Enhancing Community Engagement: Perspectives from Researchers, Community Members and Service Providers

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ABSTRACT

Purpose: Compare and contrast perspectives from Research Team Members (RT), Community Members (CM) and Service Providers/Others (SP/O) about barriers and facilitators to community engagement and participation in health research.

Methods: A cross-sectional, descriptive survey study with a convenience sample of adults who lived and/or worked in the Commonwealth of Virginia was conducted between May and July 2022. Descriptive statistics and chi-square analyses were conducted to identify similarities and differences across the three stakeholder groups.

Results: A total of 303 participants were involved in this study. In general RTs, CMs and SP/Os were similar in their responses to perceived barriers and facilitators. Still, there were five items where there was a significant association between group membership and endorsement of a barrier or facilitator. CMs were most likely to endorse the barrier that research might cause harm and the fear that one could not quit a study. Conversely, RTs were the least likely to endorse the barrier that “they don’t understand the benefit of research to society”. Among the two significant facilitators, RTs were most likely to endorse researcher training to work with diverse communities. CMs were most likely to endorse training community members to be part of the research team.

Discussion/Recommendations: Several priorities shared across all three groups as well as several divergences. To promote community trust and engagement and

diversity in research participation, academic/clinical research institutions should reward community engagement activities as part of expected tenure/work achievements and dedicate funding for researcher/community member training and community-engaged advisory boards.

BACKGROUND/PURPOSE

Rooted in the principles of equity, justice, and fairness, community-based participatory research (CBPR), also known as participatory action research (PAR) and community-partnered participatory research (CPPR), is a collaborative research approach involving the active participation of community members at each stage of the research process (Brush et al., 2020; Israel et al., 1998; Jones, 2018; Wallerstein et al., 2020). Centered on intentional relationships between academic and community partners, CBPR includes principles of co-learning, mutual benefit, and long-term commitment (Coombe et al., 2020). Through this process, researchers can identify health issues that affect communities and help develop interventions to improve health outcomes, empower community members by involving them in the research process by giving them a voice in decision-making, and build trust between by establishing partnerships and mutual respect (Wallerstein et al., 2020).

Researchers and health professionals should engage with communities at the outset of research for many reasons. For example, access to the diverse perspectives and expertise of their community can increase the value and efficiency of research (Greenhalgh et al., 2019) as well as the relevance and impact of research (Tambor et al., 2018). Indeed, inclusion of the community can foster trust and transparency in the research process and make it more likely that the findings improve health equity and help solve problems that matter most to the community (Skewes et al., 2020). In addition, building trust can improve the diversity of study participants and aid in recruitment (Tilley et al., 2021). Decades of research on community-based participatory research have demonstrated that the association between a community and the health researchers can be a rewarding and productive experience, enhances community health, and generates a beneficial and sustainable impact (Kaiser et al., 2017; Lewis et al., 2016; Tambour et al., 2019, & Wallerstein et al., 2020).

Despite the clear value of community engagement, a recent systematic review of clinical trials found that less than 1% of clinical trials engage patients in the research process and that engagement of minorities occurred only about a quarter of the time (Fergusson et al., 2018). According to Clark et al. (2019), increasing diversity in research "in an effective, sustainable, and scalable way remains a mutual challenge" (p. 150). Their team conducted a qualitative study with key stakeholders (i.e., patients, researchers, and physicians) and identified five critical barriers to minoritized groups' engagement in clinical trials: (1) mistrust (2) lack of comfort with the clinical trial process; (3) lack of information about clinical trials; (4) time and resource constraints associated with participation; and (5) lack of clinical trial awareness. The team then developed a "multistakeholder roadmap" with a set of recommended strategies (facilitators) to specifically target the barriers (Clark et al., 2019, p. 160). For many investigators, however, there are also organizational and professional barriers to building and sustaining these relationships, the result of which is an underrepresentation of racial and ethnic minorities in clinical trials (Konkel, 2015; McCarthy, 1994).

While researchers have acknowledged the many barriers to involving community members in the research process, there is relatively limited information in the literature about practical approaches to community engagement throughout the scope of a research study, with most resources focusing on community engagement only at the start of the research process (Manafo et al., 2018). Without guidance for all stages of the study, researchers may exclude the community when their input is still needed. In one study, researchers reported that community engagement requirements by funders may not always be productive based on the stage of the study or respectful of community members' time (Han et al., 2021). Participants in that study also reported that conflict between the researchers and community members is a common part of a community-engaged research process, often attributed to misaligned research priorities between researchers and community partners and a lack of clear communication about study results (Han et al., 2021). Gaining a better understanding of the barriers and facilitators to community engagement at all stages of the research process can facilitate more productive and sustainable researcher-community partnerships and potentially increase diversity in participant volunteers (Clark et al., 2019).

Since 2012, the Patient-Centered Outcomes Research Institute (PCORI) has required grant awardees to include patient/stakeholder engagement in their projects (Heckert et al., 2020). However, this requirement remains an ongoing challenge for health researchers (Samuel et al., 2018). To better understand the barriers and facilitators to engagement, Heckert et al. colleagues (2020) retrospectively examined two sets of data: their investigator reports and partner surveys. The team found three significant challenges: the need for increased infrastructure support; building authentic associations; and maintaining mutually respectful and empowering associations.

Mann et al. (2018) also retrospectively surveyed patient/public contributors and researchers involved in their study. They found that intentionally including patients and public partners in their randomized controlled trial positively impacted the study and the investigators' and the partners' self-efficacy. Patient/public respondents shared that they enjoyed being part of the study but wished they had been included earlier in the study design process. Conversely, the researchers in the study noted that there could be challenges to working with community partners who lack an understanding of the constraints inherent to the research methodology and processes. While informative, the study included a very small group (N=11). More recently, Morales et al. (2023) noted that in order to foster community engagement research teams should undertake efforts to better understand both the “unique local realities” as well as the expertise of the communities they serve. The lack of research in this area limits the ability of health researchers to design effective strategies to engage communities in research efforts and direct funding efforts toward meaningful engagement. Robust community engagement in some cases may involve a Community Engaged Advisory Board (CEAB) that provides research review for the community, access to a specialized research population and oversight of community involvement in research studies with the help of a community liaison (Halladay et al., 2019). In return, researchers can provide direct benefits to the community outside of recruitment for a study, such as health education and social resources to the community (Mitchell et al., 2020).

The National Institutes of Health Clinical and Translational Science Awards (CTSA) program aims to promote knowledge translation by engaging patients and communities in the research process (National Center for Advancing Translational Sciences, 2023). This study’s purpose was to assist institutions in the Commonwealth of Virginia in their efforts to foster community engagement in health research by surveying key stakeholder groups (i.e., research team members, community members, community service providers and others) in order to better understand their perceptions on the barriers and facilitators to community engagement and participation in research. The study’s specific objective was to identify similarities as well as differences among the three groups' perceptions on selected barriers and facilitators.

METHODS

The study was a mixed-methods cross-sectional survey design using a convenience sample of adults invited to anonymously complete an online survey. Findings reported here focus on the quantitative portion of the survey.

SURVEY INSTRUMENT

A survey instrument was developed to elicit study participants’ perceptions about the barriers and facilitators to community engagement and participation in health research. A review of the literature was first conducted to identify known barriers and facilitators to community engagement with health/clinical research. A draft survey of selected key barriers and facilitators was then developed. The team then consulted with several academic colleagues with expertise in nursing, public health, and social behavioral research as well as members of the integrated Translational Health Research Institute of Virginia (iTHRIV) to further refine the survey. Next with community engagement in mind, the study's draft aim, objectives, and survey were shared with members of a Community-Engagement Studio, provided by iTHRIV colleagues. The research team discussed the study purpose and recruitment plan with the studio members, and then reviewed the planned survey questions. The team took notes and incorporated the studio members' feedback into the survey design and study protocol. The final survey included several demographic questions including (group membership category, region of Virginia, age, education level, gender, race, ethnicity, and experience with research), along with a series of quantitative questions to measure participants' priorities and perceptions related to community-engaged research. The format for the questions included multiple choice, Likert scale (e.g., Extremely, Very, Somewhat, Slightly, Not At All) or a "Select All That Apply". The survey also included several open-ended questions where participants could free-text their answers. The survey was created in REDCap® electronic data collection tool (Harris et al., 2019; Harris et al., 2009) and was estimated to take participants approximately 10-15 minutes to complete.

PARTICIPANTS AND PROCEDURES

The study was open to adults ages 18 and over who self-identified as living and/or working in the Commonwealth of Virginia and could read and write in English. Potential participants were invited via emails and flyers that included a QR code as well as web-link to the study's REDCap® survey. Invitations were also shared via institutional listservs and announcements, social media, community meetings (online and/or in person), and/or organizational presentations. Study team members encouraged recipients to share the flyers and study information emails with community organizations and adult individuals about the opportunity to participate in the study. Data collection occurred for nine weeks during the late spring-early summer of 2022. Study data were collected and managed using REDCap® electronic data capture tool (Harris et al., 2009; Harris et al., 2019) that was hosted at our institution.

ETHICAL CONSIDERATIONS

The anonymous survey was designed so that no individually identifiable demographic data were collected. At the outset of the online REDCap® survey, participants were provided with an information sheet describing the study's purpose, the inclusion and exclusion criteria, the benefits and risks of voluntarily participating and the alternative to not participate. They were informed that answering questions on the survey would serve as their consent to participate in the study and that they were affirming that they meet inclusion criteria. The study was reviewed and approved by the Inova Health System Institutional Review Board and deemed exempt.

STATISTICAL ANALYSIS

Data analysis included descriptive statistics (frequencies/percentages) of the participants' survey answers. Due to the nominal/ordinal levels of the data, chi-square analyses were conducted to identify any group-level differences among the three groups (i.e., researchers, community members, and service providers/others). Statistical significance was set at p<.05. All analyses were conducted using SPSS version 28.

RESULTS

A total of 321 surveys were collected across the Commonwealth of Virginia. Of those, 16 were excluded because the respondent did not indicate their group membership category and two were excluded because even though they indicated their group membership category, they provided no additional answers to the survey. The final sample size included in the analyses was 303 participants (94% of the surveys collected). Of note, not all participants answered all sections of the survey, but the responses they shared were retained in the analyses.

PARTICIPANT DEMOGRAPHICS

Among the 303 participants, more than half (n=156), identified as community members (CM), 66 identified as members of a research team (RT), 62 identified as community service providers (SP/O), and 19 identified as "Other" (O). Given the small number of "Other" participants, their responses were combined with the SP/O group as (SP/O). The sample as a whole was majority female, white, 40 years or older, and had some graduate-level education or degree. Most of the respondents came from the Northern Virginia area (n=180), followed by the Roanoke area (n=46), Charlottesville area (n=35), other (n=21) and Wise area (n=13). Eight respondents did not indicate their institutional region. Given the small regional numbers (with the exception of the Northern Virginia area), the decision was made to analyze the sample as a whole and not separate by region. See Table 1 which provides the demographics of three different groups and the sample as a whole.

Table 1

Demographics of the Sample

Demographic	Research Team (RT)	Community Members (CM)	Service Providers/ Others (SP/O)	Full Sample
	n (%)	n (%)	n (%)	n (%)
Region				
Northern	36 (54.5%)	100 (64.1%)	44 (54.3%)	180 (59.4%)
Roanoke	14 (21.2%)	18 (11.5%)	14 (17.3%)	46 (15.2%)
Charlottesville	15 (22.7%)	13 (8.3%)	7 (8.6%)	35 (11.6%)
Wise	0 (0.0%)	11 (7.1%)	2 (2.5%)	13 (4.3%)
Other	1 (1.5%)	9 (5.8%)	11 (13.6%)	21 (6.9%)
Missing	0 (0.0%)	5 (3.2%)	3 (3.7%)	8 (2.6%)
Age in Years				
18-19	0 (0.0%)	1 (0.6%)	0 (0.0%)	1 (0%)
20-29	9 (13.6%)	6 (3.8%)	1 (1.2%)	16 (5.3%)
30-39	9 (13.6%)	25 (16.0%)	16 (19.8%)	50 (16.5%)
40-49	15 (22.7%)	26 (16.7%)	10 (12.3%)	51 (16.8%)
50-59	16 (24.2%)	27 (17.3%)	23 (28.4%)	66 (21.8%)
60-69	4 (6.1%)	25 (16.0%)	13 (16.0%)	42 (13.9%)
70+	0 (0.0%)	24 (15.4%)	6 (7.4%)	30 (9.9%)
Missing	13 (19.7%)	22 (14.1%)	12 (14.8%)	47 (15.5%)
Education Level				
High School	0 (0.0%)	0 (0.0%)	1 (1.2%)	1 (0.3%)
Some College	0 (0.0%)	12 (7.7%)	6 (7.4%)	18 (5.9%)
College Degree	16 (24.2%)	41 (26.3%)	18 (22.2%)	75 (24.8%)
Some Graduate	2 (3.0%)	14 (9.0%)	5 (6.2%)	21 (6.9%)
Grad Degree	35 (53.0%)	64 (41.0%)	38 (46.9%)	137 (45.2%)
Missing	13 (19.7%)	25 (16.0%)	13 (16.0%)	51 (16.8%)
Racial Category				
Asian	3 (4.5%)	4 (2.6%)	1 (1.2%)	8 (2.6%)
Black	2 (3.0%)	16 (10.3%)	6 (7.4%)	24 (7.9%)
White	39 (59.1%)	106 (67.9%)	59 (72.8%)	204 (67.3%)
Latino	2 (3.0%)	1 (0.6%)	0 (0.0%)	3 (1.0%)
Other	0 (0.0%)	1 (0.6%)	0 (0.0%)	1 (0.3%)
PNA[1]	4 (6.1%)	6 (3.8%)	0 (0.0%)	10 (3.3%)
2+ Race	4 (6.1%)	2 (1.3%)	2 (2.5%)	8 (2.5%)
Missing	12 (18.2%)	20 (12.8%)	13 (16.0%)	45(14.9%)
Gender				
Female	39 (59.1%)	112 (71.8%)	54 (66.7%)	205 (67.7%)
Male	12 (18.2%)	21 (13.5%)	14 (17.3%)	47 (15.5%)
NB	0 (0.0%)	1 (0.6%)	1 (1.2%)	2 (0.7%)
Other	1 (1.5%)	0 (0.0%)	0 (0.0%)	1 (0.3%)
PNA	1 (1.5%)	1 (0.6%)	0 (0.0%)	2 (0.7%)
Missing	13 (19.7%)	21 (13.5%)	12 (14.8%)	46 (15.2%)
Total	66	156	81	303

[1] PNA=Prefer Not to Answer

PARTICIPANT RESPONSES

BELIEF ON WHO BENEFITS THE MOST FROM RESEARCH

Participants were first asked the question, "Who benefits the most from research?", and across all three groups more than two-thirds of the respondents believed that society benefits the most. Of note, CMs were more likely to answer "Don't Know" than the other two groups (10% vs. 5%). A chi-square test of independence, however, found no significant association between the participant's group membership and their selected response (Table 2).

Table 2
Group Membership x Who Benefits the Most from Research

Who	RT		CM		SP/O		Full Sample	
Benefits	n	(%)	n	(%)	n	(%)	n	(%)
Researchers	13	(19.7%)	26	(16.7%)	10	(12.3%)	49	(16.2%)
Patients	4	(6.1%)	2	(1.3%)	2	(2.5%)	6	(1.9%)
Society	46	(69.7%)	112	(71.8%)	65	(80.2%)	223	(73.6%)
Don't Know	3	(4.5%)	16	(10.3%)	4	(4.9%)	23	(7.6%)
Total	66		156		81		303	

RESEARCHERS ENGAGING WITH COMMUNITY: LEVEL OF INTEREST

Participants were then asked two belief statements about researchers' interest in having community members help them with their studies. The 4-point Likert scale ranged from (Strongly Agree, Agree, Disagree, Strongly Disagree). However, due to low expected cell sizes, the participants' responses were collapsed to Agree vs. Disagree. Help with Designing Research Studies: Among the 292 participants who answered, the sample was generally split, but more disagreed than agreed (53% vs. 47%). A chi-square found no significant association between group membership and agreement. (X^2=2.735, df (2), p=.255). Help with Recruiting Research Participants: Conversely, among the n=275 participants who answered, a large majority of the sample (92%) agreed that researchers would like the community's help with recruitment and across all three groups, over 90% of participants agreed. Again, there were no significant association between group membership and agreement (X^2=.906, df (2), p=.636).

RESEARCH-RELATED ENGAGEMENT WITH THE COMMUNITY

The next set of questions asked participants to indicate on a five-point Likert scale the level of importance of eight different researcher-related engagement factors. Choices ranged from: Extremely Important; Very Important; Somewhat Important;

Slightly Important; or Not at All Important. Again, due to several cells having less than five expected cases, participants' responses were dichotomized to those who thought a factor was extremely/very important vs. those who only found the factor to be somewhat, slightly, or not at all important (Table 3).

Table 3
Importance of Researcher Engagement Strategies (Group Membership x Percentage Who Responded Extremely/Very Important)

Engagement Strategy		RT	CM	SP/O	
	N	n (%)	n (%)	n (%)	p-value
Knowledgeable of Community	278	56 (93.3)	130 (90.3)	66 (89.2)	.698
Trained to Work with Diverse Communities	277	55 (93.2)	127 (88.8)	71 (94.7)	.291
Institutional Resources to Recruit a Diverse Study Population	280	54 (90.0)	130 (89.7)	68 (90.7)	.972
Institutions Offer Opportunities to Collaborate with Community Members	277	45 (76.3)	122 (84.1)	64 (87.7)	.204
Discuss Their Work with Community	280	42 (70.0)	115 (79.3)	66 (88.0)	.035
Improve Health of Community	279	46 (78.0)	109 (75.2)	60 (80.0)	.709
Advertise in the Local Communities	278	48 (80.0)	101 (70.6)	65 (86.7)	.023
Improve Participant health	280	32 (53.3)	77 (53.1)	49 (65.3)	.192

Across all eight research-related engagement factors, the majority of study respondents ranked them as extremely/very important. The most highly endorsed factors were those related to knowledge of the local community, training to work with diverse communities, and institutional resources to recruit diverse study populations. The least endorsed factors were those asking if research should directly benefit the research participant and/or community health. Chi-square analyses on each factor to assess the association between group's membership and the importance of the factor, found significant differences for two of the eight factors. First, there was a significant association between group membership and the importance of researchers discussing their results with their local community: Researchers were less likely to rate it as extremely/very important (70.0%) than community members (79.3%) or SP/Os (88.0%) (X^2=6.68, p=.035). Second, there was a significant association between group membership and the importance of research teams advertising in the local community about the research projects they are doing: Researchers were more likely to rate it as extremely or very important (80.0%) than community members (70.6%) or SP/Os (86.7%) (X^2=7.53, p=.023).

BARRIERS TO COMMUNITY ENGAGEMENT IN HEALTH RESEARCH

We next sought to better understand participants' beliefs about the barriers and facilitators to community engagement in health research. Participants were first prompted to share their perceptions on those barriers which might explain why community members sometimes don't participate in research studies. The list of barriers was divided among three main categories: knowledge, concerns, and challenges. Among the 303 participants in the study, we noted that n=27 did not affirmatively answer any further questions on the survey, so they were not included in these last sets of analyses.

KNOWLEDGE-RELATED BARRIERS

The two most highly endorsed knowledge-related barriers (with more than two-thirds of SP/O and RT and more than three quarters of CM) were lack of trust in the researcher and/or institution and not thinking the research will benefit them directly. The two lowest endorsed knowledge-related barriers were not thinking the research is important and preferring to stick with "standard/current healthcare treatments". Chi-square analyses on the six knowledge-related barriers found one significant association between participant group membership and the statement, "They don't understand the benefits of research for society." Research team members were least likely to endorse this factor (55.9%), with 70.6% of community members believing this to be a barrier, and a very large proportion of community-service providers believing a lack of understanding was a barrier (87.8%) (X^2=16.93, p<.001). See Table 4.

Table 4

Percentage of Group Endorsement of Knowledge-Related Barriers

Knowledge Barrier	RT	CM	SP/O
	n (%)	n (%)	n (%)
They don't know what research is.	34 (57.6%)	67 (46.9%)	35 (47.3%)
They don't understand the benefits of research for society.*	33 (55.9%)	101 (70.6%)	65 (87.8%)
They don't think it will benefit them directly.	42 (71.1%)	111 (77.6%)	53 (71.6%)
They don't trust the researcher and/or the institution.	43 (72.9%)	110 (76.9%)	51 (68.9%)
They don't think the research is important.	20 (33.9%)	59 (41.3%)	33 (44.6%)
They would rather stick with "standard/current" healthcare treatments.	25 (42.4%)	50 (35.0%)	26 (35.1%)
Total	59	143	74

Note: N=276; * p<.05

CONCERN-RELATED BARRIERS

Among the six concerns-related barriers, the two highest concerns across all three groups were: "They think research might harm them" and "They don't want to be treated like a 'specimen". Researchers were more likely to endorse CM concern about being "treated like a specimen" (85%) than CMs (78%) or SP/O (62%). Between 40-50% of the respondents across all groups endorsed concerns related to prior "bad experience" with research and/or institutions. Less than half of respondents had concerns regarding support persons not wanting a CM to join a study or CMs being worried about quitting. Chi-square analyses of the concerns-related barriers found two significant associations between group membership and barrier endorsement. Nearly half (48%) of CM respondents endorsed the worry that a CM won't be able to quit compared to approximately a third of RTs (32%) and SP/Os (34%) (X^2=6.59, df 2, p=.037). Conversely, RTs (64%) and SP/Os (62%) were less likely than CMs (78%) to endorse a fear of research-related harm (X^2=7.03, df 2, p=0.30).

Table 5

Percentage of Group Endorsement of Concern-Related Barriers

Barrier Concern	RT	CM	SP/O
	n (%)	n (%)	n (%)
They think research might harm them.*	38 (64.4%)	111 (77.6%)	46 (62.2%)
They or someone they know had a bad experience in the past with research.	29 (49.2%)	66 (46.2%)	40 (54.1%)
They or someone they know had a bad experience in the past with the institution.	24 (40.7%)	67 (46.9%)	38 (51.4%)
They don't want to be treated like a "specimen".	50 (84.7%)	107 (74.8%)	55 (74.3%)
They don't think their family/partner would want them to be in the study.	14 (23.7%)	40 (28.0%)	17 (23.0%)
They are worried they won't be able to quit being in the study if they don't like it.*	19 (32.2%)	69 (48.3%)	25 (33.8%)
Total	59	143	74

Note: N=276; * p<.05

CHALLENGE-RELATED BARRIERS

The final set of barriers included six "Challenges" to community participation in research. The two highest selected barriers across all three groups were: "They can't take time from work to participate" and "They have too much other stress in their life (example family or job)". The majority of participants across all groups identified transportation, distance, and being paid enough as barriers. The least-endorsed challenge-related barrier was "They have participated in too many studies already" with less than 10% of participants identifying this barrier as an issue. There were no significant associations between group membership and barrier endorsement. See Table 6.

Table 6

Percentage of Group Endorsement of Challenge-Related Barriers

Barrier Challenge	RT	CM	SP/O
	n (%)	n (%)	n (%)
They have transportation challenges.	43 (72.9%)	94 (65.7%)	57 (77.0%)
They can't take time off from work to participate.	49 (83.1%)	122 (85.3%)	65 (87.8%)
They have too much other stress in their life (example family or job).	47 (79.7%)	122 (85.3%)	58 (78.4%)
They don't get paid enough for their time.	32 (54.2%)	77 (53.8%)	41 (55.4%)
They have participated in too many studies already.	6 (10.2%)	14 (9.8%)	6 (8.1%)
The research site is too far from their home or work.	35 (59.3%)	94 (65.7%)	41 (55.4%)
Total	59	143	74

Note: N=276; * p<.05

FACILITATORS TO COMMUNITY ENGAGEMENT IN HEALTH RESEARCH

We then asked the participants to share their perceptions on what "could help increase community members participation in research." There were three sets of facilitators: connection, inclusion, and investment strategies. Again, we noted a small, but further drop of six respondents (N=269).

CONNECTION-RELATED FACILITATORS

Among the six connection-related facilitators, the two most highly endorsed were related to researcher communication with the community: Across all three groups, more than 80% of respondents believed it could help if researchers "talk to the community groups about how research can benefit patients and communities" and three-quarters or more across all three groups endorsed the statement that "researchers make sure to report their findings to the community". Interestingly, the least endorsed statement was "Someone on the research team shares the same race, ethnicity, and/or culture as the community". Whereas more than 75% of RTs endorsed this statement, only 64% of CMs and 61% of SP/Os indicated it could help. Chi-square analyses on the six connection-related facilitators found one significant association between the statement "researchers are trained to work with diverse communities" and participant group membership. RTs were much more likely than the other two groups to endorse this statement (91% vs. 75% and 66%) (X2=11.40, p=.003). See Table 7.

Table 7

Percentage of Group Endorsement of Connection-Related Barriers

Connection Facilitator	RT	CM	SP/O
	n (%)	n (%)	n (%)
Researchers go to the activities in the community where they conduct research	43 (74.1%)	97 (69.3%)	48 (67.6%)
Researchers know about the neighborhoods/culture where community members live	45 (77.6%)	112 (80.0%)	52 (73.2%)
Researchers talk to the community groups about how research can benefit patients and communities	52 (89.7%)	122 (87.1%)	57 (80.3%)
Someone on the research team shares the same race, ethnicity, and/or culture as the community	45 (77.6%)	89 (63.6%)	43 (60.6%)
Researchers are trained to work with diverse communities*	53 (91.4%)	105 (75.0%)	47 (66.2%)
Researchers make sure to report their findings to the community.	51 (87.9%)	112 (80.0%)	53 (74.6%)
Total	58	140	71

N=269; *p <0.05

INCLUSION-RELATED FACILITATORS

There were four inclusion-related facilitators which centered around the principles of CBPR. The two most highly endorsed facilitators were “Researchers match their project ideas with the needs of the community” and “Researchers develop an ongoing community advisory board to help with study design and recruitment” with more than 70% of respondents in each group endorsing these statements. Only a small majority of respondents felt endorsed it would help to have “researchers work with a community group in designing a study” or have “Researchers and community members attend trainings together on the value of having community members work on research projects”. Chi-square analyses found no significant associations between the inclusion-related facilitators and group membership. See Table 8.

Table 8

Percentage of Group Endorsement of Inclusion-Related Facilitators

Inclusion Facilitator	RT	CM	SP/O
	n (%)	n (%)	n (%)
Researchers match their project ideas with the needs of the community	46 (79.3%)	113 (80.7%)	54 (76.1%)
Researchers work with a community group in designing a study	34 (58.6%)	91 (65.0%)	43 (60.6%)
Researchers develop an ongoing community advisory board to help with study design and recruitment	45 (77.6%)	99 (70.7%)	52 (73.2%)
Researchers and community members attend trainings together on the value of having community members work on research projects	33 (56.9%)	74 (52.9%)	43 (60.6%)
Total	58	140	71

N=269; *p <0.05

INVESTMENT-RELATED FACILITATORS

The final set of facilitators were related to investment. Of the four statements, the most highly endorsed was that “researchers have money in their budget to increase recruitment of a diverse group of participants” with nearly 75% of respondents in each group endorsing this statement. There was similar agreement across all three groups for “researchers offer skills training” – with 65% or more endorsing this investment. The least-endorsed was creating “Speakers Bureaus or videos”. Interestingly, there was a significant divergence in group response rates to the statement “researchers hire community members to be part of the research team”: 78% of CMs endorsed this statement, compared to only 66% of RTs and 69% of SP/Os. Chi-Square analysis found a significant association between group membership and endorsement of this statement (X2=6.86, p=.032). See Table 9.

Table 9

Percentage of Group Endorsement of Investment-Related Factors

Investment Facilitator	RT n (%)	CM n (%)	SP/O n (%)
Researchers have money in their budget to increase recruitment of a diverse group of participants.	45 (77.6%)	104 (74.3%)	54 (76.1%)
Institutions create Speakers Bureaus or videos.	32 (55.2%)	74 (52.9%)	37 (52.1%)
Researchers offer skills training.	39 (67.2%)	91 (65.0%)	49 (69.0%)
Researchers hire community members to be part of the research team.*	38 (65.5%)	109 (77.9%)	44 (62.0%)
Total	58	140	71

N=269; *p <0.05

DISCUSSION

This study identified both similarities and differences among research teams', community members' and service providers/others' perceptions of barriers and facilitators to community engagement and participation in health research. While several studies have reported on community members' and researchers' perceptions on this issue (Clark et al., 2019; Fielding-Miller et al., 2022; Han et al, 2021; Heckert et al., 2020, Mann et al., 2018), to our knowledge none has quantitatively surveyed stakeholders using the same set of survey questions. In general, the RTs, CMs and SP/Os in this study were similar in their responses to perceived barriers and facilitators. Still, there were five items where there was a significant association between group membership and the endorsement of a barrier or facilitator. These significant differences in perceptions, highlight the importance of understanding and addressing differences in order to foster effective community engagement and participation in health research.

One of the key findings of this study was that it is vital to all groups that researchers know the local community, receive training on working with diverse communities and obtain institutional resources to recruit diverse study populations. Previous work has identified researchers' training and education as a feature of successful community engagement (Harrison et al., 2018). In this study, the RT group overwhelmingly endorsed "being trained to work with diverse communities" as an important facilitator (91%) compared to the CM group's endorsement (75%) and SP/O group's endorsement (66%). Fielding-Miller et al. (2022) noted the particular salience of researcher training on the tenets of cultural humility given that researchers have relatively limited risk in community-engaged research whereas community members/groups risk potential coercion, re-traumatization, and/or stigmatization from their participation in the process.

At the same time, there were several barriers that were endorsed by a larger percentage of CMs than RTs. These barriers included community's lack of trust in researchers/institutions, a limited understanding of participant rights and how research benefits society. In addition, more than three-quarters of CMs (78%) endorsed the barrier that participants in studies could experience harm, whereas a smaller proportion of RTs (64%) endorsed this concern. These barriers underscore the importance of building trust, establishing reciprocal associations, and fostering genuine partnerships between researchers and community members, all of which have been identified as effective strategies for researchers to create authentic community engagement (Skewes et al., 2020).

Because it is especially important to build and maintain trust with historically marginalized communities, Mitchell et al. (2020) recommended researchers work with intentionality to include beneficial programs such as health education and capacity-building (as requested by the community) in return for their research engagement (e.g., Community Advisory Boards, community discussions and feedback and community liaison engagement). Indeed Mitchell et al. (2020) posited that such programmatic offerings can establish and maintain trusting associations because they provide "tangible" benefits to the community (p. 759). Others like Kaiser et al. (2017) have recommended researchers create opportunities for community empowerment and education by engaging the community early in the research process, involving them in decision-making, and in the co-creation of research objectives and methodologies.

Our findings similarly echo Han and colleagues' (2021) study where participants suggested it would be ideal if researchers became more active and involved with the community. Specifically, a higher percentage of CMs than RTs felt it was extremely/very important for researchers to discuss their work with the community. Conversely, there was a smaller proportion of CMs than RTs who felt it was important researchers advertise the research they are doing. It would be worth exploring these differences as it is possible that "advertising" research might be viewed by communities as only a one-way form of communication for recruitment purposes. Community discussions, on the other hand, could be viewed by communities as an opportunity for researchers to not only educate/explain the benefit of research to historically marginalized and/or under-invited communities, but also an opportunity for bi-directional dialogue/engagement. Clark et al. (2019) developed an excellent set of communication strategies (including a core message map and checklist) to increase community trust and participation in diversity in clinical trials research. Recent studies by McNeal et al. (2021) and Uphold et al. (2022) similarly found that researchers recognize the importance of disseminating their work to nonacademic/non-researcher audiences but often lack time, training, and/or incentives to do so.

Finally, our study findings highlight the importance to community members that they are not only valued members of the research team but also appropriately compensated for their work. This was true for SP/Os as well, but to a lesser extent. Fielding-Miller et al. (2022) highlighted that community-based organizations have concerns about allowing researchers access to their clients due to lack of respect, concerns that the researcher will reinforce harmful stereotypes with the client or create extra work for the site coordinators that are not compensated or acknowledged.

STRENGTHS AND LIMITATIONS

Many studies to date on community-engaged research have involved only one stakeholder group at a time (Killough et al., 2023; McNeal et al., 2021; Morales et al., 2023; Uphold et al. 2022) and/or conducted multi-stakeholder qualitative studies (Clark et al., 2019; Han et al., 2021; Niranjan et al., 2021). Our study appears to be one of the first to use the same quantitative survey to collect several key stakeholder groups' perspectives about the barriers and facilitators to community engagement and participation in health research. With our study design and findings researchers and CEABs in the Commonwealth of Virginia have a starting point for identifying commonalities in stakeholder priorities as well as identify where divergences warrant further stakeholder engagement/conversations. While this pilot study had several limitations it can still offer several lessons learned. First, despite employing diverse strategies to recruit across the communities of Virginia, there was an unequal representation of participants from Northern Virginia, and from those who identified as white, female, and well-educated which limits the generalizability of the study findings. Second, although the study survey tool was assessed to be at a 9th grade reading level, some participants may have found the survey questions difficult to understand and may have introduced response-bias and/or led to participant drop-out. The study lacked funding to translate the survey into Spanish, or to offer the survey in paper-form which might have been barriers to participation from underrepresented groups and thus further contributed to response bias. In several of their free-text comments, study participants articulated the need for surveys such as this one to be available in languages besides English, and we acknowledge the bias and exclusion introduced to the study by not having this resource.

RECOMMENDATIONS AND NEXT STEPS

Our study identified many perceived barriers and facilitators that were shared by all three groups as well as several where there were divergences. The differences in the perceptions between RTs and CMs in this sample suggests a misalignment of expectations, priorities, and experiences with community engagement in health research. Such a disconnect can thwart meaningful collaborations and compromise efforts toward community-engaged research particularly with historically marginalized communities. It is crucial, therefore, to acknowledge and address these discrepancies through transparent communication, training efforts, and a philosophy of mutual respect and value. CBPR principles and methods provide a framework for research teams to adopt the aforementioned strategies. CBPR proponents such as PCORI, the Kellogg Foundation, and the NIH's CTSA program also provide researchers' opportunities to secure dedicated funding for projects that promote community engagement activities and partnerships. To further promote community trust and engagement and foster diversity in research participation, academic and clinical research institutions could consider creating dedicated funding for researcher and community member training and establishment of community-engaged advisory boards. Another incentive for researchers to engage with communities in a more effective and equitable manner would be to reward community-engaged scholarship with dedicated request for proposal awards (RFA) and/or funding resources.

Training and capacity-building initiatives should also be required to help researchers enhance their communication skills when working with diverse communities. For example, CITI Program (2019) has three community-engaged research (CEnR) modules that IRBs can consider requiring of all investigators and not just those engaged in social-behavioral-educational research. Academic and health systems could further promote community capacity building by opening CITI training memberships to their CEAB members and interested community leaders.

Consistent with our recommendations, the findings from our own study will be shared with/disseminated to the community through institutional community-action committees, and through emails and social media posts in the places where recruitment was completed. Discussions about study findings through planned community studios could further generate insights into the findings and identify next steps for fostering CER collaborations in the Commonwealth of Virginia. iTHRIV continues to employ community engagement through Community Studios and distributing research grants to support research institutions partnering with community organizations to address community health priorities. With CTSA support, Inova Health System established a Research Community Advisory Board to educate and receive feedback from the community regarding research projects. This effort is continued through Inova's Health Equity Community Action Committees.

For the last two decades, federal agencies and programs as well as expert CBPR scholars in public health have been calling upon researchers to partner with communities to more effectively address persistent national health disparities (Holkup et al., 2004; Israel et al., 2001; Minkler et al., 2005; Syme et al., 2004). Yet many research-intensive universities and health systems IRBs don't require training or incentives that could foster researchers' meaningful partnership with communities in health research. Finally, we agree with Fleming et al. (2023) that as our country continues to address institutional and structural racism/discrimination, it is time for academic and health institutions with DEI initiatives to include an examination of their research teams' ability to authentically partner with historically marginalized communities whose untapped expertise is critical to achieving health equity for all.

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