LinCS 2 Durham Collaborative Council Retreat Minutes

Stanford L. Warren , Meeting Rm. 1

February 19, 2010   10:30am-2pm

Facilitator: Randy C. Rogers

Attendees

Community Members: Noah Powell, Tonya Stancil, Anthony Coston, Caressa White, Kendra Batten, Rhonda Royal Hatton, Wisdom Pharaoh

Research Team: Marcus Hawley, David Jolly, Brett Chambers, Natalie Eley, David Napp, Allison Matthews, Eunice Odhiambo, Kate MacQueen, Malika Roman-Isler, Michelle Laws, Alexandra Horne

Note Takers: Allison Matthews and Alexandria Horne

AGENDA

Process Evaluation Presentation - David Napp

- Randy facilitated discussion on strengths and challenges of process of decision-making

    Brett: open, open-access: we all have equal opportunity to throw something out on table

    Randy posed question: Do you feel like an environment is created for people to feel comfortable to share? People nodded and said, "Mmm hmm". He asked if anyone had any other opinions and no one said anything.

    Wisdom: Respect

    Brett: some people are not as vocal, so maybe we could have people write down what they want to say

    Randy: we also have evaluation process for people to express concerns, opinions

    want to encourage sense of transparency

    When we don't get consensus on an issue, we're good about following-up on issue or important decision

    David Jolly: from findings in survey, it seems like people are confused about how group makes decisions, so we might want to revisit that process every once in a while to make sure everyone is on same page

    David Napp: maybe we should come up with formal way and/or statement about how we make decisions when we're making major/important decisions

    Michelle: how do you make sure that we address issues that people have and make sure they don't feel like their opinions are lost in the mix,

not paid attention to, and make sure we don't lose them as a CC member?

Randy: we should pay attention to power dynamics/sharing between staff and community members, especially when considering amount of contribution, being paid vs volunteer, etc.

- ***Strengths and Challenges of Power Sharing***

Kendra: people feel more invested in the process

Kate: important to be thick-skinned and not take things personally

Michelle: yes, but we should remember that this issue is personal, when things get personal, it doesn't mean that they can't be effective contributors

Randy: don't want to devalue or negate individual contributions, things being "personal" can drive and motivate a person's participation

Brett: depending on the context, it's about respecting that person or persons, especially when trying to follow power-sharing framework

Maybe we should not focus as much on task-oriented agendas and allow people to express themselves and find out where they fit in the "sharing" of the process

We need to drop out JUDGEMENT

- ***Strengths and Challenges to Access to Information***

Natalie: Randy has a habit of forwarding everything via email to CC members and printing hard copies for people

Noah: We may need to take a look at our guiding principles to make sure that our actions and process are embedded in guiding principles

Randy: Do we need to revisit some of the recommendations and thoughts being said to make sure they are embedded in guiding principles?

Brett: We should have banners with guiding principles posted at every meeting to remind people about them

David Napp: Many of the questions in the survey are rooted in the guiding principles, we wanted to see if CC members and staff feel like guiding principles are being carried out

Randy: flexibility, we cannot do this work without having a level of flexibility

Michelle: After looking at disaggregated data from David Napp, it was interesting to find out that the people most concerned about power sharing were the staff, not the community members

Randy: We have talked about that in the CCWG and want to try to address those perceptions; we tend to be hyper-critical about power sharing

Natalie: website, wiki, CC website, twitter, facebook; there is access to information

Brett: We invite people to really utilize those tools, especially

because Alex works really hard to keep those things updated

           Natalie: We still need someone to volunteer to manage CC website

           Tanya: We have to remember that some people may only have access to information when they come to the meetings

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HIV Prevention Technologies Presentation - Kate MacQueen

- Kate: described the process of clinical trials for biomedical research

  Test drug or other method on animals, then small group of healthy, low-risk humans, then larger group of humans at higher risk

- Brett: Can we have people write down the questions they have to make sure they're addressed later?

  • Some studies have improved reduction of spread of HIV/AIDS among infected mothers giving birth to children by taking anti-retroviral drugs, male circumcision (reduction among men who have sex with women)

  • Other examples that may work, but haven't been proven yet: vaccine (will be more like flu vaccine because virus mutates)

  • Other trials with other methods that have promising results: microbicide gel with anti-retroviral in it; daily dose of anti-retrovirals

  • We should think about what approach we think might be most effective in Durham Black community, do people even want to do a trial or find any methods for HIV/AIDS prevention technology?

  • Randy: What are the long-term side-effects of these HIV prevention technologies? People will want to know the long-term effects of drugs on well-being.

  • Kate: I would recommend having someone who really understands the drugs come and talk, maybe someone from pharmacological field

  • Michelle: How do you present this information to people in Black community who have to deal with other issues with health disparities? People are concerned that research is only being conducted on poor, Black people and not White people.

  • Kate: The CC will be an important part of making messages relevant

  • Michelle: Black people are very aware of the negative effects of participating in research

  • David Jolly: Also been research on White gay males, they have been instrumental in lobbying for funding and changing policy related to biological prevention technologies

  • Michelle: White gay men of a certain socio-economic status increased their influence on policy; don't assume that people in poor communities are stupid, even though they may not know big words or have all information

  • Kate: That's why is so important to collaborate with community members

- Brett: We should also address literacy and level of involvement in voting, political process, improving economic and political literacy

Update on Research Literacy Curriculum Development - Malika

- We've reviewed 15 different curricula that address research literacy or HIV in some facet, don't want to recreate the wheel
    - Looking forward to conversations about the best way to package information about biomedical research, frequently asked questions and other concerns that we need to anticipate
    - There's a lot of overlap between different working groups to figure out how to develop curriculum
    - Eunice: Do you have portion that gives information on HIV transmission?
    - We have information on technologies, clinical trials, transmission methods, but also what is role of community and how do we develop and sustain relationship between research and communities?

Update on Communications WG activities - Brett

- Brett: we've been making sure we have the framework, making sure message and branding is consistent

    We need more representation from target demographic
    Can put videos of frequently asked questions on Facebook and Twitter
    Looking into way to have t-shirts and other branding for LinCS 2 Durham

- Natalie: information sheet done and flyer designed

Update on Community Survey planning and implementation - Eunice

- We're done with the pilot
    - We're editing final documents and hope to start next month
    - Still waiting on final people to come in and pilot ACASI

Update on recruitment and outreach efforts - Randy or Noah

- Noah "piloted" recruitment survey by choosing 6 organizations to contact. He is still trying to contact coordinators of organizations
    - Contacted Resident Services for Durham Housing Authority and Human Services Committee --> they wanted to know who was involved (other institutions) and wanted to know why they were relevant to our study
    - They want Noah to come in and speak with them more extensively about

project

•   Randy: will send out recruitment survey out along with minutes from retreat

Community Caucus - Randy

- How do you want to move forward with the target advisory board?

    •   Randy: Do you want to move forward with this? Group replied verbally with "Yes"

    •   Randy: Do you have any concerns? Group replied no with silence

    •   We need a working group to develop the advisory board

    •   Michelle: Is this going to be a part of the CBPR process? I would be willing to help write that up to incorporate this component of project as part of CBPR

    •   Kate: We are planning to write papers talking about process of CBPR and how difficult it has been to include target population, we have had to use innovative strategies to get them involved

    •   Noah: This will be an opportunity for us to have a way for people in target group to participate in project

    •   Randy: We also want to make sure that there aren't any issues with the IRB

    •   Michelle: Maybe if we have conversation about incentives, then people will be more willing to participate in working group

    •   Natalie: People are already stretched to capacity with other working groups, so we need to figure out if we have the "man" power to do this

    •   Brett: Maybe we should talk about this in leadership retreat, maybe opportunity to add to human capital and get this done with new people

    •   Michelle: This should not cancel out the need and efforts to recruit more people from the target population

    •   Noah: It won't be hard to get students involved because they will have academic benefit, also need person from LinCS to oversee group and make sure agenda is relevant to project

    •   Kate: We should come up with a proposal on how to keep this idea moving

Discussion on CC involvement (incentives) - Kate

- We want to make sure that we're not crossing the line between volunteerism and unpaid labor, want to make things more equitable and sensitive to these issues

    •   Not just about monetary compensation, but also about marketable skill building

    •   The group decided to start the discussion on this topic at the beginning of the next CC meeting when the majority of community members are present

    •   Randy: We need to make sure there is funding for reimbursement of activities that CC members do that are more intensive than what can be considered "volunteerism"

    •   Michelle: We need to make sure that we don't make a line of demarcation that

asserts that people who are not in the target demographic cannot be aware of or speak on the concerns of that population

- Brett: We don't want to use language that excludes people and act like people from the target demographic are not represented in LinCS 2 Durham because they are here
- Randy: We need to pay attention to the context and intent of the words said so we won't be offended, and if there are concerns about the intent, then we should feel free to voice those concerns

Follow-Up Action Items from CC Retreat:

- More extensive presentation(s) on HIV Prevention Technologies (March, April CC mtgs.)

- LinCS 2 Durham Leadership Team will assist in determining how the study should move forward with Target Advisory Board for 18-30 year old Black young adults.

- Re-visit dialogue on CC involvement and incentives

- Re-visit Guiding Principles to ensure they are being carried out in CC meetings as well as the decision making process.

- Identify a CC member(s) willing to manage the CC website.

Upcoming CC Meetings

Monday, March 14th, Downtown Library-Main Branch in the Auditorium, 6-8pm
Monday, April 18th, Stanford L. Warren Library in Rm. 1, 6-8pm
Monday, May 16th, Stanford L. Warren Library in Rm. 1, 6-8pm