

NICHD Data and Specimen Hub (DASH)

Frequently Asked Questions (FAQs)

This FAQs page provides answers to questions that users may have about the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) Data and Specimen Hub (DASH). It is organized into the following categories:

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The FAQs supplement the <u>DASH Policy</u> and the <u>DASH User Tutorial</u>. Please refer to the <u>DASH</u>

<u>Glossary</u> for an expanded list of the above terms and associated definitions, DASH sitemap to learn how to navigate to a specific function, and to DASH tutorial for step-by-step instruction how to use all above functionality.

For any questions that are not listed within this FAQ page, please contact the DASH Administrator at supportdash@mail.nih.gov.

A. General (About DASH, User Account)

1. What is the purpose of DASH, and where can I get more information about the available functionality, how DASH is governed, etc.?

The NICHD Data and Specimen Hub (DASH) is a centralized resource that allows researchers to share and access de-identified data from studies funded by NICHD. DASH also serves as a portal for requesting biospecimens from selected DASH studies. DASH serves as a mechanism for NICHD-funded extramural and intramural investigators to share research data from studies in accordance with NIH Data Sharing Policies. Many of the NICHD-funded research studies also collected biospecimens that are stored in the NICHD Contracted Biorepository. To provide access to these biospecimens, DASH will store and make available to other investigators the biospecimen catalog for studies that have associated research data in DASH. By supporting data and biospecimen access through DASH, NICHD aims to accelerate scientific findings and improve human health.

For more information on how DASH is governed, please refer to the <u>DASH Policy</u>. Please refer to the DASH sitemap to learn how to navigate to a specific function, and to DASH tutorial for step-by-step instruction how to use all the available functionalities.

2. Do I need to create an account in DASH?

You do not need to create an account and register in DASH to browse study information and search for data and biospecimens in DASH. You do need to create an account and register to download study documentation such as protocols or data collection instruments available from the study overview pages.

An account is also required for submitting and/or cataloging studies in DASH and for requesting study data and/or biospecimens.

For instructions on how to register, please refer to the Create an Account section of the <u>DASH</u> <u>Tutorial</u>.

3. I created an account in DASH but have not yet received a confirmation email. What should I do?

The confirmation email from the DASH Administrator (supportdash@mail.nih.gov) is sent within one business day of registering in DASH. If you did not receive the email, please check your spam folder to make sure the email was not automatically routed there, or contact the

DASH Administrator at supportdash@mail.nih.gov.

Please note that your account registration will not be complete until you click on the link provided in the email, and you will not be able to log in to DASH.

4. How do I change my password or profile information (e.g., forgot password, update profile information, email preferences, etc.)?

If you registered in DASH using your NIH credentials, your DASH account password is the same password you use for your NIH account. Changing your NIH password will automatically update your DASH account password. If you do not remember your NIH password, please contact the NIH IT Service Desk.

If you registered with non-NIH credentials, after you have logged in, click "Update My Profile" on the top menu bar of the DASH homepage to access your user profile information. Here you will be able to change your password, update profile information (e.g., email address, name, job title), or adjust your email preferences. If you do not remember your password, click on "I Forgot My Password" from the login page. You will be prompted to enter the email address associated with your account, and will receive an email with a link to reset your password.

5. What should I do if I suspect my DASH account is being accessed by an unauthorized user?

You should contact the DASH Administrator at supportdash@mail.nih.gov as soon as possible.

6. Can my DASH account be deactivated?

Yes, the NICHD DASH Committee reserves the right to deny access to any individual who violates the <u>NICHD DASH User Agreement</u> (signed during account creation), the <u>NICHD DASH Data Use Agreement</u> (signed during data request), the <u>NICHD DASH Material Transfer Agreement</u> (signed during biospecimen request), or who falsifies information provided during use of DASH.

If you chose to deactivate your account on your own volition, please contact the DASH Administrator at supportdash@mail.nih.gov.

B. Data and Biospecimen Search

For detailed instructions on searching for archived data and biospecimen catalogs in DASH, please refer to the <u>DASH User Tutorial</u>.

1. How can I search for data/biospecimens in DASH?

You can explore data and biospecimens from the DASH homepage by using the explorer feature in DASH.

By hovering over the *Explore Data* button located on the top navigation bar of the DASH homepage, you can search for data:

- a. <u>Explore Studies</u>: Located on the top navigation bar of the DASH homepage (Explore Data → Studies), search/browse the list of all studies with data stored or cataloged in DASH.
- b. Explore Datasets (Explore Data → Datasets): Use this explorer to search/browse all datasets available from studies stored in DASH. You can use the dataset/study filters on the left navigation bar to identify datasets of interest and add them to your Cart to request.
- c. Explore Documents: Located on the top navigation bar of the DASH homepage (Explore Data → Documents), search/browse the list of all documents available from studies

- stored in DASH. You can use document/study filters to identify documents of interest and add them to your Cart to request.
- d. Explore Data Collections: Located on the top navigation bar of the DASH homepage (Explore Data → Data Collections), search/browse the list of other NICHD-funded data collections and resources that have data available for secondary use

You can search for biospecimens using the <u>Explore Biospecimens</u> located on the top navigation bar of the DASH homepage. You can use biospecimen/study filters to identify samples of interest and add them to your Cart to request.

Please refer to the <u>DASH Glossary</u> for an expanded list of the above terms and associated definitions, DASH sitemap to learn how to *navigate* to specific function and to DASH tutorial for step-by-step instruction how to use all above functionality.

2. Can I view study data before I request it?

No, you can only review information about a study and its associated data while searching or browsing DASH, such as the study timeline and schema, study population, participant breakdown by sex/life stage/ethnicity/race/location. You can also download descriptive study documents such as study protocols or data collection instruments (after registration in DASH). To be able to view the study datasets, you will need to submit a data request and download the data after approval.

3. What information can I gather about biospecimens before requesting them?

When browsing available biospecimens, you can search for specific subject identifier (i.e., deidentified unique participant ID) or sample identifiers. You can also filter results by biospecimen type (e.g., saliva, blood), biological macromolecule (e.g., DNA, RNA), information about the participant (e.g., sex, race/ethnicity), preservation type, use restrictions, and information about the study.

Please refer to the $\underline{\text{DASH Tutorial}}$ for instructions on how to browse/search and request biospecimens.

4. How are my data/biospecimen search results sorted?

The sort criteria is displayed in the search results page at the top right; the default sort option is 'relevance'. You may change the criteria for sorting the search results (e.g., Study Name, Data Collection Start Date, Data Collection End Date) or sort by ascending or descending order.

5. Are non-human species data available through DASH?

Yes, non-human data is available for access from the Explore Data Collections page, located on the top navigation bar of the DASH homepage (Explore Data → Data Collections). Non-human data collections are stored in other publicly accessible repositories external to DASH. You can review basic information about these collections such as the description, species, and keywords in DASH but to access data and documents from collections, click on the "Data Collection Access Information" button to be directed to the external repository.

C. Data and Biospecimen Request

1. I submitted my data/biospecimen request but have not received any notifications from DASH. What should I do?

Immediately after successfully submitting your request, you should receive an email from DASH

confirming the receipt of your submission. If you do not receive the confirmation email, please check your spam folder to make sure the email was not automatically routed there. If you do not receive a confirmation email within one business day, please send an email to the DASH Administrator at supportdash@mail.nih.gov.

2. Who reviews my data/biospecimen request?

The NICHD DASH Data or Biospecimen Access Committee reviews all requests to determine that a requester's proposed use of the data and/or biospecimens is scientifically and ethically appropriate and does not conflict with constraints or informed consent limitations identified by the institution(s) that submitted the data or biospecimens.

If you request data and/or biospecimens from a study that requires approval from a study-specific approving entity such as a Study Steering Committee, the study-specific entity will first review your request for approval. The NICHD DASH Data or Biospecimen Access Committee will then review the request for final approval.

3. How long will it take for my data/biospecimen request to be reviewed and approved? How can I check the status of my request?

Requests take about two to three weeks to be reviewed and approved in DASH. Requests that require review and approval from a study-specific approving entity (such as a Study Steering Committee) will require additional time.

Please note that for biospecimens, this timeframe only reflects the request approval process. Additional time will be needed to interact with the NICHD Contracted Biorepository to fulfill your request after approval has been obtained through DASH.

You may check the status of your request at any point in the "My Cart" page until your request is approved. After you have received notification from the DASH Administrator that your request has been approved, you can manage your approved requests from the Workspace.

4. Can I edit or cancel a data/biospecimen request?

Yes, you can edit or delete requests with an "In Progress" status in your "My Cart" page in DASH. If you need to make changes to your data/biospecimen request after you have generated the request package, you must edit the request information in DASH, and then generate your request package again. It is not sufficient to edit the request package documents received by email from DASH.

If the request status is "Submitted", please email the DASH Administrator at supportdash@mail.nih.gov for assistance.

5. Will I be notified once my data/biospecimen request is approved or denied?

Yes, you will receive an email from the DASH Administrator when your request is approved or denied by the NICHD DASH Data or Biospecimen Access Committee. If your request is denied, the email will also state the reason for denial.

Data and/or biospecimen requests may not be approved for multiple reasons, including:

- Incomplete data/biospecimen request, i.e. documents are not signed
- Unable to verify the authority of your selected Authorized Organization Representative to sign the Data Use Agreement\Material Transfer Agreement on behalf of your institution
- Lack of required supporting documentation

 A determination by the NICHD DASH Data or Biospecimen Access Committee or the studyspecific approving entity that your proposed use of the data/biospecimens is not scientifically or ethically appropriate, or thatit conflicts with the submitting institution's guidelines or informed consent limitations

If you need further clarification, please contact the DASH Administrator at supportdash@mail.nih.gov.

6. Is there a cost for obtaining data or biospecimens?

No. Data stored in DASH are distributed free of charge.

Biospecimens are provided free of charge but you will be required to pay for pulling, aliquoting, and relabeling the biospecimens as needed, and to ship the material from the NICHD Contracted Biorepository.

7. Is funding required to request biospecimens?

Yes, investigators requesting biospecimens must demonstrate availability of funding prior to initiating a material transfer. If investigators do not have funding but require proof of availability of the biospecimens to apply for research funding, they must submit a request to DASH for a Letter of Biospecimen Availability. Biospecimens will not be held by the NICHD Contracted Biorepository for investigators based on the Letter of Biospecimen Availability, and requesting investigators must submit an updated request with proof of funding to DASH after securing research funding.

8. Who is the "Authorized Representative" for signing the <u>NICHD DASH Data Use Agreement</u> (for data requests) or <u>NICHD DASH Material Transfer Agreement</u> (for biospecimen requests)?

The "Authorized Organization Representative" (AOR) as defined by NIH is the individual, named by the applicant organization, who is authorized to act for the applicant and to assume the obligations imposed by the Federal laws, regulations, requirements, and conditions that apply to grant applications or grant awards. Please see the NIH Grants Glossary page for additional details. The AOR is also referred to as the Institutional Signing Official in some cases. This person must have authority to enter into agreements on behalf of your institution and we must be able to verify that authority. The AOR is typically a senior Research Administrator. Instructors and colleagues do not typically possess the authority to sign contracts and enter into agreements on behalf of an institution.

9. Why is Institutional Review Board (IRB) review required for requesting deidentified data and biospecimens from certain studies in DASH?

While all data and biospecimen catalogs submitted to DASH are de-identified, the requirement of IRB review when requesting certain studies is determined by study's informed consent. DASH allows for study-specific requirements to ensure that the governance policies for studies are adhered to when requesting data/biospecimens from DASH.

10. My data/biospecimen request has been approved. Can I use the data/biospecimens for a different research question?

No, any substantive change to the Research Plan that you entered in the DASH Data/Biospecimen Request Form would require you to submit a separate request.

Please contact the DASH Administrator at supportdash@mail.nih.gov if you are unsure whether you need to submit a separate request.

D. Data and Biospecimen Use & Compliance

1. How can I access the data once my request is approved?

Once your data request is approved, you will be able to access the study data from your Workspace. After logging into DASH, click on "Workspace" located on the top menu bar of the DASH homepage. Within your Workspace, you will see an "Inbox," which contains your approved study items. The files will be grouped by study in case you requested multiple studies. You can download the data from your Inbox.

Further instructions on accessing data after your request has been approved will be provided in the approval email you will receive from the DASH Administrator.

2. How will I obtain biospecimens once my request is approved?

After your biospecimen request has been approved, you will receive an email from the DASH Administrator with instructions regarding biospecimen access, and the NICHD Contracted Biorepository will contact you to arrange shipment of the requested biospecimens.

The biospecimens will be shipped to you via FedEx® or another carrier authorized to ship dangerous goods (biohazardous material and dry ice) from the NICHD Contracted Biorepository. You must provide the shipping address and other information for shipment of the specimens from the NICHD Contracted Biorepository, and make arrangements for payment directly with the NICHD Contracted Biorepository.

3. Does DASH provide access to all datasets from a study or only those datasets I have requested?

Some studies have "Cart level approval," meaning you will only have access to the specific study items (documents and datasets) you requested. Once approved, these specific items will be available in your "Inbox" for download.

Other studies have "Study level approval." Upon approval of your request, you will have access to all study items (documents and datasets) and not just the items you specifically requested. All study items will be displayed in the "My Approved Items" folder in your "Workspace" but the specific items you had requested will be available in your "Inbox" for download. If at a later time, you are interested in other items from the approved study, you will be able to access them without having to go through the approval process again.

During the data request process, when you add study items to your Cart, a pop-up window will appear to indicate what type of access the study allows.

4. Can I share data and biospecimens that I obtained from DASH with colleagues from other institutions?

Yes, if you are the Recipient of the data obtained from DASH, you are permitted to share data with individuals listed as Associates in the NICHD DASH Data Use Agreement that you executed with NICHD. Associates are members from your research team from a different institution, who are only permitted to access the data from the Recipient's data platform. You are also permitted to collaborate with other researchers at another institution who are under the supervision of other Principal Investigators on the same research plan (i.e., Collaborators). Collaborators are required to submit a separate Data Request Form and sign a separate DUA with NICHD.

If you are the Recipient of biospecimens from the NICHD Contracted Biorepository, you are only permitted to share biospecimens with Affiliates as defined by the <u>NICHD DASH Material</u> Transfer Agreement that you executed with NICHD when requesting biospecimens.

Please note, you can add and remove Associates from your institution to an already executed Data Use Agreement directly from your Workspace in DASH by selecting "DUA Management". For the full definition and responsibilities of Affiliates, Associates, and Collaborators in DASH, please refer to the DASH Glossary.

- 5. Are there restrictions or limitations to the use of data and biospecimens that are available from DASH?
 - All restrictions or limitations to the use of data and/or biospecimens are specified in your Data Request Form or Biospecimen Request Form (generated by DASH as part of your request package). Please refer to these documents to make sure you are compliant with restrictions or limitations for data/biospecimen use.
 - Also, during the biospecimen request process, the DASH system will ask you whether you comply with the use restrictions for specific biospecimens that you are requesting. You must first confirm that you will comply with these restrictions before you can proceed with your biospecimen request.
- 6. How long can I use the data/biospecimens I obtained from DASH?

 The NICHD DASH Data Use Agreement or NICHD DASH Material Transfer Agreement you executed with NICHD for data or biospecimen use is valid for a period of three years from the effective date of the agreement. This agreement will automatically expire at the end of this period unless renewed or terminated earlier. DASH will notify you three months in advance of when your agreement is set to expire (i.e., at the end of the three-year period).
- 7. How can I report concerns about the integrity of the data and/or biospecimens I obtained from DASH?
 - Please report any concerns to the DASH Administrator at supportdash@mail.nih.gov.
- 8. Can I pursue patent protection on any inventions or discoveries developed through the use of data/biospecimens obtained from DASH?

 NICHD encourages development of new diagnostics, therapeutics, or other interventions building on basic discoveries enabled through research data or biospecimens obtained from DASH. Data and biospecimen recipients are free to pursue patent protection on any inventions and discoveries. Please refer to the sections on Intellectual Property in the DASH Policy, the NICHD DASH Data Use Agreement, and the NICHD DASH Material Transfer Agreement.
- 9. What is a DOI

A Digital Object Identifier (DOI) is a persistent identifier used to unambiguously identify (and access) published content. DOIs contain persistent information about that published content (metadata) in machine readable format. Dataset DOIs enable researchers to properly cite in research outputs the data obtained from DASH or any other data repository, increasing the visibility of the underlying dataset and providing reliable metadata about the underlying data. DOIs also facilitate linkages between data published articles, documents, datasets, and other digital objects – increasing transparency in research.

10. What is a DASH DOI?

DASH creates a unique and persistent DOI for each study shared through DASH, through the <u>NIH DataCite Consortium</u>. The DOI for each study can be found on the respective study overview page in DASH. DASH DOIs contain study metadata such as the study name, data release date, study topics, and Principal Investigator.

11. How do I use DASH DOIs?

If you obtain data from DASH, you should use the DASH DOI to cite the study in any manuscripts or other published content resulting from the use of data from that study. You can find the bibliographic reference (or citation) for citing each study in the following DASH resources:

- 1. The Data Request Form obtained from DASH when processing a request online; the Data Request Form also includes any study-specific acknowledgements as specified by the data submitter.
- 2. The respective study overview page in DASH.

The DASH study DOI citation follows APA format; however, researchers can use this DASH DOI to generate their citation in other formats using the <u>DOI Citation Formatter</u> tool provided by CrossRef.org.

If you have submitted a study to DASH, you can use DASH DOIs to track reuse of your study's datasets using publicly available tools such as PlumX, Altmetric, Lagotto, Mendeley, and Crossref Event Data (CED).

E. Study Submission

For detailed instructions on submitting studies to DASH, please refer to the <u>DASH User Tutorial</u>.

1. Is it mandatory to submit my study to DASH if I received funding from NICHD?

No, NICHD encourages extramural and intramural research investigators funded by the

Institute to use DASH to share data and biospecimens with other investigators, but it is not mandatory. NICHD-funded investigators who do not submit their research data to DASH are strongly encouraged to provide the name of the alternate publicly accessible data archive where the data are being stored to the appropriate NICHD Program Officer responsible for the study, and are encouraged to justify why submission to the alternate archive is more suitable. This allows DASH to catalog and provide a link to data storage locations of all NICHD-funded research studies.

Investigators whose NICHD-funded study is already stored in another publicly accessible data repository can catalog information about their study in DASH to make the study findable by external investigators.

2. Can I submit my study to DASH if I have already submitted it to another publicly accessible archive?

Yes. If data from your NICHD-funded study are already stored in a *publicly accessible* repository, you have two options: one, you can still submit your study (with data) to DASH, or two, catalog your study (without study data) in DASH. To submit or catalog your study in DASH, click on "Submit Study" in the top menu bar of the DASH homepage and choose the type of submission to begin.

The <u>DASH User Tutorial</u> contains step-by-step instructions for each type of submission to walk you through the process.

3. I am interested in sharing biospecimens from my research study. Can I submit them to DASH?

Yes, provided you meet the following conditions: (1) the study data is stored in DASH, and (2) the biospecimens are stored in the NICHD Contracted Biorepository. If you meet these conditions, you can submit your biospecimen catalog, which provides information about the biospecimens (such as type, amount available, participant age, etc.) to DASH. If you have any questions, please contact the DASH Administrator at supportdash@mail.nih.gov. Please refer to the DASH User Tutorial for detailed instructions on submitting a biospecimen catalog.

4. What happens after I submit my study data (and biospecimen catalog, if applicable) to DASH?

After you submit your study data, your submission will be reviewed by the DASH Support Team for completeness and compliance with the <u>DASH Policy</u>. Submission approval may be delayed if any study information, supporting documentation, or study annotation is incomplete or if the study is non-compliant with the <u>DASH Policy</u>. Final sign-off for public release of the study in DASH will be performed by the appropriate NICHD Division or Center Director or Branch Chief.

You can check the status of your study submission at any time by clicking on "Submit Study" found on the top menu bar, which will direct you to your "Submission Dashboard" page. You will receive an email from the DASH Administrator when the submission is approved or denied, and if denied, the reason for denial.

If you have additional questions or need further clarification regarding your study submission,

5. What should I do if I started a submission and do not want to move forward with it? Can it be deleted from my dashboard?

Please contact the DASH Administrator at supportdash@mail.nih.gov if you would like to delete your submission.

6. What is the Data Preparation Tool and where can I download it?

The Data Preparation Tool (DPT) is a standalone desktop application that study submitters must use in order to organize their study items (e.g., datasets, documents), and to annotate these items prior to uploading them into DASH. Submitters can download the DPT and use it offline.

The DPT is available for download through either of the following:

- CI. During submission, you can access and download the DPT from the "Data Preparation" page.
- b. You can also download the DPT from the "Resources" tab on the top menu bar of the DASH homepage. In the list of available resources, click "Submission Resources" and click on "Data Preparation Tool" to follow the installation instructions.

After you have downloaded the DPT, step-by-step instructions are available within the application by clicking the "Help" button, represented by a question mark at the top right corner of the DPT window.

For more information, please refer to the DPT section in the <u>DASH User Tutorial</u>. You may also contact the DASH Administrator at <u>supportdash@mail.nih.gov</u> with any specific questions regarding the DPT.

7. I am applying for a NICHD funding opportunity that requires a Letter of Support from the archive that the data/biospecimens will be deposited in. Can DASH provide this letter?

Yes, please contact the DASH Administrator at supportdash@mail.nih.gov with your request to obtain a Letter of Support for archiving your study in DASH.

8. What is the DASH Codebook?

The DASH Codebook is a templated data dictionary that allows study submitters to provide detailed information on their study variables, including variable names, labels/definitions, variable types, value ranges/fields, links to standards or ontologies, and the corresponding dataset(s). The Template also provides recommended data standards and ontologies.

The DASH Codebook catalogues, describes, and categorizes each variable submitted to DASH to help other researchers to understand and accurately interpret the variables and corresponding values in the study data. It standardizes metadata associated with variables submitted to DASH to enable variable-level searches and cross-study comparison of datasets shared through DASH. Further, it promotes meaningful use of completed studies to allow for additional analyses by the research community.

The DASH Codebook Template as well as a User Guide for filling out the Codebook are available for download from the <u>Submission Resources</u> page in DASH. For questions related to the DASH Codebook, or to provide feedback on the Codebook Template, please contact the DASH Administrator at <u>SupportDASH@mail.nih.gov</u>.

- 9. If we already have a codebook in a different format, can we submit that or are we required to submit the Codebook in the DASH format?
 You are required to submit the DASH Codebook using the Codebook Template (Excel format) provided by DASH even if you have already generated codebooks in other formats.
- 10. I am unsure which Variable Category fits best for certain variables. How can I choose the correct Variable Category?
 Please refer to the "Recommended_Standards" sheet in the DASH Codebook Template for definitions for each category. This tab also includes a detailed list of recommended vocabulary standards that can be used for coding the responses. If none of the current categories align with a variable, please select the "N/A" option for not applicable.
- 11. Some of the variables in the dataset are derived variables and do not have a data collection instrument or CRF (Case Report Form) associated with them.

 Can I leave the Data Collection Instrument Name column blank for those variables?

 Yes, this column is optional and can be left blank if not available for a variable.
- 12. The Variable Unit drop-down list does not have a variable unit that corresponds with certain variables. How do I populate this column?

 If you do not see the needed variable unit in the drop-down list, please select "Other" at the end of the drop-down list in this column, and then populate the subsequent column with the variable unit that is not included in the drop-down list. For numeric variables without a specific unit,

13. If the same Global Indicators are used across multiple variable code lists, do we need to repeat the Global Indicators for each variable code list?

Yes, please include the Global Indicator(s) in each code list where they are used and captured in the data (e.g., M = Missing, S = Skip pattern).

F. Catalog Submissions

For detailed instructions on cataloging studies or data collections in DASH, please refer to the DASH User Tutorial.

1. What does it mean to "catalog" an externally stored study or data collection in DASH?

Cataloging is the process of submitting essential information (metadata) about an existing study or data collection that is stored in a publicly accessible repository external to DASH. DASH users can search for cataloged studies or data collections in DASH and will be directed to the external site to access data or additional information.

Please refer to the <u>DASH User Tutorial</u> for step-by-step instructions on how to catalog your study or data collection in DASH. Please refer to the <u>DASH Glossary</u> if you are unclear on whether your data is considered a study or data collection.

2. What happens after I catalog my study or data collection in DASH?

Your cataloged study or data collection will be reviewed by the DASH Support Team for completeness of the required fields. Approval to catalog your study or data collection in DASH may be delayed if any required study information is incomplete. You may check the status of your catalog submission by clicking on "Submit Study" in the top menu bar. You will be directed to the "Submission Dashboard" page which contains status information for your submission(s).

You will receive an email from the DASH Administrator when the catalog submission is approved or denied, and if denied, the reason for denial.

3. I have a study stored in another publicly accessible repository external to DASH. Can I make my study findable through DASH?

Yes, you can make your study stored in an external repository findable by cataloging it in DASH. To catalog your study in DASH, you will be required to provide some essential information (metadata) about your study to make it findable through DASH, but you will not be required to deposit the study to DASH. Users can then search for your cataloged study in DASH and will be directed to the external site to access data or additional information.

Please refer to the <u>DASH User Tutorial</u> for step-by-step instructions on how to catalog studies in DASH. You can also download the <u>Study Cataloging Worksheet</u> to populate your study information and then copy/paste the responses in the online study catalog form in DASH.

4. I have sets of data stored external to DASH that is not considered a "study". Can I make this data findable through DASH?

Yes, you can catalog such data stored in a resource external to DASH as a "Data Collection" and make it findable through DASH. To catalog your data in DASH, you will be required to provide some essential information (metadata) about your data to make it findable through DASH, but you will not be required to deposit the data to DASH. Users can then search for your cataloged data in DASH and will be directed to the external site to access data or additional information.

Please refer to the <u>DASH User Tutorial</u> for step-by-step instructions on how to catalog data collections in DASH. You can also download the <u>Data Collection Cataloging Worksheet</u> to populate your study information and then copy/paste the responses in the online data collections catalog form in DASH.

G. Study Update

1. I have a study stored in DASH. Now, one of my study participants has withdrawn her/his consent. How do I remove the participant from the study data and/or biospecimen catalog in DASH?

If a participant withdraws consent for sharing of their individual-level data stored in DASH, please inform the DASH Administrator at supportdash@mail.nih.gov as soon as possible.

DASH will remove the entire set of study data and/or biospecimen catalog for the study with the participant in question. DASH will then request you to furnish a redacted version of the study data and/or biospecimen catalog as a replacement for what was originally submitted to DASH.

NICHD will also terminate the <u>NICHD DASH Data Use Agreement</u> or amend the <u>NICHD DASH Material Transfer Agreement</u> established with study data or biospecimen Recipients and instruct the Recipients to destroy the study data or biospecimens in question so long as the Recipients have not already begun using the study data or biospecimens. DASH will inform previous study data or biospecimen catalog Recipient(s) if and when redacted data and biospecimen catalogs are made available through DASH.

2. I have new datasets/documents to add to my study stored in DASH. How can I add these new items to my study?

Please contact the DASH Administrator at supportdash@mail.nih.gov with your request to add datasets and/or documents to an existing study in DASH. You will need to be a registered DASH user before being granted access by the DASH Administrator to add study items.

To add new study items (datasets or documents), you must use the <u>Data Preparation Tool (DPT)</u>. Please ensure you have downloaded the latest version of the DPT from DASH. Refer to the DASH User Tutorial for step-by-step instructions on how to add study items to an existing study.

3. How can I replace datasets/documents that are stored in DASH?

Please contact the DASH Administrator at supportdash@mail.nih.gov with your request to replace datasets/documents stored in DASH. The DASH Administrator will provide instructions for the secure transfer of the replacement versions of the datasets/documents that were originally submitted to DASH.

4. Can I edit information about my study that is displayed in DASH?

Yes. Please contact the DASH Administrator at supportdash@mail.nih.gov with your request to change information about your study.