

# **Next Generation Medicine?**

## **Ethical, Legal and Technological Questions of Genomic High-Throughput Sequencing in the Clinic**

### **Date**

**July 25 / 26 2017**

### **Venue**

University Medical Center Goettingen, Lecture Hall MED 25  
Kreuzbergring 61, 37075 Goettingen

### **Organized by**

the GenoPerspektiv Consortium  
Ulrich Sax, PhD, Nadine Umbach, PhD,  
Department of Medical Informatics, University Medical Center Goettingen

Due to increasingly effective technological platforms, sequencing of the human genome is now possible within hours and for less than 1.000 Euro. This development has sparked growing interest among clinicians and molecular biologists. The aim is to target rare, clinically unrecognizable diseases or to subtype clinically indistinguishable disorders with a suspected genetic background, e.g., in the oncological context. More and more clinicians, patients, and stakeholders are becoming aware of the possibilities of biomarker-based high-throughput analyses. Genomic high-throughput technologies are frequently hailed as a revolutionary tool that will radically change clinical practice and establish “predictive”, “individualized” or “precision” medicine.

At the same time, the clinical implementation of the rapid technological advances in the field of genomic high-throughput sequencing is accompanied by practical difficulties and uncertainties. The interpretation and reporting of genomic findings in clinical practice, e.g., in molecular tumor boards, becomes more complicated, challenging the traditional roles and qualifications of medical professionals. The increasing volume of huge and highly complex data sets also poses problems regarding sustainable infrastructures for management, integration and exploration of genomic sequencing data with other clinical data. And finally, the large pool of sensitive and ambiguous data raises ethical, legal, and social questions that are still in need of clarification, especially regarding informed consent, disclosure policies, and data protection: How can we protect patient autonomy and informational self-determination in view of huge amounts of genomic information with unclear clinical significance and future usage? What kinds of genomic information should be disclosed to patients and in what way? And how should we deal with so called incidental findings, that is, originally unintended information about a person’s genetic predispositions and medical conditions?

The international workshop brings together experts from the fields of medicine, ethics, social sciences, law, and biomedical informatics as well as the public. The aim is an interdisciplinary discussion of the opportunities and challenges posed by clinical applications of genomic high-throughput sequencing.

## **Poster session**

We cordially invite the submission of abstracts that report new research developments across the breadth of clinical genomic, precision medicine, next-generation sequencing, biomarker analysis, reporting or related ethical, social, legal, and bioinformatical issues. Abstracts are considered for posters and oral presentations. Submissions are welcomed from physicians, researchers, PhDs, and students in all sectors, including academia, industry, and education.

Abstracts are limited to 500 words and should be divided in introduction, materials & methods, results, and discussion. German and English contributions are accepted.

Abstract submission will be open to June 25, 2017, 11:59 PM MEZ:  
[genoperspektiv@med.uni-goettingen.de](mailto:genoperspektiv@med.uni-goettingen.de)

## **Registration / further questions:**

Please send a mail to: [genoperspektiv@med.uni-goettingen.de](mailto:genoperspektiv@med.uni-goettingen.de)

Participation is free of charge.

# Next Generation Medicine?

## Ethical, Legal and Technological Questions of Genomic High-Throughput Sequencing in the Clinic

GenoPerspektiv Symposium

July 25 – 26, 2017

Hörsaal MED25, Kreuzbergring 61, 37075 Göttingen

Registration: [genoperspektiv@med.uni-goettingen.de](mailto:genoperspektiv@med.uni-goettingen.de)

<b>Day 1 Time</b>	<b>Speaker</b>	<b>Title</b>
12:00	Registration	
12:30	Prof. Dr. Ulrich Sax, University Medical Center Göttingen	Welcome
13:00	Dr. Jürgen Eils, DKFZ & University of Heidelberg	Genomics IT: Challenges and Lessons Learned
13:40	Dr. Dennis-Kenji Kipker, University of Bremen	Legal Challenges for IT-Security in Clinical Data Processing
14:20	PD Dr. Peter Wehling, Johann Wolfgang Goethe-University Frankfurt / Main	Expanded Carrier Screening: In Search Clinical Utility and Social Viability
15:00	Prof. Dr. Christophe Le Tourneau, Institute Curie Paris	Lessons learned from the SHIVA trial
15:40	Coffee Break & Guided Poster Session	
17:00	Dr. Leslie G. Biesecker, National Human Genome Research Institute / NIH	Opportunities and Challenges for Predictive Genomic Medicine
18:00	Reception	

<b>Day 2 Time</b>	<b>Speaker</b>	<b>Title</b>
09:00	Alexander Urban / PD Dr. Mark Schweda, University Medical Center Göttingen	What Should you do with this kind of Information?! – Expert & Lay Perspectives on the Utility of Genomic High-Throughput Sequencing
09:20	Laura Flatau / Prof. Dr. Thomas Schulze, University Medical Center Göttingen & Medical Center of the University of Munich	Openness Towards Genomic High-Throughput Data: Results from an Online Survey of 1000 Individuals regarding Attitudes, Expectations, and Fears in the Context of Genomic Investigations
09:40	Dr. Nadine Umbach / Prof. Dr. Ulrich Sax, University Medical Center Göttingen	An IT Perspective on Managing Data from Genomic High-Throughput Technologies
10:00	Julia Perera Bel / Prof. Dr. Tim Beißbarth, University Medical Center Göttingen	The Molecular Tumor Board Report: an Approach on Genomic Data Interpretation To Guide Cancer Therapy
10:20	Coffee Break	
10:40	PD Dr. Mark Schweda, University Medical Center Göttingen	Inclusive Deliberation on Future Healthcare: the Role of Patients and the Public in the Debate on Medical High-Throughput Technologies
11:20	Johanna Römmelt, Deutsche Gesellschaft für Bipolare Störungen e.V. (German Society for Bipolar Disorders)	Will ich alles wissen? Genomsequenzierung aus Sicht von Betroffenen der Bipolare Störung und deren Angehörigen
12:00	Lunch break	
13:00	Prof. Dr. Gunnar Duttge, Universität Göttingen (University of Göttingen)	Die Genomsequenzierung – Herausforderungen an das Recht
13:20	Prof. Dr. Ernst Hauck, Bundessozialgericht (Federal Social Court)	Erkrankungsrisiko als Krankheit im Sinne der gesetzlichen Krankenversicherung?
14:00	Coffee break	

14:20	Dr. Franziska Degenhardt, University Hospital Bonn	Psychiatric Genetics in the Genomic Medicine Era
14:40	PD Dr. Jochen Gaedcke University Medical Center Göttingen	Genomic Data in the Treatment of Gastrointestinal Cancer
15:00	Dr. Gökhan Yigit University Medical Center Göttingen	The Mendeliome Resolves the Diagnostic Odyssey: Results of a Pilot Study on 100 Patients with Undiagnosed Congenital Malformation Syndromes
15:20	Prof. Dr. Ulrich Sax, University Medical Center Göttingen	Concluding Remarks