

HEALTH DATA TALK SERIES:

Value of secondary use of data for health care users (data saves lives)

Health data has been on the health agenda already for many years. Since then, many pilot projects, discussion groups, roadmaps, etc. have been performed and written. Today with the European Health Data Space (EHDS)¹ regulation on our doorstep, the momentum is there to scale up what works and to bring harmonization to the bottom-up projects. The data ecosystem already agrees on several elements of **secondary use of health data**. The “Health Data Talk Series” is a series of short opinion articles from different authors within the data ecosystem explaining some of the key topics related to secondary use of health data. We acknowledge and appreciate each other’s opinion as each article is signed by several stakeholders. Our goal is to go beyond the discussion of where we already have strong knowledge and to move further building a **strong health data ecosystem** to improve our healthcare and to enforce the competitiveness of Belgium within Europe and worldwide.

WHAT ARE HEALTH DATA?

Source: Health Data Agency Academy: Health data, what you need to know.

Health data refers to personal information² (also called personal data) that relates to the **health status** of a person. This includes **medical data** (diagnosis, doctor referrals and prescriptions, medical interventions, medical examination reports, laboratory tests, radiographs, data acquired or processed in the context of health research or policy making, such as disease registries or data from registries with side effects of medicinal products or medical devices, etc.), **patient-reported data** (health results, health consequences, subjective well-being, treatment adherence, sick leave and back-to-work, ...) **administrative** and **financial information** about health (including invoices for healthcare services and medical certificates for sick leave management, etc.), but also **determinants of health** (social, behavioral, environmental)³.

1 More information on the EHDS can be found on the [Health Data Academy website](#).

2 Personal data in laymen’s terms: personal data is information about a particular natural person that allows, or could allow identifying the person. It is important to distinguish between identifiable data (even if it is key coded) and data that is rendered completely anonymous, as the Regulation applies to the former, and not the later (Recital 36). It may be any information relating to an individual, whether it relates to his or her private, professional or public life. To be covered by the Regulation the data need to be collected and used by someone else (a person or legal entity). Source : European Patients Forum : [Data protection guide for patient organizations](#)

The legal definition under GDPR: According to the EU General Data Protection personal data is “any information relating to an identified or identifiable natural person (...); an identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person” (Article 4(1) GDPR).

3 Source European Commission (2022): [A European Health Data Space: harnessing the power of health data for people, patients and innovation](#)

Health data is as such any information about health. This includes (but is not limited to):

- health conditions
- lifestyle factors (for example exercise level, smoking habits)
- demographics (for example, age, gender, education level)
- medications
- treatments
- behaviours
- diagnoses
- causes of death
- quality of life
- test results (such as blood tests, X-rays or scans)
- invoices for health services
- patient reported outcomes, patient satisfaction,...
- patient health records
- studies of the health of groups of people
- results from research studies
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All these health data are stored in many different sources (electronic health records, disease registries, wearables, hospitals, health insurances, ...)

THE USE OF HEALTH DATA

'Data saves lives'⁴ – starting with your own.

Individual health data are critical for the treating physicians and medical teams to offer the best possible treatment. If the data is collected specifically to support the individual patient care, it's called **primary use of data**.

'Data saves lives'—your data contributes to saving others.

The re-use and aggregation of combined data from patients or healthcare users is equally important, as it allows researchers, healthcare providers, and policymakers to gain deeper insights into the root causes of diseases, identify the most effective treatments, and enhance healthcare delivery. Simply put, the treatment you receive today is the result of data collected and analyzed from others with the same condition. By sharing your data, you help future patients in the same way. This practice is known as the **secondary use of data** and is key to advancing the quality of care for all. The figure below explains the different advantages of secondary use of data⁵.

WHY WILL EVERYONE BENEFIT FROM SHARING AND OPTIMALLY ANALYSING HEALTH DATA⁵

Prevention, screening and treatments



Data can tell a lot about the effectiveness of (new) drugs, (new) vaccines, (new) treatment, (new) medical technologies and preventive measures.

Health care planning and evaluation



Data help identify who has what health care needs and whether our health care system provides sufficient quality and value for what it costs us.

Individual care



It is important that all healthcare providers have the same, up-to-date information about a person's health (regarding medication, tests, treatments, results,...).

Understanding diseases



Bringing together and analyzing data from many patients can provide insight into disease onset and progression.

Patient safety



Health data are crucial for tracking adverse reactions to drugs, vaccines, medical technologies, medical procedures, ...

Disease dashboards



Using dashboards with patient community data by disease will help to track disease progress, share insights on optimal care, and ultimately enhance care effectiveness and efficiency for every disease.

4 Source Data saves lives : <https://datasaveslives.eu/>

5 This Figure was inspired by: King Baudoin Foundation (2022): [Zorg voor je gezondheidsdata](#).

PRIVACY AND DATA PROTECTION

Health data, due to its sensitive nature and the risks its use and re-use could pose to the fundamental rights and interests of individuals, has received specific protection under the EU General Data Protection Regulation (GDPR) and Belgian national rules. The GDPR key principles and safeguards are an enabler to collect and process data with respect for the data subjects⁶. GDPR embodies the willingness to work with and share data, taking into account our European fundamental rights traditions. Data protection means that data subjects, data holders and data users have rights and obligations. For a training on privacy and data protection, we refer to the training video of the Health Data Agency (HDA)⁷ in which important principles like anonymization and pseudonymization are explained as well⁸.

THE HEALTH DATA AGENCY


The HDA established by law in 2023 will facilitate and stimulate the findability, accessibility, interoperability and re-use of health data in Belgium, while maintaining strict privacy standards. Their mission is to make more quality health data available for secondary use for research, product development, AI decision tools, and policy in Belgium. Moreover, the HDA wants to improve training of all data users, data holders and citizens in their knowledge of correct secondary use of data. To support this mission, they established a dedicated HDA Academy.

DATA TALK SERIES

In the upcoming weeks, our community will share views on hot topics within the domain of secondary use of health data such as the opt-out mechanism in the EHDS, what is data solidarity, real-time patient outcomes, etc. Stay tuned at the HDA Academy website: <https://academy.hda.belgium.be/>

We hope you enjoy reading!

Signed by the Health Data Talk Series group:

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6 A data subject is the individual the personal data relates to.

7 The training on privacy and data protection can be found on the [Health Data Academy website](#).

8 For more information on anonymization and pseudonymization, see Health Data Talk Series article: *Opting-out from secondary use of personal electronic health data within the European Health Data Space* available on the [Health Data Academy website](#).