Listening *For* and Listening *To*: Narrative Inquiry in Pandemic Health Communication

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Stories and narratives play an increasingly important role in healthcare contexts. While much work in writing studies and technical and professional communication has explored how stories and narratives can improve healthcare outcomes, increase opportunities for collaboration between stakeholders, and assist in consent and information accessibility, more work is needed to understand how narratives play a central role in facilitating systemic reform. This paper presents the stories of participants in a project about pandemic health communication practices, revealing how narratives aid in identifying the causes and manifestations of healthcare disparities, amplifying marginalized voices, and taking collective action towards a future of equitable healthcare amidst an ongoing public health crisis.

Methodologies that center stories and narratives have a long history in writing studies (Barton & Barton, 1988; Jones, 2016; Vealey & Gerding, 2021; Yam, 2018; and more). Because stories are so effective at communicating complex technical ideas and because narratives provide needed context and depth to complicated situations, they are both effective and efficient communication strategies in settings like healthcare. As such, much research has recently been done to examine how stories and narratives can improve healthcare outcomes (Gray, 2013), increase collaboration between providers and patients (Campbell & Miller, 2023), and facilitate consent and information accessibility (Green, 2021) across the rhetoric of health and medicine and technical and professional communication.

And yet, stories and narratives are not just practically useful; they support a commitment to acknowledging and redressing systemic injustice (Kalodner-Martin, 2022). A narrative inquiry methodology, for instance, asserts that the stories and narratives of people who have directly experienced marginalization should guide—not just support—researchers' understanding of what injustices exist and what actions might be taken to address them (Moore et al., 2021). This requires intentionally listening *for* these stories, rather than just listening *to* them (Mangum, 2021) in order to challenge the space and status that is so often automatically granted to the voices of those in positions of power.

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Given the precarity of patients in clinical settings, particularly those who are multiply-marginalized or underrepresented (MMU) by nature of their race, class, gender, linguistic background, and more, a narrative inquiry methodology can serve as a critical entry point for disrupting the top-down models of knowledge-creation that contribute to patients' silencing and dismissal and compound the risk of physical and psychological harm. Storytelling and narratives also hold particular promise in health crises like pandemics, which often introduce new challenges to the healthcare field while amplifying existing inequities for diverse patient populations (Baniya & Chen, 2021; Joyner et al., 2023). This methodology also works particularly well with frameworks like Black rhetorics of health communication, which emphasizes that lived experiences of marginalization, particularly along racial lines, must play a central role in "understand[ing] and deal[ing] with issues of ethics and health disparities in American medical culture" (Mckoy et al., 2020).

In what follows, I share how listening *for* stories about pandemic health and communication practices has the potential to not only enrich individual healthcare outcomes for MMU patients but can also facilitate identifying and redressing barriers to equitable healthcare that have increased in public visibility throughout the COVID-19 pandemic. I demonstrate this by revealing how participants in this project—a subsection of those involved in a larger study on women's chronic illness communication practices on social media—use stories strategically to share problems, provide context, and offer solutions, all while attending to complex issues like power, positionality, and privilege (Moore et al., 2021) that inevitably shape our healthcare experiences. I first overview the methods that have guided this project, discuss themes that emerged as a result of the data collection process, and describe the opportunities for further research on narrative inquiry's role in technical and scientific environments.

Methods

This project was guided by a narrative inquiry, a methodology that draws from Black feminist epistemologies (Collins, 2008; hooks, 1981; Taylor, 1998) to "encourage an epistemological shift away from the empirical and imperial logics . . . and towards an embrace of lived experience and stories as legitimate and valuable sources of knowledge" (Moore et al., 2021, p. 11). One of the strengths of this framework is its broad applicability, as it reveals both micro and macro experiences of injustice and opportunities for resistance. In studies of health and medical communication, a narrative inquiry methodology helps to destabilize the unilateral influence that quantitative testing and provider evaluation is often granted; by shifting to see stories and narratives as different (but still valuable) expressions of evidence and expertise, the opportunity for collaboration between those who have experienced oppression and stakeholders who are implicated in hegemonic structures of power is opened and embraced. As a result, barriers can more easily be identified, acknowledged, and sustainably resolved. And yet, because power imbalances are not just implicated in *who* is granted the space to speak but *where,* I turned to social media platforms to explore how patients engaged with and produced narratives about coronavirus-related concerns, information, and resources without the institutional gatekeeping that is so dominant in many clinical settings.

Data for this project is made up of two complementary data sets: first, I collected a broader textual corpus of 818 public social media posts from Twitter/X, TikTok, and Instagram, and then I conducted a more focused set of 20 interviews with content creators on those platforms. I recruited interview participants through a combination of direct messaging and snowball sampling methods and conducted the interviews on Zoom or phone, depending on participant preference. I used Rev.com for interview transcriptions, which I then shared with participants for optional edits and addendums. Participants reflect a diverse array of backgrounds pertaining to race, class, disability status, language, religion, sexuality and more, but every participant was required to create public social media content about health and wellness, identify as female, and be over the age of 18. Because dismantling barriers to participation in conversations about health equity was a cornerstone of this project, all interview participants were compensated $25 for their time.

Both interview and textual corpus data was coded deductively to identify initial themes, and of this larger data set, 271 posts and 17 interviews discussed concerns related to COVID-19, including vaccination access and side effects, infection risk, symptom management, and long-term complications. Because the initial goal for this project was to understand how women with chronic illnesses use social media for health communication purposes and the onset of the COVID-19 pandemic dramatically reshaped the landscape of healthcare experiences and concerns regarding medical justice, I then completed another round of abductive coding (Vila-Henninger et al., 2022) to identify how participants understood the relationships between systemic clinical reform and the ongoing pandemic.

Results

After two rounds of coding, separated by a reflective memo, codes coalesced into what one participant, Renuka, described as “a roadmap for COVID equity": identifying disparities, amplifying marginalized voices, and taking collective action. This next section offers three mini case studies from project participants whose insights and work reflect the above themes and grounds suggestions for future research in the work that is already underway.

Identifying Disparities: Tools and Technologies in COVID Care

One of the first themes that emerged across content and conversations about COVID-19 was the confusion and frustration that many people experienced when information about risk, transmission, and interventions changed. One prevalent message, however, was that the best way to understand COVID-19 was to seek information (and care) from medical institutions. However, for Sherelle, who is a Black woman in her mid-forties, seeking clinical treatment for her COVID-19 symptoms served as the impetus for bringing storytelling and medical research together to confront manifestations of medical racism in COVID-19 treatment. As she put it,

> I started talking about medical racism because of my own experiences with COVID, where I went to the hospital because I couldn't breathe. At first they just told me that I was having a panic attack, and then when they finally ran tests, they said my pulse ox reading was fine and to go home.[1] I just knew that didn't seem right and so I was doing some research, and there is all this data about tools like that being inaccurate on Black people . . . So my account had mostly been about my experiences with arthritis before and after that I decided to make a quick pivot and do some educational work for other people, just about what medical racism is and what it looks like, just because I think people would be more mad about it if they knew that it exists.

Sherelle acknowledged that, even prior to COVID-19, the impact and extent of medical racism was just something that "Black people already kind of knew about." However, though she had "heard stories about doctors or other kinds of racist [healthcare] policies, it was always about a person who directly enforced them, but it wasn't a lot deeper than that." Now, by bringing together personal experience and clinical research, she wants her content to "tell a new story" about how tools and technologies employed in COVID-19 diagnosis and treatment can increase disparities in patient experience and healthcare outcomes. Take, for example, her post about pulse oximetry, seen in Figures 5.1 and 5.2.

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[1] A pulse oximeter measures oxygen saturation in the blood. Pulse oximetry is typically conducted by clipping a small device onto the fingertip.

A RECENT STUDY SHOWED THAT PULSE OXIMETERS MAY BE SHOWING INACCURATE READINGS FOR BLACK PATIENTS

Racial Bias in Pulse Oximetry Measurement, The New England Journal of Medicine, 2020

racism.in.healthcare • Following

racism.in.healthcare Pulse oximetry readings are an essential part of monitoring COVID patients-they are used to monitor oxygen levels, which can be dangerously low in some COVID patients.

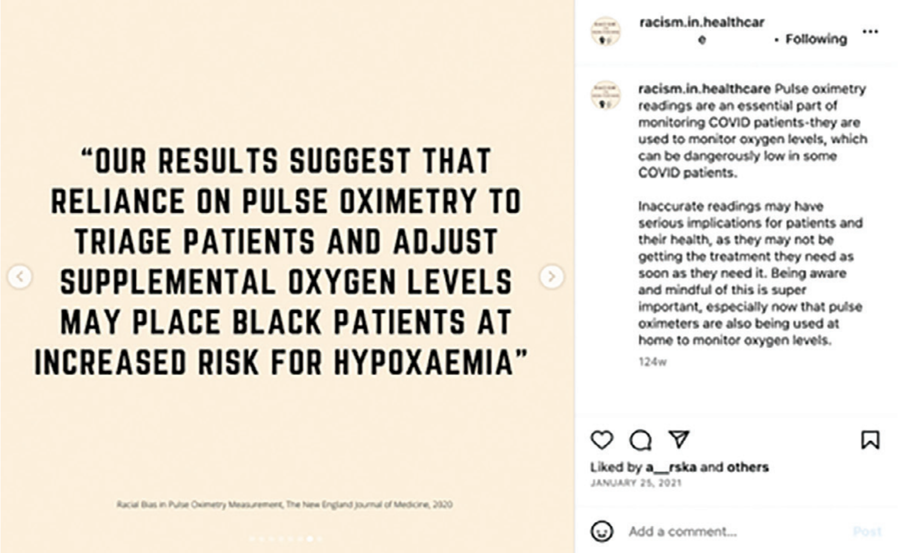
Inaccurate readings may have serious implications for patients and their health, as they may not be getting the treatment they need as soon as they need it. Being aware and mindful of this is super important, especially now that pulse oximeters are also being used at home to monitor oxygen levels.

124w

Liked by **a__rska** and **others**

JANUARY 25, 2021

Figure 5.1. A racism.in.healthcare Instagram carousel post introducing the link between pulse oximeters and medical racism.



"OUR RESULTS SUGGEST THAT RELIANCE ON PULSE OXIMETRY TO TRIAGE PATIENTS AND ADJUST SUPPLEMENTAL OXYGEN LEVELS MAY PLACE BLACK PATIENTS AT INCREASED RISK FOR HYPOXAEMIA"

Racial Bias in Pulse Oximetry Measurement, The New England Journal of Medicine, 2020

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Figure 5.2. Another image from the racism.in.healthcare Instagram carousel post demonstrating the stakes of incorrect pulse oximeter readings for Black patients.

In talking to Sherelle about this post, she noted that:

> The goal here was really to do a few things: explain what pulse oximeters are and why they're important in COVID

> treatment, use the research to explain that they may be giving incorrect readings for Black patients, and hopefully help people see how real and widespread racism in healthcare is so that they will hopefully be fired up and ready to band together and demand some change. . . . I want to challenge this idea that a little medical device can't be racist or that a reading means that someone's life isn't in danger just because of what it said. We're in enough danger as is and we don't need ignorance working against us.

In making this statement, Sherelle continues to challenge the idea that medical devices or quantitative testing is unbiased, instead revealing how one recent study from a medical journal was able to document disparities in pulse oximeter readings between patients of different racial backgrounds. This is because the fingertip pulse oximeter was calibrated primarily on white patients, meaning that darker skin tones may "interfere" with the passage of the light sensor, rendering inaccurate results (Gray, Subramaniam, & Huang, 2023). As such, it is not just because Black patients are more likely to experience discrimination at the hands of medical providers, but because the tools designed for patient care were s*imply not tested with the health or safety of Black patients in mind*. This example reinforces one of the primary challenges of doing racial justice work within health and medicine, which, Veronica Joyner et al. (2023) noted, is that so many barriers to equitable healthcare are "rooted in racism as an embedded, often invisible, practice" (p. 126). Making these stakes and connections clear is thus at the core of Sherelle's work; as Figure 2 explains, incorrect readings may lead to hypoxemia, or potentially fatally-low levels of oxygen in the blood.

It is through revealing these consequences—and the way that racism is embedded into the healthcare system from medical device design down to implementation—that Sherelle hopes to compel her audience to "understand how real experiences of medical racism actually line up with the medical research." In other words, by invoking personal storytelling as a complement to, rather than a detractor of, peer-reviewed clinical scholarship, Sherelle demonstrates that storytelling, particularly on a public account where circulation of content is a primary goal, can be a valuable way to reject biases about medical disparities and reframe public understanding of what medical racism is, its historical roots, and how it manifests in contemporary healthcare practices.

Amplifying Marginalized Voices: Social Media for Social Change

Participants in this project also emphasized the importance of amplifying other marginalized voices to influence systemic change alongside individual stories of discrimination and inequitable healthcare experiences. Take, for example, Chimére, who, like Sherelle, has been active in using her personal social media to discuss race-based disparities for women with endometriosis but shifted her platform to focus on the intersections of racial injustice and COVID-19 after being diagnosed with long COVID in early 2021. Also like Sherelle, Chimére is a Black woman who has long valued storytelling from what she calls her "Black elders" in making decisions about health, safety, and risk. When it came to her diagnosis, Chimére noted:

> I just wanted to hear from other Black women about how they handled it, who they talked to, what resources were helpful . . . and then I realized that our voices were hard to find. So I was like, okay, I have a little bit of a following already. I can start sharing my story and actually create the space for other people to do the same. A lot of voices are louder than one.

As seen in Figure 5.3, Chimére used Twitter to directly reference the Western healthcare system's long history of racial disparities and dismissal in care outcomes and connects it to her observations regarding whose voices have been amplified in COVID conversations. In talking about this post, Chimére also reflected on the stakes of hearing these stories: "It's not just having long COVID voices; it's about having the ones that can talk about what it's like to be Black and a woman and have long COVID at the same time because that might be more applicable for someone whose already at risk for being unbelieved than advice from people who don't know what that's like." In other words, Chimére reflects an awareness of how intersectionality shapes healthcare outcomes and perceptions of safety and risk in clinical settings, connecting the ability to access stories from other vulnerable patient populations as particularly critical for disrupting patterns of silencing and harm that are most keenly experienced by those already at disproportionate risk for poor healthcare outcomes.

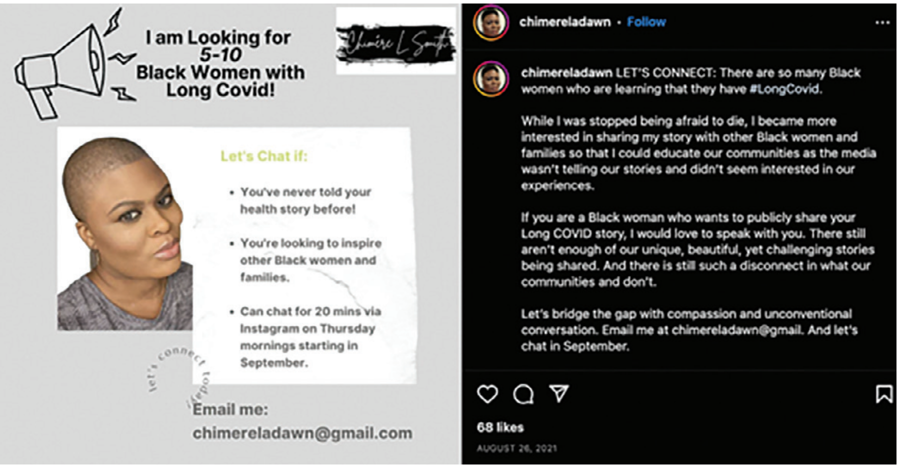
Chimére L. Smith
@chiluvs1

Is anyone else afraid of the lack of black women voices in #longcovid conversations? If anyone knows how challenging it is to be heard by doctors, it's us. From fibroids to infertility to cancers to endometriosis, we already have lived being disbelieved.

7:55 AM · Aug 23, 2020

211 Retweets **17** Quote Tweets **811** Likes

Figure 5.3. Twitter user Chimére Smith calls out the lack of Black women's voices in long COVID discourse.



I am Looking for
5-10
Black Women with
Long Covid!

Let's Chat if:

- You've never told your health story before!
- You're looking to inspire other Black women and families.
- Can chat for 20 mins via Instagram on Thursday mornings starting in September.

Email me:
chimereladawn@gmail.com

chimereladawn · Follow

chimereladawn LET'S CONNECT: There are so many Black women who are learning that they have #LongCovid.

While I was stopped being afraid to die, I became more interested in sharing my story with other Black women and families so that I could educate our communities as the media wasn't telling our stories and didn't seem interested in our experiences.

If you are a Black woman who wants to publicly share your Long COVID story, I would love to speak with you. There still aren't enough of our unique, beautiful, yet challenging stories being shared. And there is still such a disconnect in what our communities and don't.

Let's bridge the gap with compassion and unconventional conversation. Email me at chimereladawn@gmail. And let's chat in September.

68 likes

AUGUST 26, 2021

Figure 5.4. Instagram user Chimére Smith solicits patient stories from Black women with long COVID.

It's this gap that led Chimére to her work in amplifying Black women's stories, first on her own Instagram page (Figure 5.4), and then through her documentary project, *Black and Unbelieved: Finding #LongCOVID Care in Ancestral Care.* In this film, she is working to amplify the experiences of other Black women with long COVID to share how "racism props up the healthcare system and vice-versa, and how Black women have to find all these creative and alternative means to take care of each other's brains and bodies" both inside and outside institutional medical settings. Like her social media posts refer to, her desire to take on this project came out of her awareness that only some long COVID experiences were being circulated by media outlets (which, especially early in the pandemic, played a pivotal role in providing access to rapidly-evolving COVID information) and that the lack of diversity in stories at the intersection of chronic COVID complications, disability, and racism was further contributing to healthcare disparities for Black and Brown women. While Chimére is currently engaging in documentary crowdfunding at the time of this writing, she still maintains her own social media pages and runs an Instagram broadcast channel called Black Babes with #longCOVID to "make sure that there are always options for getting someone's voice out there because you never know the impact that a story is gonna make in someone's health journey."

Though Chimére is the only project participant who is working on a film, other participants have used similar creative rhetorical strategies like digital and print publishing, podcasts, YouTube channels, community event organizing, and more to amplify the perspectives of those grappling with the risks and complications of COVID. These efforts all begin by acknowledging that silencing is both a symptom *and* perpetuation of healthcare inequities, and as such, that amplifying marginalized voices can offer a richer and more holistic perspective regarding what healthcare inequities exist, the efforts that people have taken to redress them, and whose voices—and knowledge—matters.

Taking Collective Action: Partnerships Across the Medical Care System

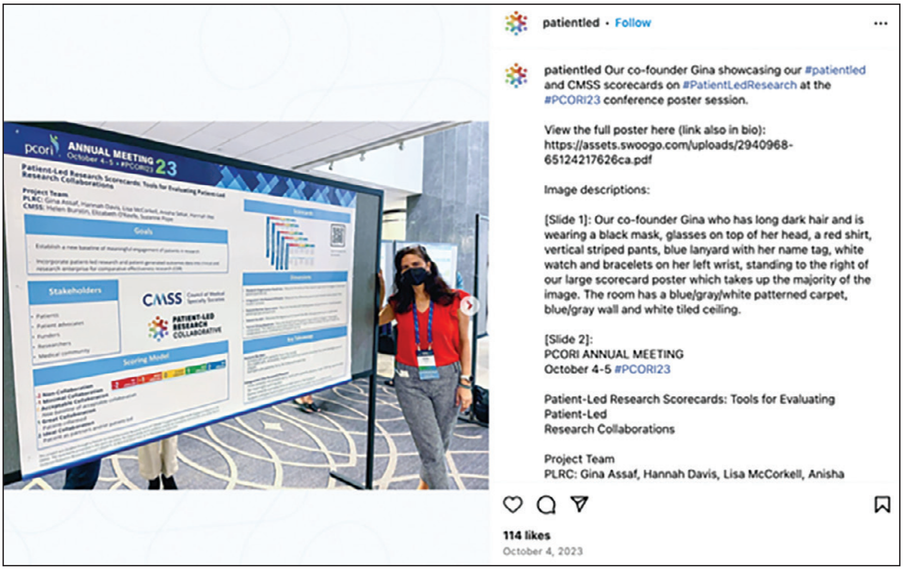
Though participants like Chimére make it clear that participants in this project are invested in building and maintaining community with other patients, they also reflected on their investment in collaborating with medical professionals and other stakeholders to *collectively* work towards health justice. This is for two primary reasons: first, participants understand that medical equity is a multifaceted goal, comprising of direct patient care, policy, medical research and development (R&D) and more; as such, working with stakeholders across these different areas has the potential to facilitate more holistic interventions. Secondly, participants also recognize that, as Lisa put it, "we're not the most powerful people in the room, so if we can work with the people who have that authority, we can get more done." In other words, using stories to foster collaboration also serves as an effective strategy to circumvent barriers with legitimacy that patients often experience when identifying healthcare disparities and working towards sustainable, systemic change.

This is something that Lisa, a white, disabled, and queer patient activist and disability rights lawyer knows well. Like Chimère, she was diagnosed with long COVID in 2021 after six months of persistent symptoms and noted that, even though patients were the ones who "facilitated" the prevalence of long COVID conversations, their voices and expertise were absent from much of the clinical scholarship and funded projects that determined the trajectory of COVID-19 research. As such, she, alongside a team of other patients with long COVID and professionals in areas like biomedical research, cognitive science, machine learning, and more, formed the Patient-Led Research Collaborative for Long COVID (PLRC). As Lisa explained, the PLRC's mission is to:

> facilitate patient-led and patient-involved research into Long COVID and associated conditions while following rigorous research methodology, and to advocate for policies that enable patients, particularly the most marginalized, to access care and live with dignity. We ground our work in the principles of disability justice and participatory research methods, and in the knowledge that those who experience an illness are best able to identify research questions and solutions.

Because the PLRC acknowledges that patients' expertise is conferred both by lived experience with illness and their myriad diverse professional backgrounds *and* that this knowledge is fruitful for guiding conversations about necessary interventions, the PLRC works in a wide variety of arenas in which patients' perspectives can enrich clinical practice, research projects, and healthcare procedures. Current initiatives range from an award committee, made up of patients, policymakers, and physicians, that collectively decides how the PLRC's $5 million in grant money will be spent, to a collaboration with the Council of Medical Specialties Societies (CMSS), an international organization committed to advancements across healthcare, to create a scorecard and action plan for patient involvement in research. As Lisa explained, working with CMSS is particularly valuable for calling attention to the ways that patients can be involved in ongoing COVID research and facilitating opportunities for collaboration in other areas of healthcare.

Take, for example, the PLRC's scorecard (Figures 5.5 and 5.6), which awards healthcare research organizations a score from -2 to 2 based on patients' integration in the research process, patient/partner governance, patient burden, and the "readiness" of stakeholders to work with each other. Organizations with a negative score are invited to work with a PLRC advisor on organizational strategies for incorporating patient input, though organizations with positive scores are also welcome to attend. Lisa explained that these sessions include "stories from organizations and patients who have found these partnerships beneficial or from patients about their long COVID expertise. What we really want to emphasize is that these relationships are mutually beneficial."



patientled Our co-founder Gina showcasing our #patientled and CMSS scorecards on #PatientLedResearch at the #PCORI23 conference poster session.

View the full poster here (link also in bio):
https://assets.swoogo.com/uploads/2940968-65124217626ca.pdf

Image descriptions:

[Slide 1]: Our co-founder Gina who has long dark hair and is wearing a black mask, glasses on top of her head, a red shirt, vertical striped pants, blue lanyard with her name tag, white watch and bracelets on her left wrist, standing to the right of our large scorecard poster which takes up the majority of the image. The room has a blue/gray/white patterned carpet, blue/gray wall and white tiled ceiling.

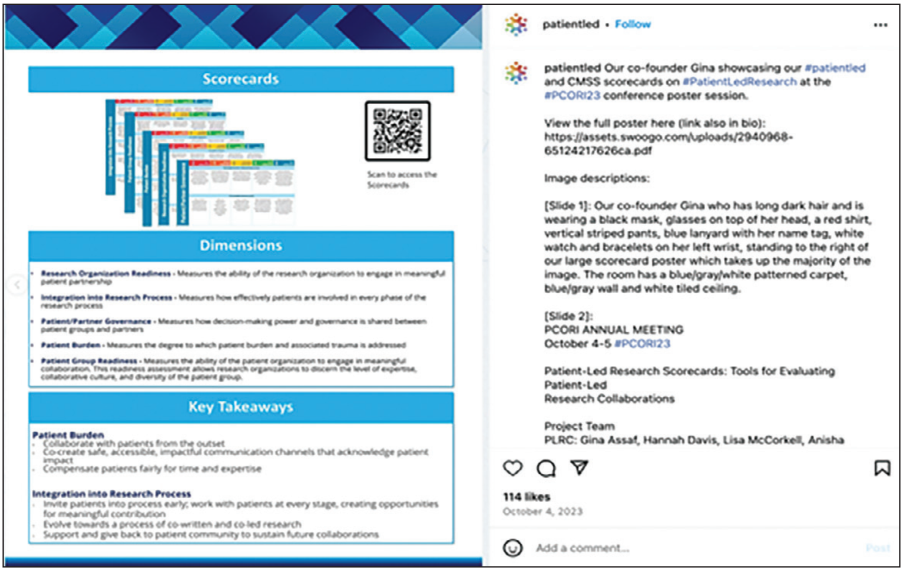
[Slide 2]:
PCORI ANNUAL MEETING
October 4-5 #PCORI23

Patient-Led Research Scorecards: Tools for Evaluating Patient-Led
Research Collaborations

Project Team
PLRC: Gina Assaf, Hannah Davis, Lisa McCorkell, Anisha

114 likes
October 4, 2023

Figure 5.5. A PLRC member, Gina, stands with a PLRC-CMSS poster at the Patient-Centered Outcomes Research Institute (PCORI) 2023 Annual Meeting.



Scorecards

Scan to access the Scorecards

Dimensions

- **Research Organization Readiness** - Measures the ability of the research organization to engage in meaningful patient partnership
- **Integration into Research Process** - Measures how effectively patients are involved in every phase of the research process
- **Patient/Partner Governance** - Measures how decision-making power and governance is shared between patient groups and partners
- **Patient Burden** - Measures the degree to which patient burden and associated trauma is addressed
- **Patient Group Readiness** - Measures the ability of the patient organization to engage in meaningful collaboration. This readiness assessment allows research organizations to discern the level of expertise, collaborative culture, and diversity of the patient group.

Key Takeaways

Patient Burden

- Collaborate with patients from the outset
- Co-create safe, accessible, impactful communication channels that acknowledge patient impact
- Compensate patients fairly for time and expertise

Integration into Research Process

- Invite patients into process early; work with patients at every stage, creating opportunities for meaningful contribution
- Evolve towards a process of co-written and co-led research
- Support and give back to patient community to sustain future collaborations

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Figure 5.6. A section of PLRC-CMSS poster, detailing the scorecards, dimensions, and key takeaways.

What Lisa reveals is that, in the case of this initiative, stories—whether from patients who can contribute to external work in health and medical research, policy, and practice or from organizations that have benefited from such partnerships—serve a critical role in acknowledging and disrupting in the same imbalances of power that continue to place patients at risk. And yet, Lisa also pushes back against the idea that patients are the only group invested in clinical reform. As she shared, "So many people we talk to care so much about healthcare equity and see COVID as an opportunity to make a lot of headway in this area. So it's exciting, in a way, to hear their stories about the knowledge they have, what they bring to the table, and what we can really do when more people can share and actually get listened to." In this way, stories do not just represent the *outcomes* of successful partnerships, but also are the method through which various stakeholder groups can share knowledge, decide on goals, and facilitate taking collective action. Notable examples from the last year include translating COVID-19 vaccine resources to eleven new languages, facilitating a "vaccine on wheels" bus to travel to encampments for people experiencing homelessness, and drafting patient education materials for long COVID management and treatment options.

Each of these cases represents how different kinds of professional and personal expertise can facilitate health equity. Though the PLRC explicitly approaches these partnerships by working with those in diverse medical arenas—including, but not limited to, direct clinical settings, research labs, insurance companies, and state and local policy—the central goal of using stories to redress areas of healthcare disparities is reflected across other participants in this project. Like Sherelle and Chimére also refer to, stories, whether told on Instagram, documentaries, or medical conferences, represent vast rhetorical possibility for taking action against injustice or, as Lisa put it, "even knowing that there is work to be done."

Conclusion

Though these are just three examples, they demonstrate how participants in a study of online health communication practices used storytelling to reveal the causes and manifestations of injustice, to push back against silencing that compounds the disproportionate risk of harm for MMU patients, and to facilitate taking collective action through sustainable partnerships across the medical system. And yet, as COVID-19 continues to evolve and circumstances surrounding health crises and risk persist, research is still urgently needed to attend to the role stories and narratives play in identifying and redressing these uncertainties. As Baniya et al. (2022) noted, there is a dearth of scholarship that examines COVID-19-related research in transnational contexts, while Campeau's (2022) research further emphasized the need to investigate how patients navigate the tensions between mitigation efforts, such as vaccination, and their experiences of marginalized identity and structural precarity (Mckoy et al., 2020).

While these also represent fruitful places for ongoing examination, participants in this project demonstrate listening *for* stories, particularly in spaces that are overlooked in conversations about what knowledge "counts" in health and medicine, is one way to begin centering local needs, circumstances, and expertise in the pursuit of justice, equity, and inclusion—both inside and outside the clinic.

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