

By Lydia Elias, BA, Emily Christopher, MPH,
and Stephanie Bultema, MAAL, PhD(c)



Landscape of Community Engagement in the Biomedical Field

2021

A Report By



**POPULATION HEALTH
INNOVATION LAB**

A Program of the PUBLIC HEALTH INSTITUTE

EXECUTIVE SUMMARY

This landscape scan was conducted to identify and describe community engagement practices, research, and actors with a focus on single-cell biology and neurodegeneration, imaging, computational biology, and open science. Evidence was gathered from multiple sources including academic and professional literature and public websites. Due to the limited number of resources that were found at the intersection of community engagement and the focus areas, this report focuses on biomedical research in genomics.

Numerous barriers exist to engaging community members in biomedical research, such as mistrust due to historical relationships and trauma between the community and past researchers; language and cultural barriers; the time- and resource-intensive nature of community engagement; training and specialized resources required; and funding timelines and restrictions.

Some strategies have been shown to be effective in engaging ethnic and racial minorities and vulnerable populations in research, such as the use of recruitment facilitators, outreach through community events, door-to-door canvassing, and peer-to-peer referrals. Near-term strategies include using storytelling to gather and share community input, qualitative evaluations, and building on existing relationships. Long-term solutions include training researchers and students in community engagement strategies and community-based participatory research (CBPR) as well as building a more diverse biomedical workforce to more accurately reflect the community. Funding structures should also change to allow for time to properly engage the community and share findings back with community participants once research has been completed.

This landscape scan, while comprehensive, has several limitations: (1) it was limited to the United States between 2010-2021, (2) it was primarily informed by genomics, and (3) no new data were collected for this scan, relying on published works.



There is recognition of the importance of community engagement and CBPR within the biomedical field, especially genomic research. The challenge lies in the need for biomedical researchers to be trained in these areas, funding structures to support community engagement and CBPR in biomedical research, and to help researchers identify solutions in the short-term for how to implement community engagement in their research despite these barriers. Biomedical researchers can take advantage of existing resources and lessons-learned as they strive to implement short- and long-term solutions that will meaningfully engage the communities in which they work.

TABLE OF CONTENTS

Executive Summary	2
Introduction	4
Methods	4
Findings	4
Barriers to Engaging Communities in Biomedical Research	4
Best Practices for Engaging Communities in Biomedical Research	6
Successful Examples of Community Engagement in Biomedical Research	8
Potential Opportunities for Engaging Communities in Biomedical Research	10
Limitations	13
Conclusion	13
Bibliography	14
Appendix A: List of resources for CZI grantees and researchers interested in community engagement approaches	16

INTRODUCTION

Community-based participatory research (CBPR) and other community engagement approaches are an essential element in conducting accurate and meaningful research. This report details the landscape of community engagement and CBPR in the biomedical field within the United States. Although community engagement is not as robust in the biomedical context as other fields of research, such as public health and social sciences research, biomedical researchers are engaging in this work - particularly genomic researchers using CBPR principles.^{1,2} Little literature exists at the intersection of community engagement and single-cell biology or neurodegeneration. No literature was found in this scan within open science, computational biology, or imaging. The importance of increasing community engagement in biomedical research is quite clear and is outlined in the findings below. This report lays out the barriers to community engagement in the biomedical context, best practices, successful examples, and solutions and potential opportunities to enhance community engagement approaches in the biomedical field. The report concludes with a list of resources for biomedical researchers seeking to integrate community engagement in their work.

METHODS

This landscape scan was conducted to identify and describe community engagement practices, research, and actors with a focus on single-cell biology and neurodegeneration, imaging, computational biology, and open science. Evidence was gathered from multiple sources including academic and professional literature and public websites. The researchers searched scientific and gray literature for terms including community engagement, community-based participatory research, single-cell biology, biomedical research, genomics, neurodegeneration, imaging, and open science. Sources were included if research was conducted in the United States and findings were published in 2010 or later. Information about community engagement in membership networks was included only if a person of color was leading the network or if the network's programmatic work targeted minority outreach at the time of the scan (October 2021).

FINDINGS

The landscape scan focused on identifying barriers to and facilitators of community engagement in biomedical research with the goal of capturing best practices, successful examples, solutions, and potential opportunities for engaging communities in biomedical research.

Barriers to Engaging Communities in Biomedical Research

While meaningful community engagement is a worthy and important undertaking, many barriers stand in the way of biomedical researchers conducting this work. These barriers relate to funding availability and constraints, and the relationship between communities and researchers themselves. When examining these challenges, it is important to note that an essential part of this work is to ensure community members and researchers have an equitable voice at the table as primary stakeholders.³

Barriers to Engaging Historically Marginalized Communities

The history of community engagement in biomedical research is rife with inequities and outright mistreatment of community members, especially in marginalized communities. In their work to develop recommendations for expanding community engagement in biomedical research, Yarbrough et al. explain:

*“Many in these communities have limited access to the health care system and thus limited opportunities to enjoy the benefits of research. These communities are also more likely to have been impacted by dark episodes in research of controversy, exploitation, and abuse. Further, individual communities have their own history with local research institutions that can influence relationships just as much as the overall historical legacy does. This local history encompasses all of that institution’s activities, not just its research. We have witnessed, for example, how local community perceptions of discrimination in a university’s undergraduate admissions practices and hospitals turning away uninsured patients frame a community’s response to researchers’ invitations to enter into relationship.”*⁴

The reasons for underrepresentation in biomedical research vary across racial and ethnic groups. While the recollection of historical abuses (e.g., Tuskegee syphilis trial) and racial discrimination are more likely to deter African Americans from participating in biomedical research, language barriers and fear of deportation are distinct among immigrant Latinos.⁵ There are also major pitfalls within medical research that translates to the biomedical field, which includes the mistrust in research which impacts communities understanding of the social benefits of research, lack of participation in research, and the dissatisfactory uptake of research findings.⁶ All of these hurdles must be considered in how biomedical researchers approach community engagement.

Barriers in Researcher Capacities

Along with the difficulty in gaining community member buy-in, there are other barriers that biomedical researchers must overcome. Researchers must recognize that community involvement requires a significant dedication of time and resources which may push back timelines for getting research results out and potentially create negative implications for improving that community’s health. Researchers may require additional training and specialized resources to establish meaningful, effective community engagement practices.⁷ There are potential opportunities to overcome face these obstacles, both in the short- and long-term, that are detailed later in the report.

Barriers to Funding Structures

Funding structures of research and payment incentives also pose challenges for biomedical researchers wishing to engage communities in their work. For instance, the funding structure of most grants does not allow for enough time or money for the development of those relationships researchers and community members must make, particularly as these relationships may need to be established prior to conducting the research or developing the protocol.⁷ Within that same funding structure, the incentives for communities to participate are counterproductive to building those type of relationships for several reasons. Grants with community participation components are usually time limited; researchers are rewarded for publications targeted to a reading audience of their peers rather than communicating findings with the public; and, some federal funding restricts certain spending, such as food purchases, thus making hosting community gatherings a challenge.⁴ These barriers impact the researchers’ ability to provide vital incentives in their efforts to begin building back trust with

communities that may already be distrustful of their efforts and intentions.⁸ Despite all the barriers that exist on the community, researchers, and funders' side, it is still imperative to engage community because it has many benefits for the relevant stakeholders. For instance, informing and consulting the broader community on current research can be considered an additional protection for ethical conduct besides the ethics committee approvals and informed consent; community involvement can increase study efficiency as it would be easier to recruit subjects if the community is more informed and more involvement can improve results uptake; also, involving the community in research builds mutual trust and shows respect to those community members beyond being study participants.⁷ Fair compensation is a key component in gaining both trust and participation from community members.

“[I]nvolving the community in research builds mutual trust and shows respect to those community members beyond being study participants.”⁷

Best Practices for Engaging Communities in Biomedical Research

Numerous best practices can guide researchers who seek to learn more about how to engage community and utilize CBPR principles in their work.⁹ Strategies such as the use of recruitment facilitators (e.g., clinicians and community organizations), outreach via community events and door-to-door canvassing, and referrals to research projects by friends have been shown to encourage participation of ethnic and racial minorities and vulnerable populations in research.⁵ Guides on how to incorporate these various approaches are included in the list of resources included in Appendix A, including step-by-step explanations for those with little or no experience in community engagement.

Community-Based Participatory Research (CBPR)

As a result of a systematic review of the literature on CBPR, Viswanathan et al. defined it as “a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change.” CBPR focuses on co-learning and sharing expertise between all participants in the process, sharing decision-making power, and a shared ownership of the research process and products. The ultimate goal of CBPR is to enhance the health and wellbeing of the community and its members.⁹ This approach views the community as the primary unit of identity, acknowledges and builds on the community's strengths, works to build productive, collaborative relationships between researchers and the community in all aspects of the research, and translates knowledge and findings into sustainable actions for the benefit of the community.³

Community Advisory Boards

Community Advisory Boards (CABs) are another commonly employed tool in community engagement. However, CABs are unable to protect communities, instead acting more as a connection and input tool between the community representatives and researchers. Nevertheless, the use of CABs could still be a model adopted in clinical trials and/or observational research if there is not another form of community representation, or in conjunction with other strategies.⁷ CABs can be supplemented by putting more resources into training researchers and placing more power in the hands of community representatives. This tool must be complemented with funding agencies recognizing the human and financial resources necessary for substantial community involvement as well as higher education institutions acknowledging community involvement when training and mentoring researchers.⁷

Community Compensation

When asking for the community's time and input, it is important to compensate them just as one would compensate research professionals. This can be done on a large scale (e.g., profit sharing) or a smaller, individual scale (e.g., direct compensation to participants). Profit-sharing is another approach that can be employed where communities are equal partners with the research institutions in deciding how profits are distributed and for what purposes. One way this can be done is creating a non-profit grant making organization to distribute the shared profits.⁴ It is important to note that although profit-sharing can be effective, it can also be difficult to implement depending on funding restrictions. Researchers must also recognize the limited funding and resources community partner organizations have, when considering equitable compensation.⁸

Fair compensation of research participants is a key component in gaining both trust and buy-in from community members and standards exist for fair compensation of participants in research. The amount of compensation offered must not be so high as to be coercive and differs from reimbursement for a research participant's time and travel to complete research-related procedures. However, if you are asking for a meaningful time commitment from community members outside of research participation, such as serving on an advisory board or supporting community outreach and relationship building, the level of compensation should be considered.¹⁰⁻¹² According to the Patient-Centered Outcomes Research Institute (PCORI):

“Patients and caregivers who provide a representative view and constituency or organizations who represent the interests of many stakeholders may be valued for their ability to engage their community, their understanding of issues deemed important by that community as they relate to the research project, their patient expertise and knowledge of the disease and its impact on the community, or may provide socio-cultural or other expertise, or leadership in communities relating to the research project. Compensation of engaged research partners should reflect the level of expertise, commitment, responsibility, the type of work involved, and the degree of participation contemplated. Fair compensation typically extends beyond the partners' reasonable out-of-pocket expenses and should reflect their role in the research project, skills and capabilities.”¹³

PCORI's Compensation Framework for Engaged Research Partners can be used as a guide.¹³

Informed Consent

Past approaches to increasing diversity among genomic research participants have run into issues when they did not place enough focus on using the process of gaining consent from participants as a step to engender trust. This is especially true in genomic research, where the social dimensions of consent expose the myth of isolated individual interests.² Therefore it may be beneficial for genomic researchers to use the process of requesting informed consent as an opportunity to build trust and establish open communication from research participants, especially those of diverse backgrounds. Additionally, a best practice for researchers is to ensure their approach mirrors an authentic community engagement process, one that begins during study development. Having the community involved early on and throughout the research process would result in more awareness of barriers to participation and allow time for study redesign, if needed.¹⁴ This avoids “outreach fatigue” among the various stakeholders by spreading community involvement over longer periods of time and allows the opportunity to build trust between the communities and researchers.¹⁴

Successful Examples of Community Engagement in Biomedical Research

As the number of researchers in the biomedical field engaging communities continues to grow, there are more successful examples that can be looked to and learned from.

Heart Healthy Lenoir

One example of successful community engagement in biomedical research comes from Heart Healthy Lenoir, a transdisciplinary project focused on creating long-term sustainable approaches to reduce cardiovascular disease risk disparities in Lenoir County, North Carolina by using a design spanning genomic analysis and clinical intervention.¹ The genomics team hypothesized that Lenoir County residents, especially African Americans, would be unfamiliar with and lack trust in genomic research and thus be reluctant to participate. The team conducted qualitative research using CBPR principles to ensure their genomic research strategies addressed the concerns, needs, and priorities of the community. They administered demographic surveys and used a semi-structured interview guide to facilitate discussions. Researchers focused on transparency, communication, privacy, incentives, and ensuring participants understood the nature of their participation. Due in part to these efforts, 80.3% of eligible African American participants and 86.9% of eligible White participants enrolled in the Heart Healthy Lenoir Genomics study, making their overall enrollment 57.8% African American.¹



Alabama Genomic Health Initiative

Another successful example is the Alabama Genomic Health Initiative (AGHI), which has worked for years to increase rates of African American participation through various community engagement techniques, in an attempt to have their participation rate match the representation of African Americans in Alabama's population.² In a study focused on using CBPR to increase diversity in genomic science, Skinner et al. describe how "AGHI engagement efforts resulted in increasing rates of African American participation over three years, beginning with 13.02% African American participation in year one, 16.53% in year two, and 30.39% in year three."² To bring about these outcomes AGHI relied on their network comprising long-standing relationships with the African American community (via the University of Alabama Recruitment and Retention Shared Facility), and engaged direct community participation through intentional democracy activities all with the deliberate aim to develop ongoing relationships separate and apart from a specific research agenda, and with a focus on building long-term trust and confidence in AGHI's commitment to ethical conduct of research.²

Community Board in Harlem, New York

To understand more about how to best approach community engagement in genomics research as well as the genetic variants that have increased the risk of kidney failure to those of African ancestry, community and clinical leaders in Harlem, New York created a community board to inform the direction of research related to this area.¹¹ The community board was comprised of study patients, community advocates, physicians, and local health care leaders. The board found that "community voices can have tangible impact on research that navigates the controversial intersection of race, ancestry, and genomics by heightening vigilance, fostering clear communication between researchers and the community, and encouraging researchers to cede some control."¹⁵ To effectively understand the various board member's experiences and/or approaches in community engagement within genomics research, the board hired a research coordinator to attend meetings and assist with storytelling. This was done by conducting open-ended interviews with six board members. The interviews included questions related to community partnership, genomics research, and the board's activities. Researchers anonymized the results in order to share direct quotes with the community board and worked with the board to identify common themes, develop a conceptual framework, and prepare the manuscript.¹⁵ Community board members and researchers co-authored the final publication resulting from the study. This methodology exemplifies the benefits of including researchers in storytelling and understanding the right questions to ask, which can be useful in community engagement, especially when trying to build trust and foster relationships.

Community voices can have tangible impact on research that navigates the controversial intersection of race, ancestry, and genomics by heightening vigilance, fostering clear communication between researchers and the community, and encouraging researchers to cede some control.¹⁵

Public Health Sector

The public health field has a longstanding, deep-seated relationship with community engagement in its research. The various response strategies to COVID-19 have provided many examples and opportunities for this intersection within the field as well. For instance, Morehouse's Prevention Research Center has well-established CBPR approaches that could be translated into the biomedical context depending on the support individual research teams and institutions may or may not have. Their approaches include a community coalition board (CCB) comprising neighborhood residents who hold all of the leadership seats in the CCB and represent census tracts with a large number and prevalence of chronic and infectious diseases, as well as academic institutions and social service providers.¹⁶ The Prevention Research Center partners with the community and the CCB to foster health research and other interventions based on a deep understanding of political, historical, clinical, and community considerations; they conduct a community health needs and assets assessment (CHNA) every four years through the CCB where survey development, data analyses, and strategies are reviewed and evaluated by the board.¹⁶ These are important elements of meaningful community engagement in research, many of which aim to build trust with communities being researched or affected by policies or decisions. Hallmarks of community engagement that many strive for in public health and social sciences research include involvement of a diverse and representative group of community representatives in leadership positions (such as CCBs, CABs, and other boards or groups); transparency in decisions and sharing back research findings; organizing meetings for community input in such a way that most members are able to attend (e.g., holding meetings outside of regular business hours, providing compensation for participants' time, or offering food or childcare services); and promoting leadership and decision-making power in organizational decisions.

Potential Opportunities for Engaging Communities in Biomedical Research

The landscape scan uncovered both short-term and long-term opportunities for effectively engaging historically marginalized communities in biomedical research.

Short-term opportunities include:

- Using storytelling to communicate research importance and results,
- Identifying low-barrier CBPR principles to incorporate in study design and implementation,
- Partnering with qualitative and/or mixed-methods researchers to evaluate effectiveness of community engagement strategies,
- Leveraging existing community relationships with institutions and community groups, and
- Using existing community engagement resources (see Appendix A).

Long-term opportunities include:

- Training researchers in effective community engagement,
- Increasing diversity in the biomedical workforce,
- Building a robust and sustainable network of community engaged researchers,
- Understanding and adapting to the limitations of randomized-controlled trials (RCTs) in community-engaged research, and
- Gaining community member buy-in through relationship-building, effective communication, and accessible research approaches.

Yarborough et al. list several barriers and strategies for overcoming them. These opportunities for community engagement help to lay the foundation for developing transparent and equitable relationships with the community. The table is adapted below.⁴

Barriers to better relationships	Illustrations of the barriers	Strategies for overcoming the barriers
Research often makes communities feel like they are being used.	Researcher outreach to communities is too frequently restricted to times when researchers need something from a community.	Encourage universities to seek relationships with local communities and their organizations before they seek their help with research projects.
	"Helicopter research," when researchers come in and 'extract' what they need from communities but leave little or nothing behind and rarely, if ever, return, is a real occurrence.	Develop mechanisms for bidirectional communication.
Universities are too mysterious	Communities have a poor understanding of both the cultures and agendas of research institutions.	Promote transparency about a university's core values and agendas.
	The "ivory tower" metaphor of universities is often still an apt one.	
Research incentives are often counterproductive to enduring relationships	Grants that fund research that involves community participation are time-limited.	Realign rewards for researchers so that they will have incentives to establish relationships with local communities.
	Researchers are rewarded for publications for their peers, not communications with lay audiences.	
	Federal funding has restrictions, such as limitations on food purchases that make funding community gatherings difficult.	
The research playing field is uneven (and often unfair)	Researchers receive immediate rewards from research, such as funding and career advancement. Research institutions benefit from research through indirect funds, prestige, intellectual property rights, and other tangible rewards.	Implement measures that will place researchers and communities on a more equal footing with one another.
	Given the uncertain nature of scientific progress, communities must patiently wait for benefits.	
	Communities must learn that "research takes a long time to pay off."	

Table Adapted from Yarborough et al.⁴

Short-Term Opportunities for Improving Community Engagement in Biomedical Research

Researchers and funders in the biomedical field can leverage short-term opportunities to improve community engagement in biomedical research. For instance, the value of storytelling and communication is evident in genomic research when seeking to gain insight on what has been most effective in community engagement approaches.¹⁵ Perhaps biomedical researchers can utilize their current network of qualitative and/or mixed-methods researchers through their institution or contracts to evaluate their CBPR or community engagement approaches as they are incorporate into research strategies. This will assist biomedical researchers with less experience in CBPR to be as successful as possible and make the best use of the resources, time, and funding allotted during a research project. Building off any existing community relationships, through institutions or community groups with which the researchers may be familiar or affiliated, is another impactful strategy that can be employed in the near-term. Researchers can also take advantage of the resources that exist within their network or institution to provide feedback or consultation. Web-based, easy-to-comprehend resources are also available to biomedical researchers (see Appendix A). Although the barriers of time, funding and lack of resources will continue to push back against these solutions, one or a combination of these short-term opportunities for engaging communities in biomedical research may be effective depending on the researcher(s) and the strength of their network and funding.

Long-Term Opportunities for Improving Community Engagement in Biomedical Research

Researchers and funders in the biomedical field can also leverage long-term opportunities to improve community engagement in biomedical research. Some of these long-term solutions include institutions prioritizing the training of researchers around community engagement and CBPR and building a more diverse biomedical workforce to reflect the community members that the researchers are trying to engage.¹⁷ Additionally, a stronger and more robust sustainable network of community-engaged researchers (CEnR) needs to be built. This can be done via training and cultivating future CEnR beginning with high school students all the way up to post-doctoral fellows. Expanding the presence of community-engaged researchers in the biomedical field can also help those in the field to recognize the limitations of randomized-controlled trials (RCT), which are considered the 'gold standard' in biomedical research. RCTs are appropriate for most biomedical questions but are not as effective for multi-factorial questions, dynamic situations, and the less controlled environment of community settings.¹⁸ It is also important for researchers to continue to set long-term goals of gaining community members buy-in. It is clearly illustrated that community members are more likely to engage in biomedical research if they believe it contributes to personal or greater good, feel they could gain useful knowledge from participation, and if potential language barriers are addressed.⁵ Although many barriers exist in leveraging these longer-term opportunities, it is important that researchers focus on meaningful community engagement, not just participation, since this can enhance community knowledge of the research process and improve outcomes related to advancing scientific knowledge.



LIMITATIONS

Limitations must also be recognized when interpreting findings from this landscape scan of community engagement in the biomedical field. First, this scan was limited to researchers engaging in the United States between the years of 2010 to 2021. There were many more examples and strategies at the intersection of global health and genomics in other areas of the world, especially Africa.¹⁹ If the landscape scan is expanded to the international level, examples of research studies done in Africa will be an important place to start due to the longer history and evidence of strategies by biomedical researchers engaging communities on that continent. Second, although this scan was focused on the biomedical field, it was primarily informed by genomics as there was very little literature found in single-cell biology or neurodegeneration and none within open science, computational biology, and imaging. Third, all sources used for this landscape scan were secondary sources gathered from the scientific literature and institutions. Collecting primary qualitative data, for instance through interviews and surveys, will help provide a more comprehensive picture of the different approaches biomedical researchers use to engage communities in their research, as well as the barriers and facilitators to the structural changes needed in funding spaces to better support community engagement in the biomedical context.

CONCLUSION

There is recognition of the importance of community engagement within the biomedical field, especially genomic research. The challenge lies in gaining buy-in from and support for biomedical researchers to become trained in these areas, funding structures to support community engagement in biomedical research, and helping these researchers identify feasible opportunities in the short-term that can facilitate implementing community engagement in their own research, despite all the barriers that do exist. Appendix A provides a good starting point for researchers to begin increasing their knowledge and understanding of various community engagement approaches. Additionally, other helpful information to utilize is the list of institutions with community engagement offices and list of successful researchers in the biomedical context that have done community engagement. As the intersection of community engagement and biomedical researcher continues to expand in the United States, these researchers and their networks will continue to grow as well, which may assist in the success of more researchers engaging communities in their work.

BIBLIOGRAPHY

1. Skinner HG, Calancie L, Vu MB, et al. Using community-based participatory research principles to develop more understandable recruitment and informed consent documents in genomic research. *PLOS ONE*. 2015;10(5):e0125466. doi:10.1371/JOURNAL.PONE.0125466. Accessed October 7, 2021.
2. May T, Bogar S, Spellecy R, Kabasenche W, Craig J, Dick D. Community-based participatory research and its potential role in supporting diversity in genomic science. *J. Health Care Poor Underserved*. 2021;32(3):1208-1224. doi:10.1353/HPU.2021.0127. Accessed October 4, 2021.
3. Weiner J, McDonald J. Three models of community-based participatory research. *Leonard Davis Institute of Health Economics*. 2013;18(5). https://ldi.upenn.edu/wp-content/uploads/archive/pdf/IssueBrief18_5.pdf. Accessed September 27, 2021.
4. Yarborough M, Edwards K, Espinoza P, et al. Relationships hold the key to trustworthy and productive translational science: recommendations for expanding community engagement in biomedical research. *Clin Transl Sci*. 2013;6(4):310. doi:10.1111/CTS.12022. Accessed September 29, 2021.
5. Cortés YI, Arcia A, Kearney J, Luchsinger J, Lucero RJ. Urban-dwelling community members' views on biomedical research engagement. *Qual Health Res*. 2017;27(1):130. doi:10.1177/1049732315627650. Accessed September 27, 2021.
6. Holzer JK, Ellis L, Merritt MW. Why we need community engagement in medical research. *J. Investig. Med*. 2014;62(6):851. doi:10.1097/JIM.0000000000000097. Accessed September 27, 2021.
7. Fregonese F. Community involvement in biomedical research conducted in the global health context: what can be done to make it really matter? *BMC Medical Ethics*. 2018;19(Suppl 1). doi:10.1186/S12910-018-0283-4. Accessed October 6, 2021.
8. Springer M, Skolarus LE. Community-based participatory research: partnering with communities. *Stroke*. 2019;50(3):E48-E50. doi:10.1161/STROKEAHA.118.024241. Accessed October 8, 2021.
9. Viswanathan M, Ammerman A, Eng E, et al. Community-based participatory research: assessing the evidence. In: *Evidence Reports/Technology Assessments, No. 99.* ; 2004. <https://www.ncbi.nlm.nih.gov/books/NBK37289/>. Accessed October 27, 2021.
10. U.S. Department of Health & Human Services. Attachment A - Addressing Ethical Concerns Offers of Payment to Research Participants; 2018. <https://www.hhs.gov/ohrp/sachrp-committee/recommendations/attachment-a-september-30-2019/index.html>. Accessed October 27, 2021.
11. Wellesley Institute. Fair & inclusive compensation for research participants: a guideline. <https://www.wellesleyinstitute.com/wp-content/uploads/2018/07/Fair-compensation-Guideline-.pdf>. Accessed October 27, 2021.
12. Cheff R, Roche B. Considerations for Compensating Research Participants Fairly & Equitably: A Think Piece. <https://www.wellesleyinstitute.com/wp-content/uploads/2018/07/Fair-compensation-Think-Piece-.pdf>. Accessed October 27, 2021.
13. Patient-Centered Outcomes Research Institute. Financial Compensation of Patients, Caregivers, and Patient/Caregiver Organizations Engaged in PCORI-Funded Research as Engaged Research Partners. <https://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf>. Accessed October 27, 2021.
14. Ojikutu BO, Stephenson KE, Mayer KH, Emmons KM. Building trust in COVID-19 vaccines and beyond through authentic community investment. *Am. J. Public Health*. 2021;111(3):366-368. doi:10.2105/AJPH.2020.306087. Accessed September 29, 2021.

15. Kaplan B, Caddle-Steele C, Chisholm G, et al. A culture of understanding: Reflections and suggestions from a genomics research community board. *Prog Community Health Partnersh.* 2017;11(2):161. doi:10.1353/CPR.2017.0020. Accessed October 6, 2021.
16. Akintobi TH, Jacobs T, Sabbs D, et al. Community engagement of African Americans in the era of COVID-19: considerations, challenges, implications, and recommendations for public health. *Prev. Chronic Dis.* 2020;17. <https://stacks.cdc.gov/view/cdc/93359>. Accessed October 18, 2021.
17. Buell K, Treston C. The National Institutes of Health can do more to strengthen racial equity, diversity, and inclusion in biomedical research and to advance health equity research. *J. Assoc. Nurses AIDS Care* 2021;32(4):528-530. doi:10.1097/JNC.000000000000279. Accessed September 23, 2021.
18. Michener L, Cook J, Ahmed SM, Yonas MA, Coyne-Beasley T, Aguilar-Gaxiola S. Aligning the goals of community-engaged research: why and how academic health centers can successfully engage with communities to improve health. *Acad Med.* 2013;87(3):285. doi:10.1097/ACM.0B013E3182441680. Accessed September 27, 2021.
19. Tindana P, de Vries J, Campbell M, et al. Community engagement strategies for genomic studies in Africa: a review of the literature. *BMC Medical Ethics* 2015 16:1. 2015;16(1):1-12. doi:10.1186/S12910-015-0014-Z. Accessed October 18, 2021.
20. Burns JC, Cooke DY, Schweidler C. A short guide to community based participatory action research. *Advancement Project*. Published online December 2011. Accessed October 20, 2021. www.advancementprojectca.org. Published online December 2011. Accessed October 20, 2021.
21. Hindorff LA, Bonham VL, Ohno-Machado L. Enhancing diversity to reduce health information disparities and build an evidence base for genomic medicine. *Per Med.* 2018;15(5):403. doi:10.2217/PME-2018-0037. Accessed October 5, 2021.
22. Pasick R, Geraldine Oliva D, Ellen Goldstein M, Tung Nguyen M, Fleisher P. Community-engaged research with community-based organizations: a resource manual for researchers. UCSF Clinical and Translational Science Institute (CTSI). http://ctsi.ucsf.edu/files/CE/manual_for_researchers_agencies.pdf. Published online 2010. Accessed October 20, 2021.
23. Scripps Translational Science Institute, Scripps Whittier Diabetes Institute. *Toolbox for Conducting Community-Engaged Research*. Published online 2014. Accessed October 18, 2021.
24. Akintobi TH, Sheikhattari P, Shaffer E, et al. Community engagement practices at research centers in U.S. minority institutions: priority populations and innovative approaches to advancing health disparities research. *Int. J. Environ. Res. Public Health.* 2021, Vol 18, Page 6675. 2021;18(12):6675. doi:10.3390/IJERPH18126675. Accessed October 18, 2021.
25. Community-Campus Partnerships for Health. Consultancy Network. CCPH. <https://ccphealth.org/consultancy-network/>. Published 2021. Accessed October 20, 2021.
26. Goytia CN, Todaro-Rivera L, Brenner B, Shepard P, Piedras V, Horowitz C. Community capacity building: a collaborative approach to designing a training and education model. *National Library of Medicine.* 2013;7(3):291-299. doi:10.1353/CPR.2013.0031. Accessed October 6, 2021.
27. de las Nueces D, Hacker K, DiGirolamo A, Hicks L. A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups. *National Library of Medicine.* 2012;47(3 Pt 2):1363-1386. doi:10.1111/J.1475-6773.2012.01386. Accessed October 18, 2021.

APPENDIX A: LIST OF RESOURCES FOR CZI GRANTEES AND RESEARCHERS INTERESTED IN COMMUNITY ENGAGEMENT APPROACHES

[A Short Guide to Community Based Participatory Action Research](#)²⁰

[Enhancing diversity to reduce health information disparities and build an evidence base for genomic medicine](#)²¹

[Community-Engaged Research with Community-Based Organizations](#)²²

[Community-based participatory research: partnering with communities](#)⁸

[Community engagement strategies for genomic studies in Africa: a review of the literature](#)¹⁹


[Toolbox for Conducting Community-Engaged Research](#)²³

[Community Engagement Practices at Research Centers in U.S. Minority Institutions: Priority Populations and Innovative Approaches to Advancing Health Disparities Research](#)²⁴

[CCPH's Consultancy Network](#)²⁵ (Resource for researchers to consult on community engagement)

[Community capacity building: a collaborative approach to designing a training and education model](#)²⁶

[A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups](#)²⁷

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 with arms raised) arranged in a circle, suggesting a community or population. The overall aesthetic is clean and modern, with a focus on health and human connection.

The [Population Health Innovation Lab \(PHIL\)](#) designs, catalyzes, and accelerates innovative approaches that advance health, well-being, and equity.

For more information, visit us online at
www.pophealthinnovationlab.com



**POPULATION HEALTH
INNOVATION LAB**

A Program of the PUBLIC HEALTH INSTITUTE