

Contents

Opa as credential 00:55 1

Labels: Patient, Person, Expert 01:51 1

Introducing Janice Tufte 05:20 2

Co-Investigator 05:50..... 2

Patient Partner 08:11..... 3

Reflections 10:50 3

Opa as credential 00:55

Boston Children's, a Harvard-affiliated Hospital, seemed credential obsessed when I started working there. While setting up my email account, I entered my credentials as Opa, RN, MPH, CPHQ. *Opa* means grandpa in Dutch and German. Opa is my most important credential. Might as well be first. During the four and a half years working at Boston Children's, only one person on the inside ever asked me what Opa meant. Almost everyone on the outside did. Many Googled it. They came up with: Office of Professional Accountability, Office of Pharmacy Affairs, Online Public Access, Office of the Patient Advocate, Oregon Paralegal Association.

Labels: Patient, Person, Expert 01:51

As you know, I'm Health Hats. As my business card evolved, I've used the titles - Owner, Consultant, Principal, and now I use the title, Person. Often, I'm the only patient in 'Patient-Centered' projects, the one patient advisor or stakeholder on a team. Granted, I'm also a clinician and have solid academic credentials. In those settings, I do want to be identified as a patient - a Patient Expert - rather than a clinician or an IT person. On the other hand, *patient* is a role, often a subservient role. In life I'm not often a patient. Mostly, I'm a person, a citizen. So, I started referring to myself as a *Citizen* Expert. But what about people who aren't citizens? I don't want to exclude immigrants and other non-citizens. The labels, Patient and Expert, don't often go together. The contrast of the two words appeals to me.

A label means something. Labels and self-identification are not the same, yet they overlap. They can offer shortcuts in communication or barriers. For example, I'm a person with disabilities. I'm not a disabled person. People self-identify. Usually, they prefer words labels that feel equal, recognize value. Partner is co-equal. Co-anything feels equal.

My multiple sclerosis is progressing very slowly, but it's progressing. My neurologist prescribed an infusion twice a year that costs \$100,000 a dose. I asked my neurologist if I needed to get it. I understood every word he said. But my brain couldn't put all the words together. Thankfully, I had my Abridge recording app turned on. I had pushed the big pink button. I went home. My wife and I listened to the transcription several times. We decided it was worth it. I'm grateful that we could take time to make an informed decision. Thank you Abridge. Abridge was created by patients, doctors, and caregivers. Check out the app at abridge.com or

download it on the Apple App Store or Google Play Store. Record your health care conversations. Let me know how it went!"

Introducing Janice Tufte 05:20

I'm delighted to speak with Janice Tufte about how she has been identified as a patient when participating in her many health-related advisory roles. Janice does Health systems quality improvement work, on local to national levels. She serves on technical expert panels, works with measurement recommendations and guidelines. Janice is a thought leader focusing on disparities and social determinants of health. Janice invited me to moderate a panel for the Society of Participatory Medicine Conference. We spoke after that conference.

Health Hats: Hi, Janice. Thanks for joining me.

Janice Tufte: Hi Danny. It's so nice to be with you today. Thank you for asking me.

Health Hats: We've been talking about being a patient expert; being a patient stakeholder; sitting on different advisory and teams. What's been your experience serving as an advisor? How have you been identified, and how have you self-identified?

Co-Investigator 05:50

Janice Tufte: Thank you for asking that. There's a lot of different names or identifications that we could go by. I originally was involved as an advisor at the health system where I'm involved, and we provided input at Health System-level and then I was a regional advisory assembly. I was a member of that. And then I went in to be a patient co-investigator on a research project, which is one of the first in the nation nobody. They're like, what does that mean? Principal investigator is usually the primary individual. We had two patient co-investigators at that time identified in that role.

Health Hats: The Principal Investigator is the boss of the research project?

Janice Tufte: I extrapolate a little bit, so they came up with that position, but we had a principal investigator who oversees the whole project and then either has different levels of within the team and then us two Patient co-investigators that brought two different skill sets and knowledge to the research project. So, I was more involved with resources that I knew that was locally available, and the other individual had worked in corporate. And so, she brought more of that corporate sense. It was very interesting to see our different views on the research project, and we did publish as patient co-investigators. And this was very early in our PCORI project. So yes, it was very interesting, and that term now is used

Health Hats: So how about when you're involved in a community project or a corporate project, and you're there as a patient stakeholder. How does that work?

Janice Tufte: There's been a variety of ways. And as you mentioned early on about the patient or a patient expert is. One of the possible terms we might use if one of the first technical expert panels. I didn't know what I was doing at the beginning and measurement development it we were termed subject experts, right? We were subject matter experts (SME). SME is widely used in the measurement

and evidence world. As a patient or member of the public, you can understand the subject from a different level than the scientists and researchers.

Health Hats: Like lived experience?

Patient Partner 08:11

Janice Tufte: Some of its lived experience, but some of it isn't. For instance, for that particular project, I was working in certain domains like beneficiaries with complex needs or with substance use. The specific areas didn't apply to me, but I had worked with health care for the homeless. So, I understood the dynamics. I consider myself a patient partner where we could be working in a large health system, or academia, or research institutions. Often there's only one patient. People identify me or call me a patient advocate. I don't identify as a patient advocate. As a patient partner I consider that we were partners, equal partners. I was very fortunate that the first time I was ever involved as a patient participant, they look at us as equals. So, I consider myself a partner and that's how I identify.

Health Hats: I like that. I often identify myself as a patient/caregiver activist. I'm trying to promote the voice of patients and caregivers and the experiences and the needs of those communities. But does it matter? Sometimes it does. One of the things that I hear you say is about the power dynamic in the terms. *Partner* and *Co-xxx* are strong

Janice Tufte: Linear or parallel.

Health Hats: As opposed to up and down.

Janice Tufte: I'll talk a little bit about advocate. I was asked three or four times at this conference, "what group are you from? What's your disease?" I said that I don't identify with any one health disease. I came in through Health Systems Improvement. I believe that we can improve how our system serves us as patients, public members, community by bringing our voice in. If we're not there in the decision-making process, in the core design process, and or providing input it through the whole process of whatever is in development – city, state, federal, or institutional level. If our voice isn't in there, then perhaps whatever process is being implemented, is not going to reflect the population that it's serving.

Health Hats: Thank you. You're welcome.

Reflections 10:50

When my grandson, Leon, was six, he and his dad intensely studied dinosaurs. Jokingly, I said to him, "Your aunt is an herbivore." No, Opa, she's an omnivore." "But Leon, she's a vegetarian." "Oh, Opa, she CAN eat meat. She's an omnivore." Leon was the expert at that table. Experience, education, skills, behavior all feed expertise. In my grandson story expertise has nothing to do with age or credentials.

In the conversation with Janice, we highlighted Patient Expert, Patient Partner. Co-Investigator, Subject Matter Expert, Patient Advocate, Patient/Caregiver Activist. The key takeaway: Whatever you call us, invite those of us with different and unique experience, skills, and circumstances to sit at decision-making tables. Then treat us as equals and respect us. Then do something with what we offer.

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