

# Five years with Danish National Genome Center

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# Agenda

- Prolog The becoming of DNGC
- Chapter 1 Danish National Genome Center (DNGC)
- Chapter 2 Renewed strategy for PM (prevention)
- Chapter 3 The Danish ecosystem
- Epilog What is next?

# PROLOG

## The becoming of DNGC

Denmark has a strong tradition for data registration in health registries and biobanks

Genetic research and individualized treatment methods are slowly advancing in RESEARCH

Pre-analysis

2017

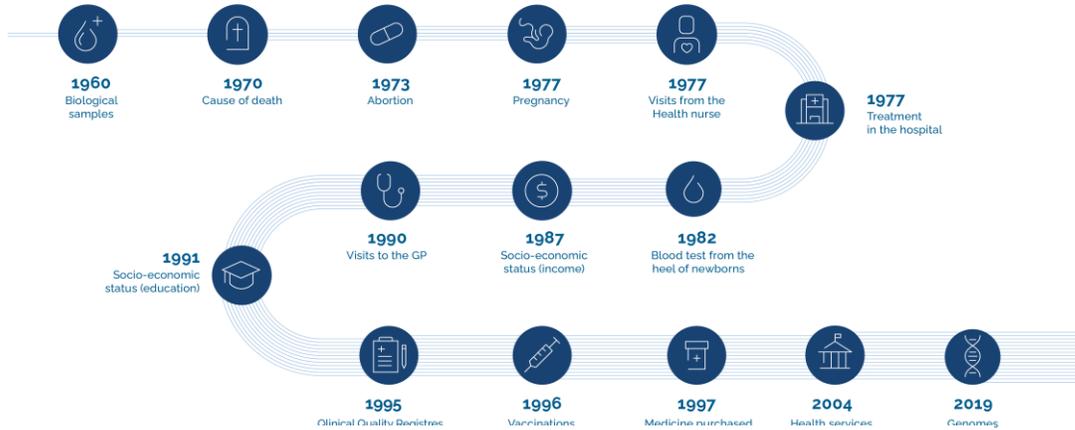
2016

Political decision: on a national strategy for Personlised Medicine



# Denmark had something to build on...

## A long history of data collection



## All data is linkable



CPR  
personal  
identifier

Strong tradition for registration of data in health registries and biobanks

Minister of Health  
2015-2016  
2022-now

Pre-analysis

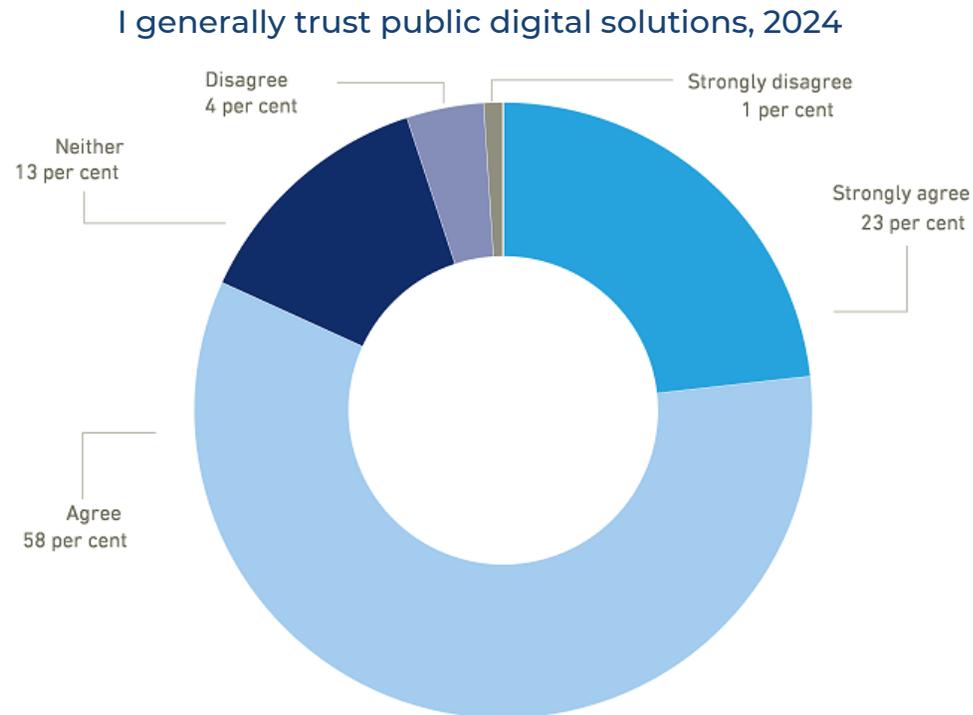


Research for patients





# High public trust and transparency



Source: [ICT usage in households and by individuals 2024 \(in Danish\)](#)

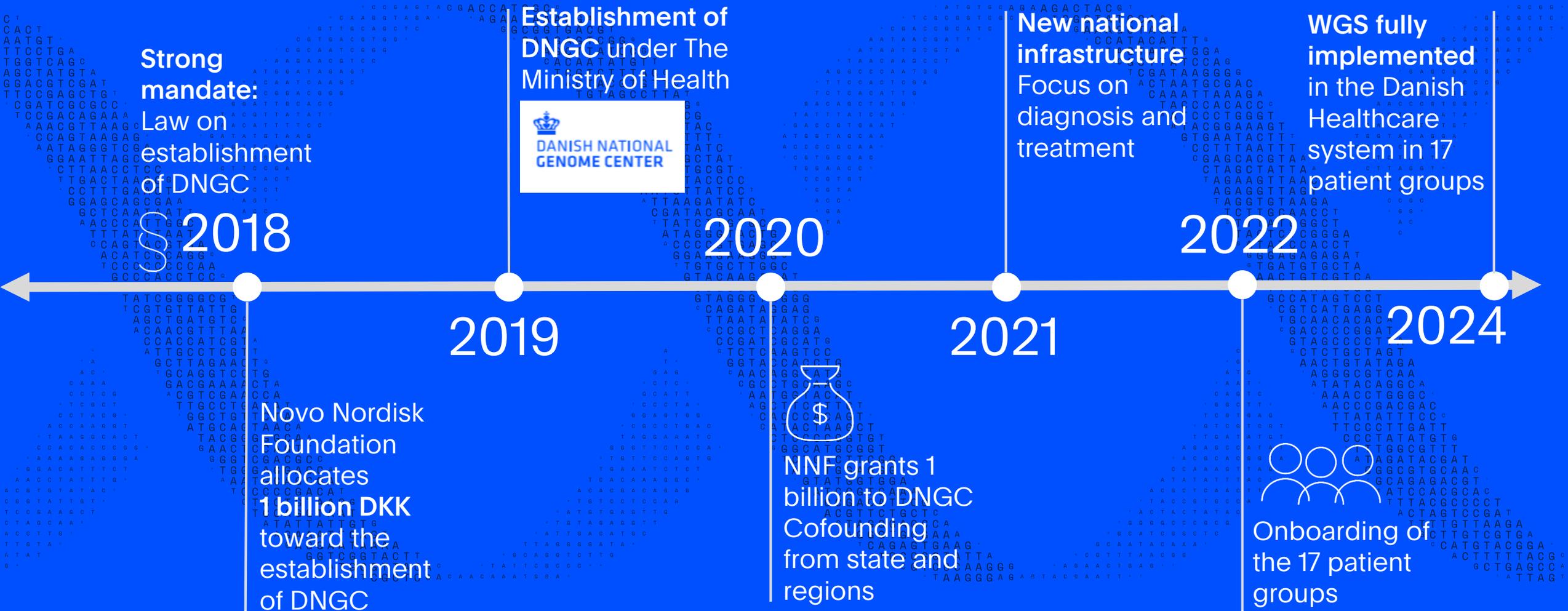
In general, Danes have a high trust in the **Danish authorities** and the **Danish digital solutions**. This is fundamental for the collection and use of information about Danish citizens.

## Why (some of the reasons)?

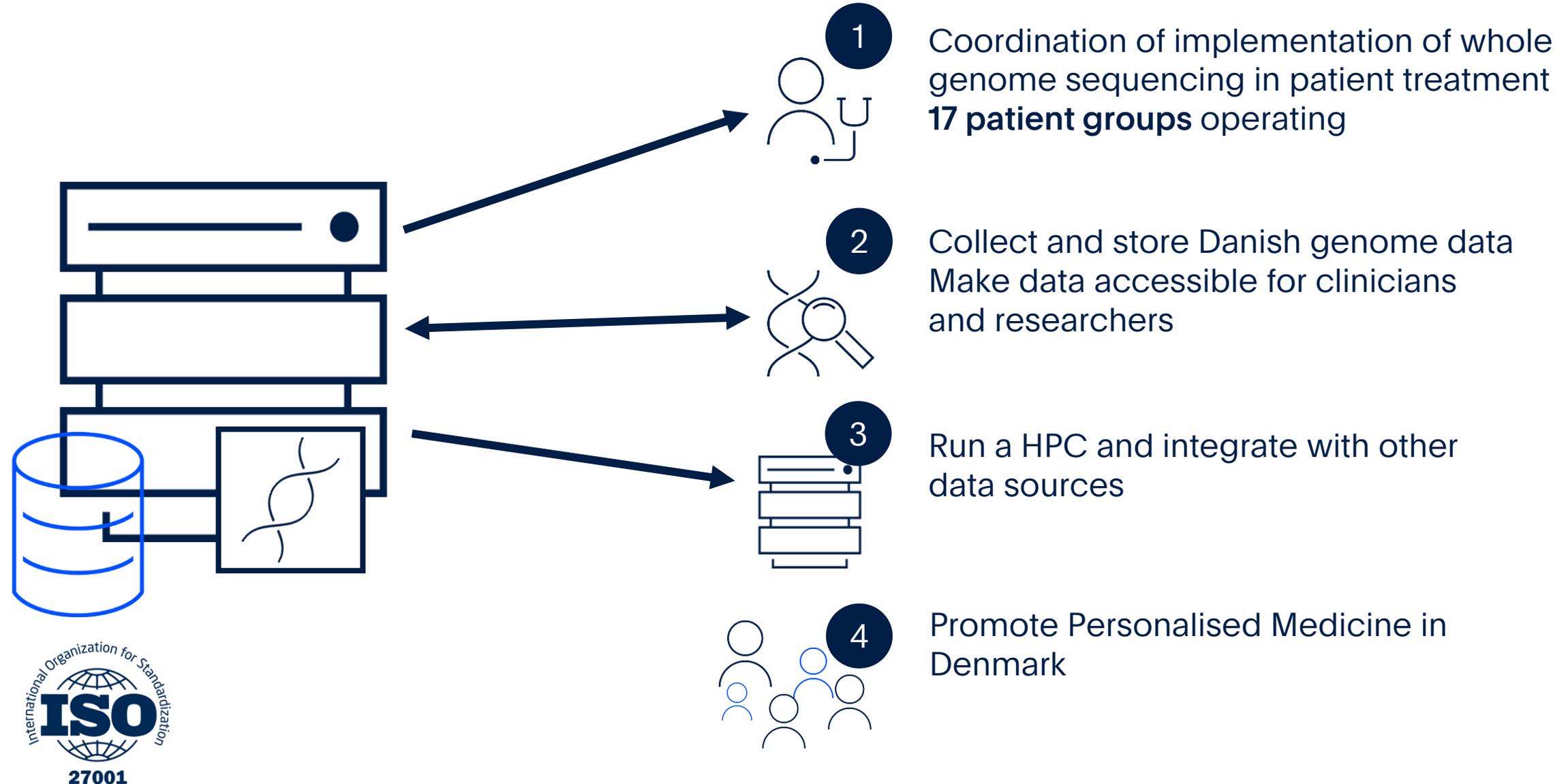
- Digital solutions create transparency and value
- High data security
- Rules to regulate the use of data

# Chapter 1

## Danish National Genome Center



# Danish National Genome Center's Core Tasks



# The national infrastructure for personalised medicine

1 HPC  
1 Genome database  
2 Sequencing sites  
5 Regions  
54 public hospitals  
Many departments and units



Sequencing



Processing



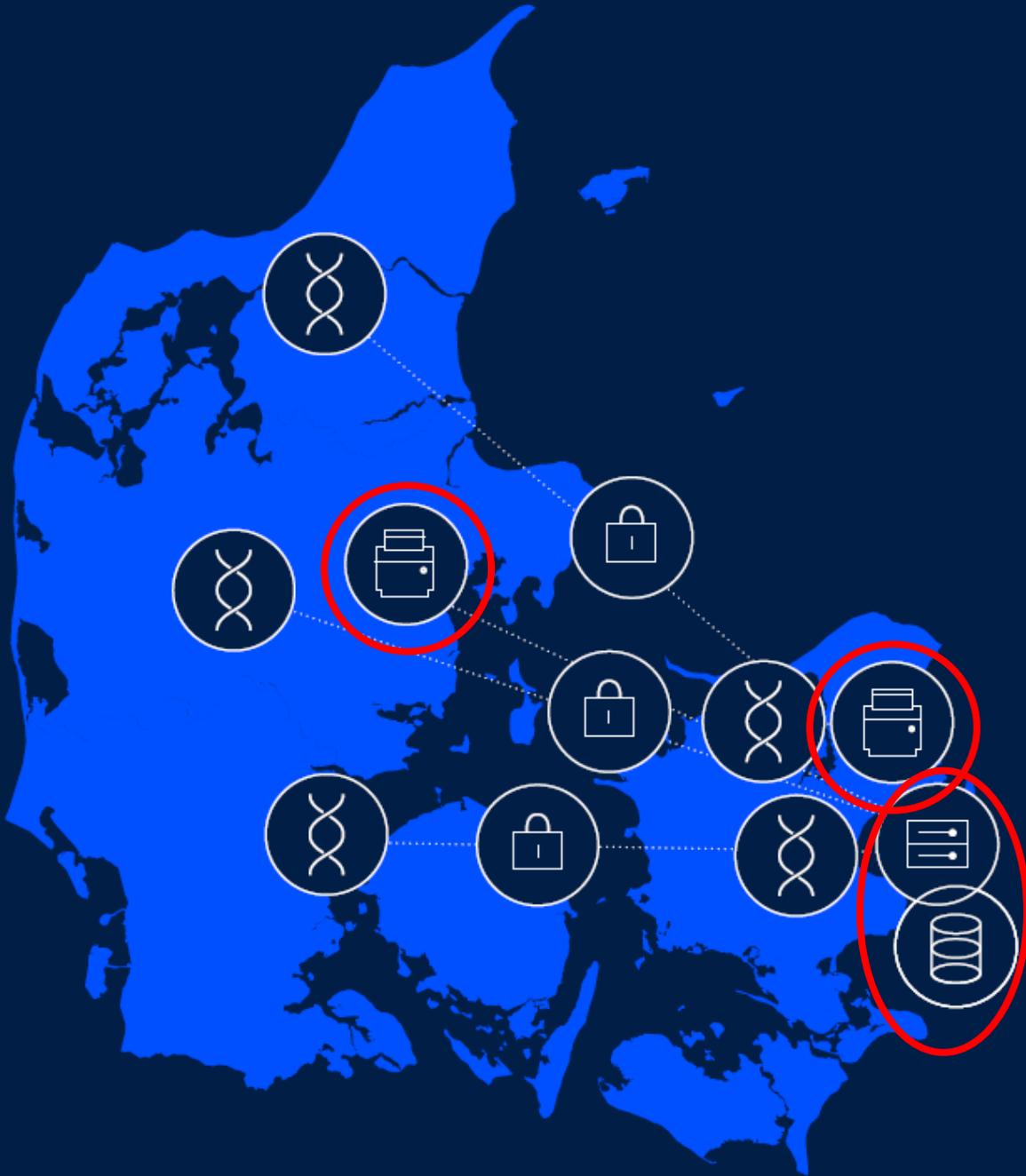
Secure connections



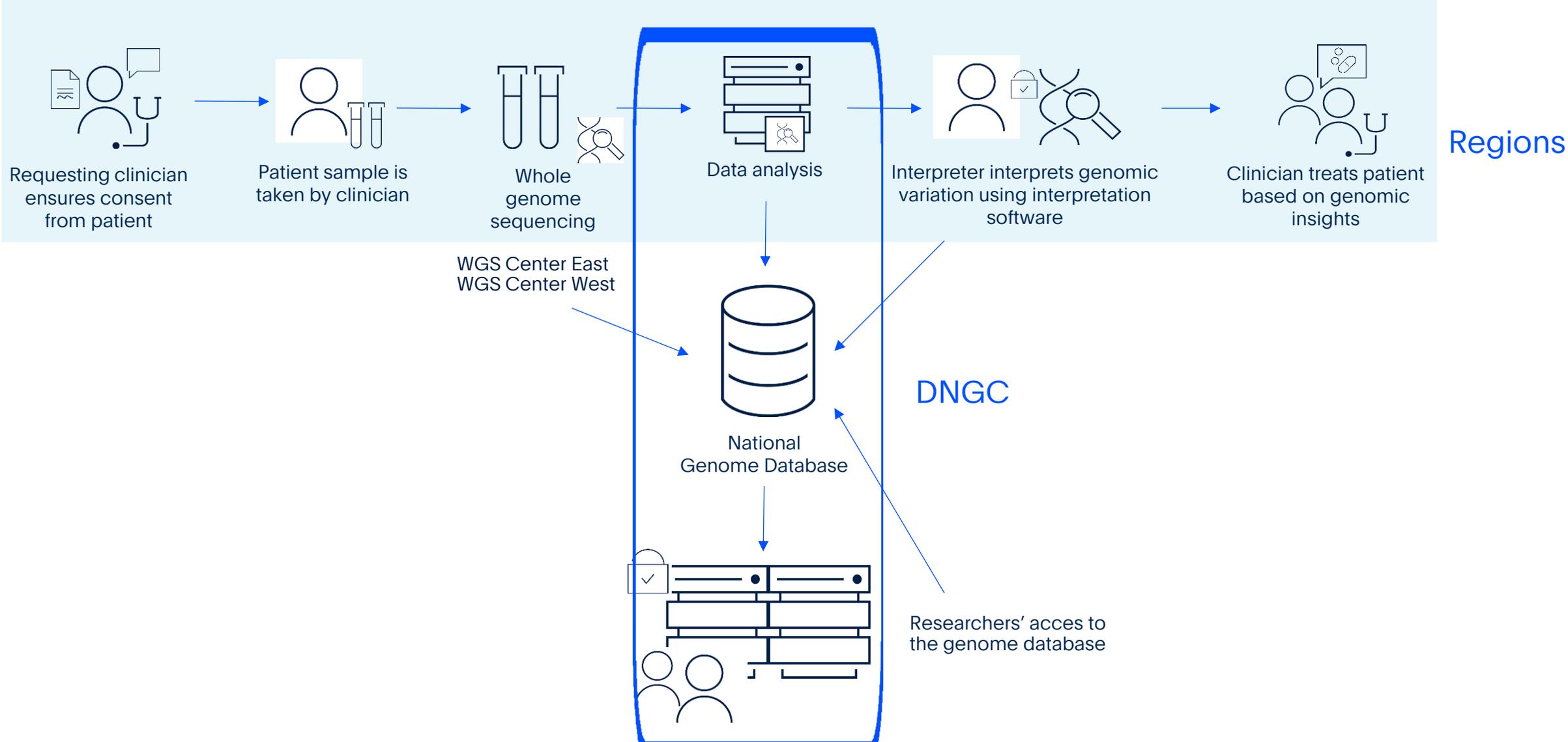
Interpretation



Storage



# Simplified WGS flow





# National implementation of WGS has contributed to

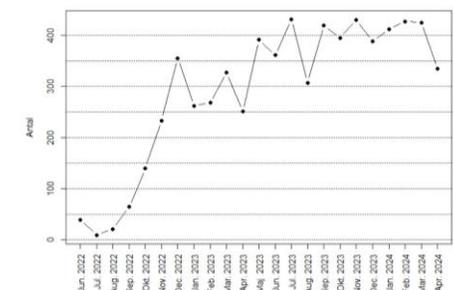
- A **consistent and systematic** offer nationally
- **Faster and more accurate** diagnosis
- More patients get the opportunity for **specific and targeted treatment**
- A **diagnosis is meaningful** for patients
- **Increased knowledge of genetics** in several medical specialties
- **Enriched collaboration** across the country
- **Research:** Storing genomes in a national database allows for reanalysis



## Internationale perspektiver belyst ved systematiske litteraturgennemgange

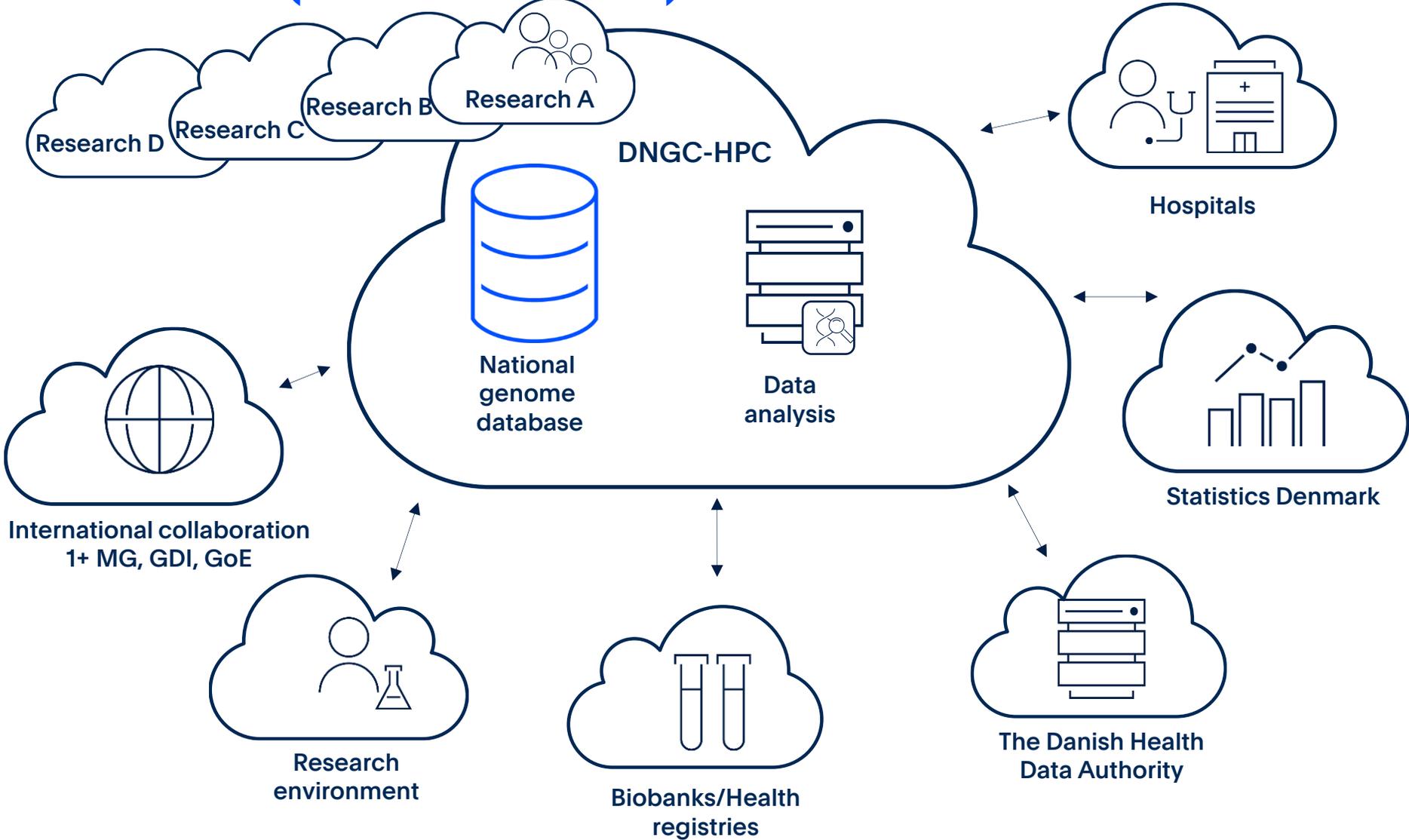
Nationalt Genom Center (NGC) har i samarbejde med specialitetsnetværkene, gennemført systematisk litteraturgennemgang for hver patientgruppe med det formål at indsamle international viden om klinisk effekt af helgenomsekventering for patientgruppen. Hver litteraturgennemgang bygger på referencer fra specialitetsnetværket samt søgning i PubMed-databasen efter nyeste videnskabelige litteratur. Metoden er inspireret af en anerkendt model til systematisk litteraturgennemgang (PRISMA) og tilpasset det aktuelle formål. Litteraturgennemgang for de 13 patientgrupper omfatter i alt 106 unikke publikationer, der belyser den nyeste internationale viden om klinisk effekt af helgenomsekventering til diagnostik af sjældne arvelige sygdomme.

## Prøver modtaget for patientgrupper med kræft

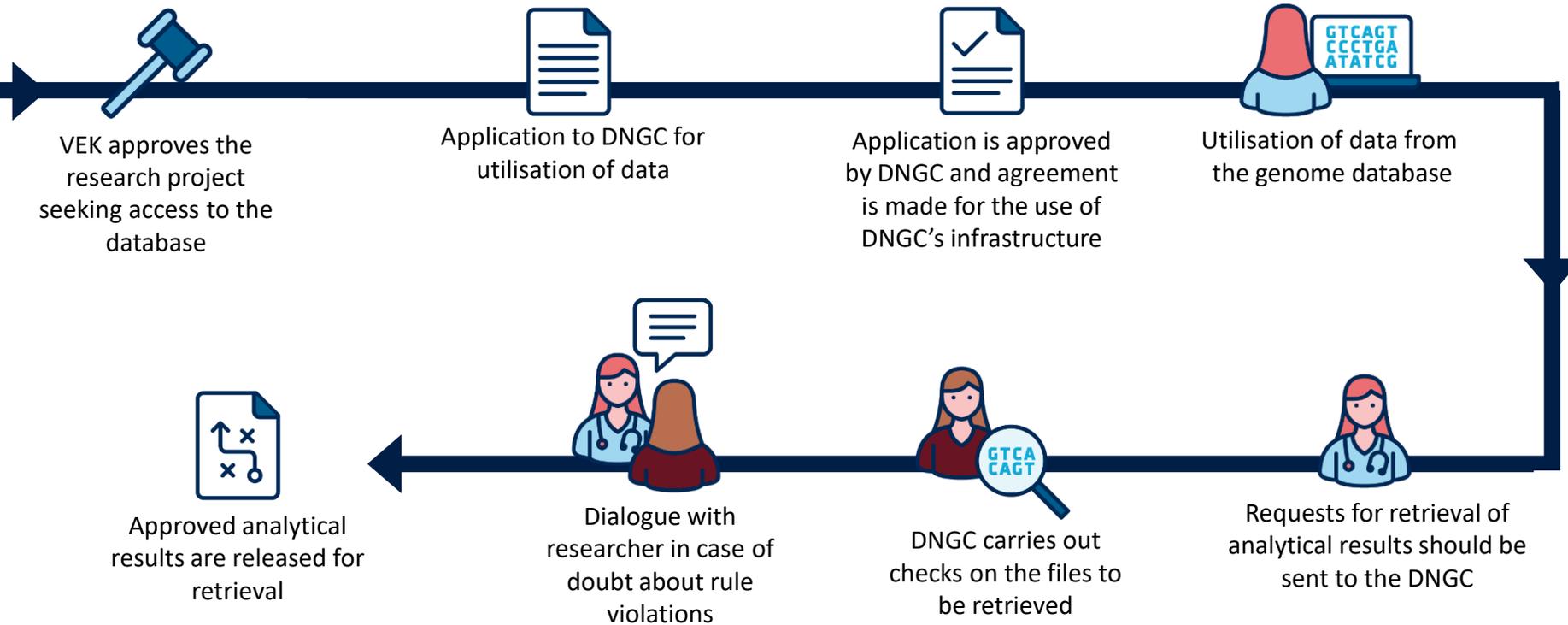


Figur 1 viser udviklingen i antallet af sekventerede prøver for de fire patientgrupper der omfatter patienter med kræft, herunder arvelig beløget kræft.

# Research access to Genomes and selected data sources (handhold)



# How to gain research access



# International collaboration is key



**Global Alliance**  
for Genomics & Health  
Collaborate. Innovate. Accelerate.



**Genome of Europe**



"It is through the research we conduct with the many that we can make a difference for the individual."

# Bilateral agreements

*Knowledge sharing, access to data, technical solutions, evaluation of clinical and economic effects*

## Genomic Medicine Sweden



## Genomics England



## French National Alliance for Life Sciences and Health



# Recommendations from Denmark

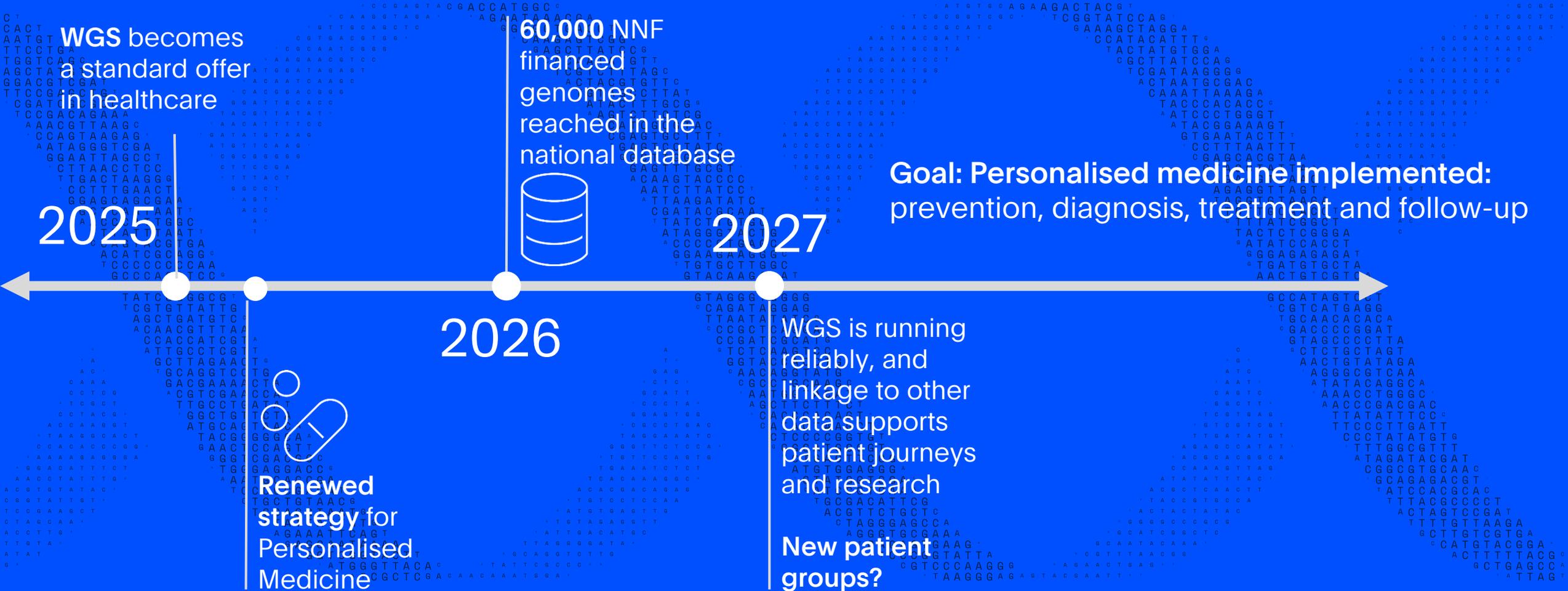
- **Work together** (policy makers, experts, national, regional, patients)
- **Centralize** as much as possible - but build an **inclusive governance**
- Follow **best** (international) **practices** – it is cost saving
- **Think smart** – prevention, diagnostics, reuse of data
- **Access to data** is mandatory - and evaluate continuously
  - \* **Clinical evidence**
  - \* **Economic impact**
- **Take your time** – a large and time-demanding task
- **Legislation and solid agreements** among partners is an imperative before you start
- **Sustainable financing** in place early



*The Danish strategy for Personalised Medicine, 2021-2022*

# Chapter 2

## New strategy - Prevention





**Strategi  
for personlig  
medicin  
2025 – 2027**



# Focus areas



Patient centricity



Personalised medicine is more than genomes

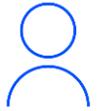


Prevention



Research: Better use of Denmark's unique health data for the benefit of patients and healthcare

# Strategy Ambitions



**Patient first:** Ensure that the patients preferences, values, and personal circumstances are actively considered in illness prevention and treatment.



**Strengthen research frameworks in personalised medicine:** Create stronger frameworks for research in personalised medicine so new knowledge is quickly translated into patient benefits.



**Make Denmark a leader in advanced therapies:** Strengthen Denmark's position as one of the leading countries in Europe in developing, testing, and offering advanced therapies as a part of patient care, so that patients gain faster access to the most effective treatments.



**Free up resources in the healthare system:** Improve treatment quality and ensure a more cost-effective use of resources through data-driven prevention and treatment targets.



**Strengthen Denmark's biobanks and health databases:** Ensure that data can be used even more effectively and across sectors – for the benefit of patients and world-class research.



**Improve the use of health data and artificial intelligence:** Harness the potential of Danish health data and AI to tailor treatments to each individual.



**Broaden the application of personalised medicine across the healthcare system:** Give more patients access to the opportunities that personalised medicine provides.

# Chapter 3

## The new Danish Ecosystem

### Objective: Smarter use of data

The Vision for  
better use of  
Healthcare data  
Funded by NNF



2028

2030

2025-2027



Continued  
strategic focus  
and investment.  
Sustainable  
operation and  
development



A future where  
treatment is tailored  
to each individual  
patient

# Still a long way to go - significant challenges ahead of us...

Overview of available data sources



Combining infrastructure and data sources while maintaining data security and trust



Multiple authorities, multiple applications



European Health Data Space – an ambitious regulatory framework

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# The Ecosystem: Access and Inter-connection

## The Danish Ecosystem for data



One single point of contact



National platform for analyses

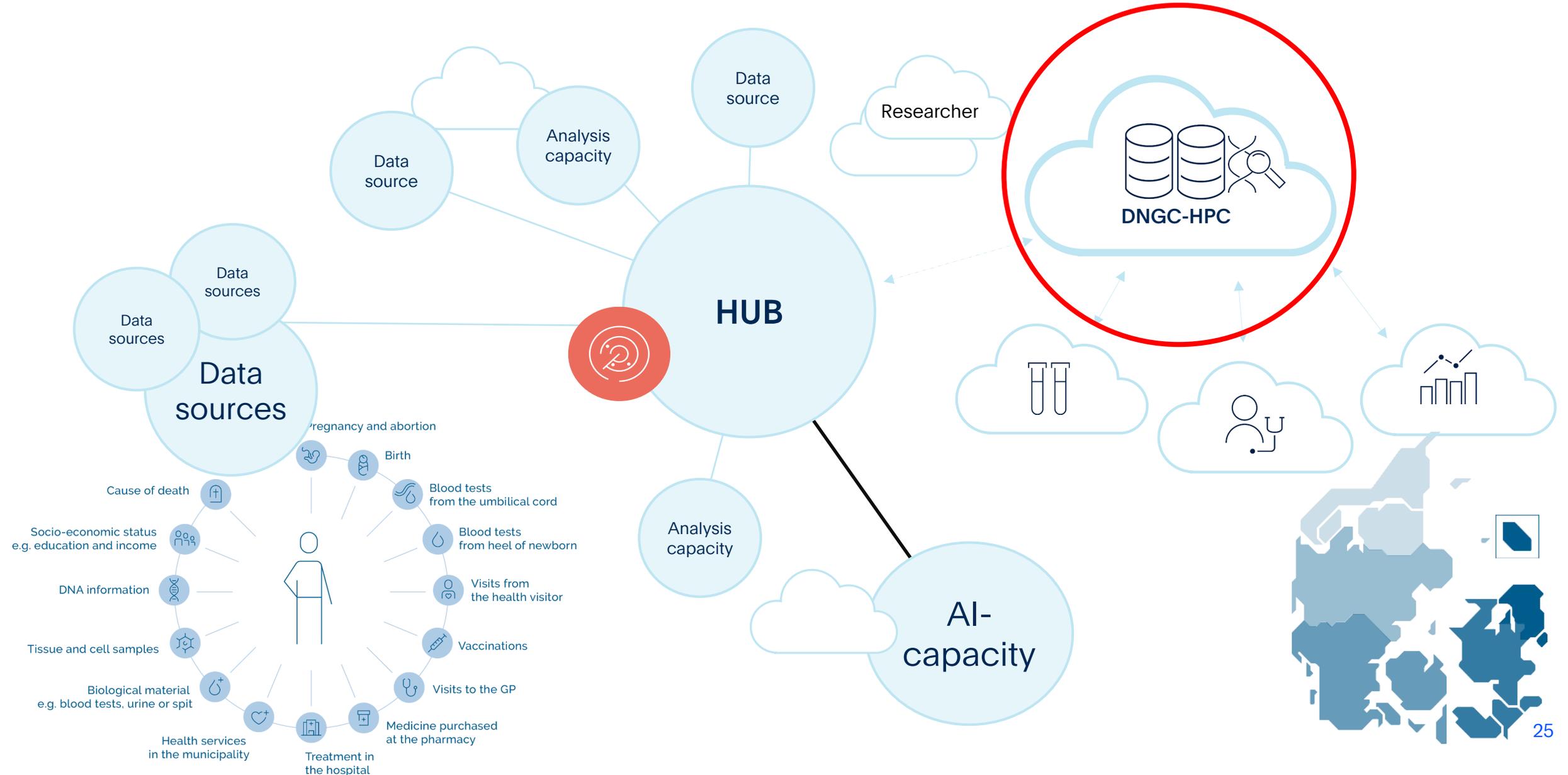
Danish National Genome Center



Expected to be  
DK HDAB

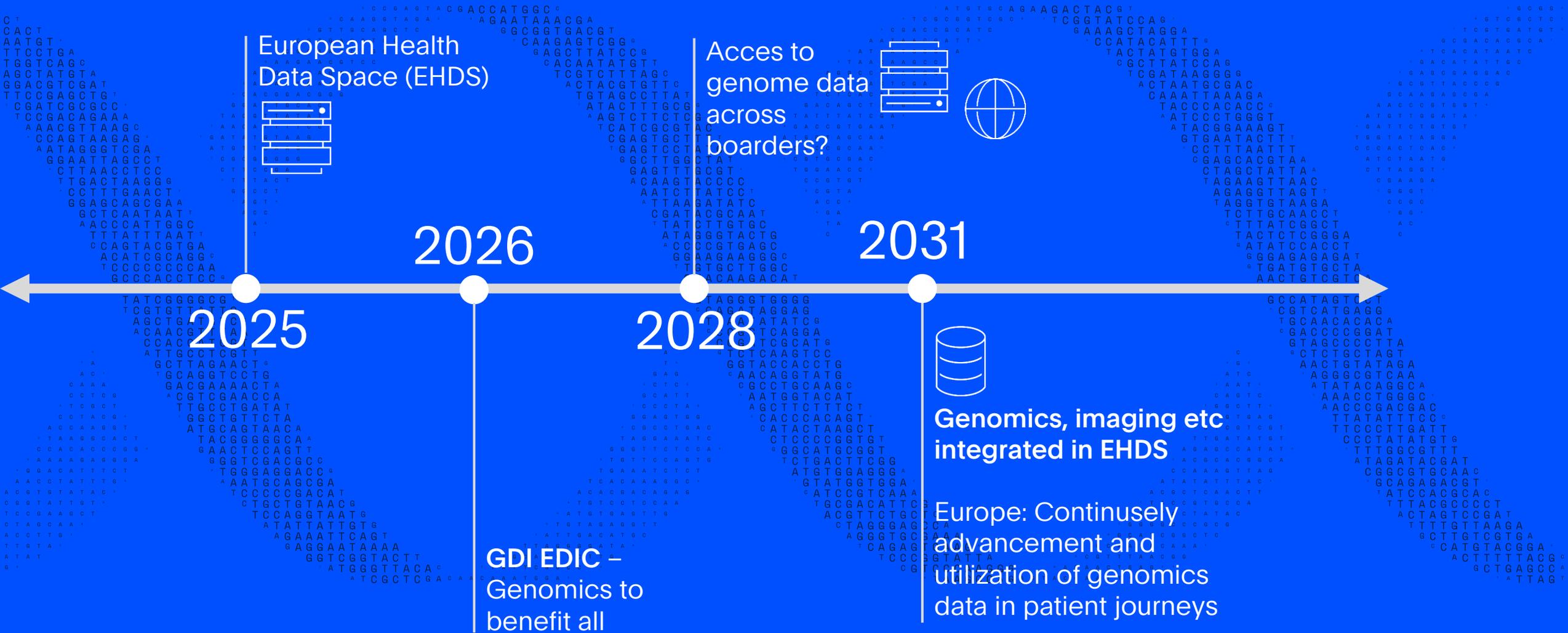


# A Danish Ecosystem – a national collaboration



# Epilog

## What does the future hold?





Together, we develop and  
implement personalised medicine

Thank you to our patients and  
collaborators nationally and  
internationally