

19th European Patients' Rights Day

Exploring the benefits of health data sharing for patients, healthcare systems and medical research at the EU level

15 May 2025 | 14:30 – 16:30
 Room ASP 3H1 | European Parliament, Brussels
 Hosted by MEP **Brando Benifei** (S&D)

with the support of: Pfizer, Boehringer Ingelheim, VIATRIS

media partners: HEALTH EUROPA, MEDVIX PUBLICATIONS, TrendSanita

in the framework of: ACTIVE CITIZENSHIP NETWORK, CITTADINANZA ATTIVA

NEXT STEPS & ACKNOWLEDGEMENTS

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Final remarks

The digital transformation of health systems is no longer a futuristic goal, but an essential strategy to address the evolving health challenges faced in Europe¹.

The European Health Data Space (EHDS) aims to transform health data management across the European Union (EU), with the overall goal of improving individual care and facilitating data re-use for broader societal benefits.

By promoting transparency, participation and empowerment, the European Health Data Space aims to create a more inclusive and equitable healthcare environment. However, its success will depend, among others, on trust, digital literacy, effective governance, and harmonised implementation across EU Member States.

The European Health Data Space must be designed with inclusivity in mind, and to ensure the widespread adoption and success of the EHDS, it is crucial that patients feel comfortable sharing their data.

¹ "Digital transformation for better health and well-being in the European Region". International Journal of Medical Informatics (Accepted 2 April 2025). <https://doi.org/10.1016/j.ijmedinf.2025.105908>

EU and national Institutions must ensure effective governance of the European Health Data Space and stakeholder involvement (first and foremost citizens and health professionals) throughout the different stages of implementation of the European Health Data Space².

The management and use of health data and the protection of citizens' privacy is a high priority for Cittadinanzattiva-Active Citizenship Network, which intends to focus increasingly on these issues, taking into consideration the challenges and opportunities they present.

For this reason, as a follow-up to this European Patients' Rights Day, we intend to carry out a series of initiatives, some of which are already planned.

Next steps

Within the framework of the European FACILITATE project, we will organise a webinar on 25 June 2025³ to explore progress made in the Return of Individual Participant Data (RoIPD), the core aspect of the FACILITATE project⁴, and then a policy dialogue event here in the European Parliament in December, to which we would like to invite you. This will be an opportunity to present the ethical and legal framework developed by FACILITATE for the return of data to clinical trial participants.

In addition to these initiatives, we will seek to engage our constituency of civil society and patient organisations on this issue with:

- 2) An **EU online survey** on barriers and difficulties in accessing digital health in different EU countries.
- 3) An **EU advocacy session**, based on data from different countries⁵, to develop civic recommendations for the implementation of telemedicine services and other digital solutions (e.g. in Italy, the electronic health record).
- 4) An **EU training** on the value of health data sharing in the context of rare diseases, as access to and re-use of health data can be life-changing for people affected by rare diseases.

² "Embracing democracy in healthcare – Creating an inclusive and trustworthy European Health Data Space" (17 September 2024): <https://eurohealthobservatory.who.int/publications/i/embracing-democracy-in-healthcare-creating-an-inclusive-and-trustworthy-european-health-data-space>

³ More info: https://www.linkedin.com/posts/imi-facilitate_facilitateproject-roipd-clinicaltrials-activity-7318251662974828547-0W9/?utm_source=share&utm_medium=member_desktop&rcm=ACoAADOWyQ0Bo8iv635e5iBhjYAPXxVg3_j-CBA

⁴ Register here: <https://lnkd.in/dH2CsBvr>

⁵For Italy, data is available in the 'Civic Report on Health 2024' published by Cittadinanzattiva. www.youtube.com/watch?v=8YpquW61JqU; <https://panoramadellasanita.it/site/wp-content/uploads/2024/10/Rapporto-Civico-Salute-2024.pdf>

5) An **in-depth study** on the return and sharing of health data, with a focus on and examples from the field of vaccines.

In addition, there are two other areas we aim to work on:

6) What is the status of implementation of the **actions outlined in the National Recovery Resilience Plan to digitise healthcare**? We see the need for a discussion with all stakeholders, starting with national and European institutions, to report on what has been achieved so far and on the state of progress.

7) **Job strain and digital transition for the health workforce**. How can the digital transition reduce work-related stress among health professionals? What do health professionals, and nurses in particular, need to drive forward the digital transition in healthcare? In Italy, we are collaborating on a research project promoted by Cittadinanzattiva, the San Donato Group in Bologna and Vita-Salute San Raffaele University⁶. It would be interesting to compare experiences and studies from different European countries.

Acknowledgements

And now, as usual, I have my long list of acknowledgements.

Thanks again to all of you for attending, including those who joined us remotely.

Thanks to the EU institutions and to the hosting MEP Brando Benifei. Thank you, Mariam, and thank you to all the speakers.

Many thanks to the Polish Institutions, in the person of:

- The Minister for European Union Affairs Adam Szłapka, who decided to grant the patronage of the Polish Presidency of the Council of the European Union, so that the European Patients' Rights Day 2025 became part of the Presidency's calendar.
- The Polish Commissioner for Patients' Rights Bartłomiej Chmielowiec for also granting the honorary patronage.

⁶Research by Valentina Di Mattei, Associate Professor at the Vita-Salute San Raffaele University, Head of the Clinical Health Psychology Service at the IRCCS San Raffaele Hospital; Gaia Perego, Researcher at the Vita-Salute San Raffaele University, Psychologist and Psychotherapist; Francesca Milano, PhD student at the University of Milan Bicocca, Psychologist specialising in psychotherapy. More info on the 'Civic Report on Health 2024' by Cittadinanzattiva. www.youtube.com/watch?v=8YpquW61JqU; <https://panoramadellasanita.it/site/wp-content/uploads/2024/10/Rapporto-Civico-Salute-2024.pdf>

And, more generally, for their decision - as already mentioned – to commit to taking concrete steps towards the official adoption of the European Charter of Patients' Rights at EU level, as set out in the recently published [White Paper “Healthcare Policy Recommendations”](#).

I would like to mention that this European policy dialogue event was also made possible thanks to the EU-funded project FACILITATE (FrAmework for ClInical trial participants' daTA reutilization for a fully Transparent and Ethical Ecosystem) and the unconditional support of Pfizer, Boehringer Ingelheim and Viatris, which I would like to thank.

Thanks also to our three media partners: Health Europa, TrendSanità-Policy and Procurement in HealthCare and Medvix Publication, publisher of the peer-reviewed Journal of Medical and Clinical Case Reports (ISSN 2997-6022).

As always, many thanks to all my colleagues who have worked on this initiative, especially Daniela, Bianca and Veronica, who are here with us today, and all those who work in Italy.

As usual, all of today's presentations will soon be published on our website and circulated through our monthly newsletter.

I wish you a pleasant rest of the day. Arrivederci.