



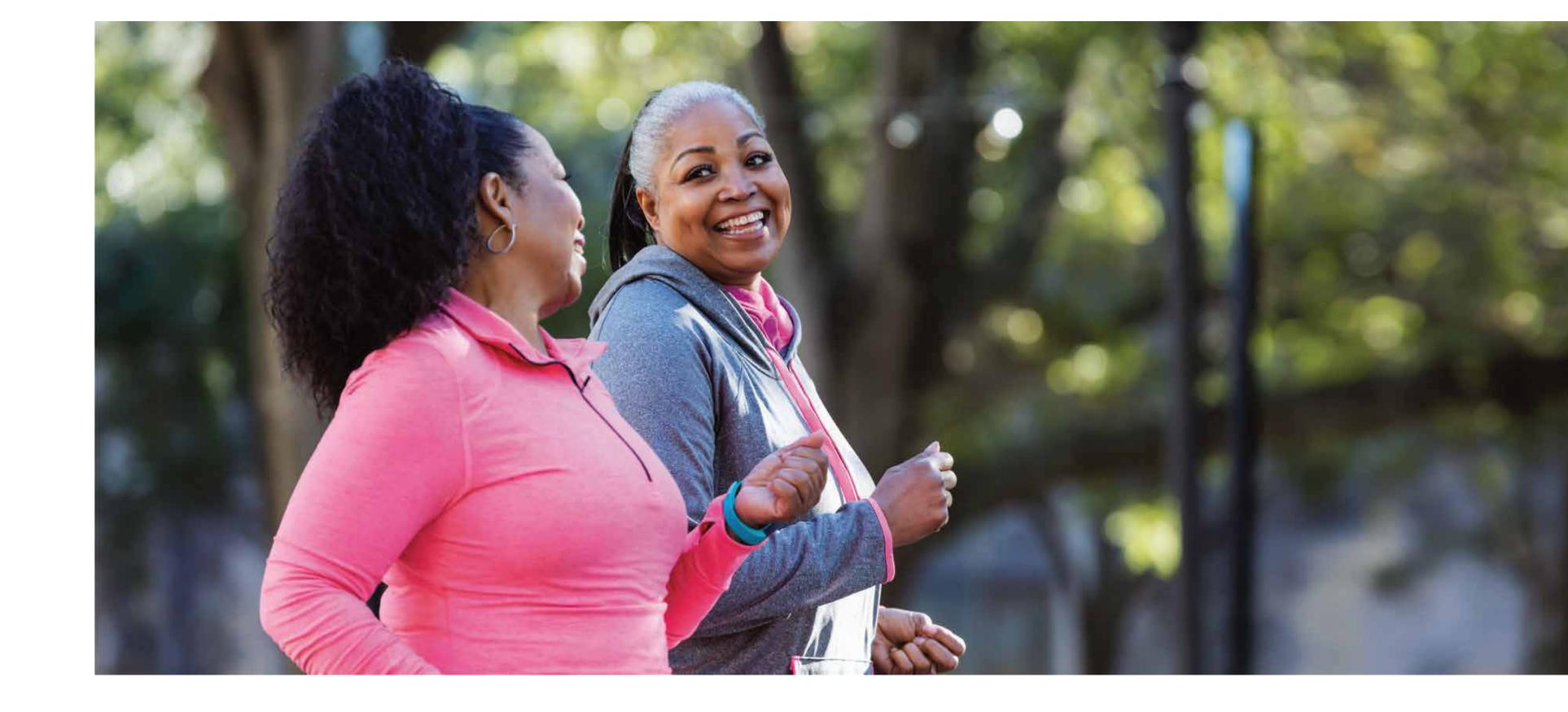
**MULTIPLE SCLEROSIS** 

# iConquerMS Research Inclusion, Diversity and Equity (RIDE) Council

Progress multiple scleroris (MS) research by elevating the voices of historically marginalized populations within iConquerMS, a people-powered research network, and the larger MS research community

#### Why It Matters

Traditionally, MS clinical research studies have lacked diversity, leading to findings that did not reflect or benefit underserved populations. Without research representation, it is impossible to know how



marginalized populations experience their MS and respond to treatment, medication, or lifestyle changes.

### Solution

iConquerMS is an innovative virtual research community platform that connects people affected by MS, researchers, clinicians, and other stakeholders for patient-centered research studies.

The RIDE Council is a group of iConquerMS members from diverse backgrounds who are providing their expertise and ideas to make MS research more inclusive.

RIDE includes sub-councils focused on specific underrepresented groups including Hispanic/Latinx, Black/African American, and emerging voices such as Asian American, rural, LGBTQ+, veteran, and disabled people. They identify barriers that affect participation of marginalized populations in MS clinical trial research and develop responses to address these barriers. Examples of programs include:

- Development of iConquerMS related materials for healthcare providers and patients to utilize that address specific concerns and issues for Black and Hispanic MS communities.
- Redesign and translation (to Spanish) of the iCMS website to make it more engaging and accessible to non-native English speakers

In addition, the RIDE Council is contributing culturally relevant strategies to disseminate data and evidence from MS research studies, beginning with 7 PCORI-funded comparative effectiveness studies.

#### Impact: RIDE Council has...



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Improved the effectiveness and cultural relevance of a survey conducted by a leading MS comprehensive care center on health equity gaps among Black and White people living with MS. RIDE members also reviewed a subsequent discussion guide for focus groups among study participants.



Provided insights for a pharmaceutical company to improve the cultural relevance of two PROMIS patient reported outcome measures in their clinical trial.

## Key Learnings

 Community engagement is crucial in engaging marginalized populations in research. Partnering with community representatives over an extended period of time is key to establishing a productive relationship based on trust.

• Cultural competency and respect for different beliefs and values is essential for effective, tailored

- communications. Information must be accessible to the desired populations.
- Be flexible and adaptive throughout program design and execution because new ideas and partnership opportunities can arise from the community at any time.

