

---

# Access to Biobank-Based Projects: The „Projektportal im Deutschen Biobanken-Register“ (P2B2)

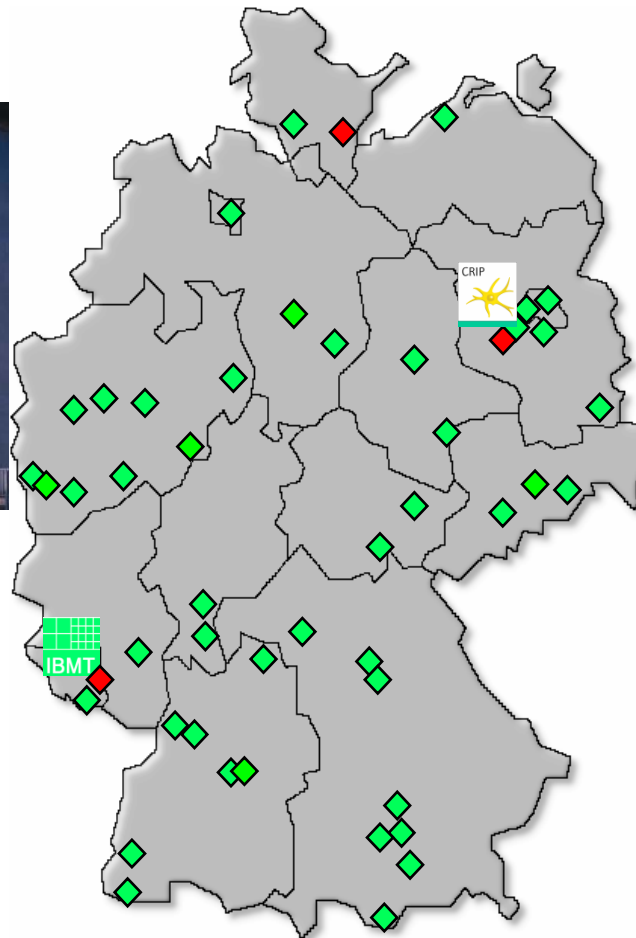
Kick-off Meeting National Biobank Initiative, Berlin, April 8, 2011

---

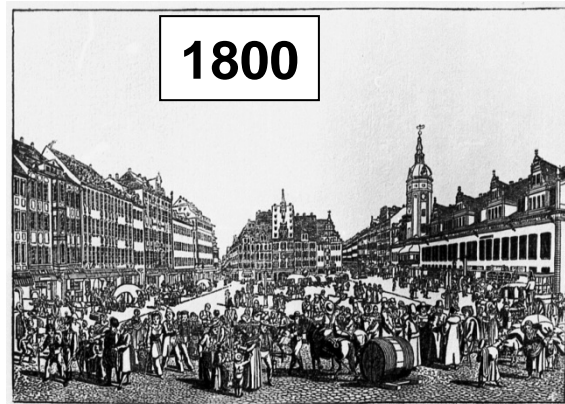
[christina.schroeder@ibmt.fraunhofer.de](mailto:christina.schroeder@ibmt.fraunhofer.de)

# Fraunhofer-Institut für Biomedizinische Technik (IBMT)

Director Prof. Dr. Günter R. Fuhr  
Deputy Director: Prof. Dr. Frank F. Bier

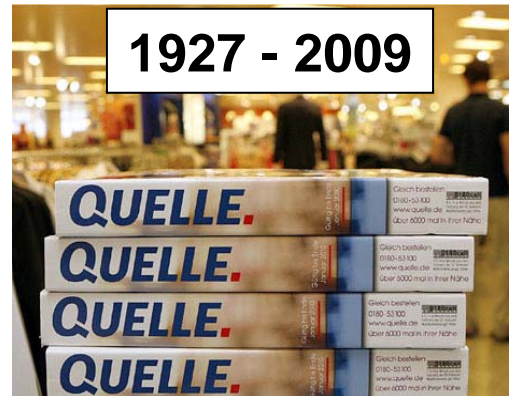


# Access to goods...



1800

Leipzig Trade Fair



1927 - 2009

Quelle Versandhaus © dpa



2011

# ...and to biospecimens for research

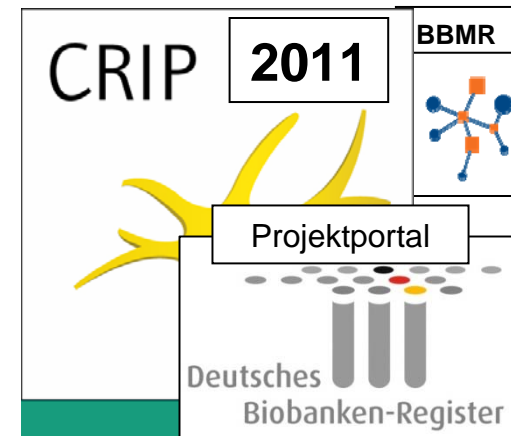


1900

[www.nhm-wien.ac](http://www.nhm-wien.ac)



2000



CRIP

2011

BBMR

Projektportal

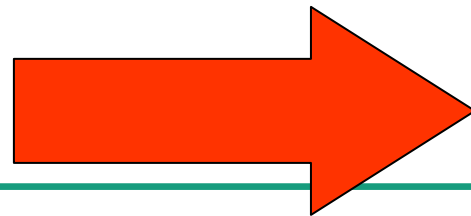
Deutsches  
Biobanken-Register

# Access to Human Biospecimens

How to pool and publish biobank data from different hospitals / institutions safeguarding (in the interest of users and biobanks)

- **Anonymization** / patients' personal rights?
- **Confidentiality**
  - of scientific projects and
  - of biobank contents and know-how?
- **Autonomy** with respect to **biobank governance**?

...and how to **motivate** biobanks to share their data (and material)?



---

**Project/business  
case?**

# Honest Broker

- Focus: Organize, facilitate and accelerate access to partner biobanks and their users
- No competitor
  - Of biobanks: no material of their own
  - Of users: no research interests of their own in the user's field
- Responsible for
  - E-infrastructure
  - Management and governance of network
- Active interface towards international infrastructures

# Register vs. „Projektportal“

## ■ Register:

- Updates done manually by questionnaires / data entry
- Drawback for users: Specific search for cases / samples impossible
- Drawback for biobanks:
  - Biobanks not informed on users / envisioned projects
  - Data granularity inversely related to privacy, confidentiality, and maintenance efforts

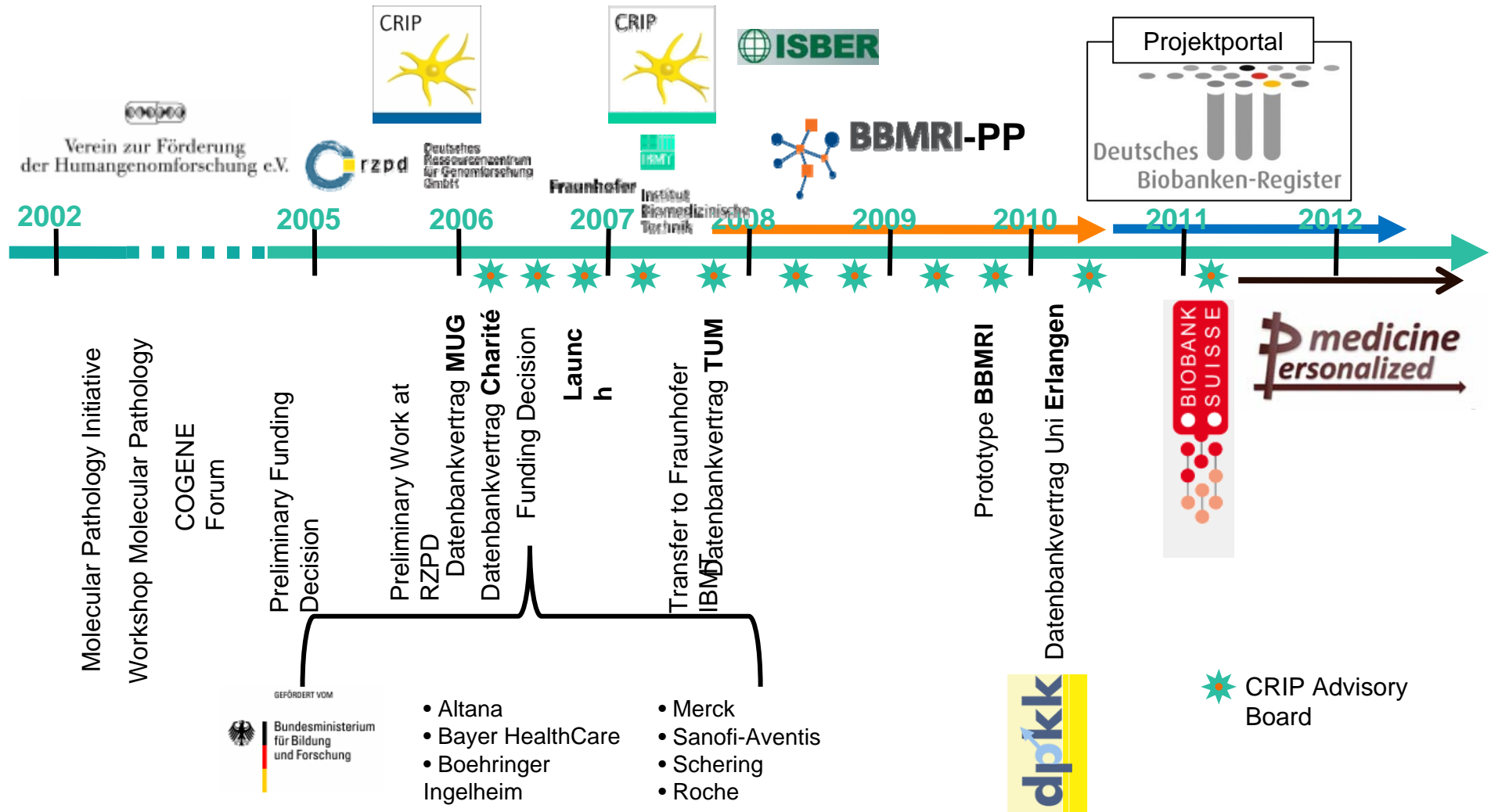
## ■ ICT infrastructure with web-based query tool:

- Automatic updates on a regular basis, controlled/initiated manually
- Drawback for biobanks: Data needs to be harmonized and anonymized
- Specific case/sample-related information for users
- Specific project-related information for biobanks
- „Spam filter“ for biobanks

# Scope of P2B2

- Project search tool (including scientific services)
  - Generic project structure
  - Expand CRIP concept towards all kinds of disease specific (Kompetenznetze) and population-based biobanks
  - Integrate project search tool into German Biobank Register ([www.biobanken.de](http://www.biobanken.de)) ⇒ Cooperation with TMF
  - Open / restricted to registered German biobanks
  - Open for additional software tools
  
- CRIP as a blueprint
  - Tissue banks / Institutes of Pathology ⇒ all disease areas
  - Operative since 2006 ⇒ proven and tested
  - Flexible architecture ⇒ **Hospital-wide biobanks** (Workshop 2010)

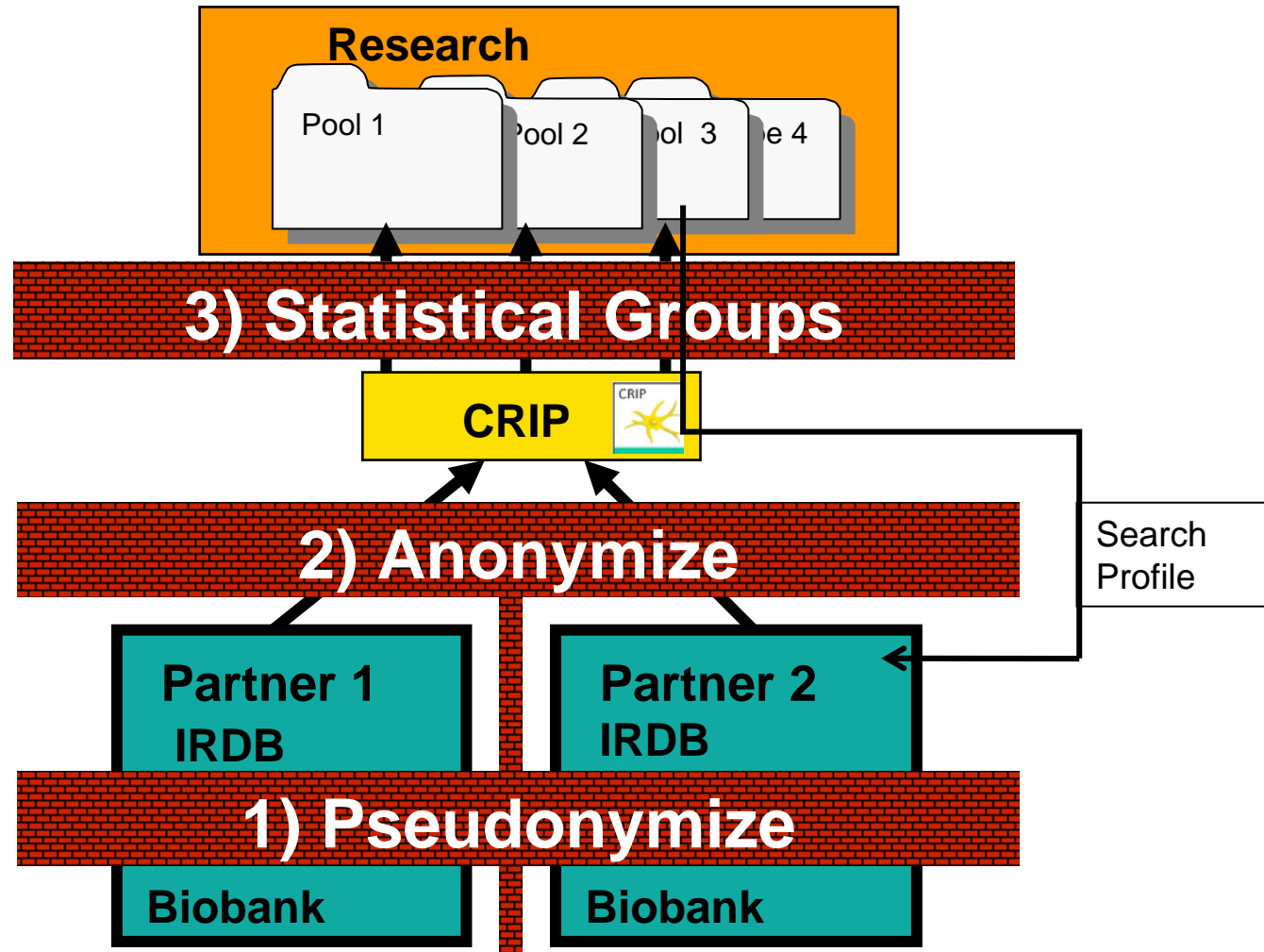
# Background





# CRIP Privacy Regime I

**DATEN  
SCHUTZ**  
Berlin  
...a model concept!



# CRIP Privacy Regime II

<http://crip.fraunhofer.de>

Cell Tissue Bank  
DOI 10.1007/s10561-010-9190-8

ORIGINAL PAPER

**Safeguarding donors' personal rights and biobank autonomy in biobank networks: the CRIP privacy regime**

Christina Schröder · Karsten R. Heidtke ·  
Nikolaus Zacherl · Kurt Zatloukal ·  
Jochen Taupitz

Received: 23 April 2010 / Accepted: 14 June 2010  
© Springer Science+Business Media B.V. 2010

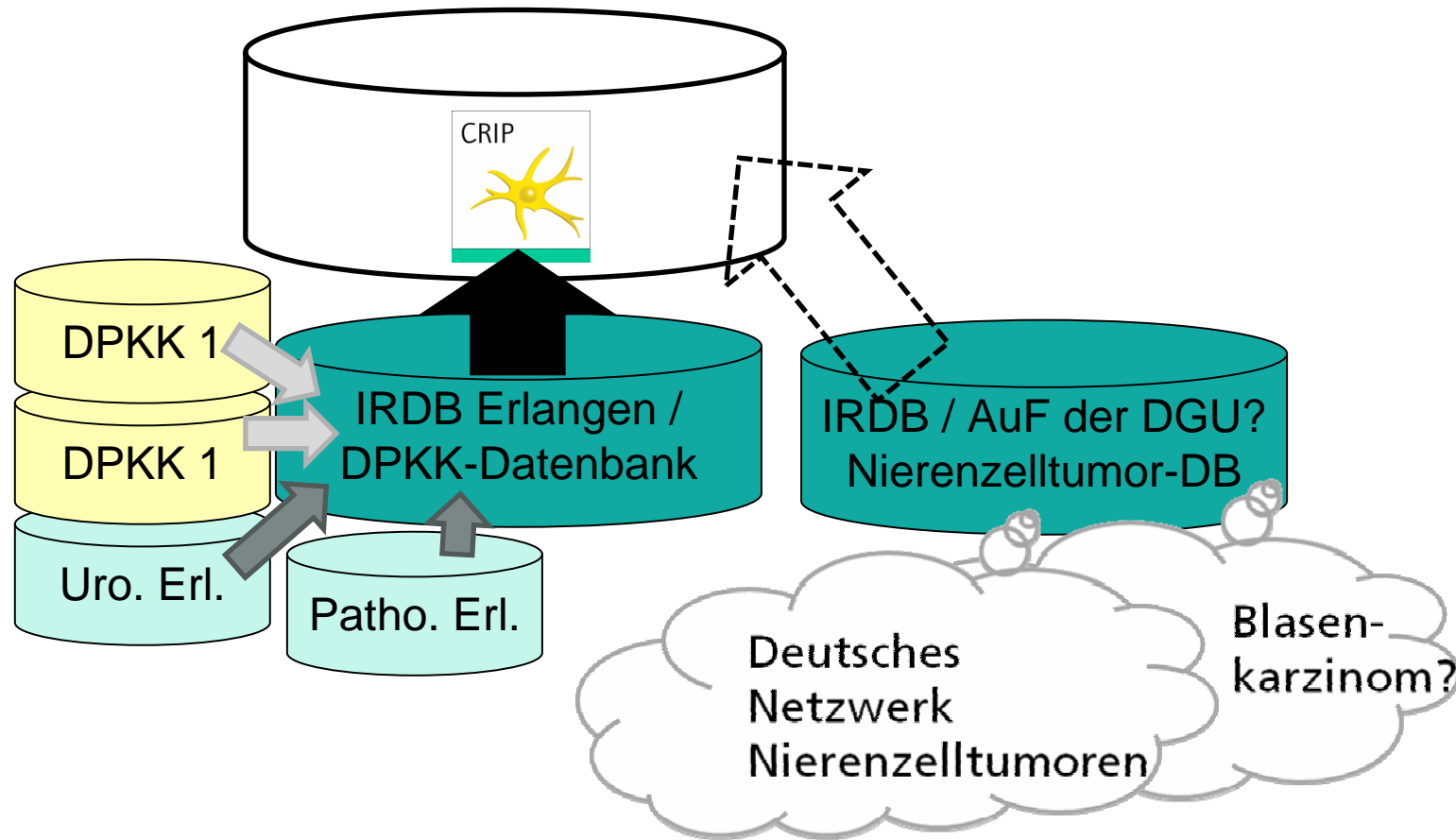
**Abstract** Governance, underlying general ICT (Information and Communication Technology) architecture, **Introduction**

<http://www.springerlink.com/content/257x56488841215k/fulltext.pdf>

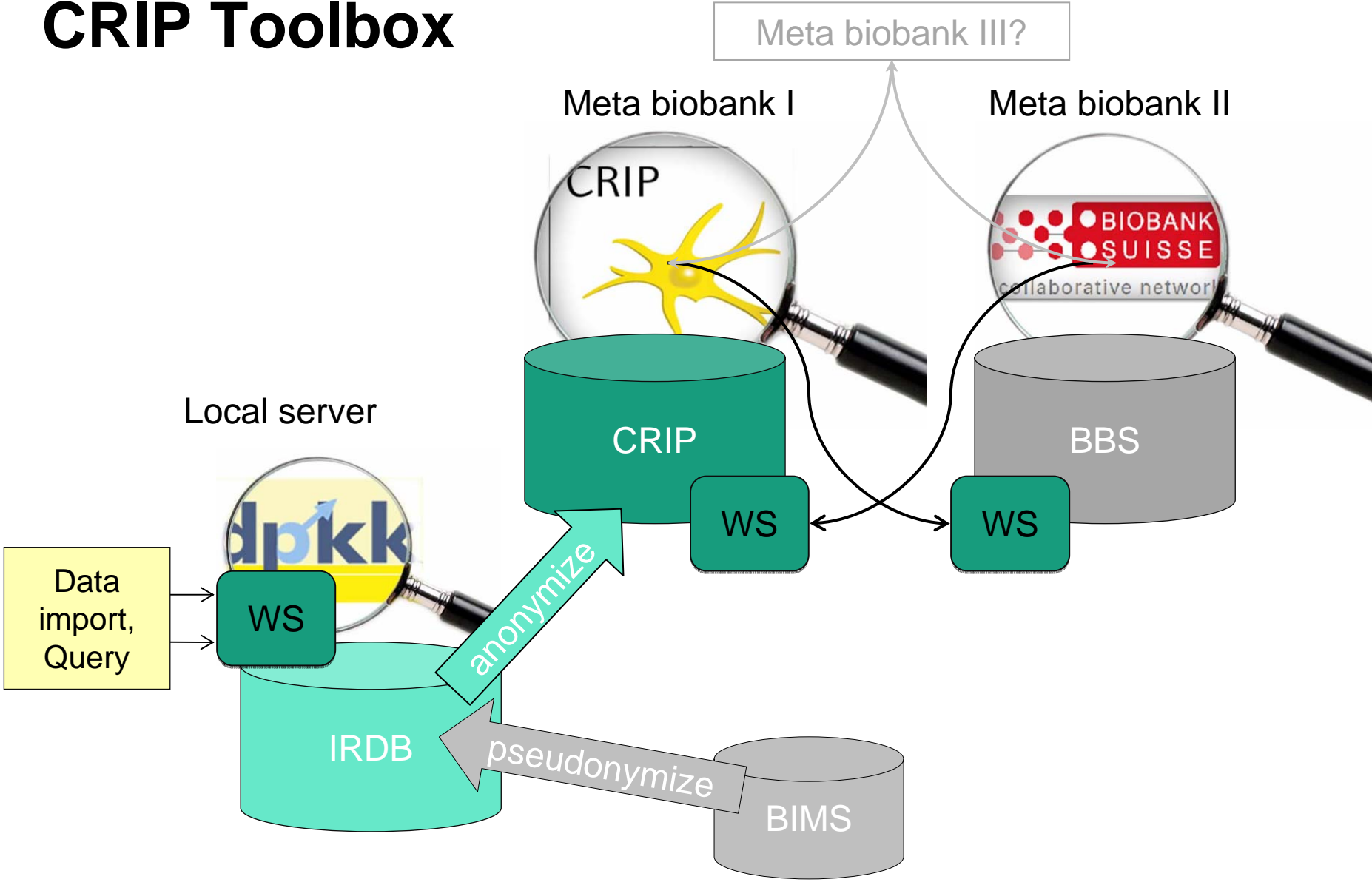
# CRIP ICT Architecture

- IBMT: Central database with web-based interactive query tool
  
- CRIP Partners: Integrative Research Databases (IRDBs; by IBMT; „local“ databases)
  - Data import (pseudonymized), export (anonymized)
  - Data harmonization
    - Pre-processing, calculation of values, mapping, etc.
  - Anonymization
  
- Web Services

# Federated ICT Architecture



# CRIP Toolbox



# P2B2

Kick-off meeting, Berlin, November 22, 2010



## Deutsches Ärzteblatt

Die Zeitschrift der Ärzteschaft | Gegründet 1872 | Ausgabe C | 21. Januar 2011

3

### BIOBANKEN

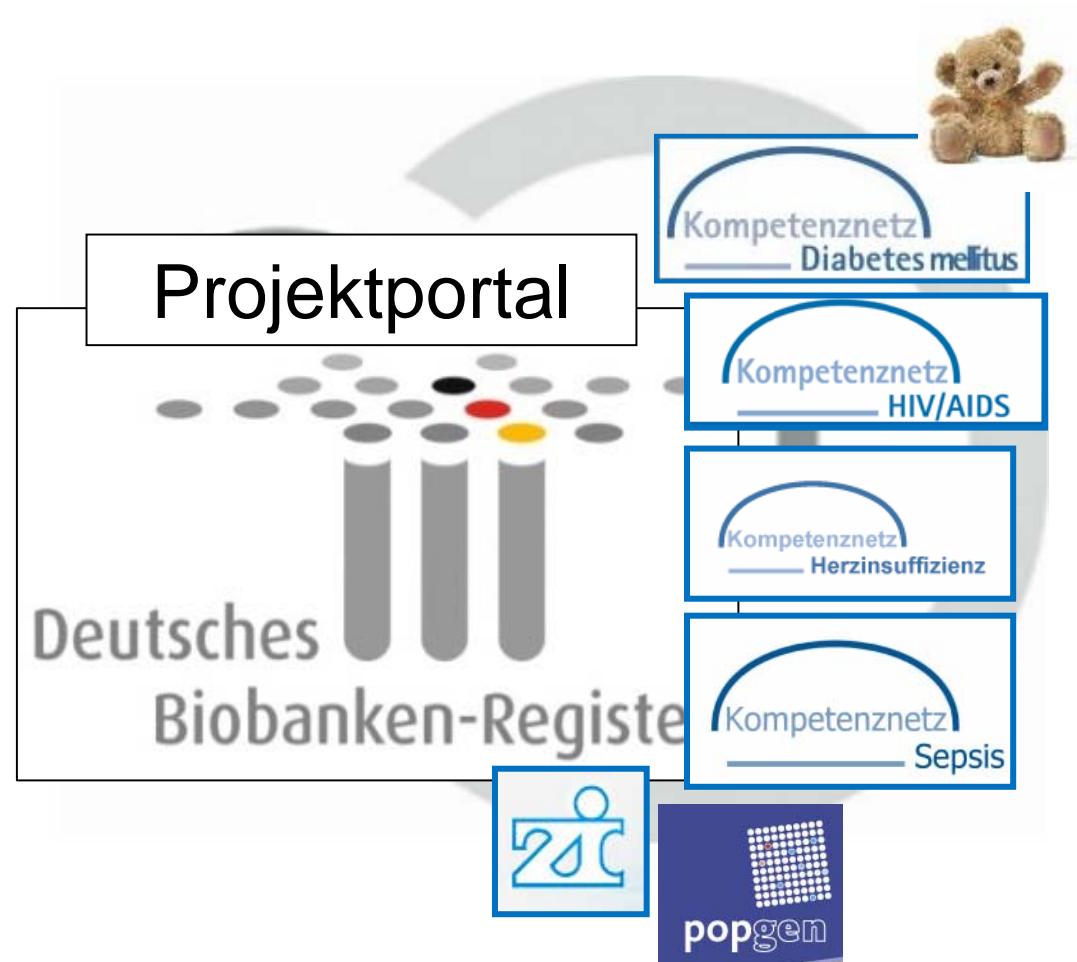
## Forscher starten nationale Infrastruktur

Rund 400.000 Euro Fördergeld des Bundesforschungsministeriums stecken das Fraunhofer-Institut für Biomedizinische Technik in St. Ingbert und die Technologie- und Methodenplattform für die vernetzte medizinische Forschung in den Aufbau einer Datenbank, die Informationen aus verschiedensten, krankheits-spezifischen und populationsgenetischen Biobänken für externe Forscher zur Verfügung stellt. Der Auftakt machten Ende 2010 die Biobank für Diabetes, die Biobank für HIV (Bochum), die Biobank CNHF, die Mann-

heimer BioPsy-Sammlung für neuropsychiatrische Erkrankungen und die epidemiologische SHIP-Biobank in Greifswald. „Um die sehr unterschiedlichen Datensätze automatisch einzulesen, haben wir bereits beim Aufbau unserer CRIP-Infrastruktur eine flexible Software entwickelt“, erklärte IBMT-Projektleiterin Dr. Christina Schröder. Die Initiative startet nach dem finanziellen Scheitern der EU-Biobank-Infrastruktur BBMRI und im Vorlauf zu einer nationalen Initiative, die darauf abzielt, an fünf Standorten in Deutschland Biomaterialbanken zu bündeln. Die entsprechende Ausschreibung wird Anfang nächsten Jahres erwartet.

**BIO** spektrum

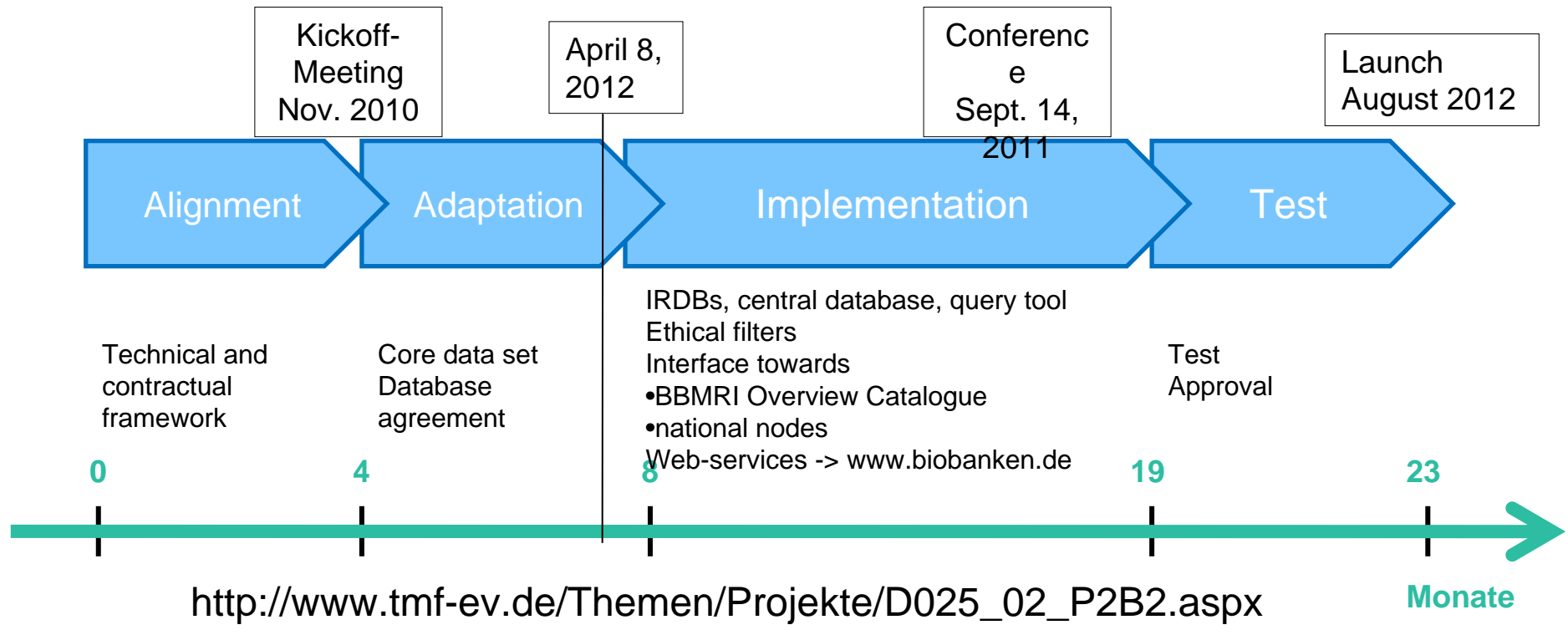
# P2B2 Biobank Partners



# P2B2 Work Plan

- Single sign-on with German Biobank Register
- Integration by web-links and web services

⇒ Register entries of P2B2 biobank partners up-date automatically





# P2B2 Database Contract

- Draft / advice by T.M. Spranger
  
- Legal framework for handling of human samples
  
- Rights and liabilities
  - Data transfer
  - Project management and delivery
  - Fees and cost recovery
  
- Same wording with all partners / equal treatment
  
- Ready for signature

# P2B2 Core Data Set

- Integrated so far: BioPsy, PopGen, KompNet HIV/AIDS
- „Case-centric“
- 28 (+) items

Nr.	Name	Beschreibung	Datentyp	Wertebereich
1	<u>biobank_name</u>	Name der Biobank	Textfeld	alphanumerisch
2	<u>biobank</u>	Kürzel ( <u>BiobankAcronym</u> )	Textfeld	alphanumerisch
3	<u>biobank_contact</u>	Name des Ansprechpartners (dieser muss nicht der Ansprechpartner für IT sein)	Textfeld	alphanumerisch
4	<u>biobank_email</u>	E-Mail-Adresse des Ansprechpartners	Textfeld	alphanumerisch zzgl. „“, „-“, „_“ und „@“
5	<u>ppsn</u>	Pseudonym* Patient / Proband	Textfeld	alphanumerisch
6	<u>psn</u>	Pseudonym Fall	Textfeld	alphanumerisch
7	<u>sex</u>	Geschlecht	eindeutige Auswahl	m, w, männlich, weiblich**, unbekannt
8	<u>age</u>	Alter bei Probenentnahme	Zahlenfeld	numerisch [Jahre]
8a	<u>dateofbirth</u>	Geburtsdatum*	Datum	Datum (JJJJ, MM/JJJJ oder TT.MM.JJJJ)
9	<u>height</u>	Größe	Zahlenfeld	numerisch [cm]
10	<u>weight</u>	Gewicht	Zahlenfeld	numerisch [kg]
11	<u>ethnicity</u>	Ethnizität	eindeutige Auswahl	kaukasisch, ...
11a	<u>mother</u>	<u>ppsn</u> der Mutter	Textfeld	alphanumerisch
11b	<u>father</u>	<u>ppsn</u> des Vaters	Textfeld	alphanumerisch

# Additional Software Modules / Tools

- IRDB-Interface / API provided (December 2010)
- IMFL Uni Münster (F. Ückert)
  - Use case HIV/AIDS
- Uni Erlangen, Lehrstuhl f. Med. Informatik (H.U. Prokosch)
  - Use Case SepNet

### Project Details

#### Scope of Project

Please give us an idea and a short outline of your work and the question(s) this project shall answer. This will help our partners to tailor their proposals to your research needs. Thank you.

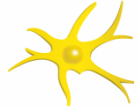
Select	Required Cases	Localization	Disease	Specimen
<input checked="" type="checkbox"/>	30	N60-N64 - Disorders of breast	900-903 - Fibroepithelial Neoplasms	Tissue (FFPE)
Further specification of cases/specimens				
<input checked="" type="checkbox"/>	50	N60-N64 - Disorders of breast	850-854 - Ductal and Lobular Neoplasms	Tissue (FFPE)
Further specification of cases/specimens				

#### Requested Methods

Select checkboxes from the list of scientific services available at the partners' institutes.

- |                                  |  |  |
|----------------------------------|--|--|
| <input type="checkbox"/> DNA PCR | <input type="checkbox"/> Tissue microarray     | <input type="checkbox"/> Gene expression profiling |
| <input type="checkbox"/> RNA     | <input type="checkbox"/> W/N/S blot            | <input type="checkbox"/> Genomic losses/gains      |
| <input type="checkbox"/> Morph   | <input type="checkbox"/> In-situ hybridization | <input type="checkbox"/> FISH                      |
| <input type="checkbox"/> Imm     | <input type="checkbox"/> Functional assays     | <input type="checkbox"/> Macro-Microdissection     |
| <input type="checkbox"/> Other/C |  |  |

CRIP



Your request concerning the following project has been forwarded to our database partners and will be answered within 10 workdays, including:

- Detailed data on required material
- Contact provider(s)

#### Scope of Project:

biomarker research

#### Requested Material:

Localization: C64 - Malignant neoplasm of kidney, except renal pelvis  
Disease: Not specified  
Specimen: Tissue (Cryo)  
Required cases: 100

#### Requested Methods:

Not specified

## P2B2

Thanks for your request, which has been forwarded to

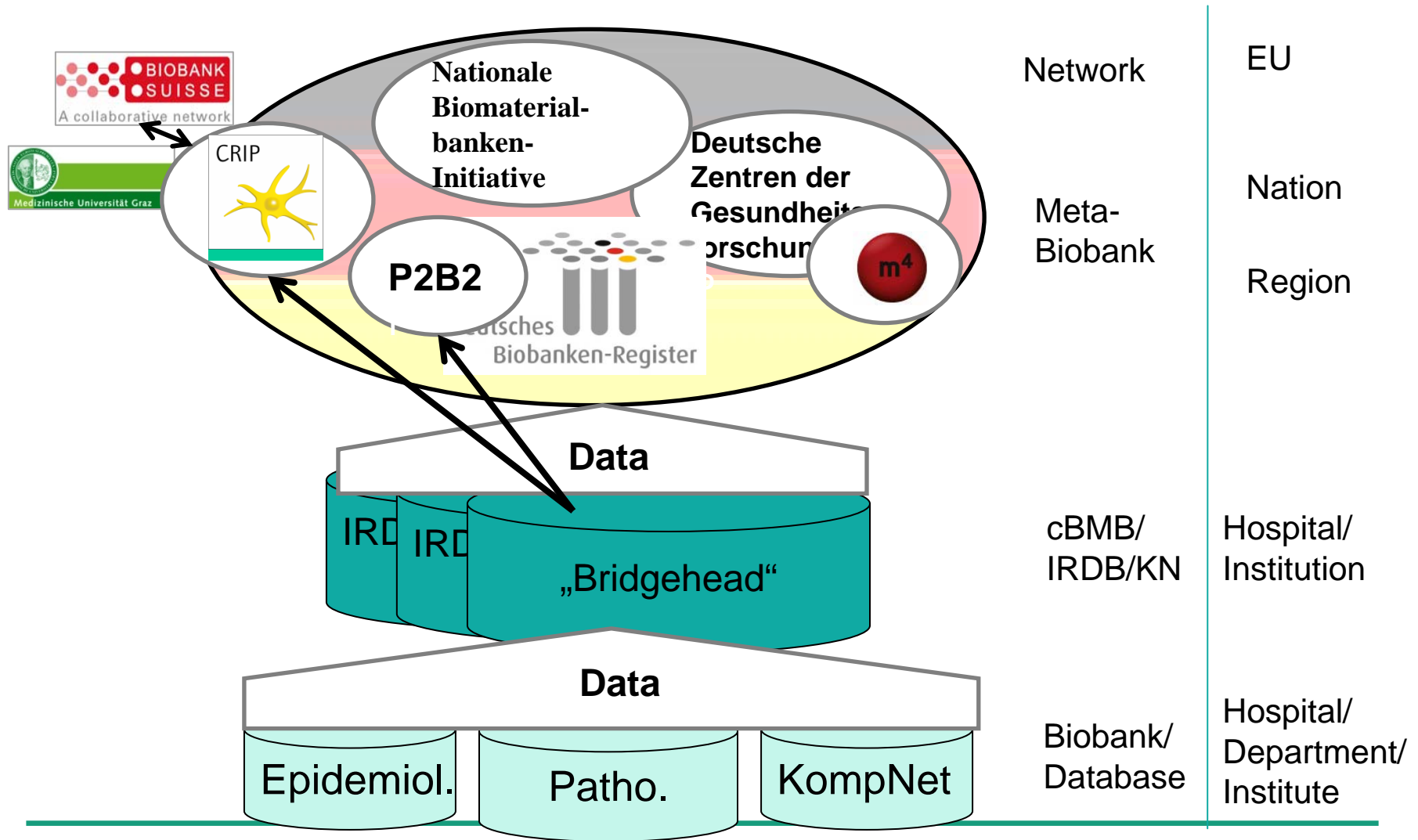


Feedback within 10 workdays / automatic reminder

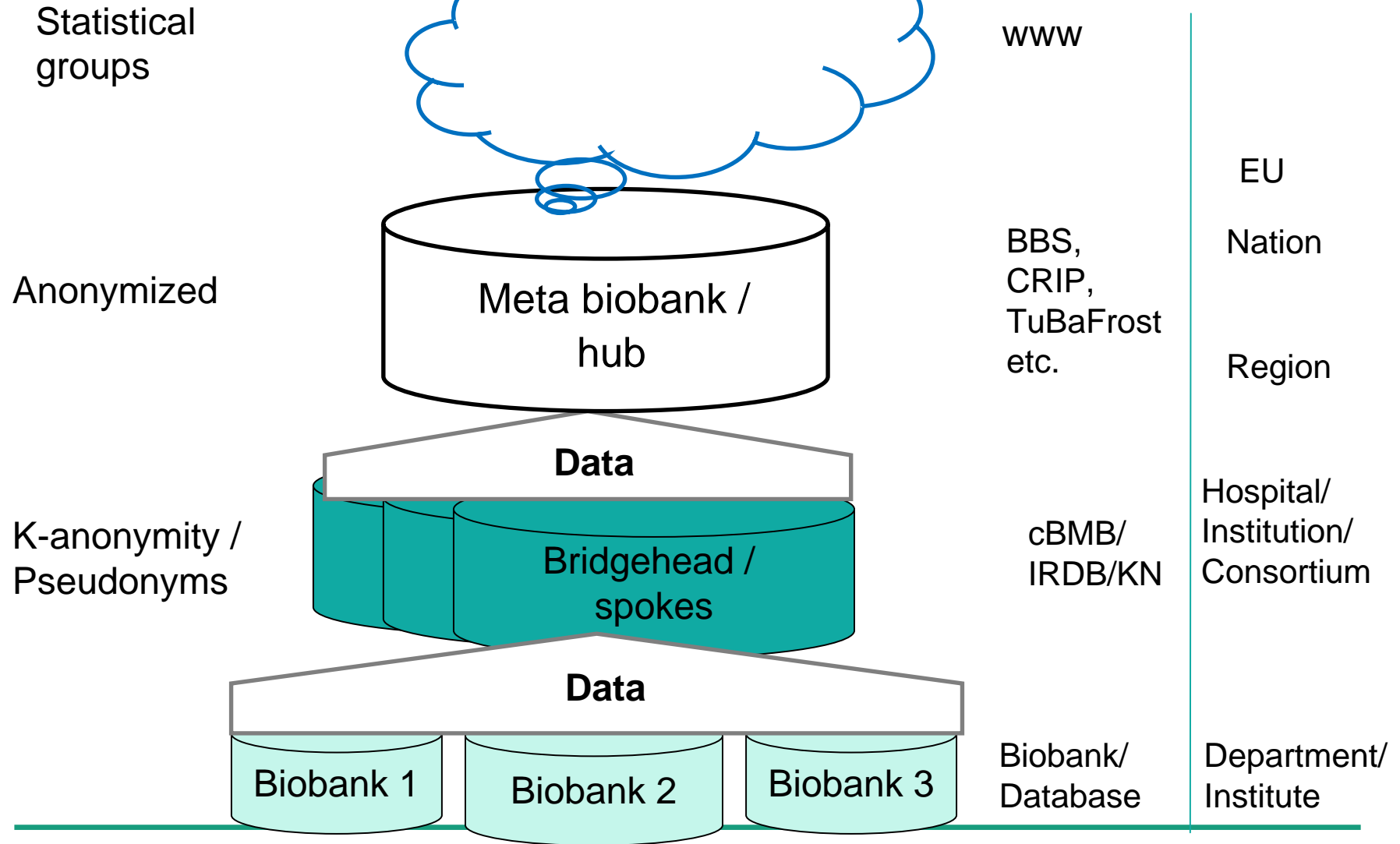
Coordination

Project proposal

# Status quo / from patchwork towards national node???



# Vision



# P2B2 vs. www.amazon.com

## Amazon's mission statement:

“We seek to be Earth's most customer-centric company for three primary customer sets:

- Consumer customers,
- Seller customers and
- Developer customers.”

The German Biobank Register and P2B should seek to be **Germany's most researcher centric biomedical research infrastructure** for three primary researcher sets:

- User researchers (from academia and industry)
- Provider researchers (biobanks) and
- Developer researchers (ICT).



# Thank you...



... Karsten R. Heidtke, Oliver Gros, Matthias Dobkowitz



...for your attention!