NAACCR Town Meeting
Registry Research
April 13, 2005
1:00 PM Central Time, 2:00 PM Eastern Time

Present: Representatives from the following registries and organizations:

Canada: Manitoba Cancer Registry, Ontario Cancer Surveillance Unit, Princess Margaret Hospital, Statistics Canada

U.S.: Alabama Statewide Cancer Registry, Alaska Cancer Registry, American Cancer Society, Arizona Cancer Registry, Arkansas Central Cancer Registry, California Cancer Registry, California-Los Angeles Cancer Surveillance Program, Centers for Disease Control & Prevention, Idaho Cancer Data Registry, Illinois-Chicago, Illinois State Cancer Registry, Information Management Services, Inc., Massachusetts Cancer Registry, Minnesota Cancer Surveillance Program, Missouri Cancer Registry, National Cancer Institute, New Jersey State Cancer Registry, New York State Cancer Registry, North Carolina Cancer Registry, Ohio Cancer Incidence Surveillance System, Oregon State Cancer Registry, Pennsylvania Cancer Registry, Rhode Island Cancer Registry, Tennessee Cancer Registry, Virginia Cancer Registry, Washington-Seattle Cancer Surveillance System

NAACCR Staff: Moderator, Holly Howe - Executive Director, Joellyn Ellison - Program Manager, Data Evaluation and Publication, Susan Sullivan - Administrative Assistant

Primary Investigators and Database Manager for the cohort study of Seventh-day Adventists: Dr. Gary Fraser, Dr. Susan Preston-Martin, Larry Beeson

Opening Remarks **Holly Howe**

Holly introduced Primary Investigators Dr. Gary Fraser, from Loma Linda University (LLU), and Dr. Susan Preston-Martin from University of Southern California (USC). Dr. Preston-Martin and Dr. Fraser are conducting a cohort study of Seventh-day Adventists that involves collaborative research with multiple cancer registries across the United States and Canada. Larry Beeson (LLU), Database Manager for the cohort study was also introduced.

Holly requested that questions from registries following the presentations of the investigators be kept on the general level and not be state specific. Individuals that have state specific questions may contact Dr. Susan Preston-Martin at spresto@usc.edu, or at (323) 865-0425.

1. Description of Study **Investigators & Staff**

a.) Dr. Gary Fraser explained that the Seventh-day Adventists are a religious group that emphasizes healthful living as a religious virtue. The focus of the study has been and will continue to be on the nutritional epidemiology of cancer. One thing that makes the study group very attractive is the variable adherents to the church's recommendations, which results in a very wide range of dietary habits. Approximately 40% of the study group are vegetarians, 5-10% are vegans, and others eat red meat to various extremes similar to their neighbors. Soy consumption is probably highest in this group than any other easily identifiable group in the United States. The group does not smoke and they virtually have no alcohol consumption. Lastly they are a reasonably well-educated and cooperative group.

The last cohort study consisted of 34,000 California Seventh-day Adventists and ran primarily from 1976-1982. Provocative findings provided the first indications of meat in these relationships. Meat consumption was related to higher risks of colon, bladder, and, ovarian cancers. Tomato consumption was related to lower rates of prostate and ovarian cancers. Fruit consumption was related to lower risks of lung, pancreatic, and prostate cancers. High legume consumption was

associated to lower risks of colon and pancreatic cancers, while soymilk consumption appeared to be related to lower rates of prostate cancer.

The National Cancer Institute (NCI) is funding the current study that began in 2001, with the goal to enroll 105,000 Seventh-day Adventists located in all 50 US states and recently Canada. The information is collected by mail survey for the whole study group. A much more detailed collaboration study is conducted on a 1,000 random sample of blood and subcutaneous fat from subjects. So far approximately 75,000 subjects are enrolled in the study; registration will continue for a couple of more years to complete the enrollment goal. The specific aims of the current project are to focus on soy intake, calcium consumption and vitamin D sunlight exposure, and red meat consumption with their associations to breast, prostate, and colon cancers. Approximately one-third of the cohort study subjects are black. The study will rely heavily on the cohort collaboration with the registries. Every two years a backup will be done using a short form for subjects to complete about their cancers and hospitalizations.

b.) Dr. Susan Preston-Martin thanked all present on the teleconference for their encouraging show of support. She continued by stating that NAACCR in an incredibly sophisticated, capable organization. The investigators are proposing to help launch the new era in the use of NAACCR data that Holly Howe, Dennis Deapen, and others have been aiming for. Not only are Seventh-day Adventists in the cohort study from across all of North America involved, they are planning to identify cancers by linkage with the population based registries in all 50 US states and all of the Canadian provinces. This ambitious undertaking is one the investigators cannot do with out the help and cooperation from all registries.

Findings so far from the six states selected for the pilot study have been successful. The six states involved were chosen because they all had a relatively high proportion of both black and white Seventh-day Adventists. States sought after were ones that would represent a range of populations by geographic area, and a range in terms of how long the population based statewide registry had been established. In every state chosen, the registry director and everyone on their staff were tremendously helpful in expediting the approval process for the project.

The research staff came upon a challenge when it was decided along with the agreement of their advisors and NCI, that registry linkage needed to be executed in a uniform manner across all states and provinces in North America. To provide uniform linkage, the research staff programmer from LLU took the Seventh-day Adventists' cohort file on a laptop computer to the registries. In some cases problems arose as many registries perform their own record linkages when they receive a file. The desire of the investigative team was to link the entire pilot file of information for the 70,000 Seventh-day Adventist subjects to each of the registries to discover how many enrolled would be located if the files were profiled. The model file used was brought to the registry on the investigator's laptop. The laptop and model were left at the registry in payment and in thanks for the cooperation the researchers had received there. This offering was suggested by the National Cancer Institute's HIV study, both to insure confidentiality and to be minimally invasive. Donations of a laptop computer to each registry in the study will continue, along with paying certain fees required by each registry to access their data. The researchers are hoping that a fee per record requirement at the registry could be waived for this study.

Receiving approval from the six states in the pilot study was extremely time consuming. In the future Dr. Preston-Martin plans to start the approval process earlier. Budget planning for the study is in process for the grant application due November 1. Holly noted that she will be compiling information from each registry on their approval process, forms required, fees that will be encountered, and links to the necessary IRB forms for posting on the website for use by researches. Investigators will approach registries for pre-approval starting the beginning of 2007 through the end of 2008 for the first actual linkage where incidence cancers will be identified.

According to IRB rules, approval may be given two to three years ahead of time for the study as long as the proposed study method does not change.

Holly noted that an announcement would be made at the NAACCR Annual Meeting in June concerning the registry information file; compilation of the file will be accomplished this summer.

c.) Larry Beeson's spoke of his role in this health study as database manager. He reported that as part of the evaluation testing of the feasibility of performing record linkage with state and provincial registries across the United States and Canada for this national cohort study was to chose six pilot states to develop the protocol. The states included are Arizona, California, Nebraska, New York, Michigan, and Missouri. These pilot states were chosen to represent areas with a lot of potential study subjects such as in California, as well as states with relatively few health study subjects perhaps like Nebraska. Another consideration of states chosen was to pick state registries that have been in operation for many years, and to also include some registries that have been fairly new to the scene of linking to researchers. The linkage time required is reported to be about a half of a day. Record linkage has recently been completed in Arizona, California, Nebraska, and New York. The investigators are scheduled to perform computer-assisted linkage with Michigan on April 20, 2005. Record linkage with Missouri will hopefully be completed by the end of April.

The two top contenders of record linkage software programs are AutoMatch and Link Plus. The major drawback with AutoMatch is the expense, perhaps $30,000 or more. Link Plus is a probabilistic record linkage program developed at the Centers for Disease Control and Prevention (CDC) in support of CDC's National Program of Cancer Registries (NPCR) and is available free to download from the CDC website. A recent benchmark that compared the true matches produced by both Link Plus and AutoMatch are documented at Link Plus identified 98.1% of the two matches identified by either protocols. The current versions of Link Plus can use a variety of input formats, including NAACCR 9 fix fielded files, delimited files, and CRF plus database. Unfortunately Link Plus cannot read the NAACCR 10 file. Registries are requested to convert their databases into a fix fielded and delimited rectangular file for input to the Link Plus linkage file player. This conversion can be completed rather quickly using the Rocky Mountain protocol or other software that can convert NAACCR 10 to create a fix fielded delimited file.

The linkage program utilizes the following fields for comparison between state registries and the Seventh-day Adventist study: name (last, first, middle), gender, date of birth (month, day, year), SSN, 10-digit phone number, address (street, city, state/province, postal code). The result of this initial linkage will be the validation of self-reported cancer registries identified by study subjects on their return enrollment questionnaires. The linkage file sent will then be repeated in 2007 or 2008 to look for incidence cancers. Currently our pilot studies identify prevalent cancers.

d.) Holly opened the floor to questions from those present.

- A representative from California endorsed the study, stating the linkage process was minimally invasive taking less than a day to complete.
- A representative from Missouri had questions concerning the correct layout of the records to be sent to the investigators. Larry Beeson responded that when record linkage is requested, a document will be sent describing the variables in the columns, such as the beginning column and the column length for each variable that is anticipated to be used in the record linkage program. It generally is both a fix fielded file and a bar delimited file.
- A representative from Minnesota asked what happens with possible links, like gray zones. Larry Beeson commented that the output of the linkage program is comprised of three outputs, definite non-matches, definite matches, and this gray zone or possible matches. A program written by an in-house programmer at LLU is used that takes output of the registries program and the input from the investigator's program and displays the records above each other (last name, first name, SSN). The Seventh-day Adventists health study group and a representative

from the registry involved meet to collectively decide which records match and only those records are taken back to the study.

- A representative from Minnesota asked what level of patient consent the study group has to perform linkages. Dr. Gary Fraser responded that on the back of the questionnaire used for subject enrollment there is a simple consent statement the subject must sign to give the study group consent to match to a tumor registry.
- A representative from Ontario requested a more detailed description of the Canadian involvement in the study. He also asked for clarification if recruits were wanted for the cohort study, or if the investigators were looking for cancers among migrants to Canada. Dr. Gary Fraser responded that recently Canada was added to the Seventh-day Adventists cohort study for potential subjects to recruit for the study. Dr. Susan Preston-Martin asked the representative from Statistics Canada for verification that the investigators should go through them to obtain information for the Seventh-day Adventists cohort study since all the provincial registries report their cancer data to Statistics Canada. The representative from Statistics Canada replied that although they collect data from the provinces, they do not have the mandate to allow access to the micro data records to researchers directly. Dr. Susan Preston-Martin suggested that perhaps the researchers could get a release from each provincial registry to obtain the data from Statistics Canada. Dr. Preston-Martin will negotiate this issue offline.

2. Draft Sentence **Holly Howe**

Holly stated NAACCR has a statement they want all researchers to add to data use activities that are making use of the NAACCR dataset. There is a need to think more broadly of collective recognition of all the partners that contribute to the development of data resources. Holly continued that development of our data resources require federal participation in the federal programs in the United States and in Canada as well. This has greatly increased the ability to have registries everywhere and to have high quality and timely registries. Seeing that all parties are recognized now that NAACCR is embarking in a huge effort to use their collective data sets is a high priority. Holly noted she found the same issues might not exist in Canada because the Canadian program is set up differently. If a national effort in Canada is being overlooked NAACCR would like to incorporate that recognition in the statement.

The statement is as follows:

> Cancer registries, in the United States, participate in one or both of the national programs, SEER or NPCR, and are included in annual updates of CINA Deluxe after evaluation by NAACCR that high quality data standards for incidence statistics have been met.

Holly solicited opinions of the statement, and also requested additional attributions that should be included for Canada, or recognition of individual registry contributions that would make the statement more inclusive.

- A representative from Manitoba stated that the Canadian Council of Registries would want acknowledgement in the statement for their participation in the work in data quality efforts.
- A representative from Minnesota suggested noting that programs receive support from multiple sources.

3. Closing Remarks **Holly Howe**

Holly thanked all for participating in the meeting. Her hope was for a teleconference that was enlightening for the representatives in attendance and a good experience for the research group from LLU and USC. Holly asked registry representatives to contact Dr. Susan Preston-Martin at spresto@usc.edu or 323-865-0425 if their registry is interested in participating in the Seventh-day Adventist cohort study and for the registry to supply information describing how the researchers can access their data.