

Open access to research
databases

A bird, fish or something
in between?

Open access

- **How is it now?**
- Definitions
- Participants' integrity
- Open access may lead to a new type of researcher/ What is intellectual property? Who should be asked for co-authorship?
- The art of collaborations and knowledge exchange
- Quality of data, analyses and publications

Today

- Problem: Groups who never share data and databases who are not used
- Normal situation with active databases:
- Researcher who wants to work with database takes contact with 'database researchers'
- Collaboration between 'database researchers' and 'outside' researchers
- Both learn from each other
- Joint papers give merits to all involved
- Meta-analyses or merged data('the 500 author paper') gives merits to home researchers and university

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Open access for who?

- Totally open databases on internet with no time limit from collection of data?
- Researchers? Journalists? Public? Family members of participants?
- Researchers with 'Driving license' approved by VR or Forte?
- Researchers take contact with responsible PI or database manager?
- Application to committee?
- Quality control?

Which studies should have open access?

- Data on all studies supported by VR or Forte, including animal studies, experimental studies, clinical studies, population studies?
- Only population-based studies? If so, why?
- Only base data, or also data refined by researchers, e.g. diagnoses based on case conferences and case record evaluations?
- Register data from Socialstyrelsen?
- Should those who use the data sets secondary have responsibility to report errors and should their created data be included in the data set?

Type of database

- Official registers
- Surveys
- Sensitive information (e.g. psychiatric and somatic disorders) from personal examinations
- Clinical data
- Data from experimental studies or basic science
- Extensive examinations including genetic information, brain imaging etc
- Active databases
- Dead databases

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Participants' integrity

- Sensitive data, including medical diagnoses, suicidal feelings, sexual behaviour etc
- 4-5 items to identify a person
- Research agencies versus Ethical Review Boards, Swedish Data Inspection and EU
- Should participants be told that their data is to be free on internet?

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Research process

The traditional
researcher

Design of study, assessments, forms
Ethical applications, writing grants
Preparing study, hiring people, training etc
Conducting studies, entry of data
Data cleaning, making diagnosis, derived
variables, assessments of scans etc,
Analyses of data and writing papers
Publication of paper

The
new type
researcher

3-6 years

Who should design and conduct studies in the future?

- Researchers who conduct studies because they have research questions and who wants to analyse the data?
- Special research administrators?
- Should we divide researchers into data collectors and those who only analyse data and write papers?
- Should we tell young researchers that it is better just to analyse data from others and avoid conducting research studies which takes time from writing papers?
- Should researchers in the future design and conduct studies?
- Are there good arguments why researchers should conduct studies?
- Is open access a good way to support lazy researchers?
- Are there other ways to support the lazy researcher?

- Who wants to be just a data collector?

Is data collection an art of science, which merits a question on co- authorship?

- Design of studies
- Conducting studies
- Data cleaning
- Derived data, diagnoses etc
- Analyses and writing
- Vancouver system

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Collaborations or just analyse open access data?

- Supports exchange of knowledge between research groups
- Foster international collaborations and contacts
- Increase critical mass
- The group who takes care of the database can help the other group to avoid misinterpretations and fallacies in the analyses
- Often difficult to understand complex databases
- Who takes responsibility that serious researchers analyse the data?
- How to avoid double work or publications?

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Cons for open access

- Participants integrity
- Ethical considerations
- Intellectual property
- Quality of research
- Researcher or data collector?
- Merits if researchers who conduct studies are not invited to be part of analysing and writing?
- Collaborations or just open access?
- Learning from collaborations
- The difficulty to understand complex data sets

VANCOUVERREGLERNA

Formulated by the International Committee of Medical Journal Editors (ICMJE)

*1. Personen ska ha stått för ett substantiellt bidrag till idé och design, insamling av data eller analys och tolkning av data.

*2. Personen ska ha skrivit första artikelutkastet eller kritiskt reviderat det med avseende på intellektuellt innehåll.

*3. Personen ska ha slutligt godkänt artikeln inför publicering.

*4. Personen ska kunna hållas ansvarig för alla aspekter av artikeln, genom att garantera att frågor gällande korrektheten undersöks på ett lämpligt sätt och löses.

****Det betonas att reglerna inte ska användas för att utesluta någon genom att inte ge dem chansen att läsa artikeln. Uppfyller en person det första kriteriet bör man få chansen att uppfylla det andra också.*

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