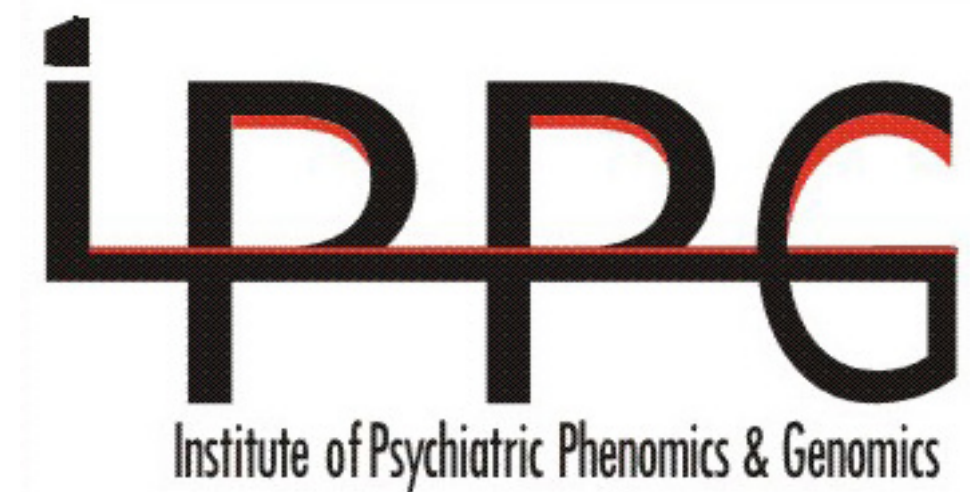


NETBI-OMICS – DATA EXCHANGE FOR DISTRIBUTED BIOBANKS IN THE INVESTIGATION OF MENTAL ILLNESS



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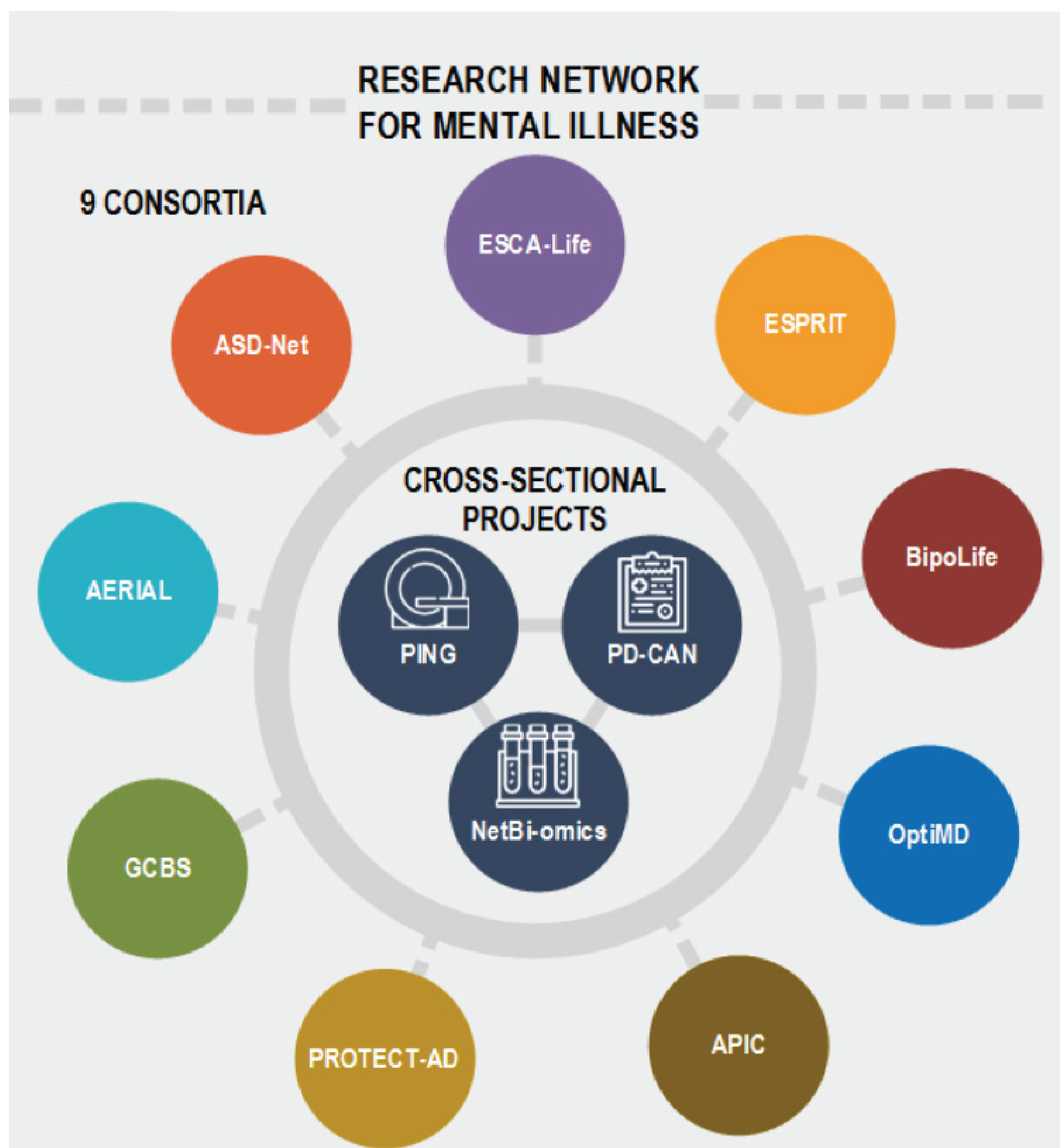
BACKGROUND

Mental illnesses are among the common diseases in Germany. In order to better understand and treat the development of mental illness, isolated research is no longer sufficient. For this purpose, the Federal Ministry of Education and Research (BMBF) supports psychiatric research in Germany. With a term from 2015 to 2019, the BMBF is funding a research network with a focus on mental and psychiatric illnesses. The „Research Network for Mental Illness“ funding initiative created research consortia for the most common psychiatric illnesses. To allow data from these consortia to flow

together, three common cross-sectional platforms for biomaterials, clinical data and imaging data were established (see graph 1). The cross-sectional project NetBi-omics should serve as a biobank. Biobanks have become a crucial component of big data research in all fields of medicine, in particular as regards genomic approaches. However, biobanking faces several non-trivial logistical and ethical questions, with the majority of logistical and conceptual issues arising from the ethical challenges (1).

Graph 2. Biospecimen, phenotypic data, imaging data which is collected within one research consortium are shared within the cross-sectional projects. The identity management transforms the first pseudonym of the consortia into a second pseudonym of the cross-sectional projects. This results in a double pseudonymisation.

Graph 1. Research network for mental illness and cross-sectional projects: NetBi-omics (biospecimen), PD-CAN (phenotypic data) and PING (imaging data)



National research consortia: ASD-Net (Autism spectrum disorder Network), AERIAL (Addiction: Early Recognition and intervention across the lifespan), GCBS (German Center of Brain Stimulation), PROTECT-AD (optimized psychotherapy for anxiety disorders), APIC (Antipsychotic Induced Brain Changes), OptiMD (Depression Network), BipoLife (Bipolar disorder network), ESPRIT (Enhancing Schizophrenia Prevention and Recovery through Innovative Treatments), ESCA-Life (Evidence-based, stepped care of ADHD along the life-span).

METHOD

Within a research network of this size a central requirement for processing any data stems from data protection requirements. As a cross-sectional project performed on many study locations, the data has to be pseudonymised in the different projects and locations. Also it has to pass every local ethics committee to get an ethics approval.

NetBi-omics explores three problem-solving approaches:

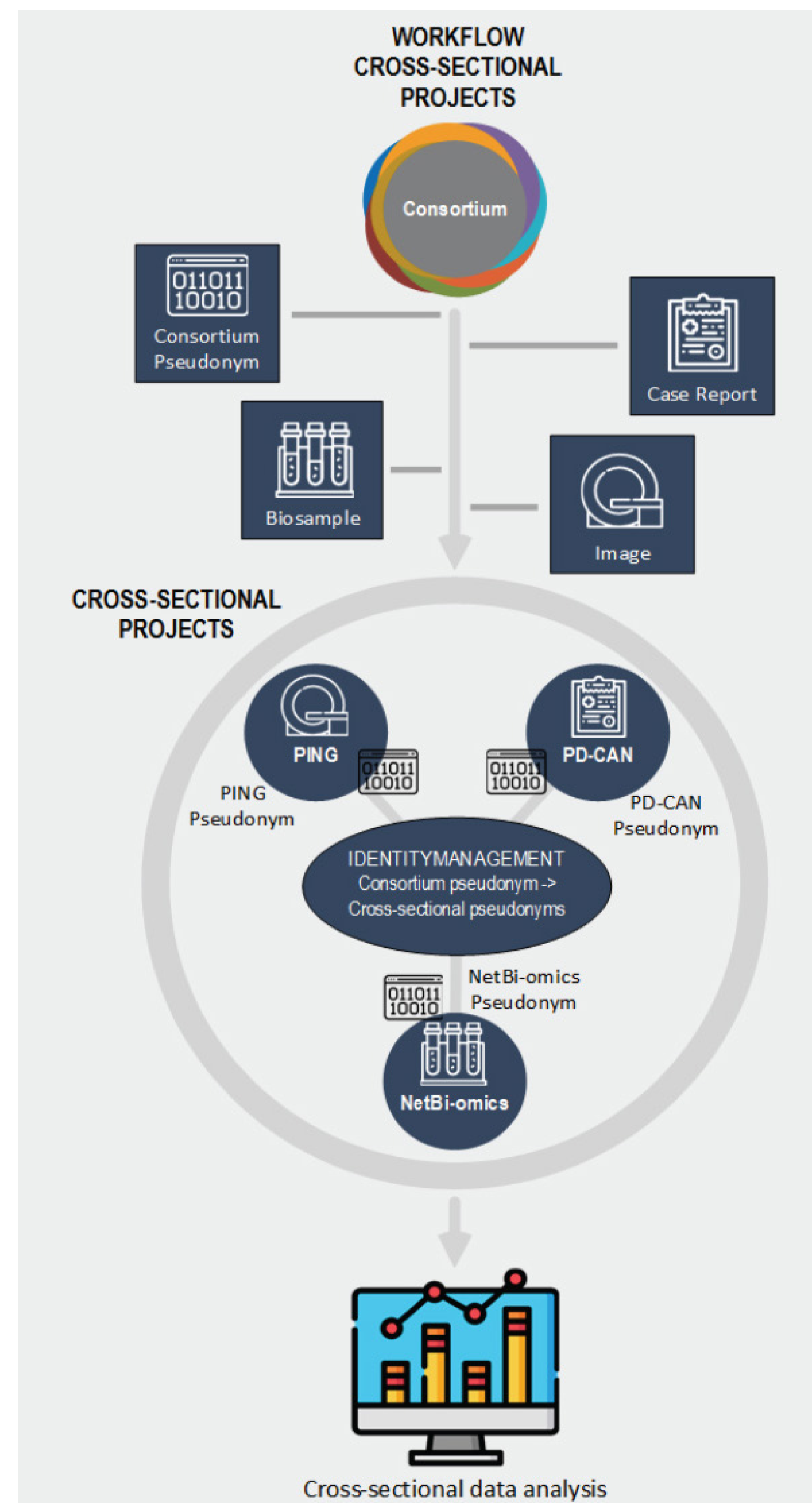
1. providing a common privacy policy for the three cross-sectional platforms
2. implementing a usable common IT-infrastructure to capture the data in a data protection compliant procedure
3. establishing the processes needed to capture biomaterial on different study locations

RESULTS

- Data protection: A data protection concept based on the national data protection guidelines was developed. This was positively assessed by the Munich ethics commission (LMU) and serves as an example for further ethics commissions (2). The participants agree to the data protection concept and the storage of biospecimen (blood, saliva, faeces, hair, liquor) for at least 10 years.
- Ethical aspects: A comprehensive patient information and a broad informed consent was edited. As large scale “omic” research potential increases the risk to reveal incidental findings, the right not to know has to be a realistic option for the participant (3). Therefore, they have to decide whether they want to be informed about incidental findings in the case of an available medical intervention or prevention or in the case of a non-actionable finding.
- IT-structure: The technological heart is a central identity management. A special characteristic of NetBi-omics is that at no time identifying patient data are stored. Pseudonyms used in each research consortium within the research network (e.g. BipoLife) are converted again into another pseudonym. This creates a chain of pseudonyms which only can be returned to the identifying data within the initial research consortium (see graph 2). The generation of pseudonyms will occur at all sites via browser-based software using a laboratory information management system. The IT-infrastructure is managed by the Department of Medical Informatics of the University Medical Center Göttingen, Germany.

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DISCUSSION

NetBi-omics is a cross-sectional biobank for the collection, storage and provision of biospecimen. Networking and international collaborations have become indispensable for successful research. As we move towards collecting more detailed data and a large quantity of biomaterials, the risk of re-identification increases; As measures to bypass technical solutions to data security and encryption are likely to develop faster than such solutions, the protection of personal rights will remain a challenge to the field of biobanking.

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