Participant Status and Cause of Death Files

David Fitzgerald, July 2015

This is a brief description of the Participant Status files and the Cause of Death files.

Participant Status

There is a Participant Status file for each of the ALSWH cohorts. These files contain information on each participant's progress through the longitudinal surveys, such as the response dates, attrition status, and death status where applicable. This information is not usually on the survey analysis data sets.

Participant Status Variables

Variables	Description	Details
IDalias	Identifier	
History	List of surveys	For example, '134' means only surveys 1, 3, and 4
	completed	were completed.
DeathDate	Date of death	
DeathDateStatus	Source of the	Accuracy status of the participant's date of death
	death	
	information	1 = date confirmed by National Death Index (NDI)
		2 = exact date given by relative/friend
		3 = estimated date given by relative/friend
		4 = date notified of death
		5 = date of death not known
PhaseNDateSurveyReturned	Date Survey N	Note that the six month follow up survey for the
	arrived or was	1921-26 cohort has the variables returndate7,
	completed	returndate8, and onwards.
Attrition1N	Attrition at	Categories:
	Survey N. Survey	1 = respondent
	1 is always the	2 = did not do survey
	baseline.	3 = no contact
		4 = frail
		5 = withdrawn
	-	6 = deceased
Withdrawn Date	Date of	Note 'withdrawn' means the respondent did not
	withdrawal	want to do any more surveys and ALSWH
		accepted this request. 'Withdrawn' in this case
		does not mean she wanted all her information
		withdrawn from the study.
Short Survey	Indicates a short	The short surveys were only an option for Surveys
	survey	2 of the 1996-beginning cohorts, and for Survey 3
		of the 1946-51 cohort.

To determine whether a respondent has died use the DeathDate variable, do not use the attrition variable. The attrition variables may not be updated from when the respondent withdrew, for example.

The attrition variable has some vague values. The difference between *did not do survey, no contact,* and *frail,* may not be obvious and it is more relevant to those in the study who need to contact participants.

Cause of Death file

This is a separate file from the participant status file. This file has the primary cause of death and secondary causes of death, and also the date of death. Please note that the Cause of Death information is typically received about 2 years later than the death date / fact of death which is on the Participant Status file.

There can be up to 19 causes of death. The first cause of death is the underlying cause of death. All other causes of death are additional causes of death. Since 1999 all Causes of death were ICD-10 coded. Those deaths that were registered in or before 1996 were recorded in ICD-9, those registered in 1997 and 1998 were a combination of ICD-9 and ICD-10. The codes for causes of death depend on when the person died and when their record was placed on the National Death Index.

ALSWH receives the data in this format described above, with the primary cause of death and the other causes listed after.

Cause of Death Variables

Variable	Description	Details
IDalias	Identifier	
COD	First Cause of	ICD-10 (or possibly ICD-9 if before 1999)
	Death	
COD2 – COD19	Secondary Causes	ICD-10 (or possibly ICD-9 if before 1999)
	of Death	
DeathDate	Date of death	This comes from the Participant Status file