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Introducing Wesley Michael 00:50

I attended yet another session with healthcare experts, where I heard clinicians and academics say, “we’re all patients.” If I spoke to them as Patient Smith rather than Dr. Smith, would they embrace their inner patient? I don’t know. I didn’t test it. Lived experience takes many forms - advocacy, coaching, expert panels, advisory panels, informing research and more. Many patient experts and advisors struggle with the tension of receiving payment for their lived experiences. What’s the value if their expertise is successful living with a medical condition? What if they were business, marketing, advocacy, policy consultants without lived experience? What would they be paid? What’s the value of this combined expertise in the market? Wesley Michael, a marketing entrepreneur, founded a company, Rare Patient Voice, to offer companies and researchers panels of rank-and-file people with lived medical experience to inform product marketing and participate in qualitative research. Rare Patient Voice pays patient-participants a flat hourly rate. Before we listen in on my conversation with Wes, I’d like to respond to those of you that have asked about the music on my podcast. My cousin, Joey van Leeuwen, provides me with all the music I use including the backing you hear now. Joey is a brilliant, talented New Orleans/Boston percussionist, composer, and arranger. Stay to the end of the episode to hear one of the tracks of his that I use. I will share other tracks in subsequent episodes. Thanks for asking. And now for the chat with Wes.

Health Hats: Good morning, Wes. Thanks for joining me.

Wesley Michael: It's great to be with you, Danny. This is exciting.

Health Hats: How do you introduce yourself in a social situation?

Wesley Michael: I have a new six-month-old grandchild. So, usually, it's all about that. I'm the grandfather of Taylor. Otherwise, I was the father of. It's never about me.

Health Hats: You'll see on my business card, one of my credentials is OPA, which is grandpa in German and Dutch.

Wesley Michael: I was wondering what that, I thought it was some sophisticated, educational thing.

Health Hats: Not at all.

Wesley Michael: In your introduction, you talked about cisgender. I had to look that up. Well, I'm cisgender, too.

Health Hats: It just means I'm straight. I do that because I'm interested in health equity, and I need to lay out upfront that I'm a two-legged, cisgender, old, white man of privilege. So, people know where I'm coming from.

Wesley Michael: That's fair.

Health Hats: If you're in a professional situation, how do you introduce yourself - not as grandpa?

Wesley Michael: Sometimes, that may happen, but typically, it revolves around the business, which is Rare Patient Voice. I'm the president and founder of Rare Patient Voice. We're a market research firm that works with patients and caregivers to allow them to take part in surveys and interviews and things like that.

Health Hats: What's your professional background?

Wesley Michael: I've been in market research for many years. I used to work in the consumer area for General Mills: Wheaties™, Total™, Betty Crocker™, those products. I also worked for McCormick, the spice company, in marketing and market research. Then 20 years ago, I got involved in the healthcare arena. It's been fascinating because a lot of these companies will try to apply some of that learning, but it's similar, but different as well. I've been working for different companies, but in market research, what are people thinking and why?

Health Hats: How did you make that leap from Wheaties™ to healthcare?

Wesley Michael: The timing was very good in the 90s when direct-to-consumer ads we see on TV with the horrible side effects became legal. All these pharma companies could be more expert and talk one-on-one with a physician and try to push their pills knew nothing about people, consumers, patients. So, they said, "we need to learn about this." That was a natural leap for me. That was my area. It was interesting to talk to these companies that were so smart about one area, but so ignorant about the other area. Then over time, not only have they gotten better, but, thank God, people have realized it's not just about the doctor prescribing something. It's about the patient. They're smart. They look things up. They have alternatives. People realize they must bring them into the party. Took a while though.

Market research from Wheaties™ to healthcare 06:34

Health Hats: Did you go from Wheaties™ to healthcare and founding Rare Patient Voice, or was there an intermediate step?

Wesley Michael: I worked for 20 years or so for healthcare market research firms. The funny thing is, one of the first clients we had was in the hemophilia space -a very small number of people have it. We were asked by a company, "Hey, this is very important to us, but we don't know much about the patients at all, could you develop a hemophilia patient panel and caregiver panel? And then we can from

time to time do interviews and surveys and learn about them.” So, we said, hmm and went to the [National Hemophilia Foundation](#), set up our table. We had giveaway items like little airplanes and silly putty. It was mostly young boys because the whole generation had been wiped out with AIDS. It was before they knew what was going on in the blood supply. So, we signed folks up. It wasn't even on the internet. It was paper and pencil. It worked out well. We got people that were interested in sharing a voice, and then from time to time, we did surveys and interviews. A few years after that, somebody came up to me and said, “I hear you have this wonderful hemophilia panel. Can we access it?” I said, “No because it's proprietary. It was developed for a client.” But it got me thinking, “I wonder if there's a business in this.” I kept telling my wife, “someday, I'm going to do this.” Over the years, I kept seeing the growth and people interested in patients and the difficulty in finding them for surveys and stuff. Then everything came together for me. It was six years ago when the company I was with was having some trouble. The timing was perfect. My wife had been out of the workforce for ten years raising our kids. She had just gotten a job and she had healthcare insurance. It's all about health care. It was perfect timing. What was the first thing I did? I went back to the hemophilia conference because I've been working in that category for years. I knew there was a demand. I knew it worked because I had done it before. Now we've got 400 diseases and 100,000 people. Last year we did a thousand studies. I knew there was something there. I didn't know how much. We do studies in every category - a hundred a month or more.

Health Hats: Are most of your clients pharma and academia?

Wesley Michael: That's a good question. Indirectly, it's pharma. Directly, it's other market research companies. They're working in turn for pharma, device companies - wheelchair studies, for example, and academics. One thing we like to do is fill requests from Ph.D. students. As part of their thesis, they need to do a survey. We work pro bono for them. They're so excited. The difference is if you're a Merck or Pfizer, their surveys are top secret, and nobody sees them. That's their marketing advantage. But when you're a student, they want to publish. So, we'll say, “you may not be able to offer a reward to people, but you can offer a summary of the results.” People are excited to do that. We're happy to do that. But, most of the studies are for other research firms. They write the survey. They're all set to do the interviews, and they've worked with their clients. They go, “Oh my God, how are we going to find these people?” Then they come to us and we do that one piece of it. We're the middleman or matchmaker. They're doing a study in this disease area, we have folks interested in doing a study, and we pull them together.

Diagnosis-based experience brokers 10:11

Health Hats: How do you differ from [WEGO Health](#) and [Savvy Coop](#), other lived experience brokers? I don't know if that's a term.

Wesley Michael: We love them and work with those companies as well as others. The big difference with WEGO is that they're best known for the patient advocates, the leaders in the area. They'll find those folks, and they invite them to the party. While we may have some of those, we're not intentionally going after the leaders. We're going after the rank and file. We'll go to events and find folks and people will refer others. Typically, our clients are looking for the run of the mill, the day-to-day patient or their family member. So, we complement each other. Sometimes we'll get a request and we'll say, “Oh, that's a WEGO request.” Savvy is interesting. They're somewhat similar, but we have different approaches. Our

approach is that we go out to the patient events to find folks. Then those folks refer others. Savvy is letting people buy into, own, a part of that. I think it's a terrific approach, but I've already put my own money into this. I'm not asking for your money. We reward. It's similar but takes a different approach.

Health Hats: When I signed up with your panel when we built this bridge, I noticed something that I notice with WEGO, too - it's heavily diagnosis-based. As opposed to mobility-focused or cognitive or function focused. I didn't see in your signup stuff where you would be collecting those characteristics or pain that are cross diagnoses.

Wesley Michael: That's an interesting question and aspect. A huge majority of the requests we get are built around a diagnosis. If you think about it from pharma's viewpoint, they're working on a new treatment for a certain thing. They want people diagnosed with that. If they are doing a clinical trial, you need people for that diagnosis.

Health equity? 12:57

Health Hats: When I looked at your website, one of the things I looked for was something about health equity. As I researched you guys, I felt a strong health equity bent. But I don't see anything about that on your website. I wonder how you manage this idea of broad representation.

Wesley Michael: I wish there were more that we could do. We make folks available. The role we play is simply bringing people to the party to tell their stories. Back when Reagan was president, he often cut programs and people got upset. But then he would meet an individual with a problem. He wanted to know how to help this person. It was all about the individual. When you're talking in generalities, it's easy to say, "let's cut some programs." When people come and do an interview or do a web thing, and if that gets to the right people, that can influence some executive in some pharmaceutical company. How do we make this available? Listen to this person, they need to get it and their insurance won't cover whatever it might be. It's an indirect effect. I can say, I wish we could do more, but I think by having their stories get out there to these corporations, it may have that same effect.

Health Hats: If we're thinking about the very simple male versus female, rural versus urban, indigenous versus immigrant versus whatever. I know that in the work that I do, for example, with PCORI in terms of thinking about the research and the equity of having broad representation at the table. The challenge of research being often done with readily available populations. Can you speak a little bit more about that?

Wesley Michael: It starts with us going to the various events around the country. When I started, I was flying around to different places. I went to the MS walk in Albuquerque, for example, and that's great. But I can't go everywhere. I can't be everywhere. Over time we developed a team - our patient advocate team. They'll go to events in their own areas. We pay them as part-time employees. We covered 350 events last year. We're able to go to these all over the country, and we reach different demographics. We'll go to Houston. We're not set up, unfortunately, to recruit in Spanish. Oh, we're happy to get people that are bilingual. Then we were at such and such event in Houston and we got a lot of Hispanics. We'll do a lot of work with sickle cell or HIV, where we get broader representation. We ask patients themselves, "do you know anybody else?" We reward people if they refer others. We don't ask them to give anybody's name. They go to that person and tell them, and then they can come to us. That helps spread the word. We'll go to different groups or support groups, and it is blanketed out. We've never

done an event in Montana, but we have plenty of patients in Montana because somebody knew somebody who knew somebody. We have a person who's good with social media. We don't just post on somebody's site, that's a good way to get in trouble. But she'll call them and explain. Then they'll post on our behalf and then suddenly we'll reach out to all these people that we wouldn't have otherwise met.

Now a word about our sponsor, ABRIDGE.

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Waving a magic wand 17:50

Health Hats: If you could wave a magic wand and change a couple of things in healthcare today from the perch you're at, what would you want to see different?

Wesley Michael: Two things come to my mind: They both start with A: access and awareness. Access, obviously - people can't get the treatment they need. It's bad enough when there's no treatment at all and they're working on something, but when there is one and somebody can't use it, that's crazy. But awareness fits into that. People have a long time being diagnosed. Some of that is a lack of awareness by the physician. They're not trained in a rare disease. They're trained in the zebra theory where physicians are taught, if you hear hoofbeats behind you, don't assume it's a zebra. Assume it's a horse. Assume the common, which was logical and makes sense. But there are zebras. There are rare diseases and sometimes nobody puts two and two together and gets to the zebra. So, raising awareness from the physician's side and the patient's side. Many of our patients come through advocacy groups. We found one key issue is that many are not aware of their advocacy groups. If you work for it, you assume people know, but they don't. My brother-in-law had serious kidney issues. My wife was working for the National Kidney Foundation. He didn't know that the Foundation had things that could help him. It's awareness of what's available right in front of you. One of the guys on our team, Kirk with MS always advises folks – there are ways you can get a wheelchair if you work with this group. He's a master of finding available things. It's all about having the awareness that somebody out there might be able to help you. Don't sit and suffer in silence. So, those are my wishes.

Paying for lived experience 20:03

Health Hats: What are you most proud of in your work?

Wesley Michael: We sign every email; we change it three or four times a year. We say we've rewarded patients with \$4.1 million for taking part in surveys. Most people tell us it's not about the money. Money's nice. It's measurable. They'll get \$100 here or there, but they'll say, "Oh my God, that helped me through a tough time, or it helped me do some things, or I'm on disability" or that kind of thing. So, in a way, we're Robin Hood, taking from the rich and giving to the poor. It's a win-win for everybody.

Health Hats: I find in my work that it's hard to get people to include paying people for their lived expertise, to get it in their budget upstream. They'll say, "Oh, we don't have money for that." It's probably awareness that it could be in their budget. They certainly budgeted for the principal investigator. They didn't forget that.

Wesley Michael: In our work, we tell patients we'll pay at the rate of \$100 an hour. An hour phone interview is \$100. There's a benefit for the client, the sponsor because you don't respect stuff that you don't pay for. We pay, let's listen to what they have to say. I think you're right about that. They'll respect it more because they're paying the physician \$300. Respect patients' time and insight. They have put a dollar value on it or we put a dollar value on it and they paid it.

Focused and growing 22:16

Health Hats: You said earlier that you're looking for the person on the street. When you were comparing yourself to WEGO, you said that you weren't necessarily looking for the advocate, the person who's done a lot of research themselves. You're interested in the lived experience. How does what you do help the average person directly? Is there a part of your program that's building skills for your panels or are you trying to stay out of it?

Wesley Michael: We do the one thing and we try to focus on that. Some sites are terrific with a lot of content and help. We haven't done that. Some places have people writing content. We have a Facebook page where we'll share things. I love to share articles that I find, a radio program or TV spot; we'll put it on there. But for the most part, we're offering just the one thing: the opportunity for people to voice their opinions and talk truth to power. Get it to the folks that are coming up with treatments that need to hear from the people that are going to be using it or taking it. I don't want to overclaim everything we do. I think people love it. We get so many people thanking us who feel like they're helping those coming after.

Health Hats: When you look a year ahead for your company, where are you seeking to get to next?

Wesley Michael: We're always looking to grow what we have with more folks in more disease areas, and we're always finding more clients. The more requests we have, the more we can put out. We have four hundred and some clients, so we're always doing that. But also, we're looking at new areas. We're just starting to get more involved in clinical trials. We certainly wouldn't tell somebody to do them, but we could bring it to their attention and ask them to talk to their doctor. We're just in the US and Canada now, so Europe seems a next step.

Caregivers sharing their voice 24:37

Health Hats: Is there anything you'd like to ask me?

Wesley Michael: I was curious, in your talks with folks across healthcare, if you're hearing anything about people wanting to get more involved in sharing, getting their voice or doing research or is that below the radar.

Health Hats: Oh, no. People are interested in sharing information, and that works both ways. People want to get their own health data more. They want to contribute their health information into the medical record. But they're also interested in having their experience have value. I think that all of that

is quite top of mind. Patients and caregivers that are dealing with acute stuff are buried trying to manage their selves, their families, their jobs. So, no. But once things start to stabilize, they're looking to contribute whatever they've learned from their tragedy or challenge to benefit others. Once they start to regularize their dilemma. I don't know if I'm saying it well, but when you're in the middle of it, it's all you can deal with. I've started to see that people are paying for respite care for caregiving so that caregivers can participate for an hour or a half a day or a day. I'm seeing some movement towards thinking about that. I feel like, okay, now somebody's getting it.

Wesley Michael: Exactly, the poor caregivers, Oh my God.

Health Hats: Sometimes caregivers know more than the person who's got the diagnosis. They're dealing with the whole constellation: transportation, finances, support systems. Wes, thank you very much. If there's anything I can do for you, let me know.

Wesley Michael: You've already provided me with this wonderful headset, so I'll be thinking of you. Isn't that good? Thank you so much. I appreciate it. And then, I'm glad that you've signed up. Give any feedback that you have, or you get.

Reflections 28:13

I mostly work in the bubble of health advocacy, policy, measurement, research, products, software, academia, and of course, communication; hence Health hats, the Podcast. I am a member of WEGO Health and Rare Patient Voice and an owner of Savvy Coop. I have had brief gigs with each. They're different and I'm grateful for the variation and the opportunities. I consider them gateways into paid work for lived experience. Next week we'll hear from Keith Scott, Vice President of Peer Support at Advocates, Inc., who taught me much about another lived experience universe. Thanks for joining me today. Stay to hear some music from Joey van Leeuwen.

Joey van Leeuwen "Up" 29:28