient organisations is increasingly embedded in EU initiatives. For example, EPF and other patient organisations are helping identify contributing patients under the EU Health Technology Assessment (HTA) Regulation. Commissioner Kyriakides concluded that "without patient involvement, the lived experience of millions of Europeans would be unheard and [the European Commission] actions would be much less effective". [Her full speech is available [here](#)]

Dr Hans Kluge, Regional Director for Europe at the World Health Organization (WHO), recalled that EPF has been a long-time partner of WHO Europe. He stressed the importance of patients' lived experience and the role they play in shaping their healthcare. As outlined in the WHO [European Programme of Work 2020-2025](#), it is essential to work with partners - including patient organisations - to create synergies around key health priorities in order to achieve better results in different countries.



Plenary One: Patient Involvement Across the Healthcare Continuum

The first panel discussion, moderated by **Anca Toma**, Executive Director of the European Patients' Forum, showed the value of patient engagement throughout the healthcare continuum, from research and development of new medicines to regulatory approval, HTA, and the organisation of healthcare systems.



Marko Korenjak, President of the European Liver Patients' Association (ELPA), welcomed the progress made in recent years in involving patients. Patient involvement has moved from a 'tick-box' exercise to real involvement - as illustrated by the increasingly active role of patients in the European Medicines Agency. He acknowledged however the challenges of moving from 'patient engagement' to 'meaningful patient engagement', which still requires collective efforts, time, and resources.

Melanie Carr, Head of Stakeholder and Communication Division at the European Medicines Agency (EMA), noted that the value of patient involvement is well understood across the regulatory network, from increasing trust in the system to making the outcomes of regulatory work more meaningful. Publications have showed the impacts of patient input, such as [modifications of scientific advice responses in 20% of cases](#). The EMA continues to promote patient involvement, in particular in medicines' development, through an upcoming reflection paper on patient experience data.

Maya Matthews, Head of Unit State of Health, European Semester, Health Technology Assessment at the European Commission DG SANTE, noted how the Health technology Assessment (HTA) Regulation embeds patient involvement in the system, stating *"This is new territory so working together to make it a success is key. The HTA Regulation establishes a conflict of interest (Col) framework to build trust. Areas such as rare diseases might require mitigating measures to ensure access to the right expertise, but a solid framework is needed considering how Cols are perceived and used."*

Frederico Guanais, Deputy Head of the Health Division at the Organisation for Economic Co-operation and Development (OECD), spoke about the [Patient-Reported Indicator Surveys \(PaRIS\)](#) initiative, which measures healthcare systems' performance from the patient's perspective. The new set of indicators will help improve healthcare by focusing on impacts on people's lives and well-being. The PaRIS survey is an example of co-production with patient organisations.

Nathalie Moll, Director General of the European Federation of Pharmaceutical Industries and Associations (EFPIA), emphasised the value of involving patients in defining research priorities, to understand areas of unmet needs and real-world impacts of treatments and diseases. She highlighted certain challenges in clinical research that impact patients, such as fragmented legislation across the EU and lack of access to cross-border trials.

- **Fireside Chat with Members of the European Parliament**



The first fireside chat was an opportunity to reflect on topics such as access to medicines, health literacy and patients' rights.

MEP Adam Jarubas (European People's Party, Poland), Chair of the European Parliament's Health Committee (SANT), highlighted some of SANT's achievements in the previous mandate, including reinforcing EU agencies and establishing the Health Emergency Preparedness and Response Authority (HERA). He hoped that the committee will continue to support greater EU involvement in health policy in the new mandate. Regarding access to medicines, he mentioned the Parliament's proposed mechanism of mandatory pricing & reimbursement filing at the request of the member states under the pharma legislation as one concrete solution to improve equity across the EU.

Regarding health literacy, **MEP András Kulja** (European People's Party, Hungary), drawing on his experience as a health influencer and health professional, stressed the importance of communicating with patients and translating complex concepts in lay language. He expressed great concern about healthcare workforce shortages across Europe, which create patient safety risks and undermine trust in healthcare systems. He emphasised the need to work with patient organisations and hear their perspective on important health issues.

Finally, **MEP Ondřej Dostál** (Non-attached Member, Czech Republic) highlighted key learnings from his past experience as a lawyer and academic, namely that patients' rights in reality are more limited than on paper – e.g. on access to basic treatments, lack of mobility, etc. – and that patient groups play a key role in conveying the patient voice to the legislators. He also mentioned the need to improve transparency and the efficiency of healthcare systems.

Plenary Two: Supporting an Effective Patient Movement: Challenges and Opportunities

The second panel discussion, moderated by **Elisabeth Kasilingam**, Vice-President of EPF and CEO of the European Multiple Sclerosis Platform, reflected on the challenges and opportunities of the patient movement. Topics addressed related to advocacy, funding, youth empowerment, digitalisation, and the interweaving of national and European levels.



Baiba Ziemele, Chair of the Board of the Latvian Network of Patient Organisations, highlighted how her personal experience led her to engage in patient advocacy. She emphasised the lack of funding for patient organisations in Latvia and the very heterogeneous landscape of patient advocacy; most of the work is voluntary, which is not acceptable. Training and support at the European level to exchange best practices is therefore valuable.

The issue of funding for patient organisations was also raised by **Ildiko Vajda**, Senior Advisor Digital Healthcare at the Dutch Patients Federation, who noted that legislation should allow NGOs to be publicly funded while remaining fully independent from the government. On patient education and training, the Netherlands provides a good example, with a central organisation funded by the Ministry of Health. Organisations like the Dutch Patients Federation provide training on other issues, such as digital health. Lack of time however impedes patient representatives' participation in these programmes.

Martin Danner, Secretary General of BAG Selbsthilfe, Germany, presented the German example; patient groups can provide input as part of the national medicines agency's working groups. He highlighted the need for involvement of patient organisations rather than individual experts, as they ensure representativeness and coordination. On the issue of online communities of patients as a new model for engagement, he noted that patient organisations' compliance with governance principles and internal democratic processes is a key difference.

Konstantina Boumaki, EPF Youth Group member and Board member, however acknowledged the role of online communities in providing important peer support, even though the spread of misinformation on these platforms is often a problem. Building on her experience as an EPF Youth Group member, she mentioned the need to give young patients the space and resources to carry out their advocacy efforts, including within established patient organisations. She concluded by calling for a united patient movement to tackle issues that affect all patients, such as HTA and antimicrobial resistance (AMR).

- **Fireside Chat with Members of the European Parliament**

The second fireside chat was an opportunity to reflect on topics such as HTA, AMR, the revision of the pharmaceutical legislation, and EU health funding. A lively debate took place among MEPs on the opportunity and timeliness of a Treaty change to increase the EU’s competences on health.

MEP Tilly Metz (Greens, Luxembourg) expressed concerns about the upcoming negotiations on the next multiannual financial framework (MFF) and a possible merger of all current funding programmes into one Competitiveness Fund. She encouraged patient organisations to advocate for health funding with their health ministries. On AMR, she supported models to foster innovation based on milestone prizes and subscription models, combined with better stewardship measures. The WHO’s AMR Accountability Index will help benchmark countries’ progress.

On the same topic, **MEP Vytenis Povilas Andriukaitis** (Socialists & Democrats, Lithuania) recommended increased efforts on vaccination and a common methodology for evaluating antimicrobials. He strongly supported increased collaboration at EU level on health issues to avoid fragmentation, as well as increased financial resources.

MEP Kateřina Konečná (Non-attached, Czech Republic) welcomed some of the progress made as part of the pharma package, including a shortage reporting mechanism for patients. She hoped that cross-border healthcare will be addressed in the new mandate to solve the issues that patients still encounter. She also strongly supports joint procurement, especially for rare diseases, as a mechanism to improve access to medicines.

MEP Stine Bosse (Renew, Denmark) expressed some reservations regarding joint procurement as she believes it benefits wealthier countries disproportionately, even though they have the means to pay for their medicines. She supports a strong pharmaceutical industry in Europe to decrease dependence on other regions. Better access to cross-border healthcare is also needed, especially for rare diseases. Regarding AMR, she noted that patient organisations must mobilise; in particular, cancer patients are very vulnerable due to weakened immune systems.



• **Closing Session**



Natasha Azzopardi Muscat, Director of the Division of Country Health Policies and Systems, WHO Europe, and **Anca Toma**, EPF Executive Director, closed the event.

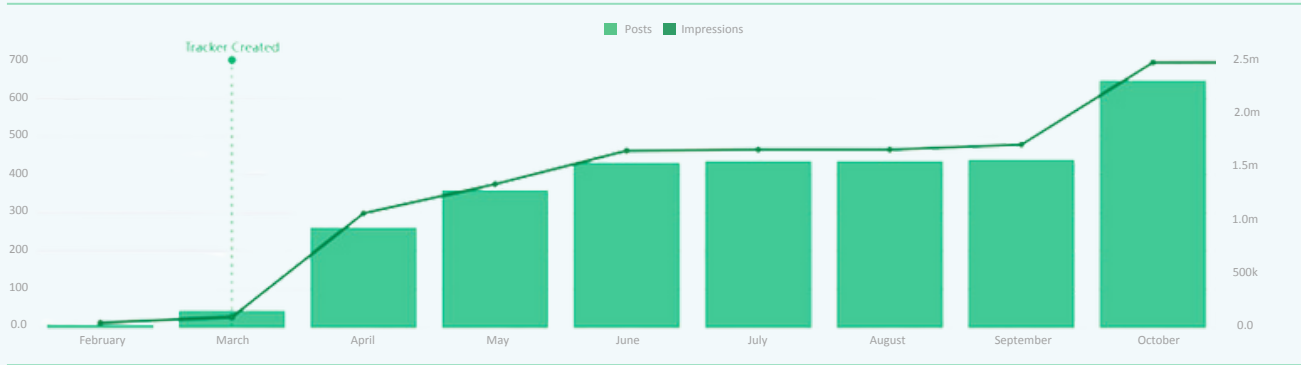
Natasha Azzopardi Muscat stressed the importance of multi-stakeholder cooperation for WHO, including patients, and encouraged patients to help transform health systems. She highlighted the need to support patients with health and digital health literacy and enable those who want to engage.

Anca Toma officially closed the event and the #Vote4Patients election campaign, which is however not the end of the journey. She outlined some of EPF’s future activities, including the development of a Barometer measuring patient involvement across European countries.



• **#Vote4Patients campaign**

The #Vote4Patients campaign generated 646 posts, 2488 engagements and 2.5M impressions on social media.



Stella Kyriakides @SKyriakidesEU · Oct 16, 2024

Patient voices must continue to be heard if we want to build people-centered health systems.

I am grateful to @eupatientsforum for their excellent contributions to our work.

#HealthUnion

European Commission and EU One Health

3 replies, 20 retweets, 56 likes, 3.2K views

Natasha Azzopardi Muscat · 1st

Director Country Health Policies & Systems at World Health Organization

No Patients and patient organizations have a key role to play in transforming our health systems

So that they will be able to trust that they will receive the right care at the right time in the right place from the right health worker without financial hardship.

This was my key message at the #VoteforPatients event organized in Brussels by [European Patients' Forum](#).

It was a privilege to hear from patients and from MEPs across the political spectrum.

[WHO Regional Office for Europe](#) is fully committed to implementing patient partnership. As our regional director Hans Kluge said at the opening "for us patient involvement is not a check list to be ticked off"

Patient engagement improves health outcomes for all.

Thank you [Anca Toma](#) for your invitation.

Boris Ajeganoff-Nielsen · 1st

Policy Advisor to MEP Stine Bosse (DK, Renew Europe) in the European Parli...

It's been a busy and productive couple of days working with MEP [Stine Bosse](#) on some of our core priorities: focusing on the link between competitiveness, delivering better public health outcomes for all Europeans, and bolstering ...more

with [Vlad Voiculescu](#) and 11 others

ELPA European Liver Patients' Association - ELPA

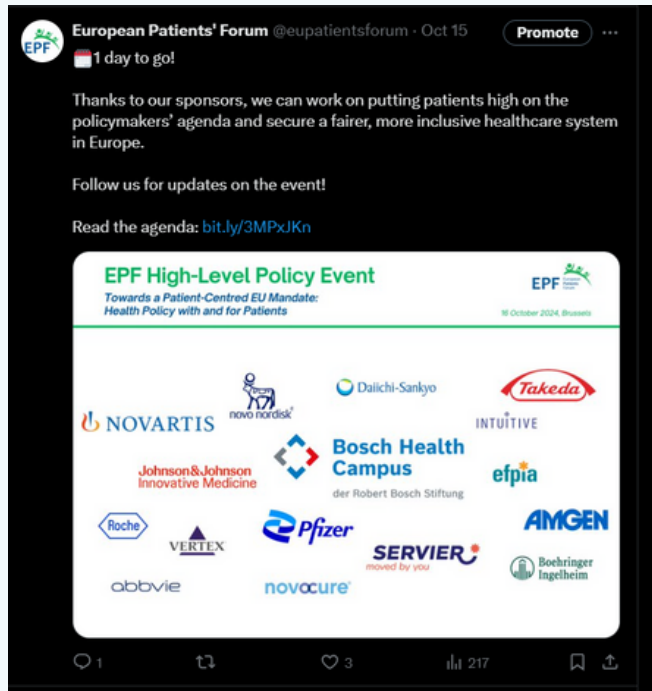
3,093 followers

"Wrapping up the EPF High-Level Policy Event with impactful closing remarks from [Natasha Azzopardi Muscat](#) of [WHO Regional Office for Europe](#), highlighting the urgent need for a patient-centred EU health mandate. ...more

• Thanks to our sponsors



• **Thanks to our sponsors**



• Event Posters and Contributions from Our Members

emsp EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Empowering Lives, Shaping the Future
A Manifesto for a United Approach to Multiple Sclerosis

EU's Disability Rights Strategy (2021-2030):
A targeted commitment aligning with human rights, equality, and social inclusion, featuring initiatives such as the Disability Employment Package and the upcoming Framework for Social Services of Excellence (expected in 2024).

EU's Incentives for research and innovation:
Through programs like Horizon Europe and EU4Health, the EU has shown significant progress in incentivising research and innovation in the field of rare diseases, including MS, playing a pivotal role in advancing treatment, symptom management, and fostering hope for an improved quality of life.

Charter of Fundamental Rights and European Pillar of Social Rights:
Ensuring the fundamental rights of older individuals and those with disabilities, emphasising dignity, independence, and active societal participation.

European Care Strategy:
A comprehensive approach spanning health, social care, employment, disability, and equality, notably emphasising long-term care challenges and the vital role of formal and informal carers.

www.emsp.org

EURORDIS RARE DISEASES EUROPE

#ACTRARE2024

CHAMPIONING THE RARE

The primary goal of the #ACTRARE2024 campaign was to urge candidates in the next European Parliament elections to prioritise rare disease. It aimed to improve the lives of people with rare diseases by advocating for better diagnosis, treatment, and care through policy changes and increased EU-level action. The campaign focused on ensuring that the central needs of the rare disease community are addressed.

1 IN 2,000 people have a rare disease	250 COMMON MEDICINES for EU
1 IN 20 people have a rare disease	20 OF FAMILY CARERS for EU
3 TIMES HIGHER number of people with rare diseases compared to the general population	

80+ MEMBER STATES
653,000 ESTIMATED PEOPLE WITH RARE DISEASES

2,000+ INDIVIDUALS AND ORGANISATIONS SUPPORTED THE OPEN LETTER SIGNATURES IN THE EU

16,902 LIVES
499 SOCIAL MEDIA IMPRESSIONS

LEARN MORE AT www.eurordis.eu AND [ACTRARE2024](https://twitter.com/ACTRARE2024)

EPF European Patients Forum

#Vote4Patients

TOWARDS A TRULY PARTICIPATORY, DEMOCRATIC, AND IMPACTFUL INVOLVEMENT OF PATIENT ORGANISATIONS

#Vote4Patients calls for a stronger involvement of patient organisations in European healthcare policy. The campaign focuses on advocating for patients to be actively included in all stages of health policy development and decision-making processes, and calls for sustainable funding to support patient organisations, ensuring their voices are heard and their missions fulfilled.

- 449 social media posts
- 1.7 million impressions
- 190+ signatories in the past 12 months
- 10+ languages for the Patients' Organisations' Manifesto

The petition **The Manifesto**

International Diabetes Federation

Together, United, Let's Act on Diabetes

Accelerating action on commitments to improve diabetes detection and quality of care.

On November 28, 2023, IDF Europe and WHO Europe signed a Declaration, recalling the urgent need for accelerating action on commitments to improve diabetes detection and quality of care. Since then, we have been encouraging individuals and organisations to endorse the Declaration to show policymakers that there is a need to be done to improve the lives of people living with diabetes (PwD) and those at risk.

About the campaign
As part of the campaign, we encouraged PwD, their families and carers, our member associations and people interested in supporting our cause to endorse the Declaration and share their reasons for endorsing in content-rich posts on our Declaration Endorsement Wall and social media.

Declaration Endorsement Wall
Since the beginning of the campaign, 90+ individuals and organisations shared their reasons for endorsing and care of diabetes in their respective countries. From better access to diabetes education and psychological support to the reimbursement of self-management technologies, our community members have the power and to make their own call for action relevant to their own priorities.

Objectives
The campaign aims to showcase what PwD would like to see improved in the prevention, management and care of diabetes in their respective countries. From better access to diabetes education and psychological support to the reimbursement of self-management technologies, our community members have the power and to make their own call for action relevant to their own priorities.

- 90+ endorsement tiles on the Declaration Endorsement Wall
- +20.5% endorsements since the signing of the Declaration
- 30+ countries engaged in the campaign
- 43K+ impressions across IDF Europe's social media channels
- 25+ languages used to translate the Declaration

Individuals and organisations endorsing the Declaration become part of a collective voice showing policymakers that health must be a priority.

#UnitedForDiabetes

European Lung Health Group

#KeepBreathing campaign

A vision for EU action on lung health 2024-2029

The European Lung Health Group (ELHG) is an informal group of nine European level patients' and healthcare professionals' organisations gathering 179 member associations across 34 European countries.

Our mission centres around bringing together know-how to support our organisations in empowering patients with lung diseases, improving early diagnosis, optimising multidisciplinary care, progressing quality of life, and research. At the European level, we reinforce the messages of our organisations to strive for better care, increased patient participation and improved prevention, to reduce fragmentation of knowledge and voices around lung health.

www.breathevision.eu

Members of the European Lung Health Group

• **Speakers**



Moderator Katrina Sichel
Brussels-based moderator



Dr Marco Greco
President of the European Patients' Forum



Stella Kyriakides
European Commissioner for Health and Food Safety



Dr Hans Henri P. Kluge
Regional Director for Europe at the World Health Organisation



Anca Toma
Executive Director at the European Patients' Forum



Melanie Carr
Head of the Stakeholders and Communication Division and Member of the Executive Board at the European Medicines Agency (EMA)



Marko Korenjak
President of the European Liver Patients' Association (ELPA) Co-chair of the Patient and Consumer Working Party and a member of the Pharmacovigilance Risk Assessment Committee (PRAC) at the European Medicines Agency



Baiba Ziemele
President of Latvia Hemophilia Society
Chair of the Board of the Latvian Network of Patient Organisations



Dr Martin Danner
Secretary General of BAG Selbsthilfe



Konstantina Boumaki
Board member of the European Patients' Forum Youth Group
Youth Group representative in the European Patients' Forum Board of Directors
Board Treasurer for the Hellenic Diabetes Federation



Kateřina Konečná
Member of the European Parliament, Non-attached, Czech Republic
Substitute member of the Environment, Health and Food Safety (ENVI) committee and the Public Health (SANT) subcommittee
Full member in the Internal Market and Consumer Protection (IMCO) committee



Stine Bosse
Member of the European Parliament, Renew, Denmark



Maya Matthews
Head of Unit State of Health, European Semester, Health Technology Assessment at the European Commission Directorate-general for Health and Food Safety (DG SANTE)



Dr Frederico Guanais
Deputy Head of the Health Division at the Organisation for Economic Cooperation and Development (OECD)



Nathalie Moll
Director General of the European Federation of Pharmaceutical Industries and Associations (EFPIA)



Dr Adam Jarubas
Member of the European Parliament, European People's Party, Poland
Chairman of the European Parliament Public Health Subcommittee (SANT)



Dr András Tivadar Kulja
Member of the European Parliament, European People's Party, Hungary
Vice-Chair in the Committee of Environment, Health and Food Safety (ENVI) of the European Parliament
Vice-Coordinator for the European People's Party (EPP), in the Public Health Committee (SANT)



Ondřej Dostál
Member of the European Parliament, Non-attached, Czech Republic
Member of the committee on Environment, Public Health and Food Safety (ENVI)
Member of the Delegation for relations with Southeast Asia (DASE).



Elisabeth Kasilingam
Chief Executive Officer of the European Multiple Sclerosis Platform (EMSP)
Vice President of the European Patients' Forum



Dr Ildikó Vajda
Senior Advisor Digital Healthcare at the Dutch Patients Federation



Tilly Metz
Member of the European Parliament, Greens, Luxembourg
1st Vice-Chair of the Subcommittee on Public Health
Member of the Environment, Health and Food Safety (ENVI), Transport and Tourism (TRAN), and Agricultural and Rural Development (AGRI) Committees



Vytenis Povilas Andriukaitis
Member of the European Parliament, Socialists & Democrats, Lithuania
Honorable chairman of Lithuanian Social Democratic Party



Dr Natasha Azzopardi Muscat
Director of the Division of Country Health Policies and Systems for Europe at the World Health Organisation