

TMF-Workshop

Best Practice – Sharing and Publishing of Human (Gen)Omics Data

Since the 1980s, both funding agencies and biomedical publishers have either recommended or demanded that nucleotide and protein sequence data be deposited in public databases at, for example, NCBI, EBI or DDBJ. Making research data publicly available has since been regarded as part of good scientific practice in that it allows for more transparency, reproducibility and sharing of these valuable resources.

In the aftermath of the Human Genome Project (2004), new methodologies such as GWAS and the various -omics technologies, including Next Generation DNA Sequencing, have arisen in biomedical research that generate huge amounts of sensitive data (genotype-phenotype relationship) in a very cost- and time-efficient manner. At the same time, it has become generally accepted that extensive sharing of these data among researchers will further improve our understanding of the mechanisms of individual disease susceptibility, progression and prognosis. The workshop jointly organized by TMF and e:Med will highlight the current challenges and best practices of publishing and sharing sensitive patient-related -omics data. These topics are becoming increasingly relevant, not only to patients and researchers themselves, but also to regulatory bodies, funding agencies, biotech industry and biomedical publishers.

The program will cover the following issues:

- Data sharing within and beyond scientific research consortia
- Publishing Sensitive (Gen)Omics Data and Respectful Sharing
- State of the Art Open Issues in the e:Med Consortia

There will be room for discussions on problems as well as challenges in Data Security and Ethics in systems medicine. The workshop is intended as an information platform and for intense exchange on the issues mentioned above.

Organisers

TMF – Infrastructures for Medical Research

The TMF is the umbrella organization for networked medical research in Germany. It is the platform for interdisciplinary exchange as well as cross-project and cross-location cooperation in order to identify and solve the organizational, legal/ethical and technological problems of modern medical research. Solutions range from expert opinions, generic concepts, and IT applications to checklists, practical guides, training, and consultation services. The TMF makes these solutions available to the public free of charge.

www.tmf-ev.de

e:Med - A systems medicine network

e:Med has the objective of establishing systems medicine in Germany. e:Med promotes system-oriented research into diseases in order to facilitate improved prevention, more comprehensive diagnostics and individually adjusted therapy schemes in individualized medicine. The program brings together scientists with molecular-genetic, clinical, mathematical and information technology expertise, with the objective of ensuring research results quickly benefit patients. Electronic processing (e:Med), i.e. computerized archiving, analysis and integration of data, plays a particularly important role here.

www.sys-med.de



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Best Practice – Sharing and Publishing of Human (Gen)Omics Data

June 8 - 9, 2016 | Berlin



Wednesday, June 8th, 2016

13:00 Welcome address & introduction

Michael Krawczak (University Medical Center Schleswig-Holstein, Campus Kiel) & Roman Siddiqui (TMF, Berlin)

13:15 Data Sharing within and beyond scientific research consortia

Chairs: Christoph Schickhardt (NCT Heidelberg), Ulrich Sax (University of Göttingen)

- Internal sharing, authorship and reward policies
Challenges of research governance at the international level
Mahsa Shabani (KU Leuven, Belgium)
- External sharing of research data
Data sharing before and after project completion
*Heidi Schuster (Max Planck Society, Munich),
Thomas Pickardt (Competence Network for Congenital Heart Defects, Berlin)*
- Patient right of withdrawal
How to comply with the right of withdrawal in research practice
*Gunthard Stübs (University of Greifswald, National Cohort),
Jürgen Eils & Chris Lawerenz (DKFZ, Heidelberg)*
- Discussion of Session Results

15:45 Coffee Break

16:15 Publishing sensitive (gen)omics data and respectful sharing

Chairs: Michael Krawczak (University Medical Center Schleswig-Holstein, Campus Kiel) & Roman Siddiqui (TMF, Berlin)

- The role of author guidelines and global trends in balancing medical research and privacy protection
Gregory Paul Copenhaver (PLoS Genetics, USA)
- Publishing sensitive data: Hands-on experience
How to put guidelines and policies into practice
Thomas Pickardt (Competence Network for Congenital Heart Defects, Berlin), Jürgen Eils & Chris Lawerenz (DKFZ, Heideberg)

- The databases' point of view
Dylan Spalding (EMBL-EBI, Hinxton, UK; European Genome-phenome Archive, EGA)

- Discussion of Session Results

19:00 Informal get-together with wine & cheese

Thursday, June 9th, 2016

09:00 Welcome address & introduction

Christoph Schickhardt (NCT Heidelberg), Ulrich Sax (University of Göttingen)

09:15 State of the Art and Open Issues in the e:Med Consortia

Chairs: Christoph Schickhardt (NCT Heidelberg), Ulrich Sax (University of Göttingen)

- The upcoming EU General data protection regulation
Boris Reibach (University of Oldenburg)
- The EU-US privacy shield and the transfer of pseudonymized clinical research data to the USA
Uwe W. Fiedler (PAREXEL International, Berlin)

11:15 - 11:30 Coffee Break

- The TMF generic data protection models: Standard Data Privacy Model (SDM)
Irene Schlünder (TMF, Berlin)

12:30 - 13:30 Lunch Break

- Inappropriate consent documents of old bio material donations: Issues around legacy samples and data ('legacy consent')
Kai Cornelius (University of Heidelberg / EURAT), Michael Hummel (Charité Berlin)

14:30 Wrap-up & future directions

Christoph Schickhardt (NCT Heidelberg), Ulrich Sax (University of Göttingen)

Date:

June 8–9, 2016

Venue:

TMF conference room
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10117 Berlin | Germany

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Registration:

Participation is free of charge. Please register online at www.tmf-ev.de/anmelden.