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# Participatory research and the medicalization of research ethics processes

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**Abstract:** This article illustrates how medicalized epistemologies and methodologies significantly influence the institutional ethical review processes applied to socio-legal research in law schools. It argues this development has elevated particular renderings of mental distress and objectivity to universal definitions, potentially placing a straitjacket on methodological innovation.  The authors use two case studies from their experiences as researchers in a UK Law School, alongside a small-scale survey of socio-legal researchers in other UK law schools, to illustrate the problems that can arise in securing ethical approval for socio-legal research, in particular with participatory research designs which mobilise ideas of mental distress and objectivity not premised on conventional medical understandings.

The article develops key proposals that the authors feel merit further inquiry. Firstly, that there should be a comprehensive evaluation of how the jurisdiction of ethical review for socio-legal research is established. Secondly, that socio-legal scholarship can contribute to debates concerning the discursive, material and procedural constitution of institutional ethics approval processes. Finally, that we might rethink the nature of, and relationship between, university-based research ethics committees and NHS research ethics committees, by placing both within wider ecologies of capacities for ethical decision-making.

**Key words:** participatory research, ethical approval, REC, medicalization, mental health, triggers, materiality

"For what it's worth, I hear widespread rumblings of discontent about [NHS research ethics committees] from other academics and researchers; we often talk about writing a paper about it but we're too scared of upsetting them and never getting ethical approval in the future!  They are widely regarded as paternalistic and a major obstacle to inclusive research."
*Socio-legal studies researcher and survey respondent*

## Introduction

In this article we seek to illustrate how medicalization – which Conrad defines as "a process by which nonmedical problems become defined and treated as medical problems" (2007: 4) – features in ethical approval processes in social science research, and with what effects. We offer two case studies drawn from the authors' experiences of obtaining ethical approval for socio-legal research projects at a UK law school. Both involved participants who experienced, or were deemed to be at risk of experiencing, mental distress.[i] Both endorsed a research ethos that embraced the situatedness of research practice, and valued collaborative and iterated research processes. In presenting an early draft of this paper at a socio-legal studies conference, we discovered that our experiences echoed those of others, from law schools across the UK and beyond. Consequently, we conducted an exploratory survey of researchers' experiences at another nine UK universities and present their responses, comparing and contrasting with our own. While we make no claims to being representative of socio-legal ethical review experiences in general, we argue that our combined experiences evidence what *can* happen in the ethical review process. The small sample size notwithstanding, on the basis of our experiences and those of colleagues at other institutions we make the case for the need to turn the gaze back upon ethical

review committees themselves, to identify the scope of the problem and innovative practices for dealing with it.

In this article, we identify two key elements in the medicalization of ethical review processes. Firstly, the increasing importance given to medical epistemologies and methodologies. Secondly, the tendency for ethical decision-making bodies to refer cases to more specialized research ethics committees where they are evaluated through a medical gaze. We argue that, together, these two key elements of medicalization produce a significant opening through which medical paradigms have influenced research ethics, epistemologies and methodologies across the board. We are particularly concerned to elaborate the implications of medicalization for the family of participative research approaches that have emerged in line with these commitments, including community-based participatory research, participatory action research, collaborative action research, co-production, feminist research and action research (Reason and Bradbury 2008, Banks *et al*. 2013).

With ethical review practices caught in shifting sands of institutional good practice guidelines and codes of conduct, we agree with the concern of colleagues at other institutions that a critical engagement with review practices should not be deferred because it is difficult to provide enduring snapshots of how it is taking place. Thus,

instead of attempting to systematically map out ethical review practices in the hope that they will not change much between the penning and reception of this article, we aim to inspire an uptake of research interest in ethical review itself, by presenting case studies, survey data and reflections on the various challenges the reforming of ethical review practices poses.

# Part I: Medicalized ethical approval?

## Situating the medical ethics creep critique

Historically, ethical review of research in Western universities has been and remains heavily dominated by a medical ethical worldview (Haggerty, 2004; Israel and Hay, 2006; Boden, Epstein and Latimer, 2009; Schrag, 2009). The institutionalisation of research ethics principles and practices has largely developed from within the medical sciences. It has been driven in part by institutional responses to negative public reactions arising from medical research scandals, such as the US Tuskagee syphilis experiments (Jones, 1993; Gamble, 1999), and the UK Alder Hey/Bristol Royal Infirmary organ retention scandal.  The tendency following such events is for the regulators, institutions and disciplines affected to produce codes, rules and procedural mechanisms to reassure the public that such aberrations have been dealt with.

Whether such a regulatory response is in fact an effective or appropriate way to prevent future inappropriate behaviour by medical researchers is, as Boden *et al.* (2009: 731) note, open to question. This is particularly the case if the problem lies not in the frameworks regulating research, but rather in how medical professionals have perceived and interacted with those with whom they work, and upon whom they have conducted their research.

Attitudes within the medical sciences to the ethical treatment of research participants have tended to be paternalistic and individualistic, adopting the position that it is the researchers' and their institutional or professional oversight bodies' roles to determine what is in the best interests of research participants (Miller & Wertheimer 2007). Such attitudes are often also disposed towards privileging a narrow 'professional viewpoint' over broader viewpoints by excluding the voices of those whose knowledge is derived outside of - or indeed is the object of study of - professional research. Miller & Wertheimer suggest that while medical *care* has increasingly promoted patient autonomy above paternalism, medical *research* has been resistant to such change (2007: 25); a stance that perhaps is only now beginning to shift (Stratford *et al.* 2015, Witham *et al.* 2015).

It is arguable that the development of a formalised system of medical research ethics regulation furthered the scope for 'ethics creep', a long-established Weberian process described by Haggerty (2004: 394) as,

> "…a dual process whereby the regulatory structure of the ethics bureaucracy is expanding outward, colonizing new groups, practices, and institutions, while at the same time intensifying the regulation of practices deemed to fall within its official ambit."

Many commentators have argued against an ever-expanding bureaucracy charged with ensuring that research is ethical (see, for example, Hammersley, 2010; Eriksson *et al.*, 2008; Eyre, 2010).  Others, such as Guta *et al.* (2012), suggest that the 'ethics creep' discourse oversimplifies and skews discussion in academic research in favour of a simplistic conception of ethical review as a gatekeeper or obstacle/barrier/obstruction placed in the way of academic freedom and research innovation. Far from discarding or resisting ethics creep, they propose that it need to be re-imagined

> "…as a phenomenon that implicates researchers, [research ethics committee] members, and ethics staff within a shared system of

constraints and opportunity. This alternative conception could help to

surface our shared challenges and the systems that create them" (*ibid.*: 8).[ii]

Our position is that criticism of the influence of medical paradigms in ethical review should not be conflated with a general challenge to the very idea of ethical review. Successfully challenging the medicalization of ethical review in socio-legal studies (and social science more generally) demands that we be clear about the context in which we seek to problematize it, and how our proposals, rather than simply casting ethical review aside, might develop the "shared system of constraints and opportunity" towards which Guta *et al*. gesture.

## Research Ethics Committees in practice

University-based Research Ethics Committees (RECs) are the first port of call for university research proposals seeking ethical review. Under certain circumstances these departmental, school, faculty and university-wide RECs will refer certain proposals onwards to national-level RECs administered by the Health Research Authority (HRA). Such HRA REC approval is required, for example, where NHS patients or service users are recruited as research participants, where social care research is being funded by the Department of Health in England, and when research involves people who lack the capacity to consent, either permanently or intermittently (and

aged 16 and over, under the Mental Capacity Act 2005) (DoH, GaFREC, 2011: paras 2.3.2-2.35).[iii]

Scholars have discussed how such a system can be problematic for time-pressed researchers (Elwyn *et al.*, 2005). In this article, we refrain from a critique of the effectiveness of the ethical review of clinical research, though we suggest that this continues to be important. Here we are concerned about implications for social science and humanities researchers who wish to undertake non-clinical studies that come to fall within the remit of these systems. We suggest the scrutiny they provide may adversely impact not just research timetables but also the ability to effectively interact with research participants, to build trust and hear the voices of the already-marginalised. We are not alone in feeling uneasy about this reliance on medical research ethics systems. Indeed, in 2004 in her Foreword to the Nuffield-funded research into the role remit and conduct of university research ethics committees, Sharon Witherspoon, then Deputy Director at the influential UK Nuffield Foundation, expressed it thus:

> "Given the nature of most non-medical research involving human
> participants, it seems unlikely that the system used to evaluate medical
> research – which generally has a greater capacity to do harm, generally

involves greater issues over conflicts of interest, and is better funded

than non-medical research – would be appropriate." (Tinker and

Coomber 2004: 7)

The challenges are not confined to social science research which directly triggers HRA

REC review, or where the researcher is advised by a departmental, faculty or

university-wide REC to seek HRA REC guidance on the grounds that the research

involves participants who fall within a restricted category. Since the early 2000s, there

has been increasing pressure to expand the ethical review of research to encompass

disciplines such as the humanities, business studies, art and design (e.g. see Tinker

and Coomber's (2005), influential *Report on Research Ethics* funded by the Wellcome

Foundation). We suspect this has spurred the proliferation of plural models for ethical

review.

In practice institutional approaches to ethical review in the university sector (including

policies and guidelines, REC terms of reference and training programmes) continue to

be developed – partially or even wholly – from medical research ethics models. For

example, at the University of Bristol,[iv] the majority of university documentation

available in the area of research ethics is based on material produced for, and by, the

medical sector. Thus, the Research Governance and Integrity Policy adopted by the

University in 2010 displays little evidence of addressing, or seeking to understand, the differences in approach to research ethics taken by social scientists, as opposed to clinical medical researchers. This policy was a response to the Code of Practice adopted in 2009 by the UK Research Integrity Office (UKRIO), a registered charity which, according to their website,

"…covers all disciplines of research. We were created to provide support to the UK life sciences research community as a pilot for a wider remit but *demand from employers and researchers led us to support all disciplines of research from early in our first phase*. Since then we have amassed considerable experience in helping employers, researchers and the public with issues of research conduct across all subject areas.

"We are not a regulatory body and have no formal legal powers. The advice and guidance UKRIO offers is not mandatory but reflects best practice and is informed by our extensive and unique practical experience" (UKRIO, undated, our emphasis).

There is no publically available information about the author of the UKRIO Code of Practice (or for that matter, until recently, little about who comprises the staff of the UKRIO, or their Panel of Advisors), what disciplines they are based in, or what criteria

were used to determine their guidance. However, a flavour of their knowledges and expertises is apparent in their list of supporters:

"UKRIO has the support of a number of UK organisations with interests in research, including the four UK Departments of Health, the four UK Higher Education Funding Councils, the Academy of Medical Sciences, the Association of the British Pharmaceutical Industry, the Association of UK University Hospitals, the Biotechnology and Biological Sciences Research Council, the Committee on Publication Ethics, the General Medical Council, the Medical Research Council, the Medical Schools Council, the Medicines and Healthcare products Regulatory Agency, Research Councils UK, the Royal College of Physicians, the Royal College of Physicians of Edinburgh, the Royal Society, Universities UK and research charities including the Wellcome Trust."

Meanwhile, in the social sciences recognition of the diversity of research contexts and methodologies has led representative groupings, such as the Socio-Legal Studies Association (SLSA) and the Association of Internet Researchers (AoIR), to develop ethical guidelines and codes (SLSA 2009; AoIR 2002, 2012). These codes set out key ethical principles in abstract but avoid establishing prescriptive mechanisms. This

abstract approach, however, does not lend itself easily to the type of ethical review processes which have developed in universities (and elsewhere) which are concerned with imposing systems of governance – what Hedgecoe (2009) describes as ' practical machinery' – designed to demonstrate and render auditable, an institution's adherence to ethical standards.  Such systems tend to expedient means of demonstrating adherence, then converting those into normative practices.  By this means, for example, an abstract principle of informed consent can be transformed into a normatively justified requirement for research participant information sheets and signed consent forms, without regard to whether this formal process truly supports the principle it professes to in a given context (Emmerich 2013).

Particularly for us, this raises questions of whether and where this 'practical machinery' has arisen and then applied universally, seemingly without significant input from participatory research epistemologies and methodologies. In the following case studies two of the authors have drawn upon research methodologies that recognised the capacities of participants to be active co-producers of research knowledge about their world. Such approaches question the assumption that academic rigour can only be achieved when the researcher produces knowledge from a vantage point somehow outside of, or beyond, the actors and relations they seek to research. Indeed, this understanding of rigour in socio-legal research has long been

contested. In health research, community-based participatory research emphasises "the participation, influence and control by non-academic researchers in the process of creating knowledge and change" (Israel *et al.*, 1998: 184). For example, Smith developed institutional ethnography as a "sociology for people" which aims to "*re-organize the social relations of knowledge of the social* so that people can take that knowledge up as an extension of our ordinary knowledge of the local actualities of our lives" (2005: 29, original emphasis). The co-production of research between academics and communities is being used to "design regulatory regimes that begin from the capabilities of communities excluded from the mainstream, finding ways of powerfully supporting the knowledge, passions and creativity of citizens" (McDermont, 2012: 1). Legal consciousness studies, which foregrounds what people think and do about law rather than stories law tells itself about itself, does something similar (Ewick and Silbey, 1998). However, our case studies demonstrate how the 'medical gaze' over research ethics in the social sciences has the power to significantly change the methods researchers were able to adopt, with the effect – in both case studies – of narrowing and redefining the fields of observation.

## Part II: Two case studies

### 1: Avoiding the medical gaze

The first case study arose when gaining ethical approval for research[v] that sought to understand the experiences of people who approached their local Citizens Advice (known as the CAB)[vi] with employment problems. The project was informed by the 'legal consciousness' literature (e.g. Ewick and Silbey, 1998), exploring the ways in which understandings of law and legality are shaped by interactions with Citizens Advice (see McDermont, 2013). The researcher was required to obtain institutional ethical approval for the programme before the grant contract could be signed with the funding body. Research methods were ethnographically informed, intending to follow people who became clients of CAB as they sought resolution to their problem. Methods included asking research participants to keep diaries – audio or written – to record the progress of these journeys. The diary entries would be used by the researchers in follow-up interviews, to help reconstruct a dialogue between the researcher and participant about everyday experiences involved in dealing with the highly legalised spaces of employment disputes.

The approach of following 'live' cases, rather than seeking data about experiences after the event, was innovative but gave rise to specific ethical concerns around

informed consent. The particular problem arose around CAB clients who might be suffering from mental health problems (which could be brought on or enhanced by a dispute at work). Sitting in the bureau's waiting room, the researcher had observed staff deal with a client who had become very disturbed during the advice interview. In this instance, the outcome was that the bureau staff had to make an application for a grant to provide support from the mental health team to work with the client in the advice process.

With this background understanding, the following question on the Law School's ethics application form:

> "Does your project involve participants who lack the capacity to consent either permanently or intermittently? If so the LREC [Law School REC] is not the appropriate body for which to apply for ethical approval" (Section 3, University of Bristol Law School *Research Ethics Application Form* 2012)

raised questions as to whether approval from the Law School REC was possible. However, discussion with a barrister who dealt with issues of capacity to give consent under the Mental Capacity Act 2005 persuaded members of the School REC that the legal test for capacity to give consent was set at a much lower level than was being

assumed and therefore the School REC was the 'appropriate body' to give ethical approval.

However, the issue returned through the materiality of putting ethics into practice. The consent form on its own became insufficient as a mechanism for ensuring that participants would be able to satisfy the abstract principle of informed consent throughout the entire research process. The researcher proposed an initial filtering process whereby CAB staff would aim to not refer any client as a participant in the research whom they judged could be distressed by the process. Once a client had agreed to take part in the research, it would then be the responsibility of the fieldwork researcher to ensure that participants remained able to give informed consent through the following provision:

> "Should it become apparent to the researcher during an interview that the interviewee may not be capable of giving informed consent then the interview would be drawn to a close in a natural way and as sensitively as possible, and all material from that interview would be destroyed."
> (excerpt from the application form approved by the School REC)

The diary methods approach complicated matters – it meant that participants would be providing research data even at points when the researcher was not present. The researcher therefore proposed a process of review:

> "If it appeared that material recorded by a research participant in their diary was recorded when the person lacked capacity then the researcher would review the material with the research participant with the support of a mental health advocate. The participant would be asked if they wished the material to be used for research purposes or destroyed. The continuing involvement of any participant who appeared to lack capacity will be reviewed by the research team, advised by a mental health advocate." (application form approved by the School REC)

The involvement of the mental health advocate to support the participant in discussions with the researcher was in sympathy with the research team's ethical approach of working *with* research participants and not *on* research subjects, attempting to co-produce data between researcher and participant.

However, this was not to be: the very mention of a mental health advocate was seen by the School REC as a 'trigger' that would mean the application would have to be referred 'upwards' to an HRA REC. Given the need to obtain ethical approval within a

timetable set out by the grant awarding body, the researcher was not in a position to engage with the potentially lengthy HRA REC review. The only solution was to remove all reference to the mental health advocate, thereby excluding any data that was inferred to have been generated when the research participant appeared not to have the capacity to give informed consent. This move potentially blocked the participant's continuing involvement.

## 2: Engaging the medical gaze

The second case study, a PhD project,[vii] sought to document the therapeutic practices of local mental health self-help and peer support groups. The researcher aimed to trace the emerging capacities and techniques of mental health service users/consumers and survivors who saw themselves as 'experts-by-experience' in mental health. Such experts-by-experience have emerged in public and political discourse as an authority in their own right (for example, Bolam *et al.*, 2010; Gillard *et al.*, 2010), with a capacity for troubling conventional ways of seeing and doing within mental healthcare and understandings of 'madness' more broadly (see Noorani, 2013). The researcher hypothesised that, if experts-by-experience are individuals who have experience of mental distress, and have worked upon and through their distress to the point where they make claims to having expertise in relation to their

experiences, one space for the genesis of such expertise would be self-help and peer support groups, where different strategies and tactics for working upon mental distress are experimented with and shared.

In presenting the proposal to the Law School REC, the researcher was advised to obtain ethical approval from the HRA REC for two reasons: the risk of involving 'vulnerable persons', whom the School REC reasoned may lack mental capacity, and the fact that the researcher wanted to interview city-wide NHS employees.[viii] In terms of the former, the School REC suggested that while the researcher may not have *needed* to go to the HRA REC, it was best to do so 'to be on the safe side'.

An application for ethical approval was submitted to the HRA REC. The researcher, unable to attend the HRA REC panel, entered into written dialogue with the panel regarding aspects of the research methodology. The researcher had intended to use a methodology that involved close and continued collaboration with research participants, wherein the methodological protocols would evolve during the research. The HRA REC, by contrast, made it clear that it needed to know the exact methodological approach from the outset, implying it was possible to evaluate the researcher's intended methodology against pre-established yardsticks of ideal research. Given the researcher's perception of himself as a student in relation to a

panel of 'ethics experts', the time constraints of the PhD research, and stories of delay

to others' research, the researcher largely acquiesced to the HRA REC's stipulations.

This experience was consistent with Lederman's (2007: 311) comment concerning the

impact of similar approaches adopted by US Institutional Review Boards (IRBs):

> "Insofar as they do not organize their research primarily around formal
>
> interviewing, ethnographers find it more than just inconvenient to provide
>
> IRBs with detailed, accurate protocols: a research design is antithetical to
>
> participant-observation".

Acquiescing to the HRA REC's stipulations dramatically changed the nature of the

research and the resulting findings. The researcher was required to stop attending the

steering group of one of the case study groups, in order to maintain what the HRA REC

considered as 'objectivity' in the research. This curtailed aspects of the research, both

in terms of observations the researcher could draw upon in subsequent interviewing,

and in gaining a general 'feel' for the research communities that could be written up

as anonymised observations. The HRA REC decision effectively rejected the tenets of

participatory research that motivated the project, instead mobilising an externalist

rendering of 'objectivity' that did not apply to the research questions at stake.[ix]

The HRA REC also asked the researcher to include a statement in the participant information sheet about what would happen if participants got distressed, and to add a tick-box in the consent sheet with the following:

"I understand that individuals from regulatory authorities or from the NHS Trust may look at data gathered during this study, to ensure research governance standards are met. I give permission for these individuals to have access to the data gathered."

Both statements raised damaging doubts among participants. The section describing what would happen if participants were to get distressed did not help build a connection with participants or make them feel safer. On the contrary, the researcher found that it actually risked alienating participants, by depicting them as vulnerable and liable to get upset or distressed during interviews – a caricature that the building of trusting relationships pre-interview had attempted to debunk. Up to the interview, participants had perceived the researcher to 'get' their complex relationship with formal and bureaucratic authorities, but including this statement threw that perception into doubt. This was especially problematic in the mental healthcare context where service users remain keenly aware of a long history of condescension by traditional authority figures – from psychiatrists to hospital employees to

community care teams. In spite of this, most participants found the situation humorous, especially when the researcher explained that 'this bit had to be included'. Presumptions of vulnerability were regarded as misplaced by the participants, who often described themselves as experts-by-experience, despite many of them having psychiatric diagnoses of schizophrenia, psychosis and/or bipolar disorder. Fortunately and not without a touch of irony, they had the insight to understand why this was written the way it was. It is noteworthy that such misplaced presumptions were excused only by the researcher creating a *distance* between himself and the 'faceless bureaucracy' of the HRA REC.[x]

The change to the consent form introduced the jargon of 'research governance standards', and evoked an image of NHS authorities reading interview transcripts. Given the familiarity with statutory coercion of many participants, this understandably set alarm bells ringing regarding the confidentiality of disclosures during the interview. With a departmental or faculty-level REC, the researcher might have negotiated a way of rephrasing such a clause. However, the researcher was unclear about how formal contestation of this request might slow the approval process with the HRA REC, so complied with the proposed change.

The imposition of additional wording into the consent form in this second case study had the potential to trouble carefully nourished relations of trust built up between the researcher and his participants. While in this case the researcher was able to continue the relationship with participants through sharing in the ludicrousness of it, others have not been so fortunate (see Dingwall, 2007: 290).

## Part III: Themes for further investigation

The above case studies illustrate how institutional ethics committee processes can draw researchers conducting research considered problematic when viewed through a medical lens down one of two paths. One route avoided onerous and time-consuming engagement with the HRA REC ethical decision-making process by designing the research to filter research participants who are seen as at risk of 'lacking capacity' (case study one). However, this could effectively write out these voices, permanently or intermittently. The other route, where seeking approval from an HRA REC was unavoidable, led the researcher to incorporate elements of a medical research paradigm into the project design, obstructing the traditional stewardship of such a project by the social science research methods community (case study two).

In this section, we place these case studies alongside findings from a survey of eleven socio-legal researchers at nine higher education institutions across the UK. This

sample was drawn from our knowledge of empirical socio-legal researchers, supplemented by suggestions for further participants from our initial contacts. We aimed to access experiences from a wide range of socio-legal research centres. 21 surveys (see Appendix A) were sent out for completion, by email or through phone interview. 11 people agreed to take part, six felt they had insufficient relevant or recent evidence to answer the questions and four people did not respond. Overall, responses suggested a diversity of experiences with RECs that both overlap and diverge from our own. Some colleagues at other institutions had had no problems with getting RECs to understand their social scientific research projects. However, all respondents were familiar with the experiences contained in our case studies. Moreover, three of our eleven survey respondents described having changed their research design after submitting proposals to HRA RECs, because the committees misunderstood their non-medical approaches. Others mentioned strategically manoeuvring around HRA RECs – for instance, two respondents made reference to colleagues who had redesigned small-scale studies as audit/evaluation rather than research in order to exempt them from requiring HRA REC approval.[xi]

In what follows we combine this data with our case studies to explore two possible avenues for future research into the medicalization of research ethics: the existence

of 'triggers' that automatically lead cases to be referred to HRA RECs, and the internal procedures and constitution of the RECs.

## Triggers for referring cases onwards to HRA RECs

One trigger used by RECs to filter out potentially high-risk participants was to encourage researchers to be wary of 'vulnerable participants'. This suggests a decisive categorisation of 'vulnerability' that the research community should conform to, potentially closing the door to the variety of voices of vulnerable people – voices which might challenge and resist the very category of vulnerable, or their placement within it. Of particular concern for REC procedures were cases where project proposals connected vulnerability with requirements of informed consent in the case of people who have experienced mental distress. This requirement had particular effects, stemming from how the protection of vulnerable participants has come to take rule-like form in social science ethics guidance. In the words of the UK Economic and Social Research Council (ESRC),

> "Typically, the information should be provided in written form, time should be allowed for the participants to consider their choices, and the forms should be signed off by the research participants to indicate consent" (ESRC, 2010: 29).

Consistent with our second case study, two survey respondents had heard of cases of applying for ethical approval where invocation by the institutional REC of the category of 'vulnerable' prompted referrals outwards to HRA RECs. Another respondent offered an example where 'mental disability' operated as a trigger:

"Even though our proposal expressly stated that we would not involve any participants who lacked mental capacity, and we would take steps to make sure capacity to consent to participation was assessed where there might be concerns, we have been told by our university REC that we need to go to a [HRA] REC for approval. This is a misunderstanding of the [Mental Capacity Act's] research requirements and also the guidance issued by [HRA] RECs. Our committee seems to be operating on the understanding that all people with mental disabilities have 'mental capacity issues', and the belief that researchers need to seek approval from a [HRA] REC simply to assess mental capacity - which is not the case...We are concerned that the approach of the research committee is not only highly risk averse, but reflects paternalistic and prejudiced attitudes towards disabled people - assuming that simply because a

person is disabled they must lack mental capacity and that they are also

somehow the property of the NHS".

Triggers might also be compounded by misperceptions about the researcher

themselves. One respondent described a worrying degree of 'protectionism' at the

HRA REC level, referring to his three most recent post-docs/PhD students. All had had

their projects refused in the first instance by an HRA REC, and despite all succeeding

upon appeal, close to six months was lost on each project – problematic given the

three-year span of a UK-based PhD. The delays were caused by a perceived lack of

expertise of the researchers, despite the projects having been vetted by national

Research Councils at the point of being funded. In one case the student was told that

it was in part because he was not being supervised by a medical doctor, while another

student was told that she was not appropriately trained to be doing the research. In

the second case, the student explained,

> "…they did not seem to think I was appropriately placed to conduct such
>
> research, as I was not a social worker [so] I wouldn't understand what it was I
>
> was observing. Which I felt was a fundamental misunderstanding of
>
> ethnographic research and kind of insider/outsider debates."

We suggest that the existence of triggers, whether particular terms that RECs are sensitive to, or particular images of researchers who are deemed inadequate to the task of research, need mapping out. In general, the power of triggers lies in the speed with which they lead to decisions being made, including decisions to defer decision-making (i.e. requests for more information). Against this situation, a participatory research ethos demands acknowledging that ethical research practices must constantly negotiate distributions of vulnerability, mental distress and (in)capacity across actors, situations and time periods.

## RECs procedures and compositions

One respondent, a PhD student, described how she had heard several "horror stories" about other people's experiences with an HRA REC, while herself experiencing the process as adversarial. She described being very hesitant about going back to them. She explained that the REC had "set themselves up as the guardians of vulnerable people", starting from a point of mistrust of her as the researcher:

> "They did have valid concerns, but I did not feel that the meeting was done in a way that made me feel as a researcher I should attempt to improve my research design, but rather that I was a bad, unethical researcher, when in fact

I had put a lot of time and effort into trying to design an ethical research plan. I came away feeling quite belittled and crushed".

Another respondent was required by an HRA REC to make changes to her information sheet for her potential participants.  Her university had proformas they "make us use, that they know will get through ethics." However, after being advised by the social worker with whom she was working that most of their clients would have difficulty understanding this technical language, she simplified it with an easy-read version. The HRA REC, in turn, felt that these changes would be insulting to service users "who did not lack [mental] capacity".  Yet, even with service users who had capacity, she often ended up using the easy-read version because people struggled with the proforma:

"I really think there's a balance here to be met between the technicalities of getting everything in there and the information that people actually need. Because sometimes I think it's very formal and makes it much scarier than it actually is".

Seven out of the eleven respondents acknowledged the lengthiness of HRA REC processes. Three described experiences of changing their research design to avoid the time-consuming process of being referred to an HRA REC. A further two respondents remarked that they would not be surprised to find examples of perceived and actual

time delays amongst their colleagues. Four respondents said that they actively discourage Masters level students from carrying out research which would involve HRA RECs because of the timescales involved. One of these four respondents offered a more nuanced version of the problem: that perceptions that institutional ethics processes are complex and lengthy are handed down by colleagues and peers and, while this does not necessarily map onto reality, the resulting climate of concern means that students avoid developing explorative and innovative methods – for example, rather than interviewing people who might be vulnerable, they opt to interview the institutions that work with the people concerned.

The constitution of the members of university-based ethics committees where survey respondents were based was also variable. From our survey, four respondents said their university-level committees had lay members. However, these lay members were revealed to offer inconsistent functions across the committees. One respondent described how their lay member saw the ethics process as needing a wide scope, including addressing issues of research design and methodology. This lay member wanted to discuss whether any given research was needed, and whether the methodology was ideal for the aims. In contrast, the rest of the committee members did not think these were, strictly-speaking, 'ethical' issues. Instead, they highlighted

issues such as whether there was an appropriate evidence trail regarding consent and whether the data was being stored in the right way for the requisite time.

By contrast, another respondent observed that a friend, who was a lay member on one of her university's ethics committees, was critical of the committee for being unable to "separate out what are essentially issues of ethics with issues of social science research design". The committee sought randomized study designs, and when faced with different designs they would often ask for clarification and suggest modifications. The respondent was in agreement with the lay member, arguing that ethics committees should not be considering questions of research design:

> "we're not supposed to be commenting on the efficacy and intellectual rigour etc of the proposal. We're only supposed to be saying are there ethical issues arising here…it would be inappropriate…to comment on the nature of the research at this stage. That is a matter for funders and for reviewers, whatever. We're just interested in safeguarding ethics".

Different understandings of the role of ethics committees underpin the differences in the outlooks of these lay members. It was nevertheless evident, in our small sample, that 'ethics creep' is not merely championed by the medically-trained – it can be buoyed by lay members of RECs also.

Three respondents argued that elements of the HRA REC process itself were better suited to evaluating quantitative methodologies than qualitative ones. As one wrote,

"My criticism around the scientific angle of the [HRA REC] process would be more aligned to the content and format of the online forms – they don't always reflect…qualitative research".

A second respondent reinforced this point:

"The questions they automatically ask you, even on the form are things like sample size and that sort of thing".

She described how the committee asked her what the point of her project was; when she explained they commented that "it seemed a very strange thing to do". They questioned the number of interviews she was going to carry out, baffled by how it could be 'representative'. Eventually she drew on her identity as a senior academic:

"in the end I just got irritated and I said look, you stick to doing what you do. I'll do what I do…I'm a professor…so you know, just, just drop it".

She noted that had she not held this position, she would have felt quite intimidated.

## Part IV: Towards participatory ethical approval

Both changing research designs to avoid HRA RECs, and acceding to a medical paradigm simply to obtain ethical approval, are problematic. Both tactics re-frame research in ways that make it difficult, if not impossible, for the voices of expertise outside of a medicalised framework to be heard in designing and conducting the research.

Some ethics committees and boards are more dialogic than others, employing networked and more iterative forms of communication than the critiques of research ethics as rigidly non-conversational spaces suggest. However, more dialogue does not necessarily lead to better decision-making. There is a danger that uncritical technocentrism celebrates technological practices, tools and/or innovations as mechanisms for dialogue. Rather, we suggest attending to the forms of communication and participation made possible in particular set-ups, which requires getting access into RECs themselves. For example, how does a format where REC members meet in person to discuss applications differ from a format where communication is decentralised and facilitated through wiki-style discussion networks? What difference does it make for the applicant to be able to discuss the ethical issues with multiple REC members at once, rather than with the one member

responsible for any given case? How does this change the affective charge of the application process – contrasting, say, an adversarial feel with a collaborative one? Are certain techniques employed to contest, provoke or push the boundaries of the status quo in research ethics deliberations? Conversely, are certain procedures best for unidirectional assessments of the viability of the research proposal? And what are the procedural differences between RECs that set up to deal with the problems of distinct disciplines?

Our case study experiences and survey responses lead us to consider the importance of allowing different knowledges to support the development of understandings of what ethical practices might be in different fields and different environments. Rather than viewing ethics committees as gatekeepers to ethical research, the *holders of expertise* about what is ethical, we might see them as *translation devices.* This means that they can act as the conduit for various knowledges about ethical practices arising from a variety of expertises, facilitating the translation of these knowledges for the particular site of research under consideration. At the same time, finding ways for more diverse knowledges to enter into the research ethics process does not necessarily mean requiring so-called lay persons to sit on the RECs. Neither does it require fully endorsing a principle of *subsidiarity* of decision-making, preferencing decisions made at the point closest to research sites. While we recognise the

importance of embracing experimentation at the university level, where ethics committee decision-making processes can assemble researchers and local experts-by-experience, this is not the whole story. Sometimes distance is useful, allowing for ethical considerations to be explored in conjunction with others at different scales or with 'outsider eyes'.

RECs today operate in a context where medical authority in the field of mental health is being challenged and contested by alternative knowledges. It would be fruitful to investigate whether and how alternative forms of knowledge are being authorised (or not), and given voice (or not) within ethical review processes. We might enquire about what invitational practices are being utilized by RECs in attempting to *listen* differently. We might consider the expertises of REC members have that are sidelined by privileging medical (and increasingly legal) expertise in REC decision-making.

Thinking in terms of the privileging and deprivileging of voices offers a different organising frame than the medical one of (individualized) vulnerability and (binarized) mental capacity. Instead, RECs dealing with social scientific research questions and methodologies might consider which voices are heard/silenced and which are not, and what the implications are for doing research. Participatory research approaches bring political questions of voice and power to the fore. They also ally themselves with

iterative design processes when research methodologies cannot (or should not) be determined in advance of conducting the research (Khanlou and Peter, 2005: 2334; 2339). This can have important implications for how we understand 'gatekeepers'. Some spokespeople and vocal members of minority groups can be powerful actors with dual roles in relation to researchers, as gatekeepers and as experts-by-experience. There is certainly scope for reconsidering how they could be incorporated into more participatory ethical review processes (for example, Banks *et al*. 2013, Flicker *et al*. 2007). Khanlou and Peter suggest that:

"…knowledgeable community members can alert Research Ethics Boards to possible risks involved to participants both at the individual and group level" (2005: 2339).

We have argued that medicalized ethical review, by framing the issues around risk-laden trigger terms, can squeeze out voices, creating categories of those who are too 'vulnerable' to be heard. We therefore take the point made by Khanlou and Peter further. Rather than query whether ethics committees are composed of the appropriate knowledges and expertises, and indeed have the right to tell researchers how best to do their work (*cf.* Hammersley, 2009), one might shift the focus by asking, *how* do we incorporate expertises/voices/claims-on-ethical-practices, beyond those

sanctioned through a medical gaze, into our research ethics procedures? Within this framing, RECs can (and some do) serve an important function in helping researchers *discover* how best to do their research.

Taking inspiration from Gibson-Graham (for example, 2006a; 2006b), we could start by documenting the plurality of ways in which researchers are related to bodies of 'ethical expertise' (including, but not limited to, RECs) and whether they are consciously seeking richer appreciation of the ethical considerations of their research. Lederman (2005; 2007) suggests that the anthropological strategy of 'relativizing comparison' is effective here. Our case studies suggest that the primary mode of engagement of researchers with RECs can all-too-easily be that of deference/acquiescence. The problem can be framed as follows: researchers (and in particular early-career researchers) defer to the expertise of university RECs, who, in harbouring concerns about jurisdiction, send applications up to HRA RECs, who defer to the authority of medical epistemologies and methodologies.

One way to begin to trace the possibilities for enriching ethical review protocols would be to consider what modes of engagement, other than 'deferring' or 'acquiescing', already exist in the enhancement of ethical practice. Examples abound, from the mentor-researcher relation, to the CAB-client relationship of the first case

study, to the peer-to-peer support relations of the second case study. Researchers can defer to the authority of medics, legal professionals, peers, experts-by-experience or whomever else; but they can also be advised, provoked, contested, empathised with, sympathised with and so on during the research process. We need to show how this is already occurring if we hope to enrich our models of best practice. Perhaps such a project would even hold off on claiming that RECs must hold the power to veto research applications, at least until we can assess whether and how vetoes are being used in practice.

Ethical problems can be recognised and engaged with in numerous ways, incorporating a range of actors and techniques, of which both medical authority and distinct RECs separated off from research teams are a single instantiation. RECs could demarcate space for the 'dissenting opinions' of REC members as distinct from the collective's decision-making. Relevant community-based organisations' ethical deliberations could be taken into account. Rather than being the sole oversight body for the ethical practice of research, any given REC can be seen as a particular skill-set. This, combined with other individuals, groups and organisations, could produce decentered ethical oversight specifically tailored to the project in question. We believe that case studies are a useful pedagogic resource in illustrating the often-

hidden diversity within ethical decision-making (for example, Banks *et al.*, 2013; Pirie and Gute, 2013).

This multiplication of relevant ethical authorities throws up new ethical dilemmas. For instance, how can we determine who counts as an expert-by-experience, without perpetuating tendencies to conflate proxies (such as belonging to a community or having had an experience or having accessed a mental healthcare service)? Understanding how we might *measure* someone's expertise by experience, or see it as constant renegotiation, feeds directly into the possibilities for operationalising an overhaul of the ethics review process. Other questions include asking what techniques are being used (and could be mainstreamed) to explore how consent can be meaningful and informed, outside of providing signed consent forms. And just how do we reconfigure questions of responsibility and accountability when both are distributed across multiple persons and sites?

The context-independence of the machinery of proceduralist approaches to ethics has been lauded for allowing universal applicability. However, in moving away from the conventional models of objective inquiry presupposed by the medical model towards paradigms of situated knowledges, we are forced to rethink the relation of the form and content of decision-making. We identify the challenge as remoulding ethical

protocols around the content of the research project under scrutiny. A first step would be to systematically draw together examples of problems thrown up for the variety of research practices where ethical issues are recognised and dealt with in more creative and participatory ways by the narrow medicalized framing of RECs.

## Conclusion

In contrast with the assumption that RECs are inert containers for the playing out of rules and practices of ethical procedure, in this article we suggest that the forms of organisation and communication of RECs and the content of their decision-making are related in important ways. Legal consciousness offers one approach for studying ethics committees and boards as research sites in their own right, both translating and producing knowledge and requiring both critical appraisal and creative intervention. We have used two case studies detailing attempts to gain ethical approval for socio-legal research projects to illustrate the effects of the increasing medicalization of research ethics procedures, supplemented with a small survey of socio-legal researchers at other institutions in the UK. We have analysed the issues in terms of jurisdictional insecurities concerning risks posed by certain terms and ideas that 'trigger' referrals from local RECs to HRA RECs, and the varying material configurations

of ethical review. We ended with a consideration of the promise and challenge provided by multiple (and multiplying) claims to knowledge, expertise and authority.

Engaging with a REC, as with an audience of strangers, is very different than discussing one's research with an audience of peers who are familiar with the approaches, the context and/or the topic. We do not deny that non-medical communities of peers can engender strong norms that are exclusionary in their own ways. However, here we are interested in the effects of the aporias that emerge in research when socio-legal scholars have to obtain permission from medically-inclined ethical approval processes.

Poitras and Meredith (2009) suggest it is useful to distinguish between social medicalization and economic medicalization. They describe the former as concerned with social control, while the latter deals "with the creation of markets for medical technology and professional services" (*ibid.*: 315). We suggest a need to consider academic medicalization, imbricated with the other two, and argue that we must actively, reflexively engage with the research ethics process as the key site of its (re-)production. Indeed, one could argue that academic medicalization accelerates social and economic medicalization by furnishing these processes with their intellectual resources. We are concerned that if we do not interrupt medicalization at the ethical review stage, research that seeks to engage those individuals, groups and matters of

concern that are deserving of attention will either be denied access or transformed to fit the *status quo*. This is a dangerously insular situation for research that engages questions of mental health, and one that also risks making academia increasingly irrelevant in wider social contexts that are opening up new possibilities for participation, voice and expertise-by-experience.

At this early stage of turning the researcher gaze upon RECs, attending to what does and does not surprise experienced researchers about applying for ethical review might offer a good way to gauge the reifying impressions of what will and will not get approved in a given REC. It could also be that the Chairs of RECs, who have witnessed the changing constitution of committees and the discourses prevalent within them, would be useful sources for preliminary inquiry. Mapping the variegated landscape – inexperienced researchers versus experienced ones; researchers who also sit on RECs versus ones standing apart from them; differences between disciplines and departments and national jurisdictions – requires resources as well as self-referential ethical review applications that pose a whole new set of issues. The goal of a shift towards broader ecologies of ethical practice will necessarily entail changes in the distribution of material relations and expertises, and wider concerns for participatory democracy provide an opportunity to open up these conversations. We propose that

the drawing together the myriad stories of challenges in ethical review is a positive

step in this direction.

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i      'Mental distress' and 'mental health problems' will be used throughout this article, to refer to the experiences with which we are concerned, regardless of whether and how this distress has been understood or interpreted through healthcare professions. They are broader and less contested terms than referring, for example, to the 'mentally ill', which in itself makes an appeal to a particular, medical framing of distress (or health problems) in terms of 'illness'.

ii      This is not uncontentious, and Schrag (2012) offers some cogent criticisms of Guta *et al.*'s arguments and analysis.

iii      The NHS RECs are focused on healthcare-related research, and run by the HRA, providing ethical review of all health research which involves patients in England. See http://www.hra.nhs.uk/patients-and-the-public-2/types-of-study. In 2015 the HRA also took on responsibility for research in adult social care, including running the National Social Care REC. This reviews a range of research proposals related to social care including social care research that involves people lacking capacity in England and Wales, and requires approval under the Mental Capacity Act. See http://www.hra.nhs.uk/resources/before-you-apply/non-nhs-recs/national-social-care-research-ethics-committee.

iv      At our university, there is a tier-based system of ethical review, entailing school-level, faculty-level and university-wide RECs. While this may differ in other universities, the distinction between university-based RECs and those operated by the HRA and based in the Department of Health will be the key distinction drawn upon in this article.

v      Funded by European Research Council grant no: 284152.

vi      Local Citizens Advice bureaux are an independent charities that provide free, impartial advice and information on a range everyday problems from employment to housing and debt: http://www.citizensadvice.org.uk/.

vii      Funded by the UK Economic and Social Research Council grant no: PTA-031-2006-00093.

viii      Since this research was conducted, the second of these reasons no longer applies, see NRES (2012). However, it mirrors a theme explored further below: that the Law School's suggestion to take the case to the HRA jurisdiction was motivated (in the main) by one concern, but once in the HRA REC jurisdiction, the case became (re)problematized in different ways that derived from the HRA REC's medical gaze.

ix      The term 'objectivity' has been heavily contested in the history of social science research. A good example is Harding's (1993) standpoint epistemology, wherein 'strong objectivity' requires (rather than avoids) a commitment to reflexivity.

x      We have found that it is in such distances that 'reparative negotiations' can occur between social science researchers and community participants.

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[xi] Where research can be understood as generating new knowledge, evaluation judges the quality of a current service, and audits measure practice against a standard (see Twycross & Shorten, 2014). However, the authors doubt whether, in the context of their own institution, evaluation research would be exempt from ethical approval.