

Terms of Reference: The DNGC's International Advisory Board

13-08-2025

Background

The Danish National Genome Center is part of the Danish Health Data Authority which is a Danish government agency under the Ministry of the Interior and Health. The primary task for the Danish National Genome Center is to run a national genome database and develop a national research infrastructure that can support the further development of personalised medicine in Denmark.

Research in and development of personalised medicine including the field of genomics is an area in constant development. Considerable advance is occurring both in Denmark and internationally. The Danish National Genome Center has a need for advice and the exchange of ideas from the utmost international experts, in order to ensure that the most recent knowledge in the field is involved with, and accommodated in the development of the Danish National Genome Center's infrastructure, and offers to patients, clinicians and researchers.

On this basis, an international advisory board has been established in order to advise the Danish National Genome Center about relevant tendencies, experiences and knowledge within the development of personalised medicine, including genomics and knowledge about development of technological infrastructure for personalised medicine.

Purpose and tasks

The international advisory board has been established under the Danish National Genome Center. The international advisory board shall advise the Danish National Genome Center within the framework of these Terms of Reference.

The international advisory board's role is to advise the Danish National Genome Center about relevant tendencies, experiences and knowledge within the field of personalised medicine, particularly genomics and the technical infrastructure used in the development of personalised medicine. Moreover, advisement of the development within relevant international and national initiatives related to the field of personalised medicine.

The advisory board's tasks can consist of:

- Be an external, impartial and critical collaborator for the Danish National Genome Center regarding questions, issues or topics of a strategic nature as well as the Danish National Genome Center's future development
- Advise the Danish National Genome Center about relevant international experiences, knowledge and tendencies within the field of personalised medicine
- Assist with reviews of reporting, implementation and exploration of development opportunities as well as international cooperation opportunities
- Advise about the development of the Danish National Genome Center's technological infrastructure (HPC)
- Interaction with clinic, patient, healthcare and research
- On the basis of international experience advise on ethical and legal issues
- Ensure that experiences from national initiatives from other countries as well as international initiatives are shared with the Danish National Genome Center

The advisory board raises issues for discussion at the request of and reports to the Danish National Genome Center. The National Board for the Operation of the Genome Database may request of the Danish National Genome Center to discuss specific topics or issues within the advisory board.

The advisory board's members

It is imperative for the advisory board's work that the members have a new and significant insight, knowledge and experience with research and development of infrastructure, as well as knowledge of large national and international programmes and efforts within the field of personalised medicine. The composition of the board must reflect relevant disciplines within the Danish National Genome Center's area of work, with a special focus on research in personalised medicine and infrastructure development. Thus, all members must have relevant expertise in relation to the board's purpose, and within at least one of the subject areas listed below.

Subject areas:

- Leading representatives from major national initiatives (at least one Nordic and one European) and major supranational initiatives (e.g. EU or similar)
- Experts in the development of supercomputers and technological infrastructure within the field of health
- Experts in bioinformatics/genetics with experience from the interaction between clinic and research

- Experts in clinical development of personalised medicine
- Renowned researchers in personalised medicine

The international advisory board consists of ten members appointed by the Danish National Genome Center.

The role of the members of the advisory board is to contribute with relevant professional expertise, *not* to represent particular personal, organisational, national, political or similar interests.

The international advisory board elects a chair and a vice-chair at the first meeting. A representative from the Danish National Genome Center attends advisory board meetings.

The presidency ensures coordination and coherence across the Danish National Genome Center's working groups, advisory boards and specialist networks.

The international advisory board has the opportunity to establish sub-workgroups as well as convene expert advice if necessary.

The members of the advisory board are obliged to notify the secretariat if they are incompetent in specific matters dealt with under the auspices of the advisory board. Members must also sign a declaration of impartiality and follow the National Genome Center's policy of impartiality.

Meetings and secretariat

The Advisory board holds meetings at the request of the Danish National Genome Center. A minimum of two meetings are to be held annually. Meetings are to be held physically or virtually at the request of the secretariat and the chair. The Danish National Genome Center will be providing secretarial services to the board. The agenda(s) will be prepared by the Danish National Genome Center, and approved by the chair.

The details of the board's work shall be laid down in the rules of procedure approved at the first meeting of the board.

The Danish National Genome Center covers expenses related to attending meetings of advisory board members in accordance with state regulations.

Ongoing evaluation of the advisory board's tasks and composition

The advisory board's members are appointed for two years, with the possibility of extending the membership. Assignments and composition are continuously evaluated by the Danish National Genome Center.

The terms of reference of the advisory board are approved by the Danish National Genome Center. Significant changes in the board's terms of reference are also approved by the Danish National Genome Center.

Addendum

- Rules of procedure for the International Advisory Board