

Frameworks for Data and System Interoperability

**The Action Collaborative on Disaster Research: Symposium on Pediatric Disaster Science
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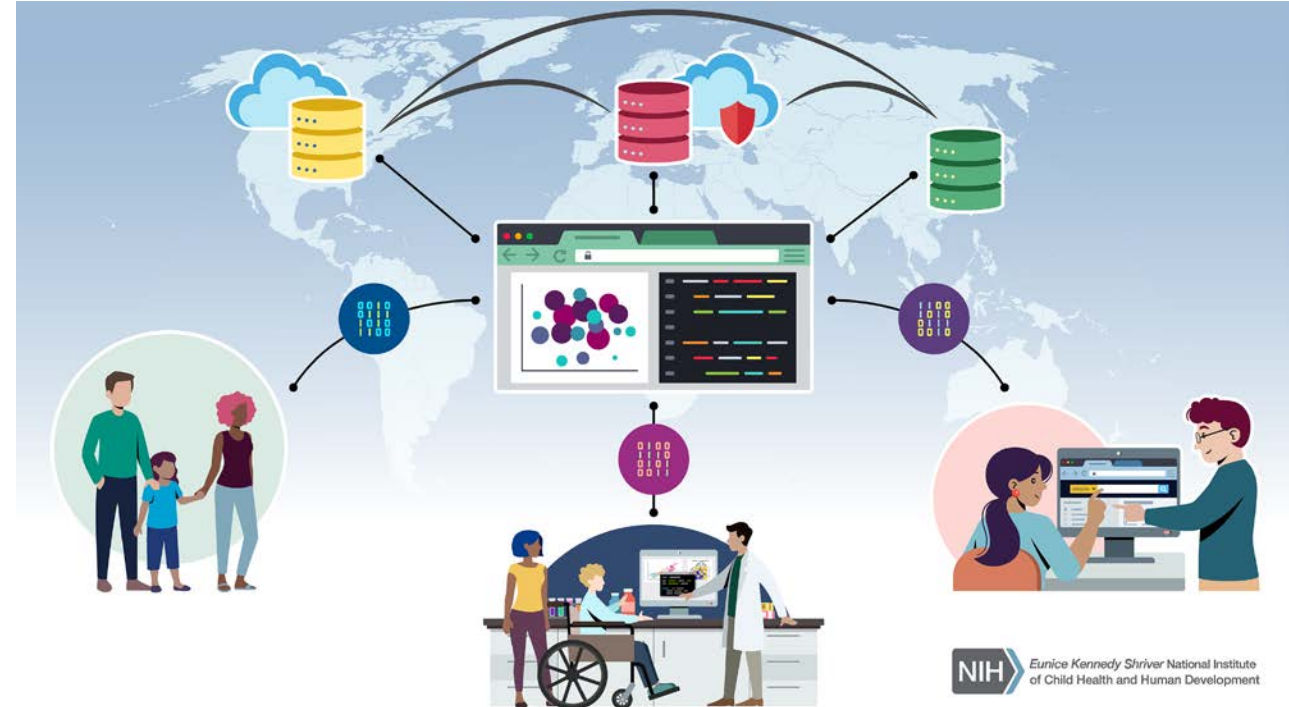
Eunice Kennedy Shriver National Institute
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Connecting Diverse Data Systems for Research

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



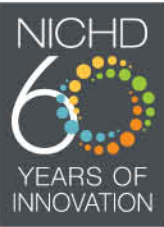
Federate Data Systems with Standards and Use Cases

NIH Cloud Platform Interoperability Effort



Convene Stakeholders to Reach Consensus

NICHD Pediatric COVID Data Linkage Assessment



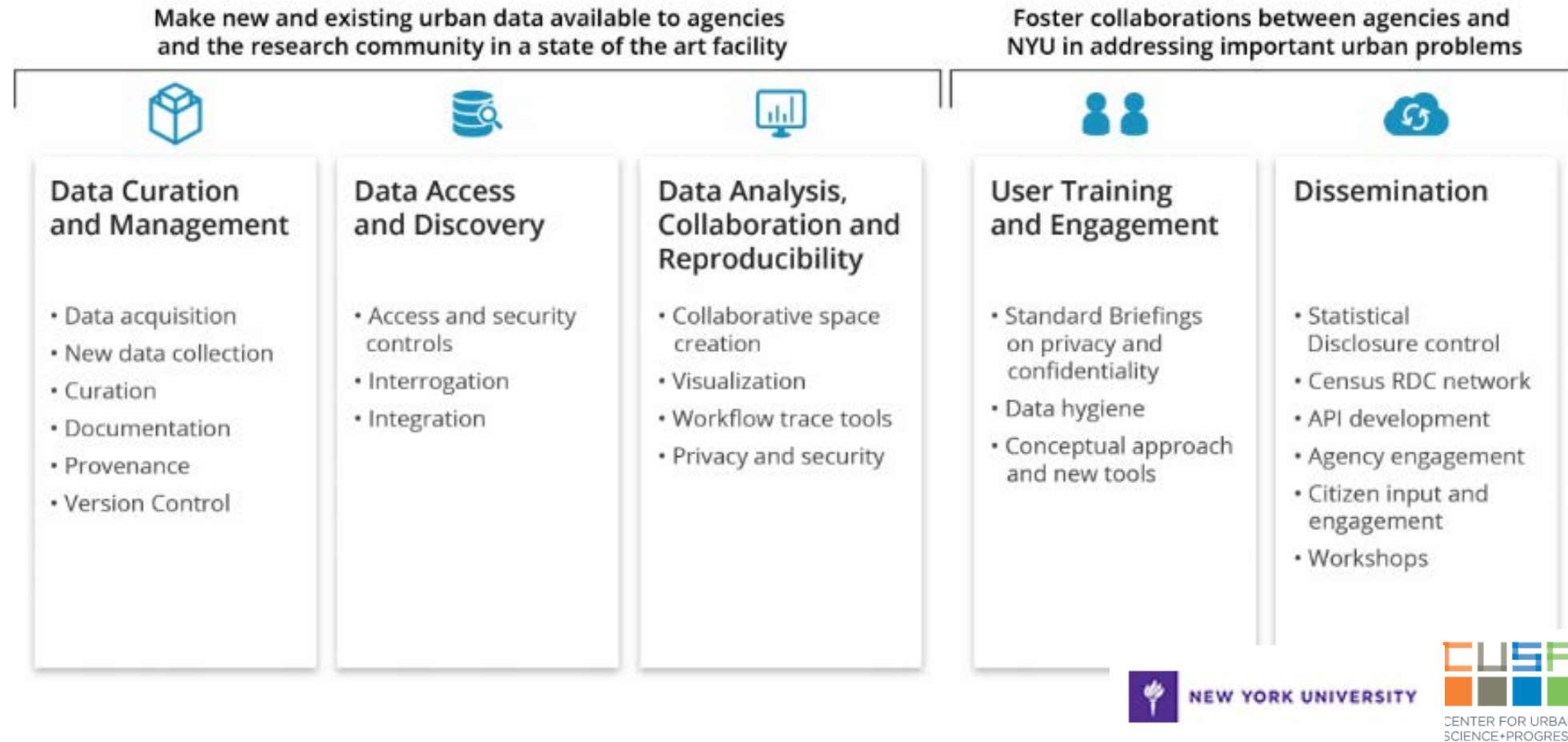
- Analysis of 13 large-scale data linkage implementations
- Primary Finding: Data systems, funders, and researchers should address key governance and technology questions at the outset:

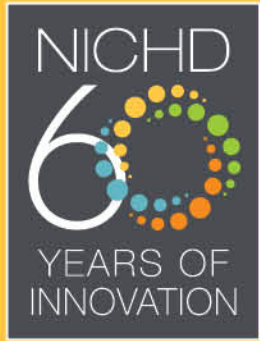
- q Determine the scope of linkage (which datasets to link)
- q Obtain approval to link
- q Identify policies relevant to specific data type(s) or participant population(s)
- q Establish which party should link the data
- q Use a variety of controls to mitigate re-identifiability risk

- 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 long-term implementations



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





THANK YOU!

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

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