



Strategies for Retaining Diverse Participants: Building Relationships at the Individual, Family, and Community Level

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OREC Session
Fall ADRC Meeting 2024

A statewide partnership between the University of Michigan, Michigan State University, and Wayne State University to support dementia research.

Disclosures

- None

2023-2024 Longitudinal Cohort Retention Data

	Visit 1-2	Visit 2-3	Visit 3-4	Visit 4-5	Visit 5-6
2023-2024	79.4% (73.3% AA)	78.9% (70.2% AA)	82.4% (91.2% AA)	78.4% (76.2% AA)	84.7% (85.2% AA)
2022-2023	79.5%	76.7%	82.0%	79.6%	87.5%

*Reasons why:

31% lost contact; 20% no longer interested in research; 9% visit too stressful / burdensome; 14% advanced health conditions; 11% no study partner; 9% back to work; 6% moved out of state

How do we build relationships with participants, families, & the community?

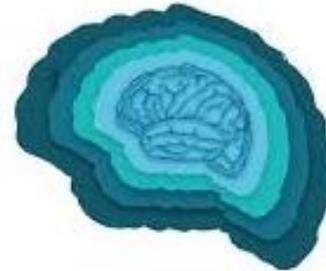
- Sustained, Personal Connections

Fostering Personal Connections

- Birthday/Holiday/Bereavement Cards
- Thank You Videos
- Appreciation Luncheon
- Community Champion Awards



Building Community Relationships



MCCFAD
MICHIGAN CENTER FOR CONTEXTUAL
FACTORS IN ALZHEIMER'S DISEASE



> [Front Public Health](#). 2023 Apr 4:11:1062385. doi: 10.3389/fpubh.2023.1062385. eCollection 2023.

Engaging diverse populations in aging research during the COVID-19 pandemic: Lessons learned from four National Institutes of Health funded-Centers

Irving E Vega ^{1 2}, Kristine J Ajrouch ^{1 3 4}, Vanessa Rorai ^{5 6}, Renee Gadwa ⁷, J Scott Roberts ^{7 8}, Linda Nyquist ⁹



Sustained Community Presence



178 Community Presentations

53 Events and Activities Focused on Underrepresented Groups

5,602 Individuals from Underrepresented Groups Reached



How do we build relationships with participants, families, & the community?

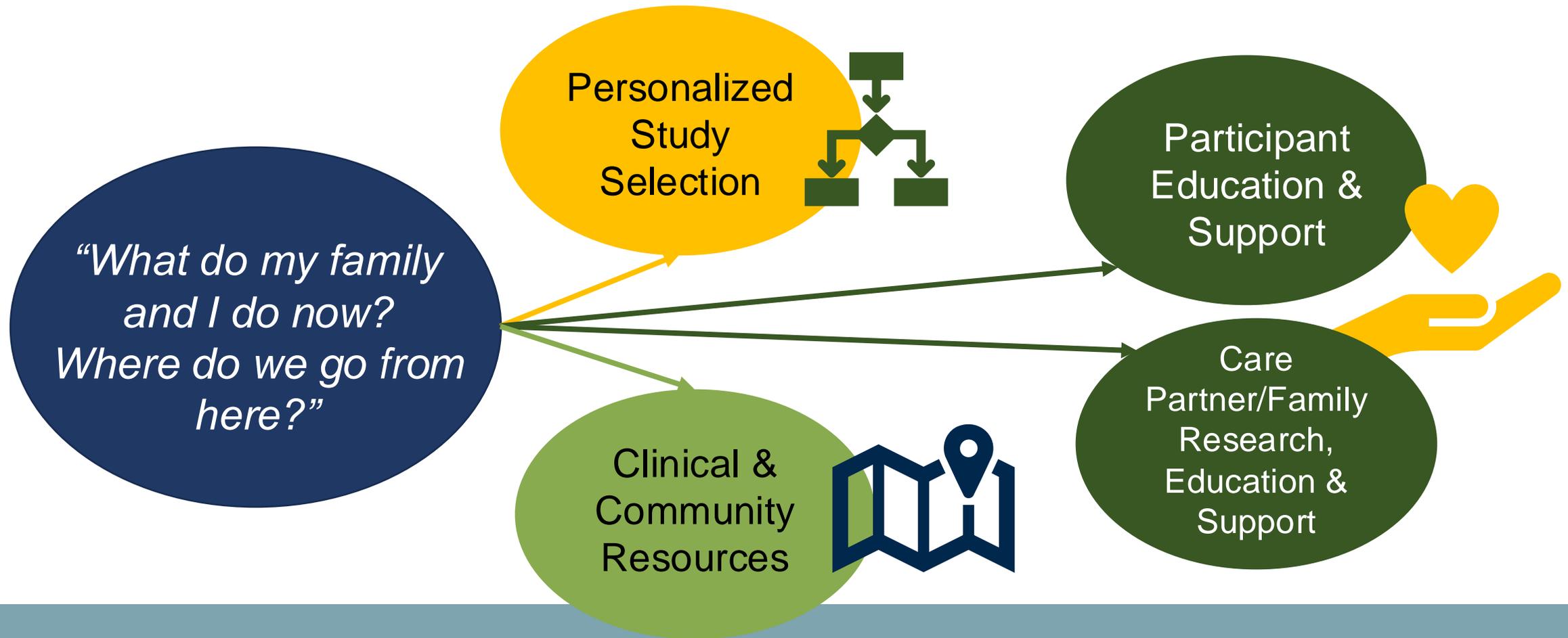
- Sustained, Personal Connections
- Iterative, Bi-directional Communication

Bi-Directional Communication: Return of Individual Research Results



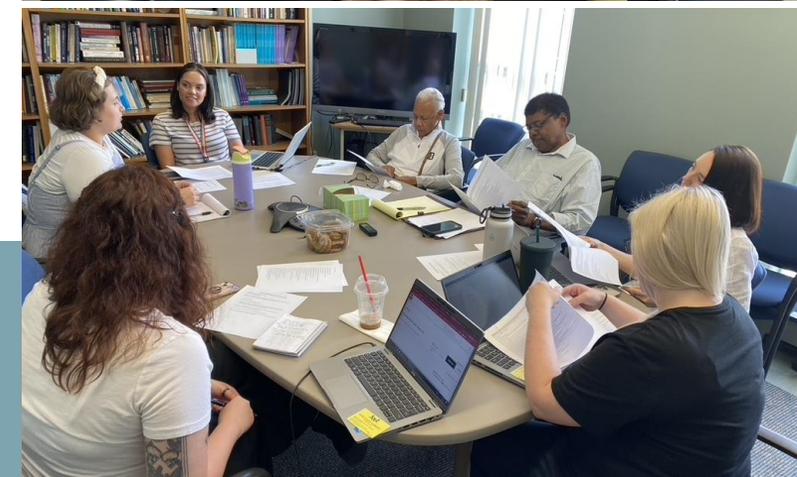
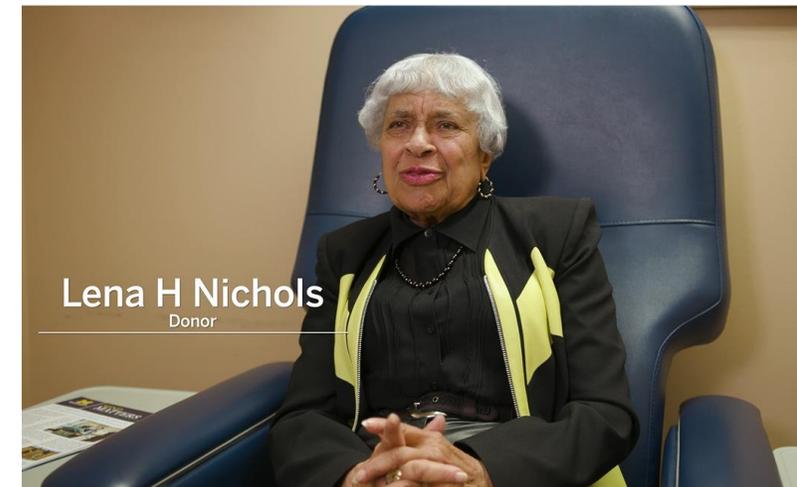
- **All** participants offered cognitive and diagnostic feedback
 - MRI, amyloid, and tau offered to subset
 - Brain autopsy results communicated to all families
- Feedback sessions were completed **efficiently**
 - 56% Zoom; 40% Phone, 4% In Person
 - Average **days between evaluation and feedback: 62**
- **1,353 total feedback visits** provided; over 500 in last year.
- ‘Warm Handoff’ to studies, resources, and clinical care

Supporting Transitions: Warm Handoffs



Asking For (and Incorporating) Feedback

- Detroit Advisory Council
- Lived Experience Advisory Panel
 - Collectively-defined roles and compensation
 - Training for CAB members
 - Input on grants, program development, events, awards
 - Participation in projects (e.g., brain donation video)
- Healthier Black Elders Center
- Flint CBOP



Return of Research Results: Program Evaluation

Outcomes Following Feedback on Research Results (OFFeR); $n = 223$

Satisfaction with Feedback Process	<i>M (SD)</i>
How well did we explain the feedback appointment?	4.92 (0.27)
How well did we explain your test results?	4.81 (0.56)
How well did we explain your research diagnosis?	4.89 (0.32)
How well did we explain our recommendations?	4.80 (0.44)
How well did we answer your/your loved ones' questions?	4.92 (0.27)



Bernardo Flores
Feedback
Coordinator/
SABER



Haley Kohl
CLARiTI Return
of Results Core
Coordinator

Comprehension and Recall of Results	Immediate	1-week	12 weeks
Participant Accuracy Score	96%	95%	95%
Co-Participant Accuracy Score	99%	N/A	N/A

Post-Disclosure Changes:

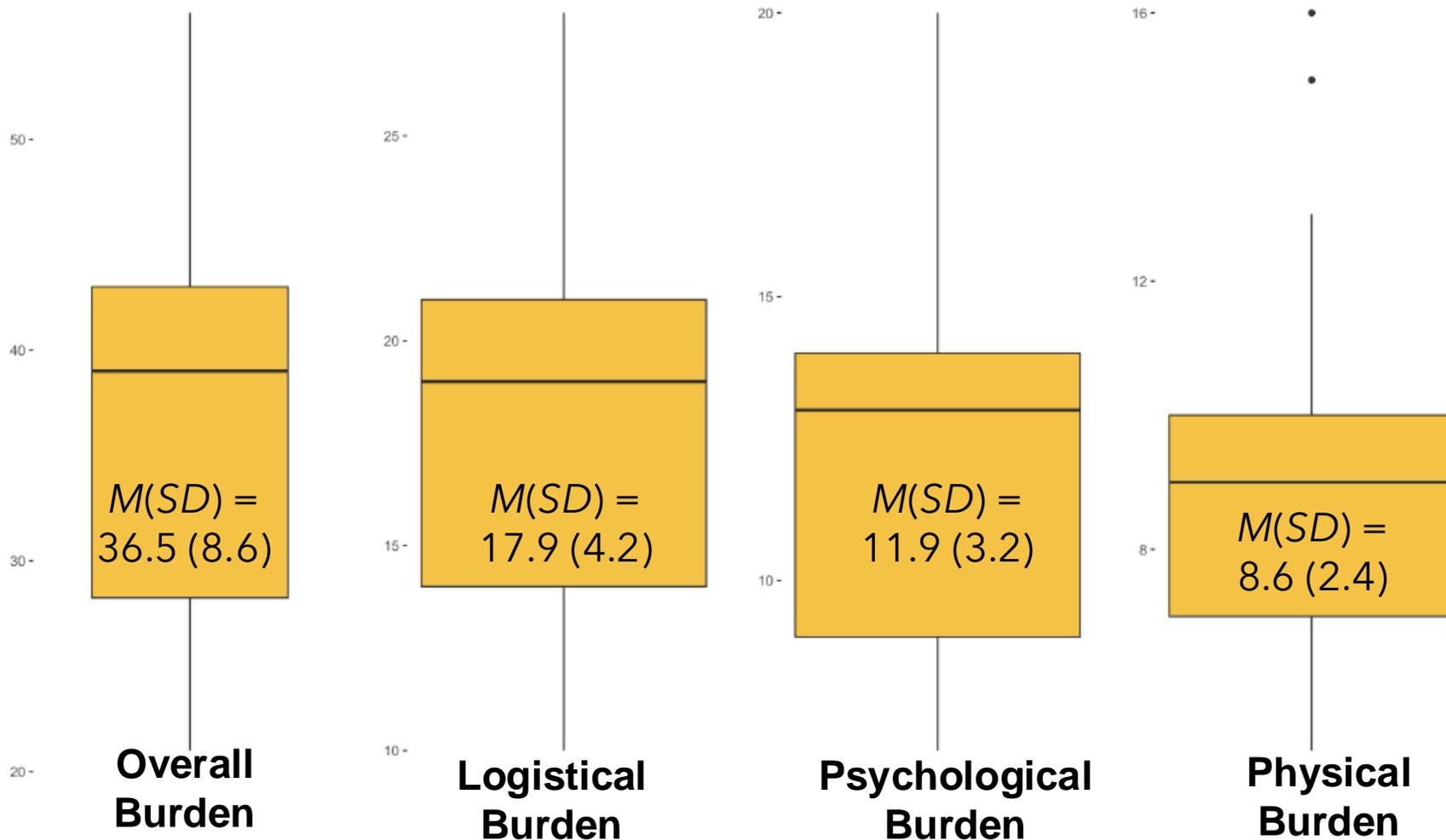
- Sharing results with family or a medical provider
- Improving diet and exercise
- Enrolling in new research studies

Program Evaluation: Burden of Annual Visit

$n = 134$



Theresa Gierzynski
OREC Manager



Growth Opportunities:

- Fasting Blood Draw → *Change: Only required at certain visits*
- Visit Length → *Change: Re-evaluating scheduling, modality, and measures*
- More Information Needed about Procedures Before Visit → *Change: Videos*

How do we build relationships with participants, families, & the community?

- Sustained, Personal Connections
- Iterative, Bi-directional Communication
- Setting a Culture

Building a Culture

- Cross-Center invitation to engage with community
- CER/CBPR Training for affiliated studies, awardees, REC trainees, etc.
- Communicating expectations for supported/co-enrolling studies



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Thank you!



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<https://www.youtube.com/playlist?list=PLNxqP-XbH8BJkxUwwe3jJ3HDGXkhkrVxL>



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