



Research Ethics and Equality, Diversity and Inclusion

This project was motivated by the challenges faced by The University of Sheffield (TUoS) Research Ethics Committee in recognising, operationalising and providing guidance within our Research Ethics Policy on Equality, Diversity and Inclusion (ED&I). The aim of the project was to explore the most appropriate way of advising on and addressing issues of ED&I in our research ethics policy and processes and, potentially, to provide guidelines for how to address these issues for use across the Higher Education (HE) sector. The project was funded by Research England as part of an internal competitive tender. It commenced late January 2023 and covered the costs of interviewing and transcription.

We used semi-structured interviews, conducted and recorded online. The aim was to engage in a reflective and critical discussion about ED&I and research ethics. There were 18 participants in total; 4 from funding bodies, 5 from TUoS, and a further 9 from research and academic backgrounds, most from other HE institutions. We deliberately involved early career researchers and postgraduate students as participants. A list of participants is provided at the end of this report, with their consent. However, in line with the consent provisions, quotes are not directly attributed and any personally identifying information has been removed.

The project sought to address the following questions:

- 1) Is ethical review the appropriate stage of the research process to address ED&I issues, or should this be incorporated at an earlier stage of the research process, or at both stages?
- 2) How we assess whether ED&I has been addressed in our ethics processes, recognising how it may be influenced by discipline? What is the burden on researchers in demonstrating that they have addressed ED&I matters?
- 3) What would we expect reviewers to do with the information provided in a question about ED&I, how should it affect their decisions on 'ethical research'? What training and/or support would need to be provided to enable this?
- 4) What would be the impact of an ED&I question on taught student projects, given that students at this level often undertake research to learn about the research process rather than to produce publishable findings?

Findings

The interview data was analysed through a thematic analytic process. Our aim is not necessarily common agreement in the presentation of the ‘findings’, but to illustrate the nature of the discussions on incorporating ED&I into research ethics policy more generally. The results are presented in the broad themes that emerged, rather than in answer to the specific questions asked in the interviews. This reflects the fact that these questions cannot be viewed in isolation from other social and political governance issues currently impacting the UK HE sector, and there is, by necessity, circularity in trying to address these.

The themes are:

- 1) defining and understanding ED&I;
- 2) good science and the role of URECs;
- 3) the purpose and the boundaries of URECs;
- 4) whether ED&I can be separated from ethical research;
- 5) the burden of assessing ED&I, minimising harm and doing ethical research;
- 6) ‘top-down’ University policies; and
- 7) other challenges.

As far as possible we use the words spoken by participants to illustrate the themes.

1) What do we mean by ED&I?

Understandably, some participants spoke of the challenges in defining what is meant by ED&I and how we define it for the purposes of ethical research. For example: ‘are we talking about making sure that equity is built in for participants? Are we talking about making sure that particular topics are robustly covered? Are we talking about decolonising research’, (Participant 3). It was also noted that there is a potential for conflict between ‘harms’ because of the research ethics policies and:

you are greatly encouraged not to involve anyone who's slightly difficult, you know, if they can't consent, if they're 16, you know. All these groups that people as white middle class professionals feel very paternalistic [towards]. And therefore, we're like, “Oh, well he hasn't talked to these minority groups because you might upset them” and but then you get into the corresponding problem of these groups don't get researched. And that's an ethical issue in itself. (Participant 8)

One participant described the ED&I umbrella term as ‘such an ugly and loaded term’ (Participant 6) and that there was the potential for ideological and political division and conflict: ‘As you’ve seen in political discourse an awful lot recently, that can get really heated, really quickly, and turn into an almost culture war type situation’, (Participant 6). At the same time, as another participant stated, ‘there is something about EDI becoming so blanket and so generic, that it becomes meaningless’. (Participant 11)

Nevertheless, it was pointed out that definitions of ED&I were available in some universities policies:

I'm kind of making an assumption that most universities, certainly where you are funding research, will have very similar approaches; there's quite a lot that's stated in there about research practices to do with ED&I and reducing harm. So, we've got a kind of definition there of ED&I which is getting broader and broader so it kind of raises questions about what we mean by ED&I when we talk about research ethics. (Participant 11)

2) Good science and the role of the research ethics committee

Several complexities are raised through the discussion of ED&I and research ethics: the role of the ethics committee, what it means to do good science, whether ethics and ED&I issues can be clearly recognised, and how and when they should be built into a research project. In answer to the question whether ethical review is the appropriate stage of the research process to address ED&I, participants generally raised questions about the remit of the REC. For example:

Are you there to kind of make sure they're doing good science? Are you there to make sure that the sample size is sensible? Or are you there to just make sure that they get consent into doing all that kind of stuff properly? Of course, they link, because you don't wanna be burdening people for no reason. So, I'm not sure. So, I think, to answer the question, I'm not sure where it should fit in, and I'm not quite sure if it's in the remit of an ethics committee. (Participant 8)

It was suggested by some participants that ED&I should be built into research processes *before* an application reaches the ethics committee, because ED&I issues need to be understood 'much earlier in the process, right back as I suggest to even thinking about what the nature of our research question is', (Participant 3). Given this, the research ethics committee (REC) might be too late for decisions about ED&I.

Therefore, there can be a perceived problem with the boundaries of the REC in determining what its role is, and this would be exacerbated by introducing questions of ED&I:

If the clinical trial doesn't include women, or it doesn't include people of colour, or it doesn't include, you know, whatever it doesn't include, that has scientific implications. It also has ethical implications. It has implications of justice. And so, I think, it's quite a difficult question to take apart from the scientific question which is one of the problems I've always had with the research ethics review process (Participant 16).

The issue of RECs and this boundary is raised again below.

3) The purpose and boundaries of a University REC

Academics raised a number of concerns relating to the introduction of questions on ED&I into the research ethics process. One of these relate to the purpose of the REC in a University and its boundaries:

Over the years, these [research ethics] committees have taken over more and more work and it actually makes no sense whatsoever, because if we're going to, as members of these committees, are going to have some sort of responsibility for more or less any ethical issues that arise in the institution, well then there's no end to it. (Participant 15)

The concern is that more issues are being addressed under the auspices of research ethics, and that this then 'precisely lets the university off the hook about actually doing anything at all about anything'. (Participant 15)

The worry is that that difficult decisions are 'pushed down the line' from higher up in an institution and onto the REC. This was expressed by many of the interviewees. For example, 'putting ED&I there again just gives the institution a reason to think, "oh well we've taken care of that now"', (Participant 16). Such behaviour could, it was suggested, result in difficult and challenging issues getting passed down and/or filtered in this way, and 'because it gets filtered through the ethics committee, they [the research committee] become the bad guys', (Participant 6). Indeed, one participant described how the REC has become: 'a bit of a Christmas tree. Anyone who wants to scrutinise anything about research kind of says "let's put it on ethics, they can have a quick look at it for us"' (Participant 3). Therefore, difficult decisions are pushed back onto the REC and this results in issues that are not about research ethics being considered under their remit, and researchers then lose confidence in the processes of the ethics committee. Participant 3 described how:

You think well, actually, that isn't ethics, that's data integrity, or that's this or that's that, you know. I think researchers, when they interface with ethics they're expecting ethics, then they get so much more than they bargained for that I think that then creates this sort of tension between researchers wanting to engage with it and then pushing back against everything because it all gets, because they're being challenged on things that aren't even ethics.

The idea that ED&I is not part of ethics review was one component of the responses to this, although there were participants who argued that it was an integral part of ethical review, as we discuss further below.

Another concern expressed was that ED&I should not be dealt with through an ethics application because it would become little more than a tick box exercise that would not do justice to the complexity of what was involved. One participant, for example, said that:

Without any, truly acknowledging how important is ED&I in our research, in all aspects of science and in every corner of science wherever it is, I think it's absolutely important. But I fail to see how putting it into research ethics is going to help, in research ethics or advancing ED&I. Actually, I would worry that it becomes another thing that we just, oh yeah yeah, I know that, I know that, and you just overlook it. (Participant 16)

4) Can ED&I be separated from ethical research?

Nevertheless, one reason to consider ED&I in the ethics process was because:

research ethics committees and universities don't exist in a vacuum. If they don't respond to the context then they get left behind and then the further they fall behind, the more likely it is that someone is going to get harmed, which is a problem. (Participant 6)

The importance of social and political context was also noted:

we all need to be aware of the sensitivities around any research we do. But I think, you know, we've got a lot better and now this is a further step in the direction of sort of understanding that what research we do and how we do that research is not in any way separate to the concerns we have because of movements like "Me Too" and "Black Lives Matter" and all of the things that are challenging our sort of settled ways of doing things. (Participant 14)

ED&I was thus viewed as *central* to the way we should be thinking about research and producing knowledge. This was expressed by one participant as:

EDI for me is not just a practice, it's a way of thinking. Even if it's a PGT student without funding, there's still principles of EDI there that relate to research, how we treat people, how we treat data, how we think about dissemination and outputs that speak to power and voice and those types of issues that I think are still – they can still be accessible to people and be written in an ethics application. (Participant 9)

This was the case *regardless* of whether the research was funded. Indeed, ED&I was seen as a form of knowledge production, built into the way research should be conducted and Participant 9 described this further:

EDI is at the very basis of how we treat people and work with people and how we share what we've produced, or how we research together. So, I think that's really important, to how we think about knowledge production.

Similarly, other participants described the importance of ED&I as central to the research process:

If your work is to have any meaning, absolutely every strand of life, to me, should be diverse. And everybody should be thinking about it at whatever level, you know? In all walks of life, we should always be trying to think about making sure we are representative of the people that we serve. (Participant 7)

The need to recognise the centrality of ED&I in research was also expressed through the recognition of relationships of power. This was seen by some participants as the key issue that a question about ED&I in the ethics application should address because:

Ethics is about power. And again, about how that power dictates or guides how we work with people that are usually less empowered than ourselves as university researchers, and what are our responsibilities to those communities is as an institution. (Participant 9)

There was considerable discussion about the relationship between ethics and ED&I and the historical legacy of abuses of power. This involved ‘an acknowledgement about how historically marginalised groups have been deeply harmed by research, and those legacies continue today’, (Participant 9). Within this context, abuses of power were linked to the production and interpretation of knowledge and ‘truth’. One example given was in relation to the inclusion of women in clinical trials:

just the mere possibility of pregnancy excludes you from trials. And then until you know, maybe the last decade or so you'd also then get excluded at the end of your life because there are very ageist restrictions on participation in research. So, and then, if you think about how protective we are of children you wonder, you know, at what phase in their life is a woman an equal participant or an equal beneficiary of medical research. (Participant 14)

Furthermore, it was noted how recruitment practices are skewed:

you don't even need to go back to Tuskegee. If you look at the recruitment practices in the 80s and 90s in this country, when private companies were taken on to recruit people to clinical trials, they'd often go to big housing estates and where people were unemployed, or you know poorly paid. Another area where it's going to become increasingly important to think in these terms is around biobanks and collection of genetic and genomic data, because again, we've sort of relied on a voluntary model for things like UK Biobank. That has probably skewed the genetic sample very much in the direction of white middle-class, middle-aged people. (Participant 14)

Issues were also raised about the exclusion of younger people:

How can that be? That's just seen as acceptable. If you look through protocols, they always have those kinds of exclusions, and usually it's based around patriarchy, isn't it? That protective element. (Participant 7)

Ultimately, participants who suggested that ED&I was an intrinsic component of research ethics did so because:

We can't separate research ethics from EDI because again, for many marginalised communities, they're so embedded in their histories, aren't they? They're not separate entities. Modern-day institutions like universities need to bring the two together. (Participant 9)

The difficulties in recognising the complexity of ED&I and then operationalising it in an ethics application was a major concern too: ‘It's a big issue by itself and so it could become, it could be easily minimised when you put it in the research ethics process’, (Participant 5). Similarly, another participant said that their concerns in having ED&I in a research ethics application was:

Not just because I don't think it's always going to be appropriate and relevant. But because it also, another incidental of that, will be just seen as another tick box

bureaucratic exercise where there's a sort of gaming of the system, where the sort of template boilerplate language that they know will satisfy reviewers will then be inserted without actual true belief, much less operationalisation on whatever is said in that language to fill that box. (Participant 12)

Essentially, adding ED&I to the research ethics application process was viewed as potentially damaging because 'most people would treat it as they treat everything else under research ethics, namely a bloody nuisance, and let's just get the box ticked'. (Participant 15)

5) The burden of assessing ED&I burden, minimising harm and doing ethical research

Participants were aware of the existing burden of research ethics processes on researchers and reviewers and the need to manage this. As a process, one participant stated that 'I sometimes, as a researcher, feel over policed by ethics committees, that they've overstepped their mark already', (Participant 3). Therefore, adding ED&I to the process would not only fail to facilitate an understanding of the importance of the topic but:

it actually doesn't achieve very much. We end up with something much more complicated and involved and for the most part [will] just annoy everyone who is trying to actually fill in the application form. (Participant 2)

In a situation where the ethics review process is seen to overburden researchers, it was acknowledged that the process of ethics review also overburdens 'the reviewers who are reviewing, with very little acknowledgement on the part of their institutions', (Participant 16). Concern was expressed that consideration of ED&I issues extended to the review process itself and recognition that it would be a particular type of academic staff member undertaking these tasks: 'often female members of staff, aren't they? Women who tend to do more of this kind of academic housekeeping role', (Participant 8). And the overburden would not carry any real capacity or authority to do anything about the issue:

As well intentioned as it might be, I don't see the point given that I don't see what the implications could be of someone saying 'no I have not thought about ED&I principles, or yes, I've thought about them, but I just can't, because there's nothing else I can do. (Participant 16)

The burden of ED&I was thus seen to fall on researchers, reviewers *and* 'on the very people that you are trying to be more inclusive and representative of and that in itself can be problematic', (Participant 3). There is thus potentially an increased burden on everyone by adding ED&I onto the ethics application:

With an extra bit of the review process that is easy to misunderstand, misapplied, and just, and at the end of the day, to call a spade a spade, it doesn't really further equality, diversity, and inclusion either. (Participant 8)

By apparent contrast, the same reason for *not* including a question on ED&I - that everything gets pushed back to the ethics committee - was also seen as a reason why it was important that ethics applications *should* include a question about ED&I. One participant said that:

The question is – should we be looking, when we’re that last stop, at any ethical issues? We assume that they’ve looked at it. Everyone is thinking that somebody else has looked at it. But who’s looked at it? (Participant 7)

Similarly, ‘If we’re not all responsible for doing it, how’s it ever get done?’. (Participant 10)

Part of the reasoning for this position related to the potential harm participants could be exposed to if ED&I perspectives are not considered. For example, one participant saw it as a simple case of having a question:

Even if it is “Have you considered equality, diversity and inclusivity?” could potentially be really valuable. Partly because researchers have the potential to frame things inadvertently which are distressing or exclusionary or upsetting. In the same way that we’d look at the framing of the question on sensitive subjects, or political things, or stigmatised conditions, or vulnerable people. (Participant 6)

Another participant saw ED&I as being intrinsic to research ethics because it was about the prevention of harm:

If it potentially causes harm, physical or mental health, it’s gonna cause harm to people. That sounds really grand, causing harm, but ultimately, at the end of the day, these things do, don’t they, further down the line? (Participant 7)

In addition:

And when we think about harm do we need to broaden our definition of harm? So, I mean there's harm to the individual, but there's also harm to the society if you're only ever getting the representation of a limited group of people. (Participant 3)

This means that it is not just the potential harm being caused to people who participate in research that needs to be considered; rather, ‘It’s the harm you might be causing to the people you’re excluding from your research and so you know, is there a group of people that your research is systematically, non-intentionally excluding?’, (Participant 3).

Having said that, this participant questioned whether it was the remit of the REC to cover this, or whether ‘one piece of research can be expected to overcome it’, especially given that there are ‘structural reasons why some of these inequalities exist but it's at what level do you intervene with that?’, (Participant 3). By contrast, Participant 7 saw the remit of the ethics committee as upholding standards: ‘This is what we expect. And this is what the public can expect, as well, either as a participant or just someone – we’re all on the receiving end of research, ultimately, because it’s there for public good, isn’t it?’

6) Top-down University policies

Some participants argued that ED&I should be an institutional approach which would be reflected in the research ethics policy but with clear statements elsewhere about expectations. This means that good research practice is ‘baked into the institutional understanding of “This is part of good practice more generally”’, (Participant 6). It was suggested that this was:

The responsibility of the rest of the university and the university leadership takes forwards a whole set of activities and projects that make it easier for you [the REC] to operate because these fundamental things have been addressed elsewhere, rather than it landing on you [the ethics committee]. (Participant 11)

A very specific example of this is in expectations around the language that is used, and this is discussed further below. But, as one participant noted, particularly in relation to the language around sexuality and rights:

You end up in this potential for disagreement that could get quite heated and so I think – and hence why I think the need for university policy which says “This is what the appropriate thing is” so that the ethics committee and the researcher and the participant can point at the paper and go: “That’s the thing. We have to stick to this because this is the recommendation by Stonewall, or Refugee Council” for various different things. (Participant 6)

The issue of ED&I was, thus, seen as much larger than what could be reflected in the University ethics policy:

I think in reality you'd have that top down, here's the ethics form, here are the questions. We're now going to start asking you, to start your reflecting about them, whilst also having that training bottom up that's more about culture change and thinking about a broader awareness of ED&I issues in research which is not then overseen by ethics but hopefully will start to infiltrate the thinking so that those top down questions are less problematic and challenging for colleagues as they encounter them. (Participant 3)

This was seen as part of a broader culture shift reflected in the requirements by funders where they:

Are asking us, as researchers, to account for who is in our teams, how does EDI relate to our ethics, what are the political imperatives of how we're going to own work, or share work, or protect work and data and so on. So, I think, given that cultural shift, I think there's a need for the University to follow suit. (Participant 9)

The idea of the culture shift, or culture change, was referred to repeatedly, but it was noted that:

The culture change takes a lot of time. And it's better to be slightly more patient and try to build something that actually works for people rather than telling people something to

do and then it not actually working at all, and you not getting the desired outcome that you want. (Participant 13)

A clear direction for the University was important and this was needed for the reputation of the University and for clarity in research:

For the pragmatic reason of universities having to do research and people needing to do research, having a set of principles that are very clear “This is what we consider appropriate language to be on...” whether that is talking about poor and rich countries, rather than first and third world or whatever it may be. Or, “We think that this is appropriate language to discuss sexuality, or gender, or race”, or whatever. That makes it very clear for the ethics committee. (Participant 6)

Problems with appropriate language were mentioned numerous times and Participant 6 explained the importance of an institutional steer here:

So [researchers] don’t inadvertently, even if they’re acting in the best faith and have done all they can, they don’t accidentally use language that is inflammatory or distressing or gets them accused of “This person at university of X said Y” and “That was language that was acceptable several years ago” or whatever it is. (Participant 6)

The impact on science of how language is used was also highlighted:

From a data point of view, people are asking for gender data and they’re getting sex data. It’s not even correct, because NHS digital – there’s only a few datasets that have got gender in there, always sex. But people are afraid to say the word ‘sex’. They ask for gender, so you’re asking for the wrong thing. Your outcomes aren’t gonna be what people think they’re going to be. We have to speak the same language, haven’t we? I know it’s a toxic debate that goes on around this and organisations are fearful of doing it. (Participant 7)

7) Other challenges

Other challenges about introducing ED&I into research ethics were that, potentially, ‘people won’t engage, because for those people who have got privilege, they just won’t see why they have to engage’, (Participant 10). For this participant, the additional challenge was then what you did with someone who was deemed to have not dealt with EDI appropriately:

What is the mechanism for dealing with that? And that’ll need to be obviously very robustly thought out. Because professor X has won 2 million pounds to do this under this timeframe. And you’re now saying, actually all of your research ethics application is acceptable except for this bit about EDI. (Participant 10)

The idea that there were tensions between how universities viewed their funding and ED&I was also noted:

When you get to discussions about UK university competitiveness in the rest of the world around research, people still see it as a binary choice between high quality research, very traditionally defined, and EDI. And it's still kind of framed as, if we have to do all this ED&I stuff, that'll stop us doing world-leading research. (Participant 11)

Another participant argued that our research activities needed to reflect ED&I issues in the recruitment and representation of the staff conducting research. Therefore, issues about ED&I also raised questions:

About fostering widening participation within university's structures for staff and for students from underprivileged communities you know. And so, the researchers themselves represent the UK society as it actually is and not the ivory tower version. (Participant 12)

And:

The challenge is finding a way to ask that question that gets productive responses and also doesn't rule out the possibility that for some research it genuinely won't be an issue. I think sometimes scientists and researchers get very upset because they think they have to do everything that's on the [research ethics application] form. Whereas in fact, you are entitled sometimes to say this isn't actually an issue for me because I'm working with fruit flies. (Participant 14)

Summary and next steps

The aim of this project was to raise the most appropriate way of advising on and addressing issues of ED&I in our research ethics policy and processes and, potentially, to provide guidelines for how to address these issues for use across the HE Sector. We sought to address the following questions:

- 1) Is ethical review the appropriate stage of the research process to address ED&I issues, or should this be incorporated at an earlier stage of the research process, or at both stages?
- 2) How we assess whether ED&I has been addressed in our ethics processes, recognising how it may be influenced by discipline? What is the burden on researchers in demonstrating that they have addressed ED&I matters?
- 3) What would we expect reviewers to do with the information provided in a question about ED&I, how should it affect their decisions on 'ethical research'? What training and/or support would need to be provided to enable this?
- 4) What would be the impact of an ED&I question on taught student projects, given that students at this level often undertake research to learn about the research process rather than to produce publishable findings?

Our conclusion is that ED&I are inextricably linked to epistemology, disciplinary expectations and different research methods, and what is meant by ethical research, and these issues should be reflected within a research project from the beginning. The inclusion of an additional question

into the research ethics process has the potential to make some researchers consider and reflect on their research practice. However, adding that question would also raise important concerns about what is meant by ED&I, how far the REC should expect such principles to be considered, and what can be done if ED&I is inappropriately handled. Recent work conducted by the Health Research Authority (HRA) also raises issues about the authority of RECs to challenge researchers on issues of ED&I (<https://www.hra.nhs.uk/planning-and-improving-research/best-practice/increasing-diversity-people-taking-part-research/rec-debate-issues-inclusion-under-served-groups-health-and-social-care-research/>).

A central concern in the interviews and discussions reported here is that ED&I could easily be diminished through an inappropriately considered tick box on an ethics application form. Consideration of ED&I issues also raises issues about the role and function of the REC, where there are difficult questions about institutional practices and frameworks around ED&I more broadly, Government policy about freedom of speech on University premises, and a backdrop of increasing social and economic inequality.

The REC does have an important role in standard setting, raising awareness and establishing a culture around expectations in research, and we recognise that funding bodies are increasing their expectation that issues of ED&I are considered in funding bids. The HRA, in their report noted above, acknowledge that that RECs have a role in educating and supporting researchers to be more inclusive in their research design. Part of their summary is that supporting an evidence-based value of the inclusivity of research could be part of a shift in culture towards greater value and recognition of ED&I in research.

This project has provided a context in which to provide additional resources on ED&I and ethical research. We are not adding a question into our ethics application on ED&I but have secured additional funding through Research England to film case studies (open access) on existing good research practice involving participants from underrepresented groups to support a culture in which this should be the expectation, rather than an explicit goal to be addressed through the REC.

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