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EXPERIENCES OF RESIDENTS INVOLVED IN A COMMUNITY/UNIVERSITY CBPR PARTNERSHIP: CHALLENGES AND OPPORTUNITIES

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Presenter Disclosures

Emily Zimmerman

(1)   The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose

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Learning Objectives

1. Discuss the *motivations* and *expectations* of residents engaged in a community-based participatory research partnership

2. Describe the *challenges* and *growth* opportunities for community residents who participate in CBPR partnerships

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About the project

Engaging Richmond: Promoting Community Participation in Health Equity Research

Supported by NIH - NCATS - 8UL1TR000058; Supplement of NIH - UL1RR031990

Engaging Richmond Team Members:

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Presentation format

- ☐ Background
- ☐ Motivations and Expectations
- ☐ Challenges
- ☐ Growth
- ☐ Meeting our goals: Work continues

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☐Background

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The Engaging Richmond team

A team effort

□ Our research team, which has been working together since December 2011, is made up of three groups:

▪ Residents and service providers from the East End neighborhood of Richmond, VA

▪ Staff from the Virginia Commonwealth University (VCU) Center on Human Needs (CHN) and VCU students

▪ Staff from the George Mason University Center for Social Science Research (CSSR)

□ This presentation focuses on the voices of team members who are community residents.

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The community

- This project was based in Richmond, VA in the Eastview, Peter Paul/Brauers, and Woodville neighborhoods in zip code 23223
- 95% of households are African American
- Median household income ranged from $11,791 to $27,431, compared to $39,608 in Richmond City and $60,674 in Virginia
- Over half (56%) of residents live below the poverty level ($22,050 for a family of four); 76% of children live below the poverty level
- Almost half (46%) of adults age 25 and over have not completed high school or its equivalency
- One in five local high school students drop out of school before graduation and two in five do not graduate on time

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Project objectives

- To engage the Richmond community as partners in ranking locally important social and environmental contributors to health outcomes and disparities
- Establish priority issues of importance to the Richmond community
- Engage community residents
- Build trusting relationships with community partners
- Promote community capacity to assess and address health priorities
- Build avenues of two-way communication between the university and the community

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□Motivations and Expectations

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Motivations and Expectations

□ Residents were hopeful that this project would finally provide a sense of ownership

□ Residents joined the team hoping for some concrete, positive changes in the community

□ However, there was a prevailing sense of skepticism and disappointment from previous projects that hadn't delivered on their promises

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Hoping for a sense of ownership

Many residents on the team had been involved in community projects before, only to feel sidelined somewhere along the way or left in the dark.

☐ *But we've always talked about our community; captured, recaptured time and time again. However we participate is fine, but I have a problem with this process. What happens when we give it? We first own it so we can give it. We don't get anything in return. We see this happen so many times, it makes it seem that it didn't matter, what we gave, and our voice doesn't matter.* (meeting 1)

☐ *I've worked with ... many different organizations who want to hear the residents, but we as a community don't know what's going on.* (meeting 1)

☐ *There needs to be a "sense of ownership" and working with this project will empower and give a "sense of ownership.* (meeting 1)

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Hoping for positive changes

☐ *I want this team to make sure people get what they need... families need to get somewhere.* (meeting 1)

☐ *It's just I want to see something positive come out of this and not something negative. I want people to know... .'Okay, well I can call this hotline or I can call this intervention, or I can have this service or I can call [this person] or I can call whomever.' I just want something good to come out of it. I don't want it to be used as a negative research, you know.* (meeting 5)

☐ *Everybody was invested some kind of way with this project prior to the project even starting. So everybody, I'm not going to say had their own visions of how they wanted it, the outcome to be, but everybody did have a vision of what the outcome is going to be.* (interview)

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Skepticism – will it get any better?

Team members expressed frustration and doubt because of the many efforts, both research and services, that have been undertaken without a sense of change for the better.

- □ *So many different groups are working with us, but none are working together so we don't see anything coming from it.* (meeting 1)

- □ *We keep having conversations with stakeholders, but how can they help me, sustain me as a resident and parent…we give the best we have, but what do we get in return?* (meeting 1)

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□Challenges

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Challenges

- Continued skepticism
- How to portray the community:
  - Fear of negative portrayals
  - Focusing on assets vs. challenges
  - Secrecy vs. transparency
  - Fear of program cuts
- Building trust in each other
- Building trust with the community
- Building trust in the process

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Continued skepticism

As residents become more comfortable with who is around the table, they still might not fully understand the scope and purpose of the project:

- *Why are you all collecting the information? What databases are going to be storing? For whose eyes? How long? What can be pulled out of there? What can't be pulled out of there? And who else could use this research that we're doing now? What other organizations could use this for their own motives, for their reasons?* (meeting 5)

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Fear of negative portrayals

- *I'm just kind of fearful. I'm fearful that if we get too much of the negative... It may not even happen. I may be like far ahead of myself, but I'm just fearful of the hurtful information of how it can come back.* (meeting 5)

- *I was just gon' say I think we all have to understand, just within the Black community in general there's a fear of us putting our business out there, and it's valid. Like I agree with that, so I do have my own personal issues, but I think it's gotten so far gone that we have to look past some of that, and having people understand, regardless of whether this study is going to happen or not or it did not happen, some of the issues that are going on in this community are going to change regardless. The question here is, how much does the community sort of weigh in on it? And I understand your fear with not wanting things to look a certain way.* (meeting 5)

- *Let's just focus on how can we take the voices that want to be heard and move them along, instead of the negative so much. There's a lot of positive. Let's take the positive and run with it.* (meeting 20)

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Focusing on assets vs. challenges

Throughout our project, people questioned whether we should focus on assets or challenges. During a focus group practice, team members said:

- *I'll tell you, the other thing is when we really spend so much time focusing on what the problems are and the issues are, I'm a tell you, what it does is, it starts draining the person, take the energy out.* (meeting 8)

- *But it's important though that we capture what is working, what is good, what are the strengths, what are the assets? I think it's really important that we have a focus on that, otherwise this is going to be a real hard process for 90 minutes.* (meeting 8)

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Secrecy vs. transparency

□ *These are issues we have we need to address. Who gon' help us? We got to stop the whispering, 'cause it's not getting nothing done. (meeting 2)*

□ *Well you know I would love to be able to go to bed every night and everything's chipper and rosy, but what this research is with the people is to give, you know put a little flashlight on the dirt too. No sense in leaving the dirt up under the rug. I'm not going to put my name on all the negative. No, I'm not, but I'm not gon' put no sugar on it .. 'cause somebody don't need no sugar... But I want to sleep at night and I promise you I'm not gon' put on airs... (meeting 5)*

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Secrecy vs. transparency (cont)

□ *And explain it to people that there does have to be a certain level of honesty and transparency for us to know where we are... because when we talk about the health disparities and people in this community viewing themselves as healthy, it may be because they don't want people to look at them as unhealthy, but... if everything is glamorized, then certain agencies and services are not going to make their way here. (meeting 5)*

□ *You can't shelter or sugarcoat that because if they don't know then that means they're gonna draw their own conclusions. Because when we say survival, survival means something different from what an outside person would think survival would mean... I know we don't want to have that dark cloud over our community and our residents in the projects.. but if that's what it is, if people saying they don't feel safe because of violence, we have to say that the people saying they don't feel safe because of violence. That's the way they can get the help that they need. But if we try to make it seem like 'it's not that bad' because we don't want people to know then we actually will be hurting the community more than helping the community. (interview)*

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Fear of program cuts

Residents in this community were fearful that any negative evidence might be used to cut programs and funding.

☐ *One of the things that we can do is stay away from saying the bad things, you know 'cause when you hear of a bad thing, then automatically you're going to start to thinking 'Take stuff out. Take this away. Take that away' 'cause it's a bad thing.* (meeting 5)

☐ *…It's going to slide across somebody's desk eventually and the first thing that this person is gon' do with it is to look at the bad things. So if you make it look like 'Okay, well this isn't a bad thing. This is just a result of the lack of something else.'* (meeting 5)

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Building trust in each other

Despite the many challenges we faced, gaining trust in each other came relatively easy, even though most members of the team did not know each other at the start.

☐ *I think there is a lot of trust. I think it has increased since we've been a team. I think we have a lot of respect for one another and each other's opinions, which is why we can agree to disagree now versus going back and forth constantly.* (interview)

☐ *I'd say it (trust) increased because as time went on we got to know each other so we know what to expect from each other. (interview)*

☐ *We all sit at the table and we all have the same reciprocity.* (interview)

Trust in the group was supported by clear group principles, being supportive of each other, listening, showing respect, sharing roles and responsibilities, becoming familiar with each other, and a strong sense that we constituted a team.

Providing meals and paying team members was a major part in building trust through respect and cultural competency.

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Building trust with the community

- This process involves interfacing with the community and building trust.
  - In many ways, we needed more communication with the community built into the process.
    - We published an article in the community newsletter
    - We planned some community events that never came to fruition
  - In some ways we succeeded:
    - By having residents do outreach, recruitment and data collection.
    - By reporting findings back to the community.

  Working with the community helped decrease some of that distrust. It's a work in progress, but it will forever be a work in progress. So we acknowledge it and own it and work to dispel it as much as we can.

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Building trust in the process

Building trust in the process was harder, in large part because we had to teach the process as we went along.

- *That's the frustration for everybody, you don't always see what you're building. But as time goes on you see what you're building. Cause that's the nature of the process and that's why the frustration sets in.* (interview)

- *I don't think I ever got my question answered. After the end of this what was going to be the outcome? Was it going to be a center that comes? More funding? What is it? And I never kind of got that.* (interview)

Sometimes there was a level of frustration that the research process takes time and residents wanted to get to the action.

- *We need some action and some solutions. I got frustrated, because it's like 'Oh my goodness, are we really going to waste this time again with the problems, what the system did, and policies?' Okay, we know all of that.* (Interview)

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□Growth

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Growth

- □ Becoming comfortable working together
- □ Getting energized by getting the work done
- □ Learning new skills
- □ Gaining new understanding
- □ Shifting responsibilities
- □ Gaining a voice
- □ Giving the community a voice
- □ Gaining a sense of ownership
- □ Becoming and advocate
- □ Rewarding experiences
- □ A sense of accomplishment

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Becoming comfortable working together

□ *Social scientists are very objective and they just report the data, but not really interested in doing anything about it, whereas the folks that are around this table are not necessarily so.* (meeting 5)

□ *Initially I didn't know who everyone was, so I tend to hold on to things until I got a feel for what was going on. Now it doesn't even matter, I just say what I want to say.* (interview)

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Energized by getting the work done

Our team did a lot of focus groups in a short time. In debriefing, team members were energized about how well everyone did.

□ *It was amazing to watch how 'Okay, well you moderate this one, and what about this one? Can you come over here and do this one?' I mean everyone was just like 'Sure. Whatever you need.'* (meeting 10)

□ *And to watch our coworkers work, it was amazing. It was more respect to watch them, to see them step up. To see them know the subject and, like he said, knock it out the park.* (meeting 10)

□ *In my humble opinion, I think that they [service providers who participated in focus groups] were impressed with what we brought to the process ...I think they were generally taken aback in a very good way that here there's this group of people in the community that are working on research in the kind of way that we are and it's like 'Where have these people been?'* (meeting 10)

□ *It's amazing that this group, it brings such a dynamic of thought. It is, because y'all did this transcript in a little bit of time and came out with such a thought-provoking conversation.* (meeting 12)

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Learning new skills

Residents discussed the new skills they valued from this project:

- Facilitating focus groups
- Coding transcripts
- Interviewing
- Presenting
- Understanding parts of the research process, such as sampling and the role of the IRB
- Computer skills, such as powerpoint
- Networking
- New interests

- *Just getting those one-on-one interaction skills with people and help sharpening skills in my community...*

- *I never in a million years would have expected to gain what I gained from it on a team level or on a personal level.*

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Gaining new understanding

- *I've become aware of a whole lot more situations and circumstances as to why things are the way they are and how to possibly fix those in some circumstances. Things that I would not have probably cared about or given a second thought before...* (Interview)

- *Now, I actually see the neighborhoods completely totally different. And I grew up in them all my life. And I just found that to be one of those WOW moments... It caused me to look a whole lot different, to have a little bit more understanding, a lot more open-mindedness.* (interview)

- *I used to wonder just like so many residents in there, about how could we go about getting more information to the community about different resources, different service providers. Why isn't this being done, why isn't that being done? Who do we go to? Who do we talk to? How do we got some of these materials? All these questions that I had in my head was answered just by me being part of this team.* (interview)

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Shifting responsibilities

Team members conveyed a sense of becoming more aware of their, and the community's, responsibilities for taking on issues. The focus of questioning shifted from 'what are you going to do' to 'what are we going to do'.

□ *One of the things that I really actually learned is exactly how lost and confused we are. We can't very well sit (well I know I can't) and use the same excuses …* (meeting 20)

□ *Somebody got to own it. And not only somebody got to own it, somebody has to step up and make the community own it.* (interview)

□ *The cultural competency committee was very useful because we got a chance to kind of review the questions that were going to be asked to make sure they weren't going to offend anybody before we just put questions out there. It kind of was like, if I was asked this question how would I feel? Would I feel like it was just going for information or was it coming from a concerned place looking for information, or was it going to pull out derogatory information? It was good to have that experience.* (interview)

□ *I feel very committed (to the decisions made by the group). Like I own part of it too.* (interview)

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Gaining a voice

Team members expressed a greater sense of agency and possibility from participation in the project and a stronger sense of their own voices.

□ *But when I became a part of this group it just enlightened a lot of things for me… It's just given me a bigger voice. More like I could really help the people that's around me.* (interview)

□ *…I've been told if the door isn't open, no, you don't kick it down. Just maybe you sneak around the back and see if you can get in back that way. I feel like now it's a lot of things that us younger people need to make awareness, go to these City Council meetings, serve on these Boards, because the young voice is the voice that they're not hearing… So I'm feeling like I need to rally up people in my generation … we need to pick that ball up and keep it going farther, and we could be a lot different places and do a lot more things for the community…* (meeting 20)

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Gaining a voice (cont)

- *I learned that everybody in the community is an asset and everybody has skill and everybody in the community has a voice. No matter how it sounds, everybody has a voice.* (interview)

- *[At a presentation I was invited to give] every now and then I have to catch myself because I'm sitting here and I'm looking at this whole big table of people, and it's like what in the world am I doing here with these people? I might be the only one here that do not have alphabets behind their name. I might be the only one here with a felony record. I might be the only one here that's from the neighborhoods that I'm from and I have to catch myself ... [I was thinking] I'm not supposed to be here. I'm not supposed to be doing this. I'm not supposed to be talking to these people. I'm supposed to be down here and they're up here. And it forced me to get out of that type of thinking, because somebody saw fit for me to be on this side of the table. So I need to just own that.* (interview)

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Giving the community a voice

- *This is a great process... There is no way possible you can help somebody without talking to the person that you trying to help. It's not going to work...* (Interview)

- *[people who attended the focus groups] wanted to speak out and wanted people to hear their opinion and things that was going on in the neighborhood and hopefully something would come out of it... Actually, it was a lot of concerned parents and they just want to better the neighborhood for the kids.* (interview)

- *We need to focus and refocus on how we can best help the community, and I think when we do it together, it's a much easier undertaking. There are some things that we can do as individuals as far as accountability and responsibility, but we also need to give the community a voice, and this is one way, a good way to give them a voice.* (meeting 20)

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Gaining a sense of ownership

- *I come back bragging about our group all the time because it is something that I went to and somebody might would be there or I would met somebody… I always would make sure whoever I'm talking to or showing our stuff to that this is ours. We sat down and we came up with this from nothing.* (interview)

- *I'm very committed, cause like I said, we're doing work and we're bringing most of this information back and the outcome of everything will affect me as a resident and that's something that I have to take back to my community.* (interview)

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Becoming an advocate

- *I can look at the bigger picture. Now I can see, I look further than helping me…* (interview)

- *...there's more I need to learn… I guess the real learning is that when we find maybe a little piece, a little nugget, I mean to move on just that little piece. You might move it an inch, but we're making progress towards some other goals.* (meeting 20)

- *I've had neighbors, 'Hey, so what are y'all doing with that information I gave you… it's a good thing for me 'cause it's kind of made me be mindful that people are watching me and people are holding me accountable for the part that I'm doing at this table, and it makes me want to, when the end result comes out, it makes me want it to be something great.* (meeting 20)

- *I mean I think some of the stuff we won't see in our lifetime, but I do think that there are some actionable things that we can definitely do and get the ball rolling. It's like we can't change the world, but we can get the conversation started, and I think that's half the battle.* (meeting 20)

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Rewarding experiences

- *Hearing the positive, immediate feedback from the people we presented to…You know, they were satisfied with what we had did and I felt like right then and there we were asking for money or something to be built just based on that 30 minutes that we gave them, they would have made some things happen for us... I was proud of that moment. I said 'we did it.' You know, we wasn't asking for anything that day.* (Interview)

- *I think that it has given us as residents a sense of purpose, a renewed sense of commitment to helping others that we may have been losing touch with.* (interview)

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A sense of accomplishment

- *We have already done some good things. We already have gotten some good information, but we got some great ideas that can actually work in the community.* (interview)

- *It basically opened the door for me to go to the next level in my life.* (interview)

- *I've grown a lot through this. I know anything is possible regardless of what type of lifestyle you lived in the past. If you decide to walk the right walk doors will open. Personally, I never thought I would be… doing a research study. Never in my life. It's wonderful.* (interview)

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☐Meeting our goals: Work continues

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Meeting our goals: work continues

☐ Reaching out to partners

☐ Desire for action

☐ Working toward our goals

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Reaching out to partners

☐ *Explaining to people that, when this study ends, [community partner] is going to be here. So if nothing more, there is a level of support that will be here much longer than VCU. (meeting 5)*

☐ *…We need to now partner with other organizations that can help us you know, move, now that we have narrowed in on the problems, some action plans on how we can solve them. Now we need partners in the community that can help us move this train along.* (interview)

☐ *The group has come up with some very good decisions and some very good ideas but as to who's actually going to implement some of those ideas is still questionable.* (interview)

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Desire for action

☐ *I thought we would have accomplished more with this project. I thought that we would have had more action items and that we would have been able to implement those action items... I really thought that we would have actually gone that far.* (interview)

☐ *I want something to happen from all of this eight months of focus groups and interviews and meetings and arguments and discussions and people going through our recordings and transcribing and all of that. People actually took time out of their life, whether they was getting paid or whether they wasn't, to work on what we came up with and at the end I want a document or something to go on somebody's table with our names on it. I want something to come from it. We don't necessarily need no credit or anything but I just want to know that our work wasn't in vein. Something happened from that. Even if it ain't no more than a petition.* (interview)

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Working toward our goals

- *…we need to pick that ball up and keep it going farther, and we could be a lot different places and do a lot more things for the community.* (meeting 20)

- *But I got great expectations because I got confidence and faith in our team and we got some good stuff. We came up with some good small scale ideas and some larger scale ideas that we might can throw across some people's desks if they want some help.* (interview)

- *We did a major project. That was a major undertaking in a short space of time. Given the resources, I think we did pretty good... I think the group has potential to do bigger and better things given the opportunity.* (interview)

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Continuing to support CBPR

- *I think that kind of participation would elevate the university in terms of how it engages and does business with the community. I really do.* (interview)

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Thank you!

□ If you have any questions or comments, please contact:

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