

# Lessons learned recruiting in Arab and Latino immigrant communities for Alzheimer's disease research

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Michigan Center for Contextual Factors in Alzheimer's Disease



# Overview

1. Michigan Center for Contextual Factors in Alzheimer's Disease (MCCFAD)
2. Community Liaison and Recruitment Core Goals (CLRC)
3. Applying Community Based Participant Research to increase Arab American and Latino participation in Alzheimer's research
4. Lessons learned

# Michigan Center for Contextual Factors in Alzheimer's Disease (MCCFAD)



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# Michigan Center for Contextual Factors in Alzheimer's Disease (MCCFAD)



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# Community Liaison & Recruitment Core (CLRC)

- Focus on Arab Americans and Latinos
  - Growing immigrant communities, concentrated regions of U.S.
    - Similar sources of stress
  - Risk factors for AD more prevalent compared to whites
    - Documented high incidence among Latinos, Arab Americans not traditionally considered underrepresented
  - Described as having strong family ties
- African Americans
  - MCUAAAR and MADRC

# Community Liaison & Research Core (CLRC) Goals

Aims	Activities	Indicators	Key Partners
Recruit/Retain Participant Resource Pool	Community outreach liaison	PRP with 300 Latinos and 300 Arab Americans	ACCESS/CALC
	Monthly CAB & Bi-monthly health education meetings	Demographic Representativeness	Hispanic Center
	Annual Reception		Religious Institutions
	Wellness program activities		MADCC

# Community Liaison & Research Core (CLRC) Goals

Aims	Activities	Indicators	Key Partners
Technique Dissemination	Scientific presentations	1 presentation/yr	RCMAR Cntrs
	Scholarly publications	Special Jrnl Issue on Techniques	MADCC
	Research/Education Core (REC)	Empirical comparative paper (Arab and Latino)	HRS
	Professional Workshops	REC seminar content	

# Community Liaison & Research Core (CLRC) Goals

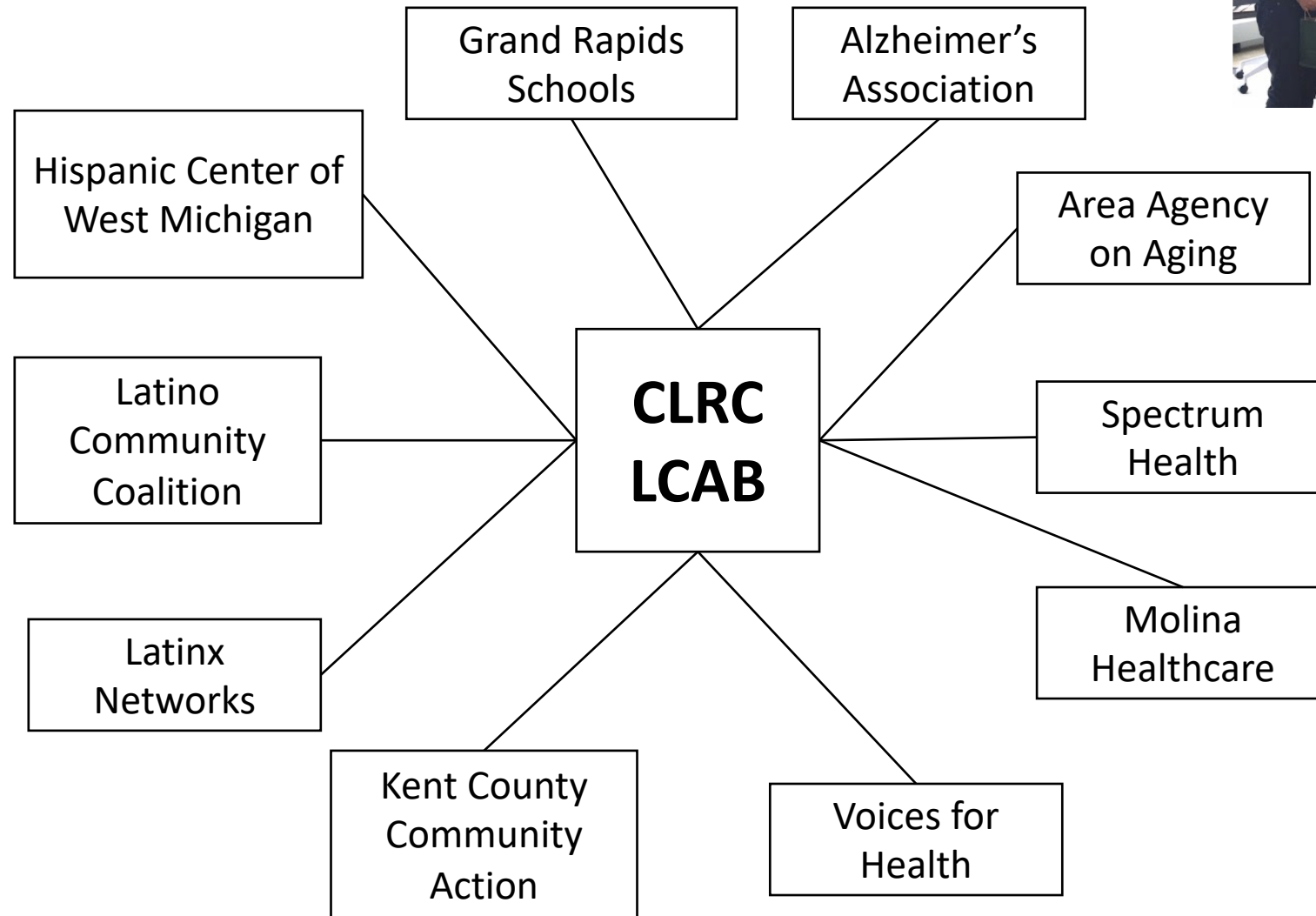
Aims	Activities	Indicators	Key Partners
Share Research Results with Communities	Semi-annual newsletter	Satisfaction ratings	ACCESS/CALC
	Annual Reception	Annual increase in event attendance	Hispanic Center
	Wellness program activities	Annual increase health-seeking behaviors	Religious Institutions
	Mini-Symposium	Community engagement	MADCC
			Healthcare providers

# Community Advisory Boards

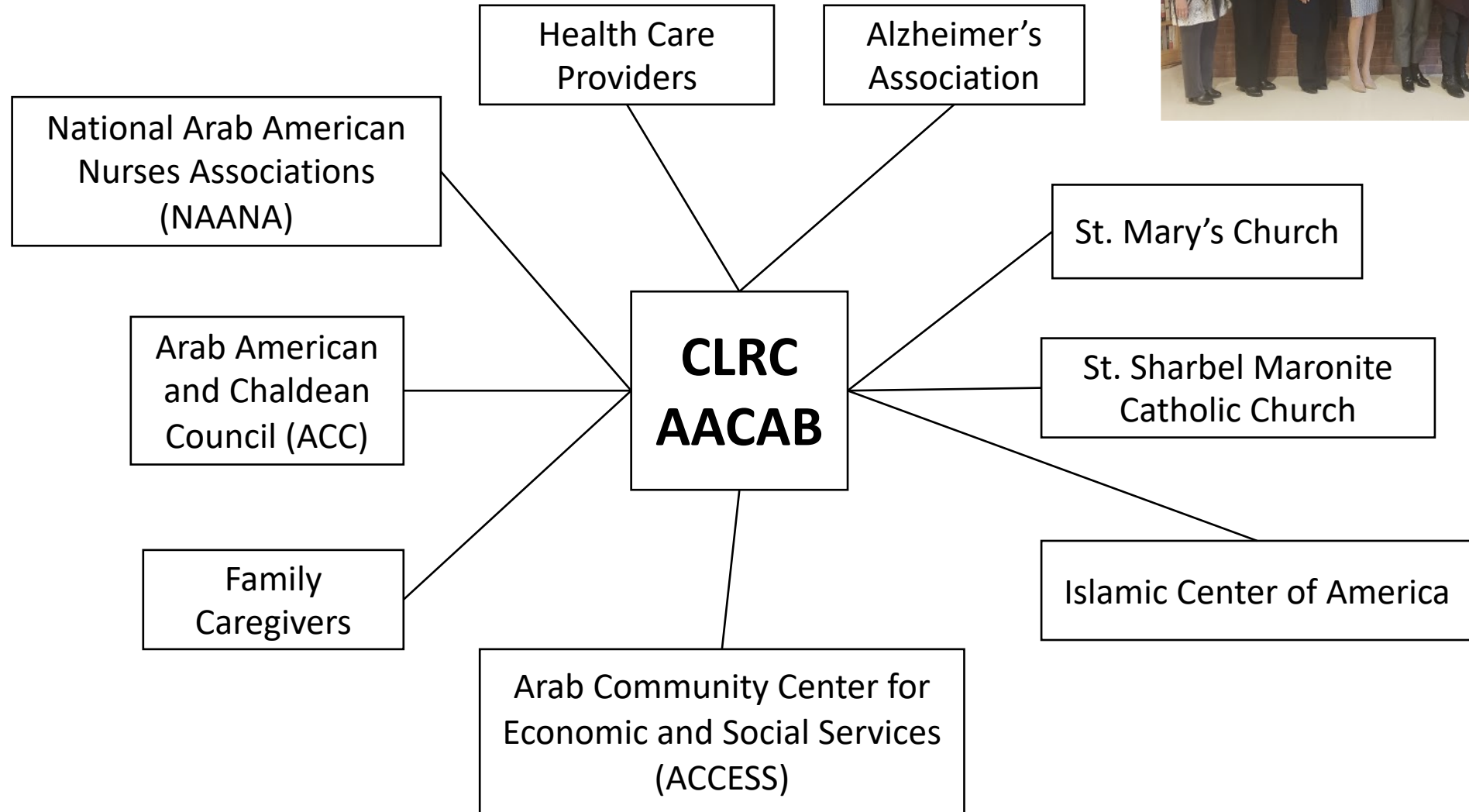




# Community Advisory Board-LCAB



# Community Advisory Board-AACAB



# Community Liaison and Recruitment Core Program Theory

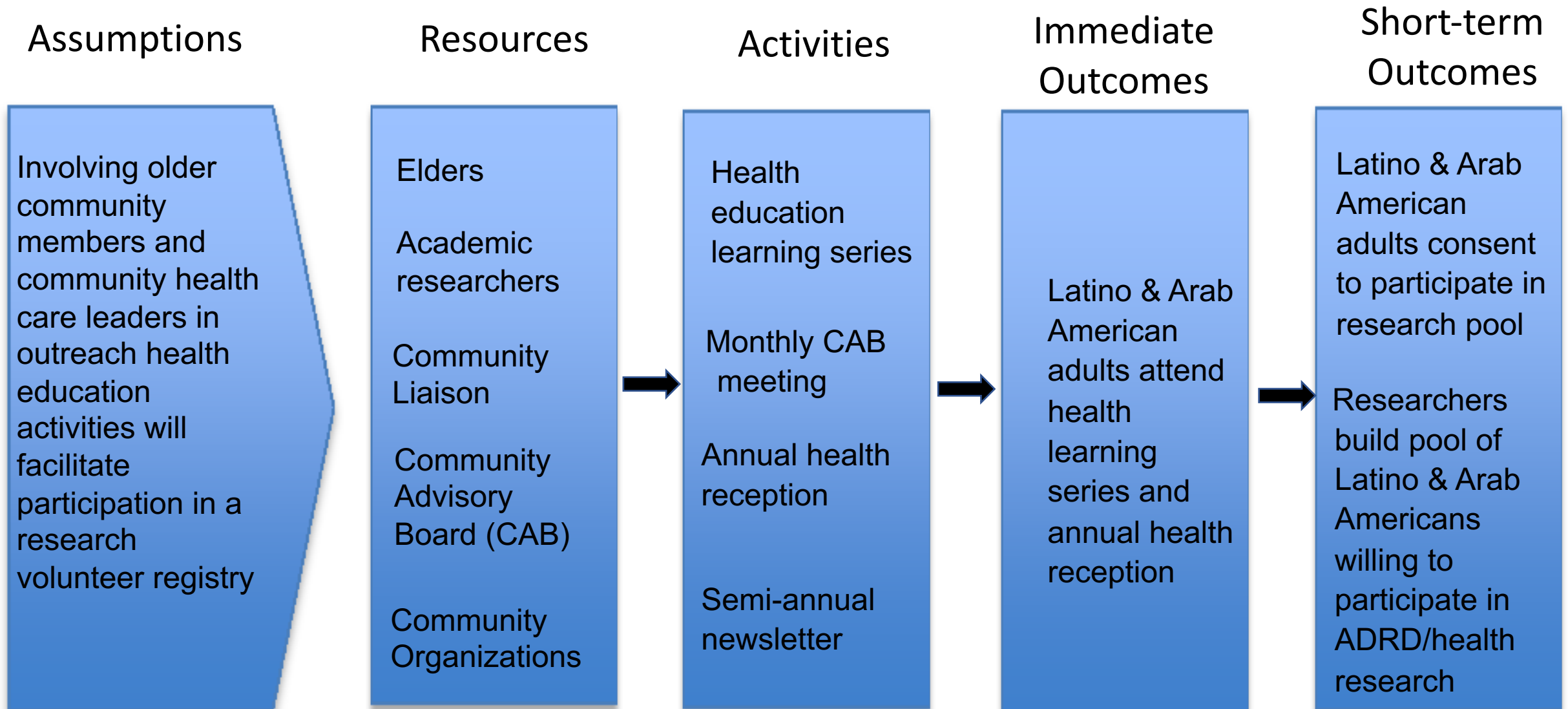


Figure 1. Logic model illustrating the recruitment process for building a volunteer research pool within the Latino and Arab American communities (adapted from Chadiha et al., 2011)



# Community Health Learning Events 2018-19



## Four Events

### Detroit metro Arab American Community

November 2, 2018, January 26, March 13, and May 16 of 2019

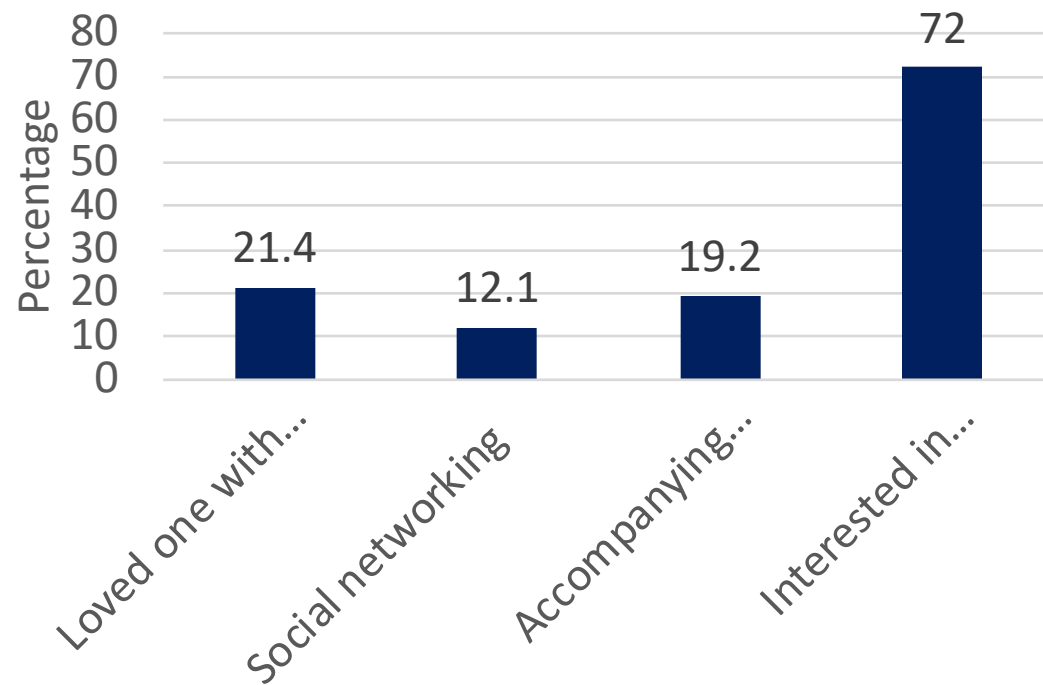
### Grand Rapids Latino/a Community

February 15, March 15, April 26, and May 15 of 2019

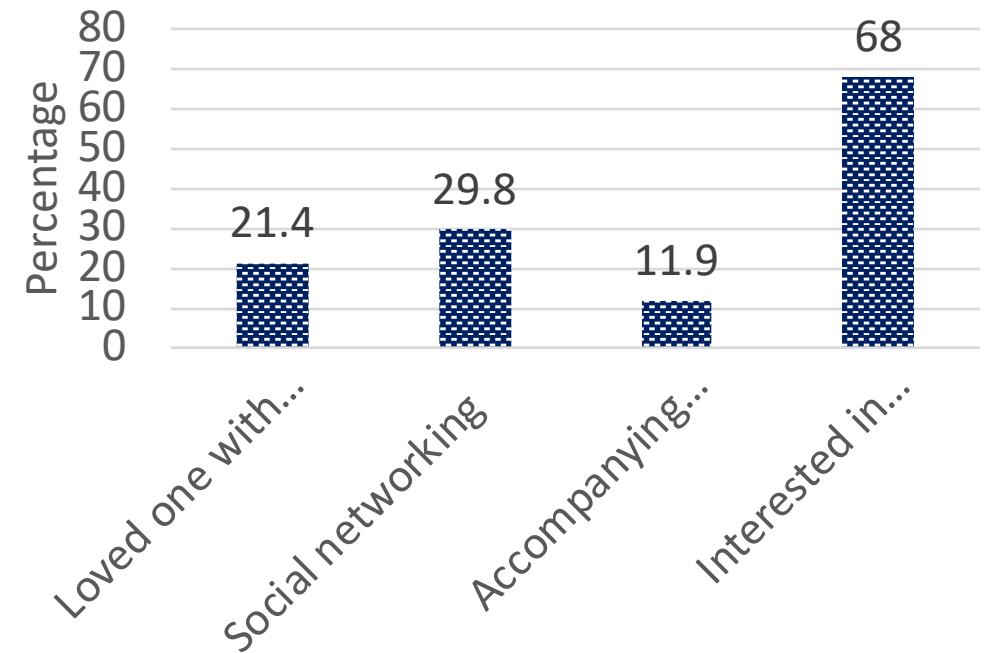


# People reported attending because they were interested in the topic

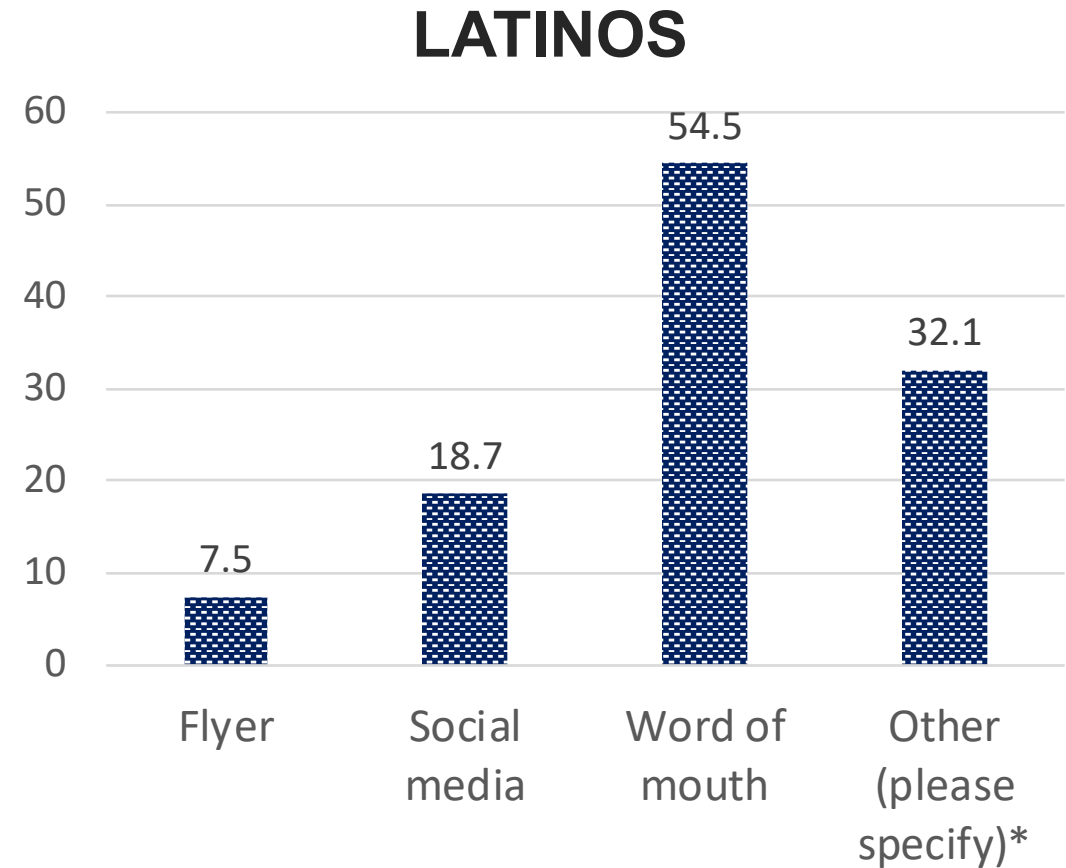
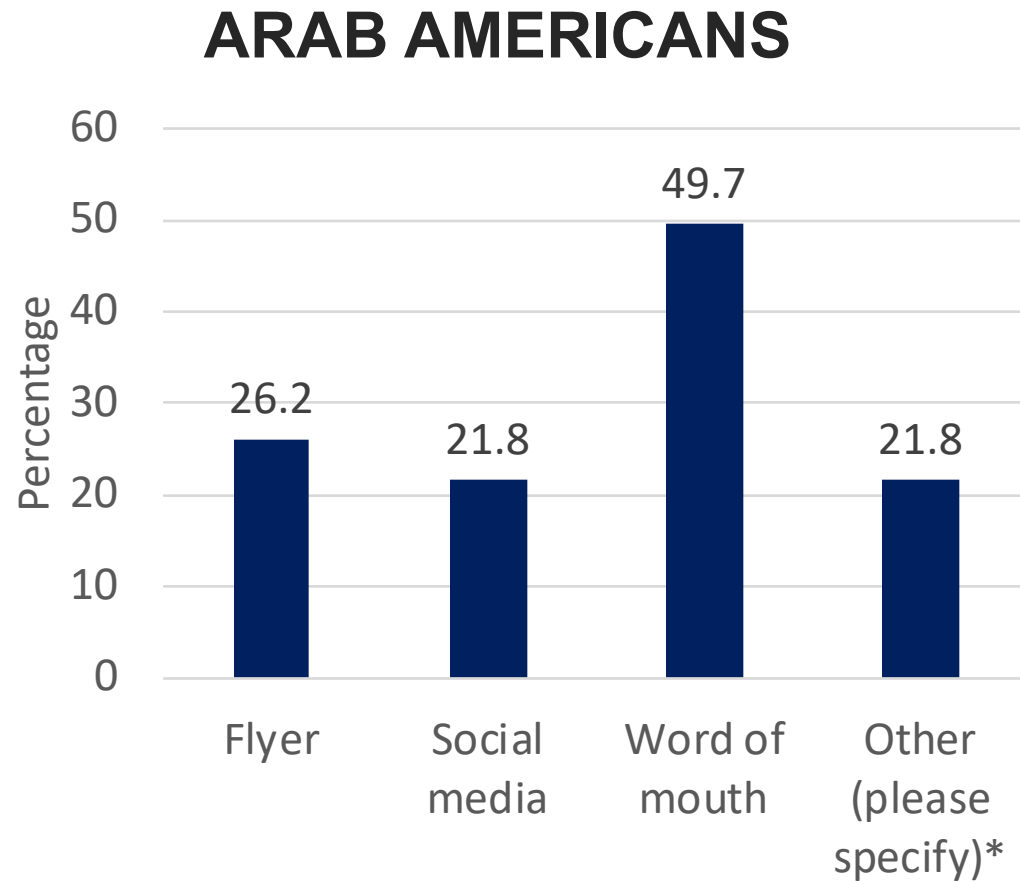
## ARAB AMERICANS



## LATINOS



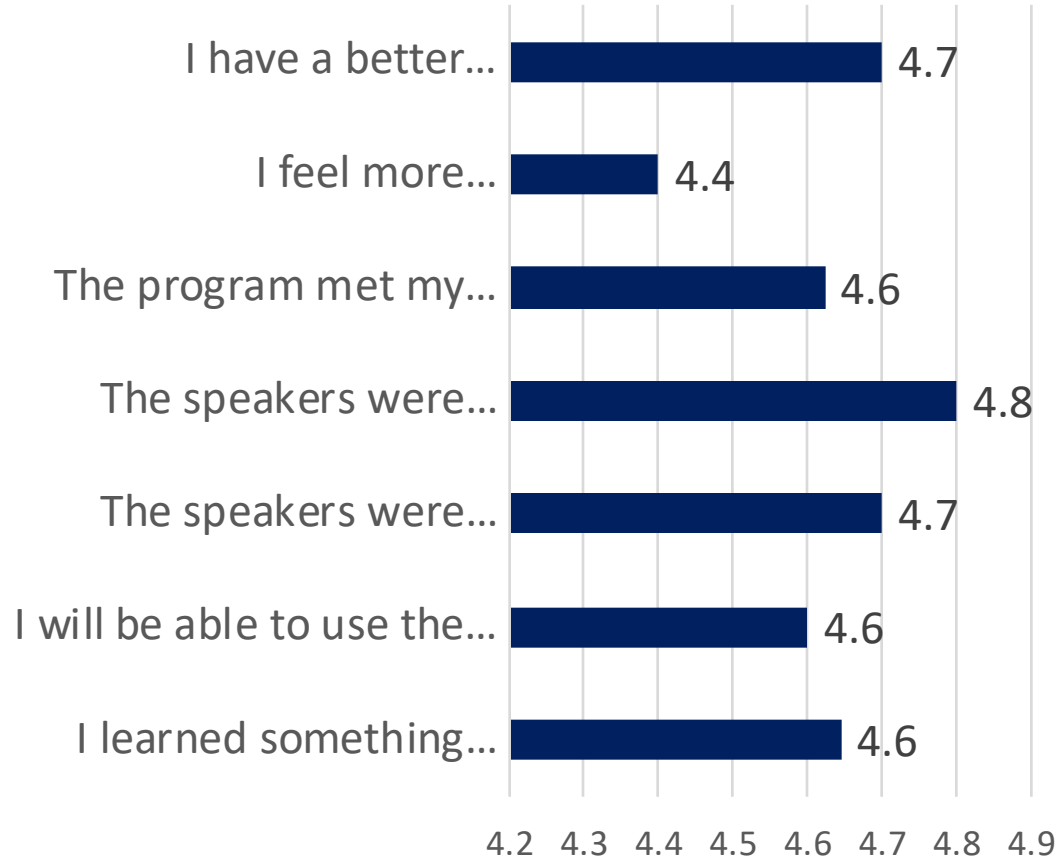
# Word of mouth was the most effective form of communication



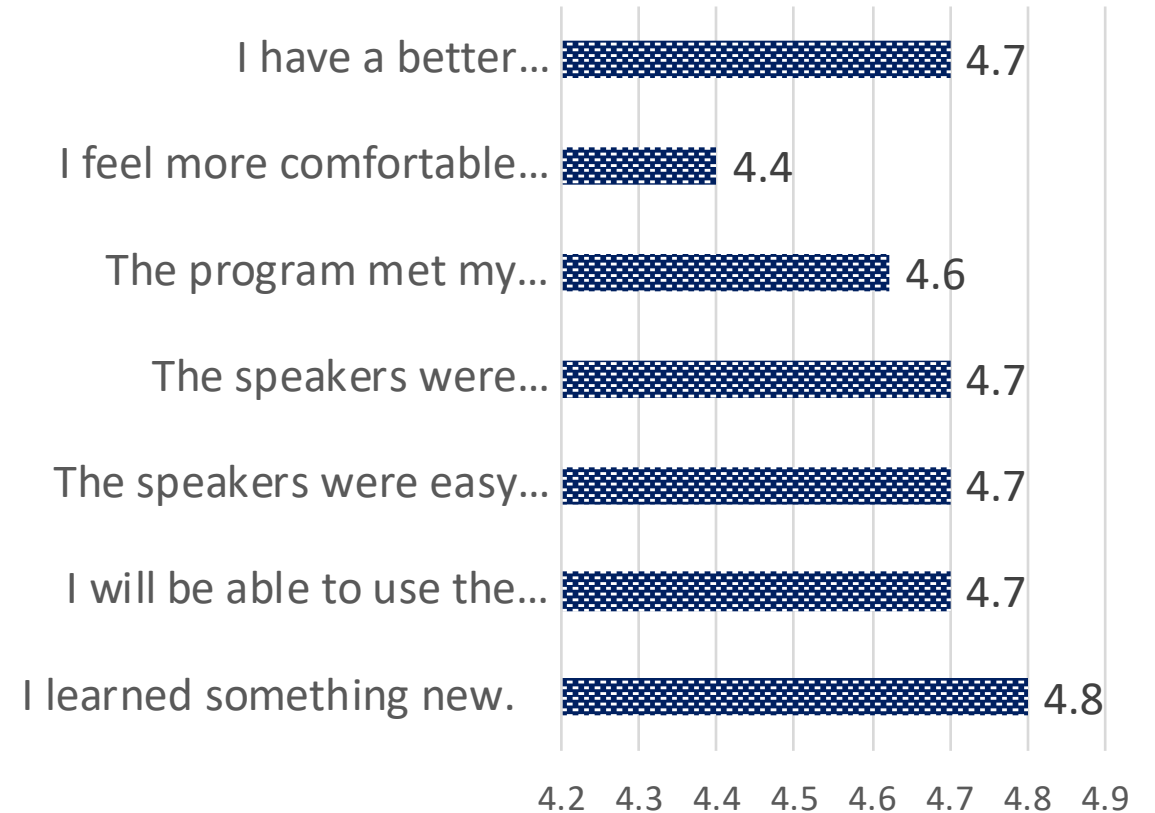


# Thinking about today's program....

## ARAB AMERICANS



## LATINOS



People were asked changes they would make as a result of program

**September 26, 2019**

Would be very helpful and informative to include a PowerPoint

More engaging and interacting activities, such as videos, socializing, and problem solving

Better speaker system. Sound was very loud and uncomfortable

Easier to understand presentation

Longer presentation

Go through medical cases in some details

Use visuals during presentation related to brain--show parts of the brain as an example.

Use an example to illustrate a little better

More info up front would be less questions at the end

Lecturer was very knowledgeable, some parts of the seminar felt a little dry in terms of being interesting

More emphasis on how to deal with it

Longer Q & A time, visual graphs on screen for all to view

# People were asked to suggest future topics

- **Preventative**

- Diet and Exercise
- Prevention of chronic diseases/conditions (e.g. heart disease, stress, depression)
- Prevalence and prevention of AD; More general information about AD's.

- **Post-Diagnosis-Related-Issues**

- Teaching community members how to care for loved ones with AD
- How to deal with behavioral symptoms of ADRD
- Information @ educational programs (“mind-teasers”) to help px stay sharp
- Help for Caretakers: education; coping with stress of regressing loved one; administering sensitive, respectful care
- Safety concerns for ADRD patients.

# People were asked to suggest future topics

- **Multiple morbidities**

- Aging and HIV; impact on Alzheimer's diagnosis; Diabetes; Early life issues related to ADRD; Smoking/Hookah; Healthy Diet; STI; Drug use/overdose; Exercise and lifestyle; Osteoporosis.

- **Cultural**

- Taboo topic that causes a lot of fear and how to address it; break the social stigma of ADRD.
- Lack of diversity in researchers conducting outreach - impacts community affected by ADRD; Being more culturally sensitive to Arab Americans\Latinx;
- More awareness in Arab American\Latinx communities
- Culturally sensitive caregiving;

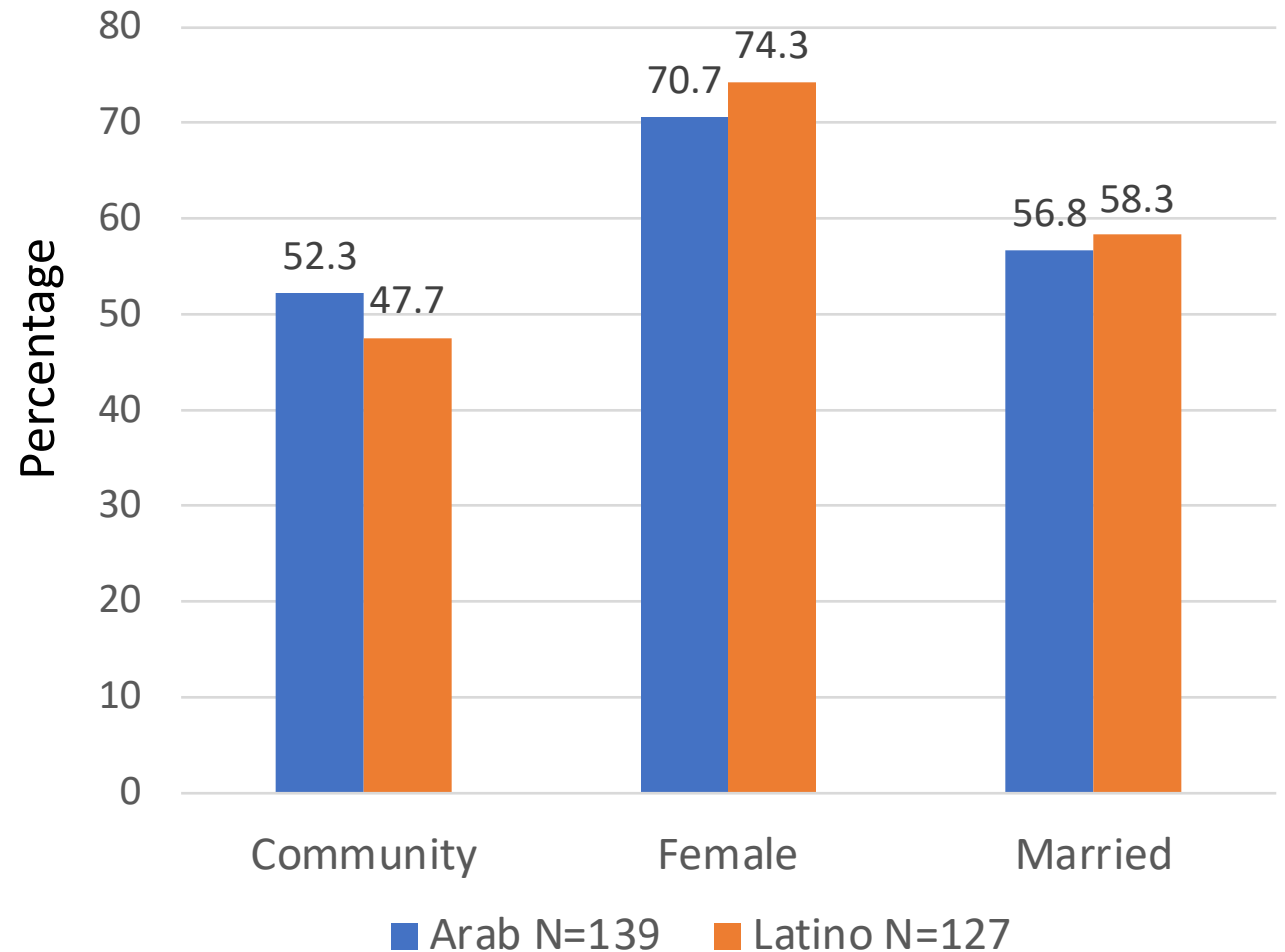
- **Scientific Progress**

- Webinars; Clinical Trials; Advancements in medication; Research indicators that show a generational study between baby boomers/gen X/millennials/gen Z

# Participant Research Pool Characteristics

# Similar Demographic Distribution of Arab American and Latino Participants

- **COMMUNITY:** Similar numbers of Arab Americans and Latino/Hispanics
- **RACE:** 30% Arab Americans; 15% Latino/Hispanics; but a variety of others as well
- **GENDER:** about 70% women; 30% men
- **MARITAL STATUS:** Half married, but people were also divorced/separated, widowed and never married.





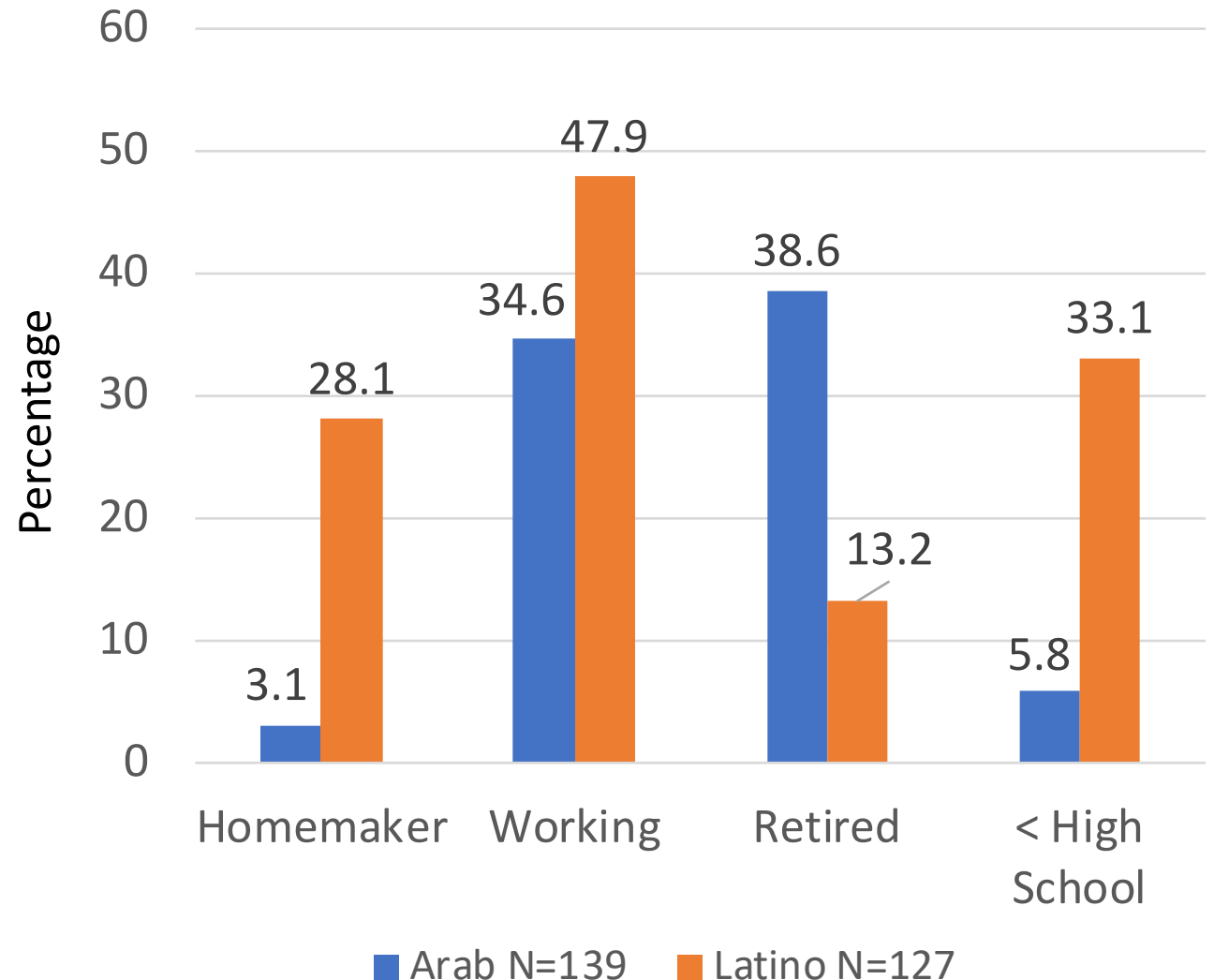
# Socio-Economic Characteristics Vary

- **EMPLOYMENT:**

- Latino/Hispanics more likely to report working for wages or homemaking
- Arab Americans more likely to be retired or self-employed

- **EDUCATION:**

- Latino/Hispanics more likely to report less than a high school education
- Arab Americans more likely to report more than a high school education



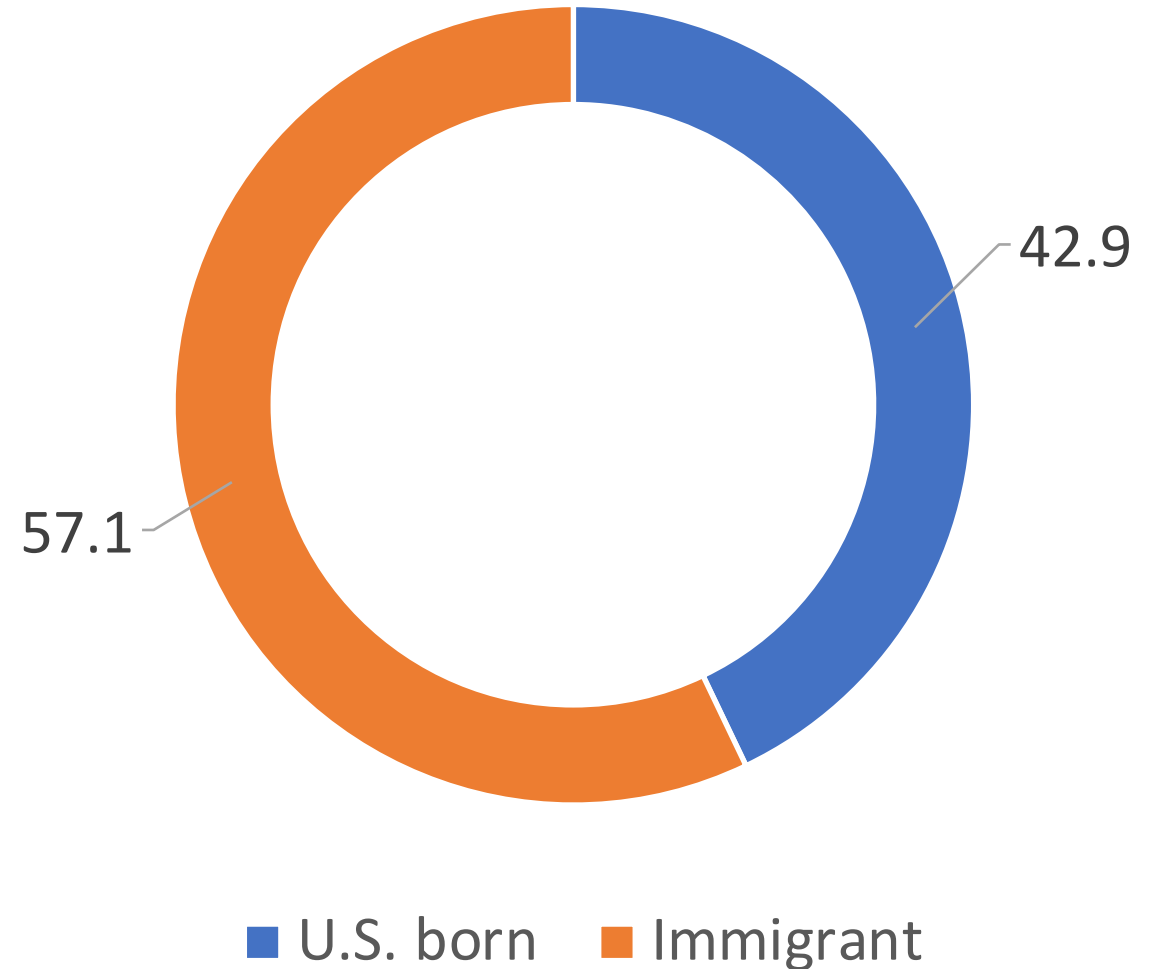
# Immigrant Characteristics Vary

- IMMIGRANT:

- More than half Arab Americans and Latino/Hispanics immigrants
- Majority born in **Lebanon** and **Mexico**

- DURATION:

- Arab Americans report higher % of having immigrated over 40 years ago
- Hispanic/Latinos reporting higher % likely to be recent immigrants (less than 10 years)



# Health Characteristics Vary to Some Extent

## SELF-RATED HEALTH:

Similar proportion fall in the middle, but Arab Americans more likely to report excellent health

## CHRONIC CONDITIONS:

*Latino/Hispanics* more likely to report *anxiety* and *diabetes*

*Arab Americans* more likely to report *cholesterol* and *hypertension*

## CONCERN ABOUT MEMORY:

About **20%** from each concerned about change in memory, thinking skills, or ability to reason

# PRP Future Topics of Interest

Theme	Narratives (< 60; n=142)	Narratives (60+; n=83)
<b><u>Memory Loss</u></b> Participants want to learn more about memory loss and diseases related to memory loss	Stages, general information, and diagnosis of AD Understanding the process of dementia Link between Dementia and other diseases	Lewy Body Dementia More information about memory loss How to treat it and take care of it Symptoms and more information about the people who develop memory loss
<b><u>General Diseases</u></b> Participants are interested in learning about various other diseases not related to memory	Cancer, obesity, diabetes, Parkinson's, heart disease, hypertension, depression, cancer, epilepsy	Diabetes, rheumatoid arthritis, M.S., asthma, internal organs The relationship between sleep apnea and Alzheimer's disease

# PRP Future Topics of Interest

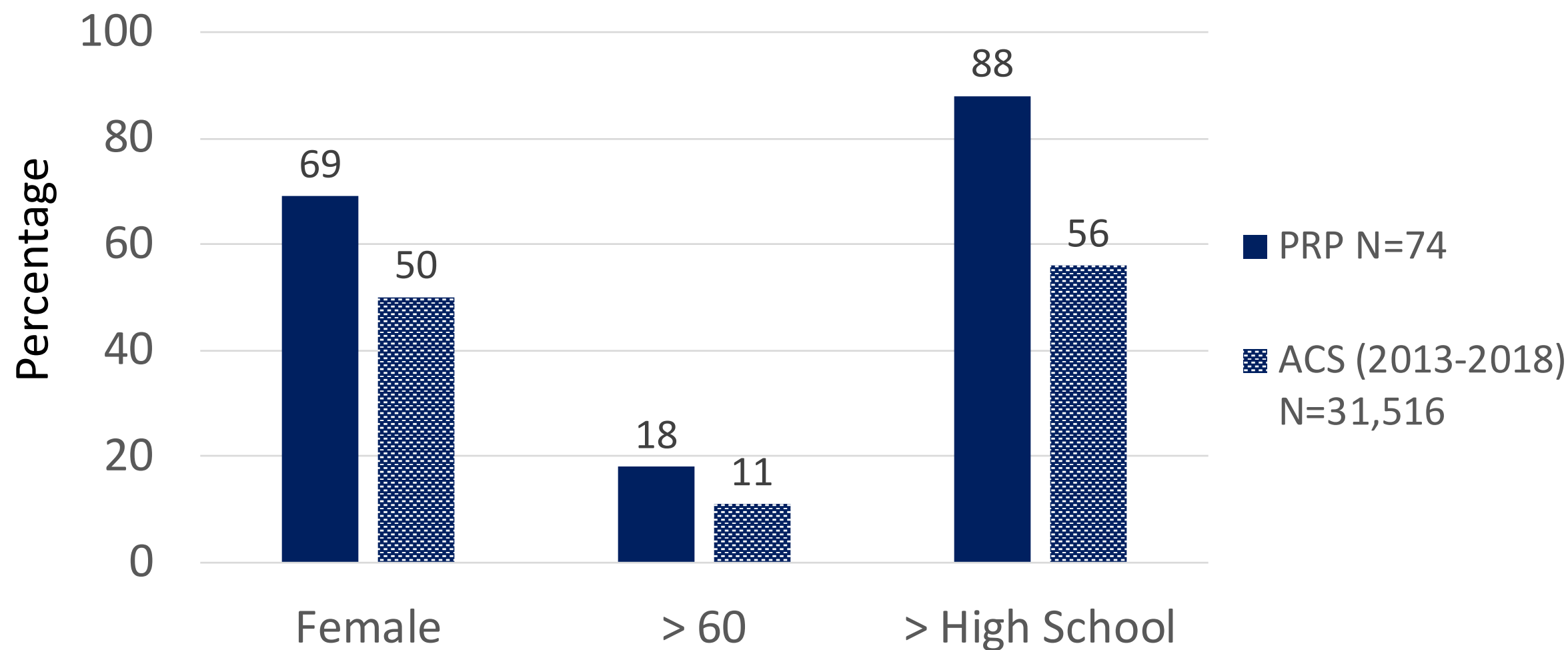
Theme	Narratives (< 60; n=142)	Narratives (60+; n=83)
<u><b>Health and Diet</b></u> Participants concern about what to eat and do to stay healthy	Nutrition/how to eat healthy Auto-immune diseases; cellular health Any health topics More health and wellness	Health in general Healthy diet and food Weight loss, cholesterol, and physical fitness Healthy cooking for diabetes
<u><b>Social Relations</b></u> Participants want more information about relationships	Support systems available for patients Effects on family, esp. children Examples of how to interact w/PWD	How to foster a better relationship with teens and other children Help in listening to our problems Care for caregivers and activities for a group of dementia patients
<u><b>Other</b></u>	Topics that affect us, but no one talks about it Any topic. All are important and interesting	All topics and to do good I am 76 years old, starting to forget.

# PRP Future Topics of Interest

Theme	Narratives < 60 (n=142)
<b><u>Prevention</u></b> Learn about how to prevent the disease and slow progression	Prevention of the disease How to maximize quality of life with this progressive disease Information for the young people to make changes in their lifestyle to prevent AD
<b><u>Research and Results</u></b> What is MCCFAD doing and what are the results	Role of PRPs in Alzheimer screening Prevalence in the Arab American Community and attitudes towards it

# Survey Non- Response Bias in the Arab American Community

Sarah Minnis, Toni C. Antonucci, Kristine J Ajrouch



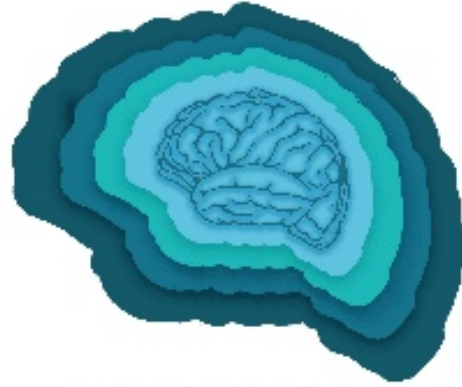
# Lessons Learned

- Connecting with leaders
  - Powerful means of connecting with community
  - Stigma minimized if leader recognizes importance
- Communities are diverse
  - Explore and expand recruitment reach in each community
  - Event location; CAB representation
    - Afro-Latino; Yemeni
  - Clearly defined mutually beneficial collaborations



# Lessons Learned

- Education skewness
  - Recruit new CAB members
  - Find new locations—schools, places where children are served
- Language used to describe ADRD and activities
  - Dementia
  - Community Health Learning Event → Community Coffee Time
  - Further address cultural issues based on participant feedback



**MCCFAD**

MICHIGAN CENTER FOR CONTEXTUAL  
FACTORS IN ALZHEIMER'S DISEASE

Thank you

# Education Level

Variable	Full Sample		Arab Americans		Latino/a	
Education Level	N	%	N	%	N	%
Did not attend high school	26	12.1	6	5.0	20	21.3
Attended high school but didn't receive a diploma	13	6.1	1	0.8	12	12.8
High school graduate (diploma or equivalent)	48	22.4	29	24.2	19	20.2
Associate degree (2 years)	28	13.1	18	15.0	10	10.6
Bachelor's degree (4 years)	47	22.0	24	20.0	23	24.5
Master's degree	40	18.7	32	26.7	8	8.5
Professional degree (JD, MD, PhD)	12	5.6	10	8.3	2	2.1

Variable	Full Sample		Arab Americans		Latino/a	
When the Participant Moved to the U.S.	N	%	N	%	N	%
Less than 10 years ago	8	11.3	3	6.8	5	18.5
10 to 39 years ago	40	56.3	21	47.7	19	70.3
More than 40 years ago	23	32.4	20	45.5	3	11.1
First Language						
English	95	40.6	63	52.5	32	28.1
Spanish	79	33.8	1	0.8	78	68.4
Arabic	55	23.5	55	45.8	0	0
Others	5	2.1	1	0.8	4	3.6

# Health Rate

Mean = 3.47, Standard Deviation = .96

Variable	Full Sample		Arab Americans		Latino/a	
Health Rate	N	%	N	%	N	%
Excellent	41	16.7	33	26.4	8	6.7
Very Good	71	29.0	43	34.4	28	23.3
Good	97	39.6	44	35.2	53	44.2
Fair	33	13.5	3	2.4	30	25.0
Poor	3	1.2	2	1.6	1	0.8

# Seeing a Physician for the Following

Variable	Full Sample		Arab Americans		Latino/a	
Seeing a Physician For:	N	%	N	%	N	%
Memory Loss	10	3.6	4	3.4	6	3.9
Anxiety	36	13.0	10	8.5	26	16.8
Diabetes	37	13.4	11	9.3	26	16.8
High Cholesterol	68	24.6	39	33.1	29	18.7
Depression	36	13.0	9	7.6	27	17.4
Heart Disease	19	6.9	8	6.8	11	7.1
Hypertension	48	17.4	24	20.3	24	15.5
Other	22	8.0	13	11.0	9	5.8

# Concern about Change in Memory, Thinking Skills, or Ability to Reason

Variable	Full Sample		Arab Americans		Latino/a	
Concern	N	%	N	%	N	%
Yes	60	22.3	30	24.0	20	20.2
Over 60 Years Old (n = 83)	23					
Under 60 Years Old (n = 142)	22					
No	174	77.7	95	76.0	79	79.8
Over 60 Years Old (n = 83)	96					
Under 60 Years Old (n = 142)	50					