

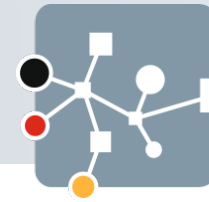
German  
Biobank Node  
bbmri.de

## Resümee der ersten Förderphase 2014 - 2016

Dr. Cornelia Rufenach

5. Nationales Biobanken-Symposium in Berlin, 8. Dezember 2016

# Two Major Tasks for GBN



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GBN will function as a central contact and exchange point for the German biobank community

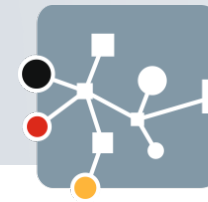
- To promote the interaction between national biobanks
- To provide harmonization and standardization for all aspects of biobanking in Germany

GBN as s German focal point for biobanks that will simultaneously act as the National Hub for BBMRI-ERIC\*

- To represent Germany in BBMRI by the National Coordinator
- To negotiate Germany's future role in BBMRI-ERIC

\*BBMRI: Biobanking and BioMolecular Resources Research Infrastructure  
ERIC: European Research Infrastructure Consortium

# 4 GBN Work Packages



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## WP1 RUNNING OF THE GERMAN CENTRAL OFFICE FOR BIOMATERIALBANKS

- Prof. Michael Hummel, Charité Berlin, National Coordinator GBN/ BBMRI.de
- Dr. Cornelia Rufenach, Charité Berlin (GBN central office), CEO GBN/ BBMRI.de

## WP2 DEVELOPMENT OF A HARMONIZED IT CONCEPT

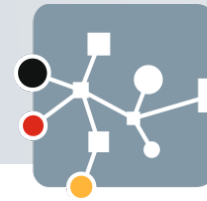
- Prof. Hans-Ulrich Prokosch, Erlangen (Medical Informatics)- Coordinator
- Prof. Frank Ückert, DKFZ Heidelberg (Medical Informatics)

## WP3 DEVELOPMENT OF A QUALITY MANAGEMENT (QM) CONCEPT IN BIOBANKING

- Prof. Peter Schirmacher, Heidelberg (NCT, BMBH)- Coordinator **Tissue**
- Dr. Sabrina Schmitt, BioMaterialBank Heidelberg - **CORE Team**
- Prof. Karl-Friedrich Becker & Dr. Julia Slotta-Huspenina (TU München)- **CORE Team**
- PD Dr. Dr. Michael Kiehntopf, Jena (Integrated Biobank Jena)- Coordinator **Liquid**
- Bettina Meinung, Jena (Integrated Biobank Jena)- **CORE Team**

## WP4 PUBLIC RELATION FOR BIOBANKING IN GERMANY

- Prof. Roland Jahns, Würzburg (IBDW Würzburg)- Coordinator
- Wiebke Lesch, GBN
- Antje Schütt, TMF head office



## National Coordinator

Prof. Michael Hummel

michael.hummel@charite.de

## Contact

German Biobank Node

Charité - Universitätsmedizin Berlin

Campus Benjamin Franklin (CBF)

Institut für Pathologie - Haus 3A

Hindenburgdamm 30, 12203 Berlin

Tel. +49. 30. 450 536 347

Fax +49. 30. 450 753 6938

<http://www.bbmri.de>

## Central Office

**woManpower:** 2 FTEs

**Executive Director** - since Aug 2014

Dr. Cornelia Rufenach

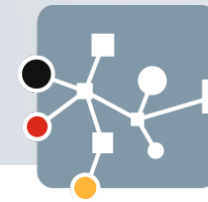
[cornelia.rufenach@charite.de](mailto:cornelia.rufenach@charite.de)

**Project Manager**- since May 2015

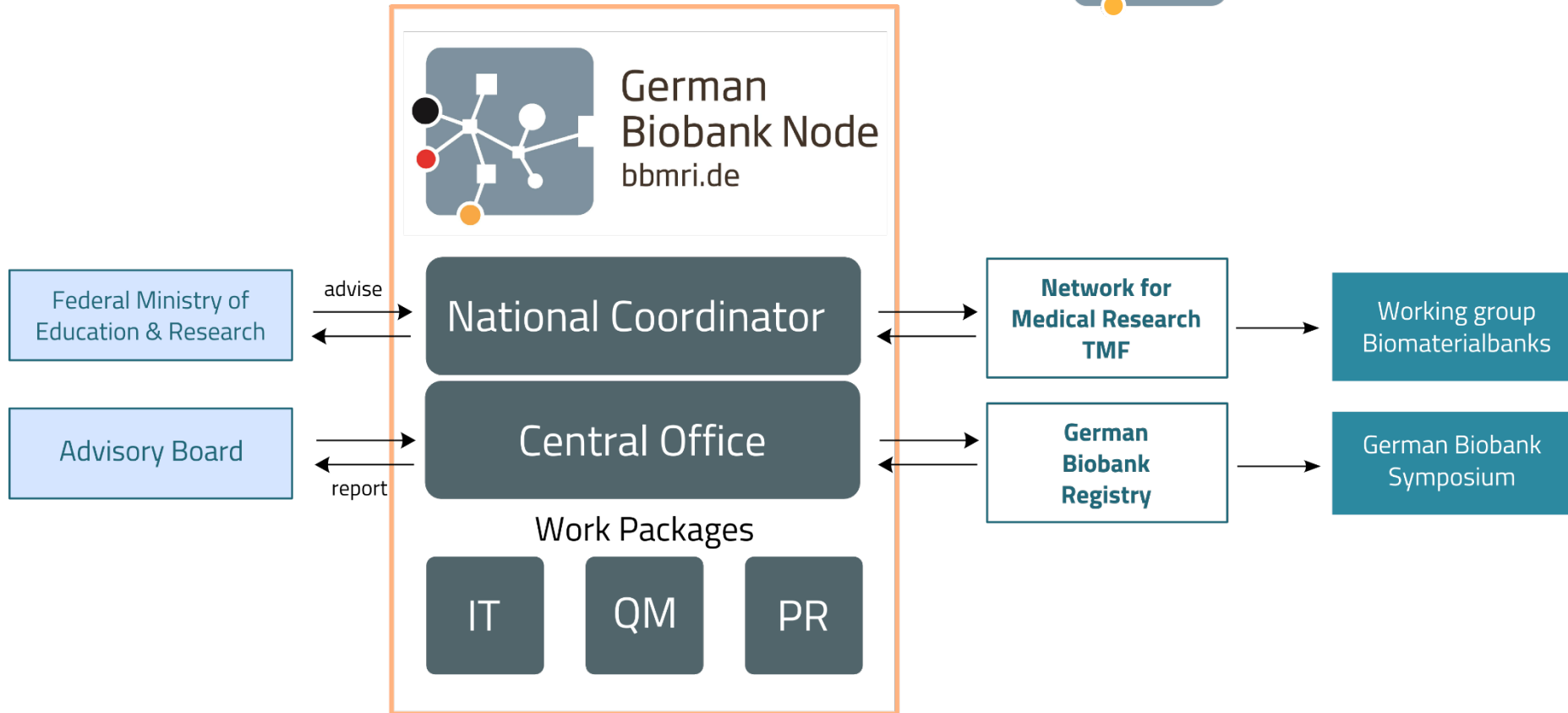
Ida Steier

[ida.steier@charite.de](mailto:ida.steier@charite.de)

# German Landscape of Biobanks



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<p><b>cBMBs</b> <b>centralized biomaterialbanks</b> Aachen, Berlin, Heidelberg, Kiel, Würzburg, <i>München</i></p>	<p><b>DZG</b> <b>Biobanks of German centres for health research</b></p> <p><b>DZG</b> DEUTSCHE ZENTREN DER GESUNDHEITSFORSCHUNG</p>	<p><b>NaKo</b> <b>National Cohort</b> <b>Population-based cohort with 200,000 probands</b></p> <p><b>NA KO</b> NATIONALE KOHORTE</p>
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# Participation of Community - 17 GBN Workshops



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## ■ Quality Management

24.7.2015, Heidelberg

8.12.2015, Berlin

18.2.2016, Berlin

4.10.2016, Berlin



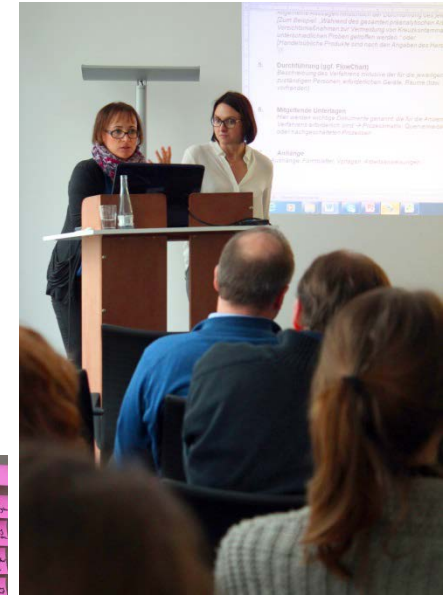
## ■ IT

21.11.2014, Erlangen

11.6.2015, Berlin

21.6.2016, Frankfurt (WP2 pilot project)

22.9.+ 11.10.+ 28.11.2016 "Hackathons" Frankfurt



## ■ Public Engagement (Concept Workshops)

12.-13.8.2015, Berlin

8.12.2015, Berlin

6.4.2016, Berlin

29.6.2016, Berlin

15.7.2016, Berlin



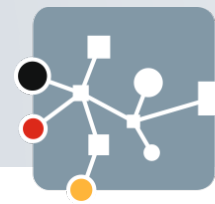
## ■ GBN Educational Workshops

6.12.2016, Berlin

"Practical implementation of international Quality Standards for Biobanks"

"Stakeholder Engagement for Biobanks"

# Regular Communication - Newsletter



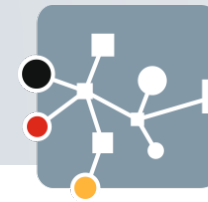
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- Target group: biobank community in D & EU
- Language: English
- Publication: quarterly, electronically
- 1st edition in Oct 2015
- Focus topics:
  - Quality
  - ELSI
  - Next: IT

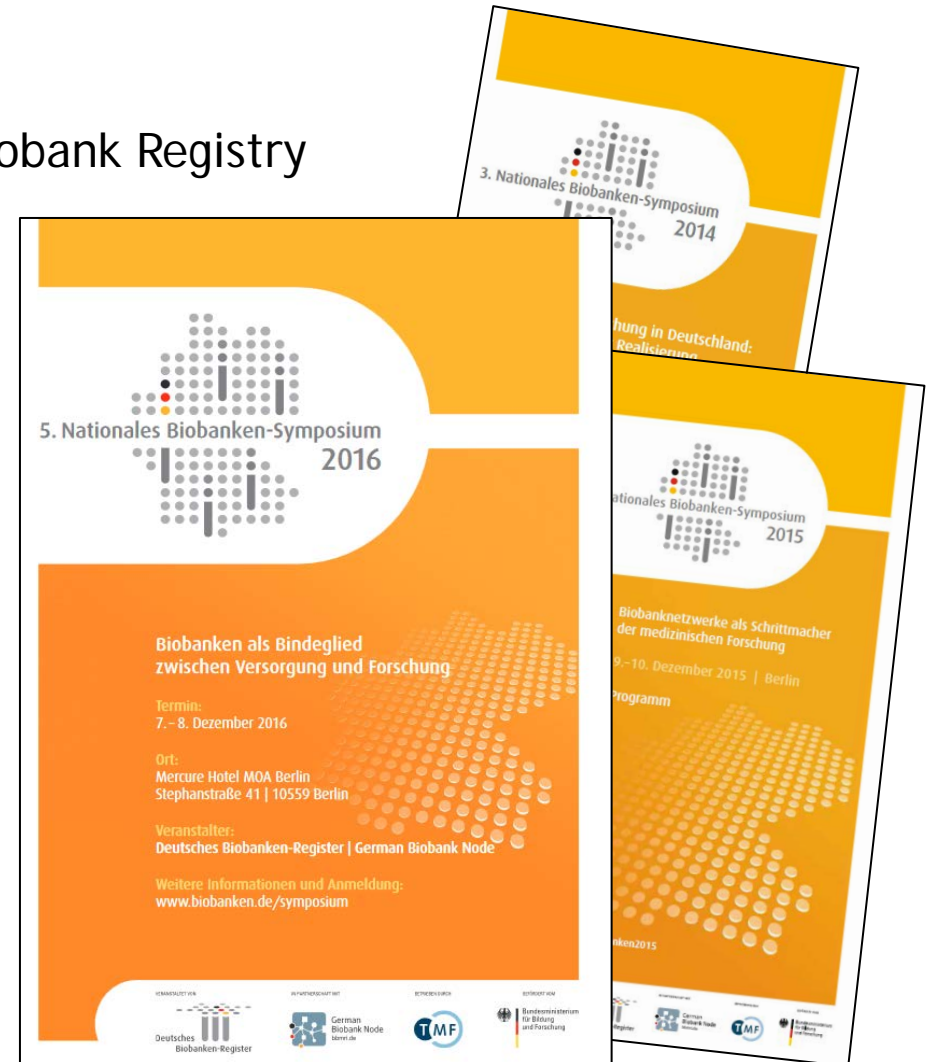


# Open Forum - National Biobank Symposium



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- established in 2012 by the German Biobank Registry
- GBN joined in as partner 2014
- Since 2015: GBN topics integrated
- takes place annually in Dec in Berlin
- ≈ 250 participants
- 5<sup>th</sup> symposium on Dec 7-8, 2016:  
**Biobanking as Connector  
between Patient Care  
and Research**







## ■ ISBER 2016 Annual Meeting & Exhibits (Berlin, 5.-8.4.2016)

- Michael Hummel "The German Biobank Node: National coordination and central point of contact for BBMRI-ERIC"
- Michael Hummel "German Biobank Node: Establishing A National Biobanking Research Infrastructure To Accelerate Biomedical Research"
- Wiebke Lesch "How Well Do Study Participants Understand the Concept of Biobanking in Medical Research? Results of a Survey Among Sample Donors in Germany"

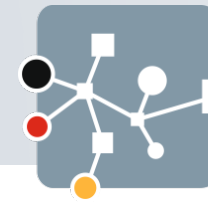
## ■ 100. Annual meeting of DGP (Deutsche Gesellschaft für Pathologie e. V.) (Berlin, 19.- 21.5.2016)

- Michael Hummel, Cornelia Rufenach „German Biobank Node: Etablierung einer nationalen Biobanken-Infrastruktur mit enger Anbindung an das europäische Netzwerk BBMRI - ERIC“

## ■ Europe Biobank Week (Vienna, 13.-16.9.2016)

- Sabrina Schmitt "German Biobank Node's concept for quality management"
- Antje Schütt "Study Participants' Attitudes towards and Understanding of Biobanks. Results of an Exploratory Survey in Germany"

# Publication - Strengthening Visibility of Biobanking



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Special edition of *Bundesgesundheitsblatt* with focus on biobanking

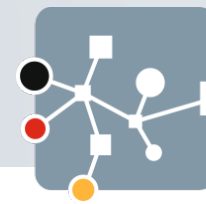
Coordination & Editorial: *Michael Hummel & Iris Pigeot*  
Publication: March 2016

## Topics:

- Biobanken zwischen Forschungs- und Spenderinteressen *Taupitz/ Schreiber*
- Errichtung und Betrieb von Humanbiobanken *Jahns*
- Nutzungskonzepte für Proben und Daten aus humanen Biobanken *Semler/ Siddiqui*
- Qualität von Biomaterialien im Biobanking von Flüssig- und Gewebeproben *Herpel/ Schmitt/ Kiehntopf/*
- Zentralisierte Biobanken als Grundlage für die klinische Forschung *Illig et al.*
- Bedeutung von Biobanken für klinische Entwicklung *Thomas et al.*
- Die Biobank der Nationalen Kohorte als Ressource der epidemiologischen Forschung *Wichmann et al.*
- UK Biobank: Genetics, lifestyle and environment *Trehearne*
- Umweltprobenbank des Bundes *Gies et al.*
- Strategien zur Vernetzung von Biobanken *Ückert/ Prokosch et al.*
- BBMRI-LPC: Vernetzung von Biobanken großer europäischer Kohorten *Kuhn et al.*
- BBMRI-ERIC: the novel gateway to biobanks *Litton et al.*
- Die Sicherung der Nachhaltigkeit von Biobanken *Kirsten / Hummel*



# Developing Strategic Directions - Position Paper of Biobanking



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## Strategic Position Paper

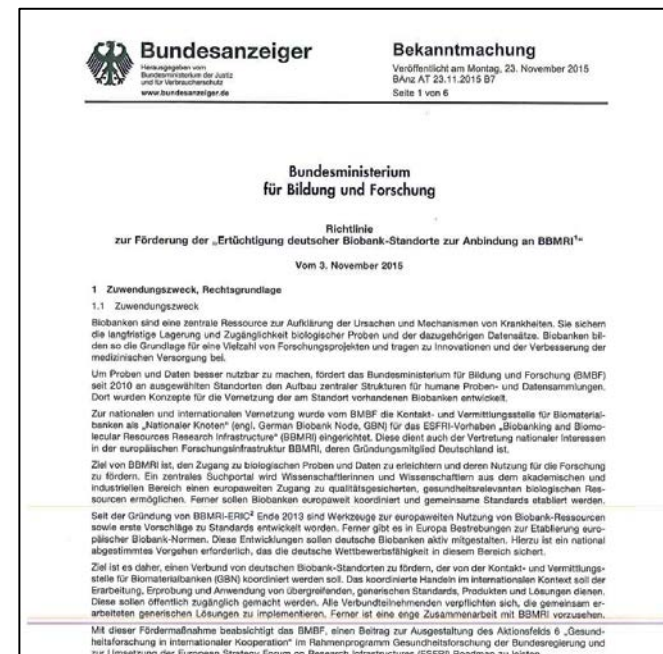
- In Q1.2015 the 5 centralized biobanks and GBN developed a biobank concept 2.0 and submitted it to the Federal Ministry of Education and Research

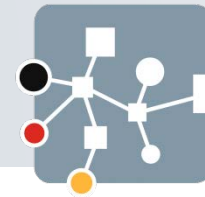


Federal Ministry  
of Education  
and Research

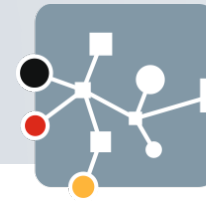
## New Call for a German Biobank Alliance

- Call was published in Nov 2015 targeted at centralized biobanks and GBN as the coordinating structure
- GBN developed concept according to funding scheme for the German Biobank Alliance in Jan 2016
- Reviewers feedback received at the end of July 2016
- Composition of work programme incl milestones and deliverables with all partners until 31.10.2016
- Waiting for feedback





- Regular participation in the Management Committee meetings and scientific retreats
- Regular information about activities in newsletter of GBN and BBMRI
- Coordination of workshops (IT & Clinical Biobanking)
- Significant contribution to the Common Service ELSI
- Active participation in the BBMRI Work Programme (Quality, IT) and involving German experts
- H2020 Proposal ADOPT (WP3; IT Gateway)
- Common Service IT: „Access“ to European biobanks and biomaterials/data

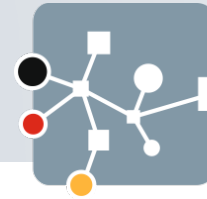


## RUNNING OF THE GERMAN CENTRAL OFFICE FOR BIOMATERIALBANKS

- Transparent communication about ongoing activities in GBN & BBMRI
- NO closed shop but open working platform
- Active involvement of biobanks from other research infrastructures
- Create interfaces between different organizations (e.g. DZGs, DIN/ISO)
- Develop strategic directions of biobanking activities in Germany
- Shape the future work programme with the German Biobank Alliance

GBN functions as a central contact and exchange point for the German biobank community

GBN as s German focal point for biobanks that will simultaneously act as the National Hub for BBMRI-ERIC



## Task 1: Biobank Communication and Public Outreach

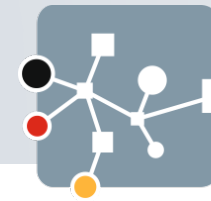
- Enhance knowledge in patients/participants and their families on the concepts, utility, and work of human biobanks and on biomedical research
- Advice German biobanks in their communication concepts and public engagement activities

## Task 2: GBN Corporate Communications

- Identification and analysis of relevant stakeholder groups
- Concept and execution of brand development for GBN



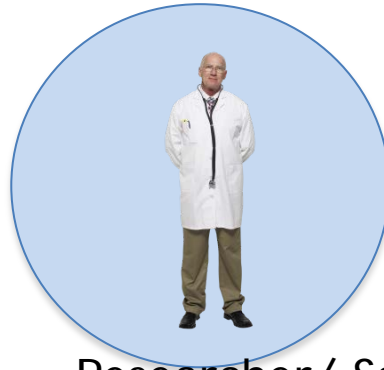
# Stakeholder Identification & Analysis



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Biobank Manager



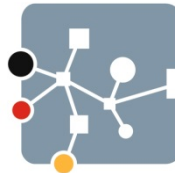
Researcher/ Sample User  
(Academia and Industry)



General Public  
(Politics, Funding  
Institutions etc)



Press

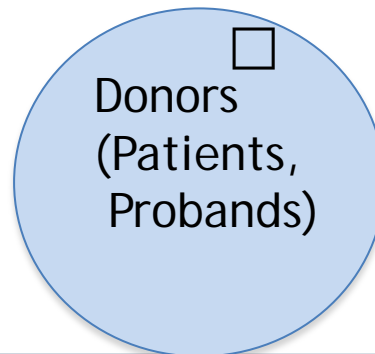


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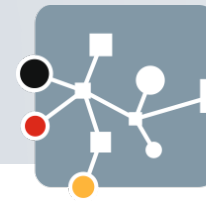
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[www.biobanken-verstehen.de](http://www.biobanken-verstehen.de)

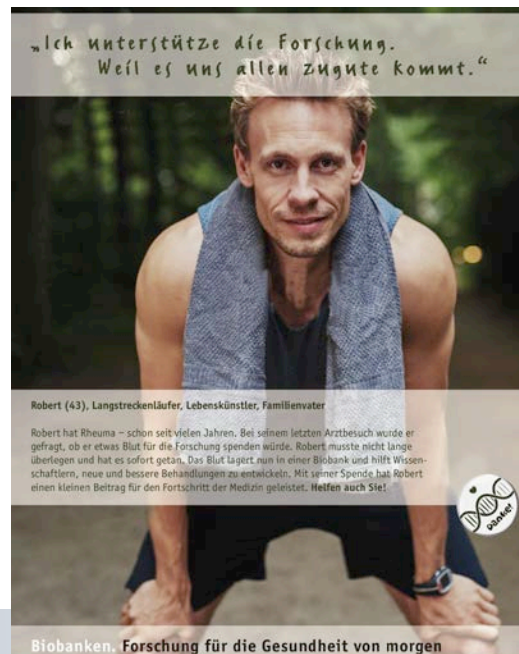


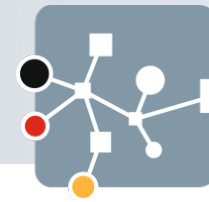
Donors  
(Patients,  
Proband)





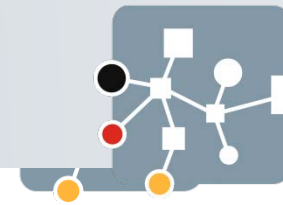
1. Publications (book and scientific journal)
2. Donor campaign (concept)
3. Flyer/Poster
4. Patient website (concept)
5. Sample texts
6. Educational film clips
7. Infographic
8. Foto archive





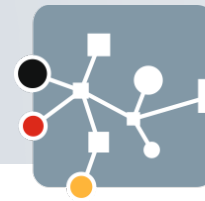
1. GBN Website (in development)
2. Expert interviews
3. Press kit (website)
4. Newsletter (integrated in website)
5. Film clips “How does a centralized biobank work?” (concept)
6. FAQ’s centralized biobanks
7. Guidelines/handout for the internal communication of a centralized biobank





- GBN is an infrastructure for biobanks (networks) and focus point for all biobank-related topics
- GBN is well embedded in the German biobank and research community
- GBN successfully achieved creating **concepts** for quality, IT and public relations

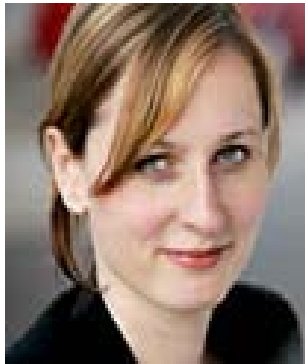
# Team WP1 & WP4



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**WP1\_Central Coordination**  
Cornelia Rufenach  
Ida Steier  
Michael Hummel



**WP4\_Public Outreach**  
Wiebke Lesch  
Antje Schütt (*TMF*)  
Roland Jahns (*ibdw*)



**WP4\_ELSI**  
Irene Schlünder (*TMF*,  
*Common Service ELSI BBMRI*)  
Roland Jahns (*ibdw*, *AKEK*)



Federal Ministry  
of Education  
and Research





Thank you for your attention!