

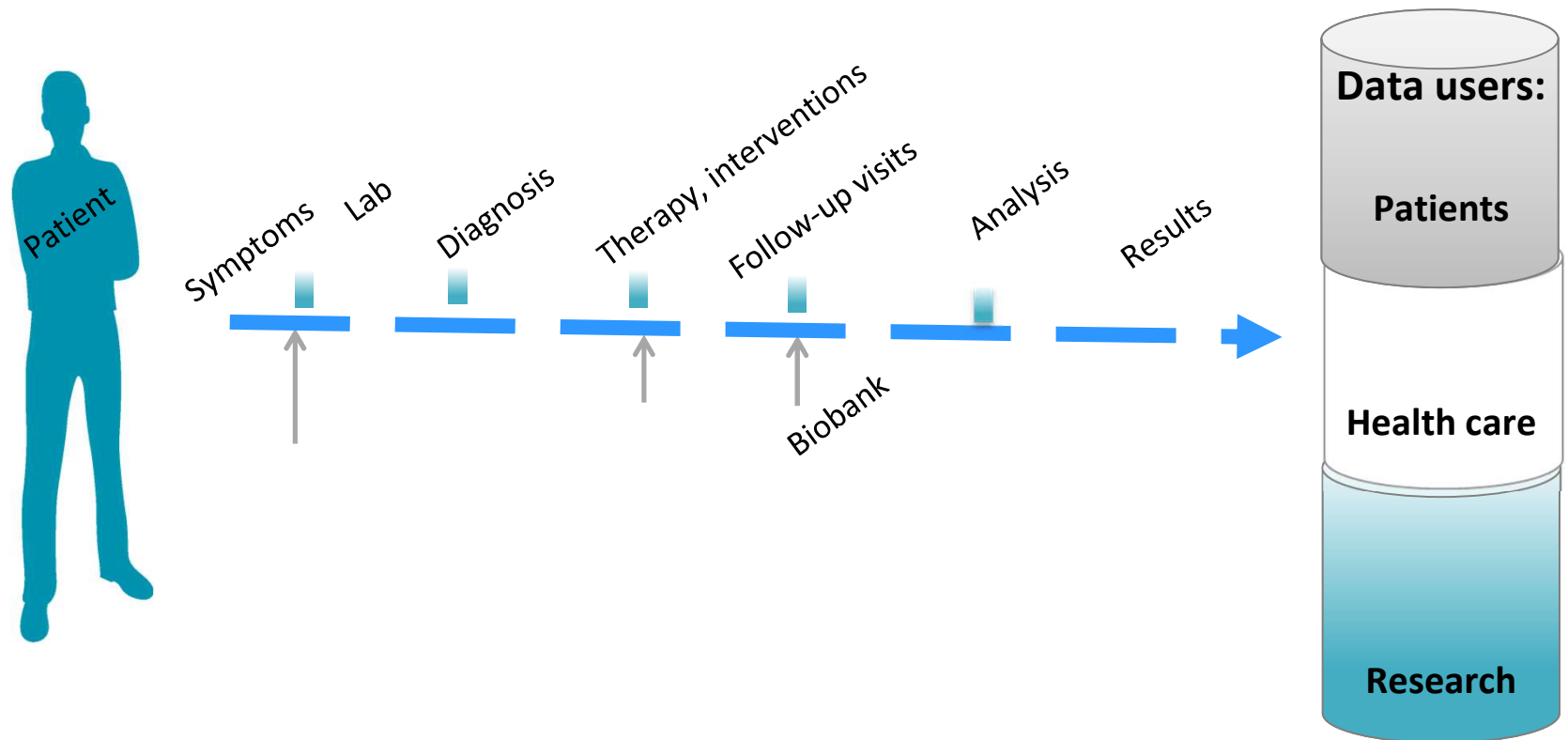
# Centre for Health Data: A new model for increased data access

Clara Hellner

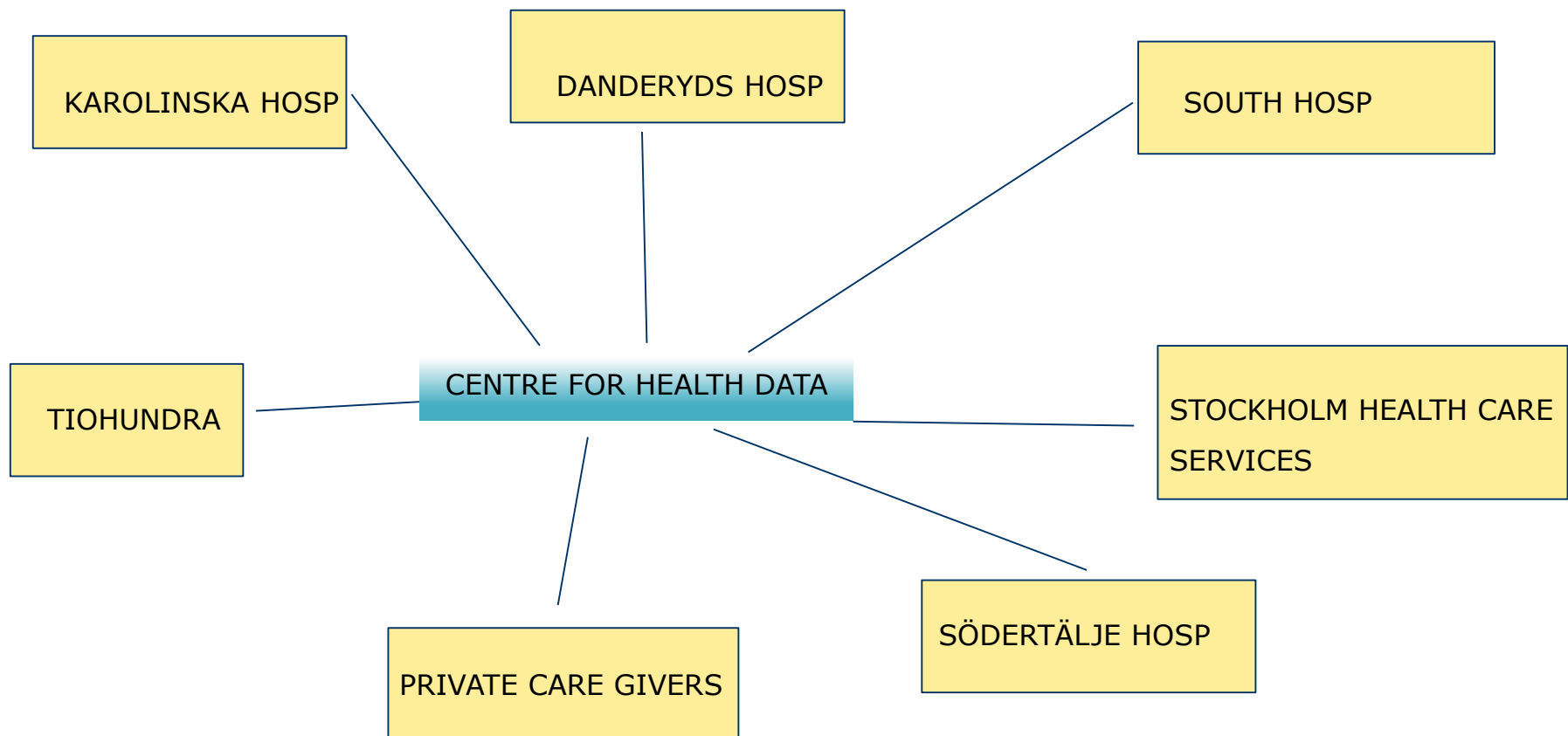
Director of Research and Innovation

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

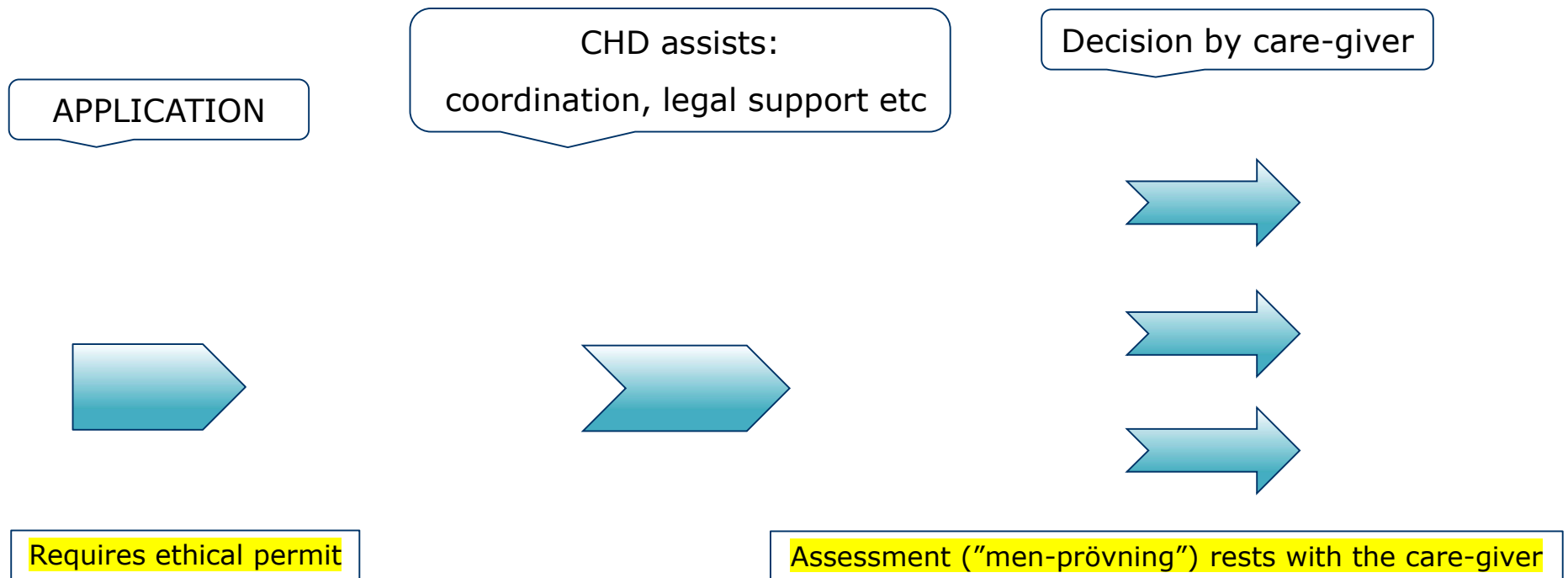
# Data sources

- 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**

KJETIL A. VAN DER WEL<sup>1</sup>, OLOF ÖSTERGREN<sup>2</sup>, OLLE LUNDBERG<sup>2</sup>,  
KAARINA KORHONEN<sup>3</sup>, PEKKA MARTIKAINEN<sup>3</sup>,  
ANNE-MARIE NYBO ANDERSEN<sup>4</sup> & STINE KJAER URHOJ<sup>4</sup>

<sup>1</sup>*Department of Social Work, Child Welfare and Social Policy, OsloMet – Oslo Metropolitan University, Norway,*

<sup>2</sup>*Department of Public Health Sciences, Stockholm University, Sweden,* <sup>3</sup>*Faculty of Social Sciences, Population Research Unit, University of Helsinki, Finland,* <sup>4</sup>*Department of Public Health, Section of Epidemiology, University of Copenhagen, Denmark*

## (Horror) Stories from Nordic research projects

### Overview

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

<sup>a</sup>The 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.

<sup>b</sup>The figures represent approximate net processing time and costs of updating and extending data set (2).



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

