Transcript

Title: Technology x Society Forum - Constructing and Deconstructing Public Interest Technology: Insights from the Development of ORBIT
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Year: 2021

Audio/video for this transcript available from: http://commons.swinburne.edu.au

PAUL LAVEY: Good afternoon, everyone. I'm Paul Lavey, the Research Events Officer in Swinburne Research. Thank you for joining us for today's webinar, Constructing and Deconstructing Public Interest Technology, which will be co-convened by Professor Lawrie Zion, Associate Provost of Research and Industry Engagement, College of Arts, Social Sciences, and Commerce at La Trobe University; Associate Professor Diane Sivasubramaniam, who is the programme leader for Public Interest Technology at the Social Innovation Research Institute at Swinburne; and Associate Professor Sam Wilson, who is a co-programme leader for Public Interest Technology with Diane for the Social Innovation Research Institute at Swinburne. We're also very pleased to welcome our guest speaker, Professor Greg Murray, Director of Swinburne Centre for Mental Health.

Before we start with today's proceedings, I would like to acknowledge our Traditional Owners. We acknowledge that we are hosting this webinar from both the lands of the Wurundjeri and Dja Dja Wurrung people of the Kulin Nation. We also acknowledge the Traditional Custodians of the various lands of which you all work today, and the Aboriginal and Torres Strait Islander people participating in this webinar. We pay our respects to elders past, present, and emerging and celebrate the diversity of Aboriginal peoples and their ongoing cultures and connections to the lands and waters.

Just some basic housekeeping-- we will have a designated Q&A session towards the end with Lawrie. We prefer, if you can, please just pop all of your questions and comments in the Q&A box rather than the chat. It just helps us sort through them when they come through thick and fast. And just to let you know that we are recording this session. If your voice is recorded-- so there is another option. Sorry, I didn't mention that if you have a question, you can also raise your hand, and we'll enable your microphone. So if your voice is recorded in that component, and you're uncomfortable with that being recorded, just message me on the email address here, and I can edit that out before we distribute that to everyone.

So at this point I will hand over to Diane with today's presentation-- I'm so sorry, over to Sam with today's presentation. Sam, over to you.

SAM WILSON: Thank you very much indeed, Paul. And hello, everyone, and thanks for joining us today at what should be a pretty exciting webinar. Before we hand it over to Diane, I would just like to take a moment to say a few words about the forum itself just so you know the context of the forum and what its intentions are.

Public interest technologies put people and society at the centre of our technological choices and strive to ensure that the benefits of technology are widely shared. However, there is currently limited understanding in Australia of the notion of public interest technology. In particular, there are few opportunities for academics interested in public interest tech to observe and learn from the development of technologies that are designed to serve the wider public interest-- the public good.

The Technology by Society Forum provides a space for engagement between STEM and HASS academics with an interest in the design, development, and application of public interest technology. The aim of these forums is to stimulate collaborations across disciplines to address complex social challenges. Forum activities include a series of curated conversations on key topics organised by forum leaders and seated by the forum steering group. The goal of each forum is to generate opportunities for research, leadership, and social innovation by researchers at Swinburne and La Trobe Universities and our partners, more generally. And Paul, could you pass on to Diane now, please?

DIANE SIVASUBRAMANIAM: Thank you, Sam. And hello, everyone. So my name is Diane Sivasubramaniam. I'm an associate professor in the Department of Psychological Sciences at Swinburne University. And together with Sam Wilson and Lawrie Zion, I co-lead the Technology by Society Forum.

So as Sam mentioned, in our forum, we're interested in supporting and in facilitating the development of public interest technology. There is a growing interest in and an understanding in Australia of this notion of public interest technology. But as Sam said, there are few opportunities for academics who are interested in public interest technology to really observe and really learn from the development of these technologies. So that's really what we're here for today. We're here today to observe and to learn.

Today, we're talking about constructing and deconstructing public interest technology. We'll start with the constructing side of things. So in this workshop, we'll be hearing from Professor Greg Murray who led the development of ORBIT, which is an online, guided self-help intervention that aims to improve quality of life in people with late-stage bipolar disorder.

So we'll start with the presentation by Greg, and so you'll get to see a really concrete example of a technology for public good. And you'll hear about the process by which this technology was developed and is being evaluated. And then we'll move on to the part about deconstructing public interest technology.

So after Greg's presentation, Greg will have a conversation with Lawrie Zion where Lawrie and Greg will delve a little further into the nature of ORBIT-- how it was developed, its implications for the public, its implications for research-- and then for the final 15 to 20 minutes of our webinar today, we're going to open this up to questions from the audience. And we'd really encourage you to ask your questions to really demystify this notion of public interest technology.

In ORBIT, we have an example of technology development in a STEM discipline where the science has to be rigorous. The researchers are developing and delivering a programme to a vulnerable

population. So today's Q&A is really an opportunity to dissect this process of stakeholder engagement, the process of co-design in the development of technology in a high-stakes context.

So we're very fortunate today to be hearing from Professor Greg Murray. Dr. Murray is Professor in Psychological Sciences at Swinburne University. He's the director of Swinburne Centre for Mental Health, and he's a practicing clinical psychologist. His major research interest is in the chronobiology of mood, especially the relationship between sleep, circadian function, and positive mood states. He has over 100 publications in this area, and his research has been supported by more than $10 million in national competitive funding and more than $2 million in industry funding.

Greg is a co-author on the Royal Australian and New Zealand College of Psychiatrists mood disorder guidelines, and he wrote the Australian Psychological Society's guidelines for psychological treatment of bipolar disorder. So without further ado, I'll hand you over to Greg Murray who will talk to us about ORBIT. Thank you, Greg.

GREG MURRAY: Thanks for that lovely introduction, Diane. What a great pleasure and what a really fascinating topic. Obviously, I've spent 10 or so years of my life thinking about this project from a clinical and scientific viewpoint, so it's really lovely to have it refreshed in my mind by having it situated in this context of public interest technology. And I'm really looking forward to chatting with Lawrie as we deconstruct, after I introduce the project to you. So I'm just going to share my screen.

The ORBIT project-- yes we do have a GIF. And for those of you on a busy schedule, this is the highlight of the talk. So this would be a good time to leave. Nothing better happens in this talk than that GIF.

A little bit of background. So bipolar disorder you've probably heard of-- a very serious, chronic mental health disorder involving episodes of mania and depression waxing and waning throughout the lifespan with various degrees of mood stabilisation between episodes. Best practise treatment of bipolar disorder is a combination of medication and psychological treatment.

But we don't have great treatments. So even with optimal combined treatments, somewhere between half and 3/4 of people relapse again within 12 months. This is not a great set of treatments. Not only that, most people don't even access the psychological bit. So me saying that best practise treatment is a combination doesn't mean that that's what most people are getting. Most people around the world are just getting medication for their bipolar disorder.

So we conclude from that that there's room for innovation, particularly in the psychological area. And we add a couple more ideas about this. One of the most burdened aspects of the bipolar population is people in what we call late stage, by which we mean people who've had a large number of episodes-- and by large, we mean 10 or more is the common way of operationalising late stage.

And before we started to do this work, one of the motivators for this work was a major randomised controlled trial, which showed that cognitive behavioural therapy, one of the standard psychological therapies for all conditions, benefitted people with bipolar disorder but only if they'd had less than 10 episodes. In fact, there was some evidence that for people who'd had more than 10 episodes,

cognitive behavioural therapy was actually iatrogenic, it actually made them worse. And there's all sorts of reasons why that might be the case.

So we, in consultation with our lived experience experts, started to think about this and playing around with, so where to next? And we ended up with these three interacting ideas. We wanted to capture this notion of stage-- the difference between early and late stage-- and we started to think about, so if we're considering people who've had a long history of bipolar disorder, and cognitive behavioural therapy doesn't work for them, what's the problem? Well, the problem might be that the reality is we aren't going to decrease their likelihood of relapse. They have to learn to live well despite the symptoms and the episodes rather than hope to never have an episode again.

So this shifted our focus in terms of our outcome variable. We thought, actually, what we're interested in is improving the quality of life of people with bipolar disorder who've had a lot of episodes and realistically are going to continue to have episodes throughout their life. So quality of life becomes our outcome variable. We're thinking about late stage. And then we started to think about what are the psychological interventions that might be useful for achieving that outcome in this population?

And it was in fact our consumer advisory group who said, what about these mindfulness interventions that everyone else gets given? So as you'll know, if you've been tracking the psychological literature and the public media, mindfulness has been the fashion of the decade, probably, since it arrived in the West through pain management-type interventions in the early 2000s. But it's spread like wildfire into just about every problem population in mental health, and to some extent, in physical health.

So not surprisingly, our consumers were saying, how come no one offers mindfulness to people with bipolar disorder? And we looked into it and thought, yeah, that would work particularly for this aim, in this subgroup, because mindfulness is all about being attuned to what's going on for yourself, to some extent accepting the challenges of the experiences you're having, and also maintaining a focus on where you want your life to go despite challenges. Some sort of values-based orientation.

And so that was the core sets of innovation. And then, because we're Swinburne University, we thought, let's put it online because we thought we won't have jobs unless we can call this technological. And so we chose to do that. And in all seriousness, we actually have deep expertise in digital therapies at Swinburne University through Mental Health Online, which is a federally funded online clinic.

So we put all that together. And I'm going to now, in the next about 10 minutes, tell you the story of what I would call the circle of life for a clinical health researcher where you start by talking to end users, and then you work through a process of incremental building of a product, investigating it, and then returning to consumers. So let's go on this little journey which, as I say, started in 2014 and ended about a month ago when the final outcome paper was accepted for publication.

So in terms of end-user engagement, most of the consumers that we consulted about this, and who drove the process, are based in Canada with an organisation called CREST.BD, which is a knowledge translation network. The Canadian health system has addressed what's known as the problem of

knowledge translation-- getting findings from the lab and the clinic out into practise. That's a well known problem in medicine. Canada has addressed that by setting up these networks of clinicians, researchers, and consumers to work together on a problem, and ours is the problem of bipolar disorder. And the consumers that we consulted about this drove us to think about quality of life, and as I say, drove us to think about mindfulness interventions.

We'll return to their input in a second. Sorry, I'm not seeing some of my slides, so I'm just going to move that. And then we built a prototype. So the prototype of this digital intervention was a five-week-long mindfulness and self-compassion focused therapy made with zero funding, absolutely zero funding. The most ambitious bit of the pilot was, because we knew that we wanted this intervention to be disseminated globally, we built the intervention at Swinburne, we delivered it from Swinburne, but we delivered it to Canada because one of the major challenges in this public interest technology is crossing jurisdictions when you're a professional who is only registered in one jurisdiction. So there are a number of issues we're thinking through-- can I be a psychologist in Canada, or do I have to pretend I'm not? We'll talk a bit more about that in a second.

So in this prototype, we built and delivered it from Swinburne. And we used cartoon-like images that were donated to us by other researchers in the field. And I literally sat in my office at Swinburne and videoed on my phone myself speaking to camera explaining the constructs. And we uploaded them and invited a small number of people in Canada to participate in an open trial.

An open trial is where you don't have a control group, and you just measure something at baseline, and measure something at the end, and see if it improved. And as I say, the outcome variable we wanted to shift was quality of life, and we did, in this small group.

And on the basis of that publication, which came out in early 2015, we were already working with senior researchers around the world through this CREST.BD organisation. We got them on board and developed a project grant for the NHMRC, and that was funded in late 2015. I think it was $1.1 million, and Swinburne put in another 300,000 to make up the salary gap. And we then set about, in 2016, actually designing the scientific study. And this is where the story gets incredibly interesting, and I'm in danger of talking for weeks about this because this has been 10 years of my life.

So imagine being the lead researcher on a novel intervention for one of the most vulnerable populations in psychiatry, and for the first time ever, you are delivering it remotely. And some of the aspects of the intervention-- there are some hints in the literature that they might be dangerous. So there were some hints in the literature that mindfulness meditation may be [INAUDIBLE]. It turns out that those concerns were overstated. But you can imagine I looked very, very hard at all of those concerns and rang people up and said, what do you really think is going on with this? So I was really anxious. I felt very responsible to invite 300 people, some from Melbourne, but some from Ohio, and some from Botswana-- anyone who could speak English could be in the trial-- and I felt responsible for them.

And it was actually in discussions with our consumer advisory group in Canada when my neurosis was getting more and more marked as we were finalising the plan and writing the protocol paper. And at some point in a discussion with the guys in Canada, one of them said to me-- I said just essentially what I just said to you-- and they said, suck it up Greg. That's your problem. We've been

living with bipolar disorder for years. We keep ourselves safe. You cannot keep us safe. When I say safe, I mean suicide is the main risk we're concerned about.

And I took that idea to a couple of international conferences and presented it and said, this is what we're thinking of doing. We're thinking of devolving responsibility to participants explicitly and unambiguously. If you come into this trial, you and your local networks are responsible for your own safety. And that's what we did, and it all worked out fine.

But there was another aspect to the ethics. Because this population is so vulnerable, I wanted to not let anyone into the trial who was currently ill. What normally happens with face-to-face trials is you wouldn't let someone in if they were manic, but you would let someone in if they were depressed. And we chose not to let them in if they were either manic or depressed just because of the novelty-- the multiply novel aspects of this design.

And that is not the decision you would have made on scientific grounds. If you want to see a change happen, you need people to be unwell. In fact, in a condition like this, if you get people who are well, you are almost certainly setting yourself up for them getting worse. And we'll talk more about that in a second.

And then nested within that is the intervention itself-- the decisions about the intervention. When we were designing the grant, we said, what's going to be in the intervention? And we said, it's going to be online and it's going to have best practise consumer engagement built in, as if the content and the form could be separated. And of course they can't.

So what we ended up with was this incredibly complex process where we knew what we wanted the content of the intervention to be. But for engagement reasons, we wanted the content to be delivered by lived-experience people on video, and we didn't want it to be scripted. We wanted it to be documentary-style.

So what do you do? You find a dozen people who have relevant experience of interventions like this, and you design a series of questions to put to them, which you video. And the videoing for each person took about four hours across multiple days for all the different elements of the design. You get those videos back, and you have to change your mind about what the intervention is because you've all of a sudden got this incredible thing you didn't know about your intervention, because people have just told you, or something about the context-- what works, what doesn't-- you think, oh, we can't lose that, that's incredible, or other things that you thought, oh, we're going to start the story here, but none of the consumers started the story there. The consumers started the story somewhere else.

So across a whole year, 2016, we did this videoing and the editing. And the content of the intervention kept changing iteratively as we made decisions about the videos, as we made decisions about the other aspects of the website, which included peer-moderated discussion boards-- again, another challenge to the science because that adds an enormous amount of lack of control, which perhaps Lawrie and I will talk about later.

So let me show you, then, what sort of thing we ended up with. I'm just going to get Paul to show us this little video. So I'm going to stop sharing. And this is how you learn about mindfulness in relationship to bipolar episodes if you're in the ORBIT trial.

MIKE: So in regards to mindfulness, I find some techniques work extremely well, but others don't. So for me, just sitting, I find, doesn't help me. I need to be moving. I need to be engaged in an activity. And I find that helps take me away from those negative feelings. So I combine movement with mindfulness.

DOV: So for me anyway, it's probably more useful in the depressive anxiety phase where I still have insight, but I'm just in a horrible place and don't really know what else to do. If I was in a state where I was just a little bit sad or a little bit anxious, then definitely I could take on board a meditation task and put a stressful day into perspective. But in the midst of being very, very unwell, it's quite difficult, for me anyway, to do too many of these things and expect too much from myself as well.

CLAIRE: I find that doing a breathing relaxation technique really helps when I'm feeling anxious because it's relatively simple to do. It's not complicated like, for example, using your senses. If you're feeling anxious, it can sometimes feel a bit much to be going through everything that you can see and hear and taste and smell. So sometimes the simpler breathing technique is really helpful for me when I'm feeling particularly anxious.

KATIE: For example, if I'm quite agitated and I'm quite annoyed or worked up, sitting down and just feeling my breathing is not helpful. If anything, it just makes me more frustrated. Whereas doing a guided meditation that does something, like a body scan, is really helpful because it's a little bit more tangible.

NAT: I really find the body scan-type mindfulness meditations a bit frustrating and boring-- where you're sort of having to think about your big toe, and then think about the ball of your foot, and it becomes a bit tedious-- and when I'm hypomanic, that sort of thing I have zero time for. I also think that hypomania is-- your thoughts are going so quickly that being mindful of them is incredibly difficult.

MAREE: Mindfulness for me, during a manic episode, was useful when I focused on the breath and just tuning into breathing. Sometimes, we can only do a limited amount of mindfulness, depending on the episode.

MIKE: It helps me recognise if a pattern is emerging. But it also helps me diffuse the onset of either depression or hypomania because I can say to myself, I think I identify some of those triggers or those feelings of depression. So I'm just going to put that in front of me and just say that's what's happening. And that allows me to then activate the other things I do to manage that. And it's the same thing with hypomania. I feel the onset of hypomania. These are the actions and the activities that I need to do to help mitigate that.

So I found in managing my bipolar that the techniques that you use are very specific to you, and you have to be pragmatic. So some of those techniques may not work and others will. But it's important to experiment with those and find the ones that work for you.

GREG MURRAY: Thanks, Paul. Aren't they great? Aren't they fantastic? I could watch those videos forever. And you can see how the consumers are actually the authors of the intervention. So you can imagine how each of those points they made we then pick up in text or exercises or bits of homework. But it's very much led by the consumers themselves.

So I've just got one or two more points to make before we have a chat, so I'm just going to share my screen again. And so this is the trial itself just as a standard representation of the trial-- 300 people, 152 in mindfulness, 150 in the control condition, people from all over the world. I think people came from 28 countries altogether, including Africa and Europe.

And this is the Boston Public Library where I was sitting in late 2019 when the statistician rang me with the outcome. It didn't work. The intervention didn't work. Not only did the mindfulness intervention not improve things more than the control intervention, but neither intervention shifted things. Now obviously, if this was a different forum, I would be saying a lot more about that. But that's actually not the focus of today's discussion.

But psychologically, of course I was very, very unhappy about that result after all the work that people had put in to get the trial up, and all the commitments that people had made. And so as part of my processing-- it's more my emotional processing of that result-- as part of sharing the findings with participants, I added a questionnaire. And the questionnaire was about what did they make of the finding. What did they make of the negative finding?

And you just cast your eye of this-- this is just the responses of-- I think we had about a hundred of the 300 people respond to this questionnaire. So it's a biassed sample, right? But what you see there is the very strong agreement on all these positive statements about the trial and also their commitment to keep working with us on improving online interventions for people with bipolar disorder, which at that time I found incredibly heartening, because the stakeholders that I was most disappointed to have not given the finding we wanted to were the consumers themselves. And I was relieved to hear that they weren't despairing, as I was tempted to do, with this negative finding. And they were very energised. And many people wrote lots on the survey about, try this, try this, what about this, what about that. And so the discussion continues. OK, that's it for me.

LAWRIE ZION: Greg, thanks very much. I'm Lawrie Zion. I'm really chuffed now to be leading a discussion with Greg and with everyone who's tuned into this webinar today. As Paul mentioned before, if you've got questions, put them in the Q&A. And I'll be keeping an eye on those as Greg and I discuss some of the detail of this extraordinary project in the deconstruction phase of our discussion and a bit about what this project might mean more broadly for co-design between disciplines, between stakeholders and researchers-- and I can't help myself Greg-- digital disruption, which in my area of media has had such a profound effect on who sets the rules for what people consume, and who are the gatekeepers of media content.

And I couldn't help-- for someone who has no real experience directly with the way clinical trials are conducted-- but I couldn't help thinking, and hearing this story about all that, that there seems to be a parallel of sorts between what's happened in media and the phenomenon known as participatory journalism or user-generated content, and what we're seeing with this novel intervention that

you've led over a 10-year period. Do you see any of that in the way that the projects unravelled for you?

GREG MURRAY: Oh yeah, definitely. In fact, in our preliminary discussion about this, Lawrie, you really got me thinking about those parallels. To take that first one you mentioned, the participatory journalism, which I hadn't really thought about, but there are really strong parallels there.

What's happened in mental health over the last decade is an elevation of the consumer voice in clinical practise. But it has also now permeated across to research. And so there's no way you'll get a trial funded now unless you say the intervention's co-designed.

However, once you got past lip service to co-design, which is very easy to do, and do something like what we did, where because of the engagement challenges online-- I didn't really emphasise that in the talk. But everyone knows in our field that the problem with online interventions is no one finishes them. And the way I talk about it at conferences and stuff is, you do need to understand you're competing with Netflix, right? Someone's on their computer. Literally, they can go across to Bosch. They can literally go across to Ted Lasso, right? Literally, then.

So how are we going to compete with Ted Lasso? He's hilarious, right? And so the engagement piece is absolutely central. And so once you pay attention to engagement, you have to say, well, what could possibly compete with Ted Lasso?

And one thing that could possibly compete is people with the same experience as you speaking about their lives. Now when you do that, you get those lovely videos that I just showed you. And again, we're so grateful to the wonderful input of those consumers, but they end up authoring the intervention. They actually take it over in the same way as they motivated the trial in the first place. But then they start to take it over.

Now, to go to your point about participatory journalism. This shift towards emphasising the voice of the consumer is great and obviously has been wonderful for us. I think one thing that has to happen next, and I don't think we've sorted it out, and I don't know if they have in journalism, is we haven't worked out how to sort of calibrate the two different types of expertise.

So there's a contextual expertise that someone with bipolar disorder has that I don't have. But there's an academic and formal expertise about bipolar disorder that I have that a consumer doesn't. And what we say in a sort of facile way, is we're going to have both.

But in fact in the room, we don't know how to optimally get those two things to come together. And that's one of the things I'm really enjoying about today's discussion. It's forcing me to think about that interface because we don't speak the same language necessarily, these two groups of people. We share similar concerns, but we don't necessarily speak the same language.

And I think the same thing must happen with the New York Times journalist versus the participatory journalist. The guy with his video camera down at Elwood Beach when the shark comes in, he's got lots of local knowledge about Elwood Beach and what's going on-- contextualised knowledge. But the New York Times reporter has knowledge about slander, and appropriate balance, and other things that go with the formal discipline of journalism. And I don't know how that's been worked out

over time. But in my field of mental health, that's really a cutting edge, is how do you bring together the different expertises. And if you go--

LAWRIE ZION: There's a whole field of digital journalism studies which has emerged around these kinds of questions because it's gone way beyond the initial, oh wow, anyone can be a sort of citizen journalist phenomenon at the start. And one of the themes that you mentioned was the way that a lot depends on the platform, as well. And I had a question really about the videos to follow up on that because they-- you mentioned Netflix. They're very well-produced videos. They look great. The people actually look great. What's the editorial process? And what kind of expertise do you have on hand to film and edit, because I'm sure not all of them were doing all that on their first take, or maybe they were?

GREG MURRAY: So we didn't really have film-making or documentary-making expertise. We brought in an outside videographer. But the direction and the editing was just done by us without any expertise at all. And I think we probably did it inefficiently.

You're right. Don't those people look great and sensible? And you really want to keep listening to them talking. And that's how the majority of things looked. But of course, some answers, some commentary, was much more useful to us than others. And you reminded me, Lawrie, that's how documentaries work.

You might think you're going to film "The Rumble in the Jungle," right, because it's an exciting sporting event? But depending on what Muhammad Ali says, that story is going to go in different directions. We weren't conscious of that when we were trying to develop these edited videos, and I think we were very inefficient.

I think if we'd had someone on the team who was a documentary filmmaker, I'm sure they have skills and plans and ways of managing workflow that-- it's kind of like we had a-- what do you call it in a movie where you have the different-- we had a screenplay. What we didn't have was the camera angles. And we didn't actually have any actors doing the words. And we didn't know about the challenge of integrating those things. So if we'd had someone used to making documentaries, I suspect that what we found to be a very difficult juggle-- we need to say this, but they've now said that-- so we just had meetings.

LAWRIE ZION: Is there any other--

[INTERPOSING VOICES]

LAWRIE ZION: So how did you go about contextualising the material? Was it just the voices of participants in these materials that were--

GREG MURRAY: No. Thank you, Lawrie. So the videos we used to introduce the topics, in the mindfulness intervention there would have been, I think, about 20 of those videos you just saw, so 20 topics across four weeks of content, about five videos a week, and then there was text to support. So in each case there's content, there's information, there's online exercises-- how would

you like to-- have you tried mindfulness before, here's an initial mindfulness exercise for you to trial online, here's one for you to download to use during the week, and next week we're going to introduce you to a longer mindfulness exercise or a more complex one-- So there was a sequential adding of components.

So week one had one module. Week two built on module 1. But there was additional text online, exercises, tracking tools, things that people could use at home. But the videos perform the job of introducing the topic and explaining it in an engaging way. All the feedback from participants, I think we had like 95% said, you've made an engaging intervention, of the 300 people. So it definitely worked. The whole issue of engagement with online interventions is its own can of worms. But the feedback they gave us was-- what we ended up with-- was appreciated.

LAWRIE ZION: And what does that mean for the future of these kind of approaches within clinical psychology? You showed the slide when you were sitting in Boston and got the call and then the subsequent engagement you had again with the participants. But what in your heart now, a few years on, do you think the legacy of that project might be for further development of these kind of approaches?

GREG MURRAY: Well what I told the NHMRC, which I actually believe, is we got a null finding. What we proved was it's safe and it's feasible. So this was unknown. So we know you can carefully roll out, safely to one of the most vulnerable populations in mental health, a challenging self-management intervention irrespective of where they're located. So that's a big-- not a paradigm shift-- but a big advance for the field. You can do it. It can be done.

Participants said they really valued the intervention, so either in the control arm or the mindfulness arm. I think we had like 92% of people said they would recommend the intervention to someone else with bipolar disorder. So it's safe, acceptable, and the science is feasible. So recruitment's really easy. Risk management was not too stressful, though I used to have more hair. But you can do it.

I think it's a trailblazing study in terms of the platform. The actual content and some of the challenges around engagement, that needs to be improved. But that's why the paper, which has a null finding-- kind of hard to get null findings published-- has been accepted by the premier clinical psychology journal in the world, because of the implications of getting this thing up and getting it flying, and it landing safely, even though it didn't do what we wanted.

But it was pushing the online interventions for high prevalence disorders-- anxiety, depression, quality of life in the general population. They're everywhere. But pushing that into the serious mental illness space-- the suicide rates in bipolar disorder are higher than in any other mental health condition-- so to push it safely into that space, especially with innovative psychological content, I think that's really what we've achieved.

And there are a number of other ideas about what we'd do next.

LAWRIE ZION: I've got one of a production question before I throw it open. And if people want to ask questions or add comments, just a reminder, go to Q&A. And getting back to those clips that we saw, I mean there's obviously the kind of production potential to create actual television content, or

a Netflix docuseries, on bipolar disorder, and possibly not for all the reasons that we've already gone through with that particular group who've clearly undertaken these interviews with particular outcomes in mind. But do you think that such a direction would be desirable?

I think bipolar disorder perhaps isn't as well understood as other psychological conditions. Could there be both a benefit for people who have bipolar disorder and a broader benefit for community understanding if you were leading through a kind of mixed method of this sort of approach in TV production, some kind of programmatic content?

GREG MURRAY: I think that's a really good idea. I mean as a mental health researcher, I'm stuck in that old model of you don't actually deliver anything unless it's been proven to be evidence-based. So that's the tradition I come from. But I completely agree with you. Well, if you want to just actually impact people's quality of life, any way you can achieve impact is a good way. Innovation you have to be careful about. First, do no harm.

Just to say one more thing about that, if this had worked, if this trial had worked, the plan was that it just sits on a website. Right? That you do the five weeks active phase with some sort of support, but then you can return to the website at any time. So it actually is working like a media tool because you can go back to the videos, you can chat on the discussion board. So it actually becomes a website, not an intervention. It's a website with an initial active phase of engagement. But it was designed to be an empowering evidence-based social networking site for people with bipolar disorder, not through television but just through the web. But because we didn't get the positive findings, that probably won't happen.

LAWRIE ZION: We've got a question here, Greg. Can you share the video links with us?

GREG MURRAY: I don't think so, actually. They kind of sit within the clinical trial. So it's only in these formal presentations that I'm comfortable showing them.

LAWRIE ZION: OK. Thanks for that. Diane, do you want to just switch your microphone on?

DIANE SIVASUBRAMANIAM: Yeah, sure. I've just put a question in the chat. I have so many questions.

[LAUGHS]

I'll just try and restrict myself to one for now. Thank you, Greg. That was really fascinating. Given that you've now shown that this is feasible to do and that it's safe to do, do you now feel brave enough to repeat this with participants who are unwell initially, included in your example?

GREG MURRAY: Yeah.

DIANE SIVASUBRAMANIAM: Is that the next step here?

GREG MURRAY: Yeah, and in fact, we didn't find an effect. In post hoc analyses of the people who had some significant depression at baseline, both interventions were very powerful. So that's potentially fundable. So 100 people had-- they didn't have a depressive episode-- but they had significant depression at baseline, and they benefitted enormously. My concern is that might be a

regression to the mean. But once I've sorted that out-- yes. And yes, I am brave enough to do it in that population. And since then, it's-- good question and yes.

DIANE SIVASUBRAMANIAM: If I can be a bit greedy and have another question, Is that OK? It just struck me as so interesting, as you said, when we talk about knowledge translation, and we talk about getting stuff out of the lab and into practise, you have all these sort of principles that you're supposed to pursue in science. It's a very reductionist kind of pursuit, really. You're trying to find the variable that has an effect and that shifts variance one way or another in your outcome variable.

But when you translate that to people, I think what struck me watching those videos, is how messy people are. Right? So one person says, well this aspect of it works for me. And someone else says, well this aspect works for me. And you have to get so far down the road until you can actually parse that out into systematic variance. And given that you're still so far from that point of figuring out what's noise and what's signal, it just strikes me as interesting that you've then got this challenge of knowledge translation from the lab to people but then having to communicate findings back to the scientific community, where at the end of the day, what you go back to the scientific community with is a null finding. But what you're doing is just bringing in the messiness of people.

GREG MURRAY: Good question, and it gives me the opportunity to say something. The NHMRC in Australia is a conservative research funding body, and randomised controlled trials are still the way that they prefer to evaluate interventions of all kinds. Randomised controlled trial is a pretty good trial design-- it's essentially an experiment-- if you've only got one variable. So if you're putting either ointment A or ointment B on a cut, a randomised controlled trial is a good idea. But if you're talking to someone about their history of bipolar disorder and responding to how they respond to you and blah, blah, blah, blah, blah. The pill metaphor, or the ointment metaphor, actually does not apply to psychological interventions. It literally does not apply. We conducted an experiment, which is a randomised controlled trial, because that's the only way to get support to build these sorts of things.

Digital interventions, however, are moving us more towards the personalised mechanistic focus, Diane, that you're raising. Rather than pretending that everyone with bipolar disorder is the same, and your randomising into two groups, and there's only one variable difference between them, which is, of course ludicrous, there are all these different as those people you just saw.

In digital interventions, we do have the opportunity to make them adaptive. So this is another way in which digital is disrupting very, very positively. Digital holds the promise that you actually can adaptively offer content to people. So you can say, you're now in the mindfulness arm. Fill in this little questionnaire to tell us which area of your life you want to improve most in terms of quality of life. And you choose your own adventure. You go down that path from then on, and you tolerate, in your statistical analyses, that people didn't get the same intervention. They actually got different inter-- sort of clusters of intervention.

And what this reminds us of is public health interventions. It's not like ointment A versus ointment B. If you try and stop a country from smoking, you can't do an RCT. But you do want to evaluate whether your billion dollars was well spent. So it's a much more complex evaluation process with public health interventions than it is with psychological interventions. And people like me are

lobbying to highlight that psychological interventions are as complex as telling a country to stop smoking. Context really matters. Context of the person. Context in which they were doing the study. Context of their mental health at the time. So we need more sophisticated evaluation procedures than randomised controlled trials-- which you're absolutely right, are very linear, black-and-white reductionist, absolutely-- and work for some things, but clearly not for psychological interventions.

LAWRIE ZION: Thanks, Craig. Fascinating, some of the directions this is going in terms of what could be opened up by the approach from your study. We've got a question now from the audience, I think. And Monica, do you want to go ahead?

MONICA: Yes, can you hear me OK?

LAWRIE ZION: We can, thanks.

MONICA: Thanks. Wonderful presentation, Greg. I really enjoyed listening to that. And what you just mentioned then about the nuance within the context of the trial relates to my question about the importance of having qualitative research included in evaluations of these kind.

It reminds me of an RCT that we just led in my team where it was mixed methods-- also found minimal impact from the intervention. But the qualitative data provided us with so much rich information that the standardised measures, the quantitative measures, couldn't actually pick up. So the little signals that we got from the qualitative data actually showed that there was particular components of the trial that worked really, really well. And I was just wondering if that's your experience, as well?

GREG MURRAY: Yeah. Thank you, Monica. Exactly. And we did do exactly that. We conducted qualitative interviews over the phone with 30 completer-- you know that is 10%-- with 30 completers. So when we conducted those qualitative interviews, which was before the data was unblinded, so I didn't know what the outcome was on the standardised measures, we thought we had a hit on our hands. We thought, this is really rocking. People love this. And they were saying really interesting things about what they loved about it. They were saying things like, I felt better because I felt less alone with my bipolar disorder.

So that was the experienced mechanism of action, that they were sitting watching-- as Lawrie said, these nice looking people, speaking sensibly about their bipolar disorder, you're happy to identify with them, they've got strengths and other qualities and there they are-- and like you, they've got bipolar disorder. And like you, they've had lots of episodes. And it makes people feel better. So I couldn't agree more that more sophisticated evaluation methods are the way to go. And you're seriously wasting opportunity if you don't overlay multiple methods of evaluation, even if you are adopting the traditional structure of a randomised controlled trial.

MONICA: Thanks, Greg. And the impact of just being involved in a trial and having really nice people that understand you, measuring your outcomes over different time points-- I've often thought about the impact of that, as well, on experience.

GREG MURRAY: People really liked being in the trial,

[CHUCKLES]

every contact that I had with people. There were three red flag events during the trial of someone mentioning something about suicide. And I was the clinician on call. And I rang these people. One was in Botswana, one was in Ontario, and one was in Sydney. And they were so happy to hear from me-- you really are keeping an eye on this stuff, no I'm fine, I just had a bad hour or so, but I'll be OK, and thanks very much for all you've done-- people really felt that someone cared about their particular problem.

And because we obviously put a lot of effort into the look of it and it was all classy and everything, people thought, you really haven't cut any corners, have you? And they felt the care that went into the design, and the safety management, and the content. Every contact that I had with participants was they really felt valued by the creation of this product.

LAWRIE ZION: Greg, it's really fascinating to hear all the dimensions of this project. Unfortunately, we're about to run out of time. And I'm going to hand it back to Diana in a sec. But thanks to everyone for coming today and being part of this whole discussion about ORBIT. And my final one, if I can squeeze it in is, if you could do this all again, would you do it fundamentally differently from how you did it?

GREG MURRAY: There have been some innovations that we've learned from this trial. Fundamentally, the same-- some sort of digital intervention for this population. We do think that the mindfulness component adds something special, and the qualitative stuff told us that. But there are a couple of other things we'd do like, Diane raised, the tailoring to the individual to make it easier for them to make space for the intervention in their lives.

Something like 60% of participants said to us, I didn't have as much time to participate as I would have liked. Life got in the way. Illness got in the way. And we really need to-- this is the big thing with digital, it's cheap, it's global, but you don't have a therapist in the room saying, come on, do this thing. It'll be good for you. Do it. Concentrate. You don't have that. So we have to make up for that somehow. And some sort of tailoring we think is really important, and some level of symptoms to motivate you to prioritise behaviour change at that time in your life.

LAWRIE ZION: Greg, thanks so much. I hope that there is follow up. And there's certainly so many themes that you've raised today that speak to co-design being so much more interesting now that we're in the digital space. And the opportunities for collaborations are limitless. So thanks for being part of this today. I'm going to hand back to Diane now, and over to you.

DIANE SIVASUBRAMANIAM: I'm just going to wrap up, really, just with a quick thank you to everyone here. So first of all, a huge thank you to Professor Greg Murray for being willing to talk to us today about your project. What a great example this is of public interest technology. It's really important for us to be able to see how this rigorous STEM tech development is done with processes that are really fundamentally consultative. So this isn't just a superficial process of consulting with clients to develop a user-friendly interface, this is real co-design, from the ground up, of public interest technology. It's real consultation about the purposes of this tool, and the principles, and the operation of this programme. So thank you very much, Greg, for sharing this process with us today.

And to our audience as well, thank you very much for taking the time to be here. As we said, the purpose of today was to really demystify this process of developing public interest technology. We want to allow people to dissect and observe the process for themselves. And I hope you've come away from this with a bit of a clearer and a more concrete idea of public interest technology.

I'd invite you to visit the website of our public interest technology programme in the Social Innovation Research Institute and to register your interest in the Technology by Society Forum. We'll be resuming our calendar of events in the New Year. We'd love you to join us to further these processes, further these discussions. Whether or not you register with the forum, please do just keep an eye out for our events in 2022, which we'll advertise through Swinburne and through La Trobe. I'm just going to hand back over to Paul to close us out.

PAUL LAVEY: Thanks, Diane. So we've got a few emails if you want to reach out to Lawrie, Diane, or Sam. Their email addresses are here. I'll share the recording shortly after. Well, we look forward to seeing you at the next session. Thanks a lot.

[END OF TRANSCRIPT]