What is Community Based Participatory Research (CBPR)?

• CBPR is often referred to as a research method. But it is not.
• CBPR is an orientation to research that emphasizes:
  • Mutual respect between partners (usually academia and community)
  • Building capacity within the community (and individuals in it.)
  • Balancing research & action (working towards change)
In CBPR The Community is the Unit of Identity

- The community is recognized as the unit of identity that we partner with
  - Community: group whose members share common identity
    (e.g., rural, southern African Americans; Urban African Americans; LGBT in Southeast [all older])
- A Community Advisory Board (CAB) partner equally with researchers
What is the relationship between CBPR and Balance of power?

- In CBPR there is a **change** in the balance of power:
  - Study respondents become more than research objects
  - They give more than informed consent & answer questions
- They participate **equally** in the research process
- They share their knowledge & experience on:
  - *All* aspects of the research process
  - Make recommendations for solutions
- We listen to & **accept** these recommendations
  - These form the healthcare program being created
  - Outcome benefits the community
CBPR has PROVEN to reduce health disparities

- Proven to reduce health disparities
  - Over and over and over and over and....

- Widely implemented in Public Health & Cancer Prevention
  - Other than Preventive Medicine, rarely (if ever) in Medicine
  - Just started being used in Palliative Care
  - [Care for anyone w serious illness (not only at end of life)]

- Our goal is to implement this widely in Palliative Care
  - Starting w focus on older minoritized adults
Study 1: Developing the first Culturally-Concordant Palliative Care Intervention

- **Goal:** Create a culturally–concordant PC intervention
- **Why:** Culture impacts serious illness & EoL care
  - Preferences for care
  - Communication methods
  - Meaning of illness, pain and death
  - Decision-making
- **Yet in US:** EoL Care Values are based on
  - White, middle class, Christian values
- **Lack of sensitivity to or respect for cultural differences & lived experiences of racism**
  - Compromises care for minoritized patients
  - Results in significant healthcare disparities higher pain, non-goal-concordant care)
We chose to focus on Rural, Southern Older Patients w Serious Illness (W & B)

Step 1: Invited community members to join the study as our CAB:
- Equal numbers of African American and White.
- We met once every single month for 3.5 years
- The CAB guided *each and every* step of the study

Step 2: Held focus groups with community members
- Whose loved one had died in hospital in the last year
- To determine their experiences w healthcare system
- Per CAB: Separate focus groups for
  - White
  - African American
- We analyzed the data and reported these to the CAB
Study 1 continued

• Step 3: CAB reviewed results, & made recommendations
  • For how clinicians should provide care & how to communicate
  • With members of their community.
  • Many differences between African American and White

• Step 4: Researchers incorporated these into PC Consult Guidelines

• Step 5: CAB members Trained The Palliative Care Physician!

• Step 6: Conducted pilot of this intervention in a rural hospitals to determine
  • Feasibility of implementation in hospital
  • Patient and family recruitment recruitment
  • Patient and family satisfaction.
First Culturally Concordant PC Consult

Now being replicated by mentees with a focus on older adults from other minoritized communities and those from other cultures. Need many more.
CAB Members Trained the P.C. physicians
We are now testing the efficacy of this Intervention in a RCT.

3 Rural Hospitals in 3 Southern States

AL.
AA & W patients (AL CAB)

MS.
AA & W patients (MS CAB)

S.C.
AA & W patients (SC CAB)
Study 2: African American Communities Speak to Healthcare Providers

- Used same approach as for Study 1
  - Different rural area
  - Only African Americans
  - Older population

- CAB created 4 videos:
  - Based on focus group results
  - How to provide culturally-concordant care for rural, southern, African American elders with serious illness
  - Each video has a different message

- Education expert added skills-based training
  - For clinicians who provide care to older African Americans with serious illness

First such training program in the US developed by the community. Need to be replicated in more groups (one study under way)
This training has been provided to:

- 160 healthcare professionals around the country (to date)
  - Majority are Palliative Care professionals.
- Preliminary data very encouraging:
  - Increased knowledge of cultural values of Southern African Americans
  - Had the confidence to change practice
  - Majority changed their practice on 3 of 4 community recommendations

Now being replicated by mentees with a focus on older adults from other minoritized communities and those from other cultures. Need more.
It is truly an honor to be part of this process.
With deep appreciation to an incredible team and NINR and NIA

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Elk/Bakitas: NINR
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“A Community-Developed, Culturally-Based PC Tele-Consult Program for African American and White Rural Southern Elders with a Life-limiting Illness”

Elk: NIA, R21AG04672
“Community-Generated Palliative Care Telemedicine for Rural Black and White Elders”

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