**Proposal Idea:**

A patient registry system for rare disease researchers and patients with the data altruism philosophy, at a European level. A “fair marketplace” for health data.

**Benefits for participants:**

The winning team will be awarded a 30,000€ cash prize (taxable income).

**The Challenge:**

It is a European Registry, but the original data does not leave the original country/jurisdiction where it was created. Thus some sort of “new” data needs to be created from the original, inside the originating jurisdiction and then transferred out to the central registry across borders.

**Tartuvian Dimension:**

We believe the functional ERDR should be based in Tartu, Estonia. And therefore, starting with UT students would be the perfect fit.

**Objectives:**

Solving the data problem for rare diseases, providing easy, quick and reliable access to health data from rare disease patients to researchers and doctors to help advance treatment and drug development.

**Outcome:**

A system design that complies with EU regulations, is easy to use, safe and secure.

**Impact:**

30 million rare disease patients in the EU could be benefited directly from this system. While 300 million could be benefited across the globe as the gathered data turns into faster diagnosis and new treatments.

**Users:**

- Patients, to upload their data.
- Researchers, to get data to analyse and develop treatments.
- Doctors, to access information for diagnosis and treatment of patients.

**Key concepts to keep in mind:**

- EU Data Governance Act (DGA, 2023-09-23)
- European Health Data Space (EHDS)
- EU Data Altruism Organization model (DAO)
- 600+ existing independent rare disease registries in Europe
- 27 different jurisdictions
- High statistical significance, needs high n (number of participants per clinical study)
- The output Data set needs to be ready for research use

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