



HIMSS
NORDIC COMMUNITY



February 29 – March 4
Las Vegas

BIG DATA FOR RESEARCH PURPOSES – WHO BENEFITS?

Ville Koiste, The Finnish Innovation Fund Sitra

 @villekoiste

 #HIMSSNordic #HIMSS16 @himsseurope

www.himssnordiccommunity.org



The Finnish Innovation Fund Sitra

- Sitra, founded in 1967, is an independent **think-and-do tank under the Finnish parliament** that operates on the yields of its endowment capital
- Sitra **promotes the stable and balanced development, qualitative and quantitative economic growth**, and international competitiveness and cooperation of Finland
- Sitra **provides funds** for surveys, activities and experiments that promote well-being and are ecologically and socially sustainable

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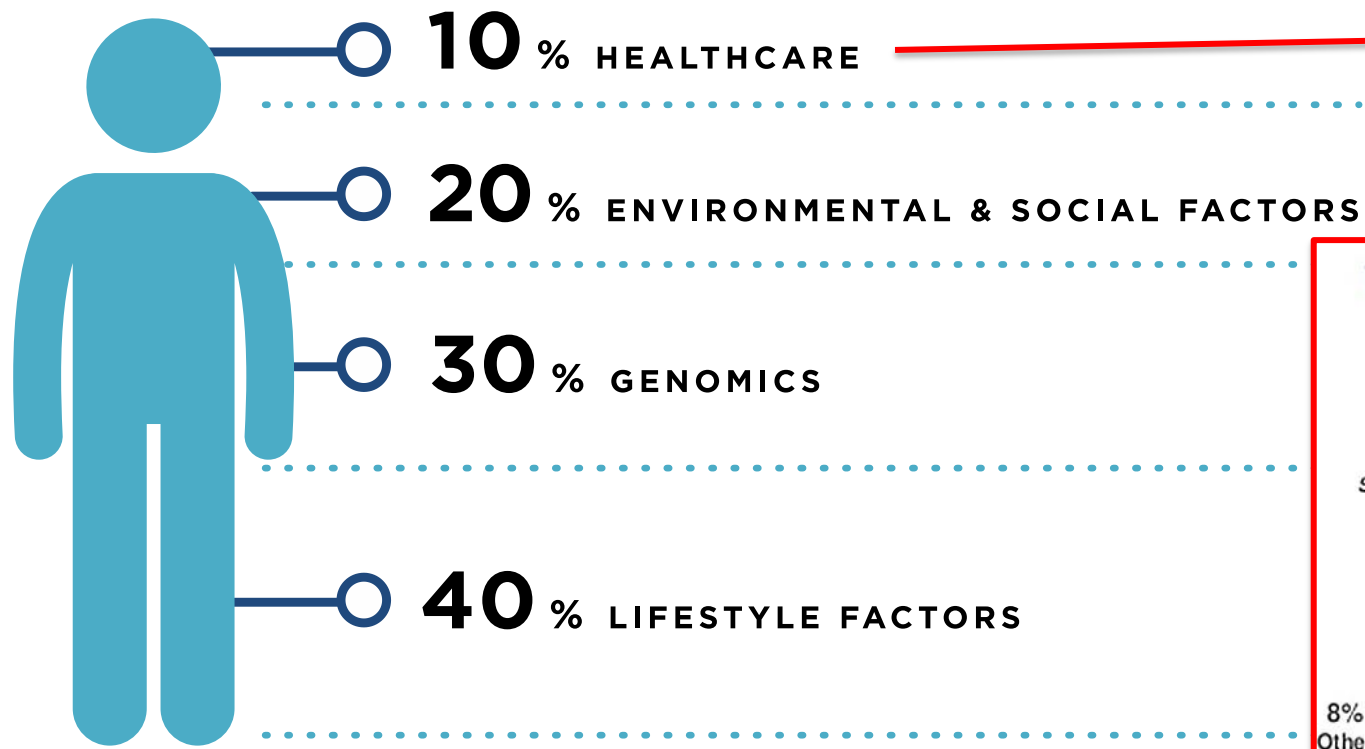
Data and information help us to make
**better
decisions**

Picture: cesletter.com/img/crossroads.png /

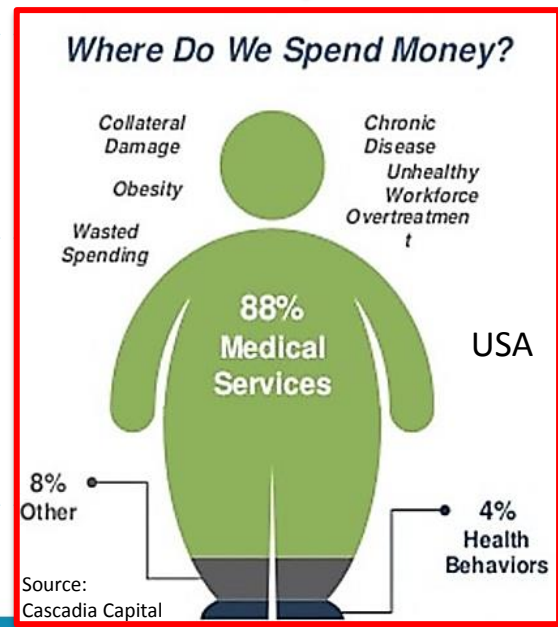
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“Digital is data”

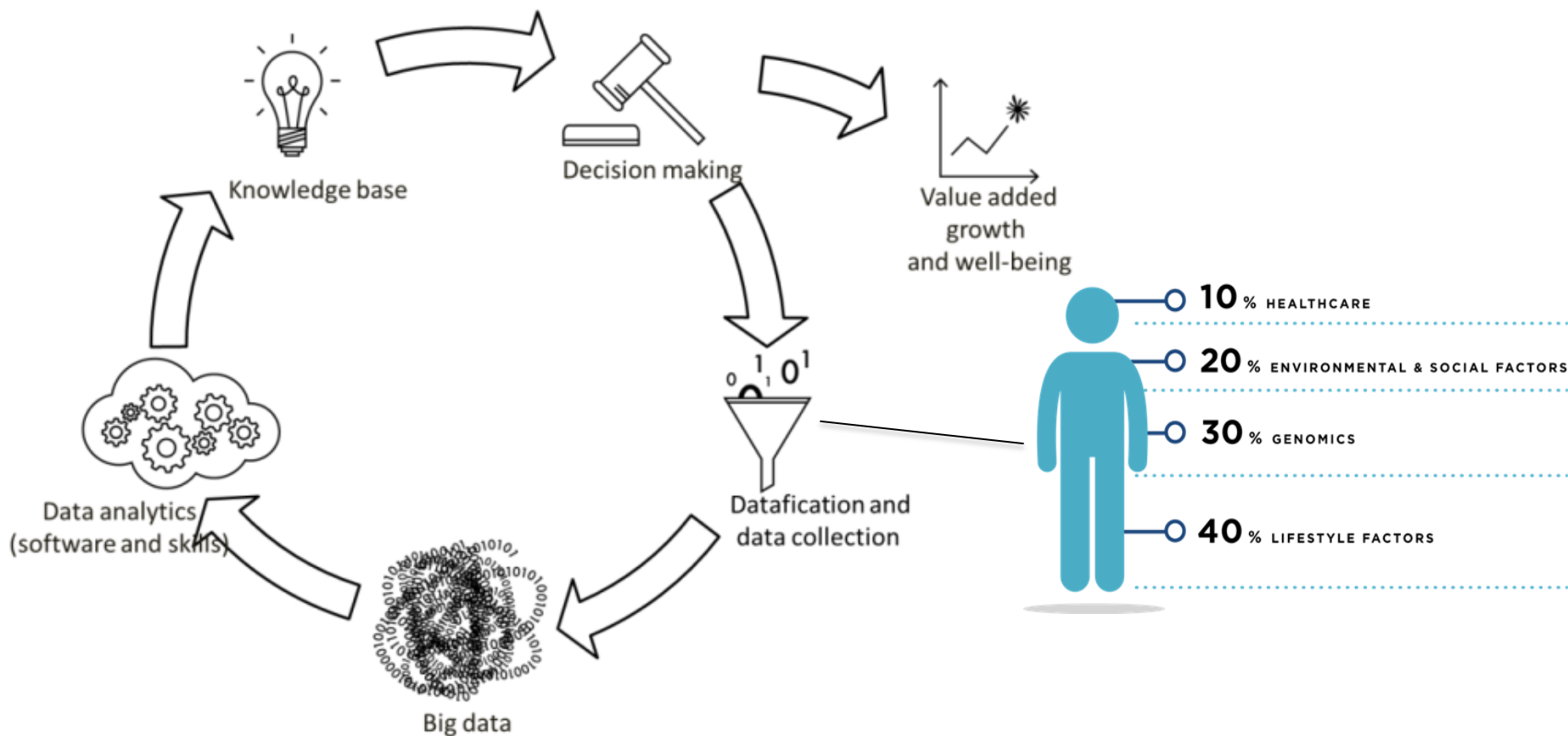
Everything is being digitized, even our health



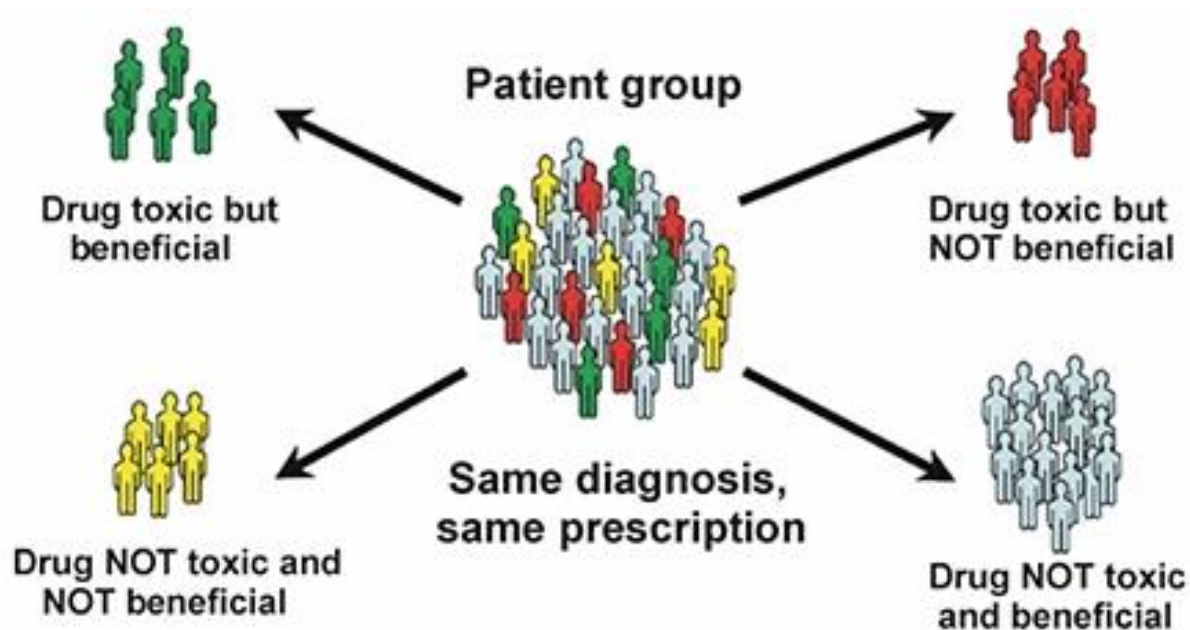
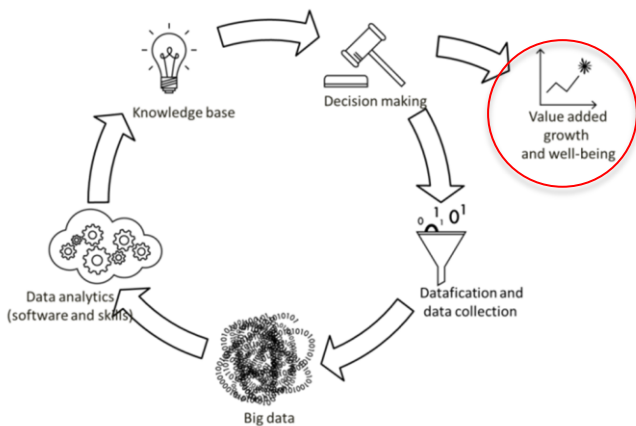
Source: McGinnis et al., Health Affairs; 21(2)2002



Growth and Well-Being From Big Data



The End of 'One-Size-Fits-All Healthcare'?



Source: http://sitemaker.umich.edu/hbhe669final/personalized_medicine

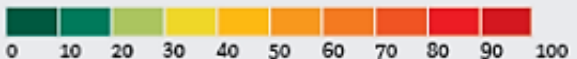


“If data is the currency
of the new healthcare,
TRUST
is the central bank”

The Generations Agree About Privacy

Financial, family, and health information are considered the most private types of data in the U.S.

% WHO CONSIDER THE DATA TYPE MODERATELY OR EXTREMELY PRIVATE



DATA TYPE	Younger Millennials	Older Millennials	Gen-Xers	Baby Boomers	Silents
Credit card data	89	90	88	84	89
Financial data	87	87	86	82	88
Information about children	72	79	80	65	74
Health/genetic information	70	65	74	66	71
Information about spouse	53	68	70	63	69
Dialed-phone-number history	69	63	67	58	65
Exact location	71	66	65	56	59
Surfing history	60	63	60	51	56
Purchase history	50	53	53	46	43
Planned purchases	47	48	48	42	47
Dates of personal significance	42	40	46	41	37
Media usage/preferences	44	36	43	32	37
Interests	24	28	26	25	31
Product needs	26	26	21	15	25
Brand preferences	24	21	21	20	17
Feedback on brands	23	21	21	14	14

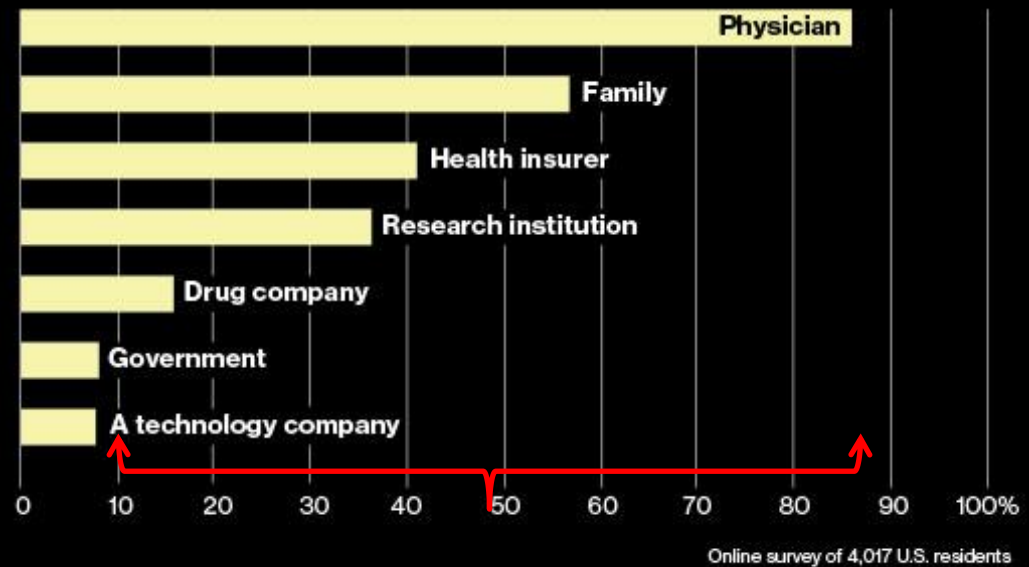
“For global organizations to obtain the greatest access to personal data, consumers need to trust that information about them will be well stewarded, meaning that it will be used for the purposes allowed—and only for those purposes.”

Source: BCG Global Consumer Sentiment Survey 2013.
 Note: Survey question: “How private do you consider the following types of personal data?” Younger Millennials are respondents aged 18 to 24; older Millennials are respondents aged 25 to 34; Gen-Xers are respondents aged 35 to 48; baby boomers are respondents aged 49 to 67; silents are respondents aged 68 and older.

“**The trust gap** may help explain why large tech companies have launched a growing number of partnerships with hospitals and medical institutions”

Trust in Health

Percent of people saying they'd share their health history with ...



Source RockHealth & <https://www.technologyreview.com/s/543536/tech-companies-are-not-trusted-with-health-data/>

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Case: Care.Data Programme, NHS England

Public trust is key to sharing health data successfully, says Fiona Caldicott

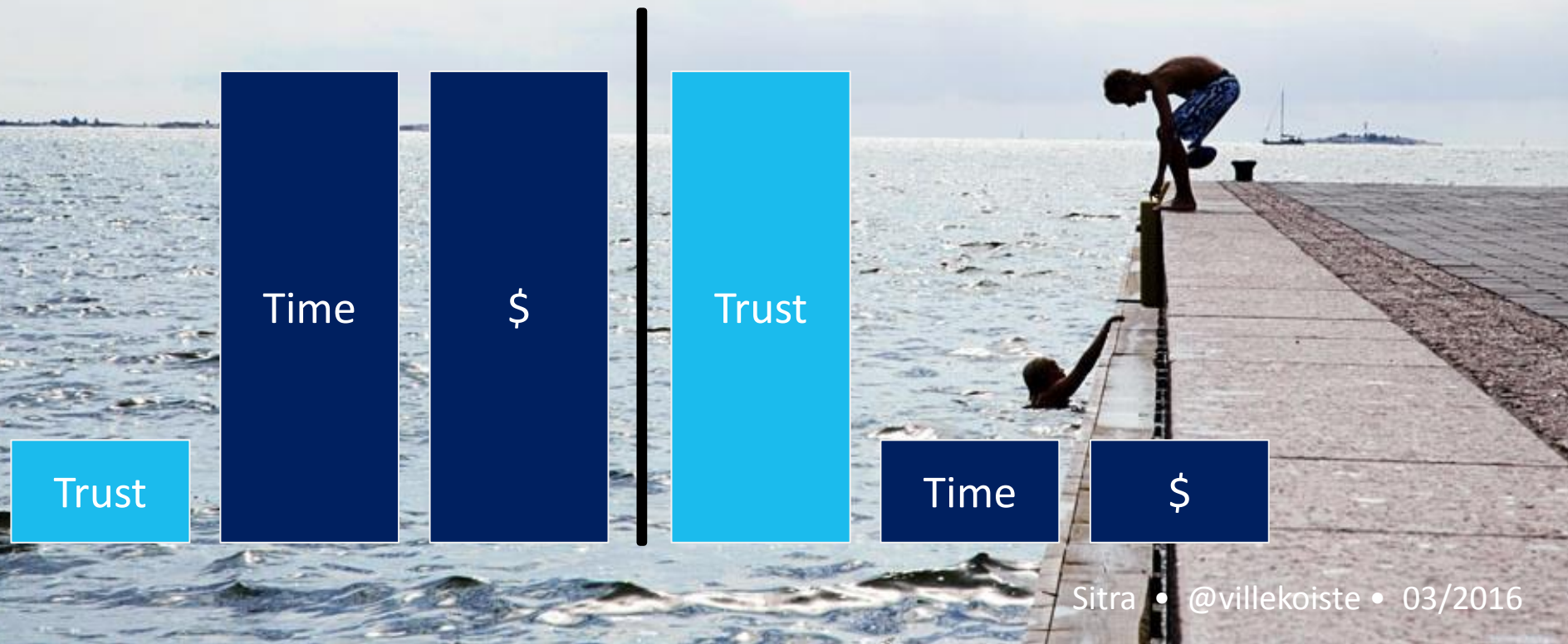
ComputerWeekly.com

“The controversial Care.Data programme...caused uproar among the public and clinicians, mainly due to **lack of information about both benefits and what would happen to the data.**”



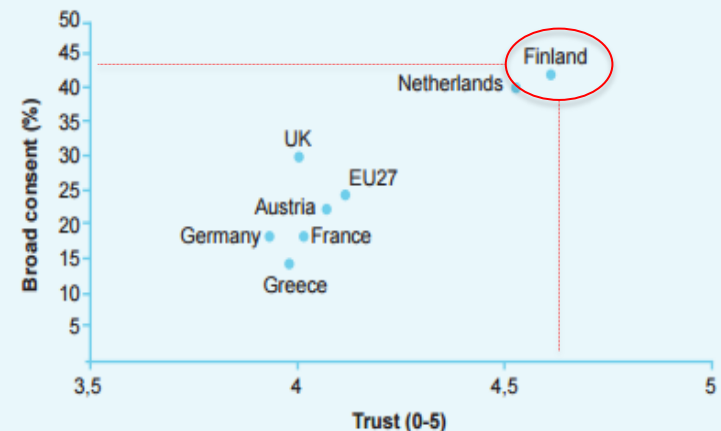
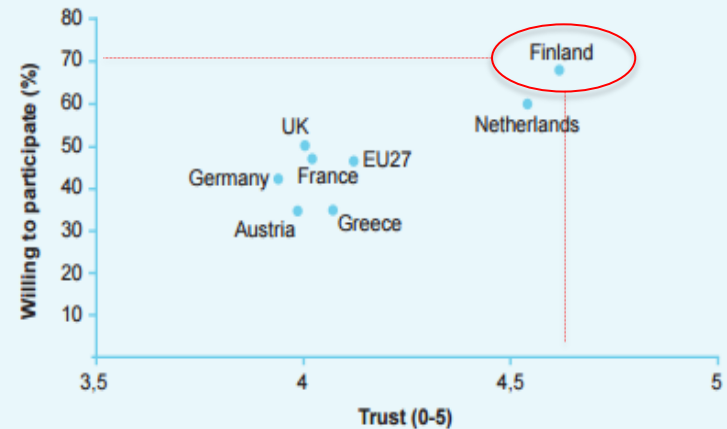
Source <http://www.computerweekly.com/news/4500256234/Public-trust-is-key-to-sharing-health-data-successfully-says-Fiona-Caldicott>

Trust Is a Measurable Economic Driver



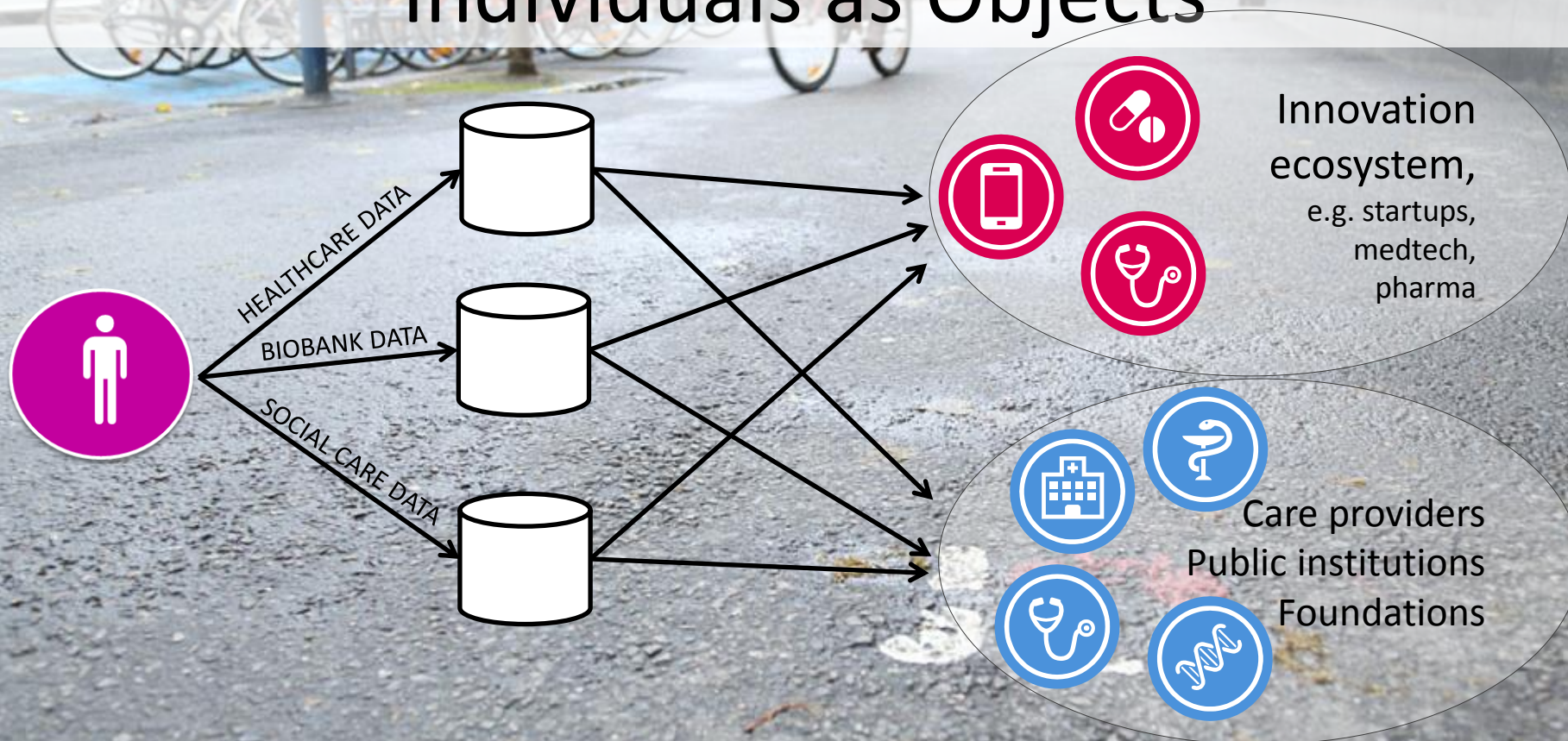
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“Greater trust makes citizens more inclined to participate in biobank research and less concerned with giving consent. In other words,
the trust of citizens is of great importance to researchers’ possibilities of delivering high-quality research.”



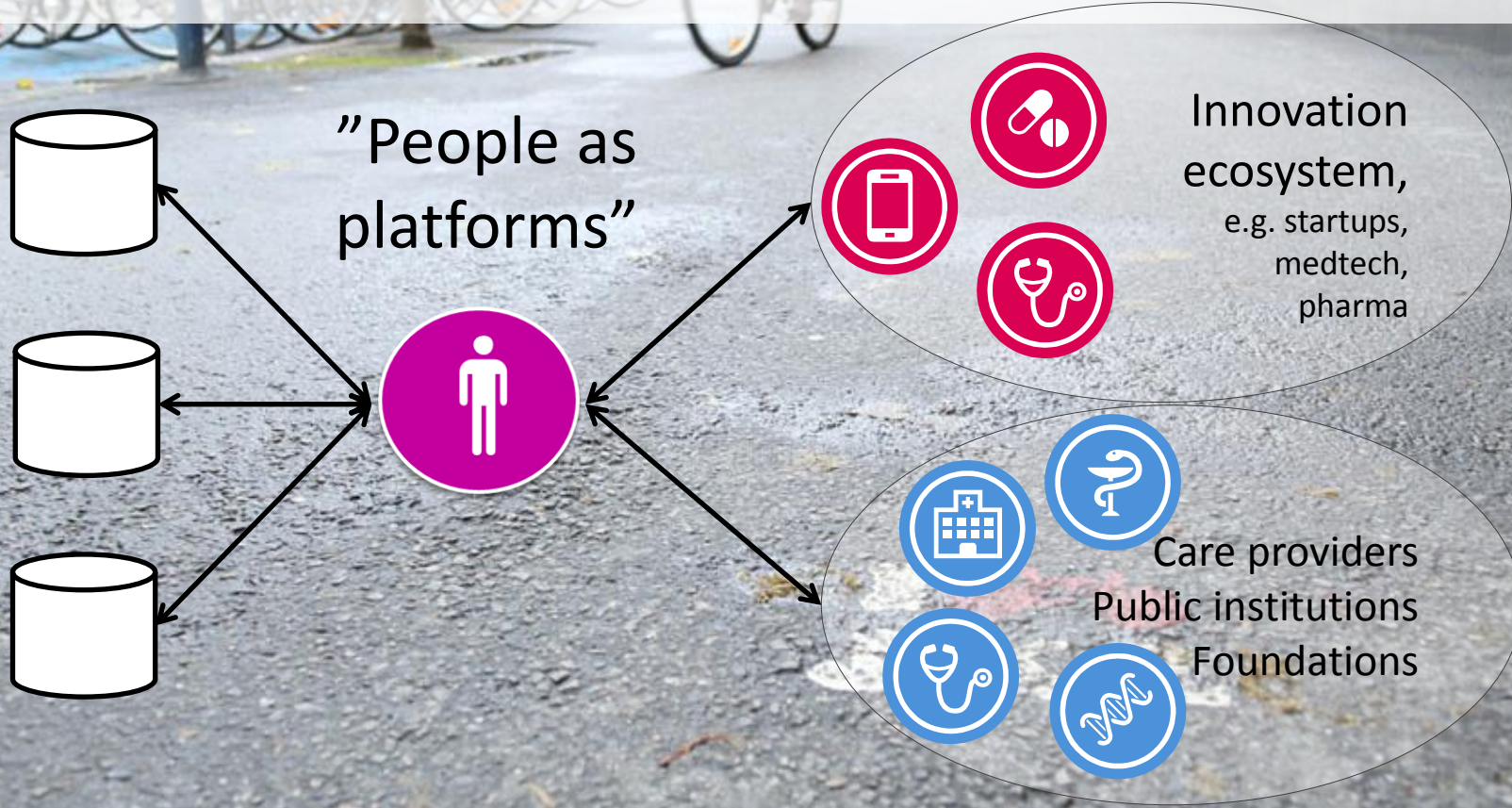
Source: Research with health data and biological material in Denmark, Danish Council of Ethics 2015

Current Health Data Environment – Individuals as Objects



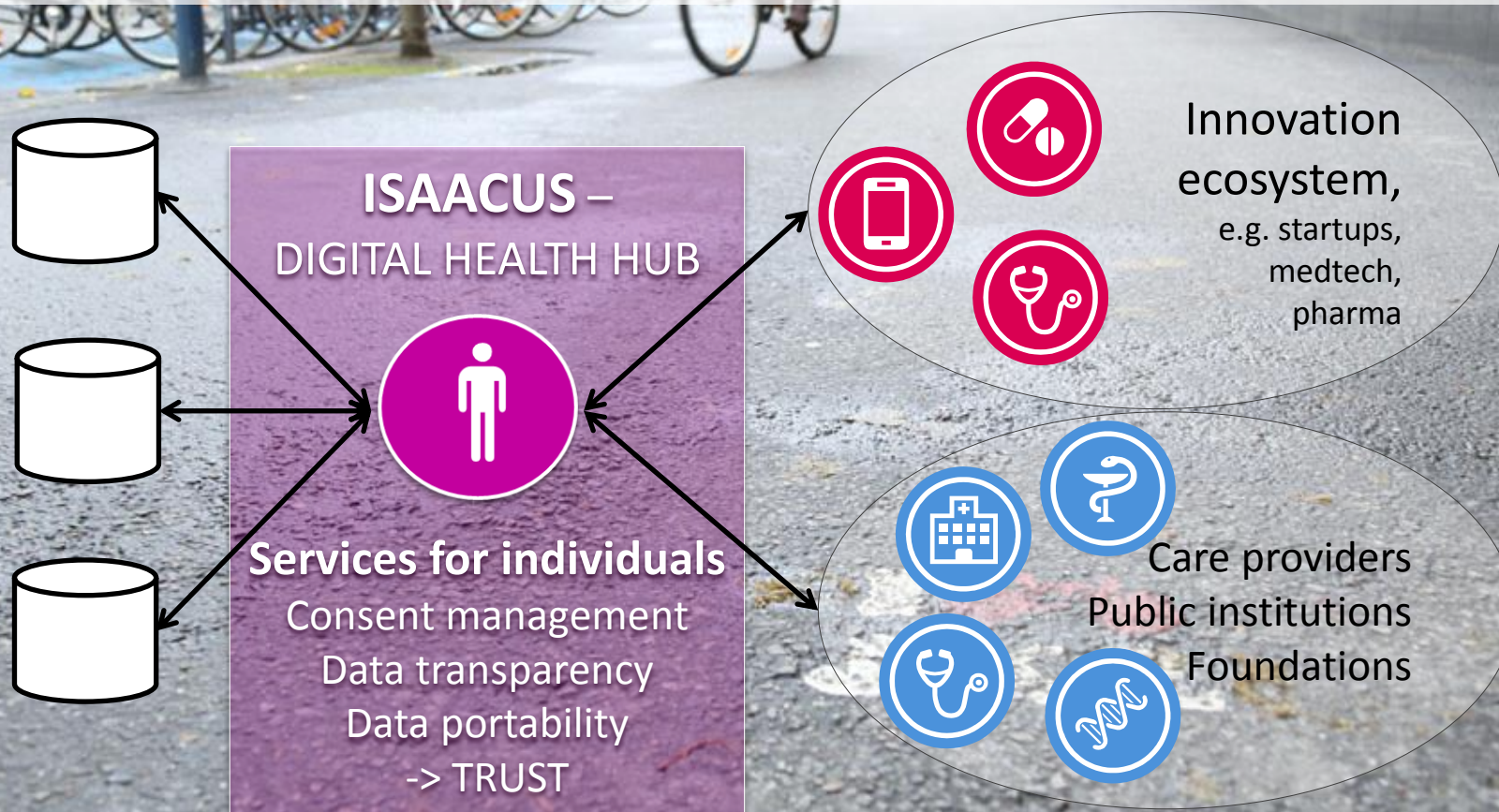
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People Powered Health Data Environment



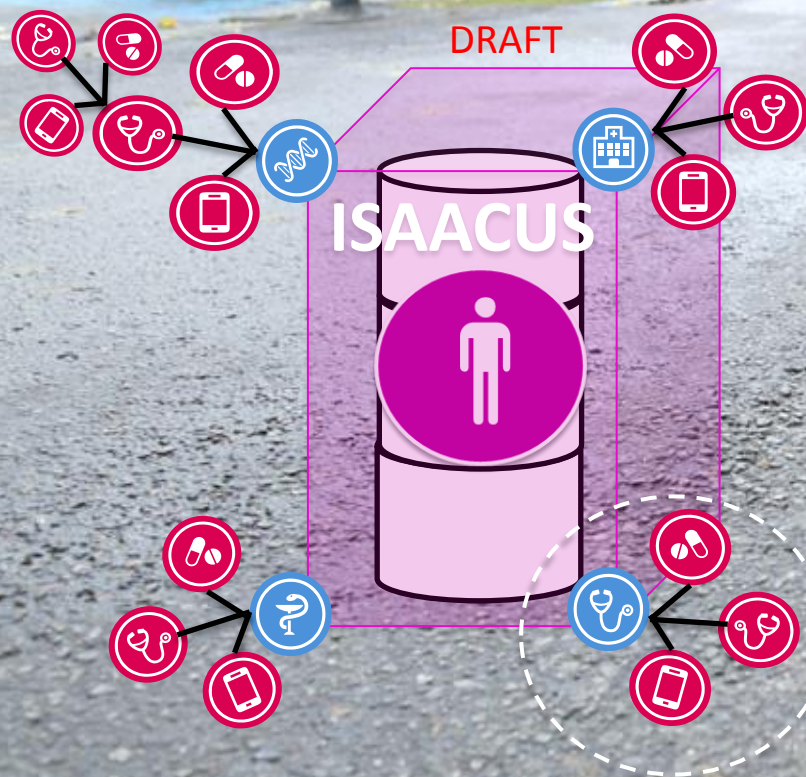
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Data Transparency Creates Trust and Efficiency



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We're Designing a Trust Enabled R&D Environment



Isaacus will be a **public authority and one-stop-service:**

- National metadata catalogue
 - Data availability service
 - Research permissions
- "Safe box" data environment, incl. multiple data sources

Public-Private Ecosystems

Corporations collaborate with institutions, such as biobanks, universities, public research and care organizations that have direct access to Isaacus "safe box"

 Companies

 Institutions

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Why Public-Private Partnerships?

TRUST

The Finnish citizenry trusts the public administration as

- a) a key partner for economic development and service delivery
- b) the mechanism to realise many Finnish values*

EFFICIENCY & INNOVATIONS

When introduced as a component within an existing formal contract,
public-private partnerships can breed innovation**

”FINNISH DATA DESIGN”



People Powered Healthcare and Research Ecosystem

Inspiration

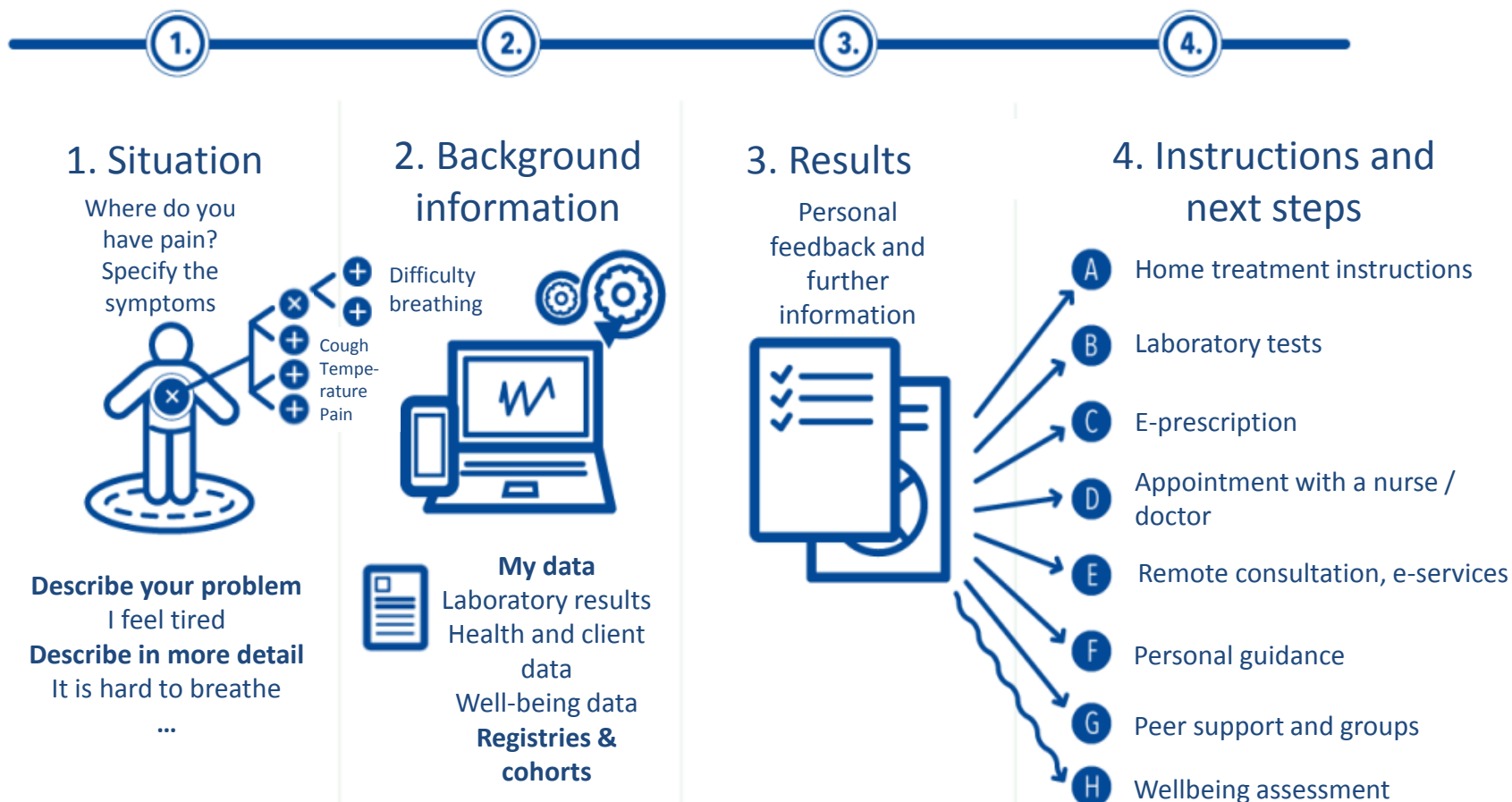
Engagement

Empowerment

Trust

Virtual clinic

Finnish eHealth service engages citizens



THE MOST ADVANCED TESTBED IN THE WORLD

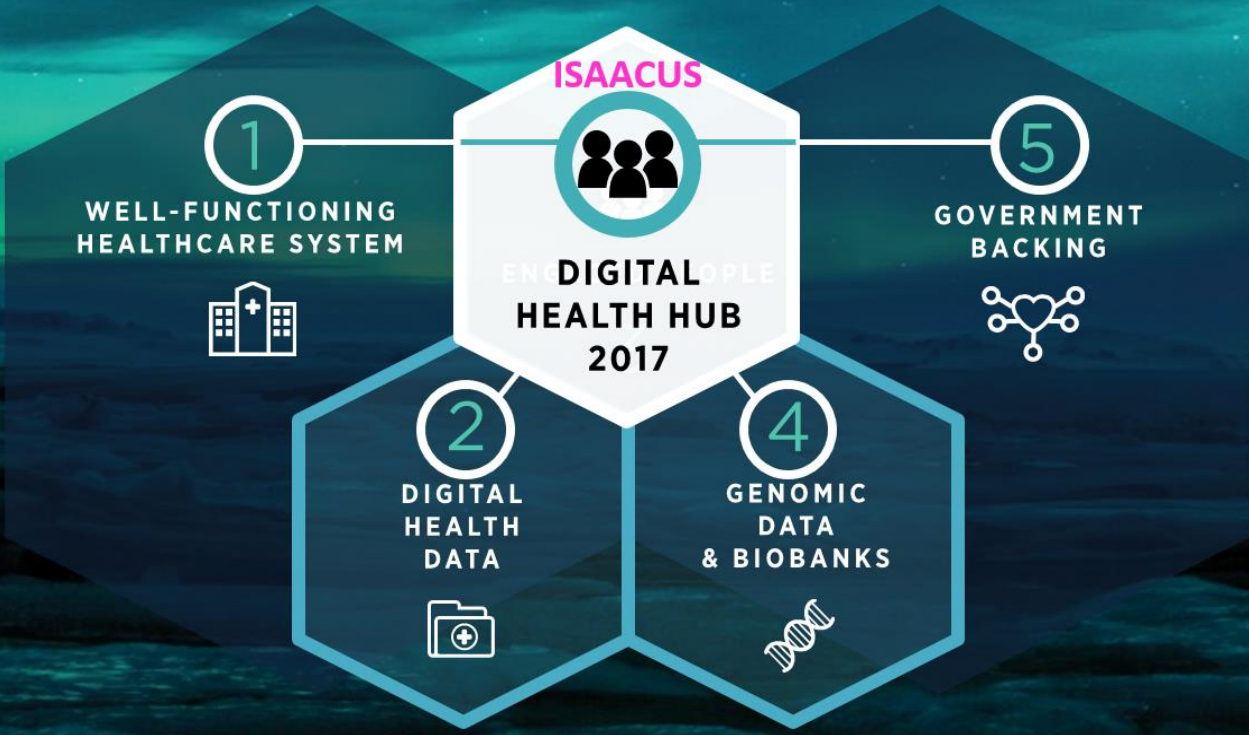


FINLAND - YOUR TESTBED



Source: <http://www.slideshare.net/SitraHyvinvointi/finland-your-testbed-for-the-next-generation-research-medical-innovation>

THE MOST ADVANCED TESTBED IN THE WORLD



COMBINING DATA FROM DIFFERENT SOURCES

FINLAND - YOUR TESTBED



“Shared control
provides
shared benefits
at an exponential rate. When
individuals inform the collective,
and the collective informs the
individual, we will have the
learning health system
we seek.”

Eric Topol, M.D., director of the Scripps Translational Science
Institute, and Leonard J. Kish of Unpatient.org

Source: <http://www.fiercehealthit.com/story/why-health-data-ownership-civil-right/2015-09-09>

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THANK YOU

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More information: <http://bit.ly/tomorrowshealth>

 @ villekoiste, #isaacus

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