DANISH NATIONAL
GENOME CENTER

# Danish National Genome Center for the benefit of patients

July 6 2023

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**CEO, Danish National Genome Center**

## Patient groups on the Danish National Genome Center's infrastructure

Hereditary heart diseases

Hereditary haematological diseases

Hereditary cholestatic and fibrotic liver diseases

Audio genetics

Endocrinological patients

Fetal medicine

Neurogenetic patients

Kidney failure

Ophthalmology

Primary immune deficiency

Psychiatry (children and young people)

Rare diseases in children and adults

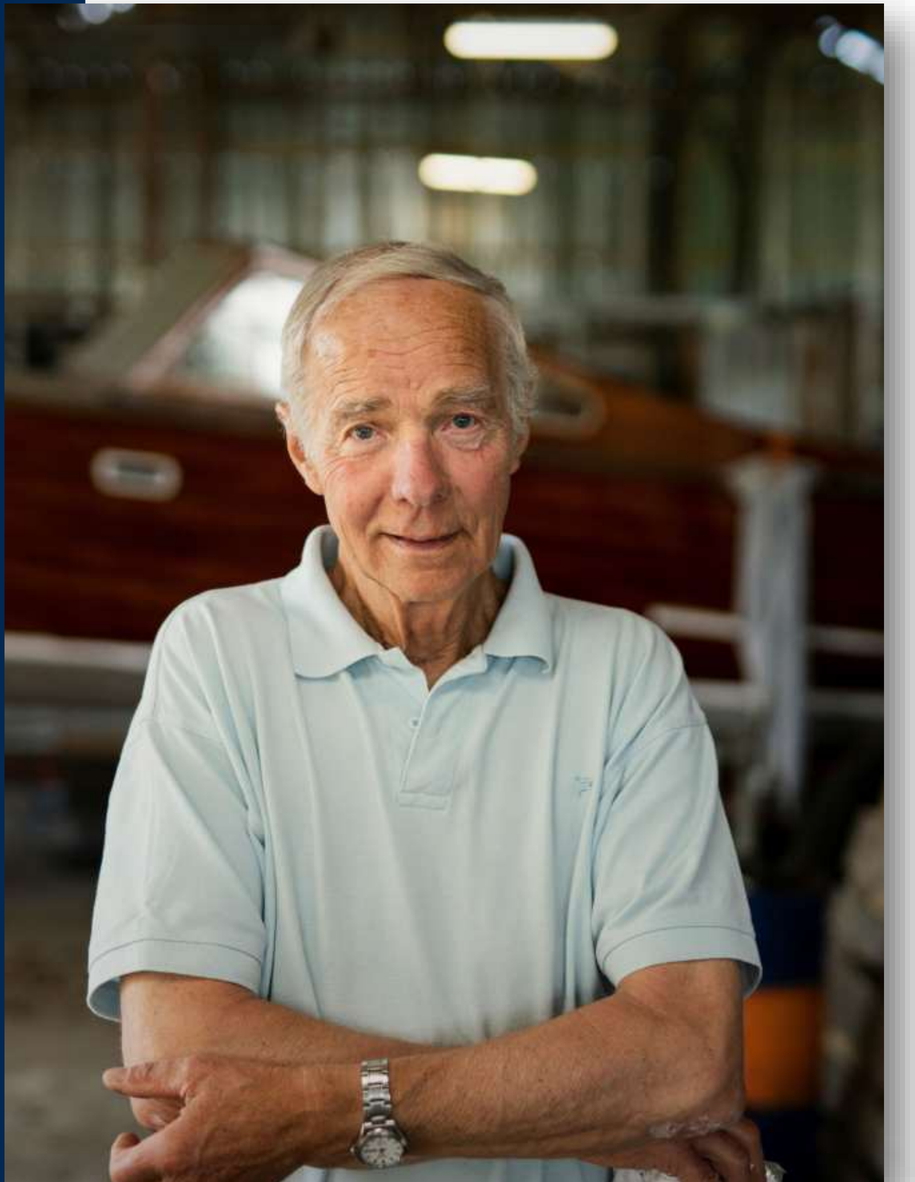
Severe hereditary skin diseases

**Cancer: Haematological cancer**

**Cancer: Children and young people**

**Cancer: Young adults (18-30 years) and adults with hereditary cancer**

**Cancer: Advanced and incurable cancer**



# Tony's cancer is reduced with the right treatment

- Standard treatment no longer works
- The cancer has spread
- Is offered genetic analysis and accepts
- Genetic findings points to possible new treatment with experimental medicine
- Say yes to new treatment
- The treatment works and the cancer is reduced
- Today he’s recovering and can continue his life

# Danish National Genomes Center's Core Tasks

- Implementation of whole genome sequencing in patient treatment
- Collect and store Danish genome data in a secure national genome database
- Make genome data accessible to medical doctors, researchers and patients
- Promote personalized medicine in Denmark

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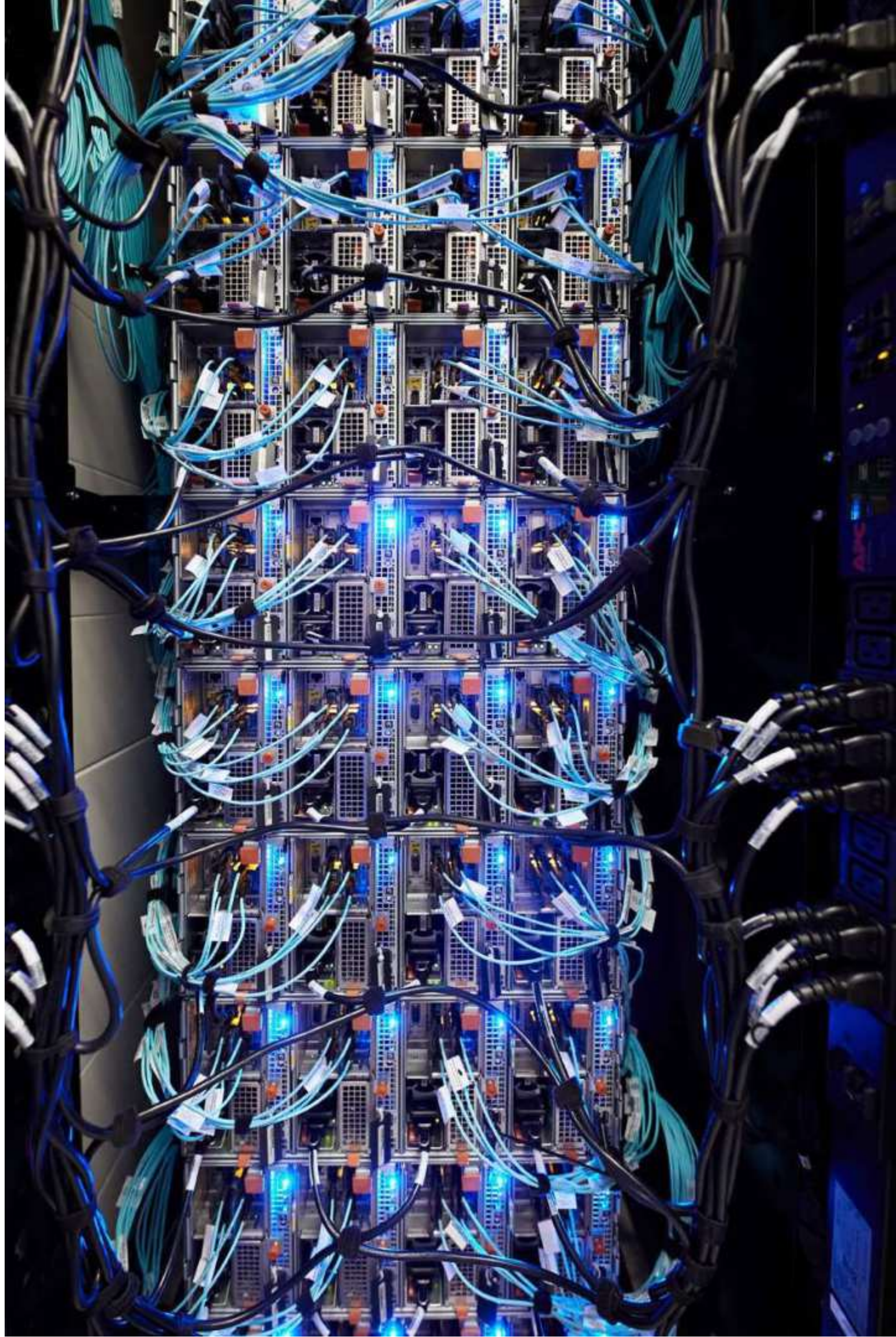
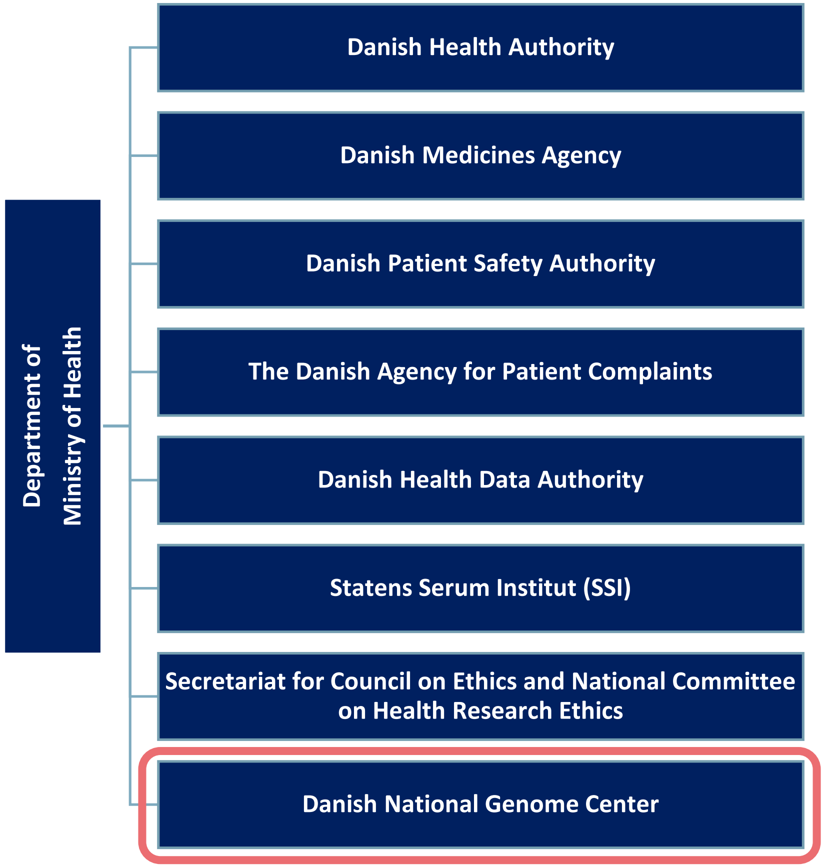


# Danish National Genome Center's mandate is defined by health legislation

**DNGC is an agency in The Danish Ministry of Interior and Health**

1. **assists the Minister** with the central administration of issues related to personalised medicine.
2. **supports the development** of personalised medicine
3. **develops** and **runs** a joint, **national information infrastructure for personalised medicine**, including a national infrastructure for performing genome sequencing and storing of Danish genome data in a national genome database.
4. **makes data accessible** to medical doctors, researchers and patients for the healthcare system (patients) and research

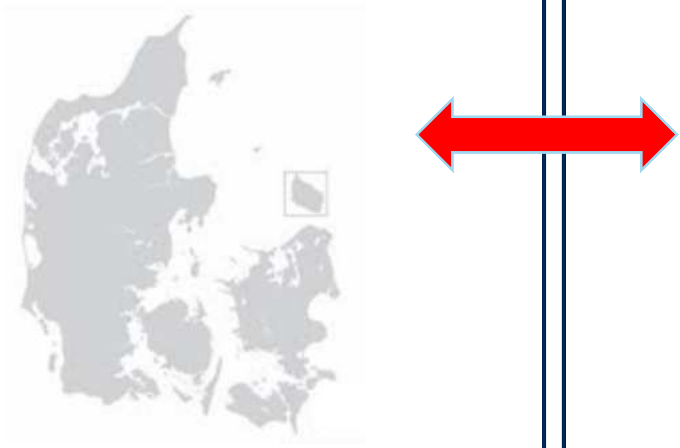


Department of Ministry of Health

- Danish Health Authority
- Danish Medicines Agency
- Danish Patient Safety Authority
- The Danish Agency for Patient Complaints
- Danish Health Data Authority
- Statens Serum Institut (SSI)
- Secretariat for Council on Ethics and National Committee on Health Research Ethics
- Danish National Genome Center

# The Danish healthcare system is decentralised and organised across 3 levels

## National level (Ministry of Health)



- Regulation and organisation of the Danish healthcare system
- Negotiation on financial framework that is to be delivered by regions and municipalities

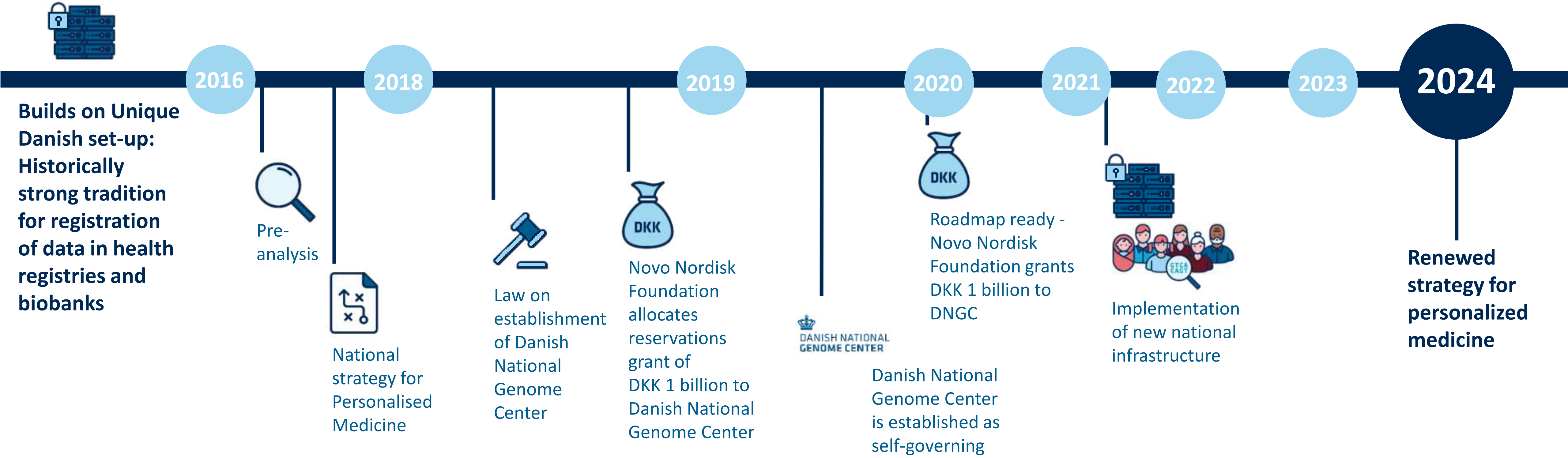
## Regional level (Regions)

- Operation of hospitals, general practitioners and specialists
- Execution of prevention, healthcare promotion, and long-term care initiatives

## Local level (municipalities)

- Provision of rehabilitation, home nursing, school health services, child dental treatments, service for elderly people

# Timeline of national strategies and infrastructure for personalised medicine



**Builds on Unique Danish set-up: Historically strong tradition for registration of data in health registries and biobanks**

Pre-analysis

National strategy for Personalised Medicine

Law on establishment of Danish National Genome Center

Novo Nordisk Foundation allocates reservations grant of DKK 1 billion to Danish National Genome Center

Danish National Genome Center is established as self-governing

Roadmap ready - Novo Nordisk Foundation grants DKK 1 billion to DNGC

Implementation of new national infrastructure

**Renewed strategy for personalized medicine**

## National Strategies and NGC 2017-2023

PERSONALISED MEDICINE FOR THE BENEFIT OF THE PATIENTS

CLEAR DIAGNOSIS
TARGETED TREATMENT
ENHANCED RESEARCH

National Strategy for Personalised Medicine →

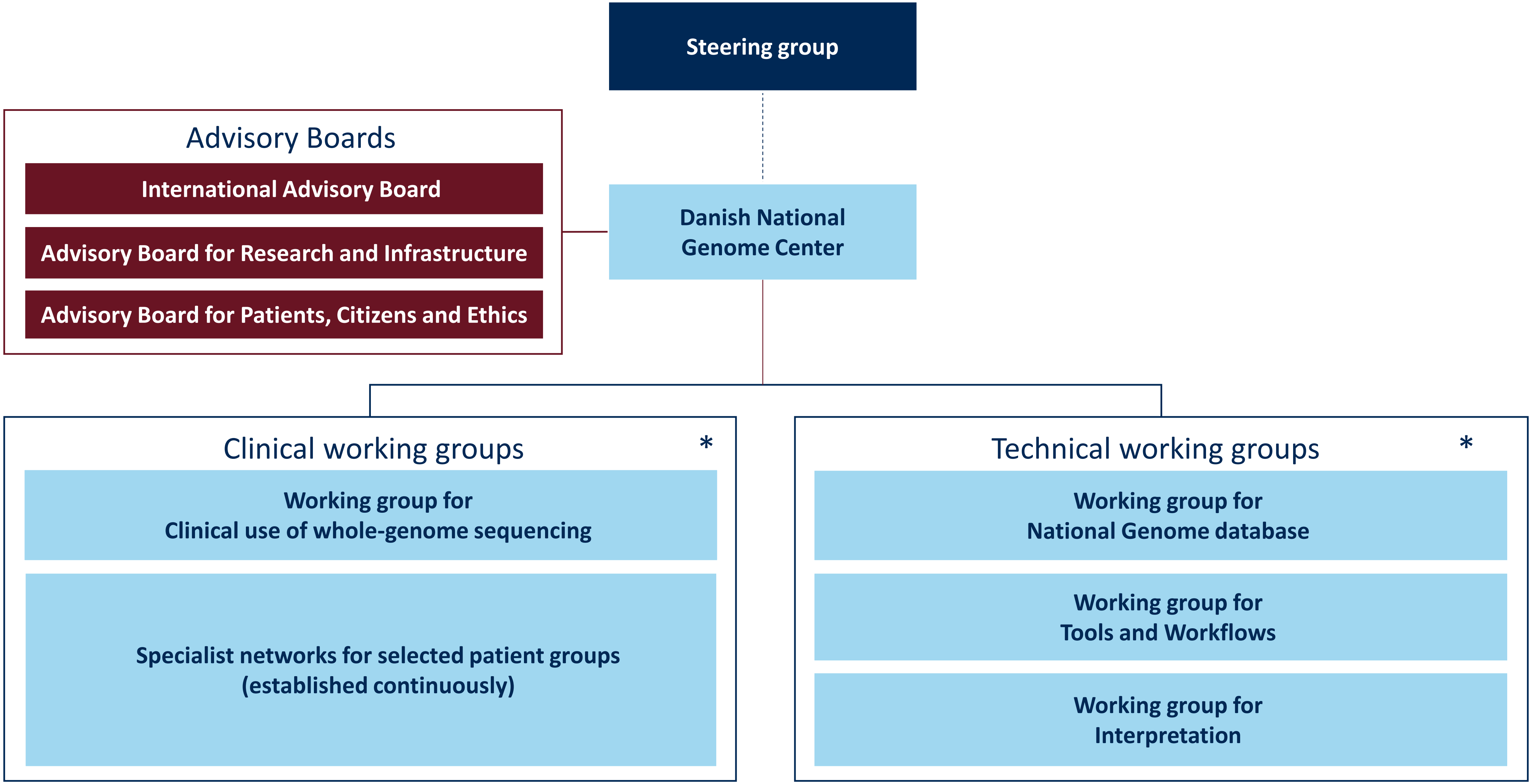
Strategi for life science

Strategy of life science →

Vision

Strategisk samarbejde for bedre brug af sundhedsdata

Vision strategic collaboration for better use of health data



**Steering group**

**Danish National Genome Center**

Advisory Boards

- **International Advisory Board**
- **Advisory Board for Research and Infrastructure**
- **Advisory Board for Patients, Citizens and Ethics**

Clinical working groups *

- **Working group for Clinical use of whole-genome sequencing**
- **Specialist networks for selected patient groups (established continuously)**

Technical working groups *

- **Working group for National Genome database**
- **Working group for Tools and Workflows**
- **Working group for Interpretation**

* The chairmanship promotes coordination and coherence across relevant working groups

# Genomes and RNA samples performed by DNGCs facilities divided into patient groups

## May 2023

| | |
|---|---|
| **Hereditary heart diseases** | **583** (+81) |
| **Hereditary haematological diseases** | **251** (+18) |
| **Hereditary cholestatic and fibrotic liver diseases** | **37** (+12) |
| **Audio genetics** | **155** (+18) |
| **Endocrinological patients** | **209** (+24) |
| **Fetal medicine** | **269** (+87) |
| **Neurogenetic patients** | **656** (+108) |
| **Kidney failure** | **85** (+8) |
| **Ophthalmology** | **123** (+23) |
| **Primary immune deficiency** | **441** (+41) |

| | |
|---|---|
| **Psychiatry (children and young people)** | **93** (+23) |
| **Severe hereditary skin diseases** | **75** (+12) |
| **Rare diseases in children and young people under 18 years** | **4,202** (+200) |
| **Rare diseases in adults** | **455** (+46) |

| **Cancer groups** | |
|---|---|
| **Cancer: Children and young people** | **490** (+59) |
| **Cancer: Haematological cancer** | **11** (+4) |
| **Cancer: Young adults (18-30 years) and adults with hereditary cancer** | **193** (+23) |
| **Cancer: Advanced and incurable cancer** | **1,669** (+305) |

*Note: The increase from last month appears from the parenthesis (+ numbers).*
*Note: The patient group Rare diseases in children and adults includes: Rare diseases in children and young people under 18 years, Rare diseases in adults and the pilot study on critically ill children.*
*Note: The number of samples include test samples for the patient groups, e.g. in the case of Haematological cancer. The total number of samples include validation samples which are not registered in any patient groups.*

# How is DNGC financed?

**Private foundation grants**

Novo Nordisk Foundation Euro 132m

**In-kind from existing regional resources**

Euro 100m

**National budget Euro** 4,5m annually

**Research**

Income covered business

Slowly growing

# National Genome Database

## May 2023

Number of genome samples performed by DNGCs facilities

**9,517**

Number of RNA samples performed by DNGCs facilities

**548**

Number of genome samples performed by the regions

**4,440**

**14,505**

**Total number of genome and RNA samples in the National Database**

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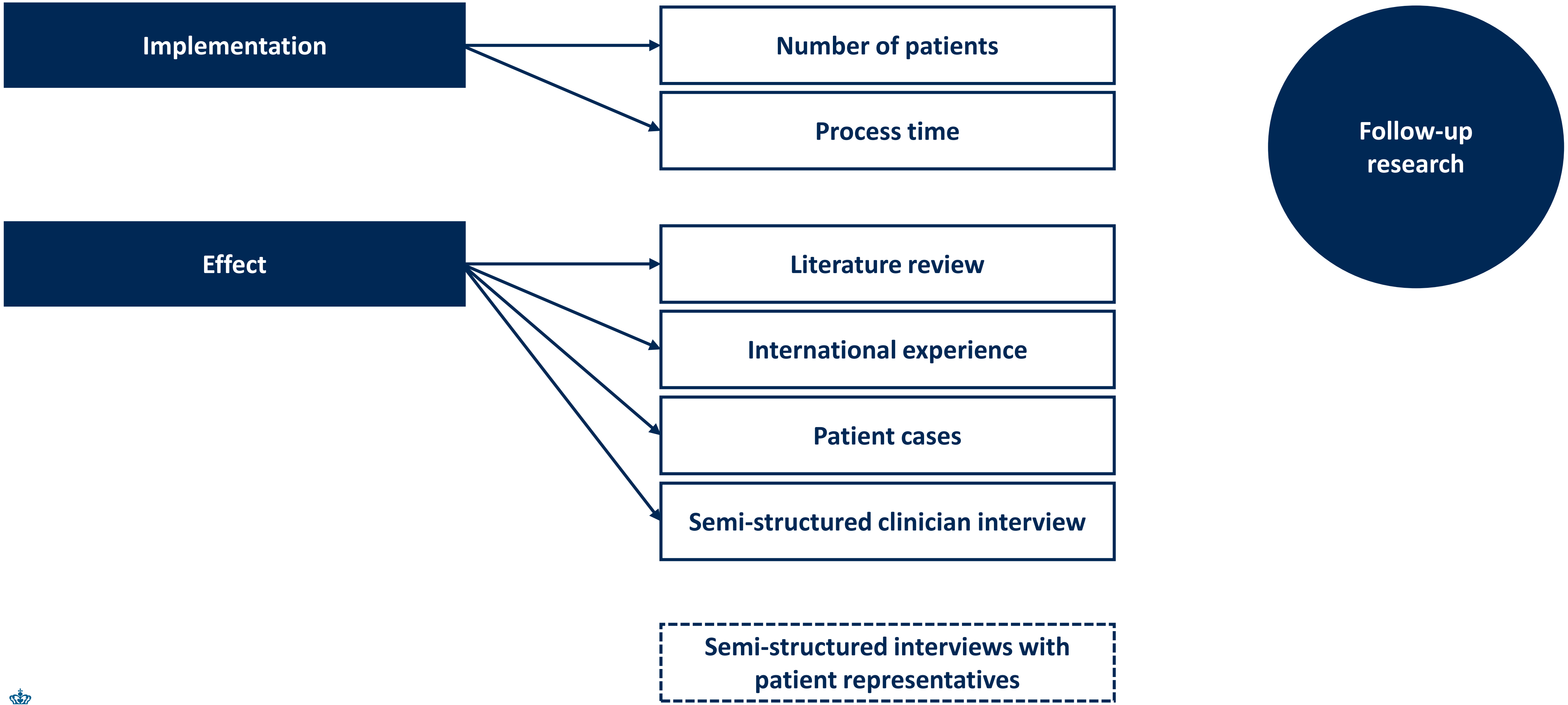
# Model for evaluating the effect of whole genome sequencing



Implementation

Number of patients

Process time

Follow-up research

Effect

Literature review

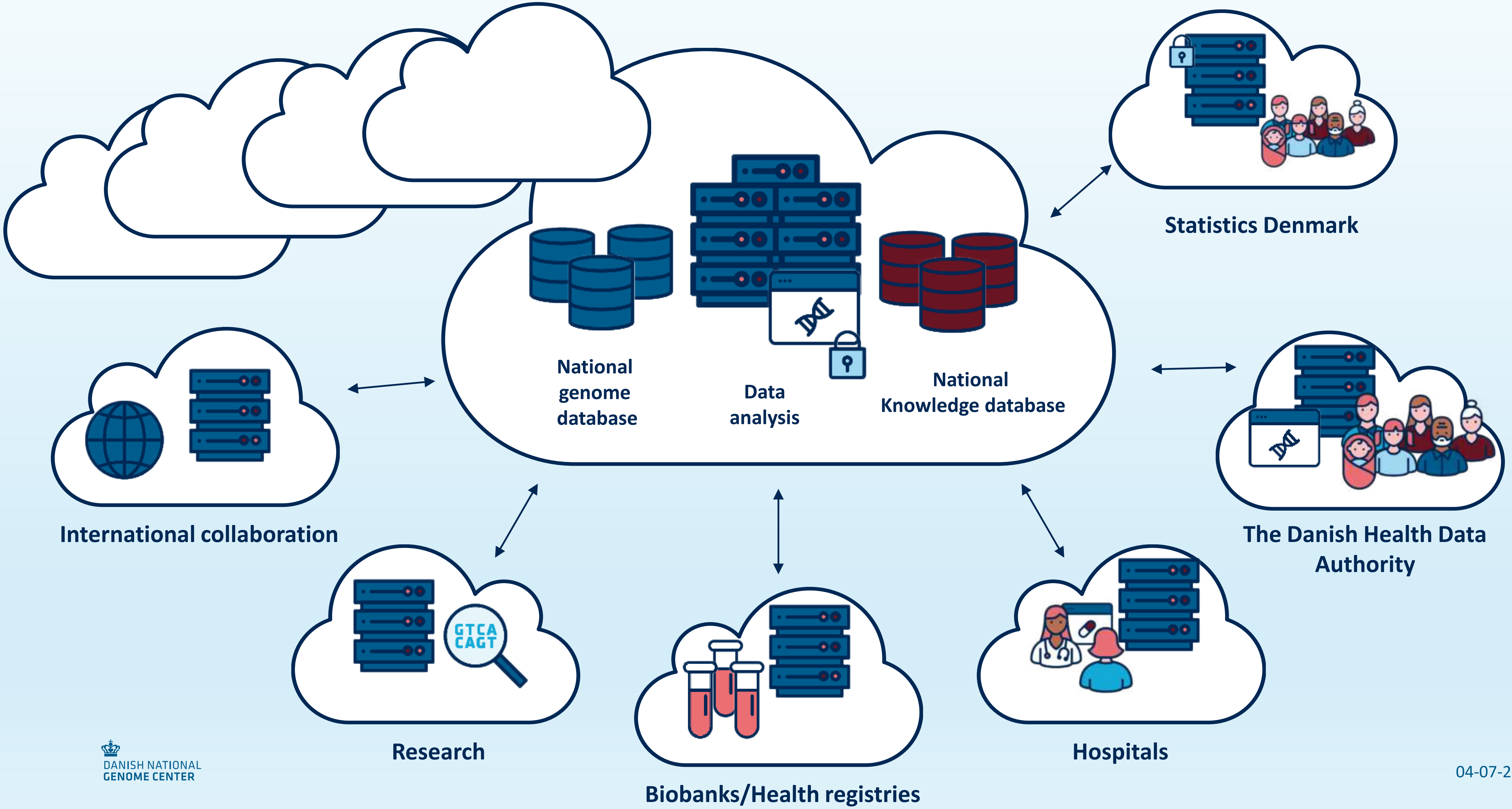
International experience

Patient cases

Semi-structured clinician interview

Semi-structured interviews with patient representatives

# Partner access to DNGC-HPC and data sources



National genome database

Data analysis

National Knowledge database

Statistics Denmark

International collaboration

The Danish Health Data Authority

Research

Biobanks/Health registries

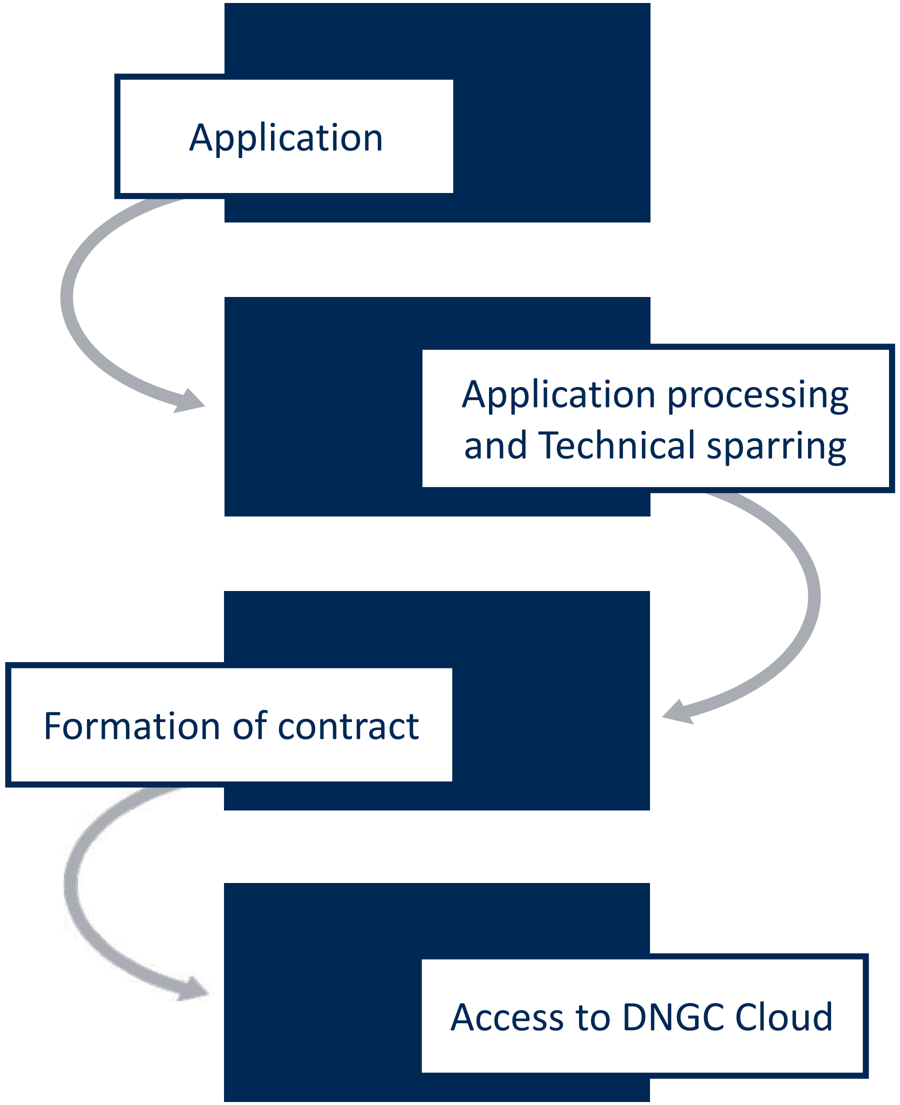
Hospitals

# Access to DNGC Research infrastructure

- Deal with personal medicine
- Be of significant societal interest
- Recognised research institutions (Companies can only benefit from data through collaboration with research groups, e.g. at a Danish university or hospital)
- Use of data under public control

**Access to the Genome database**

- Approved by Danish Ethical committee system
- Read only access to pseudonymised data (data cannot leave the infrastructure)



Application

Application processing and Technical sparring

Formation of contract

Access to DNGC Cloud

# International Collaboration

- DNGC represents Denmark in the **1+ million genomes initiative**
  - Genomic Data Infrastructure (**GDI**)
  - Genome of Europe (**GoE**) – reference genomes

- Signed MoU with Genomic Medicine **Sweden**
- Signed MoU with **French** National Alliance for Life Sciences and Health
- Strong collaboration with Genomics **England**
- Cooperation with **Norway**
- Knowledge sharing with: **Canada, Ireland, Finland, Japan, Germany, Portugal, Spain, Brazil** and others

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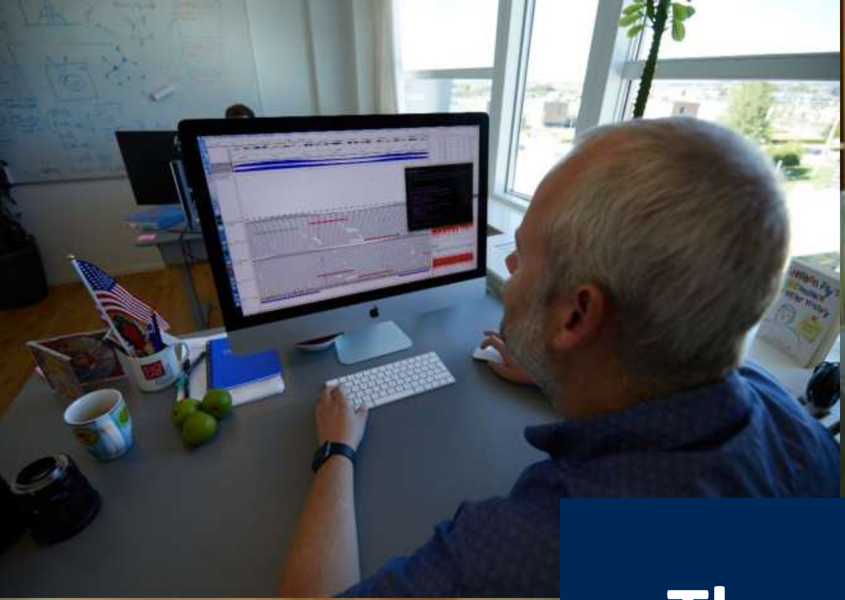
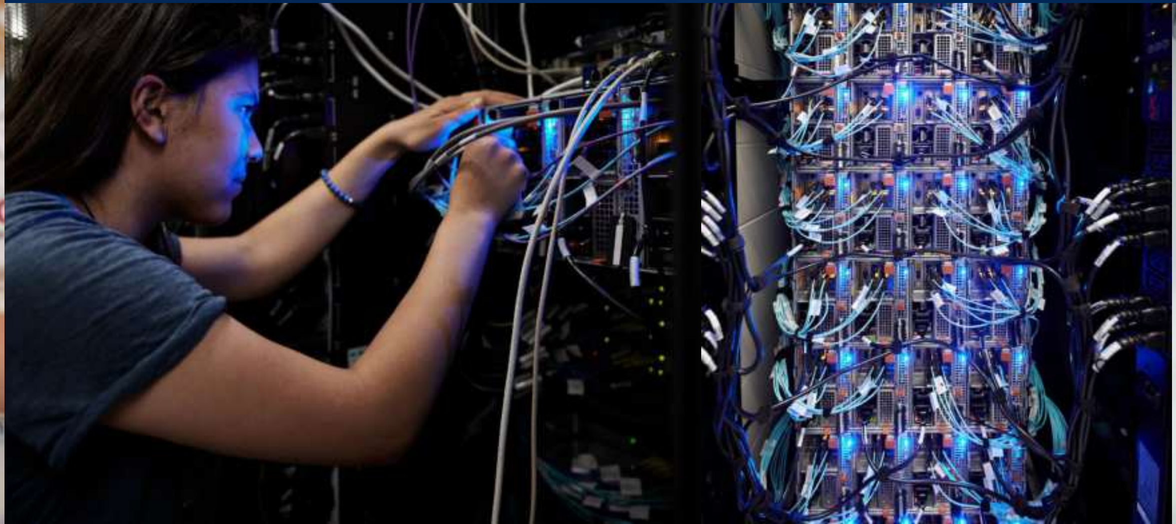
# The Future of Personalised Medicine

Genome data + Health data = The prevention and treatment of the future



# Thank you to our patients and collaborators nationally and intetnationally



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