Mining Well-being Data for Better Care: Eleven Forerunner Countries in Europe

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SITRƏ

Activities during the last 2.5 years

5 Study trips

15 International events

2 International reviews and reports

1 International round table meeting

1 Nordic-Baltic meeting

3 National Initiatives Network Skype meetings

SITRA

National Initiatives Network

The secondary use of well-being data

50
people

11
countries

29
organisations

Finland, Netherlands, Estonia, Ireland, Sweden, Scotland, Denmark, England, Switzerland, Australia, Norway

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What's happening in other countries?

Curiosity

Boosts achievement

Expands our empathy

Makes us happier

Helps strengthen relationships

Improves healthcare

Makes our brains more receptive for learning

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Netherlands

Health-RI research infrastructure is a joint effort of Dutch infrastructure providers to establish a single service centre for personalised medicine and health research. It provides researchers with a data catalogue, ethical and legal advice, IT tools and FAIRification training.

- Published business plan
- Plans to operationalise and become an own legal entity

Risk factor

Funding

Cool factor

National service desk for Ethical and Legal questions

🇫🇮 Finland

The Digital Health HUB enabled by the new Act on the secondary use of health and social data. One-stop shop which offers permits, advisory and access to data for research, development and innovations

- Governmental support
- Temporary steering group and sub groups led by the Ministry of Social Affairs and Health are in action since January 2018

Risk factor

Legislation not passing or postponed

Cool factor

Innovative legislation (GDPR proof)

🇬🇧 United Kingdom
(Scotland, Wales, England)

- The cancer registry in England
- UK Secure e-Research Platform (UKSeRP) in Wales
  – High-powered data management and sharing technology
  – Secure platform for managing, sharing and combining data
  – Based on the SAIL Databank, which has been in operation for 10 years
- Projects In Scotland
  – Developing national patient level costing data system
  – High Gains Individuals project

Risk factor

Public trust

Cool factor

Volume

🟩🟧 Ireland

The Health Research Board is building a management model for research on healthcare according to the DASSL model.

- Approved funding for a proof of concept

Funding

Ireland received 1st place in EU Open Data Maturity Assessment Initiative

Denmark

Five regions (Danske Regioner) work together with the government to establish a data entry point and regional data support centres where researchers can get advice on data access and projects.

Copenhagen Healthtech Cluster established a public-private partnership under the Data Saves Lives initiative with three specific proposed solutions: 1) national data map (metadata catalogue), 2) data entry point and 3) data sandboxes

Legislation framework

High trust in government

🇪🇪 Estonia

Building a state-level data integration and analysis platform to allow SME's and scientists to process large amounts of pseudonymised well-being data to create solutions that give more healthy years to people.

- Political initiative is under preparation to establish Digital Innovation Estonia, a single point contact to coordinate different cooperation initiatives related to secondary use of data
- Planned establishment in 2019

Risk factor

Legal challenges

Cool factor

eHealth

🇦🇺 Australia

Secondary use of the Australian My Health Record – a consolidated electronic health record system.

Planning phase is underway, and it is expected that data will be made available for medical and research purposes by 2020.

Governance is based upon the SAIL model in Wales

Interoperability and public trust

Active cooperation

🇨🇭 Switzerland

Swiss Personalised Health Network promotes personalised medicine and health. It creates a dynamic network of existing data sources and funds to make them interoperable nationwide.

Collaboration agreements signed with all 5 university hospitals. 15 projects funded in the first call for proposals.

Setup of a Data Coordination Center and BioMedIT platform

Several langauges

Funding and resources, Ethical Framework for Responsible Data Processing

🇸🇪 Sweden

The Swedish Research Council works to improve access to register data for research purposes. Register Utiliser Tool (RUT) was developed to search and match metadata both in and between registers.

Risk factor

Legal framework

Cool factor

Metadata

Norway

Norwegian health data program improves the secondary use of health data with a primary focus on health registries and RWE.

- Four projects including work on realising a national health analysis platform
- Entering execution phase
- FAIR-mapping of health registries have started

Risk factor

Silos

Cool factor

Governmental funding

WHAT HAVE WE LEARNED SO FAR?

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1

We all have
the **same**
challenges

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1   Interoperability between different IT systems

2   Public trust – how to maintain it or gain it

3   Siloes and culture in not sharing the data

4   Bureaucratic and non-transparent data infrastructure

5   Fragmentation of data sources

6   Legal framework

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1 We all have the **same challenges**

2 We all have the **same goals and objectives**

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All countries want to use their data reserves in a more agile manner than at present

1 We all have the **same challenges**

2 We all have the **same goals and objectives**

3 We don't need to innovate **everything ourselves**

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We can learn from each other

Different countries have different strengths

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#datasaveslives

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People collaborate.
Not organisations.

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BENEFITS OF COOPERATION

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1 Speed up innovation

2 Attract investment and companies to Europe

3 Strength in unity

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It doesn't matter how you start, as long as you start.

National Initiatives Network

To join, send an email to
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Two active subgroups:

1 Synthetic data

2 Metadata

Be curious, learn from others and you will succeed!

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