Michigan ADRC

Alzheimer's Disease Research Center

RP-CNBI

Research Program on Cognition and Neuromodulation Based Interventions

Disclosure of Imaging Biomarker Results in Cognitively and Ethno-racially Diverse Participants

Annalise Rahman-Filipiak, PhD

Spring ADRC Meeting 2022

Outline

- To Disclose or Not to Disclose?
- Disclosure Needs Assessment
- Multi-Marker Disclosure Protocol
- Preliminary Outcomes
- Future Directions

ADC Network Return of Results

TABLE 1 Return of individual research results, by type (N = 30 centers)

Type of information	Type of participant		
	Dementia or MCI	Normal cognition or SMC	N/A
Consensus research diagnosis	25 (83%)	23 (77%)	0
Neuropsychological test results	22 (73%)	21 (70%)	0
Amyloid PET results	13 (43%)	8 (27%)	6 (20%)
MRI results	12 (40%)	10 (33%)	3 (10%)
FDG PET results	8 (27%)	6 (20%)	10 (33%)
Genetic test results, not *APOE*	4 (13%)	3 (10%)	5 (17%)
Tau imaging results	3 (10%)	2 (7%)	13 (43%)
CSF biomarker results	3 (10%)	1 (3%)	8 (27%)
APOE genetic test results	2 (7%)	2 (7%)	0

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Roberts et al. (2021) *Alz Dem: TRCI*

Why Not to Disclose

- Different ligands, data collection and analytic methods
- No agreed-upon cut-point for 'positivity'
- Few published protocols, particularly integrating multiple markers
- Few centralized post-disclosure resources
- Limited research with racial-ethnic minorities or other minority groups
- Concerns about liability/risk

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Why are amyloid/tau particularly hard to communicate?

Etiology vs. Phenotype	Alzheimer's Disease	≠	Dementia – Alzheimer's Type
Context	Research Results	≠	Clinical Diagnosis
Dynamic Nature	Currently Not Elevated	≠	Permanently Not Elevated
Prognosis	Elevated Results	≠	Definitive Dementia Prognosis
Contribution to Clinical Picture	Elevated Results	≠	Ruling Out Other Conditions/Contributors

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Why Disclose?

- Potentially actionable results for participants & care partners
  - Clinical Care, Treatment Personalization - IDEAS
  - Behavior/Lifestyle Change – REVEAL SCAN
  - Advanced Planning – REVEAL SCAN
  - Role Preparation

- Transparency → Trust-Building
  - Higher Retention
  - Recruitment into Clinical Trials

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Research Question 1

Are diverse participants and their family members interested in learning about other risk indicator or biomarker results?

Interest in Cognitive Test Results & Phenotypic Diagnosis

		Participants (n = 57)			Co-Participants (n = 57)		
		Black (n = 22)	White (n = 35)	p	Black (n = 19)	White (n = 38)	p
Interest in Receiving Cognitive Test Results, Current Diagnosis	No Interest	0 (0.0%)	0 (0.0%)		0 (0.0%)	0 (0.0%)	
	Very Little Interest	0 (0.0%)	0 (0.0%)		1 (5.3%)	0 (0.0%)	
	Neutral	1 (4.6%)	1 (2.9%)		0 (0.0%)	3 (7.9%)	
	Moderate Interest	3 (13.6%)	3 (8.6%)		2 (10.5%)	0 (0.0%)	
	Strong Interest	18 (81.8%)	31 (88.6%)	.838	16 (84.2%)	35 (92.1%)	.040*
	Average Score	3.77 (0.53)	3.86 (0.43)	.512	3.74 (0.73)	3.84 (0.55)	.544
Would you choose to receive cognitive testing results today?	Yes	22 (100.0%)	34 (97.1%)	.999	17 (89.5%)	37 (97.4%)	.544

- Participants report high interest in cognitive test results/diagnosis regardless of race or diagnosis.
- Co-participants also report high interest; however, interest is stronger in white co-participants than in Black co-participants.

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Interest in Structural MRI Results

		Participants (n = 57)			Co-Participants (n = 57)		
		Black (n = 22)	White (n = 35)	p	Black (n = 19)	White (n = 38)	p
Interest in Receiving Structural MRI Results	No Interest	1 (4.6%)	1 (2.9%)		1 (5.3%)	0 (0.0%)	
	Very Little Interest	0 (0.0%)	0 (0.0%)		2 (10.5%)	0 (0.0%)	
	Neutral	0 (0.0%)	1 (2.9%)		0 (0.0%)	3 (7.9%)	
	Moderate Interest	3 (13.6%)	3 (8.6%)		2 (10.5%)	2 (5.3%)	
	Strong Interest	18 (81.8%)	30 (85.7%)	.901	14 (73.7%)	33 (86.8%)	.053
	Average Score	3.68 (0.89)	3.74 (0.78)	.787	3.37 (1.26)	3.79 (0.58)	.087
Would you choose to receive MRI results today?	Yes	20 (90.9%)	34 (97.1%)	.553	17 (89.5%)	36 (94.7%)	.594

- Participants report high interest in MRI results regardless of race or diagnosis.
- Co-participants also report high interest; however, there was a trend towards stronger interest in white co-participants than in Black co-participants.
- Among risk indicators, MRI results were of relatively lower interest.

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Interest in APOE Genotype Results

		Participants (n = 57)			Co-Participants (n = 57)		
		Black (n = 22)	White (n = 35)	p	Black (n = 19)	White (n = 38)	p
Interest in Receiving APOE Genotype	No Interest	0 (0.0%)	0 (0.0%)		1 (5.3%)	0 (0.0%)	
	Very Little Interest	1 (4.6%)	0 (0.0%)		2 (10.5%)	0 (0.0%)	
	Neutral	1 (4.6%)	1 (2.9%)		0 (0.0%)	4 (10.5%)	
	Moderate Interest	2 (9.1%)	2 (5.7%)		1 (5.3%)	2 (5.3%)	
	Strong Interest	18 (81.8%)	32 (91.4%)	.718	15 (79.0%)	32 (84.2%)	.066
	Average Score	3.68 (0.78)	3.89 (0.40)	.199	3.42 (1.3)	3.74 (0.64)	.214
Would you choose to receive APOE genotype today?	Yes	21 (95.5%)	34 (97.1%)	.999	15 (79.0%)	36 (94.7%)	.164

- Participants report high interest in genetic results regardless of race or diagnosis.
- Co-participants also report high interest in receiving the participant's genetic results; however, there was a trend towards stronger interest in white co-participants than in Black co-participants.

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Interest in PET Amyloid & Tau Results

		Participants (n = 57)			Co-Participants (n = 57)		
		Black (n = 22)	White (n = 35)	p	Black (n = 19)	White (n = 38)	p
Interest in Receiving PET Amyloid & Tau Results	No Interest	0 (0.0%)	1 (2.9%)		1 (5.3%)	0 (0.0%)	
	Very Little Interest	0 (0.0%0	0 (0.0%)		2 (10.5%)	0 (0.0%)	
	Neutral	0 (0.0%)	0 (0.0%)		1 (5.3%)	3 (7.9%)	
	Moderate Interest	3 (13.6%)	6 (17.1%)		2 (10.5%)	1 (2.6%)	
	Strong Interest	19 (86.4%)	28 (80.0%)	.835	13 (68.4%)	34 (89.5%)	.047*
	Average Score	3.86 (0.35)	3.71 (0.75)	.386	3.26 (1.28)	3.82 (0.56)	.027*
Would you choose to receive PET Amyloid & Tau results today?	Yes	22 (100.0%)	34 (97.1%)	.999	15 (79.0%)	36 (94.7%)	.164

- Participants report high interest in PET biomarker results regardless of race or diagnosis.
- Co-participants report moderate interest; however, white participants reported greater interest and willingness to receive the participant's PET results than Black participants.

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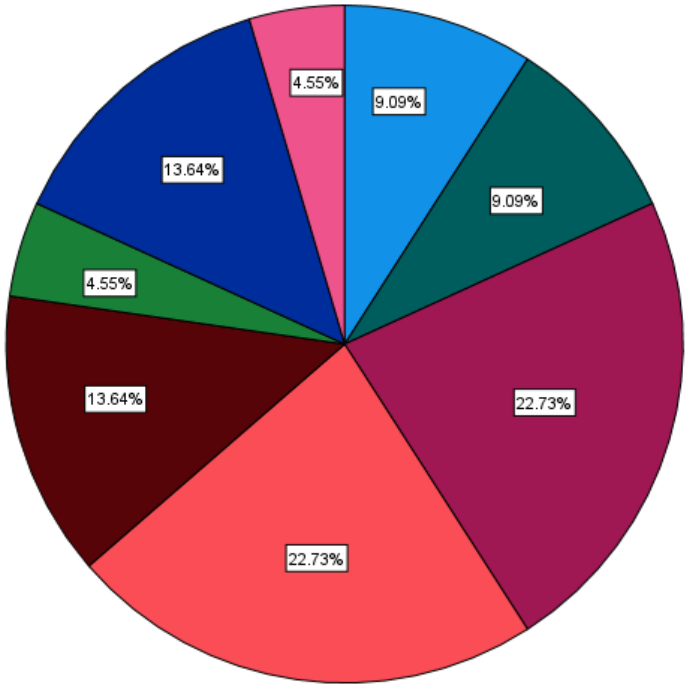
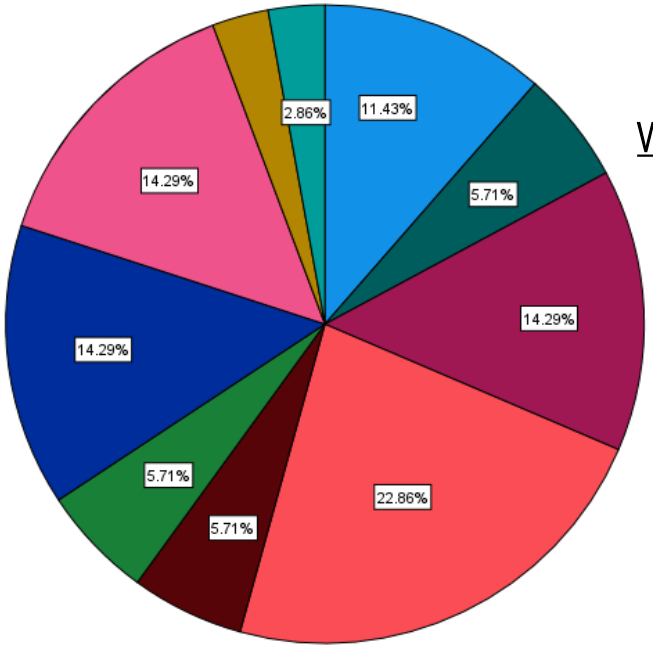
Diverse Motivations for Disclosure

Black/African American Participants



- Diminish Worry
- Learn More About Health
- Treatments/Clinical Trials
- Modify Health Behaviors
- Career/Retirement/Investment Planning
- Relationship/Reproductive Planning
- Long-Term Care Planning
- Other - Inform Family/Friends

White Participants



- General Curiosity
- Diminish Worry
- Learn More About Health
- Treatments/Clinical Trials
- Modify Health Behaviors
- Career/Retirement/Investment Planning
- Relationship/Reproductive Planning
- Long-Term Care Planning
- Other - Inform Family
- Other - Designate Decision-Maker

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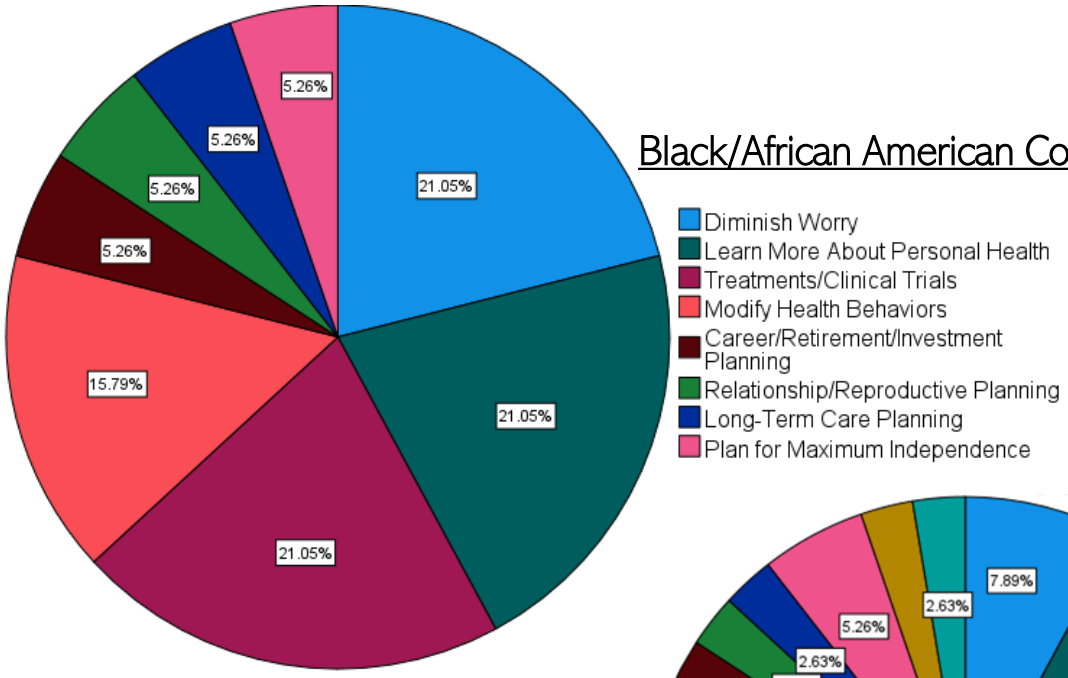
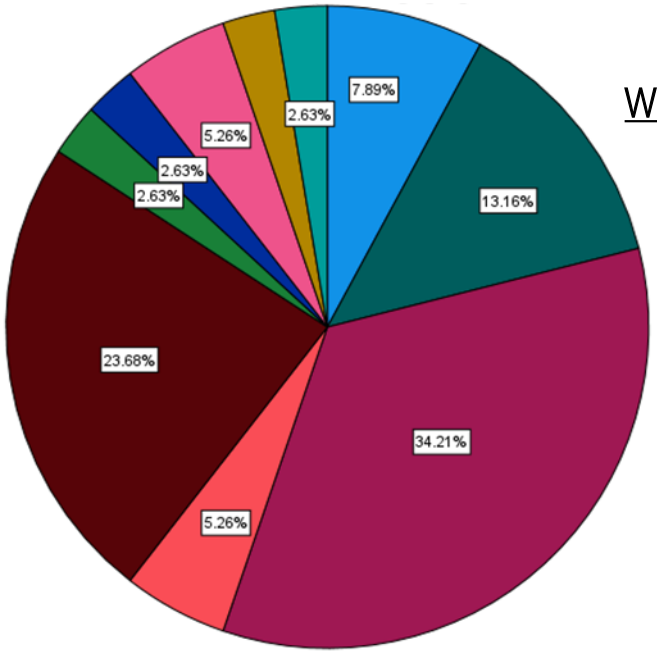
Diverse Motivations for Disclosure



Black/African American Co-Participants

- Diminish Worry
- Learn More About Personal Health
- Treatments/Clinical Trials
- Modify Health Behaviors
- Career/Retirement/Investment Planning
- Relationship/Reproductive Planning
- Long-Term Care Planning
- Plan for Maximum Independence



White Co-Participants

- Diminish Worry
- Learn More About Personal Health
- Treatments/Clinical Trials
- Modify Health Behaviors
- Long-Term Care Planning
- Share with Individual's Family
- Simplify Life, Downsize
- Provide Emotional Support
- Prepare for Behavioral Management
- Because Participant Wants To

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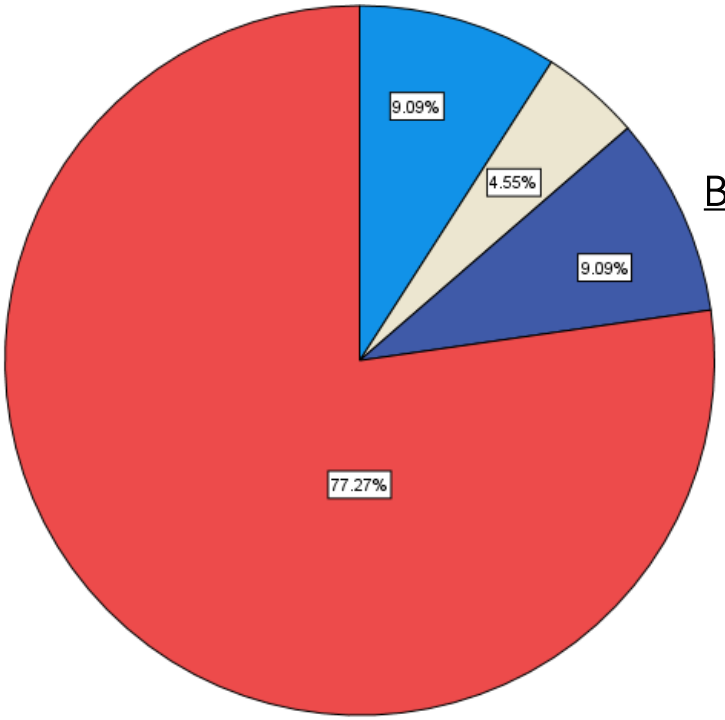
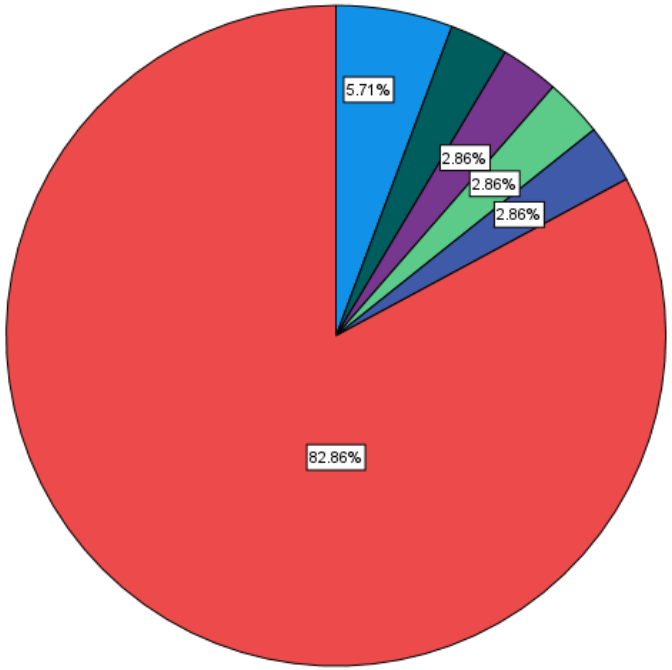
Limited Concern About Risks



Black/African American Participants

- Lack of Available Treatments
- Change in Social Relationships
- Change in Family Roles
- No Barrier At All



White Participants

- Lack of Available Treatments
- Increased Anxiety/Worry
- Inability to Act on Knowledge
- Stigma in Community
- Change in Family Roles
- No Barrier At All

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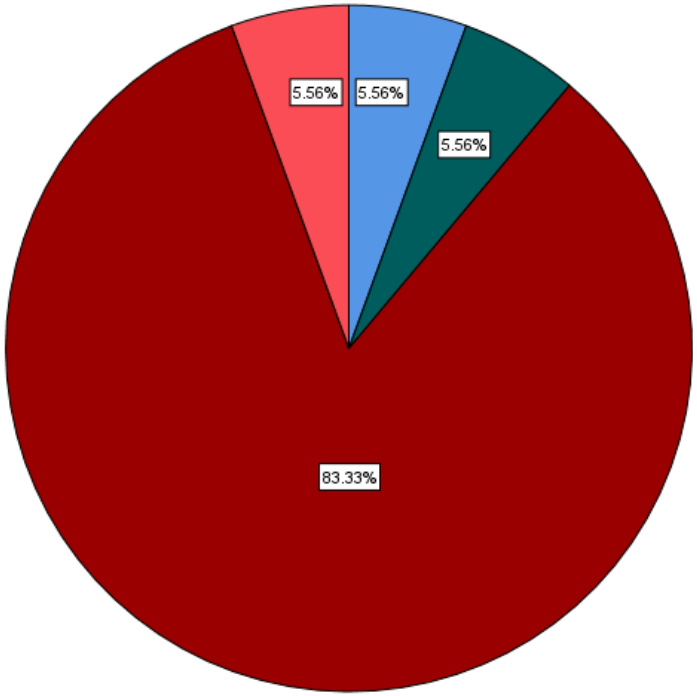
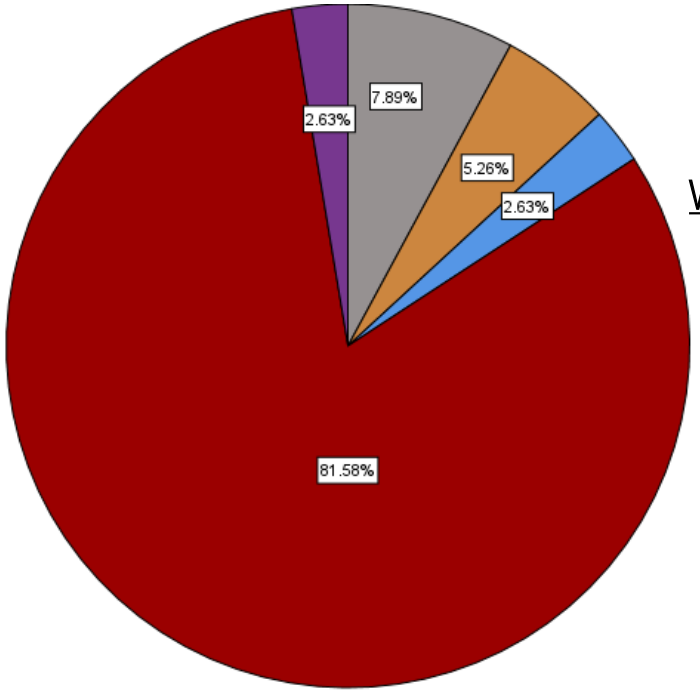
Limited Concern About Risks



Black/African American Co-Participants

- Inability to Act on Knowledge
- Concerns over Social Role Changes
- No Barrier At All
- Should be Participant's Decision Only



White Co-Participants

- Lack of Available Treatments
- Increased Worry
- Inability to Act on Knowledge
- No Barrier At All
- Information Not Reliable

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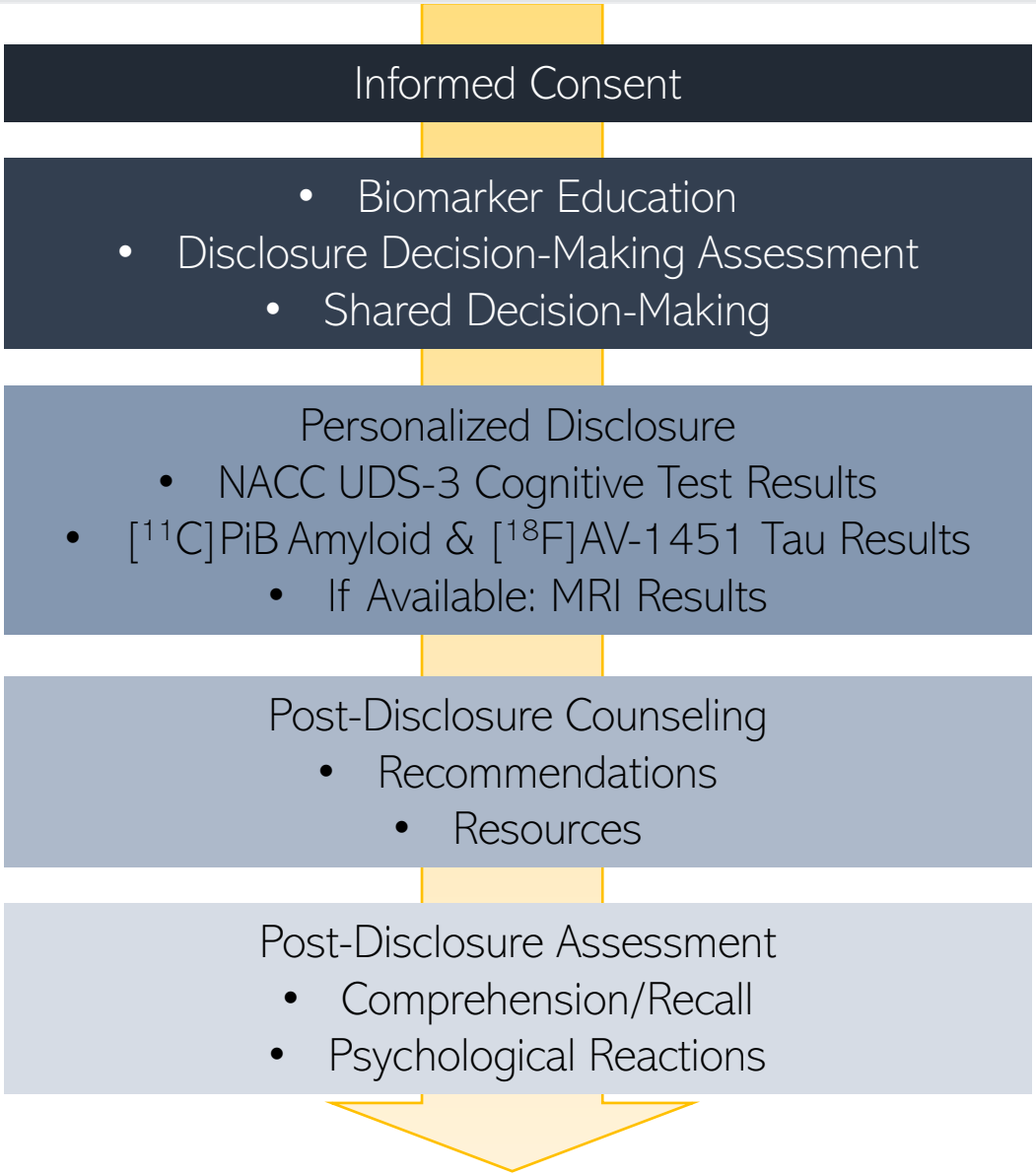
Core Question 2

How to Create a Structured but Person-Centered Protocol?

Integrating Tau & MRI



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Integrating Tau & MRI

		Cognitive stage		
		Cognitively Unimpaired	**Mild Cognitive Impairment**	**Dementia**
Biomarker Profile	$A^- T^-(N)^-$	normal AD biomarkers, cognitively unimpaired	normal AD biomarkers with MCI	normal AD biomarkers with dementia
	$A^+ T^-(N)^-$	Preclinical Alzheimer's pathologic change	Alzheimer's pathologic change with MCI	Alzheimer's pathologic change with dementia
	$A^+ T^+ (N)^-$	Preclinical Alzheimer's disease	Alzheimer's disease with MCI(Prodromal AD)	Alzheimer's disease with dementia
	$A^+ T^+(N)^+$			
	$A^+ T^- (N)^+$	Alzheimer's and concomitant suspected non Alzheimer's pathologic change, cognitively unimpaired	Alzheimer's and concomitant suspected non Alzheimer's pathologic change with MCI	Alzheimer's and concomitant suspected non Alzheimer's pathologic change with dementia
	$A^- T^+(N)^-$	non-Alzheimer's pathologic change, cognitively unimpaired	non-Alzheimer's pathologic change with MCI	non-Alzheimer's pathologic change with dementia
	$A^- T^-(N)^+$			
	$A^- T^+(N)^+$			

Jack et al. (2018) *Alzheimer's & Dementia*

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Integrating Tau & MRI

Result	Is this Alzheimer's Disease?	How does this affect risk for Dementia – Alzheimer's Type?
Neither Amyloid nor Tau Elevated	Not Alzheimer's Disease; 'Normal' Result	No increase in risk for DAT
Amyloid Elevated, Tau Not Elevated	Concern for Alzheimer's disease brain changes	Increased risk for DAT
Tau Elevated, Amyloid Not Elevated	Not Alzheimer's Disease; Concern for other abnormal brain changes	No increase in risk for DAT; Concern for other neurologic problem
Amyloid Elevated, Tau Elevated	Alzheimer's disease	Increased risk for DAT

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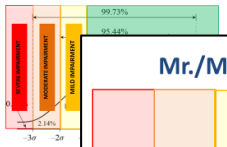
Audiovisual Educational & Disclosure Materials

Cognitive Testing

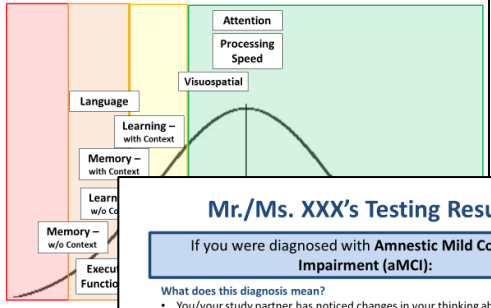
- We reviewed the results from the cognitive testing you completed as part of UMMAP/STIM/DAPPER/the Driving Study on Date of Most Recent Evaluation.
- We compared your scores to the scores achieved by other Black/African-American/White men/women who are XX years old.

Possible Results: your scores are:

- **Within Expectation –** average or above compared to your peers
- Mild Impairment – slightly below



Mr./Ms. XXX's Cognitive Testing



Mr./Ms. XXX's Testing Results

If you were diagnosed with **Amnestic Mild Cognitive Impairment (aMCI):**

What does this diagnosis mean?

- You/your study partner has noticed changes in your thinking abilities that are also evident on cognitive testing, but that these changes have not yet impacted your ability to live independently or take care of yourself.

What should I expect?

- ~1/3rd of people with aMCI will get worse over time, until they can no longer care for themselves independently. They will **convert to Dementia-Alzheimer's Type**.
- ~1/3rd of people with aMCI will **stay the same** over time.
- ~1/3rd of people with aMCI will **improve over time**, including some who will **revert to bei**

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Let's check your understanding!

In your own words, can you tell me…

Which of your thinking abilities were impaired (lower than expected for age)?

What was your research diagnosis?

What should you expect in the future?

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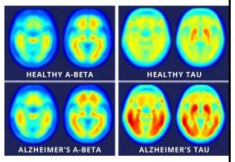
PET Amyloid & Tau Scan

- We reviewed the results from the PET scan you completed as part of STIM/the Driving Study/DAPPER on XX/XX/XXXX.
- Your results were analyzed by trained professionals to determine whether you had a significant amount of AD-specific amyloid or tau in your brain.
- You will receive separate results for amyloid and tau.

Example of Normal (top) and elevated (bottom) PET scans



Amyloid, Tau, & Alzheimer's Disease

Result	Is this Alzheimer's Disease?	How does this affect risk for Dementia – Alzheimer's Type?
Neither Amyloid nor Tau Elevated	Not Alzheimer's Disease; 'Normal' Result	No increase in risk for DAT
Amyloid Elevated, Tau Not Elevated	Concern for Alzheimer's disease brain changes	Increased risk for DAT
Elevated, Amyloid Elevated	Not Alzheimer's Disease; Concern for other abnormal brain changes	No increase in risk for DAT; Concern for other neurologic problem
loid Elevated, Tau ated	Alzheimer's disease	Increased risk for DAT

Having amyloid raises concern for Alzheimer's disease. Having amyloid and tau confirms Alzheimer's disease.

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Mr./Ms. XXX's PET Results

Results indicated that:

Your amyloid level is elevated.

Your tau level is elevated.

Mr./Ms. XXX's PET Results

If you have **Elevated Amyloid and Elevated Tau:**

What does this result mean?

- At this time, there is a significant amount of AD-associated amyloid and tau in your brain.
- This result means that there is a high likelihood that you have **Alzheimer's disease**.
- This result means that **your cognitive symptoms are likely due to Alzheimer's disease**

at should I expect?

ou are at **increased risk to develop Dementia – Alzheimer's Type.** Increased isk means there is a greater likelihood; it does NOT mean DAT is guaranteed. We cannot predict how severely or how quickly you will decline. We cannot rule in or out other conditions, including other forms of dementia

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Let's check your understanding!

In your own words, can you tell me…

Do you have an elevated level of amyloid at this time?

Do you have an elevated level of tau at this time?

Is there currently evidence of Alzheimer's Disease in your brain?

What does that mean about your risk for DAT?

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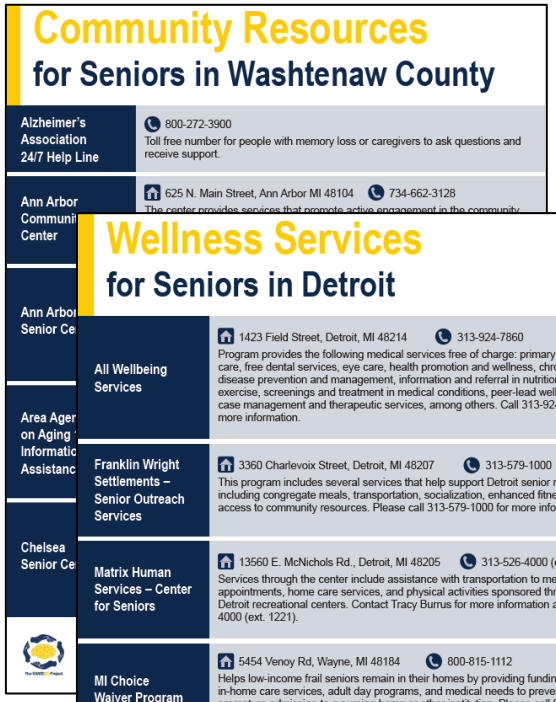
Personalized Resources



Community Resources
for Seniors in Washtenaw County

Alzheimer's Association 24/7 Help Line
800-272-3900
Toll free number for people with memory loss or caregivers to ask questions and receive support.

Ann Arbor Communi Center
625 N. Main Street, Ann Arbor MI 48104 734-662-3128
The center provides services that promote active engagement in the community

Ann Arbor Senior Ce

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Wellness Services
for Seniors in Detroit

All Wellbeing Services
1423 Field Street, Detroit, MI 48214 313-924-7860
Program provides the following medical services free of charge: primary medical care, free dental services, eye care, health promotion and wellness, chronic disease prevention and management, information and referral in nutrition & exercise, screenings and treatment in medical conditions, peer-lead wellness, and case management and therapeutic services, among others. Call 313-924-7860 for more information.

Franklin Wright Settlements – Senior Outreach Services
3360 Charlevoix Street, Detroit, MI 48207 313-579-1000
This program includes several services that help support Detroit senior residents, including congregate meals, transportation, socialization, enhanced fitness and access to community resources. Please call 313-579-1000 for more information.

Matrix Human Services – Center for Seniors
13560 E. McNichols Rd., Detroit, MI 48205 313-526-4000 (ext. 1221)
Services through the center include assistance with transportation to medical appointments, home care services, and physical activities sponsored through Detroit recreational centers. Contact Tracy Burrus for more information at 313-526-4000 (ext. 1221).

MI Choice Waiver Program
5454 Venoy Rd, Wayne, MI 48184 800-815-1112
Helps low-income frail seniors remain in their homes by providing funding for in-home care services, adult day programs, and medical needs to prevent their premature admission to a nursing home or other institution. Please call 800-815-1112 for more information on how to qualify.

Samaritas
313-823-7700
This program includes several services that help support Detroit senior residents, including congregate meals, transportation, socialization, enhanced fitness and access to community resources. Please call 313-823-7700 for more information.

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Last updated 10/2020
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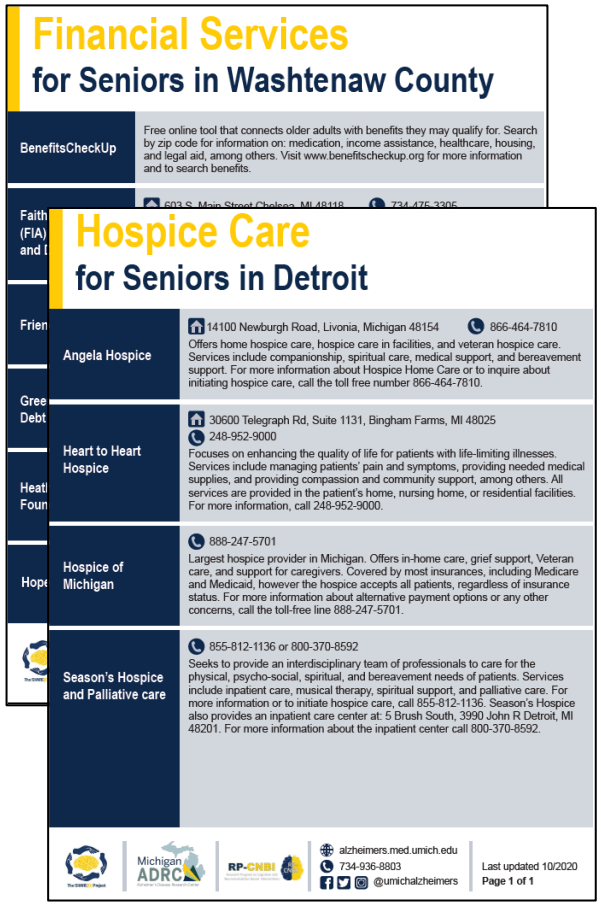

Financial Services
for Seniors in Washtenaw County

BenefitsCheckUp
Free online tool that connects older adults with benefits they may qualify for. Search by zip code for information on: medication, income assistance, healthcare, housing, and legal aid, among others. Visit www.benefitscheckup.org for more information and to search benefits.

Faith (FIA) and [
603 S. Main Street Chelsea, MI 48118 734-475-3305

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Hospice Care
for Seniors in Detroit

Angela Hospice
14100 Newburgh Road, Livonia, Michigan 48154 866-464-7810
Offers home hospice care, hospice care in facilities, and veteran hospice care. Services include companionship, spiritual care, medical support, and bereavement support. For more information about Hospice Home Care or to inquire about initiating hospice care, call the toll free number 866-464-7810.

Heart to Heart Hospice
30600 Telegraph Rd, Suite 1131, Bingham Farms, MI 48025
248-952-9000
Focuses on enhancing the quality of life for patients with life-limiting illnesses. Services include managing patients' pain and symptoms, providing needed medical supplies, and providing compassion and community support, among others. All services are provided in the patient's home, nursing home, or residential facilities. For more information, call 248-952-9000.

Hospice of Michigan
888-247-5701
Largest hospice provider in Michigan. Offers in-home care, grief support, Veteran care, and support for caregivers. Covered by most insurances, including Medicare and Medicaid, however the hospice accepts all patients, regardless of insurance status. For more information about alternative payment options or any other concerns, call the toll-free line 888-247-5701.

Season's Hospice and Palliative care
855-812-1136 or 800-370-8592
Seeks to provide an interdisciplinary team of professionals to care for the physical, psycho-social, spiritual, and bereavement needs of patients. Services include inpatient care, musical therapy, spiritual support, and palliative care. For more information or to initiate hospice care, call 855-812-1136. Season's Hospice also provides an inpatient care center at: 5 Brush South, 3990 John R Detroit, MI 48201. For more information about the inpatient center call 800-370-8592.

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Resources for Caregivers
in Washtenaw County

Adult Protective Services (APS)
855-444-3911
This program protects vulnerable older adults from neglect and exploitation by coordinating with mental health providers, law enforcement, community groups, and the aging network. Staff at adult protective services will investigate allegations within 24 hours after the allegation is received. Call 855-444-3911 any time to file a report.

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Mental Health Resources
for Seniors in Detroit

Helpline for Wayne County
313-224-7000 or 800-241-4949
A crisis intervention, suicide prevention, and information and referral helpline for Wayne County. Call 313-224-7000 or the toll free number 800-241-4949 for more information.

National Suicide Prevention Hotline
800-273-TALK

Neighborhood Service Organization (NSO)
882 Oakman Blvd., Suite D, Detroit, MI, 48238
313-961-7990 or 800-811-4211
NSO Older Adult Services (OAS) provides mental health outreach, residential and advocacy services to help older adults reach their maximum potential and remain active community participants. Through the OAS residential care program, consumers receive a full range of clinical, psychiatric nursing and occupational therapy assistance in supported living settings. Call 313-961-7990 for Older Adult Services or 800-811-4211 for information and referrals to all NSO programs.

Psychology Today
Psychology Today's database provides a comprehensive directory of therapists, psychiatrists and treatment facilities near you. This can be a useful search tool to find a therapist based on your insurance and type of therapy you're seeking. Visit www.psychologytoday.com

Senior Reach – Northeast Guidance Center
2900 Conner Avenue, Building A, Detroit, MI, 48215 313-308-1400
Senior Reach community partners identify older adults who may need help and contact the Northeast Guidance Center to make a referral. Specialists then determine willingness to accept care, as well as specific needs. Identified seniors are then connected to appropriate services such as counseling, connection to community resources, and care management, among others. For more information, or to refer a senior, call 313-308-1400.

Statewide Helpline for Gambling
800-270-7117

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Core Question 3

How well is complex information understood?

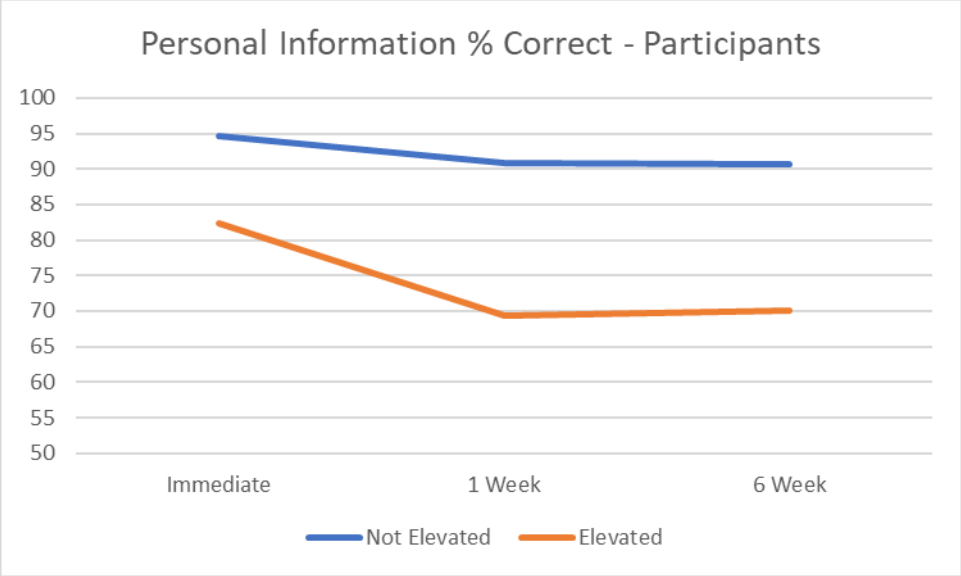
Core Question 4

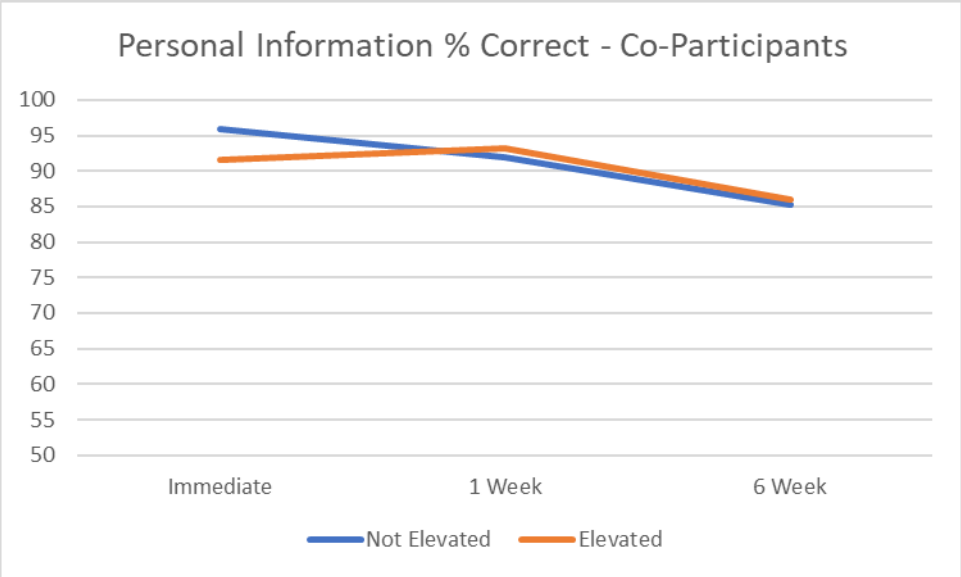
How do participants and their families react to results disclosure?

Comprehension/Recall of Results

- **Personal Information: rote memorization of results**

- Participants & Co-Participants:
  - No significant differences in recalling results at any time point in biomarker elevated vs. not-elevated participants or their respective co-participants
  - General retention of results over time





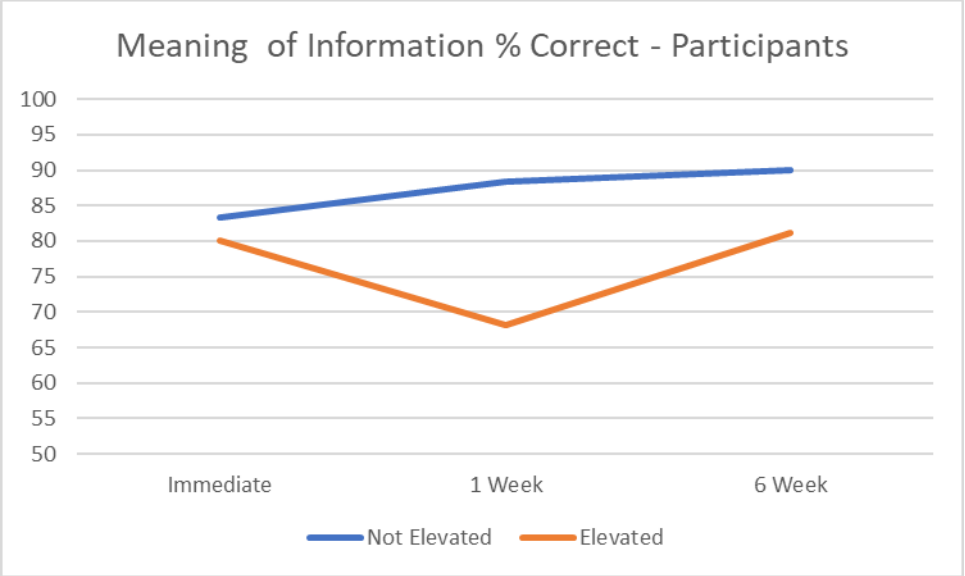
Comprehension/Recall of Results

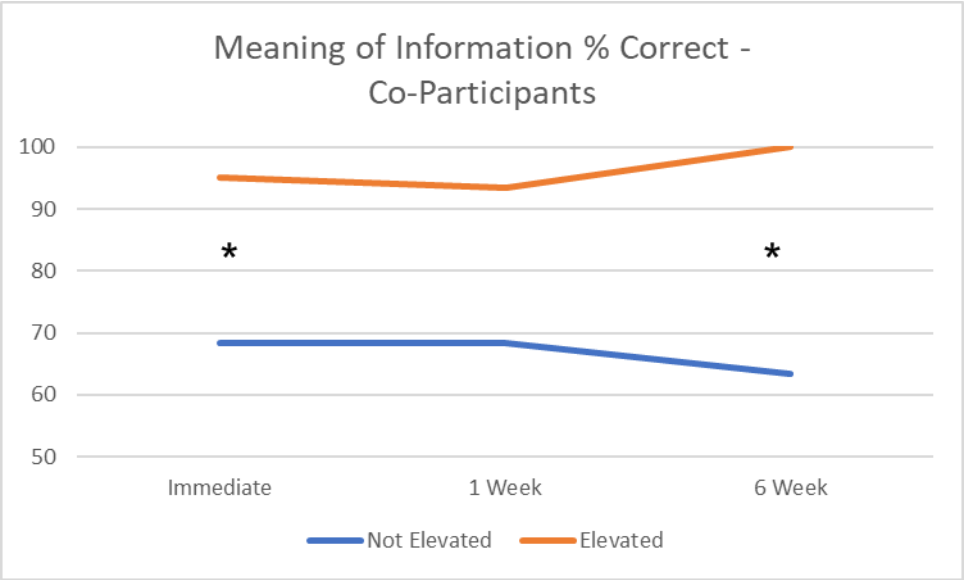
- Meaning of Information: recall of the meaning of their results (i.e., elevated amyloid = increased risk for DAT)

- Participants: No significant differences in understanding of results at any time point; general retention of results over time

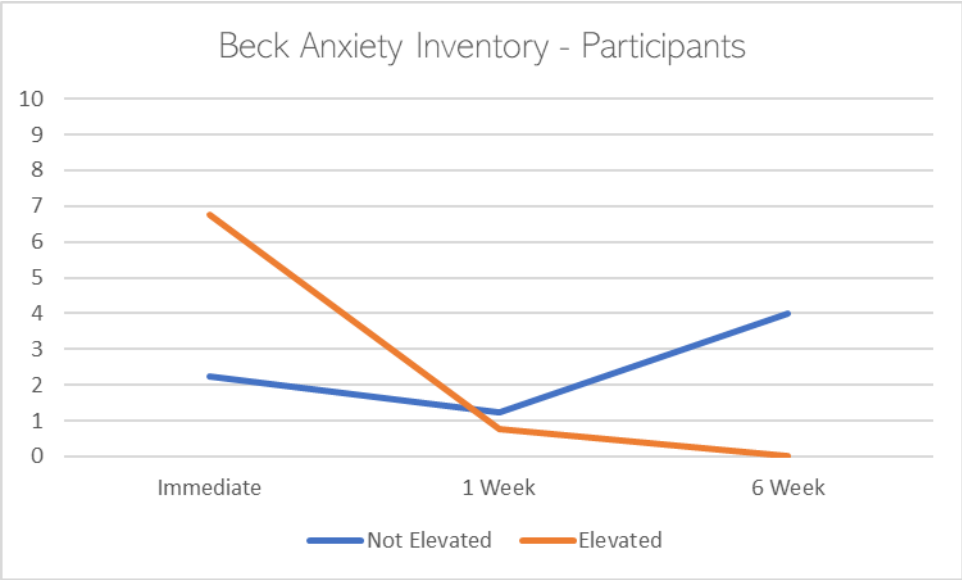
- Co-Participants: Significantly greater understanding of results immediately and at 6 weeks post-disclosure (trend at 1week) among co-participants of biomarker-elevated participants; general retention of what was understood

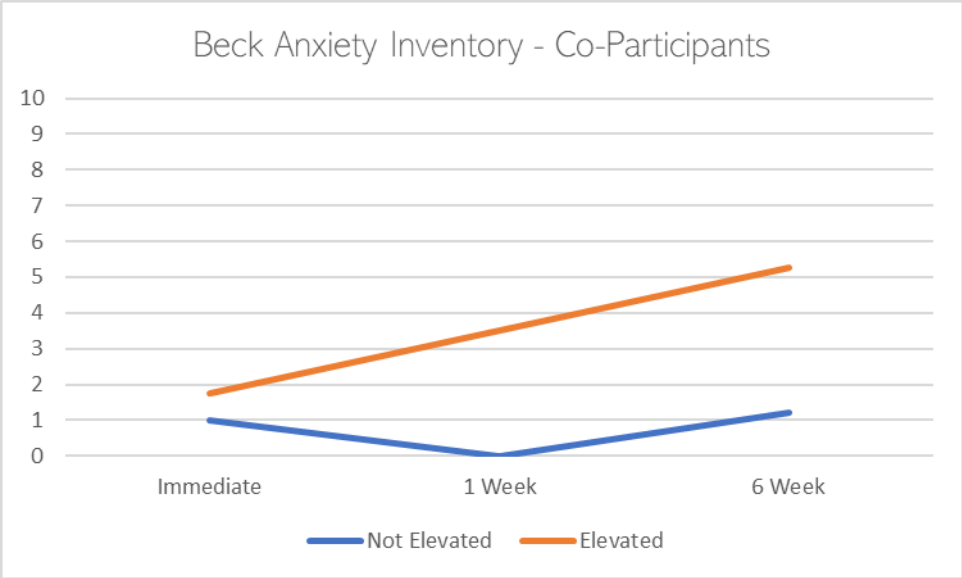
- Generally poorer understanding of the meaning of information, even when actual result is retained.





Post-Disclosure Reactions





Beck Anxiety Inventory
Test Range: 0-7 Minimal; 8-15 Mild; 16-25 Moderate; 26-63 Severe

- Participants & Co-Participants: No significant difference in BAI score at any time point based on elevated vs. not-elevated biomarker result status
- No disclosure-related elevations into clinical range (>15)

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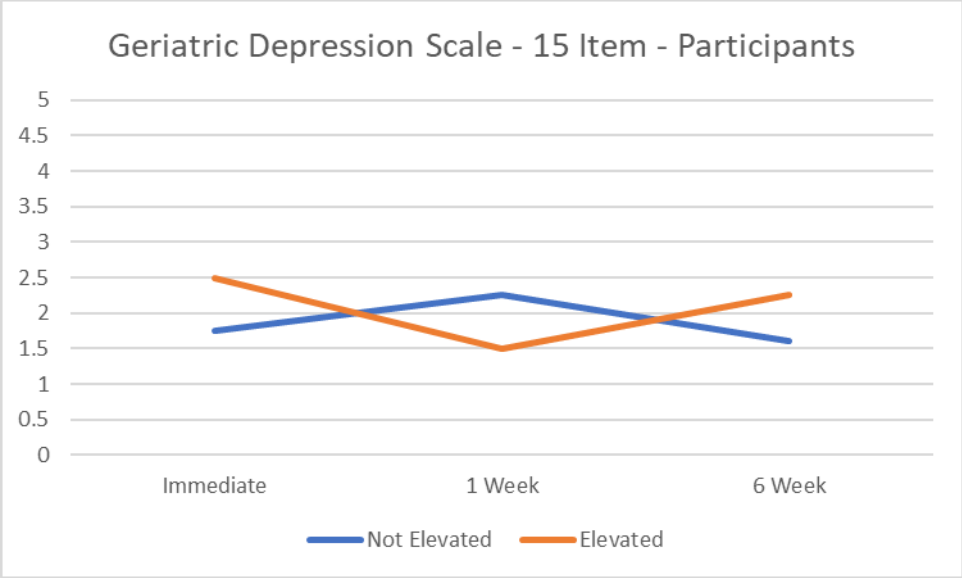
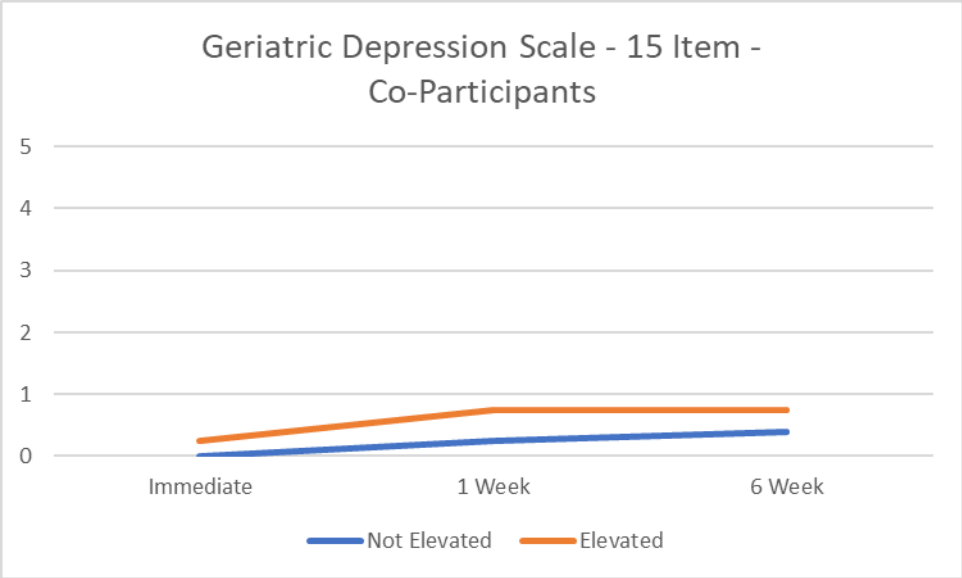
Post-Disclosure Reactions





Geriatric Depression Scale – 15 Item
Test Range: 0-4 Negative; 5-15 Positive

- Participants & Co-Participants: No significant difference in GDS-15 score at any time point based on elevated vs. not-elevated biomarker result status
- No disclosure-related elevations into clinical range (>5)

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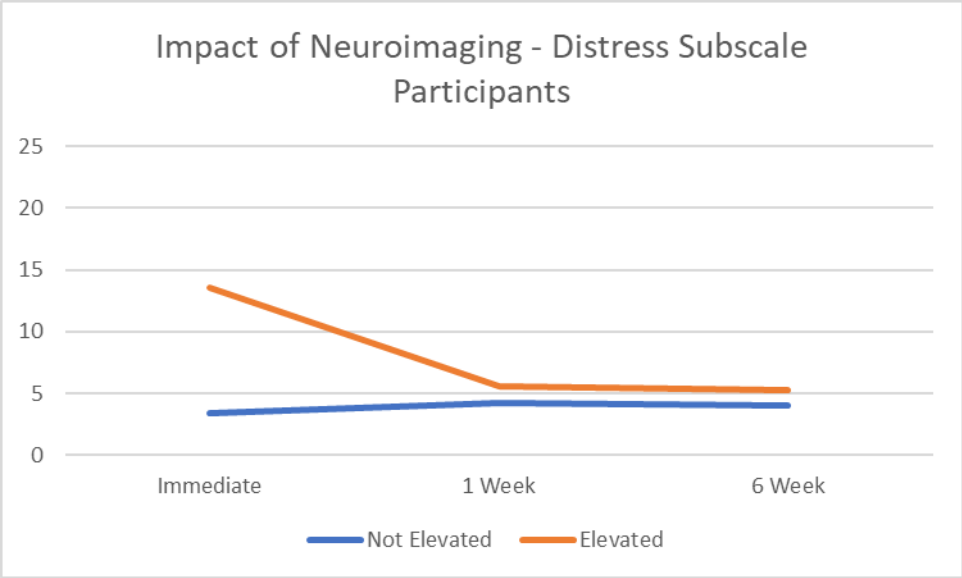
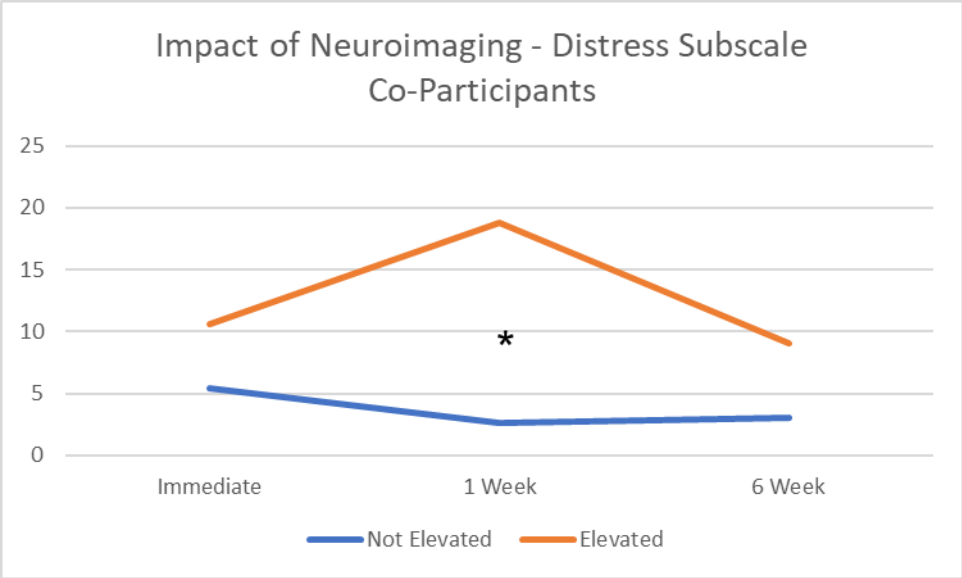
Post-Disclosure Reactions





Impact of Neuroimaging Distress Scale Range: 0-60; 0-23 Negative; >23 Positive

- Participants: Trend towards greater distress among biomarker elevated participants immediately post-disclosure; no difference at 1- or 6-weeks post-disclosure

- Co-Participants: No difference in distress immediately following or at 6-week post-disclosure; significantly greater distress among loved ones of biomarker-elevated participants at 1week post-disclosure

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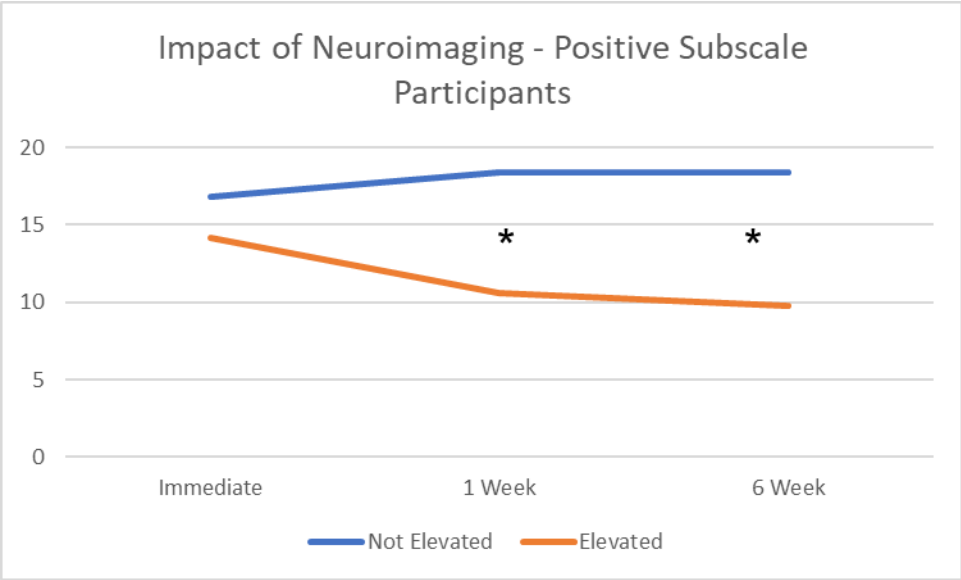
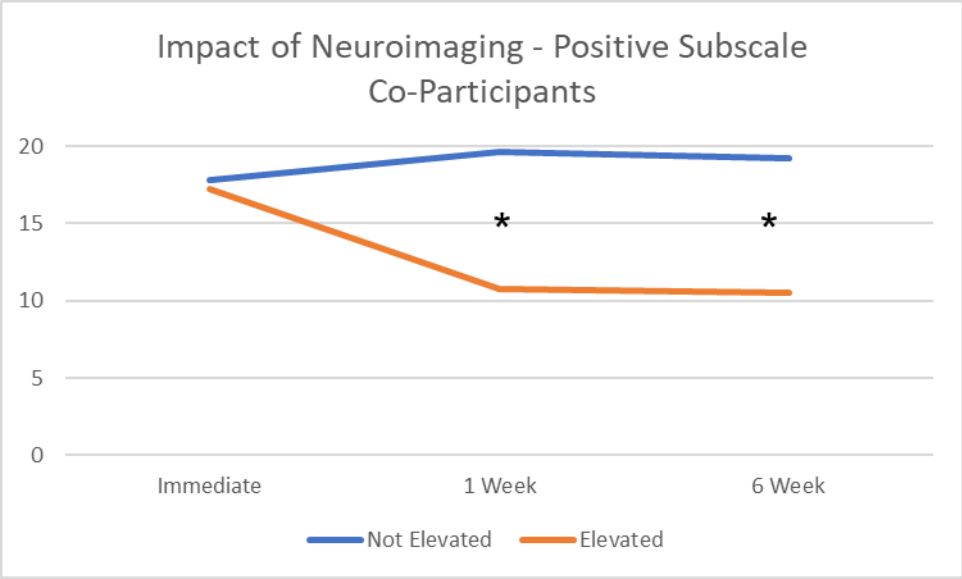
Post-Disclosure Reactions





Impact of Neuroimaging Positive Subscale Range: 0-20

- Participants: Significantly lower positive reactions among biomarker elevated participants at 1- or 6-weeks post-disclosure
- Co-Participants: Significantly lower positive reactions among loved ones of biomarker-elevated participants at 1- and 6-weeks post-disclosure

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Summary

- Disclosure of multiple imaging markers provides a unique **opportunity to improve participants' lives and the lives of their caregivers** while also **promoting recruitment, retention, and community trust.**
- Tau and other biomarkers may **increase clarity** of disclosure messaging; however, communication of risk associated with dynamic biomarkers remains complex
- Preliminary data highlight differences in disclosure interest and reactions based on **sociodemographic factors**

Future Directions

- **Long-term impacts** of disclosure for patients and families
- **Social-contextual factors** influencing post-disclosure reactions and outcomes
- **Actuarial approaches** to integrating multiple biomarkers
- Resolution of **messaging for 'conflicting' biomarker** results (e.g., imaging vs. blood-based)
- Biomarker disclosure for **other pathologies/neurodegenerative diseases**
- **Best practices, competencies, and training** in disclosure and risk communication

Thank You!

This work was made possible through the following funding:

SHARED I & II (NIA R03-AG063222-01; PI: Rahman)

STIM Bioethics Supplement (NIA R01 AG058724; PI: Hampstead)

SHARED III (NIA 1K23AG07004401-A1; PI: Rahman)

Dissertation Grant, UM SPH (PI: Feldman)

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Research Program on Cognition & Neuromodulation-Based Interventions (RP-CNBI)

Michigan Alzheimer's Disease Research Center (MADRC)

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