Towards a European Health Data Space Joint Action (TEHDAS)

Citizen [consultation](#) bring run by Belgian Public Health Agency (Sciensano) until 4th April

Why this initiative?

The European Commission will publish in early April its proposal for a European Health Data Space (EHDS) regulation. This upcoming legislation is the first of its kind at the European level and is meant to promote better exchange and access to different types of health data (electronic health records, genomics data, data from patient registries etc.), not only to support healthcare delivery (so-called primary use of data), but also for health research and health policy making purposes (so-called secondary use of data).

The EHDS might be the first structuring opportunity at EU level to organise prevention policies and the delivery of healthcare at once, granting an active role and rights to patients while deepening the doctor-patient relationship.

What is it?

While the institutions are advancing on the regulation, the EU has launched Towards a European Health Data Space Joint Action (TEHDAS), an initiative including several Ministries of Health, to support the setup of the Health Data Space. The Belgian Government has launched a consultation to gather citizens' views. The consultation is structured in four main topics around the use of health data. The results of the [consultation](#) will be then presented to the European Commission and the EU Member States.

The European Lung Health Group issued a policy brief on the future European Health Data Space regulation and has published the recommendations within that policy brief into each of the topics.

How to participate?

Ideas can be voted on by citizens so the ELHG would like to promote the ideas from the [policy brief on the European Health Data Space](#) and encourage our network of patients and healthcare professionals to vote for them.

To vote on an idea, patients need to [sign up](#). To submit an idea, patients must respect the rules. We recommend publishing ideas that do not surpass 150 characters.

1. **What should your health data be reused for?**

[HCP-patients comms] Our data should be used to improve respiratory HCP-patient communication, co-decision making and build on patient reported outcomes (PROs).
https://ourhealthydata.eu/topics/1398/entries/18430

[Multidisciplinary care] Our data should help multidisciplinary care teams to deliver better clinical and quality of life outcomes via digital tools. https://ourhealthydata.eu/topics/1398/entries/18548

[Treatments] Our data should help improve personalised access to old and new medicines, such as biological drugs and gene therapies for respiratory disease.
https://ourhealthydata.eu/topics/1398/entries/18549

[Trials] Our Real World Data should be used in remote trials to gain more understanding of how treatments work in the real world, especially in rare and low prevalence diseases. https://ourhealthydata.eu/topics/1398/entries/18550

[Environmental data] My health data should be interconnected with other data sources so that the health sector integrates external data sources relevant for public health. For example, linking lung health with environmental risk factors such as weather forecasts, activity monitors and air quality data. https://ourhealthydata.eu/topics/1398/entries/18551

2. **Under which conditions should your health data be reused?**

[Early warning] Use my data to inform disease-specific 'early warning systems' to enable patients and clinicians to spot problems, such as impending lung exacerbations. https://ourhealthydata.eu/topics/1400/entries/18552

[Mobility] My data should be used to facilitate my healthcare choices, mobility and transferability to deepen cross-border healthcare in Europe This is particularly important in rare diseases and in the context of European Reference Networks (ERNs). https://ourhealthydata.eu/topics/1400/entries/18553

[Public interest] Strong boundaries should be created, guiding the feasibility and ethics standards for big data health research to ultimately serve patients. https://ourhealthydata.eu/topics/1400/entries/18554

[AI] My data should enable Artificial Intelligence (AI) and machine learning for clinical decision support systems These support systems could lead to new diagnosis and treatment algorithms, simulating and predicting outcomes. However, there needs to be quality control and fail-safe mechanisms developed with healthcare professionals. https://ourhealthydata.eu/topics/1400/entries/18555

3. **How would you like to informed and involved in the reuse of your health data?**

[Patients' rights] Patients should be the ultimate controllers of their health data. They need to know who is using their data, where and how data are stored, monitored, shared, processed, kept safe, how consent is granted and withdrawn, and their digital health footprint, to build trust with the system. https://ourhealthydata.eu/topics/1399/entries/18556

[Patient friendly] Patients need to be informed through digital spaces that are patient and HCP friendly and affordable. https://ourhealthydata.eu/topics/1399/entries/18557

[Patient education] Patients need to be educated with patient friendly materials on how health data is produced, accessed and secured, their role and protection. https://ourhealthydata.eu/topics/1399/entries/18558

[Patient involvement] Invest in patient education to explain how health data can serve patients and the community and encourage patients to participate in their care. https://ourhealthydata.eu/topics/1399/entries/18559

[Patient data] Empower patients to manage and develop their own health data in an easy and not burdensome way. This could lead to the creation and sharing of data that is currently lacking.
https://ourhealthydata.eu/topics/1399/entries/18561

[Centralised platforms] Centralise individual patient's health data through everyday devices (i.e. laptop, smartphone, smartwatch) and platforms. Patients want to be enabled to manage their own care and HCPs of their choice, to improve their own health outcomes.
https://ourhealthydata.eu/topics/1399/entries/18562

4. **What other ideas do you have on health data reuse?**

[Framework] Establish a clear legal framework for digital solutions addressed to patient users.
https://ourhealthydata.eu/topics/1452/entries/18563

[Create registries] Foster systems to enable patients to **generate data** for their needs (self-management) and preferences. These systems should lead to the establishment and development of patient registries that collect Patient Reported Outcome Measurements (PROMs) in all aspects of care, including daily life treatment outcomes, with a view to improve patients' Quality of Life (QoL).
https://ourhealthydata.eu/topics/1452/entries/18564