Bringing it all together: How to join and analyze sensitive data from multiple sources

Florian Endel[1,2]

[1]IMEHPS.research, florian@endel.at
[2]Vienna University of Technology

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IMEHPS Improving mental health pathways

Setting & Objective

- data everywhere
  - routinely collected claims data
  - administrative data & registries
- linking, merging & integrating: bring it together!
  - technology available and in development
  - public benefit and interest possible
  - funding achievable
- domain specific characteristics of
  - data collections
  - patients, healthcare systems ("data generating processes")
  - research question & goals
  - legislation & privacy concerns
- 4 examples from Austria

Background: health insurance in Austria

- $\sim$ 8.5 million inhabitants
- mandatory insurance
  - (nearly) everyone has to be insured
  - by a specific insurance provider
  - depending on occupation, region
- 19 social security institution (insurers)
- grown historically
- organized differently
- differing payment systems, legislation, scopes
- unique personal identifier (UPI) available
- separate data collections

1) different information, similar sources

- routinely collected claims data from these social security institutions:
  - primary care
  - specialized outpatient care
  - prescriptions
- including
  - personal information from patients and providers
  - accounting details
  - $\sim$ 95% of Austrian population
- not allowed to be linked due to privacy concerns
- objective: merge these sources

1) database “GAP-DRG”

- selected subset (tables, variables)
- censored details: e.g. year of birth
- encrypted UPI: pseudonymization
- linked by common pseudonym(s)
  - linkage on personal level:
    data about same patient from different sources
  - integration without direct relationship
- nevertheless, issues occurred, e.g.:
  - definition of a standardized data model
  - quality issues depending on source
  - patients with multiple insurances
  - harmonization of accounting and coding systems
  - mix of various systems in same database
  - differing commitments of data providers
- limitation: data from 2006 + 2007; subsets from 2008-2011

Background: inpatient care in Austria

- organized differently in comparison to outpatient services
- not paid directly and only by insurance institutions
- DRG (related) payment system
- data collection
  - centralized
  - cleaned
  - used routinely
- no UPI: only episodes[1]
- limited personal information

[1] 2015: change of legislation; availability of UPI yet unknown

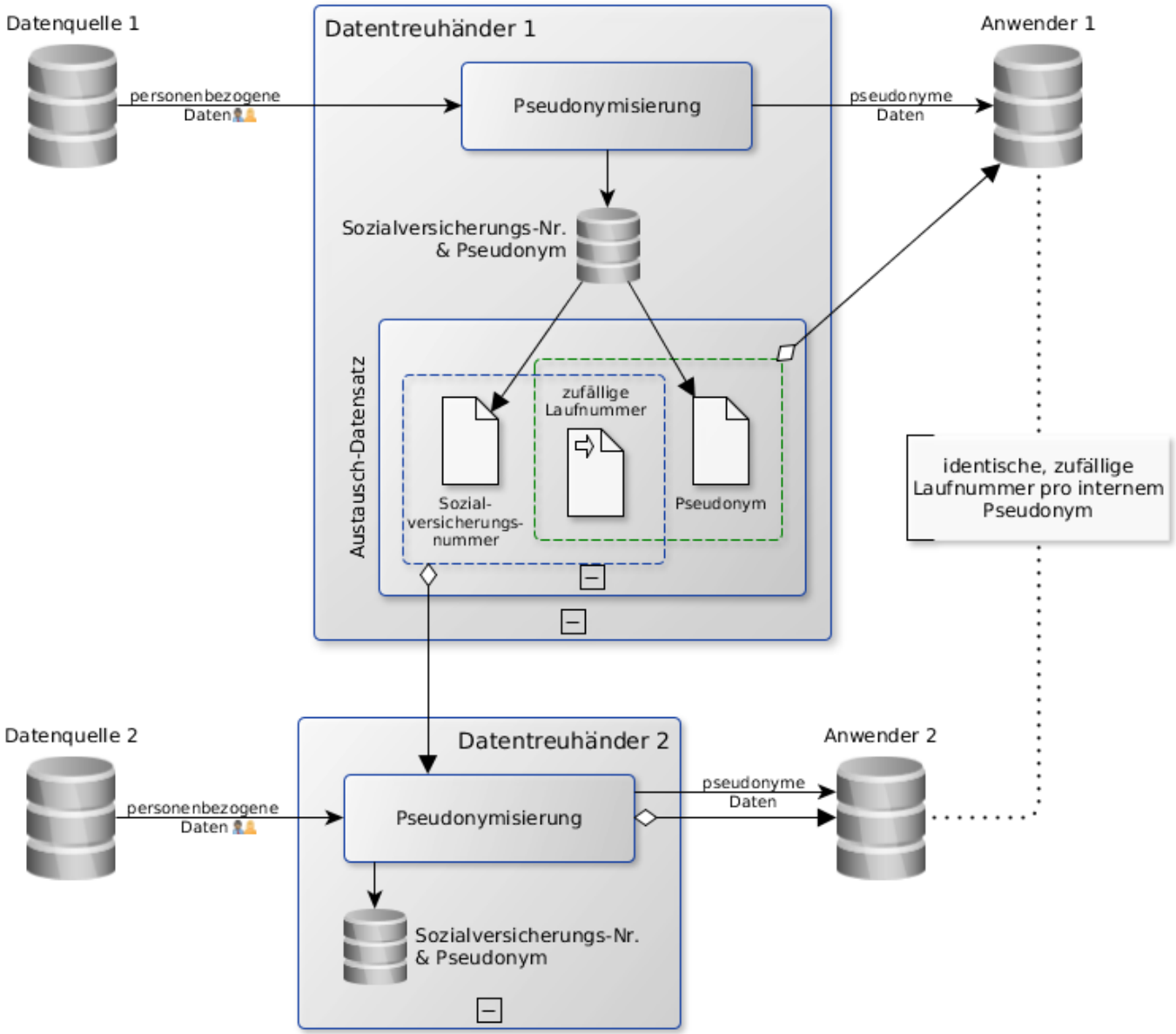
2) similar information, different sources

- objective: integrate inpatient data into “GAP-DRG”
- details: e.g. poster 1401, SHIP conference 2011, 2013
- short story:
  - insurance institutions get limited information on hospital episodes
  - differences between sources remain
  - deterministic record linkage
  - by utilizing
    - varying personal details
    - episode specifics
- whole procedure fitted to various peculiarities of
  - data (quality)
  - reporting systems
- result: “GAP-DRG” covers all sectors of the healthcare system

3) data from different domains

- objective: link GAP-DRG with data from other domains
  - example project: unemployment data
- both databases hold pseudonymized UPIs
  - from the same identification number
  - encrypted in different ways
- challenges & requirements
  - do not link sources (healthcare & unemployment data) directly
  - establish link between pseudonymized databases
  - do not leak any previously unknown information to anyone during linkage
  - prepare link but transfer data later
  - do not break encryption
  - get everyone to agree on procedure

3) data from different domains: flowchart



4) international cooperation

- EU FP7 project CEPHOS-LINK
- cooperation of several countries...
- ... differing in many aspects
- objective 1: perform comparable data analysis in parallel
- objective 2: perform pooled data analysis
  - to include system specific effects
  - compare countries in more detail
- cross-border data transfer
- not "record linkage" on personal level
- alternative: distributed data analysis [2]
  - e.g. stratified Cox regression model

[2] B. Narasimhan et al., "Software for Distributed Computation on Medical Databases: A Demonstration Project," arXiv:1412.6890 [cs, stat], Dec. 2014.

4) cross-border data transfer

- very hard to get it right
- privacy
  - approvals from ethical committees and data owners
  - anonymisation and secure data handling
- anonymisation
  - k-anonymity (l-diversity)
  - disclosure risk estimation
  - huge loss of information but multiple datasets possible
- data transfer
  - asymmetric cryptography
  - secure research environment
- harmonized variable definition
  - same structure and formatting
  - same content and meaning
  - the most complicated part!

Conclusion

- various applications of “bringing data together”
- huge spectrum of possibilities
- generalizeable methods but very specific utilization
- depending on e.g.
  - data sources and providers
  - “history” of data: from generation to researcher
  - purpose of data and project
  - objective and research question

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