Restless Legs Syndrome and Experience with Exercise

Start of Block: Consent

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![Text

Description automatically generated with medium confidence]()consent   
   
 **DESCRIPTION:** You are invited to participate in **a research study** on describing your own experiences with exercise and restless legs syndrome (RLS). You will be asked to complete an online survey that will ask questions regarding general demographic information (e.g., sex, race), your experience with RLS, your current physical activity levels, and your past experiences with exercise and symptoms of RLS. The purpose of this study is to provide a greater understanding of the role that exercise plays in the management of RLS as well as provide specific exercise recommendations for people with RLS.  
   
 **TIME INVOLVEMENT:** Your participation will take approximately 20-30 minutes. You will be able to save your progress and complete the survey at a later time for up to 1 week from the time you start the survey.  
   
 **RISKS AND BENEFITS:** The risks associated with this study are that you may experience feelings of discomfort or embarrassment when answering particular questions in the survey. The benefits which may reasonably be expected to result from this study are providing a better understanding of the effects of exercise on symptoms of RLS. **We cannot and do not guarantee or promise that you will receive any benefits from this study.**  
   
 **PAYMENTS:** You will not receive any payment for your participation.  
   
 **PARTICIPANT'S RIGHTS:** If you have read this form and have decided to participate in this project, please understand your **participation is voluntary** and you have the **right to withdraw your consent or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. The alternative is not to participate.** You have the right to refuse to answer particular questions. The results of this research study may be presented at scientific or professional meetings or published in scientific journals. Your individual privacy will be maintained in all published and written data resulting from the study.  
   
 **CONTACT INFORMATION:**  
 Questions: If you have any questions, concerns or complaints about this research, its procedures, risks and benefits, contact the Protocol Director, Dr. Emmanuel Mignot at (650) 725-6517.  
   
 Independent Contact: If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the Stanford Institutional Review Board (IRB) to speak to someone independent of the research team at (650)-723-5244 or toll free at 1-866-680-2906. You can also write to the Stanford IRB, Stanford University, 1705 El Camino Real, Palo Alto, CA 94306.  
   
 **Please print a copy of this page for your records.**  
   
 **If you agree to participate in this research, please select “Yes, I consent” below.** In doing so, you will be directed to continue the online survey.

* Yes, I consent to participate in this research study. (1)
* No, I do not consent to participate in this research study. (0)

Skip To: End of Survey If DESCRIPTION: You are invited to participate in a research study on describing your own experience... = No, I do not consent to participate in this research study.

End of Block: Consent

Start of Block: Demographics

Survey Introduction There are no correct or incorrect answers. Please answer all questions as completely and accurately as possible.

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dem\_age What is your current age (in years)?

▼ 18... 89+

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dem\_sex Sex

* Female (1)
* Male (2)
* Prefer not to answer (-55)

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dem\_race Race

* White (1)
* Black or African American (2)
* Asian (3)
* Latino/Latina (4)
* American Indian or Alaska Native (5)
* Native Hawaiian or Pacific Islander (6)
* Two or More (7)
* Other (8)

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dem\_height Height

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| Feet (1) | ▼ 1 ... 12 |
| Inches (2) | ▼ 1 ... 12 |

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dem\_weight Weight (lbs)

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End of Block: Demographics

Start of Block: RLS Clinical Characteristics

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rls\_diagnosis Have you been diagnosed with Restless Legs Syndrome (RLS)?

* Yes (1)
* No (0)

Display This Question:

If Have you been diagnosed with Restless Legs Syndrome (RLS)? = Yes

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rls\_diag\_year How old were you (in years) when you were diagnosed with restless legs syndrome (RLS)?

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Display This Question:

If Have you been diagnosed with Restless Legs Syndrome (RLS)? = Yes

rls\_diag\_physician What kind of doctor gave you the diagnosis of RLS? (e.g., primary care, sleep medicine, neurologist)

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rls\_bilateral When you have RLS symptoms, do you get them on both sides of your body or on just one side?

* Only on Left (Ex: only your left leg has symptoms) (1)
* Only on Right (Ex. only your right leg has symptoms) (2)
* Both Sides (Ex. you get RLS symptoms in both legs) (3)

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rls\_duration How many years have you been experiencing symptoms of RLS?

* Years (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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rls\_peak\_hour At what time do your symptoms usually start? (Example: 2:00 AM)

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| Time (18) | ▼ 12:00 midnight... 11:00 PM |

Display This Question:

If Sex = Female

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rls\_pregnancy\_start Did your RLS symptoms start during pregnancy?

* Yes (1)
* No (0)
* Don't Know (-55)

Display This Question:

If Sex = Female

And Did your RLS symptoms start during pregnancy? != No

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rls\_pregnancy\_stop Did your RLS symptoms stop after pregnancy?

* Yes (1)
* No (0)
* Don't Know (-55)

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rls\_treated Are you currently taking medication to manage your RLS symptoms?

* Yes (1)
* No (0)

Display This Question:

If Are you currently taking medication to manage your RLS symptoms? = Yes

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rls\_med\_responsive Does the medication you're taking for RLS relieve your symptoms?

* Completely Relieves Symptoms (2)
* Partially Relieves Symptoms (1)
* No Relief of Symptoms (0)

Display This Question:

If Are you currently taking medication to manage your RLS symptoms? = Yes

rls\_med\_name What is the name of your RLS Medication?

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Display This Question:

If Are you currently taking medication to manage your RLS symptoms? = Yes

rls\_med\_dose How much of the medication do you take? (Example: 300 mg)

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Display This Question:

If Are you currently taking medication to manage your RLS symptoms? = Yes

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rls\_med\_timing What time of day do you usually take your medication?

* Morning (1)
* Mid-day (2)
* At Dinner (3)
* At Bedtime (4)

Display This Question:

If Are you currently taking medication to manage your RLS symptoms? = Yes

rls\_med\_frequency How often do you take the medication?

* Regularly (1)
* As Needed (2)

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plm\_presence Do you experience periodic limb movements (repetitive involuntary leg movements that occur during or before sleep)?

* Yes (1)
* No (0)
* Don't Know (-55)

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secondary\_conditions Have you been diagnosed with iron deficiency anemia, renal disease, diabetes, radiculopathy, peripheral edema, or peripheral neuropathy?

* Yes (1)
* No (0)
* Don't Know (-55)

End of Block: RLS Clinical Characteristics

Start of Block: RLS Screening (RLS-SFDQ13)

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RLS-SFDQ13\_1 Do you have, or have you had, recurrent uncomfortable feelings or sensations in your legs while you are sitting or lying down?

* Yes (1)
* No (0)

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RLS-SFDQ13\_2 Do you, or have you had, a recurrent need or urge to move your legs while you were sitting or lying down?

* Yes (1)
* No (0)

Display This Question:

If Do you have, or have you had, recurrent uncomfortable feelings or sensations in your legs while y... = Yes

Or Do you, or have you had, a recurrent need or urge to move your legs while you were sitting or lyi... = Yes

RLS-SFDQ13\_3 Are you more likely to have these feelings when you are resting (either sitting or lying down) or when you are physically active?

* Resting (1)
* Active (2)

Display This Question:

If Do you have, or have you had, recurrent uncomfortable feelings or sensations in your legs while y... = Yes

Or Do you, or have you had, a recurrent need or urge to move your legs while you were sitting or lyi... = Yes

And Are you more likely to have these feelings when you are resting (either sitting or lying down) or... = Resting

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RLS-SFDQ13\_4 Do these feelings usually start when you are resting (either sitting or lying down)?

* Yes (1)
* No (0)

Display This Question:

If Do you have, or have you had, recurrent uncomfortable feelings or sensations in your legs while y... = Yes

Or Do you, or have you had, a recurrent need or urge to move your legs while you were sitting or lyi... = Yes

And Are you more likely to have these feelings when you are resting (either sitting or lying down) or... = Resting

And Do these feelings usually start when you are resting (either sitting or lying down)? = Yes

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RLS-SFDQ13\_5 If you get up or move around when you have these feelings do these feelings get any better while you actually keep moving?

* Yes (1)
* No (0)
* Don't Know (-55)

Display This Question:

If Do you have, or have you had, recurrent uncomfortable feelings or sensations in your legs while y... = Yes

Or Do you, or have you had, a recurrent need or urge to move your legs while you were sitting or lyi... = Yes

And Are you more likely to have these feelings when you are resting (either sitting or lying down) or... = Resting

And Do these feelings usually start when you are resting (either sitting or lying down)? = Yes

And If you get up or move around when you have these feelings do these feelings get any better while... != No

RLS-SFDQ13\_6 Which times of the day are these feelings **most** likely to occur? (Select one or more)

* Morning (1)
* Mid-day (2)
* Afternoon (4)
* Evening (5)
* Night (6)
* About equal at all times (7)

Display This Question:

If Do you have, or have you had, recurrent uncomfortable feelings or sensations in your legs while y... = Yes

Or Do you, or have you had, a recurrent need or urge to move your legs while you were sitting or lyi... = Yes

And Are you more likely to have these feelings when you are resting (either sitting or lying down) or... = Resting

And Do these feelings usually start when you are resting (either sitting or lying down)? = Yes

And If you get up or move around when you have these feelings do these feelings get any better while... != No

RLS-SFDQ13\_7 Which times of the day are these feelings **least**likely to occur? (Select one or more)

* Morning (1)
* Mid-day (2)
* Afternoon (4)
* Evening (5)
* Night (6)
* About equal at all times (7)

Display This Question:

If Do you have, or have you had, recurrent uncomfortable feelings or sensations in your legs while y... = Yes

Or Do you, or have you had, a recurrent need or urge to move your legs while you were sitting or lyi... = Yes

And Are you more likely to have these feelings when you are resting (either sitting or lying down) or... = Resting

And Do these feelings usually start when you are resting (either sitting or lying down)? = Yes

And If you get up or move around when you have these feelings do these feelings get any better while... != No

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RLS-SFDQ13\_8 Will simply changing leg position by itself *once* without continuing to move usually relieve these feelings?

* Usually relieves (1)
* Does not usually relieve (0)
* Don't know (-55)

Display This Question:

If Do you have, or have you had, recurrent uncomfortable feelings or sensations in your legs while y... = Yes

Or Do you, or have you had, a recurrent need or urge to move your legs while you were sitting or lyi... = Yes

And Are you more likely to have these feelings when you are resting (either sitting or lying down) or... = Resting

And Do these feelings usually start when you are resting (either sitting or lying down)? = Yes

And If you get up or move around when you have these feelings do these feelings get any better while... != No

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RLS-SFDQ13\_9a Are these feelings ever due to muscle cramps?

* Yes (1)
* No (0)
* Don't Know (-55)

Display This Question:

If Do you have, or have you had, recurrent uncomfortable feelings or sensations in your legs while y... = Yes

Or Do you, or have you had, a recurrent need or urge to move your legs while you were sitting or lyi... = Yes

And Are you more likely to have these feelings when you are resting (either sitting or lying down) or... = Resting

And Do these feelings usually start when you are resting (either sitting or lying down)? = Yes

And If you get up or move around when you have these feelings do these feelings get any better while... != No

And Are these feelings ever due to muscle cramps? != No

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RLS-SFDQ13\_9b Are they **always** due to muscle cramps?

* Yes (1)
* No (0)
* Don't Know (-55)

End of Block: RLS Screening (RLS-SFDQ13)

Start of Block: RLS Severity (sIRLS)

sIRLS\_instructions What day was 7 days ago? Think about your RLS during that day and the next 7 days up to today not just the most recent or RLS worse days. Report the usual (not most or least severe) effects of only RLS during the past 7 days regardless of any medications changes during that time Report effects of only RLS not other life or health problems in this past week.

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sIRLS\_1 In the past week…   
 Overall, how would you rate the RLS discomfort in your legs or arms?

* Very Severe (4)
* Severe (3)
* Moderate (2)
* Mild (1)
* None (0)

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sIRLS\_2 In the past week…   
 Overall, how would you rate the need to move around because of your RLS symptoms?

* Very Severe (4)
* Severe (3)
* Moderate (2)
* Mild (1)
* None (0)

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sIRLS\_3 In the past week…   
Overall, how much relief from your RLS arm or leg discomfort did you get from moving around?

* No Relief (4)
* Mild Relief (3)
* Moderate Relief (2)
* Either complete or almost complete relief (1)
* No RLS symptoms to be relieved (0)

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sIRLS\_4 In the past week…   
How severe was your sleep disturbance due to your RLS symptoms?

* Very Severe (4)
* Severe (3)
* Moderate (2)
* Mild (1)
* None (0)

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sIRLS\_5 In the past week…   
How severe was your tiredness or sleepiness during the day due to your RLS symptoms?

* Very Severe (4)
* Severe (3)
* Moderate (2)
* Mild (1)
* None (0)

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sIRLS\_6 In the past week…   
How severe was your RLS on the whole?

* Very Severe (4)
* Severe (3)
* Moderate (2)
* Mild (1)
* None (0)

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sIRLS\_7 In the past week…   
How often did you get RLS symptoms?

* Very often (This means 6-7 days per week) (4)
* Often (This means 4-5 days per week) (3)
* Sometimes (This means 2-3 days per week) (2)
* Occasionally (This means 1 day a week) (1)
* Never (0)

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sIRLS\_8 In the past week…   
When you had RLS symptoms, how severe were they on average?

* Very severe (This means 8 hours or more per 24-hour day) (4)
* Severe (This means 3-8 hours per 24-hour day) (3)
* Moderate (This means 1-3 hours per 24-hour day) (2)
* Mild (This means less than 1 hour per 24-hour day) (1)
* None (0)

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sIRLS\_9 In the past week…   
Overall, how severe was the impact of your RLS symptoms on your ability to carry out your daily activities, for example having a satisfactory family, home, social, school or work life?

* Very Severe (4)
* Severe (3)
* Moderate (2)
* Mild (1)
* None (0)

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sIRLS\_10 In the past week…   
How severe was your mood disturbance due to your RLS symptoms - for example being angry, depressed, sad, anxious or irritable?

* Very Severe (4)
* Severe (3)
* Moderate (2)
* Mild (1)
* None (0)

End of Block: RLS Severity (sIRLS)

Start of Block: Physical Activity Levels (IPAQ)

IPAQ\_instructions We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives.  The questions will ask you about the time you spent being physically active in the **last 7 days**.  Please answer each question even if you do not consider yourself to be an active person.  Please think about the activities you do at work, as part of your house and yard work, to get from place to place, and in your spare time for recreation, exercise or sport.

IPAQ\_1 Think about all the **vigorous** activities that you did in the **last 7 days**. **Vigorous** physical activities refer to activities that take hard physical effort and make you breathe much harder than normal. Think *only* about those physical activities that you did for at least 10 minutes at a time.   
    
During the **last 7 days**, on how many **days** did you do **vigorous** physical activities like heavy lifting, digging, aerobics, or fast bicycling?

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|  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

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| Days () |  |

Display This Question:

If Think about all the vigorous activities that you did in the last 7 days. Vigorous physical activi... [ Days ] > 0

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IPAQ\_2 How many minutes did you usually spend doing **vigorous** physical activities on one of those days?

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IPAQ\_3 Think about all the **moderate** activities that you did in the **last 7 days**.  **Moderate** activities refer to activities that take moderate physical effort and make you breathe somewhat harder than normal.  Think only about those physical activities that you did for at least 10 minutes at a time.     During the **last 7 days**, on how many **days** did you do **moderate** physical activities like carrying light loads, bicycling at a regular pace, or doubles tennis?  Do not include walking.

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|  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

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Display This Question:

If Think about all the moderate activities that you did in the last 7 days.  Moderate activities ref... [ Days ] > 0

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IPAQ\_4 How many minutes did you usually spend doing **moderate** physical activities on one of those days?

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IPAQ\_5 Think about the time you spent **walking** in the **last 7 days**.  This includes at work and at home, walking to travel from place to place, and any other walking that you have done solely for recreation, sport, exercise, or leisure. During the **last 7 days**, on how many days did you **walk** for at least 10 minutes at a time?

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|  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

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| Days () |  |

Display This Question:

If Think about the time you spent walking in the last 7 days.  This includes at work and at home, wa... [ Days ] > 0

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IPAQ\_6 How many minutes did you usually spend **walking** on one of those days?

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IPAQ\_7 The last question is about the time you spent **sitting** on weekdays during the **last 7 days**.  Include time spent at work, at home, while doing course work and during leisure time.  This may include time spent sitting at a desk, visiting friends, reading, or sitting or lying down to watch television. During the **last 7 days**, how much time did you spend **sitting** on a **week day**?

* Hours (1) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* Minutes (3) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

End of Block: Physical Activity Levels (IPAQ)

Start of Block: Positive Experiences with PA

pos\_exp\_explanation The following questions ask about your own, personal experience with exercise and how exercise has affected your symptoms of RLS. Please consider your overall experience with exercise on average (not just the best or worst).

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pos\_exp\_better\_cat Have you noticed that exercise has made your RLS symptoms **better**?

* Definitely No (0)
* Sometimes (1)
* Definitely Yes (2)

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pos\_exp\_TOD\_better Exercising at what time of day makes your symptoms **better** at night? (Select all that apply)

* Early morning (4 AM - 8 AM) (1)
* Mid-morning (8 AM - 12 PM) (2)
* Mid-day (12 PM - 4 PM) (3)
* Afternoon (4 PM - 8 PM) (4)
* Evening/Night (8 PM - 11 PM) (5)
* Don't Know (-55)

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pos\_exp\_essay Based on your previous experiences, please explain and/or describe the type of exercises that makeyour RLS symptoms **better**(no word limit).

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End of Block: Positive Experiences with PA

Start of Block: Negative Experiences with PA

neg\_exp\_explanation The following questions ask about your own, personal experience with exercise and how exercise has affected your symptoms of RLS. Please consider your overall experience with exercise on average (not just the best or worst).

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neg\_exp\_worse\_cat Have you noticed that exercise has made your RLS symptoms **worse**?

* Definitely No (0)
* Sometimes (1)
* Definitely Yes (2)

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neg\_exp\_TOD\_worse Exercising at what time of day makes your symptoms worse at night? (Select all that apply)

* Early morning (4 AM - 8 AM) (1)
* Mid-morning (8 AM - 12 PM) (2)
* Mid-day (12 PM - 4 PM) (3)
* Afternoon (4 PM - 8 PM) (4)
* Evening/Night (8 PM - 11 PM) (5)
* Don't Know (-55)

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neg\_exp\_essay Based on your previous experiences, please explain what exercise or physical activity has made your symptoms worse (provide examples of the types of exercise that you have found to **worsen** your RLS symptoms). (No word limit)

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ex\_questions What questions do you have about exercise?

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End of Block: Negative Experiences with PA

Start of Block: Program Evaluation

program\_description We have designed the following exercise program based on previous research and recommendations by the Center for Disease Control (CDC) and the American College of Sports Medicine (ACSM):   **3 times/week for 12 weeks**– 2 sessions in person with an exercise specialist + at least 1 session on own at home   **Cardiovascular Exercise** (walking/jogging, bicycling): 30 minutes per day, 3 days/week at moderate-to-vigorous intensity   
 **Strength training**: 8-10 multi-joint exercises on 2 nonconsecutive days/week targeting major muscle groups (e.g., quadriceps, hamstrings, abdomen, chest, back, shoulders, biceps, triceps) - approximately 30 minutes Beginner Intensity: 1-3 sets of 8-12 repetitions per exercise  
 Advanced Intensity: 2-6 sets of 1-8 repetitions per exercise   
 Example week:

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program\_need Do you think people with RLS need an exercise program specifically made for people with RLS?

* Yes (1)
* No (0)

|  |
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|  |

program\_interest Is this an exercise program you would be interested in?

* Yes (1)
* No (0)

Display This Question:

If Is this an exercise program you would be interested in? = Yes

program\_interst\_whyY Why does this program interest you? Are there any changes you would like to see?

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Display This Question:

If Is this an exercise program you would be interested in? = No

program\_interst\_whyN Why is this program not of interest to you? What changes would you like to see?

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program\_likelihood If this exercise program was available to you locally, how likely would you be to participate in the program?

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| --- | --- | --- | --- | --- | --- |
|  | Extremely unlikely (1) | Somewhat unlikely (2) | Neither likely nor unlikely (3) | Somewhat likely (4) | Extremely likely (5) |
| Likelihood to participate (1) |  |  |  |  |  |

program\_barriers What would prevent you from participating in this exercise program? (No word limit)

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| Page Break |  |

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program\_EXSE How confident are you that you would be able to complete the exercise program previously described on 3 days per week without quitting?   
    
Example week:

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 0% (0) | 10% (10) | 20% (20) | 30% (30) | 40% (40) | 50% (50) | 60% (60) | 70% (70) | 80% (80) | 90% (90) | 100% (100) |
| for TWO weeks (1) |  |  |  |  |  |  |  |  |  |  |  |
| for FOUR weeks (2) |  |  |  |  |  |  |  |  |  |  |  |
| for SIX weeks (3) |  |  |  |  |  |  |  |  |  |  |  |
| for EIGHT weeks (4) |  |  |  |  |  |  |  |  |  |  |  |
| for TEN weeks (5) |  |  |  |  |  |  |  |  |  |  |  |
| for ELEVEN weeks (6) |  |  |  |  |  |  |  |  |  |  |  |
| for TWELVE weeks (7) |  |  |  |  |  |  |  |  |  |  |  |

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program\_tolerability Based on your own experience with exercise, do you think this exercise program would be well tolerated by people with RLS?

* Probably Yes (1)
* Maybe (-55)
* Probably Not (0)

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program\_efficacy Based on your own experience with exercise, do you think this program would make RLS symptoms worse or better?

* Much worse (1)
* Somewhat worse (2)
* About the same (3)
* Somewhat better (4)
* Much better (5)

End of Block: Program Evaluation