

# Biobanking and data sharing for the progress of collaboration on GSD



The Money lender and his Wife. Quentin Massys, 1514.



International meeting Glycogen Storage Diseases associations  
Milan October 2<sup>nd</sup> 2010

Luigi Varesio

# BIOBANKS



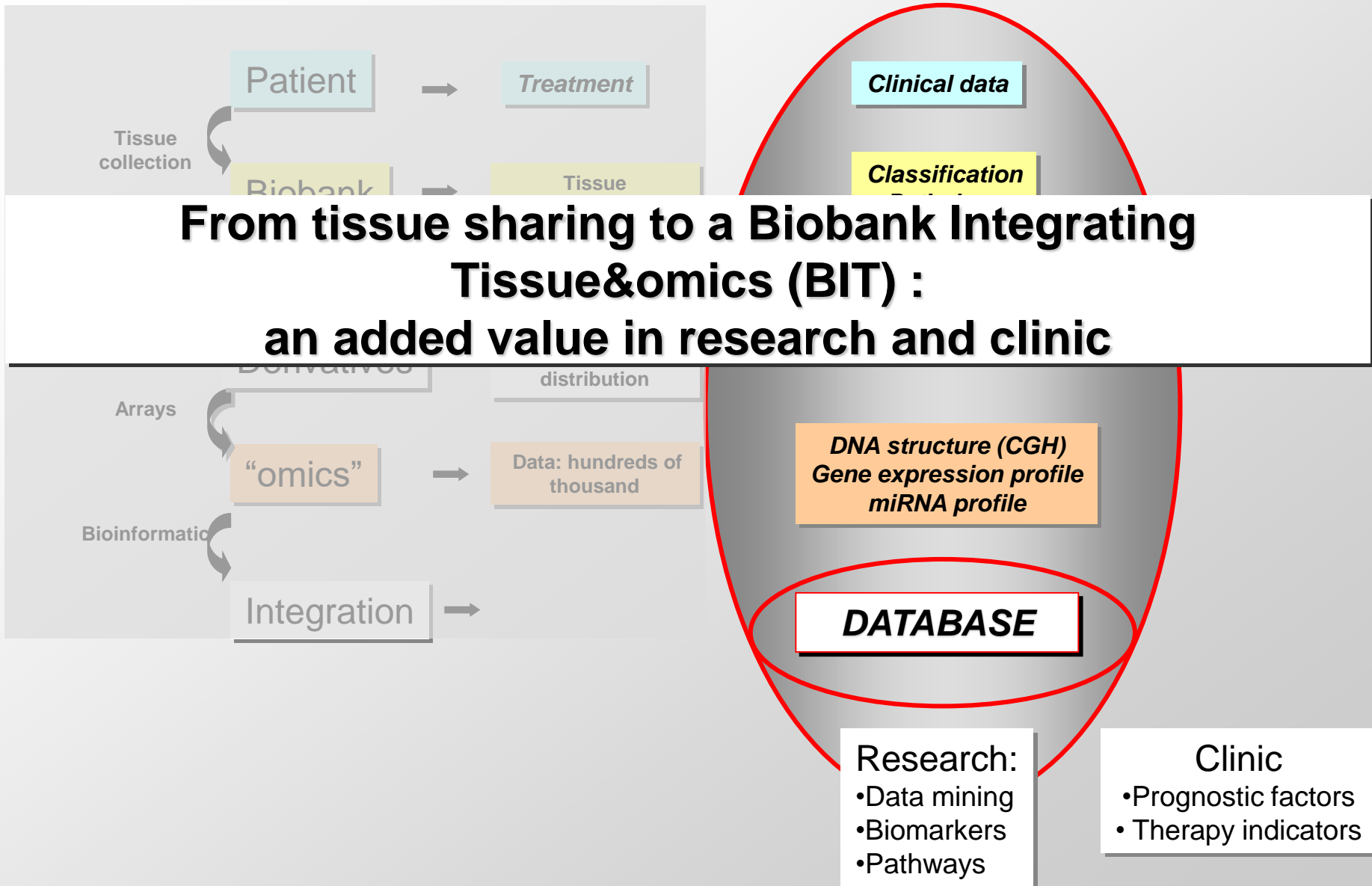
Sample collection and  
dissemination of the results

# Pediatric Biobank

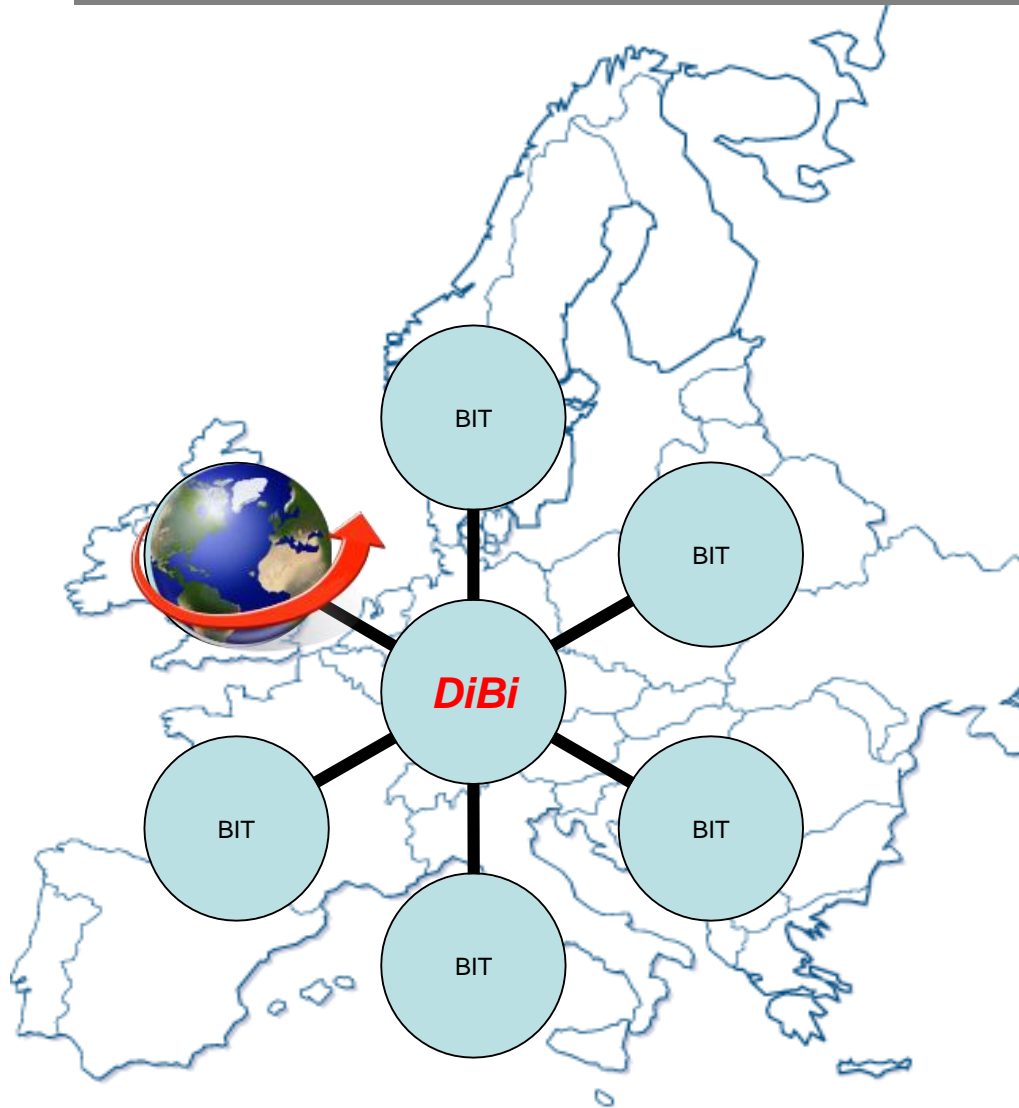
## → different

- Limited number of specimens
- Unique legal considerations
- Unique scientific questions
- Network is mandatory to reach a meaningful number of samples

# Biobank Integrating Tissue&omics (BIT) Gaslini



# Digital Biobank (*DiBi*) centralizes the databases of individual “BIT”



**The centralization of the information is indispensable to study and to treat rare diseases**

Clinical data

Classification pathology

DNA structure (GCH  
ne pXF  
S

# Digital Biobank

Several BIT can share the databases generating a

Digital Biobank

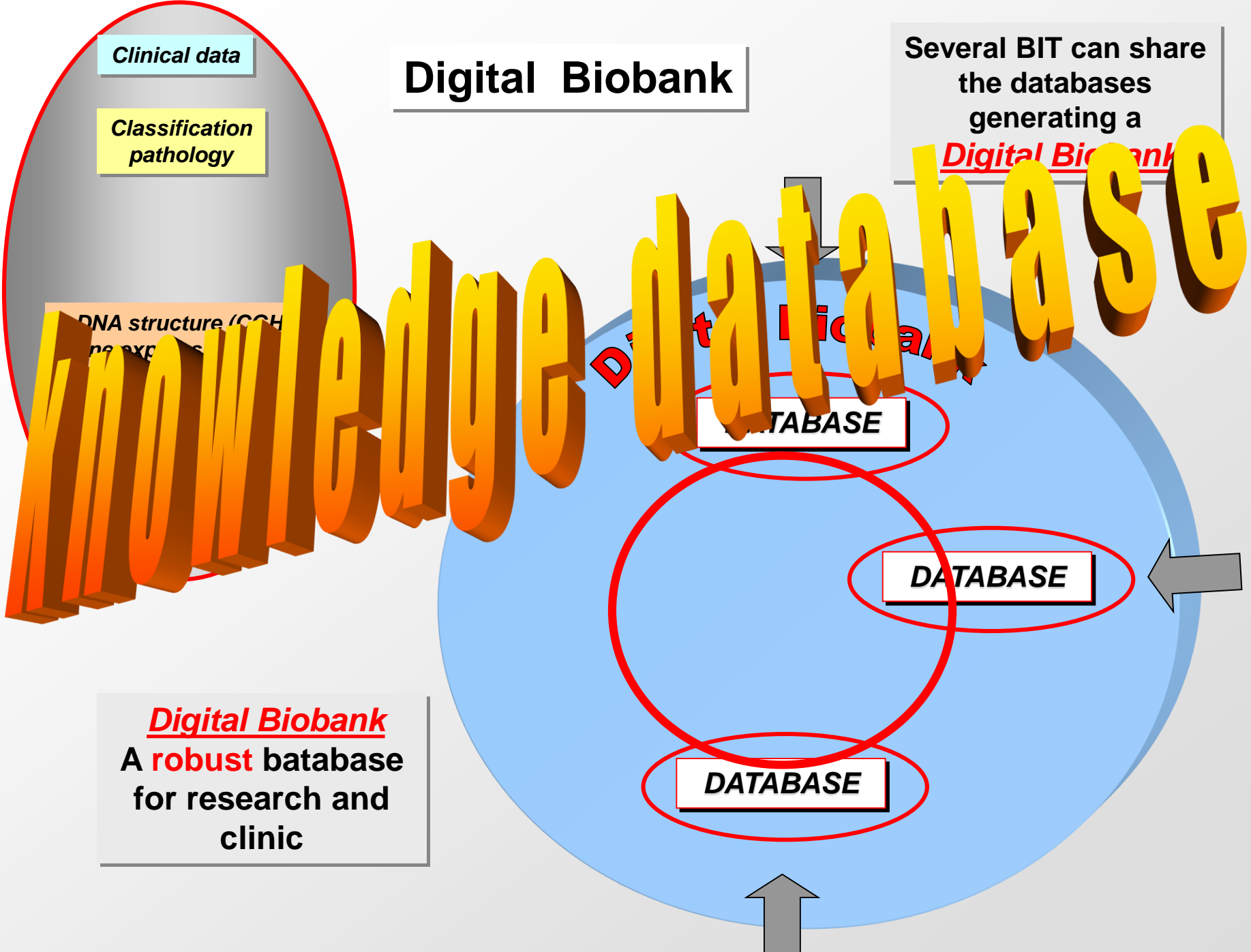
# Knowledge database

DATABASE

DATABASE

DATABASE

Digital Biobank  
A **robust** database for research and clinic



# Pediatric Biobank

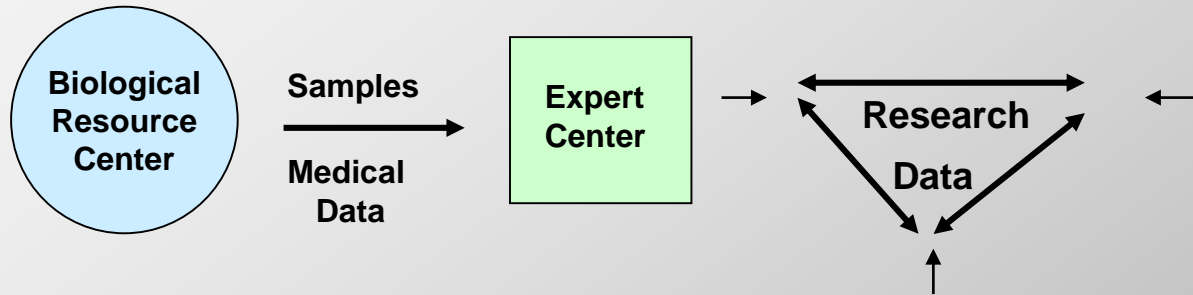
## → potential

- Molecular characterization of every patients
  - Targeted therapeutic applications
- Personalized medicine

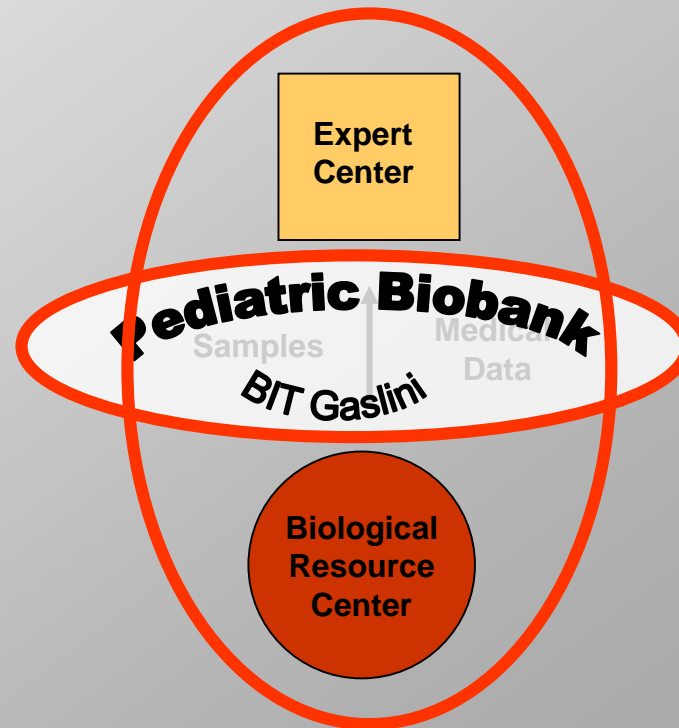


# Expert Centers as part of the Pediatric Biobank

**BBMRI**



- **Cost effective**
- **Immediate, continuous contact among clinicians, biologists, bioinformaticians**
- **A step closer towards molecular profiling of every patient in given set**
- **Center of excellence for treatment and study of specific pediatric diseases**



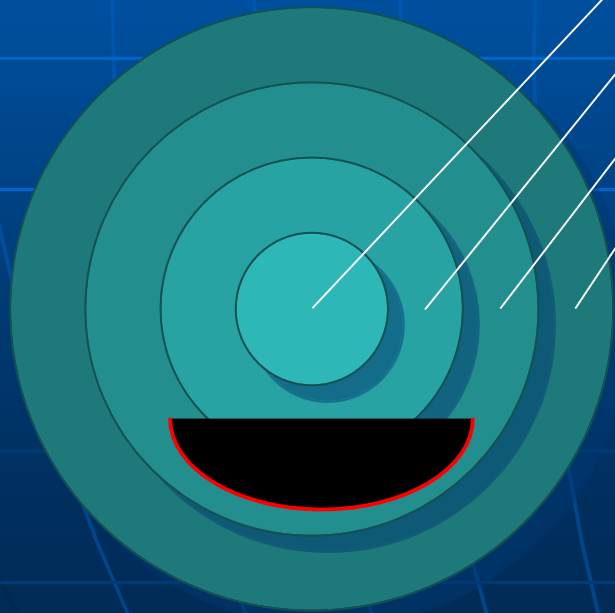
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**GSD**

**biobanks network**

**Pediatric Rare disease**



**Biobank: Data and specimens sharing**

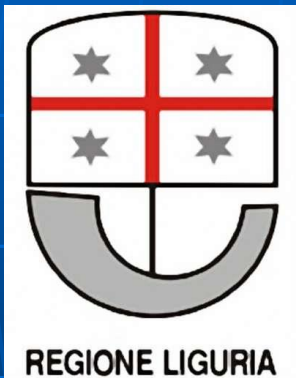
Implementation of the infrastructure

**GSD consortium**

Laboratories Network

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**Claudio Gambini**

**Paolo Fardin**  
**Fabiola Blengio**  
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Digital biobank: coming up

# Knowledge database

- Platforms for “omic” analysis
- Funding

# Pediatric GSD Biobank

## → short term goals

- Establish a network of
- Interface the network with BBMRI