

BBMRI - INSERM BRIF WORKSHOP

Bio-resources for sharing: which communities and what specific needs

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Sharing bio-resources: Communities involved

- Universities and research institutes
- Private companies
- Hospitals
- Other biobanks

- All above both national and international



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Specific needs for data sharing (1)

- Clear legal and ethical documentation
- Quality control, SOP (ISO standards)
- Proven quality of the phenotyping and biological samples (documentation, protocols)
- Supporting scientific information (e.g. sequencing, genotyping data)



Specific needs for data sharing (2)

- Transparent pricing
- Institutional support throughout the collaboration
- Labeling system allowing tracking
- Recontacting



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Additional data sharing

- Longterm follow up with the option for feedback leads to possible data sharing:
- With gene donors
 - As expected by the Estonian Human Genome Research Act
 - Accompanied by medical counselling
- With family physicians
 - Genomic data provided among all other health information



An idea for Documenting bio-resource use

- Tracking a biobank's data sharing and collaborations
- Documentation on data and sample export readily available (e.g. On BBMRI or P3G websites)



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Documenting Estonian Biobank's bio-resource use

Released to	Institution	DNA	Plasma	Serum	RNA	WBC	Total
Estonia	Estonian Biocentre	1981					1981
	Estonian Genome Center, University of Tartu	21592					21592
	Tartu University Hospital's Women's Clinic	1000	698				1698
	The Institute of Molecular and Cell Biology (IMCB), University of Tartu	180	1069		1069		2318
	The Institute of Molecular and Cell Biology (IMCB), University of Tartu and Estonian Biocentre	1181					1181
	Institute of Gene Technology, Tallinn Technology Institute	300					300
	Institute of Chemistry, University of Tartu		20				20
	Department of General and Molecular Pathology, Chair of Immunology, University of Tartu		300				300
	Egeen AS	400					400
Abroad	University of Leicester, United Kingdom	3337					3337
	Erasmus Medical Center, Rotterdam, Netherlands	8					8
	Institute for Molecular Medicine, Finland		5066				5066
	Institute of Human Genetics, Helmholtz Zentrum München, Germany			1124			1124
	University of Lausanne, Switzerland	70				70	140
	McGill University, Canada	1000					1000
	Örebro University, Sweden	400					400
Total:		31449	7153	1124	1069	70	40865



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Thank you!

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