DATA FEMINISM

5 Questions on Data and Birth Justice with Kimberly Seals Allers

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By Catherine D'Ignazio with editing by Isabel Carter

Kimberly Seals Allers is an award-winning journalist, author, and internationally-recognized advocate for maternal and infant health. Specifically her work focuses on breaking down structural barriers to health equity for women of color, including Black and Indigenous women who are three times as likely to die of pregnancy-related causes as white women. In her words, Seals Allers is on a mission to end this disparity by shifting the narrative around and empowering those most impacted to claim their place in the conversation. I met Seals Allers at the first Make the Breast Pump Not Suck Hackathon at MIT in 2014, engaged her as a keynote speaker and advisor for the second breast pump hackathon, and have been, generally speaking, a major fan girl of her participatory, equity-focused approach to healthy birth outcomes.

Seals Allers' work has now led her to collaborate with her 15-year-old son, Michael, on a data-driven app and web platform called "Irth." The name comes from "Birth" but with the B for "bias" removed. A kind of Yelp for birth experiences, it will allow users to crowdsource information about care providers and how they were treated based on their demographic indicators. We discuss Irth in "The Power Chapter" of *Data Feminism*, however it should be noted that Seals Allers' voice reappears regularly throughout the book. I spoke with her about her work around maternal and infant health in 2018. What follows is a transcript of that conversation. It has been edited for clarity.

What are some of the biggest challenges that you have encountered as you conducted this research?

One of my early experiences with understanding data, particularly as it relates to maternal health and communities, was when I first started my Kellogg project [the First Food Friendly Community Initiative] seven or eight years ago. I had this idea that we needed to better assess the community environment, which included everything from doing a media scan to literally surveying community folks around what they thought were the barriers. The Kellogg Foundation funded me, and they asked me to get an academic partner, and despite my backing it was incredibly challenging to find anybody to work with me. They said this was not research. Eventually, I found an academic advisor, but even our relationship was strained due to their skepticism about my work. I heard from many people that this was not research, and this is not really what data collection is.

So talking to people in a systematic way is not data collection? Why is it that only the numbers of the data are the things that move people as opposed to the narratives of the data? That's a question that has been an ongoing theme in my research in communities. Helping people to value what the community was saying versus this idea that the only valid research came from an academic institution or the health department or the CDC. It's extremely dangerous when what the community people are saying is considered unimportant.

I think a big part of this issue is stepping back to this framework of what is scientific data collection? Even though I may not always understand its underpinnings, I know it disproportionately harms communities of color, because their perspectives are not considered valid when it comes to developing solutions. Since that project, I've been on this quest to amplify and validate experiential data, the community data, the ideas that we know and the lived experience that is not so easy to quantify.

That's very interesting and something that feminist data science would also want to challenge. The idea that quantitative data is better than qualitative would be considered a false binary because they're different things that we would need to recognize as such and value for what they each bring to the work. What do you think about that?

One of the things I always say that gets me in a lot of trouble is that the hierarchy of data is a social construct. Like racism is a construct. Someone has decided that this type of data or this type of science is better than others, and if you go through history it was pretty much a group of old white men at the end of the 19th century, right? So this idea that there's a hierarchy of knowledge, which is really about power, and how that continues systems of oppression definitely gets lost. There is a hierarchy around knowledge, and research, and data, but that's a social construct someone made up, just like someone made up this idea that one race is better than another. I constantly try to bring that up to people which feels uncomfortable for them to be compared to racism, but it's the same.

In other words, it's a hierarchical value statement. So let's talk about the work you do in contrast to that. Tell me about how these ideas have informed your process with Irth.

So let's talk specifically about maternal health. I've also been very vocal that the statistics that are — rightfully — creating awareness around the Black maternal mortality crisis are also contributing to this gloom-and-doom, deficit narrative, and I'm very much against that. I think that data has a purpose, but the research that we have is all about the problem. None of it is about the solution. Actually, people are using the data to mystify the solutions when we know what the solutions are. This is where data has served a purpose, but there's an important tipping point that we have passed, and now it is just contributing to a deficit narrative where Black women need to be saved.

White people are like, "How can we save Black women?" And that's not the solution that we need the data to produce.

The mess that got us here won't get us out of this mess. That's really important.

Thinking about that as I've been working on Irth, there have been two things that have been really, really important to me. For me Irth is another tool to lift up experiential data. It's another way to look into the lived experience of women around birth and the time thereafter, and to turn that into something quantitative that can be used as a tool for change. The goal is to have all these experiences and to create a repository of those experiences, and then find trends, and turn that into something that we can now use as a tool for change. So listening to these experiences is actually the key to fixing the problem and addressing bias.

However, history tells me whenever we mixed technology with communities of color, there was harm. So the very first thing we have to do is make sure the data we're collecting does not do harm. That's a process that we need to be thoughtful about, and I wish more people would be thoughtful about, because many times there are these external goalposts and things to do — whether it's publishing in academic journals, a business meeting, or meeting revenue targets — that ends up in communities being harmed. That part is really important to me, and I have specifically sought grant funding instead of venture capital to make sure we have the time and space to make sure that our processes do not cause harm to communities we want to serve.

Who is your target audience and what are some of the specific outcomes you want to see from this data? Do you ever see yourself sharing data with people who are doing policy advocacy, for instance?

That's a great question. On the front end, the primary market is Black women and birthing people. That is who Irth centers first and foremost so they have a tool for more informed decision making in choosing a hospital or provider. On the back end, the primary audience is hospitals and physicians who can use the specific data in Irth to identify blind spots and make practice improvements. One of the things that's in our phase two for funding is to develop a pilot project with a hospital system where we take the information we've collected in Irth, tell them what we found and work with them to address it.

For me, what I want Irth to become is a market-leading brand around bias-free care. I want physicians to feel good about their Irth review score. They can become like the Airbnb "super host" of the Irth platform, and that's something they can be proud about and that others can learn from, and mothers and families can go into Irth to check [scores before going to see a practitioner.] So it is using collective experiences as a tool for positive change: kind of like crowdsourced peer reviews.

Also, when we think about working directly with systems, what I would like to see is not just a change on the ground, but to have something like an Irth score or Irth set of reviews be included in the pay structure. To be used as part of your professional review, and that if you haven't received good scores on these bias measures, then maybe you don't deserve a raise.

So how do we actually now get this idea into the system and create some accountability mechanisms? That's really where I want to use the data. Particularly, I think the data will also reveal bad actors that need to be called out, which to a hospital system can be dangerous as well. So how do we kind of use it for advocacy? How do we look at how we create institutional change? By pushing for changes within systems. And then also how do we kind of shift the power dynamics of whose data matters? Those are my main goals.

If someone came to us with a specific project that's not technically related to bias, but our data could be helpful within what we have shared, then I'd be happy to do that. The

community is always valued first. Also, Irth will have a content community where people can receive tools around advocating for themselves, and things like that, but if people want to be involved in other types of projects in this area, then we would be able to ask them if they want to participate. But I really want to be respectful of the trust that I'm creating within Irth, because I believe that's our competitive advantage, and that's what our community deserves.

You often bring up deficit narratives in your work as well. Can you explain that and what you're work is doing in response?

First of all, we keep telling the story of maternal mortality from the grave. We have to stop doing that. We are highlighting these women who have died, and we have to start preventing that by sharing the stories of people who actually lived, and let that be a warning.

We have to stop telling these stories from the grave.

I want Irth to be a place that women and birthing people — including same sex couples and gender diverse people — can get educated about what's happening in that experience so that we don't have to be like, "If only we knew what that nurse that Serena dealt with…" Has she been like that to other Black people? How can we know? Think about all the other women that died, all the near misses. We have to empower a place to let people have that information. It cannot be the sole domain of the hospitals, without that data trickling down to the women that are literally being killed by the experience.

Many people are out there doing needs assessments, but I'm always about the strengths assessments. Everybody now knows: don't ask me to talk about needs assessment if you haven't had a strengths assessment in your community. It's not just about mapping deficits and needs. It's also about mapping strengths. Where's the data that shows actually what are the inherent strengths among Black women that can pull them out of this situation? There's plenty of anecdotal evidence around Black women having these very strong social networks, extended family, connections to church, sororities, you name it. Where is that data? How are we looking at what are the strengths in the community that can be used as opposed to what's happening amongst them as if they're just objects?

I talk about bias-free care being a human right, and Irth being the tool for everybody that cares about bias-free care. Ultimately, we'll first help those who are most burdened by that, which is Black women and brown women, but also all marginalized groups, such as same sex couples, transgender folks, all of those can also benefit from this tool. Anyone who's from a marginalized group needs to understand what the experience of people like them is and then use that power for change.

You can follow Kimberly Seals Allers on Twitter [@iamKSealsAllers](#) and Irth on Instagram @TheIrthApp. Seals Allers is proud to announce that Irth recently topped $500,000 raised. She thanks the [California Health Care Foundation](#), the [Tara Health Foundation](#), and the [Grove Foundation](#) for their generous contributions to the project. Read Seals Allers latest pieces on data and the erosion of maternal authority for [The Riveter](#) and on obstetric violence for the [Washington Post](#). She was also recently interviewed by the [British Medical Journal](#) about her work.

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