

**EUPHORIC Project WP5.2:
Review of Finnish Quality Registers
Progress update
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	REGISTER NAME	REVIEW MATERIAL	REVIEW STATUS - COMMENTS
NATIONAL - STATUTORY			
1.	HILMO - Hospital discharge register	Quality report - Description file, general info, other material	additional info acquired by interview - Updated questionnaire in review
2.	Medical birth registry	Quality report - Description file general info, other material	additional info acquired by interview - Updated questionnaire received
3.	Register on congenital malformations	Quality report - Description file	additional info needed by interview Questionnaire in review
4.	Causes of death register	Description file, general info	additional info needed by interview Questionnaire in review
5.	Cancer register	Quality report - Description file	additional info acquired by interview Updated questionnaire received
6.	Implant register (orthopaedic & dental)	General info - Report 2004	additional info needed / co-ordinate with arthroplasty data collection
7.	Register on visual impairments	Description file - General information available	additional info needed by interview Questionnaire in review
NATIONAL - SPECIAL REGISTRIES			
8.	Finnish Registry of Renal Diseases	Description file available, general info	additional info acquired by interview Updated questionnaire received
9.	Registry of vascular procedures	General info	focused only on HUS patients after 2002 - present status unknown

Only short description: mass screening, adverse drug reactions, abortions & sterilizations

Interim Results I

Legal status

- Most large registers statutory
(impact of change in the data protection regulations?)

Staff

- not (strictly) under STAKES:
 - chief physicians appointed
 - supervisory boards (cancer, visual impairments, renal)
- STAKES registers: data entry personnel

Interim Results II

History

- 1950's-60's (causes of death, cancer etc.)
- 1990's: more serious & organised effort
- At intervals: changes & updates in terms of data collection, profile and role

Data Collection

- increasingly IT-enabled (although paper still used)
- often mixed situation (existing + extra data)
- impact of wide-scale uptake of electronic patient record systems

Interim Results III

Connection to other databases

- Discharge register: CMR, FINNVASC (validation)
- Central Population register: HILMO, MBR, CDR, Cancer,
- Causes of death statistics: HILMO, MBR, CMR, Cancer, FINNVASC (validation)
- Economic data - not identified
- Clearing of data: usually once a year or continuously
- CDR: population change register, traffic & occupational accidents
- CMR: induced abortions, medical births, visual impairment, TEO

Publications

- Annual reports (or biannual): in Finnish and English
- Scientific publications
- Ad hoc reporting - special reports (for fee)

Open issues

- Proposed time for data collection
 - categories not suitable for several registers (e.g. cancer, medical births)
 - often need for multiple answers
- Type of data collection (existing, redundant, mixed)
- Collected parameters:
 - how to present, what is relevant info? (some shared, majority is area specific)
- Clearing of data
- Classifications used
 - where is the appropriate section to present it?
- Supporting actions and publications

Validation

- generally understood as control of data accuracy
- routine checks for 'outlier' data in annual input
 - specific parameters
 - juxtaposition with data of previous year
- cross-checking with data of other relevant register
- more in-depth quality check as part of research work
 - usually focused on specific condition
 - not as frequent (resource intensive)

Data Security Measures

Degree of detail provided on the subject, as well as type of measures seem to vary

- limited number of authorized persons with access to identifiable data
- storage in locked or electronic-key-accessible locations
- offline server or work-station/passwords
- encryption of identification data

Legal framework I

GENERAL LEGAL FRAMEWORK		REGISTERS
•Law on personal/identifiable information (with regard to its use for research purposes)	523/1999	implant registers
•Law on archiving	831/1994	
•Law on the patient's position and rights	785/1992	
•Law on nation-wide healthcare registers	556/89) 3 §	STAKES registers, implant registers, Visual impairments
•Decree on nation-wide healthcare registers Modification 1993/1671	774/1989	STAKES registers, Visual impairments
•Decree on the preparation of patient documents, their management and the storage of other material related to treatment	99/2001	

Legal framework II

REGISTER-SPECIFIC LAWS		
•Law on the National Research and Development Centre for Welfare and Health	1073/92 2 and 6 §	STAKES registers
•Law on special level (hospital) care	1062/89 5§	HILMO
•Law on public health	66/72	HILMO
•Law on mental health	1116/90	HILMO
•Act on the investigation of the cause of death and related decree	459/1973, 1973/948	Causes of death register
•By-law making reporting to the Cancer Register compulsory	1961	Cancer register
•Law on pregnancy termination and related decree	239/70 8 and 11§, 359/70 8,9 and 10§	Abortions and sterilizations register
•Law on sterilizations and related decree	283/70 8§ and 427/85 7§	Abortions and sterilizations register

Evaluation: coverage of EUPHORIC indicators

- generally quite good coverage
(often as source of nominator data)
- HILMO requires separate assessment
- certain registers not covered by
EUPHORIC indicators
(visual impairments, congenital malformations)

Access to Data

- Personally identifiable information contained in the register is confidential (law on national health registers (556/89) 4§)
- Information can be released in accordance to principles and requirements specified in the law, for the purposes of scientific research.
- Non-identifiable information and statistical data on the basis of the register's data collection can and is provided to external parties.
- Variations depending on nature of register
e.g. Kidney disease register allows access of patients to own data and same applies to physicians of collaborating departments

Impact on stakeholders

- main beneficiaries: public health, sponsoring bodies, quality-related activities
- physicians and patients: mixed picture
 - patients perceived as indirect beneficiaries
 - clinicians benefit not in direct everyday work, but rather in research-oriented activities
- external auditing: rather unusual
 - realized through peer-review activities: international collaborative projects, research and scientific publications
 - internal quality control more common (meetings, advisory boards, etc).

Emerging models

CENTRALISED

- mandatory input
- no consent needed
- individuals' cannot view/correct data
- secured resourcing
- infrastructure advantage
- more standardized operations (potential disadvantage?)
- more focus on decision-making level statistics
- more distant from clinicians and patients
- less emphasis on communications and PR
- increased utilization of IT
- more distant from research activities?

LOCAL/De-centralized

- voluntary input
- consent required
- individuals can view/correct data
- resource shortage (potentially)
- infrastructure & overall maintenance more challenging
- more personal commitment
- focus on quality & clinical practices
- closer contact with specialty clinicians
- closer monitoring of patients' interests
- more emphasis on communications and PR
- less opportunities for IT utilization
- closer to research?

The PERFECT project

PERFOrmance, Effectiveness and Cost of Treatment episodes

- develops methods for register-based measurement of cost-effectiveness of treatment
- comparative database (btw. hospitals, districts, regions and population groups)
- indicators describing outcome of patients
- bridging the gap/closing the loop (at least partly) between strongly centralized statistics and practice field (although focus is still quite strongly on the decision maker level - albeit local ones)

CLINICAL AREAS: heart, hip, arthroplasty, breast CA, very low birth weight infants, schizophrenia, stroke

Report structure (proposal)

- **Background:**
introduction of project, aim of report
- **Methodology**
definition of quality registers, data collection & analysis
- **Materials**
identified registers (incl. short description), type of reference material and info collected
- **Results**
organised on basis of questionnaire structure categories -
REVISE/REGROUP?
- **Discussion**
models of register organisation in Finland, pros & cons of each approach
aspects of quality that can be followed through register data, other points
- **Annexes?**
(questionnaires, description & quality files)