

Expectations of discovery research: who holds the hope?

About:

In this podcast, Adam is joined by a fantastic panel, uniquely placed to share their lived experiences to discuss the opportunity for consumer engagement in lab-based research. Within the discussion, Adam unpacks the assumptions and attitudes of both consumers and researchers on this topic and identifies barriers to engagement from both sides. Finally, the panel suggest potential steps forward to improve engagement, communication and align expectations. Prefer to read rather than listen? Check out the Podcast script.

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Podcast Script:

ADAM: Welcome everyone, so my name is Adam Piers. And it's my pleasure to help facilitate this discussion about consumer engagement in lab-based discovery research. And I would like to begin by acknowledging the traditional custodians on the land on which we are hosting today's discussion, the Wurundjeri people of the Kulin nation and celebrate their enduring connections to country, knowledge, and stories. I would also like to pay respect to elders past and present and extend that respect to all first-nations peoples.

So, quick background about me. So, in a previous life, I was actually a lab-based researcher who worked at the bench. But I now work as a program manager within the Murdoch Children's Research Institute, which is on the Children's Campus here in Melbourne. And here, I help manage a large research program aimed at bringing together researchers, clinicians, and consumers to help improve the lives of kids with heart disease. And our research program includes a patient advocacy group, that is designed to help create a two-way flow, or relationship, between consumers and researchers. But based on my experiences in this role and previous roles, I am aware of the disconnect that exists between consumers and lab-based researchers who are undertaking discovery research.

So, today, I will be joined by a fantastic panel who are very uniquely placed to share their lived experience from either the lab-side or the consumer-side. As well as some who have experience in both. We acknowledge that the terms consumer, person with lived experience, and participant are used interchangeably in this space, and while no single word encompasses everything we're talking about today. For the purpose of this discussion, we'll be using the word consumer.

So, why are we here today and what's the aim? So, the aim is to discuss and raise awareness of the disconnect that exists between lab-based discovery research and consumers. And within this group discussion, we will unpack some of the assumptions and the attitudes of both consumers and researchers on this topic. We will identify barriers to engagement from both sides and finally, we will

suggest some potential steps that might help to improve engagement, communication, and ultimately, align expectations.

I will now ask each of our panellists to briefly introduce themselves and we'll start with Oliver, and then go to Vicki, David, and finally Holly.

OLIVER: I'm Oliver Hunter. I am 27 and I have cerebral palsy and I've been involved in the disability space in a range of different roles as a consumer investigator and research consultant, touching on access and different employment opportunities for people with disability and I also perform a bit of stand-up comedy, which is a bit of fun. So that's me!

VICKI: My name is Vicki, and I'm a parent of a 30-year-old woman with cerebral palsy. My longstanding passion is to empower other parents to have a voice and to actively participate in all aspects of their child's care so that they can achieve better outcomes. Over 25 years ago, I co-founded a parent support group, which has now grown into a leading state-wide disability organisation. And I've held senior roles across multiple disability organisations. These roles have provided me with the opportunity to represent families and develop trusted relationships with researchers to support change in the sector. I've been actively involved in multiple research projects as a parent research partner and I wish to continue to use my person and professional experiences to increase opportunities that align research goals with parent contribution. I believe that parents bring a valuable and unique perspective that can only enhance research and make it relevant and impactful.

DAVID: Hi everyone, my name is David and recently I completed a four-year research degree with Honours at Monash University with majors in genetics and biochemistry. As someone affected by Duchenne Muscular Dystrophy, or DMD for short, which is a genetic disease, I am particularly interested in medical research and how we can improve the quality of life of those affected by disease. And currently, I am lining up a PhD in genetics next year, studying how stem cells could be used to treat my own disease. So, having experienced both the lab and consumer side, I am excited to discuss how we can connect the two sides together!

HOLLY: Hi, my name is Holly Vogues, and I'm a researcher at the Murdoch Children's Research Institute. I have a Bachelor's and a PhD in Biomedical science. And my role here, is at the bench in a science lab. My work is in the field of stem cell medicine and stem cells have a huge amount of potential to treat various medical conditions. I'm trying to educate myself around consumer engagement. I think there is value in learning and better understanding the condition that I am researching from multiple different angles and that includes people with lived experience. My firsthand experience of the common, or traditional, opinion in science is that patients can't add any value to research. Including patients in scientific research is perceived by many scientists as "new age" or useless. I hope to challenge that way of thinking and open up this line of conversation.

ADAM: To start the discussion, we'd like each panellist to answer, "What does lab-based discovery research mean to you?" And Vicki, we'd love to hear from you first on this one.

VICKI: Sure. So, I often think of, you know, how can a lab-based researcher help my child? I know that there are researchers somewhere looking at finding cures or treatments, but it really just seems so far away with what I deal with on a day-to-day basis. And I don't really know what's being researched for my child's disability. So, I would like to know what is being researched and what is being done, including the unsuccessful outcomes. I'd like to see what the possibilities are, and I'd like to have some hope and a better understanding of what direction we're heading in. So, the

reason that so many families look for alternative treatments is because we don't really know what's happening in the research world. And it just feels that anything that researchers discover will take so long, decades, even lifetimes to reach me or to impact me. So, for me, they're somewhere in the background. They're not really front of mind for me.

OLIVER: Yeah, I really relate in some way to what Vicki's saying. For me, it's about my relationship with lab-based research and science. I can't really formulate in my head what any of it means because one, I don't really have a good relationship with science and this originates in my year nine science teacher, I didn't like her as a teacher, so I just switched off from 15. It's never been something I've connected with, as opposed to some of the other research work I've done in the sort of qualitative and discussion based, and philosophical based stuff, if that's the right way to say that. I guess for me, all lab-based research is the white coats and the microscopes, and I haven't really ever opened my mind to that side of the equation, or the bench, as it's come up a couple of times.

DAVID: As someone also with a condition, I definitely understand where Oliver is coming from, but obviously I'm in the unique position where I'm actually involved in the research myself. So, I think for me, I've started to learn about how, or at least for me, lab-based discovery is about determining why and how diseases occur, and then, from that, eventually trying to find a treatment. So, I think it's really important for science to be able to communicate this idea, the notion that a lot of what we know about disease actually comes from lab researchers in the first place. This is particularly because people like Oliver and Vicki as consumers are not often in my position where they are actually a researcher themselves. I think communication is really key in this area.

HOLLY: And for me, as a scientist, I do spend a lot of time in a white coat and looking down a microscope, but I view discovery research as the fundamental understanding of all medicine. And a prime example of that is the recent mRNA vaccines for COVID-19. That wouldn't exist today if 20 years plus of research hadn't been done on the fundamental research side. And to me, lab-based discovery research is the medical treatment of tomorrow.

ADAM: So now that we've got an idea about people's attitudes toward lab-based discovery research, we'd really like to know what you guys think consumer engagement means. So, Holly, as a lab-based researcher, I'm really curious to hear your thoughts on this to start with.

HOLLY: It's an important question, Adam. Consumer engagement to me means connecting with people that are affected by the disease that I'm researching and understanding directly from that person their realities and lived experience of that condition. And personally, I've had limited experience with consumer engagement in my research. My experience so far has been to reach out to organisations including Rheumatic Heart Disease Australia and Heart Kids, which are relevant to my research area and connect with these well recognised not-for-profit organisations that are trusted by their respective communities. My hope is to build mutual relationships with these organisations, to learn from their consumer groups, contribute to their information that is going out to patients, and share my research with the organisation, patients, and their families.

For me as a lab-based scientist, there is no roadmap on how to do this. There's no formal training and there's very minimal resources out there for how to engage with consumers. So, I'm kind of having to learn along the way. David, what's your take on this consumer engagement. What does that mean to you?

DAVID: Yeah, so I think what Holly says about scientists not being able to engage or not having much experience with consumers is definitely something I've seen because I know from the lab side that

researchers are not used to meeting someone like me. When they meet someone like me, they find it very interesting and intriguing. And, you know, there's comments like this is really cool to meet someone who is actually . . . to put a face to the disease that I'm researching. They might not say it explicitly like that but I definitely can tell. So, I think actually meeting a consumer and putting a human face to a disease is actually something really motivating for researchers, not only informing them how to interact with consumers, but for their own personal benefit it actually can be something that really motivates them.

And then, on the other side, many affected by disease have little knowledge of what goes on in the lab. From seeing both sides, I can see a real disconnect so to me, I really think consumer engagement should be about removing this disconnect between both sides and that means better science communication from the lab side is going to be critical in better involving consumers along the research journey.

ADAM: So, I think we've really foreshadowed some of the potential pain points inhibiting engagement, but it would be really good to unpack more specific barriers and as someone who has been in the lab side in my previous role, I know that the misalignment of expectations drives fear of providing false hopes amongst scientists, and given your role, Holly, I was hoping to start with you on this question. So, would you mind sharing some insights about this?

HOLLY: Yeah, I agree completely with that Adam. A really big fear is providing false hope to patients. As a scientist we often don't know where to start when it comes to consumer engagement. There's no training in science communication, it's almost a completely different discipline and there are some people out there that do it very well, and it's often that you learn it by doing it.

And there's also another barrier here which is a misunderstanding around the timelines that it takes for science to reach a patient in a clinic. So, a timeline like five years for a sick patient is a really, really long time, but five years in a lab in a research project goes by with a blink of an eye. And for context, the average time that it takes for a person to get a PhD in Australia is four years, and that's just the basic learning or training period. So, to go developing entire new therapy, typically, you're looking at a ten-year time frame. And these time frames are often out of our control. As a scientist, there's a lot of extra safety steps that are necessary, that are needed to move from the bench in a lab through all the pre-clinical testing and then in through all the phases of a clinical trial before it actually reaches a patient that receives it.

So, from my point of view as a scientist, those are some of the big barriers that come to mind. I don't know, David, if you had anything additional to add to that?

DAVID: Yeah, I think also an important part of what you're saying about timelines is that it can also take a while in the first place to simply understand how a disease occurs. There's a lot of effort that goes into just initially trying to understand mechanisms of disease and so that can even add more to the timeline. And in addition, there also can be a lot of trial and error involved in trying to find a treatment and then eventually approving and testing it. And by nature, discovery research is about discovering things that no one knows yet. So unfortunately, there cannot be any guarantees about timelines and as you said Holly, no steps can be skipped if you want to find a safe and effective treatment. And so unfortunately that leaves us in a place where research can take years and can't or doesn't move as quickly as consumers desire.

Also, it can take many years of collective knowledge to treat disease. For example, my disease, DMD, we've known about it for probably more than 30 years. We know how the disease works, but we still

have no real breakthrough in this area and so that is just my disease and given DMD is still relatively common amongst rare diseases it can be safe to assume that even rarer diseases may struggle in terms of timeline of research. And I think this is partly why it can be really confronting for researchers to talk to those you're researching, particularly if it's a disease of high severity because you have in the back of the mind that you don't want to feel like you were telling a consumer bad news and so that personal aspect I think can be quite confronting for a researcher and trying to balance not giving false hope.

And then I think for the consumers, one of the barriers can be that they may not have an interest in science and also for them personally, thinking about your disease can be something you want to avoid and it feels difficult for a consumer to engage with researchers because as someone with a disease myself I know the feeling of sometimes you think about your disease and you just want to stay away from it because you're having a bad day or something. So, that can be, I think some of a barrier. So, Vicki I wonder what your thoughts on this as a parent of someone with disability.

VICKI: Yeah, I can certainly see your points and you know, clearly, there's lots, many barriers for both parties. But for families engaging in research, all of these apply to lab-based research as well. However, this type of research also means that as parents, as families, we don't have any personal engagement with research, with researchers. Our direct contact is really with the doctors or clinicians or therapists. So, you know, that can be a bit of a barrier because they're not front of mind, and I think that this is more pronounced for lab-based researchers. So, we never really speak or see the lab scientists so because it feels somewhat like they don't even exist in our world we don't know what they do or how we could possibly contribute. So, questions come to mind for us like, "how could they possibly understand or help us?"

So other more general barriers I think include, you know, lack of awareness by families that they can be part of research in partnership roles and not just as participants. It's a fairly new concept. How do they know where to access it? How do they access it? Particularly for those who are isolated and don't have good social circles or connections to their community or other peers. There's also a fear of failure and I think somebody touched on this earlier – it's about you know what happens if I say something stupid? What if I can't offer anything worthwhile? Having the confidence to contribute or lead to discussions or even lead discussion or even to debate or disagree, it can be quite intimidating for those who haven't really had much to do with research partnerships before.

And also raising a child with a disability can be extremely busy and it can take a lot of our energy. So, finding time that fits around work and family commitments can be really challenging. Another last sort of barrier for me that I can see is the lack of compensation, appropriate compensation. It can also deter some parents and families either due to feelings of them being less valued or simply on a more practical level that they just cannot give up paid work or other commitments that they have to contribute their time as a partner without adequate compensation.

OLIVER: Yeah, I agree there Vicki. And I think another point, similar to what you've touched on, we've all touched on it so far about the "I've felt that I wasn't qualified enough to research but then I was validated, and I felt like I deserved to be there." But I think the interesting fact with science and lab-based research is science and lab-based is quite a skill-based thing. As a scientist, and David and Holly can attest to this, like you've trained, and you've got "science-y" skills. That's probably not a very sophisticated way of saying that . . . "science-y" . . . but you've got skills like as I said, my relationship ended with year nine science, and I picked it up again with Breaking Bad. So, I can turn on a Bunsen burner and that's about it. That's where my skill ends with science. So, I feel like that

can be a deterrent and a barrier because I don't know how to be a scientist. But in terms of the other research I've done and the discussion groups I've been part of, that's been very qualitative and very opinion based and my experience is I can inform you and we can have a conversation, I'm happy to give you my opinion. You can ask anyone related to me, stopping my opinion is more the problem! So, I feel like when I'm in those circumstances, I'll talk to anyone about anything, but when it comes to lab-based stuff, the barrier can be that I don't have the actual skills to be in a lab because, yeah.

ADAM: So, having explored some of the barriers to engagement, we'd now like to conclude our discussion with some ways where we might be able to align expectations and strengthen consumer engagement in lab-based research moving forward. So, David, can we start with you? Can you share some reflections that you might have on this?

DAVID: Yeah. So, I think the important things that I've thought about being someone on both sides is I think it's really important that we could, in some way, get consumers and scientists to meet each other in person. So, one example is bringing consumers into the labs to meet with a scientist or someone like that. If anyone knows Gordon Lynch from Melbourne Uni, he had a student with DMD called Savant, who was also studying DMD. But he had a time where he would get some of the boys in with DMD to meet researchers and I believe this was on DMD awareness day. And so, I think if really this face-to-face talking as humans is something that is really good at connecting people from any sort of background and I think that this is really something we can do to help strengthen consumer engagement in this discovery research area.

And I think also reflecting on the role that consumers can have in driving research. So, I have met a guy with DMD from the US and his parents actually founded a foundation called Cure Duchenne, which is raising money for funds, so funding research and diagnosis for DMD. And so often I think, it can be the consumers who are the most passionate because of their personal connection to whatever disease they're facing. And I think it's really important that the lab or scientists don't ignore the role that consumers can play. I think that's really important. I think Oliver, is there something you've thought about and how it can help improve consumer engagement?

OLIVER: Yeah, thanks David. I think for me just to sort of touch on what you've mentioned there, it's about just starting the dialogue isn't it? Starting the dialogue between scientists and consumers and just getting a message out there that building that relationship from the ground up. And that could be something as simple as like David, yourself and Holly, jumping on a webinar. Or Adam jumping on a webinar and going public and opening a discussion and showing both consumers and scientists that this is a relationship that could be fruitful. That we could really work together. And I think once the relationship is started and potential projects are worked on, scientists that may not be as open to consumer involvement as Holly touched on at the start . . . we can really open those doors and some really cool and impactful work can be done in the future.

ADAM: In addition to what David said about having consumers, people with lived experience coming into a lab, I'm assuming you've never been into a lab and seen what Holly does? That visual perspective of like "oh that's what that piece of equipment is, that's what that tube of DNA is, like that really fundamental stuff." But it seems like to those people in the lab, well that's what we do every day. I think it's quite magical. It's crazy what's being done in there.

OLIVER: And showing that it is accessible, not from like a disability point of view, just as people, just that yeah you can be a part of this and see it and you know touch it. I don't know, some stuff in

science you don't want to be touching . . . but be a part of it and you have that real tangible experience. Sometimes I feel with science, that I don't have anything tangible or anything I can relate to, so if you see people like David and other people with his disease have been in labs and been part of that, and then the scientists are able to put a face to the disease, which I think is huge.

HOLLY: Yeah, great points Oliver. I really agree and I think your last point about showcasing good examples of it is what we need on our side as scientists. We need public examples of people that are doing it well and the value that it has because we've touched on it before that there's mindset shift that almost has to happen on our side as scientists to want to come to the table and introduce patients to that table and see the benefit and the potentially fruitful relationship that can come from including consumers in your research. It's a lot of extra leg work I must say as well, so having a program manager for example in our group has been really key in helping me as a scientist reach out to charities and not-for-profit organisations that are helping connect patients to the research, so that's been a really fundamental change and I think if there were more people like that in other research institutes that would make a really big difference.

I also think that there has to be buy in from both sides to make this worthwhile. You don't want a patient and their family going into a room with a scientist and both parties think what's the point of us even being here. So, whether that comes down to Oliver's earlier point about dialogue and conversation, or education pieces . . . I think all of it can be really important.

Vicki as a parent what's your opinion on this?

VICKI: Yeah, I've got a few other ideas, but I do echo the comments that I've heard so far, especially about bringing people into the labs so that we can see and that brings us front of mind because I think for me what was missing was that whole world that we weren't even aware of and it does need to be something driven by the researchers as well. There needs to be buy in and there needs to be good communication. I suppose for me researchers and families together can increase awareness amongst the community as well of what lab research is and its importance, and what they do and how families can be involved and why. There just needs to be an awareness raising of all of these concerns and issues. Promoting it within peer networks, face-to-face and online. There's lots of Facebook groups where families are very actively engaged. There's lots of opportunities there that will help bridge those gaps.

Researchers could also build relationships with disability and advocacy organisations as well as service providers so allied healthcare and clinicians, and also educate and offer opportunities by connecting them to lab researchers, promoting the benefits of being involved in research. For example, there could be a potential career path for a family member or for somebody that has a personal experience of disability or even a parent - increasing their confidence and making them helping them to feel valued. There's lots of benefits for families and consumers.

Researchers could also think about maybe including budgets for their consumer involvement so not just compensation for that participation or that partnership but as well as maybe some provision for coaching and mentoring in funding applications. You know once you have a consumer who perhaps is less experienced and maybe not confident, they will need some coaching and mentoring and that takes a lot of time from the researchers to help work with them in order to make it more successful. If that coaching and mentoring is not there, then that person is more likely to feel less valued or to be able to contribute more confidently.

But most importantly, I'd like to inspire lab-based researchers to want to include families and to see the benefits of us being involved. Because when we're involved, we may be able to work with lab researchers to align our expectations and find a way to address that you know fear of false hope that's often experienced by lab researchers. We may be able to help them to feel more confident to address this issue which can often lead to families seeking unsafe treatments overseas because there is an absence of that hope by our Australian researchers.

ADAM: In listening to we all I just thought about the biggest barrier is that first step and I think everyone said that first dialogue and both sides don't really understand each other and that first step doesn't have to be perfect. You know, when you have two worlds that don't really know each other it is maybe going to be a little bit awkward or a bit strange to begin with because you're both trying to understand each other. So I think in trying to do some work and try and get a bit of understanding beforehand, just inviting people into the lab, inviting them into the conversation early and then to see what happens. I think that's a really big first step . . don't be scared. Let's just try.

OLIVER: I'm open to a tour as well Holly.

HOLLY: Come on in.

OLIVER: Get me a white coat and a HAZMAT suit. He-he-he!

ADAM: HAZMAT? What do you think we will be doing?

DAVID: HAZMAT? *(Chuckles)*

OLIVER: See this is the whole point isn't it?

DAVID: Yep!

ADAM: You're still on Breaking Bad!

OLIVER: There we go. That's all I know! So get me in there. We'll mix some dishes and make it all happen!

ADAM: Yeah. So, I really want to thank all our panelists. There's such a stimulating discussion on such a vital topic and to those listening I hope our initial discussion here has conveyed a sense of that disconnect that exists between the lab and consumers and that you've also felt a bit energized and excited and felt the positivity that we can create by just stepping outside your comfort zone and just sharing and learning together. As I said, we've only just started the conversation today, but we hope that it is stimulating and that it does make you out there think more about the barriers within your own context, whichever side you're on, as well as potential ways to overcome them and connect more in the future. Again, thank you to our fantastic panelists, your insights and reflections on this important topic and watch this space!

