

Black Equity Coalition Community Research Conversations

January 5, 2024

Purpose

For decades, researchers have designed surveys and studies to learn more about different aspects of our community and the people that call it home. These studies have helped them learn more about people's behavior, attitudes, opinions, and needs. Information provided through research can be useful in informing and targeting actions, investments, and policies, and research can provide a deeper understanding of community assets, issues and challenges.

Despite the potential value, community-based research can be an extractive and exploitative process for participants. Residents often feel they have little power to develop research priorities, influence data collection methodology and practices, bring their expertise into the data analysis process, and play a meaningful governance role in data sharing and use.

People involved in designing and conducting community surveys don't often have the ability to take a step-back and reflect on the need and purpose of the survey, the methodology including the process for designing questions, and the use and ownership of the data. There also isn't enough time dedicated to reflecting on the experience of people who are often asked to respond to surveys, or the way survey results shape the ways communities are defined by the data that is collected.

To start the process of learning from one another to build better survey practices, The Black Equity Coalition convened community leaders, members of communities that are frequently surveyed, researchers at local institutions involved in survey research, and people working in the fields of public health, community safety, and human services in five 90-minute virtual workshops (conducted on Zoom) between July 26 and September 20, 2023. These activities were designed to improve practices so that residents can have more power to direct research and govern uses of data. Jamil Bey of the UrbanKind Institute worked with Robert Gradeck, and Liz Monk of the Western Pennsylvania Regional Data Center at the University of Pittsburgh as members of the Black Equity Coalition to serve as workshop designers and facilitators.

This document serves as an artifact of a series of five workshops conducted by the Black Equity Coalition. Workshops were structured to bring researchers involved in community-based research into conversations with community leaders and community members that are often asked to partner on community research efforts. Discussion took place through a series of structured participatory conversations designed to modulate the power dynamics between researchers and community members. Output from these workshops is captured in this document, and all participants in the workshops that chose to be included as contributors are listed in this document.

Project Background

Through support from the Robert Wood Johnson Foundation, the CDC Foundation administered a multi-faceted project in partnership with the Centers for Disease Control and Prevention (CDC), the National Alliance Against Disparities in Patient Health (NADPH) and Data Equity Coalitions (DECs) in Atlanta, Detroit, Durham, Pittsburgh and San Antonio—local organizations collaborating with communities to improve access to and use of public health data.

As part of the project, the DECs and NADPH conducted coordinated and tailored research investigating opportunities for surveillance systems to better respond to local data priorities related to the social and structural determinants of health (SDOH), including the experiences and impacts of systemic injustices.

The DEC and NADPH efforts sought to understand community and local public health SDOH data needs and priorities, the strengths and limitations of existing SDOH survey tools and promising approaches for increasing access and use of public health data. The DECs and NADPH gathered community feedback through one-on-one community survey validation interviews, focus groups, testing approaches to increase survey participation, piloting SDOH survey modules and facilitating community discussions. Feedback focused on use of the Behavioral Risk Factor Surveillance System (BRFSS), Pregnancy Risk Assessment Monitoring System (PRAMS) and PLACES. Across the five locations, our DEC and NADPH partners engaged over 1,250 public health professionals, community leaders and members of groups who have been historically marginalized.

View a collaborative recap of the project and a list of promising actions for surveillance systems to consider for enhancing community engagement and developing more relevant SDOH metrics in our <u>Final Collaborative Report</u>.

Our Role

As a local DEC for the project, members of the Black Equity Coalition were funded by CDC Foundation to conduct the activities outlined herein. This report was developed by our team and does not necessarily reflect the views of the CDC Foundation or the Robert Wood Johnson Foundation.

In this effort, the UrbanKind Institute and the Western Pennsylvania Regional Data Center at the University of Pittsburgh's University Center for Social and Urban Research partnered as members of the Black Equity Coalition to participate as the local DEC of Pittsburgh/Allegheny County Pennsylvania.

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Participants (excluding facilitators) in this workshop series were offered a stipend of \$100 for participating in each workshop. Our intent was to spark conversations that can result in shifts of power to communities that are often subjects of research and serve as a guide for developing more respectful and inclusive survey research practices.

Workshop Topics and Structure

Workshops were designed and facilitated by members of the Black Equity Coalition. Each of the workshops started by reviewing a series of community agreements designed to remind everyone how to create an inclusive and respectful climate, and they ended with an "exit ticket" opportunity allowing participants to share feedback about the session. These materials are included as appendix to this document, which documents the workshop activities and conversations.

Workshops were based on the same model as the Regional Data Center's data literacy workshops, which engaged participants in a series of small and large group activities. A collaborative online document was used to capture notes and feedback during the activities and serves as an artifact of the conversations. Several guides promoting inclusive research practices prepared by Chicago Beyond and the Urban Institute served as helpful frameworks for the conversations.

The five workshops covered the following topics:

Workshop 1: Understanding the Community

Participants started the workshop in a breakout conversation where they developed a list of important considerations for making survey research respectful and inclusive. They then reflected on a list of questions to ask frequently when working with data and marginalized communities and edited and added to the list of questions.

Workshop 2: Partnerships

In this workshop, participants shared a story about a time they were involved in a community-based research partnership. We then asked them to put themselves into the shoes of an experienced researcher and offer advice to early-career colleagues looking to establish a partnership with a local community. We also asked them to assume the role of a community leader in this scenario and prepare a list of questions to ask the inexperienced researchers about how they'd like to structure a partnership.

Workshop 3: Expertise and Wisdom

We started the workshop by asking participants to create a list of the types of expertise and wisdom they bring to the research process as a community member or researcher. We then asked them to take elements from this list and assign them to the different stages of a survey research process, from planning through use of the results.

Workshop 4: Trust

In a breakout group, we asked participant to create a list of what "trustworthiness" looks like in research, researchers, institutions, and community partners. We then asked them to work with other members of their breakout group to select the top-five most-important ways to build and maintain trust from this list. We closed the meeting by sharing success stories with the group.

Workshop 5: Reflection and next steps

Participants created a list of actions and activities that can happen next to shift power to communities and develop more respectful and inclusive research practices. Facilitators used "I will..." "We should..." and "They should" as prompts to capture feedback. Participants had an opportunity to further develop a few of the ideas, and closed the session with an opportunity to share appreciation for another participant.

Takeaways and Insights

Many insights were provided by the participants in the workshop activities. Here, we have organized them for several different audiences, including public health professionals, funders, community members, researchers and local data intermediaries.

- For public health professionals working within large-scale surveillance systems: It's important to have ongoing open and difficult conversations with community members about research efforts. Researchers should show community members that they are heard and involve them in the governance of not just research projects or data collection efforts, but also research infrastructures. They should also provide community members with what's needed to participate, which includes financial support, translation services, etc. Professionals should also continuously work to improve their own practices and involve members of the community in governance structures.
- For funders: It takes time and effort to build and maintain relationships. Funders of this work should be patient and provide long-term support for building and managing relationships that result in less-extractive and more-just research practices. Funders should also think about developing and strengthening ecosystems and infrastructures in addition to supporting projects. They should also mandate that any community research project they fund includes community in making decisions and provides people with resources that enable them to fully participate.
- For community members: Community members should realize they have power in the process. It may be hidden and unrealized, but they should feel comfortable and confident in using their voice to surface their own research agendas, influence research practices, negotiate benefits, and create accountability mechanisms. They should also take advantage of opportunities to build capacity to talk about data and research with researchers (and their neighbors). Doing so can help them elevate community power.
- For researchers in academia and health care systems: Be aware of and acknowledge the power they hold in the research process. They should work with peers to make their practices more-inclusive, more-respectful, and more-just. They also have an obligation to work with communities as trustworthy, true partners through the research process, and even after the grant reports are submitted they should be present even if they're not on a grant. They should also advance the community's research agenda along with their own. The institutions should value translation of research to the community as much as they value publications.
- For other local data intermediaries: Continuously engage community members in your work and demonstrate that you can be trustworthy. It's important to build community around your data, tools, and training activities. People in our series appreciated the opportunity to be heard and look forward to staying engaged in these conversations.

Workshop 1 Topic: Understanding the Community

July 26, 2023

Workshop 1, Activity #1 – Breakout Group Conversation

After making it through the roll call, ground rules and shared agreements, participants were put into a small group of 3-5 people using the breakout feature of zoom and asked to spend a little time to "say hello" and get acquainted with one another. They were also asked to respond to the following prompt, capturing notes from the conversation in the shared document.

In your own experience, what's an important consideration for making survey research respectful and inclusive?

Notes (combined from all groups)

- Including individuals with varying perspectives, especially those from the target audience;
 iterative process; attention to language (both what is included and what is left out) +1 +1+1
- Including underrepresented & diverse individuals of the global majority at every step of research/surveys; research has historically left out many groups of people +1 +1
- Being mindful of bias (example anti-fat bias) +1 +1
- Capturing and including qualitative data +1
- Respecting each other open to listen open to completely speak +1
- Diversity and inclusion especially with AI there is a need to be aware of diversity +1 +1
- Address cultures and respect the community, target surveys to places and events such as WIC offices or community days. +1
- Including others in survey development, getting other people's opinions +1
- Making surveys engaging, accessible, linguistically equitable, using a health equity and literacy lens +1 +1
- Provide resource connections and be clear on the impact of the survey beyond just research surveys can elicit emotions and memories for folks +1
- Be aware that communities have been excluded from research and have been over-surveyed +1
- Its important to understand background, experiences of those who are being surveyed +1+1
- Provide an explanation about what the survey is trying to capture, why does it exist, +1 +1+1
- Share back survey and research results with the community. Address what came of this, what is being done with this +1
- Can there be a box where you can say I want follow up about the survey---some people may not want that feedback and some may? +1
- Follow up about the effectiveness of the resource provided
- People are very tired of doing surveys and nothing is coming of it.
- Bidirectional training and learning, importance of working with community members as surveyors/data collectors. They are experts in their communities

 Equitable compensation for those actually doing the surveys, those who are embedded in communities +1 (paying people for their expertise in their lived experiences – valuing their lived experiences)

Workshop 1, Activity 2 – Review the notes from other groups

After the conversation, participants were asked to review lists from each of the small group conversations and add a "+1" for one or two considerations that resonated with them the most. The "+1" designations appear with the text above.

Workshop 1, Activity #3 – Questions to Ask Frequently

In 2014, a number of people participating in the Responsible Data Forum in Oakland, CA developed a <u>listing of Questions to Ask Frequently</u> when working with data and marginalized communities.

A series of questions developed by the group addressed the questions that researchers and others working with data should ask themselves before beginning work in the community. The questions were designed to improve the practices of people doing data work in a community by helping them approach this work with respect and an understanding of their impact. They also developed questions about data ownership, sharing, and data use.

Here is a copy of the initial list of "Questions to Ask Frequently about the Community"

- Who is the community? What are the boundaries that surround it in terms of: ethnicity, identity, gender, race, class, sexuality, disability, language, religion, size, citizenship status, geography, etc.?
- What makes this community **marginalized**? Is it persecution and alienation from services and rights, or a combination?
- Do you understand your own **prejudice** about the community? Can you keep an open mind and allow your biases to be challenged?
- Do you fully understand the **context and nuances** of this community? What can you learn to ensure your intervention will have a positive impact? What resources are available for training or advice?
- Do you have ongoing informed consent with the community on your activities? How have you
 documented the consent?

Source: "Questions to Ask Frequently (QAFs) when working with Data and Marginalized Communities" Blog post on the fabriders website. Contributors include: Friedhelm Weinberg, Jordan Ramos, Tin Gerber, Aseem Mulji, Michael Bochenek, Martin Dooley, Kellie Brownell, Adrian Sawczyn and Dirk Slater. Published April 2, 2014, Accessed July 24, 2023. https://www.fabriders.net/gafs/

In this activity, participants were asked to review the questions listed above with their group members, and consider these prompts:

- Are there questions related to the community relationship that are missing?
- Are there questions you'd like to change?
- Would you remove any of these questions?

Suggested additions and comments from the small group conversations include:

- What barriers may be present for this community to participate in this survey?
- How are you including individuals from this community and breaking down the barriers to their inclusion? For example, arranging transportation, childcare, payment, training and support
- What methods are you employing to reach individuals that don't "normally" participate in research?
- How are you considering and working to remedy historical injustices and exclusion in your research? How are you building trust within the community?
 - How can you fill the need for some measure of consistent accountability: Who can hold you
 accountable through this process? Can you write a community accountability partner (paid
 advisors) into the grant?
- How can you include community-based partners & organizations that represent those who are
 historically underrepresented as advisors? Historically, researchers have not been responsible to the
 community for their research, research is not often not culturally relevant
- How can you provide transparency into the research process, including payments for researchers and community members, and provide information about what is being done with the research
- How can children accurately be taught their own community's history.
- How can you engage all members of the community, including young people and refugees.
- How can communities (such as small immigrant communities) that may not have an organization that supports them be included and have their voices heard in research? How can we connect with groups that may be experiencing more isolation and are harder to reach?
- When it comes to **boundaries**, how can you consider intersectional identities? Some communities possess multiple identities and experiences.
- When it comes to **context and nuances**, it's important to be aware that folks may not see themselves in the same way that the dominant culture "lumps" people together.
- How have you thought about non-written communication in terms of consent?
- Once you figure out the community, the researchers and surveyors need to ask themselves about their own biases, need to deeply interrogate their own biases. Need a built-in process for how this can be done.
- Connecting with the full team---community, researchers, surveyors---understanding identities, backgrounds, experiences before you jump into the research. Who are the people that are willing to be an advocate?
- How do you create your team so community voices can shine through and to create a safe and comfortable space for community to share and co-create?
- What are the institutional pressures and urgency that could impede community-partnered work and how can you address and disrupt that?

Workshop 1, Activity #4 – Large Group Reflection on the "Questions to Ask Frequently" activity

Following the breakout activity, participants reflected on the activity. Here are some notes from the full group conversation:

- African American community members (especially children) need to understand their true
 history and have a sense of culture and pride. History tends to reflect dominant western
 colonial culture. A survey could be a way to learn about how much people understand their
 history and culture. Results of the survey could be shared in a community meeting and would
 inform conversations.
- There can be more discussion about accountability, specifically how researchers can be held accountable by communities starting with the RFP. Solicitations should make it required that there be required participation for community that has been marginalized.
- I like the idea of having researchers partner with community organizations.
- Resource extraction and extraction of experiences is very important to consider Researchers should not be extractive and exploitative and provide compensation to the community.
- Could members of a community have access to a library of studies and surveys prepared about the community? Could this be hosted at a library in the community?
- How can we reach out to communities where relationships don't exist yet? There are some communities that lack the capacity to organize. How can we find and connect with communities that haven't been connected to researchers in part because there isn't capacity.
- Compensation is very important.
- How can you have a built-in process to think about identity, bias, positionality, etc. as part of the research?
- How can we disrupt institutional pressures so that respectful community partnered research can shine through?
- We need to remember that the refugee community isn't one community.
- Sometimes community gatekeepers play an important role (in protecting communities).
- Community residents do need to be heard. Don't want to look at this as gatekeepers. Can we look at people from Ukraine, Somali, and other communities that are newer?
- People need to know why they're being asked to participate in survey research
- I liked the questions in the previous activities. There can be a list of resources provided to researchers that can help them answer these sorts of questions.

Workshop 1, Activity #5 – Building Better Practices

The final activity in the workshop provided participants with an opportunity to contribute to a list of practices that researchers or community members can employ to improve a researcher's

understanding of community dynamics. No matter their role, participants were encouraged to contribute to both lists.

In addition to asking questions frequently, what are some things that <u>researchers</u> can do to learn more about community dynamics?

- Listening, relationship building, showing up
- Read narratives by individuals from the community; read about the history of research, including the injustices +1 (engage in different forms of media, not just books music, podcasts, poetry, tv, zines, etc)
- Spend time in the community that is being surveyed, churches, local shops, community centers.
- Advocate for institutional change, all research should be community partnered, this includes study section, peer review, in all spaces, with trainees, with mentees, in all conversations, meetings, and spaces---the goal is for every researcher to do this work.
- Being vulnerable, sharing motivations for doing research, sharing stories, showing your humanity
- Can researchers better understand different family (and community) dynamics –
 patriarchal/matriarchal as an example. can researchers attend a community event? It can be
 helpful to be invited rather than crash a meeting.
- How can researchers get funders to adopt improved practices for accountability, inclusion, and respect? They have funder relationships.
- Be an advocate for others to do better.

How can <u>community members</u> enable/help researchers to better-understand community dynamics?

- Connect researchers with community members have a conversation about community benefits
- Community members can share with researchers: How to develop authentic and expansive relationships vs transactional relationships

Workshop 2 Topic: Partnerships

August 9, 2023

Workshop 2, Activity #1 – Breakout Group Conversation

After making it through the roll call, ground rules and shared agreements, participants were put into a small group of 3-5 people using the breakout feature of zoom and asked to spend a little time to "say hello" and get acquainted with one another.

They were also asked to talk about a time when they were involved in a community-based research project or partnership, and respond to the following prompts.

- What were some things that worked well?
- What were things you'd like to do over?
- Who had power in those relationships? Was it balanced?

They were welcome to share notes from the conversation in the shared document. They're presented here:

- Anarchy and dismantling the system!
- Research processes can be extractive.
- People that invite you to the table built the table should we build a new table?
- We keep doing things to help our institutions maintain power.
- What can make it better? Suggestions: Bring in someone that is a part of the community to be a
 part of these efforts community members can benefit from training to be participants in the
 process.
- Why don't we ever see outputs/outcomes of research we're asked to participate in?
- Why do researchers come to the community only once?
- Institutions that have money and power always talk about our deficits?
- Some initiatives provide a better experience because they have focused on balancing power from the start. The Pittsburgh Study mentioned as an example.
- Many of us had been involved in research in different roles, and many in community work as
 well. Research is mostly on communities instead of with communities. Even when community
 is included in logistics, not in planning, deciding what to ask, what to do with the knowledge
 generated.
- Based on experience in community development, someone said bringing voices of community into decision making works best when people understand the process and the purpose. It is important to make those conversations transparent and informal enough that people feel they can participate.
- Important to focus on developing relationships and trust.
- We have to "meet people where they are" This might mean we need to give out information, provide transportation, etc.

- In a recent project involving young people, they had to make sure that information was disseminated back to people who were part of the project (people are already skeptical about organizations and people involved in the work). We need to make sure we're clear as to why we are gathering the information. People need to see that there is something is happening with the data that is collected. Foundations had the power; young people should have had the power or the power should have been shared.
- Foundations will throw big chunks of money at the topic/issue of the day. People who need to be at the table need to be there at the start – when the questions are developed. Money is always power.
- Hire people from the community who are interested, committed, and who have put in the work already. Universities aren't on the ground as much and don't know who to trust
- From the university perspective, it seems like the main goal is about getting money and publishing papers. Most researchers don't think about research translation and dissemination. There is a need to change institutional culture. It's very extractive.

Workshop 2 Activity #2 – Scenarios: Establishing a community research partnership

The next two activities were based on the following scenario:

Two researchers at a local university connected with a colleague in their department seeking an introduction to the executive director of a neighborhood organization they've worked with. These researchers are hoping to submit a proposal to a funder that will require the development of a resident survey to learn more about opinions related to two major sources of pollution in the community.

The community has seen a lot of change in the past thirty years, as many of the people that purchased homes there in the 1960's following the expansion of a manufacturing facility have moved on. Compared to thirty years ago, the community is more racially and ethnically diverse, and Census data shows that one in six households now speak a language other than English at home.

The research holds the potential for strong community benefit. Residents have been trying to address the impacts of pollution on the environment and resident health for a decade but have lacked the power and resources to be able to do something about it. At the same time, residents have participated in several large research projects and felt as though they weren't heard. Residents believe that their needs and interests haven't been given the same priority as the needs of the researchers and their institution.

In this activity, we asked participants to both put themselves in the position of the researcher's colleague and the executive director of the community organization. Participants remained in the same breakout groups for each of the next two scenario-based discussions.

Scenario 1

The first of the two scenarios asked them to play the role of a research colleague and is presented below.

You're the colleague of the two researchers, and they asked you to help make a connection to the community. Prior to making the introduction, the researcher would like to offer advice to their two colleagues since they don't have a long history in community-based research and haven't done much work in this neighborhood. What advice would you offer your colleagues when it comes to establishing a partnership with neighborhood residents?

Advice to researchers from the small-group conversations included:

- Outsource to a resident in the community. Find the person that has a voice in the community, the leader/go to person that is already established in the community and train them.
- Outsource the job to the community; someone who looks like the community and resonates with their concerns
- Make sure that whomever comes from the organization is fully versed in the research and not just doing it because they were told to, or this is just a job.
- Be well versed in the study, (who what when where, how, and why) and be able to answer all questions from the community residents.
- Describe what the purpose of the research is. Keep in mind the literacy and cultural background of the community
 - o Ensure the community understands research as a concept
- Ask themselves who the research will benefit
- Consider using translators
- Review survey questions with community members before distribution
- Researchers should be willing to show up to increase the trust. Not just important to show- up - how they show up is important
- Look for an ethnographic study of the community
- Acknowledge power differentials
 - Have an awareness of bias and how they show up in the community especially when working in communities with a different cultural context.
 - Articulate impacts of racism and historical bias/traumas
- Be fully transparent in terms of power and money, and talk about who is being paid and who is providing the funding.
- Acknowledge that researchers can come across as insulting/condescending
- Not assuming one community is a monolith

- The community can change literally across the street; different communities have different needs
- Ensure that the community wants the research to be done
- Who determines that this survey/research is needed? Too many people are making decisions for communities that they have no stake in.
- Don't assume that people "need" supports like bus passes, gift cards, etc.
 - Consider that gift cards might be limiting (some of the businesses may not be accessible to participants)
- Bring other people in who understand and know how do to community based participatory research (CBPR), and do your own research on CBPR before starting any community engagement
- Before developing any [specific] research questions, develop relationships by listening and showing up in the community
 - Though most if not all researchers come with some interests/questions and should remain flexible
 - o Ideally the work should be thought of as being entirely in service to community; lots of researchers aren't familiar with the concerns of residents.
 - Researchers should be able to distinguish between scientifically-important research and socially-important research.
 - Need to be transparent! Researchers motivations exist on a spectrum, and community members should be able to make an informed decision about participating
- What would be the benefit and incentive to participate in the survey?
- Who determines that this survey/research is needed? Too many people are making decisions for communities that they have no stake in.
- How long will the researchers be engaged with the community? One day? a series of days? questions, etc.
- What is the researchers' interest in our community, and what's the personal/professional motivation? It can help to ask why they're there, and who invited them to be there.
- Will you be honest about your budget?
- Is there an intervention plan after the research outcomes are met?
- Will the focus be on one community or multiple communities and how with that work?
- Will everyone have access to all the tools (and resources) needed to see this research to completion. What accommodations and support will be provided? (Provide Laptops if needed, if in person food for the participants + families, childcare, Wi-fi for people to participate via zoom. Technical assistance.
- What is the bigger picture? It has happened that communities were redlined and didn't have representation in the political world.

- Hold meetings in community, advertise them ahead of time, not just virtually—in places that people go.
- Talk to people, keep channels of communication open, keep participants updated as to what is going on during long studies
- Share results of the study with the community and with participants
- Respectfully teach people about the research process so they can understand how it works
- Provide compensation to participating community members at each phase of the research, planning, carrying out study, and reporting out the results to keep people engaged throughout
- Communicate about what is in it for the community
- Treat the community with dignity and respect
- Researcher should take a walk in the community, visiting key places in the neighborhood, including schools, libraries, police, coffee shops, etc.

Scenario 2

The second scenario asked them to play the role of an executive director of a community organization.

As the executive director of the community organization, you'd like to prepare a list of questions for an initial meeting with the researchers. You're especially interested in asking questions that can encourage them to include the community as an equal partner in the research process and ensure that the community has power to ensure that participation in the survey will benefit the community.

In the breakout groups, participants in the role of the executive director prepared the following questions for the meeting with the researchers.

- What is the cost of the study and what is the value of the benefit. How do costs and benefits compare?
- What is the value of expertise and lived experience (for both participants and community organizations)? How will this be reflected in incentives and compensation?
- Who determined that this research is needed?
- What are your plans to share the research with the community organization and community at large?
- How long will the researchers be engaged in the community? Is it one-time or a long-term commitment?
- What is your interest in doing research in OUR community? Why are you here? What is your personal and professional motivation?
- Will you share your budget?
- Will you introduce yourself to the community? Will you share your background and identities? (Racially, ethnically, SES) Why are you motivated to be there?

- How will you follow up with the community and report back out?
- Is there an intervention plan from the outcomes?
- Who invited you?
- Is the research going to be intercommunity or intracommunity?
- What type of research? What is the platform? Is the research accessible to everyone?
 Does the community have the necessary resources to participate? What accommodations (e.g. technical assistance) will you make to bring everyone to the table?
- What additional resources can you offer to the community? Or direct the community
 to?
 - Research as transactional to transformational
- What is the potential for harm with this research?
- What incentives will you provide? What residents' needs will you meet through the incentives?
- If we know what the problem is, why are you just fixing the problem, rather than doing more research?
- What are the priorities for the research and do they align with residents' priorities?
- What questions will you be asking?
- Why are you here? What have you done as a researcher?
- How will you respect families or youth? How will you keep people safe?
- How will make sure that people understand what you are doing?
- What resources and power can you leverage to do something in response to what the research shows?
- Accountability to find out what results have amounted to, what was found, what changes
- How will you use media to let everyone know what is going on. Media should cover good things that happen, and research can be good news. (this is what we learned, this is what happened afterwards).
- Communicate how will the study findings be used to make policy or changes
- Evaluation of outcomes downstream including affordability, think about how people from the neighborhoods can benefit from it.

Workshop 2 Activity #3 – Reflection

The final activity was a large group reflection on the previous scenario activity.

Notes

- Conversations about benefits/incentives aren't the same Researchers want to provide an incentive, but does that mean it's beneficial? Example incentive in the form of a gift card doesn't work if someone can't get to a store where people can use it.
- Can you bring resources to the community? Can you help the community beyond a stipend (with things like internet access, help accessing benefits)? How can research be transformational?
- Researchers don't always have leverage to make things happen after research is complete. Researchers need better training.
- There's a need for policymakers to be involved so that what's learned from the research can be addressed.
- It's ok for community members to interview the researcher. These relationships don't have to be just one sided. We can ask questions as community members It's important for someone to be an advocate for your community use your voice!
- When you come to the community as a researcher, you must do your research. It's critical to understand community context.
- It's very important to have and share a plan for how you'll do the work, share back, talk about benefits from the outset.
- Going further if someone would reach out as a community leader ask how they will share the outcome of research.
- Researchers are asking for access to a community member's social capital. There's an
 opportunity to damage a community members' social capital. Community members and
 researchers can have their credibility shot. There's often only one chance to do something in
 this town.
- Some researchers may not have a community's interests in mind. The same can also be true for some community leaders. There's a need to have a process to make sure it's the right researcher and right community member. What's the motivation?
- Be mindful or be aware when a researcher is looking to pick who they work with. They need to work with leaders that the community views as leaders.
- If multiple organizations represent the community, researchers should look at the relationships the organizations have with the community. They should look at everyone's motives and talk about partnerships.
- Researchers should provide full transparency on data collection –
- Where is the funding coming from? Who is being paid to do this? Why are you here?

Workshop 3 Topic: Bringing expertise and wisdom to research partnerships

August 23, 2023

Workshop 3 Activity #1 – Breakout Group Conversation

List some types of expertise and wisdom that <u>you</u> bring to the research process based on your role as a community member or researcher:

After making it through the roll call, ground rules and shared agreements, participants were put into a small group of 3-5 people using the breakout feature of zoom and asked to spend a little time to "say hello" and get acquainted with one another.

They were also asked to "list some types of expertise and wisdom that you bring to the research process based on your role as a community member or researcher." Notes are captured below.

Expertise Provided by Community Members

- Understanding what people care about
- Influential through advocacy
- Connections to community resources and organizations
- From Pittsburgh and have experience working in every community
- Bring historical data
- · Ability to advocate for community needs
- Awareness of institutional resources, challenges, etc.
- Personal understanding of the needs of individuals within the community children's education, tutoring, counseling; playgrounds and public spaces;
- Teaching and ability to be an advocate, and encourage people in the community to use their voice
- Bringing personal perspectives in the roles I play/inhabit
- Understanding of what children in our communities need
- Being neutral, being trustworthy and non-judgmental
- Identifying social problems that matter to communities
- Experience connecting participants to services
- Seeing the gaps between what researchers say they will deliver and the actual results of research (sometimes including the lack of deliverables).
- Common sense, lived experiences, community perspectives, perspective as a grandmother and an artist
- Bringing quirkiness and vulnerability to help others open up

Expertise Provided by Researchers

- Knowledge of research methods
- As a community researcher, understanding what research needs and questions the community has
- Being neutral, being trustworthy and non-judgmental
- Brokering resources (from funders, from universities) and providing capacity
- Study design, study fidelity, data collection
- Quantitative data collection
- Knowledge broken down in layman terms for the community, to assist in their understanding
- Helping, supporting, community to see research in a way that is going to help. This includes sharing information, how to share it, and overall transparency.

Workshop 3 Activity #2 – How does expertise and wisdom show-up in different stages of the research process?

In the second activity of this workshop, we revisited the following scenario first introduced in the second workshop (copied here),

Two researchers at the local university have secured funding to conduct a survey of residents in the neighborhood. After several meetings in the community, residents have agreed to participate in the research effort, and are pleased with the plan to ensure that residents have power in making decisions about the research.

The community has seen a lot of change in the past thirty years, as many of the people that purchased homes there in the 1960's following the expansion of a manufacturing facility have moved on. Compared to thirty years ago, the community is more racially and ethnically diverse, and Census data shows that one in six households now speak a language other than English at home.

The research holds the potential for strong community benefit. Residents have been trying to address the impacts of pollution on the environment and resident health for a decade but have lacked the power and resources to be able to do something about it.

Participants were then asked to play the role of a steering committee member on the project.

You're on the steering committee for the project. Members of the committee want to make sure that everyone has awareness of the assets that researchers and community members can bring to each stage of the project. By doing this, you hope to provide everyone with a meaningful opportunity to contribute.

In the small group activity, participants were asked to list the expertise and wisdom that each member of the research partnership brings to each stage of the survey research process in the table below, which combines responses from each of the four discussions.

Stage in the Research	Community expertise /	Researcher expertise
Process	wisdom	/wisdom
Identify the goals, objectives, and context of the research project	 Understand what people in the community care about Whether something is worth studying and how it should be studied Ensuring the right people are doing the research What pieces are missing in current research Expectations from the researchers in terms of resources and sustainability Understand what people in the community care about Areas of particular need, vulnerability, thriving, etc. What fair & respectable compensation is [& community members need to understand their value in and of themselves and in relation to the project budget/researchers' value] What is important to community members Understand what people in the community care about 	 Bringing in other relevant research findings, being able to place them into this community's context What research has been done and potential directions for future research Transparency about grant funds Sharing power and knowledge Responsibility to respect the cultures and privacy of the communities in which researchers are working Knowledge of what funding is available Ability to navigate "academic capitalistic language" (grant writing, grant reporting, administration, IRB) Knowledge of (administrative) costs of running projects
Decide who the audience is for the survey	 Community needs a voice at the beginning stage. Community needs to be at the table for all stages Let researchers know if the community can take a written survey, or an oral one. 	 Having a needs assessment taken to the community Being open to change as the community voices Think and find out if the audience for your survey can complete a written survey or can only do an oral one, taking due consideration of the

	 Also, the audience may not be technology friendly for electronic surveys. Blanket approach on how to get information from the community, to reach all community members Including young people as young as middle school in the process. Young people are the future and this would give them buy-in in their communities. Identifying the "voices" of the community based on the fullness of the answer of the research question Ensuring the research methods and language are accessible and understandable Understanding how the data may impact mental health / trauma-sensitive practices Knowledge of relevant stakeholders Relevant institutions 	technological background of the audience in thought. Bringing in and paying staff that represent the research audience Checking your bias Relevant scientific audience Funders, large NGOs (e.g., healthcare, first responders, etc.), and politicians/govt officials and agencies [if not the culture of their raising, need to understand and educate themselves about the community & to reflect on their own biases and reasons for wanting to survey community]> bring this wisdom What paperwork & permissions are required for research (& knowledge of informed consent)
	stakeholders	
	 Relevant participants (who is most affected? Ages? Locations?) 	
	Who is relevant to the	
	conversation (ex: multiple generations, right subsets of people)	
	Who is impacted & who isn't	
Determine the methods of	 Know where people come together/ Communication 	 Knowledge of research methods
data collection and identify who will be involved in the	What methods will be	Awareness of community
process	acceptable to the population	culture, language, abilities
p. 00003	Who should have access to	Knowledge of consent
	the data and how it will be	process and protection of
	maintained/disseminated	vulnerable populations

	•	Ensuring the data collected can and will be utilized	•	Tools, access, and funds to ensure human-centered
	•	Knowing who to include (age,		design and trauma-
		race, and other		informed practices
		demographics) - important to	•	Ensuring equitable,
		include the voices and		intentional, and sustainable
		perspectives of the youth		compensation
	•	Understanding there are a	•	Knowledge of research
	_	variety of communication		methods; sharing that
		styles		knowledge with community
	•	Relevant scientific audience		members so they can also
	•	Funders, large NGOs (e.g.,		contribute fully
		healthcare, first responders,	•	Knowledge of various pros
		etc.), and politicians/govt		and cons of different
		officials and agencies		methods
	•	Best ways to engage (more	•	Knowledge of research
		intimate) community		methods
	•	Ability to connect	•	Ideally, have knowledge of
		(emotionally, culturally, etc)		facilitation methods (more
		with community members		intellectual)
	•	Respect what knowledge has	•	[need to have engagement
		been shared in other more		skills]
		relational, informal,		
		culturally relevant formats		
		(poetry slams, storytelling)		
	•	Knowing what information		
		already exists		
Design and write questions	•	What is the context of the	•	Tools to ensure literacy
		research question?		levels are accessible
	•	How can the research	•	Knowledge of validated
		question be simple, direct,		measures that may be
		understandable, &		relevant
		accessible?	•	Working with community
	•	Relevance of the research		members to modify/adjust
		questions		questions to make them
	•	Appropriateness of questions		appropriate
		to community members	•	Knowledge of methods for
		(reading level, clarity, length,		assessing reliability and
		etc.)		validity
	•	Potential languages that the		
		survey would need to be		
		translated in		

	 Identifying topics to focus on that may benefit the community Making sure there is room for participants to provide feedback on the survey or add info that may not have been captured in the questions Experiences of the community –whether people have experience working with data or not 	
Test the survey	 Literacy, relevance, acceptability Understanding of who can provide feedback; who represents the population of study 	Ensuring validity
Collect and manage the data	 How the data can be stored maintained and shared equitably How the data can be utilized for positive change Ensuring that participant time is respected and compensated 	Goal of transparency Creating access to datasets, when possible
Analyze the data	 What are we using the data for? Deciding when data analysis (and dissemination) would be helpful (maybe not just waiting until the end) Interpreting data and statistics in the context of history and the community 	 Data analysis techniques Bringing variety of people and perspectives to the table Sharing power Conducting analyses Capacity building with community members who may be interested in analyses or stats
Make use of the results for positive change	Being intentional in regard to the results	Being intentional in regard to the results

- Next steps? what happens with the results
- Implementation and action steps
- Intentional follow up regarding the survey no matter what the results or final action.
- When results are out for sharing, the community should see results should be in a way that is understood.
- How to share results and in what format, to whom
- Ensuring the synthesis of results reflects community perspectives
- Identification of agencies and organizations for dissemination
- Understanding there are a variety of communication styles
- Understanding how to break the results down in palatable ways
- Hold researchers accountable for disseminating to the community

- What can actually change with the results and what that looks like, prioritize the results.
- Find out the best mechanism to share the results
- Implementation and action steps
- Be very clear on the process and time frame.
- Continued support some years down the line. 5/10 years. Some longevity support to circle back.
- Synthesizing results
- Goal of allowing iterative and honest feedback, being intentional and transparent
- Responsibility to evaluate the impact of the data on the community
- Mindfulness of how the data can be harmful
- Tools, access, money to do follow-up (workshops, resources) and ensure sustainability
- Sharing power
- Disseminate to the community

Discussion Notes

Participants shared thoughts on the activities in a brief reflection and in an "exit ticket" activity (described in the appendix)...

- How do we utilize Pittsburgh as a best practice model from the information/opinions that we have?
- I'd really like some discussion of how to share power in partnerships and the role of "capacity building" in that
- What should transparency look like from researchers?
- I'd like to hear more from community members as to why their desire to participate in studies are low
- I'm interested in talking more about how researchers and community members can disrupt inequities that are present in research. We keep referring to bad things that can happen to communities and community members through research projects; or how those projects can have a goal in mind before they even start; and how those projects are bound by red tape or by a need to make certain invested parties happy. I'm curious about how researchers and community members can take back power in the process, if at all.
- I'm curious about the ethics of collecting research from communities that are suffering instead of using that funding to provide direct action.
- Thinking about every part of the community [is important] including language barriers, accessibility. Thinking about this on both community/researcher side.

Workshop 4 Topic: Trust

September 6, 2023

Workshop 4 Activity #1 – Breakout Group Conversation – What does it mean to be trustworthy in community-based research

After saying hello to one another, respondents were asked to respond to the following prompt and capture notes in the document:

In your own words, make a list of the things that can contribute to the development of trust in community-based research. Think about trustworthiness from the standpoint of trust in research itself, trust in researchers, trust in institutions, and trust in community partners

Trustworthiness in research looks like this:

- Accountability +1+1+1 (to ones-self and the project)
- Having an active relationship with the researched community continuing beyond the time that data is collected
- Presentation of results back to the community
- Transparency +1+1
- Checks and balances systems to create and enforce accountability
- Proper representation among the study team
- Confidentiality and privacy
- Clear goals that are conveyed to community members; beneficiaries are made clear
- What is the budget? How much does the person at the top get paid? are they taking all the \$
- Sharing with the community plan? reason? results?
- Understanding the process; power-sharing and level-setting to enable the community to do research
- Understanding of the need for the research; identifying gaps
- Reliability--
- Where is the researcher from? Do they know the place and the culture? Everyone sees things through the lens of their culture? Are they from the same neighborhood? culture, background, neighborhood, network. Will people trust this researcher?
- History of the organization: how have they dealt with this community in the past
- Compliance to avoid pitfalls. Often there is one thing they forgot to do and we have to start over.
- Equitable budgeting practices: big projects with lots of funding, participants receive small stipends on grocery cards sometimes could be an issue, ex. When cards are for stores we don't have in our neighborhood. They should continue stipends as project expands or gets new funding—be transparent about budget. Reciprocity can also include hiring people from the community, and providing career paths for people in the community to become researchers and

analysts. Also value the input and the intellectual contributions of young people in the community—they should not just be subjects of research but also they should become researchers. Stipends should be larger especially when research budgets are very large.

Trustworthiness in <u>researchers</u> looks like this:

- accountability
- Would you do what you are asking me to do?
- Consistency +1; show up and deliver
- Transparency+1
- Genuineness, authenticity, taking time to know one another
- Intentionality (even with speech)
- Keeping one's word, <u>integrity</u>, implementing what they said they would, showing up in a way that is helpful
 - Integrity = Integrated = the opposite of double minded
- Consistency; show up and deliver
- · Reflect experiences similar to those who are being studied
- People who you have prior relationship with
- Setting expectations and being intentional and forthright in following through
- Making others aware of what you are doing

Trustworthiness in institutions looks like this:

- Being accountable and transparent, especially when things go wrong
- A reputation of being transparent and being accountable when things have gone poorly in the past
- Prior experience working with representatives of that institution

Trustworthiness in community partners looks like this:

- Being
- accountability
- How I am treated as I walk in the door. How the first person I meet as I come in the door.
- How the workers are treated/how staff are treated
- Want to speak to the families and how they feel
- Genuineness, authenticity, taking time to know one another
- Intentionality (even with speech)
- accountability
- Genuineness, authenticity, taking time to know one another
- Intentionality (even with speech)
- Reputation
- What is the motivation? What are their goals? What are the attitudes of the community members toward the community organization?

The following definition of trust was also shared with participants in the document.

"In general, trust refers to a firm belief in the reliability, truth, and ability or strength of someone or something. Trust has also been defined as the willingness to be vulnerable to the actions of another party, irrespective of the ability to monitor or control the other party. An individual may have trust in a specific researcher or abstract trust in the research enterprise."

Definition source: Wilkins CH. Effective Engagement Requires Trust and Being Trustworthy. Med Care. 2018 Oct;56 Suppl 10 Suppl 1(10 Suppl 1):S6-S8. doi: 10.1097/MLR.0000000000000953. PMID: 30015725; PMCID: PMC6143205. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6143205/

Workshop 4 Activity #2 – What are the most important ways to build and maintain trust?

In this activity, the participants were put back into their four breakout groups and asked to reflect on the definition above and the list created in activity one and choose the five most-important ways to build and maintain trust.

Group 1

- 1. Transparency (why we are there/motivation; open communication between all parties; from start to end)
- 2. Accountability (expectations, consistency, timeline)
- 3. Community Benefit
- 4. Building Relationships (recurring or new)
- 5. Commitment & Implementation

Group 2

Note: The following five responses were not ranked by the group:

- Building a track record of actually helping people/communities
- Being consistent
- Being transparent (including about research being "a long game" and finding ways to build tangible benefits into the research process without waiting for the big impactful results)
- Being accountable/building accountability into agreements and procedures
- Building relationships with community members/familiarity

Group 3

- 1. Equitable practices (budgeting, compensation, reciprocity)
- 2. Transparency (accountability and reliability)
- 3. Inclusion of community in decision making (upstream involvement of community and youth! in planning and developing the project)
- 4. Intentional outreach to community and participants (a. Listening, b. print, c. face-to-face, d. social media)
- 5. Long-term commitment (a. to the community, b. to the project, c. co-curricular threads (i.e. have course offerings to support intentional education for community members on the topic under study)
- 6. Follow-up and follow-through (a. with participants to make sure they have received and can use compensation, b. review at the end with the community, best practices, to evaluate how the project went)

Group 4 – how do you build and maintain trust?

- 1. Accountability
- 2. Track record (long track record). Your livelihood/how you live, how you move, how you show up in community, if you show up in community, if you go to/participate in community events. Evidence of your values. Reputation.
- 3. Transparency. Parallel process.
- 4. Communication
- 5. Persistence

Workshop 4 Activity #3 – Let's highlight ways we've gotten it right?

In this activity, participants were invited to share positive experiences they've had in community-based research, and what made it something to celebrate.

- Appreciation for having people add to the initial conversations.
- Trust building roles- you're only as good as your team.
- Accountability do what you say you were going to do.
- Appreciation for group learning
- Reciprocity view it more-broadly budgets are huge but stipends are small.
- Discussion of the end result talked about importance of intergenerational work. Invite younger people into this work. Internships, etc.
- Having background as researcher and in community work provides a unique perspective.
- The process of ranking allowed the group to discuss what each element meant.
- Talked about what experiences have or haven't worked.
- There was a lot of great conversation behind the notes
- Transparency 1st transparency is an important element to enable accountability and other things. Stew metaphor – put all of these elements together to make a meal– transparency is a foundation for how trust can be built.
- Individual vs structural dimensions of trust
- Want to see what processes we need to have not trust people but build accountability into our systems and processes. We shouldn't leave it up to a person to make the system trustworthy.
- How do we support the community- how do we flip power to the community in this?
- How do we think about equitable processes and structures reciprocity. How can we embed more power within community members in the process?
- Bring people's experiences and truths into the process
- Trust building takes work. We need to be aware of this. It won't be easy. Not an overnight thing.

Workshop 5 Topic: What should we do next?

September 20, 2023

Workshop 5 Activity #1 – Breakout Group Conversation – What stood out from the first four workshops

After saying hello to one another, respondents were asked to share one or two themes or ideas that stood out to them from an earlier workshop. To refresh their memory, we also provided them with a summary of the activities from the first four workshops:

Notes

- The series was good participants appreciated the flexibility of scheduling It wasn't mandatory to attend every workshop.
- One comment from the trustworthiness workshop "ask before you help, ask what help looks like" stuck with at least one of the participants.
- Looking forward to coming back to the community to share what became of the feedback they shared.
- People overstepping boundaries because they don't ask can make people feel incompetent.
- Transparency (from people coming into a community) plays a big part in how members of the
 community react to the offer to help. Transparency can also build trust. Tell the community
 what you are doing and follow through. Just be honest, don't mislead (or trust will be lost). Also
 educate the community about your work, why it's important, history, how it affects the
 community globally. Not giving enough information impacts how people will participate.
- Appreciation of the diversity of the group people came from all different places (education, workforce). No one was disrespectful or offensive. People were able to bring their own perspectives and come to a middle ground.
- People wanted to sustain these conversations. They asked: How do we tie this to
 projects/initiatives so people can continue to be supported in having these conversations? Can
 we create a mailing list for the group?

Workshop 5 Activity #2 – Breakout Group Conversation – <u>I</u> will, <u>we</u> should, *they* should...

In our next activity, participants created a list of what actions and activities can happen next to shift power to communities that are often subjects of research and develop more respectful and inclusive survey research practices.

In this activity, participants organized their list into the following three categories:

- / will
- **We** should
- They should (if you can, please list who the "they" is).

<u>/</u> will

- I will put the benefit of the community before myself +1
- I will be more open to research, researchers, and data
- I will discern good research and share it out with my community
- I will be a connector between my community and "good" (safe, equitable) research opportunities
- I will be gain and keep the trust of my community +1
- I will be open to the researcher (ask questions and be engaged) and open with the community (share about intentions)
- I will continue to be skeptical and ask hard questions particularly of the systems that have power over research
- I will treat those in the community with dignity and respect.
- I will always be open and transparent +2
- I will remain an advocate for our community. +1
- I will abide by guidelines for inclusive research
- I will invite this community to the Black Equity Coalition community engagement table, when projects arise I will bring it back to that group for opportunities
- Participate in more community connections, more committees, 1-2 more different committees, more involved in terms of what is happening in the Pittsburgh area
- I will intentionally not be offended
- I will learn from my mistakes +1
- I will be friendly; I will blend (not appropriation but meeting the community where they are), be down-to-earth
- I will remain humble
- I will acknowledge my positions of privilege +1
- I will be more connected with more people, taking information back to community groups
- I will respect others
- I will learn from other's as well as my own mistakes

We should

- Create a way to stay in touch with each other (email list, etc) +1
- Work harder and be more intentional about the communities we go into
- We should continue! This is a great forum---keep in contact on a monthly basis
- We should guidelines create for inclusive research
- We should continue these conversations, maybe through surveys or emails, share things that we
 have gotten through the breakout, maybe can fund a few folks from each side to continue the
 conversations
- We should make sure the needs are met in the community. +1
- We should make sure we respect the culture of the community.
- We should be open-minded and open to change
- We should ask before we help, and ask what help looks like +1
- We should make research easy to understand for the community
- We should be investigators and agitators when it comes to research and researchers be tough gate keeper to community but be open to research after thorough investigation +1
- We should find ways to divorce research and researchers from money and power with motives
- We should learn from our and others' mistakes +1
- We should ask for inclusiveness in research particularly in healthcare and medicine
- We should be very mindful of "who is missing" in the research we're being presented the limitations of the research +1
- We should continue building trust and rapport with the community
- We should continue to bridge the gap between us to make our communities thrive

They should

- Give us more funding so we can continue to carve this time out in our day
- Invest time, money, and resources into community partnered work, value this work at an institutional level, value the knowledge translation work, the high impact work, with concrete examples not just academic publications [academic institutions, funders] +2
- Keep doing the work to make a change, address some of the issues they are researching, have a positive impact [researchers]
- Ensure the research is understandable to the community (researchers and academics)
- Never ever ask for community members time, expertise, stories without equitable compensation [researchers, academic institutions] +1
- Keep their word
- Give the money from research back, share with communities, don't' keep for yourself!! [academic institutions]
- They should be more open and transparent (the researchers, the funders, the institutions overseeing the research)
- They should allow more time for us to talk! +1
- They should not extract people's dedication and passion
- They should encourage research to develop organically within communities based on need, rather than being top down from an outsider (institutions, funders)

Workshop 5 Activity #3 – Breakout Group Conversation – You'll develop a few of these ideas from the "I will, we should, they should" activity in more detail –

The group developed the concept of "ways to stay in touch with one another" as a large group activity before breaking into smaller breakout groups to develop and discuss additional ideas. Th3ey chose to further develop four of their ideas. Participants were asked to provide detail beneath each of the prompts ("who," "what," "when," "where," "how," and "why").

Idea 1: Create ways to stay in touch with one another.

Who should be involved?

- Anyone from this group!
- Pitt should facilitate at beginning ...

What are some of the important details related to this idea or concept?

• How to sustain the conversations, list...

When should this happen?

Now!

Where should this activity or action take place?

- Internet,
- In person meetings!
- Community events, gatherings,

How can this idea or activity be implemented? What are some important steps?

• [None provided due to time constraints]

Why is this activity or action important?

• [None provided due to time constraints]

Idea 2: Equitable compensation

Who should be involved?

- Researchers, academics, analysts
- Community members
- People who chose not to participate

What are some of the important details related to this idea or concept?

- Pay more people less or less people more?
- How much is enough and at what point is compensation coercive?
- Compensation goes beyond money

When should this happen?

• [No details provided]

Where should this activity or action take place?

• [No details provided]

How can this idea or activity be implemented? What are some important steps?

- Not requiring personal information (SSN) for payment
- Considering whether the form of payment makes sense for the recipients (a Giant Eagle [supermarket] gift card doesn't help people in a food desert)
- Looking at power (considering there are different forms); power to say no to research
- Consider inflation

Why is this activity or action important?

- Valuing the time and expertise of the community; valuing the information that participants provide
- Equity means different things to different people
- Important not to be coercive

Idea 3: Be mindful of who is missing

Who should be involved?

• Whoever the community believes should be there

What are some of the important details related to this idea or concept?

- People in positions of power aren't always trustworthy
- Systems are often inequitable distribute power in inequitable ways
- Survivor bias
- Research is limited by the characteristics of the study population conclusions aren't universally transferrable / won't always apply to all other groups.

When should this happen?

• [No details provided]

Where should this activity or action take place?

[No details provided]

How can this idea or activity be implemented? What are some important steps?

- System of checks and balances
- Legislation to create equity divorce money and motives from the research inquiry and work
- Create meaningful access to the field of research to people without degrees the biggest population missing from researchers are people without higher education

Why is this activity or action important?

• Working toward equity is the only way to work toward safe, meaningful change

Idea 4: Learn from our and other's mistakes

Who should be involved?

• [No details provided]

What are some of the important details related to this idea or concept?

- Being transparent, trustworthy, compensation
- Follow the golden rule
- Misunderstanding, being open

When should this happen?

Day 1 meeting with community full transparency

Where should this activity or action take place?

- In the community, on the street outreach
- In documentation

How can this idea or activity be implemented? What are some important steps?

- Be accountable
- It's ok that you don't know everything
- Make sure everyone is on board and has the time to participatex

Why is this activity or action important?

- Research is a group effort. If there is no buy-in, it won't go anywhere.
- Be accountable when efforts "go left"

Appendix: Community Agreements and Exit Ticket

Here is a listing of the community agreements presented at the start of each workshop, along with two "exit ticket" prompts used to capture feedback at the conclusion of each workshop.

Community Agreements

These agreements were reviewed at the start of each workshop.

Treating Others with Respect

- Be present and avoid distractions.
- Be mindful of one another's identities and address them respectfully
 - Please take a moment to update your name and add preferred pronouns in the Zoom participants tab.
- Try not to talk when someone else is talking.
- Please follow the instructions and the prompts, be timely.
- Respect that there are different experiences present and try to listen and understand.
- Don't rush to solve other people's problems. Instead, strive to build solidarity.
- Only speak for yourself or your organization.
- Operate under Chatham House Rules

Being Inclusive

- Everyone is an expert based on their own experience, and each of you has a unique and important contribution to bring to this work.
- Speak to the nth. The n being the number of people in the group. If there are four people, speak one-fourth of the time.
- Expand all acronyms, be wary of jargon,
- Share resources and URL's in the chat so others can benefit.
- If you can, keep your video on (no worries if you can't).
- Please let us know if we can make accommodations to help you fully-participate

Exit ticket

Participants were welcome to provide an anonymous written response beneath each of the prompts at the close of the meeting.

- What was most useful today?
- What would you most like to improve or expand on from today?