

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

The Project titled \_\_\_\_\_ includes confidential study subject, identifying information (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 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 solely for the purposes of 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.
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, 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).

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Provider Institution

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Provider Institution

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Name and Title

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Name and Title

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Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Information Management Services, Inc.

\_\_\_\_\_  
Name and Title

\_\_\_\_\_  
Signature Date