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National African American Multiple Sclerosis Registry: Advancing Equitable Care and Outcomes for African Americans with Multiple Sclerosis

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Background

- MS is an autoimmune demyelinating disorder of multifactorial etiology, involving a complex interplay of genetic and environmental factors, and sex^{1,2}
- Current understanding of the impact of **race and ethnicity** on MS pathogenesis, disease course, and treatment response is limited, which may be attributable to the **underrepresentation of minority populations in clinical trials**¹ (Figure 1)
- Historically, the risk and incidence of MS has been considered higher in Caucasian Americans versus other ethnic groups;¹ however, there is increasing evidence to support an impact of MS in other ethnicities:
 - A cohort study of 2691 Gulf War veterans (male: 66.1%; female: 33.9%) reported MS incidence rates of 12.1 and 9.3 per 100,000 for African Americans and Caucasian Americans, respectively, with African Americans having a 27% higher risk³
 - In a multi-ethnic cohort study (N=496, >9 million person-years of observation), the incidence of MS was higher among African Americans (10.2 per 100,000 person-years) than Caucasian (6.9), Hispanic (2.9), and Asian Americans (1.4)⁴
- African Americans often have **more severe MS at diagnosis**⁵ and a **more aggressive disease course** versus other racial groups in the US^{1,6}

AAwMS Experience Significant Disparities in Clinical Outcomes and Healthcare Access versus CAwMS

Disparities in Clinical Outcomes

- Greater frequency of multi-site involvement at initial clinical presentation versus CAwMS⁷
- Worse EDSS scores at diagnosis (2.9 vs 1.8; $p=0.0002$)⁸
- Increased incidence of opticospinal MS (16.8% vs 7.9%; $p<0.001$) and transverse myelitis (28% vs 18%; $p=0.001$)⁷
- Shorter median time to ambulation with a cane (16 vs 22 years; $p<0.0001$) and wheelchair dependency (30 vs 38 years; $p=0.05$)⁷
- Faster atrophy rates of:
 - Grey matter (−0.9%/year vs −0.5%/year; $p=0.02$)⁹
 - White matter (−0.7%/year vs −0.3%/year; $p=0.04$)⁹
 - Retinal nerve fibre layer (−1.1%/year vs −0.8%/year; $p=0.02$)⁹
 - Ganglion cell inner plexiform layer (−0.7%/year vs −0.4%/year; $p=0.01$)⁹

Disparities in Healthcare Access

- A greater proportion of AAwMS versus CAwMS have never been cared for by a neurologist specializing in MS or at a MS clinic¹⁰
- AAwMS are less likely to be provided with equipment, technology and modification services, case management, and nursing services than CAwMS, despite experiencing greater mobility impairment¹¹
 - Estimates of predicted Medical expenditures have been shown to be lower for AAwMS (men: \$56,088.17; women: \$56,335.60) than CAwMS (men: \$70,002.33; women: \$59,783.15)¹¹

National African Americans with Multiple Sclerosis Registry

Registry design

- Target enrollment:** 20,000–30,000 registrants in urban, suburban and rural communities
- Self-identifying AAwMS are being recruited via brochure distribution at healthcare facilities, and print, broadcast, internet, and social media outreach
- Registrants are sent an **extensive questionnaire via email after registering on the NAAMSR website**, and annually thereafter
 - Questionnaire topics include demographic and socioeconomic status, timing of symptom onset and diagnosis, MS pattern, use of DMTs, quality of life, disability status, and access to care

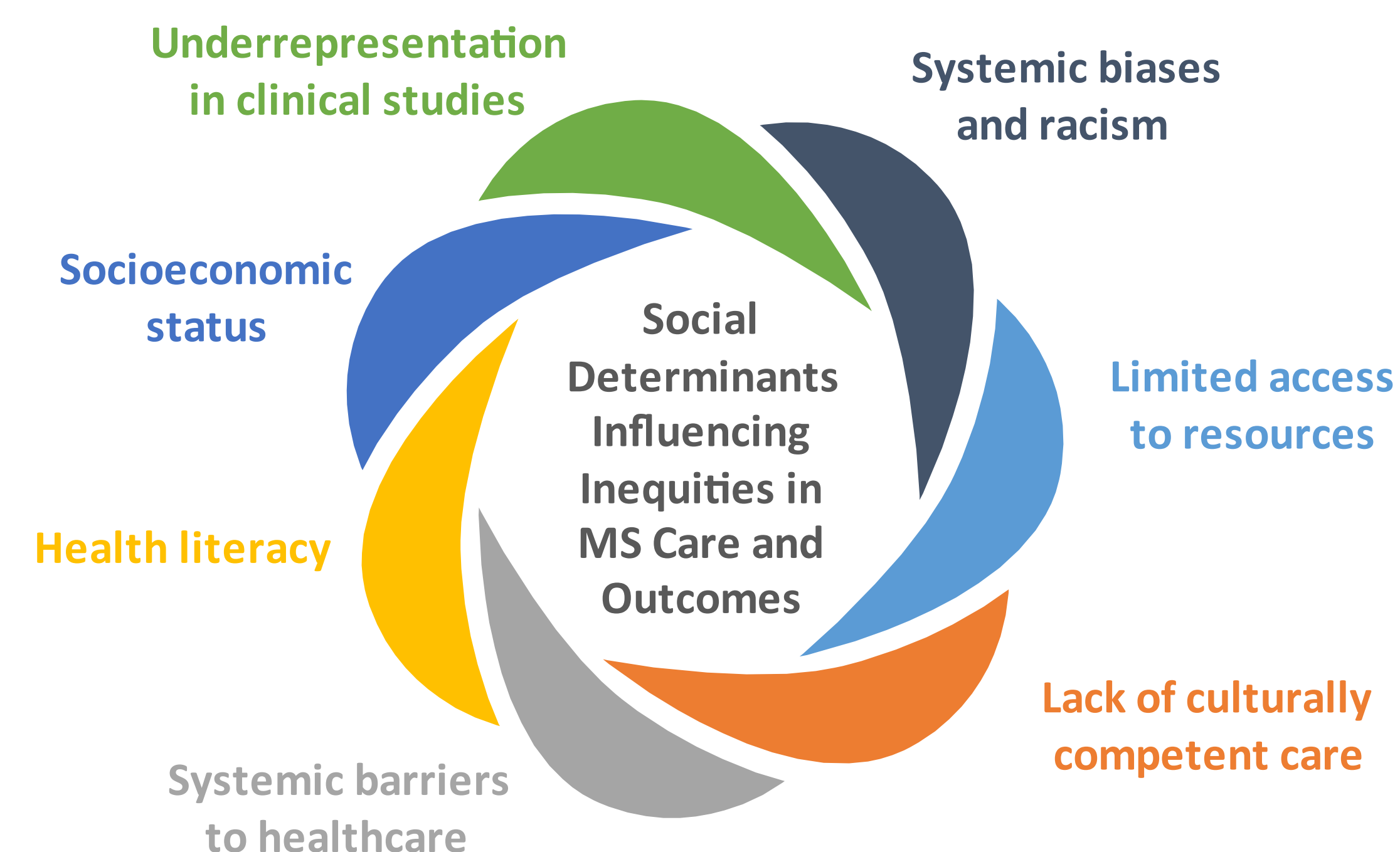
Primary Objectives

- Expand evidence-based knowledge of MS and its management in African Americans
- Educate AAwMS and increase their opportunities for clinical trial participation
- Engage in research beneficial to AAwMS

Primary measures

- The impact of social determinants of health on access to care, timeliness of diagnosis, DMT initiation, and long-term outcomes
- The potential effect of racial identity on disease pattern and severity
- The relationship between disease severity and medication efficacy
- The NAAMSR (www.naamsr.org) was launched on September 1, 2020**
- Enrollees as of March 18, 2021: 173**

Figure 1. Social Determinants Influencing Inequities in MS Care and Outcomes



Conclusions

- AAwMS may experience increased disease burden and incidence, and worsened long-term outcomes versus CAwMS¹⁻⁴
- The NAAMSR will provide a platform for addressing the critical and urgent health disparities experienced by AAwMS by:
 - Collecting real-world data on demographics, disease course, and access to care and treatment from AAwMS in different regions
 - Advancing health equity for this population through education
 - Engaging in collaborations/partnerships that advance the care and wellbeing of AAwMS

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Abbreviations

MS, multiple sclerosis; AAwMS, African Americans living with multiple sclerosis; CAwMS, Caucasian Americans living with MS; EDSS, Expanded Disability Status Scale; DMT, disease-modifying therapy; NAAMSR, National African Americans with Multiple Sclerosis Registry.

Disclosures

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