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A vision for a person-centric health data sharing

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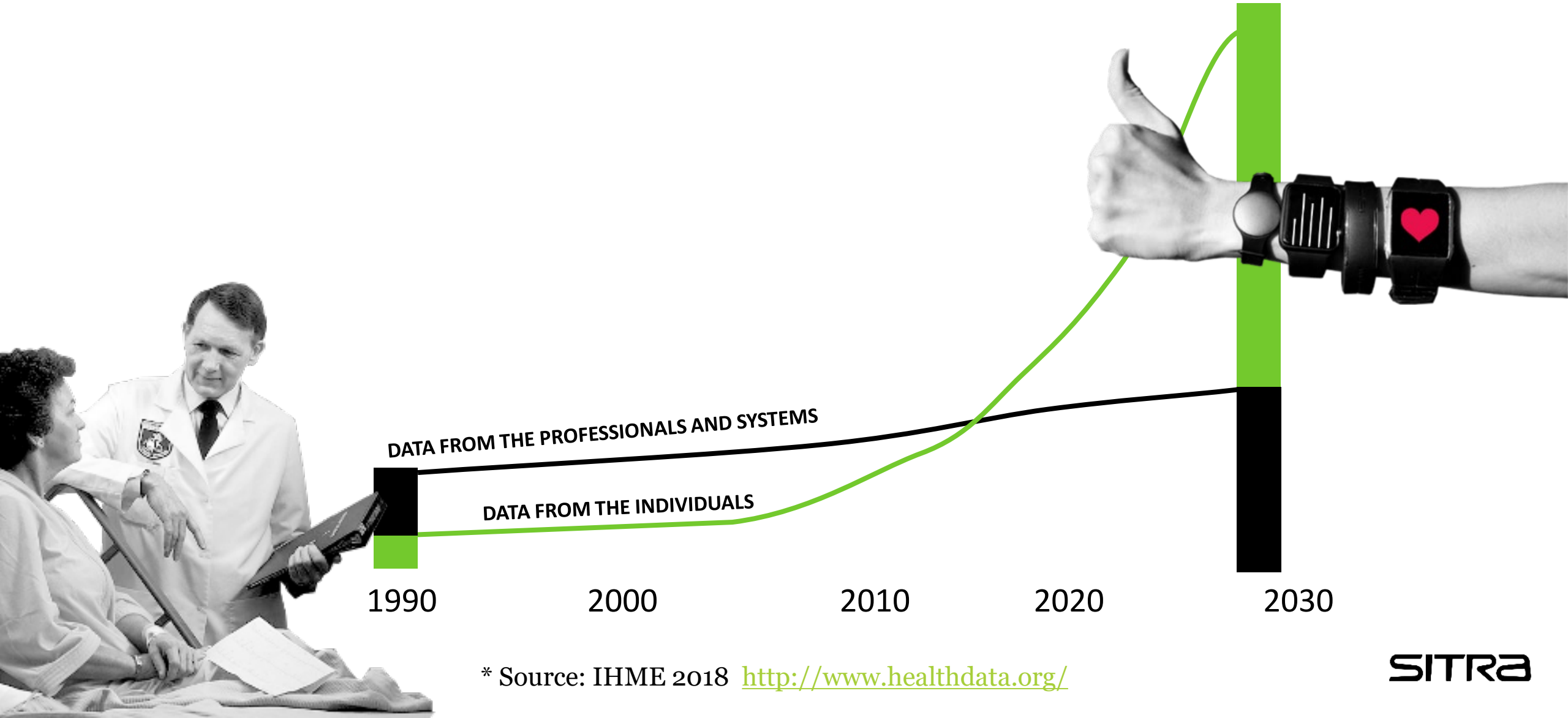
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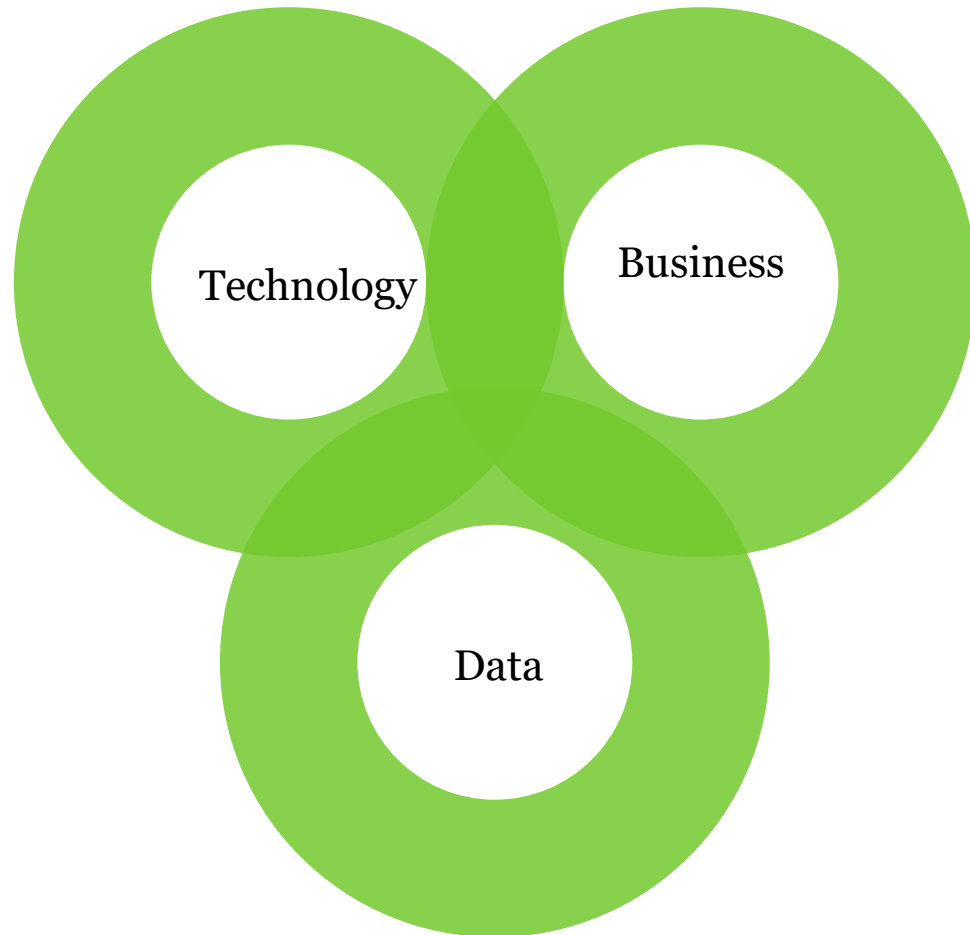
It's Going to Get a Lot More Personal



* Source: IHME 2018 <http://www.healthdata.org/>

Data economy

is technology-enabled solutions combined with customer-driven business



Fair data economy

is the part of the economy that focuses on creating services and data-based products in an **ethical** manner.

Fairness means that the rights of individuals are protected, and the **needs of all stakeholders** are taken into account. Interests of **individuals, companies/organisations and society** are in balance.



TOWARDS TRUSTWORTHY HEALTH DATA ECOSYSTEMS

How the reuse of data can create new services for the benefit of all

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Data can improve patient outcomes, foster research and accelerate the development of new health services only if it is shared between stakeholders and reused while respecting privacy, strengthening people's control over their data and guaranteeing transparency.

The working paper from the Finnish Innovation Fund Sitra provides guidelines for the future strategic use of sensitive data within European health systems. It addresses ethical, legal and self-regulatory frameworks for balanced data ecosystems, discusses the current challenges and establishes a set of recommendations for a new health and well-being data paradigm.

Vision for a person-centric, fair European data economy

- Person-centred and data-driven healthcare
- Every person has full transparency over what happens to his or her data
- Person becomes an active co-architect of health and new digital services
- In future healthcare more data is generated by individuals outside of the healthcare system
- MyData is part of the healthcare system decision making process



Benefits

- Individuals

- Informed decision-making based on personalised feedback
- Improved diagnosis and treatment through self-generated data
- Ability to become co-creators of health and well-being
- Better social and health services that match the needs of individuals

- Health systems

- Allows to plan, provide and monitor personalised treatment and services
- Increases the effectiveness of medical/well-being interventions
- Exploit untapped data resources and their potential
- Accelerate the shift from reactive to proactive healthcare
- Allows to provide new services in rural areas or areas with a poor healthcare infrastructure

Five factors to maximise the potential of data in the European ecosystem

1

Managing the cross-sectoral use of data

2

Creating a scalable infrastructure for viable data markets

3

New incentives to promote the use of person-generated data

4

Activating individuals and business to share data

5

Developing data spaces

Are the interest of individuals, companies and society in balance?

Poll question 1