



RUSH UNIVERSITY

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# The Health Equity through Aging Research and Discussion (HEARD) Study:

## A Mixed-Methods Approach to Barriers and Facilitators of Brain Donation Among Diverse Older Adults

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# Acknowledgements

## The Diversity of Community Members Engaged in Research



# Acknowledgements

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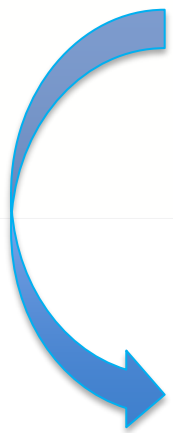
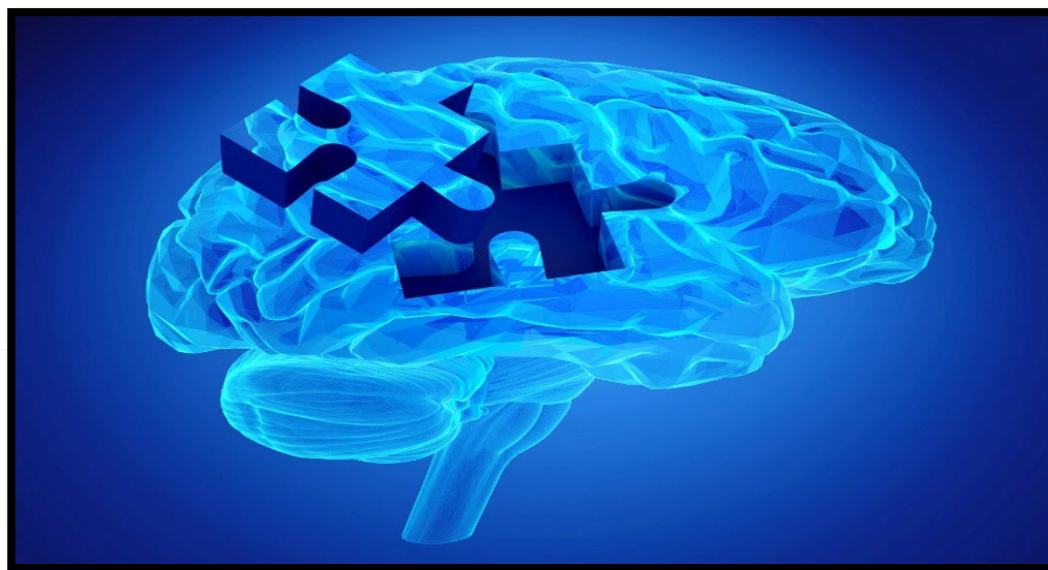
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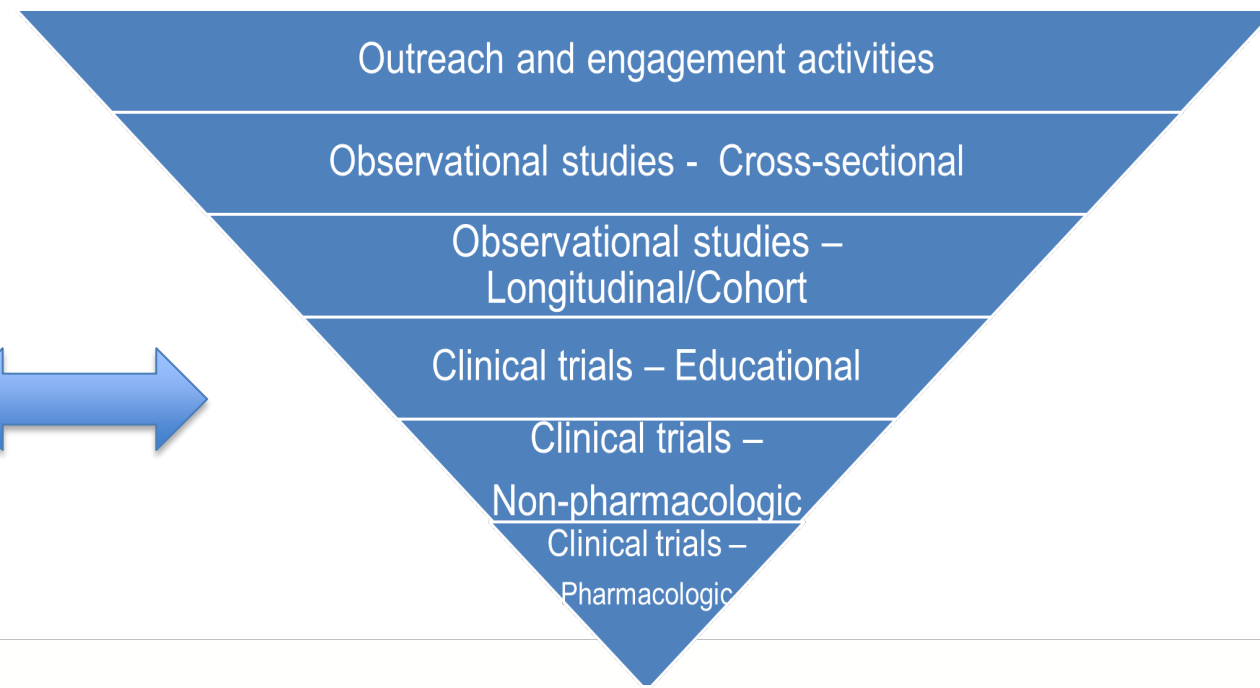
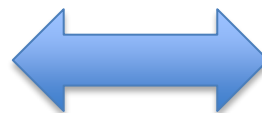
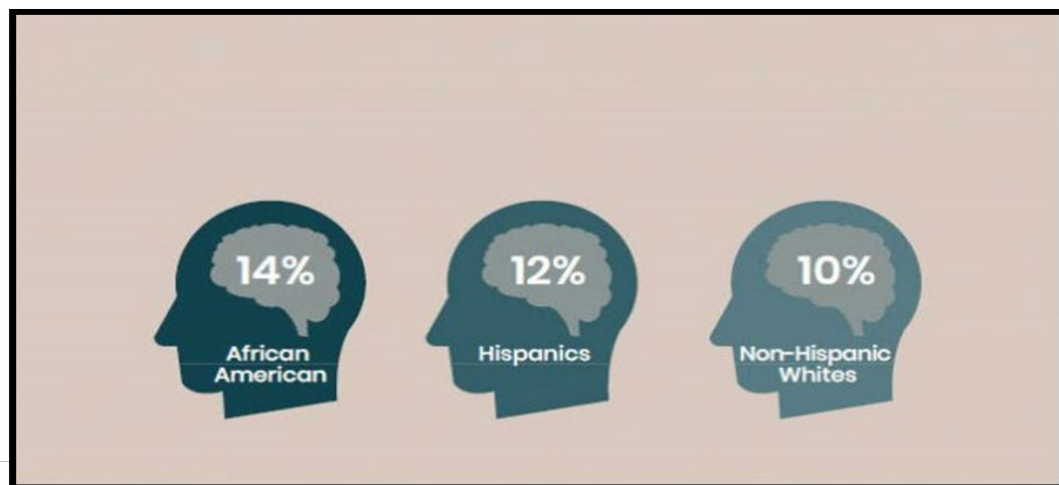
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# A Most Critical Issue



**Percentage of Adults Aged 65 and Older with Alzheimer's Disease by Race and Ethnicity**



# Challenges Related to Brain Donation

- Acceptable assessments of Alzheimer's disease (AD) now include PET brain scan
- Diagnosis of Alzheimer's disease and related dementias (ADRD) still require brain autopsy
- Low participation rates among older Black and Latino adults – despite persistent efforts
- Of older Black and Latino adults who consent, lower rates of completed brain autopsies
- Sensitive topics – process of and information gained from brain donation
- Sensitive topics – process of brain autopsy and effect on interment



# Consequences

Limited availability of brain tissue from persons who belonged to under-included and understudied populations

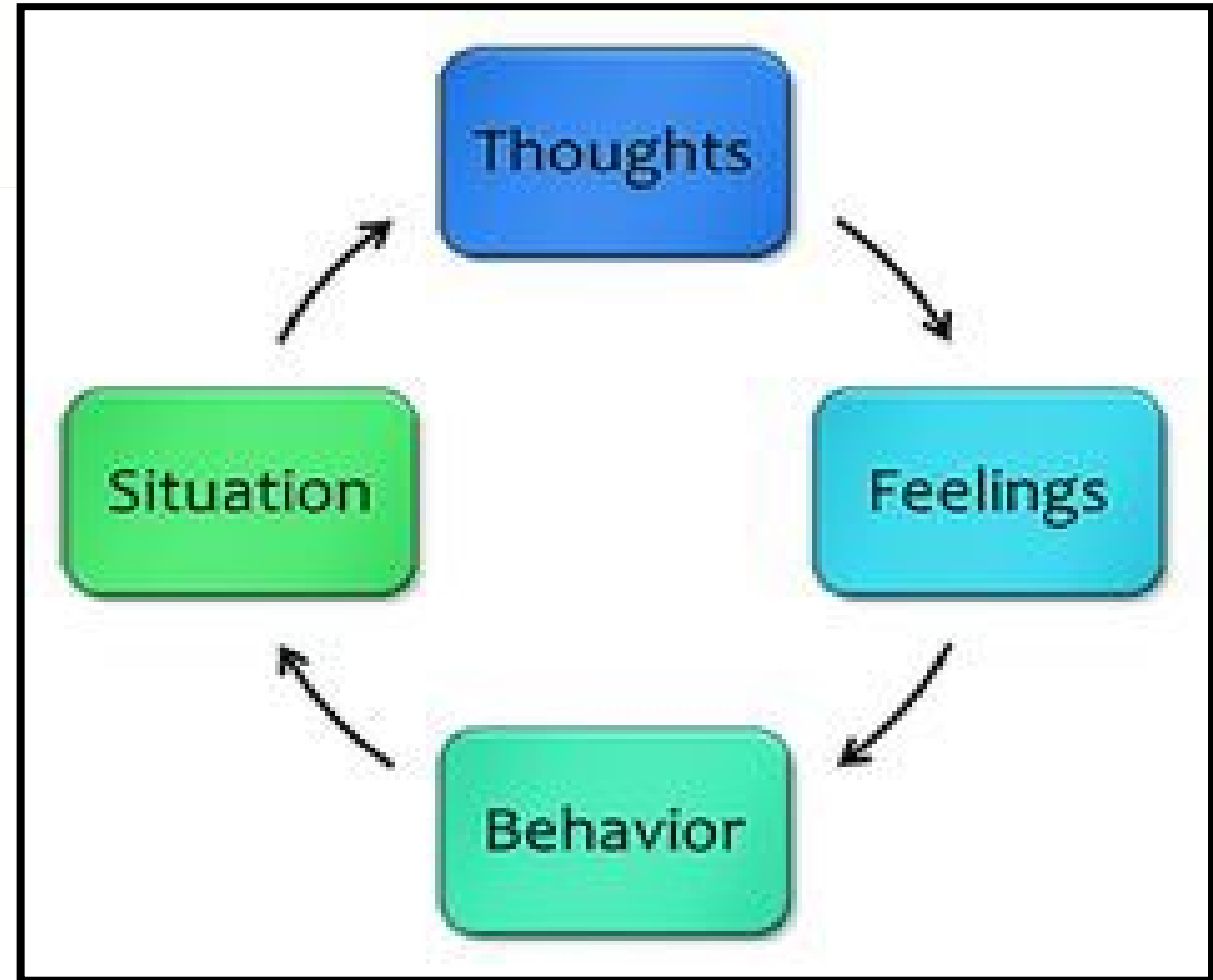
- Understanding of ADRD within diverse communities
- Identification of issues and their potential treatments and solutions
- Applicability/ generalizability of research findings to diverse populations
  - Drug and other pharmaceutical discoveries and their safety and efficacy
  - Preventive methods
  - Educational materials and outreach efforts
- Perceptions and lived experiences

Severely limited understanding of ADRD within Black and Latino communities

## **SOCIAL COGNITION** **General Definition**

The study of how people process and utilize information in social situations

“Social cognition is the study of how people make sense of other people and themselves.” (Fiske & Taylor, 1984)



# The HEARD Study

## Two-Phase Sequential Mixed-Methods Research Design

Data from the first phase inform the second phase to create a pipeline

### Phase One: Qualitative

Meaningful, pointed understandings of diverse participant perspectives

### Phase Two: Quantitative

Constructing more complete profiles of diverse participants

### Survey Instrument Development

Quantifying potential factors influencing perspectives and decision making among a larger sample of diverse participants

# Phase One: Participant Demographic Characteristics

	Barriers/ No to Brain Donation (n)	Facilitators/ Yes to Brain Donation (n)	Women (%)	Income (Median)	Age (Mean)	Years of Education (Mean)	Divorced (%)
Older Black Adults	9	8	94%	\$50,000 - \$74,999	77 years	17 years	44%
Older Latinos	7	6	92%	\$20,000 - \$24,999	73 years	14 years	54%
Older Whites with Lower Income	7	8	87%	\$15,000 - \$19,999	76 years	16 years	55%
Total Sample (N=45)	23	22	91%	\$30,000- \$34,999	76 years	16 years	51%

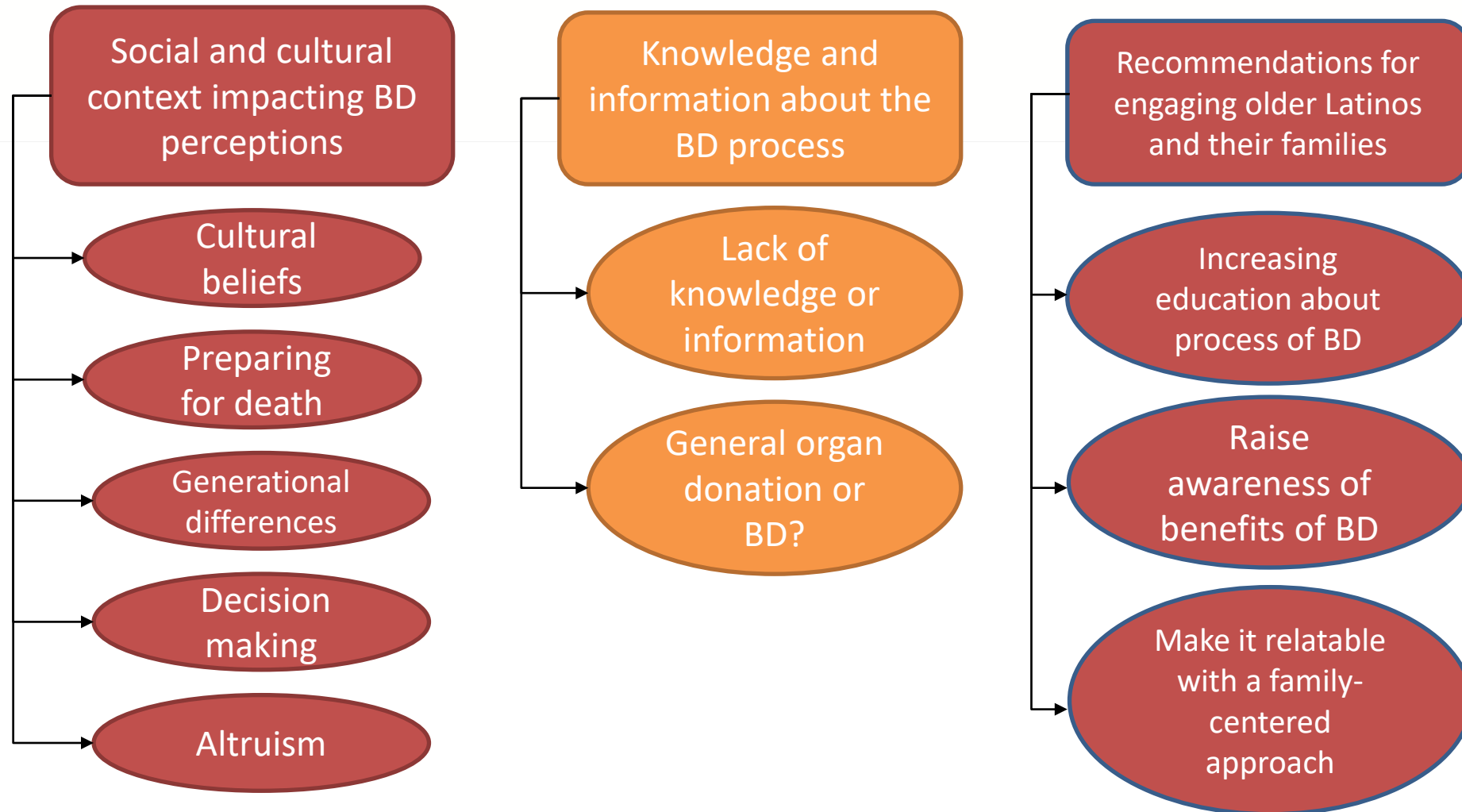
# Phase One: Facilitators of Brain Donation

Theme	Subtheme	Representative Quote
Family and the Future	<ul style="list-style-type: none"> <li>▪ Altruism and giving back</li> <li>▪ Brain donation benefits family</li> <li>▪ Participant discordant from family re: brain donation</li> <li>▪ Distinct focus on the future</li> </ul>	<p>“...that's the one reason why I decided to donate my brain is because it may not save me, but it may save somebody's grandchild.”</p>
Activity and the Acquisition of Knowledge	<ul style="list-style-type: none"> <li>▪ Active: civic, cognitive, social, religious, research</li> <li>▪ Importance of education: overall health and AD</li> <li>▪ Curious</li> <li>▪ Social networks/open transmission of knowledge</li> </ul>	<p>“So, you know, I just enjoyed learning, so- being a retired teacher, I always love education.”</p>
The Role of Research and Brain Donation	<ul style="list-style-type: none"> <li>▪ Trust/belief in research and brain donation to help self and serve community</li> <li>▪ Familiarity with research</li> <li>▪ Pride in research participation</li> <li>▪ Commitment to AD solutions through brain donation</li> </ul>	<p>“You need research, and you cannot find the answer without research.”</p>
Elements of Decision Making for End of Life	<ul style="list-style-type: none"> <li>▪ Why not/ Can't take it with you</li> <li>▪ Ownership of old age</li> <li>▪ Preparation in relation to the future</li> <li>▪ Spiritual beliefs not hindering brain donation</li> </ul>	<p>“It can benefit others, and for me, that is the spirituality.”</p>

# Phase One: Impediments to Brain Autopsy Completion

Issue	Most Affected Group	Strategies to Address
Uncertainty Surrounding the Processes of Brain Donation and Brain Autopsy	Older Whites with Lower Income	<ul style="list-style-type: none"><li>▪ Continued engagement - brain donation</li><li>▪ Continued education - brain donation/ autopsy</li><li>▪ Printed materials - brain donation/ autopsy</li><li>▪ Potential simulation of brain autopsy</li></ul>
Lack of Family Buy-In	Older Black Adults	<ul style="list-style-type: none"><li>▪ Family as participant</li><li>▪ Family engagement - loved one's research participation</li><li>▪ Family education - role of research and brain donation in AD</li></ul>
Lack of Family Follow-Through	Older Latinos	<ul style="list-style-type: none"><li>▪ Family education – the process of brain autopsy</li></ul>

# Perspectives from Adult Latino Children About Brain Donation



# Strategies to Address Brain Donation Consent and Completion

- Provide a brain donation packet to each participant who agrees to organ donation and their family members
- Ask for funeral home information at home visits
- Send letters to funeral homes informing them that a RADDC study participant has signed the Uniform Anatomical Gift Act
- Discuss brain donation with those who are not opposed but have not agreed
- Increase diversity in methodological approaches to understand and leverage diverse participant perspectives
- Develop strategies based on previous qualitative work
- Co-design and co-strategize research questions, research conduct, addressing research-related challenges, and setting research agendas and priorities

# Phase Two: Expanding Qualitative with Quantitative

## Qualitative Theme

Activity and the Acquisition of Knowledge

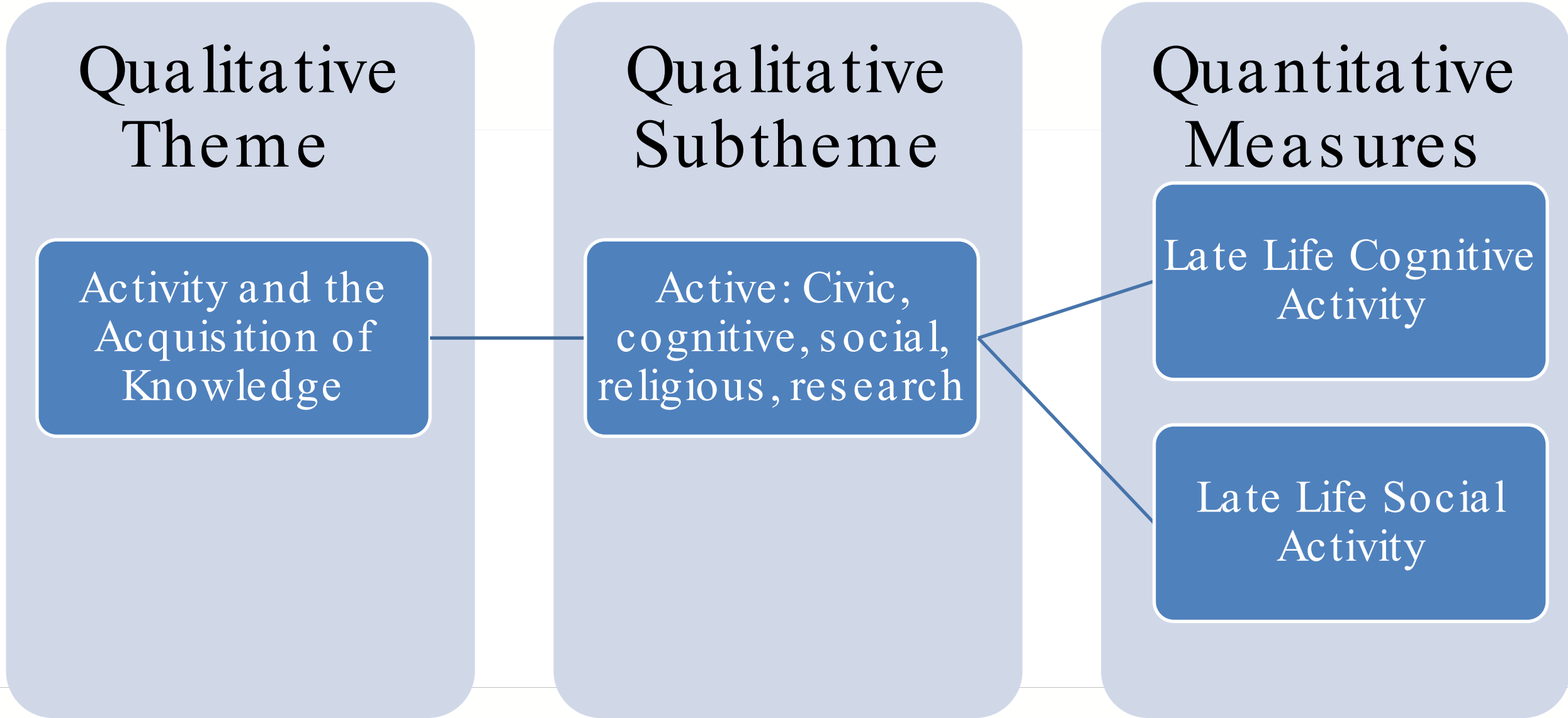
## Qualitative Subtheme

Active: Civic, cognitive, social, religious, research

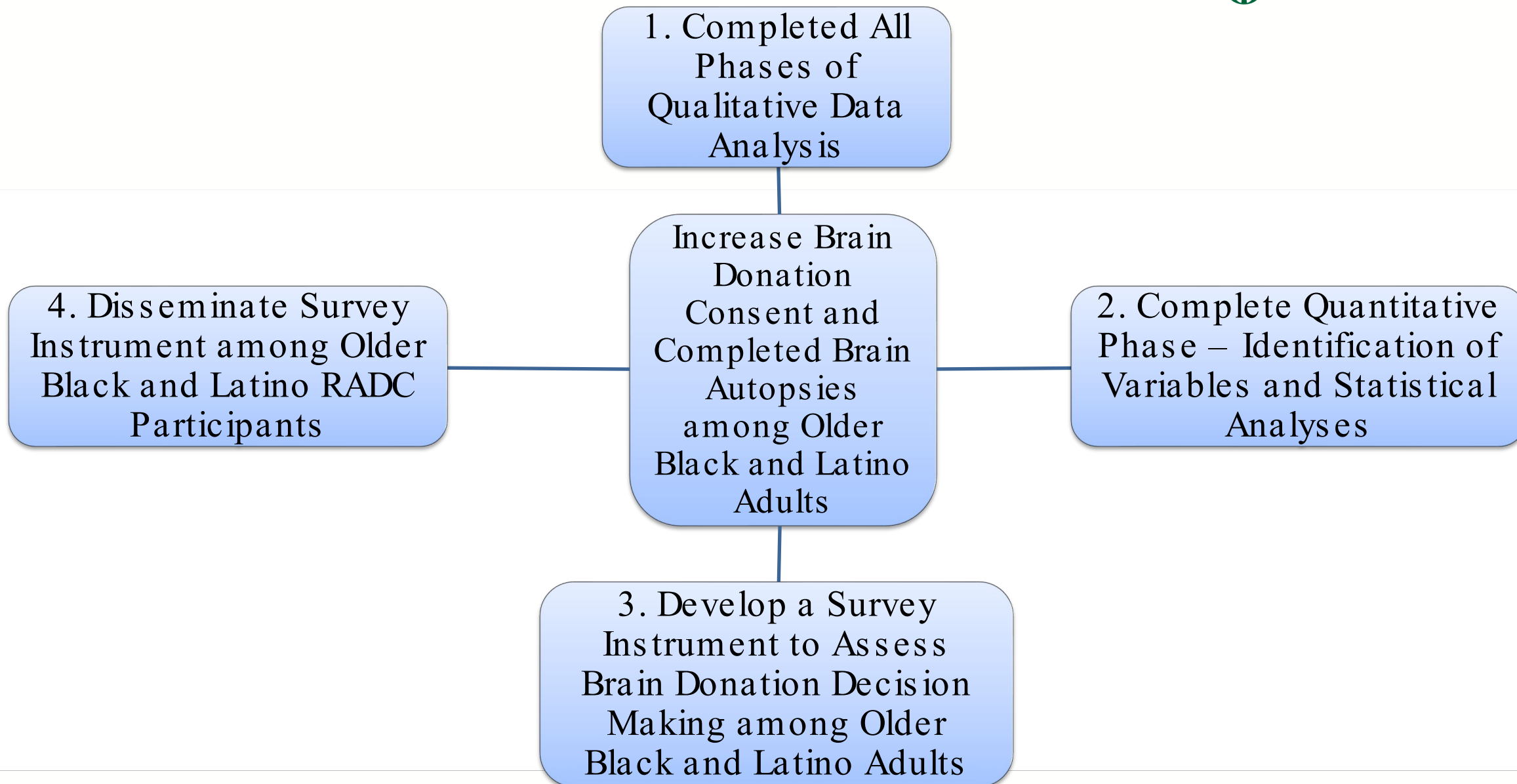
## Quantitative Measures

Late Life Cognitive Activity

Late Life Social Activity



# Next Steps: Completion of The HEARD Study



# I Welcome Questions and Comments

## RADC Research Resource Sharing Hub



Our data

Your vision

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