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## Ethics in Qualitative Research: Janet Holt on how ethics committees can adapt

### Speaker information

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- Janet Holt (Speaker) (Janet)

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[downtempo electronic music 00:00:00—00:00:14]

- 00:00:10 Sohail Hi. I am Sohail Jannesari, a migration and health researcher. I'm very excited to present to you the latest episode in the *Qualitative Open Mic* podcast. This particular series is on ethical research in qualitative health, and we are trying to highlight positive practices and discuss ways forward. In this episode, we are going to be talking about how health ethics committees can adapt, or not, as the case—as may be appropriate, to developments in qualitative health research. So we're very lucky to have with us Janet. Janet, would you like to introduce yourself?
- 00:00:49 Janet Hi. Thank you very much. My name's Janet Holt and I am the chair of the Bradford Leeds Research Ethics Committee, which is one of the Health Research Authority's ethics committees in the UK. I'm also an associate professor in healthcare ethics at the University of Leeds.
- 00:01:03 Sohail Thanks, Janet. Can you tell us a bit more about what it means to be one of the health research authorities in the UK?
- 00:01:11 Janet Well, the Health Research Authority has a number of ethics committees across all of the devolved nations, and I've been the chair of the Bradford Leeds one for ten years. I've nearly finished my term of office on this particular committee. And prior to that I was on a different committee. And what we do is we look at the research proposals that have been put forward by a variety of researchers involving research, broadly speaking, in the NHS and involving patients.
- 00:01:39 Sohail Great. So you look at research from all across Leeds or even wider?
- 00:01:46 Janet Oh, wider. Yes. There's always been that facility for researchers to book on to whatever ethics committee becomes available first. They've always had that facility. But during lockdown we moved all of our meetings to Zoom meetings, to online meetings, and that's been hugely beneficial for researchers because it means they can literally book onto the next available committee and it really doesn't matter whether it's John O'Groats or Land's End. And the researchers attend by Zoom, so that makes it a lot better for the researchers.
- 00:02:17 Sohail Right. So in a HRA ethics committee, you have the researcher sort of talk about their research, explain why they think it's ethical, the procedures they've put in place. How does that happen?
- 00:02:30 Janet So what happens is, when a researcher is ready to submit their project for ethical scrutiny, they do that as an online application. And they have to put in a form and their protocol plus all documents that relate to the research, like participant information sheets, consent forms, et cetera. And then they are sent to the ethics committee that is going to review them. And we get them usually about two weeks in advance and we have a lead reviewer system. So each project has allocated within the committee a lead reviewer and a second reviewer. When we get to the meeting day, the committee discusses the project first and we agree on the questions we want to ask the researcher, and then we invite the researcher into the meeting and we discuss with them the issues and the points that we would like answers to. I also ask the researchers if there's anything they want to ask us, because sometimes we can have some really useful dialogue about the research there. So it's very much a two-way process.
- 00:03:27 Sohail Okay, cool. That does sound really nice, especially coming from—I usually work with university ethics committees and actually having a dialogue is kind of difficult. And I feel like so much would be solved if we could talk to each other and explain things on both ends. Because sometimes I don't quite understand what they're trying to tell me and it takes quite a few emails. But I was wondering, does it always work well? Have you had issues sometimes? When—do people get quite defensive in these contexts?

- 00:03:57 Janet Well, I know what you mean about university committees because I chaired a faculty research ethics committee for a long time and tried very unsuccessfully to get people to meet round a table and have researchers in. So I think universities seem to have been very reluctant to do that. I personally haven't had much in the way of difficulty with researchers. I am very clear with our committee that being a part of a research ethics committee is a privilege. It's a really fantastic thing to do. We read amazing research projects and we meet great people. You know, we meet people—researchers who are committed to improvements in patient care. I think ethics committees in the past did have rather a difficult reputation. I think now we're very clear that our role is not gatekeepers. I do not see our role as being a gatekeeper for research. That might be something to do with the R&D department, not us. I see that we work in partnership with researchers to produce good quality research. That's certainly the theme of the HRA and it's something I sign up for and it's something I try to replicate in my committee. Therefore, I think we—you know, we must always treat the researchers as colleagues with respect. Whether they're the most junior person or the most senior professor, it doesn't really matter to me. They're all treated the same and I think that's really important. I have occasionally had researchers who perhaps think they know a lot of it, and sometimes researchers who are clearly irritated by the fact that they have to come to a research ethics committee. It's very, very rare. But if they do, then I'm afraid it just washes over me and I just treat them in exactly the same way. And I find that normally disarms people, really.
- 00:05:28 Sohail Great. Yeah. Kill them with kindness. A very good tactic for so many things. Ethics boards, mother-in-laws, everything really. I wonder, why do you think universities would be reluctant to encourage researchers to get around the table with ethics committees?
- 00:05:43 Janet Yeah. I think—when I was involved in the research ethics committees within the university, I think you've got so much diversity across faculties. So our faculty of medicine and health, of course, we were, you know, light years ahead with most other faculties in sorting that out. I did a lot of work with arts faculty, for example, and helping them sort things out. That is a bit of a two-edged sword because, you know, you're conscious of the fact we've got a very medical model here and that doesn't necessarily fit. I also learned enormously interesting things about what people in performing arts do for their research, and that wasn't necessarily fitting within our kind of—or my frame of reference, really, for research ethics. But there was this idea of—I think there is an idea of proportionality. I think, you know, you don't have to treat everything as though it's a randomised controlled trial involving drugs or something like that. It was the time factor, I found. People said that, you know, they didn't have time to do these things. I think that is probably tied in with the perceived value and the perceived usefulness of ethics review. And I suppose, because I work in a world where I was—you know, we've always done it, we perhaps had a different perspective on it. I think there's still a lot of work to do with faculties that perhaps don't see it as quite as important, and I think the important thing is to make people realise that it's not about a barrier. It's not about a hurdle; it's about trying to produce good research.
- 00:07:09 Sohail Great. Thank you. Yeah, I think certainly one of the criticisms that have been levelled at ethics committees is that it is sort of a bureaucratic hurdle; sort of a tick-box exercise. And do you feel like this has changed over time? So I feel like you mentioned before that ethics committees have already adapted a bit, so it'd be great to hear a bit more about that evolution process and where you think it's at.
- 00:07:34 Janet Well, I've been involved in healthcare ethics for rather a long time. Originally, when I first started off life working with research, more as a research midwife, actually, with hands on research rather than in an ethics capacity, we had kind of cozy types of ethics committees within hospitals. They were very dependent on who was running them. The place I was working in actually had a very good person, but I've heard of other places where they sort of said, "Oh, you know—oh, it's professor so and so, he's a good chap, you know, so it'll all be fine." So we went from that to then a national research ethics service called COREC. And that was a coordinated office for research ethics, and that

went completely the other way. So that went from being very cozy to being incredibly draconian and too much, and I think that's where some of that issue around ethics review came from. And then gradually from that, it—you know, there's been various evolutions of the service through to—what? Ten years ago now, I think, for the HRA. And I think the tone has changed in that it is about facilitation. It's about working with researchers. I wouldn't want to pretend that every chair would perhaps say the same as me, nor every member, because I think sometimes still people see it as being more bureaucratic. But for example, twice a year we have chairs meetings and one of the things that we get at that is we get our statistics, is how well we performed with keeping to timescales, that kind of thing. And the other thing we get is we get any comments that researchers have fed back to us. If they name our committee personally, then we get it individually, which is always really nice to get; you know, nice positive feedback. But otherwise it's all put in a table for us to look at. So I do know from looking at that some researchers would still feel, you know, that perhaps a very—people are quite heavy-handed about it. Or another complaint sometimes researchers say is that research ethics committees focus too much on the methodology rather than on the ethical issues. Now, I know that's too simplistic to say there's just methodology and there's just ethics, because they do coincide. But I think a lot of it is about your approach to it and certainly the standard set by the HRA and what—how we're expected to perform, I think, are ones of politeness and decency and ones of collaboration. So I think if we can focus on that, then that makes it better. So yes, over the years I've been involved in ethics one way or the other, either as a researcher or as a REC member, I think there have been a lot of changes. Positive changes.

00:10:05 Sohail

Thank you. That's really appreciated. And I think—it sounds like one of the things you mentioned is that sometimes changes happen because of different methods. So you've mentioned you've learned a lot about, I think, performing arts in research. So could you tell me a bit about, you know, where you think this will go and how do you—when you come across a new method or an approach or one which you're not so familiar with, what's the procedure like? How do you—you know, presumably there's a slightly different ethical focus or different things that you have to look at, so yeah, what do you do?

00:10:39 Janet

Well, the example about performing arts was actually within the university rather than the HRA. But if I can then focus just on the HRA, of course research involving people involved in the NHS, largely speaking, of course goes through a right—a complete range of methodologies. So there are some committees which are flagged particularly to look at what we call CTIMPs. You know, the clinical trials, if you like. And my committee doesn't do clinical trials and those committees are high bound by clinical trials regulations, which we're expecting to change with changes in the autumn because that's currently governed by EU legislation. And there are particular things that are about how—who's on the ethics committee, who reviews it and that kind of thing. And the form that researchers fill out is an interactive form. So when you go to fill out your form, you have filter questions that you start off with. And for example, you would have to tick whether your project involved children, whether it involved adults who lack capacity, whether it was a clinical trial, tissue, you know, those kinds of things. So then there is guidance for how the questions then come out in the form. So, for example, my committee is flagged for adults who lack capacity. So we're more expert in working with researchers for projects that fall under the Mental Capacity Act. Other committees are flagged for different things. There are some committees who are more specialist in qualitative research, for example. So researchers talk amongst themselves and my anecdotal evidence is that researchers know which committees to go to. And I think that is quite helpful for researchers. So for example, if a researcher was wanting to do a study that did involve adults who lack capacity, they'd probably be better off coming to my committee or another committee that's flagged for that rather than go to a committee that wasn't. In the same way, if you had a piece of qualitative research and you went to a committee that spent its entire life looking at CTIMPs, then that might be more difficult. So I suppose what is underlying that is what are the skills and experience of our REC members to be able to do that? And we do have different categories of membership, but it's a very broad church. And we—apart from the clinical trials regulations, I think it's useful for committees to see a broad range. I think it is useful to

see that. It's always messy if there's bits of legislation but—like the MCA, which you've obviously got to comply with—Mental Capacity Act—where that piece of legislation which actually govern what the researcher has to do and we have to check. But thinking about qualitative research, I think the skills in reviewing qualitative research are different. But I think the advent of qualitative research that comes before us, and there's a lot more of it now, I think has helped research ethics committees see broader ways of doing research. But there are all those sort of sticky things to get over. Like, you know, "Well there's not a proper sample size and they haven't randomised and there's no power calculation," and all of that kind of thing. So we have to make sure that our research ethics committees have training in that. So there are many, many training things throughout the year. Some of them are online, some of them are face-to-face, but most of them now we're putting online. Some of them are self-directed. On all of these different things. So if I, as a REC committee member, didn't know anything about children in research, I could go and do some self-directed learning about that, or attend a training session on that. The same about qualitative research as well. So we can't all be all things to all people, but we can know more about it.

00:14:06 Sohail Thank you. That's really appreciated. A very fair answer. I kind of wanted to focus in on survivor researchers and researchers with lived experience for a topic they're investigating. Because that has potentially come up in some of the discussions I've had with colleagues as a tricky area and I wondered if there was—you know, you mentioned that different committees might have different expertise, whether there was a committee which covered this area. So for instance, I've had colleagues talk to me about the difficulties of talking to ethics committees about how someone is a survivor of mental distress or traumatic events, and also an independent lead researcher. And this sort of dual role hasn't always been, I think, understood by some of the ethics committees my colleagues have gone to. So I wanted to know, what do you think about that? Is there work being done in this area? Are there special committees which have this sort of experience?

00:15:07 Janet I think you're—are you thinking in terms of participatory research then here, or what would be sometimes labelled as participatory research?

00:15:15 Sohail Yeah. I think it could be labelled as participatory research, or service user research is related to it. Yeah.

00:15:23 Janet Well, I think some of this probably stems from ethics committees being set up very much within a medical model. Originally, very much in a medical model. I don't think that's the case now, but I think it is difficult for ethics committees to understand sometimes the broader range of it. As I mentioned before, if you are a committee that always deals with clinical trials you'll probably find that rather difficult. So if you've got a committee that's got a broader remit, then I think that's a good thing. You could set up committees particularly for this type of research, and there is actually a social care committee, for example, but I'm actually reluctant to think that that's a good idea. Because I think it—then there becomes this kind of silo mentality that, "We don't need to know about that because they deal with that." And I think it's better for us to have—if we understand health service research or research with people with health conditions in its broadest context, then I think we need to be able to manage that. Now, for example, if you—if I got a piece of research and it was a methodology I'd never met before, and I had nobody on my committee who knew anything about it, then I can ask for help with that and I can ask for an expert view. So for example, because I have become quite well versed in research for adults lacking capacity, I have been asked by other committees to review projects or even attend meetings or at least give a written opinion on a project to help them with that. So if I did have something like that, then I think—and I looked at it and I thought, "I have no idea what this is," then I would have that facility to ask for help with it. I think that would be a better model than having people just being specialised in it. Because there probably wouldn't be enough either that you would end up with, you know, enough expertise in that. As far as what I think about it, I mean, a few years—quite a number of years ago, actually, we did have some mental health researchers in Leeds on the previous committee I was on who did do this type of research. It was quite challenging for me. I was chairing the

meeting and the people who brought the project were the service users. And this was in mental health. This must be about twelve years ago, at least. And they brought the project and it was really interesting because I think we were all caught a bit kind of, you know, "Oh, gosh! How do we talk to these people?" You know, and then you realise, really, you just talk to them exactly in the same way as the other people. I have had researchers who have brought service users to their committee, and you probably know that the HRA are very committed to, in the new strategy, to being much more inclusive in our research. And I think if researchers do bring perhaps one of their team members who may be a service user or somebody who's involved from involvement, then I think that's a real strength. It's a real strength. It's a strength for the ethics committee to hear what those people think about it, because otherwise you might be judging something that you don't know an awful lot about and the researchers are telling you one thing, but to hear it from the people who are experiencing it is much, much better. So I think that ought to be encouraged.

00:18:25 Sohail Great. Thank you. That's good to hear. I guess to be perhaps more direct: like, if you are a lead researcher and you coming at it from the position of, "I've had lived experience of this mental health service," for instance, or, "I have had lived experience of this particular trauma." People who have been in that position find it difficult to talk with ethics committees sometimes because ethics committees can be often structured in a way of, "We need to protect participants." And sometimes people have had negative experiences where they feel like, "Well, look, I'm a lead researcher in my own right and why am I now being questioned on what additional protective measures should I take for myself?" Or what—you know, or sometimes people have been asked to have a co-lead who doesn't have lived experience. So what's happening here, do you think? And is that perhaps a rare circumstance or is it something that you come across?

00:19:20 Janet I've never come across it and it would certainly never happen on my committee. I haven't come across it and interestingly, I've never heard anybody raise that in a chairs' meeting or anything. I would consider that to be really improper and not actually the role of the ethics committee at all. I mentioned earlier that separating out methodology and ethics is messy and it isn't as clear-cut as it should be, but I do think that the role of the ethics committee is to focus on the ethical aspects of it. Now, there is a thing about researcher safety. Of course there is. But the thing about researcher safety is mainly to do with, you know, lone working kind of policies, really. I think it depends. If you believe—and I think some people do believe this. If you believe your job is to be a gatekeeper, or you believe your job is to protect people and you are the only people doing that protection, then I can see why there would fall into that trap. By the time projects often get to ethics committees, they may well have gone through oodles of review from funding bodies. One thing I'm always quite keen on with my members is to say, you know, "If you've got a project that's already—that's funded by a respectable funding body, I can tell you from first-hand experience you've already had probably a dozen people looking at that, revising it, changing it, and all the things that go with the actual methods. So you don't need to get too exercised about that. What we need to get exercised about is any of the ethical issues that come across as a result of it." I think probably ethics committees may, in a spirit of kindness, want to protect people. I suppose I've always taken the view, and the question I often ask people is, "How bad would the research have to be that you thought you couldn't ask the participants in the first place? So you weren't going to allow the researcher to even ask the participants if they want to take part." So I think our job is to look at the information; the things that participants are given to make their own decision. I think I would just assume that the researchers either have done that themselves or they've done that within their teams or their supervisors have done it. [chuckles] And I wouldn't see that as the role of the ethics committee at all, to interfere in researchers taking part in it. Certainly in the projects I've been involved in, we have had service users involved as part of the research team.

00:21:30 Sohail Great. Thank you for that. Again, that was a very fair answer and I appreciate it. I wanted to move on a bit and ask you about the makeup of ethics committees. So, you talked a bit about how you need a range of different people. And I guess part of that you've mentioned is because you need a range of expertise and you might borrow

some expertise from another committee. What do you do in the context of cultural expertise? You know, so I'm, for instance, a migration researcher. So migration researchers will work with lots of different people from around the world so presumably it's going to be tough for an ethics committee to represent all these cultures or even bring in that knowledge and experience. So what do you do?

00:22:13 Janet

Well, the categories for membership at the minute are experts, and experts are usually tied in with professional qualifications. So that's medicine, dentistry, nursing, that kind of thing. So for example, I'm an expert member for the HRA. That's by virtue of my nurse registration. However, I have very little to do with patients and have had virtually nothing to do with patients throughout thirty years. [chuckles] But I have a lot of expertise in ethics; obviously, I've been doing that for thirty years instead. However, the HRA wouldn't necessarily recognise that as being expert at the moment because those views and those criteria are governed by the clinical trials regulations that I mentioned earlier on. So we have expert members and we have lay members and lay plus members. So lay members are people who are not working in a registered capacity at the moment. So for example, a retired nurse would become—could become a lay member. Lay plus members are people who have never been involved in healthcare kind of work in a formal capacity. And your committee has to have this balance of these members and though—you know, you need to have so many present at each meeting and that kind of thing. So for example, the lay members on my committee, I have somebody who has a PhD who was originally from an education background. I have another lay person—lay plus person who is a senior administrator within a university. And I have a couple of people who are involved in kind of R&D type activities, but not from a professional point of view. You could have solicitors, you could have absolutely anybody as a lay member. That's the only way that the balance is worked out. As far as I'm aware, there isn't any particular rules about gender balance or ethnicity or anything like that. Where I am in Bradford, Leeds, I do have—as you would expect in the area that we work in, we do have people of different heritage and that is really useful. Now, my committee is actually extremely exercised about excluding people who are non-English speakers, and the HRA is doing a lot of work on inclusivity at the moment and there's masses of work to do on that. And that is very, very tricky to get right. Very difficult to get right. So as far as I'm aware, there's not particular rules about things, apart from the lay members. The good thing about having lay members—if we forget about the lay plus and lay distinction. The good thing about having people who are coming from the community, if you like, is that they bring a complete different dimension to your review and they come at it from—with other interests and just that idea potentially of consumers or what would happen if they were asked, that kind of thing. So that balance is really, really good. Having said that, you know, ethics committees do look at a lot of very complicated pieces of paper and documents. We can have sometimes, you know, hundred documents that go with the project. So it is a lot of reading and a lot of stuff to look at so there are certain kind of expectations around literacy and things like that. Which, again, there are no rules about it, but obviously as a REC member you'd realise that pretty quickly. But I think getting that balance could be quite difficult simply because of what has to be done as part of the job. And of course we're all volunteers.

00:25:20 Sohail

Yeah. I was actually going to ask that. That seems a bit unreasonable that everyone is a volunteer. That's definitely going to preclude some people from joining. As you said, there's a lot of—firstly, it's an important job. Secondly, there's a lot of documentation to go through. Thirdly, you have to receive various training to build up the skills. So it feels like, if you really are going to have an accessible and diverse board, they'll have to be paid roles. Right?

00:25:47 Janet

I'm not quite sure what I think about this. It's talked about quite a lot. It raises its head every so often and it's something that I know is back on the agenda at the minute. Not sure about it. I think there's a potential to change the dynamic, which I'm not feeling would be positive. Now, I'm more than happy to be proven wrong about this. And it may be if, you know, payment was offered, you might get people from a different area of society and so perhaps that's worth trying if you want to be able to broaden the committee. Because as you say, there will be people who will be put off from that. It is

a lot of work. I mean, as a chair it's a huge amount of work actually, but, you know, I do that willingly and I've also been extremely lucky in the day job that within the university it's been seen as an important part of my role. So for me it's been fine. It's more difficult now because I'm working on very part-time hours and with a view to hopefully trying to retire properly. But that—I've been extremely lucky in that and I know that. But if that made the difference between somebody joining or not, then perhaps—and a good member, somebody who could really contribute well, then perhaps it's worth looking at. I wonder—I don't know if—what research is going on in this area. I know that HRA is doing masses of work on this at the moment. It's quite a long term project to go alongside our new strategy—for a strategy from last year. And it may be it's worth, you know, asking people themselves, "You know, would that make a difference for you?" And if it did, perhaps that's worth looking at. I'm just worried about it changing the dynamic.

- 00:27:13 Sohail      Interesting. Yeah, I think that maybe there are—there would be sort of paid roles, not for every member, but maybe paid roles for people on low incomes or something like that.
- 00:27:23 Janet      Mhm.
- 00:27:23 Sohail      So something like that could make things more accessible.
- 00:27:26 Janet      It might do, actually. Because, you know, originally when this whole thing about payment for being a participant came about, I mean, there's been a massive amount of work being done on that. It was very fraught with difficulty and it ran into problems with people on benefits and being given money. And I knew this as a researcher, you know, the complexity of trying to even reimburse people, let alone give them, you know, a recognition—a token of recognition, I think we're a long way down the line with that. And because a lot of those preliminary but very difficult issues have already been ironed out, it may be that this is the point to look at it.
- 00:27:59 Sohail      And I wondered—so I wanted to pick up again the point around, I guess, cultural expertise. This is something that's come up a lot in my research, that depending on who you work with, their background, their ethical values, you might want to structure your ethical procedures differently. And I think one of the things which is happening in, for instance, North America is the creation of community ethics boards. So, additional ethics boards which are centred on—so primarily they're built up around indigenous communities in addition to a university or a health sector ethics board. They decide what research should be done in their community and how it should be done and, I guess, bring in that cultural expertise about how they feel research should be done with their community. So I wonder what you thought of this, whether this is something which could be brought to the UK or whether it would be over complicating the process? So, I don't know. What are your thoughts around community ethics boards?
- 00:28:59 Janet      I don't think researchers would want yet another board. I think that would be one thing. So I think if that was going to happen, it needs to be integrated in some way. I think that those issues are really important. One—as I mentioned earlier on, one of the things that my committee gets very exercised about because of where we are in West Yorkshire, we have a big community of people with Pakistani heritage, for example. And there is some great projects—you've probably heard of the Born in Bradford Project, for example, which researchers in Bradford did a big epidemiological project. Enormously successful and they've now gone on to develop other parts of it. And my committee has been involved in the ethical approval with many of the projects within that. So it's basically a data collection exercise, but they've—it's very well funded. If you Google it, you'll be able to pick it up: Born in Bradford. And it's been on—they had BBC documentaries and all sorts of things on it. And it's the absolute archetype of how to do it but they do have—they are very well funded. So they make their participants feel part of the whole research and it is very much involved in the community. I think the idea of communities deciding what they want to research is great, but it—I'm not quite sure how it goes from there to actually being written into a project. Within the university, I did have some experience of international research, but this was research



that was essentially being done internationally, so research being done in other countries. And I did find then that it was absolutely necessary to ensure you were not trying to impose a British system of ethics on that. Consent is the most obvious thing. Sometimes, in some areas, people do not want to sign forms and there should be other ways of being able to do that rather than saying, “Well, that’s too bad. You are a student of whatever university and they have to have consent forms.” So I think those things are important. And they could apply equally well, I think, in the UK. Perhaps less obviously, but there will be people who their standards for consent and things are different, or the expectations for consent are different. And then I think you have to be very careful not to just say, “Oh, well, they’ve got to have a consent form because that’ll shut the ethics committee up,” and then it becomes a tick-box exercise and is entirely pointless. So I think if there are—and we have seen a lot actually with more online research. Of course, more interesting ways of getting consent and using information. I’ve seen some great videos instead of participant information sheets, which are fantastic, you know, for people to look at and find out more about the research. A researcher actually telling you about their research rather than you reading a really tedious piece of paper. So that’s good. But of course that brings other issues with it because it means that people have got to have [inaudible 00:31:32]. So I think there’s a huge scope for creativity here. I think what is great is if researchers bring their ideas to a research ethics committee. And, you know, the requirement is for consent. The requirement is not for written consent, the requirement is for consent. And if researchers can produce good ways of recruiting people, which give all the checks and balances that we want, that people can feel free to participate or not participate. And ethics committees, I think, should be prepared to hear about that from researchers and, you know, if it fits everything then I don’t see any reason why things like that can’t go ahead.

- 00:32:08 Sohail Really great ideas. Thank you so much for that. I think especially thinking about it from the perspective of a migration researcher, definitely some really, really interesting ideas. And bringing that creativity of the research method to the ethical process and really having something integrate. You know, having—almost, if you’re doing a creative research project, it makes sense that your ethics process is creative.
- 00:32:31 Janet Absolutely.
- 00:32:32 Sohail It will be more coherent and make more sense to the participants as well, I think. So, thank you so much for that.
- 00:32:37 Janet Can I just add something else though? Because I was just thinking, occasionally we’ve had—researchers have come with these really complicated recruitment processes and we thought, “Why on earth are they doing it that way? Why don’t they just do it this way?” And we’ve said to researchers, “You know, you’re doing this really complicated opt-out—opt-in kind of system, why don’t you do it the other way around?” And they’ve said, “Oh! Are we allowed?” And I’ve sort of said, “Well, of course, what do you mean, are you allowed?” And there is—I think within that research community that there are a set of rules that have to be followed and that is not the case. And participant information sheets don’t have to be on that template. The templates—I hate the templates actually, but the templates are really useful for novice researchers. And—but the idea of the template is, “These are the things you need to cover. You know, change them in a different way.” And you see lovely booklets and all sorts of things and great stuff for children and people with learning disabilities and great things that, you know, you see and that stick in your head and you remember. So I do think researchers think that there are a set of rules that have to be followed, and researchers, in my experience when I’ve talked to them about that, have been amazed. You know, they’ve only done it this way because they thought this would please the ethics committee [chuckles] and they’ve made it so torturous. And I said, “Well, no, if you do it this way I know you are going to be back to me in eight months’ time with an amendment because you haven’t recruited anybody,” because they’ve made the recruitment process so complicated.

- 00:33:58 Sohail What's happening? Why do researchers automatically assume that? Is there something that you are planning maybe in the future or thinking about in terms of communication with researchers to maybe make them aware of the flexibility?
- 00:34:10 Janet Yeah. I think the trouble is, if people have had a bad experience—and sometimes people do. And I know I'm painting, you know, a very nice picture of research ethics committees because I'm just, you know, explaining my perspective on it, and you could interview a different chair who might give you quite a different view to me on this. I think the HRA certainly is getting that idea across to our members and to our chairs. And we had yesterday, actually, our development day, so all the local committees went along and we had a great talk on artificial intelligence, for example. And we did some work on new participant information sheet templates and we had some time together as a committee. And chairs meet twice a year and there's also a Chairs' Day as well. So there is a lot of opportunity and loads of opportunities to do more; you know, be involved in all of the development work that's going on. There's always calls out for members, "Do you want to be involved?" You know, the fact that I was asked to do this on behalf of the HRA, so they are very good at getting members involved if they wish to be. So—and that gives you a better feel as part of the organisation and you can shape the organisation. I think that a lot of work is done on the part of the HRA to try and make sure that that's there. And of course all the training would help with that too.
- 00:35:21 Sohail Brilliant. Yeah. I hope the podcast is going to be a positive contribution towards that. I wanted to know, what do you think the role of guidance is in that sort of communication with researchers and ensuring ethical research? Is it a useful thing having written guidance, should it be—or should you have video guidance? Is it it—should there be more creative ways of guiding research?
- 00:35:43 Janet I think I'd go for more creative ways. I think one of the things that we used to have a long, long time ago is we used to have researcher training days, because I used to participate in those. And we used to invite researchers to come and we would talk about ethics committees and all the things that went on. And they have gone by the wayside quite a long time ago. They'd be terribly expensive to do and I also think probably badly attended now. Because these were targeted at people in practice and, you know, they just wouldn't get the time to go to things like that anymore. So I think there are opportunities to do that, but I think they were very much lovely face-to-face days, you know, on the days when we did that sort of thing. So that's not going to happen now and I think it may be finding out what medium would be better. I think perhaps more creative ways. Would people prefer to just watch a little video about an ethics committee chair saying what to expect, what the sorts of things we're interested in? You know, realising that we're actually humans [chuckles] might be useful. You know, that kind of thing. I don't know. I think the HRA is very open to suggestions, but we do need to do a lot of work with researchers. And of course researchers are very busy. You know, you're trying to write your grant, you're trying to get your grant in, you're trying to get that revised several times because the funding body wants you to change this and change that and halve your budgets and all of those kinds of things. And I think sometimes the kind ethics stuff is, "Oh my goodness! I've got this to do as well now." And perhaps we could be more positive towards it. But, yeah, I'd be open to more creative ways of working with researchers.
- 00:37:15 Sohail Thanks for that. Yeah, I think that hints at—and this is something we'll talk about in other parts of the series. There are some fundamental structural issues around how ethics is built into research that pose some barriers to a more relational model of research ethics. So thank you for raising that. And it's so interesting that you guys used to do research sort of training days and had more contact time and face-to-face time with researchers. Because I think that's so crucial otherwise ethical procedures then just get focused in—can become reduced to the procedure rather than, actually, this is a dialogue and a conversation and ideally a support.
- 00:37:59 Janet Absolutely. It's a two-way process. For me, it's all about dialogue. Now, it may be the clinical trials; this is very different, you know, and it may be if you've got CTIMPs and you've got these particular things, that might be different. But I think, if we are

embracing a huge range of methods—and health service research, you know, involves all sorts of people, not just people who do randomised controlled trials. And if we're going to do that, then I think we need to be able to think of other ways and it's not a one size fits all.

00:38:28 Sohail Brilliant. Thank you for that. So just a final quick question. Are there any resources that you'd recommend our listeners to head towards for exploring any of the issues that you've raised?

00:38:38 Janet Well, the HRA website, which is much improved. [chuckles] And the HRA website has a lot of information on there. There's lots of information there about the sorts of things I've been talking about, the specialist research with children or adults who lack capacity, qualitative research, that kind of thing. You'll also find links to relevant specific bits of legislation and things like that, should you need it. I like the Involve website as well. There's a lot of good information there for researchers and ethics committees, I think, about public and participant involvement in research, which I think is very important for ethics committees. I find that very helpful as an ethics committee member to know what people have said about that research, so that website is very good. And the HRA one. And I think as far as researchers are concerned, one thing I really recommend everybody to do—I used to tell my students to do this—is that you can actually set up your own IRAS account and you can go and set that up for yourself and you can have a go at filling out the form. And it shows you the kind of things that ethics committees are going to ask, the sort of information that they want. It won't get submitted unless you got right to the very end and it was all ready to submit, so it won't harm anybody and nobody would see what you were doing in it. So I think if you are a novice researcher or you've not gone into an ethics committee before, or, you know, students, PhD students, masters students, anybody, set yourself up with an IRAS account and have a go at filling out the form.

00:39:57 Sohail Brilliant. Thank you. I'll get my students to do that.

00:40:00 Janet Yes, do. [laughs]

00:40:01 Sohail Great idea. So, brilliant. Thank you. Thank you so much, Janet. That was really, really in depth. Lots of things to consider and lots of beautiful resources to follow up on. Thanks to all our lovely listeners. We have one final episode left in this series, that will be with Cris, [downtempo electronic music fades in] who is a professor and a global health scholar in Colombia. And she'll be talking about international inequalities and how global inequalities can affect research ethics. So please join us for that and see you soon. [music fades out]

[End of recording]