DANISH NATIONAL
GENOME CENTER

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Minutes

5th meeting in DNGC's international advisory board

Date: October 28, 2025 **Chair: Tim Hubbard**
Location: Online **Meeting secretary: Astrid Pedersen**

Item	Time	Topic	Presenter
1/7	15.00	Welcome and introduction	Tim Hubbard/All
2/7	15.10	Updated Terms and References and Rules of Procedures	Lene Cividanes
3/7	15.15	The future of DNGC • New strategy for personalised medicine • New organisation from 2026	Bettina Lundgren Lene Cividanes
4/7	15.30	The role of DNGC in the future	All
5/7	16.00	Use of data from the genome database	All
6/7	16.30	Reporting of data from research	All
7/7	16.55	Closing remarks	Tim Hubbard

Participants

Tim Hubbard (Chair)
Richard Rosenquist (Vice Chair, not attending)
Ruben Kok
Valtteri Wirta (not attending)
Heidi L. Rehm
Kym Boycott
Dag Undlien
Aarno Palotie
Julien Thevenon
Bartha Knoppers

Bettina Lundgren, NGC
Lene Cividanes, NGC
Astrid Munk Pedersen, NGC

Item 1/7 – Welcome and introduction

Two new members of the board were introduced - Julien Theveon and Bartha Knoppers.
They have both been invited to onboarding meeting, to learn more about DNGC.

Item 2/7 – updated Terms and References and Rules of Procedure

Lene Cividanes presented the few changes made to the Terms and References and Rules of Procedure, to reflect that DNGC is now a part of the Danish Health Data Authority.

Both documents were approved by the advisory board

Item 3/7 – The future of DNGC

Lene Cividanes and Bettina Lundgren presented the following to the advisory board

New governance for DNGC
DNGC has played a vital role in the implementation of WGS in the clinical setting in Denmark. However, the role of DNGC has now changed as DNGC no longer is coordinating the collection of WGS data – this is done within the Danish regions. DNGC is still collecting the genome data. Therefore, the renewed DNGC mandate is to run the HPC, store genome data, operate the genome database, and make data available for clinicians and researchers. DNGC is still responsible for engaging in collaboration with relevant international initiatives.

To reflect the new role of DNGC a new governance for the genome database has been established. DNGC's international advisory board is still part of the governance. The idea of the governance is to advise and make decision regarding the genome database.

DNGC has been merged with the Danish Health Data Authority
As of July 1, DNGC has become part of the Danish Health Data Authority. This has led to a new organisation within the Danish Health Data Authority, that will take effect from January 1, 2026.
Bettina Lundgren will be deputy director for the new area called 'Research and data infrastructure'. This consists of three departments, one being 'Research and genome center' with Lene Cividanes as department head.
For more details see the meeting presentation sent with the minutes.

The vision for better use of health data and the Danish Health Data Access body
With the vision for better use of health data Denmark aims to make it easier for researcher to gain access to health data from different data sources across the country. The idea is that you can access data from different sources in a federated system via one single (national) point of contact, which also will serve as HDAB within EHDS.

Digital Health Denmark
The merger with the Danish Health Data Authority is a first step towards a new big authority called “Digital Health Denmark”. This is a new Danish authority decided by the Danish government where different bodies working with health data and digitalisation will be consolidated.
The process for the consolidation will be developed in 2026, and as of January 1, 2027 Digital Health Denmark will be established.
The purpose of this new organisation is, among others, to collect and develop integrated health data for patient care, research, innovation, statistics, and management and to ensure unified access to health data for research.

Strategy for Personlised Medicine:
The Danish Government and Danish Regions have presented a new national strategy for personalised medicine.
For DNGC an important part of the strategy is that it has defined two initiatives regarding the establishment of a national variant database and a national frequency database.

Key points from the advisory board
- The advisory board pointed out the importance of involving the scientific community and the ministry of science in the work with Digital Health Denmark.
- This is to ensure, that the data collected and solutions developed are relevant for researchers.

<u>Comments from DNGC:</u>
- The ministry of science is not involved however, the research community is a strong part of DNGC’s governance, and therefore DNGC will bring the researchers point of view in to the organisation.
- The Vision for better use of health data also has a good collaboration with the researchers.

Item 4/7 – The role of DNGC in the future

Background

DNGC has now transitioned from a setup-phase to an operational phase. We have successfully implemented WGS in the clinic and data is being reported to the national genome database. The focus is now on running a supercomputer, running the genome database and making data available for researchers and clinicians. However, should this be the only role of DNGC or should we still have focus on other tasks such as for example facilitating implementation of WGS for more patient groups, connection of genome data with other data sources and promoting personalised medicine?

Key points from the advisory board

- The 17 patient groups are well chosen. Denmark should conduct ongoing evaluation of the effect of WGS within the 17 patient groups and only add/remove groups when evidence is found.
- The genomic data should be connected with clinical data, including primary data (clinical notes). The more data the better as this is essential for making use of the genetic data.
- A variant and a frequency database will add great value for both clinicians and researchers. Clinicians want information about how other clinicians have interpreted and treated patients with the same variant and disease.
- The genome database needs to be part of a cohort explorer, to make it possible for researchers to find if relevant data is available.

<u>Comments from DNGC</u>

- Researchers already have the possibility to gain access to clinical data including patient records. However, it is a complicated and sometimes long process. With the vision of better use of health data, it will be easier to gain access to data and to combine data from different data authorities.
- Within the vision for better use of health data a cohort explorer will be developed.
- DNGC is working with the Danish regions on establishing a frequency database, that will be made available on DNGC's infrastructure.
- The Danish regions have started an initiative on establishing a national variant database.

Item 5/7 – Use of data from the national genome database

Background

The reporting of WGS data from the clinic has been successfully implemented and the national genome database now contains over 50.000 genomes. The point of storing the data is to make it available for both clinicians and researchers therefore, we need to make sure that data is useable for the clinicians and researchers.
DNGC is subject to legal requirements that data must not leave the infrastructure, which imposes certain limitations on how data can be used. This also imposes challenges on connecting data with other data sources.

Key points from the advisory board

- DNCG could consider having different data models within each disease group stating which meta data should be reported, as what is relevant can vary between disease groups.
- DNGC should provide summary data and/or a cohort explorer, as it will make it possible for researchers to see if the database contains relevant data before they start the process of gaining ethical approval.
- DNGC should connect with clinical and research communities to promote use of data and ensure relevant data is available. E.g. the ERDERA project (rare diseases) and the Candle Project (project helping to establish the European network of cancer data nodes)
- To give value the genomic data needs to be combined with clinical data – this can be done by connecting with other data registries.
- It would be of great value for the clinicians to have a platform to share variant and phenotype data in a structured form. And not just nationally but internationally.
- EHDS will provide easier access to electronic health records, so DNGC could look into what possibilities this will give researchers.

<u>Comments from DNGC:</u>

- The vision for better use of health data is working on connecting data from different registries. However, a challenge is the data not reported to the registries e.g., patient journals.
- The vision is also a vital part of Denmark becoming a part of EHDS and making it possible to share data in EU.

Item 6/7 – Reporting of data from research

Background
DNGC aims to make it possible for researchers to report genomic data from research projects to the genome database. Data from research projects are more differentiated than data from the clinic and therefore it is important to establish requirements for the reported data. This is especially important in regards to metadata. But what type of requirements should be established for the data, and should there be an embargo period on the data?

Key points from the advisory board
Meta data:

- DNCG should look into GA4GH and follow their data standards
    - https://ga4gh.github.io/quality-control-wgs/metrics_definitions/
    - https://www.ga4gh.org/product/data-use-ontology-duo/
- It is important to have an indication of ethical approval, and maybe have a system to code data according to the consent that states what the data can be used for.

Embargo period:

- In general, no embargo period is recommended, as it is a very administrative heavy task to manage.
    - However, it could be implemented in the beginning to make sure researchers report data. But make sure the period is not too long (maximum one year).
- As DNGC offers free storage of the reported research data, it is fair to say, that data must be shared without an embargo period.
- DNGC could look into how EHDS is going to handle embargo periods.

Item 7/7 – Closing remarks

Next meeting will be held in the spring of 2026.