

Acknowledgement of CRGC Policies and Procedures

The Cancer Registry of Greater California (CRGC) is a program of the Public Health Institute. CRGC is authorized by the California Department of Public Health (CDPH) to collect data from 48 of the total of 58 California counties for cancer surveillance and research. Data are released to researchers who meet all the requirements to protect patient confidentiality and to comply with [state law](#). Data available from the CRGC include case-listings for patient contact studies as well as de-identified data for data analyses.

Please review the following information and requirements prior to submitting your application to use CRGC data.

Data Availability: CRGC does not reserve cases for studies. We can provide the researcher with an estimate on how many eligible cases are currently available, but we cannot guarantee the cases will be available by the time your application is approved. Due to cancer reporting quality control procedures, cases are not available for research purposes until approximately two years after diagnosis. Cases may be available six to eight months after diagnosis for additional cost using early case ascertainment.

Scientific Merit: Each research project requesting disclosure of CRGC data must meet standards to have scientific merit. Projects funded under organizations (NIH, NSF, CDC, DOD, etc.) with scientific peer review are acceptable. Generally, documentation of funding represents documentation of scientific merit.

CPHS/IRB: All research projects that involve individually identifiable data obtained from a state agency, source, or resource must be approved by the California Committee for the Protection of Human Subjects and by a local Institutional Review Board (IRB). CRGC requires documentation of current CPHS and institutional IRB approval.

Project Approval: Applications for disclosure of CRGC data for research will be reviewed and approved by CRGC and the California Cancer Registry. Upon approval from both agencies, CRGC will send an agreement specifying details for the release of the data.

Project Assistance: CRGC provides cancer treatment, outcome, morbidity and mortality data analysis services at competitive rates, and rapid response delivery is available for time-sensitive studies with our direct access to the data. Epidemiological, research, design, and data cleaning and analysis services are available by our team of research scientists and epidemiologists should your project require any additional assistance in reaching your project goals.

Data Requests: General data requests for incidence and mortality rates do not require IRB approval. A CRGC researcher will work with you to outline the specific request and determine feasibility.

Patient Contact Studies: All patient contact studies must make first contact with patients in writing. Each mailing must include the [California Cancer Registry brochure](#) and a letter explaining your study. CRGC requires prior approval of letters before sending. Technical assistance is available, on an as-

needed basis and at no cost to the institution, in developing patient notification letters. CRGC must be informed immediately if a patient indicates they do not want to be a part of your study and any future studies. As a condition of data disclosure, any new information, including ID's of participants who agreed/disagreed to be in the study, changes to vital status, address changes, complaints from physicians, health professionals, or study subjects obtained during the study should be documented and reported to CRGC.

Data Security and Destruction of Data: As part of the application process, CRGC requests information on how your organization will maintain confidentiality of CRGC data (Appendix 5). All institutions who have data disclosed to them must fill out a confidentiality agreement for disclosure (Appendix 3), and the form must be on file at CRGC. Any staff that will have access to the disclosed data is required to sign a confidentiality agreement for access (Appendix 2).

Identifying data cannot be transmitted via email. A CRGC researcher will inform you on the appropriate way to transmit and discuss confidential data. CRGC requires all data to be destroyed and removed from computers, servers, drives, and any other electronic devices at the conclusion of the study.

Publications and Reports: All publications and reports must acknowledge the Cancer Registry of Greater California (Public Health Institute). Citations of any manuscripts and/or reports that result from CRGC data should be provided. All publications need to include the standard CCR acknowledgement of funding sources.

Suggested acknowledgement language:

The collection of cancer incidence data used in this study was supported by the California Department of Public Health pursuant to California Health and Safety Code Section 103885; Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries, under cooperative agreement 5NU58DP006344; the National Cancer Institute's Surveillance, Epidemiology and End Results Program under contract HHSN261201800032I awarded to the University of California, San Francisco, contract HHSN261201800015I awarded to the University of Southern California, and contract HHSN261201800009I awarded to the Public Health Institute, Cancer Registry of Greater California. The ideas and opinions expressed herein are those of the author(s) and do not necessarily reflect the opinions of the State of California, Department of Public Health, the National Cancer Institute, and the Centers for Disease Control and Prevention or their Contractors and Subcontractors.

I have read and understood the CRGC Policies and Procedures.

Signature

Dated

Printed Name and Title