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Proem

Learn with people on the journey toward best health. That's my tagline. Getting to best health involves many health and care decisions, big and small, day-to-day. The learning part includes a collaboration between patients, caregivers, and their clinician partners using evidence and experience to inform health and care decision-making. Unless implemented by this triad of patient, caregiver, and their clinician partners, evidence or research is useless, merely ink on paper or bytes in space. Research is rarely implemented unless it's disseminated (shared). Sharing means spreading the word - disseminating research findings to deciders. This podcast is a dissemination tool, along with conversations, conferences, scientific journals, social media, sermons, newspapers, and books. Implementation is doing

something with the research results, like modifying a habit, changing a workflow, taking a pill, or getting help.

Share and Use: Dissemination and Implementation

Most industry investment in dissemination and implementation (D&I) of research results focuses on providers – clinicians and medical institutions, not patients and caregivers. Why? Patients and caregivers are the deciders, the end users, and implementers of their health and care decisions. I prioritize directly sharing research results with patients and caregivers in my advocacy work. I'm grateful that the Patient-Centered Research Outcomes Institute (PCORI), where I am a member of the Board of Governors, strives to meet the challenge of D&I to and with the public.

2024 Academy Health D&I Conference

Whenever I prepare for a conference, I come up with two questions to ask people I don't know. When I prepared for the 2024 Academy Health's Dissemination & Implementation Science Conference, I decided to ask, "How do you scientists partner with patients and caregivers in developing your D&I studies?" and "Why don't more patients and caregivers attend this conference?" The first three people I asked looked at me blankly. Was I having a stroke? Was it my wheelchair or my hat? Then I shifted and asked, "How do you scientists partner with **implementers** to develop your D&I studies?" Eureka, now everybody I asked had thoughts and was eager to speak and let me record.

According to Scientists, What is D&I?

Let's stop briefly and consider some D&I principles and methods that patients and caregivers might find helpful.

- **Dissemination science** studies the targeted distribution of information and intervention materials to a specific public health or clinical practice audience. The intent is to spread knowledge and the associated evidence-based interventions. Communication and Dissemination Strategies To Facilitate the Use of Health and Health Care Evidence (2012). More about references in the show notes.
I'd say *spreading the right message for the right audience, using the right channels in the right context*.

- **Implementation science** studies the use of strategies to adopt and integrate evidence-based health interventions and change practice patterns within specific settings. Communication and Dissemination Strategies To Facilitate the Use of Health and Health Care Evidence (2012).
*I have trouble with the focus on **practice patterns,** which presumes that clinician behaviors and clinical structures are an effective bridge for research to the public.*

Another definition is the study of how best to help clinics/schools/communities implement evidence-based interventions (EBI). Dissemination and Implementation Science to Advance Health Equity: An Imperative for Systemic Change.

This was the 17th annual D&I Conference, with several people on the dais mentioning the irony that, on average, it takes 17 years for just 14% of original research to make its way to practice. This is a tough-to-replicate 2000 published study. Managing Clinical Knowledge for Health Care Improvement. On the one

hand, it took 30-40 years after discovery for handwashing to become accepted. On the other hand, the Covid vaccination was rapidly implemented. I'm loving this rabbit hole. A 2024 article in Translational Behavioral Medicine noted that as few as one in seven (14%) of evidence-based practices are ever implemented, with an additional 4–12 years from guideline issuance to implementation, based on 2021 estimates for cancer treatment —embedding implementation science in the research. I can't help laughing. If 17 years later, this lack of implementation using the pervasive methods must mean that despite spending hundreds of $billion on research, something is fundamentally wrong with our approaches. My conversations with attendees of color, rare diseases, and from countries, not the United States, suggest that they focus more on research with communities and communities with research. Stay tuned until near the end, I'll share a radical story from Ghana told by my guest, Bernard Appiah.

Setup

I recorded six brief interviews with conference attendees. All but one agreed to let me use their names.

NGOs using Implementation Science

Health Hats: How do you think that like NGOs and advocacy groups can make use of implementation science?

Nothing about us without us

Tatiana Nickelson: NGOs and communities are the most important players here because there is a saying *nothing for us without us*.

They like it because who knows better than the recipients of the interventions? So, scientists are doing great role-learning and inventing something, but before politicians do any politics, we need to consult with NGOs, foundations, etc.

NGOs implement every day

Bernard Appiah: NGOs, non-profits, and non-governmental organizations are implementing programs. They must get financial support to do that. They often also have to write reports to funders. NGOs involved in implementation science can provide excellent resources for scholars because these institutions implement programs every day. So, having people with expertise in implementation science and those who are also working with NGOs can help ensure that they will improve the conditions and share the lessons and stuff like that with the scholarly community. So, NGOs are particularly key when it comes to implementing products.

Understanding the caregiver's experience

Catherine Hoyt: My research is to help young children with sickle cell disease and their families access the services they would like to have access to. I want them to be available so the families and the children can make the right choices for them. So, the implementers are both caregivers who have a

young child with sickle cell disease, but also should they choose to go forward with what we call early intervention. The implementers would then be physical, occupational, and speech therapists.

Health Hats: How were they involved in the study design questions, data analysis, and the research process?

Catherine Hoyt: In the poster you saw today, we focused on understanding caregivers' experiences with early intervention and screening for developmental delays in general, whether that was a positive experience, negative or neutral, and whether these services were desirable. We partner primarily with the St. Louis Sickle Cell Association and Rosemary Brits, a federally qualified health center chain. She was the founding director of the St. Louis Sickle Cell Association.

Research questions from implementers

Nadia Sam-Agudu: These people must be involved when designing my implementation research projects. Because I am one of them, my implementation research questions come from firsthand issues with implementation as an implementer. I naturally draw implementers into the work that I do.

Align the language

Bryan Ford: The D&I models framework that we're here showing off. It helps folks with limited implementation science skills use theories, models, and frameworks. And that for folks who don't speak the language is to align the language across multiple groups and levels. It can bring together groups with multiple understandings at various organizational levels and work toward the same goals.

Health Hats: But how are non-scientists accessing and using those tools?

Bryan Ford: Within this tool, we break down in the plan section, we break down a worksheet that helps people work through what constructs are important to them.

Health Hats: Okay.

Bryan Ford: And so effectively, a construct is just a concept that would be important to a group by breaking it down to the simplest part of planning a project. They can align what they think is important, choose a theory model or framework, and determine if they need to combine or adapt it. And then figure out how to use it within their project. Today, we're showing off the assessment section, which assesses whether their actions were effective or not.

Facilitating implementation

Health Hats: How do you think NGOs and community groups could use implementation science?

Anonymous: I'm a trained implementation facilitator. I see implementation and the implementer's role as they become the subject matter experts about the intervention. The subject matter experts are not necessarily from a healthcare standpoint—they're not doctors, nurses, psychologists, or practicing clinicians—but they become the subject matter experts in the process of implementing the initiative. And that's their role is to shortcut things, to make sure that. The information needed by the team, every team member, and varied by the team member and their role in it is given to them so they can run with it and get the innovation in place faster. It's the implementer's role to make sure that it happens. I guess they use project management on some level to ensure the right things are happening. But they have the vision; they have the 35,000-foot vision of what is supposed to happen. And which project people often focus on their role In the process.

It's the implementer's job to see everyone's role and where it fits together overall and provide the resources, skills, and training information. It is necessary to ensure the excess of each one of those people.

What is Dissemination and Implementation Science?

Once again, let's review simplified Dissemination and Implementation Science descriptions.

- **Dissemination science** studies how to best package and communicate evidence to different audiences. Core concepts include the right message for the right audience and using the right channels in the right context.
- **Implementation science** studies how to get evidence-based practices and habits adopted in real life at the personal, organizational, and systemic levels (as opposed to in laboratory and controlled research settings). When I look through the literature, I find studies about measuring success in implementation. Did the evidence reach the right people? Who are the right people? What made a difference in uptake? The implementers are the triad of patients, caregivers, clinician partners, and community groups (NGOs). Their relationship with researchers is symbiotic. They need each other. History, culture, and power dynamics impact those relationships.

Implementers at the conference

The presence of implementers at the D&I Science Conference may be a measure of the success of the nature of the implementer-researcher relationships.

Health Hats: Maybe my perception isn't accurate, but there aren't many such people here at this conference. So why do you think that is? It's like we have these panels, and there are scientists up there, but where are the implementers? The people that are doing the implementation? Why do you think there aren't more?

More intentional invitations

Bernard Appiah: In general, for one to be able to attend this conference, in many instances, you have to submit an abstract. People working with NGOs aren't necessarily scholars. It could be that not many of them are even applying.

Health Hats: To come here?

Bernard Appiah: Yeah, but it could be that the organizers are not making much effort to reach out to those who are implementing and not necessarily waiting for them to submit proposals. We can be very intentional about bringing some people on board, but we can also open up opportunities for them to apply. There's a good thing about this conference: they sometimes bring in advocates. They give some opportunities for a few advocates to come. But if we can have more practitioners here.

Partnering with Pharma

Bryan Ford: This conference focuses more on science. Other conferences focus on the implementers. There's an opportunity to bring in more. Yesterday there was a meeting with industry partners to figure out where the gaps are between industry and academics and try to figure out where a partnership could happen. Bring in more rigor to what's happening in the industry.

Health Hats: How do you define industry?

Bryan Ford: Well, yesterday, the partners I know of were pharma - bigger industry. From your perspective, community organizations and things like that are opportunities for future meetings, to bring in and have a meeting. It's a little challenging because the context varies so widely. We work in Colorado, and where we sit in Denver, a highly metro, urban area. But most of Colorado is rural, so we need to ensure that our partnerships have a very diverse set and potentially different partnerships. It might not even make sense to mix them in some cases.

Paying for implementers to attend

Catherine Hoyt: I think fewer implementers are present because it's super expensive. This conference is expensive for me

Health Hats: Expensive in terms of the registration? The travel, lodging, that kind of stuff.?

Catherine Hoyt: Everything. So, compared to some other conferences that I attend, the registration for this one is quite high. But as I'm thinking about conferences and have attended something else this year that was intended to bring together researchers and community partners and funders, too, for that matter. I noticed that there wasn't a track of learning or engagement that benefited the community partners.

So, when we look at the conversation topics, they're mostly centered on research methods or results. They're intended to be communicated to a scientific audience. If we're going to have more effective collaborative meetings, we need to be designing for that intention. And if we are going to invite community partners, there need to be laid out conversations and expectations that people are paid for their time, that their travel is compensated, and that there's a win, there's a reason and a benefit to

attend. That could help them build their nonprofit, that could help them develop more effective collaborations, and better understand perhaps the research process that the researchers have spent a long time learning. But how can you better develop those? Collaborative conversations, and if there isn't a win, why would you attend?

Experts don’t have all the answers

Anonymous: I found in talking to many of my colleagues involved in different projects and programs over the years that they don't realize that's what they're doing. And so they don't recognize that conferences like this are for and about them; they're a bit disconnected because it's not been put to them yet that this is exactly what you're doing. It's interesting to me that implementation science now is what we know about 30 years and several decades into it, and even the most schooled experts don't know it all. We don't all have the answers. And we haven't been able to communicate it in a way that people understand that they are doing implementation science. They are doing the implementation work needed to take great ideas that we know can be. Successful and to put them in place and not put them in place in one location. But to make them scalable and sustainable. And I think if they realized that's what they were doing and they had, once they recognized that about themselves, they would see it in others and be able to work together with them. So that we could make not just local changes but larger system changes through implementation.

Implementers outside the United States

Nadia Sam-Agudu: This is one of the premier implementation science conferences in the US and worldwide. Part of it is that researchers established it, as well as research funders and people with degrees in the field. So, it started with a strong theory component and focused on researchers and funders of research. And so, it didn't leave a lot of space for people who were implementers or people who were outside of the US, to be frank.

Cost and time

Tatiana Nickelson: I'm probably not the right person to ask about barriers, but I see patients and people from communities have jobs. They are active, but they need to make money somehow. So, they cannot just leave their jobs for four days and come here. Another problem and barrier may be the price of attending the conference. I don't know if there are scholarships available.

Health Hats: There are, but they need to be invited.

Tatiana Nickelson: Definitely, they need to be invited and informed about the conference. You are involved, but most active patients don't know that such a conference exists.

Radical dissemination by radio

Health Hats: The real reason I wanted to talk to you was that I loved your comment about how you communicate in your community with storytelling and play. Can you tell me about that? It is so cool.

Bernard Appiah: People love drama in Sub-Saharan Africa and many other low- and medium-income countries or regions. We have what we call education and entertainment. Combining them, we say edutainment. So, when you have drama, which is serial, meaning that the next episode follows the previous episode. People want to know this week: what thing happened to Bernard next? So, that alone is enough to motivate people to want to listen to the program. Now, we also have to find a strategy to make more people want to participate. We say birds of the same feather flock together.

Ten + ten + thirty

Community health workers have been engaging with community members. Why don't we involve them in the delivery of this messaging? So, we decided that instead of the typical programs where doctors, pharmacists, and nurses are the ones who go to the radio studio studios and talk, we want to train community health workers to be the people who go to the studio and discuss the drama. We also want them to be the ones answering questions from the listeners. So, we designed a radio program called 10 plus 10 plus 30. The first 10 minutes is the 10-minute drama, and the next 10 minutes are 10 minutes of discussion where a journalist will ask two community health workers in the studio, Hey, in this drama, Bernard did this. Why did you think he did that? They will answer it. Then, after some time, after 10 minutes, the next 30 minutes, they open four lines and say, Hey listeners, we've been talking about this.

Now we want to hear from you. Then, they had questions they asked, and then the generalist picked the question and gave it to the committee workers to answer. When we did that in Ethiopia, vaccination rates increased so much. In Ghana, we also use that on childhood nutrition, and it improved significantly. We published the Ghana project last month. We published the Ethiopian one in 2022.

Health Hats: That's so cool. I am a multimedia producer. This is music to my ears; it is just music. So far that's the coolest thing I've heard at this conference. Are any of these recorded?

Bernard Appiah: They are in the local languages.

Health Hats: There's translation.

Bernard Appiah: That is the thing also about radio. Local people use their own voice. Missing in the scholarly world is the fact that we are not using radio for interventions.

Health Hats: It's so cool.

Reflection

Do you hear a theme? Invite implementers, pay for their time and travel, and redesign the conference to demonstrate collaboration. This is patient partnership 101, as seen in PCORI's Foundational Expectations for Partnerships in Research. Academy Health and the D&I research community are moving toward more partnerships.

The Foundational Expectations for Partnerships in Research update the 2014 PCORI Engagement Rubric and provides expectations for meaningful engagement to advance patient-centered comparative clinical effectiveness research (CER).