CEPHOS-LINK

IMEHPS
Improving mental health pathways

Challenges in integrating registry based patient cohorts across EC countries

Results from the CEPHOS-LINK study

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This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 603264

Outline

1. Ensuring interoperability of data across different countries and different centres
2. Examples of challenges experienced in the EU-project CEPHOS-LINK
3. Lessons learned and outlook

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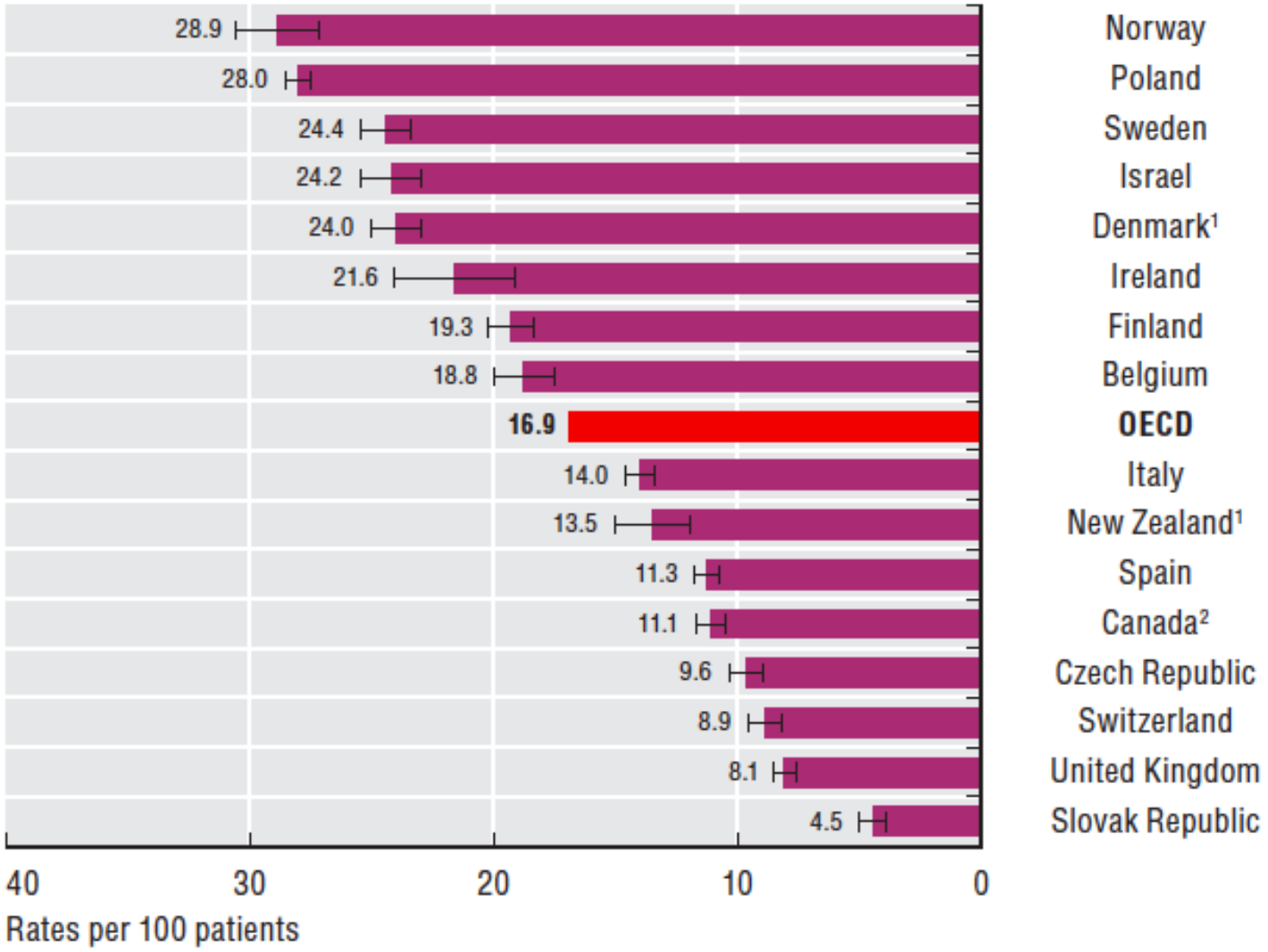
Schizophrenia 30 days readmission to the same hospital 2009, OECD 2011



The problems with comparability of routine health care data from different countries

- Data is usually not collected for research reasons
- Data has already been collected – dependent on variables included
- Differences in inclusion of service types, populations, utilisation records
- Quality of data varies e.g. due to
  - Differences in coding routines
  - Differences in health care organisation (e.g. payment meachnisms) are reflected in data
  - Data flow (depending on legal, organisational, administrative issues of a country)
  - Differences in data granularity

Ensuring interoperability in order not to compare apples with oranges

- Harmonising terminology, concepts and definitions and check how they are operationalised in the actual data
- Obtaining background information (e.g. purpose of the database)
- Understanding the health care system - differences in service organisation and provision in the different countries – e.g. financing mechanisms
- Data/variable quality check (e.g. obtaining frequencies, validating/comparing with national statistics, exploring coding practices)
- What is in, what is out - inclusion and exclusion of data/variables in the database
  - inclusion / exclusion of patient groups /populations
  - inclusion / exclusion of service providers
  - inclusion / exclusion of services provided / utilisation

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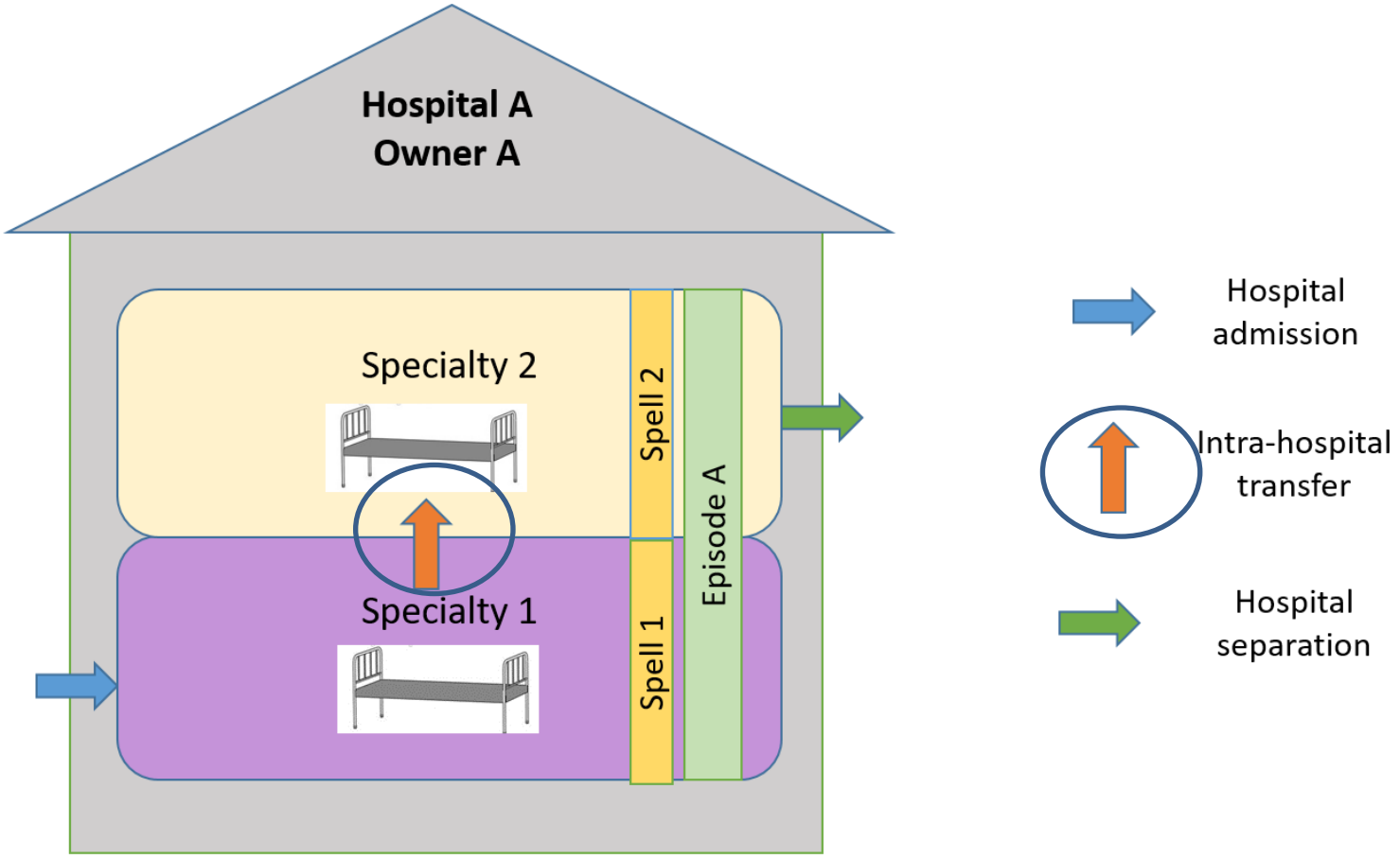
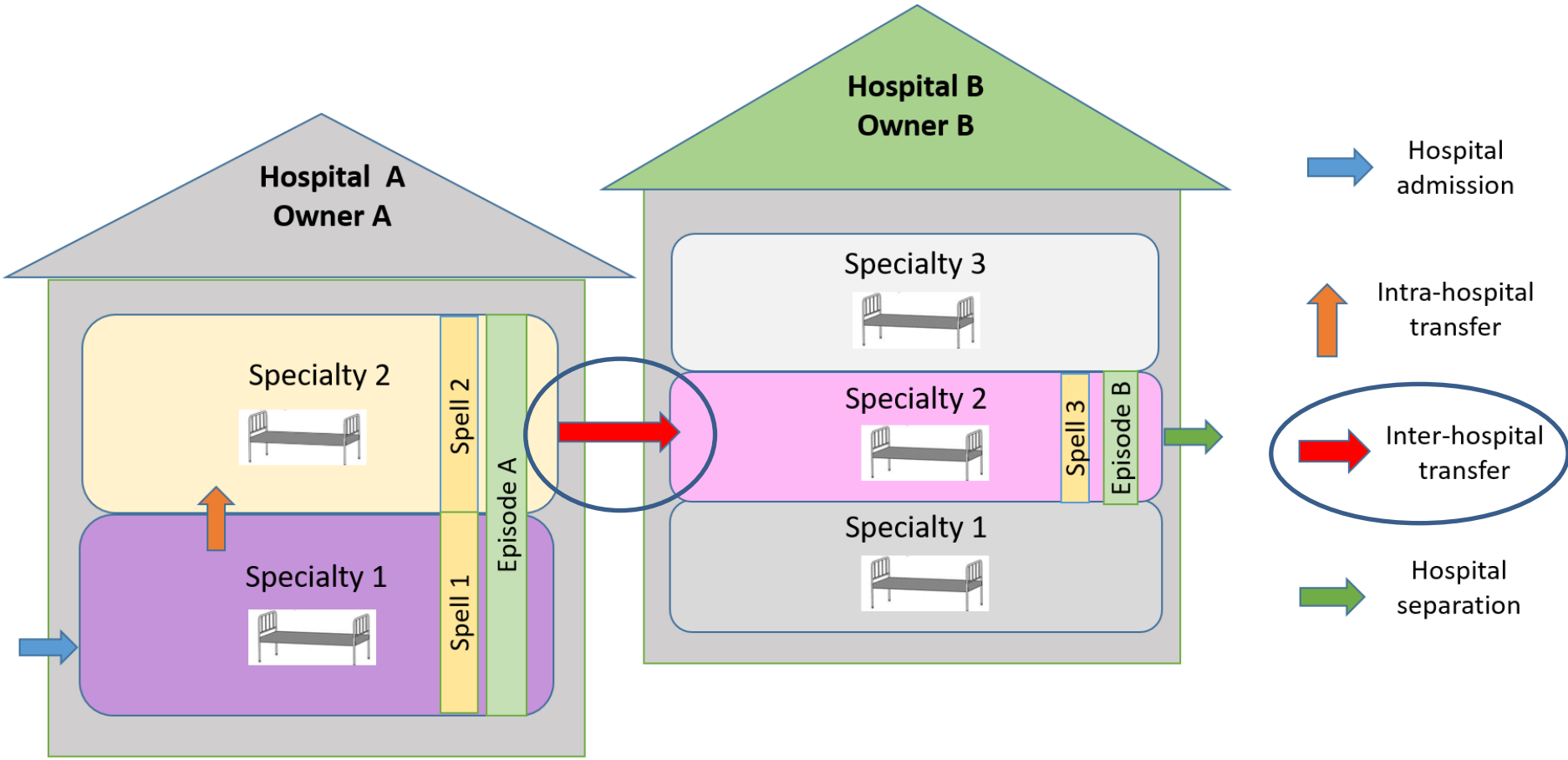
Concepts of inpatient hospital admission, intra-hospital transfer, hospital separation



Length of stay in Hospital A: Episode A composed of Spell 1 and Spell 2

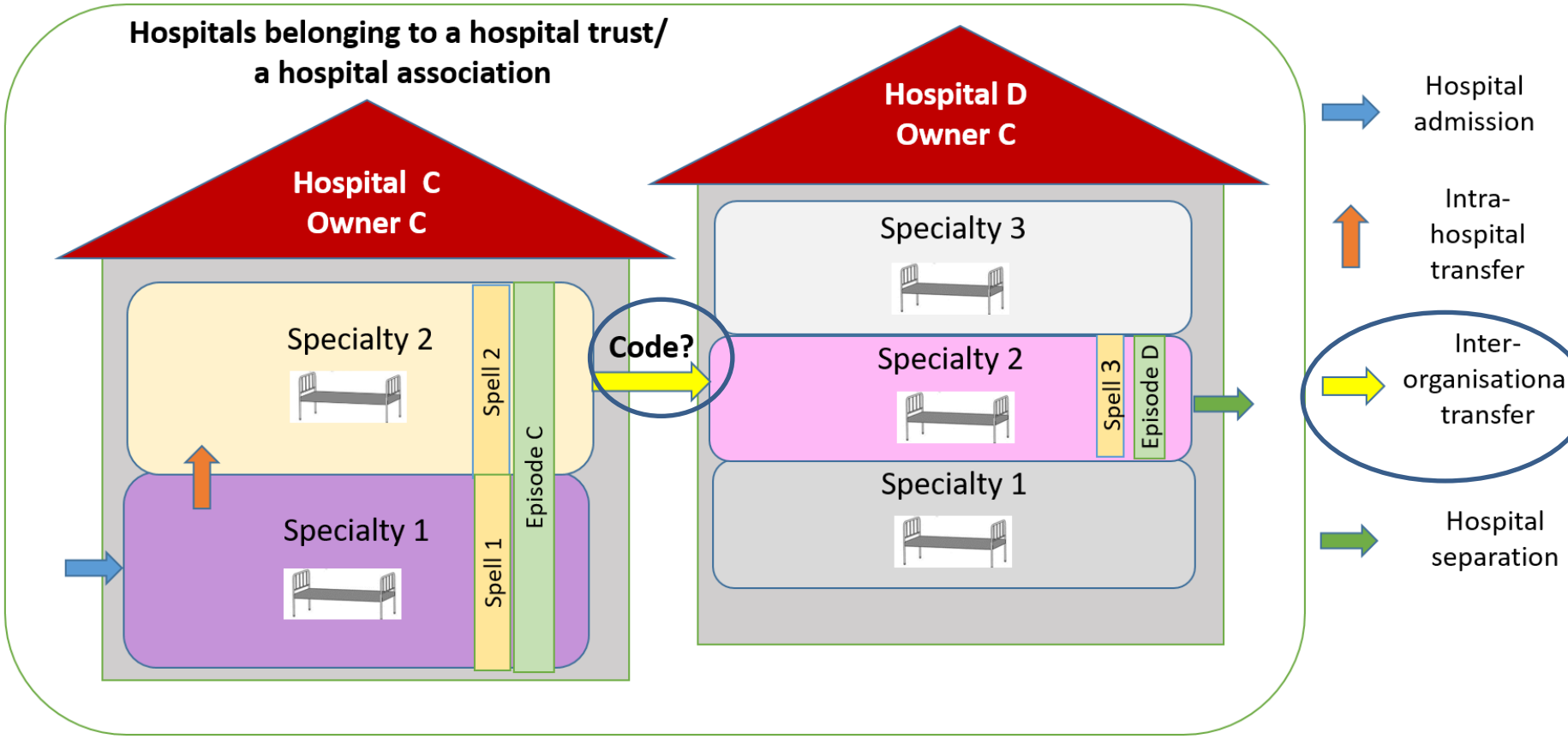
The concept of inter-hospital transfer



Length of stay in Hospital A: Episode A composed of Spell 1 and Spell 2

Length of stay in Hospital B: Episode B Identical with Spell 3

The concept of intra-organisational transfer



Problem: no clear codes of inter-organisational transfer, transfer between the hospitals is regarded and coded as intra-hospital transfer and length of stay can only be calculated for both hospitals together

Length of stay in Hospital C and D: Episode C plus Episode D

Challenges with different concepts, terminologies and reliability of variables

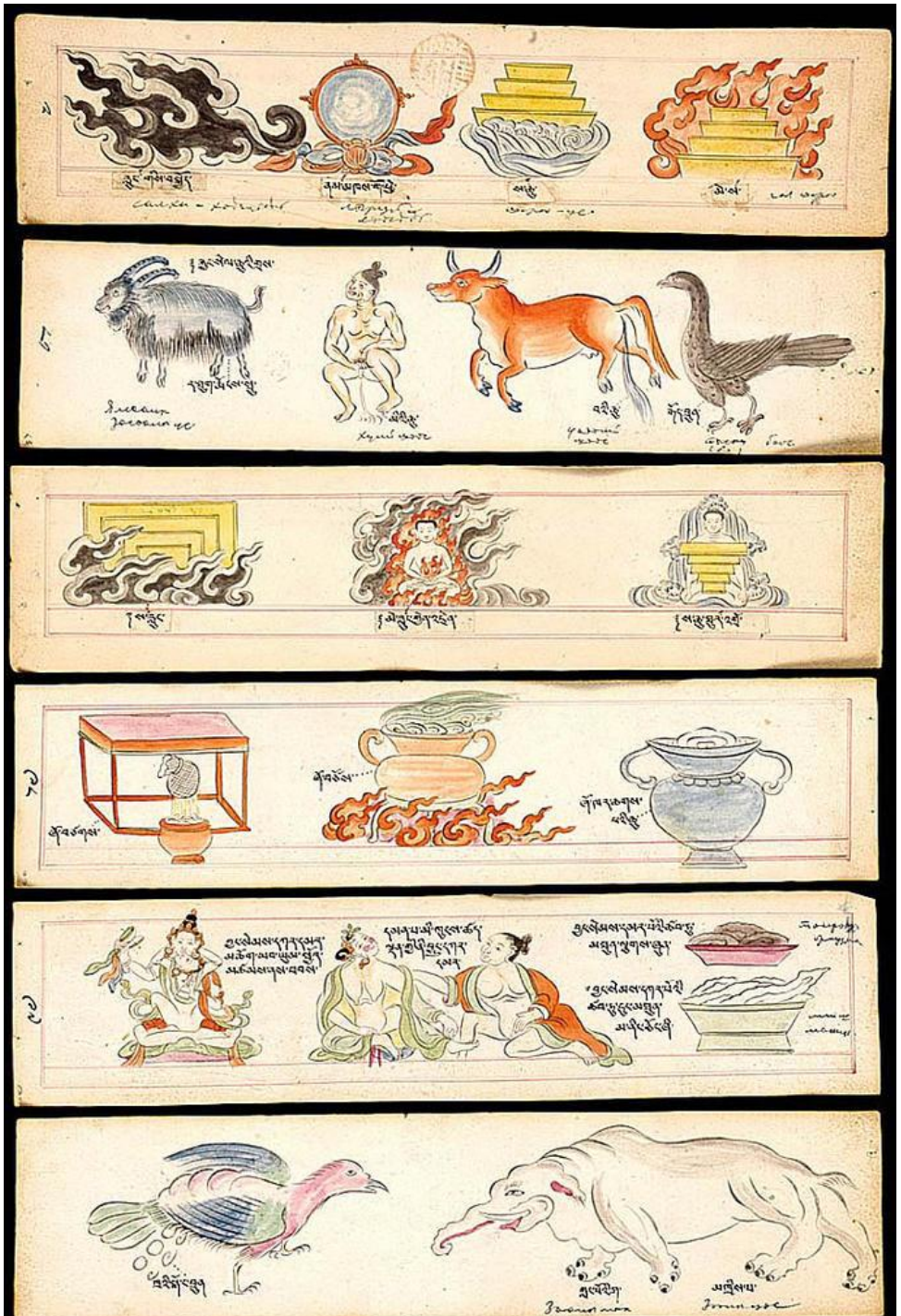
- Different meanings of the concepts discharge and “transfer”
- Difficulties in identifying inter- and intra-hospital transfers in the databases
- Variables and codes identifying a discharge and admission were not reliable (e.g. different coding cultures, inconsistencies in coding)
- Difficulties in identifying “hospital” in a comparative way >>>consequences for calculating length of stay in a comparative way

Separation codes (end of a hospital stay) Finland

3 = Dead
1 = Institutions
11 = Transfer to hospital
12 = Transfer to primary care ward in community health centre
13 = Transfer to nursing home
14 = Transfer to institution for people with learning disability
15 = Transfer to institution for people with substance abuse
16 = Transfer to institution for rehabilitation
18 = Transfer to other institutions
2 = Home and home-based care
21 = Transfer to care at home/supported housing without 24h supervision
22 = Transfer to home without repeated care
23 = Transfer to supported housing (24h support) for old people
24 = Transfer to supported housing for people with learning disabilities
27 = Other supported housing with 24h supervision

Separation codes (end of a hospital stay) Romania

1 = discharged
2 = discharged on request
3 = Transfer to another hospital
4 = died



Codes describing a hospital admission and separation differ a lot between countries and do not follow logical categories - like

Borges' Chinese encyclopedia, animals are divided into:

a) those belonging to the emporer
b) those that are embalmed
c) tame or trained ones
d) suckling pigs
e) mermaids and sirens
f) those that are fabulous
g) stray dogs
h) those included in the present classification
i) frenzied ones
j) innumerable ones
k) those drawn with a very fine camelhair brush
l) other ones

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Lessons learned

Ensuring interoperability is a major issue when integrating registry based patient cohorts across different countries

- Involves numerous steps (e.g. harmonising terminology, pilot analyses) and investigative approaches in finding out what data stands for (e.g. on-site visits with data-owners, health care providers) and is most time-consuming
- A good knowledge of the health care system, its organisation and payment mechanisms are essential in order to check plausibility of data, results and interpretation of results
- Separate analyses between region, different providers, etc. may help to explore the influence of health system factors
- Plausibility checks with existing national statistical data

Lessons learned

Understanding data and its limitations – what is in it, what is left out, how comparable is data. Differences in the databases may concern

- the inclusion and exclusion of patient groups/populations
- the inclusion and exclusion of service providers (e.g. “Wahlärzte” in Austria)
- the inclusion and exclusion of service utilisation records (utilisation of different types of care e.g. rehabilitation)

Outlook

- Systematic reviews and meta-analyses of studies carried out with different designs and different variables have their limitations – the future is data sharing and pooling after securing interoperability of data sets

- Data mining of eHealth records repositories

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Thank you for your attention!

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