



## PODCAST TRANSCRIPT

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### EPISODE 8 – Julian Elliott

**Ray Moynihan:** Hello and welcome to another episode of the Recommended Dose with me, Ray Moynihan, today in conversation with Julian Elliott, the world travelled Australian doctor, researcher, and big picture thinker who aims to use new technology to radically improve health systems and access to evidence for people around the world, be they in high or low income countries. With positions at Monash University [00:00:30] and Cochrane Australia and a specialist treating people with HIV AIDS at the Alfred Hospital in Melbourne. Julian is also something of a futurist. So at a time when all kinds of websites, apps, and wearable devices are ingesting our health and personal data I asked Julian to set out what the consequences of this might be for all of us. Should we be concerned about how our personal data will be used or hopeful about the promise that this increasing deluge [00:01:00] of data holds for understanding and improving human health? What does it mean for us as individuals and for health research and evidence more broadly?

**Julian Elliott:** Well, I guess the final reckoning of the balance of positives and negatives is yet to come, but it think at this point it's clear that there are many, many, potential benefits for the way that we can better use data.

**Ray Moynihan:** But before we get to the future we look to the past to understand the origins [00:01:30] of Julian's deep and personal commitment to improving the health and care of people everywhere.

**Julian Elliott:** Yes, I guess this really started for me when I was actually a kid, when my sister had a chronic medical condition called Mixed Connective Tissue Disorder, which is a bit like a condition known as Lupus, and so she was quite unwell through her teenage years. And then, in [00:02:00] her early adult life, she was diagnosed with a condition that affects the lungs, some scarring of the blood vessels in her lungs, and she eventually died from that as a young adult. And what was clear then was that her death probably could have been prevented if she had received the right care as a teenager.

And I guess for me that [00:02:30] really started a pretty deep and existential interest in how can we avoid situations like that, how can we improve the care of people with different illnesses, and particularly an interest in the systems because, you know, in the end her death was an avoidable medical error. If someone had put a stethoscope on her chest and listened to her heart at an [00:03:00] earlier age she would have been diagnosed much earlier and could've had treatment and probably would have still been alive today. So that's probably the start of my interest in evidence and the use of evidence to improve healthcare and outcomes for people.

Ray Moynihan: I'm very sorry to hear that story, Julian. Does your sister's death ... is that something that stays with you? Does it continue to drive you today?

Julian Elliott: Yeah, [00:03:30] I think it does actually. I mean, I think for anyone who has lost someone close to them there's always a sense of their passing and yeah, I think for me it obviously operates at quite a deep level but I think it does help drive me in the things that I'm doing to try and improve the way we generate and use evidence to improve healthcare.

Ray Moynihan: So you trained as a doctor. Where did you train?

Julian Elliott: I mostly [00:04:00] trained in Melbourne. I spent quite a bit of time in the Northern Territory also working in Aboriginal communities there and I think, as many of your listeners will know, there's a lot of quite striking difficulties Aboriginal people have with their health and so, again, you know, for me, the thing that really struck me was that we can provide the sort of individual clinical care but you get a sense that actually to make a real difference you've got to look at the underlying systems [00:04:30] and try and make a sort of deeper or more widespread change to really shift the health of large numbers of people.

Ray Moynihan: So then in the, I think in the early 2000s or around that time, you ended up working in Cambodia, presumably in HIV AIDS. Tell me a bit about the experiences, what you were doing there, what you did.

Julian Elliott: Yeah, I went to Cambodia with University of South Wales and [00:05:00] originally it was planned that I would spend most of my time setting up research projects, but in fact, that took quite a time to evolve so over the first two or three years I was there I actually spent most of my time working with the Cambodian Minister of Health to set up HIV treatment programs. This was the era when effective HIV treatment was available in high income countries but was only [00:05:30] available to a very few people in low and middle income countries. So the disparities in access to care and outcomes were just extraordinary, just so striking and so disturbing. So at that time in Cambodia there was the largest HIV epidemic in Cambodia, oh sorry, Asia, and there were 25,000 people dying each year from HIV AIDS and, again, this was a time when in Australia most people [00:06:00] with HIV were on treatment and doing very well. So I was working with the Cambodian government. They had to try and get treatment out to people as quickly as we could.

Ray Moynihan: And how did that project go? I think many listeners will have a sense of just how difficult it was to get those medicines that were available but weren't affordable in low income countries. I mean, were you able to turn that around?

Julian Elliott: Yeah, I think [00:06:30] some people may have heard of an organization called the Global Fund, which was an extraordinary initiative by many countries to fund HIV prevention and treatment at scale in low and middle income countries, and that fund awarded Cambodia a very large grant to make treatment available. And that together with some very innovative Indian pharmaceutical companies, who dramatically reduced [00:07:00] the price of the HIV medications, meant that for the first time we had a real prospective of treating large numbers of people in countries like Cambodia. That gave us the resources to make treatment available. We then had to work very hard over a number of years to make that a reality, and this is really where my, I guess detailed, interest in the way that evidence is used came from because [00:07:30] I was working together with many very bright, very committed Cambodians who were working hard to get these programs set up and we knew that people were doing very similar things all around the world.

But it was very difficult at that time to try and find the evidence that we needed to make the right decisions. We were having to make decisions every day there at a policy level or into sort of detailed clinical [00:08:00] practice guidelines. But trying to find trustworthy up to date evidence to help us make the right decisions was extremely difficult. You know, in the end I was spending a lot of my time acting as a conduit between what you could think of as the knowledge of the world, the knowledge that the world is generating, and the many Cambodians who were working to set up these programs, and [00:08:30] it really struck me that you shouldn't need an expert sitting in the country doing that. These bright and committed Cambodians should be able to access that research evidence in a way that works for them, that is trustworthy, and it is up to date with the latest knowledge. But that just wasn't possible.

Ray Moynihan: Before we talk about some of the technologies and some of the plans [00:09:00] that you have to really address that issue let's talk a little bit more about your work as a doctor that you actually treat people, I think, in a clinic in Melbourne at the Alfred Hospital, you treat people with HIV and AIDS and you also help develop guidelines for the best way to treat people. Give us a sense of some of the challenges in that work and also some of the rewards in that work.

Julian Elliott: Yeah, it's very interesting. Now, for many people with HIV, they are on [00:09:30] treatment, that treatment suppresses the virus, so it doesn't get rid of the virus, we can't yet cure HIV but it does mean that for many people their physical health can be quite good, and for many people they have a normal life expectancy. Of course there are many people who are still affected by some of the effects of HIV from before they had access to effective treatment, so they're dealing with a lot of chronic complications of the infection. [00:10:00] But for many people now, and particularly the younger people who get onto treatment early, actually their physical health can be quite good. I think the greatest challenge for people with

HIV now is really about the social consequences of living with HIV and if anything, this may even be worse than it was in the 1990s.

I think back then there was a lot of awareness of HIV and I think many people felt very [00:10:30] empathetic and very supportive of people who were dealing with a life of being with HIV. But I think now our general awareness has decreased and in some ways ignorance has increased. So many, many, of my patients the major issues they have in their life is really about the stigma and discrimination that's still prevalent in our society, and that really impacts on their ability to navigate the world and particularly [00:11:00] to develop close friendships, relationship. You know, that has quite a significant impact on people's lives. They often become quite socially isolated.

Ray Moynihan:

As well as providing individual patient care, Julian Elliot devotes a great deal of his time and energy to employing new technology to understand, connect, and reshape the practices and systems used to produce, synthesize, and share research evidence, and he's been at the forefront of the development of what are called [00:11:30] living systematic reviews, that is online summaries of the best health evidence, which are updated as soon as new information becomes available. This concept of real time living evidence is of increasing interest to people who produce evidence, people who make guidelines, people who run health systems, and doctors and other professionals around the world as a way to connect different pieces of the evidence puzzle and make them accessible. I asked Julian [00:12:00] if this approach represents a radical departure for health organizations and researchers in terms of the traditional methods used to gather, analyse, and share their findings and what the implications of this might be.

Julian Elliott:

Yeah, I think it's a great question. I think what we see at the moment is there's the world of what you could call conventional evidence base practice. It's the world that has developed over the last 30 years by Cochran and others of systematically [00:12:30] making sense of research but alongside that, there's been very exciting developments in what's been called data science, which is about using more and more sophisticated techniques for using raw data. And often these data are generated, not through specific research projects, but just at what's called a data exhaust or they're generated as an incidental output from routine [00:13:00] systems. So for example, when you have a stay in the hospital of course a lot of data are generated there and that data can be captured and it can be used in very innovative ways for new insights, for understanding what happened to you, what the influences were on the outcomes that you experienced.

So those developments are very exciting but I think, at the moment, we do have a bit of divide between these two scientific communities and in the [00:13:30] end, that may contribute to ongoing confusion about the best way we use both research and data to understand the effects of healthcare interventions or other health questions. So one of the projects we're working on is developing systems that can draw those two communities together. It is in some ways a cultural challenge, it's very puny as it were of trying to [00:14:00] break down the barriers between different scientific communities and getting people to collaborate,

interact, and talk together so that we can have not a final consensus about the way we use all of these data, but at least a common language and a common way of approaching all of the rich outputs from research and routine care.

Ray Moynihan: Often I tend to see a distinction, if you will, between two [00:14:30] elements in sides, the innovation and the evaluation, and it's my sense that there's sort of a public appreciation of the innovation, the innovative, parts of science. But there's often not enough appreciation for the need of really good evaluation. It strikes me that what you're doing, in a sense, is bringing the two together. You're thinking of innovative ways. You're using technological innovation to actually improve evaluation.

Julian Elliott: [00:15:00] Yeah, I think that what we're aware of is that you can think of this connection between knowledge and practice is not optimized. I think of it sometimes as like a copper wire, connecting the world of research knowledge and the world of health systems and health practice, and to me it just seems insane that we spend billions [00:15:30] of dollars on doing research studies and we spend trillions of dollars on our health systems. And yet, we don't have the tools that are fit for purpose to make sense of all that research and connect the two in a way that will really drive the best health outcomes. I mean, I often reflect that if you ask someone in the street, you know, when you see a health professional, do you think they have [00:16:00] trustworthy up to date summaries of research evidence to guide the way that they provide care for you? And I think most people would think that's a given, of course, don't they? I would be surprised if they didn't. But I think that the reality is unfortunately we don't have the tools to make that a reality.

Ray Moynihan: So let's take this example of living evidence and using [00:16:30] technology to get this up to date summaries available. Take us back to the Cambodia situation and if you succeed in developing some of these new technologies and they rolled out, how could these new technologies help that situation back in Cambodia that you described where people were struggling to find information to help make decisions?

Julian Elliott: Well I think one of the most exciting aspects of this work is thinking [00:17:00] about how the research evidence can be delivered to people. So we ourselves are very focused on systematic review on this step of synthesizing research evidence into a trustworthy summary, but we work very closely with colleagues who are developing systems that can now take that research evidence and then, again, efficiently develop guideline recommendations [00:17:30] but then also connect through to other tools that people can use for their own decisions. So some of those are what we call decision aids, so they're sometimes visual or graphical presentations of research evidence so that each individual people, health consumers, can make a decision about their own health. So one of the challenges in Cambodia, [00:18:00] just to get into the specifics, is that there's an even greater asymmetry of knowledge about health than there may be in other settings.

And I think people in Cambodia really struggle trying to know what the best cause of action should be for a particular health condition they may have and are often dealing with limited resources and a lot of conflicting [00:18:30] views from say traditional practitioners, private practitioners, perhaps nurses or others they might see in the public system. And for my own family, we have many Cambodian friends who have unfortunately received very, very, harmful care in the end, very suboptimal. And I think ultimately if we can deliver a system, which means that everyday people [00:19:00] in Cambodia would be able to access trustworthy up to date, usable, decision aids that can help them make decisions about their own health based upon the world's research knowledge, I think that would be a fantastic outcome.

Ray Moynihan: Do you think that will happen?

Julian Elliott: Yeah, I do, actually. I do. I think that we have the foundations for that already [00:19:30] in place. We've got some examples of where we can take research evidence through systematic reviews and guidelines into those decision aids very efficiently and we know from a lot of research evidence those decision aids can also be very effective in helping people make the right decisions. So we have the foundations there.

Ray Moynihan: [00:20:00] You're listening to the Recommended Dose with me Ray Moynihan. Our guest today is Australian Doctor, researcher, and technology aficionado Julian Elliott.

You're talking a lot about technology and for some of this can be quite scary. I mean, I think there are apps now that will actually diagnose people and in fact, someone pulled out their mobile phone the other day at a meeting where I work and they started recording people's voices and diagnosing the [00:20:30] emotional tone or even the mental state of that person, and I think there are apps now that do in fact diagnose. I mean, is this technology gone mad? What do you think?

Julian Elliott: I think that technology is clearly going to make an enormous contribution to the way that people are diagnosed and managed in healthcare systems, there's no question. And I [00:21:00] think really throughout the systems there will be very positive impacts from technology. I think that what you're touching on is this concern about the capability of machines that seem to be getting to a point that are perhaps human like or superhuman, and I think also concerns about who controls those machines and particularly who controls those data. And I think those [00:21:30] concerns are very real. It's really incumbent upon all of us to get involved in the discussions and the process that will really shape the way those technologies are used. Any technology will produce both benefits and harms and of course, what we need to do is work to maximize the benefits. And so a lot of that is really about our societies and our governments [00:22:00] really getting into the detail and understanding what the capabilities of these technologies are now and the way that they're heading, and starting to construct the sort of policy dialogue about how do we want to manage and best use those technologies.

And I think it can't be from positions of heights nor of ignorance. It has to be from the position of sort of informed analysis. [00:22:30] And so getting consumers and getting healthcare professionals and policy makers involved in technology development and involved in the discussions about how they're used I think is a critical aspect of that.

Ray Moynihan: You're also leading a very innovative attempt to engage citizens around the world in the production of good evidence. You've helped set up this thing called Cochrane Crowd as an example [00:23:00] of citizen science. Tell me a little bit about what that is.

Julian Elliott: Cochrane Crowd is a website where anyone from around the world can go and contribute to the work of systematic review. So I think, as it would be clear from our discussion, we're really struggling to produce systematic reviews and keep up to date with the deluge of new research. And one of the ways [00:23:30] we're now doing that is to send out a call for help, to really call on people of the world to help us do this, to help us make sense of research in a way that is very rigorous and trustworthy so that people themselves can make the best decisions and also health professionals can also provide the best possible care. So what it involves is people going to the website, doing very [00:24:00] brief training, and then starting to do some of the key tasks that are required in systematic review.

Ray Moynihan: And I think I'm right in saying that you've had thousands and thousands of people volunteer. It seems like an extraordinary success.

Julian Elliott: Yeah, that's right. I mean, I think many people work in the area. We'll ask the question why would anyone in their right mind go to a website and start categorizing [00:24:30] research in this way? But I think that people are very interested in making a contribution and really helping us to make sense of research. And in addition to the task I just described there are more and more tasks being developed and put onto the Crowd platform, including tasks that involve describing the topic of a research article or helping to extract information [00:25:00] from a research article or from a table or a graph. And this is a very, very, real contribution. The work that the contributors do on the Crowd platform directly affects our ability to synthesize evidence in a way that's trustworthy and then supply that evidence for health practitioners and others around the world.

Ray Moynihan: From [00:25:30] working with citizen scientists, patients, fellow researchers, and leading data scientists to traveling, presenting, and writing Julian Elliott is clearly a very busy man. I ended our conversation by asking just what it is that sustains his relentless pace and all his work to change the worlds of health and evidence.

Julian Elliott: I think I'm pretty driven. I don't actually have a hobby. I do keep fit by cycling but [00:26:00] I think the thing that really sustains me is this sense that the problems, which I have seen for many, many, years, what I can see now is that they're shifting. That's what really excites me and I think really drives me towards contributing to this work. We talked earlier about how I guess it has effected me personally and the sense I get that we will [00:26:30] soon be able to have

systems that can much more readily drive health practice with high quality, trustworthy, and up to date research evidence, you know, really excites me. And I don't have any trouble getting motivated in the morning to continue to work on that. I think it's a very important challenge for healthcare systems around the world and I think we have a very real chance of making a [00:27:00] difference and creating a system in which I think will dramatically improve the situation we have now.

Ray Moynihan: Julian, it's a rare and very fine opportunity to talk with someone who is very positive about the future for all of the right reasons, so thank you very much for your time today.

Julian Elliott: Not at all. Absolute pleasure. Thank you.

Ray Moynihan: That was a conversation with Julian Elliot and it was the final episode of the Recommended Dose for this year. [00:27:30] And thank you to everyone who has been listening to these conversations. If you've enjoyed them please subscribe to the show, rate and review us, or recommend the Dose to others. You'll find all the episodes on Sound Cloud, iTunes, or wherever you listen to your podcasts. Thanks to producer Shauna Hurley, editor Jan Muths and to Cochrane, Australia, the funder of this podcast series. We've all very much enjoyed bringing you these conversations with some of the world's leading health researchers, writers and thinkers, and we look forward to sharing more of these conversations with you in Series Two of the Recommended Dose next year. I'll get out of your way now. Cheers.