Top Target Treatments

A human-centric approach for data collection

The promise of personalised medicine

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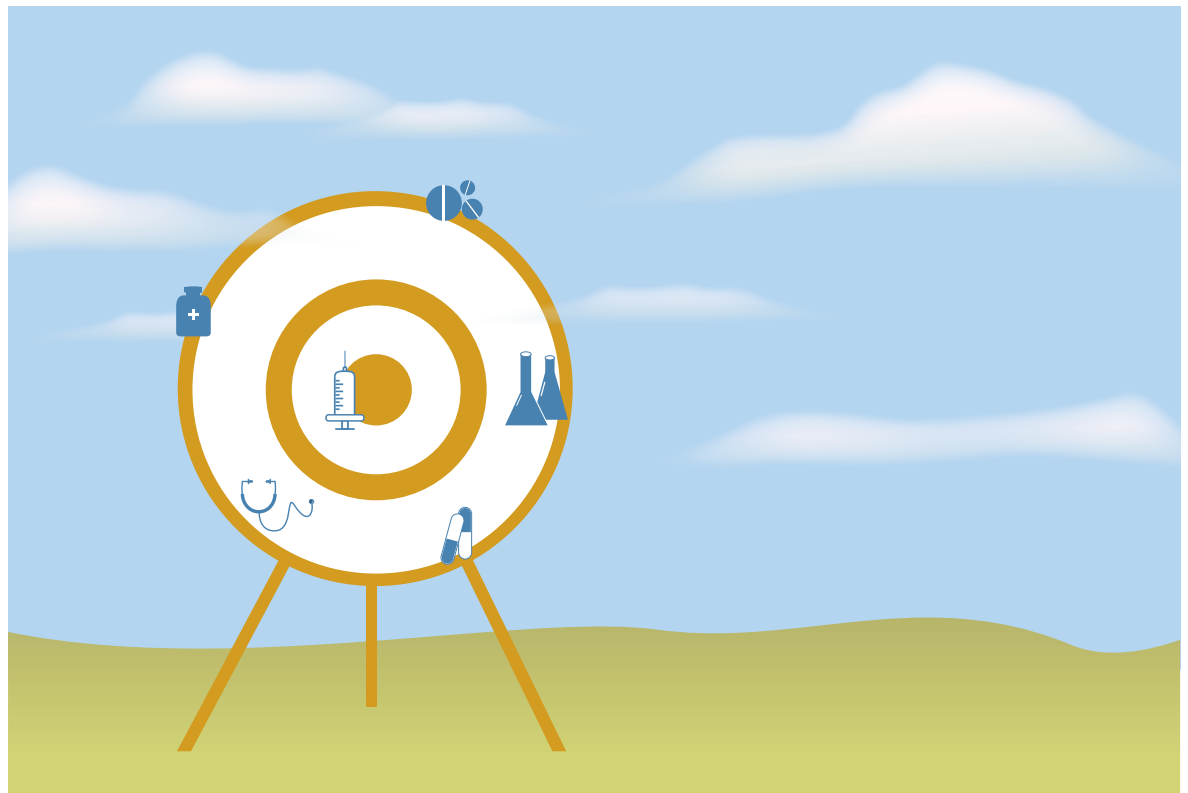
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Based on extensive market research, the precision medicine sector is fast becoming a multibillion market. It consists of innumerable companies involved in the research and development, manufacturing and commercialisation of several novel drugs and diagnostic kits to boost the precision medicine workflow (BIS Research, 2019).

Countries are competing for investments with different approaches. The Health Sector Growth Strategy was created for Finland a few years ago, pinpointing the health sector as one of the core industries for the Finnish future. The promise of precision medicine will be fulfilled with unique data reserves, technological know-how and broad public-private collaboration, like The FinnGen study that plans to tap into 500,000 unique blood samples collected by a nation-wide network of Finnish biobanks (Finngen.fi 2019).

Legislative reforms were seen as an important enabler in the Health Sector Growth Strategy.

One of the reforms was to bring Secondary Use of Health and Social Data into compliance with EU's General Data Protection Regulation (the GDPR). GDPR was applied in all EU Member States as of 25 May 2018. After few years of preparation, the Act on the Secondary Use of Health and Social Data (Government proposal HE 159/2017) was scheduled to enter into force in April 2019. Research and innovation will get an additional boost from fresh legislation as a new licensing authority is born, which will allow social welfare and healthcare data to be used more smoothly and securely.

> **❝ INCREASING THE AMOUNT OF PERSONAL DATA RAISES NEW QUESTIONS ON DATA ETHICS, TRUST AND TRANSPARENCY – MANDATORY PREREQUISITES FOR THE PHARMA AND LIFE SCIENCE INDUSTRY TO SUCCEED ❞**

In such a complex world one approach is not enough. Many organisations are already testing near real-time data processing technologies (aka data lakes) for making more use of AI and developing new AI-based solutions. More and more data are generated outside traditional registers and EHRs. For targeted treatments and research to be a reality, growth of personal healthcare devices and integration of smart technologies in the healthcare system is an important enabler. Increasing the amount of personal data raises new questions on data ethics, trust and transparency – mandatory prerequisites for the Pharma and Life science industry to succeed. According to a survey of the general public conducted in 2018 (four countries and 8,002 respondents), two in five respondents discontinued their use of digital services because of a lack of trust in the service provider (Sitra, 2019). In a 2018 Mobile Ecosystem Forum (MEF) Consumer Trust survey (10 countries and 6,500 respondents), the same response was given by 39% of respondents (MEF, 2019). This is a clear message to companies: the best way for fair companies to stand out positively is to offer clear and comprehensible terms of use that state what

the data is collected for and why, and what it will be ultimately used for.

One of the human-centric paradigms for trustworthy handling of personal data is MyData. The main objectives of The MyData movement are: 1) formal to actionable rights, 2) data protection to data empowerment and 3) closed to open ecosystems. This movement is aimed to build a fair, sustainable, and prosperous digital society, where the sharing of personal data is based on trust as well as a balanced and fair relationship between individuals and organisations (MyData.org, 2019).

Also, an increasing number of analysts are becoming interested about this kind of paradigm and the potential ecosystems being built around it. MyData is a human-centric approach to data management and well aligned with an idea of "data minimalism." In the future, more transparency is needed for consumers to trust necessary use of their data needed for new products and services. Data should also be used and stored responsibly (Trends. fjordnet.com 2019).

Sitra is now working with a new cross-sectoral initiative, known as IHAN, on a fair data economy. A fair data economy is fair for all: individuals, businesses and society. It is about just treatment of people's privacy and about sharing data in an ecosystem with consent from individuals to create new services. Sitra believes that consent-based data sharing could be something for pharma companies to ensure trust and positive attitudes for future. A human-centric data exchange may also provide new means for data interoperability.

When it comes to interoperability, it should be considered in its broadest sense - information exchange not only between domains of industry, but also spanning several countries.

One of the most impressive examples of this fair data economy is a story of a teenage girl named Alva, who suffers from type-1 diabetes. Even though the burden of the disease has an impact on her daily life, she still wants to live an active life with all the activities that teenagers of her age would normally take part in - attending school, being active with hobbies etc. When Alva travels between Nordic countries, she should be confident of receiving quality services wherever she goes.

By giving consent for the use of her data, her parents are helping their daughter to have her critical safe glucose data flow secured by bulletproof Blockchain technology. This comes from

open-source-based metering solutions to the caring doctor, but also to other authorised parties, such as a school teacher or a basketball coach, that have been given consent earlier by the family. This "ring of trust" provided by the consent identifier in a wallet of services, can be expanded by a new set of service providers as the number of fair-data services grow.

Another interesting fair data pilot case also contains cross-border elements. A bold pilot is going to be experimented with where Finnish citizens travelling to the Tokyo 2020 Olympics download a mobile app that can be used in case of the need for medical attention while travelling. The app itself will fetch travellers' medical and prescription records from the national health register, KANTA. This app will contain a translation service that will decipher, for example, ICD-10 diagnosis codes and prescription information to the target language and coding systems (eg SNOMED CT) using elaborate algorithms and metadata. This leads to better and quicker treatment if something happens while travelling. This is all made possible because of a fair data environment where the end-user is empowered and rewarded by the new set of value-add services provided by user consent.

When it comes to sports, one can also take the athletes' viewpoints. A solution is being created by the Olympic committee to gather athletes' training and wellness information from selected data sources. This consent-based data can then be used by authorised coaches and other supporting staff. This can also be extended to a national health level. The Finnish Defence Forces are recreating overall conscript training as part of their Training 2020 Programme. In the pilot the conscript's consent-based personal data can be shared to various stakeholders during the service period.

Let's imagine a case where a research pharmacy takes up a role as a service provider and, along with the pharma company, launches a study to combine target group participants' health data from national registers with self-reported data. This Patient Reported Outcome data combined with register data can describe regional differences in, for instance, rare disease prevalence, characteristics, resource use and nationwide costs. A participating person is directed to create a digital 'wallet' for managing personal consents.

This new era of a data-based gold rush is ongoing, where pharma companies are investing enormous amounts of money into value-based healthcare and real-world evidence, where customer-related data, MyData, should be incorporated into the Research and Development process for accelerated drug development processes.

These types of new services will flourish in Europe and in the Nordic countries particularly, as fair data services grow. A brand new legislation for secondary-usage of health data in Finland gives a good foundation for new service providers and data operators to thrive if the most important asset of this new economy is taken care of – the trust of citizens in these new fair data services. ∎

KEY POINTS

- ✓ Citizen trust is key to efficient use of data for healthcare purposes

- ✓ Organisations which have a human-centric approach on data use will have more success with their healthcare research and delivery objectives

- ✓ A human-centric approach to personal data can lead to a fair, sustainable, and prosperous digital society

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