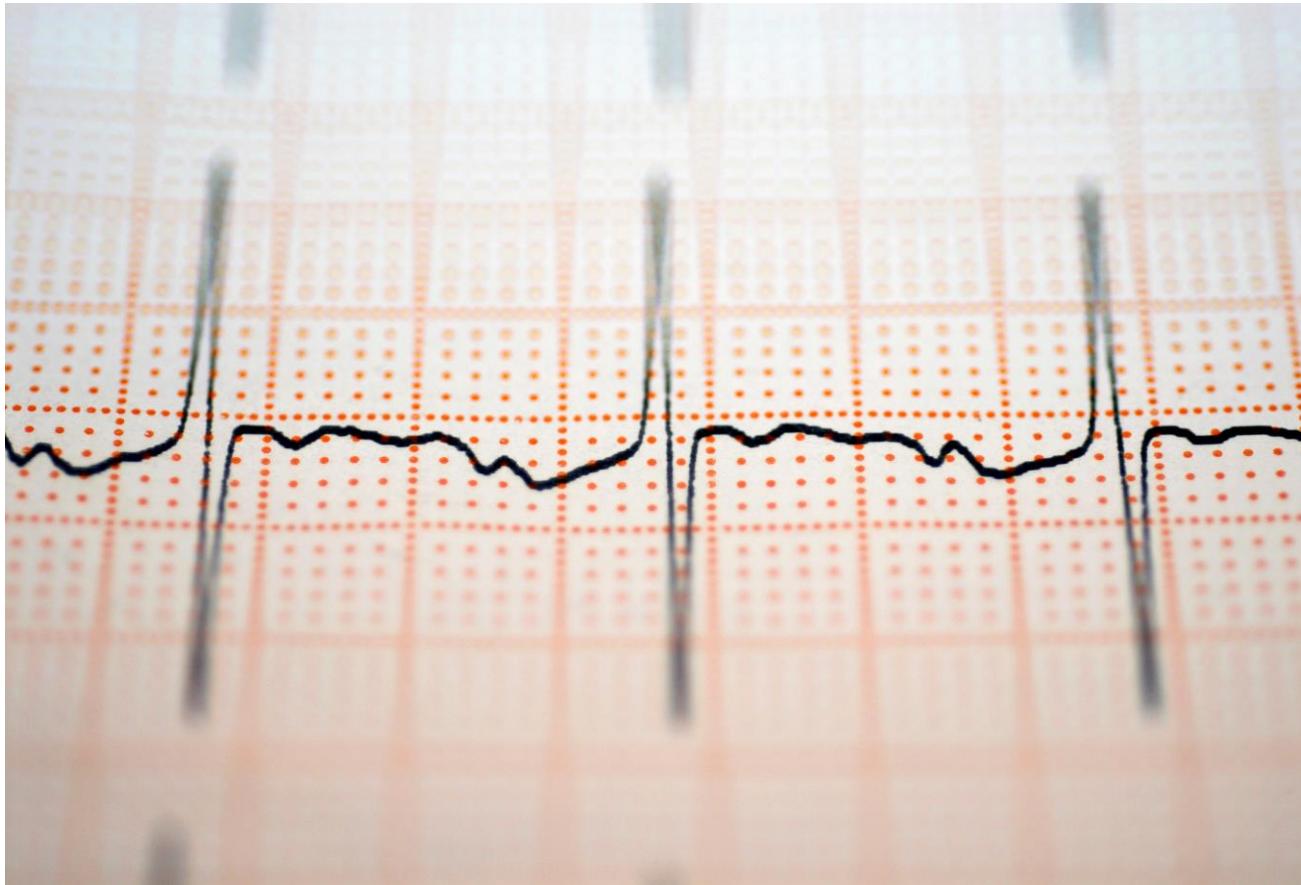




Health Data Experiences from creating a regional data access hub

Clara Hellner, director of Research & Innovation
Region Stockholm

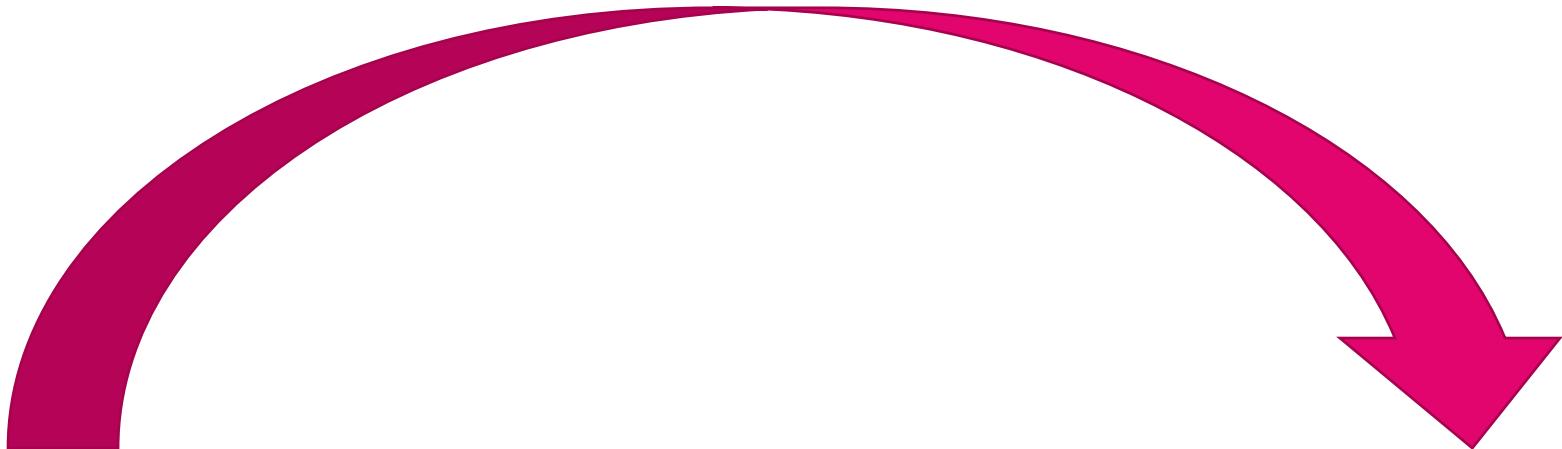
Health care has always used data – what is new?



Then

National (or other externally collected) aggregated data resources

Primary
use of data
(providing
care)

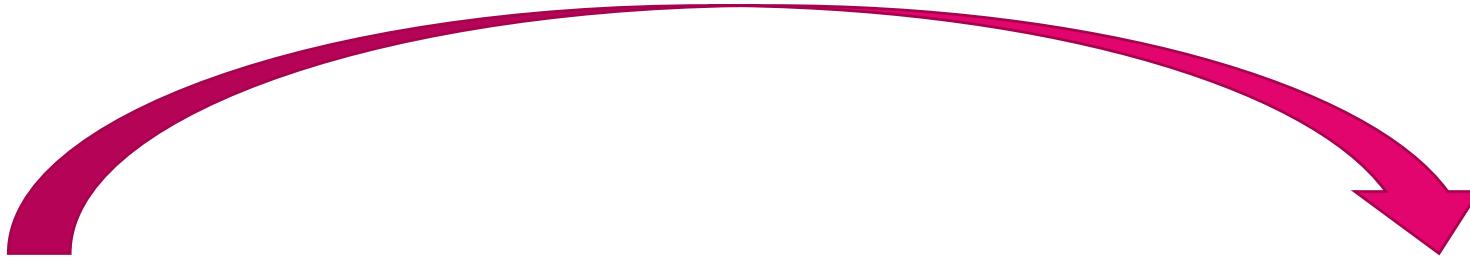


Secondary use of
data (research &
innovation)



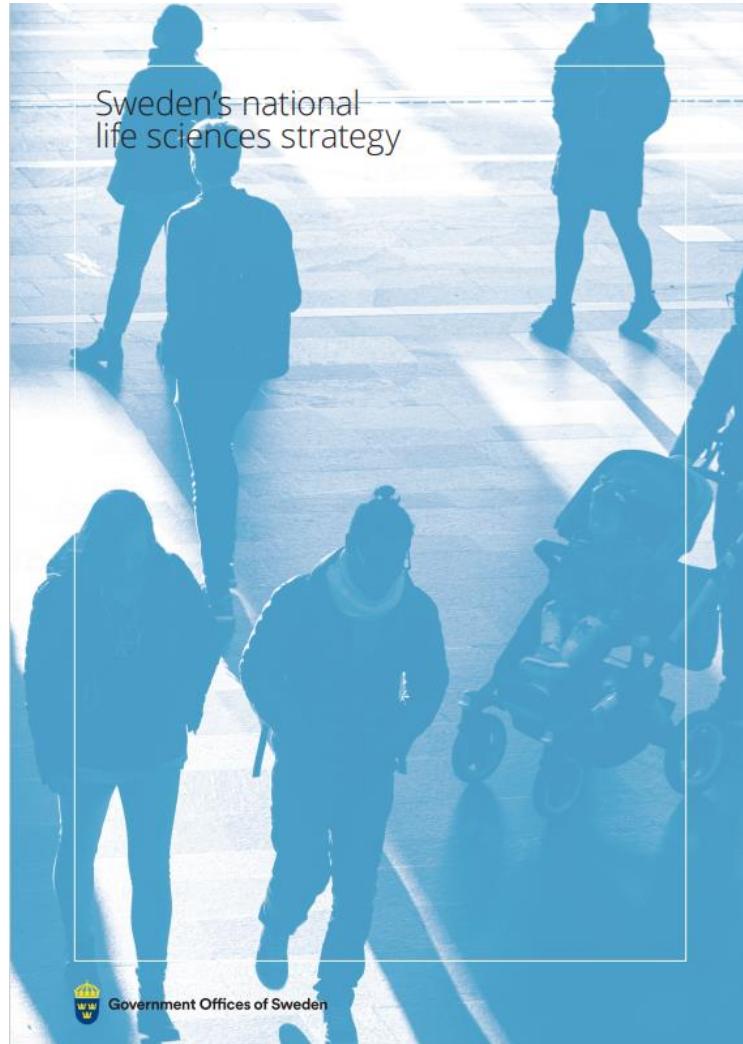
Now

National data resources



Multiple sources, high
resolution data





Health data on the Swedish national level

- Key aspect of the national life science strategy
- National authorities engaged
- Task force: Detailed action plan in 2022
- National commission overseeing Swedish legislature
- Several health data networks in progress

Life science-strategi för Stockholmsregionen

Stockholm 2025: En av världens fem ledande life science-regioner

Forsknings-, utbildnings- och utvecklingsstrategi

FÖR REGION STOCKHOLM 2021–2024

Innovationsstrategi för Region Stockholm

INNOVATIONSFÖRMÅGA TILL NYTTA FÖR ETT HÄLLBART SAMHÄLLE
Gäller för samtliga nämnder och bolag i Region Stockholm

Stockholm:
Health data and digitalization top priority in all
regional strategies



How can it be done?

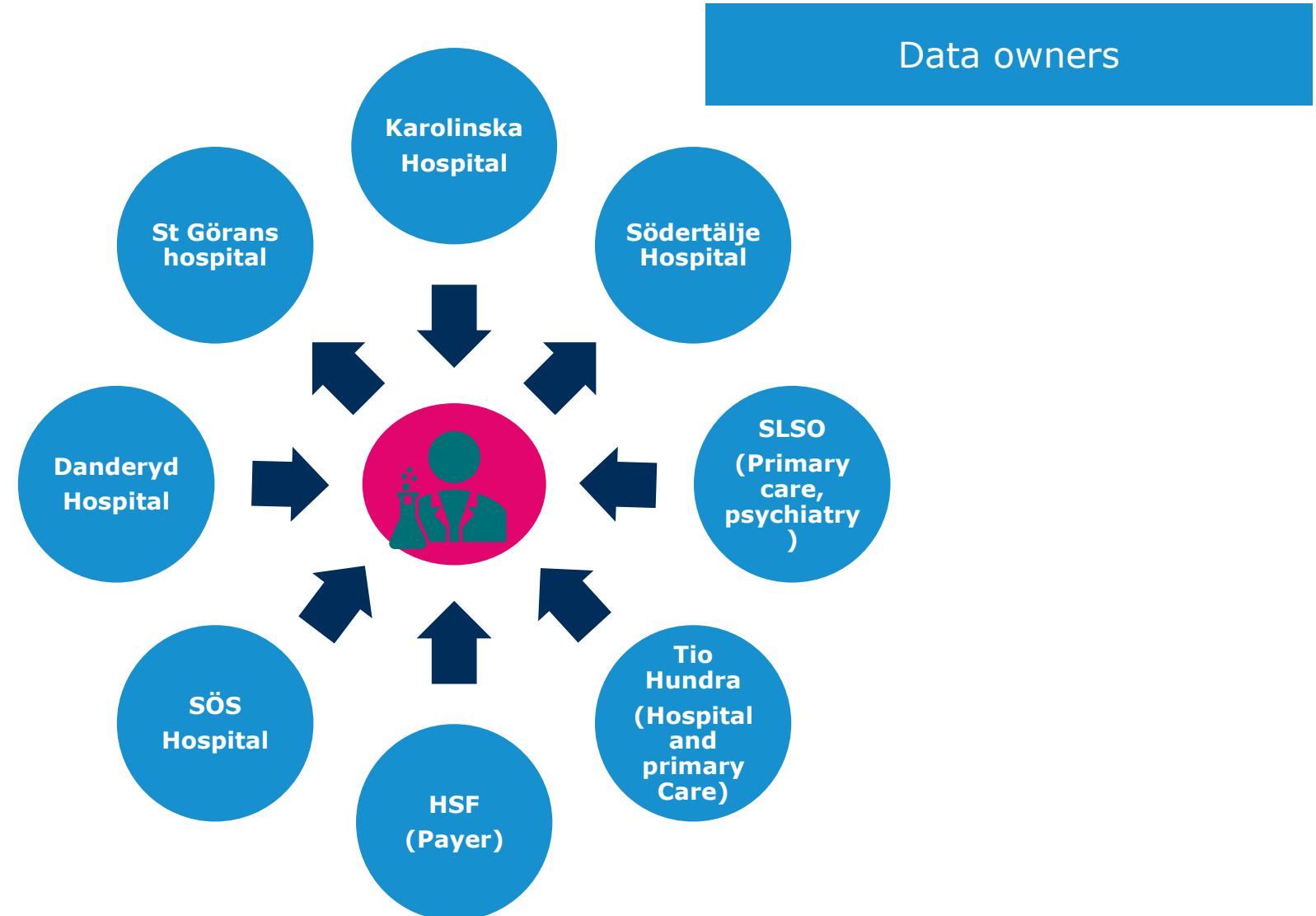
Challenge #1: The legal framework

Data ownership

- Legal entity = **caregiver**
- Confidentiality review process at caregiver level
 - >3000 caregivers in Stockholm
 - From big hospitals to small outpatient clinics

Then

The individual researcher had to contact each care provider for data



Established 2019: Centre for Health Data

Now: Centre for health data (CHD) = single point of contact

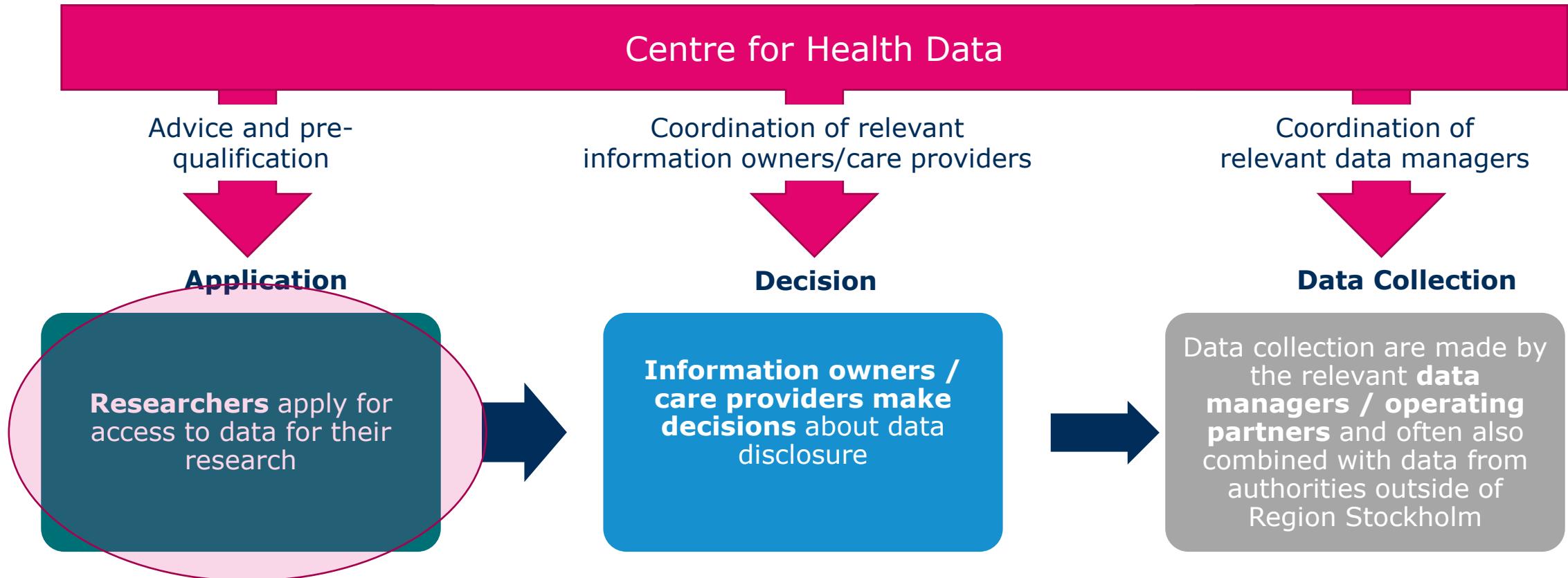


Challenge #2: Understanding the data landscape

Common questions

- What data does the researcher wish?
- Does it exist?
- Where is it stored and who is the data owner?
- How is the quality?
- Can we get it out of the system and how?
- How can it be linked to other data sources?
- How can the recipient store data safely?

CHDs data access process



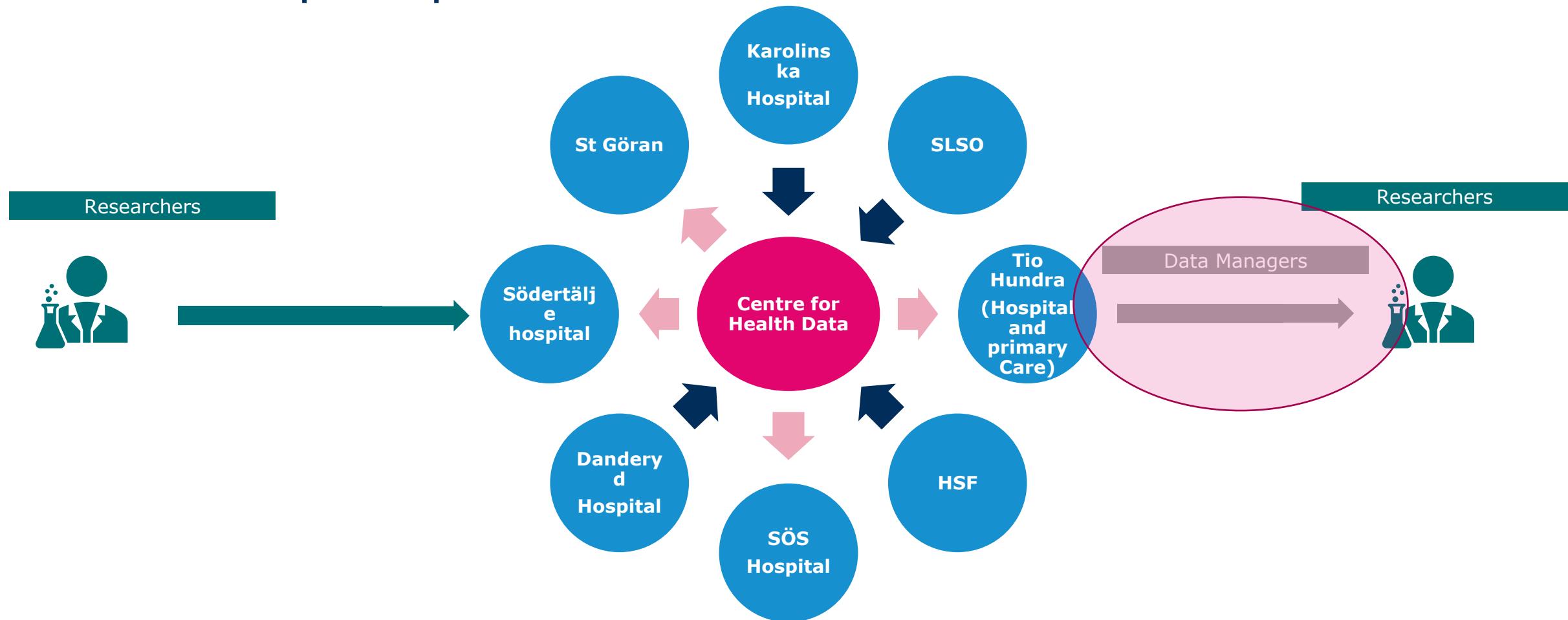
Challenge #3: Technical infrastructure

Data retrieval

- Multiple data sources
- Different data types (lab / x-rays / text)
- Requires highly competent staff who have devoted time to engage in data retrieval for secondary use
- Competence needed on the receiving side

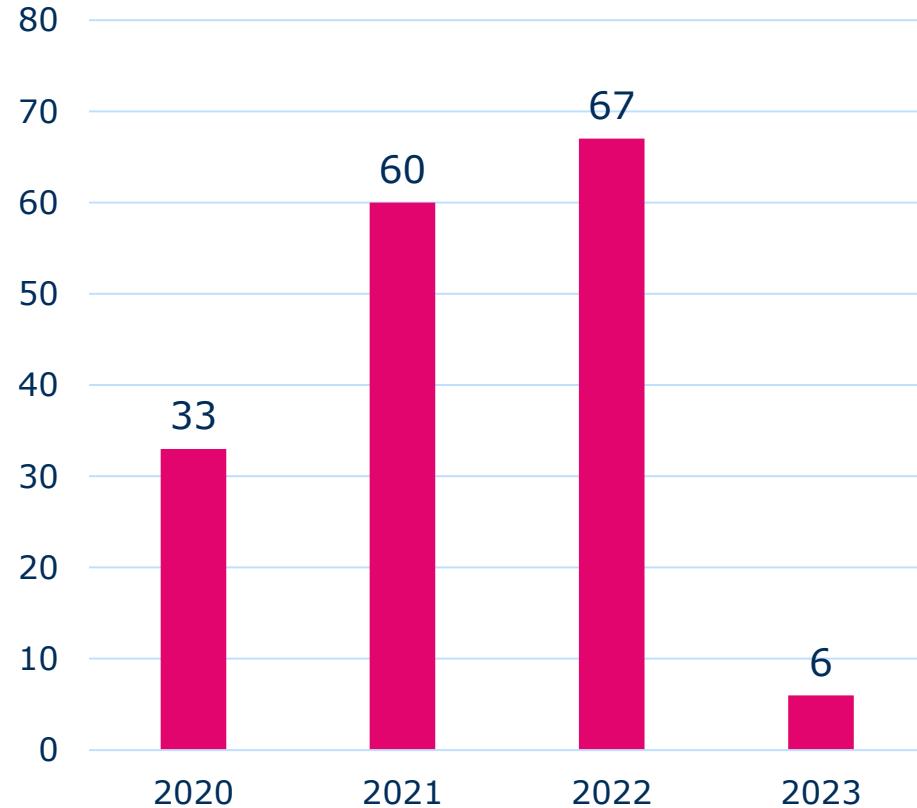
Centre for Health Data (CHD)

A one stop shop for data access



The Centre for Health Data so far

Incoming requests



Data is being used:

- Increasing no. of applications
- Waiting times still unsatisfactory
- Secondary use: shortage of staff and competence in the entire system



How will EHDS affect the data eco system in relation to research and innovation?

European Health Data Space

European Health Data Space

- Positive to enable access to data across member states
 - Unrealistic time frames
 - Requires big investments in infrastructure and staff
 - Understanding data quality (or lack there of) is key
 - Involve regional level
- Research ecosystem needs safeguarding
 - Protect the possibility to publish scientific results prior to sharing data
 - Avoid forcing researchers to use technical solutions that do not meet highest standards
 - “Data market” needs to be fair

To summarize

- Data extraction from data holder level (i.e. regional health care) possible but complicated
 - Requires resources and competence
 - Cost responsibility?
- EHDS may simplify some parts but not all
 - Quality requires knowledge of data (regional/data holder level)

Thank you!



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