

OMNI ADRD

Community Advisory Board

6/22/26 Meeting

CAB MEETING SUMMARY

Two documents were discussed: 1) OMNI ADRD Charter Draft and 2) Evaluation Framework Draft. Participants were sent a series of questions prior to the meeting regarding thoughts, reactions, and/or concerns about these documents. The agenda also included prompts about how participants define 1) cognition and 2) change in cognition, as well as meaningful definitions of positive and negative cognitive changes. The agenda also included several questions about how they monitor cognitive change, and the severity of change that would warrant concern in either themselves or from other people.

Participants started by reintroducing themselves and discussed their various experiences in clinical research and personal and professional experiences with cognitive impairment. They noted appreciation that individuals living with cognitive changes are included as equal partners rather than subjects, and emphasized that the documents appeared clear and understandable. One participant, however, noted that the language may need to be less scientific and complex if these policies were used in a public outreach capacity, which others agreed with, and that two different versions of the same document would be helpful for a lay versus a scientific audience. Two participants noted that they acknowledge the possibilities of also comparing these new tests against biomarkers such as blood for cognitive impairment, as well as the importance for public awareness of how informative midlife cognitive testing can be, including how there may be a required shift in social stigma for such testing to become normative. One participant agreed, and noted that subtle cognitive change in midlife is a crucial gap that is currently being missed in many clinical trials for dementia treatments. Another participant noted that the use of readily available tools will be especially helpful for healthcare providers, who may have more frequent and close contact with older adults and capture subtle cognitive change more precisely.

Regarding the discussion questions, the discussion started about what cognition means. One participant noted that this means the processes involved in thinking and reasoning, communicating with others, and understanding and navigating the world. Another participant added the ability to articulate and understand language. A third participant described how they think of cognition in terms of the basic processes of thinking and separate processes associated with aging, with fears about losing memory in particular.

Regarding the definition of a change in cognition, one participant stated that they refer to how flustered a person becomes and how they act once they are out of their routine as a measure of the severity of cognitive change. Another participant reported that there may be small changes that occur that are most clear to spouses or loved ones but strangers may not be able to tell. Another participant corroborated this, with one noted the importance of addressing not only cognitive domains, but also assessing executive dysfunction, and functional limitations in

performing daily tasks that may require increasing effort over time that others may not be able to readily see; on the outside, “you can look fairly good” despite experiencing frightening slips in cognition that tax individuals more than others may realize. Participants commented on how assessing cognition is less meaningful without an assessment of cognitive taxation, reliance on others vs. independence, and withdrawal from social engagement and hobbies.

Regarding cognitive changes that participants look out for, several participants commented on being in support groups in which they notice small changes in others. One example a participant gave was not being able to retrace one’s steps and remember what they had done earlier that day. Another example given was personality changes, particularly increased anger and irritability towards others perhaps as a result of having greater struggles with daily functioning or frustrations with not being able to do tasks as well, such as solving puzzles. One participant commented that there can be a loss of a sense of security and confidence and need to be “hypervigilant about everything” to stay abreast of daily tasks, and that these changes caused them to become distrustful of others and frustrated with their limitations and cognitive changes. This participant noted that the early stages of cognitive loss can be worse than later stages because the person can be aware of how much ability they are losing. Another participant noted that greater emotionality can also be important to look out for, and that it is not just anger or irritability but, for example, become much more reactive and sad in response to watching a tragic movie.

Regarding warning signs that individuals look out for in themselves, one participant described testing themselves by attempting to always remember their lock combination for their locker, and perceived that if they lost the combination that would be a clear sign of decline. Another participant noted that their driving skills have changed, with parking becoming more difficult to do and asking their spouse to watch out for warning signs when driving. Participants all confirmed that spouses can be key in monitoring their behavior and potential warning signs.

Regarding desired qualities in cognitive assessments, participants commented that executive dysfunction related to e.g., inability to make decisions and effort required to understand and make choices, tracking bills and remembering whether they had paid all of them, is key to assess. Dr. Han noted that many existing executive function tests often assess more lower-level executive function rather than higher-level executive function about organization and decision making, which have their own strengths and weaknesses in over- or under-diagnosing problems. Another participant noted that while they are able to do well in easy cognitive screeners at their physician, sometimes these tests are not sufficiently complex to assess functional difficulties.

In a follow up email, one participant commented on and emphasized the importance of commitment to varied experiences across many dimensions such as age, education, race, culture, and types of cognitive impairment. They also described the importance of understanding not just cognitive performance on tests, but also articulating and understanding language, mental fatigue during testing, and confidence and relative effort in completing daily tasks.

In a separate follow up email, one participant noted that while the shared documents were clear and accessible, clarification is needed on the purpose of the meetings, for instance, when the CAB input is and guidance is needed to move forward with an aspect of the project versus simply providing documents to the CAB so that the board is informed about current efforts. This participant also noted that it would be helpful to have clear goals for future meetings so that the CAB can be informed about ways in which input can be helpful in the near future (e.g., 3 month, 6 month goals).