



Culture-Centric Narrative as a Tool for Messaging about Brain Donation

Jennifer H. Lingler, PhD, CRNP, FAAN

Professor of Nursing and Psychiatry, Vice Chair for Research
Director of ADRC Outreach, Recruitment and Engagement Core
Co-Leader, Research Education Component

For the Pitt ADRC ORE Core: C. Elizabeth Shaaban, Melita Terry,
MaryAnn Oakley, Ann Cohen, Jennifer Seaman, Chrisala Brown

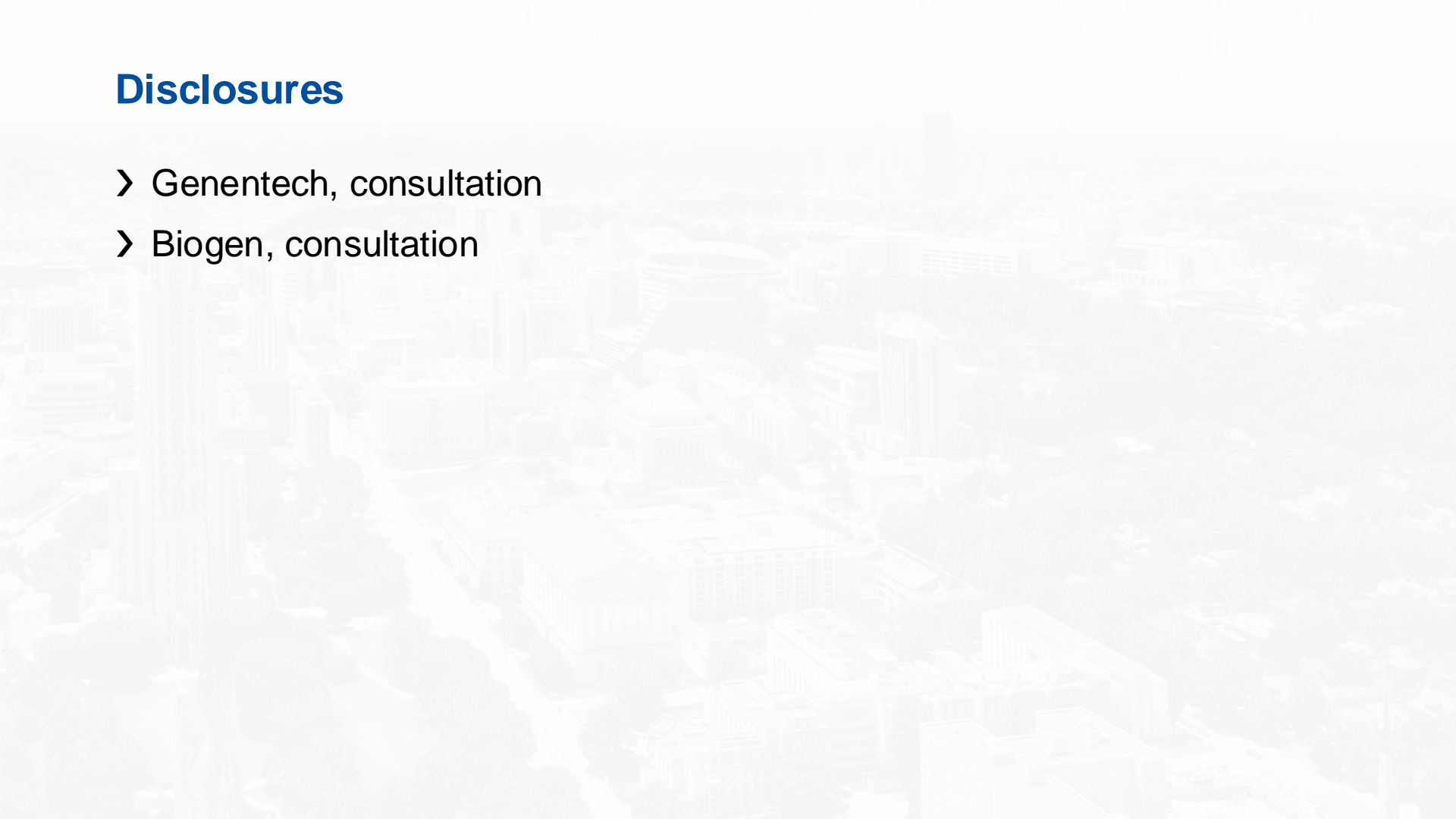


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Disclosures

- › Genentech, consultation
- › Biogen, consultation



Presentation Outline

- › Background
- › RIDE Study Overview
- › Application to Brain Donation Initiative

Background

- › Insufficient ethnoracial inclusivity is a pervasive challenge in clinical research on Alzheimer's disease¹⁻³ and this challenge extends to brain donation
- › There is a strong tradition of storytelling in the dissemination of information in many cultures⁴
- › Culturally informed narratives hold potential to impact the health behaviors of others within a culture-sharing community⁵

1. Canevelli, et al. (2019). *Neuroscience & Biobehavioral Reviews*, 101, 122-128.

2. Gilmore-Bykovskiy, et al. (2019). *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 5, 751-770

3. Lim, Barnes, Weissberger, et al. (2023). Quantification of race/ethnicity representation in Alzheimer's disease neuroimaging research in the USA: a systematic review. *Commun Med* 3, 101 (2023). <https://doi.org/10.1038/s43856-023-00333-6>

4. Houston, et al. (2011). *Ann Intern Med*. 154:77-84

5. Larkey & Hecht. (2010). *J Health Commun*. 15:114-135

Study Overview

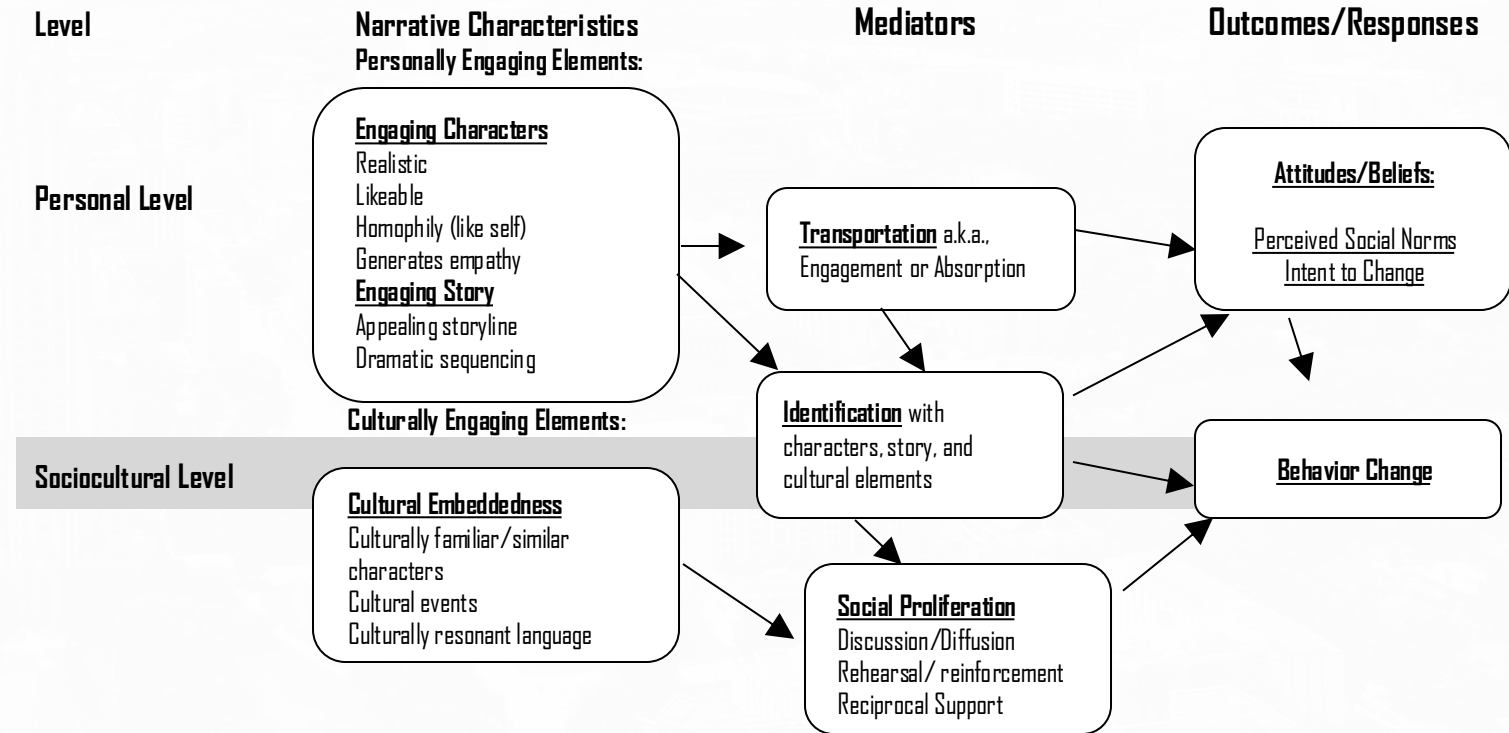
Recruitment Innovations for Diversity Enhancement (RIDE)

- Recruitment science research study
- Aims to determine the effect of a culture-centric narrative campaign on recruitment of African American- and Black-identifying adults into clinical research on ADRD
- Conceptually grounded in the Culture-Centric Model of Health Promotion (*Larkey & Hecht, 2010*)
- Applied findings from ethnographic analysis of interviews to create and test a set of narrative-based materials for messaging about ADRD research participation (*Robinson et al., 2020*)
 - Videos
 - Story Flyers
 - Question and Answer Flyers

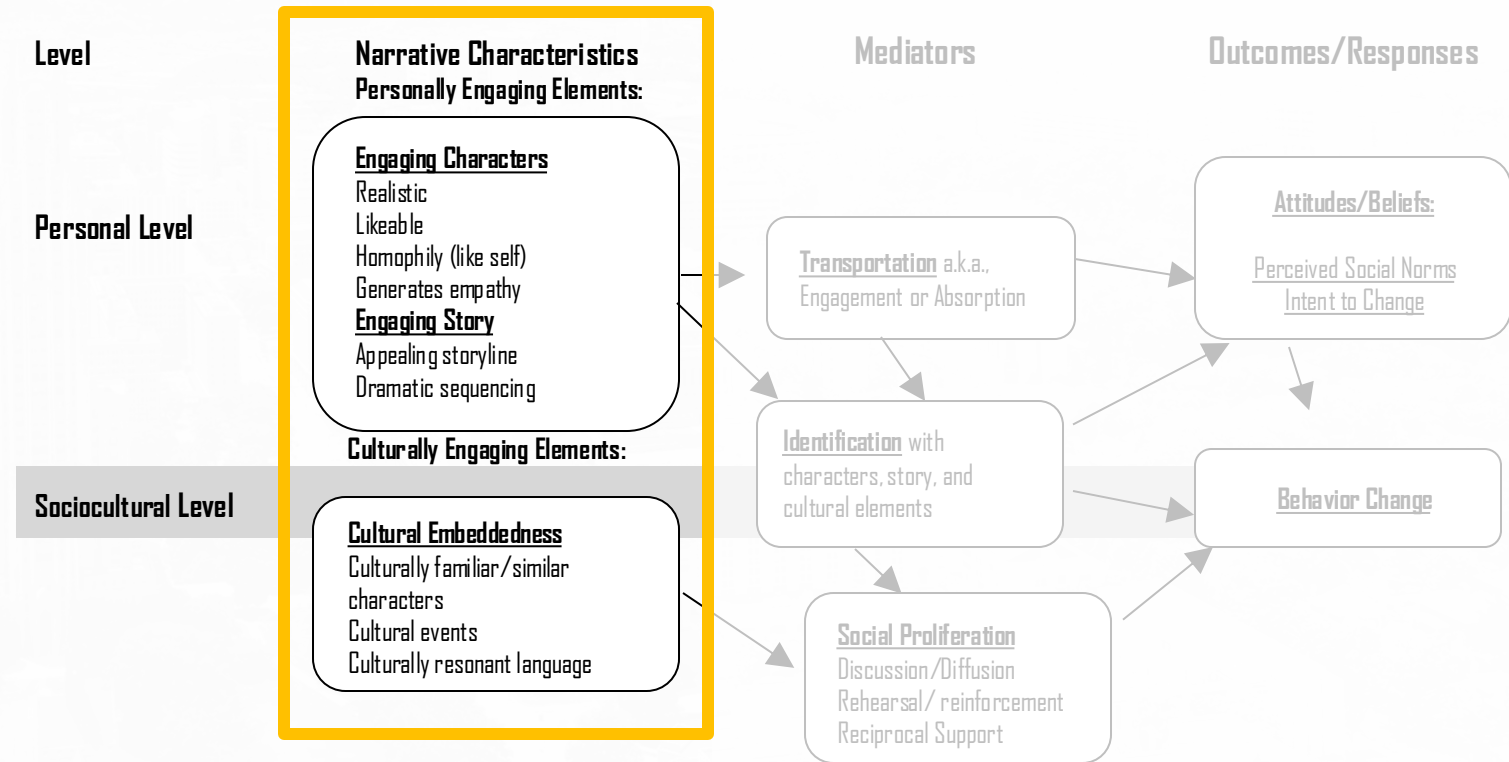
RIDE
RECRUITMENT
INNOVATIONS

NIA R01AG054518

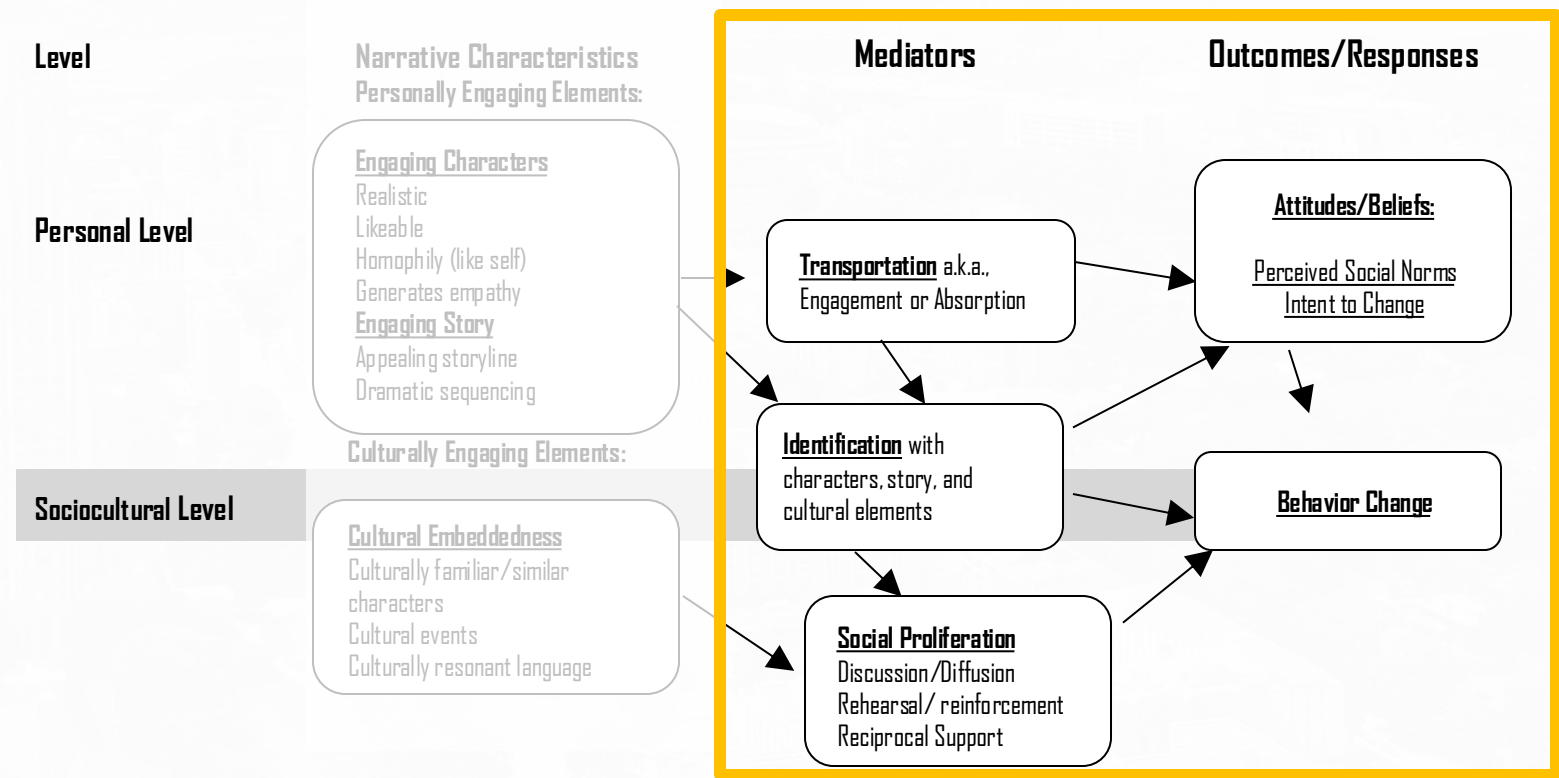
Model of Culture-Centric Narratives in Health Promotion



Model of Culture-Centric Narratives in Health Promotion



Model of Culture-Centric Narratives in Health Promotion




Linda K. Larkey & Michael Hecht. (2010). A Model of Effects of Narrative as Culture-Centric Health Promotion, *Journal of Health Communication*, 15:2, 114-135.

Advantages of Narrative-Driven Approaches to Research Messaging

Aspect	Traditional Approaches	Narrative-Driven Approaches
Primary strategy for information sharing	List information	Tell stories
Prioritization of viewpoint	Investigator-determined talking points	Stakeholders decide what is important
Medium	Text-heavy	Variable mix of text, visual, audio, and video messaging
Cultural relevance	Cultural considerations are incorporated second (or last), often in the form of adding stock images of persons of color to standard text	Cultural relevance is embedded. Uses words, voices, and images from individuals within a culture-sharing group
Method of dissemination	Materials distributed on lists or into the community by research staff or gatekeepers	Materials are shared openly among community members and proliferate within a culture-sharing group
Perceived ownership	Belong to the researcher/institution	Belong to the community
Structural level underpinnings	Flow from systems that center whiteness and have historically exploited or excluded communities of color	Draw upon cultural capital; value & prioritize voices of the minoritized

RIDE Narrative Campaign Materials for Clinical Core Recruitment



I miss my grandmother. She was my sweetheart and I hated it when she got Alzheimer's.

I want to know how people develop Alzheimer's and what researchers are doing to help.

Meet Annie.
Annie participates in Alzheimer's disease research to honor her grandmother.

[See Annie's story](#)

ADRC Spotlight



Jean

Full Version

2:07

Narrative Materials



Videos



Flyers

Primary Publications



Framework



Mechanisms

An aerial, high-angle view of a city, likely New York City, showing a dense urban landscape with numerous skyscrapers and buildings. The image is heavily faded and has a light, hazy appearance. Overlaid in the center of the image is a large, blue, sans-serif text button that reads "PLAY VIDEO".

[PLAY VIDEO](#)

Pitt ADRC RIDE Spin-Offs

1. RIDE Vanderbilt Supplement
2. Narrative as a Tool to Enhance Diversity in Research on Late Life Neurodegenerative Disorders (RIDE-PD; Adira Foundation)
3. RIDE II - Retention
4. RIDE III – Brain Donation
5. Brain and Cognitive Health Equity Campaign for Allegheny County (Brain CHEC-AC; NINDS U01NS141777)

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PLAY VIDEO

Pitt ADRC RIDE Brain Donation Initiative

- Elicit family members' stories of personal experiences with brain donation
- Elicit stories of participants who have provided provisional consent to brain donation
 - Invitation to share your "why"
- Use narrative to develop messaging for informational and promotional materials
- Deploy messaging
- Assess impact

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