Attracting Research Money in a Younger, Smaller Registry: The Oregon Experience

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Oregon State Cancer Registry

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  - Chief, Ca Tumor Registry
  - PI, Region 6 Registry
  - President of AACCPR
- 1993-1997 CDC Assignee to OHD
- Assoc. Director of OHSU Cancer Institute
Dr. Austin and OSCaR

- Drafted and supported legislation to create the Registry
- Served as Medical Director
- Member of Advisory Committee
- Promoter and user of Registry data
Oregon State Cancer Registry

- The Registry: Background and characteristics
- The Data: Providing a high quality product
- The Marketing: Getting the word out and building relationships
The Registry

- Established by the 1995 Oregon legislature
- Purpose:
  “To provide information to design, target, monitor, facilitate, and evaluate efforts to determine causes…of cancer among Oregon residents, and to reduce the burden of cancer in Oregon.”
The Registry

- Reference Date: January 1, 1996
- Oregon Population: 3.5 Million – Rank 27th
- 18,000 – 19,000 Resident cases per year
Patient Notification

🌟 Legal requirement
  - Oregon Administrative Rule 333-010-0035
🌟 Notify patient of inclusion in central registry
🌟 Patient letter
🌟 Research Reply Form
Process/Procedures

- Monthly activity
  - Performed after linking with state death records
  - Selection
    - exclude minors, deceased, federal hospital
  - Letter generation
  - Returned letters investigated for good address

- Patient Response
  - Reply forms (mail, fax, email)
  - Telephone calls
Patient Notification Letter

- Letter Content
  - Purpose of a state-wide cancer registry
  - Personal identifiers and cancer characteristics have been reported
  - Confidentiality protections
  - Indicate preference for research contact
    - Research Preference Reply Form
  - Additional enclosures
    - OSCaR Brochure
    - ACS Brochure
Research Reply Form

- Direct
  - Contact patient directly
- No Contact
  - No participation
- Physician
  - Contact patient after first consulting with physician
Responses

- Direct: 20%
- No Contact: 5%
- Physician: 75%
- Phys w/Resp: 5%
Patient Notification and Research

- Monthly update of death information
- Opportunity to correct addresses
- Responses include corrections
- Pre-screens patients who don’t want to be contacted
- Identifies patients willing to participate
Data Quality

- Rigorous QA procedures
- Audits of reporting facilities
- NAACCR Certification for each year of data
- Two NPCR audits
- The more you use it, the cleaner it gets
Getting the word out

- Data presentations
- Annual report
- Website
Getting the word out

- Data presentations
  - Physician groups
  - OHSU Cancer Institute
  - Hospital registrars
  - Non-profit organizations
  - Classes in Public Health and Medicine
  - Comprehensive Cancer Control Program
In August 1995, the Oregon Legislature unanimously passed legislation making cancer a reportable disease and established the Oregon State Cancer Registry (OSCaR) which began collecting information on all cancers diagnosed in Oregon as of January 1, 1996.

Confidential data from each cancer case are collected and entered into OSCaR. Because of OSCaR, we are now able to provide detailed information (specific to Oregon) in our annual report: [Cancer in Oregon 2000](#).

**NEW!** Colorectal Cancer Screening and Prevention (PDF)

Colorectal Cancer (CRC) is the third leading cause of cancer-related death in Oregon, behind lung and breast cancer. Every day, five Oregonians are diagnosed with invasive CRC, and it ranks fourth in incidence among cancers affecting Oregonians.

Lung Cancer in Oregon (PDF)

In this PDF, Oregonians can learn about smoking-related health problems.
Cancer Data

The Oregon State Cancer Registry (OSCaR) started collecting information on cases diagnosed in 1996 and later.

- **Cancer Statistics**
  These tables show cancer incidence data, mortality data, and county cancer data for selected cancers for Oregonians.

- **Glossary**

- **2000 Annual Report**
  The first cases were collected for diagnosis year 1996, and, due to the reporting lag time, our current report is for 2000 data.

- **Understanding OSCaR Data**
Publications

Annual Reports

To date, OSCaR has published five annual reports concerning cancer in Oregon. The 2000 report is cumulative and contains the most current data. If you are interested in obtaining an archived report for previous years, please contact us.
Research Project Abstracts
Using OSCaR’s Cancer Incidence Data

The cancer registry’s incidence data are used in many areas of research and by many groups (see listing). Before the release of any data, however, research proposals which request the use of confidential cancer registry data must be reviewed by the Oregon Health Services.

- Research Review Procedure: OSCaR data research criteria.
- Research Proposal Review Form (PDF)

Using data for cancer prevention and control is a fundamental purpose of the Oregon State Cancer Registry. Early efforts were focused on the planning and implementation phases to obtain complete and...
Abstracts of research activities using OSCaR’s data are listed below.

State/Local Research Uses

- Clackamas County Community Health Information Mapping Engine
- Cancer in a sample of factory workers exposed to TCE
- Pilot study for evaluating a clinical breast exam training program
- Surgical outcomes of a breast cancer screening program for low income women

National Research Uses

- Endometrial cancer following endometrial ablation
- Extended follow-up of the Rocketdyne worker cohort
- National Program of Cancer Registries Indian Health Services record linkage
- Quality of life study of cancer survivors

State/Local Research Uses

- Clackamas County Community Health Information Mapping Engine (CHiME)
  Alan Melnick, MD, MPH Clackamas County Health
OSCaR Research Review Procedure

Before the release of any data, all research proposals requesting the use of confidential cancer registry data must be reviewed by the Oregon Health Services for compliance with the following criteria:

Download Research Proposal Review Form  (PDF) (14 K)

1. The proposed research will be used to determine the sources of cancer among the residents of Oregon or to reduce the burden of cancer in Oregon;

2. the data requested are necessary for the efficient conduct of the study;

3. adequate protections are in place to provide secure conditions to use and store the data;
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2. the data requested are necessary for the efficient conduct of the study;
3. adequate protections are in place to provide secure conditions to use and store the data;
4. assurances are given that the data will only be used for the purposes of the study... (see Assurances Form);
5. the researcher has adequate resources to carry out the proposed research;
6. the proposal has been reviewed and approved by the Committee for the Protection of Human Subjects or is exempt from such review;
7. any additional safeguards needed due to unique or special characteristics of the proposed research have been required of the researcher; and

8. the research methodology has been reviewed for scientific excellence by a nationally recognized peer group or ...the OSCaR Advisory Committee has performed a peer review of the research.
Additionally, all relevant contracts and/or fees have been paid prior to data release.
Building Relationships

- Hospital Registrars
- Non-profit organizations
- Comprehensive Cancer Control Program
- Cancer Registry Advisory Committee
Advisory Committee

- Make-up of committee
  - State Registrars Association
  - Oregon Medical Association
  - ACoS-CoC
  - School of Public Health - PSU
  - Medical School - OHSU
  - OHSU Cancer Institute
Advisory Committee

The primary function of the Advisory Committee is to review research proposals, make recommendations to researchers, and approve Registry participation in research projects.
Recommendations

- Maintain high quality data
- Identify and inform potential users
- Provide assistance in designing research proposals
Conclusion

Thanks to

- Dr. Don Austin
- Recinda Sherman-Seitz
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www.healthoregon.org/oscar