Build It and They Will Come? 08/09/2020

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Proem 00:55

Regular readers and listeners, you likely sense a theme these past few weeks. Yes. Health Hats exists to learn on the journey toward best health to make health choices and decisions. The journey in constellations of information, personality, technology, culture, and life constantly swirl, seldom aligning. We, individuals, like planets, seem to orbit as well, somewhat habitual, hit with occasional inertia-busting forces. I'm not currently tripping on acid, instead these COVID-19 days feel like meteors that keep hitting and busting our inertia, blasting our strengths and weaknesses in high relief. Without desperately missed federal leadership and rare episodes of alignment, pods of entrepreneurs and connectors rush to fill the vacuum for profit or good works.

One of my many projects is working with AHRQ (the Agency for Healthcare Research and Quality), part of the federal Health and Human Services Department, and the MITRE Corporation to create and populate a repository of computable clinical decision guidelines for public use. As the patient-caregiver representative on the project, I advocate for these digital tools to be integrated into software, apps, and health records that laypeople use. Simply put, I have questions about the medical health of me and mine. I should be able to find and trust research-informed guidance to help me make decisions about treatment and care with my medical team. I participate in these projects to encourage developers and academics to recognize us, laypeople, and our life flows in their design, coding, and use of this digital, computer-ready information. Slow going. Very slow going.

Introducing Cherie Binns 03:19

Health Hats: *My guest today is Cherie Binns, a registered nurse with an additional degree in Gerontology and an Internationally Certified Multiple Sclerosis Nurse. She is a regular presenter of patient education programs for the Multiple Sclerosis Foundation and a writer for MSFOCUS magazine. Cherie co-chairs the iConquerMS Research Committee, is a PCORI (Patient-Centered*

Outcomes Research Institute) Ambassador, peer reviewer, and Merit reviewer and a past member of the PCORnet Engagement Committee. Cherie was diagnosed with Relapsing-Remitting Multiple Sclerosis in 1994 and has found that adopting some changes in her lifestyle has made her MS much easier to manage. Cherie and I work together with PCORI and PFCC Partners. Cherie often provides words of wisdom and common sense in the arcana of research.

Health Hats: Cherie, I'm so glad you could join me. I need your help. I appreciate that you're taking the time. How do you introduce yourself in a social situation?

Cherie Binns: It depends on the situation. If it's a situation where I'm talking to somebody like you, that I've met in a semiprofessional situation, I'll say, I'm Cherie, currently retired from clinical nursing and an internationally certified multiple sclerosis nurse. As I was aging and taking care of more elders, I got an additional degree in gerontology to support that. If I were introducing myself in a situation where somebody needed to know a little about me, I would introduce myself as Cherie, wife, mother, child of God, musical spirit, something of that nature.

Health Hats: Do you play an instrument?

Cherie Binns: At one point in my life, I played 13 different instruments.

Health Hats: Oh, my goodness.

Cherie Binns: Guitar and flute were my main instruments. I haven't done too much in the last few years because MS affected my eyesight to the point where I can't tell if a note is a G or a B. I don't know which line it's on because I see two or three staffs.

Navigating for what ails you 05:58

Health Hats: Can you tell me, in the last year or so, as you're navigating whatever ails you personally, and you are looking for evidence when you're searching for research, deciding should I do this, should I do that? How do you go about researching?

Cherie Binns: Because of my background in nursing and as an advocate, as a home care case manager, I tend to go to professional sites a lot. If I'm looking for the best practices in an area, I might go to the American College of Cardiology or the American Geriatric Society or the American Heart Association. If I'm looking for something treatment-specific, as you mentioned at the beginning of this podcast, we tend to zero in on our area of communication or expertise. I refer to that as tunnel vision. We're tunneled in the field of nephrology if we're dealing with high blood pressure. We're tunneled in the area of cardiology if we're dealing with atrial fibrillation. It's like the blind man and the elephant. Nobody sees the whole picture. If different things are going on, I personally, in addition to living with multiple sclerosis, also have a hereditary propensity to hypertension, obesity, thyroid disease, diabetes. So I'm juggling all these different things. I need to be aware of the various sites for endocrinology or for cardiology or those different disciplines to know the best practices. I think often, you go to the doctor, and your blood pressure might be up a little, and they want to give you something for your blood pressure. It's often trial and error. I've tried just about every class of blood pressure medicine, and they all raise my blood pressure. I have opposite reactions. So, I found one class of drugs with only one drug in that class that works for me. But it took going to those sites and finding out what was recommended and how I might be able to suggest tweaks to that. Fortunately, I had a wonderful nephrologist who kept up on education and cross-discipline.

Health Hats: The clinicians' education?

Cherie Binns: They're good with the cross-discipline and understand why others might recommend certain things. That can often forestall, adverse interactions in treatment plans.

Peer groups, lived experience? 09:04

Health Hats: When you say professional association, you're thinking about clinical professional associations. How do you use peer groups when you're exploring options?

Cherie Binns: You mean like a Facebook page?

Health Hats: Yes. I mean, wherever. People congregate in all sorts of different ways; some belong to the MS Association; some people do Facebook pages; some people do Twitter. I don't know, people do all sorts of different things, some have clinical expertise, and some have lived experience, different expertise. I wonder how do you make use of that angle?

Cherie Binns: If there's a clinical question, if somebody is asking me, I've got this and this going on. My doctor's recommending that I take this disease-modifying therapy. What are the implications? I will take that to the international organization of the MS Nurses chat page. We talk with each other about what's recommended and why? What are the ramifications of following this protocol versus that protocol? As a retired healthcare professional, I need somebody else who understands this lived experience from the same lens that I have. I go to a group that we've recently started on Facebook for medical professionals with multiple sclerosis. We've all got some degree of scientific training. That lens for us is a more professional lens than somebody who hasn't been through medical school or nursing school or physical therapy school or pharmacy school.

Health Hats: So, the combination of a peer with lived experience with the condition plus a similar professional background is a sweet spot for you?

Cherie Binns: It is. Yes. I find that if I'm on a group for people just with MS, for example, we've got a vast range of ages and life experiences. We've got young people who are newly diagnosed who don't know what the future holds. We've got those of us, like myself, who've been symptomatic for more than four decades, and I've learned to navigate it. So you've got the wisdom seekers and the wisdom sharers on groups like that. But I don't often find that those are the best places for me to get the support that I might need at a given point in time, maybe a place for me to lend support.

Health Hats: That makes sense.

Cherie Binns: I think we need not limit ourselves to something that's just self-serving.

iConquerMS 12:00

Health Hats: Okay. Interesting. Tell me a little bit about iConquerMS.

Cherie Binns: iConquerMS came out of the PCORI Patient-Centered Outcomes Research Institute. PCORI has a network of organizations like iConquerMS. Some of them are disease-specific. Some of them are clinical data networks like Duke University, Kaiser Permanente. Those groups do a lot of research and use several organizations. The Patient-Powered Research Networks, like iConquerMS, are generally condition-specific. Sometimes they lump similar conditions together, but they use the patient voice to guide their research. So maybe you're in a later phase of a disease process, such as I am, having had MS for more than 40 years, and you don't necessarily think that a cure for MS is where you need to be looking. Maybe your question is, 'how can I live the best quality of life that I possibly can? What goes into that? Are there dietary changes? Are there supplements I should be taking? What exercise is right?' So, people who are members of these networks direct research along those lines and types. These networks don't support lengthy drug trial research. It might be lifestyle changes. It might be if you're taking this drug, then you may not need to take this drug. It may be things that relate to what we call deprescribing, taking people off of a medication that might have adverse effects and gives minimal benefit or is preventive. I started with the iConquerMS platform about six years ago when the organization got out of its infancy. It's a brainchild of the Accelerated Cure Project for MS, which has been a not-for-profit with a biorepository that share information with researchers.

Health Hats: Biorepository, tell me what that is.

Cherie Binns: There are several biorepositories around the country. Some are disease-specific. Some of them are general for researchers to use. So, a person might donate blood that can be used by researchers to see if they can find, for example, biomarkers that might make them more predisposed to a benefit from a specific therapy. Yes, genetics is a significant area of research where this is concerned. One person donating blood can go to 50 different researchers. So those 50 different researchers might be looking at 30 various topics, but there might be similar data points that are coming out in their research. Biorepositories, patient-powered research networks, and PCORI require cooperating research to share de-identified data with a research network. The researcher gives back the information gleaned from their research to the organization. If, for example, we have a researcher coming to us and looking at mindfulness techniques and does that reduce stress levels? Does it improve mood? How do they measure that in people with MS? We might reach out to our 6,000 plus or minus member database and ask them if anybody is interested in participating with a researcher, collaborating with a researcher on this project? So that engagement might look different at different levels. We might have a group of people that want to help to design the research question. We might have a group of people that want to help recruit to the research project. We might have another group, generally our largest group, that's more than willing to answer surveys related to this researcher's interests or questions. We might have another group that is willing to review the information gathered, and another group that is into disseminating that information. Those are different layers of participation within these organizations, and they'll have a very similar focus on how they handle that information. Many of those practices are laid out by PCORI as suggested ways to do business.

Health Hats: Do I understand that there are standard sets of survey questions that people who are participating in iConquerMS may be filling out over time that's available for researchers to use? Then researchers may have a specific question that they're adding?

Cherie Binns: Adding another layer. When somebody becomes a member of iConquerMS, they fill out a basic survey that gives us demographic information: a white female, 57 years old with secondary progressive MS on this medication at this location. We find that our database pretty evenly matches gender to the national population, and with the National MS Society statistics: about 75% are female, about 25% are male. We do find that our network is a little bit older than the general population. I think that may be because the older we get, the more free time we have to do these surveys and to keep up with things. We also maybe have more experience. We want to add our voice to that experiential gathering of information. We are not as ethnically diverse as I would like to see us be. Something like 5% or 7% of our members are of African descent, and maybe 8 or 9% are of Hispanic descent, maybe 2 or 3% of Asian descent. We don't have as ethnically diverse a group as we'd like to see. It may not fully reflect to some researchers the demographic that they're looking for.

Every six months, we send out all of those surveys again, particularly those that are looking at the disease course. If there've been medication changes, which symptoms are more prominent, what have they found for symptom relief so we can track that individual's specific symptoms and disease course over time? If you've been in the system for four years, you've now got eight different data points. You can see as your MS decreases in severity. Are you sawtoothing? We've also got a diary component, so you can enter starting a new medicine at this date or started an exercise program here or began mindfulness practice and see if there's a correlation between those interventions. And along the course of this, how your disease is progressing. Researchers are looking for that kind of information because there's not a lot of it out there.

Health equity in research 21:12

Health Hats: Let's go back to the question of health equity. How does iConquerMS as an organization work to increase the range of participants and seek out communities that aren't represented as much as maybe they are in the population?

Cherie Binns: We got a PCORI engagement award a couple of years ago to look at minority participation in research. The individuals that spearheaded that within the organization were a couple of African American females and one Latina. They reached out to communities of color and did focus groups within those communities looking at what their needs were, what the perceived deficits were, where they thought fault lay in not getting the same level of care that their white counterparts were perhaps getting. What we saw with all of that was that people want to participate in research. They want to lend their voices. They feel that their voices have value, but nobody's asking them.

Health Hats: Oh, okay.

Cherie Binns: I think that that in and of itself tells us that we need to stop just looking at the people who've come to us, but we need to begin to reach out to others through the resources that we have available. If you're an African American male, you probably know a lot of African American males who have similar life experiences. Start a subgroup, get people together on a specific topic or support arena.

And then share that information back with us so that we know how to tweak what we're doing. I do have to say that after six years on the research committee with iConquerMS, I see a real evolution with the questions that we're asking people. The people that reach out to us to give input, the networks that are being broadened by people sharing. I just found out about this resource, why don't you go check it out? Because I found this on it that I hadn't been able to find anyplace else. So it's that information sharing.

Mismatch between questions and evidence 23:51

Health Hats: In my work, I see the misalignment of questions people asking about their lives, so they're satisfied with their lives and the research that's being done. Often, researchers, the funding for research, or the research that's being done there's a mismatch. What do you think about that? What's been your experience? You're invested in both sides, in the research and the lay person's side.

Cherie Binns: I think it boils down to listening skills. If I want somebody to listen to me and what's important to me, I have to listen to them and what's important to them. So, a researcher is going to come at this from a different angle than a patient. They must listen to each other's voices to see if maybe they're looking for the same result, you're just wording it differently. That's why it's essential to have the patient voice involved in the development of the research question. If you sit down with a patient focus group with a half dozen different patient voices, different ages, different experiences, and they sit with a group of researchers, a two or three-hour conversation can start here go here and end up in the middle. It ends up with both sides being drawn to the center because they find a commonality. Sometimes, the research is contrary to or not yet aligned with the patient voice because the two haven't taken the time to listen.

Community-based research 25:45

Health Hats: Well, another part that often what happens is the money, the power, the questions are with the researchers. Then they seek to embed patients and caregivers in their process.

Cherie Binns: That's a thing!

Health Hats: I'm involved with an organization now in Boston working with community-based organizations to say, what are the questions you are trying to handle, solve, learn about? Then embed researchers in their organization, taking it the other way. What's been your experience with those kinds of community-based research, community-generated, research questions, projects, whatever?

Cherie Binns: I think if you find community organizations that have a passion about getting answers to questions, that have a passionate about service, I'm looking at not so much some of the larger organizations like the National MS Society, but maybe smaller groups like the MS Foundation are more patient-centered. Most of their operating budget goes directly to the patient as programs and services rather than research. If you can activate that voice, if you can put that not-for-profit behind the patient voice, it has greater power than the patient voice alone. There's more significant potential for the embedding of the research voice in that not-for-profit than there is for embedding the patient voice within the research voice. Does that make sense?

Health Hats: Makes sense. When I meet researchers in my PCORI experience, most of the researchers that I know are through my PCORI experience. Those researchers comfortable with not being in charge, work with community organizations, following their lead, and then paying attention to the integrity of the research. But answering a question, working with the communities, those researchers are precious. It is a whole different conversation. I find that I learn a lot more about research from those scientists that are very comfortable with that because they're more patient with my quote-unquote stupid questions and common sense.

Cherie Binns: The only stupid question is one that doesn't get asked.

Health Hats: So, what do you think I should be asking you in this conversation that I'm not?

Evolution of PCORI and patient voice 29:05

Cherie Binns: I want to observe something about PCORI. When I first learned about PCORI, probably seven or eight years ago, when I went to my first PCORI annual meeting, the first annual meeting of PCORI, I saw researchers getting up in panels. I saw the researchers doing the presentations. They might have one patient on their panel, and that patient rarely ever said a word. The evolution over that interim six years has the researchers and the patients giving portions of each presentation in essentially an equal amount of information, but from different perspectives, or they have the patient presenting the information and the researcher giving an alternate view or an additional fill-in view. So PCORI is evolving. Patient voice and research is evolving. We've always been there, but I think it's more important than ever right now that we learn how to most effectively train up those patient voices, help people to find their voice. Help people to target what is critical to them as an individual or to them as a community. Are they food secure? Are they able to get fresh produce that's healthy? Are they in a community where there are farmer's markets or where there's excess produce that can be shared within the community? How do they access that? Those things were shut down with COVID right now. These are real concerns that I'm hearing from people. The supply chain has been interrupted, how do I make sure I'm getting what I need to get to take care of the physical plant so that I'm not at risk for getting sick? We also need to give people an idea of where their voices can be shared for the greatest impact.

Health Hats: Say more about that: where their voice can be shared. Give me some examples.

Cherie Binns: People can call up their local hospital or health system to ask if they have a patient advisory council. If they don't have a patient advisory council if they would like one? Go to Patient and Family Advisory Network, PFCCPartners.com, and ask for information on how to start an advisory network. Get that patient voice meeting and speaking with each other so they can come up with ways to share with healthcare practitioners, policymakers ways to more effectively get the word out or get people to buy into recommendations that have been found to be helpful in improving the quality of life or longevity.

Shift to public health 32:10

Health Hats: Cherie, throughout my career as a nurse and then as a patient-caregiver activist, I've seen such a heavy focus on medical institutions and very little focus on public health. Now that's kicking us in the ass with COVID. We have so under-invested. Taking your MS research nurse experience, what opportunities do you see in that public health versus the hospital arena?

Cherie Binns: We're great teachers. I don't know a nurse in my 45 years as a nurse; I don't know a nurse who isn't a good teacher. Who can't put across to even the least literate among us, whether it be a small child or whether it be an adult who is maybe at the opposite end of the spectrum and is cognitively impaired take a concept to the least and teach it in a manner that can be taken forward. We're so focused in this day and age on illness and tending to illness. We're not focused on health and making health pervasive. To do that, we need to take those messages into the home, into the schools, into the community centers. We need to take it outside of the healthcare institutions. The more of us that have documented lifestyle changes that have improved our quality of life and just start sharing that. I'm not in pain anymore now that I've eliminated sugar from my diet, those sorts of things. There are simple things were a lived experience, an experiential voice in that we can share with people, but I think it needs to be taken into the community and out of the health care institution.

Health Hats: Anything you'd like to ask me?

CDS Connect 34:26

Cherie Binns: You sent me a link when you asked me to participate in that about CDS, clinical decision support.

Health Hats: Yes. CDS Connect is an Agency for Health Care Research and Quality, AHRQ-funded initiative. AHRQ is part of Health and Human Services. CDS Connect is a repository of computable clinical guidelines.

Cherie Binns: You may want to take back to them that it's difficult to search for things from their site. I put in five different queries this morning when I was looking at the site. It says it supports research. I put in a query of multiple sclerosis and stem cell research. Sorry, no results found. I put in a query of aging and brain health; no results found. I put in a query for healthy heart protocols, nothing found. Then two more that were a little less specific. Every query that I put in there were no results to be found. Maybe it's a site that's just being built and hasn't been populated yet. That's what it looks like to me. After that first round, if it doesn't say anything about, please bear with us as we build this site. So, it will not be a site that I revisit. I think that they're not doing themselves a favor by having put the site up without a notification that they're building it and not populating it and not getting information into it as it becomes available,

Health Hats: That's a good point. One of the projects that I'm working on right now is about findability of evidence. It's an interesting dilemma, tagging of resources. Usually tagging, categorization, the metadata (data about data) uses PubMed or medical library types of categorization and not terms that come from questions people have. So, you're in this spot in the middle where you have your professional and research expertise, and you're very in touch with the lay life. You're searching for what's of interest to you and didn't pull up anything - that's the whole business of findability. It's not there, or it's not find-able, and those are both dilemmas. Thank you for that feedback. I'll share that. That's great. Thank you very much for your time. I appreciate it.

Cherie Binns: Thanks for asking me, Danny.

Health Hats: So, we'll talk. I'm sure we'll talk. Okay. Thanks.

Cherie Binns: You take care. Bye-bye.

Reflection 37:36

*Cherie straddles the three worlds of chronic illness, clinician, and researcher. She's a leader, an influencer, and a connector. I appreciate that Cherie took the time to explore CDS Connect. We welcome her critique about findability. She used academic and medical terms and didn't find what she sought. Cherie honed her searching strategies as a clinician, patient, and advocate. She will not likely add CDS Connect to her repertoire. Research and technology often act with a presumptive "*build it, and they will come" *attitude. Unless you're building and marketing an iPhone, that approach is seldom successful. Traditionally, Clinical Decision Support developers view app and software developers as their customers, not laypeople (patients and caregivers). Cherie represents a middle ground – informed influencer and decision-maker. If Cherie had found the library of computable clinical guidelines useful, she would have shared the resource with her professional and advocacy peers and the groups they represent. Sustainable use is the prize. Expanding the diversity of stakeholders at the tables of healthcare governance, design, operations, and learning can help reach the prize. Beyond the diversity of users, laypeople, we seek diversity of skills and perspectives - design and marketing - not just scientists, clinicians, and academia.*

My antenna flickered as Cherie and I spoke about equity in research planning, recruitment, analysis, and sharing of results. Often equity and inclusions conversations focus on matching the proportion of gender, race, and ethnicity in the study participants to the general population. Meaningful equity and inclusion progress occur when studies address the varying needs of less well-represented groups. I saw an example when reviewing PCORI funding requests: budgeting for respite care so caregivers could leave their carees and participate. Brilliant, but isolated. Do you know of other model approaches to inclusion innovation? Please share. I know the righteousness of computable clinical guidelines in my gut. We need a different approach.