#### I. PURPOSE

This form is intended to collect information about SANAR participant's sleep habits and behaviors to better understand the causes of cardiovascular disease and brain health. The sleep characteristics assessed as part of this questionnaire include sleep duration, sleep quality, insomnia, sleepiness, naps, and dreams, which are measured by a set of questions or a scale.

#### II. DEFINITIONS

Most terms used in this questionnaire are from everyday life; therefore, terms do not need to be explained. The following guidelines should be used should participants require further explanation or not understand the original wording of the questionnaire. Otherwise, if the participant asks about the meaning of any item or tries to qualify a statement, re-read the question and ask the participant to answer as s/he best understands it.

#### III. METHODS

This is an **interviewer-administered questionnaire**. Make sure the participant is in a quiet environment so that they can hear you read the questions. You can also provide the participant with a printed copy of the questionnaire if they would like to read along as you read each question.

## **General Instructions**

- 1) Remind the participant that we will use this information only for research purposes. Explain to the participant that some sleep habits and behaviors may be important to their health. Knowing about these things may help us understand the causes of dementia and brain health better.
- 2) Ask the participant to answer all items except those which are specifically instructed to skip. If s/he is unsure about the answer to a specific question, ask the participant to estimate the answer to the best of his/her ability. Emphasize that it is important to get complete data so that the study results will be valid. Emphasize that there are no right or wrong answers and that we are only interested in the feelings and opinions about sleep.
- 3) Ask the participant to carefully listen to the introduction of each section or group of questions (some questions may refer to things that happened 2 weeks ago whereas others may refer to things that happened in a different period).
- 4) In questions that ask about time, ask the participant to respond about the time in hours and minutes and check whether it is am or pm. Use two digits for the hours and two digits for the minutes, i.e., if the participant usually goes to bed at 8.30 pm, you should enter in the form 08:30 and select pm.
- 5) In questions where the participant is asked about number of hours and minutes, enter "00," in hours if it is less than one hour and also enter minutes with two digits, i.e., 5 minutes will be "05".
- 6) Pay close attention to how participants report AM and PM. Remember that times at and after noon until before midnight are PM and midnight and times until noon are AM.
- 7) For questions regarding sleep times on weekdays and weekends, the intention is to understand possible differences on work or "off" days (if the participant has a regular working schedule); otherwise, it is to understand differences between times that participant goes to sleep on Friday and Saturday and wakes up on Saturday and Sunday.

#### **Specific Instructions**

<u>Questions 1- 6 ask about participant typical sleep patterns</u>. The participant is asked to indicate what time s/he goes to bed, gets out of bed, the time it takes to fall sleep and how much time s/he sleeps on weekdays and weekends separately.

For **questions 1 and 2**, record the TIME in the space for each question. Enter the time in hours and minutes using a 12-hour clock time frame and check AM or PM. The participant should provide the times relative to their usual longest period in bed (i.e., not including naps) on their average weekday and weekend. The time should reflect times from "lights off" to arising from bed. For example, if they read in bed, or watch TV in bed before sleep, they should report the times they turn off the light and close their eyes to sleep. If they lay in bed awake in the morning, they should report the times they get out of bed. Check to make sure that the times for awakening occur after the times reported for falling asleep and AM and PM are reported correctly.

- 1. What time do you usually go to bed (to try to fall asleep):
  - a. On weekdays or work days?
  - b. On weekends (Saturday, Sunday) or days off?
- 2. What time do you usually get out of bed:
  - a. On weekdays or work days?
  - b. On weekends (Saturday, Sunday) or days off?

For **questions 3-6**, respond the number of hours and or minutes. Use two digits for the hours and two digits for the minutes. Write a number in each box.

- 3. How long does it usually take you to fall asleep at bedtime? Question refers to time participant estimates it takes to fall sleep after turning the lights off. If participants are unsure, ask them to estimate how long it usually may take, and reassure them that it is not uncommon to not to be able to know exactly how long it takes to fall asleep- that is why we are using a home sleep test to also measure sleep.
- 4. After waking up, how long do you usually stay in bed before getting out of bed? Question refers to time participant takes to get out of the bed, once s/he wakes up. Some people wake up and fall asleep multiple times over the night; "after waking up" refers to the "last" sleep before getting out of bed with the intention of "starting their day."
- 5. How much sleep do you usually get each night (or over the longest time you are in bed)

This refers to the total duration of sleep (in hours and minutes) s/he estimates s/he gets during each major sleep period (i.e., usually over the night; not including naps). Weekdays refer to sleeping Sunday through Thursday and Weekends Friday and Saturday nights (unless the participant works and works on a schedule that is not a typical M-F work week).

- a. On weekdays or work days?
- b. On weekends (Saturday, Sunday) or days off?
- 6. During a usual week, how many times do you nap for 15 minutes or more?

The participant should estimate the number of naps s/he has during a usual week. Some people plan naps while other people fall asleep unintentionally. Here a nap is defined as any period outside of their typical sleep period (usually overnight) that is at least 15 minutes long, whether they intended or didn't intend to sleep. Part b asks the participant to estimate whether all of the naps reported were planned, unplanned, or a mixture. If the participant does not know they can answer "don't know"). If the participant does not nap, you should enter "00" and skip to the following question (to Q#7).

If you usually nap 1 or more times per week:

- a. On average, how long is your typical nap?
- b. In general, were these naps planned, or did you fall asleep without meaning to?

# **Choose one of the options:**

- Naps planned
- o Fell asleep without planning to
- o Both (some planned, some not)
- o Don't know

#### Questions 7-14 ask about the quality of sleep

Below is a list of the questions that ask about the quality of participant's sleep DURING THE PAST TWO WEEKS.

7. In the past two weeks, have you had problems falling asleep, staying asleep, or waking up too early?

Choices are "yes" or "no"." Yes" should be answered if the participant perceives any problems in any of these areas.

If no, skip to question 14

When asking the participant to answer the next set of questions, remind them that the choices are none, mild, moderate, severe, or very severe. If needed, repeat the choices after each question. If the participant has difficulty understanding what each adjective means, remind them to choose the word that seems to reflect how severe the problem felt to them.

#### Possible answers for questions 8-10 if "yes" to Question 7:

- o None
- o Mild
- Moderate
- o Severe
- o Very severe
- 8. Please rate the current SEVERITY of your difficulty falling asleep. Question refers to the severity of the participant's difficulty getting to sleep after turning off the lights for their longest sleep period.
- 9. Please rate the current SEVERITY of your difficulty staying asleep. This refers to problems staying asleep due to waking up too much.
- 10. Please rate the current SEVERITY of your problem of waking up too early. This refers to waking up very early and not being able to fall back to sleep.
- 11. To what extent do you consider your sleep problem to INTERFERE with your daily functioning (e.g. daytime fatigue, ability to function at work/daily chores, concentration, memory, mood, etc.)? Here remind the participant of the new choice of responses and read these out. "Sleep problem" refers to any of the problems in falling asleep, staying asleep or waking up too early mentioned earlier.

#### Possible answers for questions 11:

- o Not at all interfering
- o A little
- o Somewhat
- o Much
- o Very much interfering
- 12. How NOTICEABLE to others do you think your sleeping problem is in terms of impairing the quality of your life? Here remind the participant of the new choice of responses and read these out. If the participant reports that there is no one in a position to notice the impact of their sleep on their quality of life, they should answer "not at all noticeable". "Sleep problem" refers to any of the problems in falling asleep, staying asleep or waking up too early mentioned earlier.

# Possible answers for questions 12:

- o Not at all noticeable
- o Barely
- o Somewhat
- o Much
- Very much noticeable
- 13. How WORRIED/ distressed are you about your current sleep problem? "Sleep problem" refers to any of the problems in falling asleep, staying asleep or waking up too early mentioned earlier.

#### Possible answers for questions 13

- o Not at all
- o A little
- o Somewhat
- o Much
- Very much
- 14. How SATISFIED/ dissatisfied are you about your current sleep pattern? Question refers to the participant's overall sleep pattern—i.e., their patterns of sleeping and waking.

### Possible answers for questions 14

- o Very satisfied
- Satisfied
- Neither Satisfied or Dissatisfied
- Dissatisfied
- o Very Dissatisfied

Questions 15-22 ask about participants sleep over the last month. Let the participant know that some of these questions may sound similar to those just asked, but these focus on how often s/he experienced the situation in THE PAST FOUR WEEKS. If symptoms have varied over this period, the participant should estimate how often the symptom has occurred on average over this time. Please state the new responses, repeating these responses with each question, as needed.

### Possible answers for questions 15-21:

- o No, not in the past 4 weeks
- o Yes, less than once a week
- o Yes, 1 or 2 times a week
- o Yes, 3 or 4 times a week
- Yes, 5 or more times a week
- 15. Did you have trouble falling asleep?
- 16. Did you wake up several times a night? (Note: assumes the participant's long sleep is during the night. If a shift worker or otherwise gets their longest sleep in the day, that should be referenced).
- 17. Did you wake up earlier than you planned to? (Note: this refers to their "final awakening").
- 18. Did you have trouble getting back to sleep after you woke up too early?
- 19. Overall, was your typical night's sleep during the past 4 weeks: (Note: this refers to overall sense of sleep quality and how much sleep felt restful or restorative).

#### Possible answers for questions 22:

- Very sound or restful
- o Sound and restful
- o Average quality
- o Restless
- 20. Only for those answering 3 or more times to items Q15, Q16, Q17 or Q18. Have you had problems falling sleep, staying asleep or waking up too early that occurred three or more times per week and lasted 3 or more months?
- 21. Do you feel your sleep has gotten worse over the past five years?

#### Questions 23-25 ask about use of medications and caffeinated drinks that may influence sleep.

The following questions ask about use of medications and caffeinated drinks DURING THE PAST FOUR WEEKS.

#### Possible answers for questions 23-25:

- o No, not in the past 4 weeks
- Yes, less than once a week
- o Yes, 1 or 2 times a week
- o Yes, 3 or 4 times a week
- Yes, 5 or more times a week

- 22. Do you ever use an over-the-counter medicine (like Benadryl or Tylenol PM) to help you sleep? (Note: this can include other similar OTC medications)
- 23. Do you ever use a prescription medicine (like trazodone or Ambien) to help you sleep?
- 24. Do you ever use caffeinated drinks (coffee, soda, energy drinks, etc.) to help you stay awake?

### Questions 25-33 ask about behavior related to feeling sleepy or alert DURING THE PAST WEEK.

The following questions ask about feeling sleepy or alert during the day in the last 7 days

#### Possible answers for questions 25-32:

- o Not at all
- o A little bit
- o Somewhat
- o Quite a bit
- Very much
- 25. I had a hard time getting things done because I was sleepy.
- 26. I felt alert when I woke up.
- 27. I felt tired.
- 28. I had problems during the day because of poor sleep.
- 29. I had a hard time concentrating because of poor sleep.
- 30. I felt irritable because of poor sleep.
- 31. I was sleepy during the daytime.
- 32. I had trouble staying awake during the day

#### Question 33 is used to determine a person's level of daytime sleepiness (in contrast to feeling tired)

33. What is the chance that you would doze off or fall asleep (not just "feel tired") in each of the following situations? If you are never or rarely in the situation, please give your best guess for what would happen.

#### Possible answers for each item of question 33:

- Not a chance
- Slight chance
- o Moderate chance
- o High chance
- a. Sitting and reading
- b. Watching TV
- c. Sitting inactive in a public place (such as a theater or meeting)
- d. Riding as a passenger in a car for an hour without a break
- e. Lying down to rest in the afternoon when circumstances permit
- f. Sitting and talking to someone
- g. Sitting quietly after a lunch without alcohol
- h. In a car, while stopped for a few minutes in traffic

## Question 34 and 35 refer to questions about sleepiness and driving that may have happened in the LAST TWO YEARS:

In the last two years, have you had any times when you:

34. Nearly fell asleep while driving? (Note: this refers to feeling as though you were dozing off but did not actually fall asleep.)

# Choices are "yes" or "no". If yes,

- a. How many times?
- 35. Fell asleep while driving? (Note: this refers to having fallen asleep while you were driving a vehicle, regardless of how short that was.)

### Choices are "yes" or "no". If yes,

- a. How many times?
- b. Did this result in a car crash?

Choices are "yes" or "no"

#### Questions 36 & 37 ask about snoring and breathing during sleep OVER THE PAST 4 WEEKS:

36-37. Ask the participant to estimate the frequency of snoring (Q 36) (or stopping breathing, Q 37) over a typical week (number of nights per week). If the participant's usual sleep time is in the day (i.e., shift workers), the participant should estimate the sleeping frequency during the longest period of sleeping in the day. She/he can report these symptoms based on self-perceptions or based on what others have told the participant. She/he does not have to judge how loudly the snoring was to answer this question. If the participant only knows how often she/he snored or stopped breathing in the past (because there were people who witnessed the participant's sleep in the past but not the present), the participant should answer the question based on the most recent information the participant is aware of. 'Stop breathing' may include breathing pauses followed by snorting sounds.

#### Choices are:

- o Never
- o Rarely (1-2 nights a week)
- o Sometimes (3-5 nights a week)
- o Always or almost always (6-7 nights a week)
- o Don't know
- 38. Ask the participant whether he ever experiences a need to move his legs because of uncomfortable feelings in his calves. This should not include feelings that his feet "fell asleep" or were "numb" but refer to more of an irritating, creeping, crawling sensation. If answering no, or do not know, then do not ask Q38a-c.
  - *a.* If answered yes, then ask if this disagreeable feeling results in a need to move his legs with walking, or rub his legs, to relieve this sensation?
  - b. If answered yes, then ask the participant if these leg symptoms are usually worse when resting and feel at least temporarily better by moving the legs. If they report they are worse at rest but not better with movement, answer 'no' to Q38.
  - c. Ask if these leg symptoms are worse later in the day or at night compared to earlier in the day. If participant asks for clarification, later in the day can be defined as 6 pm –midnight.
- 39. At what time in the evening do you feel most tired and, as a result, most in need of sleep? (Note: this does not refer to the actual times you go to sleep but the time you feel so tired you could go to sleep.)

#### Choose one answer

- o 8:00 PM-9:00 PM
- o 9:00 PM-10:15 PM
- o 10:15 PM-12:45 AM
- o 12:45 AM- 2:00 AM
- o 2:00 AM- 3:00 AM

- 40. If the participant is unsure what "morning" and "evening" types of people are, define these terms. A "morning" type tends to be more alert and fuller of energy in the morning whereas an "evening" type tends to be more alert and fuller of energy in the evening.
- 41-43. Read each listed sleep disorder to the participant and check the box if they have the condition. Check all conditions that apply. Sleep apnea is present when there are long pauses in breathing during sleep (e.g., 10 or more seconds between breaths) which cause lowered circulating oxygen levels in the bloodstream. Insomnia is the inability to sleep and/or the ability to remain asleep. Restless leg syndrome is characterized by the urge to move limbs to reduce uncomfortable sensations.

<u>Interviewer can also use the following text in Spanish to explain sleep disorders:</u>

- Q41. Apnea que deja de respirar mientras duerme
- Q42. Insomnio es la incapacidad para dormir y / o la capacidad de permanecer dormido
- Q43. **Síndrome de piernas inquietas** cuando siente un deseo profundo de mover las piernas mientras está durmiendo o reposando.

# The following asks about things that may influence sleep such as a job schedule

44. This question should refer to the participant's PRIMARY job. Many people work in shifts. The precise definitions of each shift may vary by an employer. However, if the participant needs clarification on the meaning or hours typically associated with each of these shifts, the following definitions can be provided with the understanding that the times may vary by 1-2 hours:

**DAY SHIFT:** The day shift will typically be between 6am-2pm.

**AFTERNOON SHIFT:** The afternoon shift will typically be 2pm-10pm or 3pm-11pm

**NIGHT SHIFT:** The night shift will typically be 10pm-6am or 11pm-7am

**SPLIT SHIFT:** A person with a split shift works twice over a day with 2 or more hours between work periods. For example, they might regularly work both four hours in the day and four hours in night shift on some days. **IRREGULAR SHIFT OR ON-CALL:** A person with an irregular shift is one who works when called and never knows his/her shift for certain.

**ROTATING SHIFT:** A rotating shift means that you work one type of shift sometimes and another at other times. However, this is systematic. You know which shift you will work on each day.

**DON'T WORK:** Participants who do not get paid for defined work.

## **Questions 45-47 ask about things that may influence sleep:**

45a-f. This question asks if the participant engages in any of the activities listed from a-h before going to sleep. When in bed, before going to sleep, do you usually (Note: usually means more often than not):

# Choices are "no" or "yes" for each of the following items:

- a. Watch TV
- **b.** Read books, magazines, etc (paper format)
- **c.** Read on an electronic device (Kindle, phone, etc)
- **d.** Talk or text using a phone
- **e.** Have a light on
- **f.** Listen to music
- 45g-i. This question asks if the participant engages in any of the activities listed from g-i in the 2 hours before going to sleep. *In the two hours before going to bed, do you usually:* 
  - g. Drink alcohol
  - **h.** Drink caffeinated beverages (coffee, etc.)
  - i. Smoke cigarettes, pipes or cigars

- 46. This question asks if the participant has a bedpartner, sleeps with another person in the room or sleeps alone. *Do you usually:* (choose one answer)
  - O Have a bedpartner (Note: someone you usually share a bed with)
  - O Sleep in a room with another person, but don't share a bed
  - O Sleep by yourself (Note: there is usually no one else in your bedroom)
  - o Prefer not to answer
- 47. Do any of the following make it difficult to sleep?

## Possible answers for the following items are:

- o Never
- Sometimes
- o Usually
- o Always
- a. Noise in the house
- b. Noise outside
- c. Temperature too hot or cold
- d. Too much light
- e. Worry or stress
- f. Body pain (joints, legs, back)
- g. Chest pain
- h. Headache
- i. Acid reflux/heartburn
- j. Shortness of breath or problems breathing

## Questions 48-49 ask about dream experiences:

- 48. *How often do you remember your dreams?* (Choose one option): (Note: this refers to remembering your dreams you had after waking in the morning; it does not mean fully remembering them but having a memory of a dream and a sense of what it was about).
  - $\circ$  Never  $\rightarrow$  if selected "never" go to question 49.
  - o Less than once per month
  - o About once or twice per month
  - o About once or twice per week
  - o More than 3 times a week but not every night
  - o Most nights

### If response to Q48 was not "Never", ask 48a:

a. When you do remember a dream, do you tend to recall it quite clearly?

Choices are "yes", "no", or "not sure".

## For all participants:

49. This question asks if the participant has ever been told or if they suspect that they 'act out' their dreams. If participants ask for a timeframe, administrator can say within the last year. Have you ever been told, or suspected yourself, that you seem to 'act out your dreams' while asleep (for example, punching, flailing your arms in the air, making running movements, etc.)?

Choices are "yes", "no", or "not sure".

### End of questionnaire.