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# Community Engagement in Biomedical and Health Sciences Research Study

2022

*A Report By*



**POPULATION HEALTH  
INNOVATION LAB**

A Program of the PUBLIC HEALTH INSTITUTE

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# INTRODUCTION

A review of previous biomedical and health sciences research reveals a lack of inclusion of diverse racial and ethnic groups, a factor that directly harms these communities. When biomedical and health sciences researchers only include those with European descent in their research, they miss crucial information about how diseases and treatments affect underrepresented communities of color. For instance, biomedical research has shown that certain asthma treatment medications were less effective on people of color than on those of European origin.<sup>1</sup> Failing to gather data from diverse populations can lead to large gaps in medical research datasets which has the potential of allowing racial and ethnically-linked health disparities to go unrecognized. For example, while roughly 86% of the global population is non-European, only 4% of genetic research has been conducted on non-European communities.<sup>1,2</sup> This mismatch between diverse populations and representation in research leads to issues of what communities are being underrepresented and disadvantaged in biomedical and health sciences research.

Diverse study populations in biomedical and health sciences strengthen existing findings and reveal new discoveries in the origins, treatments, and understandings of various diseases.<sup>3</sup> Striving for more diverse data and emphasizing the importance of representation in biomedical and health sciences research can begin to address the lack of race-informed decisions and treatments among researchers.<sup>4</sup> To achieve high levels of diversity in research participants, intentional efforts must be made to include and engage underrepresented communities of color who have historically been left out of this field of research. Partnering and working alongside underrepresented communities of color can reduce racial health disparities and promote health equity while deepening a researcher's understanding of how different diseases may affect various races and ethnicities.<sup>5</sup>

While community engagement itself has a long history, there is still more that can be accomplished, especially in diversifying the biomedical and health sciences field by engaging with underrepresented communities of color. Community engagement efforts in biomedical and health sciences research can be traced back to the 1960's and is becoming more widely accepted in multiple areas of scientific research.<sup>6</sup> History has shown that the involvement of communities in the research process can be beneficial to both the communities and researchers by creating partnerships among both groups, strengthening the validity of research, and promoting community-specific solutions and interventions that directly impact community members.<sup>7</sup> However, history has also shown that some approaches, such as monetary compensation or targeting specific races for studies, may result in more harm than good being done.<sup>8</sup> While these are not inherently negative, the intent behind the approach plays a large role in the outcome. For example, paying communities to enroll in studies that they might not fully understand or using strict eligibility criteria to specifically target certain demographics with malicious intent can lead to harmful consequences to the communities that participated in those studies.<sup>8</sup> This leads to the mistrust and hesitancy from communities to participate in research studies that is prevalent today. The history of harm that researchers have inflicted on these communities cannot be ignored. There is a great need to recognize both the historically positive and negative aspects of community engagement, to support a new wave of meaningful and beneficial relationships between communities and research.

This study is an exploration into the motivations, facilitators, and barriers that both biomedical and health sciences researchers and funders face when conducting community engaged research and community-based participatory research (CBPR). Research results lend insight into the current community engagement landscape by showing the various approaches employed to engage communities in research, the ways funders support community engagement, and how both researchers and funders operationalize community engagement. From this knowledge, funding organizations such as the Chan Zuckerberg Initiative (CZI) can gain a stronger understanding of community engagement and how to support researchers in community engaged research, especially those who work with underrepresented communities of color.

## Study Aims

The Community Engagement in Biomedical and Health Sciences Research study sought to:

- Gain insight into the current community engagement landscape among biomedical and health sciences researchers and funders.
- Provide a deeper understanding of the attitudes, beliefs, and motivations behind conducting and/or funding biomedical and health sciences research that directly engages underrepresented communities of color.
- Inform CZI's Single-Cell Biology Program's efforts to support deep and meaningful engagement between researchers and communities to address inequities and lack of diverse representation in biomedical research.

## Research Questions

The research study was designed to answer the following questions:

1. What are the motivations of biomedical and health sciences researchers to participate or not participate in community engagement for their research?
  - What drives researcher hesitation to participate in community engagement?
2. What attitudes and beliefs are associated with biomedical and health sciences researcher perspectives on engaging communities in their work?
3. How do funders currently support community engagement in research?
  - What are high priority topic and funding areas?
  - What barriers exist to funding community engagement in biomedical and health sciences research?
4. How do biomedical and health sciences researchers operationalize community engagement?
5. How do funders help operationalize community engagement among biomedical and health sciences researchers?
6. What are the characteristics of different levels of community engaged researchers?

# RESEARCH DESIGN & METHODS

This study used an explanatory sequential mixed-methods design, which consists of two phases: quantitative and qualitative data collection.<sup>9</sup> In the explanatory sequential mixed-methods design, the collection and analysis of quantitative data occurs first, followed by the collection and analysis of qualitative data.<sup>10</sup> For this study, a web-based survey of biomedical and health sciences field workers was conducted first, which collected quantitative data. Next, semi-structured interviews were conducted with biomedical and health sciences researchers and funders to provide a comprehensive understanding of quantitative findings by explaining or expanding on quantitative results and exploring participants' views more deeply.<sup>10,11</sup> Since "using more than one type of analysis can strengthen the rigor and trustworthiness of the findings via methodological triangulation," both quantitative and qualitative data were independently analyzed and then triangulated to develop robust evidence in support of each research question.<sup>12</sup>

## Participants

The Public Health Institute's Institutional Review Board (IRB) approved the study on December 29, 2021 (IRB #120-031). Purposive sampling and snowball sampling were used to develop sampling frames for quantitative and qualitative data collection. Purposive sampling strategy involves the identification and selection of participants based on the study's phenomenon of interest,<sup>13</sup> and snowball sampling strategy uses a referral approach where the initial group of participants refer other participants. Both sampling procedures have been useful when researchers experience difficulty recruiting research participants.<sup>14,15</sup>

Participants were identified through a landscape scan of community engagement research and funding within biomedical and health sciences conducted by PHIL's research team in October 2021. Additionally, the CZI Single-Cell Biology Program identified grantees and organizations of interest to include in the web-based survey invitation. The snowball sampling strategy allowed individuals participating in the web-based survey to refer additional participants who met the inclusion criteria and share the survey link with their colleagues. Participants recruited for the web-based survey indicated interest or experience with community engagement and met one of the following criteria: 1) identified as a researcher within the biomedical and health sciences field; 2) identified as a funder within the biomedical and health sciences field; 3) identified as both a researcher and a funder within the biomedical and health sciences field; or 4) identified as working within the biomedical and health sciences field through other roles.

For the semi-structured interviews, participants were recruited from survey respondents who indicated interest in participating in an interview at the end of the survey and met the following criteria: 1) identified as a researcher within the biomedical and health sciences field with less than 10 years of experience with community engagement; 2) identified as a researcher within the biomedical and health sciences field with more than 10 years of experience with community engagement; or 3) identified as a funder within the biomedical and health sciences field. Most study participants were based in the United States with a few participants based in countries across North America, South America, and Asia.

## Measures

A two-question screening survey was administered to determine participant eligibility for the web-based survey. The screening survey asked participants whether they currently worked as a health sciences researcher or funder of health sciences and if they had experience performing or funding community engagement and/or CBPR with underrepresented communities of color. If participants indicated working in the health sciences field, regardless of their experience with community engagement, they were allowed to participate in the study. Questions regarding research background information in both the survey and interview was used to elicit information about professional role, title, organizational affiliation, experience with community engagement, and identification as a researcher or funder in the biomedical and health sciences field.

The survey's primary goal was to gain a deeper understanding of the community engagement landscape within research and funding in the biomedical and health sciences fields. Questions asked respondents about their role and responsibilities, identification as a researcher, funder, or other professional role, and their understanding of community engagement and/or CBPR. Respondents received questions based on the role(s) they selected. If respondents identified as a researcher or other professional, they were asked about their community engagement practices and funding support received for community engagement. Respondents identifying as "other" worked within the biomedical and health sciences field in diverse roles, such as administration. If respondents identified as a funder, respondents were asked about priority topic and funding areas and ways the funding organization they represented supported community engagement efforts. If respondents identified both as a researcher and funder, both subsets of questions were shown to respondents. Respondents' experiences with community engagement were examined through closed-ended and open-ended questions.

The initial draft of the survey instrument created by PHIL's research team was reviewed by CZI Single-Cell Biology's leadership and other CZI affiliates prior to the survey distribution from January 19, 2022 to February 2, 2022. Recommendations for suggested improvements regarding content, question formatting, and language adjustments were implemented. The revised survey was then pilot tested with seven individuals from the study population from February 3, 2022 to February 9, 2022. Pilot testers were asked five additional questions about their survey taking experience and were offered a \$30 electronic gift certificate as a token of appreciation for their contributions. The survey was further refined based on pilot testing feedback. These steps ensured the survey instrument measured key concepts reliably and validly.<sup>16</sup> The web-based survey was administered via Qualtrics from February 14, 2022, to March 31, 2022.<sup>17</sup> Participants were invited to respond to the survey through multiple channels, including direct email from the PHIL research team and direct email from CZI Single-Cell Biology Program leadership. The survey took approximately 25 minutes to complete, and individuals who completed the survey were offered a \$20 electronic gift certificate.

Semi-structured interviews were used to learn about best practices to engage community members in research, the facilitators and barriers to do this work, and the key approaches involved in building meaningful researcher-community relationships. Semi-structured interviews were administered from March 18, 2022 to May 18, 2022. Semi-structured interviews expanded on surveys by providing new information on community engagement efforts not captured in the survey. Two separate interview guides were developed to better

understand participants’ experiences with community engagement based on their role as either a researcher or funder. The interview guides had a list of guiding questions and probes were developed to better understand participants’ perceptions and experiences. Participants who identified as a researcher were asked about their community engagement experience, approaches, and the systems, processes and resources that have encouraged or discouraged community engagement in research. Participants who identified as a funder were asked about the role their funding organization plays in community engagement efforts, how they support researchers who engage in community engagement, and facilitators and barriers to funding community engagement. Participants were offered a \$30 electronic gift certificate for participating in the semi-structured interviews. Semi-structured interviews were conducted remotely using Zoom Video Communications Inc., a password-protected video conferencing software, and lasted between 60 to 90 minutes.<sup>18</sup> Interviews were recorded using Zoom and transcribed using the transcription software, Otter.ai.<sup>18,19</sup>

Throughout data collection efforts, standardized definitions for community, community engagement, community-based participatory research, and underrepresented communities of color were provided. Definitions of these terms can be found in Table 1.

**Table 1. Standardized Definitions Provided to Participants**

Term	Definition
Community	Community is a “group of people living in the same locality, religion, race, profession, or with other common characteristics.” <sup>20</sup> Since this term is fluid depending on its context, for the purposes of this study community refers to communities outside of academic and research settings.
Community Engagement	Community engagement is “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.” <sup>21</sup> This involvement can be as a research participant, tissue donor, community representative on an advisory board, or other involvement in the research process.
Community-Based Participatory Research (CBPR)	CBPR entails “equal participation of community partners and researchers throughout the research process with shared decision making.” <sup>22</sup>
Underrepresented Communities of Color	Specific communities of color are underrepresented in biomedical research, including those of African, Latinx, Greater Middle Eastern, Indigenous, Oceanian, Southeast Asian, and multiple or other non-European ancestries. <sup>23</sup>

## Quantitative Data Analysis

Quantitative data were analyzed using descriptive, inferential, and predictive techniques. Descriptive analysis explored frequency, mean, and standard deviation using Qualtrics reporting features.<sup>17</sup> Inferential and predictive analysis included analysis of variance (ANOVA) and ordered logistic regression to explore the relationships among variables measuring researcher experience with community engagement, level of confidence with community engagement, community engagement approaches used, and perceived benefits to engaging community in research.

Ordered logistic regression assessed the relationship between researcher years of experience with community engaged research and their confidence with engaging community in their research. Since survey response scales were ordered (strongly disagree, somewhat disagree, somewhat agree, strongly agree) and “the correct way of modeling a dependent variable when the real distance between categories is unknown is ordered logistic regression,” this inferential technique was chosen instead of linear approaches.<sup>24</sup> The ordered logistic regression model was estimated using the MASS package in RStudio.<sup>25,26</sup>

Analysis of variance (ANOVA) assessed: 1) the extent to which perceived community engagement benefits differed based on researcher years of experience, and 2) the extent to which reported community engagement approaches differed based on researcher years of experience. In total, 21 ANOVA tests were conducted, each using reported approaches to community engagement or perceived benefits of community engagement as the dependent variable and researcher years of experience as the independent variable in analysis. Taken together, ordered logistic regression and ANOVA provided insight into the relationship between researcher years of experience, confidence, reported approaches used, and perceived benefits.

## Qualitative Data Analysis

Semi-structured interviews were audio recorded with participant consent and transcribed verbatim using Otter.ai transcription software without identifying information.<sup>19</sup> Three members of the research team independently coded interview transcripts using Dedoose qualitative analysis software.<sup>27</sup> Qualitative content analysis was used to analyze the interviews. This was done through: 1) in-depth analysis based on the emergence of key inductive themes or concepts identified by participants themselves as being important, and 2) interpretation of key concepts based on a thorough and systematic exploration of both inductive and deductive themes and the interrelationships between all themes as evidenced in the data.<sup>28</sup> Coding disagreements were discussed to reach a consensus on the final themes of the qualitative data.



# RESULTS

Quantitative and qualitative results are described below. Quantitative analysis started by describing characteristics and attitudes of survey respondents. Additional analysis was conducted to assess the magnitude, directionality, and differences in group perceptions for key variables. Qualitative analysis expanded upon quantitative findings and identified major themes related to motivations, facilitators and barriers, and approaches to operationalizing community engagement in biomedical and health sciences research.

## Quantitative Results

The survey collected data from 92 individuals with most respondents identifying as researchers within the biomedical and health sciences field. Of the 92 respondents, 72% (n=66) identified as a researcher, 9% (n=8) identified as a funder, 9% (n=8) identified as both a researcher and funder, and 11% (n=10) identified as other professional within the biomedical and health sciences field.

### Researcher Characteristics

Almost 50% (n=40) of respondents who identified as a researcher or other professional within the biomedical and health sciences field reported having more than 10 years of experience engaging communities in research; 28% (n=23) reported having 6-10 years of experience engaging communities in research and 19% (n=16) reported having 1-5 years of experience engaging communities in research. For respondents, the top benefits of engaging community in research were to improve health equity (n=76), to identify meaningful research questions (n=72), and to improve community health (n=71). The top facilitators for community engagement and CBPR included leveraging existing community relationships (n=64), receiving funding for community engagement and/or CBPR (n=57), and hiring diverse staff that represents the community and/or identifies with the community (n=56). The biggest challenges respondents faced with engaging community in research were securing resources (n=57), community's time commitment (n=45), and researcher's time commitment (n=43).

### Funder Characteristics

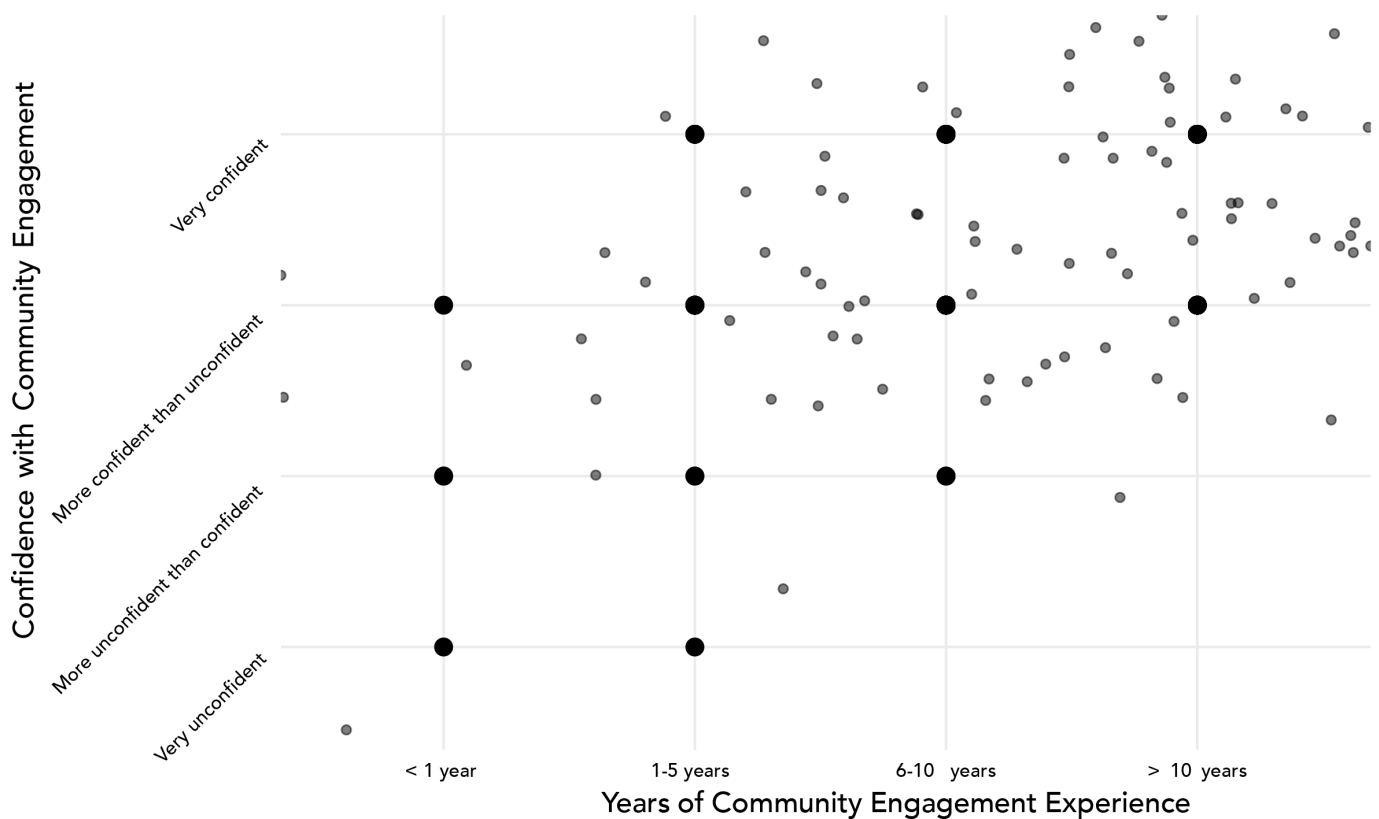
Among biomedical and health sciences funders, 44% (n=7) had more than 10 years of experience funding community engagement and/or CBPR, 19% (n=3) had 6-10 years of experience funding community engagement and/or CBPR, and 31% (n=5) had 1-5 years funding community engagement and/or CBPR. The current funding priorities for funders were health equity (n=15), patient engagement in research (n=13), and community engagement and/or CBPR in research (n=13). Funders supported community engagement and/or CBPR in biomedical and health sciences research by providing funding for researchers to engage community (n=14), providing support to partnerships between community organizations (n=13), and providing training and/or capacity building for communities (n=10). Funders were motivated to provide funding for community engagement and/or CBPR in biomedical and health sciences research because of the potential for improved health equity (n=15), the potential for improved utility of funded research (n=14), and the potential for improved community health (n=14).

### Experienced Researchers Were More Confident and Valued Health Equity

Ordered logistic regression and ANOVA were used to explore the research question, “What are the motivations of biomedical and health sciences researchers to participate or not in community engagement for their research?” Ordered logistic regression showed that reported levels of researcher confidence with community engagement significantly increased with years of experience. For every unit increase in researcher experience with community engagement, reported researcher confidence with community engagement increased by a factor of 4.75 ( $p < 0.00$ ). Figure 1 shows the relationship between researcher experience and reported confidence.

ANOVA showed that perceived benefits of engaging community in research did not vary greatly by years of researcher experience with community engagement in research, with one exception: researchers with more than 10 years of experience with community engagement were significantly ( $p < 0.05$ ) more likely to report that improving health equity was a top benefit of engaging community than researchers with 1-5 years of experience with community engagement.

Figure 1. Researcher Experience Predicts Confidence with Community Engagement



## Top Five Community Engagement Approaches Used by Experienced Researchers

ANOVA was used to explore the research question, "How do biomedical and health sciences researchers operationalize community engagement?" Results showed that researchers with more community engagement experience (more than 10 years of experience, n=40) were significantly ( $p<0.00$ ) more likely to report using certain community engagement approaches than less experienced researchers (less than 10 years of experience, n=43), including:

- Using CBPR (used by 90% of the most experienced researchers vs. 50% of the least experienced researchers).
- Establishing a community advisory board (CAB), stakeholder advisory board, or other advisory board (used by 90% of the most experienced researchers vs. 0% of the least experienced researchers).
- Conducting focus groups with community representatives (used by 75% of the most experienced researchers vs. 25% of the least experienced researchers).
- Involving community representatives in decision-making processes (used by 95% of the most experienced researchers vs. 25% of the least experienced researchers).
- Establishing bi-directional communication between researchers and communities (used by 98% of the most experienced researchers vs. 25% of the least experienced researchers).

## Spectrum of Community Engagement Approaches

Recent advances in the literature on community engagement in health-focused partnerships provides insight into the spectrum of potential community engagement approaches.<sup>29,30</sup> In a scoping review of community engagement in health-focused collaborative efforts, Petiwala et al. sought to increase conceptual clarity around definitions of community engagement and what it means to engage communities in health improvement efforts. Results indicate that both passive and active strategies can be effectively used to engage communities.

Passive community engagement strategies include basic forms of community engagement that are typically one-time activities, such as a researcher informing the community about a research project or sharing the results of the research project to the community.<sup>29</sup> In passive community engagement, the researcher may ask for feedback on their research project, but the community's input minimally influences the research process.<sup>29</sup> Passive strategies tend to take the form of data gathering, and this places fewer resource requirements on the community.<sup>29</sup> Active community engagement strategies include community engagement efforts that are bi-directional and give more power to the community by having community members in decision-making roles throughout the research process.<sup>29</sup> Active community engagement strategies include CBPR and other engagement strategies that require high capacity for time and relationship-building for the researcher and the community.<sup>29</sup>

Recent empirical research found that: 1) active community engagement strategies have a significant positive influence on perceptions of community engagement, and 2) active community engagement strategies are more strongly associated with positive perceptions of community engagement than passive strategies.<sup>31</sup> Findings are transferrable and similarly supported in this study. Figure 2 below describes characteristics of community engaged biomedical and health sciences researchers along the community engagement spectrum, as identified through descriptive and inferential quantitative analysis.

**Figure 2. Characteristics of Researchers Along the Community Engagement Spectrum**

Emerging Community Engaged Researchers	Advanced Community Engaged Researchers
<p><i>Emerging community engaged researchers are those with ≤ 5 years of experience with community engagement or feel more unconfident than confident with engaging the community in research.</i></p>	<p><i>Advanced community engaged researchers are those with ≥ 6 years of experience with community engagement or feel more confident than unconfident with engaging the community in research.</i></p>
<p>Emerging community engaged researchers were:</p> <ul style="list-style-type: none"> <li>• <b>Less likely</b> to use specialized or tailored engagement approaches when engaging underrepresented communities of color.</li> <li>• <b>More likely</b> to use passive community engagement approaches.</li> <li>• <b>Less likely</b> to use a variety of community engagement approaches.</li> <li>• <b>More likely</b> to report that hiring a researcher focused on community engagement and/or CBPR facilitated their community engagement efforts.</li> <li>• <b>More likely</b> to report that researcher’s time commitment and lack of experience with community engagement and/or CBPR were the biggest challenges faced with engaging community in their research.</li> </ul>	<p>Advanced community engaged researchers were:</p> <ul style="list-style-type: none"> <li>• <b>More likely</b> to use specialized or tailored engagement approaches when engaging underrepresented communities of color.</li> <li>• <b>More likely</b> to believe that health equity is an important benefit of community engagement in research.</li> <li>• <b>More likely</b> to use a combination of both passive and active community engagement approaches.</li> <li>• <b>More likely</b> to report that leveraging existing community relationships or hiring diverse staff that represents the community and/or identifies with the community facilitated their community engagement efforts.</li> <li>• <b>More likely</b> to report that community’s time commitment and securing resources (e.g., funding, translation services, meeting space, etc.) were the biggest challenges faced with engaging community in their research.</li> </ul>

### Qualitative Results

A total of 19 individuals participated in the semi-structured interviews, 84% (n=16) of whom identified as a researcher within the biomedical and health sciences field and 16% (n=3) identified as a funder within the biomedical and health sciences field. The major themes that emerged include: 1) Funders can be barriers to community engagement; 2) Researchers who value community perspectives and experiences are more motivated to do community engagement; 3) Researchers need to expand from only doing passive community engagement strategies to a combination of both passive and active community engagement strategies; 4) Relationship building and trust between researchers and communities are critical to preventing harmful community engagement approaches; and, 5) Recommendations by researchers to academia and funders to increase and improve community engagement efforts.

## **Funders Can be Barriers to Community Engagement**

Biomedical and health sciences researchers identified many barriers to participating in community engaged research such as the time it takes to build trust and develop relationships with the community, lack of training and experience in community engagement, and the lack of support in academia for participating in community engagement. However, the barrier most frequently described was associated with the funder.

### **Funder-Required Community Engagement**

It is important to note that while biomedical and health sciences researchers identify funders as the biggest barrier to participating in community engagement, they also acknowledged funders were facilitators to participating in community engagement. Funders facilitate by requiring grantees to include community engagement in their projects. Some researchers admitted the only reason they participated in community engaged research was due to the funder requirement. Even if the researcher did not have previous experience in community engaged research, they learned about the process due to the grant requiring community engagement.

*“I don’t think there’s anything that’s discouraged me, but the one thing I didn’t mention that has encouraged me is this became a requirement for grants. And so that brought it on my radar because, you know, when we apply to [Suppressed for Confidentiality] you know, for these grants, it’s never a consideration, right? If you put it as part of the criteria, and you put a nice page in explaining like, this is what we mean by meaningful engagement, then it opens you up to that as being, you know, being able to divert funds to that, like we’re diverting in the grant, like \$100,000 to community engagement. And that’s a budget item, right? And so, because it’s a line item in our grant, we know we can spend on that. And sometimes that is a very motivating force. Right? And so, I think if it wasn’t a budget line item for grants... we don’t have the opportunity to make it that much of a priority.”*

*“But that I was told to include a CAB, so it’s like I’m funded through a fellowship. And so, it’s like a fairly hands on thing and they required us to create a CAB. So, it was like if I didn’t even know before I was required to do it. I didn’t know what CAB stood for. It was pretty quick learning curve there. But so I was required to do it. And, and it was, you know, it was a welcomed suggestion really, I just, it had never been told, like no one had ever told me that to do it before.”*

### **Limited Funding for Community Engagement**

While funders are an important facilitator to community engaged research in the biomedical and health sciences field, funders can also impose barriers. One-way funders are a barrier to community engagement is limited funding for community engagement. Some researchers reported there was not enough funding for community engaged research. Researchers also felt that funding for biomedical and health sciences research and community engaged research need to be combined instead of “siloes.” Researchers pointed out that there was funding for community engaged research and that there was funding for biomedical and health sciences research. However, this funding should not be separate and should be combined as funding for community engaged biomedical and health sciences research.

*“And so, it’s commendable that certain funders have made it an explicit part of their research. So, the research that they fund, I think it needs to be sort of expanded or spun out, right? Because I think it’s in two regards. One is, you know, just a mountain, right? There’s just insufficient funding. And you sort of need dedicated resources to do this, as opposed to just kind of appending this on to things.”*

*“No, they’re expanding... I think. Then and hopefully, they’re expanding in a way that’s that merge, because I think historically that funding has been siloed. So that there’s community engaged funding as biomedical research funding, and there isn’t funding to marry the two.”*

### **Funders Do Not Prioritize Community Engagement**

Some biomedical and health sciences researchers reiterated that community engagement was generally not the priority of funders. Researchers described how if one conducts research in certain topic areas, such as neglected tropical diseases for example, it was possible to find funding for community engaged research. However, outside those certain topics, there is not much emphasis on community engagement. Community engaged researchers felt they needed to target funders committed to community engagement for their projects.

*“And then I think also, we’ve had some funding that allowed us to, like the funding for the work we were able to do on the chronic patients with chronic conditions. But that’s for very specific diseases. So, they suffer neglected tropical diseases where it’s already, as the assumption is, they’re already socially and economically disadvantaged. So, in that, within that space, it’s a little easier to find funders who are a little bit more open minded, to allow you to do community-based work because they recognize the role of communities, but outside of the neglected tropical disease space, no. No Challenges. Yeah.”*

*“Then, when you look at some of like, for instance, some of the funders that have provided us with funding to look at how to incorporate community engagement. They’re also committed to community development. So, I think maybe targeting funders who are committed to community development within their overall goal. Within specific calls, that’s also been facilitator.”*

### **Funding Timelines**

Most biomedical and health sciences researchers described that the funder’s timeline for research projects were not conducive to community engagement. The funding cycle was problematic to many researchers, and they felt they did not have enough time to engage the community in their proposals with the strict deadlines that were given. Researchers felt timelines needed to be more flexible to take into consideration that community engagement takes time. From the researcher’s perspective, there is a lot of pre-work and relationship building they must engage in with the community before a research proposal can be submitted.

*“Yeah, I think it goes back to a lot of what I said about the way that the funding cycles can be set up. I think I would tell funders, if they want to support good community engagement, that it’s going to take a very long time. And time is a huge resource. So, I get that that’s hard. But it’s that, they should consider the kinds of structures I described, like [Suppressed for Confidentiality] has where there’s an entire year just devoted to getting to know a community and building a relationship.”*

*“I’d ask them to make their timelines a little bit more flexible. So sometimes you find that funders send out a call, and they want it done within one or two weeks or sometimes a month, and that’s not enough time to engage actors and to identify problems, and to come up with a strong research proposal that can be funded. So, even bringing up collaboration, setting up collaborations is timely. But sometimes I think when funders are sending out their calls, the time the span of time between when the call comes out, and when they want say a concept note or a full proposal, in some cases, it’s too short for you to be able to. It privileges organizations that already have access to resources, but underserved populations don’t already have those resources. So, it already makes it difficult for them to be actively involved.”*

### **Importance of Incentivizing Communities to Engage**

Most community engaged researchers felt that incentives should be given to community partners. They felt community partners should be paid for their participation in the research process. Additionally, many researchers also felt that childcare, travel, and even food should be paid for by their grants to support community engagement efforts. However, researchers felt not enough of their grant budget was allowed for these efforts. Some grants will not pay for these types of incentives. Researchers felt these incentives are an important component of community engagement and incentivizing participation decreases the chances of community partners feeling that they are being taken advantage of by the researcher.

*“Money talks, so make sure that the funding is sufficient to support a community partner. Because when we’re planning grants, even if it’s like hundreds of thousands, or we have like a million dollars in front in direct funding for this COVID grants, the budget is tight, because there’s so many people that have to have effort on the grant. You have to have the designer, the participant incentives there’s all sorts of things you have to get paid for. And because of the way that academic incentives work, where people are expected to cover their effort, and where the incentives are towards getting more grants and publishing, etc., etc., there is less incentive to put money towards community partners. So maybe you set a threshold, you have to spend at least x percent of your budget, on your community partner. And that way, it signals exactly what the priority is.”*

*“The question is how you handle it. And, and there’s no obvious answer other than like all relationship issues, it takes listening. And sometimes you can solve it, and sometimes you can’t. I’ll give you an example that’s been painful. Often the researchers get funded to do the research, but the committee members don’t get funded to come to meetings to provide advice. They’re expected to do it for free. That’s just crazy. On the other hand, [Suppressed for Confidentiality] guidance and often institutional guidance do not permit direct funding of community members. And particularly, that would be true if folks weren’t documented citizens or immigrants. So, we’ve had to actually change an [Suppressed for Confidentiality] roles and change institutional rules to permit funding and paying of things like transportation and childcare and food for coming in direct subsidy, direct payments for the time of community members. So, we’ve had to change all those policies. That’s not already done. But the community members were correct and telling us that we they were feeling taken advantage of because they weren’t there to donate their expertise and time for frankly our benefit.”*

## **Researchers Who Value Community Perspectives and Experiences are More Motivated to do Community Engagement**

Biomedical and health sciences researchers who valued community perspectives and experiences understood how community perspectives and experiences enrich research overall. Community perspectives and experiences provided researchers with new valuable knowledge outside of their expertise and valuable insights into community contexts that could otherwise not be learned. As a result, researchers felt motivated to actively take steps and actions that promote community engagement either through their own community engagement efforts in research or by encouraging others to understand the value of community perspectives and experiences.

*“And that’s something I’m trying to figure out how to more clearly explain to people I work with or students I teach about these things? Because I think they’re kind of like, Yeah, well, what why am I going in this degree if anyone can be a researcher now, right? And that’s not really what I think engagement is trying to do. It’s not trying to make everyone into this certain specialized scientist or something like that. It’s just recognizing that people have really valuable input that looks different from what a scientist may contribute to some study, and that that’s actually a good thing. So, there’s something in there about trying to, like, help or encourage people to have an open mind like, again, sort of epistemologically about what knowledge is and where valuable knowledge exists in the world.”*

*“Sometimes, when you’re doing heavy analysis, nothing makes sense. And I go out and I design a study and the engagement strategies are working, and I get to see improvements in population level outcomes. I think that helps me and knowing that part of the reason why those kinds of strategies and those kinds of programs work is because of making sure that we incorporate different voices within communities. I think that’s been a big, significant motivation for me to keep doing community.”*

### **Valuing Community Perspectives**

Additionally, biomedical and health sciences researchers who valued community perspectives and experiences were more motivated to do community engagement because they recognized that valuing community perspectives and experiences made community members feel valued and provides community members with a voice. By providing community members with a voice and the opportunity to feel heard by researchers, researchers empowered communities by nurturing ownership and validating that their perspectives and experiences matter. Valuing the perspectives and experiences of community members deeply motivated researchers to do community engagement. These researchers understood how transformational community engagement in research can be for communities.

*“To me, just the opportunity to engage individuals into studies that they would otherwise not participate in, especially parents who come up to you. I remember in our pediatric recruitment one Dad said that he was so he actually got really emotional when we started talking to him about his child, and he said that he had never been spoken in a way that made him feel valued in the way that we did. And to me, that was really important because we were only interested in the health of his child. And he was so worried about being turned over to ICE or to deportation. You know, facilities and what have you, we were just interested*



*in helping his baby grow and succeed in that first year. So that to me, it really made an impact on me that our work is really important. Even that one day he really made my, he changed the way that I view things. In the way that we talk to the community that they want to participate, and they want to give back, but it's all the way that we speak to them."*

*"One of the more rewarding moments that I've had collecting data with participants was when we were at the clinic in the [Suppressed for Confidentiality], and at the end of the session, and I think she said it after I turn off the recorder... She said, 'You know, if I ever see this in a doctor's office, I'll know that I made important decisions about how it looks.' So, the process of being involved in the development of something gave her a feeling of ownership. And that I think has a lot of value. I can't tell you how many times it happened on Wednesday night, how many times participants have said 'Thank you, I learned a lot.' People have said that this was a great class, like a class. This is like you're teaching us, but people felt like they got something out of it. So that I feel like that's a really good indicator. And the fact that people asked me, '[Suppressed for Confidentiality], do you have any more studies?' That's a really good indicator."*

### **Under-Valuing Community Perspectives is a Barrier to Community Engagement**

Biomedical and health sciences researchers who do not value community perspectives and experiences felt less motivated to do community engagement and experience challenges with understanding the value of community engagement. This limited level of understanding discouraged researchers from pursuing meaningful community engagement leading to less intentional and basic forms of community engagement that were one-directional.

*"The people there are very soft hearted. They never challenge us or say no to us. They always say only 'Yes, yes, we will listen to you.' But the most difficult part is to really encourage them to comply. So, the most difficult part is to make them understand that we are not trying to make your life difficult. We are trying to make your life healthier, something like that. It's a difficult concept to understand because with this it's human nature. I think what you taste in your mouth is much rather than what your brain tells you to do."*

*"And how do you get them to tell you what they really think, without being complete, without being deferential or worrying too much about what you think? I think in some, in some instances, I could seriously imagine that you would, that a PI would, need to delegate that entirely to somebody who has a skill set and, you know, facilitating conversations, because I've had people say to me things like, 'Well, I did engagement. I did a seminar for the community and they just didn't come.' And it's like, so you created like that that's not engaged. Like I mean, it gets some kind of engagement, but it's not going to be effective. If the point is for you to learn from the community, you're just broadcasting at that point. You're just saying come and hear what I have to say and maybe tell me what you think."*

## Researchers Need to Expand from Only Doing Passive Community Engagement Strategies to a Combination of Both Passive and Active Community Engagement Strategies

Community engagement efforts can fall along a spectrum of different forms and practices. Several biomedical and health sciences researchers spoke about community engagement as a spectrum, from conducting only passive community engagement strategies by simply communicating research results to a combination of passive and active community engagement strategies.

*“I think it’s a spectrum, and so it can be anything from involving communities and collecting data to the opposite end of the spectrum would be more co-collaborators, really having the ideas come from community members rather than from the research team. You know, equal partnership, if not even weighing the community voices higher than the researchers’ thoughts and opinions. So, it can go from kind of light touch consultation to really involving them in all aspects of the research, both design conceptualization, collecting data, interpreting data.”*

*“I see community engagement as a more nebulous term that encompasses a broader set of practices involving community stakeholders and partners. In my work, I have seen practitioners of engagement refer to a wide variety of activities as ‘community engagement,’ including more unidirectional communicative activities (e.g., market research, one-way dissemination of information to communities and publics).”*

### Community Engagement as Process and Outcome

What determined where biomedical and health sciences researchers fell within this spectrum of community engagement depended upon researchers’ understanding of community engagement. Researchers who reported understanding community engagement as an outcome and not as a process engaged in passive forms of community engagement instead of focusing on the process of working with communities.

*“I want to start with the word operationalize... And that’s what you do is associate the measure with a process that’s, quote, unquote, observable. And so, it allows you to assess through observation or measurement, the presence or absence of the construct. Inclusiveness in research is such a broad and such a complicated topic, that, and this is the sort of technical point, there can’t be an operationalization of it. If you’re going to operationalize it, there’s going to be hundreds of thousands of different ways of doing it, depending on what kind of research you’re doing, depending on who you want to include and things like that. So, I don’t think operationalization is actually a helpful frame because it makes something that’s actually mind bogglingly difficult seem easy and technical. If only we just throw enough analytic power at it, then we’ll know how to include people.”*

*“No, I think the fact that you’ve put it as a process and not like an outcome, I think that’s valuable. Because sometimes in the work that I do, I see a lot of time that people view community engagement as an outcome, like they have done it, but the fact that it’s... you’ve retained it as a process. That’s important.”*

## Meaningful Community Engagement

Biomedical and health sciences researchers who approached community engagement with frameworks based on the principles of mutually beneficial collaborations, bi-directional engagement, and the essence of understanding community resulted in meaningful community engagement efforts. When researchers used frameworks based on these principles, researchers often engaged in deep reflection about what is truly meaningful community engagement. This led to an understanding amongst researchers on how to better meet the needs of communities and how to share power with communities.

*“I think a lot of the communication is like ‘what question do you ask which people?’ you know? Like, what is it where, not to keep things from folks, but like, how do you work with the community, and what axis of their identity or axes of their identity are you hoping to learn from? And can we learn from as many different aspects of a person as possible? Tell me what it is like to be the parent of a child with a rare disease? How do I, what do you want to know about this disease? What is the hardest thing in your life that this disease does to you or your child? That I might not guess? I might guess that the hardest thing is that you would like there to be targeted therapy, and you would like to understand. You would like us at least to understand; and ideally, you as well, if you want to. Some families don’t. They don’t want to know. They just want it to be better. But either way, they at least want the doctor to understand how it works. And that would be my guess, right? Like, you want me to give you a medicine, you want me to give you a diagnosis, and then a medical treatment, and you want to move on with your life. But it’s really interesting hearing from families that they have never understood what is wrong with their child or that they just feel deeply guilty because they did this to their child. But no one’s really explained to them kind of how to think about that.”*

*“So, the research design is how are you going to make sure that if you really want to understand this in the Black community, number one, where’s your community advisory board of people that know about the community, that are helping and guiding you, and helping you identify the research questions? What’s important? How do we distribute the funding? How do we make sure that power is shared? And how do we assess if power is shared?”*

## Engaging with Underrepresented Communities of Color

Biomedical and health sciences researchers reported using specialized or tailored engagement approaches when engaging with underrepresented communities of color. Specialized or tailored engagement approaches included researchers gaining cultural competency by learning about communities’ practices and meeting with community members and leaders in community settings such as town halls, faith-based settings, and grocery stores. Another common approach researchers used when engaging with underrepresented communities of color included sending research team members with the same language or racial identity as the underrepresented communities of color to lead community engagement efforts.

*“Most researchers are White and upper middle class, and most communities are neither, nor are many communities are neither. So, a part of the issue is we don’t have diversity of the research groups so that within a research team, there may be no one with any lived experience of the community. That is, they wish to be gauged. It’s a lot easier when you have folks in the research team who grew up have lived experience in that setting, because they’ll know they’ll at least know some of the norms. So, diversity inclusion is necessary, but not sufficient for community engagement.”*

*“And we’ve had this experience multiple times. There will be a patient that I met. She looks like she should, we should encourage her to enroll the present the study, encourage them ... using the wrong word here... and present this study to them and hope that she finds consent. And then my Latina research specialist will go to the ER or the pre-op or call them sometimes on the phone or go to the doctor’s visit. And they will say no. And I’m like, I really, really want this like this is one of the people that we need to study. And I will let some time pass, especially if they’re not going for pre-op, I let some time pass and then I’ll be the one talking about this study. And then they will say yes.”*

### **Relationship Building and Trust Between Researchers and Communities are Critical to Preventing Harmful Community Engagement Approaches**

Biomedical and health sciences researchers identified that relationship building and trust were necessary to encouraging collaboration and meaningful engagement with communities. Creating an environment where community members can voice their questions and concerns was the first step to promoting an open relationship between communities and allowed researchers to address any hesitation communities may have over participating in research studies. Acknowledging the reasons why communities were wary of interacting with research encouraged researchers to learn from the past and take the necessary steps to prevent any further harm from occurring to the communities with which they were working.

*“Part of the impetus behind it was not only to sort of meet that ethical obligation, but also to help rebuild that fabric of trust with the community because it’s everything. We’ve been interviewing people and doing focus groups related to COVID testing and vaccination. And I was just talking about this with somebody in the last meeting, that one of the participants was really kind of suspicious of how much of a push [Suppressed for Confidentiality] had done to get vaccines into certain neighborhoods, the neighborhoods that were the hardest hit, right? And the response was, ‘Are we the guinea pigs?’, because White people usually get everything first. And so, you can’t win. If you don’t prioritize people, they feel left out. If you do prioritize people, they feel targeted. And so, there’s no winning in that situation. So, you have to address the underlying cause, which is the lack of trust.”*

*“I mean, I think the whole goal of research is to give voice to the participants. And I think the more you engage them in that research, the more you’re giving them a voice. And especially when we’re working in systems with marginalized communities, we want to make sure we can amplify their voice as much as we can, we were in a position of power as researchers. And I think being able to use that power to engage communities in our work, to produce both more applicable work, but also to amplify their voices to make sure their voices are heard within research, I think is just incredibly important.”*

## **Mutual Benefit of Community Engagement in Research**

An important outcome of fostering healthy relationships between researchers and communities is that both benefit from the community engagement process. Communities that trust biomedical and health sciences researchers were empowered to ask for the interventions, resources, and data they need to address issues in their community. Similarly, researchers gained deeper insights into the issues communities may be facing by hearing firsthand accounts from community members. Making efforts to establish trust and creating space to have these conversations helped researchers understand what the community really needed, which strategies were most beneficial, and which strategies were less effective.

*“For me, I’d say making sure that the people are centered, making sure that I’m working on building relationships, and trust above everything else. And making sure that the engagement is meaningful, not just touching or superficial engagement strategies, but building on the resources that communities have, taking a step back as a researcher to make sure that my voice is not the most predominant one in terms of the work. And also playing my part, because if I’m recognizing the role that the community is playing, that means I have to also play my role as a researcher and ensure that I’m designing interventions and strategies that are targeted towards their needs and make it easy for them to interface with the health system.”*

*“I think there’s certainly benefits to research, I think those kind of vary, and how much they’re beneficial, mutually beneficial to a given community... I would say, research stands to gain from engagement, because a lot of knowledge and expertise exists within communities and people who might not have an advanced degree. I think, especially for me, some of my own work that I do outside of my current position is more focused on climate change and the health of the environment and working with Indigenous communities. We know that there’s a ton of amazing knowledge that exists about the environment created and stewarded by folks who have a close relationship to it. So, for us, there’s a lot that stands to be gained in terms of actually intervening successfully into environmental issues by talking to people who know a lot about the environment. I think we stand to learn a lot from people who have a lot of knowledge. And I think engagement can do that if people commit to the right values.”*

## **Building Relationships Takes Time**

Biomedical and health sciences researchers acknowledged that meaningful relationship building takes time. Several researchers identified time as a main barrier in building community relationships. Additionally, not allotting time for relationship building in grant proposals or requiring deliverables with hard deadlines forced researchers to forego important steps in the relationship building process, resulting in superficial relationships at best or exploited communities at worst.

*“Yeah, the funding is a huge one, because it just can have such a bearing on timing, which is such an issue in engagement, like how much time you’re able to spend working on something before you have to have some kind of deliverable. And timing as far as how early can you engage community members? And how meaningfully can they sort of shape the actual design of the study? So that’s a big one.”*

*“I think meaningful relationships take time to build... Even just coming together to have that shared understanding of what we want the goal to be. I think it takes time. And sometimes it takes a lot of time. So, I think that kind of meaningful community engagement is something that we constantly have to be working on. The initial relationship building phases of community engagement, which are the most critical, always take a really long time. And if you’re working within a grant, or a funding mechanism that only has a small amount of time to accomplish a specific goal, it can be really easy to want to skip past those kinds of lengthy processes.”*

### **Predetermined Research Foci as Limiting Factor**

Another barrier identified by biomedical and health sciences researchers was the lack of flexibility from funders regarding funding topics and areas of research. Researchers shared experiences of feeling constrained by predetermined research questions, acknowledging that often the communities they were engaging with were not interested in the topics being presented. This also limited the ability of researchers to design research questions collaboratively with the community. This decreased the chance for researchers to address the communities’ needs and build trust between them.

*“We were stepping into a decade’s old study that has a lot of history, a lot of politics, and challenging things that we’re newly navigating, and communities that we work with didn’t have opportunity to shape at an earlier stage. So, unlike a CBPR approach, where you are doing that early needs assessment, and actually working with communities to say ‘What do you want this to look like?’, we haven’t gotten to do that... When we want to do a more engaged approach, it is challenging, because that’s fundamentally not how the rest of the study has been set up. For example, the entire topic of heart disease has been decided for these communities, essentially many, many years ago, and that ends up constraining the scope of what the study is and can look at... it’s kind of awkward. Sometimes we’re going and talking to community members, and they’re kind of like, ‘Oh, we don’t even really necessarily care about this study or this thing.’ So, we can’t just go in assuming that anybody actually even cares that much about what the study has decided that we should focus on.”*

*“The IRB administration is extremely inflexible currently, and wouldn’t even know how to deal with formulating a research question with the community... they just wouldn’t know what to do with that. Because there’s no funder involved, perhaps at that stage, right? And even if there was a funder, if there’s no specific patient involved, right, then that’s going to be an issue.”*

### **Community Engagement Requires Tailored Approaches**

There is no step-by-step guide to forming and sustaining meaningful relationships with communities. Though the approaches biomedical and health sciences researchers take differ from community to community, there was a general understanding that relationship building takes time, that researchers cannot go into communities with ulterior motives, and that there needs to be pre-work done by researchers to understand the history and context of the communities with which they are interacting.

*“Going in with a funding announcement is way too late. Because this is all about relationships. So, it’s about building relationships over time and a body of work that will span many years. It’s about sustainability. So, what I tell folks is if you want to go out and meet with community, because you just saw an RFA. It’s not a good thing, almost always going to be a bad idea. And find somebody who already is working with a community and see if you can piggyback on that... it’s about sustained relationships and sustained programs. It’s not about doing helicopter research, where you fly out, do the research, and leave again.”*

*“Building trust with communities. I mean, again, I think just having, you need to spend a lot of time with people before you can expect them to even trust you... often because of this push to include more marginalized communities in research, some communities end up being like so looked at under a microscope all the time, or kind of so recruited often into certain studies as participants, but not in the participatory way, like more as like subjects of a study...I think having a good understanding of, historically and presently, like how that community has sort of been maybe treated or included or excluded from research, and what that might mean is really important. Yeah, and just understanding that, like, people might have trauma around research, they might have skepticism about certain institutions. So, I think that’s really important to know. And also, knowing when to like, step away, or, you know, not pursue a relationship, too.”*

### **Recommendations by Researchers to Academia and Funders to Increase and Improve Community Engagement Efforts**

Biomedical and health sciences researchers felt that academia needs to value community engagement to make the necessary cultural and systematic changes that support community engagement efforts. Academia currently places an emphasis on the academic career hierarchy, which revolves around academic ranks and titles and not on community engagement efforts. To achieve higher ranks and more prestigious titles, many researchers felt pressured to demonstrate their scholarship and contributions to academic institutions by teaching, publishing research, and attracting funding within a rigid timeframe. As a result, academia creates a competitive culture that values teaching, publishing research, and attracting funding over community engagement efforts.

*“I don’t get rewarded, or I don’t get acknowledged for doing community engagement. So, when I’m up for faculty review every three years, it’s not counted as much as the number of papers or grants or teaching hours that I have. So again, a lot of the community engagement that I do is done on my own time and is done using my own pocketbook at times. Yeah, and I don’t mind doing that. It’s just that I just wish that people understood, even foundations, because when we talked about foundations, sometimes they’re just equally as rigid as the university is, when it comes to community engagement and acknowledging the community.”*

*“Because sometimes, I mean, always, the researcher is just focus in the papers. But the thing is, that the academic systems push researchers for that. The academic systems doesn’t matter if you have a real public engagement program. The academic systems is just looking for your papers. I look at is not just about researchers, this is just about the whole systems that we are embedded. Okay, because the academic system is just ‘Okay, you publish or perish’.”*

### Overemphasis on Publishing

As noted by a researcher, an overemphasis on publishing leads to a “publish or perish” culture because academia creates a system built around publishing and attracting funds over taking time to develop community partnerships and engage with communities. Biomedical and health sciences researchers claimed that academia’s current metrics of scholarship, contributions around publishing, and attracting funding need to change to include metrics that value and incentivize community engagement efforts. Many researchers felt that if universities did more to prioritize community engagement, this would transform and promote their community engagement efforts.

*“But again, I think it’s highlighting that this is a priority. It’s not an afterthought. It’s not ‘this is a nice to do.’ This is a ‘you should do.’ And I think that’s going to be hard, right? In a lot of the PhD training programs, that’s not what’s done, right? You need to get this paper out into the highest impact journal possible and we need to get the next grant. And so, it’s going to require a shift in how we think about what’s important. Okay. Yeah, that makes a lot of sense. Do you see?”*

*“In terms of promotion and tenure at an academic center, ‘Oh! You do community engagement? Oh, who cares? What do you do? You do that on your own time? How many grants have you gotten, [Suppressed for Confidentiality]? How many first authors, senior author publications have you gotten?’ That’s what we care about... and until it gets incentivized people aren’t gonna care as much.”*

### Institutional Systems Impose Barriers

While changing academia’s current values is one way to transform community engagement, biomedical and health sciences researchers reported that the current institutional system needs to change and become more flexible and adaptive to the needs of researchers and communities to help promote community engagement. The current institutional system’s strict structures on research procedures and monetary compensation interfere with two main components of community engagement, as reported by researchers in this study: 1) Active participation and involvement of communities in the research process, and 2) Compensating communities adequately for their time. It dictates where community engagement researchers fall within the community engagement spectrum and strictly limits researchers from moving from the most basic form of community engagement to meaningful community engagement. Institutional systems present barriers by failing to adapt structures and policies that address the different needs of researchers and communities.

*“Yeah, we’re definitely still working out what it’s gonna look like sort of concretely, and there’s a lot of challenges to actually doing it. One of those challenges being what level of, sort of, I guess, approval like IRB approval those co-analysts would need to have in order to look at data with us. So that’s been one question that we’re trying to work out and still kind of navigating.”*

*The reason I bring it up with in like, sort of this question of resources and limitations is that paying my community advisory board has turned out to be unbelievably difficult. There’s so much red tape involved, it’s like, outrageous. I’m still like, it has taken months. And, I’ve tried to figure out who in my org, and, you know, who in this university can help me do it. And then there’s all of this paperwork people have, you know? Like, it’s just, it’s ridiculous...When you’re talking about community advisors in underrepresented communities, you need to compensate people for their time. And it is really just, it’s so stupid hard*



*to do it. And I think that's a huge problem... And like, the university organization is just completely backwards with it. It is not organized in a way that can, where that's possible. It really makes you feel like, 'I just never want to do this again. Like, why would I ever do this?' So like that, I think is a huge, big deal.*

### **Importance of Training and Knowledge-Building**

Many biomedical and health sciences researchers noted that providing more knowledge and training on community engagement as part of researchers' educational and academic endeavors will help transform community engagement. Most researchers spoke about how providing knowledge and training on community engagement can address skepticism researchers may feel towards community engagement and increase researchers' skills and confidence with community engagement.

*"Yeah, I think a lot of it goes back to the training that different investigators or scientists get earlier on in their curriculum. So, I think if you're a PI in biomedical informatics and you've never even heard of CBPR, it makes sense that you might be kind of skeptical about opening up these processes and decisions to communities. So, I think ensuring that there's more exposure within scientific curriculum and education, like there's more exposure to ideas around engagement and like frameworks of engagement. So, I, as an undergrad and certainly as a grad student, got to read a lot of social science and education literature that was like... that taught me about the history of CBPR, and other engagement approaches. I think some, like, integrating some of that into science curriculum could be really powerful. That definitely comes to mind... I talked with my colleagues a lot about what it could look like to train folks in the sciences on engagement. And I think we're pretty divided in my own lab about how useful that is because sometimes, like, I don't know... in my experience, the engagement is often outsourced to us or somebody like us, who are social science and trained engagement practitioners. Which I think is fine because that is the expertise that we bring, but I think it would also be very helpful if the collaborators we work with in those scientific contexts had a little bit more of an understanding, openness, training, and even skills and engagement. I think it would go a long way."*

*"I think in the time that they're training to be researchers. I think they need to start getting comfortable talking, going to the community fairs like the asthma fair. Talking to patient group, you know, again, the [Suppressed for Confidentiality], organization, stuff, starting there, even if you're going to be a basic researcher, because where it gets trickiest, it's the basic researchers, right? Because they're used to, like, what I you know, with mice and with, you know, primary epithelial cells or whatever, right? But they are not used to talking to people and getting their opinion because their training is based on what their principal investigator, what their boss is trying to tell them. So, I think from the beginning, you know, you are instilling that, 'Hey, if you want to actually make an impact on human health, at some point, this is part of your training now. You know, because we're going to give you this competency, the skill, in addition to being a brilliant scientist, we're going to teach you how to communicate, how not to be a jerk. How to listen.' And so, I think it starts there. So, teaching them and exposing them early on."*

### Clarity and Support from Funders

Additionally, the majority of biomedical and health sciences researchers described that funders need to further support community engagement by being more intentional about how they support researchers with community engagement efforts. A few researchers spoke to how funders need to be clear with researchers on what counts as meaningful community engagement by having clear criteria on funding calls and providing a clear example of community engagement. Aside from providing money, other researchers felt that funders should provide additional resources to researchers and community partners, including opportunities for researchers and community partners to connect or mentoring opportunities amongst emerging and advanced community engaged researchers.

*“I think the clear guidelines, the runway to say, you know, within this period we want you to engage with community. We want to hear how they participated in the writing of the grant. We want to know, like, you know, how do you plan to, for example, what will your readouts be of success? What is your measure of success of engagement? For example, some examples of success and community engagement is either engaging patients in research or being able to meaningfully present your data to them have them, you know, see the data, have them participate, have had a patient led conference that you, kind of, organize or something like that, like; but having clear criteria for, or having a clear example of, patient engagement and then when there is a funding call, kind of making sure that there is enough runway for genuine community engagement within that period.”*

*“I mean, in addition to capacity building, right? If the funder finds that, ‘Hey, there, you know?’ I know you want to it’s more of a collaborative process, right? Going and saying, ‘Hey, you may be interested in this. I know this person over here, who has worked with a similar community. Let me connect you with them so that you can talk and that you can get lessons learned from them. And maybe they’ll learn lessons from you.’ But it’s definitely just connecting people, and funders aren’t great at doing that necessarily. It’s like, it’s your, this is my project here, and instead of, because it’s always competitive. It’s like, who’s gonna get the money? Who am I going to edge out, you know, to get this award instead of, oh, let’s figure out who’s not a jerk that you can work with? Where you can try to establish something and just mentorship. Like mentoring opportunities, I think is really important to do this. It needs to be a safe space for people to be feel comfortable growing and that’s not what it feels like to me right now... At [Suppressed for Confidentiality] it’s all about the competition. No matter one up. It’s not about the people. It’s not about the people that you’re studying. It’s not about the condition. It’s about getting the money and getting the status. Yeah, I hate that... But how promotion and tenure works. It’s reinforced.”*

# DISCUSSION

Qualitative and quantitative findings revealed similar insights into how biomedical and health sciences researchers engage with communities, what their motivations are to do so, and how funders hinder meaningful engagement. The qualitative study showed: 1) funders can be barriers to community engaged research; 2) researchers who value community perspectives are more likely to do community engagement; 3) meaningful engagement requires researchers to expand their community engagement strategies to include a combination of both passive and active strategies; 4) relationship building and trust are necessary to prevent harmful community engaged approaches; 5) the importance of recommendations by researchers to academia and funders to increase and improve community engagement efforts. Additionally, quantitative analysis revealed that researchers' confidence in engaging communities greatly increased with years of experience, and that researchers with more years of experience were more likely to use certain community engagement approaches than others. Emerging researchers with five or less years of experience engaging communities were more likely to use passive engagement strategies, more often hired other researchers experienced with community engagement to assist in their studies, and were less likely to use specialized approaches when engaging with underrepresented communities of color. Advanced researchers with six or more years of experience often used a combination of passive and active engagement strategies, were more likely to hire community representatives and/or a diverse staff to help facilitate their engagement, and were more likely to use specialized approaches when engaging with underrepresented communities of color.



Emerging researchers with five or less years of experience engaging communities were more likely to use passive engagement strategies, more often hired other researchers experienced with community engagement to assist in their studies, and were less likely to use specialized approaches when engaging with underrepresented communities of color.

## Results Corroborate Past Research Findings

Many of our findings correspond to previous research regarding community engagement and researchers' perspectives and experiences. Findings regarding researchers' likelihood to engage communities are similar to studies that revealed researcher attitudes to be key factors in meaningfully involving communities in their work.<sup>32</sup> Researchers who saw community engagement as a valuable aspect of their study were often more enthusiastic at the idea of involving and working alongside community members, whereas researchers who felt community engagement was too time and/or resource consuming were less likely to make the effort. Researchers' personal attitudes often influenced their community engagement efforts. The necessity for researchers to update their community engagement approaches to better collaborate with different communities has also been cited in previous health sciences research.<sup>33</sup> Findings are also consistent with the importance of trust as an integral part of ensuring meaningful and positive community engagement.<sup>34</sup>

## Operationalizing Community Engagement

Themes drawn from study findings can inform future approaches to community engagement in biomedical and health sciences research.

### Understanding Community Engagement as a Process

Study findings showed that biomedical and health sciences researchers' understanding of community engagement influences their level of involvement with communities. Researchers who view community engagement as an outcome oftentimes engage with communities by using a checkbox framework. These researchers focus on doing community engagement by checking off boxes for different outcomes they must obtain. Researchers who used the checkbox framework for community engagement reported using passive community engagement strategies, such as light touch consultation and communicating results to communities. The checkbox framework for community engagement resulted in communities having little influence on project outcomes because the approach focuses on discrete and transactional community engagement activities, undermining how research is a process to be done *with* the community and not *on* or *for* the community. This suggests that biomedical and health sciences researchers must refrain from viewing community engagement as an outcome and instead view community engagement as a process.

If community engagement is viewed as a process, biomedical and health sciences researchers will understand that there is no one definition on what is meaningful community engagement. Meaningful community engagement varies based on each project, community circumstances, and relationships between researchers and communities. As a result, there is no one clear indicator of what is successful community engagement. Successful community engagement varies by each context and is largely defined by community perspectives. Researchers alone cannot define community engagement because community engagement is a collaborative process between researchers and communities.

### Developing Shared Understanding

From this study, biomedical and health sciences researchers can glean that they should create opportunities for shared understanding between researchers and the community to help bridge the language and power divides between researchers and communities. Developing a shared understanding helps promote effective communication through shared dialogue and balances the inequitable power between researchers and community. This can ultimately influence the willingness of communities to engage in partnerships by providing communities with an understanding of researcher's intentions, how community concerns will be addressed, and addressing any skepticisms due to historical mistrust. It also helps when researchers are clear with communities about the benefits of research participation and how they will be involved in the research process. Additionally, creating opportunities for shared understanding between researchers and the community allows researchers to understand the value behind community perspectives and experiences. Shared understanding also allows researchers to learn indispensable information about communities that they could not otherwise have learned because communities know their own community context best.

### Building Cultural Competency

Biomedical and health sciences researchers should also acknowledge underlying stereotypes and biases to improve the quality of community engagement efforts in research when working with underrepresented communities of color. Researchers should ensure that underlying stereotypes and biases do not interfere with their community engagement efforts. If researchers feel uncomfortable or unconfident working with underrepresented

communities of color, cultural competence and cultural intelligence training and strategies will help researchers feel more comfortable and confident to work across multiple diverse settings and communities. Cultural competency training and strategies involve learning best practices on how to understand and respond to cultural differences, meet the needs of communities, and develop culturally responsive practices. Cultural intelligence strategies involve researchers developing an awareness of stereotypes and biases toward diverse settings and communities and spending time with communities beyond research engagement purposes.

### **Importance of Diversity Paired with Cultural Competency**

A common approach many biomedical and health sciences researchers use when engaging with underrepresented communities of color is sending research team members with the same language or racial identity as the underrepresented communities of color to lead research activities. However, this approach fails to lead to meaningful community engagement as it siloes researchers from engaging with communities and incorporating other components needed for meaningful community engagement such as creating trust. If researchers want to move away from the most basic form of community engagement to more meaningful community engagement when working with underrepresented communities of color, researchers must engage with underrepresented communities of color beyond simply sending research team members with the same language or racial identity. Researchers need to build cultural competency and utilize cultural intelligence strategies in addition to having diversity amongst staff when working with underrepresented communities of color.

### **Funder Role in Supporting Community Engagement**

Although biomedical and health sciences researchers play a critical role in community engagement efforts as they directly interact with communities, funders can influence community engagement in research. Funders of biomedical and health sciences research have tremendous potential for informing researchers' community engagement efforts by acting as facilitators. However, this is an area often untapped by funders. Funders can guide researchers to look beyond the current research paradigm that focuses on researchers conducting research *on* or *for* a community and reframing research as research done *with* the community. This requires biomedical and health sciences funding organizations to revisit their organization's priorities, funding awards and allocations, funding cycle, and expectations for researchers to ensure they align with the learning and iterative processes of community engagement.

### **Prioritizing Community Engagement in Research Funding**

Biomedical and health sciences funders need to clearly emphasize their priority on community engagement by providing researchers with opportunities to participate in community engagement and incentivizing those who do so, while also honoring the preferences of those who may not want to do community engagement. This should be implemented by integrating community engagement as part of the request for applications process, providing clear examples and/or definition of community engagement, and providing an opt-out option for those who may not want to do so. As suggested by researchers, funders should also clearly emphasize their priority on community engagement by providing dedicated funding to both researchers and communities that support community engagement efforts. This dedicated funding should not follow strict guidelines that prohibit incentivizing community members in non-traditional ways (e.g., paying for childcare, travel, food, etc.) and should allow for opportunities to direct funds directly to

communities instead of having funds being distributed (e.g., pass through) by researchers. Additionally, biomedical and health sciences funders should reconceptualize funding cycles by providing flexibility on timeline and strict deadlines to allow for consideration of the time needed to build relationships and trust.

### **Building Community Engagement Skills and Knowledge**

While all of the aforementioned components are necessary for funders of biomedical and health sciences research to begin guiding researchers towards community engagement, it is not sufficient. Funders must support researchers who have varying levels of skills and experience with community engagement and address barriers to meaningful community engagement. As seen throughout this study, biomedical and health sciences researchers identified needing more knowledge and training on community engagement as one of the barriers to community engagement. Several researchers emphasized not learning about community engagement or receiving training on community engagement as part of their academic curriculum. Funding organizations can help build researchers' capacity in community engagement by:

1. Providing access to courses or workshops on principles of community engagement, especially on building relationships and trust, effective communication, and cultural competency. Overall, researchers indicated in this study the need for more knowledge and training on community engagement which may help increase their skills and confidence with community engagement.
2. Providing technical assistance (TA) opportunities to researchers. This may entail providing strategic planning on community engagement efforts through staff consultations and additional materials like reading lists, examples of meaningful community engagement, and other content relevant to researchers. This study's results suggest that researchers need more clarity from funders on what community engagement entails and need additional support from funders on community engagement aside from providing money. By providing TA to researchers on community engagement, funders can help address these needs and provide clarity on how and in which ways community engagement in research is a priority for their funding organization.
3. Creating a mentorship opportunity where researchers who need guidance on community engagement efforts can connect with more experienced community engaged researchers. Results provide important insights into researchers' need for more knowledge on community engagement. Mentorship opportunities can encourage emerging community engaged researchers to use a combination of both active and passive community engagement approaches by learning and adopting some of the community engagement approaches used by more advanced community engaged researchers. Additionally, mentorship opportunities can provide the space for all researchers with varying community engagement experiences to engage in reflection by sharing with each other what went well, what was challenging, and areas for improvement.
4. Providing a forum for reflection on community engagement efforts. Research findings show that researchers who engage in meaningful reflection better understand the need of communities and how to share power with communities.

## Limitations

This study is subject to some limitations. Participant recruitment was limited to researchers and funders who participated in community engaged research or were interested in community engaged research. These findings cannot be generalized to all biomedical and health researchers and funders, specifically those who are not involved in nor interested in community engaged research. The ability to generalize findings to funders of biomedical and health sciences research is also limited, since we only received 16 survey responses from funders and were only able to recruit three funders for interviews. Demographic information such as race, gender, and age, were not collected for study participants. Therefore, we are unable to formally explore if demographics play a role in perceptions of community engaged research. It would be interesting to explore the intersection of race, gender, age, and community engaged research that targets underrepresented communities of color. The study is also limited to the perceptions of researchers and does not include the perceptions of community representatives. In future work, it may be necessary to obtain the perceptions of the community to understand how they feel about community engaged research.

## Conclusions

This report illustrates the current community engagement landscape of biomedical and health sciences researchers and funders and provides a next step approach to better understand and promote community engagement when working with underrepresented communities of color. Findings can be used to inform biomedical and health sciences researchers who are interested in engaging with communities by revealing the approaches, attitudes, and understandings necessary to do so. Funders can gain insight into how to best support community engagement efforts by embracing recommendations from researchers. As a result, biomedical and health sciences researchers and funders can learn from each other and the communities around them to make strides towards meaningfully engaging with communities and ultimately promoting health equity for all.

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# APPENDIX A: COMMUNITY ENGAGEMENT IN BIOMEDICAL AND HEALTH SCIENCES RESEARCH STUDY SURVEY

## CZI Project- Community Engagement in Biomedical and Health Sciences Research

### Introduction

The [Population Health Innovation Lab \(PHIL\)](#), a program of the [Public Health Institute \(PHI\)](#), is conducting a research study to learn about community engagement in biomedical and health sciences research. **The study will deepen understanding of the attitudes, beliefs, and motivations for conducting and/or funding biomedical and health sciences research that directly engages [underrepresented communities of color](#).**

**Your Invitation:** You are receiving this invitation to participate in the study because you were referenced in the literature or referred by another researcher or funder as someone who has experience with community engagement in biomedical or health sciences research, either as a researcher or a funder. Survey questions will ask about your research and/or funding focus areas, community engagement strategies, and funding sources.

**Time Commitment:** This survey should take about **15-25 minutes** to complete. You do not need any resources to complete the survey other than your thoughts and experience with community engagement as a researcher or funder of biomedical and/or health sciences research. Survey questions will ask about your research and/or funding focus areas, community engagement approaches, and funding sources. It may be helpful to have a list of focus areas for your organization and list of funding sources.

**Thank You Gift:** We value your time, expertise, and contributions. As a thank you for your participation you will receive a **\$20 electronic gift card** upon survey completion. The gift card can be redeemed at 80+ retailers or donated to 20+ national nonprofits.

**Invite Others to Participate:** You can help ensure we hear from diverse perspectives by forwarding this survey to your colleagues who work in the biomedical and or health sciences as a researcher or funder and include a community engagement focus in their work.

**Study Funding:** The Community Engagement in Biomedical Research study is funded by the [Chan Zuckerberg Initiative \(CZI\)](#), a philanthropic organization with a mission to “build a more inclusive, just, and healthy future for everyone.”<sup>1</sup>

Aggregate, de-identified findings will be shared by PHIL with CZI to inform their efforts to support biomedical researchers in increasing ancestral representation in studies, such as contributions to the Human Cell Atlas to build a more inclusive, scientifically-relevant resource<sup>2</sup>, as one example.

If you would like to proceed with this survey, please complete the screening questions on the next page to determine if you are eligible.

<sup>1</sup><https://chanzuckerberg.com/about/our-approach/>.

<sup>2</sup><https://www.humancellatlas.org/>

## SCREENING QUESTIONS

Q1. Name:

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Q2. Organizational Affiliation:

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Q3. Title:

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Q4. Are you currently working as a health sciences researcher or funder of health sciences research? (*health sciences study all aspects of health, disease and healthcare*)

- Researcher
- Funder
- Both researcher and funder
- Neither

Q5. Do you have experience performing or funding community engagement and/or community-based participatory research (CBPR) with underrepresented communities of color in biomedical research?

- Performing
- Funding
- Both performing and funding
- Neither

### Consent

The purpose of this form is to ask for your voluntary participation in a research study. Please consider the following information carefully before you decide to participate.

#### Purpose and background of the research study

The [Population Health Innovation Lab \(PHIL\)](#), a program of the [Public Health Institute \(PHI\)](#), is conducting a research study to learn about community engagement in biomedical research and funding. The study you are being asked to participate in is intended to obtain information about how community engagement is done and prioritized, as well as attitudes and beliefs and motivations of engaging underrepresented communities of color in biomedical research. The study is led by Esmeralda Salas, PHIL Research Associate. The study Principal Investigators are Stephanie Bultema, MAAL, PhD(c) and Sue Grinnell, MPH. You were identified as a potential research participant either through your published research or participation in community engagement efforts, or through a referral from one of your colleagues.

#### Study procedures

If you agree to participate in this study, you will continue to complete this survey, which contains a series of questions relating to your experience with community engagement as a researcher or funder and your perceptions of how meaningful community engagement can and should be achieved. The survey should take approximately 15-25 minutes to complete.

### **Risks of participation**

Answering some of the survey questions may make you feel uncomfortable. However, you can decide not to answer a specific question, take a break, or stop the survey at any time. In addition, there are always some risks in giving information about yourself to someone else. To minimize these risks, the research team has instituted security procedures to protect your privacy and keep information about you as confidential as possible. For example, your completed survey will be kept using a secure, password-protected cloud storage service accessible only to the research team. Your identity will not be revealed in any publication or report resulting from the study without your explicit written consent.

### **Benefits of participation**

Participating in this research study will not benefit you personally. However, the results of this research will add to scientific knowledge about effective community engagement in biomedical research. Long-term societal benefits could include a more generalizable understanding of disease diagnosis and treatment with the involvement of a more diverse group of participants in future biomedical research efforts.

### **Payment for participation**

You will receive a \$20 electronic gift card upon survey completion.

### **Alternatives**

Although there are no alternatives associated with this study, there is no penalty for non-participation.

### **Questions**

If you have any questions about the study or your rights as a subject, you can write to Esmeralda Salas at [esalas@phi.org](mailto:esalas@phi.org) or call her during regular business hours at (424) 297-6512. Alternatively, you can call Robert McLaughlin, J.D., Ph.D., Administrator of the PHI Institutional Review Board (the committee that oversees PHI research involving human subjects) during regular business hours at (510) 285-5500.

### **Consent**

Your participation in the study is voluntary. You can decide not to participate and you can drop out of the study at any time without penalty or loss of services. If you drop out, you have the right to tell the research team to destroy any information already collected about you.

**If you agree to participate, please use your mouse to sign below.**

**\*\*Please print this page for your records\*\***

**GQ1. Please briefly describe your role and responsibilities within your organization.**

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**GQ2. Would you best describe yourself as a researcher or funder?**

- Researcher
- Funder
- Both researcher and funder
- Other, please describe: \_\_\_\_\_

**GQ3. What does community engagement and/or community-based participatory research (CBPR) mean to you, within your context? Please describe in a few sentences.**

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## DEFINITIONS

Please review the following terms and definitions. We ask that you keep these terms and definitions in mind as you proceed with answering survey questions.

**Community:** Community refers “to a group of people living in the same locality, religion, race, profession or with other common characteristics.”<sup>3</sup> It is a fluid term contingent on the goals and context of the groups of people. Within the context of the survey, community refers to communities outside of the academic or research settings.

**Underrepresented Communities of Color:** Specific communities of color are underrepresented in biomedical research, including those of African, Latinx, Greater Middle Eastern, Indigenous, Oceanian, Southeast Asian, and multiple or other non-European ancestries. Please refer to the figure on genomics research [in this article](#) to learn more.

**Community Engagement:** Community engagement is “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”<sup>4</sup> This involvement can be as a research participant, tissue donor, community representative on an advisory board, or other involvement in the research process.

**Community-based participatory research (CBPR):** CBPR entails “equal participation of community partners and researchers throughout the research process with shared decision making.”<sup>5</sup>

## RESEARCHER AND OTHER PROFESSIONAL QUESTIONS

Please answer these questions from your perspective as a biomedical and/or health sciences researcher.

**R1. Please list the primary topic areas of your research focus area(s) (e.g. provide key terms).**

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**R2. How many years of experience do you have with engaging communities in your research?**

- Less than 1 year
- 1-5 years
- 6-10 years
- More than 10 years

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<sup>3</sup>Marsh, V. M., Kamuya, D. K., Parker, M. J., & Molyneux, C. S. (2011). Working with Concepts: The Role of Community in International Collaborative Biomedical Research. *Public health ethics*, 4(1), 26–39. <https://doi.org/10.1093/phe/phr007>

<sup>4</sup>Clinical and Translational Science Awards Consortium, and Community Engagement Key Function Committee Task Force on the Principles of Key Engagement. 2011. *Principles of Community Engagement. Principles of Community Engagement. Second Edi.* National Institutes of Health. [https://www.atsdr.cdc.gov/communityengagement/pdf/PCE\\_Report\\_508\\_FINAL.pdf](https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf).

<sup>5</sup>Israel, Barbara A., James Krieger, David Vlahov, Sandra Ciske, Mary Foley, Princess Fortin, J. Ricardo Guzman, et al. 2006. “Challenges and Facilitating Factors in Sustaining Community-Based Participatory Research Partnerships: Lessons Learned from the Detroit, New York City and Seattle Urban Research Centers.” *Journal of Urban Health* 83 (6): 1022–40. <https://doi.org/10.1007/s11524-006-9110-1>.

Q125 Please keep the following definition of community in mind as you proceed with answering the following survey questions.

**Community:** Community refers “to a group of people living in the same locality, religion, race, profession or with other common characteristics.”<sup>3</sup> It is a fluid term contingent on the goals and context of the groups of people. Within the context of the survey, community refers to communities outside of the academic or research settings.

**R3. How do you engage communities in your research? Please describe specific frameworks or approaches used, if applicable.**

---

**R4. Have you utilized specialized or tailored engagement approaches to ensure your engagement includes underrepresented communities of color (i.e. information fairs, town halls, religious/community center outreach)?**

- Yes
- No
- Don't know / unsure

**R5. Please describe what specialized or tailored engagement approaches you have used to ensure your engagement includes underrepresented communities of color (i.e. information fairs, town halls, religious/community center outreach). Please be as specific as possible. *This question was only answered by those who answered “Yes” for the question “Have you utilized specialized or tailored engagement approaches to ensure your community engagement includes underrepresented communities of color (i.e. information fairs, town halls, religious/community center outreach)?”.***

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**R6. Which of the following community engagement approaches have you used? (Select all that apply)**

- Using community-based participatory research (CBPR)
- Establishing a community advisory board, stakeholder advisory board, or other advisory board
- Establishing a youth engagement program
- Administering surveys to the community
- Conducting focus groups with community representatives
- Conducting community health needs assessment
- Providing educational resources to communities (fact sheets, infographics, videos, etc.)
- Providing training for community representatives
- Partnering with community representatives to collect data
- Requesting input from community representatives
- Involving community representatives in decision-making processes
- Compensating community partners for engagement
- Sharing research findings with community representatives (presentation, report, etc.)
- Establishing bi-directional communication between researchers and communities
- Establishing a memorandum of understanding/agreement with community-based organization(s)
- Other, please describe: \_\_\_\_\_

**R7. Based on your experience, what is your definition of success with community engagement practices? Please describe in a few sentences.**

---

R8-1. How successful has your use of **community-based participatory research (CBPR)** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-2 How successful has your use of **establishing a community advisory board, stakeholder advisory board, or other advisory board** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-3. How successful has your use of **establishing a youth engagement program** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-4. How successful has your use of **administering surveys to the community** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-5. How successful has your use of **conducting focus groups with community representatives** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-6. How successful has your use of **conducting community health needs assessments** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-7. How successful has your use of **providing educational resources to communities (fact sheets, infographics, videos, etc.)** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-8. How successful has your use of **providing training for community representatives** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-9. How successful has your use of **partnering with community representatives to collect data** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-10. How successful has your use of **requesting input from community representatives** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-11. How successful has your use of **involving community representatives in decision-making processes** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*



- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-12. How successful has your use of **compensating community partners for engagement** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-13. How successful has your use of **sharing research findings with community representatives (presentation, report, etc.)** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-14. How successful has your use of **establishing bi-directional communication between researchers and communities** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-15. How successful has your use of **establishing a memorandum of understanding/agreement with community-based organization(s)** as a community engagement approach been? *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R8-16. How successful has your use of other **community engagement approaches** as a community engagement approach been? Please describe. *This question was only answered by those who indicated using this approach for the question "Which of the following community engagement approaches have you used? (Select all that apply)".*

- Not at all successful
- Somewhat unsuccessful
- Somewhat successful
- Extremely successful

R9. Why do you think the approaches you have used were **successful**? Please describe in a few sentences and provide examples if applicable. *This question was only answered by those who indicated successfully using at least one of the community engagement approaches.*

---

R10. Why do you think the approaches you have used were **unsuccessful**? Please describe in a few sentences. *This question was only answered by those who indicated not successfully using at least one of the community engagement approaches.*

---

R11. Please rate your level of confidence with engaging community in your research.

- Very unconfident
- More unconfident than confident
- More confident than unconfident
- Very confident

R12. What would **improve** your level of confidence with engaging community in your research? Please describe in a few sentences. *This question was only answered by those who rated their confidence as "Very unconfident" or "More unconfident than confident" for the question "Please rate your level of confidence with engaging community in your research".*

---

R13. What **advice** do you have for other researchers seeking to become more confident with engaging community in their research? Please describe in a few sentences. *This question was only answered by those who rated their confidence as "More confident than unconfident" or "Very confident" or for the question "Please rate your level of confidence with engaging community in your research".*

---

R14. What do you think are the **top benefits** of engaging community in your research? (Select all that apply.)

- Increase chances of funding
- Identify meaningful research questions
- Improve study results
- Increase diverse research participation
- Build study credibility
- Improve community health
- Improve health equity
- Other, please describe: \_\_\_\_\_

R15. Which of the following have facilitated your community engagement and/or CBPR efforts? (Select all that apply)

- Receiving funding for community engagement and/or CBPR
- Receiving training on community engagement and/or CBPR
- Access to community engagement and/or CBPR tools & resources
- Leveraging existing community relationships
- Being required or encouraged by your institution to engage communities
- Hiring diverse staff that represents that community and/or identifies with the community
- Hiring a researcher focused on community engagement and/or CBPR
- Other, please describe: \_\_\_\_\_

**R16. What are the biggest challenges you have faced with engaging community in your research? (Select all that apply)**

- Researcher's time commitment
- Community's time commitment
- Securing resources (e.g., funding translation services, meeting space, etc.)
- Staff capacity
- Cultural barriers
- Lack of experience with community engagement and/or CBPR
- Lack of confidence with community engagement and/or CBPR
- Lack of interest in community engagement and/or CBPR
- Other, please describe: \_\_\_\_\_

**R17. What motivates you to engage community representatives in your research? Please describe in a few sentences.**

---

**R18. Have you ever applied for funding to support community engagement and/or CBPR in your biomedical and/or health sciences research?**

- Yes
- No
- Don't know / unsure

**R19. Was your funding application successful? *This question was only answered by those who indicated "Yes" for the question "Have you ever applied for funding to support community engagement and/or CBPR in your biomedical and/or health sciences research?"***

- Yes
- No
- Don't know / unsure

**R20. From your perspective, what factors contributed to the success of your community engagement and/or CBPR proposal? Please describe in a few sentences. *This question was only answered by those who indicated "Yes" for the questions "Have you ever applied for funding to support community engagement and/or CBPR in your biomedical and/or health sciences research?" and "Was your funding application successful?"***

---

**R21. Please list the names of funding sources you have applied or considered applying for funding for community engagement and/or CBPR. For the funding sources you have applied, please indicate whether you received funding from this source.**

---

## FUNDER QUESTIONS

Please answer these questions from your perspective as a funder of biomedical and/or health sciences research.

**F1. Are you involved in supporting grantmaking and/or administering grants to researchers who conduct community engagement and/or CBPR in biomedical and/or health sciences research?**

- Yes
- No
- Don't know / unsure

**F2. How many years of experience do you have with funding community engagement and/or CBPR in biomedical and/or health sciences research?**

- Less than 1 year
- 1-5 years
- 6-10 years
- More than 10 years

**F3. What are the priority topic areas for your department or program? Please describe in a few sentences.**

---

**F4. Which of the following are current funding priorities for your organization? (Select all that apply)**

- Community engagement and/or CBPR in research
- Diversifying donor samples
- Developing open science practices
- Building computational tools
- Developing new methods
- Health Equity
- Patient engagement in research
- Other, please describe: \_\_\_\_\_

**F5. How does your organization support community engagement and/or CBPR in biomedical and/or health sciences research? (Select all that apply)**

- Providing funding for researchers to engage community in their work
- Training researchers on community engagement and/or CBPR principles and practices
- Offering tools and resources to support community engagement and/or CBPR in biomedical research
- Providing support to the partnerships between community organizations and researchers
- Providing funding for a community engagement office within a research institution
- Providing training and/or capacity building for communities or community organization to engage with academic institutions and/or research projects.
- Other, please describe: \_\_\_\_\_

F6. When reflecting on the choices selected in the previous question, does your organization use different approaches for supporting researchers who work with underrepresented communities of color than what is described above?

- Yes
- No
- Don't know / unsure

F7. Please describe how approaches differ when supporting researchers who specifically work with underrepresented communities of color versus working with the general population. Please be as specific as possible. *This question was only answered by those who indicated "Yes" to the question "When reflecting on the choices selected in the previous question, does your organization use different approaches for supporting researchers who work with underrepresented communities of color than what is describes above?"*.

---

F8. What criteria do you/your organization use when evaluating proposals for research projects that engage communities? Please describe in a few sentences.

---

F9. What indicators of success do you/your organization look for when evaluating researcher success with community engagement? (Select all that apply)

- Number of community members engaged in the research
- Community-based organizations (CBOs) are engaged in the research
- Used community-based participatory research (CBPR)
- Established a community advisory board, stakeholder advisory board, or similar
- Administered surveys to the community
- Conducted focus groups with community representatives
- Conducted community health needs assessments
- Provided educational resources to communities (fact sheets, infographics, videos, etc.)
- Provided training for community representatives
- Partnered with community representatives to collect data
- Requested input from community representatives
- Involved community representatives in decision-making processes
- Compensated community partners for engagement
- Shared research findings with community representatives (presentation, report, etc.)
- Established a memorandum of understanding/agreement (MOU/A) with CBO(s)
- Other, please describe: \_\_\_\_\_

F10. Which of the following indicators of success do you consider most important when evaluating researcher success with community engagement? Please rank the options below by clicking the option and dragging it to the appropriate rank. Rank 1 is the most important.

- \_\_\_\_\_ Number of community members engaged in the research
- \_\_\_\_\_ Community-based organizations (CBOs) are engaged in the research
- \_\_\_\_\_ Used community-based participatory research (CBPR)
- \_\_\_\_\_ Established a community advisory board, stakeholder advisory board, or similar
- \_\_\_\_\_ Administered surveys to the community
- \_\_\_\_\_ Conducted focus groups with community representatives
- \_\_\_\_\_ Conducted community health needs assessments

- \_\_\_\_\_ Provided educational resources to communities (fact sheets, infographics, videos, etc.)
- \_\_\_\_\_ Provided training for community representatives
- \_\_\_\_\_ Partnered with community representatives to collect data
- \_\_\_\_\_ Requested input from community representatives
- \_\_\_\_\_ Involved community representatives in decision-making processes
- \_\_\_\_\_ Compensated community partners for engagement
- \_\_\_\_\_ Shared research findings with community representatives (presentation, report, etc.)
- \_\_\_\_\_ Established a memorandum of understanding/agreement (MOU/A) with CBO(s)
- \_\_\_\_\_ Other, please describe: \_\_\_\_\_

**F11. What resources do you offer grantees to facilitate success with community engagement and/or CBPR in research? (Select all that apply)**

- Funding, please describe: \_\_\_\_\_
- Training, please describe: \_\_\_\_\_
- Technical assistance, please describe: \_\_\_\_\_
- Staff capacity, please describe: \_\_\_\_\_
- Tools, please describe: \_\_\_\_\_
- Resources, please describe: \_\_\_\_\_
- Meeting space, please describe: \_\_\_\_\_
- Other, please describe: \_\_\_\_\_

**F12. What motivates your organization to provide funding for community engagement and/or CBPR in biomedical and/or health sciences research? (Select all that apply)**

- Other funders are doing this
- Past research supports this approach
- Desire to diversify the evidence base
- Potential for improved community health
- Potential for improved health equity
- Potential for improved utility of funded research
- Other, please describe: \_\_\_\_\_

**F13. Please describe your greatest success with funding community engagement and/or CBPR in biomedical and/or health sciences research. Please describe in a few sentences.**

\_\_\_\_\_

**F14. What barriers does your organization face related to funding community engagement and/or CBPR in biomedical and/or health sciences research? Please describe in a few sentences.**

\_\_\_\_\_

# APPENDIX B: COMMUNITY ENGAGEMENT IN BIOMEDICAL AND HEALTH SCIENCES RESEARCH STUDY RESEARCHER INTERVIEW GUIDE

## INTERVIEW DESCRIPTION

Date of interview:  
Name of interviewer:  
PTID:

## INTERVIEW OVERVIEW

Duration: 60-90 minutes

1. Intro & General (~10 mins)
2. Experience (~15 mins)
3. Best Practices (~15 mins)
4. Systems & Processes (~15 mins)
5. Closing (~5 mins)

## INTRODUCTION

Thank you for taking the time to speak with me today. As discussed via email, the goal of the study is to gain a deeper understanding of the attitudes, beliefs, and motivations for conducting and/or funding biomedical and health sciences research that directly engages underrepresented communities of color.

Underrepresented communities of color are specific communities of color underrepresented in biomedical research, including those of African, Latinx, Greater Middle Eastern, Indigenous, Oceanian, Southeast Asian, and multiple or other non-European ancestries.

Ultimately, your feedback will help us understand best practices when engaging community representatives in research, the systems in place to do this work, and the key players involved in building meaningful researcher-community relationships

I am excited to learn more about your experiences and thoughts with community engagement in biomedical and/or health sciences research.

### What to Expect:

- Your participation is voluntary, and you are free to skip any questions that you do not want to answer, for any reason.
- Your responses will be kept confidential. Responses will not be shared in an individually identified way outside of the research team unless you provide written consent.
- The name of the organization you are representing will be shared with CZI, unless you request this information be suppressed in reporting.
- The conversation will last about 60 to 90 minutes. You are welcome to take a break or stop the interview at any time.
- If we record this interview (with your permission), the recording will be used only to verify the notes we're taking during the call and to capture any important quotes accurately.

I included a summary of your rights as participant in the consent form I sent in the reminder email.

Do you have any questions for me about that document?

Do you have any questions before we get started?

Do I have your permission to record this interview?

**\*\*START CLOUD RECORDING\*\***

*\*\*If participant did not sign the consent form, have them state once the recording starts that they consent to participate in the study.*

## INTRODUCTION

*To start, I'd like to learn more about you.*

1. What is your professional role?
  - a. On what topic(s) does your research focus on?
  - b. Does your research fall more into the biomedical or general health sciences field?
2. How many years of experience do you have with community engagement and/or community-based participatory research?

*Thank you for providing me with some insights on your professional role. The next question is:*

3. When you think of community engagement in research and/or community-based participatory research, what comes to mind first?
  - a. When you refer to community, who or what is included in this term, from your perspective?
  - b. What does not count as community engagement and/or community-based participatory research, in your opinion?
  - c. What are the benefits of engaging community in research, from your perspective?

*Before jumping into our discussion on community engagement in biomedical and health sciences research, I would like to read some definitions on some of the common terms used throughout the interview (such as community engagement and CBPR). I will also paste these in the chat for your reference.*

## DEFINITIONS

**Community Engagement:** Community engagement is “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”<sup>1</sup> This involvement can be as a research participant, tissue donor, community representative on an advisory board, or other involvement in the research process.

**Community-based participatory research (CBPR):** CBPR entails “equal participation of community partners and researchers throughout the research process with shared decision making.”<sup>2</sup>



**4. Do the definitions that I just read align with your understanding of community, community engagement, and/or CBPR?**

a. How does your understanding of these terms differ, if at all?

## **COMMUNITY ENGAGEMENT EXPERIENCE**

*The following set of questions ask about your experience with community engagement.*

**5. How do you engage community members and leaders in research? (e.g., community advisory boards, consulting community members and leaders on study design, sharing findings with participants, etc.)**

a. How do you engage diverse participants (such as underrepresented communities, communities of color, specific communities, etc.) in research?

i. What approaches or frameworks (i.e. CBPR) do you use?

ii. Can you provide examples of different ways you engage with diverse participants and communities?

b. To what extent does your research population resemble the makeup of the community, in terms of demographic factors like race/ethnicity, socioeconomic status, etc.?

**6. How does your community engagement approach differ when working with communities of color, if at all?**

**7. Please describe a specific example of when you have engaged the community in research.**

a. What communities were being engaged?

b. What was the purpose of engagement? (i.e., was it solely for research purposes?)

c. What engagement approaches were used?

d. What aspects of community engagement did you find most rewarding?

e. What aspect of community engagement did you find most challenging?

f. What was the impact of the community engagement?

i. How did community engagement influence research outcomes?

ii. Would you do it again? Why or why not?

## **BEST PRACTICES FOR ENGAGING COMMUNITY IN BIOMEDICAL AND/OR HEALTH SCIENCES RESEARCH**

*The next few questions focus on best practices when engaging community members and leaders in biomedical and health sciences research. You are welcome to speak to your own experience, the experiences of others, or best practices of which you have awareness but have not yet implemented.*

**8. What approaches have you found to be most successful for engaging community members and leaders in research?**

a. Are there different strategies you use based off the type of research project you are conducting?

b. How do you build trust with community?

c. How do you share power with community? Can you provide specific examples and practices?

9. How do you know when community is being meaningfully engaged in research?
- a. What indicators do you look for to know this is being done well?
    - i. What type of research did you conduct to learn more about community engagement?
    - ii. Did you collaborate with other institutions or individuals?
  - b. What are the benefits of engaging community in research, from your perspective?
10. What would further develop your skills in meaningfully engaging community members and leaders?

## SYSTEMS, PROCESSES, & RESOURCES

*The next few questions focus on the systems, processes, and resources that influence community engagement practices. We are particularly interested in learning about the various systems, processes, and resources that can help or hinder community engagement in biomedical and health sciences research.*

11. What systems, processes, or resources have encouraged you to engage community members and leaders in research, if any? *These may be part of your organization or an external organization.*
- a. How did the system/process/resource encourage community engagement? What did you find most helpful? What could have been improved?
  - b. Think about a time when you chose to engage community in your research. What are the main factors that weighed into your decision to engage community members and leaders in research?
    - i. Can you talk me through the decision-making process?
  - c. Have you received training that helped prepare you to engage with communities? If so, what kind of training was most helpful?

Possible probes for medical/public health researchers only:

- d. How has the field changed to incorporate community engagement?
- e. Was there anything in particular that sparked a change in funding so that community engagement became better supported?

12. What systems, processes, or resources have discouraged you from engaging community members and leaders in research, if any? *These may be part of your organization or an external organization.*
- a. How did the system/process/resource discourage community engagement?
    - i. What did you find most challenging?
    - ii. What could have been improved?
  - b. Think about a time when you could have engaged community in your research but decided against engaging community representatives. What are the main factors that weighed into your decision to not engage community representatives in your research?
    - i. Can you talk me through the decision-making process?
    - ii. Still thinking about this example, is there anything that could have happened (more time, more money, better connections?) that would have made you engage the community in this case?

13. What systems or processes need to change to facilitate meaningful engagement of community members and leaders in biomedical and health sciences research?

- a. What barriers currently exist to funding community engagement work in biomedical research?
- b. What kind of training should be provided to researchers to prepare them for community engagement?

14. Have you ever applied for funding to support community engagement in biomedical and/or health sciences research? If so, what barriers and facilitators did you experience from funding organizations?

## CLOSING

15. What advice would you give to other researchers who want to engage communities in their work?

16. What advice would you give to funders who want to engage communities in their work?

- a. What would you like to see funded (e.g., set aside funding to hire a social worker, whole grant programs around community engagement, etc.?)

17. Who else should we speak with to learn more about community engagement in biomedical and health sciences research and/or funding spaces?

18. Is there anything else you want to share?

19. Do you have any questions for me?

Thank you for taking the time to inform the study of community engagement in biomedical and health sciences research. We appreciate your time and insights. You will receive a \$30 gift card as small thank you for your participation. *I look forward to staying in touch!*

**\*\*END INTERVIEW\*\***

## DEFINITIONS

**Underrepresented Communities of Color:** Specific communities of color are underrepresented in biomedical research, including those of African, Latinx, Greater Middle Eastern, Indigenous, Oceanian, Southeast Asian, and multiple or other non-European ancestries. Please refer to the figure on genomics research [in this article](#) to learn more.

**Community Engagement:** Community engagement is “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”<sup>1</sup> This involvement can be as a research participant, tissue donor, community representative on an advisory board, or other involvement in the research process.

**Community-based participatory research (CBPR):** CBPR entails “equal participation of community partners and researchers throughout the research process with shared decision making.”<sup>2</sup>

**Community:** Community refers “to a group of people living in the same locality, religion, race, profession or with other common characteristics.”<sup>1</sup> It is a fluid term contingent on the goals and context of the groups of people. Within the context of the survey, community refers to communities outside of the academic or research settings.

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<sup>1</sup>Clinical and Translational Science Awards Consortium, and Community Engagement Key Function Committee Task Force on the Principles of Key Engagement. 2011. *Principles of Community Engagement. Principles of Community Engagement. Second Edi.* National Institutes of Health. [https://www.atsdr.cdc.gov/communityengagement/pdf/PCE\\_Report\\_508\\_FINAL.pdf](https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf).

<sup>2</sup>Israel, Barbara A., James Krieger, David Vlahov, Sandra Ciske, Mary Foley, Princess Fortin, J. Ricardo Guzman, et al. 2006. “Challenges and Facilitating Factors in Sustaining Community-Based Participatory Research Partnerships: Lessons Learned from the Detroit, New York City and Seattle Urban Research Centers.” *Journal of Urban Health* 83 (6): 1022–40. <https://doi.org/10.1007/s11524-006-9110-1>.

<sup>3</sup>Marsh, V. M., Kamuya, D. K., Parker, M. J., & Molyneux, C. S. (2011). *Working with Concepts: The Role of Community in International Collaborative Biomedical Research.* *Public health ethics*, 4(1), 26–39. <https://doi.org/10.1093/phe/phr007>

# APPENDIX C: COMMUNITY ENGAGEMENT IN BIOMEDICAL AND HEALTH SCIENCES RESEARCH STUDY FUNDER INTERVIEW GUIDE

INTERVIEW DESCRIPTION	INTERVIEW OVERVIEW
Date of interview: Name of interviewer: PTID:	<i>Duration: 60-90 minutes</i> 1. Introduction & General (~10 mins) 2. Funder Support (~15 mins) 3. Experience with Funding Community Engagement (~15 mins) 4. Barriers & Facilitators (~15 mins) 5. Looking Forward (~15 mins) 6. Closing (~5 mins)

## Introduction

Thank you for taking the time to speak with me today. As discussed via email, the goal of the study is to gain a deeper understanding of the attitudes, beliefs, and motivations for conducting and/or funding biomedical and health sciences research that directly engages underrepresented communities of color.

Underrepresented communities of color are specific communities of color underrepresented in biomedical research, including those of African, Latinx, Greater Middle Eastern, Indigenous, Oceanian, Southeast Asian, and multiple or other non-European ancestries.

Ultimately, your feedback will help us understand best practices when engaging community members and leaders in research, the systems in place to do this work, and the key players involved in building meaningful researcher-community relationships

I am excited to learn more about your experiences and thoughts with community engagement in biomedical and/or health sciences research.

## What to Expect:

- Throughout the interview, I will be using the terms community engagement and community-based participatory research.

**Community Engagement:** Community engagement is “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”<sup>1</sup> This involvement can be as a research participant, tissue donor, community representative on an advisory board, or other involvement in the research process.

**Community-based participatory research (CBPR):** CBPR entails “equal participation of community partners and researchers throughout the research process with shared decision making.”<sup>2</sup>

I will also paste these definitions in the chat for your reference.

- Your participation is voluntary, and you are free to skip any questions that you do not want to answer, for any reason.
- Your responses will be kept confidential. Responses will not be shared in an individually identified way outside of the research team unless you provide written consent.
- The name of the organization you are representing will be shared with CZI, unless you request this information be suppressed in reporting.
- The conversation will last about 60 to 90 minutes. You are welcome to take a break or stop the interview at any time.
- If we record this interview (with your permission), the recording will be used only to verify the notes we are taking during the call and to capture any important quotes accurately.

I included a summary of your rights as participant in the consent form I sent in the reminder email.

**Do you have any questions for me about that document?**

**Do you have any questions before we get started?**

**Do I have your permission to record this interview?**

**\*\*START CLOUD RECORDING\*\***

*\*\*If participant did not sign the consent form, have them state once the recording starts that they consent to participate in the study.*

## **GENERAL**

*To start, I would like to learn more about you.*

### **1. What is your professional role?**

- a. On what topic(s) does your work focus on?
- b. What organization do you represent?
- c. How do you support grantmaking in [organization]?

Thank you for providing me with some insights into your professional role. We would like to learn about the various priority areas and focal points in funding community engagement in biomedical and health sciences research. The next set of questions ask about your organizations' priority areas.

### **2. What are the high priority topic areas for [organization] in the next five years?**

- a. How were these priority topic areas identified?
- b. How do you see them shifting in the coming years?
- c. How do the high priority topic areas influence funding areas for [organization]?

**3. What are the high priority funding areas for [organization] in the next five years?** (e.g., community engagement in research, diversifying tissue sample, developing data coordination platforms, building computational tools, developing new methods, generating new data?)

- a. How were these priority topic areas identified?
- b. How do you see them shifting in the coming years?
- c. How important is it to [organization] that researchers include a community engagement component in their projects?

**4. When you think of community engagement in research and/or community-based participatory research, what comes to mind first?**

## **FUNDER SUPPORT**

*This interview focuses on understanding how funders currently support this work and priority funding areas as well as barriers that exist to funding community engagement work in biomedical and/or health sciences research. This section focuses on how your organization supports this work.*

**5. How does [organization] support community engagement in research and/or community-based participatory research?** (e.g., funding, training, resources, technical assistance, etc.)

- a. How does [organization] support engagement of diverse participants (such as underrepresented communities, communities of color, specific communities, etc.) in research?
  - i. Can you provide examples of different ways [organization] engage with diverse participants and communities?
  - ii. How, if at all, does [organization]'s approach to supporting community engagement differ when research involves communities of color?
- b. What role does [organization] play in funding community engagement and/or community-based participatory research in biomedical and/or health sciences research?
- c. What are specific opportunities, strategies, or goals for funding community engagement in biomedical and/or health sciences research with [organization]?
- d. What systems, processes, or resources does [organization] offer that are designed to encourage researchers to engage community members and leaders?
  - i. How is the system/process/resource expected to encourage community engagement?
  - ii. Which systems/processes/resources have proven most successful?
  - iii. What systems/processes/resources could be improved?

**6. Why did [organization] start funding community engagement and/or community-based participatory research in biomedical and/or health sciences research?**

- a. What inspired the focus on community engagement? Was this in response to new research, social pressures, or something else?
- b. What changes have you seen in the funding environment around community engagement in research for [organization]?
- c. How has funding support in research involving community engagement changed over time for [organization]?
  - i. Has change resulted from a slow process or an acute event? What event(s) prompted the changes?

## EXPERIENCE WITH FUNDING COMMUNITY ENGAGEMENT

*Think about your experience funding community engagement in biomedical and/or health sciences research.*

**7. Please describe one example you have seen of successful community engagement and/or community-based participatory research in biomedical and/or health sciences research.**

- a. What role, if any, did [organization] play in ensuring successful community engagement and/or community-based participatory research?
- b. How could [organization] have better supported researchers?
- c. How did [organization] build trust with the community?
- d. How was community engagement measured and evaluated?

**8. Please describe one example you have seen of unsuccessful community engagement and/or community-based participatory research in biomedical and/or health sciences research.**

- a. What role, if any, did [organization] play in the lack of success with community engagement?
- b. How could [organization] have better supported researchers?
- c. How was community engagement measured and evaluated?

**9. What advice do you have for other funders seeking to support community engagement and/or community-based participatory research in biomedical and/or health sciences research?**

- a. What are potential barriers and/or challenges in funding community engagement and/or community-based participatory research in biomedical and/or health sciences research—specifically when working with underrepresented populations and communities of color?
- b. How can other funders help address these barriers and/or challenges?
- c. What specific strategies do you have for funding community engagement and/or community-based participatory research?
- d. How can funders build trust with communities?
- e. What advice do you have for other funders for measuring and evaluating community engagement?

## BARRIERS & FACILITATORS

*Now let's talk about any barriers or facilitators that currently exist related to funding community engagement in biomedical and/or health sciences research.*

**10. What barriers currently exist to funding and/or supporting community engagement and/or community-based participatory research in biomedical and/or health sciences research?**

- a. What have been the primary issues you have seen in your work? How have they been overcome?
- b. What challenges still need to be addressed?

**11. From your perspective as a funder, what are some best practices and frameworks that can facilitate community engagement and/or community-based participatory research in biomedical and/or health sciences research?**



- a. What do you like about this practice/framework?
- b. Can you provide an example of when it has been used effectively?
- c. Where would you suggest I go to learn more about this practice/framework?
- d. What pitfalls or lessons learned can you share from attempts at community engagement that have done harm to the community?

## LOOKING FORWARD

12. How have you seen community engagement and/or community-based participatory research transform biomedical and/or health sciences research, if at all?

- a. Please provide an example of transformational community engagement.
- b. What is the most innovative practice you have seen?
- c. What have you observed that inspired you?
- d. What are the benefits of engaging community in research, from your perspective?

13. What do you think of when you envision the future of community engagement in biomedical and/or health sciences research?

- a. What do you think needs to happen for community engagement to be the norm in biomedical and/or health sciences research?

## CLOSING

14. Who else should we speak with to learn more about community engagement in biomedical and/or health sciences research and/or funding spaces?

15. Is there anything else you want to share?

16. Do you have any questions for me?

Thank you for taking the time to inform the study of community engagement in biomedical and health sciences research. We appreciate your time and insights. You will receive a \$30 gift card as small thank you for your participation. *I look forward to staying in touch!*

**\*\*END INTERVIEW\*\***

## DEFINITIONS

**Underrepresented Communities of Color:** Specific communities of color are underrepresented in biomedical research, including those of African, Latinx, Greater Middle Eastern, Indigenous, Oceanian, Southeast Asian, and multiple or other non-European ancestries. Please refer to the figure on genomics research in this article to learn more.

**Community Engagement:** Community engagement is “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people.”<sup>1</sup> This involvement can be as a research participant, tissue donor, community representative on an advisory board, or other involvement in the research process.

**Community-based participatory research (CBPR):** CBPR entails “equal participation of community partners and researchers throughout the research process with shared decision making.”<sup>2</sup>


**Community:** Community refers “to a group of people living in the same locality, religion, race, profession or with other common characteristics.”<sup>3</sup> It is a fluid term contingent on the goals and context of the groups of people. Within the context of the survey, community refers to communities outside of the academic or research settings.

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<sup>1</sup>Clinical and Translational Science Awards Consortium, and Community Engagement Key Function Committee Task Force on the Principles of Key Engagement. 2011. *Principles of Community Engagement. Principles of Community Engagement. Second Edi.* National Institutes of Health. [https://www.atsdr.cdc.gov/communityengagement/pdf/PCE\\_Report\\_508\\_FINAL.pdf](https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf).

<sup>2</sup>Israel, Barbara A., James Krieger, David Vlahov, Sandra Ciske, Mary Foley, Princess Fortin, J. Ricardo Guzman, et al. 2006. “Challenges and Facilitating Factors in Sustaining Community-Based Participatory Research Partnerships: Lessons Learned from the Detroit, New York City and Seattle Urban Research Centers.” *Journal of Urban Health* 83 (6): 1022–40. <https://doi.org/10.1007/s11524-006-9110-1>.

<sup>3</sup>Marsh, V. M., Kamuya, D. K., Parker, M. J., & Molyneux, C. S. (2011). Working with Concepts: The Role of Community in International Collaborative Biomedical Research. *Public health ethics*, 4(1), 26–39. <https://doi.org/10.1093/phe/phr007>

A large, light green circular graphic that serves as a background for the central text. It features a stylized leaf at the top and several human figures in various poses (some standing, some sitting) arranged in a circle, suggesting a community or population. The figures are rendered in shades of light green and blue.

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