

Centering Lived Experiences in Alzheimer's Disease and Related Disorders Research: The Formation of a Lived Experience Advisory Panel

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Background

- **Community-engaged research** (CER) relies on collaborative relationships with community partners and bidirectional communication between academic researchers and community representatives.
- **Community advisory boards** (CABs) are an especially important component of CER, as they provide a forum for community members to share their perspectives, values, and priorities with researchers.
- This project aimed to describe **the formation of a novel CAB** at the federally-funded Michigan Alzheimer's Disease Research Center (MADRC), which incorporates the **lived experiences of care partners and those living with cognitive impairment**.
- We elucidate the **planning, recruitment, board activities, and prospective goals** pertaining to the newly established **Lived Experience Advisory Panel** (LEAP).

Methods

- Individuals were recruited to serve on the LEAP if they met inclusion criteria:
 - **Self-identify as an unpaid care partner** (current or former) to a person living with a neurodegenerative disease
 - Are **a person living with cognitive decline** (e.g., mild cognitive impairment, dementia)
- Potential candidates were primarily identified through their participation in the MADRC's wellness programs and support groups.
- Prospective LEAP members were asked to sign a written agreement, committing to one year of service with opportunities for extension. Their participation included a small monetary compensation (i.e., \$50 per meeting).
- LEAP members met **quarterly over Zoom**. They were invited to complete **two optional electronic surveys**: an annual demographics survey and a post-meeting satisfaction survey.

Table 1. LEAP Demographic Characteristics, N = 8*

Age, Mean Years (SD), Range	71.5 (8.35), 54-79
Sex, N (%)	
Female	5 (62.5%)
Male	3 (37.5%)
Race, N (%)	
White	8 (100%)
Black/African American	0 (0%)
Level of Education, N (%)	
Some college, no degree	1 (12.5%)
Bachelor's degree	1 (12.5%)
Master's, professional, or doctoral degree	6 (75%)

Abbreviations: SD, Standard Deviation

*Demographic data only available for 8 out of 11 panelists



Results

Lived Experience Advisory Panel (LEAP) Y1 Timeline

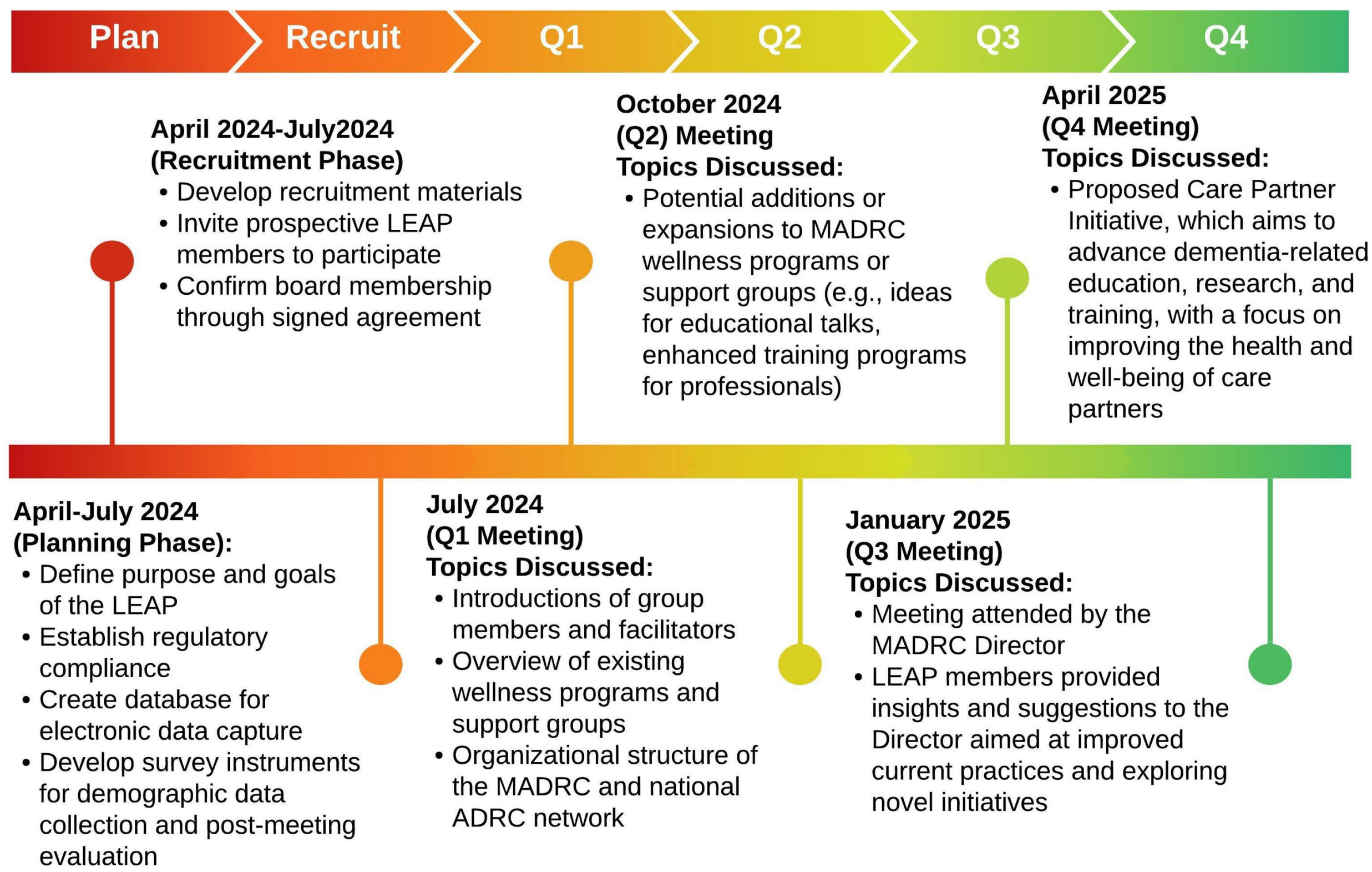


Figure 1. The timeline of LEAP activities, July 2024-April 2025.

Table 2. Summary of Year 1 Quarterly Post-Meeting Feedback***

Survey Item	Mean (SD)	%
Overall, how satisfied are you with our meeting today?*	4.19 (0.75)	
How much did you feel you were able to share your thoughts and experiences?*	4.31 (0.79)	
How much did you feel your thoughts and experiences were valued?*	4.50 (0.73)	
The length of the meeting was "just about right"***		87.5

Abbreviations: SD, Standard Deviation

*Response Choices: 1 = Not at all; 2 = A little; 3 = Somewhat; 4 = Quite a bit; 5 = A great deal

**Response Choices: 1 = Too short; 2 = Just about right; 3 = Too long

***Note: Sixteen surveys were completed across three quarterly administrations (one quarter was not administered). Response rates across timepoints ranged from 36.4% to 63.6%.

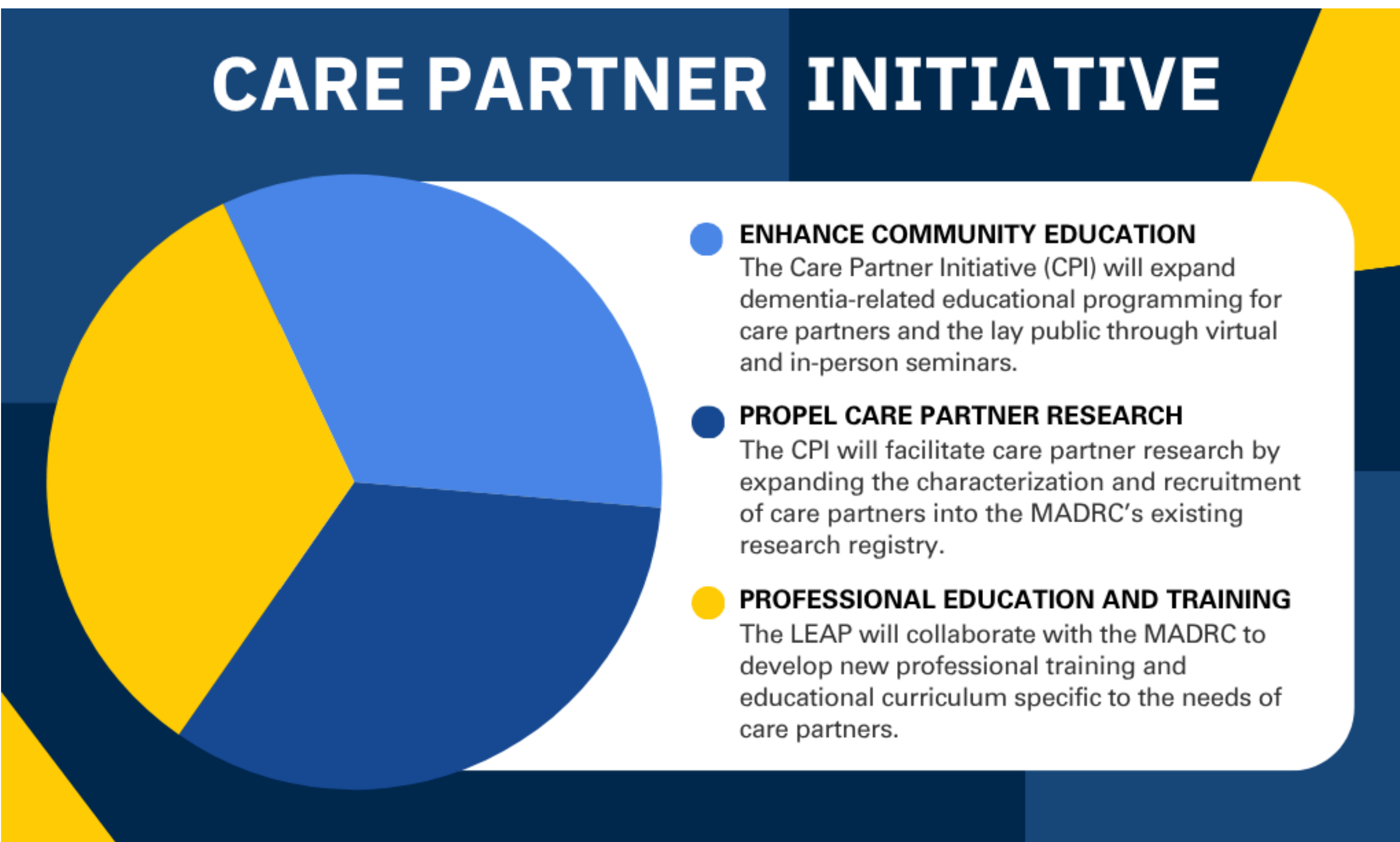


Figure 2. Three primary goals of the MADRC Care Partner Initiative, informed by the LEAP.

Conclusions

Bridging the Gap

- CABs, such as the LEAP, allow researchers to partner directly with community members, which is **essential for creating research that is relevant and accessible**.

- This **bidirectional communication** ensures that Center activities are **grounded in community values**.

Tangible Outcomes

- In its inaugural year, the LEAP moved beyond a purely advisory role by actively setting priorities for future work and informing the new **MADRC Care Partner Initiative**.

- This initiative directly addresses community-identified needs for **expanded community-based educational programming, enhanced professional training, and mechanisms to advance care partner-focused research**.

Future Directions

- Future efforts will focus on retaining LEAP members, as well as **expanding the diversity of the panel** (e.g., race, education, socioeconomic status).

- Additionally, we will continue to evaluate the effectiveness of the LEAP in supporting the **MADRC's strategic goals and mission** (e.g., recruitment of care partners into the MADRC's research registry; program evaluation of care partner-focused educational programming).

References

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Acknowledgements

This study was funded by the National Institute on Aging and the Michigan Alzheimer's Disease Research Center, University of Michigan (P30 AG072931) for making this work possible.

We also wish to thank each of the LEAP panel members for lending their time and expertise to this project.

For more information, visit the Michigan Alzheimer's Disease Center website.

