OSCARS
Open Science Clusters' Action for Research & Society

Funded Project

ARTICYST

Devising Open Science practices to promote research and treatment in cystic kidney disease

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PKD International

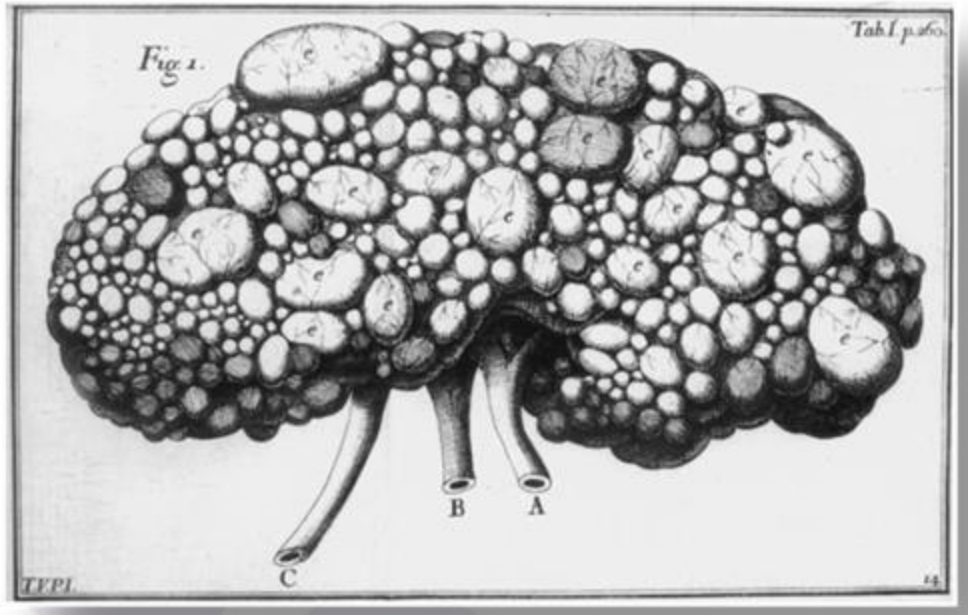
Funded by the European Union

- **A blind spot for many clinical researchers:**
  - **Catalyst role** of **Open Science** in medical research
- **ARTICYST project aspires to:**
  - Building a role-model on how to bring Open Science into the daily routine of clinical research and medical practices

ADPKD: Autosomal dominant polycystic kidney disease

Most common genetic (kidney) disease

Most common genetic disease causing kidney failure



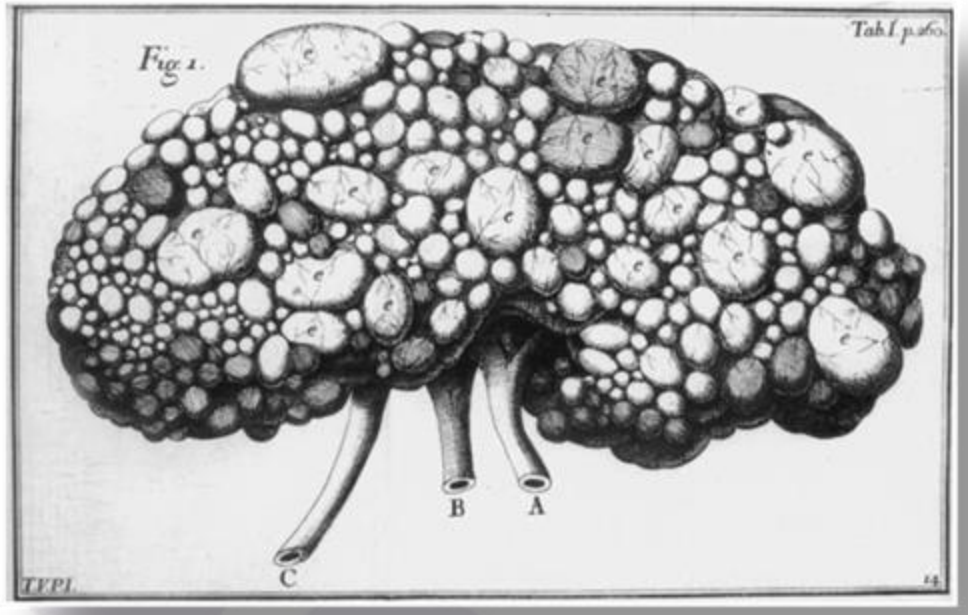
Domenico Gusmano Galeazzi (1757)

ADPKD: Autosomal dominant polycystic kidney disease

Most common genetic (kidney) disease

Most common genetic disease causing kidney failure

Genetic Prevalence: ~ 1 : 1,000
→ EU: ~ 0.5 Mio



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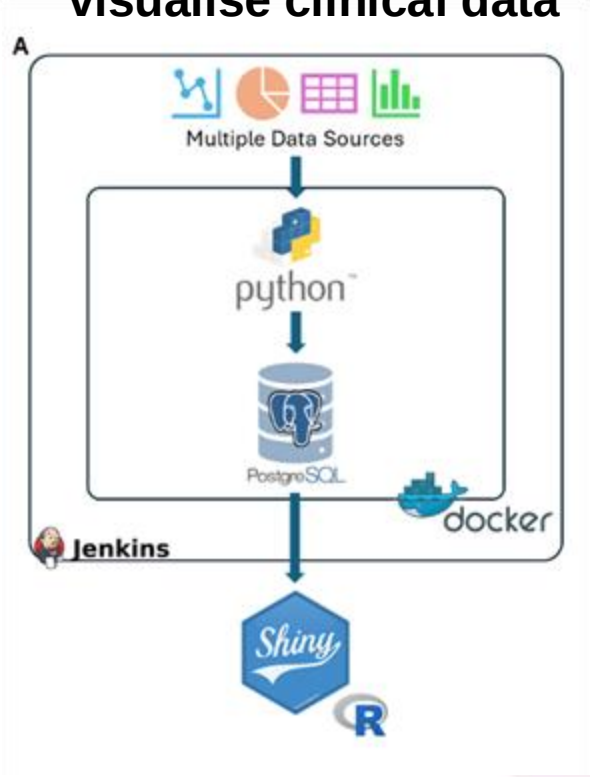
ADPKD: Autosomal dominant polycystic kidney disease

- The **prediction of clinically relevant outcomes** is essential for optimized patient care
- Currently only based on limited parameters: **technical, legal and ethical boundaries**
- **Harmonization** across Europe (and beyond) is lacking.

We want to take advantage of Open Science to overcome these boundaries to ultimately improve clinical outcome prediction by integrating multilayered data from multicentered patient cohorts

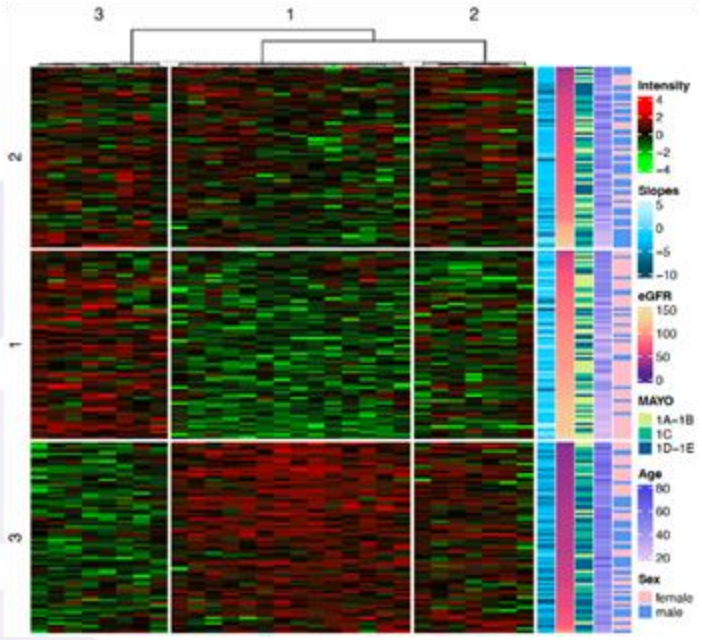
SOLUTION

Optimised data framework to integrate, analyse and visualise clinical data



Patient-driven data contribution

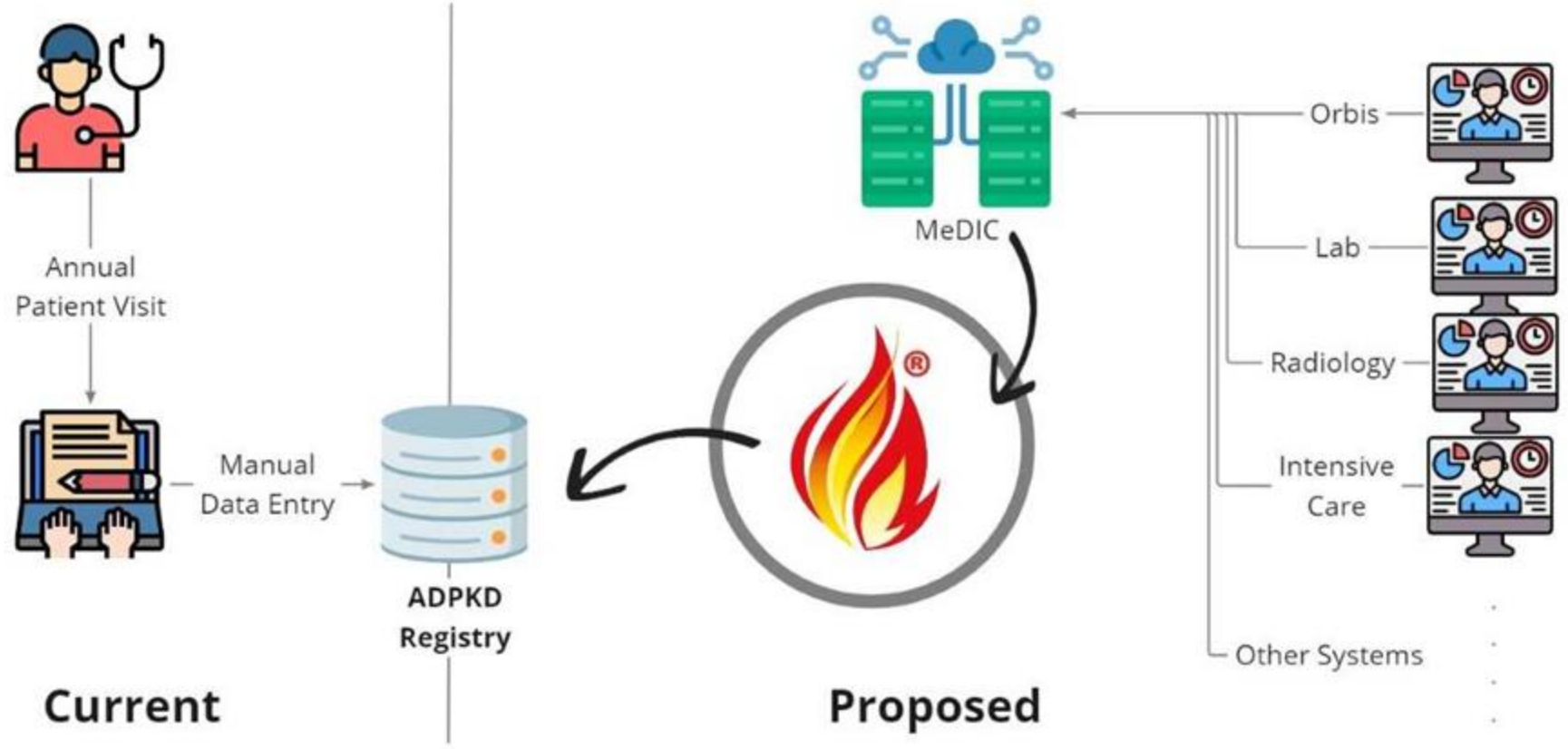
Integration of research data (e.g. omics)



Schmidt et al. *Frontiers in Medicine* 2024

Aydogan et al. *Nature Communications in revision*

Integrate & share the health data beyond the boundaries of hospitals



INTERACTION WITH OPEN SCIENCE CLUSTERS

Database integrating omics and clinical data enhanced through interaction with **ELIXIR**

Extension of the ARTICYST platform towards additional centers and their biosamples – reach out to **BBMRI-ERIC (RI for Biobanking)**

Establishment of targeted diagnostic assay panels – initiate the process through interaction with **EATRIS (RI for translational medicine)**

Prospective trial design for multinational biomarker validation studies in collaboration with **ECRIN**

What will be the results and how do you plan to make them available to the broader community?

- Cookbooks:
  - Solutions to technical challenges
  - Standard selection and recommendations
  - Interoperability across networks and data spaces.
  - Framework for sensitive data discovery and sharing

- Data sharing diaries:
  - Motivating stories from stakeholders: patients, clinicians….

RISKS

What risks could limit the success of the project, and how can they be mitigated

- Implementing Open Science practices for sensitive health data is complex and challenging.
  - Ethical and legal regulations
  - Data protection
  - Patient privacy
  - Data ownership

In ARTICYST we will come up with some preliminary recommendations and possible paths and ways to overcome this

Further work will be necessary - to this we are eager to build synergies with other OSCARS projects!

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