The Danish health data model

Lisbeth Nielsen, Director General of the Danish Health Data Authority
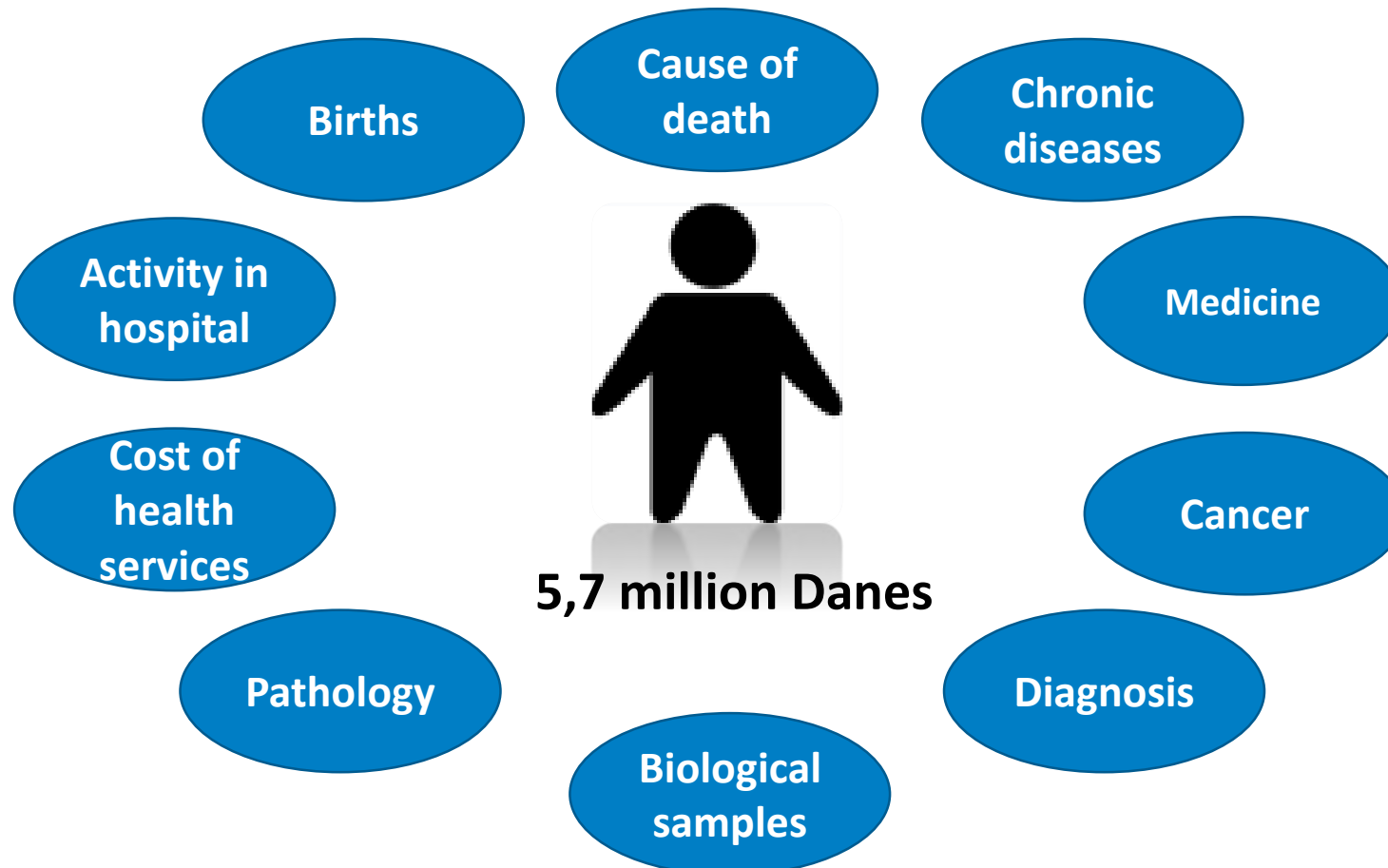
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Agenda

1. The basics of Danish health data

2. Organisation of the Danish health care system

3. The history of Denmark's health data platform

4. The overall health data system

5. The strategy for Danish health data in the future

6. GDPR and data for research purposes

7. Personalised medicine

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1. The basics of Danish health data

When an entire country is a cohort - a gold mine of health data

Births

Cause of death

Chronic diseases

Activity in hospital

Medicine

Cost of health services

Cancer

Pathology

Diagnosis

Biological samples

5,7 million Danes

2. Organisation of the Danish health care system

Key Principles

Universal coverage

Free & equal access

Financed by general taxes

A high degree of decentralization

Division of labour

National Level

Ministry of Health

- Legislation
- National health policies
- National targets
- Overall economic framework
- Structural planning
- Planning of medical specialties across regions and hospitals
- Clinical guidelines
- Auditing (patient safety etc.)

Regional Level

5 regions

- Hospitals
- Psychiatric care
- General practitioners (family doctors)
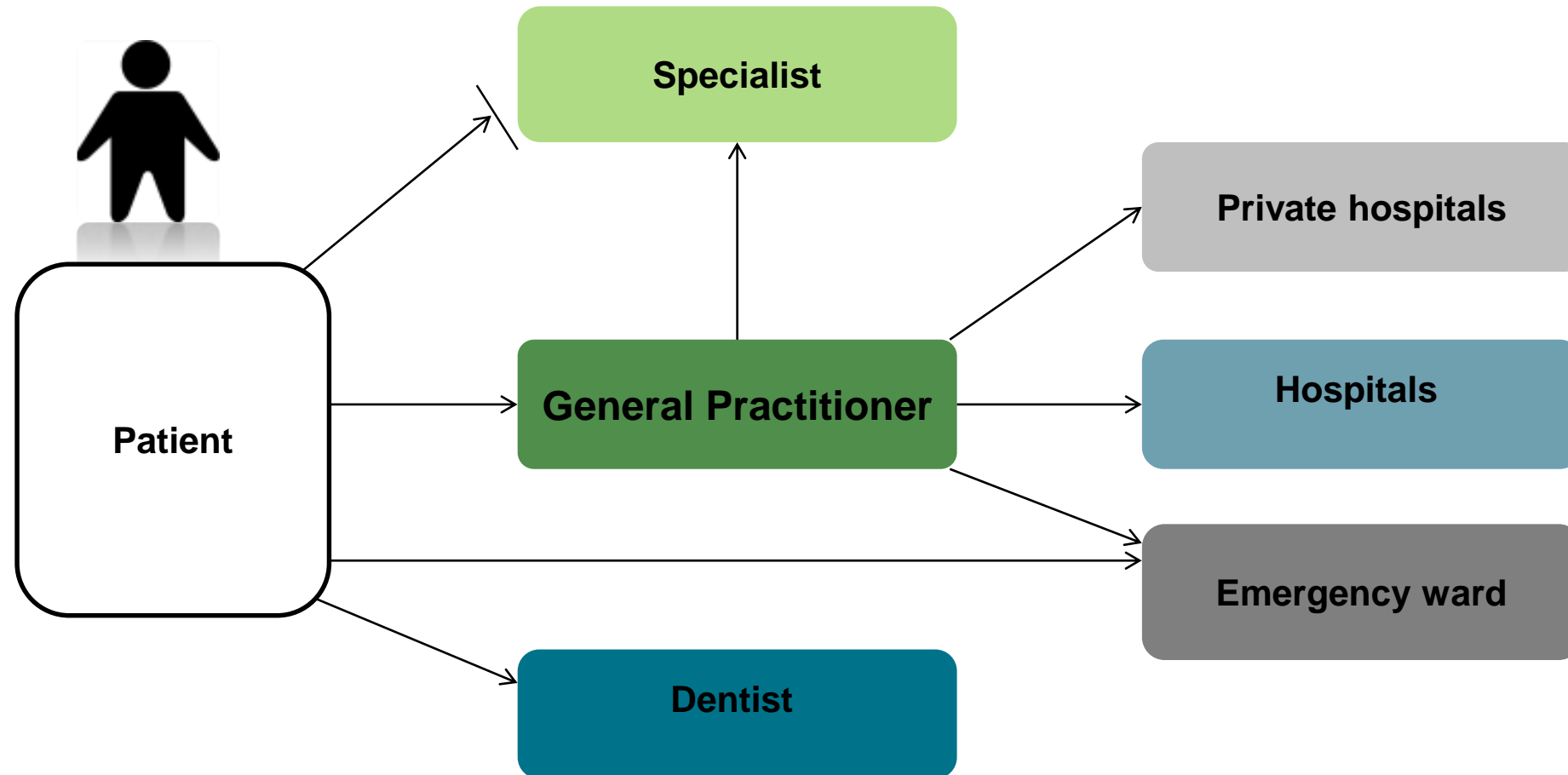- Adult dental care
- Other private practitioners

Local Level

98 municipalities

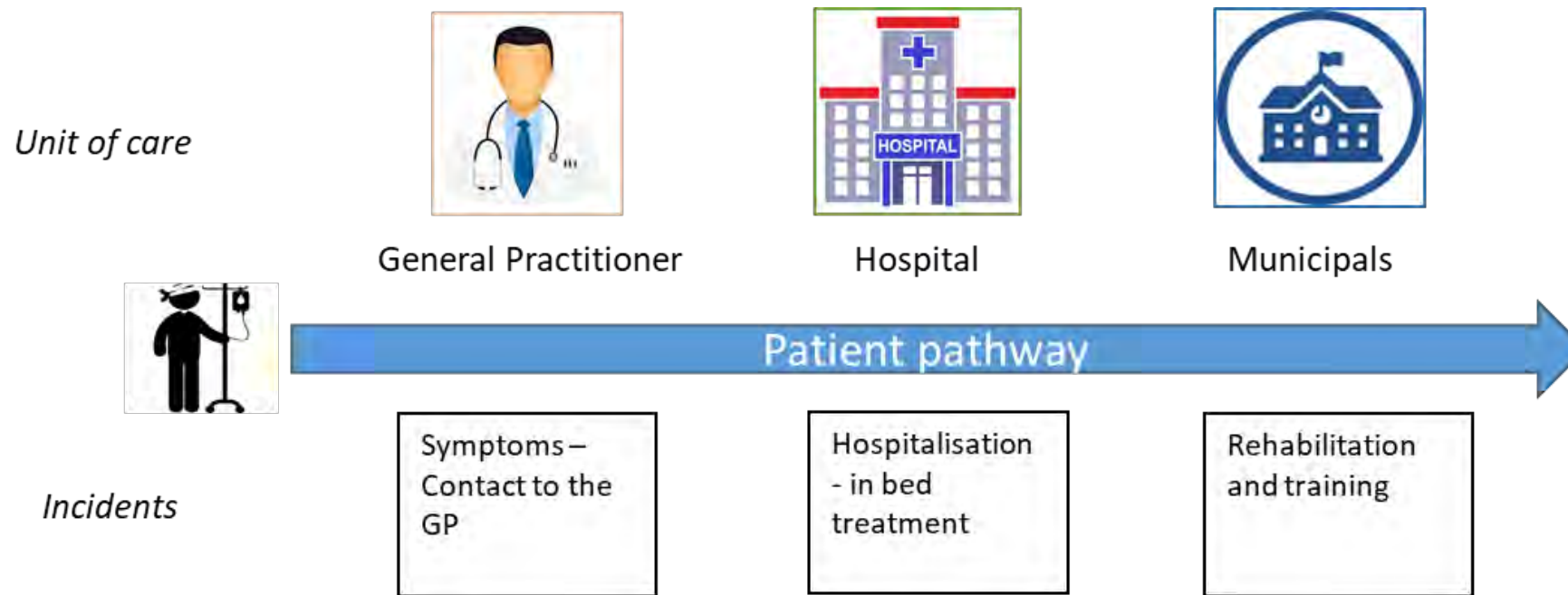- Preventive care and health promotion
- Elder care
- Non-hospital rehabilitation
- Treatment of alcohol and drug abuse
- Child nursing

Access to health care

2. Organisation of the Danish health care system

Unit of care

General Practitioner | Hospital | Municipals

Patient pathway

Incidents

| Symptoms – Contact to the GP | Hospitalisation - in bed treatment | Rehabilitation and training |

1. Primary use of data: Data used for patient treatment
2. Secondary use of data: Data used for planning, management, research

3. The history of Denmark's health data platform

❯ Unique identifiers for
- Citizens since 1968
- Authorized health professionals
- Care providing organizations

❯ National patient databases
- National patient registry since 1977

❯ Common standards and classifications
- Mandatory technical standards HL7 – CDA, QFDD, FHIR
- Limited number of classification systems ICD++, ICPC, NPU, SCT (sub)

❯ Digital signature for citizens and professionals

❯ The Danish Healthcare Data Network
- Connecting all healthcare providing institutions
- Standardized messages (MedCom)

CPR

One cohort

High level of completeness

Electronic since 1977
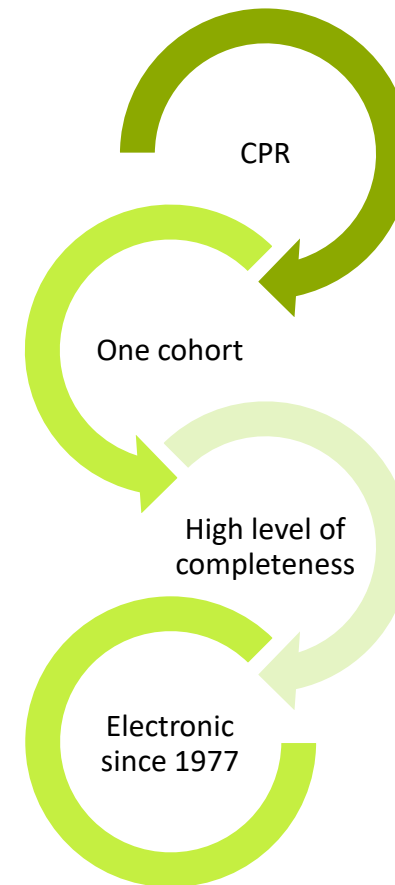
4. The overall health data system
The Danish health data landscape

Nationwide registries and databases

Regional data

Danish Health Data Authority
60 national health registries

The Danish Clinical Registries (RKKP)
89 clinical quality databases

Statistics Denmark
150 registries (socioeconomic data)

National Genome Center
National Genome Database

Patient journals
at hospitals (EHR systems)

Hospital databases and
local research databases

Biobanks

Regional biobanks

Danish National Biobank
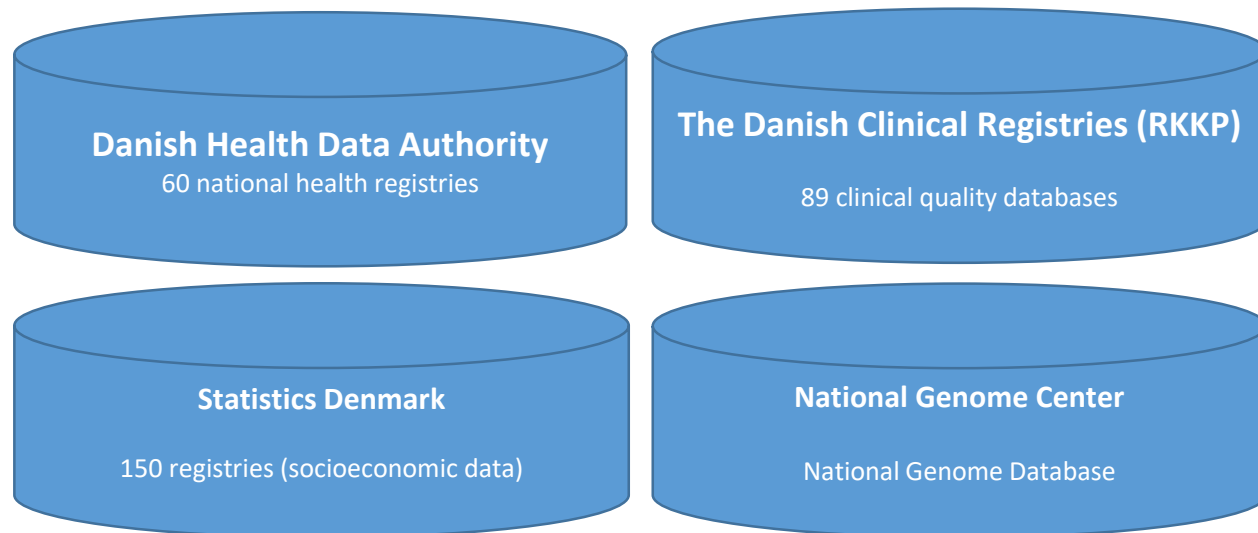
Municipal data

4. The overall health data system

Data entry

Regions (hospitals) – secondary care

Health Data

- Patient information and diagnosis
- Patient activity data (procedures, treatments)
- Patient pathway (waiting time, length of stay)
- Quality indicators
- Etc.

Municipals – primary care

Health Data

- Patient information
- Rehabilitation
- Home nursing

General Practitioners – primary care

Health Data

- Patient information
- Number of patient contacts

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4. The overall health data system

Requirements for data entry

Regions (hospitals) – secondary care

Health Data

- Patient information and diagnosis
- Patient activity data (procedures, treatments)
- Patient pathway (waiting time, length of stay)
- Quality indicators
- Etc.

Municipals – primary care

Health Data

- Patient information
- Rehabilitation
- Home nursing

General Practitioners – primary care

Health Data

- Patient information
- Number of patient contacts

Common standards, classifications and definitions

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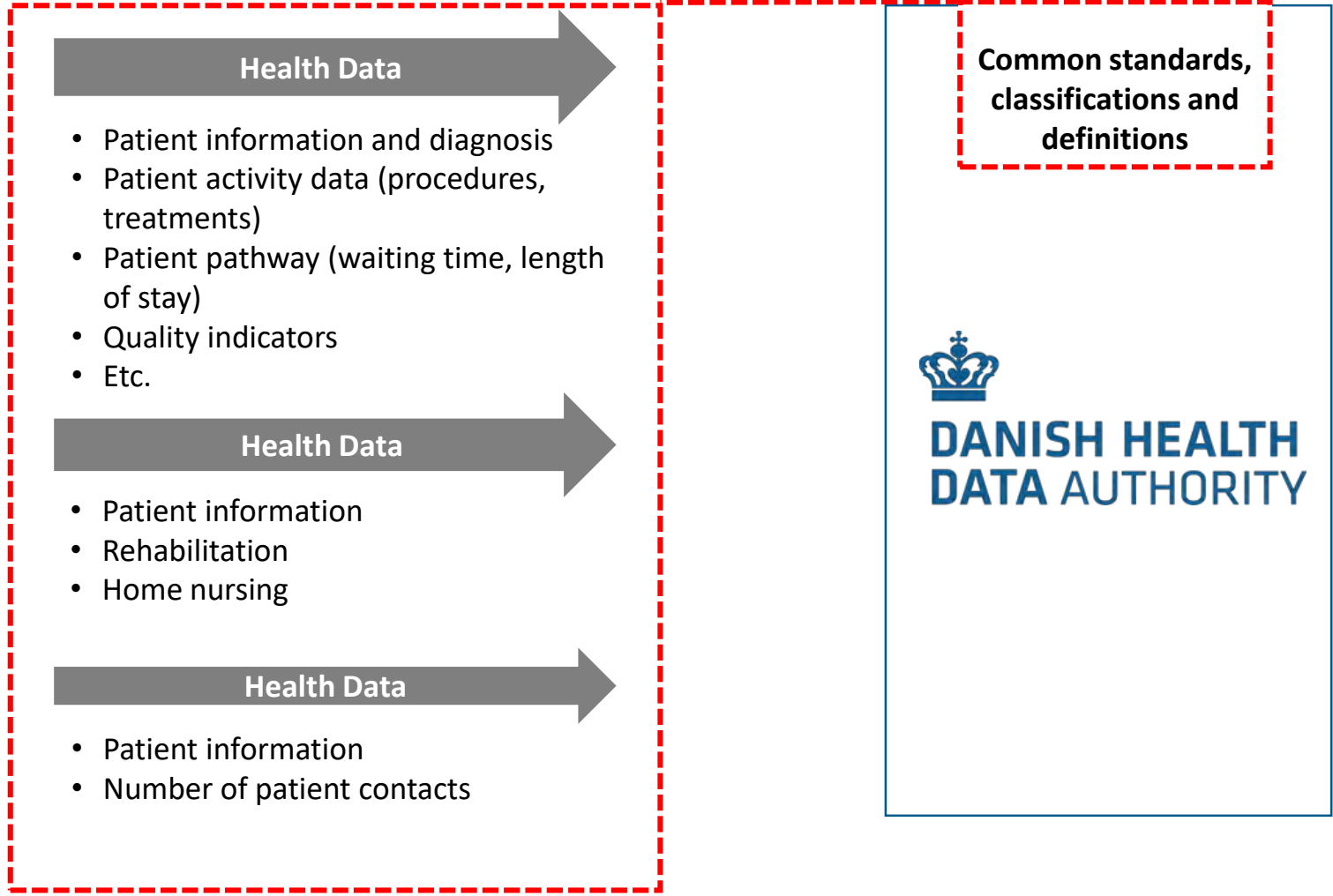
4. The overall health data system
Data management

Health data platform

| Data input | Data warehouse | Data presentation and analysis | Visualisation | Data users |

Input data → Data delivery

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Data input
- LPR
- FTP Inddata
- Clinical systems
- Other sources

Data warehouse
SQL Database Engine
- Loading and archiving
- Management and modelling

Data presentation and analysis
SQL Database Engine
- Official Databases
- Sandbox/Lab Databases
- FTP og Fileserver — Files
- Master Data — Entiteter

Visualisation
- eHealth
- Qlik
- SAS
- Excel
- Other analysis tools

Data users
- Users
- Clinicians and management
- Researchers
- Data Integration

Platform tools
- Integration Services
- Master Data Services
- SQL Agent Job automatisering
- DevOps Repos/Pipeline

Productivity tools
- DevOps Boards

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4. The overall health data system
Data utilisation at national level

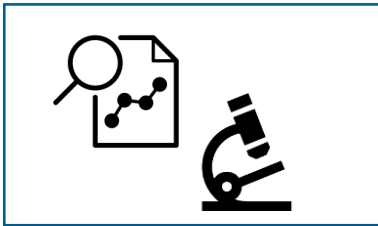**Data back to the health care system** →

- Management
- National monitoring
- National Goals
- Quality indicators

Data for policy and initiatives DMoH →

- Health Statistics
- National monitoring
- National Goals

Data for research →

- National Research Service for Health Data
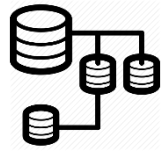- Datasets for research (times-series etc.)

Public eHealth portal →

- National Health Statistics
- Transparency on health care sector outcomes

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5. Strategy for Danish health data in the future
Challenges to the use of secondary health data

Complex and ununified data structure

Data is spread across a number of authorities with different responsibilities and interests

The need for more data from the primary care sector to reflect the patient pathway

Complex legal requirements

The fastpaced technological development

5. Strategy for Danish health data in the future
Efforts to improve the access and use of health data

The Health Data Program (2015-2020) with the aim of createing better health care through better use of national health data – modernisation of data infrastructure, platform and data management

Development of a High Performance Computing (HPC) Center designed for analysis of health and genome data

Better cooperation between the health authorities on health data

Communicating the value and potential of the use of health data and the and the good posibilities of the use of data

5. Strategy for Danish health data in the future
Efforts to improve to access

Researcher

National access point to health data

National data map

Portal for researchers applications to national and regional authorities

Information and guidance

Key institutions and authorities

Danish Health Data Authority

Danish National Genome Center

The Danish Clinical Registries

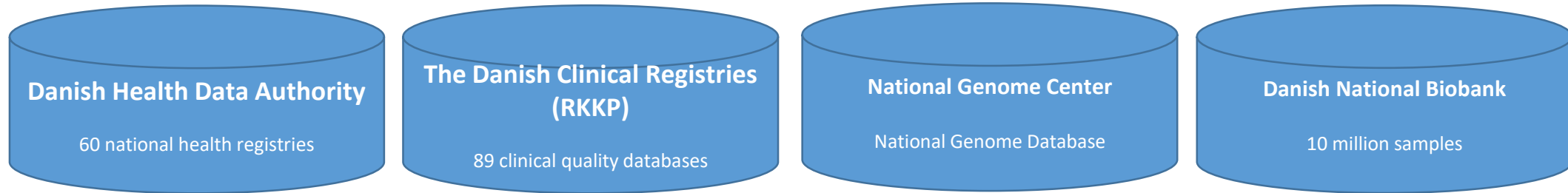Regional authorities, hospital data

Danish National Biobank

Municipalities

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6. The GDPR and data for research purposes

- Denmark adopted national legislation on access to health data before the GDPR took effect

- Legislation is within the limits of GDPR and gives wide acesss to data for research and purpose that benefit society as a whole

- Security is the foundation for trust and legitimacy:

  1. Access is given through a secure platform where researchers work with data

  2. Data is pseudonymised

  3. Logging and surveillance is conducted on the platform

7. Potentials of personalised medicine
Danish stronghelds

Danish Health Data Authority	The Danish Clinical Registries (RKKP)	National Genome Center	Danish National Biobank
60 national health registries	89 clinical quality databases	National Genome Database	10 million samples

- The strongholds comprise historical, validated data that will enable researchers to find correlations between genetic variance and the prevalence of diseases

- Effectiveness of new medicine on the market can then be proven by analysing present data in relation to historical data – so called Real World Evidence

- Denmark hopes to achieve this synergy and facilitate the development of personalised medicine with improved diagnostics and treatments

The overall health data system

Mission

To cement and strengthen Denmark's position at the global top of utilizing data and digitalization in the health sector

Vision

Better health through the use of data and digital connection in the health sector

Core tasks

- Digital solutions for the healthcare sector

- National health registries and research services

- Cyber security management of the Danish health sector

DANISH HEALTH DATA AUTHORITY

The overall health data system

Portfolio of the Danish Health Data Authority

- National health registers – collect, drive and develop

- National monitoring – cancer, hearts etc.

- Health statistic – cause of death, cancer, disease patterns, activity

- Finance and account – DRG, KMF, productivity

- Analysis of the health sector and the citizens consumption of medical products

- Available data for researchers and the health sector – research, development and planning

- Classifications and standards – content/data/organizations

- National services for patient care – FMK, CPR, patient-behandler

- Information security - The Danish Health Data Authority, The ministry, The health sector

- It-architecture – Concrete solutions

- Collaboration on digitalization across the public sector

- Operation and system responsibility for the it in the health authorities and the Ministry

The overall health data system

The use of national data

Policy
- National quality targets
- Planning of specialization
- Financial estimates
- Questions from the parliament

Administration
- Waiting periods
- Patient rights
- DRG and KMF
- Controlling
- Local planning needs

Research and improvement
- Clinical research
- Register research
- Biobank research
- Data for clinical data bases
- Population overview

Statistic
- Health statistic
- Visible results
- Annual reports
- OECD reports
- Medication statistic

Performance
- Measurement of productivity
- Measurement of activity
- Benchmarking
- Clinical guidelines
- Analysis

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