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Proem

I specialize in patient/ caregiver/ clinician/ community partnerships and the intersection between research, technology, and the health journey. This sentence describes the nut of what Health Hats offers. The key word is partnerships. My antennae quiver when I sense a mature, evolving community-research partnership. So, I readily agreed when my friends and colleagues, Janice Tufte and Sneha Dave invited me to attend the SHining the SpOtlight Wide (SHOW) Conference. The PATIENTS Program sponsored the SHOW Conference. The PATIENTS Program envisions a world in which patients and stakeholders are heard, inspired, and empowered to co-develop patient-centered outcomes research (PCOR).



<u>The PATIENTS Program</u> is an interdisciplinary research team of community partners and researchers housed at the University of Maryland School of Pharmacy that works to change the way we think about research by creating a path for health equity in West Baltimore. Our guest, Rodney Elliott, and his production partner, Eric Kettering, reached out to me after the virtual conference. They host a podcast, <u>The Bridge: Your Health</u> <u>Your Voice</u>, at the PATIENTS Program. We decided to interview each other



for our respective podcasts. <u>Here's the link to Rodney and Eric's version</u>. Stay tuned for mine. Same raw footage, very different output.

Podcast intro

Welcome to Health Hats, the Podcast. I'm Danny van Leeuwen, a two-legged cisgender old white man of privilege who knows a little bit about a lot of healthcare and a lot about very little. We will listen and learn about what it takes to adjust to life's realities in the awesome circus of healthcare. Let's make some sense of all of this.

Health is fragile: sports injury. Health Hats: When did you first realize health was fragile?

Rodney Elliott: I realized health was fragile at two distinct times. Back to that part when I said I was playing basketball overseas in Europe, I had a significant injury for one year in Italy.

I was playing, and it was the start of the game. It was a jump ball. I jumped the ball to start the game. A referee didn't move out of the way like they usually do. And I came down on his foot and fractured my ankle. I was out for the rest of the season. It was playoff time, just horrible. I rehabbed all summer, started that next year, and still had issues, so much so that I had surgery the following year. Up until that point, a sprained finger, or a bruise here and there. Nothing major that took me out. It was challenging for me mentally and financially because I couldn't report to the next team. Luckily, I was able to have surgery. I came back, wasn't a hundred percent, but I was good enough, and I could get back in many things.

Health is fragile: caregiver

And the second time was similar to one of the roles you played as a caregiver. In 2012, my mom passed away from lung cancer, but before that, I was one of her primary caregivers, myself and my dad.



Figure 1: Image by Marcelo Leal on UnSplash

That was a year, a moment I'll never forget when I was her number one caregiver when her care went from curative to palliative care. When a doctor said we were no longer treating them for a cure, we were treating and keeping her comfortable, and I may have destroyed something in that room. I didn't want to hear it because I didn't want to know. I was still determining what was next. I couldn't predict it. I just thought that she'd get better or be able to maintain. But the peace she had during this time was another level of strength that I could never imagine.

I needed to say, Okay, Rod, get it together. If she's okay with it, you must find a way to get okay with it. So that was very vital for me. The strength she showed during that time was fantastic. If I had to do it all over again, being the caregiver, I would.



But that was a challenging moment for me. Because I can go back and admittedly say I was horrible at everything else. I was a horrible parent, friend, and student because I was going back to school. Caring for my mom for those couple hours was what mattered to me.

Then that was it. But it was vital because I rebounded after my mom passed, and my time improved. I mended some relationships I fractured during that time and got back on my feet. So, it was a very vital moment back then.

The table setter for the PATIENTS Program through the Bridge podcast



Health Hats: Tell us about the PATIENTS program and your Bridge podcast.

Rodney Elliott: Sure, Danny. The PATIENTS program is the research infrastructure housed in the University of

Maryland School of Pharmacy here in Baltimore, and our overarching goal is to connect two entities: the research world, and the community. When I say community, I'm talking about the underserved community, specifically here in Baltimore, Maryland, but we've grown to work with all of Baltimore, all of Maryland.

We have national exposure now and want to ensure that when community members and researchers get together. We're talking about principal investigators on one side, researchers, and doctors. On the other side, we're talking about community members, stakeholders, and leaders in the community that when they partner for a project, or they partner for a focus group, or they partner for a conversation, we want to make sure that from the researcher's side, you need the input from the community member to make sure your research flow.

And from the community member side, we understand some things that have happened in the past, specifically here in Baltimore, when you throw the word research out.

But for things to change, for things to become better, we need your input. We need you to have a seat at the table. So let the PATIENTS's program be that table setter.



Henrietta Lacks



Rodney is referring to Henrietta Lacks. According to an article in the <u>New York</u> <u>Times</u>:

In 1951, Henrietta Lacks, a Black mother of five dying of cervical cancer, <u>went to</u> <u>Johns Hopkins Hospital</u> in Baltimore for treatment.

Without her knowledge or consent, doctors removed a sample of cells from the tumor in her cervix. They gave the sample to a researcher at Johns Hopkins University, trying to find cells that would survive indefinitely so researchers could experiment on them.

The invasive procedure led to a world-changing discovery: The cells thrived and multiplied in the laboratory, something no human cells had done before. They were reproduced billions of times, contributed to nearly 75,000 studies, and helped pave the way for the HPV vaccine, medications used to help patients with HIV and AIDS, and, recently, the development of <u>COVID-19 vaccines</u>.

See also <u>The Henrietta Lacks Initiative</u> in the show notes.

Relationship between academics and the community

Rodney Elliott: So, we have relationships with academic principal investigators and essential people in the community that when they need each other, the community's input is respected and held up to the highest of integrity the entire time. And the researchers understand that no matter how many letters you have behind your name and how many papers you publish, having input from the community matters.

Listening first wherever we can

The Bridge tries to keep our audience engaged. We found ways to stay engaging with our community members during the pandemic with our social media efforts, and now we've matured into the podcast space. We're always just trying different ways different nuggets to stay relatable, but we also want people to come to our page or our video and stay a little longer.

We turn our listening ears on when talking to and engaging the community. My role as an engagement specialist is out and about in the community. I'm out at community health fairs at back-to-school events, spreading the word about what the PATIENTS program does. When the pandemic hit, we all had a seatbelt. We couldn't go anywhere. We started on our social media page with Real Talk with Rodney on Facebook, and we had another segment called BJ's Corner, an engagement team.

It's two of us out and about in the community. So, we had two different opportunities to engage with our community on social media to talk to influential community members like yourselves, some researchers, and some community members to keep that connection going.



Internal marketing

When we couldn't get out and about, we graduated to this podcast. We talked to our supervisors and executive director about this excellent opportunity to stay connected, engaged, and innovative. This is where the exchange of information, thoughts, and ideas goes into the podcast space. I found that through the podcast, we have the ears of our community members, researchers, principal investigators, and different entities that understand the importance of sharing the word or your opinions and thoughts in a meaningful way, but also easy because I can send a link now and click it and boom, you can get it right on your phone. You're walking your dog. You can listen to it. I listen to my podcast when I'm driving in the car. I may even take the long way home to listen to the podcast in the car, folks, listen to it in the gym. So, we're more accessible now. That helps us out a whole lot.

Plug

I need help. I've expanded my podcast this year to include video, and costs have surged., while each episode takes 30 to 40 hours to produce. With growing content and shrinking bandwidth, I need support to keep creating without impacting our retirement funds. Thank you.

As I look towards the next 5-10 years, I'm building a production team of emerging adults to carry this project forward. This succession planning requires resources. But here's the deal: you can help.

Visit <u>health-hats.com/support</u> for ways to contribute. Best option? Patreon offers a monthly subscription with bonus content, Zoom meetings with me and fellow contributors, personal Bari Sax MP3s, coaching sessions, and more.

Occasional donations are welcome, and you can still subscribe for free to enjoy bonus episodes. You can also recommend us through email, social media, or postcard - postage on us! Visit <u>health-hats.com/support</u>. Your support is deeply appreciated.

Peer into the future – a year

Health Hats: When you think about your program here, pick your role in the PATIENTS's program or your podcast. Where do you want to be, say, a year from now?

What do you anticipate in terms of your growth in this work?

Rodney Elliott: That's a good question because if you had asked us pre-pandemic, would we be doing stuff on social media like we're doing now? The answer would be no. But again, we had to pivot. If I'm looking next year to see where the Bridge is going or how the Bridge can grow, I would love to speak to more people like yourself. People who wear many hats can give their perspective on life or share their experiences in a way that someone can receive, whether through our podcast or a recording.



Right now, we're all audio, but hopefully, by this time next year, we'll have the opportunity to sit in the living room or sit in someone's office or go out and meet them and have a conversation with them because as convenient as this is over Zoom, there's just something about that personal engaging because it's, that's what I missed when I couldn't go out during the pandemic. I missed it. I do not go to the bingo sessions at the senior care community center because that's where I had the opportunity to sit down with Mr. Johnson, Ms. Jenkins, and Ms. Regina and have conversations about what's going on with them and their family, but also share what the PATIENTS's program is going on now.

I would love to speak to other principal investigators or researchers who might need help understanding how important community engagement is and meeting the community where they are. If it's on a podcast, that's a crucial part of your work. If it's a personal interview where Eric and I can have a camera and talk to someone, that's important.

If I understand your busy doc, we can come to you. We can come to your office and have a conversation. We're all from meeting the community where they are. Literally and figuratively, but 2020 showed us that you must find a way to be flexible. It would be best if you found a way to be convenient but stay within how things work. Having a conversation with someone in person works. It always does. That's some of our goals for next year going.

Genuine, authentic, transparent, humble

Rodney Elliott: It's authentic. That's one of the most important things about the work that we both do. At the PATIENTS Program, we try to be authentic and genuine. So much so that if there's a question or something from the community members and we don't have an answer, we don't answer it and let them know I don't. Let me get back to you. Let me stay in contact with you. At the same time, we try to let our community, research, surgeons, and administration on that side know and say the same thing. It's okay not to know. Where you mess up is, or where you ruin the relationship, if you sugarcoat it.



Figure 2: Image from https://tshirtconne ction.org/products/ playmaker-nextplay-mentality You try to tell them, tell the community members what they want to hear, instead of just keeping it real and being transparent. We've built and sustained some of our best relationships with community members and researched others by being authentic, transparent, and accurate.

That's why, again, I don't talk about other community-engaged entities out there, but I talk a lot about the PATIENTS's program because I believe in what we do. I believe in how we do it.

Next play mentality

We also have a great way of having the next-play mentality. That's a sports reference. I was a coach, and if I was coaching a kid who messed up on a play, he

put his head down and didn't get back on defense. Dude, you can't do that. You have to have the nextplay mentality. You have to keep going. Then the next play mentality to me is it's okay to make a



mistake, or it's okay not to do well or not to succeed or have an error. But what's best is how do you follow that up with what do you, how do you follow that up?

Rodney Elliott: That's what I was thinking. I'm trying to think of analogies that I can use to go with that. The one that pops up the most is my high school teammate, who told me this years ago. We wound up being college teammates after that as well. He said going hard makes up for many mistakes. This was a basketball analogy because on the basketball court, unlike in individual sports or talent, like being a musician, yeah, you need your other band members to help, but you guys can figure that part out. In basketball, you can still contribute to the team and the goal if you're not the best shooter or the best, strongest, or tallest guy. You have to go hard at it, however. Going hard makes up for many mistakes. The repetition part you talked about, I'm going to bring that back to what we're doing there, here at the podcast.

I listened to my first social media episode I did live on Zoom not too long ago on social media to where I am now. And man, total difference. My first podcast recording of where we are now. Total difference. I can even hear the comfort that I have communicating and talking. I still get nervous before, which I like because the butterflies let me know I'm still it's still interesting. But yes, you're right. You have to be consistent. You have to be steadfast. You have to be a great listener. I've also learned to be a better listener during these podcast sessions. And. In the future, that will help me be a better podcaster, a better host, whatever you want to call it.

Podcasting communities

Rodney Elliott: Eric and I got invited and are going to the podcast movement in Denver coming up in August for the university. We were chomping at the bit, excited about learning about podcasting and being in that space. So, we can continue what we are doing now and evolve into better producers, hosts, and communicators because this isn't going anywhere. The way people perceive information and communication is going nowhere. And we want to be a part of it. So that's what's next for us regarding growing the podcast. You know what, that's a great way to end this show because that is something that we're learning and trying to figure out as well as we go.

Intern

Last week, one of our former interns was here with the PATIENTS program return. To say hello to everyone. He interned with Eric on the producer side, and now he's graduated from college and writing for a social media platform here in Baltimore. And he shared one of his stories that was produced. He had a small segment on a local news channel talking about it. It was interesting to see him grow from where he started with us to where he is now, and we will be picking his brain, so to speak, on how to communicate. This publication he's working for now in Baltimore, <u>The Baltimore Banner</u>, is online. It's an online publication, and they have a way of all over social media. They're all over, they're on. I'm not sure they have a podcast right now, but they're finding ways to stay connected and relatable to a little bit of everyone I'm talking about.



From college to talk about topics near and dear to some seniors or older adults here in Baltimore. As always, Dan, you drop jewels every time we talk or share an email. I appreciate it.

Health Hats: Thank you. Likewise, I am interested in continuing to follow your work and happy to stay connected. This has been lovely.

Reflection



Up to now, my podcasting community included only self-produced, selfowned podcasts. Some episodes of Health Hats include community partnerships, such as <u>Community/Technology Partnerships @ Health 2.0</u>, <u>Embedded Researchers-Translators, Connectors, Stewards, Communities</u> <u>Advancing Equity through Shared Measurement</u> among others. The Bridge is the first podcast I've experienced originating from academia and a research/community partnership. I asked Rodney and Eric to join my mastermind Reckoning group, where we review each other's podcast

episodes. I thought the different perspective to be valuable for the broader discussion.

Highlights for me in this episode were *next-play mentality*, appreciating failure; *unexpected benefits* from the pandemic shut-down; *internal marketing* with an academic department; and *table-setting* to bring community members to the research table.

Rodney and Eric thought I had a leg up on them as I've produced longer. I think they have a leg up on me with partnerships. Win-win.

Podcast Outro

I host, write, edit, engineer, and produce Health Hats, the Podcast. Kayla Nelson provides website and social media consultation and manages dissemination. Leon van Leeuwen edits the transcript. Oscar van Leeuwen edits the video. Joey van Leeuwen supplies musical support, especially for the podcast intro, proem, and reflection. I play Bari Sax on some episodes alone or with the Lechuga Fresca Latin Band. I'm grateful to you, who have the most critical roles as listeners, readers, and watchers. See the show notes, previous podcasts, and other resources through my website, <u>www.health-hats.com</u>, and <u>YouTube</u> channel. Please subscribe and contribute. If you like it, share it. See you around the block!

