Public Philosophy Journal

The TrustWorkers Project:
Challenges and Methods of Building Trust into Public Scholarship

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Abstract

This article grapples with a critical question in public humanities work: How should academics think of trust as a theoretical problem in current public health, policy, and academic debates but also as a practice of engagement with local communities and collaborators outside the academy? We recount our experience of the TrustWorkers project at Columbia University in 2022—a project focused on the critical role of Community Health Workers as trust builders during the pandemic—to illustrate our thinking on this matter and contribute new impulses to publicly engaged scholarship.

Volume 5, Issue 1 | 2023
DOI: 10.59522/CIOU2388

The TrustWorkers Project: Challenges and Methods of Building Trust into Public Scholarship

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¶1 In spring 2020, New York City became the United States' first hotspot of the COVID-19 pandemic. By early April, deaths and thousands of new infections were registered daily. Amid the enormous human suffering and given highly publicized initial disparities in vaccine uptake by class and race, experts and policymakers pointed the finger at the spread of misinformation and New Yorkers' susceptibility to it as a culprit for the public health disaster and the lack of trust it engendered. A palpable sense has since taken hold that attempts to contain COVID-19 in New York City and elsewhere in the United States were, in part, thwarted by profound mistrust of doctors, hospitals, vaccines, and science. When we began investigating these questions, we were skeptical that the medical system had lost the trust of many New Yorkers overnight, especially among Black and Latinx communities impacted by a long legacy of health inequities, including access to needed vaccines (NY Department of Health 2022). As social scientists, humanities scholars, and public health experts, we also believed that the attention to mistrust in the national debate proceeded from a faulty premise: namely, that people should, as a matter of course, trust the medical system and that, if they failed to do so, they must have been duped by misinformation. Public campaigns proceeding from this assumption and seeking to combat mistrust have often operated as veritable moral panics.

¶2 What was lost in such reactive approaches was the question of *trust* itself. Our main questions were, thus: What *is* trust? Under what conditions is it normally obtained? Can it be accumulated and stored as "social capital"? Is mistrust necessarily the opposite of trust? Who can repair broken or lost trust in medicine and science? Despite a wealth of trust surveys and sentiment reports in economic, policy, and corporate fields, there remains a genuine paucity of good methodologies to study trust. Especially glaring to us is the absence of attempts to learn from the experience and perspectives of "trust workers," people such as community health workers (CHWs), nurses, and physician aides, who labor at the front lines of the medical system, and who build trust as part of their daily job.

¶3 From the outset, our sense was that the focus on misinformation did not grasp the fundamental causes of the struggles over public health measures and vaccinations since the outbreak of COVID-19. Nor did it adequately represent how especially communities of color, who took a heavy toll during the pandemic, thought of their relationship to the medical field during this period of crisis and uncertainty. To better understand how trust in medical science and public health institutions shaped the course of the pandemic in local communities in New York, we felt it necessary to shift attention to those essential workers in the medical system—CHWs chief among them—who provided vital health assistance and services to their communities and who, by virtue of their job description, relied on creating and maintaining trust in their daily work.

¶4 Although CHWs know much about trust, their immense wealth of experience and knowledge has remained dispersed and untapped. We intended, therefore, to render this knowledge visible and elevate the position of CHWs in the medical field through conversations facilitated by visual, written, and artistic expressions. In the following, we reflect on how trust can be built into and inform public scholarship, conceptually and in practice, through our experience developing the TrustWorkers project, where the boundaries between academic and public knowledge remained genuinely porous and unfixed. Our approach, viewed in hindsight, was not painstakingly systematic, and the partnerships we forged along the way resulted from a series of events, encounters, and conversations that built on each other and leveraged the strength of a plurality of voices.[1] Drawing on years of experience organizing public health initiatives, collaborators in our project included practitioner-scholars from Hunter College and Weill Cornell Medical Center, including Elizabeth Cohn, Judelysse Gomez, and Lula Mae Phillips, who trained CHWs in the photovoice method in a series of workshops. It also included the Bronx Community Health Network (BCHN), a nonprofit health center system in New York that offered invaluable support in mobilizing their CHW base for participation in our project. Representatives of the New York Department of Health, foremost among them Assistant Commissioner Olusimbo Ige, offered critical insights into the city's handling of the pandemic and represented the bridge into the policy realm we sought to build. Last, but not least, the project involved our team at Columbia University's Trust Collaboratory, Cristian Capotescu, Jack LaViolette, Danielle Lee Tomson, and Gil Eyal, who organized and curated the TrustWorkers exhibit.

Communities of Color and Trust in the Medical Field

¶5 In fall 2021, we started our foray into trust with a public Zoom town hall titled "A Time to Speak Up: (L)Earning Trust between NYC Communities and the Medical System." The event invited community advocates, public health professionals, policymakers, scholars, CHWs from the Bronx, and members of the public to engage in a much-needed dialogue about the relationship between communities of color and the medical profession. At the time, only about half a year after the rollout of the vaccine campaign in New York, initial vaccination rates among Black and Latinx New Yorkers still lagged behind those of their white and Asian counterparts. While this fact led to a moral panic about misinformation in some circles, those aware of the long history of health inequities, medical neglect, bias, and racism in the medical system were not surprised. With these challenges in full view, we knew that merely raising the alarm about these concerning trends without creating an opening for a broader conversation would be perceived as laying the blame on the doorstep of already marginalized communities.

¶6 For this reason, our town hall sought to open a dialogue that allowed communities of color to articulate their thoughts on the issue of trust in medicine and science. This event also presented us with an opportunity to tease out how these attitudes and frames shaped not only vaccination behavior but also the relationship between local communities and the wider medical profession. A second event was organized as a digestive exercise in the format of a follow-up roundtable conversation that invited back participants from our town hall, including panelists, experts, and scholars. They were asked to reflect on takeaways from the town hall and sketch out action items for subsequent activities. In these conversations, three critical points emerged for our engagement with the question of trust: First, the public focus on misinformation during the pandemic had been perceived as placing the onus, perhaps even the blame, for slow vaccination rates on the people who seemingly failed to trust well-established scientific facts. This view neglected the fact that some communities in New York had legitimate reasons to be cautious or fearful of doctors and hospitals. Black communities in Harlem and the Bronx, for instance, grappled with a long legacy of historical traumas (for example, the Tuskegee Syphilis Study), pervasive health disparities, discrimination, and underrepresentation among medical professionals. To this day, racial prejudice and implicit bias against people of color are widespread in hospitals and medical facilities. The moral panic about misinformation, though it may resonate with current-day politics, wittingly or not, is perceived as stigmatizing certain communities and individuals as “distrustful” and exhorting them to unlearn their behavior and change their ways of thinking.

¶7 This aspect of our public discourse about mistrust has produced an endless array of campaigns seeking to combat medical skepticism through “more” and “better” science messaging. If we imagine that mistrust is caused by mis- and disinformation, the antidote would seem to be a campaign for “public understanding of science.” In line with this thinking, there were efforts to pressure social media platforms to remove or fact-check mis- and disinformation from their sites. But the boundaries between what “facts” and “truth” are and where mis- and disinformation starts are not clear or commonly agreed upon. Predictably, this debate exacerbated culture war battles and sidestepped genuine concerns about vaccine safety. The campaign to root out misinformation represented a kind of knee-jerk actionism (*Aktionismus*), a term coined by sociologist and philosopher Theodor Adorno (2005) to describe the reactivity to political crises that values action over careful deliberation. Precisely for this reason, it quickly became captive to political polarization and culture war rhetoric. It should also be noted that the promised results of such anti-mis- and disinformation campaigns routinely fall well behind their promised accomplishments. The limitations of chasing after mistrust via public science education are evident: it is akin to an endless game of “whack-a-mole” that, at its core, is motivated by the goal of stomping out the latest rumor, falsehood, or lie without however reflecting on and addressing the root causes for the absence of trust. Its good intentions of achieving pro-social behavior notwithstanding, repetitive health messaging from the top is likely to be perceived by local communities as paternalistic and hectoring. Because “science educators” lack longstanding relationships with the communities they try to reach and are further distanced by the pedagogic posture they assume as they parse facts from fiction, they can quickly appear untrustworthy themselves.

¶8 What these conversations also highlighted was, second, that trust is not only a problem with significant theoretical purchase but also a practice central to public engagement. Trust should guide how academics think about their relationship with the public and the work needed to make research trustworthy. Creating opportunities for engagement is not the simple act of issuing an invite to “join the conversation” via frenzied outreach campaigns that purport to open the doors of the ivory tower to the general public. As academics organizing a public town hall in the middle of the public debate about vaccines in 2021, we were thrust into a particular set of tensions between universities (particularly elite private institutions) and the neighborhoods they inhabit. The communities we hoped to bring into the fold were among those often excluded from academic life in myriad ways in the Bronx, Harlem, and other places in New York. They were, with good reason, skeptical of our intentions of broaching a topic as sensitive as trust in the medical system.

¶9 Of course, the dilemma preceding any such community-academic dialogue is that meaningful social action requires a modicum of trust between academics and their interlocutors. Unsurprisingly, while organizing the town hall, we encountered skepticism and suspicion about our intentions of inviting the community to “speak up” on these difficult topics. (This particular framing originated with one of our nonprofit partners.) This is because there is a certain "bootstrapping" aspect to building trust: To create trust, it is necessary to have an honest and open dialogue with the community. To generate opportunities for dialogue, in turn, one needs to be trusted by members of the community beforehand. Columbia University and other academic institutions that often seek to demonstrate engagement with social justice issues have, however, a history of fraught relationships with marginalized communities in their own neighborhoods. These tensions make public engagement especially difficult.

¶10 It should be of little surprise, then, that local communities are not particularly keen on welcoming academics into their midst when they are known to parachute into "research sites" without interest in long-term commitments with these places. What adds difficulty to building trust is that some communities have indeed had such dialogues in the past. Yet too often, these communities have seen little or no improvements in the public health system or positive outcomes for their neighborhoods. These failures, too, have fueled resistance or even resentment toward the academy. This reason should prompt scholars interested in working with and for the public to think deeply about social action and change, not as aspirational outcomes but as necessary to building trust, both in the present and future. With these pieces in mind, one of the most important things to remember about trust is that it takes time to build (and seconds to destroy, as the adage goes). The aforementioned bootstrapping only appears difficult if you are in a hurry to lace the recalcitrant boot. Taking the time to listen to the skepticism directed at you and addressing it not with counterarguments or protestations but with more time and long-term commitment to help ignite change does wonders.

¶11 What follows is a third and related point concerning the question of consequences and payoffs. Asking community members to share their experiences about issues plaguing them for years, if not decades, such as medical neglect, racial bias, underinvestment, and outright abandonment, requires empathy and humility but also willingness to reciprocate. At its core, the act of sharing and testifying is a form of giving. Every gift, as sociologist Marcel Mauss (2000) reminds us, enmeshes those who receive into forms of obligation to give back. What return could we offer for asking our interlocutors to share their health stories and explain their trust relationship with the medical field? Pledges to increase recognition or raise awareness for the situation of New York's marginalized neighborhoods, though well intended, appeared hardly adequate to honor the emotional labor its inhabitants were asked to make. We learned quickly that the conversation needed to move to the possibility of policy change and social action on the myriad issues reported to us and that this conversation must be a shared deliberation between disparate voices, ranging from nonprofit organizations, local community leaders, policymakers, and advocacy groups to community health workers and the people they assist.

Unlocking Trust: Turning to Those Who Know the Most about It

¶12 In the aftermath of these conversations, we decided to focus on the question of what trust is and how it can be gained and leveraged between medical institutions and patient communities. Our intention was to deliberately "provincialize" the perspectives of scholars, healthcare professionals, and medical leaders, who often reproduce the views of social elites on these questions, and to learn from CHWs directly what trust meant to them in their daily work. This approach followed the precept that knowledge of social phenomena like trust is already available in society. Trust is a category of practice that informs how people conduct their daily affairs and manage their relationships with others. Such “vernacular” knowledge may be less articulated and is often diffused and partial but, when collected and unlocked, it is far superior to approaches that attempt to study trust “from above” (e.g., surveys and trust barometers) as if it were a social scientific concept. CHWs were best positioned to guide our thinking because they are the bridges that connect New York’s neighborhoods with hospitals, health providers, doctors, and city and social welfare agencies (Ballard et al. 2022). Being trusted and trustworthy is written into CHWs’ job description and is part of the many roles they fulfill.

¶13 It should be noted that the intermediary position of CHWs makes them potentially effective messengers if one is clear-eyed about the tensions in this role. These tensions can be visualized as a peculiar trust triangle. To secure trust in the medical system, CHWs must be trusted themselves. Yet, to be trusted by their clients, they may need to distance themselves from the system, thereby undermining trust in it. During the pandemic in New York, CHWs and other mediators were asked to communicate rapidly changing recommendations without having input into their formulation. Loath to risk their own credibility among community members, CHWs were just as likely to align themselves with the patients and highlight their distance from the medical establishment. This was especially true because they were tasked to do all this while cognizant of their own experiences of being sidelined and ignored by medical institutions. As we learned through our project, this positionality is part of the constant and delicate dance CHWs have to perform as they build, maintain, and use trust to improve the health of their communities. Any intervention that seeks to use CHWs as “trusted messengers” must, therefore, recognize these complex social webs within which they operate and translate these insights into proper incentives and, most importantly, genuine consultation (Capotescu et al. 2022).

¶14 To flesh out these ideas, we convened a series of workshops with CHWs across New York’s five boroughs between March and April 2022. We worked with over sixty participants from more than ten organizations in groups and one-to-one sessions to explore ways to present their daily work to a broader public. Our goal was to create an exhibition of stories combining visual and written material into vivid testimonials about the challenges CHWs face as they provide local communities with essential healthcare services and resources. To draw out these different layers, the first workshop of each series featured a training session where our team provided context and explanation about the format and goals of our project. In the second session, we gathered stories from CHWs and discussed them in a group setting.[2] There was an imperative to do this theoretical work in consultation with CHWs because we saw considerable, if unfulfilled, potential in studying trust and contributing to the public understanding of how to rebuild trust in times of crisis. However, we also recognized intellectual discovery did not sufficiently consider the difficult work CHWs were asked to put forth to make this exhibition happen. We learned in conversations with our participants that the act of listening and recording had to go hand in hand with making an impact beyond the academy: elevating and amplifying the voices of CHWs and highlighting the unseen issues plaguing the public health system in New York City.

¶15 To align intellectual exploration and social action, we chose *photovoice* as our medium of public engagement. Photovoice is a participatory action research methodology that conjoins photography and narrative to tell a story about a community, typically to improve the living conditions of marginalized people. Stories developed using this action-oriented methodology are generally related to the assets and strengths of a community, and they highlight the material changes these stakeholders wish to see. Following this rationale, we invited CHWs to take pictures of moments, places, objects, or situations that depicted a trust relationship in their daily work with patients and the medical system. We also asked participants to write brief textual fragments that unpacked and contextualized their stories. In subsequent meetings, we workshopped what was, at first, a loose collection of early drafts into longer essays for our photovoice exhibition. At the end of this process, the visual-narrative methodology of photovoice helped us leverage the power of agency, choice, and voice to convey our participants' unique and authentic experiences. More, the resulting stories refocused the needs and identification of problems away from us scholars toward the needs of CHWs and the wider community. Indeed, photovoice enabled us to make an essential step toward centering the lives of those most affected by the conditions we unearthed that required change.[3]

Images from the exhibition "TrustWorkers—Featuring CHWs at the Frontlines of Public Health," Manhattanville, New York City (June–July 2022).

¶16 In June 2022, our workshops culminated in a public exhibition titled “TrustWorkers—Featuring CHWs at the Frontlines of Public Health.” From early June until the end of July, the collection was displayed at Columbia University’s arts and exhibit space at The Forum in Manhattanville. Twenty-seven CHWs from several organizations across the city contributed nearly fifty pieces to the exhibition, offering a critical window into the lives of an often ignored but essential group of frontline workers in the healthcare system. The photovoice collection highlighted the myriad ways CHWs communicate medical knowledge in culturally resonant frames, how they provide access to vital medical and social services, and how they turn an empathetic ear toward their community’s needs. Crucially, we were able to see better through the eyes of CHWs how they operate at the “access points” of the medical system, the crucial nexus where trust is built or lost. CHWs move in and out of places, relationships, and situations where they encounter mistrust in medicine and science, conspiracy theories, and deeply rooted fears of doctors and medical institutions that they address through their trust-building work with clients and patients. Some of that work, as depicted in many of the photovoices, occurs in clinics and hospitals where CHWs interact with patients. But the brunt of their work takes place in the community: in the homes of patients, where CHWs help clients with applications for food assistance via SNAP and other government-sponsored programs; in community centers and churches where CHWs educate the community; at health booths on the street where CHWs inform passersby about COVID-19 or monkeypox and provide direct access to vaccines; or remotely through telephone assistance and Zoom calls with patients. Although CHWs hold a hinge position as trusted mediators between the medical field and patient communities, many reported that they faced difficult challenges in their work. These ranged from lack of resources, training, pay, and visibility within the hospital system to potential burnout. Many CHWs continue to work in demanding environments where they experience daily suffering and trauma as they help patients navigate a broad spectrum of socio-medical issues. But the crucial question left unanswered by clinics and hospitals is: Who cares for the caregivers? Like many frontline workers, CHWs are expected to carry the burden of neglect and mistrust in the medical system without receiving adequate recognition and commensurate support for their daily contributions.

¶17 To make the material accessible to a broad and diverse audience and facilitate critical engagement with the deficits in the medical system that the photovoices had unearthed, we curated the collection along three themes. The first investigated what trust means to CHWs and how our participants define it. The second focused on how CHWs repair broken or lost trust, a question that had garnered considerable public attention during the pandemic, while the third explored how CHWs use trust to affect change in their communities. The three themes were accompanied by Spanish translations and curatorial materials such as master explainers and topical guides that informed visitors about the exhibition’s rationale, questions, and thematic arrangement. To add a human face to our photovoices, we recorded five dedicated interviews from our group of CHWs. These “video voices” were stationed on three TV displays facing the busy intersection of Broadway Avenue and 125th Street bordering The Forum to engage passersby.

¶18 On June 14, the day of the official launch, the collection opened to an enthusiastic crowd of 150 attendees. Audience members included CHWs from partnering organizations such as BCHN, New York Presbyterian Medical Center, Health People, Make The Road New York, Riseboro, and many others, as well as their families, friends, and coworkers, and representatives of the larger New York community representing the Bronx, Harlem, and other neighborhoods. Our goal for the event was to celebrate the essential role of CHWs in the medical system but also to spur a much-needed conversation about systemic deficiencies in clinics and hospitals and point to opportunities for reform, such as more funding, support, better training, and visibility of CHWs.

Images from the exhibition "TrustWorkers—Featuring CHWs at the Frontlines of Public Health," Manhattanville, New York City (June–July 2022).

¶19 The official event program encompassed a brief segment of speeches from selected stakeholders, including three CHWs, nonprofit health advocates, and policymakers, such as representatives of New York City's Department of Health and New York Presbyterian Medical Center. The speeches were followed by a reception that offered a chance for discussion and exchange. On a dedicated website, the exhibition materials and impressions of the opening night, including an online version of the collection, a short feature film, and the video voices of our CHWs, will continue to engage New Yorkers and a broader audience for the foreseeable future.

¶20 To be sure, it is too early to tell if the TrustWorkers project will lead to sustained changes at the community and institutional levels. What we recognize, however, is that this work provided CHWs with an opportunity, perhaps for the first time, to share their concerns and hopes for reforms in the medical system with a larger public and point policymakers in the direction of change they wish to see. The TrustWorkers project is certainly not the end of a public conversation about frontline workers in the public health system but an attempt to forge a new kind of engagement around this critical issue. At the center of it, in our minds, renewed efforts must be made to rebuild trust and to move those essential to the health and welfare of our city and nation from the margins of institutional arrangements to the center. For us, this work has just begun as we continue to work toward forging sustained modes of collaboration with CHWs through programming and capacity-building initiatives (e.g., microgrants). As researchers, we have learned immensely from this work to understand trust and its necessity. Most importantly, we have come to understand that inculcating trust in public scholarship as a practice is equally important as studying what trust is in theory.

¶21 The TrustWorkers exhibit is currently touring New York City in changing locations and formats and can be visited, day and night, at trustworkers.org.

Notes

1. For an important guide to community engagement, see CTSA Task Force (2011).
2. These workshops also led to the identification of five health priority areas, which were then used to inform a set of seed grants funded by the National Institutes of Health National Institute of Minority Health and Health Disparities (NIMHD 5P50MD017341) to redistribute federal dollars to community-based organizations meeting the needs of Black, Latinx/e, and Indigenous communities long before the COVID-19 pandemic.
3. See also Lechuga-Peña et al. (2021); Leibenberg (2022); and Wang and Burris (1997). This methodology, also known as "photonovella" was developed by Wang, Burris, and Xiang (1996) in collaboration with Chinese rural women, considered "visual anthropologists," to shed light on these women's contributions in the labor force. The foundation of photovoice, or photonovella as described by Wang, Burris, and Xiang (1996), is based on the principles of liberatory pedagogy and praxis (theory and reflexive practice) and culminates in presentation of the findings of the exploration (i.e., data in visual and narrative form) to policymakers with the explicit expectation of changing policy to benefit the community.

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Judelysse Gomez, PhD, is a counseling psychologist. She was born and raised in the Washington Heights neighborhood of NYC and is the daughter of immigrant parents from the Dominican Republic. The philosophy informing Dr. Gomez's work centers on the understanding that individuals' lived experiences are influenced by the contexts in which they are embedded. Her experiences, both personal and professional, have informed her passion for trauma-informed anti-racist/anti-oppression, empowerment, and liberation-focused community-based participatory action and psychological understandings. This cuts across her community, clinical, research, and consultation work, as well as her mentoring and teaching. Dr. Gomez transitioned out of the tenure-track assistant professoriate during the "Great Resignation" of 2020/2021 and is currently Program Director of Community CONNECTOME at Hunter College.

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Citation

Capotescu, Cristian, Elizabeth Cohn, Gil Eyal, Judelysse Gomez, Jack LaViolette, and Danielle Lee Tomson. 2023. "The TrustWorkers Project: Challenges and Methods of Building Trust into Public Scholarship." *Public Philosophy Journal* 5, no. 1. https://doi.org/10.59522/CIOU2388.