



making a **difference**

Using Patient-Centered Research Results in the Real World

Tele-Exercise and Multiple Sclerosis (TEAMS) Study

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 **ANNUAL MEETING**
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#PCORI2019

Tracy Flemming Tracy and Dolly Stokes

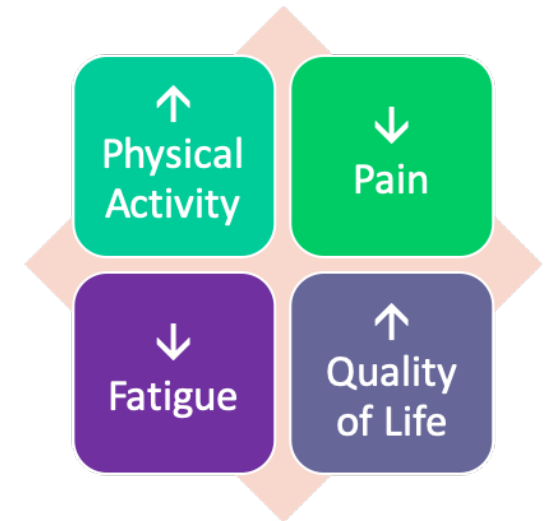
- Have nothing to disclose.



TANNER FOUNDATION
FOR NEUROLOGICAL DISEASES

Tele-Exercise and Multiple Sclerosis (TEAMS)

- Aims to compare the effects of delivering an exercise-based rehabilitation program at-home (TeleCAM) versus providing the therapy in a clinic (DirectCAM)
- Outcomes we hope to achieve are improved physical activity, decreased pain and fatigue, and improved quality of life
- Complementary Alternative Medicine (CAM)
 - Combines yoga, Pilates, and dual-tasking exercises
- Seeks to reduce barriers to receiving exercise treatment by utilizing technology
 - Tablet and Interactive Voice Response (IVR)



What makes this study different?



Engaged Diverse Stakeholders

Persons living with MS
Caretakers
Government Representatives
Non-Profit Executives
Exercise Specialist
Clinicians
Hospitals



Implemented across 3 states

43 sites across Alabama, Mississippi
and Tennessee
Over 80 therapists trained



Recruitment began before funding

~1500 completed prescreening form
600 enrolled and completed
baseline survey
100 completed study so far



Partnered with non-profits and other organizations

Consortium of Multiple Sclerosis
National MS Society
MS Views and News
MS Foundation
iCounquerMS™
North American Research
Committee on MS
Neurology Practice
Hospitals

Engagement Strategies

Stakeholder Panel

- In person and virtual meetings (4 per year)
- Individual conversations and contributions requested based on stakeholder members' area of expertise
- Involvement of stakeholders in local events to assist with recruitment and retention

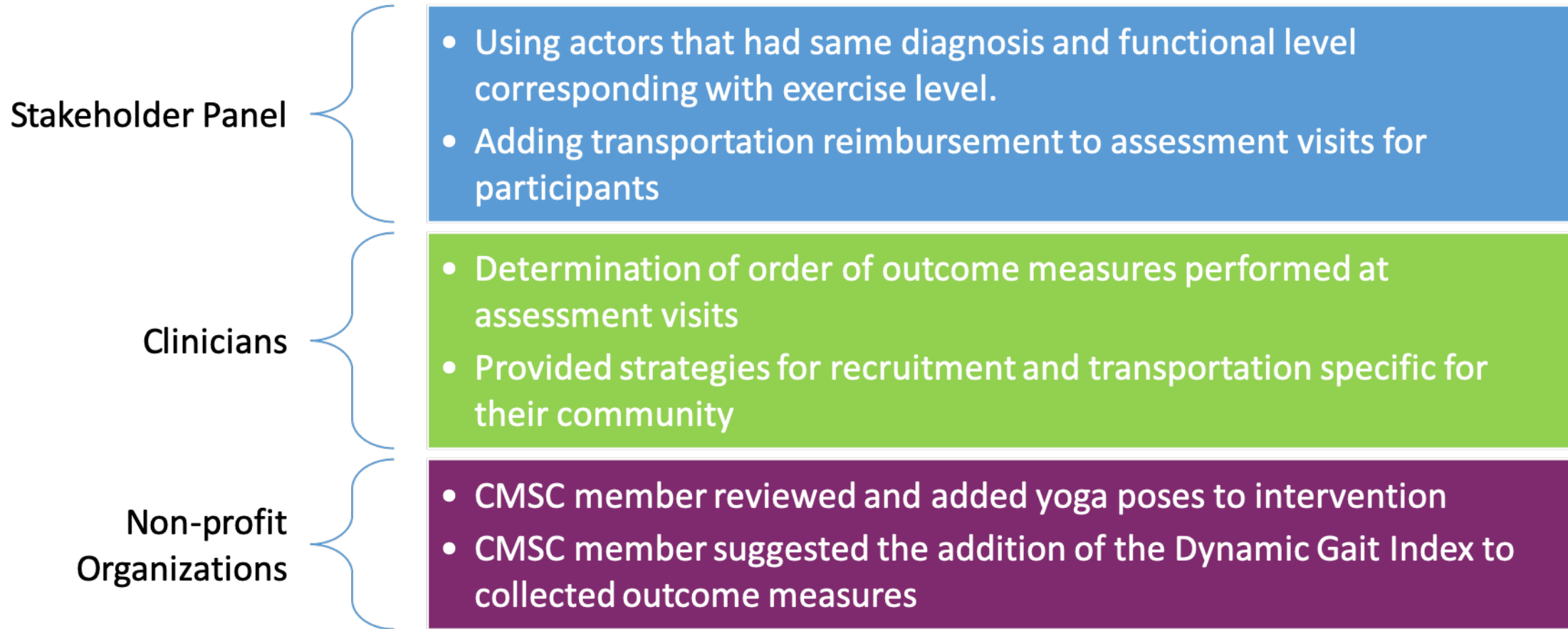
Clinicians

- In-person training provided and CEUs offered
- On-site assistance with initial baseline visits
- Email and phone correspondence for continued support
- Use of platforms such as Zoom for distance learning/discussions
- Communication through HIPPA compliant web based app

Non-profit Organizations

- Providing feedback regarding protocols in initial phases of the study
- Allowing attendance at events and self help group meetings
- Promotion of the study through website, email, and brochure distribution

Impact and Influence of Engagement



WHAT WORKED... and what did not

- What worked:
 - Sense of being "heard" thus taking ownership in the study by our stakeholders is a positive point
 - Everyone has their role- stakeholders strategically chosen based on their location and area of expertise adds "color" to the discussion.
- What did not:
 - Tension points regarding limitations in technology with both tablet and IVR system within research team, stakeholders, and clinicians
 - Communication across the three states with both stakeholders and clinicians at times difficult
 - Less self help groups meeting in person making recruitment difficult

Thank You!

Tracy Flemming Tracy

Clinical Research Coordinator

Dolly Stokes

Stakeholder Partner

[Comparing Clinic- and Home-Based Exercise Programs to Help Adults with Multiple Sclerosis --
The TEAMS Study](#)

Discussion and Q&A