Due to the limitation of the Privacy Impact Assessment (PIA) form, please find below the full response to Question #37:

At the end of SEED Teen, the PII will be retained, as per the consent agreement, to enable future contact with the participants. At the conclusion of the overall SEED program, all PII will be retained by CDC for one year as per the CDC Scientific and Research Project Records Control Schedule. After one year, all identifiable information must be destroyed in accordance with the Certificate of Confidentiality approved application. The study periods for SEED and SEED Teen are 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 SEED data analysis is submitted for publication. No identifiable information will be retained or transferred to the National Archives.

a. Retention Time Information Will Be Kept in Identifiable Form

Identifying information will be collected during the data collection period and will be kept private in a separate file from the other data collection elements. Only the research staff will have access to a list linking a participant's study ID to his/her study data. Each SEED Teen site's data will be stored separately from all others and no site will have the means to access the personally identifiable data stored by another site unless granted permission to do so for specific study purposes.

Study participants will be asked in the written consent form for permission for study personnel at the site to retain access to this study link after the study period, in order to allow for potential re-contact for follow-up studies, and for genetic data sharing. Participants can give consent to all, any one, or none of these individual permission requests. For participants who agree, this study link will remain indefinitely. For participants who do not allow the link to be kept, this information will be destroyed at the end of the study period. The Data Coordinating Center will maintain the central database with all the study data.

Scientific and Research Project Records Control Schedule (Additional Information)

Scientific and Research Project Records

1. Precedent-Setting Scientific and Research

Records represent scientific data and all aspects of research including project development, demonstration, distribution, assessment, testing, and related tasks. Systems that document the planning, history, results, and outcome of a scientific and or research project conducted as part of CDC/ATSDR's mission or under the supervision of CDC/ATSDR employee(s).

These records include but are not limited to planning documents, and/or documents that evaluate or appraise a project or other research during its course. Records include but not limited to original observations, laboratory notebooks, databases that contain scientific observations, modeling and sampling methodologies, and any other research-related documentation.

Master file, system or database that is precedent-setting, received remarkable interest from the public health community and garnered extreme interest by the public, media, and health researchers; these records have long-term evidentiary and informational value.

a. Long-Term ongoing Studies that contain cumulative research data

Authorized Disposition: PERMANENT: Transfer “snapshot” copy of data to NARA in 1 year intervals (or other time period established with NARA); the first transfer to occur within the first year after the approval of Records Control Schedule. Electronic media will be transferred to NARA formatted in accordance with current applicable regulations regarding transfer of electronic records.

b. Completed Studies

Authorized Disposition: PERMANENT: Transfer to NARA a copy of the completed database no longer than one year after the end of the project. Electronic media will be transferred to NARA formatted in accordance with current applicable regulations regarding transfer of electronic records.

Selection Criteria for Permanently valuable data: Includes, but not limited to, research records meeting one or more of the following criteria:

- Records of scientific investigations that are deemed to be Influential Scientific Information or Highly Influential Scientific Assessments (per Office of Management and Budget (OMB) Bulletin for Peer Review, December 15, 2004):
- Scientific information that CDC reasonably determines will have or does have a clear and substantial impact on important public policies or private sector decisions.
- An evaluation of a body of scientific or technical knowledge, which typically synthesizes multiple factual inputs, data, models, assumptions, and/or applies best professional judgment to bridge uncertainties in the available information.
- A scientific assessment is a subset of "influential scientific information" and is considered "highly influential" by the agency or the OIRA Administrator [Office of Information and Regulatory Affairs in OMB] determines the dissemination could have a potential impact of more than $500 million in any one year on either the public or private sector or that the dissemination is novel, controversial, or precedent setting, or has significant interagency interest.
- Long-term data collections and monitoring efforts of national or international interest.
- Datasets that is irreplaceable, critical to the CDC mission, and in a condition which allows future use.
- Scientific investigations that receive national or international awards of distinction.
- Works of prominent CDC investigators of widely recognized professional stature, or who have received national or international recognition outside their professional discipline.
- Activities that result in a significant improvement in public health, safety, or other vital public interest.
- Significant contributions to new national or international health policies, or had a significant impact on the development of new national or international scientific, political, economic, or social priorities.
- Subjects of widespread national or international media attention.
- Materials related to significant social, political, or scientific controversy.
- Activities subject to extensive Congressional, Department of the Interior, or other government agency scrutiny or investigation.
- Precedents that significantly change CDC scientific investigations.
- All projects published and unpublished publications.