

AHEAD

Towards the Development of a National Health Data Platform

Contract - B2/202/P2/AHEAD

SUMMARY

CONTEXT

Belgium has a rich health information landscape, including valuable information originating from many different sources, such as administrative sources (e.g. concerning health care use, mortality, causes of death, social security, etc.), population health surveys and health surveillance systems. These different data sources are managed by different academic and governmental actors. To date, however, an integrated health information system is lacking, which hampers the valorisation of these data sources.

OBJECTIVES AND METHODS

The overall aim of the AHEAD project was to offer an active push towards the development of a national health data platform, by taking steps that will allow to move closer to the holy grail of a single integrated health data platform. It achieved this aim through the following specific objectives/work packages:

- WP1: The characterization and documentation of the Belgian health information system, and this by (i) proactive stakeholder engagement and (ii) bringing together all involved parties via the organization of webinars and study days
- WP2: The identification of ethical, legal, and technical bottlenecks in the prospective development of an integrated health data platform, and this by (i) the development of an online citizen consultation on the secondary use of health data and (ii) the development of a business case built around prospective linkages between Sciensano's Health Interview Survey (BHIS) data and administrative data sources
- WP3: The elaboration of recommendations for developing a national health data platform as an accessible, long term monitoring and research infrastructure

During the course of the AHEAD project, the Belgian Health Data Agency (HDA) got established. This provided valuable synergies, as several of the objectives and recommendations of AHEAD fall within the mandate of the HDA. The AHEAD project was therefore able to shift focus to areas that were complementary to the short-term objectives of the HDA.

CONCLUSIONS

A better valorisation of (health) related data within the Belgian health information landscape is of utmost importance to be able to provide answers to policy-relevant research questions. Belgium, being a country with many authorities, services and agencies but short communication lines, might hold the right cards and offer suitable opportunities to build an infrastructure holding longitudinal collections of health and administrative data. The AHEAD project explored these opportunities, but also the challenges, in the development of a national, integrated health data system. The different activities of AHEAD resulted in the following 10 recommendations:

- 1- Clarify the current Belgian health information landscape and provide and sustain up-to-date metadata
- 2- Establish a consortium of the willing
- 3- Standardize linkage procedures
- 4- Develop an ethico-legal framework
- 5- Increase digitalization
- 6- Secure a long-term financial and organizational effort
- 7- Identify and tackle ethical and legal bottlenecks
- 8- Respect the data relationship between citizens and health (related) data in the secondary use of health data
- 9- Maintain a suitable power balance in the secondary use of health data
- 10- Establish a citizen-powered framework for the secondary use of health-data

KEYWORDS

Belgian health information landscape; Health data reuse; Secondary use of health data; Data linkages; Administrative health data cohorts; Research infrastructures; Citizen consultation