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*Proem 00:53*

*In 1997 I participated in my first patient family advisory council. I convened the member panel as Director of Quality Management for a managed care company. We set up a provider (clinician) advisory panel at the same time. My boss, the executive director, was psyched. The panels started as a show and tell platform for us leaders. Actually, kind of boring. The turning point came when both panels wanted to talk about the pre-authorization process. Managed care companies often need to pre-approve a block of visits before they pay - frustrating for clinicians and members, expensive for the company, time consuming for everyone. As a result, the managed care company changed practice to pre-approve seven visits without pre-authorization. We dealt with over-utilization on the back end. If providers appeared to provide services that didn't seem medically necessary, we dealt with those clinicians. We stopped making it harder for all the rest. I led many patient-family advisor panels since then, some window dressing, some meaningful.*

*Introducing James Harrison 02:30*

*I invited James Harrison to join us to talk about his study of patient family advisors. James and I met through PCORI (the Patient-Centered Research Outcomes institute). Our favorite topics include making health choices and engagement of academia and hospitals with patient family advisors. Our mutual favorite questions: So what? Does it matter? Is it meaningful? Who does it serve? James Harrison's career has focused on research and quality improvement efforts that seek to improve the delivery and experiences of healthcare for people who have been hospitalized. He joined the University of California, San Francisco, UCSF, Division of Hospital Medicine (DHM) in 2012 and is an Assistant Professor of Medicine. Before UCSF, James was based at the Surgical Outcomes Research Centre (SOuRCe) at the University of Sydney and*

*Royal Prince Alfred Hospital in Australia. It was in Sydney that James completed his Master of Public Health and Ph.D.*

**Health Hats:** James, thank you so much for joining me. I appreciate you taking the time. We've known each other a while. We've worked on many projects together, and we made it a practice that when we could travel, we got together often. That means a lot to me. You're one of my go-to people when I realize I have no idea what I'm talking about, and I need somebody to give me a reality check. You're perfect for that. So, thank you.

**James Harrison:** Thanks, Danny. Interestingly, you say that because you're my reality check, too.

**Health Hats:** Good that works. James, how do you introduce yourself in a social situation?

**James Harrison:** I'm James Harrison, a researcher living in San Francisco, born in Britain, also lucky to have an Australian passport. Lots of influences on who I am. Professionally, I'm an assistant professor at the University of California, San Francisco. My research focuses on creating age-friendly care transitions for older adults leaving the hospital. Also, how we connected - patient stakeholder engagement in research.

Eyes open to engagement in research 05:16

**Health Hats:** I'd like to focus our conversation about patient and caregiver engagement in research, especially research that informs collaborative decisions that people make with their clinical team. The reason you're one of my go-to people is that you've had varied experiences and varied dilemmas with the challenges of patient and caregiver engagement and research. You've tried different approaches. Some worked well; some of them haven't. I like that you're continually trying stuff out, learning, then trying something different and adapting it to whatever situation that you happen to be in. Can you talk about your evolution of that interest? How did you get here?

**James Harrison:** It was actually through attending the first PCORI meeting where I met you and some other people. This whole idea of patient and caregiver engagement in research was new to me. It wasn't community-based participatory research, clinical research, health services research, other types of research, but trying to bring in the patient and family member. Of course, this makes sense. The light bulb went on. But then as a researcher, the lens I bring to this conversation, we weren't taught how to do this when I trained. Patients and caregivers were research subjects or participants. I could interview them as part of a study, or do a survey, observe people. One wouldn't know the first thing about how to engage them as partners in the research process. That's where PCORI and then various advocates, stakeholders in PCORI opened my eyes. Okay, I can do this. I first started with some advisors at UCSF. I'd not done this before, nor had they. So, we started the journey together. Now I conceptualized it as three buckets of engagement: the individual researcher level, the department specialty level - I work in hospital medicine - and then at the institutional level - UCSF, an academic medical center. I've been fortunate, through some of my efforts, but also working with other amazing people, being able to have these opportunities to look at different ways of engaging patients and families. At the individual researcher level, I've been fortunate to be involved in the development of two patient and family advisory councils. One for hospital medicine at UCSF, one called [Home Run hospital medicine](#) re-engineering network, which is a network of hospital medicine researchers who have been working

together for about a decade. And then, about five years ago, I got involved, and we needed to get the patient voice in what we're doing. How can we improve hospital care without talking to patients and their families? So, we created an advisory council for this network, which I've been fortunate to be able to access for my research. Both of these forums are used by investigators, faculty, staff, and leaders from both UCSF and hospital medicine research to get their input on projects. It's built capacity for hospital medicine as a field for researchers to come to the PFAC.

PFAC Patient Family Advisory Council 09:43

**Health Hats:** PFAC, patient family advisory councils?

**James Harrison:** Yes. That is just one model. It's not perfect. One of the big criticisms is they aren't representative, only a small selection of people. There are ways around that. We've done some work with my PFAC to explore how you research PFACs. I've been lucky with these PFACs. You've got your project, you either go for a consultation, or you get the PFAC that works with you throughout the whole process. But flipping that thinking, I've been lucky that I'm part of an acronym, [ASPIRE the accelerating systematic stakeholder patient and institutional research engagement](#) - led by Tung Nguyen, Nynnika Palmer, Erica Wong, and Paula Fleischer, an amazing group. I'm on the board for ASPIRE, which pulled me in. This group thinks at an institutional level: how does a complex place, such as UCSF, an academic medical center, do this kind of work? How do they have the infrastructure and the systems in place that researchers can partner with patients, families, and community members? It's been great.

On the one hand, ASPIRE, through outreach and talking to researchers, it's highlighted that they have challenges finding patients to partner with, they need training, how to do it, and how to do engagement. Also, they need support in how they nurture and sustain these relationships. But the mind-blowing thing for me has been working with community members about research engagement. Listening to the ASPIRE group tell their stories. I don't want to steal their thunder, but I want to take my hat off. The quick summary is the community said, look research engagement is important, but hold your horses, we've got a lot of other things we need to talk about first. We need to talk about the lack of trust we have with large health systems. We've got to talk about health equity. We've got to talk about how they're always coming to us, asking for input. How about you do something for us, you listen to us. So, it's highlighted even before we can get to this engagement about research. We've got to level the playing field with these community groups are working with, so anyways, that's a long way.

Partnering with communities 12:37

**Health Hats:** It's interesting. You're talking about how partnering with these community and patient groups has maybe reprioritized or reoriented the way of thinking about the trust, the equity. Do you find that there's an issue with the established institutions being able to integrate and change anything with the input that they get?

**James Harrison:** Thinking of those two levels, on an individual project level, without a doubt people come to the patient and caregiver stakeholders and ask them about do these questions resonate? Are these important to you, and then that feedback can shape the project. We've had through the Home Run Network, there was a COVID grant we put in, and we spoke to the advisors and said, well, what outcomes are most important to you? It was those outcomes that they thought were most important that we prioritized. All the things about looking at patient-facing materials, making sure that they are

relevant, can be read. So, I think on an individual researcher level, yes. I think when you talk about institutions, they're a bit more, as we know, they're larger, they're more complex, right?

**Health Hats:** I mean, doctors have a hard time changing them.

**James Harrison:** But I think there's a mood for change. Maybe I'm optimistic. The fact increasingly recognized across the board is that this kind of engagement is good, not just for research, but for so many different things. Building trust, building relationships helps both parties, helps the institution, but it also helps the community as well. That said, it's not easy. How do you compensate patients and caregivers? That mechanism isn't there. But there are ways, and I think slowly but surely happening. And I think with some of the engagement awards, the PCORI funding other foundations fund as well about trying to work out how a system-level we can make these changes. I think I would hope. I think it is going to change.

Recruiting PFAC members 15:10

**Health Hats:** Your practice is in acute care so, hospitalization. Obviously, everybody who comes into the hospital comes from home, whatever they consider home. They go back into the communities. The institution life is just a drop in the bucket. How do your advisors broadening the scope beyond the walls of the institution into the communities they come from and go back to?

**James Harrison:** That's a big question. I'm a researcher, not a clinician, I'm embedded in the health system. We're lucky in hospital medicine that it's a generalist unit. You get all comers. When admitted to the hospital, chances are you see a hospitalist. So, in terms of diagnosis and backgrounds, you're going to see a lot of different people. As you say, it's hopefully just a small part of your health care journey that you're in a hospital. So definitely, there are challenges to recruiting people for PFACs, to try and identify people. We've got our processes in place for that. We approach it that at some point, unfortunately, most people are going to be hospitalized. In comparison, it's a normal environment for those that work there. For patients and caregivers and members of the community, it is not normal. One of my friends and colleagues is a patient advisor. She says this is not normal. You think it's all normal. This is not because it's a completely foreign environment. People are very willing to participate and get involved. Still for our institutional PFACs, (patient and family advisory council), people come to us for meetings, now Zoom meetings. For the Home Run Network, this national network, we've got people from all over the place. They've all been hospitalized or cared for to someone that's been hospitalized in various settings. So, they bring those different perspectives. But after their meetings, they go back to their communities, however community is defined. We not only share what's going on in the research world, their role in what we're doing, but also, they're back in their communities, living, learning, and then bringing that lived experience back to us.

Recovery plan 18:29

**Health Hats:** So, what kinds of decisions, clinical decisions, health decisions are people making as they are returning home? People who get admitted to a hospital, obviously the largest proportion of people who go to the hospital are probably there for maternity. From there, it's probably joint orthopedic stuff, and then cardiac and chronic illness. I don't know, I made that up. But I'm probably not that far off. They're going home. Going to the hospital is such an interruption. Something drastic happened; they went to the hospital. Then they're going to go home, and they're going to face something really

different. As a nurse, we thought of a discharge plan. The discharge plan should have started the day somebody was admitted, or it's a life plan, not really a discharge plan. It's like what's happening next in your life? And so how does having engagement with patients and caregivers, does that influence that kind of process? And if it does, how does it.

**James Harrison:** There's another way to consider this discharge plan. Yes, you're right. It should start on the day of admission, but also thinking that it's a recovery plan, as well. When you think about it, there's engagement with those decisions, and there are two types of engagement I see. As a patient, you engage with your healthcare team in developing that recovery plan, so you're comfortable. If you're comfortable sharing your views or your care team invites you to share your views, you have a shared decision-making approach to your recovery plan, where you're thinking about your goals. What are your aspirations for when you get home? What do you think are going to be the challenges? We know this. We thought it was great focusing on the medical problems and the disease problems, but maybe not thinking about how are you going to get your groceries when you get home? How are you going to get up and down your stairs? How are you going to get out of bed? Now moving as I have into the geriatric space, the focus is about how are you going to live independently? So that's engagement on the patient perspective when you're sitting in the hospital. But I think from the research engagement perspective, it's working with advisors and as partners who have been able to share, 'look, despite all these grand plans of shared decision making, having a recovery plan in their life- that ain't happening.' That's not happening, and they've been able to identify from their perspective where the pain points are. The last thing that's enabled us then to say, okay, we need to do something about that.

**Health Hats:** Give me an example of a pain point.

[Back to basics 22:15](#)

**James Harrison:** A big one in hospital medicine, and this impacts on the whole healthcare experience in the hospital, patients ask 'what's a hospitalist? I don't know what a hospitalist is.' We're told that over and over again. My colleagues, who are hospitalists, and were around when it was first coined about 20 years ago, actually by the chair of medicine at UCSF Robert Wachter. They've been around a long time, and patients still ask what the hospitalist is? How is this person different from my primary care provider? And there's confusion that we've been told. That impacts on everything because they're the person leading my team. Even the concept of a team can be foreign. My colleagues, as I say, that were around at the beginning of the hospital medicine journey going, wow, we're back there again. I think other things we've learned; I know all these simple things. I was involved in, the [iHope study](#), improving hospital outcomes through patient engagement.

**Health Hats:** Oh, iHope. Yes. I was there.

**James Harrison:** This was where researchers from across the country, hospital medicine, and we partnered with 37 stakeholder groups from across the country, patients, caregivers, provider groups, research groups. The idea was to find out what were the pain points of being hospitalized or, more importantly, what are the top priorities to improve hospitalization. As a researcher, I was so excited thinking we are going to get these topics no one's ever heard of. And then we are going to be able to go and do research change and have such a big impact. And also, everyone's going to want to fund us because we're going to get these things no one's ever heard of. Most humbling experience. What were

the top things we found? We want shared decision making. Patients want to participate in decisions about their healthcare.

We already know that. We're obviously not doing that. I want to know who to call when I go home after I've been in hospital—one of the simplest things. So, we've been trying to address having phone numbers for patients to call. We're not doing that well, preparing patients for discharge to home or a skilled nursing facility. People are saying, I don't understand what's going on. We've been trying to do that for years. Obviously, we're not doing it right. So. It was through that engagement, as we identified all these problems which we already knew were problems. We thought we were addressing them. Obviously, we're not. And as I say, humbled by this talking to people, that said, I still, despite we didn't find these unique novel needs, priorities that no one had ever heard of. But the fact that we identified the ones that we did pushed all of us to think, okay we need to go back to basics.

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Computerizing decision support 26:28

**Health Hats:** In the clinical decision-making world that I operate in, there's this real push to computerize, technology assist, computer-assisted decision-making. You and I have probably talked about this ten times, over the years, or maybe I'm exaggerating maybe five times, but more than once. It's the human piece first, and then thinking about can this be scaled through computerization? When you're thinking about some of these things that you've been talking about, who is everybody, what are phone numbers, is that stuff that lends itself to technology assist, or is that just very human just fundamentally human?

**James Harrison:** I think in an ideal world, it's a bit of both that the technology can support that human element. Particularly in San Francisco, Silicon Valley's down the road; there's an app for that. We can solve it all with an app. I think that can support a lot of these problems, but the feedback we get from people is we need the person to sit down with us and say who they are and explain who they are. So, I think they have to complement each other. Technology is great, and it really can, it does help in so many of these problems that we have in healthcare. But I think for a lot of the stuff I deal with and working about patient experience, and you really do need that human element added to it.

**Health Hats:** When I worked at Boston Children's Hospital, I led their patient family experience initiative. One of the more exciting projects that I saw there came out of the emergency department where people were inventorying community services when people were being discharged either from the hospital or the emergency department. There was this library that was app-accessed services. It was a lot of work because things are always changing. You can update it; you got to keep it up. People are making decisions when they go home often more about their life than their medical treatment.

**James Harrison:** This makes it hard because the health systems gear to teaching. It's set up to focus on those medical problems, not so much, the life and social concerns. So yes, there's that tension for sure. I think that example you gave of the community resources, technology definitely can play a role. But one of the things that is important is how we implement these things in real-world practices? We can have the apps, decision support tools, research, evidence that all work in theory in research studies. Of course, you need that evidence, but then how do you get people to use them on the busy floor if you're a provider or if you're sick and in a hospital bed? I'm not sure if we need to invent anything else. We've probably got all the answers out there. We just need to know how to implement it. As you know, there's this whole implementation science. It's about how we work out and determine the best methods to implement these tools. A lot of that is through engagement, through working with patients families, providers, health systems, talking to them, looking at workflows and see how we can get these embedded in real-life settings.

Involve stakeholders early 31:01

**Health Hats:** I've become more and more aware of the mismatch between the questions people have about their health, their medical care, their life, and the evidence and the tools. There's a mismatch. Sometimes, I think that these tools are developed, but they're not addressing what people are trying to deal with. So, there's no getting people to use them because they don't necessarily serve a purpose to people.

**James Harrison:** This is why you need to talk to your stakeholders at the beginning when you're developing these things to make sure it's going to be impactful, relevant. We're preaching to the choir here because you and I both have similar views on this, and as much as they say, I'm very hopeful that the world is changing to think more like this, there's still a significant proportion of academic medicine and research that doesn't think this way. That's why there are people like you doing or what you're doing to get that message out. We may be in the choir, but we still need to sing to all the people that don't hear this or understand this.

CDS Connect 32:20

**Health Hats:** I did ask you to look into one of the gigs I have is working with AHRQ, and the MITRE Corporation on CDS Connect, a repository of computable clinical guidelines. I asked if you are aware of it? If you are, what are you thinking? If you're not, would you look at it? Give me your two cents worth.

**James Harrison:** I didn't know about it before you'd sent the email. That said, I'm not a clinician. I think it's probably a great research resource to find out about current guidelines. I saw some tools in there, like decision aids and decision support tools, and so on, which I thought would be useful for me as a patient, as a researcher, or as a clinician. But my question back to you and it links to our previous discussion, how do we implement these? How do we get people to use them? They've obviously been evaluated, and they work then if they're guidelines, some of them are based on evidence. What's the step about how do you get people to use that information in their practice?

**Health Hats:** That's a good question on several levels. There are the traditional people who work on clinician use of that. I think about how do patient-caregiver influencers, patient-caregiver decision-makers, so whether they're a family decision-maker or a pod decision-maker or an organization decision-maker, Are these decision aids useful to people who represent larger groups of people? I think

about how that fits in life flow, as opposed to clinician workflow. Pretty much it doesn't. That's a challenge because it's fairly remote. If we're stuck at the clinician workflow, then the layperson, the knowledgeable layperson. I don't want to say it like that, but you know what I mean. People, who are already familiar with healthcare systems and already familiar with research, how can they use it? It's funny because I've been involved in this for many years and in my gut, this is really important. I think that the first step in improving anything is to have an inventory of what's available. An inventory of what is, that's where you start. And then you can do a gap analysis, and then you can guide it in a good direction. I appreciate the idea of a repository, because then there it is - a library, you go look and, but it's a library of stuff that matters to people? I don't know if I'm saying that right.

**James Harrison:** I'd say matters to you if you have the condition or the illness that it's trying to help. You mentioned there about the workflows, and I think part of this goes back to the implementation aspect. Yes, we need to work out getting into doctors' workflows. Still, it's also how do we engage and empower patients and caregivers to use this information so they can one access it one, to understand it, but then also when they're with their care provider go, okay, how do we use this together? Again, I hope it's not just this overly optimistic view of medicine, but I would hope that's what we're trying to achieve here.

[The elephant in the room 36:41](#)

**Health Hats:** That's an interesting point because I know that, for example, so, you know I have MS. When I have seen the neurologist, and I use chiropractic and acupuncture and massage, and meditation. And the neurologist says, 'I have patients that use that stuff. I don't know that much about it, but I'm into anything that works for my patients. So, tell me more.' I feel like, okay, so that is an opening. And then I can then bring in my perspective or the research that I've done, and they'll help me put it in context. They'll say, well, this, this, and this is good, but this piece, this is contraindicated with over the counter thing, and they'll say, no, this interferes with that? So, we explore together. From that point of view, when I go in, and I feel like I'm more knowledgeable, I can motivate a conversation that's a lot richer and helps me get closer to where I want it. But I'm not any kind of example. I'm out there, I'm an out-there patient, I'm intelligent, and I'm a pain in the ass and, and sometimes I think my clinicians tolerate me and sometimes they appreciate me. Depends.

**James Harrison:** You raise the elephant in the room with a lot of the engagement and advocacy work that we both do is it's always thinking about you're not going to get the be generalizable or representative of everybody. But we've still got to be asking those questions because you're very health literate. You're a pain in the ass, you will speak up when something's not sitting right with you, but a lot of people won't. Thinking about engagement, how do we encourage that engagement from people that aren't as comfortable, familiar with the health system to participate in these decisions, use these support tools that you've spoken about. The opening feels comfortable to mention to their provider. What about this? Cause as you say, it's essential to know that if some of the things you're doing if there are contraindications to something that the doctor's prescribing you or suggesting for you. So, I think we've always got to be mindful of that, that with the work we're doing around engagement is to give voice to everybody. How can we support everybody so that they can be involved in the decision making, whether it be around their own health care or about a research study?

**Health Hats:** well, thank you so much. This is great. I appreciate it.

## Reflection 39:56

*Another signature win with patient family advisors occurred later in my career and resulted in a major ah-ha for the long-term care organization I worked for. I was sharing recent survey results with the PFAC. The survey consisted of standard questions with Likert scale responses (1-5). We were underwhelmed with the survey results and hoped the PFAC would help us improve the survey scores. Instead the PFAC complained that unexpected, unannounced changes in key direct care staff upset patients and families. They had relationships with the staff and suddenly they were gone - no notice, no explanation. It never occurred to us. Easy fix for us to communicate better. Three months later survey scores across all questions improved.*

*In my experience, brilliance is simple. Treat others as you wish to be treated sounds simple. Eight words serve as the cornerstone of many religions - certainly, a north star for me. Simple, but wildly difficult to do. Drink water, exercise every day, foster good sleep, I call them magic levers for good health – simple and tough to do. I love that James aims high and keeps coming back to basics: listen, build trust, foster health equity, communicate understandably, start inclusion early. James is a learning machine. He knows that the basics don't come easy and never go away. They require vigilance and perseverance. Thank you, my friend - good chat as always. Onward.*