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*Proem 00:58*

*Pain management, medical choices, technology, and health equity all converge during this episode in a free-wheeling conversation with my compatriots of privilege from the [Patient-Family Advisor Network](#) chronic pain task force. Let's unpack that stew of an introductory sentence a bit. People with chronic pain need tools and plans to manage their pain. Tools include medication, therapies, exercises, dietary, and more. We choose tools to help us manage pain best when we have a team to help us discover tools, fit the right tool to the right time and circumstances, support our experimentation, and make the whole managing process easier and easier. Technology may or may not help us connect, experiment, and make the process easier. Those of us with chronic pain do not all have access to the same variety of tools and supportive team members. Inequity and institutional racism, sexism, ageism, tribalism, and other power imbalances significantly impact our ability to manage and reduce suffering from pain. In previous episodes, I introduced several projects in which I participate: Reducing opioid use and managing chronic pain from a patient's point-of-view; developing an app for clinical decision support in chronic pain management; and considering equity and inclusion in patient engagement. Pain, choices, tech, and equity - phew. Does that make sense?*

*Here's a map of the conversation that follows. Libby Hoy, Joan Maxwell, Charlene Setlow, and Dick Michael from the PFANetwork opioid/chronic pain task force joined me for a second talk about a pain management app. The first time we looked at wireframes (snapshots of screens of an app) to advise on language, content, and usefulness. I invited them to join me again today to talk about using apps in general for health and pain management. In the invite and scheduling process, they asked to broaden the conversation to health equity in patient advising. I was delighted to accept this request. I will likely interrupt the conversation from time to time to help you follow. Here we go.*

*Using apps in general 03:56*

**Health Hats:** A while back, we had a conversation, looked at a chronic pain management app, and you gave us some valuable feedback. I've been thinking about what we've done and about technology and

managing health and wellness. I wanted to ask, 'in everyday life, what apps do you have on your phone that you use regularly, and why do you use them?'

**Joan Maxwell:** I use maps, of course, like Google Maps for directions. I use airline apps for reservations and tracking. I use Instagram, Facebook, and LinkedIn apps for social media. I use Stitcher to listen to podcasts and MyPhotos to share photos amongst our family. I use the New York Times app. On rare occasions, I use Yelp for recommendations.

**Health Hats:** It's interesting to me that none of these are healthcare-related, correct? Say something about that. Have you ever used health and wellness apps? Why and why not? Did you stop?

**Joan Maxwell:** Unfortunately, some of my doctors use the John Muir Health, and some use Diablo Valley Oncology apps, but they don't talk to each other very easily. That's the main reason I tend not to use them. It's just frustrating. And the Diablo Valley Oncology app doesn't report my lab results. I would like to know my blood test every time I go. I can't see that on there. All I can see is my height and weight, which I don't need. I already know that. So, it doesn't really, give me the info I want.

**Libby Hoy:** Don't they have to report blood work?

**Joan Maxwell:** If I ask for it, they will send it to me, but it doesn't automatically appear. I literally need to call and request it. So, it's just a pain, really annoying. I use the John Muir Health app a little bit more, and it does put the results out there for me, but some results don't mean anything unless you have the doctor's perspective. So yes, this result is high. What does that mean and what should I do about it? The notes from your appointment will then show up, and you have those to refer to, which I guess is helpful. But I do still find that my connection by phone or a chat by video chat or an in-person visit is more useful to me.

**Health Hats:** Libby, what would you say differently?

**Libby Hoy:** I'm going to take a different tack. I use a lot of the same social media and family, but overall, I use apps that make things easier for me in terms of my health. I look at [Strava](#) every day. It records all my activities. I network with my family and other friends who hold me accountable for my exercise routine through that. I use [Peloton](#) to get access to yoga and cycling programs online. I use [UCLA Mindfulness for meditation](#). I look at My City of Hope portal maybe once a week or so. However, it does get frustrating for several different reasons, such as the inability to correct things most of all.

**Charlene Setlow:** Number one, I don't use any social media except LinkedIn. I do check LinkedIn because I am in contact with many of my previous colleagues. My brother and I often communicate for scholarship work via LinkedIn. In terms of my health, I have begun staying away from any COVID-19 news because it is so skewed. I find it difficult to believe, no matter which political side or quadrant you happen to be in. I just find it very confusing. But I do go to the [NASA](#) site a lot. I go through any science application, anything that has to do with science, whether it's medical or subatomic, any of that because I think it's just fascinating. But, other than that, I tend to not. I'm not very social. I'm more of a geek.

**Health Hats:** So, Dick, how about you?

**Dick Michael:** If I use health-related sites, I tend to use mostly - not necessarily apps - but websites of health systems, maybe Unity Point. Large health systems, like [Mayoclinic.org](#), rather than anything that

ends with dot com or dot net at least for COVID information. I've helped develop some of those patient portals I've got with different provider groups. It seems like all of them have portals. The drug information within those provider portals is well documented. I don't think they would set themselves up for anything without having input from medical providers on down to patients. Most of the information embedded within portals is reasonably reputable. As far as other apps, it seems like I've got five different ones for meetings to Zoom in, Woven in, Microsoft team meeting in.

*Although we met to discuss a patient-facing pain management app, these four people (not a scientific sample) don't use pain management apps, or many health apps, for that matter. They do use their health system and provider practice portals with varying degrees of satisfaction. I find it challenging to locate useful information about the use of health apps. [Research says that most people \(80%\) have smartphones. 52% of smartphone users collect health-associated information on their devices](#) and 8% of smartphone users between the ages of 30 to 49 have medical app downloads. In five minutes of searching, I couldn't find a definition of use, just of downloads. I'm a heavy downloader of health apps (about 50-60 in the past two years, but I only use one more than once a month (Abridge). [Download](#) does not mean use. Do any readers or listeners know of a scientific definition for app use? Ok, let's move on to our discussion of health equity. Remember, this group asked to include health equity issues in this second evaluation call.*

Health equity – more than seats at the table? 12:44

**Health Hats:** We talk a lot about health equity issues. Often when we - I'm talking about the global we, as opposed to the five of us - when I hear people talking about health equity, it's mostly - meaning more than half the time, I have nothing scientific here - but people are talking about having diverse seats at the table and or that the population of a study mirrors the population of whatever universe the study is about. I confess that it raises my hackles in a way because I think about patient engagement. How many times have the five of us or the larger group talked about the challenge of being the token patient at the table and how hard it is to think that people are thinking we're speaking for everybody? We're smart, and we're connected, but we're not speaking for everybody. So, when somebody says, 'we want to have more health equity,' and then we have a Hispanic at the table, or we have a person of color at the table, or we have, again, a token somebody. That does not smell like health equity to me. But beyond that, I don't know what it is. When I think about technology in health and health equity, people must have access. That all different communities have access. People's varied circumstances must be considered in the design of tools that are supposed to help make things easier. But this is about as far as I've thought about it. And I want to think about it more deeply. We know about pain, that's how we met. I met you guys in this opioid pain group. I should be thinking more about health equity in the work that we're doing. But I don't even know the questions to ask. I feel like there's something here, and I just am looking for some thoughts from you guys? Like how do you think about this stuff? Joan, let's start with you.

**Joan Maxwell:** I just want to tell you a quick story. So, I'm on the patient-family advisory committee at John Muir Hospital. Their second hospital in Concord has a little more diverse population. I'm sitting on the nurses' council this year, and they are taking on a special project about patient belongings. I'm the patient representative for this discussion about patient belongings. People bring in guns, knives, drugs, all their belongings because they're homeless, and the hospital is trying to figure out how to keep their

staff safe, their patients have some level of respect and for their belongings, et cetera. And here I am patient on this conversation who's not homeless and doesn't have guns or knives or drugs, anything. So I think that's an excellent example for me of what health equity would be now. How are you going to have a homeless person in the room? Maybe ask them the question? I don't exactly know. I did my best to reach out and ask patients, 'what are the belongings that you're worried about when you go to the hospital?' I did my best to do some research and have good feedback, but I'm just saying I'm a poor person for that project. So that's a simple example of health equity needs.

**Health Hats:** That's a priceless example. Thank you. Wow, interesting. Charlene, what about you?

**Charlene Setlow:** Danny, I was just going to echo your words. That is an excellent example. I'm fortunate in the fact that I have never been in those situations. That would have never occurred to me. We do have a few people who are homeless in my neighborhood. I just walked by a woman this morning who had managed to get out of her wheelchair onto the lawn because it was cool. I did stop and ask her if she's going to be able to get back into her chair. She assured me that she would be able to do that. But it is interesting how, when you've never been exposed nor ever wandered into those areas, the lack of awareness, and I must admit, I was shocked at myself to have never thought about the drugs particularly. And opioids being another one, we all know people who've taken that. So, in terms of inclusion for economic reasons, for all of the other reasons that we try to be inclusive, that is a tough question because my local community is mostly Latino. We do have a few African Americans. We do have a few native Americans. We do have some Hispanic, some Asian, some Japanese, we do have a few, but we're not diversified here in terms of those other areas. And religiously also the vast majority are Christian, whether it's Catholic or Mormon or LDS or whatever. So I think you just have to keep working at it and increasing our awareness just as Joan has done. And Libby, you are probably another good example of that, coming into contact is serving on several of the other family councils. Danny, I am with you. They're not terribly inclusive. And the cohorts in some of the studies that I've looked at the abstracts from PCORI. Number one, there is a paucity of women represented because most of those cohorts come from the VA hospitals. Now that's changing gradually over time. So, there are more and more women included. In the past, it was all men. This is why women's health studies; heart studies have been so far behind the times because they never included us. It's tough. You have to keep working at it.

Systematic inclusion. Put your money where your mouth is. 20:14

**Health Hats:** One of the places - I use this example because it's the only one I have - I reviewed a funding request once where respite care is budgeted for caregivers' careers so that caregivers could participate in leadership in a research study. Now that's inclusion; they put their money where their mouth was. It's one thing to have to say you want people to have seats at the table. It's another to understand the challenges that it takes to be there. Dick, what do you think?

**Dick Michael:** I was thinking about a hospital that I worked at and in the broader system, now that I'm involved in governance. They have diversity councils typically made up of all providers - all nurses typically, quality improvement people. They're predominantly Christian or predominantly white here in Iowa. But our bigger system has a diverse population group. I always say you don't have any patients on your diversity council. That's the first step, put a patient on there. They probably don't want me, but if they do, I hear that just like we're talking about here. Gosh, I don't know what it's like to be poor and

drug-seeking somebody who lives in a homeless shelter at night; that's a large number population. I can't represent that very well. But I don't wonder if that's typical that those cultural or cultural diversity councils, whatever kind of a title I put on them, who makes those up? Does anybody know about that?

**Health Hats:** You're asking a question. I would say right now is it really varies.

*Patient-caregiver engagement can occur in governance (strategy and the board), design (planning) operations (running the place), and learning (research and quality improvement). A diversity council could span all of those. Diversity seems necessary, but not sufficient. Inclusion of patients, caregivers, acute (one-time, preventive) users, chronic (frequent) users, teens, single parents, elderly, those with handicaps? Then, what's their authority - listen-only, advise, plan, decide, disseminate?*

From token to sustainable 23:40

Libby, what's your experience?

**Libby Hoy:** We as an organization have been on a journey since Memorial Day weekend to dive further into equity and what it does? We're struggling with a lot of these same questions, Danny, for sure. It's not that I have an answer per se, but I'll share what I've learned thus far. And this is, in large part, to due to the diversity equity and inclusion workgroup that we started. So, workgroups like this one. However, that workgroup is made up of 10 members of the PFA network who represent the black community. So, they're leading out. I have learned from them to shift my thinking from 'we need to create seats at the table' to 'we need to provide them the hammer, the nails, and the wood and encourage other communities who are underrepresented to build the tables and invite us to them.' That's a flip in the thinking. As I speak with this workgroup more and more, I think we get to equity, not by just inclusion. One of our core values as an organization has always been inclusion. Everyone who has entered our door, we've been inclusive. But equity means you have more than one door, right? So, at this point, we are adopting the value of creating multiple doors and create doors in underserved communities. Rather than asking people who are homeless to come to us, how can we go out, Joan, and have some conversations and do peanut butter and generous? So, our staff retreats, before COVID, we would make sack lunches, peanut butter jelly sandwiches, and a piece of fruit and take it to homeless in our community and just have a conversation about that foot looks horrible. How are you getting that cared for? What does that mean to you? I think that's a first step. What I'm learning is that to build trust with underserved populations so that it's not a trend in response to George Floyd, or it's not that token. I hear a lot of pushback from my colleagues who are people of color who were saying, don't just start something as a token. I've come to think about, and I don't know if I'm correct, but come to think if we're challenging ourselves to do something completely different, it's going to be token for a while. The proof will be sustaining it, right? And growing it and nurturing it and developing it. When I started this journey, I thought of diversity, inclusion, and equity as all the same. The same thing all wrapped up together. But I'm now seeing each, as it complements and supports the other.

Trust, inequity, and power 26:41

*My friend and colleague Jan Oldenburg turned me on to an article in Health Affairs entitled, [On Racism: A New Standard for Publishing On Racial Health Inequities](#). Trust and inequities and institutional racism bind together to impact chronic pain management and any ill health, for that matter. We often think of*

*inequities in terms of genetics (race, ethnicity), but that puts it on the individual and avoids questioning institutional racism, sexism, ageism... Power imbalances.*

**Health Hats:** I have a dear friend who has sickle cell. She and I became close several years ago over chronic illness challenges. Then she moved away and got pregnant and was living in a strange community trying to deal with pain management in a hostile environment. It so wasn't about technology, that's for damn sure. I could be helpful and supportive to her, but I learned way more than I offered in the experience. I appreciate what you're saying about the hammer, the nails, and the wood, and being present for a few moments in somebody else's life and trying to learn the circumstances, the challenges, and then ask the questions or listen for the questions they're asking. Then thinking about what are the tools? So here I'm thinking about this pain management app, which is how this conversation started. We're not going to learn that with a bunch of clinical decision support techno geeks sitting around the table.

**Libby Hoy:** Not that that doesn't have value. I am also thinking about power, and I would love to hear you guys' thoughts in terms of it's not a finite entity that I have, and I give to somebody else. I don't think it is. I think when we have equity, everybody has power over their own health, over their own trajectory. I don't know that one replaces another. I think that's an important piece to hold on to. I'm not saying I'm holding my space. I will give up, I have given up my seat. I've given up our budget. I've given up all that because I believe strongly that that's the move right now. That's important, but I think over the long haul, I don't think of power as a finite thing that I can impart on somebody else. That's pretty high and mighty of me. Isn't it? That doesn't feel good.

Who empowers whom? 29:51

**Charlene Setlow:** I concur. You really cannot empower another person. That power has to come from within that person. Unfortunately, some people have more of a reserve and can draw upon that power but I concur it's a two-way street, our electronic, electromagnetic waves go in both directions.

**Libby Hoy:** But I do think that you can change the circumstances around people to help raise empowerment and resilience. I do. Yes, certainly.

**Charlene Setlow:** You can't really give it to them. We can make it available.

**Health Hats:** Joan, I see a question or a comment on your face. Is that right?

**Joan Maxwell:** Yeah. I think this is such an interesting conversation. And so just, first of all, Danny, thanks for allowing us to have it. With hospitals closing in rural areas, I heard a story, a woman interviewed on [60 Minutes](#). Her husband had died because they couldn't get to the hospital now over 200 miles away. They couldn't get there. There had been a hospital nearby. To me, that was health equity. The other thing I heard about rural is the need for therapy for teenagers who are struggling and maybe have addiction issues and need serious therapy, and help doing that by telehealth. Is there a way that we can help them? I feel like there's so many examples that I've heard. But to your point, Danny, which I think is so interesting, is how do we pull it all together? How do we talk about it? How do we help as patients? I like what Libby said. I think that's probably the look on my face that you were reading was appreciating her saying that it's giving them the tools and letting them lead the way. I think up until she said that I still thought we had to help them.

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What questions do we ask? 33:30

**Health Hats:** When something is hard for me to get my head around, I tend to revert to 'what are the questions I need to ask?' I'm a nurse and a nurse problem solver. I'm a do it, figure it out kind of guy. Ok, you got this problem. What are we going to do about it? Blah, blah, blah. That approach has its place, but it's not always the most helpful. This is one of those situations that I need to figure out when I am in a venue that may not be as friendly as this one where I feel like I can just try stuff out for size, and we'll have an exchange. But I need some questions to ask. Questions like, 'how can something shift the conversation or direct the conversation? With these people developing this pain app or whatever it is, what are the questions? It's not sufficient to say, 'what about health equity?' That is not a helpful question. My last question is, 'what are questions that we can ask when we're in a setting where we're an advisor and to stimulate a helpful conversation? A shift in thinking Libby has been talking about.

**Joan Maxwell:** I guess one thing that comes to mind specifically related to the health app is who is going to be using it and what do they need to be able to use it effectively?

**Health Hats:** Ok.

**Libby Hoy:** I think too, And Danny, I totally am action oriented too. And so I want to just jump in and solve and it's been a remarkable lesson in self-restraint to slow down and realize my husband dropped me off for work today and he said, so what are you working on today? I said, we've got opioids, equity, and then COVID and he goes, yeah, good luck. Like why I think that I have any solutions to any of this, we have to commit to the process on this one and it's not clean and it's not easy. I love Joan's questions. I would ask who could benefit most from this technology, like who is marginalized right now that could benefit most from this technology that we're moving through? And then that might lead to Joan's question of what do they need, what do they need to be able to access it?

**Health Hats:** So, meaning like in one of the examples, not closing down hospitals as a business decision and thinking about access or is there broad band so that these things can be used? That kind of thing?

**Libby Hoy:** Yeah. Should we be partnering with the Institute for Technology what is it technology access or Janice has been talking about. but yeah. Should we be partnering with this group or should we be partnering with community-based organizations that support underserved populations to make sure we know? It's so clear to me now that it's the same thing as designing a hospital flow policy, without asking the patient. Like you're going to miss, you're going to design something that works for the organization, but the risk of missing what your patients need is really high. This is the same thing. How did we assume we thought we would know what was needed for some of these communities without asking that or when you hear 'meeting people where they are.' We strive at that, but to do that, you have to go into your community, establish some trusting relationships, and work together. I don't

**Health Hats:** Ask questions. Yeah. Dick, what do you think?

**Dick Michael:** Oh, just like how different this conversation we're having today would be oh a year ago from today or a year from now, from today. Just so that things that this COVID has adjusted, go to talk, go to a community meeting and talk about. Who has community meetings anymore? Where there were some community groups, hospitals, and provider groups. They're more interested in their bottom line right now, trying to keep open. Where are the patient's coming from? What kind of patients we're going to get and take care of them? The pandemic has thrown a lot of things into motion that isn't easily solved besides taking care of patients and making patients well and public health concerns and stuff that. I don't know how much; it's going to be hard to get equity on the front burner? I'm afraid Danny,

**Health Hats:** yeah. Ok. But no. That's ok. no. Hey, it's real.

**Libby Hoy:** It is. it absolutely is. And I just keep thinking, but it's a public health crisis. Shouldn't be that be the time that we're talking to the public and you're right. Dick you're absolutely right. It's very hard to prioritize equity and at the same time, I feel like. It's a solution in a lot of ways.

**Health Hats:** All right. two things, any last words of wisdom?

**Charlene Setlow:** That's a pregnant pause. With all of this conversation and of course with my bias, I really feel that there is going to be a lot more technology involved and I don't quite understand, locally, we do have a lot of telemed, because of course, we're close to Stanford and the community hospital in Monterey, which serves Carmel, which, the myth is such a wealthy community. It's really not. There's a lot of money there, but they come and go. I think a lot more technology is going to be involved, and I think one way to reach some of the homeless and the people who are displaced and not doing the representative in finding out what they need is to take a laptop and go out and ask. Then, unfortunately, there's going to be a certain number of the population who won't trust that technology. And so you'd have to build some trust is, as Libby has mentioned. But at least that would be a start. And you could find out if in fact that those people who are in desperate need, who need emergency help, Oh, there it is. You can take it back and find out if somebody can go and help them, somehow somehow and build a partnership with emergency area offices. We do have urgent care here. But of course, it's not mobile. You have to go into them. And it would be nice if there were people like you, Danny, nursing are able to take their skills out into the field. My sister had done that. And of course, visiting nurses is another organization that does go out into the homes and cares for some patients. I don't know if they would go to a homeless shelter or not. I'm sure they probably do. But when you stop to think about it, there's lots of opportunities. It's just getting it down to someplace where it's manageable and also something that can be an ongoing, not a flash in the pan. So, I think that's sustainable.

**Health Hats:** Thank you.

Black Lives Matter. Stay home to advocate. 41:26

**Joan Maxwell:** Charlene, that was well said. I just want to add to that as I think about it, it reminds me of one of the many things I've learned from Black Lives Matter is that the place that I can help is in my community. Don't march in Oakland. Stay in my town and figure out what needs to be done there and help do that. I wonder if health equity is similar in that you can't lump homelessness and poverty and rural, and all the different issues, prejudice, everything that we're talking about together. But instead,

you go to each community and figure out what they need and address those individual needs in that community. Charlene, you probably said it a lot better than I just did, but that made me think that the community-based approach is so critical.

**Health Hats:** Thank you. All right, guys. Thank you so much. This was valuable for me.

**Joan Maxwell:** Thanks for including us. And thanks for bringing up this topic. It's important.

Reflection 43:10

*We did it - pain management, medical choices, technology, and health equity in one conversation! Sifting sand through the screen, I hear confirmation that people do not commonly use pain apps for pain management. Perhaps we haven't found the function most needed yet. I hear that we privileged patient-family advisors deeply consider the challenge of health equity. We're aware of our privilege and limited perspective. We're attracted to impact health equity in the communities we know and share the skills learned with communities we don't know. Chronic pain is universal. Health equity is complicated—my lesson today: open mind, open heart, experiment. Thanks for joining us. Keep the faith. Onward!*