

**Summary of research for participants and the Health Research
Authority**

**‘An ethnographic study of National Health Service Research Ethics
Committees: Mapping Ethics Review’**

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Contents

Background to the study	3
Aims and objectives of the study	5
Methodology	6
Methods	6
Data types used in analysis	6
Analysis of data	7
Ethical approval and institutional permissions	7
Consent	7
Anonymity and confidentiality	7
Findings	7
The ‘architecture’ of ethics review	7
The relevance of researcher attendance	8
The significance of membership	8
Judgements and decision-making – “is this okay?”	9
‘It’s kind of subjective - but not’ – the place of trust	10
Judgements transformed to decisions - using procedures and ‘recognition work’	10
Expressing uncertainty- acknowledging ambiguity	11
Discussion	11
Insights revealed through the research and relevance to REC training	12
Researchers and vulnerability	12
Implications for research ethics education	12
Qualitative research – the question of bias	13

Trust and trustworthiness – ‘the way they answer questions, their conduct, their modesty, admitting and acknowledging mistakes’ 13

Consent and capacity – procedure and practice 14

Potential for future research 14

Acknowledgements 15

Appendix: Mapping ethics review 16

References 17

Table of abbreviations

NHSREC	National Health Service Research Ethics Committee
REC	Research Ethics Committee
IRB	Institutional Review Board (ethics review committee in the United States)
NRES	National Research Ethics Service
HRA	Health Research Authority
NVivo	Qualitative data analysis software

Background to the study

Ethical regulation in general and ethics review more specifically are perceived as challenging for researchers and have been subject to critique from both qualitative and quantitative research paradigms. Existing critique clusters around the following themes:

Bureaucracy and its impact on research. Authors here suggest that there are unacceptable delays in receiving decisions on ethics in review or that the requirements of review are excessive, unachievable and constitute a barrier to research. (Dingwall, 2006; Hammersley, 2010; Stewart et al (2008).

Dominance of quantitative research paradigms. There is perceived lack of understanding of qualitative research and quantitative 'bias' (Burr and Reynolds (2010); Murphy and Dingwall, 2007; Hammersley, 2009, 2010). Alongside critics of the system, particularly in the social sciences, other commentators have identified the potential educative value of engaging with review systems (Wiles,2012; Guillemin and Gillam, 2004; Israel and Hay, 2006) despite acknowledging some of the (historic) limitations in relation to qualitative research paradigms.

Centrality of the *informed* consent requirement. This has been problematised from a range of perspectives which view it as unachievable in some methodologies, as necessary but problematic, or as an overly bureaucratic requirement which makes it informed but not necessarily genuine (O'Neill, 2003). The shortcomings of procedural consent in medicine and biomedical contexts and which also relate to consent in research ethics have been highlighted by philosophers (O'Neill 2003; Kittay, 2007; Manson and O'Neil, 2007) while sociologists have commented on the potential privileging of consent over other ethical considerations and described informed consent as an 'ethical panacea' (Corrigan, 2003). Furthermore, the importance of context in consent (Greenhough, 2007) and the need for it to be seen as an ongoing process rather than a 'on-off' event (Corrigan, 2016) has also been highlighted

Procedure and principles. Concerns with the overly-procedural nature of review in general is criticism of the principlist approaches which inform the review process. Hammersley (2015) claims that judgements are derived in a 'quasi- logical way from given principles' (p445).

Gaps in existing research. The literature review evidenced the paucity of discussion about and inquiry into how reviewers in RECs are involved in the review process. Existing accounts of review and the role of consent have not explored how reviewers' activities are carried out, where procedures and principles are enacted and where judgements about research take place. Exceptions are Hedgecoe (2008; 2009; 2012) in the United Kingdom and Laura Stark on Institutional Review Boards (IRBs) (2012 and 2013) in the United States.

Conclusion

Much is claimed about the barriers and limitations which the review of ethics presents to researchers, however, there is little evidence which starts from the standpoint of committee members and explores how the work of review is accomplished in the everyday contexts in which decisions are made. Sheehan (2013) has responded to criticisms of the functioning of RECs as over-generalised and therefore inaccurate. He argues that critique requires evidence and this is not always apparent in the arguments for changes in the current system of ethics review. This research provides detailed investigation into RECs to discover how their work is achieved.

The focus of the study was NHSRECs which are 'flagged' to review studies which involved participants who may lack capacity to consent. This meant that reviewers had undertaken additional training on the Mental Capacity Act 2005.

Aims and objectives of the study

Overall Aims:
<ol style="list-style-type: none">1. To provide an interpretive ethnographic description and 'mapping' of the everyday work of RECs by use of institutional ethnography.2. To illuminate processes in ethics review.3. To promote a reflexive approach in the further development of NHSRECs.
Objectives:
<p>Primary Objectives:</p> <ol style="list-style-type: none">1. To investigate <i>how</i> RECs reach opinions in their review of research applications.2. To explore <i>how</i> research applications (including capacity and consent) are operationalized (use of requirements in practice) in meetings; and,3. To investigate <i>how</i> research applications (including capacity and consent) are conceptualized (thought about and discussed) in meetings, by members and by researchers.4. To describe ethics review in NHSRECs from the perspective of those who live it, experience it and talk about it.5. To analyse ethics review in order to provide a 'mapping' of processes in the REC. <p>Secondary Objectives:</p> <ol style="list-style-type: none">6. To explore <i>whether</i> there are differences in the review of qualitative and quantitative research.7. To investigate the experiences of researchers of attending for review and their conceptions of consent.

Methodology

The study used institutional ethnography to ‘map’ the work of RECs. Theoretically, institutional ethnography starts with the standpoint of those involved in the seemingly mundane and everyday work of institutions. The research sought to deepen understanding and provide insights into how committee members view their work and their perspectives on research and researchers. Interpreting the everyday is foundational to institutional ethnography and the endeavour also seeks to describe how work is shaped and organised by wider social discourses. A further component of institutional ethnography is exploration of ‘texts’ which in this context refers to the words, images or sounds which are observable as well as specifically about how documents and their functions are incorporated into work practices.

Lastly and importantly, the research did not set out to evaluate or portray practice as good or bad. Its intent was discovery and the creation of knowledge in order to reveal important work where it takes place – in the committee meetings.

Methods

The methods employed were observation and interview.

Data types used in analysis

1	Transcribed observation notes
2	Transcribed interview records- committee members including Chairs and reviewers
3	Transcribed interview records- researchers
4	Transcribed field-notes.

In addition, there was a *post-hoc* analysis of a significant text (The Mental Capacity Checklist) and its use during meetings. This analysis is not presented in detail in this summary. Altogether, there were nine observations of RECs with a total of seventeen research applications heard. Twelve individual interviews were conducted with reviewers and eight with researchers who had attended the REC at the time of my observations

Analysis of data

Data were managed with NVivo software, organised into themes and then analysed with the aim of producing a detailed ethnographic description of the work undertaken. Analysis was based on crystallization (Tracey, 2010) which was selected as the study utilised multiple data sources and theoretical lenses to interpret data. The advantage of this conceptual frame of analysis, which contrasts with triangulation, is that it allows for a more complex and in-depth analysis and creation of knowledge about the topic

Ethical approval and institutional permissions

The study and design were approved by the National Research Ethics Service (now incorporated into the HRA). Scientific review of this study was undertaken and reviewed internally by the Executive Committee of the School of Nursing, Midwifery and Social Work at the University of Salford. Given favourable opinion by the University of Salford's Research Ethics Committee (Reference HSCR11/17) in January 2011.

Consent

Letters and participant information sheets were provided to participants. Verbal and/or email consent was provided for interviews. In addition, as noted by the HRA (2013) recent evidence has indicated that 'talking one-to-one was the most effective way to provide information that was understood.' In this way, consent was negotiated at each observation and at the time of interview.

Anonymity and confidentiality

Individual members of RECs and researchers have details, for example, gender changed or are referred to as s/he. Where research applications were referred to, in each case, details were modified and minimal details provided, though sufficient to make sense of commentary.

Findings

The 'architecture' of ethics review

RECs are steeped in bureaucracy. The meetings are structured and follow a sequence which assists with achieving their work. Membership is important. Micro-level analysis of who speaks at meetings and the exchange with the researcher is

relevant in how deliberations lead to decisions. All RECs are different and yet the sequences followed ensure that work is co-ordinated across sites. This is also important in the need to demonstrate equity and fairness in the system.

Institutional review of research ethics is constrained in time and space by the REC meeting. The business of the RECs can only be achieved by following certain sequences of action (including the appointment of reviewers, debate, researcher interview, further debate leading to decision). The settings of RECs influence the atmosphere of meetings, for example, hospital settings, and formal committee rooms.

The sequence of events at the RECs was important in that decision-making was managed and achieved. Committee members move from one focus to the next in considering each application. This can be shown as three stages:

Stage 1	Discussion of application by the REC
Stage 2	Interview/discussion with the researcher
Stage 3	Discussion leading to decision

This sequence supports the achievement of the business. Sequencing enabled:

- Disagreement to be managed
- Outcomes to be achieved
- Containment of the discussion

Meetings therefore establish direction and assist in justifying decisions.

The relevance of researcher attendance

The micro-analysis of who spoke at the meetings revealed that the most frequent and longest exchanges were generally with the researcher. There were numerous examples in the data of reviewers asking detailed questions of researchers.

This back and forth checking with the researcher about design and purpose was common to all meetings observed.

The significance of membership

Lay membership has significance beyond the committee. The desire for lay members to be included is crucial in countering the 'bias' and 'orientation' of RECs to

a biomedical approach. There is a dominance of medical members and there is a familiarity with quantitative research and a tendency to see this as 'proper' research. However, lay members did make a significant contribution in the REC. Time was given to their views and they often opened up debate, raising questions which might have appeared obvious to medical members but which nonetheless brought attention to pertinent issues.

Interview with reviewer: *We try to allocate to background but everyone can express views. Lay views are just as important. We don't weigh a medic more highly than a lay. It's a collective view.*

Most lay members had skills or knowledge from their own professions. Examples of lay membership were barristers, statisticians and philosophers. Those interviewed clearly brought recognisable skills and knowledge with them into the meetings. Professional knowledge and expertise was valued.

Judgements and decision-making – "is this okay?"

'Judgement' and 'decisions' could be distinguished in deliberations. NHSRECs formally 'give an opinion' in ethics review, however, in reaching that opinion, the study revealed that committee members exercised '*judgement*'. This involved discernment and a qualitative weighing up of complex factors in the balance to arrive at a decision (referred to as an 'opinion' by the HRA).

Observations revealed how much of the REC discussion was outside of the constraint of requirements with open questions being asked: Is it right to? Should this happen? What is the purpose?

Interview with reviewer: *I try to keep in mind what could go wrong for the patient. I try to be creative – how would I feel. The guidelines are difficult to keep in mind.*

Reviewers drew on personal values and experiences. The regulations are 'kept in mind' But in order to make moral sense of what would happen in the study, the committee member asks questions of a personal and emotive nature – would I want this to happen? This demonstrates how judgement is at the same time abstract and practical. The ethical requirements are a logical framework, an ethical framework to be kept in mind but judgements are integral to making a decision.

'It's kind of subjective - but not' – the place of trust

Relationships with each other in the committee and particularly with researchers were significant. All reviewers were positive about researchers and sought to facilitate their research. The face to face contact at meetings was

Reviewers discussed applications and then decided what they wished to check out with the researcher. 'Checking out' was not solely about the application but about trust. For example, after a lengthy discussion of paperwork, one reviewer said '*Okay, let's see the cut of his jib!*'

Interview with reviewer: *It's not to do with their moral life but when they come in, what they show. Are they trustworthy, do they have integrity and an understanding of what they are doing? (It's) the way they answer questions, their conduct, their modesty, admitting/acknowledging mistakes.....*

When there were doubts about the research, the impression made by the researcher was a crucial factor in making a judgement about the application.

In one observation, the concern of the committee was the requirement in the MCA 2005 that a study could not take place without the inclusion of those lacking capacity.

Observation: *Reviewers probed the researcher so that researchers defended and could provide a rationale for inclusion of people who lacked capacity. Reviewers took responses seriously. They also considered the right of people to be included in research.*

Here, reviewers were pushing the researcher to defend the choices made, 'testing out' responses, wanting to be convinced. The subsequent discussion leading up to a decision was a detailed discussion of requirements but the researcher's integrity had impressed.

Observation

Reviewer 1: S/he wants to include (this group of participants) in the pursuit of knowledge, so why should we stand in her way?

Reviewer 2: It's flawed but maybe it's as good as it can be.

In the end decisions were made based on pragmatic judgements.

Judgements transformed to decisions - using procedures and 'recognition work'

The REC spent a great deal of time looking for evidence in the applications they reviewed of the concepts required by the regulatory text. These are informed by the

ethical principles of autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress, 2013). I describe this reviewer activity as '**recognition work**'. Reviewers had considerable skill in understanding requirements and in how they must adjust their judgements to correspond with them. Nevertheless, RECs resist confining their judgement to procedures 'texts' and engaged in practices which connect with the moral and ethical elements in research applications.

Committee members considered the abstracted ethical principles which inform regulation and procedure, but they used subjective means to translate these into meaningful and practical concepts and requirements.

Committee members referred to procedures to legitimise their judgements. A detailed analysis of the use of a 'text' used in NHSRECs, the 'Mental Capacity Checklist' was conducted and this demonstrated how committees make their judgements 'fit' with requirements, looking for evidence of the required categories in the application and in the dialogue with researchers.

Expressing uncertainty- acknowledging ambiguity

RECs did not see their role simply as 'rubber-stamping' research. There was a wider purpose which was to provoke awareness among researchers. Another reviewer talked about the ethical requirements in the MCA (2005) and procedures were not an easy fit with the ethical quandaries which were presented by the applications. At the start of the interview she was sure that the requirements and the capacity checklist used was helpful but then became more hesitant and uncertain as the interview progressed. Her responses show how committee members were often holding two incommensurate positions - that of having to comply (in the same way as the researchers) and reduce complexity to bureaucratic requirements whilst feeling doubt and uncertainty about their decision making. In other words, thinking solely about what 'ought to be done could lead to uncertainty about whether decisions were 'right'.

***Interview with reviewer:** The checklist was seen as helpful as it helped to distinguish capacity issues in treatment and research. The law had to be adhered to but it was acknowledged that something that was legal might not feel ethical.*

Discussion

Insights revealed through the research and relevance to REC training

Reviewers are so immersed in the *doing* of the work and in the texts of ethical regulation that it becomes difficult to examine processes. Much becomes taken for granted or obvious. The consequence of this is that work becomes familiar and routine. It therefore becomes difficult to conceptualise alternative ways of working.

The HRA is committed to training of reviewers and offers training days. Space on training days for a reflexive consideration of processes in committees could be beneficial for reviewers. Training focussed solely on bureaucratic process is limited in its potential to improve practice in a meaningful way as it focuses primarily on efficiency. Furthermore, an acknowledgement of the use of subjective judgement in decision-making would be positive as would allow members to consider what influences their decision-making. An important part of this would be developing a critically reflective approach which acknowledges the factors shaping of review for examples, the role of bias, individual morality and overarching discourses of trust and accountability. All these inevitably impact on the work undertaken in review.

Researchers and vulnerability

The insights I provide also reveal positive practice. A substantial part of the discussion and deliberation at meetings was with the researcher. This demonstrated a genuine interest and support for research and willingness to engage with researchers' challenges in practice. The most frequent response to my question of who is vulnerable in research, was 'researchers'. Members are keen to protect researchers and ensure they have support in conducting research. I have not included findings from researchers in this summary.

Implications for research ethics education

Qualitative and quantitative researchers have criticised the REC processes generally and the NHS review process in particular. The critiques centre on the overly bureaucratic nature of review and the bias in review against qualitative research. The review also raised the concern that researchers moderate their proposals, particularly with 'incapacitate' people to achieve ethical approval (Juritzen et al, 2011). The reach of this dominant way of seeing ethical regulation extends to and

influences some curricula content of research ethics teaching in Universities in the United Kingdom.

Qualitative research – the question of bias

Curricula frequently take a procedural perspective in teaching. Unsurprisingly this is because student researchers need to have approval from (potentially) a range of RECs, including the University REC. However, this research has shown that committees are open to dialogue and interested in research. Reviewers acknowledged that they did not always ‘get’ qualitative research but this did not necessarily mean that they were against it. However, this may have meant in practice that reviewers acted more cautiously as committees were often concerned with inexperienced researchers and their protection within research teams or by supervisors. Qualitative researchers are perhaps less likely to be supported by the kind of established structures which are familiar in biomedical research. Nonetheless, researchers are part of a community responsible for ethical research and therefore have some responsibility for raising the level of debate in review beyond the procedural.

Trust and trustworthiness – ‘the way they answer questions, their conduct, their modesty, admitting and acknowledging mistakes’

Trust played a significant role in judgements made about research and researchers. Researchers are not expected to have anticipated all the potential challenges of design or ethics. One reviewer put it like this:

They (researchers) don't know the answers but the project will help find some of them. Because we trust them (even if we don't fully understand the methodology) we will approve.....

So, (we're) not bogged down with minutiae – (we are) willing to trust.

In this interview, ‘minutiae’ referred to the ‘principles-informed’ regulations and requirements. This perspective seems to contradict Hamersley’s (2015) critique of the nature and role of principles in ethical regulation arguing that the principles informing frameworks are turned into specific judgements about research in RECs and become ‘prescriptions’ and ‘proscriptions’ required of researchers (p444).

It is important then for teaching content in curricula to reflect these findings which may empower student researchers to be bold in their ideas and be accountable for

them in review of ethics. Rather than teaching reflecting a solely procedural view of ethics, it may be more valuable to acknowledge the complexity of issues, of consent for example, as this may better equip students to respond to reviewers' questions. Similarly, whilst holding in mind the protection of research participants, teaching needs to enable researchers to articulate the balance of risks and benefits in their research and argue persuasively in ethics applications.

This point echoes Wiles (2012) view that review can potentially assist researchers with ethics questions at the anticipatory stage of research.

Consent and capacity – procedure and practice

Reviewers had a good working knowledge of the Mental Capacity Act 2005 and used the 'checklist' in decision-making. They engaged with issues of capacity to consent in a sensitive manner. However, critiques of the gap between consent in research practice and consent in procedure are relevant. RECs have no authority to follow up on the proper conduct of research and current systems and consent is primarily procedural and seen as a 'one-off' event. Reviewers and researchers spoke of an identified person who would be 'taking consent' suggesting that it is a discrete activity and one which is abstracted from the context of research.

Potential for future research

The prospective of a pilot training project would be dependent on the HRA and willingness of members to engage when their commitment is substantial anyway. However, there would be potential benefits to such an initiative and research might evaluate advantages to members and lead to action in the form of change in processes or the organisation.

This kind of reflexive analysis requires of committee members a different way of thinking about review. The benefits of this are that members themselves may potentially influence the organisation rather than the organisation setting further training priorities. Although some legal and regulatory requirements are non-negotiable, recognition of the ways in which RECs achieve their work by members themselves is an important step in achieving what Gorli et al (2015) have termed 'organisational authorship'. Organisational authorship means increasing professionals' influence on the development of an organisation's work. Using a

straightforward conceptual tool, comprising exploration of work practices, analysis and action.

The findings may therefore assist in finding new ways to further develop the review system.

Future work is also needed to better understand how researchers view ethics review and to explore the gap between procedural ethics and ethics in research practice, perhaps particularly focussing on consent.

Researchers may also benefit from gaining insights from 'inside' the ethics committee, increasing their knowledge of review from the perspective of those making decisions.

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Appendix: Mapping ethics review

Mapping ethical regulation in the Research Ethics Committee

1. The ordering of ethics work

Setting, order and membership organise the work of the committee at the micro-level of each committee and across committees.

This assists with need for transparency in proceedings, ideas of fairness, equity and objectivity.

2. Making judgements

Ethics work carried out in the committee is subjective and includes use of emotions - thinking themselves into research.

Sensitive to capacity in its complexity.

Identifying ethical elements in studies.

Relationships - with each other and with the researcher are significant in judging research.

Reviewers engage with overarching principles and the framework of requirements by use of subjective means.

3. Making decisions

Importance of texts - the form of requirements needed in decision-making.

Back and forth activity of judging application and then making a 'fit' with requirements once judgement is made.

Looking for evidence of the required categories in application and researcher.

Working up to a decision.

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