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Proem: A Reluctant Keynote Speaker's Confession

A confession: I'm a keynote speaker who's ambivalent about keynote speeches. Give me the hallway conversations, the poster sessions, and the coffee-break connections—that's where my unexpected

learning happens. But when my friend and podcast guest, Mark Hayward Johnson, invited me to speak at the American Nursing Informatics Association conference in New Orleans, I faced a delicious challenge: how do you transform a formal presentation into the kind of authentic exchange that changes how people approach their work?

Grandkid Wisdom

The answer, it turns out, lies in the space between listening and action—and in the wisdom of my two teenage grandsons, who advised me to stop burying the lede and use fewer words on my slides, along with my international colleagues who offered expertise in honing audience engagement through storytelling and keeping the focus on the ask.

Lead with the Lede

The conference took place at the end of March. I received the full professional multimedia recording of the presentation in mid-May, and I'm starting the episode production in early June. Before I can create a lede introducing the episode, I need to clarify its purpose. What action do I hope readers, listeners, and viewers will take after consuming this content?

The lede for the presentation is:

> *Collaborate with patients, caregivers, and their clinician partners to develop and evaluate tools that inform health and care decision-making.*

So, is my purpose to share the recording of the presentation and hope podcast consumers take one more step in partnerships? Or is the process of creating a presentation more valuable to my followers? Can I do both?

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.

Prepare for Action

What is my ambivalence about attending and speaking at conferences? As an attendee, I want to learn a nugget and leave inspired to take a specific action that could alter my path. When I listen, I silence my inner voice that asks, 'How does this affect me?' What do I want to say? So what? However, as a patient/caregiver partner and advocate, listening is the beginning. What did I hear and learn? How does that connect to other ideas and people? How can I adjust? Real change happens when I shift my habits one step at a time.

I had six months to prepare. As a world-class networker, I engaged others in the development of my presentation. My grandsons and international colleagues, who weren't experts in my topic but were knowledgeable about communicating with diverse audiences, leading to action. They asked me what I wanted attendees to leave with: curiosity, connection, energy, and perhaps, take one more step in

collaboration. We discussed using a multimedia approach, keeping the audience engaged, and managing a hybrid conference (in-person and virtual).

This episode focuses on collaborating with patients, caregivers, and their clinician partners to develop and evaluate tools that inform health and care decision-making.

Start with Self-Knowledge

I'm a two-legged, cisgender, old white man of privilege who has MS. I've been a care partner to my grandmother, my mother, and a son's end-of-life journey. I'm a nurse. I have led several EHR implementations. I've held the C-suite position of VP of Quality Management in healthcare and have also consulted. I wear a lot of hats, hence. Health Hats.

MS Detective: Dr. Sherlock

So, when I was diagnosed with secondary progressive MS, my neurologist said, "you don't know anything about multiple sclerosis." I know a lot about multiple sclerosis, but I don't know anything about you. Your job is to learn about multiple sclerosis, and my job is to learn about you. I thought I had died and gone to heaven. Then he said, "okay, so when you come back, I want you to tell me what's important to you." I talked to my wife and kids, and I returned with the idea that I want to progress as slowly as possible. I want to stay safe. I want to keep playing my saxophone, and I don't want to interfere with my pathological optimism. He said, "we can work with that."

Activists, Disruptors

As you can probably tell, I'm an activated patient, and you may be one too. You're certainly an activated informaticist, or you wouldn't be here. Activated people are disruptors. And they are most likely to use the products that you work on, and they're going to make 'em better. The rest of this presentation will help you understand what it is, assess the current situation in your shop, and then you can decide what to do next and how to adapt.

The Bottom Line

The bottom line here is that we're beginning right now with self-knowledge. You learned a little bit about me. You've just learned a little bit about each other. We're going to focus on the triads of deciders patients, caregivers, and their clinician partners. We're going to appreciate people who hack healthcare; we're going to talk about engagement as a dynamic of power. We're going to think about the infrastructure that collaboration operates within. And I'm going to encourage you to take one more step in your collaborations.

Health and Care Decisions, Like Kitchen Renovation

Making decisions in healthcare is a lot like putting in a kitchen. There are endless decisions to make: the cabinets, the workflow, the appliances, and the hardware. Are you going to use gas or electricity? Your budget versus what you want. In healthcare, making informed decisions about health and care is a similar process. My wife and I made decisions about our kitchen together, which really meant she made the decisions, and I cared about a few things. I cared that the heavy things were low. I cared about the

lighting, and I wanted to ensure we had the best hardware possible, as well as plenty of room to move around. But otherwise, she made all the decisions. And it's like making healthcare decisions. I vetted, and I trust my wife and my partner clinicians. Except for a few things that are important to me, I'm happy for them to make the decisions. There are just too many, and it's based on the things I said before. I want to keep playing my saxophone. I want to stay safe; I don't want to mess with my pathological optimism.

However, as informaticists, we don't know who is making the decisions. The work we do needs to benefit all those people, for that whole triad.

Bobbleheads of Informaticists

We're all informaticists. I believe in bobbleheads. These bobbleheads you see here are visible from my desk. Bobbleheads are essential because they give me an idea of who my audience is when I'm doing my work. It's like, who's my audience? You might think of them as personas or use cases.

The diversity of people is just incredible. I find it helps me to think about Bobbleheads, and so there's Scarecrow: if I only had a brain. Informaticists develop clinical decision support systems. Some of you know Rosie the Riveter. My mother-in-law was a Rosie the Riveter. She worked in an automobile plant in Buffalo. Rosie the Riveter is about worker empowerment. And they train healthcare staff on new technologies. Then you have Sheri, the Avenger. My grandkids introduced me to Sheri the Avenger, based on a Marvel comic, and James Bond character Q as a tech-savvy princess. Sheri implements and optimizes electronic health records. Finally, there's Dana Scully, an FBI agent in the X-Files, and she's about hard science. She's a skeptic, and then when she agrees, she's all in. Now we have a sense of who we are.

In Defense of Healthcare Hackers, the Good Kind

Usually, we think of hacking as a crime involving someone intruding into our system and demanding ransom. Hackers are the most dedicated users of systems, adapting them to fit their workflow. They develop workarounds and have innovative uses for the systems. They seek more functionality and spot cracks and flaws in the systems they utilize. Everyone hacks. The EHR was designed primarily as a billing system and excels at that. Regulatory features were added out of necessity, and clinical aspects were subsequently shoehorned in. Patients and caregivers are placed far down the priority list. Therefore, it's no surprise that hacking the EHR is needed; it's structured in a way that invites hacking.

My Hacks

I've done all sorts of different hacking. The simplest one was with my son. There was no proxy log-on. I used his login and password. With my mother, there was a proxy, but it was a pain, and we ignored that and did it that way as well.

I'm not sure about you, but I don't recall a doctor's visit. I work here as a nurse, and I've been in healthcare for 50 years. When I go home, I remember, at best, 25% of what happened. So, I record to share with my wife.

The hack I'm currently experimenting with is the shiny object: AI. I keep a spreadsheet to track what's important to me. It includes the time I play music. It consists of the steps I take every day (I aim for 3,500 steps a day), falls, and my weight. I want to use Claude to create a graphic that I can take to the doctor or any other clinician I'm visiting. And I want it to help me with doctor speak. So far, I've failed. I'm still learning prompting. Perhaps I need a solver.

Call to action

I now have one URL for all things Health Hats. https://linktr.ee/healthhats. You can subscribe for free or with a contribution through Patreon. You can access show notes, search the 600-plus episode archive, and link to my social media channels. Your engagement by listening, sharing, liking, and commenting makes quite an impact. Thank you.

Inevitable Disruption, Pearls

We're here because we're all informaticists, and as an informaticist, I am intrigued by hacks and workarounds. I must confess that my staff, not so much. They think workarounds are a pain, and they often saw hackers as the enemy. How do hackers affect you, and how do workarounds impact you? I'm sure they do. I'm sure that people complain about hackers and workarounds. They're not wrong to be annoyed by it. It's disrupting. It's a problem because healthcare is often viewed as a factory, right? It's a factory line, and its smooth operation is crucial. When implementing something new, the degree of disruption it causes for everyone is crucial.

But once you start to appreciate the value of hacking and start working with people who are doing the hacking, and so patients, caregivers, and their partner, clinicians, and probably you once you start seeing how people are hacking well, that helps you then to anticipate the disruptions that might be happening. What if you had involved them earlier? What if you had involved them from the beginning? So anyway, I've always found workarounds and hacking to be diamonds. They point us to what we don't know. The more I learn, the more I realize I don't know.

Cat Herding 101: Without Losing Your Mind

Let's consider collaboration. I've led two EMR implementations. I had no training in information technology. I still have no formal training in information technology. It was 2008, and I worked for an agency that provided integrated substance abuse services. And we also had a contract to manage the behavioral health benefits for a local insurance company. We had two legacy claim systems, which were, of course, different, with the clinical system being entirely paper-based.

Collaboration: Sharing Your Toys

My boss, in his wisdom, chose me to lead this implementation. As the ignorant person that I was, the first thing I did was invite everybody who was going to touch this system to a seat around the table. This includes patients, caregivers, clinicians, community partners, as well as the usual suspects of nursing, laboratory, radiology, and registration staff. We began before selecting a vendor, and we met weekly for years. People showed up and participated. I learned how to herd cats.

House Cleaning before Reorganizing

I made one huge mistake, being the ignorant person that I was, in not cleaning up the core data sets from these legacy systems. As you can imagine, having two legacy systems and then trying to go live with a new single system was a mess. But I was considered a success. Who knew? The parent health system invited me to lead their transition to a new electronic health system. I insisted that we clean up the core data sets before we started. That was a fight. Then, I wanted to invite everybody who would interact with it to a seat around the table. I was not successful. It's too hard to do. I'd used up all my political capital on the data sets, so we didn't do that.

Partnership from the Ground Up

I served as Vice President for Quality Management at Advocates Inc., supporting about 40,000 people with disabilities in central Massachusetts. This was an exciting organization. They had patients, clients, residents —whatever you want to call the people they served —participating in every decision-making body they had, from the board, if they lived in a residence, to the residents' decision-making group. The people who served in governance had paranoid schizophrenia, brain injuries, or were deaf, blind, or nonverbal. They added a lot—one of the things that I found being in the C-suite is you hang out with this small group of people, and you know what they think and the power dynamics, and it, there's it's tough to get a new idea in a C-suite. One of my jobs at Advocates Inc. was to prepare patients, residents, and consumers for the board meetings.

I also work with the community-based University of Maryland School of Pharmacy in West Baltimore, which has a steering committee that is more than 50% comprised of consumers. They do not begin a service or start any research if the advisory board or the steering committee nixes it.

The Power Dynamics Tango: Who's Leading This Dance?

Collaboration is about power. It's about ego and power, and the more people hoard power, the less they're able to collaborate. Starting to think about collaboration as a power dynamic, you can see that there is a continuum of power, and relinquishing power is challenging for people, including you and me. If you're going to collaborate, that means you're going to listen, and sometimes, people have a better idea than you do. This means you're doing something different.

As you can see, I'm genuinely passionate about collaboration. I've done it my whole career. I've experimented with it. But I am not proselytizing to you where you should be in collaborating with patients, caregivers, and partner clinicians. Every place is different, and you have to be comfortable with

what you're doing. As a change agent, one of the things I've learned is that you can't be more than 15 minutes ahead of your constituency. If you are, you have to go back and get them. That's hard to do.

Foundational Expectations

Collaboration occurs in a context. It occurs in a context of values, foundational expectations, and infrastructure. Let's consider the PCORI, or the Patient-Centered Outcomes Research Institute, and its Foundational Expectations. I want to highlight three of them for you. The first one is diversity and representation. The universe of people is massive. I know it's not PC to talk about diversity anymore but just think about the languages people speak. People may prefer to read, listen to, or watch. People are older, people are younger, some are introverts, and some are extroverts.

Capacity

How did I get started in this kind of work? I'm Health Hats, and I'm disabled. People can check off many boxes. I'm a low-risk participant, and so my job has been to create new seats for people, for more people, and invite them in.

Then there's capacity. At PCORI, people have drunk the Kool-Aid—everybody from the board to leadership to staff believes in collaboration. And we have money. Now what? The capacity of ourselves and our partners varies. There is a lot of work involved in developing the capacity to collaborate effectively.

The .300 Batting Average Philosophy

Finally, there is the ongoing review and assessment, as there is no one way to do this. Failure lurks everywhere. I have failed many times. Frankly, if you really want to know, I've been fired twice and laid off twice. It's not easy. My goal is to bat .300. If you don't know baseball, that means you fail more than you succeed, but you keep going, you swing again.

Culture, Listening, Sharing Power

Now, let's think about infrastructure. I am blessed to wear many hats. I've had a 50-year career in nursing, quality management, and consulting. I'm committed to collaboration. I've done it. It is just what I do. I've always been this way, and I'm always gonna be this way. I often got in my way. I frequently didn't have anything that I needed. My best boss told me I was an acquired taste. My wife says that I need a boss with a lot of self-confidence. My favorite position was being at the right hand of the boss because that's where you set the culture of listening, the culture of sharing power, mutual support, and curiosity. It takes money, staff, and time. It's not easy, nor is it for the faint of heart, but it's worth it. I'm going to assume that most of you would like to increase the amount of collaboration and partnership you do with the triad of decision-makers. And if you're not, congratulations. You should become a mentor.

Next Steps

There are some steps you can take. This is lonely work, and the first step is to find a team who will do this with you. I don't necessarily mean your informatics team; I just mean some other people in your organization who believe in collaboration with patients, caregivers, and their clinician partners. A step is to analyze readiness. So that's first yourself. How ready am I for this? How ready is my team? How ready is my hierarchy? And then to analyze that and think about it in terms of the foundations and the infrastructure. And then you just gotta start somewhere. And if you don't know, phone a friend and experiment. And when I say 'experiment,' batting .300 is fabulous.

Reflection

I thoroughly enjoyed presenting to the Nurse Informaticists and collaborating with my virtual Monday Morning Coffee group and my grandsons. I learned a great deal while embodying collaboration. I received both kind and critical feedback during three sessions from trusted colleagues who had never heard of nurse informaticists. Introducing them to my audience helped me refine the content and flow, especially with the inclusion of bobbleheads. My collaborators encouraged me to add two interactive sessions and a short video, in addition to the Q&As, to directly engage the audience and keep blood flowing to their brains. This was crucial since the presentation began at 8 am, after attendees had a lively late night in New Orleans' French Quarter.

I began preparing four months in advance of the gig, with several opportunities to rehearse. Despite the considerable lead time, I made significant revisions to the presentation in the last week, when my grandson pointed out that I was still burying the lede, and again the night before, during a final dry run with my cousins, who had hosted me. Since my collaborations took place virtually, I was prepared for a hybrid audience.

When I looked out at the audience, I noticed people dragging in and peering down at their phones. Nevertheless, I could sense their laughter and sighs in response to my stories and wry comments. The interactive sessions had attendees share, When did you first realize health was fragile? What next step will you take when you return to work? I appreciated the dull roar in the Ballroom and heavy activity in the chat. My worry about the virtual audience's inclusion and attention proved unfounded as the 120 virtual attendees asked twenty questions compared to the four from the 320 live attendees. Almost 80% of the evaluations were completed, with more than 95% rating the event positively.

Finally, my takeaways from the experience are to walk the talk of collaboration; bounce ideas, structure, and content off trusted people who know how to provide warm, actionable criticism. Connect with the audience through stories, use multimedia, allow space for them to interact with each other, and remove content as needed. Allow plenty of time for the form to iterate without letting it paralyze you. Be ready to rewrite when the advice calls for it. Take opportunities to rehearse, and by all means, don't bury the lede.

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.

https://www.health-hats.com/pod235

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