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### Digital Health Hub at Your Service - If You Earn Citizen Trust



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The Digital Health Hub is a joint project of Sitra, the Finnish Innovation Fund and The Ministry of Social Affairs and Health. The project goal is to facilitate the use of national data reserves and design of the one-stop shop for health and social care data.

The mention of data exploitation may sound scary, but at its best it can mean new, more effective, targeted medicines when whole genome data sets will be available to predict the effects of medication. It can mean better diagnoses and more up-to-date information about the quality of care by different—public and private—actors.

To enable data-driven economic growth and to respond to future needs of innovative research and development, Sitra has launched a project called Isaacus – the Digital Health HUB. From a single access point, this service organisation will provide data that can influence wellbeing and open data gathered from various registers and sources. When gathering and processing this data, special attention will be paid to privacy protection and data security so that citizen trust is maintained.

The project is being taken forward in close cooperation with the central stakeholders. The project implements the growth strategy for the health sector of the Ministry of Social Affairs and Health, the Ministry of Employment and the Economy and the Ministry of Education and Culture.

Big data and analytics are changing our mindset on how to benefit from the data. Information management practices and architecture need to be updated. The goal is to establish rules and to create agile and safe frameworks that take the interests of the individual into account in the exploitation of data and smooth the processes needed for R&D and Innovation.

See Also: [Hacker 2017 Targets](#)

#### What Makes Our Approach Unique?

There are similar initiatives going on around the globe, but national consensus and interagency cooperation is unique. The objective of the Ministry's draft Act on Safe Use of Health and Social Data is to ensure that it will be possible to use customer and personal data in Finland more effectively, for example when devising public policy and in the development of services. The change would ease and increase the use of information on health and social matters and open many new possibilities, not just for academic research, but also for commercial research and innovation.

Ultimately, an individual would benefit from better transparency of the use of data and new evidence-based care methods developed by swifter use of information as all permits to use the data would be granted by one permit authority. Data-secure operating environments and communication would be created for sending and handling the data.

The government bills would bring the provisions on handling personal data into conformity with the EU Data Protection Regulation, which

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entered into force on 25 May 2016. The reforms are due to come into force in stages, starting from 1 January 2018.

## **Citizen Trust on Authorities – Findings From the Survey**

According to Sitra's survey conducted by TNS Gallup in June 2016, Finns are willing to anonymously submit their social welfare, health and genetic data for the purpose of service development and scientific research. The survey examined citizen attitudes towards the secondary use of wellbeing data collected about the Finnish population. Secondary use includes, among other things, research, statistical purposes, development and innovation activities and knowledge management.

The survey results show that citizens are interested in the use of their social welfare and health data and support their use for development and research purposes. However, people also want to be informed about the use of their personal social welfare and health data. The most important issues that concern people are the ability to see their own data and the possibility to correct, or, if necessary, even to forbid its use.

The survey confirmed that Finns have a high level of trust in the authorities. The police force is the most trusted authority and there is also a high level of trust in the public social welfare and healthcare system. The majority of the respondents also felt that it was important for an authority to oversee the use of data as well as the appropriateness of its use. Over 90 percent of the respondents felt that the following points were either important or very important:

- Being able to see their own data
- Being able to correct any errors in their own data
- Knowledge of purposes for which their data would be used and who would be using it
- Being able to forbid the use of their own data.

Finns want to control the use of their own data through express consent. Nearly 90 percent of the respondents felt that it was important or very important that an individual should be able to decide what the data collected about them was used for, especially if the data could reveal the person's identity.

## **Data-Driven Economy Thrives With Trust**

The citizen's perspective and data protection issues must be taken strongly into consideration in the planning of operations and operational practices. The new actor must be able to work transparently. An information security audit provides a holistic picture about the current state of data processing in an organisation and an assessment about the realisation of data protection, data security and privacy protection. It is essential that the new actor will, at the very least, conduct an information security audit of its operations and ensure the data is handled in a secure manner.

However, for a data-driven economy to succeed there are also several dimensions on trust that are critical at the enterprise level as stated in a recent survey conducted by KPMG in October 2016 on data and analytics (KPMG 2016). When an enterprise plans for its strategy on analytics KPMG report recommends that they build a systematic approach that spans the lifecycle of analytics and focuses on four key anchors of trust: quality, effectiveness, integrity and resilience.

These are crucial dimensions even when planning for a national health hub. For winning the trust from the researchers and companies aiming to use the data, we need to ensure transparency and an audit trail to the data sources, and maintain good quality of data management tools and processes. Building good quality is a phased approach; in an early phase "good enough" quality might be sufficient. However, what is essential for the success in nationwide data gathering is to ensure semantic interoperability and define national metadata. This is essential not just as a one-off effort but also for best information management practices for updating the metadata with fast-changing data sources. If we cannot show audit trails all the way to the raw data it is difficult to trust analytics made from that data. What is essential in our effort is to ensure that data is going to be used in an acceptable way so Health Hub needs to be aligned with regulations and ethical principles. This is an area of uncertainty and rapid change, with enormous potential for reputational risk and perhaps even failure of the entire project. This also puts pressure on a good governance model throughout the data lifecycle. In short, for Sitra, and everyone else hoping to succeed in a data-driven economy, trust is a must.

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## **Key Points**

- Digital Health Hub project from Sitra is a joint project of Sitra, the Finnish Innovation Fund and the Ministry of Social Affairs and Health. The project goal is to facilitate the use of national data reserves and design of the one-stop shop for health and social care data. The new authority will be up and running in 2018.
- According to a survey, Finns are willing to anonymously submit their social welfare, health and genetic data for the purposes of service

development and scientific research.

- Data-driven economy is based on trust.

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