Data Saves Lives

– let's use it better!

Data
Saves
Lives.

In the autumn of 2017, Copenhagen Healthtech Cluster established a partnership of public and private players under the Data Saves Lives initiative. The partnership shares a common vision:

In Denmark, we need to be much more active in using our unique health data to prevent disease and provide more targeted treatment.

Danish health data contains records of about five million people's health over the past 50 years. Together with new lifestyle data, these records could form the basis for developing preventive, life-saving medicine and more targeted treatment. Currently, it is difficult to get access to Danish health data and that is delaying development.

The Data Saves Lives partnership has been working to identify the fundamental challenges and to define specific proposals for better use of Danish health data whilst maintaining a high level of data security. Model solutions have been tested for legal and technical IT issues. This has led to three specific proposed solutions.
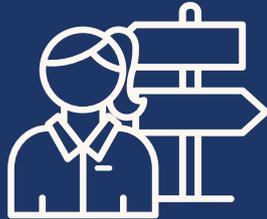
1

National data map

Challenge:
Danish health data is spread across more than 164 different databases. So, researchers and companies use enormous resources to investigate whether and where the data is located. Only then can the lengthy application process for access to data start.

Solution:
We propose creating a map of Danish health databases to provide a quick overview of the Danish health data landscape. The national data map will make it easy to see what health data is held on various registers and the data quality involved, so-called metadata. There are no legal obstacles to implementing the idea and there are various existing IT platforms that could support the initiative.
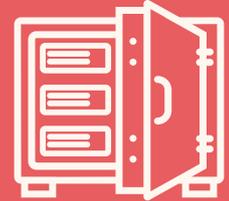
2

Data entry point

Challenge:
When researchers and companies have identified a dataset in the Danish registers, a lengthy, complicated application process starts, which could be alleviated by better coordination and advice.

Solution:
We propose setting up a data entry point where researchers and other users can get guidance on official approval, design and on undertaking projects based on health data. The data entry point must provide advisory services across the various register owners in the state, regions and municipalities. Responsibility for data would remain with the present register owners who have the legal and technical competencies. It is essential that advisory services are demand-driven so that there are no time-consuming bottlenecks.

3

Data sandboxes

Challenge:
Health data is stored in silos which make it difficult to combine data. And it is precisely in combining data that the potential for preventative action and more targeted treatment is to be found.

Solution:
We propose establishing data sandboxes in which register owners, healthcare professionals and private partners can combine data and test new algorithms in a secure environment. These environments could contain test data and anonymised or pseudonymised samples from larger datasets. Legally speaking, sandboxes based on anonymised data are not a challenge, but the use of non-anonymised data is more problematic. Achieving the full potential of these environments will require amendments to the legislation, as in Finland for example.

Partners in Data Saves Lives

Proposed solutions for better use of Danish health data have been created in a collaboration with the following organisations:

abbvie AMGEN® BAYER COPENHAGEN CAPACITY COPENHAGEN HEALTHTECH CLUSTER DANSK ERHVERV DANSKE REGIONER 2 Health Innovation Institute

IQVIA™ CITY OF COPENHAGEN LEO Innovation Lab LEO Lif Lundbeck NOVARTIS novo nordisk®

Pfizer pharma danmark The Capital Region of Denmark Rigshospitalet Roche SAP SIEMENS Healthineers

Expert knowledge has also been contributed by Prof. Søren Brunak, University of Copenhagen, IBM Danmark ApS, Danish Regions' Clinical Quality Development Programme and various patient associations.

Contact Copenhagen Healthtech Cluster at cphhealthtech@copcap.com to hear more about the Data Saves Lives partnership.

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