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Health data – simpler and safer access

LEDER

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In Norway we have universal health services, rich sources of personally identifiable health data and high trust among the population. This provides us with unique opportunities to use these data, but the access to them must be improved.

Norwegian health data encompass the entire population throughout their lifetime and are linked to national identity numbers. This enables us to collate information from different sources and monitor the health and welfare of the population. Health data are typically generated when people encounter the health services, but also when gadgets such as pulse watches are used.

In health registries such as the Medical Birth Registry of Norway, the Cancer Registry of Norway and the Norwegian Cause of Death Registry, health data from the population are collected and structured, so as to be supplied to and used for research purposes and other analytical ends (1). To obtain a complete picture, supplementary data from other registries that collect information on matters such as education, income and employment will often be needed. In order to achieve an evidence-based healthcare system we need all these data.

However, obtaining access to health data is not always straightforward, either for research (2) or other purposes. The data are regulated by a number of laws and regulations that are under the administration of various agencies, and the users need to have a black belt in application writing to get their hands on the data. Clearly, control must be exercised when it comes to deciding who should gain access to the data and the purposes for which they use them – after all, these data are of a sensitive nature. On the other hand, there is no need for months and years to go by before researchers and other users finally have their permits and deliveries in place (3, 4). The current system is not designed to promote simple and secure use of our valuable health data for legitimate and socially beneficial purposes.

In the Health Data Commission, which was appointed in June 2016, we have discussed these issues, and on 30 June this year we submitted a report to the minister of health with specific proposals to establish a simpler and safer system for access to health data (4). In parallel, efforts have been underway to implement the EU Data Protection Directive in Norwegian legislation (5) and to upgrade the regulations for health data. In addition, we now have a national strategy for e-health and an action plan for the period 2017–22, and the Directorate

of e-Health has initiated preparatory studies for a national health analysis platform. The idea is that data from the health registries and the National Population Registry can be made available for analyses from the platform, without having to be copied and sent to the users.

The commission welcomes the preparatory studies and development of such a platform and proposes that both health and socioeconomic data be made available for analyses on the platform. Furthermore, the commission proposes that access be regulated through a single national agency that can provide support and services, process applications for access and finally grant the users access to the health data they need. In addition, the commission proposes that the regulations be simplified, and that advance approval by the Data Protection Authority and/or the Regional Committees for Medical and Health Research Ethics no longer be required before researchers and other experts can be granted access to health data.

Technological development has entailed that much greater amounts of data than those found in the traditional health registries are now being rapidly generated. This includes health data from medical-technical equipment, welfare technology, smartphones and pulse watches, as well as from modern laboratory analyses, such as full-genome sequencing. Moreover, the capacity for storing and analysing large amounts of data is greater today than only a few years back. This may give rise to completely new opportunities for analyses, for example in research. Sophisticated statistical models and artificial intelligence or machine learning can be used to detect correlations and new knowledge without any prior clearly defined research question.

In industry, health data are gaining in importance as a tool (6). The use of so-called 'real-world data' in the approval process for drugs and medical-technical equipment and for development of customised precision drugs provide examples. The Standing Committee on Business and Industry has requested the government to submit a separate white paper on the health industry (7). They have also asked for a more detailed study on Norway's advantages when it comes to health data and e-health.

The Health Data Commission's report and advice to the minister of health are only a small contribution to the debate on how we as a responsible welfare society can embrace the large and exciting new realities when it comes to health data. In addition to creating a better system for access to and use of existing sources, we need to make wise and future-oriented choices for ownership and access to the new sources of health data and the knowledge that these may provide. We need to ensure that the data and the integrity of the inhabitants are protected, that the system enjoys confidence and that these collective goods are made available to the population. A national health analysis platform that uses modern technology to make relevant health data available for analysis in a simple and secure manner could represent a step in the right direction.

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