

**WHI Memory Study – Supplemental Case Ascertainment Protocol (WHIMS – SCAP)**  
**Investigator Data Release**  
**Data Preparation Guide**  
**January 2022**

## **1. Introduction**

This release consists of a single data set from the WHIMS Supplemental Case Ascertainment Protocol (SCAP) study. The data provided are the results of the Dementia Questionnaire and information regarding the classification of cognitive status based on the SCAP for deceased participants or those for whom only the proxy could be contacted. Data is available from 2005 through the end of the study, (WHIMS-ECHO completion was August 31, 2021).

## **2. Description of WHIMS SCAP**

SCAP was instituted in 2005 to identify cases of Probable Dementia (PD) and Mild Cognitive Impairment (MCI), in the deceased and proxy-dependent participants. SCAP includes the Dementia Questionnaire (DQ) [Silverman, 1986], a standardized, validated instrument used to reliably classify dementia and specifically, Alzheimer’s disease in deceased persons. It has demonstrated sensitivity and specificity. The SCAP survey consists of 48 items assessing memory and other cognitive functions, language, daily functioning, insight, and other medical and psychiatric difficulties. The DQ is a semi-structured interview that was administered by telephone to informants previously selected by the participant, who are knowledgeable about the participant’s medical history and ante-mortem functional status.

SCAP relies on telephone interview data from a proxy to classify cognitive decline. July 1 was selected as the month and day for all year variables because the Dementia Questionnaire (DQ) asks what year particular events began happening, but not the exact date. The dataset contains time from randomization for all variables. For example, if a proxy noted that a participant began having memory problems in 2001, that date was converted to 7/1/2001 and then calculated days since randomization to 7/1/2001.

Included are the results from the DQ as well as classifications (probable dementia (PD), minor cognitive impairment (MCI), or no dementia (ND)) of those cases that were adjudicated by a central panel of cognitive experts. **This dataset is deidentified, so no dates are included.** Follow-up time measurements (scap\_dy) are the number of days from randomization date to d\_scap, and the variable d\_scap has different definitions based on the final classification and the status of the participant (deceased or proxy-dependent) as summarized in the table below. If the participant has been classified as PD or MCI in SCAP and is proxy-dependent, d\_scap is the midpoint of the date of the participant’s last 3MSE or TICS and the date of the DQ interview. If the participant is deceased and classified as PD or MCI, d\_scap is the midpoint of the date of the participants last 3MSE or TICS and the date of death. On the other hand, if the participant is classified in SCAP as ND and she is proxy-dependent, d\_scap is the maximum of the date of the last 3MSE or TICS and the date of the

DQ interview. If the participant is deceased and classified in SCAP as ND, d\_scap is the date of death. In the event that the DQ was not administered or classification is still in process, d\_scap is defined as the date of the last 3MSE or TICS. Importantly, d\_scap was used to define scap\_dy, the days from from randomization to d\_scap, but **d\_scap is not included in the dataset.**

#### Definition of Date of SCAP (d\_scap)

Participant status	SCAP Classification		
	PD or MCI	ND	Missing data
Proxy-dependent	Midpoint of date of last 3MSE/TICS and date of DQ	Maximum of date of last 3MSE/TICS and date of DQ	Date of last 3MSE/TICS
Deceased	Midpoint of date of last 3MSE/TICS and date of death	Date of death	Date of last 3MSE/TICS

### 3. Data File Setup

The data file is a SAS data set with one observation per participant eligible for SCAP. The identifying variable in each file is Participant ID, 'ID' (referred to as the "common ID" in the WHI documentation). Computed variables have also been included and are described in detail under the next section, contents of the DQ. Refer to the Appendix for further details on the tests and questionnaires.

### 4. Contents of the SCAP Dataset

Test/Scale	Variable name	Variable description
Not Applicable	ID	Participant ID
Not Applicable	Phase	Phase when data was collected
Not Applicable	Scap_ppt_status	Status when participant became SCAP eligible
Not Applicable	Death_dy	Days from HT Trial randomization to death
Not Applicable	Dq_status	Status of the Dementia Questionnaire 1) Completed 2) Declined 3) Unable to Complete
Not Applicable	Scap_dy	Days from HT Trial randomization to SCAP
Not Applicable	Final_dx	Classification of participants as follows

		<p>0) Probably No Dementia</p> <p>1) No dementia (no cognitive impairment)</p> <p>2) Mild cognitive impairment (MCI)</p> <p>3) Probable dementia (PD)</p> <p>4) Unable to classify – cognitive impairment</p> <p>5) Unable to classify – functional impairment</p> <p>9) Cannot Classify (SCAP)</p>
Not Applicable	Finalclass	<p>Classification of participants with a probable dementia diagnosis into the following classes:</p> <p>1) Probable Vascular</p> <p>2) Probable Alzheimer’s</p> <p>3) Dementia: Mixed Type</p> <p>4) Dementia: Etiology Unknown</p> <p>5) Other</p> <p>9) Under Review</p> <p>*Note: classification of PD type stopped in 2013 due to adjudicators feeling that they did not have enough information to determine the classification</p>
Not Applicable	Dq_dy	Days from HT Trial randomization to Dementia Questionnaire
Dementia Questionnaire – MEMORY/COGNITION	<p>Mc_memory</p> <p>Mc_memory_dy</p> <p>Mc_names</p> <p>Mc_faces</p> <p>Mc_indoors</p> <p>Mc_indoors_dy</p> <p>Mc_streets</p> <p>Mc_streets_dy</p> <p>Mc_shortlist</p>	<p>Any problems with memory</p> <p>Days to problems with memory</p> <p>Any problems with remembering people’s names</p> <p>Any problems with recognizing familiar faces</p> <p>Any problems with finding way about indoors</p> <p>Days to problems with finding way about indoors</p> <p>Any problems with finding way on familiar streets</p> <p>Days to problems with finding way on familiar streets</p> <p>Any problems with remembering a short list of items</p>

	<p>Mc_shortlist_dy</p> <p>Mc_trouble</p> <p>Mc_course</p> <p>Mc_doctor</p> <p>Mc_cause</p>	<p>Days to problems with remembering a short list of items</p> <p>Did the trouble with memory begin suddenly or slowly?</p> <p>Has the course of the memory problems been a steady downhill progression, have there been abrupt declines, or has it stayed the same?</p> <p>Is a doctor aware of his/her memory problems?</p> <p>What does the doctor believe is causing the problems?</p>
<p>Dementia Questionnaire – EXPRESSION</p>	<p>Exp_word</p> <p>Exp_word_dy</p> <p>Exp_talkless</p> <p>Exp_talkless_dy</p> <p>Exp_past</p> <p>Exp_past_dy</p>	<p>Ever have trouble finding the right word or expressing self?</p> <p>Days to trouble find the right word or expressing self</p> <p>Has talking become less over time?</p> <p>Days to talking becoming less over time</p> <p>Tendency to dwell in the past</p> <p>Days to tendency to dwell in the past</p>
<p>Dementia Questionnaire – DAILY FUNCTIONING</p>	<p>Df_household</p> <p>Df_household_dy</p> <p>Df_money</p> <p>Df_money_dy</p> <p>Df_grasping</p> <p>Df_grasping_dy</p> <p>Df_workoutside</p> <p>Df_age</p> <p>Df_retired</p> <p>Df_retired_dy</p> <p>Df_difficulty</p> <p>Df_difficulty_dy</p> <p>Df_dressing</p> <p>Df_dressing_dy</p> <p>Df_feeding</p> <p>Df_feeding_dy</p> <p>Df_bladder</p>	<p>Trouble with household tasks</p> <p>Days to trouble with household tasks</p> <p>Trouble handling money</p> <p>Days to trouble handling money</p> <p>Trouble grasping situations or explanations</p> <p>Days to trouble with grasping situations or explanations</p> <p>Does/Has he/she (ever) work(ed) outside the home?</p> <p>At what age did he/she retire?</p> <p>Is he/she retired?</p> <p>Days to retired age?</p> <p>Does he/she have difficulty at work?</p> <p>Days to difficulty at work</p> <p>Trouble dressing or caring for self including choosing clothes or tying shoes</p> <p>Days to trouble dressing or caring for self</p> <p>Trouble feeding self including cutting meat and buttering bread</p> <p>Days to trouble feeding self</p> <p>Trouble controlling bladder or bowels</p>

	<p>Df_bladder_dy Days to trouble controlling bladder or bowels</p> <p>Df_bed Trouble getting out of bed and into a chair</p> <p>Df_bed_dy Days to trouble getting out of bed and into a chair</p> <p>Df_bathing Trouble bathing, including getting in and out of a shower or tub and washing independently</p> <p>Df_bathing_dy Days to trouble bathing</p> <p>Df_agitation Agitation and nervousness</p> <p>Df_agitation_dy Days to agitation and nervousness</p>
<p>Dementia Questionnaire – RECOGNITION OF PROBLEM</p>	<p>Rp_first Who was the first person to notice he/she was having memory problems?</p> <p>Rp_first_relative Who was the first person to notice?</p> <p>Rp_noticed_a What was noticed? a.</p> <p>Rp_noticed_b What was noticed? b.</p> <p>Rp_noticed_c What was noticed? c.</p> <p>Rp_noticed_other Who was the first person to notice? Other specification</p> <p>Df_lasttime_dy When was the last time he/she seemed to be really well or his/her old self?</p>
<p>Dementia Questionnaire – OTHER PROBLEMS</p>	<p>Op_highbp High Blood Pressure</p> <p>Op_stroke Stroke</p> <p>Op_stroke_dy Days to stroke</p> <p>Op_weaker Is one side of the body weaker than the other side?</p> <p>Op_parkinson Parkinson's disease (tremor, shuffling gait, limb rigidity)</p> <p>Op_parkinson_dy Days to Parkinson's disease</p> <p>Op_head Injury to head resulting in loss of consciousness for more than a second or two</p> <p>Op_head_dy Days to injury to head</p> <p>Op_seizure Seizure or fits</p> <p>Op_seizure_dy Days to seizure or fits</p> <p>Op_syphillis Syphilis</p> <p>Op_syphillis_dy Days to Syphilis</p> <p>Op_diabetes Diabetes</p> <p>Op_drinking Drinking Problem</p> <p>Op_memory Does he/she have memory problems that coincide with drinking?</p> <p>Op_depressed Ever depressed or sad for two weeks or more?</p>

	<p>Op_depressed_treat Op_high</p> <p>Op_high_treat</p> <p>Op_psychiatric</p> <p>Op_psychiatric_hosp</p> <p>Op_psychiatric_hosp_dy</p> <p>Op_famds</p> <p>Op_famds_who</p> <p>Op_other</p>	<p>Ever seek treatment for depression</p> <p>Ever very high, euphoric, top of the world</p> <p>Ever seek treatment for being very high, euphoric, top of the world</p> <p>Ever seek psychiatric help for any reason?</p> <p>Ever hospitalized for psychiatric illness?</p> <p>Days to hospitalization for psychiatric illness</p> <p>Has anyone in the family ever had Down's syndrome?</p> <p>Who in the family has had Down's syndrome?</p> <p>Other medical problems other than the ones we have talked about</p>
<p>Dementia Questionnaire – MEDICAL CONTACTS</p>	<p>Mdc_meds</p> <p>Mdc_examf</p> <p>Mdc_mri</p> <p>Mdc_mri_dy</p> <p>Mdc_institution</p> <p>Mdc_institution_year1_dy</p> <p>Mdc_institution_year2_dy</p> <p>Mdc_institution_year3_dy</p> <p>Mdc_diagnosis</p>	<p>Did he/she ever receive medications for memory problems?</p> <p>Did he/she ever have a neurological or psychiatric exam?</p> <p>Did subject ever have a CAT scan or MRI of the head?</p> <p>Days to CAT scan or MRI of the head</p> <p>Ever in an institution (Nursing Home)?</p> <p>Days to first admission</p> <p>Days to second admission</p> <p>Days to third admission</p> <p>What was the diagnosis given for problems?</p>
<p>Dementia Questionnaire – OTHER INFORMATION</p>	<p>Oi_school</p> <p>Oi_contact</p> <p>Oi_contact_most</p> <p>Oi_contact_most_other</p> <p>Oi_drive</p> <p>Oi_stopdrive</p> <p>Oi_stopdrive_when_dy</p> <p>Oi_stopdrive_lost</p> <p>Oi_stopdrive_eye</p>	<p>How much schooling did (does) he/she have?</p> <p>How often did/do you have contact with him/her?</p> <p>Most frequent type of contact</p> <p>Most frequent type of contact: Other Specification</p> <p>Did he/she ever drive?</p> <p>Did he/she ever stop driving?</p> <p>Days to stopped driving</p> <p>Why did (s)he stop driving? Gets lost/confused</p> <p>Why did (s)he stop driving? Poor eyesight</p>

	<p>Oi_stopdrive_ill Oi_stopdrive_reflex</p> <p>Oi_stopdrive_accident</p> <p>Oi_stopdrive_fear</p> <p>Oi_stopdrive_cognitive</p> <p>Oi_stopdrive_other Oi_stopdrive_other_sp</p> <p>Oi_stopdrive_dk</p> <p>Oi_stopdrive_na</p> <p>Oi_drive_problems</p> <p>Oi_drive_problems_lost</p> <p>Oi_drive_problems_eye</p> <p>Oi_drive_problems_ill Oi_drive_problems_reflex</p> <p>Oi_drive_problems_accident</p> <p>Oi_drive_problems_fear</p> <p>Oi_drive_problems_cognitive</p> <p>Oi_drive_problems_other Oi_drive_problems_other_sp/</p> <p>Oi_drive_problems_dk Oi_drive_problems_na</p> <p>Oi_autopsy</p>	<p>Why did (s)he stop driving? Illness</p> <p>Why did (s)he stop driving? Bad coordination/reaction time/bad reflexes</p> <p>Why did (s)he stop driving? Frequent accidents</p> <p>Why did (s)he stop driving? Fear/nervous driving</p> <p>Why did (s)he stop driving? Other cognitive problems</p> <p>Why did (s)he stop driving? Other</p> <p>Why did (s)he stop driving? Other Specification</p> <p>Why did (s)he stop driving? Don't Know</p> <p>Why did (s)he stop driving? Not Applicable</p> <p>Is (did) he/she having (have) any problems with driving?</p> <p>What type of problems? Gets lost/confused</p> <p>What type of problems? Poor eyesight</p> <p>What type of problems? Illness</p> <p>What type of problems? Bad coordination/ reaction time/ bad reflexes</p> <p>What type of problems? Frequent accidents</p> <p>What type of problems? Fear/nervous driving</p> <p>What type of problems? Other cognitive problems</p> <p>What type of problems? Other</p> <p>What type of problems? Other Specification</p> <p>What type of problems? Don't Know</p> <p>What type of problems? Not Applicable</p> <p>IF DECEASED, was an autopsy done?</p>
<p>Dementia Questionnaire – STROKE INFORMATION</p>	<p>Si_admitted</p> <p>Si_body</p> <p>Si_body_part</p>	<p>Was he/she admitted to a hospital?</p> <p>Did he/she experience problems with any part of his/her body?</p> <p>Which part of the body?</p>

Si_body_problem	What was the problem with that part of the body?
Si_speech	Did he/she experience any speech problems?
Si_memory_before	Did he/she have problems with his/her memory before the stroke?
Si_memory_after	Did he/she have problems with his/her memory after the stroke?
Si_betterworse	Did his/her memory get better or worse after the stroke?
Si_medications	Was he/she given any medications?
Si_medications_what	What medications?
Si_onestroke	More than one stroke?
Si_onestroke_yr2_dy	Days to second stroke
Si_onestroke_yr3_dy	Days to third stroke
Si_onestroke_admitted	Was he/she admitted to a hospital?
Si_onestroke_body	Did he/she experience problems with any part of his/her body?
Si_onestroke_part	Which part of the body?
Si_onestroke_problem	What was the problem with that part of the body?
Si_onestroke_long	How long did the problem with that part of the body last?
Si_onestroke_speech	Did he/she experience any speech problems?
Si_onestroke_speech_long	How long did the speech problems last?
Si_onestroke_before	Did he/she have problems with his/her memory before the stroke?
Si_onestroke_after	Did he/she have problems with his/her memory after the stroke?
Si_onestroke_betterworse	Did his/her memory get better or worse after the stroke?
Si_onestroke_medications	Was he/she given any medications?
Si_onestroke_medications_what	What medications?

**5. Data Conventions**

Dates

No actual dates are included in the data files. All dates have been converted to the number of days since WHI randomization. A negative number of days indicate the date occurred before randomization. Likewise, a positive number indicates occurrence after randomization.

Data Edits



At data entry, the built-in features of the study database application prevented entry of most invalid or impossible data values for categorical variables. Broad range checks applied to continuous variables have set out-of-range responses to missing. There still may be values that appear extreme; **it is up to the user to examine all data before proceeding with data analysis.**

#### Missing Data

Missing data can result from a participant not completing all tests or assessments. Missing values in the data files are represented by a single period (“.”) for quantitative variables or blank (“ ”) for character variables.

## **6. Appending and Merging Data Files**

If you wish to expand your data analyses to include WHI Clinical Trial data, you can use the ID variable in the WHIMS–SCAP data set and the ID variable in the WHI Clinical Trial data set to merge data sets. The WHIMS and WHI Clinical Trial data releases use the same participant ID.

The SCAP data is a full set of all observations including those released in the 2010 SCAP data release; therefore, this dataset should not be appended to the previously released version, rather it should replace the previous version.

For further information about this data release, please contact Katelyn Garcia at [kgarcia@wakehealth.edu](mailto:kgarcia@wakehealth.edu) or Julia Spell [jurobert@wakehealth.edu](mailto:jurobert@wakehealth.edu).