CATEGORY III: PLANNING FOR A NATIONAL SCALE DATA PLATFORM FOR PERSONAL DATA

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External Collaborators

MIMIC

ICPSR

HEALTHeLINK™

Pegasus
Workflow Management System

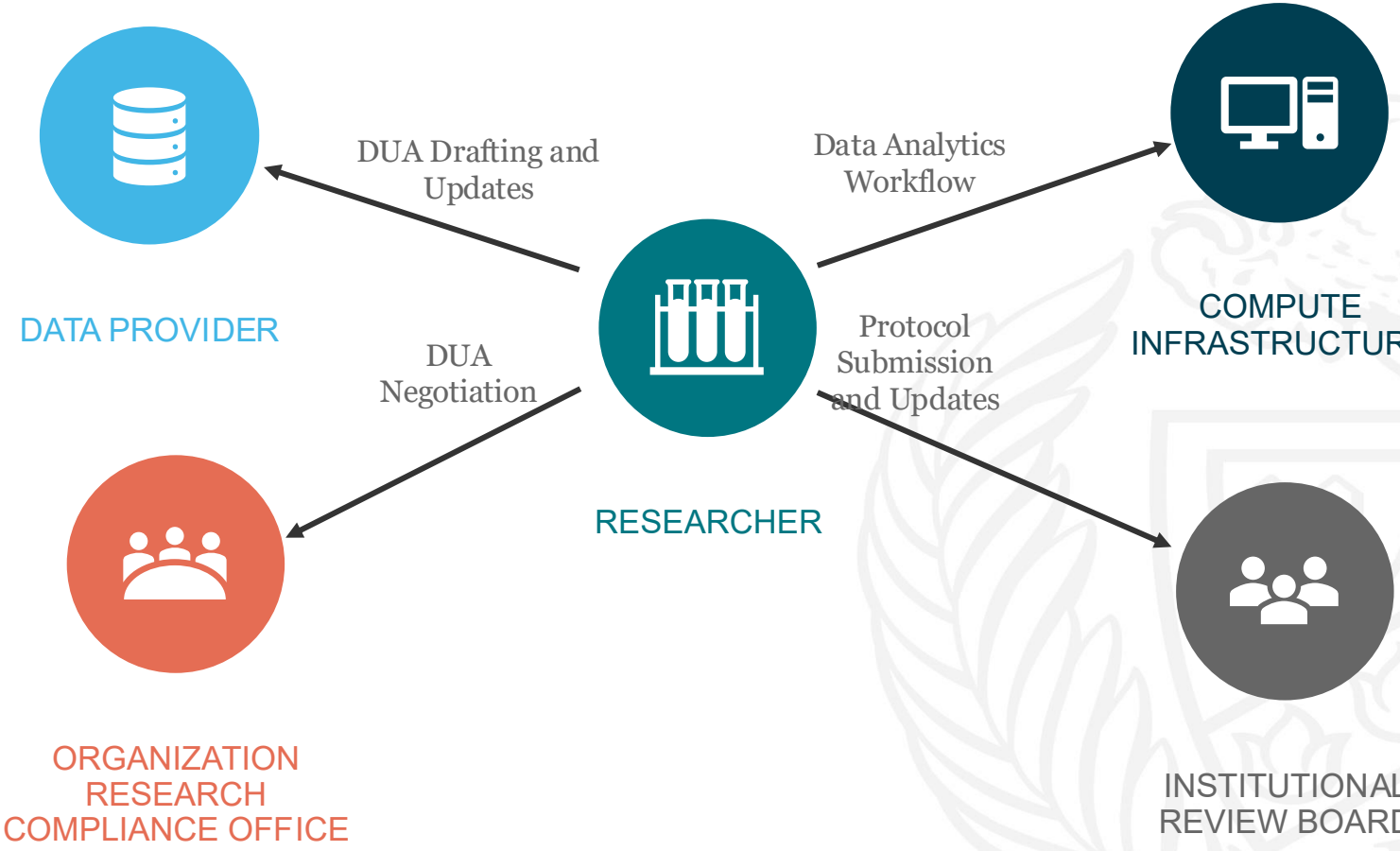
NSDF
National Science Data Fabric

Objective – Reducing the Time to Science with *Sensitive* Data

- A national scale data platform to support researchers working with ***sensitive*** data
  - Personal data
  - Or any data that carries significant legal, financial, or ethical risk, if exposed
- Streamlining data use agreements, user management, data anonymization workflows within secure and compliant enclaves
  - At low cost

Personal data - *any research data asset that contains direct identifiers, indirect attributes, or behavioral patterns that can be linked back to a specific living individual or sensitive sub-population.*

Key Entities and Interactions



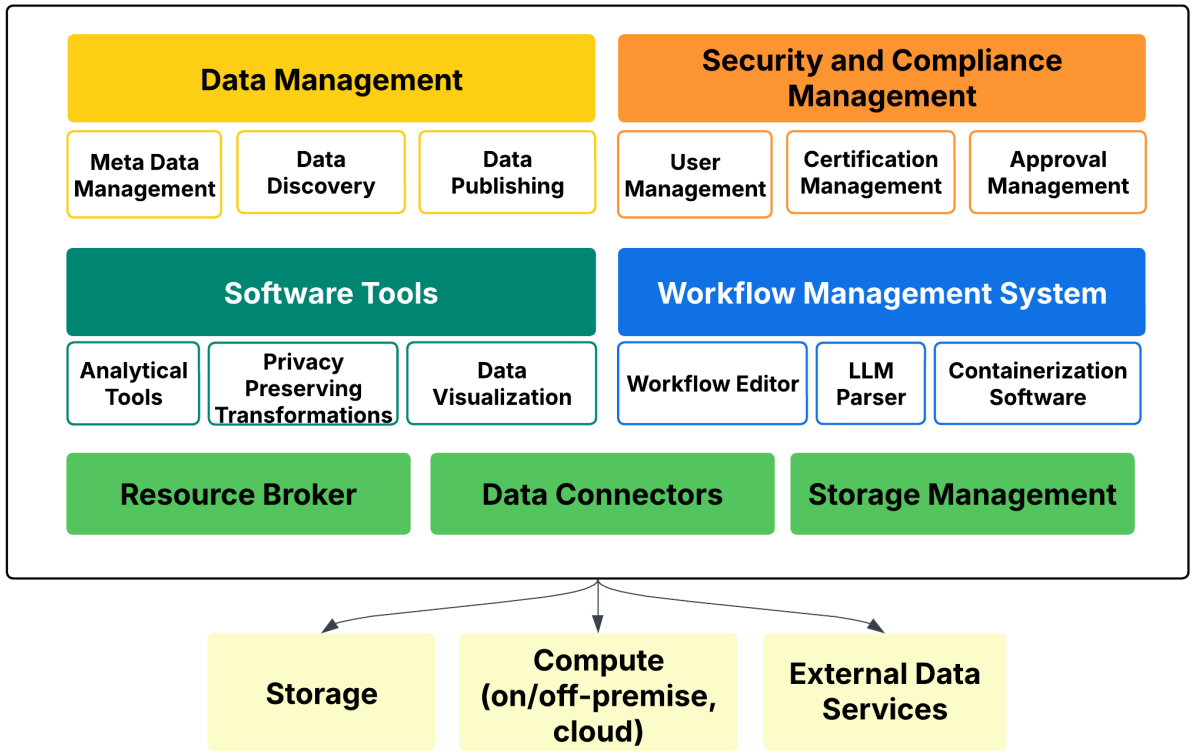
Key Challenges – Streamlining Interactions at Low Cost

- Diverse needs of a broad research community
- Support for regulatory standards
  - HIPAA, CCPA, SOC2, GDPR
- Supporting regulatory boards and data providers
- Integrating compute with data
- Integrating with national data CI ecosystem
- Sustainability

Key Capabilities

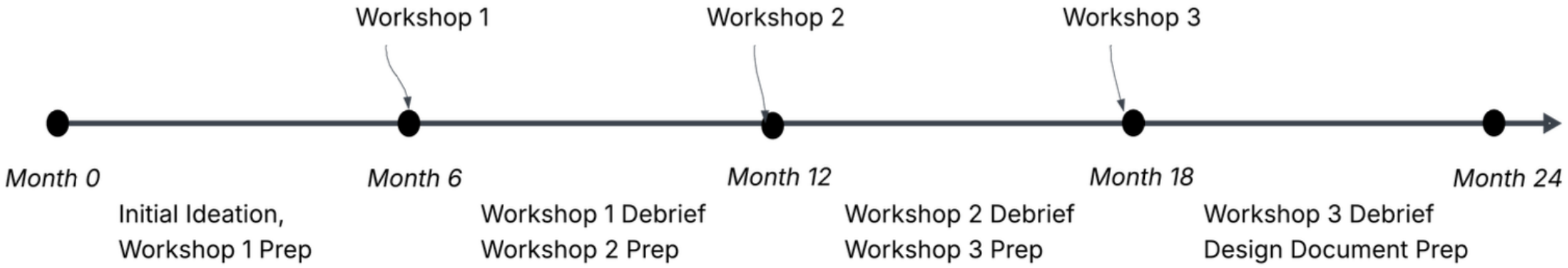
- Provisioning **secure and compliant enclaves** for a research team working with sensitive data
- Secure user and data management tools for data stewards
- Secure workflow management tools, deidentification workflows and other analytical layers
- Workflow deployment on underlying compute
- Connectors to external data and analytics endpoints
- Open marketplace to share results with larger community

Preliminary Design



Timeline

- Planned workshops



Workshop stakeholders:

- Workshop 1 – Researchers
- Workshop 2 – Data Providers and Institutional Review Boards
- Workshop 3 – Compute providers and IDSS/NSF CI Ecosystem

Thanks for listening

- We welcome your thoughts on how we can collaborate with and benefit from the larger IDSS ecosystem

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