## A PARTICIPATORY ACTION RESEARCH FIELD GUIDE

FROM THE HEALTHY NEIGHBORHOODS STUDY



### JULY 2020

Healthy Neighborhood Study | www.hns.mit.edu

#### July 2020

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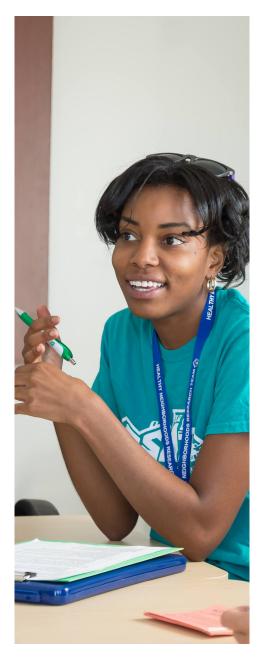
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# Section 1. Introduction

On a hot, sunny day in July 2019, the Cape Verdean community in New Bedford came together to celebrate Cape Verdean Independence Day. They held a parade and celebrated Cape Verdean culture through dance, music, cuisine, language, and, of course, the people themselves. Dina Abreau, a Cape Verdean leader in New Bedford, walked up and down the parade to celebrate with her community.



Figure 1: The New Bedford mural celebrating Cape Verdean heritage on Acushnet Street

At the end of the parade, the festival-goers gathered in a parking lot on Acushnet Street, next to the Cape Verdean Civic Association of New Bedford. There, on the side of the Association's building, Dina unveiled a new mural to honor New Bedford's Cape Verdean heritage. Dina explained the importance of the mural and emphasized key details of the mural.

### **Key Terms**

Resident Researchers: Residents of Healthy Neighborhoods Study communities who are formally trained to do research.

The mural features a mother and daughter standing between the islands of Cape Verde and the city of New Bedford. The girl is holding a model ship, a call-out to the community's connection to New Bedford's whaling industry. An "I Voted" button is shown on the mother's purse. This detail in reflects a call for the community to stay engaged, to vote to preserve the neighborhood, and protect it from gentrification. Unbeknownst to many people at the parade, the design of the mural was influenced by the results of a survey from the Healthy Neighborhoods Study. This Field Guide describes how we, the partners of the Healthy Neighborhoods Study, do research in 9 communities in Eastern Massachusetts: New Bedford, Fall River, Brockton, Mattapan, Roxbury, Dorchester, Chelsea, Everett, and Lynn.

Our communities are home to of people of color, immigrants, and workers that have been overlooked and disinvested for decades. We research how neighborhood changes, like gentrification, impact people's health. Our research is done by Resident Researchers - residents of Healthy Neighborhoods Study communities who are formally trained to do research.



Figure 2: The HNS Team from the 2018 Collaborative Data Analysis Session

We use a research approach called Participatory Action Research (PAR). This approach is based on two concepts. First, people who are most impacted by a problem are in the best position to understand and solve that problem. Second, the best way of understanding a complex problem is by trying to solve it. For us, this means that research on gentrification and its impacts on health should be led by people in communities experiencing gentrification, focus on their experiences and expertise, and support real-time action to address the harms of gentrification in their communities. We are proud of what we've accomplished so far doing PAR.

After years of research together, we wrote this guide to share some of what we learned about doing participatory action research in our communities.

"For Participatory Action Research to be effective it relies almost entirely on the effective collaboration of multiple people with a common vision. And I would say that in fact both residents and community members are needed to successfully execute the research. It's like all parties have an active role and I would say all parties have an active voice. I define PAR through collective work and responsibility"

-- Josee Genty, Resident Researcher on the Everett team

### Our Participatory Action Research Process

We don't claim that the way we use Participatory Action Research --which we call "PAR" for short -- applies to everything. And we don't claim ownership of the PAR research approach or method. PAR has its origins in Latin American social movements decades ago, in the work of leaders like Paulo Freire, and has been used around the world by communities seeking to build power and change the conditions around them. There is no one right way of doing PAR. PAR is an evolving approach that supports communities in using research as a tool to better understand problems and take action to solve those problems. It has a deep history and is influenced by many different people and communities. The Healthy Neighborhoods Study is proud to be one of many projects using and advancing PAR practices. In that spirit, we hope this guide will be valuable for other community-based organizations, research partnerships, and those who are interested in doing their own PAR projects.

When we introduce new residents to our project, we first frame PAR by describing what PAR is not. There is a long, harmful history of research in our communities. Again and again, history shows researchers experimenting on and extracting from our communities in the name of science without regard for harm or benefits to people in our communities. Here's a typical example of how research using surveys tends to happen **to** our communities, not **with** them.

A university professor gets an idea about what should be studied in a community and, without checking if anyone in the community actually wants this work carried out, hires a team of students from their college to go out, collect some data on the problems they see in the community, and then are never heard from again. The professor analyzes the data and publishes papers that advance their career, but the publications don't benefit the residents themselves. And, even if residents knew where to find the research the publications are often locked away in journals that people can't access.

This type of dynamic plays out again and again in our communities. The residents don't have a say in whether research in their community is allowed or welcomed in the first place. They don't have a say in what topics the research investigates or how the research is carried out. They don't do the research themselves. They don't ever hear back about the results of the research, and the research does not lead to action the community wants to see happen.

"PAR isn't a specific set of methods but rather an approach to really uplifting the community experience."

-- Reann Gibson, Senior Research Fellow

Now that we know what PAR is NOT, let's talk about what PAR IS. PAR is an approach - a way to do research with and for communities that emphasizes community participation in conducting the research and action as a result of it. Rather than having a specific research process or method, PAR projects use practices and methods from other fields and disciplines to express this intent. Because of this, PAR projects can look very different and focus on many different topics.

For example, The Healthy Neighborhoods Study borrows community organizing, community engagement, popular education, community-based participatory research methods from the fields of urban planning, community development, and public health. We formed a team of academics, practitioners, advocates, and residents to use these tenets and methods to co-design a process and tools to carry out the study. We will describe our team and process in detail later in the guide.

"PAR provides tools for people who have not belonged in a research space to build power through research."

-- Vedette Gavin, Co-Principal Investigator

In this Field Guide, we will describe the cycle of our PAR process:



- 1. Establish community partnerships
- 2. Recruit Resident Researchers
- 3. Develop research questions
- 4. Design and test research tools
- 5. Complete ethics and field research training
- 6. Collect data
- 7. Analyze secondary data
- 8. Collaboratively analyze data
- 9. Action projects

Since this is a Field Guide for PAR projects, we provided a more in-depth "how-to" about the activities that happen in the field such as training on research ethics, collecting data, and managing logistics. As we describe our step-by-step process, keep in mind that things come up in the field and these steps aren't always followed in a cut and dry way. Doing research in the field (out in the community) often requires experimenting, improvising, pausing to figure out what's working and what's not, and course correction to improve as you go.

Many things in the research process can change as you go, especially when working as a big team. We stay connected and aligned across communities and over the years by following a shared set of values. In this guide, you will find the steps of our PAR process and examples that illustrate how we put our values into practice.

## HNS Principles to Guide the Practice of PAR

Here we offer principles -- norms that express our values and guide our actions -- for the practice of the PAR method to build power and equity with communities.



Figure 3: Resident Researcher Azan Reid

- Accountability We are accountable to ourselves and to our communities. Historically, some research has harmed and continues to harm our communities. In order to not perpetuate those harms, as researchers, we hold ourselves to the highest ethical standards. Further, we hold ourselves accountable to each other and the community by sharing the data we collect with our communities. We give the data to our communities for their ownership and use.
- Action The best way of understanding a problem is by trying to solve it. We are not doing research for the sake of research. We seek to change neighborhood conditions for the better while acknowledging that there is much in our neighborhoods that we want to keep unchanged. We put our research into action in ways that are relevant and culturally appropriate to our communities.

### Key Terms

Principle (noun) – a fundamental truth that is commonly understood, and guides the beliefs and behaviors of a person or group of people.

- Leadership Resident Researchers are leaders who care about our communities.
  - The actions that stem from our research are shaped by our passions. We use research as a way of forging connections among our neighbors. We use research to better understand our communities' strengths and needs in order to better support our communities.
- **Power** We are attentive to the ways that historic and ongoing power dynamics play out in our work.
  - We seek to shift the power dynamics that have traditionally claimed to create knowledge. We center and privilege resident expertise and lived experience in our research, aspiring to put residents in control of the research.
- **Reciprocity** There is a mutual benefit when Resident Researchers meet together and when we survey residents in our communities.
  - When we meet, we share our experiences and learn from each other. When we survey other residents, we do so with non-judgment and with empathy. We value people's participation by giving them a gift card as a thank-you for completing the survey. But, more importantly, we see surveying as an opportunity to create space for people to be heard and to heal.

"The Healthy Neighborhoods Study actually built the community up." -- Azan Reid, Mattapan Resident Researcher

# Section 2: Setting Up a PAR Project



Figure 4: Chelsea Site Coordinators Maria Belen-Power and Leilani Mroczkowsk

### Getting the Project Off the Ground: The Background of HNS

The Healthy Neighborhoods Study explores how the health of residents is impacted by urban development processes, like smart growth, transformational development, or gentrification, that drastically change their neighborhoods. These changes can be economic, cultural, social, and physical. We gather and analyze information in a many different ways. We use interviews, surveys, block by block street assessments, and big data to understand these connections. But the main tool we use is an 11-page survey that asks ~200 questions on covering themes about neighborhoods and health. The survey themes were identified by residents as the things that matter most for people to be well, where they live. The survey was created, administered, analyzed, and put into action by Resident Researchers. Because we are a PAR project, our goal is that Resident Researchers have control over the entire research process.

Through our process, to date, we have completed 3,300 surveys, nearly 100 in-depth interviews, a dozen analyses projects, and more than 10 action projects using what we've learned. Together, we surveyed and interviewed people who speak dozens of languages and represent dozens of ethnicities and countries.

### How Did We Get Started?

The Healthy Neighborhoods Study was originally funded in 2014 as an evaluation project to assess the impacts of real estate investments from the Healthy Neighborhoods Equity Fund (HNEF) on health. HNEF is a real estate development fund that provides loans to support health-focused, mixed-use housing development projects in the metro-Boston area. While there was already good evidence to suggest that investing in communities -- especially historically disinvested communities -- can support good health, there is less evidence about *how* to do it. Some of those unknowns included:

- 1. How to ensure those investments positively impact residents' overall well-being, especially the residents who were already living there;
- 2. Understanding the impacts of gentrification and displacement on health;
- 3. How these investments impact people in the same community differently or create tradeoffs because of differences in financial means, housing security, and wellness.

These questions are complex and cannot be answered without understanding the perspective and lived experiences of community members. Principal Investigators Vedette Gavin at the Conservation Law Foundation (CLF) and Dr. Mariana Arcaya at the Massachusetts Institute of Technology (MIT) decided that a PAR approach would be more effective at answering these questions and to help communities address inequitable development. By making this change, they aimed for the research to inform the types of financing and development practices communities need in order for development to be equitable, and promote good health, and to deepen our understanding of how living through neighborhood development and change affects people's health. With support from the Robert Wood Johnson Foundation, the team got the funding to launch the Healthy Neighborhoods Study.

We had two major goals:

1) To better understand the relationship between development, the built environment, and population health.

2) Build power with residents and organizations to create healthier communities.



Figure 5: Resident Researcher Shannon Simpson getting ready for the field in 2016

With these goals in mind, we sought out communities and partners to participate in the study. Using PAR to guide us, we understood that the residents and advocates most adversely impacted by these development processes should be leading this study. To identify those communities and partners we used data from our regional planning agency, state health department, and the US Census to identify the communities experiencing lots of urban development and health challenges. Ultimately, our nine HNS communities in metropolitan Boston met the criteria. The HNS team reached out to potential partner organizations that were actively working on issues of neighborhood development and health in each of these communities.

### **Establish Community Partnerships**

**Purpose:** The practice of PAR relies on the lived experiences of people to better understand and solve challenges that affect their everyday lives. The structure of an effective PAR project engages community residents through strong partnerships with community organizations. Partnerships should center, engage, and properly support organizations to co-lead PAR projects with academic researchers.

Funders and people from nonprofits that historically have more power or aren't based in communities have a habit of funding community partners at the bare minimum, excluding overhead costs associated with their work or the actual cost of the time for everyone who needs to be involved in the project. **Community partners bring expertise and capacity to engage residents and move research into action to solve community challenges. Our goal is to pay community partners for the actual cost of working together, not just to provide a small stipend.** 

The method for reaching out to and establishing partnerships with each of the HNS partners was not straightforward. When HNS first started, CLF and MIT were not well-known in our partner communities and did not have reputations for doing community-based research. communities. Still, in order to have a strong connection to the places where we wanted to conduct research, we needed to partner with local organizations. We were looking to form one organizational partnership for each of the nine communities.

How did we establish partnerships? First, we identified what type of organization would make the best partner for this work. The HNS team looked for and approached community-based organizations with: deep roots in their communities, the ability to readily connect with 200 or more residents, an interest in doing research, and active work in the areas of health, housing, or environmental justice. We used Google, Facebook, and recommendations from colleagues to find at least three organizations in each community that met these criteria and sent a "request for partners" by email. The organizations we reached out to run the range from community development corporations, environmental justice non-profits, community organizing initiatives, housing justice organizations, neighborhood associations, and national non-profits. We had oneon-one meetings with potential partner who responded to share information about the study, the the funding, the focus, and the initial questions we were hoping to answer. We also openly shared why we were seeking community partners and residents to work with us to design a study to answer those questions, and our very real budget and timeline constraints. We also wanted to learn why they were interested in the project, how the research could support their work, what critical questions and data needs they had that could be met through the research, how much funding and the types of support they need to do this work, and what concerns and recommendations they had for the project.

These initial conversations revealed important information about the partner expertise, goals, concerns, and ideas that we were able to address upfront, and be transparent and honest about things we could not change. We learned things, like the value of the study and need for data was around addressing the broader challenge in gentrification in their communities, rather than the development alone, or what types of process and practices partners and residents would need to see in order to build trust in this project and with academic partners. We went through this process with each potential partner and shared their feedback with others. We used their combined feedback to shape the project. We expanded the research focus to explicitly include gentrification. We created a flexible budget and contract terms to allow partners to use funds and work in ways that are most valuable to them. We developed a partnership agreement outlining the roles, expectations for the academic, and community partners.

What do community partners do? Our community partners work directly with CLF, MIT, and Residents to keep residents engaged and keep the project aligned with community needs and action. They are the gears that keep the project connected and moving forward. In HNS, community partners served as a physical home and informational hub for HNS in their communities. They provided a staff member to serve as the Site Coordinator, who works directly with CLF, MIT, and community residents to design and carry out the study. Site Coordinators recruit Resident Researchers, coordinate their training, data collection, analysis, and action activities as a team, and manage the payment process. Site Coordinators themselves are also leaders in the study, helping to form hypotheses, connect the study to other projects, and applying the findings to their organization's work.

**Power Dynamics.** In addition to fighting against the harmful legacy of research in our communities, there are uneven power dynamics at play between well-resourced institutions and grassroots community-based organizations. There are other dynamics at play between older organizations and new organizations with less money and history. Below, we offer tips to rebalance these power dynamics by ensuring that the organization with resources is transparent about what they're bringing to the table and what they expect from a partnership.

With organizational partnerships in place, the next step was to recruit teams of Resident Researchers in each community.

## **Funding a PAR Project**

**Purpose:** PAR projects, like all research projects, require resources. Because they are collaborative and involve action, they can often require more resources. Funding and the way it is shared between partners and used to accomplish goals influences the power dynamics of PAR projects. In PAR it is as important to prioritize community power, learning, and action in the budget as it is in the project structure and activities.

An important part of shifting HNS from an evaluation for a community-based PAR project was aligning the budget to properly support community partners, Resident Researcher, and residents being surveyed for their time and expertise. Working with and across communities also required more time and resources to coordinate communication and collaboration between them. Funding for coordination and administration is key. Research projects often still need guidance from academic partners or consultants, which can consume lots of resources. In HNS we funded community partner organizations to coordinate activities on the ground, asked high-cost academic partners to serve as advisors, and used students seeking internships or field learning experience as often as possible.

Doing work collaboratively with partners can cost more than doing it alone. Many times securing the funding for PAR projects requires combining several sources of funding for different parts of the project. Many PAR projects are also funded in phases, starting with an initial evaluation, assessment, or engagement grant that produces important learning and meaningful action, then adding in the next phase of the project. In HNS, we used an evaluation grant to design and test our survey, establish partnerships and train resident researchers, and answer their critical questions about gentrification, displacement, and housing affordability, and their relationship to health. We also secured small grants that we used to buy access to other datasets, survey more people, build websites, and launch action projects.

Funding the project can be a bit of a chicken and egg dance. What comes first, the topic, and the grant to get the funding or the partners and then the topic and the funding? Funding a PAR project is an important part of the PAR process and should honor the PAR principles (accountability, leadership, action, power, and reciprocity) whether the funding or the partners come first. If the funding comes before you have partners in place, as it did in HNS, you can honor the principles by building time in your work plan to revise the research questions and budget once partners are on board.

## How-Tos for organizations who have resources and want to establish community partnerships:

- Show up. Many community-based organizations have standing membership meetings and other events. Having a respectful presence in these spaces is necessary to build authentic relationships and trust. It also shows that you don't expect community-based organizations to come to you for support.
- **Engage community partners from the beginning**. Co-designing the project together creates a shared understanding of goals, resources needed, and interests in the research.
- Understand that forming partnerships takes time. It may take months to establish an organizational partnership with an organization in a community, and things can change on a dime. Embrace these dynamics by designing processes that do not have rigid timelines and terms.
- **Pay people.** And pay them well. Show up with resources for your partners that are adequate and appropriate. It was eye-opening to many supervisors what the market value was for research.
  - **Do some of the case-making in advance.** It may not be immediately clear how a research project aligns with the interests of an organization. There should be alignment between an organization's mission, an organization's current initiatives, and the research. Partner organizations should have a clear answer to the question, "What's in it for me?"
  - **Commit to using the research to help partners fulfill their priorities.** What each partner expects and needs from this work is different. Have open and clear conversations with partners to determine how the research does or does not connect with their work.
  - Be transparent about the resources you're bringing to the table upfront. All partners in HNS support paying people a living wage. HNS offers each partner organization a \$10,000 stipend for 3-years of support for the research and pays each Resident Researcher a rate of \$15 per hour for 150 hours of work each year. This rate increased each year, paying up to \$18 per hour in the fourth year of research.
  - Leverage sources of funding and the relationship between funder and the grantees. Relationships should be leveraged to support grassroots organizations that otherwise don't have the same type of connections or relationships with foundations.
- **Be flexible about administrative needs like payroll processing.** Rigid, prescriptive administrative processes around check-ins, reporting, and payment can be burdensome to community-based organizations. We worked with each community-based organization to develop the processes that worked best for them.
- Be clear about expectations and capacity. An organization should know exactly how much time is required to participate in the research and what final products they are responsible for. Be really clear if you expect organization leads to sometimes, always, or never, or participate in meetings. Expect that the cost of the work might change depending on the level of involvement that is required.
- Know what YOUR organization needs to be prepared to change? Flexibility with grassroots community-based organizations is crucial. But that flexibility is not often built into the administrative processes and structures of large organizations.
- Be clear about where other organizations fit into this process. Everyone should have a clear idea about where they fit into the larger coalition of organizations. Gail Roderigues, Site Coordinator in New Bedford, puts it like this, "I don't have all the answers, but I know who to ask." Everyone should know who to ask when they have questions.

In addition to fighting against the harmful legacy of research in our communities, there are uneven power dynamics at play between well-resourced institutions and grassroots community-based organizations. There are other dynamics at play between older organizations and new organizations with less money and history. These tips are intentionally designed to rebalance these power dynamics by ensuring that the organization with resources is transparent about what they're bringing to the table and what they expect from a partnership. With organizational partnerships in place, the next step was to recruit teams of Resident Researchers in each community.

### **Recruiting Resident Researchers**

**Purpose:** Resident Researchers provide community leadership and expertise for PAR projects. Resident Researchers are community residents who have first-hand experience with the challenge at hand. They receive training in research methods as a part of their participation in PAR projects. In PAR, they use their expertise to determine what questions to answer, design research tools, collect data, engage their communities, and lead action using the data and insights they create.

The Healthy Neighborhood Study relies on the expertise of Resident Researchers to develop and deploy the survey, help analyze the data, and share the data back with the community. As such, Resident Researchers should reflect the diversity and identity of their communities. Between 2016 and 2020, over 60 Resident Researchers collected data for the Healthy Neighborhoods Study. Half of them have been researchers for all four of those years. While Resident Researchers receive extensive training in research methods through HNS, most don't join the project with advanced skills in this area. However, their personal and professional experiences and backgrounds often help prepare them for the role. Experiences like bartending, service-oriented jobs, community organizing, case management, teaching English, or civic volunteering make them excellent with people, following processes, organizing information, and working in teams prepare them to be successful Resident Researchers.

Resident Researchers come from all walks of life and they are deeply proud of their communities. Some are new to the neighborhood, others are born and raised there. Regardless of how long they've lived in their community, they see themselves as people who strive to make a positive impact in their communities. They are leaders.

How did we find Resident Researchers? To find these types of lay leaders we asked each HNS community partner organization to recruit a team of four residents to become Resident Researchers. Similar to forming partnerships with organizations in our communities, the way teams were formed was different in each community. Some organizations already had a team in place from an existing initiative. Other organizations recruited them from among a group of residents who were already wellknown as leaders in the community. We asked each Resident Researcher to commit to 150 hours each year, including nine training sessions, and to work together in their teams of four to complete 100-150 surveys per year in their communities.



"For me, being part of the Healthy Neighborhoods Study is about knowing that I'm making a difference within my neighborhood and other neighborhoods."

-- Arnetta Baty, Dorchester Resident Researcher

Figure 6: Resident Researchers Arnetta Baty and Carl Baty

"Living in a new community where I didn't know anyone and then participating in this project was the best thing for me, because I learned a lot about the community, the people, how they think about the community, how they feel...As a shy person I never get to really talk to people too much. But this gave me leadership skills. Now I can go to people and then talk to them and learn about what's going on."

-- Josee Genty, Everett Resident Researcher



Figure 8: Resident Researcher Goldean Graham

"I believe in the village mentality. I believe that it's not just one person. I believe that whatever is going on in our community, we, as individuals, are all responsible for."

> -- Andrea Tulloch, Mattapan Resident Researcher

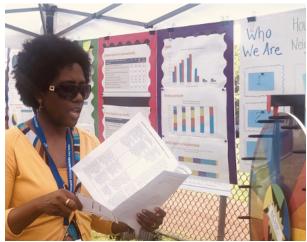


Figure 7: Resident Researcher Josee Genty

"I think that we're needed because we are living this every day ourselves, and we could bring truth to it. And I think when we get our ideas heard people actually become empowered in this study, I think that's incredible to me. That's what I think is most valuable."

> -- Goldean Graham, Lynn Resident Researcher



Figure 9: Resident Researcher Andrea Tulloch

### **Tips for Site Coordinators:**

- Be transparent about pay rate, time commitment, and language requirements.
- Be flexible about work hours. Meaning, be accessible during the evenings or in the mornings when Resident Researchers are available.
- Be as clear as possible about logistics such as how to get paid or how to properly store and return surveys.
- Be flexible about meeting start times. Resident Researchers have busy lives. Trains and buses get delayed. Weather slows down traffic. Construction creates unexpected detours. No matter how late we start the meeting, we always try to end the meeting right on time.
- Be flexible about communication. We communicate with Resident Researchers using the styles they prefer. We text, call, e-mail, and meet in person to schedule meetings. We follow-up on missed calls and voicemails. Once a meeting date works for the Resident Researcher teams, we adjust our schedules around it unless there is an absolute conflict on our own personal calendars (like a federal holiday). Flexibility is key to managing the research project across teams.
- Make meetings comfortable and enjoyable. Meetings longer than two hours should have refreshments or, better yet, full meals for people to enjoy.
- Do some of the case-making in advance. Similar to establishing partnerships with community-based organizations, residents should be able to answer "What's in it for me?" The pay rate is competitive and we are clear about the skills that people learn through our training, which can be useful in other jobs.

• Skills and other characteristics to look for when you recruit Resident Researchers:

- People that are connected one way or another to another organization or project. This isn't required, of course, but it helps identify people with a passion for their communities.
- People that reflect the diversity of the community where the research is taking place.
- Long-time residents know a lot about the neighborhood where they live. That's a major plus!
- Good communication and listening skills.
- People that speak the diversity of languages of the community.

## **The HNS Team Structure**

Once we established community partnerships and recruited teams of Resident Researchers, the structure of the Healthy Neighborhoods Study looked like this:

### PAR Team Structure

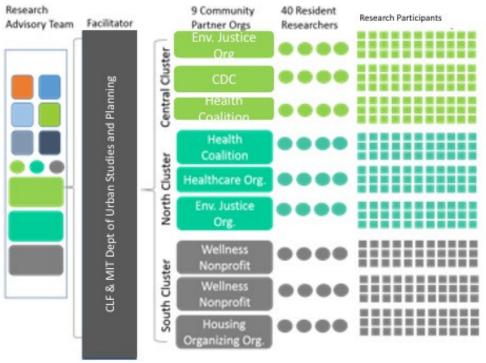


Figure 10: HNS Consortium PAR Structure

We also had a research advisory team to help steer the overall design of the project. The Advisory team included people from all parts of the network: Resident Researchers, staff from community partner organizations, academics, and partners from regional and state governments.

CLF acted as a facilitator and project manager for the advisory team. The 9 community-based organizations represented their communities. With the help of a site coordinator, each organization recruited teams of Resident Researchers.

Then, finally, the teams collected data from 100 people each year. Academic and government partners worked with Resident Researchers and community partners to analyze the survey data, bringing in other sources of data as needed. More details on this process in the Analyzing Data section.

## Section 3: Developing Research Tools and Questions

## **Developing a Research Question**

**Purpose:** PAR enables communities to ask and answer questions whose answers 1) help them better understand the challenges they are facing and 2) enable them to take action steps to address those challenges. Producing these types of action-oriented answers begins with asking the right questions. Research questions guide the work, allowing communities to continually assess their progress on getting the answers they need and adjust the research along the way. In PAR, research questions should be: practical, fill gaps in information needed to advance advocacy and action, and translate lived experience into questions that can be answered with project data.

After the teams were formed, we developed the research questions to guide the Healthy Neighborhoods Study in the first year of the project. Each year, as we discovered and learned more from our data and experiences, we developed new questions to help us get to answering guiding questions. Repeating this exploratory step is crucial for framing and directing the research agenda and developing strong survey questions. Through collaborative workshops with Resident Researchers and the full Advisory team,we settled on three questions.

#### **Our Research Questions:**

As development unfolds in our communities

- 1. What changes in experiences, opportunities, health, and quality of life are residents experiencing as neighborhoods change?
- 2. How does what is built, how it's built, and for whom it's built impact health?
- 3. What roles do residential mobility and displacement play in changes in population health?

Examples of additional learning questions developed each year: Year 2

- What is gentrification and is it happening in our communities?
- Are people being displaced from our communities, and if so how does that impact health?

Year 3

Is there a difference between the health of people who move into communities, those who move out of a community, and those who stay? While your PAR project will not be focused on these same questions, the design of our workshops still might be valuable.

### **Tips for Designing and Facilitating Workshops:**

- Go to where the Resident Researchers are. Usually, we meet in a communitybased organization's biggest room. But we travel to public libraries, restaurants, parks – wherever is the most convenient place for the teams.
- Bring flip-charts, post-it notes, pens, and paper in advance.
- Build-in time for people to arrive.
- Begin with an ice-breaker and intros.
- Come to a consensus on Ground Rules for the discussion.
- Set a clear agenda and ensure that everyone understands the meeting goals.
- Be specific about the type of contribution you are expecting from participants. For example, is this session focused on being creative, or is it focused on decision making, or is it focused on team building? Let the conversation develop organically.

Build-in time to check for understanding. It's important to recognize that people from different organizations, with different expertise and cultural backgrounds might use and understand the same words differently.

Make sure everyone is on the same page throughout the meeting.

Use activities for different types of processing and sharing. Some people are able to process information just by hearing it. Others need to see it in writing or in a diagram. People may prefer to share by writing or in a small group, or in a language other than English.

Speak from your own experience and hear others isten to understand, share to be understood → No one knows everything, together we know a lot · Move up, move up Keep time -mbrace (uriosit 1111111111

Figure 11: Ground Rule from an HNS Collaborative Data Analysis Workshop

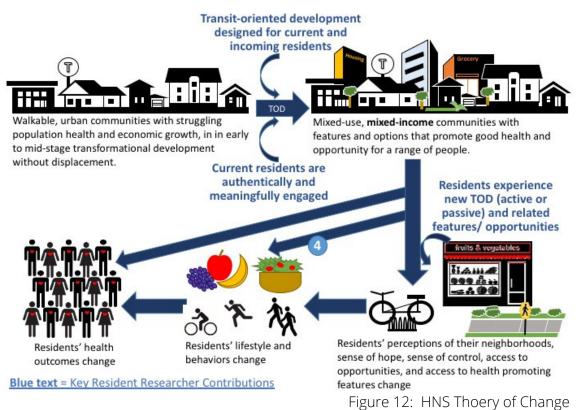
## **Developing a Theory of Change**

**Purpose:** A Theory of Change uses our best understanding of how the world works in general. They give us a way to visually map out the outcomes we expect to see as a result of certain conditions and actions, and the scientific evidence we have for expecting that outcome. Theories of change are specific. They go beyond describing how we think things work in general to identify what is needed in a particular time and place to create a specific outcome. They help us to complete the statements - "if we do X, then Y will change because Z", where X is a specific action, Y is the outcomes of the action, and Z is the evidence we have that makes us certain that outcome will occur.

## With the research questions in place, the next step was developing a Theory of Change.

Communities are diverse and dynamic. They often need answers to more than one question and data around more than one topic. We use Theories of Change to articulate and test multiple hypotheses at a time. We recommend that action-oriented research projects have their own Theories of Change to guide their work. A Theory of Change can, and often should, use expert insights from both the lived experiences of residents and from scientific evidence (information found in scientific journals, reports, and books). However, the ultimate goal of the Theory of Change is to describe a set of specific conditions and actions that must happen to achieve change.

To create our theory of change we used existing research and evidence on how development supports health through things like increasing green space, physical activity, the quality of housing, and access to healthy food. We also drew on the expert knowledge of Resident Researchers and Community Partners about where those models fall short, how development impacts their lives, and how development should actually be done through things like community control to have the intended impact.



# The Theory of Change for the Healthy Neighborhoods Study (depicted above) describes the changes we expect to see from investments and development happening in our communities. It goes like this:

Many walkable, urban communities have gone decades without investment, have poor health, struggling economies, and are experiencing new development around transit hubs. If transit-oriented development is designed for current and incoming residents and engages residents in an authentic and meaningful way, the development will produce mixed-income, mixed-use communities with healthpromoting options that residents can actually use and benefit from. As they experience changes in their communities that were designed for them, residents' sense of power, control, and hope and real opportunities for better health also improve. As a result, people in the community are able to do things from day to day that are important to them for good health and, ultimately, the health of all residents in the community, including those that were already there, improves.

Research questions help us test our Theory of Change and identify the places where there are assumptions, conflicts, or gaps in evidence to explore by collecting data. In our case, we used the Theory of Change to help us understand how neighborhood development, and the tradeoffs and inequities that often accompany it, change the conditions of the neighborhood and affect residents' health. For example, in our theory of change, numbers 1-4 are the actions found in the literature that make development healthy for people. The "blue text" are the insights and recommended actions from Resident Researchers and Community Partners that are necessary to make these actions true.

### **RECAP OF OUR PROCESS THUS FAR:**

➤ First, we formed partnerships in communities, our partners recruited teams of Resident Researchers, then, through facilitated workshops, the Resident Researchers developed and critiqued the first phase of our Theory of Change, which assumes positive public health effects of transit-oriented real estate developments.

➤ Only after Resident Researchers' input was incorporated into the Theory of Change -- indicated by blue text in the diagram -- did we start collaborating on how to gather data from their communities and what specific questions to ask on the survey.

> We focused our survey questions on the parts of the theory of change that have been least explored in other published research or where the experiences of residents reflect a different truth than the evidence found in published research. For example, there is very little research on how development impacts the health of residents already living in a neighborhood, or what effect authentically and meaningfully engaging residents in new developments have on the health benefits of developments that are designed to improve health, such as creating better pedestrian infrastructure or more green space.

## **Designing and Testing Tools**

**Purpose:** In PAR Resident Researchers, community organizations, and academic partners design information-gathering tools in ways that build community trust, awareness, capacity, and power to act on the issue(s) being researched. Designing these data collection tools and processes with Resident Researchers ensures that data collection: 1) reflects the community's priorities, strengths, culture, values, and norms, 2) enables authentic and meaningful engagement with participants, and 3) is done safely and reliably to get the data needed to answer your research question.

There are lots of ways to gather data. Focus groups, interviews, and surveys are common methods. Partners in the Healthy Neighborhoods Study chose to use a survey, which allowed them to engage their neighbors in greater numbers than focus groups or interviews alone. When we began to develop the survey, we assumed that each community would want to have their own unique version, but after learning about the shared interests and goals of the other communities the teams decided to use the same survey.

In the spirit of mutual benefit, the teams were willing to take on the challenge of coming to an agreement on the topics and questions to include in a single survey to be used across all communities. Partners understood that the survey wouldn't only reflect their own priorities, but those of other communities that they may have had no prior experience with. The topics covered in the survey were identified by Resident Researchers as the things that matter about living in their communities for their health. The survey questions are a mix of validated questions, meaning that they've been used on other surveys, and new questions designed by the Resident Researchers.

### **Tips for Designing and Testing Data Collection Tools:**

- Start by asking what's important to understand about the topic and relationships you're interested in. For example, we were interested in the topic of neighborhood development and the relationship between gentrification and health. Digging into this relationship meant learning about what people already know and don't know. This research is about both lifting up existing knowledge and filling gaps in knowledge.
- Identify what information you'll need to understand those relationships. For the Healthy Neighborhoods Study, we knew we wanted to collect information related to health, housing, and demographic information like income.
- Decide how to get that information. You can collect data through interviews, focus groups, surveys, and secondary data that's already been created.
- Develop specific questions on the tools themselves. Once you decide on what relationships are the most important to research, what information you need to understand that relationship, and how best to get the information, then you should start focusing on the specific questions.
- Have a plan for how to revise questions, if at all. Note that if you change questions year after year, it makes it difficult if not impossible to measure change over time.

"A really good workshop strikes a balance between making space for people's different threads of inquiry. A good workshop weaves these threads into one fabric."

-- Andrew Binet, Doctoral Student, MIT

## **Field Research Training and Ethics**

**Purpose:** In PAR, resident researchers are experts on their communities, and use that expertise to design research tools and collect data. To ensure residents become skilled and effective Resident Researchers' PAR projects should include thorough, interactive, hands-on trainings to build their research knowledge and skills in small groups. Training should provide opportunities for Residents Researchers to understand the goals of the research, contribute to the design of the project, practice collecting data accurately and ethically, and learn to surface valuable insights. Taken year after year, the training should increase Resident Researchers' capacity to lead research and lead change in their communities.

There are four trainings in HNS.

- The first training set shared goals and learning objectives for the project, and establish partners and roles and expectations which builds relationships and trust between partners and academics.
- The second training gets Resident Researchers field ready. We review the survey tool, practice using it, and set procedures for how to use it in the field when things go according to plan, and when they don't!
- The third training prepares Resident Researchers to understand and uphold the research ethics guidelines of the Institutional Review Board (IRB), which oversees all research involving human beings in the US.
- Lastly, we head out to the field as a team for a practice round of surveying. In this practice Resident Researchers, learn what works, and plan for challenging scenarios.

The ethics training is based on material from the Center for Clinical and Translational Research community involvement in research CIRTification training. [3] The rest of the trainings were designed to prepare Resident Researchers for surveying people in their neighborhoods. (Note that these trainings were developed after we generated our research questions and our survey.)

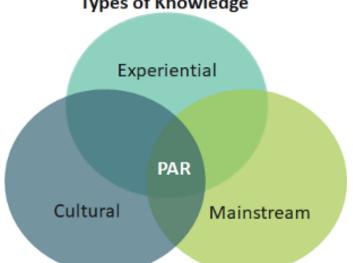
### **Training #1: Introduction**

Training #1 is often the first time a new Resident Researcher meets the rest of their team and the research staff from CLF and MIT. During the training, we provide an overview of the project, describe the expectations for Resident Researchers, and facilitate several activities about PAR. This is also the training where new Resident Researchers start the on-boarding process to get on the payroll of the community partner organization. Here are the goals of the 3-hour

- Resident Researchers understand the goals of HNS.
- Resident Researchers understand PAR as a research approach used to understand complex problems and act to solve them.
- Resident Researchers develop an understanding of the role of power in research and community change.
- Resident Researchers complete paperwork to join the study, be paid by community partners and join the IRB.

We provide an overview of the Healthy Neighborhoods Study and review the project goals using a short PowerPoint presentation, and discuss Resident Researchers' goals for the study and the difference they want the research to make in their communities. Resident Researchers also receive paperwork including a Conflict of Interest form for the IRB and a Resident Researcher agreement. The agreement outlines the timeline and phases of the project, the job roles and duties, time commitment and pay rate, and the skills Resident Researchers will develop during the project.

The majority of the first training is spent learning about PAR as a research practice that builds power in communities. Our trainings and workshops are interactive and conversational rather than lecture-style, and they have facilitators who lead group learning activities rather than trainers to teach **people skills**. Through these conversations, Resident Researchers walk away with their own personal understanding of PAR and why it is important. Our training use tools and exercises developed by the DataCenter [4] - an independent research organization for social justice movements and grassroots organizing. The first activity is called, "Types of Knowledge."





#### Activity #1: Types of Knowledge

Using this graphic, we talk through different types of knowledge: experiential, cultural, and mainstream. Thinking about different types of knowledge can be new to people, so first we make sure that everyone around the table has a shared understanding of their meanings.

<u>"Experiential" knowledge</u> is understood through the senses. It's what people see, feel, hear, taste, smell in their daily lives.

<u>"Cultural" knowledge</u> is understood through communities. It's song, dance, cuisine, language, story, art, all kinds of ways of expressing community life. We ask Resident Researchers to name examples of these kinds of knowledge. They share examples from their own communities in open dialogue with each other.

<u>"Mainstream" knowledge</u> is created by institutions like universities, governments, and other big organizations. Mainstream information often overlooks direct experience and community voice. As a team-building activity, "Types of Knowledge" also surfaces surprising differences and similarities between team members.

For the purposes of our research together, **the point of the activity is to situate PAR within the larger context of knowledge creation.** Unlike quantified knowledge which privileges what can be uniformly counted and measured, PAR methods attempt to honor experiential and cultural knowledge. Resident Researchers are experts about their communities and their own experiences. It's precisely their experiential and cultural knowledge about their communities that we center in the Healthy Neighborhoods Study.

By comparing these kinds of knowledge with mainstream knowledge, we are framing our PAR approach as an intentional effort to co-create new knowledge about our communities from the expertise of residents of those very communities. Through PAR, their expertise will guide the design of the research agenda so that the data we collect is a better representative of the cultural and experiential life of their communities. Note in this graphic, though, that PAR also has a role to play in mainstream knowledge. We talk about the relationship between PAR and mainstream knowledge by talking about power.

#### Activity #2: Whose Got the Power?

As a small group, the facilitator asks someone to read a story out loud. Sometimes people are shy about reading out loud, so it's important that the facilitator is patient and supportive if people read slowly or have trouble pronouncing words. Here's the story:

"A family who live near a bus depot suffers from asthma caused by exhaust fumes and pollution. The mother reports this verbally at the local city council hearing. She says many of her neighbors and coworkers share this experience. She is dismissed by the city officials, saying there is no connection between her family's asthma and the depot. The following month, the Environmental Protection Agency (EPA) sends a report to the City Council saying that asthma in the area is caused by pollutants from vehicles. The City Council declares immediate action should be taken."

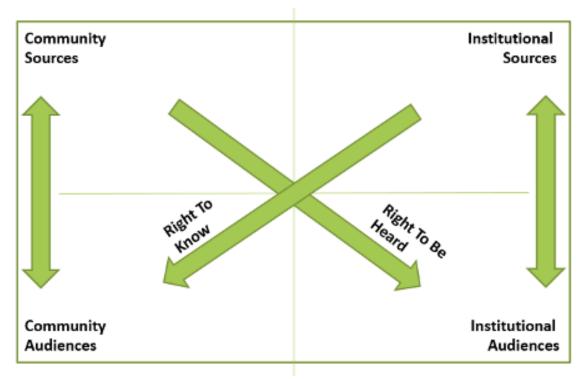
When Resident Researchers first hear this story, they often nod along. That's because the power dynamic that plays out is common in our communities. Building from **"Types of Knowledge,"** this activity shows an example of where experiential knowledge -- the knowledge the mother has about her family's asthma -- is not valued by the people with the power to do something about the problem. The mother's testimony falls on deaf ears. Why?

The goal is to get people to share their experiences about how and what different types of knowledge are used. There is no single, exact, or right conversation about this story. Resident Researchers often point to the fact that the mother does not have any power over the City Council, while the EPA does. We ask open questions, like, "How was community voice regarded in this example?" or "Have you seen similar situations in your own life?". Through the conversation, the team comes to their own understanding of how research is linked to struggles for justice. We use this example because it also introduces the action-orientation of PAR.

Partners often struggle to have control over what gets built where in their communities, because these decisions are often controlled by institutions like city councils, zoning boards, and planning agencies, with little or no regard for input from community members about their needs. Residents also have little control over these decisions, even though they can literally mean life or death for their communities. We discuss the HNS PAR approach as a way to create knowledge with communities that is directly relevant to real-time decisions about neighborhood change and development.

#### Activity # 3: "The Knowledge Factory"

The Knowledge Factory is the final activity of Training #1. We use it to describe how the Healthy Neighborhoods Study connects types of knowledge with different audiences to build and shift power. This activity is the most interactive of the three. We facilitate the conversation using this graphic:

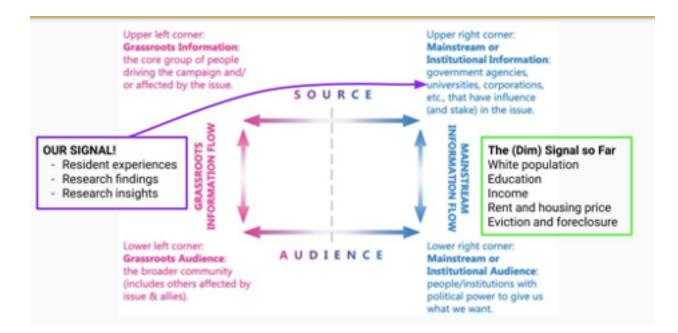


We draw this graphic on flip-chart paper and, as a team, fill in the four boxes in the diagram together.

Examples of "community sources" of knowledge might be word of mouth, local newspapers, or a regular event at a church, while institutional sources might be national newspapers, tv programs, city officials, or academia.

Community audiences include people's neighbors or community-based organizations, for example, while institutional audiences might be other academics or policymakers.

After the team fills each box of the diagram, we draw two arrows - one down from left to right and the other down from right to left. The arrow going from "Community Sources" to "Institutional Audiences" represents the "Right to be Heard." Meaning, community sources of knowledge have a right to be heard by institutional audiences. The arrow going from "Institutional Sources" to "Community Audiences" represents the "Right to Know." Meaning, institutional sources of knowledge should make their way to, and be understood by communities. We draw one more arrow on this diagram to represent the action we are taking with our work.



The "Our Signal" arrow from the bottom left corner of the graph to the top right corner of the graph describes how our PAR approach brings cultural and experiential knowledge about our communities to mainstream audiences. Each community tries to accomplish this by sharing their data back with their communities in the action phase of our process.

These three activities produce very rich, meaningful conversations and serve to introduce the teams to PAR. Our approach to PAR challenges the status quo that institutions are the default and valid speakers of truth who get to create facts about our communities. Instead, these activities use the lived experience and residents' direct testimony of how neighborhood changes are impacting residents as truth and fact.

"How can our PAR process amplify voices that are not heard into the spheres of influence of mainstream institutions?"

-- Robyn Gibbs, Site Coordinator and Resident Researcher, Mattapan

"And so I think what PAR does is it opens the gate and allows a bunch of people into a credible, formal position of authority in the act of asking questions and creating truth." -- Vedette Gavin, Co-Principal Investigator-



Figure 13: Mattapan Site Coordinator Robin Gibson

### **Training #2: Research Methods**

Training #2 is an overview of the research methods we use in the Healthy Neighborhoods Study. We go through the survey question-by-question and answer questions that Resident Researchers have as they come up. We also develop sampling plans for the year.

Our learning objectives for the training are that Resident Researchers:

- Become familiar with the research methods used in HNS,
- Understand the topics covered and types of questions asked in the HNS survey,
- Understand the process for completing a survey on paper or on a tablet,
- Have the skills and confidence to approach survey participants and ask them to participate in the study, and
- Know how to program and use their tablets for field use.
- An additional goal is that Site Coordinators understand the process for distributing surveys and incentives to Resident Researchers.

DATA ANALYSIS Cata (Qualitative + Quantitative) variable analysis research question hypothesis Stratification relationship/association

**During Training #2 Resident Researchers go through and practice the survey section by section, question by question.** We spend extra time on the sections of the survey which are difficult to navigate. We go at a slow pace to ensure that everyone has time to get their questions answered. People who plan to survey in multiple languages often find it helpful to look at the surveys side by side to make sure they understand the intent of all of the questions on the translated survey because sometimes the direct translation does not fully capture the meaning of the question.

The more Resident Researchers are familiar with the survey in advance, the easier it will be to survey and the less course-correction is needed along the way. The people we survey tend to have questions about specific questions, so the more Resident Researchers understand about the sections and why we ask the questions we do, the better they'll be able to answer questions from people in the field.

This training also provides an opportunity for returning Resident Researchers to share what it's like to survey, raise common questions participants have about the survey, and also get their questions answered after having some surveying experience under their belts. We practice our pitches and learn about how to complete surveys following a check-in, check-out process that is clear to everyone involved. Oftentimes, the teams will use some of this training time to make sure that everyone is on the same page in terms of the logistics of getting surveys and returning surveys. Ideally, any remaining administrative details around payroll for the Resident Researchers should be completed by the end of this training.

#### Using Technology in Surveying

This training is where we also introduce people to tablets if they'd like to use one for surveying. We find that while tablets reduce time spent on data entry and may reduce error associated with complex parts of the survey, people being surveyed are more receptive to someone walking up to them with a paper survey than a tablet. We use Redcap's mobile app, which is secure and allows for data collection even without wi-fi access, but it is not without its glitches.

#### Pros and Cons of Using Tablets

Using Technology in Surveying PROS	Using Technology in Surveying CONS
<ul> <li>Reduces the amount of data entry and paper survey printing and tracking needed.</li> <li>Automatic survey logic - no need to remember when to skip questions.</li> <li>Surveyors will always have the most up-to-date version.</li> <li>Easy to keep track of and monitor progress.</li> </ul>	<ul> <li>Perceived threat by some potential participants about where the data is being saved, what's actually being collected. This is true in all of our communities, but especially in communities with more immigrants and greater concerns about ICE.</li> <li>Safety concerns related to carrying around an expensive piece of technology in addition to participant gift cards.</li> <li>Requires an internet connection to upload surveys</li> <li>Concern about uploading the surveys and other technology glitches that would cause data to get lost.</li> <li>Participant preference for surveys - easier to see the questions being asked and the information being documented.</li> </ul>

### **Training #3: Ethics**

While all four trainings are important, training #3 is the only one required for Resident Researchers by our IRB. **The Healthy Neighborhoods Study is human subjects research**, **which means that we collect information about living human beings. The ethics training is required by the Institutional Review Board which oversees the ethics of our research**. Universities and other research institutions have IRBs. The IRB has complete oversight over our research, which includes all the processes, procedures, and materials we use. The IRB itself is made up of independent people not affiliated with our work. Federal law mandates that any human subjects research at an institution that receives federal money -- MIT in our case -- must ensure that research takes place according to the principles of respect, justice, and beneficence.

#### In general, an IRB review is needed when:

- You're collecting information from people about themselves,
- The information you're collecting from people will be used for research in other words, to form insights into how the world works, in general, to share with the public, or
- It is required by your partners and/or funders

Note: it's not always clear whether or not a project meets these criteria. If you have concerns about this we recommend seeking further guidance before moving forward. It's better to find out beforehand because if you realize partway through your project that it needed approval, you may not be able to use the information you collected in the ways you were hoping.

The three principles of respect, justice, and beneficence were chosen in 1974 as guidelines for ethical human subjects research. There is a formal curriculum for this ethics training, which we based on the CIRTification [5] training with approval from our IRBs. Not all PAR projects need to have this level of certification. Even if your PAR project doesn't have access to academic training programs, the CIRTification training is publicly available. There is still a lot of value in having ethics training. The objectives of our training are:

- Resident Researchers will learn about human subjects research and the role of research ethics and the IRB.
- Resident Researchers will understand the three components of research ethics and be able to identify when they have been breached.
- Resident Researchers will understand the purpose, components, and process to properly obtain informed consent.
- Resident Researchers will understand their role in upholding research ethics and informed consent in the Healthy Neighborhoods Study, and will understand the steps to take in the event of an ethical violation.



Figure 14: Resident Researcher Yasmine Jewell

Research has a long, tragic history of harming our communities. Much injustice has been done in the name of research. We prevent perpetuating these injustices or inflicting more harm on others by thinking critically about the ethical questions raised by our own research process. We frame the ethics training around the Belmont Principles:

**Respect for Persons:** "Respect for persons incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy."[6]

➤ The Healthy Neighborhoods Study is voluntary. Through the informed consent process, Resident Researchers ensure that the people we survey are participating with a full understanding of the risks and benefits of our survey. For our survey, the IRB determined that there were no expected risks and benefits associated with the research, so we relay that information to the participants.

**Justice:** "Who ought to receive the benefits of research and bear its burdens? This is a question of justice, in the sense of 'fairness in distribution' or 'what is deserved.' An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly. Another way of conceiving the principle of justice is that equals ought to be treated equally." [7]

➤ The sampling plans for the Healthy Neighborhoods Study are designed so that people have a fair opportunity to participate in the study.

**Beneficence:** "Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their wellbeing. Such treatment falls under the principle of beneficence. The term 'beneficence' is often understood to cover acts of kindness or charity that go beyond strict obligation... Two general rules have been formulated as complementary expressions of beneficent actions in this sense: 1) Do not harm and 2) Maximize possible benefits and minimize potential harms."

➤ For the Healthy Neighborhoods Study, the Resident Researchers determine what is beneficial about the research, but, materially, everyone who completes a survey gets a \$20 gift card.

"You have to put yourself in people's shoes when they have frustration about others coming into the community to do research and why they say that they don't want to do the research project." -- Yasmine Jewell, **Informed consent** is the conversation between researchers and potential participants where they discuss the study, it's goals, what it means to be a research participant, and give their formal permission to the participant. HNS uses a verbal informed consent process in which Resident Researchers read the information about the study to the participant, discuss and questions the participant may have, and get the participant's verbal confirmation that they understand the information shared with them and that Resident Researcher can proceed with the survey.

In general, the information presented in the informed consent process should include the following:

- The purpose of the research (HNS: to understand the effects of neighborhood change on people's health)
- That the research method (HNS: a survey)
- Time commitment (HNS: the survey takes a half-hour to complete)
- Risks and benefits of the research (HNS: to protect participants' privacy and information, surveys are anonymous, participants can answer what they want to answer, and they can stop anytime. Participants also receive a gift card as a thank you)
- Confidentiality (HNS: surveys are anonymous and data is securely stored)
- Contact info for questions and more info

It is crucial that our research has the informed consent of our participants because it is the right thing to do and because we do not want to perpetuate the long history and on-going harms of research abuses in our communities. During the training, Resident Researchers ask questions about and practice the informed consent process.

## In terms of the practice of obtaining informed consent in the field, in addition to the formal verbal consent protocol, we also suggest that Resident Researchers:

- Know the procedures and context of the language of the formal verbal consent protocol, practice explaining it, and answering questions about how the research will be used.
- Encourage participants to ask questions. We really want people to give their informed consent to be part of our research. If a participant can't ask the questions they need to understand what they're consenting to, then they aren't able to provide informed consent.
- Maintain participants' privacy, which means keeping research materials secure and organized and following their team's survey check-in/check-out process.
- Don't rush through the informed consent process, which is a two-way conversation.
- Spend more time with those who seem not to have understood the first time you read it.
- If you think someone doesn't understand, ask them to explain it back to you.
- There are instances when the people being surveyed may at first appear to be able to give informed consent, but then, after a few questions, it becomes clear that the person is not able to give their full informed consent. When the Resident Researcher realizes this, they end the survey. This may happen due to language or other barriers.

Teams learn about the Belmont Principles and the informed consent process through open dialogue. We go through historical research abuses to apply the Belmont Principles, and describe how our research follows the principles. We also discuss common scenarios where informed consent might be in question while surveying in the field.

### **Tips: Field Research During the Ethics Training**

- Administer the survey 1-on-1. Since we set a benchmark with our teams of Resident Researchers of 100 surveys per year, there was pressure on the teams to complete a certain number of surveys within a certain period of time. This pressure made it tempting to pass out surveys to groups of people, wait for the people to complete the surveys themselves, hand back the survey, and then receive a gift card. This method might work for surveys which are not complex and are easy to check for mistakes. But the Healthy Neighborhoods Study includes hundreds of questions with options to skip some. When people take the surveys themselves, they tend to make mistakes, which invalidates the results. One-on-one surveying also helps to ensure that our research is conducted ethically because the surveyor has an opportunity to make sure that the person taking the survey fully understands the research and the questions being asked, and is able to verbally opt-out if they feel uncomfortable.
- Make sure the person you're surveying is over 18. Our research is not approved for minors
- Don't take person's contact information. Instead, offer times when you are able to
  meet or an organization to call. This always draws questions from Resident
  Researchers who are drawn toward direct service and community organizing. In
  talking to lots of people, they may meet folks who are struggling with food access or
  housing and are tempted to collect contact information in order to help. We
  encourage Resident Researchers to connect people to their partner organization or
  recommend a specific service or program, but it would be unethical for Resident
  Researchers to have contact information for people they survey.
- When inviting people to participate **don't lead with offering them an incentive**. Lead with the purpose and then share that there is an incentive involved.
- When surveys end early, Resident Researchers use their judgment to determine when/if to give an incentive.
- Non-judgment about if and how people answer questions.
- Don't make assumptions about people or ask leading questions. Do not make assumptions about respondents' gender or race/ethnicity. Instead, allow them to selfidentity

"Sometimes you'll say something to a resident, and just from the look on their face or from the answer that they give, you can kind of tell that they didn't really understand what the question-- or some people will be very up-front and say, "Well, what do you mean by that?"

-- Andrea Tulloch, Mattapan Resident Researcher

"You have to put yourself in people's shoes when they have frustration about others coming into the community to do research and why they say that they don't want to do the research project."

> -- Yasmine Jewell, Mattapan Resident Researcher

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Training #3 has the most jargon of all the training and many of the concepts and words may be new to Resident Researchers. The stories and discussions are often difficult to process and to hear, as they focus on research abuses and injustice. There is also a lot of material to cover in this training. These are the reasons why it's important that the training includes different ways of engaging teams of Resident Researchers (See tips above).

In this training, we pair the information delivered verbally with small group breakout sessions to discuss different ethical violations, and then end with a game of red light/green light, where we pose different scenarios that may occur in the field and ask Resident Researchers to hold up a "red light" card if the scenario warrants stopping, and a "green light" if it would be okay for a surveyor to continue on. If there is any confusion or disagreement, we use this as an opportunity to discuss it. This activity helps to ground the information presented during the certification in real-life practice.

#### Activity: Red Light/Green Light

You are canvassing in the park and meet someone who would like to participate in the survey. They are too busy to take the survey at that movement and ask if they can take the survey later. You say yes, set a time to meet at that same location next Wednesday, and write down their name and phone number so that you can call or text them a reminder the day before.

Red light or green light?

When we read this scenario out loud during trainings, the Resident Researchers say, "Red light!" That's because the scenario describes an ethical violation in our research. Namely, out of respect for persons, we maintain the privacy of the people we survey. We can't protect people's privacy if we are writing down their personal information.

### **Training #4: Sampling and Field Research Practice**

The more experience Resident Researchers have with the survey, the more comfortable they will be in the field. Many new Resident Researchers are apprehensive about their pitch to people they want to survey. Not a lot of people have experience walking up to strangers and asking them for something. Most of the time during Training #4 is set aside to practice pitches and to actually go out into the field to collect their first surveys. But before the teams go into the field to survey, they develop their sampling plans.

#### Activity 1 - Sampling

**Purpose**: In research, we are often studying a relationship between two things (like development and health) or something happening at a large scale that you want to estimate (like eviction rates). Similar to getting a sample of ice cream on a tiny spoon in an ice cream shop, a sample in research is a small part of something that represents the larger whole. An important part of developing a community survey is to figure out the group of people you want to take your survey (your population of focus), and to develop a sample of that population (a smaller portion of that group to survey). This is important because it is often impossible or very expensive and time-consuming to survey every single person in your population of focus. Ensuring the smaller sample reflects the larger population makes it possible to learn things from the smaller group that you can reasonably say are true of the larger population. Much like a small taste of ice-cream tells us what the entire container will taste like.

The Healthy Neighborhoods Study surveys people who live ½ mile or closer to a train station or bus hub in each of our 9 research communities. Resident Researchers aren't able to survey every single person who lives there, so we create sampling plans. The goal is to develop a sample that represents the larger community of people they aren't able to survey.

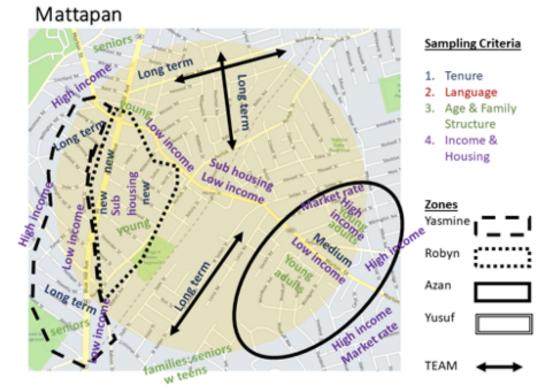
**So how do you develop a sample?** In many research projects, people use large datasets like the U.S. Census to get a sense of the larger population. How many people are there? What are their ages? What are their gender, racial, and ethnic identities? What languages do they speak? However, we recognize that these larger national data sets often exclude the most overlooked people in communities like immigrants, people of color, and homeless people. Because of this, each team in HNS develops their sample to include the groups. To select their sample they pick four characteristics that they feel are most important to represent their population of focus, such as languages spoken, income, race, and country of origin. Resident Researchers and community partners use their expertise and lived experience to identify those characteristics so that their survey sample represents their community's voices.

There are three types of samples. Let's use a bag of M&Ms to understand them:

- Proportional sample: Take a handful of M&Ms out of the bag. Each handful should have a proportional number of each color M&M as is present in the entire bag. So, if a bag has 50 pieces made up of 20 brown, 10 yellow, 10 blue, 5 red, and 5 orange pieces, then a handful of 25 pieces should have 10 brown, 5 yellow, 5 blue, 2 red, and 2 orange pieces.
- Equal sample: Each handful should have an equal number of each color. So, if a bag has 50 pieces made up of 20 brown, 10 yellow, 10 blue, 5 red, and 5 orange pieces, then a handful of 25 pieces should have 5, brown, 5 yellow, 5 blue, 5 red, and 5 orange pieces.
- Oversample. You may want to make sure to sample more of some groups to ensure that their voice is represented in the survey data. If a bag has 50 pieces made up of 20 brown, 10 yellow, 10 blue, 5 red, and 5 orange pieces, and you want to over-sample for blue, red, and yellow pieces, then a handful of 25 pieces should have 10 blue, 5 red, 5 orange, and 5 brown pieces.

Once the teams clearly understand who the groups of people are who they want to hear from through surveys, the next step is to build a sampling plan to recruit them. We ask them to choose four categories from the survey to build their sampling plan. Some communities want to sample based on self-identified race, by age, by how long people have lived in their community, by their country of birth, or by their incomes.

After teams select their sampling categories, the next step is to find places in the community where they can go and find people from these categories. These places can be social gathering (like community events, garden clubs, soccer leagues, or parent associations), or physical locations (like train stations, parks, stores, churches, or door knocking on certain streets). When surveying in these places it is important to have a plan to invite people to participate to provide and equal opportunity for everyone who is there to hears about the survey and decide to participate or not. Remember, the sample has to be random. In other words, we can't go to a park and only approach people who we know already. We have to use a consistent process such as asking every 3rd person you pass, knocking on every other door, or asking everyone who signs in at a community meeting.



Here's an a sampling plan created by the Resident Researcher team in Mattapan in 2019:

The yellow circle on this map is the half-mile radius around the Morton Street commuter rail station in Mattapan, a neighborhood of Boston.

The team chose tenure, language, age and family structure, and income and housing as their four sampling criteria.

- For **tenure**, or how long residents have lived in the neighborhood, they thought new residents were people who moved to Mattapan in the last 3 years, residents who have lived in Mattapan for around ten years had "medium" tenure, and residents who have lived in Mattapan for greater than 30 years had "long term" tenure.
- For **language**, the team wanted to be sure to sample people who spoke English, Spanish, Haitian Creole, Jamaican Patois, and Ghanian Patois at home.
- For **age and family structure**, the team wanted an equal proportion of young families and older people. Young families included young single people and parents under 40 who had school-age children. Older people were empty nesters between 40 and 65 and also seniors.
- Finally, the team wanted to sample **low-income residents** compared to high-income residents who had subsidized rents versus market-rate rents, respectively. Low-income residents made between \$18,000 and \$35,000 a year, while high-income residents made between \$50,000 and \$75,000 a year. Of course, it's impossible to know exactly if someone meets these criteria before surveying them, but the idea is that they should survey in places where they are likely to find a particular audience.

The goal of the sampling plan is to ensure that the survey does in fact uplift the voices of those most impacted.

Each of the sampling criteria is color-coded. The team then mapped where they would randomly encounter people who matched these criteria in the neighborhood. Through our approach to PAR, the perspective of our Resident Researchers is invaluable in creating these kinds of detailed maps of communities. In the field, Resident Researchers are received much differently by their neighbors than outsiders. Their connection to their communities helps capture the experiences of those who might be skeptical to participate in traditional research.

Once the teams decide and map their sampling criteria, they also develop a strategy for randomly sampling people, which means once we identify the sample group, we survey people in the sample randomly. We use random sampling to ensure that we aren't just surveying people we already know. We do this by surveying different events and public locations, door knocking on every third street, knocking on every third door on a street, or asking every third person at a park to take the survey. These types of techniques help ensure that no one is more likely to get surveyed than anyone else. Random sampling might be new to some of the Resident Researchers. Here's how we explain it:

If we aren't careful to make our sample random, we might only ask our friends, or people who are similar to ourselves to be in the study. For example if I am an older woman doing surveys at a festival, i might feel more drawn to ask other older women because they are more relatable or comfortable to me. This introduces bias and goes against the justice principle -- that everyone should have an equal opportunity to be in the study. But, if I ask every third person no one at the event is more or less likely to be surveyed than anyone else.

Each team creates a plan like this every year. We hold check-in meetings every other week during the survey princess. At each check-in we revisit the sampling plan to make sure we are surveying in the areas we selected, and check on how well we are meeting our sampling goals, and make sure overlap isn't happening between Resident Researchers (i.e. everyone surveying at the library, just on different days). We also updated the plan as necessary to meet the sampling plan. Similarly, before a new sampling plan is created, demographic survey data is reviewed for each community.

> "When we went to the Council on Aging, we know the director of the senior center. So when we came in, we already had that credibility. And I think people may have been more willing to share information because we weren't going in as some outsider that they were concerned about. They might be a little bit more open to sharing information because of the credibility we had, thanks to the people with whom we already had connections"

> > -- Marcia Picard, Site Coordinator Fall River team

#### Activity 2 - Practice and Role Play

Before they go into the field, teams of Resident Researchers practice surveying together. The survey for the Healthy Neighborhoods Study is long and can be complex. Each survey takes around a half-hour to complete. Sometimes Resident Researchers have questions that don't come up until they're actually surveying people in the field.

Teams go out in groups, or new Resident Researchers pair up with Resident Researchers who have done surveys. This is a crucial step in making sure that both Site Coordinators and Resident Researchers have everything they need to survey successfully.

> "Have a friendly attitude. Interact with everybody as though you really want it to have a beneficial effect on their life. Try not to see people in a very negative way especially in terms of circumstances, in terms of who it is that you might be interviewing for the participating study. Be polite. Be courteous" -- Goldean Graham, Lynn Resident Researcher

"But you got to make people at ease. If you see people-- my approach is I talk to people calm and humble. If you're not calm and humble, then they're not going to talk to you."

> -- Cliff Bennett, Roxbury Resident Researcher

# **Section 4: Data Collection**

**Purpose:** Surveying is probably the most familiar step in most community-based research processes. This is where you talk directly with residents and gather the information you need to answer your research question. Most people have participated in a survey at some point in their lives so this step can seem very simple. But, there are very important steps to take to ensure that the data is collected and submitted accurately and correctly. Collecting data in a PAR project also means ensuring that this process considers and meets the needs of both Resident Researchers and the community members who participate in the survey. Lastly, many unexpected things happen in the field that can affect your data and your team. Having a plan to manage them when they arise is key!

In the Healthy Neighborhoods Study, surveying is a large operation with many moving parts. For Resident Researchers the process of getting blank surveys, completing them, turning them in, and getting paid should be seamless. Having ways to keep materials very organized and track what materials each person has from each week are essential to creating a seamless process. Each community received a package of 100 surveys (in English and Spanish) and 100 gift cards to give to survey participants. Each team also received survey tracking sheets, electronic tablets, clipboards, and lanyards for each Resident Researcher.

We attached an information sheet and a gift card to each survey. The information card has a copy of the informed consent and contact information for the community partner organization, the academic research partners, and the IRB. Providing contact information is important so that people know who to get in touch with for more information on the study, study results, community resources, or problems or complaints about the research. We numbered the gift cards and wrote the number of one gift card on each survey so that each survey was linked to one incentive. Linking them helped us track the number of completed surveys over time, track how many surveys each Resident Researcher completed, and helped us identify each survey in the dataset as it grew from year to year.

#### The entire project hinges on whether the Resident Researcher teams have everything they need to collect and return quality survey data from their

**communities**. To start the data collection process we hold a Data Collection Kick-Off meeting in each community. At that meeting, we deliver paper surveys and gift card incentives to the Resident Researcher teams. If the paper surveys aren't completed in the right way, for whatever reason, the rest of the analysis is at risk and, in turn, our ability to use research to answer questions and to take action. When Site Coordinators received their package of survey materials, they were able to immediately distribute the surveys to Resident Researchers and track which researchers got which surveys. Often, the teams of four split their 100 surveys equally, but how the surveys got distributed was ultimately left up to each team. Resident Researchers also had the choice of completing their surveys on paper or on a tablet.

**Collecting data in our own communities is powerful!** HNS data is collected by Resident Researchers using a survey they designed with their communities' needs, priorities, and experiences in mind. Each survey in our dataset is a moment when someone in our communities shared their story and experience with a Resident Researcher. **Since Resident Researchers are leaders in their communities, each opportunity to survey is an opportunity to build power!** Many Resident Researchers have shared that when they complete a survey with someone in their communities, there is a mutual moment of gratitude for sharing, being heard, and hope for the future between them and the person who was surveyed.

> "Don't overthink it. Just follow the survey. The survey will tell you exactly what to do. Don't skip any steps. Make sure you read all of the directions and read everything. And you're going to feel awkward at first, but the more you do it, the better you'll feel. It's just like anything else. And that you don't have to be an extrovert, or you don't have to be the type of person who engages with a lot of people to be someone who can successfully give these surveys."

> > -- Jessie Furtado, Fall River Resident Researcher

"Be thoughtful. Be thorough." -- Krystle Latimer, Roxbury Resident Researcher

> "Now, here during the Codman Square Coffee Hour, you had a bunch of older Black people, and you know what their experience is with any type of research. They were living doing their own just minding their own. So you know what their idea of research is. But we kept them coming to the Coffee Hour and take part in planting bulbs and stuff with the seniors. And when we handed out those surveys, everybody took them. Building relationships prior to surveying is key." -- Carl Baty,

Dorchester Resident Researcher

### **Tips: Collecting High-Quality Data**

- Write the incentive number on each survey by hand. The Healthy Neighborhoods Study used incentives as a unique ID for each survey. There should be some way of tracking where each survey is in the field, and to find each survey in the database.
- Log the surveys in a spreadsheet. Each survey should have a unique ID and be assigned to a specific neighborhood/team and a Resident Researcher. When surveys get distributed, completed, and returned, they should be logged in this spreadsheet.
- Format, print, assemble, and package all materials in advance. Site coordinators' and Resident Researchers' time is precious. They should have everything they need to start surveying as soon as they receive all the material.
- Have a file management plan. Piles of surveys scattered all over the place will make the tracking surveys very difficult. For the Healthy Neighborhoods Study, we had separate folders for blank surveys, completed surveys, and sampling plans.
- Provide clear instructions to Resident Researchers and Site Coordinators about how to track completed surveys. Surveys will get lost in the shuffle of day-to-day life if there isn't a clear process in place for Resident Researchers to turn in their surveys. It's best for Resident Researchers, Site Coordinators, and the organization to have and use tracking forms. This way if a survey goes missing, it's easy to figure out where it went astray. Site Coordinators should have one secure place to store surveys once they're complete.
- Be clear about what is not allowed by the IRB in terms of handling research materials.
- Schedule regular check-ins to collect completed surveys and to troubleshoot as needed. Regular check-ins ensure that everyone has an opportunity to course-correct if needed during the field research process.
- Be open to troubleshooting and course correction. There will be times when Resident Researchers have questions about surveying or things that come up in the field. They should feel comfortable going to Site Coordinators and other research staff for help. Especially at the beginning, it is important for research staff to be available in case Resident Researchers have questions while they are out surveying, which may be on a weekend or in the evening.

## **Data Analysis**

**Purpose**: Communities have the right to speak and the right to be heard, In PAR we collect data to translate lived experiences and insights into the mainstream information. PAR projects can use many types of data to accomplish this. Primary data is data we collect ourselves about conditions and experiences in our communities. Secondary data is data that's already been collected by others and data that has already been collected by others.

**Communities have the right to access and use all of these types of data, although they are usually hard for community organizations and residents to access.** Another strength of PAR is that institutional partners also support communities in being able to access and expertly use such valuable sources of data around things like evictions, rent prices, policing, air quality, or health. In HNS, working with MIT made it possible to access rich health claims data to see how the health of people changed as they moved into and out of our communities. Residents' insights about how people were being "pushed out" made it possible to partner with the Federal Reserve Bank to use credit score data to see where people moved from year to year. Partnering with the regional planning authority made it possible to access real estate and housing deed records to track evictions, house flipping, and changes in housing prices.

In PAR, data is both collected and analyzed collaboratively by Resident Researchers, community partner organizations, and academic researchers. This step is important and powerful! Together, they combine data and lived experience to make meaning of trends in the data and establish new findings and facts to be used by communities and practitioners for action. Resident Researchers participate in and direct every phase of the Healthy Neighborhoods Study including framing of the research questions, the selection, and creation of questions on the survey, selecting survey participants, and conducting surveys. Once the surveys are completed, teams from MIT and CLF entered the paper survey data into a database. Once the data was ready, all partners analyzed the data together through a process we call "Collaborative Data Analysis".

#### **Collaborative Data Analysis**

In HNS a workshop series which we call Collaborative Data Analysis -- "CDA" for short -brings all the community partners, Resident Researchers, and academics together to review the survey results and determine what we learned. CDA usually happens once a year and includes 2-3 workshops that last 2 to 6 hours. Each group of partners plays a critical role in this collaborative data analysis and meaning-making process.

Academic partners are responsible for entering and cleaning the survey data, identifying initial trends, making sure those trends are statistically valid, and presenting them back to partners for review and meaning-making in ways that are complete, comprehensive, and easy to understand. Well facilitated processes and workshops that bring these groups together to review data, share their perspectives, and come to a consensus are the glue that holds this process together.

To ensure that this happens in HNS, our statistics team cleans and runs that data, then works with a facilitator who designs and leads workshops to share the data back with community partners and analyze trends. Workshops are highly interactive, visual, and designed to require as little additional training or teaching as possible for non-academics to understand. For example, instead of explaining the "statistical significance" of a data point, we say "we're 95% sure the trend that we found in the data is not just by chance, so we can trust it".

Community partner organizations and Resident Researchers use their lived experience and knowledge from leading work in their communities to review the data from academic partners, develop insights that why we see the trends that we see, form hypotheses to test those insights to see if they hold up in the data and draw conclusions about what the results of those tests tell us.

#### For example,

- **Survey result:** The survey data shows that more than half of the people surveyed have had to move in the past five years.
- **Insight:** Resident Researchers develop the insight that feeling like you are being forced to move and moving because you want to are two different experiences with different outcomes.
- **Hypothesis:** The reasons people move matter for their health. People who move because they want to have better health than people who are forced to move.
- **Conclusion:** People who move because they want to have better physical health, mental health and are happier.

As we designed CDA, we found that there was not a lot of guidance from other PAR projects in the past about how to do participatory analysis. We have since published a paper about how to design and facilitate this kind of workshop. A big lesson we've learned is that since the focus of CDA is on developing findings and results that will be used to solve real-life problems, it is critical to design workshops in ways that bring all expertise from all partners, including academics to the table for community partners and residents researchers to understand and utilize in their decision-making during the analysis process. For example, we designed CDA sessions that defer to Resident Researcher and partner expertise to make decisions about measures to use in surveys or interpret the trend in the data.

At times, Resident Researchers have pushed back on making these decisions without their academic partners, pointing out that their expertise is equally important to their solving the problem despite the traditional power imbalances in research between academics and community members that we designed the workshops to correct. The important lesson for us is to design sessions that share, combine, and use the knowledge of all partners and maintain the power of community partners and Resident Researchers to decide. For some, the value of involvement is not just being centered in the process. Rather, the value is in being able to know the collective group, including that of academics, which traditionally is not available to them, to inform their decision-making in analysis, a role typically not available to them that rightfully should be.

#### **Secondary Data Analysis**

Insights and conclusions from CDA workshops often open the door to other questions that we can't answer using our survey data alone.

Our partners at MIT brought much-needed technical expertise about data management and statistical analysis. These are usually questions about the "cause" of the conclusion (how and why two things are related), the "generalizability" of a conclusion (is this instance unique or is this true with other groups or in other places), or the "context" (needing information about what's happening in the broader community or moment in time). In these instances, we work with our academic and government partners to find and use secondary data (datasets that already exist in other places) to answer them. Some sources of data are free to the public and easy to use while others are privately owned, require a license to use, and can be quite expensive.

For these reasons we only recommend using secondary data when you can't reliably answer the question with the data you collected. And when secondary data is needed and resources to pay a trained analyst or pay for a data license are scarce, we recommend using public sources of data that another agency, university, or partner has already packaged like the US Census, the 500 Cities dashboard, or the County Health Rankings dashboard.

Question we wanted to	Need for secondary data	Source of secondary data
answer	Contact and an analizability	Uselth serve in surgery also
How does health change as people move into and out of neighborhoods?	Context and generalizability. The HNS Survey does not follow people as they move from year to year	Healthcare insurance claims data
Are communities gentrifying?	Context	US Census Development permit database

Examples of questions answered with secondary data

Overall, when analyzing data remember that measures do not need to be exact. Having a measure of a concept tells you more than having nothing at all. **Finding the right dataset is important and isn't ways straightforward. It took us four years to find and access a dataset that could follow people as they moved from place to place across the entire state!** 

# Section 5: From Research to Action

#### Purpose

Action is one of the most important parts of PAR projects. In PAR, research and analysis are practical and community-driven. Meaning PAR should help us ask and answer questions posed by communities that enable them not only to better understand a challenge but to take action to solve in real-time. Taking action serve as a "litmus test" of sorts for the relevance of our results by demonstrating 1) whether or not they can be put into action, 2) if that action results in improvement, and 3) what additional learning or evidence is needed to fully solve the problem. Most importantly, taking action as part of the research process closes the lag between the time a study is conducted and the time a community hears about or can benefit from the results.

#### The last step of our PAR process is about putting our research into action. The

relevance of the Healthy Neighborhoods Study depends on each Resident Researcher's personal interest in the project, as well as the mission and ongoing projects of the organizational partner in each community. The "Action" part of our PAR process is focused on action projects when each team shares their data back with communities. In a typical research project, this might involve the research organization holding a community forum to share slides with interested community members, but we recognize that these forums do not always reach the intended audiences, and are not often action-oriented.

We are not overly prescriptive about what, exactly, an action project is supposed to look like. Here are descriptions of the 2019 action projects by community:

- New Bedford: Developed a mural highlighting the local Cape Verdean community and the challenges they face related to gentrification. The mural was unveiled at the annual Cape Verdean Parade alongside a speech about the study and the findings.
- Fall River: Used the survey data to understand resource access in their community, and used what they learned to train community leaders to use a pre-existing resource guide.
- **Roxbury**: Tabled at two community events: National Night Out and a back to school festival. Shared HNS findings with residents using the tagline "The Chase is On."

- **Dorchester**: Used the findings to understand food access. Distributed coupons to a local grocery store with healthy food, The Daily Table, and tracked their use to understand whether the age groups that redeemed the coupons were those most in need based on survey data.
- **Mattapan**: Shared findings on food access and physical activity at neighborhood association meetings while promoting upcoming related events.
- Lynn: Presentation during a meeting about the affordable housing crisis in Lynn.
- **Everett**: Jeopardy Game at the YMCA's Summer Kick-Off Event.
- **Chelsea**: Shared data and led a discussion at a "Housing Games," event.

The details of the action projects were determined by each team through workshops and meetings. That said, the process was not totally open-ended. We asked that each action project be based on data from the Healthy Neighborhoods Study and that each team had a discrete plan for how to share that data back with their communities.

> "The changes that they want to see, not changes that others think are best for them. But the actual changes that the community wants."

> > -- Nicole Graffam, Everett Site Coordinator

### **How-Tos for Launching Action Projects:**

- Ensure everyone has what they need to use data to tell a story. This includes the ability for teams to review relevant data points in real-time in whatever way is preferred, such as through charts, tables, or summary bullet points.
- Come to a shared understanding of what data is most relevant to the team. Coming to a shared understanding may take time.
- Encourage projects with the greatest potential for impact.
- Determine the audience by answering the question, "Who should know about these data?"
- Once you have an audience, figure out the best place and time to meet with them. This could be a community event if the audience is the general public, a key stakeholder meeting or convening, a city council meeting or hearing, or a community meeting/town hall if the goal is to reach people who are interested in a specific topic.
- Once you have a place and time to meet their audience, plan an outreach strategy to them. Figure out how to let people know you'll be there and why.
- Messaging for the target audience.
- Build an agenda -- literally, what you will say in front of your audience. What you want the audience to hear, learn about. What's your ask?
- Plan a media strategy if applicable. Infographics and visualizations are important to be effective. People don't have a lot of time to read during the action project. Decide if there are reporters or news outlets you'd like to approach you.
- Create a check-list of all the materials you'll need. This takes time at the outset, but it saves a lot of time as you get further into planning.
- Create a line-item budget so you know how many resources you'll need to get all the materials. Each team had \$1,000 for their action project. Some used more than \$1,000 and some used much less. In the overall project budget, we had a line item specifically for translating research into action.
- Create a timeline for the action project.
- Set roles for each team member. Does everyone know what, exactly, they need to do and by when to launch the action project? "Who will buy the balloons?
- Identify any additional resources, funds, or other needs.
- Encourage outside-the-box action projects. The more creative and fun, the easier it will be to engage with your audiences.

### Pictures from the Field - 2019 Action Plans



Figure 18: Roxbury Action Project

### Pictures from the Field - 2019 Action Plans



Figure 19: Dorchester Action Project





Figure 21: Dorchester Action Project

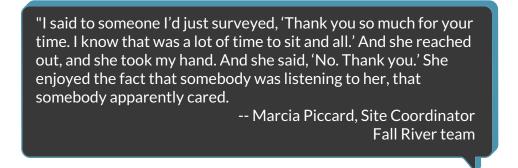


Figure 22: Mattapan Action Project

## Conclusion

We hope this Field Guide is useful to you! We end with two more quotes.

The first, from Marcia Piccard, describes a moment that is shared by many Resident Researchers. It describes how the experience of surveying itself can be healing for some people.



The second quote, from Reann Gibson, describes how meeting together to talk about the issues in our communities is a powerful experience. There is real power in Participatory Action Research.

> "I hear a lot of resident researchers talk about how powerful it is to just be in a room with other people who see the world that they do the way that they do, and having that space to talk about those things, even if they're not-- even if it's resident researchers from Roxbury, Dorchester, and Mattapan, and they're not actually doing an action project together or anything like that, I think that having those spaces to talk about systemic injustices the way we talk about them in Healthy Neighborhoods Study, that is powerful in itself, and that creates some healing " -- Reann Gibson, Senior Research Fellow, CLF

# Appendix A Partner Organization Agreement



#### Site Coordinator Role Overview

Healthy Neighborhoods Study June 2019 – June 2020

<u>Overview:</u> Site Coordinator will work with CLF and a team of resident researchers (RRs) to explore and understand the relationship between urban development and people's health. Site Coordinators will recruit and maintain a team of at least four RRs from their community and coordinate check-in meetings, field activities, and project administration to ensure the team completes 100 Healthy Neighborhood Study (HNS) surveys. Site Coordinators will coordinate other HNS meetings and projects both in collaboration with CLF and your partner organization.

Eligibility: Site Coordinators should live or work in the community and be familiar with the Healthy Neighborhoods Study.

Responsibilities:

Coordinate Research and Data Collection

- Recruit and onboard a minimum of four people high school age or older living or working in the community to serve as Resident Researchers.
- Coordinate and participate in four training sessions to onboard Resident Researchers, and develop survey plan.
- Secure, store, distribute, collect, and track all surveys and incentives according to CLF protocol.
- Ensure that RRs follow research protocols, including storage of research materials in designated RR clipboards. Inform CLF staff IMMEDIATELY if protocol is broken or materials are lost.
- Coordinate with CLF and RRs to schedule and arrange check-ins every 3 weeks during data collection period, and other meetings as needed. Provide meeting space and food (for meetings lasting more than 2 hours).
- Attend RR check-ins and meetings as requested by CLF staff.

• Support RRs in data collection. Provide input on local locations/events for surveying. Reach out to network to secure locations to set up tables to recruit participants to complete surveys. Complete surveys if interested and trained.

Payroll & Invoicing

- Onboard RRs into payroll system, manage timesheets, and facilitate paycheck distribution. If unable to cut checks within the first month of the first training, let CLF staff know ASAP.
- Ensure that RRs understand payroll schedule and process for submitting timesheets.
- Submit quarterly invoices to Janet Daisley (<u>jdaisley@clf.org</u>) for organizational stipend payments and reimbursement for RR compensation. (see project calendar for invoicing dates)

Advising & Advocacy in Action

- Work with the RRs to plan and execute an action campaign to share the results with the broader community, and/or use the research to support local advocacy efforts.
- Communicate regularly with partner organization about HNS progress, goals for the project, and potential data needs.
- Attend quarterly meetings of the Healthy Neighborhoods Research Consortium and Linc Lab to develop ways to use. our research for direct action at the local and regional levels

<u>Financial compensation</u>: Site coordinators are compensated at a rate determined by your partner organization. All reimbursements for food, travel, and other necessary items should be made through your partner organization. **2019-2020 Project Timeline**:



I acknowledge that I have read and understood the terms to participate in the Healthy Neighborhood Study as outlined above, and agree to satisfy them to the best of my ability:

Signature:

Date: \_\_\_\_\_

## Appendix B Resident Researcher Agreement



MIT URBAN PLANNING

#### **Resident Researcher Role Overview**

Healthy Neighborhoods Study August 2019 – June 2020

<u>Overview:</u> Resident Researchers will continue to work together to collect information in their communities to explore the relationship between urban development and people's health. We will focus on neighborhoods where lots of new development projects are happening. <u>Eligibility</u>: Resident Researchers should live, work, or volunteer in the community, be at least 16 years old, comfortable working in English, and able to participate for the full length of the project.

#### Activities:

The fourth phase of the project will run from August 2019 – June 2020. We will ask that Resident Researchers be able to commit to ~170 hours.

- ~12 hours of mandatory training
- ~90 hours of data collection
- ~8 hours of regular data collection check-ins with CLF \*minimum 2 check-ins required
- ~20 hours of data analysis
- ~20 hours to plan and launch a project to share the results with your community and/or use the data to create change (action project)
- ~20 hours working with our Healthy Neighborhoods Study consortium to apply what we're learning to the real world to support equitable, healthy development (Linc Lab)

<u>Financial compensation</u>: Resident Researchers will receive a stipend for their participation. New Resident Researchers will receive \$16/hour, returning Resident Researchers will receive \$18/hour. Stipends are issued by your community partner organization upon mandatory submission of a paper timesheet.

Skills developed over the course of the year will include:

- Developing research questions
- Identifying data needs and sources within the community
- Interviewing and surveying
- Training on research ethics
- Qualitative and quantitative data analysis
- Sharing research with the rest of the community

#### Project timeline:

August	August-November	Feb-April	Apr - Jun	
Prep: 4 training workshops	Research: Collect data	Analysis and Writing	Act: share result & advocate	е

I acknowledge that I have read and understood the terms to participate in the Healthy Neighborhood Study as outline above, and agree to satisfy them to the best of my ability:

Name (print):	
Signature:	Date:

## Appendix C Ethics and Field Research Trainings Facilitation Guides and Agendas (sessions 1-4)

#### Healthy Neighborhoods Study Resident Researcher Training Curriculum

Curriculum Overview		
Session	Title	Duration
1	Introduction: Onboarding, Project Overview, and PAR Skills	3hrs
2	Research Methods: Survey Overview, Sampling and tablets	3hrs
3	Training: Ethics	3hrs
4	Practice: Role playing and field practice	3hrs

#### **Training Completion Guidelines**

- Each Resident Researcher must complete all four sessions to be fully trained.
- Resident Researchers must compete, at minimum, sessions 2 and 3 to accompany staff and fully trained Resident researchers in the field or participate in team check-ins, analysis sessions and action plans.
- In the event a session is missed, two make up dates will be offered. In the event the make-up dates are also missed, the Project Lead (Reann Gibson) can schedule a make-up session with CLF/MIT staff at her discretion.

#### **Training Principles**

The HNS RR Training curriculum has equally important and interdependent goals: 1) to provide Resident Researchers with the information and skills needed to do their jobs well, and 2) to build capacity and power with Resident Researchers and Community Partners to co-lead PAR processes.

In pursuit of these goals, we incorporate the following principles into the facilitation of each session:

- Build distributed leadership among residents and teams.
- Create equitable learning environment for all styles of learners.
- Balance power between partners and roles, and build capacity, confidence and power of partners to co-design and co-lead the process.
- Provide the opportunity to practice exercising leadership, failing, succeeding, reflecting and improving processes and outcomes.
- Inviting people into opportunity to lead. Accept and honor their readiness and response.

#### Session 1 - Introduction: Onboarding, Project Overview, and PAR Skills

#### Session Objectives

**Objective 1:** Resident Researchers will understand of the goals of HNS:

- HNS Goal 1: to understand how development fuels neighborhood change, and how neighborhood change impacts the health and well-being of neighborhood residents
- HNS Goal 2: to produce information with residents and community advocates that can be used in their work to build power, equitable development and wellbeing in their communities.
- HNS Goal 3: to support residents and communities in using the information we produce together to drive change in their communities

**Objective 2:** Resident Researchers will understand participatory action research (PAR) as a research approach used to understand complex problems and act to solve them

**Objective 3**: Resident Researchers will develop an understanding of the role of power in research and community change

**Objective 4**: Resident Researchers will be familiar with HNS goals, purpose, design, process, and timeline

**Objective 5**: Resident Researchers will complete paperwork to join the study, be paid by community partner and join the IRB

#### **Evaluation Knowledge Skills and Attitudes (KSAs)**

- What makes PAR a special kind of research?
- Goal of HNS (neighborhood change + health)
- How RRs fit into goal of HNS. What is your job? What are you going to be doing? (ask these 3 questions after the neighborhoods + health discussion and again at the end of the session. Document the responses on post-its then share out)

#### **Agenda Overview**

- Welcome, Introduction & Team Norms (20 mins)
- Meeting goals and agenda (15 mins)
- Project Overview (20 mins)
- BREAK (15 mins)
- PAR Activities (60 mins)
  - Exercise 1: Who's Got the Power?
  - Exercise 2: Types of Knowledge
  - Exercise 3: Welcome to the Knowledge Factory
- Roles and Responsibilities: RR, site coordinator/partner org, and CLF/MIT (20 mins)
- Review survey (20 mins)
- Evaluation, wrap-up and next steps (10 mins)
  - Exercise 4: Chip Toss (optional)

#### Materials

- □ Sign-in Sheet (name, mailing address, email, phone, social media)
- □ 1 folder for each researcher
  - HNS slide deck (1 per RR) include website in Deck; include images for PAR exercises
  - o Survey construct handouts
- □ RR forms
  - Commitment forms (2 per RR)
  - COI forms (2 per RR)
- Activity materials
  - Post its
  - o Markers
  - Flipchart and marker for activities (or confirmation that whiteboard will be available)
     Pre-filled charts:
    - Agenda and goals
    - Knowledge factory
    - Types of knowledge
    - Evaluation questions (2 sets)

#### **Facilitator Guide**

#### I. Welcome, Introduction and Team Norms (20 mins)

- Introductions and Icebreaker (materials: sign in sheet; RR folders)
  - What brought you to this project?
- Team Norms (materials: ground rules flip chart)
  - Share ground-rules from analysis session. Ask if they want to add anything
  - Note that we will set norms for each team in session 4

#### II. Meeting Goals and Agenda (15 mins)

(materials: post-its, meeting goals & agenda flipchart)

- 1. Review meeting goals and agenda
- 2. Ask each participant what their personal goal is for today's meeting (have them write one goal on a post-it note.) Have RRs read what they wrote on their post-its round robin.
- 3. Place the post-it notes on the agenda/meeting goals flip chart. Theme the notes and share a recap with the group.

#### III. Project Overview (20 mins) (materials: HNS Overview)

- HNS Overview with standard slide deck (slides 1 XX) Highlight the following
  - Goal: understand and address changes in place that impact peoples' wellbeing
  - Research questions
  - Locations and partners
  - Theory of change highlight resident inputs and gaps in the mainstream understanding of the connections in the diagram.
    - ask them if they think where they live impacts their health. How and why.
  - Team structure
  - Pre-Evaluation Question: Ask the group:
    - Show of hands: who has heard of PAR? Who can describe what PAR is?
    - What is PAR and what makes it a special kind of research? (record responses on flip chart)
  - PAR components, principles, and application to HNS
  - 5 step PAR process: training, design, collection, analysis, dissemination/action
  - Action projects

#### IV. [BREAK] 20mins

#### V. PAR Activities (60 mins)

- Exercise 1: Who's Got the Power? 15mins (materials: Who's Got the Power scenario)
  - Present the following anecdote: A family who live near a bus depot suffers from asthma caused by the exhaust fumes and pollution. The mother reports this verbally at the local city council hearing. She says many of her neighbors and coworkers share this experience. She is dismissed by the city officials, saying there is no connection between her family's asthma and the fields. The following month, the Environmental Protection Agency (EPA) sends a report to the City Council saying that asthma in the area is caused by pollutants from vehicles. The City Council declares immediate action should be taken.
  - Discussion questions
    - How was the community voice regarded? Why?

- How was the institutional voice regarded? Why?
- Who are the people in power most likely to listen to? Why? o Have you seen similar situations in your own life?
- Key Takeaways: People often view research by institutions and professionals as valid and authoritative while information from non-institutional sources is considered invalid and less reliable. This can leave communities feeling powerless and undervaluing their own knowledge. In order to make real changes in our city we must fight against research injustice by proactively creating "validity" behind our voice.
- Exercise 2: Types of Knowledge 20mins (materials: post-its, flip chart/white board and markers)
  - **Discussion Points:** PAR uses different types of information. To understand a complex problem, we need to understand it from the perspective of all stakeholders involved. But, stakeholders value and use different types of information. PAR allows us to use the different types of knowledge that each group holds, and equally weight them. When taken together, we generate knowledge that overlaps all three types.

• Explain the types of knowledge and give an example of each. (if returning RRs are present, ask them to provide examples):

- Mainstream: widespread and dominant types of information. *ie. research report; news story*
- Cultural: collective way of being, shared experiences/norms (directly or indirectly experienced) *ie. shaking hands when you meet people*
- Experiential: individual lived experience (you actually experience it yourself) ie. tips for moms of newborns
- Activity: Ask participants to share their own examples of each type of knowledge. Talk about types of knowledge that overlap. These are valuable in identifying gaps in information and creating understanding across stakeholders

**Key Takeaway:** Everyone has knowledge, and there are multiple types of knowledge. Our goal is to draw on all forms of knowledge to create information that reflects a holistic picture, and can be understood and used by all stakeholder

#### • Exercise 3: Welcome to the Knowledge Factory 20mins

(materials: knowledge factory flip chart, post-its, markers)

- Discussion Points: This exercise elaborates the values behind "research justice" that we intend to embody.
  - Calls to Action from organizing that we use in our research: 1) Speak truth to Power.
    2) All power to all people.
  - What do these sayings mean? Thinking about our earlier activities Who's Got the Power and Types of Knowledge:
    - What is truth, and how do we speak it? Wat role might PAR play in helping us create and speak truth?
    - In research who traditionally has power? In our research and in PAR, who has power? What role might PAR play in helping us build power among people.
- Activity: See instructor guide attached
  - Review knowledge factory diagram. Point

- The Knowledge Factory of our society reveals how information can flow within and across sectors and the political implications associated with it. The good news is, although community knowledge often stands at a disadvantage in terms of moving policy makers, you can control the means of your own knowledge production and move the information in the way you see fit along the arrows in the Knowledge Factory. And that's what we call Research Justice!
- The upper

**Key Takeaways**: Our research is different. We are challenging common assumptions about who gets to create fact. We are intentionally "criss-crossing" across the different sides of the Knowledge Factory

Everyone has knowledge and creates information, but information moves differently in communities and institutions. Decisions about our communities are largely made in institutions. We are creating information that BOTH communities and institutions can understand and use.

## VI. Roles and Responsibilities: RR, site coordinator/partner org, and CLF/MIT (15 mins) (materials: COI, RR forms)

- Resident Researcher Role Overview and form signing
  - Review the resident researcher agreement with all resident researchers, noting the number of hours and the rate of pay. It is important to note that hours for data collection are shared across all researchers on their team.
  - Point out what is the same this year and what is different
  - We should also talk about the advocacy and community change goals that other communities have and let them know we will ask them for work with the Partners to form their own.
  - Review the site coordinator role and have the site coordinator explain the processes for:
    - getting on payroll, submitting timesheets and receiving paychecks
    - attending check-ins and meetings
  - Review the role of CLF/MIT staff
  - Activity: Sign RR forms (1 copy to be turned in to CLF team, 1 copy for RR to keep) Sign COI form (1 copy to be turned in to CLF team, 1 copy for RR to keep)
- Conflict of Interest form signing
  - Introduce the IRB research ethics board that oversees all research done on humans. This board gives us permission to do this study and ensures that data is collected safely and people are treated fairly.
  - Introduce thee Conflict of Interest form to ensure that research is done ethically the IRB makes sure that no one conducting the research has a hidden financial or political interest. (ie. if I am doing pharmaceuticals research and am a owner of stocks in that company). We use this form to tell the IRB abort potential conflicts people may have
  - Activity: Complete the COI form.
    - Read through each line of the COI form to ensure the RRs understand what it is asking.
    - Remind RRs to write their names at the top of the form, and sign and date the bottom.

#### VII. Review Survey Components (15 mins)

- Review survey
  - Walk through the section titles and constructs that relate to each section.
  - Point out the constructs that were newly created by Resident Researchers Ownership of change, the questions about priorities.
- Activity: how teams use constructs for action campaigns.
  - Ask RRs to identify constructs you have used/ would use to support their action plans or advocacy in their organizations

#### VIII. Wrap-up and Explain Next Steps

- Activity (Optional) Chip Toss
- Post Evaluation Questions (scribe responses on flip chart)
  - a. What makes PAR a special kind of research?
    - b. Goal of HNS (neighborhood change + health)
    - c. How RRs fit into goal of HNS. What is your job? What are you going to be doing?.

#### **On-Site Post Session Activities**

Collect and properly store work products

- Collect COI and RR commitment forms. Return to CLF, scan to teamwork/sharepoint, and store hard copies in research folder
- Take pictures of the following work products and upload them to google drive/sharepoint:
  - Pre evaluation questions flip chart
  - **Post evaluation questions** flip chart
  - o Types of knowledge flip chart
  - o Knowledge Factory flip chart
  - Originals can be thrown away to returned to CLF and stored in the research cabinet.

## Healthy Neighborhoods Study Training Session 2 – Data Collection Methods - Survey and Tablet Training

#### Objectives

- Resident Researchers understand the topics covered and question types included in the HNS survey tool
- Resident Researchers will understand the process of completing a survey on paper or on tablet.
- Resident Researchers will have the skills and confidence to approach survey participants to ask them to participate in the study.
- Resident Researchers who wish to use tablets will receive, program and test their tablets for field use.
- Site Coordinators who will understand the process for distributing surveys and incentives to Resident Researchers.

#### **Evaluation Knowledge Skills and Attitudes (KSAs)**

- Resident Researchers will be able to describe the purpose of each section of questions (measure verbal description)
- Resident Researchers will properly complete the cover page of a survey for BOTH paper survey and tablet surveys (measure completion of exercise and correction of errors, if any)
- Resident Researchers will properly document the incentive number on the cover sheet of the survey for BOTH a paper and tablet survey (measure completion of exercise and correction of errors, if any)
- Resident Researchers will develop and practice at least one "pitch" to use to approach survey participants. (measure completion of role play and pitch exercise. correction of errors, if any)
- Resident researchers who wish to use tablets will receive, and program their tablets (measure completion of exercise)
- Resident Researchers who wish to use tablets will complete and submit a test survey (measure. completion of exercise, and check by CLF team for accuracy)
- CLF team will properly document the tablet numbers, tablet logins, redcap user names, and redcap passwords for all tablet users (*measure completion of activity by CLF team*)

#### Agenda Overview

- I. Check-in, recap, introduction (10 min)
- II. Survey Overview (20 mins)
- III. Survey Walk Through & Practice (1hr 20mins)
  - Exercise 1: Cover Sheet and Incentives (10mins)
  - Exercise 2: What's Your Pitch (10mins)
  - Exercise 3: Partner up for Survey Practice (1 hour)
- IV. Break (10)
- V. Tablet Training (1hr)
  - Exercise 1: Tablet Setup and Programming (20mins)
  - Exercise 2: RedCap and Surveys (10 mins)
  - Exercise 3: test survey (30 mins)
- VI. Wrap-up and homework (10 min)

#### Materials

- Practice copies of HNS survey and info sheet (1 per RR)
- Tablet setup guide (1 per RR)
- Programmed tablets (1 per RR and facilitator)
- Sample incentive
- Flip chart and markets

#### **Detailed Agenda**

#### I. Check-in, Recap, & Introduction

- Icebreaker (5min)
  - Opening question: What does health mean to you? (round robin)
- Recap (5min)
  - What we did last time (learned about the project and explored PAR) and what we are going to do today (review the survey and learn how to administer it)

#### II. Survey Overview (20minutes)

- Review the survey sections
   Key Points
  - Give an overview of how the survey is to be administered (5mins)
    - ANONYMOUS
    - One on one, or (two on one at most)
    - Read completely, or in part by RR. Do NOT give to participant to complete on their own
    - Random intercept at public places or in homes
    - Participants should be people who LIVE in the area on your map... not people who just happen to be in that area, but live elsewhere.
      - (ask RRs why this is important. Because we want to see how the experiences of people living there change over time. When you are not from a place, your perspective of what happens there is very different)
    - We pick the areas where we will survey by using a sampling plan (which we will develop in session 4)

- Activity: Review of Sections and question types (10 mins)
  - <u>Informed consent:</u> Read through the informed consent page. Emphasize the informed consent questions. Review the info sheet and when to give a copy to the participant. (5mins)
  - <u>Section themes and question types:</u> Ask RRs to read the description of each section (round robin) (10mins)
    - Point out the different types of questions included in each section. (ie. check all that apply, open ended, skip logic, Likert scale etc.)
  - Data quality: Discuss data quality, and data quality concerns from past years

#### III. Survey Walk Through & Practice (1hr 20minutes)

#### Exercise 1 - Cover Sheet and Incentives (10mins)

- Key points:
  - The following MUST be filled on the cover sheet for EVERY survey (English, Spanish, Paper and Tablet)
    - YOUR name
    - Date
    - Time of day
    - Location
    - Spot on the map where the survey is being done (not where the participant lives... that would jeopardize the survey being anonymous)
    - NO PEROSNAL INFORMATION ABOUT THE PARTICIPANT
  - Activity: Role play have the RRs describe how to properly fill out the cover sheet in each of the following scenarios
    - Scenario 1: On Tuesday August 6<sup>th</sup> you are walking door to door around 6pm with another RR. A woman invites you into her home to complete a paper survey in Spanish. You administer the survey and your partner accompanies you, is just there to listen.
    - Scenario 2: On Saturday August 10<sup>th</sup> you are at a little league soccer game at 9am. You compete a survey on a tablet
    - Scenario 3: You are recruiting participants outside of Save A Lot on a Sunday afternoon. A woman wants to take the survey but does not live in the area on the map.
    - Questions and discussion
- Exercise 2 What's Your Pitch 10mins
- (materials: flip chart paper and markers)

#### Key Points

- What you can and can't do when approaching participants to take the survey (write the list below on flip chart paper in two columns and review it with the group) 3mins
  - CAN
    - MUST: Make sure they are 18 years of age or older
    - Tell them it's a survey for research purposes
    - Can tell them it will take 20-30 minutes depending on their answers
    - Can tell them there is a \$20 "thank you gift card" AFTER you mention the research purpose
    - Can tell them anything on the informed consent page
    - Give them your contact information and have them get back in touch with you to take the survey at a later date/time.
  - CAN'T

- Lead with the incentive
- Take their personal contact information and reach back out to them later (why? Because we CAN'T collect any personal information on participants. Then they are no longer anonymous)
- Survey people under the age of 18.
- Ask for other CANS and CANT's and make not of them on flip chart paper
- Activity (8mins)
  - Invite returning RRs for share pitch techniques that have worked for them personally in the past.
  - Ask each RR to write down one or two 30 second pitches that they would use to approach a person to take the survey. Have them test their pitches in pairs.
    - Ask the listener to identify the CAN and CAN'TS in their partner's pitch and provide feedback for improvement

#### • Exercise 3 - Partner up for Survey Practice

- Activity: Split the group into pairs. Have the pairs administer the survey to one another. Each partner gets 30minutes max to complete the survey.
  - Partners should ensure they properly:
    - Complete the coversheet (and document incentive number)
    - Complete the informed consent page
    - Hand their partner the info sheet
    - Use the facilitator prompts for when to hand the survey to their partner, and when the partner should hand it back
    - Actually write down the answers to practice what it's like.
  - At the end of the exercise, discuss what went well and what was hard. Answer any questions from the group.

#### IV. Tablet training (30 minutes)

- Assign Tablets: CLF team should give each RR a programmed table and be sure to log the following information into the google sheet
  - Tablet PIN
  - Redcap user ID
  - Redcap PIN
  - Tablet number
- Setup Tablets
  - See tablet training worksheet
  - \*\*\* note point out help cheat sheet on the tablet cover
- Tablet practice

#### V. V) Wrap-up and homework

Next Steps

- Next Session Ethics (confirm date time and location)
- Practice survey at home practice tablet and paper with at least two people

#### Healthy Neighborhoods Study Training Session 3 – Research ethics

#### Session Objectives

Objective 1: RRs will learn about human subjects research and the role of research ethics and the IRB

**Objective 2:** RRs will understand the three components of research ethics and be able to identify when they have been breached.

**Objective 3**: RRs will understand the purpose, components and process to properly obtain informed consent

**Objectives 4**: RRs will understand their role in upholding research ethics and informed consent in the HNS, and will understand the steps to take in the event of an ethical violation.

#### **Evaluation Knowledge Skills and Attitudes (KSAs)**

- RRs will be able to define the 3 principles of research ethics in their own words: benefit, justice, respect for persons
- RRs will be able to identify the components and principles of informed consent.
- RRs will be able to demonstrate the correct process to obtain informed consent in HNS.
- RRs will be able to describe their role in uploading research ethics
- RRs will be able to recognize ethical dilemmas and properly consult CLF staff when necessary

#### Agenda Overview

- I. Welcome, icebreaker and meeting goals (10 mins)
- II. Ethics Part I (30 mins)
  - What is research? What are ethics? Why do they matter?
- III. Ethics Part II (60 mins)
  - Ethics case studies
- IV. Break (15 mins)
- V. Informed Consent (30 mins)
  - Exercise 1: Identify the components of informed consent
  - Exercise 2: Informed consent practice
  - RR Role in upholding ethics (15 mins)
    - Exercise 3: Is it consent or not?
- VII. Evaluation, wrap-up and next steps (20 mins)
  - Exercise 4: Informed Consent Quiz

#### Materials

VI.

- □ 1 ethics packet per RR (includes slides and case stories)
- □ 2-3 sets of Ethics notecards (3 cards, each with the name of one of the research principles written on them)
- □ Info sheets (1 copy per RR)
- □ Red light, green light scenario sheet and two sets of cards
- Facilitation materials
  - Post-its
  - Markers
  - Flipchart and marker for activities (or confirmation that whiteboard will be available)
     Pre-filled charts:
    - Agenda and goals
    - Informed consent

# **Detailed Agenda**

I) Welcome, Icebreaker, Agenda, and Meeting Goals (10mins)

(materials: Agenda and Goals flip chart; post-its, markers)

- Welcome: describe what you did in the last session (survey practice) and the focus of this session (Ethics to properly administer the survey on the public; certification)
- Agenda: review the agenda for the day
- Icebreaker and meeting goals:

(Facilitation techniques): round robin. 1 min each. Assign time keeper

<u>Activity</u>: State your icebreaker answer and your personal goal for the day's meeting on a posit (write the goal on a post-it note).

- o Icebreaker question: what the parts of this project are you most looking forward to?
- Facilitator: collect the goal post-its as people share out. Please the post-it by the section of the agenda that addresses that goal. If there are goals that do not match a section of the agenda, work together as a group to create space in the agenda to address them.

II. Ethics Part I (30mins)

(materials: ethics packets)

- What is research and why are ethics necessary?
- ASK: What do people in your communities know and think about research?
- **<u>ASK</u>**: What do you think of when you hear the phrase 'human subjects research'? How might human subjects research be different than other types of research (i.e. research on plant cells?)
  - $\circ~$  Because human subjects research involves people working with other people, we want to make sure our research is done in a way that is ethical.

• Through federal law, any research taking place at an institution that receives federal money must work to ensure that research takes place according to the principles of respect, beneficence, and justice.

- $\circ$  ~ To do so, universities and other research institutions have IRBs.
- In 1974 (not too long ago) guidelines for ethical human subjects research were decided. They included three main principles: beneficence, justice, respect for persons.
- Key points:
  - Research vs human subjects research:
    - research is a process to answer a question.
    - $\circ$   $\,$  inquiry vs research: formal process with standard steps to answer a question AND share the results with the general public
    - o Human subjects research: involves humans in the process of answering questions
  - Why are research ethics necessary? (oversight is critical because people have been harmed by what is done AND what facts are introduced into the world)
    - When research involves humans, we need guidance to ensure that the questions asked, information produces and facts that people then consume and believe do no harm to people.
    - **ASK**: does anyone have examples of research done about or on people that produced information that was harmful to society? Discuss examples
      - Race studies that justified slavery of African people
      - Gender studies that justified differences in roles and compensation of men and women
      - Environmental studies that deny climate change

## • IRB (the body that performs ethics oversight)

- To prevent these harms, US law requires the oversight of all human subject research by an ethics board. That board is called the IRB – Institutional Review Board
  - Ask Returning RRs to describe to the best of their ability what the IRB is.
  - Review what an IRB is
    - Institutional oversight of institutions doing research. This means all human subject research must by law be connected to an institution, n to by an independent individual.
    - Review all processes, procedures, materials complete oversight
    - Board made up of independent people some from research, some not – that work together to oversee research
  - This board looks for three things to determine if research is ethical

# • Ethics Principles

- Review the three components of ethics.
  - Beneficence
    - Key point: beneficence is about benefit
    - Discussion points
      - What does the word benefit mean in real life, and what might it mean in research?
      - Research Definition: Beneficence has two parts: 1) do no harm, and 2) maximize benefit
        - Who determines what is beneficial?
      - Example from our study: participatory research. RRs determine what is beneficial
    - <u>Activity</u>: Ask each participant to sum up the meaning of beneficence in a single word.
    - Justice
      - Key point: justice is about fairness
      - Discussion points
        - What does justice mean in real life? What might it mean in real life?
        - Research definition: Everyone should have a fair opportunity to participate in the study, AND risks and benefits should be shared in an equitable and fair way
        - Who has the power to decide who participates in research? In our study?
        - Example from our study: sampling plan. Selecting voices of the most impacted, who are usually also the most marginalized.
           Equal opportunity for voices who are heard to be heard in research.
      - <u>Activity</u>: Ask participants to sum up the meaning of justice in a single word.
    - Respect for Persons
      - Key point: respect for person is about respecting people's right to choose
        - What does it mean to respect people? What does that mean in research?

- Research def: people should decide for themselves that they want to participate
  - How do we determine who has the ability to decide for themselves? Who does not?
    - Discuss special groups: age, language, substance abuse, mentally impaired, prisoners, other?
- Example from our study: informed consent. And who we cannot survey: no minors, only English and Spanish. Others?
- **<u>Activity</u>**: Ask participants to sum up the meaning of respect for persons in a single word.

III) Ethics Part II (60minutes)

#### (materials: ethics packets and note cards)

- <u>Activity</u>: read cases
- Have researchers pair up and discuss 1-2 cases and how they relate to the 3 principles beneficence, justice, respect for persons. Do this for the following cases: Nazi, Willowbrook, Milgram, Tearoom, and Havasupai
- After paired discussion, return to large group and have pairs present.
  - Everyone should be given a card with one of the three principles.
  - Each pair must report how the principle on the card related to the case they read.
  - Cards should be passed to the left.
  - Then, as a large group, read and discuss the Tuskegee Syphilis Study.
  - Main takeaways from each case are listed below:
    - Nazi concentration camps:
      - Note the date: 1947
      - Resulted in the Nuremberg Code first set of research ethics guidelines, voluntary, US did not sign on
      - Beneficence: harmful, Justice: risk/benefit was not shared, respect: not voluntary, no consent, lasting harm
      - Findings are still used today
    - o Willowbrook
      - Students and parents did not have the choice to participate, not were they fully informed;
      - o students were under 18 years of age and unable to consent fort themselves.
      - This too, like so many other studies was focused on health
      - Cannot require participation in research as a part of enrollment in the school.
         Similar, we cannot require all people who use a community program or belong to a community group to participate in the study
      - Benefited millions of people in the long run, but harmed the participants. Benefits and risks were not equally shared.
    - Milgram
      - Note: may need to review the study design
      - Year: 1963 (after Nazi concentration camps, after Nuremberg Code)
      - Application of principles
      - This research mirrors our study, meaning that our study as a Principle Investigator, who hires someone else, who in turn administers the study – proceed with caution
      - Research still used but do ends justify the means?
    - Tearoom trade

- Year: mid-60s
- Who did this study? Why? What gets to count as research?
- Risk/benefit: who was harmed? Who benefited? What determined what was beneficial?
- Note: this study was also about health! Health has always been an inclusion and justice issue.

• Tuskegee – for this case, have researchers read out loud, stopping paragraph by paragraph to discuss

• P1: note the year, location, context (Jim Crow south), population, incentive, prevention from seeking the known treatment to see what would happen

• P2: findings were published – who reads medical journals in 1936?, note length of time before objection and what happened, who continued to allow the study (people with financial stake in it) – no neutral body overseeing study, role of the media . note that things did not change until the public had access to the research. (this is why action plans are a part of our work)

• P3: led to the development of the 3 Belmont principles in 1973, despite this, there is still a lot of mistrust for the medical profession and research ... especially related to health.

IV) Break (10mins)

V) Informed Consent (45mins) (materials: info sheets, Red light, green light cards))

- This section discusses informed consent-- do research participants know what they're getting into how their information will be used, and do they agree to it?
- KSA ASK: have you heard of informed consent? Can you describe what it is? facilitator: scribe their answers on flip chart paper
- <u>Two basic components of informed consent (15mins)</u>
  - Informed consent is: a <u>voluntary process</u> to provide participants with information and an opportunity to decide to participate in research.
    - <u>Voluntary</u>: the participant's agreement cannot be forced or coerced. Should not be pressured, made to feel bad, threatened, offered unreasonable incentives (ie. lots of money) to do risky things
    - 2. A process that includes 4 steps:
      - Step 1: give information
        - read them the information on the informed consent sheet. Only allow them to read it themselves if they request to do so. This is so that we can ensure they understand the information.
        - In HNS we ensure this by asking: do you understand?
        - Step 2: a dialogue,
          - it's not enough to just give participants the information; they must also understand what you tell them. Give them a chance to ask questions. Answer all of the questions they have to the best of your ability. If you do not know, call Andrew or Reann.
          - In HNS, we ensure this by asking: "do you have any questions"
        - Step 3: a decision to participate
          - o The participant must be allowed to decide to voluntarily participate.

- In HNS they do this verbally by asking: May we proceed with the survey?"
- Step 4: give them the info sheet
- <u>Required Information</u>

Now that we know the process, let's dig deeper into what type of information we are required to give on the survey. (we give them a lot more than what is required, but these are the things that we are required to explain)

- o Purpose
- o Procedures involved (methods)
- o Length of time
- Known risks/benefits
- o What will be done to keep the information confidential
- o Who to contact with questions
- Participation is voluntary (and they can stop participating at any time)
- **Exercise 1**: Identify the Components of Informed Consent (15 mins) Ask RRs to pair off. Review the info sheet and underline the required information in the info sheet. Draw a circle around other important information that we provide, but is not required.
- Ask teams to share out the types of required and unrequired information that is shared.
- Answer any questions they have
- Exercise 2: Informed consent practice (15 mins)
  - Ask RRs to pair with a new person and practice the 4-step informed consent process.
     (Step 1: give information; Step 2 have a conversation; Step 3 decision to participate; Step 4 – give info sheet)
    - Each partner gets 5 minutes to practice the process and receive feedback from their partner.
  - Ask the partner to rate their partner based on the informed consent process checklist
  - Swap roles
  - **ASK**: Were there any challenges or questions you and your partner ran into? Answer any question the group may have

VI) Resident Researcher Role in Upholding Ethics (materials: post its. Is it or Isn't it scenarios)

 Let's apply what we've learned about ethics and informed consent to the Healthy Neighborhoods study.

- Group Discussion
  - **ASK**: What risks does our research pose to participants?
    - How might we mitigate these risks?
    - What are our responsibilities as researchers?
      - Examples include:
        - Know the procedures and context well, practice explaining it and answering questions about how the research will be used
        - Encourage participants to ask questions
        - Maintain participants' privacy keep research materials in approved research clipboard, check-in/check-out survey ON TIME
        - Don't rush
        - Spend more time with those who seem not to have understood

• If you think someone might not understand, ask them to explain the research to you

## • Exercise 3: Red Light, Green Light (10mins)

With what we've learned today in mind, let's play a team game to be sure we have the rules of ethics and informed consent down.

- Instructions:
  - Split the room into two teams. Give each team a pad of post-its. Ask each team to designate a speaker to share their team's response.
  - Read each scenario below and give the teams 30 seconds to talk among themselves and decide if the scenario is ethical or properly consented (Green light) OR if it is unethical or improperly consented.
  - The team should pick a red card or green card for each scenario. They should hide their card until the 30 seconds is up and its time to reveal their choice.
  - If the team agrees that it IS properly consented or is ethical they will pick the green card for "KEEP GOING". If the team agrees that it is NOT proper consent or not ethical, they choose the red card for "STOP AND REDIRECT".
  - At the end of 30 seconds, both teams must place their cards on the table. Teams get 1 point for correctly answering red or green. They get an additional point if they can correctly explain why.
  - Facilitator: keep score

#### VII) Evaluation, wrap-up and next steps (20mins)

(materials: informed consent quiz)

- KSA Evaluation: hand out the informed consent quiz.
  - Ask each RR to complete it independently.
  - Review the results as a group.
  - Ask RRs to make corrections to their quizzes you review the correct answers.
  - Collect quizzes at the end
- Wrap up
  - Round robin ask RRs for one things they learned that was new from the day and one question they have (if they still have questions).
  - Work as a group to answer one another's questions.
  - Revisit the meeting goals and make sure all goals were met
- Next Steps
  - Make up session
  - Session 4 sampling and practice

# Activity: Red Light, Green Light

Scenario Sheet

Facilitator: Read as many of the scenarios below as you'd like. Or add your own!

# Scenario 1: Informed consent

You are door knocking and meet someone who would like to take the survey. You being to read the informed consent to them and they say "give it to me… I can read it myself". You give them the survey, they read the page in 30 seconds and hand it back. You suspect that they read the page much too fast to have truly understood what they read. You ask them if they under stood what they read. They say yes, I'm ready to begin the survey. You flip the page and begin. Red light or green light?

Red – if you suspect they did not understand, do not proceed until you confirm that the understand the required information: purpose, methods, time, risks and benefits, confidentiality, voluntary, and who to contact with questions.

Question: what steps did we miss in this scenario?

- Dialogue. Ask Do you have any questions?
- Decision to participate. May we continue?
- Giving them a copy of the Information sheet

# Scenario 2: Anonymity & Confidentiality

You are canvassing in the park and meet someone who would like to participate in the survey. They are too busy to take the survey at that movement and ask if they can take the survey later. You say yes, set a time to meet at that same location next Wednesday and write down their name and pheon number so that you can call or text them a reminder the day before. Red light or green light?

Red - cannot collect personally identifiable information of any kind. Our survey is anonymous.

Follow up question: what other things can we do in this scenario?

- Let the survey go and recognize there will be other people to complete a survey with.
- Give them your contact information and have them reach out to you to arrange another day and time
- Give them the next date, time and location of a check-in or group survey day

#### Scenario 3: Risks and Benefits

Your team identified immigrants as a group to include in your sampling plan. You go door knocking in a neighborhood that is home to many immigrant families. Many people do not answer the door, and those who do are skeptical about participating and share personal information because of recent increases in ICE deportations. You explain that you are not connected to ICE and that their responses will really be helpful to help the community understand how to they the neighborhood more affordable, healthier and safer. They say the project sounds nice, and agrees to participate!". Red light or green light?

Green – technically there were no violations. There are perceived risks for this group in participating. There are no real risks of their information getting to ICE through the survey since it is anonymous, but we should minimize the level of risk they experience.

Follow up question: what can we do to minimize the risk to the participant?

- Engage immigrant families at safe, trusted community gathering spaces (ie. recreation centers, churches, ESL classes)
- Make sure to have someone from the immigrant community on our RR team, or working with your team a partner.
- Ask people who have completed the survey to give you suggestions on other places to go where you might find other people who might be comfortable participating.

#### Scenario 4: Voluntary participation

You are conducting surveys at a community festival with the rest of your RR team. A woman approaches the table and asks what's going on. You tell her that you are a resident doing surveys with neighborhood as a part of a research study to find out how people feel about development happening in the community and how it impacts their health. She says she is interested. You read her the informed consent form and ask if she understands. She responds yes. You ask if she any questions. She says yes and asks what happens if she doesn't have 30 minutes to complete the survey and if there is another time she can take it. Another RR on your team chimes in and says "come on! Don't you want \$20? We'll be quick. It will only take 20mins. Come on and do it. You're already here and it'd be a shame to miss out on \$20!". She agrees. Red light or Green light?

Red - participation must be voluntary. The participant cannot be coaxed into doing it

Follow up question: what is a more ethical way to try to encourage her to take the survey?

- Remind her she can stop at any time
- Remind her that its 20-30 minutes depending on her answers, so it may take less than 30 minutes
- Explain that her input and experience are valuable to your community and it would be meaningful and valuable to have her participate

#### Scenario 5: Respect for Persons and Vulnerable Populations

You meet a person on the street, give them your pitch and they agree to take the survey! You read them the informed consent page and properly complete the 4-step informed consent process. You begin the survey and discover that the participant was born in the year 2004. Red light or green light?

Red light – It's not an IRB violation, but its not the most ethical approach. Respect for persons. She is a minor and does not have the legal right to give consent to participate for herself

#### Scenario 6: (Bonus question. 2points for a correct answer)

A person began a survey and it became clear to you as they are answering questions that the person being surveyed has a cognitive impairment. You are not sure that the person actually understood the information in the informed consent process even though they said they did, had no questions and have permission for you to proceed with the survey. What would you do in this scenario? How might this situation be avoided?

Red light: This is a tough judgement call. Stopping the survey might be awkward, especially if it's a paper version. OK to go ahead and finish, and compensate the person at the end for their time. In this case you could note on the survey that the data should not be used. In some cases this may not be the best decision, but use your judgement.

#### Healthy Neighborhoods Study Resident Researcher Training Curriculum

#### Session 4 - Sampling and Group Surveying

#### Materials:

- sampling criteria/map from previous year
- clean map
- 1 copy of the data report (to reference demographics)
- English and Spanish community surveys
- Site coordinator survey tracking sheet
- Resident researcher survey tracking sheet

#### Sampling (30 minutes)

- 1. Overview of sampling
- When we collect data, we want to be intentional about the sample of people we select to participate
- In this case we want to make sure that we have a random sample. ASK: What does this mean?
  - If we aren't careful to make our sample random, we might only ask people who have something similar to ourselves to be in the study, we might only ask our friends. This introduces bias and goes against the justice principle (everyone should have an equal opportunity to be in the study).
- Can be discussed in terms of the actual data that is available from prior years of data collection
  or use the example provided below.
- Example: Bag of M&Ms
  - Proportional sample: each handful should have a proportional number of each M&M as is present in the entire bag. If a bag has 50 pieces (20 brown, 5 red, 10 yellow, 10 blue, 5 orange) the handful of 25 should have 10 brown, 2 red, 5 yellow, 5 blue, 2 orange)
  - Equal sampling: each handful should have an equal number of each color. If a bag has 50 pieces (20 brown, 5 red, 10 yellow, 10 blue, 5 orange), the handful of 25 should have 5 brown, 5 red, 5 yellow, 5 blue and 5 orange.
  - Over-sample: you may want to make sure to sample MORE of some groups to ensure that their voice is represented in the survey data.
- 2. Discussion and Mapping
- Review the sampling criteria from the past year. Use the data report and map from previous year to help shape this conversation.
  - <u>ASK:</u> do we still want to use last year's sampling criteria? If not, what do we replace it with?
- Use the map to identify places to survey where sampling criteria can be met.
  - Important because we want to make sure we are going to the right places in order to sample the right people. EX: if you want to make sure our sample includes older people, you also want to make sure your sampling plan doesn't only involve surveying in playgrounds.
- As places are being identified, discuss:
- How to sample from these regions.
  - le. Door to door, on the street, at events?

- Divide regions between surveyors.
- Decide logistics:
  - What day and time of day?
  - Individually or in pairs?
- Reminders to the team:
  - Don't oversample in a certain building or location
  - Check in with your teammates frequently to make sure you're getting a somewhat representative sample and are not sampling the same places
  - o During check-in meetings, the sampling criteria and map will be reviewed
- Facilitator should DOCUMENT the 4 criteria (noting oversample vs proportional) and locations where the specific criteria are met

#### Wrap-up

I. Next Steps

- SCHEDULE first check-in
- Confirm that everyone has been trained, get timeline for recruitment/onboarding/training for any new RRs who have not completed training

#### Group surveying

- Give surveys to site coordinator, who will determine the best way to divide them with the RRs.
- Remind RRs and coordinator that all surveys should be accounted for at all times because we want to be sure to keep personal information private. Give everyone their tracking sheets and remind them that we also keep our own at CLF.
- For RRs surveying in Spanish and on tablets, recap the correct processes for documenting completed surveys.
  - For Spanish: if survey isn't collated with incentive, take the incentive # from the English survey and write it in the yellow box. Return the English survey along with the completed Spanish survey.
  - For tablets: document that survey/incentive # in Redcap, return the corresponding paper survey with "tablet" marked.
- New people should be prioritized when going out to survey. If appropriate/low traffic, new RRs can pair up with old RRs or facilitators.
- People surveying on the tablet should practice using the tablet. If anyone decides that they no longer want to survey on a tablet it should be returned to CLF.

# Appendix D Action Project Facilitation Guides and Agenda

Agenda: Action Planning

Meeting 1 – Data in Action Objectives:

- Review and refine action plan
- Review and discuss completed data request
- · Decide additional data needs, and why
- Decide on data formats

#### Materials:

- Community Action plans document
- Copies of CDA variable list
- Copies of survey
- Data from data requests

#### Agenda

Time	Activity	Notes	
30m	Arrival and introductions		
5m	Introductions <ul> <li>Name</li> <li>Your community and your role in project</li> <li>Icebreaker</li> </ul>		
5m	Agenda Review – this meeting will focus on data, the next one logistics review CLF agenda items, as if there is anything else to add		
5m	<ul> <li>Re-introduce ground rules</li> <li>Note that we haven't been setting ground rules in prior meetings this year but should get back into the practice. Ground rules are a way to make sure that we all hold the same expectations for respecting ourselves, each other, and the PAR process. We have some standard ground rules that we use, shown here.</li> <li>With your knowledge of your group's norms and behaviors, do you have any additions/modifications to make?</li> <li>Great. These are our ground rules, which we should collectively hold ourselves and each other responsible for.</li> </ul>	Ground rules should be written-up on sticky paper	
20m	Review action plan		
PREP	Copy of updated action plan guide for each person		
5m	<ul> <li>Review action plan instructions on 1<sup>st</sup> page</li> <li>Review community problem statement, goals</li> <li>KEY TAKEAWAY: Overview action plan</li> </ul>		
15m	<ul> <li>Facilitate <u>brief</u> discussion about basics of the team's action</li> <li>Audience</li> <li>Date/location</li> <li>Action/activities</li> <li>Major funds/resources needed</li> <li>KEY TAKEAWAY: Overview of community's plan documented</li> </ul>	FLIPCHART this so that we have record	

55m	Use of data	
5m	<ul> <li>Re-introduce main ways to use data <ul> <li>To understand/describe a problem</li> <li>To understand potential solutions</li> <li>To describe a problem/motivate people to take action</li> </ul> </li> <li>Point to sections of the survey identified during CDA</li> </ul>	Flipchart the 3 ways to use data (1 per sheet)
15m	<ul> <li>KEY TAKEAWAY: Overview of ways to use data</li> <li>Discuss data needs, categorizing the data into the 3 categories</li> <li>Begin with data from the data requested – how will you use this data help to advance the action project? (place responses into the three categories)</li> <li>Note that the data requests will be entered into the data request form, as a reminder about the online form that can be used by anyone who works on the study.</li> <li>TAKE PHOTOS/NOTES and enter into data request form</li> <li>KEY TAKEAWAY: Community's new data requests documented</li> </ul>	BRING: copies of the survey and variable list Prepare to enter data requests into form (real- time or later)
20m	<ul> <li>Review and discuss data from data request</li> <li>What stands out?</li> <li>How is this information useful for your project?</li> <li>KEY TAKEAWAY: Review data requested at CDA</li> </ul>	
15m	<ul> <li>Thinking about the 3<sup>rd</sup> use of data (motivate people to take action), what will be the main takeaway of your project? How will you share this with other people who were not present for your event (blog, one-pager, pictures, news story, etc.?)</li> <li>Should also be thinking about what you will say about the project itself.</li> <li>What format would you want your data to take? Basic statistics, charts, etc.</li> <li>How will this get produced?</li> <li>KEY TAKEAWAY: Documented plan for how the team will present the data</li> </ul>	
15m	Wrap-up and Next Steps	
15m	<ul> <li>2 more CLF planning meetings</li> <li>Confirm dates</li> <li>Next meeting: deep dive into logistics (outreach strategy, agenda, media strategy, materials, budgeting) – come with ideas</li> <li>LEY TAKEAWAY: Review of</li> </ul>	

Meeting 2 – Logistics of event/activity

Objectives:

- Review and discuss completed data request
- Decide necessary information/steps for group to complete their action plan

#### Materials:

- Community Action plans document
  Copies of CDA variable list

- Copies of survey
  Data from data requests
  Budget worksheet
- Next steps worksheet

Agenda

Agenda Time	Activity	Notes
30m	Arrival and introductions	
5m	Introductions <ul> <li>Name</li> <li>Your community and your role in project</li> <li>Icebreaker</li> </ul>	
5m	Agenda Review - review CLF agenda items, as if there is anything else to add	
5m	Reminder of ground rules	Ground rules should be written-up on sticky paper
20m	Review action plan	
5m	<ul> <li>Review action plan instructions on 1<sup>st</sup> page</li> <li>Review community problem statement, goals</li> </ul>	
15m	<ul> <li>Share <u>brief</u> update about data obtained since last meeting</li> <li>Review plan for sharing with community (report, one-pager, etc.)</li> </ul>	
65m	Logistics for action	
5m	Introduce the main logistical matters to cover: • Outreach strategy • Agenda • Media strategy • Materials list + budget <u>ASK</u> if there are any other logistical topics that need to be covered today	
30m	<ul> <li>Have everyone think about which pieces they are most interested in/suited for thinking through. Have people break into groups to work on:</li> <li>Outreach strategy</li> <li>Agenda</li> <li>Media strategy</li> <li>Materials/budget</li> </ul>	Give each group a flip-chart to write notes to present back to the team
20m	Each group shares what they've come up with and large group adds/forms consensus (5min per group)	
10m	Decide next steps for each, and who needs to do what, by when, complete task list	
15m	Wrap-up and Next Steps	
15m	<ul> <li>1 more CLF planning meetings</li> <li>Set date</li> <li>Next meeting: final loose ends, practice!</li> </ul>	