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Privacy Impact Assessment Form

v 1.21

Status | Form Number | Form Date 02/18/26

	Question	Answer
1	OPDIV:	CDC
2	PIA Unique Identifier:	TBD
2a	Name:	Survey to Promote Resources and Opportunities for aUtistic Tee
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.	Initiation
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: Epidemiology Team Lead POC Name: Angela Thompson-Paul POC Organization: NCBDDD POC Email: eup4@cdc.gov POC Phone: 770-488-8536
7	Is this a new or existing system?	◉ New ○ Existing
8	Does the system have Security Authorization (SA)?	○ Yes ◉ No
8b	Planned Date of Security Authorization	☒ Not Applicable

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8c	Briefly explain why security authorization is not required	Because the data is collected through a Cooperative Agreement (CoAg), security authorization requirements do not apply. (NOTE: Grantees will be using their own Research Electronic Data Capture (REDCap) instance to collect the data and are responsible for safeguarding the data collected.)
10	Describe in further detail any changes to the system that have occurred since the last PIA.	N/A
11	Describe the purpose of the system.	This surveillance project, the Survey to Promote Resources and Opportunities for aUtistic Teens and young adults (SPROUT), aims to collect and manage timely, unique data; translate data into high quality public health products; and disseminate public health information. It will utilize cohorts from the Study to Explore Early Development (SEED) Phases 1-3 (collected from 2007-2020. SPROUT will be comprised of caregiver and self-report surveys. This survey will provide unique information not available in other surveys, claims, or administrative data on service and support needs and the impact of co-occurring conditions on autistic people and their families; and the educational, transitional, social, and /or vocational needs and experiences of autistic adolescents and young adults. The data collected will help inform ways to lessen individual, familial, and societal costs associated with autism; reduce morbidity and mortality; and improve health and well-being.
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.)	The system will store participant information (e.g., name, phone number, mail address, email address) needed for recruitment and will be used to track participant contacts and survey completion. The system will also be used to collect survey data from the participants. The survey will collect information on demographics (e.g., date of birth, sex, race/ethnicity, education level, household income); healthcare status and utilization (e.g., types of well and sick care received in the past year, hospitalizations); diagnosis of co-occurring mental/developmental (e.g., autism, ADHD, anxiety disorder, bipolar disorder, oppositional defiant disorder, depression) and medical conditions (e.g., allergies, asthma, migraines, diabetes), their impact on functioning, and receipt of medication or specialist treatment; communication (e.g., abilities, modes); service needs (e.g., health insurance, healthcare access); healthcare transition (e.g., plans for transitioning from pediatric to adult healthcare); health knowledge (e.g., how to contact their doctor, what medications they are supposed to take); and future planning (e.g., plans for employment, education, independent living).

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13	Provide an overview of the system and describe the information it will collect, maintain (store), or share, either permanently or temporarily.	Each grantee will host their own copy of a CDC-programmed (but not hosted) REDCap database. The grantees will load existing information on people eligible to be included in the data collection based on their previous participation in SEED. This contact information will be used to recruit participants to complete an online survey that will be administered directly through REDCap. REDCap will be used to generate unique survey links and send emails to participants with their unique survey links. When participants complete the online surveys via those links, the data will automatically be stored as part of their record in REDCap. The system will include participant and survey data including name, phone number, mail address, email address; demographics including date of birth, sex, race/ethnicity, education level, household income; healthcare status and utilization (e.g., types of well and sick care received in the past year, hospitalizations); diagnosis of co-occurring mental/developmental (e.g., autism, ADHD, anxiety disorder, bipolar disorder, oppositional defiant disorder, depression) and medical conditions (e.g., allergies, asthma, migraines, diabetes), impact on functioning, and receipt of medication or specialist treatment; communication (e.g., abilities, modes); service needs (e.g., health insurance, healthcare access); healthcare transition (e.g., plans for transitioning from pediatric to adult healthcare); health knowledge (e.g., how to contact their doctor, what medications they are supposed to take); and future planning (e.g., plans for employment, education, independent living). De-identified data will be downloaded from REDCap at defined intervals and securely transmitted to CDC for concatenation into analytical datasets including de-identified data from all grantee sites.
14	Does the system collect, maintain, use or share **PII**?	(•) Yes ( ) No

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15	Indicate the type of PII that the system will collect or maintain.	☐ Social Security Number ☒ Date of Birth ☒ Name ☐ Photographic Identifiers ☐ Driver's License Number ☐ Biometric Identifiers ☐ Mother's Maiden Name ☐ Vehicle Identifiers ☒ E-Mail Address ☒ Mailing Address ☒ Phone Numbers ☐ Medical Records Number ☐ Medical Notes ☐ Financial Account Info ☐ Certificates ☐ Legal Documents ☐ Education Records ☐ Device Identifiers ☐ Military Status ☐ Employment Status ☐ Foreign Activities ☐ Passport Number ☐ Taxpayer ID Education level Race/ethnicity Health insurance status/type of insurance Sex Household income
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: Cohorts who participated in SEED 1-3, including children and young adults aged approximately 10 to
17	How many individuals' PII is in the system?	500-4,999
18	For what primary purpose is the PII used?	Date of birth is used to calculate participant age at the time survey completion. Name, mailing address, email address, and phone number are used for survey recruitment. Medical information and employment information is collected in order to fulfill the goals of the data collection. Safeguards are in place to protect minors' information as described below.
19	Describe the secondary uses for which the PII will be used (e.g. testing, training or research)	Contact information will be used for study recruitment
20	Describe the function of the SSN.	N/A; SSN is NOT being collected
20a	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.	Sections 301(a) and 317C of the Public Health Service Act, [42 U.S.C. Sections 241(a) and 247b-4, as amended]
22	Are records on the system retrieved by one or more PII data elements?	○ Yes ◉ No

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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.	In process.
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
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)).	
24c	Describe the procedures for accounting for disclosures	

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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.	Participants will receive an information sheet by previously-provided email about the project that will include text similar to the following: You are being invited to take part in this SPROUT because you and your family participated in SEED in the past and agreed to be contacted again. Any information that you give us about you and your family will be kept private. Only SEED and SPROUT staff and their research partners will be able to look at any information you give us. Personally identifiable information that you give will only be used for this study. Your information will remain confidential unless otherwise required by law. We will never use your name in any report or publication. The information you give will always be combined with information from all other participants in reports. Only staff working on the study will have access to your personal information. Results from the study will not be linked to your name. Findings will only be linked to the study ID assigned to you and your family when you first participated in SEED. This link will be maintained on a database that is kept on a secure computer.
26	Is the submission of PII by individuals voluntary or mandatory?	(•) Voluntary ( ) Mandatory
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.	Participants may opt out by not completing the survey or by contacting the project staff to indicate they wish to withdraw from the survey/project. They are also told that they can skip individual questions.
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.	If there are major changes to the system, participants will be contacted by Email, Phone, or Postal Service Mail by the site Principal Investigators (PIs)
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.	Potential and participating individuals who have concerns about the use/misuse/inaccuracy of their PII can contact their local clinics project staff at the study site or study PI contact information printed on the survey information sheet; and request for their information to be corrected or withdrawn. Participants in the study can request to be removed from the study and have their PII removed/destroyed at any point.
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.	CDC will provide technical assistance to the sites for data cleaning queries, including removal of PII including date of birth, and review of open text fields. Sites will be instructed to review these data for integrity, availability, accuracy, and relevancy prior to removing from the shared dataset.

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31	Identify who will have access to the PII in the system and the reason why they require access.	☒ Users	Grantees will have access for study recruitment and data management.
		☐ Administrators	
		☐ Developers	
		☐ Contractors	
		☐ Others	
32	Describe the procedures in place to determine which system users (administrators, developers, contractors, etc.) may access PII.	Role-base Access Controls (RBAC) are in place to ensure the concept of "least privilege" is implemented for functional as well as security purposes. Information displayed to a particular role is limited to necessary “need to know” information based on a specific role’s required tasks throughout the study.	
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.	CDC will advise grantees to provide their users with access to database modules containing PII only as necessary to complete their job function.	
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.	All personnel collecting and working with data will receive confidentiality training, annually, from CDC program staff as part of their technical assistance.	
35	Describe training system users receive (above and beyond general security and privacy awareness training).	In addition to general security and privacy awareness, system users receive annual confidentiality training specific to the SPROUT surveillance project. This training covers, but is not limited to, the following areas of concern: restrictions on use of information, enhanced protection of computerized files as part of study implementation, dissemination of results, data sharing with other study partners, analytic data access policies and procedures, instructions concerning confidentiality procedures, procedures for traveling with confidential study materials, loss of study materials containing confidential data. In addition, personnel in specific roles receive training and awareness related to those roles as needed, e.g., computer system administrators and other IT personnel receive training on computer system security, annually. CDC program staff will provide training as part of their technical assistance.	
36	Do contracts include Federal Acquisition Regulation and other appropriate clauses ensuring adherence to privacy provisions and practices?	○ Yes ◉ No	
37	Describe the process and guidelines in place with regard to the retention and destruction of PII. Cite specific records retention schedules.	Records of the data provided to CDC, which include de-identified, individual-level survey responses, are retained and disposed in accordance with the Scientific and Research Project Records Control Schedule NC1-90-78-1, Item 60. The study period is defined to include data analysis and publication. The end of the study period will be considered to be 1 year after the final manuscript from a SPROUT surveillance data analysis is submitted for publication. No identifiable information will be retained or transferred to the National Archives.	

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38	Describe, briefly but with specificity, how the PII will be secured in the system using administrative, technical, and physical controls.	

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?	◯ Yes ◯ No
Reviewer Notes		
2	Does the PIA appropriately communicate the purpose of PII in the system and is the purpose justified by appropriate legal authorities?	◯ Yes ◯ No
Reviewer Notes		
3	Do system owners demonstrate appropriate understanding of the impact of the PII in the system and provide sufficient oversight to employees and contractors?	◯ Yes ◯ No
Reviewer Notes		
4	Does the PIA appropriately describe the PII quality and integrity of the data?	◯ Yes ◯ No
Reviewer Notes		
5	Is this a candidate for PII minimization?	◯ Yes ◯ No
Reviewer Notes		
6	Does the PIA accurately identify data retention procedures and records retention schedules?	◯ Yes ◯ No
Reviewer Notes		
7	Are the individuals whose PII is in the system provided appropriate participation?	◯ Yes ◯ No
Reviewer Notes		
8	Does the PIA raise any concerns about the security of the PII?	◯ Yes ◯ No
Reviewer Notes		
9	Is applicability of the Privacy Act captured correctly and is a SORN published or does it need to be?	◯ Yes ◯ No
Reviewer Notes		

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	Reviewer Questions	Answer
10	Is the PII appropriately limited for use internally and with third parties?	◯ Yes ◯ No
Reviewer Notes		
11	Does the PIA demonstrate compliance with all Web privacy requirements?	◯ Yes ◯ No
Reviewer Notes		
12	Were any changes made to the system because of the completion of this PIA?	◯ Yes ◯ No
Reviewer Notes		
General Comments		
OPDIV Senior Official for Privacy Signature	JARELL OSHODI -S Digitally signed by JARELL OSHODI -S Date: 2026.04.22 07:52:43 -04'00'	HHS Senior Agency Official for Privacy