



Instructions

Thank you for taking the time to enroll with the CoRDS/Hypersomnia Registry. This module will ask you questions specific to your diagnosis. The questions below were developed in partnership with the Hypersomnia Foundation. Please note, this module:

- Takes approximately 1 hour to complete
- Will refer to the person with the diagnosis as “**the participant**”
- References the participant’s genetic report
- Can be updated at any time by logging into the CoRDS online portal or by contacting CoRDS personnel

If you have any questions while completing this form, please contact CoRDS at (877) 658-9192 during business hours, 8:30 am-5:00 pm (Central Time) Monday through Friday. If you need assistance after business hours, please leave a message or email cords@sanfordhealth.org.

Permissions & Data Sharing

I give permission to CoRDS to provide the participant’s information that may or may not be identifiable to the following Patient Advocacy Group (PAG) for non-research purposes.

***CoRDS does not share names or other contact information with its partners. However, due to the rarity of the participant’s disease, CoRDS may share information about their diagnosis, symptoms, or other aspects of the disease and regional location that may indirectly identify the participant to the Patient Advocacy Group.**

<input type="checkbox"/> Hypersomnia Foundation	<input type="checkbox"/> I do not give my permission
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SLEEP DURATION & FREQUENCY

1. When (date OR at what age) did the participant first start feeling as if they were excessively sleepy or needed more sleep than most people?

Date:	Age: _____
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2. When (date OR at what age) did the participant (or their parent(s)/guardian(s)/LAR) first seek help for their excessive sleepiness or need for sleep?

Date:	Age: _____
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3. What is the longest the participant has ever slept at one time while TAKING MEDICATION for their excessive sleepiness or need for sleep (please round to the nearest hour)?

_____ Hours	
4. What is the longest the participant has ever slept at one time while NOT TAKING MEDICATION for their excessive sleepiness or need for sleep (please round to the nearest hour)?	
_____ Hours	
5. How often does the participant have difficulty waking up for the day? Please select ONE response.	
<input type="checkbox"/> Never	<input type="checkbox"/> 1-2 times a week
<input type="checkbox"/> Less than once a month	<input type="checkbox"/> 3-4 times a week
<input type="checkbox"/> Less than once a week	<input type="checkbox"/> Daily or almost daily
6. How often does the participant usually feel rested after waking up for the day? Please select ONE response.	
<input type="checkbox"/> Daily or almost daily	<input type="checkbox"/> 1-3 times a month
<input type="checkbox"/> 3-4 times a week	<input type="checkbox"/> Less than once a month
<input type="checkbox"/> 1-2 times a week	<input type="checkbox"/> Never
7. How long does a typical nap last for the participant (hours and/or minutes)?	
Hours: _____	Minutes: _____
8. After a nap, how does the participant typically feel? Please select ONE response.	
<input type="checkbox"/> Not refreshed	<input type="checkbox"/> Refreshed
<input type="checkbox"/> Somewhat refreshed	

SLEEP SYMPTOMS

When answering questions 9 and 10, please think back to when the participant's symptoms WERE THE WORST they have ever been.

9. Was the participant taking medication to treat their excessive sleepiness or need for sleep when the symptoms were the worst they have ever been?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
10. When the SYMPTOMS WERE THE WORST they have ever been, how often did the participant experience each of these symptoms? Please select ONLY ONE response for each row.	

Symptom	Never	Once or twice in my life	Once or twice a year	Monthly	Once or twice a month	Weekly	Every day	More than once a day
Excessive daytime sleepiness								
Long sleep (sleeping longer than 10 hours at a time)								
Intentional nap (sleeping more than once in a 24-hour period)								
Fall asleep during the day without meaning to								
Use more than one alarm device to wake up								
Trouble waking up (sleep inertia) and functioning with normal alertness (sleep drunkenness)								
'Brain fog' (unable to think clearly or concentrate at any time throughout the day)								
Difficulty remembering things								
Weakness or slackness in the jaw, face, or neck with laughter or strong emotions such as anger, fear, stress, or excitement								
Sleep paralysis (being unable to move when falling asleep or waking up)								
Night sweats								
Restless sleep								

Hypersexuality								
Hyperphagia (Abnormally increased appetite and ingestion of food [typically junk food])								
Hypnagogic hallucinations (seeing or hearing things that aren't really there) when falling asleep								
Hypnopompic hallucinations (seeing or hearing things that aren't really there) when waking up								
Automatic behavior (doing something without realizing/being aware) - Automatic behavior usually happens when sleepy but trying to stay awake (e.g., arriving at a destination without being able to recall how)								

When answering questions 11 and 12, please think back over the past 30 days

11. Has the participant been taking medication (as it is normally prescribed) for their excessive sleepiness or need for sleep over the PAST 30 DAYS? Please select ONE response.

Yes

No

No medication prescribed

12. Over the PAST 30 DAYS, how often has the participant experienced each of the following symptoms? Please select ONLY ONE response for each row.

Symptom	Never	Once or twice	3 or 4 times	2-6 times each week	Every day	More than once a day
Excessive daytime sleepiness						

Long sleep (sleeping longer than 10 hours at a time)						
Intentional nap (sleeping more than once in a 24-hour period)						
Fall asleep during the day without meaning to						
Use more than one alarm device to wake up						
Trouble waking up (sleep inertia) and functioning with normal alertness (sleep drunkenness)						
'Brain fog' (unable to think clearly or concentrate at any time throughout the day)						
Difficulty remembering things						
Weakness or slackness in the jaw, face, or neck with laughter or strong emotions such as anger, fear, stress, or excitement						
Sleep paralysis (being unable to move when falling asleep or waking up)						
Night sweats						
Restless sleep						
Hypersexuality						
Hyperphagia (Abnormally increased appetite and ingestion of food [typically junk food])						
Hypnagogic hallucinations (seeing or hearing things that aren't really there) when falling asleep						
Hypnopompic hallucinations (seeing or hearing things that aren't really there) when waking up						
Automatic behavior (doing something without realizing/being aware) - Automatic behavior usually happens when sleepy but trying to stay awake (e.g., arriving at a destination without being able to recall how)						

SLEEP SCHEDULE

Please answer the following questions as they relate to a workday (which would include paid employment, volunteer work, school, or other obligations that require the participant to be out of bed at a specific time) or non-workday (any day in which the participant does not have to be up at a specific time).

13. What time does the participant usually go to bed on workdays (ONLY SELECT either AM/PM)?

_____ : _____ AM OR _____ : _____ PM

14. What time does the participant usually wake up on workdays (ONLY SELECT ONE AM/PM)?

_____ : _____ AM OR _____ : _____ PM

15. What time does the participant usually get out of bed for their workday (ONLY SELECT ONE AM/PM)?

_____ : _____ AM
OR _____ : _____ PM

16. How long does the participant usually sleep (NOT just lying in bed) at night on workdays?

Hours: _____ Minutes: _____

17. What time does the participant usually go to bed on non-workdays? (ONLY SELECT ONE AM/PM)

_____ : _____ AM
OR _____ : _____ PM

18. When does the participant usually wake up on non-workdays? (ONLY SELECT ONE AM/PM)

_____ : _____ AM
OR _____ : _____ PM

19. What time does the participant usually get out of bed for their non-workday? (ONLY SELECT ONE AM/PM)

_____ : _____ AM
OR _____ : _____ PM

20. How long does the participant usually sleep (NOT just lying in bed) at night on non-workdays?

_____ Hours & _____ Minutes

21. How long does the participant usually need to sleep in order to feel rested when they wake up for the day?

Not applicable – participant never feels rested

_____ Hours & _____ Minutes

PHYSICIAN/MEDICAL PROFESSIONALS

22. How many doctors or medical professionals has the participant seen while trying to get a diagnosis/treatment for their excessive sleepiness or need for sleep? (0-25)

23. What type of doctor or medical professional diagnosed the participant’s hypersomnia (gave a name to their excessive sleepiness or need for sleep)? Please select all that apply.

Not applicable – participant’s excessive sleepiness or need for sleep has never been diagnosed. If not applicable, please skip to question 24.

Nurse practitioner

General psychiatrist

Physician assistant

Sleep doctor - Neurologist

General internist

Sleep doctor - Psychologist

Family physician

Sleep doctor – Psychiatrist

General neurologist

Sleep doctor – Pulmonary/lung specialist

Pediatrician

Sleep doctor – Specialty Unknown

Other medical professional (please specify below)

If “Other medical professional”, please specify: _____

DIAGNOSES

24. Please indicate whether any of the following disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant’s doctor indicated that this disease or disorder was the cause of the participant’s excessive sleepiness or need for sleep.

Disease or disorder	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant’s excessive sleepiness or need for sleep
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Acromegaly				
Alzheimer disease				
Diabetes (type 1 or 2)				
Dysautonomia				
Hypothyroidism				
Myotonic dystrophy				
Obesity				
Parkinson disease				
Postural orthostatic tachycardia				

25. Please indicate whether any of the following disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep
Alcoholism				
Anxiety				
Attention deficit disorder (ADD)/Attention-deficit hyperactivity disorder (ADHD)				
Bipolar disorder				
Depression				
Seasonal affective disorder				
Substance abuse (including prescribed medication or other substances)				

26. Please indicate whether any of the following disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep
Connective tissue disorder				
Ehlers-Danlos syndrome				
Fibromyalgia				
Systemic exertion intolerance disease (also known as chronic fatigue syndrome, myalgic encephalopathy or myalgic encephalomyelitis)				

27. Please indicate whether any of these circadian rhythm disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep
Advanced sleep phase syndrome				
Delayed sleep phase syndrome				
Non-24-hour sleep-wake disorder				
Shift work sleep disorder				

28. Please indicate whether any of the following disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep
Brain tumor				
Encephalopathy				
Epilepsy or seizures				
Headaches; Chronic				
Headaches; Migraine				
Head trauma (concussion, whiplash, traumatic brain injury, loss of consciousness)				
Hydrocephalus				

29. Please indicate whether any of these hypersomnolence disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep
Hypersomnia (not otherwise specified)				
Idiopathic hypersomnia				
Kleine-Levin syndrome				
Narcolepsy; Type 1 (with cataplexy or hypocretin deficiency)				
Narcolepsy; Type 2 (without cataplexy or hypocretin deficiency)				
Narcolepsy; Type not specified				

30. Please indicate whether any of these parasomnias were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep
Acting out dreams during sleep (REM sleep behavior disorder)				
Body rocking				
Head banging during sleep (jactatio capitis nocturna)				
Sleep talking (somniloquy)				
Sleep walking (somnambulism)				

31. Please indicate whether any of the following disorders were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep
Insufficient sleep (that is, the participant just needs to sleep more)				
Periodic limb movements of sleep				
Restless legs syndrome				

32. Please indicate whether any of these forms of sleep apnea were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep
Sleep apnea; Central				
Sleep apnea; Obstructive				
Sleep apnea; Mixed				
Upper airway resistance syndrome				

33. If the participant's sleepiness or excessive need for sleep began after an infection, please select the most appropriate responses below.

Infection	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep
Epstein-Barr virus				
Encephalitis				
Encephalitis lethargica (sleepy sickness)				
Guillain-Barre syndrome				
H1N1/Swine flu				
HIV/AIDS				
Meningitis				
Mononucleosis or mono				
Whipple's disease				
Other infection (specify below)				

If "Other infection", please specify:

34. Please indicate whether any of these types of strokes were a diagnosis the participant had in the past or the participant currently has and whether the participant's doctor indicated that this disease or disorder was the cause of the participant's excessive sleepiness or need for sleep.

Disease or disorder	Never been diagnosed	Diagnosed in the past, but no longer a diagnosis	Current diagnosis	Doctor said this was/is a cause of the participant's excessive sleepiness or need for sleep
Stroke; Bleed (hemorrhagic)				
Stroke; Clot (thrombotic or embolic)				
Stroke; Don't know				

35. If the participant's sleepiness or excessive need for sleep began after a diagnosis that is not listed, please specify below:

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36. Did the participant's excessive sleepiness or need for sleep begin shortly after receiving a vaccination?

Yes

No

If "Yes", please select all that apply:

Human papillomavirus (HPV)

Seasonal influenza (flu)

Meningococcal meningitis

Other vaccine (specify below)

If "Other vaccine", please specify: _____

MEDICATION

37. What stimulant medications has the participant been prescribed by a medical doctor or other medical professional for their excessive sleepiness or need for sleep? Please select ONLY ONE response for each row.

Medication	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day
Dexmethylphenidate (Focalin)				

Dextroamphetamine (Dexedrine)				
Lis-dexamfetamine (Vyvanse)				
Mazindol				
Methylphenidate (Ritalin, Metadate, Concerta, Daytrana)				
Mixed amphetamine salts (Adderall)				
Pemoline (Betanamin, Cylert, Tradon, and Ceractiv)				

If the participant's stimulant medication is not listed, please specify name(s) and whether the participant is currently taking this medication and, if so, how often:

Medication	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day

38. What wakefulness-promoting agents has the participant been prescribed by a medical doctor or other medical professional for their excessive sleepiness or need to sleep? Please select ONLY ONE response for each row.

Wakefulness-promoting agent	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day
Armodafinil (Nuvigi)				
Modafinil (Provigil)				

If the participant's wakefulness-promoting agent is not listed, please specify name(s) and whether the participant is currently taking this medication and, if so, how often:

Other wakefulness-promoting agent	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day

39. What sleeping pills (sedative/hypnotics) has the participant been prescribed by a medical doctor or other medical professional for their excessive sleepiness or need to sleep? Please select ONLY ONE response for each row.

Sleeping pill (sedative/hypnotics)	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day
Alprazolam (Xanax)				
Clonazepam (Klonopin)				
Diazepam (Valium)				
Doxepin (Silenor)				
Eszopiclone (Lunesta)				
Ramelteon (Rozerem)				
Suvorexant (Belsomra)				
Temazepam (Restoril)				
Trazodone (Desyrel, Oleptro)				
Triazolam (Halcion)				
Zaleplon (Sonata)				

Zolpidem (Ambien, Ambien CR, Intermezzon, Stilnox, Stilnoct, Sublinox, Hypnogen, Zonadin, Sanval, Zolsana)				
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If the participant's sedative/hypnotic medication is not listed, please specify name(s) and whether the participant is currently taking this medication and, if so, how often:

Other Sleeping pill (sedative/hypnotics)	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day

40. What antidepressant medication has a medical doctor or other medical professional ever prescribed for the participant for their excessive sleepiness or need to sleep? Please select ONLY ONE response for each row.

Antidepressant medication	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day
Amitriptyline (Elavil)				
Bupropion (Wellbutrin)				
Citalopram (Celexa)				
Clomipramine (Anafranil)				
Duloxetine (Cymbalta)				
Escitalopram (Lexapro)				
Fluoxetine (Prozac)				
Fluvoxamine (Luvox)				
Phenelzine (Nardil)				

Protriptyline (Vivactil)			
Sertraline (Zoloft)			
Tranlycypromine (Parnate)			
Venlafaxine (Effexor)			

If the participant's antidepressant medication is not listed, please specify name(s) and whether the participant is currently taking this medication and, if so, how often:

Other Antidepressant medication	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day

41. What thyroid supplements has a medical doctor or other medical professional ever prescribed for the participant for their excessive sleepiness or need to sleep? Please select ONLY ONE response for each row.

Thyroid supplement	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day
Armour Thyroid				
Levothyroxine (Synthroid)				
Liothyronine sodium (Cytomel)				

If the participant's thyroid supplement is not listed, please specify the name(s) and whether the participant is currently taking this medication and, if so, how often:

Other Thyroid supplement	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day

42. What other medications has a medical doctor or other medical professional ever prescribed for the participant for their excessive sleepiness or need to sleep?

Other medication	Never Taken	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day
Atomoxetine (Strattera)				
Baclofen				
Clarithromycin (Biaxin)				
Clonidine (Catapres, Dapvay)				
Flumazenil				
Guanfacine (Intuniv, Tenex)				
Melatonin				
Sodium oxybate (Xyrem)				

If the participant's medication for their excessive sleepiness or need to sleep is not listed in any of these sections, please specify name(s) and whether the participant is currently taking this medication and, if so, how often:

Other medication	Taken in the past, but not taking now	Currently taking at least once a week but less than every day	Currently taking every day or almost every day

43. Please list all of the participant's current prescription medications (which WERE NOT USED TO TREAT THEIR EXCESSIVE DAYTIME SLEEPINESS OR NEED FOR SLEEP) and what condition the medication is used to treat.

Other medication 1:	Condition for medication 1:
Other medication 2:	Condition for medication 2:
Other medication 3:	Condition for medication 3:

44. What over-the-counter and other non-pharmaceutical substances does the participant use to help treat their excessive sleepiness or need for sleep? Please select all that apply.

<input type="checkbox"/> Ephedrine	<input type="checkbox"/> Caffeine
<input type="checkbox"/> Energy drinks	<input type="checkbox"/> NMDA
<input type="checkbox"/> Khat	<input type="checkbox"/> Herbal or botanical products
<input type="checkbox"/> Cocaine	<input type="checkbox"/> Methamphetamine
<input type="checkbox"/> Melatonin	<input type="checkbox"/> Other (please specify)

If "Other", please specify: _____

Thank you for your participation!

Questions? Contact CoRDS Personnel

Sanford Research | 2301 East 60th Street North | Sioux Falls, South Dakota 57104

Phone (toll-free): 1 (877) 658-9192 | **Email:** CoRDS@sanfordhealth.org