National Program of Cancer Registries (NPCR) and Surveillance, Epidemiology and End Results (SEER) Incidence – United States Cancer Surveillance (USCS) Public Use Research Database Data Use Agreement

For data submitted in November, 2016

The Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI) make NPCR and SEER data available to the public and researchers through various data release activities. The NPCR and SEER Incidence – USCS Public Use Research Databases are an unrestricted subset of data submitted to CDC and SEER and made available only through the National Cancer Institute's SEER*Stat statistical software.

CDC has obtained an assurance of confidentiality for NPCR pursuant to Section 308(d) of the Public Health Service Act, 42 U.S.C. 242m(d). Any effort to determine the identity of any reported cases, or to use the information for any purpose other than statistical reporting and analysis, is a violation of the assurance. All direct identifiers, as well as characteristics that might easily lead to identification of individuals, are omitted from the NPCR and SEER Incidence – USCS Public Use Research Databases. Certain demographic information has been included for research purposes; thus, all SEER*Stat results must be presented or published in a manner that ensures that no individual can be identified. In addition, there must be no attempt to identify individuals from any computer file or to link with a computer file containing patient identifiers.

Data users must agree to the following provisions prior to receiving access to the NPCR and SEER Incidence – USCS 2001–2014 and 2005–2014 Public Use Research Databases.

As the recipient of access to NPCR and SEER Incidence – USCS Public Use Research Databases through SEER*Stat, I will:

- Not use or permit others to use the analytic results in any way other than for statistical reporting and analysis.
- Use appropriate safeguards to prevent use or disclosure of the information other than as provided for by this
 agreement.
- Ensure all members of the research team who have access to the NPCR and SEER Incidence USCS Public Use Research Database through SEER*Stat have signed this agreement.
- Not attempt to link or permit others to link NPCR and SEER Incidence USCS Public Use Research Data with individually identifiable records from any other dataset without CDC approval.
- Not attempt to use the analytic results or permit others to use them to learn the identity of any person or establishment included in any dataset.
- Take the following actions if the identity of any person or establishment is discovered inadvertently:
 - Make no use of this knowledge.
 - Notify CDC by sending an e-mail to uscsdata@cdc.gov.
 - As requested by CDC, safeguard or destroy the information that identifies an individual or establishment.
 - Inform no one else of the discovered identity.

In addition, I will make every effort to release all statistical information in such a way as to avoid inadvertent disclosure. I will:

- Ensure that no data on an identifiable case can be derived through subtraction or other calculation from the combination of tables in the given publication.
- Ensure that no data permit disclosure when used in combination with other known data.
- Not disclose or otherwise make public data on any unit smaller than 16. If the total number of cases in a cell is fewer than 16, the cell data will be suppressed in oral and written presentations.

My signature below indicates that:

• I will adhere to the requirements of this Data Use Agreement and understand that my access to the data will be revoked if these requirements are violated.

- I have read the data documentation file and have an understanding of the data available in the database and the
 restrictions related to their use. If I have questions regarding my analytic approach, I will contact CDC NPCR
 (uscsdata@cdc.gov) for assistance.
- I am familiar with the use of **SEER*Stat** in analyzing data or will complete the needed training.
- I understand that all NPCR data are owned by the states and territories. The states and territories have established agreements with CDC regarding the use and dissemination of the data.
- I understand that I am responsible for the results of my own analysis. The findings and conclusions resulting from the analysis of these data are those of the authors and do not necessarily represent the official position of CDC.
- I will acknowledge central cancer registries whenever data are presented, released, or published by including the following (or similar) statement:

These data were provided by central cancer registries participating in CDC's National Program of Cancer Registries (NPCR) and/or NCI's Surveillance, Epidemiology, and End Results (SEER) Program and submitted to CDC and NCI in November, 2016.

	Signature	Date
Name:		
Title and organization:		
Telephone number:		
E-mail address:		

By e-mail to <u>uscsdata@imsweb.com</u>.

Please complete the above fields, sign and date the agreement, and send it: