



REPUBLIC OF ESTONIA  
MINISTRY OF SOCIAL AFFAIRS

# Supporting a Data Driven Patient Journey in Europe – How Can Member States Help Drive Results?

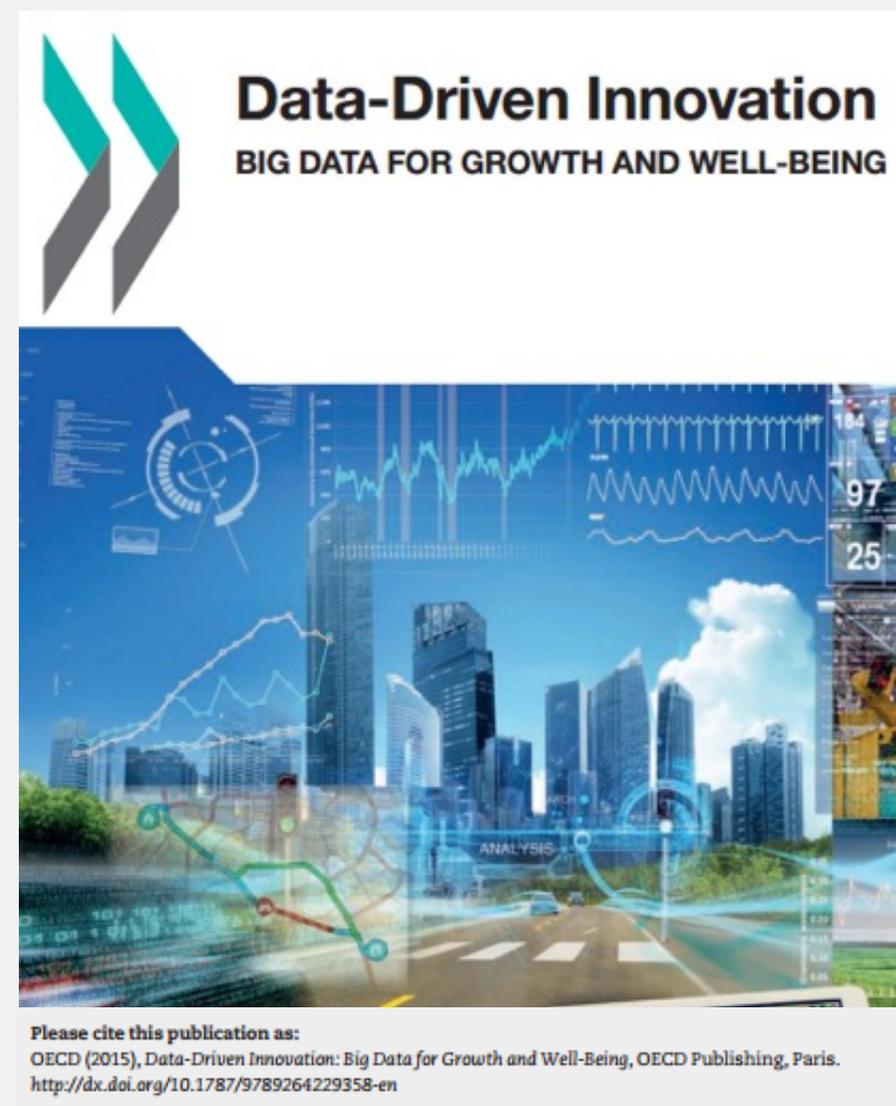
Ain Aaviksoo, MD MPH  
deputy secretary general for e-services and innovation (CIIO)

29.06.2017 | Tallinn, Estonia

Data will drive the  
innovation &  
we don't even know  
exactly yet,  
what will it look like

Big data is not just a quantitative  
change, it is a conceptual and  
methodological change.  
It will reform the way we do  
science and the way we deliver  
care.

*(Rossor/OECD (2014))*



„ Data is the new oil!“

*Clive Humby (2006)*

*Meglana Kuneva (2009)*

...



**Citizens truly in control of their health and the data + system that support it**



**Health care as an asset not cost item for public budgets**



# E-services in Estonia

Internet banking (99%)

E-school

E-health record  
(99% population)

E- Business registry

E-land Registry

Digital signature

E-police

E-pensions account

ID-ticket

E-tax and customs service  
(97% income tax)

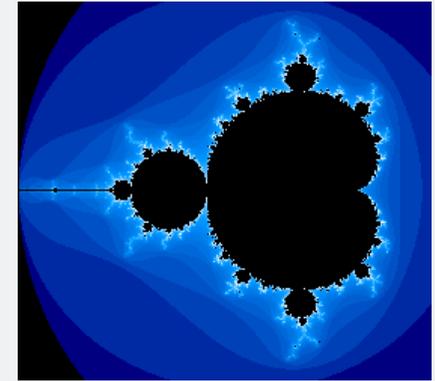
E-voting (30%)

E- self-services

E-state service  
portal

E-prescription  
(99% population)

# It takes ...



- ✓ lots of **information** from various sources
- ✓ powerful **information systems** to process the data
- ✓ smart **people** to find the meaning from noise or random (though sometimes beautiful) patterns

and ...

... a lot of **trust** (from data subjects)

# Access and control of health data becomes crucial

Fundamental principle:

Health data belongs to the data subject

1. Access to my data
2. Control of my data use
3. Delegation of my access and control rights
4. Individual monitoring of requests for my data

# EU General Data Protection Regulation facilitates better use of personal data



The screenshot shows the top navigation bar of the European Commission website. It features the European Commission logo on the left, the word 'JUSTICE' in large blue letters, and the tagline 'Building a European Area of Justice' below it. A breadcrumb trail reads 'European Commission > Justice > Data protection > reform'. Below the navigation bar are links for 'HOME' and 'ALL TOPICS', and a search box with a magnifying glass icon. The main content area has a purple header for 'DATA PROTECTION' and a sub-header 'Reform of the data protection legal framework'. The main title of the page is 'Reform of EU data protection rules'.

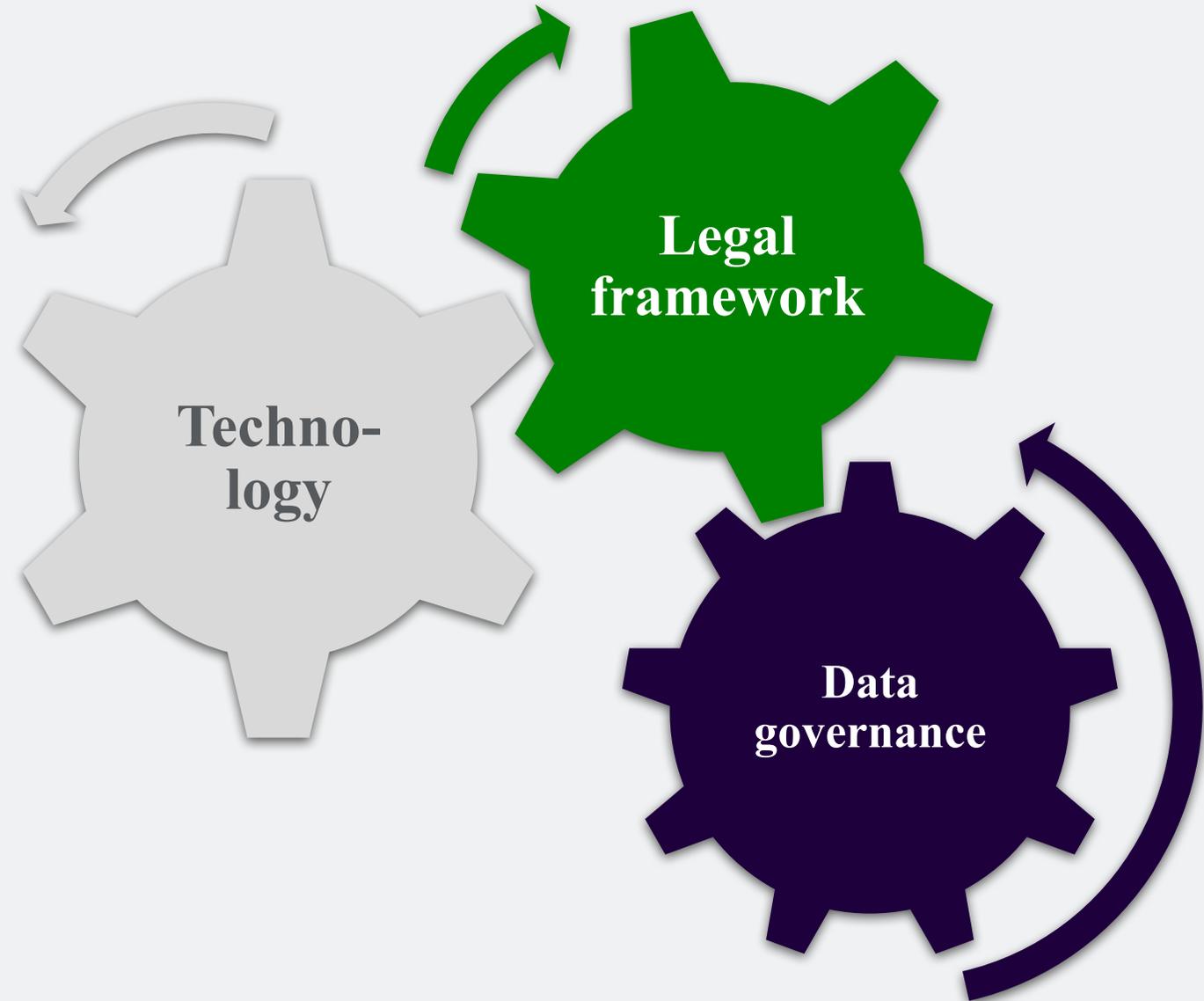
The new Regulation will also guarantee **free and easy access to your personal data**, making it **easier** for you to see what personal information is held about you by companies and public authorities, and make it easier for you to **transfer your personal data** between service providers – the so-called principle of ‘data portability’.

**Privacy means that personal data should be used securely, but not to be secured from being used**



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# Digital Society Trust Recipe



# Personalised approach using existing assets

**Genome Bank  
(est. 2001)  
52 000 donors  
(5% of the population)**

+

**Digital health data  
from 9 sources  
(+10y history)**

+

**International  
investments  
for personalized  
medicine**

**Estonian National  
Personalised Medicine  
Programme**

2016-2020

1. Feasibility and value in clinical environment
2. ICT infrastructure build-up
3. Innovation ecosystem for collaborative R&D, clinical and business development

**Internationally open  
research and business  
development  
collaboration platform**

**Personalized medicine  
centre of excellence**

**Rapid clinical application  
of personalized medicine  
approach & decision-  
support tools**

**International  
business collaboration**

# A precise and learning system with constant clinical/care knowledge creation

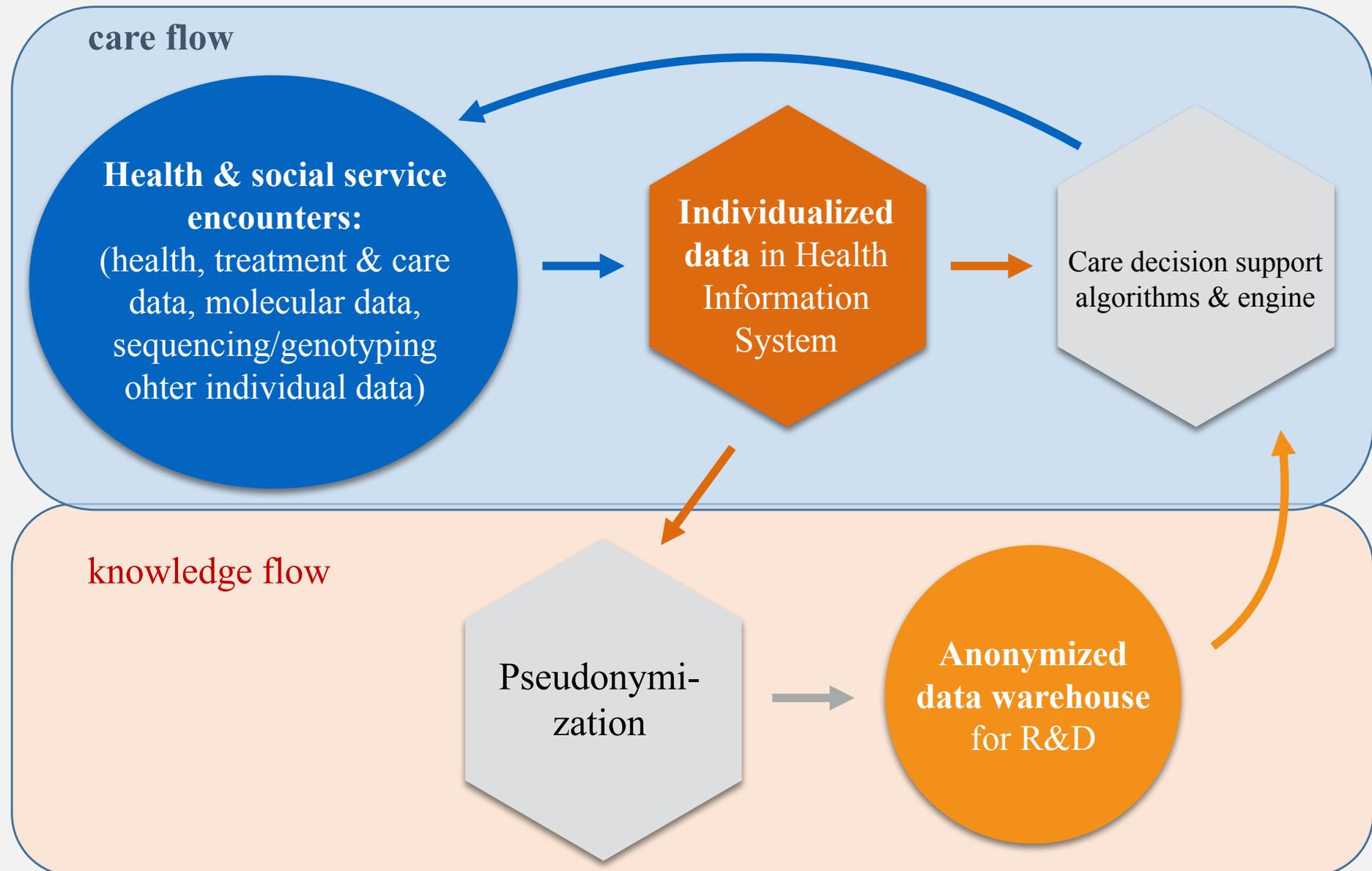




Foto: Sima Kase

In the end there will always come summer..

For more, please visit...

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high level eHealth conference

**„Health in the digital society  
Digital society for health“**

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Digital Health Society

- ✓ Stakeholder Declaration on eHealth
- ✓ Action Commitments



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further inquiries: [ain.aaviksoo@sm.ee](mailto:ain.aaviksoo@sm.ee)