

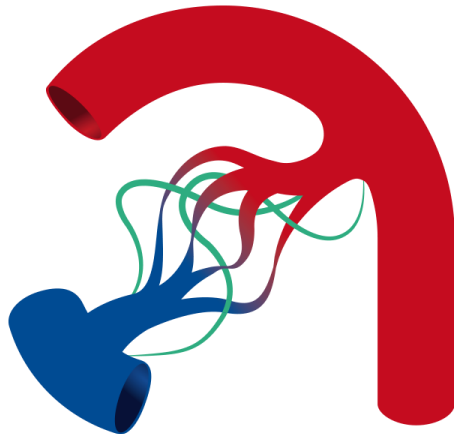


**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

 **Network**

Vascular Diseases  
(VASCERN)



# Registries (*WP8*)

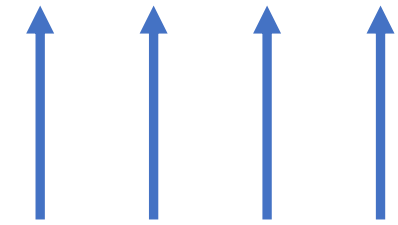
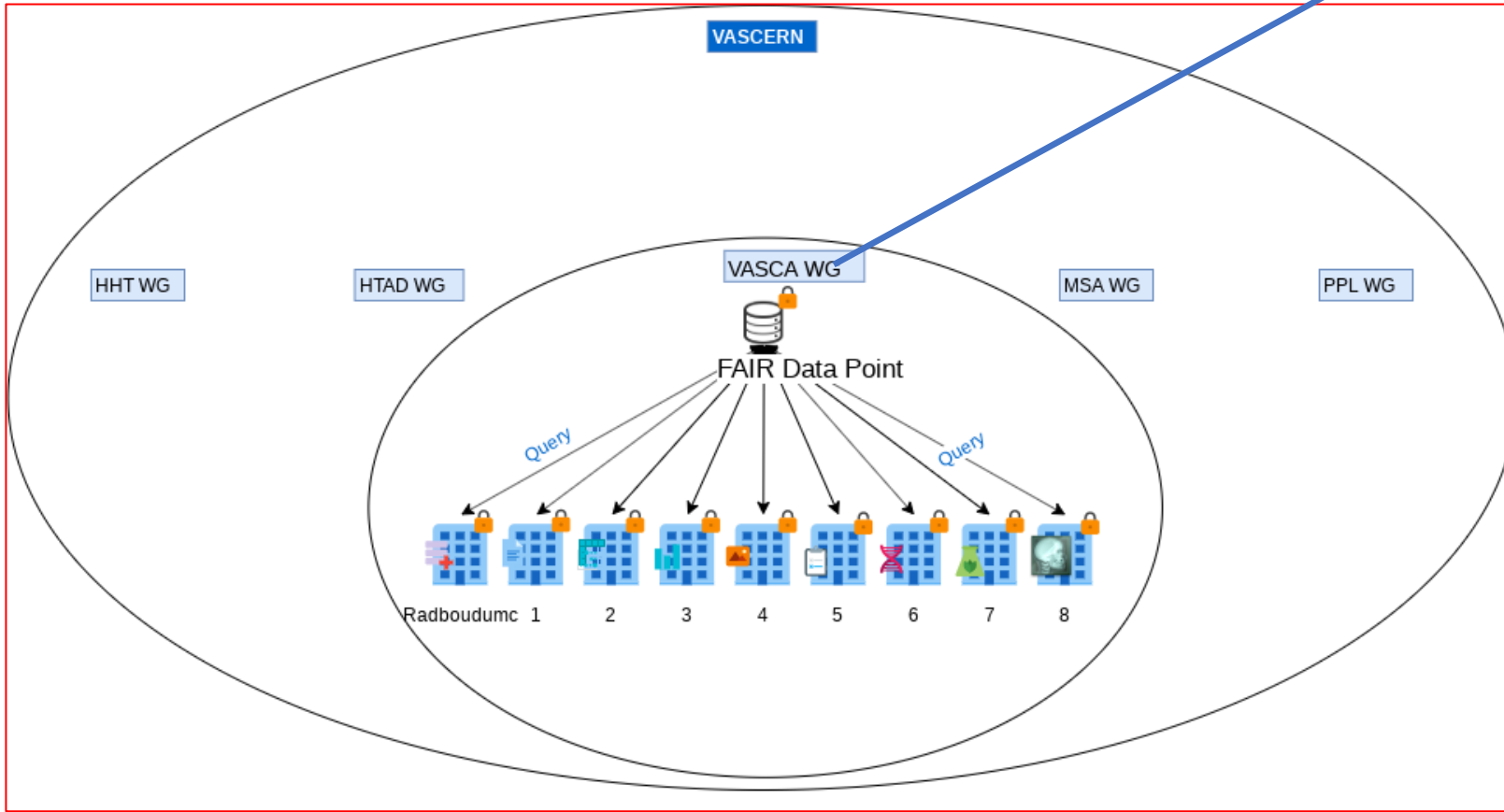
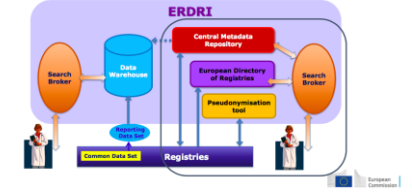
*Leo Schultze Kool*

<https://vascern.eu/what-we-do/patient-registries/>

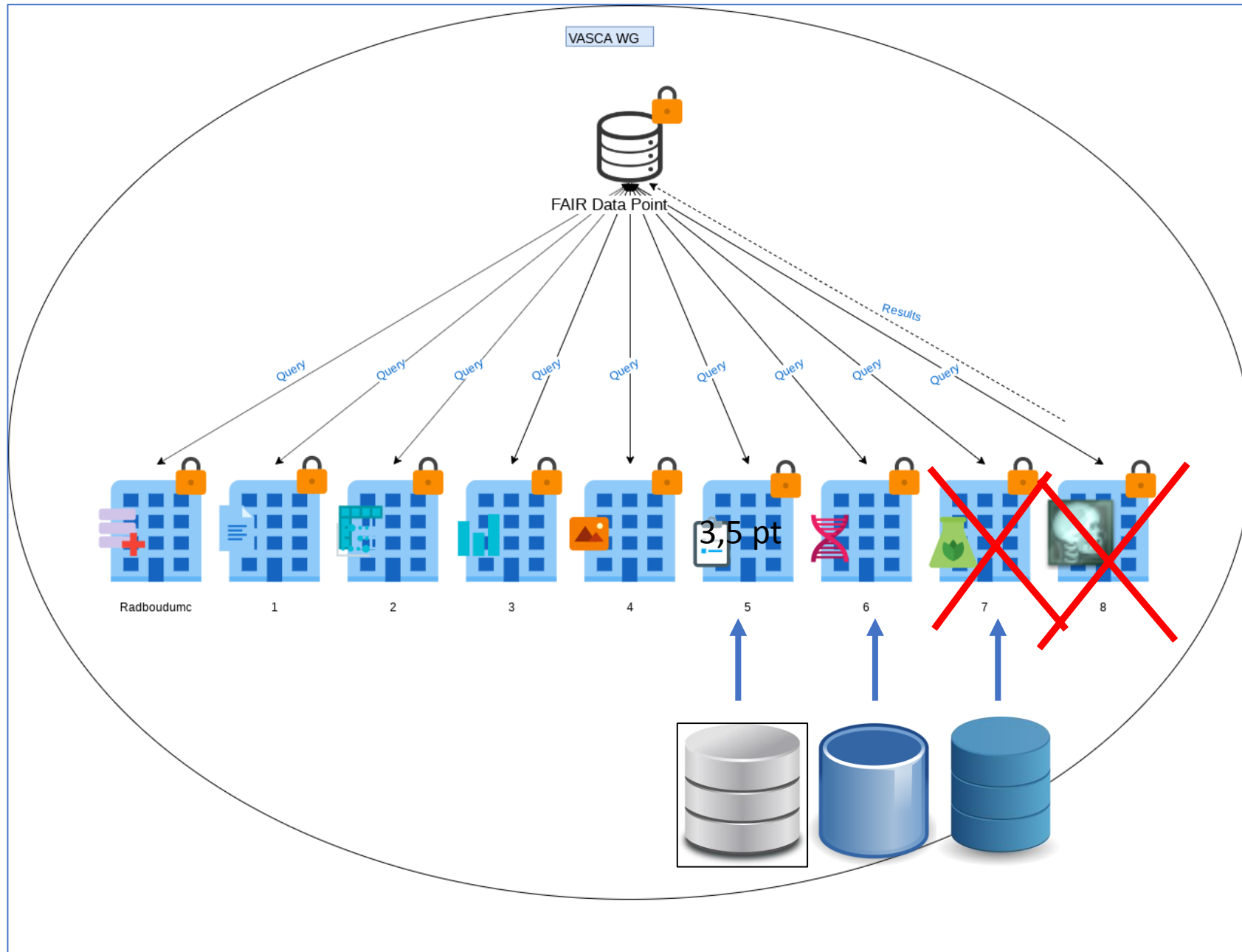


# registries

- Top priority
  - Horizon 2020
  - Mentioned in every grant proposal
  - Seen as a way to develop new treatments/evaluation/genes etc
  - Will be linked to all other existing EU platforms
  
- EJP-RD linked to GA4GH (global alliance for genomics and health)
- Go-FAIR
- Elixer RD (european infrastructure for life sciences)
- IRDiRC (International Rare Disease Research Consortium)
- BBMRI (biobanks infrastructure)



ERNs



FAIR registry

# Structure of VASCERN Registry Project

