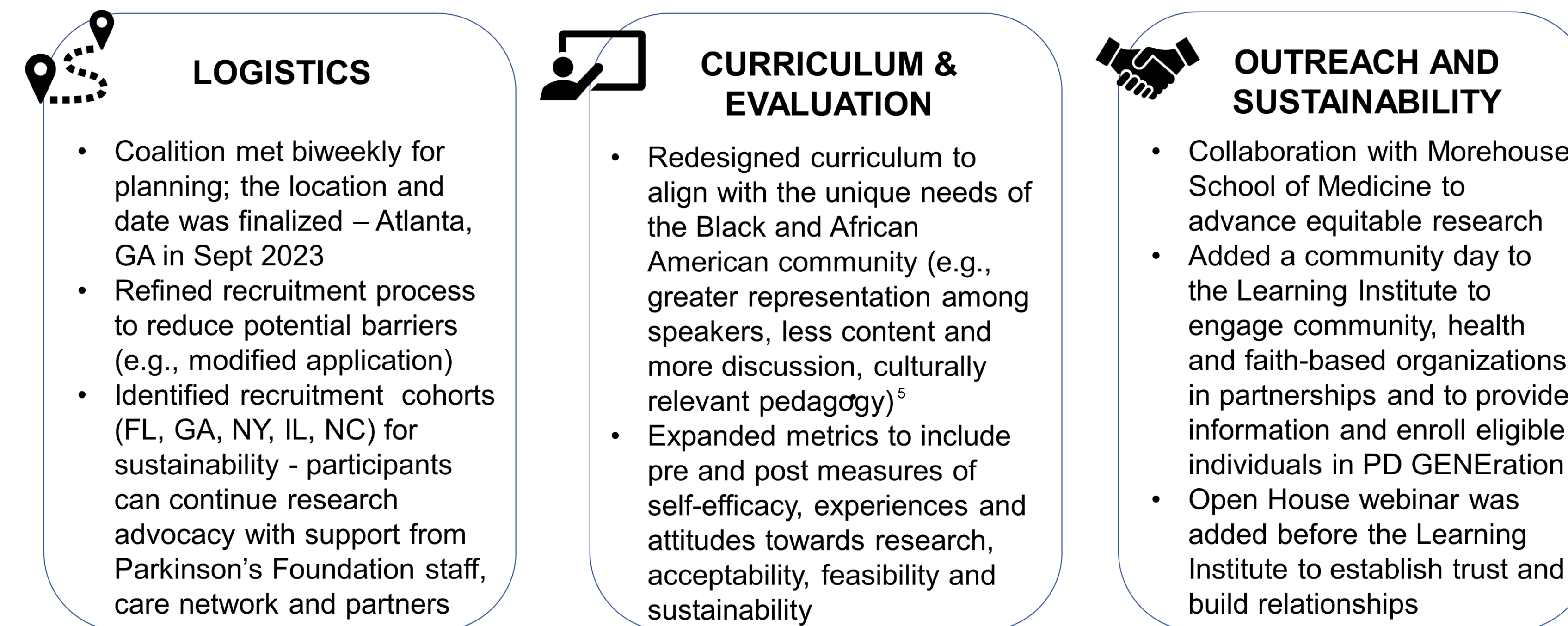


Background

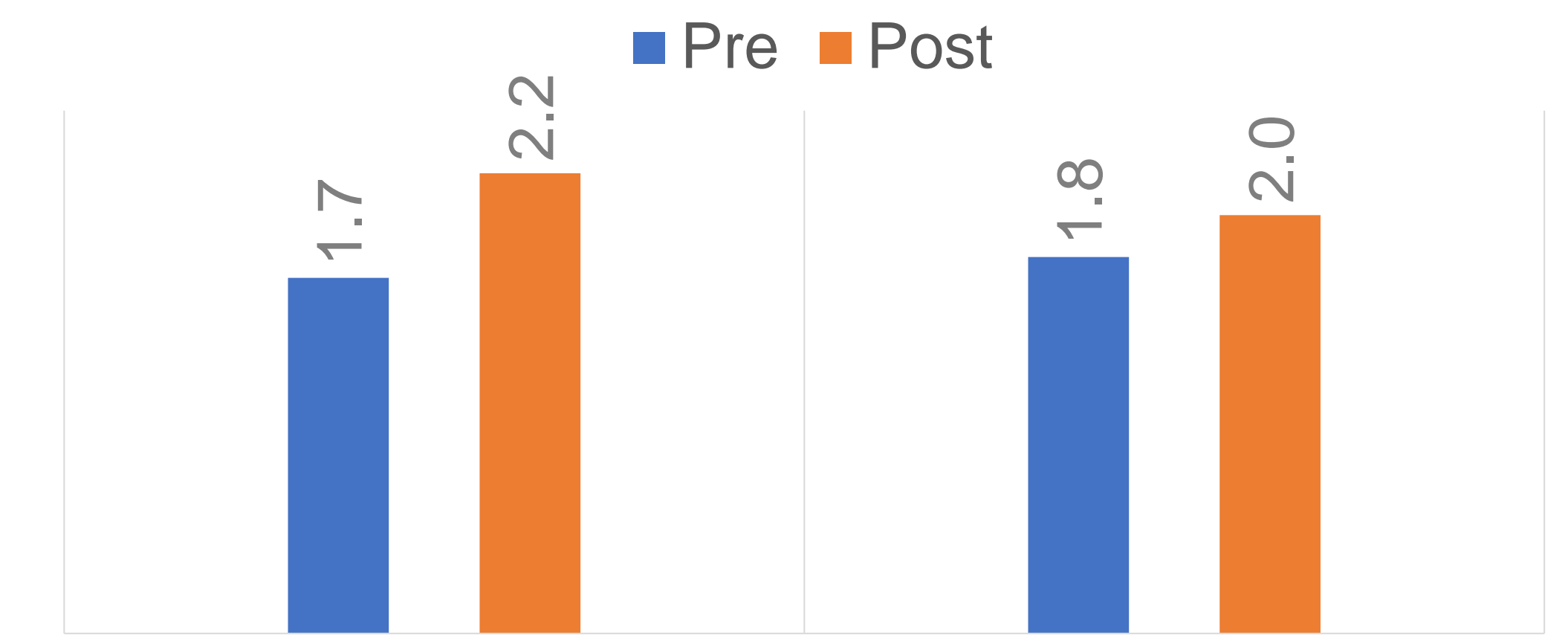
- Black and African American people with Parkinson's disease (PD) face significant disparities in care, including delays in diagnosis and treatment, limited access to care, and historical exclusion from research.^{1,2}
- To address these challenges, the **Parkinson's Foundation Research Advocacy Training** program, the **Learning Institute**, was tailored to engage, educate, and empower the Black community in Parkinson's research.

Figure 1: Redesign of the Parkinson's Foundation Research Advocacy Training



Results (continued)

KNOWLEDGE AND SKILLS



After attending the Learning Institute...	Moderate/Very
How prepared do you feel about getting involved in Parkinson's advocacy?	79%
How much has your perspective changed regarding the role people with Parkinson's and care partners can play in the research process?	91%
How excited are you about the work you can do as a Research Advocate?	83%

Results

Attendees (n=59) included members of the planning committee, faculty speakers and participants being trained as research advocates. 90% identify as Black or African American.

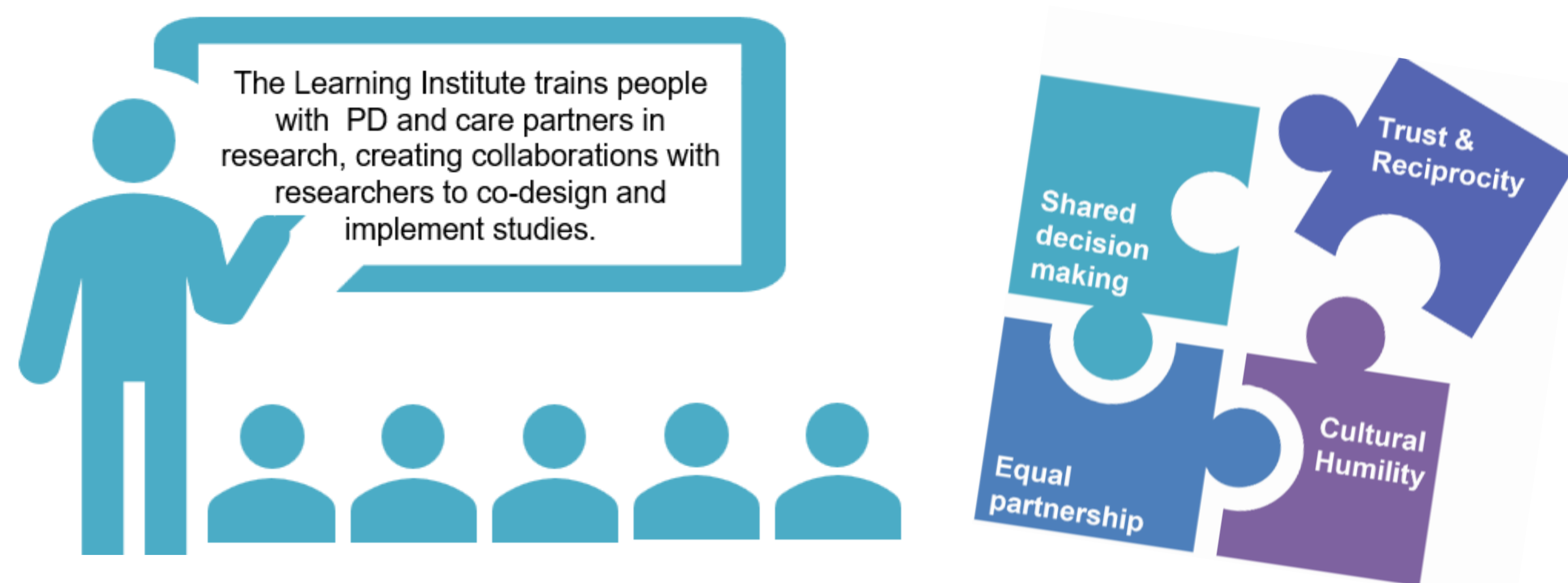
Planning Committee/Faculty

- 5 people with Parkinson's, 4 care partners
**All are current Research Advocates, attended a prior Learning Institute*
- 3 Movement Disorder Specialists
- 3 Patient/Research Coordinators
- 1 Social Worker
- 7 Parkinson's Foundation Staff
**Includes executive leadership, patient engagement team, research team*

Research Advocates

- 17 care partners, 16 people with Parkinson's
- 73% receive care from a Movement Disorder Specialist
- 73% female
- Average age = 58 years old (range 30-79yrs old)
- Average years of diagnosis = 8 years (range 2-23 years)
- 90% live in suburban/urban area (recruited from Atlanta, Chicago, Charlotte)
- 71% have never been invited to take part in a clinical trial

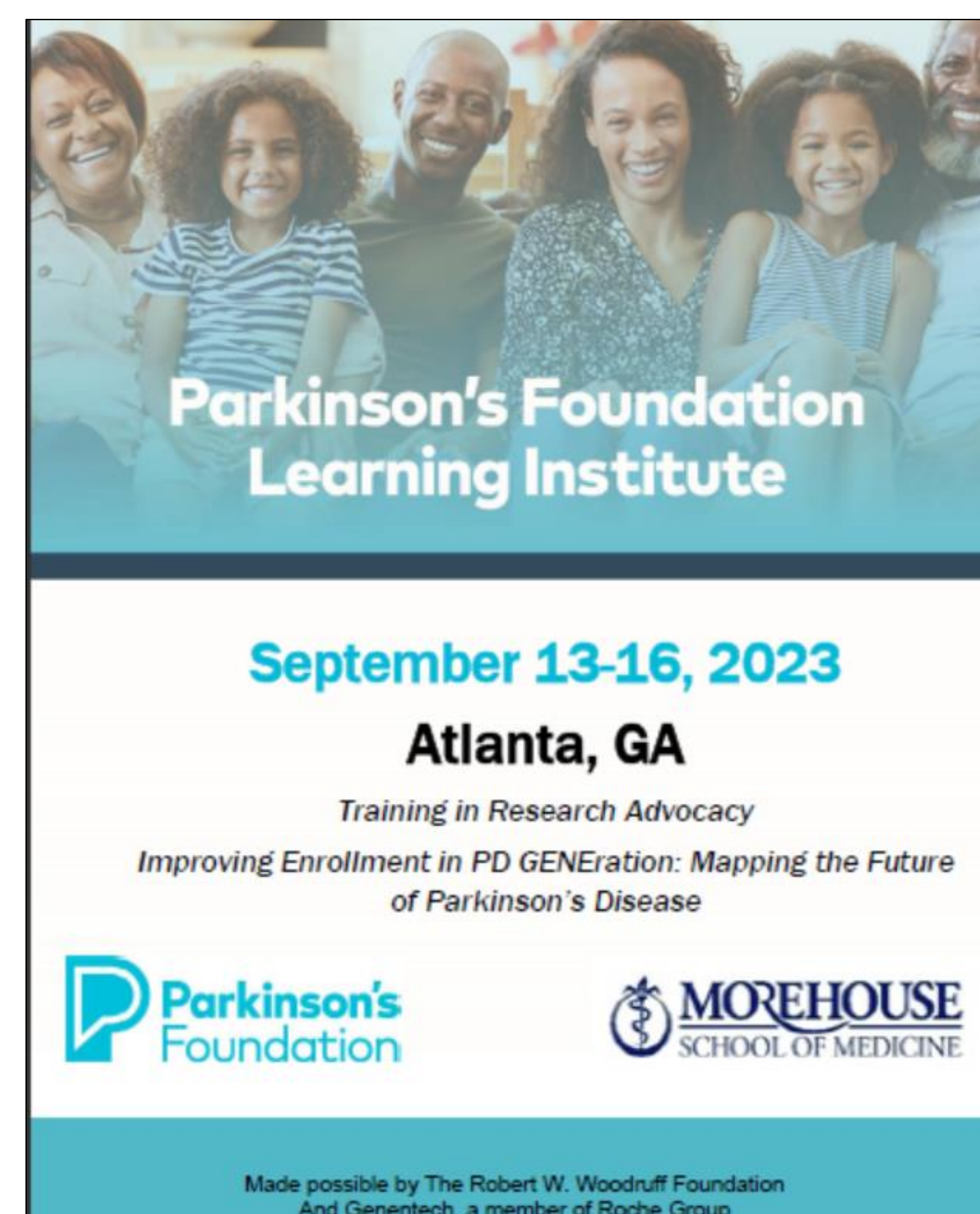
Methodology



The Parkinson's Foundation Learning Institute was established in 2008 and has trained over 400 volunteers in research and patient engagement (research advocacy). We have created a national network of research advocates around the U.S. that are actively changing the face of Parkinson's disease research.

- Guided by best practices in diversity, equity and inclusion (DEI) and patient engagement^{3,4}, the Parkinson's Foundation built a coalition in 2020 led by Black and African American people with Parkinson's and their care partners.
- Black and African American clinicians, social workers, nurses and researchers were invited to join the coalition as key partners to driving systemic change among organizations and communities.

The first goal of the coalition was to **redesign and execute the Parkinson's Foundation Learning Institute** in a culturally responsive way for Black and African American communities and improve enrollment in **PDGENERation: Mapping the Future of Parkinson's Disease**, our groundbreaking initiative offering genetic testing, counseling and return of results at no cost to people living with Parkinson's. **(See Figure 1)**



Quote from a participant
"Blessed my relationship with my wife, a light went on because she was able to talk to other individuals, things that I have been trying to tell her for so long."

Conclusions: Looking Ahead

- Engagement of the Black Parkinson's community as Research Advocates is important to advancing health equity.
- Continued education and skill-building on research and patient engagement is needed as research advocates form partnerships with researchers and scientists developing treatments.
- The Parkinson's Foundation Learning Institute is a model to provide tailored training, shift perspectives, and generate excitement to help bridge the gaps in Parkinson's research and care.

References

1) Bailey M. et al (2020). Parkinson's Disease in African Americans: A Review of the Current Literature. J Parkinsons Dis. 10(3):831-841.; 2) Schneider MG . et al (2009) Minority enrollment in Parkinson's disease clinical trials. *Parkinsonism Relat Disord* 15, 258–262; 3) Vaswani PA, et al (2020). Overcoming Barriers to Parkinson Disease Trial Participation: Increasing Diversity and Novel Designs for Recruitment and Retention. *Neurotherapeutics*, 17(4):1724-1735. 4) Feeney M, et al (2020). Utilizing patient advocates in Parkinson's disease: A proposed framework for patient engagement and the modern metrics that can determine its success. *Health Expect*.(4):722-730. 5) Ladson-Billings, G. (1995) Toward a theory of culturally relevant pedagogy. *American Education Research Journal*, 32(3), 465-491