Rethinking Access to Data and Tools for Community Partners in Research

Maria Barker[1] and Rachel Bloom-Pojar[2]

1 Planned Parenthood of Wisconsin, Inc. (PPWI)

2 University of Wisconsin-Milwaukee

Abstract

This article builds on the authors' 2021 ATTW keynote, "The Power of Language in Building Confianza with Communities." It emphasizes the importance of maintaining confianza (trust/confidence) over time and encourages researchers to share results in accessible and usable ways for community members who participated in their projects. Drawing from their work with a group of promotores de salud (health promoters) and the promotores' work with the 2020 Census, the authors share guiding questions for both community leaders and researchers to consider when engaging in projects together. Ultimately, they discuss the importance of planning for a "dissemination phase" that leaves behind herramientas (tools) and does more than simply share information without regard for how community members may want to access and use that information in the future.

Introduction

Right before the start of a focus group in 2019 with promotores de salud (health promoters) in Madison, Wisconsin, Rachel asked if there were any questions before they began recording. One of the promotoras said yes, actually, she wanted to know what would happen with the information they shared and whether they would hear about the results of the study. The promotora explained that they get asked to participate in a lot of focus groups, but they don't often hear about what happens after they have participated. Rachel was sorry to hear this and explained that she did plan to share findings and information about the study along the way. She said she hoped to be transparent with them throughout the study wherever it might lead. After sharing with Maria about this interaction and other questions the promotores asked during the focus group, Maria felt proud of the promotores for feeling confident enough to ask such direct questions to Rachel as a researcher they hardly knew. As the director of the promotores program, Maria was glad that the promotores were standing up for themselves as deserving to know more about what would happen in the study, and Rachel often thinks of this conversation when considering how she is sharing information with the promotores alongside sharing information for academic audiences.

We have been working together since 2019 as academic-community partners in research and other activities related to the promotores de salud at Planned Parenthood of Wisconsin, Inc (PPWI)[1]. We were grateful to be invited as the keynote speakers for the 2020 Association for Teachers of Technical Writing (ATTW) conference, which ultimately was delivered at the 2021 ATTW

---

[1] *The findings and conclusions in this article are those of the authors and do not necessarily represent the views of Planned Parenthood Federation of America, Inc.*

Virtual Conference. Our keynote, "The Power of Language in Building Confianza with Communities," focused on our relationship as collaborators and what we have learned about confianza (trust/confidence) from these promotores de salud who work with Latinx communities across Wisconsin. In our keynote, we discussed the importance of language and how we present ourselves to others as an indication of whether they can trust us or not. We also provided some recommendations for more ethical practices in building relationships for community-engaged research.

Since the 2021 ATTW conference, we have continued to discuss language, access, and power in relation to the various projects we are working on. We are especially concerned with how many researchers and policy makers continue to seek access to communities for input and "data" with little to no regard for sharing the results of their research in accessible and meaningful ways with the people who contributed to that work. Promotores de salud have long been recognized as helpful partners for research and institutional outreach (Marsh et al. 2015; Otiniana et al. 2012). Their ability to access "hard to reach" communities for institutions and researchers can often be taken advantage of for the data collection phase of research projects. Less frequently, they are seen as key partners to help ensure that research findings are communicated to participants in accessible and usable ways. At the end of our keynote, we shared the following recommendations:

1) Get involved in the community where you live and focus on building genuine connections without an agenda.
2) Let the relationships, community interests, and shared values guide the development of a project (if there will even be a project).
3) Make your findings accessible to the communities who contributed to it.

To expand on the third point, we stated, "Publish your work in ways that the community can understand and access." In this article, we want to pick up where we left off with these recommendations to emphasize the importance of maintaining confianza over time to share results from community-engaged research in accessible ways for those community members to understand and benefit from them. It is important that researchers who engage communities in their work do more in the "dissemination phase" to make their findings accessible and usable for communities and that they leave behind herramientas (tools) for the community members to thrive. To demonstrate an example of the need for this, we'll begin with a story about the promotores' work with the 2020 Census and Maria's subsequent search for usable and accessible data for her work on a statewide health equity council.

The 2020 Census in Wisconsin (Maria)

The *promotores* from Wisconsin had the opportunity to work on the 2020 census through a grant we received from Planned Parenthood Federation of America (PPFA). A representative from the Public Affairs department and I went to PPFA corporate office for a two-day training on how to best do census work in communities who were less likely to participate. The focus was on creating the trust needed for these communities to be willing to fill out the census. *Promotores* from Wisconsin were asked to participate because of our expertise in creating trust and connecting people to reputable community resources. Many people distrust the government, and the census is something people do not want to fill out because of the extensive information we are asked to give. People are always leery of what the information is used for and do not completely believe that the information is used to allocate resources. The PPWI *Promotores* work with harder to reach populations such as Spanish speakers who may be undocumented. This community often lives under the radar, not wanting to have anything to do with

the government. The grant we received was to engage this community in conversations about the importance of filling out the census and sharing what the information is used for.

By spring 2020, all was ready for us to do this work by meeting with people in person, and then, the Covid-19 pandemic hit. Covid put our country at a standstill. Schools and businesses shut down, people were asked to work from home, and technology now became the way of doing business. No longer could we meet in person; we now had to meet virtually or make phone calls. We met with *promotores* to make a plan for using technology to connect with people, and phones became the way we did the majority of the census work. Our *promotores de salud* began making phone calls to all of the people who had attended our past programming and quickly found out that people did not have access to filling out the census online. This made us realize that we had to become proficient in helping people fill out the census. While we were on the phone with our participants, our *promotores* logged onto the census pages and helped thousands of people fill out the census. In a 6-month period, Wisconsin *promotores de salud* had conversations with approximately 3,000 heads of household and helped fill out the census for about 5,000 individuals. It was another job well done by our *promotores*. We hoped that in completing this census work, we had contributed to important data collection that could bring more resources and support to our communities.

A year later, I became one of the people who needed to access data from the census. My most recent need to access this data was for a project I am working on for the Governor's Health Equity Council, which is a council made up of community leaders who are charged with looking at how government programming, initiatives, and funding can be more equitable for Wisconsinites. While doing online census research to gather information for this project, I faced a lot of challenges. First, the census website was not easy to get to because when I used the word "census" for the Google

search, I saw a lot of sites that are ads or other organizations who use census data. Then once I got to the official census site, it was not easy to maneuver. Accessing what I consider simple data, such as the number of foreign-born people and language spoken at home, was not easy. There is a lot of information, but it is not easy to get to. This made me realize that when I chose to involve myself on the census initiative, I should have asked for a deliverable to be knowledge on how to access and use the data. This was a deliverable I had not ever asked for before.

Navigating Research Results (Rachel)

Our conversations throughout the process of preparing this piece have reminded me that research partners have information literacy skills (ACRL 2015) that can both be resources to share and potential impediments to our understanding of what constitutes "accessible information." As Maria expressed her frustrations with me about trying to access census data, I started to do similar searches online to familiarize myself with the sites and paths she was navigating for her own research. I agreed that the data, as it was presented on the Census Bureau site and related websites that gave census quick facts, was not user-friendly for the *promotores* or other non-researchers. Besides the simple yet glaring lack of site content and information in Spanish or other non-English languages, the site contains information for a variety of audiences that may get distracting or confusing if one cannot find what they're looking for right away. Then I realized in another search that the census website has a whole section called "Explore Data" and their "Census Academy," which are meant to help a variety of users make sense of Census data and even request workshops that are led by their dissemination data specialists ("Request" 2021). The workshops are available in a number of languages, but the navigation to arrive at these pages are only in English and filled with lots of different information that may easily become overwhelming.

Maria and I discussed these resources and how we could ask the *promotores* and others at PPFA if they wanted to request a workshop for all the people who helped with garnering Census participation across the U.S. But Maria also pointed out that this resource seemed to be something that was a lot easier for me to find than for her. She asked about how much control researchers have over how data and websites appear to everyday people seeking information from them, and I shared a bit about how algorithms, browsers, browsing history, and other things may impact what shows up when anyone enters a certain term in their search bar. I shared that I thought it might've been easier for me to find simply because so much of my job is researching information online and so I have a certain level of information literacy for navigating these websites. These sites are also often set up in a way that is easy to navigate for a primary audience like me (white, English-speaking, academic researcher) while the census site in particular has even more of an appeal for researchers and policy makers who are more familiar with quantitative data than I am. What may seem "easy to find" or "out there for anyone to access" can actually still be inaccessible for anyone without the same level of information literacy that the creators have.

The option to request training workshops was interesting, but it was not something that was mentioned to Maria or the *promotores* when they first started working with the census. It appears to rely on people finding their way to this part of the Census Bureau website in search of this type of resource. Many people work to make the census what it is and various census workers, community leaders, and grant funders need to communicate about what sort of follow-up is available for the community members who helped increase turnout for the process.

While the census and academic research are connected in many ways, we admit that this is a unique form of "community-engaged"

research that is distinct from academic research teams or individuals who initiate community-engaged research projects. However, we think there is a lot to learn from the process and the need for community leaders and researchers to more intentionally consider and discuss how they will make findings, data, and tools accessible and usable for the community members who made them a reality.

Demanding Access (Maria)

In my experience, the importance of research findings being at a literacy level that is accessible to community members, holding the researchers accountable for this and for leaving usable tools behind, is not often thought about by community partners involved in research projects. As community leaders, we get caught up in the sales pitch of what the researchers want–to help–and we take what we get–morsels–because that is what we have always gotten. We talk to the community about being critical thinkers and forget to be critical thinkers ourselves. We must think about what is in it for our community if we participate in research. How will we get access to the results? What will be left in our communities after the project is done? Community leaders who have the trust of the community must pay attention to the end results by making sure people in communities understand the findings, know where and how to get to these findings, and who is accountable for ensuring these things happen. Those of us who do the front-line work must demand access to what we helped to collect.

Researchers publish their findings to become known as experts in that content area and these publications are most often read by others in academia. This is a good thing because sharing knowledge is good for communities and networks; however, sharing findings with the communities directly impacted by the research needs to be the number one priority. This is a very simple thing to do; it just has to become a conscious effort to do so. How

do researchers know their research findings will be published and at what level they will be recognized as experts? As a non-academic, I do not know the answer to these questions, but I can tell you how your research findings will impact my community. How do I know this? Because I know my community and have partnered with researchers on well-intended projects. We help on research projects and plan the one event to disseminate the findings, but we are not asked to help with ensuring the findings continue to be accessible to the community, and we are not asked to play a role in the development of whatever tool or thing that will be left behind for the community to use as a resource to ensure the community continues to thrive.

Herramientas (Tools)

In this section, we talk a bit more about the idea of leaving herramientas behind for the community to use as a resource. Sometimes these herramientas are specific concrete tools or technologies that can be used by individuals, and other times they take the form of knowledge sharing, events, and professional development opportunities. In considering herramientas to leave behind for a project, researchers in technical and professional communication (TPC) must be cautious about the ways their biases and privileges may impact any tools they create, and they must consider how these herramientas can work to resist oppression rather than reinscribe it on communities they work with (Jones and Williams 2018). With this in mind, we present a series of questions to consider for community leaders to advocate for what their communities want and need out of specific projects and partnerships. We also encourage researchers to consider a few things when deciding how to proceed with research plans that plan for herramientas to be shared once a project is done.

Some questions for community leaders to consider and discuss might be:

- What will our participation look like throughout the life of the project? Who will be our main contact(s) when we have questions or concerns?
- How will the results from the project be shared with those who participated? Is a final PowerPoint enough or do we want to request something else from the dissemination phase of the project?
- What might be some deliverables we'd like the research partner to prepare that can be usable and easily accessible by participants or other interested community members?
- Will this research/participation help us prosper? If not, why get involved?

Community-based participatory research should start with not only the hypothesis, but also identifying the "thing" this research will leave in the community for the success and use of the community. If there is nothing that is left behind for the community to use for their well-being and for the community to thrive, the research should not happen. What are some of the things that should be considered to be left behind for communities to thrive? To answer this question, let's look at what thriving communities and people have: access to a good education, good health care, good jobs, good housing, good childcare, good community centers, safe streets, safe and nice recreation areas that are both indoors and outdoors, and more. They have access to all these things in the language spoken by most, staffed by people who look like them and understand their culture. This is what researchers have, and this is what the communities you are studying don't have, and it is what we want.

To figure out how to identify this "thing" that will be left behind, researchers should answer the following questions:

- How will your research impact access to things like a good education, health care, jobs, housing, childcare, etc. in the community where you are doing your research?
- What can your research leave behind that will help better these disenfranchised communities who are regularly researched?
- How do people have access to reading the findings of the research so they can continue to use those findings as data for work they do in their community?
  - What language support and feedback mechanisms should you plan for in preparing accessible communication about the outcomes of your research?

Even if the goals of the research or the needs of the community change over time, it is important to begin with clear goals for making findings accessible for the community. These things should be explicitly discussed with key partners from the community and their input on these issues should be solicited at the start of the research design process. Then there should also be a way that they can weigh in on things throughout and at the end of the research process.

Reflecting on my Research Process (Rachel)

We have been discussing these topics of *confianza* and leaving behind tools for communities for a couple years now. The opportunity to explore them deeper through conversations about language, access, and power at the 2021 ATTW conference helped us think about how others are exploring these topics and how we might want to engage researchers in conversations. The subsequent process of writing this article has been especially beneficial as it has allowed us to reflect on our experiences with community-engaged research thus far and how we want to share the story of that with others. Our partnership has been the longest one either of us has had with an academic or

community partner. For me, that has been possible because of multiple privileges that I've gained over the past couple of years: I published my first book, secured a new position in a city I wanted to live in long-term, and was granted tenure at my university. This all felt like it collectively gave me permission to slow down and spend time doing community-engaged research in the way I had always wanted to, but that various factors such as moving, tenure expectations, and more kept preventing. But none of it guaranteed a strong relationship built on *confianza*, which was something that took time to develop. So, when I first connected with Maria in 2017, I hoped it might be the start of a nice relationship with a local community leader, but I had no idea we would end up where we are now in 2022.

At times, I am not sure what parts of my engagement with the *promotores de salud* are "research" and what might be classified as other things. Some of it entails programmatic support and consultation while other parts have entailed teaching specific skills and processes with writing. Some weeks I'm just grateful they let me continue to participate in meetings and learn about what they're doing across Wisconsin. I'm sure all of it can be considered as things that inform my research, but the organic process of building *confianza* that I've tried to be open to has set aside primary research goals and focused on how I can be responsive to my partners' interests and needs in our collaborative work. My conviction in this approach has been informed and strengthened by other examples of community engagement in TPC that emphasize participatory methods and social justice (Agboka 2013; Walton, Zraly, & Mugengana 2015; Gonzales 2021).

I shared with Maria that I was not sure whether I could explicitly state what the "tool" is that I have or will leave behind once my project is done. Part of that may be that I can't see a clear "end date" for my engagement with the *promotores*, but part of it was also that my initial goals for the project were to highlight the expertise of the *promotores* for other audiences. I did not enter this partnership with the thought that they specifically needed anything from me, but rather, I would be happy to help support or provide resources for things we might identify along the way. Last year, I shared that usual PowerPoint

presentation that noted what I was finding in the study and what I was recommending to others at PPWI, but it was by no means "the end" of the project and simply marked a stage where I had something to share while noting that I would continue to be in touch as other things developed. Since then, I have moved into other roles supporting the program, like facilitating meetings with health promoters who serve on a newly-formed curriculum revision committee, teaching a community writing class, and providing feedback and technical support for *promotores* who have begun training other *promotores* outside of Wisconsin.

These experiences have led me to believe that the specific *herramientas* that researchers should "leave behind" may look different depending on their level of engagement with community partners. For some, it might be a specific concrete product that the community members can access and use for the future. For others, it might be ongoing support through a variety of avenues that share resources, knowledge, and connections with others who might lift up the good work that community members are already doing. Or it may be specific advocacy work that leads to material and economic change in coalition with others across the community. For all of us, I hope whatever the *herramientas* are that we agree to create or share are things that we have discussed and developed *with* our community partners' input rather than *for* them with what we think might best help them.

Sharing Knowledge (Maria)

Rachel is correct—one must put real thought into what the *herramientas* will be because they will not always be a manual or a tangible thing. The tool Rachel continues to leave with the team of PPWI *promotores* is knowledge! Rachel shares her expertise as an educator and is continuously supporting us in our professional journey, finding nontraditional and innovative ways to help increase our knowledge on writing skills, presentation and facilitation development, researching resources, our right to privacy, how to be conscientious of stories we share, and many

other things. I don't believe Rachel started working with us planning to "teach," but that is the valuable *herramienta* she is leaving us, individually, as a team, and with our community.

Some Final Thoughts

In our keynote presentation and a previous article, we emphasize that *confianza takes time* and "needs to extend beyond any specific project, grant, or interaction. It must be built up through consistent and genuine interactions that center relationships and mutually beneficial goals" (Bloom-Pojar and Barker 2020, 92). Building genuine *confianza* cannot just happen in a few interactions. For that to continue building throughout the life of a research project, *confianza* must be taken into account with the ways that research findings are "disseminated" to and used by community partners. So many research projects would not be successful without participation from key community partners. It is essential that researchers design their projects to include steps that increase access to the data from that research, and along the way, be in conversation with stakeholders about what tools or knowledge they can share that will benefit the people who made their projects possible. With more attention to the language, power, and *confianza* that can impact community-research partnerships, we all can better attend to the technical communication needs of the dissemination phase of research. Attending to linguistically and culturally appropriate communication along with clear guidance on navigating digital resources will better ensure that community partners who helped make the research a reality can then reap the benefits of accessing that information in the future.

References

ACRL (Association of College and Research Libraries). 2015. *The Framework for Information Literacy for Higher Education.* https://www.ala.org/acrl/standards/ilframework.

Agboka, Godwin Y. 2013. "Participatory Localization: A Social Justice Approach to Navigating Unenfranchised/Disenfranchised Cultural Sites. *Technical Communication Quarterly* 22(1): 28–49. https://doi.org/10.1080/10572252.2013.730966

Bloom-Pojar, Rachel and Maria Barker. 2020. "The Role of Confianza in Community-Engaged Research for Reproductive Justice." *Reflections* 20.2 (Fall/Winter): 84-101. https://reflectionsjournal.net/wp-content/uploads/2020/12/Reflections-20.2-V4-11.14.20.pdf.

Gonzales, Laura. 2021. "(Re) Framing Multilingual Technical Communication with Indigenous Language Interpreters and Translators." *Technical Communication Quarterly* 31(1): 1-16. https://doi.org/10.1080/10572252.2021.1906453.

Jones, Natasha N. and Miriam F. Williams. 2018. "Technologies of Disenfranchisement: Literacy Tests and Black Voters in the US from 1890 to 1965." *Technical Communication Online* 65(4): n.p. *https://www.stc.org/techcomm/2018/11/08/technologies-of-disenfranchisement-literacy-tests-and-black-voters-in-the-us-from-1890-to-1965/*

Marsh, Terry, Kathryn Pitkin Derose, Muriel Rios, and Deborah Cohen. 2015. "*Promotoras* as Data Collectors in a Large Study of Physical Activity in Parks." *Health Promotion Practice* 16.3 (May): 354–361. https://www.doi.org/10.1177/1524839914563076.

Otiniana, Angie Denisse, Amy Carroll-Scott, Peggy Toy, and Steven P. Wallace. 2012. "Supporting Latino Communities' Natural Helpers: A Case Study of Promotoras in a Research Capacity Building Course." *Journal of Immigrant Minority Health* 14: 657–663. https://www.doi.org/10.1007/s10903-011-9519-9.

United States Census Bureau. n.d. "Request a training" Last modified December 20, 2021. https://www.census.gov/data/academy/request.html.

Walton, Rebecca, Maggie Zraly, and Jean Pierre Mugengana. 2015. "Values and Validity: Navigating Messiness in a Community-Based Research Project in Rwanda." *Technical Communication Quarterly* 24(1): 45–69. https://doi.org/10.1080/10572252.2015.975962

About the Authors

Maria Barker is the Director of Latinx Programming and Initiatives for Planned Parenthood of Wisconsin, Inc. (PPWI). A bilingual (Spanish/English) community educator of Mexican origin who is keenly aware of the need to provide education to communities in their language and with their culture in mind, about 90% of the programming Maria supports is facilitated in Spanish by *Promotores de Salud* to meet the needs of the Latinx communities throughout Wisconsin. She is well-recognized for training and using lay community workers known as *Promotores de Salud* to reach the Latino community. Maria is a graduate of the Latino Nonprofit Leadership Program through the University of Wisconsin-Milwaukee and Cardinal Stritch University. She is a certified Sexuality Educator by Planned Parenthood of Western Washington and Centralia College.

Rachel Bloom-Pojar is an Associate Professor with the program in Public Rhetorics and Community Engagement at the University of Wisconsin-Milwaukee. Her research examines communication about health with a specific focus on the rhetorical practices of Latinx communities, interpreters, and *promotores de salud* (health promoters). She was a 2020-2021 Mellon/ACLS Scholars and Society Fellow with Planned Parenthood of Wisconsin, Inc. (PPWI) and has continued working with the PPWI *promotores de salud* as a community writing teacher and program development consultant. Her published work has appeared in the NCTE Studies in Writing and Rhetoric Series, *Reflections*, *Present Tense*, the *Journal of Applied Communication Research*, and *Methodologies for the Rhetoric of Health and Medicine* (Routledge).