

Biobanks and databases: basis for translational research

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DESIRE
Development & Epilepsy



Strategies for Innovative Research to
Improve Diagnosis, Prevention and Treatment
In Children with Difficult to Treat Epilepsy

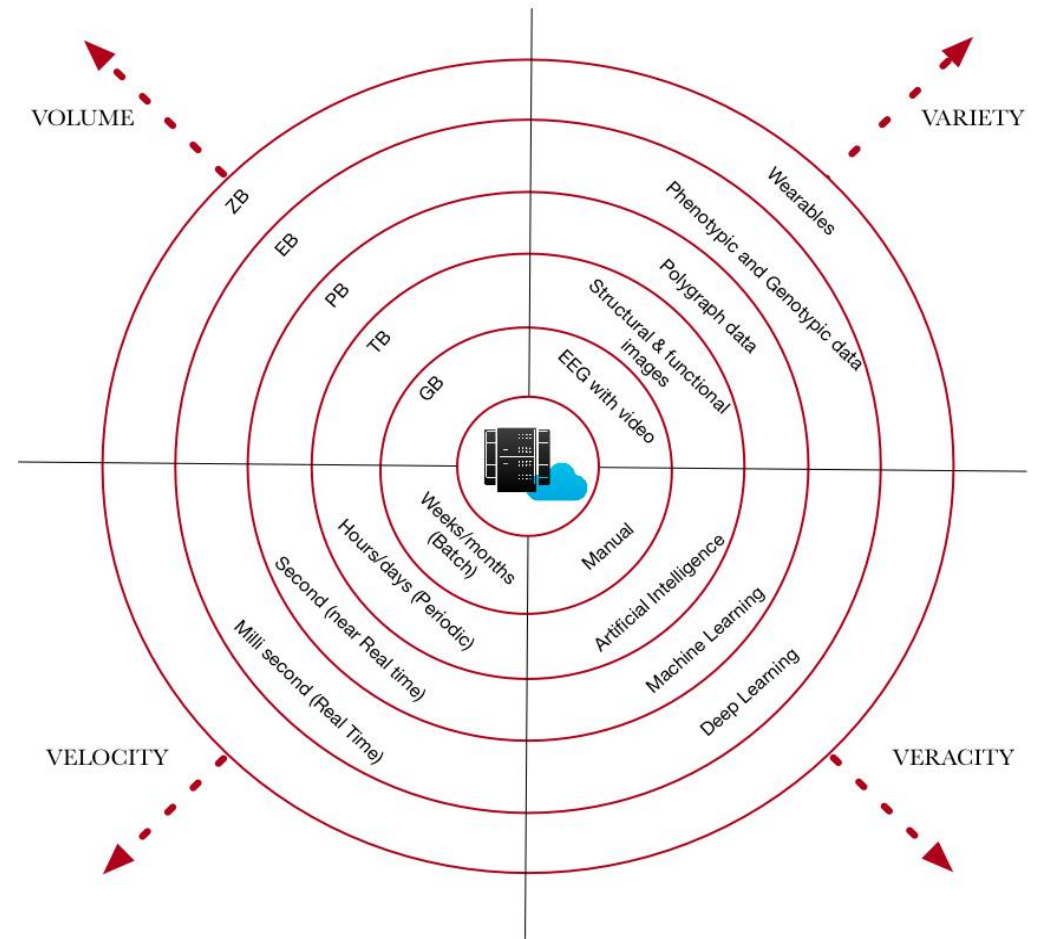
Biobanks: What we need to consider...

- Scale, organization and security of existing biobanks
 - Space, GDPR, costs
- Quality of tissue
- Type of tissue
 - Whole brain tissue (kryo, FFPE), blood (EDTA, citrate), blood compartments, individual cell populations, fibroblasts, other?
- Limitations in access
 - Harmonization of ethics and MTAs
- Join biobanks and databases
 - Bioinformatics



Talking big data...

- large volumes of high velocity, complex and variable data that require advanced techniques and technologies to enable the capture, storage, distribution, management, and analysis of the information
- Big Data are as inviting as they are challenging!



Databases: Gaps to be filled...

- Getting The Basics Right
 - Epilepsy Ontology and Classification
 - Common Data Elements, Minimal Data Set
- Challenges to data transfer for storage and transfer to researchers
 - Technical infrastructure
 - Local servers vs. Commercial cloud (iCloud vs. myCloud, ...GDPR and ethics)
 - Access limitations
- Maintenance of databases
- Joining databases...



Thank you!

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