

German
Biobank Node
bbmri.de

External Scientific and Ethical Advisory Board (SEAB) meeting in Berlin on
21 September 2018

SEAB recommendations for the German Biobank Node and German Biobank Alliance

General comments on 2018

The SEAB congratulates GBN and GBA for their extraordinary achievements and the work completed over the past year. Everything delivered as part of this project is outstanding and unprecedented in Europe and the rest of the world. The members of the SEAB believe that the achievements in Germany make GBN/GBA a role model for Europe. Furthermore, the products generated are of high importance for the development and support of biobanks in Europe, primarily via the BBMRI-ERIC network.

Specific comments on 2018

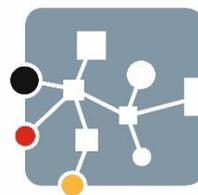
WP1 – Coordination and stakeholder activities

Concerning all of the stakeholder work, we especially encourage the continuation and intensification of the very important interaction with industry, which has already been initiated. At the same time, we also recommend reaching out to ethics committees and clinicians as further, very important stakeholder groups. Following the *User Satisfaction Survey* addressing biobank users, we propose adding a question regarding the impact of biobank services on achieving the research project aims.

GBN's products are very useful to the biobank community and meet their needs exactly, hence it is very important to continue this work. This also includes common position papers, which could be highly significant to biobanking at the national level in Germany. With regard to the interaction with industry, the development and provision of a contract template and a common pricing strategy would be greatly beneficial to the whole community. A harmonized pricing strategy within GBA (and beyond) would moreover ensure transparency for patients and help to gain their trust. Together with the politicians and lawyers, we encourage you to further their involvement and to continue inviting these stakeholders to relevant occasions and events – as was the case during the successful workshop held in May 2018.

WP2 – IT network

The SEAB is impressed with the live online search for biomaterials and data across six different GBA biobanks. Having witnessed this live search, we highly recommend intensive outreach activities not only in Germany but also on the European level to broadly



German
Biobank Node
bbmri.de

demonstrate what has been achieved. We therefore strongly encourage you to give such a live online presentation in London during the next BBMRI-ERIC Management Committee meeting (8–9 October 2018). This should be mirrored on the national level through the active involvement of non-GBA biobanks in the alliance. Start marketing and communicating your activities and achievements to the community now and not just at the end of the project.

Concerning the competition with commercial IT platforms, we suggest you benchmark your system by comparing the differences, relative advantages and disadvantages. One unique advantage of GBN/GBA is that its biobanks are embedded in academic environments and their host institutions would be reluctant to enter patient data in another privately-owned platform. Since the project is driven by both sides – by researchers as well as by the biobanks – we recommend further intensifying the focus on the users' needs, including socio-technical aspects. Also reflect on how to handle the different IT interfaces of the users, especially the researchers and clinicians. Consider the role of biobanks as an entry point for a researcher into the IT network by performing overarching searches for samples and data. This digitalisation will support your role to be a science enabler or even a science driver.

WP3 – Quality management system

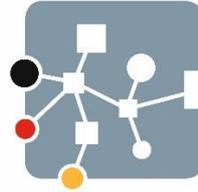
The SEAB is very positive about GBN's support for GBA biobanks with the conducting of "friendly audits" as a first step on their way to accreditation according to the recently published ISO 20387 norm. Concerning the quality assurance for biomarkers, we encourage GBN to allocate sufficient funding to complete the work programme of the liquid and tissue samples.

WP4 – Public relations and communication

The GBN website is very well designed and informative. We recommend that you provide a list of all products available to the community to increase their visibility and accessibility.

WP5 – Ethical, legal and social issues (ELSI)

We urge you to publish a position paper as a follow-up from the ELSI workshop ("My genes belong to me!") on incidental findings held in May 2018. Due to the complexity of this topic, no definite solution could be found on how to translate research findings into medically relevant information and what role biobanks should play in this process. We suggest establishing a small working group to discuss this topic again and reach a consensus. You should also consider the regulations in Switzerland and in the United States during this process.



German
Biobank Node
bbmri.de

WP6 – Education and training

We agree with Dr. Nußbeck's idea of prioritising e-learning according to the content and experiences of the quality work package, especially the ring trials. This will maximise the impact since it corresponds to the practical work of biobank-related technicians.

Sustainability

Focusing on the future of the project and the sustainability, it is essential to start planning now with a focus on the products with the highest value and impact. The SEAB expressed its willingness to review this sustainability concept and to share its opinions and advice.

With respect to sustainability, it should be ensured that the project continues at the national level without interruption, especially in terms of the IT developments, so that the developments can be finished and operations can be rolled out by GBN. Outreach work and the involvement of non-GBA biobanks should not dilute the efforts at this point; they can be involved at a later stage.

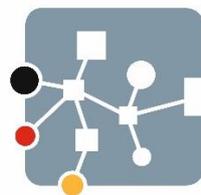
In order to reach out to the community, you should start planning communication of the most important activities to maximize further use of your products. This could be documents or some sort of workshop. You need to explain to non-GBA biobanks how to proceed, how to implement solutions and to motivate them to get involved.

One particular suggestion is a document describing the “lessons learned” while setting up your national IT network, but also including European experience from the BBMRI-ERIC (ADOPT) Colon Cancer Data Collection. This would be most informative for future developments, ensuring your work and experience are documented for posterity.

The SEAB especially welcomes the collaboration with the German Medical Informatics Initiative (MI-I) and recommends fostering this cooperation by developing a work plan defining the next steps for joint activities. Clearly state the common ground with the MI-I and also indicate the differences. This especially holds true for GBN's advanced IT development, which covers important aspects that are also relevant for MI-I. The close cooperation with MI-I is of great importance for GBN since political decisions might also be influenced by demonstrations of the added value derived from this interaction.

The final and most important point relates to the sustainability of the GBN/GBA project after the funding period ends. Regarding decisions to be made, we encourage you to engage with funders and ministries immediately. One opportunity to do so could be created by inviting them to the national annual biobanking symposium in December 2018. Politicians and other responsible persons should also be invited to this event – it is very important to reach out to them at this stage, too.

So once again, congratulations on everything that has been achieved!



German
Biobank Node
bbmri.de

SEAB/biobank	Participants
Scientific and Ethical Advisory Board	Dominic Allen, Fay Betsou, Kurt Zatloukal, Stefanie Houwaart, Gianluigi Zanetti, Jochen Taupitz, Johann Eder, Kristian Hveem
Aachen	Michael Rose
Berlin/GBN	Michael Hummel, Cecilia Engels, Christiane Hartfeldt, Verena Huth, Magdalena von Jagwitz, Cornelia Specht, Ida Steier
Erlangen	Hans-Ulrich Prokosch
Frankfurt	Daniel Brucker
Greifswald	Theresa Winter
Göttingen	Sara Nußbeck
Hannover	Thomas Illig
Heidelberg (BMBH)	Peter Schirmacher, Esther Herpel
Heidelberg (DKFZ)	Martin Lablans
Jena	Michael Kiehntopf, Bettina Meinung
Leipzig	Ronny Baber
Lübeck	Jens Habermann, Petra Duhm-Harbeck
Munich	Gabriele Anton, Christian Gieger
Würzburg	Roland Jahns