

Recommendations of the External Scientific and Ethical Advisory Board (SEAB) for the German Biobank Node and German Biobank Alliance

SEAB meeting on 16 September 2020 (virtual)

When evaluating the German Biobank Node and the German Biobank Alliance, the image of a long-distance runner comes to mind. There has been a remarkable continuity, stamina and direction in what has been achieved. The consortium has a clear structure, and the amount and quality of work has been very impressive throughout. There is an enormous strength in purpose within the organisation which is accompanied by an atmosphere and an approach of inclusiveness, openness and sharing. This is one of the contributing factors to the success of what GBN/GBA have done. Congratulations!

A good illustration of that is how GBN/GBA are making resources available and are also systemically asking for feedback. This long-term approach and consistency have now been rewarded by an answer to the sustainability question which the SEAB brought up in previous meetings. The link with the Berlin Institute of Health is a great success. It is an excellent move and development for the future. It will also provide a link within the German system of health and research of which biobanking is an important part.

There are several areas in which GBN/GBA are now leading. Examples are the quality indicators – a remarkable amount of work has been done here - and the Sample Locator. Considering the latter, there are many other examples around, but none with so many biobanks linked and the possibility to query such a big database connected to it.

Remarks about the future of GBN/GBA

1. The reason of biobanking is to promote research: providing samples and having impact. There was not too much reference to this in the presentation earlier. However, working on the impact through distribution should remain a leitmotiv of the whole operation. It is what it will be judged on looking out over the years. The organisation needs to get to that last element - in terms of the long-distance runner image, it is getting over the finishing line with success.
2. The link to BIH is a major evolution. It also has challenges to go with it because GBN is becoming part of another organisation which has its own objectives. It will be very important for GBN to align itself with the BIH. During the time before that integration, GBN will be able to create and harmonise common projects. This process hugely depends on the relationships that will be built in the coming years between the GBN management and the corresponding members within BIH.

Specific comments

- **IT/Sample Locator:** The open source documentation of the IT-infrastructure should be completed and published soon.
- **Stakeholder Management:** The results of the focus group that were presented were very useful. The SEAB encourages GBN to use the focus groups as a way to anchor their actions in what the patients and donors think because they make the biobanking world possible.
- **New project:** GBN/GBA are well connected with the Federal Ministry of Education and Research. A stronger linkage with the Federal Ministry of Health could facilitate the initiation of long-term storage of samples from care for being able to return them particularly in case of hereditary diseases.
- **Funding for GBA biobanks:** The funding for the move to BIH is focused on the sustainability of GBN. However, the constituent biobanks must survive. The idea of the biobanks in Heidelberg and Jena becoming a proficiency testing (PT) provider linked to quality control (QC) laboratories with the appropriate accreditations was put forward. The SEAB encourages GBN to prepare a business plan for this development, which could also be relevant for industry cooperation. Requiring quality certificates, industry often sources samples from commercial suppliers. To provide such certificates linked to the provenance of the samples - biobanks accredited to ISO 20387 - could be one of the outputs of this idea.

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