

# THE NGAGEDD MODEL:

## RESEARCH EFFORTS WITH LATINO COMMUNITIES, BEFORE AND DURING COVID-19

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Keynote Address

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# Acknowledgments



- ☐ NIA and All ORE Core Teams
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  - ☐ Dr. Lisa L. Barnes, Leader of the Clinical Core
  - ☐ Dr. Raj C. Shah, Past Leader of the ORE Core

**Dr. David X. Marquez, Leader of the Latino Core at the Rush ADC**

**The Rush ADC ORE Core and Latino Core Teams**

**All Caregivers and Community Members Engaged In Research**

# Overall Goal of the Rush ADC ORE CORE

To cultivate inclusive and engaged participation of diverse persons underrepresented and understudied in research on the etiology, pathogenesis, diagnosis, treatment, and prevention of ADRD.

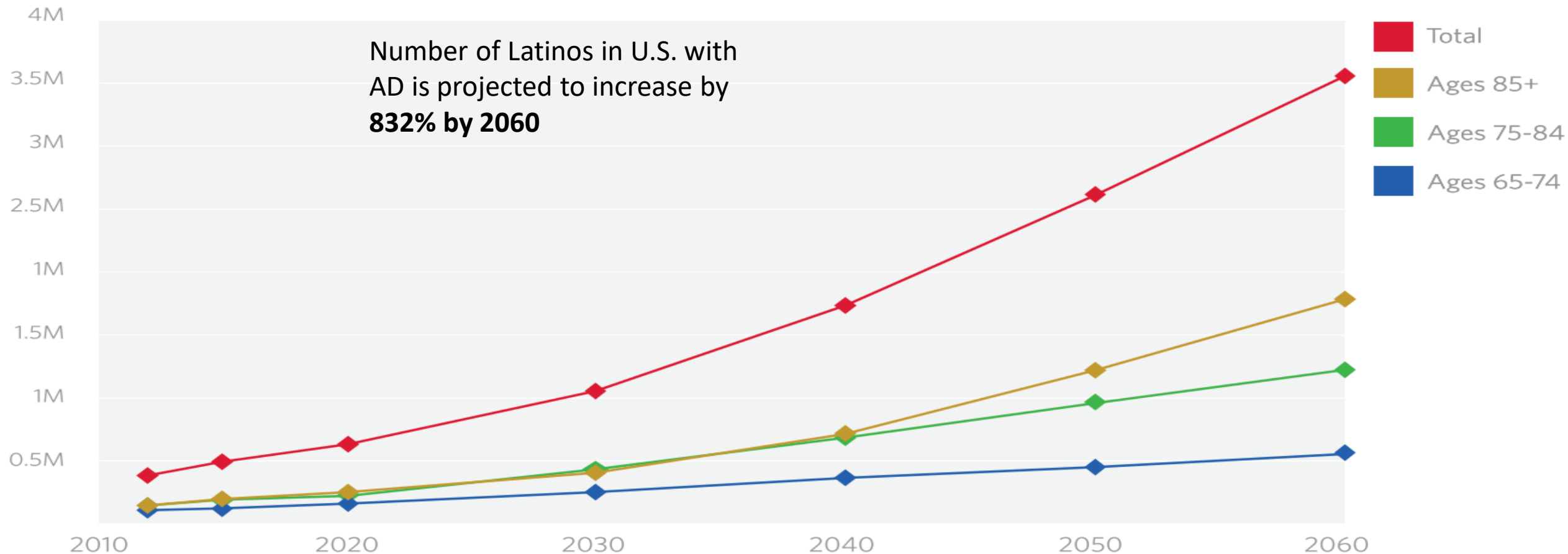
# Demographics: A Focus on Latino Communities

- ❑ Currently, largest ethnic minority group in the U.S. - 18% and rising
- ❑ From 2017 to 2050, the number of older Latinos is expected to increase from 4.2 to 15.9 million
- ❑ 33 subgroups – Largest being Mexican, Puerto Rican, and Cuban
- ❑ Varying in culture and related practices, race, language, and immigration status
- ❑ Illinois ranks 7th in the U.S. for the number of older Latinos, mostly in Chicagoland



# ADRD: A Focus on Latino Communities

**FIGURE 2. PROJECTION OF LATINOS WITH AD THROUGH 2060, BY AGE (IN MILLIONS)**



(Wu, Vega, Resendez, Jin, & Scholar, 2016)



National Institute of Aging, 3P30AG010161-25S1

**Rush  
Alzheimer's  
Disease  
Center**



# Why a Latino Core?

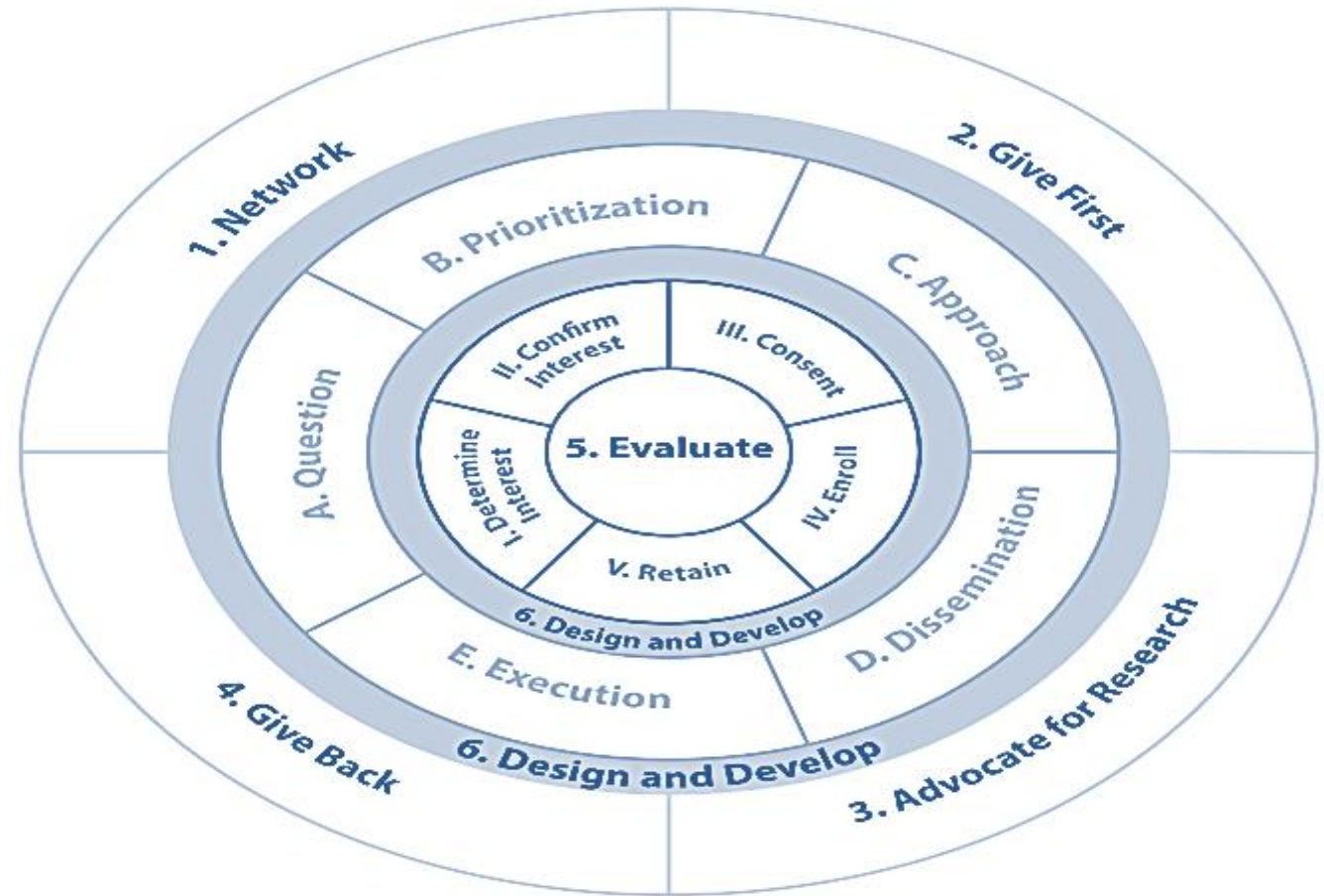
- ❑ Findings from ADRD studies with older non-Latino Whites may not apply
- ❑ Older Latinos face potentially distinctive:
  - ❑ Risk factors for ADRD such as structural assimilation
  - ❑ Resilience factors like familial relationships and religiosity
- ❑ Requires a minority health/health equity lens

**To identify potential causes and related risk reduction strategies specific to older Latinos in relation to ADRD**

# The NGAGEDD Model – General Premise

## The NGAGEDD Model

Network  
Give First  
Advocate for Research  
Give Back  
Evaluate  
Design  
Develop



Outer circle represents community activities, middle circle represents participant input on research, and inner circle represents individual study activities.



# NGAGEDDD Efforts: A Focus on Latinos



- ❑ Diverse demographic and professional team-based approach
- ❑ Cultural competence, as implicit and explicit biases can rear their heads
  - ❑ Learning and appreciating the lived experiences of participants
  - ❑ Learning and understanding historical knowledge regarding diverse Latino communities
- ❑ Shared/common values (e.g., Familismo, Personalismo, and Fatalismo)

# Bilingual and Shareable Products



**Mentes sanas empiezan en la cocina**  
**Healthy minds start in the kitchen**

**10 Alimentos saludables para el cerebro**  
**10 Brain healthy food groups**

- Vegetales de hojas verdes / Green Leafy Vegetables
- Otros vegetales / Other Vegetables
- Pescado / Fish
- Nueces / Nuts
- Bayas / Berries
- Frijoles / Beans
- Granos Integrales / Whole Grains
- Aves / Poultry
- Acetite de Oliva / Olive Oil
- Vino / Wine

**5 Alimentos no saludables para el cerebro**  
**5 Unhealthy brain foods**

- Carnes rojas / Red Meats
- Mantequilla y margarina / Butter and Margarine
- Queso / Cheese
- Comida rápida o frita / Fast or Fried Food
- Reposterías y dulces / Pastries and Sweets

La dieta "MIND" fue creada por la Dra. Martha Clare Morris de Rush University Medical Center. The MIND diet was developed by Dr. Martha Clare Morris from Rush University Medical Center.

**Otros consejos para mejorar la salud de su cerebro**  
**Other tips to boost your brain health**

- Sea social, involúcrese / Socialize, Get Involved
- Ejercite su cerebro / Exercise Your Mind
- Duerma lo suficiente / Get Enough Sleep
- Tenga un propósito / Have a Purpose
- Muévase en su comunidad / Move around your Community
- Mueva su cuerpo / Move your Body

Para más información llame al Centro de la Enfermedad del Alzheimer al (312) 542-8432. For more information please call the Rush Alzheimer's Disease Center at 312-542-7732.

# Research Efforts in Latino Communities: July 1, 2019 - August 31, 2020

## NGAGEDD Activities

## Research Participation

Event or Activity (N=794)	# Participants	Ethnicity Latino	Activity	# Participants	# Latino
1. Network	8,561	2,911 (34%)	Signed into Rush Memory Clinic Data and Specimen Repository	33	2 (6%)
2. Give First	10,713	4,607 (43%)			
3. Advocate for Research	5,844	2,194 (36%)			
4. Give Back	7,766	699 (9%)	Enrolled in Rush ADC and NIH-Supported Studies	561	40 (7%)
TOTAL	32,884	10,194 (31%)			

# Design and Develop: A Focus on Latino Communities

- ❑ Shared/common values are important, but other factors also impact Latinos
- ❑ Focused on participant perspectives to better understand individuals
  - ❑ Background including their lives in the U.S. and/or immigration experiences
  - ❑ Current resilience and coping mechanisms, and challenges and barriers
  - ❑ The role of research and related experiences

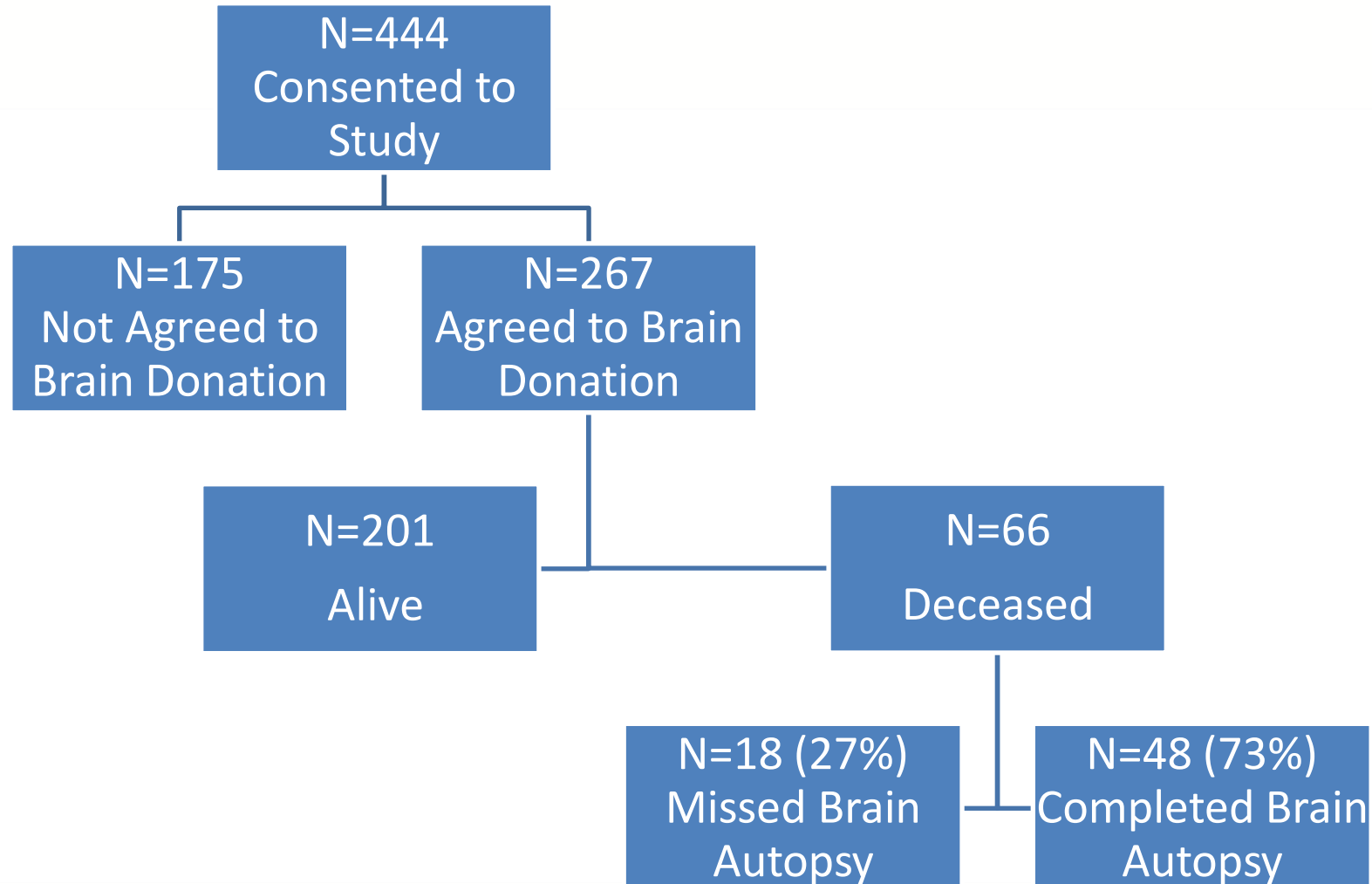
# Brain Donation: A Focus on Latino Communities

- ❑ Low Latino participation in brain donation – despite persistent efforts
- ❑ Of older Latinos who agreed, lower rates of completed brain autopsies
- ❑ Limited availability of brain tissue from older Latinos
- ❑ Severely limits our understanding of AD/RD



# Brain Donation Across 5 Rush ADC Cohort Studies

## Latinos



# Barriers and Facilitators of Agreeing to Brain Donation Among Older Latinos

**The Role  
of Family**

Barriers Among Older Latinos Who Have Not Agreed to Brain Donation	Facilitators Among Older Latinos Who Have Agreed to Brain Donation
<div><input type="checkbox"/> Lack of family buy-in, in general</div> <div><input type="checkbox"/> Culture and family blended and overlapped</div> <div><input type="checkbox"/> Male-centered approval in brain donation decision making</div>	<div><input type="checkbox"/> Altruism and giving back</div> <div><input type="checkbox"/> Brain donation benefits family</div> <div><input type="checkbox"/> Avoidance of sadness of AD</div>

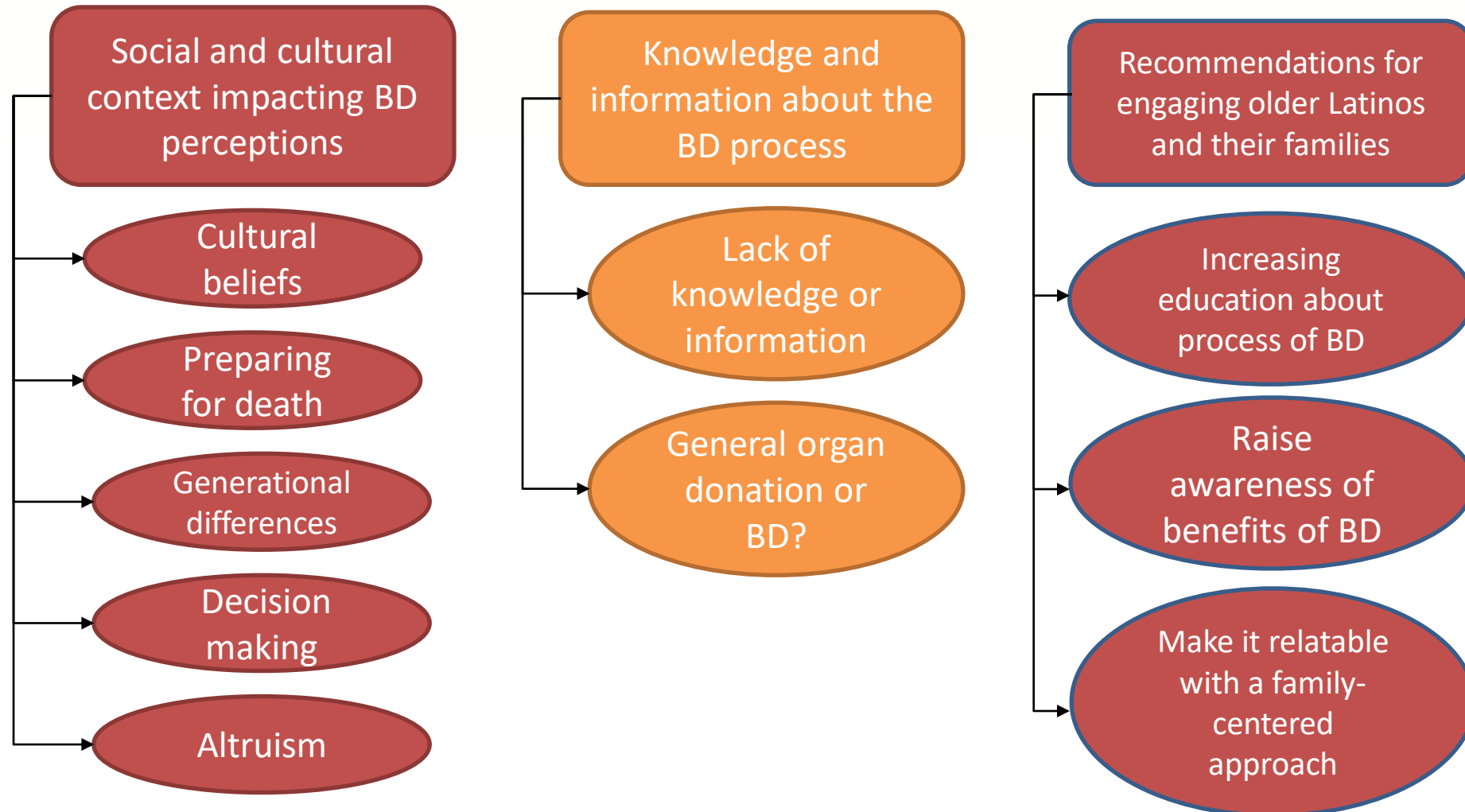
# Perceived Impediments to Completed Brain Autopsies Among Older Latinos Who Have Agreed to Brain Donation



Perceived Impediment	Most Affected Population	Representative Quote	A Sample of Potential Ways to Address
Lack of Family Follow-Through	Latinos	“And so the children have to know that because my son said-one of my sons said, ‘I’m glad you’re telling me this. And I’m glad it’s written down because I would’ve fought hard not to have any of this done.’”	<ul style="list-style-type: none"><li><input type="checkbox"/> Family as participant</li><li><input type="checkbox"/> Family engagement - loved one’s research participation</li><li><input type="checkbox"/> Family education - role of research/brain donation</li><li><input type="checkbox"/> Family education - process of brain autopsy</li></ul>



# Perspectives of Adult Children of Older Latinos Regarding Brain Donation for ADRD Research



# Strategies to Address Brain Donation: A Focus on Latinos



- ☐ Provide a packet to each participant who has agreed to brain donation
  - ☐ And their family members
- ☐ Ask for funeral home information at home visits
- ☐ Send informational letters to funeral homes regarding Rush ADC study participant
- ☐ Discuss brain donation with those who are not opposed but have not agreed
- ☐ Developing strategies based on previous qualitative research

# Next Steps in ORE and Other Research Activities With Latino Communities

- ☐ Continue quarterly “Cafecitos” as retention events
- ☐ Continue addressing intertwined needs for bicultural and/or race/ethnicity-matched staff
  - ☐ Especially those who are bilingual in English and Spanish
- ☐ Continue community-based efforts
- ☐ ORE efforts with older Latino men, specifically
- ☐ ORE efforts with diverse Latinos

# A Partial Pivot: Research As Service

## CDC Has Information For Older Adults at Higher Risk

**8** out of **10** COVID-19 deaths reported in the U.S. have been in adults 65 years old and older. Visit [CDC.gov/coronavirus](https://www.cdc.gov/coronavirus) for steps to reduce your risk of getting sick.



[cdc.gov/coronavirus](https://www.cdc.gov/coronavirus)

## COVID-19 CASES, HOSPITALIZATION, AND DEATH BY RACE/ETHNICITY

FACTORS THAT INCREASE COMMUNITY SPREAD AND INDIVIDUAL RISK



CROWDED SITUATIONS



CLOSE / PHYSICAL CONTACT



ENCLOSED SPACE



DURATION OF EXPOSURE

Rate ratios compared to White, Non-Hispanic Persons	American Indian or Alaska Native, Non-Hispanic persons	Asian, Non-Hispanic persons	Black or African American, Non-Hispanic persons	Hispanic or Latino persons
CASES <sup>1</sup>	2.8x higher	1.1x higher	2.6x higher	2.8x higher
HOSPITALIZATION <sup>2</sup>	5.3x higher	1.3x higher	4.7x higher	4.6x higher
DEATH <sup>3</sup>	1.4x higher	No Increase	2.1x higher	1.1x higher

Race and ethnicity are risk markers for other underlying conditions that impact health — including socioeconomic status, access to health care, and increased exposure to the virus due to occupation (e.g., frontline, essential, and critical infrastructure workers).

# A Partial Pivot: Research As Service (COVID-19)



- ❑ Provided informational letters – Spanish and English
- ❑ A series of Townhalls addressing COVID-19 and Latino communities – Spanish and English
- ❑ Hosted a webinar on the proper use of PPE – Spanish and English
- ❑ PPE drives and distribution, especially focused on Latino and other diverse communities
- ❑ Laundromat Health and Wellness Fairs
  - ❑ Partnered with local laundromats owned by Latinos and other persons of color
  - ❑ Provided informational materials, PPE, and resources for laundering
  - ❑ Focused on communities of color, especially essential workers

# A Partial Pivot: Research As Service (ORE As Usual)

- ☐ Curbside Cafecitos – First One Next Month!
- ☐ Virtual Memory Café/ Café de los Recuerdos
- ☐ Almorzando Juntos – Caminando Juntos AARP Caregiving Conference
- ☐ Brain Activity Journal – Spanish
- ☐ Stressbusters for Caregivers - Spanish



# In Closing....

## Inequality

Unequal access to opportunities



## Equality?

Evenly distributed tools and assistance



## Equity

Custom tools that identify and address inequality



## Justice

Fixing the system to offer equal access to both tools and opportunities





# Thank You...Questions and Comments

