

# Personal data: It's about control, not ownership

In the age of Big Data and personalized medicine, health research is increasingly driven by vast amounts of personal data. This data holds the promise of groundbreaking insights, from understanding complex diseases to tailoring treatments for individual patients.<sup>1</sup> Amid this data revolution, sometimes we hear the assumption that individuals “own” their personal data. However, when we examine the legal framework in the European Union (EU) and in Belgium, we find that “data ownership” does not exist. In reality, the data protection legal framework speaks about rights and obligations granted to and imposed on different parties, and emphasizes data control.

## WHY DO WE STILL HEAR ABOUT DATA OWNERSHIP?

As explained by prof. Griet Verhenneman in HDA's training on “The right to privacy and data protection”,<sup>2</sup> legally data ownership would imply that we acknowledge to one party the exclusive right to solely decide about who can e.g. hold, collect, or destroy data. However, such a property or ownership right is not recognized in the EU or in Belgium. People rather use it as a metaphor: individuals who say they ‘own’ their personal data often want ‘to have a say in who uses their personal data, how, and to prevent possible abuses against them based on their data’. It is an intuitive statement about control over data, as well as about dignity and autonomy.<sup>3</sup> Our right to data protection cannot simply be traded, nor personal data can be considered as a “tradeable commodity”.<sup>3</sup> Therefore, the existing legal framework does provide ways to be in control and carefully balances the individual versus the societal interests in data use, while protecting the individuals' fundamental rights.

## SO WHAT ABOUT DATA PROTECTION AND DATA CONTROL?

The notion of data control is central to the fundamental right to data protection and to the EU General Data Protection Regulation (GDPR). According to the European Commission, control can be achieved through “tools and means to decide at a granular level about what is done with [the individual's personal] data”.<sup>4</sup> We could understand such tools as individual and collective. Research has shown that patients highly value both types of control.<sup>5</sup>

**Individual data control** tools from a legal perspective could be, e.g., the rights provided to individuals under the GDPR (so called data subject rights). These rights impose obligations on other parties who use the data (so called data controllers, e.g. hospitals, companies...). Examples of such rights are the right to be informed (which is crucial for enabling control), the right of access, right to data portability<sup>6</sup>, the right to erasure, the right to object to the processing of personal data... The new European Health Data Space (EHDS) regulation will further strengthen such rights, thus providing individuals with greater control.<sup>7</sup> For example, the EHDS aims to ensure individuals have access to their health data in electronic form immediately and without any cost (and fun fact: Belgium is the frontrunner among EU Member States in providing access to electronic health records, according to a recent report by the OECD and the European Commission<sup>8</sup>). The EHDS establishes also an opt-out when it comes to the secondary use of data.<sup>9</sup>

1 For more information, see Health Data Talk Series, HDA Academy: Value of secondary use of data for health care users: <https://academy.hda.belgium.be/course/view.php?id=30>

2 For more information, see Privacy & Data Protection, HDA Academy : <https://academy.hda.belgium.be/course/view.php?id=11>

3 Prainsack, B., Forgó, N. Why paying individual people for their health data is a bad idea. Nat Med 28, 1989–1991 (2022). Available at: <https://www.nature.com/articles/s41591-022-01955-4>

4 European Strategy for Data, available at: <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52020DC0066>

5 Laloja-Spinks T, Saesen R, Silva M, Geissler J, Shakhnenko I, Camaradou JC and Huys I (2024) Patients' knowledge, preferences, and perspectives about data protection and data control: an exploratory survey. Front. Pharmacol. 14:1280173. Available at: <https://www.frontiersin.org/journals/pharmacology/articles/10.3389/fphar.2023.1280173/full>

6 The right to receive our personal data in a structured, machine-readable format and transfer it or request for it to be transferred to another data controller (e.g., another hospital), if this is technically feasible (see also article 20 of the GDPR).

7 Questions and Answers on the European Health Data Space, available at: [https://ec.europa.eu/commission/presscorner/detail/en/qanda\\_24\\_2251](https://ec.europa.eu/commission/presscorner/detail/en/qanda_24_2251)

8 OECD/European Commission (2024), Health at a Glance: Europe 2024: State of Health in the EU Cycle, OECD Publishing, Paris. Available at: [https://www.oecd.org/en/publications/health-at-a-glance-europe-2024\\_b3704e14-en.html](https://www.oecd.org/en/publications/health-at-a-glance-europe-2024_b3704e14-en.html)

9 For more information, see Health Data Talk Series, HDA Academy: Opting-out from secondary use of data: <https://academy.hda.belgium.be/course/view.php?id=34>

**Collective data control** tools are increasingly recognized and discussed as well. For example, such tools could include delegating individual control to a trusted third party (as proposed in the Responsible Research and Innovation (RRI) tool 8 caring technology principles<sup>10</sup>), or enriching individuals means of control with collective actions – e.g., the GDPR provides not-for-profit organizations with the right to make complaints and litigate in the name of individuals. New laws (such as the EHDS regulation and the Data Governance Act, DGA) also establish tools that can be seen as collective ones. The DGA puts in place a special category of data intermediation services which seek to assist individuals in exercising their data subject rights. Moreover, collective control could be linked to patient engagement and involvement at a community level – for instance, involving patient representatives in strategic decisions about data use and data sharing. Finally, collective control could play a valuable role in mitigating some of the risks that individual control could hold (e.g., in instances when individual control is being framed as a personal responsibility, resulting in an excessive administrative and psychological burden for citizens).

**We should remember that control is not absolute** – the law balances the individual rights versus the societal interest in using personal data, and control might not be possible to exercise in full in some cases, for justified reasons. For instance, the right to erasure might not be available when the data is being used for scientific research and the party using the data provides appropriate safeguards.

Moreover, **control must not burden** individuals with the responsibility to prevent misuse of their personal data. Rather, we should strive towards keeping and building a research system that fosters trust and where all stakeholders involved in data use are held appropriately accountable. One of the means to achieve this is **data solidarity**<sup>11</sup>. A prerequisite to guarantee trust is (digital) health literacy, a person's ability to understand health information so that they can maintain or improve their health and their quality of life. In health literate organizations this is an organizational value infused into all aspects of planning and operations.

## KEY MESSAGE

While the language of data ownership might at first glance resonate with our intuitive understanding and moral beliefs, it is essential to be aware of and understand the existing data protection framework and the opportunities that data control present. The existing laws in the EU and Belgium ensure that personal data can drive innovation while protecting the fundamental rights of individuals.

## Signed by the Health Data Talk Series group:

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<sup>10</sup> For more information, see: <https://www.caringtechnology.be/8-principles>

<sup>11</sup> See Prainsack B, El-Sayed S, Forgó N, Szoszkiewicz Ł, Baumer P. Data solidarity: a blueprint for governing health futures. Lancet Digit Health. 2022 Nov;4(11):e773–e774. Available at: [https://www.thelancet.com/journals/landig/article/PIIS2589-7500\(22\)00189-3/fulltext](https://www.thelancet.com/journals/landig/article/PIIS2589-7500(22)00189-3/fulltext) and Health Data Talk Series, HDA Academy: Data Solidarity in Health Data <https://academy.hda.belgium.be/course/view.php?id=31>