EPF's reaction to the adoption of the WHO Roadmap for Action on Artificial Intelligence in Health in the European Region 2026–2033

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On October 29, the WHO Roadmap for Action on Artificial Intelligence in Health in the European Region 2026–2033 was adopted at the 76th session of the WHO Regional Committee for Europe in Copenhagen. The European Patients' Forum (EPF) welcomes the WHO Roadmap as an important framework for advancing the safe, ethical and human-centred adoption of artificial intelligence (AI) in healthcare, in line with the findings of our AI report published in May 2026. While supporting its overarching principles and priorities, EPF calls for the explicit recognition of patient organisations as essential partners in AI governance, meaningful patient involvement throughout the AI lifecycle, and greater attention to the opportunities and risks associated with AI-generated health information. EPF also stresses the importance of investing in high-quality, interoperable and secure health data, strengthening AI literacy, and ensuring that AI development is driven by clearly defined healthcare needs and delivers tangible benefits for patients.

Recognising patient organisations as essential partners in AI governance and implementation

The Roadmap identifies several principles and key actions that strongly resonate with the priorities of patient communities. We particularly welcome:

- The development of health-specific national AI strategies, which address the particular needs and sensitivities of AI in healthcare and ensure the integration of human rights, patients' rights, ethical values, equity and public interest principles
- The development of strong regulatory frameworks for AI tools
- The recognition of patients' role in reporting AI-related safety incidents
- The development of clear legal liability standards to protect patients
- The emphasis on strengthening national health data governance frameworks and digital infrastructure to build public trust, with data security, interoperability, public interest, and data quality and representativeness at the core
- The recognition of AI literacy for all, including healthcare professionals and the general public, as a key priority, with concrete actions proposed

At the same time, we regret that patient organisations are not explicitly mentioned as partners in the AI transformation. While WHO proposes actions to support community-building activities to facilitate engagement and collaboration among key stakeholders, but patient involvement should be embedded as a general principle across all activities and not limited to ad-hoc consultation. In the past, WHO had *acknowledge*d that "p*atient associations remain significantly underrepresented in these processes, highlighting a gap in inclusive engagement. Limited engagement carries the risk of producing tools that fail to meet real-world needs, reduce adoption or exacerbate inequities.*"[1]

We hope that this principle can be clearly reflected in the AI Roadmap. Patient organisations bring unique expertise on specific health conditions and lived experiences. They can provide valuable insights into the relevance, usefulness, accessibility and appropriateness of AI solutions in different healthcare settings. More specifically, this should translate into:

- **Meaningful patient involvement throughout the AI lifecycle**

In current practice, patient involvement in the design and development of AI solutions for healthcare remains limited, particularly during the earliest stages of development. Meaningful patient engagement should be embedded throughout the entire lifecycle of AI solutions, from the identification of unmet needs and the definition of research priorities to design, development, testing, deployment and post-market monitoring.

Involving patients in the development of AI technologies can contribute to a better understanding of these tools, which can, in turn, strengthen patients' acceptance of AI-enabled healthcare.

- **Addressing the growing role of AI in patient information**

An important development that could feature more prominently in the Roadmap is the rapidly growing use of AI chatbots by patients seeking health information.

Health-related questions are among the most common uses of AI chatbots, reflecting a broader transformation in how patients access health information and thereby reshaping the patient-doctor relationship.

While AI-generated health information can be misleading and lack clinical context, AI chatbots also offer opportunities to strengthen health literacy through low-cost, round-the-clock access to information in plain language, including for patients living in remote areas.

Realising these benefits requires educating patients and the general public about the opportunities and limitations of AI chatbots and other AI tools, while also integrating

[1] World Health Organization. Regional Office for Europe (2025). Artificial intelligence is reshaping health systems: state of readiness across the WHO European Region. World Health Organization. Regional Office for Europe. https://iris.who.int/handle/10665/383509. License: CC BY-NC-SA 3.0 IGO

training on how to discuss AI-generated information with patients, address misconceptions and support decision-making, into healthcare professionals' courses.

- **Empowering patient organisations to harness the health data transformation**

The growing political and financial attention devoted to AI should also recognise the fundamental importance of investing in high-quality, interoperable and secure health data infrastructure, with strong data protection and cybersecurity safeguards. Such infrastructure is a prerequisite for the safe and effective deployment of AI in healthcare. In this context, we see an opportunity to empower patient organisations to contribute to the collection of high-quality, representative health data, including through patient-led registries.

Patient organisations can help build trust, promote the inclusion of underrepresented populations and ensure that data collection reflects patients' needs and experiences. Patients and their representatives should also be meaningfully involved in the governance of health data access systems, helping to ensure that decisions on data use are transparent, accountable and guided by the public interest.

- **Ensuring that AI serves clearly defined healthcare objectives and patients' needs**

Ultimately, **AI is a means to an end, not an end in itself.** From a patient perspective, the central question should be: *what do we want AI to improve in our healthcare systems, and how can we ensure that these improvements translate into tangible benefits for patients?*

In a large-scale survey conducted by EPF, our members highlighted several areas where AI could bring significant benefits:

- More personalised care
- More accurate and timely diagnoses
- Better adherence to treatment and support for self-management
- Stronger prevention by supporting the transition from predominantly "reactive" healthcare systems towards more preventive models of care
- Improved access to reliable, understandable health information

These patient-identified priorities should guide the development, deployment and evaluation of AI in healthcare. Ultimately, the success of AI should be measured not by the pace of technological innovation or its uptake, but by its ability to improve health outcomes, patients' quality of life and equitable access to high-quality care.

In this endeavour, a strong and independent civil society voice is essential to ensure that the development and deployment of AI in healthcare are guided by patients' needs, fundamental rights and the public interest. Patient organisations have a crucial role to play in bringing patients' perspectives into policy and regulatory decisions, building trust, promoting AI literacy and ensuring that the benefits of AI reach all patients. Their meaningful involvement must therefore be recognised and adequately supported at every stage of AI development, governance and implementation.

About EPF

The European Patients' Forum (EPF) is an umbrella organisation of patient organisations across Europe and across disease areas. Our 81 members include disease-specific patient groups active at the EU level and national coalitions of patients representing 24 countries across Europe. www.eu-patient.eu