



**UsAgainst  
Alzheimer's**

A Community-Based Approach to Palliative and End-of-Life Care Equity: Partnering with the Black Church

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# Talking Points

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Participatory Methodologies

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Community Partners

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Engaging the Black Church as Partners in Research



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# Disclosures

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- No relevant conflicts of interest
- Financial support
  - Cambia Health Foundation Sojourn Scholar Award Program
  - National Institute of Minority Health and Health Disparities-Administrative Supplement
  - Johns Hopkins Center for Health Disparities Solutions

# Community - Based Approaches

- Community-Based Participatory Research (CBPR)
  - Collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each bring
  - Participatory and action oriented
  - CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities”  
Israel BA, Schulz AJ, Parker E, Becker AB in Public Health, Ann. Rev. Public Health. 1998. 19:173-202
- Community-Based Research
  - Research in the community
  - Community participation in community intervention studies

## Community-based Partnerships

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Help to address cultural barriers and build trusting relationships with historically excluded communities

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Faith and community leaders serve as gate keepers

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Impact of work/intervention is tangible with more of an immediate community impact

# Critical Questions for CBPR

## Whose issues get to the table?

- Different agendas/values between institutions/systems and community

## Who sits at the table?

- There is community mistrust of institutions
- There is institutional reluctance to relinquish control

## Who “sets” the table?

- Structures/procedures, decision-making, budget negotiation, implementation, dissemination

## Where is the table?

# Engaging with the Community

## Identify

- Identify community stakeholders/influencers

## Establish

- Establish community advisory board

## Host

- Host introductory meeting with faith leaders and stakeholders

## Engage in

- Engage in transparent communication strategies and efforts

## Report back

- Report back to faith leader throughout process

## Increase

- Increase visibility of diverse organization



### **Black American participant perspective on research**

“I think that some people feel like researchers come and take away from the community and go back and don't leave anything behind that is positive, so you are thinking both about damage in terms of lack of feeling and lost trust... feeling researchers got a lot more out of it than they did.”

## **Why the Black Church?**

- African American faith belief is a source of comfort and coping in illness and at the end of life
- History of racism and discrimination impacts African American's attitudes toward care seeking and clinical research.
- Historically, the Black church has served as a vital and trusted community resource and linkage to services and support
- Church leaders and members can build a bridge of trust to provide reputability to partner organizations and gather and share information regarding advanced illness care with patients, families, and caregivers.

# Role of Faith Leaders and the Church in Health Care

## Tertiary Prevention

- Serve as liaisons between hospitalized patients & family
- Hospice/Palliative Care
- Counseling & Support

## Secondary Prevention

- Provide supportive/therapeutic services and programs
- Allied health professional roles and programs

## Primary Prevention

- Health education-promotion
- risk reduction services
- Liaison between community health programs and congregations
- Social Change Agents

Healthy Churches 2030, Balm and Gilead road map



*New Hope Baptist Church*



JOURNAL OF PALLIATIVE MEDICINE  
Volume 19, Number 2, 2016  
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DOI: 10.1089/jpm.2015.0019

## Brief Reports

### Church-Based Health Promotion Focused on Advance Care Planning and End-of-Life Care at Black Baptist Churches: A Cross-Sectional Survey

Danetta Hendricks Sloan, PhD, MSW, MA,<sup>1</sup> Theodora Peters, MHS,<sup>1</sup> Kimberly S. Johnson, MD,<sup>2,3</sup> Janice V. Bowie, PhD, MPH,<sup>4</sup> Yang Ting, PhD, MHS,<sup>5</sup> and Rebecca Aslakson, MD, PhD<sup>4,5,7</sup>

#### Palliative and Supportive Care

Church leaders and parishioners speak out about the role of the church in advance care planning and end-of-life care

cambridge.org/jpm

#### Original Article

**Cite this article:** Sloan DH, Gray W, Harris D, Peters T, Belcher A, Aslakson R, Bowie J (2016). Church leaders and parishioners speak out about the role of the church in advance care planning and end-of-life care. *Palliative and Supportive Care*, 1–7. <https://doi.org/10.1089/jpm.2015.0019>  
S418185201600066

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Partnering with National Organizations that have Community Presence

USAgainstAlzheimer's  
Alzheimer's Association



In Partnership, The Johns Hopkins Bloomberg School of Public Health and First Baptist Church, Norfolk, Va. Hosts

### The Dementia and Brain Health Workshop

Join Us at the Murray Center  
455 E Brambleton Ave.  
Norfolk, VA  
8/6/2022 11:00 am - 2:00 pm  
Registration call  
410-614-4908

**For Questions**  
Principal Investigator  
Dr. Donetta S. Henderson  
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*... be transformed by the renewing of your mind, Romans 12:2*

You must be an Adult >18 and able to understand and give informed consent

Date: August 6, 2022  
Time: 11am - 2 pm

A JHSPH Research Study IRB #16603

#### Topics Include

- Dementia vs. Alzheimer's
- Alzheimer's Symptoms & Effects
- Planning Ahead
- Future Care

[Click Here to Register](#)

*... be transformed by the renewing of your mind. Romans 12:2*



# Key Facilitator Training



## Building a Relational Culture

- Have conversations that strengthen connection
- A health care culture that is caring, that supports the sharing of knowledge and value the contribution of the patient, caregiver and extended family, which is empowering, inclusive and welcoming.



Key Facilitator  
Engaging in an  
ACP  
Discussion  
with  
Participants



