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GDPR-friendly Patient Data: Finland Leads the Way



Patient data is one of the keystones to streamlining and making healthcare more effective. But, added to in-house operational obstacles is the [General Data Protection Regulation \(GDPR\)](#) which imposes stringent restrictions on data use across sectors.

A leader in healthcare digitalisation and, patient data collection and use in particular, Finland has become the first country to successfully meet the strict requirements of GDPR while using citizen data for the advantage of the healthcare sector and patients.

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In today's digital world the generation of data has grown enormously. In Finland, the amount of data collected in relation to social welfare and healthcare is ever increasing. Such data however is generated by many different registries; thus, for researchers, health authorities and other parties, **making use of the data has been difficult and inefficient.**

The creation of a new one-stop shop, **Findata**, aims to allow the secure and easy use of social and health data. As the new central data permit authority in Finland, Findata's mandate is to balance the needs of multiple stakeholders and ensure that the high level of trust people have in the authorities handling their data is maintained. The new agency is expected to make the work and knowledge-based management smoother for researchers and businesses in particular.

The establishment of Findata has been facilitated by new GDPR-friendly legislation. The Act on the Secondary Use of Health and Social Data was passed by the country's Parliament on 13 March 2019. In fact, [Finland has become the first country in the world to successfully enact a law on the secondary use of well-being data that meets the requirements of the GDPR.](#) The new law, which took effect on 1 May 2019, aims to make the secondary use of social welfare and healthcare data easier and make the data more available, as well as to promote its secure use for more extensive purposes.

Implementing the New Model for Better Use of Health Data

Sitra is among the key organisations who worked hard towards the establishment of the new operating model for the [better use of health and social care data](#) in Finland. It cited some important challenges in the development work that were related to public-sector funding, coordination with funding providers, operating methods and siloed operating models.

In a report, Sitra offers a list of recommendations for implementing and developing the upcoming service. "[Customer-centricity](#), effectiveness and realising benefits for the whole ecosystem around the secondary use of health and social care data are a necessity for the new agency to succeed in the long term," Sitra says, noting that the new agency (Findata) needs to cooperate with customers, data providers, partners and other relevant agencies.

Aside from operating in a customer-oriented way, the performance of the new agency in fulfilling its mandate should be monitored using a set of indicators, according to Sitra.

Towards Customer-centricity

The drafting of the **new legislation** was based on the national **health-sector growth strategy**, which aims to make Finland an internationally renowned pioneer in health business and in well-being. In creating the new centralised data service, attention was paid to developing the cooperation between registry authorities. This is to ensure that researchers, companies, and other parties in need of data can access and use the services they need smoothly, all through **one centralised operator**. Changing the mindset from production-centricity (data stores and their handling) to **customer-centricity** is a necessity for modern agencies to work effectively.

Importance of Diverse Expertise

Numerous representatives from different fields of expertise have been actively involved in the process of developing the new operating model. These include researchers, entrepreneurs, and representatives of the business community and patient organisations, who were also heard during the drafting of the new legislation. A particularly important success factor has been the encounters with active parties at different events and in various forums that have provided direct input into the development work, according to Sitra.

The drafting of the new legislation was also part of more extensive inter-ministry cooperation in the development of **digitisation, data economy and ecosystems**. Well-being and health was considered a key focus area primarily because it is highly data-intensive and already has extensive national and international data repositories.

Earning Public's Trust

With the new act in force, Finland can be viewed as an international pioneer in the development of legislation related to the **proper use of social and health data**. An international study commissioned by the Ministry of Social Affairs and Health found that, among the 10 countries included in the survey, none of them had an equally comprehensive act on the management of

health and social care data. Instead, the comparison countries had several acts or laws related to different data controllers.

When dealing with sensitive health data, maintaining the trust of the public is an important consideration. In general, people in Finland have very high levels of trust in government and this proved to be one of the critical success factors for the new legislation and supportive operating model.

According to a 2016 study by Sitra, people in Finland are interested in finding out what kind of data is collected about them and where it can be found. In addition, people are interested in the purposes for which data about them is used and in the related terms, conditions and authorisations. The survey also indicates that recent data breaches have had some effect on [people's trust in digital services](#).

Towards a Human-centric Model

Although the newly created agency will be subject to many expectations, requirements and needs by many healthcare and research organisations, as well as business companies, Sitra emphasises that "[the starting point must always be the individual as the producer of data and the final beneficiary](#)." In addition, Sitra says, there is increasing interest in the opportunities that exist to exercise influence over and manage one's own data. This trend can be seen in the activities of the [MyData](#) movement, for instance. The aim of the movement is to take personal data management and processing from the current organisation-centric model towards a human-centric model.

Sitra's fair data economy project, launched in spring 2018, aims to develop a system for human-driven data exchange. The IHAN® project expands the horizon beyond social, health and registry data and opens up opportunities to find new ways to **manage one's own data**. One way to ensure future well-being, Sitra explains, is to have a simple, cost-efficient and easy-to-use way to disclose one's own data for research purposes.

Source: [Sitra](#)

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