National Program of Cancer Registries (NPCR) and Surveillance, Epidemiology and End Results (SEER) Incidence – U.S. Cancer Statistics Public Use Research Database Data Use Agreement

For data submitted in November, 2018

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 – U.S. Cancer Statistics 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 – U.S. Cancer Statistics 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 – U.S. Cancer Statistics 2001–2016 and 2005–2016 Public Use Research Databases. *Please initial after each statement to indicate agreement.*

As the recipient of access to NPCR and SEER Incidence - U.S. Cancer Statistics Public Use Research Databases:

- I will adhere to the requirements of the Data Use Agreement and understand that my access to the data will be revoked if these requirements are violated. Initials:
- 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. Initials:
- I will not use or permit others to use the analytic results in any way other than for statistical reporting and analysis.

 Initials:
- I will use appropriate safeguards to prevent use or disclosure of the information other than as provided for by this agreement. Initials:
- I will ensure all members of the research team who have access to the NPCR and SEER Incidence U.S. Cancer Statistics Public Use Research Database through SEER*Stat have signed this agreement. Initials: SV
- I will not attempt to link or permit others to link NPCR and SEER Incidence U.S. Cancer Statistics Public Use
 Research Data with individually identifiable records from any other dataset without CDC approval. Initials:

 SV
- I will 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. Initials:
- I will take the following actions if the identity of any person or establishment is discovered inadvertently:
 - o Make no use of this knowledge.
 - o Notify CDC by sending an e-mail to <u>uscsdata@cdc.gov</u>.
 - o As requested by CDC, safeguard or destroy the information that identifies an individual or establishment.
 - o Inform no one else of the discovered identity. Initials:
- I will make every effort to release all statistical information in such a way as to avoid inadvertent disclosure by:
 - o Ensuring that no data on an identifiable case can be derived through subtraction or other calculation from the combination of tables in the given publication. **Initials:**
 - Ensuring that no data permit disclosure when used in combination with other known data. Initials:

 Not disclosing or otherwise making public data on any unit smaller than 16. If the to a cell is fewer than 16, the cell data will be suppressed in oral and written presenta 	otal number of cases in tions. Initials:
 I have read the data documentation file and have an understanding of the data available in restrictions related to their use. If I have questions regarding my analytic approach, I will co (uscsdata@cdc.gov) for assistance. Initials: 	the database and the ontact CDC NPCR
I am familiar with the use of SEER*Stat in analyzing data or will complete the needed training.	ing. Initials:
 I understand that I am responsible for the results of my own analysis. The findings and con the analysis of these data are those of the authors and do not necessarily represent the off Initials: 	clusions resulting from ficial position of CDC.
 I will acknowledge central cancer registries whenever data are presented, released, or pub following (or similar) statement: 	lished by including the
These data were provided by central cancer registries participating in CDC's Nation Registries (NPCR) and/or NCI's Surveillance, Epidemiology, and End Results (SEI submitted to CDC and NCI in November 2018. Initials:	
As appropriate, I will cite the data –	
For the 2001-2016 database: National Program of Cancer Registries and Surveillar End Results SEER*Stat Database: NPCR and SEER Incidence – U.S. Cancer State Research Database, Nov 2018 submission (2001-2016), United States Department Services, Centers for Disease Control and Prevention and National Cancer Institute 2018, based on November 2018 submissions. Available at <a href="https://www.cdc.gov/cancer/pu</td><td>tistics Public Use
It of Health and Human
e. Released June</td></tr><tr><th>For the 2005-2016 database: National Program of Cancer Registries and Surveillar End Results SEER*Stat Database: NPCR and SEER Incidence – U.S. Cancer State Research Database with Puerto Rico, Nov 2018 submission (2005-2016), United State Health and Human Services, Centers for Disease Control and Prevention and National Released June 2018, based on November 2018 submissions. Available at <a href=" https:="" th="" www.cduse.com="" wwww.cduse.co<="" wwww.cduse.com=""><th>tistics Public Use States Department of onal Cancer Institute.</th>	tistics Public Use States Department of onal Cancer Institute.
Please complete the fields below, sign and date the agreement, and email both pages to usc	sdata@imsweb.com.
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Signature Signature	Date
Name: Sarah Van Alsten	8)
Title and organization: Graduate Student, Washington Univers	sity in St. Louis
SEER*Stat username*: 19677 - Nov 2018	9,0 (19 (19 (19 (19 (19 (19 (19 (19 (19 (19
Telephone number: 860-904-8777 E-mail address: Sarah. Vanals	ten Quustled
*If you have an existing SEER*Stat username/SEER ID that SEER provided you, please note it in one, leave this field blank.	this field. If do not have

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