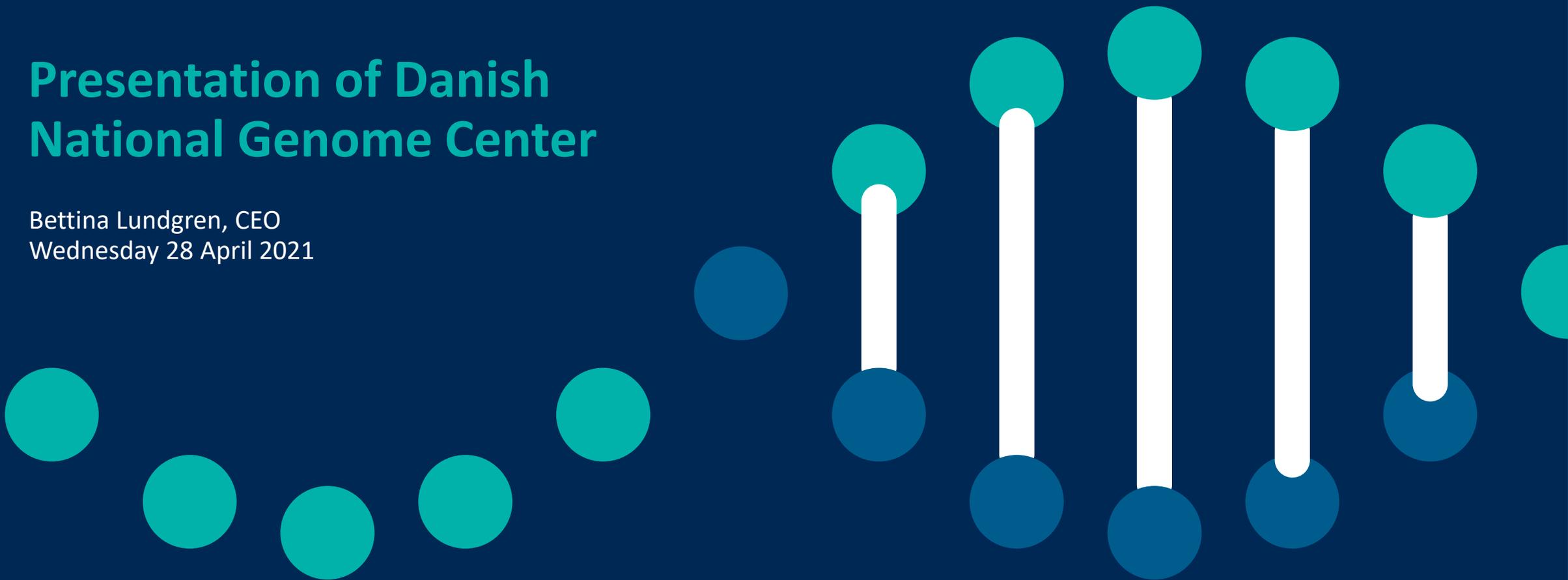


Presentation of Danish National Genome Center

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

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)



Infrastructure

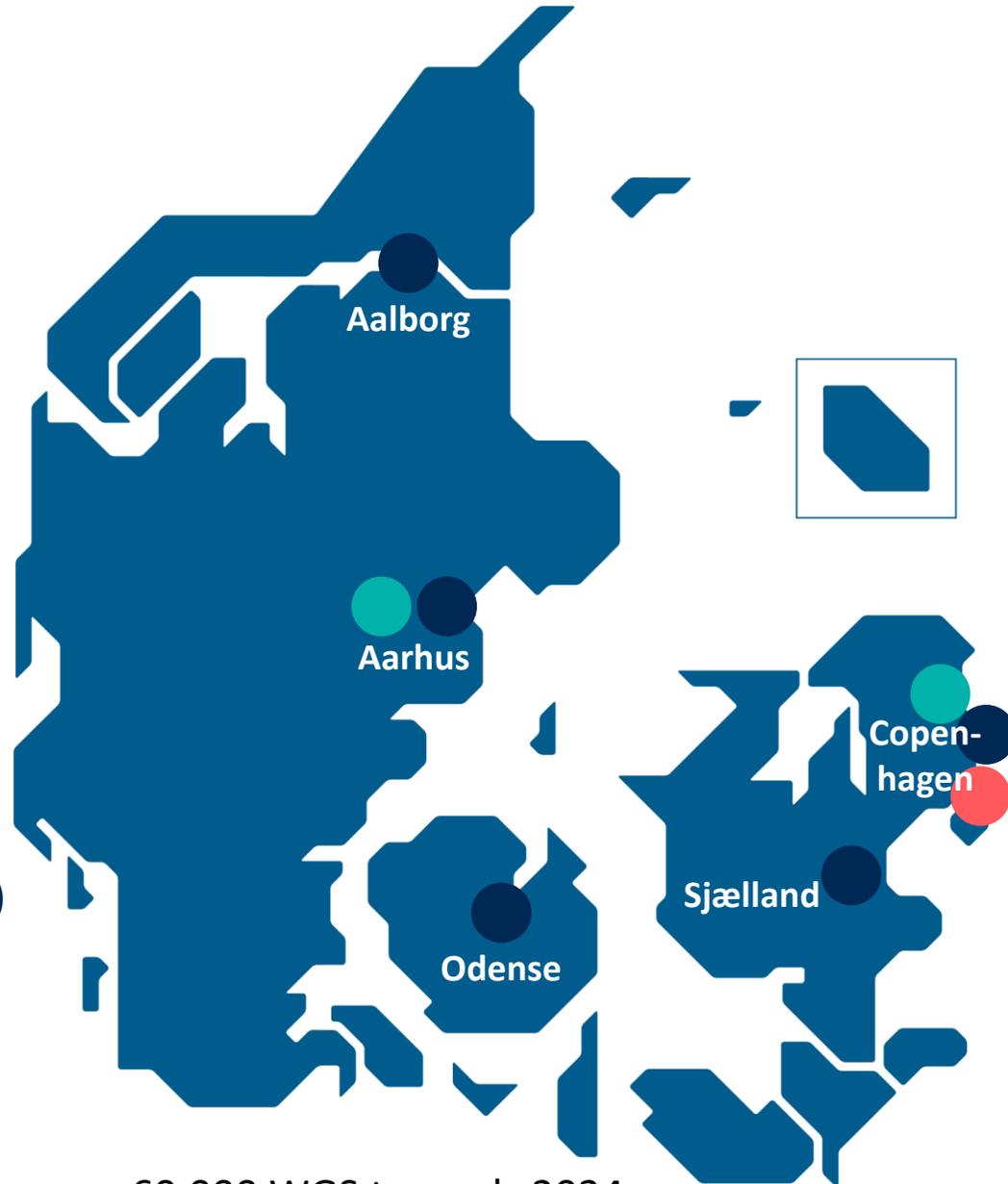


Danish National Genome Center: Infrastructure for Personalised Medicine

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



Collaboration with Aarhus (MOMA) and Copenhagen (GM)



- University Hospitals
- National WGS center East and West (Head Office Aarhus)
- Danish National Genome Center



Collaboration with Danmarks Tekniske Universitet and KU

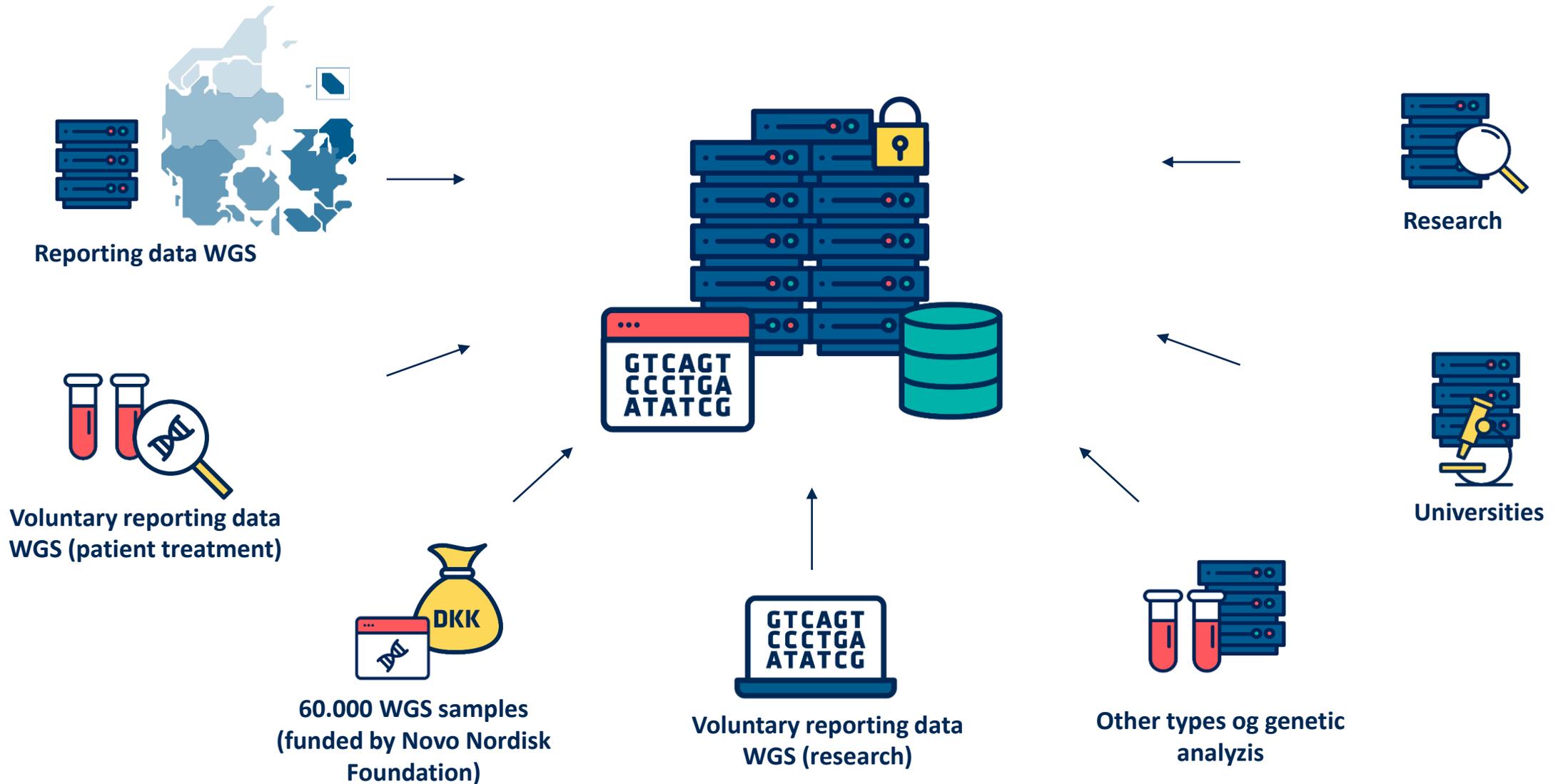
60.000 WGS towards 2024

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

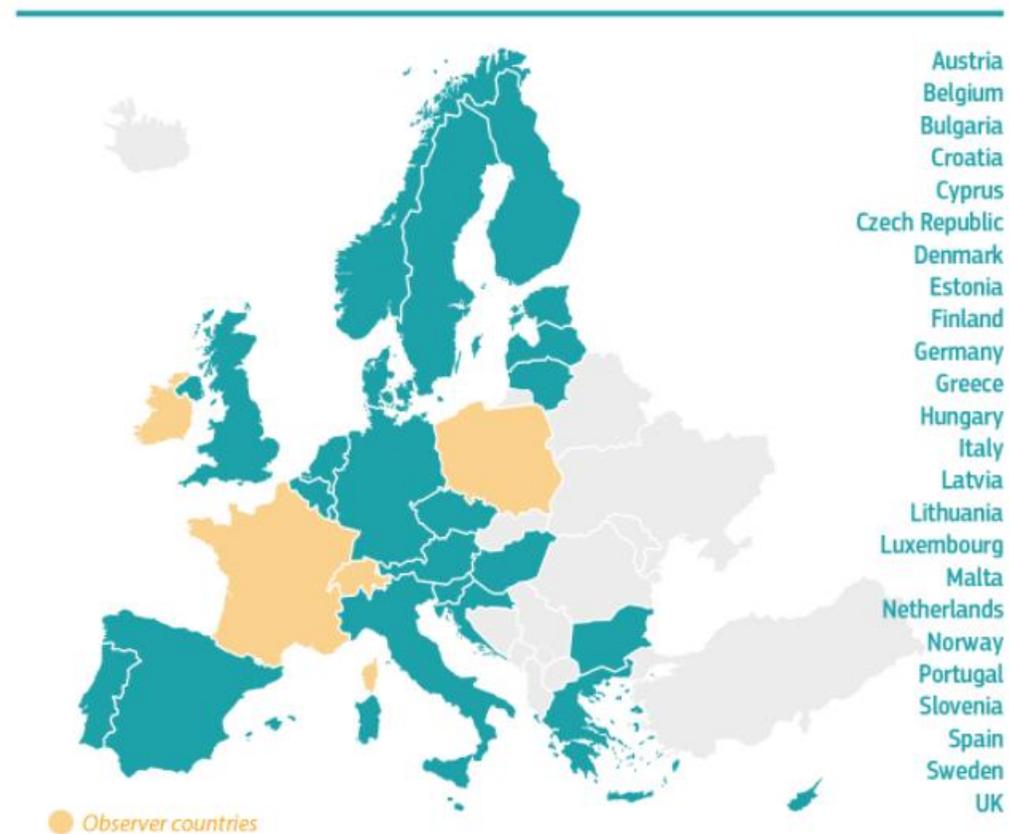


Denmark has joined 1+ Million Genomes Initiative

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.

Countries that have signed the 1+MG Declaration since 2018



updated on 2 February 2021

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News

- Ngc.dk under Nyheder : <https://ngc.dk/nyheder/>
- Eng.ngc.dk under News: <https://eng.ngc.dk/news/>



Personlig Medicin til gavn for patienterne

Fremtidens behandling er skræddersyet til den enkelte patient. Det kaldes personlig medicin eller præcisionsmedicin. I Nationalt Genom Center arbejder vi for at understøtte, at læger og forskere ved hjælp af viden om patienters gener og sygdommes årsager kan udvikle skræddersyet behandling.

[Se filmen om Personlig Medicin >](#)



Om teknologien bag

Mød supercomputeren >

Danmarks nye supercomputer stiller sin regnekraft til rådighed for alle landets hospitaler, og giver mulighed for, at mange af fremtidens patienter kan se frem til mere præcise diagnoser, bedre behandling og høj datasikkerhed.

Den giver læger og forskere mulighed for at inddrage genetiske data i forskning, der skal gøre os klogere på sygdomme og føre til nye eller forbedrede behandlinger.

[Læs mere om supercomputeren](#)



Om udvælgelse af patientgrupper

Hvordan vælger vi patienter, der skal tilbydes analyser? >

Sundheds- og Ældreministeriet har fået en rammebevilling fra Novo Nordisk Fonden, så det danske sundhedsvæsen kan tilbyde 60.000 omfattende genetiske analyser over de næste 4½ år til danske patienter via Nationalt Genom Center. Men hvordan arbejder vi med at udvælge patientgrupper, der skal have gavn af den nye infrastruktur? Det kan du læse mere om på vores side, som er dedikeret til sundhedsfagligt personale.

[> Læs mere om arbejdet med at udvælge patientgrupper.](#)



Om at være patient

Er du patient? >

Nationalt Genom Center opbevarer din genetiske oplysninger, hvis du får foretaget en omfattende genetisk analyse som led i din behandling. Centeret sørger for, at oplysningerne opbevares sikkert og er til rådighed for det sundhedsfaglige personale, så de kan give dig optimal behandling.

Centeret har også ansvaret for den samtykkeblanket, lægen skal bruge, og som du skal underskrive, før lægen kan gennemføre undersøgelsen, og for den skriftlige information, du får udleveret.

Vi har samlet de mest relevante informationer og blanketter fra Nationalt Genom Center, så du bedre kan få et overblik.

[> Læs mere om at være patient](#)

**Thank you for the
attention**

