ADCS - ACTIVITIES OF DAILY LIVING (ADL) INVENTORY

NOTES: (1) {P} refers to the participant and should be replaced by the participant's name or relationship to the study partner each time an ADL question is asked of the study partner.

(2) This ADL inventory must be given in the format of an interview of the study partner, either directly or by telephone. The form should NOT be given to a study partner to complete on his/her own.

READ THE FOLLOWING INSTRUCTIONS TO THE STUDY PARTNER:

I am going to ask you about a number of daily activities that {P} may have performed during the past 4 weeks. Please tell me about {P}'s actual performance, not about what he/she could have done if an opportunity had arisen. For each activity that {P} attempted, I'm going to ask you to choose one out of a number of descriptions that best fits his/her most usual performance.

For some activities, I'll ask about whether {P} performed independently, or with supervision or help. Let me explain how we are defining these words:

- **Independently** means that {P} completed the activity without being helped. We still consider it independent if {P} was reminded or prompted to get started, or received a little prompting while performing the activity.
- **With supervision** means that {P} required verbal reminders and instructions while doing the activity.
- With help means that {P} was given some degree of <u>physical assistance</u> by another person to perform the activity.

INSTRUCTIONS FOR THE RATER:

If the study partner states that $\{P\}$ had no opportunity to perform the task during the past four weeks $(e.g., \{P\})$ did not have access to a telephone, therefore could not possibly make phone calls), the response should be recorded as 'no.'

If either the study partner's answer or the questionnaire are unclear, please make notes on the case report form detailing the problem.

For questions regarding specific ADL items, please refer to the ADL Response Card.

ADCS – Activities of Daily Living (ADL) Inventory

A. General Remarks

There are widely varying ways to carry out ADL, especially Instrumental ADL. This leads to difficulty when trying to obtain ADL ratings from an informant in a standardized way for a clinical trial. The ADCS - ADL Inventory approaches the problem by offering detailed descriptions of each activity, and by asking the informant to describe observed actions or behaviors. The informant is asked to focus on the past 4 weeks. The informant must not estimate what the patient might be able to do had an opportunity arisen, but on what the patient actually did. The informant should not try to interpret the patient's thought processes or intentions. To help the informant to remain focused on observed actions and behavior during the past 4 weeks, it may be useful to ask him/her for examples of what the patient did regarding the ADL in question.

B. Administering the ADCS – ADL Inventory

The ADCS – ADL Inventory was developed and tested as an interview administered by a rater in person or by telephone. It should not be filled out by the informant.

C. Format of Questions

- For each basic ADL (questions 1-5, 6A), there is a forced choice of best response.
- All other ADL consist of a main question followed by subquestions (descriptors).
- Subquestions are arranged in hierarchical fashion, starting with the highest (most independent) level of

- ADL performance and ending with the lowest.
- For each ADL, the initial response to the main questions is "yes", "no" or "don't know". If an informant gives 4 or more "don't know" responses, it is worth trying to identify an alternative informant.
- After a "no" or "don't know" response, the subquestions are disregarded unless specific instructions indicate otherwise. "No" or "don't know" act as fast forward cues to proceed to the next ADL.
- After a "yes" response, there are 2 possible paths:
 - 1. From several descriptors, the informant chooses the one that best matches the patient's performance (e.g., question 6A). The informant should be offered as many descriptors as necessary to describe the patient's ADL ability, starting from the highest level and proceeding downwards

or

2. The informant makes a "yes" or "no" choice for each subquestion. There is a reminder in these cases to ask every question after an initial "yes" (e.g., question 8).

D. Standardizing "independently", "with supervision", and "with help"

For many ADL, the hierarchy depends on how much intervention is needed by the informant or others to enable the patient to perform the ADL.

Independently = the patient completed the ADL without physical help, and at most with reminders to do the task, or a brief prompt during the ADL.

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With supervision = the patient required verbal reminders and instructions while doing the ADL; this occupied the caregiver's (or informant's) time.

With help = the patient was given some degree of physical assistance by another person to perform the ADL.

E. "Usual" performance of ADL

Patients may vary from day to day in their ADL performance. If an informant responds that a patient sometimes performs ADL at one level and sometimes at another, the interviewer should ask him/her to choose the most commonly applicable level/descriptor.

When In doubt about a higher or lower level of ability, rate the higher one if the patient does manage to perform at that level fairly consistently.

- F. Comments on specific questions in the Inventory
- 1. Eating: self-explanatory
- 2. **Walking**: we are interested in mobility, not specifically walking. If the patient used a walker or wheelchair, but was mobile outside of home without help, he/ she is independent.
- 3. Toileting: self-explanatory
- 4. **Bathing**: minor physical help includes actions such as washing hair, help with drying, running the water or adjusting its temperature. More extensive help should be scored as needing to be bathed.
- 5. **Grooming**: toenail cutting is not rated since physical difficulty may impede this aspect of grooming, even in cognitively normal elderly.
- 6A. "Selecting" clothes implies active participation by the patient. This may

involve physically selecting clothes, or providing input to the caregiver about wishes or preferences. It is rated separately from physically getting dressed.

- 6B. **Dressing**: the 3rd and 4th levels are similar. The intention is that "help only for buttons, clasps or shoelaces" implies only a minor contribution from the caregiver, i.e., the patient performs some degree of fastening, zipping or tying. Using "clothes needing no fastening or buttoning" implies that these have been completely abandoned. Velcro counts as a fastener
- 7. **Telephone**: reminders or supervision are allowable but not help, e.g., a patient can be prompted to dial directory assistance, or told the number and still score at the highest level. If the patient makes calls only if the numbers are dictated by the caregiver, or if the telephone is set up to automatically dial one of a preselected group of numbers on pressing a single button, the patient scores 2 points.
- 8. **Television**: if the patient sits in front of a television screen without demonstrating awareness or recollection of something he/she sees, then all subquestions will be answered as "no". "Talk about the content of a program" should be interpreted fairly broadly; the patient does not need to initiate the conversation, but should require more than a "yes" or "no" answer to a question like "Did vou enjoy the program?"
- 9. **Conversation**: "paid attention" implies more than being present and seemingly alert during a conversation. The patient must participate verbally. Since it is difficult to judge whether nonverbal participation in a conversation is meaningful, it is not an option among the descriptors.
- 10. Clear dishes from a table: the patient does not have to clear the table entirely, but should participate enough to



make a useful contribution. Clearing items other than dishes e.g., glasses or utensils are acceptable as alternatives.

- 11. **Finds personal belongings:** it may be helpful to give examples such as clothing, glasses, wallet, keys, etc.
- 12. **Beverage**: getting or preparing a beverage after instructions or a reminder counts as no physical help.
- 13. **Meal or snack**: if the patient required supervision to cook or microwave, but functioned without physical help, score as the highest level. Mixing or combining items without cooking can also include supervision. An example of the lowest level of a "yes" response is the patient who finds and eats food preprepared by someone else.
- 14. Dispose of garbage or litter: does not only refer to major household garbage produced in a kitchen. Disposing of any trash in an appropriate container qualifies for a "yes" response.
- 15. **Travel**: intended to cover the patient's ability to remain oriented, not get lost and be able to venture beyond home. It does not matter whether the patient walked, drove, took public transport or was a passenger in a car. The distance of 1 mile is arbitrary and implies travel beyond sight of home.
- 16. **Shopping**: shopping is a complex activity. We have focused on the two most essential aspects (after getting to the shop, covered by question 15), choosing items and paying. If the patient goes shopping with a prewritten list and a sum of money provided by someone else, that should be scored as without supervision, provided the patient selected the items on the list. Paying for items could involve cash, check or credit; the issue is whether supervision

or help is needed.

- 17. **Keep appointments or meetings**: mainly aimed at monitoring memory. An "appointment/meeting" may be liberally interpreted to include almost any kind of preplanned meeting, outing or excursion. It does not matter who made the appointment or whether the patient traveled alone or with somebody else. The highest level implies the patient remembered the appointment on his/her own, memory aids are acceptable.
- 18. **Left alone**: if the patient was left alone for an hour or longer at home, then they automatically will score a "yes" for descriptor c, "less than 1 hour at home."
- 19. Talk about current events: the patient does not need to initiate conversation about current events, but must demonstrate awareness or recollection by providing details of the event(s). Merely agreeing or disagreeing with other people by saying "yes or "no" is not sufficient to display knowledge/recall of current events. Patients who are severely aphasic will score "no" for talking about current events.
- 20. Reading: looking at a book, magazine or newspaper and turning the pages for more than 5 minutes on end may equal reading. Unless the patient communicates the content of what he/she reads to someone else, it is not possible to judge whether he/she actually reads or not, in a way that shows elements of comprehension and retention of information. The informant should be encouraged to interact with the patient to be able to make an accurate judgment.
- 21. **Writing**: short notes or messages can be either spontaneous or written to dictation. A shopping list, "to do" list, or taking an intelligible telephone message would qualify.
- 22. Pastime, hobby or game: the

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menu of hobbies or games is to help the informant and may provide us with secondary information if complex hobbies are lost and replaced by simpler ones. A hobby should involve element(s) of concentration, knowledge and memory, and manual skills. If hobbies other than those in the menu are offered, try to describe what the patient does in some detail so that we can monitor this.

23. Household appliance: an appliance is defined as a device with one or more switches or controls, usually (though not necessarily) with an electrical or other power source, used to do chores. For men, tools with controls or switches would qualify, but not a screwdriver, hammer or saw. Again, if the patient needs only minimal verbal prompting to operate the appliance, press a switch, or operate a control, the highest level is scored.