

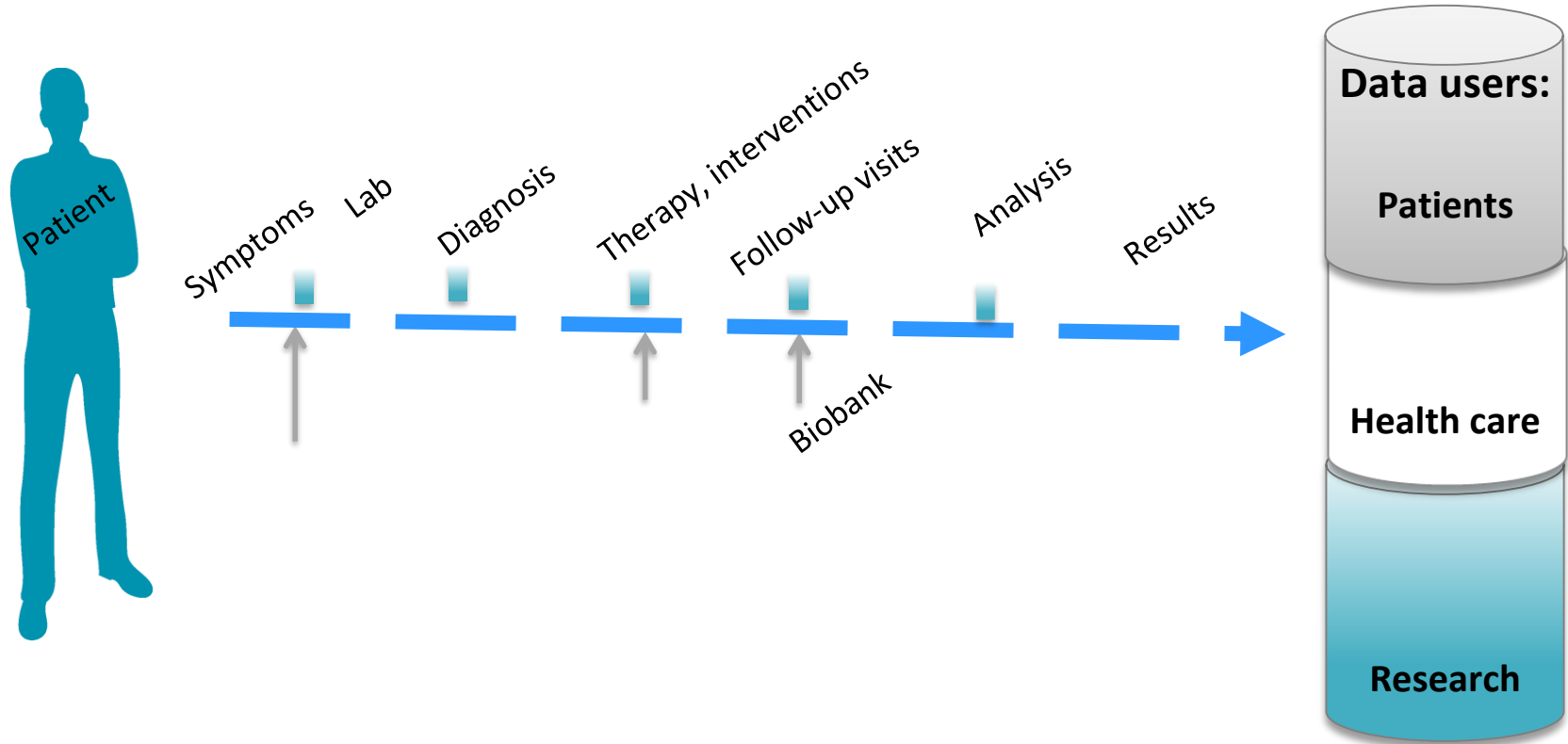
Centre for Health Data: A new model for increased data access

Clara Hellner

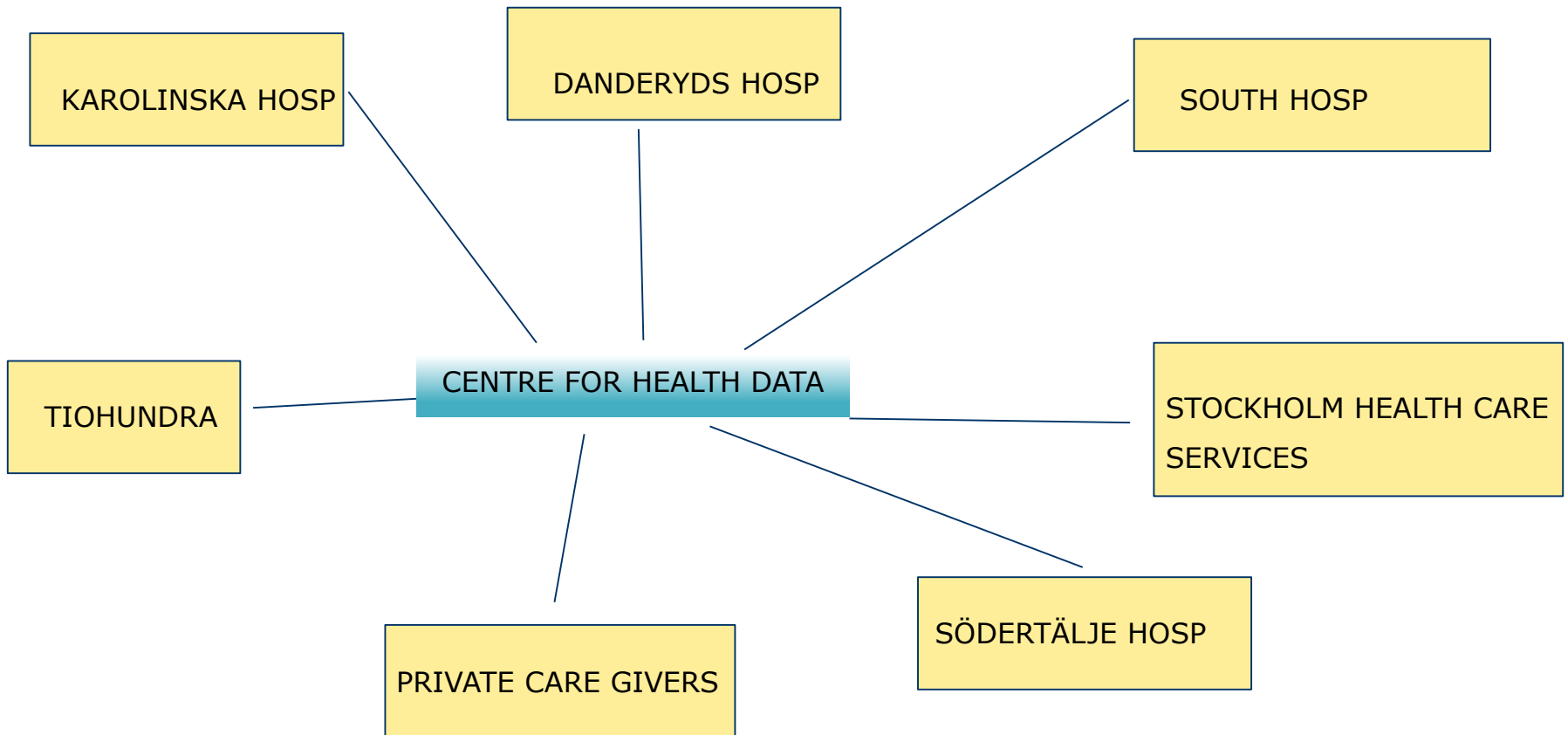
Director of Research and Innovation

Region Stockholm

Data from each patient stored in electronic medical records



Stockholm: Several big hospitals/outpatient units, each their own information owner



Centre for Health Data

- Created in 2019
- Aim:
 - Single point of contact for researchers and companies in need of health data
 - Coordinated application and assessment process in the entire region

Centre for Health Data

- Tasks:
 - Assist researchers who need data from > one caregiver
 - Assist the health care system (internal follow-up of health care quality)
 - Method development

Overarching goal

- Facilitate the development of precision medicine

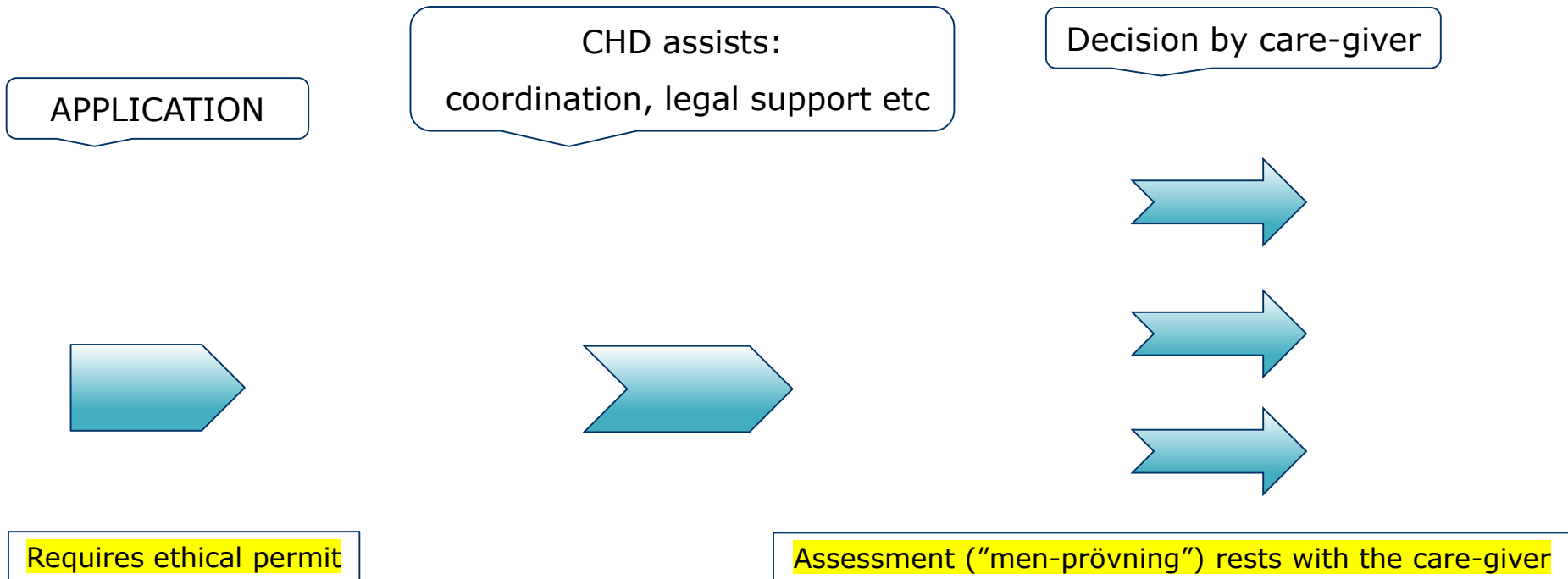
Data sources

- Stockholm Regional Data Ware House (VAL-databasen)
 - Limited information but high coverage
 - Well described, easy to retrieve data
- Electronic Medical Records
 - Unlimited information
 - Not well organised/described
 - Incomplete coverage, free text etc

Data sources

- Numerous “subunits” for different types of data (lab, EKG, x-rays etc)

PROCESS





Scandinavian Journal of Public Health, 2019; 47: 618–630



ORIGINAL ARTICLE

A gold mine, but still no Klondike: Nordic register data in health inequalities research

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(Horror) Stories from Nordic research projects

Overview

	Denmark	Finland ^b	Norway	Sweden
Net processing time (days)	100/150 ^a	210	774/237	399
Costs in 1000s €	6	25	36	10
Number of decision makers	2(5)	3	6/7	3(4)
Number of data retrievers	1(2)	3	5	2

^aThe processing time was approximately 100 days from submission of first application and approximately 150 days including consultancy and processing time together with the Public Health Database staff.

^bThe figures represent approximate net processing time and costs of updating and extending data set (2).



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Kjetil van der Wel *et al.* *Scandinavian Journal of Public Health*, 2019; 47: 618–630 7

Challenges: several



Incomplete applications

Lack of knowledge/understanding among applicants



Lack of agreement between care-givers

Assessments of legal issues, it-security etc



Lack of capacity to retrieve data

Challenges

- In reality access is limited
- Large resources required to retrieve them
- On a positive note: Room for improvement!

What do we do?

- Scrutinize each step of the process
- Increase data extraction capacity
 - Electronic Medical Record system Take Care

What do we do?

- Method development
 - Synthetic data?
 - Changing the format free text in EMDs?
 - Data lakes?

What do we do?

- Close collaboration with partners
 - Royal College of Technology: IT, security
 - Stockholm university: Legal development

What do we do?

- Create consensus among care givers
- Involve stakeholders (patients, life science sector, researchers)

Thank you!

CHD: current case-flow

