



MS Minority Research Engagement

PARTNERSHIP NETWORK

Opinions and Experiences about Research

Results from a survey of people with MS
January 5, 2018

The background of the slide features a repeating pattern of stylized hands in a light gray color, arranged in a grid-like fashion. The hands are depicted in various orientations, some facing up and some facing down, creating a sense of interconnectedness and support. The pattern is set against a white background in the top and bottom sections, and a dark purple background in the middle section where the text is located. The middle section has a gradient from orange on the left to dark purple on the right.

Background

Why we conducted this survey

What is the MS Minority Research Engagement Partnership Network?

- We are a group of:
 - People with multiple sclerosis (MS)
 - Doctors, nurses, and scientists
 - People from MS non-profit organizations
 - People from minority health and support organizations
 - People from companies that provide MS treatments
 - Communications experts
- We have learned that MS research studies often don't include many people belonging to racial and ethnic minority groups.
- This is a concern because it keeps us from learning how MS affects people in minority groups. We're also not learning which treatments work best for them.
- We want to make sure that future research studies include **all** types of people so the results can be used to help **all** types of people.

Why did we conduct a survey?

- Some work has already been done to learn why participation in research studies is lower for people belonging to minority groups.
- However, this work has been conducted in other diseases. We wanted to find out which reasons were most important for **people with MS**.
- We also wanted to find out what types of benefits that could be offered by a research study would be most interesting to people with MS.
- By sharing our findings with researchers and health care providers, we hope to improve how research is designed and communicated so that it includes and helps all people with MS.

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Methods

How we created and conducted the survey

How the survey was developed

- The members of the network came up with a list of topics to include in our survey. For instance, we wanted to know how people felt about research in general, whether they had ever participated in research, and any concerns they had about research.
- We also looked at surveys that had been developed and used by other groups for additional ideas.
- Some of the members created a set of questions to ask in the survey. Other members reviewed these questions to make sure they could be understood.
- We had an expert translate the survey into Spanish. Members of the network who speak Spanish reviewed this version.

How the survey was conducted

- We set up the survey on an Internet site (SurveyGizmo.com) and tested it to make sure it was working correctly.
- We then invited people with MS to take the survey, with the help of other MS organizations who offered to assist us. We sent out:
 - Email invitations
 - Social media posts (Twitter, Facebook)
 - Paper hand-outs for MS clinics
- Email invitations from MS organizations got the most responses.
- After the survey had been up for two months, we closed the survey and downloaded the data.
- In total, over 2,600 people with MS took the survey. Most of the people who took the survey (93%) were living in the United States.

The background of the slide features a repeating pattern of stylized hands holding hands, rendered in a light grey color. This pattern is visible in the top and bottom sections of the slide, which have a white background. The central section of the slide is a large rectangle with a vertical gradient from orange on the left to dark purple on the right. The text is centered within this gradient area.

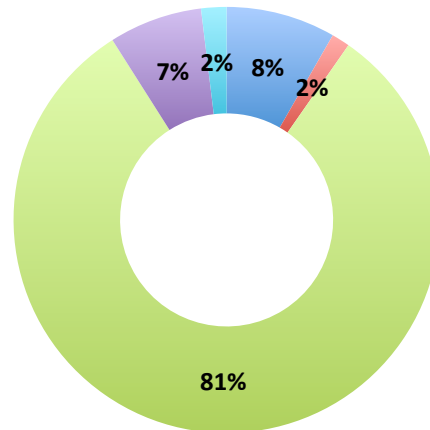
Results

What we learned from the survey

Who took the survey?

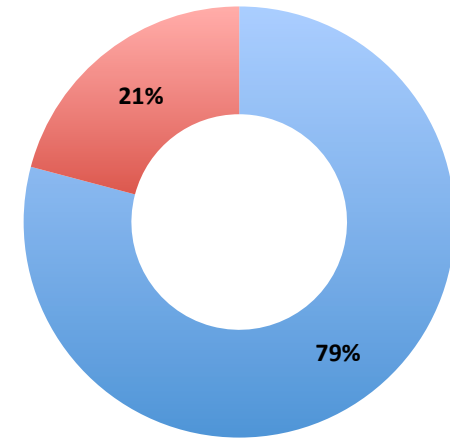
By racial group

- Black/African-American
- Native Hawaiian, Asian, American Indian
- White/Caucasian
- Multiracial or Other
- Preferred not to say



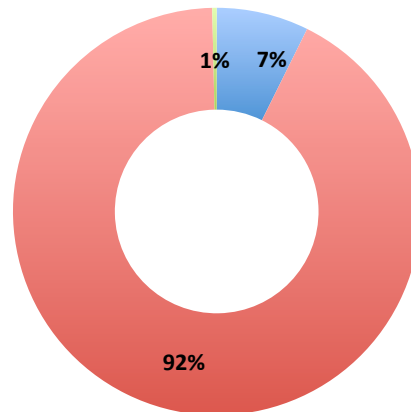
By sex

- Female
- Male

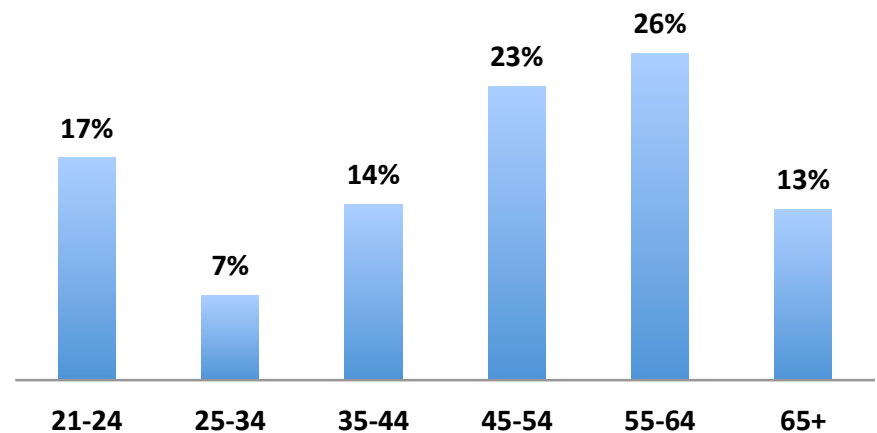


By ethnic group

- Hispanic or Latino/a
- Not Hispanic or Latino/a
- Don't know/Preferred not to say



By age

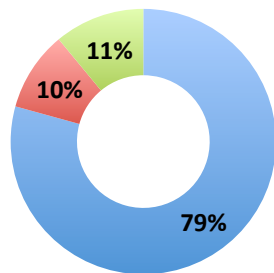


How people feel about MS research in general

We asked whether people agreed or not with the following statements:

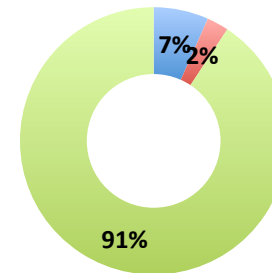
Medical research has led to better MS treatment

■ Agree ■ Neutral ■ Disagree



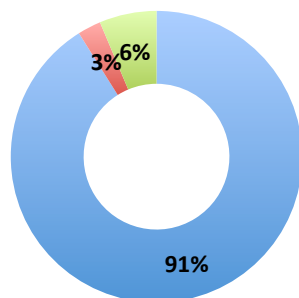
There is not much left to be learned about MS

■ Agree ■ Neutral ■ Disagree



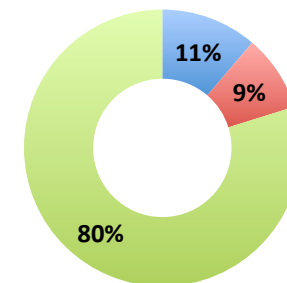
More research with MS patients is needed

■ Agree ■ Neutral ■ Disagree



Researchers can learn about MS without studying people with MS

■ Agree ■ Neutral ■ Disagree



How different groups responded

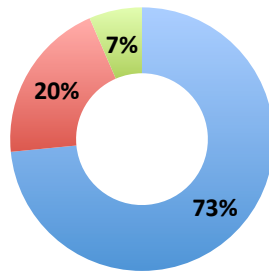
- We compared answers from people in different racial and ethnic groups. We included groups that had at least 150 people: African-Americans, Caucasians, Hispanics, and non-Hispanics.
- People across all groups generally agreed that:
 - Medical research has led to better MS treatments.
 - More research involving people with MS needs to be performed.
- African-Americans were more likely to be neutral than Caucasians on “Medical research has led to better MS treatment” (18% vs. 8%).
- More African-Americans disagreed with the statement “Researchers can learn about MS without studying people with MS” than Caucasians (85% vs. 79%).
- Hispanics were more likely to believe that “There is not much left to be learned about MS” than non-Hispanics (12% vs. 6%).
- But, in general, the responses to these statements were very similar across racial and ethnic groups.

Concerns about participating in research

We asked people how important the following 7 concerns were to them when considering participating in research.

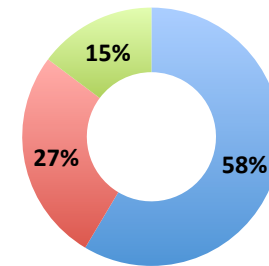
Not being fully informed about the study

■ Strong concern ■ Minor concern ■ Not a concern



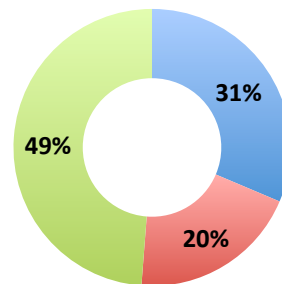
Having their personal information released without their approval

■ Strong concern ■ Minor concern ■ Not a concern



Risks to their jobs or legal status

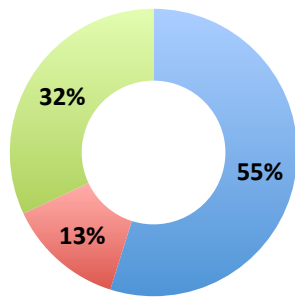
■ Strong concern ■ Minor concern ■ Not a concern



Concerns about participating in research

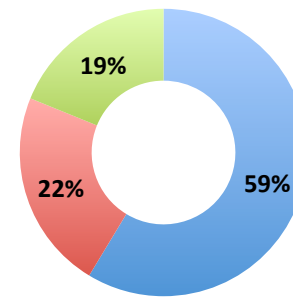
Losing their health insurance

■ Strong concern ■ Minor concern ■ Not a concern



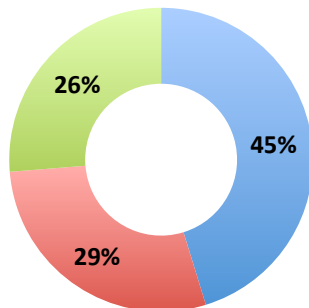
Receiving poor quality medical care

■ Strong concern ■ Minor concern ■ Not a concern



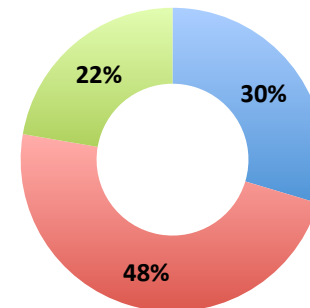
Being used or taken advantage of by the research team

■ Strong concern ■ Minor concern ■ Not a concern



Not being able to do what the study asks them to do

■ Strong concern ■ Minor concern ■ Not a concern

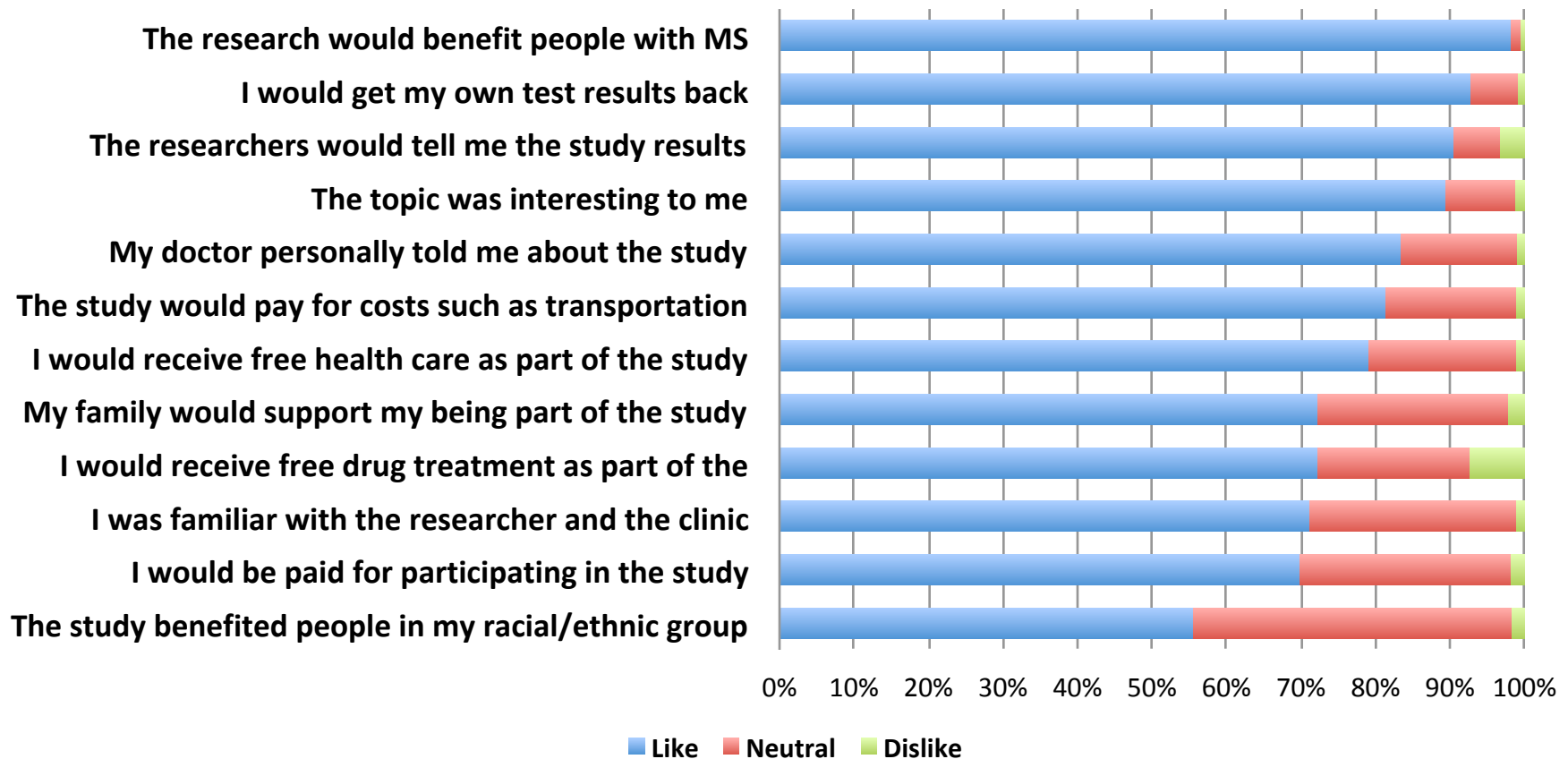


How different groups responded

- African-Americans and Hispanics were usually more likely than Caucasians and non-Hispanics to say that a risk or issue was a “strong concern.”
 - For example, African-Americans were more concerned than Caucasians about being used or taken advantage of by the research team (62% vs. 41%).
 - Also, 66% of African-Americans vs. 56% of Caucasians had a strong concern about having their personal information released without approval.
 - Hispanics were more likely to have a strong concern about risks to their jobs or legal status (44% vs. 30% for non-Hispanics).
 - And 71% of Hispanics compared with 57% of non-Hispanics had a strong concern about receiving poor quality medical care.
- Across all groups, the biggest concern had to do with not being fully informed about the study. 72% to 80% of each group said this was a strong concern.

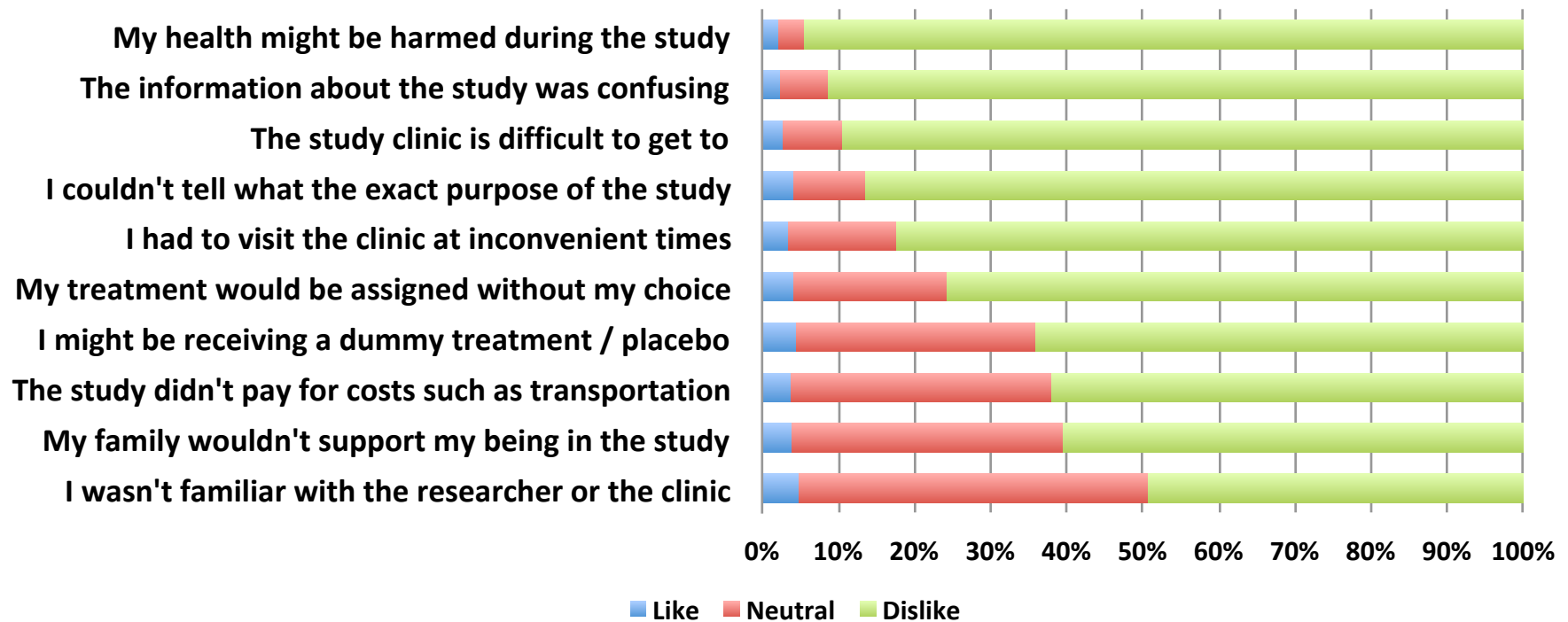
Likes and dislikes about research studies

We asked people to tell us how much they would like or dislike different aspects of research studies. Here are the aspects that they **liked** overall:



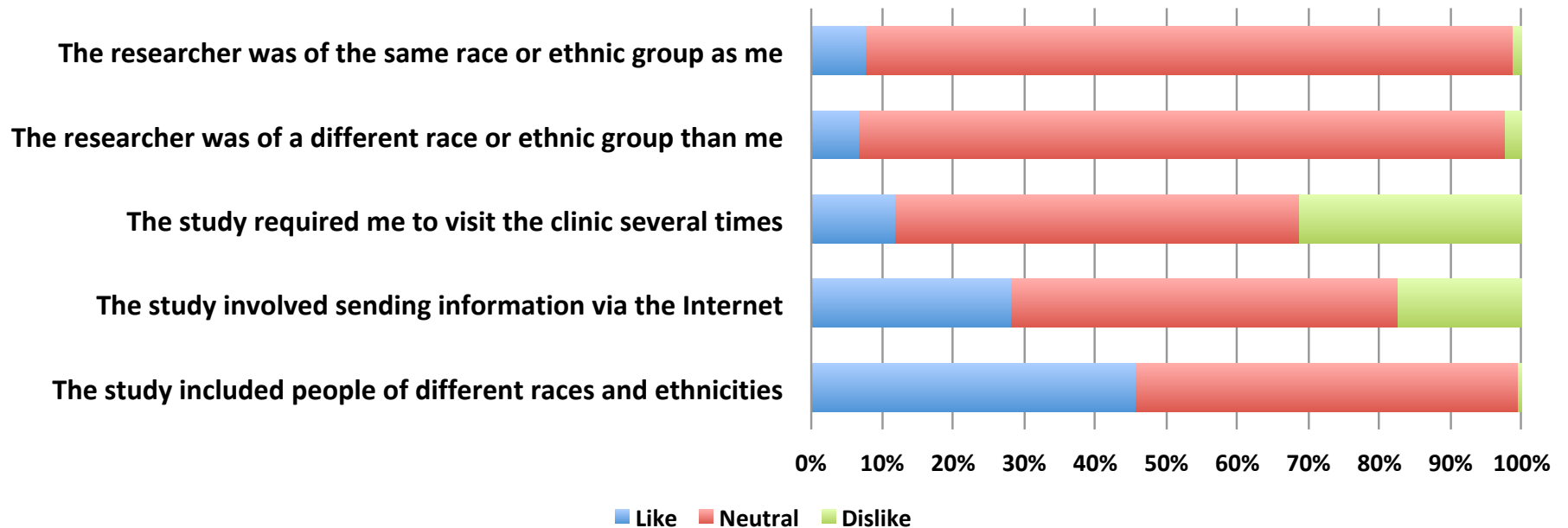
Likes and dislikes about research studies

Here are the aspects that people **disliked** overall:



Likes and dislikes about research studies

Finally, there were some aspects that didn't matter as much overall:

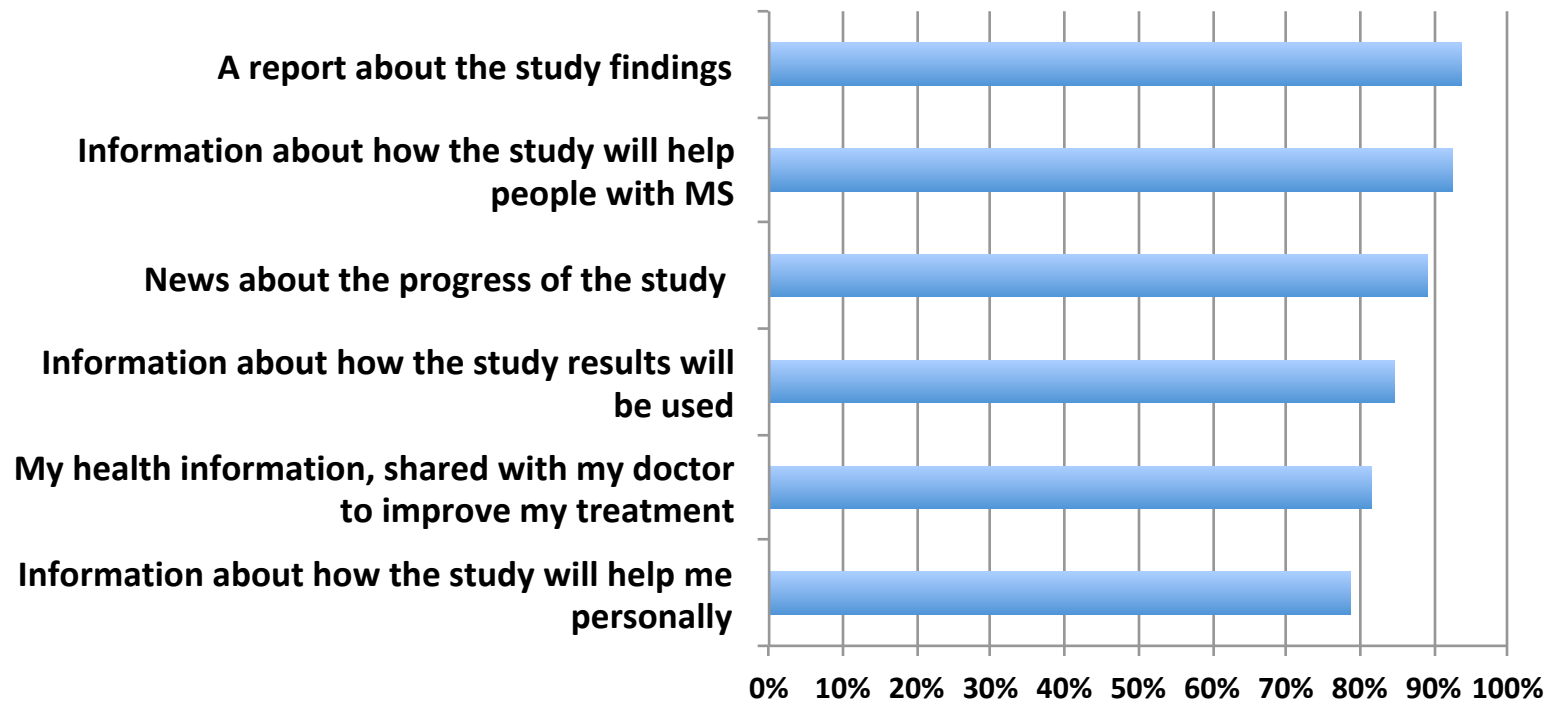


How different groups responded

- The factors that people **liked** the most were very similar across groups: People like research that benefits people with MS. They also like for researchers to share study results and test results with participants.
- African-Americans were more positive than Caucasians about research that benefited people in their racial/ethnic group (86% vs. 52%).
- African-Americans were also more likely to favor research that included people of different racial and ethnic groups (63% vs. 43%).
- The same was true for Hispanics. 77% of Hispanics vs. 55% of non-Hispanics liked research that benefits their racial/ethnic group.
- And 57% of Hispanics vs. 45% of non-Hispanics liked research that includes people of different racial and ethnic groups.
- The factors that people **disliked** the most were very similar across groups. These include possible health harms, confusing study information, and difficulty getting to the clinic.

What people would like to get in return

We also asked people to tell us what they would like the researchers to share with them if they participated in a study. Here are the results:



Sources of information about research

- We asked where people would **look** for information about research studies. The top sources were MS organizations and MS websites or blogs.
- We also asked who people would **trust** for information about research studies. The top two sources were doctors and nurses, and MS organizations.

Research experiences and interests

- We asked whether people had participated in research before.
 - 39% of our respondents had participated in a research study in the past.
 - 75% of these people thought it was a good experience, and 88% said they would participate in research again.
- We asked whether people would consider participating in research on different topics.
 - More than 90% of people would consider research that involved surveys, brain training games, non-drug treatments like yoga, or lab testing.
 - 88% of people said they would consider research involving special diets. African-Americans and Hispanics were more willing to consider this.
 - Research involving drug treatments was the least popular choice, but 65% still said they would consider it.

Conclusions

- The purpose of this survey was to ask people with MS about their experiences with research as well as their opinions about research. We wanted to see how people responded overall, and we also wanted to see if different racial or ethnic groups had different responses.
- In general, we found that responses from different groups were similar to each other. We also found that people across all groups had positive opinions about research and were willing to consider joining a research study.
- However, we did notice some differences. For example, African-Americans were more concerned about being taken advantage of by the research team. This is in line with other studies that have asked African-Americans for their opinions about research.
- We also found that both African-Americans and Hispanics had a greater preference for studies that might benefit their racial or ethnic community, and for studies that included people of different racial and ethnic groups.

Recommendations

- Based on the results of this survey, we can make some recommendations to researchers that may help them include more minority participants:
 - **Talk to people in minority groups about your study.** People of all racial and ethnic groups value research and are willing to consider taking part. However, some people never hear about opportunities to participate in research.
 - Show people in minority groups **how your research study will benefit them** and their communities.
 - **Explain the rules and processes that are in place to protect their health** and their rights as a research participant.
 - **Be sure to fully explain the study**, using words and phrases that everyone can understand. **Provide translations** for people who don't speak English.
 - **Show that you plan to give back to participants** by sharing information about the study, such as the study findings or progress reports.

Next steps

- We will be sharing our recommendations with scientists at meetings and on our web site.
- We will also be analyzing our findings in more detail. For instance, we will look into how other factors affect how people responded. These factors might have a stronger effect than race and ethnic group in some cases. They include:
 - Age and sex
 - Education and income level
 - MS factors such as time since diagnosis
- Finally, we will continue to talk with MS groups and individuals through events, publications, and social media. We will keep learning about how people with MS feel about research, and will work to make sure MS research helps all people.

Thanks to everyone who helped!

- Thank you to everyone who took the survey! We appreciate your taking the time to give us your input on this important topic.
- We also want to thank everyone who helped invite people to take the survey:
 - Can Do MS
 - MS Foundation
 - MS Views and News
 - The Shepherd Center, Atlanta GA
 - Stanford Neuroimmunology Clinic, Palo Alto CA
 - University of Texas Southwestern Medical Center, Dallas TX
- Thank you also to everyone who helped develop the survey, including people who shared information about similar studies and people who helped test our survey.

For more information

- Visit our web site to learn more about this project, including additional reports about this survey:
<https://www.acceleratedcure.org/ms-minority-research-network>
- Find information about research participation written for people with MS:
<https://www.acceleratedcure.org/people-ms>
- Contact us by email at msminorityresearch@acceleratedcure.org if you have any questions or would like to learn more about our project.

Thank you for your interest!

The MS Minority Research Engagement Partnership Network Members

Organizations:

Accelerated Cure Project * Ogilvy | FKH
Multiple Sclerosis Association of America * National Multiple Sclerosis Society
National Black Nurses Association * National Hispanic Medical Association
MANA, A National Latina Organization * National Minority Quality Forum
Biogen * Genentech

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April Moreno * Anita Williams * Mitzi Williams

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