

European Health Data Space: Giving Patients Control

European Health Data Space Policy Brief | [Download PDF](#)

The aims of the [European Commission's](#) European Health Data Space (EHDS) are twofold:

1. To improve people's access to, and control over their personal electronic health data in the context of healthcare (primary use).
2. To better use health data for other purposes that would benefit society, such as research, policy-making and innovation (secondary use).

Unfortunately, the attainment of these goals is under threat. Instead, there is a risk that patients will lose control over their health data, that their data are exploited and that people, particularly those in vulnerable situations, will be negatively impacted. However, the EHDS legislation does provide an opportunity for Member States to introduce stronger protections of patients' rights.

In this policy brief we give examples of potential scenarios examples to demonstrate the potential consequences of a failure to act, as well as recommendations for concrete measures to ensure that patients are truly in control of their data.

Our recommendations cover the following:

- Limit the use of opt-out exceptions
- Make opt-out processes accessible and involve patient groups in their development
- Create an opt-in mechanism for genetic data
- Guarantee that the EHDS serves the public interest

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