

The Implementation Science at Work Podcast

Transcript - Episode 5: Planning for Sustainability

Guests: Rachel Shelton, Associate Professor, Sociomedical Sciences, Columbia University

Host: Meera Kumanan

October 2022

Meera Kumanan (00:00):

From the Impact Center at UNC's, Frank Porter Graham Child Development Institute, this is Implementation Science at Work. You might hear a few unavoidable phone notifications in this episode. Please ignore and enjoy the following content. Today's guest is Dr. Rachel Shelton from Columbia University. Dr. Shelton is an implementation scientist with a focus on equity, sustainability and cancer prevention. In this episode, she talks about her work with the National Witness Project, which is a community-based, storytelling-driven program designed to increase breast cancer screenings and mammography among underserved African American women. Welcome to Implementation Science at Work. We're really excited to have you here. Could you start us off by sharing a little bit about your journey to implementation science, how you got started, and what projects you've been working on?

Rachel Shelton (01:02):

Happy to be here. Thanks for having me. So I will say really the partnership that I started, I guess it was around 2009 with National Witness Project really brought me to the field of implementation science. So, you know, I had been doing work for some time on kind of issues of equity and cancer screening, but I kept feeling like I was getting further removed from really translating that work into kind of having impact on the ground, particularly in community settings. So I was doing work on, you know, racism and how it impacts cancer screening. But I really wanted to think about, you know, are there already programs on the ground that are addressing health inequities, that are addressing a lot of the root issues that we talk about in terms of, you know, structural factors, issues of mistrust, experiences of discrimination. So one of my mentors was already doing work with this really amazing group of African American cancer survivors and lay health advisors who developed this program, kind of a peer-led, community-based, you know, assets-based that really provides kind of group education navigation support. It's really this empowerment model and you know, provides role modeling where peers from the community really help women kind of navigate the systems, learn how to communicate and provide education around cancer screening. So I connected with this program to really understand, you know, what was the impact they were having on their communities. And you know, when we started partnering they said, you know, that's great. Spend a lot of time getting to know them. And

they said the issue that we really care about are issues of sustainability.

Meera Kumanan (02:39):

Today's episode focuses on sustainability. We have talked a lot on this podcast about how do we use implementation science frameworks and theories to translate evidence-based practices into community settings that are culturally appropriate and accessible. Today with Rachel, we're gonna be talking about sustainability. How do we make sure that the programs that we implement remain successful even beyond our involvement? Rachel, could you talk a little bit about sustainability when it comes to the National Witness Project? I know they've been around for quite some time and that you've been a partner with them for a while as well. How have they remained so strong in their success, especially with changing cancer screening guidelines and just overall changes in public health practice? How long had they been around before you started working with them?

Rachel Shelton (03:27):

At that point, they had been in place about 20 years and right around kind of the economic downturn, they had lost about half of their programs. So they're an exemplar in terms of sustainability to be in community settings and be around that long, I think, you know, speaks to the strength of the model in terms of being community-led, being strengths-based, addressing an important gap in terms of health inequities. But despite that, you know, there were challenges with sustainability. So we partnered around then and wrote a grant together to think about understanding some of those challenges, understanding how we could better support lay health advisors and navigators and cancer survivors in those roles. And now 12 years later, we're still doing this work. You know, we had periods of, of funded grants together, times where we're not unfunded. But the goal of that work has really been to understand how can we support and sustain, again, community led programs and really understand the factors, the multi-level contextual factors that impact sustainability in these settings and really think about how we can bring an equity lens to that and identify, you know, not just those surface level factors, but a lot of those more policy and contextual factors.

Rachel Shelton (04:36):

And then really think about long term, how could we actively impact what are the strategies we could use to actually plan for and support sustainability in these settings. So that's a lot of the work that we've done. And again, they brought me to this area of implementation science to really try and answer these questions because I know that will, it will actually be translated, you know, they're doing this work no matter if I'm involved. And so really trying to think about how can we answer questions that are meaningful, that will have impact and that are priorities already for communities was really important.

Meera Kumanan (05:07):

Thank you for sharing. I think your journey parallels a lot of peoples in starting in that

research arena and then moving into the focus on translation. And what I appreciated most was when you said that the work is gonna happen regardless of whether or not you're there. And I think that's a mindset that all of us in community-based work should have. Right. With the national witness projects origins and the development as a community-driven and owned initiative, do you think that it's almost the prerequisite when we're talking about sustainability? Do you think that the reason it has been around since the nineties so successfully is because it was strongly grounded in the community and whether or not an academic or an institutional partner was involved, they were gonna keep going with their initiative?

Rachel Shelton (05:51):

Yes, absolutely. I think that for them is one of the number of reasons why they have been sustained and so impactful despite all of the challenges and lack of resources and all the funding issues that we can talk about. You know, I think that that is one of the biggest challenges that we face in implementation science is, you know, we often have not involved early on the community's experiencing structural racism, structural barriers to health. You know, as we're developing the interventions, they're not always involved in co-creating those, right? When we develop and test them, they aren't necessarily reflected in a lot of the evaluation trials. And so often there's this really big disconnect between the evidence base, like what we're actually trying to implement and sustain, and the reality of a lot of the populations, you know, and settings experiencing inequities. So I think it's often not a surprise to me that we're not able to sustain if we're not making those connections early and we're not thinking about issues of feasibility, resources, acceptability, cultural norm strengths, you know, if it's, if there's such a disconnect. And if a lot of those interventions aren't even seeking to address equity or addressing a lot of those structural factors. And it can just reinforce, I think, when there is that disconnect when the evidence doesn't reflect their lived experience or hasn't necessarily valued that there's kind of this disconnect and I think it can really reinforce some of the mistrust and kind of lack of trustworthiness that a lot of research institutions have to address. So I think there's a lot of connections between equity, community engagement and sustainability.

Meera Kumanan (07:27):

Definitely. And while we're acknowledging that mistrust, where do you see the ideal fit for a researcher or a public health practitioner to ensure that the partnership is mutually beneficial and we're uplifting the community while still providing some of those institutional resources that are helpful? And what are the discussions that we should be having when we're starting out on these implementation projects?

Rachel Shelton (07:50):

Yeah, I mean I think it goes way back to even a, like what are the research questions we're asking, right? And again, not doing this in isolation in our silos, right? Often it is like in these academic settings where we're, you know, developing these interventions and then, you know, we get to the real world settings and there's, there's just so many challenges

with that. So again, we have to be thinking much more about kind of the decision making, the resource and the power distribution, not in that translation phase. It has to be upfront in the co-creation and the development, right? We have to be identifying what are the solutions, the community-driven solutions that are maybe already being delivered but haven't been evaluated. How can we partner with them to kind of provide resources and support around that? How can we think about, you know, it requires shifting a lot of our institutional norms, right?

Rachel Shelton (08:42):

And our funding practices in terms of the models we have for funding. But I think we really have to adapt and expand our notion of evidence base who's involved in that co-creation, if we truly want to kind of transform what the impact can have in terms of sustainability and equity. So, you know, often this takes a long time. This is not something where it can just be about a research grant. It usually has to be much broader and has to start with the community, identifying what's important to them, and then kind of taking advantage of opportunities that might come along where there are resources to put towards that, right? And then having plans in place, like how can we continue the, the relationship? What are things that we can bring to the community? What can we learn from them to continue that when there's not research in place?

Rachel Shelton (09:29):

And then when there are opportunities again to really synergize around that. And it can't, again, just be about the publications. If we're getting the work done, how are we then bringing those results back to community? You know, what's the kind of translation and impact? And we have not, you know, often as researchers, we haven't been trained to do that. Well, there's often such a, a disconnect about that. But I think if we are kind of developing and testing these interventions, making this investment right, with communities and then things are discontinued or not sustained I think it has huge implications, right?

Not just for our individual relationships with the community members, but our institution and what we represent, right? It's gonna, again, workforce and they might be less likely to engage your system probably will be frustrated, right? Whatever the implementers or, you know, because of all that wasted time and resources and the implications it has for them to be able to engage. And then the funders are frustrated because they've made this investment. You know, so there's some real issues I think around accountability, trust, mistrust trustworthiness for our institutions in doing this. Well, and I definitely don't have all the answers, but I think it's important that we at least start to think about it.

Meera Kumanan (10:39):

From your experience in doing this work and talking about it, what do you consider as some of the top priorities for implementation scientists and practitioners when it actually comes to sustainability and equity?

Rachel Shelton (10:52):

Yeah, I think there are just a couple issues to consider, especially with, with implementation science and equity. I think one is we often think about things as very one directional and we'll do kind of our, our implementation work and then we'll leave, right? And I think we have to be thinking about kind of strategies that are much more focused on capacity building, right? If we're, if we're gonna engage communities, we have to think about what are we leaving, you know, what is maintained in terms of whether it's the skills or the resources or the infrastructure or a policy shift. So I think we have to be thinking much more about the capacity building that happens during that implementation phase. And again, kind of planning for sustainability, not at the end, not waiting until the end. You know, we have really thought about being really intentional and tracking all those metrics along the way to identify when and where and equities arise so that we can actually promote, make adaptations and kind of plan for sustainability.

Rachel Shelton (11:51):

So that's one thing that I'd say. I think the other thing is there's been some really interesting work that's been done by Juliet Iwelunmor, who's done work looking at at sustainability in low and middle income countries and focused on Africa. And she's found that the strongest predictor of sustainability in those settings is the extent to which the community's engaged and the adaptation and the community ownership and the mobilization upfront. So even if they weren't involved in the development of the intervention that they're involved in, they have some ownership, right? To make adaptations and to ensure that it kind of addresses the political and social context and political context might be completely different than the original. So I think, I think that piece is really critical.

Meera Kumanan (12:34):

That's really interesting. I'll definitely have to check out that work. And I've heard you talk about this as well through the National Witness Project in that having those champions and partnerships, and not just in the community settings, but I've heard you talk about academic and healthcare settings is really critical in securing resources, whether that be space funding, the organizational infrastructure to really bring that stability that's necessary for sustainability. And I think that, you know, that work and yours is a really good reminder that while there are definitely uphill battles when doing CBPR work with the current institutional structures and power systems, it's not just the right and equitable way of doing our work, but without that initial capacity building and partnership forming, we'll never really see outcomes either. And so it's important advice and I think it does a really great job in connecting with your other focus in equity. You mentioned how equity is what really sparked your focus in implementation science as it related to cancer screenings and health disparities. Where do you see equity and implementation science frameworks overlapping and how can we use them in implementation practice?

Rachel Shelton (13:44):

From my perspective, I think a lot of us in the field of implementation science were brought to the field because we have such an interest in addressing and equities. And we all have been kind of doing this work with partners thinking about this. But then, you know, in a lot of the frameworks and metrics and everything we've been applying over the last 10 years, you know, equity has been not necessarily explicit or foundational. A lot of the frameworks have been developed in, you know, more academic, you know, organizational settings that again, don't necessarily reflect a lot of the community and co social contextual factors, particularly that matter for equity. Like we have rarely mentioned things like power. We have rarely mentioned like actually naming like how structural racism is operating or might influence the adoption and implementation and sustainability of intervention. So I think we're seeing a shift where people are really making the connections and people are really now thinking about how do we make this explicit and foundational in, you know, in everything that we do in the field.

Rachel Shelton (14:44):

So we're starting to see now this, this shift which is exciting and this momentum. And I think for me, me, it's really about not doing like this one size approach, one size fits all approach. You know, health equity means very different things based on the context, the population, the setting that you're working in. So I think really being really specific and concrete about, you know, what you mean when you're doing work on health equity is critical. So it might be about really reflecting on, you know, again, this issue of who was involved in the development and the selection of the intervention, right? For whom is an, is an intervention evidence-based whose perspectives have not been included. And if that is the case, maybe again, either broadening our evidence-based interventions or thinking about how they can be adapted or refined with, with the communities that we're working with before we implement them.

Rachel Shelton (15:37):

You know, as we're doing our contextual assessments being really explicit about all those factors around mistrust, structural race and discrimination stigma, the power dynamics, all those factors that haven't received attention but that we know really matter for implementation and sustainability in order to have an impact on equity. So again, even if that's not the focus, even if we're not trying to shift those in the context of our implementation trial, we have to understand and recognize some of those historical relationships. How things like residential segregation have long lasting implications in terms of which settings even have access to evidence-based programs and which don't.

Meera Kumanan (16:17):

This is a field where we love to measure things, whether that be our process evaluations, our outcomes, are we meeting our implementation goals or sustainability goals and our funders goals. So how do you keep equity and sustainability in mind when you're actually at that measurement phase of your work?

Rachel Shelton (16:37):

We have to be partnering with communities to understand what is meaningful to them, how are we tracking that in terms of our equity determinants and our outcomes? And then again, not just waiting and publishing on those, but actually returning that data, learning from that, right, refining and adapting and sharing that information. Cause I think right now we have a lot of ideas, but we don't have a lot of evidence on how to do this well. And I think all of us are at the phase where we're kind of reflecting how are we conducting research and implementation science that isn't inadvertently reinforcing inequities, right?

Meera Kumanan (17:11):

Oh, definitely. And it's a point that we've touched on a lot in this podcast. It's difficult to have the level of self-awareness, especially in a field that's meant to be equity driven and really question if what we're doing is truly changing existing power structures or just further contributing to them. As someone who's also starting out in this field, do you have advice or some examples on ways that we can actually implement this equity driven mindset throughout the scale of our work? And what are some of the ways that you are doing that with the National Witness Project?

Rachel Shelton (17:45):

Yeah, I can give a couple examples. So with, with witness one thing that has become so important and because really again, that return of data and again, not waiting till the end. So it's made me much more aware of being accountable to really lifting up from them, learning from them, refining the frameworks around sustainability that we're testing, learning from them and reflecting on what's missing, giving them that data to use for grants. And then now we're at the stage where we're really thinking about co-creating those sustainability strategies, right? It's not me looking at this like taxonomy and saying, yes, yes, yes. But saying like, does this resonate? Is this feasible? Do you think this would address some of these issues around equity? So, you know, really working with them to co-create those strategies and those frameworks. The other thing that we're doing in all the studies I'm doing now is thinking about are we including settings that reflect the range of experiences and populations? Cuz I think often in implementation science and a lot of these large trials where you have like 40 to 60 sites, you get the sites that are like more resourced and more motivated. And so I think that's a way where implementation scientists need to be a lot more intentional in thinking about the settings and populations and organizations that are reflected or not.

Meera Kumanan (19:03):

What about some of the strategies that may be more community led?

Rachel Shelton (19:08):

Yeah, so there's a couple ways that we've thought about that. So National Witness Project has kind of done some of that originally on their own where they would have kind of

meetings where they would come together and share lessons learned around implementation challenges, things that worked or didn't. And then amidst c that became really challenging, you know, just because now you know there's nothing in person. And so now one of the sustainability strategies that we're really thinking about is really bringing everyone together, all the sites together to learn about successes, challenges, how they're addressing them with respect to equity. Like some of them, you know, have really had to pivot amidst COVID because a lot of the populations they're working with are addressing, you know, are facing things like food insecurity housing insecurity. And so really thinking about how can we adapt to address the needs of the population and think about kind of expanding the model to promote its sustainability, how they might be able to kind of share resources, best practices around some of that.

Meera Kumanan (20:12):

It's also really interesting that you mentioned the population shifting just as you are. I remember from some of the data reports we worked on last summer, a lot of the National Witness project population was aging and that came with changes in cancer screenings and other considerations that, you know, you hadn't really considered at the onset of the project. And going back to this idea of sustainability, what are some of the strategies that we can keep in mind to grow alongside the community so that it truly is sustainable?

Rachel Shelton (20:43):

Yeah, that is such a good point. And there's this whole notion and implementation science of this dynamic sustainability, right? That it's not like this end goal and that, you know, over time, again, our context change, the scientific evidence change, the population needs change and we have, if we wanna sustain, we have to adapt to that. I mean, I think about it all the time with witness because it's like no one can do, you know, the mammogram and the cervical screening if they're not addressing these other social needs. So I see those adaptations as going hand-in-hand with sustaining the program. I think part of it is though is just thinking about we often when we make these adaptations, we think about them or we have thought about them as deviations from fidelity. So it's more about understanding, you know, how does the program continue, but also how does it adapt and evolve in response to changing population needs and context and what's the, you know, we often don't think about what are the implications of that for sustainability.

Rachel Shelton (21:42):

We don't track that kind of return on investment and I think that's a real last opportunity. One thing I'll say related to that is, you know, we've really been looking into this notion of like how do programs evolve and adapt over time as the evidence changes? And one thing that we really learned during COVID and and pre-COVID was, you know, the cancer screening guidelines have changed a lot in the last 30 years since the program's been in place. And we wanna understand whether or not they were adapting or not to it and whether or not they were taking out breast self exam, which is a part of the program or updating the screening interval or age. And it's been really illuminating because all the

sites, you know, have really high knowledge of the guidelines. They're aware they, you know, they have the new curricula, they have the new training and everything, but they really feel like the guidelines which is accurate do not reflect their lived experience of black women.

Rachel Shelton (22:35):

You know, they're not, most of these guidelines or have not included large numbers of Black or African American women and they have, you know, Black women have more aggressive tumors at younger ages, so they don't feel like the data that's informed the guidelines and the science reflects their population and experience, right? And so for lots of reasons, they're distrustful of it. And think that, you know, doesn't reflect us, doesn't reflect our values and lived experience. And also it's just gonna keep changing. And if we adapt to this, you know, women in the community are gonna say, you know, are gonna distrust us, we're gonna lose that relationship. And you know, also the breast self exam is often how a lot of the cancer survivors in the program identified their own cancers. And so it's been such a foundation. So they've really shifted that framing of the breast self exam as being an empowerment tool a tool that they can use and really frame kind of a shared decision making model and communication with their provider or with other women as opposed to saying, you know, this is a screening, a screening tool.

Rachel Shelton (23:36):

That has been, I think for me it's really reframed a lot of my thinking about how we should be introducing these changing guidelines and really weighing the benefits and potential harms making adaptations when again it might reinforce some of those issues of, of distrust or, or lack trustworthiness of institutions and science.

Meera Kumanan (23:58):

Right? Definitely. And I think it also makes us rethink what we consider as objectivity and evidence if it's not aligning with our community's lived experiences. And I really think that we're going to have to radically reimagine knowledge creation and dissemination to include these lived experiences rather than just dismissing them as anecdotal, especially within our western academic apparatus. But that might have to be an episode all in film. So to conclude today's episode, what is the vision you see for the field in the next 10, 20, 30 years? Where do you think we're headed? Where would you like for us to go? Any last parting advice for our listeners?

Rachel Shelton (24:36):

Yeah, I would say it is such an exciting time because I have never in my life seen such an evolution and growth of the field in such a quick time. You know, it started out kind of very academic and I, what I love is that there is appeal to people no matter whether they are interested in kind of being researchers or if they're practitioners or if they're organizational leaders at the policy level. And globally, like there is such, there's such relevance to the work and I think it has such potential. I think my hope would be that I think a lot of the work,

again, has tended to be so research focused. And my hope is that we do not kind of continue to contribute to the delay in terms of the translation through our own channel that we used to have impact.

Rachel Shelton (25:30):

So I would say that, you know, I think we have to, I don't know if it's a shift in the field in terms of who we're training, how we're training people or what we're rewarding and a lot of our institutions so that it can be aligned with actually having that impact, right? Not just doing the, the research on implementation science, which is important, but that we're taking it next step and next level. So I think that, and then I think where the health equity piece is not seen as like a niche or specialized area, but that it again, is integrated into everything that we're thinking about. I think both the, the community engagement piece and the equity piece should be kind of like the foundation from where we're starting. And that I think that we're starting to see that. But again, I just hope that it's not just kind of these ideas and that we're able to like actually operationalize that and then have impact.

Rachel Shelton (26:20):

Because I think, again, many of us were brought to this because of that, but I don't think we've had that translation in terms of applying implementation science to actually have an impact to reduce inequity. So that, that would be one of my greatest hopes for the field. And it would be great if everyone is trained right so that we all, it's not seen as like a specialized knowledge, but again, can be kind of a widely accessible field. Cause I think that that is, is such the beauty of it to me. Like I love it when community partners are excited about it and hear about it and want to learn the frameworks and the skills. So how can we, you know, spread the impact of that to everyone more broadly I think is important too.

Meera Kumanan (27:03):

I mean, that's what this podcast was kind of worn out of as well. And it's really cool to see so many other people doing that work of making implementation science approachable and accessible to everyone in this field. And, you know, speaking as a student in your class this semester, I really appreciate your efforts to do that both in the classroom and in your practice. And I'm always excited to hear you talk about your work. So thank you for joining us today.

Rachel Shelton (27:29):

Thank you. That is so exciting. And I think that's, that's a challenge we face in the field is that the, it's not that the language can be a hurdle, right? It doesn't feel that accessible and there is all this terminology and a lot of confusion of like, you know, all the frameworks. And so I love that you're doing this to make it more accessible and kind of the storytelling piece of it is so important. So thank you.

Meera Kumanan (27:53):

To learn more about the Impact Center's initiatives, visit impact.fpg.unc.edu. This episode was produced and edited by Meera Kumanan, Original music by Robin Jenkins, Artwork by Julie Chin. Special thanks to concept and creation to Sandra Diehl and Meera Kumanan technical advice from Katherine Neer and funding from the Duke Endowment and the North Carolina Division of Social Services.