

*ACTION IMPACT XXV - Patient Engagement in
Planning, Conduct & Implementation/Dissemination of CPR*

October 28, 2021

*A Matter of Record
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5	INITIATIVE ON METHODS, MEASUREMENT, AND PAIN
6	ASSESSMENT IN CLINICAL TRIALS
7	IMPACT XXV
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9	Patient Engagement in Planning,
10	Conduct and Implementation/Dissemination of
11	Clinical Pain Research
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14	Virtual Meeting
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16	Thursday, October 28, 2021
17	11:00 a.m. to 2:30 p.m.
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1	P R O C E E D I N G S	
2	(11:00 a.m.)	
3	Welcome and Housekeeping – Bob Dworkin	
4	DR. DWORKIN: Welcome back, everybody.	
5	Thank you for rejoining us for the second day of	
6	the IMPACT XXV meeting. I'm Bob Dworkin. I think	
7	we had a consensus already, after only one day of a	
8	three-day meeting. And it seems clear to me, and I	
9	think to a bunch of us who talked after the meeting	
10	yesterday, that the consensus is that the meeting	
11	was incredibly interesting and valuable in terms of	
12	what was discussed, what was presented in the	
13	presentations, the questions, and the discussion.	
14	So that was one consensus.	
15	The second consensus is that Chris Veasley	
16	and Bob Kearns did an absolutely fantastic job of	
17	putting together the agenda. So we already have,	
18	after only one-third of the meeting being complete,	
19	two consensuses. I don't know; is that consensi?	
20	I should check. One of us should check whether	
21	it's consensuses or consensi.	
22	But we've got two consensuses. I'm not sure	

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1 whether that's publishable in and of itself. We
 2 could ask Frank Keefe and Mark Jensen tomorrow
 3 whether that would be a publication. But I think
 4 I'm equally convinced that the next two days of the
 5 meeting are going to provide lots of additional
 6 information, and that Simon is going to be able to
 7 draft an absolutely terrific and potentially major
 8 contribution to the literature, based on this
 9 meeting. So welcome back, everybody.

10 The housekeeping is the same as yesterday
 11 with one major exception. We have now allowed
 12 chat. Chat should be used primarily for references
 13 to articles, links, that kind of thing, and that
 14 will all be collated and aggregated after the
 15 meeting, and distributed in whatever way is most
 16 appropriate and most valuable.

17 If for some reason you need to put a comment
 18 in the chatbox, that's ok, too. But given how much
 19 is going on at these meetings simultaneously and
 20 parallel, we can't guarantee that someone will be
 21 monitoring the chatbox for comments and
 22 suggestions, but we'll do our best.

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1 I think everything else was already reviewed
 2 ably yesterday by Dennis. Nothing else has
 3 changed, and the publication policy remains the
 4 same. We will end promptly today at 2:30 and
 5 resume tomorrow at 11 a.m.

6 As this slide indicates, if you have any
 7 questions about anything, please contact Valorie,
 8 or me, or Dennis, or certainly Bob Kerns and Chris
 9 Veasley. But I am happy to reintroduce Bob and
 10 Chris, and I think Chris will be leading today, so
 11 please take it away, Chris.

12 MS. VEASLEY: Thanks, Bob.

13 It's great to have power today in the
 14 northeast, and to be back home, and to have had a
 15 shower, and heat. So I'm happy about that. But I
 16 concur with you, day 1 was terrific. We really had
 17 some great discussions.

18 As I mentioned yesterday as we wrapped up,
 19 today we're really trying to get into the how-to's,
 20 so we don't want to just leave people with this
 21 30,000-foot overview. Although best practices, and
 22 values, and all those things are absolutely

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1 critical, we really want to give investigators who
 2 will be reading the manuscript very practical
 3 guidance for how they can, if they're already doing
 4 engagement, improve it, and if they're not doing
 5 it, how to start it.

6 So, we've organized a series of four talks
 7 this morning that will go through each step of the
 8 research life cycle. And I'm pleased to introduce
 9 our first two speakers, Karen Morales and Gail
 10 Graham, who are both with the PATIENTS Program at
 11 the University of Maryland School of Pharmacy.
 12 Karen is the associate director of engagement for
 13 the program, and Gail is a patient consultant.

14 So you take it away.

15 Presentation – Gail Graham

16 MS. GRAHAM: Hello, everyone. My name is
 17 Gail Graham. In 1997, I was diagnosed with HIV
 18 positive. Once I was diagnosed, I decided that I
 19 wanted to learn as much as possible about HIV so
 20 that I could tell others about it in hopes of
 21 preventing them from going through the different
 22 things that I went through to help them deal with

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1 the stigma, and to help them deal with finding the
 2 correct specialists.

3 Also I was a single mom of two kids, so,
 4 basically, I just wanted to live long enough to see
 5 my kids graduate. At that time, the life
 6 expectancy wasn't really that long.

7 But fast forward to 2007, and my best friend
 8 was going to a church and she invited me to come.
 9 The church was Mount Lebanon Baptist Church, and I
 10 liked it. So she asked me one day when will I join
 11 the church, and I said, "Well, I need to talk to
 12 the pastor because I don't want to bring the stigma
 13 of HIV to the church."

14 When I met with the pastor and I told him my
 15 story, he said, "Gail, this is your ministry."
 16 Now, I thought he was a little crazy because he
 17 didn't really know me, but he was cute. But I
 18 still wanted to go there anyway. A year later, we
 19 started the Mount Lebanon Baptist Church HIV/AIDS
 20 Outreach Services.

21 This church is actually located in a zip
 22 code in Baltimore, which has one of the highest

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1 rates of HIV and AIDS, and I became very protective
 2 of my community. We had different organizations
 3 and companies coming in, and they wanted to get
 4 information from us. They were like helicopter
 5 research. They'd come in, get their information,
 6 then they'd leave, and it was of no benefit to my
 7 community as a whole.

8 So what ended up happening was when anybody
 9 came through and they wanted to do research surveys
 10 or whatever, they would always offer gift cards.
 11 For it being a food desert and for it being very,
 12 very low income, people decided that they were just
 13 going to tell the researchers whatever they wanted
 14 to hear so that they could get that gift card.

15 One day I was volunteering for my pastor's
 16 church, and he told me, "Gail, you're coming to
 17 this meeting." So when he says that, it's usually
 18 to give me more work, so I was like, "Nope, I don't
 19 want to go." But I ended up going to the meeting,
 20 and it was with the University of Maryland PATIENTS
 21 Program. Dr. Daniel Mullins was talking about the
 22 PATIENTS Program, and gave me a nice long spiel

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1 about what it was about. And when he finished, he
 2 said, "Well, Gail, do you think you'll be
 3 interested?" So I said, "Nope, not at all. I'm
 4 not interested."

5 He asked again after a while. He rephrased
 6 some things, and he said, "Well, now do you think
 7 you'll be interested?" And I said, "Nope, I'm
 8 still not interested." So he said, "Well, maybe
 9 one day, one of my post docs can meet with you just
 10 to see if you would change your mind." So I said
 11 ok, because at that point I just wanted to get out
 12 of the meeting.

13 So when the person came and they were
 14 talking about the same thing Dr. Mullins was
 15 talking about, I said no. So she said, "Well, do
 16 you think we can have a table at your World AIDS
 17 Day event?" That event is where we will give away
 18 free turkeys to anybody that got tested. So I was
 19 thinking I'm just going to put them to the side and
 20 watch them and make sure they don't really interact
 21 with my community.

22 Well, this organization showed up. They

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1 were the first ones to show up. They helped me set
 2 up. And then when the community came in, they
 3 said, "Well, can we go get doughnuts and coffee for
 4 them?" I was just so thankful, I said, "Sure."

5 So I ended up doing some other things, and
 6 then I remembered I'm supposed to be looking at
 7 them to make sure they're not really bothering my
 8 community, and I saw them sitting with my community
 9 and holding their hands, and actually listening to
 10 them. And for somebody that's HIV-positive, that
 11 touch is a mighty thing. So from that point on, I
 12 said, "Ok, Dr. Mullins. You have me."

13 One of the things I really want to leave you
 14 with is, trust is earned and trustworthiness is
 15 nurtured. That's one thing that the University of
 16 Maryland PATIENTS Program has done with my
 17 community. Thank you.

18 Presentation – Karen Morales

19 MS. MORALES: Thank you so much, Gail, for
 20 sharing your story, as you do so eloquently.

21 The PATIENTS Program started in 2013. Why
 22 do I start with the Voice of the Patient? Because

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1 the PATIENTS Program believes that patients and
 2 stakeholders are heard, inspired, and empowered to
 3 co-develop patient-centered outcomes research, and
 4 that the Voice of the Patient is the most important
 5 thing to us.

6 We start our engagements, all types of
 7 engagements, with the Voice of the Patient. Front
 8 and center is our advocate, Ms. Gail Graham, and I
 9 appreciate you for sharing your story.

10 Yesterday, we heard a lot. We heard a lot
 11 about statistics, we heard a lot about the need for
 12 engagement, and I valued that conversation
 13 yesterday so much; so much so that I actually added
 14 some things to my slides for today. But today
 15 we're talking about the planning process.

16 The PATIENTS Program has been in the process
 17 of transforming the research enterprise since 2013.
 18 In 2012, Dr. Mullins and the team created, or
 19 developed, an article about patient engagement, the
 20 10-step Framework for Continuous Patient
 21 Engagement. We have now segregated that down to
 22 three phases, which is the planning phase, the

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1 doing phase, and the delivery phase.
 2 We also call that listening, bridging, and
 3 delivering as well, which is another acronym we
 4 use, LBD, to say that in our first phase, we're
 5 listening to our patients. We're hearing from our
 6 partners about what their concerns are. There are
 7 three categories that patients have been able to
 8 assist in, and that's the topic selection in the
 9 planning phase; step 2 is prioritization; and
 10 framing the question.
 11 In order to talk more in detail about the
 12 planning -- there's doing and delivering as well,
 13 but I think some others are going to talk about
 14 that, so I'm going to move on to slide number 3.
 15 The planning phase, as I mentioned earlier,
 16 participants have worked with us at all levels. I
 17 think what we've learned over time is that it's
 18 very important that you set expectations from the
 19 very beginning of the planning process about who
 20 you're going to have involved in your project.
 21 Yesterday, I heard mentioned about having certain
 22 types of individuals on your team. Yes, you want

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1 to have equity in your team. Yes, you want to have
 2 diversity in your team.
 3 Right now, we're working on the project with
 4 the NIA, and one of our post docs feels that she's
 5 not the adequate person to be able to address the
 6 focus group participants in this particular project
 7 because she is not a person of color and we're
 8 interacting with African-Americans in this
 9 particular project. Well, that may be true, but
 10 there's no set answer.
 11 While we do believe that you do want to have
 12 a diversity of participants, as well as a diversity
 13 of focus group leadership and focus group staff, or
 14 project staff, when you're setting your
 15 expectations from the beginning of your project,
 16 try to include what you're going to need from the
 17 very beginning; not bringing in someone to only do
 18 the focus group who's a person of color, but also
 19 having participants in your staff who can interact
 20 with their community or your community from the
 21 very beginning if you want diversity of the
 22 participants in your project.

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1 The next bullet you see is advisory boards.
 2 Our participants work with us from the very
 3 beginning, as I said, in the planning phase. They
 4 don't just come in on a project and give us our
 5 survey answers. Gail and others work with us as
 6 we're actually planning out what projects we're
 7 going to participate in, what we're going to do for
 8 the year.
 9 We have stakeholder involvement from the
 10 very beginning of the actual planning phase. From
 11 the strategic planning phase of our program,
 12 they've become partners with our program, and
 13 they're now helping to set the agenda of what the
 14 PATIENTS Program is going to do and how we're going
 15 to do it.
 16 Another thing we've learned is our use of
 17 language when we're communicating with our
 18 partners. Again, having language that your patient
 19 groups can understand, that's clearly
 20 understandable for them, is a critical component of
 21 your engagement efforts and your planning process
 22 from the very beginning as well, because if your

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1 language isn't accurate, isn't understandable, then
 2 it's of no significance. And you'll see, once I
 3 get through the slide, how language changed the
 4 question that was being posed in this particular
 5 study.
 6 As I said earlier, topic selection,
 7 prioritization of your project, and framing the
 8 question are some areas that our participants have
 9 been able to assist us with in the planning
 10 process.
 11 One of the critical components of planning
 12 is your pre-engagement. The PATIENTS Program has a
 13 concept of, again, you don't just -- as Gail
 14 mentioned -- come in and start engaging the
 15 community to participate with you, but you have a
 16 period of pre-engagement, a time where -- like
 17 Dr. Mullins did -- it wasn't a project that we went
 18 there for. He actually went there to engage the
 19 community, and he was engaging before we had a
 20 study that was active; so getting to know the
 21 community, understanding the community and your
 22 participants that you want to bring in, and not

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1 just telling them, okay, we want you to come in and
 2 do this for us, but understanding what their needs
 3 are, as well.
 4 Engaging, you want to engage early and
 5 often. Early is before your project, and often is
 6 during certain intervals. You don't want to just
 7 wait until, again, your project needs a survey
 8 answer. You want to engage with them around their
 9 activities, as we did with Testing for Turkeys.
 10 And I've been to one, and trust me, Gail runs a
 11 smooth operation there, and it has been a
 12 successful event each opportunity I've had to
 13 participate; so kudos to Mount Lebanon and Gail.
 14 Working with the community health workers
 15 and engagement specialists, we utilize them in that
 16 position and that role to engage with the
 17 community. Yes, Dr. Mullins goes out, I go out,
 18 but the staff who actually do the daily or weekly
 19 engagements are our community health workers and
 20 our engagement specialists. These are individuals
 21 who have a pulse of the community. These are
 22 individuals who are actually integrated within the

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1 community itself.
 2 So while it's important to have, yes, the
 3 positions, it's also important to have someone who
 4 knows that community, who can interact from the
 5 perspective of an understanding of what's happening
 6 within that community.
 7 As I mentioned yesterday, I do believe
 8 during the pandemic, we missed an opportunity. I
 9 know there were funding issues, things were
 10 shutting down, but I think we missed the
 11 opportunity to use community health workers to
 12 really make phone calls to touch base with the
 13 community that they knew to see how people were
 14 doing, and whether or not there were needs in the
 15 community. Some organizations did that, but I
 16 believe as a whole, we kind of all shut down, and
 17 in some ways we kind of missed that opportunity to
 18 utilize that position.
 19 Pre-engagement includes our community
 20 events. We are constantly out in different
 21 community events. One of the things I was thinking
 22 about is how do I relate that to pain? How does

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1 that affect what we're talking about today in this
 2 particular conference? I'm assuming that there are
 3 conferences that highlight the pain perspective,
 4 and inviting community members to pain
 5 conferences -- not just the researchers, but also
 6 the community members -- to have an outlook as to
 7 what's transpiring will bring more community
 8 participation into this particular concept.
 9 Community health fairs, our engagement, we
 10 constantly go to health fairs. That's one of the
 11 things that we find when we're able to garner more
 12 participation from our community. We've had a
 13 database of community participants that has reached
 14 about 4,500 participants in our database, and that
 15 was over a five-year period, where we were able to
 16 go out and engage with the community and come up
 17 with those numbers. We've since cleaned it and did
 18 some things with it, but 4,500 for about five years
 19 we thought was a pretty good number to have
 20 generated over that particular period of time of
 21 participants.
 22 Now yes, some of them may have said they

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1 were there to get something. As Gail mentioned
 2 earlier, you really need to have a relationship
 3 with your community so that they believe and trust
 4 you, because it's one thing to trust the data that
 5 they're giving you. Sometimes you think you have
 6 good data, and the answers that you're getting are
 7 not true answers. They're just answers on your
 8 survey so that they can get the ending compensation
 9 or whatever it may be.
 10 So what we've tried to do is show that we're
 11 trustworthy in that we come back to our
 12 communities. We don't do the helicopter research,
 13 and we actually learn what's important to the
 14 community. So those are some steps that you want
 15 to take in your pre-engagement efforts when you're
 16 planning your projects. Yes, it does require time.
 17 Yes, it does require commitment.
 18 The next bullet I have is -- I'm going to go
 19 through this a little bit quicker because I see I
 20 have about five minutes left -- partnering with
 21 community churches, which Gail is from one of those
 22 churches that we partner with. We found that to be

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1 a helpful opportunity for the PATIENTS Program,
 2 community churches and educational institutions.
 3 We have a partnership with Morgan, and we engage
 4 with them and their community opportunities as
 5 well.
 6 The planning phase, how am I doing this?
 7 Well, you have partners already that are working in
 8 the same field that you're in. Partnering with
 9 them is key to developing your current
 10 relationships. Trying to go out and generate new
 11 relationships isn't always the easiest thing to do,
 12 so you build off of the ones that you currently
 13 have, and that in turn builds -- oops, my phone in
 14 the background.
 15 Sorry, ignore that. Engaging community
 16 clinics, senior centers, community associations,
 17 advocacy groups, and other institutions is what the
 18 engagement team of the PATIENTS Program does on an
 19 ongoing, steady basis to keep the pre-engagement
 20 efforts going, ongoing and continued.
 21 We talked about continuous engagement as
 22 part of the planning process because we know when

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1 we're planning our studies, we also have to put in
 2 specific points where we're going to continue to
 3 engage our partners, our patients, our
 4 stakeholders.
 5 We look at our patients as partners; not
 6 just as participants on the study, but as partners,
 7 and we ask them, what are you interested in? What
 8 do you want to know? Asking and not telling is
 9 something that we've heard from our partners that,
 10 basically, the PATIENTS Program ask; they don't
 11 tell.
 12 Because we do ask, we found their investment
 13 in our program to be highly significant. And like
 14 Gail, there are several others who come back on an
 15 ongoing basis. And you would wonder, are they
 16 going to get tired of working with you after a
 17 while?
 18 Gail, are you tired of working --
 19 MS. GRAHAM: No.
 20 (Laughter.)
 21 MS. MORALES: Excellent.
 22 Gail has been working with us for at least

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1 six years, about six years.
 2 MS. GRAHAM: Eight, I think, yes.
 3 MS. MORALES: Eight? I'm sorry?
 4 MS. GRAHAM: Eight.
 5 MS. GRAHAM: Eight. Okay; eight years.
 6 So it's been a journey for Gail as well. So
 7 not only has it been a learning process for us, but
 8 we're learning from Gail, and she in turn learns
 9 from us. So that bidirectional opportunity has
 10 been ongoing. Your partners will be invested if
 11 you're asking them what their needs are, and
 12 they'll invest with you as well.
 13 Respecting and valuing the community, those
 14 are critical values that we have learned, that the
 15 community members, they want to participate. They
 16 want you to respect what it is they have to say.
 17 And how do you do that, we'll hear about that in
 18 the dissemination process, I hope.
 19 But feeding back to them what it is that we
 20 heard them say in the planning process has been
 21 absolutely critical. Our patients have said, "You
 22 know what? I didn't expect to get that back. I

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1 didn't expect to hear that you used something I
 2 said, and that you actually changed something."
 3 I'm going to skip now because I see I'm
 4 running out of time, but some of the others here
 5 are using social media, newsletters, and all these
 6 things of building trust to stay engaged with the
 7 communities over periods of time.
 8 The last box here talks about a specific
 9 study that we had, which was a RadComp breast
 10 cancer trial. Our patients helped to change the
 11 question that was being asked, which was, "Does
 12 proton therapy reduce major cardiovascular toxicity
 13 compared to photon therapy?" I can't even hardly
 14 say the word, right?
 15 In a patient's voice, the question was
 16 changed to, "What type of radiation is better for
 17 heart health?" That's what we got from our
 18 patients. Does it answer the question that was
 19 originally proposed? The patients believe that it
 20 did, so the patients actually helped change what
 21 the question was that the study investigator was
 22 looking for. That's the planning process.

1 The PATIENTS Program, as I said, we look at
 2 all phases of engagement throughout the planning,
 3 doing, and the delivery of processes, which is
 4 during the doing phase, which patients and
 5 stakeholders are participants and co-developing
 6 study protocols; reviewing or selecting survey
 7 instruments and choosing when and how to gather
 8 data; advising how to recruit, engaging, and
 9 retaining participants; and then, again, in
 10 delivering solutions. I would have been remiss if
 11 I hadn't gone through some of the things that we do
 12 as the PATIENTS Program in these two categories.
 13 I'm going to finish up. Delivering
 14 solutions; patient advisory groups blogging about
 15 our studies. We have our patients who actually do
 16 videos for us, infographics, and help with
 17 developing manuscripts. Gail actually had a blog
 18 that she did with us, and that was her first time
 19 actually creating the publication that went into
 20 the publication sphere. We were proud to be able
 21 to have that, and we have another community partner
 22 who did the same.

1 patients and Latinos, there's been an increase in
 2 that area as well.
 3 Thank you. Sorry. I think I went over by
 4 about a minute or so. My apologies.
 5 Questions?
 6 Clarifying Q&A
 7 MS. VEASLEY: No problem, Karen and Gail.
 8 Thank you guys so much for kicking us off this
 9 morning and talking about the important work that
 10 needs to be done in the planning phase.
 11 We have a few minutes for one or two
 12 clarifying questions. We just want to note that we
 13 have ample time for discussion at the end of the
 14 day, so if you have more deep-dive questions,
 15 please keep track of them throughout the day, and
 16 you can ask our speakers later in the day.
 17 But if there are any clarifying questions
 18 for Karen and Gail at this point, please raise your
 19 hand emoji.
 20 (No response.)
 21 MS. VEASLEY: I don't see any. But, Karen,
 22 I'll pose this to you and to Gail.

1 PATIENTS Day, we have a traditional event
 2 that we do at the end of it all, where our patients
 3 and our stakeholders hear all that we do throughout
 4 the year. Unfortunately, last year we couldn't do
 5 that. We're planning for 2022, and we're excited
 6 to be able to host the community.
 7 This slide here just shows in red how the
 8 PATIENTS Program actually recruits faster. These
 9 are some other studies as we compared the PATIENTS
 10 Program to other studies that we've had,
 11 traditional studies here in blue, and the PATIENTS
 12 Program methods. So we can see we've actually
 13 recruited faster and have been able to have
 14 retention in our studies.
 15 This slide here is showing the increase of
 16 our racial and ethnic diversity. At one point,
 17 this was what traditional studies showed for
 18 Caucasians, and now we see that we've expanded
 19 other groups over time. This is comparing to the
 20 PATIENTS Program, and this is traditional clinical
 21 studies. The PATIENTS Program, our numbers have
 22 increased in our African Americans. Our Hispanic

1 We've been talking about there's quite a
 2 dichotomy and diversity across institutions in the
 3 United States. I don't want to put you on the spot
 4 to give me an exact statistic, but how common is it
 5 for universities to have programs like this
 6 available?
 7 MS. MORALES: I would say that it's becoming
 8 more common. We are in partnership with Johns
 9 Hopkins, who's also doing a community engagement.
 10 We're in partnership with Morgan. The PATIENTS
 11 Program came out of, I believe, seven institutions
 12 across the country who were also doing
 13 patient -- it was a grant funded by AHRQ, and there
 14 were seven other institutions that were doing the
 15 same thing.
 16 So we've seen over time a growth in patient
 17 engagement and engaging patients around
 18 patient-centered outcomes research. I don't have
 19 the exact statistics, but it has grown over time.
 20 MS. VEASLEY: That's great.
 21 MS. MORALES: It wasn't very common when we
 22 first started, back in 2013.

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1 MS. VEASLEY: Gail?
2 MS. GRAHAM: We're also developing the
3 PATIENTS Academy, PATIENTS Professors Academy, so
4 that we can work with other organizations and
5 institutions throughout the United States, or
6 further, to develop their communications with the
7 community between researchers, between medical
8 fields, patients, and other community advisory
9 boards.
10 MS. VEASLEY: That's great.
11 Kathryn, I see you have a quick question.
12 DR. MARTIN: I sure do. Here in the UK, we
13 are finding that, increasingly, patient public
14 involvement is so important, but in the planning
15 stages there aren't as many opportunities to
16 actually fund it. Even if a research council is
17 wanting PPI in a grant application, it isn't
18 necessarily allowing for funds to do some of that
19 work and renumerate [ph] appropriately.
20 What is going on in the U.S., and how,
21 Karen, would you approach that, or have you gotten
22 around to that in any way; not around it, but how

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1 are you funding it?
2 MS. MORALES: The PATIENTS Program, as far
3 as our funding for our pre-engagement, for our
4 participants to actually be able to assist us with
5 developing our research protocols, they're not all
6 compensated opportunities. There have been some
7 opportunities where our participants have been
8 compensated for X, but haven't always been
9 compensated for every phase.
10 Now, it's important. We do -- as Gail
11 notes -- because she's been with us for eight years
12 now, and she's been on this journey because
13 of -- yeah, she's been compensated, but she also
14 gives back her time when she's not compensated.
15 So I think part of that pre-planning phase,
16 when you're developing those relationships, allows
17 your participants to, again, realize that
18 over -- it's a long-haul opportunity. It's not me
19 coming in only now; it's me coming in as part of
20 the journey with your organization.
21 We had a \$5 million opportunity funding from
22 AHRQ when we started, and part of it was you have

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1 to figure when you're establishing your projects
2 how you're going to incorporate the planning phase
3 because that funding has to stretch, as we know.
4 But when you develop your participant pool from the
5 beginning, that will allow you an opportunity to
6 work with participants who may not necessarily
7 expect to have any type of funding right from that
8 moment.
9 MS. VEASLEY: Thanks so much.
10 Bob, you have a quick question?
11 DR. DWORKIN: Yes, just a very quick
12 question.
13 Very impressive data that you presented on
14 the differences between the studies where patients
15 were involved and those where patients weren't.
16 Was that local data or just studies where
17 Baltimore, the greater Baltimore area, was a site,
18 or were those national and international data?
19 MS. MORALES: That's correct. Yes, It was
20 national, and we are a site. So it was compared to
21 other sites across the country. All of the data
22 hasn't even been published yet, but this is coming

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1 out now, and I expect to have the actual
2 publication information soon. But this was
3 compared to other sites across one project, yes.
4 DR. DWORKIN: So it's the Baltimore site
5 versus other sites that actively engage patients.
6 MS. MORALES: Across the country.
7 DR. DWORKIN: Fascinating. Thank you.
8 MS. MORALES: Exactly.
9 MS. VEASLEY: Penney, a real quick question.
10 We need to move on to the next speaker.
11 MS. COWAN: One of the things -- and I
12 compliment you much for all that you've
13 accomplished -- is that going into the community
14 rather than working with healthcare providers
15 really engages people a lot more. It's just a
16 different approach that I think can be extremely
17 successful. So I applaud you for that.
18 MS. MORALES: Thank you, Penney.
19 MS. VEASLEY: Alright. Thank you, Karen and
20 Gail, for kicking us off so well this morning. We
21 appreciate you being here and contributing.
22 Next, we're going to hear from Dr. Jonathan

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1 Jackson. He's the director of the CARE Research
 2 Center at Mass Gen and Harvard Medical School, and
 3 that stands for the Community Access, Recruitment,
 4 and Engagement Research Center. He's going to talk
 5 to us about how do we engage with diverse,
 6 hard-to-reach, and disparate populations.
 7 Jonathan?
 8 Presentation – Jonathan Jackson
 9 DR. JACKSON: Thank you so much Chris.
 10 Hopefully, everybody can see me. I am thrilled to
 11 be here and thrilled to be able to talk to you
 12 about how we can prioritize and focus on the
 13 inclusion of marginalized, minoritized, and other
 14 hard-to-reach populations, or as many people in my
 15 line of work say, the hardly-reached populations.
 16 What I'm hoping to do is to talk to you
 17 about how to make sure that you are advocating for
 18 this. Whether you are somebody who is designing
 19 research trials; whether you are participating;
 20 whether you are involved in the day-to-day
 21 operations and logistics, there's a role for
 22 everyone to play. And I'm going to give you kind

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1 of a whirlwind tour, and hopefully we'll be able to
 2 close any loops and gaps during the Q&A period.
 3 I don't often like starting my talks with
 4 quotes, but sometimes the quote is just so good,
 5 and it sums up the problems just so nicely that
 6 you've got to start here. So this is a quote
 7 offered by Dr. Martin Luther King back in 1965 at
 8 the end of the Selma marches, where he said, "Of
 9 all forms of inequality, injustice in health care
 10 is the most shocking and inhuman."
 11 While he was talking about the problems in
 12 access, the ongoing segregation and the separate
 13 but unequal care that many people were receiving
 14 back in the mid-60s, he was actually laying the
 15 groundwork for a much more serious and broader
 16 discussion of some of the concerns that kind of
 17 plague us today.
 18 In particular, I think one of the things
 19 that we need to take away from this quote is the
 20 importance of thinking about justice in health care
 21 rather than thinking about it as a problem of lack
 22 of representation in clinical research or

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1 inequities. We're going to talk about that term
 2 "inequities" in just a few slides, but I really
 3 want you to focus on this idea of justice, which is
 4 going to be the heart of today's presentation.
 5 Now, when we talk about clinical research
 6 and we talk about these marginalized, minoritized,
 7 hard-to-reach populations, you may think that the
 8 reason why we need to include them is because it is
 9 the moral thing to do; it is the correct thing to
 10 do. The problem with a moral argument in a highly
 11 operationalized, scientific enterprise is that it
 12 is hard to operationalize what morality looks like.
 13 Is it just a matter of trying to do the right thing
 14 or are we actually judged for doing the right thing
 15 at scale?
 16 So let's try to think about the diversity
 17 problem through a slightly different lens. If we
 18 think about it as a scientific problem, it becomes
 19 easier to operationalize with our scientific
 20 practices. So if you think about the science, 1 in
 21 5 approvals from the FDA over a period of about 5
 22 or 6 years show that there was some sort of

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1 differential exposure or response just as a
 2 function of racial or ethnic group.
 3 So imagine that. You're getting through all
 4 the trials, the first in human, the phase 2, and
 5 the phase 3. It goes up for FDA approval. The FDA
 6 approves it, and then you find out, kind of in this
 7 postmarket analysis, that it doesn't actually work
 8 the same for everyone everywhere, on the basis of
 9 something like race and ethnicity. That shows that
 10 we have a problem of generalizability and that the
 11 science is not quite as rigorous or robust, or
 12 perhaps as nuanced, as we need it to be.
 13 Now, when we talk about pain management in
 14 particular, there's a rich history of difficulties
 15 of trying to make sure that we have appropriate
 16 diversity and representation in our research
 17 studies. Work by Karen Anderson did a really great
 18 selective review in Journal of Pain. We've got
 19 work by Carmen Green and others and Salimah
 20 Meghani. All of them really show that there's a
 21 rich history of a lack of diversity that gives way
 22 to some of the disparities that we see when it

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1 comes to pain outcomes.
 2 Now, I think that the problem is actually a
 3 little bit more complex than that. It's not just
 4 the fact that we're seeing problems after FDA
 5 approval, we're seeing problems in terms of just
 6 overall diversity, but if we think about the actual
 7 research statistical models that we're building, if
 8 we have some sort of differential selection, or
 9 differential rates of retention or attrition in our
 10 trials -- let's say that all of the rich people are
 11 able to stick with our studies, whereas people who
 12 don't have as much money drop out -- that's going
 13 to skew our baseline estimates of causal factors,
 14 which means that we aren't quite as confident that
 15 our statistics are showing us what we think they're
 16 showing.
 17 If we don't recruit representatively, what
 18 does that look like? The reason why I'm using this
 19 term "representative" is to distinguish it from
 20 diverse. Right now, the way that we are thinking
 21 about recruiting diversely is that we kind of have,
 22 again, this sort of separate but equal system where

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1 all of the privileged people will come in through
 2 our usual clinical workflow, and then the diverse
 3 people require some kind of additional outreach.
 4 So we'll go into community environments, whereas
 5 the more privileged population get recruited
 6 through a clinic. What does that mean if we do
 7 that? What does that do to our models?
 8 I want to show you an example from one of
 9 the areas where I originally did my training, which
 10 is in Alzheimer's disease and dementia, looking at
 11 the change in risk. Don't worry if you're not
 12 necessarily very comfortable with Kaplan-Meier
 13 curves. It's not a big deal. What this curve is
 14 simply showing is the rate of progression of people
 15 who have mild cognitive impairment, sort of like a
 16 pre-dementia, and how they eventually convert or
 17 progress to frank dementia. The steeper the curve,
 18 the quicker the rate of progression is for
 19 individuals.
 20 What you see here is a comparison between
 21 white people, in red, and black people, that are
 22 kind of represented in this bluish teal.

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1 Ultimately, what we know and what I'm going to say
 2 is, irrespective of looking at the slide, one thing
 3 that we do know for sure is that black people are
 4 about 2 to 4 times as likely as white people to
 5 progress to frank dementia -- we know that; we know
 6 that based on lots and lots of studies done over a
 7 couple of decades now -- but what you see here from
 8 this slide, it shows you exactly the opposite.
 9 It's showing you that the steeper rate, that faster
 10 decline, that faster rate of progression, is coming
 11 from the white group, not the black group.
 12 So you might be thinking, "Okay, alright,
 13 Jonathan. Look, I don't know a lot about
 14 Kaplan-Meier curves. Maybe they just mislabeled
 15 it. Maybe this is supposed to be the black group;
 16 this is supposed to be the white group." It's not
 17 the case; I promise. I talked to the group that
 18 published this. They double-checked.
 19 What's really remarkable is that this is one
 20 of the largest studies in that field, so this
 21 represents 6,000 individuals that have been tracked
 22 at 59 sites across the United States. So what is

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1 going on here?
 2 The truth of the matter is that this is not
 3 comparing white people and black people. This is
 4 comparing that separate but equal system of
 5 recruitment that currently dominates our diversity
 6 efforts. So what we've got here is all of the
 7 white people are presenting to a memory clinic and
 8 all of the black people are coming out from
 9 community settings.
 10 So the truth of the matter is that you're
 11 not really comparing apples to apples here; you're
 12 comparing apples and oranges. You've got a bunch
 13 of people who are presenting to a memory clinic, so
 14 of course they're more likely to have memory and
 15 dementia problems, whereas the black people, who we
 16 know are at a higher risk for dementia, are coming
 17 from a community setting, which is going to have a
 18 lower rate of memory concerns and the likely
 19 incidence of dementia.
 20 What we have here is a problem, and this is
 21 a problem that we are likely to face if we continue
 22 our separate but equal method and systems of

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1 recruitment. We've got to be better than that;
 2 otherwise, we're likely to exacerbate these
 3 disparities while we're trying to claim to overcome
 4 them.
 5 Now I want to talk to you a little bit about
 6 what we mean, or what I mean, specifically when
 7 I've been using this term "disparities."
 8 Historically, all differences between groups were
 9 kind of lumped into this single term,
 10 "essentialized or biological disparities" with an
 11 underlying assumption that that these differences
 12 between groups were inherent, that they were
 13 somehow immutable.
 14 Nowadays, we understand that while there may
 15 be some, maybe, biological differences between
 16 groups, social inequities drives a lot of the
 17 differences that we observe. However, I think it's
 18 important to recognize that even this parsing
 19 leaves a whole lot to be desired and often puts the
 20 blame and the onus on the very groups that we're
 21 trying to rescue, that we're trying to save, those
 22 vulnerable underserved and marginalized groups.

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1 So what I've been doing, what I propose, is
 2 that what we actually think of as disparities looks
 3 a little bit more complicated. It looks a little
 4 bit more like this, and it kind of reconnects this
 5 work of disparities with domains where we as
 6 researchers have the ability and, frankly, the
 7 responsibility to assess model and limit.
 8 If we use pain management as an example,
 9 what we historically thought of as racial
 10 differences to pain was initially inherent. We
 11 thought that some groups felt pain and some groups
 12 just didn't, and that's justifying all sorts of
 13 atrocities that are kind of littered throughout the
 14 history of the way that we treat pain and manage
 15 pain. But in reality, the difference in these
 16 groups is much more complex. So maybe -- maybe,
 17 just maybe -- there is some inherent difference.
 18 But before we can come to that conclusion,
 19 before we can be confident in that conclusion, we
 20 have to think about selection bias, for example.
 21 So we have to think about those who we bring into
 22 our studies of pain management in the first place.

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1 And, obviously, in recent history that tends to
 2 favor much more privileged populations. And
 3 assuming we get past this period, we can't jump to
 4 assuming that the racial differences, or gender
 5 differences, or educational differences are
 6 inherent, that they're biological; we have to go
 7 through each of these steps.
 8 So after selection bias, we have to think
 9 about measurements in terms of the validity of
 10 different pain-rating scales as they interact with
 11 culture and pain presentations for populations that
 12 are not well represented in research due to
 13 selection bias.
 14 Then once we get here, there are also
 15 perioperative implementation biases in terms of how
 16 patients are prepped and how they're treated and
 17 cared for. And then, obviously, beyond that, there
 18 are additionally social inequities that leave some
 19 groups to have better or worse access to care and,
 20 of course, pain management in the first place.
 21 Then there are environmental factors that compound
 22 these social inequities that affect both chronic

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1 and acute pain.
 2 So if, and only if, you can apportion a
 3 variance appropriately and tease out these other
 4 four buckets, and you still have some left over
 5 that explains the differences between groups, you
 6 might be able to conclude that there's somehow a
 7 biological difference between the two. However,
 8 most of our research, most of our work, most of our
 9 recruitment for research, it doesn't necessarily go
 10 through these very careful methods of analysis.
 11 In order to contextualize what I'm going to
 12 be talking about next, most of what we think of
 13 when it comes to disparities are just lumped into
 14 these two groups and a little bit of this one.
 15 What I'm going to be highlighting is the
 16 opportunity to understand and address issues that
 17 may be related to selection bias and implementation
 18 bias.
 19 So let's talk about why we can't recruit
 20 diversity or why we can't recruit representatively,
 21 which I think is the better term. It turns out
 22 that it doesn't matter what kind of work you do,

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1 what kind of research you're looking in, it really
 2 comes down to these top 10 reasons, ranging from
 3 lack of awareness of research opportunities; to
 4 limited diversity on study staff; different kinds
 5 of problems with selection and eligibility
 6 criteria; and the fact that people don't really
 7 know what they're getting out of it, so they have
 8 an insufficient return to value.
 9 So the problem is not that we don't
 10 understand what the problem is. The problem is
 11 that, just like the questions that we just heard
 12 before, we have limited time, limited expertise,
 13 limited tools, and limited resources. How can we
 14 tackle all 10 when we've also got to do the study,
 15 and we've got to do maybe five or six other studies
 16 on top of it? For patients, how can we be expected
 17 to navigate all 10 of these barriers, in most
 18 cases, when we've got a whole life to attend to?
 19 Now, what we do at my group within the CARE
 20 Research Center is we present this problem
 21 differently. Instead of saying there's a top 10
 22 list of reasons, good luck in figuring it out, what

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1 we have done instead is we've tried to present this
 2 as a workflow problem, where you need to address
 3 earlier problems within the workflow before you can
 4 see downstream results.
 5 So you can actually take this top 10 list of
 6 reasons, and then map them onto a very ordered
 7 workflow, which I want to just emphasize maps on
 8 very well to some of the talks that we've heard
 9 earlier about these pre-engagement activities,
 10 these pre-recruitment activities.
 11 You need to start with identifying a
 12 sampling frame, so that's being very clear about
 13 who is eligible and likely to be interested in your
 14 study, and then you need to move on to making sure
 15 that you build clear awareness. In the previous
 16 talk, we heard a little bit about attending health
 17 fairs and going into churches. And that's not
 18 necessarily to throw a study at someone; that's to
 19 tell people why it's important to stay engaged with
 20 this stakeholder group, what research can do more
 21 generally, and then you start to build these
 22 processes related to engagement, and trust, and

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1 interest in education. And as you can see, you can
 2 map on all 10 of these lists of reasons to
 3 different aspects of this workflow.
 4 So ultimately, you end up with this kind of
 5 recruitment funnel that really focuses on this
 6 problem selection bias. And what I think is really
 7 important to emphasize here is that everything that
 8 we think of in our research studies is in this red
 9 box. The other five stages of decisional stakes
 10 that patients and participants need to go through
 11 are usually not covered in our research protocols.
 12 So privileged people can dance through these other
 13 steps and jump right into our prescreening or
 14 screening protocols. Everyone else -- and I mean
 15 everyone else -- will usually get hung up at one of
 16 these stages, so we need to have a plan to address
 17 those.
 18 So how can we start to do that? Let me give
 19 kind of broad advice. This is a paper published
 20 with a couple of colleagues of mine, Andrea
 21 Gilmore-Bykovskiy and Consuelo Wilkins. We wrote
 22 it about a year ago, and it was published in Trends

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1 in Molecular Medicine. It really talks about this
 2 problem of justice, and it focuses on six really
 3 crucial principles of research justice.
 4 These are the things that you have to do in
 5 order to not only improve diversity, and
 6 recruitment, and inclusion in your research
 7 studies, but to really serve justice, to truly
 8 empower and focus on the marginalized,
 9 hard-to-reach, hardly-reached populations.
 10 What we have here is first a problem of data
 11 fidelity. You have to strengthen regulations
 12 around reporting and compliance and transparency
 13 because we don't fully know the scale of the
 14 problem, because when it comes to trying to
 15 identify and track how diverse and representative
 16 our studies are, there are usually a lot of holes,
 17 a lot of gaps, and relatively poor data fidelity.
 18 I think we also need to identify, measure, and
 19 systemically address exclusionary research, and of
 20 course that means an end to ongoing research
 21 practices that are unethical or ethically gray, or,
 22 frankly, out-and-out abusive.

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1 So we have to recognize that the problem is
 2 we often tell ourselves that science is objective,
 3 so we assume that because we are doing science, we,
 4 too, are objective, but reality is that it's just
 5 the opposite. Because we are flawed and subjective
 6 in our reasoning, that waters down the quality of
 7 our science.
 8 We have to make sure that our assessments
 9 and our measures aren't necessarily validated on
 10 highly biased samples. We have to make sure we're
 11 taking a hard look at lots of research practices
 12 that we don't even question.
 13 Like, for example, many of our research
 14 studies have a de facto English language
 15 requirement. There is nothing about speaking
 16 English that gets in the way or that contributes to
 17 our scientific enterprise. So if we are, without
 18 even asking a question, assuming that all of our
 19 research participants speak college-level English,
 20 then we are diminishing the quality, the
 21 reproducibility, and ultimately the rigor and the
 22 integrity of our research science.

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1 So we have to move beyond proportional
 2 representation, not just for races, different races
 3 and ethnicities, but thinking a little bit more
 4 broadly beyond that.
 5 But if I do have to make one comment on
 6 race, I'm going to take a strong stance here. And
 7 again, this is something that many researchers
 8 haven't even questioned. We must stop, ending our
 9 basis, for using whites as a referent group in our
 10 research models. Frankly, there is very, very
 11 little utility to including race as a variable in
 12 our research. It's good for helping us understand
 13 our demographics, but it's of limited value
 14 elsewhere.
 15 I know that's a bit of a hot take. I'm
 16 happy to talk about that in the QA. But I want to
 17 get to the other three elements of trying to serve
 18 justice in research opportunities.
 19 We also have to think about building
 20 sustained reciprocal relationships with
 21 marginalized communities. That of course means
 22 that the key goal is to stop centering research

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1 goals on individual researchers and the larger
 2 institutions that work with it. That means
 3 focusing on patient-centered outcomes, but also
 4 patient-centered partnerships; ensuring that
 5 patients have the opportunity to design not just a
 6 secondary or tertiary outcome in a research study,
 7 but that they have an opportunity to design the
 8 whole thing.
 9 If we don't need to have a study visit every
 10 two weeks, is there any way to consolidate those
 11 study visits? Is there any way to think about
 12 measuring what the participants' experience has
 13 been like, especially in pain trials where there is
 14 often a huge placebo effect, for example?
 15 Understanding what the participant is going
 16 through, what their subjective experience is like,
 17 and using that to improve the fidelity of our
 18 research studies isn't just good for the
 19 participant. It's not just good for the patient;
 20 it's good for us as research scientists.
 21 So by building these reciprocal, mutually
 22 beneficial relationships with marginalized

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1 communities, we can really start to serve justice
 2 while also creating a much higher standard of
 3 science.
 4 This is, frankly, a note to self, of
 5 anything. We need to recognize that there are
 6 multiple sciences here of research participation
 7 and inclusion, and we've got to start addressing
 8 them. We need to think about the mechanisms that
 9 govern study design, that govern recruitment,
 10 engagement, retention, things that we don't spend
 11 enough time thinking about as researchers.
 12 We need to ensure that we take the
 13 responsibility to address those research barriers.
 14 That top 10 list of research barriers I highlighted
 15 earlier is not a suggestion. It's not a list of
 16 something to get to if you have time. And it's
 17 certainly not something that we need to be putting
 18 the onus on our research participants to navigate.
 19 Then finally, we also have to recognize that
 20 there is an indelible connection between research
 21 and health inequities. Without serving justice in
 22 research, we will not be able to solve health

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1 DR. FARRAR: Yes.
 2 Jonathan, great talk, and very important. I
 3 think the Alzheimer's slide that you showed is one
 4 of the best examples I've seen of something that
 5 people have begun to worry about, and I just
 6 wondered what your thoughts were. I have seen very
 7 few studies that actually comment on the selection
 8 bias of access to care in the large database
 9 studies that are now being done, and it has been a
 10 been a significant concern, and it sounds like it
 11 really ought to be.
 12 I just wondered what your thoughts were on
 13 that issue. The differences between race, and
 14 socioeconomic class, and so on, depend on whether
 15 people actually access care adequately to be
 16 recorded.
 17 DR. JACKSON: I have a lot of opinions, a
 18 lot of very loud opinions on this topic. I think
 19 ultimately what we're going to have to do is that
 20 there's going to ultimately be a step change in the
 21 way that we think about differential and different
 22 aspects or different orthogonal levels of selection

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1 bias in our research studies.
 2 I think that it's going to take a few years
 3 for this to settle. It's going to take a few years
 4 for this to move from disease area to disease area.
 5 But ultimately, I think we're going to look back on
 6 this time the way that we look back on scientific
 7 studies from the 1940s, which is it's interesting,
 8 it's an idea, but there were a lot of things that
 9 they didn't realize, so we're going to have to do
 10 some of that stuff over again.
 11 In the meantime, there are some short-term
 12 steps that we can do. Epidemiology in particular
 13 has developed this concept of transport tools or
 14 transportation tools. So inverse probability
 15 weighting, G-estimation are really great bridge
 16 measures that I think will become much more common,
 17 especially as our sample size gets a little bit
 18 bigger in clinical trials, and they can be much
 19 more robust to things like inverse probability
 20 weighting.
 21 IPW, just as a quick example, takes this
 22 idea of saying you've got like maybe a couple of

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1 people that belong to this particular group or
 2 identity. Can you extrapolate from those and
 3 impute as though you had a representative sample?
 4 So it's not perfect, but it is a really great
 5 measure of data imputation, and it's something that
 6 I'm hoping to bring to EPPIC-Net next in the near
 7 future as kind of an estimate.
 8 But I think that's going to be our immediate
 9 next step, so using some of these transportation
 10 tools to do a retrospective analysis to see if
 11 these studies actually have this problem of
 12 sampling bias that affects their causal reasoning.
 13 But in the long term, I think we're going to have
 14 to start to build in protocols that think about
 15 these things far earlier in the process than at the
 16 stage of peer review, or after peer review, which
 17 is the state right now.
 18 DR. FARRAR: Thank you.
 19 MS. VEASLEY: Thanks.
 20 Isabel, you have a question?
 21 MS. JORDAN: Hi. Thank you. That was a
 22 great talk. I really appreciate it.

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1 One question that I have, and something that
 2 I've been thinking about a lot, is that when folks
 3 generally talk about hardly reached populations, it
 4 often gets missed, disability as identity, and that
 5 as a population, we're often overlooked and are
 6 intersectional with a lot of other populations, and
 7 just are often missed as a separate group, and I'm
 8 curious about your thoughts on that.
 9 DR. JACKSON: You know, I don't think I
 10 could put it any better than you put it. I think
 11 the disability community is almost entirely left
 12 out of these conversations, and I think it's a real
 13 shame because what I think is that the disability
 14 community is the perfect way to highlight not only
 15 the intersectional aspects that are really crucial
 16 when it comes to studying these things, but also
 17 the fact that there are often overlapping
 18 conditions or morbidities that effectively bar this
 19 group from participating at all under this guise of
 20 very paternalistic reasoning that it's for their
 21 own good.
 22 That kind of highlights the central concern

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1 of clinical trials, is that we think about the
 2 risks of inclusion, but we never consider the risks
 3 of exclusion. I think a classic example of
 4 this -- just to kind of go a little bit outside of
 5 your question and then come back -- is the way that
 6 we've been thinking about the COVID-19 trials,
 7 where we excluded children and we excluded people
 8 who were pregnant, to the fact that there was very,
 9 very confusing advice and a much longer extension
 10 to the pandemic because we only thought about the
 11 risks of inclusion, and we had to kind of grip with
 12 the risks of inclusion as a society.

13 Now, with the disability community, we have
 14 this very paternalistic concern about the risks of
 15 inclusion, but there's no society to grapple with
 16 the risks of exclusion because society in general
 17 effectively erases disability as any kind of
 18 issues.

19 I'm getting on a soapbox, so I apologize.
 20 But I do think that this is an enormous problem,
 21 and I think it highlights kind of the diversity
 22 within individual communities. So there's no way

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1 to talk about a canonical or a standard disabled
 2 person, but you also can't talk about -- a
 3 canonical or standard -- a woman, or a black
 4 person.

5 So I think if we can do a better job of
 6 centering the disability community, it will help us
 7 understand how to grapple with all these other
 8 groups that we're trying to include in research
 9 studies that we tend to reduce to monoliths.

10 So I don't have any great suggestions, apart
 11 from being really thoughtful, about our inclusion
 12 and exclusion criteria in particular, but also
 13 thinking about especially the built social and
 14 structured environment that's required to access
 15 research studies.

16 The pandemic brought with it a lot of
 17 opportunities to re-examine that, and I think that
 18 we've done a very haphazard job of thinking about
 19 decentralized or virtual trials, and thinking about
 20 effectively democratizing or spreading access to
 21 research studies that are a bit more thoughtful and
 22 a bit more inclusive.

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1 So I think that there's a lot of work to be
 2 done, and I really, really hope that if we can
 3 start to center the community of individuals who
 4 are disabled or living with a disability, it will
 5 help us unlock some of these other problems that
 6 feel so intractable.

7 MS. JORDAN: Thanks.

8 MS. VEASLEY: Jennifer, do you have a real
 9 quick question before we move on?

10 DR. GEWANDTER: Well, mine's not super
 11 quick, so maybe I can ask him in the next part.

12 MS. VEASLEY: Are you going to be able to
 13 stay with us, Jonathan, until the end of the day,
 14 or do you have to jump off?

15 DR. JACKSON: I will be able to pop in and
 16 out, but I should be back for a little bit later,
 17 yes.

18 MS. VEASLEY: Well, why don't you ask it,
 19 then, Jennifer, so we have plenty of time for
 20 discussion later. Go ahead.

21 DR. GEWANDTER: Sure.

22 I guess my question is, I liked your

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1 framework where you used all these different places
 2 that we can possibly intervene, instead of just
 3 thinking about this as general disparities in
 4 biology. But from a practical perspective, trying
 5 to find these underserved populations in the clinic
 6 isn't going to happen.

7 So I guess my question is, as you said, we
 8 shouldn't put race in the model. So do you think
 9 that part of the solution is putting other things
 10 in the models, as well, or different things that
 11 are more representative of our actual selection
 12 biases versus race as a kind of marker of that?

13 Is that one of the ways you think we can
 14 address this problem, at least in the more shorter
 15 terms? These systems are not going to change
 16 overnight, but we want to try to address these
 17 problems quicker than just that bigger change.

18 DR. JACKSON: I think there are kind of two
 19 answers to your questions. Number one, race
 20 shouldn't be in our models because I think,
 21 999 times out of 1,000, we are not trying to say
 22 that the amount of melanin in someone's skin has

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1 some sort of differential effect on our outcomes.
 2 Race is almost always either a kind of a
 3 data reduction tool or a proxy for something else,
 4 but it's not a great proxy for any of those things.
 5 So instead of using it as a substitute variable,
 6 let's just actually measure the things that we
 7 think are the drivers of that.
 8 Now, the second thing is about trying to
 9 drive recruitment to our research studies. I think
 10 we need to think beyond the clinic wherever we can
 11 for research studies, but the bigger problem is
 12 that we try to, again, sort of reduce groups to
 13 monoliths. So we assume we're going to get like
 14 our regular population through the clinic, and then
 15 we're going to try to diversify by reaching outside
 16 of the clinic. And we sort of assume that maybe
 17 all of our people of color will come from some
 18 other setting.
 19 Now, that's going to set you up for the kind
 20 of data that I showed earlier from Alzheimer's
 21 disease, where you end up comparing apples and
 22 oranges. Instead, we really need to be thoughtful

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1 about how to be more inclusive in our research
 2 studies from the very beginning.
 3 Early data from my group really shows that
 4 it's not just one bubble that we're trying to pop
 5 here, but there are usually like two or three
 6 bubbles. So it turns out that most of the time in
 7 our clinic settings, we can get some semblance of
 8 that diversity that we're looking for -- maybe not
 9 all of it, but at least some of it -- so then we
 10 can start to implement models like I was talking
 11 about earlier, inverse probability weighting and
 12 G-estimation, to help bridge the gap the rest of
 13 the way while we're trying to work on these larger
 14 structures to be more inclusive in the first place.
 15 So it's sort of a three-step solution in
 16 order to try to address this. But the bottom line
 17 is that using race as a variable in our research
 18 studies is not going to help us. We're really
 19 going to regret this. It's going to be like a bad
 20 haircut that we got in high school in 10 to
 21 15 years time.
 22 DR. GEWANDTER: Thanks.

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1 MS. VEASLEY: Thanks so much, Jonathan. I
 2 hope you're able to join us later on for some
 3 discussion.
 4 So we're going to move on to our next set of
 5 speakers. We have Dr. Kathryn Martin and Lynn
 6 Laidlaw, who are from The Institute of Applied
 7 Health Sciences at the University of Aberdeen, all
 8 the way from Scotland.
 9 Go ahead.
 10 Presentation – Kathryn Martin
 11 DR. MARTIN: Lynn and I are very, very
 12 pleased to be here today and choose to speak with
 13 everyone about the how tos, I guess, of
 14 incorporating patient partners in the conduct of
 15 clinical pain research. Lynn had reminded me
 16 earlier about the great quote by George Bernard
 17 Shaw, "The British and Americans are two great
 18 peoples divided by a common tongue." This is
 19 really putting the onus back on the importance of
 20 terminology.
 21 It was noted yesterday, so I'll just briefly
 22 mention that today in our presentation we'll be

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1 using the term "patient and public involvement" or
 2 PPI, and we are following the NIHR involved
 3 definition of this as we conceptualize it as unique
 4 and different from participant, participation, or
 5 engagement.
 6 Lynn?
 7 Presentation – Lynn Laidlaw
 8 MS. LAIDLAW: This slide comes from a paper
 9 that was published this year called, More Than a
 10 Method, which discuss productive tensions, and,
 11 crucially, it was co-authored by some patient
 12 partners. We really like this because it just
 13 represents that patient public involvement isn't a
 14 tick box; that patients should be at the axis from
 15 which activities evolve from. So it's a fluid
 16 process. It's a changing dynamic. It's not an
 17 absolute, and, crucially, it's not a method.
 18 So therefore, you can't just tick off a list
 19 of patient public involvement and consider it
 20 involvement. There's no minimum, no maximum, and
 21 it's context-specific and value-specific as well.
 22 DR. MARTIN: We must, really, at the start

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1 here think about the values that are forging the
2 foundation, that true north of patient and public
3 involvement. We believe we should be involving
4 people with lived experience of chronic pain for
5 the right reasons. We have to do this for the
6 right reasons.

7 We want to approach this first with the
8 commitment of equality in the relationship and be
9 mindful that the power imbalances that can emerge
10 between researchers and patient partners are ever
11 there, that could bubble to the surface. So we
12 want to consider the importance of truth and
13 honesty of working with patient partners to ensure
14 that there's a certain level of transparency across
15 the working teams about all the research aims and
16 the activities that go in there. This was noted
17 earlier. Gail and Karen talked about this level of
18 truth, transparency, and trust.

19 Inclusivity we believe is of utmost
20 importance, such that patient partners are involved
21 in and about all of the aspects of the research and
22 not being constrained to just tokenistic

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1 activities, as this tickbox exercise, if you will.
2 Rather, we believe that the opportunities should
3 exist for involvement across the project, from
4 establishing the methods and the primary outcomes,
5 all the way through to data analysis and manuscript
6 preparation.

7 We think that space should be dedicated for
8 an idea exchange, allowing the patient partner the
9 ability to act as a critical friend. And from this
10 very critical element, trust, it can flourish and
11 continue to support the establishment of good
12 working relationships.

13 We think that an important part of the
14 team's core values is always to be mindful of the
15 human experience, and indeed all people are maybe
16 more than their level of experience however they
17 bring that, from a research perspective or from a
18 lived experience. We do think it's important to
19 avoid boxing people in and only see them as one
20 thing or another. This is especially so of people
21 with lived experience of chronic pain.

22 We think that each patient partner is unique

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1 in their own experience, and for many, it might be
2 even a complex medical and personal journey
3 complete with the emotions that have brought them
4 there to become involved in research in the first
5 place. So while we have identified these values as
6 central to patient and public involvement, we think
7 that there shouldn't be a set list of right or
8 wrong values. Instead, it has to be a collective
9 identification of these values from the team to
10 ensure that there's buy-in and to ensure that
11 involving people with lived experience of chronic
12 pain is not and should not be purely transactional.

13 MS. LAIDLAW: Thanks, Kathryn.

14 So we've heard earlier from Karen and Gail
15 that involving patient partners at the beginning
16 with the planning of research is so important, but
17 likewise this must continue once funds have been
18 identified and the research begins in earnest.

19 This can bring into focus what is most
20 important to people living with chronic pain.
21 Where many of the methods may have been established
22 and identified during the planning process, people

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1 living with chronic pain should be involved in the
2 identification of primary outcomes. These need to
3 be meaningful to people living with chronic pain
4 and sensitive to change; otherwise, we would
5 suggest that the studies are disadvantaged from the
6 outset.

7 The kind of idea of rubbish in/rubbish out
8 makes a lot of sense to me in this because if you
9 don't ask the right question, it doesn't matter how
10 sophisticated your methods are and how wonderful
11 your research team is. If you don't ask the right
12 research question, one that's meaningful to people
13 living with chronic pain, then I would question how
14 successful your research has been.

15 A real-world example of this is a study that
16 identified the primary outcome for people with
17 chronic pain as being able to exercise for
18 30 additional seconds on a treadmill. And while
19 this may have scientific merit and the rationale
20 for being chosen, how meaningful is it for that
21 person living with chronic pain?

22 The same goes for these 6-minute walk tests

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1 or walking up the stairs. And perhaps the question
2 is not can it be done, but what is the impact
3 afterwards on the person living with chronic pain
4 and how long the recovery is?
5 People have spoken about how patient
6 partners must be consulted on study activities and
7 thinking for the timing of the clinic visits and
8 activities that might take place. A lot of time
9 when I'm in conversation with researchers, it's
10 like, "Oh well, people are coming to the hospital
11 anyway, so we can just ask them to do this and
12 that, or we don't need to pay for their traveling
13 expenses." To me, that just makes it a bit
14 transactional because I think you should always
15 offer travel reimbursement and meals and snacks to
16 ensure people's comfort, and all these elements
17 impact recruitment and retention.
18 I think in methods, there are some real
19 productive tensions here -- isn't there? -- between
20 what's measurable versus what's meaningful. Do we
21 only measure what's measurable, not what's
22 meaningful to people? When we're using things like

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1 forms or validated questionnaires, what do we mean
2 by validated and from whose perspective? Because
3 often these weren't validated on diverse
4 populations. I think chronic pain and
5 questionnaires around catastrophization can be seen
6 as patient blaming, and can be really tricky.
7 Finally, in ethics, in the UK we're moving
8 towards a situation where research teams may not
9 get ethical approval if they can't demonstrate that
10 they've meaningfully involved patient partners or
11 members of the public when designing or developing
12 the research project, and that's certainly
13 something that I would support.
14 Over to you, Kathryn.
15 DR. MARTIN: Thanks, Lynn.
16 Following then from the methods, we really
17 want folks to be thinking about the data because we
18 do believe that researchers should be working with
19 patient partners in this area. But it's often an
20 area where patient partner involvement can be
21 overlooked and certainly may not be considered easy
22 or as streamlined as it could be.

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1 Data collection, analysis, and
2 sense-checking activities really can enhance the
3 research, study findings, and the contextualization
4 of that, but it does require a certain level of
5 commitment on the part of the researchers, as well
6 as patient partners, because both groups need to
7 overcome biases that might be associated with being
8 involved with the data and the handling of that.
9 Beyond having patient partners maybe pilot
10 paper electronic surveys to ensure the
11 acceptability and accessibility of instruments, and
12 instructions even, as well as understanding how
13 long it might take, for instance, for a participant
14 to complete it, it's really an instrumental element
15 of patient partners picking up on logistical issues
16 and things like skip patterns and things that don't
17 make sense once someone with lived experience is
18 going through it.
19 We do think the patient partners should be
20 considered in joining, say, as a researcher in some
21 of the steps of the process of running a study, and
22 they might even be open to helping to collect data.

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1 For example, they might undertake training to
2 actually conduct qualitative interviews and think
3 about, say, focus groups. They might actually
4 become involved in data analysis and helping the
5 researchers look for patterns of missing data or
6 even undertaking thematic analysis of collected
7 qualitative data.
8 Finally, the sense of sense-checking
9 exercises and discussions with patient partners
10 really can help the research team put the data into
11 context. A master student working on a research
12 project with me recently, we did a sense-checking
13 activity with individuals, and it was just
14 absolutely fantastic to see their interpretation of
15 the data and get them formally involved, the
16 patient partners formerly involved with the data.
17 We don't want people to be limited by lack of
18 thought or imagination, and careful reflection of
19 where that can happen is important.
20 There are a number of resources in journal
21 articles discussing how to build patient partners
22 into this process and how to involve

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1 multidisciplinary people on teams. Nicola Gray has
 2 written a really wonderful piece, and then Louise
 3 Locock has written a really great piece about
 4 having analytic conversations with patient
 5 partners.
 6 I'll just leave for this slide that there's
 7 a patient partner in Birmingham [ph], Margaret
 8 O'Hara, who has a real web presence on Twitter, and
 9 she's always a very big advocate of checking your
 10 models and getting patient partners involved in
 11 that analysis, because the more perspectives, the
 12 stronger the relevance will be back to people
 13 living with chronic pain.
 14 MS. LAIDLAW: Thanks, Kathryn.
 15 I think we can all agree that communication
 16 is really important. People want to participate in
 17 research. A lot of people have altruistic motives
 18 for doing that, but with the best will in the
 19 world, people are not going to participate in your
 20 research if you make it too burdensome. I think
 21 we've heard a lot today in terms of involving
 22 patient partners in that, that your communication

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1 should be culturally competent and sensitive.
 2 I just wanted to speak a bit about the
 3 participant information sheet. The question I
 4 would ask is whose participant information sheet is
 5 it anyway? Do we tell potential trial participants
 6 what they want to know, or what we want to tell
 7 them, or think that we should know? I think the
 8 issues here are do we need an 18-page participant
 9 information sheet? How can we ensure that there is
 10 informed consent if people can't understand the
 11 information that they've been given? Have
 12 participant information sheets become legal
 13 documents and people become covering themselves,
 14 rather than what they should be, which is a
 15 fundamental part of the ethics process?
 16 It's really challenging. I understand the
 17 challenges here. I understand that there can be
 18 pushback from sponsors and legal departments, but I
 19 think it's something that we've got to get right.
 20 In the UK, the Health Research Authority has
 21 distinct ethics, and the work package at the
 22 moment -- which I'm involved in -- and one of the

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1 work streams in that is to look at participant
 2 information sheets and to try and do better.
 3 If there's not clear communication about the
 4 expectations put on participants once they agree to
 5 take part in research studies or trials,
 6 misunderstandings can exist, and participants may
 7 not be a hundred percent sure of what they signed
 8 up for. In fact, research by Katie Gillies and
 9 colleagues in Aberdeen has indicated that people
 10 often drop out of research because dates and
 11 expectations are unclear, and some people didn't
 12 even know that they dropped out of research.
 13 The final thing I would say in communication
 14 is that it's so important to keep people updated
 15 throughout the study and also with the results,
 16 because to not do so is actually, I think, quite
 17 rude. I know that I wouldn't participate in
 18 research anymore that won't tell me what the
 19 findings were. I think that this can leave people
 20 feeling used and that researchers are dismissive of
 21 their human experience.
 22 The next this is emotions and feedback, and

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1 this is, of course, tied to communication, but we
 2 felt it was deserving of its own space. I
 3 encourage you to think about emotions as they
 4 relate to everyone on the research team. Patient
 5 partners, particularly those living with chronic
 6 pain, are bringing their whole self to the
 7 discussions, and sometimes individual responses can
 8 impact on everyone. That's why we need regular
 9 meetings, and email communications are essential.
 10 It's about creating time and space, safe
 11 space, for reflection and opportunities for
 12 receiving and providing feedback to one another. I
 13 know that we think researchers are babies -- don't
 14 we? -- and then if some people tell us our baby is
 15 ugly, that can be really difficult to hear
 16 sometimes. But it's vital that patient partners
 17 feed back to the research colleagues and that
 18 researchers are able to accept that feedback.
 19 Again, this harkens back to the values underpinning
 20 patient public involvement, ensuring space for
 21 challenging discussions and promoting critical
 22 thought, but done professionally.

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1 DR. MARTIN: Thanks so much, Lynn.
2 This is an important area, I think, to think
3 about, and certainly I had raised it earlier. I
4 know in my role here as champion PPI in Aberdeen,
5 this is always at the forefront of a researcher's
6 mind.
7 It's really important to think about costs
8 because involvement is not free, and then there's
9 this power dynamic that's inherent even in the way
10 that we discuss this as researchers and with our
11 patient partners. Terms like "payment,
12 reimbursement, or a thank you," these all come up,
13 and words matter. I personally like to use the
14 word "renumeration" [ph]. It's I guess what I
15 prefer, but offering renumeration is a way to
16 acknowledge that time is valuable to those
17 individuals living with chronic pain who wish to
18 take part in research. A lot of individuals may
19 have left employment due to their health or their
20 condition, and those funds can really help to
21 facilitate involvement, particularly from those who
22 are seldom heard in research.

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1 So what's the right amount? Everyone always
2 wants to know, "Well, how do I cost this in and
3 what do I do?" There are, at least in the United
4 Kingdom, guides of how to cost for involvement to
5 ensure that patient partners are being remunerated
6 appropriately, and consistently, and fairly for
7 their time and resources.
8 Planning involvement activities and costing
9 those in is, again, essential to ensuring that
10 there are funds available to undertake meaningful
11 PPI. Less so are funds available for the earlier
12 initial planning stages, although that's not
13 necessarily what we're meant to cover here. But
14 really, money is always essential, isn't it?
15 I think we can facilitate involvement by
16 ensuring how patient partners maybe have a choice
17 in how they'll get remunerated. Sometimes
18 outlaying funds to travel to meetings may mean that
19 they can't attend, so it's important to think
20 through the study timeline and identify when and
21 how patient partners might be contributing, whether
22 there will be any costs that they have to bear

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1 initially, and trying to proactively plan, and make
2 that process as easy as possible so they don't have
3 to front that.
4 We have found that bank transfers can be
5 really challenging. Some patient partners might
6 not have access to a bank account, and offering
7 cash is not always a lot of institutions, so
8 vouchers, or gift cards, and pre-loaded cash cards
9 can be a viable solution. But even involvement
10 comes with tax obligations that could threaten
11 government benefits for some patient partners, at
12 least here in the UK. So there has to be an open
13 conversation about the true cost of involvement
14 between the patient partner and the research team
15 to make sure we can facilitate that involvement
16 whenever possible.
17 I think it's really important here to
18 highlight that there are so many other ways to
19 facilitate involvement beyond cash, or gift
20 vouchers, or payments; not that they should be in
21 lieu of, but they can go along side of it. For
22 instance, ring-fencing funds for computing, Wi-Fi

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1 isn't free, so that cost is borne somewhere else.
2 A lot of patient partners that we work with have
3 Page-Go [ph] telephones, mobile phones, so they
4 have to do a top-up for their connectivity. If
5 they're using it for involvement activities, they
6 can't use it to speak to friends, or family, or
7 their work, and thinking about purchasing computer
8 or other techware that could be useful to them.
9 The other thing, it goes for electricity
10 costs. If people are on prepayment electricity
11 meters, thinking through that they need to use
12 their electricity for involvement, we may have to
13 compensate in addition to that as well.
14 Thinking through other things like honorary
15 university staff positions can allow for patient
16 partners to have access to things like email
17 accounts, even Microsoft Office Suite, things we
18 take for granted as researchers as being linked in
19 with universities. This could be especially useful
20 for accessing software, things like teams meetings
21 that, at least here in Aberdeen, is our preferred
22 method. We're not allowed to use Zoom because of

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1 security reasons, so other patient partners
 2 find -- I know Lynn does -- that it's very
 3 difficult to attend meetings as an external
 4 attendee.
 5 So sometimes we have to make sure that we
 6 provide training about systems and setting aside
 7 funds for other trainings, and even attending
 8 local, international, or national conferences
 9 wherever possible.
 10 MS. LAIDLAW: We encourage you to think
 11 cake, a fruit cake to be precise. A lot of good
 12 work often gets done over a fine cup of coffee and
 13 cake, and this speaks to the relational aspect of
 14 working with patient partners. Really, at this
 15 moment this is what we feel is missing during these
 16 virtual times, but also because this image of the
 17 fruit cake will help reinforce the importance of
 18 baking patient and public involvement into your
 19 process and into your research because it can't
 20 just be added on the top like icing on top of the
 21 cake.
 22 Careful consideration needs to be given to

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1 all these elements because funding agencies support
 2 tokenistic activities, I think especially in the UK
 3 where patient partners are increasingly doing grant
 4 reviews and sitting on funding subcommittees. When
 5 in doubt, seek help. Admit that you don't know how
 6 to do it and ask for help.
 7 We'd really like to stress that patient and
 8 public involvement is not a methodology; rather,
 9 it's a carefully constructed set of relationships,
 10 and it's about conversations, and it's about
 11 collaboration, and these need to be nurtured. No
 12 one will care about your research more than the
 13 people living with chronic pain because research is
 14 hope. If I didn't feel that the unique insight of
 15 patients could help, then I wouldn't waste your
 16 time, and I wouldn't waste mine either. The impact
 17 of research mixed with policy can have a major
 18 impact on people's lives and their well-being, and
 19 that's why this matters.
 20 DR. MARTIN: As Rachel mentioned yesterday,
 21 the Advanced Pain Discovery Platform is a
 22 five-year, \$24 million pound initiative funded

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1 through the government's Strategic Priorities Fund,
 2 and it's delivered in partnership through a number
 3 of government funding agencies, the charity, Versus
 4 Arthritis and Eli Lilly.
 5 This is something that I wanted to highlight
 6 because this is a project, a consortium, that Lynn
 7 and I are working on together. This is the
 8 PAINSTORM. This is the Partnership for Assessment
 9 and Investigation of Neuropathic Pain: Studies
 10 Tracking Outcomes, Risks and Mechanisms. Within
 11 this consortium, we're seeking, through a program
 12 of work, to look at individuals living with or at
 13 risk of neuropathic pain; improve the way that
 14 neuropathic pain is assessed; how it impacts on
 15 daily life; how it's measured; and to learn more
 16 about genetic risk factors using biomarkers, tissue
 17 samples, and imaging to better understand the
 18 mechanisms and to think through about maybe
 19 developing causal models of psychosocial risk
 20 factors; so seven work packages, very in-depth.
 21 We have right from the start engaged with
 22 four patient partners -- Lynn is one of them -- who

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1 are living with neuropathic pain from different
 2 health conditions.
 3 Lynn, do you want to come in and say a
 4 little bit more about how -- well, you've been
 5 embedded into the process from early on when we
 6 were initially starting conversations about
 7 submitting a grant proposal for this, but how
 8 things have gone and involvement to date?
 9 MS. LAIDLAW: I think we've had some
 10 productive tensions, haven't we? We've had some
 11 challenging conversations, and I think that the
 12 patient partners have got in about, as we would say
 13 in Scotland, the grant application before it was
 14 submitted, and obviously so excited that we're
 15 funded.
 16 I think that we have made a difference
 17 because we've been allowed to make a difference.
 18 Some of the things that we've changed is just the
 19 recognition that there's been very little
 20 qualitative research on people's lived experience
 21 of neuropathic pain, so we've brought that in.
 22 We've brought in some different patient cohorts,

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1 and one of the patient partners proposed a series
 2 of podcasts, and we're being really keen for the
 3 research team to adopt some creative methodologies
 4 and whatever, as well. So I think it really has
 5 been a partnership and a collaboration, which has
 6 been fantastic.
 7 DR. MARTIN: Watch this space, right?
 8 MS. LAIDLAW: Yes.
 9 DR. MARTIN: We're just on the beginning of
 10 this for your journey, so there will be lots to
 11 talk about and meetings to come.
 12 We have some further readings, as we
 13 mentioned throughout the presentation, additional
 14 studies and research, another blog from Simon
 15 Stone, and things that folks might be interested in
 16 as they carry out their research.
 17 The final slide, I love Rodin's Thinker, and
 18 it's a nice picture to encapsulate this idea of
 19 let's keep thinking about how we involve patients
 20 in chronic pain research and pain research in
 21 general, and thinking of ways that we can do that.
 22 Lynn is prolific on Twitter. She's amazing.

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1 Follow her. I'm a bit more analog, if you will.
 2 Just send me an email if you want to stay in touch.
 3 I think, overall, we don't want anyone to
 4 think of this as a process and that there's any one
 5 set methodology, but rather to actually stop and
 6 think of the different stages of conducting
 7 research and where patient partners can be
 8 embedded, utilized, and brought in to make things
 9 much stronger and robust. So there we are. Thank
 10 you very much.
 11 Clarifying Q&A
 12 MS. VEASLEY: Thank you both. That was
 13 truly a terrific talk.
 14 Simon has his hand raised very quickly, so
 15 I'll let you ask your question.
 16 DR. HAROUTOUNIAN: Yes. Sorry for the
 17 premature hand raise. Kathryn and Lynn, thank you
 18 for the fantastic presentations. It was really
 19 insightful.
 20 Kathryn, when you were talking about
 21 involvement across the process, you did mention
 22 that it's important to involve patient partners, or

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1 PPI, in the section of data analysis as well, sort
 2 of interpretation, and this has been a somewhat
 3 controversial point where people have been arguing
 4 back and forth.
 5 I was wondering if you have perhaps some
 6 examples of how to meaningfully engage patients in
 7 that specific area of data analysis and potentially
 8 interpretation.
 9 DR. MARTIN: Sure. The two papers that I
 10 mentioned that are there -- I think ultimately
 11 you're so right. I think it's about coming away
 12 from our biases of giving over control, but it
 13 doesn't have to be here's a data set; now go off
 14 and do it. I think it works really well when you
 15 actually are able to have that conversation and
 16 plan out the analysis, and are these the questions
 17 we should be asking. It sort of goes back to that
 18 planning phase and setting your aims and
 19 objectives, but getting individuals involved at the
 20 different stages.
 21 We've talked a little, Lynn and I, about
 22 qualitative work, and when the researcher goes

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1 away, to actually think about developing and
 2 reading through the interview guides and the data
 3 that come from interviews.
 4 The themes that emerge might be all
 5 generated by the researcher, so it would actually
 6 be interesting to then go back to the individuals
 7 themselves, to the patient partners, or even
 8 participants for that matter, and go back and say,
 9 "These themes that we've generated from your data,
 10 were these accurate? Are these themes relevant?
 11 Do you see the same themes when you read the
 12 transcript guides?" and getting individuals and
 13 training them to do some research alongside us.
 14 Lynn, do you have any good examples?
 15 MS. LAIDLAW: I've used the analytic
 16 conversations method with Louise Locock. I've been
 17 funded to do some patient light research, a small
 18 piece of qualitative research, and we have
 19 recruited a patient advisory group who's going to
 20 be helping us with the qualitative analysis. We're
 21 using a framework approach, and they're going to be
 22 helping us build the framework as well.

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1 Actually, I talk about some of the pushback
2 that I've had from researchers when I have
3 volunteered to help with the qualitative analysis,
4 and it's been suggested that patient partners come
5 from a position of bias. But I would say that
6 everyone comes from a position of bias.
7 What sometimes feels really uncomfortable to
8 me is that if I'm participating in the qualitative
9 interview, I give my insights, and then researchers
10 take that away, and they analyze it using
11 frameworks that have no meaning for me. And they
12 assign meaning to what I say, and that might not be
13 what I meant. I think if we're looking at
14 robustness, for want of a better word, it's about
15 completing the circle, and to make sure that we're
16 not missing anything.
17 DR. HAROUTOUNIAN: Thank you so much.
18 So is it a notion that data analysis might
19 be uncomfortable for patient partners? Is it just
20 a paternalistic sort of view that researchers might
21 hold, rather than truly involved in that meaningful
22 conversation and being open to hearing what the

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1 patient partners actually think about that?
2 DR. MARTIN: Absolutely.
3 MS. LAIDLAW: Yes.
4 DR. MARTIN: Sorry, Lynn. We're in
5 agreement there.
6 It's interesting. In a recent patient
7 partner group I was at, folks said, "We really want
8 to be used wherever we're most useful." You will
9 undoubtedly get different patient partner groups,
10 whether they're advisory committees or whatnot, and
11 people from all sorts of backgrounds and all sorts
12 of interests. And they bring with them their own
13 experiences, their own expertise, and their own
14 interests.
15 Some people won't touch data with a 10-foot
16 pole, but others might be interested or intrigued.
17 And actually, if you sent them on a statistics
18 course, and they were interested in learning and
19 wanted to work alongside some of the researchers,
20 then surely that is a wonderful opportunity to work
21 with patient partners in a way that is meaningful
22 and beneficial to everyone.

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1 I don't know how many people want to sit and
2 learn data, but I think that we could harness our
3 patient partners, and experiences, and expertise in
4 a way that maybe we haven't yet because we've been
5 a bit uncomfortable with that.
6 So again, Lynn, don't you think that that's
7 part of that pushback in the conversation, that
8 it's going places where maybe we haven't always
9 gone?
10 MS. LAIDLAW: Absolutely. I think this
11 speaks to sometimes patient public involvement in
12 research is a bit transactional. I just always
13 want more. I'm just one of these people that
14 always want more, and I just want to push back.
15 And while I'm happy to look at patient materials
16 and whatever, if I'm being asked to comment on a
17 document that's already written, that's just moving
18 words around the spreadsheet when actually I don't
19 want barriers put on my involvement. And this is
20 why it comes back to these conversations, the
21 relationships, and the collaboration.
22 In honesty as well, if you can't

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1 involve -- I need to know what I'm signing up for.
2 If you only want me to become involved in a
3 participant information sheet, then tell me that at
4 the start, and then I can have some choice over
5 whether I become involved or not. But I wouldn't
6 be interested in working on that basis.
7 DR. HAROUTOUNIAN: Thank you so much.
8 MS. VEASLEY: Yes, that's a great point,
9 Lynn, about trustworthiness, transparency in the
10 process, and bi-directional communication, and
11 continued communication. So thank you both, again,
12 for a really terrific talk.
13 We're going to move on to our last talk of
14 the day, and I'm really pleased to introduce
15 Dr. Christine Chambers. She and I met about four
16 years ago at a Banbury conference, and I just have
17 to say that after about 25 years of being involved
18 in science meetings, she was the very first
19 scientist that I ever heard talk about anything
20 past the point of actually publishing a scientific
21 paper and talking about actual dissemination or
22 implementation efforts of the research that's

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1 coming out of her lab and others.
 2 She's the professor of psychology, and
 3 neuroscience, and pediatrics at Dalhousie
 4 University, and her partner Isabel Jordan is the
 5 strategic lead for patient partnerships within her
 6 lab. So I'm really pleased to introduce both of
 7 you.
 8 Presentation – Christine Chambers
 9 DR. CHAMBERS: Thanks, Chris. It's great to
 10 be here and really appreciate that kind
 11 introduction. Thank you again for inviting us here
 12 today to talk about meaningful and active patient
 13 engagement as part of the dissemination and
 14 implementation phase of clinical pain research.
 15 Before we start, we would like to offer land
 16 acknowledgments in Canada. A land acknowledgement
 17 is an act of reconciliation that involves making a
 18 statement recognizing the traditional territory of
 19 the indigenous people who called the land home
 20 before the arrival of settlers, and many cases
 21 still do call it home.
 22 So I'm speaking today to you from Halifax,

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1 Nova Scotia, Canada, which is located in Mi'kmaq,
 2 the ancestral and unceded territory of the Mi'kmaq
 3 people.
 4 Presentation – Isabel Jordan
 5 MS. JORDAN: And I'm speaking to you today
 6 from the traditional unceded territories of the
 7 Squamish people, also known as Squamish BC, where
 8 I'm grateful to live, learn work, and play.
 9 DR. CHAMBERS: First to introduce ourselves,
 10 as Chris mentioned, I'm a clinical psychologist and
 11 health researcher who has studied children's pain
 12 management for over 25 years. My focus has been
 13 generating new knowledge on the role of families
 14 and a variety of psychosocial factors in children's
 15 pain, with a particular interest in what parents
 16 say and do and how that influences children's pain
 17 experiences.
 18 I lead a research lab that's based at our
 19 local children's hospital, and I also serve as the
 20 lead of a new federally funded national knowledge
 21 mobilization network that launched in 2019 called
 22 Solutions for Kids in Pain, also known as SKIP.

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1 SKIP's mission is to improve children's pain
 2 management through coordination and collaboration.
 3 So in addition to the work that I've done
 4 generating new knowledge as a scientist in my
 5 research lab, I'm also committed to mobilizing it
 6 through SKIP.
 7 Just of note, in 2020, I took on a new role
 8 as scientific director of one of the 13 institutes
 9 of the Canadian Institutes of Health Research,
 10 which is the Canadian version of NIH.
 11 MS. JORDAN: I come to this work from a
 12 background of lived experience. I have two kids,
 13 both of whom have chronic pain. Twenty years ago,
 14 my oldest, Zachary, was born. When he was about a
 15 year-and-a-half old, we started on a diagnostic
 16 journey to learn why he wasn't developing like
 17 other kids. This was a path that kept us deeply
 18 embedded in a health system where he didn't fit in,
 19 where our roles became that out of advocates, care
 20 coordinators, and researchers to try to figure out
 21 what was going on.
 22 As we traveled between clinics, and

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1 specialists, and systems of care, we had a unique
 2 view on the gaps and enablers while we were
 3 learning on our feet; and sadly, most often we
 4 learned after the fact, as in after we found the
 5 gaps that caused harm. Eventually this led my
 6 husband and I to be co-founders of the Rare Disease
 7 Foundation, a national foundation in Canada, where
 8 we collaborated with other parents, clinicians, and
 9 researchers to share our knowledge to improve the
 10 lives of those with rare disease, and eventually
 11 led me to work with researchers as a person with
 12 lived experience across the country.
 13 DR. CHAMBERS: So you might be wondering how
 14 we met. We actually met online through our Twitter
 15 feeds early in 2015. I was using social media to
 16 share my research, and when I started my It Doesn't
 17 Have to Hurt Initiative, I was looking to engage
 18 parents, and I met Isabel.
 19 It Doesn't Have to Hurt was a CIHR-funded
 20 science media partnership with a major Canadian
 21 digital marketing agency that had extensive
 22 experience in the Canadian mom social media space.

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1 Our goal was to increase parents' awareness and use
 2 of research evidence about children's pain through
 3 the co-creation of a branded content campaign
 4 called, It Doesn't Have to Hurt.
 5 MS. JORDAN: We actually finally met in
 6 person when I came to Halifax, way across the
 7 country, to participate in the It Doesn't Have to
 8 Hurt launch event in 2015, and we've been
 9 collaborating ever since. Now I work with
 10 Christine and her team strategically in patient
 11 partnerships in her research lab, and I serve as
 12 co-chair of the Patient and Caregiver Advisory
 13 Committee at Solutions for Kids in Pain, as well as
 14 working with several other researchers in both
 15 sharing my lived experience, as well as mentoring
 16 them on how to do patient partnership in an
 17 authentic way.
 18 So why now? I think a lot of us know that
 19 data illustrated by story or narrative can have
 20 greater impact. Patient partners can not only
 21 contribute to that narrative; we can help ensure
 22 that language and images used are accessible, and

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1 we also have access to networks outside of academia
 2 where research results can be disseminated.
 3 DR. CHAMBERS: My why, I'll confess, the
 4 first time I ever engaged a patient partner in a
 5 project was because I had to. The granting agency
 6 required that it acknowledges or be engaged in the
 7 project, so I did, and it's been a whole shift in
 8 perspective for me.
 9 As a researcher, I always felt that I had
 10 patients' best interest at heart; after all, I'm a
 11 parent myself. But I started to realize the
 12 limitation of only bringing the researcher
 13 perspective to my work. I'll give you an example.
 14 I was a co-investigator on a randomized
 15 trial of co-bedding to reduce pain in preterm twins
 16 in the neonatal intensive care unit. I had
 17 reviewed all the ethics of materials and approved
 18 the consent forms. But a few years into the study,
 19 I actually gave birth to a set of late preterm
 20 twins who were enrolled in the study because they
 21 met eligibility criteria. And all of a sudden,
 22 when I was reading the consent form as a caregiver

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1 and a parent/patient, I saw it in a completely
 2 different way.
 3 There have been so many benefits to engaging
 4 patients in my research and in my lab. We now
 5 engage patients at every step of the way, from idea
 6 generation to publication. We'll give you one
 7 example.
 8 We were developing a two-minute animated
 9 network video for our Solutions for Kids in Pain
 10 network launch. We were working with the video
 11 producer, and we sought feedback from a variety of
 12 stakeholders, including Isabel.
 13 MS. JORDAN: I'm a disabled woman, and I
 14 have two disabled kids. This is a big portion of
 15 who our audience is and who we reach in the work at
 16 SKIP. I noticed in the whole video, there was no
 17 disability representation in any of the children,
 18 and I let Christine know it was really important.
 19 DR. CHAMBERS: So I flagged this for the
 20 video producer who added in a child in a wheelchair
 21 in one section of the video, and we thought that
 22 would address the concerns. So I happily sent the

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1 revised video back to Isabel to review.
 2 MS. JORDAN: And I have to say, it was great
 3 to get that immediate response from Christine,
 4 because I've done this before, where I wasn't
 5 listened to before. So I was sitting in the
 6 airport in Vancouver waiting for my flight to go to
 7 Halifax for the launch event, where this video
 8 would be seen for the first time, and I looked at
 9 the video, and it was worse. They made it worse.
 10 The disability representation was of a sad,
 11 little wheelchair user in the middle of happy,
 12 able-bodied children. I had to let Christine know,
 13 and it was 24 hours before the launch.
 14 DR. CHAMBERS: Right. So we talked, and we
 15 came up with a solution to insert the child in the
 16 wheelchair in a scene holding hands alongside other
 17 children so it would appear more natural and
 18 integrated. We were really down to the wire, but
 19 this feedback made a critical difference.
 20 So this is just one example. Patient
 21 partners have helped us in so many other ways like
 22 this to interpret findings by providing context.

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1 They support our recruitment and engage their
 2 networks to promote sharing. They've introduced us
 3 to new partner organizations, and they suggest
 4 unique models of dissemination. But I have to
 5 admit that I was reluctant to agree to give a
 6 presentation today here on engaging patients in the
 7 dissemination/implementation of research because I
 8 don't believe it's appropriate to just engage
 9 patients at this stage.

10 In my experience, successful dissemination
 11 and implementation hinges on patient engagement
 12 throughout earlier stages, and we've had some
 13 fantastic presentations today illustrating that.
 14 Successful partnerships between researchers and
 15 patients are dependent on building relationships.
 16 I'm convinced that knowledge mobilization is all
 17 about relationships.

18 Patients can't be expected to promote or be
 19 engaged in sharing the results of research if they
 20 haven't been part of shaping. In our, It Doesn't
 21 Have to Hurt project, parents were involved in
 22 shaping and launching the project. They led us to

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1 topics they wanted to know more about. They
 2 co-created the content. They vetted everything,
 3 just like the scientists vetted it before it went
 4 live.

5 So as a result, Canadian parents actually
 6 became empowered to be the primary disseminators of
 7 our research on children's pain, and because of
 8 parents, the project was a huge success. We went
 9 on to win all kinds of awards in the science and
 10 health space, but also in the marketing and digital
 11 publishing spaces. But the success with our
 12 dissemination was built on strong relationships and
 13 a foundation of quality engagement throughout the
 14 project, not just at the end.

15 MS. JORDAN: Just as Christine said,
 16 principles of engagement, regardless of where
 17 you're putting them, whether at the beginning of a
 18 project or a dissemination, are the same. I'd
 19 really like to take a little pause here and talk
 20 for a moment about respect and safety in engagement
 21 and partnership and what that means.

22 As patient partners, we're coming from a

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1 really vulnerable place. We are low on a power
 2 hierarchy that needs to be recognized. We bring
 3 expertise that's often formed through trauma, and
 4 we're trusting researchers to create opportunities
 5 that will respect us as full team members.

6 How do you do that? It starts by valuing
 7 the expertise we bring, by creating safety for
 8 sharing our knowledge and by recognizing that our
 9 values may look different from yours. But mostly
 10 recognize this. We're not here for you to take
 11 care of, even though that could be something that
 12 you feel from a really good place in your heart.
 13 We're here for you to work with. We are partners
 14 in a piece of shared work.

15 DR. CHAMBERS: Another way to demonstrate
 16 respect for the expertise, experience, and skills
 17 that patient partners bring to the team is through
 18 providing fair compensation. Compensation is so
 19 important for equal opportunity patient engagement.
 20 I'm here today because it's part of my job. I get
 21 paid to do the work that I love to do.

22 Many patient partners take time away from

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1 their families and may incur additional costs like
 2 caregiving expenses to participate. Financially
 3 compensating patient partners for their time and
 4 expertise, in addition to covering any expenses in
 5 advance related to their participation is
 6 equitable. It respects their vulnerability and
 7 removes barriers. In particular, marginalized
 8 populations are confronted with financial and
 9 social determinants that are often barriers to
 10 engagement, so compensation is a way to engage a
 11 more diverse group of perspectives.

12 I highly recommend this publication. It's
 13 one of several that Isabel and I provided in
 14 advance of the meeting. Isabel's a co-author on
 15 this paper, and it really does a deep dive on some
 16 of these issues related to equity, different
 17 motivations, respect for vulnerability, commitment,
 18 and barrier removal.

19 Many organizations are developing
 20 compensation policies and guidelines for assigning
 21 financial value to patient expertise and are
 22 available publicly. You can review ours on the

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1 "Patients Included" section of our Solutions for
 2 Kids in Pain website, kidsinpain.ca, and I'll paste
 3 that in the chat after the presentation.
 4 MS. JORDAN: Another way to show respect for
 5 us is to include patients in dissemination
 6 opportunities like inviting them to conferences.
 7 This goes beyond that inspiring patient's story to
 8 kick off a conference that has often been the
 9 traditional way to include patients in conferences.
 10 Inviting patient partners to co-present -- like
 11 Christina and I are doing here, and you've seen
 12 earlier as well today -- not only makes often for
 13 more memorable presentations, it also models
 14 engagement while practicing engagement.
 15 For folks organizing conferences, the
 16 patientsincluded.org charter has a
 17 self-accreditation guideline on how to start down
 18 that journey of authentically and safely including
 19 patients in conferences. The charter clauses
 20 include things like having patients as part of
 21 organizing committees; patient partners
 22 participating in conference content, as well as

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1 having them in the audience; supporting patients'
 2 travel expenses; and meeting our disability
 3 requirements. Of course, partnering with patients,
 4 co-presenting means supporting our efforts in
 5 preparation. Some people might need more support
 6 or less support, and compensating us for our time.
 7 DR. CHAMBERS: Along with co-presenting the
 8 work at conferences and other public speaking
 9 engagements, another way to let patients in, and
 10 open doors, and respect them as full team members
 11 is to create opportunities for authorship by
 12 inviting them to engage in co-authorship on
 13 published manuscripts. There's a great paper here
 14 that discusses and provides guidance on authorship
 15 with patient partners.
 16 Researchers need to adopt a wide variety of
 17 dissemination avenues, including both these
 18 traditional opportunities of presentation and
 19 publication, but also non-traditional opportunities
 20 such as co-creating infographics and visual
 21 summaries; co-engagement with news and media;
 22 co-writing blog posts, newsletters, and social

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1 media posts about the work.
 2 So where to start? When I first started
 3 engaging with patients as partners in research,
 4 this was new territory for me. I didn't know what
 5 I was doing or how to do it right. And even though
 6 I was trained as a clinician, a clinical
 7 psychologist -- I knew how to interact with
 8 patients, or I thought I did -- nothing in my
 9 training had prepared me for how to engage with
 10 patients in this way. In fact, my clinical
 11 training had enforced boundaries, and role
 12 differentiation, and hierarchies that actually made
 13 it harder for me to engage with patients in my
 14 research.
 15 I was anxious that I would be a burden or be
 16 asking too much of parents who had many, many
 17 challenges on their plates related to their
 18 families and their children. Sometimes as a
 19 researcher, my projects had firm timelines and
 20 deadlines that were not flexible, so I set up a
 21 panel of parents so that no one parent would feel
 22 all the responsibility was on them to engage in the

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1 project.
 2 At the beginning of the project, it was
 3 hard, but as I went along, I sought input and
 4 guidance. I could see it was making the project
 5 better, and so could the parents. So I kept
 6 asking, and gradually got more comfortable, and
 7 didn't feel as though it was a burden. Parents who
 8 were able to contribute did, and it was their
 9 choice.
 10 So my advice to other researchers is it's ok
 11 to start small and gradually, but just to start.
 12 Some examples; the next time you're writing a grant
 13 application, consider adding a patient as a
 14 collaborator or co-investigator, which will help
 15 facilitate your engagement in dissemination and
 16 implementation later. Ask if they're interested in
 17 co-creating a dissemination plan or any materials.
 18 Invite a patient partner to attend your lab
 19 meeting. I recommend this to my basic science
 20 colleagues all the time. I've met so many
 21 colleagues in basic science whose trainees and
 22 themselves say they've never even had a chance to

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1 meet a patient with pain until much further along
2 in their career.
3 Invite a patient to attend a conference and
4 cover their expenses, or invite them to judge
5 posters. It's such a valuable experience for
6 poster presenters to engage with patients about
7 their work. As conference organizers, you can
8 co-present the research with a patient partner -- I
9 do this all the time -- and invite a patient
10 partner to join your students thesis or
11 dissertation committee. We also do this in my lab.
12 MS. JORDAN: I'd just like to underline a
13 little bit of what Christine says about this. One
14 of the worst feelings I've ever had is being the
15 only patient partner on a research project. The
16 feeling that I have to be "the" patient voice is
17 particularly unfair for a couple of reasons.
18 One is that I can't represent all people; I
19 can only talk about my own experience. And as a
20 person with chronic illness who parents two people
21 with chronic illness, when things go awry in any of
22 our lives, my choices can often be to either

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1 neglect myself or my family or attend a lab or
2 research meeting. So I can either choose to know
3 that no patient voice will be at that meeting or
4 make myself more ill, and that's just fundamentally
5 unfair to everybody.
6 I'd also like to underline how important it
7 is to have a mosaic of engagement in any research
8 project. We all as patient partners have a variety
9 of ways that we can contribute, and no way is
10 better than others. So from a full co-investigator
11 on a project to being able to consult on a
12 infographic are all valid and important ways to
13 contribute.
14 From project to project or day to day, we
15 might have different ways that we're capable of
16 contributing or have the capacity to contribute,
17 and the more variety of opportunities you create
18 within the project, the more diversity of
19 opportunity and information you're going to be able
20 to get from your patient partners.
21 We'd all like a checklist of engagement,
22 something that will tell us how to do this right

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1 and how we can keep from failing. So many folks I
2 have spoken to in a mentoring capacity have given
3 voice to fears about engaging with patient
4 partners, fears that they'll make a mistake, that
5 they'll cause offense or, worse, that they'll cause
6 harm.
7 I'm here to let you know that no checklist
8 will keep you from making mistakes, and in fact
9 we're all learning together. I know it's really
10 hard to let go and begin a process that's outside
11 of your comfort zone, but honestly, the biggest
12 gift you can give yourself is to let go of your
13 assumptions about what and how patient partners can
14 contribute, and just ask us. These conversations
15 can feel awkward, but the more you initiate them,
16 the easier that they'll get to navigate.
17 In good engagement opportunities, you can
18 co-create a safety net that's under all of us, one
19 made of mutual respect, clarity, and open
20 conversations. Patient partnership isn't something
21 you do right. Different people need different
22 tools. It's okay to make mistakes if you

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1 acknowledge them and commit to learning. There's
2 no checklist for patient partnership done well.
3 Every person you work with will have unique
4 perspectives, challenges, barriers, and gifts.
5 DR. CHAMBERS: From the researcher
6 perspective, I think fear really does hold a lot of
7 researchers back. Many researchers and clinicians,
8 again, have been trained that there's distance
9 between researchers and patients. So you will make
10 mistakes, and as Isabel said, just be sure you
11 learn from them.
12 Patient engagement in research is a really
13 different kind of relationship with a patient than
14 perhaps you've considered, so it may be
15 uncomfortable, and feel vulnerable, and that's ok.
16 Recognize barriers and perceived hierarchies.
17 Pretending they don't exist doesn't fix anything or
18 help anyone.
19 Good patient engagement means giving up
20 control and relinquishing some of your power, and
21 that's really hard for researchers and academics to
22 do because we are socialized to be control freaks.

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1 So you have to be open to new perspectives and
2 ideas, create space for conversations, and not
3 limit or direct them.
4 When you're engaging patient partners in
5 your research and in the dissemination and
6 implementation of the results, demonstrate
7 partnership like Isabel and I are doing right now.
8 Don't just talk about partnership; do it. I won't
9 give a talk about patient engagement or partnership
10 without presenting alongside a patient partner.
11 And yes, it is more work. Yes, it takes more
12 preparation for Isabel and I to co-deliver, but
13 it's the right thing to do.
14 MS. JORDAN: It's more fun, too.
15 Lately I've been thinking about patient
16 engagement like going for a hike. It's a journey
17 that you're in together. We all go on a hike with
18 different experiences. Maybe you grew up near the
19 woods. Maybe you're new to the forest. Maybe
20 you've been lost in the woods before and are
21 cautious to try again.
22 We can all use a trail map to start off the

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1 journey, but each of us may need different
2 resources: a hat, hiking boots, walking stick, and
3 maybe chocolate-filled granola. Walking together,
4 each with the resources, we can learn together and
5 learn from one another, respecting and valuing each
6 for what we bring. Thank you.
7 Clarifying Q&A
8 MS. VEASLEY: Thank you both. That was
9 terrific. I have lots of questions, but I'll open
10 it up to the group first.
11 (No response.)
12 MS. VEASLEY: Okay. Well, I'll ask my
13 questions then. I'm curious. I have two
14 questions. One's for you, Isabel, and the other I
15 think is for both of you.
16 My first is, Christine, you said you started
17 doing this because you're required to via funding.
18 My question is, how do we change the perspectives
19 of investigators to do this and to do it well?
20 Like you said, you can start small and grow; or do
21 you think we can do that without making it a
22 requirement of funding; or do you think that's the

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1 only way we're really going to enact kind of
2 widespread change?
3 Then my question for you, Isabel, is
4 about -- and I completely agree with you. I've
5 been that one patient advocate on many panels,
6 committees, and advisory groups over the years.
7 Given the logistics of the fact that you can't
8 include any number of people on a committee or a
9 particular project, I guess the question is, how do
10 we know who to include and how many to include in a
11 particular project?
12 As you mentioned, there are many different
13 ways of including people across. You can do larger
14 survey samples or so on and so forth, but when
15 you're putting together a stakeholder advisory
16 group or a patient panel, how do we know whether we
17 need 2, or 5, or 15, especially with chronic pain,
18 which can be so diverse and dichotomous between
19 people?
20 MS. JORDAN: Christine, do you want to do
21 yours first, and I'll do mine?
22 DR. CHAMBERS: Sure.

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1 Chris, I'll go back to the earlier question
2 on how to encourage patient engagement, I guess, in
3 the research environment. Of course, now I'm
4 wearing a hat as a funder, as well, through the
5 Canadian Institutes of Health Research. In my own
6 experience, I don't know that I would be doing this
7 had I not been required at a couple of stages to
8 engage patients partners, and then have the
9 opportunity to realize how impactful it was.
10 So I think requiring it for certain types of
11 funding opportunities is an important lever, and I
12 think we need to use all the levers that we have to
13 make change.
14 That said, I also believe that we need to
15 engage or expose trainees to this as early as
16 possible. I think we really need to give careful
17 thought to how we embed these perspectives in
18 training. I'll say at the North American Pain
19 School, for example, that I co-direct with Jeff
20 Mogil, we have had patient partners participating,
21 helping to shape the program, and engaging with all
22 of our trainees, and I know that those interactions

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1 have led to really important perspective shifts on
 2 the parts of trainees.
 3 So I think there are lots of intervention
 4 points in the system where we can encourage people
 5 to embrace patient engagement.
 6 Isabel, did you want to speak to Chris'
 7 question around numbers and how many?
 8 MS. JORDAN: I'm just going to add something
 9 to yours, too. Sorry; I'm obnoxious that way.
 10 I'm a big believer that it's important to
 11 have those requirements for engagement, but I also
 12 think it's fundamentally unfair to require
 13 researchers to do patient engagement when we
 14 haven't given them the tools to how to do it well.
 15 And it's unfair to the researchers, but it's also
 16 unfair to the patient partners because it doesn't
 17 create safety for good engagement opportunities.
 18 So I think that training piece is really
 19 important, but not just for the trainees, but also
 20 for the senior researchers and the mid-career
 21 researchers. I think we need to find ways to help
 22 give them the tools to do it well because,

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1 otherwise, people are going to get a grant that
 2 requires patient engagement, it's not going to go
 3 well, and then they'll walk away from it. They'll
 4 be that person that got lost in the woods, and
 5 they're like, "I'm not going for a hike again.
 6 That just did not work out well for me." So I
 7 think it's really important to have those carrots
 8 along with the sticks and do that.
 9 As to your other question about the numbers,
 10 it's kind of what we said before. There's no one
 11 answer. When I'm entering folks on their projects
 12 as opposed to being the patient partner with lived
 13 experience, what I often tell people is, "What
 14 population is your study research targeting, who
 15 are you talking about, and is that being
 16 represented in your group?"
 17 If it's an advisory group, when I work as an
 18 advisor, my job isn't necessarily to provide my
 19 lived experience but to help access communities
 20 that can give more information on what their
 21 experiences are like.
 22 I used to work for a national healthcare

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1 quality improvement organization as a patient
 2 partner, and there was an expression there about
 3 the big bird and the little birds. And as a
 4 patient partner there, I was the big bird, but my
 5 job was to find lots of the little birds in the
 6 communities that we were accessing so that it
 7 wasn't all about what I thought was happening, but
 8 my job was to find other communities so that it
 9 wasn't all about my lived experience.
 10 So I don't have a neat and tidy answer for
 11 you because it really depends on the project, and
 12 it's always going to depend on budgeting as well.
 13 Do you have budget for a 10-person -- that's
 14 actually too big, too many people -- an 8-person
 15 advisory committee that can then go out into their
 16 communities? Do you just have the funds for two
 17 people who are patient partners that are really
 18 good at engagement and can then create an
 19 engagement plan for your project?
 20 That's not an easy answer, and I'm sorry I
 21 can't be more specific.
 22 MS. VEASLEY: Well, it was kind of a trick

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1 question, so I was hoping that you'd kind of talk
 2 about the strategic framework. One of the things
 3 that we'd like to do through this meeting and the
 4 publication that comes out of it is to help people
 5 think about, strategically, who do I need to? What
 6 methods do I need to engage? How many? What's the
 7 diversity? So, I'm glad --
 8 MS. JORDAN: I was going to say, one of the
 9 things that I like to think about is, in my own
 10 personal and family's health journey, we had a
 11 terrible time. I could tell you stories that will
 12 curl your toes, and we are incredibly privileged.
 13 One of the things that kind of drove me into doing
 14 the things that I do is that I think with all this
 15 privilege and things look so badly, what happens
 16 with other folks that don't have the privileges we
 17 have?
 18 One of the things that I often think about
 19 is, if we can make research better or health care
 20 better for the people who have the biggest
 21 barriers, then everybody else is taken care of. I
 22 really think that we need to work hard to have the

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1 folks who haven't been heard and haven't been
2 represented traditionally, and make sure we find
3 ways for them to be comfortable, and safe, and
4 create safety for them to have their voices heard,
5 because after that, everybody else will be taken
6 care of, too.

7 MS. VEASLEY: Absolutely.

8 Just one last question before we open up to
9 general discussion; I'm curious about your position
10 within Christine's lab, and I'd like to hear from
11 both of you.

12 One, Christine, what made you go to the
13 point of actually incorporating somebody who's
14 actually in charge, strategically in charge of
15 this, and then what the role is for Isabel -- if
16 either one of you want to answer it or both of
17 you -- within your lab? It's very rare that you
18 actually see someone that's in this type of a role
19 within a research lab. I find it very interesting,
20 and I think people could learn from that.

21 DR. CHAMBERS: Yes. This has really been an
22 evolution over the last five or, I guess, six

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1 years, where initially when I started our patient
2 engagement work, I was working on a shoestring
3 budget. And I'll say that there are ways that you
4 can do patient engagement that are not super
5 resource-intensive, and I had a really, really
6 limited budget for the work that we did.

7 But as time grew, or as time passed, it was
8 just clear that this external advisory capacity
9 that we set up for the panel was really useful for
10 the project in that there started to be this
11 disconnect between what I was doing and the work
12 that was happening with the co-investigators and
13 the experiences that my staff and trainees were
14 having.

15 So by bringing Isabel into the lab and
16 actually carving out a patient partner leadership
17 role, that she helped to co-create -- I mean, she
18 really helped map this out, which is fantastic, and
19 I'll let her speak to that of course -- it's been
20 amazing to have her in the lab. My trainees meet
21 with her. She comes to our lab meetings. The
22 questions she ask at different stages of the

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1 project are incredible. She helps my trainees
2 figure out what kind of patient partners, or
3 networks, or organizations they should tap into for
4 their research.

5 So it's really just been an evolution. And
6 now over at SKIP, we also employ someone with lived
7 experience, so it's just become something that is
8 baked into what we do, and it's very different from
9 how I ran my research lab for many, many years, so
10 it's a departure.

11 I will acknowledge I have a stable funding
12 situation right now. That is not always the case
13 for researchers, so that is something that I feel
14 very fortunate to be able to do right now.

15 Isabel, did you want to add to that?

16 MS. JORDAN: I don't have a lot to add to
17 that. But I'll tell you what I find exciting about
18 doing this work with your lab is that I can
19 see -- I mean, the work that you were doing with
20 your trainees before, that I would get involved
21 with if I got pulled into a project or people that
22 I know would be on a project, there was an ethic

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1 within your lab of patient partnership, but it was
2 more -- I don't want to say ad hoc, but there was a
3 certain institutional knowledge within your lab of
4 like, "Oh, what do I do next?" or they talked to a
5 more experienced trainee or somebody on staff that
6 had done the work before.

7 What I'm doing now, alongside with the
8 mentoring, is trying to create a more organized
9 system that they can go to, guideline documents so
10 that if somebody more experienced, when they move
11 on and away from the lab, that institutional
12 knowledge doesn't leave; or if Christine's not
13 available or a staff person isn't available, then
14 the trainee can start down that path on their own
15 with their project, and then meet with me saying,
16 "This is what I've done so far; here's where I am,"
17 and then get input from me.

18 I think that lets them have a bit more
19 independence on starting that patient partnership
20 journey, rather than going, "This is really scary."
21 I think that's really important to be able to feel
22 like they have the tools to start down that path.

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1 I'm finding it really exciting to do this work with
 2 them.
 3 Discussion and Development of
 4 Recommendations for Publication
 5 MS. VEASLEY: Absolutely. Absolutely.
 6 Alright. Well, we're going to open it up to
 7 all panelists, all discussants, so please feel free
 8 to ask questions of each other; or attendees,
 9 please feel free to ask questions of the panelists
 10 or each other.
 11 (No response.)
 12 MS. VEASLEY: And I know this group is not
 13 shy, for sure, but I'll start with a question.
 14 Jonathan, are you still on?
 15 DR. JACKSON: Yes, I'm here.
 16 MS. VEASLEY: I really appreciated your
 17 presentation today, and obviously if we're going to
 18 generate data that's meaningful to the masses, we
 19 have to diversify our clinical trial population.
 20 I was just wondering if you could kind of
 21 bridge the gap between how important it is to
 22 actually include diverse populations in the

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1 planning and conduct of trials itself as a means of
 2 increasing diversity in the trial, and if you could
 3 give us some concrete examples of ways in which
 4 either you're doing that through EPPIC-Net or some
 5 other work that you're doing.
 6 DR. JACKSON: Yes. I think this is an easy
 7 question to answer in that it is absolutely
 8 paramount to make sure that patients are included
 9 as early as possible in the design phase of our
 10 research studies. It's really the only way that
 11 you're going to be able to successfully and
 12 confidently achieve the diversity and the
 13 representation that you're looking for, no matter
 14 what it is that you're trying to study.
 15 That is mainly because we as
 16 researchers -- and this is something that I often
 17 say in my talks -- we forget how weird we are.
 18 People don't know what research is. They certainly
 19 don't know what clinical research is, and we talk
 20 about it with other people who already know what
 21 research is. So we miss a lot of the very, very
 22 common blind spots, gaps, and pitfalls that make it

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1 hard to participate in a study, and I think
 2 especially hard to remain engaged with a study. So
 3 bringing participants on board as early as possible
 4 is really, really vital.
 5 There are a few ways to do this really well.
 6 The most common way is to leverage something that's
 7 called the Community Engagement Studio. The CE
 8 Studio approach was developed out of the
 9 Vanderbilt-Meharry Group by Consuelo Wilkins and
 10 her team a few years ago. There are a few great
 11 publications on it, and I would say it's pretty
 12 much state-of-the-art.
 13 What's different about the CE Studio than
 14 your typical patient advisory board or an advisory
 15 group is that in a CE Studio, you have community
 16 experts and patient representatives as co-creators
 17 in your research design, and it is a very iterative
 18 process. So instead of saying, "Here's our
 19 protocol; give us feedback in the next 48 hours,"
 20 you bring them on and you treat community partners
 21 and patients as co-investigators in your study.
 22 You pay them for their time. You give them credit

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1 on your publications. You really bring them into
 2 the design process, and that has yielded fantastic
 3 and phenomenal results I think all across the
 4 country.
 5 Within EPPIC-Net, I mentioned that we are
 6 doing kind of a two-stage process where we have a
 7 patient advisory board to talk to us about the
 8 structure of EPPIC-Net and answer the big
 9 questions: What kind of outcomes should we be
 10 looking for? What are some common pitfalls that we
 11 need to be thinking about across all of our trials?
 12 That has yielded really, really great
 13 results. That has meant that new protocols that
 14 are coming down our pipeline are being more
 15 thoughtful for funding for elder, and childcare,
 16 and even for pet care; thinking about scheduling
 17 patient visits outside of bankers hours; thinking
 18 about lots of aspects of being flexible with the
 19 way that we talk about reimbursement, remuneration,
 20 and payments; making sure that we are having really
 21 thoughtful conversations about patient burden, so
 22 thinking about do we need to measure this

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1 particular outcome in this way or is there a
 2 simpler, easier, less invasive way of collecting
 3 this data.
 4 Then in addition to having that kind of
 5 broad group to give us broad feedback, we do have a
 6 group of patients that are arranged in kind of a
 7 focus group setting to weigh in on protocols as
 8 they are written. So instead of writing it,
 9 getting it IRB approved, and then asking patients
 10 for their opinion, before, at the very early stages
 11 of that process, during the very frenzied protocol
 12 writing period, we are engaging with patient focus
 13 groups to talk to the people who are implementing
 14 the study, as well as people who are leading the
 15 various studies, in real time to talk about
 16 specific deliverables.
 17 So I think this two-stage process is our
 18 version of that CE Studio approach, where we are
 19 giving patients lots of opportunities to weigh in
 20 on the way that we construct the design trials, the
 21 way that we evaluate trials for success, and making
 22 sure that we are compensating for their time and

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1 treating them as experts.
 2 There are lots and lots of other things that
 3 you can do related to raising awareness such as
 4 having a really great patient-facing website, a
 5 strong social media presence, making sure that
 6 there's effectively no wrong way to access
 7 information about a particular study, and then also
 8 tapping into patient centricity models for future
 9 design.
 10 So instead of saying we've got so-and-so
 11 company that is interested in trying a therapeutic,
 12 you're asking participants and patients what kind
 13 of pain relief they're looking for, where they've
 14 had particular trouble, and then going out and
 15 looking for particular vendors or industry sponsors
 16 that may be willing to provide some sort of
 17 treatment for that; so really designing research
 18 studies from the perspective of that patient
 19 centricity.
 20 I know your question was about diversity,
 21 but it turns out that designing for diversity means
 22 you really need to design from a very

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1 patient-centric perspective. In this case, the two
 2 approaches are effectively identical.
 3 There are lots of other things that we need
 4 to think about. One of the things that I think is
 5 not considered widely enough is thinking about site
 6 selection, because more and more studies are
 7 getting larger and larger. There are lots and lots
 8 of different groups that are involved. We tend to
 9 pick the groups that we've worked with before. We
 10 tend to pick the groups with a famous PI that we've
 11 heard of, and that means that we tend to have a
 12 relatively narrow range of who can be involved in
 13 the study.
 14 By thinking a little bit more broadly about
 15 who can participate in research studies, who can
 16 support sites, who can help with that engagement
 17 and initial recruitment effort, that gives us a leg
 18 up on thinking more broadly about who can be
 19 involved in the research process.
 20 I won't bore you with all of the details
 21 that we're doing, but we are seriously rethinking
 22 what research has to look like. Instead of

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1 thinking that it has to come from a very small,
 2 narrow set of very elite universities and academic
 3 medical centers, we are starting to re-examine that
 4 question much more broadly because we can provide
 5 that very centralized infrastructure and support to
 6 make sure that all sites are able to recruit in a
 7 timely and efficient way.
 8 MS. VEASLEY: Absolutely. Thanks.
 9 Here's the number one question we get from
 10 investigators, which is how do I find these people?
 11 It's a logistical question. If you have not been
 12 engaged in doing this before -- Christine mentioned
 13 that her and Isabel connected over Twitter -- how
 14 do you go about finding people in the
 15 community -- and Gail touched on this
 16 earlier -- that are representative of the
 17 population that you're studying, and you do have
 18 diversity, and you're reaching hard-to-reach
 19 populations?
 20 DR. JACKSON: I think all of us speakers are
 21 going to have an opinion on this, but I would say
 22 in my experience -- and I'll give a very brief

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1 answer; I promise -- if you have some way of
 2 engaging the community, or even community
 3 stakeholders, it is really not so hard to find the
 4 group that you're looking for.
 5 There's a reason why I told that really
 6 terrible dad joke at the beginning of my talk about
 7 thinking from hard to reach to hardly reached. It
 8 turns out that there are lots and lots of avenues
 9 to reach exactly the group that you're hoping to.
 10 It just requires you to kind of move outside of
 11 your workflow for a day or two. And if you can
 12 make a little bit of time, it turns out that you'll
 13 yield really large benefits. It is really not so
 14 hard to reach these groups that we're dying to
 15 reach.
 16 MS. JORDAN: I have -- sorry.
 17 Christine, did you want to go first?
 18 I have a friend who's great at community
 19 outreach, and it's not so hard. It means leaving
 20 your office, and grabbing a coffee with somebody,
 21 and making that first step and asking. Again, it
 22 can be a scary thing, and it can be a vulnerable

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1 thing, but you know what you're studying. You know
 2 what represents a disease group or a pain
 3 condition.
 4 There are patient groups out there. There
 5 are community groups out there. There are
 6 communities of care out there. And people
 7 understand if you're going to them with clarity and
 8 openness, and are willing to forgive a lot if you
 9 go there with clarity and openness, and saying this
 10 is what I'm doing and this is what I'm looking for.
 11 And be honest with them about that, and don't
 12 expect people to come to you; go to them.
 13 MS. VEASLEY: Yes, absolutely.
 14 Christine, did you want to piggyback off
 15 that? And then we'll go to a couple other
 16 questions.
 17 DR. CHAMBERS: Sure. I see a few other
 18 hands up, too. But just to say, in the early days,
 19 I didn't have a lot of infrastructure to support
 20 the reach out, so I really just crowd-sourced over
 21 social media and got an incredibly diverse group of
 22 participants or patient partners. And because the

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1 project itself was all digital, we were able to
 2 engage people who were living in rural areas, so it
 3 was really fantastic.
 4 In our SKIP network, we actually have a
 5 database of patient partners. We have an open call
 6 for patient partners who would like to volunteer
 7 where they can express interest in different types
 8 of engagement activities, so, yes, I'd like to be
 9 involved in media or I'd like to be involved in
 10 this. When we have opportunities arise, we can
 11 actually reach out to specific patient partners who
 12 are registered with us, and they know that they'll
 13 be compensated. So that's been a really fantastic
 14 way to do it.
 15 Recently, one of my students needed to find
 16 some patient partners in the arthritis space, and
 17 Isabel helped her come up with an outreach plan.
 18 Our national arthritis society ended up doing a
 19 huge outreach for her, and she had the problem of
 20 having too many patient partners who wanted to
 21 participate and having to navigate that. So yes,
 22 actually people are happy to help, and there are

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1 different ways to approach it, informally and
 2 formally.
 3 MS. VEASLEY: Right. Thanks.
 4 Karen, I think you were next.
 5 MS. MORALES: I just wanted to mention the
 6 concept of a trusted messenger. When you're
 7 interacting with a specific organization or group
 8 that has that specific expertise in the area you're
 9 looking for, you kind of get a better turnout from
 10 the community organization for your particular
 11 study.
 12 One of the things I also want to mention is
 13 renumeration [ph] is important, but there are
 14 opportunities where you can do things for your
 15 partners that will assist as well, such as we've
 16 had opportunities where we've gone and actually
 17 participated in the events of our partners, where
 18 we may not have been able to compensate them
 19 initially earlier on, but because we went there and
 20 we did something that helped their particular
 21 efforts, that was compensation in their eyes; or we
 22 were able to create a video for them that they were

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1 able to put on their site, which generated income
 2 for them; or we were also able to help with
 3 completing a resume.
 4 So there are crafty ways to be able to
 5 assist your community partners outside of providing
 6 finance. Finance is always important. I never
 7 want to say that you don't offer financial
 8 incentives, but there are other ways to compensate
 9 your community partners that will also be
 10 appreciated outside of the financial component.
 11 MS. VEASLEY: Absolutely. One of the main
 12 themes that we've heard from people in terms of why
 13 they don't continue is because they never heard
 14 back. So they were more than happy to start the
 15 engagement process and to contribute, but then they
 16 felt like the scientists came in, they got the
 17 information they needed, or the participation that
 18 they needed, and they left. And they never heard
 19 whatever happened to this study, what were the
 20 outcomes of this study, and how was my contribution
 21 to the study meaningful or how did it impact the
 22 study. I think that's really an important point.

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1 Lynn, I think you're next.
 2 MS. LAIDLAW: It's interesting. I speak
 3 about how hard it was for me to become involved,
 4 and the amount of time and effort, and knocking on
 5 doors, and emailing, and jumping up and down
 6 saying, "Involve me," and people didn't want to.
 7 And yet, on the other hand, I hear researchers
 8 saying, "Well, I can't find people to involve," so
 9 some of us have to work really, really hard.
 10 I was thinking about what Jeremy said
 11 yesterday about working with communities. What is
 12 our definition of communities? Because sometimes
 13 it seems like it's too easy to reach out to a
 14 patient organization, but who's that patient
 15 organization not engaging with, or who's that
 16 community organization not engaging with?
 17 I was involved in a couple of organizations,
 18 and then when I didn't become involved with them
 19 anymore, I was thrown off the stuff that I was
 20 involved with. Now, I hadn't changed, my
 21 experiences hadn't changed, but because I wasn't
 22 representative now of the organization, that was a

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1 problem.
 2 That's the other thing I kind of wanted to
 3 mention, this thing of representativeness. I think
 4 as we move now towards EDI -- inclusivity,
 5 diversity, equality -- it's really, really
 6 important, but sometimes it seems like, oh, if we
 7 involve someone from that ethnic community, or if
 8 we're involved with that disability, a big sigh of
 9 relief, that box is ticked, and now we have that.
 10 It's more than that because you can't make
 11 one person, and would we expect the statistician to
 12 be representative of all statisticians, or
 13 epidemiologists? And we're not, but sometimes with
 14 patient partners, we're like Goldilocks porridge,
 15 and we have to be just right, either the right
 16 color, or the right gender, or whatever. And it's
 17 not us that have the power to say what's right;
 18 it's other people that seek to involve us.
 19 So I think we just need to be very clear
 20 about how we're talking, what we're talking about,
 21 and how were defining some of these issues.
 22 MS. VEASLEY: Yes, absolutely.

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1 Gail, I think you're next.
 2 MS. GRAHAM: I wanted to piggyback on what
 3 you were saying, Chris, about coming in, getting
 4 information, and then leaving. We consider that as
 5 helicopter research. And that's why when you go
 6 back to that community, they don't want to give you
 7 authentic answers because you were working on
 8 earning their trust, but you left, so you became
 9 untrustworthy.
 10 So it's important that once you engage these
 11 communities, that you nurture the community also,
 12 where you go to them respectfully, and you tell
 13 them about what you're thinking, and ask if they're
 14 interested or what would interest them, and to
 15 actually go back and let them know what their
 16 answers generated so you can disseminate that
 17 information back to them. It means a lot.
 18 Again, when it comes to monetary things, my
 19 community, where my church is sitting, is a food
 20 desert. The University of Maryland had connections
 21 with the Maryland Food Bank, and they allowed us to
 22 get in contact with them, and we were able to do

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1 food drop-offs to the community, so that made a big
 2 difference. The community started looking for the
 3 University of Maryland and telling them different
 4 things that's going on. So where it started out
 5 with maybe blood pressure research things, they
 6 found out that that church had people there who are
 7 HIV-positive or people there who were diabetics.
 8 So you have a rich opportunity for other research
 9 studies.

10 But again, when you go into those
 11 communities -- especially if you go into a black
 12 community or Latino community -- you have to be
 13 honest about the fact that research messed up at
 14 one point. With the Henrietta Lacks study, with
 15 the Tuskegee Institute study, you have to
 16 acknowledge that, and then you have to let them
 17 know about the advancements that were made since
 18 then. One thing that I did, I was talking about
 19 clinical trials, but I never did one. So I did one
 20 so that I could go back to my community and say,
 21 "Look, this has changed dramatically." So that's
 22 just something to think about.

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1 MS. VEASLEY: That's great. I wanted to
 2 follow up with you on a question as well. You
 3 talked about your hesitancy in the beginning to
 4 become involved as a patient in patient engagement
 5 efforts with the University of Maryland. You
 6 talked about your diagnosis and the stigma around
 7 that.

8 Are there other reasons why you were
 9 hesitant to come on board, or what do you think the
 10 other reasons are, other than some of the ones that
 11 you just mentioned, the distrust and the historical
 12 perspective? Are there other major issues that you
 13 think impede people from making the decision to get
 14 more involved in advising in that way from the
 15 patient community?

16 MS. GRAHAM: Actually, I was thinking, okay,
 17 they just want to check off a box and they get
 18 somebody who was HIV positive to be a part of this,
 19 and that's all they were looking for me for; not
 20 that they would listen to what my thoughts were or
 21 anything would come of that. That was one of the
 22 things.

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1 Again, the history that we had with other
 2 organizations -- not just researchers, but other
 3 people coming in to our community -- and then not
 4 respecting the people in the community just soured
 5 me on research, and it just so happens a lot of
 6 them were researchers. So it soured me on that.
 7 So when I heard that it was a group of researchers
 8 coming, I was like, "No. Hell no, I don't want to
 9 be involved." But that was the reason why.

10 MS. VEASLEY: Yes, that's helpful. Thank
 11 you.

12 Isabel, I think you're next.

13 MS. JORDAN: Well, I think a lot about power
 14 hierarchies and how that can influence how a
 15 patient partnership can go or the nuances of it.
 16 And something that Lynn said made me think about it
 17 in terms of who is being asked to participate in
 18 these partnership opportunities. Because even in
 19 the patient community, there's a certain power to
 20 being part of patient groups that are already
 21 partnering with big research groups that can
 22 exclude others.

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1 I know that it can be easier to go to the
 2 patient groups that others have gone to or that
 3 you've traditionally gone to. But I think it's
 4 important to think about who hasn't been welcomed
 5 or who doesn't feel comfortable being part of those
 6 patient groups, and to look outside of those and
 7 think about who are the folks that are in those
 8 patient groups and where you can access them
 9 outside of those patient groups.

10 MS. VEASLEY: Yes, I think that's a critical
 11 point because it's an issue that we have. As a
 12 director of an advocacy organization, I can tell
 13 you that our patient population is not diverse.
 14 When you think about the overall percentage of
 15 people with any given medical condition, who
 16 associate with a nonprofit organization or advocacy
 17 group for that particular condition, it's a very,
 18 very small percentage.

19 So you can't just say, okay, we've done the
 20 advocacy group and we have a representative sample
 21 because it's not necessarily the case. There are
 22 many different ways in which you can identify

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1 patient partners -- both, like you said, as within
2 organizations -- and there may be important
3 differences.
4 Ian, I think you're next.
5 DR. GILRON: Yes. Thank you. Just a couple
6 of comments, and then a specific question.
7 First of all, thank you so much to all of
8 you, investigators and patient partners, for
9 excellent talks and discussion today, and for your
10 thoughtful passion in doing this. And just to say,
11 for me, in open disclosure, quite honestly, this
12 has been a relatively new concept for me as a
13 researcher over the past, let's say, 5 to 8 years.
14 I'm one of the principal investigators on
15 the Canadian Chronic Pain Network that Dr. Khan
16 spoke about yesterday. And as you know, patient
17 engagement was sort of an integrated aspect of the
18 rollout of that research network and something that
19 we all learned a lot about, and really looked at it
20 as something novel, and that we wanted to roll it
21 out slowly, and carefully, and advance things
22 slowly, rather than be too ambitious and do things

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1 too quickly, and make mistakes, and have to retract
2 in any way.
3 Just coming from that perspective, it has
4 been, I would say, a positive experience. We've
5 had some great partnerships. For example, Maria
6 Hudspith from Pain BC, who is one of the leaders in
7 patient engagement, helped us with careful
8 selection of patient partners that you've discussed
9 already.
10 I have a specific question that's kind of
11 delicate and awkward, but it's worth pursuing. I
12 guess from the perspective of an investigator who
13 is looking for patient partners with their
14 research, how much does the investigator really
15 need to know about the clinical background of a
16 specific patient partner, inasmuch as that clinical
17 experience informs their ability to advocate on the
18 basis of patients? How much of the clinical
19 history should they know and is that even relevant
20 when setting up a patient partnership?
21 MS. VEASLEY: Thanks, Ian. I think it's an
22 important question and I'm glad you asked it. I'm

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1 going to invite some of our patient partners to
2 respond. I have thoughts, but please go ahead.
3 MS. JORDAN: I don't mind taking that on.
4 Thanks for that question, Ian.
5 I think there's a difference between a
6 patient partner and an advocate, so I'm going to
7 use the term "patient partner" because I think the
8 role of the patient partner in a research project
9 is really to provide their perspective on what that
10 research question is and what your project is. I
11 think their health and personal lived experience
12 background needs to be relevant to the research
13 question, and they need to be willing to bring that
14 to the research project and to that question.
15 The details of their clinical background I
16 think are for them to disclose as they feel is
17 relevant, depending on what's happening in the
18 research project, rather than for the researcher to
19 ask them. If they're willing to be part of a
20 research project, then they're already in the space
21 of wanting to disclose some of that. But their
22 ability to do that in a safe way that is minimally

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1 re-traumatizing requires the researcher to have a
2 setup that creates that safety. That's a whole
3 other talk that requires some things to be in place
4 for that to happen.
5 Does that kind of address it a little bit?
6 DR. GILRON: Yes. Thank you.
7 MS. VEASLEY: Ian, I'm just curious. Maybe
8 Penney or Lynn have some responses to that.
9 But I'm just curious why you asked the
10 question. Have you had experiences where you
11 included patient partners in a project and didn't
12 ask that information, and then it turned out that
13 their experience wasn't relevant to what you were
14 hoping they could advise you on, or was it
15 something else?
16 DR. GILRON: No. I don't have any specific
17 experience that points to that question. It seems
18 to be such an obvious question. And I'll be quite
19 honest with you; part of taking this slowly,
20 delicately, and carefully has been something
21 that -- the work that we've been doing with patient
22 partners within our network has not -- there's been

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1 a lot of work with patient partners involved in the
2 governance of the network and issues like that,
3 where we're not necessarily working in the level of
4 a clinical trial where it's investigator and
5 patient-centered. We're working like as we are
6 now, in a professional setting, where it would seem
7 quite obvious that you wouldn't expect to hear
8 details. And if someone discloses it on their own,
9 you appreciate that, but certainly there's no
10 expectation.

11 So yes, I don't have any specific reason to
12 ask the question, but it would seem obvious that
13 that patient partner's specific background is
14 relevant to what context they can provide. It's
15 just more of a theoretical question of when it
16 comes to patient selection and screening for
17 partnership, it's a theoretical question of whether
18 this needs to be addressed, or should it, or how
19 much should it.

20 MS. VEASLEY: Yes. And I think what Lynn
21 said earlier about transparency on both sides is
22 really important. For example, I was thinking if

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1 you're doing a trial that's on opioid tapering, for
2 example, just a hypothetical, having somebody who
3 never took opioids probably wouldn't be a good
4 advisor in that circumstance. I'm thinking about
5 transparency on both sides, what you're looking for
6 from the side of an investigative trial or
7 pragmatic trial, whatever you're doing.

8 As Lynn mentioned earlier, be very frank
9 about what kind of activities you're looking for
10 them to do, then that way the partner can decide if
11 they want to disclose that information, if they
12 don't feel comfortable doing that, and also have a
13 good idea of what it is and how they will be
14 involved throughout the process so that they can
15 make an informed decision about participating.

16 Penney, please weigh in.

17 MS. COWAN: One of the things that I've
18 always been very careful about is not talking about
19 any of my health care. I'm a person with pain, but
20 it was never important, for me, for them to walk
21 through the whole background or even what my
22 condition is more so than what I can bring to the

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1 table, which is the experience of that person
2 living with pain and really understanding what
3 their needs are, and listening to them for the last
4 40 years, and what are their questions.

5 As long as, I think, the person meets the
6 criteria of the study -- in other words, if it's an
7 opioid-use disorder study, then of course if they
8 didn't take opioids, they're not appropriate. But
9 maybe they are because maybe there was a reason
10 that they didn't take it, and they may bring even a
11 different -- I mean, you don't know.

12 I think it's individual. Some people are a
13 lot more comfortable than others. I just don't
14 want people to [inaudible - audio gap] -- and
15 everyone knows this; not as a patient, I'm a
16 [inaudible], and I've been talking about that to
17 IMPACT for many -- that's not who I am, and I
18 guess I feel really strongly about that. But I do
19 have a question.

20 MS. VEASLEY: Lynn, did you have a comment
21 to Ian's question? And then we can move on to
22 Penney's thought.

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1 MS. LAIDLAW: Yes. I'll post it in the
2 chat, but there was a really nice paper written
3 last year called, Who Should I Involve with My
4 Research and Why? I think it was really thinking
5 very seriously about should it be patients with
6 specific lived experience, should it be members of
7 the public, and whatever, and the pitfalls that can
8 happen with your research. So I'll post that.

9 I think this is such an interesting
10 question. I didn't have a CV until I started
11 getting involved in patient public involvement and
12 research, and sometimes it's like, "Yeah, we want
13 to involve you, but, actually, you know what? We
14 want you to write these three paragraphs, these
15 three wonderful paragraphs, and then after that,
16 you might get through to the next section, and
17 you'll be interviewed by three people over Zoom,"
18 or wherever.

19 Again, this always comes back to power: who
20 is deciding what the criteria is; who is deciding
21 how people will be chosen; who is deciding on
22 putting in a CV on whatever; and what is the impact

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1 on inclusivity and diversity?
 2 I was thinking back to an excellent point
 3 that Isabel made earlier about if people like
 4 me -- white, middle-class, educated people like
 5 me -- find it really difficult to get involved,
 6 then what chance does anyone else have? Because it
 7 goes back to this Goldilocks thing again; that I
 8 have to be just right, that I have no control over
 9 what just right looks like, and a lot of patient
 10 public involvement is about power. We just can't
 11 get away from the power angle.
 12 MS. VEASLEY: Yes, that's an interesting
 13 point, and I thought about that earlier as well.
 14 From the scientific side, it's always thought,
 15 well, what additional training do patients need to
 16 be able to participate and advise in clinical
 17 research? But we also need to think about what
 18 training do clinical researchers need in order to
 19 understand patients, communication, moderation of
 20 discussions, involvement, and all kinds of things?
 21 And for the most part, they haven't been trained.
 22 So there's training that needs to go both

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1 ways, and like you said, it's based upon equal
 2 value. First of all, everybody has to value each
 3 other equally, and to go from there.
 4 I'd like to get back to this point of
 5 training in a minute but, Penney, please go ahead
 6 and ask your question.
 7 MS. COWAN: I just had a question a little
 8 off -- well, maybe it's not off topic. We talked
 9 about dissemination and implementation, and I'm
 10 just wondering, when all is said and done -- I
 11 mean, so many people are now looking on the
 12 internet for information, and I know that the
 13 research papers are always written [inaudible -
 14 audio gap] -- they've come across my desk, and I've
 15 read [inaudible] of them, and many of them I
 16 struggle with. I don't understand them, and I have
 17 a pretty good background in all of this.
 18 Is there any effort to make these simpler?
 19 Like the patient part you have, do they go out into
 20 the public and educate, or is there a consumer
 21 report based on the work that you've done? We've
 22 heard talks earlier from PCORI about shared

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1 decision-making, but if a provider gives you one of
 2 these research papers, it's going to be way over
 3 [inaudible - audio gap].
 4 So in the end, after all is said and done,
 5 and all that research, when it comes down to shared
 6 decision-making and consumers actually looking at
 7 making a decision about one or two different, or
 8 maybe even three different, treatments, do they
 9 understand what they're reading, and is there any
 10 effort from any of you to actually get that
 11 information out to the public? I think that would
 12 be really important. Thank you.
 13 By the way, you guys did a wonderful job.
 14 Thank you, all of you, for sharing. Great. Thank
 15 you.
 16 MS. VEASLEY: Christine, did you have a
 17 response to that?
 18 DR. CHAMBERS: Yes. I'll just jump in
 19 there. I completely agree, Penney. Once the
 20 publication is submitted, or as it's being
 21 published, there's so much more that we need to do.
 22 Patient partners can play a really critical role in

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1 helping to map out that dissemination plan. It
 2 could involve writing newsletters or blog posts
 3 with different patient organizations to share
 4 results. It could involve social media engagement,
 5 an Instagram live, or a Facebook chat.
 6 We employed all of these strategies with our
 7 It Doesn't Have to Hurt project. This is exactly
 8 what the project was focused on. I was frustrated
 9 that all this science that I had contributed my
 10 whole career to wasn't getting used to the benefit
 11 of my own children when they were interacting with
 12 health care. So that's why we developed this whole
 13 campaign, leveraging social media.
 14 But that is what our entire SKIP network is
 15 focused on, is taking content that would normally
 16 sit in a journal, buried behind a paywall, and
 17 working to figure out what's the best way to get in
 18 front of different knowledge-user audiences.
 19 Patients obviously are one knowledge-user audience,
 20 health professionals, policymakers, and
 21 increasingly we're writing policy briefs. We have
 22 them right now at the federal Canadian Pain Task

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1 Force that has been doing incredible work, but how
 2 do you make research digestible for policymakers?
 3 So it's a great question. And I now ensure
 4 that all of my students, every time they publish a
 5 paper in a journal, also write some sort of blog
 6 post, often co-written with a patient partner, to
 7 help amplify and make sure that those results are
 8 shared in more accessible ways.
 9 MS. VEASLEY: Thanks, Christine. I'm going
 10 to ask you another hard question, which is not all
 11 scientists feel that it's their responsibility or
 12 obligation to go past the point of writing a
 13 journal paper and to do dissemination or
 14 implementation work.
 15 So I guess my first question to you is, how
 16 do we change the perceptions or the paradigm of the
 17 research life cycle to go beyond just publishing a
 18 paper -- and I'm not discounting the importance of
 19 that; it clearly is important -- and how do we
 20 change the perspectives of our funding agencies to
 21 maybe require some of that work beyond just
 22 publication of a paper?

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1 DR. CHAMBERS: Yes. I love that you ask
 2 that, Chris. Thank you so much, because not only
 3 do some scientists not see it as their role or
 4 their place, a lot of scientists, let's face it,
 5 aren't good at it. I've really reflected a lot on
 6 this because I think I've made a big dent in my own
 7 particular research area because I had an interest
 8 and ability to engage outside of traditional
 9 dissemination platforms.
 10 Obviously, working closely with others, I
 11 was willing to put in the time to learn and build
 12 new relationships. Not everybody is going to have
 13 that interest, and I've reflected a lot on the
 14 inequities that that can create, and how and what
 15 types of knowledge get mobilized.
 16 So is it fair that my research on children's
 17 pain has been put more into practice because I've
 18 had that interest? What about other areas of pain
 19 research, or health research more broadly?
 20 I think it's important that everybody
 21 receive training, and it's the baseline level of
 22 awareness. There's an incredible course that my

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1 colleague, Melanie Barwick, in Toronto offers
 2 that's a knowledge translation course for
 3 scientists. I think it's fantastic, because some
 4 people will have the talent and interest; others
 5 won't.
 6 It's not to say that we should expect it.
 7 We need people in their labs doing great work,
 8 although I think that work can be improved and
 9 enhanced by engaging different types of partners,
 10 and those partners then can take the lead. But
 11 also we do need dedicated funding. Just like we
 12 fund knowledge generation, we need to acknowledge
 13 that mobilizing knowledge is not just something you
 14 do on the side; that it does require dedicated
 15 expertise and resources.
 16 We've been really fortunate to have funding
 17 from the federal government to do this, but not
 18 everybody who generates the knowledge should
 19 be -- sometimes it could actually be
 20 counterproductive. Those people could
 21 actually -- and I've seen this happen, where people
 22 have actually damaged relationships and put up

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1 walls where there shouldn't have been walls, that
 2 have actually impeded the ability to disseminate
 3 and implement; so recognizing this as a special
 4 area of expertise that requires resources, the
 5 right leadership the right infrastructure, and the
 6 right approach.
 7 MS. VEASLEY: Yes, absolutely. I think it's
 8 going to take funders as well to come to the table
 9 and recognize the importance of that and put up
 10 resources to help investigators do that.
 11 Like you said, it's another member of the
 12 team. You've added Isabel to your team as a lead
 13 of strategic partnerships with patient groups and
 14 others as a communications person needed to be
 15 brought to the team in order to identify -- I mean,
 16 we can't be experts in everything, but I do think
 17 there's an important role there for funders as
 18 well, and changing their perceptions.
 19 Karen, you've had your hand up for a while.
 20 Please go ahead.
 21 MS. MORALES: Yes. There's not a lot to add
 22 to what Christine just said because I think that's

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1 great. I just want to also include the idea of
 2 including dissemination at the very beginning in
 3 your planning process.
 4 You can't all of a sudden come to this with,
 5 "Oh, we've done the study, and now let's figure
 6 out --" no, you have to include that as a metric of
 7 your planning process, and that dissemination needs
 8 to go out, yes, to your journals, to all of your
 9 publications, but also a one-pager back to the
 10 community that helped you generate the information
 11 from your study in a plain-language document.
 12 What we try to do at the PATIENTS Program is
 13 to suggest that we put our plain-language document
 14 at a 6th-grade level of readability so that any and
 15 everyone who wants to read it hopefully can
 16 understand what it is that we're disseminating, and
 17 sometimes using graphics, always thinking about how
 18 can they better understand it. We have people who
 19 learn from different styles, and sometimes using
 20 graphics help some communities because you may not
 21 have people who are readers, and thinking about
 22 those who are blind, and those who have other

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1 languages.
 2 We did an FDA study where we had the Spanish
 3 population, so we thought about that from the
 4 beginning, that we have to translate our results
 5 into Spanish as well. And that's exactly what we
 6 did in order to disseminate that information back
 7 to that community as well.
 8 So I think your dissemination starts in your
 9 planning process as well, how you're going to
 10 disseminate, what that looks like, and what the
 11 audience is that's going to be receiving that
 12 information.
 13 MS. VEASLEY: Absolutely. I'm actually
 14 involved in another committee with an institute
 15 within the National Institutes of Health that's
 16 looking at reducing health disparities in
 17 neurologic disease. I'm not a communications
 18 expert and was put in charge of a group just
 19 because I have a personal interest in
 20 communications about this, how do we communicate
 21 the findings of neurologic health research in an
 22 effort to reduce health disparities? And,

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1 actually, what you just said was one of the major
 2 recommendations that we made.
 3 It can't be an afterthought. It can't be
 4 like, "Okay, we've done this. Before we move on to
 5 the next project, let's think about what we might
 6 want to say about it." It's got to be planned from
 7 the very beginning. A key part of being able to
 8 communicate findings is engaging with stakeholders,
 9 patients and other stakeholders, community
 10 stakeholders, from the very beginning of the
 11 project. Because you can't bring somebody to the
 12 table at the end of the project, and then say,
 13 "Here you go. Take this and give it around to
 14 everybody" if they haven't been involved with the
 15 project from the get-go; so very important points.
 16 Isabel?
 17 MS. JORDAN: There are some really great
 18 threads coming together here. I want to say this
 19 with total kindness to people. But one of the
 20 things that I did before my son was born is I was a
 21 technical writer, and I used to help lots of folks
 22 in business write things that they wanted to put

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1 into trade journals or they wanted to go out to the
 2 public, because they did lots of great things in
 3 business, but writing things that folks could
 4 understand outside of their specialty was not their
 5 strength.
 6 I find this happens a lot in the research
 7 world. There are resources out there. There are
 8 plain-language writers that do incredible work.
 9 And what I find often when I see folks in science,
 10 folks in research who think they're writing in
 11 plain language, they're really not. And they're
 12 doing their best at it, but it's really hard for a
 13 lot of people to bust out of that bubble.
 14 One way to do it, you can hire a
 15 plain-language writer, but you can also co-create
 16 with patient partners; not go to them for editing
 17 afterwards, but co-create with them what you are
 18 doing, because they will also tell you the points
 19 that are important to that community that you
 20 really need to focus on.
 21 Also with that, doing things with graphics.
 22 I helped co-create an iPad version of a consenting

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1 document that had visuals to go with it, because
 2 when you're consenting for a biobank, you're in a
 3 moment of stress, and you can't understand things
 4 when you're in a moment of stress. This happens
 5 also for clinical trials sometimes, and you need
 6 things to help you understand things.
 7 So creating those with patient partners can
 8 make sure that they're understandable for you. And
 9 I'll put a link for how to co-create patient-facing
 10 documents in the chat.
 11 MS. VEASLEY: Yes, that's a great point.
 12 I think another point that we don't really
 13 recognize is that failure to do dissemination
 14 efforts I think actually discourages people from
 15 participating in clinical research in the future,
 16 and we have a big problem right now with not having
 17 enough people to participate in clinical research.
 18 John, go ahead.
 19 DR. FARRAR: Thank you very much. I'm
 20 sorry. I had to drop off for the last 45 or
 21 50 minutes, so if this has already been covered,
 22 please just let me know.

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1 One of the biggest issues these days is the
 2 mix of information and misinformation, and I
 3 wondered whether anybody had commented on that. So
 4 let me ask that first. If not, I'd like to speak
 5 about that briefly.
 6 (No audible response.)
 7 DR. FARRAR: No? Okay.
 8 MS. VEASLEY: I think Kathryn maybe is going
 9 to respond, or Christine. Go ahead.
 10 DR. MARTIN: My comment is about something
 11 entirely separate from his question.
 12 Sorry, John.
 13 MS. VEASLEY: Okay. No problem.
 14 Christine, are you going to respond or no?
 15 DR. CHAMBERS: Yes. I can just jump in
 16 there and say I completely agree, John. This is
 17 one of the reasons why I wanted to engage with
 18 dissemination/implementation around children's pain
 19 research because as a parent, I was seeing so many
 20 posts on social media that included misinformation.
 21 I think it's even more important that those of us
 22 in science, who understand science, are present and

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1 willing to engage to make sure that appropriate
 2 information is accessible.
 3 One of the things that I found in the parent
 4 space is that a lot of websites and books that look
 5 really glossy and look really professional are
 6 completely not evidence based. And let's face it;
 7 we researchers often do a terrible job at creating
 8 websites and videos. We're in a white coat
 9 speaking off of a piece of paper, and that's not
 10 how different knowledge-user groups want to engage.
 11 So I think we need to be present, but we
 12 need to kind of up our game and partner with people
 13 who know how to engage and be present in an
 14 accessible way. And that's really why I've been
 15 active on Twitter because I wanted people to know
 16 there was someone that they could follow to get
 17 cutting-edge evidence. We don't want people
 18 getting their health information from people like
 19 Jenny McCarthy or Gwyneth Paltrow, so we need to
 20 get more visibility.
 21 I honestly think, and I'm so fascinated by
 22 what we're all living through right now, that we

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1 have failed when it comes to science communication
 2 and knowledge translation. Look, the vaccine was
 3 the easy part of what we're dealing with. Now it's
 4 the human behavior piece of that. I completely
 5 agree that the misinformation piece is fascinating,
 6 and we all have an important role to play, but our
 7 system hasn't been set up in such a way that really
 8 facilitates that.
 9 DR. FARRAR: If I might just follow on with
 10 that, and then ask Gail or other of our partners,
 11 how do you decide where to go look for your
 12 information? It seems to me that getting our
 13 clinical and patient partners involved in that
 14 decision also is key. I mean, Twitter is fine if
 15 they find you and they follow you, but if they find
 16 somebody else who promises them a cure with a stem
 17 cell injection, and just fly down to Mexico, how do
 18 you decide? We have a good sense about what's
 19 evidence based and what's not. But, honestly, the
 20 rest of the world, there isn't an obvious place to
 21 do that.
 22 Gail, I wonder if you could give us a

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1 thought about that or somebody else, too.
 2 MS. GRAHAM: Well, to be honest, I used to
 3 be the Google queen, and each time something
 4 happened or I felt a certain way, I would Google my
 5 results, or whatever, and then look at what Google
 6 had.
 7 But I trust my doctors, so I would go back
 8 to my doctor, and I would ask questions. My doctor
 9 is very receptive. I have an HIV specialist and I
 10 have a cardiologist, and they will answer any
 11 question that I have, and I trust them. They will
 12 also refer me to other -- if I wanted more
 13 information, they would give me the documents that
 14 I could look through, and if I had any questions, I
 15 could go back to them.
 16 So that's one thing I tell patients, that
 17 they can feel free to go to their doctor. And if
 18 they don't feel comfortable with going to their
 19 doctor asking that question, maybe that's not the
 20 right doctor for you because your doctor should be
 21 a person that you trust and would give you the
 22 right information. I hope that answered that.

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1 DR. FARRAR: No. I love the answer. The
 2 problem, of course, is that doctors come in lots of
 3 flavors, too, and there are some doctors that are
 4 promulgating misinformation in the current COVID
 5 situation that is scary. So I agree with you;
 6 going and having a good doctor, and having somebody
 7 to approach.
 8 But it also approaches the concept,
 9 Christine, that you were saying, is how do you
 10 decide how to put out the information? Should it
 11 be connected to a website? Should you get NIH to
 12 put it on the NIH website, or CDC, or someplace? I
 13 think there isn't an answer to all these questions,
 14 but I think it's clearly something that we ought to
 15 be considering in thinking about how to disseminate
 16 our information.
 17 MS. VEASLEY: Yes. Thanks, John.
 18 One of the other recommendations -- and it's
 19 interesting that you're bringing this up -- that
 20 came out of that work group is there's need to do
 21 qualitative research around communications; so you
 22 need to know who is the audience that needs to get

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1 this information.
 2 Sometimes it might be primary care
 3 providers, or nurse practitioners, or clinicians.
 4 It's not always patients or the public, but who are
 5 those target audiences, going to those audiences
 6 ahead of time, and doing qualitative research,
 7 focus groups, surveys, and so on and so forth to
 8 learn from them: A, like you said, how do they get
 9 their information; what are their preferences; what
 10 type of information are they looking for; and what
 11 format might it be helpful. And getting that
 12 information in the beginning so that you're better
 13 equipped to be able to develop it at the end of a
 14 project.
 15 Kathryn, I you had your hand up.
 16 DR. MARTIN: I do. I don't want to take us
 17 off course from where we've come from, but I think
 18 it adds to it nicely, is thinking about the way in
 19 which we make this culture shift to try and ensure
 20 that patient partner involvement is happening and
 21 we're involving members of the community and the
 22 public in our research, because I feel as if

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1 sometimes there's a bit of skepticism around this.
 2 I think, Chris, you were bringing this up in
 3 terms of the expertise, or should we be having
 4 other members of the team and different folks
 5 coming together with those other skills to take
 6 some of the pressure off of the researcher so they
 7 don't feel that they need to be the expert in all
 8 of the aspects when they undertake a patient and
 9 public involvement.
 10 I have heard from colleagues that have said
 11 "Well, I really don't want to engage in that way.
 12 I don't want to involve patients, but I guess I'll
 13 have to because funding agencies are starting to
 14 ask for it." I think we need to ensure that the
 15 motivations for including members of the public and
 16 people's lived experience are quite pure, if you
 17 will, but also recognizing that there are going to
 18 be external pressures and factors, and people are
 19 going to try and do this, but maybe they don't want
 20 to.
 21 So it's trying to bring that culture shift
 22 in so folks understand and see the benefits and the

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1 true values, and for those skeptics that if they
2 don't get funding, then they'll start to do it.
3 But I think it's about empowering them because I do
4 think that there's a lot of confidence to do it
5 well, and so then people are resistant. So I think
6 it's identifying those other members with the
7 expertise to facilitate it and to help researchers,
8 whom maybe are a bit on the fence, to bring about
9 that culture shift.

10 I have even heard people say, "Well, this is
11 just a passing fad. In a few years --" I see Lynn
12 smiling; I think she knows. But anyway, this is
13 just a passing fad, and it will all be sort of over
14 in a couple of years. I think actually, no, it
15 isn't. It's here to stay, so we have to ensure
16 that that work is being evidenced and that we're
17 showing and demonstrating the impact. A lot of the
18 research that was presented, some of the slides
19 today on just that, was just so evident in how
20 involvement can actually make such a huge
21 difference in the outcome of the research.

22 So I just wanted to put that out there in

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1 that we have quite a bit of work because some of
2 the people around the table, we've all drunk the
3 Kool-Aid, I guess, because we know it works, and we
4 enjoy it. But not everyone is going to be that,
5 not every pain researcher, so we have a bit of
6 work.

7 MS. VEASLEY: Yes, I totally agree with
8 that. That's another one of the first questions we
9 get, is what evidence do you have that this makes
10 any difference? So tomorrow we're going to have a
11 conversation about metrics, around measuring
12 patients, and how do we measure patient engagement
13 across the research life cycle and also with
14 journal editors, because if we're measuring it, are
15 we reporting it? Is it included in the manuscripts
16 that are being reported and can we learn from that?

17 Another topic that came up is that we really
18 need testimonies, scenarios of patients and
19 investigators that have worked together as teams
20 out there in the media, and available to
21 investigators that they can actually see the
22 change.

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1 As Christine mentioned earlier, before she
2 did it, her views changed afterwards. And I've
3 heard that from so many people. Not saying she was
4 skeptical, but other people have gone into
5 incorporating patient engagement, and they're
6 completely skeptical that it would have any impact
7 on their research, but they absolutely would not
8 ever go back to not doing it after they started
9 doing it. So I think we have a ways to go, but
10 that measurement and reporting piece is so
11 important.

12 Lynn, you've had your hand up for a while.
13 Please go ahead.

14 MS. LAIDLAW: Just in the communication
15 thing, communication has got to be two-way. I
16 think often if there's a communication vacuum or an
17 information vacuum, then people will fill it with a
18 narrative that's easily accessible and people that
19 want to engage with them.

20 We have to come to a stage where there's no
21 such thing as a stupid question. That's really
22 what I saw happen in COVID, that people had genuine

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1 concerns, and those concerns were dismissed by the
2 establishment as being silly, and why would you
3 think that? So people went elsewhere for their
4 information? So communication has got to be
5 two-way.

6 I think in terms of research results, it's
7 who has more skin in the game. Who needs these
8 research results? Certainly, in the UK, there's a
9 lot known about self-management and about shared
10 decision-making, but often it's manage your disease
11 the way the clinician wants you to manage it, or
12 shared decision-making is actually choose from one
13 of the options that I'm presenting to you.

14 But I think if we disseminate research in a
15 way that people understand, then what I really want
16 to see is people taking that research and putting
17 it down on the consultant's table and saying, "What
18 about that? Could I have access to that treatment?
19 Would that work for me?" And then, really, that's
20 when we'd get to a situation where it's kind of
21 parachuting and that we're not put into the kind of
22 patient box, and just choose.

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1 So I think communication is really complex
 2 and it's multilayered, but sometimes we think of
 3 communication as you doing what we tell you to do.
 4 MS. VEASLEY: Yes, absolutely. And I think
 5 that goes back to the importance of training on
 6 both sides of all partners involved in a research
 7 project on an equal basis and all the values that
 8 you brought up during your presentation as well.
 9 Gail, your hand's up.
 10 MS. GRAHAM: I just wanted to go back to
 11 John's comment, too. I know when COVID hit, our
 12 community relied a lot on the University of
 13 Maryland PATIENTS Program. They became a trusted
 14 source to us. As the University of Maryland was
 15 finding out about COVID, they gave us that
 16 information, whether they came to us, whether they
 17 developed a video with one of our community leaders
 18 on it that goes out on social media, or whatever;
 19 they gave us trusted information. If there was any
 20 misinformation, they came back and they said this
 21 is not correct, don't use these pills like such-
 22 and-such said. That's not the safe way to do it.

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1 So because they became a trusted source and
 2 they had other partners, they were able to reach a
 3 lot of people in Maryland -- not just Baltimore,
 4 but in Maryland -- as far as what's happening with
 5 COVID.
 6 The researchers themselves, once you develop
 7 that relationship with your community partners,
 8 then they will be your source to disseminate that
 9 information back. If you explain it to them
 10 correctly, it will get out there to the community
 11 correctly if you make yourself available and you
 12 speak to the community. Like they said, "No
 13 question is a stupid question," but it is the way
 14 that you phrase some things that can come off a
 15 little harsh. So maybe working on that, too, will
 16 help reach more people.
 17 DR. FARRAR: Thank you, Gail.
 18 MS. VEASLEY: Absolutely.
 19 Isabel?
 20 MS. JORDAN: I find this conversation really
 21 interesting. Going back a couple of points about
 22 how you motivate or interest researchers on how to

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1 do patient-oriented research or patient
 2 partnership, like Christine said, she really wasn't
 3 interested in doing patient engagement until it was
 4 in a grant. I think that can be a great carrot for
 5 those who could be interested in it, even if
 6 they're skeptical, but I have some disquiet around
 7 making people do it who really don't want to do it
 8 because I think there's a danger presented to
 9 patient partners, like a very real danger of
 10 traumatizing us.
 11 I know I've been in situations where -- I
 12 like to think now I'm pretty good at smelling out
 13 when I'm being put in a bad situation where my
 14 participation is going to be abused in such a way
 15 that I will be re-traumatized, but it still happens
 16 once in a while, and I see it definitely happen to
 17 folks who haven't been doing this for 13 years like
 18 I have.
 19 So I think it's really an interesting
 20 problem to figure out how do you motivate people
 21 who are hesitant because of fear, or not having the
 22 tools, versus -- this could be a controversial

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1 opinion, but I just think people that don't want to
 2 do it should have access to those funds. I think
 3 more funds should be made available for funded
 4 patient partner research. But I think people that
 5 don't want to do it just shouldn't have access to
 6 those funds because they will do harm.
 7 MS. VEASLEY: Yes. I really understand that
 8 perspective and certainly have been in that
 9 scenario as well. We posed the question yesterday,
 10 how do we do this and how do we do it well and
 11 avoid tokenism? Because so many of us have had
 12 that experience where we've been brought into a
 13 committee or whatever because they had to do it,
 14 and we've just sat there for however long and tried
 15 to participate, but weren't really valued. And it
 16 does harm; it definitely does.
 17 Kathryn?
 18 DR. MARTIN: So on that note, I completely
 19 agree. I think that this is one of the things that
 20 Lynn mentioned about a lot of patient insight
 21 partners or patient partners being brought on to
 22 teams reviewing grant applications. This is really

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1 quite common and becoming even more so across the
 2 different funding agencies in the UK, and even
 3 charitable organizations.
 4 I think that it's -- Lynn might be able to
 5 say a bit more here -- quite, I suppose, easy for
 6 folks to spot the tokenism that actually is coming
 7 out -- sorry, it is getting late here, so that's
 8 why I'm tongue-tied -- and I think that's when
 9 people are actually getting downgraded on their
 10 scores, and they aren't getting funded. But I
 11 think, still, it's trying to persuade gently and
 12 demonstrate the value.
 13 I know here in Aberdeen we've been doing a
 14 lot of trainings and a lot of posting of
 15 conversations around patient and public
 16 involvement, trying to get people who might be
 17 interested but that cautiously are hesitant and not
 18 quite sure, what do I do, and offering them true
 19 support for them to see, and having them come and
 20 observe.
 21 Actually, I think that's the initial way
 22 forward. But I also think it's about training

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1 students at the undergraduate or masters level, and
 2 certainly of course our doctoral students and
 3 post docs, to get involved early as well because
 4 it's about training the next generation. So very
 5 quickly, I think that culture shift could happen,
 6 which is really exciting.
 7 MS. VEASLEY: Yes, definitely.
 8 Hannah?
 9 DR. GROL-PROKOPCZYK: Hi. I have a question
 10 that's actually going back to Dr. Jackson's talks
 11 about representativeness. One thing I've learned
 12 from a number of IMMPACT meetings is that the
 13 people who are eligible for clinical trials are
 14 very often very different from the typical pain
 15 patients that clinicians see. The clinical trial
 16 participants may be excluded due to physical
 17 comorbidities, mental health comorbidities, drugs
 18 they're already taking, or whatnot.
 19 It seems to me that if some of these
 20 comorbidities are more common in certain groups,
 21 those groups may end up being excluded, not
 22 deliberately, but just sort of as a byproduct of

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1 the inclusion criteria. So I wondered if part of
 2 trying to increase representativeness means taking
 3 some kind of stance about what kinds of trial
 4 designs are better.
 5 Then another related question is thinking
 6 about patient roles at various stages of the whole
 7 research processes, and what does it mean if you
 8 have patients involved from the beginning, but it
 9 turns out that most of those patients wouldn't be
 10 eligible to participate in the trial itself?
 11 Is that a problem or is that ok; and you
 12 just accept that patients, some can play a role in
 13 initial planning, and others can play a role in
 14 dissemination, and a different group of patients
 15 can be the ones who are actually part of the trial?
 16 Those are the two questions I had.
 17 MS. VEASLEY: Yes, that's interesting
 18 because it relates back to a conversation that the
 19 meeting planners had last night, which is there
 20 isn't always going to be consistency or congruity
 21 between what the patients want and what the RFA
 22 states or what the researcher's interest is.

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1 So the point that you just brought up about
 2 comorbidities, our organization advocates for
 3 research particularly in women who have multiple
 4 chronic pain conditions and non-pain comorbidities,
 5 but as you said, in most clinical trials, you are
 6 excluded if you have multiple pain conditions, pain
 7 in multiple parts of your body, or you have
 8 non-pain comorbidities.
 9 It's an interesting point because there's
 10 not always going to be hundred percent congruity
 11 between what the patients are telling you is
 12 important or meaningful for them. Obviously, if
 13 they're in a trial, they want to know if you do
 14 have a pain condition, plus sleep disorder, and
 15 mood disorder, they may want to know -- meaningful
 16 outcomes to them are not just whether their pain
 17 score decreased by two points on a scale but what
 18 their quality of life is and what the impact on
 19 these other conditions may be.
 20 I'm interested to hear other's response to
 21 your question. I know some of our trialists on the
 22 meeting have opinions, because I know you.

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1 Simon, you want to tackle it?

2 DR. HAROUTOUNIAN: No, I can take it. I

3 want to make one brief comment that it's not

4 necessarily the specific RFA or research interest.

5 I think for drug-related studies, oftentimes it's

6 the regulatory perspective as well.

7 For example, you may have a drug trial where

8 there might be a drug interaction, for example,

9 with an antidepressant, and then the FDA may say,

10 "Well, if you have any patients who are taking any

11 antidepressants, you may not be able to enroll

12 them." And you completely then exclude your entire

13 patient population that may have coexisting

14 antidepressants, which may sometimes be really hard

15 because then you have a very skewed sample of

16 patients who may not even represent the condition

17 if you're treating something like chronic

18 neuropathic pain, or fibromyalgia, or something

19 like that.

20 So rather than an answer, just another

21 limitation or potentially another barrier.

22 MS. VEASLEY: Yes.

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1 Okay. We have five minutes left. Does

2 anybody have one last burning question? I think

3 today's discussion has been great.

4 John?

5 DR. FARRAR: Yes. I was searching around

6 for my hand. With regards to the question before

7 about the inclusion and exclusion of people, I

8 think we need to be cognizant of the fact that not

9 all trials and studies are created equal. In the

10 era of an attempt to try and personalize medicine,

11 getting back to what Dr. Jackson said, we need to

12 understand what it is that we need to control for

13 or consider when we include or exclude people.

14 Even the comment that was made about

15 excluding kids from the initial COVID vaccine

16 trials, yes, it delayed their getting the COVID

17 vaccines and may have caused or resulted in more

18 deaths than we might have thought. But their

19 concern about taking vaccines with a brand new

20 vaccine and its possible implications for kids

21 would give one pause. If you caused abnormalities

22 in kids with COVID vaccine, it would have set back

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1 the whole thing a huge amount.

2 I don't mean to make an argument that

3 there's a right and wrong. What I'm saying is that

4 there are other considerations that go into it.

5 The first-time-in-human studies phase 1 trials, you

6 would certainly not use children and you would not

7 use pregnant women. You would use healthy adults

8 as a primary because you're being careful. With a

9 second phase 2 trial, you may also be much more

10 restrictive.

11 What I've been hearing today, though, and it

12 makes great sense, is that you have to be more

13 inclusive in phase 3 trials, and you have to be

14 very clear about what the goal is, and figuring out

15 who it will work for and who it will not work for,

16 and move towards a better understanding. That does

17 create an increased cost for trials, so there's

18 been a little bit of conversation about that.

19 I hope that helps to make it a little bit

20 more understandable. But it's an issue of not

21 using one brush to paint the landscape, but using

22 and being careful about what we do, and being

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1 thoughtful.

2 MS. VEASLEY: I agree. I think that what

3 you find is when you do get an engaged group of

4 stakeholders involved in research, if you're open

5 and transparent about that, and saying we want to

6 study this, but in this particular type of study

7 because of X, Y, and Z regulatory requirements and

8 yaddi, yaddi, yadda, we can't, what you'll find is

9 that people are actually receptive to that.

10 What normally happens is we say what we

11 would like. The scientists say, "Well, that's not

12 what we're doing," or "We can't do that," and then

13 they don't have the conversation. When the

14 conversation happens, I think you find that people

15 are a lot more reasonable and understand that not

16 all science is created equal and not every question

17 can be answered with every study. But if there's a

18 true partnership and team response there, or effort

19 there, it does make a big difference, I think, on

20 both sides.

21 Well, we have three minutes left. Today has

22 been absolutely terrific. Just to give you a heads

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1 up for tomorrow, we're going to hear from another
2 important stakeholder in the conversation tomorrow,
3 industry, because they've been doing patient
4 engagement for a long time as well. We're going to
5 hear some perspectives from regulatory agencies in
6 the U.S., Canada, and Europe.

7 We're going to have a talk tomorrow on how
8 do we actually measure patient engagement and
9 report on it, not just measuring it from the side
10 of was it impactful or meaningful, but also talking
11 maybe about, hopefully, how do we measure the
12 impact on the investigators and change in
13 perceptions and attitudes.

14 Then we're also going to have a conversation
15 with some journal editors about are we reporting on
16 this; are we measuring it; are we reporting it or
17 do editors want to know about it; and what do we
18 need to do to get buy-in on all levels to be able
19 to encourage this across the board?

20 I'm going to ask if Simon, Bob, or Dennis
21 have anything that they want to say in the next
22 couple of minutes before we wrap up, and if not, we

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1 will see you here tomorrow morning at 11 o'clock
2 Eastern.

3 Simon, anything?

4 DR. HAROUTOUNIAN: No. I think you did a
5 terrific job, Chris. Anything I add would be a
6 detriment.

7 MS. VEASLEY: I doubt that, but that's very
8 kind of you to say.

9 Bob, Dennis, anything you'd like to add
10 before we wrap up? And Bob Kerns, he apologizes.
11 He had to leave a little early today, but I know he
12 would have the same sentiments as I.

13 DR. DWORKIN: I'd just second what Simon
14 said. I think you did a terrific job, Chris, and I
15 look forward to tomorrow.

16 Adjournment

17 MS. VEASLEY: Okay. Everybody have a great
18 afternoon, and we'll see you back on Zoom in the
19 morning. Bye.

20 (Whereupon, at 2:30 p.m., the meeting was
21 adjourned.)

22

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