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## Ethics in Qualitative Research: Leslie Cannold on becoming an ethical researcher

### Speaker information

- Sohail Jannesari (Interviewer) (Sohail)
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[downtempo electronic music 00:00:00—00:00:10]

00:00:10 Sohail Hi. I am Sohail, a qualitative researcher on migration and mental health. And I'm very excited to host the Qualitative Applied Health Research Centre's *Qualitative Open Mic* podcast. Today is very exciting because we are starting a new series on ethics in qualitative research. So, this series aims to highlight positive ethical practices in qualitative health research, particularly with marginalised groups. And we want to think about the difficulties in doing genuinely ethical qualitative research. So, today we're very, very lucky to have with us Dr Leslie Cannold. Would you like to introduce yourself, Leslie?

00:00:48 Leslie Yes. And thank you so much for having me, Sohail. My background is in ethics. So I've done a master's degree in medical ethics after I did a psychology undergraduate degree. And then I did my PhD in social psych as well. And so, a lot of my research in my early years as an academic was doing what they now call moral psychological work. So, I was looking into kind of the empirical elements of how people behave ethically and why sometimes they don't. And since then, I've chaired a lot of ethics committees. So, I've had some very practical engagement with actually the doing of ethics and the creation of systems to ensure that ethics gets done—probably most notably for your listeners at Marie Stopes International; I was running their ethics committee for many years. And also at the health department here in Melbourne, Australia. And now I am the Head of Programs at the Cranlana Centre for Ethical Leadership. So, there's a lot of ethics floating around. And I'm hoping I can help you to sort of lay some sort of foundation, and—in terms of thinking about ethics for qualitative health researchers.

00:01:55 Sohail Brilliant. Thank you so much. Yeah. So, this episode is a foundational one, looking at why are qualitative ethics even important? Why should we be talking about them and not perhaps have them as an addendum or a sort of afterthought, even? Why should we centre them? So, I'd just like to ask and start by asking, what are qualitative research ethics? You know, where do we start? How do we define them? What is qualitative research ethics, specifically in a health context?

00:02:28 Leslie Well, I guess my general feeling about it is that there's nothing particularly magical or special about any type of research—or in fact, any type of practice. You need ethics because sometimes people do the wrong things. And sometimes people do the wrong things because they're accountants. And sometimes people do the wrong things when they're researchers. And sometimes people [chuckles] do the wrong things because they're, I don't know, car parking attendants. Unluckily, there have been so many high profile and quite terrible abuses of power that have happened in the quantitative medical field that research has become one of the few areas where there are formal requirements, at least for some areas of the workforce, to take ethics into account. But if you really understand what ethics is, it's, you know—if you live in a cave and you never have any contact with another human being, ethics is not really a concern of yours. Because ethics is really about the relationships that you have with other people and trying to regulate them and ensure that they're not exploitive or harmful. 00:03:30 And that they are imbued with trust and all of the other elements that make for good, respectful, positive relationships with other human beings. And so, we need ethics and qualitative research in the same way we need ethics pretty much everywhere. I can go on and definitely talk about, you know, how quantitative and qualitative methods may require slightly different approaches. But in general, I'm an ethics enthusiast. So yeah, I definitely think we need them.

00:04:00 Sohail Great, thank you. So, there's nothing—there's not a different philosophical approach to thinking about research ethics versus legal ethics, for instance?

00:04:10 Leslie There's not a core difference. So, when we tend to think about what is it that makes human relationships work, what is it that makes them productive? What is it that

makes them non exploitative? What is it that makes them operate in a way that nobody gets harmed? Those are general kinds of principles. So, if you're in banking, there's probably more open discussion about, you know, fiduciary responsibilities. If you're a professional, you might be focusing on the suite of things that a professional in a particular area needs to do. And research is very much like that. There's a certain level of—there's a certain patten of the way that we work when we're researchers that are going to reliably bring up certain kinds of ethical issues. But in terms of a broad way of looking at those ethical issues, they're all really the same. They all really come down to, "When you interact with people, you need to be careful to do no harm." That's a baseline. That's similar if you're a medical professional, as it is if you're any kind of researcher, including a health researcher. Because you're capable of actually doing both physical and emotional harm to people. If you are a researcher, there's going to be a process where it's going to be important to ensure that people understand clearly what it is that you're proposing to do, so that they can provide an informed and a voluntary consent to that interaction. But then again, that's pretty similar to contract. The notion of a valid contract goes to this idea of, you know, is there a very clear offer? And was the person, you know, of right mind and competent and capable to accept that offer, or else the contract tends to get nullified. So, in fact, there's a lot of overlap and similarity which go to the kinds of things that can go wrong in human relationships no matter what domain you're operating in.

00:06:01 Sohail

Brilliant, thank you for that. That kind of made me think of the sort of parallels between consent in research practice and consent in relationships. And in the lectures that I give around ethics, I find that analogy really powerful. That there's a lot of conversation around relationship consent, consent around sexual harassment and assault. And actually that really, really helps students to think about what it means to have proper consent in research ethics. So, is that something that you, in your sitting on ethics committees, do you draw often a lot on different practices from across different areas? And is that something that's useful in helping people think through ethics?

00:06:45 Leslie

Well, look. I spend a lot of time trying to get people to think through ethics. And I very much will always be adapting, you know, what I'm saying to kind of what the level of experience is. But certainly, one of the most profound experiences I had when doing ethics was when I was at Marie Stopes. But I was asked to do a job by somebody who had used to be at that organisation and then had moved on. And they were working with a group of community-based activists in Lambeth. And it was very, very interesting for me to be able to go in, speak to those people, have a feel for kind of how they felt that traditional ethical frameworks did and didn't really work, and were going to work and were not going to work for the communities where they wanted to do research. And I remember that after we did a lot of, you know, sort of deep talking about what they felt were the core ethical principles that were going to need to be in place for them to be able to go into communities that were really quite exhausted—they'd been over-researched. There had been a sense that the research had been very extractive and that people had just given and hadn't got anything back. 00:07:49 So there was a lot of loss of trust. But at the end of the whole discussion of speaking about the various principles of autonomy, and voluntary and informed consent, and non-maleficence, which just means don't do any harm, and beneficence, which just means trying to do things that benefit people. A lot of the reaction of the people [chuckles] in the room was to say, "Gosh! This just explained so much to me about—" and then it was just a cascade of things, you know. "About what my experience of feeling exploited as a Black person has been." We can assume that people have the kind of words and lexicon and linguistic fluidity around ethical terms. And yet, just as you're pointing out in this example about the ways in which things can go awry in sexual encounters, we don't actually have a very good vocabulary and fluidity of thought and understanding around ethical relationships. 00:08:48 We take a lot of stuff for granted. We think we understand how it is that you treat people properly. But often we're quite confused. We think, you know, saying 'please' and 'thank you', which is just etiquette and not ethics, is, you know, the answer to how you make relationships go smoothly. Sometimes we think the best thing to do is not to talk about things, even when in fact, you know, they're sitting under the surface and desperately need to be spoken about. So, I think we're so immersed in relationships that we think that means we know

something about how they work, but often we don't. And so, I think one thing that has struck me time and time again is that when you teach people ethics, no matter what the context is—whether it's the context I'm in now, which is about leadership, whether it's the context of talking about qual research or quant research, they always end up feeling very enriched and with a kind of lexicon and set of understandings and vocabulary that allows them to understand ethical relationships in a much broader context.

00:09:45 Sohail

Thank you. That's really beautiful. And something worth considering, I think, when you do research, that actually engaging people in an ethical process has potentially benefits on how people interpret their experiences in their lives. And having that in mind is going to be really, really important, I think. So, you've mentioned this qual/quant sort of divides, let's say, a few times now. And you mentioned that a lot of our medical ethics are perhaps coming from mistakes that were made in quantitative studies. Not that qualitative studies don't make many mistakes either. But it would just be good to hear a bit more about that, and how, perhaps—what are the implications for qualitative health researchers that there has been a strong quantitative influence on medical ethics?

00:10:33 Leslie

Sure. So, I mean, prior to the Second World War, there was no such thing as ethics, formally, of any sort. There was a whole bunch of assumptions that people who were in respected positions like medical researchers would do the right thing. But what we came to understand is that, yes, most of the time most people do do the right thing. But sometimes people don't. And those people should, they have a lot of power and a lot of trust can really do a lot of damage. Well, first of all, we had the nightmare of the Second World War and Dr Mengele and his twin and dwarf and other horrendous experiments. Which I think was a huge shock to people, that somebody who was a medical doctor—you know, it's something that was often said in hushed tones, "He's a medical doctor," you know, could do something like that. And prior to that, we'd had the Tuskegee Syphilis Experiment in the United States, the Willowbrook, the Jewish Chronic Disease Hospital. And all of these incidents were examples of where medical professionals who were very interested and ambitious, and often very well-meaning—and this is very important to remember: who actually thought they were doing the right thing to be using populations that they thought it was fair enough to use, even though they were populations that were not fully voluntary because they were often institutionalised, or they lacked education, or they simply hadn't been given any informed consent, or all three of those things—were being used to undertake medical research that was, potentially, you know, that doctor thought, very important, but was causing harm and perpetrating exploitation that was really just unforgivable. And when the whistle was finally blown on those events, there was this awakening. And I think it had a lot to do with the post-World War II environment and the sense of horror at what human beings could do while telling themselves they weren't doing anything wrong. When what they were doing was so unbelievably, outrageously, unequivocally, [chuckles] dangerously, terrifyingly wrong. And that is a disconcerting experience, especially when the people doing that wrong are people who you think can be trusted and have been given trust by society. There was a sense that something had to be done. And so initially there were just codes of ethics. And there was an assumption that people would just follow the codes. We now know—I mean, we're all very experienced, sophisticated, your listeners would be—that you can't just roll out codes and expect people to follow them. I mean, sometimes people will read them, and sometimes they'll understand them, and sometimes they'll implement them. But often they'll do none of those things. And so eventually, there was a recognition that there had to be committees. And those committees had to ensure that the requirements around ethical research were enforced. And those core requirements are things that apply both to quantitative and to qualitative method research. So, they're things like 'non-maleficence', which basically means do no harm. They're things like 'beneficence', which means that you need to be benefiting people, or at least not doing any harm. But preferably providing some benefit for them in terms of being involved in the research, even if it's just the satisfaction of knowing that you might be doing something that will help someone else in your situation or with your condition. 'Justice'. So there needs to be a fair distribution of benefits and burdens. There's been a long history—and this is

much closer to the time of people who are listening to this in our own era—where there's been a tendency to use populations in less advantaged countries, say, to test drugs that will never be affordable or available in those countries, in order to release white and more privileged populations from the burden of taking the risks of the research. You outpost the risks and the benefits come back to the wealthy country. So all of those things ethics tries to speak to. And even though it is less likely that you see some of the capacity for exploitation in qualitative research, I think all four of those core ideas are incredibly important as an A, B, C lexicon, and understand the different things that come out of them. So, for instance, out of autonomy, which is about respecting people's right to live according to their own values, comes informed consent. So, if you want to respect my idea about how I want to live my life, you need to make sure that I have capacity. And then you need to fully explain to me what it is you want to do, and then you need to respect my decision as to whether or not that falls in line with how I think about my life, rather than what's useful for you in terms of my participation.

- 00:15:21 Sohail Great, thank you. That's a very, very useful overview. I kind of wanted to ask, we often start our histories of ethics, you know, either around World War II or a little bit before. And you know, we've just done, for instance, a series on anti-racist qualitative health research. In that sort of spirit, I wanted to ask, is this a very Western framing of ethics? People were presumably producing knowledge across the world. You know, maybe it didn't look exactly like the sort of university research, perhaps, that we're used to, in the sense of knowledge production. But people were producing knowledges. And there presumably was ethical practices and principles and codes in many parts of the world and many cultures. So, is there something that we are missing with this ethical origin story? That's my question basically. Is—you know, are we a bit Western-centric when we tell the story?
- 00:16:19 Leslie I'm sure that we are. [laughs] Because we always are. There's certainly no corner on powerful people exploiting more vulnerable ones to get things from them that those powerful people want. And sometimes what those powerful people want is data and information that helps them to build their own careers as researchers. And certainly, that is by no means restricted in terms of what Western researchers were doing in a whole range of places outside the borders of the United States. But I think your question was also kind of driving at are there other sorts of ethical knowledges? Is that what you were going for? Is that—you know, are there other people besides Westerners who have tried to think about and systematise ideas about how you can undertake knowledge practices without being exploitative or otherwise crossing the ethical lines? You know what, I don't know. That's the sad answer. I truly don't know.
- 00:17:13 Sohail Well, thank you for being honest. And I think it's good to ground some of this discussion in—basically you're talking about imperial—imperialism and I think that's important to sort of acknowledge, that there were—there was very unethical research happening during British colonialism, for instance. During all sorts of colonialism. So it's nice just to think about how this story—we might start it at various points, but it is an ongoing long history of an ethical practice. So I appreciate that.
- 00:17:45 Leslie Can I just say, Sohail? Thus it has ever been. And that is what is so extraordinary about institutional ethics. For all its shortcomings, for all the things that we think need to evolve in terms of our current practice, it is really extraordinary for us to try to draw a line under the kinds of exploitation that have been going on for so long. Because we have always operated in ways that essentially have centred power and the powerful. And they have always seen the rest of us as fodder. Women, children, people of different colours, people of different faiths. Whoever was being othered at the time was always seen as fodder. And research, in its formalised kind of capacity as I have experienced it, is a relatively recent phenomenon in those, you know, millennia of history. But I think it's important for researchers not to see researchers sitting outside of that global history where the powerful exploit the powerless. And if we're going to stop that, we need to have a look at those relationships and we need to try to put some kind of break into how it normally runs. Because that's how it normally runs.

- 00:18:57 Sohail I was thinking universities may partner, for instance, you know, in a health context, with a pharmaceutical companies to conduct research. And so, perhaps I can see in a university context, maybe it's easier to commit to a redistribution of power because you're ostensibly a non-profit organisation. But what happens when universities and researchers start working more with commercial interests? Is there a risk then of some of these ethical principles being undermined?
- 00:19:32 Leslie Yes. Yes and no. So, on the 'no' side, you know, there is just as much of a rigid institutionalisation—again, I have to just stick to Australia—of ethics frameworks within Big Pharma. In fact, I've worked briefly in kind of clinical ethics environments. And on the one hand, they've ripped the heart and soul and blood and pulse out of ethics. Because it is so institutionalised that in some ways I don't think anybody other than, I don't know, the person creating the form up on floor twenty-seven actually understands a thing about what it is they're asking about. And yet the processes do, very much, kind of even in a robotic way, ensure that there is informed consent, ensure that there is pre-screening. They're worried about legal liability. They're worried that there'll be something wrong with the study and that it'll discount it and discredit it and they'll lose money. I don't necessarily think the motivations are there in the way that we tend to think of ethical and moral motivation. But there definitely are very rigid processes that enforce 'the rules' as we've understood them in terms of ethics. You know, there must be informed and voluntary consent. You must know the person has capacity. There must be a fairness in terms of the way that you distribute benefits and burdens. But at the same time, I think there is a bloodlessness about the way that we go about ethics because it has become so institutionalised. And I guess the older I get, the more I tend to see everything having, you know, an upside and a downside. And I think the upside is that everyone accepts in almost kind of like a knee-jerk twitchy way that you can't do any research without getting ethics approval. Because it means, at least, at the very, very least, there is another set of eyes on your research. It's another set of eyes that looks at whether or not you are using a method that is going to produce valid results because otherwise you're just wasting people's time. And it's a process that asks questions that would never otherwise be asked, about, you know, "Is it really fair to recruit from this group of people? They're kind of over-researched. Maybe you should be recruiting from these people." It's an important interrogation process that in some ways researchers find irritating, but it's because it is another look at your process. So, I do think that is terribly important. But on the other hand, when you institutionalise things, they become very ritual. And I guess what I was just describing [chuckles] about what happens in kind of a clinical research area is a really good example of that. Like, it doesn't feel like anybody cares that someone isn't exploited. It's more that we have such efficient rules now that try to get at non-exploitation that most of the time, even though they don't care, they'll end up not exploiting people because they've kind of got a set of rules. But when we think about ethics, we tend to think about it being kind of the heart and soul of what matters about how we relate to others. And so there feels like something kind of is lost in the translation of the imposition of all these structures and rules. And especially when you're a qualitative researcher, which I have been, sometimes you can end up feeling like all of this well-meaning, well-rehearsed stuff doesn't really fit what you are trying to do in a way that would be ethical, but that you don't have the freedom to do it that way.
- 00:23:07 Sohail Thank you for that. Could you maybe expand a bit upon the point of what qualitative researchers might feel? So, we talked a bit about, yes, maybe there shouldn't be a difference in ethical principles between qualitative, quantitative research. You know, can you talk a bit more about why qualitative health researchers might have to grapple with these things more? Is it about the methods? Is it about the sorts of people [chuckles] who do qualitative researchers? Is about the topics? What is this tension and why is this tension important to qualitative researchers?
- 00:23:41 Leslie I guess my experience of qualitative research and qualitative researchers is that we are much more intimate and up close and face-to-face with our participants. So again, I've been in a kind of, you know, medical research sort of factory, you know. And there there's so many different people who have contact with their participants. And there's

so much pre-screening. And there's so much—it's so—it's like a factory. You know, this person pulls the bloods, and this person does the consent, and this person does the pre-screening, and this person does the follow-up call, and.... There there's not an intimacy of connection. And typically, a qualitative researcher is not in that kind of clinical research kind of mode. [chuckles] They're just the one person, or maybe there's a few. They're having a personal and an intimate relationship with the people who they're researching. And that means that even though I do think those, you know, four core values—those four core virtues of autonomy and justice and maleficence and beneficence do matter. I think you can find in particular populations that other things matter just as much or perhaps more. My first kind of, I guess, window into that was when I was, you know, getting my own doctorate. And having the experience—I've always worked in sensitive areas. So I've researched on abortion. I've researched men who have HIV back at a time when that was a death sentence and looked into their intimacy needs. I've spoken to women who don't have children and who actually wanted to. So, I'm always in kind of areas where there's a lot of sensitivity and I'm acutely grateful for people's willingness to, you know, let a stranger into their house and, you know, spend two hours telling and talking about something that is so intimate and painful for them. And my experience of trying to do something which, in the abstract, I totally agree with, which is informed consent. Okay. I don't want that person to be under any misapprehension about what I'm there for, what I'm going to do with their data—also what I'm not going to do with their data. But what I'm there for. And if they're not competent, I don't want them agreeing. So, I like that kind of theory of the protection. But what I was finding in practice was I would come through the door, they would welcome me, they would give me a cup of tea, I would start to form, you know, some rapport, I think is the, you know, terminology. I build some rapport—which really is just a way of saying 'starting to build some human to human contact and trust'. And then I plonk down [bangs table] this horrendous form, which completely would throw whoever it was just back on their heels. Because now what I think is they were thinking, "Oh, I thought we were building a relationship of trust. I thought this was about trust, and you were letting me get to know you a little bit so that I could decide if I wanted to trust you. And now suddenly [bangs table] it's not about trust. It's about contract. We're not talking about trust, we're talking about contract." [bangs table] And they sometimes [chuckles] would look at me and they'd go, "Should I sign this?" [laughs] So, you know, I created enough trust that I was now, you know, the person who they were turning to for advice. And of course I can't, you know, back to contract, I'm conflicted. I can't advise them as to whether or not to—it was just a mess. So that's one area in which, you know, you can immediately see that even though the intention around informed consent is spot on and completely correct, there must be other ways by which you can assure yourself that someone has capacity, fully understands what it is they're agreeing to, and is agreeing to it in a voluntary way, without having to go through a legalese kind of a form. Because those forms are not really what informed consent is about. So, in some ways, you know, what I think qualitative researchers like me object to is not so much what informed consent is, but what we've turned it into—big institutions have turned it into, like universities—which is a contract. It's not meant to be a contract. It's not meant to be a contract in quantitative research or qualitative. It's meant to be a conversation. Informed consent is meant to be a conversation. It's an engagement in which you ask me questions, and I tell you information, and you stop me if you're confused. And I make sure that you really are on board. And we're both tickety-boo that this is actually something that that should go ahead. But we end up being concerned, you know, we don't have a signature. We don't have proof that we went through the process. And what if somebody calls us up and says, "Oh, you know, you didn't give me informed consent." So, we we're all worried. So now we have to have signatures on forms. And it just kind of spirals down from there. And the other thing, if I could just bang on for two more seconds. Is that I think that there's certain populations where—and this was very much the case when I was, you know, speaking to the community-based researchers in Lambeth—is that they felt like this was such a vulnerable population. And that there—because they were of that community, they were able to speak for that community. And when we started exploring what the core values were for them, what I asked them was, "Okay, if somebody was going to come into your community and ask your fellow members of your community, and perhaps ask you, to consider taking part in research, how would you like them to do that? How

would you like them to behave? Where would you like to be asked? Where would you not like to be approached? What kinds of things would you be interested in? What would be important about their attitude and the way that they spoke?" And the answers were, you know, very, very unique, I think, to that community—or maybe not. I just don't have a broad enough experience to know. But what felt right to me was to ask those questions. And what you ended up with with that particular group was a lot of talk about trust—so just what I've just spoken about in terms of that trust piece and not contract, but trust. And a lot of talk about respect and regard. Which is not out of left field in terms of your standard ethics values. So, respect and regard are very much in the justice/autonomy basket. But the way in which those were centred because this was a community of people who had not felt respected, who had not felt regarded. There was a sense that on the one hand, they'd be thrilled to bits to have people ask their opinion because often their opinions were not considered important. But at the same time, they would need to know that this was not just a 'tick a box' exercise. That there was not just people coming in to grab stuff for themselves that was never going to come back to the community, or just tick a box and not have them be listened to at all. So, there was something very important for this community because of its very specific instance of being over-researched that there needed to be more like a beefing up of the ways in which researchers showed respect. They wanted that little bit of assurance that this time it was going to be different. And that seemed totally fair to me. And a situation where if you didn't know that specifically, you could really get your ethics process not like wrong, exploitative wrong, but like wrong to the left of what was needed.

- 00:31:09 Sohail Thank you. So, when you were talking, I just thought that maybe one of the issues is that our ethical principles are imposed from top down. So, they're imposed by universities, or companies, or ultimately governments and government legislation, I imagine. But your project which you spoke about, in Lambeth, took a more bottom-up approach to ethics. So, do you think there's something about how effective ethics are?
- 00:31:40 Leslie I think if I was to say to you, "How can I make this go the way that you'd like it to go? How would it go? What would I say? What would I definitely not say? What would I do? What would I definitely not do? What's the attitude you'd like to see me come in with?" I mean, those kind of open-ended [chuckles] conversations are just so valuable. And I suppose, you know, in a charitable way of thinking about the ethics that we've got, while they didn't come out of conversations like that, you know, they looked at a disaster scene and they went, "Okay, we've now looked at all the terrible, terrible things that have happened. And we're now going to build a kind of set of defensive principles that sort of say, 'Absolutely no to this. Don't even think about that. You must do this; you must never do that.'" They're sort of the floor for what not to do in order to ensure that you have a baseline of ethicality going on. But there's more. You know, there's more to what you could nurture in that relationship. Because I think often people who do qualitative research—certainly I was like that—the last thing we want to do [chuckles] is do any harm. We're actually trying to do some good. And so there must be ways that we could do better than just kind of that lowest common denominator. But I do think the initiatives that we have here in Australia, for instance, around Indigenous ethics, those have been very, very broad based consultative engagements in which the Indigenous community has been able to say, "Look, this is how we operate. We don't like it when you do that. If you're going to come in here, we want you to do this. it's really important to us that you don't do that." And it is an alternative set of ethics. Is it, you know, unrecognisable as research ethics? Not at all. It's very recognisable. But it's—just as you said, it's got kind of accents in ways that reflect the particular cultural preferences and concerns of that group.
- 00:33:43 Sohail You know, in terms of helping researchers, what should be the focus for, you know, ethical guidance?
- 00:33:50 Leslie Look, there's a couple of different approaches. So, let's jump to where I am now. What I do now is I train people to be ethical leaders. There's no longer any kind of reliance in the work that I'm doing in broad guidelines that everybody who's doing X has to follow. Instead, it's much more individualised. It's much more talking about—you know, just

the way you've passed all the tests so you get a master's degree, and then, you know, I don't have to breathe down your neck any more to make sure that you know how to write a paper. It's kind of the same thing. And I think—I certainly think that one way of getting out of the bind that we have experienced around ethics and its institutionalisation and the limits of that is perhaps to just kind of think of a completely another way that you might reassure yourself that the researchers that you send out under your name, you need to make sure that those people are not doing any harm. But I think you could accredit people. Like that would be another completely different approach. And so, they would come, they would take maybe a short course. You would ensure that they're the kind of people who have understood the foundational thing that we're trying to achieve here, which is making sure nobody gets hurt. Making sure people are treated with respect. Making sure that trust is engaged. Making sure that people are not taken advantage of. That there's no exploitation. All of these broad general ideas of how you treat other people with respect and with dignity and ethically. And then you could just send them off. And maybe they wouldn't have to come back for another five years when you'd, you know, kind of update them and accredit them again. That's the only way I've ever been able to think about it. As a process where you could give an institution an assurance that this person is going to be capable of doing this tricky task. It's tricky. For me, that's the only way I've ever been able to think about how you could get around this very cookie cutter and rigid way of constraining all researchers under one pretty standard package umbrella.

00:35:59 Sohail Great. That's a really interesting idea. And hopefully we can explore that a bit more later in the series. Thinking about being very tailored around an ethical approach, but also having to have perhaps broad ethical guidelines. And also getting into, if you had an accreditation system, who would do the accreditation? Who has this moral authority? And I think that sets the scene really nicely for the rest of our podcast series. So, are there any resources that our listeners should look out for, particularly around your work, if they want to find out a bit more?

00:36:32 Leslie I have not, interestingly, written all that much about research ethics. I've written a lot about abortion, informed consent in *Hypatia*. And I've got a few things that are connected to HIV. And I've also written a couple of books. So, I've written a book about abortion, which people can find. And I still don't think it's all dated, given everything that's happened. It's extraordinary. It should be terribly dated. But unfortunately it's not. So, people might still find that relevant. I've written a book called *What, No Baby?* which is about women who don't have children and the different kinds of reasons that that ends up happening apart from infertility. And I've written a novel, which is called *The Book of Rachael*. Which is a kind of Shakespeare's sister kind of imagining about the sister of Joshua of Nazareth. And my background's Jewish. So, you know, it was kind of an imagining of what that Jewish girl's life would've been like, having such a famous brother and not herself being able to be educated or really considered to be much more than a sheep at the time, which is what the her name means. That's what 'Rachael' means. It means 'ewe'. [laughs] So, I've kind of gotten around, I guess, in the different ways of writing about things. And, you know, people can find me if they want to email me if they've got any questions. I'm at the Cranlana Centre for Ethical Leadership in Melbourne.

00:37:52 Sohail Thank you so much. What an array of different things that we can read up on. That's really brilliant. Thank you're the first guest who has written a novel. So very excited to offer that to the listeners. [laughs] So thank you so much. Thank you so much for your time. Really appreciate it. Really fascinating discussion, which sets us up perfectly. [downtempo electronic music fades in] In the next episode, we're going to get into the nitty gritty of what are the skills required to be an ethical researcher, if that's even possible to gain. So really building on what you were saying there. Thank you so much for your time and see you all next time. [music fades]

[End of recording]