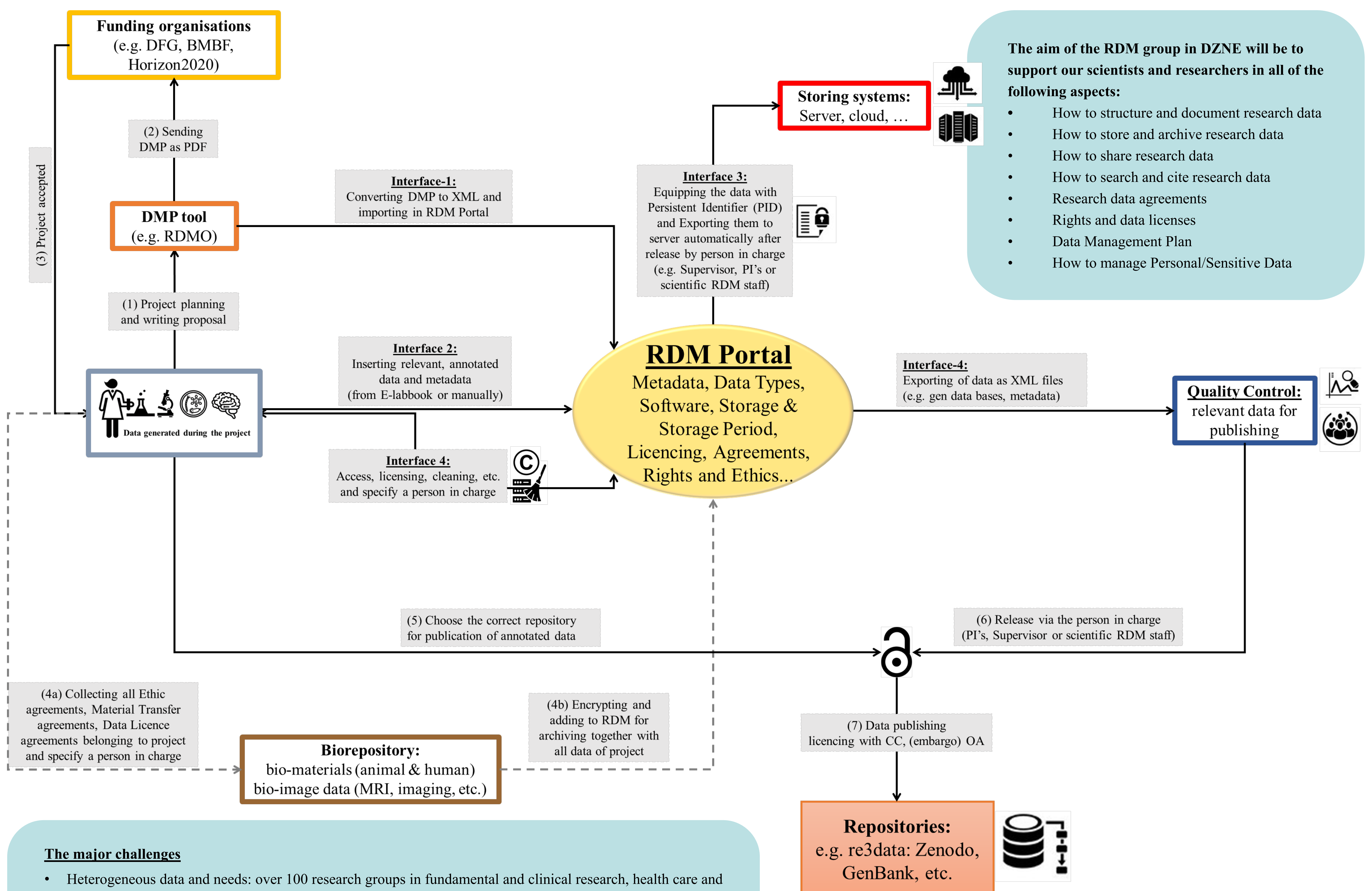


“Knowledge drives from data.” (1) Data has gained a central role in today’s science landscape. Therefore, the need of knowledge transparency and data accessibility has grown in this digital era. Never before **Research Data Management (RDM)** has been as important as it is today, in the time of data plenitude, volatility and complexity largely attributable to the digitalization and to the advances in Big Data.

RDM at Deutsches Zentrum für Neurodegenerative Erkrankungen e. V. (DZNE): The DZNE is a neuroscience research centre with more than 100 research groups distributed across ten different locations, engaged in interdisciplinary research to tackle neurodegenerative brain diseases. The work of scientists at the DZNE covers *Fundamental Research, Clinical Research, Population Sciences* (also called *Rhineland Study*) and *Health Care Research*. The **main challenge** for the implementation of RDM at the DZNE continues to be the heterogeneous data collection as well as different needs of all research groups in all the research areas mentioned above."

Good management and sharing of research data remain a key principle for DZNE. DZNE already fulfils the recommended Best Practices in compliance with all regulations in particular for the handling of sensitive personal data in its Clinical Research and Population Study. For the DZNE, however, the primary challenge for implementation at hand is the **Fundamental Research**, since the Clinical Research and the Rhineland Study already have consolidated databases and RDM procedures in place. The Fundamental Research data is also demanding because it exists in so many forms, and decisions about sharing, quality control and rights are left to the research group leaders rather than centralized. Furthermore, a cultural shift is required, especially in raising the awareness of scientists for sustainable data management and data sharing. Hence, the DZNE will support systematic and rigorous Data Management and Data Sharing by implementing a suitable RDM system in fundamental research field and continuing to carefully address all relevant ethical, scientific and legal aspects but also the quality control.

Project plan for implementation of RDM in Fundamental Research at DZNE



The major challenges

- Heterogeneous data and needs: over 100 research groups in fundamental and clinical research, health care and population studies
- Dealing with highly sensitive data (clinical data, human data, personal data)
- Distributed centres: DZNE is distributed across 10 cities in Germany (Consideration of different legal interpretations in the federal and state governments)
- International regulations: as leading edge neuroscience research centre, DZNE collaborates with scientists and researchers from 5 Continents