Contents

Proem 00:53

The bottom is falling out of the world. I'm scared. I feel hopeless and small. My apocalyptic and pathologically optimistic selves do battle daily. Paradoxically, with COVID-19, my life has changed only a small bit. No more hugs, no more travel. No more band rehearsals. I still see my family, do my work. I can pay my mortgage. I'm privileged. I want to contribute to this COVID-19 morass. So, what am I doing? How am I contributing?

Greetings, my friends, my listeners, and readers. A small but mighty band of volunteers are working together to better understand how people can manage the many uncertainties COVID-19 introduces into their lives. We call the project Safe Living in an Epidemic. We want to better understand the historical and often ignored need for everyday people for rapid access to trusted information they need to make

choices in an emergency, in an epidemic. This band of volunteers includes the facilitators, yours truly and Laura Marcial, plus Natalka Slabyj, Cynthia LaRouge, June Levy, Kelly Reeves, Ellen Schultz, Sameemuddin Syed, Michael Waters, Michael Mittelman, Maria Michaels, Sharon Hibay, and Victoria Lyon.

Last week Laura and I met on a Zoom call with a Mastermind Group that I host to tell them about our project and seek their counsel about how to proceed. Mastermind groups serve to help achieve success – more great minds. I call this group the 3Ts and 2Cs. Sound familiar? <u>*Trust, time, talk, control, and connection, attributes for informed decision-making.*</u> *You can be a fly on the wall at this Mastermind group during this episode. I'll interrupt from time to time to be sure you understand what's going on. Participants include* [Adrian Gropper](#)*, CTO of Patient Privacy Rights and Principal at Trustee;* [Amy Price](#)*, CEO at Empower2Go and an editor at the BMJ;* [Dafna Gold Melchior](#)*, Communications Consultant Specializing in Messaging and Speaker Training at Message Experts. Dafna's from Jerusalem and isn't in healthcare. Not from this country and not from healthcare. I usually seek people for a team who are outside the bubble and who think differently.* [Jan Oldenburg](#)*, Principal at Participatory Health;* [Juhan Sonin](#)*, a designer at GoInvo Studios, He calls himself Creative Sandpaper;* [Libby Hoy](#)*, Founder and CEO of* [PFCCpartners](#)*, Patient and Family-Centered Care Partners; and* [Pat Mastors](#)*, President and Founder of Patients' View Partners.* [Laura Marcial](#)*, a research scientist at RTI International.*

I'm going to be talking about the computerization of evidence and data. That means that data technology folk code research results and store them in repositories and databases for use in electronic medical records, software, and apps to help patients, caregivers and clinicians make decisions about care and treatment. Full disclosure: I respect science and evidence, but I respect people more. Here we go.

We need help 05:26

Health Hats: We're working on a project that we call *Safe Living in an Epidemic*. We're going to share what we're doing. We're going to ask you, what do you think we got right here? What did we get wrong, or what's missing? We need to channel you, action-oriented people, as we try to figure out the next move we should make. How should we partner? How should we disseminate, and what's our ask? The challenge right now is that most attention in this COVID world, especially in the computerization of evidence and data, focuses on saving lives in hospitals and clinics for doctors. However, we know most of what happens to people in this pandemic occurs in the community, homes, however, they define home, but outside of hospitals and clinics. This makes sense - first, we need to save people's lives. In the community, people face a dizzying array of choices and challenges as they manage the risk of COVID. What should they do? What should they do with their kids, their work, their day-to-day lives? It seems that evidence-informed guidance, clinical guidelines, research feel pretty remote for most people. Who can relate to those concepts? When you look at the information that's out there, information on the web, in social media, in the popular press, the single most common characteristic that we see is mistrust. People just don't believe. They believe very little. How can the computerization of research and guidelines help people live safely? That's the dilemma.

End users, audience, and the band 07:46

This small group of us started thinking about how we were doing this for everyday people: patients and caregivers. How do they manage safe living in this epidemic? We wanted them to be able to access

information that they could trust quickly, but we realized that all people are not the minimum viable audience. It's too big. It's too many people. So, we started thinking about who's really our audience. We understood that our audience actually is people who work with individuals whether those are caregivers or coaches or teachers or writers or media people., They have essential skills. They're comfortable looking for information; they're comfortable with health systems and health information. They seek data translation; they don't just accept stuff at face value, and are trusted communicators representing various communities, and serve the end-user.

Minimum viable audience 09:01

Health Hats: *I can't over-emphasize the importance of clarity about audience. In advocacy work, we often this of our peers (people with similar situations as us) as our audience. But that's not good enough. Advocacy serves to move the dial – make something happen. As Seth Godin says* [The goal isn't to serve everyone. The goal is to serve the right people.](#) *That's the Minimum Viable Audience. So, while people like you and me may be the end-users, our audience is those that influence them. Back to the conversation.*

Health Hats: I'm not going to get into the etiology of this group, we're just a small band of volunteers, 10 or 15 people, sometimes three, sometimes four people working on this issue. None of us want to start a business. You've heard me say before that I don't want to run anything anymore. But here I am running something. This is about as much as I want to do in terms of running it. We're trying to focus on the audience, the end-users.

Our approach 10:27

Health Hats: We're finding value in entering into what we call *adjacent partnerships*. That'll come clear in a few minutes. We're exploring what's already going on out there that can help us, not reinvent the wheel. I'll share what we've been doing, but a key is journaling while we're doing it. What can we learn from the process of doing? What are we learning? We are trying to lay out the materials for a foundation that other people can build on. And we want to disseminate our adventures and we want it to be open source. We realized that most people who are involved in evidence and the computerization of evidence and research, study what they can get money for. They study what's important to clinicians. But not so much what is important to people as they make choices in their daily lives. We found that we had to start from the person (Pat, you'll appreciate this because you've got me started in this whole direction). We needed to understand the end-users; we needed to hear their stories.

Stories, personas 12:00

Health Hats: As we listen to people's stories who were living with, managing, struggling with COVID-19 or the fear of COVID-19, defined different characteristics. From those characteristics, we were able to cobble together different common personas. For example, we could group people by the density of living situation: density at home, at work, in transportation, in neighborhoods. Also, whether they were symptomatic or not, whether they were themselves high risk or not, whether they were in an occupation that was considered essential or not or high risk or not. What was the support of the communities that they lived in, and what kind of insurance did they have? Make sense? We found six or seven different personas. Here's an example of one of them: multi-generation family, presumed not infected, living densely, and in an essential, high-risk occupation. This is about Maria, who works at

Walmart and her family. And then we started thinking about, what are the questions that this person is going to have about safe living in their community. Once we began to identifying personas, we realized it was way too big, so we narrowed this down to testing. Maria wants to know whether testing could help alleviate her concerns.

Multi-generational, presumed uninfected, dense living, essential high-risk occupation 13:54

Health Hats: *Here's the full persona: Maria H, a 36-year old Walmart employee with responsibilities to stock shelves or checkout, is considered an "essential employee." She works during her state's stay-at-home orders. Since her children, ages 9 and 12, are home full time, Maria's mother stays at their home during the day and some evenings. Maria's many concerns regarding the COVID-19 pandemic include her risk of becoming infected and spreading the infection to her children or her mother, who has diabetes.*

Marie wants to know whether testing could help alleviate her concerns. For instance, even though she has no symptoms, should she be tested regularly? If the test should be positive, how can she quarantine herself from her family? Should she seek a test for antibodies to the virus and be confident that she won't spread the infection to her family? If either type of testing makes sense for her, how does she arrange to get the test? Who pays? Her employer? Her high-deductible health insurance plan? What cost will she be responsible for? Natalka Slabyj put this persona together.

Questions people ask 15:35

Health Hats: Next, we went out and started listening to different communities. Each of us spoke with people we knew: our family, friends, coworkers. We sat in on meetings like Libby's Friday coffee sessions. We lurked on social media communities. In a week, we came up with 75 different questions we heard people ask about COVID-19 testing. We distilled them down to eleven questions. Should I get a test? How often should I get a test? How good are the tests? Do I have to quarantine?

When we said Libby's Friday Coffee, we're referring to Libby Hoy's PFA Network (Patient Family Advisors Network). She hosts a Friday Zoom Coffee.

We talked about the 75 different questions we heard that we distilled down to eleven. Here are the rest of the eleven:

1. *How long after I test positive do I have to quarantine?*
2. *How much will a COVID-19 test cost me?*
3. *If a test shows that I have antibodies to COVID-19, am I safe?*
4. *When will I be able to get a test that I can do at home to find out if I have COVID-19?*
5. *Who, besides me, will get my test results? What will they do with it?*
6. *What is my employer doing about testing? What if they don't have a plan?*
7. *Am I being enrolled in an experiment?*
8. *If I get an antibody test and have antibodies, do I still need to wear a mask?*

Seek themes in answers 17:52

Health Hats: Next, six or seven of us went out with one question and spent an hour looking for answers. In our journaling, we came up with some issues. We combined all the issues and distilled them down to twelve themes. The biggest is mistrust. Everybody said mistrust was an issue. We found an incredible

mismatch between what people were concerned about, the questions they were asking and what research and evidence were available, findable, so little correlation. That was everybody. We found ourselves going down searching rabbit holes as we tried to find answers to the questions. We found that material was not understandable; it was contradictory; there was no lead voice. We actually found better information from other countries, Canadian or French, than American.

Themes we're heard:

- *A dramatic mismatch between concerns/questions and available evidence*
- *What you find depends on where you start searching*
- *The evidence is fluid and evolving*
- *It's easy to go down a rabbit hole that doesn't answer the question*
- *The resources reflect a lack of clarity about people's risk tolerance*
- *Evidence lacks authority – one leading voice*
- *People vary in their habit to follow the evidence*
- *When a reliable source found, confusing, not consistent*
- *Answers are often wordy, lengthy explanations*
- *People have discomfort with what they don't know*
- *Other nations may have better information*

Content process. Content stakeholders. The cycle. 20:50

Health Hats: Now that we listened to people's stories and questions and sought answers, it was now time to better understand our place in the computerization of evidence, where do we sit in that environment? Laura put together this chart. Our group started with the problems that people are having and the questions they're asking? Can people find what they're looking for, and can they trust it? Those were the most prominent themes that we found.

It's hard to describe a chart. The whole slide deck is in the show notes. In the center, you find the patient/caregivers' Problems and Questions. Around the center, we have Evidence creation, Guideline development, Content production, Content standardization, Data element management, content quality appraisal, curation, cataloging, aggregation, syndication, and measure development.

Metadata: Can people find it and trust it? 22:17

Health Hats: We began to look at that and ask, 'now, where do we go with this? We started thinking about the metadata - data about data, so people can find it and trust it, whatever it is in terms of information. In terms of trust, we started thinking about a nutrition label and, Juhan, as we go through this, one of the things that would be interesting to hear your take on how you might design something like this, let alone, what does it get populated with? A couple of years ago, Laura and I had partnered on a project about trust in clinical decision support led by Jodyn Platt at the University of Michigan. As you can see on the left, that project came up with different factors of trust.

The article, Recommendations for Building and Maintaining Trust in Clinical Decision Support Knowledge Artifacts was authored by Middleton B, Platt JE, Richardson JE, Blumenfeld BH for Research Triangle Park's Patient-Centered Clinical Decision Support Learning Network in 2018. The trust dimensions were transparency, organizational capacity, discoverability/accessibility, consistency, patient-centeredness,

competency, compliance, feedback and updating, evidence-based. Once again, look at the chart in the show notes.

Health Hats: Then we started thinking, what might be in a nutritional label? Like who's the audience for a piece of evidence? What's the source? How did that source get paid? When was it last updated? Is it readable? Is it in formats that people can be simpatico with, et cetera? Next, we started looking at this whole business of findability. We began working with Brian Alper and EBSCO, who were electronically classifying a shitload of COVID-related citations. But they're using are Pub Med-like searching and tagging taxonomy: clinical care, public health treatment, and prevention, diagnosis, specific populations. We're thinking about who searches for stuff using these terms if you're not a researcher, an academic, or a librarian? Our small group did an exercise where we picked several resources that we had found asking one of the eleven questions. We picked one resource we liked and one resource we didn't like. We asked ourselves how might you categorize or tag those resources? What keywords would you use? It didn't line up with pub med at all. We just did this this week, so this is not refined at all.

Search engines already categorize and tag material that responses to peoples' typed words or questions. Our dilemma: how can we help make those queries more sensitive and responsive? Can we help the computerization of content so material is more findable? Our brief exercise shows us we have much to learn. This is in our to-do queue.

So what? Now what? 26:32

Health Hats: So what? What do we do with this? How do we move along? We've been talking to other people about the project. Data management/decision science professionals say, 'this is totally the right thing to be doing.' And they have almost nothing to offer. It's important but doesn't fit in the way they think or in the work they're currently doing. When I talked about it with my cousin or some layperson, they say, 'Oh man, are you kidding? This is really important. How can I help you?' I don't know what to say to their enthusiasm. We need help. Are we on to something? What's missing? What's wrong with this? What do we do next? How do we partner? How can we take this further? So, Laura, how'd I do?

Laura Marcial: I think it was great. Yeah. I think there's a little bit of chat activity. Be great to hear; get your input. I think the point Pat's making the chat is that the information changes so quickly. How would you even manage something like a nutrition label? I agree.

Health Hats: *There's a Zoom Chat going on between Pat Mastors and Juhan Sonin saying that unlike a nutrition label, COVID-19 information changes almost daily and that we would need a score for trustworthiness.*

Health Hats: That's a good point. One of the things, Pat, that we've been trying to understand the Wikipedia model better. Actually, in my work with PCORI, they attempted to… Oh, Daphna, PCORI is the Patient-Centered Outcomes Research Institute, patient-centered research. I can explain it more to you another time. PCORI's been trying to develop a cadre of people to be editors in Wikipedia to increase patient-centered evidence that's available in Wikipedia. We're also fascinated by Wikipedia's crowdsourcing methods. Pat, to keep up with rapid change, you need an army of people. You're bringing up an excellent question. That's the best I can do now with how we're thinking about it.

Trust in Journalism. Trust in anything. 29:53

Jan Oldenburg: There's an initiative in journalism that I've been in touch with led by Joy Mayer called the Trust in Journalism Project? Has anybody else been following that? She started with a grant and has been looking into how to build trust between journalists and their communities. What that needs to look like, what it means to involve the community in discussion with journalism, and what it means to build trust? The commonalities strike me. We might be able to learn some things from the work that her group has been doing. She's very collaborative. It might be interesting to pull her into a meeting for the discussion.

Health Hats: Thank you. That's a good lead.

Adrian Gropper: So, here's my take on this. I read the slides carefully before the call. I think these sides are by far the best exposition of the problem that I have ever seen. The slides themselves are the best exposition. But here's my point. I think you're dancing around the issue of the root of the mistrust. The root of mistrust is that people do not necessarily trust experts anymore because of how badly they fucked up. The fact that the New York Times - and I don't count journalists, I think journalists are an exception to some extent - the fact that the New York Times had to sue the CDC to get racial disparities data in healthcare just basically says it all. I don't think you're dealing in the slides anywhere near enough, with who you are? What are your motives here? Are you trying to be better experts than the other experts? Are you trying to defund the experts and move them into the community? Those are two radically different ways of reading your slides. That's what I don't get.

Health Hats: Thank you for that.

It's a river 32:22

Pat Mastors: Following up on what Adrian was saying, I have made the mistake before of envisioning a service or fulfilling a need that I knew was there. But unless we get clear on what people are looking for in real-time and can identify that in a granular way and ensure that we can answer that need through this project by whatever means, which will involve finding somebody with some resources to make it happen. If we don't begin with the premise that before we build it, we can't assume they will come. This is challenging, given the trust issue for the reasons Adrian laid out. Also, it's moving all the time. It's a river. They're now saying this is airborne. What will they say next week? So, I should have started by saying he's right. This is a beautiful exposition of the problem. This identifies so well what's not out there for real people to use. I just admire the passion you have for this. If there's a way we can answer those questions, let me know how I can help.

Health Hats: Thanks, Pat. I want to emphasize, what's so weird about doing this, is we don't want to supplant anything. We don't want actually to provide the service ourselves. We all have busy lives. Part of me - I think this sound's wrong - but I want to start a movement. We want to excite somebody else or other people to take this on. We don't want to do it, but it needs to be done. That's a dilemma, a fundamental dilemma. We don't want to do a startup. I'd rather hang out with my grandkids and play my horn. Yet, this is important stuff. So, I think Pat, you are totally right. And Adrian, I think you're totally right. That's the dilemma: how to proceed, to generate excitement, and have other people who want to do this?

Systemic racism 34:54

Adrian Gropper: I'm sorry to be talking so much, but it's not about COVID. It's about structural racism. The same dilemma that you're describing is the institutional or the structural racism that we're not talking about, and focusing on COVID for the nutrition label. Your persona is, I think, a gap in this process. Because if you want the answer to the question you just asked, that is what the black lives matter people are trying to figure out.

Health Hats: Thank you.

Libby Hoy: I think it follows on with Adrian's comments and Pat's as well about the dynamic nature of what we know. Part of what we've been learning in terms of breaking down structural racism is the redistribution or democratization of power, right? Moving the power shift into groups that have traditionally not held that kind of influence. On a broader concept, I'm just thinking what if you flipped completely using a Wikipedia-type of open source where you are. We are not experts. We're creating a box for people to give their expertise, their lived experience, and expertise, and their questions. It could be moderated by folks with more of a clinical or research background, who are people who are uniquely skilled at creating a bridge between research and the general public. But in that way, I think that it could remain dynamic. You could continually learn. And Danny, you've seen this on the coffee chats as much as I have. The discussions and concerns we had in March are no longer, or they've been now added to, replaced with the conversations and concerns that we're having now. So, resources are a tricky thing. The moment you publish them, they're out of date. This is what I get you're trying to do differently is to create, again, the container for ongoing dynamic resources that can then be dynamically responsive to the needs and concerns as those grow.

Asking questions of the research 27:30

Jan Oldenburg: I have an adjacent thing that might intersect; there might be a way of using some of the joint resources. So, Deven McGraw recruited me for a project called the DataVant COVID research project. Has anybody else heard of that? I think of DataVant as a company specializing in building link secure - impenetrable linkages -between the identified data sets so that you can find the same person across data sets without breaking the de-identification. They have pulled together a consortium of people, lots of research organizations, lots of holders of data to build a conjoined database for COVID research. Everybody's got a pledge to do it not-for-profit. I'm a part of the patient-focused and privacy-focused advisory committee. The point I'm making is that they're pulling all of these very diverse resources into identifying COVID based research questions and asking them of this conjoined database, again, assuming that they meet the criteria. So, they're screening out a lot of garbage, and part of what they want is to figure out how to get it, make it accessible to patients. To ask research questions, which they may not do, but want somebody else to do. I'm wondering whether there might be a way of thinking about an intersection between these questions that need to be answered for the consumers that change all the time and a research question database? Perhaps there might be an intersection in a communication environment.

Now a word about our sponsor, ABRIDGE.

Use Abridge to record your doctor visit. Push the big pink button and record the conversation. Read the transcript or listen to clips when you get home. Check out the app at abridge.com or download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!"

Health Hats: Yes, it does. Amy, I'm interested in hearing from your perspective.

Wikipedia 40:25

Amy Price: I liked the Wikipedia-type approach. Wikipedia is far better than people realize. It's used as a major source of health information in low resource countries. It's accessible to everyone and they've already worked through ways to make it accessible and yet keep the technical language. I hear the poverty, the racism kind of stuff, that it's cloaked behind COVID-19 or whatever. But in essence, I think that might be a good thing because the fact that we have COVID-19 means that you don't necessarily have to approach it directly. You can come in from improving this for the sake of COVID and, at the same time, making changes to those other areas as well.

Drip, drip, drip, persist 41:35

Health Hats: I took a walk the other day with my older son.   We were having this conversation about what a disaster everything is. I was telling him about this project, and in a way, he sounded like Adrian. I got overwhelmed. It's just too big. I asked him, 'are you advising that this isn't worth it because it's too big?' He responds. 'no, no, no, no. I'm not saying that at all. Someday, somebody or some people are going to be ready for this, and by having done some of this work, they'll be six inches farther along by taking advantage. I felt a relief to hear that because this seems so monster, so culturally against the grain, and politically impossible and whatever. I'm a *drip, drip, drip, persevere, persist* kind of guy. Let's just make one more step, one more step, one more step, and we'll see.

Other potential partners 42:44

Health Hats: So, what we've talked about is some of the partnering opportunities. Dafna, I saw your thing about the Alan Alda Center for Communicating Science. Yes. They're excellent. And yes, that's a very good suggestion.

Dafna Gold Melchior: You're looking for somebody who has time and motivation to take on managing some piece of this. So, I wonder given at any given moment across the entire United States, how many research students in any relevant field, data, science, health, public health, medicine, nursing, communication of any kind and probably many additional fields, social work, urban planning. There are many different fields that this touch. Because, as you said, this isn't about the professionals. This is about everybody, right? So, aren't any research students looking for relevant, timely topics to study? And isn't this a research project, or even one seminar paper, if not a full master's or Ph.D. Where are the pools of projects that people take and use them as their research topic?

Adrian Gropper: If we're looking for expert volunteers, they're all on Wikipedia already. We should do just that. If we're looking for journalists who can do the kind of communication professionally, that Danny is talking about, there is the New York Times, and they're paid. The third category are paid experts - however they are paid - we still need whether they're paid by Harvard or by the federal

government through Harvard. It doesn't matter. But to me, it seems like we already know the answer to what Danny is asking. There are three categories for what the slide deck is looking for. One of them is volunteer, and it's called Wikipedia. The other two are pay, and we don't need any new ones is my point.

Health Hats: Laura, what do you hear here?

Laura Marcial: I think we could find ways to evangelize and look for a student researcher that wanted to take it on. I believe that a Wikimedia project is a great idea. I don't know what the arrangement is, how people have been successful at Wikipedia, and what makes projects successful. Do we need to have a Wikipedia presence before we go forward? I also like the DataVant opportunity. It would be worth talking about that and find out if there's an intersection. I know that from the research perspective, there would be a lot of value and understanding of what people have questions about in framing research questions. That would be a good collaboration.

I don't know if you guys are familiar with - back on slide 11 - this Swiss-based initiative, the HON Code? Websites would apply. It's rudimentary but effective. Some sites still place HON code approval on their websites, where they are meeting some minimal requirements for the way they present health information. The acronym is Health on the Net. The idea, of course, is that they've had some interaction with the organization that provides HON code approval, and that gives a sense, at least to the viewer, that they've met some basic criteria for the way that that information is created and presented. So, I think we're talking about placing together in some standard and prominent and meaningful way with metadata that would ultimately help a user decide, is this a good use of my time? Is my investigation on this question getting me closer to something that represents the truth?

Interested in facts, in evidence? 47:07

Laura Marcial: It does presume, and we had this conversation earlier, that people want to know the truth, and they don't want just to reinforce what they already believe or look for information that is in the channels that they always look for information. But it's a step. I guess I'd ask that question of you as well. What do you think?

Health Hats: I'm one of those people who look for information that honors what I already think. I'm just as guilty of that as the next person. Adrian, what do you think about this after your comments about systemic racism? What do you believe in terms of the possibility of incrementalism?

Nutrition labels and conflict of interest 48:01

Adrian Gropper: I think of myself as a world expert in what's wrong with these kinds of nutrition labels. I don't mean that facetiously. Because of my role with patient privacy rights and being unable for six or seven years to find a sustainability model for our nonprofit. I created a nutrition label like this about three or four years ago, which I think you have seen in the past and maybe others. More recently, I have spent the past year active in the MyData, group out of Finland. They've got thousands of members now who are struggling with a sustainability model. They have a very different perspective because they're mostly European or global, and they are failing miserably at it. So, I would call it an impossible task. I can go into details of all of these experiences that I've had, and why I've assembled more expertise in this area than absolutely anybody I know. But it boils down to the problem of solving the conflict of interest

problem. If there's any money involved in the interest of sustainability, then it always raised a conflict of interest problem, unless you behave like Consumer Reports, which strictly, absolutely, refuses to take money from anybody other than individuals. Consumer Reports is not a great model, but it is the only model I know of that starts with the conflict of interest issues and ends up with a sustainable model. I know there are lots of organizations that I trust immensely, like, for instance, EFF (Electronic Frontier Foundation), but they don't attempt to label things in this way. Other than Consumer Reports - and not for the lack of trying for seven or eight years - I have never seen anybody solve this problem, including me.

Health Hats: Oh, this is also sober. Final thoughts

Dafna Gold Melchior: We are one institution that we trust.

Health Hats: Well, guys, I love you. Thank you so much. It just means a lot to me that you respond when I call. You guys have some of the greatest minds I know, have a good day.

Reflection 51:00

Let's remember why we're having this conversation. *Maria H, is a 36-year old Walmart employee with responsibilities to stock shelves, an "essential employee." Her children stay home. Maria's mother stays with them. Marie worries that even though she has no symptoms, should she be tested regularly, et.cet. This story reflects healthcare decisions many, if not most, people face Living Safely in an Epidemic. How can people find and trust science, research, and evidence? How can computerization make this finding and trusting easier and faster for everyday people – meeting them where they are at?*

There is a community of people called knowledge managers or knowledge experts. I am part of this community, a tough community to be part of. The community is made up of technologists, researchers, scientists, and clinicians. They usually start with research, clinical guidelines, the electronic health record, and try to computerize that evidence or research. We, on the other hand, would rather start with people, their conditions, genetics, situations, environment, preferences, and desires. Then we listen to the questions they ask to make choices about their health and safety and then look for some answers. Finally, last, not first, we think about computerization to scale the process, make it faster, more accessible, and more equitable. Findability, trust, and alignment of the questions and the evidence are the holy grail here—daunting challenges. The findability of evidence seems to be an engineering problem. With will, money, and persistence, it can be done. On the other hand, trust, power, and institutional racism are human behavior, tough nuts to crack. I see two options: the second coming or drip, drip, drip, one foot in front of the other, build coalitions, nudge, nudge, persist. Crazy stuff. Fun though. Reasons this can't, won't work, are legion. If not us, who?