



## **Genomic Medicine in Europe – Blueprints for Germany**

May 27, 2019 Max Planck Institute for Molecular Genetics, Berlin

# TMF



- non-profit umbrella organization for networked medical research
- established by the BMBF in 1999
- registered association as of 2003 (65 members)
- funded by three federal ministries (BMBF, BMG, BMWT) and several other bodies (e.g. DFG, EU)
- German Centers for Health Research
- several Medical Faculties
- The National Cohort
- Networks for Rare Diseases
- Coordinating Centers for Clinical Trials
- German Biobank Node
  - ... and many more



http://www.tmf-ev.de



## **Goal: Jointly Solve Researcher-identified Problems!**

- IT infrastructure for clinical research (tools, audits)
- research methodology (harmonized SOPs, checklists)
- biobanking (quality management, IT, logistics, sustainability)
- ELSI frameworks (data protection concepts, consent blueprints)
- lobbying (politics, society, funding bodies)

## TMF Working Groups

- IT Infrastructure and Quality Management
- Data Protection
- Biobanking
- Management of Clinical Studies
- Medical Bioinformatics and Systems Medicine
- Science Communication
- Data Quality (Summer 2019)

### **TMF** Workshop

#### Omics in Medical Research 2nd edition

The workshop will address important topics from omics-based medical research, with a sideways glance at their potential relevance to clinical care. Presentations will highlight the role of omics in cardiovascular disease and oncology in particular, and will also address the emerging use of artificial intelligence in the clinic.

As a special focus, the workshop will take a look at the role of Germany in current international efforts to establish omics-based medical research as a driver of 'next generation medicine' (e.g. Human Cell Atlas, ICGC-ARGO, GA4GH). Distinguished speakers will present the visions underlying these initiatives and examine Germany's readiness to meet the challenges of future medicine.

Since all the above efforts depend upon access to, and use of, highquality clinical data, the workshop will also explore how systems medicine and bioinformatics may benefit from the 'Medical Informatics Initiative', a recent national funding program by BMBF. More specifically, the workshop will contour the links required between clinical data standards (HL7, LOINC etc.) and the omics world.

The workshop will also address the prerequisites to integrate and responsibly share large amounts of sensitive medical data for research. Since international cooperation is paramount for the translation of basic research into clinical practice, special attention will be paid to the legal framework of collaborative research in genetics and genomics.

Of note, the day after the workshop, the 7th National Biobanking Symposium will take place at the same venue and open under the headline "Fit for purpose – Omics and novel medical models and materials", pinpointing the great demand for high-quality human biomaterial for omics-based research.

Further information:

- Workshop flyer, 2017
  www.biobanken.de
- Workshop summary, 2017
  www.tmf-ev.de

#### TMF – Infrastructures for Medical Research

TMF is the umbrella organisation for networked medical research in Germany. It is a platform for interdisciplinary exchange, crossproject and multi-site collaboration – with the aim of identifying and resolving the organisational, legal/ethical and technological issues encountered in today's medical research. It makes a number of resources available free of charge to the general public – such as expert opinions, generic concepts, software applications, checklists, practical guides, training, and consulting services.

www.tmf-ev.de

TMF – Technologie- und Methodenplattform für die vernetzte medizinische Forschung e.V.

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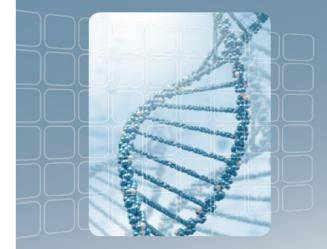


Deutsche Forschungsgemeinschaft German Research Foundation

### **TMF** Workshop

### Omics in Medical Research 2nd edition

December 10, 2018 | Berlin



TMF - Technology, Methods, and Infrastructure

for Networked Medical Research

Nr. 324/November 2018 Analysen & Argumente





Medizinische Genomsequenzierung: Warum Deutschland nicht länger abseits stehen darf

Hans-Hilger Ropers

## **Genome Medicine**

## A Driver for Research and Care

- Whole genome sequencing (WGS) greatly facilitates the diagnosis, therapy and prognosis of, as well as research into, genetic diseases.
- Immediate clinical benefit from WGS arises in
  - treatment of cancer
  - *diagnosis of rare diseases (total prevalence: 5%)*
- Pilot projects are helpful, but do not obviate the long-term establishment of WGS as a standard diagnostic tool.
- Implementation of WGS as a link between medical research and care is ongoing in many countries (e.g. US, Canada, Australia, China, UK, Netherlands, France, Sweden).

## **Genome Medicine**

## **Quo vadis, Germany?**

- Genome Medicine plays a less prominent role in Germany, with fewer public investments (e.g. infrastructure, research) made than elsewhere.
- Instead of "re-inventing the wheel", a German Genome Medicine initiative should draw upon the experience of others.
- National (and local) implementation processes must take relevant legal, ethical and organizational peculiarities into account.
- In the interest of patients, researchers and society, rapid action is required.

## Programme

## **Organisational Issues**

#### 11.00 Welcome Date: Panel discussion: Genomic Medicine in 16.00 Michael Krawczak | TMF Berlin, UKSH Campus Kiel May 27, 2019, 11.00 - 18:00 (11 am to 6 pm) Germany - the way forward Michael Krawczak | TMF Berlin, UKSH Kiel Venue: 11.10 Genomic Medicine in the UK Max-Planck-Institute for Molecular Genetics Panelists: Tim Hubbard | King's College London, Genomics Ihnestrasse 63-73 Saskia Biskup | Praxis für Humangenetik Tübingen; England 14195 Berlin, Germany CeGaT GmbH Jutta Gärtner | University Hospital Göttingen Contact: Annette Grüters-Kieslich | University Hospital Heidelberg 11.55 France Médecine Génomique TMF e.V. Christof von Kalle | DKFZ Heidelberg; Franck Lethimonnier | Inserm, Paris Roman Siddigui Sidra Medicine Katar Phone: +49 30 2200 247-52 | roman.siddigui@tmf-ev.de Olaf Rieß | University Hospital Tübingen Juliane Gehrke (organisational issues) Jürgen Schäfer | University Hospital Marburg 12.25 Genomics Stockholm / Sweden Phone: +49 30 2200 247-17 | juliane.gehrke@tmf-ev.de Gerhard Schillinger | AOK-Bundesverband GbR Valtteri Wirta | Karolinska Institutet, Stockholm **Registration:** Experts in the first row: Please register online at www.tmf-ev.de/anmelden. Tim Hubbard, Franck Lethimonnier, Valtteri Wirta, Han 12.55 Lunch break Brunner, Julia Wilkins, Hans-Hilger Ropers Scientific Organisation: Michael Krawczak | TMF Berlin, UKSH Campus Kiel Nijmegen - The Netherlands 13.55 Roman Siddiqui | TMF Berlin 17.30 Resumé – Next Steps – Closing Remarks Han Brunner | Radboud UMC+, Nijmegen Hans-Hilger Ropers | MPIMG Berlin Michael Krawczak | TMF Berlin, UKSH Campus Kiel

Networking

18.00

- 14.35 Economic burden of undiagnosed rare diseases Julia Wilkins | Imperial College Health Partners London
- 15.15 Refreshments
- 15.45 Wrap up Hans-Hilger Ropers | MPIMG Berlin