**Oregon State Cancer Registry – Cancer Data Request Application**

The Oregon State Cancer Registry (OSCaR) supports scientific research projects aimed at improving the quality of cancer treatment and studies designed to benefit the public's health. Research proposals requesting the use of confidential cancer registry data or cancer data requests requiring OSCaR staff time must be reviewed and approved by the Oregon Public Health Division. More information about the OSCaR program can be found on the web at: https://www.oregon.gov/oha/ph/DiseasesConditions/ChronicDisease/Cancer/oscar/Pages/index.aspx

**OVERVIEW:**

Before any confidential data can be released to researchers, the following steps must be completed.

1. Researcher completes and submits this Request Form along with all required documents (research protocol, external IRB approval, peer review approval, completed Data Items Form, and evidence of project funding).
2. OSCaR reviews the documents submitted and follows up with the researcher as needed, including gathering any additional information and necessary documentation.
3. OSCaR schedules a review of the research study by the OSCaR Advisory Committee.
4. The OSCaR Advisory Committee reviews and approves the research study. (Researcher makes any necessary changes to the study protocol as required by the Advisory Committee).
5. For requests including release of confidential data as part of a research study, OSCaR refers the researcher to the Oregon State Public Health Division Institutional Review Board (PH IRB).
    a. Researcher completes the PH IRB Initial Review Questionnaire (IRQ) found at this web address https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/INSTITUTIONALREVIEWBOARD/Pages/forms.aspx and submits all required documentation.
    b. PH IRB reviews and approves the research study.
    c. Researcher makes any necessary changes to the study protocol as required by the PH IRB.
6. After the PHD IRB approves the study, a Data Use Agreement is signed and executed by the researcher and OSCaR.
7. If at any time OSCaR or the PH IRB decline to approve Researcher's request for release of OSCaR data, Researcher will be promptly notified and the review process will be considered closed.
8. If the cancer data request includes cause or fact of death as requested data elements, the researcher must submit a separate application to the Oregon Center for Health Statistics for authorization for OSCaR to release requested death data.
9. If patients are to be contacted as part of the research study, the researcher will be responsible for recruiting patients. This includes contacting all patients' physicians to make sure it is appropriate to contact patients, and then contacting the patients to determine if the patients wish to learn more about the study. If the patients' physician sees no issues with contacting the patient and the patient indicates interest in learning about the study, the researcher may then contact the patient directly to discuss the details of the study, and the patient can then determine if they wish to participate in the study.

10. Researcher will provide OSCaR with a list of people contacted who do not want to be contacted again regarding any OSCaR research studies.

Please fully complete all sections in the application below and attach any necessary supporting documents with your submission. Completed applications should be sent to:

oscar.ohd@state.or.us ; or
Oregon State Cancer Registry (OSCaR)
800 NE Oregon St, Ste. 730
Portland, OR 97232

Please direct any questions about OSCaR or this application to: oscar.ohd@state.or.us or 971-673-1040

Contact information:

Applicant Name: _____ Date: _____

Title: _____

Principal Investigator (if different than applicant)_____

Organization: _____

Street: _____

City: _____State: _____ Zip: _____

Phone: _____

Email: _____

List other institutions or agencies that will be collaborating on this project:

**PROJECT SUMMARY**:

1. Project title: _____
2. Briefly state the purpose of the project and how the proposed research will be used to determine the sources of cancer among the residents of Oregon, reduce the burden of cancer in Oregon and/or improve public health interventions for cancer:

3. What are the key research questions or hypotheses of the project?

4. If the project described above involves patient recruitment for participation in the study, please list applicable patient inclusion criteria (age, cancer type, years of dx, etc.):

5. Identify the data elements required for the study by filling out the attached "Requested Data Items" form. Please read the description of registry cancer data and note the limitations on data release stated in the Instructions and Notes sections of the form.

6. What is the timeline on your project? (Include anticipated start and end dates)

7. Describe any planned reports and/or presentations based on the analysis of the requested data:

8. All external requests for confidential data must be approved by the appropriate Committee for Protection for Human Research Subjects Institutional Review Board (IRB) established in accordance with 45 CFR 46. Please indicate whether this proposal already has IRB approval or if IRB is pending:

□ Yes - Approval date: _____ □ No – Anticipated review date: _____

If your proposal has been approved by an IRB, please attach a copy of the approval.

9. All protocols including a request for confidential data should also have peer review for scientific merit. If peer review has already been completed for your proposal, please attach a copy of the approval from the peer review committee. If your proposal has **not** been reviewed for scientific merit by a nationally recognized peer review group, OSCaR or the Oregon Public Health Division (PHD) may convene a peer review committee to review the proposal. Review for scientific merit must be completed prior to PHD IRB review.

□ Yes - Review date: _____ □ No – Anticipated review date: _____

If your proposal has been peer reviewed, please attach documentation of the review.

10. It is essential that the data provided by OSCaR for the study be protected against inadvertent disclosure and loss of confidentiality. Please address the following issues below:

a) How you will provide secure conditions to use and store the data:

b) Assurances that the data will be used only for the purposes of the study:

c) Assurances that confidential data will be destroyed at the conclusion of the research:

11. Prior to the release of confidential data, assurances must be provided that the proposed study has adequate funding.

□ Yes – Documentation available

□ No – Anticipated date funding documentation will be available: _____

Please attach documentation confirming that the proposed study has adequate funding. **Documents to be Attached with this Application**:

- Research protocol
- External IRB approval
- Peer review approval (if available)
- Requested Data Items Form (filled-out)
- Evidence of project funding

**Researcher Assurances:**

- Researcher will comply with all appropriate ethical standards in the conduct of the research for which OSCaR data is used;
- Any proposed changes to the study protocol (including any change in venue, PI or other investigators, change in study design, and any change requiring IRB approval), must be reviewed and approved by OSCaR prior to implementation;
- Any unanticipated problems, protocol violations, and breaches of confidentiality must be reported to OSCaR immediately;
- Copies of any articles or formal presentations generated using OSCaR data must be submitted to OSCaR with sufficient time for review prior to publication; and
- Any confidential data received from OSCaR shall be destroyed upon conclusion of the study and OSCaR will be notified once data destruction is completed.

Non-compliance with this agreement by Researcher (and any data use agreement related to the release of OSCaR data to Researcher) shall result in termination of the study approval and Researcher will be required to destroy all data obtained from OSCaR for the purposes of this study.

**Signature:**

By signing this application, I verify that the information contained within this Data Request Application is complete and accurate, and constitutes agreement with the following conditions for receipt of OSCaR data:

Name: _____ Date: _____

Signature: _____