

# Enhancing Research Literacy in underserved populations

*NIMHD PA-12-149 Research Supplements to  
Promote Diversity in Health-Related Research*

Lauren Powell

Doctoral Student

Clinical and Population Health Research  
University of Massachusetts Medical School

# Background



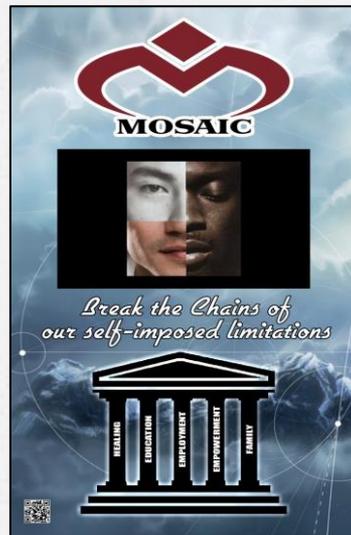
**The rapidly changing U.S. demographics indicate that minority populations will soon comprise the majority of the U.S. population.<sup>2</sup>**

- o Less than one-third of those enrolled in research studies sponsored by the National Institutes of Health (NIH) are minorities, with African Americans and Latinos comprising 12.6% and 7.5% of this group, respectively. <sup>1</sup>
- o CHEIR Hypothesis: stories have the potential to increase self-efficacy and enhance outcome expectations through observational learning/role modeling

<sup>1</sup>Pinn VW, Roth C, Bates AC, Wagner R, Jarem K: Department of Health and Human Services. National Institutes of Health. Monitoring Adherence to the NIH policy on the Inclusion of Women and Minorities as Subjects in Clinical Research. Comprehensive Report: Tracking Human Subjects Research in Fiscal Year 2007 and Fiscal Year 2008. 2009.

<sup>2</sup> U.S. Census Bureau. Statistical Abstract of the United States. 2012.

# Community Engagement Core project



## Project details:

- o Formative research to inform development of storytelling vignettes
- o Developing storytelling vignettes
- o Disseminating storytelling vignettes to researchers to use in development of a recruitment in studies addressing health disparities.

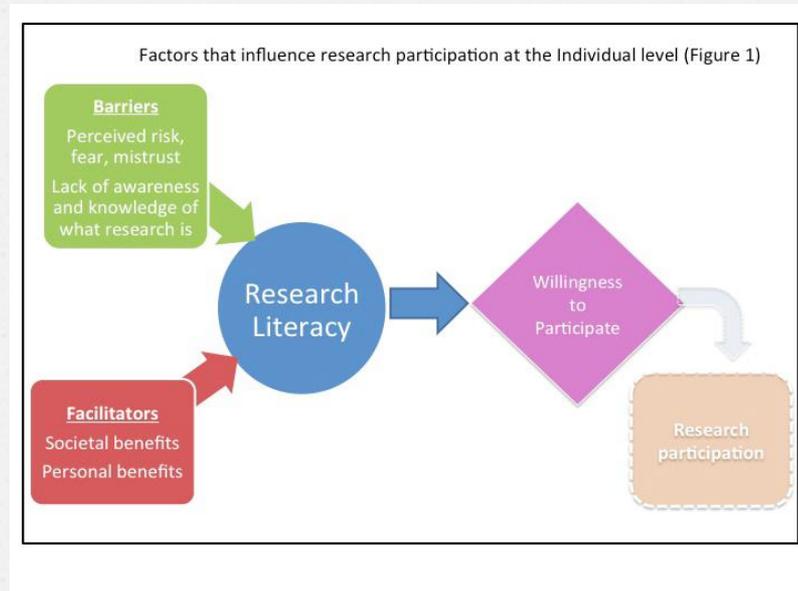
# Storytelling

- o We anticipate that stories will illustrate key facilitators to research participation including:
  - o perceived societal and personal benefits
  - o how barriers to research participation were overcome
  - o Descriptions of phases of research process

**Storytelling** is at a *pivotal moment*.  
STORYTELLERS are in need of  
a COMMUNITY to  
Encourage } **ONE**  
Listen to } **ANOTHER.**  
Critique }  
**GIVE** *your time &*  
*your attention*  
generously to other storytellers.  
**Everyone** has a story  
worth telling. An AUDIENCE exists  
for every **STORY**. *They are waiting*  
*to hear from* **YOU.**  
ARE YOU  
READY?  
Find your VOICE. Be BRAVE.  
*Enrich THE WORLD with your tale.*

# Research Literacy

- The capacity to obtain, process and understand basic information needed to make informed decisions about research participation.



# Specific Aims

- o **Specific Aim 1:** Developing a culturally responsive measure of research literacy in a diverse sample. This will be achieved by:
  - o Developing an item bank informed by literature review and previously conducted focus group findings.
  - o Conducting cognitive pre-testing interviews with 10-15 individuals of diverse backgrounds.
  - o Administering the culturally responsive survey to 100 people and examining its psychometric properties.
  
- o **Specific Aim 2 (future work):** Pilot testing the feasibility and efficacy of storytelling videos in improving research literacy by:
  - o Conducting a pre/post-test evaluation of change in research literacy and willingness to participate in research
  - o Evaluating reactions to videos before/after viewing

# Working Tasks



- o Lit Review- determining how to define research literacy
- o Revise conceptual model/ framework
- o Key informant interviews to gain feedback on proposed conceptual model
  - o community/ academic input
  - o multiple levels of training/ interest
- o Create survey measure of research literacy
- o Conduct psychometric testing
- o Administer survey

# Dissemination plans

- Publications based on:
  - conceptual framework of research literacy/ focus group findings- what participants should understand about research vs. what they actually do understand
  - Survey results
- Abstracts/ presentations at national meetings and within the community



