Acknowledgement of CRGC Policies and Procedures

The Cancer Registry of Greater California (CRGC), a program of the Public Health Institute, is a nonprofit corporation that collects and discloses data from 7 of the 10 California regional registries to researchers who meet all the requirements to protect patient confidentiality and to comply with state law. CRGC is authorized by the California Department of Public Health (CDPH) to operate with the California Cancer Registry (CCR), covering Regions 2, 3, 4, 5, 6, 7, and 10. Data available from the CRGC includes case-listings for patient contact studies, de-identified data for data analyses, and data linkages. CRGC provides data in two ways: data access and data disclosure. **Data access** means the right to examine the data, but not the right to keep or duplicate the data. **Data disclosure** means the right to examine the data, and to retain a copy for institutional use.

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 you with an estimate on how many 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, CRGC may not be able to provide you with current diagnoses. It can take one to two years before a single year's diagnoses are considered complete in our database and available for research purposes. For early case ascertainment studies, cases may be available six weeks after the date of diagnosis.

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. All other project proposals will be reviewed by CRGC to determine feasibility and scientific merit.

CPHS/IRB: All research projects must be approved by the California Committee for the Protection of Human Subjects and by a local Institutional Review Board (IRB). CRGC must be updated with the new IRB approval if any changes were made to the study or if IRB is renewed.

Project Approval: Projects and project applications will be reviewed and approved by CRGC and the California Cancer Registry. Upon approval from both agencies, CRGC will send a contractual 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. Any new information, including contact and vital status, obtained during the study is required to be documented and reported to CRGC.

Progress Reports: Progress reports are required and are dependent on the length of the study. The number of progress reports will be agreed upon at the time of study approval. For patient contact studies, the progress reports must include timeline updates, 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. For case-listing only studies, CRGC requires notification only of issues and timeline of data use. All manuscripts and reports published with CRGC data are required to acknowledge 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). Staff changes must be reported to CRGC with appropriate forms filled out.

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

Publications and Reports: All publications and reports must acknowledge the Cancer Registry of Greater California (Public Health Institute). CRGC needs to be informed when manuscripts and/or reports are published and a citation will be provided if necessary. All publications need to include the standard CCR acknowledgement of funding sources.

I have read and understood the CRGC Policies and Procedures.

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Signature **Dated**

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Printed Name and Title

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