



Type of measure: Active task.

Definition of measure: Passive measurement.

Definition of measure: The amount of time it takes a person with ADRD to get to sleep and/or the frequency of wake events experienced in the sleep period.

Considerations: This measure is defined as two separate measurements.

Outcomes to be measured: Initial sleep onset latency (duration), frequency of wake events (count, ratio).

Example: Using an accelerometer or an electrocardiogram (ECG) headband, estimating how long it takes an individual with ADRD to fall asleep after they intended to go to sleep. Using the same technology, estimating the number of times the individual wakes up in the night.

Sleep disruption measurement in the literature: <u>Usability of wearable</u> <u>sleep tech</u>, <u>frequency of wake events</u>

From patients and care partners:

"I am in a hurry to go to bed early and can't Sleep. I get Sleepy during the daytime. I get Sleepy even if I go to a day service." - *Patient, Japan*

"Now I can't sleep well and I'm tired. I want to go to bed and fall asleep, not wake up at night. Then I find it hard to fall asleep. I am tired during the day." - *Patient, Bulgaria*

"[If my sleep improved I'd be in] better spirits, [if it worsened I'd be] unable to care for [my]self, [with a] worsening mood." - *Patient, China*

"It will make everyone around her emotionally unstable. Again she needs enough Sleep and rest and the lack of it will be a worry to her situation." - Care partner, Ghana

"I will have peace of mind and not waking up or having sleepless night because of him cause it's telling on my health already I get pains often." - *Care partner, USA*

"If my mom had more sleep, then I could have more sleep... her sleeping all the way through the night would be a huge help for all of us not just her but us too." - *Care partner, USA*

Resource quicklinks 🔗

View the full <u>Core Digital Measures of ADRD conceptual model</u> or jump to another ontology:



<u> Visuospatial</u> <u>memory</u>





View the <u>discussion guide</u> for expressive communication







Non-sedentary

behavior



Digital Health Measurement Collaborative Community









Data

Ð

It is necessary to report and specify the data collected by the technology employed. This reporting enables the specification of sleep measures in line with the <u>DiMe Core Digital Measures of Sleep project</u>. An additional advantage is that the data can then be available to individuals appraising the planned or conducted work. In research activities where data is made available for secondary research (i.e., data hosted on the <u>Alzheimer's Disease Data Initiative</u>), users can assess the feasibility of the data for their own study aims.

Features

Report the features output by the technology. Specify the epoch length of the output and the data labels that are output or derived. Evidence supporting the procedure and algorithms used to extract or derive features and data labels from the collected data must be provided.

For an example data structure, please see this example from the <u>DiMe Core</u> <u>Digital Measures of Sleep</u>.



Initial sleep onset latency

Ð

Initial sleep onset latency is the duration of time an individual takes to first achieve sleep after intending to sleep. It is necessary to consider and document the aspects of sleep measurement that are combined to create this estimate.

Time attempting to sleep start time

A timestamp that relates to inferred or reported initiation of sleep attempt (i.e., patient starts trying to sleep). Report how the selected technology estimates or records the point at which an individual initiates a sleep attempt. Report evidence for any algorithms that are used for the estimation of time attempting to sleep start time.

Many technologies algorithmically estimate sleep attempt initiation, but it can also be manually recorded on a digital device to prevent false negatives arising from someone in a resting state, reading a book, or engaging in other activities without the intention of sleeping.

Duration

The difference between time attempting to sleep start time and initial sleep onset (minutes, seconds).

Initial sleep onset

A timestamp that relates to inferred initiation of the first sleep event after intending to sleep (i.e., the point at which the individual first falls asleep). Report how the selected technology estimates this point, including any confirmation criteria (i.e., the first detected sleep event that lasts longer than X minutes/epochs). Provide evidence supporting this criteria in the intended population along with evidence for the underlying estimation algorithm.

Technologies will vary in the methods they use to estimate sleep. Some are proximal to the brain activity of the individual and others are more distal. Documenting the selection of and rationale for a given technology in the intended population is important.



<u>Frequency of</u> <u>wake events</u>



The frequency of wake events is the number of times an individual wakes up in the night while still attempting to be asleep.

Initial sleep onset

A timestamp that relates to inferred initiation of the first sleep event after intending to sleep (i.e., the point at which the individual first falls asleep). Report how the selected technology estimates this including any confirmation rule (i.e., the first detected sleep event that lasts longer than X minutes/epochs). Provide evidence supporting this criteria in the intended population along with evidence for the underlying estimation algorithm.

Sleep offset

A timestamp that relates to inferred termination of sleep. This termination could be deliberate (waking up to end the sleep period) or it could be unintended (waking up in the night unintentionally). Evidence must be provided for the algorithmic detection of sleep offset.

Wake event

Rationale should be provided for any confirmation criteria that differentiates between a sleep offset that counts as a wake event and one that does not (based on the duration of the wake event).

For example, multiple wake events could occur throughout the sleep period. However, researchers may be interested only in wake events that last longer than a prespecified time or number of epochs.

Measurement interval



It is necessary to specify the frequency of assessment. Although sensor-based technology, particularly wearable technology, can be used to collect continuous data, patient burden should still be considered. Maintaining the technology (charging, etc.) or remembering to wear it (e.g., for technology worn only at night) can be burdensome.

Deliberately selecting a set period of time, linked to time periods with rich clinical data (i.e., clinic visits), will help to increase the utility of the data collected (e.g., for validation efforts) and can aid in patient adherence to using the technology. The exact frequency of data collection is likely specific to the research question, and can be supported through a data-driven approach showing the ideal frequency for a specific measure, like reliability.

Passive, longitudinal recording

Daily for a period of time relevant to the needs of the study or health care provider (HCP) assessment.

Passive recording can take place continuously. However, to ensure compliance, a limited time window (e.g., seven days prior to clinic or trial visits) may be preferred.

CORE MEASURES of **ADRD** | Digital Measures Development

Note: An overall count of the number of wake events can be used; however, it may be appropriate to account for the length of time the person with ADRD had the opportunity to sleep, which can be calculated as the time between the initial sleep onset through to the final wake event. See <u>total</u> <u>sleep time (duration)</u>.