

# Between the bench, the bedside and the office: The need to build bridges between working neuroscientists and ethicists

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## Abstract

This paper presents findings from an empirical study that explored the meaning of ethics in the everyday work of neuroscientists. Observation and interviews were carried out in one neuroscience research group that was involved in bench-to-bedside translational research. We focus here specifically on the scientists' perceptions of bioethics. Interviewees were often unfamiliar with bioethics as a discipline, particularly the more junior members of the group. Those who were aware of its existence largely viewed it as something distant from them, and as either too abstract, not relevant or an alien imposition on their work. Some interviewees themselves pointed to the need for better 'bridge building' between ethical principles and real-world examples drawn from scientific practice, and we argue that this space is where a more empirically grounded ethics may be useful in terms of actually engaging scientists at both the bench and the bedside.

## Keywords

Bioethics, empirical ethics, neuroscience, scientists, translational research

## Introduction

This paper draws on observations and interviews with members of one UK group engaged in basic and clinical neuroscientific research. The study it springs from was an exercise in both sociology of science and empirical ethics – investigating the experiences, perspectives and practices of scientists, including the ways in which they encounter and conceptualise 'ethics'. Part of the rationale of the study – a familiar concern for empirical ethics – was to understand and illustrate what, if anything, ethics looks and feels like 'on the ground'. The broad findings are reported elsewhere<sup>1</sup> but will be very briefly summarized here to provide context. This paper, as well as focusing upon previously unanalysed and unpublished data from the study, asks questions about the 'gaps' that exist between neuroscientists and bioethicists. Whilst acknowledging that there can be good reasons for bioethics to be detached from neuroscience practice, we want, first, to illustrate the different kinds of gaps that can exist between researchers in the two fields, and second, to argue that bioethicists have something valuable to gain by engaging with clinical and basic scientists more fully and closely.

## Background

Applied ethics, including bioethics, trades on its relevance to the 'real world' – framing this as what differentiates it from 'pure' ethics or ethical theory, sometimes disparagingly referred to as 'armchair ethics'. Tod Chambers<sup>2</sup> highlights the significance of place in such depictions of ethics. He notes that 'tales of moving from the armchair to the bedside' (p.23) form a central motif in bioethicists' accounts of their work and professional identity: 'in leaving their academic offices and entering into a hospital, medical clinic, or nursing home' (p.22), bioethicists have often portrayed themselves as insiders in the world of medicine and academic philosophers as on the periphery. However, as Chambers goes on to show, *physicians'* accounts of clinical ethics have sometimes explicitly positioned bioethicists as outsiders in the medical

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field – no longer in the armchair perhaps, but mere observers nonetheless. Certainly, academic bioethics is very often conducted at one remove from practice and in terms that are typically far from transparent to those in the substantive fields it covers. Indeed, most bioethicists have not left the ‘office’ on a permanent basis, and continue to work primarily within the sphere of academia, largely in communication with and accountable to their peers.

Insider versus outsider status is clearly a matter of perception, but it is important to understand how bioethics is perceived in a given field in order to understand and predict its impact. Dialogue about ethics between bioethicists and the professionals, researchers and others they study by no means happens automatically and involves the crossing of epistemological and cultural boundaries. This issue has now been extensively discussed in relation to the ethics of clinical treatment, where there has been substantial cross-fertilisation and dialogue between ‘external’ academic and ‘internal’ professional ethics, but where the persistence of a ‘two tribes’ element continues to be acknowledged and addressed in the literature.<sup>3,4</sup>

In clinical and basic bioscientific *research*, such cross-fertilisation seems to have been less pervasive. Studies show that scientists at both the laboratory bench and clinical bedside have typically had little exposure to ethics as a discipline.<sup>5,6</sup> ‘Ethics’ for them often means formal regulatory frameworks and the research ethics approvals required to conduct work in these fields, and researchers appear to feel more as though they are acted upon by such regulatory regimes than that they have agency in shaping the ethics of science.<sup>1,7</sup>

Various barriers to bioscientists’ engagement with bioethics have been identified. Scientists interviewed in Smith-Doerr’s<sup>5</sup> study reported that time and resource pressures in science meant they did not have time to ‘sit around’ and think about ethical issues (p.13) (clearly invoking an image of ethics as an armchair pursuit detached from daily work). Formal training in ethics is often lacking. Ethics education is not a compulsory part of graduate biology training in the UK, and although it is more common in North America, ethics courses are generally a minor part of the curriculum, and students report frustration with the lack of relevance to, and time taken away from, ‘real work’.<sup>5,6,8</sup> Notably, although ethics is a staple of medical school curricula, there too it is often treated as less important than other areas in terms of space allocation in the timetable and the attitudes of students and staff.<sup>9</sup>

These boundaries between what is and is not seen as relevant to science in education seem to be replicated in professional work.<sup>10</sup> When working in science, what comes to be of moral concern to people is often very

closely related to and demarcated by their day-to-day work and their specific roles. In several studies, technicians, bench scientists and clinical scientists have reported different ethical concerns when working on the same line of research, their concerns being focused on their own activities rather than linking to broader questions about the ethical implications of the research.<sup>1,11,12</sup> Regulatory frameworks are also often deferred to as a way of solving ethical issues,<sup>1,10,13</sup> while scientists continue to frame science and ethics as separate domains.<sup>5,7</sup> It seems then that academic bioethics has not become integrated as a regular source of guidance or reflection for bioscientists in their work.

Neuroethics is a relatively new area of applied ethics, dedicated specifically to exploring the moral dimensions of neuroscience.<sup>14</sup> From the beginning, neuroethicists have sought explicitly to foster the cross-fertilisation of ethics and neuroscience.<sup>14,15</sup> Neuroscientists themselves have been instrumental in developing the field, and there is an emphasis on exploring the wider ethical implications of technologies regularly used in neuroscientific practice.<sup>14–16</sup> It is not clear that neuroethics has had any more of an impact on day-to-day work in neuroscience than general bioethics has, however. Neuroethicists have also pointed to the lack of neuroethics education in neuroscience training.<sup>17</sup> Among the neuroscientists included in the study discussed here, when they were asked about the role of ethics in their work, neuroethics was not mentioned once. Moreover, the ethical issues that were seen as relevant by our neuroscientists were not those receiving attention in neuroethics.

As we report elsewhere,<sup>1</sup> within the group we studied, multiple moral frameworks guided the scientists’ work, none of which mapped clearly onto an identifiable area of academic ethics. Regulatory frameworks provided overarching ethical guidance, while professional and personal perspectives allowed the scientists to carve out well-defined moral spaces in which they were comfortable working. Another moral sphere that we call ‘tangible ethics’ was located in actual practice, where scientists sometimes experienced moral qualms when actually undertaking activities that were otherwise consistent with their regulatory, professional and personal ethical frameworks. Ethical boundary work<sup>10</sup> was performed between the clinical and basic neuroscience work. The group was engaged in bench-to-bedside translational research, but group members drew clear lines between the ethical issues seen to be relevant in the laboratory, where some of them worked, and in the clinic, where the rest of them were based. Here, we discuss both sets of researchers’ perspectives on bioethics, showing that a further boundary was constructed between the scientists’ everyday work and what seemed

to them a set of distant, abstract ideas – illuminating what might be described as a gap between the bench, the bedside and the ‘office’.

## Methods

The research set out to explore the meaning of ethics for this group of neuroscientists and how its meaning related to their day-to-day work. For this reason, data collection (undertaken by author CB) involved both interviewing the scientists and observing their activities over a period of 7 months. The group was part of a university and was selected because its work included both basic scientific and clinical aspects of neuroscience, enabling the researcher to observe a range of practices under one roof and to explore the relationship between them. Each neuroscience group member worked predominantly either in the laboratory or clinic, and interviewees are designated here as laboratory or clinical researchers (LR or CR). Semi-structured interviews were conducted with 14 researchers, including the Group Leader (GL1) and the leader of another associated neuroscience research group (GL2). Interviews were recorded, transcribed and analysed thematically using NVivo to organise the data.

## Results

The participants in this study, when explicitly asked about the relationship between bioethics and the science they were engaged with, generally struggled to offer a response. This included, but was not limited to, simply being very unclear and unsure about what was referred to by the term ‘bioethics’. The responses of LR3 and CR1 were not unusual:

CB: So to what extent do you think, or do you know, scientists are interested in or engage with the kind of bioethics work going on?

LR3: Can I ask you to define bioethics?

CB: Well yes, it’s kind of tricky. I mean the kind of work that professional ethicists are doing, like papers they’re writing about the ethics of different aspects of science in bioethics journals.

LR3: Right, I don’t know too much about that to be honest. I don’t really know how to answer you sorry.

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CB: So I don’t know if you know to what extent scientists, or people doing your kind of work, engage with, or are interested in, bioethics and the kind of bioethics work that’s going on.

CR1: Bioethics?

CB: Like academic bioethics. So like, there’s journals of bioethics that talk about, you know, what’s

ethical and what’s not in different areas of science and medicine.

CR1: Okay.

CB: So have you ever come across any of that kind of work?

CR1: No, no. So people are researching whether science is ethical?

There is no designated bioethics centre at the university where the participants work, meaning that these scientists are possibly less likely to be exposed to the discipline than at some other locations. Yet, in a recent survey of neuroscientists in Canada, respondents from 17 different institutions reported no knowledge of a bioethics centre on their campus, when in 12 of these institutions there actually was one.<sup>6</sup> It is apparently not uncommon for bioscientists to be quite oblivious to bioethics scholarship and bioethics colleagues.

Some other members of the group, especially senior members, had more of a sense of the domain of bioethics. However, the strongest thread that ran through the participants’ responses was still that bioethics was something ‘distant’ from them. The accounts of this distance were constructed with various emphases but there was a consistent message that bioethics was simply not close to, let alone integrated with, their own day-to-day concerns. In summary bioethics was constructed as (a) potentially important and interesting but too abstract and/or (b) boring, irrelevant and forgettable and/or (c) an alien imposition on the field.

LR1 was the most emphatic about the importance and potential interest in bioethics but also described what she saw as the substantial communication gap between bioethicists and working neuroscientists.

CB: So to what extent do you think scientists are interested in or engage with the bioethics talk around science and medicine?

LR1: I don’t know, we definitely don’t talk about it, so it’s not an issue that is there. But I find it interesting, so I would think most people would find it interesting, well, interesting and important that their ethics and bioethics and ethics to do with the kind of research we do. But the problem is that when I’ve been to a couple of conferences where there was a talk on bioethics... that it’s too philosophical what they say, not tangible, and they talk and talk, and by the end of it, you don’t remember anything because – I think people working on it, when they want to talk to scientists, they should go down to examples, so that we get the ideas better. Or maybe I’m very simple and I don’t understand! But I would think it’s a general problem that we are not used to the kind of concepts that they

use, like the average researcher, and it would be better – because I mean I'm sure they must think of applications or examples when they develop all their ideas and their talk. There *has* to be a relationship with what we *actually* do.

Overwhelmingly bioethics was seen as something that takes place, and is encountered, outside the lab or the clinic and which does not connect sufficiently with those settings. It is also, as indicated by the above remarks, conducted in what can be experienced as a foreign language. The Group Leader, who himself saw bioethics as of considerable potential relevance, was sceptical about the effective reach of the subject given these factors:

- GL1: I think the only problem I have with ethicists, philosophers, that type of thing, is that it can often become very cerebral and somewhat esoteric and rather detached from the patient in front of you and the cells upstairs [*in the laboratory*].
- CB: Yeah. To what extent do you think scientists are interested in engaging with the kind of bioethics work that goes on?
- GL1: I think they're interested to a point; I think it's very individual. I think some people really love it, and lots of people think it's a lot of noise and is nothing really.

The Group Leader's language here again points out the apparent three-way divide between a 'cerebral' ethics carried out in the mind of the philosopher, practical laboratory-based work on cells and work with patients in the clinic. Given that it was already an ongoing challenge for the Group Leader to bring together the laboratory and clinic-based science, it is easy to see how an ethics that did not speak clearly to either side would seem even less relevant to the group's work.

The second Group Leader interviewed was similarly sceptical about the way bioethics failed to 'filter through' to working neuroscientists:

- GL2: I don't feel, I mean I've read, I mean there are very excellent books on animal rights and stuff that I've read, but I don't think that it's been discussed in any formal framework. I don't think there is any, that it impinges on us people doing life science work. Maybe not enough? But I think it's true of the society at large as well, it's a reflection of the fact that these people are working away and looking at philosophical and ethical issues and it doesn't seem to filter through in any kind of way.

Indeed this combination of abstraction and 'foreignness' can make bioethics seem both to be of limited relevance and avoidable. As LR1 explains:

- LR1: I like to see that there is a talk on that, and I would go. In the first conference where I was, I think people were kind of excited to know what it was going to be like. In the second conference, I think many people didn't go, and thought, 'Okay we can skip this one and go to walk around and visit the place where we were.' Yes, because I think there is this thing of, 'Oh it's boring.'

There was also an associated tendency – seemingly partly produced by the conflation of bioethics with research ethics – to see ethics as something which one engages with only on a 'need to know' basis in order to comply with official ethical requirements:

- CR4: In terms of do we look, research, into the ethical side of things, outside of what we need to know and the GCP side of things, I wouldn't say we do necessarily. Just I guess, because – I mean anything that affects us, then I think we would. But if it doesn't affect us, then... I mean I don't know really where we would gain more kind of – I mean I think we know everything that we should know for ethics, and I don't know where we'd go for more ethical information, because everything that is relevant to us, we need to know and do know.

...

I haven't read anything from a journal that is purely on ethical issues. I think it's a good thing. I mean I think you've got to make our research as ethical as possible really. But I think it is very ethical already.

Given that the regulatory or governance dimensions of research ethics represent the most routine and 'powerful' sense in which scientists encounter ethics it is unsurprising that they have a tendency to see bioethics as something of a barrier to, or as a – sometimes unwelcome – imposition on, their work. One participant, referring to prior experiences of medical school as well as current neuroscience work, commented:

- CR2: I know they're kind of enforcing it more and more, and in our clinical school years, there was a lot of, 'Oh it's an ethics lecture,' [*derogatory tone*] and that sort of thing.

...

So I think people acknowledge it, but only when they're sort of stuck in a situation. That's

kind of what I think. Like, as an actual discipline, I don't think people follow it that closely. But I don't know, I might be the exception! But no it's always seen like, certainly, ethics lectures and that sort of thing, it's just seen as something that people just turn up to because they have to have their name signed off. It seems very, very detached when you see it as a discipline to, you know, how it is in practice.

I mean it's the same with like, when you talk about ethics, you know, getting ethical applications. You don't really see that it is actually useful, you just kind of see it as something you have to do, a big barrier to get over.

A small number of interviewees said they did in fact feel the ethics approval process was useful, but again this was framed in a rather procedural way, in terms of helping with planning research in advance and being able to justify the procedures. LR5 was adamant that the formal ethical regulation of science was more of a hindrance than a help:

CB: To what extent do you think scientists are interested in or engage with the kind of discussions that are happening in bioethics?

LR5: Well my view wouldn't represent the view of other scientists, but personally I just hope that to just leave me alone to do my science work – don't bother me with other things. I mean, of course, we inherently, I believe as scientists, we have a line, we don't cross the line. For example, there used to be some mad scientists, they wanted to do human cloning. But my impression is that not only do the general public have serious concerns about this work, the scientific community had concerns about it as well. So we believe that we cannot have, you know, at least most of us understand why we are doing it, what can be done and what cannot be done. So I mean we don't cross the line.

...

it's just not fair from my perspective that our work is being intervened in by people who don't really know anything about it.

## Discussion

This paper builds on existing studies of scientists' engagement with ethics by examining specifically how neuroscientists working on translational research viewed bioethics. The various gaps between bioethics and neuroscience summarized here could be seen as reflecting a deficit on the part of neuroscientists

and/or on the part of the community of bioethicists, or perhaps as simply not a problem. The latter reading could apply if we stress the value of separate, independent communities of scholars fuelled by different interests, questions, methods and so on. To some extent this is a sensible reading. There is no harm in different people studying different things and there are obvious advantages in an academic division of labour. However, there also seems to be much more scope for fruitful engagement between the two sets of researchers. This possibility is clearly suggested within the data set reported here, where there is a call, from some of the participants, for better 'bridge building' between the discussion of abstract principles and 'real world' examples rooted in practice. Both the importance of, and one of the main barriers to this bridge building – the relative lack of necessary knowledge and understanding on both sides – is described in the data by LR2:

LR2: I mean personally I've not really, I do find the ethical questions interesting, but I wouldn't say that I've been very well informed of them. I do think there's a lack in education for scientists... I guess it can be quite frustrating for scientists maybe, especially since I guess some of the people making the ethical arguments might not fully understand the science behind it. But equally some of the scientists who understand the science, might not understand the ethical issues properly. So I think it's important to have people that are kind of on both sides of the fence. So, scientists that get involved in the debate properly and maybe ethicists that go into the science quite deeply. But yes I think the main thing is that scientists aren't really educated in ethics at all. And I think the biology is quite important.

For the purposes of this article we are primarily interested in the advantages for bioethicists of engaging with neuroscientists (although the reverse is, of course, a relevant set of questions). There are both pragmatic and, interlinked with these, more fundamental reasons for encouraging such bridge building. The practical value of closer engagement is evident – there is scope to learn more about how to make bioethics more accessible to other researchers, and, of course, to learn more about examples and contexts of work, and thereby produce work that is both more grounded and 'travels' further. This could be underpinned by, and contribute to, the broader and more effective participation of bioethicists in the basic and ongoing professional development of scientists, as suggested by some of the participants. All of this supports the growing preoccupation in research policy circles with

'knowledge exchange' and 'impact'. But these same factors also point to some more fundamental theoretical – epistemological and ethical – reasons for engagement.

Understanding the gap – including the gap between bioethicists' account of the ethics of neuroscience and the account from the neuroscientists themselves – illuminates the nature and agenda of bioethics in productive ways. The gap highlights the different substantive ethical agendas of the two groups of researchers – the different 'layers' of neuroscience ethics. The bioethics literature typically deals with the broad direction of what ought to be permissible or promoted rather than the issues that arise in the actual day-to-day conduct of the science. But, given that the former is necessarily only ever enacted through the latter, there is a danger that this is only doing 'half the job' (as if the 'ethics of war' was settled through discussions about justifiable grounds for war without much attention to the conduct of warfare). Similarly the literature is typically focused on the 'what' of ethics rather than the 'how' of ethics. That is, it typically considers the question of 'in principle' justification but this still leaves the question of what individual agents ought to do in specific roles and circumstances relatively undetermined. (Again, by analogy, defending a policy that justifies a specific policy (abortion, informed consent, etc.) does not get us far in determining exactly what specific practices a specific individual should be allowed, empowered or encouraged to undertake.)

To what extent neuroscience ethics should be derived from practice or from abstract argumentation is itself a thorny ethical and theoretical issue. Clearly, if ethical frameworks become too applied, they will ultimately have no relevance beyond a narrow area of practice. Abstraction is necessary to allow generalisability and reasoned debate and defence. Approaches that are both empirically relevant and open to abstract debate are, we suggest, likely to enhance both bioethics and neuroscience. Engaging with practical science may help bioethicists to bridge gaps with scientists, and equally, engaging with bioethics frameworks may help scientists to bridge gaps between different areas of practical work. That is, rather than scientists staying focused on tightly bounded ethical domains located at the level of practice, accessible bioethics frameworks may help scientists to think outside their own area and perhaps across the lab and clinic, a divide seemingly so difficult to traverse in translational research. A voice from the 'office' that could be heard by neuroscientists across different areas may actually contribute to bridging the bench–bedside gap in neuroscience.

Closing the gap between ethics and neuroscience points, at minimum, towards a much richer field for a bioethics of neuroscience, and the possibility of broader, more inclusive forms of conversation and

debate. However, it also suggests that a potentially more profound form of cross-fertilisation may be available – one in which a grounded understanding of the 'how' questions of lived research ethics and the 'what' questions about the principled defence of research trajectories are, at least partly, considered alongside each other and tested against one another.

### Ethical approval

Ethical approval was granted by Geography, Gerontology and SCWRU Panel of the Research Ethics Committee at King's College London (REP(GGS)/09/10-38). All study participants gave written informed consent.

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### Declaration of conflicting interests

None declared.

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