MS® Corporate Healthcare
ROUNDTABLE

# Corporate Healthcare Roundtable: Consensus Statement on Health Equity in Clinical Trials and Real-World Evidence Data Collection

People with MS need solutions to live their best lives and find a cure. The lack of diversity in clinical trials and the disparity in healthcare delivery are impediments to finding solutions and cures for everyone. Access to high quality, personalized healthcare is vital to ensuring each person with MS can get the treatments and care that is right for them. Inclusivity in clinical trials is critical for generation of data leading to a better understanding what medication is right for each person with MS and achieving the goal of personalized healthcare for all individuals living with MS.

The National MS Society's Corporate Healthcare Roundtable has established the following principles to increase inclusivity and address health inequities in the healthcare system.

Clinical trials and data collection should be:

1. **Patient-focused from ideation of clinical trial through real-world evidence data collection**
   People with MS are the experts on their disease. They, along with their care partners and loved ones, hold valuable perspectives which could contribute to the design and structure of clinical trials and data collection. These perspectives can ensure clinical trials, registries, and other data collection efforts are designed with patient focus up front to include meaningful outcome data, have realistic requirements, and ensure appropriate accommodations to maximize participation. People with MS feel involved, welcomed, and respected from the start.
   - Prioritize inclusion of people affected by MS in the process of clinical trial design development and implementation
   - Recognize that representativeness is important. Trial participants want to know the trial is for people like them
   - Gather as many diverse perspectives as possible
   - Consider both research needs and/ease of access for trial participants and data collection
   - Leverage registries as tools for real-world evidence observational methods to collect uniform data on specific outcomes
   - Collect standard inclusive demographic information including gender identity, sexual orientation, and race/ethnicity when local laws and regulations allow

2. **Realistic and Inclusive**
   Clinical trials should strive for sound design, meeting data collection needs, and be pragmatic. Each step of the trial should be as inclusive as possible and consider the input of people with MS in making design and participation decisions. Inclusive trials help to meet the goals of personalized healthcare so both people and the healthcare system better understand what medication is right for each person with MS.
   - Think through how inclusion/exclusion criteria could be structured to represent a more diverse trial population while also ensuring the ability to rigorously answer the trial's scientific questions
   - Explore how social determinants of health (SDOH) may impact trial recruitment and participation. Seek to understand the burden on trial participants, families, and support partners within trial design. Consider issues around transportation, missed work, physical and cognitive accommodations, perceptions of trustworthiness, and other factors
   - Identify what data must be collected on site vs. remotely

To address health equity and achieve these goals in clinical trials and data collection, we must focus on:

3. **Effective Education that Resonates with Target Audiences**
   Effective clinical trial education from trusted sources is a pivotal component to bringing more diverse participants into clinical trials and data collection efforts. Development of educational materials should consider how target audiences best receive information and who is best to deliver it. Focused offerings from peers in both formal and informal settings may help gain trust.
   - Develop range of educational offerings to reflect different ways people learn and receive information
   - Ensure all materials reflect health literacy principles
   - Create educational materials that are multilingual, reflect cultural differences, include social determinants of health resources, and promote shared decision making. Educational materials should include the current considerations and best practices of MS treatment so people can make informed decisions
   - Increase connections to and use of trusted sources, ambassadors, care partners, and peers

4. **Diversifying Outreach and Clinical Trial Sites**
   Many people with MS do not have access to or routinely see an MS specialist healthcare provider and some are not regularly connected with the healthcare system. Thinking differently about clinical trial site locations, trial investigators and how information about clinical trials is shared may open pathways to more inclusive trial participation.
   - Explore opportunities for clinical trial sites to align with underrepresented populations
   - Educate current and future general neurologists about clinical trial opportunities
   - Invest in programs to equip and educate general neurologists to serve as trial locations
   - Support innovative partnerships to diversify trial locations, outreach, and investigators

In conclusion, as members of the MS Corporate Healthcare Roundtable, we support the inclusion of these principles in public policies and commit to practicing these principles as individual organizations and in partnership.

**About the MS Corporate Healthcare Roundtable:**

The National MS Society's Corporate Healthcare Roundtable serves as a forum for engagement of corporate pharmaceutical partners and the National MS Society. Members of the Roundtable contribute to direct and focused dialogue with the purpose of collaborating on shared interests as well as addressing issues that directly impact the MS community.

The goal of the Corporate Healthcare Roundtable is to enhance collective impact through a common vision, shared resources, and ongoing commitment to people affected by MS.

**2021 Roundtable Membership:**

Biogen
Bristol Myers Squibb
EMD Serono
Genentech A Member of the Roche Group
Greenwich Biosciences
Janssen Neuroscience Pharmaceutical Companies of Johnson & Johnson
Optum
Novartis
Sanofi Genzyme
MS National Multiple Sclerosis Society