

**NICHD Data and Specimen Hub:
N-DASH**

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Agenda

- ▶ NICHD Data and Specimen Hub (N-DASH) – UPDATE AND REVIEW OF ACTIVITIES
 - Implementation Phases
 - Policy and Governance
 - Technical View
 - Next Steps and future directions
 - Committee Membership



N-DASH will be a publically accessible online system that will enable sharing of data and specimens from completed NICHD-supported studies

- ▶ The Archive will:
 - Enable researchers to organize, store, and mine data from completed NICHD supported studies for secondary use
 - Allow users to annotate study data and artifacts, search for files using either metadata or indexed content, and request study files (and eventually biospecimens) for secondary use
 - House 8-10 NICHD studies ranging in data complexity when launched in June 2015
 - Follow an established governance structure that will comply with applicable federal and NIH policies, and ensure ongoing, high-level institutional oversight
 - Manage and adjust operations in accordance with NICHD's Post-Study Data Archive Policy and procedures through the Archive Committee



Active and ongoing coordination between the Archiving Committee and the Technical Development Team is critical to ensuring the successful implementation of NICHD DASH

Non-Technical Considerations (Committee)

- Study Selection
- Organizational and Governance structure
- Policies and Processes
- Stakeholder Management
- Performance Management
- Operational Risk Management

Outputs:

- Study Portfolio
- Archive Policy, Governance & Operational Processes

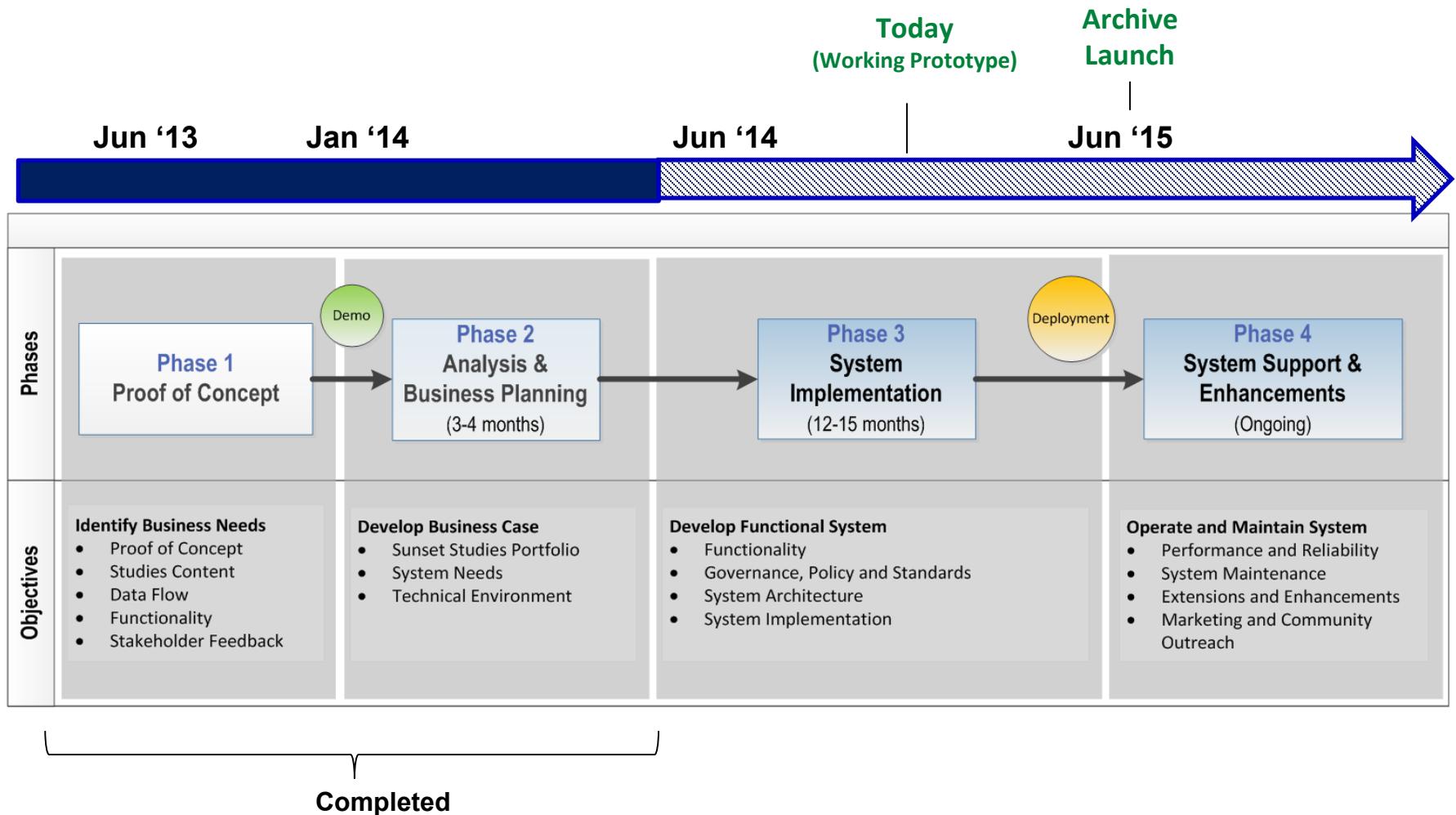
Technical Considerations

- Functional/Business Requirements
- System Requirements
- System Design
- Architectural Design
- Data Design

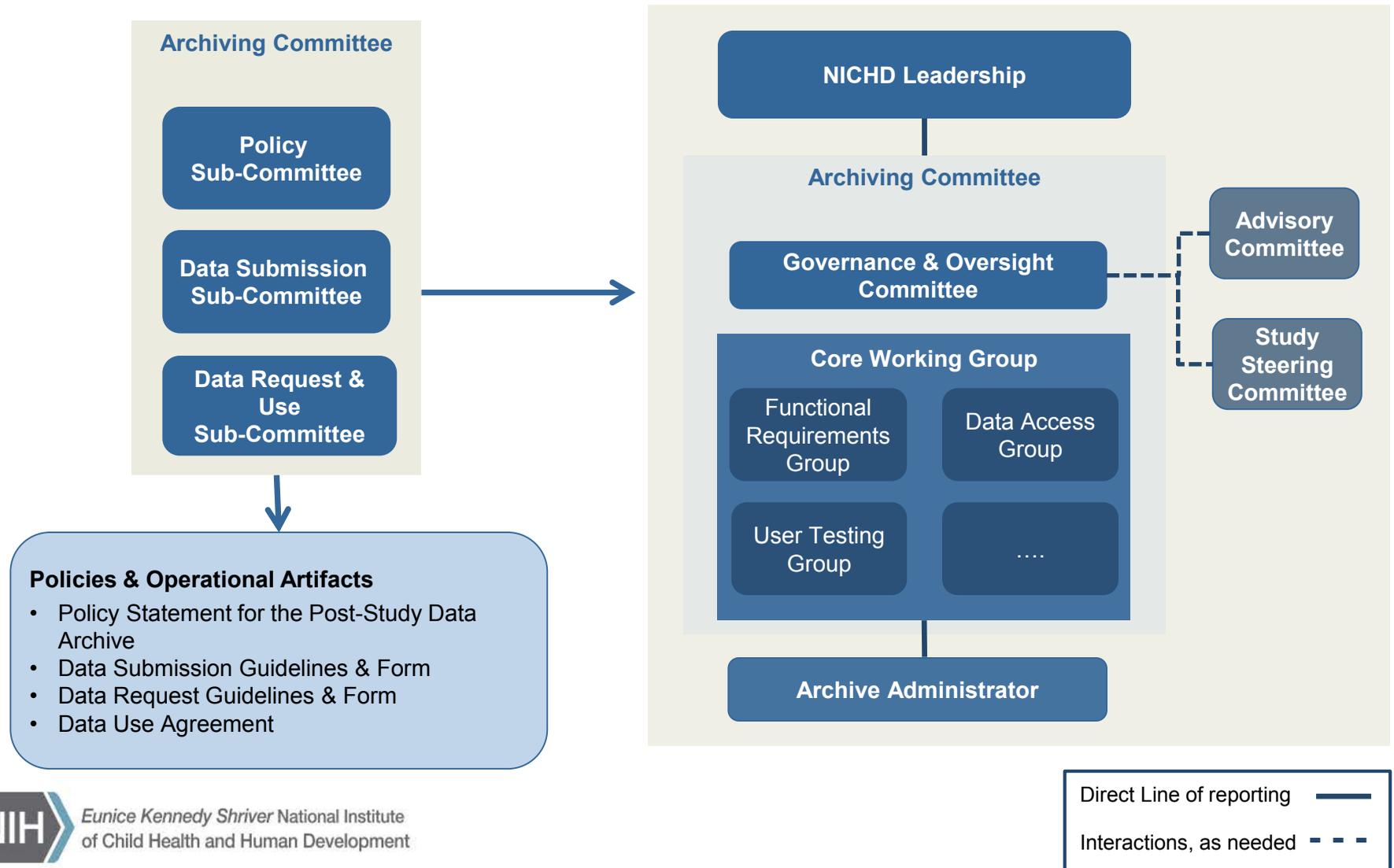
Outputs:

- Data Archive System with functionalities for the Researcher, NICHD Leadership and Archive Administrator

N-DASH is being developed and implemented in a phased manner with active engagement by the Archiving Committee



The NICHD Data and Specimen Archiving Committee developed policy, instituted governance and operational processes for N-DASH



NICHD DASH – Home Page

Home Find Study Data Resources ▾ Help ▾

 Create An Account ▾  User Login ▾



NICHD - DASH

Browse the GPN Study

Get clinical data from the Genomic and Proteomic Network for Preterm Birth Research study

[Learn More](#)

Search for studies or specific study items such as audio files, biospecimens, data sets, documents, genomics, images and more.



New to the Archive?

Learn about the data archive, view tutorials and download supporting documentation.



Available Topics

- HIV/AIDS
- Infant Care and Infant Health
- Preconception Care and Prenatal Care
- Pregnancy
- Pregnancy Loss
- Preterm Labor and Birth

Browse Studies

- Genomic and Proteomic Network for Preterm Birth Research
- NISDI Pediatric cohort
- NISDI Pediatric Latin American Countries Epidemiologic Study
- NISDI Perinatal cohort
- NISDI Longitudinal Study in Latin American Countries
- LOI 2-BIO-18: The National Children's Study - Placenta Project

Researchers can only request data with the right documentation and approvals

Add Data to Cart

- Requires the researcher to create an account in the Archive
- Must provide contact and institution information

Describe Research Purpose

- Data requests must be for research purposes
- Requestor should provide: goals of the new study; how the requested data will be used to support the new study; and for some studies the researcher may need to provide the analysis plan

Provide Request Documentation

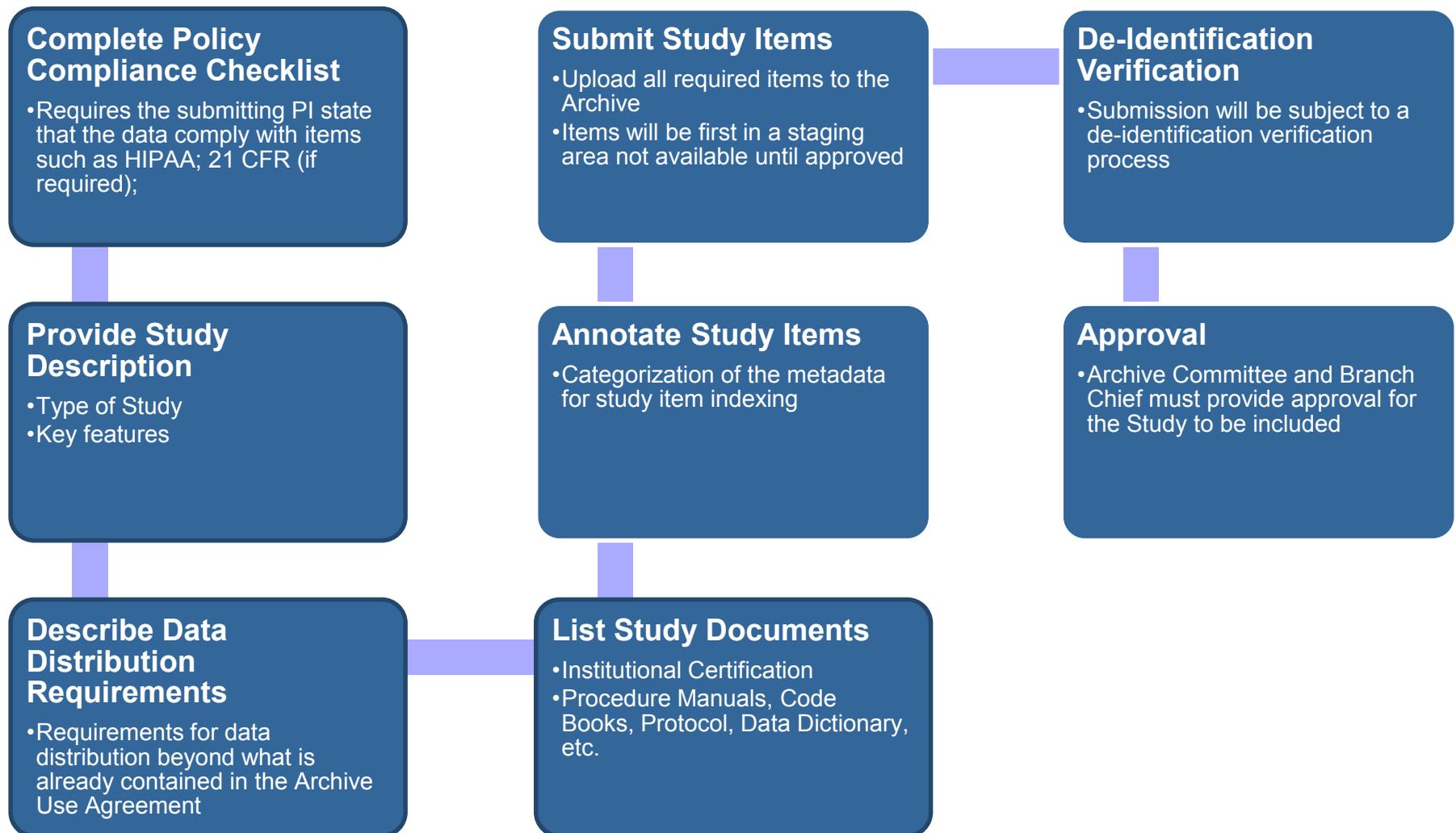
- Signed Data Use Agreement – requires PI and Institutional Official signature
- Institutional Certification of Use
- Indication of IRB approval (if required)

Approval

- The Archive Committee or a Study's Steering Committee/PI will approve the request
- Requestor must provide annual IRB updated documentation (if needed) and a summary report
- Requestor must destroy the data at end of use agreement



Similarly for data to be housed in NICHD DASH, the submitting PI and Institution must comply with Archive policies



Next Steps and Future Directions

- ▶ Launch in June
- ▶ Add new studies (aiming for 8-10 per year)
- ▶ Connectivity to the NICHD Biorepository
- ▶ Analytics Workbench
- ▶ Connectivity with external resources
- ▶ Data visualization

Thank you to the Archive Committee

Division/ Branch/ Center/Office	Members
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Contraceptive Discovery and Development Branch (CDDB)	• Chon-Hwa Tsai-Morris
Developmental Biology and Structural Variation Branch (DBSVB)	• Mahua Mukhopadhyay
Fertility and Infertility Branch (FIB)	• Esther Eisenberg
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Office of Science Policy, Analysis and Communication (OSPAC)	• Jennifer Guimond
Information Resource & Management Branch (IRMB) – Technical Lead	• Dave Songco, Archana Mohale • Booz Allen contract team