

Investigator: \_\_\_\_\_ Date: \_\_\_\_\_  
Last name, first

Project title: \_\_\_\_\_

## **SEER- CONSUMER ASSESSMENT OF HEALTHCARE PROVIDERS AND SYSTEMS (SEER-CAHPS) DATA USE AGREEMENT (DUA) PRINCIPAL INVESTIGATOR**

Information regarding persons with cancer is sensitive. Therefore, specific laws have been enacted to ensure the confidentiality of individuals included in cancer registry data. In utilizing data on such individuals for research purposes, it is absolutely necessary to ensure, to the extent possible, that uses of such data will be limited to research. Uses for any other reason, particularly those resulting in personal disclosures, will be prosecuted to the full extent of the law. In addition, release of information about the health plans or providers, i.e., the physicians and hospitals that provide care for cancer patients, may compromise the willingness of these providers to cooperate with the activities of the cancer registries. Therefore, considerations regarding the privacy of providers are also of great importance.

**In order for the National Cancer Institute to provide the linked Surveillance, Epidemiology and End Results (SEER)-Consumer Assessment of Healthcare Providers and Systems (CAHPS) data to you, it is necessary that you agree to the following provisions:**

1. You agree that the statements and methods made in your attached research proposal are complete and accurate.
2. You will not use the data for purposes other than described in your research proposal.
3. You will not permit others to use the data except for collaborators within your institution involved with the research as described in your proposal. Within your institution or organization, access to the SEER-CAHPS data shall be limited to the minimum number of individuals necessary to achieve the purpose stated in your proposal. The number of locations where the data are located shall also be minimized and specific location details must be provided in your proposal's data storage and management plan. If you plan to move the data to a new location at your institution you must contact NCI in writing prior to moving the data for instruction on how to handle the SEER-CAHPS data.
4. You will establish and maintain the appropriate administrative, technical, and physical safeguards to protect the confidentiality of the data and to prevent unauthorized use or access to it, as described in your proposal. The safeguards shall provide a level and scope of security that is not less than the level and scope of security established by the Office of Management and Budget (OMB) in OMB Circular No. A-130, Appendix III—Security of Federal Automated Information Systems ([http://csrc.nist.gov/drivers/documents/appendix\\_iii.pdf](http://csrc.nist.gov/drivers/documents/appendix_iii.pdf)) which sets forth guidelines for security plans for automated information systems in Federal agencies.
5. You agree not to place the SEER-CAHPS data on personal computers, portable devices and removable media unless these media are password protected AND encrypted. Portable devices include any non-fixed equipment that contains an operating system which may be used to create access or store SEER-CAHPS data. This includes but is not limited to laptops, personal digital assistants (PDAs), and smart phones. Removable media include, but are not limited to: CDs, DVDs, MP3 players, removable memory, and USB drives (thumb drives). Approved encryption standards must be FIPS-140 compliant and include Advanced Encryption Algorithm (AES) that uses a 128, 192, or 256-bit key size. In the event that the data are lost or stolen, you agree to report the loss to the

SEER-CAHPS contact within 24 hours/first business day of discovering the loss. Cloud storage does not meet privacy rules and is not acceptable for storing SEER-CAHPS data.

6. You may use an institutionally provided VPN to link to a time sharing system for data access. In this case, the remote PC may support the VPN but the SEER-CAHPS data must remain on the institution's server.
7. You will store all media on which the SEER-CAHPS data are delivered in a secure location, such as a locked file cabinet in a locked office, only accessible by you or appropriate designated staff.
8. You must maintain all datasets containing restricted variables physically separate from any other SEER-CAHPS files. Separate access controls with strong user authentication (username/password, digital certifications, etc.) must be established to allow limited access to these files. You should be able to track all access to these files.
9. All SEER-CAHPS data must reside at your institution under your purview. If you plan to move to a different institution, you must contact NCI in writing prior to moving for instructions on how to handle the SEER-CAHPS data. You may not duplicate any SEER-CAHPS files prior to moving nor can you take SEER-CAHPS data with you without written permission from NCI. If you chose not to take the data with you, you must destroy the files or designate a new PI prior to moving and notify NCI. SEER-CAHPS data are not permitted to be housed outside of the United States.
10. You will not attempt to link nor permit others to link the SEER-CAHPS data with individually identified records in another database without the written consent from the applicable SEER registries.
11. No one having access to the data will attempt to learn the identity of any persons with cancer in these data and/or their health plan, physicians or treating hospitals. In the event that you discover or are able to deduce the identity of a specific patient, health plan, physician or treatment hospital, you agree that you will not attempt to contact these individuals.
12. No findings or information derived from the SEER-CAHPS data may be released if such findings contain any combination of data elements that might allow the deduction of a patient's, health plan's, or provider's identity. In tables, cell sizes less than 11 (eleven) must be suppressed. Also, no use of percentages or other mathematical formulas may be used if they allow the derivation of patient, facility, or provider counts less than 11. Mapping of data to reflect incidence, treatment, or survival at the registry-specific level or at other small areas is not permitted without prior approval from NCI and the involved registries. Although it is permissible to report registry names with registry-specific cancer rates (e.g., incidence, complications, mortality), registry names must be anonymized when reporting the quality or completeness of registry-specific data (e.g., case or treatment ascertainment). You agree that NCI shall be the sole judge as to whether any finding derived from the SEER-CAHPS data would, with reasonable effort, permit one to identify an individual, health plan, or provider, or to deduce the identity of an individual, health plan, or provider to a reasonable degree of certainty.
13. You agree to provide a copy of all manuscripts to NCI for review and comment prior to publication submission. You further agree not to submit such findings to any third party prior to completion of NCI review. NCI agrees to complete the manuscript review process within 4 weeks of receiving any manuscript. NCI's review of the manuscript is for the sole purpose of assuring that data confidentiality is maintained (e.g., individual patients and/or providers cannot be identified), that the focus of the manuscript was outlined in the approved SEER-CAHPS proposal,

and to provide general guidance and feedback on interpretation. Revisions will be necessary, if NCI determines that the format in which data are presented may result in identification of individual patients and/or providers or if the scope of the manuscript is not consistent with the approved proposal, and/or if there are any major issues with the analysis or interpretation of the data.

14. You agree that in the event NCI determines or has a reasonable belief that you have violated any term(s) of this agreement, NCI may request that you return the data and all derivative files to NCI. You understand that as a result of NCI's determination or reasonable belief that a violation of this agreement has taken place, NCI may refuse to release further SEER-CAHPS data to you for a period of time to be determined by NCI.
15. All files received may be retained for a maximum of five years. At the completion of the project or five years from receipt, all files must be destroyed, and notification of destruction must be sent to NCI. Investigators who need to retain files beyond that period must contact NCI.

**Please indicate the SEER-CAHPS files you are requesting:**

<b>Name of file</b>	<b>Years available</b>	<b>Years requested</b>
<b>CAHPS Survey Files</b>		
Medicare CAHPS Survey Data (MA-only) This file contains the only available survey data for the MA cohort between 1997-2005.	(survey) 1997-2005	
Medicare CAHPS Survey Data (MA-only) This file includes records for individuals with MA plans without a Prescription Drug Plan (PDP) between 2007-2015.	(survey) 2007-2019	
Medicare CAHPS Survey Data (MA-PD) Collection of this data began in 2007 and is used for individuals with MA and PD coverage.	(survey) 2007-2019	
Medicare CAHPS Survey Data (MA-PPO) This file corresponds to a survey that was only active in 2009-2012.	(survey) 2009-2012	
Medicare CAHPS Survey Data (FFS-only) This file contains the only available survey data for the FFS cohort between 2000-2004 and 2007-2010, and surveys reflect all aspects of care.	(survey) 2000-2004; 2007-2010	
Medicare CAHPS Survey Data (FFS+PDP) Collection of this data began in 2007 and is used for individuals with FFS and PDP coverage, and surveys reflect all aspects of care	(survey) 2007-2010	
Medicare CAHPS Survey Data (FFS) This file corresponds to surveys administered to those with FFS plans and FFS+PDP plans, and surveys reflect non-Part D aspects of care.	(survey) 2011-2019	
Medicare Prescription Drug Plan (Prescription Drug Plan) This file contains surveys of beneficiaries with FFS+PDP coverage and surveys reflect Part D aspects of care.	(survey) 2011-2019	
<b>Cancer File</b>	1999-2019*	
<b>Medicare Enrollment Files</b>		
Master Beneficiary Summary File (MBSF) Base (A/B/C/D) (Cancer)	1999-2019	1999-2019**
Master Beneficiary Summary File (MBSF) Base (A/B/C/D) (Controls)	1999-2019	
Chronic Conditions Flags (27 conditions)	1999-2019	
Chronic Conditions Flags (30 conditions)	2017-2019	
Other Chronic or Potentially Disabling Conditions	2000-2019	
Plan Characteristics File	2007-2019	
<b>Medicare Claims and Events Files</b>		
MedPAR	1999-2019	
Carrier Claims (NCH)	1999-2019	

<b>Name of file</b>	<b>Years available</b>	<b>Years requested</b>
Outpatient	1999-2019	
Home Health Agencies (HHA)	1999-2019	
Hospice	1999-2019	
Durable Medical Equipment (DME)	1999-2019	
Part D Event (PDE)- with Drug Characteristics File appended	2007-2019	
Formulary File	2010-2019	
Prescriber Characteristics File and Bridge File	2007-2019	
Pharmacy Characteristics File and Bridge File	2007-2019	
Part D Medication Therapy Management File	2013-2019	
<b>Medicare Assessment Files</b>		
Minimum Data Set (MDS)	1999-2019	
Outcome and Assessment Information Set (OASIS)	1999-2019	
<b>Ancillary Files</b>		
Medicare Data on Provider Practice and Specialty (MD-PPAS)	2008-2019	
Hospital Characteristics File	1996, 1998, 2000-2016	

\*Cancer cases from the expansion registries are diagnosed in 2000 or later.

\*\*All years of MBSF enrollment information will automatically be provided for the requested cancer cases and, if applicable, for the non-cancer controls.

**These files will include:**

Cancer cases

Non-cancer cases\*\*

*\*\*NOTE: The survey years of non-cancer cases will be based on the survey years of cancer cases requested, unless otherwise noted by the investigator in the application.*

**Please consider the following carefully:** Multiple requests to use SEER-CAHPS data may be received, and the approval process should not be understood as a guarantee preventing overlapping research aims. Reviewers intend to be good stewards of the data and will make efforts to notify investigators when this may be the case. Thus, to promote transparency and collaboration where possible, the leadership team of SEER-CAHPS is interested in making selected information about new and existing DUAs public.

**Check this box if you are willing to allow the National Cancer Institute to make the title, name/affiliation of the PI(s) and specific aims of your DUA public and included on our SEER-CAHPS public website (<https://healthcaresdelivery.cancer.gov/seer-cahps/>). Questions should be directed to NCISEER-CAHPS@nih.gov.**



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City/State/ZIP code

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Phone number – including Area Code

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Fax number

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Email address



**Optional: Additional Study Personnel with Access to SEER-CAHPS Data (if more than one person, duplicate boxes below)**

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Signature of Additional Study Personnel

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Date

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Name of Additional Study Personnel

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Title (in association with this DUA)

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Institution/Organization

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Street Address

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City/State/ZIP code

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Phone number – including Area Code

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Fax number

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Email address