

# SURVEILLANCE RESEARCH PROGRAM

Winter 2012 e-Newsletter

<http://surveillance.cancer.gov> • <http://seer.cancer.gov>

The Surveillance Research Program (SRP) directs the collection and analysis of data to answer key questions about cancer incidence, morbidity, mortality, and cancer-related health status in diverse regions and populations in the United States.

## Highlights

### Carol Kosary Appointed SEER Program Manager

In the summer of 2011, Carol Kosary assumed the new position of Program Manager for the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) Program. In this position, Dr. Kosary has been developing a new structure for managing SEER. "I think the new structure is exciting because it's going to engage so many people within SRP," said Dr. Kosary.



Carol Kosary

The new structure is being implemented gradually, with the final part likely to be put into operation by the end of March 2012. For more information about the new structure, see the next article.

In her new position, in addition to developing a new SEER management structure, Dr. Kosary represents SEER on the SRP Leadership Team and manages contracts between SEER and the 20 SEER-funded cancer registries. As a member of the Leadership Team, she participates in discussions on budgets, administrative issues, and other topics; as a manager of SEER contracts, she reviews the registries' invoices and manages the renewal of their contracts every 7 years.

Dr. Kosary brings extensive education and experience to her position. She earned a bachelor's degree in physiological psychology, a master's degree in statistics, and in 2011, a doctorate in organizational science—the study of how people interact within organizations. A self-described generalist, Dr. Kosary has worked in areas such as designing computer-assisted telephone interviews, survey methods, information technology, descriptive epidemiology, and cancer registry operations. During her 18-year involvement with SEER, she has interacted with cancer registries and developed relationships with them.

Dr. Kosary is enthusiastic about her new position, especially her role in developing and implementing the new SEER management structure. She commented, "It is very exciting to be given the opportunity to build a new structure like this."

## In This Issue:

### Highlights

- ▶ **Carol Kosary Appointed SEER Program Manager**
- ▶ **SEER Management Structure Reorganization**
- ▶ **SRP and EGRP Collaborations**

### Events and Training

- ▶ **SRP Staff Participate in the 2011 Joint Statistical Meetings**
- ▶ **SEER PI Meeting 2011**
- ▶ **2011 International Association of Cancer Registries Meeting**
- ▶ **African Organization for Research and Training in Cancer Meeting**

### Announcements

- ▶ **SEER Registry Operations & Quality Improvement Team Seeks Cancer Research Training Award Fellow**

## **SEER Management Structure Reorganization**

A management reorganization is under way for NCI's SEER Program. SEER collects information about cancer patients (including their demographics and specific cancer type) from 20 cancer registries across the United States and uses the information to compute cancer-related statistics. Although the previous management structure involved relatively few participants, the new structure will incorporate staff members from across SRP and other organizations, including many people who previously were not involved with SEER.

The new structure likely will lead to "more collaboration, more staff empowerment, and more people bringing ideas to the table," said Dr. Carol Kosary, newly appointed SEER Program Manager and principal developer and implementer of the new SEER management structure.

Under the new structure, SEER will consist of five core teams—the registry, research, information technology (IT), program management, and operations teams—each to be led by a different SRP staff member and to include three to seven members. The registry team—"the heart and soul of the entire structure," noted Dr. Kosary—will be led by Antoinette Percy-Laurry and consist of members who serve as liaisons with SEER cancer registries throughout the United States; the research team, led by Denise Lewis, will focus on possible future collaborations and statistical research studies; the IT team, led by Peggy Adamo, will focus on identifying IT resources that will be needed in the future; the program management team, led by Dr. Kosary, will focus on managing finances and contracts with SEER registries; and the operations team, led by Lois Dickie, will focus on assessing and improving the quality of SEER data. Teams will meet regularly with Dr. Kosary and will have considerable autonomy.

Additional input regarding SEER activities will come from SEER's strategic partners and stakeholders, and from a SEER advisory team comprised of staff from NCI's Division of Cancer Control and Population Sciences (DCCPS), which includes SRP and the SEER Program.

Dr. Kosary began developing the new SEER management structure in late summer of 2011, with assistance from DCCPS' Stacey Vandor, Kathy Cronin, Zaria Tatalovich, Peggy Adamo, and Rachel Benkeser. "These people have been a very big part of helping me build this," said Dr. Kosary. She emphasized that Ms. Benkeser, a Presidential Management Fellow, has played a major role in the new structure's development by generating ideas and serving as a sounding board.

Parts of the new SEER management structure still are being developed; other parts already have been implemented. For example, the SEER registry team met for the first time in late October and was introduced to the SEER research Principal Investigators (PIs) at the SEER PI meeting in November. The other teams will be implemented one-by-one, with the last—the advisory team—likely to be implemented by the end of March 2012. "I'm looking forward to seeing how things are going a year from now and what these teams have accomplished," said Dr. Kosary.

## **SRP and EGRP Collaborations**

On January 5, 2012, members of DCCPS' SRP and Epidemiology and Genomics Research Program (EGRP) met for a half-day retreat to discuss potential collaborations between the two programs. After participating in a brief icebreaker, attendees split into seven topic groups: (1) environmental epidemiology, (2) using SEER data and linkages, (3) increasing awareness about surveillance and epidemiology, (4) software and tools, (5) genetic analytic methods and genetic epidemiology, (6) knowledge management and integration, and (7) best practices in management. Each group discussed potential SRP-EGRP collaborations related to its topic area and identified specific action items that were presented in a plenary session. Action items included establishing a collaborative forum on environmental epidemiology, teaching EGRP members about SEER, teaching SRP members about grants funded by EGRP, planning a conference session on risk-prediction models, discussing statistical and computational challenges in the use of next-generation sequencing data, building a DCCPS-wide collaboration on knowledge integration, and identifying opportunities for training in budgets and grants.

In preparation for the retreat, Muin J. Khoury, EGRP's Acting Associate Director, presented an overview of EGRP research activities to SRP staff on December 7, 2011. Kathy Cronin and Rocky Feuer, chiefs of SRP's Data Analysis and Interpretation Branch and Statistical Methodology and Applications Branch, respectively, presented an overview of SRP's research activities to EGRP staff on December 14, 2011. Although SRP and EGRP currently occupy offices in separate buildings, starting in early- to mid-2013 they will occupy the same floor of the new NCI Shady Grove site, which likely will facilitate the development of future SRP-EGRP collaborations.

## Events and Training

### SRP Staff Participate in the 2011 Joint Statistical Meetings

The Joint Statistical Meetings (JSM), held July 30–August 3, 2011, in Miami Beach, FL, brought together statisticians from many different fields. As the largest annual statistics meeting in the world, it was attended by members of six international professional societies, including the American Statistical Association (the meeting organizer), and featured an exhibit hall, scientific talks and posters, and professional meetings. SRP staff members participated in the JSM in various ways, including organizing and staffing a National Institutes of Health (NIH) booth, answering questions about grants at an invited session and a program officer meeting, serving on the meeting's program committee, and presenting statistical research findings.

The NIH booth, one of SRP's most visible activities at the JSM, was organized by Michelle Dunn and staffed by SRP members Angela Mariotto, Annie Noone, Hyunsoon Cho, and Dr. Dunn, as well as NIH employees from the National Institute of Allergy and Infectious Diseases, National Institute of General Medical Sciences, and National Center for Complementary and Alternative Medicine. At the booth, staff members disseminated information about Institutes' missions, NIH grants, and available statistics jobs. They also distributed an NIH brochure containing basic information aimed at statisticians.

SRP staff also disseminated grant information at other JSM venues. For example, Dr. Dunn, along with Sastry Pantula of the National Science Foundation (NSF, a major funder of nonhealth-related sciences), spoke about NIH and NSF priorities and answered questions at an invited session. In addition, Drs. Dunn and Mariotto participated in JSM's first program officer meeting, during which NIH and NSF program officers involved in administering grants met with other JSM attendees to answer questions and give advice about grants. One-on-one conversations focused on the specifics of individual grant applications.

SRP's Benmei Liu was asked to serve as poster section chair by JSM program chair David Judkins. As chair, Dr. Liu attended committee meetings, encouraged and invited statisticians to send proposals for posters, and selected posters to be included in the invited sessions. She allocated more than 360 submitted posters to five sessions. "The invited and contributed poster sessions went successfully," wrote Dr. Liu. "I enjoyed being a chair for the poster section and would like to do it again if there is a chance in the near future."

Also at JSM, SRP's Mandi Yu presented her recent work on assessing statistical disclosure risk. This research was performed in collaboration with SRP's Kathy Cronin and Westat's Dave Stinchcomb to raise awareness of cancer patient privacy issues associated with population-based cancer registry data. Dr. Yu also served as the chair for a contributed paper session.

The next JSM will be held July 28–August 2, 2012, in San Diego, CA.

### SEER PI Meeting 2011

The SEER PI's annual meeting was held November 15–16, 2011. At the meeting, held on the main NIH campus in Bethesda, MD, each SEER registry gave a presentation on its challenges and successes during the previous year. Common challenges included staffing and funding shortages, incomplete data on the treatment of cancer patients, and difficulty matching patients' health care visits over time. Successes included establishing new collaborations, transitioning toward "going paperless," and implementing E-Path software for remote collection of pathology data. SEER PIs and registry staff appreciated the new meeting format, which provided an opportunity to discuss issues and exchange ideas.

In addition to discussing challenges and successes, meeting attendees were introduced to the new SEER registry team, whose members serve as liaisons between NCI SRP staff and the SEER registries. The team consists of SRP staff members Antoinette Percy-Laurry, liaison to the Los Angeles, Greater Bay, and Greater California registries; Sean Altekruise, liaison to the New Jersey and Hawaii registries; Denise Lewis, liaison to the Detroit and Utah registries; Jennifer Ruhl, liaison to the Connecticut, Georgia, and Iowa registries; Nadia Howlader, liaison to the Seattle and Alaska Native registries; Lois Dickie, liaison to the New Mexico, Arizona Indians, and Cherokee Nation registries; and Missy Jamison, liaison to the Louisiana and Kentucky registries.

## **2011 International Association of Cancer Registries Meeting**

The International Association of Cancer Registries (IACR) held its annual meeting October 11–13, 2011, in Balaclava, Mauritius, an island approximately 700 miles east of Madagascar. The meeting featured opening remarks by Brenda Edwards, president of IACR, and by The Hon. N. Ramgoolam, the Prime Minister of Mauritius. In addition, the Mauritius Minister of Health and Quality of Life opened the poster exhibits and hosted a cultural evening; and eight internationally known researchers gave keynote speeches, engaged in discussions with participants, and joined other experts in an extended press conference.

Discussion topics included the Global Initiative for Cancer Registries (GICR), an effort to develop regional cancer registry hubs in low- and middle-income countries throughout the world (<http://gicr.iarc.fr>). This initiative, convened by the International Agency for Research on Cancer (IARC) in partnership with public and civil societies/organizations, aims to increase the capacity to produce reliable, high-quality information on the burden of cancer to enable development and implementation of effective cancer control policies and programs. The regional hubs developed under this initiative will work to form additional cancer registries in their regions. The first hub was established in Mumbai, India, in 2011. Within the next 5 years, the GICR hopes to establish five to seven additional hubs in other countries/areas.

“A lot of my conversations at the IACR meeting were about development of registries in low- and middle-income countries because there’s a need to build our global capacity for measuring the growing cancer burden in these areas,” said Dr. Edwards.

Dr. Edwards chaired the executive board discussions on opportunities for strengthening IACR’s role in registry-based cancer surveillance worldwide. She had a major role in planning the meeting, including developing the scientific program, identifying speakers, and enlisting Terri Harshman’s editing expertise in preparing the book of abstracts. Lynn Ries, a senior consultant to the SEER Program and IACR treasurer, also attended the meeting in Mauritius.

The location of the IACR meeting rotates among the continents and serves as the site for a regional meeting held directly after the IACR meeting. As the 2011 meeting was held off the coast of Africa, it was followed by the Regional Network Meeting of the African Association of Cancer Registries, which focused on cancer registries in Africa. Dr. Edwards and Ms. Ries attended the regional meeting in addition to the international one.

The next annual IACR meeting will be held September 17–19, 2012, in Cork, Ireland.

## **African Organization for Research and Training in Cancer Meeting**

Brenda Edwards represented DCCPS at the biennial conference of the African Organization for Research and Training in Cancer (AORTIC) meeting, held November 29–December 2, 2011, in Cairo, Egypt. Themed “Entering the 21st Century for Cancer Control in Africa,” the meeting focused on basic and clinical research and on managing cancers relevant to Africa.

Highlights of the meeting included:

- A multiday preconference workshop (in French) on CanReg-5, a web-based software program that is used to manage cancer registry data. The software was developed by the IACR and is funded in part by NCI.
- A presentation announcing that South Africa recently passed legislation requiring that cancer cases be reported to cancer registries.
- A 1-day session on palliative care and psycho-oncology for cancer patients, conducted by international experts from the United States and Africa. Session participants learned about cultural and clinical barriers to relieving suffering. For example, many doctors in Africa do not believe in treating pain.
- Funmi Olopade, AORTIC Council Member and Chair of the National Cancer Advisory Board Global Health Subcommittee, organized a plenary session on breast cancer that was delivered through web-based technology and included participation by experts on the U.S. east and west coasts, in addition to those in Egypt.

# Announcements

## SEER Registry Operations & Quality Improvement Team Seeks Cancer Research Training Award Fellow

*Join the National Cancer Institute (NCI) Surveillance Research Program (SRP) and become part of the world-renowned Surveillance, Epidemiology, and End Results (SEER) Program Data Quality Team!*

### **Position Description:**

NCI seeks applicants for a Cancer Research Training Award (CRTA) position in Registry Operations and Data Quality Improvement for the Surveillance Systems Branch (SSB), Surveillance Research Program (SRP), Division of Cancer Control and Population Sciences (DCCPS).

The successful candidate will participate in the planning and implementation of a quality improvement program for cancer registries that participate in the Surveillance, Epidemiology, and End Results (SEER) Program, a program mandated by the National Cancer Act of 1971 and administered by SRP. Several SEER registries are responsible for cancer surveillance for specific states as part of those states' health departments. Others cover geographically defined metropolitan areas and form a part of their state's cancer surveillance system. The quality improvement team obtains quantitative measures of data quality and registry operations that pertain to the accuracy of data being submitted to NCI, as well as that used by the states locally for research and cancer control purposes in support of their public health programs.

As a member of the quality improvement team, the successful candidate will assist senior SEER quality improvement staff with a variety of projects, including:

- Entering and editing database information;
- Analyzing and presenting quality control study findings to state health departments, registry personnel, and NCI staff;
- Reviewing study findings to identify specific problems with data quality;
- Conducting Internet and literature searches;
- Assisting in writing journal articles; editing publications and instructional manuals; and
- Developing, implementing, and conducting training programs to improve the quality of data collection and procedures.

### **Required Qualifications:**

- Bachelor's degree or equivalent.
- A strong interest in population-based research and cancer control.
- Proficiency in MS Office suite.
- Knowledge of medical terminology.
- Knowledge of anatomy and physiology.
- Skills in literature searching and Internet searching.
- Excellent organizational skills.
- Attention to detail and data management skills.
- Ability to work independently and on teams.

### **Desirable Qualifications:**

- Knowledge of cancer registry principles and practices.
- Basic statistical skills.
- Knowledge of database concepts.

### **Application Process:**

- One-page cover letter explaining your interest in registry operations, cancer control, and public health, as well as how you see this position furthering your career goals. Please indicate your earliest available start date.
- CV or resume.
- Contact information for two professional references.

**Stipend and Benefits:**

The CRTA position is a 1-year award with SRP, with the option to renew for an additional year. Salary is commensurate with experience and education. The stipend starts at approximately \$30,000 for a trainee with a relevant bachelor's degree and could vary depending on years of relevant post-bachelor's degree experience. Health benefits and training opportunities are provided.

**Start Date and Location:**

The start date is to be determined. Position is located in Rockville, MD.

**Application Deadline:**

Applications will be accepted until the position is filled.

**Inquiries:****Peggy Adamo, RHIT, CTR**

Surveillance Research Program

Division of Cancer Control and Population Sciences

National Cancer Institute

Email: adamom@mail.nih.gov

**To Apply:**

Send applications electronically as PDF attachment to Rachel Benkeser (benkeserrm@mail.nih.gov).

**DHHS and NIH are Equal Opportunity Employers**

Please visit our Web pages: <http://seer.cancer.gov/> and <http://surveillance.cancer.gov/>