

North American Association of Central Cancer Registries Virtual Pooled Registry Cancer Linkage System Data Confidentiality and Data Use Agreement

The Project titled _____ includes confidential identifying information for the study subjects (the “Data”). This Data Confidentiality and Data Use Agreement (“Agreement”) is hereby made between Information Management Services, Inc. (IMS), the data stewards on behalf of North American Association of Central Cancer Registries (NAACCR), and the data provider (“Provider”) listed below. For the purposes of this agreement, IMS includes IMS employees, staff, and independent contractors, assignees and/or agents of IMS. IMS agrees to be bound to this Agreement and further agrees to protect the confidentiality of the Data released to IMS by the Provider for the purposes of the Virtual Pooled Registry Cancer Linkage System (VPR-CLS) linkage.

The provisions of this agreement are as follows:

1. The Provider assures that any and all necessary approvals for use of the Data have been secured and will share such documentation upon request.
 2. The Provider will provide the Data to IMS for use in the linkage with Central Cancer Registries (CCRs). The Data will be provided via a secure data transmission to ensure data confidentiality.
 3. The Data provided to IMS will be used by IMS for the following purposes:
 - a. The primary use of the Data is the data linkage, which will occur at the CCRs and result in a report of the aggregate counts of matched cases by diagnosis year. The Provider will not attempt to learn the identity of any persons included in the match counts. If individual-level data are desired for matched cases, Provider will complete the applications and agreements necessary for release of such information from the CCRs.
 - b. The data may also be used internally by IMS for the purpose of testing linkage algorithms. During such testing, the data would remain behind the IMS firewall on IMS servers and would only be viewed by IMS personnel involved in the improvement of the linkage process. The only released results for linkage testing would be aggregate match counts. Such testing is only concerned with the improvement of linkage processes, not with any research or study outcomes.
- No other use of the data is allowed.
4. The Data provided to IMS will not be released, viewed, shared, used, transmitted, transferred, or otherwise made known to any person and/or organization and/or entity by IMS, except for those persons working directly on the linkage project at IMS and the CCRs.
 5. Written or electronic copies of Data received or created by IMS will be maintained in a secure location. IMS will maintain the security and confidentiality of the Data in accordance with industry best practices and applicable law. When no longer needed, and at the request of the Provider, the Data will be disposed of securely by IMS. Paper documents will be shredded, and electronic files will be rendered unreadable to not allow retrieval of any Data.
 6. Any breach of confidentiality by IMS or data security breach involving Provider Data will be reported to the North American Association of Central Cancer Registries and the Provider within 24 hours of detection.
 7. Uses of the Data do not constitute an endorsement of the opinion or conclusions of the Provider by any CCR or NAACCR, and none should be inferred. The Provider will cite the source of the CCR data in all publications (data linkage through North American Association of Central Cancer Registries Virtual Pooled Registry Cancer Linkage System (NAACCR VPR-CLS) which includes data from CDC’s National Program of Cancer Registries (NPCR) and the NCI’s Surveillance, Epidemiology and End Results (SEER) Registries, linked MM/DD/YYYY).

<Signature page follows>

Provider Institution

Provider Institution

Name and Title

Name and Title

Signature Date

Signature Date

Information Management Services, Inc._____

Ginger Carter, Vice President_____
Name and Title

Signature Date