

# Privacy Impact Assessment Form

v 1.33

Status  Form Number  Form Date

Question

Answer

1 OPDIV:

2 PIA Unique Identifier:

2a Name:

3 The subject of this PIA is which of the following?

- General Support System (GSS)  
 Major Application  
 Minor Application (stand-alone)  
 Minor Application (child)  
 Electronic Information Collection  
 Unknown

3a Identify the Enterprise Performance Lifecycle Phase of the system.

3b Is this a FISMA-Reportable system?

- Yes  
 No

4 Does the system include a Website or online application available to and for the use of the general public?

- Yes  
 No

5 Identify the operator.

- Agency  
 Contractor

6 Point of Contact (POC):

POC Title POC Name POC Organization POC Email POC Phone 

7 Is this a new or existing system?

- New  
 Existing

8 Does the system have Security Authorization (SA)?

- Yes  
 No

8a Date of Security Authorization

<p>9 Indicate the following reason(s) for updating this PIA. Choose from the following options.</p>	<p><input checked="" type="checkbox"/> PIA Validation (PIA Refresh/Annual Review)      <input type="checkbox"/> Significant System Management Change <input type="checkbox"/> Anonymous to Non-Anonymous      <input type="checkbox"/> Alteration in Character of Data <input type="checkbox"/> New Public Access      <input type="checkbox"/> New Interagency Uses <input type="checkbox"/> Internal Flow or Collection      <input type="checkbox"/> Conversion <input type="checkbox"/> Commercial Sources</p> <input type="text"/>
<p>10 Describe in further detail any changes to the system that have occurred since the last PIA.</p>	<p>General Maintenance.</p>
<p>11 Describe the purpose of the system.</p>	<p>-The purpose of the ALS Web Portal is to provide users with more information regarding the disease and to facilitate research for medical professionals and individual researchers. The ALS Web Portal will help in completing the following:</p> <ul style="list-style-type: none"><li>- Collect ALS patient information as it relates to the patient's background information, occupational history, military history, smoking and alcohol habits, physical characteristics and activity, family history of disease, and the patient quality of life.</li><li>- Make available to the patients and general public educational materials about ALS.</li><li>- Identify the incidence and prevalence of ALS in the United States.</li><li>- Collect data important to the study of ALS.</li><li>- Promote a better understanding of ALS.</li><li>- Collect information that is important for research into the genetic and environmental factors that cause ALS.</li><li>- Strengthen the ability of a clearing house.</li><li>- Collect and disseminate research findings on environmental, genetic, and other causes of ALS and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS.</li><li>- Make available information to patients about research studies for which they may be eligible.</li><li>- Maintain information about clinical specialists and clinical trials on therapies.</li><li>- Enhance efforts to find treatments and a cure for ALS.</li></ul>

<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>	<ul style="list-style-type: none"><li>- Collect ALS patient information as it relates to the patient's background information, occupational history, military history, smoking and alcohol habits, physical characteristics and activity, family history of disease, and the patient quality of life.</li><li>- Make available to the patients and general public educational materials about ALS.</li><li>- Identify the incidence and prevalence of ALS in the United States.</li><li>- Collect data important to the study of ALS.</li><li>- Promote a better understanding of ALS.</li><li>- Collect information that is important for research into the genetic and environmental factors that cause ALS.</li><li>- Strengthen the ability of a clearing house.</li><li>- Collect and disseminate research findings on environmental, genetic, and other causes of ALS and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS.</li><li>- Make available information to patients about research studies for which they may be eligible.</li><li>- Maintain information about clinical specialists and clinical trials on therapies.</li><li>- Enhance efforts to find treatments and a cure for ALS.</li></ul>	
<p>13 Provide an overview of the system and describe the information it will collect, maintain (store), or share, either permanently or temporarily.</p>	<p>The ALS Web Portal collects ALS patient information as it relates to the patient's background information, occupational history, military history, smoking and alcohol habits, physical characteristics and activity, family history of disease, and the patient's quality of life. The ALS Web Portal also collects minimal identifiable information from researchers and the general public such as name, affiliation, email and location. Business addresses are collected in order to mail registry brochures.</p> <p>The purpose of the ALS Web Portal is to provide users with more information regarding the disease and to facilitate research for medical professionals and individual researchers.</p>	
<p>14 Does the system collect, maintain, use or share PII?</p>	<p><input checked="" type="radio"/> Yes <input type="radio"/> No</p>	

15 Indicate the type of PII that the system will collect or maintain.

<input checked="" type="checkbox"/> Social Security Number	<input checked="" type="checkbox"/> Date of Birth
<input checked="" type="checkbox"/> Name	<input type="checkbox"/> Photographic Identifiers
<input type="checkbox"/> Driver's License Number	<input type="checkbox"/> Biometric Identifiers
<input type="checkbox"/> Mother's Maiden Name	<input type="checkbox"/> Vehicle Identifiers
<input checked="" type="checkbox"/> E-Mail Address	<input type="checkbox"/> Mailing Address
<input checked="" type="checkbox"/> Phone Numbers	<input type="checkbox"/> Medical Records Number
<input checked="" 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 checked="" type="checkbox"/> Military Status	<input checked="" type="checkbox"/> Employment Status
<input type="checkbox"/> Foreign Activities	<input type="checkbox"/> Passport Number
<input type="checkbox"/> Taxpayer ID	<input type="checkbox"/> Yes (Race, Gender, Marital Status, Family History, Patient's Quality of Life)

SSN: Last 5 digits  
Birth date: Month, year

16 Indicate the categories of individuals about whom PII is collected, maintained or shared.

Employees

Public Citizens

Business Partners/Contacts (Federal, state, local agencies)

Vendors/Suppliers/Contractors

Patients

Other

17 How many individuals' PII is in the system?

18 For what primary purpose is the PII used?

(1) The ALS Web Portal collects ALS patient information as it relates to the patient's background information, occupational history, military history, smoking and alcohol habits, physical characteristics and activity, family history of disease, and the patient's quality of life. The ALS Web Portal also collects minimal identifiable information from researchers and the general public such as name, affiliation, email and location. Business addresses are collected in order to mail registry brochures.

(2) The purpose of the ALS Web Portal is to provide users with more information regarding the disease and to facilitate research for medical professionals and individual researchers

19 Describe the secondary uses for which the PII will be used (e.g. testing, training or research)

20 Describe the function of the SSN.

20a Cite the **legal authority** to use the SSN.

21 Identify **legal authorities** governing information use and disclosure specific to the system and program. Comprehensive Environmental Response, Compensation, and Liability Act of 1980" as amended by "Superfund Amendments and Reauthorization Act of 1986" (42 U.S.C. 9601, 9604); and the "Resource Conservation and Recovery Act of 1976" as amended in 1984 (42 U.S.C. 6901).

22 Are records on the system retrieved by one or more PII data elements?  Yes  No

22a 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:

Published:

Published:

In Progress

23 Identify the sources of PII in the system.

Directly from an individual about whom the information pertains

- In-Person
- Hard Copy: Mail/Fax
- Email
- Online
- Other

Government Sources

- Within the OPDIV
- Other HHS OPDIV
- State/Local/Tribal
- Foreign
- Other Federal Entities
- Other

Non-Government Sources

- Members of the Public
- Commercial Data Broker
- Public Media/Internet
- Private Sector
- Other

23a Identify the OMB information collection approval number and expiration date.

24 Is the PII shared with other organizations?  Yes  No

24a Identify with whom the PII is shared or disclosed and for what purpose.

- Within HHS
- Other Federal Agency/Agencies
- State or Local Agency/Agencies
- Private Sector

<p>24b 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>24c Describe the procedures for accounting for disclosures</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 notified during the self-registration process. ALS Patients will be notified, before creating an account, how their data will be used in the ALS System. There will be a "Privacy Information" link provided on the registry homepage that will allow users to view an outline of the ALS Privacy Policy. There will also be a standard Privacy Notice and customized Consent Form that allows ALS patients to agree or disagree with ATSDR's terms. The decision of the patient is voluntary and will determine whether or not an account is created.</p>	
<p>26 Is the submission of PII by individuals voluntary or mandatory?</p>	<p><input checked="" type="radio"/> Voluntary <input type="radio"/> 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>Individuals are notified during the self-registration process. Users can contact ATSDR via the contact information provided on the ALS website SORN if any issues occur.</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>In the event of significant system changes, a modified SORN would be published in the Federal Register.</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>Individuals should contact the system owner as indicated in the SORN, reasonably identify the record and specify the information being contested, the corrective action sought, and the reasons for requesting the correction, along with supporting information to show how the record is inaccurate, incomplete, untimely, or irrelevant.</p>	
<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.</p>	<p>The system data will be reviewed annually during the Annual Self Assessments or Recertification process. The system will be reviewed also through the Change Management Process.</p>	
<p>31 Identify who will have access to the PII in the system and the reason why they require access.</p>	<p><input type="checkbox"/> Users <input checked="" type="checkbox"/> Administrators <input type="checkbox"/> Developers <input type="checkbox"/> Contractors <input checked="" type="checkbox"/> Others</p>	<p><input type="text"/> To maintain data <input type="text"/> <input type="text"/> Statistician: To analyze data</p>
<p>32 Describe the procedures in place to determine which system users (administrators, developers, contractors, etc.) may access PII.</p>	<p>Roll based access, least privilege.</p>	

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.	SQL read/write permissions controlled by user roles and privileges. Active Directory controls administrator access. E-Authentication control for external users.	
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.	Annual Security and Privacy Awareness Test (SAT)	
35 Describe training system users receive (above and beyond general security and privacy awareness training).	There is individual training available within ATSDR, DTHHS,EHSB on an individual basis and with user manuals for the system.	
36 Do contracts include Federal Acquisition Regulation and other appropriate clauses ensuring adherence to privacy provisions and practices?	<input checked="" type="radio"/> Yes <input type="radio"/> No	
37 Describe the process and guidelines in place with regard to the retention and destruction of PII. Cite specific records retention schedules.	Records are retained and disposed of in accordance with the ATSDR Comprehensive Records Control Schedule (B-371). Current procedures allow the system manager to keep the records for 20 years unless needed for further study. Registry records will be actively maintained as long as funding is provided for by legislation. Retention periods vary depending on the type of record. Source documents for computer tapes or disks are disposed of when no longer needed in the study as determined by the system manager, and as provided in the signed consent form, as appropriate. Records may be transferred to a Federal Records Center for storage when no longer needed for evaluation or analysis. Disposal methods include the paper recycling process, burning or shredding hard copy records, and erasing computer tapes and disks.	
38 Describe, briefly but with specificity, how the PII will be secured in the system using administrative, technical, and physical controls.	Administrative: Users are assigned unique roles and privileges depending on their user status. ALS patients are able to create an "ALS Patient" account, while all other public users are required to create a "Public" account. The ALS "System Administrator" can manage patient and public accounts and download data. ALS Patients must also pass a validation process before creating an ALS Patient Account. The validation process is a series of questions that determine if a patient has ALS. The general public can create a Public account without going through a validation process.  Technical: PII fields will be masked on the GUI depending on the sensitivity of the data. For example the last 5 numbers of the SSN will be masked. All PII including SSN will be encrypted using CDC approved methods. To encrypt/decrypt data in database columns designed to hold PII data, a user must be given access to open and close a symmetric key.  Physical Controls: Production and test servers are stored in a server room secured by the CDC. Access tools are in place to secure entry into CDC buildings (Guards, ID Badges, Key Card, Cipher Locks, and Closed Circuit TV).	

39 Identify the publicly-available URL:

40 Does the website have a posted privacy notice?  Yes  
 No

40a Is the privacy policy available in a machine-readable format?  Yes  
 No

41 Does the website use web measurement and customization technology?  Yes  
 No

41a Select the type of website measurement and customization technologies is in use and if it is used to collect PII. (Select all that apply)

Technologies	Collects PII?
<input type="checkbox"/> Web beacons	<input type="radio"/> Yes <input type="radio"/> No
<input type="checkbox"/> Web bugs	<input type="radio"/> Yes <input type="radio"/> No
<input checked="" type="checkbox"/> Session Cookies	<input type="radio"/> Yes <input checked="" type="radio"/> No
<input type="checkbox"/> Persistent Cookies	<input type="radio"/> Yes <input type="radio"/> No
Other... <input type="text"/>	<input type="radio"/> Yes <input type="radio"/> No

42 Does the website have any information or pages directed at children under the age of thirteen?  Yes  
 No

43 Does the website contain links to non- federal government websites external to HHS?  Yes  
 No

**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.

Reviewer Questions	Answer
1 Are the questions on the PIA answered correctly, accurately, and completely?	<input type="radio"/> Yes <input type="radio"/> No
Reviewer Notes <input type="text"/>	
2 Does the PIA appropriately communicate the purpose of PII in the system and is the purpose justified by appropriate legal authorities?	<input type="radio"/> Yes <input type="radio"/> No
Reviewer Notes <input type="text"/>	
3 Do system owners demonstrate appropriate understanding of the impact of the PII in the system and provide sufficient oversight to employees and contractors?	<input type="radio"/> Yes <input type="radio"/> No
Reviewer Notes <input type="text"/>	
4 Does the PIA appropriately describe the PII quality and integrity of the data?	<input type="radio"/> Yes <input type="radio"/> No



Reviewer Questions		Answer	
Reviewer Notes	<input type="text"/>		
5	Is this a candidate for PII minimization?	<input type="radio"/> Yes <input type="radio"/> No	
Reviewer Notes	<input type="text"/>		
6	Does the PIA accurately identify data retention procedures and records retention schedules?	<input type="radio"/> Yes <input type="radio"/> No	
Reviewer Notes	<input type="text"/>		
7	Are the individuals whose PII is in the system provided appropriate participation?	<input type="radio"/> Yes <input type="radio"/> No	
Reviewer Notes	<input type="text"/>		
8	Does the PIA raise any concerns about the security of the PII?	<input type="radio"/> Yes <input type="radio"/> No	
Reviewer Notes	<input type="text"/>		
9	Is applicability of the Privacy Act captured correctly and is a SORN published or does it need to be?	<input type="radio"/> Yes <input type="radio"/> No	
Reviewer Notes	<input type="text"/>		
10	Is the PII appropriately limited for use internally and with third parties?	<input type="radio"/> Yes <input type="radio"/> No	
Reviewer Notes	<input type="text"/>		
11	Does the PIA demonstrate compliance with all Web privacy requirements?	<input type="radio"/> Yes <input type="radio"/> No	
Reviewer Notes	<input type="text"/>		
12	Were any changes made to the system because of the completion of this PIA?	<input type="radio"/> Yes <input type="radio"/> No	
Reviewer Notes	<input type="text"/>		
General Comments	<input type="text"/>		
OPDIV Senior Official for Privacy Signature	<input type="text"/>	HHS Senior Agency Official for Privacy	<input type="text"/>

