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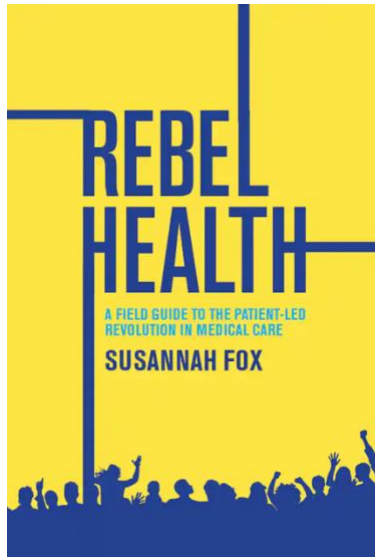
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Proem



As a student of advocacy and activism, I draw warmth from the heat of others' passion, marvel at the diversity of origin stories, and burst with curiosity about what might come next. How did they start on this journey, and why do they persist? I've been a nurse for 50 years. One of the best things about nursing for me was the license to be nosy – for a brief time - a visit or a stay. This nosiness melds nicely as a podcaster for an episode. I often ask guests, “When did you realize health was fragile?” Another student of advocacy and activism is our guest, Susannah Fox. Susannah is a health and technology strategist. Her book, [Rebel Health: A Field Guide to the Patient-Led Revolution in Medical Care](#), has just been published by MIT Press. She is a former Chief Technology Officer for the U.S. Department of Health and Human Services, where she led an [open data and innovation lab](#). She has served as the [entrepreneur-in-residence at the Robert Wood Johnson Foundation](#), and she directed the health portfolio at the [Pew Research Center's Internet Project](#).

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 Hats: Susannah Fox, how are you? It's so good to see you. I've been looking forward to this. You've been my idol for a long time. I first learned about you when you were at [Pew Research Center](#), and I thought your perspective and research were so helpful.

Realizing the Fragility of Health

When did you first realize health was fragile?

Susannah Fox: Wow. The first time I realized that health was fragile was when my dad was a flatliner on the table at the hospital after his heart attack. He was in his fifties and someone who, to anyone who looked at him, would've thought he was a health nut. He went four miles three times a week. He was fit. He loved to hike. He was a mountain climber. And yet he had genetically high cholesterol and a hidden, blocked artery. So, they luckily were able to revive him, and he had open heart surgery and lived long enough to then get kidney cancer in his sixties and melanoma in his seventies.

My dad was my model for lifelong health and perseverance. I love this question because it explains how you learned that health is fragile. But then also what? What happened when you learned that health was fragile? For me, it was seeing my dad persevere to regain his health each time he had a setback.



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Health Hats: That's admirable.

Transition from Research to Activism

Health Hats: You had these experiences and are now in activism. How did that path happen? How did you get where you are now?

Susannah Fox: I don't think of myself as an activist. I think of myself as a researcher and a strategist who collects data, studies the landscape, and then tells the truth about what I see. I want people to enter a landscape with an understanding that if they build something on the frontier of healthcare and technology, they must build it on sound foundations.

They need to understand the truth of the situation. However, I evolved as a researcher when I started this work and met [Tom Ferguson](#), my mentor when I was working at the Pew Research Center for [Lee Rainie](#). We hired Tom as an advisor. I went to Tom to understand the future of healthcare and technology. He said you must spend time with patients. They are the hackers, rebels, and cowboys on the frontier, bending tools until they break.

I started spending time in online patient communities in 2001. Tom would have identified as an advocate and activist, often pulling me toward that. And I was, frankly, resisting and saying, no, I'm over here as a researcher. I don't judge whether something is good or bad. I just tell people the way the data lies. Yet, after 14 years at the Pew Research Center, I went to Lee Rainie and the then-president of the Pew Research Center, [Alan Murray](#), and said, I've written 50 papers about the internet and healthcare, and I think I know what should happen next. I have opinions about the megatrends that are changing healthcare. And they said that's great. You can't work here anymore because the Pew Research Center rightly holds it as a core value that their researchers don't have an opinion about how things should go. I've maintained my sense of being a researcher where I follow the data, yet I also recognize that being a researcher is where I train my gaze. I think of myself as if I have a miner's light on my head, and where I train my gaze to look is an editorial choice. By looking closely at patients, survivors, and caregivers, I know that I'm choosing to honor the work that they're doing. In that sense, I've gotten pulled towards advocacy. But I don't identify as an advocate.

The Role of Perception in Healthcare



Figure 1: Image by Bradley Pisney on Unsplash

Health Hats: It resonates with me when you say that. Because you've helped to inform my work, mostly in perception, like how people perceive. At Pew, you did a lot of surveys, and now you're collecting hacks and experiences. Do you see yourself as a perception researcher?

Susannah Fox: The basis of my work was the telephone surveys we did at the Pew Research Center paired with my fieldwork, acting like an anthropologist going into these online patient communities.



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After I left the Pew Research Center, I worked at the Robert Wood Johnson Foundation. And then at the Department of Health and Human Services (HHS). While at HHS, I put away my research and leaned into my work's strategic side. But since then, I've partnered with my colleague and friend, [Vicki Rideout](#), to produce research for clients like [Hope Lab](#), the [California Healthcare Foundation](#), and [Common-Sense Media](#) again, paired surveys with quantitative and qualitative work to give a clear picture.

I saw it in getting pulled into those higher-level conversations about health and healthcare at the Robert Wood Johnson Foundation, at HHS, and being part of the federal government. People who haven't had the privilege to spend time in online patient communities did not see what I saw, which is how much innovation was growing up between the cracks of what we can all acknowledge is a broken healthcare system.

A System Versus Community View of Healthcare Innovation

Health Hats: That's so interesting. I'm on the Board of [PCORI](#) (Patient-Centered Outcomes Research Institute), an exciting place to be. My image is not so much the cracks. I think we have the same idea, looking at it differently. I feel that innovations are happening in communities. People have a problem to solve, and people get other people together. They figure out what's going to work for them. To a system, it looks like things are coming through the cracks, but that's a system view. The underground seed, with all these roots and activity, then some little thing breaks up through the institutions. That's a community view.

Hacking Healthcare and Startups

Health Hats: I never thought of hacking as you do in your language. Hearing you write about hacking made me think that maybe hacking is all there is. I have this idea that activism should change the system. Maybe it's better to cultivate hacking. It doesn't affect the whole country like business does, going after the dollar, but it still impacts people.

Motivation to Solve

Susannah Fox: Yeah, I want to react to that because I love this provocation of the metaphor of something growing up between the cracks as a system-centered view. I love that. The other way I think about it is the patient-led, caregiver-led, survivor-led revolution. Is that what they are? We are building the missing infrastructure. Some things are missing, and they're building that infrastructure for themselves. I also want to say that, often, when describing a team of people that come together to solve a problem, you could use the same language to describe many startup companies. It's a team of people who come together to solve a problem they think has the answer and want to affect the system. They want to help people. They want to scale. And that's the same thing we see in the patient-led revolution. They want to help people, and they want to scale. It's a fascinating question to think about. What are the motivations? The motivation to help people is at the base of many startup companies, nonprofits, and patient-led teams. Yet, how do you do that? You need resources. So, how do you get those resources? That is interesting. I appreciate that provocation. Thank you.



Call to action

I need your help to expand my audience to younger people in advocacy. I'm doing more in short-form videos. Please help by pointing me to communities of young advocates and the channels and hashtags they use so I can listen and learn. I now have one URL for all channels and media. <https://linktr.ee/healthhats> is where you can subscribe, access episodes, my website, and social media, and search the Health Hats archive. Your support is appreciated.

Seekers

Health Hats: I'm looking forward to your book. I am intrigued by your talking about seekers, networkers, solvers, and champions, but I want to start with which archetype you are.

Susannah Fox: It is a good question. Let me quickly describe each one. Then, I'll share which one I identify as most often. The first group is seekers. Seekers feel that they're not getting answers to their questions. The key here is that they decide whether their questions are being answered. They get to decide if the information is enough, and they decide. To go out on the hunt for more and better information, and it's that spark, that jolt of energy that makes someone become a seeker. That is what I'm intrigued by. Often, when someone gets hit by a health challenge, they might be too stunned or exhausted to raise their hand and try and go out on the hunt. So that's seekers. They go out on the hunt for information and don't give up.

Networkers

The second group is networkers. Networkers are people who naturally learn in the community. They can't help but talk to others, whether online or offline. When they find something useful, they can't wait to share it with their community. They're people who pool resources and create a community where, frankly, wherever they go.

Solvers

The third group is solvers and attack problems. If they are faced with an assistive device or medical device that isn't working for them, they will try to take it apart and put it back together again. They will hack it, meaning they will. Try to find an elegant solution as a workaround, which is the original definition of a hack. Solver can also look at a system and see its flaws and, again, want to contribute to fixing that system.



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Champions

The fourth group is Champions. Champions have access to resources generally controlled by mainstream healthcare or institutions - funding, media attention, regulatory guidance, access to labs and manufacturing facilities, or unique materials. A champion will look across the landscape. See a patient-led or survivor-led team with a great idea but needs the resources they control, and they will share them with them. They'll infuse that team with a resource the patient-led team needs to scale their idea.



Figure 2: Image by Thought Catalogue on Unsplash

Networker, Seeker, Solver, Champion

So, you ask, which do I identify as? At my core, I'm a networker. I am almost infamous for being unable to resist talking to people. And I love it. It's a feature or flaw. It's part of who I am. I love to learn from people, which is a trait of networkers. I would say that when I've needed to, I've taken on the role of a seeker and even a solver. I don't think I'm a natural solver, but I figured out how to fix something when I've had to. And I also stepped into a role as a champion when I was at HHS, for example, starting the Invent Health Initiative, which brought this idea of patients, survivors, and caregivers who are. Creating new assistive and medical devices, the hardware of healthcare, that them into this conversation at the federal government level.

Networker, Champion, Solver

Health Hats: I think that. I am also, at heart, a networker, and a champion. And I think that a champion now that I'm older and I'm quote unquote retired and I've got this seat on the board of PCORI, and I have a podcast. I'm not so much a seeker. I'm a solver, but mostly, I use other people.

Persisting Boss

When I was a boss, I spent time looking at my team. First, I don't know. I would cull the herd. It's not a lovely way to say it. Some people had no business being on the team and dragged everybody down. And when that happens, they must go. And then I would look at what was missing. I'm a person who has a lot of ideas and a lot of energy. I'm a good leader, and I can do the grunt work. But I'm not a maintainer and wouldn't say I like it. I need help once it's figured out. You must persist. There are different kinds of persistence. There's problem-solving persistence, and there's maintenance persistence. So, I would look for people with what I or the team didn't have, which was beautiful because it works much better.



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Leading by Helping the Helpers



Figure 3: Image from Shutterstock

I didn't think about seekers, networkers, solvers, and champions, which is a different way of looking at it. And so now I feel like my work is, I help the helpers, I don't do that much, man, I spent 50 years as a nurse where I spent 20 years as a direct care nurse, and then I got into, being a student of organizational health rather than individual health. And so, then, I was a leader. And the challenge now is seeing people who are champions. Just because you're a champion doesn't mean you're a good leader. I feel that understanding seekers, networkers, solvers, and champions helps people who are champions be better champions. Does that make any sense?

Actors on the Stage of Innovation

Susannah Fox: It makes sense because I was writing this book. I didn't start to include the archetypes. I originally started the book to trace the stages of innovation that the patient-led revolution is going through. However, I realized that in trying to explain the various stages of innovation, I became increasingly intrigued by the actors on each stage and their roles. And I realized that it would be more helpful to, instead of talking about these stages, talk about the people, talk about the actors, and talk about the traits that I'm observing. And I went back into my field notes. I have 20 years of field notes of talking to people, interviewing people, and survey research to start identifying the archetypes. Then, I did fresh interviews to test these ideas. And I also want to share that the seekers, networkers, and solvers emerged immediately.

It was apparent to me. Often, when I talk about peer-to-peer healthcare and the patient-led revolution, people say, oh, I know exactly what you mean. And they describe networkers. They describe people who have started Facebook groups who use Twitter to organize, etc. And I say yes, and there's another group of people who are seekers who may never actually be networkers. Some solvers also may not be interested in sharing their inventions, but who can't help but keep inventing things?

Emergence of Champions

Susannah Fox: The archetype of champions emerged as I wrote the book because I realized how powerful it is. When does something move from being a grassroots initiative where something is helping a few people? How do you scale that to move to something recognized by the mainstream that has been lifted and given the resources it needs? And it's only through the intervention of champions unless an incredible group of people can. They are networkers and don't need the mainstream to notice their actions to serve their community. But that's an exceptional group of people.

Serving Communities

Health Hats: There are two examples I am aware of this minute about more generalizations: the Camden Coalition and the World Health Network. Those are two organizations that intrigue me. Be, I



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think it's tough to expand beyond. The common thing about seekers, network solvers, and champions is they have a fire, and you can taste it.

Revolutionary Energy – Regina Holliday and Casey Quinlan

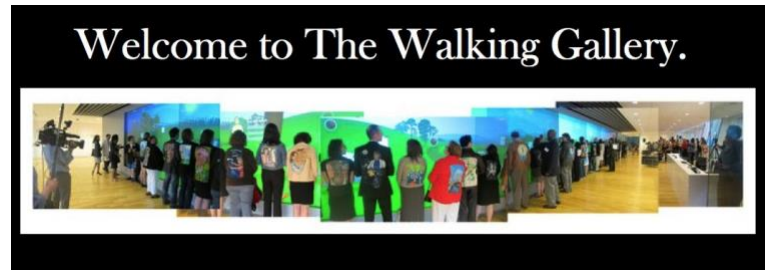


Figure 4: Image from <https://reginaholliday.blogspot.com/2016/03/how-do-you-join-walking-gallery.html>

Health Hats: And to me, I sometimes must protect myself because it's so intense. When I first met Regina Holliday, it was like, oh my God, I needed a bullet-proof suit, and then I learned that I learned to thrive on it rather than protect myself from it.

Susannah Fox: There is an energy field around revolutionaries. Not everyone is cut out to be a Rebel. One

important thing to know is that you don't have to be a rebel to gain the skills and value from the patient LED revolution. You could temporarily recruit somebody to your team. So, thank you so much for bringing up this energy that can surround someone; also, people are hesitant and say, wait, I don't want to be a rebel. I don't want to cause a revolution, but my mom or my kids. So, you can tap into the revolution. You could tap into the energy and get what you need. And you don't have to be part of the revolution. You don't have to be a rebel to benefit from the patient-led revolution.

Health Hats: I used to have this conversation with Casey Quinlan because Casey is a public revolutionary. There's just no question. She was the epitome of a revolutionary in healthcare. And I would tell her I like to work from the inside.



Figure 5: Mighty Casey Quinlan

Draft Counseling – Working from the Inside

Health Hats: I like to understand how things operate. For example, I dealt with the draft when I was 16 and worried about being drafted. I trained to be a draft counselor because I wanted to learn the ins and outs, which made me want to work from the inside.

But I couldn't have done it without the revolutionaries who started the programs and trained me. And you're right. So, again, I think this business of archetypes and energy is. I am learning how to create the balance for the moment to get the next thing done.

Champions Stoke Fires

Health Hats: People I work with who are hackers, change agents, or activists are often disappointed. Energy wanes, waxes, and wanes - I think it's okay. I'm more of a, where are we today? What are we



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going to do now? That's how I manage my health, and it is okay. I have MS. It sucks. Okay, here I am. What do I do? Okay, this new thing is happening. What do I do now? I want to do something but don't have the capabilities right now. How could I have the capabilities? What do I need? Anyway, it changes, and so I think with champions- I don't even see- I'm focusing on champions in this conversation. I think champions need a lot of help.

It's hard work. It's such a, I think it's a lot of them. Is it fair to say many people who work with them are hurt? Why does somebody get into healthcare advocacy and healthcare hacking? It's something shitty happened, to them, to theirs. And so that's a sort of head of steam. It's a kind of head of steam. I don't mean a head of steam. It's a type of head of steam that's hard to work with sometimes. And I so I read your PDF when you sent it out, and now your pub. Oh, so your book, but anyway, one minute, and then we're going to, you're going to tell us about your book in more detail, but I'm ready to. I'm waiting for the publication on February 13th.

Rebels in Health – You Are Not Alone

Health Hats: So, tell us about your book.

Susannah Fox: Oh, we did. We've gotten into the archetypes that I introduced in the book. When you referred to the PDF, I should share that you were part of a small group of people with whom I shared a preview, and I sent you the PDF so you could read it. We could have this conversation and other conversations. Thank you so much for being a preview reader. So, Rebel Health, the field guide to the patient-led revolution in medical care, is coming out from MIT Press on February 13th; you can pre-order it now. I wrote it so that anyone who gets hit by a diagnosis, a health challenge, or whatever in their life finds themselves in the maze of healthcare and feels alone. Please know that you are not alone. A group of people would love to help you find the way out of that maze if they only knew how to find you. If you can find the courage to raise your hand, go out on the hunt as a seeker, or join a group as a networker, some people are ready to help you. So, I wrote it for the general population. I think everyone is going to have a health challenge. It's not a question of if but when. And that's one group of people that I wrote for this book.

C-Suite and Government Meet Rebels

I was also thinking about my friends in the c-suite of healthcare who serve in government positions and have a lot of severe challenges in terms of their business, research, policies, and how they could benefit. From the incredible innovations and learning happening just underneath the surface of their gaze, the patient-led revolution. If you can align the patient-led revolution goals with your goals, whether your business, your policymaking, or your research, you will benefit from the energy being produced. We all have something to learn from patients, survivors, and caregivers.

Health Hats: Wow. Okay. What do you think are the most important things we've talked about?



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Step into Your Power

Susannah Fox: One of the book's most important messages is that you can step into your power. As a patient, caregiver, and leader, I tried to introduce a way to think about power, a way to think about either stepping into your power or sharing the power that you already have with people to solve healthcare problems.

Health Hats: It's heavy. May the force be with you.

The Enemy is Disease

Susannah Fox: One other point that I wanted to make is something they came out in, one of the discussions in the preview group, someone asked in the group, so if there's a rebel alliance in healthcare, who's the empire? Who's the enemy? And Ben West, a fantastic data hacker in the diabetes space, said that the enemy is a disease. We won't point fingers at any entity or any part of the industry. The common enemy of humanity is disease, and we need to stay united in working against the spread of disease. I love that. As another theme, Rebel Health is about lifting science and the social nature of healthcare. It's about accelerating what is happening, an ancient human condition where we want to connect with others. And solve problems together, and technology is helping us to do that faster.

Health Hats: Thank you. This is great.

Reflection



Figure 6: Image by Ann Boland

I can't recommend Rebel Health by Susannah Fox enough. The enemy is disease - thanks for that golden rule. Susannah's archetypes: Seeker, Solver, Networker, and Champion meld well with one of my frames for health and advocacy, the three Ts and 2 Cs (Trust, Time, Talk, Control, and Connection). As a person who sees life as grey, not black and white, the one absolute I've found is that almost all leaders in healthcare perceive that they lead chaos. The archetypes plus the 3Ts and 2Cs may help leaders slightly controlled the chaos. Some order may be all we can ask for.

Podcast Outro

I host, write, and produce Health Hats the Podcast with assistance from Kayla Nelson and Leon and Oscar van Leeuwen. Music from Joey van Leeuwen. I play Bari Sax on some episodes alone or with the Lechuga Fresca Latin Band.

I buy my hats at [Salmagundi Boston](#) and coffee from the [Jennifer Stone Collective](#)—links in the show notes. I'm grateful to you who have the critical roles as listeners, readers, and watchers. Subscribe and contribute. If you like it, share it. See you around the block.



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