

EUPHORIC Project WP5.1.5: Review of Finnish Quality Registers Progress update

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Method of work

- Criteria for inclusion of 'quality' registers
- Collection of info on basis of questionnaire through online info, other materials -
Questionnaire draft
- Personal interviews or requests for draft review and additional info
- Extraction of info into Excel - Synthesis of findings
- Report drafting

Finnish Health Care Registers

Extensive review of the national situation in 1997¹
Finnish health care registers were distinguished in four separate types:

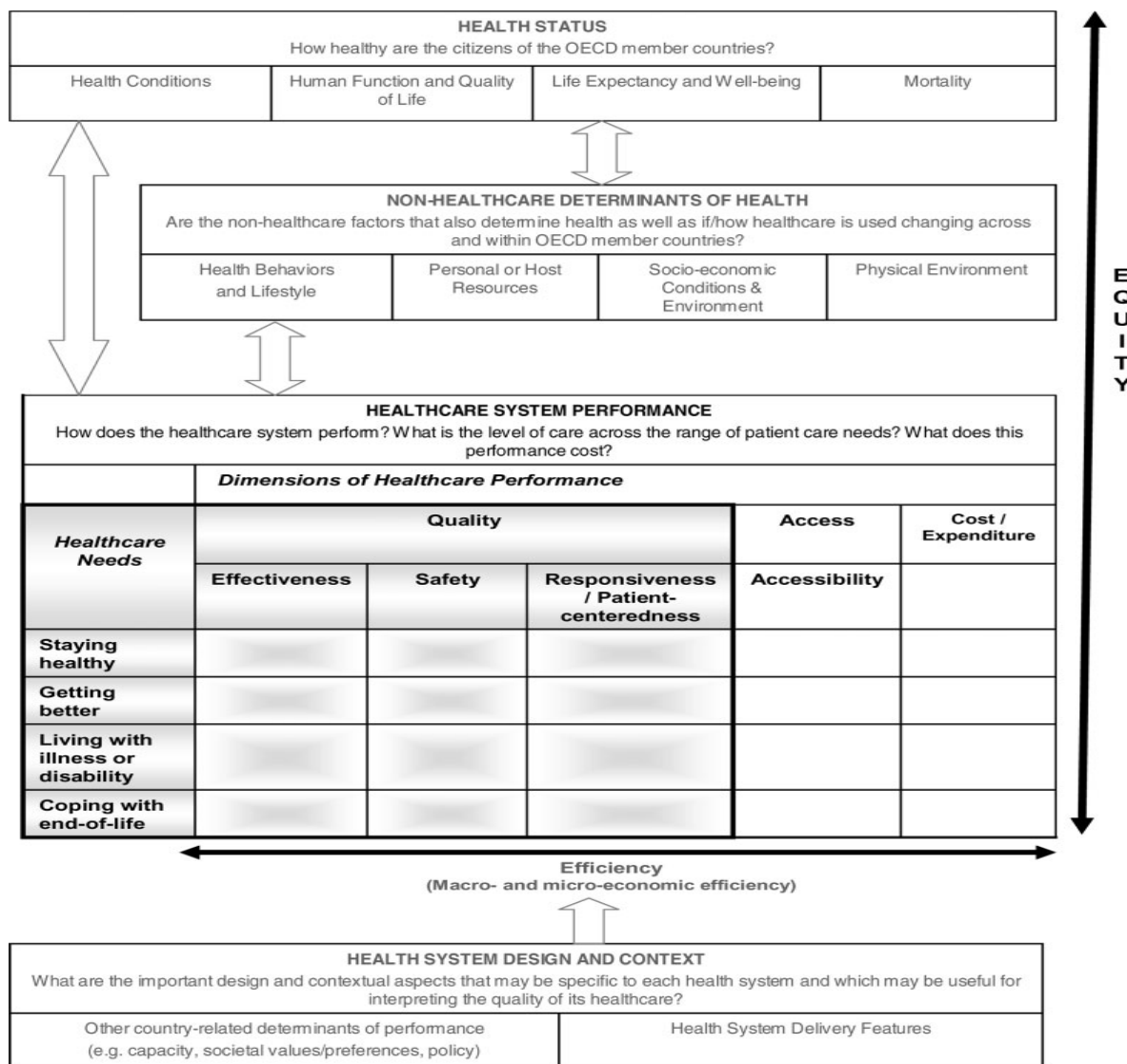
- a. Statutory nation-wide registers (specified by law)
- b. Research registers
- c. Patient registers of healthcare units
- d. Other (special) registers (usually local)

48 registers were studied in detail

Mäkelä M, Lappalainen M, Oirre S. Terveystieteen Erillisrekisterit -
Selvitys Suomessa ylläpidettävistä valtakunnallisista ja alueellisista potilasrekistereistä.
FinOHTA report no.3, 1997

Defining 'Quality Registers' in Finland

- OECD HCQI project conceptual framework
effectiveness, safety, patient-centeredness, responsiveness
- Nation-wide coverage
- Sufficiently large number of patients
 - tenths or hundreds of thousand cases included
 - annual flow of at least several hundreds



	REGISTER TYPE - 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 in review
3.	Register on congenital malformations	Quality report - Description file	additional info needed by interview
4.	Causes of death register	Description file, general info	additional info needed by interview
5.	Cancer register	Quality report - Description file	additional info needed by interview
6.	Implant register (orthopaedic & dental)	General info - Report 2004	additional info to be co-ordinated with arthroplasty data collection
7.	Register on visual impairments	Description file - General information available	additional info needed by interview
NATIONAL - SPECIAL REGISTRIES			
8.	Finnish Registry of Renal Diseases	Description file available, general info	additional info needed by interview
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
- 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)

Problem areas

- Proposed time for data collection
 - categories not suitable for several registers (e.g. cancer, medical births)
 - often need for multiple answers
- Collected parameters:
 - how to present, what is relevant info?
(some shared, majority is area specific)
- Validation: probably not regular, difficult to trace - 'validation' of annual data most commonly referred to
- Evaluation: indicators;
 - perhaps too extensive to include all?
 - How to present this part, what is relevant information?
- Impact

Questionnaire gaps

- Size of register: impact on resources, purpose etc.
- Data entry personnel in staff listing
- Legal framework:
perhaps of interest to investigate which laws are referred to & if there is consistency
- Security measures taken:
degree of detail, as well as type of measures seem to vary considerably
- Classifications used

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

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

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
- **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?**