

PRiMHE

Programme in the Methods of Health Economics

“The healthdata.be project: Minimalisation of registration burden, Maximalisation of Return On Information”

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Summary: Quality of care registries and epidemiological surveillances play an important role in today’s public health policy. Over the past 30 years, more than 160 registries started to collect data in Belgian hospitals, laboratories, private medical practices... These registries are known for their heterogeneous data collection methods and information models, low transparency and high administrative burden. Often, the same information is recorded multiple times by the data providers, resulting in a high costs for data providers. Some of the registries lack privacy and security measures. Furthermore, most data providers receive no or little return on information.

Since 2013, the national “Action plan eHealth 2013-2018” prioritizes the consolidation and standardization of the scientific registries. A new department “healthdata.be” within the Scientific Institute of Public Health (WIV-ISP), funded by National Institute for Health and Disability Insurance (INAMI-RIZIV), was created to coordinate this reform of the registries. The department also actively facilitates (in terms of technology and process management) the data exchange between healthcare professionals and researchers according to “only once” principle and the re-use of data, in order to increase public health knowledge and to adjust health care policy, with respect for privacy of patient, healthcare professional and medical confidentiality. The mission of the project is to reduce the administrative burden of clinicians so that they can spend more time for their patients, resulting in higher quality of care, and that researchers have more time for the analysis and interpretation of the data, resulting in a higher quality of research. Also, the cost for the creation and the maintenance of new patient registries supporting public health policy should decrease significantly.

Since September 2015, the healthdata.be platform went into production and started to collect data for the Belgian Cystic Fibrosis Registry. More than 40 other registries will also migrate before the end of 2017.

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