



NICHD Privacy Impact Assessment (PIA)

The following required questions represent the information necessary to complete the PIA Summary for transmission to the Office of Management and Budget (OMB) and public posting in accordance with OMB Memorandum (M) 03-22.

Note: If a question or its response is not applicable, please answer "N/A" to that question where possible. If the system hosts a website, the Website Hosting Practices section is required to be completed regardless of the presence of personally identifiable information (PII). If no PII is contained in the system, please answer the related questions accordingly and then promote the PIA to the Senior Official for Privacy who will authorize the PIA. If this system contains PII, all remaining questions on the PIA Form Tabs must be completed prior to signature and promotion. Answers should be written using plain language. Spell out all acronyms at first use (except HHS and NIH).

Table with 2 columns: Field Name, Value. Rows include System Name (NICHD Data and Specimen Hub), System Acronym (NICHD DASH), and Contract Number (GS00F029DA).

Privacy Impact Assessment	
1. OPDIV	NIH
2. PIA Unique Identifier	P-9979169-864809
a. System Name	NICHD Data and Specimen Hub
3. The subject of this PIA is which of the following?	<p style="text-align: center;">Select One:</p> <input type="checkbox"/> General Support System (GSS) <input checked="" type="checkbox"/> Major Application <input type="checkbox"/> Minor Application (stand-alone) <input type="checkbox"/> Minor Application (child) <input type="checkbox"/> Electronic Information Collection <input type="checkbox"/> Unknown
a. Identify the Enterprise Performance Lifecycle Phase of the system.	<p style="text-align: center;">Select One:</p> <input type="checkbox"/> Initiation <input type="checkbox"/> Concept <input type="checkbox"/> Planning <input type="checkbox"/> Requirements Analysis <input type="checkbox"/> Design <input type="checkbox"/> Development <input type="checkbox"/> Test <input type="checkbox"/> Implementation <input checked="" type="checkbox"/> Operations and Maintenance <input type="checkbox"/> Disposition
b. Is this a FISMA-Reportable system?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
4. Does the system include a Website or online application available to and for the use of the general public?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
5. Identify the operator	Select One: <input checked="" type="checkbox"/> Agency <input type="checkbox"/> Contractor
6. Point of Contact (POC)	
a. POC Title	Rebecca Rosen
b. POC Name	NICHD DASH System Owner
c. POC Organization	<i>Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)</i> NICHD/OD/ODSS
d. POC Email	rebecca.rosen@nih.gov
e. POC Phone	(240) 447-7723
7. Is this a new or existing system?	<input type="checkbox"/> New <input checked="" type="checkbox"/> Existing
8. Does the system have Security Authorization (SA)?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No

a. Date of Security Authorization	6/11/2020
9. Indicate the following reason(s) for updating this PIA. Choose from the following options.	<p style="text-align: center;">Select All that Apply:</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> PIA Validation (PIA Refresh/Annual Review) <input type="checkbox"/> Anonymous to Non-Anonymous <input type="checkbox"/> New Public Access <input type="checkbox"/> Internal Flow or Collection <input type="checkbox"/> Commercial Sources <input type="checkbox"/> Significant System Management Change <input type="checkbox"/> Alteration in Character of Data <input type="checkbox"/> New Interagency Uses <input type="checkbox"/> Conversion
10. Describe in further detail any changes to the system that have occurred since the last PIA.	NICHD DASH has a new 2023 Authorization to Operate
11. Describe the purpose of the system.	<p>The <i>Eunice Kennedy Shriver</i> National Institute of Child Health and Human Development (NICHD) Data and Specimen Hub (NICHD DASH) is a centralized resource for researchers to store de-identified data and to access data and associated biospecimens from NICHD supported studies for use in secondary research. It serves as a mechanism for NICHD-funded extramural and intramural investigators to share de-identified research data from studies in accordance with the NIH Data Management and Sharing Policy. By supporting data sharing through NICHD DASH, NICHD aims to accelerate scientific findings and improve human health.</p>

<p>12. Describe the type of information the system will collect, maintain (store), or share. (Subsequent questions will identify if this information is PII and ask about the specific data elements.)</p>	<p>The system collects and maintains personal information (Name, Position, Institution, Division, email address, phone number and password) from individuals registering to create accounts in the system.</p>																								
<p>13. Provide an overview of the system and describe the information it will collect, maintain (store), or share, either permanently or temporarily. This is a summary/copy of Q12.</p>	<p>The <i>Eunice Kennedy Shriver</i> National Institute of Child Health and Human Development (NICHD) Data and Specimen Hub (NICHD DASH) is a centralized resource for researchers to store de-identified data and to access data and associated biospecimens from NICHD supported studies for use in secondary research. It serves as a mechanism for NICHD-funded extramural and intramural investigators to share de-identified research data from studies in accordance with the NIH Data Management and Sharing Policy. By supporting data sharing through NICHD DASH, NICHD aims to accelerate scientific findings and improve human health.</p> <p>The system collects and maintains personal information (Name, Position, Institution, Division, email address, phone number and password) from individuals registering to create accounts in the system.</p>																								
<p>14. Does the system collect, maintain, use or share PII?</p>	<p><input checked="" type="checkbox"/> Yes <input type="checkbox"/> No</p>																								
<p>15. Indicate the type of PII that the system will collect or maintain.</p>	<p style="text-align: center;">Select All that Apply:</p> <table border="0"> <tr> <td><input type="checkbox"/> Social Security Number</td> <td><input type="checkbox"/> Date of Birth</td> </tr> <tr> <td><input checked="" type="checkbox"/> Name</td> <td><input type="checkbox"/> Photographic Identifiers</td> </tr> <tr> <td><input type="checkbox"/> Driver License Number</td> <td><input type="checkbox"/> Biometric Identifiers</td> </tr> <tr> <td><input type="checkbox"/> Mother Maiden Name</td> <td><input type="checkbox"/> Vehicle Identifiers</td> </tr> <tr> <td><input checked="" type="checkbox"/> E-Mail Address</td> <td><input type="checkbox"/> Mailing Address</td> </tr> <tr> <td><input checked="" type="checkbox"/> Phone Number</td> <td><input type="checkbox"/> Medical Records Number</td> </tr> <tr> <td><input type="checkbox"/> Medical Notes</td> <td><input type="checkbox"/> Financial Account Info</td> </tr> <tr> <td><input type="checkbox"/> Certificates</td> <td><input type="checkbox"/> Legal Documents</td> </tr> <tr> <td><input type="checkbox"/> Education Records</td> <td><input type="checkbox"/> Device Identifiers</td> </tr> <tr> <td><input type="checkbox"/> Military Status</td> <td><input type="checkbox"/> Employment Status</td> </tr> <tr> <td><input type="checkbox"/> Foreign Activities</td> <td><input type="checkbox"/> Passport Number</td> </tr> <tr> <td><input type="checkbox"/> Taxpayer ID</td> <td></td> </tr> </table>	<input type="checkbox"/> Social Security Number	<input type="checkbox"/> Date of Birth	<input checked="" type="checkbox"/> Name	<input type="checkbox"/> Photographic Identifiers	<input type="checkbox"/> Driver License Number	<input type="checkbox"/> Biometric Identifiers	<input type="checkbox"/> Mother Maiden Name	<input type="checkbox"/> Vehicle Identifiers	<input checked="" type="checkbox"/> E-Mail Address	<input type="checkbox"/> Mailing Address	<input checked="" type="checkbox"/> Phone Number	<input type="checkbox"/> Medical Records Number	<input type="checkbox"/> Medical Notes	<input type="checkbox"/> Financial Account Info	<input type="checkbox"/> Certificates	<input type="checkbox"/> Legal Documents	<input type="checkbox"/> Education Records	<input type="checkbox"/> Device Identifiers	<input type="checkbox"/> Military Status	<input type="checkbox"/> Employment Status	<input type="checkbox"/> Foreign Activities	<input type="checkbox"/> Passport Number	<input type="checkbox"/> Taxpayer ID	
<input type="checkbox"/> Social Security Number	<input type="checkbox"/> Date of Birth																								
<input checked="" type="checkbox"/> Name	<input type="checkbox"/> Photographic Identifiers																								
<input type="checkbox"/> Driver License Number	<input type="checkbox"/> Biometric Identifiers																								
<input type="checkbox"/> Mother Maiden Name	<input type="checkbox"/> Vehicle Identifiers																								
<input checked="" type="checkbox"/> E-Mail Address	<input type="checkbox"/> Mailing Address																								
<input checked="" type="checkbox"/> Phone Number	<input type="checkbox"/> Medical Records Number																								
<input type="checkbox"/> Medical Notes	<input type="checkbox"/> Financial Account Info																								
<input type="checkbox"/> Certificates	<input type="checkbox"/> Legal Documents																								
<input type="checkbox"/> Education Records	<input type="checkbox"/> Device Identifiers																								
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<input type="checkbox"/> Foreign Activities	<input type="checkbox"/> Passport Number																								
<input type="checkbox"/> Taxpayer ID																									
<p>16. Indicate the categories of individuals about whom</p>	<p style="text-align: center;">Select All that Apply:</p>																								

PII is collected, maintained or shared.	<input type="checkbox"/> Employees <input type="checkbox"/> Public Citizens <input type="checkbox"/> Business Partners/Contacts (Federal, State, and Local Agencies) <input type="checkbox"/> Vendors/Suppliers/Contractors <input type="checkbox"/> Patients
17. How many individuals' PII is in the system?	<p style="text-align: center;">Select One:</p> <input type="checkbox"/> Less than 100 <input type="checkbox"/> 100-499 <input checked="" type="checkbox"/> 500-4,999 <input type="checkbox"/> 5,000-9,999 <input type="checkbox"/> 10,000-49,999 <input type="checkbox"/> 50,000-99,999 <input type="checkbox"/> 100,000-999,999 <input type="checkbox"/> 1,000,000 or more
18. For what primary purpose is the PII used?	To identify and authenticate access and communicate with individuals submitting data or requesting data and biospecimens.
19. Describe the secondary uses for which the PII will be used (e.g. testing, training or research)	Application Administrator will use email addresses or names to inform users of updates and request approvals.
20. Describe the function of the SSN.	N/A
a. Cite the legal authority to use the SSN.	N/A
21. Identify legal authorities governing information use and disclosure specific to the system and program.	United States Congress, Public Health Service Act 42 U.S.C. Section 241, 242, 248, 281, 282, 284, 285a, 285b, 285c, 285d, 285e, 285f, 285g, 285h, 285i, 285j, 285l, 285m, 285n, 285o, 285p, 285q, 287, 287b, 287c, 289a, 289c, and; 44 U.S.C. Section 310l
22. Are records on the system retrieved by one or more PII data elements? If Yes, a SORN is needed and you must complete 22a.	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
a. Identify the number and title of the Privacy Act System of Records Notice (SORN) that is being used to cover the system or identify if a SORN is being developed.	
Published:	09-25-0200 Clinical, Basic and Population based Research Studies of the National Institutes of Health (NIH)
Published:	Click here to enter text.
Published:	Click here to enter text.
In Progress	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Select All that Apply:

<p>23. Identify the sources of PII in the system.</p>	<p><u>Directly from Individual:</u></p> <p><input type="checkbox"/> In-Person <input type="checkbox"/> Hard Copy: Mail/Fax <input type="checkbox"/> Email <input checked="" type="checkbox"/> Online <input type="checkbox"/> Other</p>	<p><u>Government Sources:</u></p> <p><input checked="" type="checkbox"/> Within OPDIV <input type="checkbox"/> Other HHS OPDIV <input type="checkbox"/> State/Local/Tribal <input type="checkbox"/> Foreign <input type="checkbox"/> Other Federal Entities <input type="checkbox"/> Other</p>	<p><u>Non-Government Sources:</u></p> <p><input checked="" type="checkbox"/> Members of the Public <input type="checkbox"/> Commercial Data Broker <input type="checkbox"/> Private Sector <input type="checkbox"/> Other</p>
<p>a. Identify the OMB information collection approval number and expiration date.</p>	<p>The OMB Control Number is 0925-0744 and the expiration date is 06/30/2024.</p>		
<p>24. Is the PII shared with other organizations?</p>	<p><input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</p>		
<p>a. Identify with whom the PII is shared or disclosed and for what purpose.</p>			
<p>Within HHS</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No Purpose: Click here to enter text.</p>		
<p>Other Federal Agency/Agencies</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No Purpose: Click here to enter text.</p>		
<p>State or Local Agency/Agencies</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No Purpose: Click here to enter text.</p>		
<p>Private Sector</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No Purpose: Click here to enter text.</p>		
<p>b. Describe any agreements in place that authorizes the information sharing or disclosure (e.g. Computer Matching Agreement, Memorandum of Understanding (MOU), or Information Sharing Agreement (ISA)).</p>	<p>Click here to enter text.</p>		
<p>c. Describe the procedures for accounting for disclosures.</p>	<p>Click here to enter text.</p>		

<p>25. Describe the process in place to notify individuals that their personal information will be collected. If no prior notice is given, explain the reason.</p>	<p>Individuals are displayed a warning banner regarding privacy and security on the login page. The users of the system are also displayed the DASH User Agreement during registration.</p>
<p>26. Is the submission of PII by individuals voluntary or mandatory?</p>	<p><input checked="" type="checkbox"/> Voluntary <input type="checkbox"/> Mandatory</p>
<p>27. Describe the method for individuals to opt-out of the collection or use of their PII. If there is no option to object to the information collection, provide a reason.</p>	<p>The collection of information is required for the creation of an account and there is no opt-out option. Individuals may browse or search studies without creating an account. However, in order to request data and biospecimen and to submit data, they must enter their information and create an account.</p>
<p>28. Describe the process to notify and obtain consent from the individuals whose PII is in the system when major changes occur to the system (e.g., disclosure and/or data uses have changed since the notice at the time of original collection). Alternatively, describe why they cannot be notified or have their consent obtained.</p>	<p>Major system changes are conveyed to registered users through emails from SupportDASH@mail.nih.gov. A Quarterly Update email notifies users of major system changes and is sent to registered users who have not opted out of the update email. Individual users are emailed from SupportDASH if a change occurs that impacts their specific data/biospecimen request or submission.</p>
<p>29. Describe the process in place to resolve an individual's concerns when they believe their PII has been inappropriately obtained, used, or disclosed, or that the PII is inaccurate. If no process exists, explain why not.</p>	<p>If an individual has a concern that their PII has been inappropriately obtained, used, or disclosed, they may contact the System Administrator at SupportDASH@mail.nih.gov. This email address is provided throughout the system. They may also contact DASH through the Feedback button to share a concern. The concern will be investigated and addressed by our development team.</p>

30. Describe the process in place for periodic reviews of PII contained in the system to ensure the data's integrity, availability, accuracy, and relevancy. If no processes are in place, explain why not.	Individuals have access to their profile in the system and can make any changes needed to their personally identifiable information (PII) through the profile page. Accuracy is tested quarterly through the responses to the Quarterly Update email. Accounts that are “undeliverable” or with automated responses indicating they are no longer with their original institution are updated accordingly.
31. Identify who will have access to the PII in the system and the reason why they require access.	
Users	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Reason: Users can review and update their PII in the system.
Administrators	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Reason: To resolve account queries or disputes, or to assist with password resets or updates and email registered users as necessary.
Developers	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Reason: To investigate and resolve user issues when requested by the user.
Contractors	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No Reason: Users, Administrators and Developers may all be direct contractors.
Others	<input type="checkbox"/> Yes <input type="checkbox"/> No Reason: Click here to enter text.
32. Describe the procedures in place to determine which system users (administrators, developers, contractors, etc.) may access PII.	The principles of least privileged access are applied. The system uses roles and each role has different access levels. Default role has least privilege. Approval by system administrator is needed to change role.
33. Describe the methods in place to allow those with access to PII to only access the minimum amount of information necessary to perform their job.	The principles of least privileged access are applied. The system uses roles and each role has different access levels. Default role has least privilege. Approval by system administrator is needed to change role.

<p>34. Identify training and awareness provided to personnel (system owners, managers, operators, contractors and/or program managers) using the system to make them aware of their responsibilities for protecting the information being collected and maintained.</p>	<p>The NIH Security Awareness Training course is used to satisfy this requirement. According to NIH policy, all personnel who use NIH applications must complete security awareness training every year. There are five categories of mandatory IT training (Information Security, Counterintelligence, Privacy Awareness, Records Management and Emergency Preparedness).</p>
<p>35. Describe training system users receive (above and beyond general security and privacy awareness training).</p>	<p>System owners, managers, and operators are also required to take role-based training.</p>
<p>36. Do contracts include Federal Acquisition Regulation and other appropriate clauses ensuring adherence to privacy provisions and practices?</p>	<p><input checked="" type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>37. Describe the process and guidelines in place with regard to the retention and destruction of PII. Cite specific records retention schedules.</p>	<p>The records schedule item 01-003: Records of All Other Intramural Research Projects. Disposition: Cut off annually at termination of project/program or when no longer needed for scientific reference, whichever is longer. Destroy 7 years after cutoff (DAA-0443-2012-0007-0003).</p>
<p>38. Describe, briefly but with specificity, how the PII will be secured in the system using administrative, technical, and physical controls.</p>	<p>Administrative controls: Restricted access to only authorized administrators of the system. Only application administrator user role may perform those actions. Technical controls: Access is provided only to Developers, System Administrators through a Virtual Private Network (VPN) connection using multi-factor authentication. Physical controls: Access to physical systems are restricted by the system's Cloud Service Provide (CSP) Amazon Web Services.</p>
<p>39. Identify the publicly-available URL.</p>	<p>https://dash.nichd.nih.gov/</p>
<p>40. Does the website have a posted privacy notice?</p>	<p><input checked="" type="checkbox"/> Yes <input type="checkbox"/> No</p>

a. Is the privacy policy available in a machine-readable format?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
41. Does the website use web measurement and customization technology?	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
a. Select the type of website measurement and customization technologies is in use and if it is used to collect PII.	
Web Beacons	In Use: <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No
	Collects PII: <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
Web Bugs	In Use: <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
	Collects PII: <input type="checkbox"/> Yes <input type="checkbox"/> No
Session Cookies	In Use: <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
	Collects PII: <input type="checkbox"/> Yes <input type="checkbox"/> No
Persistent Cookies	In Use: <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
	Collects PII: <input type="checkbox"/> Yes <input type="checkbox"/> No
Other...	In Use: <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
	Collects PII: <input type="checkbox"/> Yes <input type="checkbox"/> No
42. Does the website have any information or pages directed at children under the age of thirteen?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
a. Is there a unique privacy policy for the website, and does the unique privacy policy address the process for obtaining parental consent if any information is collected?	<input type="checkbox"/> Yes <input type="checkbox"/> No
43. Does the website contain links to non-federal government websites external to HHS?	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No

<p>a. Is a disclaimer notice provided to users that follow external links to websites not owned or operated by HHS?</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
<p>REVIEWER QUESTIONS: The following section contains Reviewer Questions which are not to be filled out unless the user is an OPDIV Senior Officer for Privacy.</p>	
<p>1. Are the questions on the PIA answered correctly, accurately, and completely?</p>	
<p>2. Does the PIA appropriately communicate the purpose of PII in the system and is the purpose justified by appropriate legal authorities?</p>	
<p>3. Do system owners demonstrate appropriate understanding of the impact of the PII in the system and provide sufficient oversight to employees and contractors?</p>	
<p>4. Does the PIA appropriately describe the PII quality and integrity of the data?</p>	
<p>5. Is this a candidate for PII minimization?</p>	
<p>6. Does the PIA accurately identify data retention procedures and records retention schedules?</p>	
<p>7. Are the individuals whose PII is in the system provided appropriate participation?</p>	

8. Does the PIA raise any concerns about the security of the PII?	
9. Is applicability of the Privacy Act captured correctly and is a SORN published or does it need to be?	
10. Is the PII appropriately limited for use internally and with third parties?	
11. Does the PIA demonstrate compliance with all Web privacy requirements?	
12. Were any changes made to the system because of the completion of this PIA?	

Status and Approvals	
IC Status	<input checked="" type="checkbox"/> Approved <input type="checkbox"/> Rejected
IC Signature (ISSO)	