

## **Researcher Check List for Data Disclosure**

The following are required documents to obtain CRGC data for research.

- O Acknowledgment of CRGC's Policies and Procedures
- O Application for Disclosure of Confidential Registry Data for Research
- O Appendix 3: Confidentiality Agreement for Disclosure of CCR Data\*
- O Copy of institutional IRB approval letter
- O Copy of the California State Committee for the Protection of Human Subjects (CPHS) IRB approval letter\*\*
- O Committee for the Protection of Human Subjects (CPHS)-approved study protocol\*\*
- O List of CPHS-approved requested data items including brief justification for each data item.\*\*
- O If requesting vital statistic variables, a copy of the Vital Statistics Advisory Committee (VSAC) approval letter\*\*\*
- O Notice of grant reward, if applicable

Please complete and send these documents in one email to <u>crgc-data@crgc-cancer.org</u>. If you have questions regarding initiating process of requesting a case listing or policies and procedures, please contact CRGC research staff at above email.

\*Submit appendix 3 signed by your institution's officials along with your CRGC application to us at <u>crgc-data@crgc-cancer.org</u>.

\*\*Before submitting your application to CRGC, the California State Committee for the Protection of Human Subjects (CPHS) must review and provide approval for your study. The portal for submitting a CPHS application can be found <u>here</u>, and information about the committee, such as meeting dates and submission deadlines, can be found on their <u>website</u>. Please note that the CPHS application requires a departmental letter of support (LOS) from CCR/CDPH. **To obtain the LOS**, please send a PDF draft of your CPHS protocol application and your list of requested data items with a justification for the use of each item to us at <u>crgc-data@crgc-cancer.org</u>. We will review and inform you of any changes needed prior to forwarding these documents to request the LOS on your behalf. The variable list with justification must be approved by the CCR before the LOS request is provided. It generally takes 4 weeks for the CCR to review and provide the LOS.

\*\*\*California Cancer Registry data are linked to vital statistics data and contain several death related variables. Authorization to access and use these variables for research falls under the Center for Health Statistics and Informatics (CHSI), and approval to use these variables must be granted by their Vistal Statistics Advisory Committee (VSAC). If your research requires any of these variables (see appendix 5 of the data dictionary to identify variables) to assess survival outcomes, you must submit a joint application with CCR to VSAC and obtain approval. You can find more information, instructions, and contact information on the Center for Health Statistics and Informatics' website <u>here</u> under the "California Cancer Registry (CCR)" section.