

**Breast Cancer Surveillance Consortium Confidentiality Agreement**

Under 42 U.S.C. 299c-3(c) [also cited as Section 924 (c) of the Public Health Service Act], set out below, data that identify individuals or establishments collected as part of activities supported by the Agency for Healthcare Research and Quality (AHRQ) may be used only for the purposes for which they were supplied. Thus, under this statute, the intent and understanding of the supplier controls and limits what may be disclosed from identifiable data. Therefore, it is particularly important to secure and document agreement and consent from each supplier of data (or data subject) to a statement of the purposes for which the identifiable data are supplied that is broad enough to allow all of the anticipated and intended uses as well as other reasonable potential uses. Disclosures or releases of identifiable information about individuals are specifically restricted by the statute and require consents. To protect against being forced to make disclosures about identifiable establishments, an appropriately restrictive and exclusive statement of intended uses, including the specification of permissible groups or types of users, should be carefully prepared for data suppliers or data subjects so that their agreement to any such disclosures can be documented, or they can clearly indicate their understanding there will be none. Unauthorized disclosure of confidential identifying information protected under this provision is subject to penalty under 42 U.S.C. 299c-3(d) [Section 924(d) of the Public Health Service Act] (see text below).

(c) No information, if an establishment or person supplying the information or described in it is identifiable, obtained in the course of activities undertaken or supported under this subchapter may be used for any purpose other than the purpose for which it was supplied unless such establishment or person has consented (as determined under regulations of the Director) to its use for such other purpose. Such information may not be published or released in other form if the person who supplied the information or who is described in it is identifiable unless such person has consented (as determined under regulations of the Director) to its publication or release in other form.

(d) Any person who violates subsection (c) shall be subject to a civil monetary penalty of not more than \$10,000 for each such violation involved. Such penalty shall be imposed and collected in the same manner as civil money penalties under subsection (a) of section 1320a-7a of this title are imposed and collected.

**EACH INDIVIDUAL WITH ACCESS TO IDENTIFIABLE DATA ABOUT INDIVIDUALS OR ESTABLISHMENTS IS TO SIGN A COPY OF THE ATTACHED ACKNOWLEDGEMENT AND SEND THE DOCUMENTS WITH ORIGINAL SIGNATURES TO:**

Susan Meikle, M.D., M.S.P.H.  
AHRQ BCSC Collaboration Advisor  
Center for Outcomes and Evidence  
Agency for Healthcare Research and Quality  
540 Gaither Road  
Rockville, MD 20850

I acknowledge that I have received and reviewed a copy of 42 U.S.C. 299c-3(c) and (d) [Section 924 (c) and (d) of the Public Health Service Act], described and set forth above. I understand that establishment- and person-level data collected as part of the Breast Cancer Surveillance

Consortium are subject to the confidentiality protections of Section 924 (c) and (d) of the Public Health Service Act described above.

Typed/Printed Name

Signature

Date

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Breast Cancer Surveillance Consortium Site

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