
How to Navigate the European (and Global) Biobanking Landscape Best?

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Fraunhofer at a Glance

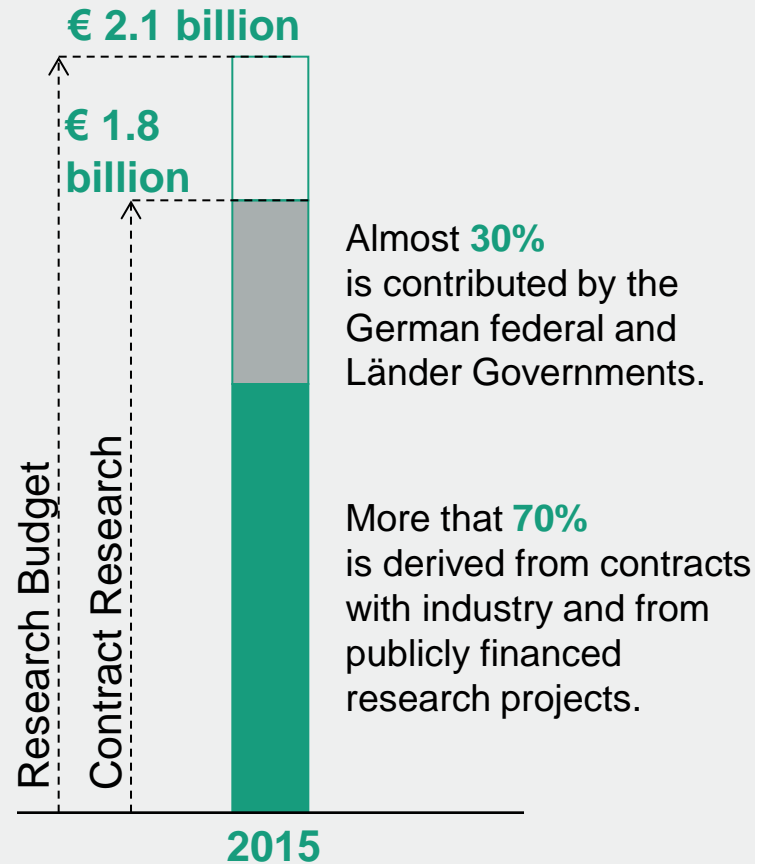
Fraunhofer is a not-for-profit organization undertaking applied research of direct utility to private and public enterprise and of wide benefit to society.



24,000 staff



67 institutes and research units



OVERVIEW

- The Biobanking Landscape
- The ESBB Biobank Directory
- Project Status

The Biobanking Landscape...



...is still fragmented

The image shows a screenshot of a biobanking website interface. At the top right, the logo for **BBMRI-ERIC** is visible, with the text "Biobanking and BioMolecular resources". Below this, the text "B B M R I • N L" is displayed. The main content area features a search bar and a list of sample collections. Three red callout boxes are overlaid on the page, each containing a URL and a count of biobanks:

- <https://www.irlocator.isber.org/>
(35 human specimen repositories)
- <https://catalogue.bbmri.nl/>
Some 200 biobanks
- <http://biobanken.de/>
126 Biobanks

The website also includes a navigation menu with items like "Home", "Über uns", "News", "Biobanken", "User Forum", and "Symposium". The footer contains the text "© Fraunhofer IZI-BB" and the Fraunhofer IZI logo.

Biobank and (scarce) Biospecimen Locators cannot/do not Interoperate

Biobank Catalogs / Directories:

- Updates manually (paper-based or web-based questionnaires) or over MIABIS
- Overview biobank information

Biospecimen Locators / Metabiobanks:

- **Automatic updates** on a regular basis, yet **controlled** manually
- Simultaneous query (including stratification of connected biobanks)

Default infrastructure for
pathology repositories

„Negotiator“:

- envisioned with BBMRI

Industry's Specific Requirements are Unmet by Existing Infrastructure

- **Need to “distinguish the ones you can work with”**
- **Exemplary industry questions to “fit-for-purpose” biobanks include:**
 - **Therapy / prescription data available?**
 - Yes, electronically; Yes, paper; No
 - **Are consent templates available in English?**
 - **Custom prospective collections possible?**

Industry-oriented Biobanks' Open Question

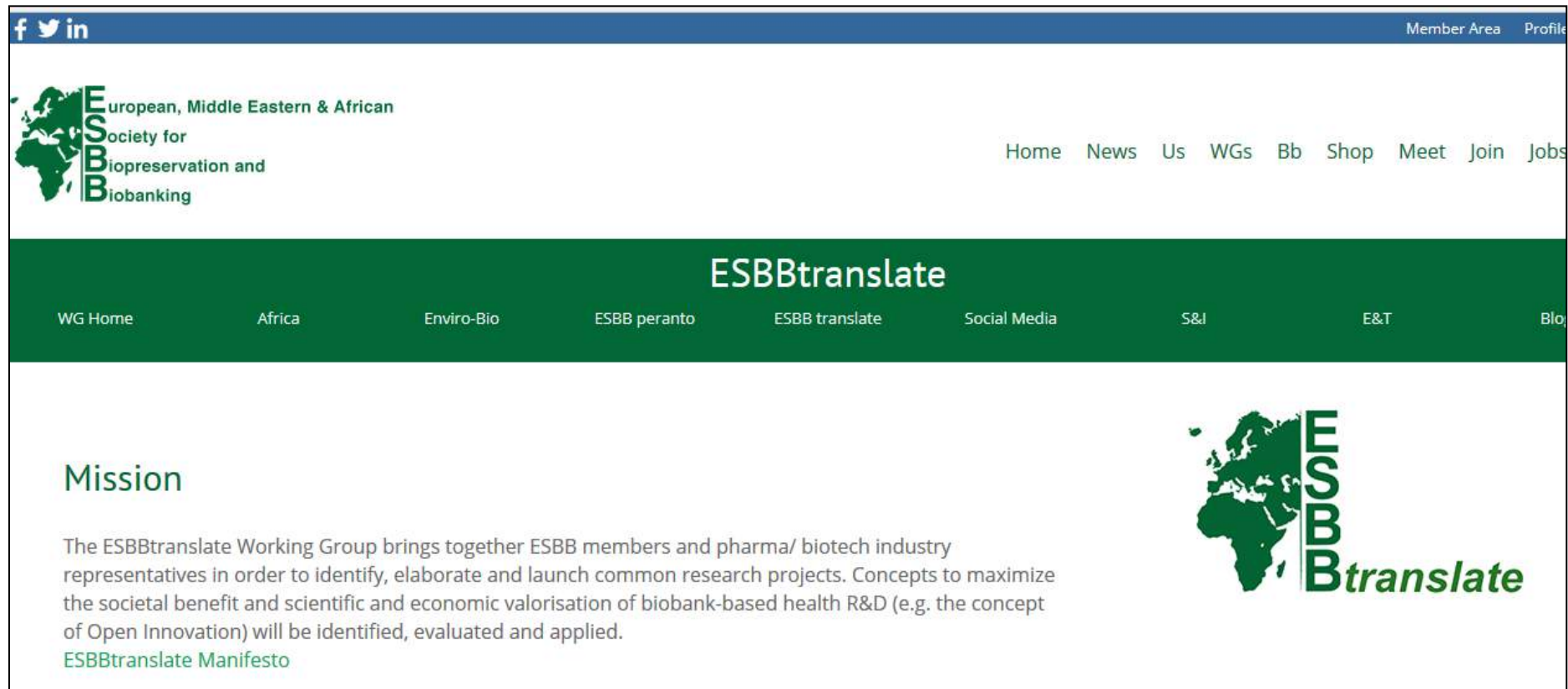
How to showcase our services and resources best?

- Simply
- Efficiently
- Compliant with ethical and legal regulations

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ESBBtranslate brings together biobanks and industry



The screenshot shows the ESBBtranslate website. At the top left, there are social media icons for Facebook, Twitter, and LinkedIn. The main header features the ESBB logo (a green map of Europe, the Middle East, and Africa) and the text "European, Middle Eastern & African Society for Biopreservation and Biobanking". To the right of the header is a navigation menu with links for Home, News, Us, WGs, Bb, Shop, Meet, Join, and Jobs. Below the header is a dark green navigation bar with the text "ESBBtranslate" in white, and a secondary menu with links for WG Home, Africa, Enviro-Bio, ESBB peranto, ESBB translate, Social Media, S&I, E&T, and Blo. The main content area has a white background with the heading "Mission" and a paragraph: "The ESBBtranslate Working Group brings together ESBB members and pharma/ biotech industry representatives in order to identify, elaborate and launch common research projects. Concepts to maximize the societal benefit and scientific and economic valorisation of biobank-based health R&D (e.g. the concept of Open Innovation) will be identified, evaluated and applied." Below this paragraph is a link to the "ESBBtranslate Manifesto". To the right of the text is a large ESBBtranslate logo featuring a green map of the region and the text "ESBBtranslate".

<http://esbb.org/working-groups/esbbtranslate/>

ESBBtranslate have developed „Industry’s“ Questionnaire

ESBB translate meeting at Leipzig October 2014, by A. Schmitz & A. Cooreman

What is in your Bio Bank?

Suggestions for a multiple choice questionnaire which could be filled in by the ESBB member biobanks and connected to the ESBB member database and made available - to members only; pseudonymized with ESBB acting as a broker; or even publicly.



<i>Question</i>	<i>Answer options</i>
Disease Areas	
Identify the top three disease areas represented in your bank:	Three database fields, each to tick one of predefined options (which are the same for all fields) - e.g. neurodegeneration (brain), cardiology, respiratory, gynaecology, urology, auto-immune, gastro, endocrinology, etc
What is the approximate size of sample cohort in top three disease areas	Three fields, one for each, with predefined options – 10 – 100- 1000 - 10000
Types of sample	
What types of samples does your Bio Bank hold?	One database field with predefined options – tissue, blood fraction, tissue & blood fraction, other biofluids
Tissue preservations	One database field with predefined options – Only FFPE, only frozen, only OCT, FFPE and frozen/OCT
SOPs for preservation methodologies?	YES/NO
Processing time known? from warm ischemia to preservation	YES/NO
Matched samples available?	YES/NO
Multiple time points?	YES/NO
Can patients be asked for further samples?	YES/NO

...by Ann Cooreman,
Arndt Schmitz and
Annika Fischer

ESBB and Fraunhofer CRIP Group are offering a demonstrator

https://preview-crip.fraunhofer.de/intern/fragen-demo/cgi/fragen.cgi

ESBB Btranslate

Biobank Directory v0.1 / Demonstrator

powered by Fraunhofer IZI

criteria: biobanks

reset all No. of matching Biobanks: 0

continue

General info Disease areas Sample types Ethics & Consent Donor data Process info

Country -

Based on test data from 6 ESBB member biobanks

<https://preview-crip.fraunhofer.de/intern/fragen-demo/cgi/fragen.cgi>

Features of Demonstrator Include Query Tool...

https://preview-crip.fraunhofer.de/intern/fragen-demo/cgi/fragen.cgi

Suchen

ESB Btranslate

Biobank Directory v0.1 / Demonstrator

powered by Fraunhofer

General info Disease areas Sample types Ethics & Consent Donor data Process info

Main types of samples -

Method of preservation -

SOPs for preservation methodologies -

Sample processing time known Yes

Are matched samples available? -

Can patients be asked for further samples? -

Are custom prospective collections possible? -

criteria biobanks

reset all

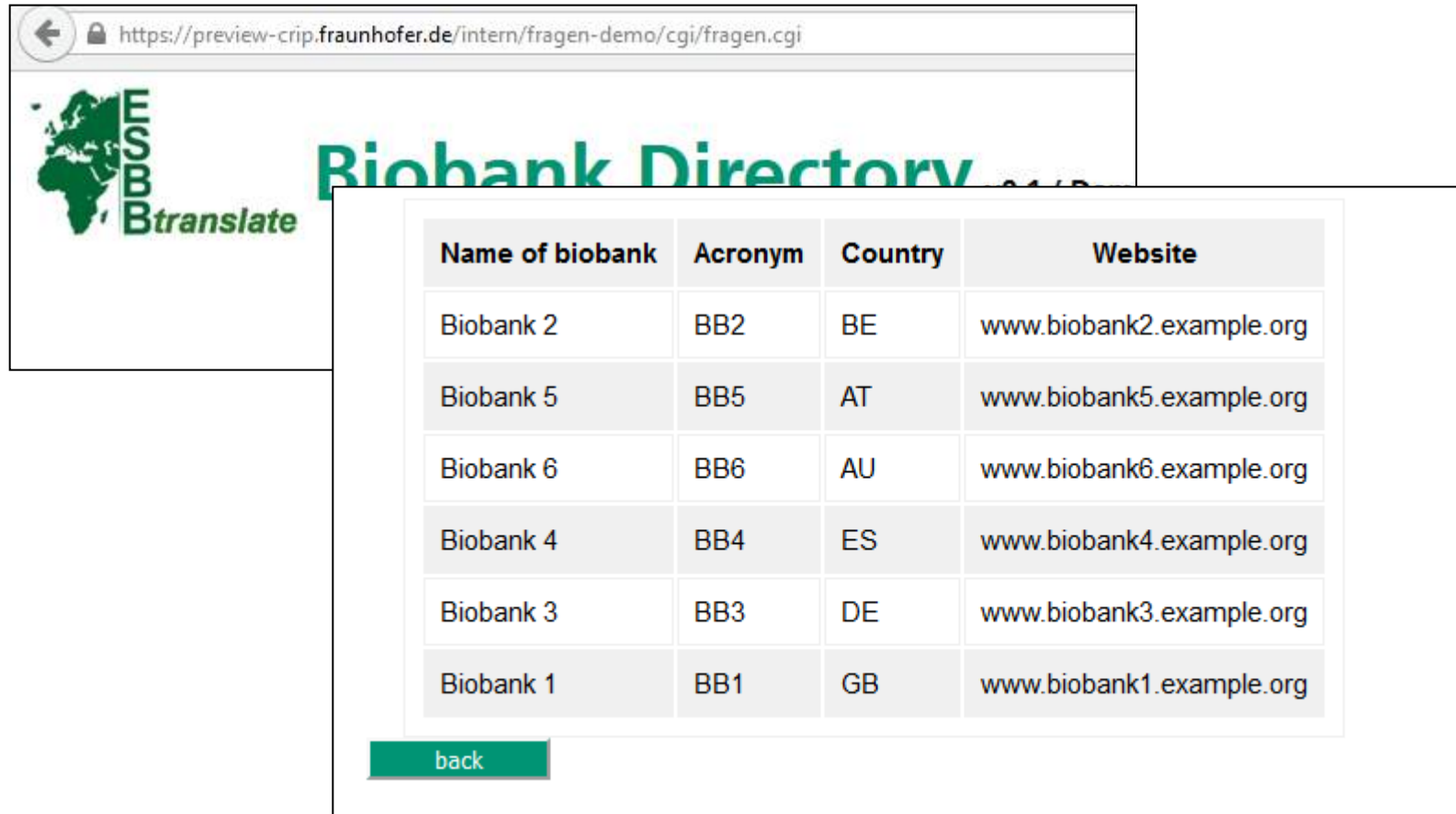
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No. of matching Biobanks: 6

Your Selection:

- Country all
- Time known? Yes

...and Links to Fit-for-purpose Biobanks



https://preview-crip.fraunhofer.de/intern/fragen-demo/cgi/fragen.cgi

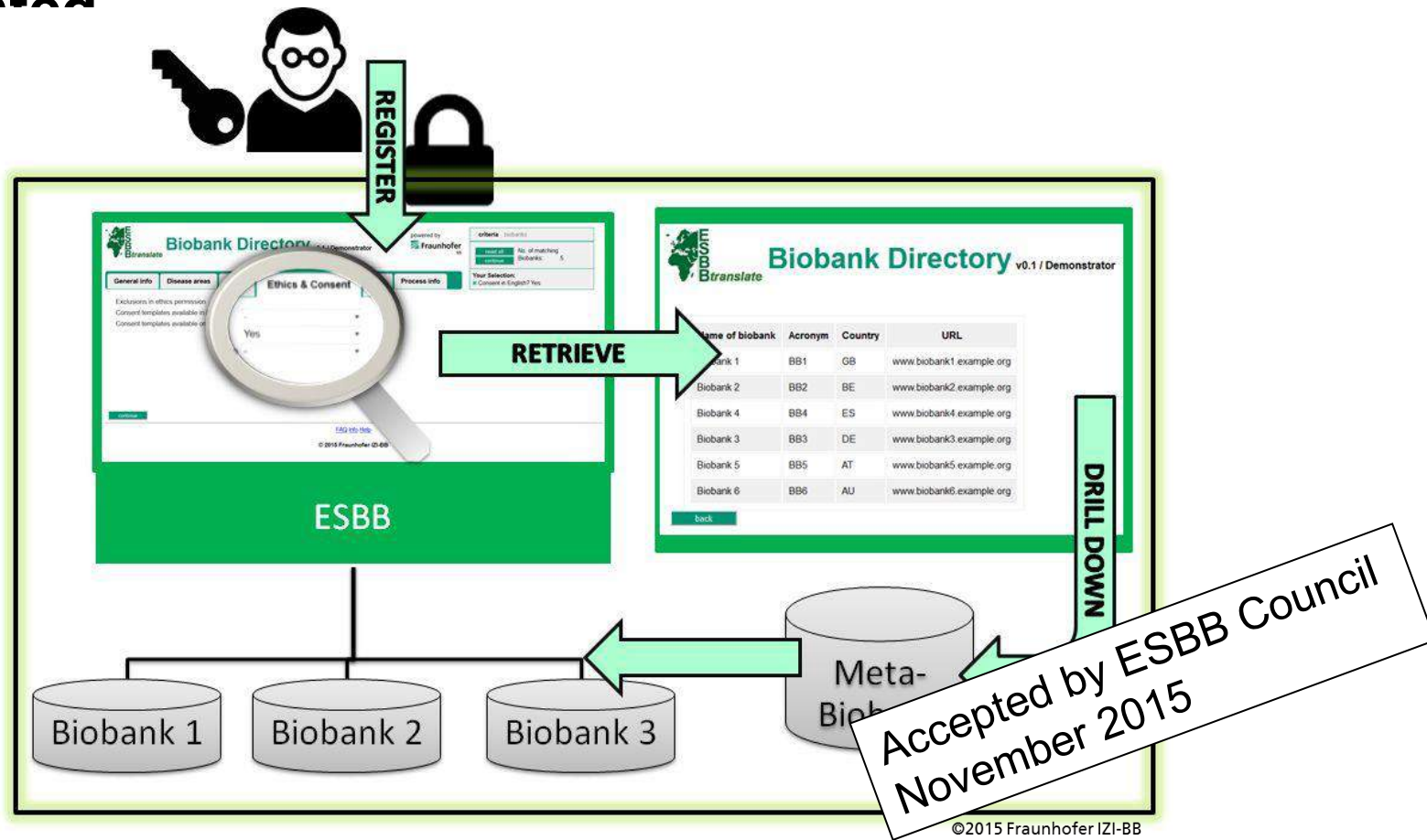
EUSM
Btranslate

Biobank Directory

Name of biobank	Acronym	Country	Website
Biobank 2	BB2	BE	www.biobank2.example.org
Biobank 5	BB5	AT	www.biobank5.example.org
Biobank 6	BB6	AU	www.biobank6.example.org
Biobank 4	BB4	ES	www.biobank4.example.org
Biobank 3	BB3	DE	www.biobank3.example.org
Biobank 1	BB1	GB	www.biobank1.example.org

back

Concept for ESBB Biobank Directory has been conserted



- **Level 1:** Retrieve biobanks
- **Level 2:** Drill down to retrieve cases and specimens

ESBB Biobank Directory will be implemented with two query levels

- „Retrieve biobanks“:
According to Demonstrator
- „Drill down“:
Links to metabiobanks or sample stratification functionalities of connected biobanks, e.g.
 - Fraunhofer Metabiobank;
<https://metabiobank.fraunhofer.de/>
 - Breast Cancer Campaign;
<http://www.breastcancertissuebank.org/>

ESBB Biobank Directory will be seamlessly integrated into existing Biobanking Landscape

- Level 1 „Retrieve biobanks“:
 - Automated upload of MIABIS datasets
 - Integration with metabiobanks
 - Information **complementary** to existing databases
- Level 2 „Drill down“/ Fraunhofer Metabiobank:
 - Direct integration with partner biobanks
 - Webservices to share requests with partner directories (Example CRIP – biobank suisse)
 - Integration with upcoming Fraunhofer platform

Fraunhofer Metabiobank

- Online since March 2016
- Based on CRIP Concept* and software portfolio (CRIP Toolbox <http://crip.fraunhofer.de/en/toolbox>)
- Will replace CRIP and P2B2
- Foreseen to participate in wider Fraunhofer platform for Biomedical Research Information, Communication, and Computation
 - https://bricc.fraunhofer.de/htdocs/pdf/BRICC_v1.0.pdf
 - <https://www.fraunhofer.de/de/forschung/fraunhofer-initiativen/industrial-data-space.html>

*Schröder C, Heidtke KR, Zacherl N, Zatloukal K, Taupitz J: *Safeguarding donors' personal rights and biobank autonomy in biobank networks: the CRIP privacy regime*. Cell Tissue Bank **12** (2011), 233 – 240.

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

Many Features Render Fraunhofer Metabiobank a Tailor-made Use Case for Industrial Data Space (IDS)

IDS-Use Case-Merkmale	CRIP-Toolbox / Metabiobank
Verknüpfung Daten von mehreren Datenquellen	Extern: Daten aus unterschiedlichen Biobanken / verschiedener Standorte Intern: Zusammenführung von Daten aus KIS, LIMS, BIMS, ...
Integration verschiedener Datenarten	Daten aus KIS, LIMS, BIMS; Qualitätsmerkmale; SOPs; Informed Consent; ...
Kombination verschiedener Datengüter	Privat: Probanddaten, Falldaten, Patientendaten (anonymisiert), SOPs; Öffentlich: Klassifikationen, Kodierungen, Datensätze (ICD, SNOMED, UICC, SPREC, MIABIS, ...)
Beteiligung mindestens zweier Unternehmen	12 Biobankpartner, Research Community
Integration Unternehmensarchitekturebenen	Versorgung, Biobank, Forschung
Grundlage für das Angebot „smarter Services“	Metabiobank Portal, CRIP, P2B2, p-bioSPRE, BRICC

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- **Project Status**

ESBB Biobank Directory is ready for take-off

- ✓ Concept and proposal consented with ESBBtranslate and approved by ESBB
- ✓ Further details: Interview with Dr. Oliver Gros,
<https://www.youtube.com/watch?v=0jQmwmhVwlQ>
(recorded by ESBB's CEO Dr. Robert E. Hewitt in April 2016)
- ✓ Fundraising ongoing

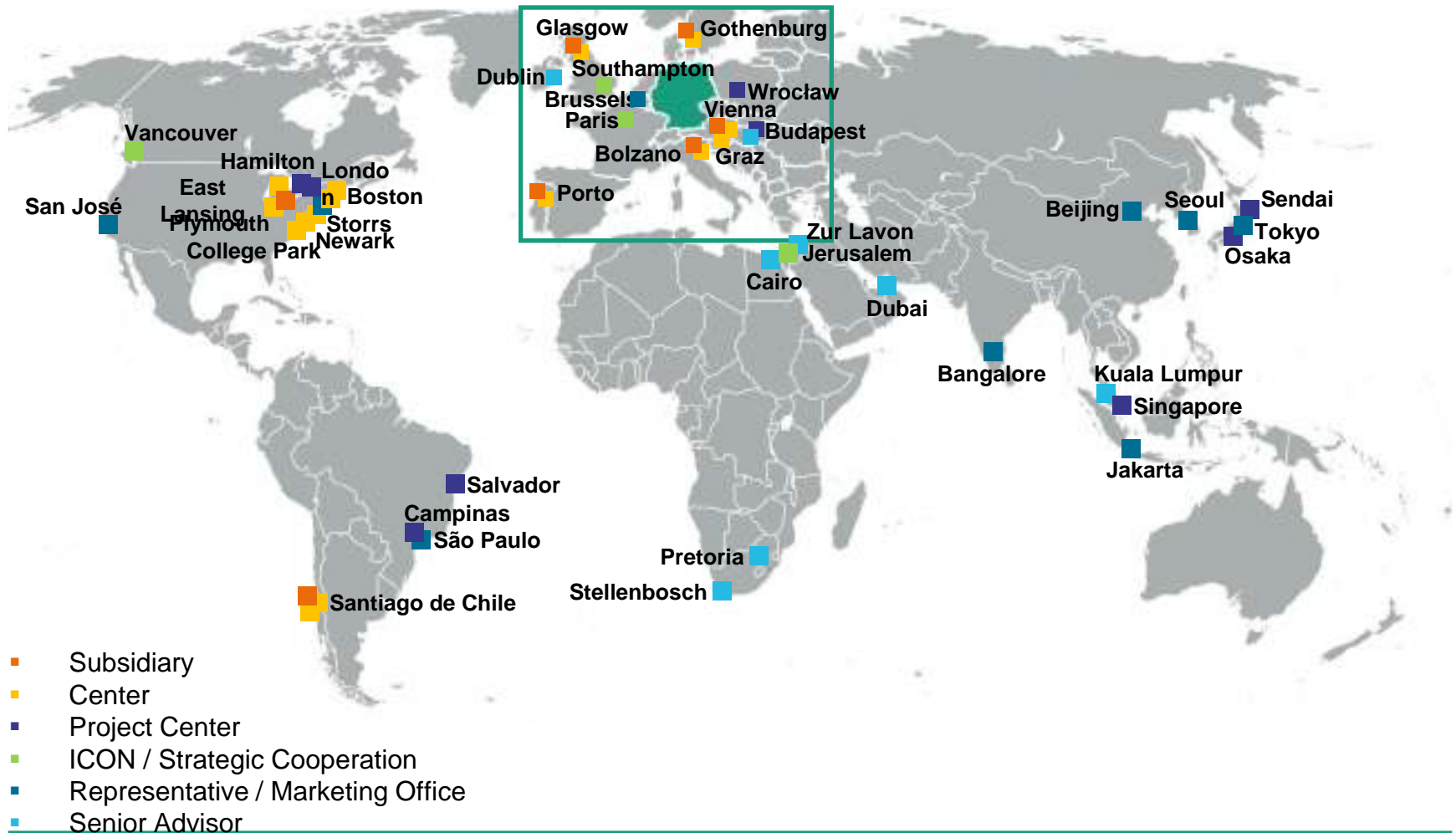
<https://www.facebook.com/biobanks/photos/pcb.747578452009235/747578408675906/?type=3&theater>



ESBB Biobank Directory will be a critical and sustainable piece in the worldwide biobanking puzzle...

- ✓ Compliant with all ethical and legal regulations
- ✓ Driven by leading (clinical) biobanks
- ✓ Geared towards Industry's Requirements
- ✓ Full interoperability / no duplication of effort and data

...supported by a German not-for-profit organization: Fraunhofer worldwide



Thank you!



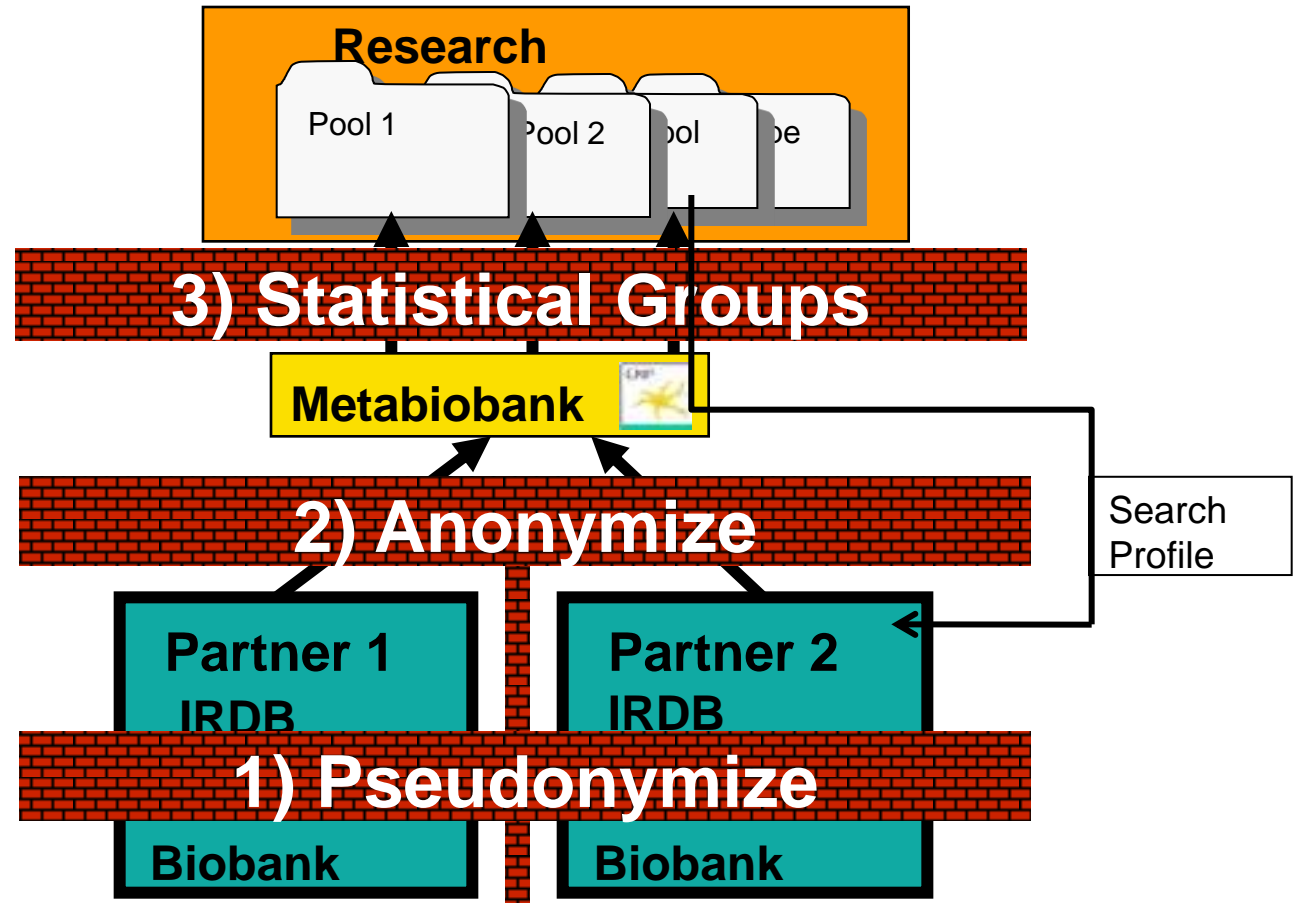
...Matthias Dobkowitz, Rukeia El-Athman, Thomas Finkenwirth, Harry Freitas da Cruz, Oliver Gros, Karsten R. Heidtke, Tim Jüttner, Sascha Kunze



CRIP Privacy Regime



...beispielhaft!



Schröder C, Heidtke KR, Zacherl N, Zatloukal K, Taupitz J: *Safeguarding donors' personal rights and biobank autonomy in biobank networks: the CRIP privacy regime*. Cell Tissue Bank **12** (2011), 233 – 240.

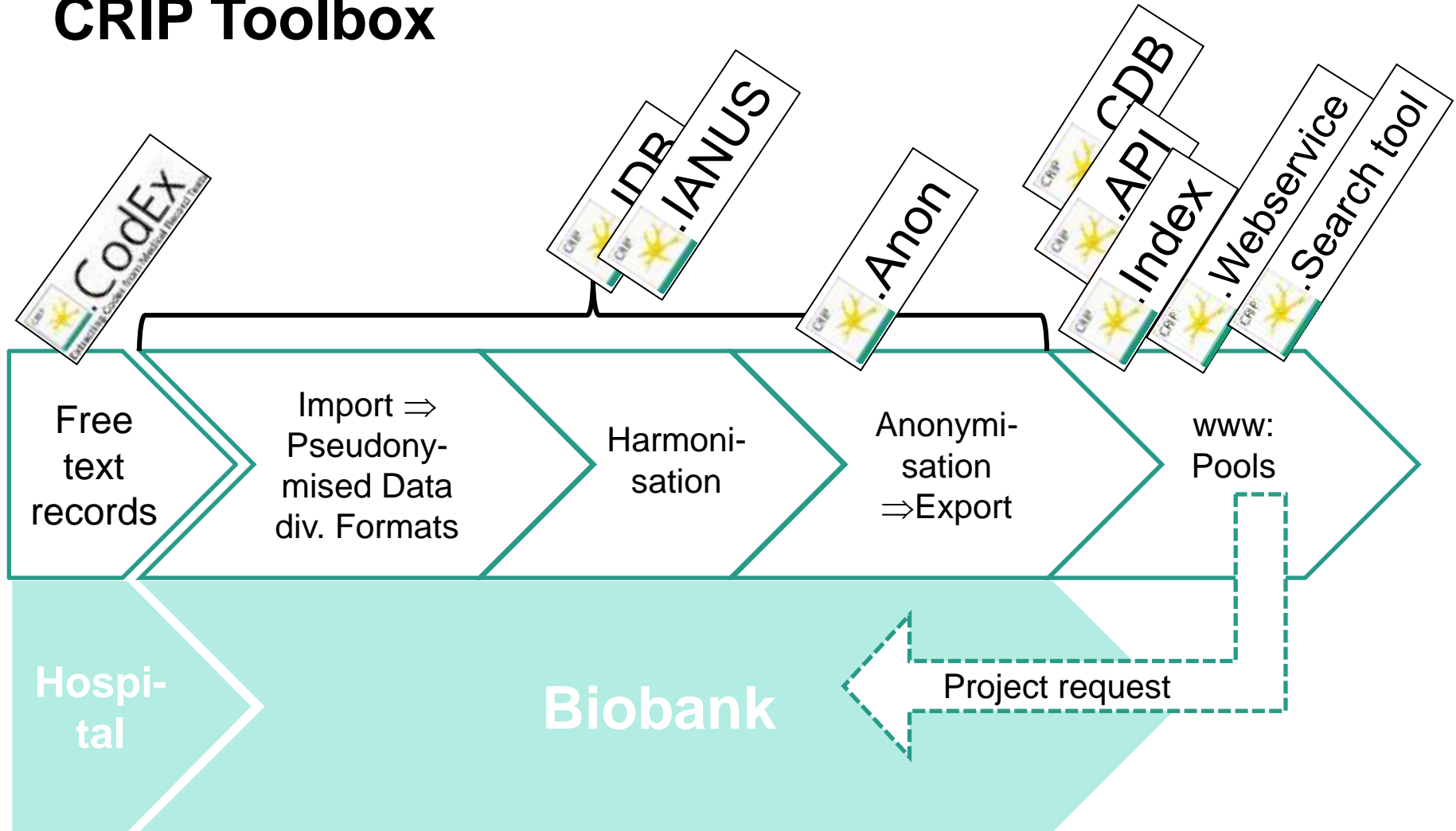
<http://www.springerlink.com/content/257x56488841215k/fulltext.pdf>

Features of our metabiobanks

Retrieve data / cases and specimens on a **case-by-case** and **sample-by-sample basis**

- ...over Web-based parameterized queries ...
- ...across the entire spectrum of diseases...
- ...on anonymized data only: Privacy preserving
- Utilize all pre-existing information management systems
- No ICT skills required
- Semi-automated / controlled data export
- Project request:
→ Establish „Biobanking on demand“?

CRIP Toolbox



<http://www.crip.fraunhofer.de/en/toolbox>