



Wake Forest University
School of Medicine

Allison Caban-Holt¹, Michael L. Cuccaro², Ashley Gregory¹, Persis Ayeh¹, Takiyah Starks¹, Larry D. Adams², Jenny Chavez³, Paris Pryor-Banks⁴, Shawnta Lloyd¹, Reilly R. Kandice¹, Aylin Aguilar¹, Jonathan L. Haines^{4,5}, Christiane Reitz³, Jeffery M. Vance², Margaret A. Pericak-Vance², and Goldie S. Byrd¹

(1)Department of Social Sciences and Health Policy, Wake Forest University School of Medicine, Winston-Salem, NC, USA; (2)John P. Hussman Institute for Human Genomics, University of Miami Miller School of Medicine, Miami, FL, USA; (3)Sergievsky Center, Taub Institute for Research on the Aging Brain, Departments of Neurology, Psychiatry, and Epidemiology, College of Physicians and Surgeons, Columbia University, New York, NY, USA; (4)Department of Population and Quantitative Health Sciences, Case Western Reserve University, School of Medicine, Cleveland, OH, USA; (5)Cleveland Institute for Computational Biology, Case Western Reserve University, School of Medicine, Cleveland, OH, USA



BACKGROUND

- Adults of African Ancestry (AAA) are nearly twice as likely to develop Alzheimer’s disease (AD) as non-Hispanic White adults yet are underrepresented in brain tissue donation (BTD) and AD research.
- Health Literacy Education is a primary strategy for increasing research participation; however, most approaches focus on improving factual knowledge rather than understanding how individuals evaluate the credibility of research information received and how this process influences decisions about research participation.
- Prior research shows that individuals rely on multiple information sources to navigate concerns about trust and misinformation.
- Understanding how research information is evaluated is critical for designing communication strategies that support informed engagement in BTD and AD research.

METHOD

- To explore perceptions of AD research and BTD among AAA, 12 in-person focus groups were conducted in four US locations, hosted by regional universities in North Carolina, Ohio, Florida, and New York (three focus groups per location) .
- Focus groups section lasted approximately 83 minutes on average and were audio-recorded and transcribed verbatim using a professional transcription service.
- Participants were de-identified during transcription. Illustrative quotes are labeled using specific study identifiers (e.g., P1FG1 = Participant 1, Focus Group 1) to maintain confidentiality.
- Transcripts were analyzed using thematic analysis. A codebook was developed using both inductive and deductive approaches and applied using Atlas.ti (version 24).
- Two analysts independently coded transcripts and met regularly to resolve discrepancies and refine themes through consensus.

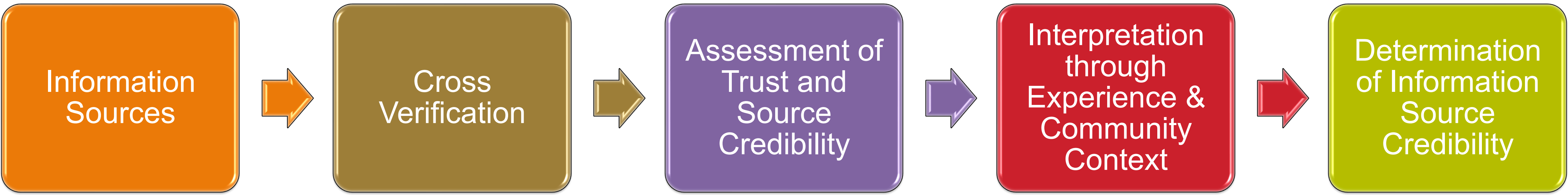
RESULT

- The focus groups yielded a total of 81 AAA participants with a mean age of 66.13 years (30 – 98 years old) ; 80.72% identified as female, with an average of 13.88 years of education (2 – 24 years).
- All participants were recruited from community settings and reported no prior involvement in AD research or BTD education.
- The study identified four key themes related to how participants evaluate the credibility of BTD information: (1) **multi-source verification**, (2) **conditional trust in clinicians**, (3) **platform skepticism and institutional preference**, and (4) **experiential and community-based interpretation**.

Key Themes and Credibility Drivers

Theme	How Participants Evaluate Information	Illustrative Quotes	What Signals Credibility
Multi-Source Verification	Participants actively cross-checked information across clinicians, internet sources, and family or peer networks. Information was rarely accepted without comparison.	<i>“Checking multiple places and seeing if it’s repeating.” (P1FG3)</i>	Consistency across multiple sources validated accuracy
		<i>“If you see the information in more than one spot, more than one location, usually an indication of whether it’s valid or not.” (P3FG2)</i>	
Conditional Trust in Clinicians	Clinicians were viewed as important and trusted sources, particularly when long-standing relationships existed. However, participants frequently verified clinician information independently.	<i>“Well, I believe in my primary care doctor. I been with her for ‘bout 12 years. Yeah, I have a lotta faith in her.” (P2FG8)</i> <i>“I go to the doctor a lot. A lotta times, I check on what the doctor said. At the end of the day, I go by how my body feels ‘cause I know my body better than the doctor.” (P4FG4)</i>	Trust built through relationship and reinforced through confirmation
Platform Skepticism and Institutional Preference	Online platforms were commonly used to access information; however, participants expressed concerns about misinformation and unreliable content. Institutional sources (e.g., universities, healthcare systems) were preferred to confirm and validate information credibility.	<i>“— ‘cause you can’t trust everything that you see on the internet ‘cause a lot of that stuff just ain’t happenin’ ‘cause it ain’t real.” (P2FG1)</i> <i>“I’ll look at more medical universities, like John Hopkins—places like that. I figure that the information’s more viable.” (P4FG9)</i>	Credibility linked to institutional authority and perceived expertise
Experiential and Community-based Interpretation	Participants interpreted information through personal and family experiences with AD and validated understanding through discussions in trusted community spaces such as churches and senior centers.	<i>“My church has a health group and they periodically have quite a few meetings in reference to health issues.” (P7FG1)</i> <i>“We get a lotta information here at [Center]. We have speakers that comes in—medical, pharmacy, banks and different places that give us a lot of information.” (P1FG9)</i>	Lived experience and collective discussion confirmed relevance and trustworthiness

Information Source Credibility Pathway



CONCLUSION

These findings highlight the complexity of navigating research information amid abundant and often inconsistent sources that could influence AAA to, or not to, participate in AD and BTD research. Trusted sources such as family, friends, physician knowledge, respected institutions and lived experiences are all relied upon to assess the credibility of health and research information. Future directions include the development of decision-making tools and community-anchored educational materials to be provided to trusted sources such as community-based organizations and clinicians to support informed engagement in BTD and AD research for AAAs.

ACKNOWLEDGEMENTS

We appreciate all participants in this study. We acknowledge the support of the National Institute on Aging (U01AG052410 and AG057659) and the resources provided by Wake Forest University School of Medicine. Additional research support was provided in part by the Qualitative and Patient-Reported Outcomes Shared Resource of the Wake Forest Baptist Comprehensive Cancer Center’s NCI Cancer Center Support Grant P30CA012197.

Wake Forest University School of Medicine is the academic core of Atrium Health.