

Cancer event data collected in the Strong Heart Study (SHS) and Strong Heart Family Study (SHFS)

The SHS CC has received inquiries regarding cancer event data. In an effort to assist investigators with making informed decisions about a potential cancer topic, Dr. Ying Zhang, Dr. Wenyu Wang, Dr. Dorothy Rhoades, Dr. Lyle Best, Dr. Navas-Acien, and Ms. Kimberly Hollabaugh worked together and drafted the following memo.

We hope that this document may help investigators to better understand what kinds of cancer event data have been collected in the study. In addition, we wish that this document is helpful to investigators who are working on grant proposals to improve the completeness of SHS cancer data.

1. Participants' consents:

SHS1 - SHS5: Cancer was *not* included in the informed consent as a disease to study.

SHS6 - SHS7: Cancer has been included in the informed consent as a disease to study since SHS6.

2. Cancer mortality data:

All mortality events have been reviewed in order to determine the primary cause of death. So cancer deaths should have been captured in either death certificates (SHS1 to March/April 2011), or the mortality final decision form (SHS3 onward), or both.

Please note that, although cancer deaths were generally captured, those events have been reviewed by *only one* reviewer. There is *no adjudication procedure* for cancer mortality events.

Investigators may find cancer mortality events from the following data sources:

- 1) Cancer deaths happening *between the beginning of SHS and March/April 2011* could be identified by using the ICD-9 codes recorded in the death certificates. Unfortunately, after March/April 2011, due to funding issues, the nosologist's reviewing and coding of deaths stopped.
- 2) *Since SHS3*, cancer deaths have been captured in the Mortality Final Decision Form. Reviewers may check "Malignant neoplasm" and write down the primary site of cancer if deemed appropriate. For example, if a participant died of cancer, the cause-of-death should be recorded in the following question of the Mortality Final Decision Form.

Cause of Death

| 2 | 1 |

If is Non-CVD death, choose one from the following list and complete the evidence code:

21 = Malignant neoplasm

Primary site: _____

3. Cancer morbidity:

1) Morbidity surveillance

- a. From *SHS1 to SHS5*, non-fatal cancer events were not abstracted from medical charts. Morbidity reviewers usually did not record cancer events in the Morbidity Final Decision Form except those written sporadically in the following question.

Diagnosis (enter appropriate code number)

| 1 | 0 |

10. Non-CVD, specify _____

- b. Since *SHS6*, non-fatal cancer events have been abstracted if field M&M coordinators happen to see a cancer diagnosis in participants' medical charts. A morbidity reviewer may record a non-fatal cancer event in the following question of the Morbidity Final Decision Form:

10. Non-CVD, specify _____

- 2) Self-reported cancer history has been collected since the beginning of the SHS.
- a. From SHS1 to SHS5, it was recorded in the following question of the Medical History Form:
Has a medical person ever told you that you had any of the following conditions?
Cancer, including Leukemia and lymphoma Yes No Unknown
 If "Yes", specify type of cancer: _____
- b. In SHS6, it was recorded in the following question of the Contact & Medical History Form:

23. Has a health care provider ever told you that you have/had cancer? Y||N||U|| (If No or Unknown: Female skip to question 25; Male skip to question 31)

If "YES," what type is/was it? Check all that apply from the following list:

a.	<input type="checkbox"/>	Breast	f.	<input type="checkbox"/>	Kidney/Bladder
b.	<input type="checkbox"/>	Ovary/uterus	g.	<input type="checkbox"/>	Liver
c.	<input type="checkbox"/>	Prostate	h.	<input type="checkbox"/>	Mouth / Throat
d.	<input type="checkbox"/>	Lung	i.	<input type="checkbox"/>	Melanoma and/or Skin cancer
e.	<input type="checkbox"/>	Colon/Rectum	j.	<input type="checkbox"/>	Blood or immune system
k.	<input type="checkbox"/>	Other, not on this list: _____			

4. Adjudication/confirmation procedure

There were no systematic adjudication/confirmation procedures for fatal or non-fatal cancer events.

5. Ongoing efforts to improve the completeness of SHS cancer event data

Dr. Dorothy Rhoades and Dr. Amanda Janitz submitted a R21 grant to link SHS data with cancer registry data. As of March 2020, it is pending re-submission.

6. Recommendations regarding the use of cancer event data collected in the SHS/SHFS

- 1) *Cancer mortality events* have been reasonably captured. Some of the recent publications about cancer mortality are listed as follows.
- Telomere length and cancer mortality in American Indians: The Strong Heart Study. *GeroScience*. 2019 Jun;41(3):351-361. doi: 10.1007/s11357-019-00080-4.
 - Association of diabetes and cancer mortality in American Indians: The Strong Heart Study. *Cancer Cause and Control*, 2015. <http://link.springer.com/article/10.1007/s10552-015-0648-7>
 - Cadmium exposure and cancer mortality in a prospective cohort: the strong heart study. *Environ Health Perspect*. 2014 Apr;122(4):363-70
 - Arsenic exposure and cancer mortality in a US-based prospective cohort: the strong heart study. *Cancer Epidemiol Biomarkers Prev*. 2013 Nov;22(11):1944-53.
- 2) *Non-fatal cancer events data* are incomplete. However, if Dr. Rhoades' and Dr. Janitz's grant proposal is funded, or if other funding of chart review for SHS/SHFS cancer events is secured, this situation may be improved substantially.