



**Nordic Alliance  
for Clinical  
Genomics**

# *CONSTITUTION*

Version 3

# About this document

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**Document title:** Constitution of the Nordic Alliance for Clinical Genomics

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**Version:** 3

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**Approved by:** NACG steering committee

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**Changes in this version:**The constitution was updated to reflect the addition of steering committee team to include deputies.

Specific changes include:

- Section 4.6 addition of steering committee team deputies.
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# CONTENTS

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About this document .....	1
ABOUT NACG .....	2
1. Mission .....	3
2. Founding Principles .....	3
3. Goals and Activities .....	3
4. Organization .....	4
5. Membership .....	6
6. Open Intellectual Property .....	8
7. Policies .....	8
8. Funding .....	8
9. Amendment .....	8
10. Records .....	8

## ABOUT NACG

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For more information about NACG, visit <https://nordicclinicalgenomics.org/> or contact us at [post@nordicclinicalgenomics.org](mailto:post@nordicclinicalgenomics.org).

## Adopted

This Constitution sets forth the mission, objectives, and structure of the Nordic Alliance for Clinical Genomics (NACG) as was initially adopted at the inaugural meeting taking place in Høvik, Norway 16<sup>th</sup> November 2017.

# 1. Mission

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We work together and learn from each other to lift our performance standards. We aim at responsible sharing of trustworthy data for improved diagnosis and treatment, and as a resource for research.

# 2. Founding Principles

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The founding principles of the NACG are:

- **Respect** for individuals who contribute their personal data for the advancement of human health;
- **Collaboration** to share data and information to advance human health;
- **Innovation** to develop an environment that accelerates progress;
- **Accountability**, developing and demonstrating adherence to best practices in clinical diagnostics, sequencing technologies and ethics;
- **Inclusivity** by partnering and building trust among Nordic and International stakeholders.

# 3. Goals and Activities

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Below are goals and desired activities of the NACG.

- *Facilitate the responsible sharing of genomic data, bioinformatics tools, sequencing methods and best practices for interpretation of genomic data.*
- *Enhance quality of genomic data and processes, and explore methodologies to provide assurance.*
- *Understand legal barriers to the implementation of personalised medicine and to engage with key stakeholders that influence these barriers*
- Develop demonstration projects that challenge perceived legal barriers that limit responsible and ethical sharing of genomic and health data.
- Build bridges between research and clinical communities, technologies and practices to foster innovation

# 4. Organization

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Below is an overview of the organizational structure of the NACG.

**4.1 Independence.** The NACG is an independent, non-governmental, not-for-profit, Nordic association that also welcomes non-Nordic partners. It is not controlled by any individual healthcare provider, research institution, research funder, disease advocacy organization, life science or information technology company, or other single entity.

**4.2 Structure.** The NACG is an unincorporated association among legal entities and non-legal entities (networks, partnerships, projects, etc.) as well as individuals interested in pursuing the NACG's goals as outlined in Section 3. The work of the NACG is supported by Host Institutions and other Funders (defined below) and is carried out by Organizational and Individual Members. The term "Membership" encompasses Host Institutions, Organizational and Individual Members. The roles and criteria for Organizational and Individual Members are further defined in Section 5.

**4.3 Host Institutions.** The NACG is administered and hosted by a small number of organizations (the "Host Institutions"), each of which must be an Organizational Member in good standing of the NACG. Where possible the NACG shall have at least one host institution from each of the Nordic countries and these shall coordinate and promote the alliance in their respective countries.

**4.3.1 Function of Hosts Institutions.** The Host Institutions will provide services and administrative support (e.g. space, grants management, and human resources) on behalf of the NACG. Commitments on sharing of cost and other resource requirements among the Host Institutions and other entities (whether Organizational Members, funding sources, or other entities) will be set forth in a collaboration agreement entered into between the individual Host Institutions. No Host Institution will be required to provide services, space, or staff support for the NACG beyond that to which it has committed and for which sufficient funding has been provided in such Host Institution's sole discretion. Host Institutions will be entitled to nominate a representative who will attend Steering Committee meetings *ex officio* as a non-voting member.

**4.3.2 Selection of Hosts.** New Host Institutions may be approved, and existing Host Institutions removed, by a two-thirds vote of the Steering Committee. The NACG will endeavour to ensure long-term relationships with Host Institutions, to promote stability.

**4.4 Funders.** Funders will be defined as organizations that provide financial support to the NACG. Major funders of the NACG will receive regular, direct updates from the Steering Committee, and can provide regular direct input to the Steering Committee. Representatives of the major funders may be invited to regularly attend meetings of the Steering Committee.

**4.5 Steering Committee.** The Steering Committee is a voluntary body responsible for executive decisions about the direction, values, and work products of the NACG. Steering Committee responsibilities include holding the Secretariat accountable, responding to Membership needs and concerns, and supporting fundraising efforts. The Steering Committee appoints one Committee Chair and two Vice Chairs by a majority vote. The Chair is responsible for setting the agenda of the Steering Committee.

*4.5.1 Steering Committee Accountability.* The Steering Committee will provide regular and direct updates to the Membership, and provide methods to solicit and take into account advice and views from Membership.

*4.5.2 Steering Committee Membership.* The initial Steering Committee members will be made up of the Transitional Steering Committee members+, who will initiate a process to stagger current terms and appoint new members. The Steering Committee will have no fewer than five (5) members and no more than nine (9) members. New members will be appointed from nominations solicited from the full NACG Membership, and selected by majority vote of the Steering Committee, with input from the Membership taken into account. Candidates will be selected so as to ensure that all necessary competencies are represented and to achieve a diversity of perspectives, backgrounds, and Nordic countries that reflects the Membership of the NACG.

*4.5.3 Steering Committee Term.* Members of the Steering Committee will serve for a three (3) year term, renewable for up to two (2) consecutive terms, with the ability to extend to a third term with a two-thirds vote of the Steering Committee. Steering Committee members' terms will be staggered to promote stability. The Steering Committee has the right to remove any individual member by a two-thirds vote of the Steering Committee membership at any time.

*4.5.4 Steering Committee Meetings and Voting.* Steering Committee meetings shall be presided over by the Chair, or in his/her absence, a Vice Chair, and may be held in person or by video/teleconference. Regular meetings will be called at the direction of the Executive Team. Special meetings may be called at the request of any three or more members of the Steering Committee and with five days' notice to the Chair. Except where otherwise specified in this Constitution, a majority vote of all active members of the Steering Committee shall constitute the act of the Steering Committee, and votes can be taken via email or other electronic means. In the event of a tie, the Chair will have a casting vote. Steering committee members will not vote on matters affecting their own appointment or replacement.

*4.5.5 Executive Team.* The Executive Team is comprised of the Steering Committee Chair and Vice Chairs, and Director of the Secretariat of the NACG. The Executive Team will be responsible and accountable for moving forward the NACG agenda, with the ability to approve documents and communicate with Membership. The Executive Team will be answerable to the Steering Committee and will consult, as appropriate and needed, with the broader Membership.

*4.5.6 Chair and Vice Chair Terms.* The Chair and Vice Chairs will be appointed by vote of the Steering Committee for three (3) year, renewable terms. Terms will be staggered to promote stability. The Steering Committee has the right to remove the Chair or Vice Chair from their executive position by a majority vote at a duly constituted meeting.

*4.6 Deputies* The steering committee team may each appoint a deputy who shall (a) carry out the duties and powers prescribed by the steering committee team; and (b) serve in steering committee meetings in the absence of the steering committee member. The deputies may be invited to steering committee meetings when the steering committee decides so.

*4.7. Secretariat.* The Secretariat will be selected and can be removed by the Chair and Vice Chairs, with approval of the majority of the Steering Committee. The secretariat will be led by a Director and the position shall represent in-kind voluntary funding contributions to the NACG but can also be

remunerated if agreed by a majority vote of the steering committee. Chair and Vice Chairs are responsible for the performance management of the Secretariat.

**4.8 Working Groups.** Working Groups will be established to produce concrete, actionable deliverables in their respective areas. The initial four Working Groups are: (i) Data Sharing, (ii) Benchmarking, harmonization and Standardization, (iii) Bioinformatic tool development, and (iv) Research. Additional Working Groups may be established, and current Working Groups may be discontinued, both by majority vote of the Steering Committee. Working Groups will have open dialogue and transparent communication with Membership.

**4.8.1 Working Group Leadership.** Chairs or Co-Chairs of the Working Groups are appointed by the Steering Committee.

**4.8.2 Process for Developing Work Products.** Working Groups will be responsible for developing draft deliverables based on their own research and internal discussions, and soliciting and taking into consideration consultation with Membership. Working Groups will have the responsibility for developing the deliverables and must share a draft and solicit input from the Membership before the work product is final. Any final deliverables that shall be promoted by the NACG must be approved by a two-thirds vote of the Steering Committee.

**4.8.3 Collaborative Projects.** The NACG can collaborate with Membership and outside entities to catalyze and support specific projects that further the goals and objectives of the NACG and accelerate the positive impact of genome sequence information on medicine and human health.

## 5. Membership

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Below is an overview of the Membership roles and criteria of the NACG.

**5.1 Organizational Members.** Organizational Members will be entities, either not-for-profit or for-profit, in fields such as healthcare, public health, biomedical and other research, information technology and life sciences, and disease and patient advocacy that subscribe to the mission, founding principles, and goals of the NACG as set forth in Sections 1-3. Individuals from Organizational Members may play various roles, including membership of Working Groups (at invitation of the Working Group Chair), other committees, and the Steering Committee. Each Organizational Member will have the right to designate individuals from its organization who will represent the organization in NACG-related work, meetings, and governance matters.

**5.1.1 Founding Partners.** The Organizations listed below have worked together to initiate and establish the NACG and are recognized as Founding Partners. These Organizations have signed non-binding letters of intent with NACG and can choose to transition to Organizational Members of the NACG as described in this Constitution. Founding partners are:

- Copenhagen University Hospital (Rigshospitalet) and the University of Copenhagen, Center for Genomic Medicine, Denmark
- Copenhagen University Hospital (Rigshospitalet) and the University of Copenhagen, Department of Clinical Genetics, Denmark
- DNV GL A.S.

- Karolinska Universitetssjukhuset, Centre for Inherited Metabolic Diseases (CMMS), Sweden
- Karolinska Universitetssjukhuset, Clinical Genetics, Sweden
- Landspítali University Hospital, Department of Genetics and Molecular Medicine, Iceland
- National Genomics Initiative, SciLifeLab, Sweden
- Norwegian Consortium for Sequencing and Personalized Medicine (NorSeq)
- Oslo University Hospital, Department of Medical Genetics, Norway
- Karolinska Institutet, Department of Microbiology, Tumor and Cell Biology (MTC),
- SciLifeLab, Clinical Genomics Stockholm facility, Sweden

*5.1.2 Steering Committee Discretion for Organizational Members.* Organizations may apply to be an Organizational Member, and such applications will be considered for approval by the Steering Committee. Organizational Members that do not adhere to the mission and founding principles of the NACG as set forth in Sections 1 and 2, or that act in such a way as to damage the interests or reputation of the NACG, may be removed from Membership by a majority vote of the Steering Committee. Organizations that are removed as Members will be provided a written communication of this action, including a description of the reasons leading to the removal. Steering Committee members that are affiliated with Organizations that have been removed as members will also lose their position on the Steering Committee.

*5.2 Individual Members.* Individuals who provide expertise and knowledge in relevant fields and who support the data sharing mission and efforts of the NACG may apply to join the NACG as Individual Members. Individual Members will be knowledgeable about and may contribute to the work of the NACG through participation in Working Group work product development and review processes, committee membership, and other collaborative efforts.

*5.2.1 Steering Committee Discretion for Individual Members.* Individuals may apply to be an Individual Member, and such applications will be subject to approval by the Steering Committee. The Steering Committee will have the sole discretion and responsibility to accept or reject a membership application based on the individual's expertise, potential contribution, or other factors. Individual Members who do not adhere to the mission and founding principles of the NACG as set forth in Sections 1 and 2, or who act in such a way as to damage the interests or reputation of the NACG, may be removed from Membership by a majority vote of the Steering Committee. Individual Members who are removed in this manner will be informed in writing.

*5.3 Conflict of Interest.* If an Organizational or Individual Member is subject to certain policies and requirements or has pre-existing relationships that create a fundamental conflict with the Membership criteria of the NACG, the Steering Committee has the right to reject or remove the Member from Membership. Individual Members who choose to participate in the NACG must do so subject to the policies and requirements of their employers and/or the primary organizations with which they are formally affiliated. It is understood that Organizational and Individual Members, Funders, Host Organizations, and Steering Committee members may have existing or future business interests or other potential conflicts that will require disclosure and recusal from certain proceedings, projects, or votes.

*5.4 Plenary and Other Meetings.* Much of the work of the NACG will be conducted by email and teleconference, but plenary meetings will be held roughly biannually. Additional meetings may be held, with invitations directed to relevant Membership at the discretion of the Steering Committee.

## 6. Open Intellectual Property

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It is a guiding principle of the NACG that work products developed as part of the NACG Steering Committee and Working Group processes will be openly shared for the benefit of humanity. Appropriate intellectual property policies will be developed and promulgated.

## 7. Policies

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Early in the course of NACG efforts, the NACG will develop appropriate policies concerning its operations, including, without limitation, policies regarding, managing dissent, report development process, and reviews and appeals.

## 8. Funding

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The NACG will seek financial support from various sources, including philanthropic, government, for-profit, and institutional sources, to fund its core operations. As future circumstances warrant, the NACG may consider requesting a form of Membership fee. All funding raised by the NACG shall be applied to further the mission of the NACG and for no other purpose.

## 9. Amendment

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This Constitution may be amended from time to time by vote of a two-thirds majority of the Steering Committee, with feedback requested from the Membership prior to a vote being held.

## 10. Records

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Records of organization (section 4) and members (section 5) are kept updated in the document “The Nordic Alliance for Clinical Genomics, roles and responsibilities”.