



Stakeholder Needs Analysis

Section 1: Needs Assessment Design (from our original proposal approved by PCORI)

We will conduct 10 to 15 focus groups consisting of 8 to 10 persons each during which participants will complete the relevant program measures and conclude with a 90-minute discussion. We will also invite participants to complete individual interviews if they would feel more comfortable providing the information this way. Our goal with this phase of our work is to complete a capacity analysis of stakeholders and communities of interest. As groups are ongoing, we present preliminary findings for work completed through August 5, 2016.

In this report, we are focusing on the primary targets of our information gathering for Black faith community knowledge (i.e. PCOR, CER and mental illness). Though we used multiple surveys our needs analysis for this report focuses on the following relevant surveys:

1. To ascertain knowledge about PCOR and CER:

We requested permission from the corresponding author and were permitted to adapt 2 questions from a measure developed by Cameron, P., Pond, G., Xu, R., Ellis, P., & Goffin, J. (2013). A comparison of patient knowledge of clinical trials and trialist priorities. *Current Oncology*, 20(3), e193-e205.

The questions are answered on a Likert scale 1 (strong disagree) to 5 (strongly agree) and include the following:

- a. I have a good understanding about how Patient Centered Outcomes Research works.
 - b. If I had the option, I would definitely consider participating in Patient Centered Outcomes Research.
 - c. I have a good understanding about how Comparative Effectiveness Research works.
 - d. If I had the option, I would definitely consider participating in Comparative Effectiveness Research.
2. To ascertain knowledge about depression and its impacts: The International Depression Awareness Literacy Survey (IDLS) ¹, a measure developed specifically to examine depression stigma, knowledge, attitudes toward treatment and beliefs about need for treatment in diverse populations.

Section 2: Overview of Engagement Findings

To date we have completed 6 focus groups with 58 total participants/respondents. Respondents include 8 youth and 50 adults from Washington, DC and the surrounding areas and from the triangle area of NC. Our goal is to meet with 150 adults and 50 youth by October 31, 2016. In the area of need, our primary goal is to ascertain the level of knowledge in the community related to Patient Centered Outcomes Research and Comparative Effectiveness Research as well as attitudes about the interest and capacity of Black faith communities to engage in research and programming related to PCOR and CER for youth mental health.





First, we provide a table that briefly describes our outreach and engagement activities and provides preliminary insight into their effectiveness.

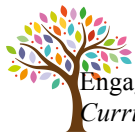
Recruitment Strategies for Needs Assessment Focus Groups	
Referral Source	Participants Enrolled
Faith Based Leader Referral	13
The Adult Advisory Board	0
Community Leads	28
Community Seminars	0
Principal Investigator/Award Lead	0
Participant to Participant	14
Total	55
^a RSF – Recruitment Success Factor $RSF = (P+1)/(C+1)$ where P = participants yielded and C = contacts made (Not calculated for current iteration of program. To be calculated at end of needs assessment.)	

Section 3: What have we learned?/What are the needs?

What works best in engagement for our population? We have found that our greatest asset is our community leads in NC and DC. Our current group of engaged participants for the focus groups has come almost exclusively from their outreach efforts.

What has not worked to date? In our other collaborative efforts (i.e. those not associated with the Engagement Award), our community seminars have yielded many participants. In this first half of our outreach to participants for the focus groups, this has not been the case. We attribute this outcome to 2 primary factors. First, it takes a great deal of effort to coordinate focus groups and register people to participate. This requires multiple contacts with community liaisons and dedicated staff to complete the outreach and follow up until a focus group is scheduled. Given the multi-faceted nature of our outreach (i.e. we are seeking partners as well as focus group participants), we exert a greater portion of effort toward both activities such that we are not able to focus exclusively on focus group recruitment (as focus group recruitment is not the sole focus of the award). Secondly, the fact that we are running a multisite program means that our resources are spread across 2 states requiring a great deal of communication effort. We suspect that the time involved in building and nurturing relationships for dual purposes (focus groups and enlarging our faith community network) has contributed to our inability (to date) to convert community seminar participation to focus group participation. We are however, currently collaborating with 3 churches that recently attended one of our community outreach programs to schedule focus groups.





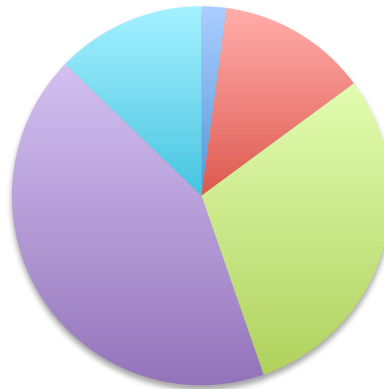
What do Black faith communities know about PCOR and CER?

Please see two pie charts with explanation following:

As you may note, of our 55 respondents (there were fewer person who completed questionnaires than who participated in focus group discussions), the majority report agreeing with the statement that they have a good understanding of how PCOR works (N= 20).

The second largest group of respondents is those who responded that they held a neutral feeling about their knowledge of PCOR (N = 14).

PCOR - I have a good understanding about how Patient Centered Outcomes Research works.

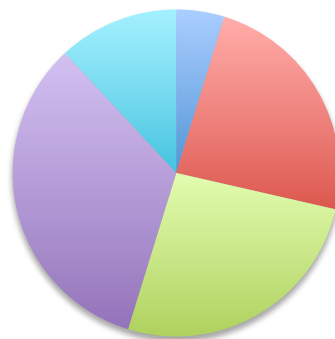


- 1-Strongly disagree
- 2 - Disagree
- 3 - Neutral
- 4 - Agree
- 5 - Strongly Agree

As you may note, of our 55 respondents (there were fewer person who completed questionnaires than who participated in focus group discussions), the majority reported feeling neutral toward or disagreeing with the

statement that they have a good understanding of how CER works (N= 10 disagree and 11 neutral). An additional 14 participants reported that they agreed with the statement that they understood CER. (N = 14).

CER - I have a good understanding about how Comparative Effectiveness Research works.



- 1 - Strongly Disagree
- 2 - Disagree
- 3 - Neutral
- 4 - Agree
- 5 - Strongly Agree





What are Black Faith Community persons' feelings about mental illness?

The ILDS asks respondents to select the top 6 causes of illness or injury in their home country from a list of 24 health problems or health events (e.g. lung cancer, diabetes, HIV/AIDS). Of our 55 respondents (including youth) 61.8%, or 34 included at least 1 mental illness in their list of responses.

Section 4: Conclusions

Overall, our findings suggest that Black faith communities can be engaged for research planning and outreach, that community members (including youth, patients, caregivers and stakeholders) can be very effective partners in program outreach and outreach and that people have some familiarity with terminology related to PCOR and CER. As well, we have a community of engaged persons with some knowledge of the import of mental illness as a cause of concern in the U.S.

Our next steps included continuing to collect focus group information, continued engagement of patients, stakeholders, communities and youth and continued work on the building of our curriculum to build capacity in Black Faith communities for mental health PCOR and CER.





References

1. Hickie AM I, Davenport T, Luscombe G, Rong Y, Hickie M, Bell M. The assessment of depression awareness and help-seeking behaviour: experiences with the International Depression Literacy Survey. *BMC Psychiatry*. 2007;7(1):48.

