

Appendix 2: Confidentiality Agreement for Access to CCR Data

Name of applicant: _____

Title: _____

Organizational affiliation: _____

Street address: _____

City/state/zip code: _____

Instructions

Access to California Cancer Registry (CCR) data (i.e., the right to examine CCR data) is strictly limited under California law. Persons seeking access to CCR data in the custody of the California Department of Public Health, Cancer Surveillance and Research Branch, the Public Health Institute, or a regional registry (hereinafter the “CCR Data Custodian”) must complete this application, sign and submit it to the custodian of the data. Attach additional pages as necessary. Approval will be mailed to Applicant at the address shown above.

1. Applicant requires access to CCR data to engage in the following demographic, epidemiological or other similar studies related to health:

2. The specific purpose for which Applicant will use CCR data and the data files to be accessed (e.g. type(s) of cancer, patient characteristics, diagnosis years, geographical areas) and other relevant information are:

3. Applicant's qualifications to engage in these activities are as follows:

4. In consideration for CCR Data Custodian's approval of this application, Applicant represents, warrants, and agrees as follows:
 - a. For purposes of this confidentiality agreement, "CCR data" means all information relating to cases of cancer collected at any time by the California Department of Public Health, a regional cancer registry designated by the Department or any other individual or institution under the authority of California Health and Safety Code Section 103885 and predecessor statutes, whether or not such information identifies an individual or could be used to identify an individual. CCR data also means all documents, files or other records, regardless of format or medium, containing CCR data (whether alone or in combination with other data).
 - b. California Health and Safety Code Section 103885 contains various provisions relating to use, access, disclosure, and publication of CCR data. These provisions may be different from the laws, regulations or policies applicable to other data used by Applicant. Applicant represents and warrants that: (a) Applicant has reviewed section 103885, the California Department of Public Health, Cancer Surveillance and Research Branch, "Policies and Procedures for Access to and Disclosure of Confidential Data from the California Cancer Registry" (www.ccrca.org) (hereinafter "CCR Data Access and Disclosure Policies"), and the terms and conditions of this confidentiality agreement; (b) Applicant has had a full opportunity to discuss any questions or concerns Applicant may have regarding the interpretation of section 103885, Applicant's duties and obligations under the statute and the terms and conditions of this confidentiality agreement with Custodian; (c) any such questions or concerns have been resolved to Applicant's satisfaction; and (d) on the basis of the foregoing review and discussions, Applicant is prepared to access and use CCR data in conformity with section 103885 and the terms and conditions of this confidentiality agreement.
 - c. Applicant agrees to comply with the requirements of California Health and Safety Code section 103885, any and all other federal and state laws or regulations relating to confidentiality, security, use, access, and disclosure of CCR data, and the CCR Data Access and Disclosure Policies.
 - d. Applicant agrees to access and use the requested CCR data in strict conformity with the specific purposes set forth in his or her application. Applicant agrees not to use the CCR data for any other purpose. Applicant agrees not to copy or reproduce the CCR data in whole or in part, in any manner or format, or permit others to do so.
 - e. Applicant may describe the results of Applicant's use of CCR data in professional journals, public reports, presentations, press releases and other publications, provided that a copy is provided to the institution from which Applicant receives access and that all publications contain the acknowledgment and disclaimer set forth in section VI.4. of the CCR Data Access and Disclosure Policies.

- f. If Applicant becomes aware that any person or institution not authorized to access CCR data has attempted to gain access or gained access to the CCR data, Applicant agrees to immediately notify CCR Data Custodian. If Applicant inadvertently gains access to CCR data for which he or she has not been approved, Applicant agrees not to make use of the data, not disclose the data to any other person or institution, to notify the CCR data custodian, and take immediate steps to prevent any recurrence.
- g. CCR Data Custodian reserves the right to withdraw Applicant's right to access and use CCR data at any time without cause. Upon receipt of notice thereof, Applicant agrees to immediately terminate its access to and use of CCR data.
- h. Applicant acknowledges that if he or she fails to comply with any of Applicant's obligations under this confidentiality agreement, CCR Data Custodian and the State of California will suffer immediate, irreparable harm for which monetary damages will not be adequate. Applicant agrees that, in addition to any other remedies provided at law or in equity, CCR Data Custodian and the State of California shall be entitled to injunctive relief to enforce the provisions of this agreement.
- i. Notwithstanding any other provision of this confidentiality agreement, CCR Data Custodian shall have no obligation to grant Applicant access to CCR data unless and until his or her application is approved.

By my signature I declare as follows:

I have read the foregoing agreement. By signing below I make the agreements and representations contained therein. I understand that these are material representations of fact upon which reliance was placed when this transaction was entered into.

Signature

Printed Name and Title

Dated

APPROVAL BY CCR DATA CUSTODIAN:

Signature

Dated

Printed Name and Title