

The German Biobank Registry – Vision & Lessons Learned



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Working Groups of TMF



„Human biobank“: postgenomic child



2001

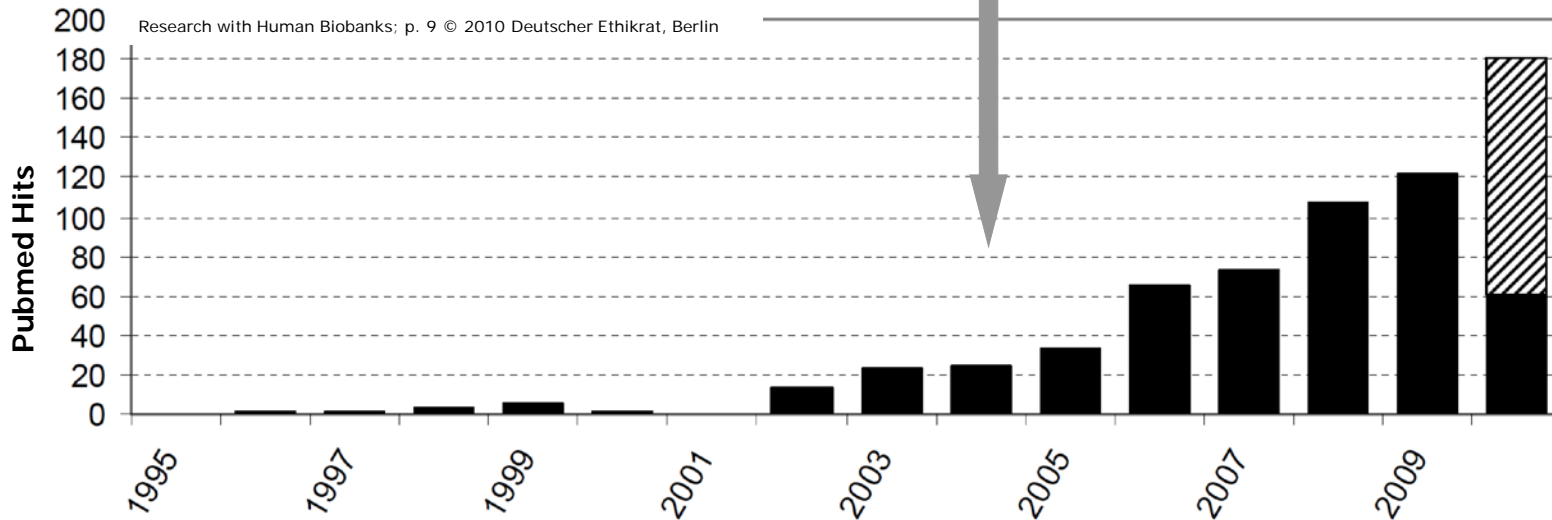
articles

Finishing the euchromatic sequence of the human genome

International Human Genome Sequencing Consortium*

*A list of authors and their affiliations appears in the Supplementary Information

The sequence of the human genome encodes the genetic instructions for human physiology, as well as rich information about human evolution. In 2001, the International Human Genome Sequencing Consortium reported a draft sequence of the euchromatic portion of the human genome. Since then, the international collaboration has worked to convert this draft into a genome sequence with high accuracy and nearly complete coverage. Here, we report the result of this finishing process. The current genome sequence (Build 30) contains 2.85 billion nucleotides interrupted by only 241 gaps. It covers ~99% of the euchromatic genome and is accurate to an error rate of ~1 error per 100,000 bases. Many of the remaining euchromatic gaps are associated with segmental duplications and will require focused work with new methods. The near-complete sequence, the first for a vertebrate, greatly improves the precision of biological analyses of the human genome including studies of gene number, birth and death. Notably, the human genome seems to encode only 20,000–25,000 protein-coding genes. The genome sequence reported here should serve as a firm foundation for biomedical research in the decades ahead.





Key benefits of a biobank registry

German Health Research Council

(December 12, 2008)

Visibility *national – international*

- co-operation & collaboration, e. g. Pan-European infrastructures (BBMRI-ERIC)
- data & sample exchange, e. g. Global Alliance for Genomics and Health

Resource „human biospecimen“

- avoiding redundancy
- preventing depletion of precious biospecimens
- harmonisation / standardization of quality management

German Ethics Council

(June 15, 2010)

Transparency *ethics & regulations*

- funding
- informed consent – open consent
- privacy & data protection
- public awareness (patients, donors)
- trust in biomedical research

Proof of Excellence

- in research
- know-how transfer
- competition for grants

BMBF-funding: www.biobanken.de
 TMF | 2010-2012



Nation-wide visibility of biobanks

- biospecimens (type, number, storage)
- disease, phenotype (e. g. ICD, OMIM, MeSH)
- availability of biospecimen and associated data according to consent
- funding

Module I
 Aggregated
 Biobank Internals

Online-Forum



- platform for biobanking-specific topics

Module II
 Communication
 Forum

Project-mediating portal at the sample level

– P2B2 (Fraunhofer IMBT)

- in GBR registered biobanks are eligible to participate in P2B2 (voluntary!)

Module III
 „Sample Locator“

Modules

Search in registry:
Browsing by default

Register field

Checkboxes
single / multiple
selection

Magnifier: Simple view

Pdf-report of selections

[DE](#) | [EN](#) | [Register](#) | [Login](#)

Deutsches Biobanken-Register

Home
About us
News
Biobanks
Projectportal
User Forum
Symposium

Browse
Search

Filter set in following Views

No Filters selected

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Biobanks
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Filter	+Biobank	+City	+Website
<input type="checkbox"/>	ARCAGE-Bremen *	Bremen	http://www.bips.uni-bremen.de/projekte.php?projID=48
<input type="checkbox"/>	ASK-Tx	Gauting	http://www.asklepios.com/klinik/default.aspx?cid=685&pc=04&did2=307538
<input type="checkbox"/>	AVG - UKJ	Jena	http://www.avc.uniklinikum-jena.de/Klinik+f%C3%BCr+Allgemein+Viszeral+und+G%C3%A4%C3%9Fchirurgie.html
<input checked="" type="checkbox"/>	BBGRND *	Bonn	http://www.kompetenznetz-depression.de/
<input type="checkbox"/>	BBTU	München	http://www.path.med.tum.de/index.php?id=7
<input type="checkbox"/>	BKB	Sulzbach	http://www.biokryo.com
<input type="checkbox"/>	BLTB *	Bonn	http://www.kinderkrebsinfo.de/fachinformationen/zentrale_einrichtungen/tumorbanken/tumorbank_fuer_solide_tumoren/index_ger.html
<input type="checkbox"/>	BMB HSP *	Jena	http://www.uniklinikum-jena.de/Wir_%C3%BCber_uns.html
<input type="checkbox"/>	BMB Vascular Anomaly *	Freiburg	http://www.uniklinik-freiburg.de/kinderklinik/live/ambulanzen/haemanqiomrunde.html
<input type="checkbox"/>	BMB*of EWOG-MDS/JMML	Freiburg	http://www.ewog-mds.org/
<input type="checkbox"/>	BMBH	Heidelberg	http://www.biobank-heidelberg.de
<input type="checkbox"/>	BMBM LT	Mainz	http://www.unimedizin-mainz.de/pkmp/uebersicht.html

124element(s)

Select all
Delete all filters

Create report



PDF report

COSYCONET

Generiert durch <http://www.biobanken.de>

Biobank

Akronym COSYCONET
Name German COPD and Systemic Consequences - Comorbidities Network
Institution / Organisation Universität des Saarlandes, Klinik für Innere Medizin V, Pneumologie
Netzwerk asconet.e-trials.de
Straße Kirrberger-Str. 100
 66424 Homburg
 Saarland
Website www.asconet.net/html/cosyconet/teilprojekt4

Biobank

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Website oder Homepage des Ansprechpartners

Förderungen

Förderinstitution	Förderkennzeichen	Förderbeginn	Förderende
BMBF (Bundesministerium für Bildung, Wissenschaft, Forschung und Technologie)	01GI0881	01.11.2008	31.01.2012

Funding

Probandengruppen



Data sharing according to informed consent
Sample sharing according to informed consent

Age Group

Sex

Persons

COSYCONET

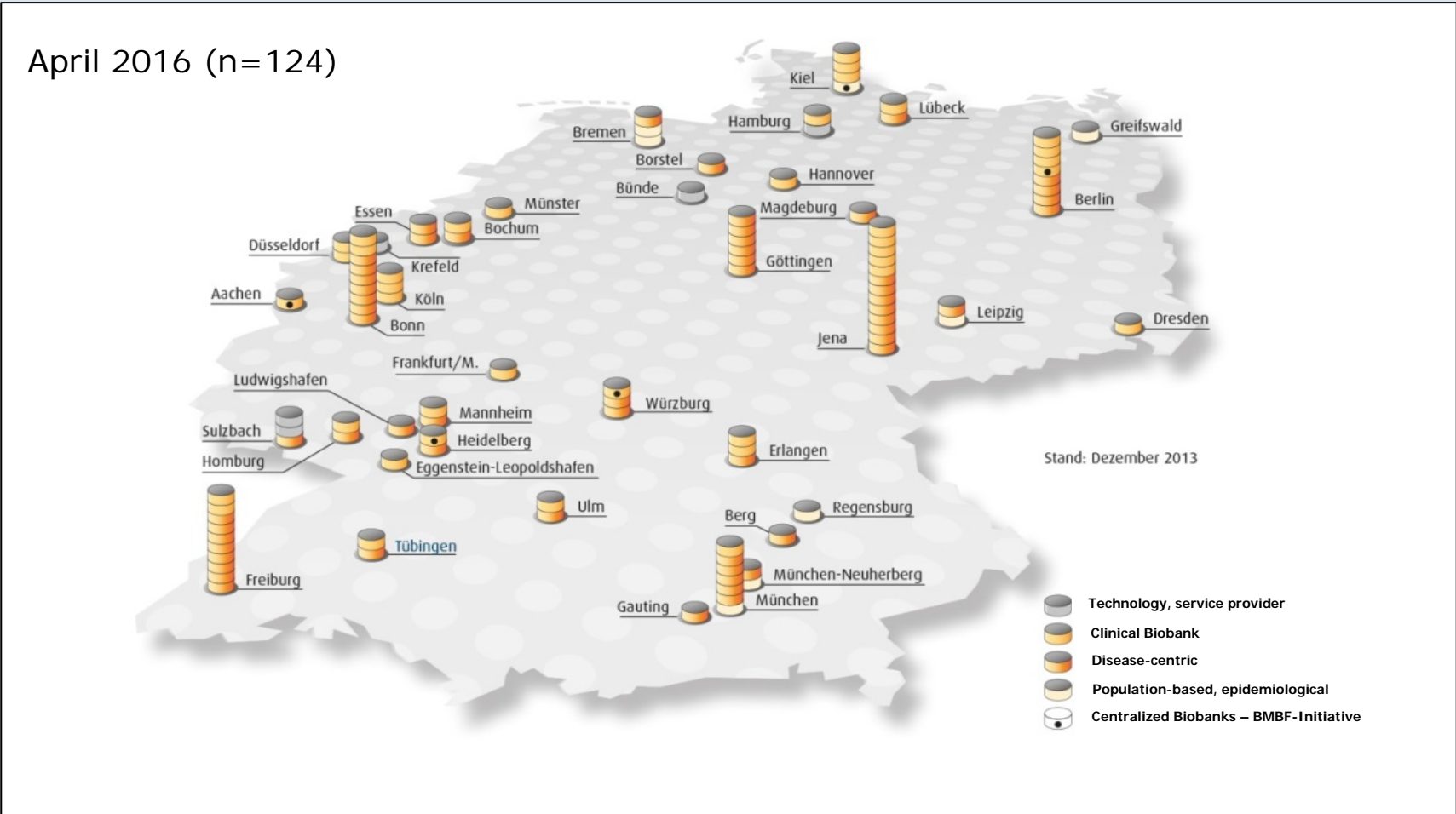
Probandengruppe	Phänotyp	Weitergabe von Daten	Weitergabe von Proben	Follow Up	Altersgruppe	Geschlecht	Anzahl
COPD	Sonstige chronische obstruktive Lungenkrankheit J44.0 ICD-10-GM 2012 Sonstige chronisch obstruktive Lungenkrankheit J44.1 ICD-10-GM 2012 Sonstige chronisch obstruktive Lungenkrankheit J44.2 ICD-10-GM 2012 Sonstige chronisch obstruktive Lungenkrankheit J44.3 ICD-10-GM 2012	Yes	Yes	Yes	adult	beide	1500

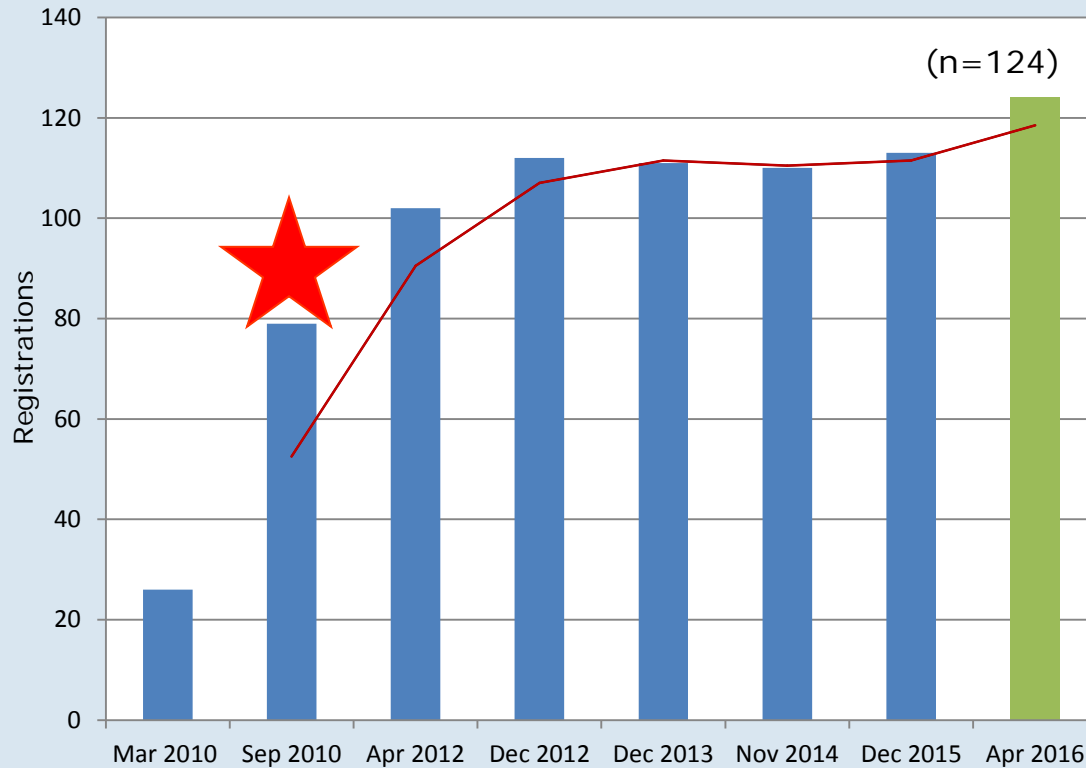
Biospecimen Type **Temperature** **Storage format** **Pre-analytic Doc.**

Materialgruppen						
Kodierung	Lagertemperatur	Lagerformat	SPREC code	Aliquots	min. Aliquots / Person	
Serum (SER)	-80 °C	450 µl Röhrchen	SER-SST-A-B-N-B-A	6800	3	
Serum (SER)	-150 °C (N2-Gasphase)	450 µl Röhrchen	SER-SST-A-B-N-B-A	7000	3	
Serum (SER) P100-stab	-150 °C (N2-Gasphase)	2,5 ml, Röhrchen	SER-PIX-A-B-N-B-A	1400	1	
Urine (URN)	-80 °C	450 µl Röhrchen	URN-PPS-A-B-N-B-A	13420	3	
Citrat-Blut	-80 °C	450 µl Röhrchen	SER-SST-A-B-N-A	8430	3	
Citrat-Blut	-150 °C (N2-Gasphase)	450 µl Röhrchen	SER-SST-A-B-N-A	8430	3	



Betsou et al. 2010

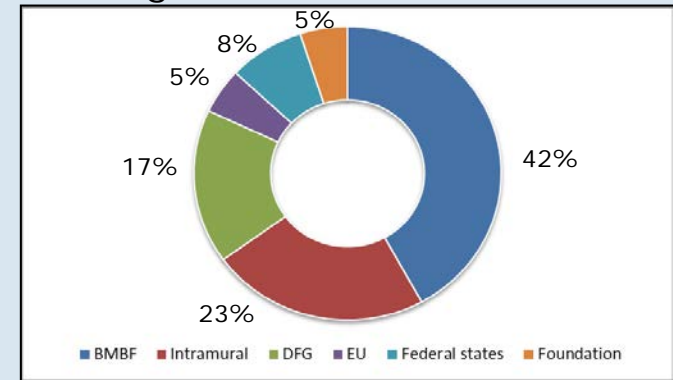




Biobank type

□ Clinical- / disease-centric	~90%
□ Population-based	~8%
□ Therapeutical, model orgs.	~2%

Funding





- ISBER: International Repository Locator (2014)

<https://www.irlocator.isber.org/>



- MIABIS 2.0-based Registries (Merino-Martinez et al. 2016. Biopreserv Biobank. 2016 Mar 15. [Epub ahead of print])

- EU: Catalogue of European Biobanks (2008/9)

www.bbmriportal.eu/bbmri2.0/jsp/core/login.jsf

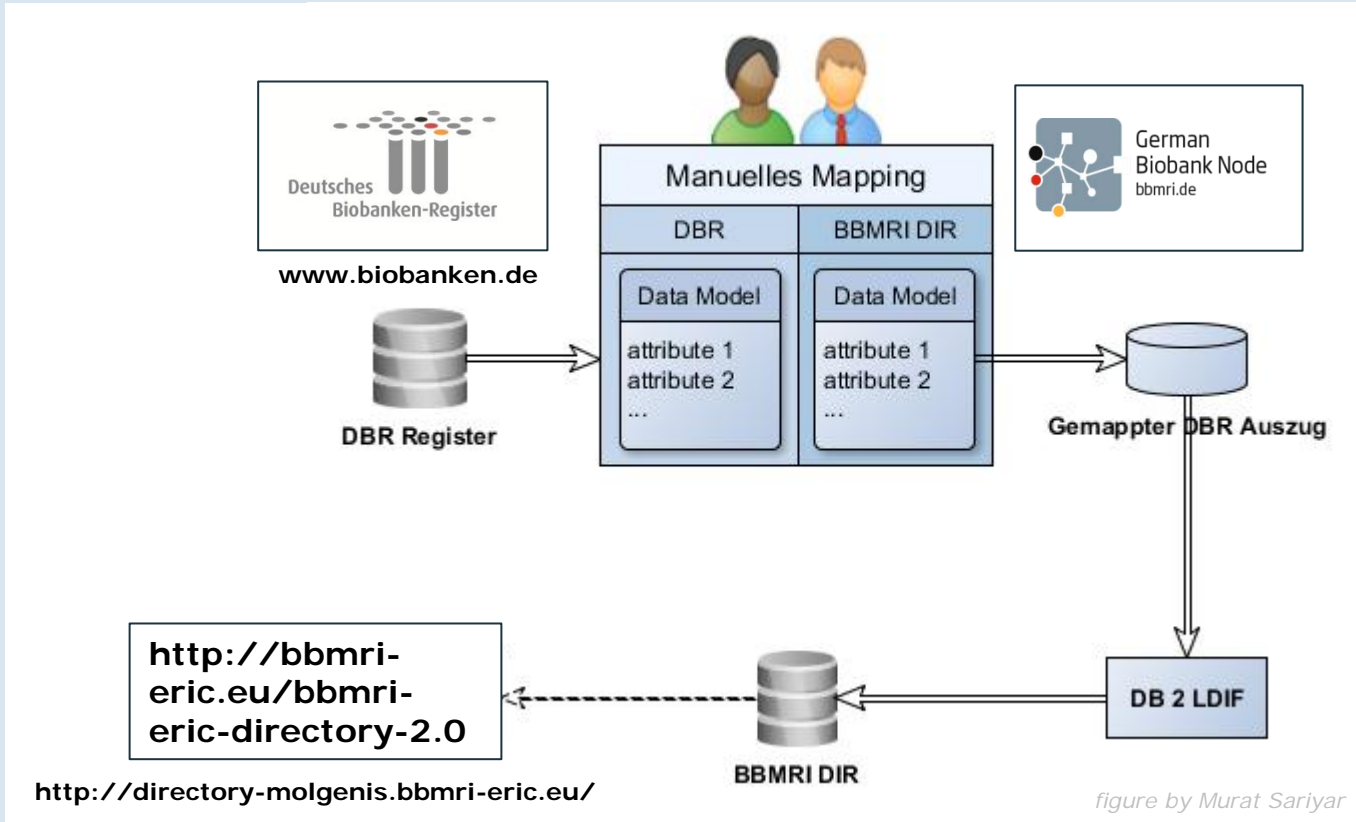
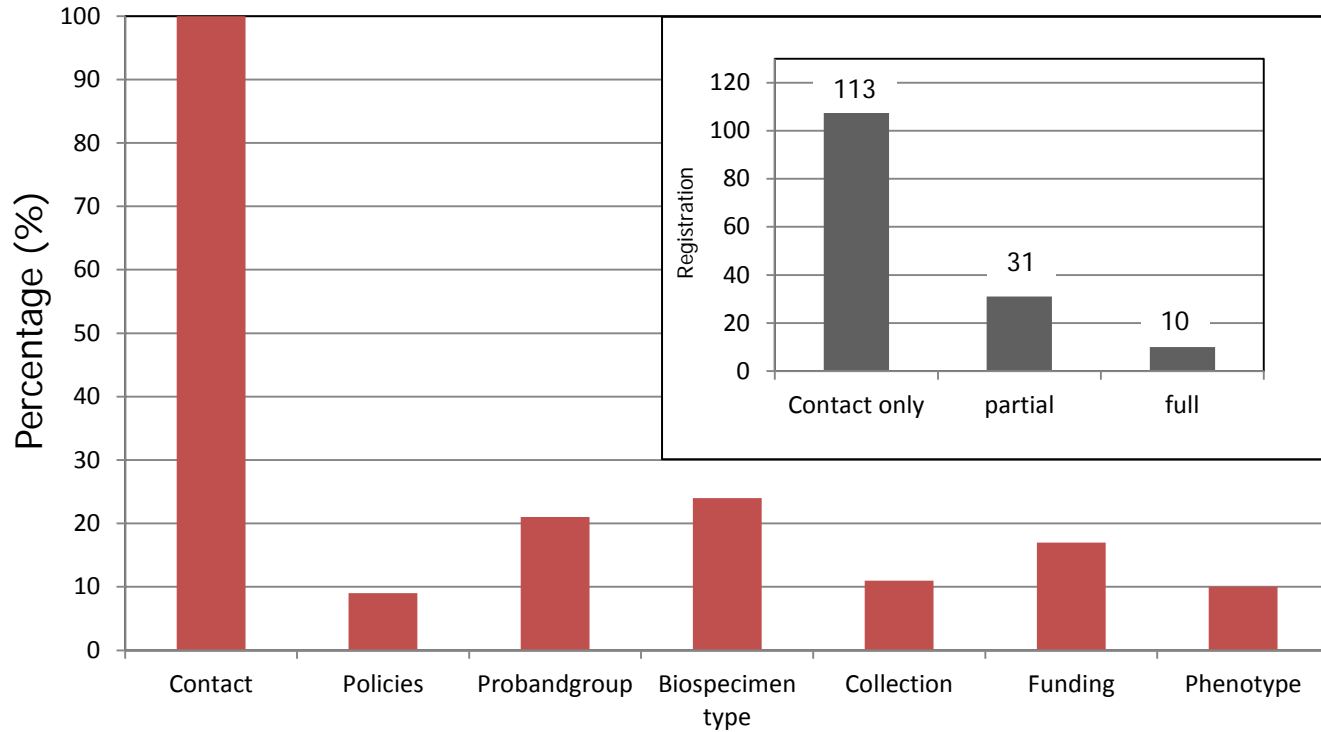


figure by Murat Sariyar



Dec 2015

legal anchoring

e. g. Finland, Spain

requirement by funding bodies / by ISO & DIN

criterion for getting research funded

demand (not recommendation!) by scientific publishers

author guidelines: source of biospecimen from a official registry as a first step toward quality awareness

improve IT for the „analog to digital conversion“

... that would allow to process the information about their many individual samples into an aggregated form – at the push of a button...

tools for use by biobank

analysis / statistics / visualization software – e. g. the Herniamed Registry
facilitation for certification and accreditation

- registry with aggregated data
- homes clinical, disease-centric, population-based & epidemiological biobanks (academia & industry), clinical relevant model organisms
- ICD-, OMIM, MeSH & other
- open source & platform-indep.
- interactive manual registration
- parsimony of register attributes (47)
- pre-analytic documentation (SPREC)
- export, import (xml, csv etc.) not yet implemented
- all data are publically visible
- free of charge – no membership
- linked to biobanking-specific user forum
- ...

Lessons

- embedding in national regulatory framework
- embedding in national funding policies
- embedding in international publishing and national / international standardization policies
- support IT competence to overcome gap in “analog to digital conversion”

Acknowledgement



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 Murat Sariyar, Charité Berlin TMF
 Sebastian C. Semler, TMF

More information:

- www.biobanken.de
- www.tmf-ev.de
- roman.siddiqui@tmf-ev.de





31 attributes mandatory
16 attributes optional
47 attributes in total

Biobank

- BiobankName**
- BiobankAcronym
- BiobankLegalEntity
- BiobankStreet
- BiobankZip
- BiobankCity
- BiobankCounty
- BiobankURL
- BiobankNetworkURL*
- ContactLastName**
- ContactFirstName
- ContactEmail
- ContactTitle*
- ContactFunction*
- ContactURL*
- PolicyURL**
- PolicyDescription
- FundingBody**
- FundingID
- FundingStart
- FundingEnd*
- CollectionName

16 mandatory
5 optional
21 for Biobank

Collection/Probandgroup

- CollectionName
- CollectionPersonNumber
- CollectionNumberAliquots
- CollectionMinAliquots*
- BiospecimenID**
- BiospecimenType**
- BiospecimenStorageTemp
- BiospecimenNumberAliquots
- BiospecimenStoreFormat
- BiospecimenMinAliquots*
- BiospecimenSPREC*
- ProbandgroupName**
- ProbandgroupNumber
- ProbandgroupSampleSharing
- ProbandgroupDataSharing
- ProbandgroupFollowUp*
- ProbandgroupAgeNewborne*
- ProbandgroupAgeJuvenile*
- ProbandgroupAgeAdult*
- ProbandgroupAgeOLD*
- ProbandgroupSexMale*
- ProbandgroupSexFemale*
- ProbandgroupSexMaleplusFemale*
- PhenotypeDescription**
- PhenotypeCode
- PhenotypeClassificationVersion

15 mandatory
11 optional
26 for Collection/Proband