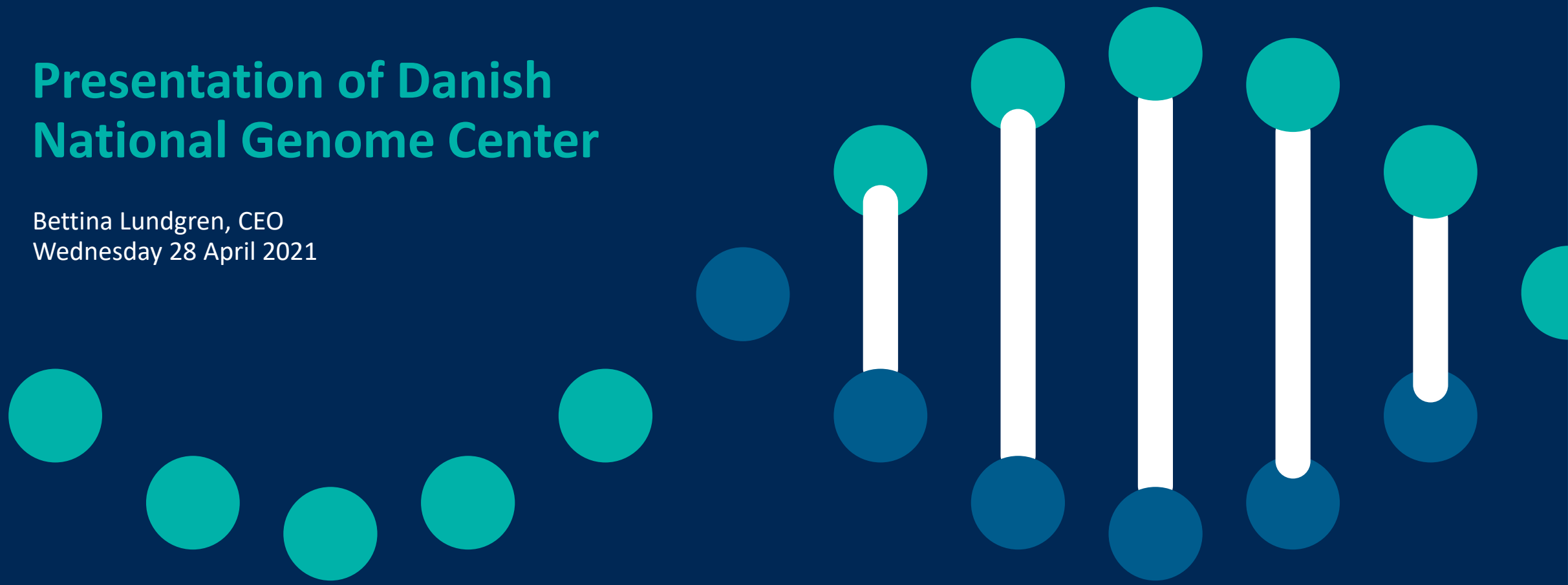
DANISH NATIONAL
GENOME CENTER

# Presentation of Danish National Genome Center

Bettina Lundgren, CEO
Wednesday 28 April 2021



# Bettina Lundgren, CEO, Danish National Genome Center

Bettina Lundgren, CEO, M.D., D.M.Sc.

**Profile**

- Clinical microbiology specialist and doctor of medical science (DMSc) from the University of Copenhagen.
- Strong leadership profile, in-depth knowledge of the Danish healthcare system and extensive clinical experience from a range of clinical departments.
- Chair and member of numerous committees, including several clinical health and large regional and national healthcare IT-system and quality initiatives.

**Curriculum vitae**

- CEO of Danish National Genome Center
- Centre director, Diagnostic Centre Copenhagen Rigshospitalet, University Hospital
- Head of department, Hvidovre Hospital, Department of Clinical Microbiology
- Head of department and consultant - Statens Serum Institut (SSI), Department of Mycobacteriology

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# About Danish National Genome Center

# NGC is building on strengths that are unique for the Danish set-up


- **Focus on treatment and diagnosis of patients**
- **Broad political support and state anchoring** under the Ministry of Health
- **National Strategy**
- **Broad support from regional healthcare system, The Organisation of Danish Medical Societies and universities**
- **Law on data reporting** of comprehensive genetic analyses to NGC
- **Financial foundation through financing** from the state, existing regional funds, the Novo Nordisk Foundation and others (e.g. research funds in the future)
- **Strong tradition** for registration of data in **health registries and biobanks**

# NGC supports further development of Personalised Medicine

**Vision**
To support further development of a more precise diagnosis of patients and target treatment more accurately with access to state-of-the-art whole genome sequencing and to develop a platform for state-of-the-art research.

**Mission**
To develop a secure and state-of-the-art infrastructure in operation across Denmark with access to state-of-the-art whole genome sequencing and personalised medicine.

# Danes support the use of genetic testing

- **84** pct. of Danes are positive towards getting genetic testing

- **75** pct. of Danes consider research in genetic data important or very important
  **3** pct. find it unimportant

*Citizen survey December 2019 (prepared by external company at the request of the Patient & Citizen Committee)

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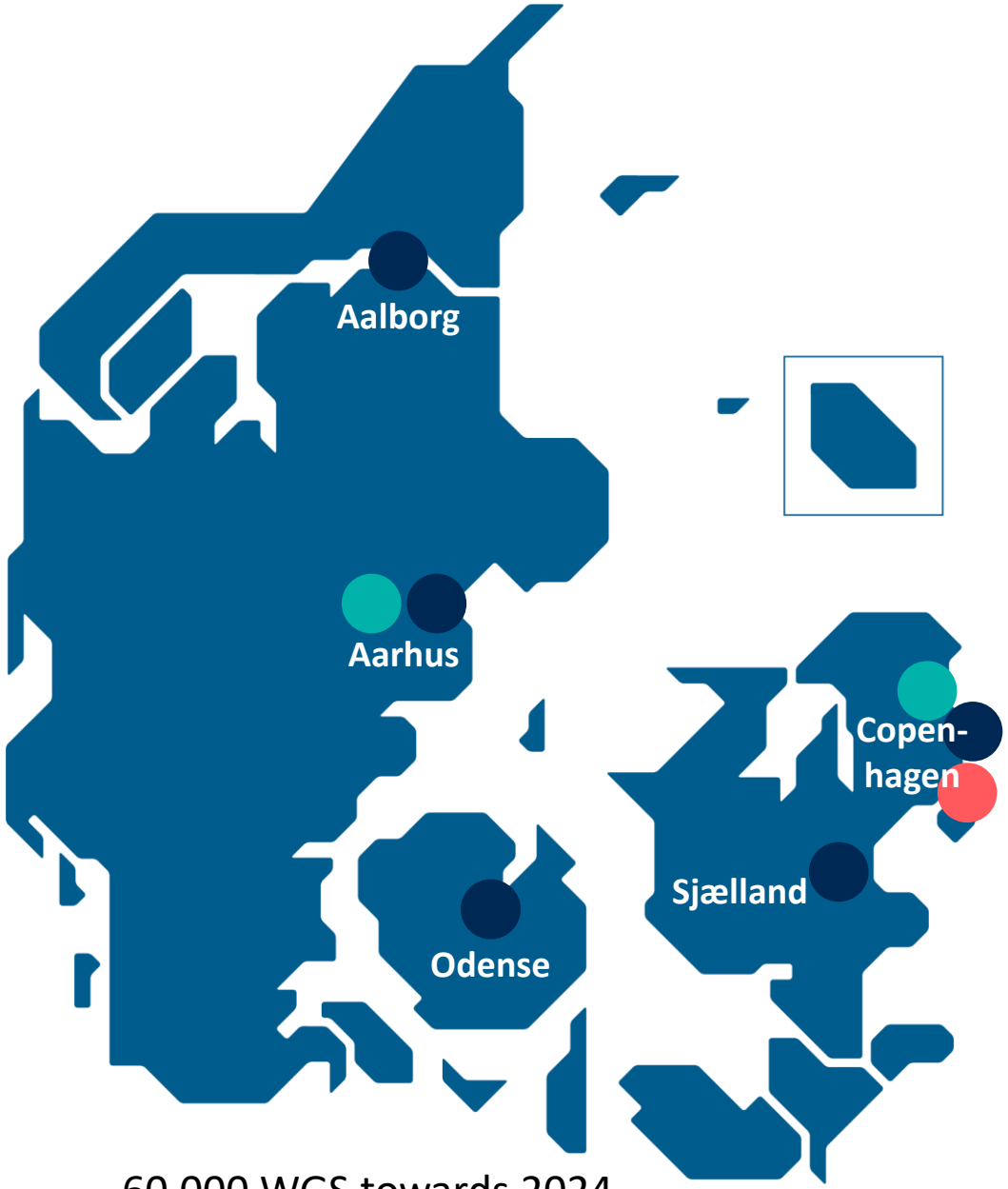
# Infrastructure

# Danish National Genome Center: Infrastructure for Personalised Medicine

- Transformation of the healthcare system
- National standardisation
- Equal access

Collaboration with Aarhus (MOMA) and Copenhagen (GM)

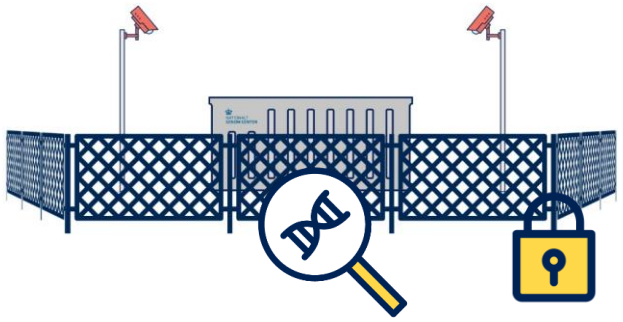



60.000 WGS towards 2024

University Hospitals

National WGS center East and West (Head Office Aarhus)

Danish National Genome Center

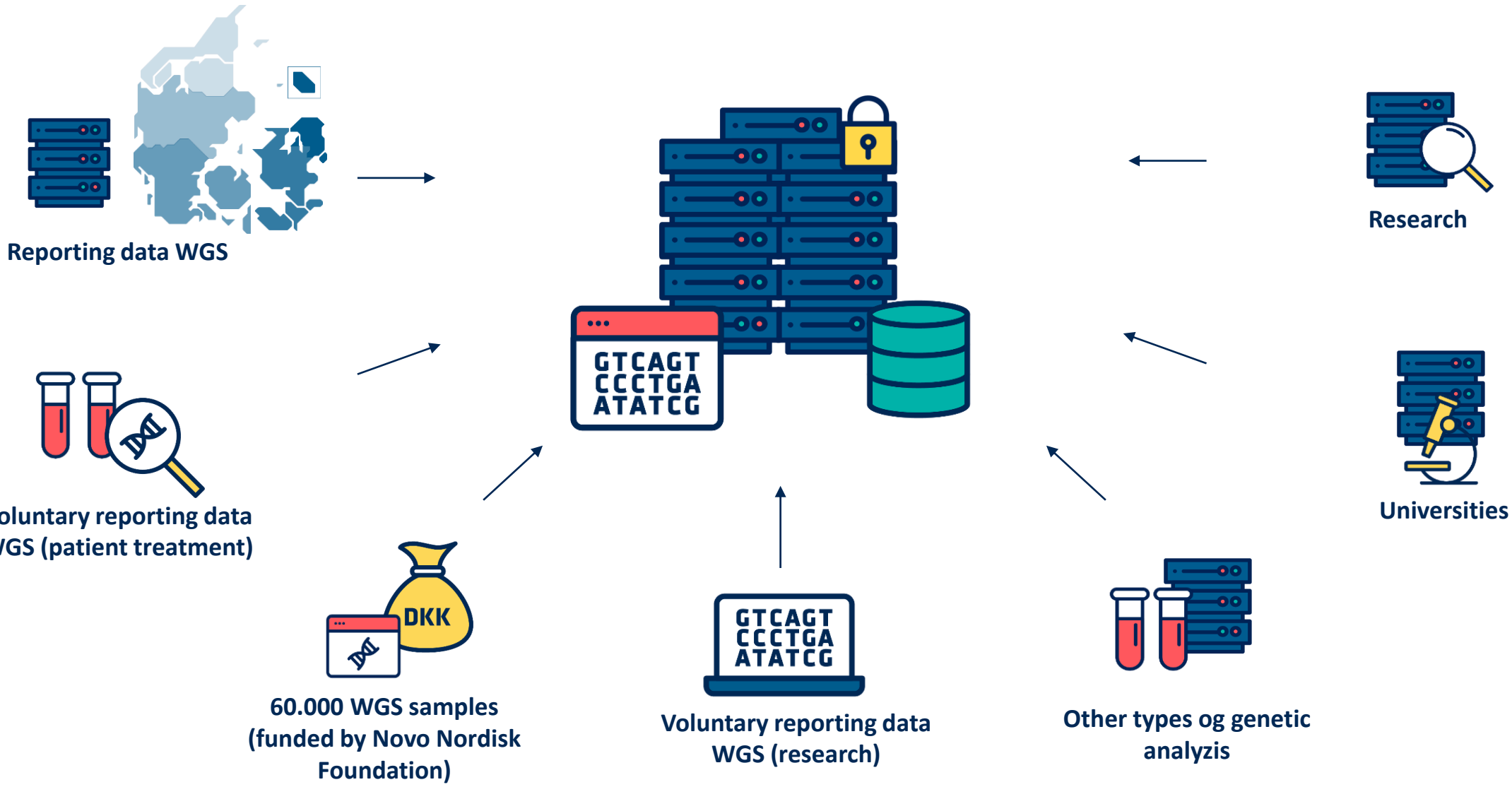


Collaboration with Danmarks Tekniske Universitet and KU

# Selected patient groups

1. Rare diseases in children and young people under 18 years
2. Hereditary haematological diseases, incl. children and young people under 18 years with unresolved cytopenia
3. Haematological cancer
4. Endocrinology patients
5. Cancer in children and young people under 18 years and hereditary cancer in adults
6. Incurable cancer
7. Primary immunology
8. Hereditary heart diseases
9. Kidney failure
10. Rare diseases in adults over 18 years
11. Neurogenetic patients
12. Fetal medicine
13. Psychiatry (children and young people under 18 years)

# Sequencing data to the national genome archive



# Research access to NGC-”Private cloud”

- Research governance
- Research service
- Agreements
- Public Cost models
- Non-binding mapping of interests
- NGC ”Private Cloud” launched ultimo 2021

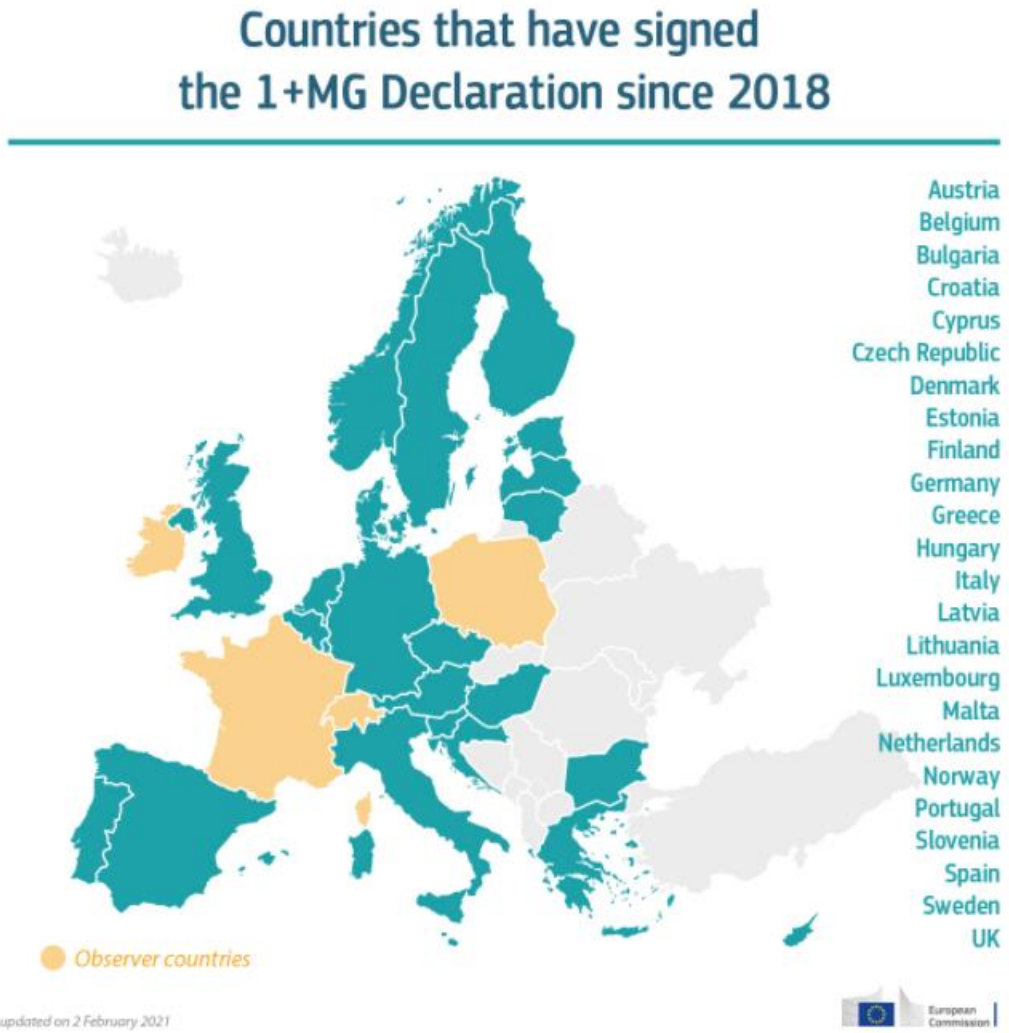
# How to get research access to the data in NGC databases?

- Access for all certified research institutions
- All companies can 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 requires research ethics approval
- Pseudonymous  data

# Denmark has joined 1+ Million Genomes Initiative

Various objectives. Among these, are:

- Appropriate technical infrastructure is available across the EU, allowing for secure, federated access to genomic data
- Ethical and legal implications of genomics are clear and taken into account
- The general public and policy makers in Member States and signatory countries are well informed about genomics, in order to ensure its uptake by healthcare systems and integration into personalised healthcare.



# Contact

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**News**

- Ngc.dk under Nyheder : https://ngc.dk/nyheder/
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# Thank you for the attention