Supplementary online-only material for Pimentel Maldonado DA, Moreno A, Williams MJ, Amezcua L, Feliciano S, Williams A, Machemer D, Livingston T, LaRocque M, Glim M, Schmidt H: Perceptions and preferences regarding multiple sclerosis research among racial and ethnic groups. Int J MS Care. *2021;23(4):170-177.*

Table S1. **Multiple sclerosis (MS) characteristics of survey respondents**

	African American N= 215	*White N= 2111*	*P value*	*Hispanic N= 188*	*Non-Hispanic N= 2369*	*Ethnicity Unknown N= 42*	*P value*
Years since diagnosis			<.001				<.001
0-5	68 (31.62%)	542 (25.67%)		75 (39.89%)	620 (26.17%)	9 (21.42%)	
6-10	61 (28.37%)	454 (21.50%)		45 (23.93%)	516 (21.78%)	8 (19.04%)	
11 or more	80 (37.20%)	1089 (51.58%)		65 (34.57%)	1201 (50.69%)	24 (57.14%)	
No answer	6 (2.79%)	26 (1.23%)		3 (1.59%)	32 (1.35%)	1 (2.38%)	
Site of normal MS care			.4				.3
MS center	73 (33.95%)	702 (33.25%)		56 (29.78%)	798 (33.68%)	13 (30.95%)	
General neurology clinic	123 (57.20%)	1171 (55.47%)		110 (58.51%)	1295 (54.66%)	21 (50.00%)	
Primary care clinic	7 (3.25%)	69 (3.26%)		7 (3.72%)	82 (3.46%)	2 (4.76%)	
Not sure / other / no treatment	12 (5.58%)	164 (7.76%)		14 (7.44%)	189 (7.97%)	4 (9.52%)	
No answer	0 (0.00%)	5 (0.23%)		1 (0.53%)	5 (0.21%)	2 (4.76%)	
Provider of normal MS care			.05				<.001
MS specialist	117 (54.41%)	1221 (57.83%)		103 (54.78%)	1361 (57.45%)	27 (64.28%)	
General neurologist	88 (40.93%)	737 (34.91%)		82 (43.61%)	832 (35.12%)	13 (30.95%)	
Primary care clinician	2 (0.93%)	71 (3.36%)		0 (0.00%)	80 (3.37%)	0 (0.00%)	
Not sure / other / no treatment	7 (3.25%)	76 (3.60%)		2 (1.06%)	86 (3.63%)	2 (4.76%)	
No answer	1 (0.46%)	6 (0.28%)		1 (0.56%)	10 (0.42%)	0 (0.00%)	
Frequency of MS care visits			<.001				.01
Every 6 months or more often	175 (81.39%)	1600 (75.79%)		155 (82.44%)	1790 (75.55%)	30 (71.42%)	
Yearly or less often	40 (18.60%)	503 (23.82%)		33 (17.55%)	568 (23.97%)	12 (28.57%)	
No answer	0 (0.00%)	8 (0.37%)		0 (0.00%)	1 (0.04%)	0 (0.00%)	
Currently taking MS medicine?			.01				.2
Yes	184 (85.58%)	1652 (78.25%)		157 (83.51%)	1862 (78.59%)	32 (76.19%)	
No	31 (14.41%)	453 (21.45%)		31 (16.48%)	499 (21.06%)	10 (23.80%)	
No answer	0 (0.00%)	6 (0.28%)		0 (0.00%)	8 (0.33%)	0 (0.00%)	

Figure S1. **Consideration of research study activities by ethnicity and race**

Percentages given are for “would consider it” and “probably would consider it” responses. AA indicates African American

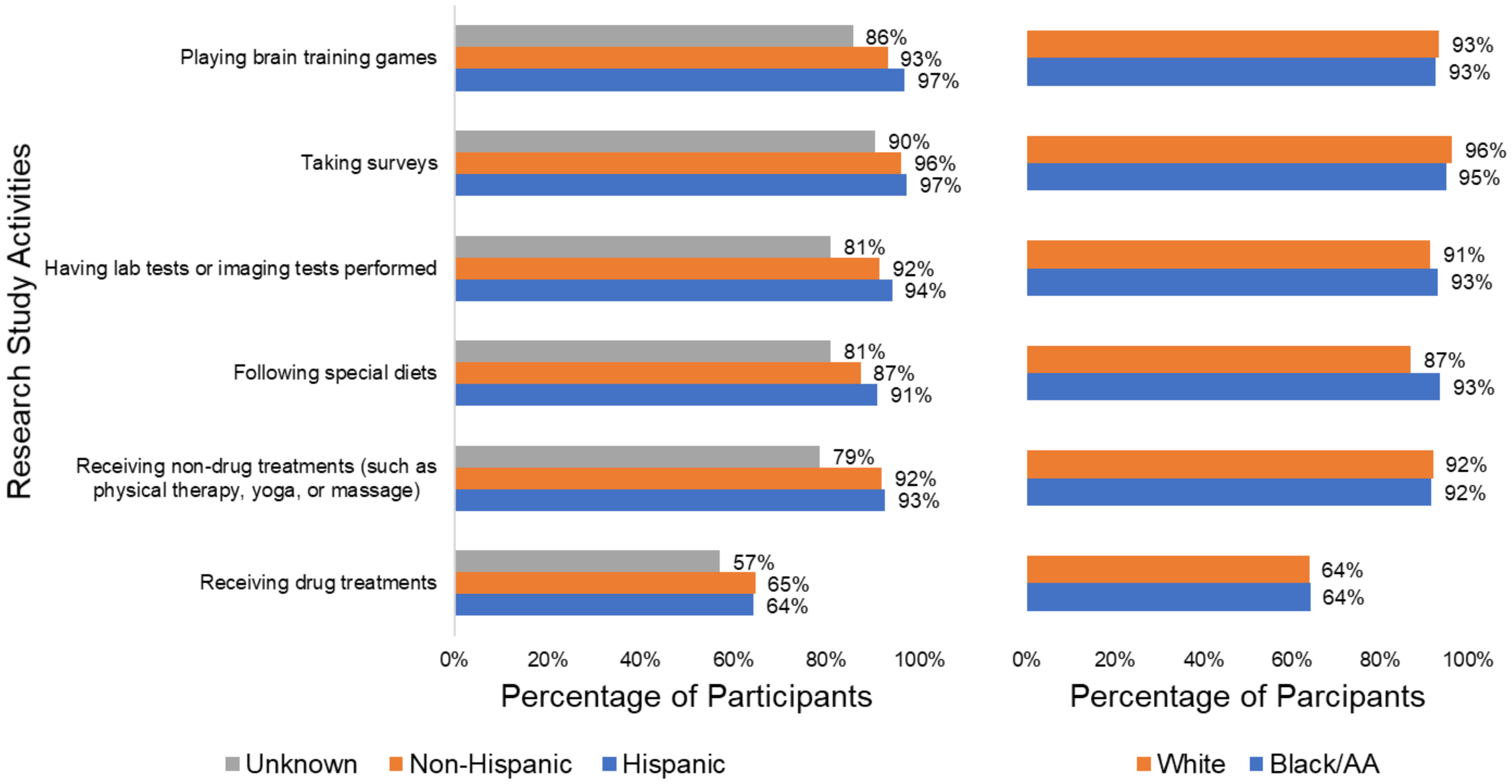


Figure S2. **Concerns regarding participation in research by ethnicity and race**

Percentages shown for "minor concern and "strong concern." AA indicates African American.

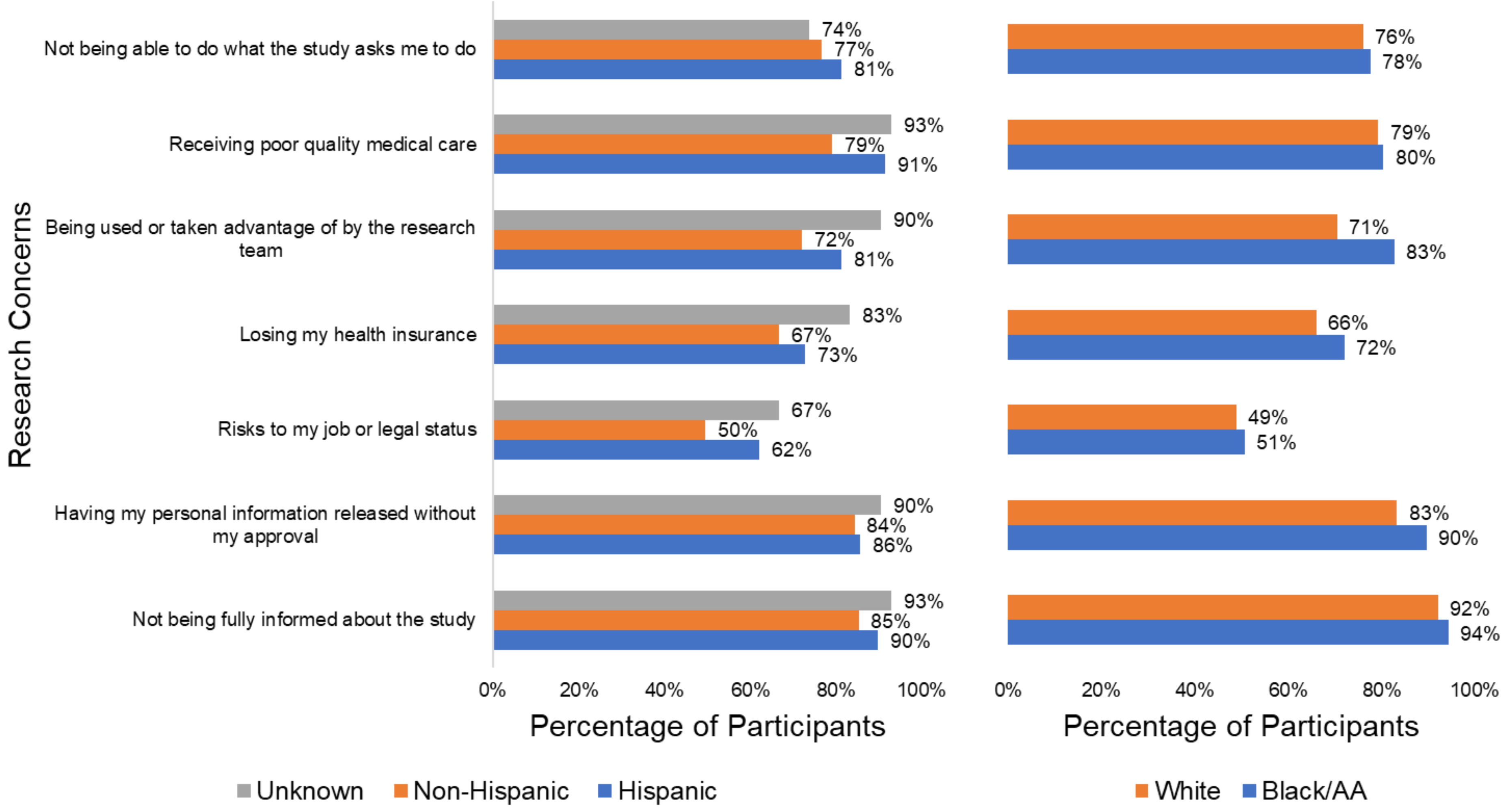
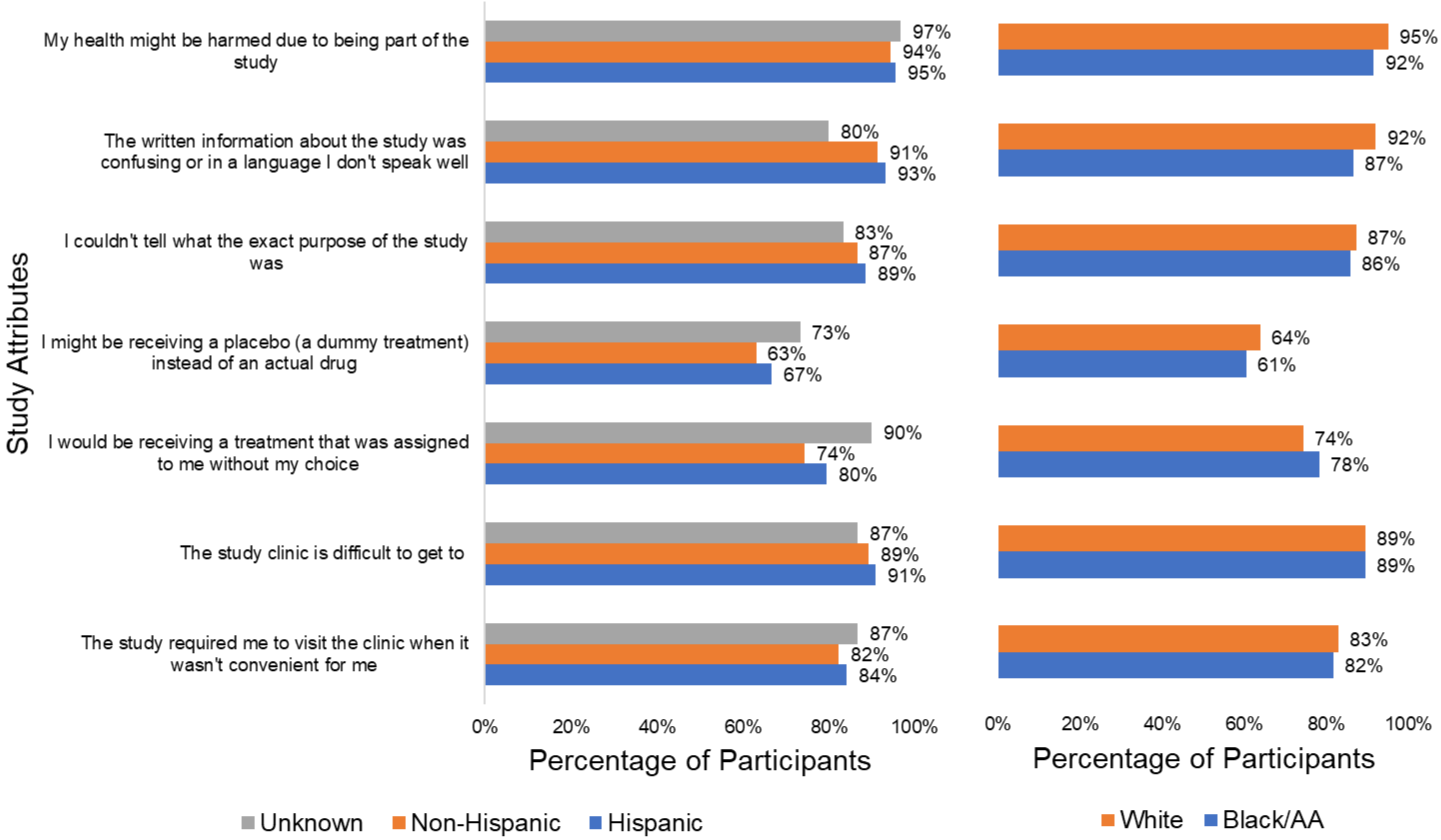


Figure S3. **Disliked research study attributes by ethnicity and race**

Percentages shown for "I wouldn't like it at all" and "I would dislike it somewhat." AA indicates African American.



Appendix S1. **Survey**

Multiple Sclerosis Research Participation Survey

Thank you for your interest in this survey. We are a group of people with multiple sclerosis, doctors and other health leaders working together.

We want to understand how people with MS from different backgrounds and races think about medical research. What do you think is important to study? What would help you be a part of a study?

If you are over 21 years of age and have multiple sclerosis, we invite you to complete the survey. The survey should take around 15 minutes to complete. This is an anonymous survey, and no one but our group will see your answers.

This study's sponsor is the Accelerated Cure Project, a nonprofit organization. It is funded by the nonprofit Patient-Centered Outcomes Research Institute.

Thank you for your time.

For more information about this project, click here. If you have any questions, please send an email to msminorityresearch@acceleratedcure.org.

1) **I have been diagnosed with MS and am at least 21 years old.***
( ) Yes
( ) No

(untitled)

This survey is only open to people who have been diagnosed with MS and are at least 21 years old. Thank you for your interest. If you would like to learn more about this project, please visit the MS Minority Research Engagement website.

Please tell us about your MS.

2) **How long ago were you diagnosed with MS?**
( ) Less than 1 year
( ) 1-5 years
( ) 5-10 years
( ) 10-20 years
( ) More than 20 years

3) **Where do you normally go to get medical care for your MS? If you receive MS medical care at more than one location, choose the one that provides most of this care.**
( ) MS center
( ) General neurology clinic or office
( ) Primary care clinic / community health center
( ) Other - Write In: ____
( ) I'm not sure
( ) I don’t receive treatment for my MS

4) **What type of health care provider do you normally see for your MS? If you see more than one person, choose the one who you see most often for your MS.**
( ) MS specialist
( ) General neurologist
( ) Primary care doctor or nurse
( ) I'm not sure
( ) Other - Write In: ____
( ) I don’t receive treatment for my MS

5) **Do you currently take medicine for your MS?**
( ) Yes
( ) No

6) **If yes, are you happy with how well it is working for you?**
( ) Yes
( ) No
( ) I can't tell / I don't know

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7) **When you think about the term "medical research," what comes to mind?**
____
____
____
____

8) **How much do you agree or disagree with the following statements:**

	Strongly disagree	**Somewhat disagree**	**Neutral**	**Somewhat agree**	**Strongly agree**
Medical research has led to better MS treatment	( )	( )	( )	( )	( )
There is not much left to be learned about MS	( )	( )	( )	( )	( )
More research with MS patients is needed	( )	( )	( )	( )	( )
Researchers can learn about MS without studying people with MS	( )	( )	( )	( )	( )

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9) **How important do you feel the following topics are for MS researchers to study?**

	Not at all important	**Somewhat important**	**Very important**
Treatments to keep MS from getting worse	( )	( )	( )
Treatments to improve MS symptoms	( )	( )	( )
Ways to prevent MS	( )	( )	( )
Ways to diagnose MS more quickly	( )	( )	( )
Non-drug treatments (such as yoga or massage)	( )	( )	( )
Diet and exercise	( )	( )	( )
How MS affects a person's lifestyle	( )	( )	( )

10) **Where would you go for information if you wanted to learn about research or find a study? (Check all that apply)**
[ ] Medical clinic
[ ] MS organizations (such as the National MS Society, the MS Association of America, or the MS Foundation)
[ ] Websites or blogs about MS
[ ] Social media websites such as Facebook and Twitter
[ ] Drug company websites
[ ] ClinicalTrials.gov
[ ] Other people with MS
[ ] Google/Internet search
[ ] My church / place of worship
[ ] Other - Write In: ____
[ ] I wouldn’t know where or how to find this information

11) **Which of these would you trust as sources of information about MS research? (Choose all that apply.)**
[ ] Your doctor or nurse
[ ] A hospital
[ ] A university

[ ] MS organizations
[ ] Television/radio
[ ] Newspaper/magazines
[ ] Leaders in your community
[ ] Friends and family members
[ ] Other people with MS
[ ] My church / place of worship
[ ] Other - Write In: ____
[ ] I wouldn’t trust any of these sources

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12) **Have you ever participated in a research study?**
( ) Yes
( ) No
( ) I don’t know

Logic: Hidden unless: Question "Have you ever participated in a research study?" #12 is one of the following answers ("Yes")
13) **What types of activities have you ever done as part of a research study? (Choose all that apply.)**
[ ] I received a medicine
[ ] I received another type of therapy (such as physical therapy, yoga or massage)
[ ] I had lab tests or imaging tests
[ ] I made a change to my diet
[ ] I answered a questionnaire
[ ] Other - Write In: ____

Logic: Show/hide trigger exists. Hidden unless: Question "Have you ever participated in a research study?" #12 is one of the following answers ("Yes")
14) **How did you learn about the research study you took part in? (Choose all that apply if you took part in more than one study.)**
[ ] Doctor or nurse
[ ] An Internet site
[ ] Friend/family
[ ] Another person with MS
[ ] Brochure or poster
[ ] Other - Write In: ____

Logic: Hidden unless: Question "How did you learn about the research study you took part in? (Choose all that apply if you took part in more than one study.)" #14 is one of the following answers ("An Internet site")
15) **Which website(s)?**

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Logic: Hidden unless: Question "Have you ever participated in a research study?" #12 is one of the following answers ("Yes")
16) **What was your experience with the study? (Answer for the most recent study if you have been in more than one.)**

	Disagree	**Neither agree nor disagree**	**Agree**
The research study directly helped me	( )	( )	( )
The research study helped people with MS overall	( )	( )	( )
Participating in the research study was a good experience	( )	( )	( )
I would participate in a future research study for MS	( )	( )	( )

Logic: Show/hide trigger exists. Hidden unless: Question "Have you ever participated in a research study?" #12 is one of the following answers ("No","I don't know")
17) **Have you ever considered participating in a research study?**
( ) Yes
( ) No
( ) Don't know/not sure

Logic: Show/hide trigger exists. Hidden unless: Question "Have you ever considered participating in a research study?" #17 is one of the following answers ("Yes")
18) **Why did you decide not to participate in the study?**
[ ] I didn't like one or more aspects of the study
[ ] I wasn't eligible to participate
[ ] The study wasn't enrolling participants
[ ] Other - Write In: ____

Logic: Hidden unless: Question "Why did you decide not to participate in the study?" #18 is one of the following answers ("I didn't like one or more aspects of the study")
19) **What aspect(s) of the study did you dislike?**
____
____
____
____

20) **Would you consider participating in a research study involving the following:**

	Would consider it	**Probably would consider it**	**Probably would not consider it**	**Would not consider it**
Receiving drug treatments	( )	( )	( )	( )
Receiving non-drug treatments (such as physical therapy, yoga, or massage)	( )	( )	( )	( )
Following special diets	( )	( )	( )	( )
Having lab tests or imaging tests performed	( )	( )	( )	( )
Taking surveys	( )	( )	( )	( )
Playing brain training games	( )	( )	( )	( )

21) **What types of studies would you prefer to participate in? Rank these options from 1 (most preferred) to 4 (least preferred).**
_________A study that involves visiting a medical clinic
_________A study taking place on the Internet (such as an Internet survey)
_________A study where I fill out a written survey or diary, or take a written test
_________A study where I answer questions over the phone

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22) **How important are the following concerns to you when considering participating in research?**

	Not a concern	**Minor concern**	**Strong concern**
Not being fully informed about the study	( )	( )	( )
Having my personal information released without my approval	( )	( )	( )
Risks to my job or legal status	( )	( )	( )
Losing my health insurance	( )	( )	( )
Being used or taken advantage of by the research team	( )	( )	( )
Receiving poor quality medical care	( )	( )	( )
Not being able to do what the study asks me to do	( )	( )	( )

23) **Do you have any other concerns about participating in research?**

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____
____
____

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24) **Imagine that you learned about a research study for MS. How would you feel if the study had the following features?**

	I wouldn't like it at all	**I would dislike it somewhat**	**It wouldn't matter to me**	**I would like it somewhat**	**I would like it very much**
I wasn't familiar with the researcher or the research clinic	( )	( )	( )	( )	( )
The study required me to visit the clinic several times	( )	( )	( )	( )	( )
The study required me to visit the clinic when it wasn't convenient for me	( )	( )	( )	( )	( )
The study clinic is difficult to get to	( )	( )	( )	( )	( )
I would be receiving a treatment that was assigned to me without my choice	( )	( )	( )	( )	( )
I might be receiving a placebo (a dummy treatment) instead of an actual drug	( )	( )	( )	( )	( )
The study didn't pay for costs such as child care or transportation	( )	( )	( )	( )	( )
The researcher was of a different race or ethnic group than me	( )	( )	( )	( )	( )
I couldn't tell what the exact purpose of the study was	( )	( )	( )	( )	( )
My family would not support my being part of the study	( )	( )	( )	( )	( )

The written information about the study was confusing or in a language I don't speak well	( )	( )	( )	( )	( )
My health might be harmed due to being part of the study	( )	( )	( )	( )	( )
I was familiar with the researcher and the research clinic	( )	( )	( )	( )	( )
My doctor personally told me about the study	( )	( )	( )	( )	( )
I would receive free health care as part of the study	( )	( )	( )	( )	( )
I would receive free drug treatment as part of the study	( )	( )	( )	( )	( )
My family would support my being part of the study	( )	( )	( )	( )	( )
The study would pay for costs such as transportation and child care	( )	( )	( )	( )	( )
I would be paid for participating in the study	( )	( )	( )	( )	( )
The study involved sending information through the Internet	( )	( )	( )	( )	( )
The researcher was of the same race or ethnic group as me	( )	( )	( )	( )	( )

The study included people of different races and ethnic groups	( )	( )	( )	( )	( )
I believed the research would benefit people with MS	( )	( )	( )	( )	( )
I believed the research would benefit people in my racial or ethnic group	( )	( )	( )	( )	( )
I would get the results of my individual tests during the study	( )	( )	( )	( )	( )
The researchers would tell me the study results once the study was done	( )	( )	( )	( )	( )
The topic was interesting to me	( )	( )	( )	( )	( )

25) **If you participated in a research study, what would you like the researchers to share with you? (Choose all that apply.)**
[ ] News about the progress of the study
[ ] A report on the study results and findings
[ ] Information about how the study will help me personally
[ ] Information about how the study will help people with MS
[ ] Information about how the study results will be used
[ ] My health information, shared with my doctor to improve my treatment
[ ] Other - Write In: ____

26) Do you have any other thoughts on the topic of research participation that you'd like to share?

____
____
____
____

Please tell us about yourself:

27) **Are you Hispanic or Latino?***
( ) Yes
( ) No
( ) I'm not sure / I don’t know
( ) I prefer not to answer

28) **Which of the following best describes your race? (You can choose more than one.)***
[ ] Black or African-American
[ ] American Indian or Alaskan Native
[ ] Asian
[ ] Native Hawaiian or other Pacific Islander
[ ] White/Caucasian
[ ] Other - Write In: ____
[ ] I'm not sure / I don’t know
[ ] I prefer not to answer

Logic: Show/hide trigger exists.
29) **What country do you currently live in?**
( ) United States
( ) Afghanistan
() etc.

Logic: Hidden unless: Question "What country do you currently live in?" #29 is one of the following answers ("United States")
30) **What state do you live in?**
( ) Alabama
( ) Alaska
( ) etc

31)
Which description best describes the area where you live?
( ) Urban/city
( ) Suburban/outside of a city
( ) Rural or small town (not near a city)
( ) I'm not sure / I prefer not to say

32) **What year were you born?**

____

33) **What is your sex?**
( ) Female
( ) Male
( ) Other - Write In: ____
( ) I prefer not to answer

34) **What is the highest level of education you have completed?**
( ) No formal education
( ) Elementary or middle school
( ) Some high school
( ) High school degree or equivalent (e.g., GED)
( ) Some college / associate degree
( ) Bachelor degree
( ) Graduate school / advanced degree
( ) Trade or other technical degree or certification
( ) I prefer not to answer

35) **Which range best represents your household income?**
( ) Less than $15,000
( ) $15,000 to $30,000
( ) $30,001 to $50,000
( ) $50,001 to $100,000
( ) $100,001 to $200,000
( ) $200,001 or more
( ) I prefer not to answer

Thank You!

Thank you for taking the time to complete this survey. Your answers will help us understand how people with MS feel about participating in research studies.

Please share this survey with any friends or family members with MS who may be interested.

If you would like to learn more about MS research, please visit the "For People with MS" section on the MS Minority Research Engagement website. You can request a copy of the final report of this survey there. Please note, your request for the survey results will not be linked to the information you provided in this survey.

Once again, thank you for participating in this survey!