The Health Data Programme – New solutions, services and interfaces for cooperation

Unique data

The COVID-19 pandemic has clearly demonstrated how sharing and analysis of data across sources can yield results that can benefit society. Norwegian health data, administrative data and personal information collected over several generations constitute a unique source of information and knowledge, both in and outside the health sector. Better utilisation of existing quality-assured health data in research quickly produces good results that can help to improve public health, increase productivity and quality in the health sector, and develop and strengthen the healthcare industry.

www.helsedata.no/en

Norwegian health data are underused in research. One of the main reasons for this is researchers' experience that it takes too long to access the data. However, researchers can now apply for access to health data from around fifty different data sources through a *common application form* at www.helsedata.no/en

Reducing the waiting times for access to these data is an express goal. The number and types of data sources that the application form covers are expanded on a continuous basis. Work is under way to include all central health registers, national medical quality registers, health studies and relevant microdata from Statistics Norway in a common application form. Another goal is to simplify and coordinate the application process with the Regional Committees for Medical and Health Research Ethics (REC).

In addition to an application guide and the common application form, www.helsedata.no/en/ also provides a variable explorer, data analysis services and other information about health data and personal data.

Health Data Service (HDS)

The opening of a permanent national health data service (HDS) is planned for the second half of 2021. The service will have administrative authority over data stored in registers that fall under the scope of the Personal Health Data Filing System Act. HDS will offer services for research and other secondary uses of health data. HDS is a collaboration between health register managers and other data managers. The goals is that researchers will have *one door in* to receiving guidance and applying for access to health data. Following the approval of HDS and REC, data will be made available for analysis on the Health Analysis Platform and other national analysis platforms for sensitive personal data (Services for sensitive data (TSD), HUNT Cloud, SAFE).

The Health Analysis Platform (HAP)

The Health Analysis Platform is also scheduled to open in the second half of 2021. Here, researchers and others will have quick access to data that can be analysed across sources in **secure analysis rooms.** Data that fall under the scope of the Personal Health Data Filing System Act will be available as data products on HAP and the administrative authority will rest with HDS. Own data or data from other public sources can be uploaded to secure analysis rooms on HAP on a project basis. Public health and personal data managed by other authorities (such as Statistics Norway and the regional health authorities) and stored under

acts other than the Personal Health Data Filing System Act maycan also be transferred directly to a secure analysis room in HAP.

HAP will be a main component of a *national ecosystem* for health analysis where data from health registers, quality registers, health studies and Statistics Norway will be made available for faster disclosure and analysis. Arrangements will be made to facilitate anonymised analyses and production of synthetic data.

HAP will comprise a cloud-based computer platform with privacy by design and will offer advanced analysis services and secure, scalable services that protect personal data and that can process large quantities of health data in researchers' own analysis rooms.

To enable analysis of health data at the individual level without the need to apply, *exploratory analysis services* will be established that only expose anonymous or aggregated data.

HAP will also offer a *marketplace for data products and analysis services* from public and private enterprises. Commercial and public enterprises will have access through user payment, which is also the current practice, so that the parties that provide data products and services on the platform can be compensated for their efforts and the value creation they facilitate.

Involving the users is a crucial aspect of the development of HAP. There is also a wish for more projects and actors to actively contribute to the further development of the ecosystem connected to HAP. More reuse of data and algorithms and data products being made available to other actors are express goals.

This new way of gaining an overview of, applying for and being granted access to data analysis will be considerably *quicker*, *simpler and more secure* than at present. The plan is to launch the services that will be most useful to researchers and research projects in the period 2020–2022.

Relevant solutions at helsenorge.no

A secure service for dialogue with people in Norway will be developed and launched at www.helsenorge.no. Research projects can use the service to e.g. submit requests for consent and expand consents or to provide information to project participants/data donors. Inhabitants can also see a list of the consents they have provided and access their own data. Structured data for research can also be obtained.

Read more about the progress of new solutions and services on HAP and HDS here.