

# A Patient Call to Action

## *For a Trustworthy EHDS*

On 15 April 2026, patients met with researchers and policymakers at the European Parliament to share their expectations.

Building on these exchanges, this Call to Action outlines key principles for a trustworthy, patient-centred European Health Data Space (EHDS).

- **Ensure** transparency, security, and accountability across all systems and processes.
- **Promote** community-level representation in both the design and implementation phases.
- **Enable** seamless data sharing and collection in ways that reduce the burden on patients.
- **Strengthen** education and communication around use, including digital literacy and the benefits of EHDS.
- **Establish** clear oversight mechanisms to enforce and continuously improve systems at the national level.
- **Guarantee** individual control over personal health data, giving patients the ability to exercise their rights in practice.
- **Emphasise** the role of AI as a tool to enhance - and not replace - human interaction, supporting stronger engagement between patients and clinicians.

**Patients recognise the value of systematic data sharing and collection. Their main concern is ensuring these are implemented effectively across Member States so they can experience real benefits in practice.**