

RECOVERY AND RESEARCH —

# WHY AM I ALWAYS BEING RESEARCHED?

COVID-19 EDITION

CHICAGO  
BEYOND →

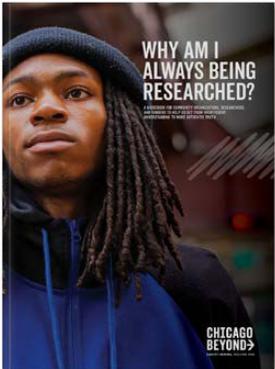
EQUITY SERIES, VOLUME TWO

# INTRODUCTION

Research and data help us make decisions, inform actions, and allow us see what we might otherwise miss. Research and data also play a big part in how stories are told, how power gets perpetuated, and how inequities remain in place. If evidence matters to how we use this crisis as an opportunity to create a more just and equitable society, we must care about how the evidence gets made.

In response to COVID-19, many funders are seeking to make evidence-based decisions about what comes next. Pre-existing efforts to collect and analyze data have been disrupted. Many are launching new efforts.

If we want to avoid perpetuating the same systemic problems and structural biases that have persisted in communities of color for generations, and which COVID-19 is now presenting to us in full color, we need to change our orientation in how we produce, analyze, use, and assess the validity of evidence.



Pre-COVID-19, Chicago Beyond published *“Why Am I Always Being Researched?”* a guidebook to offer “how” we can begin to level the playing field and reckon with unintended bias when it comes to research. It was written to help shift the power dynamic and the way community organizations, researchers, and funders uncover knowledge together. It is an equity-based approach to research that offers one way in which we can restore communities as authors and owners.

“Why Am I Always Being Researched?” was written based on the steps and missteps of Chicago Beyond’s own experience funding community organizations and research, the courageous and patient efforts of our partners, the youth they serve, and others with whom we have learned. Our first audience was ourselves. However, in the year since its publication, “Why Am I Always Being Researched?” has been used in more than 70 countries and all 50 states, and helped to inform the actions of significant funders, researchers, community members, nonprofits, journalists, and more, who discovered the guidebook and applied it in their own work.

Here we have taken the core Seven Inequities Held in Place by Power from “Why Am I Always Being Researched?” and applied them to offer a way forward through and post-COVID-19.

**IF WE WANT TO AVOID PERPETUATING THE SAME SYSTEMIC PROBLEMS AND STRUCTURAL BIASES THAT HAVE PERSISTED IN COMMUNITIES OF COLOR FOR GENERATIONS, AND WHICH COVID-19 IS NOW PRESENTING TO US IN FULL COLOR, WE NEED TO CHANGE OUR ORIENTATION IN HOW WE PRODUCE, ANALYZE, USE, AND ASSESS THE VALIDITY OF EVIDENCE.**

# WHEN IT COMES TO LONG-TERM RECOVERY FROM COVID-19—ACROSS PHILANTHROPY, RESEARCH, AND NONPROFIT RELATIONSHIPS—LET US NOT “GO BACK TO NORMAL.”

**THIS GUIDE IS BY NO  
MEANS AN ANSWER,  
BUT IT IS A START.**

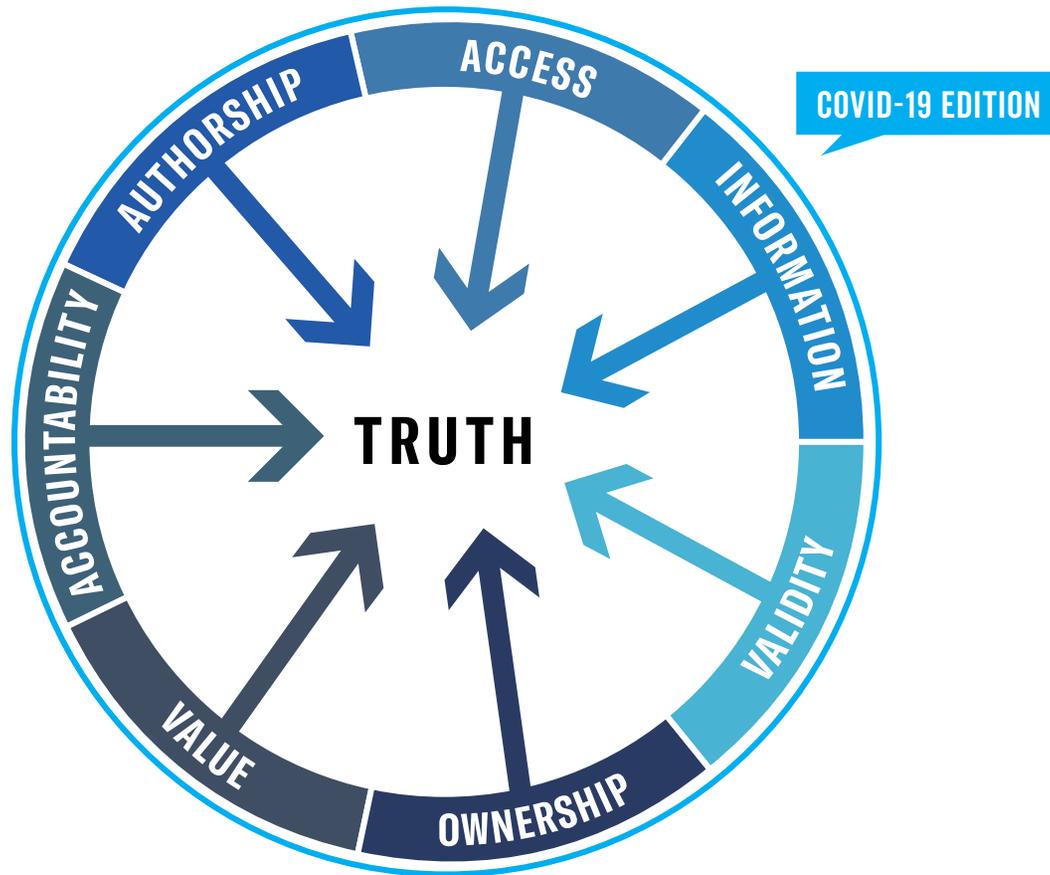
## THIS GUIDE IS FOR:

- ▶ Funders doing strategic planning, scenario planning, and making decisions about what comes next, incorporating evidence into their process;
- ▶ Funders using outcomes metrics to make new grants or manage existing grants for COVID-19 recovery;
- ▶ Current research and data collection efforts that have been disrupted;
- ▶ New efforts to learn and analyze, including new research and data collection;
- ▶ Community organizations and community members seeking to lead on decisions about their communities;
- ▶ Community organizations and community members who may participate in evidence-making.

# STARTING COMMITMENT

## THE CHALLENGE

The work of changing “how it’s always been done” is hard. The most important thing for all of us is human engagement and a continuous effort to check our biases. Making technical changes without this commitment to openness will not work.



## WHAT CAN WE DO DIFFERENTLY?

**Community organizations, researchers, and funders can...**

- Bring awareness to your own biases and assumptions.
- From this commitment to self-awareness, be open to new ways of relating to each other.



**THIS GUIDE CAN HELP**



# 01 ACCESS.

## THE CHALLENGE

Access to creating knowledge about communities and the programs that serve them is often controlled by people outside those communities.

Conversations about resources and “solutions” often happen without community organizations or community members at the table, or on an “invitation only” basis on others’ terms.

## HOW IT SHOWS UP IN COVID-19

### AT THE SYSTEMS-LEVEL:

In previous crises, those with access to decision-making tables often had more success accessing resources for recovery.

In previous crises, response efforts ended, while for some communities, the impact of the crisis continued. For example, in Louisiana, in the aftermath of [Hurricane Katrina](#), full recovery has not been accessible to communities with higher concentrations of poverty and communities of color.

In Chicago, the impact of the [2008 financial crisis](#) remains in many of the same communities where COVID-19 deaths are highest. Experiences of COVID-19 – from food access, to testing access, to healthcare access, to access to remote learning, to access to the financial reserves to survive – vary widely. [Mutual aid organizations](#) and volunteer efforts help us see how the barriers to access are hyperlocal and context-specific.

### IN THE EVIDENCE:

Who and what are counted in the data, and who has access to the decision-making about response efforts, determines which experiences actually inform response efforts.

When voices are missing from the table, we perpetuate bias and fail to factor in the specific realities of those directly impacted. Therefore the “solutions” we put in place will always be insufficient.

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For practical actions, please see Volume 1 of our equity series, [“Why Am I Always Being Researched?”](#) Pages 30-59 for community organizations, pages 60-83 for researchers and pages 84-105 for funders.

## WHAT CAN WE DO DIFFERENTLY?

### Community organizations can...

- ▶ Recognize that the power dynamic, and challenges to survive, make it difficult to speak up.
- ▶ Where possible, ask for the support necessary to amplify your voice and help shape efforts that will actually serve your community.
- ▶ Do not be pressured to participate in research—or if you do participate, seek terms that work better for you.

### Researchers can...

- ▶ Design research around serving the community rather than treating community engagement as an aside.
- ▶ Not participate in research that perpetuates the researcher as “brains” and community as “brawn” stereotype.
- ▶ Be aware of how virtual interactions can exacerbate “invite only” conversations about resources and solutions. Insist that conversations about community happen with community.

### Funders can...

- ▶ Fund research that informs action on root causes.
- ▶ Fund research that community organizations want, need, and are able to lead.
- ▶ Decline to fund research where the questions asked and the approach taken reinforce pre-existing power dynamics that often show up between funders, nonprofits, and researchers. *For more on power dynamics in the field, see equity series Volume 1 page 6 of “Why Am I Always Being Researched?”*
- ▶ Be aware of how virtual interactions exacerbate “invite only” conversations about resources and solutions. Insist that conversations about community happen with community.



## 02 INFORMATION.

### THE CHALLENGE

Information about the process of how research studies work often resides with researchers, funders and government, but less often with community. Many times, the community is left out of the conversation because they do not have access to adequate information to participate in research design or data collection, such as what questions are asked and why, what outcomes are the focus, and what data sources are used.

Further, the community often does not have the information about what is being considered to verify whether a proposed “solution” will or will not fit their context, or to interrupt misinformation about them.

### HOW IT SHOWS UP IN COVID-19

#### AT THE SYSTEMS-LEVEL:

Misinformation and slow message delivery to communities about how to respond to COVID-19, and who is (or is not) at risk, has magnified the disparate impacts of the virus. Mainstream information sources present information in culturally-relevant, accessible, and trustworthy ways to white, wealthier, English-speaking communities.

Power dynamics place more established organizations closer to information flows about resources like small business loans. Therefore, individuals who are marginalized often face greater barriers to receiving accurate and valuable information, leaving them less likely to benefit from resources that may be technically available.

#### IN THE EVIDENCE:

Who has full information to participate in data efforts relating to COVID-19 drives who actually does participate, and therefore whose experience is counted.

When one party does not have full information, it is difficult to partner effectively, ask or answer the right questions, or get to the full truth.

## WHAT CAN WE DO DIFFERENTLY?

### Community organizations can...

- Where possible, get informed. Know your options, know your rights, know the risks.
- Where possible, seek and use information to ask questions about decisions and inputs.

### Researchers can...

- Share information in relevant ways for the specific context, recognizing that without it a community organization cannot actually consent to participating in the evidence.
- Have reciprocal exchange about decisions and inputs.

### Funders can...

- Hold themselves, researchers, and communities mutually accountable for shared, full information.
- Ensure information on options and risks is not only shared but received and understood.



## 03 VALIDITY.

### THE CHALLENGE

Community organizations and members are often viewed as credible sources when talking about the community, but they are not viewed as voices with authority to sway decision-makers, for example, in government and philanthropy.

The institutions, frameworks, methods and data sources seen as most authoritative and valid are often far from community reality. Yet, evidence coming from these sources drive resource decisions made on behalf of communities.

### HOW IT SHOWS UP IN COVID-19

#### AT THE SYSTEMS-LEVEL:

Experiences of COVID-19 vary widely. For example, sheltering in place looks very different if you can work from home, if you are a frontline essential worker, if your home is multi-generational and family members share one or two bedrooms, and if you are experiencing homelessness. When only some of these experiences are treated as valid inputs to make decisions - because only some of these experiences are included in the most validated frameworks or are captured in the most authoritative data sources - we miss critical opportunities to respond.

In previous recovery efforts, the organizations seen as having the validity and capacity to lead response efforts were infrequently from within the communities hit hardest, meaning recovery dollars did not flow through those communities. This matters because those decisions continued to hold systemic injustices in place, furthering inequitable distribution of resources for recovery and pushing those communities further back.

#### IN THE EVIDENCE:

We have bias-based concepts of who the “deserving poor” are, and who is “undeserving.” The evidence base can recreate this. If bias shapes what questions are (and are not) asked in the most authoritative research, then evidence-based decisions may drive resources away from those assumed to be less deserving from the start.

When outside experts hold the sole authority to produce and interpret knowledge, we diminish the value of community voice. Without that community wisdom, we accept partial truths as the full picture.

## WHAT CAN WE DO DIFFERENTLY?

### Community organizations can...

- Recognize the power dynamic socializes us to feel the outside expert is “more valid.”
- Where possible, value the validity of your own voice at the table, especially on the questions, the inputs to answer the questions, and how participants experience research.
- Build a relationship with the researcher or funder. Check partial truths, ask for clarification, and call out disparities.

### Researchers can...

- Recognize how the research frameworks, process and inputs reinforce power dynamics. Recognize what is actually influencing decision-making in the research, versus merely an input gathered. Bring your creativity to changing decision-making inputs.
- Recognize how demonstrating your own vulnerability and taking input seriously can shift power dynamics. Build relationship with the community or community organization.
- Check partial truths, ask for clarification, and call out disparities.

### Funders can...

- Be accountable for what questions the research you fund asks, and what processes and inputs it is (and is not) validating. Be accountable for what is actually influencing your decision-making, versus merely an input gathered.
- Create accountability for authentic engagement between community and researchers. This will support partial truths getting corrected and disparities being addressed.



## 04 OWNERSHIP.

### THE CHALLENGE

Community organizations often cede critical decisions about how data collection and analysis operate, what to measure, how study tools are developed, and what participants experience in the process, because they do not feel they have ownership in data and research. This is solidified in legal agreements and permissions, which may say that the community organization cannot access the data itself, does not own data produced by the study, or must seek permission to speak about the evidence.

### HOW IT SHOWS UP IN COVID-19

#### AT THE SYSTEMS-LEVEL:

COVID-19 has revealed many underlying fragilities in the systems we have built. In many cases, it is hitting communities where barriers to ownership are high—whether it is ownership of homes, businesses, or media narratives.

Those who own the production of evidence control what questions can be asked and what questions are answerable. For example, only where states share data by race is the racialized impact of the virus broadly visible and therefore potentially addressable. Where states have not shared data and response efforts are based on aggregate impact, historical evidence suggests that the inequities will only worsen.

#### IN THE EVIDENCE:

Amidst struggles to survive, decisions being made on behalf of communities without communities can ingrain power dynamics even more deeply.

COVID-19 has interrupted many programmatic, research and data-collection efforts. In these cases, who has the ownership to decide what happens next?

Without shared ownership, the process of research can take from, rather than build up, the community, relegating inputs and answers to be incomplete.

## WHAT CAN WE DO DIFFERENTLY?

### Community organizations can...

- ▶ Recognize that survival challenges and the power dynamic make it easy to cede ownership.
- ▶ Where possible, build your ownership of your study, which starts with knowing what you want to learn, and why. It is likely that your organization or your community has the most at stake.

### Researchers can...

- ▶ Invite co-ownership of research or data, in your processes and legal agreements. Re-evaluate previous agreements, for example where study resources could be made available to the community, or could be made available more easily.
- ▶ Provide tangible value from the research or data for the community, early on and through the process, not just at the end, to support shared ownership.

### Funders can...

- ▶ Set expectations for co-ownership of research or data, in processes and legal agreements. Re-evaluate previous agreements, for example where study resources could be made available to the community, or could be made available more easily.
- ▶ Set expectations that the research or data yield tangible value for the community early on and through the process, not just at the end, to support shared ownership.



## 05 VALUE.

### THE CHALLENGE

#### *Value for whom?*

Often, evidence lacks the nuance to identify what is working, and communities participate in research without seeing tangible benefit from that research for their community. At the same time, creation of that evidence base often comes at a high tangible and intangible cost. Community organizations and community members shoulder some financial and relational costs that are not explicit, visible, or compensated.

### HOW IT SHOWS UP IN COVID-19

#### **AT THE SYSTEMS-LEVEL:**

While the COVID-19 virus is not biased, the costs and risks of COVID-19 are more concentrated among those who have experienced bias over generations.

Work now defined as essential is, in many cases, work that was neither most socially valued nor economically compensated before COVID-19. Essential workers from janitorial staff to postal workers to grocery and transit employees are facing life and death risks that were never anticipated or explicit.

#### **IN THE EVIDENCE:**

In previous crises, efforts to collect data and create evidence often did not lead to equitable impacts from recovery efforts. For example, data on average impact masks who is served most, who is served least, and where gaps are widening.

Not focusing on the specific and full benefits, costs, and risks for communities allows investment to be high, while impact is low.

## WHAT CAN WE DO DIFFERENTLY?

### **Community organizations can...**

- ▶ Get aware of the potential tangible and intangible costs to your participants, organization and community, and advocate for a full accounting.
- ▶ Get clear and speak up on how research can produce value for your community.

### **Researchers can...**

- ▶ Recognize the full cost of the research including tangible and intangible costs to participants, the community organization, and the community and find ways to support it. Consider new potential risks and costs in light of COVID-19.
- ▶ Shape research so producing value for the community is central.

### **Funders can...**

- ▶ Account for the full cost of the research—including costs to recruit additional participants, intangible costs borne by participants, staffing at the community organization—and support these costs. Consider new potential risks and costs in light of COVID-19.
- ▶ Insist on clarity: How will the research benefit the community? According to whom? And, how?



## 06 ACCOUNTABILITY.

### THE CHALLENGE

Who bears accountability to whom?

Community organizations have to prove their effectiveness and fidelity in response efforts, while funders and researchers can be exempt from the same scrutiny and vulnerability.

Often, when research creates an unintended consequence—for example a design flaw leads to a null result, or bias-based questions are asked—it is the community organization or community that bears the greatest risk.

### HOW IT SHOWS UP IN COVID-19

#### AT THE SYSTEMS-LEVEL:

During the COVID-19 crisis, many funders are noticing how much of their pre-existing processes focus on compliance and holding community work accountable.

Moving forward from COVID-19, the possibility exists that funders and researchers will not be held accountable for the effectiveness of response efforts, while the effectiveness and fidelity of community work will continue to be scrutinized.

#### ON EVIDENCE:

With COVID-19, pre-existing bias about unaccountability of Black and brown communities and youth can play into what evidence is considered relevant, what questions are asked, and what implications are drawn. This in turn can reinforce limited investment in these communities.

Without mutual accountability, trust is limited, and the work cannot be as bold. Worse, communities can be harmed.

## WHAT CAN WE DO DIFFERENTLY?

### Community organizations can...

- ▶ Recognize that the power dynamic normalizes not expecting accountability from funders or researchers. Build trust-based relationships. Where possible, speak up with funders and researchers with whom you have built trust.
- ▶ Identify and mitigate risks to you and to your stakeholders.

### Researchers can...

- ▶ Build trust-based relationships with the other entities. Be accountable to understand the context and to ensure that context is integrated in what you disseminate.
- ▶ With any research efforts disrupted by COVID-19, be accountable to your role in the effort including how you might need to shift.
- ▶ Own your role in missteps.
- ▶ Help identify and mitigate risks.

### Funders can...

- ▶ Build trust-based relationships with the other entities. Be flexible in timelines so trust can develop.
- ▶ Be accountable to understand the context, and ensure that context is integrated when you use or disseminate the evidence.
- ▶ With any research efforts disrupted by COVID-19, be accountable to your role in the effort including how you might need to shift.
- ▶ Own your role in missteps.
- ▶ Help identify and mitigate risks.



## 07 AUTHORSHIP.

### THE CHALLENGE

Often, the power dynamic lifts up the voices of researchers and funders to shape the narrative. Often, the power dynamic has socialized community organizations and community members to step back when researchers or funders are making data into meaning. Racial dynamics between white researchers and funders and communities of color contribute to the imbalance. Funders are often cast as “outside of the work,” and researchers as objectively neutral and merely “observing the work.” This does not account for the biases and perspectives every person brings to the work, and every approach embeds in the work.

### HOW IT SHOWS UP IN COVID-19

#### AT THE SYSTEMS-LEVEL:

COVID-19 is revealing multi-layered, systemic, and interconnected problems that our evidence base had not highlighted in many cases. It is bringing to the forefront many narratives that had not previously been fully heard.

#### IN THE EVIDENCE:

While narrative-building and evidence-making may seem fundamentally different, narratives shape what research questions are asked, what comparison points appear relevant, what solutions seem possible, and how resources flow.

When we restrict authorship and ignore bias, it allows incorrect meanings to be drawn.

## WHAT CAN WE DO DIFFERENTLY?

### Community organizations can...

- ▶ Recognize that the power dynamic socializes us to treat funders and researchers as sole experts.
- ▶ Where possible, participate in how data is made into meaning, and gets shared. Are the numbers framed by relevant context? Are your community's voices coming through loud and clear?

### Researchers can...

- ▶ Invite co-ownership in contextualizing and sharing evidence. Seek out and share funding to support this.
- ▶ Analyze and frame data with an equity lens for greater impact.

### Funders can...

- ▶ Set expectations for coownership of contextualizing and sharing evidence. Financially support this.
- ▶ Create accountability for an equity lens for greater impact.

# THE BEGINNING

This supplemental guidebook to “Why Am I Always Being Researched?” is a start, and by no means the answer. We see these guides not as solutions, but as kindling to something greater, and a new path toward “how” we can all arrive at a more authentic truth.

To download the full version of “Why Am I Always Being Researched?” visit [ChicagoBeyond.org/researchequity](https://chicagobeyond.org/researchequity). See Also *Chicago Beyond's Six Core Equity Principles in Responding to COVID-19*.

**IN THE YEAR SINCE ITS PUBLICATION, “WHY AM I ALWAYS BEING RESEARCHED?” HAS BEEN USED IN MORE THAN 70 COUNTRIES AND ALL 50 STATES, AND HELPED TO INFORM THE ACTIONS OF SIGNIFICANT FUNDERS, RESEARCHERS, COMMUNITY MEMBERS, NONPROFITS, JOURNALISTS, AND MORE, WHO DISCOVERED THE GUIDEBOOK AND APPLIED IT IN THEIR OWN WORK.**

# CHICAGO BEYOND➔

EQUITY SERIES, VOLUME TWO



## Chicago Beyond, 2020

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“Why Am I Always Being Researched?” are the words of Jonte Durr, a young Chicagoan who asked this profound question.