Personal data in the life sciences: helping researchers handle data protection and ethical requirements

A BioMedBridges knowledge exchange workshop hosted by TMF

Location: TMF rooms, Charlottenstraße 42/Ecke Dorotheenstraße,10117 Berlin

Time	Session/topic and speaker	
09:00	Introduction and aims of the workshop	Murat Sariyar
Overview of challenges		Chair: Murat Sariyar
09:10	EU data protection regulation: implications for scientific research	Irene Schluender
09:40	BBMRI-ERIC Common Services on ELSI	Markus Pasterk
10:10	Discussion: using sensitive data	
10:45	Coffee break	
Existing resources and tools for the evaluation of ethical and legal requirements		Chair: Töresin Karakoyun
11:15	- IPAC (International Policy interoperability and data Access Clearinghouse)	Anne-Marie Tassé
11:35	- BBMRI-WIKI	Jasper Bovenberg
11:55	- HSERN: Human Sample Exchange Regulation Navigator	Gauthier Chassang
12:15	- BioMedBridges online tool for the assessment of legal and ethical requirements	Murat Sariyar
12:35	- Resource Entitlement Management System (REMS)	Jaakko Leinonen
12:55	Discussion: ethical and legal requirement resources	

13:15	Lunch	
Identifying synergies and collaboration potential		
14:00	Mapping tools and resources/requirements	Chair: Murat Sariyar
14:30	Group sessions: defining gaps and integration potential	Facilitator: Steffi Suhr
15:30	Feedback from group sessions	
16:00	Coffee break	
16:15	Discussion: integrating tools	
16:45	Workshop summary	
17:00	End of workshop	

Workshop outline

- Venue: TMF rooms, Berlin, Germany
- Date: 30 June 2014
- Workshop chair: TMF
- Organisers: Murat Sariyar, Krister Helbing, Irene Schlünder (TMF)
- Administrative support: Juliane Gehrke (TMF)
- Participation: By invitation

Background

BioMedBridges establishes data interoperability between twelve emerging European life science research infrastructures. Some of these data underlie ethical and/or legal constraints, and combining different data resources and sharing data across borders can bring up a number of additional challenges. Navigating the complex landscape of national and European laws while addressing potential ethical concerns is difficult if not impossible for the individual researcher trying to use valuable data resources to address a scientific question.

Workshop overview

This knowledge exchange workshop will provide a forum to investigate collaboration potential between related initiatives providing tools and resources supporting researchers in the assessment of legal and ethical requirements connected to sharing and using life science data. In interactive discussions, possible integrative solutions will be explored that would maximise support to researchers.

Presentations on the new EU data protection regulation and resulting requirements for life science research will set the frame for the following sessions. Biomedical science research infrastructures and external participants will then briefly present their perspectives and potential solutions. In interactive discussions, (1) feedback on suggested solutions will be provided and (2) these solutions will be evaluated through gap analyses. Finally, integration potential as well as potential collaborations will be investigated.

Audience

This workshop is for biomedical researchers and research infrastructure operators facing data protection issues as well as other experts in the field. Participants will bring knowledge of the needs and background surrounding data protection as well as currently available services and approaches for the assessment of legal requirements.

Workshop objectives

During the workshop participants will discuss the challenges of and solutions for legally compliant data exchange faced by biomedical science in Europe. Collaboration potential between different initiatives for integrating and enhancing existing solutions will be identified.

The workshop will:

— Define a list of current and potential future challenges faced by researchers when utilising sensitive data resources
— Create a list of existing tools and relevant resources on data protection
— Discuss recommendations for new collaborative solutions
— Propose how to action these solutions