

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 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. 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

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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.

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(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.