

EPF's policy priorities for the new mandate

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As we prepare to tackle current and future cross-border health challenges, the European Health Union must step up its coordination efforts to pave the way for greater access to high-quality healthcare for all. From equitable access to healthcare and medical products shortages, to cross-border health threats and EU health funding, EPF has put forward patient-centred proposals for the new mandate.

EQUITABLE ACCESS TO HEALTHCARE

Unacceptable inequalities remain within the EU in terms of access to medicines and healthcare more broadly. Between 2016 and 2019, out of 152 centrally authorised medicines, up to 88% were accessible to patients in larger Member States. Patients in small or low GDP Member States had access to fewer than 32% and had to wait significantly longer to access medicines¹. We support further EU action on:

- Expanding **regional cooperation initiatives on pricing & reimbursement** of new medicines and **use of joint procurement for medicines** that are less commercially attractive or out of reach in the poorest EU member states, including highly innovative treatments, orphan products, or older generics that are in shortage.
- Ensuring **adequate implementation of the Health Technology Assessment (HTA) Regulation**². The HTAR has the potential to significantly improve coordination of HTA processes across Member States, thereby reducing inequalities in access and improving transparency. We hope the HTAR will also support greater uptake of good practices related to patient involvement in HTA processes.
- As the EU reviews the **Pharmaceutical Legislation**³ and considers a future **Biotech Act**, it is essential to ensure a balanced approach between encouraging rapid research & development of safe and effective products that provide real added value to patients and ensuring equitable access. Innovation is only relevant if it reaches all patients and addresses unmet needs, as defined by patients. The regulatory framework for medical products and clinical trials should create the right environment for research and development while ensuring patient safety and access to the products they need.
- While providing accessible healthcare as close as possible to the patient should remain a priority, ensuring a robust framework for **cross-border access to healthcare** can help address remaining gaps. This is important for people who fall sick abroad, need access to different planned care options, and for patients with rare diseases who cannot access treatment at home⁴. We urge EU institutions to address gaps in the current framework for cross-border access to healthcare, thereby expanding patients' options and enabling them to receive the care they need.

¹ European Commission, EU Pharmaceutical Reform: Access to medicines in all Member States, February 2024: https://health.ec.europa.eu/document/download/5d6fb6a0-357f-47c9-8e11-844d17468bc8_en?filename=factsheet_market-launch_en.pdf

² EPF [joint statement](#) on joint clinical assessments and feedback on joint scientific consultations on [medicines](#) and [medical devices](#).

³ EPF recommendations for the revision of the EU pharmaceutical legislation, July 2023: <https://www.eu-patient.eu/contentassets/df1fab825da414aa4230a7abb1e1208/20230712-epf-recommendations-on-the-pharmaceutical-legislation.pdf>

⁴ Matthias Wismar et al.: Crossing the boarder for healthcare: adding value for patients and health systems, 2022: <https://iris.who.int/bitstream/handle/10665/351085/Eurohealth-28-1-51-56-eng.pdf?sequence=1&isAllowed=y>

MEDICAL PRODUCTS SHORTAGES AND A FUTURE CRITICAL MEDICINES ACT ⁵

In 2023, medicine shortages continued to affect all European countries and worsened compared to 2022 in most countries⁶. Shortages of medicines primarily impact patients, through unavailability of treatment, use of less suitable alternatives, and potential increases in safety issues. As a result, it is essential that any legislative or non-legislative measure to address this issue is **driven by public health**. We call for a comprehensive approach to shortages that prioritises communication to patients, coordination among all stakeholders, and transparency. In particular we call for:

- An effective **solidarity mechanism** between Member States, which must be accompanied by transparency on available stocks.
- An evidence-based approach to **public procurement** of medicines which takes into account security of supply as part of the award criteria.
- A thorough impact assessment of measures considered to **diversify and improve the resilience of the supply chain in Europe**. In this process, public health should be the driving factor. It is key to ensure that relocation of production improves the availability and quality of medicines available for patients and does not result in rising out-of-pocket costs and deprioritising other necessary public health investments.
- A thorough assessment of the implementation of the **medical devices and in-vitro diagnostic medical devices** regulations to gain a granular understanding of their impacts on patient safety and on availability of existing and new devices⁷.

CROSS-BORDER HEALTH THREATS

⇒ ANTIMICROBIAL RESISTANCE

According to recent data by the ECDC, antibiotics consumption has increased by 1% in 2023 compared with the baseline year 2019; 90% of total human consumption of antibiotics is in the community sector⁸. The incidence of certain antibiotic-resistant infections, such as carbapenem-resistant *Klebsiella pneumoniae* bloodstream infections, has worsened, sometimes significantly, over the same period⁹. This shows the need for increased action to reach the targets set in the European Council recommendations by 2030, including a 20% reduction in total human consumption of antibiotics.

A comprehensive approach to tackling AMR is needed, centred around community engagement and awareness-raising campaigns at EU level among healthcare professionals, patients, and the wider public, in close

⁵ EPF's call for action to ensure patients' continued access to safe, high-quality medicines across the EU: <https://www.eu-patient.eu/globalassets/policy/epfs-call-for-action-to-ensure-patients-continued-access-to-safe-high-quality-medicines-across-the-eu.pdf>

⁶ PGEU Medicine Shortages Report 2023: <https://www.pgeu.eu/wp-content/uploads/2024/01/PGEU-Medicine-Shortages-Report-2023.pdf>

⁷ Patient Perspectives on Implementation Challenges of the EU Medical Devices Regulations: EPF Survey Findings, November 2024: https://www.eu-patient.eu/globalassets/101176367_deliverable-3.1_patient-perspectives-on-mdrf-implementation.pdf

⁸ European Centre for Disease Prevention and Control, Antimicrobial resistance in the EU/EEA (EARS-Net) - Annual Epidemiological Report 2023, November 2024: <https://www.ecdc.europa.eu/en/publications-data/antimicrobial-resistance-eueea-ears-net-annual-epidemiological-report-2023>

⁹ European Centre for Disease Prevention and Control, Antimicrobial resistance in the EU/EEA (EARS-Net) - Annual Epidemiological Report 2023, November 2024: <https://www.ecdc.europa.eu/en/publications-data/antimicrobial-resistance-eueea-ears-net-annual-epidemiological-report-2023>

collaboration with civil society organisations¹⁰. The EU must further support member states to identify clear measures to reach the Council Recommendations targets by 2030 and effectively address the threat of AMR.

⇒ CHRONIC DISEASES

85% of deaths in the EU are due to chronic diseases including cancer, cardiovascular disease, chronic respiratory disease, diabetes, and mental illness¹¹. We need to learn the lessons of disease-specific initiatives such as the Beating Cancer Plan to apply across disease areas and focus on the impacts on healthcare systems.

⇒ THE HEALTH IMPACTS OF CLIMATE CHANGE

In a number of areas, the links between the environment and health are strong (pandemic preparedness and the risks posed by zoonotic diseases, food labelling, environmental risk factors of diseases). While supporting policies that promote a healthier environment, it is important to ensure that the green transition is well-coordinated and contributes to more sustainable and resilient healthcare systems.

EU HEALTH FUNDING

As the largest EU health programme ever implemented, the EU4Health programme aimed to support the strengthening of healthcare systems to prepare for future health threats in the aftermath of the Covid pandemic¹². It reflects available evidence that health is an investment, not a cost, with every euro invested in health estimated to generate, on average, an economic return of €14¹³. In this respect, we regret the budget cuts to the EU4Health programme and stand ready to work with the European Commission to ensure that the EU4Health programme is accessible to civil society organisations and that it is adequately funded to achieve its objectives.

Similarly, a strong research & innovation programme such as Horizon Europe supports essential public research that addresses identified health needs and dedicated health funding under the Cohesion Policy supports health action at regional level. As the EU institutions prepare the next **Multiannual Financial Framework**, we urge them to prioritise a strong, integrated, and streamlined EU health budget. We call on EU institutions to ensure that **this budget supports public health objectives, as well as research and policies that benefit patients and society at large**. Key focus areas from our perspective include:

- Strengthen the **resilience and sustainability of healthcare systems** to improve preparedness and better address future health threats. Almost five years after the COVID-19 pandemic, addressing healthcare professionals' shortages and ensuring more patient-centred healthcare systems remain key public health priorities. Twenty EU countries reported a shortage of doctors in 2022 and 2023, while 15

¹⁰ The European Patients' Forum (EPF), The AMR Narrative, Call for greater involvement of patient organisations to address antimicrobial resistance: <https://www.eu-patient.eu/globalassets/news/the-amr-narrative---epf-statement-unga-amr-september-2024-1.pdf>

¹¹ Brennan P, Perola M, van Ommen GJ, Riboli E; European Cohort Consortium. Chronic disease research in Europe and the need for integrated population cohorts. *Eur J Epidemiol.* 2017 Sep;32(9):741-749. doi: 10.1007/s10654-017-0315-2. Epub 2017 Oct 6. PMID: 28986739; PMCID: PMC5662668; <https://pmc.ncbi.nlm.nih.gov/articles/PMC5662668/>

¹² The EU4Health Civil Society Alliance's Statement For a Strong and Stable EU4Health Programme: <https://eu4health.eu/content/uploads/2024/05/for-a-strong-and-stable-eu4health-programme-eu4health-csa.pdf>

¹³ Masters, R., Anwar, E., Collins, B., Cookson, R., & Capewell, S. (2017). Return on investment of public health interventions: a systematic review. *J Epidemiol Community Health*, 71(8), 827-834: <https://pubmed.ncbi.nlm.nih.gov/28356325/>

countries reported a shortage of nurses. More than a third of doctors and a quarter of nurses in the EU are aged over 55 and expected to retire in the coming years¹⁴.

- Prioritise **health literacy and digital health literacy** to support a successful, patient-centred, digital transformation of healthcare systems. With the emergence of digital health technologies and limited healthcare resources, patients are increasingly expected to take a more proactive role in managing their health. In the general population, health literacy is a precondition to improve prevention, promote early diagnosis of diseases and fight misinformation, ultimately leading to better health outcomes. Citizens' awareness of their rights and understanding of the use and benefits of data-sharing are prerequisites for a successful implementation of the European Health Data Space at national level. As a result, we urge EU institutions to drastically step up their investment in health literacy and digital health literacy activities to promote patients and citizens' empowerment. This includes partnering with patient organisations to strengthen the governance of health data infrastructure and roll-out targeted campaigns and programmes to foster trust, training and education. Initiatives such as EPF's [Data Saves Lives](#) should be leveraged to ensure inclusive design of educational materials and spread awareness about the importance of health data, and improving understanding of how it is used. This includes explaining basic concepts related to data sharing, the data journey, and the safeguards in place to protect privacy and ensure ethical use.
- In line with the WHO Resolution on Social Participation¹⁵ and WHO Europe Engagement Plan with Non-State Actors¹⁶, recognise the **central role of civil society organisations** in supporting the EU in achieving its public health objectives. We call for the institutionalisation of sustainable, inclusive, and accessible operating grants to ensure civil society organisations have the resources and stability they need to fulfil their public health mission. This means, for example, a EU4Health programme with greater predictability, reduced bureaucracy, and lower levels of co-funding¹⁷.

Achieving these priorities requires engaging with patient organisations, which can make a major contribution to the development of more patient-centred healthcare systems. From reporting to communication and participation in policy-making processes, patient organisations play a key role along the healthcare continuum. They ensure that healthcare systems and policies meet the needs of those they are serving: the patients. EPF's manifesto highlights 10 key points to support more democratic and systematic involvement of patient organisations¹⁸.

About EPF

¹⁴ Health at a Glance: Europe 2024 State of Health in the EU Cycle: https://www.oecd.org/en/publications/health-at-a-glance-europe-2024_b3704e14-en.html

¹⁵ WHO, Social participation for universal health coverage, health and well-being, 28 May 2024, https://apps.who.int/gb/ebwha/pdf_files/WHA77/A77_ACONF3-en.pdf

¹⁶ WHO, Engagement plan with non-State actors: <https://iris.who.int/bitstream/handle/10665/379323/WHO-EURO-2024-2948-42706-59554-eng.pdf?sequence=1&isAllowed=y>

¹⁷ EPF's Interim evaluation of the EU4Health Programme 2021-2027, <https://www.eu-patient.eu/globalassets/the-european-patients-forums-feedback.pdf>

¹⁸ EPF's Patient Organisations Manifesto, towards a truly participatory, democratic, and impactful involvement of patient organisations: <https://www.eu-patient.eu/globalassets/manifesto-eng.pdf>

The European Patients' Forum (EPF) is an umbrella organisation of patient organisations across Europe and across disease areas. Our 80 members include disease-specific patient groups active at the EU level and national coalitions of patients representing over 20 countries across Europe. www.eu-patient.eu