Q&A CONCORD-2 Study Data Extraction Program

Q: How do we get a copy of the SAS program and the EDITS metafile?

A: The SAS program and EDITS metafile will be distributed through the NAACCR listserv on Monday, March 18, 2013.

Q: just want to comment on the description of the IACR multiple primary rules. You can have two breast, but the reason for the second case can not be laterality or timing - but if it differs by morphology, it's okay.

A: Understood and thank you for the clarification.

Q: Are your cases for solid tumors excluding 9590-9989; 9050-9055, 9140?

A: No. Per Annex 3 of the CONCORD-2 data submission instructions, hematological malignancies are selected on the basis of morphology codes, but the other nine index cancers are selected only on the basis of topography codes. Thus, some malignancies will appear in two of the datasets.

Q: It looks like the program is only selecting insitu and invasive, but the C2 data specification says to send ALL behaviors 0,1,2,3?

A: The final version of the SAS program selects all behavior codes per the CONCORD-2 specifications. A separate CONCORD-2 case selection document will be distributed via the NAACCR listserv with the SAS program.

Q: I ran the IARCcrgTools and worry that it excluded for one pt mult lung primary small cell ca and non-small cell ca and said to overwrite a lung 'large cell ca' with either/both. Is that correct?

A: The IARCcrgTools output does sometimes provide suggestions for replacing less specific morphology codes with more specific when two cases are “merged,” but this is not necessary for the level of analysis that will be performed in the CONCORD-2 study. The SAS program handles the implementation of the IARC/IACR multiple primary rules, and it will not be necessary to try to modify morphology codes when two cases are “merged.”

Q: Is the extraction criteria for the Call for Data and Concord the same?

A: The extraction criteria are specific to the CONCORD-2 study protocol. A separate CONCORD-2 case selection document will be distributed via the NAACCR listserv with the SAS program.

Q: What should registries whose privacy office precludes them from sending full date of birth and full date of diagnosis do?

A. Please contact the CONCORD PI (Prof Michel Coleman). He and his staff have been completing state specific data release forms to obtain full dates. Full dates are necessary to properly characterize excess mortality immediately following diagnosis where many of the disparities in survival appear. Unlike the first CONCORD study which focused primarily on 5-year survival, the CONCORD-2 study will focus on both short term and long term survival to better characterize and understand population disparities in cancer survival.

Q: Can you please remind us what the due date is for the CONCORD Call For Data submission?

A: Canadian and US registries may submit data by the end of April 2013. If you anticipate needing an extension, please contact the CONCORD study staff directly: Natalia.Sanz@lshtm.ac.uk

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Q: When should we send the life tables to Concord?

A. Cancer registries in the US and Canada do not need to send life tables to CONCORD. Data for life tables will be submitted centrally.

Q: What if you haven't linked with NDI in over 5 years. Can you still participate?

A: If you are able to, please update your follow-up data with current NDI information prior to submitting your data to CONCORD. If you are not able to do this, you can still participate in CONCORD, but your data will only be able to be used up to the last year of NDI deaths you have linked to.

Q: What happens if we are going to do the link with NDI after April, and the last link was done several years ago?

A: If you are able to, please update your follow-up data with current NDI information prior to submitting your data to CONCORD. If you are not able to do this, you can still participate in CONCORD, but your

data will only be able to be used up to the last year of NDI deaths you have linked to. Please contact the CONCORD study staff directly (Natalia.Sanz@lshtm.ac.uk) regarding the extension you may need to the April 30, 2013 submission deadline.

Q: Has the criteria for submission been sent out to all cancer software vendors?

A: The software vendors are not preparing the data submission files. The SAS program discussed on the March 14, 2013 webinar uses a NAACCR V12.2 record layout file as input, which every registry should be able create. A separate CONCORD-2 case selection document will be distributed via the NAACCR listserv with the SAS program.

Q: Can we replace SS link or it has to be NDI?

A: SS does not record all deaths in the US. NDI linkages are necessary to obtain complete death information.

Q: When/Where can we download the SAS program?

A: The SAS program and EDITS metafile will be distributed through the NAACCR listserv on Monday, March 18, 2013.