

Registries, practical challenges – Data sharing (1)

STATUS – We have high quality data in the Nordic countries – but how to get access to it across borders – pool the data – reinforce statistical power

- EU harmonization ongoing – **send question to local computer databases instead of asking for data** – and opportunity for nordic collaboration across data bases
- Centralize datacenter for Nordic – researcher send questions – “ TEDDY”
- Prescription data base mining ongoing in Nordic
- **Challenge:** Who gets access to data – all equal ? – eg certain stakeholder like industry could there be risk of commercialisation – a set of rules should be defined

Support operations – Data sharing (2)

- Individual data mining technical /statistical requirements a challenge – how to get access/link to registries
- “Selling data to industry / other stakeholders” is that an opportunity
- How to practically approach this = **Objective : How to collect data that benefits the patient ?**
 - This can be across countries ? May data leave country ?
 - Legislative perspective – can we share data ?
- Focus on the data for an individual – this may loosen up the restrictions and motivation

Ethical review – mutual recognition

- **STATUS**

- **DK – national committee for review of health research only**
- **SWE – all research covered by committee with 1 set of rules applying – act as courts**
- **NO - 7 regional committees – 1 appeal court on top (medicin, technical, humanity)**
- **EU – Legislation on clinical trials – one web portal for applications (a vote ongoing in Q-2014)**
- Can we at Nordic level **agree on one ethical mutual recognition when EU legislation on clinical trials is approved ?** – Can Nordforsk facilitate this process ?
- The EU webportal needs to be operational – time perspective

Technical Solutions – challenges

- Nordic e-infrastructure collaboration (NEIC)
 - Data storage facilities – economies of scale – 1 localization on Iceland due to price
 - Beware funding issues for systems
- The technical gap is minor in relation to the legal gap

Facilities for unified data sharing in each country

STATUS – countries have several systems

- DK - " The Cloud " – web based – set of rules needed
- Danish solution on health data unique – not the same as cloud – ministry of health based
- NO several systems / several areas – high cost to do linkage
- SWE systems actually not generated for data sharing with researchers
- ICE simplification is ongoing – focus on integration
- **IMPORTANT** : Have organizations harmonized collection of data types ? *A precondition for sharing*
- **What happens when misuse of data ?**

Research pilots / ideas - (funding available by NordForsk)

1. Database design (data origin , data type) – how to unify data – transform data to one format
2. Patient reported outcomes a more systematic collection in Nordic region – QoL focused – focus on patient
3. Nordic initiative to support monitor and develop register based research.