

# **Health and Retirement Study**

## **2016 Harmonized Cognitive Assessment Protocol (HCAP)**

Study Protocol Summary

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## **HCAP Study Objectives**

The Harmonized Cognitive Assessment Protocol (HCAP) is a substudy within the ongoing Health and Retirement Study (HRS). It is part of an ongoing international research collaboration funded by the National Institute on Aging (NIA) to measure and understand dementia risk within ongoing longitudinal studies of aging around the world using a Harmonized Cognitive Assessment Protocol (also HCAP). We collect a variety of established cognitive and neuropsychological assessments and informant reports to discriminate Normal, Cognitive Impairment, and Dementia status in a sub-sample of the HRS. The protocol was designed to harmonize well with prior studies, including the Rush University Memory and Aging Project (Bennett, et al, 2012), the 10/66 studies that rely primarily on the Community Screening Interview for Dementia (CSI-D; Prince, et al, 2011), and the previous HRS dementia study known as ADAMS (Langa, et al, 2005). Versions of HCAP are being conducted in Mexico, India, England, China, and South Africa. The HRS can provide assistance with interviewer training and protocol implementation to studies interested in using HCAP.

HCAP cases includes a pair of interviews, one by the Target Respondent (pre-selected HRS panel member, age 65+) and one by an Informant (nominated by the Target Respondent). Ideally, both interviews are conducted at the same time with a trained HRS interviewer in the Target Respondent's home. When schedules do not permit, the Informant interview was conducted by telephone. The final HCAP sample included 3496 cases. While the majority of HCAP cases included both a Target Respondent and Informant interviews, there were some instances where a Target did not nominate any potential informants (n = 313). There were also a few cases where only an informant interview was conducted (n = 149) as the Target Respondent was not well-enough to attempt an interview. The consent and interview protocols and materials were developed with a series of pilot studies. HCAP was administered in both English and Spanish.

Data from the HCAP study will be linked to the Respondent's HRS data, and thus the HCAP strategically excluded the measurement of some factors relevant to performance on cognitive tests because that information is already captured in HRS (such as a stroke diagnosis). The end of the HCAP Respondent interview does include an assessment of current depressive symptoms (CES-D, abbreviated) as well as a test of olfaction which is presented as optional for the Respondent.

## **Subject Population**

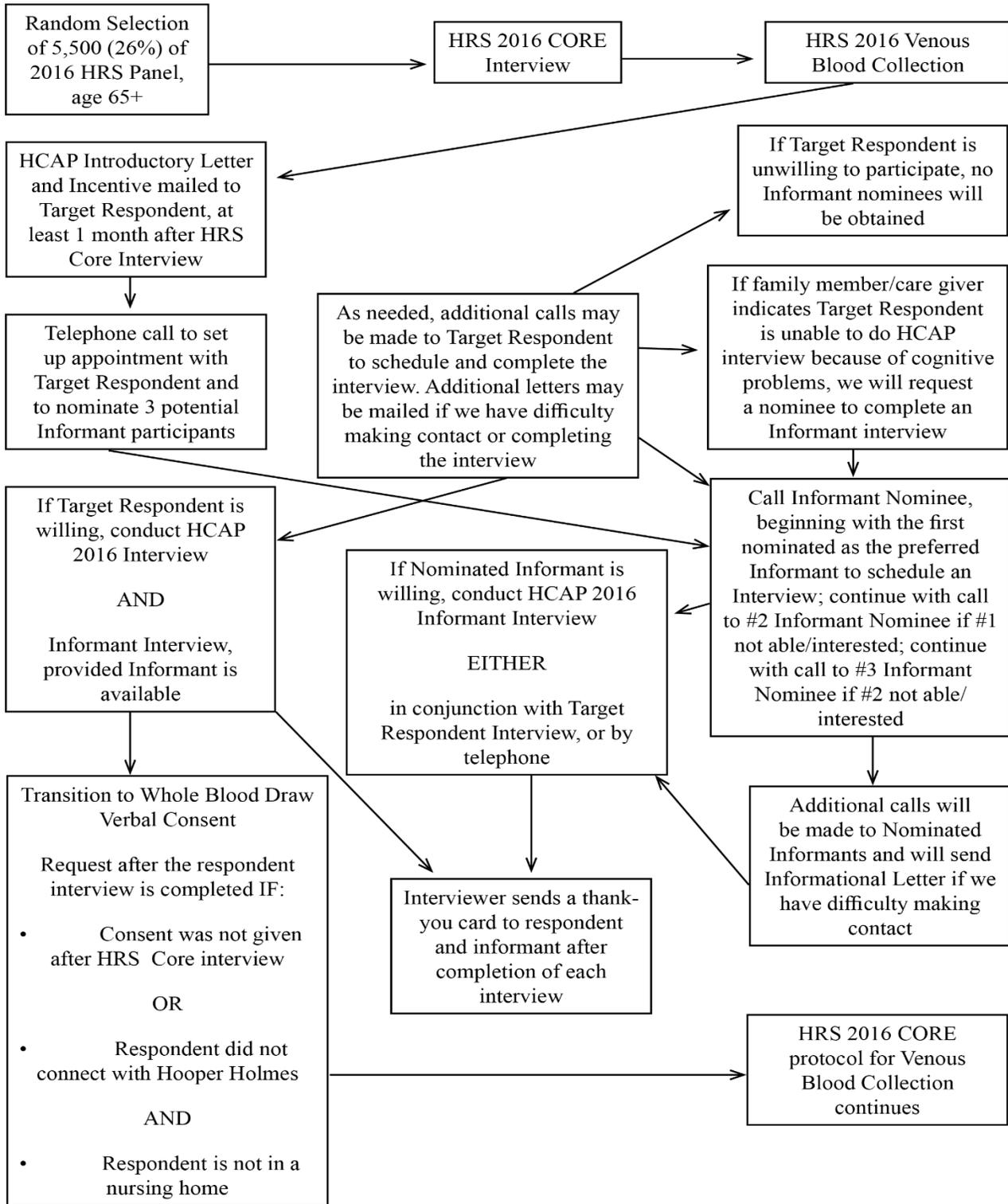
The eligible sample consisted of pre-selected HRS Panel respondents, age 65 or older (birth year 1952 or earlier), who completed their 2016 interview before they become eligible for the HCAP study. Of those who were age-eligible and who completed their 2016 Core Interview, those eligible for HCAP were selected via the following process:

- 1) Randomly select 1/2 of uncoupled Respondents.
- 2) Randomly select 1 Respondent from each coupled household.

## **HCAP Recruitment and Interview Process**

A detailed diagram of the process by which HRS participants were contacted, recruited, consented, and interviewed for the HCAP study is illustrated in Figure 1. Note that in addition to completion of the 2016 HRS Core interview, those respondents who had a scheduled Venous Blood Collection appointment also had to complete that component of the study before they were contacted about HCAP. In addition, for those respondents who were eligible for the HRS Venous Blood Collection who declined to participate or were unable to schedule an appointment prior to participating in the HCAP study, these cases were given another the opportunity to consent to participate in the Whole Blood collection when they completed their HCAP interview (as reflected in the figure).

Figure 1. HCAP Recruitment Protocol Diagram



## HCAP Respondent and Informant Interview Summary

The HCAP Respondent interview is estimated to take roughly 1 hour to complete, followed by a 20-minute Informant interview. The content and order of Respondent (Table 1) and Informant (Table 2) interviews are below.

<b>Table 1: Respondent Interview</b>
A – MMSE
B – TICS
C – Word List Learning & Recall - Immediate
D – Retrieval Fluency
E – Letter Cancellation
F – Backward Count
G – 10/66 - Respondent
H – Word List Recall - Delayed
I – Story Memory - Immediate
J – Word List Recognition
K – Constructional Praxis - Immediate
L – Symbol-Digit Modalities Test
M – Constructional Praxis - Delayed
N – Story Memory - Delayed
O – Logical Memory - Recognition
P – Number Series
Q – Raven’s
R – Trail Making
S – CES-D Depressive Symptoms
T – Smell Test (Optional)

<b>Table 2: Informant Interview</b>
A – Informant Demographics
B – Jorm IQCODE
C – Blessed Part 2
D – Activities
E – CSI-D – Cognitive Activities
F – 10/66 - Informant
G – Blessed Part 1

## **HCAP Respondent Interview Detail**

This section includes information on the specific tests and protocol used for the HCAP Respondent interview. Information on copyright is also included.

### *Mini-Mental State Examination (MMSE)*

This test includes 22 items (10 orientation, 8 language, 1 of each: registration, memory, spelling backward, and construction). The maximum score = 30. Reference Folstein et al. (2001) for administration details. A license to administer MMSE was obtained from Psychological Assessment Resources (PAR), Inc.

### *HRS-TICS (abbreviated)*

This section includes three questions from the HRS-TICS that did not overlap with content in other sections of the HCAP Respondent interview. This includes questions to identify two name two words (vocabulary) and naming the President of the United States. This measure is based on the full Telephone Interview for Cognitive Status (Brandt, Spencer and Folstein, 1988).

### *CERAD Word List Learning and Recall (Immediate)*

This test visually presents 10 high imagery words for 2 seconds each. The respondent reads each word aloud as it was presented and is then tested on an immediate recall procedure. The respondent is presented this list three times in different orders and is asked to recall as many words as possible after every presentation. The immediate recall score used is from Trial 1. In addition to correct recall responses, intrusions are also recorded. See CERAD (1987) for administration and scoring. A license to administer all CERAD instruments was obtained from the Consortium to Establish a Registry for Alzheimer's Disease (CERAD) through Duke University.

### *Retrieval Fluency*

This test of retrieval fluency is the same that is administered in the HRS Core survey. This test is a typical neuropsychology test and was adapted by McArdle and Woodcock from the WJ- III Tests of Achievement: Retrieval Fluency (© Riverside Publishing). The measure consisted of a single item in which respondents were asked to name as many animals as they could within a 60-second time limit. This measure is consistent with animal fluency measures commonly administered in other neuropsychological exams (e.g., the CERAD animal fluency measure; Morris et al., 1989).

### *Letter Cancellation (ELSA)*

This test has been included in ELSA and assesses attention and speed. Respondents are given a paper with a large grid of letters and are asked to scan the grid as quickly as possible in a minute and to cross out as many "P" and "W" letters as they can in that time. Scores include the last letter an individual arrived at, the number of correctly crossed-out letters, the number of missed letters, and the number of incorrectly crossed-out letters. This test is administered with paper and pencil and is sent back to Survey Research Operations at the University of Michigan to be scored after the interview is completed. This test was originally developed for the 1946 birth cohort study (Richards, Kuh, Hardy, & Wadsworth, 1999).

### *Backward Count (MIDUS)*

This test assesses speed and attention and is derived from the Backward Count measure in the MIDUS Study. Respondents are asked to begin at 100 and to count backwards as fast as possible. They are given 30 seconds and the number they reach and number of errors are recorded. See Lachman, Agrigoroaei, Tun, & Weaver, 2013) for more details.

#### *10/66*

This series of questions derive from the 10/66 and CSID surveys to assess cognitive impairment and dementia. The questions evaluate language, knowledge and the ability to follow directions.

#### *CERAD Word List Recall – Delayed*

This is a single trial to recall the list of 10 words from the CERAD Word List Learning and Recall (Immediate) task. Respondents are asked to freely recall as many words as possible from that list. The interviewer records all correct responses as well as intrusions (words not on the original list).

Respondents are given up to 2 minutes to complete this task.

#### *Story Memory - Immediate (Brave Man and WMS-IV Logical Memory I)*

This section involves the reading of stories to the Respondent and is scored based on the number of story points the respondent can immediately recall after hearing each story. The first story read to the respondent is the Brave Man story, included in many dementia studies around the world. The second story read to the Respondent is one of two from the Wechsler Memory Scale (WMS-IV). This story is longer and has more content than the Brave Man and the scores are based on the number of story points correctly named immediately after the story is read to the Respondent. For administration and scoring guidelines for the WMS-IV Logical Memory (Immediate, Delayed and Recognition), see Wechsler (2009). A license to administer the WMS-IV Logical Memory (Immediate, Delayed, Recognition) was obtained from Pearson Education, Inc.

#### *CERAD Word List Recognition*

This is a recognition trial of the CERAD 10-word list, where the Respondent is visually presented a series of 20 words including 10 from the list and 10 foils and asked to identify whether each word was on the list (Yes / No).

#### *CERAD Constructional Praxis – Immediate*

The CERAD Constructional Praxis test is adapted from Rosen's assessment of constructional praxis (Rosen et al., 1984), and tests the ability of the subject to copy four geometric forms of varying difficulty (circle, overlapping rectangles, diamond and cube). For scoring CERAD Constructional Praxis (Immediate and Delayed), see CERAD, 1987; Yuspeh, 1998.

#### *Symbol-Digit Modalities Test (SDMT)*

The test is administered with the official SDMT paper form and requires the Respondent to substitute a number for randomized presentations of geometric figures. A printed key is provided which pairs the Arabic numbers 1-9 with a specific symbol so that each number has its own unique symbol. The Respondent completes as many pairings as possible in 90 seconds. The score is the number of correct pairings minus any mistakes/skips. For scoring and administration, see Smith (1982). The official forms to administer this test were purchased from Western Psychological Services (WPS).

### *CERAD Constructional Praxis – Delayed*

This is a delayed recall of the geometric shaped drawn in the test of CERAD Constructional Praxis – Immediate. Respondents are asked to draw the shapes from earlier in the interview to the best of their memory.

### *Story Memory – Delayed*

In this section, Respondents are asked to think back to the two stories read to them earlier and recall as much about each story as they can. The scoring is identical to the immediate recall of the stories. If individuals refused to do the Story Memory – Immediate section, administration of the delayed section is skipped.

### *WMS-IV Logical Memory – Recognition*

Following the Story Recall – Delayed section, we administer a set of follow-up story recognition questions based on the WMS-IV story. This is a series of 15 questions which ask the Respondent to identify (Yes or No) whether a specified story point was part of the story they were read. The questions include correct and incorrect story points, and the total score is the sum of correctly answered questions.

### *HRS Number Series*

Developed for the HRS, this section evaluates Respondents' ability for numeric reasoning by presenting a series of 6 individual series of numbers, where one or two numbers in the series is missing. The Respondent is asked to take as much time as s/he needs, with the help of scrap paper and a pencil, to identify the missing number/s. This test, documented in detail here: <http://hrsonline.isr.umich.edu/sitedocs/userg/dr-027b.pdf>, is a block-adaptive test. Respondents are given a set of three number series questions of varying difficulty to first complete. Based on the number of correct responses in this first set of three (score Range = 0 to 4), Respondents are then assigned to a second set of three questions, for which the difficulty level is based on the number correct on the first set. The HRS uses two versions of the Number Series questions and respondents are assigned to the version that was not done in the previous wave. For HRS-HCAP, Respondents were assigned to the Number Series that was not assigned in the 2016 Core interview. If a Respondent was not able to do the Number Series section in the 2016 Core interview (not able to do practice questions, was too confused), then they were skipped out of this section.

### *Raven's Standard Progressive Matrices*

This test evaluates picture-based pattern reasoning of varying difficulty. Each question presents a geometric picture with a small section that appears to have been cut out. The Respondent is shown a set of smaller pictures that fit the missing piece and are asked to identify which is the correct one to complete the pattern. For HRS-HCAP we have selected a subset of 17 questions out of the 60 in the full test, including one practice question. The Raven's Standard Progressive Matrices administration booklets and materials were ordered from Pearson Education, Inc. See Raven et al. (2000) and Raven (2000) for administration and measurement properties.

### *Trail Making Test (A and B)*

The test is administered in two parts, A and B. The Respondent is asked to draw lines connecting consecutively numbered circles on a worksheet (Part A) and connect consecutively numbered and lettered circles on another worksheet (Part B) by alternating between the numbers and letters. The Interviewer is instructed to point out errors to the Respondent and have the Respondent go back to the previous circle and move on to the next correct one. The scores for this test is the number of seconds to complete Part A and Part B, where the time to correct errors serves to increase the total time to complete the test. See Reitan (1992) for procedure and scoring. The official Trail Making test forms were ordered from Reitan Neuropsychology Laboratory as part of the Halstead-Reitan Neuropsychological Test Batteries.

### *CES-D Depressive Symptoms*

To measure the impact of current depressive symptoms on test scores, we include a brief version of the CES-D inventory. This is an abbreviated version that, similar to the HRS Core administration, uses a Yes/No response frame rather than the full Likert scale. The version in HRS-HCAP is an 11-item list. See Radloff (1977) for information about the inclusion of CES-D in surveys and for details on the HRS CES-D abbreviated version see <http://hrsonline.isr.umich.edu/sitedocs/userg/dr-005.pdf>.

### *Smell Test (NSHAP)*

After completing the main portion of the HCAP Respondent Interview, sections MMSE through CES-D, Respondents are asked if they are interested in completing one additional task involving the sense of smell. The protocol for this task was adapted from that used in NSHAP the specific protocol is only able to be shared with permission of NSHAP. The protocol is roughly 10 minutes to complete, and includes the use of pens specially produced to test an individual's sense of smell as well as ability to recognize well-known scents. See <http://www.whitehair365.com/support-files/20541-questionnaire.pdf> for NSHAP protocol documentation.

## **HCAP Informant Interview Detail**

This section includes information on the specific tests and protocol used for the HCAP Informant interview. Ideally this interview is completed with the informant in-person directly after completing the HCAP Respondent Interview, with the Respondent in another room. A response booklet is used for this interview to minimize the sensitive nature of the informant's responses to the questions. The Informant Interview has also been adapted for telephone and paper administration.

### *Informant Demographics*

This section collects information about the Informant and about the Informant's relationship with the Respondent. This includes Informant age, gender, education level, relationship to Respondent, years Informant has known Respondent, frequency of contact with Respondent in previous year, whether the Informant is a caregiver for the Respondent, and whether the Respondent has been diagnosed with stroke, Parkinson's Disease, Alzheimer's Disease, or memory problems.

### *Jorm IQCODE*

This instrument asks the Informant to compare current functioning to 10 years ago. If the Informant has known the Respondent for less than 10 years, the length of time they have known one other is automatically filled into these questions. These questions are adapted from the short form of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE; Jorm, 1994).

### *Blessed Dementia Rating Scale – Part 2*

This set of three questions asks the Informant to indicate the Respondent's ability to do basic self-care activities, including getting dressed, eating, and using the toilet. Blessed Dementia Rating Scale details can be found in Blessed, Tomlinson & Roth (1968) and Morris et al. (1989).

### *HRS-Activities*

This section was developed by HRS to assess Respondent activity engagement that was not captured by other standardized informant questionnaires, based on gaps noted in HRS-HCAP pilot testing.

### *CSI-D Cognitive Activities*

This section includes questions about the Respondent's cognitive activity engagement and ability, derived from the Cognitive Screening Interview for Dementia. These items assess changes in the Respondent's ability to remember things and engage in activities of varying cognitive demands. See Hall et al. (2000) for more details on the CSI-D instrument.

### *10/66 Informant*

This section is a short series of questions from the 10/66 Brief Screener for Dementia that assesses the Respondent's ability to do daily activities such as household chores or handle money. Details on this instrument can be found in Prince, Acosta, et al. (2011).

### *Blessed Dementia Rating Scale– Part 1*

This final section includes a series of question about additional activities and mental abilities, whether the Respondent has experienced a loss in the ability to do these activities, and whether the loss is due

to mental, physical, or both mental and physical reasons. Blessed Dementia Rating Scale details can be found in Blessed et al. (1968) and Morris et al. (1989).

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