Streamlining Research Collaboration with State Cancer Registries

NAACCR 2010 Conference
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Deborah Hurley, MSPH
South Carolina Central Cancer Registry
SC Department of Health & Environmental Control
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• being organized
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Overview: Streamlining Data Requests

Why is it important to streamline?
• promote data use & research
• promote collegial working relationships
• promote collaboration & build partnerships

What do we hope to accomplish?
• educate & inform
• make a difference in cancer outcomes
Streamlining Data Requests

What is your role at the registry?

• explain the process
• be involved: (ideally) from start to finish
• provide cancer data expertise
• promote best practices for working together

Challenges

• timeliness
• confidentiality
• balancing data utilization & data protection
### Part 1: Promoting Data Use

**Who has data?**
- cancer registries
- government agencies
- other

**Who needs data?**
- researchers
- community members
- stakeholders

**How can you promote data use?**
- internet
- networking
- posters & abstracts
- reports & publications
- other
Promoting Data Use

South Carolina Central Cancer Registry

The SC Central Cancer Registry (SCCCR) was established in September 2004 and awarded five-year funding through a cooperative agreement with the Centers for Disease Control and Prevention. With enabling legislation passed by the SC General Assembly, SCCCR currently operates 20 comprehensive cancer registries in nine hospital-based and three stand-alone registries across the state. SCCCR serves as a population-based data collection system that collects cancer incidence and mortality data and is used to study trends in how often cancers occur in a defined area, and what factors contribute to cancer prevention and mortality (deaths) is collected by the Division of Vital Registration and Health Information within DHEC.

Cancer mortality data can currently be queried on the South Carolina Cancer Mortality Website. The SCCCR also has several publications which highlight cancer incidence and mortality data, and concerns through community cancer assessment investigations. For more information on the SCCCR, please visit their website.

The SCCCR office is located in Columbia. The SCCCR also has staff in Charleston and Spartanburg.

Contact Information
S.C. Department of Health & Environmental Control
S.C. Central Cancer Registry
810 Dutch Square Blvd., Ste. 220
Columbia, SC 29210
Telephone: 803-734-7900, 7901

Internet
- registry main page
- online data access
- other sites
Promoting Data Use

SCAN Cancer Incidence

S.C. Department of Health and Environmental Control

Step One
Select row variable (default: Year).
- Year
- Race
- Age
- Sex
- Stage
- Grade
- Region
- Primary Cancer Type

Step Two
Select column variable (default: Primary Cancer Type).
- Year
- Race
- Age
- Sex
- Stage
- Grade
- Region
- Primary Cancer Type

Step Three
Select years of interest (default: 1996-2005).
- 1996
- 1997
- 1998
- 1999
- 2000
- 2001
- 2002
- 2003
- 2004
- 2005

Step Four (Optional)
Specify Race, Age, Sex, Stage and/or Grade Below (default: All Races, All Ages).

Race
- White
- Black
- Other
- Unknown

Age
- 0-4
- 5-9
- 10-14

Sex
- Male
- Female
- Unknown

Grade
- All Grades
- Well Differentiated
- Moderately Differentiated
- Poorly Differentiated

Stage
- All Stages
- In-situ
- Local
- Regional
- Stage 4

Step Five
Select Geographic Area of Analysis (default: Counties).
- Zip Codes
- Counties
- DHEC Regions

Step Six
Select Regions of interest (default: All Counties in South Carolina)

Cancer Incidence: Statistical File
For South Carolina Residents, 2001-05

County: All Counties in South Carolina
Primary Cancer Sites: Lung and Bronchus
Race

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<th>Black</th>
<th>Other</th>
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<tr>
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<td>1,124</td>
<td>1,249</td>
<td>6,298</td>
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<td>3,624</td>
<td>3,399</td>
<td>15,980</td>
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Rate: Age Adjusted Rate calculated per 100,000 population. Using the 2000 Standard Population
Promoting Data Use

Dear Students,

The South Carolina Central Cancer Registry (SCCCR), South Carolina Department of Health and Environmental Control (SC DHEC) would like to inform you of research opportunities and data/statistical assistance using SCCCR data.

The SCCCR has a rich data set of cancer incidence and mortality data for SC. SCCCR Research Staff are able to provide data for and to advise students on compiling, organizing, managing, and analyzing data for theses and dissertations. We will work with appropriate faculty (e.g., student’s committee members) in order to ensure that the activities support the overall goals of the project and its data analysis plan.

Note: All projects are accepted on a space available basis and must be approved by appropriate entities.

Attached is an informational sheet outlining the essential functions and limitations of the SCCCR Research Staff, as well as staff contact information.

Regards,

Susan Bolick-Aldrich, MSPH, CTR
Director, SC Central Cancer Registry
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<td>SC Community Assessment Network (DHEC)</td>
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<td><strong>Other</strong></td>
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Part 2: Being Organized

SCCCR Research Staff:

***Initial Point of Contact: Jonathan Savoy, MSPH***

Jonathan Savoy, MSPH (Research Analyst/Epidemiologist)
Email: savoyje@dhec.sc.gov, Phone: (803) 731-1419 ext. 117

Deborah Hurley, MSPH (Assistant Director/Epidemiologist)
Email: hurleydm@dhec.sc.gov, Phone: (803) 731-1419 ext. 111

Margaret Ehlers, MSPH (Research Analyst/Biostatistician)
Email: ehlersme@dhec.sc.gov, Phone: (803) 731-1419 ext. 114

Susan Bolick-Aldrich, MSPH, CTR (SCCCR Director/Epidemiologist):
Email: bolicks@dhec.sc.gov, Phone: (803) 731-1419 ext. 107

Personnel

• ONE designated point of contact
• ONE person who handles documentation

Materials

• updated
• electronic
• online or email
Part 3: Data Application Package

What to include

- data release protocol
- general information for researchers
- best practices for students & researchers
- list of available data items
- data application w/ built-in checklist
- fee schedule
# Principles and Protocols for the Release of SCCCR Data

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Essential functions & limitations

• state what data & statistical services you usually provide for any project

• state what statistical or other support is available beyond a routine request

• indicate if fees & acknowledgements or authorship are expected or applicable for work or services beyond the minimum

• communication, needs assessment


**Essential Functions and Limitations**

Researchers:
- SCCCR Research Staff will support researchers in developing data sets for *approved* research projects.
- SCCCR Research Staff will provide *limited* data/statistical support for research projects.
- SCCCR Research Staff will consult on, and may assist in providing general access or linkage to large public-access datasets.

Students:
- SCCCR Research Staff will *assist* students with data acquisition, data set creation, and data analysis for dissertation, thesis, and research proposals on a *space available basis* for *approved* research projects.
- SCCCR Research Staff will *not* complete the analysis for the student; however, SCCCR Research Staff will advise students on the best approach to complete these tasks, including sample programming, if needed.
- SCCCR Research Staff will consult on, and may assist in providing general access or linkage to large public-access datasets.
Appointments: SCCCR Research Staff will primarily see students and researchers by appointment only. However, time permitting, we will be available for “drop-ins” to assist those having technical difficulties with work for which they have already been advised. Note: “Drop-in” assistance will be time permitting; assistance requiring an extended time commitment may be deferred to an appointment.

Availability of Services: Typically data, and statistical support for research projects are not available for free; however, limited data and data/statistical support may be provided free though the SCCCR DHEC. Note: this applies to routine data requests and data/statistical support on a space available basis as time permits. All projects must have appropriate approvals (all IRB approvals as well as the Cancer Control Advisory Committee Surveillance Subcommittee (CCAC-SS) approval).

1. Researchers: May apply for data and request limited data/statistical support for this work. Data/statistical support beyond what is considered to be a routine request may incur monetary charges or fees to offset the expenses incurred by the SCCCR. Alternatives to charges and fees for greater than routine support include in-kind support from the researcher (e.g., graduate assistants) or the role of the SCCCR being that of a collaborator.

The SCCCR welcomes requests for collaboration from any researcher, student, or agency. All requests will be considered and carefully reviewed before any commitment is given. Criteria for collaboration include, but are not limited to: quality of research project, feasibility, timelines, available staff and current workload, and funding.

Note for Researchers: To provide appropriate statistical assistance to researcher, SCCCR Research Staff will need to become familiar with your data and statistical needs well in advance of any deadlines. Therefore, it is strongly recommended that the PI (or Co-PI or Project Manager) schedule a planning meeting prior to any deadlines that allows appropriate time for work to be completed. Researchers should also request a copy (via email) of Working with the South Carolina Central Cancer Registry (SCCCR), Best Practices for Students & Researchers from Catishia Mosley or Deborah Hurley, prior to this meeting.

2. Students: Students doing approved thesis or dissertation work may apply for data and request data/statistical support (mentoring) for this work.

Note for Students: SCCCR Research Staff will need to read and interpret student project proposals and consult with faculty (committee members) to become familiar enough with the project to provide appropriate statistical assistance. Therefore, each student should plan at least one brief introductory meeting before any work is to begin. Students are required to request a copy (via email) of Working with the South Carolina Central Cancer Registry (SCCCR), Best Practices for Students & Researchers from Catishia Mosley or Deborah Hurley, prior to this meeting. Students should be fully prepared for this meeting as described in the Best Practices.

NOTE: If considerable assistance is given on any particular project, the SCCCR project staff should be included as a co-author for publication, when appropriate. However, an Acknowledgment for using SCCCR data as always required.
Data Application Package

Best practices for students & researchers

- when to approach the CCR about your project
- researcher planning & needs assessment
  - timeline, deadlines
  - skills, limitations, support
- appointments
  - before, during, after
Working with The South Carolina Central Cancer Registry (SCCCR) 
Best Practices For Students & Researchers

These guidelines have been developed to help you get the most from this office and to ensure fair access to the office and to its data and services for the largest number of people.

1. When should you approach the SCCCR about a project? 
Get the SCCCR involved from the beginning (or as close to the beginning as possible) of thesis or dissertation projects, or research projects. The SCCCR project staff may have suggestions for available data sets that would be appropriate for your work, or may have suggestions on study design and data management for your data set, or may know of difficulties you are likely to encounter in your research.

2. What questions should you ask yourself prior to approaching the SCCCR about a project? 
   a. What are my research skills and limitations? What do I want to accomplish? How much help will I need for statistical “support”: data acquisition, data entry, data management, descriptive analysis, modeling, or statistical guidance?
   b. What other support is available, including my committee (students), or staff (researchers)? Does my committee need to meet with the consultant as well? Will data or services from other offices or agencies be needed?

3. Planning. Have an idea about your timeline expectations. (Students, check if these are realistic with your committee ahead of time.) Students: Determine your needs and develop an implementation plan with your committee first, then schedule consultation meetings accordingly. Researchers: To provide appropriate data and statistical assistance to researchers, SCCCR project staff will need to become familiar with the project background and statistical needs well in advance of any deadlines. Therefore, it is strongly recommended that the PI (or Co-PI, or Project Manager, if appropriate) schedule a planning meeting prior to any deadlines that allows appropriate time for work to be completed.

Do not expect quick answers, especially if you have had no prior consultation. The Cancer Control Advisory Committee Surveillance Subcommittee (CCAC-SS), our data oversight committee, requires a formal process for data acquisition and use. This committee requires receipt of an IRB review (and the results) from your institution. Once this committee has reviewed the project and given approval, we can provide assistance with your data and statistical needs.

4. Make an appointment. Though there will be limited hours available for drop-in consultation, these times will be for simple questions or initial contact. For anything that will require more time, please schedule an appointment.

5. Before the appointment: At least one week before the meeting you should provide several items to the appropriate SCCCR staff person: 
   a. Provide a brief summary, just 2 to 5 pages with a short introduction, hypotheses or research questions, and proposed methods (including study design), as well as 1 or 2 key articles about this topic (not 10), that illustrate the type of data elements you will need and the analysis you are likely to perform.
   b. Provide clear hypotheses or research questions. This is one of the most important steps in this process.
   c. Provide background on what is generally used in the type of research you are proposing (i.e., data elements, statistics, study design) and how things are normally presented on this topic. This will allow SCCCR project staff to discuss the project with you and ask questions for clarification (saving us both time).
   d. Provide a draft of the Data Application that will be required for your data request or project. SCCCR project staff will provide feedback on the application and help you to complete the application fully and accurately.

6. At the appointment: Be prepared to view a succinct presentation on general principles of cancer registry data standards, management and utilization. Also be prepared to simplify and explain technical issues, terms, and acronyms that you will be using. In addition to your research questions, be prepared to discuss the following:

   a. What variables are of interest? How are the variables defined? What is the sample size you desire? Will data format need to be manipulated or will new variables need to be defined? Will the data need further cleaning, recoding, or linking? SCCCR project staff may have ideas to simplify this process for you. We can give you an idea about limitations of the data set and the limitations of the variables (e.g., how data is collected, data quality, sampling, contamination).

   **NOTE:** We assume your scales are reliable and valid. If that is part of the study to investigate this, then it should be among the research questions and included in the analysis plan.

   b. If you already have a data set, be prepared to leave a copy of the data with SCCCR project staff. We may need to look at how your data are set up, as well as other data set characteristics to determine what you have “to work with”. This is especially important when you are requesting a data linkage.

   c. Know that you don’t have to know everything about the SCCCR data or appropriate statistics to work with these data before your meeting. Please stop and ask questions immediately as they arise.

   d. Know that we may not have answers for you at this time, but will likely need to schedule a second meeting (or more) to discuss a plan of action for your project.

   e. If considerable assistance is given on any particular project, the SCCCR project staff should be included as a co-author for publication, when appropriate. However, an Acknowledgment for using SCCCR data as always required.
Data Application Package

List of available data items

- commonly requested
- complete data dictionary
- unrestricted
- restricted
- recoded or calculated
- available by linkage
Data Application Package

Data application w/ built-in checklist

• instructions & other information
• investigator & institutional information
  • PI, co-investigator, student investigator
• sponsoring agency & funding information
• other institutional or agency information
• institutional review board (IRB) information
• data set information
• data linkage information
• project summary
Data Application Package

- additional documentation & information
  - grant proposal or study protocol
  - informed consent, questionnaires, tests, abstract forms
  - biosketch information
  - IRB approval, human subjects training
  - list of all others who will have data access
  - CCR protocol, general information, best practices
- other notes, details, or information researcher would like to include
Separate checklist for student thesis/dissertation applicants

1) Request SCCCR data application and working with the South Carolina Central Cancer Registry (SCCCR), Best Practices for Students & Researchers from Cathryn Mosley or Deborah Hurley

2) Read over Working with the South Carolina Central Cancer Registry (SCCCR), Best Practices for Students & Researchers

3) Fill out SCCCR data application

4) Set up brief introductory meeting with SCCCR to discuss data and statistical needs and reasonable timeline

5) At least one week prior to the introductory meeting, forward the SCCCR the following items:
   - Draft of data application
   - Detailed description of variables needed from SCCCR and why
   - Clearly stated statistical hypotheses
   - Specific statistical methods
   - Expected outcomes of data
   - Tentative Timeline

6) During introductory meeting
   - Review SCCCR PowerPoint presentation
   - Discuss all items listed under number 6 in the Working with the South Carolina Central Cancer Registry (SCCCR), Best Practices for Students & Researchers
   - Set up any follow-up meetings, if needed

7) Submit final data application with any needed revisions and USC or home institution IRB approval for study (IRB approval from the student’s home institution MUST be obtained prior to submitting any application materials to CCAC-SS or DHEC IRB)

8) After all items have been submitted and are complete, the SCCCR will:
   - Present application to CCAC-SS
   - Supply student with CCAC-SS letter
     - If CCAC-SS needs clarification(s) regarding analysis or application, the student will need to provide clarification to the SCCCR and then the SCCCR will need to submit clarification(s) or revised application to the CCAC-SS
   - Present to DHEC IRB for approval (given CCAC-SS approval)
   - Supply student with DHEC IRB letter
   - Conduct linkage (BCN, ORS), if applicable
   - Prepare data-use agreement
   - Prepare final data set for student
   - Submit final data set to student/researcher

9) Meet with Deb Hurley within three weeks of having the data file to discuss progress and/or any problems with the data or the analysis. We need to make sure that the data set contains all of the data elements you need (and is set up in a way) for you to answer your research questions. Hopefully, this will help to prevent multiple IRB review and data set change delays.
Fee schedule

- follows approved protocol & guidelines
- requestor information
- 1-page summary of data requirements
- staff fees: data requests & statistical analysis
- data set fees: data files & data linkages
- materials & indirect fees
- fee worksheet
Part 4: Staying Organized

Document and review actions with dates and notes

- date of first contact
- application submission
- dates: sent to state oversight committee
- review and approval/disapproval
- all documentation
- data set completed & distributed
- proposed and actual end of study date(s)
Part 5: Follow Up

Mapping Cancer Mortality-to-Incidence Ratios to Illustrate Racial and Sex Disparities in a High-Risk Population

James R. Hébert, MSPH, ScD1,2,3, Virginie G. Daguise, PhD2,3,4, Deborah M. Hurley, MSPH5, Rebecca C. Wilkerson, MSPH2,6, Catishia M. Mosley, MSPH6, Swann A. Adams, PhD1,2, Robin Puett, PhD1,2, James B. Burch, PhD1,2, Susan E. Steck, PhD1,2, and Susan W. Bolick-Aldrich, MSPH, CTR5

BACKGROUND: Comparisons of incidence and mortality rates are the metrics used most commonly to define cancer-related racial disparities. In the US, and particularly in South Carolina, these largely disfavor African Americans (AAs). Computed from readily available data sources, the mortality-to-incidence rate ratio (MIR) provides a population-based indicator of survival. METHODS: South Carolina Central Cancer Registry incidence data and Vital Registry death data were used to construct MIRs. ArcGIS 9.2 mapping software was used to map cancer MIRs by sex and race for 8 Health Regions within South Carolina for all cancers combined and for breast, cervical, colorectal, lung, oral, and prostate cancers. RESULTS: Racial differences in cancer MIRs were observed for both sexes for all cancers combined and for most individual sites. The largest racial differences were observed for female breast, prostate, and oral cancers, and AAs had MIRs nearly twice those of European Americans (EAs). CONCLUSIONS: Comparing and mapping race- and sex-specific cancer MIRs provides a powerful way to observe the scope of the cancer problem. By using these methods, in the current study, AAs had much higher cancer MIRs compared with EAs for most cancer sites in nearly all regions of South Carolina. Future work must be directed at explaining and

Stay in touch with data users until project is complete

- IRB expiration
- IRB renewals
- data updates
- publications
- data destruction
In addition to surveillance, part of our charge as state cancer registries is to:

Provide

• high quality data
• cancer data expertise

Enables public health professionals to

• study cancer more efficiently & effectively
• make a difference in cancer outcomes
**Summary**

**Streamlining the process**

- includes an application & approval process where registry & researcher responsibilities are well-defined & well-understood

**Result**

- promotes data use & collaboration
- creates a more successful & rewarding collaborative research experience
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Office: (803) 731-1419 ext. 111
Cell: (803) 465-3232
Fax: (803) 731-1455

SCCCR main page:
http://www.scdhec.gov/co/phsis/biostatistics/SCCCR/SCCCRmain.htm
References:

Working with The South Carolina Central Cancer Registry: Best Practices For Students and Researchers

(Adapted with permission from: Moore, CG., Hurley, DM.)

References:


Moore, CG. (2004) Suggestions on Working with a Statistician or Biostatistician. Department of Epidemiology and Biostatistics, Arnold School of Public Health, University of South Carolina, Columbia, SC.