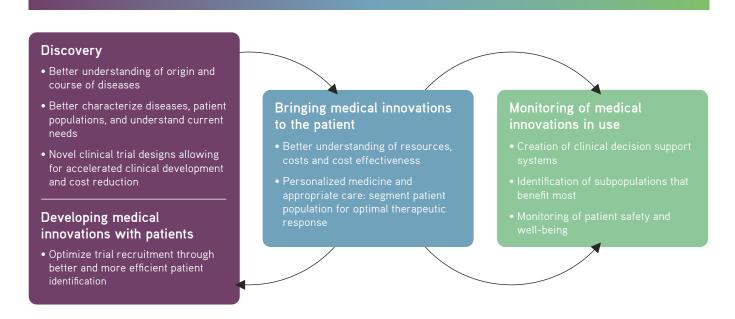
HEALTH DATA TALK SERIES:

Secondary use of data leading to innovation in health (from an industry perspective)



WHAT IS IT ABOUT?

Secondary use of health (care) data in the industry refers to utilizing **real world data** (RWD) originally collected during routine healthcare delivery (e.g. data from electronic health records, medical devices, (insurance) claims) for purposes beyond the original intent, typically for **policy making, research and innovation purposes**.

Secondary use of health data leads to innovation in medicines and medical technologies

The (bio)pharmaceutical and medical technology (medtech) sector invests more than any other sector in research and development (<u>EU industrial R&D investment scoreboard 2020</u>). Around 7.000 medicinal products are in development that will play a key role in solving problems of patients and healthcare systems. One of the most powerful levers for innovative research and evidence generation in these sectors are health (care) data collected during clinical trials, which are more and more supported with the evidence from secondary use of health (care) data.

In (bio)pharmaceutical and medtech research, the potential of health data is relevant throughout the whole lifecycle of a medicine or medical technology and enables to:

- gain deeper **scientific insights** into diseases (for example by combining data from clinical trials with data from electronic health records or patient registries we get a more comprehensive view of a disease);
- better **understand** how different people respond to different treatments (for example by stratifying patients by clinical or demographic characteristics (based on the input from secondary data sets) we get a better understanding how different people respond to treatments);
- develop innovative treatments and/or diagnosis tools based on these scientific insights;
- discover new therapies using **Artificial Intelligence** (AI) (for example AI can analyze complex (real world) genetic datasets to identify biomarkers that can guide the development of new medicines and diagnostics);
- optimize clinical trial protocols and compare a broader range of outcomes;
- optimize cost-effectiveness analyses to support reimbursement decisions;
- improve **patient safety and well-being** (for example by assessing long-term efficacy and safety of treatments with data routinely collected by health care providers);

Additionally, secondary data use helps also to identify trends and patterns in healthcare, essential for developing effective and efficient healthcare strategies.

What about patient privacy?

Strict European regulatory frameworks protect personal data and set clear guidelines for data usage and sharing. ensuring patient privacy. Because health data is sensitive, it can only be "re-used" for research in compliance with the General Data Protection Regulation (GDPR), the European Health Data Space (EHDS) regulation and Belgian data protection and privacy rules. To stimulate secure data research, the life science industry together with several data holders have agreed upon common principles and translated these together into guidelines1 and templates for research based on secondary use of data.

Moreover, new technologies as federated data networks prevent data from being transferred from its source to the data user. The data stays at its location where the research question is brought to the data in a secured environment and only the anonymous, aggregated results are transferred to the researcher. As a life science sector we support these privacy by design networks that also can connect data sources in this secured environment leading to better substantiated results.

The Belgian health data ecosystem can be outstanding in Europe

Belgium holds important keys to building a robust health data ecosystem and strengthening its position in the healthcare sector. Belgium already collects a vast array of health data, ranging from administrative data², clinical results typically collected by the physician³ and information on the scale and use of interventions and medicines to genetic and molecular data4. In terms of e-health and data infrastructure, Belgium is ranked number one in Europe, according to the European Commission's e-health indicator study (2024). In other words, many elements of a health data ecosystem are present, but the elements are not connected and not performing at their best yet.

To enable a high-quality data-driven healthcare improving patient outcomes and increasing Belgium's competitiveness, a **shared vision** is needed. The (bio) pharmaceutical and medtech industry have amassed extensive experience and knowledge in data projects. With public-private partnerships we can build capacity, networks, legal frameworks to secure safe and easy access to health (care) data and improve the quality and timely access of up-to-date national health (care) data sets. There is no time to lose in implementing this ambitious data policy further.

We look forward to continuing the digital transformation of the Belgian healthcare ecosystem.

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- https://pharma.be/sites/default/files/2024-07/secondary-use-of-patient-data-for-scientific-purpose.pdf
- e.g. insurance claims data collected by National Institute for Health and Disability Insurance (RIZIV-INAMI-NIHDI) or hospital data collected by Federal Public Service Health
- e.g. within patient health records 3
- from sources like the cancer register, healthdata.be, Sciensano, RIZIV-INAMI-NIHDI