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Introducing Liz Salmi 00:59

Making health choices and decisions and communicating health information as we learn on the journey toward best health: my mission in life in a nutshell. Nowhere have these merged more strongly to support the clinical relationship between regular people and direct care clinicians than in the [OpenNotes](#) movement. *Everyone on the Same Page*. OpenNotes is the international movement promoting and studying **transparent communication in healthcare** helping patients and clinicians share meaningful notes in medical records. OpenNotes fosters trust, control, and connection. For me, Liz Salmi personifies the OpenNotes crusade, a regular person with passion, smarts, charisma, and endurance. I’m delighted to have her as a guest today. Listen especially to Liz talk about the community organizing aspect of change management and implementation of evidence-informed innovation. Liz inspires me.

Health Hats: Liz, it is wonderful that you could join me today. I've been excited about the opportunity to hear about what you're doing and pick your brain. I was trying to remember when we first met.

Liz Salmi: Thank you for having me on the podcast. Super excited. I think I first saw your name on the Society for Participatory Medicine message board and then through the Twitters or other platforms. But I believe we met in person in real life at the first Society for Participatory Medicine, SPM, conference in Boston. I want to say 2017, 2018ish.

Health Hats: So why don't you introduce yourself. Pick any slice of yourself that you want to introduce?

Liz Salmi: I'd say an appropriate introduction would be related to your podcast title of Health Hats. I think I have a lot of hats going on. I'll introduce myself in this way. Hello, I'm Liz. I'm some random person from the internet. I'm also a person living with a malignant brain tumor diagnosed in 2008. My background is in communications. I've always been fascinated by how you take something complicated and then making it easier to understand. That's how I approached living with brain cancer with no healthcare background over the last now 12 years. I still identify as a patient for sure. You become a

volunteer if you become active in patient advocacy. So, I was a volunteer, an advisor, on various boards and eventually started working in healthcare in palliative care, advanced care planning, end of life care with a nonprofit organization, learned to speak a little bit around medicine and work with clinicians.

From brain tumor to OpenNotes 04:12

Fast forward to today, I now get to work in academic medicine with Beth Israel Deaconess Medical Center on the [OpenNotes Project](https://opennotes.org), which is at opennotes.org. Go there. But long story short, it's a research team that's been studying the concept of patients having full access to their medical records, including their clinic notes, for the last ten years or so. When patients have access to their clinic notes, benefits happen. They can remember what happened at the visit, possibly better understand their care, and maybe even trust their doctors more just from the concept of having openness. I've gotten into this new world of patients involved in the design and conduct of research, and I've been learning more and leading the way, from the brain tumor community side, on how we can get more folks living with brain tumors their care partners involved in research.

Health Hats: When you say, 'involved with research', I assume you're talking about all participation levels from governance to being part of a clinical study?

Liz Salmi: Yes, thank you for clarifying. I don't just mean being the subject of research, but in the Patient Centered Outcomes Research Institute or [PCORI ethos model](#) of patients and care partners involved with picking which questions to explore in research for folks impacted by brain tumors; or working with the researchers on the design of an intervention; or working with researchers to interpret the findings from the research; and working with researchers on the publication of those results in academic journals and so on, so forth.

Moving mountains - from dissemination to implementation 05:52



Health Hats: Wow. I want to pick at a bunch of those things. I had a conversation the other day with some PCORI folk, thinking about the dissemination that leads to implementation. So, spreading the word that leads to research results being part of workflow and life flow. We put all this effort into the academia and clinical dissemination - journals and conferences and stuff like that—so much a partnership. Yet, I don't know that we're very good at it. And when I say we, I don't just mean researchers - because frankly researcher usually stink at communicating to the lay public about research - but I think that even those of us that are involved in

research and live in the lay world are not that good at communicating and sharing those results to the people who are going to use them every day in their lives. So, what's your take on that?

Liz Salmi: Oh, research dissemination communication and science is the most important thing, and it's hard, like you said, that the researchers aren't necessarily trained to go out and spread the good word about research. I was hired by the OpenNotes research team to focus on research dissemination and talking and communicating about the research. Early on, I was not one of the researchers on the team. I

am today, many years later, but how do you talk about it? One of the things I learned about OpenNotes is that it's a major culture change for clinicians, especially physicians and staff to share their notes hidden from patients unless they made the full medical records requests but were not as easy to access. When we shared our research at conferences and through journal articles, as you said, clinicians would read those articles and say, 'yeah, but this isn't for me, or my patients won't understand these notes, or it's going to increase my workload.' Then we would say, 'the research shows that this is not going to happen to you, and all these great benefits are going to happen.' And I thought, slightly naively as a patient working with this team, 'screw the clinicians, let's just talk to the patients.' We're going to have this patient movement where patients will ask for the notes and go to their hospitals' meetings and say, this is something we want. That was the research dissemination strategy we were behind for the first wave of OpenNotes, the 2016 to 2018 wave. We thought people would like this and ask for them. But we learned that when the Patient Family Advisory Councils and these active individuals advocate on behalf of other patients who might not even know this was a thing they could do, they could try hard to talk truth to power. Often, the power, which was the hospital's leadership or the clinicians, would say no. They couldn't get the health systems to listen and say, you're right, this is your record. This is about you. The woke health systems decided to be transparent and share their notes. We could say, Kaiser Permanente and Washington State are woke health systems. When you talk about the adoption curve of innovation, you get early adopters. And then, some folks come on later. So, there are a couple of health systems: we get this, we're going to listen to you. But the vast majority of organizations are like; I don't know about this. And then the power structure of every hospital, by the way, is its own city. It has its own culture, its own family dynamics. And you would think everybody's the same. They have the same dynamics. It's not the case we've learned. We've learned that it could be one hospital and one guy who's been around forever. It could be everybody wants to do it. But the one guy in like cardiology says we're not doing this. Over my dead body, are we going to do something like OpenNotes? No way. And then it stops the conversation. What do you do with these resistant organizations that aren't open to change or don't listen to the Patient and Family Advisory Councils?

Change management champions 10:40

We thought OpenNotes could be this patient consumer movement. When you get to that power hierarchy, and you can't go, no one shall pass, no change will happen. It's what do you need to do for the rest of the large majority of folks? That's where we learned a lot more that OpenNotes is not a health IT project. It is change management. There's a political process of someone, some clinician, who needs to become a champion within the organization and community organize around every department, talk to them, bring presentations, hold their hands, ask, answer questions, and set up presentations. So, the health systems that brought on OpenNotes later, the dissemination aspect was less about papers and conference presentations and posters and more about community organizing and storytelling and handholding. Sometimes the storytelling or patient advocates who'd be brought in to tell a little story, or it was a clinician saying my patients read my notes and it's changed my practice and they love me now and it's okay. When you have a new intervention, it's exciting. From our work on OpenNotes, the dissemination is not just the paper. The paper will sit unread somewhere. But it's for us; we've become this support team to the clinician champions within organizations

Health Hats: That is really profound.

Liz Salmi: It's unique, though. If OpenNotes is an intervention, it's a new medicine, a new, not a physical thing you take, but a new possible way of communicating with patients. And it's not like we're asking people to take this drug, and then you were convincing everybody to start prescribing a thing. I don't think our model would work the same way with every new patient.

Community organizing – handwashing to OpenNotes
12:43

Health Hats: I have a feeling that hand washing was similar. Don't sell it short. I'm a nurse, and I've had a career in healthcare management at many levels. And I think you're right. I've never really thought about it that way, but I think your frame of community organizing I have thought about it is that I'm a catalyst for change and that a lot of the work was really not about science. And Lord knows, we can see now that in this COVID-19 world, it's certainly not about science. It is so much about community. Chew on that, but I really think you're onto something significant. Maybe what activists like us can do whether it's about maternal mortality rates or it's about vaccination, or it's about OpenNotes, it is about community organizing. What I hear you say is that instead of thinking about that laypeople, patients and caregivers are going to disseminate now on different channels, like social media, popular media that maybe it's instead of focusing on that, it's focusing on how you become a community organizer, wherever it is you have influence. That's profound.



Liz Salmi: I love that you said handwashing because that's public health, and we've seen what's happened and years later, washing your hands is a good idea. Gosh, there are so many directions I'll go, but I'll focus on something I've been thinking about lately is that when you have access to your full medical record, that's helpful. But as we move into a new space in the coming years where it will be a federal mandate that health systems that didn't turn on OpenNotes early will now be required as of April 5th, 2021, because of the 21st Century Cures Act to share everything with patients through their digital portals. The good fight we've been fighting and working with the community organizers will just be the law of the land. And suddenly, all of this information will be shared with patients. We have two groups of constituencies, clinicians, and hospitals, and then the public. And there's going to be a lot of clinicians in hospitals are anxious. They're anxious right now. Oh my gosh, I didn't want to share my notes, but now I'm sharing my notes. I'm a social worker OpenNotes isn't about me, and now I've got to do this. So, there's that group, which we've got to calm and soothe. And then there's a future campaign of now that the notes are there, do people know the notes are there the full record? Is there, are they going to read it? How are they going to use it? Because it's not introduced to them? I mentioned I'm a person living with a serious chronic condition, a brain tumor, and I was very engaged. I had no idea my record included details like the doctor's notes until 2017, eight years later. So, if even the very engaged might not know about all of the details in the record and they might not care. Still, those dealing with serious stuff may benefit from reading that information or reviewing it later, et cetera. And we can get

into that because I know you have questions. But there, I think it is now a whose job is to provide education about digital health literacy, what's in the record, and then who you share that information with now that these records can be connected to other platforms and apps and tools those third-party groups. I might be sharing with Apple health records or others, my whole record, because I like it, but what are they going to do with it and those privacy policies and stuff? I can see this digital health literacy space needing to be developed ASAP or now, or in the coming years.

Unintended consequences of OpenNotes 16:51

Health Hats: Wow. Two things happened to me with OpenNotes. One of them is that I get some of my care at Beth Israel Deaconess, which was the start of this movement, with my neurologist. My challenge with my neurologist, who's an OpenNotes advocate, is that his notes are incomprehensible. I've had these conversations with him. What I need to know from your notes is am I progressing? Should I get immunized for COVID? How should I get vaccinated? So, the first thing I had brought to him was this issue of his notes; he's just cutting and pasting all this jargon. And I told him, I want to know every visit, am I progressing or not? And he said, Oh, that's right here. And he scrolls down the third or fourth screen, and he shows me a scale that he puts in all of that. And I said, why don't you put that on top because that's what I want to know? I have a progressive disease. I want to know am I progressing? And he said, all of that is a great idea and never did it. It's okay. But it just points to me that just because you have a win of OpenNotes does not mean that you're done. Now I'm educating this very engaging clinician who is like a dream clinician. When I go in, we have two outcomes for me. The outcomes that we always track, the first thing we talk about is have I fallen and am I still playing the saxophone? Those are important outcomes for me on so many different levels. I love that he could engage on that level, but then he has this note that's incomprehensible that does not include falling or the saxophone, even though those are our agreed upon outcomes that we track is not in those notes.

Liz Salmi: Oh, so falling and saxophone are not in your notes as part of the social history? I am asking a totally random question here.

Health Hats: I guess if I have fallen, it's in there.

SOAP notes, digital notes for patients. What's next? 19:30

Liz Salmi: Okay. We're at an interesting point. Historically, the notes were not written for patients, and that hence the dilemma or the whole point of studying this concept and why it's so radical. The clinical notes, the SOAP note, which is an acronym for Subjective, Objective, Assessment, and Plan is an acronym for how to write a clinic note. That format was created by Dr. Larry Weed. If you go on YouTube, you can put in [Larry Weed SOAP note](#) and watch this grand round presentation in 1971, the problem-oriented medical record. It's in black and white, and it's a guy speaking 1971 style language. If you're a big nerd about clinical documentation, go on YouTube and watch it. But he's talking about how records back in the day were not standardized, and people would write whatever they want. It was really confusing, and you couldn't follow the patient's care. But when you standardize the note-taking process, you can hand over our chart to another clinician, and they can scan it and say, okay, here's how the patient is doing. That way of formatting a patient's chart has continued since the late sixties to today. When these paper records were brought over to digital, they just copied what was going on in paper and didn't update it. We might reframe how we do things when things are digitized or on the

web. When OpenNotes was studied originally as a pilot project, none of the clinicians were told change the way they write because patients are reading. It was a study of what if patients saw what you're already doing. This has been around for ten years, so many clinicians in practice today still do what they were trained to do. I've heard that many medical students are not trained much on clinical documentation. It becomes learned by trial by fire. You suddenly learn on your first few days of charting a patient in real-time what everybody else is doing. They learn from each other and then keep doing what they learn. So, we're moving into a space where now the OpenNotes is at 250 organizations around the country; millions of patients could read their notes if they log into the portal and find them. Patients are reading the notes as they were designed and taught to clinicians for years since the late 1960s. Some of the studies show, when they say, do doctors change the way they document, like your doctor, it sounds like your doctor neurologist hasn't changed anything. We're learning from a couple of studies that about a third of doctors do nothing to change their documentation. A third decided to experiment and maybe make their notes longer or shorter. They might do a little bit of changing, and then others do extreme changes. Everyone's figuring out now that they know there's an added audience, what should they do? There is no understanding of what's the best way. There are studies of what do patients think of these notes. Do they understand them? In multiple studies, around 96% of patients say they understand almost all of their notes. There's a new paper published in 2020 in the [Journal of General Internal Medicine](#) about patients; what do they think? What do people like you think of the notes? 93%ish say that the note describes the visit, it's accurate. But around 6% - and you might fall into the 6% - I'm sure the number ranges from five to 10%, or simply depending on who you are saying that they think this note could be better or I have a suggestion for how I might get more out of this note in some way, no suggestions. This is not my research, but the people I work with. I'm a fan of talking about the research. Those patients say this could be improved related to structure. Like you were saying the important things at the bottom. I wish this were at the top. So, structure and some of the content jargon and then the accuracy. So, you said my mom had breast cancer, but really, it's my sister who had breast cancer, things like that. There are innovative clinicians right now, who are advocating that soap note structure, subjective, objective assessment and plan be flipped where the acronym is, say the assessment first, because that's not just what the patient wants to see first, but that's also what my colleagues want to see. First, if they end up in their clinic, the assessment, and then the plan, the assessment might be Danny still does an awesome amount of saxophone; Danny didn't fall since I saw him last. That's the assessment. And then the plan is keep going and go ahead and get a COVID test. And then do the subjective-objective, like his neurological evaluation was X, Y, and Z. There's a crew of folks thinking about changing clinical documentation regardless of OpenNotes because it would be a better tool. It's been around since the late 1960s. It might look better in an EHR and a quick scan and without a ton of scrolling but could also benefit patients as well.

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OpenNotes highlights errors. Fixing errors. 25:46

Health Hats: One thing about OpenNotes is that I'm shocked at the errors that I see. I'll tell two stories. One of them is mine, and one of them is somebody else's. My story is that my father died when he was 45 of his second heart attack. I have multiple sclerosis and they're connected. They're connected because when I got diagnosed, the neurologist said, you've had this for 25 years. What happened is I would have an episode, I would get a cardiac workup, which would be negative. And then, whatever episode I had would be over. So, for 25 years, like twice or three times a year, I would get this cardiac workup. I cannot get out of my medical record that I have heart disease when I really have MS. I was misdiagnosed. So that's one story. Another story is that I have a friend who is, 5'3", 5'4", weighs 137 pounds. Somebody typed in that she weighed 317 pounds and cannot get obesity off her problem list. You can imagine how mine is annoying, hers has serious implications with dosages and everything. It is so difficult to get errors changed. By people seeing their notes, that must happen more often. What about that? Why isn't it part of this deal to fix the errors?

Liz Salmi: I mentioned, a date a few minutes ago, April 5th, 2021, the day when everybody is going to have easier access to their full record, we know from OpenNotes research about patients finding errors in records now that they're reading them more. About 20% of people say they find an error or something wrong with the records. If you apply that number now suddenly to the whole country, everyone who receives care will see the records. It doesn't mean they're going to, but those who do, there's a chance that people will find something wrong or inaccurate. And in the study of who finds something inaccurate, they also said to their clinicians, do you think what the patient said is accurate is actually inaccurate and about half of what the patients say are inaccurate the clinicians agree. That's serious. So, what is an inaccuracy? [This work is by Dr. Sigall Bell](#). She's our leader in patient safety work and OpenNotes. I'm just a peon learning from her, reading the papers. Now I'm a coder in a project we're doing right now. I'm not an expert, but I'm learning. When you look at what patients say is an inaccuracy, it can vary from something like, they say I take 350 milligrams of this medication, but it's actually 300, and that's a little thing. But to have the medication list accurate is so important. There's the thing about family history. Oh, I said my mother had breast cancer, but you said it was my mother, but really it's my sister. People are having disagreements about their weight. The person might say I disagree with the physical exam and say my weight was 150, but really, I think I'm 120 pounds. So is it be a subjective or an objective thing, but then there's really important stuff like wrong side. Oh, my left knee. I said my left knee hurt, but they said it was my right knee, and the wrong side of documentation is a big deal. That stuff goes unnoticed until the person, the patient, is reading the record. And you think about a doctor, they might have their eyes on a thousand charts, but really you only have your eye on one chart.

Health Hats: You're the expert on that chart.

Liz Salmi: Yeah. And there could be disagreements, but there are facts and not facts. As we move into a new reality where people have easier access to this information, I think there will be more requests to update the record, to remove a thing. To be honest, working in the OpenNotes space and knowing this federal mandate is coming soon. There are concerns from health systems and the clinicians who are a part of this rollout. What are we going to do with our medical records department? Do we need to beef up person-power to respond to these things? Who responds? Is that the doctor who had the typo, or is

this a major disagreement and the care overall? For the most part, the things are minor, and it'll be like, Hey, you said left knee. It should be the right knee. And the clinician will go, you're right. It is. That was a typo on my part or dictation error, or I hit the wrong dropdown menu, and they agree the record should be accurate, but it's for the most part, like little things like that are a big deal, but they're little things.

Health Hats: I see six different specialists that use three different systems, and the idea of getting my cardiac history off three different records, is daunting.

OpenNotes and mental health/substance use records 31:07

The one other thing that I wanted to talk to you about is the behavioral health notes, whether it's mental health or substance abuse notes, what's happening with that. What's the OpenNotes approach to those kinds of notes?

Liz Salmi: There is research into the space of sharing mental health, behavioral health notes, social work notes. The original work started at Beth Israel, of course, with Steve O'Neill. He's our mental health liaison. Awesome guy. If you went to opennotes.org and found the [mental health section](#), you'll see an overview of that as well as links to many published research papers. They'll say the work that was done at Beth Israel, that Steve O'Neill figured out that people made the notes part of the therapeutic alliance between the patient and the clinician. They would go over them together. The concern from many other mental or behavioral health clinicians is patients will read this and get extra obsessed with certain things, but really the way you, and I'm not a mental health professional. I've learned from other folks if you're concerned about somebody who's obsessing or paranoid, the note would say, Danny's thinking this. Still, we discuss X, Y, and Z. We agreed together this, and in this note, as a reminder that together, we talked about this and he's going to work on X, Y, and Z. So there becomes this kind of co-production process in it. The VA health, Veterans Affairs health administration has been doing OpenNotes long before we studied OpenNotes, and they've been doing OpenNotes and mental health for years. Their expert is a different guy named [Steve Dobscha](#) and he's done a ton of published work in the space, including a whole toolkit to help [clinicians and patients work together to use the note](#) as part of the therapeutic process. So that's another person, folks. And as we move into this April 5th date, those notes must also be shared as part of this federal rule that I could keep mentioning. Yeah.



The kitchen sink of OpenNotes 33:38

Health Hats: All right. I'm wrapping up. What should I be asking you that I'm not, or what should we be talking about that we've missed?

Liz Salmi: Oh, man, you told me to prepare for this. And I did not. I would say what's next for things like OpenNotes, is a good one. There are several people I've talked to who were helping shepherd as we get closer to this date where OpenNotes is the law of the land. I'm putting quotes around that law of the land and sharing what we've learned from working with at least 250 organizations who flipped the switch and started to be open and then helping everybody else. And there are thousands of health systems around the country. And so we've been open about that, but I've had folks say, are you done researching this? Is it over? And we're like, no, we're still researching this, but in more nuanced ways, sometimes spinoff ways. I mentioned

Our Notes, the idea of patients being involved and adding and contributing to the note and having that voice in there. So that's something we're doing something called our diagnosis, which is, I mentioned Sigall Bell, the person who focuses on safety who says if you're reading your note. Then you find some things that's incorrect; she's building a tool to click on that part of the left, right inaccuracy, and then flagging what was wrong.

You can say, in real-time, Hey, here's where it is. And it's done digitally. We're working on a tool right now to pilot. We're working with Beth Israel and Boston Children's Hospital. It's going to be piloted first in a children's hospital, so parents are involved, and we're working with patient family advisory counselors on the language. Because if you're building up a tool for patients and saying what's wrong, it needs to be in patient language. We're doing that in Spanish, too after the English version is done. We're also working on a project around EHR proxy access. I have access to my clinic, my patient portal, but if I'm really sick and brain cancer gets wild, my proxy, which is my husband, Brett, he'll be logging in. But most patients do not share their EHR login with their proxies. Usually, what happens is a large majority of care partners will log in as the patient. Then the doctor's confused, saying, who's writing to me right now because clearly, this person who's not doing well with brain cancer is not writing this fully formed paragraph, long-form. We're working with three health systems around the country around their proxy portal registration rate and then the communications tools around that. I could keep going on the projects we have going on. Then advanced care planning OpenNotes. We're interested in social determinants of health, and there's the effort by the Office of the National Coordinator for Health IT to standardize how social determinants are documented in the record. The question is, for folks who are of populations that have the social determinants being documented, how will they feel about reading those things about themselves in their record? How do we document that in a culturally appropriate way? So that's another project we're working on.

Health Hats: Wow.

Liz Salmi: Sky's the limit.

Health Hats: Hats off. You're doing some amazing stuff, I knew you were doing amazing work, but I didn't know the extent of it.

Liz Salmi: One thing leads to the next. I'm also really proud to be part of the team, that the folks who lead this work thought to take a risk to hire someone who's a very loud patient advocate. We've got professors of medicine at the Harvard Medical School on our team. And they're all PhDs and MDs and so on, and in the meetings they're like, is this right, Liz? Constantly bringing me in. I don't know if anyone else has done this in academic medicine. I hope so; I want to continue to do a good job. Perhaps other innovative researchers and folks working on healthcare solutions think just like PCORI put you on the Board of Governors and anointed you. When the next innovative group comes around, folks like us get patient activists on their team, pays them, and continues to mentor them, so they learn for the entire time they're there.

Health Hats: Brilliant. Hey, this is great. Thank you so much. We could talk for quite a bit longer.

Liz Salmi: Absolutely. Till next time.

Health Hats: It's lovely to see you, and I'm glad you're doing so well. And you're doing such amazing work. There's anything I can do for you; you know where I live.

Liz Salmi: That's right.

Health Hats: Thank you.

Reflection 38:45

Let me catch my breath. Liz shared her story from communication professional to patient with a brain tumor, to student of brain tumors and self-advocacy, to advocacy for others, to researcher, to student of change management, and most recently to community organizer. Clearly not a straight line, but a burst of enthusiasm and activity. Many of my fellow patient-caregiver activists wow me with the depth and breadth of their work, all while managing self-care and caregiving. In a second I think of Geri Lynn Baublatt, Janice Tufte, Penney Cowan, Freddie White-Johnson, Morgan Gleason, Mike Mittelman, Alexis Snyder, Teresa Wright-Johnson, Mary Anne Sterling, Casey Quinlan. They all have similar stories and expertise and impact. Gold mines of passion, thoughtfulness, connection, capacity. They've all absorbed a gut-punch of dashed dreams, crippling pain, stringent doubt. Yet they've rebounded like coiled springs in service to us. Makes me want to laugh, cry, and scream. Thanks, Liz, thanks all for what you do for us. You provide hope in an infected and divided world. Onward.