Lisbeth Nielsen â?? Director General, Danish Health Data Authority

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Lisbeth Nielsen of the Danish Health Data Authority outlines the organisationâ??s purpose and mission, how it contributed to Denmarkâ??s robust COVID-19 response, and the challenges of making Denmarkâ??s comprehensive patient data sets available to researchers while maintaining patient confidentiality and trust.

What is the purpose and mission of the Danish Health Data Authority?

Our purpose is to create as much value in health as possible using data and the force of digitalization. Data has been collected within Danish healthcare nationally for more than 40 years. The data collected extends beyond the national patient registry to include a broad range of data points, from IVF to the birth registry, abortion, the weight and height of children, and beyond. Danish citizens are registered throughout their lives in different aspects of the healthcare system and these subsets of data are reported to the Health Data Authority.

These data sets are used as the basis for official statistics, for analytics, insight into the wellbeing of the health system, the health of the Danish population, and for research. Danish legislation is open to individual health data being used for research, however, there are restrictions to limit those using the data to research groups, or those working with public universities or hospitals in the country.

Furthermore, access is only available on the Health Data Authorityâ??s servers, therefore, research is only able to extract aggregated data.

Part of the work is ensuring the high quality of the collected data and regularly checking that the relevant data sets are collected. The Health Data Authority is driving digitization within the Danish healthcare system as a prerequisite for collecting data. This data is captured in the clinical setting, giving it a high level of validity. The hospitals will get back the consolidated data that can be used for monitoring waiting times, cancer packages and quality registries on a day-to-day basis.

Digitalization is part of daily patient care. For example, all prescriptions in Denmark are electronic or digitized in the pharmacy upon registration. Doctors can prescribe patients medicine from their smartphone or patient record systems, with this highly structured data then being put into a central server.

Once the prescription is complete, the patient can go to any pharmacy in the country to receive their medication. Concurrently, compensations are calculated on the spot if applicable and there is no requirement to request a refund. Furthermore, a patientâ??s prescription is the basis of a list of current medications the doctor can adjust. Adjustments are shared with the patient and displayed on an app. Hospitals will have access to a medication list and can upload additional medication or altered doses onto the list to be displayed across all health providers. These benefits are all made possible through the work of the Danish Health Data Authority.

What is the level of public trust in Denmark as to governmental use of personal data?

The general level of trust is high. Furthermore, the Danish governmentâ??s transparency and openness, in addition to the release of information regarding the dataâ??s use, helps foster a high level of trust here. The data can be accessed by the individual through the national health portal to view the recorded data, and health care professionals must have a provider relationship for accessing patient data. Danish citizens can see which doctor or nurse have access to which data and legal steps can be taken if there is reason to believe the data is being accessed illegally.

Over the past 18 months, booking COVID-19 PCR tests and receiving the results has been made possible through the health app or health portal and there is an established tradition in the country of patients being able to know the information kept in these files.

Is balancing being open to researchers and maintaining patient confidentiality a challenge?

Yes, however, the Health Data Authority is based on three pillars. Firstly, the sharing of data across the healthcare system for the purpose of treating patients. Secondly, collecting and using that data to reflect the healthcare system and the patientâ??s experience for analytical purposes. Thirdly, ensuring information security and trust with the general public through the manner in which the data is collected and used.

Nevertheless, there have been discussions concerning using public health data to kickstart the pharmaceutical industry. To be clear, the Danish Health Data Authority does not sell data and access is only given if there is a legitimate purpose and data analysis is led by a Danish Hospital or research organization such as a university. There is a cover received for the cost of making the data available, however, this is not a source of income for the Danish authorities or anyone else that is part of the research.

What do you see as your role in helping develop medicines and demonstrate efficacy?

One of the Health Data Authorityâ??s most important roles is to ensure that the data we collect contributes to providing better care. As a result, research is required beyond the development of medicines or pharmaceuticals to the entire lifespan of a medication. This stresses the importance of the data moving back and forth for the lifespan of the patient and the population more generally, to guarantee the correct data for sound judgement and decision making.

Our latest registry compiles all medicines given in the hospital on an individual level and this information is combined with other information concerning the patients to gain an insight into the side effects or other reactions. Consequently, the entire vaccination process is being conducted concurrently with a research program using national registers, vaccination registers, and all other medication.

What limitations does the countryâ??s relatively homogenous and small population put on Denmark as a research destination?

Due to the constraints of Denmarkâ??s population, our focus is on high-quality data and a high level of trust that allows for greater detail. As a result of the unique personal identifiers, socioeconomic data can be combined with other data from the same individual, however, the desire is to find compliant ways to combine Danish data with data from other countries to counter the population issue.

How has the health data authority responded to the pandemic and what might be the longer-term impacts?

Both data and data flows were reworked to allow data to be provided on a significantly more frequent basis such as twice a day.

The entire digital infrastructure supported the strategy for testing the public and allowed for free and easily accessible tests anywhere in the country. The threshold of the testing for both the PCR test and the antigen test was kept low, which is counterintuitive to normal healthcare system practices due to the possibility of overwhelming the system. In the case of a positive result, the patient then received information regarding the need to isolate as well as the health advice from their doctor at the same time. This strategy empowered the population to help themselves while freeing time to follow up on those requiring additional instruction or care.

Contrastingly, access to vaccinations was initially deliberately restricted due to the limited number of doses available. The vaccination program was centrally controlled, and personal invitations were sent to citizens in their digital post to book the vaccine appointment online in order of vulnerable groups, followed by age groups. The registration into the vaccination registers at the point of care allowed for real-time data on progress. Denmarkâ??s success in fighting the pandemic can be credited to vaccinating the right people in the right order as well as making vaccination centres readily available across the country.

Do you see any other changes in your work coming out of the pandemic?

The close cooperation across all levels of healthcare and levels of government has helped the countryâ??s successful fight against the pandemic. Therefore, the continued ability to work together to the same extent for issues following the pandemic can allow Denmarkâ??s government to make significant and positive changes for the country.

What would you like to achieve within the Health Data Authority and more broadly in Denmark over the next few years?

I would like the organization to continue working faster and delivering value on shorter notice while simultaneously increasing efficiency to produce positive outcomes with less effort.

For the future, large investments into the healthcare system in Denmark can make it easier for researchers and pharmaceutical companies to use data for improving health. The Health Data Authority needs to keep the country relevant by having the right data available and providing access to this data within the set regulations. In addition, I would like to see an improvement in the ability to work across countries more seamlessly.

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