NordForsk PhD course in Register-Based Epidemiology

Nordic Commons for Register Data

Nordic Commons

The vision is the Nordic region as a world-leading region for secondary use of health data

This requires

1. A Nordic federated secure platform for processing sensitive personal data – a Nordic Health Cloud
2. Nordic health data described with rich metadata according to the FAIR criteria – a Nordic Health Metadata Repository
3. A coherent legal and ethical framework
4. A research funding programme for technology and competence development.

NordMAN
- Nordic Microdata Access Network

- → All Nordic Statistical Institutions (NSI) give national researchers access to de-identified microdata
- → In 2015, the NSIs agreed upon a common cooperation model enabling researchers to access Nordic social microdata for statistical purposes
- → Access to microdata from NSIs and researchers' own data
- → The PI applies for remote access to Nordic microdata from the national NRI
- → De-identified datasets according a "need to know" principle
- → Access to cross Nordic microdata through existing local remote access systems
  - → Denmark, Finland and Sweden
- → Single access point where the microdata are stored
- → Data will never leave the Nordic NSIs
- → All output subject to output control

Tryggve
- Nordic platform for sensitive data

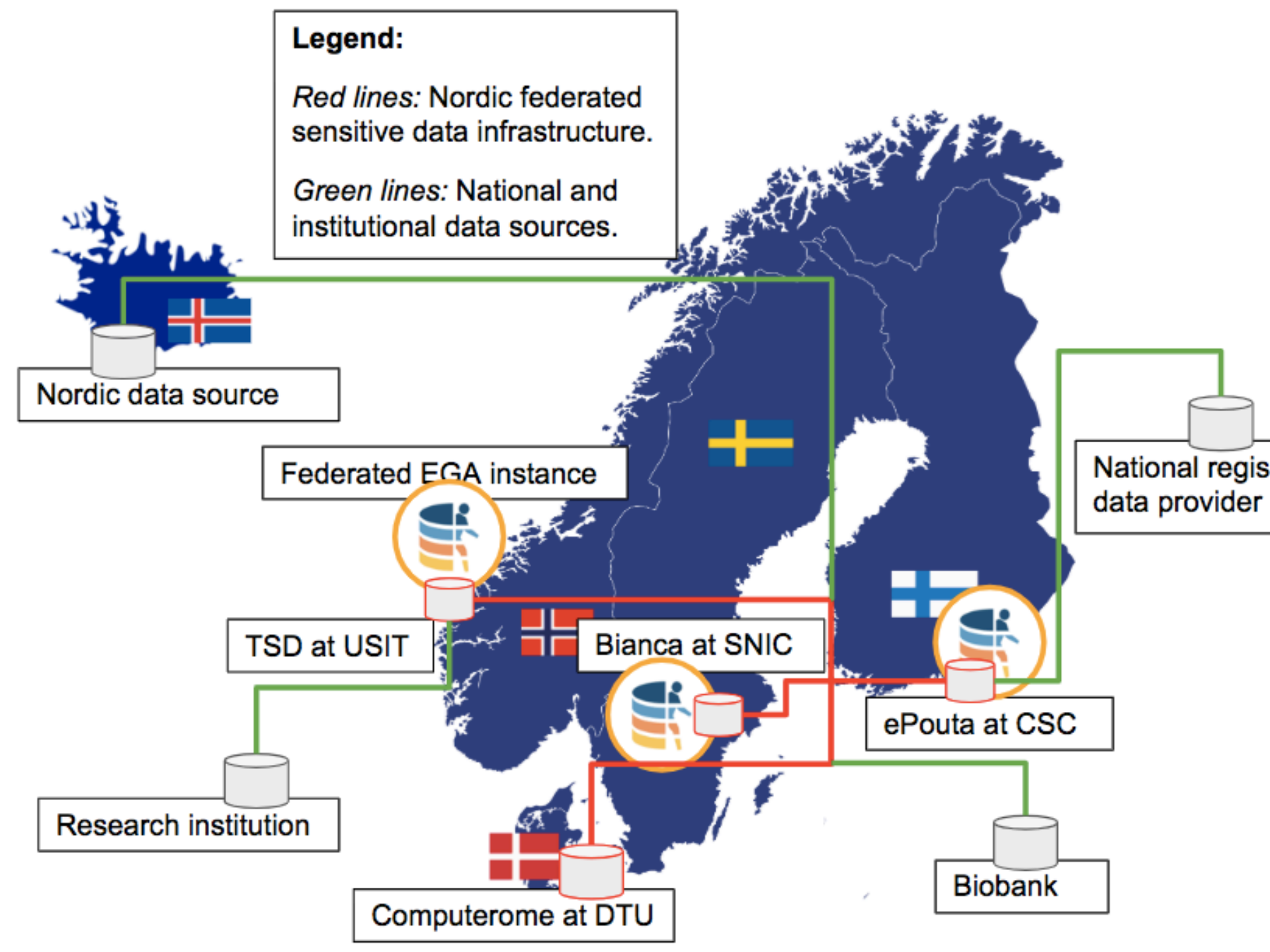
→ The Nordics have unique digital health registers, biobanks, genome and other data collections

→ Nordic collaboration for sensitive data funded by NeIC and ELIXIR nodes
  → NeIC = Nordic e-Infrastructure Collaboration
  → ELIXIR = European research infrastructure for life science information

→ Challenge is to balance benefit for the society and privacy of individuals
→ Secure IT is needed in solving this challenge

→ Tryggve develops and facilitates access to secure e-infrastructure for sensitive data, suitable for hosting large-scale cross-border biomedical research studies

→ Use cases


Legend:
Red lines: Nordic federated sensitive data infrastructure.
Green lines: National and institutional data sources.
Nordic data source
Federated EGA instance
TSD at USIT
Bianca at SNIC
ePouta at CSC
National regis
data provider
Research institution
Computerome at DTU
Biobank

Computing with distributed data

→ How to compute securely on distributed data sets

→ Tryggve currently working on three alternatives

1. Pooling of data (technically simple but not always possible)
2. Federated model: compute close to data and combine the partial results (effectively separate processing)
3. Data streamed on-the-fly to joint analysis (data moves but is not stored outside the home repository)