

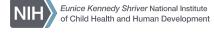
Frameworks for Data and System Interoperability

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Connecting Diverse Data Systems for Research Key Considerations



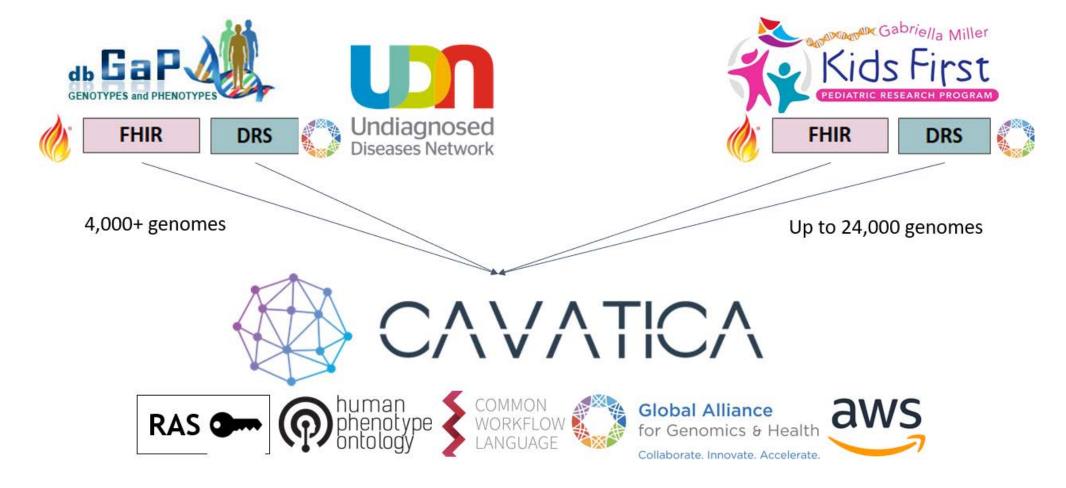
- Leverage existing investments (data repositories, tools, web services, etc.)
- Connect data systems, develop processes, and build technologies based on user needs (human centered design)
- Utilize open metadata, data, and software standards
- Convene stakeholders in advance to define scope and establish governance
- Engage and train diverse researchers, developers, and other community members
- Follow privacy and security by design principles





Federate Data Systems with Standards and Use Cases NIH Cloud Platform Interoperability Effort







Convene Stakeholders to Reach Consensus NICHD Pediatric COVID Data Linkage Assessment



- Analysis of 13 large-scale data linkage implementations
- Primary Finding: Data systems, funders, and researchers should address key governance and technology questions at the outset:
 - q Determine the scope of linkage (which datasets to link)
- q Obtain approval to link
- q Identify policies relevant to specific data type(s) or participant population(s)
- q Establish which party should link the data
- q Use a variety of controls to mitigate reidentifiability risk

- q Collect & standardize PII elements for high linkage quality
- q Regardless of PPRL tool selected, configure the algorithm to align with available (or feasible to collect) PII and use an appropriate gold standard dataset
- q Select a PPRL technology that meets basic requirements
- q Consider technology sustainability for longterm implementations



Incentivize Data Contribution, Secure Access, and Use NYU Center for Urban Science & Progress Data Facility



Make new and existing urban data available to agencies and the research community in a state of the art facility Foster collaborations between agencies and NYU in addressing important urban problems











Data Curation and Management

- Data acquisition
- · New data collection
- Curation
- Documentation
- Provenance
- · Version Control

Data Access and Discovery

- Access and security controls
- Interrogation
- Integration

Data Analysis, Collaboration and Reproducibility

- Collaborative space creation
- Visualization
- · Workflow trace tools
- Privacy and security

User Training and Engagement

- Standard Briefings on privacy and confidentiality
- Data hygiene
- Conceptual approach and new tools

Dissemination

- Statistical Disclosure control
- Census RDC network
- · API development
- Agency engagement
- Citizen input and engagement
- Workshops









THANK YOU!

https://www.nichd.nih.gov/about/org/od/odss

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