

ICPSR 36036

**ACTIVE (Advanced Cognitive  
Training for Independent and Vital  
Elderly), 1999-2008**

Manual

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# **ACTIVE (Advanced Cognitive Training for Independent and Vital Elderly), 1999-2008**

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## ICPSR PROCESSING NOTES FOR #36036

*ACTIVE (Advanced Cognitive Training for Independent and Vital Elderly), 1999-2008*

### Manual

1. **Document Relationships:** The sections of this manual describe the administration of the various forms and assessments which were used to collect the data in this study. The table below describes the relationship between each section of the manual to the datasets in this study.

ACTIVE Section	ICPSR Datasets
Final Disposition Form #001 Question by Question Specifications	1
Deceased Participant Disposition Form #002 Question by Question Specifications	2
Individual Assessment Part I Question by Question Specifications	3, 4, 5, 6, 9, and 21
Individual Assessment Part II Question by Question Specifications	7, 8, and 22
Group Scripts	10, 11, 12, 13, 14, 15, 16, and 17
Group Assessment Question By Question Specification	10, 11, 12, 13, 14, 15, 16, and 17
Abbreviated Testing Batteries Question by Question Specifications	18,19, and 20

# **Guideline to the ACTIVE Trial**

*Excerpt from ACTIVE Trial Manual of Operations*

## **I. STUDY OVERVIEW**

### **A. Study Significance**

The long-term goal of the ACTIVE study is to reduce the increasing public health problems of need for formal care, hospitalization, and substantial loss of independence in the nation's growing older population. Persons over the age of 65 account for almost half of all days of care in short stay hospitals and constitute the majority of residents of nursing homes. Interventions that can postpone or prevent hospitalization or need for formal care, therefore, have much to contribute both to public health and to the quality of life among older people. The immediate goal of this initiative is to examine the effects of cognitive interventions on more proximal outcome measures that are associated strongly with hospitalization and need for formal care.

The impetus for this trial came from a) the success of a number of prior different cognitive or related perceptual, intervention techniques at enhancing some aspects of ability or functioning; b) the increasing evidence that cognitive factors are associated with key public health outcomes such as hospitalization and death; and c) the increasing need to find preventative techniques that successfully maintain the quality of life of the rapidly increasing older population.

Recent research had confirmed earlier findings of an association between decline in cognitive functioning and measures of hospitalization, need for formal care, and mortality. Several studies using a range of measures of cognitive impairment had established associations with quality of life of family members and risk of institutionalization. Some investigators had identified an association between both mild and severe cognitive impairment and mortality in community-dwelling elderly.

Such findings demonstrated the success of cognitive interventions at improving performance in activities of daily living, and illustrated the links between decline in cognitive function and subsequent hospitalization, need for formal care, and mortality. Nevertheless, no clear consensus existed on the likelihood of success of cognitive interventions at reducing the public health problems of hospitalization and need for formal care in the older population. Differences in the outcome measures examined, the interventions tested, and the samples recruited have made generalizations across different findings impossible. This trial addressed these problems by testing a planned intervention on defined samples using common outcome measures.

### **B. Study Goal**

The scientific goal of the trial was to test the effect of three cognitive training programs on improving both cognitive function and the ability to perform certain daily tasks that rely on mental abilities.

### **C. Study Design**

The design (Figure 1) for ACTIVE was a randomized control trial. Subjects were randomly assigned to one of three treatment groups:

- 1) Memory training;
- 2) Reasoning training;
- 3) Speed of Processing training; or
- 4) no training (control)

The interventions occurred in replications, with each replication taking approximately 16-18 weeks. All subjects were assessed at baseline, immediately after the intervention period (post-test), and then at 12-months and 24-months. Booster sessions for each of the three training interventions are conducted within 45 days before the 12-month assessment. Phase II consisted of an assessment at 60 months following completion of training. Phase III consisted of an assessment at 120 months following completion of training. This memo summarizes Phase III activities.

### **D. Variables of Interest**

A description of the variables of interest in this study and the tests or questions to measure these variables are described in the following sections.

#### **D.1 Proximal Outcomes: Measures of Cognitive Function**

Proximal outcomes are measures that tell us whether the cognitive training in ACTIVE worked. By giving a measure before and after subjects received training, we can determine whether participants get better, or improve, after training. Since the training in ACTIVE focused on remembering (memory), concentrating (visual processing speed), and problem solving (inductive

reasoning), proximal outcomes are measures of memory, visual attention/visual processing speed, and inductive reasoning. Each of these measures is described below.

#### a. **Memory**

**Rivermead Behavioral Memory Test:** In ACTIVE, we selected a particular subtest of this test which emphasizes memory for stories. Formally, this ability is known as “prose memory”. Subjects were read (via a tape player) a brief 4-5 sentence paragraph. They were then asked to remember as much of the story as they can. They had 3 minutes to write down as much of the story as they can remember.

**Hopkins Verbal Learning Test (HVLT):** The HVLT measures three things. First, it measures how well older adults can remember word lists (each twelve words long) when those lists consist of words in several meaningful categories (e.g., animals, housing types). Second, it measures how much older adults can improve their memory for these words after hearing them several times (this is called “learning”). Third, it measures whether individuals can recognize words that they have heard when those words are mixed in with a number of words that they haven’t heard. Subjects were read (via tape player) a list of twelve words, with a new word stated every 2 seconds. Then, they were given 2 minutes to write down all the words they can remember. After hearing the words three times in a row, they moved on to another exercise, but then were asked to recognize as many words from this list as they can later on.

**Rey Auditory Verbal Learning Test (AVLT):** This test is similar to the HVLT. First, it measures how well older adults can remember lists of unrelated words (each 15 words long). Second, it measures how much older adults can improve their memory for these words after hearing them several times (this is called “learning”). Third, it measures whether individuals can recognize words that they have heard when those words are mixed in with a number of words that they haven’t heard. Subjects were read (via tape player) a list of 15 words, with a new word stated every 2 seconds. Then they were given 2 minutes to write down all the words they can remember. After hearing the same list 5 times, they were presented a list of 15 new words and asked to write down as many words from the second list as they could remember. After this second list, they were asked to write down as many words as they could remember from the first list without hearing the first list again. Finally, they were read a list of 50 words with a new word stated every 2 seconds, and asked to indicate if the word was from the first list of words.

#### b. **Inductive Reasoning**

Broadly speaking, inductive reasoning refers to our ability to “figure things out”, especially when we are examining things we haven’t seen before. Whenever we encounter new situations (a room of unfamiliar strangers at a party; a tax form we’ve never completed before), we have to determine the pattern (“which group would I be best off talking to?” “which lines of this form apply to me?”). Research suggests that measures of inductive reasoning are related to everyday problem solving (e.g., reading a bus schedule, completing an order form, following directions on medication labels). In ACTIVE, we tested inductive reasoning with a variety of abstract materials (letters, days of the week), to determine whether individuals could ‘figure out’ the patterns in these stimuli.

**Letter Series:** Letter Series measures whether individuals can determine the pattern in a list, or series, of letters in order to determine what letter would come next in that series. Each series of letters follows a different pattern description rule. On the left side of the page, subjects saw a row of letters like “a c b a d b e \_”, and determined, from an answer row on the right (e.g., “a b c d e f g h”) which letter would come next in the series. Subjects were given 6 minutes to complete the test.

**Word Series:** Word Series measures whether individuals can determine the pattern in a list, or series, of words in order to determine what word would come next in the series. Each series of words follows a different pattern description rule. In this test, the word series are usually made up of months of the year, or days of the week. Moving down a column, subjects saw a list of words (“January February February March April April \_”), and determined, from a separate column of answer choices (“January February March April May June”) what word would come next in the series. Subjects were given 6 minutes to complete the test.

**Letter Sets:** In this test, subjects viewed several sets of letters and identified the set that did not use the same pattern rule as the other sets in that group.

Subjects saw a page with 15 lines of letter sets. Each line contained 5 sets of letters. Subjects were instructed to mark an x through the letter set that did not fit the rule. Subjects were given 7 minutes to complete the test.

#### c. **Speed of Processing**

As persons age, it is thought that there is a generalized slowing down of the nervous system. This includes the time it takes for a person to see and respond or react to something (a stimulus) presented to them. In ACTIVE, four tests will be used to measure speed of processing. Two tests were paper-and-pencil tests, and two tests were administered using a computer with a touch-screen.

**Digit-Symbol Substitution Test:** This test measures how quickly a person can copy symbols that are paired with a number. That is, it measures how quickly someone can look at a number, find the symbol that is paired with that number, and copy that symbol correctly.

Subjects were given a form with rows of boxes. Each box had a number with a space below it to draw a symbol. Above this grid was a key containing nine boxes, each with a number and a symbol. Subjects used this key to find the correct symbol for each blank box. Subjects were given 90 seconds to copy as many symbols as they could.

**Digit Symbol Copy Test:** This test is somewhat similar to the *Digit Symbol Substitution Test* except that subjects are required only to copy symbols as fast as they can.

Subjects were presented 100 boxes (7 practices), each of which had a symbol with a space below it in which they were instructed to copy that symbol. They were timed to see how long it took to copy all symbols. The number of symbols accurately copied was factored into a score which was used to control for writing speed when assessing the results of the *Digit Symbol Substitution Test*.

**Useful Field of View (UFOV):** This test was administered on a computer. This test measures how well subjects can notice objects around them when they are paying attention to something in front of them. This ability to divide attention and notice things to the side is needed for getting around safely in the environment.

The UFOV is comprised of three subtests, each of which builds on the previous subtest. The first subtest required the subject to identify which of two objects (a silhouette of a car or a truck) was presented inside a box. How long the target was shown on the screen was manipulated to determine a threshold value for correct identification. The second test included a central identification task, but in addition, the subject was required to locate a peripheral target object. The location of the target changed from trial to trial and once again a threshold for both the identification of the central target AND correct localization of the peripheral target was determined by manipulating the length of time the object was displayed. The third test requires the subject to perform the central identification task and the peripheral task. However, the peripheral target was surrounded by other objects called distracters. Once again, amount of time for correct performance of both the identification and localization tasks was determined.

#### d. General Knowledge

**Vocabulary:** This test of verbal ability assesses recognition vocabulary. This is a test of general knowledge in which subjects are asked to select a word with a meaning similar to an identified word. This is a timed test.

Subjects were presented a list of 18 words. Each word had five response choices, and subjects picked the word with a similar meaning. Subjects were given 4 minutes to complete the test.

## D.2 Primary Outcomes: Measures of Daily Functioning

The primary outcome measures are measures thought to assess the central goals of this trial: How independent are the ACTIVE elders? How capable are they of performing tasks of daily living and self-care? Because of the cognitive focus of ACTIVE, a number of our primary outcome measures specifically tried to get at the mental capacity to perform everyday tasks. Other measures focus on specific areas of everyday task performance -- like driving -- or they tried to assess how well individuals could perform more general everyday tasks (without specific reference to mental functioning).

**Everyday Problems Test (EPT):** The EPT measures adults' ability to understand and solve problems involving everyday printed materials dealing with seven domains of daily living (food preparation, medication use, telephone use, financial management, shopping, transportation, and housekeeping and laundry). It is significantly related to measures of intellectual ability and to a person's self-rating of how well they can perform instrumental activities of daily living. In the EPT, individuals saw 15 different everyday printed materials (e.g., a tax form, a medication label). For each printed material, they were asked to practice problems about the stimulus (e.g., when shown a drug label, participants might be asked the maximum number of teaspoons they should take over a 2-day period).

**Observed Tasks of Daily Living (OTDL):** The OTDL is a performance-based assessment of an older adult's functioning in three IADL domains: medication use, telephone use and managing finances. Unlike the EPT, the OTDL assesses performance via direct observations of subject behavior.

In the OTDL, subjects were shown certain items like medicine bottles or a utility bill. They were presented with questions printed on cards and asked to provide the answer, using the item (e.g., medicine bottle) to find the requested information.

**Timed IADLs:** This test consists of five common activities of daily living all of which involve searching for, and processing information regarding target objects or information: finding a telephone number; making change; reading can ingredients; finding items on a shelf; and reading directions on medicine bottles.

For this test, subjects were presented with an object(s) and asked to perform a task. For example, a subject was given a telephone directory and presented with a name. The subject had to find and call out the telephone number for this name.



Performance was timed to measure the speed of information processing and visual search while involved in these everyday activities.

**Complex Reaction Time (CRT):** The CRT test involves a measurement of how quickly a subject can recognize that one of four possible traffic signs has changed relative to the other three signs. This test was administered to all subjects on a computer terminal. The stimuli consisted of international road signs (pedestrian, bicycle, right and left turn arrows) with and without a red slash through them. Subjects were instructed to ignore signs containing a red slash and to react to signs without a red slash. One of three reactions was required. For bicycle and pedestrian signs without a slash, the subject was required to press a button on a computer mouse as quickly as possible. The action signaled by the right or left turn arrow without a slash was to move the mouse in the direction indicated by the arrow as quickly as possible. The number of stimuli on the screen at any given time ranged from three to six signs. Without a trial, the number of stimuli was held constant although the positions of the signs change throughout the frames.

**MDS-HC:** The MDS-HC measures the subject's general functional ability. It is a self-reported measure of a subject's ability to perform 3 activities of Daily Living (ADLs: dressing, bathing, personal hygiene) and 7 Instrumental Activities Of Daily Living (IADLs: preparing meals, housework, managing finances, managing health care, phone use, shopping, and travel). Each task is broken down into subtasks.

This information was collected by interviewing the subject, asking a series of questions for each task or activity. Self-reported self-performance was assessed for the 7 days prior to the interview, using a 5-point scale of independence to total dependence. An additional 3-point scale measuring degree of difficulty was used for the IADL items only.

### **D.3 Primary Outcomes: Estimation of effects of ACTIVE Training to General Population**

To estimate and project the effects of ACTIVE training to the general population of older adults by linking the measures and outcomes of ACTIVE to the Health and Retirement Study, a population-based, nationally-representative cohort." The linkage was accomplished by adding the Telephone Interview for Cognitive Status (Form 300) which allowed ACTIVE to map Tenth Annual findings onto a nationally representative sample (the Health and Retirement Study, HRS). ACTIVE was linked to the HRS using a combination of demographics and cognitive performance, adjusting for imbalance in the composition of the ACTIVE study and selective participation due to cognitive ability. The end product was an estimate of the magnitude of the ACTIVE intervention effects if the program were available (and similarly effective) in a nationally representative sample.

### **D.4 Secondary Outcomes**

#### **a. Health Care and Service Utilization**

A secondary interest in the ACTIVE study was whether the effects of the cognitive training, by improving daily function, affected the use of health and social services. Therefore, information about use of these services was collected at 120 months after completion of training. The information is collected through self-report.

Participants were asked in interview format for the following information:

- a. availability of a regular physician or other health care provider
- b. number of physician/provider visits
- c. recency of last visit for medical care
- d. recency of last visit for dental care
- e. number of hospital admissions
- f. number of hospital days
- g. number of nursing home admissions
- h. number of days in nursing home
- i. number of emergency room admissions
- j. number of physical therapy sessions
- k. number of audiologist sessions
- l. number of visiting nurse visits
- m. number of home health aide visits
- n. number of personal care attendant visits
- o. number of adult day care or day activity center visits
- p. number of psychologist or mental health worker visits

#### **b. Driving Habits**

The Driving Habits Questionnaire was used to obtain information about driving exposure and avoidance of difficult driving situations. Two forms of this questionnaire were used: 1) for current drivers and 2) for non-drivers. The information was collected

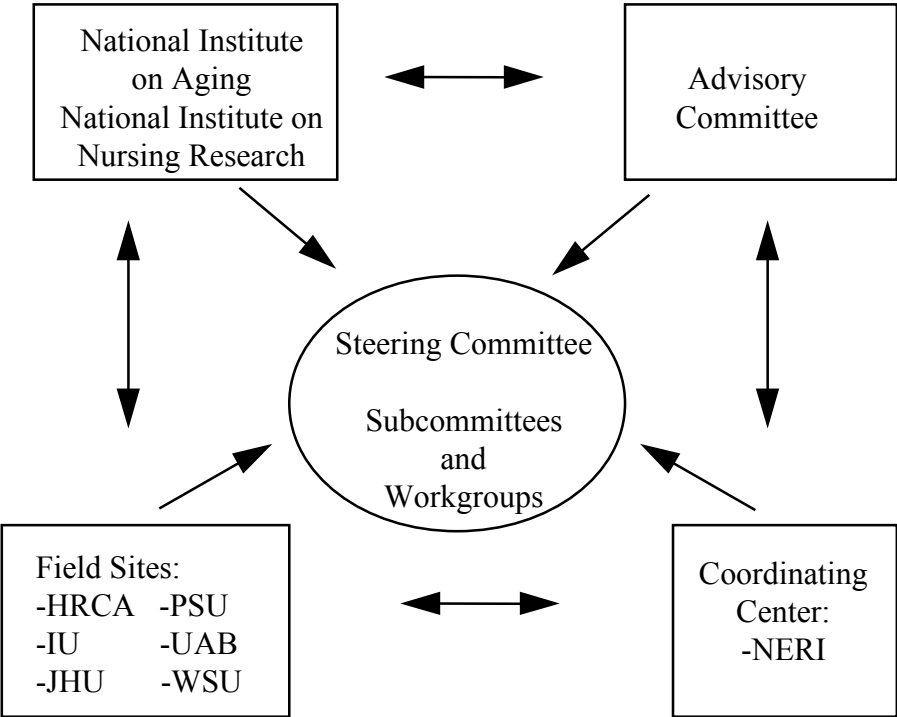
by interview format. With respect to driving exposure, this questionnaire contains several items which asked about exposure -- how many miles, how much time, how many trips during some specified time period. Answers to these questions were combined to arrive at an estimate of driving exposure expressed in terms of miles/year. With respect to avoidance of difficult driving situations, there were eight questions which asked how often the subject avoided difficult driving situations. For example, "Do you avoid driving in rush-hour traffic?", and the response choices are never/rarely/sometimes/often/always. Other situations asked about include inclement weather, alone, parallel parking, making left-hand turns across traffic, high speed interstates/expressways, at night, on high traffic roads. These "avoidance" questions provided information about how each subject restricts their driving exposure.

**c. Mobility:**

Two self-report questionnaires were used. The Falls and Mobility Questionnaire deals with postural instability, falls, the use of canes or assistive devices, etc. The Life Space Assessment is a measure of the extent to which individuals are able to go outside of their homes. This instrument considers "life space," as a series of concentric zones such as bedroom, house, yard, neighbors, block, town, community, etc. This information was collected by interview format.

**II. ORGANIZATION OF THE STUDY**

Figure 1 presents the overall organizational structure for ACTIVE which is described in the sections that follow,



**A. Participating Institutions**

The ACTIVE trial is being carried out by six Field Sites, a Coordinating Center, and the Project Offices at NIA and NINR. The Field Sites are:

<u>INSTITUTION</u>	<u>P.I.</u>
Hebrew Senior Life*, Boston	Richard N. Jones, ScD, John Morris, Ph.D.
Indiana University	Frederick Unverzagt Ph.D.
Johns Hopkins University	George Rebok, Ph.D.
Pennsylvania State University	Sherry Willis, Ph.D.
University of Alabama at Birmingham	Karlene Ball, Ph.D.
Wayne State University/University of Florida	Michael Marsiske, Ph.D.
* Formerly Hebrew Rehabilitation Center for Aged	

The Coordinating Center was the New England Research Institutes (NERI) in Watertown, MA. Sharon Tennstedt, Ph.D. is the P.I.

At the end of the study, the NIA Scientific Coordinator was Jonathan King, Ph.D., Program Director, Division of Behavioral and Social Research.

At the end of the study, the NINR Scientific Coordinator was Susan Marden, Ph.D., Program Director, Symptom Management, Research Methods.

### III. ELIGIBILITY AND RECRUITMENT

#### A. ELIGIBILITY CRITERIA

The target population for this trial consisted of older persons who were living largely independent of formal care at the point of entry into the study but who were at risk of loss of functional independence.

Inclusion criteria consisted of:

- age  $\geq$  65 years;
- living in non-institutional setting; and
- available in study area for duration of study.

Exclusion criteria consisted of:

- age  $<$  65 years;
- vision impairment, (total vision score  $\leq$  39);
- reported disability (i.e., extensive assistance or total dependence) in one or more of 3 ADLs (i.e., dressing, personal hygiene, bathing);
- diagnosed cancer within the last 5 years, with a limited life expectancy (i.e., lung, liver, stomach, pancreas, esophagus);
- current chemotherapy or radiation;
- diagnosed Alzheimer's disease;
- CVA (stroke) in previous 12 months;
- cognitive impairment (MMSE  $<$  23);
- impaired communication;
- participation in a cognitive training/research program similar to ACTIVE in prior 2 years; and
- likely unavailability for duration of study (i.e., planned move from study area or absence from study area for extended periods of time that conflicts with study participation).

### IV. FINAL STATUS FOR 10TH YEAR POST-TEST

A Final Disposition battery was used at the time of the final Post-Test assessment (10th Year) for previously or to be deactivated (living or deceased) participants. The purpose was to obtain final disposition limited data on health and functional status. The assessment was completed by telephone or in-person with a participant and/or proxy informant for the deceased participants.

Further, in analydat\_A10 dataset, the variable **death\_indicat** shows the mortality status (1=yes (death)/0=no(alive)) and the variable **death\_dur** shows the duration from randomization date to death date (unit: day).

### V. SKIP/MISSING PATTERN

#### A. GENERAL MISSING CODING POLICY

Each data set has a related instrument (form) that was filled out during the ACTIVE trial. The forms are located in the folder "To Burn\Data Manuals". Inside each form is the question relating to each variable in the SAS data set. Under each question with a corresponding variable in the SAS data set is the distribution table. The distribution table is either a frequency distribution or a table showing the N, missing number, mean, standard deviation, minimum, median, and maximum. Any missing values are tabulated below this distribution table. For example, the following comes from Form 815. Here you can see that we recorded the time to read the can ingredients for Can 1. The distribution for the variable can1\_tntim is shown. If the data was missing, a negative number was shown (-9) to indicate the missingness.

**TASK A: FINDING A TELEPHONE NUMBER****CORRECT NUMBER = 408-9888**C1. TIME  :  :  TIME LIMIT IS 3 MINUTES

Variable	N	N Miss	Mean	Std Dev	Median	Minimum	Maximum
can1_tntim	910	1	16.6	18.3	9.7	0	120

can1_tntim	Frequency	Percent	Cumulative Frequency	Cumulative Percent
-9	1	0.11	1	0.11

The table below shows the general missing value code.

-1	Not applicable
-2	Skip (question not asked based on form skip pattern)
-3	Cannot be determined
-4	Illegible
-7	Refused
-8	Don't know (as answered by participant)
-9	Missing (e.g., blank)

**B. SPECIAL CODING POLICY**

For the questions D3 and D12 in Form 300, the participant repeats the words and the tester must code the serial position of the words in the space allotted. If the participant does not recall a word, negative value -11 (NR: Not Recalled) was used. In the questions of D7a1-10, D8a1-10, D9a1-10, D10a1-10, the testers tracked the accuracy of the participant's reciting a backwards count of 10 numbers. In the questions of D11, D11a, D11b, D11c, D11d, the tester ask the participant to complete subtraction series in repeated questions. The table below shows the special missing code used for these above-mentioned questions in Form #300.

-11	Not recalled
-22	Skip
-33	Skip all remaining until the next question
-77	Refused
-88	Don't know
-99	Missing (e.g., blank)

**C. VERSION TYPES IN FORM #001 AND FORM #002**

Two different versions (A and B) were used for Form #001 and Form #002. The questions C2k-q of Form #001 and D2k-q of Form #002 were added later in the version B. Therefore, for the participants who used the version A of these forms, the questions C2k-q of Form #001 and D2k-q of Form #002 were not completed and missing code (.) was used for those questions in the version A.

# ACTIVE

Question by Question Specifications Guide for Administration of

## Final Disposition Form #001

### I. Purpose

This interview is to be completed for all randomized, living ACTIVE participants who have been or will be deactivated. This would include participants who have moved out of a study area, who withdrew completely from the study, who are rollovers or for whom family refused access. This also includes participants who refuse study participation for any other reason/s. This interview will capture some health status, most recent functional status and updated contact information for these participants. The participant/proxy respondent must give verbal consent to this interview prior to administration. This interview can be administered in-person or on the telephone. This interview is completed with a participant and/or their proxy. It should take approximately 20 minutes to complete the Final Disposition interview.

### II. Section by Section Review

#### A. Identifying Information

- A1. Study ID: Affix the participant's study ID label in the space provided.
- A2. Visit #: This item is pre-coded, **FINL**.
- A3. Form Version: **08/27/2008**
- A4. Coordinator/Tester ID#/Initials: Write in your assigned ID# or initials.
- A5. Date completed: Write in the date you complete the interview from.
- A6. Time started: Record the exact time the General Introduction begun, circle **AM** or **PM**.

**GENERAL INTRODUCTION:** Read the Participant or Proxy specific Introduction script to participant/proxy. Read confidentiality statement to the participant or proxy. Interviewer: record name and date before proceeding.

**Interviewer must record permission from participant/proxy to conduct this interview and record in A7.**

- A7. Permission of Participant or Proxy: Record interview consent by coding "Yes" or "No". **If "NO", end the interview and skip to C4.** If "YES" proceed to Section B.

#### B. Pre - Interview Information

- B1. Mode of Interview: Indicate how the interview was completed, via in-person or telephone.
- B2. Whom Interviewed Code: Indicate with whom you completed the interview.
- B2a. Proxy Relationship Code: If a proxy is interviewed for this measure, circle applicable relationship code.

## C. Section C: The MDS

### 1. Self Performance of Instrumental Activities of Daily Living (IADL)

#### a. Description

The intent of these items is to examine the areas of function that are most commonly associated with independent living.

#### b. Administration

Introduction participant/proxy scripts have been provided for use by interviewer/tester. The participant or proxy is questioned about the participant's performance of normal activities of daily life around the home or in the community **during the last 7 days** including weekdays and weekends. There are 19 activity categories in the IADL scale, and there are two questions the tester must ask and code for each of the activity categories.

Below find the definition for each of the 19 activity categories.

#### c. Definitions

- (a) **Planning meals, reading recipes, assembling ingredients** — How meals are planned (e.g., thinking ahead about the week's schedule, menu planning, reading recipes and gathering required ingredients, noting what is missing.)
- (b) **Setting out food and utensils** — How meals are assembled, including setting out packaged prepared food and utensils. (e.g. setting the table with proper utensils).
- (c) **Cooking** — How meals are cooked (e.g., baking, heating up leftovers, frying, and warming frozen dinners).
- (d) **Doing dishes, dusting, making bed, tidying up** — How dishes are cleaned, rooms are cleaned (e.g., making bed, changing bed linen, dusting furniture, sweeping/vacuuming floors).
- (e) **Laundry** — Washing of clothes, sheets, towels, etc. Someone else transporting a participant's laundry from her/his apartment/room to the laundry machine is not included.
- (f) **Handling money, writing checks** — How money and checks are handled and paid out as needed. This does not include going to the bank to do banking or using bank machines.
- (g) **Ensuring that all bills are paid on time** - How bill due dates are monitored and adhered to.
- (h) **Balancing checkbooks** - How additions and subtractions are entered into the checkbook, including balancing the amount.
- (i) **Keeping household expenses balanced** — How decisions are made about household expenses based on resources.
- (j) **Keeping track of doctor appointments** - How health care appointments are remembered and adhered to.
- (k) **Remembering to take medications on time and as prescribed by doctor** - How medication schedules are complied to. (e.g., remember to take medicines, including pills, injections, eye drops, and ointments at specified times.)
- (l) **Opening medicine bottles, taking own medications** - How oral medications are prepared for administration and actually administered. (e.g. opening bottles, measuring liquids, scoring pills.)

- (m) **Giving self injections, applying ointments, changing bandages** -
- (n) **Looking up phone numbers - either in phone books or by calling “information”** - How needed phone numbers are obtained.
- (o) **Remembering often called numbers without having to look them up** - Recalling frequently called numbers, and dialing them without first looking them up. (e.g. family or friends phone numbers.)
- (p) **Answering phone when someone calls** - How phone is answered and handled. (e.g. finding the phone when ringing, terminating unwanted solicitations.)
- (q) **Hanging up at end of call** - How the line is terminated at the end of a conversation. (e.g. pressing the “off” button on a cordless, returning the receiver to its cradle)
- (r) **Shopping for food and household items** - How food or household items are obtained. (e.g. creating a list of sorts of needed items, determining where to go for supplies, getting the desired supplies purchased and into home.)
- (s) **Travel by vehicle to go to places beyond walking distances** - How travel occurs beyond reasonable walking distance. (e.g. arranging for and/or taking a taxi, bus, car, ride with a friend.)

d. Coding

There are two questions the tester must ascertain from the participant for each of the activities in the Self Performance of IADL scale.

The tester must select a code for each of the two questions for the participant's performance for each of the 19 activities over the past 7 days by circling the code number in the appropriate column.



## C1. Self Performance of IADL

**Question #1:** In the last 7 days, how much of the activity did you (PARTICIPANT) do on your (his/her) own?

There are five coding options available for the first question. Choose the best option from the following list.

- (1) **Did all on own:** Use this code if the activity occurred at least once during the past seven days and every time the activity occurred, it was done completely by the participant.

**Do not use this code, if the activity did not occur in the last seven days OR if the participant received any help with this activity in the last seven days, even if the help was not needed and even if the help was only given on one occasion.**

- (2) **Some help some of the time:** Use this code if the activity occurred one or more times during the past seven days and at least once, but not every time, the participant received help.

**Do not use this code if the activity did not occur in the last seven days OR if the participant received help every time the activity occurred.**

This code is a bit more complicated when an activity includes more than one sub-task; for example, ‘giving self injections, applying ointment, changing bandages.’ For these activity categories, the tester must inquire about the actual sub-tasks that did occur in the last seven days. Use this code if on any of these occasions, but not all of the occasions, the participant performed any of the sub-tasks on his/her own. The following example is provided as an illustration:

On Monday morning, Mrs. Smith applied her own ointment and her husband gave her an injection. On Thursday morning Mrs. Smith applied her own ointment and received no injection. This qualifies as ‘*some help, some of the time*’ because on one occasion Mrs. Smith received help but on another occasion she did not. Whether or not Mrs. Smith is able to give an injection to herself does not matter. Use this code as long as on one occasion, but not every occasion, Mrs. Smith performs the sub-task that does occur on her own.

- (3) **Help all of time:** Use this code if the activity occurred at least once during the past seven days and at every occasion the individual received help, but still did part of the activity on at least one occasion.

**Do not use this code if the participant was not involved in the performance of the activity in the last seven days.**

**Do not use this code if the activity did not occur in the last seven days.**

This code is also a bit more complicated for those activities that include more than one sub-task. Using the same activity of ‘giving self injections, applying ointments, changing bandages’: as with code 2, the tester must inquire thoroughly about the specific occasions when these sub-tasks occurred in the past seven days. Use this code, if on all of these occasions the participant received help from others performing any of the sub-tasks, but participated in performance of other sub-tasks on at least one occasion. Here is another example:

On Monday morning Mrs. Smith applied her own ointment and her husband gave her an injection. On Thursday morning Mrs. Smith’s husband gave her an injection and

applied the ointment. This is *'help all of the time'* because Mrs. Smith received help on both occasions but she did perform one of the sub-tasks on one occasion. It should be noted that even if Mrs. Smith did not completely perform a sub-task, but had helped in a sub-task (e.g. had taken the lid off the ointment bottle), then this code would still apply.

- (4) **Fully performed by others:** Use this code if the activity occurred at least once during the past seven days, and on every occasion it was performed completely by someone other than the participant.

**Do not use this code if the participant ever performed or ever helped to perform the activity in any way on any occasion.**

**Do not use this code if the activity did not occur in the last seven days.**

- (5) **Activity not performed by you (him/her) or others:** Use this code if the activity did not occur even once during the past seven days by either the participant or any individual on behalf of the participant.

**Question #2: How difficult was it (or would it have been) to do on your (his/her) own?**

If the participant reports in Question 1 that s/he was involved in performance of the activity over last seven days, (coded 1, 2, or 3) ASK: *"How difficult was it to do on your own?"*

If the participant reports in Question 1 that s/he was not involved in the activity in last seven days (e.g., others did it or there was no need to do it; coded 4 or 5), ASK: *"How difficult would it have been to do on your own?"*

There are three coding options available for the second question. Choose the best option from the following list.

- (1) **Not difficult:** Participant did not have difficulty, or would not have difficulty completing the activity or sub-task(s) on their own.
- (2) **Some help needed or I am (he/she was) slow, or I (he/she) became tired:**  
Participant did require or would require some help, or was slow in performing task(s) or became fatigued.
- (3) **Great difficulty:** Participant had great difficulty or would have great difficulty performing all sub-tasks on their own.

**C2. Self Performance of Activities of Daily Living (ADLs): Dressing, Personal Hygiene, Locomotion, Transfer, Toileting, and Bathing**

a. Description

The intent of the Self Performance of ADL Performance Scale is to record the participant's self-care performance in activities of daily living (i.e., what the participant actually did for himself or herself and/or how much verbal or physical help was required by caregivers) during the **last seven days**. CAUTION: Two coding schemes are used for these items, one for the activities related to dressing, personal hygiene, locomotion, transfer, and toileting (items a – q) and another for activities related to bathing (r – v). The coding rules for scoring these ADLs appear in the data form.

b. Administration

A participant's ADL self-performance may vary from day to day, or even within the 24 hour period. There are many possible reasons for these variations, including mood, medical condition, relationship issues (e.g., willing to

perform for a home caregiver he or she likes), and medications. The responsibility of the person completing the assessment, therefore, is to capture the total picture of the participant's ADL self-performance over the seven day period, 24 hours a day.

In order to accomplish this, it is necessary to ask the participant or proxy to think about the last 24 hours, then consider the last 7 days. Ask about variations during the week; when help was available and when it was not. Ask questions pertaining to all aspects of the ADL activity as defined in this guide. Since accurate coding is important, be sure to consider each activity's definition fully.

The wording used in each coding option is intended to reflect real-world situations, where slight variations are common. Where variations occur, the coding ensures that the participant is not assigned to an excessively independent or dependent category. For example, by definition, codes 1, 2, 3, and 4 in the Dressing, Personal Hygiene, Locomotion, Transfer, and Toileting scheme (Independent, Supervision, Limited Assistance, and Extensive Assistance) permit one or two exceptions for the provision of heavier care. This is clinically useful and increases the likelihood that tester will code ADL self-performance items consistently and accurately.

c. Definitions for Dressing, Personal Hygiene, Locomotion, Transfer and Toileting

**ADL SELF-PERFORMANCE** — Measures what the participant actually did (not what he or she might be capable of doing) within each ADL category over the last seven days according to a performance-based scale.

- (a) **Picking out and gathering clothes** - How clothing is selected and gathered, including any prosthesis.
- (b) **Dressing or undressing lower part of body** - How socks, shoes, pantyhose, underwear and pants are put on and taken off (not including fastening, tying or buttoning).
- (c) **Tying/untying shoes, fastening/unfastening pants** - How shoes and pants are fastened and unfastened.
- (d) **Putting on or taking off shirt/blouse, dress, bra** - How upper body clothing is put on and taken off (not including fastening, tying or buttoning.)
- (e) **Fastening/unfastening bra, buttoning or unbuttoning, zippering or unzipping** - How upper body clothing is fastened.
- (f) **Gathering wash cloth, soap, shaving kit, makeup, toothbrush etc** - How personal hygiene supplies are gathered, including adaptive equipment.
- (g) **Washing and drying perineum** - How the perineum is washed and dried (the area occupied by urogenital passages and the rectum). For perineum, the words private parts or groin can be substituted. Be certain that it is clear what is being discussed.
- (h) **Washing and drying face** - How the face is washed and dried
- (i) **Brushing teeth, Shaving face, Make up application** - How natural or artificial teeth are cared for shaving, and make-up application.
- (j) **Combing/brushing hair** - How hair is groomed and arranged.
- (k) **Securing support articles or devices (braces, canes, walker, wheelchair)** - Some elders use equipment to help them move about inside and outside of their home. We are interested in the level of dependence persons who use such equipment have in assembling and using the device. For example, if an elder uses a cane to walk around the home or outside the home, but can manage the use of this equipment independently, code a "1", "Independent". If the elder uses a wheelchair for mobility, and requires assistance every time for set up and transfer, code "5" "Total Dependence". Code "8" if the elder never uses a piece of equipment such as a wheelchair, walker, cane or brace.

- (l) **Moving between locations on the same floor** - How the elder moves about where they live on a single level, for example, from room to room, between locations on the same floor, for example, between a living room and a kitchen or bedroom.
  - (m) **Moving to sitting position** - How to transfer from moving to sitting position such as bed or chair or wheelchair. This excludes transfer to and from bath or toilet.
  - (n) **Moving to and from standing position** - How to transfer from moving to and from standing position
  - (o) **Moving on and off toilet** - How to transfer on and off the toilet
  - (p) **Cleaning self after using the toilet including managing use of pads** - How the perineum (the area occupied by urogenital passages and the rectum) is cleaned after using the toilet. For perineum, the words private parts or groin can be substituted. This includes changing sanitary pads.
  - (q) **Adjusting clothes** - How clothes are adjusted prior to and after using the toilet
- d. **Coding for Dressing, Personal Hygiene, Locomotion, Transfer and Toileting:**

For the ADL categories of Dressing and Person Hygiene (items a-j) code the appropriate response for the participant's actual performance during the past seven days. Circle the code in the appropriate column. Consider the participant's performance during 24 hours over the last week. For Dressing, Personal Hygiene, Locomotion, Transfer and Toileting, use the coding scheme provided in the form. The Dressing, Personal Hygiene, Locomotion, Transfer and Toileting coding scheme is as follows.

<b>CODE</b>	<b>DESCRIPTION</b>	<b>DEFINITION</b>
<b>(1)</b>	<b>INDEPENDENT</b>	No help or caregiver oversight <b>-or-</b> caregiver help/oversight provided only one or two times during the last seven days
<b>(2)</b>	<b>SUPERVISION</b>	Oversight, encouragement, or cueing provided three or more times during last seven days <b>-or-</b> supervision (3 or more times) plus physical assistance provided only one or two times during last seven days.
<b>(3)</b>	<b>LIMITED ASSISTANCE</b>	Participant highly involved in activity, received physical help in guided maneuvering of limbs or other non-weight-bearing assistance on three or more occasions <b>-or-</b> limited assistance (3 or more times) plus more help provided only one or two times during last seven days
<b>(4)</b>	<b>EXTENSIVE ASSISTANCE</b>	While the participant performed part of activity over last seven days, help of following type(s) was provided three or more times: <ul style="list-style-type: none"> <li>• Weight-bearing support provided three or more times</li> <li>• Full caregiver performance of activity (3 or more times) during part (but not all) of last seven days</li> </ul>
<b>(5)</b>	<b>TOTAL DEPENDENCE</b>	Full caregiver performance of the activity during entire seven-day period. Complete non-participation by the participant in all aspects of the ADL definition.
<b>(8)</b>	<b>ACTIVITY DIDN'T OCCUR DURING THE ENTIRE 7-DAY PERIOD</b>	Over the last seven days, the ADL activity was not performed by the participant or caregiver. e.g., <u>the particular activity did not occur at all.</u>

e. Definitions for Bathing Activities

**SELF-PERFORMANCE OF BATHING ACTIVITIES** — Measures what the participant actually did (not what he or she might be capable of doing) for each **bathing activity** over the last seven days according to the performance-based scale below.

- (r) **Gathering soap, towels, shampoo** - How shower/tub supplies are gathered, including adaptive equipment.
- (s) **Getting in and out of tub/bath** - How the participant manages getting in and out of the tub/shower, including the use of adaptive equipment.
- (t) **Washing/drying: lower extremities excluding perineum** - How lower extremities are washed and dried, including the use of adaptive equipment.
- (u) **Washing/drying hair** - How hair is washed & dried excluding combing & grooming.
- (v) **Washing/drying upper extremities** - How upper extremities are washed and dried (excluding the back).

f. Coding for Bathing

Remember, there is a different coding scheme for bathing. It has the same number of response alternatives, and the alternatives have the same feel in terms of the level of dependency, but the words and definitions are different. For the coding scheme for dressing and personal hygiene, we rely on the fact that there are multiple events during any given period. This differs significantly for the ADL bathing activities. Bathing is the only ADL where, over a weeks time, there may be only 1 or 2 events. Therefore, a separate coding scheme has been established for the bathing items (k-o). For example, in the bathing scheme, if you code a participant as independent in bathing, they must do the activity on their own EVERY time. Review the bathing coding scheme closely.

For the ADL category of Bathing (items k-o), code the appropriate response for the participant's actual performance during the past seven days. Circle the code in the appropriate column. Consider the participant's performance during 24 hours over the last week. For Bathing, use the coding scheme provided in the form. The Bathing coding scheme is also included below.

CODE	DESCRIPTION	DEFINITION
(1)	Independent	Did on own
(2)	Supervision	Oversight help only
(3)	Limited Assistance	Received assistance in transfer only
(4)	Assistance	Received assistance in part of bathing self.
(5)	Total Dependence	Total dependence
(8)	Activity didn't occur	Activity did not occur at all.

**C3.** This is a health status question that asks if a doctor ever told a participant they had Alzheimer's disease or dementia. Proxy may or may not know this information.

At the end of the interview, thank the participant or proxy for completing the interview.

**C4:** Record Interview End Time: Record the time you complete the Final Disposition Form.

# ACTIVE

## Question by Question Specifications Guide for Administration of

### Deceased Participant Disposition Form #002

#### I. Purpose

This interview is to be completed with a family member/proxy for all randomized ACTIVE participants who have died and are deactivated. This interview will capture recent functional status, health status and appropriate contact information for these participants. The proxy informant must give verbal consent to this interview prior to administration. This interview should be completed in one session. This interview can be administered either in-person or by telephone. It should take approximately 20 minutes to complete the Deceased Participant Disposition interview. This interview must be administered by ACTIVE staff familiar with the testing battery, i.e., PI, Site Coordinator or certified Tester.

#### II. Section by Section Review

##### A. Identifying Information

- A1. Study ID: Affix the participant's study ID label in the space provided.
- A2. Visit #: This item is pre-coded, **FINL**.
- A3. Form Version: **08/27/2008**
- A4. Coordinator/Tester ID#/Initials: Write in your assigned interviewer ID # or initials.
- A5. Date completed: Write the date the interview completed on.
- A6. Time started: Record the time you begin the General Introduction, circle **AM** or **PM** as appropriate.

##### GENERAL INTRODUCTION:

Read the General Introduction script to the family member/ proxy.

Read the confidentiality statement verbatim to the family member/proxy. The interviewer's name and date must be recorded at the bottom of this page.

**Interviewer must obtain permission to administer the interview from family member/proxy:**

- A7. Permission of Family Member/Proxy: Interviewer records the consent to interview by coding "YES" or "NO". If "NO", end the interview and skip to D3. If "YES", proceed to Section B.

## Section B: Pre - Interview

The interviewer completes this section.

- B1.** Mode of Interview: Indicate how the interview was completed, via in-person or telephone.
- B2.** Proxy Relationship Code: Indicate with whom the interview is being completed. A proxy informant should be a family member or someone who had daily or frequent interactions with participant prior to death.

## Section C: Deceased Status Update

Questions C1. – C4. Ask the proxy

- C1.** Record the date of the participant's death. Interviewer should probe for month/day/year as needed to assist in participant recall. If the proxy cannot remember the date, code "DK" (Don't Know), probe for month and year. If proxy cannot remember the complete date, code "DK" for entire date and **GO to C1a**. If date provided by proxy in C1, **skip to C2**.
- C1a.** Interviewer provides the participant's date of death to proxy if not obtained in C1. Interviewer must have at least participant's month and year of death in order to complete this interview. The date of participant's death should be available for referencing. This information is obtained from the Deactivation Form #901 or provided in reports, prior to the interview for confirmation and for question timeframe referencing purposes.
- C2.** Record verbatim the cause of death. If proxy cannot specific cause of death, record DK in specify.
- C3.** Record where the participant died. If proxy cannot recall where, record DK in margin.
- C4.** This is a health status question; if a doctor ever said/told the participant that they had Alzheimer's disease or dementia. (Circle only one answer.)

**Questions C5. – C6. & Section D**, establishes a 'specific week and year' time frame for asking these questions.

**The 'specify week and year' time is 5 weeks prior to the participant's death.**

To calculate a 'specify week & year': use a multiyear calendar and have the participant's date of death available from the Deactivation Form. The 'specify week & year' should be written on a piece of paper prior to the interview/call in order to better orient proxy to the time period and asked as follows; e.g., "last week of June, 2008" or "first week in June, 2008".

**C5. - C6.** asks about the participant's ability to do everyday activities approximately 5 weeks prior to participant's death. Interviewer should be prepared to prompt proxy with the 'Specify Week and Year', as needed.

- C5.** This question asks the proxy about the participant's physical ability approximately 5 weeks prior to their death. This question **compares** the physical abilities of participant at 5 weeks prior to their death, to 6 months prior to their death.  
To calculate these timeframes: first, figure 'specify week & year' then date 6 months before death date as follows: e.g., "Thinking about the (last week in July, 2008), how would you describe his/her physical ability to do everyday activities as compared to (January, 2008). Would you say it was: Better, About the same or Worse". Code according to the proxy's best estimate. (Circle only one answer.)
- C6.** This question asks the proxy about the participant's ability to carry out personal care or household tasks, 5 weeks prior to death; provide proxy with 'Specify Week and Year' as reference. The proxy must determine if the participant was able to complete these tasks on his/her own or with help from others. If the participant received any amount of help, please proceed and complete the MDS. If the participant was unable to carry out personal care or household tasks, **end the interview and skip to D3**. (Circle only one answer.)



## Section D: The MDS

### 1. Self Performance of Instrumental Activities of Daily Living (IADL)

#### a. Description

The intent of these items is to examine the areas of function that are most commonly associated with independent living.

#### b. Administration

Introduction proxy scripts have been provided for use by interviewer/tester. The proxy is questioned about the participant's performance of normal activities of daily life around the home or in the community **approximately five weeks prior to the participant's death**. This timeframe is asked as a week and year date reference. There are 19 activity categories in the IADL scale, and there are two questions the tester must ask and code for each of the activity categories.

Below find the definition for each of the 19 activity categories.

#### c. Definitions

- (a) **Planning meals, reading recipes, assembling ingredients** — How meals are planned (e.g., thinking ahead about the week's schedule, menu planning, reading recipes and gathering required ingredients, noting what is missing.)
- (b) **Setting out food and utensils** — How meals are assembled, including setting out packaged prepared food and utensils. (e.g. setting the table with proper utensils).
- (c) **Cooking** — How meals are cooked (e.g., baking, heating up leftovers, frying, and warming frozen dinners).
- (d) **Doing dishes, dusting, making beds, tidying up** — How dishes are cleaned, rooms are cleaned (e.g., making bed, changing bed linen, dusting furniture, sweeping/vacuuming floors).
- (e) **Laundry** — Washing of clothes, sheets, towels, etc. Someone else transporting a participant's laundry from her/his apartment/room to the laundry machine is not included.
- (f) **Handling money, writing checks** — How money and checks are handled and paid out as needed. This does not include going to the bank to do banking or using bank machines.
- (g) **Ensuring that all bills are paid on time** - How bill due dates are monitored and adhered to.
- (h) **Balancing checkbooks** - How additions and subtractions are entered into the checkbook, including balancing the amount.
- (i) **Keeping household expenses balanced** — How decisions are made about household expenses based on resources.
- (j) **Keeping track of doctor appointments** - How health care appointments are remembered and adhered to.
- (k) **Remembering to take medications on time and as prescribed by doctor** - How medication schedules are complied to. (e.g., remember to take medicines, including pills, injections, eye drops, and ointments at specified times.)

- (l) **Opening medicine bottles, taking own medications** - How oral medications are prepared for administration and actually administered. (e.g. opening bottles, measuring liquids, scoring pills.)
- (m) **Giving self injections, applying ointments, changing bandages** -
- (n) **Looking up phone numbers - either in phone books or by calling "information"** - How needed phone numbers are obtained.
- (o) **Remembering often called numbers without having to look them up** - Recalling frequently called numbers, and dialing them without first looking them up. (e.g. family or friends phone numbers.)
- (p) **Answering phone when someone calls** - How phone is answered and handled. (e.g. finding the phone when ringing, terminating unwanted solicitations.)
- (q) **Hanging up at end of call** - How the line is terminated at the end of a conversation. (e.g. pressing the "off" button on a cordless, returning the receiver to its cradle)
- (r) **Shopping for food and household items** - How food or household items are obtained. (e.g. creating a list of sorts of needed items, determining where to go for supplies, getting the desired supplies purchased and into home.)
- (s) **Travel by vehicle to go to places beyond walking distances** - How travel occurs beyond reasonable walking distance. (e.g. arranging for and/or taking a taxi, bus, car, ride with a friend.)

d. Coding

There are two questions the interviewer/tester must ascertain from the proxy for each of the activities of the participant in the Self Performance of IADL scale.

The interviewer/tester must select a code for each of the two questions for the participant's performance for each of the 19 activities over a one week time period circling the code number in the appropriate column.

**Question #1: During the (SPECIFY WEEK and YEAR), how much of the following activities did he/she do on his/her own?**

There are five coding options available for the first question. Choose the best option from the following list.

- (1) **Did all on own:** Use this code if the activity occurred at least once during the specified week and every time the activity occurred, it was done completely by the participant.

**Do not use this code, if the activity did not occur in the specified week OR if the participant received any help with this activity in that week, even if the help was not needed and even if the help was only given on one occasion.**

- 2) **Some help some of the time:** Use this code if the activity occurred one or more times during the specified week and at least once, but not every time, the participant received help.

**Do not use this code if the activity did not occur in the specified week OR if the participant received help every time the activity occurred.**

This code is a bit more complicated when an activity includes more than one sub-task; for example, 'giving self injections, applying ointment, changing bandages.' For these activity categories, the tester must inquire about the actual sub-tasks that did occur that week. Use this code if on any of these occasions, but not all of the occasions, the participant performed any of the sub-tasks on his/her own. The following example is provided as an illustration:

On Monday morning, Mrs. Smith applied her own ointment and her husband gave her an injection. On Thursday morning Mrs. Smith applied her own ointment and received no injection. This qualifies as '*some help, some of the time*' because on one occasion Mrs. Smith received help but on another occasion she did not. Whether or not Mrs. Smith is able to give an injection to herself does not matter. Use this code as long as on one occasion, but not every occasion, Mrs. Smith performs the sub-task that does occur on her own.

- (3) **Help all of time:** Use this code if the activity occurred at least once during the specified week and year and at every occasion the individual received help, but still did part of the activity on at least one occasion.

**Do not use this code if the participant was not involved in the performance of the activity in the specified week.**

**Do not use this code if the activity did not occur in the specified week.**

This code is also a bit more complicated for those activities that include more than one sub-task. Using the same activity of ‘giving self injections, applying ointments, changing bandages’: as with code 2, the tester must inquire thoroughly about the specific occasions when these sub-tasks occurred that week. Use this code, if on all of these occasions the participant received help from others performing any of the sub-tasks, but participated in performance of other sub-tasks on at least one occasion. Here is another example:

On Monday morning Mrs. Smith applied her own ointment and her husband gave her an injection. On Thursday morning Mrs. Smith’s husband gave her an injection and applied the ointment. This is ‘*help all of the time*’ because Mrs. Smith received help on both occasions but she did perform one of the sub-tasks on one occasion. It should be noted that even if Mrs. Smith did not completely perform a sub-task, but had helped in a sub-task (e.g. had taken the lid off the ointment bottle), then this code would still apply.

- (4) **Fully performed by others:** Use this code if the activity occurred at least once in the specified week, and on every occasion it was performed completely by someone other than the participant.

**Do not use this code if the participant ever performed or ever helped to perform the activity in any way on any occasion.**

**Do not use this code if the activity did not occur in the specified week.**

- (5) **Activity not performed by him/her or others:** Use this code if the activity did not occur even once during the specified week by either the participant or any individual on behalf of the participant.

## Question #2: How difficult was it (or would it have been) to do on his/her own?

If the proxy reports in Question 1 that the participant was involved in performance of the activity during that week & year, (coded 1, 2, or 3) ASK: “How difficult would it have been for (PARTICIPANT’S NAME) to do on his/her own?”

If the proxy reports in Question 1 that the participant was **not** involved in the activity during that week & year (e.g., others did it or there was no need to do it; coded 4 or 5), ASK: “How difficult would it have been for (PARTICIPANT’S NAME) to do on his/her own?”

There are three coding options available for the second question. Choose the best option from the following list.

- (1) **Not difficult:** Participant did not have difficulty, or would not have difficulty completing the activity or sub-task(s) on their own.
- (2) **Some help needed or he/she was slow, or became tired:** Participant did require or would require some help, or was slow in performing task(s) or became fatigued.
- (3) **Great difficulty:** Participant had great difficulty or would have great difficulty performing all sub-tasks on their own.

## 2. Self Performance of Activities of Daily Living (ADLs): Dressing, Personal Hygiene, Locomotion, Transfer, Toileting, and Bathing

### a. Description

The intent of the Self Performance of ADL Performance Scale is to record the participant’s self-care performance in activities of daily living (i.e., what the participant actually did for himself or herself and/or how much verbal or physical help was required by caregivers) during **that week and year**. CAUTION: Two coding schemes are used for these items, one for the activities related to dressing, personal hygiene, locomotion, transfer, and toileting (items a – q) and another for activities related to bathing (r – v). The coding rules for scoring these ADLs appear in the data form.

### b. Administration

A participant’s ADL self-performance may vary from day to day, or even within the 24 hour period. There are many possible reasons for these variations, including mood, medical condition, relationship issues (e.g., willing to perform for a home caregiver he or she likes), and medications. The responsibility of the person completing the assessment, therefore, is to capture the total picture of the participant’s ADL self-performance over that week.

In order to accomplish this, it is necessary to ask the proxy to think about the specific week & year. Ask about variations during the week; when help was available and when it was not. Ask questions pertaining to all aspects of the ADL activity as defined in this guide. Since accurate coding is important, be sure to consider each activity’s definition fully.

The wording used in each coding option is intended to reflect real-world situations, where slight variations are common. Where variations occur, the coding ensures that the participant is not assigned to an excessively independent or dependent category. For example, by definition, codes 1, 2, 3, and 4 in the Dressing, Personal Hygiene, Locomotion, Transfer, and Toileting scheme (Independent, Supervision, Limited Assistance, and Extensive Assistance) permit one or two exceptions for the provision of heavier care. This is clinically useful and increases the likelihood that tester will code ADL self-performance items consistently and accurately.

c. Definitions for Dressing, Personal Hygiene, Locomotion, Transfer and Toileting

**ADL SELF-PERFORMANCE** — Measures what the participant actually did (not what he or she might be capable of doing) within each ADL category over the last seven days according to a performance-based scale.

- (a) **Picking out and gathering clothes** - How clothing is selected and gathered, including any prosthesis.
- (b) **Dressing or undressing lower part of body** - How socks, shoes, pantyhose, underwear and pants are put on and taken off (not including fastening, tying or buttoning).
- (c) **Tying/untying shoes, fastening/unfastening pants** - How shoes and pants are fastened and unfastened.
- (d) **Putting on or taking off shirt/blouse, dress, bra** - How upper body clothing is put on and taken off (not including fastening, tying or buttoning.)
- (e) **Fastening/unfastening bra, buttoning or unbuttoning, zippering or unzipping** - How upper body clothing is fastened.
- (f) **Gathering wash cloth, soap, shaving kit, makeup, toothbrush etc** - How personal hygiene supplies are gathered, including adaptive equipment.
- (g) **Washing and drying perineum** - How the perineum is washed and dried (the area occupied by urogenital passages and the rectum). For perineum, the words private parts or groin can be substituted. Be certain that it is clear what is being discussed.
- (h) **Washing and drying face** - How the face is washed and dried
- (i) **Brushing teeth, Shaving face, Make up application** - How natural or artificial teeth are cared for shaving, and make-up application.
- (j) **Combing/brushing hair** - How hair is groomed and arranged.
- (k) **Securing support articles or devices (braces, canes, walker, wheelchair)** - Some elders use equipment to help them move about inside and outside of their home. We are interested in the level of dependence persons who use such equipment have in assembling and using the device. For example, if an elder uses a cane to walk around the home or outside the home, but can manage the use of this equipment independently, code a "1", "Independent". If the elder uses a wheelchair for mobility, and requires assistance every time for set up and transfer, code "5" "Total Dependence". Code "8" if the elder never uses a piece of equipment such as a wheelchair, walker, cane or brace.
- (l) **Moving between locations on the same floor** - How the elder moves about where they live on a single level, for example, from room to room, between locations on the same floor, for example, between a living room and a kitchen or bedroom.
- (m) **Moving to sitting position** - How to transfer from moving to sitting position such as bed or chair or wheelchair. This excludes transfer to and from bath or toilet.
- (n) **Moving to and from standing position** - How to transfer from moving to and from standing position
- (o) **Moving on and off toilet** - How to transfer on and off the toilet
- (p) **Cleaning self after using the toilet including managing use of pads** - How the perineum (the area occupied by urogenital passages and the rectum) is cleaned after using the toilet. For perineum, the words private parts or groin can be substituted. This includes changing sanitary pads.
- (q) **Adjusting clothes** - How clothes are adjusted prior to and after using the toilet

d. Coding for Dressing, Personal Hygiene, Locomotion, Transfer and Toileting:

For the ADL categories of Dressing and Person Hygiene (items a-q) code the appropriate response for the participant's actual performance during that specific week & year. Circle the code in the appropriate column. Consider the participant's performance during that week. Dressing, Personal Hygiene, Locomotion, Transfer and Toileting, use the coding scheme provided in the form. The Dressing, Personal Hygiene, Locomotion, Transfer and Toileting coding scheme is as follows.

CODE	DESCRIPTION	DEFINITION
(1)	INDEPENDENT	No help or caregiver oversight <b>-or-</b> caregiver help/oversight provided only one or two times during that week.
(2)	SUPERVISION	Oversight, encouragement, or cueing provided three or more times during that week <b>-or-</b> supervision (3 or more times) plus physical assistance provided only one or two times during that week.
(3)	LIMITED ASSISTANCE	Participant highly involved in activity, received physical help in guided maneuvering of limbs or other non-weight-bearing assistance on three or more occasions <b>-or-</b> limited assistance (3 or more times) plus more help provided only one or two times during that week.
(4)	EXTENSIVE ASSISTANCE	While the participant performed part of activity during that week, help of following type(s) was provided three or more times: <ul style="list-style-type: none"><li>• Weight-bearing support provided three or more times</li><li>• Full caregiver performance of activity (3 or more times) during part (but not all) of that week.</li></ul>
(5)	TOTAL DEPENDENCE	Full caregiver performance of the activity during entire week. Complete non-participation by the participant in all aspects of the ADL definition.
(8)	ACTIVITY DIDN'T OCCUR DURING THAT WEEK	During that week, the ADL activity was not performed by the participant or caregiver. e.g., <u>the particular activity did not occur at all.</u>

e. Definitions for Bathing Activities

**SELF-PERFORMANCE OF BATHING ACTIVITIES** — Measures what the participant actually did (not what he or she might be capable of doing) for each **bathing activity** over that week & year according to the performance-based scale below.

- (r) **Gathering soap, towels, shampoo** - How shower/tub supplies are gathered, including adaptive equipment.
- (s) **Getting in and out of tub/bath** - How the participant manages getting in and out of the tub/shower, including the use of adaptive equipment.
- (t) **Washing/drying: lower extremities excluding perineum** - How lower extremities are washed and dried, including the use of adaptive equipment.
- (u) **Washing/drying hair** - How hair is washed & dried excluding combing & grooming.
- (v) **Washing/drying upper extremities** - How upper extremities are washed and dried (excluding the back).

f. Coding for Bathing

Remember, there is a different coding scheme for bathing. It has the same number of response alternatives, and the alternatives have the same feel in terms of the level of dependency, but the words and definitions are different. For the coding scheme for dressing and personal hygiene, we rely on the fact that there are multiple events during any given period. This differs significantly for the ADL bathing activities. Bathing is the only ADL where, over a week's time, there may be only 1 or 2 events. Therefore, a separate coding scheme has been established for the bathing items (k-o). For example, in the bathing scheme, if you code a participant as independent in bathing, they must do the activity on their own EVERY time. Review the bathing coding scheme closely.

For the ADL category of Bathing (items k-o), code the appropriate response for the participant's actual performance during that week and year. Circle the code in the appropriate column. Consider the participant's performance during that week. For Bathing, use the coding scheme provided in the form. The Bathing coding scheme is also included below.

CODE	DESCRIPTION	DEFINITION
(1)	Independent	Did on own
(2)	Supervision	Oversight help only
(3)	Limited Assistance	Received assistance in transfer only
(4)	Assistance	Received assistance in part of bathing self.
(5)	Total Dependence	Total dependence
(8)	Activity didn't occur	Activity did not occur at all.

At the end of the session read the closing script to the proxy and thank the proxy for completing the interview.

**D3:** Record Interview End Time: Record the time you complete the Deceased Participant Disposition Form. Remember to circle **AM** or **PM** in the space provided.



# ACTIVE

## Question by Question Specifications Guide for Administration of the Individual Assessment Part I (10<sup>th</sup> Year Post-Test) Measurements

### I. Purpose

The measures in the Individual Assessment Part I (10<sup>th</sup> Year Post-Test) are designed to measure aspects of the subject's cognitive functioning, useful field of vision and complex reaction time. The results of the measures completed at the 10<sup>th</sup> Year Post-Test visit will be compared to results obtained at earlier points in the study.

### II. Study Sample and Administration

10<sup>th</sup> Year Post-Testing will be completed on all ACTIVE subjects still participating in the study. The ideal order of administration of these 10<sup>th</sup> Year Post-Test Measures is as follows:

1. Individual Assessment Part I
2. Take-Home Questionnaire
3. Individual Assessment Part II
4. Group Measures

However, this order is not strict. You may need to alter the order of administration to accommodate either subject or Field Site scheduling conflicts.

### III. Administration Protocol

The following items should be assembled in advance of the subject's appointment time.

#### A. Materials

- Individual Assessment Part I (10<sup>th</sup> Year Post-Test) Form #805 with ID label attached
- TICS Data Form # 300 with ID labels attached to all pages
- HVL T Subject Data Forms Packet #310a with ID labels attached to all pages
- Word Series Data Form #311 with ID label attached
- HVL T Recognition Data Form #312 with ID label attached
- Take Home Questionnaire Form #5 with ID label attached
- QxQ Specifications Guide for Administration of the Individual Assessment Part I (10<sup>th</sup> Year Post-Test)
- Snellen Acuity Score Comparison Table
- Subject's Vision Report Form

## **B. Equipment**

- Vision acuity supplies:
  - GOOD-LITE LD - 10 Vision Chart
  - GOOD-LITE MODEL 600A light box
  - spare fluorescent bulb
  - ten foot string
  - electrical extension cord
- MMSE supplies:
  - Wrist watch
  - 3 pieces of 8 1/2 x 11 inch blank, white paper for completing directives, writing a sentence and drawing shapes
  - 'Close your eyes' Show Card
  - pencil
  - 'Intersecting Shapes' Show Card
- HVLt supplies:
  - Sony Boom Box Model CFS-B15
  - The HVLt Administration Audiotape for the 10<sup>th</sup> Year Post-Test Visit
  - Electronic timer
  - Pencils for subject's use
- Useful Field of View (UFOV) and Complex Reaction Time (CRT) supplies:
  - computer
  - UFOV software
  - CRT software
- Spare batteries should be carried for all battery operated equipment

## **C. Preparation**

1. Testers must be certified as an ACTIVE Tester. Certification status must be current.
2. Be prepared, it will take 3 workstations to complete the Individual Assessment Part I Measurements. A desk or table for two with a smooth working surface is needed for the subject and tester for recording and testing during administration of the HVLt and Word Series tests. A computer station is used for the UFOV and CRT computer tests and a separate station is required for the Good-Lite Vision Box for the Vision Testing.
3. The area selected must allow for private, confidential testing with minimal background noise.
4. In advance of the subject's appointment time, testers should assemble a packet with all forms necessary for completion of the Individual Assessment Part I (10<sup>th</sup> Year Post-Test) Measurements. All forms should be pre-labeled with the subject's full study ID Labels.

5. Prior to the start of the session, the tester should set up and test equipment to be sure that all equipment is in proper working order, including the audiotape player, Vision Box, electronic timer, computer and related software for UFOV and the CRT tests. Spare batteries should be carried for all battery operated equipment.

#### **D. Order of Administration**

The ACTIVE Steering Committee has prescribed the order of administration for the tests included in the Individual Assessment Part I (10<sup>th</sup> Year Post-Test) Measurement battery. The order is:

1. Vision Test
2. Mini Mental Status Exam
3. HVLТ
4. Word Series
5. HVLТ Recognition
6. BREAK POINT
7. UFOV
8. CRT

You must follow this order exactly. Ideally, the assessment can be completed in one session. A break must be offered after the completion of the HVLТ Recognition Test. It can take 30-40 minutes to complete the remainder of the assessment, so subjects should be encouraged to take even a small break to avoid a break during the UFOV and CRT testing. Nonetheless, the tester is allowed to continue the assessment if the subject refuses a break. If for any reason the tester feels the subject cannot complete the assessment in one session, the session should be stopped at the break point. Any deviation from the prescribed order should be documented on the form and reported to the PI of the Field Site. The CC should also be informed of the alteration in administration.

#### IV. Section by Section Review

##### Section A. Identifying Information

Items A1. – A4. should be completed by the ACTIVE tester prior to the start of the measurement.

- A1.** Study ID: Affix the subject's study ID label in the space provided. Do not hand write the ID number. Double-check the ID number against the subject's visit control sheet. Confirm the subject's name at the start of measurement to be sure you are using the correct ID for the subject.
- A2.** Visit #: This item may be pre-coded. Various forms will be used at the time of the Individual Assessment Part I, (10<sup>th</sup> Year Post-Test) (Visit ID10). The code for Individual Assessment Part I (10<sup>th</sup> Year Post-Test) is **ID10**. Be sure to circle the visit number on the form.
- A3.** Form Version: Be sure the form version on the form matches the current approved version. Note the year appears as a 4-digit number.
- A4.** Tester ID/Initials: Write in your assigned tester ID or initials.
- A5.** Date completed: Write in the date you complete the Individual Assessment Part I (10<sup>th</sup> Year Post-Test); if the measures are completed in more than one day, use the date the measures were completed. Record the date as month, day and year. Note the year must be recorded as a four digit number; e.g., 2008. Do not leave blank spaces; use leading zeros as required.
- A6.** Time started: Record the exact time you begin the General Introduction to the Individual Assessment Part I in A6. Use a 12-hour clock; circle **AM** or **PM** as appropriate.

## Section B. Vision

### 1. Description

Visual acuity will be measured with the GOOD-LITE LD-10 CHART IN A GOOD-LITE MODEL 600A light box. The chart is designed to be used at a 10 foot text distance. To insure uniformity of illumination, the fluorescent bulb should be replaced every two years or after 1000 hours of use. Replacement bulbs can be ordered from the GOOD-LITE company, as indicated on the yellow notice that accompanied this instrument.

The plastic eye chart can be washed with a gentle, non-abrasive detergent (such as a liquid dish soap) to remove dirt and fingerprints, but care should be taken not to scratch or disturb the matte finish. Excessive heat will warp the eye chart, so use care when storing the apparatus in closed cars during summer months. Replacement charts can be ordered from the manufacturer.

### 2. Administration

#### a. Setup

The light-box should be set on a stable surface such as a table, shelf or counter near an electric outlet. After plugging in the box, the button on top is depressed and held down until the bulb turns on.

The subject should be seated at eye level, 10 feet from the box. An easy way to insure the 10 foot distance between chart and subject when testing is to attach a string to the top handle, which measures out 10 feet from the surface of the chart (not the handle) to the subject's eyes. When the string is extended out, this is the position of the subject. If data collection will be located in the same place for an extended time period, it may be easier to simply set up the chart in a fixed location (on the wall) and then put tape on the floor marking the 10 foot distance from the surface of the chart.

Room illumination should be dimmed. That is, turn off the overhead lights. Subdued lighting elsewhere in the room is okay. Care must be taken that no intense lighting falls directly on the chart or shines directly into the subject's eyes (e.g., from a window or overhead light source).

#### b. Test Procedure

All testing is performed binocularly with the subject's customary indoor (no sunglasses or shades) glasses used for distant vision. If bifocals are worn, the subject is instructed to look through the portion of the glasses that s/he normally uses when looking at objects that are far away. The tester should indicate on the data form whether the subject wore the correction he/she normally uses for distance vision (B11 and B12).

The script for administration appears in the form. Follow the scripts precisely.

After adjusting the distance of the subject for the 10 foot viewing distance, warn him/her that you are going to turn out the overhead lights. If there is a dramatic change in light levels (from room illumination to total darkness), the subject may need a moment to adjust.

The examiner indicates to the subject the row of letters with the large number 5 (row B4 on the data form) and asks the subject if he/she can easily read the letters. If so, the test begins here. If the subjects report that they cannot read row 5 easily, start the test at the top of the chart.

If the subject claims that he/she can easily see the letters in row 5 and you start there but the subject actually misses a letter, or appears to be straining to read these letters, the tester should start the test at the top of the chart.

Once the starting row is determined, the subject is instructed to slowly read across the row from left to right. If there is any confusion during the test, the tester may indicate, by pointing, which row is currently being tested, but should not point to individual letters in a row. If a subject cannot read any letters on the top line, record this on the scoring sheet by drawing a bold line through the entire top line.

The first time a subject says that he/she can't see a letter, the tester should encourage the subject to make their best possible guess. Use the prompt provided in the data form. Similar encouragement should be provided with subsequent hesitancy. Follow the prompts in the form.

Many subjects are often cautious and conservative about naming letters on a letter chart. It is very important that the subject respond with a letter, not "*I don't know*" or "*I can't see it*", etc. Experienced testers can often overcome the subject's hesitancy and coax some additional guesses which turn out to be correct identifications. Obviously, a tester has to get a feel for how much encouragement is warranted. Performance on the previous line is often a good guideline. For example, a subject typically doesn't go from getting all letters on a given row correct to zero letters correct on the next line.

A guide is provided to the left of the row to assist testers in determining if the subject meets the criterion for the row, e.g. for B1 –B5 'If  $\geq 2$ ; continue'; for B6 – B8 'If  $\geq 3$ ; continue'. The test is concluded when this criterion has been reached.

### 3. Coding and Scoring

#### a. Coding - Table 1: The Number Correct in each Row

As the subject reads the letters aloud, the tester marks Table 1 by circling correct letters and drawing a diagonal line through incorrect letters. For each line attempted there should be either a circle or a diagonal line through each letter on that line. After the criterion for stopping has been met, the tester should draw a straight line through the middle of the letters on all subsequent lines not attempted.

Next, the tester must determine and record a code for each row in Table 1. The codes for the row should be recorded in the column labeled '**CODE**' (1. – 9.) The code for the row is defined as the number of correct letters in the row called out by the subject during the test. These are the letters that the tester has circled. For each line, record the code (i.e. total number of correct letters for the row) in the space on the right at the end of each row in Table 1, labeled **CODE**. To assist in counting the correct letters quickly, a number guide is provided along the very top of the table. Each row in Table 1 must be assigned a code. When rows 1 – 3 are skipped (i.e. for subjects that begin the test at the row with the 5), the totals for these rows should be recorded as the maximum possible for that row, e.g., for row 1 (B1), the total would be 4; for row 2 (B2), the total is 5; and, for row 3 (B3), the total is 7. When rows at the end of the test are not administered (i.e. after the criterion has been met for the preceding row), enter a score of zero (0) for the row.

b. Scoring – Table 2: Score for the Row

Table 2 provides a guide for quick and easy scoring. Follow these steps to determine the proper vision score:

1. Use the code (number correct) you recorded for the row in Table 1;
2. Find the number correct for the row at the top of Table 2;
3. Read down to the appropriate row in Table 2,
4. Determine the (conversion) score for the row and
5. Record this score in the space on the right of Table 2 (labeled as the **SCORE** column), in the appropriate box labeled 1a – 9a.

For example, if a subject correctly identifies 3 letters in Row B1:

1. Using the code 3 you assigned in B1 for row 1,
2. You would find the number 3 in the third column in Table 2;
3. Read down Table 2, column 3 to row 1;
4. Determine that the score for the row is 7.5 and
5. Finally, you would record 7.5 in the space marked 1a on Table 2.

Similarly, if the subject correctly identified three letters in Row B4, the appropriate score to be written on Table 2 would be 5. Again, assign the maximum for rows 1 – 3 if the subjects begins the test in the row with the 5; and enter zero for rows that have not been attempted after the subject meets the ‘test end’ criterion. The coding and scoring must be completed immediately after vision test has ended. Scores will be converted to a Snellen Eye Chart equivalence and given to the subject prior to leaving.

c. B10 - Total Vision Score

The total vision score is recorded in (**B10**) and is the sum of all the row scores from Table 2. Carefully check and recheck your addition before recording this value.

d. Reporting Findings to the Subject.

Locate the total vision score on the Acuity Score Conversion Table (See Attachment A). Identify the Snellen equivalent on the table. Record the Snellen score on a Subject Vision Report Form (Attachment B) and check the appropriate box for follow-up recommendations. If the subjects’ Snellen score is 20/30 or better (e.g., 20/25), the subject report informs them that their vision is in the normal range for their age group. If their score is less than 20/30 (e.g., 20/40), the report informs them that their vision may be able to be improved. Carefully check and recheck your calculations and the table values before recording the Snellen score.

**Example 1**

- B1.** If  $\geq 2$  ; continue  
**B2.** If  $\geq 2$  ; continue  
**B3.** If  $\geq 2$  ; continue  
**B4.** If  $\geq 2$  ; continue  
**B5.** If  $\geq 2$  ; continue  
**B6.** If  $\geq 3$  ; continue  
**B7.** If  $\geq 3$  ; continue  
**B8.** If  $\geq 3$  ; continue  
**B9.**

**Table 1: # Correct in the Row**

	1	2	3	4	5	6	7	8	9	10	# Correct
	K	H	O	R							4
	C	K	Z	D	V						4
	O	Z	N	R	H	V	C				5
	R	K	C	S	Z	H	V	D			1
	S	D	K	H	O	R	C	V			0
	H	O	C	Z	R	K	D	S	V	N	0
	N	Z	C	O	S	K	D	V	R	H	0
	D	C	S	K	O	V	R	N	H	Z	0
	Z	S	V	D	K	H	N	O	R	C	0

**Table 2: Score for the Row**

	1	2	3	4	5	6	7	8	9	10	Score for Row
<b>B1a.</b>	2.5	5	7.5	10							10
<b>B2a.</b>	2	4	6	8	10						8
<b>B3a.</b>	1.4	2.9	4.3	5.7	7.1	8.6	10				7.1
<b>B4a.</b>	1.3	2.5	3.8	5	6.3	7.5	8.8	10			1.3
<b>B5a.</b>	1.3	2.5	3.8	5	6.3	7.5	8.8	10			0
<b>B6a.</b>	1	2	3	4	5	6	7	8	9	10	0
<b>B7a.</b>	1	2	3	4	5	6	7	8	9	10	0
<b>B8a.</b>	1	2	3	4	5	6	7	8	9	10	0
<b>B9a.</b>	1	2	3	4	5	6	7	8	9	10	0

**B10.**

TOTAL VISION SCORE:

26.4



**Example 2**

- B1. If  $\geq 2$  ; continue  
 B2. If  $\geq 2$  ; continue  
 B3. If  $\geq 2$  ; continue  
 B4. If  $\geq 2$  ; continue  
 B5. If  $\geq 2$  ; continue  
 B6. If  $\geq 3$  ; continue  
 B7. If  $\geq 3$  ; continue  
 B8. If  $\geq 3$  ; continue  
 B9.

**Table 1: # Correct in the Row**

**# Correct**

1	2	3	4	5	6	7	8	9	10	
K	H	O	R							4
C	K	Z	D	V						5
O	Z	N	R	H	V	C				6
R	K	C	S	Z	H	V	D			8
S	B	K	H	O	R	C	V			3
N	O	X	Z	R	K	D	S	V	N	1
N	Z	C	O	S	K	D	V	R	H	0
D	C	S	K	O	V	R	N	H	Z	0
Z	S	V	D	K	H	N	O	R	C	0

**Table 2: Score for the Row**

**Correct for**

	1	2	3	4	5	6	7	8	9	10	Row
B1a.	2.5	5	7.5	10							10
B2a.	2	4	6	8	10						10
B3a.	1.4	2.9	4.3	5.7	7.1	8.6	10				8.6
B4a.	1.3	2.5	3.8	5	6.3	7.5	8.8	10			10
B5a.	1.3	2.5	3.8	5	6.3	7.5	8.8	10			3.8
B6a.	1	2	3	4	5	6	7	8	9	10	1
B7a.	1	2	3	4	5	6	7	8	9	10	0
B8a.	1	2	3	4	5	6	7	8	9	10	0
B9a.	1	2	3	4	5	6	7	8	9	10	0

B10.

TOTAL VISION SCORE:

43.4

- Use a horizontal line ( \_\_\_\_\_ ) for all lines not attempted.
- Use a strike mark ( \ ) for letters attempted but incorrect.

## Section C. Mental Status (MMSE)

### 1. Description

The Mini Mental Status Exam (MMSE) gives a brief assessment of the person's orientation to time and space, recall ability, short-term memory, and arithmetic ability. It is being used as a screening test to identify cognitive loss.

The MMSE includes 12 items, divided into two sections. The first section requires verbal responses to orientation, memory, and attention in questions. The second section requires reading and writing and covers ability to name, follow verbal and written commands, write a sentence, and copy a polygon.

### 2. Administration/Script

All questions should be asked in the exact order shown in the data form. Each question can be asked a maximum of three times unless otherwise noted. If the subject does not respond, code 0 (zero) for the item; if the subject's response is incorrect, code 0 for the item. **DO NOT PROMPT THE SUBJECT IN ANY WAY.** Do not cue them regarding the correct answer or indicate your approval or disappointment after they have indicated their response. For example, do not say "good" after a subject answers the question. You might say "O.K." or "Thank-you." The MMSE scoring rules are conveniently summarized for your use during testing, see Attachment C.

**C1. and C2.** These questions measure orientation. Ask the questions as written. Record the subject's response verbatim on the response line. Allow 10 seconds for each reply. In general, you will give one point for each correct response, record 0 if incorrect. Refer to the scoring card for specific rules. Acceptable answers for C1 and 2 appear in the table below.

Item #	Question	Acceptable Response(s)
<b>C1a.</b>	What year is it?	Exact year or partial year, i.e. '08'.
<b>C1b.</b>	What season is it?	During the last month of the previous season or first month of the new season: accept either season, i.e. . <ul style="list-style-type: none"><li>• March = Winter or Spring</li><li>• June = Spring or Summer</li><li>• September = Summer or Fall</li><li>• December = Fall or Winter</li></ul>
<b>C1c.</b>	What is today's date?	Accept exact date, previous date, or next date, e.g., on the 7th, accept 6,7, or 8.
<b>C1d.</b>	What day of the week is it?	Exact day only.
<b>C1e.</b>	What month is it?	Accept exact month. However, on the first day of the new month, or last day of previous month, accept either month. If subject gave the correct month in C1c, you do <u>not</u> need to ask for month again in C1e.

- C2a.** What state are we in? Exact answer only (or site-specific answer if no state).
- C2b.** What county are we in? Exact answer only (or site-specific answer if no county).
- C2c.** What town (city) are we in? Exact answer only.
- C2d.** What building or place are we in? Accept exact name of an institution or facility if appropriate. Consider the answer correct if subject gives the formal name of the building/place. If subject gives a partial answer, e.g., “the University” or “senior center”, prompt, “could you be more specific?” The street address is not acceptable.
- C2e.** What floor are we in? Exact answer only.
- C3.** This item measures registration. The tester should name the three objects “*apple*,” “*penny*,” “*table*” taking one second to say each. Then ask the subject to repeat all three after you have said them. Circle the words in the response field as the subject repeats them. Give one point for each correct answer named on the first attempt regardless of order given. Allow 20 seconds for a reply. If the subject does not repeat all 3, give one point for each item named on the first attempt, but then repeat them until the subject learns them, up to a maximum of 5 times. That is, accept the first answer but then repeat until the subject learns them for the recall question that comes later (C5). Three points is the maximum a subject can score for this question; record 0, 1, 2 or 3 in the space provided.
- C4.** This question measures attention and calculation. Follow the directions. Stop the subject after 5 answers. Record the subject’s responses in the space provided. Give one point for each correct answer. Five points is the maximum a subject can score for this question; record 0, 1, 2, 3, 4, or 5 in the space provided. If the subject makes an error, but from that number correctly subtracts 7, count those responses as correct. For example, subject says 93, 85 (incorrect), 78, 71, 64; the code would be 4 for 4 correct responses.
- C4a.** This question is sometimes used as an alternate to C4. In this study, we will ask both C4 and C4a. Record the subject’s responses in the spaces provided.
- C5.** This question measures recall. Ask for the names of the three objects given in Q3., “*apple*,” “*penny*,” “*table*”. Circle the words in the response field as the subject repeats them. Give one point for each correct answer regardless of order given. Allow 10 seconds for a response. Three points is the maximum a subject can score for this question; record 0, 1, 2 or 3 in the space provided.

**C6.-C11.** The remaining questions measure language.

- C6.** Point to a pencil and a watch (one at a time) and ask the subject to name them by asking “What is this called?” Circle the words in the response field as the subject repeats them. Give one point for each correct answer. For watch you may accept a response of ‘watch’ or ‘wristwatch’. These are the only correct responses. No alternates are allowed for pencil. Two points is the maximum a subject can score for this question; record 0, 1, or 2 in the space provided.
- C7.** Ask the subject to repeat the phrase, ‘*no ifs ands or buts*’. Give one point if correctly repeated. One point is the maximum a subject can score for this question; record 0 or 1 in the space provided.
- C8.** This question asks the subject to follow a three-stage command. ‘*Take the paper in your right hand. Fold the paper in half. Put the paper on the table.*’ Give all three components of the command as one statement. Hold the paper in front of you. Be sure to read all three commands before you give the paper to the subject. Do not extend the piece of paper all the way to the subject. Circle the commands completed correctly. Give one point for each stage correctly completed. Three points is the maximum a subject can score for this question; record 0, 1, 2, or 3 in the space provided.
- C9.** Show the subject the card with “CLOSE YOUR EYES” written on it. Tell the subject to read the instructions on the card and do what it says to do. Give one point if the subject closes her/his eyes. If the subject just reads the card but doesn’t close her/his eyes repeat... ‘Read the instructions on the card and do what it says.’ You can repeat this prompt up to 3 times for the subject to get credit for the response. Allow 10 seconds for the response. Score one point only if the subject closes his/her eyes. One point is the maximum a subject can score for this question; record 0 or 1 in the space provided.
- C10.** Give the subject a piece of paper and a pencil. Ask him/her to write a sentence of his or her own choice. If subject says that they don’t know what to write about, prompt: “Write a sentence about the weather.” Give one point if the sentence contains a subject and a verb and makes sense. Ignore spelling errors when scoring. One point is the maximum a subject can score for this question; record 0 or 1 in the space provided. Allow 30 seconds.
- C11.** Give the subject the paper with the polygon design on it. Present the card in the horizontal position. Ask the subject to copy it. Give one point if correctly copied. Allow multiple tries until the subject is finished and hands the paper back to you. Accept the first drawing given to you. Do not urge the subject to try until s/he gets it right. The subject must draw two, 5-sided figures, intersected by a 4-sided figure. One point is the maximum a subject can score for this question; record 0 or 1 in the space provided.

### 3. Scoring

**The total MMSE score will be computed by the ACTIVE Data Management System. The maximum score is 30. If a subject cannot or does not respond to or complete a task, this should be coded as a zero.**

## Section D. HVLТ Word List 1

### 1. Description

The Hopkins Verbal Learning Test (HVLТ) is a test of new verbal learning and memory. Unique HVLТ word lists will be used at each study visit. The test is administered in two parts with the second part being administered after the Word Series Test. Three trials are conducted in the first part of the test. Read the Introduction and give the subject the pre-labeled packet of forms entitled “HVLТ Data Forms Packet.” This is a timed test. Allow precisely 2 minutes for completion of each of Trials 1-3.

### 2. Materials / Equipment Needed

- Sony Boom Box Model CFD-S01CD
- The HVLТ Administration Audiotape for the ‘10 Year, 07/2008’
- Electronic timer
- Pencils for subject’s use
- Individual Assessment Part I (10 Year Post-Test) Form #805 with ID label attached
- HVLТ Subject Data Forms Packet #310a with ID labels attached to all pages  
(NOTE: The same HVLТ Subject Data Forms Packet will be used for all study visits.)

### 3. Administration

The instructions for this task have been audiotaped for consistency in administration across sites. Be certain to use the HVLТ audiotape prescribed for the 10<sup>th</sup> Year Post-Test visit version 07/08. In the event of tape or cassette player failure, the tester should administer the test using the Instructions provided as Attachment D.

Record the Trial 3 end time in item D1 of the Individual Assessment Part I data form, page 10.

In the event of a mechanical failure during the test, administer using the script. Re-start the test at the beginning of the Trial in which the failure occurred, e.g., if the tape fails after the second word in Trial 2, start Trial 2 again with instructions. It is not necessary to go back to Trial 1 if the failure occurs during Trial 2 or Trial 3.

In situations where interruptions occur that might interfere with hearing the tape or concentration (e.g., a fire drill; someone entering the testing room; loud noise lasting more than a few seconds), rewind the tape to the beginning of the word list. If interruption occurs during the instructions, rewind and replay the instructions in their entirety. Describe interruption on VCS.

### 4. Scoring

Coding for this test should be completed in the HVLТ Coding Forms after the testing session for each subject.

Complete scoring rules are provided in the ACTIVE scoring manual for the HVLТ.

## **Section E. Word Series Test**

### **1. Description**

This is a test of inductive reasoning in which the subject is shown a series of days of the week or months of the year and must select the next week/month in the series from among five choices.

### **2. Materials / Equipment Needed**

- Electronic timer
- Pencils for subject's use
- Individual Assessment Part I (10<sup>th</sup> Year Post-Test) Form #805 with ID label attached
- Word Series Data Form #311 with ID label attached

### **3. Administration**

Follow the script and directions on the test form precisely. Use a copy of the test form (#311) to read the script. This is a timed test of 6 minutes. You may suggest that subjects use a ruler or card to keep their place in the test form. Be sure subjects are on the last page of the instructions before you tell them to turn the page and begin the test. Go over each example no more than 2 times. If the subject does not understand the pattern for the example after 2 tries, move to the next example. Once the subject starts the test, if you notice that s/he is spending a very long time on a problem, encourage her/him to move to the next problem. A long time is defined as being on problem #1, 2, or 3 at the end of 3 minutes.

### **4. Scoring**

The Word Series data from the subject's data form will be entered directly into the ACTIVE DMS. Scores will be computed by the DMS.

## Section F. HVLТ Recognition

### 1. Description

The HVLТ Recognition task is the second part of the Hopkins Verbal Learning Test (HVLТ) conducted earlier in the assessment. It is a test of new verbal learning and memory.

### 2. Materials/Equipment Needed

- Sony Boom Box Model CFD-S01CD
- The HVLТ Administration Audiotape for the ‘10th Year, 07/08’
- Pencils for subject’s use
- Individual Assessment Part I (10<sup>th</sup> Year Post-Test) Form #805 with ID label attached
- HVLТ Recognition Data Form #312 with ID label attached

(NOTE: The same HVLТ Recognition Form #312 will be used for all study visits.)

### 3. Administration

The instructions for this task have been audiotaped for consistency in administration across sites. Be certain to use the HVLТ audiotape prescribed for the 10<sup>th</sup> Year Post-Test visit. In the event of tape or cassette player failure, the tester should administer the test using the Instructions provided as Attachment D.

In the event of a mechanical failure, continue to administer the test using the script. If in the middle of the instructions, re-read the instructions. If in the middle of the word list, start reading the script at that point in the list. Do not go back to the beginning of the word list.

In situations where interruptions occur that might interfere with hearing the tape or concentration (e.g., a fire drill; someone entering the testing room; loud noise lasting more than a few seconds), rewind the tape to the beginning of the word list. If interruption occurs during the instructions, rewind and replay the instructions in their entirety. Describe interruption on VCS.

### 4. Scoring

The HVLТ Recognition data from the subject’s data form will be entered directly into the ACTIVE DMS. Scores will be computed by the DMS.

More complete scoring rules are provided in the ACTIVE scoring manual for the HVLТ.

## **Section G. Break Point**

Always use the standardized break point to offer the subject a brief break to stretch, relax, get a drink of water, go to the bathroom, etc. A break must be offered after the completion of the HVLT Recognition Assessment. It can take 30-40 minutes to complete the remainder of the assessment, so subjects should be encouraged to take even a small break to avoid a break at a later point in the battery.

If for any reason the tester feels the subject cannot complete the assessment in a single session, the session should be stopped at the break point.

The intent of the 'break point' protocol is to standardize, study-wide, the points at which subjects are refreshed for the testing tasks in the batteries.

- G1.** Indicate in this item whether or not a second session was required to complete this assessment.
- G1a.** If a second session is required, record the end time of Session 1 in this data field. Record the time you complete the HVLT Recognition Assessment. Use a 12 hour clock; circle **AM** or **PM** as appropriate.
- G1b.** Record the date Session 1 was conducted. Record the date as month, day and year. Note the year must be recorded as a four digit number; e.g., 2008. Do not leave blank spaces; use leading zeroes as required.
- G1c.** Record the start time for Session 2.



## Section H. Useful Field of View (UFOV)

### 1. Description

The UFOV is comprised of four subtests, each of which builds on the previous subtest. The first subtest requires the subject to identify which of two objects (a silhouette of a car or a truck) was presented inside a fixation box. The exposure duration of the target is manipulated to determine a threshold value for correct identification. The second test includes a central identification task, but in addition, the subject is required to locate a peripheral target. The location of the target is varied randomly from trial to trial and once again a threshold for both the identification of the central target AND correct localization of the peripheral target is determined by manipulating the duration of exposure to the display. The third test requires the subject to perform the central identification task and the peripheral localizing task, however, the peripheral target is embedded in a field of distracters. Once again, the threshold exposure duration for correct performance of both the identification and localization tasks is determined. The fourth test requires the subject to identify when the center task is different or the same and localization of the peripheral task. Once again, the threshold exposure duration for correct performance of both the identification and localization tasks is determined.

### 2. Administration

These instructions provide general guidelines to follow during testing. They will be better understood after administering the test.

**Verbal responses:** You may have to remind the subject to touch the screen to respond to the questions. You should instruct the subject to touch the screen as if they are lightly making a fingerprint, in other words, do not use their fingernail or point of their finger, but rather the “pad” of their finger, as if they were making a light finger print. They touch and then release. They do not need to hold their finger on the screen or slide their finger. Just touch with their fingerprint. In the beginning, many like to respond verbally only. If the subject continues to respond verbally throughout the trials, inform her that she does not have to tell you the name of the vehicle, she just needs to touch the vehicle on the screen when she is asked to identify which vehicle was inside the white box. If she continues to make verbal responses throughout the trials, no harm is done.

**Responses not timed:** You may have to explain to some that their responses are not timed. It doesn't matter how long it takes them to touch the screen. It matters whether their responses are correct/incorrect.

**Practice trials:** Each UFOV task will allow you to have a beginning trial, and then 3 more practice trails after that if need be.

**Task1, 2, 3 and 4:** Since the targets are generated randomly, when going through the practices, you will have to note the identity of the center target and the location of the peripheral target for each trial.

Often at this point you'll have questions whether the vehicle inside the box and the vehicle on the outside the box are the same. Inform the subject that the vehicle on the outside is always a car. He/she doesn't have to worry about what it is, but where it is. If he/she responds verbally throughout the task that the vehicle on the outside is the same or opposite of the vehicle inside the box, you may explain again that the identity of the outside vehicle plays no part in his/her score, but it is its location that they need to remember.

Starting off, you may have to lead subjects through the questions. Sometimes they want to jump to locating the outside car before answering what was inside the box. As you go through the demonstration trials, provide feedback whether the center and peripheral responses were correct. If the peripheral response was incorrect, inform the participant of the correct location.

Point out that the correct identification of the center target is more important than the correct location of the peripheral target. The trial will not count if the center target is missed, even if the peripheral target is located correctly.

Throughout Task 2, Task 3 and Task 4, if the subject misses the identity of the vehicle in the white box two or more times, remind the person to focus on the box and identify the vehicle inside.

### **Answers to common questions:**

Subjects can do the test with their glasses on or off-whichever way they are most comfortable.

Viewing distance from the screen is variable, but the recommended distance is approximately 24 inches. The subject should sit at a distance at which they are comfortable, but this distance should be comfortable to the extent that the subject can touch the screen to enter their responses.

If a subject has a physical limitation which makes it difficult for him/her to touch the screen, the subject may verbally respond and the tester may touch the screen for him/her.

**Program Flow:** The first screen will calibrate the software for you. Click the “ok” button to accept the automatic calibration. The main UFOV screen will appear with a task bar at the top left hand side. Select the “Client Info” drop down box for the input of subject identification information. Select the “New Client” option. Enter the subject’s ACTIVE Identification number under ACTIVE ID #. It will accept a letter as well as numerals. Enter the TESTER name for “First Name”. Tab to the next box. Enter the tester last name for “Last Name”. Enter the date of the test instead of the client’s date of birth, since we do not want any identifying information linked to the ACTIVE subject number. Under the drop down menu “Screening”, select task “1-4” combination. Follow the prompts to continue through each task. You will be allowed a trial for each task, as well as 3 additional practice trials, if needed.

At this point you are ready to begin the actual test. To do so, read the script below, and then follow the directions on the screen. You should read the directions along with the subject. After the test is finished, a screen will say “ This concludes the test. Thank you for participating.” (NOTE: If the participant performs worse than the guidelines decided upon by ACTIVE, the computer will automatically kick the participant out of any remaining tests. If the participant continues to do well, the computer will continue to take the participant through all 4 tasks.

To print the subject’s results, go to the drop down menu for “Reports”. Select “Screening History of Current Client”. Select the “print screen” icon (appears as a picture of a small printer) to print this report.

Reminders:

1. Allow the subject to use/not use eyeglasses as they choose.
2. Try to maintain a viewing distance of 24 inches  $\pm$  8 inches.
3. When the prompts on the screen identify an object, point to that object.
4. Responses are not timed.

5. Practice Criteria:

<u>Task</u>	<u>Criteria</u>
1	4 out of 4 correct
2	4 out of 4 correct (a correct response includes both correct central target identification <u>and</u> peripheral target localization).
3	2 out of 4 correct (same definition of correct as for task 2).
4	3 out of 4 correct for central discrimination task <u>only</u> .

3. Tester's Script

*The next test is a visual attention test called the Useful Field of View. This test will measure how well you can notice objects around you when you are paying attention to something in front of you. This ability to divide your attention and notice things to the side is needed for getting around safely in the environment.*

*You will go through a series of brief exercises. These exercises will become harder and harder. For each exercise, you will quickly reach a point where it will become too fast for you to see everything. This is OK. We are looking for the speed at which the exercise becomes too difficult. At this point, you will have to guess at the correct response. Guessing is OK because many times you will be correct even when you are not sure.*

READ DIRECTIONS ON SCREEN.

## Section I. Complex Reaction Time/Road Sign Test

### 1. Description

The Complex Reaction Test/Road Sign Test involves a measurement of how quickly a subject can recognize that one of four possible traffic signs has changed relative to the other three signs.

### 2. Administration

This test is administered on a computer terminal. The stimuli consist of international road signs (pedestrian, bicycle, right and left turn arrows) with and without a red slash through them. Subjects are instructed to ignore signs containing a red slash and to react to signs without a red slash. One of three reactions is required. For bicycle and pedestrian signs without a slash the subject is required to press a button on a computer mouse as quickly as possible. The action signaled by the right or left turn arrow without a slash is to move the mouse in the direction indicated by the arrow as quickly as possible. The number of stimuli on the screen at any given time ranges from three to six signs. Within a trial, the number of stimuli is held constant although the positions of the signs change throughout the frames.

### 3. Access the CRT (Complex Reaction Test)/Road Sign Test

Click on the **Road Sign Test v2.1** icon.

The initial screen will show a menu with the following options:

**“Enter Participant Data”,**

**“Review Instructions”,**

**“Practice Test”,**

**“Begin Test”,**

**“Print Last Test Result”**

and **“Quit”**.

Begin by clicking on the **“Enter Participant Data”** option. A screen will appear and prompt you for the following:

**Site:** You will enter F. (The instructions on the screen say enter F or P but all sites are F because it used to stand for our old data entry system FoxPro). This is the letter at the beginning of the ACTIVE subject number. You will then enter the identifying number for your site, for example Birmingham is 1 (this is the first number after the F).

**Participant ID #:** this is the 4 digits after the F1 or F and the number which identifies your particular site.

**Participant Check #:** This is actually the last digit of the ACTIVE subject number. For example if your subject number is F123456, F1 = the site; 2345 = the 4 digits; and the check # is the last number of the subject number “6”. If your participant number is F134567, then the site number = F1; the 4 digits = 3456; and the check # = 7.

**Visit #:** Type in capital letter “I” and the number 7. (5<sup>th</sup> annual was I6 so 10<sup>th</sup> Annual will be I7.)

Now click **SAVE**.

#### 4. INTRODUCTORY SCRIPT

Please read the following script to the participant:

Introduction: *This is a traffic sign recognition test. It will measure how fast you can recognize that one sign has changed relative to other signs. This ability to notice and react to changes in objects is helpful for mobility in everyday life.*

#### 5. REVIEW INSTRUCTIONS

Select the “Review Instructions” prompt. This contains both mouse practice and 4 trials of sign practice.

REMINDER: AT SOME POINT DURING THE INTRODUCTION, TRACE THE RED SLASHES TO MAKE THEM CLEAR TO THE SUBJECT.

#### 6. SCRIPT FOR MOUSE PRACTICE:

Please read the following script to the participant:

*Before we begin the actual task, I want you to practice using the mouse. Let us read the directions together from the computer screen.*

If you feel the participant needs more mouse practice, simply select the “Review Instructions” prompt again. If they do not need any more practice, select the “Practice Test” prompt.

#### 7. PRACTICE TEST

Select the “Practice Test” prompt. Read the directions with the participant from the computer screen. When they have completed this practice, select the “Begin Test” prompt.

#### 8. BEGIN TEST

##### SCRIPT

Read the following script to the participant:

*“We will now begin the task.”*

Select the “Begin Test” prompt to begin. They are approximately 10 seconds allowed before the screen will automatically go to the next trial.

There will be a slight break in the middle of the trials. See if the participant wants to rest their hand for a minute or two or continue. When the participant is ready, click “Continue”.

## 9. PRINT OUT

Select the “Print Last Test Result” prompt. An information screen will appear. The screen prompts you to print out the results. “Results sent to default printer?” Select the “ok” prompt.

NOTE: It takes approximately 45 seconds for the information to be sent to the printer. You do not need to ask it for multiple printouts during this time lag. It will print, it is just not a speedy process.

## 10. EXIT CRT/Road Sign Test

To exit out of the entire program select the “QUIT” prompt.

## **Section J. End Time**

Session end time: Record the session end time when you complete the CRT.

### **Instructions for the Cognitive Training Form # 301**

At the end of the session read the closing script to the participant. The closing script that includes instructions for the Take-Home Questionnaire is included to provide Testers with the text if necessary at Part II. If the subject received the Take-Home Questionnaire at Part I and returned it at the start of this Session, you do not have to read these instructions. The closing script will guide you in distribution of the Take Home Questionnaire if necessary. Use this script if you distribute the Take Home Questionnaire at the end of this Assessment Session.

### **Instructions for the Take-Home Questionnaire**

At the end of the session read the closing script to the subject. The closing script appears in the data form. Read the script verbatim. The closing script will guide you in distribution of the Take-Home Questionnaire, as well as reminders for the next in-person visit.

## **K. Tester's Assessment of the Interview**

This section includes questions designed to gather feedback from testers regarding the subject's overall receptivity to, and cooperation with, the instrument and the degree of difficulty responding to/completing the measures. Space is provided to identify specific items and describe the difficulty. Please provide as much information as you can.

# ATTACHMENT A

## ACTIVE Acuity Score Conversion Table

Score	Snellen Equivalent at 10 ft.	Score	Snellen Equivalent at 10 ft.
1	20/123	51	20/39
2	20/121	52	20/38
3	20/188	53	20/37
4	20/115	54	20/36
5	20/112	55	20/36
6	20/110	56	20/35
7	20/107	57	20/34
8	20/105	58	20/33
9	20/103	59	20/32
10	20/100	60	20/32
11	20/98	61	20/31
12	20/96	62	20/30
13	20/94	63	20/30
14	20/91	64	20/29
15	20/89	65	20/28
16	20/87	66	20/28
17	20/85	67	20/27
18	20/83	68	20/26
19	20/81	69	20/25
20	20/80	70	20/25
21	20/78	71	20/25
22	20/76	72	20/24
23	20/74	73	20/23
24	20/73	74	20/23
25	20/71	75	20/22
26	20/69	76	20/22
27	20/68	77	20/21
28	20/66	78	20/21
29	20/65	79	20/20
30	20/63	80	20/20
31	20/62	81	20/20
32	20/60	82	20/19
33	20/59	83	20/19
34	20/58	84	20/18
35	20/56	85	20/18
36	20/55	86	20/17
37	20/54	87	20/17
38	20/53	88	20/17
39	20/51	89	20/16
40	20/50	90	20/16
41	20/49	91	20/16
42	20/48	92	20/15
43	20/47	93	20/15
44	20/46	94	20/14
45	20/45	95	20/14
46	20/44	96	20/14
47	20/43	97	20/14
48	20/42	98	20/13
49	20/41	99	20/13
50	20/40	100	20/13



## ATTACHMENT B

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# ACTIVE

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Name: \_\_\_\_\_

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Vision: \_\_\_\_/\_\_\_\_

☐

20/30 or better

The results of your vision screening test today indicate your vision is in the normal range for your age group.

☐

less than 20/30

The results of your vision screening test today indicate your vision may be able to be improved. You may wish to consider care from an eye specialist, if you are not already under the care of a doctor for your vision.

Please keep in mind that the vision screening test you received today in no way replaces a comprehensive eye exam performed by a certified eye doctor (ophthalmologist or optometrist). The results of this test were obtained under non-clinical conditions and may yield different values under standard, clinical conditions. This test was conducted for research purposes only.

# ATTACHMENT C

# ACTIVE

## MMSE SCORING RULES

<u>Question</u>	<u>Max Score</u>	<u>Rule</u>
C1a. What year is it?	1	Exact year or partial year, i.e. '03'.
C1b. What season is it?	1	During the last month of the previous season or first month of the new season, accept either season. March = Winter or Spring June = Spring or Summer September = Summer or Fall December = Fall or Winter
C1c. What is today's date?	1	Accept exact date, previous date, or next date, e.g., on the 7th, accept 6,7, or 8.
C1d. What day of the week is it?	1	Exact day only.
C1e. What month is it?	1	Accept exact month. However, on the first day of the new month, or last day of previous month, accept either month.
C2a. What state are we in?	1	Exact answer only (or site-specific answer if no state).
C2b. What county are we in?	1	Exact answer only (or site-specific answer if no county).
C2c. What town (city) are we in?	1	Exact answer only.
C2d. What building or place are we in?	1	Accept exact name of an institution or facility if appropriate.
C2e. What floor are we in?	1	Exact answer only.
C3. Repeat names of 3 objects.	3	1 point for each correct reply regardless of order <u>on first attempt</u> .
C4. Counting backwards.	5	5 points: all correct 4 points: 4 correct, 1 wrong 3 points: 3 correct, 2 wrong 2 points: 2 correct, 3 wrong 1 point: 1 correct, 4 wrong

C5. Remember names of 3 objects.	3	1 point for each correct reply regardless of order.
C6. Name 2 objects.	2	1 point for each correct response. Must state “pencil”; Accept either “watch” or “wristwatch”
C7. Repeat a phrase.	1	Must be an exact repetition.
C8. Follow 3-step command.	3	1 point for each instruction correctly executed.
C9. Read words and do what it says.	1	Subject closes eyes. Does not have to read out loud.
C10. Write a sentence.	1	Sentence should make sense. Ignore spelling errors.
C11. Copy a design.	1	Subject must have drawn a 4-sided figure between the two 5-sided figures.
MAXIMUM TOTAL SCORE	30	The total score will be computed by the ACTIVE Data Management System.

## ATTACHMENT D

# ACTIVE

### HVLT and HVLT RECOGNITION INSTRUCTIONS

This next section is a measure of your ability to learn and remember a list of words. For this section you will use these forms. (HAND THE SUBJECT A PRE-LABELED PACKET OF FORMS TITLED “HVLT DATA FORMS PACKET.”) We will start with the form marked Number 1.

**TRIAL 1:** The first thing I will do is read you a list of words one at a time. Listen carefully because when I stop, I want you to write down as many of the words that you can remember on the form marked NUMBER 1. It doesn't matter in what order you write them. Just try to remember and write down as many of the words as you can. When you can no longer remember any more words, place your pencil on the table.

FOR EACH TRIAL, AFTER INSTRUCTIONS AND BEFORE THE WORD LIST, ASK IF THERE ARE ANY QUESTIONS. ANSWER APPROPRIATELY.

Are there any questions? I will not be able to answer questions once I start reading. Please do not talk during the test. Ready?

PAUSE 10 SECONDS. THEN READ THE WORD LIST ALOUD. USING A TIMER, PAUSE 2 SECONDS BETWEEN EACH WORD.

# Seconds

SUGAR	1
TRUMPET	4
VIOLIN	7
COAL	10
GARLIC	13
KEROSENE	16
VANILLA	19
WOOD	22
CLARINET	25
FLUTE	28
CINNAMON	31
GASOLINE	34

PAUSE 2 SECONDS AND THEN SAY: Now write all the words you can remember.

START TIMER. AT THE END OF 2 MINUTES, SAY: *Stop!*

**TRIAL 2: (COLLECT THE NUMBER 1 DATA FORM)**

Now I am going to read the same list again. When I stop, I want you to write down as many words as you can remember, including the words you wrote down the first time. This time use the form marked NUMBER 2. It doesn't matter in what order you write them, just write as many of the words as you can remember whether or not you wrote them down before. When you can no longer remember any more words, place your pencil on the table. Are there any questions? Ready?

PAUSE 10 SECONDS, THEN READ THE WORD LIST ALOUD. PAUSE 2 SECONDS BETWEEN EACH WORD.

PAUSE 2 SECONDS AND THEN SAY: Now write all the words you can remember.

START TIMER. AT THE END OF 2 MINUTES, SAY: *Stop!*

**TRIAL 3: COLLECT THE NUMBER 2 DATA FORM.**

Now I'm going to read the same list once more. When I stop I want you to write down as many word as you can remember including the words you wrote down the first two times. Remember it doesn't matter in what order you write them, just write as many words as you can remember whether or not you wrote them down before. When you can no longer remember any more words, place your pencil on the table. Are there any questions? Ready?

PAUSE 10 SECONDS, THEN READ THE WORD LIST ALOUD. PAUSE 2 SECONDS BETWEEN EACH WORD.

PAUSE 2 SECONDS AND THEN SAY: Now write all the words you can remember.

START TIMER. AT THE END OF 2 MINUTES, SAY: *Stop!*

RECORD THE TRIAL 3 END TIME IN THE DATA FORM.

## HVLT RECOGNITION INSTRUCTIONS

HAND THE SUBJECT THE FORM #312.

Now I am going to read you another list of words. Some of them are from the list I read before, some of them are new words. For each of the words I read, please write down Y for YES if the word is from the original list. If the word is not from the original list, write N for NO. Again, write Y in the box if the word is from the original list and N if the word is not from the original list. You will only have time to write a Y or an N because the words will be read very quickly. Remember, do not write YES or NO, just Y or N.

AFTER INSTRUCTIONS AND BEFORE THE WORD LIST, ASK IF THERE ARE ANY QUESTIONS. ANSWER APPROPRIATELY.

Are there any questions? I will not be able to answer questions once I start reading. Please do not talk during the test. Ready?

PAUSE 10 SECONDS. THEN READ BOTH THE ITEM NUMBER AND RECOGNITION WORD LIST ALOUD. PAUSE 2 SECONDS BETWEEN EACH WORD.

- |              |                 |
|--------------|-----------------|
| 1. Pepper    | 13. Drum        |
| 2. Ball      | 14. Chair       |
| 3. Trumpet   | 15. Flute       |
| 4. Kerosene  | 16. Sand        |
| 5. Garlic    | 17. Oil         |
| 6. Salt      | 18. Coal        |
| 7. Basement  | 19. Electricity |
| 8. Vanilla   | 20. Piano       |
| 9. Wood      | 21. Sugar       |
| 10. Priest   | 22. Clarinet    |
| 11. Cinnamon | 23. Moon        |
| 12. Gasoline | 24. Violin      |

# ACTIVE

## Question by Question Specifications Guide for Administration of the Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) Measurements

### I. Purpose

The measures in the Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) are designed to measure aspects of the subject's functional status, speed of processing, mobility, and health status. The results of the measures completed at this visit will be compared to results obtained at earlier points in the study.

### II. Study Sample and Administration

10<sup>th</sup> Annual Post-Testing will be completed on all ACTIVE subjects still participating in the study. The ideal order of administration of these 10<sup>th</sup> Annual Post-Test Measures is as follows:

1. Individual Assessment Part I
2. Take-Home Questionnaire
3. Individual Assessment Part II
4. Group Assessment Measures

However, this order is not strict. You may need to alter the order of administration to accommodate either subject or Field Site scheduling conflicts.

### III. Administration Protocol

The following items should be assembled in advance of the subject's appointment time.

#### A. Materials

- Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) Form #815 with ID label attached
- Digit Symbol Substitution & Digit Symbol Copy Form #411a with ID label attached
- Digit Symbol Substitution & Digit Symbol Copy Data Coding Form #411 with ID label attached
- ACTIVE Blood Pressure and Pulse Reporting Form
- OTDL Data Form #422 with ID label attached
- QxQ Specifications Guide for Administration of the OTDL
- QxQ Specifications Guide for Administration of the Individual Assessment Part II (10<sup>th</sup> Annual Post-Test)

## **B. Equipment**

- Omron Automatic Digital Blood Pressure and Pulse Monitor
- Two OMRON blood pressure cuffs: standard and large adult sizes
- Right angle Handi-Stat wood piece
- 8 foot wood folding carpenter's ruler
- Luekopor medical paper tape
- Large digital display scale with extra wide base
- Germicidal handi-wipes
- Paper towels
- Jamar Adjustable Hydraulic hand dynamometer
- Electronic timer
- Digital stopwatch
- Timed IADL Administration Kit
- OTDL Administration Kit
- Spare batteries should be carried for all battery operated equipment
- Digit Symbol Substitution Task Scoring Stencil

## **C. Preparation**

1. Testers must be certified as an ACTIVE Tester. Certification status must be current.
2. Ideally, all Individual Assessment Part II Measurements can be completed in one general exam room or private workstation. The area selected must allow for private, confidential testing and interviewing with minimal background noise.
  - To complete the height measurement, a wall space or door jam space without baseboard or threshold is required. The floor must be free of carpeting.
  - To complete the weight measurement, a hard, flat, uncarpeted floor space large enough to accommodate the digital scale will be required.
3. In advance of the subject's appointment time, testers should assemble a packet with all forms necessary for completion of the Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) Measurements. All forms should be pre-labeled with the subject's full study ID Labels.
4. Prior to the start of measurement, the tester must remove phone book, digital stopwatch, coins, the three food cans, and the two medicine containers from the Timed IADL kit. Close up the kit so the food array in the box is not visible to the subject.
5. Prior to the start of the session, the tester should remove items and question cards from the OTDL Kit. Organize items in precise order of use for testing.
6. When you greet the subject, note clothing compatibility for the blood pressure measurement. If the shirt or sweater seems to be incompatible, ask the subject to change shirts.



7. Prior to the start of the session, tester should set-up and test Omron B/P & Pulse Monitor equipment.

#### **D. Order of Administration**

The ACTIVE Steering Committee has prescribed the order of administration for the tests included in the Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) Measurement battery. The order is:

1. MDS
2. Timed IADL
3. Digit Symbol Substitution Task
4. Digit Symbol Copy Task
5. Blood Pressure
6. Pulse
7. Height
8. Weight
9. Grip Strength
10. 360° Turn
11. BREAK POINT
12. OTDL
13. Mobility Questionnaire (Life Space, Falls and Driving)
14. Health Questions and Health Services Utilization

You must follow this order exactly. Ideally, the assessment can be completed in one session. A break must be offered after the completion of the Turn-360 Test. It can take 30-40 minutes to complete the remainder of the assessment, so subjects should be encouraged to take even a small break to avoid a break during the OTDL, Mobility, Health Questions/Health Services Utilization, and TICS testing. Nonetheless, the tester is allowed to continue the assessment if the subject refuses a break. If for any reason the tester feels the subject cannot complete the assessment in one session, the session should be stopped at the break point. Any deviation from the prescribed order should be documented on the form and reported to the PI of the Field Site. The CC should also be informed of the alteration in administration.

#### IV. Important Matters related to Standardization of the Data Collection Methods

Whenever many individuals are responsible for data collection, the possibility of observer bias exists. Simply put, this means that differences in the technique used to collect the data can be responsible for variations in the results. Observer bias can also occur in the collection of physiologic measures if a different technique is used or simply by being casual or unfamiliar with the protocol.

A great deal of time and effort has been spent developing protocols that accurately measure physical and functional capabilities. Each protocol has been written with the principles of accuracy, consistency, safety and comfort in mind. It is essential that **ALL TESTERS SHOULD ADHERE TO THE PROTOCOLS AS WRITTEN**, since even a seemingly unimportant omission or variation in technique can make a significant difference in the measurements recorded.

There will be times when a deviation from the protocol is necessary and unavoidable. An example would be the man who has broken his left arm and must have his blood pressure taken on the right arm; or the woman who is physically unable to position her head against the wall for the height measurement. When these situations occur, use the margins of the form to record the measurements as taken and note the variation in the technique used for the measurement and the reasons for the deviation from protocol.

#### V. Section by Section Review

##### Section A. Identifying Information

Items A1. – A4. should be completed by the ACTIVE tester prior to the start of the measurement.

- A1.** Study ID: Affix the subject's study ID label in the space provided. Do not hand write the ID number. Double-check the ID number against the subject's visit control sheet. Confirm the subject's name at the start of measurement to be sure you are using the correct ID for the subject.
- A2.** Visit #: This item may be pre-coded. Various forms will be used at the time of the Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) (Visit # **ID10**). The code for Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) is **ID10**.
- A3.** Form Version: Be sure the form version on the form matches the current approved version. Note the year appears as a 4-digit number.
- A4.** Tester ID/Initials: Write in your assigned tester ID or initials.
- A5.** Date completed: Write in the date you complete the Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) Measurements; if the measures are completed in more than one day, use the date the measures were completed. Record the date as month, day and year. Note the year must be recorded as a four digit number; e.g., 2008. Do not leave blank spaces; use leading zeros as required.
- A6.** Time started: Record the exact time you begin the General Introduction to the Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) in A6. Use a 12-hour clock; circle **AM** or **PM** as appropriate.

**GENERAL INTRODUCTION:**Read the General Introduction verbatim to the subject.

## **Section B: MDS**

### **1. Self Performance of Instrumental Activities of Daily Living (IADL)**

#### **a. Description**

The intent of these items is to examine the areas of function that are most commonly associated with independent living. The MDS provides a self-report of a subject's ability to perform these common tasks.

#### **b. Administration**

The subject is questioned/interviewed directly about his or her performance of normal activities of daily life around the home or in the community in the last 7 days. There are 19 activity categories in the IADL scale, and there are two questions the tester must code for each of the activity categories. Review Section B, Part 1 of the instrument carefully. Note the 19 activity categories and the 2 questions that must be answered. Although the tester should complete the MDS as an interview, they must also use their own observations while completing the assessment. If a subject's behavior is not congruent with a subject's self report, the tester should re-ask the question as a prompt prior to coding the activity.

Below find the definition for each of the 19 activity categories.

#### **c. Definitions**

- (a) **Planning meals, reading recipes, assembling ingredients** — How meals are planned (e.g., thinking ahead about the week's schedule, menu planning, reading recipes and gathering required ingredients, noting what is missing.)
- (b) **Setting out food and utensils** — How meals are assembled, including setting out packaged prepared food and utensils. (e.g. setting the table with proper utensils).
- (c) **Cooking** — How meals are cooked (e.g., baking, heating up leftovers, frying, and warming frozen dinners).
- (d) **Doing dishes, dusting, making bed, tidying up** — How dishes are cleaned, rooms are cleaned (e.g., making bed, changing bed linen, dusting furniture, sweeping/vacuuming floors).
- (e) **Laundry** — Washing of clothes, sheets, towels, etc. Someone else transporting a subject's laundry from her/his apartment/room to the laundry machine is not included.
- (f) **Handling money, writing checks** — How money and checks are handled and paid out as needed. This does not include going to the bank to do banking or using bank machines.
- (g) **Ensuring that all bills are paid on time** - How bill due dates are monitored and adhered to.
- (h) **Balancing checkbook** - How additions and subtractions are entered into the checkbook, including balancing the amount.

- (i) **Keeping household expenses balanced** — How decisions are made about household expenses based on resources.
- (j) **Keeping track of doctor appointments** - How health care appointments are remembered and adhered to.
- (k) **Remembering to take medications on time and as prescribed by doctor** - How medication schedules are complied to. (e.g., remember to take medicines, including pills, injections, eye drops, and ointments at specified times.)
- (l) **Opening medicine bottles, taking own medications** - How oral medications are prepared for administration and actually administered. (e.g. opening bottles, measuring liquids, scoring pills.)
- (m) **Giving self injection, applying ointments, changing bandages** -
- (n) **Looking up phone numbers - either in phone books or by calling “information”** - How needed phone numbers are obtained.
- (o) **Remembering often called numbers without having to look them up** - Recalling frequently called numbers, and dialing them without first looking them up. (e.g. family or friends phone numbers.)
- (p) **Answering phone when someone calls** - How phone is answered and handled. (e.g. finding the phone when ringing, terminating unwanted solicitations.)
- (q) **Hanging up at end of call** - How the line is terminated at the end of a conversation. (e.g. pressing the “off” button on a cordless, returning the receiver to its cradle)
- (r) **Shopping for food and household items** - How food or household items are obtained. (e.g. creating a list of sorts of needed items, determining where to go for supplies, getting the desired supplies purchased and into home.)
- (s) **Travel by vehicle to go to places beyond walking distances** - How travel occurs beyond reasonable walking distance. (e.g. arranging for and/or taking a taxi, bus, car, ride with a friend.)

d. Coding

There are two questions the tester must ascertain from the subject for each of the activities in the Self Performance of IADL scale.

The tester must select a code for each of the two questions for the subject's performance for each of the 19 activities over the past 7 days by circling the code number in the appropriate column.

**Question #1: In the last 7 days, how much of the activity did you do on your own?**

There are five coding options available for the first question. Choose the best option from the following list.

- (1) **Did all on own:** Use this code if the activity occurred at least once during the past seven days and every time the activity occurred, it was done completely by the subject.

**Do not use this code, if the activity did not occur in the last seven days OR if the subject received any help with this activity in the last seven days, even if the help was not needed and even if the help was only given on one occasion.**

- (2) **Some help some of the time:** Use this code if the activity occurred one or more times during the past seven days and at least once, but not every time, the subject received help.

**Do not use this code if the activity did not occur in the last seven days OR if the subject received help every time the activity occurred.**

This code is a bit more complicated when an activity includes more than one sub-task; for example, ‘giving self injections, applying ointment, changing bandages.’ For these activity categories, the tester must inquire about the actual sub-tasks that did occur in the last seven days. Use this code if on any of these occasions, but not all of the occasions, the subject performed any of the sub-tasks on his/her own. The following example is provided as an illustration:

On Monday morning, Mrs. Smith applied her own ointment and her husband gave her an injection. On Thursday morning Mrs. Smith applied her own ointment and received no injection. This qualifies as ‘*some help, some of the time*’ because on one occasion Mrs. Smith received help but on another occasion she did not. Whether or not Mrs. Smith is able to give an injection to herself does not matter. Use this code as long as on one occasion, but not every occasion, Mrs. Smith performs the sub-task that does occur on her own.

- (3) **Help all of time:** Use this code if the activity occurred at least once during the past seven days and at every occasion the individual received help, but still did part of the activity on at least one occasion.

**Do not use this code if the subject was not involved in the performance of the activity in the last seven days.**

**Do not use this code if the activity did not occur in the last seven days.**

This code is also a bit more complicated for those activities that include more than one sub-task. Using the same activity of ‘giving self injections, applying ointments, changing bandages’: as with code 2, the tester must inquire thoroughly about the specific occasions when these sub-tasks occurred in the past seven days. Use this code, if on all of these occasions the subject received help from others performing any of the sub-tasks, but participated in performance of other sub-tasks on at least one occasion. Here is another example:

On Monday morning Mrs. Smith applied her own ointment and her husband gave her an injection. On Thursday morning Mrs. Smith’s husband gave her an

injection and applied the ointment. This is '*help all of the time*' because Mrs. Smith received help on both occasions but she did perform one of the sub-tasks on one occasion. It should be noted that even if Mrs. Smith did not completely perform a sub-task, but had helped in a sub-task (e.g. had taken the lid off the ointment bottle), then this code would still apply.

- (4) **Fully performed by others:** Use this code if the activity occurred at least once during the past seven days, and on every occasion it was performed completely by someone other than the subject.  
**Do not use this code if the subject ever performed or ever helped to perform the activity in any way on any occasion.**

**Do not use this code if the activity did not occur in the last seven days.**

- (5) **Activity not performed by you or others** Use this code if the activity did not occur even once during the past seven days by either the subject or any individual on behalf of the subject.

**Question #2: How difficult was it (or would it have been) to do on your own?**

If the subject reports in Question 1 that s/he was involved in performance of the activity over last seven days, (coded 1, 2, or 3) ASK: "*How difficult was it to do on your own?*"

If the subject reports in Question 1 that s/he was not involved in the activity in last seven days (e.g., others did it or there was no need to do it; coded 4 or 5), ASK: "*How difficult would it have been to do on your own?*"

There are three coding options available for the second question. Choose the best option from the following list.

- (1) **Not difficult:** Subject did not have difficulty, or would not have difficulty completing the activity or sub-task(s) on their own.
- (2) **Some help needed or I am slow, or I became fatigued:** Subject did require or would require some help, or was slow in performing task(s) or became fatigued.
- (3) **Great difficulty:** Subject had great difficulty or would have great difficulty performing all sub-tasks on their own.

## 2. Self Performance of Activities of Daily Living (ADLs): Dressing, Personal Hygiene, Locomotion, Transfer, Toilet and Bathing

### a. Description

The intent of the Self Performance of ADL Performance Scale is to record the subject's self-care performance in activities of daily living (i.e., what the subject actually did for himself or herself and/or how much verbal or physical help was required by caregivers) during the **last seven days**. CAUTION: Two coding schemes are used for these items, one for the activities related to dressing, personal hygiene, locomotion, transfer, and toileting (items a – q) and another for activities related to bathing (r – v). The coding rules for scoring these ADLs appear in the data form.

### b. Administration

A subject's ADL self-performance may vary from day to day, or even within the 24 hour period. There are many possible reasons for these variations, including mood, medical condition, relationship issues (e.g., willing to perform for a home caregiver he or she likes), and medications. The responsibility of the person completing the assessment, therefore, is to capture the total picture of the subject's ADL self-performance over the seven day period, 24 hours a day.

In order to accomplish this, it is necessary to ask the subject to think about the last 24 hours, then consider the last 7 days. Ask about variations during the week; when help was available and when it was not. Ask questions pertaining to all aspects of the ADL activity as defined in this guide. Since accurate coding is important, be sure to consider each activity's definition fully.

The wording used in each coding option is intended to reflect real-world situations, where slight variations are common. Where variations occur, the coding ensures that the subject is not assigned to an excessively independent or dependent category. For example, by definition, codes 1, 2, 3, and 4 in the Dressing, Personal Hygiene, Locomotion, Transfer, and Toileting scheme (Independent, Supervision, Limited Assistance, and Extensive Assistance) permit one or two exceptions for the provision of heavier care. This is clinically useful and increases the likelihood that tester will code ADL self-performance items consistently and accurately.

### c. Definitions for Dressing, Personal Hygiene, Locomotion, Transfer and Toileting

**ADL SELF-PERFORMANCE** — Measures what the subject actually did (not what he or she might be capable of doing) within each ADL category over the last seven days according to a performance-based scale.

- (a) **Picking out and gathering clothes** - How clothing is selected and gathered, including any prosthesis.
- (b) **Dressing or undressing lower part of body** - How socks, shoes, pantyhose, underwear and pants are put on and taken off (not including fastening, tying or buttoning).
- (c) **Tying/untying shoes, fastening/unfastening pants** - How shoes and pants are fastened and unfastened.
- (d) **Putting on or taking off shirt/blouse, dress, bra** - How upper body clothing is put on and taken off (not including fastening, tying or buttoning.)

- (e) **Fastening/unfastening bra, Buttoning or unbuttoning, Zippering or unzipping** - How upper body clothing is fastened.
- (f) **Gathering wash cloth, soap, shaving kit, makeup, toothbrush etc** - How personal hygiene supplies are gathered, including adaptive equipment.
- (g) **Washing and drying perineum** - How the perineum is washed and dried (the area occupied by urogenital passages and the rectum). For perineum, the words private parts or groin can be substituted. Be certain that it is clear what is being discussed.
- (h) **Washing and drying face** - How the face is washed and dried
- (i) **Brushing teeth, Shaving face, Make up application** - How natural or artificial teeth are cared for, shaving, and make-up application.
- (j) **Combing/brushing hair** - How hair is groomed and arranged.
- (k) **Securing support articles or devices (braces, canes, walker, wheelchair)** - Some elders use equipment to help them move about inside and outside of their home. We are interested in the level of dependence persons who use such equipment have in assembling and using the device. For example, if an elder uses a cane to walk around the home or outside the home, but can manage the use of this equipment independently, code a "1", "Independent". If the elder uses a wheelchair for mobility, and requires assistance every time for set up and transfer, code "5" "Total Dependence". Assistance is characterized by the provision of articles, devices, or preparation necessary for the person's self-performance of an activity. Code "8" if the elder never uses a piece of equipment such as a wheelchair, walker, cane or brace.
- (l) **Moving between locations on the same floor** - How the elder moves about where they live on a single level, for example, from room to room, and between locations on the same floor, for example, between a living room and a kitchen or bedroom. The elder may receive assistance in the form of a helping hand while walking or being pushed in a wheelchair. If someone remains nearby to watch over the person, the elder is receiving oversight, and thus the code should be "2" "Supervision".
- (m) **Moving to sitting position** - How to move from a prone position to a sitting position, such as bed or chair or wheelchair. An example is from lying in bed to sitting on the side of the bed. This item excludes transfer to and from bath or toilet.
- (n) **Moving to and from standing position** - How to transfer from moving from a sitting position to a standing position, and then back to a sitting position.
- (o) **Moving on and off toilet** - How to transfer on and off the toilet
- (p) **Cleaning self after using the toilet including managing use of pads** - How the perineum (the area occupied by urogenital passages and the rectum) is cleaned after using the toilet. For perineum, the words private parts or groin can be substituted. This includes changing sanitary pads.
- (q) **Adjusting clothes** - How clothes are adjusted prior to and after using the toilet



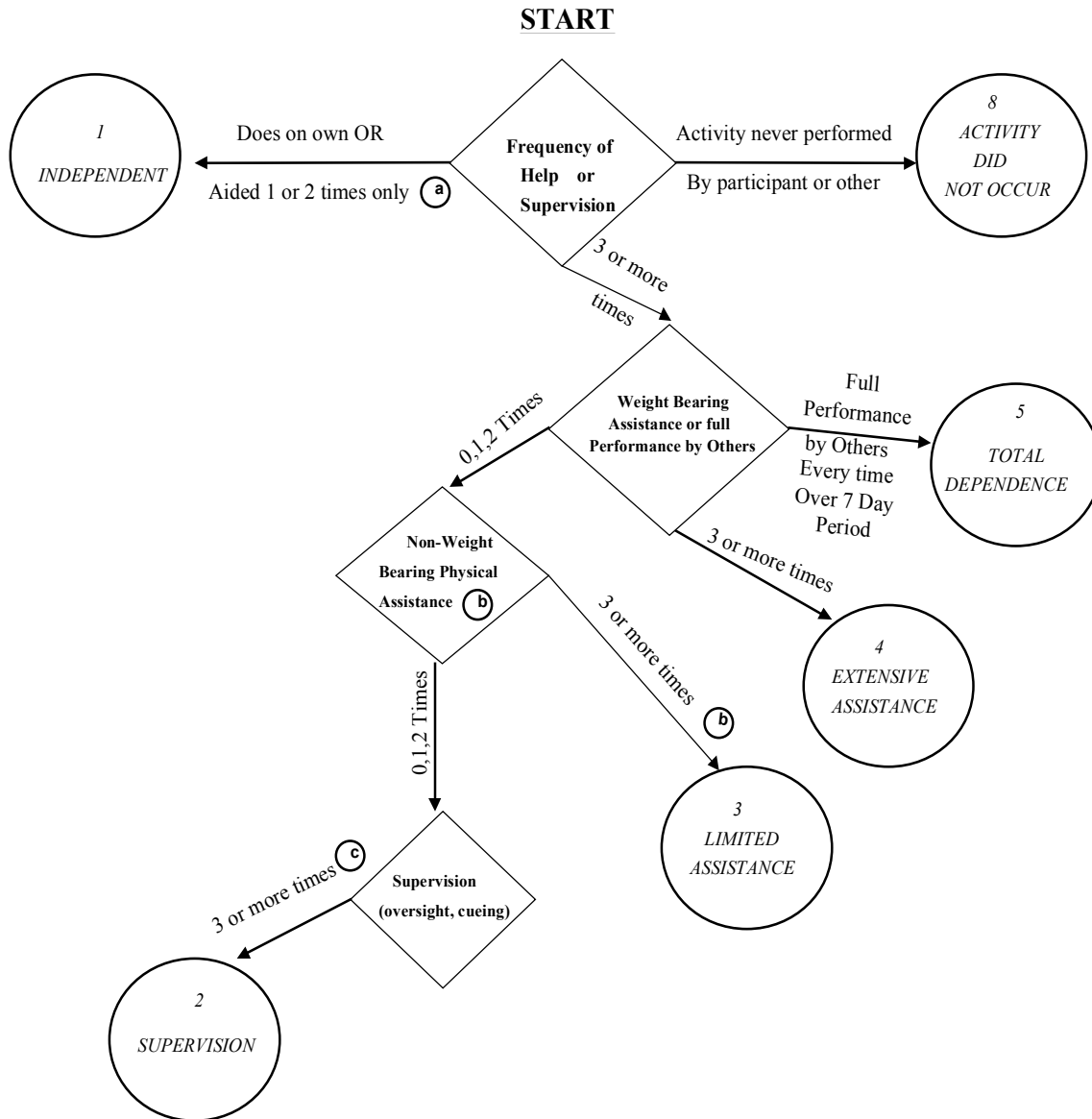
d. Coding for Dressing, Personal Hygiene, Locomotion, Transfer, and Toileting

For the ADL categories of Dressing, Personal Hygiene, Locomotion, Transfer, and Toilet (items a-q) code the appropriate response for the subject's actual performance during the past seven days. Circle the code in the appropriate column. Consider the subject's performance during 24 hours over the last week. Use the coding scheme provided in the form. The coding scheme is as follows.

CODE	DESCRIPTION	DEFINITION
(1)	<b>INDEPENDENT</b>	No help or caregiver oversight <b>-or-</b> caregiver help/oversight provided only one or two times during the last seven days
(2)	<b>SUPERVISION</b>	Oversight, encouragement, or cueing provided three or more times during last seven days <b>-or-</b> supervision (3 or more times) plus physical assistance provided only one or two times during last seven days.
(3)	<b>LIMITED ASSISTANCE</b>	Subject highly involved in activity, received physical help in guided maneuvering of limbs or other non-weight-bearing assistance on three or more occasions <b>-or-</b> limited assistance (3 or more times) plus more help provided only one or two times during last seven days
(4)	<b>EXTENSIVE ASSISTANCE</b>	While the subject performed part of activity over last seven days, help of following type(s) was provided three or more times: <ul style="list-style-type: none"><li>• Weight-bearing support provided three or more times</li><li>• Full caregiver performance of activity (3 or more times) during part (but not all) of last seven days</li></ul>
(5)	<b>TOTAL DEPENDENCE</b>	Full caregiver performance of the activity during entire seven-day period. Complete non-participation by the subject in all aspects of the ADL definition.
(8)	<b>ACTIVITY DIDN'T OCCUR DURING THE ENTIRE 7-DAY PERIOD</b>	Over the last seven days, the ADL activity was not performed by the subject or caregiver. e.g., <u>the particular activity did not occur at all.</u>

The flow-diagram on the following page illustrates the decision rules testers should use to determine the proper coding for the Dressing, Personal Hygiene, Locomotion, Transfer, and Toileting items.

## SCORING ADL SELF PERFORMANCE



- a. Can include one or two events where received supervision, non-weight bearing help, or weight bearing help. NOTE: If only one or two events, score for the least dependent (Example 1: hair combed or brushed twice, once by hair dresser and once by subject would receive a score of 1, Independent. Example 2: hair combed or brushed only once by the hairdresser would receive a score of 5, Total Dependence).
- b. Can include one or two episodes of weight bearing help--e.g., two events with Non-weight bearing plus two of weight bearing would be coded as a "2".
- c. Can include one or two episodes where physical help received--e.g., two episodes of supervision, one of weight bearing, and one of non-weight bearing would be coded as a "1".

e. Definitions for Bathing Activities

**SELF-PERFORMANCE OF BATHING ACTIVITIES** — Measures what the subject actually did (not what he or she might be capable of doing) for each **bathing activity** over the last seven days according to the performance-based scale below.

- (r) **Gathering soap, towels, shampoo** - How shower/tub supplies are gathered, including adaptive equipment.
- (s) **Getting in and out of tub/bath** - How the subject manages getting in and out of the tub/shower, including the use of adaptive equipment.
- (t) **Washing/drying: lower extremities excluding perineum** - How lower extremities are washed and dried, including the use of adaptive equipment.
- (u) **Washing/drying hair** - How hair is washed & dried excluding combing & grooming.
- (v) **Washing/drying upper extremities** - How upper extremities are washed and dried (excluding the back).

f. Coding for Bathing

Remember, there is a different coding scheme for bathing. It has the same number of response alternatives, and the alternatives have the same feel in terms of the level of dependency, but the words and definitions are different. For the coding scheme for dressing and personal hygiene, we rely on the fact that there are multiple events during any given period. This differs significantly for the ADL bathing activities. Bathing is the only ADL where, over a weeks time, there may be only 1 or 2 events. Therefore, a separate coding scheme has been established for the bathing items (r-v). For example, in the bathing scheme, if you code a subject as independent in bathing, they must do the activity on their own EVERY time. Review the bathing coding scheme closely.

For the ADL category of Bathing (items r-v), code the appropriate response for the subject's actual performance during the past seven days. Circle the code in the appropriate column. Consider the subject's performance during 24 hours over the last week. For Bathing, use the coding scheme provided in the form. The Bathing coding scheme is also included below.

CODE	DESCRIPTION	DEFINITION
(1)	Independent	Did on own
(2)	Supervision	Oversight help only
(3)	Limited Assistance	Received assistance in transfer only
(4)	Assistance	Received assistance in part of bathing self.
(5)	Total Dependence	Total dependence
(8)	Activity didn't occur	Activity did not occur at all.

## Section C. Timed IADL

### 1. Description

The phenomenon of age-related slowing is the best documented and least contested of any in the field of aging and cognition. The Timed IADL task consists of five common activities of daily living, all of which involve searching for, and processing information regarding, target objects or information. All activities are timed to facilitate a measurement of the speed of information processing and visual search while engaging in these everyday activities.

The measures are designed to assess the effects of the cognitive interventions on functional outcomes. The five simple tasks are basic to activities of daily living and are easily amenable to being timed. They come from the domains of telephone communication, shopping, financial abilities, medication usage, and nutrition evaluation. The brevity of the tasks, and the ease with which they can be standardized across sites, and used in repeated testing situations, were important considerations in their choice.

### 2. Materials needed

All items needed for the administration of the Timed IADLs are packaged in a container suitable for carrying. This kit includes:

- Phone book (Timed IADL Task A)
- Coins (3 quarters, 4 dimes, 3 nickels, & 4 pennies) (Timed IADL Task B)
- Three cans of food (Timed IADL Task C)
- Array of food items (Timed IADL Task D)
- Two medicine containers (Timed IADL Task E)
- Digital stopwatch (All Timed IADLs)

### 3. Administration

This guide provides background information on, and procedural details relevant to, the 5 Timed IADL tasks. Testers administering this assessment must master this protocol. Since performance on these activities is timed, the tester should ensure that the subject is focused on the task at hand.

The time taken to perform an activity should be recorded from the stopwatch in the following format: minutes: seconds: hundredths of seconds. For example, a task taking one minute thirty two and forty eight hundredths seconds would be simply recorded as 1:32:48 in the appropriate space.

### NOTES AND CAUTION:

- Since all five tasks involve the use of near vision, and some involve reading small print, make sure that the subject is wearing the optical correction (reading glasses) that they typically wear for near vision activities prior to the start of the Timed IADL tasks.
- Always check to ensure that the digital stopwatch has been reset to zero and starts properly at the start of timing each of the Timed IADL activities. If it hasn't, you must start the task over again. Be sure to have the timer ready before starting each activity.
- Since the correct answers are on your data form, make sure that the subject cannot see your data form at any time during testing.

## **Task A**    **Finding a Telephone Number**

### **Description of task**

The subject is instructed that s/he will be given a name of an individual whose number s/he should look up in the phone book and say aloud. For example, at this assessment, the subject is given the name Steven N. Nelson (the tester then spells out the full name). The subject, to ensure comprehension, is asked to repeat the name for which he/she will be searching. The subject is handed the phone book and when the subject opens the book, start the timer. The timer is stopped when the subject finds the number and says it aloud. There is a time limit of 3 minutes.

### **Instrumentation**

- Phone book (included in the Timed IADL Kit);
- Digital stopwatch.

Multiple copies of an identical, real phone book (Birmingham, AL 2008) have been provided to each of the ACTIVE Field Sites. Multiple copies will be provided since the phone book will need to be replaced periodically because of the wear and tear associated with heavy use in testing.

### **Procedure**

To eliminate any memory effects and reduce wear and tear on specific pages of the phone book, the subject will be asked to lookup different names during different assessments. All the names are from the middle portion of the phone book, contain a middle initial, and are not found at the beginning of a page, column, or surname listing.

Watch subject do the task. If s/he asks what the name was, give the target name again, spelling it out if necessary. If the subject has questions relating to alphabetical order, do not give help, just restate the target name. (Allowable prompts: target name only).

## **Task B**    **Making change**

### **Description of task**

The subject is told to count out 67 cents in change and place it on the table. The subject is then handed a handful of change (3 quarters, 4 dimes, 3 nickels, & 4 pennies), and the stopwatch is started. Be sure the stopwatch is reset to zero. Putting the change in the person's hand reduces the contribution of motor deficits the subject might have in picking up coins off of a flat surface. The subject picks out the change and places it on the table. The timer is stopped when the subject has selected the change. There is a time limit of 2 minutes on this task.

### **Instrumentation**

- Coins (3 quarters, 4 dimes, 3 nickels, 4 pennies)
- Digital stopwatch

NOTES AND CAUTIONS:

- The coins should be placed in the non-dominant hand so they can be picked out with the dominant hand.
- **Motor problems/deficits:** If the subject is unable to hold the coins in one hand and select the appropriate coins with the other, spread the coins on the table and cover them with your hand. Ask the person to count out 67 cents by moving 67 cents to a different location on the table. Start the timer when you uncover the coins.
- Watch the person doing the task. If the person asks what the target amount is, tell them "67 cents" again. Do not give feedback about their accuracy during the task or indicate to the subject how much they have already counted out. (Allowable prompts: target amount only).

## **Task C    Reading Can Ingredients**

### **Description of task**

The subject is instructed to find and read aloud the ingredients on three cans of food. This is a real-life visual search task that provides important nutritional information. The subject is handed one can at a time. The stopwatch is started when the subject is handed the can. The stopwatch is stopped after the subject reads the third ingredient listed. There is a time limit of two minutes on this task. This task is a modified version of a three-can task used previously in a gerontological study at the University of Alabama at Birmingham.

### **Instrumentation**

- Digital stopwatch
- An identical set of three different cans, labeled '1', '2', and '3' has been provided to all sites. Cans have been covered with clear tape to avoid wear and tear with continued use.

### **NOTES AND CAUTIONS:**

- Start the stopwatch when you hand the can of food to the subject. Hand the can to the person with the front label facing him/her. (The arrow on top of the can should point toward the subject).
- The only prompt to be given to the subject in response to any question is: "I want you to read the ingredients. It will say the word 'ingredients' on there." This prompt should only be given in response to a question.
- It is common for the subject to read the nutritional information (protein, fat, etc.). If the subject reads the nutrition information and continues, without asking any questions, to read the list of ingredients, simply let the timer go until the third ingredient is read. If the subject asks you something like, "Is that what you want me to read, the response is: "I want you to read the list of ingredients."
- Stop the timer when the subject reads the third ingredient. Record the elapsed time, and check the appropriate accuracy category.

## **Task D**    **Finding Items on a Shelf**

### **Description of task**

This is a timed visual search task using real targets and distracters to simulate locating items on a supermarket shelf. The subject is given two food items to locate in a standardized array of food products. The location of the targets and distracters will be standardized by providing identical kits to each testing site. The shelf containing the food items is placed on a table within arm's reach of a seated subject. The subject is told what two items s/he has to find. After establishing that the subject understands what items s/he is looking for, the array is uncovered and the timer is started. The stopwatch is stopped when the subject has touched the two target items. There is a time limit of 2 minutes on these tasks.

### **Instrumentation**

- Digital stopwatch
- Kit with arrangement of food items

### **Procedure**

Move the closed Timed IADL Kit with the food array to a location on a table within easy reach of the subject. Place the box directly in front of the subject. The shelf should be at eye level. Placing the array on a table with the subject sitting at the table is fine. Ensure that the array is not open such that the subject can view the contents prior to this task.

## **Task E**    **Reading Directions on Medicine Containers**

### **Description of Task**

This task involves instructing the subject to read the directions on two medicine bottles. The ability to find instructions on a medicine container and read them correctly is an important one in the lives of most elderly people. Two real medicine containers are used (supplied in the Timed IADL Kit). The stopwatch is started after giving the subject the medicine container and is stopped when s/he finishes reading the directions. Timing for the two medicine containers is done separately. The time limit for each task is 2 minutes.

### **Instrumentation**

- Digital stopwatch
- Two medicine containers labeled '#1', & '#2'. All sites will use identical medicine containers with identical labels. The labels have been covered with clear plastic to avoid the effects of wear and tear.

## Section D. Digit Symbols Substitution Task

### 1. Description

The Digit Symbol Substitution Task is designed to measure how quickly a person can substitute a symbol for a number that is paired with the symbol. The task assesses visual-motor speed, visual search, and visual-motor coordination. The subject must copy each of the symbols that are paired with digits. Subjects are given precisely 90 seconds to complete as many substitutions as possible. The tester must time the task precisely using an electronic timer.

### 2. Materials \ Equipment Needed

- Digit Symbol Subject Data Forms #411a with ID label attached
- Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) Form #815 with ID label attached
- Electronic timer
- Pencils without erasers
- Digit Symbol Substitution Scoring Stencil
- Digit Symbol Coding Form #411

### 3. Administration

Testers must provide a smooth drawing surface for the task. Subjects should be given pencils without erasers. Give the subject the booklet titled: *Digit Symbol Substitution & Digit Symbol Copy Form #411a*. The complete script and administrative directives are provided in the Tester's Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) Form # 815. Follow the script for the task verbatim. Remember, this is a timed test, allow only 90 seconds. Precise timing is essential.

During the sample exercise, look to see if a *left-handed* subject blocks or partially blocks the key when filling in the marks. If this occurs, fold a separate record form in half, exposing only the digit symbols worksheet, and place it next to the subject's worksheet on the subject's right-hand side so that the extra key is aligned with the one blocked by the subject's hand. Have the subject use the separate key to complete the sample items and to take the actual test.

### 4. Coding

Coding should be completed after the testing session is complete. Use the *Digit Symbol Substitution & Digit Symbol Copy Coding Form #411*. For each item in the task, select the appropriate code for the following list:

CODE	DESCRIPTION	DEFINITION
1	Correct	The subject correctly copied the symbol.
2	Incorrect	The subject incorrectly copied the symbol.
3	Attempted/missing	The subject did not copy this symbol but copied other symbols that came after it.
4	Not attempted/missing	The subject did not copy this symbol or any symbols after it.



## Section E. Digit Symbol Copy Trial

### 1. Description

The Digit Symbol Copy Trial assesses visual motor speed and provides a control against which to interpret the results of the Digit Symbol Substitution Task. The tester will time the trial allowing the subject as much time as required to copy all 93 symbols in the task. The subject must reproduce each of the symbols in the coding box beneath the printed symbol. No time limit is assigned. Allow the subject to complete all the symbols. The tester must time the trial precisely using a digital stopwatch.

### 2. Materials needed

- Individual Assessment Part II (10<sup>th</sup> Annual Post-Test) Form #815 with ID label attached
- Digit Symbol Subject Data Forms Packet #411a with ID label attached
- Digital stopwatch (note this is different from the Digit Symbol Substitution Test for which an electronic timer was used.)
- Pencils without erasers
- Digit Symbol Coding Form #411

### 3. Administration

Testers must provide a smooth drawing surface for the trial. Subjects should be given pencils without erasers. The subject will use the same booklet distributed for the Digit Symbol Substitution Task: *Digit Symbol Substitution & Digit Symbol Copy Data Forms Packet #411a*. The complete script and administrative directives are provided in Form # 815. Follow the script for the task verbatim. Remember, you must time this task. The subject will be told to complete the entire task. Precise timing is essential. Be sure your digital stopwatch is re-set to zero before you begin the task; record the total time required to complete the task in **E1** on Form # 815. The time it takes to perform the task should be recorded from the stopwatch in the following format: minutes: seconds: hundredths of seconds. For example, if the task takes two minutes thirty two and forty eight hundredths seconds, you would record 02:32:48. Monitor the subject closely throughout the test. The end time is when the subject completes the last symbol.

### 4. Scoring

Coding should be completed after the testing session is complete. Use the *Digit Symbol Substitution & Digit Symbol Copy Coding Form #411*. For each item in the test select the appropriate code for the following list:

CODE	DESCRIPTION	DEFINITION
1	Correct	The subject correctly copied the symbol.
2	Incorrect	The subject incorrectly copied the symbol.
3	Attempted/missing	The subject did not copy this symbol.

## Section F. Blood Pressure, Pulse, Height, and Weight

### F1 - F5. Blood Pressure and Pulse

#### 1. Description

The first physical measurements are the measurements of blood pressure and pulse determined using the Omron Automatic Digital Monitor. For this study, blood pressure and pulse are considered indicators of health status. Before the first blood pressure and pulse rate are obtained, the subject must be sitting for 5 minutes. The **left** arm should be used consistently for both measurements.

#### 2. Materials/Equipment needed:

- Omron Automatic Digital Blood Pressure and Pulse Monitor
- Two blood pressure cuffs: adult and large adult sizes
- Clock for timing the rest periods
- ACTIVE Subject Reporting Form

#### 3. Measurement

##### a. Preparation:

1. The blood pressure and pulse should be measured in a quiet location where there is minimal movement and no loud talking.
2. The Subject should sit quietly in a relaxed position for 5 minutes prior to the first measurement. If the subject gets out of the chair before 5 minutes have passed, start over when she/he sits down again. It helps to let subjects know this so they can cooperate.
3. If the subject cannot sit as prescribed, measure BP in whatever position they are most comfortable and record the position next to the reading in the margin of the form (e.g. lying, standing).
4. Explain to the subject that, as a matter of routine, her/his pressure and pulse will be checked twice. Ask that they keep their legs uncrossed and their feet flat on the floor while their pressure and pulse are being measured.
5. Position the digital display facing the tester so the readout cannot be viewed by the subject.

##### b. Measurement:

1. Ask the subject to refrain from talking during the rest periods and during the readings. Do not direct questions to the subject during the measurements or during the rest periods.
2. The measurements should always be taken on the subject's **left** arm so ask the subject to bare their **left** arm. If a rolled up sleeve is very tight, the subject will need to change shirts. This should be noted at the beginning of the interview before everyone has been seated. On occasion, one arm can be slipped out of the sleeve back towards the body and then brought back out bare without having to remove the shirt. Make sure the subject is not chilly. In certain

instances a blood pressure measurement on the left arm may be impossible or medically contraindicated. Examples include a renal shunt for kidney dialysis; left arm amputation; pain on cuff inflation secondary to left breast mastectomy; or muscular or skeletal disease. A subject may refuse to allow blood pressure measurement on the left arm for other reasons. As necessary, complete the blood pressure and pulse measurements on the right arm. Always document the arm used for the measurements on the data form.

3. The arm used for the measurements should be supported at heart level on a surface such as a desk or table. The arm should be slightly flexed with the palm facing upward.
4. The cuff should be assembled correctly when it is removed from the box. If it is not, pass the end of the cuff furthest from the tubing through the metal D-ring to form a loop. The smooth cloth should be on the inside of the cuff loop. When the cuff is assembled correctly, the sewn hook material will be on the inside of the cuff loop and the metal D-ring will not touch the subject's skin.
5. Choose the correct cuff size. This should be done before the first measurement and the same size cuff must be used to obtain both measurements. To get an accurate reading, the cuff chosen must fit the person properly. If it is too narrow, the reading may be falsely high. If it is too wide, the reading may be falsely low. Cuff size indicates the width of the cuff's bladder, not the length of the cuff. The standard cuff will fit the average adult arm.
  - Locate the subject's brachial artery by pressing two fingers approximately one inch above the antecubital fossa (elbow crease) on the inside of the left arm. Determine where the pulse is strongest.
  - Put the subject's arm through the cuff loop making sure that the bottom edge of the cuff is approximately one-half inch above the antecubital fossa. A green border appears on the lower border of the cuff. Make certain the green area of the cuff is directly above the brachial artery.
  - Pull the end of the cuff so that the top and bottom edges of the cuff are evenly tightened around the subject's arm. When the cuff is positioned correctly, press the Velcro together firmly. Make sure the cuff fits snugly around the subject's arm; it should make good contact with the subject's skin. Make sure that the subject's skin will not be pinched in the D-ring when you inflate the cuff bladder. **(If the skin becomes pinched during inflation, immediately deflate the cuff bladder and readjust the cuff. If this happens, wait 2 minutes before re-inflating the cuff.)**
  - Insert the air plug of the arm cuff selected into the air jack of the monitor. Make sure that there are no kinks in the air tubing.
6. Press the ON/OFF button on the monitor. Remind the subject to remain still during the measurements. All display symbols appear for approximately one second, this is the initial LCD test.
7. After the monitor completes the necessary preparations before measurement, the "Ready to Measure" symbol ( ♥ ) will appear next to the zero on the digital panel.
8. Press the START button. As the cuff inflates, the monitor automatically determines the subject's ideal inflation level. During this process the 'INTELLISENSE' symbol will be flashing on the display. Remind the subject to remain still throughout the measurement.

9. When the measurement is complete, a heart symbol flashes again and the arm cuff will automatically deflate. The monitor will alternately display the subject's blood pressure and pulse on the digital display panel.
10. Record the first blood pressure and pulse readings on the ACTIVE data form exactly as they appear on the monitor's digital display. Record the systolic and diastolic blood pressure and the 60 second pulse rate. Recheck your recordings on the data form against the readings on the monitor prior to turning OFF the monitor. Any and all abnormalities or emergencies must be noted on the data form.
11. Press the ON/OFF button to turn off the monitor.
12. Instruct the subject to wait 2 minutes prior to the second reading. Use a clock to time the rest period accurately. The cuff may stay in place on the subject's arm during the rest period. Be certain the cuff is in proper position prior to the second reading.
13. Repeat the procedure and record the second blood pressure and pulse readings on the data form. Recheck your recordings on the data form against the readings on the monitor prior to turning off the monitor.
14. Record the second readings for the subject on an ACTIVE Blood Pressure Reporting Form (See example below), and check the appropriate corresponding category box. Give this form to the subject to keep. The guidelines are taken from the National Heart, Lung and Blood Institute of the National Institutes of Health.

Never refer to a subject's blood pressure as "normal, high or low." It is best to say "according to American Heart Association guidelines, it is best to see a blood pressure below 140/90." Remember - we do not diagnose, and under no circumstances do we tell someone they have high blood pressure or "hypertension." That condition cannot be determined by an isolated reading. If a referral is recommended by our guidelines, check the appropriate box and stress the importance of a follow-up re-check.

c. Error Messages:

1. In some instances, a subject's physiological characteristics may require a higher level of inflation than the monitor accommodates on the first inflation attempt. These circumstances may include a weak pulse or an elevated systolic blood pressure. When this occurs, the monitor may re-inflate to a level of about 30 mm Hg higher than the first inflation level (but never higher than 275 mm Hg). Automatic reinflation will occur only once. You should record the values from these readings on the data form. You must also document that a second automatic inflation was required to obtain the reading.

If the monitor is unable to obtain a systolic blood pressure at the second automatic inflation, do not attempt to obtain another reading. Note this in the margin of the form. Strongly encourage the subject to have their blood pressure checked by a health care provider as soon as possible as the systolic pressure may be higher than 240 mmHg.

2. If you want to stop the measurement for any reason, push the ON/OFF button. The monitor will stop inflating and start deflating rapidly, then the monitor will power off.

---

# ACTIVE

Name: \_\_\_\_\_

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_

Pulse: \_\_\_\_\_ beats per minute

Blood Pressure: \_\_\_\_/\_\_\_\_ mm Hg

- ☐ Below 140/90 -- Annual recheck recommended.
- ☐ 140/90 or above: Please notify your health care provider.
- ☐ 160/100 or above: A physician should check your blood pressure today or tomorrow.

The American Heart Association recommends that a physician should recheck any blood pressure above 140/90.

The results of this test were obtained under non-clinical conditions. If you have concerns, this test should be repeated under standard, clinical conditions, which may result in different values. This test was conducted for research purposes only.

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## F6. Height

### 1. Description

Height will be measured and used with weight to calculate the subject's body mass index (BMI), a general indicator of health status.

### 2. Materials Needed:

- Right angle Handi-Stat wood piece
- 8 foot wood folding carpenter's ruler
- Luekopor medical paper tape

### 3. Measurement

#### a. Preparation:

- Explain the procedure to the subject.
- Floor should be a hard, even, flat, un-carpeted surface.
- Measurement location may be inside a doorway, against a closed door, or in a hallway.
- Areas with a baseboard, threshold, or other protrusion should not be used.
- Ask the subject to remove shoes.
- Ask the subject to stand with feet flat on the floor, heels together, with heels, hips, shoulders and head directly against the wall.
- Ask the subject to tilt head forward, so that you can place a strip of medical paper tape on the wall in a vertical position over the approximate area where height will be marked. (To avoid marking or tearing the wall during removal, do not press tape tightly to the wall.)
- Once the tape is in place, ask the subject to stand up straight and look straight ahead with head against the wall.

#### b. Measurement:

- Rest the wooden base of the Handi-Stat against the wall above the subject's head with the right angle toward the floor.
- Slide it slowly down until it touches the top of the subject's scalp, carefully centered with subject's nose. Make sure the wooden edge is flat and held steadily against the wall.
- Using a pencil, mark the tape on the wall exactly where the corner of the right angle touches the tape. Be sure to mark the tape from underneath the wood, pencil angled upward.
- Remove the Handi-Stat and ask the subject to step away from the wall.
- Carefully open the folding ruler and make sure it is straight.
- Secure the ruler against the wall by pressing it with your foot at the '0' end.
- Keeping the ruler flat against the wall, read the measurement closest to the mark on the tape and record to the nearest half inch; round up.
- Use a straight chair or stool to read the measurement if the subject is taller than you.
- Record the measurement on the data form and carefully remove the tape from the wall/door.

c. Exceptions:

If for any reason (kyphosis, wheelchair-bound, unsteady without a cane, etc.), the subject cannot complete the measurement according to the protocol, do not record a measure in F6; rather, record “missing” in the margin next to the F6 data fields and complete F6a and F6b. F6a allows you to code the reason why the measure was not completed; F6b requests the subject’s self -reported height.

4. Coding

Height should be recorded in inches to the nearest half inch, rounded up to the nearest half inch.

**F7. Weight**

1. Description

Weight will be measured and used with height to calculate the subject’s body mass index (BMI), a general indicator of health status.

2. Materials needed

- Large digital display scale with extra wide base
- Metal disc standard weights for Q.C. calibration
- Germicidal handi-wipes
- Paper towel

3. Measurement

a. Preparation:

- The scale should be placed on a level floor surface. Avoid carpets or rugs of any kind.
- The subject removes shoes, belt, sweaters and outerwear prior to measurement; all pockets should be empty of heavy objects.
- The tester should check that the scale is programmed to the pound mode and that it balances at zero before each measure.

b. Measurement:

- Body weight is obtained with the subject standing motionless in the center of the scale looking straight ahead with arms relaxed and hanging loosely at the sides.
- Note the digital readout and record to the nearest .5 lb. on the form.

c. Coding

- Record weight in pounds to the nearest .5 lb in F7.
- Record the ID# of the scale used in F7c.

#### 4. Exceptions

If for any reason the subject cannot complete the measurement according to the protocol, do not record a measure in F7; rather, record “missing” in the margin next to the F7 data fields and complete F7a and F7b. F7a allows you to code the reason why the measure was not completed; F7b requests the subject’s self-reported weight.

#### 5. Cleaning the Scale

Clean the scale after each use. Wipe the surface of the scale using a germicidal handi-wipe. Dry the scale using a paper towel.

#### 6. Primary Calibration Procedures

- a. Calibrate scales with standard weights at two weight levels (i.e. 50 and 100 lbs. or 25 and 50 kgs.) prior to the start of the 10<sup>th</sup> Annual testing period and every 6 months thereafter. Record findings in pounds or kilograms on the proper Calibration Log form provided in Attachment A. The Site Coordinator should review completed Calibration Log Forms after every calibration as a local QC check. Logs should also be available for review by CC staff during site visits.
- b. Re-evaluate scales if they mismeasure standards in either of the two weight levels by more or less than five (5) pounds or two (2) kgs (see acceptable ranges in Tables 1 and 2 below). Be certain the scale is on a level floor surface without carpet or rug of any kind. Check that the scale is programmed to the proper mode, i.e. pounds or kilograms, to match your standard weights and that it balances at zero before your test. If necessary, replace the batteries and repeat calibration procedures *precisely*.
- c. If the scale still mismeasures the standards by more or less than 5 pounds or 2 kgs. **DO NOT USE THE SCALE FOR ACTIVE MEASUREMENTS.** Follow the manufacturer's recommendations for replacement or reconditioning.

Table 1: Acceptable ranges for calibration of scales using <b>pound</b> weights	
Standard weight in lbs.	Evaluate scale if test weight is more or less than 5 lbs. off standard measure as follows:
50 lbs.	< 45 lbs. <b>or</b> > 55 lbs.
100 lbs.	< 95 lbs. <b>or</b> > 105 lbs.

Table 2: Acceptable ranges for calibration of scales using <b>kilogram</b> weights	
Standard weight in kg	Evaluate scale if test weight is more or less than 2 kgs off standard measure as follows:
25 kg	< 23 kgs <b>or</b> > 27 kgs
50 kg	< 48 kgs <b>or</b> > 52 kgs



## 7. Alternate Calibration Procedures

The following alternate procedures may be used in the event that a site cannot follow the standardized calibration procedure described above. The alternate calibration procedure allows sites, under specified conditions, to use a pre-approved balance beam scale as a 'gold standard' instrument against which the ACTIVE portable digital scale can be calibrated.

- a. The site must first 'register' a 'gold standard' balance beam scale that can be used for the required calibration procedures. Prior to use as a 'gold standard,' the balance beam scale must be registered and approved by the CC. The following information must be provided to the Coordinating Center along with the request for approval for a 'gold standard' scale:
  1. Reason why an alternate procedure is required.
  2. Description of the 'gold' standard' balance beam scale including manufacturer and model number.
  3. Location of the balance beam scale including address and or clinic or unit number and relation to the ACTIVE field testing areas.
  4. Official certification documentation and/or log attesting to the calibration of the 'gold standard' scale including name, address and telephone number of the certifying organization.
  5. Dates of the most recent calibration should also be included.

Once the balance beam scale has been approved, the following calibration procedures must be followed:

- b. Calibrate scales prior to the start of the 10<sup>th</sup> Annual testing period and every 6 months thereafter using a 'gold standard' balance beam scale registered/approved by the CC. Scales should be calibrated at a weight not less than 100 pounds. Record findings in pounds or kilograms on the Calibration Log form provided as Attachment B. The Site Coordinator should review completed Calibration Log Forms after every calibration as a local QC check. Logs should be sent to the CC for Q.C. review every 6 months. Logs should also be available for review by CC staff during site visits.
- c. Re-evaluate scales if they mismeasure by more or less than five (5) pounds or two (2) kgs. Be certain the digital scale is on a level floor surface without carpet or rug of any kind. Check that the scale is programmed to the proper mode, i.e. pounds or kilograms to match the 'gold standard' scale and that it balances at zero before your test. If necessary, replace the batteries and repeat calibration procedures *precisely*.
- d. If the scale still mismeasures the standards by more or less than 5 pounds or 2 kgs. **DO NOT USE THE SCALE FOR ACTIVE MEASUREMENTS.** Follow the manufacturer's recommendations for replacement or reconditioning.

## **Section G. Grip Strength (Jamar Dynamometer)**

### **1. Description**

Grip strength is a measure of hand strength that influences performance of ADLs.

### **2. Materials needed**

- Hydraulic hand dynamometer
- Paper towel

### **3. Measurement**

#### **a. Preparation:**

- The grip strength measure should not be completed on subjects who report recent worsening of pain or arthritis in their wrists or recent tendonitis. Also skip this measure on subjects who report surgery on their hands or wrists in the last 3 months. “Yes” responses to questions G1 and G2 will rule out these subjects. Follow the skip pattern and move to Section H when you complete the coding for G1 and or G2.

#### **b. Measurement:**

- The grip strength measure will be completed on the dominant hand only. For the ACTIVE study the dominant hand is defined as the hand the subject uses to write his/her name (G3). Complete the measure on the subject’s dominant hand as reported in G3.
- Seat subject in a chair, legs uncrossed with back supported and arm at his/her side in 90 degrees of elbow flexion, forearm and wrist in neutral alignment. The arm cannot be supported or resting on an object.
- The dynamometer is placed in the palm of the subject’s dominant hand with the global gauge facing outward. The handle grip size is adjusted so that the middle section of the middle finger is flexed to 90 degrees. Record the hand width setting on the data form.
- Tester should be seated in front of subject. One hand stabilizes dynamometer in vertical position with gauge readings obscured from the subject’s view.
- Demonstrate the measure for the subject.
- Now have the subject grasp the dynamometer handle.
- Subject should be instructed to squeeze as hard as possible when instructed to do so and hold the contraction until told to relax.
- Cue the subject to begin with “OK squeeze now.” When they begin to squeeze, coach them by saying, “squeeze, squeeze, squeeze, relax.”

- Subject is instructed to perform 2 test trials on their dominant hand with the same cueing as above.
- Allow one minute of rest between the first and second trials.

#### 4. Coding

- Record the dynamometer hand width setting in G4. Record #1 for the smallest grip setting (i.e., bars are closest together) to #5 for the largest grip.
- The force reading is recorded in kilograms (outside scale on the gauge) from the dynamometer on the data collection form for each test trial in G5, 1<sup>st</sup> try, and G6, 2<sup>nd</sup> try. Round up to the nearest whole kg. Gauge reading is in increments of 2kg. If reading is in the middle of 2 lines, record the interim odd kg. The dynamometer is reset to zero after each trial.

#### 5. Service Tips and Calibration

If the dynamometer fails to perform properly follow these guidelines.

- **POSTS:** Remove the adjustable handle and check that each post moves up and down freely on its guide (the part that the post bears on), even when you exert pressure on the side of the post. About once a year, place a small amount of grease on the two guides. If excessive friction exists between the post and the guide, return the dynamometer for service.
- **HYDRAULICS:** To check the hydraulic mechanism, first remove the adjustable handle. While watching the top post, push down on the bottom post. Normally, both posts should travel about 1/8\*, with top and bottom posts traveling in opposite directions. Travel less than 1/16\*, indicates a probable leak in the hydraulic system, which requires service.
- **HANDLE:** Grasp the instrument normally and look carefully at the way the forks of the adjustable handle are supported on the posts. Each fork should touch the post at approximately its mid-point. If this is not the case, return the instrument to JAMAR Technical Services for adjustment.
- **PEAK-HOLD NEEDLE:** Check for excessive friction in the peak-hold assembly by turning the peak-hold knob counter-clockwise. If the peak-hold needle deflects the gauge needle, return the gauge for service. If the peak-hold needle is knocked off its support pin, it can readily be repositioned. Unscrew the crystal and turn it upside down. Locate the brass pin in the center of the crystal (the pin is part of the chrome knob on the outside of the crystal). Locate the slot on the brass pin and place the peak-hold needle into this slot.
- **CALIBRATION:** The instrument is calibrated at the factory by loading it at the center with weight and making appropriate adjustments in the gauge. It is not recommended that the user perform this operation, but rather, that the instrument be returned to JAMAR Technical Services for calibration. The calibration should be checked on a regular, annual basis. If the instrument has been dropped or there is some particular reason to suspect that the calibration is an error, the instrument should be serviced immediately. Sammons Preston will perform the first yearly calibration free of charge. Thereafter, recalibration will be done for the prevailing service charge.

## Section H. Turn-360 Test

### 1. Description

The Turn-360 Test is a dynamic measure of balance that is related to falls and influences performance of ADLs.

### 2. Measurement

Position subject with feet slightly apart (about as far apart as shoulders). Demonstrate the starting position. Following the script, you will ask the subject to make a complete turn in place as quickly and safely as s/he can. Do not demonstrate the turn.

Stand close to the subject in case the subject begins to lose his/her balance, but be certain you have a clear view to allow an accurate count of steps. Subjects are not allowed to remove their shoes; subject MAY use an assistive device -- cane, walker -- if s/he cannot perform the test safely without it.

The turn should be repeated. If the subject is dizzy or unstable after the first turn, allow subject to sit down. If the test cannot be completed safely, record zero in STEPS on form and proceed to Section I.

### 3. Coding

Record the number of steps taken to return to the start position for each of the two turns in H1 and H4. Each lifting and lowering of the foot counts as a step. The most dramatic turn -- the pirouette - counts as **one step**, as one foot must be lifted and lowered to pivot the body on the other foot. If the test cannot be completed by subject, record zero in STEPS on form and reason not completed.

Record the use of an assistive device.

### 4. Responses to Possible Questions

Subject: "I don't understand what I'm supposed to do. What do you mean, 'turn'?"

Tester: "What we're interested in here is how you can turn around. (Demonstrate by making a circle with your finger). In other words, beginning with your current position, how quickly but safely can you turn completely around, or 360 degrees."

Subject: "I still don't understand. Can't you demonstrate?"

Tester: "No, I can't demonstrate. If I show you how I would do this task, it might influence how you do the test. What is not clear to you? I can try to explain how it is done once more."

Subject: "I don't feel safe. I don't want to do this. I'm afraid."

Tester: "We only want you to try this test if you can do so quickly and safely. You are allowed to use a cane or walker, if you have one. [ASCERTAIN IF THIS WILL SOLVE THE PROBLEM. IF NOT:] If you do not feel safe, I do not want you to try this test."

## Section I. Break Point

Always use the standardized break point to offer the subject a brief break to stretch, relax, get a drink of water, go to the bathroom, etc. A break must be offered after the completion of the Turn-360 Test. It can take 30-40 minutes to complete the remainder of the assessment, so subjects should be encouraged to take even a small break to avoid a break at a later point in the battery.

If for any reason the tester feels the subject cannot complete the assessment in a single session, the session should be stopped at the break point

The intent of the 'break point' protocol is to standardize , study-wide, the points at which subjects are refreshed for the testing tasks in the batteries.

- I1.** Indicate in this item whether or not a second session was required to complete this assessment.
- I1a.** If a second session is required, record the end time of Session 1 in this data field. Record the time you complete the Turn-360 Test. Use a 12 hour clock; circle **AM** or **PM** as appropriate.
- I1b.** Record the date Session 1 was conducted. Record the date as month, day and year. Note the year must be recorded as a four digit number; e.g., 2003. Do not leave blank spaces; use leading zeroes as required.
- I1c.** Record the start time for Session 2.

## Now Complete the OTDL

Complete the OTDL after the Break Point and before the Mobility Questionnaire. Use the OTDL Data Form # 422, the OTDL Administration Kit and the Question-by-Question Specification Guide for Administration of the OTDL.

## Section J – M. Mobility Questionnaire

### Introduction:

The Mobility Questionnaire is a questionnaire designed to assess the extent of the subject's usual mobility and driving habits. Specifically, the questionnaire assesses:

- a) the range of a person's **life space**
- b) the extent to which they have trouble with **falls**
- c) a person's **driving** habits

The instrument is particularly suited for assessment of these mobility-related behaviors in older individuals. Functional independence and mobility are critical elements of an older person's quality of life and therefore represent important outcome measures.

The questionnaire is divided into four sections:

1. Section J. Life Space
2. Section K. Falls
3. Section L. Driving Habits of Current Drivers
4. Section M. Non-Drivers

## Section J. Mobility Questionnaire/Life Space

### Introduction

This section assesses the range of the life space. It starts with a question on household composition. This information is for persons living independently, either in a private house/apartment or in congregate, community-based setting (i.e., assisted living or congregate housing) but **not in a nursing home**. We are basically interested in finding out how much the person gets out and about and the spatial extent of the person's typical life space, i.e., what is the usual range of places in which the person engages in activities. We are interested in the places the person has been recently. The questionnaire asks nine questions about where a person travels to in a particular period of time. The nine questions are sequenced in a hierarchical fashion to reflect an expanding life space, ranging from being confined to one's bedroom and moving successively to the exterior of the home, to the immediate home surroundings, to the immediate neighborhood, to the community, beyond one's community, beyond one's city or county, out of state, and finally beyond one's region of the country. If the subject's life space extends beyond the immediate surroundings of his/her home, the questionnaire assesses whether the subject personally drives to these destinations. These supplementary questions on driving assess the subject's autonomy in functional mobility in their life space.

- The time period for the question will change from seven days (Questions 2- 7) to two months (Questions 8 - 10), so be sure to be clear about the time frame you are referring to. For more distant places, the time frame is two months, and for all other places, the time frame is the last seven days, excluding the day of the assessment.
- Since we are interested in their usual behavior, we do not want to include any travel necessary to participate in the present appointment since this assessment appointment may be out of the ordinary for some people. Therefore one must stress that the questions do not pertain to travel on the day of the assessment.

- It is recommended that you mention the specific time frame you are asking about (e.g., if the questionnaire is being administered on a Thursday one would say, "between last Wednesday and yesterday have you been ....."). The provision of a more concrete time frame should help the subject in remembering their various destinations.
- For the primary component of Questions 5 to 10, it is not important how the subject got to these destinations, i.e., they might have been driven by another person, wheeled in a wheelchair, taken a taxi cab, or used public transportation. However, for the secondary component of these questions which asks did they "personally drive there" themselves, the subject must have driven, i.e., operated the vehicle, in order to respond with a "Yes".

**J1:** This question collects information about how many persons live with the subject and the relationship of these persons to the subject.

There are four response choices listed:

1. LIVES ALONE IN HOUSE/APT.....1 (J2)
2. LIVES WITH OTHERS IN HOUSE/APT.....2 (J1a)
3. LIVES IN ASSISTED LIVING/CONGREGATE HSG.....3 (J2)
4. LIVES IN NURSING HOME.....4 (GO TO SECTION K)

Response choices (1) and (2) refer to residence in a house or apartment (including independent senior housing). If the subject reports living alone, code (1) and skip to J2. If the subject reports living with others, code (2) and ask J1a and J1b. If the subject reports living in assisted living/congregate housing setting, code (3) and skip to J2. If subject reports living in nursing home setting, code (4) and skip to the next section. When you ask how many people live with the subject, s/he will often give you the answer to J1b without you having to ask the question. You can use the questions for J1b as probes if the subject does not offer the information. Record the number reported for each category. Record 0 if none (e.g. children) are mentioned. If the number/s reported for J1b do not equal the number in J1a, probe to correct the inconsistency.

**J2:** This question asks about going to places outside the room where they usually sleep. This includes other rooms of the home such as the bathroom, kitchen, den, living room, etc. A person would only answer "No" to this question if they had been bed-bound for the last 7 days.

**J3:** This includes going to, or through, places immediately outside the home area but still adjacent to the home. These places include a porch, deck, patio, garage, or hallway of an apartment building. The places covered by this question don't have to be destinations. For example, a person going to their mailbox or down the block would obviously pass through one, or more, of these places and should answer "Yes".

**J4:** This includes going to, or through, places outside the home area and into places immediately surrounding the home such as the yard, driveway, sidewalk, courtyard, or parking lot. As in the previous question, a person going through these places on their way to a more distant destination should answer "Yes" to this question.

**J5:** This includes going to, or through, places beyond the property where their home is located. For homeowners, this refers to places beyond the property line. For those living in city apartments, this

refers to places beyond the immediate block. For rural areas, this includes leaving the property lines. This part of the question refers to places they have been regardless of the mode of travel (walking, car, etc.), even if someone else drove.

**J5a – J10a:** The subject must have actually physically driven the vehicle him/herself. Being a passenger in a car, taxi, or using public transportation doesn't qualify for a "Yes" answer. If subject reports that s/he walked, the answer is "No".

**J6:** This includes going to, or through, places outside the neighborhood surrounding the home. In a city, this would be places beyond the surrounding 5 blocks. In a suburban area this refers to places about 3 streets from the home. For sparsely populated rural areas, this includes going to places on the other side of the closest neighbors. The first part of the question refers to places they have been regardless of the mode of travel (walking, car, etc.), even if someone else drove.

**J7:** This includes going to, or through, places outside the town or community area nearest the home. This refers to places outside a particular sub-region of the city. This could be areas with a distinct name, or city areas such as east, west, north, or south. For rural areas, this includes going to places on the other side of the nearest town. This part of the question refers to places they have been regardless of the mode of travel (walking, car, train, subway, etc.), even if someone else drove.

**For Questions J8 – J10,** note the change in the reference time frame to the last two months. The specific time frame must always be given to the subject to improve their recall (e.g., if the questionnaire is administered on July 16<sup>th</sup>, the administrator would say, "Today is July 16<sup>th</sup>, so we are asking about the period of time from May 16<sup>th</sup> up to, and including, yesterday").

**J8:** This question refers to the past 2 months but not today. This includes going to, or through, places on the other side of the county line (where substantial travel is involved) or to places on the other side of a large city. Subjects living near a county line where crossing into another county does not constitute a significant distance should not respond "Yes" here. In rural areas one could use a 20 mile radius as a guideline to answering questions of clarification on J7.

**J8a:** The subject must have actually, physically driven the vehicle outside the county or city. Being a passenger in a car, taxi, or using public transportation doesn't qualify for a "yes" answer.

**J9:** This question refers to the past 2 months but not today. This includes going to, or through, places over the state line. Subjects living close (less than 20 miles) to the state line should not answer "Yes" to this question unless they traveled a substantial distance (more than 20 miles) into a neighboring state. This part of the question refers to places they have been regardless of the mode of travel (car, train, airplane, etc.), even if someone else drove.

**J9a:** Flying to another state and then driving does not justify a "Yes" response for this question. The person must have actually driven to another state.

**J10:** The region of the country should be specified site-specifically and the appropriate states listed as in the following list. "By this region, we mean the states of \_\_\_\_\_".



ACTIVE FIELD SITE	STATES
UAB	Alabama, Florida, Georgia, Louisiana, Mississippi, or Tennessee
PSU	Maryland, New Jersey, New York, Ohio, Pennsylvania, or West Virginia.
JHU	Delaware, Maryland, New Jersey, Pennsylvania, Virginia, or West Virginia.
WSU	Indiana, Michigan, Ohio, or Ontario (Canada)
IU	Illinois, Indiana, Kentucky, Michigan, or Ohio
HSL	Connecticut, Maine, Massachusetts, New Hampshire, New York, Rhode Island, or Vermont.

The first part of the question refers to places they have been regardless of the mode of travel (car, train, airplane, etc.), even if someone else drove.

**J10a:** The subject must have actually, physically driven the vehicle outside their region of the US.

Examples include:

- 1) Riding in the car while the spouse drove. Code this as NO
- 2) Driving for 1 hour while the spouse rested or slept. Code this as NO
- 3) Flying somewhere and then driving a short distance. Code this as NO
- 4) Driving more than half the trip out of the region. Code this as YES.

## Section K. Mobility Questionnaire/ Falls

### Introduction

This section is adopted from the NIA-funded Salisbury Eye Evaluation (SEE) study (a population based study on vision impairment and functional disability in older adults). In the SEE study, the time frame was 12 months; for the repeated testing in the ACTIVE project, the time frame was shortened to ‘the last 2 months’. This change will serve to reduce memory demands.

The questions in the section will ask the subjects about falls in the last 2 months. If the subject reports falling in the last 2 months, the frequency and contributing factors are explored for the most recent fall. Falling is associated with functional (including cognitive) impairment, morbidity, and mortality. It is a highly relevant adverse outcome, as evidenced by the voluminous literature addressing falling in the elderly.

The subject is asked whether they had a fall in the past 2 months. In the literature, falling is broadly defined as "unintentionally coming to rest on the ground or at some other level such as a chair". Since this might be a little too abstract for the subjects, an effort is made to try and convey the idea in more concrete terms. It is important, therefore, to convey a broad definition of falling. Such a definition includes:

- 1) losing balance and falling on the ground, or falling against something such as furniture in the home or elsewhere.
- 2) missing a step, tripping over something, stumbling off the curb and falling, slipping on wet grass, pavement, ice or snow and falling etc.

If the subject reports a fall in the last two months, then s/he should be asked to answer the follow-up questions on the frequency, severity of the falls, and the circumstances surrounding their most recent fall.

**K1:** The specific time frame must always be given to the subject to improve their recall, e.g., if the questionnaire is administered on July 16<sup>th</sup>, the administrator would say, "Today is July 16<sup>th</sup>, so we are asking about the period of time from May 16<sup>th</sup> up to, and including, yesterday."

**K2:** Have the person make the best guess they can. If they have no idea, try to get them to estimate by asking if it was more than 1, more than 3, more than 5?, more than 10? etc.

**K3:** This question is aimed at assessing the severity of the fall.

- 1) Injury: Ranges from bruises, soreness, to muscle, ligament, or bone damage resulting from the fall.
- 2) Medical attention: Refers to attention for a fall injury from a nurse, paramedic, doctor, or other medical personnel.
- 3) Hospitalization: This includes a visit to a hospital emergency room or clinic, or stay in a hospital or clinic for injuries caused by the fall.
- 4) Loss of consciousness: This includes fainting or blacking out at the time of, or after, the fall. Even if this is for a brief period of time, the subject should answer "Yes" to this question.

**Questions 4, 5, and 6:** all refer to the most recent fall in the previous 2-month period. By focusing on the most recent fall, it is hoped that details of the fall will be remembered more accurately. The questions attempt to identify whether external, environmental, or internal factors, or both, contributed to the most recent fall.

**K4:** This question refers to the most recent fall. If there were 5 falls in the past 2 months, you are interested in the last one that happened. The question is trying to see if any external, environmental factors contributed to the fall. For example, did the subject slip on something, did s/he trip over something? Did something such as a rug, stairs, a curb, or ice contribute to this most recent fall?

Subjects should answer "Yes" to this question if they can identify some external factor or circumstance which contributed to their falling. A subject should answer "No" to this question if there was nothing in the environment which contributed to their falling, i.e., they fell because of some internal factor such as a medical condition, dizziness, musculoskeletal weakness etc. Clarify any questions the subjects might have.

**K5:** This question is attempting to find out whether there were other factors besides external, environmental factors that contributed to the last fall. For example, did any physical or medical condition of the respondent contribute to the fall (e.g. dizziness; orthostatic hypotension; inner ear problems; vertigo; motor or gait problems; vestibular problems; medication-induced confusion, etc.)

**K6:** Only ask this question of subjects giving a 'Yes' response to Question 5. The answer to this question should provide an explanation of the internal factors that contributed to the most recent fall. The person should write down any such factor in the space provided.

## Section L. Mobility Questionnaire/Driving Habits of Drivers

For this section, the tester must first establish whether the subject is a current driver. We define a current driver as one who has driven in the last 12 months and who currently would drive a car if they needed to. Using this definition therefore, a current driver need not be a regular driver, but he/she could and would drive a car if needed.

### Driving Habits for Current Drivers

This section assesses the subject's driving status and driving habits. Section L is completed by current drivers. It is modified from the interviewer-administered Driving Habits Questionnaire used extensively in previous studies on driving in older populations. Section L asks questions about typical driving habits, accident frequency, and perceived difficulty in eight challenging driving situations.

**L1 and 2:** These questions are not asking about frequency or duration. They are referring to whether the person drives if s/he needs to go somewhere or whether they simply do not go if no one can drive them to their desired destination. L2 is simply a verification question. It is best to be certain you are completing the correct section for the subject, i.e. driver vs. non-driver.

**L3:** This refers to the way the person **prefers** to get around, i.e., how they want to travel and how they like to travel, not the way they usually travel. Example: The subject may actually do all the driving, although they would **prefer** someone else drive them. Alternatively, a subject might usually be driven around but would actually prefer to do the driving him/herself.

**L4:** This does not refer to driving faster or slower than the speed limit. Subjects might say they drive at the speed limit. The question refers to the subject's driving speed in relation to the rest of the traffic on the road. For example, if a person always drives at the speed limit (say, 55 mph) but everyone else passes them because all the other cars are driving 70 mph. Such a person should respond with "Much slower" than the general flow of traffic.

**L5:** This is how the subject rates his/her own driving. This should be what the subject thinks about his/her own driving and not what his/her spouse or children say about his/her driving abilities.

**L6:** This is the average number of days per week out of 7 days that the subject gets into his/her car and personally drives the car somewhere. It does not matter how far s/he drives as long as the respondent actually operates the vehicle.

**L7:** Asks the subject to estimate the number of miles s/he drives in an average week. If s/he has no idea, prompt with "less than 25?"; "between 25 & 50" "More than 50?"; "more than 100?" etc.

**Please note that the next series of questions ask about the subject's driving during the last two months.**

The specific time frame must given to the subject to improve his/her recall; e.g., if the questionnaire is administered on July 16<sup>th</sup>, the administrator would say, "Today is July 16<sup>th</sup>, so we are asking about the period of time from May 16<sup>th</sup> up to, and including, yesterday."

**L8:** This question refers to driving when it is raining during the day or night. Rain includes any kind of rain (light shower to heavy rain). If the subject pulled his/her vehicle over during rain, s/he should still answer "Yes" to this question.

**L8a:** The subject is asked to rate the difficulty driving in an average rain shower (not limited to extreme cases of very heavy rain which would be difficult for everyone).

**L8b:** This question refers to avoiding driving in the rain by intentionally not going out until after the rain shower stopped. The subject should not categorize her/himself as an avoider if, by chance, s/he were never caught in the rain.

**L9:** This question refers to driving a vehicle with no other person in the car. Pets don't count.

**L9a:** The subject is asked to rate the difficulty of driving with no one else in the car.

**L9b:** This question refers to avoiding driving alone by insisting that someone ride with her/him when s/he drives, or forgoing a trip because no one is available to ride with her/him.

**L10:** This refers to waiting for the traffic to clear and making a left turn across lanes of oncoming traffic. This question is not asking about whether the subject pulled out into oncoming traffic. The 'left turn' does not refer to turns made with a green left-turn arrow at a traffic light (i.e., a protected left turn). This turn can occur at a median, from a center turn lane, at a green light (unprotected by a left-turn arrow) etc.

**L10a:** The subject is asked to rate the difficulty of making left turns across traffic. This refers to waiting for the traffic to clear, judging the distance of other cars, and determining the distance needed to make a safe turn.

**L10b:** This question refers to actively avoiding these turns by going out of the way to catch a traffic light with a green arrow, or making several right turns around the block to get to the desired street. A subject might respond "No" if s/he never had an occasion to make such a turn, or all such turns were protected by left-turn traffic control devices.

**L11:** This refers specifically to entering the highway or expressway from an entrance ramp. Some traffic should be present to justify a "Yes" response.

**L11a:** The subject is asked to rate the difficulty of entering the highway or expressway.

**L11b:** This question refers to avoiding the highway or expressway altogether and driving an alternate route to get to their destination.

**L12:** This refers to driving on roads with a lot of traffic such as 2 or 3 lane roads or a main road in your area that might be congested with a lot of traffic. This does not include the highway or expressway.

**L12a:** The subject is asked to rate the difficulty of driving on high-traffic roads.

**L12b:** This question refers to avoiding high traffic roads by planning an alternative route where there is less traffic on the road.

**L13:** This question refers to driving during normal rush-hour traffic (which will vary for each location). This time is usually during the morning from 7 to 9 am and in the afternoon from 4 to 6 p.m.

**L13a:** The subject is asked to rate the difficulty of driving on during rush hour.

**L13b:** This question refers to avoiding rush-hour traffic by scheduling driving to occur before or after rush-hour traffic hours.

**L14:** This is driving during the nighttime hours (after the sun went down).

**L14a:** The subject is asked to rate the difficulty of driving at night. This includes difficulty with bright headlights from other cars, seeing glare from streetlights, having difficulty reading street signs, etc.

**L14b:** This question refers to avoiding night driving by scheduling activities so that the person does not have to drive a car when it is dark.

**L15:** This question refers to making lane changes to pass another vehicle, or switching lanes in traffic to get to a turn lane. The question covers lane changes on any type of two-lane road, highway, or expressway. Changing lanes in the absence of any traffic to get to a turn lane or turning onto an exit ramp do not justify a "Yes" response for this question. The idea is that the lane change was made in the presence of surrounding traffic which had to be noticed in order for the maneuver to be completed safely.

**L15a:** The subject is asked to rate the difficulty making these lane changes in the presence of traffic.

**L15b:** The question refers to avoiding lane changes to pass a slower vehicle and preferring to stay in the same lane while on the road.

**Please note that the remaining three questions ask about things that might have happened to the subject in the last twelve months, rather than over the last two months.**

For questions **L16-L18**, the specific time frame must be given to the subject to improve his/her recall (e.g., if this questionnaire is administered in July, 2008 the administrator would say, "Now, I want to know about the time period between (ONE YEAR AGO- MONTH/YEAR) July, 2007, and up to and including yesterday?").

**L16:** This question refers to a serious suggestion coming from anyone (spouse, children, doctor, friend, etc.)

**L17:** This includes all fender benders, minor or major accidents even if it was the other driver who caused the accident. Example: A subject would answer "Yes" if that person was sitting at a light and someone else hit them from behind. The subject must have been the driver, not a passenger.

**L18:** This does not include being stopped at routine driver's license checkpoints. This refers to being stopped for speeding, or some other violation.

**L18a:** Refers to receiving a ticket (speeding etc.)

## Section M. Mobility Questionnaire/ Driving Habits of Non-Drivers

This section assesses the driving status for non-drivers, including their reasons for stopping driving, and vehicular accident history. This section is completed for subjects who meet the ACTIVE definition of current non-drivers. The section has been modified from the Driving Habits Questionnaire used extensively in previous studies on driving in older populations.

**M1:** This question is not asking about frequency or duration. It is referring to whether the person drives if s/he needs to go somewhere or whether s/he simply does not go if no one can drive her/him to the desired destination. M1 is a verification question. It is best to be certain you are completing the correct section for the subject, i.e. driver vs. non-driver.

**M2:** This refers to the way the subject **prefers** to get around, i.e., how s/he wants to travel and how s/he likes to travel, not the way s/he usually travels. Example: The subject may actually do all the driving, although s/he would **prefer** someone else drive her/him. Alternatively, someone might usually be driven around but would actually prefer to do the driving her/himself.

**M3:** There may be subjects who never drove. These people would respond "No" and would be finished with the Mobility Questionnaire. If the respondent once held a driver's license or drove at some stage of their lives, then s/he should answer "Yes" on the question and proceed to the remaining questions.

**M4:** Write down the reason(s) the subject gives for stopping driving. Try to pin down whether it was a particular event that happened? Was it due to a medical condition? Was it due to poor vision? Was it a choice? Was it required? Was it due to stress and anxiety? What was the reason?

**M5:** The subject should estimate the number of years and/or months since s/he last drove a car. You can prompt the subject by saying, "was it in the past month?; the past 6 months?; within the past year? within the past 2 years?"

Refer to the information received for Question 5. If the subject stopped driving within the last two years, proceed with the rest of the questions. If the subject stopped before that, then the questionnaire is complete.

**M6:** The suggestion coming from anyone (spouse, children, doctor, friend, etc.) to stop or limit the subjects driving in the last twelve months.

**M6a:** Try to pinpoint who suggested that they curtail their driving.

**M7:** The subject should estimate the number of driving accidents s/he was involved in over the last twelve months. This includes all fender benders, minor or major accidents even if it was the other driver who caused the accident. Example: A person would answer "Yes" if that person was waiting at a light and someone else hit them from behind. The subject must have been the driver, not a passenger.

**M7a:** This should estimate the number of times the subject was pulled over by the police in the last twelve months. This includes all accidents where the police came, even if it was the other driver who caused the accident. The subject must have been the driver, not a passenger.

**M8:** This does not include being stopped at routine driver's license checkpoints. This refers to being stopped for speeding, or some other violation.

**M8a:** Refers to receiving a ticket (speeding etc.)

## **Section N. Health Questions**

The purpose of **N1 (a-q)** is to obtain a listing of chronic diseases diagnosed.

The stem question, “Has a doctor/nurse told you that you have...”, is specifically worded so that the subject does not make up diagnoses. For example, the subject may have some difficulty seeing and think s/he has cataracts, but if s/he has not been told this by a doctor (nurse or Physician's Assistant), it should not be coded as ‘Yes’.

**N1r, N1s and N1t.** If the subject answers **YES to N1q**, i.e. cancer(s) were diagnosed, then these sub-questions should be asked. The three sub-questions are asked to obtain additional information regarding cancer types and treatments received. The questions allow recording information for up to three cancer types/organs, if currently receiving chemotherapy or radiation treatment and/or if chemotherapy or radiation treatment was **ever** received.

Recording sub-questions: For sub-questions N1r-t, enter in the first reported cancer type and then follow the arrows to the end of N1t. Do this for each cancer type listed.

**N2 – N2b** asks the subject if current a cigarette smoker and obtain the quality of exposure. For N2, if subject responds, “I have never smoked”, code NEVER SMOKED and skip to N3.

**N3 and N3a** asks the participant about their alcohol exposure and may be sensitive questions. If there is a hesitation, it would be appropriate to reassure the subject again that all information will be kept in strictest confidence.

**N4 and N4a** asking about pain that has occurred in the last twelve months. Before starting these questions, the tester should have the **month + year as the date for twelve month ago** written on a piece of paper and available to provide to the subject.

**N4a** is trying to determine if the subject has limitations in activity due to joint or body pain. If the subject answers yes to a specific location, ask again if the pain in that location limits their activity.

**N5 – N7a** is asking about the type of insurance the subject has. Insurance type may affect how easy it is for subjects to get care. For question N5b, obtain a list of local HMO programs from your Site Coordinator or PI. Have this list ready to read to the subject when asking the question.

## Section O. Health Services Utilization

### 1. Description

The use of health services is an outcome of major interest. The purpose of the questions in this section is to determine the type, amount, and reasons for use by the subject in the last twelve months.

### 2. Administration

**O1-4:** Inquire about the subject's usual source of care, referring to the site of this care and the medical specialty of the physician whom the subject sees regularly. If the subject reports receiving care from multiple doctors, ask them for the specialty of the doctor they see most frequently, or see for routine care or minor problems. If subject states that the physician is both an internist and cardiologist, or internist and geriatrician, code the narrower specialty, i.e., cardiologist or geriatrician.

**O5-O14 Introduction:** "The next set of questions asks about your use of doctor, hospital, or other health care services in the last twelve months. "Today is (MONTH + YEAR), so I will be asking you about the period of time from (ONE YEAR AGO - MONTH + YEAR), up to, and including, yesterday." (PROVIDE THE MONTH + YEAR ON A PIECE OF PAPER FOR PARTICIPANTS REFERENCE)

NOTE: In order to assist with subject time period recall for these questions, testers should have a calendar handy and the month/year written out prior to sessions.

**O5:** Record the number of times the subject was seen by or has talked to a physician on the phone about their health in the last 12 months. . If the subject cannot remember the timeframe, probe for month and year. Code, 'DK' for don't know response. If zero times, code zeros and skip to O8.

**O6:** Record the date of the most recent contact (visit or telephone) with any physician. If the subject cannot remember the day, probe for month and year. In this case, code "DK" in spaces for the day.

**O7:** This question inquires about the reason(s) for the most recent contact (visit or telephone) with a physician (i.e., the contact noted in O6). Do not read the responses. Code based on subject's response.

**O8:** Record the number of times the subject has seen or talked to a dentist about his/her oral health in the last twelve months. If the subject cannot remember the timeframe, probe for month and year. Code, DK for don't know response. If zero times, code zeros and skip to O10.

**O9:** Record the date of the subject's most recent contact (visit or phone) with any dentist. If the subject cannot remember the day, probe for month and year. In this case, code "DK" for the day.

**O10:** Record the number of times the subject was a patient overnight in a hospital in the last twelve months. These questions refer to overnight hospital stays, not outpatient services such as day surgery. Code, DK for don't know response. If zero, skip to O12.

**O10i:** Record the total number of nights the subject spent overnight in a hospital in the last months. Code, DK for don't know response.

**O11:** Record verbatim the MAIN reason for the last hospitalization. The reason might be reported as a diagnosis (e.g., heart attack); symptom (e.g., chest pain); or procedure (e.g., tests; angiogram). List only one reason for this item. Probe for the main reason. Code, DK for don't know response.



**O12:** Record the number of times the subject was a resident in a nursing home in the last twelve months. If subject currently a full time nursing home resident, tester records # of times as **99** and must make a comment in the margin to that effect. Code, DK for don't know response. If zero, skip to O13.

**O12i:** Record the total number of days the subject spent in the nursing home in the last twelve months. If subject currently a full time nursing home resident, tester records # of days as **365** and must make a comment in the margin to that effect. Code, DK for don't know response.

**O13:** Record the number of times the subject received treatment in an emergency room in the last twelve months. This includes both urgent care (e.g., for an injury, chest pain) or routine care when subject did not have access to a physician. Code, DK for don't know response.

**O14a-g:** This question asks about the frequency of use (TIMES) by the subject of different types of Community-based health or supportive services. Record the total number of times the subject used these services in the last twelve months for each of the services listed in the first column. Do not include these services if received in a nursing home. Code, DK for don't know response.

**O15-18:** In addition to self-reported use of health services, data regarding utilization will be collected from health insurance claims files. In order to obtain these data, ask the subject for their Social Security number, Medicare number, and Medicaid number (if applicable). Many persons carry these cards with them, and the numbers can be recorded directly from the cards. If the subject does not have the numbers available, you should obtain them by telephone.

Subjects might be reluctant to provide these numbers. In fact, they might have been advised not to give these numbers (particularly their Social Security number) to anyone. Read the script regarding confidentiality, assuring the subject that no individual information will be reported nor will their name appear in any report. If a subject wants to consult a spouse or offspring, you can offer to speak to that person and then collect the numbers by telephone if they agree.

If subjects say they have already reported these numbers at the earlier visits, read the script regarding capturing updated information.

If a subject refuses to provide the number, record "REF" in the data fields. If a subject does not have a number, particularly a Medicaid number, record "NA" in the data fields. If a subject responds that they don't know (e.g., if they have Medicaid), attempt to have the subject look for the card, calling at home if necessary. If response remains don't know, record "DK".

**O18:** Driving history is an outcome of interest. In order to collect data about the subject's driving history, ask the subject for their driver's license number and record the two letter abbreviation for the state. Most persons who drive carry their driver's license with them. If not available, the number can be obtained by telephone.

If a subject refuses to provide the license number, record "REF" in the data fields. If a subject does not have a driver's license number, record "NA" in the data fields. If a subject responds that they don't know if they have a driver's license number, attempt to have the subject look for the license, calling at home if necessary. If response remains don't know, record "DK".

**O19:** Record Interview End Time: Record the time you complete the Health Services Utilization questions. Remember to circle **AM** or **PM** in the space provided. If two sessions are required to complete the assessment this time will be the end time of session 2.

### **Instructions for the Take Home Questionnaire**

At the end of the session read the closing script to the participant. The closing script that includes instructions for the Take-Home Questionnaire is included to provide Testers with the text if necessary at Part II. If the subject received the Take-Home Questionnaire at Part I and returned it at the start of this Session, you do not have to read these instructions. The closing script will guide you in distribution of the Take Home Questionnaire if necessary. Use this script if you distribute the Take Home Questionnaire at the end of this Assessment Session.

### **Section P: Tester's Feedback**

This section includes questions designed to gather feedback from testers regarding the subject's overall receptivity to, and cooperation with, the instrument and the degree of difficulty responding to/completing the measures. Space is provided to identify specific items and describe the difficulty.

ATTACHMENT A page 1: LOG & PROCEDURES FOR CALIBRATION OF DIGITAL SCALE IN POUND MEASURE

- Calibrate scales with standard weights at each of two weight levels (i.e. 50 and 100 lbs.) prior to the start of the10<sup>th</sup> Annual testing period and every 6 months thereafter. Record findings in pounds on the Calibration Log form provided below. The Site Coordinator should review completed Calibration Log Forms after every calibration as a local QC check. Logs should be sent to the CC for Q.C. review every 6 months. Logs should also be available for review by CC staff during site visits.
- Re-evaluate scales if they mismeasure standards by more or less than five (5) pounds. Be certain the scale is on a level floor surface without carpet or rug of any kind. Check that the scale is programmed to the proper mode, i.e. pounds vs kilograms to match your standard weights and that it balances at zero before your test. If necessary, replace the batteries and repeat calibration procedures *precisely*.
- If the scale still mismeasures the standards by more or less than 5 pounds **DO NOT USE THE SCALE FOR ACTIVE MEASUREMENTS**. Follow the manufacturer's recommendations for reconditioning.

Acceptable ranges for calibration of scales using <b>pound</b> weights	
Standard weight in pounds	Evaluate scale if test weight is more or less than 5 pounds off standard measure as follows:
50 lbs.	< 45 lbs. <b>or</b> > 55 lbs.
100 lbs.	< 95 lbs. <b>or</b> > 105 lbs.

SITE: (circle one)

1. UAB

2. IU

3. HSL

4. JHU

5. WSU

6. PSU

DATE	SCALE #	INITS	50 lbs.	100 lbs.
1. ____/____/____	1 2 3 4 5 6	____ _	lbs.	lbs.
2. ____/____/____	1 2 3 4 5 6	____ _	lbs.	lbs.
3. ____/____/____	1 2 3 4 5 6	____ _	lbs.	lbs.
4. ____/____/____	1 2 3 4 5 6	____ _	lbs.	lbs.
5. ____/____/____	1 2 3 4 5 6	____ _	lbs.	lbs.
6. ____/____/____	1 2 3 4 5 6	____ _	lbs.	lbs.
7. ____/____/____	1 2 3 4 5 6	____ _	lbs.	lbs.
8. ____/____/____	1 2 3 4 5 6	____ _	lbs.	lbs.
9. ____/____/____	1 2 3 4 5 6	____ _	lbs.	lbs.

**ATTACHMENT A page 2: LOG & PROCEDURES FOR CALIBRATION OF DIGITAL SCALE IN KILOGRAM MEASURE**

1. Calibrate scales with standard weights at two weight levels (i.e. 25 and 50 kgs.) prior to the start of the 10<sup>th</sup> Annual testing period and every 6 months thereafter. Record findings in kilograms on the Calibration Log form below. The Site Coordinator should review completed Calibration Log Forms after every calibration as a local QC check. Logs should be sent to the CC for Q.C. review every 6 months. Logs should also be available for review by CC staff during site visits.
2. Re-evaluate scales if they mismeasure standards by more or less than two (2) kgs. Be certain the scale is on a level floor surface without carpet or rug of any kind. Check that the scale is programmed to the proper mode, i.e. pounds or kilograms to match your standard weights and that it balances at zero before your test. If necessary, replace the batteries and repeat calibration procedures *precisely*.
3. If the scale still mismeasures the standards by more or less than 2 kgs **DO NOT USE THE SCALE FOR ACTIVE MEASUREMENTS.** Follow the manufacturer's recommendations for reconditioning.

Acceptable ranges for calibration of scales using <b>kilogram</b> weights	
Standard weight in kg	Evaluate scale if test weight is more or less than .2 kgs off standard measure as follows:
25 kg	<23 kgs <i>or</i> > 27 kg
50 kg	<48 kg <i>or</i> > 52 kg

**SITE:** (circle one)

1. UAB      2. IU  
 3. HSL      4. JHU  
 5. WSU      6. PSU

DATE	SCALE #	UNITS	25 kgs	50 kg
1. ____/____/____	1 2 3 4 5 6	____ _	kgs	kgs
2. ____/____/____	1 2 3 4 5 6	____ _	kgs	kgs
3. ____/____/____	1 2 3 4 5 6	____ _	kgs	kgs
4. ____/____/____	1 2 3 4 5 6	____ _	kgs	kgs
5. ____/____/____	1 2 3 4 5 6	____ _	kgs	kgs
6. ____/____/____	1 2 3 4 5 6	____ _	kgs	kgs
7. ____/____/____	1 2 3 4 5 6	____ _	kgs	kgs
8. ____/____/____	1 2 3 4 5 6	____ _	kgs	kgs
9. ____/____/____	1 2 3 4 5 6	____ _	kgs	kgs

# ATTACHMENT B : LOG & PROCEDURES FOR CALIBRATION OF DIGITAL SCALE USING A GOLD STANDARD BALANCE BEAM SCALE

1. Calibrate scales prior to the start of the 10<sup>th</sup> Annual testing period and every 6 months thereafter, using a 'gold standard' balance beam scale registered/approved by the CC. Scales should be calibrated at a weight not less than 100 pounds. Record findings in pounds or kilograms on the Calibration Log form below. The Site Coordinator should review completed Calibration Log Forms as a local QC check. Logs should be sent to the CC for Q.C. review every 6 months. Logs should also be available for review by CC staff during site visits.
2. Re-evaluate scales if they mismeasure by more or less than five (5) pounds or 2 kgs. Be certain the digital scale is on a level floor surface without carpet or rug of any kind. Check that the scale is programmed to the proper mode, i.e. pounds or kilograms to match the 'gold standard' scale and that it balances at zero before your test. If necessary, replace the batteries and repeat calibration procedures *precisely*.
3. If the scale still mismeasures the standards by more or less than 5 pounds or 2 kgs. **DO NOT USE THE SCALE FOR ACTIVE MEASUREMENTS.** Follow the manufacturer's recommendations for replacement or reconditioning.

SITE: (circle one)

1. UAB      2. IU  
3. HSL      4. JHU  
5. WSU      6. PSU

DATE	SCALE #	UNITS	Gold Standard weight (lbs or kgs)	ACTIVE Digital scale weight (lbs or kgs)
1. ____/____/____	1 2 3 4 5 6	____ _		
2. ____/____/____	1 2 3 4 5 6	____ _		
3. ____/____/____	1 2 3 4 5 6	____ _		
4. ____/____/____	1 2 3 4 5 6	____ _		
5. ____/____/____	1 2 3 4 5 6	____ _		
6. ____/____/____	1 2 3 4 5 6	____ _		
7. ____/____/____	1 2 3 4 5 6	____ _		
8. ____/____/____	1 2 3 4 5 6	____ _		
9. ____/____/____	1 2 3 4 5 6	____ _		

**10<sup>th</sup>**

**ACTIVE**

**Group Assessment Scripts**

**10<sup>th</sup> Year Post-Test**

**Form # 6a**

### **Group 10th Year Post-Test Assessment Forms:**

For each subject in the group session, the tester should prepare the following forms in advance of the session:

1. AVLT Subject Data Forms packet #611a with ID labels attached to all pages
2. AVLT Coding Form #611 with ID label attached
3. Letter Series Form #612 with ID label attached
4. AVLT Recognition Form #613 with ID label attached
5. Letter Sets Form #614 with ID label attached
6. Rivermead Story #3 Data Form #615a with ID label attached
7. Vocabulary Form #616 with ID label attached
8. EPT Form #617 with ID label attached
9. AVLT Coding Form #619 (Intrusion & Perseveration Errors) complete by certified scorer.
10. Rivermead Scoring Form #615 completed by certified scorer.

One of each of the following should be prepared in advance of the Group Assessment:

11. Tester's Record Book, Form #6
12. A Group Assessment 10<sup>th</sup> Year Post-Test Scripts Form #6a
13. The AVLT & Rivermead Story Audiotape for the 10<sup>th</sup> Year Post-Test version 07/2008.  
(Testers must be certain to have the correct audiotape for the planned session prior to the start of the group assessment.)

### **Equipment required for the Group 10<sup>th</sup> Year Post-Test Assessment**

- electronic timer
- clock with digital display
- rulers or 5x8 cards for each subject
- pencils for subjects
- Sony Boom Box Model CFS-B15
- AVLT & Rivermead Audiotape for the '10<sup>th</sup> Year Post-Test 7/08'

### **Order of Administration for the Group 10<sup>th</sup> Year Post-Test Assessment**

- |   |                            |
|---|----------------------------|
| 1 | AVLT Recall Word List      |
| 2 | Letter Series              |
| 3 | AVLT Recognition Word List |
| 4 | Letter Sets                |
| 5 | Rivermead Story # 3        |
|   | BREAK POINT                |
| 6 | Vocabulary                 |
| 7 | EPT                        |

## SCRIPTS

**RECORD THE GROUP SESSION APPOINTMENT TIME IN A5 ON THE COVER OF THE TESTER'S RECORD BOOK.**

### **GENERAL INTRODUCTION**

Thank you for agreeing to participate in today's group session. As you know, the purpose of this program is to determine whether training in later adulthood can improve concentration, memory, and problem solving. In addition, the study will determine if older adults who have had this type of training remain healthier, more emotionally positive, and function more easily in daily activities, such as managing finances, taking medication, using the telephone, or driving.

Today you are being asked to complete some activities that assess your mental abilities such as memory, reading comprehension, and reasoning abilities.

All of these activities will be in the form of paper and pencil questionnaires. The entire session should take about two hours to complete.

### **THE FOLLOWING CONFIDENTIALITY STATEMENT MUST BE READ TO ALL PARTICIPANTS**

Before we begin, I'd like to mention a few things. All of your responses are completely confidential and will only be seen or heard by people directly associated with the study. The information you provide will be grouped together with others in the study and your name will never appear in any report. No information about any specific individual will ever be reported. You may refuse to answer any questions or stop at any time. Do you have any questions before we begin?

### **FAREWELL STATEMENT – THE FOLLOWING STATEMENT MUST BE READ TO ALL PARTICIPANTS EITHER AT THE BEGINNING OR END OF THE SESSION.**

Before we (begin or end), I would like to remind you that this is our last session together for this part of the study. However, we may extend the study in the future to include additional visits and we will contact you at that time. Thanks again on behalf of myself and all the ACTIVE staff here at \_\_\_\_\_.

(Institute/University)



## **1. AVL T**

PRE-SET THE ELECTRONIC TIMER TO 2 MINUTES.

HAND EACH SUBJECT A PRELABELED PACKET OF AVL T DATA FORMS, #611a.

RECORD 'TIME INSTRUCTIONS BEGAN' IN THE TESTER'S RECORD BOOK, AND BEGIN.

INSTRUCTIONS: This first activity is called the Auditory Verbal Learning Test. It is a measure of your ability to learn and remember a list of words. For this section you will use these forms. The test will be presented on audiotape. Please listen carefully.

START THE TAPE PLAYER.

STOP THE TAPE AFTER THE INSTRUCTIONS. ASK IF ANY QUESTIONS AND ANSWER APPROPRIATELY.

I must mention to you that once the recording starts, I will not be able to talk to you or answer any questions. Please listen carefully. Ready?

START THE TAPE PLAYER. STOP THE TAPE PLAYER BETWEEN EACH TRIAL. STOP EACH TRIAL AFTER 2 MINUTES. COLLECT FORMS FOR EACH TRIAL AS COMPLETED.

RECORD THE 'TIME TEST ENDED' IMMEDIATELY AFTER THE LAST TRIAL.

### **SCORING FOR THE AVL T:**

ALL SCORING AND CODING SHOULD BE COMPLETED AFTER THE GROUP SESSION IN THE AVL T CODING FORM #611.

AUDIOTAPED INSTRUCTIONS WILL BE USED FOR THIS TEST, BUT WE HAVE INCLUDED FULL SCRIPTS FOR YOUR REFERENCE OR FOR USE IF YOU HAVE EQUIPMENT PROBLEMS. SEE ATTACHMENT A.

## 2. Letter Series

PRE-SET THE ELECTRONIC TIMER TO 6 MINUTES.

HAND EACH SUBJECT A PRELABELED LETTER SERIES FORM, #612.

RECORD 'TIME INSTRUCTIONS BEGAN' IN THE TESTER'S RECORD BOOK AND BEGIN.

INSTRUCTIONS: This activity is called Letter Series. This is to see how well you can follow a series of letters.

AS YOU READ EXAMPLES, EMPHASIZE THE PATTERN WITH YOUR VOICE.

Study the series of letters in Example A below on the left. What letter should come NEXT?

Answer Choices	
A.    a b a b a b a b	<input checked="" type="radio"/> a b c d e

The series goes like this: **ab ab ab ab**. The NEXT letter in the series should be **a**. The letter **a** in the row of Answer Choices for Example A has been circled.

Now study the series of letters in Example B below. Decide what the NEXT letter should be. Circle the NEXT letter in the series from the Answer Choices on the right.

B.    c a d a e a f a	c d e f g
-----------------------	-----------

The series goes like this: **ca da ea fa**. You should have circled **g** in the Answer Choices on the right.

Now study the series of letters in Examples C, D, E and F below. In each series decide what the NEXT letter should be. Circle the NEXT letter in the series from the Answer Choices on the right.

EXPLAIN EACH EXAMPLE NO MORE THAN TWICE.

Answer Choices	
C.    c d c d c d	a b c d e
D.    a a b b c c d d	a b c d e
E.    a b x c d x e f x g h x	h i j k x
F.    a a a b b b c c c d d	a b c d e

In Example C the series goes like this: **cd cd cd**. You should have circled **c** in the Answer Choices on the right.

In Example D the series goes like this: **aa bb cc dd**. You should have circled **e** in the Answer Choices on the right.

In Example E the series goes like this: **abx cdx efx ghx**. You should have circled **i** in the Answer Choices on the right.

In Example F the series goes like this: **aaa bbb ccc dd**. You should have circled **d** in the Answer Choices on the right.

When you are given the signal to begin, you are to work more problems like those above. If you come to a problem you cannot work, skip it and go on to the next problem. If you have time, go back to the hard problems. You will have two pages of problems and you will have 6 minutes to complete the pages. You are not expected to finish in the time allowed.

Do not turn the page until you are asked to do so. Do you have any questions? Turn the page and begin.

TIMER SHOULD BE SET FOR 6 MINUTES. BEGIN TIMING SUBJECT AND RECORD 'TIME TEST BEGAN' IN THE TESTER'S RECORD BOOK. .

AT THE END OF 6 MINUTES SAY: *Stop!*

RECORD 'TIME TEST ENDED'.

### **3. AVLT Recognition**

HAND EACH SUBJECT A PRELABELED AVLT RECOGNITION FORM, #613.

RECORD 'TIME INSTRUCTIONS BEGAN' IN THE TESTER'S RECORD BOOK AND BEGIN.

INSTRUCTIONS: The next activity consists of word lists similar to the lists earlier. Again, I will use an audiotape to present the instructions and words. You will be writing Y for YES or N for NO in each box on the form. You will only have time to write a Y or an N because the words will be read very quickly. Remember, do not write YES or NO, just Y or N. Please listen carefully to the instructions.

START THE TAPE PLAYER.

STOP THE TAPE AFTER THE NARRATOR'S INSTRUCTIONS. ASK IF ANY QUESTIONS AND ANSWER APPROPRIATELY.

I must mention to you that once the recording starts, I will not be able to talk to you or answer any questions. Please listen carefully. Ready?

START TAPE PLAYER AND RECORD 'TIME TEST BEGAN' IN THE TESTER'S RECORD BOOK.

STOP TAPE PLAYER AND COLLECT FORMS IMMEDIATELY AFTER WORD LIST IS COMPLETED.

RECORD 'TIME TEST ENDED' IN THE TESTER'S RECORD BOOK.

AUDIOTAPED INSTRUCTIONS WILL BE USED FOR THIS TEST. FULL SCRIPT IS PROVIDED IN ATTACHMENT B FOR YOUR REFERENCE OR USE IF YOU HAVE EQUIPMENT PROBLEMS.

#### 4. Letter Sets

PRE-SET THE ELECTRONIC TIMER TO 7 MINUTES.

HAND EACH SUBJECT A PRELABELED PACKET OF LETTER SETS FORM, #614.

RECORD 'TIME INSTRUCTIONS BEGAN' IN THE TESTER'S RECORD BOOK, AND BEGIN.

INSTRUCTIONS: This next set of problems is called Letter Sets. It is a measure of a person's ability to find rules or patterns that make different sets of letters alike in some way.

Each problem in this measure has five sets of letters with four letters in each set. Four of the sets of letters are alike in some way. You are to find the rule that makes these four sets alike. One letter set is different from the others and will not fit this rule. Mark an X over the set of letters that is different.

**NOTE:** The rules will not be based on the sounds of sets of letters, the shapes of letters, or whether letter combinations form words or parts of words.

---

**Example A:**    N O P Q    ~~D E F L~~    A B C D    H I J K    U V W X

---

In **Example A**, four of the sets have letters in alphabetical order. An X has been drawn over DEFL, which does not follow the same rule or pattern.

Now work **Examples B & C**. Mark an X through the letter set that does not fit the rule in each one.

---

**Example B:**    N L I K    P L I K    Q L I K    T H I K    V L I K

**Example C:**    B C D F    F G H J    K L M P    N O P R    S T U W

---

EXPLAIN EACH EXAMPLE NO MORE THAN TWICE.

In **Example B**, four of the sets contain the letter L. You should have marked an X through THIK, as there is no letter L in this set.

In **Example C**, four of the sets contain a pattern in which one letter was skipped. You should have marked an X through KLMP, as 2 letters were skipped between M and P.

You will be allowed 7 minutes for this measure. REMEMBER: Mark an X through the set of letters that is different.

Do not turn this page until asked to do so. Do you have any questions? Turn the page and begin.

BEGIN TIMING SUBJECT IMMEDIATELY AFTER PAGE IS TURNED AND RECORD 'TIME TEST BEGAN' IN THE TESTER'S RECORD BOOK.

AT THE END OF 7 MINUTES SAY: *Stop!*

RECORD 'TIME TEST ENDED' IN THE TESTER'S RECORD BOOK.

## **5. Rivermead**

PRE-SET THE ELECTRONIC TIMER TO 3 MINUTES.

HAND EACH SUBJECT A PRELABELED RIVERMEAD – STORY 1 FORM, #615a.

RECORD 'TIME INSTRUCTIONS BEGAN' IN THE TESTER'S RECORD BOOK, AND BEGIN.

INSTRUCTIONS: In this task, we would like you to listen to and remember a story. You will hear a brief story describing an event. You will then be asked to write down as much of the story as you can remember. Once again, I will use an audiotape for this task.

START THE TAPE PLAYER.

WHEN THE TAPE SAYS "Ready?", HIT PAUSE. SAY: Here's the story. WAIT 5 SECONDS. THEN START TAPE.

WHEN THE STORY IS FINISHED, STOP THE TAPE AND TELL TO SUBJECTS TO BEGIN WRITING AS YOU START THE TIMER. RECORD THE 'TIME TEST BEGAN' IN THE TESTER'S RECORD BOOK.

AT THE END OF 3 MINUTES, SAY: *Stop!*

RECORD THE 'TIME TEST ENDED' IN THE TESTER'S RECORD BOOK.

AUDIOTAPED INSTRUCTIONS WILL BE USED FOR THIS TEST, BUT WE HAVE INCLUDED FULL SCRIPTS IN ATTACHMENT C FOR YOUR REFERENCE OR FOR USE IF YOU HAVE EQUIPMENT PROBLEMS.

## **6. Break**

OFFER A BREAK NOW.



## **7. Vocabulary**

PRE-SET THE ELECTRONIC TIMER TO 4 MINUTES.

HAND EACH SUBJECT A PRELABELED VOCABULARY FORM, # 616.

RECORD 'TIME INSTRUCTIONS BEGAN' IN THE TESTER'S RECORD BOOK, AND BEGIN.

INSTRUCTIONS: This is a test of your knowledge of word meanings. Look at the sample below. One of the five numbered words has the same meaning or nearly the same meaning as the word that is underlined above. Indicate your answer by putting a circle around the number of the word that you select.

**Example:** 1. jovial  
1. refreshing  
2. scare  
3. thickset  
4. wise  
5. jolly

The answer to Example 1 is jolly; therefore, number 5 has been circled.

Now work examples 2 and 3:

**Example 2.** quiet

1. blue
2. still
3. tense
4. watery
5. exact

**Example 3.** safe

1. Secure
2. Loyal
3. Passive
4. Young
5. Deft

The answer to Example 2 is still; therefore, you should have circled number 2. The answer to Example 3 is secure; you should have circled number 1. You will have 4 minutes for this test. The test has three pages.

Do not turn this page until asked to do so. Do you have any questions?

Turn the page and begin.

BEGIN TIMING SUBJECTS IMMEDIATELY AFTER PAGE IS TURNED AND RECORD 'TIME TEST BEGAN' IN THE TESTER'S RECORD BOOK.

AT THE END OF 4 MINUTES SAY: *Stop!*

RECORD 'TIME TEST ENDED' IN THE TESTER'S RECORD BOOK.



## **8. (EPT) Everyday Problems Test**

HAND EACH SUBJECT THE PRE-LABELED EPT FORM, # 617

RECORD ‘TIME INSTRUCTIONS BEGAN’ IN THE TESTER’S RECORD BOOK, AND BEGIN.

ASK THE SUBJECTS TO TURN TO PAGE ONE. READ THE INTRODUCTION ALOUD.

INTRODUCTION: The purpose of this test is to examine how well you can read and understand the kinds of materials that many older adults see in everyday activities. These materials include such things as medicine labels, phone bills, and mail order forms.

At the top of each page there will be material, such as a label or chart. Below there will be 2 questions about the material. You are to write answers to the questions. First, look over the questions to get an idea of the kind of information that you should be looking for. Then read the selection and write the answer on the lines below.

You do not need to write complete sentences to answer the questions. You may answer the question in a few words. Please attempt to answer every question. There is no penalty for guessing.

Do not spend too much time on any one question. There are 28 questions in the test.

Before we go over the examples, I need to tell you a few things. This is the last set of problems for today. You can leave when you are finished. This means that some of you will leave before others, but you should take as much time as you need to finish these problems.

Turn the page and we will go over two example questions.

EXAMPLE PROBLEMS:

ASK THE SUBJECT TO TURN TO PAGE 2. READ THE SCRIPT.

At the top of the page is a recipe for Sour Milk Biscuits. Read Question A “Which ingredient is mixed with the sour milk?” Find the answer to the question in the recipe.

DO NOT READ THE RECIPE.

READ THE SCRIPT FOR EXAMPLE A:

Which ingredient is mixed with sour milk?

The correct answer is “soda”. Therefore, the word “soda” should be written on the line below the question.

READ THE SCRIPT FOR EXAMPLE B:

Now look at Question B.

If you wanted to make just 6 biscuits, how much flour would you use?

Find the answer in the recipe. Write the answer on the line below Question B.

ASK THE SUBJECT TO LOOK AT THE RECIPE AND ANSWER THE QUESTION.  
THEN READ THE SCRIPT.

The correct answer is “1 cup”. Six biscuits would require only half the amount in the recipe given. You should have written “1 cup” on the line.

Are there any questions about what you are to do in this test? First look over the 2 questions on a page. Find the answer in the material at the top of the page. Write the answer on the line below each question. You do not need to write a complete sentence to answer the question.

IF THE SUBJECT DOES NOT UNDERSTAND OR CANNOT ANSWER QUESTIONS A OR B:  
THE INTERVIEWER CAN POINT TO THE PLACE IN THE RECIPE WHERE THE CORRECT  
ANSWER IS FOUND AND EXPLAIN THE ANSWER TO THE QUESTION.

IF THE SUBJECT SAYS SOMETHING IN RESPONSE TO QUESTION B LIKE “I always double the recipe for biscuits.” THE INTERVIEWER SHOULD REPLY “Answer the question as it is written; do not base your answers solely on your own experience. Use the recipe at the top of the page to answer the questions.”

THE INTERVIEWER SHOULD ASK IF THERE ARE ANY QUESTIONS. THE FOLLOWING ARE  
COMMON QUESTIONS WITH RESPONSES:

- SUBJECT SAYS “I do not understand what to do.” INTERVIEWER REPLIES “First read the question. Then look at the material at the top of the page and decide what is the answer to the question. Write the answer on the lines below the question.”
- SUBJECT SAYS “Do I have to write in complete sentences?” OR “I can’t write so much.” INTERVIEWER REPLIES “You do not need to write a complete sentence to answer the question. Answer the question in only a few words when possible. For example, Question A was answered with one word.”
- SUBJECT SAYS “I could spend a lot of time on one question.” INTERVIEWER REPLIES “Do not spend too much time on any one question. Just answer the best you can and go on to the next question.”
- SUBJECT SAYS “I won’t be able to answer some of the questions.” INTERVIEWER REPLIES “If you have difficulty with a particular question, give it your “best shot” and go on to the next question.”

- SUBJECT ASKS “Will I be penalized for guessing?” INTERVIEWER RESPONDS “No, there is no penalty for guessing.”

AFTER QUESTIONS ARE ANSWERED REGARDING EXAMPLES AND PROCEDURE, ASK SUBJECT TO TURN THE PAGE AND BEGIN THE QUESTIONNAIRE.

OK. Turn the page and begin.

RECORD ‘TIME TEST BEGAN’ IN THE TESTER’S RECORD BOOK.

WHILE SUBJECTS ARE COMPLETING THE QUESTIONNAIRE, THE INTERVIEWER:

- A) CAN ONLY ANSWER QUESTIONS RELATED TO THE TEST PROCEDURE
- B) MUST NOT TELL THE SUBJECT THE ANSWER TO A QUESTION OR “GIVE A HINT”.
- C) MUST NOT POINT TO THE ANSWER IN THE MATERIAL AT THE TOP OF THE PAGE.
- D) MUST NOT TELL THE SUBJECT WHETHER HIS/HER ANSWER IS RIGHT OR WRONG.

IF THE INTERVIEWER SEES SUBJECT WRITING EXCESSIVELY LONG ANSWERS TO THE QUESTIONS, TELL THE SUBJECT “You don’t need to write a complete sentence to answer the question -- just answer in a few words.”

IF A SUBJECT SAYS TO THE INTERVIEWER “I don’t understand this question,” TELL THE SUBJECT “If you have difficulty with a particular question, give it your ‘best shot’ and go on to the next question.”

IF THE INTERVIEWER SEES THE SUBJECT SPENDING AN EXCESSIVE AMOUNT OF TIME ON A PARTICULAR QUESTION, SUGGEST TO THE SUBJECT “If you have difficulty with a particular question, give it your ‘best shot’ and go on to the next question.”

## COMMONLY ASKED QUESTIONS AND SUGGESTED RESPONSES

Q1, Q2 If the subject says “I always use Pledge” tell the subject “Use the information at the top of the page to answer the question.”

If the subject says “I don’t see the answer” tell the subject “The information you need is in the chart at the top of the page. Just answer the best you can and go on to the next question.”

Q3, Q4 If the subject says “I don’t remember the name of my local phone company,” tell the subject “Look at the telephone bill at the top of the page for the information you need to answer the question.”

If the subject points to a phone number on the phone bill and asks, “Is this the right answer?” tell the subject “I cannot tell you whether this is right or wrong, just answer the best you can and go on to the next question.”

Q5, Q6 If the subject says “I don’t drive, so I am reading this from the pedestrian’s point of view” tell the subject “You do not need to drive in order to answer the question; the information you need is in the material at the top of the page.”

Q7, Q8 If the subject says “I don’t see the answer in the form” tell the subject “All the information you need to answer the questions is on the form. Just answer the best you can and go on to the next question.”

If the subject says “What does NRP stand for?” tell the subject “The form does not give this information but the information is not needed to answer the questions.”

Q9, Q10 If the subject says “Do I have to check all of the things that are wrong with me?” tell the subject “Read the question and provide the answer based on the question.”

If the subject says “Should I write the letter for the line on which the answer is given?” tell the subject “Yes, write the letter indicating the line on which the answer is given.”

Q11, Q12 If the subject says “Does a dose equal a teaspoon?” tell the subject “You will find the dosage in the label at the top of the page.”

If the subject says “Someone with a smoker’s cough should see a doctor” tell the subject “Write the answer based on the information in the label at the top of the page.”

Q13, Q14 If the subject says “I think you need to buy two 3-packs” tell the subject “Read the question and answer the best you can.”

If the subject says “It says to send the UPC symbol” tell the subject “Read the question and answer the best you can.”

Q15, Q16 If the subject says “I don’t ever ride in a taxi, so I don’t know how much the fares would be” tell the subject “Look at the chart at the top of the page for the information you need to answer the question.”

If the subject asks “Can I do the calculation on the side of the page?” tell the subject “Yes, you can do the math on the side of the page and write the answer on the line provided.”

Q17, Q18 If the subject says “I don’t fill out these forms, my \_\_\_\_\_ does this for me. I never do this.” tell the subject “Look at the top of the page for the information you need to answer the question. Just answer the best you can.”

If the subject says “I make less than \$15,000 a year.” tell the subject to “read the question and give the answer according to what is asked in the question.”

Q19, Q20 If the subject says “This is women’s work - I don’t cook” tell the subject “The information needed to answer the question is in the directions; you do not need to be able to cook to answer the question.”

If the subject says “I always make stuffing from scratch” tell the subject “Assume someone else is making stuffing using a stuffing mix. Answer the question using the directions at the top of the page.”

Q21, Q22 If the subject says “I never try to fix an appliances, my \_\_\_\_\_ does this” tell the subject “Look at the chart at the top of the page; the information needed to answer the question is in the chart.”

If the subject says “Do I need to write all the information given under Possible Reason?” tell the subject “Just answer the question in as few words as possible.”

Q23, Q24 If the subject asks “Was Mr. Jones in the nursing home from January to July?” tell the subject “The question says that Mr. Jones was in the nursing home in July.”

If the subject says “The benefits are only listed for the first 60 days” tell the subject “Based on the chart give the best answer to the question.”

Q25, Q26 If the subject says “How do I know how much is in a serving of cereal?” tell the subject “Look at the chart at the top of the page; the information needed to answer the question is in the chart.”

If the subject says “The chart says 230 mg of sodium” tell the subject “read the question and then look at the chart at the top of the page, the information needed to answer the question is in the chart.”

Q27, Q28 If the subject says “I always call my children on weekends” tell the subject “Read the question and give the answer needed to answer the question.”

If the subject says “My phone plan does not have these rates” tell the subject “Base your answer on the chart at the top of the page. The information needed to answer the question is in the chart.”

ATTACHMENT A

# ACTIVE

## AVLT SCRIPTS AND DIRECTIONS

USE THE SAME DIRECTIONS FOR EACH TRIAL. THE WORDS SHOULD BE READ ALOUD EXACTLY AS THEY ARE PRINTED. USING A TIMER, READ EACH WORD FROM **WORD LIST A**. USING A TIMER, PAUSE 2 SECONDS BETWEEN EACH WORD.

PRE-SET THE ELECTRIC TIMER TO 2 MINUTES.

HAND EACH SUBJECT A PRELABELED PACKET OF AVLT DATA FORMS, #611a.

RECORD 'TIME INSTRUCTIONS BEGAN' IN THE TESTER'S RECORD BOOK, AND BEGIN.

INSTRUCTIONS: I am going to read you a list of words. Each word will be read only once and cannot be repeated. Listen carefully, for when I stop, you are to write down as many words as you can remember. It doesn't matter in what order you write them. Just try to remember as many as you can. Please write down as many words as you can remember in any order. When you can no longer remember any more words, place your pencil on the table.

AFTER INSTRUCTION READ, ASK IF ANY QUESTIONS AND ANSWER APPROPRIATELY.

Are there any questions? I will not be able to answer any questions once I start reading. Please do not talk during this test. Ready?

WAIT 10 SECONDS, THEN READ WORD LIST A.

PAUSE 2 SECONDS AND THEN SAY: Now write all the words you can remember.

STOP THE SUBJECT AFTER 2 MINUTES AND COLLECT THE AVLT - A1 FORM.

Now I'm going to read the same list again, and once I stop, I want you to write down as many words as you can remember, including words you wrote the first time. It doesn't matter in what order you write them. Just write down as many words as you can remember whether or not you wrote them before. When you can no longer remember any words, place your pencil on the table.

WAIT 10 SECONDS. THEN, READ **LIST A** AGAIN. USING A TIMER, PAUSE 2 SECONDS BETWEEN EACH WORD. PAUSE 2 SECONDS AND THEN ASK SUBJECTS TO WRITE DOWN AS MANY WORDS AS THEY CAN REMEMBER ON THE SHEET MARKED **AVLT-A2**.

STOP EACH TRIAL AFTER 2 MINUTES. COLLECT FORM FOR EACH TRIAL AS COMPLETED.

REPEAT THE SAME INSTRUCTIONS FOR EACH OF THE THREE REMAINING TRIALS - **A3**, **A4**, AND **A5**. FOR EACH TRIAL READ EACH WORD FROM **LIST A**, PAUSING 2 SECONDS BETWEEN EACH WORD. FOR THE THIRD RECALL TRIAL, ASK THE SUBJECTS TO WRITE DOWN AS MANY WORDS AS THEY CAN REMEMBER ON THE SHEET MARKED **AVLT-A3**; FOR THE FOURTH TRIAL ON THE SHEET MARKED **AVLT-A4**; AND FOR THE FIFTH TRIAL ON THE SHEET MARKED **AVLT-A5**.

Word List A	# SECONDS	Word List B
DOLL	1	DISH
MIRROR	4	JESTER
NAIL	7	HILL
SAILOR	10	COAT
HEART	13	TOOL
DESERT	16	FOREST
FACE	19	WATER
LETTER	22	LADDER
BED	25	GIRL
MACHINE	28	FOOT
MILK	31	SHIELD
HELMET	34	PIE
MUSIC	37	INSECT
HORSE	40	BALL
ROAD	43	CAR

#### SCRIPT AND DIRECTIONS FOR TEST B1:

UPON COMPLETION OF THE **FIFTH TRIAL**, TELL THE SUBJECTS THAT ANOTHER LIST (I.E., **WORD LIST B**) IS GOING TO BE READ TO THEM AND THEY SHOULD WRITE DOWN AS MUCH OF THIS ENTIRE LIST AS THEY CAN.

Now I'm going to read a second list of words. This time, again, you are to write down as many words as you can remember from the second list. Again, the order in which you write the words does not matter. Just try to remember as many as you can. When you can no longer remember any more words, place your pencil on the table.

WAIT 10 SECONDS. THEN READ ALOUD EACH WORD FROM **LIST B**.

USING A TIMER, PAUSE 2 SECONDS BETWEEN EACH WORD.

PAUSE 2 SECONDS AND THEN SAY: Now write all the words that you can remember.

STOP SUBJECT AFTER 2 MINUTES. COLLECT THE AVLT- B1 FORM.

SCRIPT AND DIRECTIONS FOR TEST A6:

NEXT YOU WILL ASK SUBJECTS TO WRITE DOWN AS MANY WORDS AS THEY CAN REMEMBER FROM LIST **A** ON THE SHEET MARKED **AVLT-A6**. DO NOT READ LIST A TO SUBJECTS.

Now I would like you to write down as many words as you can remember from the first list. Again, the order in which you write the words does not matter. When you can no longer remember any more words, place your pencil on the table.

STOP SUBJECTS AFTER 2 MINUTES. COLLECT THE AVLT A6 FORM.

RECORD 'TIME TEST ENDED' IN THE TESTER'S RECORD BOOK.



## ATTACHMENT B

# ACTIVE

### AVLT RECOGNITION SCRIPT AND DIRECTIONS

HAND EACH SUBJECT A PRELABELED AVLT RECOGNITION FORM, #613.

RECORD 'TIME INSTRUCTIONS BEGAN' IN THE TESTER'S RECORD BOOK AND BEGIN.

INSTRUCTIONS: Now I'm going to read you another list of words. Some of them are from the first list I read before, and some of them are from the second list or are new words. If the word is from the first list, I want you to write Y for YES on your answer sheet. If the word is not from the first list, write N for NO on your answer sheet. You will only have time to write a Y or an N because the words will be read very quickly. Remember, do not write YES or NO, just Y or N.

AFTER INSTRUCTION READ, ASK IF ANY QUESTIONS AND ANSWER APPROPRIATELY.

Are there any questions? I will not be able to answer any questions once I start reading. Please do not talk during this test. Ready?

WAIT 10 SECONDS. THEN READ EACH WORD FROM THE **RECOGNITION WORD LIST**. USING A TIMER, PAUSE 2 SECONDS BETWEEN EACH WORD TO GIVE SUBJECTS ENOUGH TIME TO WRITE Y OR N IN THE BOXES ON THE ANSWER SHEET MARKED **AVLT-A7**.

RECORD 'TIME TEST BEGAN' IN THE TESTER'S RECORD BOOK.

#### **RECOGNITION WORD LIST**

- |            |              |            |             |             |
|------------|--------------|------------|-------------|-------------|
| 1. NAIL    | 11. ENVELOPE | 21. LADDER | 31. FOOT    | 41. WATER   |
| 2. SAND    | 12. CAR      | 22. MIRROR | 32. BREAD   | 42. JOKER   |
| 3. BED     | 13. FACE     | 23. SCREW  | 33. DESERT  | 43. COAT    |
| 4. PONY    | 14. TOAD     | 24. MUSIC  | 34. STREET  | 44. CAPTAIN |
| 5. JESTER  | 15. SILK     | 25. DISH   | 35. MACHINE | 45. TOOL    |
| 6. MILK    | 16. HILL     | 26. PIE    | 36. HEAD    | 46. FLY     |
| 7. PLATE   | 17. FOREST   | 27. WOOD   | 37. GIRL    | 47. SONG    |
| 8. HEART   | 18. SAILOR   | 28. BALL   | 38. HORSE   | 48. DOLL    |
| 9. JAIL    | 19. DART     | 29. HELMET | 39. SOOT    | 49. STALL   |
| 10. INSECT | 20. ROAD     | 30. STOOL  | 40. LETTER  | 50. SHIELD  |

COLLECT THE AVLT-A7 FORM.

RECORD 'TIME TEST ENDED' IN THE TESTER'S RECORD BOOK.

**ATTACHMENT C**  
**ACTIVE**  
**RIVERMEAD SCRIPT AND DIRECTIONS**

PRESET THE ELECTRIC TIMER TO 3 MINUTES.

HAND EACH SUBJECT A PRELABELED RIVERMEAD STORY - FORM, #615a.

RECORD THE 'TIME INSTRUCTIONS BEGAN' IN THE TESTER'S RECORD BOOK, AND BEGIN.

I am going to read you a passage of about four or five lines. Listen carefully, and when I have finished, write down as much as you can remember. You will have 3 minutes to write down what you can remember about the story you just heard.

We are interested in what you remember about the substance of the story, including both the main ideas and the details. That is, write as much as possible, but it is not necessary to reproduce the story word for word.

You may use your own words, those in the story, or both. Try to write as clearly as possible, but don't worry about minor spelling and punctuation errors.

Remember you will have 3 minutes to write. Also remember that we are interested in what you can remember about the substance of the story rather than whether you can recall it word for word.

Ready? Here's the story.

WAIT 5 SECONDS AND BEGIN READING THE STORY:

Two hundred men at a shipyard in New Jersey went on strike this morning. The men walked out over a dispute concerning fifty lay-offs. The shop steward Mr. Thomas Lindsay told reporters 'It is outrageous! The Company has full order-books for the next two years'. A management spokesperson said 'We are hoping to begin fresh negotiations at main office tomorrow'.

Now turn to the lined page and write down as much of the story as you can.

START TIMER. RECORD THE 'TIME TEST BEGAN' IN THE TESTER'S RECORD BOOK.

AT THE END OF 3 MINUTES SAY: *Stop!*

RECORD 'TIME TEST ENDED' IN THE TESTER'S RECORD BOOK.

# ACTIVE

## Question By Question Specification Guide For Administration of The Group Assessment

### I. Purpose

The Group Assessment battery will assess the subjects' memory and reasoning skills. The results of the tests in the group battery will be compared over time to assess changes in the subjects' abilities in completing the measures to evaluate the effectiveness of the ACTIVE interventions.

### II. Study Sample and Administration

Ideally, the Group Assessment measurements will be completed on all subjects after the Individual Assessment measures are completed. One ACTIVE Tester should complete the Group Assessment with 2-5 subjects in a group session. A Group Assessment will be administered to subjects at the 10<sup>th</sup> Year Post-Test visit.

In general, the tests in the Group Assessment session are the same throughout the ACTIVE study. Exceptions include:

1. Unique AVLTL Word Lists will be used for each study visit.
2. A unique Rivermead Story will be used for each study visit.

### III. Administration Protocol

#### A. Materials

For each subject in the group session, the tester should prepare the following forms in advance of the session:

- 1) AVLTL Subject Data Forms packet #611a with ID labels attached to all pages.
- 2) AVLTL Word List Coding Form #611 with ID label attached. (NOTE: a unique AVLTL Word List Coding Form will be used for this study visit)
- 3) Letter Series Form #612 with ID label attached
- 4) AVLTL Recognition Form #613 with ID label attached.
- 5) Letter Sets Form #614 with ID label attached
- 6) Rivermead Story Form #615a with ID label attached. (NOTE: a unique Rivermead Story Form will be used for this study visit)
- 7) Vocabulary Form #616 with ID label attached
- 8) EPT Form #617 with ID label attached
- 9) Medication Audit Form #618 with ID label attached

- 10) AVLT Coding Form #619 (Intrusion & Perseveration Errors) complete by certified scorer.
- 11) Rivermead Scoring Form #615 completed by certified scorer.

One of each of the following should be prepared in advance of the Group Assessment:

- 12) A Tester Record Book Form #6
- 13) A Group Assessment Scripts Form #6a
- 14) An AVLT Word List and Rivermead Story Administration Audiotape  
A **unique** audiotape will be used for this study visit. Each audiotape will be clearly labeled with the study visit name on the jacket, e.g. '10<sup>th</sup> Year 07/08'. Testers must be certain to have the correct audiotape for the planned session prior to the start of the group assessment.

#### Equipment

- electronic timer
- clock with digital display
- rulers or 5x8 cards for each subject
- pencils for subjects
- Sony Boom Box Model CFS-B15
- AVLT & Rivermead Audiotape prescribed for the Visit

#### **B. Preparation**

1. Testers must successfully complete all requirements for Certification as an ACTIVE Tester.
2. Ideally, all Group Measurements can be completed at a large table setting with up to five subjects. The room must allow for a private and confidential setting for test completion with minimal background noise.
3. In advance of the session, testers should assemble the subjects' packets with all forms necessary for completion of the Group Measurements. All forms should be pre-labeled with subject ID labels.
4. Prior to the start of the session, the tester should set up and test equipment to be sure that all are in proper working order, including the electronic timer, clock with digital display, tape playing machine, AVLT and Rivermead audiocassette, and subject supplies. Spare batteries should be carried for all battery operated equipment.

### C. Order of Administration

The ACTIVE Steering Committee has prescribed the order of administration for the tests included in the Group Assessment Battery. The order is:

ORDER	TEST NAME
1	AVLT Word List
2	Letter Series
3	AVLT Recognition
4	Letter Sets
5	Rivermead Story
	BREAK POINT
6	Vocabulary
7	EPT
8	Medication Audit

Tester must follow this order exactly. Ideally, the assessment can be completed in one session. A break must be offered after the completion of the Rivermead Story. It can take 45-50 minutes to complete the remainder of the assessment, so subjects should be encouraged to take even a small break to avoid a break at a later point in the battery. If for any reason the tester feels a subject cannot complete the assessment in one session, the session should be stopped for that subject at the break point. The CC should also be informed of the alteration in administration.

## IV. Test by Test Review

### A. Section A Identifying Information

All test forms have a Section A. Most items in Section A should be completed by the ACTIVE tester prior to the start of the Group measurement.

Subject ID: Affix the subject's study ID labels to all the forms in the space provided. Do not hand write the ID number. Double check the ID number against the subject's visit control sheet.

Visit #: A Group Assessment will be completed at all 10<sup>th</sup> Year Post-Test visits (GP10). A visit # code must be identified for all data forms completed. Sometimes the visit # is a pre-coded data field, sometimes testers must circle the appropriate code. Each visit is assigned an alpha and a numeric code **GP10**. Be sure to circle or code the correct visit number on all forms.

Form Version: Be sure the form version on the form matches the current approved version.

Tester/Scorers ID#/Initials: Write in your assigned tester ID# or initials.

Date completed: Write in the date the measure is completed. If the measures are completed in more than one day, use the date the measures were completed. Record the date as month, day and year. Record 4 digits for the year, e.g., 2008. Do not leave blank spaces; use leading zeros as required.

Scheduled Start Time: Scheduled Start Time of the group session is recorded on the Tester's Record Book in A5. Record the time just prior to the start of the General Introduction (Scripts Book, page 3).

Time completed: Time completed is required on the EPT data form. Record the time each subject completes their EPT in the space provided in Section A of Form #617.

## **B. AVLT (Rey Auditory Verbal Learning Test) (Form #611a)**

### **1. Description**

This test is a measure of the subject's ability to form and retain new verbal memories by counting the numbers of words recalled across five trials. Unique AVLT Word Lists will be used at each study visit.

### **2. Materials / Equipment Needed**

- Electronic timer
- Sony Boom Box Model CFS-B15
- The AVLT audiotape with Instructions and Word Lists prescribed for the visit.
- AVLT Subject Data Forms Packet #611a with ID labels attached.
- Group Assessment Scripts Form #6a
- Pencils for subjects' use

### **3. Administration**

The instructions for this task have been audiotaped for standardization in administration across sites. Be certain to use the AVLT audiotape prescribed for the visit. In the event of an audiotape or tape player failure, the tester should administer the test using the Instructions provided in Attachment A of the Group Assessment Script (Form #6a). Seven trials will be conducted. This is a timed test. Before you begin, pre-set the electronic timer at 2 minutes (120 seconds). Stop each trial precisely after 2 minutes.

If there is a mechanical failure during one of the recall trials, stop the tape player and resume test administration by reading the script. Start the trial during which the problem occurred at the beginning of the trial. It is not necessary to go back to Trial 1.

In situations where interruptions occur that might interfere with hearing the tape or concentration (e.g., a fire drill; someone entering the testing room; loud noise lasting more than a few seconds), rewind the tape to the beginning of the word list. If interruption occurs during the instructions, rewind and replay the instructions in their entirety. Describe the interruption on the VCS.

### **2. Coding**

Coding for this test will be completed after the Group Session. Tester should use AVLT Coding Form #611. One AVLT Coding form will be required for each subject. (NOTE: A different AVLT Word List Coding Form will be used for each study visit. Although the form number will remain the same, the title, version date and the Word List will be different for each study visit. Testers should be sure to use the proper form.)

For each word on Word List A and Word List B, code 1 (yes) if the subject wrote (recalled) the word. Code 2 (no) if the subject did not write (recall) the word. Total scores will be calculated by the computer.

More complete scoring rules are provided in the ACTIVE Scoring Manual for the AVLT.

## C. Letter Series Test (Form #612)

### 1. Description

This is a test of inductive reasoning in which subjects view a set of letters and determine which letter comes next in the series. The test is timed. Subjects are allowed 6 minutes to complete the test.

### 2. Materials / Equipment Needed

- Electronic timer
- A Letter Series Form #612
- Group Assessment Scripts Form #6a
- Pencils for subjects' use
- Ruler or Index Cards

### 3. Administration

Pre-set the electronic timer to 6 minutes. Give the subjects the pre-labeled data form (#612) titled "Letter Series". Six examples are provided to familiarize the subject with the test. Use the script in Form #6a to read the instructions for each example and to explain the examples. Use your voice to emphasize the pattern in the example series. Explain each example no more than twice. Tell the subjects they may use a ruler or index card to hold their place on the page. Next, read the instructions at the bottom of the page. Answer any questions. Remind subjects to answer every problem and to skip hard problems and return to them if they have time.

Tell subjects to turn the page and start the timer. Allow precisely 6-minutes for the test. If you notice a subject on problem 1-3 at 3 minutes, encourage her/him to move on to the next problem.

At the end of 6 minutes say: *stop*.



## **D. AVLT Recognition Test (Form #613)**

### **1. Description**

The AVLT Recognition Task is the second part of the Rey Auditory Verbal Learning Test (AVLT) conducted earlier in the group assessment. It is a test of new verbal learning and memory.

### **2. Materials / Equipment Needed**

- Sony Boom Box Model CFS-B15
- The AVLT Audiotape with Instructions and Word List prescribed for the visit
- AVLT Recognition Form #613 with ID labels attached. (NOTE: the same AVLT Recognition Form (#613) will be used for all study visits.)
- Group Assessment Scripts Form #6a
- Pencils for subjects' use

### **3. Administration**

For the AVLT Recognition Task, subjects are read a list of 50 words and asked to indicate if the word is from the first list or not by marking Y for yes or N for no. This test is administered using an audiotape; it is not a timed test.

If there is a mechanical failure during the Recognition Test, continue the test from that point using the instructions provided in Attachment B of the Group Assessment Group Scripts (Form #6a). For example, if the tape breaks at word #15, continue the test starting with word #15. Do not go back to the beginning of the test.

In situations where interruptions occur that might interfere with hearing the tape or concentration (e.g., a fire drill; someone entering the testing room; loud noise lasting more than a few seconds), rewind the tape to the beginning of the word list. If interruption occurs during the instructions, rewind and replay the instructions in their entirety. Describe the interruption on the VCS.

### **4. Coding and Scoring**

Subjects' responses are data entered directly into the ACTIVE DMS. No tester coding is required. The total scores for the Recognition trial will be calculated by the computer.

More complete scoring rules are provided in the ACTIVE Scoring Manual for the AVLT.

## **E. Letter Sets (Form #614)**

### **1. Description**

The Letter Sets Test is a test of the subjects' inductive reasoning, specifically of their ability to find rules or patterns in sets of letters. The test is timed. The subject is allowed 7 minutes to complete the test.

### **2. Materials / Equipment Needed**

- Electronic timer
- Letter Sets Form #614
- Group Assessment Scripts Form #6a
- Pencils for subjects' use
- Ruler or Index Cards

### **3. Administration**

Pre-set the electronic timer to 7 minutes. Give the subjects the pre-labeled data form (#614) titled "Letter Sets." Follow the script in Form #6a. Three examples are provided to familiarize the subjects with the test. Read the instructions and point to Example A. Read the explanation of Example A. Tell the subjects to try Examples B and C. Explain each example no more than twice. Tell the subjects they may use a ruler or index card to hold their place on the page. Then, using the prepared text, explain both examples. Use your voice to emphasize the pattern. In explaining Example C, the tester should say the letter sets aloud emphasizing the skipped letter(s). BCD (E) FGH (I)J KLM (NO) P NOP(Q)R STU(V)W.

Next read the instructions at the bottom of the page. Answer any questions. Remind subjects to answer every problem and to skip hard problems and return to them if they have time. Tell subjects to turn the page and start the timer. Allow precisely 7 minutes for the test.

Do not coach the subjects once the test begins. If a subject asks for help, say: "*do the best you can.*" If you notice that a subject is only on problems 1-3 halfway through the test (i.e., at 3 ½ minutes), encourage her/him to move on to the next problems.

At the end of 7 minutes say: *stop*.

## **F. Rivermead Behavioral Memory Test (Form #615a)**

### **1. Description**

This is a test of a subject's ability to remember a brief story.

### **2. Materials / Equipment Needed**

- Sony Boom Box Model CFS-B15
- The Rivermead Audiotape with Instructions and Story prescribed for the visit
- Rivermead Story Form #615a with ID labels attached.
- Group Assessment Scripts Form #6a
- Pencils for subjects' use

### **3. Administration**

Pre-set the electronic timer to 3 minutes. Give the subjects the appropriate Rivermead Story Form #615a. This test is administered by audiotape. Start the tape to play the instructions then pause the tape after the instructions before the story begins. Ask if the subjects are ready to begin, and then start the tape again to play the Story. When the Story is finished, stop the tape and tell the subjects to begin writing when you say 'start'. Begin timing with "start". Stop the subjects precisely at 3 minutes.

In the case of mechanical failure, follow the instructions provided in Attachment C of the Group Assessment Scripts (Form 6a) to administer the test. If this happens, start the test over from the beginning.

In situations where interruptions occur that might interfere with hearing the tape or concentration (e.g., a fire drill; someone entering the testing room; loud noise lasting more than a few seconds), rewind the tape to the beginning of the story. If interruption occurs during the instructions, rewind and replay the instructions in their entirety. Describe the interruption on the VCS.

## **G. Break Point**

### **1. Description**

The intent of the 'break point' protocol is to standardize, study-wide, the points at which subjects are refreshed for the testing tasks in the batteries.

### **2. Administration**

Always use the standardized break point to offer the subjects a brief break to stretch, relax, get a drink of water, go to the bathroom, etc. A break must be offered after the completion of Rivermead. It can take 45-50 minutes to complete the remainder of the assessment, so subjects should be encouraged to take even a small break to avoid a break at a later point in the battery. If for any reason, the tester feels a subject cannot complete the assessment in a single session, the session should be stopped at the break point for that subject.

### **3. Coding**

All break point information should be coded in the Testers Record Book Form #6, Section C.

## **H. Vocabulary Test (Form #616)**

### 1. Description

This is a test of general knowledge in which subjects are asked to select a word with a meaning similar to an identified word. This is a timed test. Subjects are allowed 4 minutes to complete the test.

### 2. Materials / Equipment Needed

- Electronic timer
- Group Assessment Scripts Form #6a
- Pencils for subjects' use
- Ruler or Index Cards

### 3. Administration

Pre-set the electronic timer to 4 minutes. Give the subjects the pre-labeled data forms (#616) titled "Vocabulary." Follow the script in Form #6a. Three examples are provided to familiarize the subject with the test. Read the instructions and point to Example 1. Review Example 1 with the subjects, then tell the subjects to work Examples 2 and 3 on their own. After the subjects have completed Examples 2 and 3, review them together. Tell the subjects they may use a ruler or index card to hold their place on the page. This is a timed test. Tell the subjects to turn the page and start the timer. Allow precisely 4 minutes for completion.

At the end of 4 minutes say: *stop*.

## **I. EPT (Everyday Problems Test) (Form #617)**

### **1. Description**

The Everyday Problems Test (EPT) is an assessment of an older adult's ability to solve problems related to tasks that many elderly encounter in their daily lives. Seven domains of daily activities have been identified as important for living independently in our society. This questionnaire examines the elder's ability to solve problems associated with each domain. The domains are: ability to take medications and carry out common health practices; ability to prepare meals and maintain adequate nutrition; ability to use the phone; ability to shop for necessities; ability to manage one's finances; ability to manage one's household; ability to use transportation.

The older adult is shown printed material related to the task (e.g., medicine bottle label) and asked to answer two questions related to the material. The adult must write a brief answer to each of the questions on the lines below the question.

The test stimuli are taken from "real life" material that the elderly may experience in their daily lives, including phone bills, medicine bottle labels, and nutrition information from a box of cereal.

### **2. Materials / Equipment Needed**

- EPT Form # 617
- Pencils for subject's use
- Clock with digital display

### **3. Administration**

Give the subjects the pre-labeled packet titled "Everyday Problems Test" Form #617 and ask the subjects to turn to page one. Follow the script in Form #6a. The responses to commonly asked questions can be found at the end of the script for EPT in Form #6a.

This test is not a timed. However, we are interested in knowing how long it takes for each subject to complete the test. Record the time each subject finishes their test in A6 on the cover of their EPT Form #617.

## J. Medication Audit (Form #618)

### 1. Description

Medications may improve or hamper some activities. The objective is to obtain a listing of all medications, including name, dose, route, and frequency.

### 2. Materials / Equipment Needed

- Medication Audit Form #618
- Paper bags / sacks

### 3. Administration

Testers should complete a Medication Audit for each subject while the subjects are completing the EPT. If the subject brings the medicine bottles to you, be very careful to keep the bottles in a separate sack or container so they are not lost or mixed with others. It would be good to write the subject's name on the paper bag or container. At the time of receiving the bag of medications, be sure to ask the subject if these medications are all current. That is "Are you still taking all of these medicines or have you stopped taking some of them?" If they have stopped taking some, those medications should not be recorded. Also include any over-the-counter medications that a subject says that a doctor has told them to take on a regular basis; e.g., Motrin or ibuprofen for arthritis.

The information is to be taken from the labels on the bottles. SPELL MEDICATION NAME EXACTLY AS YOU SEE WRITTEN ON THE LABEL. CHECK THE SPELLING TWICE, as the spelling of generic drug names can be difficult. To save time, this can be done for most subjects while they are taking the EPT. Some bottles will be labeled "as needed". It will be necessary later to ask the subject, "How often do you take this medicine?" They will frequently answer, "Whenever I need to." This can be followed by your asking, "How often do you need to take this medicine?"

### **Attachments A, B & C:**

- A** A list of common medications for reference
- B** An example of prescription labels used to complete Attachment C
- C** A complete *sample* of a Medication Audit Form #618

### 4. Specific recording instructions:

1. The **general rule** is to record as much information as possible, and the most detailed level of information that you can. For example, if you have the following information:

Tylenol 325 mg. Take 2 tablets every 4 hours as needed for pain.

You have the exact dosage (e.g., 325 mg) AND take "2 tabs."

Record the more specific information possible – 325 mg – rather than the 2 tabs.

## 2. Units

Below is a list of unit dosages and their abbreviations:

UNIT	ABBREVIATION
milligrams	<b>mg</b>
units	<b>units</b>
micrograms	<b>mcg</b>
milliliters	<b>ml</b>
grams	<b>grams</b>
centimeters	<b>cm</b>
teaspoon	<b>tsp</b>
tablespoon	<b>tbl</b>
drops	<b>drops</b>
dropperful	<b>dropper</b>
tablets	<b>tab</b>
applicator	<b>app</b>
suppository	<b>supp</b>
puffs	<b>puffs</b>
sprays	<b>sprays</b>

## 3. Route

ROUTE	ABBREVIATION	COMMENTS
Oral	O	Circle the appropriate designation for these codes
Patch	P	
Injection	I	
Inhalation	Inh	
Eye drops	Eye	
Ear drops	<b>ear</b>	For these routes, write “see comments” in the route space, and write in the appropriate word in the comments section
Nasal sprays	<b>nasal</b>	
Rectal	<b>rectal</b>	
Vaginal	<b>vaginal</b>	

## 4. Times & Frequency

- Every other day – record as .5 per day
- Every 6-8 hours – record the maximum dose possible.  
Every 6 hours = 4 times per day; every 8 hours = 3 times per day  
Record 4 times/day.
- Every other week – record as 14 days per month
- Take for 28 days per month – record as 1 per day, but write in the comments section “takes 28 days per month”



## **K. Tester's Record Book (Form #6)**

### **1. Description**

The primary purpose of the Testers' Record Book (Form # 6) is to provide a data form to record the time it takes to administer each of the tests in the Group Assessment battery. One form is completed for each Group Assessment session. For accuracy, testers should use a clock with a digital display.

### **2. Materials / Equipment Needed**

- clock with digital display
- Testers Record Book Form #6

### **3. Section by Section Review**

#### **Section A: Identifying Information**

Site Code: Site code is required on the Tester's Record Book. Please record the 2 digit, site specific code in the space provided.

01	UAB
02	IU
03	HSL
04	JHU
05	WSU
06	PSU

Scheduled Start Time: Scheduled Start Time is required on the Tester's Record Book. Record the time the session started in the field provided. Record the time just prior to the start of the General Introduction (Scripts Book, page 3).

#### **Section B: Record of Timed Tests**

This section is for recording the timing of each of the tests in the battery. For each of the tests completed by the subjects, testers must record the following information:

- The time they begin the instructions for the test;
- The time the actual timed testing begins (e.g. the time the tester starts the 6 minute timer for the Letter Series tests)
- The time the timed testing ends

For the EPT 'time test ends', the tester should record the time the last subject completes the EPT.

### **Section C: Break Point**

This section is for recording information about the break point.

C1. Indicate in this item whether or not a second session was required to complete this assessment.

C1a. If a second session is required, record the end time of session 1 in 1a. Record the time you complete Rivermead. Use a 12 hour clock; circle **AM** or **PM** as appropriate.

C1b. Record the date Session 1 was conducted. Record the date as month, day and year. Note the year must be recorded as a four digit number; e.g., 2008. Do not leave blank spaces; use leading zeroes as required.

C1c. Record the start time for session 2.

### **Section D: Tester's Feedback**

This section is for tester's feedback on the subjects' overall performance and comfort during the Group Assessment session.

### **Section E: Environmental Conditions**

This section is for tester's report of the environmental conditions of the room in which the testing was conducted.

**ATTACHMENT A**  
**Standardized Drug Names**

ACCUPRIL	CYCLOBENZAPRINE HCL
ACETAMINOPHEN	CYTOTEC
ACTIGALL	DARVOCET
ADALAT	DAYPRO
AEROBID	DEMADEX
ALBUTEROL	DIAZEPAM
ALDACTAZIDE	DILACOR
ALDORIL	DILANTIN
ALLEGRA	DIMETAPP
ALLOPURINOL	DIOVAN
ALOMIDE	DIPYRIDAMOLE
AMBIEN	DITROPAN
AMILORIDE HCL	DOCUSATE SODIUM
AMITRIPTYLINE	DYAZIDE
AMITRIPTYLINE HCL	DYNACIRC
ANTIVERT	ECOTRIN
ASPIRIN	ERYTHROMYCIN
ATENOLOL	ESTRADIOL
ATIVAN	ESTROGEN
ATROVENT	FERROUS SULFATE
AXID	FLONASE
BELLADONNA W/PHENOB	FLOVENT
BENAZEPRIL HCL	FLUPHENAZINE HCL
BETAGAN	FUROSEMIDE
BETOPTIC	GEMFIBROZIL
BUSPAR	GLIPIZIDE
CALAN SR	GLUCOPHAGE
CALCIUM	GLUCOTROL
CAPTOPRIL	GLYBURIDE
CARDIZEM	GLYNASE
CARDURA	HUMULIN
CHLORDIAZEPOXIDE	HYDROCHLOROTHIAZIDE
CHLORPROPAMIDE	HYDROXYZINE
CHLORTHALIDONE	HYDROXYZINE HCL
CHLORZOXAZONE	HYTRIN
CHOLINE MAGNESIUM TRISALICYLAT	IBUPROFEN
CIMETIDINE	INDAPAMIDE
CLARITIN	INDERAL
CLONAZEPAM	INDOCIN
CLONIDINE HCL	INDOMETHACIN
COLCHICINE	INSULIN REGULAR
COREG	INSULIN LENTE
COUMADIN	INSULIN NPH
COVERA-HS	INSULIN
COZAAR	IPRATROPIUM BROMIDE
	ISOPTIN

## **ATTACHMENT A (cont.)**

ISORDIL  
ISOSORBIDE DINITRATE  
K-TAB  
KLONOPIN  
KLOTRIX  
LACTULOSE  
LANOXIN  
LASIX  
LESCOL  
LEVOTHYROXINE SODIUM  
LEVOXINE  
LEVSINEX  
LIPITOR  
LISINOPRIL  
LODINE XL  
LOMOTIL  
LOPID  
LOPRESSOR  
LORAZEPAM  
LOTREL  
LOZOL  
MAXZIDE  
MECLIZINE  
MECLIZINE HCL  
MEDROXYPROGESTERONE  
METHOCARBAMOL  
METHYLDOPA  
METHYLPHENIDATE HCL  
METOPROLOL  
METOPROLOL TARTRATE  
MEVACOR  
MEXITIL  
MIACALCIN  
MICRO-K  
MICRONASE  
MODURETIC  
MONOPRIL  
MULTIGENICS  
MULTIVITAMIN  
MYLANTA  
NAPROSYN  
NAPROXEN  
NEPHROCAPS  
NITROGLYCERIN  
NITROSTAT  
NORVASC

OCUVITE  
OMEPRAZOLE  
OS-CAL  
OXYBUTYNIN CHLORIDE  
PAXIL  
PENICILLIN  
PEPCID  
PERSANTINE  
PHENOBARBITAL  
PILOCARPINE  
PLENDIL  
POTASSIUM CHLORIDE  
PRAVACHOL  
PRAVASTATIN SODIUM  
PREDNISONE  
PREMARIN  
PREMPRO  
PRILOSEC  
PRINIVIL  
PRINZIDE  
PROCAN  
PROCARDIA  
PROLIXIN  
PROPRANOLOL  
PROPULSID  
PROVENTIL  
PROVERA  
QUINIDINE GLUCONATE  
QUININE  
QUININE SULFATE  
RANITIDINE HCL  
REGLAN  
RELAFEN  
RHINOCORT  
SALACID  
SELDANE  
SPIRONOLACTONE  
SULFAMETH/TRIMETHOPRIM  
SULFAMETHOXAZOLE  
SULFASALAZINE  
SULINDAC  
SYNTHROID  
TAGAMET  
TAMBOCOR  
TAPAZOLE  
TEGRETOL

## **ATTACHMENT A (cont.)**

TENORETIC  
TENORMIN  
THEO-DUR  
THEOPHYLLINE  
TICLID  
TIMOLOL MALEATE  
TOLECTIN  
TOPROL XL  
TRAZODONE HCL  
TRENTAL  
TRIAMTERENE  
TRIHENYDYPHENIDYL HCL  
TRUSOPT  
ULTRAM  
UNIVASC  
VANCENASE  
VANCERIL  
VASOTEC  
VERAPAMIL  
VITAMIN B  
VITAMIN B COMPLEX  
VITAMIN C  
VITAMIN E  
VOLTAREN  
WYGESIC  
XALATAN  
XANAX  
ZANTAC  
ZESTORETIC  
ZESTRIL  
ZIAC  
ZOCOR  
ZOLOFT  
ZYRTEC

## ATTACHMENT B

<b>Rx# 556144 DR. Smith</b> <b>NAME:</b> Active Participant  Take one tablet per day with breakfast.  Coumadin 10 mg <b>No Refills</b>	<b>Rx# 556145 DR. Smith</b> <b>NAME:</b> Active Participant  Inject 10 units every morning and 5 units every evening  Insulin <b>No Refills</b>	<b>Rx# 556146 DR. Smith</b> <b>Name:</b> Active Participant  Take 1 suppository every 12 hours as needed for nausea & vomiting.  Compazine 5 mg. <b>No refills</b>
<b>Rx# 556147 DR. Smith</b> <b>NAME:</b> Active Participant  Inhale .5 ml (combined with one ampule cromolyn sulfate) 4 times a day as needed  Ventolin .5 mg/1 ml <b>No Refills</b>	<b>Rx# 556148 DR. Smith</b> <b>NAME:</b> Active Participant  Apply one patch each morning.  Nitrodur 10 cm <b>No Refills</b>	<b>Rx # 556149 DR. Smith</b> <b>NAME:</b> Active Participant  Take 2 sprays in each nostril daily as needed for nasal congestion or allergy symptoms. Nasacort AQ <b>No Refills</b>
<b>Rx# 556150 DR. Smith</b> <b>NAME:</b> Active Participant  Instill two drops daily into right eye.  Betoptic <b>No Refills</b>	<b>Rx# 556151 DR. Smith</b> <b>NAME:</b> Active Participant  Take 1 tablet sublingually every two hours, as needed for chest pain.  Nitroglycerine .4 mg <b>No Refills</b>	<b>Rx # 556152 DR. Smith</b> <b>NAME:</b> Active Participant  Insert one applicator (2 grams) daily for 3 weeks per month, none for one week; then repeat schedule. Premarin Vaginal Cream <b>No Refills</b>
<b>Rx# 556153 DR. Smith</b> <b>NAME:</b> Active Participant  Instill one dropperful into left ear every 2-4 hours as needed for pain.  Tympagesic Otic Solution <b>No Refills</b>	<b>Rx# 556154 DR. Smith</b> <b>NAME:</b> Active Participant  Take one tablet daily.  Berocca Plus <b>No Refills</b>	<b>Rx# 556155 DR. Smith</b> <b>NAME:</b> Active Participant  Take 2 tabs twice daily for 2 days, then take 2 tabs once daily for 3 days, then take 1 tab daily for 5 days Sterapred 5mg <b>No Refills</b>

## ATTACHMENT C

Copy the name of the PRESCRIBED medicine, the strength in milligrams (mg) or other unit dose, and the total number of doses prescribed per day, per week, or per month. Circle a Route, Frequency, and As Needed for each medicine listed. Include pills, dermal patches, eye and ear drops, inhalants, nasal sprays, suppositories, vaginal cream and injections. Skin creams or salves can be excluded.

	Medication (Print name clearly)	Dose	Units	Route (Oral, Patch, Injection, Inhalation, Eye drops)	Times	Freq	As needed	Comments
B2	<i>Coumadin</i>	<i>10</i>	<i>mg</i>	<input checked="" type="radio"/> O <input type="radio"/> P <input type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye	<i>1</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input type="radio"/> Y <input checked="" type="radio"/> N	
B3	<i>Insulin</i>	<i>10</i>	<i>units</i>	<input type="radio"/> O <input type="radio"/> P <input checked="" type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye	<i>1</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input type="radio"/> Y <input checked="" type="radio"/> N	<i>a.m.</i>
B4	<i>Insulin</i>	<i>5</i>	<i>units</i>	<input type="radio"/> O <input type="radio"/> P <input checked="" type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye	<i>1</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input type="radio"/> Y <input checked="" type="radio"/> N	<i>p.m.</i>
B5	<i>Ventolin</i>	<i>0.5</i>	<i>ml</i>	<input type="radio"/> O <input type="radio"/> P <input type="radio"/> I <input checked="" type="radio"/> Inh <input type="radio"/> Eye	<i>4</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input checked="" type="radio"/> Y <input type="radio"/> N	<i>not taken last month</i>
B6	<i>Nitrodur</i>	<i>10</i>	<i>cm</i>	<input type="radio"/> O <input checked="" type="radio"/> P <input type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye	<i>1</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input type="radio"/> Y <input checked="" type="radio"/> N	
B7	<i>Betoptic</i>	<i>2</i>	<i>drops</i>	<input type="radio"/> O <input type="radio"/> P <input type="radio"/> I <input type="radio"/> Inh <input checked="" type="radio"/> Eye	<i>1</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input type="radio"/> Y <input checked="" type="radio"/> N	<i>right eye only</i>
B8	<i>Nitroglycerine</i>	<i>0.4</i>	<i>mg</i>	<input checked="" type="radio"/> O <input type="radio"/> P <input type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye	<i>12</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input checked="" type="radio"/> Y <input type="radio"/> N	<i>every 2 hours sublingually, for chest pain</i>
B9	<i>Tympanesic</i>	<i>1</i>	<i>dropper</i>	<input type="radio"/> O <input type="radio"/> P <input type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye <i>See comments</i>	<i>12</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input checked="" type="radio"/> Y <input type="radio"/> N	<i>Ear, left ear for pain</i>
B10	<i>Berocca Plus</i>	<i>1</i>	<i>tab</i>	<input checked="" type="radio"/> O <input type="radio"/> P <input type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye	<i>1</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input type="radio"/> Y <input type="radio"/> N	
B11	<i>Compazine</i>	<i>5</i>	<i>mg</i>	<input type="radio"/> O <input type="radio"/> P <input type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye <i>See comments</i>	<i>2</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input checked="" type="radio"/> Y <input type="radio"/> N	<i>rectal</i>
B12	<i>Nasacort AQ</i>	<i>2</i>	<i>sprays</i>	<input type="radio"/> O <input type="radio"/> P <input type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye <i>See comments</i>	<i>1</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input type="radio"/> Y <input type="radio"/> N	<i>nasal</i>
B13	<i>Premarin</i>	<i>2</i>	<i>grams</i>	<input type="radio"/> O <input type="radio"/> P <input type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye <i>See comments</i>	<i>21</i>	<input type="radio"/> D <input type="radio"/> W <input checked="" type="radio"/> M	<input type="radio"/> Y <input type="radio"/> N	<i>vaginal, take for 3 weeks, then none for 1 week</i>
B14	<i>Sterapred</i>	<i>5</i>	<i>mg</i>	<input checked="" type="radio"/> O <input type="radio"/> P <input type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye	<i>4</i>	<input checked="" type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input type="radio"/> Y <input checked="" type="radio"/> N	<i>take 2 tabs twice daily for 2 days, then 2 tabs daily for 3 days, then 1 tab daily for 5 days</i>
B15				<input type="radio"/> O <input type="radio"/> P <input type="radio"/> I <input type="radio"/> Inh <input type="radio"/> Eye		<input type="radio"/> D <input type="radio"/> W <input type="radio"/> M	<input type="radio"/> Y <input type="radio"/> N	





# ACTIVE

## Question by Question Specifications Guide for Administration of the Abbreviated Testing Batteries for the 10<sup>th</sup> Year Post-Test Measurements

### I. Purpose

At the time of enrollment, ACTIVE study participants are 65 years of age or older, living in non-institutionalized settings but at risk of loss of functional independence. Because of the potential for a change in health status, functional status or residence, it is prudent to prepare for the possibility of follow-up testing with disabled/institutionalized participants or participants who re-locate prior to completion of the study protocol.

In anticipation of these possibilities, ACTIVE Investigators have developed a two-tiered Abbreviated Testing Battery that can be used at the time of this post-test visit.

### II. Overview

When a participant cannot/will not agree to full participation at the time of an study assessment, the Field Site Staff must determine which measures, if any, can be completed. To allow for appropriate planning, Testers must first gather as much information as possible about the participant's current situation. A standardized Testers' Guide is provided here as Attachment A. Field Sites' senior staff (i.e. Principal Investigator, Site Coordinator or Designated Specialist) will use this information to determine the most appropriate plan for the follow-up visit.

In some instances, special accommodations may be instituted to allow the subject to complete the **full Post-Test Battery**, e.g. transportation may be provided, testing may be conducted in the participant's home, etc. In other cases, an abbreviated testing protocol will be required to conduct as many follow-up measurements as possible.

A two tier abbreviated testing protocol has been designed. Measures included in **Level I** (the minimal data set) can be administered in approximately 75 minutes either in-person or as a telephone interview. Level I tests include the MDS-HC, Mobility Questionnaire (Mobility, Life Space, Falls), Driving Habits, Health Conditions, Health Services Utilization, SF-36, Medication Audit and the EPT.

The **Level II** battery includes all Level I measures and the AVL T Recall, Letter Series, AVL T Recognition, MMSE, Timed IADL and UFOV. It takes approximately 2 hours and forty-five minutes to complete all Level II measurements, i.e. 75 minutes for Part 1 plus 90 minutes for Part 2. At least two sessions are required, although several sessions may be necessary.

A few of the measures can be completed in a **Proxy Interview**. The following measurements may be completed with a proxy: MDS-HC, Mobility Questionnaire, Driving Habits, Health Conditions and Health Services Utilization and the Medication Audit. It takes approximately 40 minutes to complete the Proxy Interview.

### **III. Eligibility**

When an ACTIVE participant cannot or will not complete a full post-test assessment during the prescribed study visit window, Field Sites will use the Abbreviated Battery protocol to gather a minimal amount of critical outcome data from the participant.

The most common reasons for non-participation include:

- The participant is suffering from a serious or debilitating illness and/or they are institutionalized.
- The participant moved too far away or they are living in another location during the entire study visit window.
- A close family member is suffering from a serious illness, or there has been a major change in an alternate obligation preventing full participation.
- The participant simply refuses to participate stating reason such as, “I just am too busy to continue.”, “It just takes too long.”, “I can’t go through that again.”, “Please don’t ask me to do that again.”, etc.
- A household member reports that the participant has died.

#### **A. Eligibility for completion of the full Post-Test Battery**

To be eligible to participate in the full Post-Test Battery the participant must:

- With special accommodations, be willing/able to complete all the measures in the full Post-Test battery including Individual Parts 1 and 2 and Group. Each session lasts as long as 2 hours. If necessary, sessions can be split per the current protocol. Additional breaks may be added to accommodate a participant with a debilitating condition.
- Have the general physical strength/stamina to tolerate three, 2-hour sessions, or several 1-hour sessions.
- Be capable to complete all measurements in the battery.
  - ✓ Can/will the participant travel to the testing site or can a tester travel to the participant’s home or alternate location?
  - ✓ Can the participant read? Are there changes in the participant’s vision? Changes in comprehension?
  - ✓ Can the participant write? Is there paralysis or significant weakness in dominant hand?

## **B. Eligibility for completion of the Level I Abbreviated Battery**

To be eligible to participate in the **Level I Abbreviated Battery** the participant must:

- Be willing/able to complete a 1-hour interview in-person or on the telephone. The interview can be split into more than one session.
- Have the general physical strength/stamina to tolerate at least a 15-minute telephone interview.
- Be willing/able to complete the EPT either in-person or at home. The EPT takes approximately 15 minutes. A Tester, a proxy or another person may record the participant's responses on the data form if s/he cannot write her/his own responses due to a debilitating condition.
- Be capable to complete the measures in the battery.
  - ✓ Can the participant understand the questions? Are there changes in comprehension?
  - ✓ Can the participant write? Is there paralysis or significant weakness in dominant hand? (An ACTIVE Tester may record the participant's responses on the EPT form.)

## **C. Eligibility for completion of the Level II Abbreviated Battery**

To be eligible to participate in the **Level II Abbreviated Battery** the participant must:

- Be willing/able to complete all measures in the Level I protocol (see above).
- Be willing/able to meet with a Tester in-person to complete Part 2 of the Level II battery. If completed in one session, Part 2 lasts approximately 90 minutes (not including the break) or it can be split into more than one session. A break can be taken after any test in the battery.
- Have the general physical strength/stamina to tolerate a 60 – 90 minute testing session
- Be capable to complete all tests in the battery.
  - ✓ Can/will the participant travel to the testing site or can a tester travel to the participant's home or alternate location?
  - ✓ Can the participant read? Are there changes in the participant's vision? Changes in comprehension?
  - ✓ Can the participant write? Is there paralysis or significant weakness in dominant hand?

## **D. Eligibility for completion of the Proxy Interview**

To be eligible to complete a post-test battery with a **proxy**, the participant must:

- Be too weak to tolerate at least a 15 minute in-person or telephone interview.
- Be too disabled to complete the tests in the Level I battery.
  - ✓ Cannot read? Cannot see? Cannot understand?
  - ✓ Cannot write? Has a paralysis or significant weakness in dominant hand?

#### IV. Administration Protocol

The Abbreviated battery has been divided into two parts to meet both administrative and scientific objectives. All Level I measurements are included in the Part 1 battery. The measures included in Part 1 constitute the minimal data set and must be completed first, in their prescribed order, for both Level I and Level II subjects. The Part 2 battery should always be completed after Part 1 for Level II participants. A description of Parts 1 and 2 of the Abbreviated Battery appears below.

##### A. Form #707 Abbreviated Battery Part 1 (for both Level I and Level II participants)

The Part 1 instrument, **Form #707** has been developed for use in 10<sup>th</sup> Year Post-Test. Part 1 of the Abbreviated Battery is considered the minimal data set. Measurements included in the Part 1 battery should be completed for both Level I and Level II subjects. Ideally, the Part 1 measurements will be conducted during an in-person session, although most can be conducted on the telephone if necessary. The only exception is the EPT, which must be completed as a self-administered measurement at the end of an in-person session or at home with mailed return. In-person testing may be conducted at the established testing site, at the participant's home or at an alternate location. Testing sessions that occur at a health care institution (hospital, nursing home, etc.) may require special authorization from the institution, family member, an appointed guardian, or someone else.

##### 1. Materials / Equipment Needed

The following items should be assembled in advance of the subject's appointment time.

- Alternate Visit Form # 902 with ID labels attached
- Abbreviated Battery, Part 1, 10<sup>th</sup> Year Post-Test, Form #707 with ID label
- Medication Audit Form # 618;
- EPT Form #617 for in-person administration OR EPT Form #717 with a self addressed stamped envelope for take-home or mail-home administration
- Pencils for subject's use

##### 2. Preparation

- a. Only certified ACTIVE Testers are qualified to complete this session.
- b. Ideally, this session will be completed as an in-person interview, but it may be completed as a telephone interview.
- c. An appointment should always be negotiated/established with the participant in advance of the session. If completed in one sitting, the session may take as long as seventy-five minutes including the EPT and a break. It may be completed in two or more sessions.
- d. Inform the participant that you will need to review all of their prescribed medications. Ask them to bring their medications, in their bottles, when they come for the testing session.
- e. In advance of the testing session, the tester should assemble all the forms necessary to complete the battery.

- f. The area selected to complete the interview must allow for the conduct of a private, confidential interview. A flat writing surface must be available to complete the EPT. If completing the interview on the telephone, remind the participant to be seated in a comfortable chair.

3. Order of Administration

The ACTIVE Steering Committee has prescribed the order of test administration for the Abbreviated Battery. The order of administration for the Part 1 battery should be as follows:

- MDS (15 minutes)
- Driving/Life Space/Falls (10 minutes)
- Health Conditions (5 minutes)
- Health Services Utilization (5 minutes)
- SF-36 (10 minutes)
- Medication Audit (10 minutes)
- EPT (15 minutes) (either in-person or as a mailed/take home questionnaire)

Part 1 can be completed in a single session if the participant can tolerate a 1-hour testing session, or it can be split into more than one session at any point in the testing battery. Likewise, a break can occur at the end of any test. Part 1 should last approximately 60 minutes, not including a break or completion of the EPT.

4. Section by Section Review

a. **Section A. Identifying Information for Form # 707, Part 1 of AB,**

- A1.** Study ID: Affix the subject's ID label in the space provided. Do not hand write the ID number. Double-check the ID number against the subject's visit control sheet. Confirm the subject's name at the start of measurement to be sure you are using the correct ID for the subject.
- A2.** Visit #: This item will be precoded with various Visit #'s, e.g. the code for the 10<sup>th</sup> Year Post-Test is Visit # **AB10**. Be sure to circle the visit # that coincides with current annual follow-up.
- A2a.** Level: Code the correct Level of this assessment. The Site PI, Coordinator or Designated Specialist will determine the appropriate Level for the Abbreviated Battery.
- A3.** Form Version: Be sure the form version on the form matches the current approved version. Note the year appears as a 4-digit number.

- A4.** Tester ID/Initials: The Tester's ID should go in this field. In some cases more than one tester may complete the measurements in Part 1. These testers will be identified in each of the respective sections of the forms.
- A5.** Date all measures completed: Write in the date that the last measurement in Part 1 is completed. Record the date as month, day and year. Note the year must be recorded as a four-digit number; e.g., 2008. Do not leave blank spaces; use leading zeros as required.
- A6.** Time started: Record the exact time you begin the General Introduction in A6. Use a 12-hour clock; circle **AM** or **PM** as appropriate.

**b. Sections Preceding Each Measure, Sections B, D, I, L, N, P**

A standard set of questions has been added to the beginning of each of the measures in Part 1 of the Abbreviated Battery. A description of these questions follows here:

- Q1.** Was the measurement completed at this follow-up? If the measurement was completed, code 'yes' and complete the rest of the questions in this section. If the measurement was not completed, code no and skip to the next measurement.
- Q2.** Code the date the measurement was completed. Follow the standardized convention for coding dates described elsewhere.
- Q3.** Indicate the mode of the interview. Only modes allowed for the measure are included in the coding scheme for each respective measure. For example, it is not allowed to complete the EPT as a telephone interview, so telephone interview does not appear as a category for this measure.
- Q4.** Indicate with whom you completed the interview. Only allowable codes are listed for each respective measure. For example, it is not allowed to complete the SF-36 interview with a proxy so the proxy categories do not appear for this measure.
- Q4a.** If a proxy is interviewed for any of the items in the measure, record a proxy code in this data field.
- Q5.** Record the ID/Initials of the Tester who completed the measure.
- Q6.** Record the start time for the measure. Follow the standardized convention for coding times described elsewhere.

**c. Section C: The MDS**

Changes have been made to the procedures for administration of the MDS. The MDS has been revised to incorporate new Activities of Daily Living (ADLs): Locomotion, Transfer, and Toilet. The time frame reference of a seven day period, 24 hours a day and the coding scheme still apply. The “Bathing” section was therefore renumbered after item ‘C2j’. Follow the procedures for administration of the MDS described elsewhere. This measure may be administered to a proxy.

**d. Sections E, F, G and H: Life Space, Falls, and the Driving Questions**

The Mobility Questionnaire is a questionnaire designed to assess the extent of the subject's usual mobility and driving habits. Specifically, the questionnaire assesses:

- a) the range of a person's **life space**
- b) the extent to which they have trouble with **falls**
- c) a person's **driving** habits

The instrument is particularly suited for assessment of these mobility-related behaviors in older individuals. Functional independence and mobility are critical elements of an older person's quality of life and therefore represent important outcome measures.

No changes have been made to these procedures. Follow the procedures for administration of these measures described elsewhere. The Life Space and Falls questions may be administered to a proxy but the Driving Questions may **not** be asked of a **proxy**.

**e. Section J: Health Conditions Questions**

The purpose of questions **J1 (a-p)** is to obtain a listing of chronic diseases that a participant has ever been diagnosed with (by a doctor or a nurse).

**The questions may be administered by proxy.**

The stem question, “Has a doctor/nurse ever told you that you have.:", is specifically worded so that the participant does not make up diagnoses. For example, the participant may have some difficulty seeing and think s/he has cataracts, but if s/he has not been told this by a doctor (nurse or Physician’s Assistant), it should not be coded as ‘Yes’.

**J1q, J1r and J1s.** If the participant answers **YES to J1p**, i.e. cancer(s), then these sub-questions should be asked. The three sub-questions are asked to obtain additional information regarding cancer types and treatments received. The questions allow recording information for up to three cancer types/organs, if currently receiving chemotherapy or radiation treatment and/or if chemotherapy or radiation treatment has ever been received.

Recording sub-questions: For sub-questions J1q-s, enter in the first reported cancer type and then follow the arrows to the end of J1s. Do this for each cancer type listed.

**f. Section K: Health Services Utilization Questions**

The use of health services is an outcome of major interest. The purpose of the questions in this section is to determine the type, amount, and reasons for use by the participant in the last twelve months. In order to help the participants recall the 12 month timeframe, for these questions, testers should have a calendar handy and write out the month+ year prior to sessions.

Changes have been made to the procedures for administration of the Health Services Utilization Questions. Specifically, it has been revised to incorporate ascertainment of participants' Social Security Number, Medicare, Medicaid and Drivers License Numbers. Follow the procedures described elsewhere. These measures may be administered to a proxy.

**g. Sections M: The SF-36 Questions**

Administration of the SF-36 is different in the Abbreviated Battery. In this battery, it is administered as a tester-administered interview. Otherwise, no changes have been made to the questionnaire. It should **not** be administered to a **proxy**.

**h. Section O: The Medication Audit**

No changes have been made to the procedures for administration of the Medication Audit. Follow the procedures described elsewhere. The Medication Audit may be administered to a proxy. As per protocol, Tester should use ACTIVE Form # 618 to complete this measure.

**i. Section Q: The EPT**

For the Abbreviated Battery, the EPT may be taken home or mailed to the participant's home to be completed independently. Ideally, it will be completed during an in-person session. It should not be administered to a proxy. Testers should have the participant use Form # 617 for in-person administration of the EPT. Form, #717, has been developed for use when the EPT is sent home with the participant or mailed to the participant's home and completed independently. In addition, it is permissible for the participant to receive physical assistance in recording responses to the questions in the EPT. Such assistance may be required for participants who otherwise may be unable to write their responses due to limited physical strength or stamina or limited motor control secondary to a paralysis or paresis.

The following changes were made in previous annual visits to the EPT form # 717 for use in independent or at-home administration.



Section A was formatted to capture the ID/Initials of the person who distributes the form, the date of distribution and the date the form was returned.

- A written introduction to Participants has been added and appears as page 2.
- Participants are asked to record the date & time they start the test, items A8 & 9
- Participants are asked to record the time they complete the test, item B30.
- Participants are asked to record any break time, item B31.
- Participants are asked to ‘certify’ that they completed the test on their own. Physical assistance in writing responses is allowed.
- Finally, participants should be provided a self-addressed stamped envelope to return the EPT.

The following points should be included in a script or cover letter when distributing Form #717 to participants.

- Thank the participant for agreeing to complete the EPT at home.
- Provide the participant with a site contact name and phone number for use if s/he has questions.
- Remind the participant that s/he should complete the EPT independently. Someone may provide physical assistance in writing responses if the participant is unable to write their own responses but no assistance is permitted for the actual content of the responses.
- Provide the participant with a self-addressed stamped envelope and instruct them in how and when to return the completed EPT to the Study Center.
- Set a date for the expected return of the EPT and continue to track all distributed tests until they are returned.

**j. Section R: The Tester’s Assessment of the Interview/Testing Session**

As always, this section includes questions designed to gather feedback from testers regarding the subject’s overall receptivity to and cooperation with, the instrument and the degree of difficulty responding to/completing the measures. Space is provided to identify specific items and describe the difficulty.

**B. Form # 715, Abbreviated Battery Part 2 (only used for Level II participants)**

A unique form has been developed for administration at each Post-Test visit. The **Form # 715** has been developed for administration at the 10<sup>th</sup> Year Post-Test only.

The measurements in Part 2 of the Abbreviated Battery **must** be conducted **in-person**.

**None** may be completed with a proxy. Part 2 may be conducted at the field site's testing site, in the participant's home or an alternate location requested by the participant or determined by the study staff. Testing sessions that occur at a health care institution (hospital, nursing home, etc.) may require special authorization from the institution, family member, an appointed guardian, etc.

1. Materials / Equipment Needed

The following items should be assembled in advance of the subject's appointment time.

- Alternate Visit Form # 902 with ID labels attached
- Abbreviated Battery, Part 2 data **Form # 715** with ID label attached
- AVLTL Subject data forms packet #611a with ID label attached to all pages
- AVLTL Post test coding Form #611 with ID label attached
- Letter Series data Form # 612 with ID label attached
- AVLTL Recognition Form #613 with ID label attached
- The proper AVLTL Audiotape
- MMSE supplies, i.e. wristwatch, 3 pieces of 8 ½ x 11 inch blank, white paper for completing directives, writing a sentence, and drawing shapes, 'Close Your Eyes' Show Card, pencil, and 'Intersecting Shapes' Show Card
- Useful Field of View supplies, i.e. computer, UFOV software
- Electronic timer
- Clock with digital display
- Ruler or 5 x 8 card for subject's use
- Sony Boom Box Model CFS-B15
- Pencils for subject's use

2. Preparation

- a. Only certified ACTIVE Testers are qualified to complete this session.
- b. This session must be completed as an in-person interview; it may be completed in two or more session.
- c. In advance of the session, the tester should assemble all the forms, supplies and equipment necessary to complete the measurements.
- d. The area selected must allow for private, confidential testing with minimal background noise.
- e. Ideally, all Part 2 measurements can be completed at 2 workstations. A table for two with a smooth working surface is needed for the subject and tester for recording and testing during administration of the AVLTL, Word Series, MMSE and Timed IADL. A computer station is used for the UFOV.
- f. Prior to the start of the session, the tester should set up and test equipment to be sure that all equipment is in proper working order, including the audiotape player, electronic timer, computer and related software for UFOV. Spare batteries should be carried for all battery operated equipment.

### 3. Order of Administration

The order of administration for the Part 2 testing session should be as follows:

- AVLT Recall (25 minutes)
- Letter Series (10 minutes)
- AVLT Recognition (5 minutes)
- MMSE (10 minutes)
- Timed IADL (17 minutes maximum)
- UFOV (20 minutes)

Part 2 must be completed after Part 1 measurements during an in-person session in one or more visits. If completed in one session, Part 2 should take approximately 90 minutes, not including a break. Although a break may be taken at the end of any test, testers should not split the session prior to the completion of the AVLT Recognition.

### 4. Section by Section Review

#### a. **Section A. Identifying Information for Form # 715, Part 2 of the AB.**

- A1.** Study ID: Affix the subject's ID label in the space provided. Do not hand write the ID number. Double-check the ID number against the subject's visit control sheet. Confirm the subject's name at the start of measurement to be sure you are using the correct ID for the subject.
- A2.** Visit #: This item is precoded. The code for the 10<sup>th</sup> Year Post-Test is Visit # **AB10**.
- A3.** Form Version: Be sure the form version on the form matches the current approved version. Note the year appears as a 4-digit number.
- A4.** Tester ID/Initials: The Tester's ID should go in this field. In some cases more than one tester may complete the measurements in Part 2. These testers will be identified in each of the respective sections of the forms.
- A5.** Date all measures completed: Write in the date that the last measurement is completed. Record the date as month, day and year. Note the year must be recorded as a four digit number; e.g., 2008. Do not leave blank spaces; use leading zeros as required.
- A6.** Time started: Record the exact time you begin the General Introduction in A6. Use a 12-hour clock, circle **AM** or **PM** as appropriate.

**b. Sections Preceding the Measures, Sections B, F, H, J**

A standard set of questions has been added to the beginning of each of the measures in Part 2 of the Abbreviated Battery. A description of these questions follows here:

- Q1.** Was the measurement completed at this follow-up? If the measurement was completed, code 'yes' and complete the rest of the questions in this section. If the measurement was not completed, code no and skip to the next measurement.
- Q2.** Code the date the measurement was completed. Follow the standardized convention for coding dates described elsewhere.
- Q5.** Record the ID/Initials of the Tester who completed the measure.

**Item number varies: Start and End Times:** Record the start and end times for the measure. Follow the standardized convention for coding times described elsewhere.

**c. Section C: AVLT Recall**

No changes have been made to the procedures for administration of the AVLT Recall measure. Follow the procedures for administration of the AVLT Recall documented in the 10<sup>th</sup> Year Post-Test materials. This measure may **not** be administered to a **proxy**.

**d. Section D: Letter Series**

No changes have been made to the procedures for administration of the Letter Series measure. Follow the procedures documented elsewhere. This measure may **not** be administered to a proxy.

**e. Section E: AVLT Recognition**

No changes have been made to the procedures for administration of the AVLT Recognition. Follow the procedures documented in the 10<sup>th</sup> Year Post-Test materials. This measure may **not** be administered to a proxy.

**f. Section G: MMSE**

Essentially no changes have been made to the procedures for administration of the MMSE. No eligibility scoring is required for the Abbreviated Battery. Follow the procedures documented in the QxQs for the 10<sup>th</sup> Year Post Test Individual Assessment Part I session. This measure may **not** be administered to a proxy.

**g. Section I: Timed IADL**

No changes have been made to the procedures for administration of the Timed IADL. Follow the procedures documented elsewhere. This measure may **not** be administered to a proxy.

**h. Section K: UFOV**

No changes have been made to the procedures for administration of the UFOV. Follow the procedures documented elsewhere. As always, if the participant has a physical limitation that makes it difficult for him/her to touch the screen, the participant may verbally respond and the Tester may touch the screen for him or her. This measure may **not** be administered to a proxy.

**i. Section L: The Tester's Assessment of the Interview/Testing Session**

As always, this section includes questions designed to gather feedback from testers regarding the subject's overall receptivity to and cooperation with, the instrument and the degree of difficulty responding to/completing the measures. Space is provided to identify specific items and describe the difficulty.

## C. The Proxy Interview

Selected tests/interviews in the Abbreviated Battery may be completed with a proxy. Proxy interviews may be conducted on the telephone or in-person, either at the field site's testing site, at the participant's home, at the proxy's home, or an alternate location. All tests that may be completed with a proxy are included in Part 1 session. Part 1, Form # 707 has been developed for proxy use in the 10<sup>th</sup> Year PT. Form # 707 clearly indicates which measures may be completed with a proxy. The text of the sentences will need to be altered a bit to accommodate the proxy interview.

### 1. Selection of a Proxy

In order to collect accurate data, the proxy informant should be someone who lives with, or has frequent (preferably daily) contact with the participant. Typically, a proxy informant is a family member and often will co-reside with the participant. However, if a participant does not have family members close by or is in a nursing home or other institution, the appropriate proxy can be a non-relative or a formal caregiver. Again, this person should have frequent contact with the participant to be able to provide the information requested. Only factual data are collected from proxy informants.

### 2. Materials / Equipment Needed

The following items should be assembled in advance of the proxy interview.

- Alternate Visit Form # 902 with ID labels attached
- Abbreviated Battery, Part 1, 10<sup>th</sup> Annual PT Form # **707** with ID label attached
- Medication Audit Form # 618

### 3. Preparation

- a. Only certified ACTIVE Testers are qualified to complete this session.
- b. Testers should review and practice the interview as a proxy interview prior to actual administration. Measures that may be administered to a proxy are clearly marked in Form # 707 but Testers should flag the tests in advance of an actual proxy interview and make special notations in the margins to allow for a smooth delivery.
- c. An appointment should always be scheduled with the proxy in advance of the session. If completed in one session (preferable) the interview may take as long as 45 minutes.
- d. Ideally, this session will be completed as an in-person interview, but it may be completed as a telephone interview.
- e. Inform the proxy that you will need to review all the participant's prescribed medications. Ask them to assemble the medications, in their bottles, in preparation for the interview.
- f. In advance of the interview, the tester should assemble all the forms necessary to complete the interview.
- g. The area selected to complete the interview must allow for the conduct of a private, confidential interview. If completing the interview on the telephone, remind the proxy to be situated in a comfortable chair.

4. Order of Administration

The order of administration for the Proxy Interview should be as follows:

- MDS (15 minutes)
- Life Space/Falls (10 minutes)
- Health Conditions (5 minutes)
- Health Services Utilization (5 minutes)
- Medication Audit (10 minutes)

Ideally, a proxy interview will be completed in a single session.

## **ATTACHMENT A**

### **Testers' Guide for ACTIVE Participants Who Cannot/Will Not Schedule an Appointment for a Post-Test Session.**

ACTIVE Testers should use this guide when calling participants to schedule 10<sup>th</sup> Year Post-Test sessions. At the time of telephone contact with the participant or household member, the tester may discover that the participant cannot or will not schedule an appointment for Post-Testing during the prescribed study visit window. The following are the most common reasons participants/relatives will cite for non-participation.

- The participant is suffering from a serious or debilitating illness and/or they are institutionalized
- The participant moved too far away or they are living in another location during the entire study visit window
- A close family member is suffering from a serious illness, or there has been a major change in an alternate obligation preventing full participation
- The participant simply refuses to participate stating reason such as, "I just am too busy to continue." "It just takes too long." "I can't go through that again." "Please don't ask me to do that again.", etc.
- A household member reports that the participant has died

When a participant cannot/will not schedule an appointment for an 10<sup>th</sup> Year Post-Test during the prescribed study visit window, the Tester should use the guides below to gather as much information as possible regarding the participant's situation. This information should be reported to the PI/Study Coordinator for determination of the appropriate follow-up action. It is important to gather as much information as possible to allow planning for the most appropriate follow-up.

The following script outlines are provided as rough guides and should be expanded as needed to address specific participant situations.



### **Debilitating Illness with or without Institutionalization**

1. Offer condolences.
2. Inquire about the participant's well being. Inquire about the seriousness of the participant's illness/disability. Inquire about the prognosis/expected progress toward recuperation? Get specifics without acting like an interrogator, i.e. What happened?, Was there a main event, e.g. stroke, fracture,?, When did it happen? Is their vision affected, hearing, ability to read or write, upper/lower extremity mobility?
3. Determine if participant is living at home or in an institution such as a hospital, a rehabilitation center, a nursing home, an assisted living center, etc.
- 3a. If the participant is living in an institution:
  - Get the name/general location of the institution or center (city and state).
  - Inquire about the expected length of stay.
4. Get a sense of the participant's cognitive status, physical and mental strength/stamina.
5. Determine if the participant could travel to the testing center to complete all or any of the measures. Does the participant require transportation be provided?
- 5a. If the participant cannot travel to the testing center, would they allow a tester to come to their home or institution to complete all or any of the measures?
6. If appropriate, tell the participant you will consult with your supervisor re: the best way to proceed and that you (or someone else) will call them back very soon (specify when). Determine convenient callback times.

### **Moved too far away**

1. Obtain contact information for direct telephone and written contact.
2. Contact participant directly.
3. Determine when the participant moved.
4. Determine if the move is permanent or temporary.
5. If temporary, determine when participant will return. If yes, schedule a time to complete the full battery per protocol. If the move is permanent or return is after the close of the study visit window, determine if the participant is located close to an alternate ACTIVE study site.
- 6a. If yes, make arrangements for alternate study site staff to complete follow-up testing.
- 6b. If no, ask participant if they can complete some ACTIVE measures on the telephone.
6. If appropriate, tell the participant you will consult with your supervisor re: the best way to proceed and that you (or someone else) will call them back very soon (specify when). Determine convenient callback times.

## **Deceased**

1. Offer condolences.
2. Identify the informant by name and relationship to the participant.
3. Attempt to determine when the participant died, where they died, what was the cause of death.
4. Thank the informant and provide appropriate assurances if possible. Comment about the fact that the participant made a valuable contribution to the ACTIVE project.

## **General Refusal**

1. Express regrets.
2. Ask the participant for reason why they are refusing.
- 2a. Is there a problem with transportation? Could they participate if transportation was provided for them?
- 2b. Do they have a very busy daytime schedule? Could they participate if the appointment time or place was changed to be more convenient to them?
- 2c. Were there aspects of the testing (or training) that they found upsetting or too burdensome? If yes, which aspects?
- 2d. Are they refusing because they have a partner/spouse/family member that is seriously ill or disabled that requires their undivided attention? If yes, offer condolences. Inquire about their partner's well being. Get specifics without acting like an interrogator, i.e. What happened?, Was there a main event, e.g. stroke, fracture,?, When did it happen?