



**Nordic Alliance  
for Clinical  
Genomics**

# *INVITATION*

NACG symposium and workshops  
19.-21. November 2019

# About NACG

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The Nordic Alliance for Clinical Genomics is an independent, non-governmental, not-for-profit, Nordic association open for organizational and individual members.

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

Our goals are to

- 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

To learn more about the Nordic Alliance for Clinical Genomics please visit our website at <https://nordicclinicalgenomics.org/> or contact us at [post@nordicclinicalgenomics.org](mailto:post@nordicclinicalgenomics.org).

# NACG Symposium

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## Agenda 19<sup>th</sup> November 2019

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<b>11:30</b>	Registration and lunch	
<b>12:30</b>	Welcome and opening remarks	Dag E. Undlien, OUS, NACG chair Kenneth Vareide, CEO Digital Solutions, DNV GL Norwegian Minister of digitalization, Nikolai Astrup (tbc)
<b>13:15</b>	National initiatives	Bettina Lundgren, Director of the Danish National Genome Centre Anna Lindstrand, Genomic Medicine Sweden / Karolinska Institute Aarno Palotie, research director of the Human Genomics program at FIMM, Finland
<b>15:15</b>	Break	
<b>15:45</b>	The European 1+ Million Genomes Initiative from a Norwegian perspective	Grethe Synnøve Foss, project manager for the Norwegian Strategy for Personalised Medicine at the Directorate for Health and Care
<b>16:15</b>	Regional initiatives: EU	Milan Popovic, European commission, DG Research & Innovation, Healthy Lives Unit
<b>16:45</b>	Nordic Per Med Law initiative on the regulatory framework for personalised medicine	Anne Kjersti Befring, UiO
<b>17:00</b>	Dynamic consent	Tbc
<b>17:30</b>	Health economics and genomics	Tbc
<b>18:00</b>	End	
<b>19:00</b>	NACG symposium dinner	

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## Agenda 20<sup>th</sup> November 2019

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<b>8:30</b>	Morning coffee	
<b>9:00</b>	Genomic medicine in cancer & clinical trials	Karolinska Institute – speaker tbc Kristoffer Rohrberg, head of phase I unit, Rigshospitalet, Copenhagen Helsinki University Hospital / University of Helsinki – speaker tbc
<b>10:30</b>	Genomic medicine in cancer & clinical trials – precision drugs	AstraZeneca – speaker tbc Roche – speaker tbc Takeda – speaker tbc
<b>11:15</b>	Panel discussion with speakers from morning sessions	
<b>11:45</b>	Symposium closing remarks	Dag E. Undlien, OUS, NACG chair
<b>12:00</b>	Lunch	
<b>13:00</b>	NACG workshops start	

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# NACG Workshops

Wed 20th Nov (afternoon)	Thu 21st Nov (morning)	Workshop	Keywords	Responsible organiser
To be scheduled		Benchmarking, harmonization and standardization	Benchmarking of variant interpretation, especially VUSes Consent for NGS The perfect requisition	Kaisa Kettunen, FIMM/ HUSLAB & Sharmini Alagaratnam, DNV GL
To be scheduled		Structural variants	Benchmarking of SV pipelines Benchmarking of the SV nomenclature (HGVS, ISCN). Sharing of SV	Mads Bak, Rigshospitalet & Oleg Agafonov, DNV GL
To be scheduled		Bioinformatic tools development	Matchmaker Exchange status update Uploading variant classifications to external databases Data compression Structural variants tools	Tony Håndstad, OUS
<b>½ day</b>	<b>½ day</b>	NGS for cancer diagnostics	Organizational and clinical needs Pipeline mapping; upstream, bioinformatics, data sharing	Courtney Nadeau, DNV GL & Vibeke Binz Vallevik, DNV GL/ BigMed
To be scheduled		IVDR - how to address the upcoming regulations?	Introduction to IVDR Discussion on implications for clinical labs	

# NACG symposium and workshops – practical information

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## Registration

Please register for the NACG symposium and workshop here:  
<https://forms.gle/yBmWCczSxdEeAEzX6>

## Venue

The events will take place at the Veritas centre, Veritasveien 1, Høvik, Norway. For information on how to get there: <https://www.dnvgl.com/contact/headquarters.html>.

## Accommodation

Thon Hotel Oslofjord is located in Sandvika, close to the Veritas centre, and **participants can book and pay rooms directly** using the **event code 28403996** to [oslofjord.booking3@olavthon.no](mailto:oslofjord.booking3@olavthon.no). The price is 1185,- per night in standard rooms, including breakfast. The hotel will start releasing reserved rooms after October 1<sup>st</sup>, after which availability cannot be guaranteed.

## Adjacent Nordic conference: The legal framework for personalised medicine

Adjacent to the NACG event and organized at the same venue there will be a conference on The legal framework for personalised medicine (Rettslige reguleringer av persontilpasset medisin). For more information please visit:  
<https://www.jus.uio.no/ior/forskning/prosjekter/bigmed-jus/arrangementer/konferanser/personilpasset-medisin/index.html>

## Event overview

	<b>Monday 18. Nov</b>	<b>Tuesday 19. Nov</b>	<b>Wednesday 20. Nov</b>	<b>Thursday 21. Nov</b>
<b>Morning</b>	The legal framework for pers. med.	The legal framework for pers. med.	NACG symposium	NACG workshops
<b>Afternoon</b>	The legal framework for pers. med.	NACG symposium	NACG workshops	

## Duck up night

During the event we would like to organise an informal session for sharing of failures. Please inform upon registration if you would like to contribute to this session.



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