Working with the South Carolina Central Cancer Registry (SCCCR): General Information and Best Practices for Students and Researchers

General Information

SCCCR Research Project Staff:
*****Initial Point of Contact: Stephanie Chiodini*****

Stephanie Chiodini, MSPH (Epidemiologist)
Email: chiodisc@dhec.sc.gov

Deborah Hurley, MSPH (Director/Epidemiologist)
Email: hurleydm@dhec.sc.gov

SCCCR Main Phone Number: 803-898-8000

Mailing Address:
SC Central Cancer Registry, SC DHEC
2600 Bull Street
Columbia, SC 29201

Office Hours: By appointment.[1] (During normal business hours: M-F, 9:00 am – 5:00 pm)

Essential Functions and Limitations

Researchers[2]:

- 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 data sets.

Students[2]:

- 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 limited sample SAS programming, if needed.
- SCCCR Research Staff will consult on, and may assist in providing general access or linkage to large public-access datasets.

[1]**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.*

[2]**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. This includes all IRB approvals in addition to approval from the data oversight committee, the Cancer Control Advisory Committee Surveillance Subcommittee (CCAC-SS).

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.

a. 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*. It is *strongly* recommended that researchers plan at least one brief introductory meeting (in person or by telephone call) before submitting a data application. In order to be fully prepared for this meeting, it is also strongly recommended that researchers read the following section, *Best Practices,* in advance.

> **Important note for researchers:** To provide appropriate statistical assistance to researchers, SCCCR Research Staff will need to become familiar with the 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 deadline in order to allow appropriate time for work to be completed.

b. Students doing approved thesis or dissertation work may apply for data and request limited data/statistical support (mentoring) for this work. In general, fees for data and statistical support for students are typically waived if the student has no funding from his/her academic institution or other source. If only unrestricted data items are requested, students may also be eligible for an expedited approval process.

> **Important 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 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 is always required.

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Best Practices

These guidelines have been developed to help you get the most from the SCCCR and to ensure fair access to the office and 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 research projects and/or thesis and dissertation projects. The SCCCR project staff may have suggestions for appropriate data elements and/or other 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. What kind of planning is needed?

Timeline: Have an idea about your timeline expectations.

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.

Students: In addition to the researcher information (above), check with your committee ahead of time to see if timeline expectations are realistic. Determine your needs and develop an implementation plan with your committee first, then schedule consultation meetings accordingly.

Note: 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 proof 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. Will I need to schedule appointments with the SCCCR?

YES.

a. Make an appointment: Although 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.

b. Before the appointment: At least one week **before** the meeting you should provide several items to the appropriate SCCCR staff person:

1. 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.

2. Provide clear hypotheses or research questions. *This is one of the most important steps in this process.*
3. 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).
4. 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.

c. 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:

1. 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.

2. If you already have a data set, you may want to leave a copy of the data with SCCCR project staff or schedule enough time to take a look at the data during your consultation. We may need to look at how your data are set up (and other data set characteristics) to determine what you have "to work with." This is especially important when you are requesting a data linkage.

3. 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.

4. 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.

5. What acknowledgments or authorship is expected by the SCCCR?

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 is always required.

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

References:

Boen, JR, Zahn, DA. (1982) *The Human Side of Statistical Consulting*. Belmont, CA: Lifetime Learning Publications.

Derr, J. (2000) *Statistical Consulting: A Guide to Effective Communication*. Duxbury Press, Thomas Learning, Canada.

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.

Hurley, DM. (2005) *Guidelines on Working with a Biostatistician/Epidemiologist.* Department of Epidemiology and Biostatistics, Arnold School of Public Health, University of South Carolina, Columbia, SC.