

„Sharing experiences and lessons while operating National Biobank Registers“

Germany

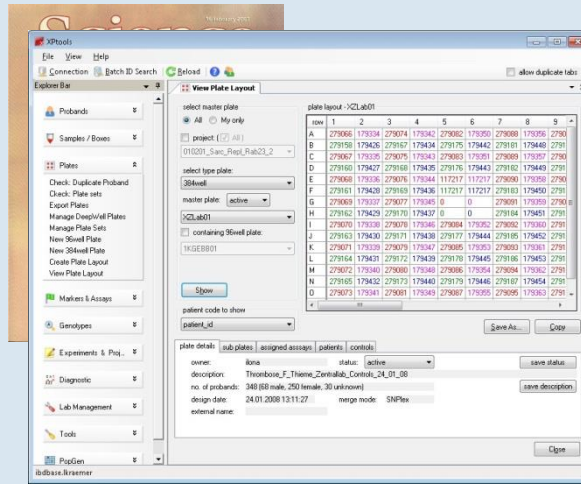
The German Biobank Registry

www.biobanken.de

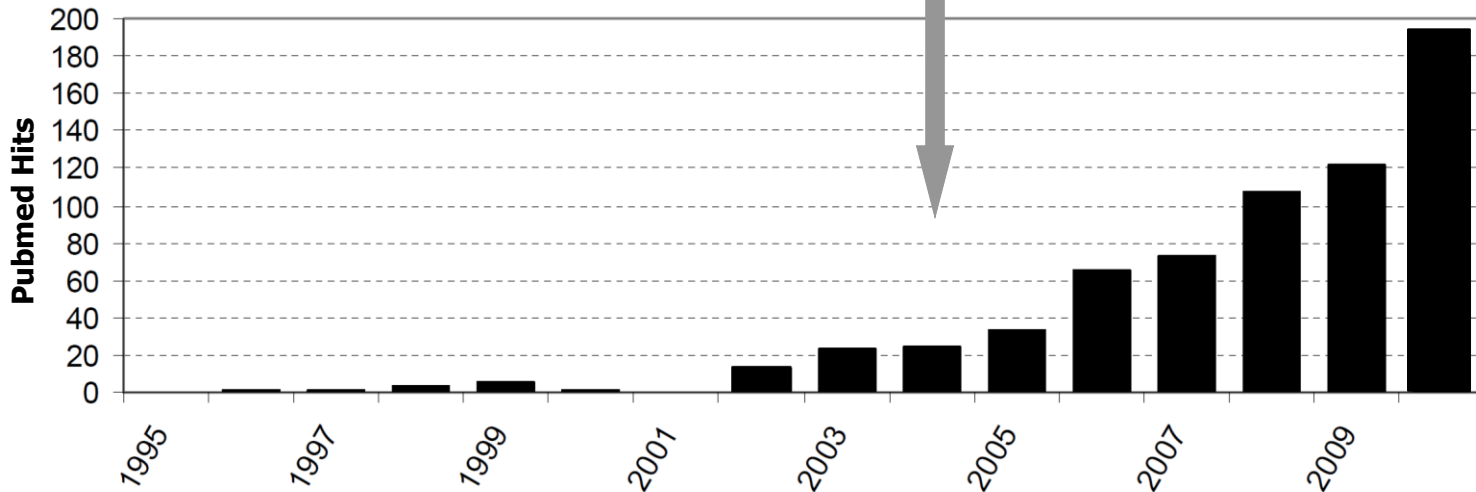
Roman Siddiqui, TMF e. V.



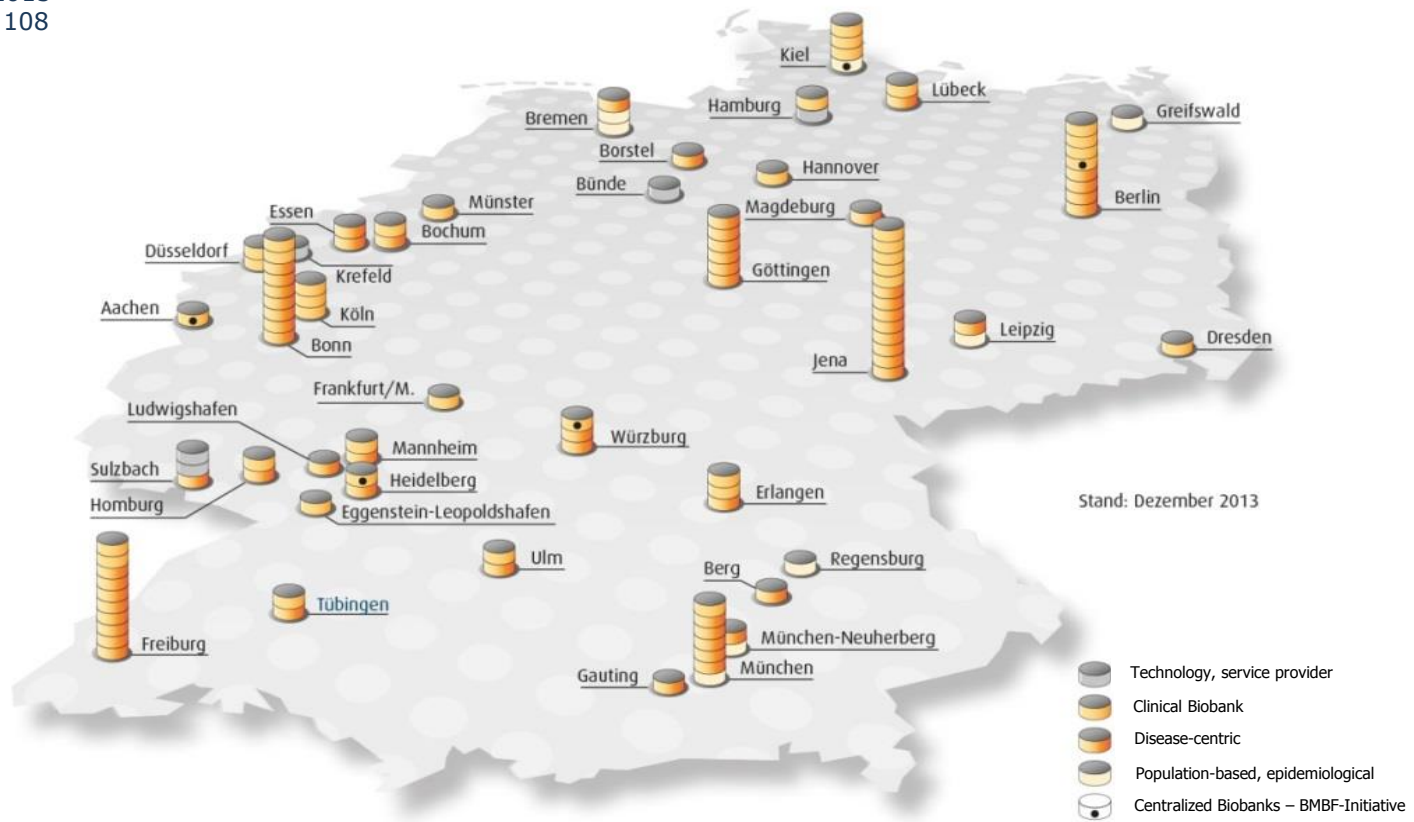
(Information and views set out in this presentation are those of the author and do not necessarily reflect the official opinion of the TMF e. V.)



“OMICS & NEXT-GENSEQ”



February 2015
Biobanks: 108



BMB-Characteristics (n=108):

- clinical- / disease oriented: ~86%
- epidemiological: ~8%
- therapeut., modelorg. etc.: ~2%

„Resource human biospecimen“

- avoiding redundant research
- preventing depletion of human biospecimen
- harmonisation of quality management

Transparency *bioethics & regulations*

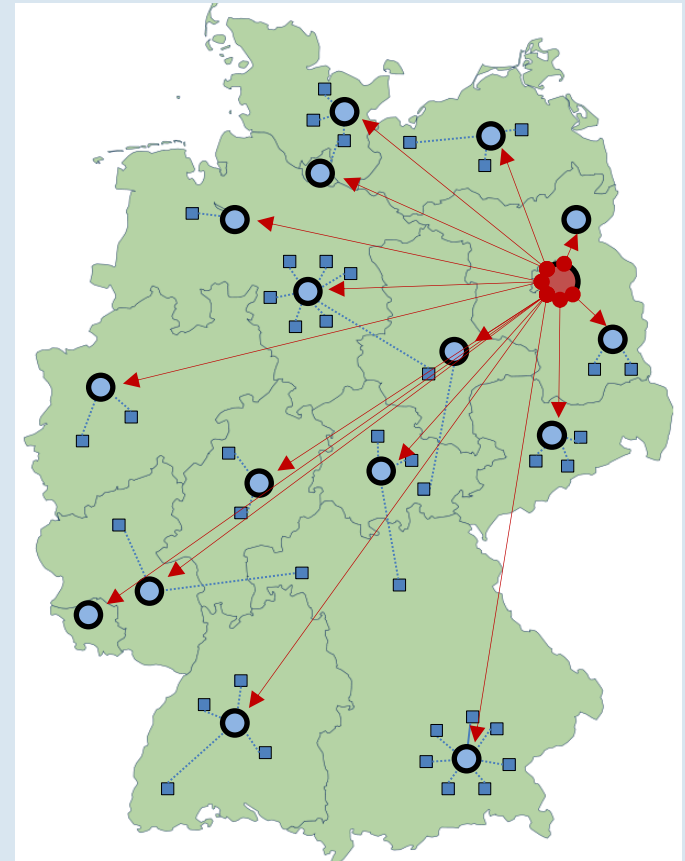
- funding
- public awareness (patients, donors)
- informed consent – open consent
- ensuring privacy & data protection
- biobank secrecy
- trust

Visibility *national – international*

- Pan-European Infrastructures (BBMRI-ERIC)
- co-operation & collaboration
- data & sample exchange

Proof of Excellence

- for research
- competition for grants

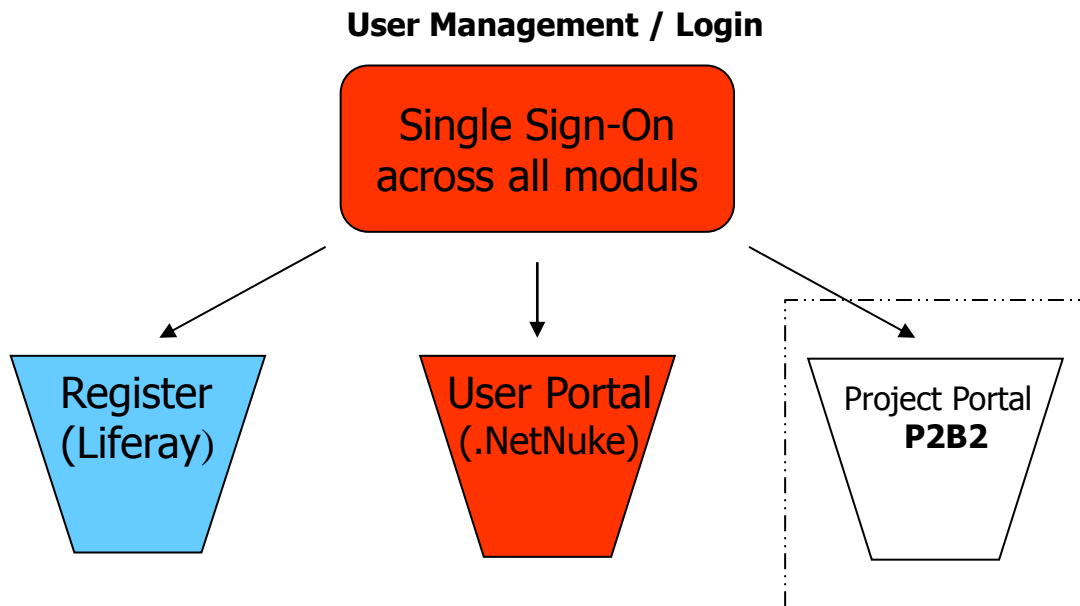


Register
database

User
Forum

Biospecimen
Locator

	Allowed to register a biobank	Search Profile Saving	Search	User Forum Read & write	User Forum Read only	P2B2
Authorized USER						
Guest	no	no		no		no



- **Liferay (Registry Application)**
 - **Java based Content Management System**
 - **Database: MySQL**
 - **Tomcat Webserver**
- **DotNetNuke (User Portal)**
 - **ASP.NET**
 - **Database: MSSQL 2010**
 - **IIS Webserver**

PHP | PEARL | SQL

Access to Biobank-based Projects - at the sample level - biospecimen locator

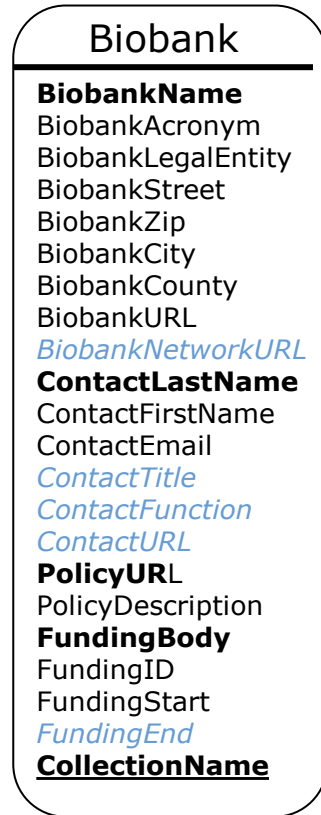
Tool integrated since 2013 in the German Biobank Registry - (P2B2)
 by Dr. C. Schröder,
 (Fraunhofer IZI, Potsdam)

Use Cases

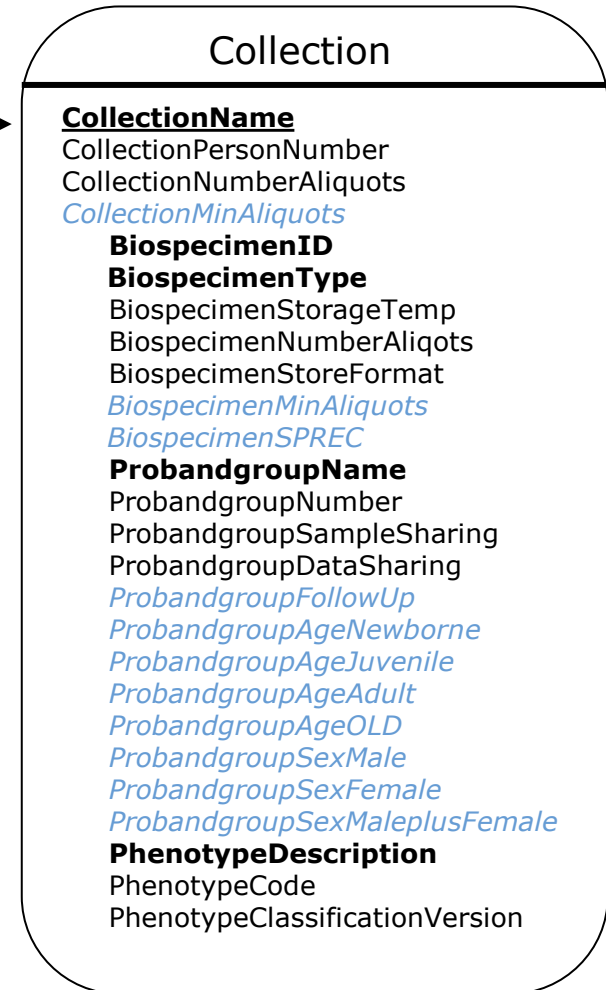
- minimum data set must allow heterogenous biobanks, to get registered
- register data set must allow to maintain easily a concise biobank profile in an actual state
- search for biospecimen collections, research focus (the diseases investigated) of one specified, or more selected biobanks
- all biobanks with data for probands with a special disease (ICD-, MeSH, OMIM, other classification systems)
- what kind of diseases or conditions are being studied in selected areas of the country
- search, which disease areas are over-represented in the country
- which funding bodies support what kind of research
- ...



31 attribute mandatory
16 attributes optional
47 attributes overall

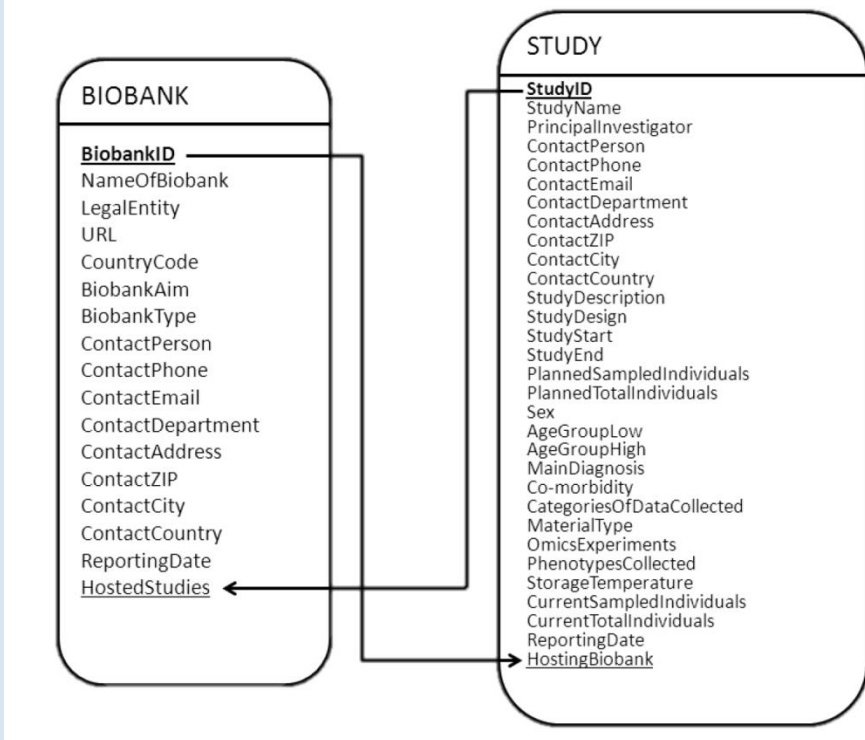


16 mandatory
5 optional
21 overall

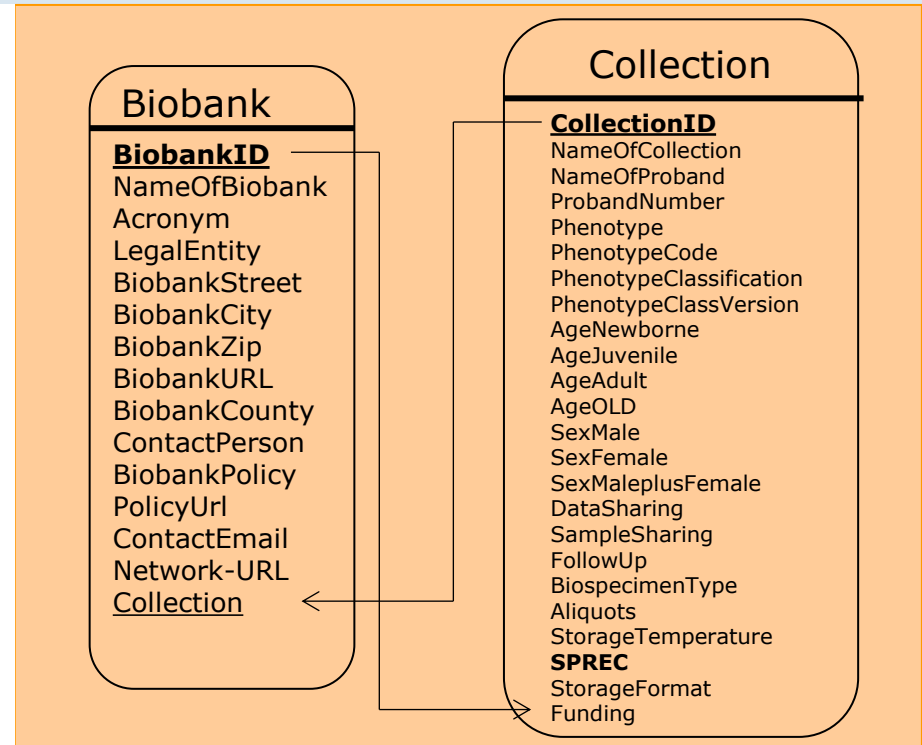


15 mandatory
11 optional
26 overall

BBMRI.se - Sample Collection Register



German Biobank Registry (DBR)



Jan-Eric Litton
EuroBioForum
Is Europe ready for Personal Medicine?
18 April 2012, The Dominican Hotel,
Brussels

„Retrospective“ - study-centric vs. collection-centric

Moduls

**Search in registry:
Browsing by default**

Different Views

**Checkboxes
single / multiple
selection**

Magnifier: Simple View

pdf-Report of selections

The screenshot shows the website interface for the German Biobank Register. At the top, there is a navigation bar with 'Home', 'Biobanken', 'User Portal', 'P2B2', 'News', and 'Über uns'. Below this is a search bar and a 'Filter gesetzt in folgenden Ansichten' section. A table lists various biobanks with columns for 'Biobank', 'Ort', 'Website', and 'Updated'. The table is annotated with a red box and an arrow pointing to the 'Updated' column, labeled 'Date of database entry'. On the left side, there are logos for the 'Bundministerium für Bildung und Forschung' and 'TMF'. At the bottom, there are buttons for 'Alles auswählen', 'Alle Filter löschen', and 'Report erstellen'.

Filter	*Biobank	*Ort	*Website	*Updated
<input type="checkbox"/>	ARCAGE-Bremen *	Bremen	http://www.bips.uni-bremen.de/projekte.php?projID=48	09.01.2012
<input type="checkbox"/>	ASK-TX *	Gauting	http://www.askleprios.com/klinik/default.aspx?cid=685&pc=04&did2=307538	05.12.2011
<input type="checkbox"/>	BBGRND *	Bonn	http://www.kompetenznetz-depression.de/	29.11.2011
<input type="checkbox"/>	BDB *	Freiburg	http://www.uniklinik-freiburg.de/p/splash/start.html	02.12.2011
<input type="checkbox"/>	BDB BRK *	München	http://www.bio-bank.de/de/index.php	29.11.2011
<input type="checkbox"/>	BKB *	Sulzbach	http://www.biokryo.de	14.03.2012
<input type="checkbox"/>	BLTB *	Bonn	http://www.kinderkrebsinfo.de/e2381/e2411/e8699/index_qerhtml#12.10.2005	29.11.2011
<input type="checkbox"/>	BMB HSP *	Jena	http://www.uniklinikum-jena.de/Wir_%C3%BCber_uns.html	01.12.2011
<input type="checkbox"/>	BMB Vascular Anomaly *	Freiburg	http://www.uniklinik-freiburg.de/kinderklinik/live/ambulanzen/haemangiomierrunde.html	01.12.2011
<input type="checkbox"/>	BMB*of EWOG-MDS/JMML	Freiburg	http://www.ewog-mds.org/	06.12.2011
<input type="checkbox"/>	BMB-CCCNKI *	Kiel	http://www.uni-kiel.de/moloncol/	05.12.2011
<input type="checkbox"/>	BMB-Patho CAU *	Kiel	http://www.uni-kiel.de/path/	05.12.2011

Query the register by two modes:

- Browse through the content
- search by filters „and“ / or“
- create reports

Deutsches Biobanken-Register

Home **Biobanken** User Portal P2B2 News Über uns

Browse Suchen

Filter gesetzt in folgenden Ansichten: Biobanken > **Phänotypen** Filter anzeigen Letzten Filter löschen

Filter	Phänotyp	Kodierung	Version	Biobank	Updated
<input type="checkbox"/>	Sonstige chronisch obstruktive Lungenerkrankheit	J44.1	ICD-10-GM 2012	COSYCONET	12.01.2012
<input checked="" type="checkbox"/>	Sonstige chronisch obstruktive Lungenerkrankheit	J44.2	ICD-10-GM 2012	COSYCONET	12.01.2012
<input checked="" type="checkbox"/>	Sonstige chronisch obstruktive Lungenerkrankheit	J44.3	ICD-10-GM 2012	COSYCONET	12.01.2012
<input type="checkbox"/>	Sonstige chronische obstruktive Lungenerkrankheit	J44.0	ICD-10-GM 2012	COSYCONET	12.01.2012
<input type="checkbox"/>	COPD	J43, J44	ICD-10-GM, 2011	EBSE	14.03.2012
<input checked="" type="checkbox"/>	Gallensteinleiden	K80	ICD-10-GM, 2010	EBSE	14.03.2012
<input type="checkbox"/>	Ikterus	R17	ICD-10-GM, 2010	EBSE	14.03.2012
<input type="checkbox"/>	Prostatakarzinom	C61	ICD-10-GM, 2012	EBSE	14.03.2012
<input type="checkbox"/>	Zirnhose	K74.3	ICD-10-GM, 2010	EBSE	14.03.2012
<input type="checkbox"/>	Niereninsuffizienz	N19	ICD-10-GM 2012	GCKD	21.03.2012
<input type="checkbox"/>	Adipositas und sonstige Überernährung	E65-E68	ICD-10-GM 2012	IBMB	21.04.2012
<input checked="" type="checkbox"/>	Diabetes mellitus	E10-E14	ICD-10-GM 2012	IBMB	21.04.2012
<input type="checkbox"/>	Entzündliche Krankheiten der weiblichen Beckenorgane	N70-N77	ICD-10-GM 2012	IBMB	21.04.2012
<input checked="" type="checkbox"/>	Krankheiten der Mamma (Brustdrüse)	N60-N64	ICD-10-GM 2012	IBMB	21.04.2012
<input type="checkbox"/>	Krankheiten des Atmungssystems	J00-J99	ICD-10-GM 2012	IBMB	21.04.2012

18 Element(e)
 Alles auswählen Alle Filter löschen
 Report erstellen

Alle mit einem Stern (*) markierten Biobanken wurden mit Ihren Kontaktdaten aus dem Vorläuferregister übernommen.

Deutsches Biobanken-Register

Home **Biobanken** User Portal P2B2 News Über uns

Browse Suchen

Suche nach: Biobanken enthält (nicht) %
 über: Materialgruppen enthält (nicht) well
 über: Phänotypen enthält (nicht) epp
 über: Sammlungen enthält (nicht) zB: Popgen, Berlin, KBB
 über: Förderungen enthält (nicht) zB: BMBF, NGNF

Filter hinzufügen Suchen Hilfe

Biobank	Ort	Website	Updated
Biopsy *	Mannheim	http://www.zimannheim.de/biobank.html	29.11.2011
COSYCONET	Homburg	http://www.asconet.net/html/cosyconet/06/03/0604.html	20.03.2012
EBSE	Berlin	http://www.biobanken.de	14.03.2012
IBMB	Stuttgart	http://www.ibm-consulting.de	21.04.2012
IBMB-StuttMann	Mannheim	http://www.ibm-consulting.de	21.04.2012

Selection of phenotypes → which biospecimens?



Home Über uns **Biobanken** User Portal Projektportal News

Browse

Suchen

Filter gesetzt in folgenden Ansichten

Phänotypen

Filter anzeigen

Letzten Filter löschen

Biobanken	Kontakte	Policies	Probandengruppen	Materialgruppen	Sammlungen	Förderungen	Phänotypen
Filter	Phänotyp	Kodierung	Version	Biobank	Updated		
<input checked="" type="checkbox"/>	Sonstige chronisch obstruktive Lungenkrankheit	J44.1	ICD-10-GM 2012	COSYCONET	12.01.2012		
<input type="checkbox"/>	Sonstige chronisch obstruktive Lungenkrankheit	J44.2	ICD-10-GM 2012	COSYCONET	12.01.2012		
<input type="checkbox"/>	Sonstige chronisch obstruktive Lungenkrankheit	J44.3	ICD-10-GM 2012	COSYCONET	12.01.2012		
<input type="checkbox"/>	Sonstige chronische obstruktive Lungenkrankheit	J44.0	ICD-10-GM 2012	COSYCONET	12.01.2012		
<input checked="" type="checkbox"/>	Niereninsuffizienz	N19	ICD-10-GM 2012	GCKD	21.03.2012		
<input type="checkbox"/>	entzündliche Erkrankungen	ICD-10	ICD-10 GM 2011	GEZEH	09.05.2012		
<input type="checkbox"/>	Angeborene Herzfehler	ICD-10 und EPCC (European Paediatric Cardiac Code, http://www.aepc.org/european-paediatric-cardiac-codi/)	ICD-10-GM 2012, EPCC Version May 2012	NRCHD	12.06.2012		
<input type="checkbox"/>	Tumore des CNS	C70-C72, C47	ICD-10-GM 2012	NTB	16.05.2012		
<input type="checkbox"/>	Brustkrebs	C50	ICD-10-GM 2011	PATH	21.03.2012		
<input type="checkbox"/>	Essentieller Tremor	G25.0	ICD-10 GM V2012	Popgen	02.05.2012		
<input type="checkbox"/>	Hirnfarkt	I63.0 - 63.9	ICD-10 GM V.2012	Popgen	02.05.2012		
<input type="checkbox"/>	Patients undergoing heart surgery on cardiopulmonary bypass	*	*	Popgen	26.04.2012		
<input type="checkbox"/>	Primäres Parkinson-Syndrom	G20	ICD-10 GM V2012	Popgen	02.05.2012		
<input checked="" type="checkbox"/>	Sarcoidosis	D86	ICD-10-GM 2012	Popgen	27.04.2012		
<input type="checkbox"/>	ICD-10	C40	ICD-10	TranSaRNet	31.08.2012		

17 Element(e)

Alles auswählen

Alle Filter löschen

Report erstellen

GEFÖRDERT VOM



Bundesministerium
für Bildung
und Forschung

BETRIEBEN DURCH



Result for biospecimens associated with the phenotypes, selected before

Home Über uns **Biobanken** User Portal Projektportal News



Browse

Suchen

Filter gesetzt in folgenden Ansichten

Phänotypen

Filter anzeigen

Letzten Filter löschen

Biobanken Kontakte Policies Probandengruppen **Materialgruppen** Sammlungen Förderungen Phänotypen

Filter	↕ Material	↕ Anzahl Aliquots / Schnitte / Blöcke	↑ Biobank	↕ Updated
<input type="checkbox"/>	Citrat-Blut	8430	COSYCONET	15.11.2012
<input type="checkbox"/>	Citrat-Blut	8430	COSYCONET	15.11.2012
<input type="checkbox"/>	Serum (SER)	6800	COSYCONET	15.11.2012
<input type="checkbox"/>	Serum (SER)	7000	COSYCONET	15.11.2012
<input type="checkbox"/>	Serum (SER) P100-stab	1400	COSYCONET	15.11.2012
<input type="checkbox"/>	Urine (URN)	13420	COSYCONET	15.11.2012
<input type="checkbox"/>	EDTA-Plasma	4378	GCKD	24.02.2012
<input type="checkbox"/>	EDTA-Vollblut	3000	GCKD	24.02.2012
<input type="checkbox"/>	Lithium-Heparin-Plasma	4378	GCKD	24.02.2012
<input type="checkbox"/>	Serum (SER)	13150	GCKD	24.02.2012
<input type="checkbox"/>	Urin zentrifug.	13134	GCKD	24.02.2012
<input type="checkbox"/>	DNA	1	Popgen	02.04.2012
<input type="checkbox"/>	EDTA-Blut	1	Popgen	02.04.2012
<input type="checkbox"/>	RNA PaxGene	1	Popgen	02.04.2012

14 Element(e)

Alles auswählen

Alle Filter löschen

Report erstellen

GEFÖRDERT VOM



Bundesministerium
für Bildung
und Forschung

BETRIEBEN DURCH





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

Kontakte

Dr.rer.physiol. Christian Herr

Funktion Administrator
E-Mail christian.herr@uks.eu

Contact

Website oder Homepage des Ansprechpartners

Prof. Dr. med. Dr. rer. nat. Robert Bals

Funktion Director
E-Mail Robert.Bals@uks.eu

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



COSYCONET		Data sharing according to informed consent	Sample sharing according to informed consent		Age Group	Sex	Persons
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 Storage temperature Storage format Pre-Analytics

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

Overall

31 attributes sufficient

16 attributes optional

47 attributes overall

Biobank-centric

16 sufficient

5 optional

21 overall

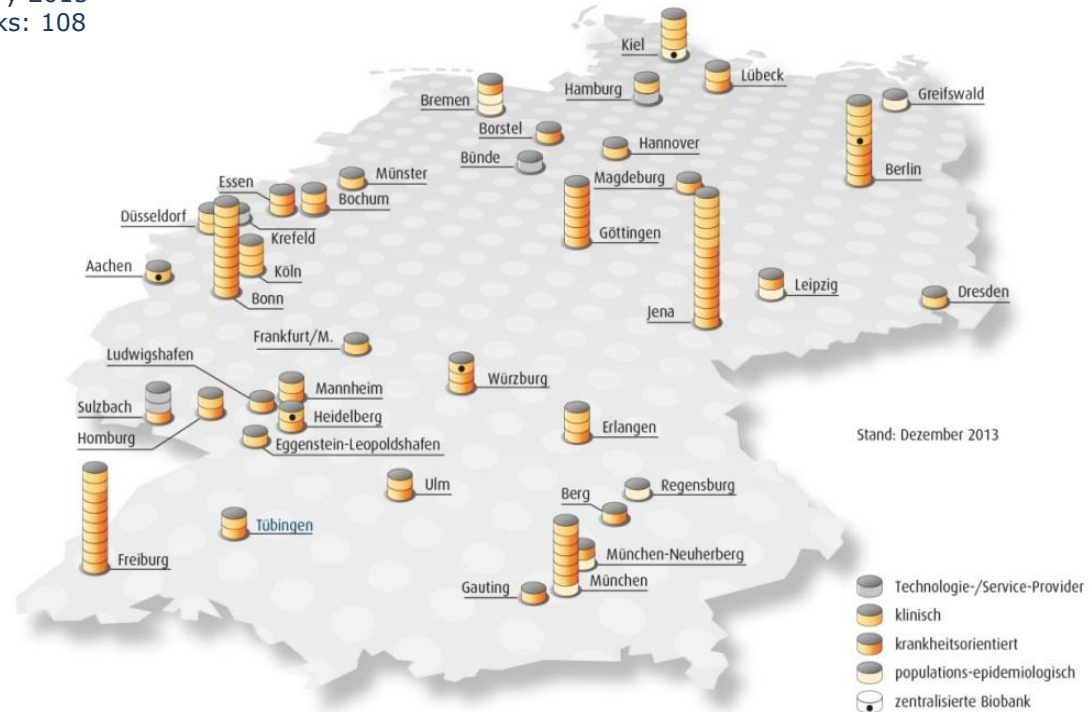
Collection-centric

15 sufficient

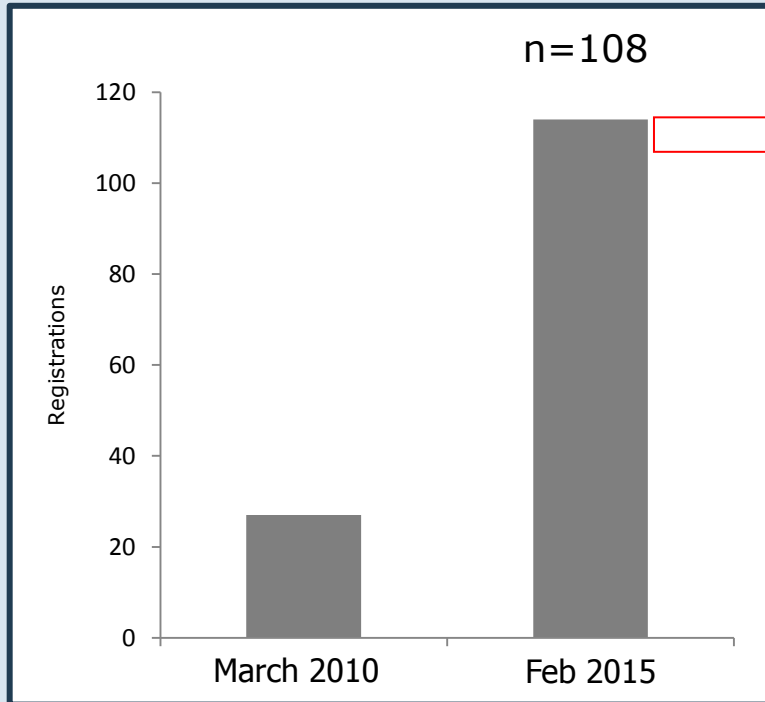
11 optional

26 overall

February 2015
Biobanks: 108



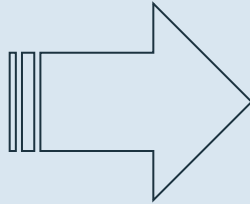
How many Biobanks / biospecimen collections?



36 ¹GERMAN MED. FACULTIES X **30**_{BMBS} = **1080**

50 disease-oriented specimen collections / biobanks
in **medical university / faculty Innsbruck, AT**
(Hofer et al. Stud Health Technol Inform. 2014; 205:293-7)

¹(www.mft-online.de)



The screenshot shows the Xptools software interface. The main window is titled 'View Plate Layout' and displays a grid of sample IDs for a plate layout named 'XZLab01'. The grid has 16 rows (A-O) and 9 columns (1-9). Below the grid, there are fields for 'patient code to show' and 'patient_id'. At the bottom, there is a 'plate details' section with tabs for 'sub plates', 'assigned assays', 'patients', and 'controls'. The 'patients' tab is selected, showing details for a patient named 'ilona' with a status of 'active'. The details include a description, number of probands (348), design date (24.01.2008 13:11:27), and merge mode (SNPlex).

row	1	2	3	4	5	6	7	8	9
A	279066	179334	279074	179342	279082	179350	279088	179356	2790
B	279158	179426	279167	179434	279175	179442	279181	179448	2791
C	279067	179335	279075	179343	279083	179351	279089	179357	2790
D	279160	179427	279168	179435	279176	179443	279182	179449	2791
E	279068	179336	279076	179344	117217	117217	279090	179358	2790
F	279161	179428	279169	179436	117217	117217	279183	179450	2791
G	279069	179337	279077	179345	0	0	279091	179359	2790
H	279162	179429	279170	179437	0	0	279184	179451	2791
I	279070	179338	279078	179346	279084	179352	279092	179360	2791
J	279163	179430	279171	179438	279177	179444	279185	179452	2791
K	279071	179339	279079	179347	279085	179353	279093	179361	2791
L	279164	179431	279172	179439	279178	179445	279186	179453	2791
M	279072	179340	279080	179348	279086	179354	279094	179362	2791
N	279165	179432	279173	179440	279179	179446	279187	179454	2791
O	279073	179341	279081	179349	279087	179355	279095	179363	2791

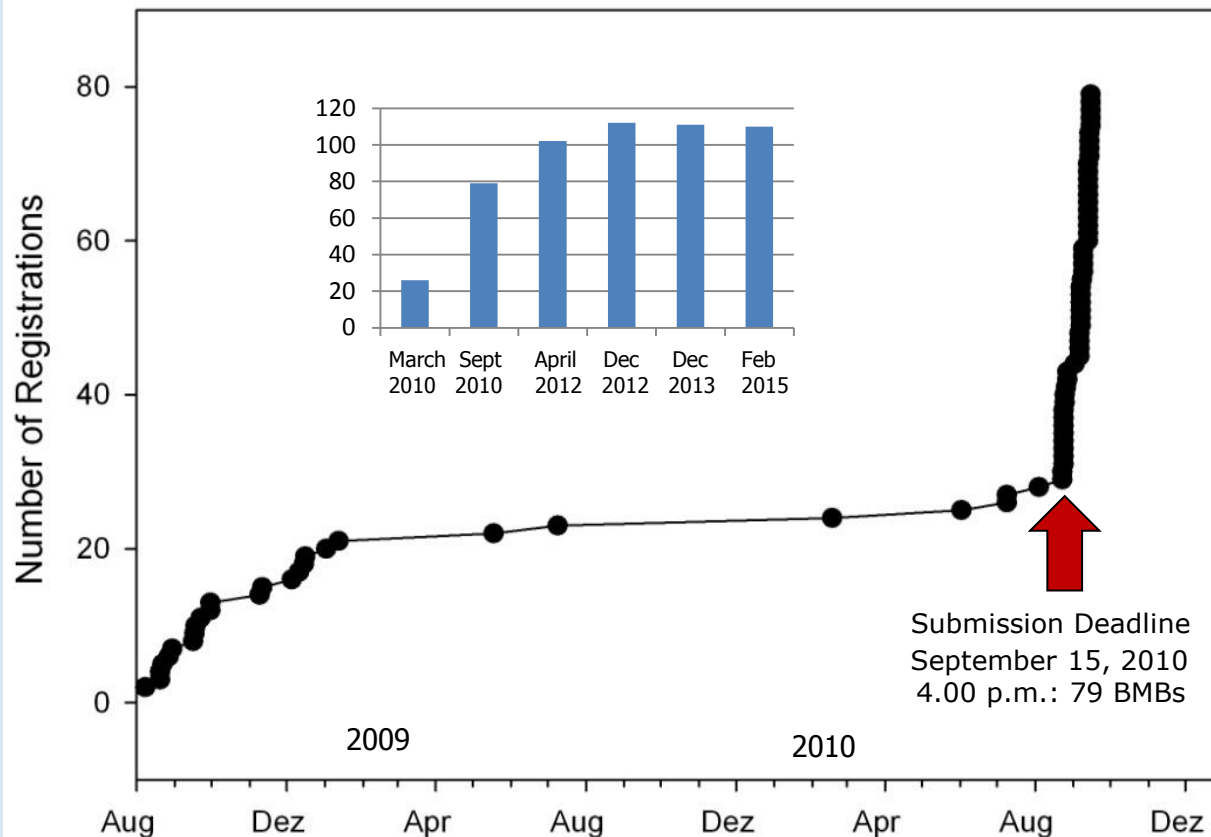
... that would allow to process the information about their many individual samples into an aggregated form – at the push of a button



... telling arguments do not last ...

„Purpose is but the slave of memory, of violent birth, but poor validity“

William Shakespeare, Hamlet, Act 3, Scene 2



Submission Deadline
September 15, 2010
4.00 p.m.: 79 BMBs



Co-op TMF with BBMRI-PP



Begin of
„DBR“-
development



Publication of tender –
BMBF-Initiative -
Centralized Biobanks

- register with aggregated data
- own minimum data set development
- homes clinical, disease-centric, population-based & epidemiological biobanks
- academic & industrial biobanks, clinical relevant model organisms
- ICD-, OMIM, MeSH & other (text)
- open source & platform-independent
- web-based interactive manual registration
- parsimony of register attributes (47)
- option for pre-analytic documentation (SPREC)
- export, import (xml, csv etc.) not implemented
- all data are publically visible
- biobanking-specific user forum is available
- mirror-interfaces planned as service
- counselling services in TMF-working groups
- public project funding
- no real marketing campaigns
- no metrics to measure the use
- not embedded in funding policies, nor regulations
- ELSI issues less problematic with aggregated data

Acknowledgement

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Michael Krawczak, Uni Kiel

Sebastian C. Semler, TMF

Christina Schröder, Fraunhofer



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