Protocol for Identifying and Coding FHS Cancers

FHS Cancer Surveillance

Questions about tumors, cancers and malignancies are asked of FHS participants in formal interviews and surveys, including FHS research examination questionnaires and biannual FHS health history updates. The data from study participants' self-reports are followed by documentation of cancers by FHS staff with records from health care providers and from other registries. All pertinent and available records are reviewed; especially pathology and surgical reports, and data are abstracted and coded for the FHS cancer file. Records generated at time of death are similarly reviewed. The FHS cancer file is updated every year with newly documented cancer cases.

FHS Cancer Review

All available and pertinent records of reported FHS cancer cases are reviewed by an FHS physician and a trained staff member. Information is abstracted from the record and coded independently by each reviewer, compared and recorded on an FHS cancer worksheet, and entered into the FHS working cancer file.

FHS Cancer Coding, Inclusions and Exclusions

Please refer to the FHS cancer coding manual for details. All primary cancers identified in the FHS study population by self reports or death records, and verified by pathology reports and clinical records, are coded and entered into the FHS working file. The FHS reviewers use the ten digit codes from the 1976 WHO ICD-O code. (This year, a few additional Morphology codes from ICD-O 3rd edition, are being added to the FHS cancer coding system). The ICD-O code is further characterized at FHS as based on microscopic, clinical or death certificate information. All FHS cancers from completed FHS cancer reviews, with a Behavior of 2 (in-situ) or 3 (malignant), are re-keyed, cleaned and entered in the FHS Cancer Data file. Tumors with Behavior codes of 0 (benign) or 1 (borderline malignancy) are not included in FHS Cancer Data file. Cancers described as Metastatic in medical records, are coded at FHS as BEHAVIOR = 3 with the topology as that of the primary site. If the primary site is unknown, then topology is coded as 199. Multiple primary cancers of different cell types (Morphologies) for individual participants diagnosed on the same or different dates, in the same or

different locations, are included. However, recurrences of basal cell and of squamous cell skin cancers are not included; only the first occurrence of each cell type is included for an individual.

Topology and Site: The first four digits, including one decimal place, indicate the location of the primary cancer, according to anatomical systems.

Morphology/ Behavior and Grade. The last six digits characterize the histology or cell type of the cancer.

Date of Diagnosis: The earliest documented date of diagnosis, usually from a biopsy is also recorded. The date is further characterized at FHS as exact or approximate.

If the "INDICATOR" variable is set to "0" this implies that this record passed all edit checks by using the ICD-O-1 code book. If the "INDICATOR" is set to "1" additional codes from ICD-O-3 code book were used. See note under "HIST" variable. If the "INDICATOR" is set to "2" these records were re-reviewed and over road the rules from ICD-O-3 code book. These rules can be found in the front of the ICD-O-3 code book.