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Nathan Emmerich

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Original paper

On the ethics committee: the expert member, the lay member and the absentee ethicist

NATHAN EMMERICH

School of Sociology, Social Policy and Social Work, Queen's University Belfast, Northern Ireland

Email: nemmerich01@qub.ac.uk

This paper considers the roles and definitions of expert and lay members of ethics committees, focussing on those given by the National Research Ethics Service which is mandated to review all research conducted in National Health Service settings in the United Kingdom. It questions the absence of a specified position for the 'professional ethicist' and suggests that such individuals will often be lay members of ethics committees, their participation being a reflection of their academic interest and expertise.

The absence of a specified position for professional ethicists and the concomitant but implicit denial of ethical expertise appear to be an anomalous state of affairs if one considers that the training offered to members of ethics committees is often delivered by academic ethicists. It is suggested that this is based on a misunderstanding of the concept 'ethical expertise' and that properly understood the ethicist can assist the work of ethics committees by drawing on their expert knowledge.

Keywords: applied ethics, ethicist, expertise, lay, expert.

Ethics committees and their members

The membership of ethics committees, whether they are 'clinical' or 'research' focussed, is mostly comprised of experts of the subject that concerns the committee. For example a committee charged with reviewing research in sociology will be largely composed of sociologists. Such committees are almost always mandated to contain at least one lay member [1]. Whilst it may not be the case that the vast majority of research ethics committees are concerned with healthcare or biomedicine¹ these committees are the most prominent both in the academic literature and in terms of the public's awareness. My comments should be taken to apply to both clinical and research committees concerned with healthcare and biomedicine as well as ethics committees operating in other disciplines. Committees concerned with the review of the ethical aspects of healthcare often have specified positions for a variety of named healthcare specialisations. In order to meet the needs of ethical review the appropriate expertise needed to comprehend the research proposal must be present in the committee. Whilst lay summaries of research are part of the appli-

cation procedures to many ethics committees and whilst ethics committees are not charged with the scientific or peer review of research adequate understanding of the scientific dimension of research is necessary to analyse, understand and judge the ethical issues which the research may raise. Occasionally there may be a space reserved for a religious minister, particularly in the context of a hospital clinical ethics committee with an active chaplaincy or a University with an explicitly theological ethos.

What is not a mandated position is the 'academic ethical expert' considered as either a moral philosopher, an applied ethicist or as a theologian with a particular interest in 'applied ethics' where applied ethics is properly understood to be a varied and interdisciplinary academic field of professional ethics, bioethics, research ethics, business ethics, nursing ethics, healthcare ethics, social work ethics etc.² Such academics, particularly those who are explicitly identified as 'applied ethicists,' are often those who provide training for the members of ethics committees. Training in ethics review often utilises the theories and perspectives generated by the aforementioned dis-

¹ There is no way to tell exactly how many ethics committees exist, but presuming that most academic departments now have one it may be the case that the majority are not biomedical in their remit.

² From this point on I predominantly use the terms ethicist and applied ethicist. However in using these terms I mean to include all those who operate in the field of applied ethics but who may not consider themselves to be applied ethicists.

ciplines and its academic literature. That there is no mandated position for the expert ethicist on ethics committees may come as no surprise to some. The notion of the 'ethical expert' is a contested idea. Discussion of ethical expertise and what it might mean is extant in the literature on applied ethics and arguments both for and against the idea has been raised [2-11]. The concept is often taken to imply some moral authority and a kind of 'moralism' which is at odds with our multicultural society and its ideas of the moral autonomy of the individual.³ However, it seems strange to privilege an area or discipline of academia and its academics in the training of members of research ethics committees, implicitly recognising the 'expertise' of the discipline and its members, yet not mandate specific places on research ethics committees for such individuals. Discussion of the place and purpose of the lay member on the ethics committee is also prevalent in the literature of applied ethics. The concepts of expert and lay stand in relation to one another and ethical expertise seems, in its moralistic sense, pejorative of the laity, ie the non (ethical) expert, and by implication their moral autonomy; their ability to decide right from wrong for themselves.

NRES committee members

The National Research Ethics Service (NRES) is but one example of the way in which ethics committees are organised in the UK. However, it is the most prominent body charged with research ethics governance and offers the most explicit guidance on the categorisation of 'expert' and 'lay' members. The definitions offered do not seem to be at odds with those of other bodies and so it is valid to analyse the statements made in NRES documentation in order to make the general point this paper is seeking to present. NRES acknowledge that what is to be considered an expert 'may have different meaning in...professional and organisational contexts...other...than the ethical review of medicinal trials'[12] yet nowhere do they acknowledge the expertise of the ethicist for the ethics committee. Indeed they seem to deny its relevance when they define those with 'professional qualifications or experience relating to the conduct of, or use of statistics in clinical research' [12] as experts excepting the case when 'those professional qualifications or experience relate only to the ethics of clinical research or medical treatment' [12].

NRES offers the following definitions of expert, lay and lay+ members in the document 'Membership of Research Ethics Committees' [12]. A lay+ member 'is not and never has been' a: 'healthcare professional;

a person involved in the conduct of clinical research; or a chairman [sic], member or director of a health service body or any other body providing healthcare' [12]. A lay member may have been a healthcare professional (although not a doctor or a dentist) or a chairperson, member or director of a health service body or any other body providing healthcare. A lay member may have been involved in the conduct of clinical research but may not have professional qualifications or experience in the conduct of clinical research with the above noted exception that if these qualifications or experience relate to the ethics of clinical research then they may still qualify for lay or lay+ membership.

Broadly speaking the lay member is defined negatively, ie as someone 'who does not qualify as an expert member' [12]. In this case the expert is predominantly considered to be a registered healthcare professional including those registered under the Health Professions Order 2001⁴ [13] or, in the case of doctors and dentists someone who currently is or previously was registered as such. Additionally NRES considers those with 'professional qualifications or experience relating to the conduct of, or use of statistics in clinical research' [12] to be experts. As the document points out, this might indicate that statisticians, data managers, clinical psychologists and medical device experts meet the conditions of 'expert member' for the purposes of NRES research ethics committees.

It is not clear whether or not qualitative social science researchers qualify for expert membership. Whilst qualitative research in healthcare has been a particular and growing focus of academic social scientists it is difficult to construe this as always being 'clinical' research [14]. The definition of clinical research offered by NRES mentions quality of life outcomes but not all qualitative research can be said to be about quality of life. Further, clinical research appears to mean predominantly research concerning patients. Many social science projects do not focus on the patient rather they are concerned with healthcare professionals and their practices. This is certainly research in a clinical setting yet whether this indicates the researcher ought to be considered an expert for the purposes NREC ethics committee membership seems uncertain.

The expert and the lay members.

The lay member might be said to bring the perspective of the patient or research participant, although some have questioned if this is the view they present in practice [15]. As noted various healthcare professionals are sought to be included on research ethics

³ Which have their roots in Kantian conceptions of the moral subject.

⁴ This order provides for the registration of paramedics, arts therapists, dieticians, speech and language therapists and radiographers, amongst others.

committees because of both their scientific expertise and their knowledge of healthcare practice. Thus they bring to ethical review knowledge of how this might affect their colleagues in their working lives. Further theorising on these points can be found in ideas of standpoint epistemology [16] although it may simply be that lay membership is included on the basis of open ethical review and good practice. Whatever the reason for the inclusion of lay membership the categories 'expert' and 'lay' clearly stand in relation to one another. The categories form a kind of binary pair each giving definition to each other. Whilst the category of the expert may be defined on its own terms it implies the existence of the non-expert. The category 'lay' can, however, only be defined in contrast to the expert. Indeed the category 'lay' is defined as that which falls outside the category 'expert'.

My point here is not meant to be naively critical; the category 'lay' must be defined by some reference to the category 'expert'. The origin of the very word 'laity' lies in its meaning as 'the people in contradistinction to the clergy' [17]. Rather my point is that what the category expert is defined to include, in this case healthcare professionals and those recognised as conducting research on 'health' broadly understood, has the result that everything which does not meet the criteria of expert being automatically considered as meeting the criteria of lay.

At this point one might pause to consider the rise of patient groups, patient advocates, various pressure or interest groups and the 'expert patient;' concepts such as these abound in current times. The inclusion of each of these perspectives and areas of expertise on ethics committees is certain to lead to 'expert member inflation' and questions the very notion and utility of the lay member. The utility of the lay member in the process of research ethics review would be somewhat denigrated by the presence of an 'expert patient' whether it be one who is expert in the particular illness the research happens to be focused on, by virtue of either having the illness or having previously had the illness or whether they be expert in terms of belonging to an informed interest group such as Mencap, for example.

These issues aside, the concern I wish to express is that the exclusion of ethical expertise from the category 'expert' for the purposes of the ethics committee has the consequence that any notion of ethical expertise is, by implication, denied. Those who may be considered ethical experts are often lay members of ethics committees yet any expert view they may be able to bring is delegitimized and refused by the constitution of the committee and the designation 'lay'. NRES acknowledge what it is to be an expert differs relative

to the circumstances of the research and the remit of the committee, but this seems only to be in relation to scientific, disciplinary or methodological knowledge⁵. Whilst ethical expertise is a contested idea there are many undergraduate and postgraduate academic programmes which explicitly teach applied ethics, the vast majority of which are concerned with biomedical, medical professional or healthcare ethics. Those who take such courses are, of course, demographically varied. The intercalation year made available to many undertaking undergraduate medical degrees can be spent gaining a Bachelors degree in Healthcare Ethics, at the University of Leeds for example. The MA courses as offered by institutions such as Manchester, Leeds, Bristol and Keele Universities are taken both by healthcare professionals, ie experts, as well as those that would be considered as lay members of ethics committees. Additionally, the training offered to many members of ethics committees often takes a form similar to the education those undertaking these postgraduate courses experience. In some cases the members of ethics committees may be offered the opportunity to take such postgraduate courses sponsored, subsidised or in some way supported by the body responsible for the ethics committee. This education and training must be based on some knowledge and/or skills which are imparted and/or developed over the duration of the course. As such there must be some sort of 'ethical expertise' involved.

My point is not to merely take issue with such training as is offered to members of committees. Rather it is to highlight the fact that the non-acknowledgement of ethical expertise on ethics committees produces a contradiction. We acknowledge the expertise of the ethicist in accepting them as educators and we actively seek out the education they offer for both expert and lay members of the ethics committee. Yet we do not seek out that same expertise in constituting or conducting ethics committees.

This supposed contradiction is produced by the presumed content of 'ethical expertise.' Whilst the applied ethics professional is involved in the training of ethics committee members it is presumed that such training is not hortatory. The ethics trainer does not seek to moralise from a lectern turned pulpit and inculcate particular ethical viewpoints in committee members. Rather the training seeks to provide opportunity for the ethics committee member to engage with the wider notions of their own ethical presuppositions, other possible ethics perspectives and the general purpose of the ethics committee for example. In contrast the ethical expert is regarded as being hortatory insofar as it appears to be an acknowledgment of their being someone with greater knowledge of

⁵ Of course the ethical expert has their own scientific, disciplinary and methodological knowledge and this is the point I am seeking to make and return to below.

ethics and access to ethical truth than the non-expert is an acknowledgement of a privileged ethical viewpoint and judgement. Here the echo of the etymological root of laity, as opposed to the clergy, is clear. The ethical expert is presumed, like the clergy, to sermonise and to moralise; to lead the ethical way.

This is of course the type of expertise that is being rejected by the ethics committee when they do not include ethical expertise, including direct experience of the ethics of clinical research, as reason to categorise such individuals as expert. It is also a concept of ethical expertise that ethicists themselves reject. The notion that this is what the concept of ethical expertise is or implies leads to the ambivalent relationship professional and academic ethicists have with the idea. The suggestion of ethical expertise as justifying a hortatory response on the part of those in possession of it and a commensurate acknowledgement on the part of those who do not is, I would suggest, incorrect. Thus another account of what ethical expertise might be needs to be given.

The ethicists' expertise.

Applied ethicists do not simply concern themselves with particular ethical problems which they seek to solve and then, having settled the problem and its answer, exhort others into accepting their view. Such a view is predicated on the so called engineering model of bioethics, a view which fails to understand the varieties of focus adopted by the applied ethicist [18]. As we have seen ethical experts provide training to the members of ethics committees and education to various other individuals who wish to pursue an interest in the subject. They also take an interest in the construction of ethics committees and their work [19]. They taken an interest in academic ethical theory beyond that offered in training or, indeed, in most postgraduate applied ethics courses [20]. They take part in jurisprudential debate, policy construction [21] and sociological analysis [22]. They seek to understand the process of education in ethics and its consequences [23]. They seek to understand medicine, to criticise it, and to rebuild it [24]. They seek to recover lost methods of ethics and to broaden applied ethical discourse by reference to traditions which have not traditionally been used in the field [25]. They seek to explore the ethical aspects of healthcare in theory, in practice and in its history [26]. On this understanding of the activities of applied ethicists the engineering model of applied ethics appears profoundly impoverished and its suppressed presence in the general understanding of ethical expertise impoverishes the very idea. The exploration of such academic research is beyond the remit of training in applied ethics offered to members of ethics committees and much of it will be beyond the remit of any one specific Masters Degree.

Whilst the modern field and discipline of 'applied ethics' is perhaps only forty or fifty years old it is diffuse and diverse and continues to develop both in terms of its disciplinary and methodological allegiances as well as its in its subject matter [27-29]. The expertise of the ethical expert is not to be found in their ability to access ethical truth, rather it lies in their ability to understand, generate and engage with the varieties of research which constitute their field. In an essay denying the possibility of ethical expertise Johnson notes that his discussion might allow 'a claim to expertise ... but not moral expertise. If bioethicists are experts, they are experts on the state of play in the bioethics community. While the bioethicist has no authority to state the correct view, she is qualified to explain the main approaches to a particular issue that are currently considered reasonable in our society.' [30]

By suggesting that the possible expertise of the bioethicist is limited to the views 'currently considered reasonable' of their discipline Johnson's view is more limited than my own. He seems to suggest that knowledge of the discussion pertaining to a particular issue or ethical case in which applied ethics has engaged is all an ethical expert can bring. This seems to me to be over reliant on the engineering model of applied ethics. I am suggesting that applied ethics engages in a variety of discourses, disciplines and research. Some of which is properly described by the engineering model, much of which is not. Such research and the theoretical and empirical knowledge it generates must, I contend, be considered relevant to the practises of ethics committees. Much of this research is not directly normative; much of it does not generate rules or principles which can be applied to generate ethical conclusions. Yet this is not to say that this research has no 'normative' implication. One might consider the work of Foucault here. It is not directly normative insofar as it engages in the generation of rules or principles or even insofar as it is directly critical on ethical grounds. Yet the historical analysis in which Foucault engages certainly has normative dimensions [31]. Much of the applied ethics literature contributes to the wider understanding of ethics in our society and the specific situations it creates and which demand our ethical engagement. It is important that construction of context, say modern medicine, and of process, say the ethics committee, is properly understood if we are to promote ethical behaviours and governance in a proper and open fashion.

Conclusion

I have suggested that the idea of ethical expertise is discredited because it is incorrectly understood. This is partially as a result of the expert-lay binary used to define the ethics committee's membership and it is also a result of the engineering model of applied

ethics. Many have pointed out the failings of this model of applied ethics [32] and that the work of the applied ethicist is rarely hortatory, if indeed it can ever be correctly understood as such. The engineering model of applied ethics is based on the assumption that applied ethics is the application of ethical theory to certain problems or circumstances in order to explicate a solution. However even this does not necessarily imply that any solution offered is seen as anything more than another contribution to the debate surrounding both the ethical problem and/or the circumstances under discussion but also to ethical theory itself. Particularly in the case of bioethics many have reflected on the wider activities, engagements and research conducted under its rubric by its practitioners. Yet the implication of this professional activity and the understanding it generates is not reflected in ideas of ethical expertise. If we are to make full and proper use of the academic and the knowledge the discipline generates, the concept of 'ethical expertise' and the 'ethics professional' needs proper and accurate articulation. This suggestion is yet another activity for the applied ethicist to engage in and another form of knowledge on which their 'ethical' expertise should be founded.

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