

Beyond the Manuscript: Critical Reflections on This Historical Moment for Community-Engaged and Participatory Research

Ysabel Duron, Milton “Mickey” Eder, Leo S. Morales, Keith Norris, and Linda Sprague Martinez

Welcome to *Progress in Community Health Partnerships*’ latest episode of our Beyond the Manuscript podcast. In this special episode of Beyond the Manuscript, Associate Editor, Linda Sprague Martinez interviews Ysabel Duron, Milton “Mickey” Eder, Leo S. Morales, and Keith Norris, four of the eight authors of the editorial, “Critical reflections on this historical moment for community-engaged and participatory research.”

Linda Sprague Martinez: Welcome, everyone, to another episode of Beyond the Manuscript. I’m Linda Sprague Martinez and today I’m here with four authors, Mickey Eder, Leo S. Morales, Keith Norris, and Ysabel Duron, who have written a thought-provoking editorial, “Critical Reflections on This Historical Moment in Community-Engaged and Participatory Research,” that will be featured in our issue 17.4. I’m going to start us off by asking each of the authors to introduce themselves to our audience. And so maybe, Mickey, we can start with you and you can pass it off to your coworkers?

Mickey Eder: Sure. I’m Mickey Eder. I’m an Assistant Professor in the Department of Family Medicine and Community Health at the University of Minnesota. And Ysabel?

Ysabel Duron: Thank you very much, Mickey. Ysabel Duron, the Founder and Executive Director of the Latino Cancer Institute. We’re based in California. Leo?

Leo Morales: Thank you. So, my name is Leo Morales and I am an Assistant Dean with the Office for Healthcare Equity at the University of Washington School of Medicine and codirect the Latino Center for Health, also at the University of Washington. Keith?

Keith Norris: Hi, I’m Keith Norris, a Professor of Medicine at UCLA, and I codirect the Community Engagement Research Program for the UCLA Clinical and Translational Science Institute.

Linda Sprague Martinez: Great. Thank you so much for introducing yourselves to our audience. I’m wondering if we can start just by taking a minute to reflect on your piece, “This Critical Historical Moment,” and a little—maybe you could talk a little bit about your inspiration for the piece and what you’d like readers to take away from it.

Mickey Eder: Sure. Well, as the first author I’ll start but I certainly encourage everyone to contribute because this was genuinely a collaborative effort. And just very briefly, Nina Wallerstein, who is an internationally known community-based participatory researcher/expert in participatory forms of research convened a thinktank for one of her projects, and the majority of us on this call were at that thinktank. And one of the things we were thinking about was how we could contribute to push both federal agencies and our institutions in the direction of not only recognizing the value of the knowledge that exists in

our communities but in developing ways that we could more effectively involve community partners in every aspect of research.

And I also in addition to greatly appreciating the contributions of all the authors on the paper—there are a few who are not participating in the call today due to scheduling conflicts—but just to acknowledge that we received excellent guidance as well from the editorial staff in crafting this. Let me turn it over to some of the others who may want to expand on other reasons why we put this together.

Ysabel Duron: Shall I pick it up as the patient advocate in the room? *[Laughs]*

Keith Norris: Go right ahead, Ysabel.

Ysabel Duron: Well, I'll tell you based on the whole concept of community-based participatory research, which we know has been going on for decades, we finally see that in fact academia is moving towards community as opposed towards community always moving to research. And that's the only way in which I think we're ultimately going to reach that quality and address the disparities that we keep talking about, we keep saying we want to resolve, and we keep saying we're investing in but we really don't see the equity there. And so, I'm really—I know that when the paper was put on the table for edits et cetera I said, "Oh, this is not my bailiwick. How do I contribute? How do I move into the middle of this language that is not mine, that is very academic, and that is very thoughtful and smart? But how do I as a patient advocate, a community member actually interpose our concerns in this paper so that it stands out, that it shines, that it has purpose?" So, this is a constant learning for me, being so enmeshed within academia and its verbiage, if you will.

And I think this is quite frankly where community and why community doesn't get involved, because the language in and of itself is off-putting. We don't know that we're talking to each other in the right way. And I like that the paper itself helped move that. *[Phone rings]* I'm very sorry for the phone, but . . . But that's the way I felt. And I'm always feeling that my brain is growing, my knowledge is also growing, but I also hope that very intentionally our feelings from community are reflecting more and more. And one more point: not just our feelings but in fact those relationships are shifting and changing so that it's bidirectional. It's not academics up here and community down here thanking them for involving us, but in fact we're on the same plane and really contributing each on our own to the answers that we're looking for.

Linda Sprague Martinez: Excellent. Excellent points.

Ysabel Duron: Keith?

Keith Norris: I'm happy to add. So, yeah, there are a couple of things that really stand out. So, you just heard there's really been this push toward community engagement and more true partnership between communities and academia, and particularly over the last 30 years or so in medicine. Prior to that, those activities happened but they happened in nursing, they happened in social work, they happened in psychology, public health, but not in medicine. Medicine was only interested in recruiting people into trials pretty much.

And so, there's really been a shift emerging over the last 30 years of a more purposeful interaction between the practice of medicine and really engaging patients and community members so that their voices are heard and that there's a partnership and a sharing in thinking through what the best solutions are. And for many communities they have an understanding of what's happening in their

community and what the problems are, and we come in—we in academia frequently come in with our impressions but we don't really know. And if we don't ask, then we may be addressing the wrong issue. And the same thing with patients from a patient perspective, if we're not really asking the patient but we're telling them what we think is going on with them. And there are certain things we know but there are other things we don't know. And we have to have their voice and their partnership in this.

And so, one, this has been moving along, and now also there's going to be a new director for the National Institutes of Health. And it appears Dr. Bertagnolli is the emerging candidate, and she has a track record of working in patient-centered research. And so, while there's been clearly a lot of increasing support at NIH, having a leader who actually does that sends a—it sends an important message. And for many of us in the research community it says to us this could be a change where there's now an even greater acceleration with an emphasis on patient-centeredness and community centeredness.

Linda Sprague Martinez: One quick question before we jump forward. Really important points you've made there. And I'm wondering—you made this point around we've seen community-based participatory research—or CBPR—participatory approaches moving forward in other disciplines—in nursing, you mentioned, and social work. What is it about medicine? What do you—I'm wondering why the slow uptake in medicine? And then, what about this critical moment is it that's driving more of a speedy uptake, or why we're seeing it move forward now?

Keith Norris: I can give my bias because I don't really know. I hate to say it, but as a physician we tend to be the most elite, at least in our mind, of all the disciplines. And so, there's much more of a reticence to have this sense that someone else could tell us what might be helpful because we sort of know everything. And that's sort of been the mantra in medicine, that we know it all. And so, I think that goes a long way in the slow uptake in medicine.

And then, the way medicine was structured, there really wasn't the type of regular, ongoing interactions between physicians and community members at least. There was more with patients, but the patient interaction was really just for that—addressing that issue. And the amount of energy that's—that had been given to what the patient has to say had not been, I think, what many patients would like it to be. So, I'm sure there's others. I'll see if my colleagues want to add to that.

Leo Morales: Yes, I'd like to add to that analysis. And I guess the way—I wanted to say first of all I think it's not just a research endeavor within the academic medical home or medical centers. It's really about also the provision of care. And I think all of that needs to move towards more community engagement. And I think much of community engagement was kind of episodic and still continues to be episodic, meaning that projects take someone to a community for a period of time, and often those individuals are not from the community. They come in, they do some research which typically involves data collection, and then they leave. And that leaves a very bad feeling in communities. I can tell you that.

And so, I think the institutions, not just the individual investigators, need to engage with communities on an ongoing and continuous basis and invest in those communities, in their connection to the community. Then research becomes—makes more sense. And I'll—and I think the research itself will be better because there's a conversation that's ongoing. It's not sort of being driven by an RFA, a request for application being issued by NIH. So, I think that all—I think we need to stop talking about recruitment. We need to start talking about engagement and commitment.

I'll add the other piece, I think, that holds us back from truly moving in that direction is our—the way we finance health care. So, we have a market-driven health care system, and health systems respond to those incentives by serving the communities that have the ability to pay for care. And I think—let us—I think—from my own perspective and I think with our—my colleagues here, we're talking about underserved communities, communities that have been marginalized and underserved and continue to be. The market structure doesn't support delivering that kind of care working in those communities because of the reimbursement structure that's in place.

So, I think along with this we need to really talk about how we finance health care, where we put those priorities, and are we really committed to providing care based on need rather than ability to pay?

Yeah, those would be some of my reflections.

Ysabel Duron:

And so, can I pop off the—oh, sorry, Milton. I'm—my old journalism training is always doing a "Let's follow up on that." But responding to Leo, I think part of the problem too is when we talk about shifting the dynamics about how we fund, we're—who's making the decision about how we fund? The community needs to be in—at that table to point to just what Keith said. In a community, with the lived experience they know where money is needed. I tongue-in-cheek say that implementation scientists come to us with a logic model. The community uses logic and goes to work.

So, I think that the lived experience of communities is—can really help reshape the thinking about where there is need, where people are hurting, what are the biggest health issues that need to be addressed. I would really like to see that kind of bidirectional conversation all the time. I am recently engaged in some wrestling actually with the NCI where we—where a project has been funded to look at the environmental impact on pregnant women for long-term impact on babies and around cancer issues. And we think that this is not only unique but necessary for long-term health in particularly communities of color where there's exposure around environmental—different—even neighborhoods where they live or even working in agricultural fields. Either way, it's huge. But it's the NIH deciding what the cutoff should be, what the parameters should be. It is not the community saying, "We want to do this. We think it's important. We're right there with you engage. How can we help? Where's the money?" So, it is necessary. And I keep calling for those equal investments.

And I think what's historical and what Mickey brought out to me in that paper is showing the community voice and its concerns—at least my concerns, since I was one of the folks sitting at that table and putting those concerns in. But someone needs—some nice philosopher said, "Health begins in community, not at the door of the clinician's office or inside Emergency." Right? So, if we're not allowing community to help us to pinpoint those issues that need to be addressed, we'll never diminish risk. We'll never improve health outcomes. We'll just be putting a Band-Aid on the sore.

Mickey Eder:

So, I appreciate that. I want to add a couple of thoughts, not to—really, to refine what's been said by all three individuals who just went before me. And Linda, you asked about the historical moment. And I think one of the external factors that is playing into and helping us define this historical moment is that our language is shifting somewhat from a kind of infatuation with examining problems and deficiencies under the label of health disparities and thinking more about how do we achieve equity and provide not just a set of services that we say in theory are available to everybody but we think about the kinds of services that individuals need.

And when Keith talked about medicine and the issue of physicians interacting with patients and listening to them, I also want to say that there's been a recognition that research itself has moved on

from a very early set of structures, ways of operating, and processes that were focused on discovering new therapies, and we've evolved over time to also include, as Ysabel and Leo were just talking about, research about how we can implement what we've discovered and learn to create better outcomes across the entire population. And I think we have to recognize that our institutions have systems; they've evolved systems. How do we use money? How do we organize research?

One of the things that I hope people pick up from this article is that we have to make a commitment to developing a better infrastructure in the community so that when research is done collaborative with community partners, community benefits as well. It's not just "We want data and we want information and we're going to go away," but we want people—there are skills that are translatable from research into clinical practice, and we want to make sure that as we're out there in the community building a research program that we're enabling the community to have long-term infrastructure and benefits that can have outcomes for everyday clinical outcomes as well.

Keith Norris:

Yeah. And I'll add one more reflection around why now. What has happened—so, we just came—so, we're just coming through this global pandemic, and then we had the murder of George Floyd. And what those two episodes reinforced that was still not widely accepted was the structural inequities in society, and particularly through the pandemic how the structural inequities in the allocation of health and life-affirming resources to different communities vary dramatically—and so, we saw marked differences in the rates of COVID infections, hospitalizations, and death. And so, it said "Wow," as we just heard from my colleagues, we have these vast differences in communities just in health-affirming resources, which are then reinforced with a structure of how health care is delivered and who is able to get health care.

And so, this is an opportunity, we thought, to sort of raise this conversation and make sure the visibility is maintained around the importance of maintaining communication with—and highlighting the real needs that marginalized communities and under-resourced communities are suffering from, and what part we as the medical community could and should and could possibly do to help have an impact. And so, that's, I think, another—I think there's so many things that were going on but all of those—the confluence of them sort of came together and said "This is something we should really talk about."

Ysabel Duron:

And can I pick it up from there, Keith?

Keith Norris:

Please do.

Ysabel Duron:

Because I think you brought up a really critical example of community-engaged response and reaction to a disease within or a health problem within a community. How many communities across the country actually with their community health workers were sent out into community to convince them to step up and get vaccinated, to break down that fear, and to provide the proper information instead of the disinformation? I saw it here in the Bay Area where numbers of Latinos were sent out and some in very scary situations, even in the Monterey County, which is highly agricultural and where farm workers who didn't even speak Spanish, much less English, and who were trying to understand what the issues were. With the dispersal of these community health workers out into these communities geographically zip code by zip code and attending to the basic need of the community to start with, which was information, we did not see the public health care system or the comprehensive cancer systems sending their people out into the community. It was the community itself doing the work.

There was investment from the federal government as well as from public health to hire and train, and this is how I see a partnership working.

And if you build that out and you keep those people at the table, not only for these pandemics but for all health issues, you're building this long-term, cohesive partnership that really can make a difference in the lives of the people who need it most. And I fear that despite this fabulous example they've returned to normal. And one of my colleagues was heard to say, "We can't return to normal because normal is what got us here in the first place."

Keith Norris:

Well said.

Leo Morales:

I'm just thinking—one of the contrasts that we saw just recently with this is free COVID shots but flu shots cost you something, and cost you enough that they can be prohibitive for families, larger families. It's—that's the juxtaposition. The old: Let's charge. The new: Let's do the right thing. Let's vaccinate people regardless of their ability to pay without a lot of questions. Both are important illnesses to prevent and it just—the contrast was just amazing.

Mickey Eder:

So, let me just add one thing, Linda, and sorry if I'm jumping in here. We really need a health care system that has a more sophisticated approach to economics. We can't use short-term thinking and really develop a health care system that's focused on prevention. Even some of our research programs are not long-enough-term to determine whether or not some of the public health initiatives that we should be putting forward—around cardiovascular disease, for example, which has often a ten-year risk outlook. If we really want to think about how we change health outcomes in the country, we have to be willing to say we're going to spend money now that we may not see the outcome for in three to five to maybe ten years. But the returns can be immense.

And we can't consider—we can't continue spending almost one out of every five dollars of GDP on health care and think that it's a sustainable model and that it's really going to transform public health. Ysabel said it: If we keep doing what we're doing, we're going to be in the same place we are right now.

Linda Sprague Martinez: Definitely.

Mickey Eder:

So, we need a different way to think.

Leo Morales:

So, I was—I'd like to just share: I was in a conversation with a funder and we were having—this was actually being convened by the State Department of Health and we were talking about recruitment into clinical trials, and I'm trying to push the conversation towards community engagement. And the funder said, "Well, we have to fund research and so we would need to talk about a different bucket of money for community engagement." And I thought that was just so telling. We need—actually, community engagement is necessary for research. And that's the paradigm shift. It's not like "Oh, there's science over here and then there's community engagement over there." You do good science, the kind of science we're talking about, translational science, health science, it's about communities. It has to be. And we need to—people need to start thinking of that as one thing rather than two separate things.

Ysabel Duron:

And that's why, Linda, I think we also need—as part of a historical shift in thinking, we need to rethink the funding mechanisms by the federal government. Every time you look at an NCI grant or an NIH grant it always requires the researcher to lead. And I say what about the community leading the research question and bringing those guys with to help us prove our model, to create an evidence-based

response so that we can then scale it out and put it out to our other communities? “Hey, this is tested and true and you can do it in your backyard?” But we can’t seem to get government to think past the research. So, once again, it’s snobbery because you have—sorry, guys—because you have the Ph.D. and the M.D. you know best. But it is people living with the disease who really know where the gaps are in service, what the pain is, and what would be a good response to it.

We’re seeing that in some of the research we’re doing—once again, in Monterey County—with patients who went from five years, Spanish-speaking patients who went for five years without really understanding their cancer diagnosis. We put in Spanish language patient navigators and within three months they were asking their doctor new questions. They were feeling heard. And we were responding to external issues that they needed, like food, like transportation, like access even to telehealth—how to use it, what to do with it, why was it critical?

So, it isn’t always just what you learn in the doctor’s office and what the doctor learns about the patient; it is what’s those extremal factors that are impacting and exacerbating those health disparities? And until we address the whole, both the community and the patient in the 360-degree model, we’re not going to change. But we need it from the top. And so, that’s where I think the institute is trying to push, at the—I don’t like the sausage-making but I suddenly recognize you can help one patient at a time. But if you do not change systems and policies you’ll never get—and Mickey already pointed it out—we’re never going to get to the other side of the rainbow where people are really, really having good help and we’re not spending so much money on it. I’m all for prevention. Yippee! Let’s do it! *[Laughs]*

Keith Norris: And Ysabel, to your point about the perceived expertise, there’s two terms my community partners and colleagues have used. One is the “Ph.D. of the sidewalk.” And the other is the “WMD,” which is a “what matters degree.”

Ysabel Duron: Oh, there you go. I love those. I’ll put those in my lexicon.

Linda Sprague Martinez: So, what I’m hearing, I’m hearing a lot of great things and I think our readers are really going to enjoy your piece. People in communities know what they need to be healthy. We need funders to start recognizing that and to rethink the way that they’re funding and thinking about how do they—instead of focusing so much on researchers, focus on centering communities and that good research is community-engaged participatory research, and that we really need to pull the market out of this process and that we can’t let the market drive what we are doing in that sense. I really appreciated that point and thinking about the political economy and how that is influencing what we’re seeing as well.

Any final thoughts from you all?

Ysabel Duron: Let Mickey wrap.

Linda Sprague Martinez: Do you rap?

Ysabel Duron: Wrap.

Linda Sprague Martinez: Oh, wrap up.

[Laughter]

I was like “Wow, they’re really good.”

Ysabel Duron: W-R-A-P.

- Mickey Eder:* I don't think you want to hear me rap.
- Keith Norris:* Wrap up.
- Linda Sprague Martinez:* Okay. I was like "Wow."
- Ysabel Duron:* He's going to tie the ribbon around it. That's what I was saying.
- Mickey Eder:* Yeah, no. Let me just say that I hope that the professionals that we have in some ways been criticizing can remember that an important part of education is to continue to ask questions and to question our own assumptions and our own understandings of the world. And I think we are at a moment where there is hopefully an increased recognition of the value of expanding those involved in conversations so that we can be somewhat self-critical and self-aware and can grow together. And that is really an aspect of education that I think participatory research places in the center and that we really have to continue to return to.
- So, that's how I'd wrap it up.
- Linda Sprague Martinez:* Great. Any others? That's it? You got a thumbs up. Okay. Well, with that I would thank each of you. I would encourage our audience to take a look at your piece. Again, it's going to be in Volume 17.4, "Critical Reflections on This Historical Moment for Community-Engaged Participatory Research."
- Ysabel Duron:* Thank you.
- Mickey Eder:* Thank you.
- Leo Morales:* Thank you.
- Keith Norris:* Thank you.
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