Amplifying of the Patient Voice in PCOR Design and Implementation

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Background:

- CRC screening rates are relatively low among Hispanics as compared to non-Hispanic whites and African Americans.
- Effective interventions are needed to raise CRC screening rates , reduce mortality, and increase survival in this growing segment of the population.
- Bidirectional engagement empowers patients to learn about research processes and inform the research question, design, intervention and dissemination.

Objective:

To engage patients in the design, development and implementation of patient-centered outcomes research (PCOR), specifically a multi-level decision support and navigation intervention aimed to increase colorectal cancer (CRC) screening in the Hispanic community.

Engagement Design:

Multi-stage Focus Groups (FGs) design:

- (4) grant development
- (2) pre-intervention
- (2) post intervention

Continuous intervention oversight is conducted by a patient-led Patient and Stakeholder Advisory Committee (PASAC).

Setting:

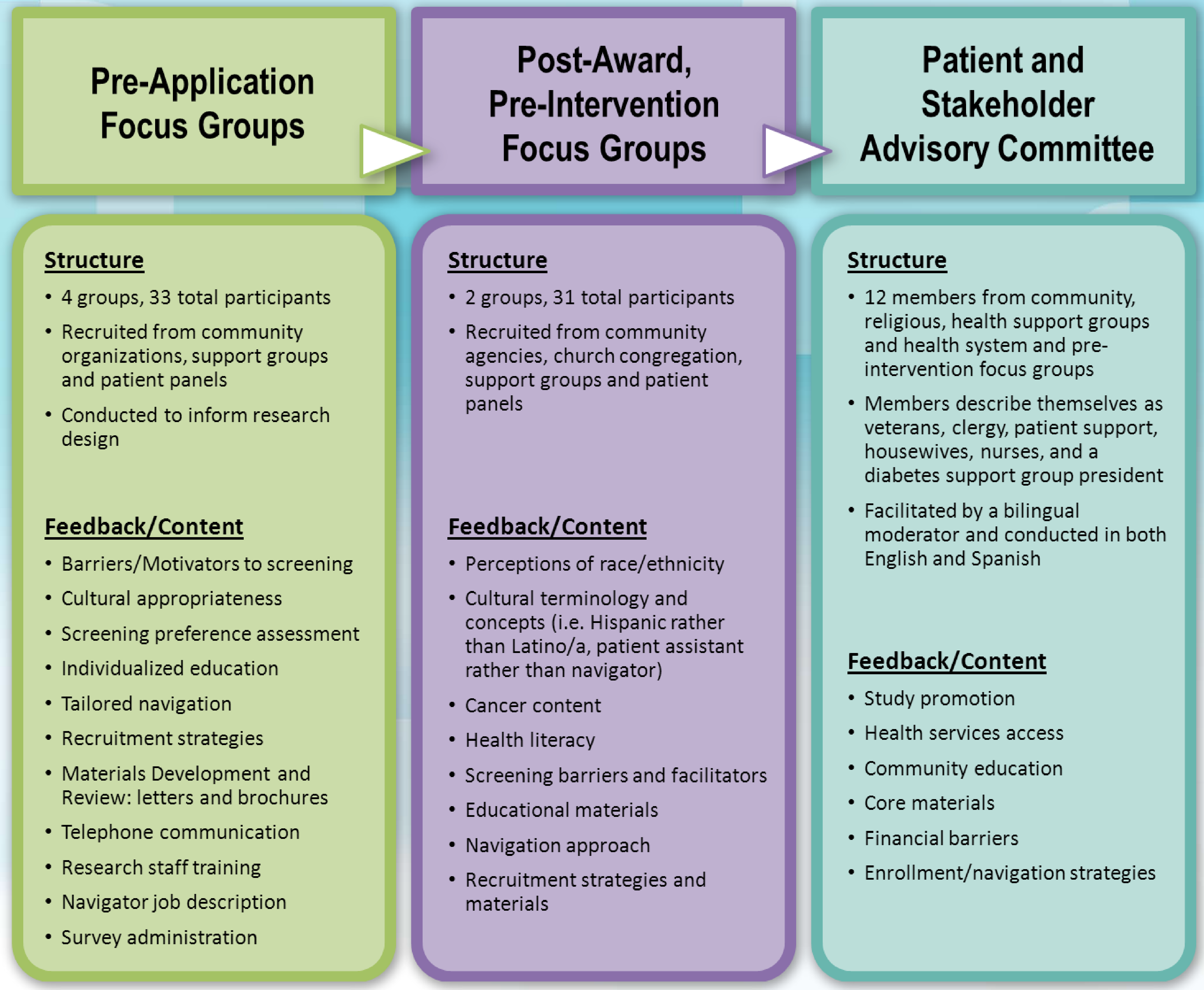
Healthcare, Community and Church locations, urban community in Eastern Pa, served by large health network system.

Participants:

Autonomous patients and community members, self-reporting Hispanic, >/=50 years of age.

Data Collection/Analysis:

Audio recordings are transcribed and translated prior to coding process. Output is reviewed to identify common themes and responses. Basic descriptive statistics (frequencies) are used to identify key themes.



Pre-Application Focus Groups

Structure

- 4 groups, 33 total participants
- Recruited from community organizations, support groups and patient panels
- Conducted to inform research design

Feedback/Content

- Barriers/Motivators to screening
- Cultural appropriateness
- Screening preference assessment
- Individualized education
- Tailored navigation
- Recruitment strategies
- Materials Development and Review: letters and brochures
- Telephone communication
- Research staff training
- Navigator job description
- Survey administration

Post-Award, Pre-Intervention Focus Groups

Structure

- 2 groups, 31 total participants
- Recruited from community agencies, church congregation, support groups and patient panels

Feedback/Content

- Perceptions of race/ethnicity
- Cultural terminology and concepts (i.e. Hispanic rather than Latino/a, patient assistant rather than navigator)
- Cancer content
- Health literacy
- Screening barriers and facilitators
- Educational materials
- Navigation approach
- Recruitment strategies and materials

Patient and Stakeholder Advisory Committee

Structure

- 12 members from community, religious, health support groups and health system and pre-intervention focus groups
- Members describe themselves as veterans, clergy, patient support, housewives, nurses, and a diabetes support group president
- Facilitated by a bilingual moderator and conducted in both English and Spanish

Feedback/Content

- Study promotion
- Health services access
- Community education
- Core materials
- Financial barriers
- Enrollment/navigation strategies

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FOX CHASE CANCER CENTER TEMPLE HEALTH

Ongoing Process:

While each focus group was a single meeting, the PASAC is convened 3x's/yr for 2 hour meetings, and is sent monthly study updates via email. To date, 5 meetings have been held.

Preliminary Results:

An integral role in the research team, PASAC members report feeling that they are an extension of their community and have a duty to share their study knowledge with that community. As such, the committee provided strategies on how to disseminate findings in the larger community via various outlets. The PASAC members report feeling comfortable in the group and that their opinions are both heard and acted upon.

While members have provided feedback on study materials and protocols, most felt that their primary role was in disseminating the results to educate the Hispanic community about colorectal cancer screening. Fewer members acknowledged the role of the group in research design and implementation though several described themselves as part of the team.

Next Steps:

- The PASAC will continue to meet for the duration of the study.
- Two post -intervention focus groups will be conducted eliciting participant perceptions about intervention contacts and barriers to and facilitators of screening.

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