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Proem 00:53

Activists seek to inform and nudge change for the better – political, social, cultural, healthcare, service change. I'm a patient-caregiver activist learning and sharing what works to make safe health choices and decisions, now in these times of a pandemic. Activism involves groups of people, communities – few to no changes arise from a single person. Successful, sustainable community activism depends on building coalitions and infrastructure.

A couple of weeks ago, I introduced a new community movement: Person-First Safe Living in a Pandemic. We need to build coalitions and infrastructure. Actually, we need partnerships (coalitions) to build infrastructure because we have no funding source. Movements need infrastructure, whether they have a funding source or not. So, we seek partners who can offer infrastructure. What is infrastructure? For Person-First Safe Living, infrastructure includes a central point of contact, like a website; channels of real-time and asynchronous communication - real-time, like Zoom; asynchronous like Facebook, Twitter, email; and a repository of resources – a searchable library like Google Docs, Wikipedia, Confluence, SharePoint.

Coalitions and infrastructure aren't free, even if you don't have money to spend. They require time and energy - people - while hopefully wasting as little time and energy as practical. Time and energy are their own kind of expensive. As you might imagine, coalitions bring people and organizations together, aligned for a common purpose, perhaps many common purposes. I will share our coalition and infrastructure building journey from time to time in these Health Hats podcasts.

Again, sustainable grassroots change projects, whether cultural, health, service, products, or research implementation, are all community action opportunities. Today, I'm considering the challenge of creating and maintaining a communication platform for our movement. We need places to meet. We use Zoom –

low maintenance, inexpensive - several participants have accounts – no added cost. We're standing up a website on an existing web host server with room to spare. Next, we need a place for people to congregate virtually and speak to each other. We could use the WordPress website with a forum plugin. A plugin is added programming bolted on to a website that's ready to register and host people. The upside is that it's cheap and we could manage it. The downside is that we would have to manage it. We received an offer to use a hosted forum platform, the [Digital Quality Forum](#), created by NCQA (the National Committee for Quality Assurance). Let me give you some background about [NCQA](#). NCQA began in the early 1990s to measure and accredit health plans. Accredited is a seal of approval. I led a project with a behavioral health managed care plan for NCQA accreditation. NCQA developed a system called [HEDIS,](#) which measures health plan performance. Little did I think that I would be circling back to NCQA as a patient-caregiver activist. Who knew?

Introducing Ben Hamlin 05:18

So, let me introduce Ben Hamlin, the Senior Research Informaticist in the Department of Performance Measurement at NCQA, specializing in clinical quality, context-specific decision support, and the use of predictive analytics for quality improvement. Ben currently co-leads NCQA's [Digital Measure Roadmap](#) initiative, which is committed to improving the generation of knowledge tools derived from the process of quality measurement. I'll let him tell you about that work.

Health Hats: Good morning, Ben Hamlin. Good to see you. I just have to say that I'm looking at Ben Hamlin in the Millennium Falcon cockpit. It's impressive. Ben, how do you introduce yourself? What do you want people to know about you?

Ben Hamlin: I like to be known as a disruptor. My career has always been focused on the end-user of this information. I'm at NCQA working in quality for many years now. I've managed to maintain that perspective through that period. I'm a bit of a troublemaker, pushing boundaries. My real focus has been on the quality of healthcare in the US. It's been an underlying aspect of my career ever since I got into health policy over two decades ago.

The disrupter 06:53

Health Hats: What have you disrupted recently?

Ben Hamlin: During the last several years, I've pushed to change how people think about quality measurement. We have had a technological revolution globally. Healthcare tends to be a little behind the curve in terms of taking advantage of all the opportunities this technology allows us to make our lives better. I try to open people's eyes that the quality measurement establishment has demonstrated successfully that quality is important. All the rules for Obamacare, healthcare reform involved quality value-based care with quality as a major aspect of care delivery. So, we've been successful in making quality a primary concern, but we haven't kept up technologically with the things we could do better in quality. Now that we've got it in front of everybody, it is an extraordinarily complicated thing. There are many moving parts. There are many people involved. It's hard to remove the human factor from quality, and we shouldn't necessarily do that. We need to put the humans where they can take advantage of this without removing them entirely because we're treating humans obviously in healthcare. We want to make sure that we never lose that perspective. That's what I'm talking about. The end-user of this technology of this quality information - that's knowledge that we generate from doing quality

measurement - those end users are a number of people, but the people most forgotten are patients. We're providing patients with information, telling them how to get better healthcare and how they might improve their quality of life.

Health Hats: Okay. I'm not sure I hear the disruptor part.

Ben Hamlin: People don't like change. The quality measurement establishment is well-established. Much of the rules of how we do it are built into federal legislation, which takes a lot to change. I'm pushing for some fairly radical change. The quality measurement environment has been built upon the retrospective report card model that presents you with dashboards and report cards at the end of the process. But that doesn't help you provide better care to patients in a forward-thinking manner,

Looking in the rear-view mirror 09:19

Health Hats: Looking in a rear-view mirror?

Ben Hamlin: It's a rear-view mirror. 'Oh, I should have done better. Maybe I'll try harder next time around. The clinicians and patients are too busy in day-to-day care to think on top of what they're already doing. That knowledge is helpful, but unless you're motivated and have many resources available, it's not going to help you think forward. So, trying to shift the entire quality measurement environment to be a helpful tool to people who are busy and avoids information overload. We can winnow through volumes of data using this technology and the quality measure specifications that guide that data to where it's most useful; when it's most useful; and needs to be updated. They're not very efficient right now. They're still very clunky and medieval. I'm looking to a Renaissance, an age of enlightenment. I call it immune quality measurement. We're still using medieval specifications but trying to deploy them, just by automating them, which is kind of steampunk if that gives you an analogy.

Health Hats: Quality measurement and all these data often feel like it's not the right data. It's claims data, electronic medical record data. It misses the boat. That's a challenging thing to disrupt.

Ben Hamlin: Yep. I'm not saying that we should lose that data. We should use it. It is a valuable source of information; both of those two sources are. But they're not the only sources of information, right? We are generating ourselves volumes of data every day through all of our interactions, wearables, home health monitoring devices, and even things like patient assessments that you can do on your iPad at-home tracking - your weight, physical activity, and diet…

Health Hats: Your symptoms.

Ben Hamlin: You can track your symptoms. You can also track all these things using these tools that clinicians use when they see you in the office. They'll ask you questions and record these things instead of generating a view of you. We can do that on our own and help with our self-management by providing how we're feeling today and what we might want to do differently, or how we want to set goals for what we want to do. That's not in that administrative data; it's not even in claims data. There's not a lot of it in the EHR data either. Setting care plans with patients is not typically documented such that it could be reused for some other reason. In the notes of a patient visit and a provider and a patient can sit down and review those notes and say, we discussed this last time. How are you today, and what do you want? Has anything changed since last time? But that's a very human interaction that the

technology can't help you with. Whereas if you brought in those apps that help check your goals or check your progress against goals daily, that might keep you more engaged. That might keep you more interactive instead of every month or every three months, every six months, whenever you're seeing your provider.

Health Hats: The other part that fits in with the forward-thinking is that each of us is an experiment of one. We're trying stuff to help us feel better, to function better, to have more satisfaction in our lives. We don't use data to help us understand these populations in these circumstances; this worked, this didn't work. We've done the research, and it seemed that A was more likely than B to be effective. But we don't keep going and say, did it really?

Ben Hamlin: Yeah. One of the disruptive things in quality measurement is that in the current paradigm, we distill all these people into individual variables, individual processes, individual conditions, right? None of which are at the patient level or with a patient focus. They're all intermingled. On the quality measurement side, we look at your diabetes separately from your rheumatoid arthritis, separately from your asthma, separately, from your whatever. We have a very narrow focus. If you don't meet that very narrow definition, you're excluded from that measurement piece. So, we're removing patients because they don't meet a very narrow definition. In a forward-thinking quality measurement paradigm, you don't exclude patients; you redirect them to a more appropriate path that's more relevant. This idea of thinking about the individual and the individual's needs versus what generally a population might do overall, like the 80/20 rule: if it's good for 80% of the population, it's probably best for the rest. You can assume that it won't kill anybody, but it's probably it'll give those other 20%. But the reality is we're excluding many more patients from our quality algorithms than we include in many tests because they have a co-morbid right. And in the sort of retrospective individual process measurement, a comorbidity confuses that linear algorithm.

Mutual benefit 14:49

So, what do NCQA, quality measurement, and data management have to do with Person-First Safe Living? *What bridge links them? I live in each of these worlds, as Health Hats, plus I'm a dot connector. A growing number of people in the research, measurement, and provider communities grapple with the logic, ethics, and opportunities present in patient-centeredness. They experience dissatisfaction with the outcomes and spread of their professional work. Proven science doesn't spread or spreads very slowly. Organizations work to improve their measure results (study to the test, game the system), rather than improve the delivery of care the measures are meant to influence. Management of big data doesn't consistently lead to healthier populations. So, some professionals look outside their professional bubbles wanting to enhance and benefit from patient engagement. Ben is one of those professionals. Some of the people, like me, working on this* Person-First Safe Living *project come from Ben's quality measurement and data measurement world. We speak their language. We intrigue them. They need our perspective, our translation skills, and our networks. Do we need them as much as they need us? Let's see. Let's continue the conversation with Ben.*

Data management tools to understand people 16:36

Health Hats: You and I talked in the group of people looking at safe living in a pandemic where we're thinking about starting with the patient, the person, rather than thinking about being patient-centric

after the fact. We realized that there are characteristics, groupings in COVID that have value. Do you have a preexisting condition? Do you live or work in a dense setting? Are you in a high-risk occupation? Do you live in a geographic hot spot? These are not diagnosis-specific but are natural groupings of people in this crazy circumstance of a pandemic. We don't have the tools to break down our analysis by things that makes sense for people.

Ben Hamlin: We do. We just don't use them.

Health Hats: Say more.

Ben Hamlin: I think all of those variables you've discussed are all data about a patient and their personal scenario. In that model where I talked about as we divert patients down a more relevant path for the quality of care, those variables are extremely important in defining what that path for you is. All those variables are important. We have great ways now of understanding which ones are most appropriate. Our ability to crunch volumes of data and create these scenarios that match each person's circumstance best is current technology. There are wonderful predictive algorithms; we call electronic (or digital) phenotyping. (Link to article in the show notes) We create you based on your data, like how we became our data. And there's wonderful science around that. It takes a machine to figure out, to use all that data to put you down that right path. But we're not doing that; your living situation, your ability to access care, your profession, like all those things you just mentioned, are all important variables in that electronic phenotype of you and what you need. We have the technology to develop a quality measure that our quality prospective quality pathway for you, individually. Because we've got all the science and we've got the technology and the ability of the standards that will allow us to do that. But doing that and deploying that into a national quality measurement program is that there's still a huge chasm there between those two things because we're just not, that's what I'm talking about when I'm saying we're not leveraging, we're not using it. No, we're not using those tools. We have the wonderful tools. They're cool. For geeks like myself, they're fascinating. This is why I get up and come to work every day. But it's frustrating that the old paradigm still is what everyone's building their value-based programs off of. They're saying its patient-centered. There's no such thing as a patient-centered retrospective quality program. It just doesn't exist. It's just not possible.

NCQA collaboration 19:40

I asked Ben to tell us more about the direction NCQA is taking to improve healthcare that might be relevant for we activists. You'll hear CMS soon – Center for Medicare and Medicaid Services and Institute of Medicine. IOM is now NAM, the National Academy of Medicine.

Ben Hamlin: In my role now, I'm trying to shift people towards doing this (improving healthcare) digitally and doing this better. The prior model has been that the accreditors come out with their standards and their measures.

Health Hats: Hold on 'accreditors.' What are you accrediting, and what does that mean accreditation?

Ben Hamlin: NCQA accredits healthcare payers, like Blue Cross, Kaiser, membership organizations which provide healthcare, who pay for people's healthcare. That accreditation is based on a complex set of standards for how they provide services and manage their members. Performance is part of that. These organizations must ensure that their members receive high-quality care. They report almost a hundred

performance measures to NCQA every year on their members, which helps us ensure that they are providing high-quality care. Over the last few years, I've been trying to evolve into using an organization like NCQA, which has this national program for health care accreditation and healthcare performance measurement. I think personally and others would agree NCQA is the right vehicle to do so. Measurement information is used by CMS, for example, and used by many payers in their different programs, is used by some States for their programs and Medicaid and other things. It's a great vehicle to try and make change, but it is like trying to steer the Titanic away from the iceberg with a paddle. The big program has its downsides, too. We have been trying to do a much less top-down approach to how we think about quality with a much more stakeholder consensus-based approach. Suppose we are going to deploy these radical new quality measures. How do we ensure that when we deploy them, they really are going to be those meaningful things that we promised they're going to make care better at the patient level? They're more relevant, meaningful to the individual clinicians who are treating these patients? We've developed a new collaboration model that involves the payers who are our primary customers and clinicians and patients and the vendors of information, the data aggregators, the States, the policymakers, and you name it. It's a whole new world. Collaboration is difficult, but if you do it well and you follow the existing models, it can be done, and it can be successful. Before I came to NCQA, I was at the Institute of Medicine. It was two decades ago, but it's this idea of bringing a group of stakeholders to the team to pure problem solve very specific issues on a grand scale. That is, if you're trying to do issue by issue with a group of experts, it's a little easier, but when you're trying to bring in a really large variety of perspectives such as patients and policymakers together at a table as I'm sure you well know, having been in that space for some time. That's where it gets a lot more nuanced. So, we'd be trying to become the facilitator of those conversations to help our experience in consensus-based development of quality measures to help people get to this brand new paradigm of how we suppose quality will become. It's a new role for us. It's taken a lot of work to help people understand what we're trying to do because they're used to us telling them exactly what to do and how to do it. When you start introducing new things, they get upset with us because they're like, 'Oh, but you were telling us how to do it before. Why are you telling us to do it differently now?' It's taken a lot of massaging, and I've learned how to communicate radical new ideas to the bigger world out there. It has been a learning experience for me, as well.

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A collaborative space 24:30
Health Hats: You introduced me to a collaborative space that you're hoping to have different stakeholders, including patients and caregivers, chew on together, asynchronously work on different changes you're talking about. Why should patient-caregiver activists, such as me, be interested in working with NCQA, whose primary customer is health plans and can seem remote to us? What's the pitch there?

Ben Hamlin: As I mentioned before, the consensus model is to get a bunch of people around the table. In the past, I have found that they tend to be within a certain silo, right? There's many different silos in the quality space, and the patients and caregivers are certainly one of them. The thing we're trying to do differently is two things. You're referring to our digital community, leveraging technology for the quality space. We're also trying to leverage these wonderful technologies to help the collaboration piece be much more effective and help break down some of those barriers between those different siloed entities. And being more inclusive and offering a safe space or a collaboration space with a lot of the technologies available to those collaborations. We think the first step is to help break down some of those barriers. Each silo has its own unique knowledge, and unique perspectives and each is equally important in this entire process. They frequently don't understand each other they may be saying the same thing, but they're saying it from their version or their perspective. And I don't want to say we're acting as an interpreter. Still, we're trying to find ways to create a common message and ways to communicate better, creating asynchronous, if you want to call it, collaboration space or creating collaboration space. Using things like discussion forums and frequent podcasts like this and another sort of latest and greatest information sharing helps drive those conversations and work and have a facilitator for each workgroup. It's almost like having your focus group for each idea or issue, but they're all happening together. By participating in all these different conversations, we're also trying to identify things that might be of interest to other groups that they might not have otherwise found out about if they weren't collaborating in a space that's not really monitored, but is facilitated by a bunch of different people, all from with one unique idea. We're seeding information back and forth. Our early versions of this were small. We developed learning collaboratives, bringing together different stakeholders on a small scale. We're trying to up the scale now, and where we're trying to use technology to help us do that so that it doesn't become a management nightmare.

Patient voices – mutual benefits 27:32

Health Hats: I still get back to the 'what's in it for me.' I think there are so many. I agree that connection is important and connection with people who are chewing on similar things and coming from different perspectives is important. There are many forums to do that with varying, effectiveness and tenure, and reputation., For this, NCQA is new on the block. NCQA is not new, as you said, 30 plus years, but again, why?

Ben Hamlin: We're not just doing this to be a convener. I know we're getting a lot of benefit out of this too. Like you said, the payers are our primary customers. But our actual primary customer are those end-users, those patients we don't have access to because we work with payers or we work with the standards developers. So, for us to have access to their perspectives and give them a voice in this very specific environment of quality measure development we're hoping to use this digital collaboration hub to be able to identify what's most important to patients and caregivers. For example, we know we have individual research projects that are working on patient-caregiver issues, social determinants, and all these wonderful things that are happening with NCQA in a different division. But, facilitating a learning collaborative that gives an equal voice, if you will, to payers, to policy people, to the vendors, and to the patients and the clinicians, all as a group. We want to develop a new quality measure around X; here's our idea; here's what the clinical evidence says; here's our ideas based on our experience. But we need to know whether that even makes sense to you. Is this a validity issue? With your experience as a patient, would this give you enough knowledge? Having access as a researcher to that kind of

information is extraordinarily valuable. Focus groups are not used nearly enough in measure development as a way to get the patient perspective. I love doing them. But I rarely get an opportunity. So this is my way of doing an end-run around that to get a digital collaboration community space, where I can have a focus group, and I can ask those questions directly to patients, directly to providers, and use that as we develop this new paradigm. Like I said, when I say equal voice and equal weight to these voices, that's where I think NCQA has the benefit because we don't have a vested interest in the payer's perspective. Like we don't develop things just for them. We develop things to improve the quality of healthcare. Our mission is to do that, including those other people that I don't normally have access to.

What's the pitch? 30:23

Health Hats: You've been talking about why it's valuable to you and NCQA. If there were a vacuum in such forums, that would suck patient-caregiver activists towards that. That would be one thing, but there isn't a vacuum. There are many forums with varying ranges of effectiveness. It seems that you're going to have to be way more proactive in terms of being enticing. I'm just thinking about my colleagues and compatriots in this space. If I talk to them about this and encouraging them to participate, what's the motivation?

Ben Hamlin: Yeah, I should be clear. We're not trying to replace any of the existing conversations or workgroups. We're trying to support those any way we can, too. We've also had some conversations about can NCQA provide a space in this platform for those groups? For example, if you need more resources, we're going to try and help you continue those conversations. Again, knowing what those conversations are even happening is really valuable to us. We can then again understand and invite folks who are having those conversations to either present to other groups in the collaboration space or just do like a podcast like this. We will then post that in our resources section, we then advertise throughout the entire community members to help people be aware of the conversation happening. And so we're hoping that we'll be able to ramp up support those other works. We don't want to recreate the wheel. We're not competing for this space. We're just trying to offer a public utility that will help reduce some of the aggravation of trying to make things happen in this space. I think that's really what our idea is and our goals are; this is not a competitive model for us. We're a nonprofit company. We're not trying to appease our shareholders by getting all the information in one place because I know it's also not going to happen. It shouldn't replace the standards development community. We shouldn't develop the patient care work groups or patient centered clinical decision support workers. I've got that already happening. But I think there's a lot of connections that could be made. And by just again, creating a uniform platform that people can use has resources available for people to use to help facilitate those conversations. But also, to help advertise their work even to other people in the larger community, I think it is a huge value add. So that's why we're, that's what we're hoping to do.

Health Hats: Okay. That makes sense. I like that. I hooked on what you said was creating a utility. That makes sense. It is not easy to find an effective and friendly infrastructure to host these conversations. Yeah. It varies from fair to not so good.

Ben Hamlin: I agree.

Learning what works 33:19

Health Hats: What should I have asked you that I haven't?

Ben Hamlin: Again, I think that the idea behind this is that we haven't found the perfect solution for this either. We've looked at other collaboration work, and we're trying out new technologies and applications that may help facilitate this work. We'll see what works. We'll see what doesn't, and we're going to work with our different workgroups. This is a new way of doing business. This is a new way of us trying to support the healthcare community and the quality communities. Things take time to come to fruition and to get value out of it. But I'm hopeful that people optimistically see the value in this kind of activity. I hope people have been really on board with changing the quality measurement environment from a measurement environment to a quality-focused, end-user supportive kind of thing. We talk about CDS or clinical decision support as a quality paradigm. We talk about evidence generation on the fly, in terms of the COVID knowledge accelerator projects and things like that. People must understand, we're not trying to undermine what you're already doing. We're just trying to make things better for you. We're trying to find efficiencies and make your jobs easier so that we can all get together and improve quality. And healthcare, as a rule, tends to lag in this space. I understand why, but as someone who has close acquaintances and family members who have healthcare issues and serious health issues, it's important that we just kind of keep this rolling as a together mindset and think about the social aspects of what we're trying to do. I probably shouldn't be saying this, but I will anyway, because I can't help myself. But the majority of the digitalization and the quality environment, whether it's the CMS CQM program or even digital HEDIS, have been driven by the vendor community. Even in the EHR vendor space, the quality aspects, the people doing that kind of programming, do not have the vision of social responsibility, perhaps that an organization like NCQA does. So, we have this overarching social responsibility to improve the quality of healthcare. Most of the private companies that are doing a lot of data aggregation see value in that data because the data is valuable, but not in the context of creating a public utility of that data because they have to speak to their shareholders. In this changing quality environment, we have to think about the patient at the center again, but what is the best path towards a socially responsible quality program that will help everybody. We'll help the organizations that are trying to do that, keep the lights on. We have to work; we have to pay our mortgages. So, we had to figure out a model where the organizations doing great work in this space can continue to do. And that's going to require a lot of federal support. It's going to require a lot of private support, public payer partnerships to do this. We all must bring the best to the table. We all must support each other, but this is highly complex, and there's not; there's a huge amount of money in healthcare, but it's a lot of it is wasted. I think we can divert some of that to more effective solutions. And I think that's really what we must try and keep fighting for. So that's my message.

Health Hats: There you go. Thank you.

Ben Hamlin: Thank you. Sure. It's been wonderful. Thank you for giving me the platform to speak like this. I love my bully pulpit if you will.

Health Hats: Thank you so much, Ben. Take care of yourself.

Reflection 36:38
Fascinating. I'm intrigued by change from top-down to the grassroots, patient-centered approach that NCQA is exploring. Yes, giant ships change course slowly. Setting up a small department within a large organization does not mean guaranteed sustainable change. But they're considering and experimenting. As my partner in crime, Laura Marcial, observed:

From Ben, I hear the need to get in front of or ahead of quality by focusing on the right metrics, not just reporting them (including bad or wrong data) more efficiently. I hear people/patients need to be in control of healthcare quality in all of its complexity. I hear that we need to leverage technology to simplify this process while ensuring that this connection between humans and quality is made. The quintessential example here is that outcomes should be a measure, not of life or death, but of reaching some desired goals, preventing comorbidity, or preserving/enhancing the quality of life. To me, this overlaps a lot with both the clinical decision support and trust work we've been doing in terms of shifting the balance back to focusing on the patient by making that piece well understood, defined, and integrated. I also think they share some elements on using technology to support this effort, these connections. In information science, we like to talk about the role technology plays in disruption. It is perceived as <u>reducing</u> human-human interaction when it is probably actually <u>increasing</u> it dramatically.

This minute I sense that they need us more than we need them. Looking at their Digital Measurement Forum, I see nothing patient-facing and nothing person-first. There's a vacuum. On the other hand, I know and trust Ben. My personal experience with NCQA has been positive. They are a not-for-profit, mission-driven organization. I want to learn more about digital phenotyping. That aligns with our non-scientific persona approach to finding answers to people's questions about safe living during COVID-19. I'm about building coalitions, and we need help with our infrastructure. I approach activism as I approach pain management. It's a never-ending experiment. You try stuff. Nothing ventured, nothing gained. If it doesn't work, try something else. I'm inclined to bring up Ben's offer of collaboration with my [Person-First Safe Living](#) *team and see if someone wants to manage the collaboration. Again, collaboration is work. My dance card is pretty full. How's your dance card? Have the energy to join us. Let us know at* info@safeliving.tech*.*