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Institute for Social & Preventive Medicine

Swiss Health Data

Time to Color a Blank Spot

SAMW Symposium Versorgungsforschung

6.11.2013

Milo Puhan, MD, PhD

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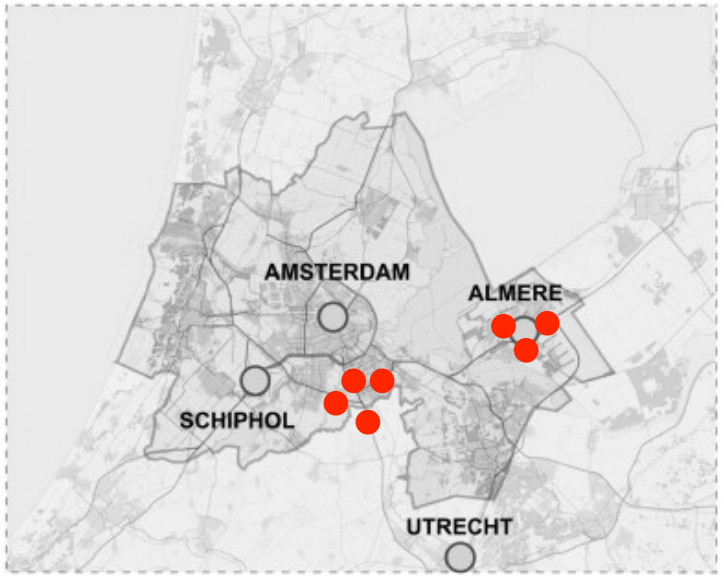
2008: Setting up a COPD cohort in primary care



Electronic health records → Easily recruited 251 patients in 12 months

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In Switzerland…

Identification very challenging

→ Recruited 158 patients in 15 months

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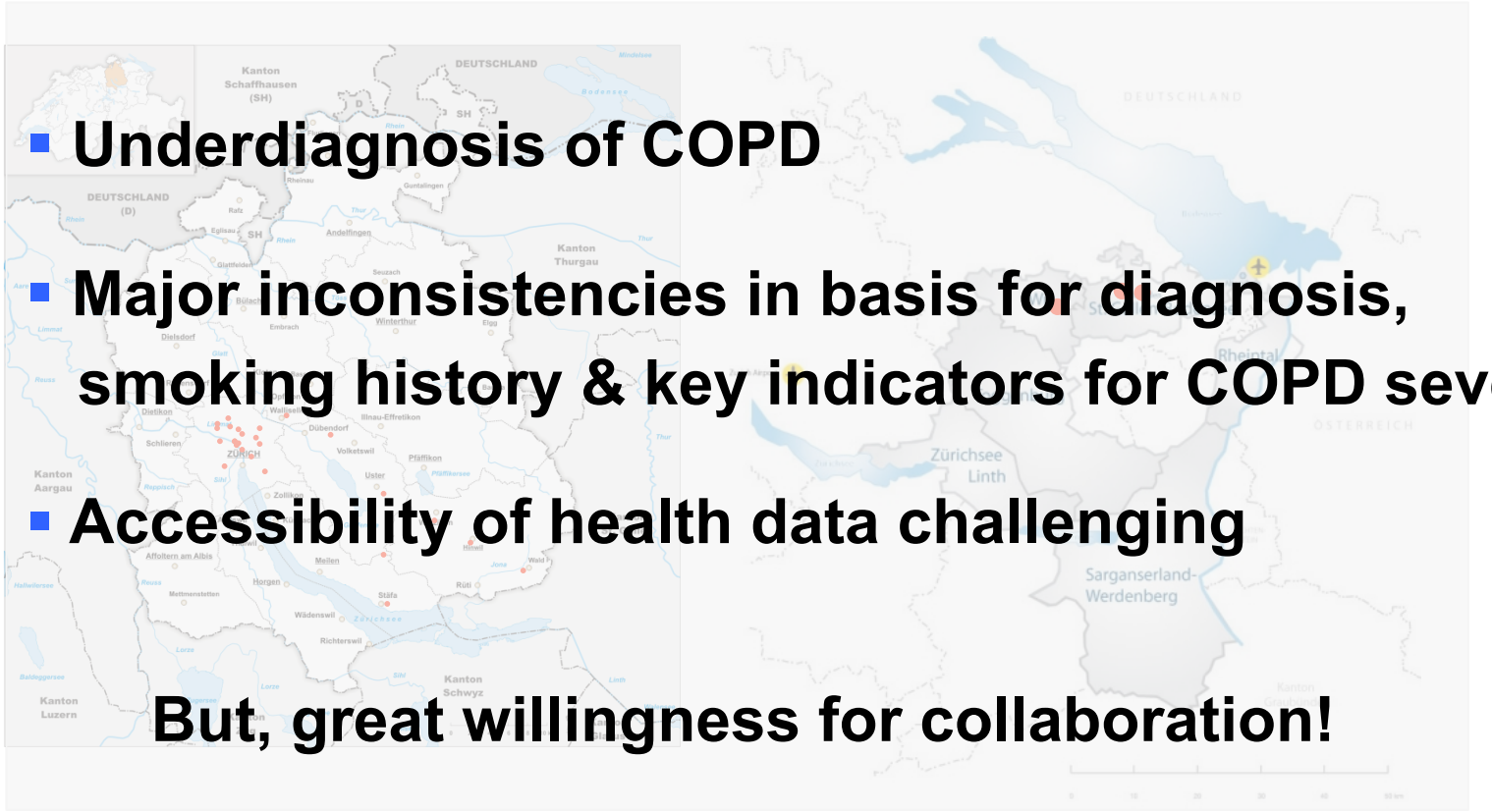
In Switzerland…



- Underdiagnosis of COPD
- Major inconsistencies in basis for diagnosis, smoking history & key indicators for COPD severity
- Accessibility of health data challenging

But, great willingness for collaboration!

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Research in primary care possible, but challenging

Entire data collection done by research team with

rich data (5 years of FU. Detailed „phenotyping“)

high retention: >80% of living patients in study after 4 ½ years

high quality data (e.g. centrally adjudicated exacerbations)

→ **Nice model for an epidemiologic study**

but not for health services research

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The health data problem in Switzerland

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Imagine we want to learn about chronic disease care in Switzerland

Almost impossible because data are

- **incomplete**
- **incorrect**
- **not linkable**
- **not comparable**
- **not available**
- **not longitudinal**

Manifest

Bessere Gesundheitsdaten

für ein effizienteres Gesundheitswesen

Improve completeness
(e.g. large population-based studies, integration of general practitioners)

Improve linkability
(e.g. unified ID number for anonymization)

Improve utilization and quality of health care data

Improve availability
(e.g. utilization of individual patient data)

Improve comparability
(e.g. standardization of data on risk factors, diagnoses, treatments)

Translated by E. von Elm from: Health Data Manifesto. Public Health Schweiz 2013. www.public-health.ch/

The Swiss Society for Public Health

PUBLIC HEALTH SCHWEIZ
SANTE PUBLIQUE SUISSE
SALUTE PUBBLICA SVIZZERA

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Availability of data

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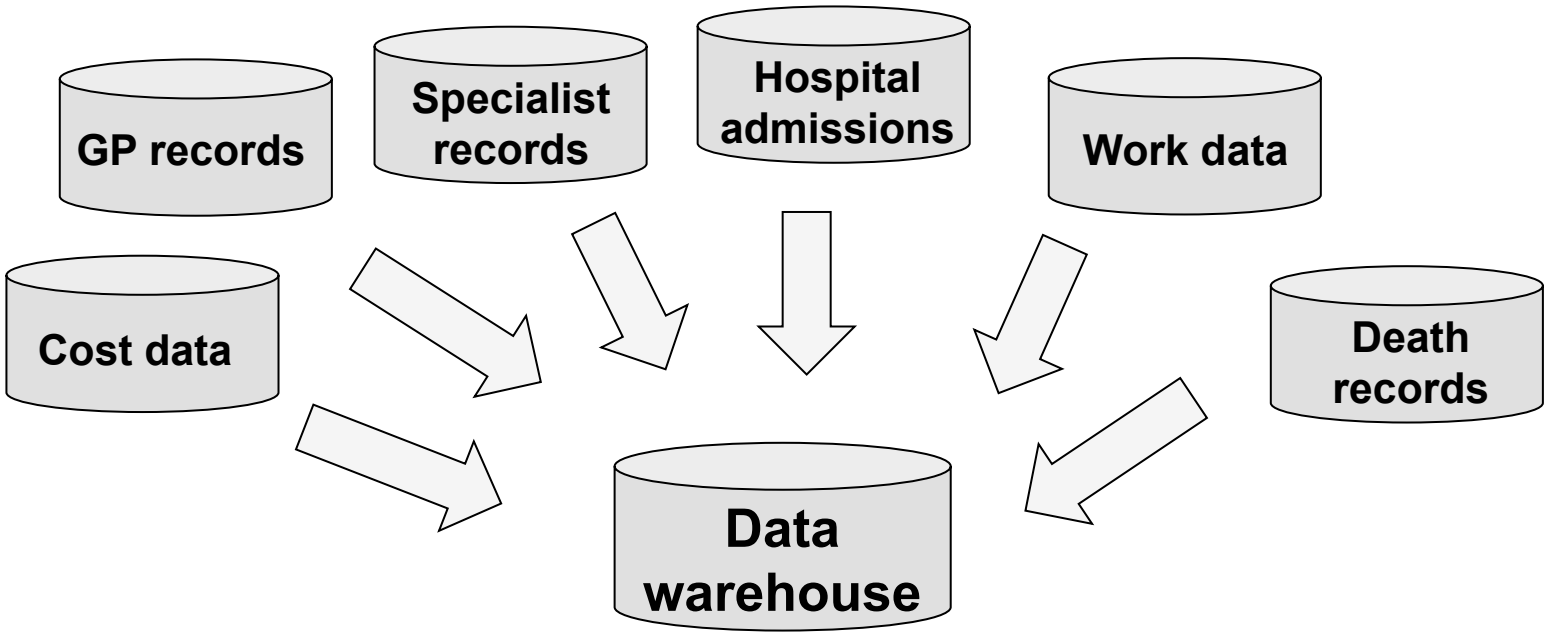
Ability to link data from different sources



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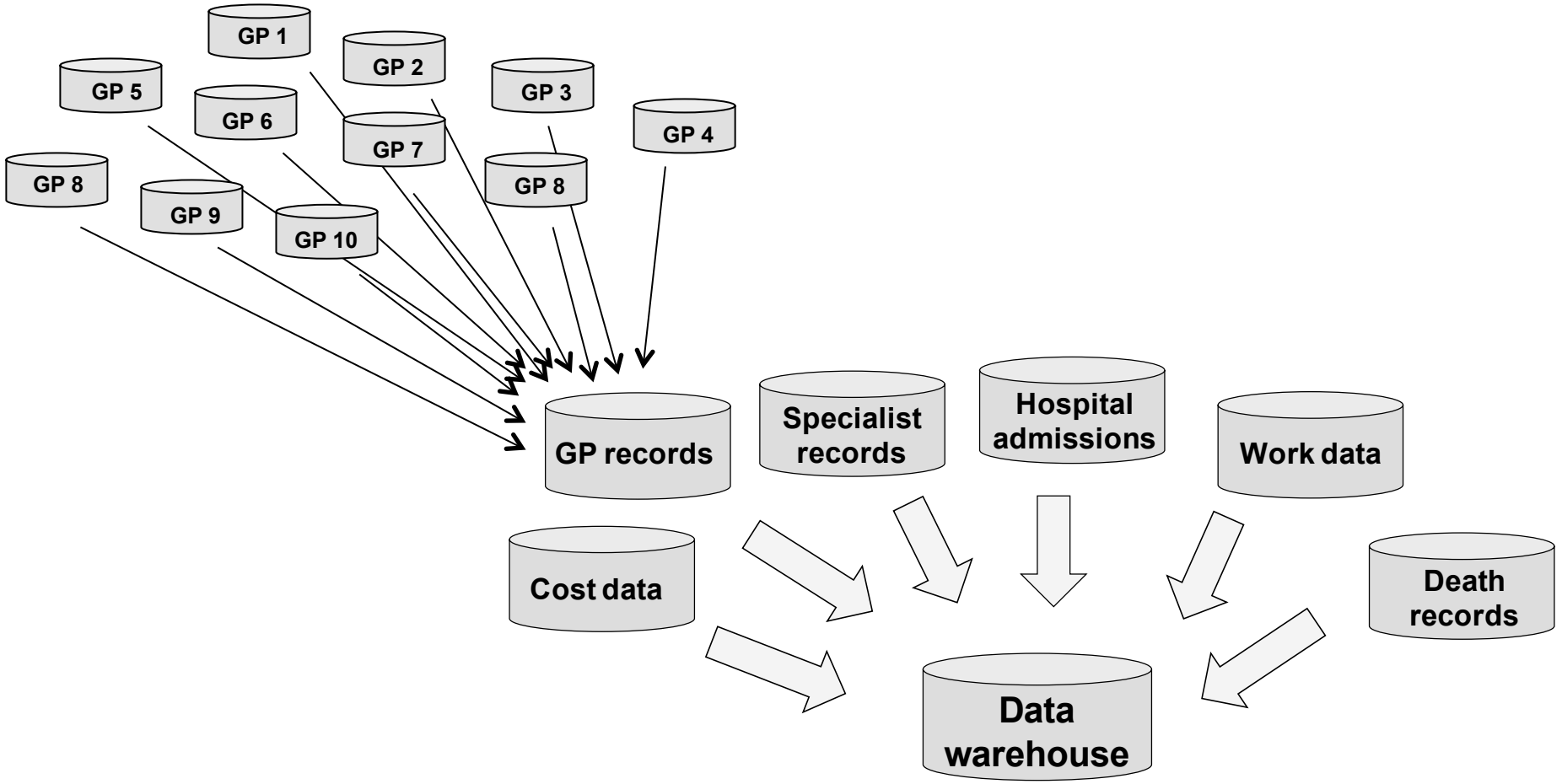
Harmonize data capture



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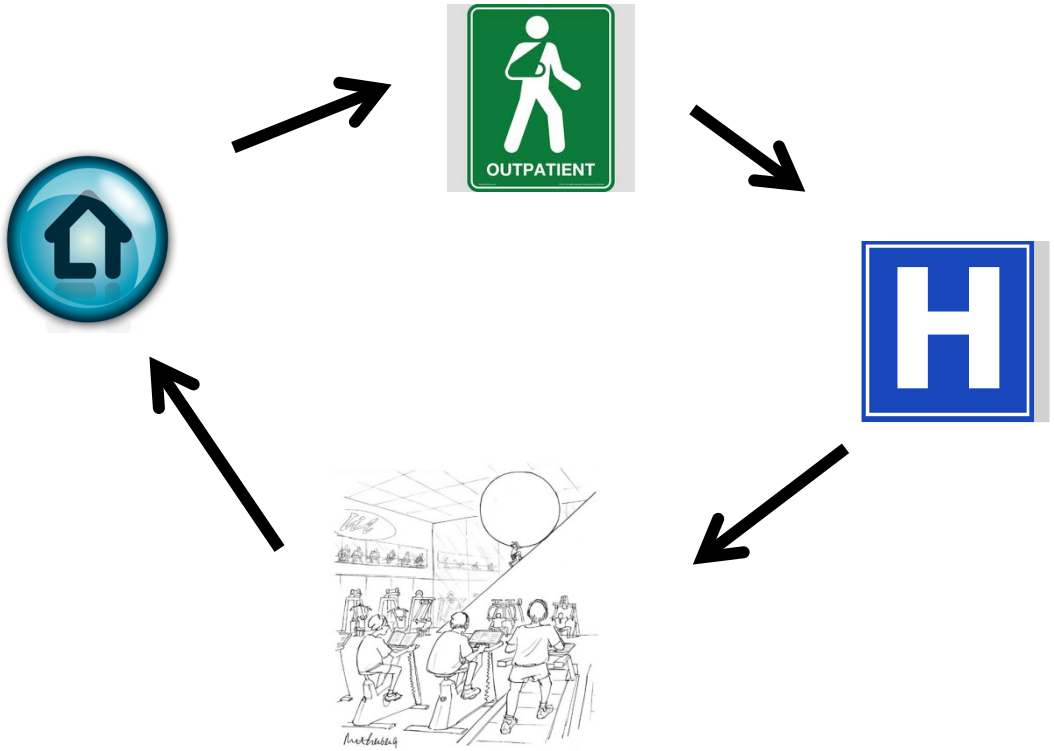
Improve completeness

For example, tracking over time



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Four specific suggestions that must be in compliance with data protection regulations

4. Swiss universities organizes a large scale, population based cohort

1. Swiss confederation and cantons introduce unique identification number

3. Patients make routine data available for research

2. Swiss confederation pushes harmonization of data