National Institute of Diabetes and Digestive and Kidney Diseases

Office of Clinical Research Support

NIDDK Data Sharing Landscape:

The Role of Generalist Repositories

Virtual Generalist Repository Ecosystem Initiative (GREI) Workshop

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NIDDK Data Sharing Landscape

We are committed to strengthening & advancing NIH/NIDDK's data ecosystem

Challenges

- Researchers need options to deposit data
- There is a gap in domain-specific and institution-specific repositories

Opportunities

- Realize the potential of publicly available data for secondary research
- NIH's GREI initiative demonstrates the agency's vision and commitment to advancing the data sharing ecosystem

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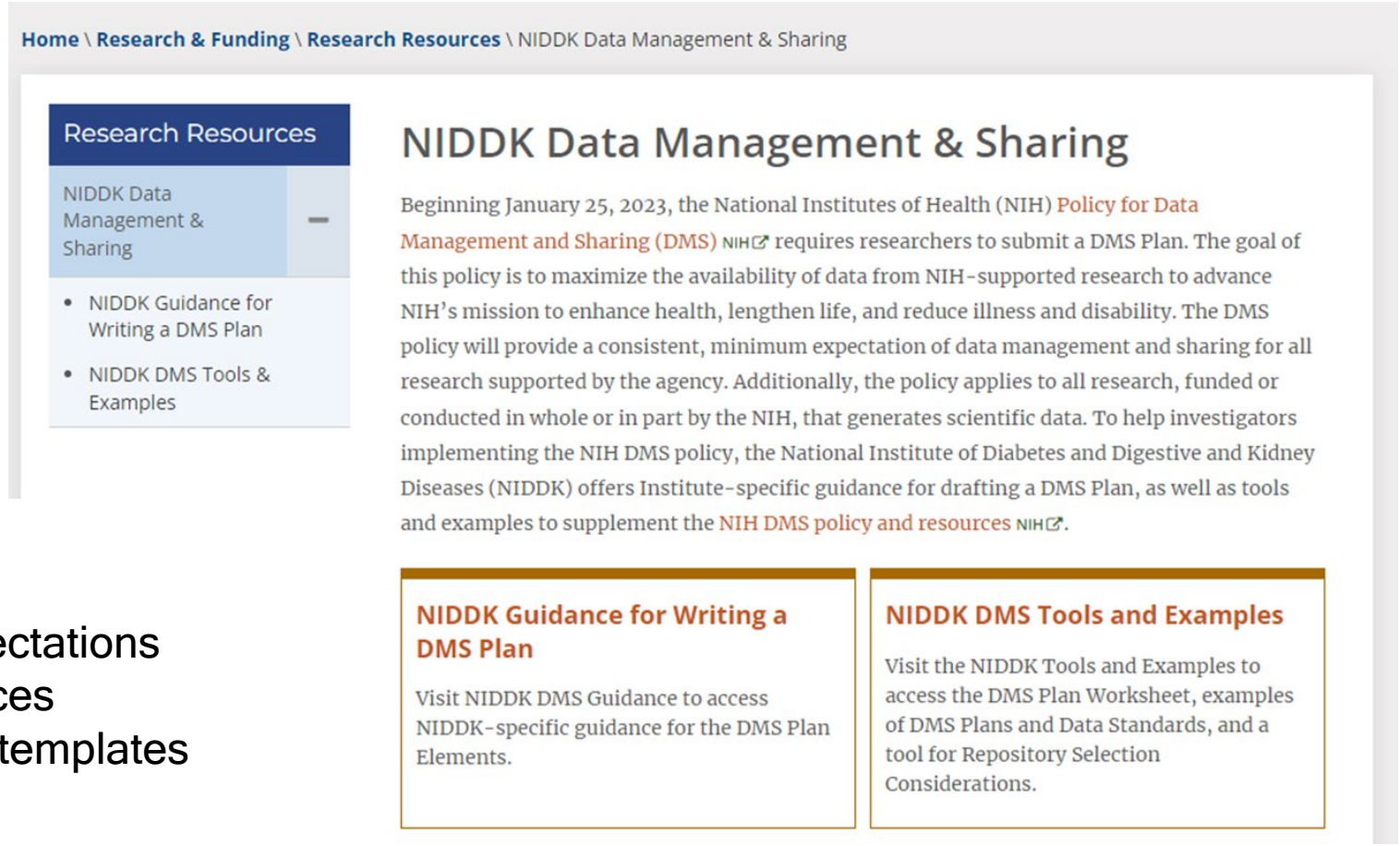
NIDDK Data Sharing Landscape: DMS Policy



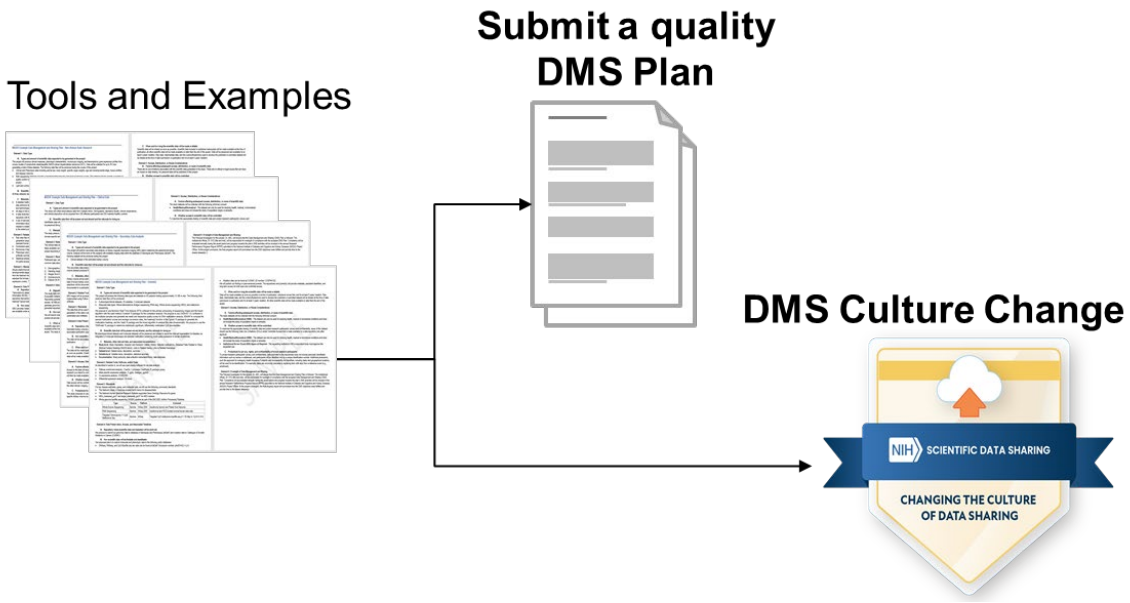
What can you find?

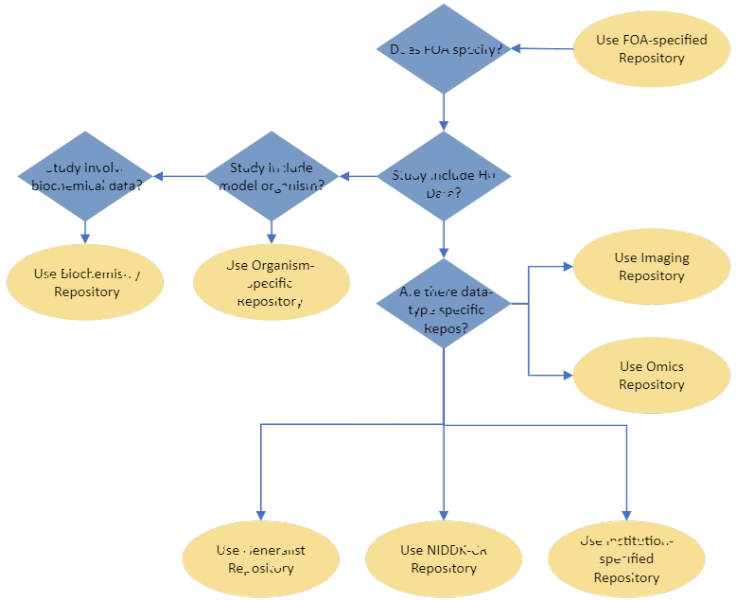
- NIDDK-specific DMS guidance and expectations
- Relevant links to sharing.nih.gov resources
- NIDDK-specific sample DMS Plans and templates
- Repository Selection Considerations

https://www.niddk.nih.gov/research-funding/research-resources/data-management-sharing

Repository Selection Considerations

- Intended to assist researchers in selecting an appropriate data repository with desired characteristics (NOT-OD-21-016) to deposit their data and maximize sharing
  - ➢ Domain-specific, data type-specific, institution/community based, and generalist repositories





NIDDK DMS Policy & Role of Generalist Repositories

Building infrastructure & strengthening opportunities for NIDDK's scientific community

Generalist Repositories,

- Broaden exposure and discoverability of NIDDK-funded research
- Support data ecosystems under FAIR and TRUST principles
- Reduce (and eliminate) data silos
- Improve reuse of NIDDK resources and increase their scientific value

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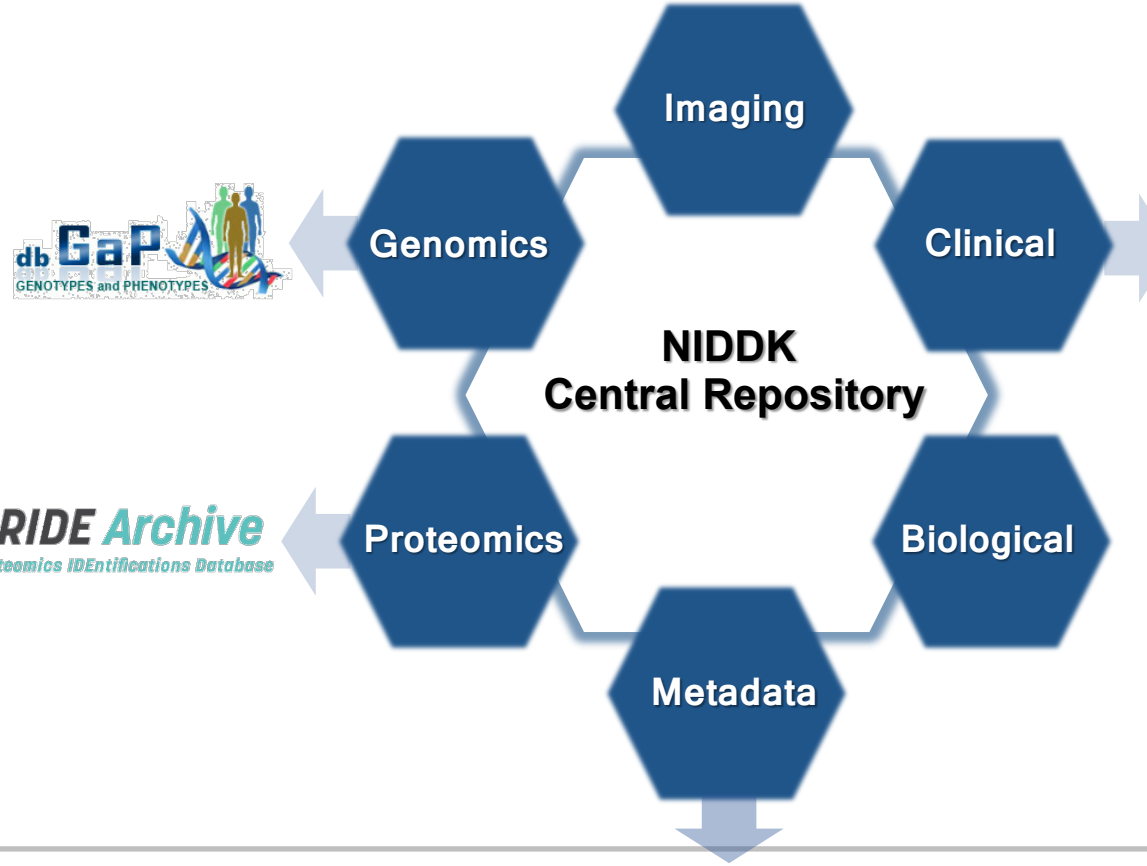
NIDDK Data Sharing Ecosystem



Additional resources

KPMP
ImmPort
Bioinformatics For The Future Of Immunology
JCHR
JAEB Center for Health Research
T1D
Type 1 Diabetes Consortium

PRIDE Archive
PRoteomics IDEntifications Database

FAIRsharing.org
standards, databases, policies

DataCite
Find, Access, and Reuse Data

re3data.org
Registry of Research Data Repositories

DK net

Vivli
Center for Global Clinical Research Data

Planning Phase

figshare

NIH HEAL INITIATIVE

Google Dataset Search / Schema.org

NIH U.S. National Library of Medicine
ClinicalTrials.gov

NIDDK Central Repository Vision & Mission

Expand the usefulness of NIDDK funded research by enabling qualified investigators to reuse existing resources to generate new findings

Strategic Goals:

Improve resources' FAIR-ness and TRUST-worthiness and minimize barriers that limit resource utilization

Increase impact of resources, enhance data and biospecimen discoverability, provide tools that facilitate new research, and improve user experience

Advance understanding of best practices, develop and implement policies, and increase stakeholder engagement

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Generalist Repositories and NIDDK-CR Vivli use case

Data not eligible for NIDDK-CR submission

- NIDDK-funded projects' data (e.g., R01) may be deposited into Vivli
  - Projects are then indexed and searchable through NIDDK-CR
  - NIDDK-CR redirects requestors to Vivli to gain access following Vivli's established procedures

Data deposited at NIDDK-CR

- NIDDK-CR studies' metadata are indexed and searchable in Vivli
  - Vivli redirects to NIDDK-CR for data request and approval per established NIDDK-CR procedures
  - Must be registered with NIDDK-CR to request access to data
- Approved requestors may upload data into Vivli for analysis
  - Must have an approved project specifying an intent to combine data
  - May combine only with data from Vivli members available in Vivli's secure environment

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THANK YOU

For NIDDK DMS Policy information, visit
https://www.niddk.nih.gov/research-funding/research-resources/data-management-sharing
and NIDDK Information Network (dkNET)
https://dknet.org/rin/research-data-management

For Repository Program Administrative enquiries, email us at
NIDDK-CRAdmin@niddk.nih.gov

For information on assigning permanent identifiers for your NIDDK-funded research outputs contact us at
NIDDKDataCite@niddk.nih.gov

For more information on services and support visit our website at
https://repository.niddk.nih.gov or email us at
NIDDK-CRsupport@niddk.nih.gov

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APPENDIX

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NIDDK Central Repository

Embracing flexibility to continue to support NIDDK's evolving mission

- Rapidly growing number of collections
  - Impressive number of collections available to the external community
  - Equal impressive number of investigators accessing resources
- Centralized biospecimen inventory
  - Vial level visibility
  - Rich and comprehensive biospecimen metadata
- Streamlining to reduce (real | perceived) barriers to access
  - Improving metrics to better monitor progress and compliance

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