

Sharing experiences and lessons learned while operating National Biobank Registers

Human biobanks are collections of bio-specimens from human body substances which are linked to clinical or / and socio-demographic records of donors. They represent essential tools for patient-oriented health research and epidemiological studies. Being visible in webbased registries increases their efficient usage and accessibility by the scientific community.

Objectives of the workshop

It is the overall objective of the workshop to discuss the biobank register concepts from 7 countries (Austria, Belgium, Denmark, Finland, Netherlands, Sweden, Germany) from different perspectives. Amongst others, following questions, will be addressed:

- Which incentives are offered for biobanks to participate?
- Are the registers embedded in funding policies and regulations?
- Which data models are used (granular vs. minimal data sets)?
- Which codes and thesauri are used for phenotype annotations (epidemiological vs. clinical biobanking)?
- Is a standard vocabulary (designations of attributes) for biobank registries needed?
- Can quality issues of the biospecimens become displayed appropriately in the registers?
- How is public relations and land engagement put into practice by the registers?
- How is sustainability of the registers realised?

The workshop will be held in English.

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

The German Biobank Registry

Since 2012, the German Biobank Registry provides a publicly available overview of relevant biomedical biobanks existing in Germany. The aim is to make better use of existing resources and continue supporting the exchange between biobank operators and researchers.

The German Biobank Registry not only provides the contact data of the registered biobanks but also supplies information about the respective biospecimens kept in stock and the respective research focus. Participating biobanks can customize and update their data at any time.

The registry is operated by the TMF and funded by the German Federal Ministry of Education and Research (BMBF).

www.biobanken.de



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February 18 - 19, 2015 | Berlin



Programme

Wednesday, February 18, 2015

- 14.00 **Welcome - Goals of the Workshop**
Roman Siddiqui & Murat Sariyar | TMF
- 14.10 **Presentations of the National Registers**
- Austria**
Horst Pichler | University of Klagenfurt
- Belgium**
Annelies Debucquoy | KU Leuven
- Denmark**
Bartłomiej Wilkowski | Statens Serum Institut
- 15.40 **Coffee Break**
- 16.00 **Finland**
Kaisa Silander | National Institute for Health and Welfare
- Netherlands**
David van Enckevort | University Medical Center Groningen
- Sweden**
Roxana Merino Martinez & Loreana Norlin | Karolinska Institutet
- 17.30 **Coffee Break**
- 17.45 **Germany**
Roman Siddiqui | TMF
- Discussion - Commonalities & Differences**
- 19.00 **Get Together**

Thursday, February 19, 2015

- 10.00 **Resume and Conclusions from Day 1**
Roman Siddiqui & Murat Sariyar | TMF
- 10.15 **Special Topics**
Biobank Register Vocabulary
- MIABIS - History and International Developments**
Loreana Norlin | Karolinska Institutet
- MIABIS 2.0 - an Extendable, Modular Minimal Data Set**
David van Enckevort | University Medical Center Groningen
- 11.15 **Recording and Displaying Biospecimen Quality**
- Biomaterial Quality Issues in Registers**
Daniela Skrowny | University of Göttingen
- 11.45 **Coffee Break**
- 12.00 **Defining and Capturing Process Quality in RD-Connect**
Heimo Müller & Robert Reihls | Medizinische Universität Graz
- 12.30 **Wrap up - Closing Remarks**
Roman Siddiqui & Murat Sariyar | TMF
- 13.00 **Lunch & Farewell**

Organisational Issues

Date:

February 18 - 19, 2015

Venue:

TMF conference room
Charlottenstraße 42/Dorotheenstraße
10117 Berlin | Germany

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Registration:

Participation is free of charge. Please register online by 8th of February 2015 at www.tmf-ev.de/anmelden.

Scientific Organisation:

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