

Webinar:

What is a register ?





What is a register ?

Definition

A register is ...

- a *systematic* collection of
- *standardized* data
- within a *defined* population
- and for a (predefined) *specific* purpose



Quality criteria for a register

- Defined source population („What is the source population that gave rise to the cases?“)
- Completeness in numbers („All cases assessed?“)
- Completeness in data („All items documented?“)
- Correctness of documentation („No typos/missings?“)
- Timely documentation („Real time assessment?“)



Types of registers

1) Epidemiologic registers

Always have a population reference i.e. a defined source population, e.g. the inhabitants of the city of Münster/ the state of Northrhine-Westfalia/ Germany

2) Clinical registers

Have a patient reference i.e. patients with a specific disease treated in a specific infrastructure (hospital/ outpatient setting)

3) Other registers

Different references, various purposes



Purpose of registers

1) Epidemiologic registers

To assess the incidence of diseases within a population

Examples:

- the incidence of different cancers in the state of Northrhine-Westfalia, their temporal trends and regional distribution (Cancer Register NRW)
- The incidence of stroke, its subtypes and treatment location (hospital) and temporal trends in the city of Erlangen (Erlangen Stroke Register)

If the coverage of the source population and completeness of case assessment is high, disease prevalences can also be analysed



Purpose of registers

2) Clinical registers

To document the process of treatment/ care in a specific institution (hospital/ group of hospitals)

Examples:

- The assessment of quality indicators for stroke treatment to allow a benchmark comparison between hospitals in the acute treatment (Stroke Register Northwest Germany)
- The assessment of treatments, procedures, complications and survival in patients with different cancers in hospitals and outpatient clinics (Clinical Cancer Register NRW)



Purpose of registers

3) Other registers

Examples:

- Death registers: Number and causes of death, temporal trends
- Statistical registers: births, deaths, movements, life expectancy at different ages
- Patient organisation registers: living situation (with disease), socio-economic situation, quality of life, health services utilisation
- Pharmacovigilance registers: (Serious) Adverse events of treatments in patients with a specific disease/across diseases (e.g. phase IV study)



Register methods: Chances

- Time trends, disease frequencies, spatial distribution
- Quality assurance and improvement of care, guideline adherence
- Health care utilisation and economic analyses
- Patient safety for different treatments, efficacy in groups rarely included in clinical trials
- Hypothesis generation for clinical research (studies), patient recruitment (hybrid designs)



Register methods: Challenges

- Implementation and coordination of a register is a complex task
- Needs considerable financial and (trained + extra) personnel resources
- Effective management is necessary for ...
 - Interfaces (data entry, informatics, statistics, center management/reimbursement)
 - Data related tasks (control of completeness, quality, categorisation, analysis)
 - Ethical questions and data security issues
- Preparation/Implementation of register (study) protocol, data reports, advisory board, quality assurance measures must be considered



Registers: More to read...

English

JAMA[®]

Online article and related content
current as of August 25, 2009.

Registries for Robust Evidence

Nancy A. Dreyer; Sarah Garner

JAMA. 2009;302(7):790-791 (doi:10.1001/jama.2009.1092)

<http://jama.ama-assn.org/cgi/content/full/302/7/790>

- „Interest has increased in the role of observational studies, and more specifically in registries and other electronic data sets, as a way to fill critical gaps in evidence“.
- „Methodological research is needed to increase understanding of what constitutes quality in these data sources“.

German

Deutsches Netzwerk für Versorgungsforschung
(www.dnfv.de)

Memorandum III, Teil 2:

(Register für die Versorgungsforschung
& Methoden der gesundheits-ökonomischen
Evaluation in der Versorgungsforschung)



Effective Health Care Program

Registries for Evaluating Patient Outcomes: A User's Guide

Second Edition