“Health Equity Rituals: A Case for the Ritual View of Communication in an Era of Precision Medicine”

by
Samuel R. Mendez

A.B. Visual and Environmental Studies, Harvard University, 2014

Submitted to the Program in Comparative Media Studies/Writing in Partial Fulfillment of the
Requirements for the Degree of Master of Science in Comparative Media Studies
at the Massachusetts Institute of Technology

May 2020

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ABSTRACT

This thesis explores the meaning and implications of a ritual view of communication in the field of public health. This thesis uses the budding field of precision medicine to frame arguments and discoveries, referring back to the Precision Medicine Initiative in chapter introductions, conclusions, and illustrative examples throughout. The introduction presents the script for an interactive online live stream performance summarizing this thesis. Chapter 1 highlights the dominance of a transmission view of communication in public health, which tends to focus on top-down transfer of knowledge from experts to general audiences. This chapter highlights the limitations of such a view, especially when it comes to meeting the needs of medically underserved communities. This chapter highlights the gaps that a ritual view of communication could fill in public health research and practice. Chapter 2 further examines what a ritual view of communication entails in public health, and how to conceive of it in relation to participatory research frameworks. This chapter closes with the design of a conversational tool to help academic-community partnerships employ a ritual view of communication on a project-level scale. Chapter 3 describes the development of “A People’s Guide” community engagement program, employing a ritual view of communication to reconfigure the social roles and power dynamics in public health community engagement. This community engagement program uses workshops and interviews with members of medically underserved communities to publish a zine, which is then the basis of conversation in academic journal club workshops. This chapter uses a developmental evaluation framework to inform the program development process and suggest next steps that can be taken to develop this program further. Overall, this thesis employs a combination of theory, applied media practices, educational field work, and design to highlight the opportunities that a ritual view of communication presents to advance health equity.

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BIOGRAPHICAL NOTE.

My experience growing up in a Mexican-American community in Chicago initially informed my interest in health equity. My college education in media arts combined with research experience in the Viswanath Lab at the Harvard School of Public Health drew me to develop my own questions about how creative arts could be used to advance health equity. Between college graduation in 2014 and starting my master’s program at MIT in 2018, I worked as a video project director internationally, then as a research assistant in the Simon Lab at Northwestern University Feinberg School of Medicine. These experiences made me curious about how to intervene in the research infrastructure that makes community-based research difficult to get funded and taken as seriously as biomedical research. That path of questioning led me to create this thesis. I am moving on from this master’s thesis to a PhD program in Population Health Sciences at the Harvard T.H. Chan School of Public Health. There I aim to develop the methods of this thesis into the start of a line of public health research.

ACKNOWLEDGEMENTS.

First I'd like to thank my advisors: Dayna Cunningham at the MIT Department of Urban Studies and Planning, K. Viswanath at the Harvard T.H. Chan School of Public Health, and William Uricchio at MIT's Comparative Media Studies program. This work would not have been possible without the lenses you offered me to view my work.

I'd also like to thank the members of the Simon Lab at the Northwestern University Feinberg School of Medicine and the ChicagoCHEC 2019 summer fellows. The development of chapter 3 of this thesis would not have been possible without your participation.

Finally, I'd like to thank my family for raising me to be the person I am today. My classmates at MIT for providing support throughout this process. My partner Xiaogao and all of my friends, colleagues, and acquaintances who humored me as I talked about these ideas incessantly for months.

INTRODUCTION ABSTRACT TIME AND SPACE.

In case you weren't aware, I'm writing this in May 2020 in the US, and time has recently stopped working. It's slowed down and sped up, without warning, somehow both at once. It's the same day for a minute, the same a month for a year, and the same hour for a week. Tell me how that math works out. Oh, and how could I forget? The world turned upside down—my eyes are still having major trouble adjusting.

I have more time to cook now, but with these eyes, going to the grocery store is harder than ever. Going anywhere is harder than ever, really. And, ironically, so is staying in. It seems I am having trouble navigating this world now that right is left and up is down. See, when light travels through the lens that is my eye, the journey it takes causes images of the world to hit my retina upside down. My brain flips that image upside down again in order to make sense of it in relation to all the other information it's taking in. So, scratch that. It's 2020 and my eyes are fine. It's my brain that's having trouble adjusting. By my calculations, the upside-down image of an upside-down image of an upside-down world is the same picture my brain has always worked tirelessly to fix. After a lifetime of editing my view of the world to make sense of it in real time, seeing everything so plainly is a shock to the system... especially when real time doesn't seem to exist anymore. But maybe this shouldn't be such a shock. As new as this situation is, I can't help but feel like I've been here before.

I first learned the term "health disparity" when I was 17. I was in an internship program for high schoolers from underrepresented backgrounds in cancer research. A presenter was telling my cohort about the unjust inequalities in health in the US. There was a word for this. People with less money and education having worse health. People living in different neighborhoods having different life expectancies. People of different races having different relationships with the medical system. I grew up seeing the impacts of these disparities in my own family. Someone had health insurance when they needed it, and someone else didn't. Someone had easy access to fresh foods and someone else didn't. And there in front of me in that internship was someone showing me proof that it's not just my family. At 17, I thought the solution was just to get the word out. The situation seemed so atrocious that obviously people just didn't know the scope of the problem. If everyone knew, then obviously we could find a solution. Obviously no one could look at the graphs that a scientist just showed me and then do nothing about it. As it turns out, the link between information, trust, and collective action is not a straight line.

I was 18 when I learned that the term “public health” described a whole field of research. I was interviewing for a spot in another internship program for college students from underrepresented backgrounds in cancer research. I knew I didn’t want to spend my days in a lab, working with clumps of cells that could produce information that might lead to a medicine 10 years down the line if I was lucky. I wanted to help improve disadvantaged groups’ opportunities for health in daily life, and I knew that clinical research could help improve the medical system. So, I tried to let the interviewers know about my interest in clinical research and health disparities. I wanted them to see that I had focus and motivation to perform well if I were just placed in the right lab. The interviewers asked me about the possibility of working in a public health lab. Relying heavily on context clues to guide me through that conversation, I said that would be great. I ended up in a public health communication lab, spending the summer examining social media posts by community-based organizations. During my interview, I hadn’t known that was possible.

Turning 18, moving from Chicago to the East Coast, and learning about the theoretical existence of health disparities from inside the privileged gates of Harvard was one long “Was my world upside-down this whole time?” moment for me. I think it was manageable, though, because time was still working the way I needed it to. It wouldn’t stop until I was 25.

About two weeks after my 25th birthday, I was helping plan the funeral for one of my best friends from college. The 5 months before that were filled with measurements and statistics and big words from medical professionals that couldn’t tell us the answer to the only question we cared about: what’s going to happen? Eventually, the answer came from inside my friend’s body, and the battle metaphors no longer worked. The war was over. The clumps of sick cells won and then died, along with all the non-sick cells whose fates were tied to them. What came next: a surprise two-week stay in another state, a flash move-out from an apartment, phone calls to government offices, dealing with finances, and weird meals. That week lasted a year, each day flew by, and each hour was too long. At the intersection of the ripple effects of that breakdown in time meeting the ripple effects of immigration was a mourning room full of 20-somethings who grew up in the US meeting a handful of older adults who grew up in a different set of borders.

Now, that breakdown in time was wrapped inside another, like a Russian nesting doll. Those same 5 months had previously come for my uncle, except his case ended up lasting for actual calendar years, much to everyone's surprise. The phone calls to government offices and dealings with finances had come much earlier and lasted much longer, but they were preventing the second wave of phone calls and finances that, for a while, almost seemed like they would never come. Against all odds, my uncle was living while my friend was dying. Well, even in a nested series of time loops, it turns out 5 months can't last forever. About two weeks after my 26th birthday, my uncle left this world too. In a world like ours, time has a way of getting back on its feet and marching forward, no matter what else happens. Bills need to be paid. Work needs to be done. Holidays come, and the seasons change, and I end up moving from Chicago to the East Coast again.

After time and space broke down again this year, I moved back to Chicago. And now here I am trying to figure out how to exist in the US in May 2020. At some point, time will pass and the seasons will change and I'll move from Chicago to the East Coast again. As unprecedented as this situation is, I can't help but feel like I've been here before. Problems with phone calls to government offices are in the news. People's bodies give them answers before medical professionals can. Weird meals are on social media. People who want answers to questions that no one can answer stand outside of government halls, looking like they're in the middle of a war. And that metaphor still doesn't work because their fates are tied to those of the sick and the non-sick alike. Sudden move-outs and surprise two-week stays are the new normal. Somehow even more tragically, so are funerals attended by only a handful of family members.

And who is bearing the brunt of this public health disaster? The same people that have long carried the weight of this country's history. The history that manifests in tired hearts and tired lungs in 2020, and that manifested in those same tired organs I learned about when I was 17. But I know better now than I did when I was a teenager. I know that most people will perceive the scientists trying to explain what's going on. Some will understand what they have to say. Some will trust what they have to say. Some will want to return to the ways of life that brought us here anyway, but I truly don't believe that describes most people in the US.

I'm familiar with a lazy critique of a fair amount of work that I look up to: you're preaching to the choir. A younger version of me would want to avoid this kind of work like the plague. Now I know, however, that sometimes a choir needs a preacher and the preacher needs the choir just as much in return. What are any of those community members without each other? Every so often, they need to share in a ritual that signals to themselves and to the rest of the world that they are not alone in trying to live by a certain set of values. Regularly performing the ritual lets other people know where to find them and how to join in. We see these rituals play out online, and we call them echo chambers. Now, I don't know much about singing, but an echo chamber sounds like the kind of space well-suited for a choir practice. (At the very least, it's better than a government office or a clinic.) Carrying out the ritual lets other people know where to find them and how to join in. Again, I don't know much about singing, but my guess is that if you send a scientist to lecture at a choir, they'd be drowned out and ignored at best. At worst, the scientist would become a nuisance getting in the way of the things that need to be done.

In May of 2020, it is stranger than ever to see the way that public health in the US relies almost exclusively on government offices and scientists, and so little on the community leaders, arts, and media that people turn to in their daily lives. In the year-and-a-half I had when time and space worked the way I needed them to, I learned that I don't want to spend my life telling people that their image of the world is upside down. Instead, I want to work with others to create an image of the world we want to see, and figure out how to get there. I don't want to spend my life broadcasting measurements and statistics and big words to people in the middle of choir practice. Instead, I want to commune with others and bend time to our will.

Every day, through art, people make images of worlds that don't exist and bend time to their will. A performer can create a space where nothing else matters but that space they're creating on stage. An animator can string still moments into nonexistent lifeforms. A documentary filmmaker can turn a decade into 90 minutes. Through art, personal stories and feelings become generalizable, shared experiences that can help form a community. This community, in turn, can be the engine of change that draws on the various kinds of knowledge and expertise of its members to make a new world a reality. This is why I try my hardest to bring my whole self to my work in public health. This is why I try to integrate art and design and attention to aesthetics into my academic passions. I know I’m not alone, and I need to let other people know how to find me. Together, we’ll do things that all the graphs, statistics, and big words could never accomplish.

✨ Abstract ✨

The following is the script for my thesis presentation, an interactive live-streaming performance using a camera feed and screenshare of a custom-built website. See Appendix E for screenshots of the performance. My hope is that this performance gave audience members a general sense of the main ideas I am arguing for in my thesis. I also hope that they left the performance with more questions about participatory research, health equity, and/or precision medicine. I also hope that this experience was positive and entertaining, making these topics feel approachable and relevant to their own life experiences. As such, I hope this script performs a similar function in this thesis, providing the broad strokes of my ideas while sparking curiosity.

Who is this?

Hi. I'm Samuel R. Mendez. (I only use that name in writing. This might be the first time I've ever said it out loud.)

This is the script for my presentation of my master's thesis in Comparative Media Studies at MIT. Its title is, "Health Equity Rituals: A Case for the Ritual View of Communication in an Era of Precision Medicine." In it, I experiment with various media as ways to offer insights into public health topics. So, I want to try that here as well. Now let's move onto the part where I tell you what the big idea is.

What's the big idea?

In my thesis, I spend many pages using many ways to support one big idea: communication isn't just about information, but also about social roles. And this has big implications for health equity in the US. Especially in an era of precision medicine.

I use the word "ritual" to describe this view because I like the questions it raises. Who's at the table? How are they expected to act toward each other? Who's in what roles? I think these are important questions to ask in public health. Without them, I think US public health researchers risk unintentionally reinforcing social roles that can harm medically underserved communities.

So I’m 4 paragraphs in, and I recognize there’s already a lot going on. Let’s go over a few key definitions so we’re a little closer to being on the same page.

What do I need to know?

I’m going to ask for some help in reading out these definitions to get us started. [Sam calls on members of the audience to read these definitions aloud from the screen.]

Health Equity. Health equity is social justice in health. It is justice in access to health opportunities for members of historically disadvantaged groups (Braveman, 2014). It is the idea that everyone should have the chance to live a healthy life as they see fit, no matter who they are.

Medically Underserved Community: a group facing societal, economic, cultural, or linguistic barriers to healthcare. This includes people experiencing homelessness, migrant workers, undocumented immigrants, people with low incomes, people without health insurance, people in geographically isolated areas, gender and sexual minorities, Indigenous communities, people of color, and people with disabilities. This is an expansion of the definition of “medically underserved populations” by the US Bureau of Health Workforce (2019).

Precision Medicine. Precision medicine is a budding approach to medicine and disease prevention. It uses data about a person’s genes, lifestyle, and environment to tailor health care. (Lister Hill National Center for Biomedical Communications, 2020). As such, it depends on large amounts of data from a large number of patients for analysis. Right now, the concept of precision medicine is more of an aspiration than it is a specific technique.

Ritual Communication. In public health, a ritual view of communication focuses on the social structures that a communication process maintains. Communication maintains social structures by outlining power dynamics, social roles, expectations, conflicts, and feedback loops. This definition draws on the work of James Carey, Stuart Hall, and Nancy Fraser.

And now, onto the show.

The Show.

The Rules.

This show is called "✨ Abstract ✨" (with an emphasis on the sparkle emojis). This is not my thesis. It's a weird online performance meant to share what I learned through the process of making my thesis. Hopefully, it also paints me as someone who knows what they're talking about when it comes to health equity and public health community engagement.

This show is inspired by the work of The Chicago Neo-Futurists. As such, it's made up of 10 short non-fiction plays that I will try to perform in 25 minutes. I don't know what order these plays will come in. I'm going to need your help for that, so stay on your toes.

There's a lot going on, but hopefully things will become clearer as time goes on. And with that, let's start the timer. [Sam proceeds to call on a volunteer to decide which play to perform first.]

The Plays.

- 💩 "An honest check-in, more or less"
- 👏 "A Moment of Recognition for Barbara Israel"
- 🔊 "Ritual and Transmission"
- 📖 "A People's Guide to Precision Medicine"
- 💻 "A PEOPLE'S GUIDE TO PRECISION MEDICINE: THE DEVELOPMENT AND DESIGN OF A MEDIA-BASED COMMUNITY ENGAGEMENT PROGRAM," or "THE CONFERENCE I MADE THIS POSTER FOR GOT CANCELLED AND I SPENT TOO MUCH TIME TURNING A GOOGLE SLIDE INTO A POSTER FOR NO ONE TO SEE IT, SO GUESS WHO'S HOSTING A POP-UP POSTER SESSION~"
- 🔄 "A KALEIDOCYCLE!"
- 👀 "A zine"
- 💃 "HER Model of Community Engagement"

- 😸 “A taste of a summer workshop”
- 👽 “The Future of All of Us”

Performance Scripts.

💩 “An honest check-in, more or less”

This is a really weird time. There’s a pandemic going on. I’m living with a nagging underlying fear for my family and for the community I grew up in. Yet somehow I’m still working on my thesis and pouring hours upon hours upon hours into perfecting my virtual island in Animal Crossing. I’m happy about the prospect of graduating this spring and excited about starting a PhD program in public health in the fall.

I feel the need to be in public health now more than ever. The coronavirus is shining a heartbreaking light on systemic issues. The burden of infection and death that black communities across the country are bearing right now is the result of generations of injustice. The danger that uninsured and food-insecure communities are facing right now is an escalation of risks they have long been forced to take. I see the harsh reality of the state of health disparities in the US.

Yet I also see generosity, resilience, and advocacy that point to the path forward. One day, the state of the US in 2020 will be a case study on the public health impacts of social inequalities. One day I might even teach my future students about it. Even then I doubt I’ll be able to talk about it without the visceral memory of bruising my shins against a shopping cart full of boxes, in a drizzle, racing to the U-Haul on Main Street to lock my things away into storage before it closed.

But that’s a little too long of an answer for, “How are you,” so these days I usually just say, “Good,” and I think people get it.

👏 “A Moment of Recognition for Barbara Israel”

The idea of changing the social structures of research isn’t new. There are many participatory research frameworks that do just that. One recognized framework in public health is community-based participatory research (CBPR). CBPR centers long-term partnership with the community being studied, from framing research questions to analyzing and sharing results. One key CBPR scholar in public health is Barbara Israel at the University of Michigan. I draw on her work a lot when I think about what a ritual view of communication can bring to public health.

One key characteristic of academic-community research partnerships is that they require a lot of work that often falls outside of academic job titles and project evaluation metrics. This is especially true when working with underserved communities. At a large scale, I worry that this creates incentives to not work with medically underserved communities or to take a top-down approach, working with community members as consultants.

I think incorporating a ritual view of communication into project planning and evaluation within the National Institutes of Health can bring a more comprehensive view of CBPR and non-participatory research alike. Long-term, I think this can better promote participatory research methods and advancing health equity by recognizing the importance of research that intervenes in typical social structures. I look at researchers like Barbara Israel to find inspiration for these lofty goals. So, I’d like to share a small glimpse of that right now:

[Sam visits the website of the Neighbors Working in Partnership project out of the Detroit Community-Academic Urban Research Center. He describes how it builds community capacity for advocacy and aiming for policy change. He mentions that it’s inspiring to him to think about how categorizing such work as falling within the scope of public health research partnerships might have seemed impossible around the time he was born.]

🔊 “Ritual & Transmission”

Can I get three volunteers from the audience?

We have health expert A, medical professional B, and layperson C here to illustrate health communication. Health expert A, I’m going to send you a message. Your job is to get it to medical professional B. Medical professional B, your job is to get the message to layperson C. I am going to play the part of a health researcher by observing and analyzing this whole process. [The volunteers will hopefully follow the instructions that Sam confidentially passes onto health expert A, aiming to get layperson C to smile and wave at the camera.]

Great. Now, I'm going to examine this process through a transmission lens of communication. That is to say, I'm going to focus on how well my message got from A to C. [Sam will talk about the speed of the process, the accuracy of the message, and the performance of layperson C.] Following from these observations, my recommendations for improvement will focus on the message and how it is delivered. We could take a technological approach and switch to a VR-enable communication system where things like body language We could take a health literacy approach and teach layperson C how to better understand the kind of messages that will come from medical professional B. We could take a cultural competency approach and train medical professional B how to tailor a message more specifically for people like layperson C. We could take a policy approach and have clearer guidelines and definitions coming straight from health expert A so there is little ambiguity for medical professional B.

That was the transmission lens of communication. Now I'll examine what just happened through a ritual lens of communication. That is to say, I'll focus on the relationships and social structures that this process just created. I positioned myself at the outside expert, solely responsible for the outlining of goals and the metrics of success. I defined the process as starting with A, and moving in one direction to C, but maybe we'd all like the outcomes better if C had a chance to say what they'd like to be able to do, and worked with A and B to make it happen. I alone decided what message was worth communicating, without input from the people required to make it happen. What would it look like to repeat this with shared decision making power?

In the real world, obviously, a health communication process isn't quite this straightforward. But one really broad argument I make in my thesis is that there's a lot to be gained from learning how to use a ritual lens of communication in public health. There's a real opportunity for positive impact by learning where there's more room for dialogue and shared decision making around the roles that people get to play and the common interest at hand.

📖 "A People's Guide to Precision Medicine"

[Sam pulls up the website for the zine, "A People's Guide to Precision Medicine". He asks someone from the audience to pick an article that he can quickly summarize. Refer to Appendix A to find all zine articles.]

💻 “A PEOPLE’S GUIDE TO PRECISION MEDICINE: THE DEVELOPMENT AND DESIGN OF A MEDIA-BASED COMMUNITY ENGAGEMENT PROGRAM,” or “THE CONFERENCE I MADE THIS POSTER FOR GOT CANCELLED AND I SPENT TOO MUCH TIME TURNING A GOOGLE SLIDE INTO A POSTER FOR NO ONE TO SEE IT, SO GUESS WHO’S HOSTING A POP-UP POSTER SESSION~”

[Sam gives an elevator pitch of Chapter 3 of this thesis, using an online slideshow consisting of a conference poster, an abstract, and figures from Chapter 3 of this thesis.]

Context: University-based research partnerships bringing together students, professional researchers, and community-based organizations. Examples include U54 partnerships and Clinical and Translational Science Centers.

Resources Online infrastructure for editing, compiling, and publishing zine articles; Student workshop instructor(s) and developer(s); Audio-visual documentation of workshop outputs; Journal club workshop (facilitators) and developer(s); Interviewer(s) and Interviewees for zine articles; Existing partnership infrastructure and staff; Agreement on a health topic of interest

Activities Student workshops; Personal interviews for zine; Zine production; Journal club workshops; Curation/adaptation of educational materials for zine; Zine publication; Launch event; Ongoing evaluation

Outputs # Student workshop participants reached; Workshop curricula created or adapted to local context; # Articles in zine; # Journal club workshop participants reached; # Target audience members reached with zine; # Target audience members reached with launch event

Outcomes Student confidence in discussing and questioning health topic of focus; Academic researcher understanding of community questions and health concerns; Community-based organization concerns incorporated into partnership work; Network-specific advocacy outcomes

Assumptions: This program rests on the assumption that a functional partnership exists and members are interested in advancing health equity. It also relies on partnership members agreeing on a topic of interest and target audiences for the zine.

Figure 24: Logic model for the “People’s Guide” community engagement program. (See page __ for this figure in context.)

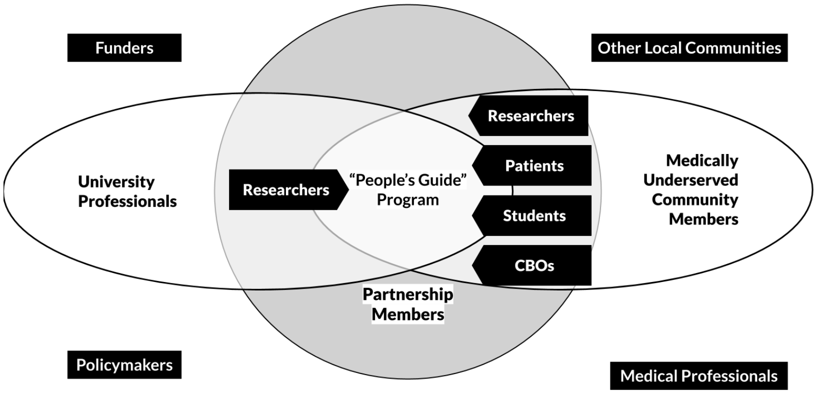


Figure 25: Network map for the “People’s Guide” community engagement program. (See page __ for this figure in context.)

🔄 "A KALEIDOCYCLE!"

[Sam demonstrates the function of the HER model's physical kaleidocycle on camera.].

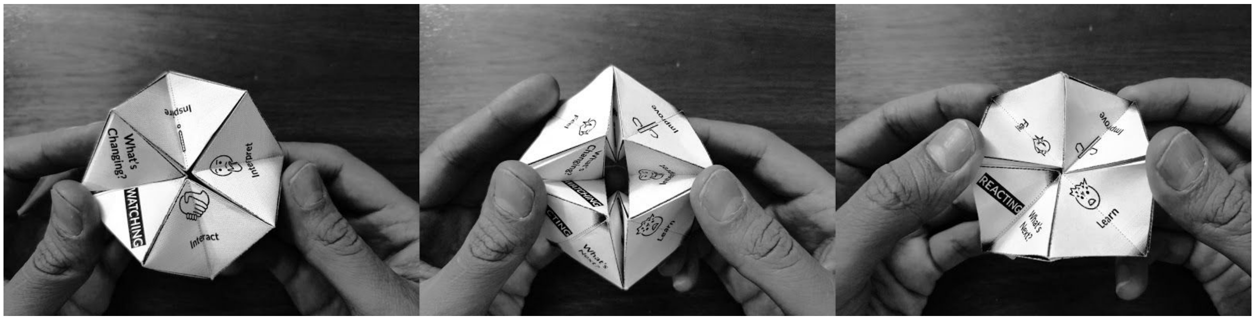


Figure 18: A demonstration of the HER model's kaleidocycle rotating around itself. (See page __ for this figure in context.)

This is a kaleidocycle! I love the way you can just fidget with this thing forever. And it's a model of community engagement on top of that. It's a conversational tool that academic and community research partners could use in evaluative conversations about their work. It divides community engagement into a 4-phase cycle, with different prompts and questions in each one: planning, acting, watching, reacting.

Everyone around the table in this conversation would have their own kaleidocycle with these speaking prompts. This represents the fact that there isn't just one singular objective view that can summarize public health work. It's a social process, and understanding the varying, potentially conflicting viewpoints and priorities within it can lead to a more accurate understanding of its actual impact.

It's meant to help pace a conversation between project partners. The conversation can't move forward until everyone flips their paper to the next phase.

I've saved the exploration of the prompts for a different play. So for now, I'll just say that these prompts are based on theories by Stuart Hall and Nancy Fraser. They highlight the way that different audiences can have different perspectives on the same communication program, as well as the need to surface and discuss conflicts rather than create a homogenous view of public good.

👀 “A zine”

[Sam demonstrates the physical function of the HER model’s zine on camera.]

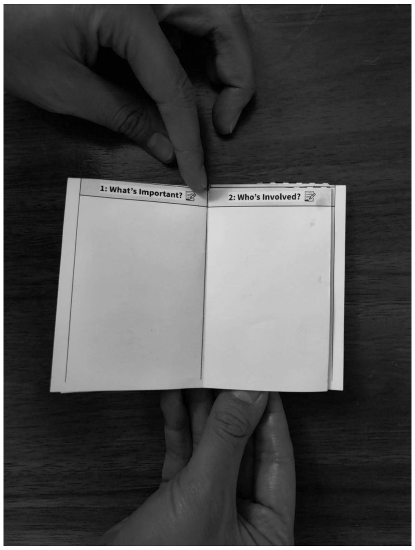


Figure 21: Pages 1 and 2 of the HER model zine. (See page __ for this figure in context.)

This is a zine. It’s meant to help each person in a conversation about an academic-community partnership document an evaluative conversation. It’s made by folding up and cutting an executive summary of an academic-community partnership. It has spaces to take notes on each phase of a 4-phase conversation about a community engagement process, with a built-in break to reflect on the actual conversation. And then at the end you turn it into a zine by giving it a front and back cover. The front cover depicts a success story. And the back depicts a failure.

Each person has their own interpretation of the conversation and of the partnership itself, even in light of standard metrics that might be used to evaluate it.

💃 “HER Model of Community Engagement”

[Sam walks through the phases and prompts of the Health Equity Rituals Model of Community Engagement he developed for this thesis.]

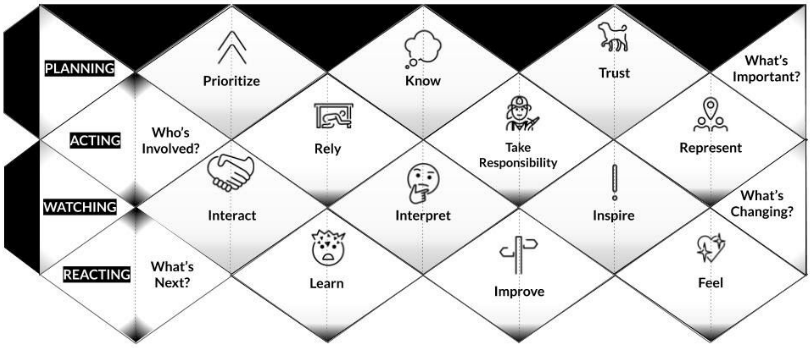


Figure 13: Kaleidocycle portion of the HER model of community engagement. Icons courtesy of the OpenMoji Project. This tool is available under a CC BY-SA 4.0 license. (See page __ for this figure in context.)

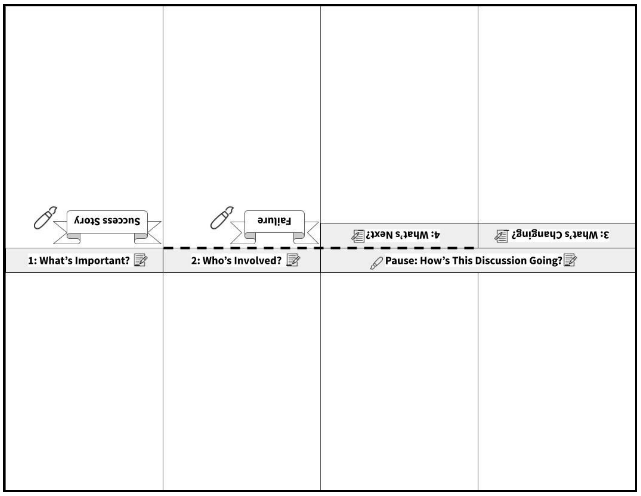


Figure 19: Zine portion of the HER model of community engagement. Icons courtesy of the OpenMoji Project. This tool is available under a CC BY-SA 4.0 license. (See page __ for this figure in context.)

😸 “An excerpt from a summer workshop”

[Sam runs an excerpt from the *#PMtldr* workshop with the audience. See Appendix A for the workshop guide. He asks for responses to this excerpt’s question in an online chat box.]

Section 4: Precision Medicine and Disease Prevention.

So far we’ve focused on precision medicine as an approach to medical treatment. However, precision medicine impacts disease prevention too. Precision medicine might help predict what kinds of people will get a disease in the first place. Again, what does “kinds of people" mean? It might mean a particular combo of genes, environment, and lifestyle. It's hard to say right now.

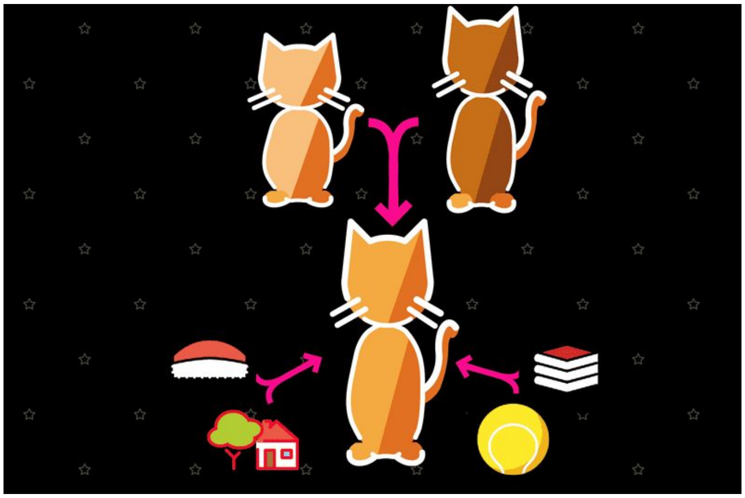


Figure 0: Genetics and environment came together to shape the cat we see today.

But these ideas about disease prediction aren't new. We already use genetic and hereditary information to predict disease and make health decisions. For example, you might know of certain health conditions that run in your family. And tests for mutations in genes related to cancer have been available for decades. However, there's still a lot we can't predict. It's possible we just don't know all of the risk factors for certain diseases. Or, we don't know about specific combinations of risk factors that lead to an actual disease. One of the promises of precision medicine is to help provide more information to make better predictions.

You might be familiar with commercial genetic testing for health. Genetic testing companies can tell you if you have a certain version of a gene that's known to lead to a specific disease. These companies can also tell you if you a have a version of a gene that lots of people with a certain disease also have. Precision medicine aims to go beyond this, incorporating genetic information, lifestyle info, medical history, etc. to better predict whether someone will get a certain disease. The idea is that more info can lead to better predictions for more people.

Ideally, precision medicine can help all people be healthier by providing better predictions about their health. They'll be able to talk with their health care providers about their risks. They'll be able to make informed decisions about their lifestyle and their medical care. However, things probably won't be that simple for everyone.

Question Time.

- We already know that diet and exercise are important to health. We already know that sleep and social support are important to health. **Do you think precision medicine can offer useful information for you to form healthy habits? Why or why not?**

👽 "The Future of All of Us"

[Sam silently plays the "What is All of Us" animated introductory video to the *All of Us* research program. Meanwhile, Sam speaks the lines below. Once he is done, he will turn on the video's audio track. This should be around the point in the video at which the narrator describes how everything changes once enough people join the project.]

In the year 2060, the National Institutes of Health (NIH) will have long moved past its original 10-year timeline for the All of Us precision medicine research program. Right now, the idea of research participants as partners is still forming. I'd like to think this mission will live on through an expanded scope of work. Federal research grants will include requirements around research training and professional development for people from medically underserved communities. Review boards will employ people who have experienced the health issues being researched. The NIH will mandate collaborative research with communities that have historically experienced health inequities. Translational research will be included in this scope. Such work will help operationalize the findings of biomedical research into community development plans, health interventions, and policy decisions. The NIH will require community benefits agreements and collaborative evaluation plans. Members of research institutions' surrounding communities will be trained to document scientific research processes and use creative means to educate others about All of Us findings. Such community engagement will be evaluated in part by the kinds of connections formed and relationships maintained throughout the process. Unfortunately, there's no reference to cite for this paragraph's claims. It's my own lofty vision for the world I want to live in when I'm 68 years old.

Works Cited.

Braveman, P. (2014). “What are health disparities and health equity? We need to be clear.” *Public Health Reports*, 129 (Suppl 2), 5–8.

Bureau of Health Workforce. (2019, June). “Medically Underserved Areas and Populations (MUA/Ps)*.” HRSA.gov*. https://bhw.hrsa.gov/shortage-designation/muap

Lister Hill National Center for Biomedical Communications. (2020). “Precision Medicine.” In *Help Me Understand Genetics* (pp. 297–305). US National Library of Medicine. https://ghr.nlm.nih.gov/primer#precisionmedicine

CHAPTER I: A LOOK AT THE LIMITS OF PUBLIC HEALTH COMMUNICATION AS IT EXISTS TODAY.

“The future of health begins with you.” This slogan greets me as I visit the website for the National Institutes of Health (NIH) *All of Us* research program. A photo of people of varying sizes, ages, races, and abilities fills the left side of the page. Their smiling faces match the optimistic tone of the paragraph on the right side of the page. It describes the groundbreaking effort of *All of Us* to include over one million people in precision medicine research. That is, research drawing on large amounts of genetic, behavioral, and clinical data to develop more targeted methods of medical care.

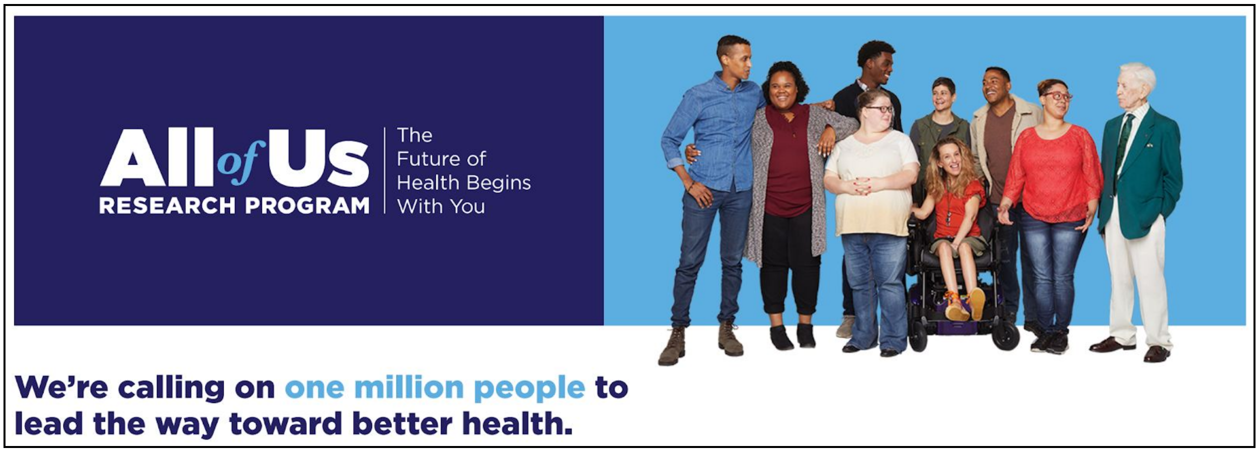


Figure 1: Header image from an informational brochure for *All of Us*. (All of Us Research Program, n.d.-c)

Barack Obama set this optimistic tone when he announced the Precision Medicine Initiative (PMI) in his 2015 State of the Union Address. He charged the PMI with the responsibility to “bring us closer to curing diseases like cancer and diabetes, and to give all of us access to the personalized information we need to keep ourselves and our families healthier.” (*Remarks by the President in State of the Union Address*, 2015). Accounting for over 60% of the $215 million PMI budget, it is clear that the NIH is positioning *All of Us* as a key step in shaping the future of health research (Precision Medicine Initiative (PMI) Working Group, 2015). *All of Us* has united universities, hospital systems, for-profit companies, and non-profit organizations across the country to achieve its research recruitment goal of one million people—and it is well on track to do so. After starting recruitment in May 2018, this coalition recruited over 200,000 people in its first year (All of Us Research Program Investigators, 2019).

When I look at the *All of Us* research program, I see its overarching message: diverse representation in research will benefit everyone. More participants will lead to more data. More data will lead to more scientific knowledge. More scientific knowledge will lead to more personalized health information and care. And that will lead to better health for all of us. As the program's animated introductory videos promises, "Once enough people join, suddenly everything changes." (All of Us Research Program, 2017).

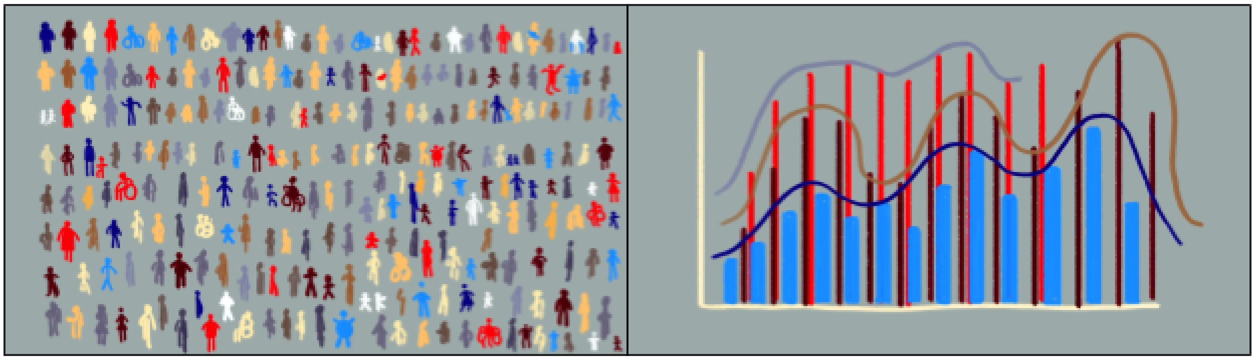


Figure 2: Two frames from an *All of Us* intro video. They illustrating a relationship between diverse participation in research, data, and advanced medical knowledge (All of Us Research Program, 2017).

I want to believe this message. I want to immerse myself in this bright, straightforward image of an equitable future. I want to be in those smiling photos. I want to feel like I'm part of a population that acts in the interests of everyone's well-being. I want to live in the *All of Us* world, where scientists and health professionals can alchemize datasets into health equity. But I know that this is a romanticized picture of scientific research. It's disconnected from the inequities in the way of the PMI's lofty vision. Not that there's anything wrong with a lofty vision… It's just that I read this story about the future as one that the NIH did not create with the communities whose lives it would like to improve.

I go to the *All of Us* YouTube channel and click on a video about LGBTQI communities. It starts with medium close-up shots of LGBTQI health professionals speaking about personal experiences with discrimination and stigma in the medical system. Somber music plays in the background. The interview subjects paint a picture of how these kinds of experiences lead to worse health for LGBTQI communities. Then around the 2-minute mark, the background music takes an inspirational turn. The speakers describe a vision of the future that the viewers can look forward to. And the solutions to these cultural and societal problems somehow revolve around more data (All of Us Research Program, 2019a).

It is true that underrepresentation in medical research is a serious problem. The unknowns of queer communities' health have negative impacts in people's lives. That's why the Sacramento LGBT Community Center uses the phrase "knowledge is power" in its promotion of *All of Us* (Peak, 2019). The Sacramento center does not seem to be alone in this sentiment, as a national survey showed LGBT adults expressing high support for the PMI and willingness to donate biological samples (Kaufman et al., 2016). However, the *All of Us* promise of addressing social issues through biomedical and clinical research rings untrue to me. After all, medical breakthroughs will be most accessible to people who can safely access medical care. In the US, this depends on factors like geography, income, insurance status, and the safety of social interactions within medical institutions.

Now, I am not arguing against precision medicine or current practices of health research writ large. Rather, I am arguing for improved conceptions of communication and community engagement to be integrated into such work. I argue that this can help the US health system better serve the needs of medically underserved communities through research and clinical care. I argue that this is a necessary part of advancing health equity. With a clear charge to improve health for "all of us," it is clear that this motivation aligns with the goals of the Precision Medicine Initiative. And it's fortunate that this national program is positioned to help advance health equity. Why? Because health equity is not a niche interest. Health equity must be a key part of the future of this country.

In the year 2060, nearly 1 in 5 Americans will be immigrants. Nearly 1 in 4 will be elderly. No racial/ethnic group will make up a majority of the population. (Colby & Ortman, 2015). The US government has the opportunity and the imperative to better support historically marginalized people in a world even more pluralistic than our present. That involves learning tough lessons from our world as it is, including a longstanding environment of intertwined disparities in health, income, education, and employment (Centers for Disease Control and

Prevention, 2013). How will this country grow to keep its population healthy and happy in 2060? The highly collaborative structure and multi-pronged approach of *All of Us* helps me imagine the possibilities.

In the year 2060, the NIH will have long moved past its original 10-year timeline for the *All of Us* research program. I would like to think that the *All of Us* mission will live on through an expanded scope of work. Federal research grants will include requirements around research training and professional development for people from medically underserved communities. Review boards will employ people who have experienced health issues being researched, charged with an understanding of research ethics that moves beyond individual protections to community benefits. Further, the NIH will mandate collaborative research with communities that have historically experienced health inequities, and it will provide infrastructural support to ensure this happens responsibly. Translational research will be included in this scope. Such work will help operationalize the findings of biomedical research into community development plans, health interventions, and policy decisions. The NIH will require community benefits agreements and collaborative evaluation plans. This will help track the benefits/responsibilities for academic researchers and community partners involved in such work. Members of research institutions' surrounding communities will be trained to document scientific research processes and use creative means to educate others about *All of Us* findings and maintain accountability. Unfortunately, there's no reference to cite for this paragraph's claims. It's my own lofty vision for the world I will live in when I am 68 years old.

As I said earlier, there's nothing wrong with a lofty vision. I firmly believe in the need for stories and dreams to latch onto while doing the long, arduous work of cleaning up the mess of current health inequities. Like everyone, I live at the intersection of many social forces and personal identities. These intersections inform my ideas about what the future should look like. I have professional experience grappling with issues of equity and wellbeing in the abstract as a public health researcher. I have personal experience with the same issues as part of a medically underserved community growing up. I know the anxiety that comes with navigating an uninsured family member through a major medical crisis. I know what it's like to find out that there are entire worlds of resources and privilege that I had not been privy to growing up. I carry these experiences with me. They simultaneously fuel my passion and cause me to trip over myself as I figure out how to act on it. It helps to imagine wildly different worlds and use them to orient my attitudes and actions. That's not so different from the images of scientific progress and universal benefit that *All of Us* promotes, is it?

The existence of precision medicine technologies means little to me until I can picture a use for them that can fix power imbalances across our society. That's a slightly different picture than the one the NIH is painting via precision medicine, focusing on health outcomes and research. Regardless, it looks like the NIH and I have more similarities than differences. We both want to use communication and media to create images of possible futures. I don't think we're particularly concerned with getting people to memorize the details of these worlds. Nor do I think we're particularly concerned with logically convincing people of these worlds' merits. I don't think these forward-looking communications rely on intellect or logic to make their case at all. They're not instruction booklets. They're windows into an imagined future. They let health professionals, researchers, policymakers, patients, and communities see a path to a community of shared values. The innovation at the heart of *All of Us* isn't technological, but social. To paraphrase John Dewey, it isn't the outward event itself that's news, but the human emotion and perception of it (Dewey, 1927/2012, p. 141). Like much other science communication, I think *All of Us* is an attempt to progress toward what Dewey called the public's most urgent problem: finding and identifying itself (Dewey, 1927/2012, p. 159).

Figure 3: A picture from a design fiction workshop I ran with 2019 ChicagoCHEC Research Fellows. One group imagined a future with equitable access to income, housing, and transportation. In this case,

their character Nicole only has one main concern when it comes to addressing her health issues: her shyness.

I. A: Health communication in the US largely focuses on one-way transmissions of information.

Before its days as a formalized field, US public health had roots in the contradictions of the top-down promotion of national well-being through controlling specific populations' bodies. Such efforts began with settler colonialism and the violent control of enslaved people alongside minimal efforts to keep them alive. From these roots eventually grew local policies to capitalize on international trade while addressing concerns of ships and immigrants bringing disease to coastal cities. Eventually came wartime efforts to keep soldiers from dying of disease (Fee, 1994, pp. 224–230). As US public health became a formal field in the late 19th century, health professionals prioritized biomedical solutions and perceptions of political neutrality over reform of education, labor, housing, etc. to improve health outcomes (Fee, 1994). In this tension, I see a history of professionalized public health efforts overshadowing grassroots socio-political change. Sociologist Max Weber described such a phenomenon in terms of a relationship between capitalism, bureaucracy, and professionalization, in which these three forces reify each other as part of a society focused on the pursuit of impersonal, so-called rational goals (Ritzer, 1975).

It is important to note that this tension between top-down expertise and grassroots social change is not unique to public health. There are similar conflicts between top-down expertise and community-based action in education (Freire, 1970/2005), arts (Boal, 2006), and democracy itself. Though scholars have exaggerated the extent of a bipolar debate between John Dewey and Walter Lippmann, the contrast between their espoused views of "the public" represents longstanding debates about American society (Jansen, 2009). Lippmann described his contemporary society as masses in need of experts to devise plans (Lippmann, 1922, p. 231). He doubted the ability of people to enact democracy by making informed decisions. He questioned the practice of leaders swaying the opinions of people who knew less than they did about matters of policy. His proposed solution to these questions of social order was a network of specialized bureaus charged with gathering information and making decisions. This would free up citizens to “refuse... the burden of these decisions” (Lippmann, 1922, p. 401). John Dewey, meanwhile, eschewed the idea of external authority and intense specialization. Instead of shifting power further to an expert class, he argued for an even more participatory democracy than that of the US. Dewey called for wider spheres of interest and greater dialogue among citizens, enabled by accessible education and erasure of class divisions (Dewey, 1916, p. 101). Such an equitable context would allow a network of interconnected citizens to discover a common interest and take action toward it.

It is important to note that the tension between specialized expertise and grassroots social change is artificial. Yes, there is a huge difference between a panel of experts making decisions for people and communities making decisions for themselves. However, there is no reason that professional experts and local communities must be in conflict with each other. This is already evident in public health today. To address an issue like the spread of human papillomavirus (HPV) requires various kinds of expertise—not just professionalized medical expertise. Teams of researchers must use their education and training to learn about the structure and function of the virus, develop a vaccine, and ensure it is safe and effective. Manufacturers must have the expertise to ensure adequate supplies of safe, effective vaccines for the population. Health care professionals must learn how to administer the vaccine, contribute to best practices around it, and monitor for complications. Local community members must use the knowledge of their own communities and political structures to ensure widespread access to the vaccine in order to minimize the public health risk of HPV. Each realm of expertise is necessary to address this public health issue. Importantly, no group can solve the problem on their own. Any successes and failures among one of the groups has an impact on how the rest of the groups can respond.

Public health already depends on the interactions between numerous groups with varying kinds of expertise. Whether or not it’s explicit, community engagement is part of all public health work. In this chapter, I argue that dominant conceptions of communication and community engagement limit the impact of public health work in the US by focusing on a top-down transfer of information at the expense of improving the networked interactions already critical to public health.

I. A1: A “transmission view” of communication can work in tandem with a “ritual view” in the field of public health.

Communication scholar James Carey coined the terms “transmission” and “ritual” to argue for the importance of including cultural lenses in communications research (Carey, 1989). He identified a focus on audience reach, short-term effects, and laboratory studies in the field at the time. He associated these dominant trends in research with a “transmission view” of communication that focused exclusively on the transfer of information. He described the limits of such research, which produced scientific knowledge unable to account for cultural meanings and systems-level impacts of communication. He proposed the “ritual view” to describe an alternative that focuses instead on how a communication process maintains the social structures that it is a part of.

Figure 4 illustrates the difference between these two views through the example of a newspaper story about the health benefits of eating salmon. In the transmission view of communication, the story influences the reader to eat salmon and feel good about it. In the ritual view of communication, the story filters through the reader’s preexisting positive feelings about salmon. The interaction between the story and the reader’s worldviews maintains a positive relationship between the reader and the newspaper. It also reinforces the reader’s perception of belonging to a community of salmon lovers that get their news from this paper.

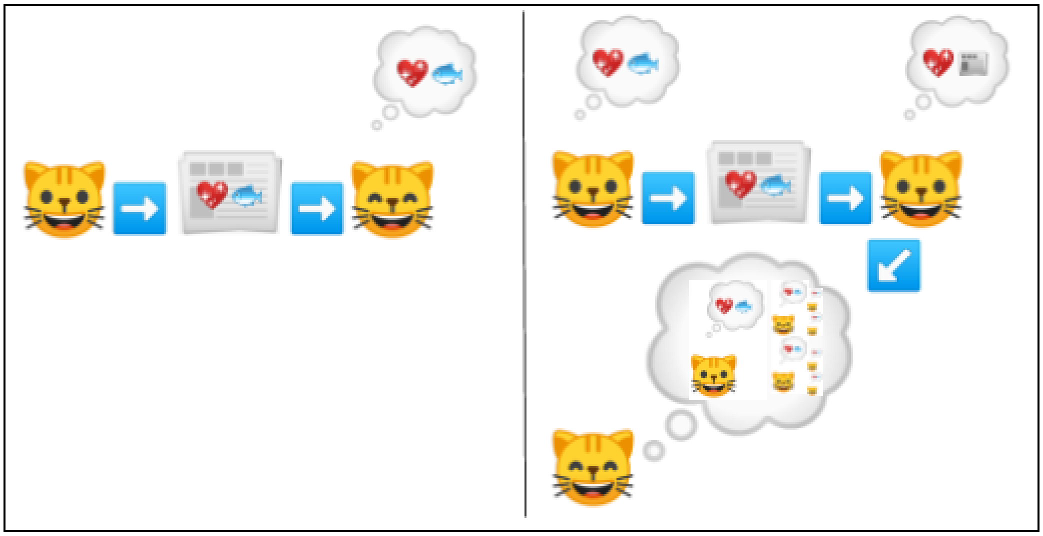


Figure 4: Illustration of the difference between the transmission view (left) and ritual view (right) of communication.

The original conception of ritual and transmission views of communication did not describe health communication specifically. However, it is clear that both of these views can lead to productive public health research and practice. Consider patient-provider relationships in medically underserved communities as an example. Researchers operating under a transmission view of communication might examine whether underserved community members receive relevant medical advice from providers in federally qualified health centers. In an applied setting, public health officials might focus on supplying prevention information on a particularly common health issue within such centers. Focusing on the transmission of information alone, however, overlooks the broader environment of possibilities for acting on that information, as well as the cultural significance of long-term interactions with health information, medical professionals, the federal government, etc.

A ritual view of communication can lead to research questions that focus more on the system of power and culture in which communication operates. For example, communication researchers might investigate whether patient-provider relationships foster trust in federally qualified health centers broadly. In an applied setting, public health officials might focus on how federally qualified health centers' communication efforts incorporate medically underserved communities' local knowledge.

The transmission and ritual views of communication focus on different facets of the communication process. They are equipped to handle different, yet complementary scopes of research and practice that can help improve real-world communication. This multifaceted view of communication is necessary to account for the ways that long-term relationships, cultural meanings, and power relationships complicate notions of communication as a simple transmission of information.

I. A2: The transmission view of communication dominates in US public health.

Although there are fruitful possibilities for both transmission and ritual views of communication in public health, Carey's critique of transmission-focused communication studies applies in the field of public health today. For example, examine the impact of the Health Belief Model (HBM) on public health research in the US. Social psychologists at the US Public Health Service created the model to describe how perceptions of risk, benefit, and efficacy impact health behaviors (Janz & Becker, 1984).

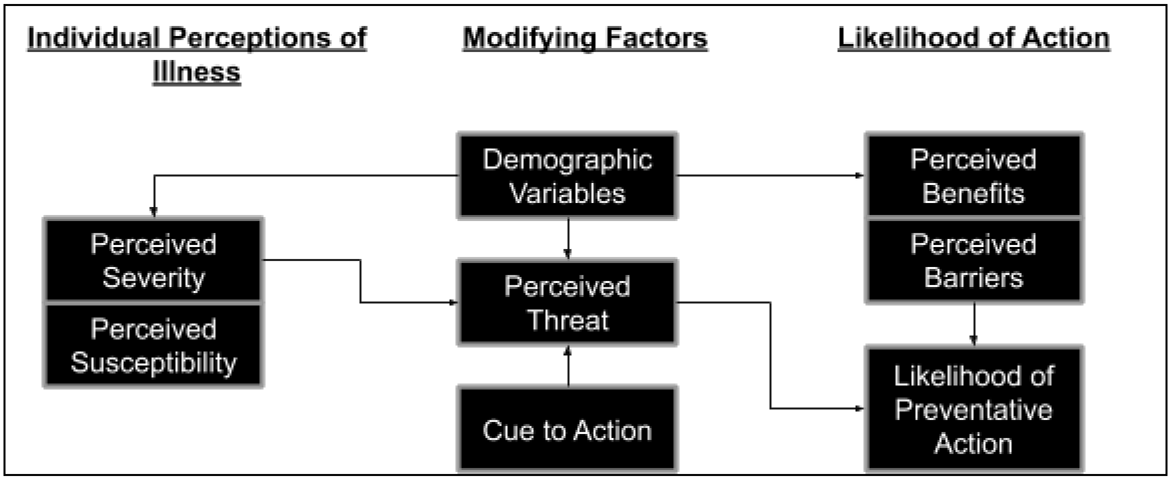


Figure 5: Diagram of the Health Belief Model from Janz and Becker (Janz & Becker, 1984, p. 4).

HBM remains widely influential in health research, with over 3500 citations of Janz and Becker's 1984 review of the model in Web of Science databases and over 950 in PubMed Central (the National Library of Medicine's research archive). Importantly, HBM does not actually describe what communication is or the mechanism by which it works. Rather, health researchers have largely used HBM to conceptualize the ways that communication impacts health behaviors through aiming the transmission of information at one of the factors HBM outlines. As such, HBM has informed research-tested communication interventions that the National Cancer Institute highlights for use in highly targeted populations. Examples include:

- Telephone counseling and mailed print materials to promote colonoscopy screening for family members of someone with a colorectal cancer diagnosis (National Cancer Institute, n.d.-b)
- Targeted mailing to increase mammogram rates among Medicare recipients (National Cancer Institute, n.d.-c)
- Educational presentations and videos to increase colorectal cancer screening rates among uninsured Hispanic adults (National Cancer Institute, n.d.-a).

The focus on a transmission view of communication goes beyond the influential Health Belief Model. The National Library of Medicine defines communication as an "exchange or transmission of ideas" (U.S. National Library of Medicine, n.d.-a). It further specifies health communication as "the transfer of information from experts in the medical and public health field to patients and the public" (U.S. National Library of Medicine, n.d.-b). As part of the federal government's curated vocabulary to index health-related research, these definitions represent the broad strokes of research around health communication: getting information from A to B. Federal research funding has the power to reinforce this transmission view, such as through the National Cancer Institute's (NCI) funding preference for research on individual-level communication interventions (Ramírez et al., 2013).

A transmission view of communication dominates in applied settings as well. For example, in its guide to communication programs, the NCI focuses on how communication can spread information that will influence people's health decisions. It offers theoretical frameworks and models as planning tools (National Cancer Institute, 2004). Some tools, like the Consumer Information Processing Model and the Diffusion of Innovations theory, provide ways to think about how information spreads. Others, such as the Social Cognitive Theory, outline pathways to health-related behaviors and highlight opportunities for communication to influence them. The National Institutes of Health propagates this transmission view broadly, not just through the National Cancer Institute. For example, "A Checklist for Communicating Science and Health

Research to the Public" focuses on the language, tone, and overall scope of information (National Institutes of Health, 2018). Grants to establish "Centers of Excellence in Cancer Communication Research" focus on how to "extend knowledge benefits equitably throughout the population." (National Institutes of Health, 2007)

The *All of Us* research program enacts this focus on the transmission of information as well, dating back to its initial promise that the Precision Medicine Initiative will "give all of us access to the personalized information we need to keep ourselves and our families healthier." The promise of information is central to the NIH's stated benefits of the program, which includes centralized access to research data for scientists, personal data portals for participants, and public data portals for high-level aggregate figures.

The community engagement materials mirror this centralized structure for distributing information nationwide. The announcement of the funding opportunity for the *All of Us* publicity campaign outlined its overarching goals: conveying the value of participating in precision medicine research using consistent wording that can be used by multiple partners (National Institutes of Health, 2015). The award ended up going to a Los Angeles-based ad firm that has worked on previous nationwide research campaigns (*Project Information: 3OT2OD023205-01S1*, n.d.). The results are a top-down communication program that distributes uniform messages across the country. Paradoxically, these messages universalize the narrative around precision medicine while attempting to speak directly to the concerns of various smarginalized groups.

This narrow focus on the transmission view of communication is not limited to public health, which draws on other fields of communication research. For example, in *A Survey of Scientific Communication Theory* Pavitt notes that most communication models do not focus on communication processes and systems. Rather, they focus on the reception or the production of one-off messages to achieve a specific goal, without acknowledging any feedback loops. (Pavitt, 2016, p. 347). However, the effects of this narrow focus have especially significant implications in health-related fields. This focus is limiting the impact that health research and community engagement can have in medically underserved communities.

Figure 6: A composite of the front covers of the All of Us brochures intended for various populations. The Hispanic community cover is top left, Asian community at the top right, African American community at bottom left, and general community at bottom right. The text on the inside of the brochure is identical across the 4 brochures. (All of Us Research Program, n.d.-a, n.d.-b, n.d.-c, n.d.-d)

I. B: The dominance of the transmission view of communication limits the impact of public health work in medically underserved communities.

I look at the coordinated effort that makes up the *All of Us* research program and see a tremendous opportunity. *All of Us* program partners span geographic areas, public and private sectors, and constituencies in the US. The list of partners includes: American Medical Association, American Public Health Association, Asian Health Coalition, Asian & Pacific Islander American Health Forum, Baylor College of Medicine, BloodCenter of Wisconsin, Boston Medical Center, Broad Institute, Henry Ford Health System, Iota Phi Theta Fraternity Inc, Kappa Alpha Psi Fraternity Inc, Mayo Clinic, Morehouse School of Medicine, National Association of Hispanic Nurses, National Baptist Convention, National Black Nurses Association, National Rural Health Association, NYC Health + Hospitals/Harlem, PatientsLikeMe, Stanford Medical School, Vanderbilt University Medical Center, University of Miami Miller School of Medicine, University of Mississippi Medical Center, US Department of Veterans Affairs Medical Centers, Walgreens, WebMD, YMCA of the USA Greater Houston… and that’s not the half of it.

Renowned universities and research institutions working in tandem with groups like historically African American fraternities and local community centers have a great opportunity to intervene in power dynamics that encompass their partnership. Health systems working with groups like the National Association of Hispanic Nurses and National Black Nurses association can learn how to better support their own staff in the pursuit of health equity. Companies like Walgreens and PatientsLikeMe can learn more about how to make their services more impactful for the constituencies of groups like the US Department of Veterans Affairs and the National Rural Health Association. This is the kind of learning that will be necessary for precision medicine to actually improve healthcare for all of us. This is the kind of learning that can help ensure these partnerships and engagement efforts amount to more than just pipelines for centralized flows of data and information.

At the same time, I'm afraid that this kind of learning and intervention process isn't a national priority in federal bodies like the NIH. There are a lot of nuanced tensions underlying research participation. As Mahri Bahati of PRIDEnet says in an interview on the All of Us YouTube channel, "I think our community wants to be a part of these medical breakthroughs that are going to be coming through." (All of Us Research Program, 2019b). This view aligns with movements from queer communities that have organized around research representation and medical care as a right. Historically, the AIDS Coalition to Unleash Power (ACT UP) protested the US Food & Drug Administration's early approach to HIV/AIDS research (Eigo et al., n.d., sec. I). The group also produced their own calls for researchers to recruit groups experiencing HIV/AIDS health disparities into clinical trials (Eigo et al., n.d., sec. II). A present-day example is the National Center for Transgender Equality (NCTE), and its calls for questions about gender identity and transgender status in government surveys (*Research & Data Needs*, n.d.) as well as access to better sexual health education (*Transgender Sexual and Reproductive Health: Unmet Needs and Barriers to Care*, 2012). Such interventions would help ensure medical professionals have adequate information to promote better health care for transgender people. This is exactly the kind of informational intervention that precision medicine can carry out using a transmission view of communication. This potential benefit underscores Bahati's statement that, "you can't get treatment that works for us unless we're a part of it" (All of Us Research Program, 2019b).

However, I’m afraid that community engagement around precision medicine will stop there, before addressing the wider concerns of equity. For example, in the same document that the NCTE called for better sexual education, it also called for nondiscrimination training and adoption of formalized policies of nondicrimination and respect. Without improving the social structures through which information will travel, *All of Us* (and precision medicine more broadly) has the potential to inadvertently maintain LGBTQI health disparities by narrowly defining the scope of success.

This example of the *All of Us* campaign’s approach to its LGBTQI research shows the effect that dominant views of communication in public health have on medically underserved communities. Technical and informational solutions will not be able to solve the social issues that contribute to health disparities. Below, I outline how a transmission view of communication contributes to this situation, as well the opportunities that a ritual view of communication presents to correct them.

I. B1: A transmission view of communication ignores message receivers’ power. A ritual view focuses on power dynamics.

A defining characteristic of the transmission view of communication is its lack of recognition for the power of message receivers. Message senders may adjust their messages, goals, and approaches in ways that determine what success and failure look like. Message receivers interpret and either accept or reject the sender’s message, with message senders evaluating the outcomes in terms of a desired response. In the case of public health work, the desired response is usually a specific behavior, espoused opinion, or information recall. At the end of the day, the message receiver either had the desired response or they didn’t. An exclusive focus on this binary outcome ignores rich sites of action that could help advance health equity.

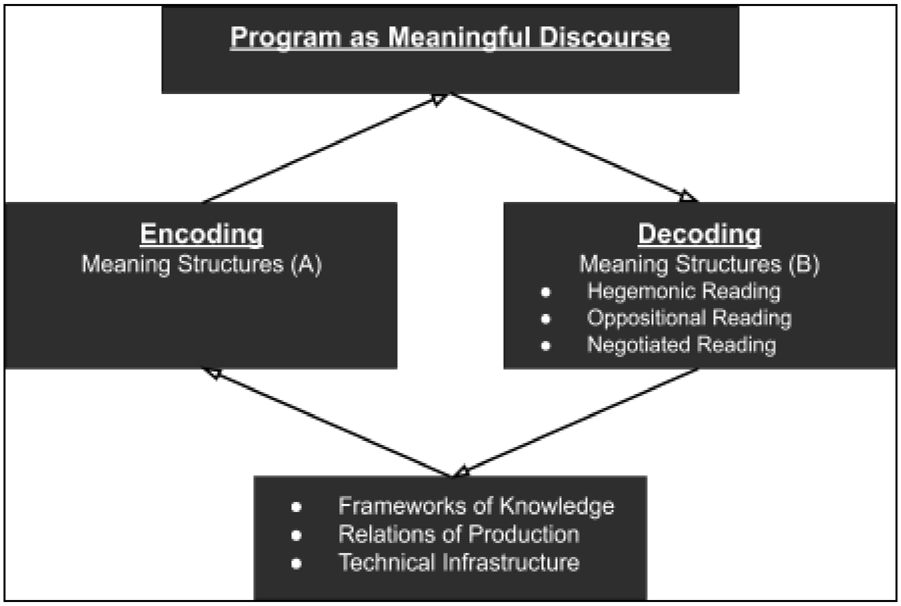


Figure 7: Visual representation of Stuart Hall's model of encoding/decoding. Systemic factors shape the messages encoded into mass media. The media in turn shapes the audience's decoding process. Finally, the audience's interpretations shape the systemic factors that will shape more media programs. (Hall, 1973/2007, p. 94)

In contrast, Stuart Hall describes mass communication as a process of encoding and decoding meaning. Media producers, funders, and distributors encode intended meanings into their communication programs. While they may influence audience interpretation, they cannot control that process completely. As such, audience members have the ability to accept the intended meaning, reject it, or negotiate a new meaning. Importantly, these audience interpretations provide feedback into the environment that facilitated the making of the communication program in the first place (Hall, 1973/2007). This encoding/decoding model acknowledges the power and creativity of the audience to impact their broader environment through their interpretation process. Bell hooks further elaborates on the generative process of interpretation through her concept of the oppositional gaze. She describes how black women in particular consume media with an oppositional gaze, creating unintended meanings for white- and man-centric media that do not speak to their reality. The oppositional gaze is a technique of finding personal value in spite of (and in conversation with) the ways the media products represent and maintain social inequities (Hooks, 1992).

The field of public health could greatly benefit from such engagement with message receivers' power to shift the communication environment through unexpected interpretations. Studies on research recruitment of medically underserved communities provide a fruitful illustration. There is a federal mandate to include women and racial/ethnic minorities in NIH-funded clinical research (National Institutes of Health, n.d.), as well as increasing research attention on health disparities, as evidenced by the Precision Medicine Initative's targeted recruitment of racial/ethnic minority and LGBTQI communities. With this increased attention paid to recruitment of underrepresented populations, the field of public health contains a plethora of studies on how to better represent racial and ethnic minorities in research. Even a cursory literature review will yield many research-based suggestions on topics including: recruitment channels (Guillory et al., 2018), sampling strategies (Shaghaghi et al., 2011), informed consent processes (Kraft & Doerr, 2018), and targeted retainment efforts (Warren-Findlow et al., 2003). The emergence of this line of work led to sociologist Steven Epstein to identify it as a new field: recruitmentology (Epstein, 2008). Such research is concerned with one short-term metric of success: research participation.

To be sure, representation in research is an important issue, especially in the context of precision medicine research. However, current recruitment work focuses on the ways that recruiters and researchers can transmit information effectively to increase research participation. In doing so, it reinforces the position of power of people in federally funded research institutions. Health is good, and thus health research must be good, and thus potential research participants just need to be convinced—in the right way—of the benefits of research participation long-term. Recruitment research focuses on how to make that persuasive process more effective. It does not typically question, for example, whether the only time someone from a medically underserved community interacts with someone at a university is when there is data to be gathered.

It's hard to say exactly what recruitment research might look like if it overcame the aforementioned hurdles of transmission communication. Some signposts are available from research with African American communities, pointing to personal negotiations between mistrust of research and the importance of representation in research (Scherr et al., 2019). One way this might manifest is through research participation in spite of mistrust, as Hagiwara et al. found in a telephone survey of African American people in the Detroit area (Hagiwara et al., 2014). Thus recruitment research using a ritual view of communication might help examine and intervene in the social structures that lead to desired recruitment metrics but not increased trustworthiness on the part of research institutions. For example: should communication around precision medicine even happen at an individual level? It is debatable whether an individual can ethically volunteer genetic information that they share with their kin (Nelson, 2016, p. 16). Considering that environmental health research findings will presumably apply to everyone living in a certain geographic area, should recruitment and consent happen at a neighborhood level? Should considerations of individual protections extend to community-level protections? Would participants in a trial of a health intervention make the same participation decisions if they saw examples of the ways that scholars will generalize their outcomes to represent, for example, all uninsured Hispanic adults over age 40?

Such moral questions do not lie within the scope of public health communication research when viewed through a transmission lens. Though health equity may point to answers for such "should" questions, the individualistic frame of reference in a transmission view of communication makes it difficult to consider community-level impact or power relationships between groups of stakeholders. However, the ritual view opens up space to consider what power dynamics are at play in a communication process. By considering social structures and inter-group dynamics, questions of power and community-level impact are up for discussion.

I. B2: A transmission view of communication ignores impactful feedback loops. A ritual view examines how various actors shape the environment in which they interact.

A transmission view of communication ignores the dynamic exchange between everyone involved in communication and the environment in which it takes place. A community's relationship with a research institution, scientific research in general, or the health topic at hand will not go into stasis just because a study ended. As an influential theory in public health, social cognitive theory provides a fruitful example of the limits of the dominant paradigm in health communication to address this.

Albert Bandura proposed social cognitive theory as a way to describe the environmental influences on human behavior, including observational learning (Bandura, 1977). The NCI describes Bandura's theory in relation to interpersonal communication. It highlights observational learning as a key mechanism through which health communication programs can work (National Cancer Institute, 2004, p. 223). As Pavitt notes in his survey of communication theory, social cognitive theory does not explain what communication is or how it works. Rather, it highlights a pathway through which communication can influence behavior through observational learning—still focusing on the possible effects of the one-way transmission of information. Bandura himself used this theory to hypothesize about the ways in which violence on television might contribute to more aggressive behaviors in the audience (Pavitt, 2016, p. 62). In public health, this line of thinking influences health interventions that focus on communication to enhance self-regulation, such as the numerous information-based behavioral interventions in chronic health conditions (Tougas et al., 2015).

Like other transmission-focused models of communication, social cognitive theory is equipped to address individual-level impacts of new information (or new methods of sharing it). What the social cognitive theory does not address is the way that communications and populations will change in response to each other. For example, people receiving messages about health behavior changes might respond differently over time. One such case is response fatigue for one-way SMS messaging to promote adherence to a medical treatment regimen. Extant research points to the possibility of two-way communication being more effective than one-way messaging (Amankwaa et al., 2018). However, without an expanded view of communication, such methods will still be in service of limited short-term outcomes, important as sticking to a medical treatment may be.

Much like James Carey in the 1980s, communication scholar Annie Lang criticized the field of communication studies in 2013 for focusing on short-term effects in a supposedly static system of communication. She called for an approach to communication research that acknowledges the dynamic nature of human systems, examining the changing nature of interactions between messages, humans, and the environment over time. According to Lang, a key issue with the current paradigm of communication research is that it assumes that communication has a clear-cut beginning and end. She noted that this shortcoming has effectively led to the division of communication studies into two subfields. One subfield is humanistic, examining questions of power and culture (which resonates with the ritual view of communication). The other is a social scientific field still focused on media effects (which resonates with the focus of health communication research I have outlined above). She called for an approach to communication research that instead focuses on specific individual-level cognitive, emotional, and motivational variables that influence a person's adaptations to a communication environment over time (Lang, 2013).

Such a cognitive approach to health communication research could help produce health interventions with a better base of background knowledge about why they work, not just under what conditions. However, as a field deeply invested in real-world interventions as well as generalizable knowledge, public health researchers cannot afford to make such a clear-cut distinction between humanities research and social science research. Research findings are useless in the field of public health if they do not have supports for use in real-world settings awash in health disparities, coexisting cultures, preexisting relationships to media channels, and uneven distributions of power. Real-world outcomes shape research questions in turn, leading to lines of research around "underserved," "underrepresented," and "hard-to-reach" populations. Research using a ritual lens of communication could help fill in the gaps of how these relationships between communities and research institutions create an environment that will impact public health

A ritual view presents a framework for research and practice that can supplement transmission-focused and cognitive understandings of communication. It is necessary to have research that shows a particular communication campaign can achieve specific outcomes, as well as research that can explain why such methods work on an individual level. However, these lines of inquiry are insufficient to explain what supports or hinders a communication campaign in a medically underserved community. They also cannot account for the historical and social contexts in which public health communication takes place. Communities exist in a particular point in time and space, which will necessarily introduce new factors into the best evidence-based plans. A ritual view accounts for the social context in which communication takes place, not just allowing an examination of the ways this context shapes communication but also the ways that communication will shape the environment. A positive experience with one campaign from a public health institution may prime an audience for future interactions. A breach of trust from one research institution may negatively impact projects coming out of other institutions. A transmission view cannot account for such important factors.

I. B3: A transmission view of communication ignores the political nature of public health. A ritual view gives attention to the broader social contexts in which communication takes place.

Public health communication typically rests on assumptions of the neutrality, objectivity, and sufficiency of scientific knowledge in its capacity to facilitate positive health outcomes. This is the underlying logic of the *All of Us* research program and of the approach to precision medicine more broadly. It is important to acknowledge the rigor of scientific research and the utility of its findings for effective health promotion. However, ignoring the political nature of scientific research and public health work has created barriers to health equity that a transmission view of communication is ill-equipped to address on its own.

First, public health is political in the sense that it shapes the systems of power in which social groups interact, and those systems of power in turn shape public health. For example, the process of forming research questions does not happen in a vacuum. It is a human decision influenced by personal experience, existing research, and funder priorities. Whose personal experience typically gets to factor in? Well, at least in biomedical research, only 18% of full professors are women and about 5% of full professors are blacks/African American, Hispanic, Native American, Pacific Islander, or multiracial (Valantine et al., 2016).

Related to issues in representation in the research workforce are questions surrounding underlying worldviews that influence research questions. Some groups call for inclusion in dominant research paradigms, such as in the case of endometriosis activists who worked to reframe the understanding of the illness as a complex medical condition warranting more funding for a standard biomedical research agenda (Čapek, 2000). This contrasts with less mainstream epistemologies, which would call for different kinds of research questions and long-term measures of success. For example, an Indigenous research agenda might center self-determination and ask questions based around decolonization, healing, and survival rather than how to best be served by people currently in power (Tuhiwai, 1999). A research agenda informed by Deaf culture might focus on ways to improve quality of life for people with hearing impairments while affirming the views of deaf people who want to be recognized as a member of a linguistic minority community rather than individuals with medical problems to be solved (Lane, 1995/1997).

So while health research, especially biomedical research, might be seen as politically neutral, able to benefit all of us, the inclusion of certain health topics and the acceptance of certain kinds of epistemologies are signs of its political nature. Further, the process of obtaining funding to investigate research questions is limited by structural discrimination, as evidenced by men with previous NIH grants having higher application and funding rates than women with similar career experience (Pohlhaus et al., 2011) and the significantly lower likelihood of the NIH to award black scientists R01 funding than applicants of other racial/ethnic groups (Ginther et al., 2011).

The knowledge gained from research is not politically neutral either. Donna Haraway has discussed the illusion of objectivity and perfect understanding common in the rhetoric of science. As opposed to objectivity as currently understood, she argues that all knowledge is situated in a specific context. A more ethically responsible alternative to the pursuit of complete, objective knowledge is the pursuit of a multiplicity of incomplete knowledges. Importantly, this knowledge should clearly indicate the context in which people produced it. She describes the strength of the knowledge of subjugated groups due to their experiences identifying and overcoming privileged groups' attempts to declare their own viewpoints objective and universal (Haraway, 1988). As Kimberlé Crenshaw notes, the ability to produce, frame, and wield statistical knowledge is a tremendous power. Due to intersecting systems of subjugation, women of color are often denied access to this power and most vulnerable to being harmed by it on multiple fronts (Crenshaw, 1990). Given its focus on the social relationships and power dynamics that a communication process maintains, the ritual view of communication is necessary in public health to address the ways that knowledge carries with it political power. It is also necessary to examine and intervene in the ways that such political power is unequally distributed.

Finally, US public health professionals have long been aware that acting in the interest of "the public" involves making change at governmental levels. As such, actually acting on findings from public health research requires navigating scientific knowledge through the gatekeeping of policymakers. This is especially true when acting in the interest of medically underserved communities. For example, the American Public Health Association has used health equity as a frame to argue for policy change on a variety of social issues that include raising the minimum wage, implementing universal preschool, and supporting affirmative action programs (American Public Health Association, 2018). The link between public health and social justice means that public health advocates must find ways to argue for policy change in an environment of corporate mass communications that rely on ideas of "market justice" (Dorfman et al., 2005). As such, the Robert Wood Johnson Foundation has published a guide to framing messages about social determinants of health differently for Democrats and Republicans to help lobby for policy change that can actually reduce health disparities (Robert Wood Johnson Foundation et al., 2010).

The transmission of information is not a sufficient framework to effectively investigate and interact with the broader social system in which public health communication takes place. Political systems shape the effects that information has. As such, a ritual view of communication will be necessary in using communication as a way to link research findings with real-world health outcomes that government policies can support and maintain.

I. C: Conclusion.

In this chapter, I have argued that a transmission view of communication dominates in US public health. I have illustrated the impacts of this situation on health equity, owing to the inadequacy of a transmission view of communication to account for audience power, feedback loops, and politics. I have demonstrated the gaps that a ritual view of communication can fill. In the rest of this thesis, I will theorize about the ways that a ritual view of communication intersects with existing research frameworks, propose a tool to leverage a ritual view of communication in academic-community research partnerships, and describe the ongoing development of a community engagement program that operates through a ritual lens.

Works Cited.

All of Us Research Program. (n.d.-a). *National Brochure - African American Community*. Retrieved December 17, 2018, from https://www.joinallofus.org/sites/default/files/2018-07/AoU_NAT_Brochure_AfricanAm_Community.pdf

All of Us Research Program. (n.d.-b). *National Brochure - Asian Community*. Retrieved December 17, 2018, from https://www.joinallofus.org/sites/default/files/2018-07/AoU_NAT_Brochure_AsianAm_Community.pdf

All of Us Research Program. (n.d.-c). *National Brochure - General Community*. Retrieved December 17, 2018, from https://www.joinallofus.org/sites/default/files/2018-07/AoU_NAT_Brochure_General_Community.pdf

All of Us Research Program. (n.d.-d). *National Brochure - Hispanic Community*. Retrieved December 17, 2018, from https://www.joinallofus.org/sites/default/files/2018-07/AoU_NAT_Brochure_Hispanic_Community.pdf

All of Us Research Program. (2017, October 10). *What is All of Us?* [Web Video]. Youtube. https://www.youtube.com/watch?v=ti50nS7B5vI

All of Us Research Program. (2019a, January 9). *All of Us Research Program | Voices of the LGBTQI Community* [Web Video]. Youtube.

https://www.youtube.com/watch?v=lyTVFhhvM0c

All of Us Research Program. (2019b, April 10). *Why Diversity in Health Research is Important | The Dish (2019)*. Youtube. https://www.youtube.com/watch?time_continue=51&v=lOHn51a159g&feature=emb_title

All of Us Research Program Investigators. (2019). The "All of Us" Research Program. *The New England Journal of Medicine*, *381*(7), 668–676.

Amankwaa, I., Boateng, D., Quansah, D. Y., Akuoko, C. P., & Evans, C. (2018). Effectiveness of short message services and voice call interventions for antiretroviral therapy adherence and other outcomes: A systematic review and meta-analysis. *PloS One*, *13*(9), e0204091.

American Public Health Association. (2018, November 13). *Achieving Health Equity in the United States*. APHA.org. https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2019/01/29/achieving-health-equity

Bandura, A. (1977). *Social Learning Theory*. Prentice-Hall.

Boal, A. (2006). A Theoretical Foundation. In A. Jackson (Trans.), *The Aesthetics of the Oppressed* (pp. 11–43). Routledge.

Čapek, S. M. (2000). Reframing Endometriosis: From a "Career Woman's Disease" to Environment/Body Connections. In S. Kroll-Smith, P. Brown, & V. J. Gunter (Eds.), *Illness and the Environment: A Reader in Contested Medicine* (pp. 345–363). New York University Press.

Carey, J. W. (1989). A Cultural Approach to Communication. In *Communication as Culture: Essays on Media and Society* (pp. 13–36). Unwin Hyman.

Centers for Disease Control and Prevention. (2013). *CDC Health Disparities and Inequalities Report — United States, 2013*, 62(3). https://www.cdc.gov/mmwr/pdf/other/su6203.pdf

Colby, S. L., & Ortman, J. M. (2015). *Projections of the Size and Composition of the U.S. Population: 2014 to 2060*. US Census Bureau. https://www.census.gov/content/dam/Census/library/publications/2015/demo/p25-1143.pdf

Crenshaw, K. (1990). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review* 43(6), 1241-1299.

Dewey, J. (1916). *Democracy and Education*. The MacMilian Company.

Dewey, J. (2012). *The Public and its Problems*. The Pennsylvania State University Press. (Original work published 1927)

Dorfman, L., Wallack, L., & Woodruff, K. (2005). More than a message: framing public health advocacy to change corporate practices. *Health Education & Behavior: The Official Publication of the Society for Public Health Education*, *32*(3), 320–336; discussion 355–362.

Eigo, J., Harrington, M., McCarthy, M., Spinella, S., & Sugden, R. (n.d.). *FDA Action Handbook* (ACTUPNY.org). {Aids Coalition to Unleash Power}; The ACT UP Historical Archive. Retrieved January 2, 2020, from https://actupny.org/documents/FDAhandbook1.html (Original work published 1988)

Epstein, S. (2008). The rise of “recruitmentology”: clinical research, racial knowledge, and the politics of inclusion and difference. *Social Studies of Science*, *38*(5), 801–832.

Fee, E. (1994). Public Health and the State: The United States. In D. Porter (Ed.), *The History of Public Health and the Modern State* (pp. 224–275). Rodopi.

Freire, P. (2005). *Pedagogy of the Oppressed* (M. B. Ramos, Trans.; 30th Anniversary Edition). The Continuum International Publishing Group Inc. (Original work published 1970)

Ginther, D. K., Schaffer, W. T., Schnell, J., Masimore, B., Liu, F., Haak, L. L., & Kington, R. (2011). Race, ethnicity, and NIH research awards. *Science*, *333*(6045), 1015–1019.

Guillory, J., Wiant, K. F., Farrelly, M., Fiacco, L., Alam, I., Hoffman, L., Crankshaw, E., Delahanty, J., & Alexander, T. N. (2018). Recruiting Hard-to-Reach Populations for Survey Research: Using Facebook and Instagram Advertisements and In-Person Intercept in LGBT Bars and Nightclubs to Recruit LGBT Young Adults. *Journal of Medical Internet Research*, *20*(6), e197.

Hagiwara, N., Berry-Bobovski, L., Francis, C., Ramsey, L., Chapman, R. A., & Albrecht, T. L. (2014). Unexpected findings in the exploration of African American underrepresentation in biospecimen collection and biobanks. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, *29*(3), 580–587.

Hall, S. (2007). Encoding, Decoding. In S. During (Ed.), *The Cultural Studies Reader* (third, pp. 477–487). Routledge. (Original work published 1973)

Haraway, D. (1988). Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies: FS*, *14*(3), 575–599.

Hooks, B. (1992). The Oppositional Gaze: Black Female Spectators. In *Black Looks: Race and Representation* (pp. 115–131). South End Press.

Jansen, S. C. (2009). Phantom Conflict: Lippmann, Dewey, and the Fate of the Public in Modern Society. *Communication and Critical/Cultural Studies*, *6*(3), 221–245.

Janz, N. K., & Becker, M. H. (1984). The Health Belief Model: a decade later. *Health Education*

Quarterly, *11*(1), 1–47.

Kaufman, D. J., Baker, R., Milner, L. C., Devaney, S., & Hudson, K. L. (2016). A Survey of U.S Adults' Opinions about Conduct of a Nationwide Precision Medicine Initiative® Cohort Study of Genes and Environment. *PloS One*, *11*(8), e0160461.

Kraft, S. A., & Doerr, M. (2018). Engaging populations underrepresented in research through novel approaches to consent. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, *178*(1), 75–80.

Lane, H. (1997). Constructions of Deafness. In L. J. Davis (Ed.), *The Disability Studies Reader* (pp. 153–171). Routledge. (Original work published 1995)

Lang, A. (2013). Discipline in Crisis? The Shifting Paradigm of Mass Communication Research. *Communication Theory (1050-3293)*, *23*(1), 10–24.

Lippmann, W. (1922). *Public Opinion*. Harcourt, Brace and Company.

National Cancer Institute. (n.d.-a). *Against Colorectal Cancer in Our Neighborhoods (ACCION)*. Research-Tested Intervention Programs (RTIPs). Retrieved December 5, 2019, from https://rtips.cancer.gov/rtips/programDetails.do?programId=26767808

National Cancer Institute. (n.d.-b). *Family CARE (Colorectal Cancer Awareness and Risk Education) Project (FCARE)*. Research-Tested Intervention Programs (RTIPs). Retrieved December 5, 2019, from https://rtips.cancer.gov/rtips/programDetails.do?programId=24393369

National Cancer Institute. (n.d.-c). *Targeted Mailing: Increasing Mammogram Screening Among the Elderly*. Research-Tested Intervention Programs (RTIPS). Retrieved December 5, 2019, from https://rtips.cancer.gov/rtips/programDetails.do?programId=124412

National Cancer Institute. (2004). *Making Health Communication Programs Work*. National Cancer Institute. https://www.cancer.gov/publications/health-communication/pink-book.pdf

National Institutes of Health. (n.d.). *Inclusion of Women and Minorities as Participants in Research Involving Human Subjects*. Grants.nih.gov. Retrieved December 12, 2019, from https://grants.nih.gov/policy/inclusion/women-and-minorities.htm

National Institutes of Health. (2007, December 13). *Request For Applications (RFA) Number: RFA-CA-08-004*. NIH.gov. https://grants.nih.gov/grants/guide/rfa-files/RFA-CA-08-004.html#SectionV

National Institutes of Health. (2015, November 27). *Funding Opportunity Announcement, OT-PM-16-002*. NIH.gov. https://allofus.nih.gov/sites/default/files/20151116-pmi-comms-ota-sow_1.pdf

National Institutes of Health. (2018, March 12). *A Checklist for Communicating Science and Health Research to the Public*. NIH.gov. https://www.nih.gov/about-nih/what-we-do/science-health-public-trust/checklist-communicating-science-health-research-public

Nelson, A. (2016). *The Social Life of DNA: Race, Reparations, and Reconciliation After the Genome*. Beacon Press.

Pavitt, C. (2016). *A Survey of Scientific Communication Theory*. Peter Lang Publishing.

Peak, K. (2019, January 10). *How Precision Health Can Help The LGBTQ+ Community*. Sacramento LGBT Community Center; Sacramento LGBT Community Center. https://saccenter.org/lgbt-community-health-nih-precision-medicine/

Pohlhaus, J. R., Jiang, H., Wagner, R. M., Schaffer, W. T., & Pinn, V. W. (2011). Sex differences in application, success, and funding rates for NIH extramural programs. *Academic Medicine: Journal of the Association of American Medical Colleges*, *86*(6), 759–767.

Precision Medicine Initiative (PMI) Working Group. (2015). *The precision medicine initiative cohort program-building a research foundation for 21st century medicine*. National Institute of Health. https://www.nih.gov/sites/default/files/research-training/initiatives/pmi/pmi-working-group-report-20150917-2.pdf

Project Information: 3OT2OD023205-01S1. (n.d.). NIH RePORT; National Institutes of Health. Retrieved November 20, 2018, from https://projectreporter.nih.gov/project_info_details.cfm?aid=9404498&icde=35954775

Ramírez, A. S., Galica, K., Blake, K. D., Chou, W.-Y. S., & Hesse, B. W. (2013). Cancer communication science funding trends, 2000-2012. *Journal of the National Cancer Institute. Monographs*, *2013*(47), 133–139.

Remarks by the President in State of the Union Address. (2015, January 20). Whitehouse.gov. https://obamawhitehouse.archives.gov/the-press-office/2015/01/20/remarks-president-state-union-address-january-20-2015

Research & Data Needs. (n.d.). National Center for Transgender Equality. Retrieved December 13, 2019, from https://transequality.org/issues/research-data-needs

Ritzer, G. (1975). Professionalization, Bureaucratization and Rationalization: The Views of Max Weber. *Social Forces; a Scientific Medium of Social Study and Interpretation*, *53*(4), 627–634.

Robert Wood Johnson Foundation, Carger, E., & Westen, D. (2010). *A New Way to Talk About the Social Determinants of Health*. Robert Wood Johnson Foundation.

Scherr, C. L., Ramesh, S., Marshall-Fricker, C., & Perera, M. A. (2019). A Review of African Americans' Beliefs and Attitudes About Genomic Studies: Opportunities for Message Design. *Frontiers in Genetics*, *10*, 548.

Shaghaghi, A., Bhopal, R. S., & Sheikh, A. (2011). Approaches to Recruiting "Hard-To-Reach" Populations into Re-search: A Review of the Literature. *Health Promotion Perspectives*, *1*(2), 86–94.

Tougas, M. E., Hayden, J. A., McGrath, P. J., Huguet, A., & Rozario, S. (2015). A Systematic Review Exploring the Social Cognitive Theory of Self-Regulation as a Framework for Chronic Health Condition Interventions. *PloS One*, *10*(8), e0134977.

Transgender Sexual and Reproductive Health: Unmet Needs and Barriers to Care. (2012, April 1). National Center for Transgender Equality. https://transequality.org/issues/resources/transgender-sexual-and-reproductive-health-unmet-needs-and-barriers-to-care

Tuhiwai, S. L. (1999). *Decolonizing methodologies: Research and indigenous peoples*. Zed Books Limited.

U.S. National Library of Medicine. (n.d.-a). *Communication - MeSH Descriptor Data 2019*. Meshb.nlm.nih.gov. Retrieved December 15, 2018, from https://meshb.nlm.nih.gov/record/ui?ui=D003142

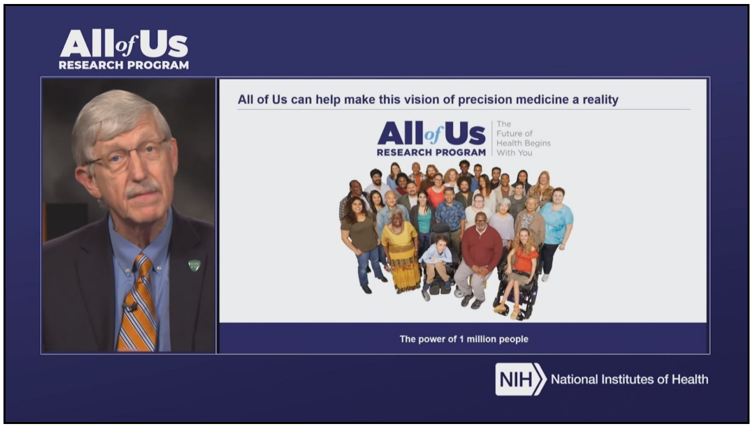
U.S. National Library of Medicine. (n.d.-b). *Health Communication - MeSH Descriptor Data 2019*. Meshb.nlm.nih.gov. Retrieved December 6, 2018, from https://meshb.nlm.nih.gov/record/ui?ui=D058015

Valantine, H. A., Lund, P. K., & Gammie, A. E. (2016). From the NIH: A Systems Approach to Increasing the Diversity of the Biomedical Research Workforce. *CBE Life Sciences Education*, *15*(3). https://doi.org/10.1187/cbe.16-03-0138

Warren-Findlow, J., Prohaska, T. R., & Freedman, D. (2003). Challenges and opportunities in recruiting and retaining underrepresented populations into health promotion research. *The Gerontologist*, *43 Spec No 1*, 37–46.

Chapter II. A RITUAL-BASED TOOL FOR HEALTH EQUITY.

Through recurring motifs of scientific breakthroughs, technological progress, and generations to come, imagined futures are at the heart of the Precision Medicine Initiative (PMI). From the beginning of the PMI, the Obama White House imagined a future where health data would be portable enough to share between healthcare providers, researchers, patients, and research participants (*The Precision Medicine Initiative*, n.d.). Shortly after the PMI launch, National Institutes of Health (NIH) Director Francis S. Collins and National Cancer Institute (NCI) Director Harold Varmus imagined how the initiative would support the next generation of scientists to “develop creative new approaches for detecting, measuring, and analyzing a wide range of biomedical information” (Collins & Varmus, 2015). They even laid out a vision of the future in which the PMI is able to have a global impact through collaborations with similar projects in other countries. The tagline of *All of Us*, the PMI recruitment and research program, orients audiences toward the “future of health,” with improved health for future generations thanks to research participation today (All of Us Research Program, n.d.).



All of Us RESEARCH PROGRAM

All of Us can help make this vision of precision medicine a reality

All of Us RESEARCH PROGRAM | The Future of Health Begins With You

The power of 1 million people

NIH National Institutes of Health

Figure 8: A still from “The Future of Health Begins with All of Us: A Conversation with the NIH Director.” The NIH director discusses how this visionary project depends on a large, diverse cohort of research participants to make it a reality. (All of Us Research Program, Streamed live on Mar 14, 2019).

With considerable resources, cooperation across federal agencies, and a comprehensive national network of project partners, these imagined futures easily translate into plans of action. A project as big as the PMI needs a lot of support to work. The National Cancer Institute received $70 million for identifying genomic drivers of cancer to develop new treatments. The Food and Drug Administration received $10 million to develop databases in support of the PMI regulatory structure. The Office of the National Coordinator for Health Information Technology received $5 million to develop interoperability standards for data-sharing across health systems (Office of the Press Secretary, 2015). Before recruiting research volunteers, the PMI laid out its goals, governance, and overall approach. This level of coordination across government agencies is impressive. Simultaneously creating legal, technological, professional, and social systems to enable research will definitely lead to the discovery of new medical treatments and screening methods. That's what it was designed to do. It just strikes me that this sort of top-down planning is at odds with the ethos of the *All of Us* research program, encapsulated in its motto: the future of health begins with you. It's hard to take that sentiment at face value with so much planning ahead of time to outline the methods and goals of interactions between participants, researchers, and institutions.

The values of the *All of Us* research program position participants as partners, with their security, privacy, and access to research information ensured (National Institutes of Health, n.d.-b). I see this public claim of partnership as a promising recognition of the need to rethink the social structures of health research. At the same time, I question whether these values are enough to make a meaningful impact on health equity in the context of precision medicine. The US has a long, complicated history of public health research ethics and community engagement among medically underserved communities. This history includes infamous events like the Tuskegee study, lasting from the 1930s to the 1970s, in which health care workers left hundreds of African American men untreated for syphilis (Jones, 1981/1993). The response to this egregious study included the Belmont Report, which outlined basic ethical principles for human subjects research. These principles focused on respect for personal autonomy, maximized individual benefits, minimized individual risks, and justice (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

Individual protections for research participants are necessary. However they are not sufficient to advance health equity, especially in the context of precision medicine. One's genetic information is shared with their family members. It can also be used to draw inferences about others from presumed similar geographic origins. Data about one’s environmental health factors also apply to their neighbors. Are individual consent, protections, and benefits enough to account for the ripple effects of population-level research?

An era of precision medicine requires an expansion of research ethics and a reconfiguration of the standard tools of research to better ensure health equity. Researchers using community-based participatory methods have noted the need to go beyond traditional interpretations of Belmont Report values to ensure equity in community partnerships, as well as community benefits and empowerment (Shore, 2006). Tribal review boards provide noteworthy models of the reconfiguration of research to build capacity and improve health of medically underserved communities (Around Him et al., 2019). Such reconfigurations are necessary, as illustrated by the early 2000s case of the Havasupai Tribe. Tribe members volunteered blood samples for use in diabetes research by Arizona State University (ASU) researchers in the 1990s. Some later discovered that their samples had been used for other areas of research they were not aware of. Members took legal action against the university and the tribe banished ASU members from their land as a result (Harmon, 2010). I worry about the professional response to such situations. Focused on individualized concepts of ethics, scientists may focus on building in more explicit language about potential reuse of biospecimens and research data while ignoring questions of community sovereignty (Garrison, 2013). I see changes to US research regulations in 2017 enabling this kind of thinking, with clearer guidelines and allowances for such practices, termed “broad consent” (Office for Human Research Protections, 2018). This is consistent with an individualized view of protection, privacy, and justice. If someone gives their consent to broad reuse of their biosamples, then what’s the harm? If the samples are de-identified, then such consent may not even be necessary since such materials no longer qualify as human subjects.

I argue that a lack of community engagement in forming research questions, using biospecimens, and using research data is still a form of community engagement. It is still impacting the relationship between researchers and medically underserved communities, as in the case of the Havasupai Tribe. It reinforces an extractive relationship in which one group of people are a source of data that another will use to build their careers, with the benefit of a far-off promise of population health improvements. This has long been the promise of health research, and yet the US still sees devastating health disparities today. Present day efforts like *All of Us* seek to deliver on this promise not just with medical breakthroughs, but also with individual access to health information garnered through precision medicine research. *All of Us* is taking steps beyond individual protections and benefits by incorporating participant ambassadors into its Advisory Panel, Steering Committee, and Executive Committee (National Institutes of Health, n.d.-a). If equity, innovation, and partnership are the future of health, then I hope that this is the prologue. I hope that such steps are just the beginning of the program's expansion of research ethics and community engagement, signalling a changing tide in the way health research is evaluated and funded.

In the previous chapter, I outlined the negative impacts of a dominant transmission view of communication in public health. It leaves questions of power, feedback loops, and politics unexamined, which has a negative impact on health equity as public health research institutions continue to neglect medically underserved communities. I also highlighted opportunities to fill in these gaps using a ritual view of communication. In this chapter, I define what a ritual view of communication entails in the field of public health. I then explain the affordances of this view of communication, especially in participatory research frameworks. Finally, I offer an evaluation tool that leverages a ritual view of communication for use in public health academic-community partnerships.

II. A: What Does a Ritual View of Communication Entail in Public Health?

"Henrietta Lacks." This one name was all it took to raise a chorus of nodding heads and hummed agreements at a focus group I was facilitating around participation in clinical trials. Earlier on in the discussion, the patrons generally agreed that clinical trials needed to include more African Americans and other people of color. However, once we brought the conversation down to the individual level... Well… Look at what happened to Henrietta Lacks. They stole her cells and let scientists all over the world use them without her consent. And what good did it do for her, her family, or her community? For the focus group participants around the table, Henrietta Lacks represented a history of unethical research on African Americans, the imbalances of representation in the scientific research workforce, and an overall lack of trustworthiness in the US medical system. Henrietta Lacks may have been a historical case, but for the patrons in the room, her story illustrated ongoing inequities.

I have not seen forward-looking efforts like the Precision Medicine Initiative meaningfully engage with the past. As a public health researcher, I can see the motivation behind this approach. Such projects represent new directions for research and community engagement, which don't need to be mired in associations with research that took place well before many of today's public health professionals were even born. As a member of a medically underserved community myself, however, I can't help but think of questions I know some of my family members and neighbors would have. Are government institutions like the NIH hoping we don't know about issues like the Tuskegee study or Henrietta Lacks? I'm sure researchers working on those projects said they were doing good things too. These genetic researchers are only advertising the good parts of their work, right? What are they hiding? How would we ever know? As someone bridging the gap between research institutions and a medically underserved community myself, I can point to federal laws, research regulations, and internal review boards to show how things have changed for the better. But then when I look at the makeup of the medical field and the health research workforce, I'm not so sure. When I see the promise of precision medicine research to lead to better health for all of us, I can't help but wonder: aren't these the kinds of promises my parents heard?

Delivering on the promise of improved health for all requires wrestling with the past, and applying lessons learned to our visions of the future. To impact a wide variety of communities, this work requires collaboration with a wide variety of partners. I feel encouraged by the partnerships that the *All of Us* research program has formed, as well as by the participatory aims of its governance structure. But I worry that these networks will be leveraged in the primary pursuit of transmitting the reasons to trust precision medicine research and participate in it. I wonder what it would take to leverage these networks to make the project more responsive to medically underserved communities needs'. How can *All of Us* position medically underserved communities as sources of knowledge and authority, and allocate resources for their benefit accordingly? How can *All of Us* move beyond a project-by-project, individualistic notion of research ethics to better position medically underserved communities for improved health? I believe that a ritual lens of communication can shed light on possible answers.

II. A1: What does a ritual view of communication imply for community engagement in public health?

Definition.

Within the realm of public health, I define a ritual view of communication by its focus on the social structures that a communication process maintains, via shaping power dynamics, social roles, expectations, conflicts, and feedback loops. This definition of ritual takes James Carey's concept of a ritual view of communication as a starting point, synthesizing it with Stuart Hall's concept of "encoding/decoding" and Nancy Fraser's concept of "multiple publics" to be of use in real-world community engagement settings. I do not propose that this concept of ritual replace more transmission-focused conceptions of communication altogether. Rather, I propose that it highlights opportunities for intervention and research in advancing health equity where current approaches to communication and community engagement fall short.

My use of the term "ritual" takes James Carey's contrast of ritual and transmission views of communication as a starting point. In short, a transmission view of communication focuses on the transfer of information, whereas a ritual view focuses on the broader system that the communication process maintains. Carey highlights how communication resembles a traditional Christian church service, wherein people come together in specific roles to maintain shared worldviews and community ties (Carey, 1989). In the realm of public health communication, this focus on roles, worldviews, and community implies examining community engagement efforts in terms of how they shape relationships, shared knowledge, and power dynamics between the stakeholders involved. While this abstract concept of ritual is useful for high-level critical thinking about mass communication, its application in the intervention-focused field of public health requires more detail about stakeholder interactions.

I fill in these gaps by incorporating Stuart Hall's encoding/decoding model of communication into my conception of the term "ritual." Hall's model focuses on the relationship between the intended messages that producers encode into mass media and the variable meanings that audience members interpret via decoding them (Hall, 1973/2007). According to Hall's model, an audience member may completely align their personal reading of a mass media message with the producer's intended meaning, completely oppose the intended meaning, or negotiate a separate meaning. However, as Hall's model emphasizes, structural factors shape the intended meanings that get encoded into communications. The decoded messages that audiences interpret then feed back into the very systems of knowledge and power that will shape future communications. For example, consider how federal funding structures outline expected meanings for health communication before a project team even conceives of their own goals. Eventually, the research team will interpret audience perceptions and interactions with their program in reference to existing evidence-based communication programs and ideas about communities that may or may not be "hard to reach." These outcomes will then contribute to the body of knowledge around public health communication and inform the aims of future communications. Thus, I incorporate the idea of encoding/decoding into my conception of ritual to account for varying audience interpretations, as well the feedback loops involved in community engagement long-term.

Finally, my conception of a ritual view of communication incorporates Nancy Fraser's concept of multiple publics to address the potential political conflicts that arise in public health communication. As Fraser argues, the "public sphere" actually comprises multiple publics with their own norms, needs, and values (Fraser, 2007). Fraser notes that these publics may have varying—and sometimes conflicting—priorities. Thus a multifaceted view of the "public good" is necessary for the advancement of equity, rather than smoothing over differences to create a homogenized view of "the public" with a unified "public good." Such homogenization will marginalize minority communities by prioritizing the majority's views. Such a multifaceted perception of the public sphere is a key component in my conception of ritual communication, as it underscores the reality that the same community engagement efforts will look different from the perspectives of different groups. This is key in the advancement of health equity, where it is necessary to examine how community engagement efforts address the priorities, needs, and perceptions of people within medically underserved communities. Further, it prompts an examination of the ways that funding, research, and publication turn public health professionals into a separate audience for community engagement programs as well.

Implications.

By utilizing these previous concepts in the field of public health, this ritual view of communication prompts an examination of community engagement from the lens of multiple populations, teasing out differing audience responses, and examining the power these audiences have in shaping ongoing communication efforts. For example, consider a hospital-run community engagement program around breast cancer screening. A hospital running such a campaign may examine links between campaign exposure and provision of mammograms to evaluate their efforts. A patient exposed to the campaign may evaluate it in terms of how the hospital facilitated follow-up to the results of their own screenings. Finally, an advocacy group may evaluate the campaign in terms of the resources that flowed into communities bearing the brunt of breast cancer disparities. Synthesizing these differing definitions of success into a multifaceted analysis could reveal the synergies, conflicts, and social roles that together paint a more accurate picture of the campaign than any one of the viewpoints could produce on their own. In this case, we might look at how well the campaign met each group's priorities, as well as what long-term outcomes are likely if this campaign is taken as a successful model for the hospital to follow in the future. Who will be served? Who will have decision-making power? Who will be left out? These are the kinds of questions that a ritual view of communication will promote, which can help advance health equity. This scope of knowledge and action has more potential to reduce health disparities compared to the scope of questions focused solely on the effects of transmitting information.

This view of communication is equipped to address the areas that a transmission view of communication ignores, as I outlined in the previous chapter: power, feedback loops, and politics. This can shed new light on communication efforts aimed at increasing knowledge or shifting perceptions of health topics. Whether or not the resulting dynamic is intentional, these efforts maintain a specific relationship between the target communities and the institution reaching out to them. A transmission view of communication would leave this dynamic unexamined. A ritual view of communication would expand research and evaluation programs that inform the judgement of whether the community engagement efforts were successful. How was decision-making power distributed in the work? What was the representation like for medically underserved communities? How did this effort interact with other social issues and institutional interactions with the target communities? Did the project make any headway on social determinants or political issues contributing to the public health issue at hand? While much work remains to be done on how to answer such questions, it is necessary to begin with conceptions of research and community engagement that support researchers to ask them in the first place.

II. A2: What are current approaches to reconfiguring research and community engagement in public health?

The ritual view I've outlined focuses on how varying actors maintain a social structure through communication. Thus it suggests the need to incorporate knowledge from the positions of all actors involved in order to accurately understand and intervene in that social structure for improved health outcomes. This has notable implications for public health research, program planning, and evaluation alike. There is a need to move beyond communication research focused solely on how well specific information travels through specific pipelines. There is a need to move beyond notions of professionalized expertise as a privileged viewpoint in planning community engagement efforts. There is a need to move beyond the pursuit of accurate evaluation of community engagement through a singular, so-called objective analysis. So, what does this ritual view of communication look like when acted upon in public health? Essentially, it looks like participatory research.

Public health professionals currently recognize the need for more collaborative and participatory processes. Though not framed in terms of communication and ritual, there are a variety of participatory research frameworks that aim to better integrate community engagement into research for the sake of more impactful research outcomes. Here, I will discuss several notable frameworks that have gained support in the field of public health in recent decades: participatory action research (PAR), community-based participatory research (CBPR), citizen science, and participatory design. Then, I will discuss how framing these research frameworks through a ritual view of communication reveals opportunities to strengthen such work.

Participatory Research Frameworks

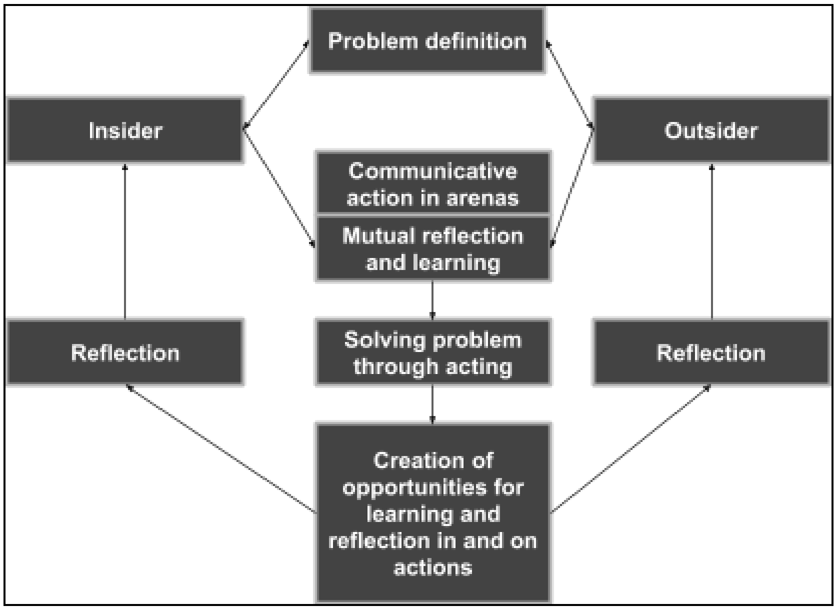


Figure 9: A model of action research from Greenwood and Levin. It highlights an insider/outsider division and the importance of communicative arenas for generating knowledge and acting on solutions (Greenwood & Levin, 2007, p. 94).

Participatory action research (PAR) is one such framework that proposes a reconfiguration of the power relationships between subjects, researchers, and society. In essence, PAR proposes that marginalized communities learn about the world through intervening in it for social change. Its professional recognition in the US dates back to Kurt Lewin's work in the 1940s, when he advocated for "action-research" as a means to integrate social science into a cycle of action, research, and training to solve cyclical issues facing minority communities (Lewin, 1946). Modern manifestations of PAR also have roots in Paulo Freire's work in the 1960s to facilitate education and social change in oppressed Brazilian communities through political consciousness (Freire, 1970/2005). As PAR has gained a wider following in academic settings, researchers have theorized what it means for professionals to enact the values of PAR in their work. Greenwood and Levin formally describe action research in terms of knowledge co-generation between insiders who "own" a problem and outsiders who are professional researchers facilitating a co-learning process to solve it (Greenwood & Levin, 2007, p. 93). They describe a communication arena as a key component of action research, in which insiders and outsiders carry out a process of co-learning and reflection that drives cycles of progress towards solutions (Greenwood & Levin, 2007, Chapter 6). Similarly in public health, PAR is understood as a deeply reflective process, in which participants seek to improve their own practices while taking action to examine and change a real-world system (Baum et al., 2006). The earliest paper archived in PubMed employing the term "participatory action research" is a 1991 publication arguing for PAR as a necessary part of self-help research to produce better, more useful knowledge for scholars and the self-help movement alike (Chesler, 1991). Photovoice is perhaps the most widely known method associated with PAR in public health, using community-led photography and storytelling for both qualitative research purposes and advocacy around community issues (Wang, 1999).

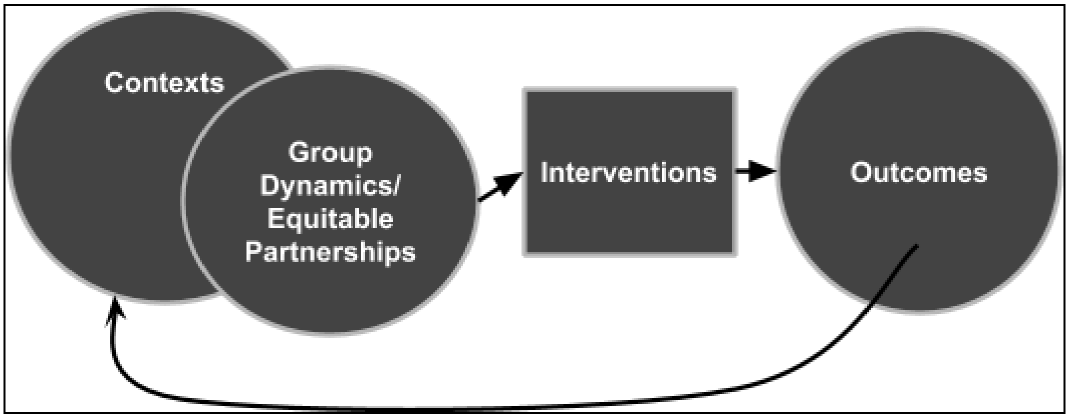


Figure 10: A model of the factors influencing CBPR projects from Wallerstein et al. It acknowledges the cyclical nature of research impacting the context in which partnerships form (N. Wallerstein et al., 2008)

Related to PAR but less explicitly focused on issues of political consciousness, community-based participatory research (CBPR) is a framework that promotes equitable partnership between researchers and the population being studied at every step of the research process. Barbara Israel is a seminal figure in the use of CBPR in public health, with a 1998 paper cited over 1100 times in PubMed archives (B. A. Israel et al., 1998). She has continued to advance CBPR methodology in public health, examining: the sustainability of CBPR partnerships (Barbara A. Israel et al., 2006), CBPR's potential to eliminate health disparities

(Barbara A. Israel et al., 2010), and CBPR principles (Barbara A. Israel et al., 2018). See Wallerstein and Duran's work for more insight into the history and theory of CBPR (Nina Wallerstein & Duran, 2018). CBPR has gained structural recognition in the form of the CBPR Research Program run by the National Institute on Minority Health and Health Disparities (National Institutes of Health, 2018). The program provides project funding through U01 Cooperative Agreements Research Project Grants "to enhance community capacity in research for which they will directly benefit; support collaborative intervention projects addressing health disparities; and accelerate the translation of findings into improved health and health outcomes." (National Institutes of Health, 2015).

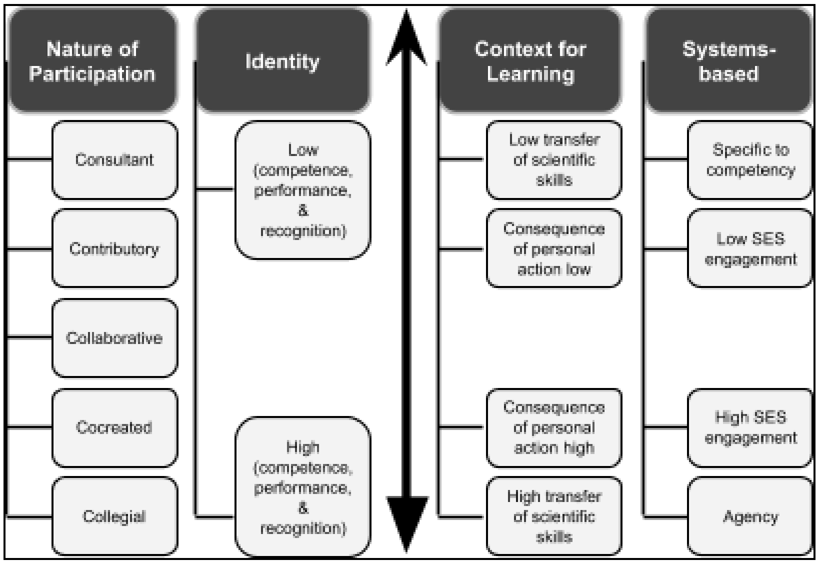


Figure 11: A model for conceptualizing citizen science from Jordan et al. This model presents several spectra of alignment for such work: public participation, impact on self-identification with respect to science, educational goals/context, and impact on systems of knowledge production (Jordan et al., 2015).

Citizen science is a participatory research framework that is less focused on a concept of equitable partnership than PAR/CBPR. It focuses on collaborations with public audiences, but does not center questions of equity in the relationships between professional researchers and other collaborators (Wiggins & Wilbanks, 2019). Although members of various publics have long gathered scientific data, the earliest publication employing the term "citizen science" archived in PubMed is a 2003 paper about The Fish Survey Project carried out with the help of SCUBA diving communities starting in 1993 (Pattengill-Semmens & Semmens, 2003). This example illustrates the niche that citizen science has risen to fill within the context of professionalized science. Citizen science provides a framework to address large-scale research questions that are impossible or impractical to address without a large scale of cooperation. Citizen science can also address localized research questions that may not garner the professional recognition typically called upon to justify resource allocation for a larger professional research team (Miller-Rushing et al., 2012). The US federal government supports a community of practice, maintains resource toolkits, and coordinates with academic and industry partners to support citizen science through the Federal Community of Practice on Crowdsourcing and Citizen Sciences (FedCCS), supported through the Citizen Science Act of 2016 (Federal Community of Practice for Crowdsourcing and Citizen Science, n.d.). Part of this work happens on the *CitizenScience.gov* platform, which includes access to research toolkits and a catalog of citizen science and crowdsourcing projects seeking volunteers. Here, the federal government highlights the opportunity for citizen science to address societal needs and accelerate scientific progress (U.S. General Services Administration, n.d.).

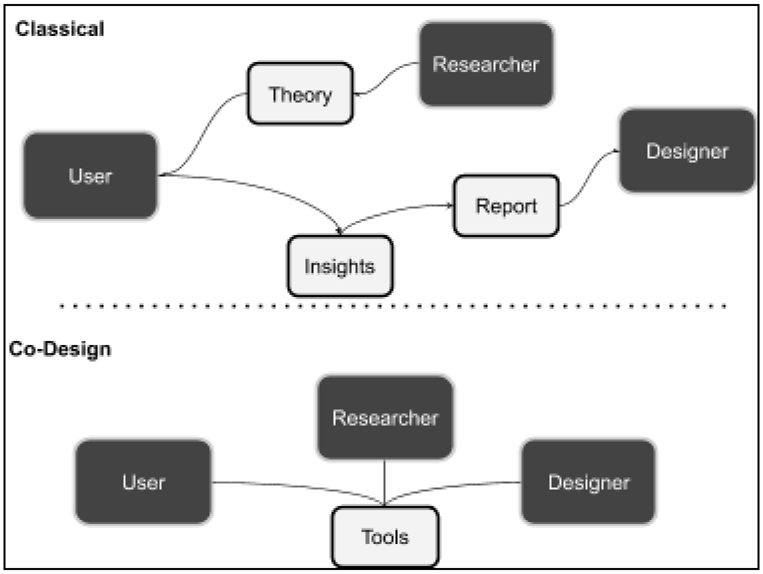


Figure 12: A model of co-design compared to classical design processes, from Sanders and Stappers. The classical design process separates users, researchers, and designers into distinct roles with distinct tools. Notably, the user is a passive subject of observation. Co-design does not prescribe such distinct roles, with users, researchers, and designers gathered together around the same set of tools. (Sanders & Stappers, 2008)

Within public health, participatory design frameworks have been extending the rise of collaborative and participatory processes into translational work as well. Participatory design is a framework that proposes input from end-users in every step of a development and deployment process. It originated among Norwegian union workers in the 1970s advocating for more control over the introduction of new technologies in their workplace (Kuhn & Winograd, 1996). Though it has been around for decades, the rise of participatory design in public health is much more recent, with over half of the existing studies archived in PubMed employing the term coming out since 2016. An early use of a self-described participatory design process in a clinical setting reveals the tensions in using such frameworks in professionalized research fields. Although Tovar et al. describe their design process of case management software as participatory, the only form of user input was through formative research interviews (Tovar et al., 1991). The intended users provided information, but did not make decisions around the development or deployment of the technology in their workplace.

Implications for the Future.

As outlined above, many participatory research frameworks have roots in political movements and efforts to dismantle oppressive power structures. There are limitations to what this might mean in the space of federally funded research projects. However, it is clear that the values of participatory research have impacted the US federal government's approach to public health research. The *All of Us* research program, for example, frames research program participants as partners. Its governance structure includes participant representatives who provide input on the program through advisory roles (National Institutes of Health, n.d.-a). In drawing on the methods and language of participatory research frameworks, *All of Us* illustrates the opportunities of collaborative and participatory research by government-funded institutions. Public service provision can respond directly to research findings. Research questions can respond directly to the needs of project community partners. With a focus on partnering with medically underserved communities, this project can be an engine for health equity. However, in drawing on participatory frameworks, the PMI also becomes part of an ongoing tension between the promises of participatory research and its implementation in real-world professionalized settings.

Existing scholarship on CBPR suggests that many aspects of the US health research infrastructure inhibit a focus on the social structures formed during health research. For example, short-term evaluations miss the long-term ripple effects of trust-building and power-sharing (Jagosh et al., 2015). Typical funding availability and timelines do not match the long, unpredictable processes of forming relationships and maintaining research partnerships in medically underserved communities (Barbara A. Israel et al., 2006). Further, building research capacity among community partners can fall outside the realm of standard research job descriptions and funding categories (Strickland, 2006).

At a broad scale, this implies the need for funding structures that are more supportive of research that accounts for the relationships and social structures that it forms. The federal government has specific funds for such research, such as the National Institute on Minority Health and Health Disparities CBPR Research Program. However, there is room to expand the evaluation methods and funding guidelines through a ritual view, to better promote relationship building and capacity building as well as capture their ripple effects. For example, Clinical and Translational Science Centers (CTSC) could benefit from a ritual view of communication in their planning and evaluation processes, as a key goal of a CTSC is to engage patients and communities in every phase of the translation process from scientific discoveries into clinical breakthroughs (National Center for Advancing Translational Sciences, 2018). What kinds of changes do partners hope to see in the relationship between clinical/research institutions and patients? How will these manifest in capacity-building, co-learning, institutional policy, decision making process, hiring practices, and more? Incorporating these kinds of questions into the formal analysis of funded centers could help account for a lot of the work already required to achieve community engagement goals.

On a program level, this also implies that the Precision Medicine Initiative can promote health equity through such changes in its own partnerships, as well as in its terms of access to its research databases. What if the evaluation process for projects seeking access to *All of Us* data included a focus on community benefit agreements with local partners? What if potential impact was judged in part by how the research process would impact a community experiencing health disparities in the area of health being researched? What if *All of Us* community partners were part of review boards and received project progress reports? There are myriad ways that the Precision Medicine Initiative could scaffold the planning and evaluation of community engagement efforts to incorporate a ritual view of communication to advance health equity. Alongside breakthroughs in medical treatments, such a regulatory breakthrough could serve as a model for health research more broadly.

II. B: What is the Health Equity Ritual Model of Community Engagement?

A ritual view of communication focuses on the relationships and social structures that a communication process maintains. This is a fundamental shift in focus from the dominant transmission-focused lens of communication. In public health, this implies that a ritual view of communication has broad-ranging impacts on all aspects of community engagement, from planning to evaluation. As noted above, participatory research methods can serve as models for implementing such a framework. However, these research frameworks face difficulties in aligning with typical funding structures and grant timelines. There is a need for broad change across funding opportunities to better address community engagement through a ritual view to advance health equity.

That being said, a ritual view of communication can still help advance health equity on an individual partnership level. Absent federal guidelines or clear metrics of evaluation, an academic community partnership can still leverage a ritual view of communication to evaluate their work. Here, I present a conversational tool meant to assist ongoing academic-community partnerships do just that. Following the example of Frauenberger et. al in pursuing rigor in participatory design, I propose a tool-to-think-with (Frauenberger et al., 2015). This tool is meant to help academic and community partners reflect on their work as it is, what shaped it, and what room there is to further advance health equity.

The tool I propose is called the Health Equity Ritual (HER) model of community engagement. It is meant to help guide academic-community partnerships in their evaluative conversations. It is not meant to function as an academic evaluation framework, such as the conceptual framework Ward et. al proposed for CBPR research (Ward et al., 2018). Rather, it is a conversational tool that can help academic and non-academic research partners engage in evaluative conversations about their work using the same lens. Ideally, partners will come to the table with various kinds of information and experience with which to judge their work. As such, this model does not just include guiding concepts and questions. It also includes a series of steps and frameworks of interaction to guide the interpersonal aspects of conversation. The aim is to encourage sharing of varying viewpoints and sources of knowledge, even if they are in conflict with each other. In this way, the HER model leverages a ritual view of communication by focusing on the kinds of power that various stakeholder groups have in shaping the partnership.

The design of this model further incorporates a ritual view of communication to help shape the social structures formed at an interpersonal level within the partnership itself. The HER model comprises two paper-based tools to help guide conversation. The first tool is a papercraft kaleidocycle, meant to reflect the cyclical nature of community engagement while providing a physical prompt to help guide an evaluative conversation. The second tool is a zine, made on the back of an executive summary of the partnership's work. It is meant to guide self-reflection and documentation throughout the conversation. Together, these tools incorporate a ritual view of communication into evaluative conversations while providing a common language to do so. See Appendix C for instructions on assembling the HER model pieces.

II. B1: Tool 1. Papercraft Kaleidocycle.

The first component of the HER model is a representation of the community engagement process as a 4-phase cycle. Media studies and cultural studies theories of communication inform this representation, which aims to tease out the varying viewpoints and priorities of academic and community partners in public health research.

Conceptual Design: 4-Phase Cycle

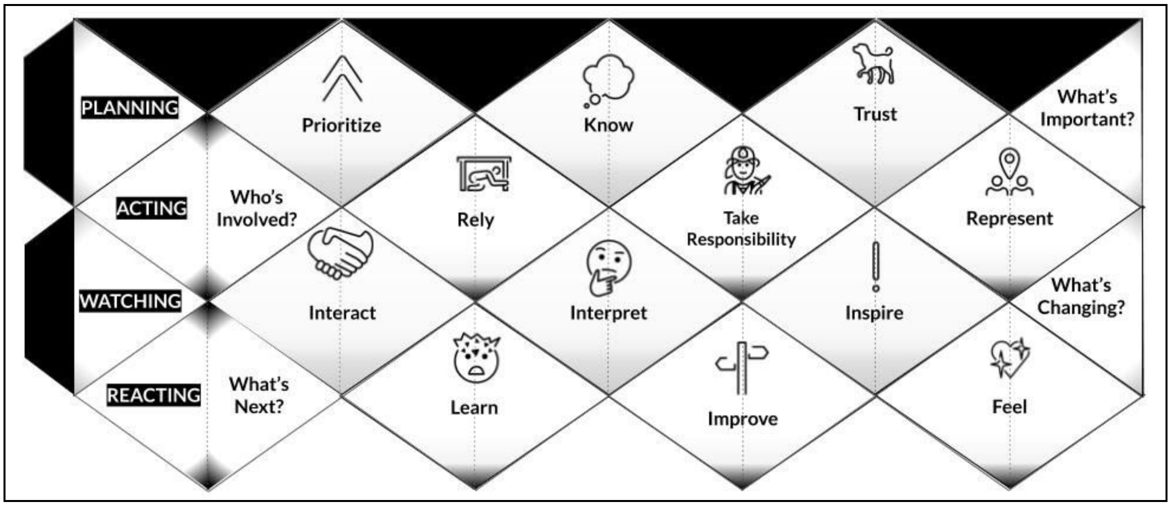


Figure 13: Kaleidocycle portion of the HER model of community engagement. Icons courtesy of the OpenMoji Project. This tool is available under a CC BY-SA 4.0 license.

The HER model divides community engagement into 4 phases: planning, acting, watching, and reacting. While real-world community engagement does not always progress in such a cleancut linear fashion, this model simplifies the representation of such work so as to prioritize usefulness in teasing out the social structures of real-world partnerships. As such, each phase includes 3 prompts to tease out the impact and limitations of academic-community public health project partnerships from stakeholders' varying viewpoints and social positions. As this tool is meant to prompt discussion about equity in academic-community partnerships, it is especially important that members of medically underserved communities are part of the conversation. When using this tool, partners should acknowledge that stakeholder groups, including medically underserved communities, will not all share the same priorities or viewpoints on public health topics. Thus, even in deeply collaborative partnerships with community representation, there will likely be unheard voices. With this caveat in mind, the HER model can nevertheless help tease out the current strengths, weaknesses, and impact of an academic-community project.

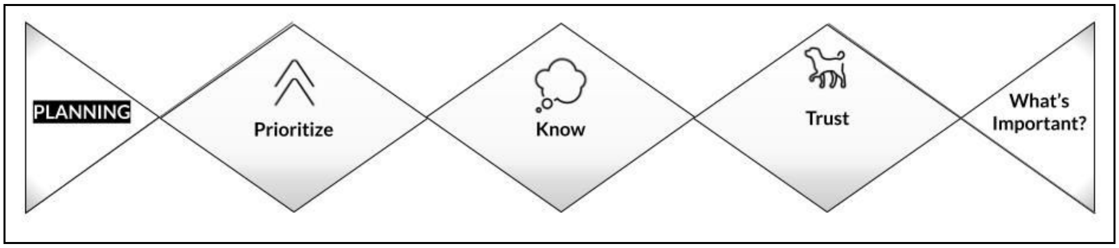


Figure 14: The "Planning" phase of the HER model of community engagement.

Planning. The overarching question of the planning phase is: what's important? What goals and scope of focus has been baked into a particular project from the beginning? This phase of community engagement draws on Stuart Hall's concept of encoding. Structural factors, existing frameworks of knowledge, and human decisions influence the intended message of a communication campaign (Hall, 1973/2007). In public health, these structural factors include available funding and professional pressures. These factors incentivize certain kinds of research or a focus on specific health topics. Existing frameworks of knowledge include prominent theories and existing research. These factors highlight what kinds of research questions or best practices to employ. Human decisions include the personal motivations of researchers and community partners, as well as the priorities of specific grant reviewers or program managers. These factors directly influence which options a program pursues. In sum, structural, knowledge-based, and human factors influence the priorities of a specific community engagement effort. They may incentivize formation of research questions with community partners focusing on a specific health topic, for example. Or they may incentivize academic researchers looking for a community partner to help recruit participants in an established protocol. While the planning phase does not entirely determine a project's outcomes, it does shape definitions of success, allocation of resources, and projected timelines. Thus the planning phase has serious implications for health equity, as it shapes the kinds of community involvement a project will actively foster. As such, the HER model of community engagement prompts stakeholders to reflect on the varying sources of knowledge and priorities that inform their work even before they formalize a project:

- Prioritize: what does each stakeholder group prioritize? How do these compare to what has been prioritized in the partnership?

    - There may be differences in project priorities across stakeholder groups. For example, academic stakeholder groups may be more concerned with research rigor than community-based organizations (CBOs), which may prioritize providing services to underserved communities.
    - Personal priorities will influence the project as well. For example, a research trainee may only be employed part-time and thus will count on this project alone to provide them with their first academic publication. A more senior researcher may view the project as a relatively minor part of their portfolio. One CBO partner may view the project as a low-effort way to maintain a relationship with a particular research lab, while another may have sought out this opportunity to increase their research capacity.
- Know: what does each stakeholder group know about the topic at hand? How did these kinds of knowledge each inform the partnership?
    - There are varying kinds of knowledge that can inform a community engagement strategy. Academic researchers will have the toolkits to easily draw on examples from existing research papers. Advocacy groups will have an understanding of the levers of change and available strengths in their community. Individual patients may know the reputations of various medical providers and institutions in their community.
- Trust: who does each stakeholder group trust regarding the health topic at hand? How were these various sources incorporated into the partnership's work?
    - Different levels of trust in various sources of information and services will inform community engagement. Public health professionals may be reluctant to provide community members information that is not coming directly from a recognized source such as the NIH. Meanwhile, centering a distant government agency may be less comforting for medically underserved communities compared to a trusted local community member like a librarian or a teacher.

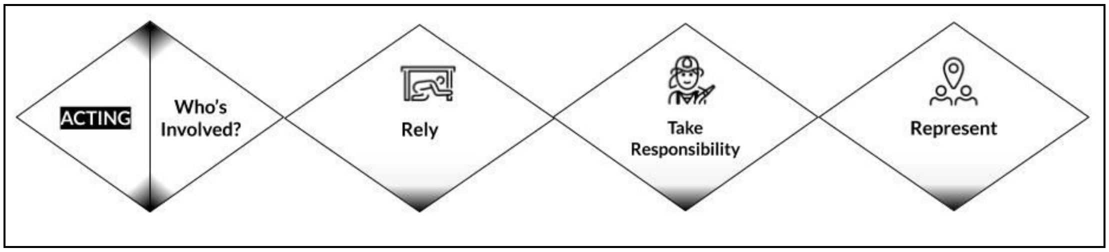


Figure 15: The "Acting" phase of the HER model of community engagement.

Acting. The overarching question of this phase is: who's involved? Who is in what roles in the project, and what are the methods of accountability?

- Represent: who is representing various stakeholder groups in the implementation of this project?
  - There is only so much room in budget, space, time, etc. for participants in an academic-community partnership. Thus representatives of stakeholder groups will play a large part in advocating for the needs of their community on the ground. For example, staff at a community-based organization will likely be focused on making sure the community engagement work reaches their constituents. Researchers may be concerned with making sure the project will lead to continued streams of funding so their team can continue to work on projects that can advance health equity. It is crucial for partnerships to keep in mind that the representatives on their team cannot possibly represent the needs and perspective of everyone in their community. As such, it is important to reflect on the limits of the project's representation and the methods through which the partnership can grow their representative perspectives.
- Rely: to what extent do various stakeholder groups rely on the success of this project, and why?
  - Varying kinds of reliances on a particular project may contribute to power imbalances. As such, it is important to reflect on any differences so as to correct for them in the partnership's decision making processes. For example, resulting publications may be just another entry in a CV for researchers at one institution, whereas it may provide more critical evidence of research competency for others.

A CBO may rely more on a specific project to fund the time of an employee than another CBO with more financial resources. Members of a medically underserved community may not have much outside access to the benefits that a research study or public health campaign may offer.

- Take Responsibility: what level of responsibility do various stakeholders have, both internally and externally? How has this impacted the course of the project?
    - In any group project, there will be a division of responsibilities. For example, it makes sense to capitalize on the training researchers have received to collect data and the infrastructure a CBO has in place to mobilize a community. However, it is important to reflect on whether the partnership is locking certain stakeholder groups into certain roles unnecessarily. For example, can clients or employees of a CBO receive training to be part of the data collection process? Can researchers receive training from CBO partners to learn more about reaching out to medically underserved communities?

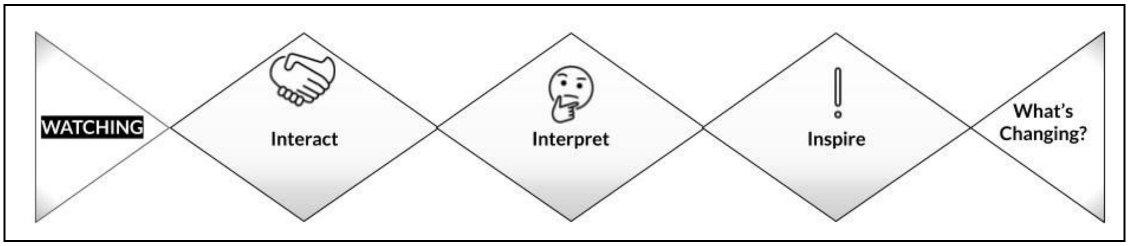


Figure 16: The "Watching" phase of the HER model of community engagement.

Watching. The overarching question of this phase is: what's changing? What are the impacts of this project, and how are they differing across stakeholder groups? This phase of community engagement programs draws on Stuart Hall's concept of decoding, in which audience members draw meanings from a communication campaign. The campaign producer's intended message influences this process, but cannot completely control it in the face of structural factors and individual experience (Hall, 1973/2007). Similarly, despite best efforts in the planning and acting phases of a community engagement program, not everyone in a target audience will take away the intended message. Further, a community engagement program may not reach entire segments of an intended audience. Health professionals' evaluation of a program may be accurate while not capturing the full scope impact in local communities. These factors are important, as they impact the lessons learned from this program, shape the narrative around it, and influence various stakeholders' next steps. It is important to think about how these dynamics impact health equity, as a sign of success that should be repeated for one stakeholder group may not impact another as much. The watching phase of this model is an opportunity to confirm whether desired project outcomes are having an impact in medically underserved communities, and whether segments of those communities are being ignored. As such, the HER model of community engagement prompts stakeholders to reflect on the varying perspectives that together form a holistic view of the outcomes of community engagement efforts:

- Interact: how do various stakeholder groups interact with the community engagement work? What are the implications for health equity?
    - One common metric in community engagement work is the number of people in the target audience reached, and through what methods. It is important to further reflect on what resources might be required to interact with the program in such a way. For example, perhaps the most common method of engagement requires a certain set of physical abilities, language capabilities, or free time. What contexts might leave part of the target audience underserved, and is there a way to better serve people in those contexts? Beyond these transmission-focused metrics, academic-community partnerships can also examine how various stakeholders interact with the project as it is being enacted. Are specific people gaining on-the-ground insights while others are focusing on the data collected? How might this impact various stakeholders' views when evaluating the process?
- Interpret: how do various stakeholder groups interpret the community engagement work? What are the implications for health equity?
    - Commonly used survey methods can provide some answers to this question from the audience point of view. Beyond this set of audience-focused questions, a ritual view of communication also prompts academic-community partnerships to reflect on how various partners interpret the project in its final form. Perhaps a project lives up to the metrics of success as defined in the planning phase, but now there

are differing opinions about whether that contributed to the intended impact. It's also possible that the focus of the project drifted over time from the initially stated goals. Or perhaps the project accomplished everything as planned, but some stakeholders saw missed opportunities to go further. Not all of such concerns will make it into a final report, an academic paper, or a news article about the project. However, these views will shape the ways that stakeholders interact with each other around this project and beyond. It is important to reflect on how the partnership might privilege certain stakeholders if there is not a serious consideration of varying interpretations of the same set of results or process evaluations.

- Inspire: what does the community engagement work inspire in the various stakeholder groups who interact with it? What are the implications for health equity?
    - One common metric in community engagement work is whether the target audience took a specific action (e.g. adopted a health behavior, got a screening, etc.), shifted their perspective on a health topic, or gained knowledge. Beyond these kinds of metrics, an academic-community partnership can consider what the project has inspired within its own stakeholders. Did people have to come up with solutions to problems that were not accounted for in the planning phase? Did the project foster new ideas or new partnerships on the ground? Were there co-learning opportunities among stakeholders?

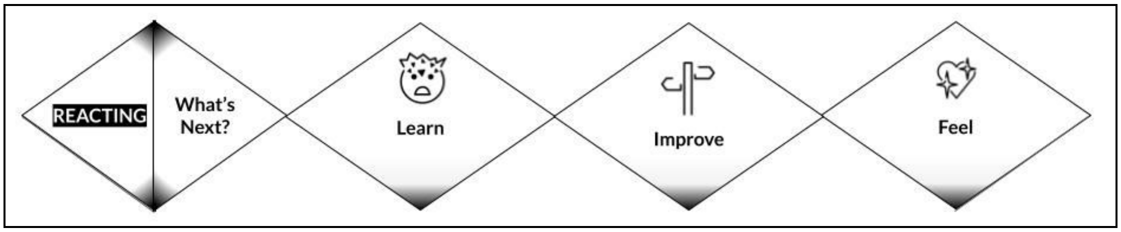


Figure 17: The "Reacting" phase of the HER model of community engagement.

Reacting. The overarching question of this phase is: what's next? What lessons are various stakeholder groups drawing from the previous phases, and what are the implications for health equity? Again, this phase of the HER model relates to Stuart Hall's model of encoding/decoding, in which an audience's decoding process feeds back into the frameworks of knowledge and structural factors that will inform future communication programs (Hall, 1973/2007). In an academic-community public health partnership this might take the form of published journal articles that will inform future research. It might also take the form of best practices for community-based organizations. It might even take the form of increased community trust in a partner institution or specific health professionals. As such, the HER model acknowledges the feedback loops inherent in community engagement. The HER model prompts project partners to think about the long-term impact of their work, not just in the predefined target audience, but also on their own practice, their personal outlook, and their field.

- Feel: how do various stakeholder groups feel about what happened?
    - Typical evaluations of community engagement work may include a focus on audience perceptions, satisfaction, etc. In a ritual view of communication, researchers would want to examine such measures in the context of feelings and perceptions of various stakeholder groups working on the project. Are there differences in the levels of pride that stakeholders feel around this particular project? Was the process more draining for some people than others? Are there differences in satisfaction of the division of labor and learning opportunities across stakeholders? Is everyone comfortable with the balance of emotional and mental labor with the pursuit of the project's measures of success? Do any related trade-offs impact certain groups of stakeholders more than others? Such reflection can help uncover power dynamics in which certain stakeholder groups or are disproportionately expected to make sacrifices in emotional and mental well-being. Intervening in such dynamics is especially important in projects which may seek to draw in more employees or trainees from underserved communities.
- Learn: what did various stakeholder groups learn from the project?
    - Lessons learned from an academic-community partnership are often written up in academic journal articles and grant reports. If the partnership has access to traditional mass communications resources, they may also share lessons learned in press releases or news media coverage. Due to conventions in such media,

    these lessons will likely seek to present a definitive, objective point of view on the partnership's work. In a social process, however, a singular objective view is impossible. While there may be strategic reasons to attempt to present such a view, it is important that an academic-community partnership not internalize this way of thinking. What did stakeholder groups learn from each other? What did stakeholders learn about each other? Was there co-learning in place throughout the process? Did one stakeholder group learn something another already knew?

- Improve: how do various stakeholder groups want to improve on this project?
    - Various stakeholders will be able to provide differing insights into what improvements can be made to improve the partnership's work, or to improve future iterations of the project at hand. As in the previous phases, it is important to reflect on the insights that differing kinds of knowledge and differing social roles can offer. This prompt is also an opportunity to reflect on the ways that the partnership's work can further advance health equity. What hurdles to access can stakeholders remove? What extra outreach efforts can partners conduct? What power dynamics can the partnership intervene in? These are the kinds of improvements that can help improve the ability of academic-community partnerships to better serve medically underserved communities.

Physical Design: Conversational Tool

The HER model of community engagement is meant to exist as a physical object. It is to be cut, folded, and glued into a kaleidocycle—a 3-dimensional papercraft object that a user can continually rotate around itself. This is meant to represent the cyclical nature of community engagement and communication, as well as provide a physical prompt to help pace a conversation. The discussion should only focus on one phase at a time, and should not continue past the current phase until everyone has flipped their kaleidocycle over to the next one.

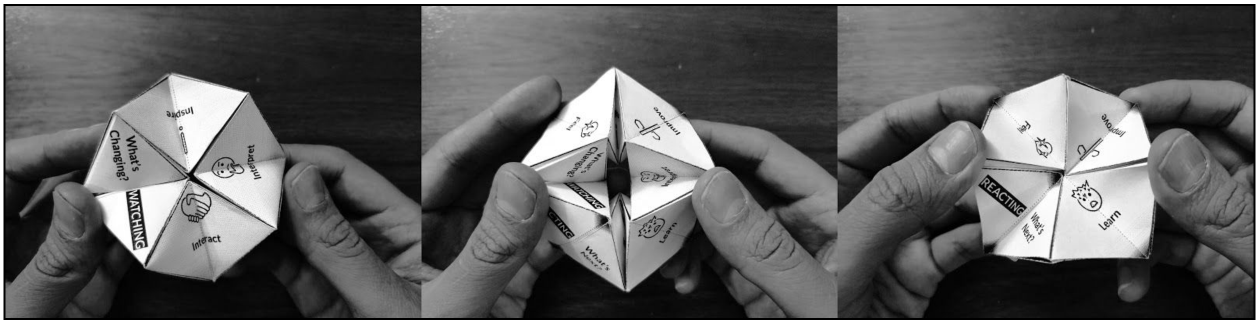


Figure 18: A demonstration of the HER model's kaleidocycle rotating around itself.

As a tool meant for evaluative conversations in academic-community partnerships, each participant in such a conversation is meant to have their own kaleidocycle. Every participant is meant to reflect on the prompts for each phase, relying on the single-word prompt and icon to spark their own personal reflection. As such, representative voices from each stakeholder group should be at the table to speak to each prompt. This aspect of the HER model draws on Nancy Fraser's work, highlighting the need to tease out varying viewpoints of public good and maintain space for dialogue in which conflicts can be explored—not necessarily resolved into a single homogenous view (Fraser, 2007).

II. B2: Tool 2. Zine.

The second tool in the HER model of community engagement is a zine template. It is meant to act as a reflection and documentation tool in an evaluative conversation in an academic-community partnership alongside the kaleidocycle above. It is designed to be made on the back of an executive summary, press release, or otherwise official description of an academic-community partnership project. Project partners then cut and fold the single-page summary to make a 6-page zine with a front and back cover.

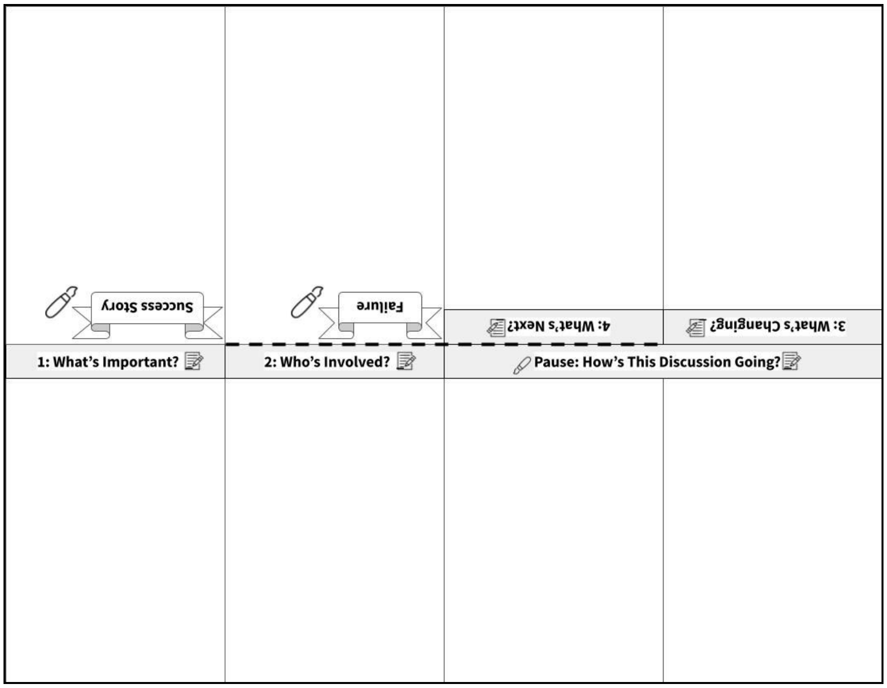


Figure 19: Zine portion of the HER model of community engagement. Icons courtesy of the OpenMoji Project. This tool is available under a CC BY-SA 4.0 license.

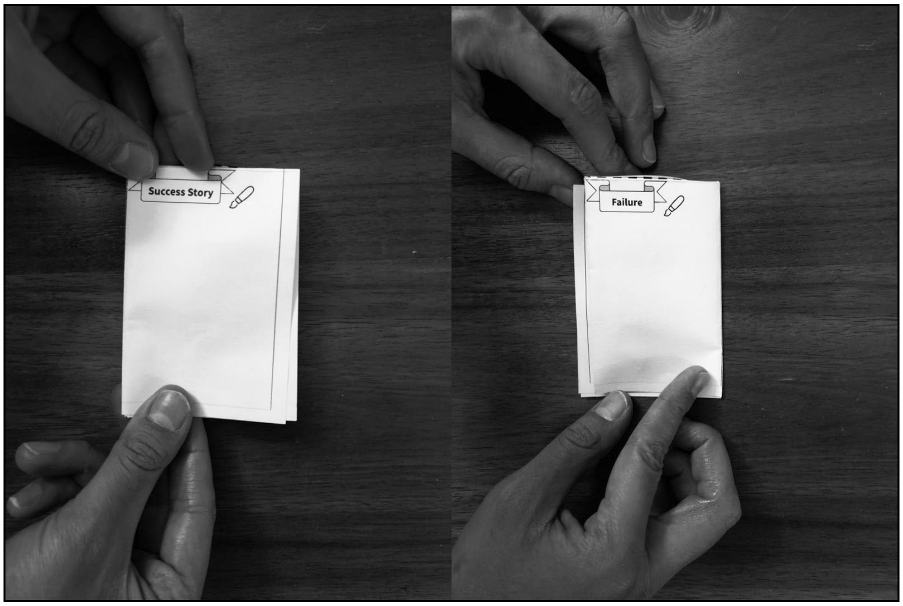


Figure 20: The front and back covers of the HER model of community engagement zine.

At the start of an evaluative conversation, academic and community partners can fill in the front cover with a drawing representing a success of their current project. Then they can fill in the back cover with a drawing representing a failure of their current project.

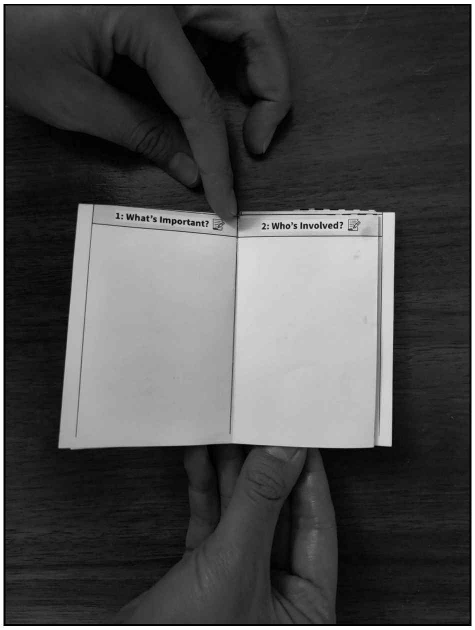


Figure 21: Pages 1 and 2 of the HER model zine.

As the conversation continues to the planning phase and acting phase of the project, they can use the first two pages of the zine to take brief notes.

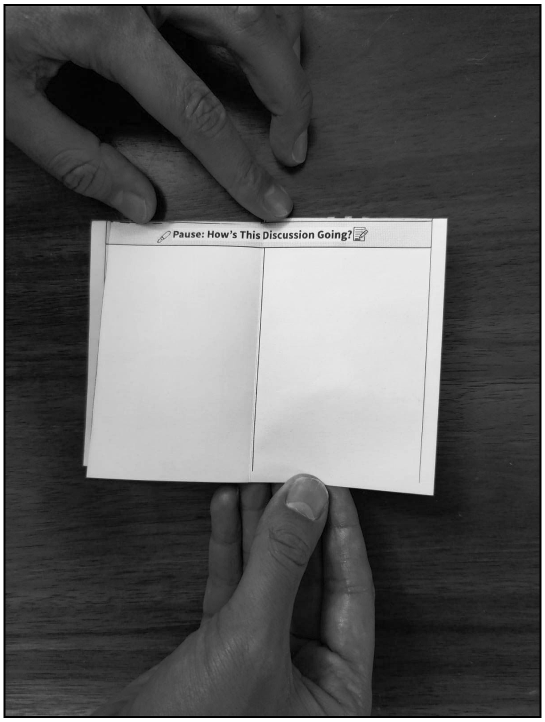


Figure 22: The pause-and-reflect spread of the HER model zine.

Then, all participants are invited to pause to reflect on how the conversation is going, through a combination of drawing and writing.

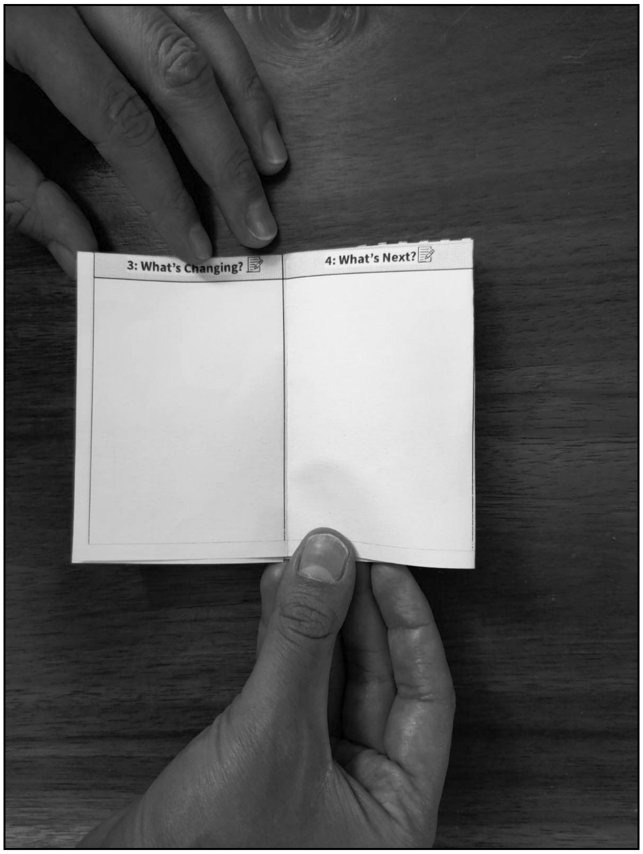


Figure 23: The final two pages of the HER model zine.

Finally, participants can move onto the watching and reacting phases of the HER model of community engagement. The last two pages of the zine provide a space for each participant in the conversation to take notes.

By inserting pauses and multiple modes of reflection into an evaluative conversation between project partners, this zine aims to intervene in typical conversation flows that may serve to reinforce in-group social roles. By giving each participant the power to create a representation of their own narrative around the partnership's work, this zine aims to act against the idea of a singular objective truth about the public health impacts of community engagement. The resulting zine serves as a documentation of each participant's perspective on a collective process. It can later provide succinct symbols of partnership and project dynamics. It can inform process improvements for future partnership conversations, as well as potential reconfigurations of agenda-setting and decision-making power.

II. C: Conclusion

In *Pedagogy of the Oppressed*, Paolo Freire frames dialogue as a form of co-creation, not a transfer of ideas. He calls dialogue transformational, describing how the act of naming the world transforms and humanizes it. As such, it is important that marginalized people have the power to meaningfully contribute to the conversation. Right now, such groups face structural barriers to joining in these processes, including research. Beyond that, various forms of prejudice and discrimination make it harder for their voices to be hard. This means that bringing different people together in a co-creative community not only requires fixing structural inequalities. It also requires love, humility, and faith in people (Freire, 1970/2005, Chapter 3).

In my experience, public health professionals don't often talk about warm and fuzzy emotions. But it seems clear to me that seriously believing that we can move from an inequitable world to an equitable one requires a fair amount of faith in humanity. To devote a life's work to reaching such an abstract, far-off goal requires a fair amount of love. To form partnerships and constantly submit yourself to scrutiny from peers, funders, and public audiences requires a fair amount of humility. While the tools that public health professionals use to act on these feelings might require years of specialization, the underlying motivations are more universal. I hope that a ritual view of communication in public health can draw attention to the personal and emotional sides of health as a base on which co-creative communities can form.

In this chapter, I proposed one tool that can help maintain such co-creative communities: the HER model of community engagement. In the next chapter, I describe the process of designing a community engagement program acting on a ritual view of communication through co-creation.

Works Cited.

All of Us Research Program. (n.d.). *National Brochure - General Community*. Retrieved December 17, 2018, from https://www.joinallofus.org/sites/default/files/2018-07/AoU_NAT_Brochure_General_Community.pdf

All of Us Research Program. (Streamed live on Mar 14, 2019). *The Future of Health Begins with All of Us: A Conversation with the NIH Director* [Livestream]. Youtube. https://www.youtube.com/watch?v=qjNnhdsgWsU

Around Him, D., Aguilar, T. A., Frederick, A., Larsen, H., Seiber, M., & Angal, J. (2019). Tribal IRBs: A Framework for Understanding Research Oversight in American Indian and Alaska Native Communities. *American Indian and Alaska Native Mental Health Research* , *26*(2), 71–95.

Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology and Community Health*, *60*(10), 854–857.

Carey, J. W. (1989). A Cultural Approach to Communication. In *Communication as Culture: Essays on Media and Society* (pp. 13–36). Unwin Hyman.

Chesler, M. A. (1991). Participatory action research with self-help groups: an alternative paradigm for inquiry and action. *American Journal of Community Psychology*, *19*(5), 757–768.

Collins, F. S., & Varmus, H. (2015). A new initiative on precision medicine. *The New England Journal of Medicine*, *372*(9), 793–795.

Federal Community of Practice for Crowdsourcing and Citizen Science. (n.d.). *Federal Community of Practice for Crowdsourcing and Citizen Science*. US Genera Services Administration. https://www.citizenscience.gov/assets/FedCCS.pdf

Fraser, N. (2007). Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy. In S. During (Ed.), *The Cultural Studies Reader* (third, pp. 488–506). Routledge.

Frauenberger, C., Good, J., Fitzpatrick, G., & Iversen, O. S. (2015). In pursuit of rigour and accountability in participatory design. *International Journal of Human-Computer Studies*, *74*, 93–106.

Freire, P. (2005). *Pedagogy of the Oppressed* (M. B. Ramos, Trans.; 30th Anniversary Edition). The Continuum International Publishing Group Inc. (Original work published 1970)

Garrison, N. A. (2013). Genomic Justice for Native Americans: Impact of the Havasupai Case on Genetic Research. *Science, Technology & Human Values*, *38*(2), 201–223.

Greenwood, D. J., & Levin, M. (2007). *Introduction to Action Research: Social Research for Social Change* (second). Sage Publications.

Hall, S. (2007). Encoding, Decoding. In S. During (Ed.), *The Cultural Studies Reader* (third, pp. 477–487). Routledge. (Original work published 1973)

Harmon, A. (2010, April 21). Indian Tribe Wins Fight to Limit Research of Its DNA. *The New York Times*. https://www.nytimes.com/2010/04/22/us/22dna.html

Israel, B. A., Coombe, C. M., Cheezum, R. R., Schulz, A. J., McGranaghan, R. J., Lichtenstein, R., Reyes, A. G., Clement, J., & Burris, A. (2010). Community-based participatory research: a capacity-building approach for policy advocacy aimed at eliminating health disparities. *American Journal of Public Health*, *100*(11), 2094–2102.

Israel, B. A., Krieger, J., Vlahov, D., Ciske, S., Foley, M., Fortin, P., Guzman, J. R., Lichtenstein, R., McGranaghan, R., Palermo, A.-G., & Tang, G. (2006). Challenges and facilitating factors in sustaining community-based participatory research partnerships: lessons learned from the Detroit, New York City and Seattle Urban Research Centers. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, *83*(6), 1022–1040.

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: assessing partnership approaches to improve public health. *Annual Review of Public Health*, *19*, 173–202.

Israel, B. A., Schulz, A. J., Parker, E. A., Becker, A. B., Allen, A. J., Guzman, J. R., III, & Lichtenstein, R. (2018). Critical issues in developing and following community-based participatory research principles. In N. Wallerstein, B. Duran, J. Oetzel, & M. Minkler (Eds.), *Community-based participatory research for health: Advancing social and health equity* (third, pp. 31–44). Jossey-Bass.

Jagosh, J., Bush, P. L., Salsberg, J., Macaulay, A. C., Greenhalgh, T., Wong, G., Cargo, M., Green, L. W., Herbert, C. P., & Pluye, P. (2015). A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. *BMC Public Health*, *15*, 725.

Jones, J. H. (1993). *Bad Blood: The Tuskegee Syphilis Experiment* (new and expanded). The Free Press. (Original work published 1981)

Jordan, R., Crall, A., Gray, S., Phillips, T., & Mellor, D. (2015). Citizen Science as a Distinct

Field of Inquiry. *Bioscience*, *65*(2), 208–211.

Kuhn, S., & Winograd, T. (1996). Profile 14. Participatory Design. In T. Winograd (Ed.), *Bringing Design to Software*. Addison-Wesley. https://hci.stanford.edu/publications/bds/14-p-partic.html

Lewin, K. (1946). Action Research and Minority Problems. *The Journal of Social Issues*, *2*(4), 34–46.

Miller-Rushing, A., Primack, R., & Bonney, R. (2012). The history of public participation in ecological research. *Frontiers in Ecology and the Environment*, *10*(6), 285–290.

National Center for Advancing Translational Sciences. (2018). *Clinical and Translational Science Awards Program*. National Institutes of Health. https://ncats.nih.gov/files/ctsa_program_factsheet.pdf

National Institutes of Health. (n.d.-a). *All of Us Participant Partners*. AllOfUs.gov. Retrieved February 13, 2020, from https://allofus.nih.gov/about/who-we-are/all-us-participant-partners

National Institutes of Health. (n.d.-b). *Core Values*. Allofus.nih.gov. Retrieved April 3, 2020, from https://allofus.nih.gov/about/core-values

National Institutes of Health. (2015, May 18). *RFA-MD-15-010: Advancing Health Disparities Interventions Through Community-Based Participatory Research (U01)*. NIH.gov. https://grants.nih.gov/grants/guide/rfa-files/rfa-md-15-010.html

National Institutes of Health. (2018, October 2). *Community-Based Participatory Research Program (CBPR)*. NIMHD. https://www.nimhd.nih.gov/programs/extramural/community-based-participatory.html

Office for Human Research Protections. (2018, July 30). *Revised Common Rule Q&As*. HHS.gov; US Department of Health and Human Services. https://www.hhs.gov/ohrp/education-and-outreach/revised-common-rule/revised-common-rule-q-and-a/index.html

Office of the Press Secretary. (2015). *FACT SHEET: President Obama's Precision Medicine Initiative* (https://obamawhitehouse.archives.gov/). National Archives. https://obamawhitehouse.archives.gov/the-press-office/2015/01/30/fact-sheet-president-obama-s-precision-medicine-initiative

Pattengill-Semmens, C. V., & Semmens, B. X. (2003). Conservation and management applications of the REEF volunteer fish monitoring program. *Environmental Monitoring and Assessment*, *81*(1-3), 43–50.

Sanders, E. B.-N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *CoDesign*, *4*(1), 5–18.

Shore, N. (2006). Re-Conceptualizing the Belmont Report. *Journal of Community Practice*, *14*(4), 5–26.

Strickland, C. J. (2006). Challenges in community-based participatory research implementation: experiences in cancer prevention with Pacific Northwest American Indian tribes. *Cancer Control: Journal of the Moffitt Cancer Center*, *13*(3), 230–236.

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979). *The Belmont Report*. US Department of Health, Education, and Welfare. https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html

The Precision Medicine Initiative. (n.d.). Obama White House. Retrieved February 1, 2020, from https://obamawhitehouse.archives.gov/precision-medicine

Tovar, M. A., Rutledge, G. W., Lenert, L. A., & Fagan, L. M. (1991). The design of a user interface for a ventilator-management advisor. *Proceedings / the ... Annual Symposium on Computer Application [sic] in Medical Care. Symposium on Computer Applications in Medical Care*, 828–832.

U.S. General Services Administration. (n.d.). *About CitizenScience.gov*. CitizenScience.gov. Retrieved February 13, 2020, from https://www.citizenscience.gov/about/

Wallerstein, N., & Duran, B. (2018). Theoretical, Historical, and Practice Roots of CBPR. In N. Wallerstein, B. Duran, J. Oetzel, & M. Minkler (Eds.), *Community-based participatory research for health: Advancing social and health equity* (third, pp. 17–29). Jossey-Bass.

Wallerstein, N., Oetzel, J., Duran, B., Tafoya, G., & Rae, R. (2008). What predicts outcomes in CBPR? In N. Minkler & N. Wallerstein (Eds.), *Community Based Participatory Research for Health: Process to Outcomes* (second, pp. 371–392). Jossey-Bass.

Wang, C. C. (1999). Photovoice: a participatory action research strategy applied to women's health. *Journal of Women's Health / the Official Publication of the Society for the Advancement of Women's Health Research*, *8*(2), 185–192.

Ward, M., Schulz, A. J., Israel, B. A., Rice, K., Martenies, S. E., & Markarian, E. (2018). A conceptual framework for evaluating health equity promotion within community-based participatory research partnerships. *Evaluation and Program Planning*, *70*, 25–34.

Wiggins, A., & Wilbanks, J. (2019). The Rise of Citizen Science in Health and Biomedical Research. *The American Journal of Bioethics: AJOB*, *19*(8), 3–14.

CHAPTER III. A PEOPLE'S GUIDE TO PRECISION MEDICINE.

Situating myself between the arts and public health, I try to have the best of both worlds. I imagine new futures, reframe the present, and critique existing social structures through attention-grabbing means aimed at promoting dialogue. At the same time, I aim to help improve health outcomes in real-world communities. Knowledge isn't just an object waiting to be found and collected. It's a living thing to be nurtured in a community. Communication isn't just a way to fill people's heads with ideas. It's a way to formulate and refine those ideas together. The act of communication can have positive impacts through the formation of social relationships, the sharing of experiences, and the co-creation of knowledge. I believe these are vital processes in the advancement of health equity. And I aim to use this view of communication to make more space for underserved and underrepresented voices in health research.

I know I can't accomplish this alone. No one can. As discussed in the previous chapter, public health research already draws on participatory research frameworks to create new kinds of learning communities that can accomplish these lofty goals. This allows participants to help each other tie together research with advocacy and community engagement. In my graduate studies in comparative media studies, I've been able to see the ways that media makers accomplish similar goals using frameworks of co-creation. When it comes to health equity, I think this framework is quite useful as it is a reminder that at the end of the day, something needs to be created. It's not enough to critique existing processes and social structures. It's not enough to learn more about the exact ways that health disparities manifest. It's not even enough to develop evidence-based interventions and best practices. Though health equity can be a bit of an abstract concept, it will look like opportunities for health in every community. Where those opportunities do not currently exist, they will need be created. That is not something a medically underserved community can do completely on its own, and it's not something a government agency, hospital, or research institution can do completely on its own either.

In this chapter, I draw on this concept of co-creation to imagine what will need to happen on the ground to advance health equity. While a ritual lens can help explain the full scope of work involved in such a project, co-creation is a useful shorthand for what this looks like.

III. A: Abstract.

Aims.

With this project, I aimed to develop the "People's Guide" media-based community engagement program, around the topic of precision medicine in US research university settings. This project explored what community engagement could look like if it employed multimedia modes of understanding to reverse typical flows of knowledge in academic-community exchanges. The intended purpose of the resulting program-in-development is to intervene in public health partnership dynamics to better facilitate responsiveness to the needs of medically underserved communities.

Methods.

I used multimedia modes of engagement to curate knowledge from members of underrepresented communities in STEM research fields. These included dialogue-based workshops to understand precision medicine and design-based workshops to envision what such research could lead to. I then conducted interviews with professionals who have direct links to the issues the workshops surfaced. I compiled the interviews and workshop outputs into an online zine (informal publication) for use in academic workshops. This second wave of workshops included medical students, doctoral candidates, postdocs, and professional research scientists. These workshops incorporated zine articles for discussion and brainstorming prompts, alongside a lightning talk on the ritual lens of communication. The outputs of these brainstorms were compiled into the final component of the zine for publication and dissemination among contributors.

Evaluation.

This project employed a developmental evaluation framework to inform key developments of a program logic model, including: establishing program activities, defining desired outcomes, and identifying target audiences. Evaluation methods included surveys of

academic workshops participants, content analysis of workshop materials, and exit interviews with select zine contributors.

Results.

The developmental evaluation resulted in a logic model and network diagram to guide further program refinement and testing of outcomes and assumptions. The target communities for this program are public health partnerships that unite students/trainees, academic researchers, and those working in community-based organizations. While this project focused on the topic of precision medicine, the resulting logic model allows for the topic of interest to respond to community partnership needs.

Significance

This project highlights the potential of media-based community engagement to disrupt typical flows of knowledge in public health research partnerships. It also highlights the potential of developmental evaluation within public health.

III. B: Design Brief.

III. B1: Background.

Precision medicine is a data-driven approach to disease treatment and prevention that takes into account a person's individual combination of genetic, environmental, and behavioral factors (Genetics Home Reference, 2015). The concept of precision medicine is multi-faceted and its relationship to health equity is yet to be defined. National efforts like the Precision Medicine Initiative promise to improve population health by improving healthcare and disease prevention for everyone in the US (Collins & Varmus, 2015). A lack of participant diversity in existing genomic research, however, raises serious concerns about the potential negative impact precision medicine techniques may have on health equity (Martin et al., 2019). Beyond representation, structural issues of power contribute to an environment in which biomedical research findings may be misinterpreted and misused to contribute to the false essentialization of biomedical factors related to the social identities of race (Kahn, 2008), as well stigmatization of medically underserved communities (Dingel & Koenig, 2008). Further, a focus on the genetic aspects of precision medicine has cast doubt on the compatibility of this individualistic approach with the structural and population-level focus of public health (Chowkwanyun et al., 2018). However, proponents of "precision public health" argue that it can successfully bridge population-level interventions with personalized health concerns (Chowkwanyun et al., 2018).

The relationship between precision medicine and health equity remains unclear. However, it is clear that health equity in an era of precision medicine will require community engagement that intervenes not only in the diversity of research samples, but also in the power dynamics present in academic research. This project thus explores what such community engagement efforts could look like. As such, this project operates under a transformative research paradigm, aiming to produce knowledge that can help reconfigure social systems that marginalize underprivileged groups (Mertens, 2007).

Medically Underserved Communities.

This project focuses on the potential of a media-based community engagement program to make research partnerships more responsive to medically underserved communities' needs. I define a "medically underserved community" as one with societal, economic, cultural, and/or linguistic barriers to health. In the US this includes: people experiencing homelessness, migrant workers, undocumented immigrants, non-English speakers, people with low incomes, people without health insurance, people in geographically isolated areas, gender and sexual minorities, Indigenous nations, people of color, and people with disabilities. Notably, this is a more expansive version of the definition of "medically underserved areas/populations" by the Bureau of Health Workforce, which focuses on access to healthcare providers (Bureau of Health Workforce, 2019).

The concept of a "medically underserved community" is useful to orient public health programs towards health equity. It is helpful to have language that can funnel resources to people experiencing inequities that negatively impact their health. However, using such a unifying concept presents its own challenges, as medically underserved communities are not homogeneous. Structural changes can eliminate health disparities. However, individual programs will likely not make sweeping structural changes. Instead, they will work with limited resources on limited timelines, leading to a focus on specific health topics and community members. As priorities differ between and within medically underserved communities, it is important to be clear about who exactly a program is reaching. This reality typically contributes to highly targeted interventions and community engagement programs that focus on reproducibility among similar demographic groups. This project focused instead on creating a community engagement program that is adaptable to many contexts.

Sources of Knowledge.

A transmission view of communication focuses on communication as a means to transfer information, whereas a ritual view focuses on communication as a means to maintain relationships and social structures (Carey, 1989). As discussed in Chapter 1, a transmission view of communication dominates in public health communication research and practice. This contributes to an environment of health disparities by focusing communication efforts on the efficiency of information transfer, rather than the equity of relationships between public health institutions and medically underserved communities. This project aims to express a commitment to health equity by employing a ritual lens of communication to intervene in the relationships and social structures formed in community engagement. As such, this project aims to rethink what it looks like to be recognized as a producer, interpreter, and wielder of knowledge in public health by experimenting with the tools of a journal and a journal club.

Having a recognized platform to produce, interpret, and wield knowledge is an immense privilege. Recognized knowledge creators have the power to shape the evidence that informs policy, social programs, and further research. Recognized knowledge interpreters have the power to draw on evidence to create narratives that inform public opinion, media portrayals, and policy goals around social issues. Recognized knowledge wielders have the power to use evidence to create common knowledge that informs further research questions, worldviews, and interpretive frameworks. Disparities in access to recognized tools of knowledge threaten the well-being of groups marginalized on the basis of intersecting identities, such as women of color. For example, Crenshaw highlights how feminist and antiracist policies have actually intersected to marginalize women of color, leaving them vulnerable to structural and personal violence (Crenshaw, 1990). Rectifying disparities in the professionalized research workforce is a worthy goal that can help address this issue. However, there is also a parallel need to expand notions of expertise to better include the kinds of knowledge that accumulate through firsthand navigation through structural obstacles to health equity. Health equity depends on a democratization of science and cognitive justice, as Santos, Nunes, and Meneses describe it (Boaventura et al., 2007). As such, this project sought to establish methods that can operate within public health research partnerships to broaden the scope of recognized expertise.

Media Interventions.

This project employs a multimedia approach to communication, incorporating design activities, illustrations, and personal stories into a public health publication. Participatory research methods like PhotoVoice have shown value in bridging knowledge production, community engagement, and advocacy in public health (Wang, 1999). Outside the realm of research, media arts have proven themselves powerful tools for sparking social change. One significant example is the National Film Board of Canada's "Fogo process" of using participatory documentary filmmaking as a way for communities to surface problems and generate productive dialogue around them. The Fogo process has also proven useful in settings like hospitals and prisons, wherein conversation is difficult between people in rigid roles like patients/providers and guards/prisoners (Wiesner, 1992/2010). Importantly, PhotoVoice and the Fogo Process both highlight the importance of participatory processes and the collective analysis that happens around media products. By situating these participatory methods in conversations of power, such programs expand their impact by teaching audiences to listen (Marjoribanks et al., 2013), putting people in new social roles (Atkinson & Rosati, 2013), and expanding power (Ryan et al., 2013).

III. B2: Methods.

With this project, I focus on the development of a two-phase community engagement program titled, "People's Guide." This program revolves around a zine (an informal, self-published publication). Phase 1 focuses on producing the zine through workshops and interviews with members of medically underserved communities. Phase 2 focuses on using the zine in journal club workshops. This project explores the relationship between the two program phases, resources required to run both phases, and potential program outcomes. I employed a developmental evaluation framework to continually track the development of the program and incorporate process improvements along the way. As such, I approached implementation and evaluation as a tightly connected reciprocal pair. Evaluation findings informed key program developments, and developments informed evaluation strategies.

Context.

This project took place from April 2019 to April 2020. I conducted this work as part of my master's thesis in Comparative Media Studies at MIT. As such, I did not conduct this work in the context of an ongoing public health research partnership. On one hand, this is a limitation of this current project, as such a partnership is the intended context for this program. On the other hand, this lack of formal structure facilitated this project's flexibility. This allowed key program developments to rapidly respond to real-time observations and feedback. A Priscilla King Gray Public Service Fellowship supported my work on this project from June 2019 to August 2019.

Research Ethics.

This project's activities were exempt from internal review, as documented by the MIT Committee on the Use of Humans as Experimental Subjects. This project comprised a benign behavioral intervention, surveys, interviews, and observation in educational settings. As such, this project presented minimal risk to participants. I informed all workshop participants that workshop outputs would be part of an online zine and showed them where I would publish it. I informed student participants that I would credit them collectively, with the opportunity to identify themselves individually if they wished. Prior to interviews, I informed public health professionals that I would disseminate their responses online. I informed zine interviewees of my intended publication process and gave individuals the option to participate anonymously.

Beyond reduction of individual risk, I sought to bring benefits to participants where possible. I gave additional guest lectures and mentorship to the cohort of summer students I interacted with. I sought to bring attention to the work of interviewees who wanted their names published. Future iterations of this project should go further to expand community benefit.

Implementation Methods.

Outreach emails. I reached zine contributors and workshop participants through my existing professional networks. I worked with point people in research labs and student groups to recruit participants for journal club workshops.

Zine hosting. I created a community space for this project on PubPub, a collaborative authoring/publishing platform. I structured the content such that this project would result in the first issue of an ongoing publication. I intended to create a structure to publish future iterations of this project, workshop guides, and other content alongside the zine resulting from this project.

Student workshops. I ran a series of 3 workshops with undergraduate students in a research training program for students of underrepresented minority backgrounds in STEM research. The first workshop was a dialogue-based session to learn about precision medicine and identify personal opinions, questions, and critiques of efforts like the Precision Medicine Initiative. (See “#PMtldr: Precision Medicine; too long, didn't read. (Workshop Guide),” in Appendix A.)

The next workshop was a speculative design workshop to imagine what precision medicine technologies could look like if they took the form of everyday objects and focused on community-building. Participants presented an illustration and brief write-up of their product designs. This workshop leveraged the opportunity that speculative design offers for learning about capabilities and issues of a technology (Lukens & DiSalvo, 2012). This workshop drew on Coding Rights’ workshop, “Oracle for Transfeminist Technology” (Coding Rights, n.d.). (See “Balloons, Bears, Candles, & Sunglasses: Joyful futures of precision medicine,” in Appendix A for the workshop writeup.)

The final workshop had participants use design fiction to imagine how artificial intelligence might help people address health issues in the future. The workshop focused on worldbuilding and character building. Participants then imagined a technology that would fit into the character’s life and their world. As part of my mentoring relationship with the students that summer, I gave students a lecture on participatory research frameworks and gave them feedback on project proposals. Neither of these final activities is part of “People’s Guide” program activities. However, they represent the other kinds of interactions instructors might have with students in a research partnership setting.

Soliciting article contributions and interviews. I attempted to include 6 professional and patient story-based articles in this project's zine. These were to be in the form of either a direct submission or an interview. Initial outreach for article submissions resulted in the suggestion to conduct interviews instead. Thus, I ended up including both options in later article outreach. I was able to schedule 3 interviews, one each with: a public health researcher, a community-based organization (CBO) director, and a patient. As there was no budget to compensate for time/effort, a certain amount of attrition was expected. The interviews that ended up working out were with individuals that knew me previously. I approached the researcher and patient interviews in an open-ended journalistic style to gather personal stories. I conducted the CBO director interview via email, writing interview questions as a means for the director to share their professional expertise of their community's needs and assets.

Zine articles. I edited interview and workshop outputs into an online zine for use in subsequent journal club workshops.

Journal club workshops. I conducted 5 workshops with different participants, including: artists, medical students, doctoral candidates, postdocs, and professional research scientists. The first workshop with artists focused on gathering feedback and responses to zine articles. The remainder of the workshops incorporated a curated selection of zine articles for discussion, a lightning talk on the ritual lens of communication, and a group brainstorming session. (See Appendix D for the journal club workshop materials resulting from this project.).

Zine publication. I compiled the outputs of workshop brainstorms into the final component of the zine for publication and dissemination among all contributors. (See Appendix A for the zine.)

Developmental Evaluation.

Developmental evaluation is an evaluation framework useful for developing innovations in complex settings. It is an approach that responds to the dynamic nature of problem spaces that lack detailed knowledge of factors that contribute to practical, scalable solutions. (Patton, 2011, Chapter 1). This approach stands in stark contrast to randomized control trials and other summative evaluations, which seek answers about causality and effectiveness of standardized protocols. It also offers more flexibility to account for dynamic contexts and developing processes/outcomes in comparison to formative evaluations. Though still being defined, developmental evaluation shows promise in health promotion settings, especially in settings where systems are the units of change (Fagen et al., 2011). I chose a developmental evaluation framework for this project so as to allow for exploration and learning about the affordances of this program while still creating it. As the program continues to develop, a developmental evaluation framework may still be the most appropriate option, as the unit of change is a partnership network, rather than a specific population or geographic community. Further, as this program is meant to be adaptable to various topics and partnership settings, it is possible a logic model for this program may never be linear enough to be suitable for a summative evaluation, even as the program matures.

In keeping with the developmental evaluation framework, data collection and analysis was a continual process in this project, informing and informed by key developments. The evaluation utilized a "What? So what? Now what?" inquiry framework (Patton, 2011, p. 231). This framework comprised 3 continual evaluation questions, as Patton outlines:

- What is being developed *now*?
- What do the results of these developments mean *now*?
- What do we do with this knowledge *now*?

Data collection and analysis focused on answering these questions as the program developed, employing continually shifting methods as the implementation methods shifted over time.

Data Collection and Analysis Methods.

Student Post-workshop surveys. Student workshop participants submitted post-workshop feedback as part of their training program. While this feedback generally indicated satisfaction with the workshops, it did not provide me with much information to further refine the student workshops.

Real-time feedback forms. Journal club workshop participants were given packets to provide real-time feedback and notes. Due to the small amount of feedback per workshop, I did not systematically analyze the researcher feedback in Dedoose until the end of the project.

Instead, I looked at each piece of feedback individually and noted its implications for editing the workshop.

Workshop facilitator notes. As the workshop facilitator, I took notes on each workshop. I combined these notes with post-workshop feedback to continually refine the journal club workshops. These refinements largely focused on time management and shaping the group discussion.

Pre/post surveys. Journal club workshop participants completed pre/post surveys on their perceptions of the relationship between communication, health equity, and precision medicine. A content analysis of these documents in Dedoose informed the resulting logic model and workshop materials for this project.

Exit interviews. After the final journal club workshop, I interviewed zine contributors and the coordinator of the final workshop about the program development overall. These interviews informed the resulting logic model for this project.

Key Developments.

Two-phase program structure. The original decision to compile student workshop outputs into a zine alongside interviews for use in journal club workshops was informed by theoretical work as outlined in the Background section of this brief.

Infrastructure for zine publication: PubPub and style guide. This project started off with the creation of a website to host the zine. I chose PubPub (a project of the MIT Media Lab's Knowledge Futures Group) as the platform for this project, owing to its features geared toward publishing within academic communities. Among the features of interest are: clear authorship roles, collaborative features, generation of citations, curation of distinct issues, and creation of CrossRef DOIs for articles. I then created a submission guide for articles, outlining article categories and a style guide. (See Appendix C for this project's submission guide.) Starting off with a platform and a submission guide significantly aided workshop development and content editing for articles.

Design-based student workshops. I decided to run design fiction and speculative design workshops with students to critically examine the concept of precision medicine while producing visual/narrative content for zine articles, based off of existing research as noted above,

Article solicitation and Interviews. While editing the design-based workshop outputs into zine articles, I became unsure of researchers' willingness to engage with the design workshop outputs alone. I decided to include articles from viewpoints of professionals and patients as a way to provide more context for journal club workshops. Two major topics of discussion during the design workshops were social equity and the unintended consequences of technology on communities of color. I decided to solicit articles and request interviews to include perspectives of professionals and patients who could speak to these topics. Although article solicitation did not yield any submissions for this project, results may differ in an established research partnership setting.

Three-part journal club workshop format. The first workshop focused almost exclusively on zine articles. Its lack of a goal led to a very unfocused discussion. Subsequent workshops built toward a brainstorming session, informed by the zine articles paired with a discussion of the ritual view of communication and its implications for public health. The second and third workshops remained largely the same, but with more focus on what could be changed about current community engagement practices. The fourth and fifth workshops used a story from the zine to focus on what community engagement could look like and feel like in a world with health equity. Exit interviews with zine contributors informed the modification of that discussion to favor more engagement with zine articles, as described in this project's resulting logic model.

Determination of ideal program context. The 2 journal club workshops conducted with research labs led to the most in-depth and personal-level discussions, as well as concrete brainstorm outputs. Exit interviews indicated a sense of detachment from the process for interviewees, since they did not have a chance to follow-up with readers, or hear the readers' responses. Thus, the program logic model and network map indicates specific types of public health partnerships that bring together students, researchers, and local community members repeatedly. Examples include NIH-funded U54 grant partnerships, as well as Clinical and Translational Science Centers.

Specificity of zine topic. The student workshops produced flexible enough outputs to fit a variety of topics. However, journal club workshop participants expressed a desire for focus on the context in which to think about precision medicine. In workshops that stated a focus on immigrant health and precision medicine, participants appreciated discussions in a predetermined focus area. The ideal level of specificity of the zine topic remains unclear. For now, the program logic model proposes selecting a zine topic as one of the program activities.

Addition of educational materials, launch event, and advocacy outcomes into the program logic model. These additions to the logic model resulted from exit interviews with zine contributors. Community-based organizations may have a very specific audience they'd like to reach with personal stories and research findings, e.g. individual policymakers and funders. Student professional networks can be nurtured through gathering people together for a launch event. Students' own community members may benefit from seeing more didactic educational materials on the health topic that students examined. I added components to the logic model that I did not have the chance to test in this project as a guide for future iterations of program development.

III. B3: Results.

The developmental evaluation resulted in a logic model and network map for the further development of "People's Guide" community engagement program. for use in academic-community partnership settings. While the topical focus of this particular project was precision medicine, the resulting logic model is intended to fit a range of topics in response to the contextual needs of the partnership setting at hand.

Logic Model.

A logic model provides a useful definition of what a program is, outlining a linear relationship between program activities and impacts (W.K. Kellogg Foundation, 2004). In a formative or a summative evaluation framework, a program's logic model will guide evaluation questions and dictate what evaluators track. In contrast, a logic model may actually be an outcome of a developmental evaluation, providing a framework to conceptualize a program that is still developing (Lam & Shulha, 2015).

In this project, the developmental evaluation resulted in a logic model as a heuristic tool, supplying answers to this project's 3 evaluation questions with the information available right now. This logic model highlights a particular theory of change in which the "People's Guide" community engagement program makes an academic-community partnership more responsive to community partner needs and priorities. It enacts this change by outlining specific relationships between students, professional researchers and community-based organizations. This logic model describes the anticipated linear relationship between resources, activities, outputs, and outcomes, which can be refined and better tested in future iterations of this program.

Context: University-based research partnerships bringing together students, professional researchers, and community-based organizations. Examples include U54 partnerships and Clinical and Translational Science Centers.

Resources Online infrastructure for editing, compiling, and publishing zine articles; Student workshop instructor(s) and developer(s); Audio-visual documentation of workshop outputs; Journal club workshop (facilitators) and developer(s); Interviewer(s) and Interviewees for zine articles; Existing partnership infrastructure and staff; Agreement on a health topic of interest

Activities Student workshops; Personal interviews for zine; Zine production; Journal club workshops; Curation/adaptation of educational materials for zine; Zine publication; Launch event; Ongoing evaluation

Outputs # Student workshop participants reached; Workshop curricula created or adapted to local context; # Articles in zine; # Journal club workshop participants reached; # Target audience members reached with zine; # Target audience members reached with launch event

Outcomes Student confidence in discussing and questioning health topic of focus; Academic researcher understanding of community questions and health concerns; Community-based organization concerns incorporated into partnership work; Network-specific advocacy outcomes

Assumptions: This program rests on the assumption that a functional partnership exists and members are interested in advancing health equity. It also relies on partnership members agreeing on a topic of interest and target audiences for the zine.

Figure 24: Logic model for the "People's Guide" community engagement program.

Context:

University-based research partnerships bringing together students, professional researchers, and community-based organizations. Examples include U54 partnerships and Clinical and Translational Science Centers.

Resources Required:

- **Online infrastructure for editing, compiling, and publishing zine articles.**
    - This project used PubPub, a project of the MIT Media Lab Knowledge Futures Group.

- **Student cohort.**
    - The student design-based workshops depend on knowledge shared during the dialogue-based workshops.
- **Dialogue-based workshop instructor(s) and developer(s).**
- **Design-based workshop instructor(s) and developer(s).**
- **Audio-visual and textual documentation of workshop outputs.**
    - This project’s student workshops used either audio recording or worksheets to provide zine article content.
- **Journal club workshop facilitator(s) and developer(s).**
- **Interviewer(s) and Interviewees for zine articles.**
- **Existing partnership infrastructure and staff.**

Activities:

- **Establish topic of interest for zine.**
- **Establish external target audience(s) for zine, if any.**
    - Examples include local politicians, medical professionals, students in a local school, etc.
- **Establish style guide for zine.**
    - Reading grade level, image captions, language use, etc. impact zine accessibility. See Appendix B’s “Style Guide” section to see this project’s style guide.
- **Conduct dialogue-based workshops with student cohort.**
- **Conduct design-based workshops.**
- **Conduct interviews for zine.**
- **Solicit articles for zine.**
- **Produce zine articles.**
- **Publish zine.**
    - Publish in web and print as needed to hold a zine launch event and reach target audiences.
- **Conduct journal club workshops.**

    - These workshops combine three portions: reading and discussing a curated selection of zine articles, including a mix of interview and design-based outputs; a discussion of the ritual view of communication; and a brainstorming session on the future of public health community engagement informed by the zine articles. This project used the same 3 articles across workshops.
- **Curate/adapt educational materials for zine.**
    - These materials should follow the same style guide as the rest of the zine articles. Adaptation of existing educational materials may be necessary.
- **Hold zine launch event.**
    - Research partnership needs and zine contributor input should shape this event.
- **Disseminate zine.**
- **Conduct developmental evaluation throughout.**
    - This program's adaptable nature requires a lot of on-the-ground decision making about how to reach desired outcomes, As such, a developmental evaluation framework is best suited for continual process improvement.

Outputs

- **# Student workshop participants reached.**
- **Workshop curricula created or adapted to local context.**
- **# Articles in zine.**
- **# Journal club workshop participants reached.**
- **# Target audience members reached with zine.**
- **# Target audience members reached with launch event.**

Outcomes

- **Student confidence in discussing and questioning the health topic of focus.**
- **Academic researcher understanding of community questions and health concerns; incorporation of factors into ongoing work.**

- **Community-based organization concerns incorporated into partnership work.**
- **Context-specific advocacy outcomes.**

Assumptions

This program rests on the assumption that a functional partnership exists and members are already interested in advancing health equity. It also relies on partnership members reaching agreement on a topic of interest and target audiences for the zine.

Network Map.

A logic model is useful for tracking a program's linear progression from inputs to outputs to impact. However, such a linear view of impact may ignore important networked effects, especially when the definition of a program is still developing. As such, a network map can serve as a tool for conceptualizing a nonlinear, networked thinking of events and impacts in the context of a developmental evaluation (Patton, 2011, p. 119). Thus this project's outcomes include a network map meant to serve alongside a logic model as a heuristic tool for further program development.

This project's network map highlights how university professionals and members of a medically underserved community interact through a research partnership. In the formal structure of a research partnership, they will likely fill the roles of community-based organization (CBO) partners, academic partners, and students/trainees. This program network map responds to that structure while also acknowledging that some university researchers may themselves be members of the medically underserved community in question. In this way, program stakeholders can track program impact by observing changes in the nature of interactions and relationships between major stakeholder groups.

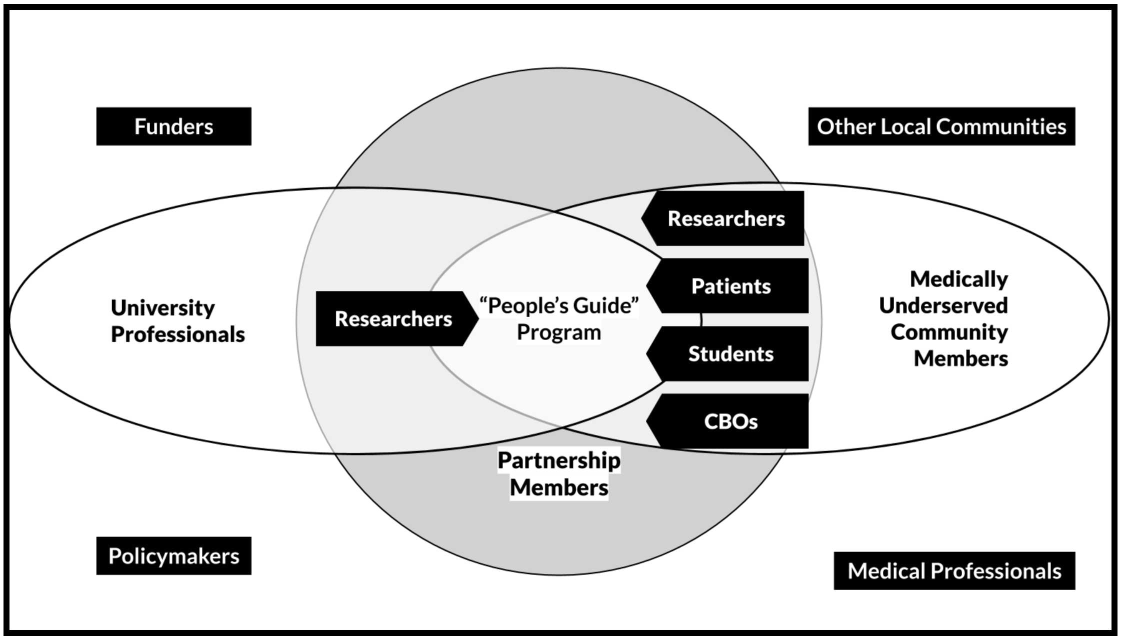


Figure 25: Network map for the "People's Guide" community engagement program.

This network map acknowledges that program stakeholders may wish to leverage their work to change their interactions with external stakeholders. For example, students may wish to use their involvement in such an academic-community partnership to expand their professional network of university researchers. CBO partners may wish to use a "People's Guide" publication and launch event to draw the attention of policymakers to specific health issues. Patients may wish to advocate for more culturally competent care for their communities. While tracking program progress, it will be helpful for program participants, planners, and evaluators to flesh out more detailed descriptions of stakeholder priorities in their own program context. This will help point to useful methods of evaluating the networked impacts of the "People's Guide" program, such as social network analysis or tracking policy changes.

With a more open-ended approach to defining and evaluating desired relationships between stakeholders, this network map can help capture more unintended program impacts than a typical logic model. As these relationships will be highly context-specific, a participatory network mapping method such as the Participatory Network Mapping Tool (Wijenberg et al., 2019) will be most appropriate to build on the network map above. As the program will have network impacts over time, it is best to conduct network mapping periodically over the course of the program, from planning for the zine to disseminating the published version.

III. B4: Discussion.

This community engagement program, even in its developmental stage, illustrates the possibility of reconfiguring public health communication through a ritual view of communication. Instead of focusing on top-down transfers of knowledge, public health communication can focus on creating a community of learning. The “People’s Guide” suggests what this might look like, with reconfigurations of typical power structures in academic-community partnerships creating new social roles for participants.

This project also shows the affordances of developmental evaluation to advance innovation in public health. As the methods are still developing for the kinds of reconfigurations this project proposes, it is important to draw on the work of other fields to figure out how to evaluate in-progress programs to share timely insights and create communities of practice.

Works Cited.

Atkinson, J. D., & Rosati, C. (2013). Media Intervention in the Struggle Over Cityscape. In K. Howley (Ed.), *Media Interventions* (pp. 73–88). Peter Lang Publishing.

Boaventura, de S. S., Nunes, J. A., & Meneses, M. P. (2007). Introduction: Opening Up the Canon of Knowledge and Recognition of Difference. In B. de S. Santos, J. A. Nunes, & M. P. Meneses (Eds.), *Another Knowledge is Possible: Beyond Northern Epistemologies* (pp. ix – lxii). Verso.

Bureau of Health Workforce. (2019, June). *Medically Underserved Areas and Populations (MUA/Ps)*. HRSA.gov. https://bhw.hrsa.gov/shortage-designation/muap

Carey, J. W. (1989). A Cultural Approach to Communication. In *Communication as Culture: Essays on Media and Society* (pp. 13–36). Unwin Hyman.

Chowkwanyun, M., Bayer, R., & Galea, S. (2018). “Precision” Public Health - Between Novelty and Hype. *The New England Journal of Medicine*, *379*(15), 1398–1400.

Coding Rights. (n.d.). *THE ORACLE FOR TRANSFEMINIST TECHNOLOGIES*. CodingRights.org. Retrieved March 9, 2020, from https://www.transfeministech.codingrights.org/

Collins, F. S., & Varmus, H. (2015). A new initiative on precision medicine. *The New England Journal of Medicine*, *372*(9), 793–795.

Crenshaw, K. (1990). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, *43*, 1241.

Dingel, M. J., & Koenig, B. A. (2008). Tracking Race in Addiction Research. In B. A. Koenig,

S. S.-J. Lee, & S. S. Richardson (Eds.), *Revisiting Race in a Genomic Age* (pp. 172–197). Rutgers University Press.

Fagen, M. C., Redman, S. D., Stacks, J., Barrett, V., Thullen, B., Altenor, S., & Neiger, B. L. (2011). Developmental evaluation: building innovations in complex environments. *Health Promotion Practice*, *12*(5), 645–650.

Genetics Home Reference. (2015, April). *What is precision medicine?* Genetics Home Reference; {US National Library of Medicine}. https://ghr.nlm.nih.gov/primer/precisionmedicine/definition

Kahn, J. (2008). Patenting Race in a Genomic Age. In B. A. Koenig, S. S.-J. Lee, & S. S. Richardson (Eds.), *Revisiting Race in a Genomic Age* (pp. 129–148). Rutgers University Press.

Lam, C. Y., & Shulha, L. M. (2015). Insights on Using Developmental Evaluation for Innovating: A Case Study on the Cocreation of an Innovative Program. *American Journal of Evaluation*, *36*(3), 358–374.

Lukens, J., & DiSalvo, C. (2012). Speculative design and technological fluency. *International Journal of Learning and Media*, *3*(4). http://access.portico.org/Portico/show?viewFile=pdf&auId=phx73mtvht4

Marjoribanks, T., Farquharson, K., Nolan, D., & Gawenda, M. (2013). Resources of Belonging: Assessing the Consequences of Media Interventions. In K. Howley (Ed.), *Media Interventions* (pp. 55–72). Peter Lang Publishing.

Martin, A. R., Kanai, M., Kamatani, Y., Okada, Y., Neale, B. M., & Daly, M. J. (2019). Clinical use of current polygenic risk scores may exacerbate health disparities. *Nature Genetics*, *51*(4), 584–591.

Mertens, D. M. (2007). Transformative Paradigm: Mixed Methods and Social Justice. *Journal of Mixed Methods Research*, *1*(3), 212–225.

Patton, M. Q. (2011). *Developmental Evaluation: Applying Complexity Concepts to Enhance Innovation and Use*. Guilford Press.

Ryan, C., Jeffreys, K., Ellowitz, T., & Ryczek, J. (2013). “I Mattered and It Mattered”: The Theory and Practice of Media Interventions. In K. Howley (Ed.), *Media Interventions* (pp. 225–246). Peter Lang Publishing.

Wang, C. C. (1999). Photovoice: a participatory action research strategy applied to women’s health. *Journal of Women’s Health / the Official Publication of the Society for the Advancement of Women's Health Research*, *8*(2), 185–192.

Wiesner, P. K. (2010). Media for the People: The Canadian Experiments with Film and Video in Community Development. In T. Waugh, M. B. Baker, & E. Winton (Eds.), *Challenge for Change: Activist Documentary at the National Film Board of Canada* (pp. 3–14). McGill-Queen’s Press. (Original work published 1992)

Wijenberg, E., Wagemakers, A., Herens, M., Hartog, F. den, & Koelen, M. (2019). The value of the participatory network mapping tool to facilitate and evaluate coordinated action in health promotion networks: two Dutch case studies. *Global Health Promotion*, *26*(3), 32–40.

W.K. Kellogg Foundation. (2004). *Using Logic Models to Bring Together Planning, Evaluation, and Action: Logic Model Development Guide*. W.K. Kellogg Foundation.

CHAPTER IV. CONCLUSION.

To summarize this thesis in one sentence: public health communication is about relationships and social structures, not just information. To round it out with a few more sentences… I find it useful to describe the relationships and social structures of communication as a ritual. Who gets to take part, and in what roles? With what power dynamics? Failure to recognize these ritual aspects of communication can contribute to health disparities by ignoring the social factors that fuel them. Targeting the ritual aspects of communication through public health research and practice can create space for new kinds of research questions and metrics of success that relate to the needs of medically underserved communities.

To summarize my motivations for writing this thesis: I believe a focus on equity is the future of health and medicine in the US. With shifting demographics, a global environmental crisis, and the long-term impact of a devastating pandemic on our hands, it has to be. Whether the US will ever achieve health equity, I can't say. But I know for sure that it's possible.

Throughout this thesis, I combine theoretical arguments with personal accounts, methods incorporating art/design, and historical cases to support my claims about communication and equity. In the introduction, I describe how my own experience navigating health disparities and death motivate my personal approach to health communication through art and design. If communication helps maintain social relationships, I'd prefer the approach of an artist inviting discussion of their work rather than a lecturer on a soapbox.

In Chapter 1, I describe the focus of transmitting information in public health communication, and I tease out its shortcomings. By ignoring power, politics, and feedback loops, this information-focused view of communication leads to public health community engagement that maintains unproductive relationships with medically underserved communities. By putting power, politics, and feedback loops on the table in public health research and practice, a ritual-focused view of communication can create opportunities to improve these relationships so as to better serve these communities.

In chapter 2, I describe what this ritual view of communication might look like in practice: participatory research. The ritual lens of communication offers a way to understand the expanded scope of work that participatory frameworks bring into the realm of research. They don’t just help build research capacity in community partners or increase the impact of scientific research, they also create new kinds of relationships between public health professionals and various publics. These participatory frameworks can help people realize the array of roles open to them. Scientists can be advocates. Local community members can be experts. Health professionals can be trusted neighbors. I recognize that organizations like the National Institutes of Health (NIH) still need to learn how to systematically evaluate research and community engagement through this expanded lens. So, in the meantime, I offer the Health Equity Rituals model of community engagement for individual partnerships to do so for themselves.

In Chapter 3, I describe the ongoing development of a community engagement program that relies on co-creation as a means to act on a ritual lens of communication. It starts with a simple question: what if community engagement flowed in the opposite direction of what I’m used to seeing? In this program, scientists do not play the role of experts. Students, artists, and community leaders share their expertise through a “People’s Guide,” incorporating personal experiences, professional opinions, and art/design work. What happens when researchers interact with this collection of knowledge as they would an academic journal? My experience with this method so far suggests that it might be a useful way to reshape academic-community research partnerships in public health so as to better meet medically underserved communities’ needs.

In this concluding chapter, I do 2 things. First, I summarize the main points of my thesis. Then, I tell you what needs to happen.

When I started work on this thesis in 2018, precision medicine seemed to signal the future of health research and health care in the US. Precision medicine promises more precise disease treatment and prevention through ever-larger amounts of data: genetic, clinical, behavioral, environmental, and so on. Through the *All of Us* research program, the NIH offers a vision of the future in which data and technology help the US move past health disparities and overcome the burden of life-threatening conditions like cancer through precision medicine. To be sure, precision medicine does not represent every single health research project, and *All of Us* does not fully represent precision medicine as an emerging field. While this image of precision medicine is just one forward-looking vision, it is remarkable in its coordination of government agencies, corporations, nonprofit organizations, healthcare systems, universities, technology development, and policy work at the national level. Whether or not it achieves all of its goals, *All of Us* will impact research questions, methods, and community engagement practices for time to come.

As such, it is important to point out that *All of Us* feels as much like a vision of the future as it does a rehashing of the past. There is a history of marginalized groups volunteering their bodies, biological samples, and data for health research, only to receive none of the health benefits that were promised to be available to everyone. The NIH's participatory framing of *All of Us* also draws on a rich history of political movements that sought to change oppressed people's relationships to research, media, and technology. In doing so, precision medicine becomes the next chapter in an ongoing story about power and equity in the US, including the ways these struggles manifest in health disparities. The emergence of precision medicine presents an opportunity to for this story to play out differently than it has in the past.

In 2020, these struggles are manifesting in health disparities at lightning speed. To be sure, the entire US health system is feeling the strain of the ongoing COVID-19 pandemic. A dreamy vision of the future now involves basic material goods that, up until recently, were easy to overlook as medical technology: masks, gloves, and swabs. Technically, yes, the virus does not discriminate. Anyone can get sick, but it's already very clear that certain communities are in much graver danger. So, which communities?

Figure 26: A poorly drawn simulation of a Chicago health data visualization. Let's say this one depicts breast cancer incidence.

Immigrants in meat-packing plants. African American communities. Latinx communities. Elders and people with disabilities in long-term care facilities. Native tribes. People experiencing homelessness. Notice how this doesn't call to mind the international jetsetters, high profile celebrities, and star-athletes who were the first faces of this outbreak in the US. Notice how those first faces were people who managed to get access to diagnostic tests while healthy enough to tell their own story. Now, I am not making light of anyone's experience with this pandemic. When I have concerns about my health, I too use the resources available to me to alleviate them. But there are dangerous patterns in who has access to health resources. So, if the virus doesn't discriminate, then what does?

Figure 27: The rough outline of pretty much any data visualization of a health issue in Chicago. Let's say this one depicts COVID-19 incidence.

As the picture of the impacts of this pandemic became clear, it was not a surprise to see where the deaths and the growing number of cases were concentrated in my hometown of Chicago. In heat maps, the south and west sides of the city stood out like sore thumbs. There were odd pockets here and there, but the pattern was clear. It was a new retelling of the same old story.

And now is a good time to tell you about why I hate data visualizations of the geographic spread of illnesses in the US. For the most part, they tell the same old story. The south and west sides of Chicago are suffering. If you're from the US, I'm sure you could substitute the names of areas of your own home state or hometown that are usually depicted as dangerous, unfortunate places. And yet, somehow, the human side of this suffering, the human face of resilience, and the human actions that led to the need for this resilience in the first place are hidden behind clean, computerized lines and data-based colors. The sterile nature of these visualizations suggest a schematic. While that does not reflect the human decisions that go into the making of its visuals or interpreting them, it does accidentally offer insight into the root of the problem. Health disparities are not some unpredictable outcomes of a series of well-functioning social systems. This is what it looks like for these systems to operate as designed.

Figure 28: ____________. You know what this is by now. Fill in the blank title with any health issue that is impacted by socioeconomic factors.

Heart disease and cancer are the leading causes of death in the US, accounting for nearly half of the lives lost in 2017 (Heron 2019). You could make a map of deaths from these illnesses by ZIP code in Chicago, and it'd look a lot like the doodle in Figure 28. These disparities have always been related to the conditions in which someone eats, sleeps, works, and socializes. With conditions like heart disease and cancer, these disparities play out over the course of years. With COVID-19, however, these disparities have played out over the course of weeks. In the initial outbreak, the keystone of community risk mitigation was clear: stay home. If you can't stay home, you can at least stay away from others and wear a facemask.

So, it's no surprise that some communities faced less good fortune and more danger than others. What are you supposed to do if you can't afford to stay home from work or wait for a stimulus check or a backlog of unemployment applications? What are you supposed to do if you have no home to stay in? How do you maintain physical distance from others if you rely on public transportation? What if encountering a police officer while wearing a mask poses more danger than the virus? An expert epidemiologist could tell you the general kinds of population health outcomes to expect under certain conditions of mitigation and spread. While a vital part of the public health response to this disease outbreak, such knowledge will not help answer the above questions. Quickly and assuredly, an epidemiologist could tell you why it's probably not a great idea for shoppers to gather indoors during an outbreak of a highly communicable respiratory illness without at least basic personal protective equipment. Just as quickly and assuredly, someone with the lived experience of over-policing could tell you why it's probably not a great idea for members of their community to wear a bandana as a substitute for a surgical mask. In order to achieve health equity, it's clear that health policy must incorporate such varying kinds of expertise. But how?

Therein lies the tricky problem with advancing health equity. Solutions have to provide immediate relief for community health issues and set the stage for long-term systemic change. It's not enough to train more people from underrepresented backgrounds to one day become the experts who will shape policy. What about all the lives that will be lost in the meantime? It's also not enough to just give people disaster relief. What about preventing the next disaster? I like using the ritual lens of communication to understand public health work because it reminds me that people can fill many different kinds of social roles under the right conditions. A community advocate can also be a researcher. An epidemiologist can also be an advocate. This adaptiveness is required to ensure health equity in complex situations like pandemic prevention and response. It will also be required to ensure health equity in the complex arena of precision medicine. Through co-creative methods, different groups of people will be able to come together to produce the kinds of relationships and social structures that will allow this adaptiveness to flourish.

I close out this thesis with a call to action for more co-creative methods in public health to address the many complex questions our society will face in the years to come. Pandemic fallout, climate change, and the increasing prevalence of genetic technologies to name a few. I have outlined the potential of a ritual lens of communication as a way to understand the kind of change that needs to happen in the face of these issues. To be sure, other lenses could also be helpful: feminism, participatory research, social justice, and environmentalism just to name a few. As I prepare to receive the training required to be a public health expert, I call on my peers to use whatever combination works to help you advance health equity through community engagement. The issues of disinformation, medical mistrust, and conspiracy theories on full display during the COVID-19 pandemic illustrate what happens when people reshape relationships to research institutions and medical experts for profit, political gain, or even just a sense of control in a dire situation. Without health equity, whole communities will continue to hold onto fear and mistrust. They will in turn be vulnerable to exploitation by those who know how to use the ritual tools of communication to let others know where to find them and how to join them. If public health professionals aren't making their own calls for community action and offering support around health equity, it should come as no surprise when vulnerable communities turn elsewhere.

APPENDIX A: “A PEOPLE’S GUIDE TO PRECISION MEDICINE” ZINE ARTICLES.

The following articles are taken from the zine produced as part of the development of “A People’s Guide” community engagement program. The articles exist online at https://hercommunication.pubpub.org/issue-1 at the time of publication of this thesis. Text and images are pasted below. URLs to online resources and accessibility features like alt text are not available in this printed format. The style guide for the zine aims to address these issues in print by requiring article titles, sources, and image captions in plain text throughout.

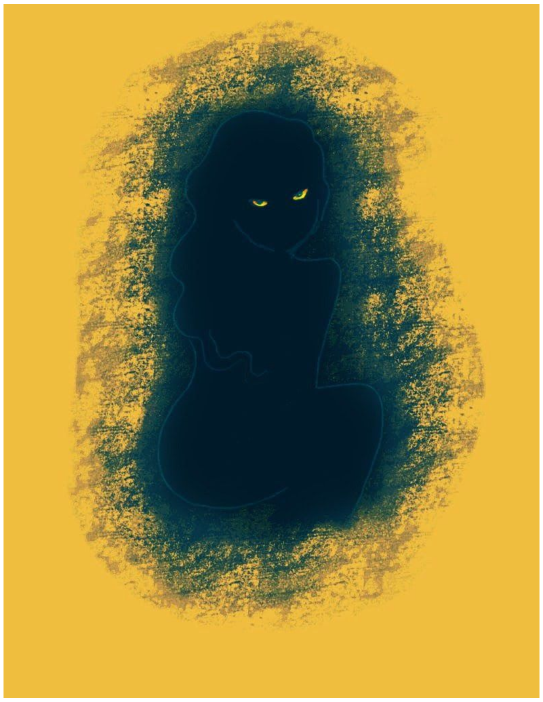
Cover Art: The 4 Spirits of Precision Medicine

by Samuel Mendez

Apr 01, 2020

Last year I didn't know what this zine would be. But I knew I needed inspirational cover art. I reached out to my friend @lolosketches to help. I talked with them about precision medicine's potential effects.

Precision medicine is an approach to medical research and care. Precision medicine's just starting. But it has a lot of promise. It will use lots of data to personalize health care. It will use lots of data to target disease prevention and screening. This includes genetic data. It also includes health records and habits. It will likely lead to medical breakthroughs. But what else will it lead to? These illustrations start the train of thought for the rest of this zine.



The Hard-to-Reach Spirit.

Illustration by @lolosketches

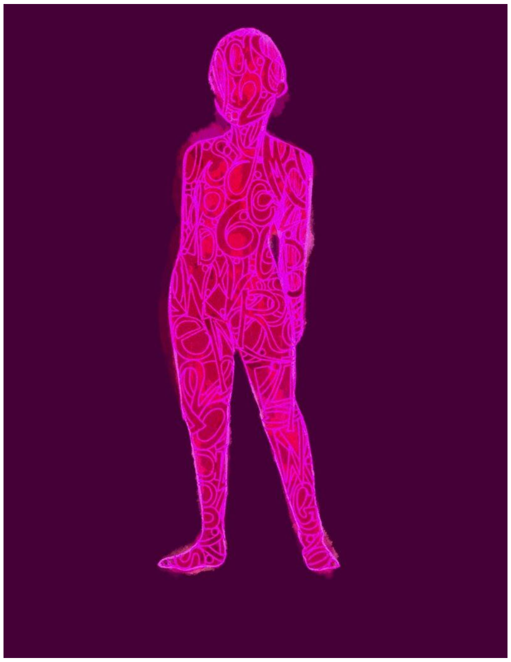
Not everyone trusts the medical system. The system doesn’t serve everyone well. Not everyone trusts research institutions. These institutions don’t serve everyone well.

Precision medicine research requires lots of data. But some communities might not take part. They’ll likely have good reasons to say no. But in the end, research data won’t represent everyone. This creates a dilemma. Your community might need to take part in research for precision medicine to serve you. But how likely will does that seem if the medical system doesn't serve you well now? Solving this problem will take collaboration. Dialogue. Community engagement. Co-learning.

I fear researchers might label communities "hard to reach" before labeling themselves "bad at reaching out." The Hard-to-Reach Spirit is one side of the coin.

The See-Through Spirit.

Illustration by @lolosketches



Precision medicine promises knowledge. Big data that researchers can use. Research findings that doctors can use. Health information that you can use. Will you find a statistic that can calm your fears? What will it mean to have more statistics and projections on hand? What does it mean to see your body as a puzzle you can solve? The See-Through Spirit is an open question.

The Average Spirit.

Illustration by @lolosketches

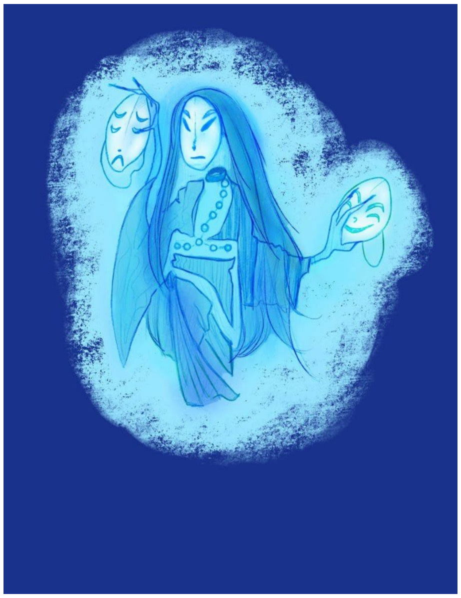
Precision medicine promises personalized health care. Yet that will depend on comparisons to larger populations. At some point, this will mean lumping people together. In clinical settings. In public health communication.

I trust researchers will do this work carefully. But I still worry about how this will interact with stereotypes. I worry about things like genetic discrimination. About people misusing scientific findings to try to defend their prejudice. I wonder if implicit bias will inspire research questions in the first place. The Average Spirit is a prompt. Who gets to lump people together?

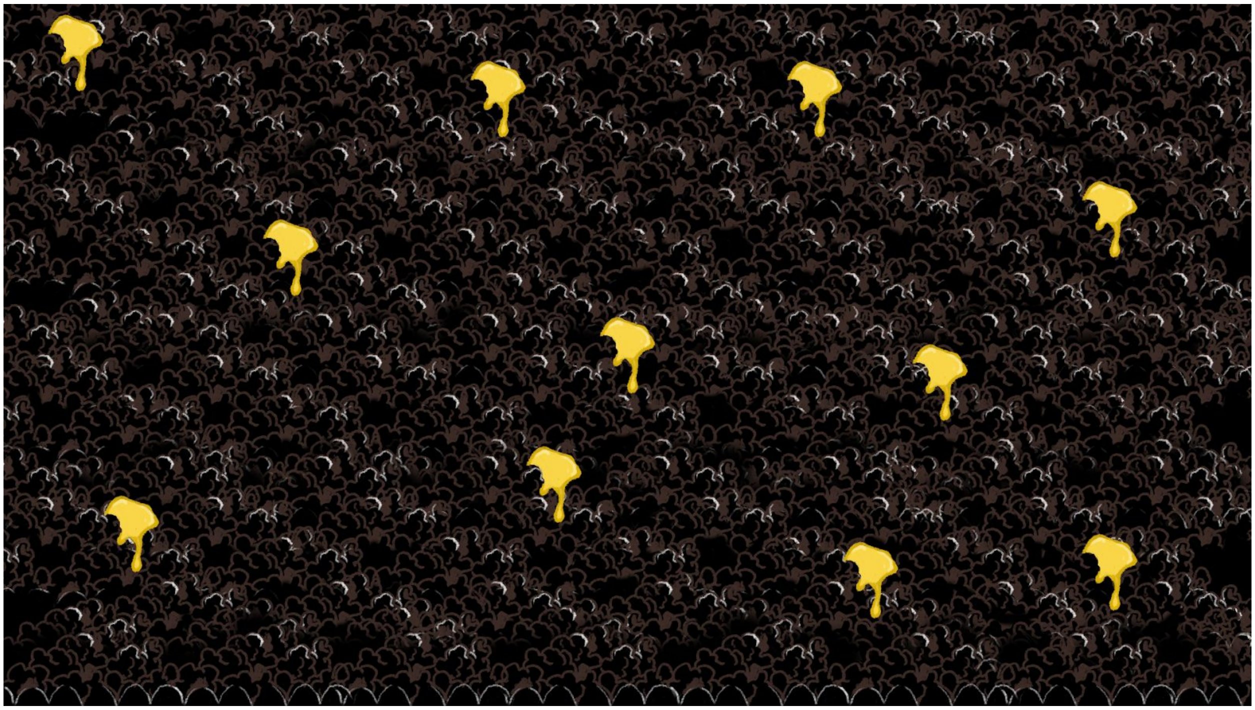
The Storytelling Spirit.

Illustration by @lolosketches

Scientific findings aren't much of a story on their own. Who gets to decide if scientific discoveries are exciting? Or if they're scary? Whose version of the story will get the most attention? The Data Storytelling Spirit is a reminder. Stories are powerful.



Every Fucking Time: A story about genetic testing.



Aug 06, 2019

by Anonymous

Updated on: Oct 03, 2019

Intro.

I led this interview with someone who took a genetic health test that her workplace offered. She has a family history of cancer. So, I was curious about what she wanted that she didn't already know.

Her results suggested that she might have a higher risk of getting colon cancer. I was also curious about what it's like to get this kind of news. These results don't mean she **will** get colon cancer, but it still seems scary. Then again, these results could also be a helpful tool. I wanted to learn more about this mix of emotions.

I included her story in this zine because her experience might be more common in the future. If genetic health info becomes more common, others will likely face similar emotional journeys. This story is a look into the future that precision medicine might help create.

-Samuel R. Mendez

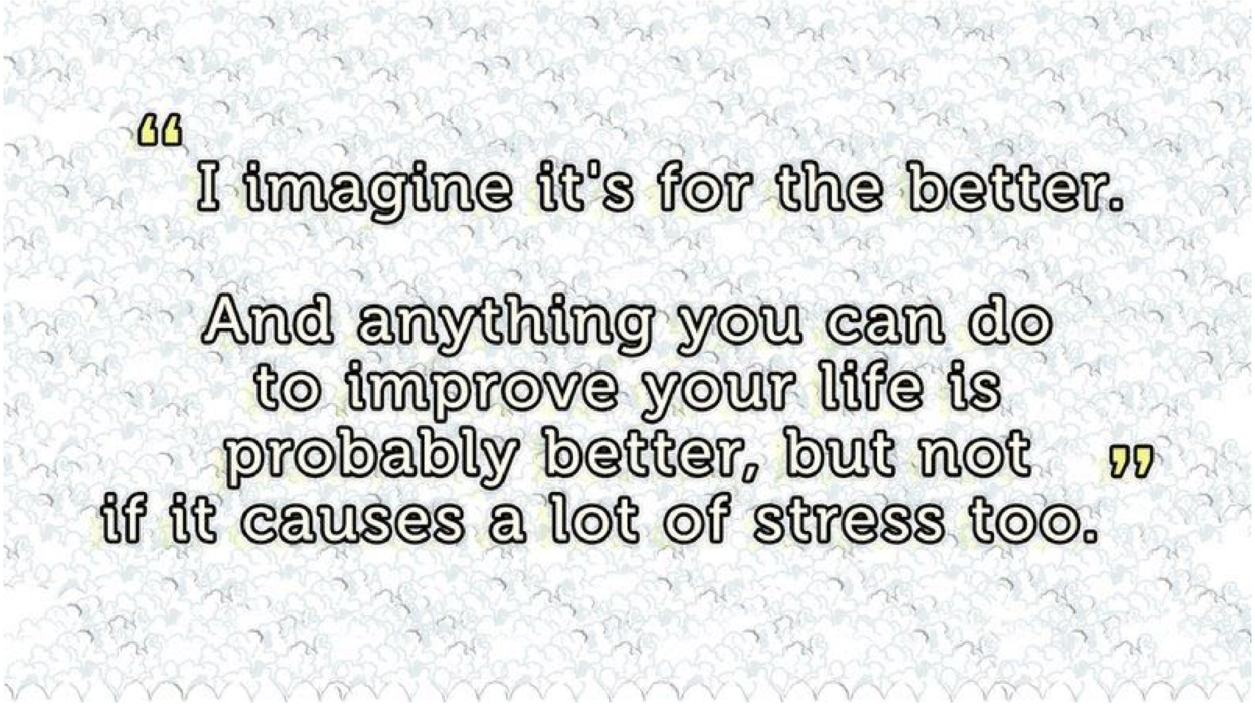
Interview.

Why did you take the specific genetic test you did?

The only reason I did this particular test... [my employer] was offering it for free. In some way I was probably putting too much faith in them. If they're making this available to people for free, they must have done their due diligence that this is a reliable [genetic testing] company.

What happened when you received the test results?

You book an appointment [with someone to] walk you through the results. So when she was walking through it, it was kind of a shock. It's kind of how I imagined a cancer diagnosis to be.



“I imagine it's for the better.

And anything you can do
to improve your life is
probably better, but not
if it causes a lot of stress too.”

Pull Quote: “I imagine it’s for the better. And anything you can do to improve your life is probably better, but not if it causes a lot of stress too.”

She said, okay, here is your mutation, specifically with this gene. Let’s say the average population has a 10% chance of developing [colon cancer]. For those with this mutation, it's maybe 80%. She was very clear, though, to say that these were groups of people. It was not specifically me. That was very comforting of her just to say this doesn't mean it's going to happen. She did say there was a specific department at [a local hospital] that focuses on cancers based on mutations in genes. She gave me the name of a specialist doctor/researcher in gastroenterology.

What kind of sucked is before I learned the test results, I had just changed my insurance provider. So I couldn't see the recommended GI specialist till the following year. I decided to wait till then to get a colonoscopy and deeper diagnosis. It was a bit of a relief to put it off, but also caused some anxiety. Who knows what could develop in a year’s time untreated? A close friend had recently passed away within months of discovering she had stage four cancer - and it caused me to question how much getting more tests done immediately versus later mattered.

With that feeling hanging over me, I decided even though I would wait to see the GI specialist, I might as well still get my annual physical done to know what baseline “healthy” looks like for me. His reaction to the gene testing was kind of skeptical. He was kind of like, “You know, those tests, they're only so accurate, right? There's not a lot of sound research behind them… You know, [our hospital] also has that kind of program,” and blah, blah, blah. He wasn't putting a lot of faith behind it, I guess and I was a little biased [when I heard that]. He’s not working in a specialty hospital, right? You go there for your annual physical and that's it.

After a year passed, I was eligible to switch insurance providers and could see the GI specialist. It’s been a few months and I haven’t scheduled it yet... but I plan to.

How did you feel after receiving the test results?

For the first few months, I was a little paranoid… I went to a comedy show and [the performer] was saying she loves to eat popcorn. And her father died of colon cancer. Her doctor told her to stop eating so much popcorn because it messes with your colon, or something like that. And I remember that moment just being like, “Fuck! That's kind of like me, right?” Those are things that I should probably be looking out for.

Illustration description: a woman looks at a giant box of fresh popcorn performing on stage in front of a microphone. Credit: Annie wang.

I think my fear with some of the cancer stuff is that the people I know [who have had cancer], I don't think it was something they were or weren't doing about their health. My aunt who died of lung cancer was not a smoker. She lived in Hong Kong, so it was probably her environment. But there are millions of people who live in Hong Kong without getting lung cancer. My mother with a brain tumor... there was probably nothing that she was or wasn't doing to cause that. Both of my grandfathers had prostate cancer. So is it bound to happen no matter what I do? How much control can you really have over it?

Have your genetic test results made you think differently about the future?

I think had [my friend not gotten cancer], I wouldn't have felt such a need to take the test right then. I think her situation pushed me to do it a little bit sooner, even [change] some of the ways I'm living my life in general.

Let's say I do get colon cancer and I have to step away from everything I know. Will I be most disappointed that I didn't get promoted? Or disappointed that I won't be able to spend time with family and friends? Or mad at myself for not taking better care of myself?

I'm in my late twenties now. And people are getting married and they're having kids and all that stuff… If I have kids, am I passing on bad genes? If I don't have kids, it's kind of the end of my family line. [But] I may be saving a child from having a lot of issues...

I feel like I'd be asking some of these questions regardless of the test though. I feel like it was just like a quarter life crisis that came up. And I think it's more related to [the death of my friend] than to the [genetic test results].

Overall, do you think your genetic test results had a positive or negative impact in your life?

The popcorn example… every time I eat popcorn, I question if it's causing colon cancer. I still eat it. But I question it every fucking time now. I used to have acid reflux. I blamed it on my birth control more than anything. Now when things like that happen, it does scare me a little bit. Like, my stomach's upset. Is this something?

It also kind of distracts me from other things. I don't think about skin cancer anymore. It's almost like colon cancer's going to get me first. Heart disease is probably a more common killer than colon cancer. Am I worried about the amount of meat I'm eating or my cholesterol or anything? No. Am I worried about popcorn in my colon? Yes.

I imagine it's for the better. And anything you can do to improve your life is probably better, but not if it causes a lot of stress too. So I don't know. I do kind of feel like I should take [another test] though. I would probably pay for it. I don't think I would have paid [for my genetic test] had [my employer not offered it for free].

Notes.

This interview is anonymous because it includes sensitive health information. The original interview is much longer than this article. I transcribed it and edited it down to this current length. I also broke up long passages into the short sections you see above. Once I finished editing, I sent it to the interviewee for her review, edits, and approval.

-Samuel R. Mendez

#PMtldr: Precision Medicine; too long, didn't read. (Workshop Guide)

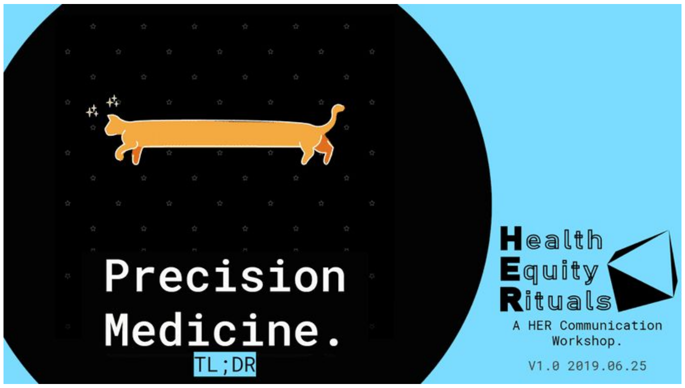
by Samuel R. Mendez

Jun 25, 2019

Updated on: Jul 25, 2019

Background.

This workshop guide helps introduce topics and questions around precision medicine and health equity. I aimed to create a guide that would prompt participants to ask questions about the stories of research they encounter. I aimed to prompt readers to imagine alternatives they might like to see.



Precision Medicine.

TL;DR

Health
Equity
Rituals

A HER Communication Workshop.

V1.0 2019.06.25

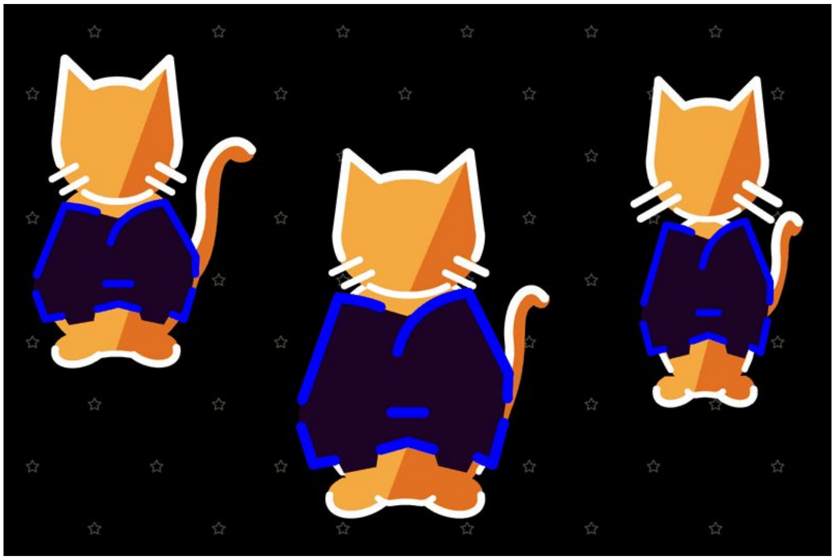
A Google Slide Deck for the Workshop is available.

The web version of this guide is below, with a Google Slide deck included. A PDF and a video version of this guide will be available soon. If you use this guide, please share your story in the Discussions section below!

1: You vs. an "Average Person."

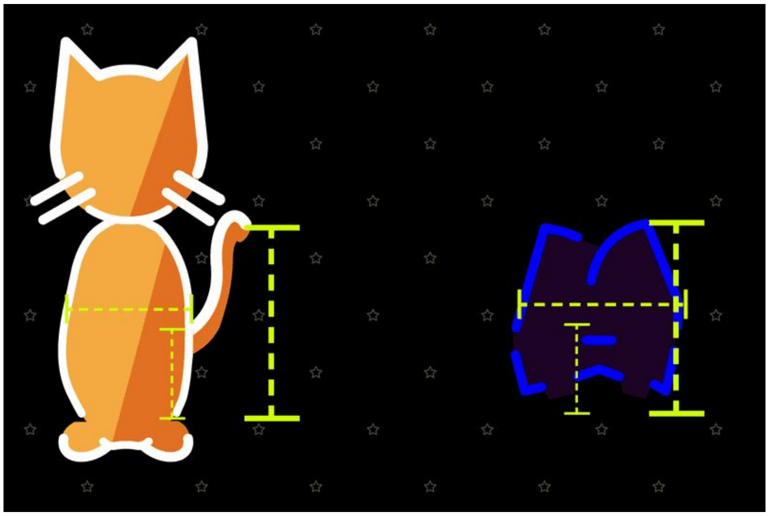
Three different-sized cats wearing a one-size-fits-all coat.

Let's say a designer made a one-size-fits-all coat for an "average person." It might fit a lot of people *okay*. But it definitely wouldn't fit everyone. And it likely wouldn't fit many people *well*.



Three different-sized cats wearing different sized coats: small, medium, and large.

Now let's say the designer made a new coat for people in standardized categories. For example: small, medium, and large. That's better, isn't it? But what about people who wear clothes outside of these sizes? What about someone between a "medium"" and a "large"? What about people with shorter arms than the “average person” of their size? These size categories are both useful and flawed. It’s useful that people can quickly get an idea whether a coat will fit them. But as we just saw, organizing people into broad categories will never work perfectly. So, what if every store could tailor these coats so they fit the wearer?



A cat and a tailored coat.

Precision medicine is an approach to health care that asks a similar question. The US National Institutes of Health (NIH) describes precision medicine in contrast to a one-size-fits-all approach. They say that current medications are developed and tested for effectiveness in a broad range of people.

With the Precision Medicine Initiative, the NIH aims to fund research that asks how health care workers can tailor health care to individuals. These questions aren’t new, but developments in research and technology are fueling new kinds of answers.

Question Time.

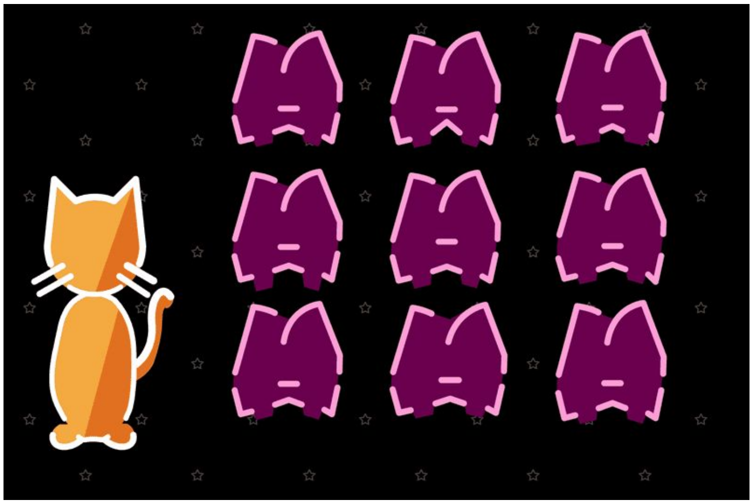
1. Health care professionals already base their work on medical knowledge and patient info. If they know a patient’s mom had breast cancer, they might follow research-based guidelines that suggest more frequent mammograms. As another example, a patient might talk about her troubles taking a birth control pill every day. In that case, a health care

worker might suggest an IUD instead. **What are other ways that health care workers base their work on what they know about a patient?**

2. We know that health doesn't begin or end in a doctor's office. We can imagine the "precision medicine" approach helping us in many aspects of our lives. For example, a doctor could give you a nutritious recipe book that matches your budget and taste. Or a nurse could point you to housing options that won't upset your allergies. **What are other cases where personalized info could help someone lead a healthy lifestyle overall?**

2: You vs. a More Specific "Average Person."

A tailor can re-stitch a coat so it fits you just right. But a health professional can't work with medical treatments that way. These treatments go through testing and approval for very specific uses. So, instead of "tailoring" an existing medical treatment, a health care worker would help you find the best option out of many. Or they might help you find the right combination.



One cat choosing from many seemingly similar coats. They all have the potential for the same outcome.

One goal of precision medicine is to help you find your "just right" medical treatment. A health care worker might use information about how a medicine usually interacts with genes, a work environment, everyday habits, and a medical history like yours. This means they would still choose a "just right" treatment for you based on an idea of an "average person." It's just that this "average person" would match you more closely in more ways.

This approach to medicine would require a lot of detailed information. It would require a lot of your own personal data. And it would require a lot of data about the treatment itself.

Question Time.

1. Clearly, "precision coat-buying" wouldn't work for everyone. Some people who want a coat don't want someone else to have all their measurements. Some people who need a new coat can't afford one. Some people live in hot climates where they don't even need coats. **What are some situations where a precision medicine approach might not work for someone?**

3: You and Whoever's in the Database.

Precision medicine requires answers to lots of questions. Who takes a certain medication? How well does it work for them? Does it work better for some people than others? One goal of precision medicine is to use the answers to these kinds of questions to personalize medical treatment. So…

A cat compared to other cats in a database.

This means that precision medicine requires a lot of people to give researchers their personal data. This also means that for precision medicine to work for **you** specifically, there need to be people like you in research databases.

But what does "like you" mean? It could mean someone with similar health issues as you. It could mean someone with similar genes. It could mean someone with a similar lifestyle. It could even mean a combination of all of the above. This is why large numbers of diverse research participants is key to precision medicine. This will help researchers and health care workers learn more about how a treatment works under all sorts of real-world conditions. For example, the *All of Us* Research Program aims to recruit 1 million people to be part of a precision medicine research database.

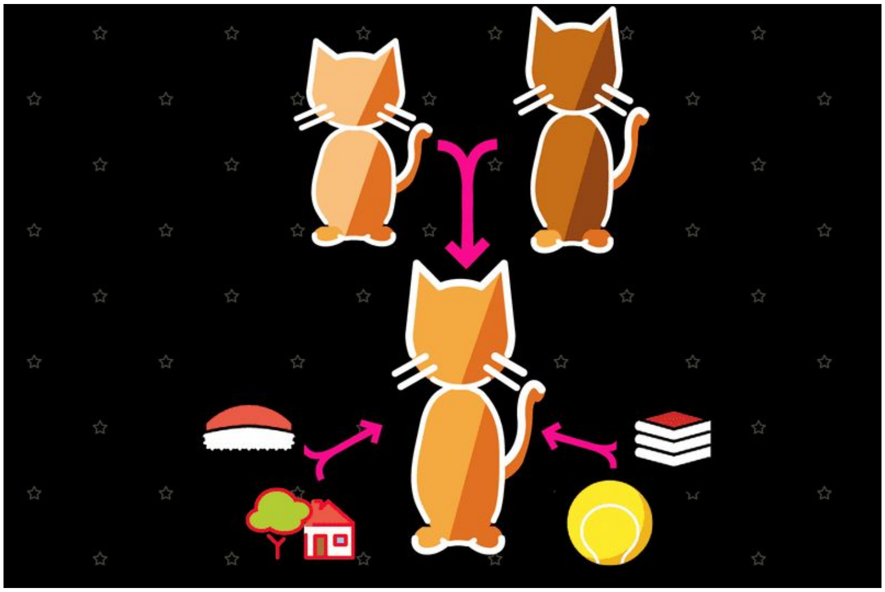
Right now, there are a lot of unknowns when treating diseases. We know that some people will respond well to certain medications. And we know that some people won't. But we don't always know how to predict those outcomes. And as a patient, this can feel like random chance. Precision medicine aims to use more information from research to make more accurate predictions about medical treatment.

Question Time.

1. **Do you think you would give your genetic information to a research study? Why or why not?**
2. **Would you give a research study your medical records? How about survey responses? Or data from an activity-tracking smartphone app? Is there a difference between these different kinds of data for you?**

4: Precision Medicine and Disease Prevention.

So far we've focused on precision medicine as an approach to medical treatment. However, precision medicine impacts disease prevention too. Precision medicine might help predict what kinds of people will get a disease in the first place. Again, what does "kinds of people" mean? It might mean a particular combo of genes, environment, and lifestyle. It's hard to say right now.



Genetics and environment came together to shape the cat we see today.

But these ideas about disease prediction aren't new. We already use genetic and hereditary information to predict disease and make health decisions. For example, you might know of certain health conditions that run in your family. And tests for mutations in genes related to cancer have been available for decades. However, there's still a lot we can't predict. It's possible we just don't know all of the risk factors for certain diseases. Or, we don't know about specific combinations of risk factors that lead to an actual disease. One of the promises of precision medicine is to help provide more information to make better predictions.

You might be familiar with commercial genetic testing for health. Genetic testing companies can tell you if you have a certain version of a gene that's known to lead to a specific disease. These companies can also tell you if you a have a version of a gene that lots of people with a certain disease also have. Precision medicine aims to go beyond this, incorporating genetic information, lifestyle info, medical history, etc. to better predict whether someone will get a certain disease. The idea is that more info can lead to better predictions for more people.

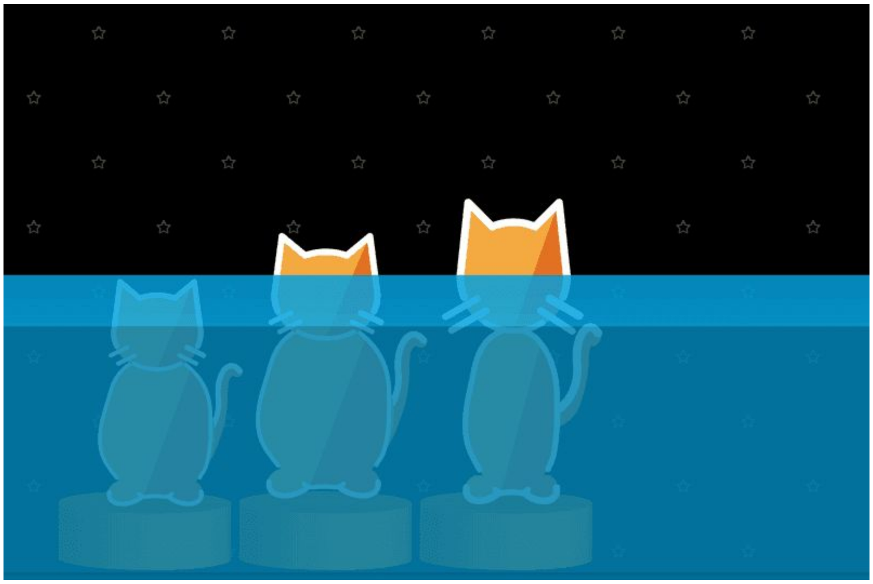
Ideally, precision medicine can help all people be healthier by providing better predictions about their health. They'll be able to talk with their health care providers about their risks. They'll be able to make informed decisions about their lifestyle and their medical care. However, things probably won't be that simple for everyone.

Question Time.

1. We already know that diet and exercise are important to health. We already know that sleep and social support are important to health. **Do you think precision medicine can offer useful information for you to form healthy habits? Why or why not?**

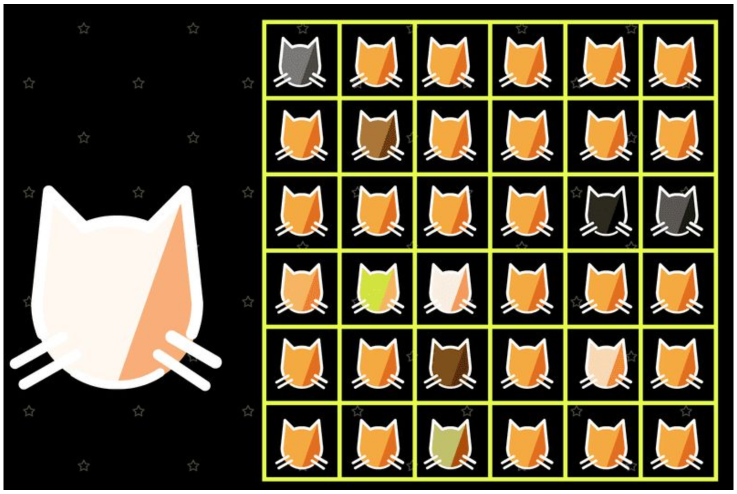
5: Precision Medicine and Health Equity.

"Health equity" describes an ideal situation in which everyone has the chance to be healthy. Right now, we don't see health equity in our society. It's harder to be healthy if you can't afford to see a doctor. It's harder to be healthy if you live in an area where fruits and vegetables are hard to find. These kinds of social inequalities make it harder for some people to be healthy.



Three cats of different heights trying to see over a wall, standing on identical platforms. The tallest is the only one that can actually make use of the platform given to it.

As it's defined right now, precision medicine won't make it easier to act on medical information. Precision medicine may help provide people with more personalized health information. But it won't change their income, their insurance status, or their neighborhood. Precision medicine might help health care workers make better decisions about people's health care. But it won't help people access medical care in the first place.



A cat compared to other cats in a database. There aren't that many similar to it, even though the database is big.

It's not just things like income or medical care that shape precision medicine's impact on health equity. Research participation is important too. We mentioned earlier that precision medicine techniques can work well for you if there is information from other people "like you" in research databases. For that reason, diversity in research participation is pretty important. For example, if participants in clinical trials all come from similar backgrounds, then it's hard to say that the trial results apply to broad range of people.

However, there are a lot of reasons someone might not want to be a research participant. Maybe they want as few people as possible to have access to their personal information. Maybe they have a very busy life and it's hard to make time for a research study. Maybe the physical layout of the city makes it hard for them to get around, and they can't reach a research lab to participate.

This creates an unfortunate situation for medically under-served communities. They need more representation in medical research. But they also face a lot of reasons to not participate. This is a problem that precision medicine researchers will have to help solve if they want to see progress.

In this early stage, it's important to think about the broad implications of precision medicine too. What if we find out that people from specific backgrounds are more likely to get a certain kind of illness? Could that lead to a new level of discrimination? What if pharmaceutical companies find ways to target medicines to populations that live in wealthier areas? Could that lead to a new levels of inequality?

Precision medicine holds a lot of promise. But that doesn't mean it's guaranteed to advance health equity. Like all things, it has both risks and challenges. Hopefully this workshop has helped you feel more comfortable discussing precision medicine and asking questions about it.

Question Time.

1. **Do you see any tension between development of medical technology and health equity? Do you think it's possible to advance both at the same time?**
2. **Do you usually hear about health equity when you hear about medical research? Why do you think that is?**

6. Learn More.

Thank you for taking the time to think about precision medicine! You're now better equipped to think about the messages you hear and ask questions as you hear about precision medicine in the future.

If you want to keep learning more, here are some resources:

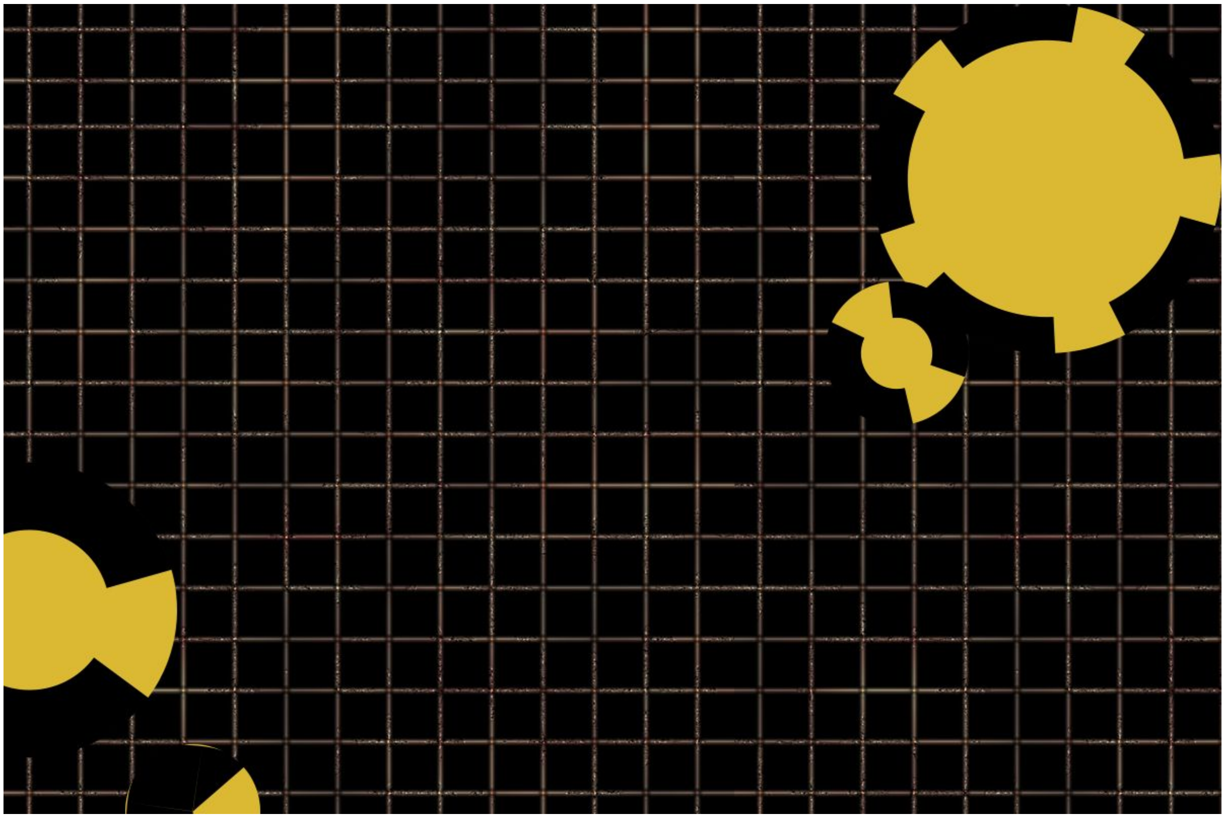
- "What is the Difference between Precision Medicine and Personalized Medicine?" from the US National Library of Medicine.
- "FACT SHEET: President Obama's Precision Medicine Initiative," from the Obama White House archive.
- "Help Me Understand Genetics," by the US National Library of Medicine.
- "Precision Medicine in Cancer Treatment," by the National Cancer Institute.
- "What is Precision Medicine?" from Learn.Genetics, by the University of Utah.

Acknowledgements.

The Allied Media Project's "A People's Guide to AI" was a big inspiration for this piece.

I adapted OpenMoji emojis to make the graphics for this workshop guide. The emojis are available under the Creative Commons Share Alike 4.0 (CC BY-SA 4.0).

The Future of Anything: A conversation about history, survivorship, and justice.



by Oluwaseyi Adeleke and Samuel Mendez

Sep 24, 2019

Updated on: Nov 05, 2019

A decorative patch from the "Black Women Are the Future" line by PRGRSSN

Oluwaseyi Adeleke is a researcher and artist at the University of Illinois at Chicago. He is the founder of Progression With The Krown (PRGRSSN for short), a clothing line that takes inspiration from moments in black history. Past clothing lines include "Black Women are the Future," commemorating Marsha P. Johnson, a prominent queer rights activist, as well as present day black transgender activists continuing the fight for for a liberatory future. More recently, PRGRSSN dropped a line referencing the Afrocentric fashions of the 80's and 90's.

PRGRSSN also serves as a platform for community events, exhibitions, and parties to help connect people with these important historical moments. PRGRSSN also uses a portion of its profits to offer scholarships for high school and college students. You can learn about them at PRGRSSN.com or on Instagram: @prgrssn_

Author's Note: I interviewed Oluwaseyi to learn more about his views on the intersection of community-based art and health research institutions. I really liked how he incorporated history into his discussions of the present and the future. And I thought other researchers would be able to learn something from our discussion of the unique stressors that first-generation students face as they move into the workforce in health fields. I edited this interview for length. I sent it to Oluwaseyi for his review, edits, and approval.

A poster for the PRGRSSN event, "Building Blocks of Fashion," an interactive fashion show and exhibition exploring how fashion is influences by Black social movements in America.

What's the Big Picture?

Sam: *What's the big picture of what you'd like to accomplish at the intersection of clothing design and health research?*

Olu: I would like to see a lot more institutions [like hospitals] put their money where their mouth is. Say, we get a few people to tell their story [about cancer] on T-shirts and the hospital helps us throw an event where they're able to showcase them in an exhibition and auction them off. And the proceeds go back to those families. Because, yes, cancer research is super important, but what does it mean if the people who need it most can't access it because it's so expensive? I actually lost my uncle to cancer, and that's his story. My family tried to pull money together and he still ultimately ended up dying because he just didn't have the funds to actually get that care.

I shared this idea with a cancer survivor and she was explaining how it's an amazing idea to her, but it scares her in the sense that she's not ready to do that unpacking. And she was saying that an opportunity like this would make her more open to unpacking some of that stuff. And we had a conversation about the support for a lot black and brown cancer survivors. What does that actually look like? And are they given the platform to express themselves? And are they being encouraged to unpack the trauma that might be associated? Overcoming [cancer] doesn't mean that it wasn't a traumatic experience. Or the fear of it coming back, the bills that might've come out of it as well.

A model wearing pieces from the PRGRSSN line celebrating afrocentric fashions of the 80s and 90s.

How do you navigate being in 2 worlds at once?

Sam: *A similar thing happened to my uncle who died of cancer while I was working at Northwestern. And it was weird. I had no way to help him even though I was surrounded by all* *of the research and all the professionals and everything. How do you think about being in these two worlds at once?*

Olu: I know I'm probably not okay with existing in these two worlds. I know that it's necessary because otherwise I might not have a platform. I won't have a seat at the table to even get some of these ideas out there. I think that as far as you are navigating through this weird system and being true to yourself and not sacrificing so much of your integrity, I think it'll be an internal struggle that will at least allow you to go to sleep at night. You can't help everybody. But if there is one thing that you can do, you don't necessarily have to hurt anybody along your journey either. And I think that that's pretty much how I navigate those two worlds.

You hit the nail on the head, though. I remember when my mom came to me about my uncle. At the time I was still premed, and she was just like, "What do you know? Who can we talk to?" Especially being first-generation. A lot of your family's thinking because you exist in a certain system that you have access to everything and running in that reality. But, I don't, right? I've taken all these classes with these professors. I'm interning with doctors. But no one can really help me. And even if they wanted to help me, care costs money.

How can researchers learn from the past when thinking about the future of medicine?

Sam: *One last thing I'm interested in: precision medicine might really change our relationship to health and disease. There might be new forms of discrimination based on genetics... There's a lot of unanswered questions. I was interested in your view, given your focus on learning from the past and amplifying certain voices right now.*

Olu: The only way that we'll be able to make sure that the conversation about precision medicine never becomes racist is if we make sure that we include people in the research and make sure they have a voice to speak up. When you think about the Jim Crow laws, when they were reversed, it came out of the United States finally hearing black people out. But as a result of the people executing a lot of those changes, they weren't being pushed from a black lens. They were still being pushed from a white lens.

So, who are our cancer center directors? Who are the presidents for the National Cancer Institute or American Cancer Society? Who are all of these people that we're choosing to put in power? For example, I am not queer. So as a result, I will never ever be able to speak for queer people and tell queer people what they need. I'm not a woman. I can never speak for women. There are certain things that require certain people in power. And I think that's the most important thing that a lot of people can do. When it comes to precision medicine, or just the future of anything, it's about making sure that people with power are actually of that community that we're trying to serve.

Balloons, Bears, Candles, & Sunglasses: Joyful futures of precision medicine.

by ChicagoCHEC 2019 Research Fellows

Jul 08, 2019

Updated on: Feb 08, 2020

Introduction.

What might precision medicine look like if it spread joy? What if it built community? The ChicagoCHEC Research Fellows proposed some answers to those questions.

Who?

The 2019 ChicagoCHEC Research Fellows are a group of undergraduate and post-baccalaureate students. They bring diverse perspectives and experiences to help advance health equity. They come from City Colleges of Chicago, Northeastern Illinois University, Northwestern University, and University of Illinois at Chicago.

What?

The Fellows completed a speculative design workshop. Samuel R. Mendez facilitated it, adapting the format of "THE ORACLE FOR TRANSFEMINIST TECHNOLOGIES" to on community health. In small groups, they responded to the following design prompt:

In Chicago 100 years from now, this object builds community & spreads joy. It uses the data-driven techniques of precision medicine. Its target audience includes the descendants of someone in your group. They might be biological descendants, ideological descendants, etc. There are many ways to be a family.

Each group was randomly assigned an Object, a Principle, and a Value. They came up with an Object design that centered their Principle and embodied their Value. They then presented their designs to the rest of the groups. The workshop ended with guided feedback and suggestions on sticky notes.

Where & When?

The Fellows did this workshop in Northwestern University's medical campus on July 2, 2019.

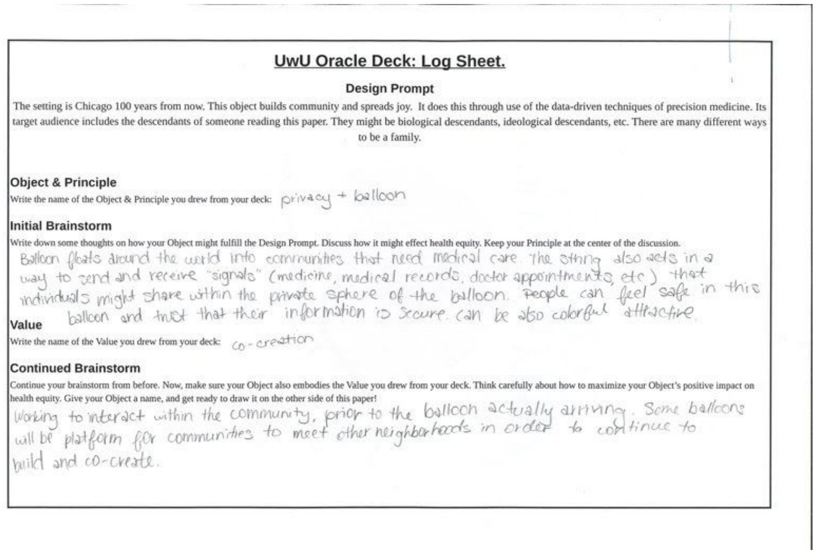
Why?

These designs work as a conversation starter. They're not meant to be practical product designs. They're not meant to be fleshed out business plans for medical technologies. They're meant to imagine what might precision medicine might lead to if there were different baseline assumptions. Can medicine spread joy? Can medicine build community? Should joy be part of discussions of medicine? What might medicine look like with a focus on communities instead of individuals? Hopefully, these designs can prompt you to question your own assumptions about medicine, community, values, and tech.

Design 1: Floaters.

Brainstorm:

The Floaters group worked first with the cards: “Privacy” and “Balloon.”



UwU Oracle Deck: Log Sheet.

Design Prompt

The setting is Chicago 100 years from now. This object builds community and spreads joy. It does this through use of the data-driven techniques of precision medicine. Its target audience includes the descendants of someone reading this paper. They might be biological descendants, ideological descendants, etc. There are many different ways to be a family.

Object & Principle

Write the name of the Object & Principle you drew from your deck: privacy + balloon

Initial Brainstorm

Write down some thoughts on how your Object might fulfill the Design Prompt. Discuss how it might effect health equity. Keep your Principle at the center of the discussion.

Balloon floats around the world into communities that need medical care. The string also acts in a way to send and receive "signals" (medicine, medical records, doctor appointments, etc) that individuals might share within the private sphere of the balloon. People can feel safe in this balloon and trust that their information is secure. can be also colorful attractive.

Value

Write the name of the Value you drew from your deck: co-creation

Continued Brainstorm

Continue your brainstorm from before. Now, make sure your Object also embodies the Value you drew from your deck. Think carefully about how to maximize your Object’s positive impact on health equity. Give your Object a name, and get ready to draw it on the other side of this paper!

Working to interact within the community, prior to the balloon actually arriving. Some balloons will be platform for communities to meet other neighborhoods in order to continue to build and co-create.

“Floaters” brainstorm log sheet.

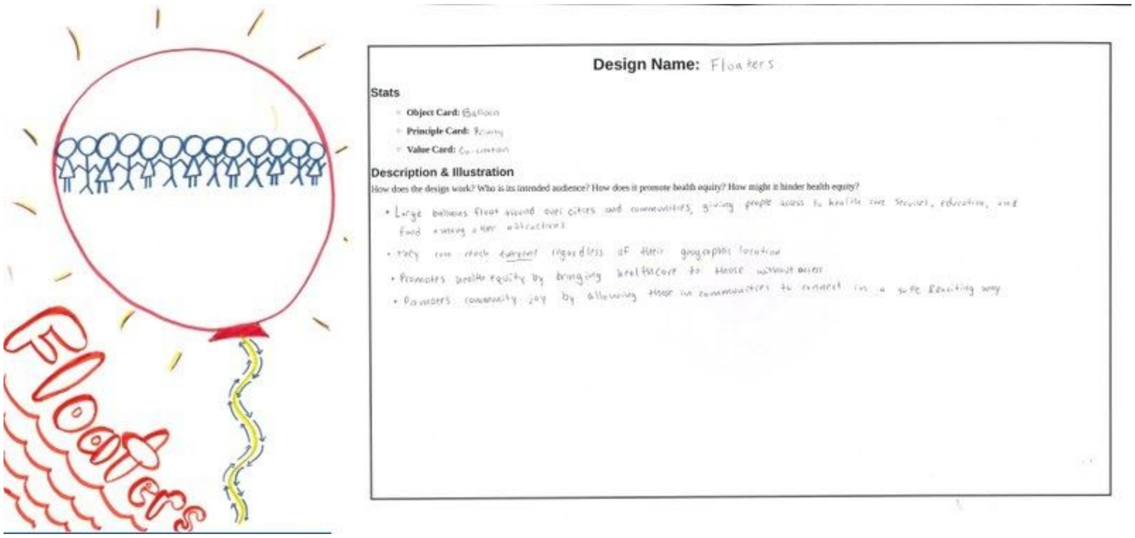
They made the following notes in their brainstorm log sheet:

> “Balloon floats around the world into communities that need medical care. The string acts in a way to send and receive ‘signals’ (medicine, medical records, doctor appointments, etc.) that individuals might share within the private sphere of the balloon. People can feel safe in this balloon and that their information is secure. Can also be colorful and attractive.”

They then drew the “co-creation” card and continued their brainstorm:

> “Working to interact within the community, prior to the balloon actually arriving. Some balloons will be platform for communities to meet other neighborhoods in order to continue to build and co-create”

Final Design:



Design Name: Floaters

Stats

- **Object Card:** Balloon
- **Principle Card:** Privacy
- **Value Card:** Co-creation

Description & Illustration

How does the design work? Who is its intended audience? How does it promote health equity? How might it hinder health equity?

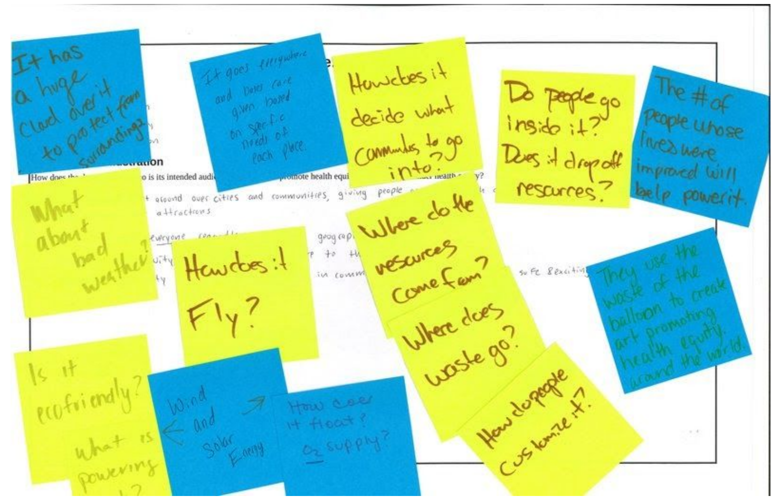
- Large balloons float around over cities and communities, giving people access to health care services, education, and food among other attractions
- they can reach everyone regardless of their geographic location
- Promotes health equity by bringing healthcare to those without access
- Promotes community joy by allowing those in communities to connect in a safe & exciting way

"Floaters" final design write-up.

Object Card: balloon. **Principle Card**: privacy. **Value Card:** co-creation. **Description:**

- Large balloons float around over cities and communities, giving people access to health care services, education, and food among other attractions.
- they can reach **everyone** regardless of their geographic location.
- Promotes health equity by bringing healthcare to those without access.
- Promotes community joy by allowing those in communities to connect in a safe & exciting way.

Sticky Note Feedback:



It has a huge cloud over it to protect from surroundings

It goes everywhere and bases care given based on specific needs of each place

How does it decide what communities to go into?

Do people go inside it? Does it drop off resources?

The # of people whose lives were improved will help power it.

What about bad weather?

How does it Fly?

Where do the resources come from?

Where does waste go?

They use the waste of the balloon to create art promoting health equity around the world.

Is it ecofriendly? What is powering

Wind and Solar Energy

How can it float? O2 supply?

How do people customize it?

Floaters" final design commentary.

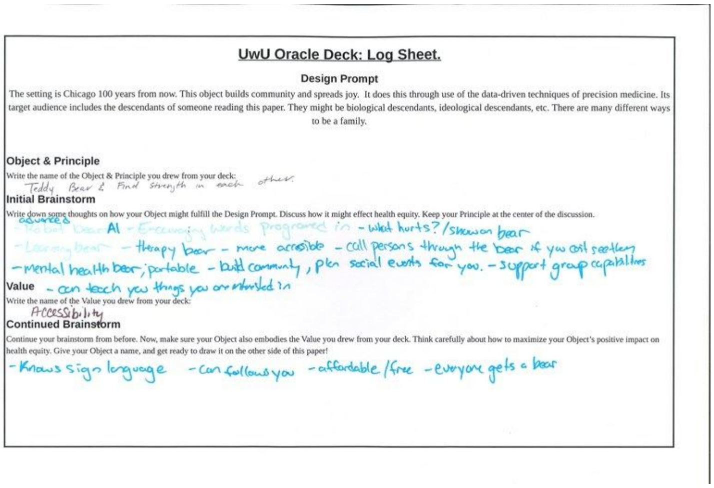
They received the following feedback and suggestions from other groups:

- What about bad weather?
    - It has a huge cloud over it to protect from surroundings
- Is it eco-friendly? What is powering it?
    - Wind and solar energy
    - The # of people whose lives were improves will help power it.
- How can it float?
    - O2 supply.
- How does it decide what communities to go into? How do people customize it?
    - It goes everywhere and bases care given on specific needs of each place.
- Where do the resources come from? Where does waste go?
    - They use the waste of the balloon to create art promoting health equity around the world.
- Do people go inside it? Does it drop off resources?

Design 2: Health Equity Bear.

Brainstorm:

The Health Equity Bear group first worked with the cards: “Teddy Bear” and “Find strength in each other.”



UwU Oracle Deck: Log Sheet.

Design Prompt

The setting is Chicago 100 years from now. This object builds community and spreads joy. It does this through use of the data-driven techniques of precision medicine. Its target audience includes the descendants of someone reading this paper. They might be biological descendants, ideological descendants, etc. There are many different ways to be a family.

Object & Principle

Write the name of the Object & Principle you drew from your deck:

Teddy Bear & Find strength in each other.

Initial Brainstorm

Write down some thoughts on how your Object might fulfill the Design Prompt. Discuss how it might effect health equity. Keep your Principle at the center of the discussion.

-Robot bear advanced AI - Encouraging words programed in - what hurts?/show on bear

-Learning bear - therapy bear - more accessible - call persons through the bear if you can't see them

-mental health bear; portable - build community, plan social events for you. - support group capabilities

- can teach you things you are interested in

Value

Write the name of the Value you drew from your deck:

Accessibility

Continued Brainstorm

Continue your brainstorm from before. Now, make sure your Object also embodies the Value you drew from your deck. Think carefully about how to maximize your Object’s positive impact on health equity. Give your Object a name, and get ready to draw it on the other side of this paper!

-Knows sign language -Can follows you -affordable/free -everyone gets a bear

“Health Equity Bear” brainstorm log sheet.

They made the following notes in their brainstorm log sheet:

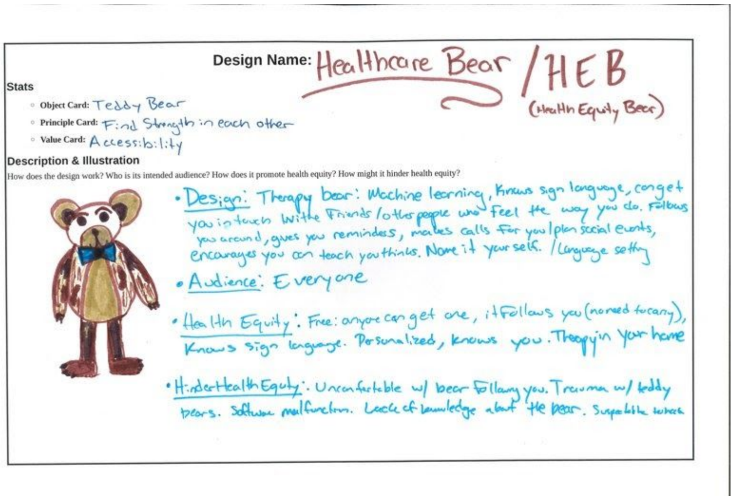
- Advances robot bear AI.
- Encouraging words programmed in.
- What hurts? Show on bear
- Learning bear
- Therapy bear
- More accessible
- Call persons through bear if you can’t see them
- mental health bear
- portable
- build community, plan social events for you
- support group capabilities

- can teach you things you are interested in

They then drew the “accessibility” card and continued their brainstorm:

- Knows sign language
- can follow you
- affordable/free
- everyone gets a bear

Final Design:



Design Name: Healthcare Bear /HEB (Health Equity Bear)

Stats

- Object Card: Teddy Bear
- Principle Card: Find Strength in each other
- Value Card: Accessibility

Description & Illustration

How does the design work? Who is its intended audience? How does it promote health equity? How might it hinder health equity?

- Design: Therapy bear: Machine learning, Knows sign language, can get you in touch with the Friends/other people who Feel the way you do. Follows you around, gives you reminders, makes calls for you/plan social events, encourages you can teach you things. Name it yourself. /Language setting
- Audience: Everyone
- Health Equity: Free: anyone can get one, it Follows you (no need to carry), Knows sign language. Personalized, knows you. Therapy in your home
- Hinder Health Equity: Uncomfortable w/ bear Following you. Trauma w/ teddy bears. Software malfunction. Lack of knowledge about the bear. Susceptible to hack

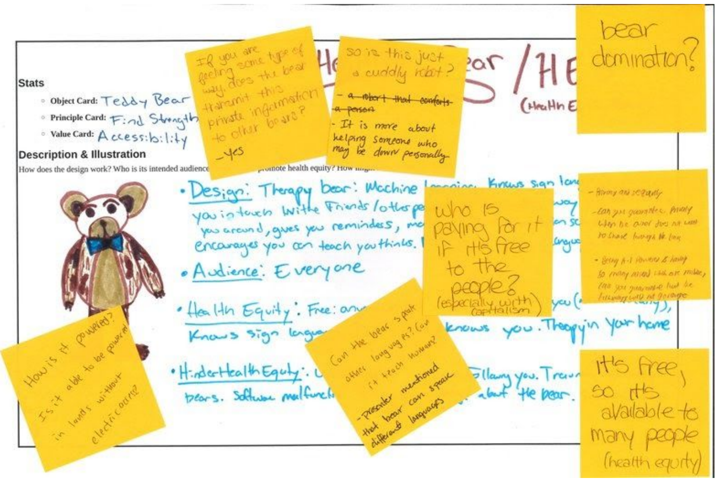
“Health Equity Bear” final design write-up.

Object Card: Teddy Bear. **Principle Card**: Find strength in each other. **Value Card:** Accessibility. **Description:**

- **Design:** Therapy bear. Machine learning. knows sign language. Can get you in touch with friend/other people who feel the way you do. Follows you around. Gives you reminders. Makes calls for you. Plans social events. Encourages you. Can teach you things. Name it yourself. Language setting.
- **Audience:** everyone.

- **Health Equity:** Free, anyone can get one. It follows you (no need to carry). Knows sign language. Personalized, knows you. Therapy in your home.
- **Hinder Health Equity:** Uncomfortable with bear following you. Trauma with teddy bears. Software malfunction. LAck of knowledge about the bear. Susceptible to hack.

Sticky Note Feedback:



Stats
- Object Card: Teddy Bear
- Principle Card: Find Strength
- Value Card: Accessibility

Description & Illustration

How does the design work? Who is its intended audience … promote health equity? How …

- Design: Therapy bear: Machine … Knows sign lan… you in touch with Friends / other pe… you around, gives you reminders, … encourages you can teach you things. …
- Audience: Everyone
- Health Equity: Free: an… Knows sign langu… knows you. Therapy in your home
- Hinder Health Equity: … follows you. Traum… bears. Software malfunc… about the bear.

bear domination?

If you are feeling some type of way, does the bear transmit this private information to other bears?
-yes

so is this just a cuddly robot?
- ~~a robot that comforts a person~~
- It is more about helping someone who may be down personally

who is paying for it if it's free to the people? (especially with capitalism)

It's free, so it's available to many people (health equity)

How is it powered? Is it able to be powered in lands without electric access?

Can the bear speak other languages? Can it teach humans?
- presenter mentioned that bear can speak different languages

"Health Equity Bear" final design commentary.

They received the following feedback and suggestions from other groups:

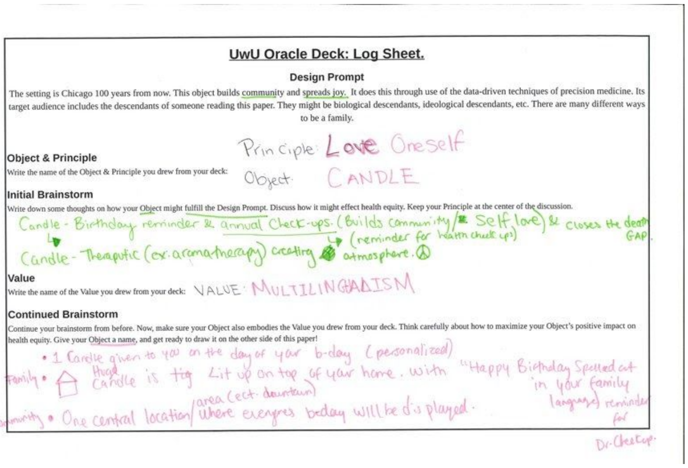
- bear domination?
- How is it powered? Is it able to be powered in lands without electric access?
- Who is paying for it if it's free to the people? (especially with capitalism)
- If you are feeling some type of way, does this bear transmit this private information to other bears?
    - yes
- So is this just a cuddly robot?
    - It is more about helping someone who may be down personally
- Can the bear speak other languages? Can it teach humans?
    - Presenter mentioned that bear can speak different languages?

- It’s free, so it’s available to many people. (health equity)
- Privacy and security
  - Can you guarantee privacy when the owner does not want to share through the link?
  - Being AI-powered and having so many around that are mobile, can you guarantee that the technology would not go rogue?

Design 3: The Candle of Life.

Brainstorm:

The Candle of Life group worked first with the cards: “Love Oneself” and “Candle.” They made the following notes in their brainstorm log sheet:



UwU Oracle Deck: Log Sheet.

Design Prompt

The setting is Chicago 100 years from now. This object builds community and spreads joy. It does this through use of the data-driven techniques of precision medicine. Its target audience includes the descendants of someone reading this paper. They might be biological descendants, ideological descendants, etc. There are many different ways to be a family.

Object & Principle

Write the name of the Object & Principle you drew from your deck: Principle: Love Oneself
Object: CANDLE

Initial Brainstorm

Write down some thoughts on how your Object might fulfill the Design Prompt. Discuss how it might effect health equity. Keep your Principle at the center of the discussion.

Candle - Birthday reminder & annual Check-ups. (Builds community/ Self love) & closes the death GAP.
(reminder for health check ups)
Candle - Theraputic (ex: aromatherapy) creating atmosphere. ☮

Value

Write the name of the Value you drew from your deck: VALUE: MULTILINGUALISM

Continued Brainstorm

Continue your brainstorm from before. Now, make sure your Object also embodies the Value you drew from your deck. Think carefully about how to maximize your Object’s positive impact on health equity. Give your Object a name, and get ready to draw it on the other side of this paper!

• 1 Candle given to you on the day of your b-day (personalized)
Family • Huge Candle is tig Lit up on top of your home. with “Happy Birthday Spelled out in your family language) reminder for Dr. CheckUp.
Community • One central location/area (ect. downtown) where everyones bday will be displayed.

“The Candle of Life” brainstorm log sheet.

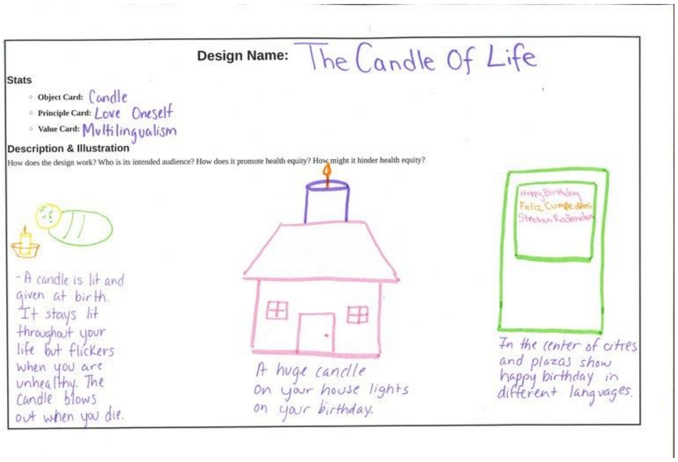
- Birthday reminder & reminder for annual health check-up. (Builds community/self love) & closes the death gap.
- Therapeutic (ex: aromatherapy), creating atmosphere. ☮

They then drew the “sustainability” card and continued their brainstorm:

- 1 candle given to you on the day of your b-day (personalized)

- Family: Huge candle is lit up on top of your home. With “Happy Birthday” spelled out in your family language. Reminders for [check-ups at the doctor].
- Community: One central location/area where everyone’s b-day will be displayed.

Final Design:



Design Name: The Candle Of Life

Stats

- Object Card: Candle
- Principle Card: Love Oneself
- Value Card: Multilingualism

Description & Illustration

How does the design work? Who is its intended audience? How does it promote health equity? How might it hinder health equity?

- A candle is lit and given at birth. It stays lit throughout your life but flickers when you are unhealthy. The candle blows out when you die.

A huge candle on your house lights on your birthday.

In the center of cities and plazas show happy birthday in different languages.

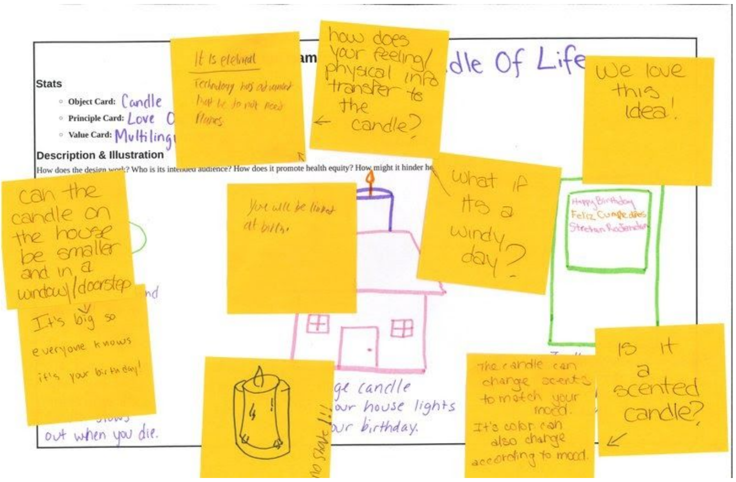
“The Candle of Life” final design write-up.

Object Card: Candle. **Principle Card**: Love Oneself. **Value Card:** Multilingualism.

Description:

- A candle is lit and given at birth. It stays lit throughout your life but flickers when you are unhealthy. The candle blows out when you die.
- A huge candle on your house lights on your birthday.
- In the center of cities and plazas, show happy birthday in different languages.

Sticky Note Feedback:



"The Candle of Life" final design commentary.

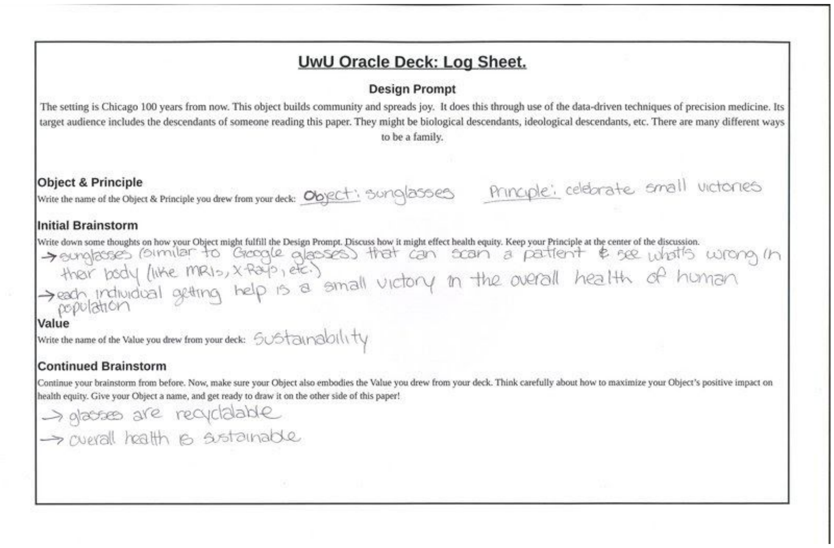
They received the following feedback and suggestions from other groups:

- Can the candle on the house be smaller and in a window/doorstep?
  - It's big so everyone knows it's your birthday!
- We love this idea!
- Is it a scented candle?
  - The candle can change scents to match your mood. Its color can also change according to mood.
- How does your feeling/physical info transfer to the candle?
  - You will be linked at birth.
- What if it's a windy day?
  - It is electrical. Technology has advanced [so] that we do not need flames.

Design 4: At First Sight.

Brainstorm:

The “At First Sight” group first worked with the cards: “sunglasses” and “Celebrate small victories.” They made the following notes in their brainstorm log sheet:



UwU Oracle Deck: Log Sheet.

Design Prompt

The setting is Chicago 100 years from now. This object builds community and spreads joy. It does this through use of the data-driven techniques of precision medicine. Its target audience includes the descendants of someone reading this paper. They might be biological descendants, ideological descendants, etc. There are many different ways to be a family.

Object & Principle

Write the name of the Object & Principle you drew from your deck: Object: sunglasses Principle: celebrate small victories

Initial Brainstorm

Write down some thoughts on how your Object might fulfill the Design Prompt. Discuss how it might effect health equity. Keep your Principle at the center of the discussion.

→ sunglasses (similar to Google glasses) that can scan a patient & see what's wrong in their body (like MRIs, X-Rays, etc.)

→ each individual getting help is a small victory in the overall health of human population

Value

Write the name of the Value you drew from your deck: sustainability

Continued Brainstorm

Continue your brainstorm from before. Now, make sure your Object also embodies the Value you drew from your deck. Think carefully about how to maximize your Object's positive impact on health equity. Give your Object a name, and get ready to draw it on the other side of this paper!

→ glasses are recyclable

→ overall health is sustainable

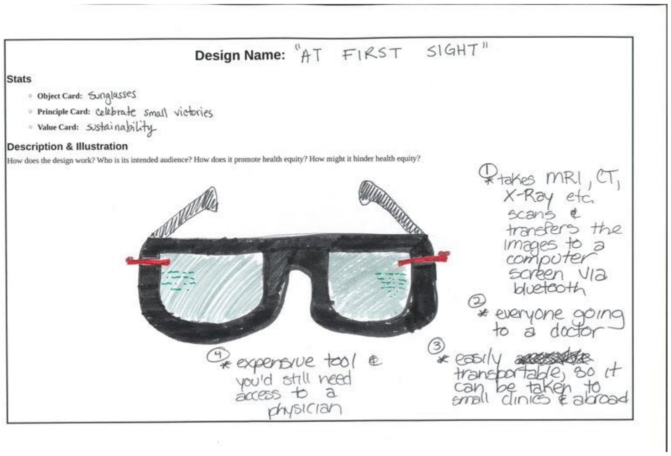
“At First Sight” brainstorm log sheet

- Sunglasses (similar to Google glasses) that can scan a patient & see what’s wrong in their body (like MRIs, X-Rays, etc.)
- Each individual getting help is a small victory in the overall health of human population

They then drew the “sustainability” card and continued their brainstorm:

- Glasses are recyclable
- Overall health is sustainable

Final Design:



Design Name: "AT FIRST SIGHT"

Stats

- **Object Card:** Sunglasses
- **Principle Card:** celebrate small victories
- **Value Card:** sustainability

Description & Illustration

How does the design work? Who is its intended audience? How does it promote health equity? How might it hinder health equity?

① * takes MRI, CT, X-Ray etc. scans & transfers the images to a computer screen via bluetooth

② * everyone going to a doctor

③ * easily transportable, so it can be taken to small clinics & abroad

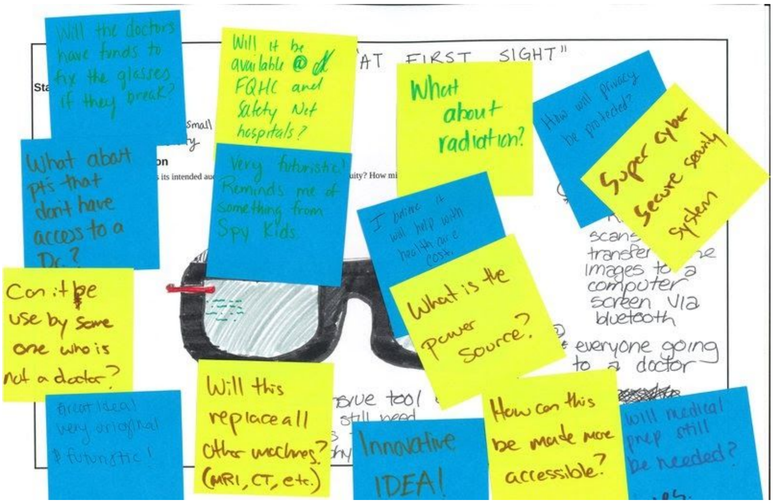
④ * expensive tool & you'd still need access to a physician

"At First Sight" final design write-up.

Object Card: Sunglasses. **Principle Card**: Celebrate small victories. **Value Card:** Sustainability. **Description:**

1. **How does the design work?** Takes MRI, CT, X-Ray, etc. scans & transfers the images to a computer screen via bluetooth.
2. **Who is the intended audience?** Everyone going to a doctor.
3. **How does it promote health equity?** Easily transportable, so it can be taken to small clinics and abroad.
4. **How might it hinder health equity?** Expensive tool & you'd still need access to a physician.

Sticky Note Feedback:



"At First Sight" final design commentary.

They received the following feedback and suggestions from other groups:

- Will the doctors have funds to fix the glasses if they break?
- What about patients that don't have access to a doctor?
- Can it be used by someone who is not a doctor?
- Great idea! Very original and futuristic!
- Will it be available at Federally Qualified Health Centers and Safety Net hospitals?
- Will this replace all other machines? (MRI, CT, etc.)
- Very futuristic! Reminds me of something from Spy Kids
- What about radiation?
- What is the power source?
- I believe it will help with health care costs.
- Innovative IDEA!
- How can this be made more accessible?
- Will medical prep still be needed?
    - Yes.

- How will privacy be protected?
    - Super cyber security system

#AICoffeehouse: "A Whole New World" & "Lush"

by ChicagoCHEC 2019 Research Fellows

Oct 21, 2019

Updated on: Mar 08, 2020

Introduction

Here are 2 stories from the 2019 ChicagoCHEC Research Fellows. These stories dig into potential unintended consequences of Artificial Intelligence (AI) applications in health.

Who?

The 2019 ChicagoCHEC Research Fellows are a group of undergraduate and post-baccalaureate students. They bring diverse perspectives and experiences to help advance health equity. They come from City Colleges of Chicago, Northeastern Illinois University, Northwestern University, and University of Illinois at Chicago.

What?

Small teams of fellows made these stories in a design fiction workshop. Samuel R. Mendez facilitated it, following the #AICoffeehouse storytelling workshop guide. Participants focused on developing their world and their main character. Then they told an oral story about the role an AI health tool might play in their life.

Where & When?

The Fellows did this workshop in Northwestern University's medical campus on July 2, 2019.

Why?

The writing process helped workshop participants discuss potential impacts of emerging technologies. The workshop focused on making a character first. This put a fictional face to abstract discussions of technology, security, and health. In this publication, these stories are meant to help readers do the same.

“A Whole New World.”

A clay figure of Nicole, in a drawing of her house.

So, our character's name is Nicole. She's black. She's about average height. She's fashionable. She likes going outside of her comfort zone... she tries. She's pretty shy, but she does have confidence in herself and the decisions that she makes. And she's very empathetic, she likes empathizing with others. She really admires integrity in people. And something that really annoys her is lying. She wants to have more courage. Although she is confident in the decisions that she makes, she wants to be more confident, like in reaching out to new people and getting to know others.

So she is from the suburbs. In this world, all the suburbs are just townhouses and they all look the same. They all have the same features and stuff like that. You don't buy a house, you're just given a house. So there's no homelessness or anything like that. In terms of the buildings that surround her, it's pretty futuristic and they're made of glass. And everyone has their own car regardless of income. And we can upgrade every two years and they're ergonomical and fuel efficient.

Like I said before, everyone has housing. And everyone is given the same amount of money each month so they can spend it on food and living expenses, like going out and having fun. People work 30 hours per week and they're given a month of vacation time every year. People spend most of their time with their families and friends. All kids go to school because it's free and it's accessible. People get around via car, but there is public transportation for people who are not able to drive a car, or for kids. People mostly interact face to face or via advanced technology, like holograms... or Face Time, the old school.

So in terms of health equity, healthcare is free. You can just go to the doctor whenever you're sick. Or if you're not physically able to go to the doctor, it's like a hologram sort of thing. So like your doctor can be in your room and not really be in your room. So the only health problems that are present are those caused by pollution, lack of exercise, addiction and genetic factors. And we chose those because those are things that you really can't help. Like, although this world is like essentially communist, you can't really tell people to not smoke or not drink or exercise. Or you can't help the genes that someone is born with. That's just what you're born with, and it just makes you more susceptible to getting a certain issue.

In terms of responsibility for health equity, that would be the doctors because they need to inform their patients of any diseases that they might be at risk of. That'll be the individual, because they need to educate themselves and read up on illnesses that they may be susceptible to having. And the community, because I think community is a big role in like just spreading information.

So a recurring emotional issue that Nicole has is that she's shy, as she is afraid of talking to the people. And this affects her in a big way because it is difficult for her to reach out to her doctor and her friends and her community about any health issues that she may be more prone to having, or any health issues that she is currently experiencing.

So there is a certain AI tool, it's not too much different from what we have today. It's a cell phone, and everyone has one, regardless of whether you're an adult or a child. You're just given it and you don't have to buy it or pay for it or anything like that. You can use it in your daily life. You have to consciously use this tool because I think it's a breach of security if it's just working and you're not aware that it's working. So like if you feel sick, then you would go to this tool or you contact your doctor and they would tell you what further actions actually take. In terms of how this AI tool helps Nicole, because she's shy, she wants to work on that. She has therapy three times a week with her little AI tool.

Story 2: "Lush."

[The story refers to details in a collage illustration. The illustration is missing from this write-up.]

So we came up with this little perfect world, we call it. So here's our perfect world, just to keep it short and sweet. So an idea we came up with, I've had in my mind for a couple of years:we thought of little pods like cornerstores. So every pod that's on the corner, it's like a Target, a Walmart, a Jewel Osco, kind of like a CVS thing. Each pod is different and you can go to these pods just to get your groceries. You can get your electricity and water. You can go get your medications and drugs.

And Panchito over there is actually the villain in our story because he is not accepted in our world, or he's the one that stands out in the world because he is addicted to drugs. So in our picture we have a man going to get his medicine from the pod. So you just scan your prescription and then it automatically comes out instead of having to wait, you know, 30 minutes or a day sometimes, to process your medication. And over here Panchito's standing outside because he's gonna go rob the guy for his drugs because he's addicted.

In order to keep you protected, this little blue thing right here is our force field. So once he enters the pod—each person in our perfect world has bio-markers. So there's a little bio-marker that will show that he is addicted to drugs and he's in an unhealthy place.

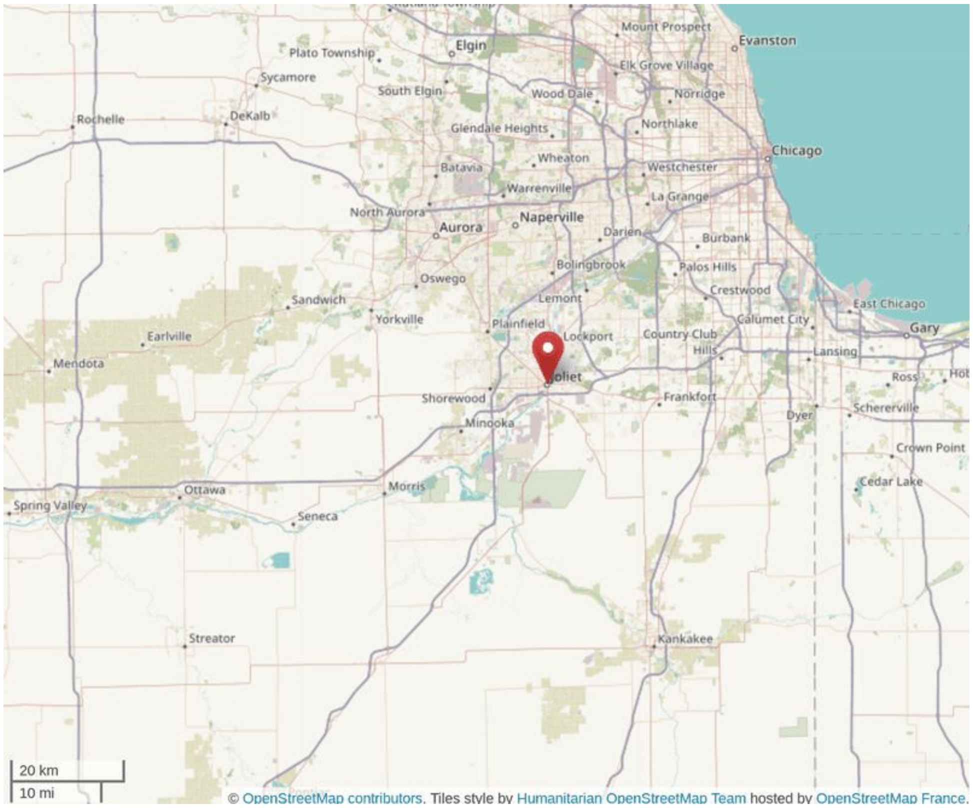
So as soon as he walks into the force field, the force field is going to basically clean up his system and give him a fresh start. So it's going to detox his body, and unfortunately he's battling with his emotions. Once he detoxes, he's gonna remember the tastes of the drugs, and he doesn't have a support system at home. So then he's going to go back to the drugs. So then the cycle kind of repeats itself. So we had like a flying car here, our city, and then we found a picture of him battling cigarettes, but in reality in our story it's drugs.

Chilling Effect: A view of public health from the Spanish Community Center

by Veronica Gloria

Oct 07, 2019

Editor's Intro: The Joliet Spanish Community Center (SCC) is a community-based service nonprofit in Joliet, Illinois. The article below is a written interview I did with the SCC director, Veronica Gloria. I sent her the intro and the questions via e-mail. After she responded, I reformatted the text and added photos from the SCC website. -by Samuel R. Mendez



© OpenStreetMap contributors. Tiles style by Humanitarian OpenStreetMap Team hosted by OpenStreetMap France.

A map showing Joliet's location in Illinois. It is about 30 miles west of Chicago, with a population of about 150,000. The city's population is about 16% African American and 28% Hispanic/Latino.

A large poster on the side of Chicago Street First Midwest Bank, advertising the SCC's services.

I'm hoping you can answer these questions in your capacity as the director of the SCC, based off of what you've seen and your ties to your community members. I know you can't really speak on behalf of a heterogeneous community. But you do have a lot of insight and knowledge that I want other people to hear. I tried to move the questions away from framing you as an all-knowing spokesperson and more towards someone with a personal and population-level view of a set of issues. Let me know if I missed the mark.

Can you tell me about the Spanish Community Center and the community it serves?

Spanish Community Center is a bilingual nonprofit agency with a 50 year history that provides wrap-around social and educational services to the Spanish-speaking community in the southwest suburbs of Chicago. Our services include bilingual childcare, food pantry, adult education classes, immigration legal services, housing counseling, resource and referral, among others. We serve primarily low-income immigrants from Latin America.

What are some of the pressing health issues you see this community face today?

Although we see patients with a variety of health needs, the most pressing are mental health, diabetes, cancer, and palliative care which are all hard to come by, especially for undocumented and low-income folks.

Pictured: The SCC offers a weekly food pantry.

Do you think there are health disparities within this community? Do some groups face more hurdles to living healthful and fulfilling lives?

Those who are undocumented have the largest disparities. Undocumented children are covered by health insurance thanks to All Kids Insurance, but once they hit 18, they are in the same boat as their parents: uninsured and with limited access to affordable, quality care. There are a few nonprofit clinics in the area that can assist with more common health concerns like the common cold or infections, but more complicated physical ailments or mental disorders require treatment that is typically expensive, far away, and often outside of families' awareness. Regardless of status many families struggle to find reliable transportation, translation, timely appointments, extensive time with the doctor, and options to choose between. Our community members regardless of status have often noted that they do not feel welcome, respected, or heard by the medical community due to their race and/or language. Many in the community seek alternative forms of medicine as a more trustworthy source of health services, such as curanderos, sobanderos, religious institutions, and home remedies because they are within a cultural and linguistic realm that is more familiar to them, although I wouldn't have the data to say how widespread this is. Many folks also wait to see doctors until their health concerns have worsened due to both cultural and economic factors, such as the taboo of speaking of mental health and stress related illnesses, as well as affordability concerns.

Pull-quote: "…it is difficult to imagine how precision medicine will reach us or affect us."

When ICE agents have raided our area or been prevalent in the news, many noncitizens will forego medical care altogether because they worry that immigration officials could either deport them or make them deportable for becoming a "public charge" on society. This is often referred to as a "chilling effect." Folks who are eligible for medical insurance are dis-enrolling their entire families from Medicaid and All Kids insurance for fear of their enrollment blocking their pathway to citizenship in the future, even though many of these same folks would not be affected by the new public charge laws that the federal government is proposing. That being said, there are many families who would be affected, and thus the chilling effect is a widespread response to more restrictive immigration policies. We even recently heard of a case where a local, well-known bilingual doctor has had to sell his home and private practice when his clients dried up due to fears of engaging with professional medical services.

What are some of the strengths and assets this community already has? How do you think these assets could be part of improving community health?

Some of the assets are that there are strong networks of churches, nonprofits, and bilingual professionals from the local community who are trusted in the community to share reliable information. There are also more and more activists and advocates pushing for bilingual, culturally competent care across different fields, including health. Social media is another important tool. Latinos are among one of the most active demographics on Facebook, and we have found relative success in reaching communities through bilingual Facebook posts and videos. The community also has a strong communication network through word of mouth, which is both a positive and a negative in that both rumors and truths can be spread quickly through existing, real-world social networks.

What lessons do you think health/medical professionals could learn from this community?

Many doctors are already aware that immigration status, income, language, and culture impact patients' ability to access quality care, but I would encourage medical systems to ask themselves how their work insures that these barriers are alleviated instead of reinforced. I would encourage them to form relationships with the nonprofits, clinics, and other networks that are trusted in the community. Those who are trusted should be at decision-making tables. Bilingual and bicultural professionals should be actively trained and recruited.. Otherwise, their work will continue to reinforce the disparities that exist and they will need to accept that their work will have cultural, linguistic, and legal limitations that affect large sections of the public.

Could you imagine precision medicine playing a role in supporting this community's health? Why or why not?

When even basic care is hard to come by or trust in our local community for those who face barriers related to income, language, culture, and/or immigrant status, it is difficult to imagine how precision medicine will reach us or affect us.

Introduction

Here are 3 stories from the 2019 ChicagoCHEC Research Fellows. These stories dig into potential unintended consequences of Artificial Intelligence (AI) applications in health.

Who?

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What?

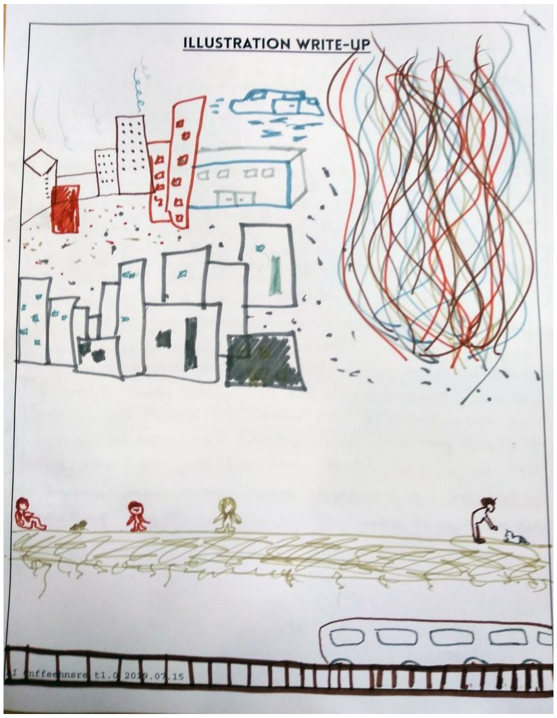
Small teams of fellows made these stories in a design fiction workshop. Samuel R. Mendez facilitated it, following the #AICoffeehouse storytelling workshop guide. Participants focused on developing their world and their main character. Then they told an oral story about the role an AI health tool might play in their character's life.

Where & When?

The Fellows did this workshop in Northwestern University's medical campus on July 2, 2019.

Why?

The writing process helped workshop participants discuss potential impacts of emerging technologies. The workshop focused on making a character first. This put a fictional face to abstract discussions of technology, security, and health. In this publication, these stories are meant to help readers do the same.



“Almost Human.”

So Cyrus Huerta lives 200 years in the future and desolate wasteland that used to be the United States. This dystopian reality, that's the one, his family from him. Um, this has Macon, like this isn't the story, but this has made him very bitter and everybody thinks there's something wrong with him because he hates people. He doesn't trust anybody. And he, um, is kind of like an outcast in the society.

With all the emerging technology, the income gap has become wider. And because he showed great promise and interest in robotics at a young age, he was able to advance his class past that of his family, which in this world is typically unheard of. Usually when you're born into a class, you stay in that class in this dystopian world. When he got older there was a fire in his neighborhood and when the emergency like services came in they only came in and saved him, because he was given priority because his proficiency in robotics. So they were able to save him and they gave him robotic prosthetics. And all of his family perished because they were not saved, even though they could have been saved. He covers up his prosthetics because he feels guilty that he was saved and his family wasn't.

He was extremely depressed for years, but one day when he was walking in his old neighborhood, he came up with the idea for a robot to be able to help people because there was no one there to help his family. He has a pet (robot) bird named Sanchez who was his only friend. He doesn't like talking to people. So he talks to his pet bird robot. It's very kind. And it's able to reproduce itself. One day he lets it out into the neighborhood, shortly before he passes away himself. And what he doesn't know is this invention was actually able to help people and generations to come. So that way these health inequities don't continue. And, um, what happened to this family doesn't happen to other people.

“Afterworld.”

Okay. Our story is called “Afterworld” and our character is named Humana. Our world is set in outer space.

Humana is a 24 year old female who weighs 135 pounds. She lives in a society where all women are required to be 125 pounds or lower. Her ability to keep her job as a doctor—health care is free and highly monitored in this world—is dependent on her maintaining the weight requirement as a female. She hasn't told anyone that she's overweight, but the annual weigh-in is coming. She lives in the spaceship called "Amerikkka" with three k's instead of a "c," after a nuclear disaster made the earth uninhabitable.

The weight restrictions are used to keep the spaceship afloat—or that's what the powers-that-be tell people.

She has an AI teddy bear that reminds her to work out and stuff. It is created from the consciousness of the people in the before-world. The powers-that-be tap into the bears, but the bears are finding ways to fight back. She ultimately overthrows the government by telling the people that their weightless in space. Her bear has the consciousness of a past astrophysicist. She connects the bear to the main control system of the spaceship, and from there he speaks, and he revels the truth of the society.

If you've ever seen *Astroboy*, that was the basis for our story.

APPENDIX B: “A PEOPLE’S GUIDE TO PRECISION MEDICINE,” SUBMISSION GUIDE.

Types of Submissions.

Sharing HER

These submissions focus on sharing personal insight on a specific health topic. They might be personal stories. They might re-frame common questions and concerns around a health topic. They might explain a health topic in a new and interesting way. Whatever form they take, these submissions promote a new kind of understanding of a complex topic. They do so while acknowledging the specific points of view creating them. Suggested maximum length: 1500 words or 7 minutes.

Analyzing HER:

These submissions analyze a process, piece of media, or phenomenon. This might look like a textual analysis of the portrayal of health in a popular book. It might look like a content analysis of a series of public service announcements. Whatever form these submissions take, they shed light on something happening in the real world. These submissions include the following :

- Background research describing what kind of work has been done on similar topics before.
- A description of the methods the submitter(s) used
- A description of the results of the analysis
- A discussion of the significance of the results
- A 100-word abstract or summary at the beginning.

Suggested maximum length (without the abstract): 2000 words or 10 minutes.

Observing HER:

These submissions share a community or professional insight related to health equity. They might highlight a community-generated solution to a public health issue. Or they might describe a current issue and an existing community asset that could help address it. Suggested maximum length (without the abstract): 1200 words or 6 minutes.

Response:

These submissions respond to other people's work. It might be a written response to a research article, a news article, a research project, etc. It might be a photo essay showing an untold side of a story in the media. It might be a critique of a public health program's approach. Whatever format they take, these submissions help people question "business as usual". Suggested maximum length: 1000 words or 5 minutes.

Imagining HER:

These submissions imagine the possibilities of health equity. They might speculate about what the future could be. They might write an alternate history. They might be works of fiction. They might propose policies. Whatever form they take, these submissions help people think outside the box. No suggested maximum length.

Breaking HER boundaries:

Anything that doesn't fit in the above categories.

Licensing Submissions.

All content on this website is available under a Creative Commons Attribution (CC-BY) 4.0 License. This means readers are free to share and adapt the content however they want. They must give credit for the original work, share the content under similar conditions, and note any changes they make. These license terms are standard across the PubPub platform.

We understand that not everyone wants to share their work under their terms. As alternatives to sharing your final work under this license, we suggest:

- Uploading lower-quality, watermarked versions of photos under the CC-BY license.
- Providing links to audio and video content hosted elsewhere, under your preferred license.

We do not currently offer an alternative for written content.

Submission Style Guide.

The *HER Communication* style guide focuses on accessibility. We want to make our content available to the largest number of people possi

Giving Credit.

Citations.

Submissions may draw on specific knowledge from other people's work. In these cases, authors must acknowledge the contributions of others' ideas. Authors coming from an academic field might be comfortable with formal citations and and a reference list. If that's the case for you, feel free to follow the guidelines in the next section. In other cases, a list of acknowledgements or inspirations may make more sense. We ask for consistency and enough details so a reader would have a clear idea of what the exact contributions were.

Citation Format.

Authors who are used to these kinds of citations may use APA format, with the following changes:

HER Communication articles use an adaptation of APA format for in-text citations and lists of references. APA format requires author-year format within sentences for citations in parentheses. Example: "(Rodriguez, 2011).". We prefer to have the citation in a full sentence format, within parentheses. Example: "**(See reference: Rodriguez, 2011.)**"

Footnotes and End notes.

We do not publish submissions with footnotes or end-notes. Please include all important notes directly in the body of text you are writing.

Acknowledgements.

In some cases, a written explanation of acknowledgements may be the most appropriate format for giving credit to others. We ask for consistency and enough details so a reader would have a clear idea of what the exact contributions were.

Text.

Readability.

Articles on *HER Communication* should be around an 8th grade reading level. Ideally, they will be closer to a 6th grade reading level. We use the Flesch-Kincaid readability test to measure reading grade level. We recommend authors use the free Readability Calculator by Online-Utility. You might also want to use Hemingway Editor online.

We recommend a few general guidelines:

- Avoid passive voice.
- Avoid complicated words and jargon.
- Avoid long sentences.
- Avoid adverbs as much as possible.

Structure.

Submissions to *HER Communication* must use heading levels to provide structure. Each submission begins with a title, which automatically uses a level 1 Heading. Written articles use level 2, 3, and 4 subheadings for structure as appropriate. All headings and subheadings end with a punctuation mark.

Links.

Make sure that the text of a link describes the location that the link takes readers to. So, "Click Here to read *HER Communication*." is not appropriate text for a link. But, "Read the latest issue of HER Communication," is.

If possible, please put a list of links at the end of the submission. This way a reader could still find the exact link if they were reading the article from a print-out.

Images (Photos, Graphs, Figures).

A picture is worth a thousand words. But you can't control a reader's context. Our style guide makes sure folks don't miss out on vital info if they can't see an image. This style guide also is also helpful if people print out articles in black and white.

Captions.

All images must have a caption. No exceptions.

Graphs, Charts, Figures.

Include key takeaways in captions of complex visualizations like graphs.

Images with Blocks of Text (Posters, Fliers).

Images with vital text must have high contrast between text and background colors. We recommend using the WebAIM Color Contrast Checker.

Include short amounts of text in an image caption. Include a transcript for longer amounts of text. Use your best judgement to define “short” and “long”.

Multimedia Content.

Video.

We ask that you upload video content directly to the PubPub platform. (Only if you have the rights to do so). If you prefer to upload it elsewhere, do not embed it into your submission. Instead, provide a link to the external content.

Include a screencap image for any videos in your submission. Provide a caption for the image.

Provide a content warning if it’s appropriate. Always provide a content warning for videos that have fast flashing images or strobe effects.

At the end of the submission, include a descriptive transcript for all video content you embed or link to.

Audio.

We ask that you upload audio content directly to PubPub. (Only if you have the rights to do so). If you prefer to upload it elsewhere, do not embed it into your submission. Instead, provide a link to the external content. Include a screencap image for any videos in your submission.

Provide a content warning if it’s appropriate.

At the end of the submission, include a transcript for all audio content you embed or link to.

Embedded Content.

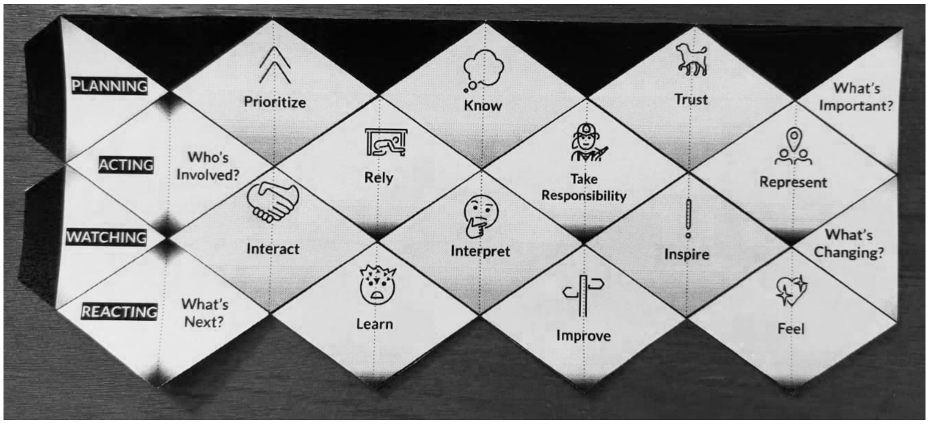
HER Communication will not publish embed code from commercial websites. This includes content from YouTube, Facebook, Twitter, Instagram, and Vimeo. We ask that you take at least one of the following steps to share such content:

- Upload multimedia content directly to the PubPub platform. (Only if you have the rights to do so).
- Provide a link to external content.
- Provide a transcript or description of multimedia content.

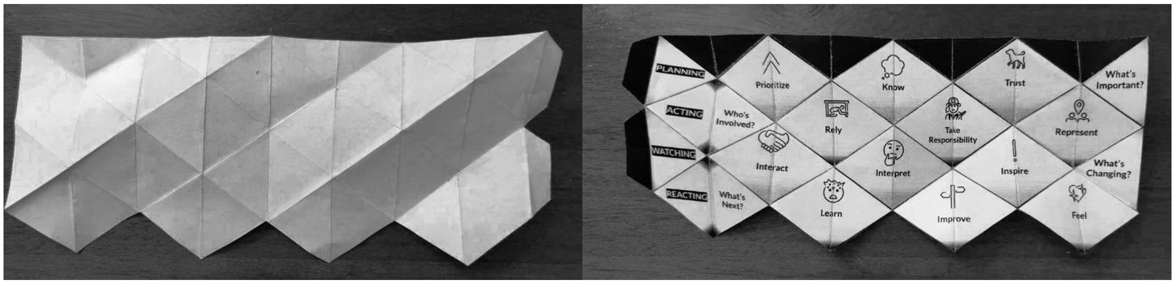
APPENDIX C: HER Model of Community Engagement (printable).

Kaleidocycle Instructions.

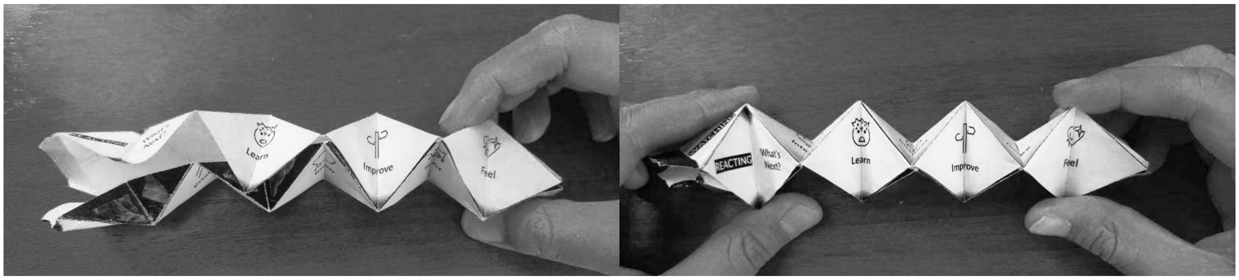
Cut out the template along the outer edges.



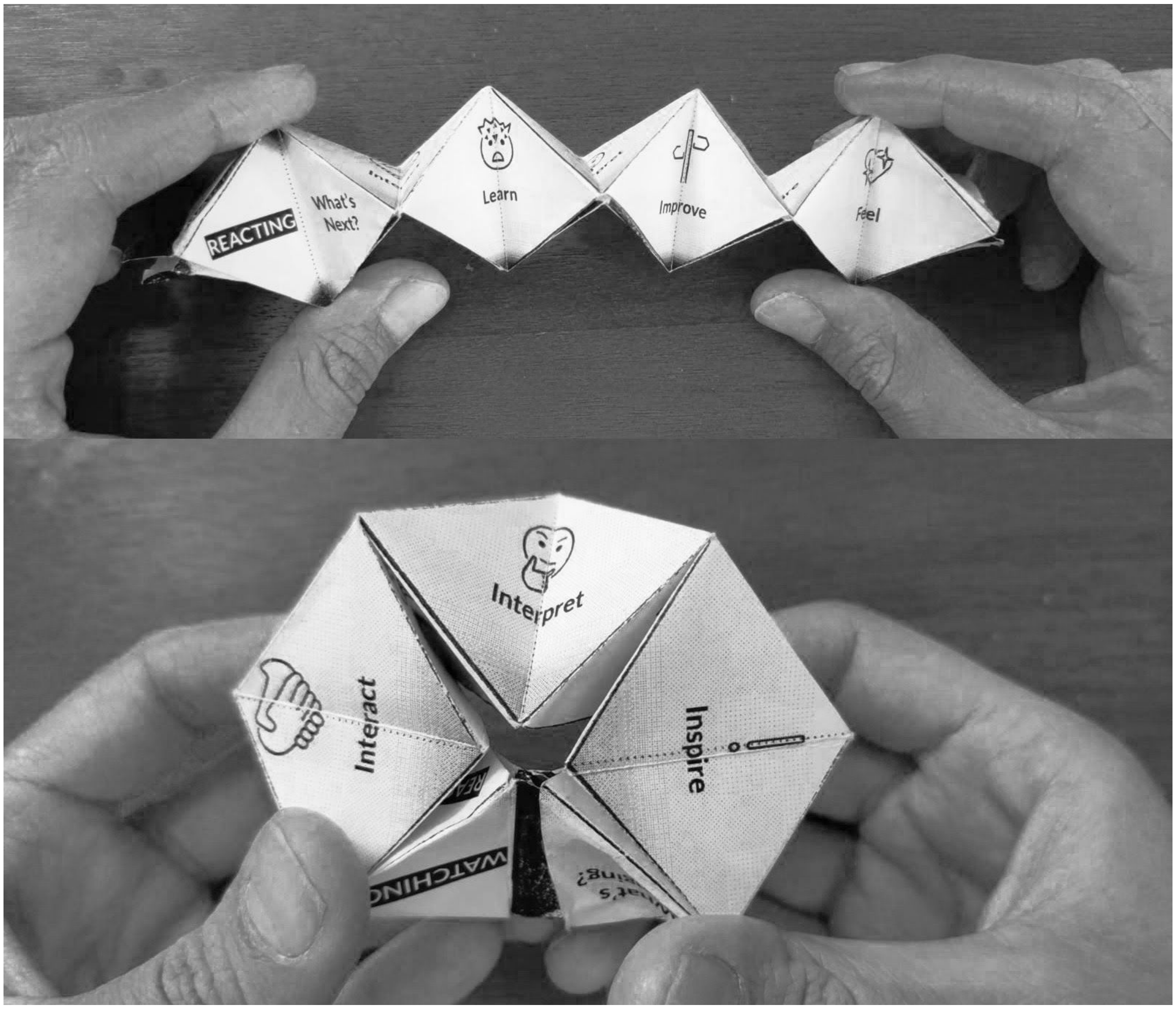
Fold and make a sharp crease at every vertical dotted line as well as every diagonal solid line.

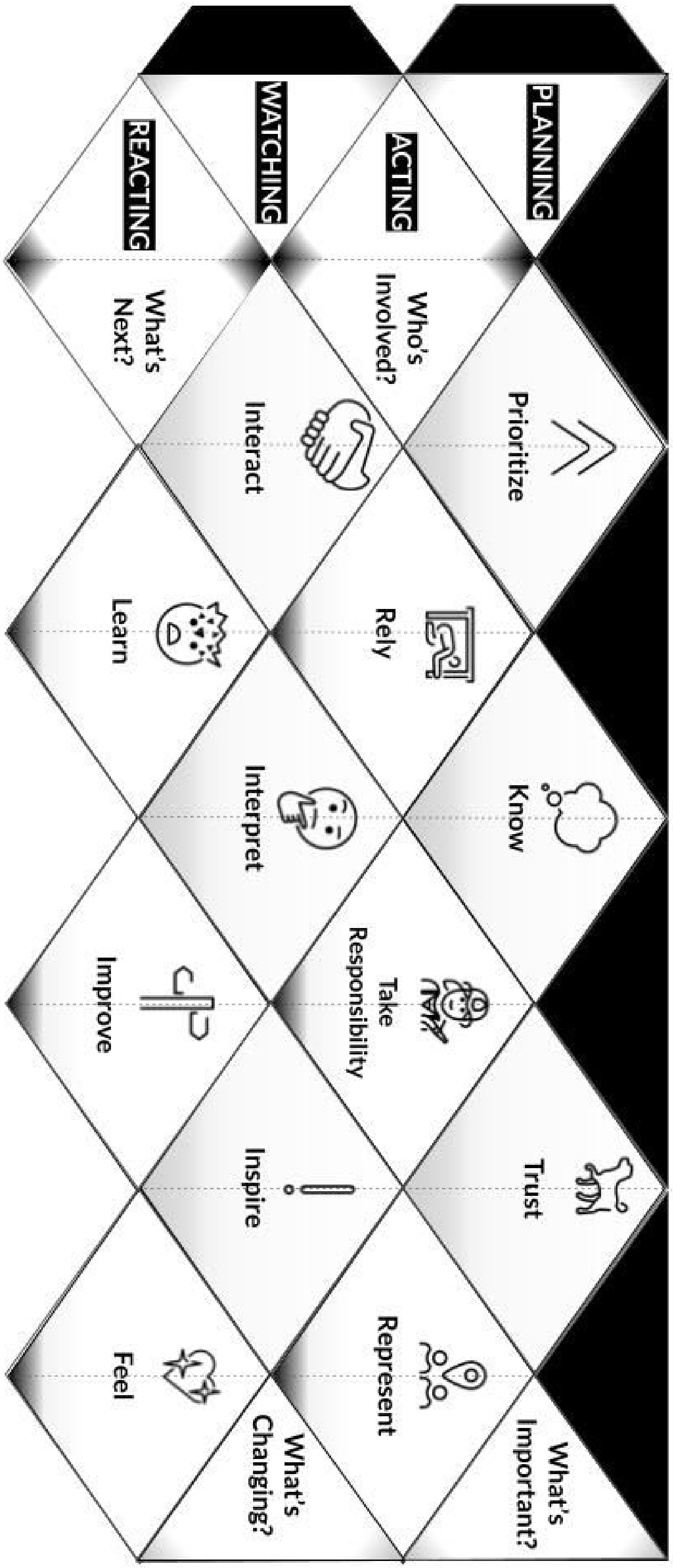


Gently use the existing creases to fold the "reacting phase" diamonds over on top of the solid black triangle. Use glue or tape on every solid black triangle to attach the "reacting phase" diamonds, creating a three-dimensional chain.



Finally, use glue or tape on the solid black tabs to join the chain together in a ring.

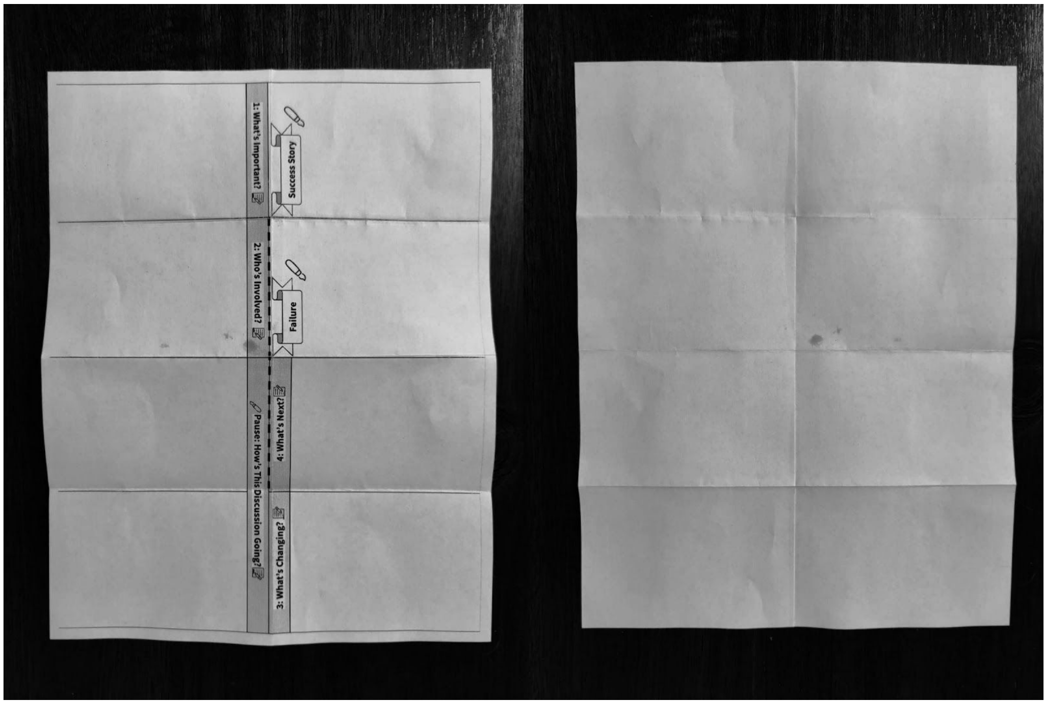



PLANNING
ACTING
WATCHING
REACTING
Who's Involved?
What's Next?
Prioritize
Interact
Rely
Learn
Know
Interpret
Take Responsibility
Improve
Trust
Inspire
Represent
Feel
What's Important?
What's Changing?

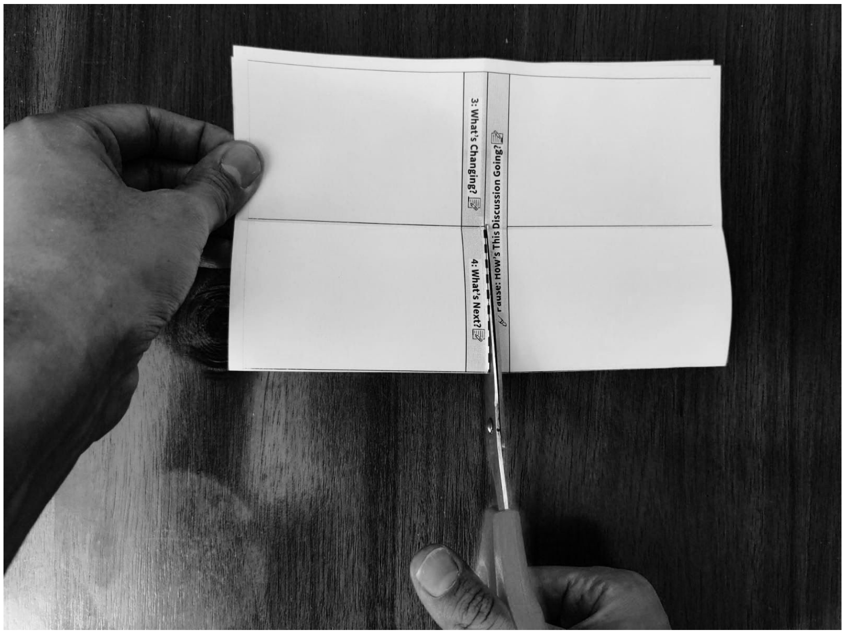
Zine Instructions

Print the zine template on the backside of an executive summary, press release, or other single-page summary of a public health project. Alternatively, follow the below instructions for folding and cutting the zine without printing, and label the pages by hand.

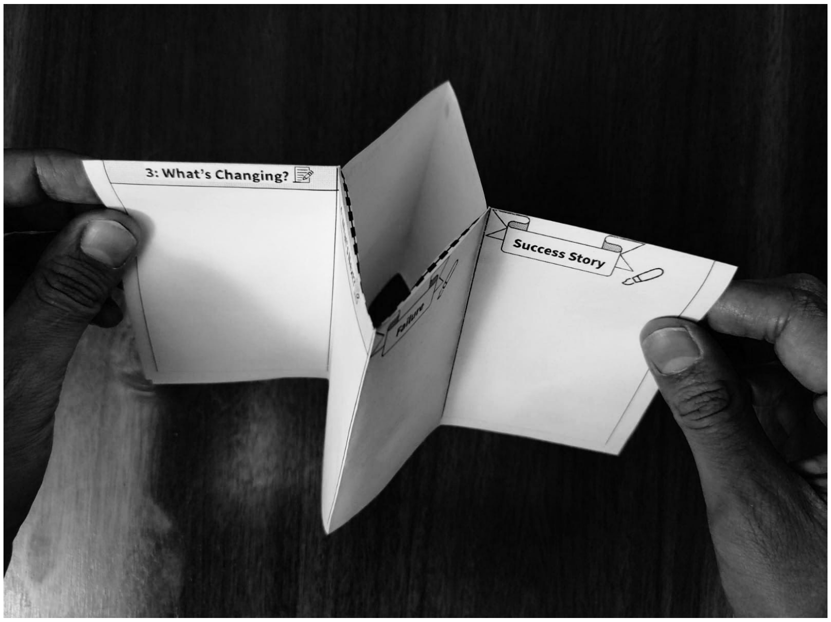
Hold the paper vertically, and fold the top edge down to meet the bottom. Keep the paper folded in half and fold the left edge over to meet the right, as if closing a book. Keep the paper folded into quarters and fold the top edge down to meet the bottom again. Unfold, refold, and sharpen the creases as necessary. When you are done, your paper should be divided into eighths.



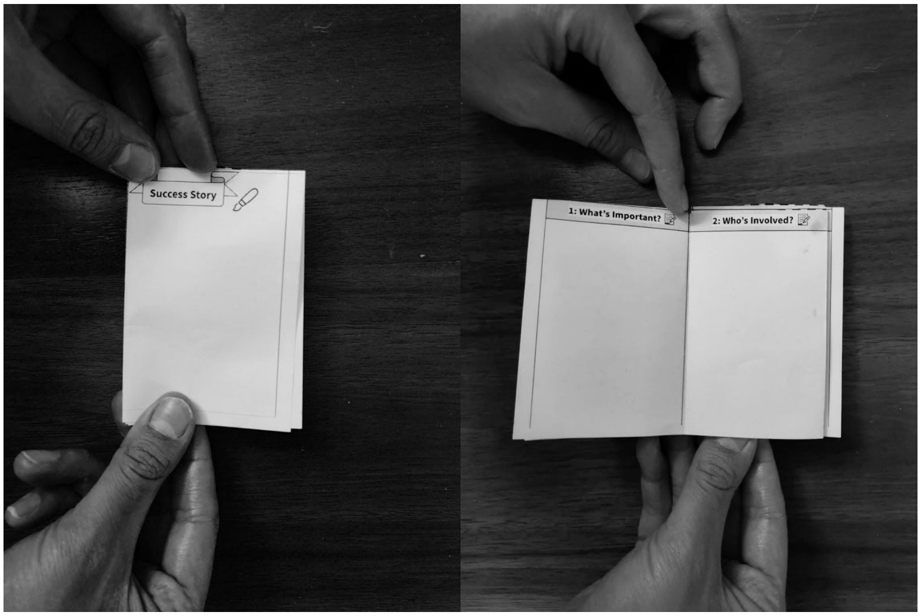
If you're using the printed zine template, the next step might be easier if you face the template away from you, as in the right half of the photo above. Now fold the paper in half by folding the bottom edge up toward you to meet the top edge, so you can see half of the zine template. The bottom edge should now be a fold, and the top should be a flap.

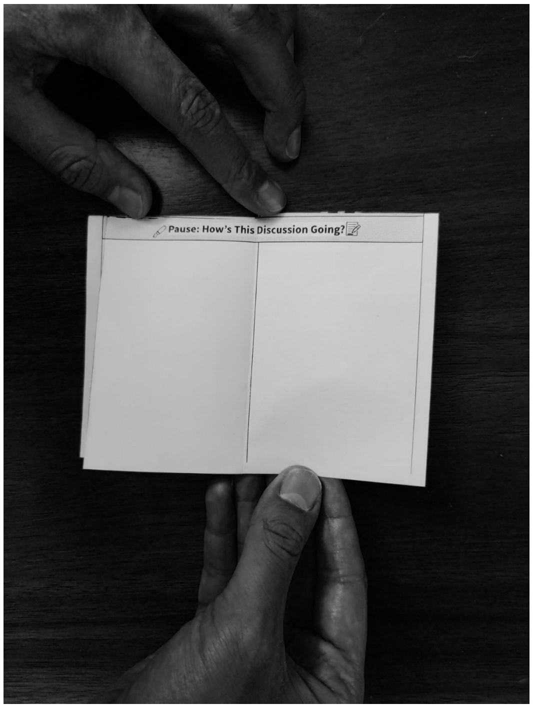


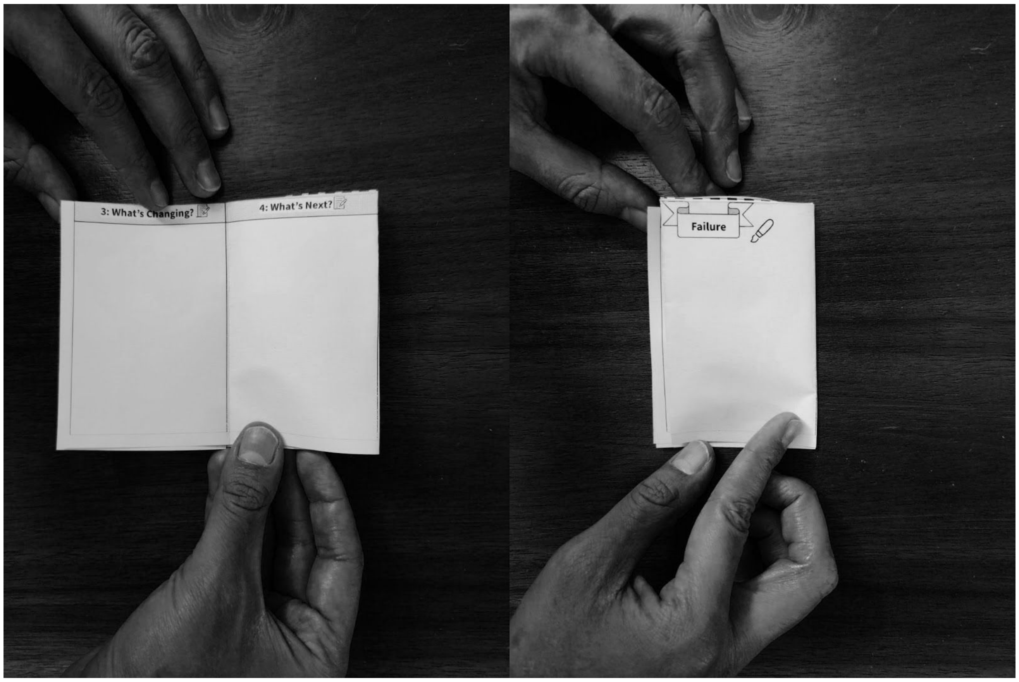
Now use scissors to cut along the middle crease up to the corner where it meets the center crease, as in the photo above. The zine template includes a dotted line indicating where you should cut. Now unfold the paper and fold it left to right like a book again. If you hold the top and bottom edges with your hands, you should be able to use the existing creases and cut to bring the pages together into a booklet, as in the photo below.

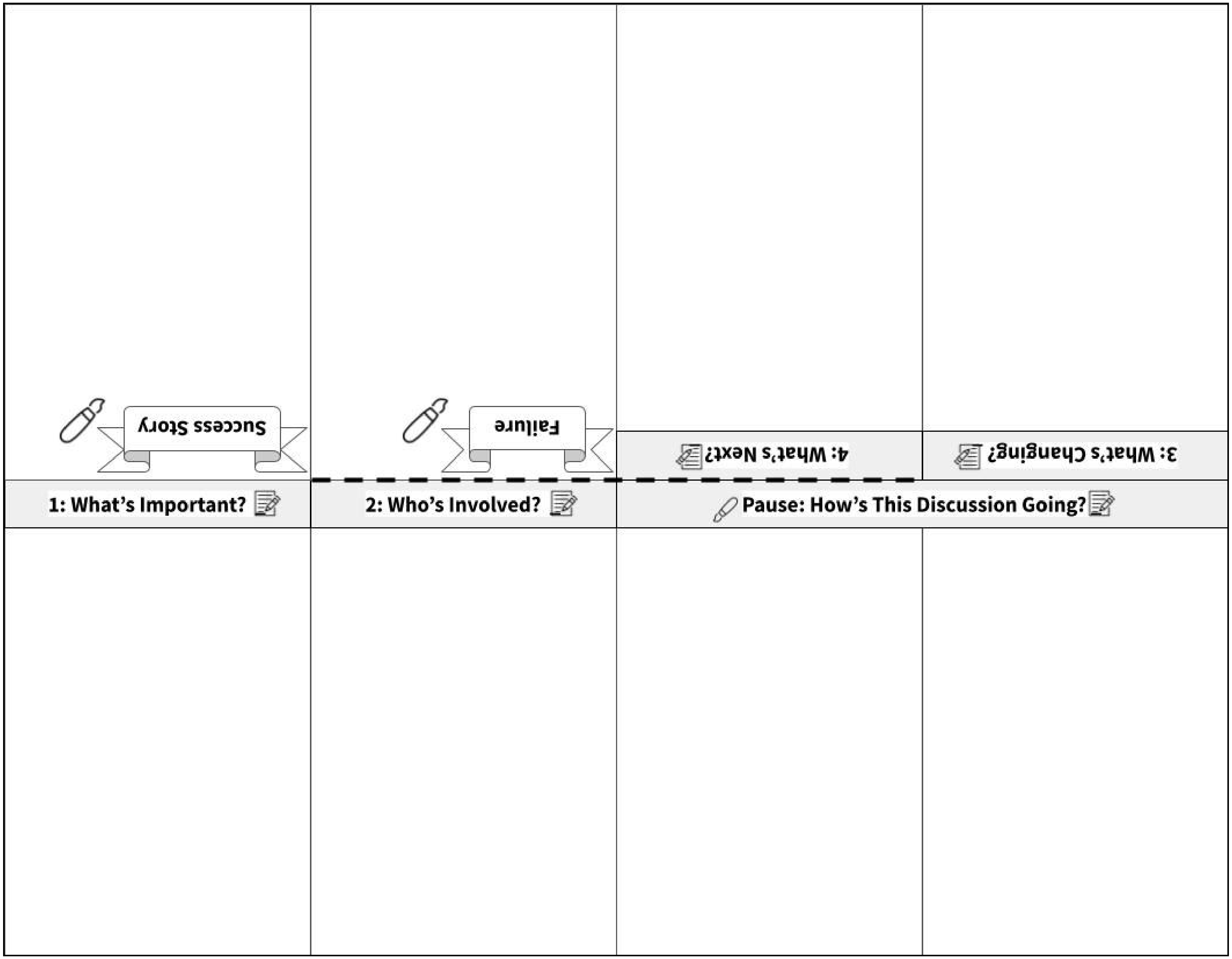


Now fold your booklet so the front cover is “Success Story” and the back cover is “Failure”. Your zine is ready, with the pages in the following order: “Success Story” (front cover), “1: What’s Important?”, ‘“2: Who’s Involved?”, “Pause: How’s this Discussion Going?”, “3: What’s Changing?”, “4: What’s Next”, and “Failure” (back cover). Use the photos below for reference.






3: What's Changing?
4: What's Next?
Failure


Success Story
Failure
4: What's Next?
3: What's Changing?
1: What's Important?
2: Who's Involved?
Pause: How's This Discussion Going?

Appendix D: "A People's Guide to Precision Medicine" Journal Club Workshop Materials

The following are images of slides used in the journal club workshops described in Chapter 3 of this thesis. Following the slides are the pages provided to participants for reflection, note-taking, and feedback.

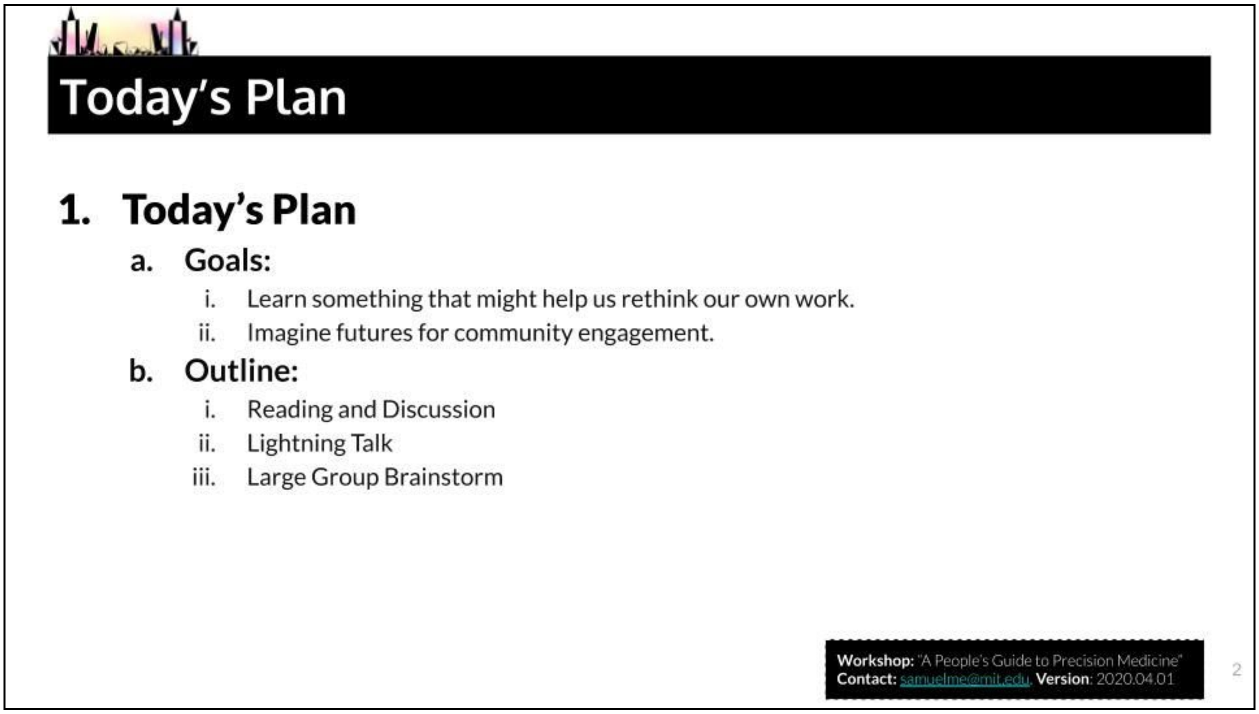
These workshops incorporated two interviews ("The Future of Anything" and "Chilling Effect") and one design-based story from the zine ("A Whole New World"). These articles are available in Appendix A.

Workshop Slides

A People's Guide to Precision Medicine

Imagining Futures of Community Engagement

Workshop: "A People's Guide to Precision Medicine"
Contact: samuelme@mit.edu, **Version**: 2020.04.01



Today's Plan

1. **Today's Plan**
    a. Goals:
        i. Learn something that might help us rethink our own work.
        ii. Imagine futures for community engagement.
    b. Outline:
        i. Reading and Discussion
        ii. Lightning Talk
        iii. Large Group Brainstorm

Workshop: "A People's Guide to Precision Medicine"
Contact: samuelme@mit.edu. **Version**: 2020.04.01

Introduction

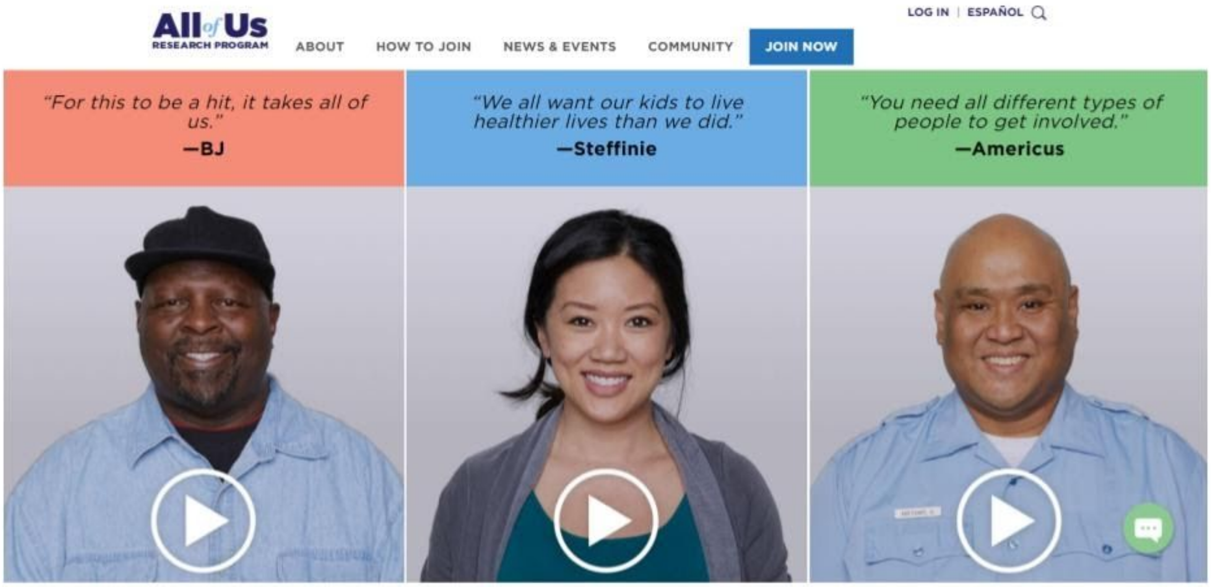
1. **Me**
    a. **Background in media arts & public health research.**
    b. **Thesis on integration of media studies theories into public health.**
    c. **Experience with art and growing up as part of an immigrant community in Chicago informs my approach.**
2. **My Motivations**
    a. **Prepare for an academic career focused on community engagement.**
    b. **Desire to help advance health equity, communication as one key piece.**

Workshop: "A People's Guide to Precision Medicine"
Contact: samuelme@mit.edu. **Version**: 2020.04.01

All of Us

- Precision Medicine as a way to benefit all people
- PM as an improvement on current practices
- Research participation as a way to advance health equity
- All of Us as a way to mobilize universities, hospitals, and community organizations

---

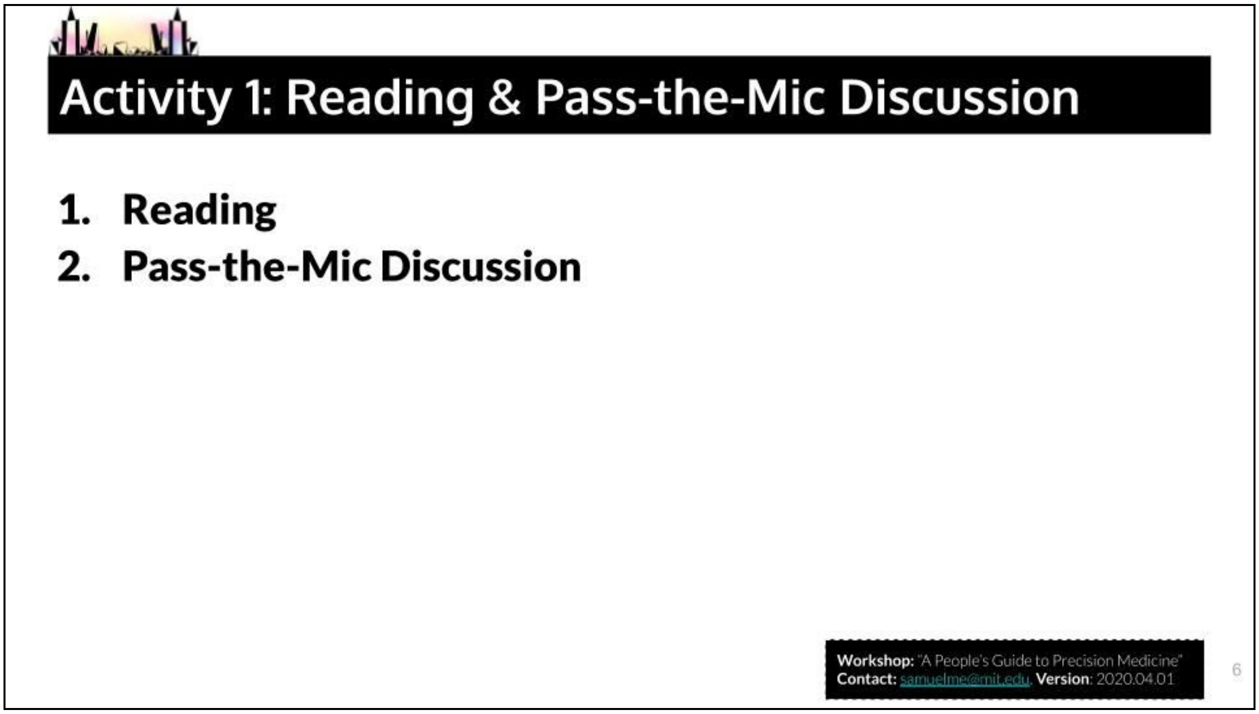


"For this to be a hit, it takes all of us."
—BJ

"We all want our kids to live healthier lives than we did."
—Steffinie

"You need all different types of people to get involved."
—Americus

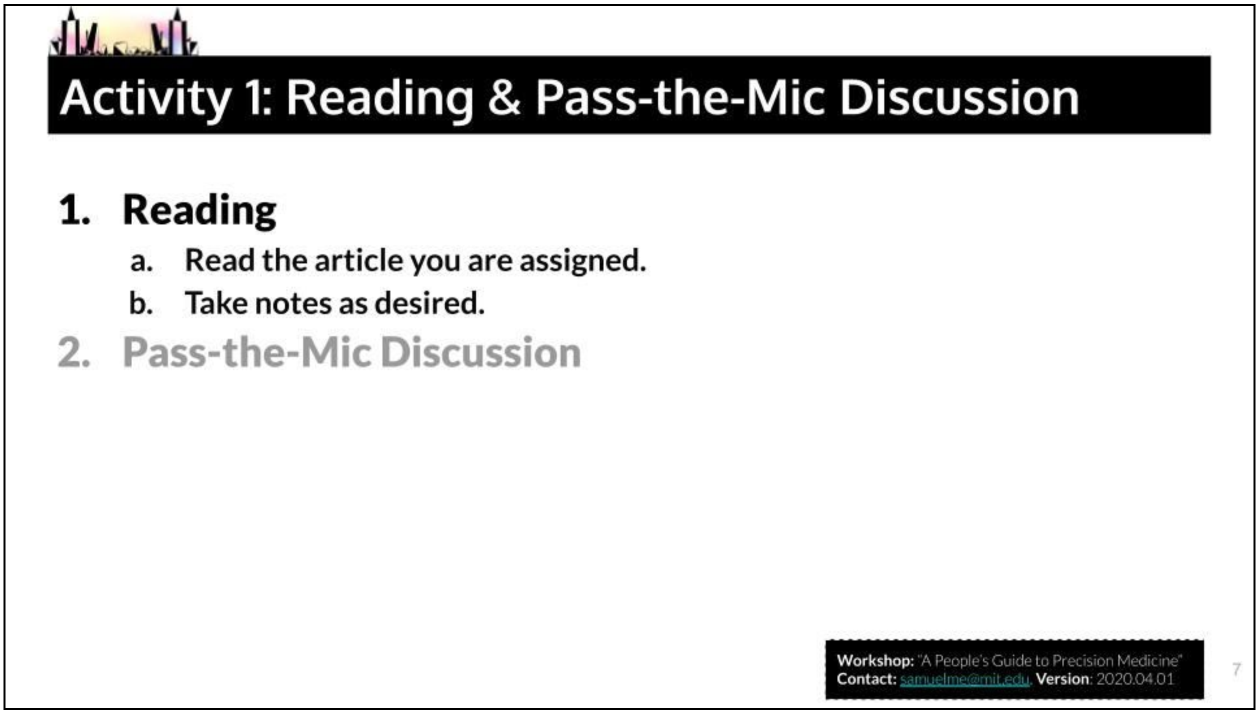
Workshop: "A People's Guide to Precision Medicine"
Contact: samuelme@mit.edu, **Version**: 2020.04.01



Activity 1: Reading & Pass-the-Mic Discussion

1. **Reading**
2. **Pass-the-Mic Discussion**

Workshop: "A People's Guide to Precision Medicine"
Contact: samuelme@mit.edu, **Version**: 2020.04.01



Activity 1: Reading & Pass-the-Mic Discussion

1. **Reading**
    a. **Read the article you are assigned.**
    b. **Take notes as desired.**
2. **Pass-the-Mic Discussion**

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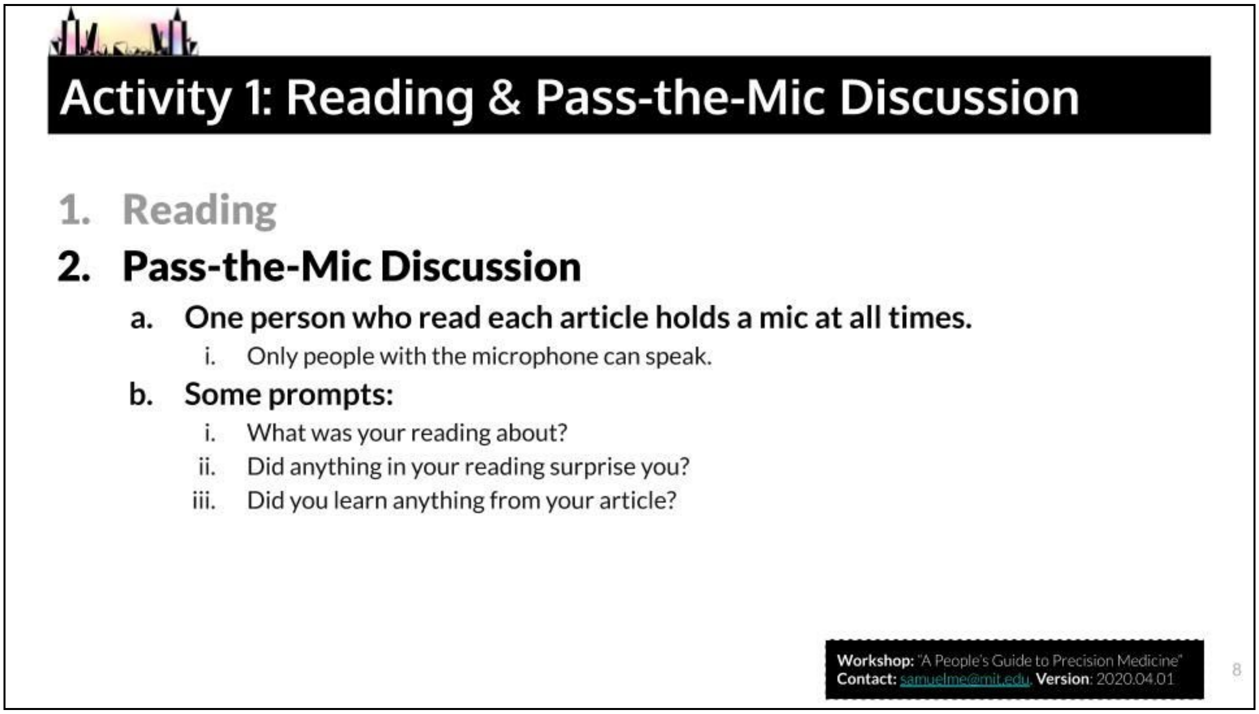
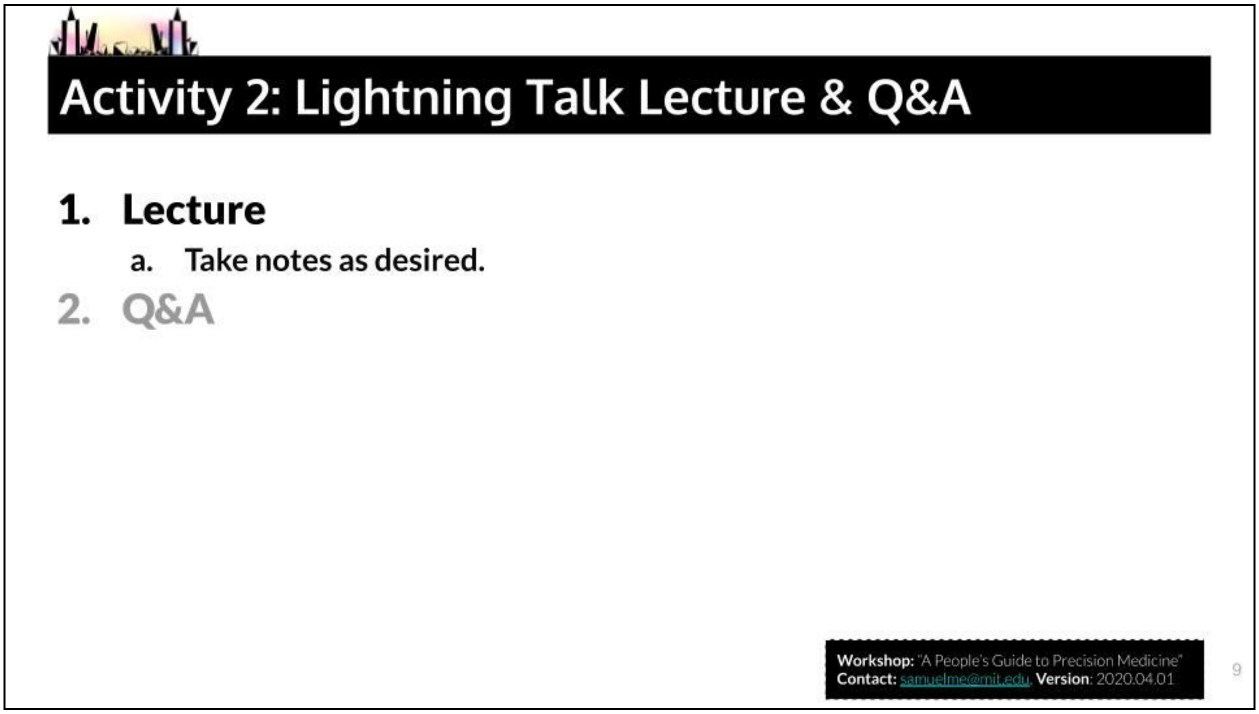


Activity 1: Reading & Pass-the-Mic Discussion

1. Reading
2. **Pass-the-Mic Discussion**
   a. **One person who read each article holds a mic at all times.**
      i. Only people with the microphone can speak.
   b. **Some prompts:**
      i. What was your reading about?
      ii. Did anything in your reading surprise you?
      iii. Did you learn anything from your article?

Workshop: "A People's Guide to Precision Medicine"
Contact: samuelme@mit.edu, **Version**: 2020.04.01

8



Activity 2: Lightning Talk Lecture & Q&A

1. **Lecture**
   a. **Take notes as desired.**
2. Q&A

Workshop: "A People's Guide to Precision Medicine"
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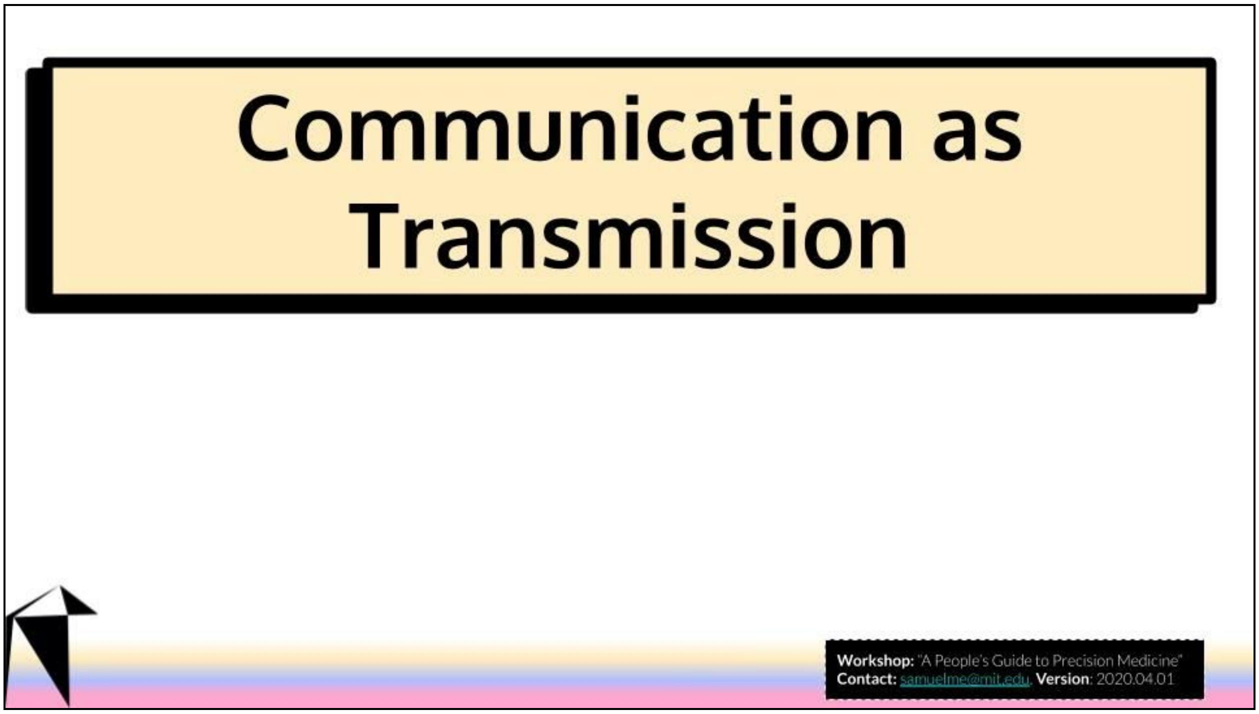

Communication as Transmission

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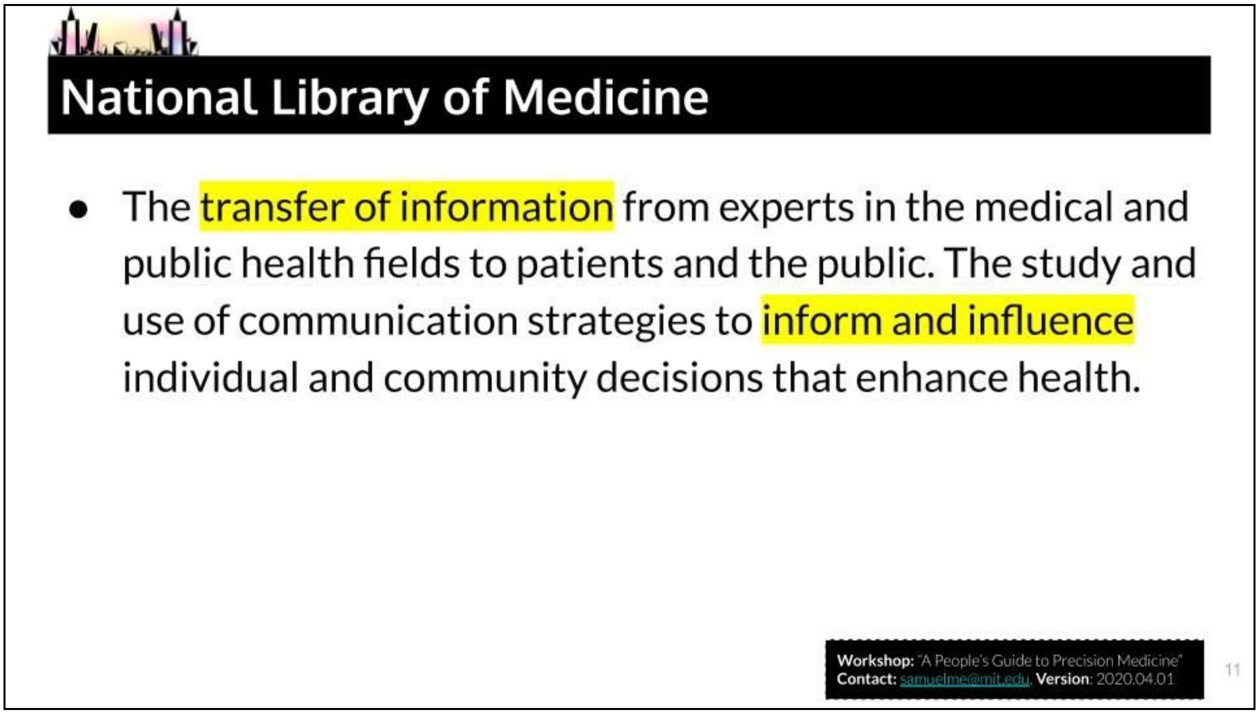

National Library of Medicine

- The transfer of information from experts in the medical and public health fields to patients and the public. The study and use of communication strategies to inform and influence individual and community decisions that enhance health.

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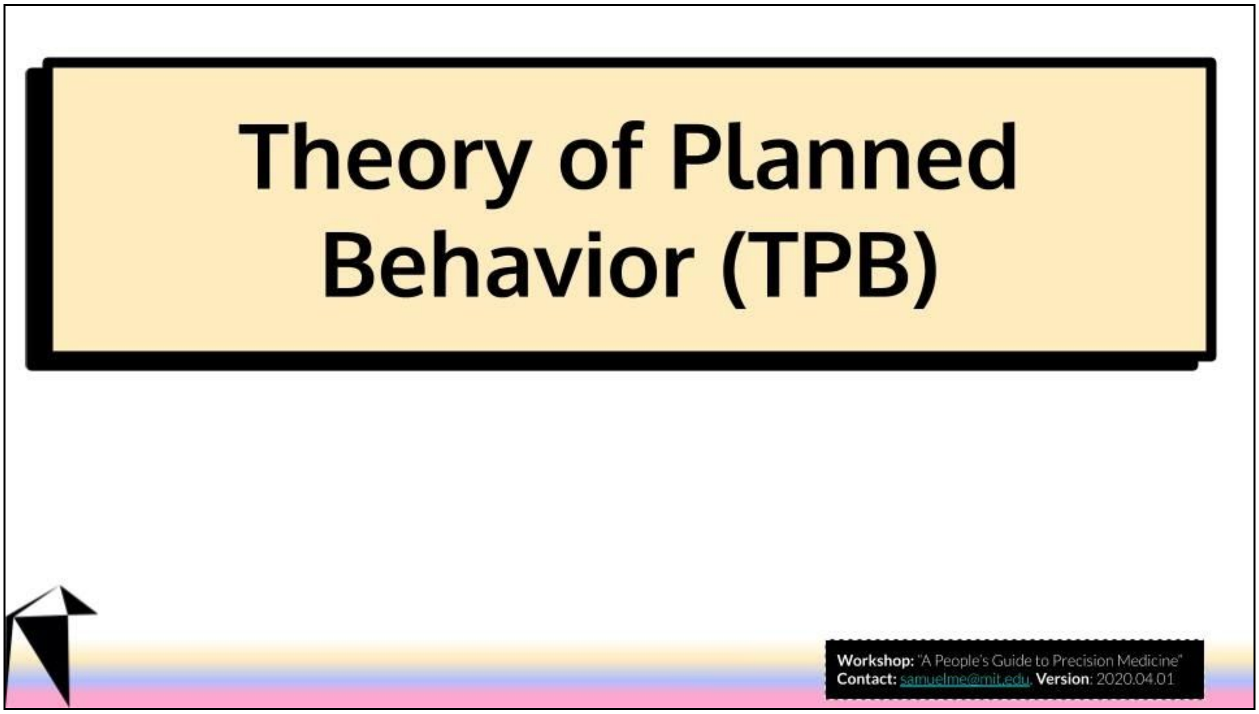

Theory of Planned Behavior (TPB)

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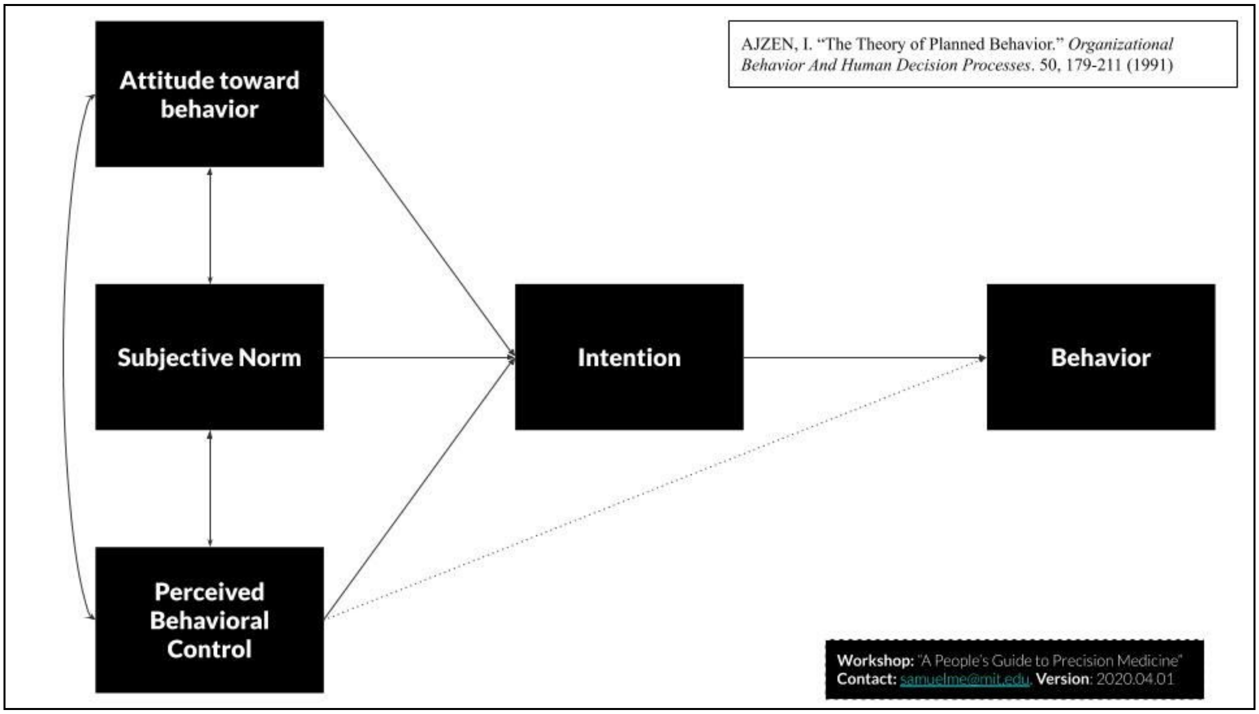

AJZEN, I. "The Theory of Planned Behavior." *Organizational Behavior And Human Decision Processes*. 50, 179-211 (1991)

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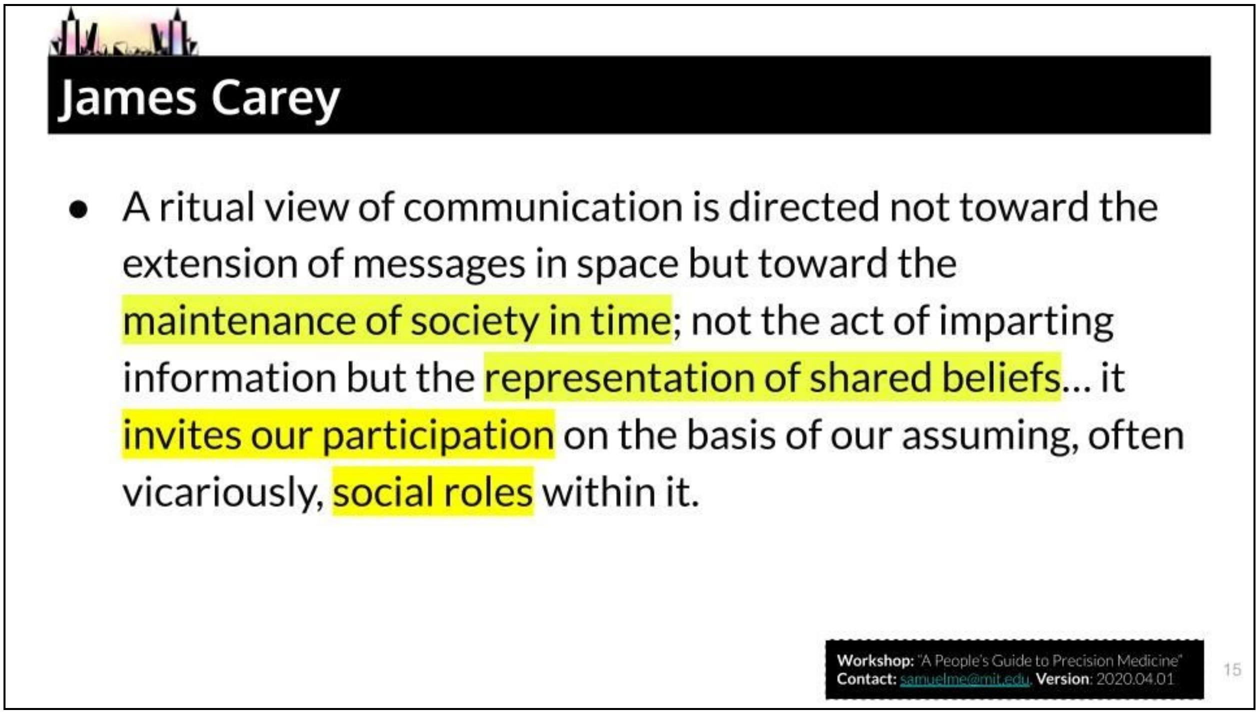
Communication as Ritual

Workshop: "A People's Guide to Precision Medicine"



James Carey

- A ritual view of communication is directed not toward the extension of messages in space but toward the maintenance of society in time; not the act of imparting information but the representation of shared beliefs… it invites our participation on the basis of our assuming, often vicariously, social roles within it.

Workshop: "A People's Guide to Precision Medicine"

Health Equity Ritual (HER)
Model of Community Engagement

Workshop: "A People's Guide to Precision Medicine"
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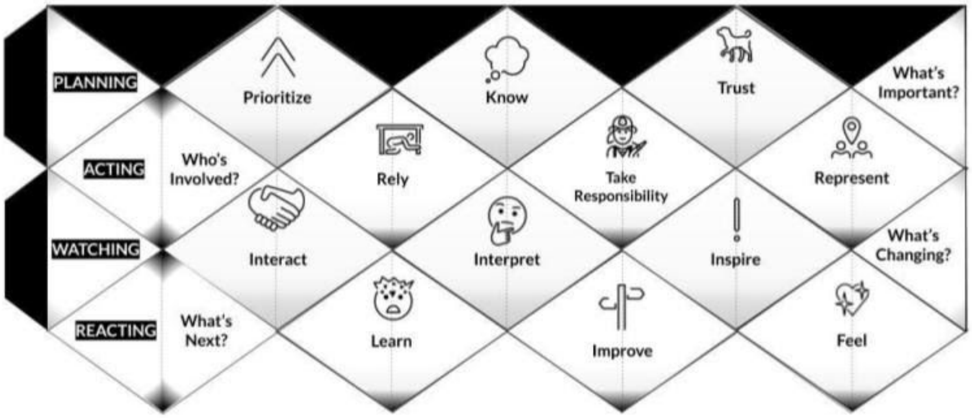

PLANNING
ACTING
WATCHING
REACTING

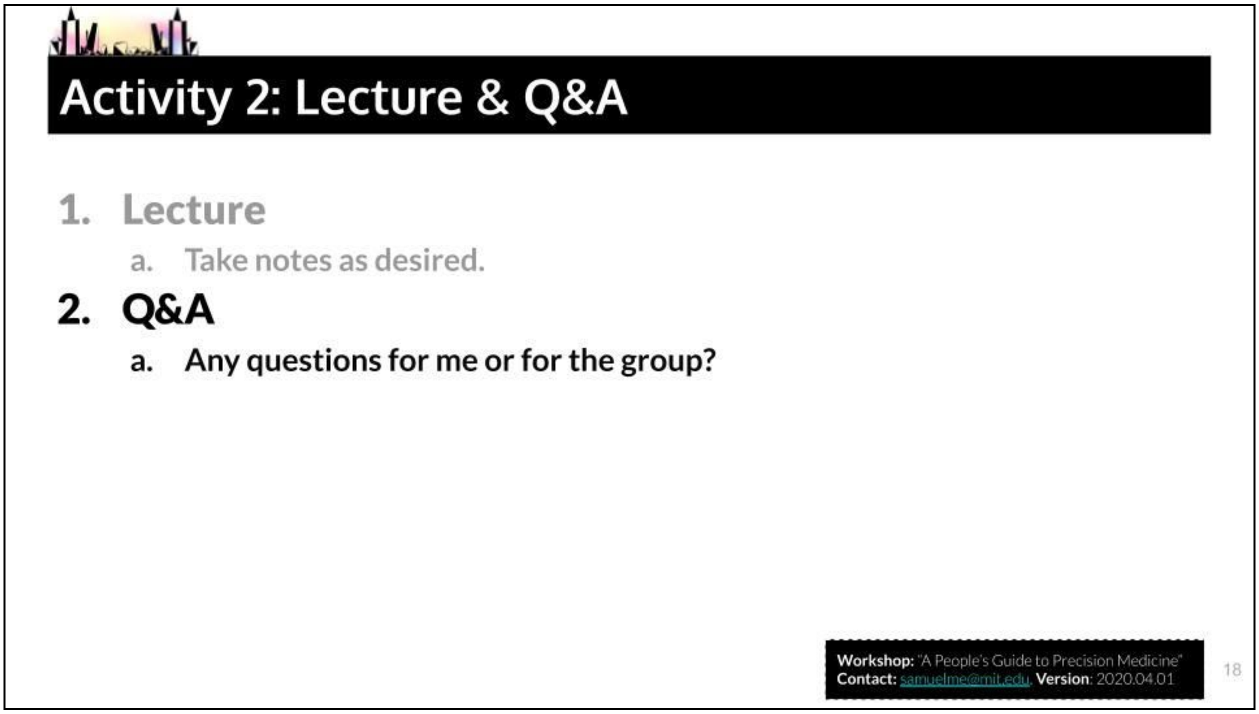
Prioritize
Know
Trust
What's Important?

Who's Involved?
Rely
Take Responsibility
Represent

Interact
Interpret
Inspire
What's Changing?

What's Next?
Learn
Improve
Feel

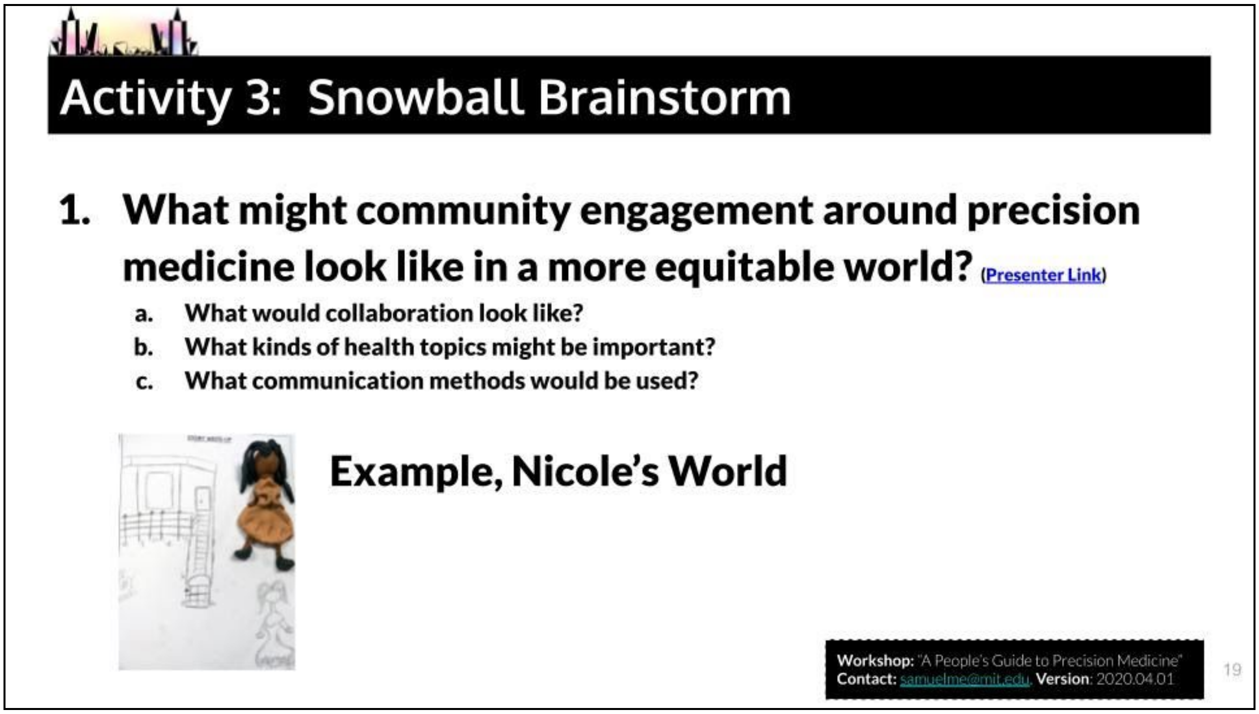
Workshop: "A People's Guide to Precision Medicine"
Contact: samuelme@mit.edu. **Version**: 2020.04.01



Activity 2: Lecture & Q&A

1. **Lecture**
    a. Take notes as desired.
2. **Q&A**
    a. **Any questions for me or for the group?**

Workshop: "A People's Guide to Precision Medicine"
Contact: samuelme@mit.edu. **Version**: 2020.04.01



Activity 3: Snowball Brainstorm

1. **What might community engagement around precision medicine look like in a more equitable world?** (Presenter Link)
    a. **What would collaboration look like?**
    b. **What kinds of health topics might be important?**
    c. **What communication methods would be used?**

Example, Nicole's World

Workshop: "A People's Guide to Precision Medicine"
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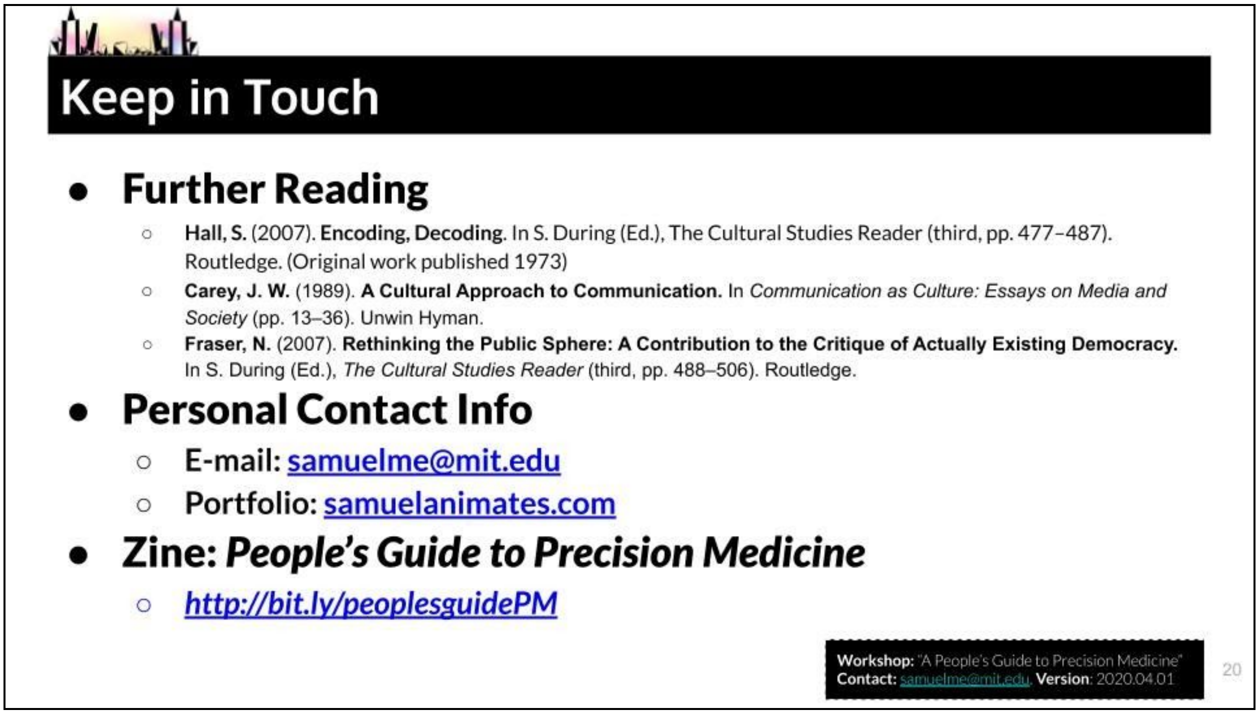


Keep in Touch

- **Further Reading**
    - **Hall, S.** (2007). **Encoding, Decoding**. In S. During (Ed.), The Cultural Studies Reader (third, pp. 477–487). Routledge. (Original work published 1973)
    - **Carey, J. W.** (1989). **A Cultural Approach to Communication.** In *Communication as Culture: Essays on Media and Society* (pp. 13–36). Unwin Hyman.
    - **Fraser, N.** (2007). **Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy.** In S. During (Ed.), *The Cultural Studies Reader* (third, pp. 488–506). Routledge.
- **Personal Contact Info**
    - **E-mail:** samuelme@mit.edu
    - **Portfolio:** samuelanimates.com
- **Zine:** ***People's Guide to Precision Medicine***
    - *http://bit.ly/peoplesguidePM*

Workshop: "A People's Guide to Precision Medicine"
Contact: samuelme@mit.edu, **Version**: 2020.04.01

Workshop Feedback and Note Taking Forms

Workshop: A People's Guide to Precision Medicine.

Before: Reflection

Take a few minutes to answer the following questions briefly. Feel free to skip any questions you would rather skip, respond with “not sure,” etc.

1. What is your job title (or current level of study), and what is your area of work?

2. What role do you think communication plays in health equity?

3. Do you think you can personally do anything to help advance health equity in precision medicine? Why or why not?

4. What do you hope to gain from this workshop?

Activity 1: Readinges & Pass-the-Mic Discussion

Take a few minutes to read your article and reflect on it below:

- What format was your reading? What was it about?

- Did you learn anything from your reading? If so, what? If not, why?

Take notes on the group discussion here:

Activity 2: Lightning Talk

Take notes on the lightning talk here:

Activity 3: Snowball Brainstorm

Write down anything you think is important to document from the large group brainstorm:

Activity 4: Reflection and Next Steps

Feel free to skip any questions you would rather skip, respond with “not sure,” etc.

1. Do you have any new thoughts about what role you think communication plays in health equity?
2. Do you have any new thoughts about what you can personally do anything to help advance health equity in precision medicine? Why or why not?
3. Did you gain what you expected from this workshop? Why or why not?
4. Any feedback on the workshop?

Contact Info

Name:

Affiliation:

If you would like to receive updates on this project or participate in future workshops around health equity and communication, please provide your contact info below:

Keep this page for your own reference

This workshop is part of my (Samuel R. Mendez) Master's thesis in Comparative Media Studies at MIT, scheduled for completion in May 2020.

In my thesis, I am considering how to bring in ideas about communication from media studies into public health. One portion of this work is a zine titled, "A People's Guide to Precision Medicine." I am also producing workshops and educational materials to complement the zine as an effort to improve community engagement practices on the academic side of research partnerships.

As such, I am using your anonymous written responses to evaluate and refine the workshop and zine content. I will transcribe and anonymize the handwritten responses for digital storage, then destroy the original copies. If you gave me your contact info, I will store that info in a separate mailing list for people interested in the zine project.

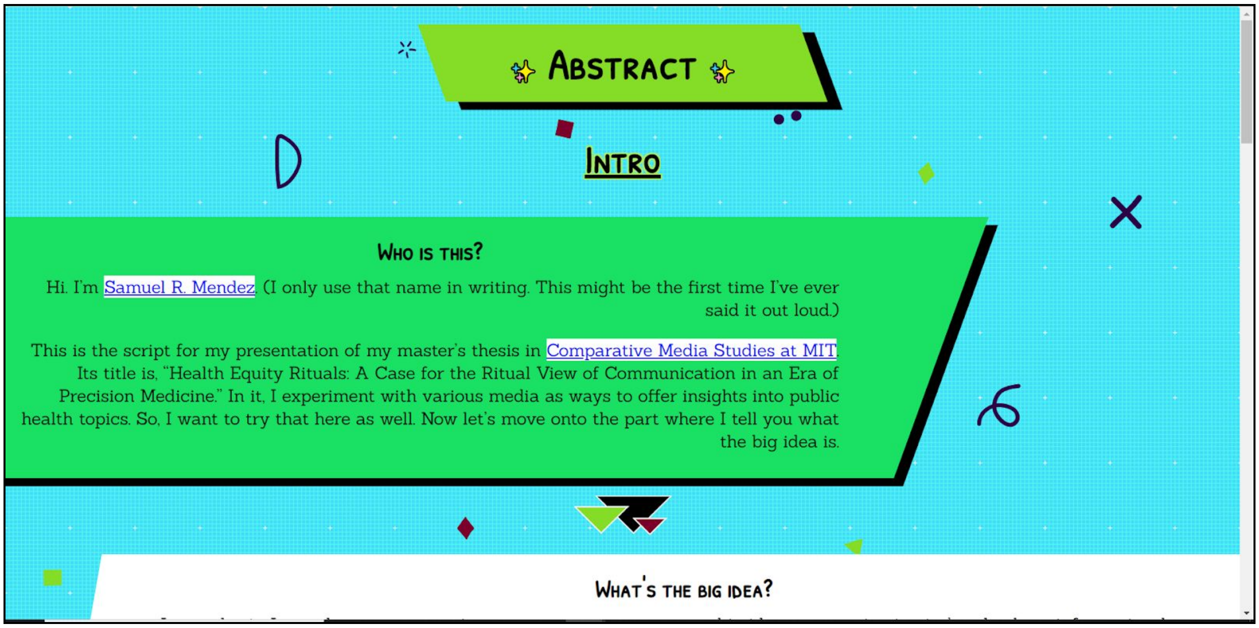
At the end of these workshops I will self-publish the collective brainstorm list as part of the zine, where I will invite zine contributors to comment on them. By default, I will credit participants of these workshops collectively. Once the list is online, I will send it to everyone on the zine mailing list for commentary, and for the chance to be named specifically in an "Acknowledgements" page.

Please reach out to me with any questions or comments:

Samuel R. Mendez
samuelme@mit.edu

Zine: bit.ly/peoplesguidePM

APPENDIX E: "✨ Abstract ✨" SCREENSHOTS



✨ ABSTRACT ✨

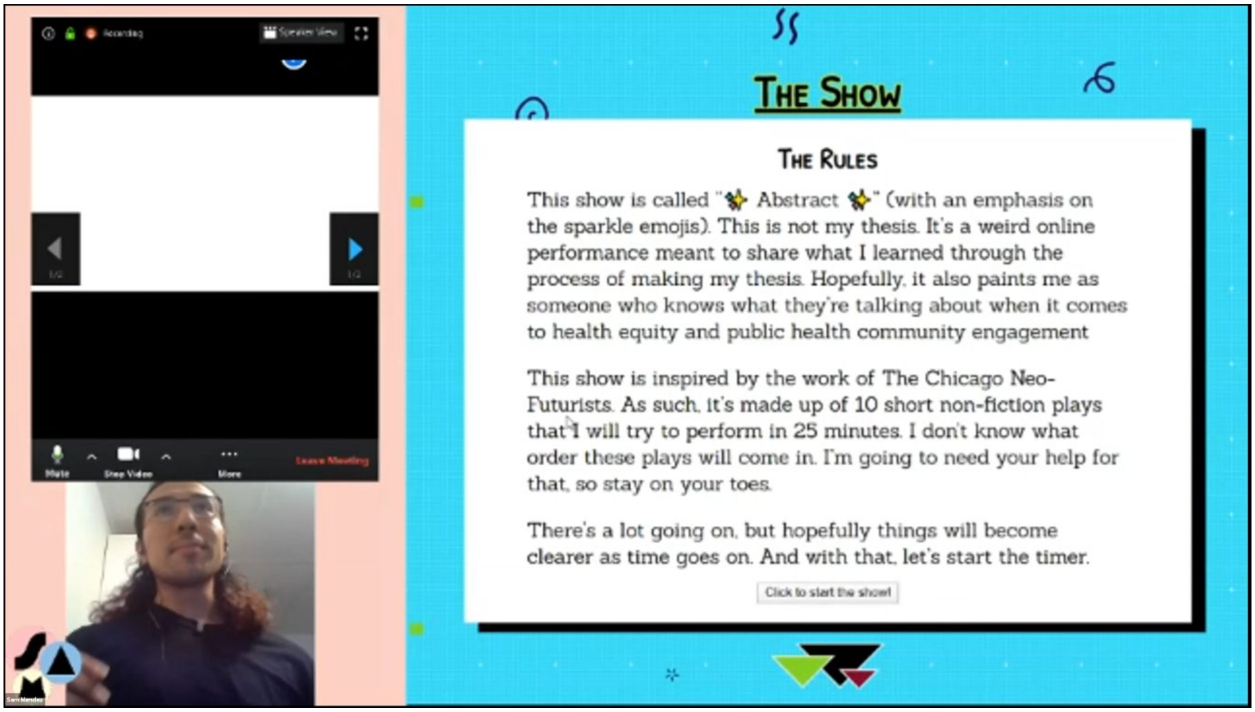
INTRO

WHO IS THIS?

Hi, I'm Samuel R. Mendez. (I only use that name in writing. This might be the first time I've ever said it out loud.)

This is the script for my presentation of my master's thesis in Comparative Media Studies at MIT. Its title is, "Health Equity Rituals: A Case for the Ritual View of Communication in an Era of Precision Medicine." In it, I experiment with various media as ways to offer insights into public health topics. So, I want to try that here as well. Now let's move onto the part where I tell you what the big idea is.

WHAT'S THE BIG IDEA?



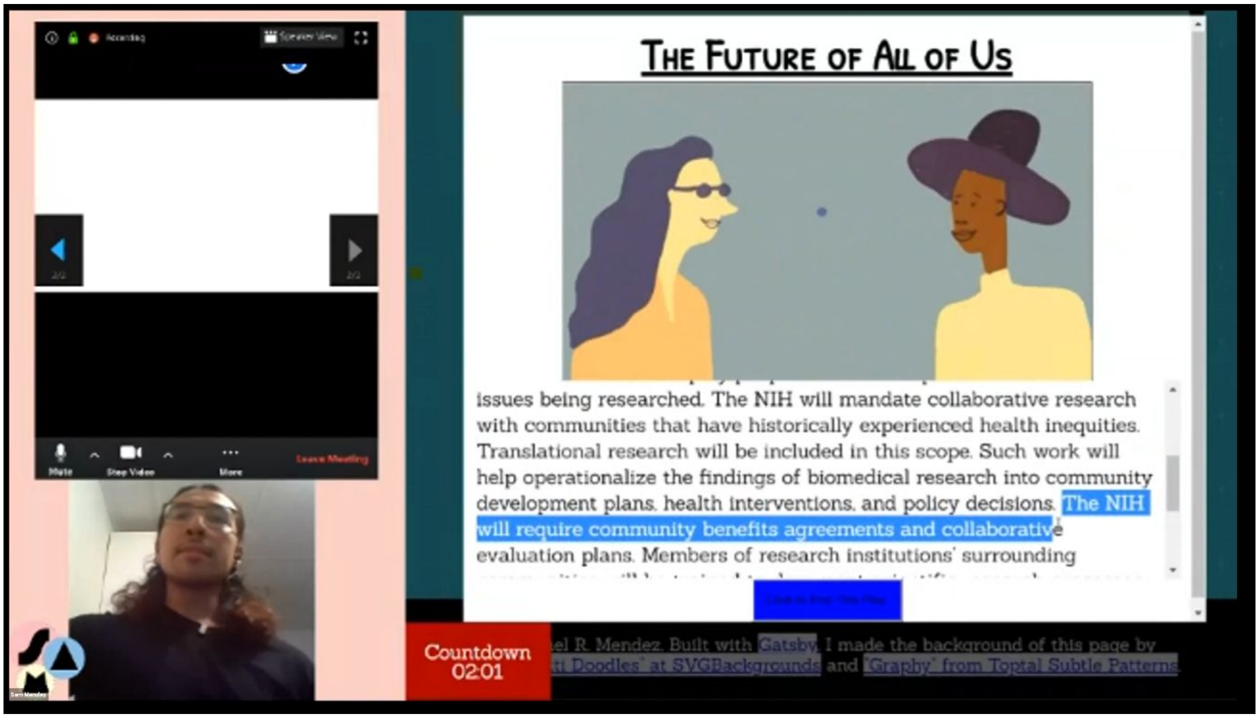
THE SHOW

THE RULES

This show is called "✨ Abstract ✨" (with an emphasis on the sparkle emojis). This is not my thesis. It's a weird online performance meant to share what I learned through the process of making my thesis. Hopefully, it also paints me as someone who knows what they're talking about when it comes to health equity and public health community engagement.

This show is inspired by the work of The Chicago Neo-Futurists. As such, it's made up of 10 short non-fiction plays that I will try to perform in 25 minutes. I don't know what order these plays will come in. I'm going to need your help for that, so stay on your toes.

There's a lot going on, but hopefully things will become clearer as time goes on. And with that, let's start the timer.



The Future of All of Us

issues being researched. The NIH will mandate collaborative research with communities that have historically experienced health inequities. Translational research will be included in this scope. Such work will help operationalize the findings of biomedical research into community development plans, health interventions, and policy decisions. The NIH will require community benefits agreements and collaborative evaluation plans. Members of research institutions' surrounding

Countdown
02:01

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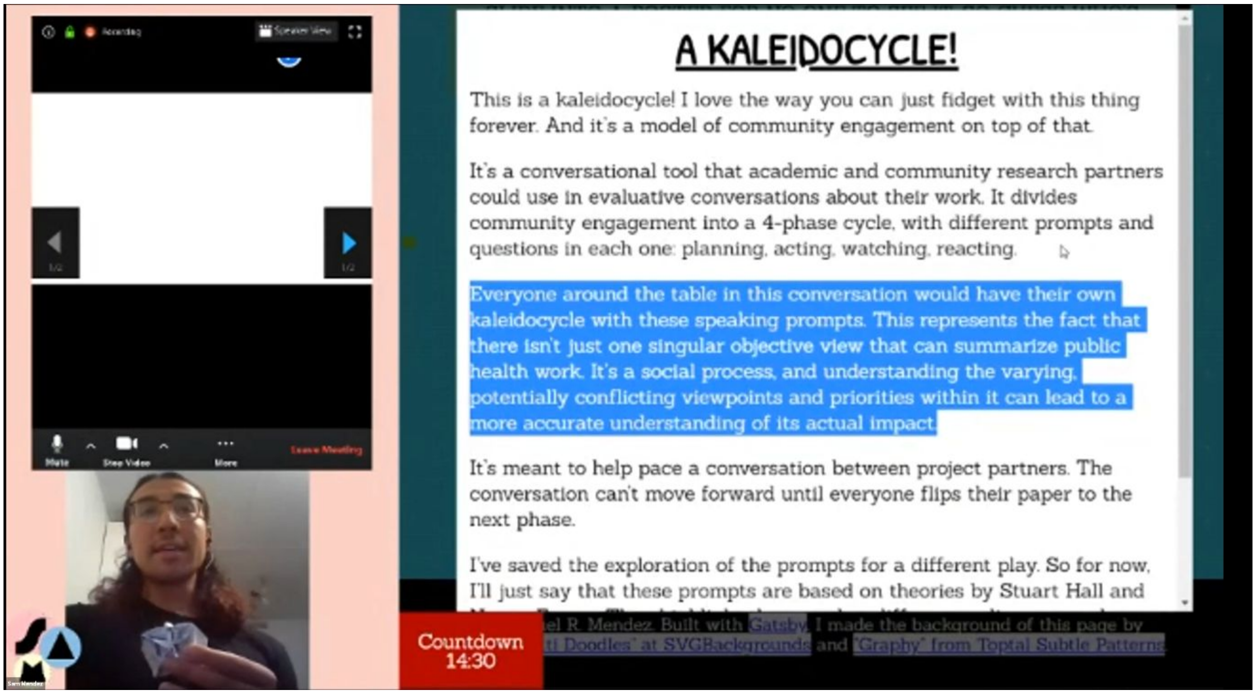
ti Doodles' at SVGBackgrounds and 'Graphy' from Toptal Subtle Patterns.



A KALEIDOCYCLE!

This is a kaleidocycle! I love the way you can just fidget with this thing forever. And it's a model of community engagement on top of that.

It's a conversational tool that academic and community research partners could use in evaluative conversations about their work. It divides community engagement into a 4-phase cycle, with different prompts and questions in each one: planning, acting, watching, reacting.

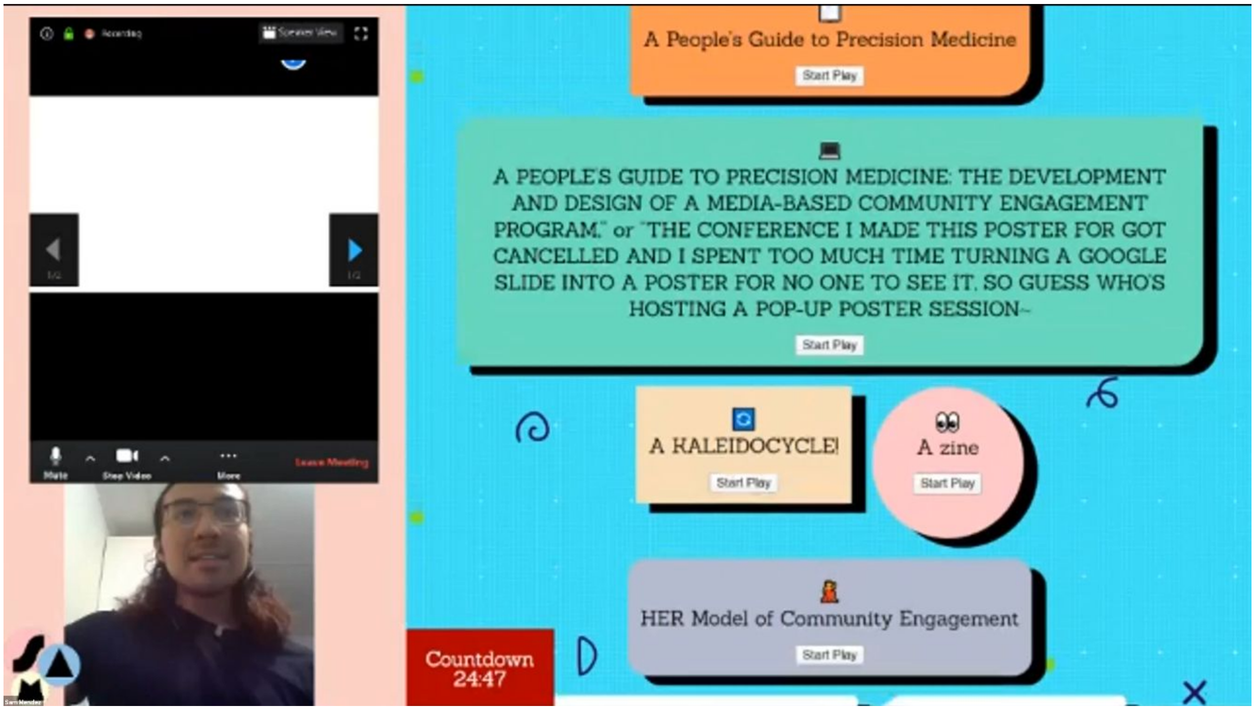
Everyone around the table in this conversation would have their own kaleidocycle with these speaking prompts. This represents the fact that there isn't just one singular objective view that can summarize public health work. It's a social process, and understanding the varying, potentially conflicting viewpoints and priorities within it can lead to a more accurate understanding of its actual impact.

It's meant to help pace a conversation between project partners. The conversation can't move forward until everyone flips their paper to the next phase.

I've saved the exploration of the prompts for a different play. So for now, I'll just say that these prompts are based on theories by Stuart Hall and

Countdown
14:30

el R. Mendez. Built with Gatsby. I made the background of this page by
ti Doodles' at SVGBackgrounds and 'Graphy' from Toptal Subtle Patterns.



A People's Guide to Precision Medicine

A PEOPLE'S GUIDE TO PRECISION MEDICINE: THE DEVELOPMENT AND DESIGN OF A MEDIA-BASED COMMUNITY ENGAGEMENT PROGRAM," or "THE CONFERENCE I MADE THIS POSTER FOR GOT CANCELLED AND I SPENT TOO MUCH TIME TURNING A GOOGLE SLIDE INTO A POSTER FOR NO ONE TO SEE IT. SO GUESS WHO'S HOSTING A POP-UP POSTER SESSION~

A KALEIDOCYCLE!

A zine

HER Model of Community Engagement

Countdown
24:47