COMMUNITY PARTNERSHIPS PLAYBOOK

How to Create Equitable Partnerships
between Technical and Community Experts

FORD SCHOOL
SCIENCE, TECHNOLOGY,
AND PUBLIC POLICY
UNIVERSITY OF MICHIGAN

DETROIT
DISABILITY
POWER

DETROIT
JUSTICE
CENTER

WE THE
PEOPLE
MICHIGAN
ACTION FUND

COMMUNITY PARTNERSHIPS PLAYBOOK

Science, Technology, and Public Policy program
Madison Cutler
Molly Kleinman
Divya Ramesh

Detroit Disability Power
Kaci Pellar
Eric Welsby

Detroit Justice Center
Erin Keith

We the People Michigan
Marita Ky
Yvonne Navarrete

1.
INTRODUCTION

As the popularity of community engagement grows among technologists and academics, it is vital to ensure that they engage communities in ways that benefit the people they claim to serve and do not cause harm.

While science and technology have tremendous power to make our lives better, they are just as capable of doing the opposite. Machine learning algorithms reproduce systemic biases in their design and use, while crucial medical technologies like vaccines are inaccessible to those who need them most.

Even community engagement efforts intended to enhance the societal benefits of research and development can perpetuate inequity and injustice. Researchers may gather data from communities without respecting their knowledge, time, and contributions. They may treat the engagement as simply a public relations exercise, or use the information they get to do inadvertent harm. Often, researchers do not return to the community to share their learnings or the resulting technologies. How can technologists and scientists engage communities in a spirit of partnership, without such extractive practices? How can community organizations work with researchers in ways that benefit their communities and expand their capacity, rather than burdening their staff?

This Community Partnerships Playbook is a guide for creating more equitable partnerships between technical and community experts. It is a collaboration between the Science, Technology, and Public Policy

program (STPP) at the University of Michigan and three community-based non-profit organizations: Detroit Disability Power (DDP), Detroit Justice Center (DJC), and We the People Michigan (WTPMI). The Playbook brings together advice from staff at DDP, DJC, and WTPMI who have had a range of both positive and negative experiences with researchers, academics, and technologists, along with insights developed from STPP's Community Partnerships Initiative (CPI) and up-to-date scholarly literature.

About the playbook

This playbook is intended as a guide to support better and more equitable partnerships between academics and technologists on the one side, who we refer to collectively as "researchers," and community-based organizations, groups, and individuals on the other, who we are calling "community organizations." It is designed to empower both groups. It includes:

- Qualities of good researcher/community partnerships

- Guidance for community organizations

- Guidance for researchers

- Questions that both partners should answer before the project begins

- An overview of the literature on approaches to community engagement in research and technology development

Throughout the playbook, we provide real world examples from the co-authors' experiences on both sides of community partnerships. Though STPP received the grant that funded this project, and took the lead on assembling it, staff from DDP, DJC, and WTPMI are co-authors, not research subjects. When we say "we" or "our," we are speaking collectively as a group. When we say "they" or "their," we are speaking

about one of the contributing authors or organizations, such as STPP or DJC. In addition, there are direct quotes sprinkled throughout from individual contributors that came up during our discussions.

Purpose of the playbook

Too often, even the most well-intentioned researchers lack the skills to ensure that their community engagement is truly equitable and fruitful for both parties. They will come to a community with the aim of answering a specific question, developing a kind of technology, or helping to solve a particular problem, without confirming that people in the community actually agree with them on what the problem is or what a desirable solution might be. Researchers gather data from a neighborhood, or "pick the brain" of staff in a community organization, without ever sharing the final report once it is done, or crediting them, or even letting them know how their expertise was used. This extraction, where researchers derive valuable data, experiences, and knowledge from community members but fail to return anything of value back to the community, has long characterized the dynamic between academia and the public.

As a result, many people and community organizations are understandably skeptical when a researcher approaches them about a partnership. They have firsthand experience with investing limited time and resources into a project from which they end up seeing no benefit, when they could have put that energy into work that directly serves their community. Even assessing each request to discern which ones are worth considering requires staff time and effort. They feel unheard, frustrated, and disempowered when researchers approach them, but often do not feel that they can push back and offer a different approach that respects their knowledge and addresses their priorities. The fact that often, the researchers are white and wealthier, while the communities they want to research are Black, indigenous, and/or people of color and poorer, intensifies this unbalanced power dynamic. This is a growing problem, because funding institutions are increasingly encouraging researchers to learn from communities. As a result, community organizations must field

an enormous number of requests from researchers with little experience in such engagement.

This playbook aims to guide researchers while supporting and lending authority to community organizations as they advocate for partnerships that will more clearly benefit their constituencies.

About STPP's Community Partnerships Initiative

The CPI supports advocacy and direct service organizations on issues related to technology and science, helping to bring community expertise into decisions about science and technology policy. Its work is rooted in the understanding that everyone has important knowledge about how science and technology can benefit their communities and how it can cause harm. They listen and learn from their community partners, then provide them with tools to engage in technical and policy advocacy. The process begins by meeting with staff of local organizations to understand where their concerns match STPP's expertise. These projects involve research; presentation of findings through policy briefs, one pagers, and FAQs; and advocacy support as needed, always centering the priorities of the partner organizations.

Researchers tend to be quite slow in doing original work, and their timelines don't fit with civil society organizations who usually need immediate help on a pressing issue. That's why it's actually a good thing that we often don't do original research; we just look systematically at the work that others have done, which allows the findings to reach community organizations more quickly.

Examples of CPI projects that the co-authors have done together include:

- Identifying best practices for including people with disabilities in city climate change preparedness plans with Detroit Disability Power

- A policy memo about the risks of using algorithmic pre-trial risk assessment tools in lieu of cash bail with Detroit Justice Center

- A report on how Consumers Energy, a Michigan-based investor-owned utility, harms Michigan residents in the pursuit of higher profits with We the People Michigan.

The CPI puts staff and student skill and expertise, along with the resources of a large research university, into the hands of people on the ground doing advocacy and direct service work. The partner organizations set the direction for the work, while the CPI translates academic scholarship for policy, service, and social change. The work does not begin with an academic research question or even a topic area beyond "science or technology, broadly defined." It is built on a foundation of partnership and collaboration. The Community Partnerships Initiative has shown that it is possible for researchers and community-based organizations to work together in ways that are equitable, collaborative, and that evolve to fit ever-changing community strengths and needs.

2.
A POSITIVE VISION FOR PARTNERSHIP

Good partnerships share certain qualities that help ensure both the process and the final products are equitable and useful for everyone involved. To those in community organizations, it's often apparent that the institutions that produce innovative technologies or reliable research are distanced from the needs of people in marginalized communities; partnerships are a path to shrinking that distance.

Qualities of a good partnership

// Shared values
// Recognizes everyone's expertise
// Mutual benefit

Shared values

Approaching a project with a shared set of values is critical for a successful partnership between researchers and community organizations. **Community-based organizations are usually mission-driven, with clearly articulated values, and any time and resources they invest in a partnership project need to be in service of that mission. It is not enough for researchers to be curious about a question, there has to be a desire to move towards a goal.** For example, DJC is an abolitionist organization, meaning they fight to end incarceration and policing for the safety and well-being of their communities, while also focusing on what they are building in place of those systems. In considering a partnership, DJC recognizes that not every organization is abolitionist, but staff ask themselves: Is the researcher at least dedicated to working towards non-carceral approaches? Do they recognize the problems with mass incarceration and understand the importance of and have respect for abolitionist organizations? Even if their values are not perfectly aligned, does the project feel like it serves a greater purpose that would adhere to DJC's values?

Recognizes everyone's expertise

Often, when a researcher is working on a community engaged project, they see themselves as "the expert," imparting their knowledge to "the public." But there are many more types of expertise than merely technical.

Residents of a community are experts on their own lives and often have richly varied expertise related to their work, hobbies, and experiences. Staff at a service organization are experts in the needs of the people they serve, the challenges they face, and the obstacles that make their work difficult. Organizers at an advocacy group are experts in what their members care about, how to communicate effectively with their community and policymakers, and what policies need to change and why. **Partnerships are successful when they make full use of everyone's expertise and treat all parties as full and equal contributors.**

For example, STPP and DDP worked together on a project about the use of algorithms in hiring and the potential impacts on jobseekers with disabilities. STPP brought research skills and an understanding of problems that are likely to arise from algorithmic bias. DDP brought knowledge of existing employment anti-discrimination laws, members who have direct experience being a disabled person on the job market, and expertise in how to produce materials that would not only have useful content, but also be accessible for people with a range of disabilities.

Mutual benefit

There is often a dramatic difference in wealth

Three people sit at a table with papers in front of them. Credit: Vice Gender Spectrum Collection

and power between a university or a tech company and a community-based non-profit organization. Ensuring that resources, including funds, flow from the wealthier institution to the less wealthy is a key element of equitable partnerships. If information—in the form of survey responses, user testing, or interview data—comes from the partner organization

and their members, and they do not receive anything in return, that is extraction and exploitation.

There are several ways that the Community Partnerships Initiative strives for mutual benefit. STPP pays student research assistants who investigate questions that partner organizations ask and produce deliverables based on what the partner needs. Depending on the partner, STPP then coordinates the design of those final deliverables at the University of Michigan itself. STPP has also written direct partner payments into project grants; the MacArthur grant that funded this playbook included money for the partner organizations who are coauthoring it.

"At the end of the day, we're organizing because our communities need things, not because we want to fulfill research needs."

YVONNE NAVARRETE, *WTPMI*

Why are partnerships with researchers potentially valuable for community groups?

// Increased credibility

// Access to expertise

// Funding and resources

// Increased capacity

// Meeting community needs

Partnerships with outside institutions can allow community organizations to better execute their mission. A successful partnership with a research institution can give community advocates added credibility, access to funding and resources, and expanded logistical capacity and expertise. Such benefits help hardworking community organizations ensure that there is research and technology that meets the needs of people on the ground in the communities they serve.

Increased credibility

Partnering with a research institution can give community organizations additional credibility, especially when working with policy makers and

other authorities. When advocating for change, it is essential to both show and tell why such changes are necessary. Research institutions can provide advocates with the kinds of evidence, like quantitative data and published research, that decision makers may take more seriously than community testimony, which they may dismiss as anecdotes. We the People Michigan has seen policymakers trying to discredit their advocacy efforts, saying things like "That's just a story," when Detroiters came to City Council to oppose ShotSpotter, an acoustic gunshot detection system that places microphones around cities to notify police of possible gunshots.

The prestige and history of the institution itself can bolster more effective advocacy, even allowing community organizations to be in the room with the right stakeholders. For example, Detroit Disability Power partnered with The Carter Center, an international human rights non-profit organization, to do the biggest disability polling audit ever conducted in the United States. The Carter Center's prestige, as one of the most respected election protection organizations in the world, opened doors that DDP alone could not.

Three people stand in front of a building greeting each other smiling. Credit: iStockPhoto

While community organizations often have substantial credibility within the neighborhoods and populations that they serve, partnerships with research institutions can help ensure that policymakers and influential stakeholders take their knowledge more seriously.

> *"Decision makers are used to hearing from community advocates all the time and they, for one reason or another, will find ways to discredit us."*
>
> **YVONNE NAVARRETE,** *WTPMI*

Access to expertise

Similarly, partnerships can help level the playing field for organizations that do not have researchers on their team. For a non-profit that focuses on community organizing, like We the People, or legal aid, like Detroit Justice Center, there may not be enough staff with adequate technical or policy research skills. Working with academic partners, who have extensive research training as

Two people sit at a table looking at a computer together, smiling. Credit: Marcus Aurelius / Pexels

well as technical expertise, can increase organizational capacity and information quality. This is particularly valuable when you are organizing against a more well-resourced opponent. Through research partnerships, community organizations can gain access to specialized expertise and expand their reach, while remaining focused on what they already do well.

Funding and resources

Partnerships with researchers, both in academia and the private sector, can also unlock access to funding and other resources. Possibilities include having academic partners write community organizations directly into grants, tech companies providing resources like computers or tablets, and researchers offering direct payments to community members who participate in interviews or focus groups. A partnership can enable opportunities that the organization's budget or connections would not allow for. It is also a material way to signal a commitment to a reciprocal and equitable relationship.

For a community organization and its staff, these resources can allow them to invest the time and necessary resources in a partner project

that would otherwise be a drain on the organization. In our experience, research partners whose leaders are fully invested and willing to provide funding and other resources can lead to the most impactful projects; they help build the community organization up, rather than deplete it.

Increased capacity

Community organizations often simply do not have the staffing to conduct research, even when it would help them reach decision makers and achieve their goals. Outside institutions can contribute in ways that directly fill gaps in the capacity of community organizations, and this combination facilitates progress. For example, We the People MI uses polling to inform and advocate for its advocacy priorities, but does not have the infrastructure to accurately and effectively conduct polling in their target population. Working with a partner to conduct polling has enabled it to learn more about the communities it serves, without having to build that capacity itself.

Four people wearing light blue shirts standing in a group. One person is smiling, holding a clipboard, gesturing as he talks to the others.

Meeting community needs

Community organizations are deeply knowledgeable about what issues are important to their members, and when they are involved in shaping research and development priorities, it leads to studies and technologies that are more relevant to community interests and more likely to meet the needs of community members. For a community organization, it can be worth the investment of time and effort to work with a research partner when the end result is something that it can actually use, like a study that answers a question about effective policy, or a piece of software that fills a gap.

Why are community partnerships valuable for researchers?

// Increased impact of research
// Increased quality of research
// Improved design/function
// Increased reach
// Increased credibility

The rise of community engagement as a requirement for research funding, the explosion of user research as a field, and the growing appetite on university campuses for engaged learning opportunities for students all represent the value of at least appearing to work in the community. Achieving this can bring meaningful benefits, including increasing the impact of research, increasing the quality of research, improving the design and functionality of technology, increasing the reach of research and development, and giving researchers credibility with the communities they are trying to serve.

Increased impact of research

When researchers come from outside, they tend to focus on problems that do not concern the community. They may get all the way to the point

of developing a solution before consulting with the people they are trying to help, at which point they are likely to hear, "That was not actually the problem." Partnerships that begin well before even posing a research question or proposing a technical solution can produce better, more useful research from the first step. For example, We the People worked with an external polling firm that surveyed attitudes about immigrant rights in Michigan. WTPMI does extensive lobbying and organizing on the ground on several issues that impact the state's working class, including immigration. Their staff know what legislators ask about and the messaging that resonates most with community members. In one survey, the language used by pollsters did not fully take into account WTPMI's knowledge about messaging on this controversial topic, and unfortunately led to results that were muddy and did not adequately answer key strategy questions for the organization. In a second survey, the polling firm was able to shape the language to reflect WTPMI's messaging approach, yielding answers to the exact questions they wanted.

Increased the quality of research

Collaborating with those whose knowledge and expertise come from lived experience can help researchers see a problem in new ways, frame questions that more closely align with the reality on the ground, gather better or different kinds of data, and identify barriers and pitfalls they might have missed. All of this contributes to improving the quality of research. This could mean investigating a question that your field has not previously addressed, getting richer and more honest responses from study participants, and finding results that are novel in the literature but common in people's lived experiences.

Improved design and functionality

User research is a standard step in technology development. But in many cases, especially on college campuses where "tech for good" hackathons and public interest technology design competitions are common, the

disconnect between the people building the technology and the people who are meant to benefit from it is enormous. Often, the products developed without community input provide a technical solution when the problem is actually social. For example, algorithmic risk assessment tools are supposed to reduce bias in pre-trial risk decisions compared to cash bail, and many states and cities are replacing cash bail with these tools in the name of equity. However, many of these risk assessment tools are trained on biased data, and reproduce the exact same racial and socioeconomic biases they are meant to fix, jailing people who have not yet been convicted of a crime due to a perceived but nonexistent risk of flight or repeat offenses.

Increased the reach of research and development

People in community-based organizations are much better than many academics and technologists at getting the word out and distilling research and information into more accessible forms. Organizers and advocates are expert communicators, especially when it comes to communicating with the people they serve. So when a research publication or new piece of software is useful to members of a specific community, local organizations are a great way to put it in people's hands. When STPP published a report about the drawbacks of acoustic gunshot detection systems like ShotSpotter, WTPMI and DJC both amplified it, because it was directly relevant to their efforts to stop the city of Detroit from spending pandemic relief funds on a ShotSpotter expansion. **When you begin with community wisdom, the core assumptions that you design your research or technology around will change, and you will produce something with more widespread appeal and use.**

Increased credibility

We mentioned above that partnering with a research institution can give community organizations additional credibility, but it goes the other way as well. If a researcher or company wants to work in a particular community over the medium to long term, connections to respected leaders and organizations can help build trust. So many people in cities like Detroit have been burned by outside researchers before, who swoop in to do a study and then disappear without returning anything useful to the people who gave them their time and energy. It leads to an unwillingness to do the same thing again. **Having a local institution vouch for you and your work can smooth the path to recruiting participants in your project.**

3.
GUIDANCE FOR COMMUNITY ORGANIZATIONS

As community organizations make decisions about partnering with researchers, they can take steps to help ensure the partnership is a compatible match and the project eventually produces the intended results and benefits.

Most of the co-authors of this report have had both positive and negative experiences in partnerships, and what follows is hard-earned advice for forming beneficial collaborations: be selective, take the lead, choose partners who add capacity, and build long-term relationships. "You" in this section is directed to staff at community organizations, volunteers, organizers, advocates, activists, and anyone who fields requests for research partnerships.

Be selective

Although many research institutions can offer various opportunities, from funding to connections, that make a partnership with them difficult to turn down, the answer should only be yes if it is a very good fit. Though it might not always feel like it, community organizations have the power to say no to a partner that does not meet their standards. At minimum, does the proposed partnership have the qualities of good partnership: shared values, recognizes everyone's expertise, and benefits everyone?

Detroit Disability Power uses the 10 principles of disability justice, developed by a New Orleans-based disability rights group called Sins Invalid, to guide their work. When evaluating potential partners, they ask, is this person or organization even familiar with the concept of disability justice (DJ)? Is the project aligned with DJ principles like intersectionality and long-term sustainability? Does it feel like the researcher wants our intellectual contributions, or do they just want to study us? It can be especially helpful to interview a potential partner with the purpose of

> "If it's not a hell yes, it's a no."
> **ERIN KEITH,** DJC

exploring their values, cultural competence, approach to partnership, and whether the research team includes people who look like the community they want to study. Doing a little digging into their past projects can also tell you a lot about who they work with, how accessible and inclusive their work is, and more.

Take the lead

One way to ensure your goals are best supported in partnerships is to play an active role in seeking partners and directing the project. When you identify a research need, you do not have to wait for a researcher to come to you. If you wait for them to come to you, you might be able to modify their plans a bit, but ultimately you are stuck with what they want to research, as opposed to driving the research towards what you really need.

There are a few ways to find potential research partners. Many colleges and universities have offices of community engagement whose role is to match community groups to researchers with relevant skills and expertise. You can also ask coalition partners, colleagues in other organizations, or your funders if they have worked with any researchers they would recommend. Finally, look at resources you use and like. Who produced them? Who do they quote or cite? Not all researchers are open to or available for partnership requests, but they may be able to connect you with someone who is.

Choose partners who add capacity

A common pitfall is when a partnership demands labor and resources from a community organization without returning something useful. These partnerships reduce an organization's capacity, rather than expanding it. It feels extractive, like you are being used. But if a research partner already understands the landscape, and what your organization needs or wants, they can contribute capacity, expertise, and labor that you do not have

Five people stand outside wearing masks, looking at notebooks together in discussion. Credit: iStockPhoto

the resources to do. When We the People was fighting the expansion of ShotSpotter, they had to put a campaign together very quickly, on a topic on which they did not have much past experience. STPP pulled together the research and briefed WTPMI staff, and then WTPMI was able to turn around and produce community-facing materials, like a one pager and social media images, to build support for their campaign. The partnership enabled WTPMI to do more of what they already wanted to do.

Build long-term relationships

It takes time to learn how to work together successfully, especially across fields and sectors, but there is always pressure not to focus on those human connections and just get the project done. It is worth investing the time in building relationships with partners. When that does not happen, partnerships often fizzle out after a single project, and all the work you put into learning to work together is lost. But if you put in the effort to build relationships, you get sustainable partnerships where you continue to work together, learn from each other, and build power.

Focusing on relationships is also a way to protect against researchers who parachute in, get what they want, and then never circle back to share their final product. This could mean asking potential partners about their interest in longer-term work with your organization, and rejecting proposals that would not lead to a useful ongoing relationship if they do not carry some other benefit for you or your community. Inviting researchers into coalitions is another way to sustain a relationship with them between projects and helps them stay more organically plugged into

4.
GUIDANCE FOR RESEARCHERS AND TECHNOLOGISTS

The following guidance will help researchers engage communities in a spirit of partnership, creating more equitable collaborations between technical and community experts. The advice that follows is rooted in the experiences of the co-authors, who have been on both sides of community partnerships.

Much of this section came from the responses of community organizations to the questions: "What do you wish you could tell researchers before they try to do community engagement or partnerships with community organizations? What do you wish they knew?" In short, the answers were: welcome community expertise, pay your partners and participants (with money), let values lead, include members of the community on your team, share your findings, and build long-term relationships. For those who want to go deeper into decades of academic scholarship on how researchers engage with communities, we provide an overview of that literature in Section 6. Throughout this section, "you" is directed to designers, researchers, technologists, academics, students, university staff, and anyone who is interested in doing community engaged research, development, or teaching.

Welcome community expertise

If you take away only one thing from this entire playbook, let it be this: **Regular people are experts in all kinds of things, and recognizing, respecting, and welcoming that expertise is fundamental to forming robust community partnerships.** Often, even community-based and participatory research is interested solely in data about the community or participants rather than for or with them. Including ordinary people in study design is treated as a way to improve the quality of the data and accuracy of the findings within an academic value system. Fewer researchers actually recognize community partners as equals, with equally relevant knowledge about the systems, structures, and politics behind your data and findings. As a result, the co-authors have all seen research reports with conclusions or recommendations that seem great in theory, but are completely disconnected from reality.

When two academics from different disciplines collaborate, they recognize that each of them knows things and has expertise that the other does not, and in working together, they draw on each person's strengths to produce better research. The same should be true when your collaborators come from outside academia or industry. Organizers

know more about messaging than you do. People with disabilities know more about processes for requesting (and hopefully accessing) accommodations. Defense attorneys know more about how judges think. Embrace it! Welcome it! The foundation of your partnership should be the understanding that every contributor is an expert in something.

Pay your partners and participants. With money.

The researchers with an interest in doing good often focuses on people who are struggling. If you are asking people, particularly those who are historically marginalized, to give you their limited time and energy, with no immediate benefit to them, you need to pay them generously for their time. While it is relatively common

Photo of the corner of a fifty dollar bill.
Credit: Karolina Grabowska / Pexels

to pay study participants a token amount for attending a focus group or interview, chances are you could and should be paying them more. DDP will not promote a study to their members that pays less than $50. They prefer projects that pay more. The researchers needs to be making an investment in that community today, not when an app launches in six months or a journal article comes out in two years.

Build partner and participant payments into your research budget. For technologists in the private sector, this is part of the cost of doing business. For those in universities, put it in your grant proposals up front. More and more funders are recognizing that paying participants fairly is an equity issue. You should also be finding ways to pay the organizations you partner with, especially if there is no other tangible benefit coming to them from the collaboration. Because many of the projects that STPP

does are driven by the partner's research needs, and the deliverables are tailored to be useful for the partner, it generally does not pay its partner organizations. However, it does pay those who participate in larger projects. STPP secured the grant for producing this playbook, and included payments to each partner organization in the budget, to help cover the labor that would go into co-authoring it.

A note: depending on your institution, it can be complicated to process payments; as much as possible, give people cash or pre-paid credit cards that can be used universally, like Visa cards.

Let values lead

Often, the stated purpose of community engaged research and development is to fulfill a commitment to diversity, equity, and inclusion (DEI). However, in practice we have seen many projects where the talk about DEI is superficial, without actual principles to back it up. Part of getting to a place where you and your prospective partner have shared values is learning what their values are and figuring out what yours are. Do not expect potential partners to teach you themselves, unless training is a part of what they do, and in that case, pay them for their time the way you would any other trainer (see above). Instead, look at the resources they point to or have created. If they are using a word or principle that is unfamiliar, look it up, the same way you would in a technical or academic setting.

Too many times, we have seen projects where the researchers who come into our communities treat it like an intellectual or educational exercise.

> *"Time is the most expensive thing out there because I can't get more of it."*
> **KACI PELLAR,** *DDP*

> "One of the major concepts we operate under as an organization is, 'The way we do the work is the work.' We can't create social justice for people with disabilities if we're treating, or our partners are treating, our DDP employees and our members in unjust ways."
>
> **ERIC WELSBY,** DDP

Their goal is not to end mass incarceration or deportations or ableism, but just to learn or talk about those things. Community organizations need to know that a potential project at least has the goal of making a positive impact on the populations they serve and care about, and that means doing work that is mission driven.

A banner held by many disability justice warriors reads "Interdependence is Survival" a quote and call to action by Naomi Ortiz. The phrase "Disability Justice is Racial Justice is Environmental Justice" follows. This group of two dozen disabled people and caregivers pose in front an inspiring mural of a child holding flowers in their fist.

Include members of the community on your team

We need more culturally competent and diverse researchers, and one way to build that pipeline is to create opportunities for people who come from the communities you are studying to participate in the work in a meaningful way. Not just being a part of a focus group, for example, but giving them an internship to help develop the questions and write the report. Until there are more BIPOC, disabled, poor, immigrant, queer, and otherwise historically excluded people in tech and academia, in the interim, community partnerships can help form pathways to bring them into these careers. Not only is it another way to benefit the community, it also improves the quality of your work, because you have someone who can say, "I don't like the way this is phrased," or "This is gonna rub people the wrong way."

Share your findings

One of the most common mistakes that researchers make after they have worked with a community based partner is not to share the results with them. It is an excellent way to alienate a partner and make sure they never want to work with you again. When people say community engagement is extractive, this is often what they mean. Whether it was a single phone conversation to get background on a neighborhood, or piloting a product, or a study that they helped recruit participants for, always find a way to circle back and let them know how things turned out. During the launch of the first covid-19 vaccines, for example, civil society groups and government agencies around the country reached out to DDP asking for guidance on improving vaccine access for people with disabilities—there were so many they lost count. It was a crisis, and DDP did what they could to help keep people safe and save lives. But when attention shifted and non-disabled people decided the crisis was over, DDP was forgotten. It was discouraging never to hear back from any of those groups to recognize DDP's contribution, share what they learned, or continue carrying the work forward "after" the pandemic by maintaining access measures instead of rolling them back.

Build long-term relationships

When you focus on relationship-building, it benefits both you and the community you aim to work in. There is labor involved in hammering out routines and processes, learning from mistakes, and adjusting to each other's work cultures and expectations. It goes much more smoothly when you take the time to connect with the staff or community members you are working with, get to know them, and develop trust. Furthermore, it is important to approach these relationships with humility. We the People has experienced coalitions where some partners operate in a hierarchy, and value their role as more important than others because it is more technical. Setting a foundation of mutual respect makes it easier to bridge gaps in terms of language and understanding, and to recover from setbacks or disappointments.

The long-term part of this guidance is also important. It helps combat extraction and improve the relationship between your institution and your partners. But it can also improve your own work, enabling you to develop long-term understanding. How does a project or research question change when you commit to staying in a community for the long haul? What more can you do? Maintaining these relationships even between projects also means a partner is more likely to come to you first when they have an idea for a new tool or a research need, creating opportunities for you.

> *"If a researcher or institution lacked the humility to really get to know the organizing efforts and the people who are doing the organizing, that would definitely be a big red flag."*
>
> **MARITA KY,** *WTPMI*

5.
QUESTIONS TO ANSWER BEFORE YOU BEGIN

These questions are designed to help everyone involved in launching a new partnership—community organizations, researchers, technologists—start from a strong foundation. You can use them as is, or as a base on which to create your own set of standard questions to ask potential partners. DDP has a list of questions it uses internally to evaluate potential partner projects; we adapted some of its questions here to work as conversation starters, in addition to including questions that STPP often covers in prospective partner meetings, and others that arose out of our conversations about past experiences with good and bad partnerships.

Values

What **values or principles** are guiding the project/partnership?

Is each partner involved **adequately educated on the issue** at hand and relevant context? If not, how will everyone be brought up to speed?

How will each partner **benefit** from the project? Who else will benefit? In what ways?

Are there potential **drawbacks or harms** from the project? What are they and who would they affect?

If the project is focused on a particular **marginalized group**, are members of that group **represented** on both sides of the team? *E.g., if the project is to improve access to vaccines for queer and trans people, are there queer and/or trans people on the research side as well as the community side?*

How does each partner want their contributions to be **recognized**? *E.g., co-authorship, acknowledgements, something else? Would one partner prefer not to be recognized?*

Goals

What are the **project goals**? Are they well developed and clearly communicated?

What will the **final products** be?

How will the **results** of the project be **communicated** and to whom? How widely accessible will the benefits/products/outcomes of the partnership be?

How will this work contribute to the **larger goals** of each partner?

Logistics

How much **time** will this project require from each partner?

How often and in what manner will partners **meet**?

Is one or both partner(s) **compensated** and how will this **funding** be secured?

Is there a **project budget** and, if so, what is it?

What **contributions** (e.g., labor, financial, technology, other resources) will be required from each partner?

Who else, if anyone, is participating in this work?

What is the **timeline**? How will both partners know when the project is complete?

How will the partners stay in touch **after the project is complete?**

6.
LANDSCAPE OF COMMUNITY ENGAGEMENT APPROACHES IN SCIENCE AND TECHNOLOGY RESEARCH

Though researchers have engaged communities for decades, there has been a sharp increase in this work over the last few years. Funders and research institutions are encouraging community-engaged work, but what does it mean in practice?

In this section, we review and categorize the broader literature on community-engaged research for those who want to understand the landscape more deeply, and also to place our own community partnerships approach in context.

We have organized the following section around the goals of community engagement, the different modes of including community members in research, and the roles of different stakeholders and participants; in other words, Why? How? Who? Community engagement represents a broad collection of methods and goals under names like user-centered design, human-centered design, participatory action research, and community-based participatory research. Rather than break down the specifics of each method, which others have already done well,[1] we focus here on providing a structure so that readers, both researchers considering a community-engaged project and individuals and organizations considering participating in such a project, can use it to think through the different aims of community-engaged research, possible ways of doing it, and the various roles that community members can play. We draw on literature from across disciplines, with a large selection coming from computer science and human-computer interaction.

Goals of community engagement for scientists and technologists

In much of the literature on community-engaged research, researchers may engage with the public to maximize commercial viability of their technological designs and outcomes, to democratize science and technology, or to pursue other social goals such as accessibility, equity and justice. Some of these goals overlap with the arguments discussed above for why community partnerships are valuable for researchers, but not all.

Maximizing commercial viability

Researchers seek to understand consumer desires, demand, and experiences in order to make products that people want to use and buy. Human-centered design[2] and user-centered design[3] are two popular frameworks that researchers frequently use to study people's interactions with technologies, testing out design prototypes, watching how people use the technology, and asking about their experiences and opinions.[4] Work in this space generally frames community members as users or potential users. Researchers interested in commercial viability of products use success metrics related to user satisfaction, novelty, imagination, and creativity.[5]

Democratizing science and technology

In the wake of controversies over genetically modified organisms (GMO),[6] nuclear power,[7] and other emerging technologies, researchers have become more interested in understanding public opinion, and gaining input and approval from communities on their proposed research or technological projects. To do this, they may engage with community members to identify local needs and priorities, gather feedback about options, and determine the appropriateness of projects. Deliberative[8] and participatory[9] frameworks are two popular approaches that scientists and technologists use to bring community perspectives into their work.

Promoting accessibility, equity, and social justice

Researchers may be interested in pursuing social goals either through science and technology or as they intersect with science and technology. Participatory action research[10] and community-based participatory research[11] are some well-established frameworks scientists and technologists use to bring community knowledge into their work, with the aim of ensuring equitable distribution of opportunities and resources, and

reducing risks and harm. Success metrics go beyond immediate project results, to include process and outcome details such as shared ownership of projects, policy and practice changes, and intangibles like friendships, deep collaborations, and trust.[12]

Two people lean over a desk to look at a contraption with wires, one wearing a white lab coat. Credit: iStockPhoto

Modes of engaging community in science and technology

When researchers engage community members, there is a spectrum of inclusion, from one time participation to long-term partnership and collaboration. Different approaches may be appropriate in different contexts, but as we have made clear throughout this Playbook, in general we believe deeper ongoing engagement produces better research that is more likely to serve communities. It is important to note that without effort, all of these modes can default to privileging the voices of dominant groups already overrepresented in science and technology research and decision making.

One-time and short-term research projects

Study teams often invite community members to participate in one-time or short-term research projects using both qualitative and quantitative methods such as interviews,[13] surveys,[14] focus groups, and user testing

like design probes[15] and usability evaluation tests.[16] While these may be simpler ways to conduct research, the communities under study run the risk of being reduced to sources of data for scientific projects, and resulting decisions and policies may not meet their deeper needs.[17] A significant characteristic of these studies is that they tend to be transactional arrangements, and researchers generally do not engage with community members after data collection.

If the goal of a project is to promote social goals like equity and justice, structuring it around brief, one-time interactions with participants may limit its impact. For example, an academic research team conducting a study with older adults faced significant distrust from participants that affected the validity of their study.[18] Later, the team learned that some of the participants had been in and out of numerous longitudinal "inclusion" studies at the same university for over 20 years, which shaped their attitudes towards this project. The research team reflected that short-term engagement of marginalized communities allows researchers to establish quick evidence for design or decision making, but does not enable the nuanced contextual listening necessary to help undo structural injustices.

Deliberative assemblies, panels, and workshops

Scientists, technologists, and policymakers may invite community members to participate in community assemblies and panels,[19] democratic deliberations,[20] and participatory assessments and workshops[21] to enhance public participation in decision-making for science and technology. These can be short or long term, and can inform both research and policymaking. For example, the European Data Protection board held a series of public consultations to inform its guidelines on facial recognition technology for law enforcement.[22]

While such assemblies, panels, and workshops have the potential to bring voices of marginalized communities into decision-making about

technological projects that affect them, they often do not achieve these outcomes in practice. Technical experts frequently determine the terms of participation, which privilege technical framings of problems, and rigid boundaries that could reinforce power imbalances between the ultimate decision-makers and overburdened communities.[23] Further, time-intensive approaches like consensus panels and deliberative assemblies tend to include people who are highly educated and already engaged in science and technology issues, and exclude important marginalized communities and their perspectives.[24]

Researcher-led community science projects

Often enabled by the internet and the powerful capabilities of smartphones and home computers, researchers invite the public to take part in studies as amateur or hobby scientists.[25] Here, researchers create physical or online spaces where volunteers can contribute,[26] while volunteers gather, process and analyze data,[27] share information about themselves,[28] and produce research and knowledge collectively.[29] These projects are often medium to long term, and in many cases, the participating community members are not providing data about themselves, but rather serving as a kind of volunteer research assistants, collecting data about something else. Participation in hobby and amateur projects may enhance the science knowledge and literacy of the participants.[30] However, studies show that participation in online community science projects is not equitably distributed; contributors are found to be primarily white, younger than average, middle class and men.[31] And like the modes above, community scientists rarely contribute to decisions about research questions, methods, or terms of participation.

Long-term research projects

Researchers may invite community members into earlier stages of research, with the intention to work together long-term to co-create studies, and develop solutions to problems the community identifies.[32]

Sometimes community members may initiate these collaborations with researchers.[33] Here, activities may involve gathering long-form narratives from community members,[34] assessing and evaluating impacts of designs or policies, and identifying future research directions.[35] Community members may receive monetary compensation as co-designers or credit as authors on research articles.[36]

Through long-term projects, researchers develop relationships with community members and become familiar with their beliefs, experiences, and needs by volunteering their time,[37] organizing with local groups,[38] or through community partner organizations and outreach programs.[39,40] They require significant effort to build mutual trust. These personal connections can increase accountability, and encourage researchers to respond to other needs of community members[41] and advocate for them at local, state and national levels.[42]

Activism

Activism is a longstanding mode of engaging with science and technology for community members who are motivated by notions of democracy, openness, and social change, and whose expertise is not recognized by scientists and technologists.[43] As activists working outside the scientific establishment, community members can reframe issues to gather public support,[44] conduct their own citizen science research and develop their own methods,[45] seek out coalitions with other community and grassroots organizations that have shared goals,[46] and introduce new policy-making facts and logics.[47] Through organizing together, community members may push back against certain technologies, demand

A person wearing a white hoodie that says "Building a multi-racial working class movement" on their back is holding a sign that says "We Who Seek- Justice".

rights, and advocate for changes in science and technology projects and approval processes.[48] Community activism can increase scrutiny into the ethical and social dimensions of technological innovation,[49] unearth inequitable impacts of technological innovations,[50] and ensure that technological innovation aligns with the needs of marginalized communities.[51] Though it is common for scientists and technologists to resist community activism,[52] researchers who care about equity, justice, and inclusion can instead choose to learn from, collaborate with, and amplify activist voices.

Roles of community members

Community members can play a number of different roles in science and technology research. These loosely map to the spectrum of inclusion discussed above; the role of research subject is more common in one-time and short-term projects, while the role of research collaborator is present in longer-term partnerships, but other combinations are possible. When a community organization is considering working with a researcher, it may be useful to discuss what type of role their staff or members will be playing and to determine what level of involvement is preferable.

Research subjects

Research subjects participate in studies that aim to gather information from them or about them, often related to their needs, desires, experiences, and challenges. The study team usually develops the research questions, methods, recruitment strategies, data collection and analysis, and technology design and/or writes and publishes the outcomes of the research.[53] Community members, as research subjects, act as sources of data and may receive compensation.[54] They are only occasionally invited to give inputs on the analysis or the final conclusions of the research study. Serving as a research subject is often one-time

or short-term, but for people who live in neighborhoods or are part of communities that are subject to a great deal of research interest, the cumulative demand for study participants can lead to fatigue and mistrust.[55]

Consumers or users

Companies, or technologists hoping to start companies, do user research with people they hope are potential customers. These projects can range from participatory processes in which potential users contribute throughout the design process, to projects where researchers are refining the interface or user experience of a product that is mostly complete.[56] Because these are often for-profit endeavors, participants should receive compensation.

Clients

In the role of clients, community members work with design and/or technology teams to solve problems that require technical expertise. Universities often recruit community members and organizations to serve as clients in student projects, described as service learning or engaged learning, where teams of students work with the client throughout an academic term.[57] Clients articulate their needs and parameters, and student teams produce prototypes, reports, or finished products. While participation in these projects may be intensive over a relatively short period of time, because the main points of contact are students they may not lead to longer term relationships without careful stewardship by the university.

Democratically engaged community members

Community members can shape science and technology by advocating to influence research funding and priorities,[58] as well as regulation of

controversial technologies[59] that have uncertain social, ethical, or equity implications. They may participate in activism,[60] deliberative panels,[61] consensus conferences,[62] participatory workshops,[63] or community science projects.[64]

Research collaborators

In community research collaborations, community members are full partners in a project and contribute expertise throughout. Community members and researchers may collaboratively come up with research agendas, questions, and methods, and analyze and publish any subsequent findings.[65] Though more time intensive and potentially demanding for everyone involved, projects in which community members fully participate as collaborators may extend the concepts of democracy, openness, and shared power to give communities more agency to contribute to technology designs and function, more control over research agendas, and facilitate social action.[66]

7.
FURTHER READING

"10 Principles of Disability Justice." Sins Invalid. (2015)

"Mapping Injustice: Navigating the Criminal Legal System Syllabus. Resources to Empower Communities Fighting Mass Incarceration." (2021)

"Why Am I Always Being Researched? A Guidebook For Community Organizations, Researchers, And Funders To Help Us Get From Insufficient Understanding To More Authentic Truth." Chicago Beyond. (2018)

Design Justice: Community-Led Practices to Build the Worlds We Need. Sasha Costanza-Chock. (2020)

8. CONTRIBUTING ORGANIZATIONS

Detroit Disability Power

Detroit Disability Power is a
membership organization focused
on leveraging and building the
organizing and political power of
the Disability Community to ensure
the full inclusion of People with Disabilities in Metro Detroit and across
Michigan. They aim to mobilize People with Disabilities and allies, as
well as other organizations and partners, around issues that affect
Disabled People. They conduct one of the largest Disability-focused voter
engagement and election protection programs in the nation, including
the most comprehensive accessible polling location audit in U.S. history.
DDP facilitates Anti-Ableism Workshops for organizations wishing to
better understand the systemic oppression of Disabled People and how
to dismantle able-ism in their work. They also offer Disability Access
Consulting services to support organizations' efforts to create accessible,
inclusive spaces and events.

DDP—Detroit Disability Power logo

Detroit Justice Center

The Detroit Justice Center is a non-
profit law firm working alongside
communities to create economic
opportunities, transform the criminal

DJC—Detroit Justice Center logo

legal system, and promote equitable and just cities. DJC knows that cities cannot be fair and equitable unless they are free from the harms of mass incarceration. This mission requires innovative ways of community lawyering and organizing–rooted in fights for racial justice and economic equity–that build up low income residents through direct services and novel approaches to land use, housing stability, and employment. DJC uses a three-pronged approach–that they call "defense, offense, and dreaming" to serve individual clients, build power and catalyze systemic solutions. DJC also aids movement organizations with litigation, policy advocacy, and other strategy expertise when necessary. They also are engaged with work to expand access to restorative justice services and to promote divesting from carceral structures to fund community needs.

We the People Michigan

We the People Michigan is statewide organizing non-profit working to build multi-racial working class power across Michigan. From the Motor City to the shore of Lake Superior, We the People Michigan works hard to ensure dignity, safety, and a prosperous future for every Michigander. WTPMI is building long term organizing infrastructure across issues, from fighting corporate greed and the influence of investor-owned utilities in our democracy, to organizing for funded resources our communities actually need, we can make Michigan a place where everyone thrives.

WTPMI—We the People Michigan logo

Science, Technology, and Public Policy program

University of Michigan's Science, Technology, and Public Policy (STPP) Program, based in the Ford School of Public Policy, is a research center dedicated to fostering more equitable and just technology, science, and

related public policies. We accomplish this through applied research for our Community Partnerships Initiative (CPI) and Technology Assessment Project, public and policy engagement, and educational initiatives including our massive open online course, research corps, and graduate certificate program, which train students to understand the social, ethical, and policy dimensions of emerging technologies.

**FORD SCHOOL
SCIENCE, TECHNOLOGY,
AND PUBLIC POLICY**
UNIVERSITY OF MICHIGAN

STPP—Science, Technology, and Public Policy program logo

9. ACKNOWL-EDGMENTS

10.
ENDNOTES

1   Leydens, J.A., Lucena, J.C., and Nieusma, D., 2014. What is Design for Social Justice? In *121st ASEE Annual Conference & Exposition*.

2   Cooley, M., 2000. Human-centered design. *Information design*, pp.59-81.

3   Kuniavsky, M., 2003. *Observing the user experience: a practitioner's guide to user research*. Elsevier.

4   Walker, M., Takayama, L., and Landay, J.A., 2002. High-fidelity or low-fidelity, paper or computer? Choosing attributes when testing web prototypes. In Proceedings of the human factors and ergonomics society annual meeting, vol. 46, no. 5, pp. 661-665. Sage CA: Los Angeles, CA: Sage Publications.

5   Vredenburg, K., Mao, J.Y., Smith, P.W. and Carey, T., 2002, April. A survey of user-centered design practice. In Proceedings of the SIGCHI conference on Human factors in computing systems pp. 471-478.

6   Aga, A., 2021. Environment and its forms of knowledge: The regulation of genetically modified crops in India. Journal of Developing Societies, 37(2), pp.167-183.

7   Verma, A., Ahmad, A. and Giovannini, F., 2021. Nuclear energy, ten years after Fukushima. Nature, 591(7849), pp.199-201.

8   Berg, M. and Lidskog, R., 2018. Deliberative democracy meets democratised science: a deliberative systems approach to global environmental governance. Environmental Politics, 27(1), pp.1-20.

9   Kensing, F. and Blomberg, J., 1998. Participatory design: Issues and concerns. Computer supported cooperative work (CSCW), 7, pp.167-185.

10   McNiff, J., 2013. Action research: Principles and practice. Routledge.

11   Shalowitz, M.U., Isacco, A., Barquin, N., Clark-Kauffman, E., Delger, P., Nelson, D., Quinn, A. and Wagenaar, K.A., 2009. Community-based participatory research: a review of the literature with strategies for community engagement. Journal of Developmental & Behavioral Pediatrics, 30(4), pp. 350-361.

12   Brush, B.L., Mentz, G., Jensen, M., Jacobs, B., Saylor, K.M., Rowe, Z., Israel, B.A. and Lachance, L., 2020. Success in long-standing community-based participatory research (CBPR) partnerships: A scoping literature review. Health Education & Behavior, 47(4), pp.556-568.

13   Renaud, K. and Van Biljon, J., 2008, October. Predicting technology acceptance and adoption by the elderly: a qualitative study. In Proceedings of the 2008 annual research conference of the South African Institute of Computer Scientists and Information Technologists on IT research in developing countries: riding the wave of technology, pp. 210-219.

14   Hornbæk, K. and Hertzum, M., 2017. Technology acceptance and user experience: A review of the experiential component in HCI. ACM Transactions on Computer-Human Interaction (TOCHI), 24(5), pp.1-30.

15   Hutchinson, H., Mackay, W., Westerlund, B., Bederson, B.B., Druin, A., Plaisant, C., Beaudouin-Lafon, M., Conversy, S., Evans, H., Hansen, H. and Roussel, N., 2003, April. Technology probes: inspiring design for and with families. In Proceedings of the SIGCHI conference on Human factors in computing systems, pp. 17-24.

16   Nielsen, J., 1994. Usability engineering. Morgan Kaufmann.

17   Liang, C.A., Munson, S.A. and Kientz, J.A., 2021. Embracing four tensions in human-computer interaction research with marginalized people. ACM Transactions on Computer-Human Interaction (TOCHI), 28(2), pp.1-47.

18   Vines, J., Clarke, R., Wright, P., McCarthy, J. and Olivier, P., 2013, April. Configuring participation: on how we involve people in design. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (pp. 429-438).

19   Dryzek, J. S., Nicol, D., Niemeyer, S., Pemberton, S., Curato, N., Bächtiger, A., Batterham, P. et al. "Global citizen deliberation on genome editing." Science,

369, no. 6510 (2020), pp. 1435-1437.

20   Ada Lovelace Institute. 2021. The Citizens' Biometrics Council. Available at: https://www.adalovelaceinstitute.org/report/citizens-biometrics-council/

21   Cynthia Selin (2008). "The Future of Medical Diagnostics." Scenario Development Workshop Report. The Center for Nanotechnology in Society. Arizona State University.

22   EDPB. 2023. EDPB adopts final version of Guidelines on facial recognition technology in the area of law enforcement. Available at: https://edpb.europa.eu/news/news/2023/edpb-adopts-final-version-guidelines-facial-recognition-technology-area-law_en

23   Brown M., 2006. "Citizen Panels and the Concept of Representation." Journal of Political Philosophy. 14(2): 203-225

24   Björgvinsson, E., Ehn, P. and Hillgren, P.A., 2012. Agonistic participatory design: working with marginalized social movements. CoDesign, 8(2-3), pp.127-144.

25   Giardullo, P., 2023. Non-experts' participation in processes of scientific knowledge creation: The case of Citizen Science. Sociology Compass, p.e13100.

26   Stelzer A., 2016. "Oakland hackers take a stab at making crowdfunded insulin." Science. Jul 2016.

27   Fortson, L., Masters, K., Nichol, R., Edmondson, E.M., Lintott, C., Raddick, J. and Wallin, J., 2012. Galaxy zoo. Advances in machine learning and data mining for astronomy, 2012, pp.213-236.

28   Wicks, P., Massagli, M., Frost, J., Brownstein, C., Okun, S., Vaughan, T., Bradley, R. and Heywood, J., 2010. Sharing health data for better outcomes on PatientsLikeMe. Journal of medical Internet research, 12(2), p.e1549.

29   Strasser, B., Baudry, J., Mahr, D., Sanchez, G. and Tancoigne, E., 2019. " Citizen science"? Rethinking science and public participation. Science & Technology Studies, 32(ARTICLE), pp.52-76.

30   Aristeidou, M. and Herodotou, C., 2020. Online citizen science: A

systematic review of effects on learning and scientific literacy. Citizen Science: Theory and Practice, 5(1), pp.1-12.

31   Curtis, V., 2015. Online citizen science projects: an exploration of motivation, contribution and participation. Open University (United Kingdom).

32   Hsu, Y.C., Dille, P., Cross, J., Dias, B., Sargent, R. and Nourbakhsh, I., 2017, May. Community-empowered air quality monitoring system. In Proceedings of the 2017 CHI Conference on human factors in computing systems (pp. 1607-1619).

33   Erete, S., Dickinson, J., Gonzalez, A.C. and Rankin, Y.A., 2022, April. Unpacking the complexities of community-led violence prevention work. In Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems (pp. 1-15).

34   Cooper, N., Horne, T., Hayes, G.R., Heldreth, C., Lahav, M., Holbrook, J. and Wilcox, L., 2022, April. A systematic review and thematic analysis of community-collaborative approaches to computing research. In Proceedings of the 2022 CHI Conference on Human Factors in Computing Systems (pp. 1-18).

35   Leydens, J.A., Lucena, J.C. and Nieusma, D., 2014. What is design for social justice?. In 121st ASEE Annual Conference & Exposition.

36   Tandon, U., Khovanskaya, V., Arcilla, E., Hussein, M.H., Zschiesche, P. and Irani, L., 2022. Hostile Ecologies: Navigating the Barriers to Community-Led Innovation. Proceedings of the ACM on Human-Computer Interaction, 6(CSCW2), pp.1-26.

37   Calacci, D. and Pentland, A., 2022. Bargaining with the Black-Box: Designing and Deploying Worker-Centric Tools to Audit Algorithmic Management. Proceedings of the ACM on Human-Computer Interaction, 6(CSCW2), pp.1-24.

38   Ghoshal, S., Mendhekar, R. and Bruckman, A., 2020. Toward a grassroots culture of technology practice. Proceedings of the ACM on Human-Computer Interaction, 4(CSCW1), pp.1-28.

39   Hui, J., Barber, N.R., Casey, W., Cleage, S., Dolley, D.C., Worthy, F., Toyama, K. and Dillahunt, T.R., 2020, April. Community collectives: Low-tech

social support for digitally-engaged entrepreneurship. In Proceedings of the 2020 CHI conference on human factors in computing systems (pp. 1-15).

40   Vigil-Hayes, M., Collier, A.F., Hagemann, S., Castillo, G., Mikkelson, K., Dingman, J., Muñoz, A., Luther, J. and McLaughlin, A., 2021. Integrating cultural relevance into a behavioral mHealth intervention for Native American youth. Proceedings of the ACM on human-computer interaction, 5(CSCW1), pp.1-29.

41   Harrington, C., Erete, S. and Piper, A.M., 2019. Deconstructing community-based collaborative design: Towards more equitable participatory design engagements. Proceedings of the ACM on Human-Computer Interaction, 3(CSCW), pp.1-25.

42   Irani, L., Hussein, M., Zschiesche, P., Tandon, U., Arcilla, E., Hickman, L., Goldsmith, M., Khovanskaya, V. and Singh, S., 2021. Transportation for Smart and Equitable Cities: Integrating Taxis and Mass Transit for Access, Emissions Reduction, and Planning.

43   Gingery D., 2021. "Patient Support May Have Helped Push Aduhelm Toward Approval."Pink Sheet. June 7, 2021.

44   Morris A., 2021. "From Civil Rights to Black Lives Matter." Scientific American. February 3, 2021.

45   Ottinger, G. 2010. Buckets of resistance: Standards and the effectiveness of citizen science. Science, Technology, & Human Values, 35(2), pp. 244-270.

46   Tomes N., 2011. "From Outsiders to Insiders: The Consumer-Survivor Movement and Its Impact on US Mental Health Policy." Patients as Political Actors. Edited by Beatrix Hoffman, Nancy Tomes, and Mark Schlesinger. New Brunswick, NJ: Rutgers University Press.

47   Parthasarathy, S., 2010. Breaking the expertise barrier: understanding activist strategies in science and technology policy domains. Science and Public Policy, 37(5), pp.355-367.

48   Epstein, S., 1995. The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. Science, technology, & human values, 20(4), pp.408-437.

49   Ottinger, G., 2013. Refining expertise. In Refining Expertise. New York University Press.

50   Brown, P., 2007. Toxic exposures: contested illnesses and the environmental health movement. Columbia University Press.

51   Corburn, J., 2005. Street science: Community knowledge and environmental health justice. MIT Press.

52   Epstein, S., 1995. The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. Science, technology, & human values, 20(4), pp.408-437.

53   Vines, J., Clarke, R., Wright, P., McCarthy, J. and Olivier, P., 2013, April. Configuring participation: on how we involve people in design. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (pp. 429-438).

54   Pater, J., Coupe, A., Pfafman, R., Phelan, C., Toscos, T. and Jacobs, M., 2021. Standardizing reporting of participant compensation in HCI: A systematic literature review and recommendations for the field. In Proceedings of the 2021 CHI conference on human factors in computing systems, pp. 1-16.

55   Chicago Beyond, 2019. Why am I always being researched? https://chicagobeyond.org/wp-content/uploads/2019/05/ChicagoBeyond_ 2019Guidebook.pdf

56   Vines, J., Clarke, R., Wright, P., McCarthy, J. and Olivier, P., 2013, April. Configuring participation: on how we involve people in design. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (pp. 429-438)

57   Leidig, P.M., Ferguson, R. and Leidig, J., 2006, June. The use of community-based non-profit organizations in information systems capstone projects. In Proceedings of the 11th annual SIGCSE conference on Innovation and technology in computer science education (pp. 148-152).

58   Kolker, E.S., 2004. Framing as a cultural resource in health social movements: funding activism and the breast cancer movement in the US 1990– 1993. Sociology of Health & Illness, 26(6), pp.820-844.

59   Parthasarathy, S., 2011. Whose knowledge? What values? The

comparative politics of patenting life forms in the United States and Europe. Policy Sciences, 44, pp.267-288.

60   Parthasarathy, S., 2011. Whose knowledge? What values? The comparative politics of patenting life forms in the United States and Europe. Policy Sciences, 44, pp.267-288.

61   Young, M., Magassa, L. and Friedman, B., 2019. Toward inclusive tech policy design: a method for underrepresented voices to strengthen tech policy documents. Ethics and Information Technology, 21, pp.89-103.

62   Kleinman, D. L., Powell, M., Grice, J., Adrian, J. and Lobes, C., 2007. A toolkit for democratizing science and technology policy: The practical mechanics of organizing a consensus conference. Bulletin of Science, Technology & Society, 27(2), pp.154-169

63   Hamidi, F., Mbullo, P., Onyango, D., Hynie, M., McGrath, S. and Baljko, M., 2018, December. Participatory design of DIY digital assistive technology in Western Kenya. In Proceedings of the Second African Conference for Human Computer Interaction: Thriving Communities (pp. 1-11).

64   Nugent, J., 2018. INaturalist. Science Scope, 41(7), pp.12-13.

65   Tandon, U., Khovanskaya, V., Arcilla, E., Hussein, M.H., Zschiesche, P. and Irani, L., 2022. Hostile Ecologies: Navigating the Barriers to Community-Led Innovation. Proceedings of the ACM on Human-Computer Interaction, 6(CSCW2), pp.1-26.

66   Anuyah, O., Badillo-Urquiola, K. and Metoyer, R., 2023, April. Characterizing the Technology Needs of Vulnerable Populations for Participation in Research and Design by Adopting Maslow's Hierarchy of Needs. In Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems (pp. 1-20).