

# STRENGTH IN DIVERSITY: HOW A MULTI-STAKEHOLDER PARTNERSHIP NETWORK IS ADDRESSING MINORITY UNDERREPRESENTATION IN MS RESEARCH

Hollie Schmidt, MS

Accelerated Cure Project for Multiple Sclerosis

# ABOUT MULTIPLE SCLEROSIS

MS is a disease of the central nervous system that affects nearly 1 million Americans

It is the most common disabling neurological disease among young adults

Effects include visual impairment, motor weakness/paralysis, bowel and bladder dysfunction, cognitive impairment, depression and anxiety, and many others

There are 17 FDA-approved disease-modifying therapies with more in the pipeline

- **But no evidence to support personalized choice of therapy**

MS is found worldwide, and is more common away from the equator

# TWO MISCONCEPTIONS ABOUT MS

Misconception #1:

MS is a white matter disease



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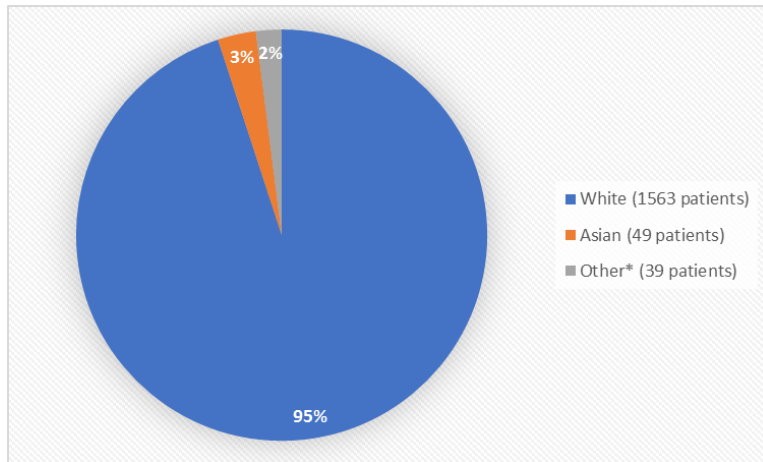


Misconception #2:  
MS is a white person's disease



# MINORITIES ARE MISSING IN MS RESEARCH

Siponimod, approved for MS in 2019



**Table 1. Demographics of Trials by Race**

Race	Number of Patients	Percentage of Patients
White	1563	95%
Black or African American	10	Less than 1%
Asian	49	3%
Other	29	2%

*From FDA's Drug Trials Snapshots*

# WHY DOES IT MATTER?

We can't apply results of studies to populations that weren't represented

- **No hope of personalized medicine for minorities with MS without greater inclusion and participation**

We have an incomplete picture of MS if everyone isn't included

- **For instance, what causes MS may be different from group to group**

Research priorities won't reflect topics that matter to everyone

- **Lack of inclusion and participation means lack of engagement; lack of engagement leads to lack of a voice in decision-making**

# HOW WE'RE ADDRESSING THIS PROBLEM

With funding from a PCORI Engagement Award:

- Formed a multi-stakeholder network to combine knowledge and assets
- Researched the barriers and facilitators affecting minority engagement in MS research
- Conducted outreach activities aimed at promoting minority research recruitment and participation

# THE MS MINORITY RESEARCH ENGAGEMENT PARTNERSHIP NETWORK – ORIGINAL MEMBERS

## People with MS/Project Advisors

- *Shawn Feliciano*
- *Anita Williams*

## MS Researchers/Clinicians

- *Lilyana Amezcua*
- *Mitzi Williams*
- *Daniela Pimentel Maldonado*

## MS Advocacy Organizations

- Accelerated Cure Project – *Hollie Schmidt*
- MS Association of America – *Gina Murdoch*
- National MS Society – *Deb Frankel and Coleen Friedman*

## Minority Health Associations

- MANA – *Amy Hinojosa*
- National Black Nurses Association – *Erica Davis*
- National Hispanic Medical Association – *Minerva Campos*
- National Minority Quality Forum – *Laura Lee Hall*

## Pharma/Biotech

- Biogen – *Terrie Livingston*
- Genentech – *Daniel Machemer and Damian Fiore*

## Strategy/Public Health and Science Communications

- Feinstein Kean Healthcare – *Monique LaRocque and Melissa Glim*



# UNDERSTANDING THE PROBLEM

Literature review – see [bit.ly/MSMHH](http://bit.ly/MSMHH)

## MS Minority Health Hub

Research and Reports on Minority Participation in Clinical Trials and MS in Minority Communities:

The Partnership Network is collecting articles, reports, and news about MS in minority communities, minority participation in research and in the research sciences, ongoing projects, and patient information for minority audiences. We hope you find these resources useful. If you know of any additional resources that could be shared here, please email us at [msminorityresearch@acceleratedcure.org](mailto:msminorityresearch@acceleratedcure.org).

*In Journals*

### **Hispanic Americans and African Americans with multiple sclerosis have more severe disease course than Caucasian Americans**

Rachel E Ventura, Ariel O Antezana, Tamar Bacon, Ilya Kister. Multiple Sclerosis Journal (November 2016)

### **The Significant Impact of Education, Poverty, and Race on Internet-Based Research Participant Engagement**

Sarah M. Hartz, M.D., Ph.D., Tiffany Quan, Abiye Ibiebele, Sherri L. Fisher, M.S., Emily Olfsen, M.D., Ph.D., Patricia Salyer, M.Ed., Laura J. Bierut, M.D. Genetics in Medicine (July 2016)

### **Diversity in Clinical and Biomedical Research: A Promise Yet to Be Fulfilled**

Sam S. Oh, Joshua Galanter, Neeta Thakur, Maria Pino-Yanes, Nicolas E. Barcelo, Marquitta J. White, Danielle M. de Bruin, Ruth M. Greenblatt, Kirsten Bibbins-Domingo, Alan H. B. Wu, Luisa N. Borrell, Chris Gunter, Neil R. Powe, Esteban G. Burchard PLOS: Medicine (December 15, 2015)

### **Multiple Sclerosis in US Minority Populations: Clinical Practice Insights**

Omar Khan, M.D., Mitzi J. Williams, M.D., Lilyana Amezcua, M.D., Adil Javed, M.D., Ph.D., Kristin E. Larsen, Ph.D., Jennifer M. Smrtka, N.P. Neurology: Clinical Practice (April 2015)

### **Role of the Patient-Centered Outcomes Research Institute in Addressing Disparities and Engaging Patients in Clinical Research**

Romana Hasnain-Wynia, Ph.D., Anne C. Beal, M.D., M.P.H. Clinical Therapeutics (May 2014)

### **A Systematic Review of Barriers and Facilitators to Minority Research Participation Among African Americans, Latinos, Asian Americans, and Pacific Islanders**

Sheba Geesee, Ph.D., Nelida Duran, R.D., M.S., and Keith Norris, M.D. American Journal of Public Health (February 2014)

# UNDERSTANDING THE PROBLEM

Literature review

Original research

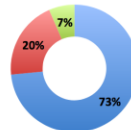
- Internet-based survey of 2600 people with MS
- See lay language report at [bit.ly/msresall](http://bit.ly/msresall)

## Concerns about participating in research

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

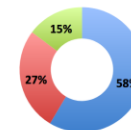
**Not being fully informed about the study**

■ Strong concern ■ Minor concern ■ Not a concern



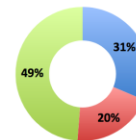
**Having their personal information released without their approval**

■ Strong concern ■ Minor concern ■ Not a concern



**Risks to their jobs or legal status**

■ Strong concern ■ Minor concern ■ Not a concern



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# UNDERSTANDING THE PROBLEM

Literature review

Original research

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Community events (Atlanta and LA)



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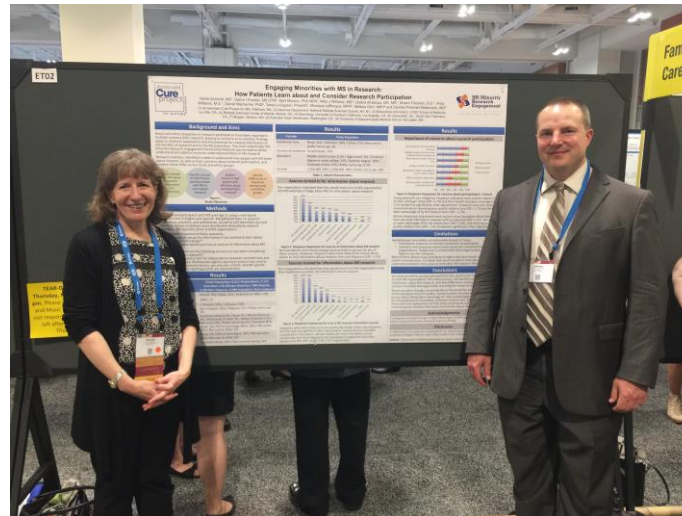
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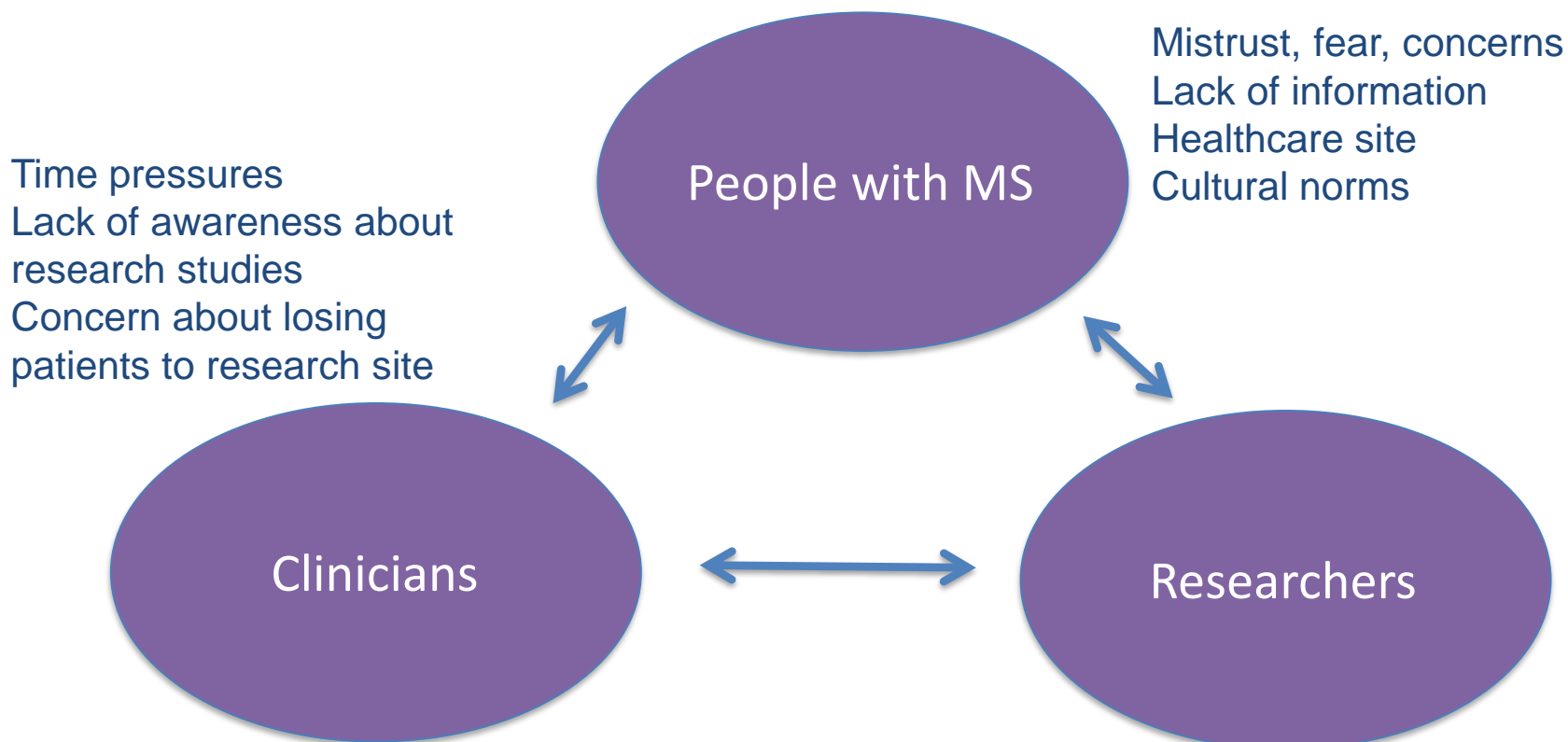
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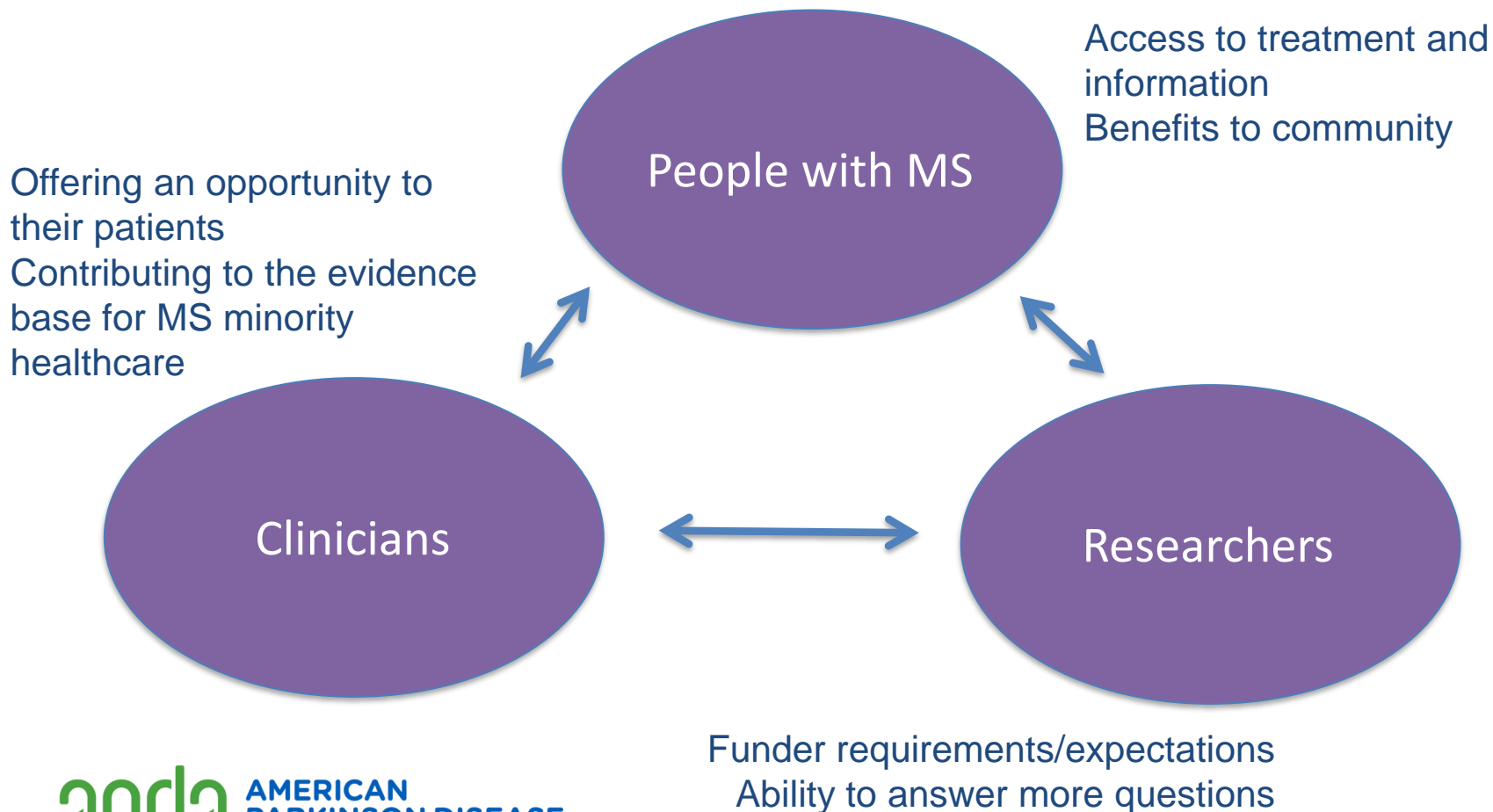
Conversations with researchers and clinicians



# BARRIERS TO MS MINORITY RESEARCH ENGAGEMENT



# FACILITATORS OF MS MINORITY RESEARCH ENGAGEMENT




# OUTREACH EFFORTS

## Partner and professional toolkits



# OUTREACH EFFORTS

## Partner and professional toolkits Conference posters and presentations




for multiple sclerosis

### Engaging Minorities with MS in Research: How Patients Learn about and Consider Research Participation

Hollie Schmidt, MS<sup>1</sup>, Debra I Frankel, MS OTR<sup>2</sup>, April Moreno, PhD MPA<sup>3</sup>, Mitzi J Williams, MD<sup>4</sup>, Liyana Amezcua, MD, MS<sup>5</sup>, Shawn Feliciano, B.S.<sup>1</sup>, Anita Williams, M.S.<sup>1</sup>, Daniel Machamer, PhD<sup>6</sup>, Terrie Livingston, PharmD<sup>7</sup>, Monique LaRoque, MPH<sup>8</sup>, Melissa Glim, MPH<sup>9</sup> and Daniela Pimentel Maldonado, MD<sup>10</sup>

(1) Accelerated Cure Project for MS, Watkin, MA, (2) Services Department, National Multiple Sclerosis Society, NY, NY, (3) Biomedical Informatics, UCSF School of Medicine, La Jolla, CA, (4) Multiple Sclerosis Center of Atlanta, Atlanta, GA, (5) Neurology, University of Southern California, Los Angeles, CA, (6) Genentech, Inc., South San Francisco, CA, (7) Biogen, Weston, MA, (8) Feinstein Kean Healthcare, Washington, DC, (9) University of Massachusetts Medical School, Worcester, MA



PARTNERSHIP NETWORK

Racial and ethnic disparities in research participation have been reported in multiple sclerosis (MS) research, leading to concerns about whether findings apply to the ethnic populations and the potential for unequal distribution of the benefits of the research. The purpose of this study was to determine if the MS Minority Research Engagement Partnership Network was formed to better understand and address minority underrepresentation in MS research. We used the research identified in the literature and how people with MS learn about the research, as well as their concerns about research participation, and if whether these differ across racial and ethnic groups.

Survey people with MS about research perspectives and preferences

Identify sources of information used by people with MS to learn about research

Explore concerns about research participation among racial and ethnic groups

Identify differences in responses among racial and ethnic groups

**Figure 1**  
Study Objectives

We surveyed participants with MS over a 2-year period using a web-based questionnaire in English and Spanish. We gathered information about their research experience, concerns, and preferences, as well as self-identified race and ethnicity. Survey invitations were distributed nationally by network members, MS specialty clinics, and MS organizations.

We analyzed responses to these questions:

- "When would you request information if you wanted to learn about research participation in a study?"
- "Which of these would you trust as sources of information about MS research?"
- "How important are the following concerns to you when considering participating in research?"

Chi-square was used to test for independence between race/ethnicity and each answer choice. Multivariate logistic regression analysis was used to adjust for socioeconomic factors. Significant results are shown in bold. All p-values are specific covariates. Results teaching  $p < 0.05$  are reported here.

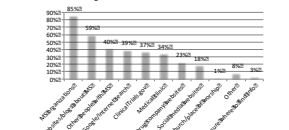
Variable	Study Population (2,611 Respondents)	2,114
Race	Caucasian: 2,164 African-American: 88 Hispanic: 2,232	2,114
Sex	Female: 1,964 Male: 2,157	2,114
Year of birth	<10 years: 1,964 10 years: 1,062	2,114
Years since diagnosis	Non-Hispanic: 1,147 Hispanic: 294	2,114
Ethnicity	2,114	2,114
Race	American Indian: 297 Asian: 1,367 African American: 829 Multiracial: 1,076 Native Hawaiian: 297 Non-Hispanic: 3,027 Prefer to be categorized: 1,142	2,114
MS Care Center	None: 277 CP: 1,076 Neurology: 1,594 MS Center: 2,334	2,114
MS Care Provider	None: 154 CP: 1,076 Neurologist: 1,594 MS specialist: 2,587	2,114
MS Medication	Currently taking: 2,597 Not currently taking: 2,114	2,114

**Table 1. Cohort Characteristics**

Variable	Study Population
Residential Area	Rural: 12.1% Suburban: 36.7% Urban: 38.1% Not sure: 13.1%
Country of Residence	United States: 93%
Education	Middle school: 1.5% High school: 19.7% Technical degree: 30.0% College: 27.9% Bachelor's degree: 19.0% Graduate school: 7.7% Prefer to be categorized: 13.2%
Income	<\$50,000: 35.7% \$50,001-\$64,999: 18.6% Prefer to be categorized: 19.2%

**Table 2. Sources Trusted for Information about Research**

Our respondents indicated that they would most trust MS organizations and MS websites to blog about MS for information about research.

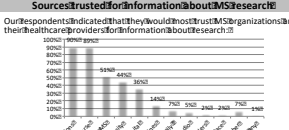


**Figure 2. Response requests for sources of information about MS research**

No associations were found among racial and ethnic groups for any of these sources. However, Hispanic research is likely to be surveyed where to find information about research than non-Hispanic (OR=2.31).

**Table 3. Sources Trusted for Information about MS Research**

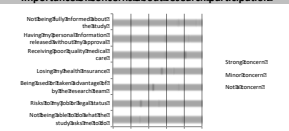
Our respondents indicated that they would most trust MS organizations and their health care providers for information about research.



**Figure 3. Response requests for trust in MS research information sources**

Hispanic were more likely to trust community leaders than non-Hispanic, but this was not significant after adjusting for socioeconomic variables. Compared to Caucasians, African-Americans were less likely to trust universities and health care providers (as measured by the trust people with MS) (OR=0.60, 0.55, 0.57 respectively).

**Importance of Concerns about Research Participation**



**Figure 4. Response requests for concerns about participating in research**

Compared with non-Hispanics, Hispanics indicated more concerns about risks to their job/legal status (OR=1.70) and their health insurance coverage (OR=1.53, borderline significance after adjustment). Hispanics were also more concerned about the coverage of quality medical care (OR=0.75) and being taken advantage of by the medical team (OR=1.79).

African Americans expressed more concern than Caucasians about having their personal information leaked without approval (OR=1.57), being misled or taken advantage of by the researchers (OR=2.05), and receiving poor quality medical care (OR=1.45, borderline significance after adjustment).

Sampling was incomplete and potentially biased in 2 ways:

- Participants required an internet connection to participate
- Outreach responses were obtained primarily by invitations from MS organizations. People not in contact with these organizations were less likely to be surveyed.

Both of these factors may contribute to higher education levels in the cohort characteristics. It is likely that academic education is more represented in this survey as well as the MS research efforts.

All racial and ethnic groups indicated that they would most trust friends or family, MS organizations, MS online sources, and health care providers for information about MS research, with the differences among groups. These sources should be leveraged when recruiting for research studies.

All groups were strongly concerned about the possibility of not being fully informed about research studies. Concerns were elevated within minority groups but being taken advantage of, risks to jobs/legal status/health insurance/personal information, and poor medical care efforts to reduce these risks and explanations of how study participants are expected to help minority group members feel more comfortable about research participation.

**Acknowledgements**

Funding was provided through Eugene Washington Center Engagement Award by the Patient-Centered Outcome Research Institute (PCORI).

**Disclosure**

D. Machamer is an employee of Genentech, Inc., South San Francisco, CA. J. LaJoie is an employee of Biogen (Weston, MA). The authors have nothing to disclose.

Contact: Please email hollie@acceleratedcure.org for more information about the study.



# OUTREACH EFFORTS

Partner and professional toolkits  
Conference posters and presentations  
Journal manuscript for survey results

# OUTREACH EFFORTS

- Partner and professional toolkits
- Conference posters and presentations
- Journal manuscript for survey results
- Postcards for partner events
- **NMSS African-American conferences**



**MS Research Needs You**  
Strength in Diversity | Power in Participation

**Did you know?**

MS affects African Americans and Hispanics in different ways compared with other ethnic groups. Symptoms may differ, the disease may progress faster, and treatments may have different effects.

African Americans and Hispanic/Latinos are underrepresented in research studies. That makes it difficult to tell which treatments are best for them, or how to reduce the risk of MS in these groups.

**You can make a difference!**

- Talk to your health care provider about participating in a clinical trial or other types of research.
- Join [iConquerMS.org](https://www.acceleratedcure.org/MSResearch), a research network open to all people with MS, and learn about other research studies here: [acceleratedcure.org/MSResearch](https://www.acceleratedcure.org/MSResearch)
- Learn why participation in research is important, and find out how you can help educate others: [acceleratedcure.org/MinorityNetwork](https://www.acceleratedcure.org/MinorityNetwork)



**MS Minority Research Engagement Partnership Network Members:**

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

**Individuals:**  
Lilyana Arnezcuca  
Shawn Feliciano  
Daniela Pimentel Maldonado  
April Moreno  
Anita Williams  
Mitzi Williams

**The National Multiple Sclerosis Society is a member of the MS Minority Research Engagement Partnership Network, a group that is addressing the problem of minority underrepresentation in MS research.**

Together we are learning why racial and ethnic minorities aren't fully represented in MS research, and developing solutions to help increase research opportunities for these communities. Without you, it is more difficult to develop insights and solutions for all people with MS. Help us increase minority representation in MS research.

[www.acceleratedcure.org/ms-minority-research-network](https://www.acceleratedcure.org/ms-minority-research-network)  
[msminorityresearch@acceleratedcure.org](mailto:msminorityresearch@acceleratedcure.org)  
Find Twitter posts on this topic: [#MSResearch4All](https://twitter.com/MSResearch4All)

Funding for the MS Minority Research Engagement Partnership Network is provided through a Eugene Washington Award from the Patient-Centered Outcomes Research Institute.

# OUTREACH EFFORTS

Partner and professional toolkits

Conference posters and presentations

Journal manuscript for survey results

Postcards for partner events

- **NMSS African-American conferences**

Community events – planting a seed

# RESULTS, REFLECTIONS, LEARNINGS

Strength in diversity: Multi-stakeholder network approach led to greater learning, greater impact

Priorities changed during the project

- **Expansion of survey, addition of manuscript**
- **Recognition of pivotal roles of researchers and clinicians; addition of professionals toolkits**
- **Reduced emphasis on social media; removed MS Sunday event**

Engagement and communication challenges

- **Only one face-to-face meeting; monthly conference calls**
- **Inconsistent awareness of goals and status**

# IDENTIFIED NEEDS AND NEXT STEPS

## New needs identified:

- **Absence of (and desire for) organized communities and channels around MS in minority groups**
- **Need for more research focused on people with MS in minority groups**
- **Need for education addressing misconceptions about research**

## Next steps:

- **Hold “Mythbusters” webinars and live events**
- **Hold regional events to learn about research interests and priorities in minority communities**
- **Conduct research and education about needs of MS caregivers in underserved communities**
- **Continue to meet and add new members**

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THANK YOU FOR YOUR  
ATTENTION!



AMERICAN  
PARKINSON DISEASE  
ASSOCIATION

Strength in optimism. Hope in progress.

# DISCUSSION #2: WHAT CAN WE LEARN/ADAPT FROM WHAT HAS ALREADY BEEN DONE IN OTHER FIELDS?

Allison Willis, MD, MS  
Moderator  
Assistant Professor of Neurology  
University of Pennsylvania



THANK YOU



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