



# Proposal for e-Questionnaire on Perinatal Derivatives

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# Aim

- Overview and define the PnD area (SOPs, protocols, sample sizes, ...) and positioning the SPRINT COST consortium in Europe
- e-Questionnaire that will collect general data about samples in community research groups
  - Shortened to leverage between collecting useful data that allows mapping and is feasible enough for participants to provide data with as little as possible burden
- Text-mining from PubMed publications
  - Domain ontology/vocabulary/dictionary/keywords

# Results

- Knowledge (data)base of metadata that can grow up easily
- Position/Review paper in IF journal
- Data model / (bio)schema for common data collected (for every sample or as deep as we would like to go) as a foundation for international (EU and wider) registry of sample data

# Future

- Establishing registry and providing APIs for local IS for all community research groups
- Following FAIR (Findable, Accessible, Interoperable, Reusable) data principles
- Challenge: Funds (H2020 or Horizon Europe projects) for sustainability and maintenance of registry

# Registry

## Functions:

- search engine for FAIR metadata over all data
  - direct data acquisition via web GUI
  - data acquisition/harvesting via APIs from local IS
  - summary data reports and analyses
- Every PI is owner of raw data, only metadata are shared.
  - Only PI approves access to data.
  - DAC (Data Access Committees) approve usage of anonymised data.

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research groups / data providers

