

Resume and Conclusions from Day 1

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(Information and views set out in this presentation are those of the author and do not necessarily reflect the official opinion of the TMF e. V.)

1. Structured yellow pages are deemed important
 - Informing different stakeholders (Transparency)
 - Relevant (not necessary big!) biobanks should be covered

2. Biospecimen Locators are desired, but not easy to realize
 - ELSI issues (anonymity)
 - How to motivate participation („my treasure“)?
 - How open should such a registry be?

3. Regulations/Money are necessary
 - For motivating/enforcing registration
 - Soft criteria like transparency are frequently no incentives for action

4. Tracking of user queries

- Increases transparency
- Enables some control over user activities

5. Problems of definitions

- What is a biobank?
- What are sample collections?
- Needs a context-dependent operational definition.

6. Do not

- Rely on utility metrics for assessing your performance
- Try to validate the quality of your data (up to the user)

7. Is sample sharing a realistic task for registries?
8. How (structured) should quality be captured?
9. To what extent is the registry responsible for the content?
10. What kind of additional services should a registry offer?
11. Should we define/have recourse to use-cases?
 - Typical scenarios of inquiries
 - Informing the data Model (MIABIS)
12. BBMRI ↔ National Nodes?