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EDITORIAL

Getting from the Ethical to the Empirical and Back Again: The Danger of Getting it Wrong, and the Possibilities for Getting it Right

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Anna Smajdor · Jonathan Ives · Emma Baldock · Adele Langlois

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Introduction

'Bioethics: past, present and future' was a conference whose purpose was to create a snapshot of postgraduate work in bioethics. This work, it was hoped, would be illustrative of the new generation of academics working in the field, and of their attitudes towards their discipline. The conference attracted postgraduates from diverse areas and backgrounds, unified by their shared work in bioethics. Given such a disparate group one might have thought there would be a great deal of disagreement about what bioethics is and what counts as 'doing bioethics', yet this was not the case. There were variations of interpretation as to what constitutes bioethics, but the points on which there was agreement were far more striking. Throughout the 2 days of the conference, during formal presentations and informal

A. Smajdor
Medical Ethics Unit, Imperial College London, Charing Cross campus, Reynolds Building,
St. Dunstan's Road, London W6 8RP, UK
e-mail: acsmajdor@yahoo.co.uk

J. Ives (✉)
Department of Philosophy, Centre for the Study of Global Ethics, The University of Birmingham,
Edgbaston, Birmingham B25 2TT, UK
e-mail: j.c.ives@bham.ac.uk

E. Baldock
Institute of Psychiatry, King's College London, De Crespigny Park, Denmark Hill,
London SE5 8AF, UK
e-mail: e.baldock@iop.kcl.ac.uk

A. Langlois
Development Policy and Practice/Innogen, The Open University, Walton Hall,
Milton Keynes MK7 6AA, UK
e-mail: a.langlois@open.ac.uk

discussions, ran a pervasive theme: in order to contextualise the normative claims at the heart of bioethical debate, we need to make appropriate use of empirical data.

Since we are talking here about the future of bioethics, it might be tempting to assume that the work has been done, and the answer found: the future of bioethics is empirical bioethics. However, this is too simple. Bioethics is perhaps best conceived as a broad field of inquiry rather than a distinct discipline. It encompasses a number of disciplinary approaches which can be brought to the table and applied to specific problems. Whether an enquiry counts as 'bioethics' depends largely on the nature of the problem, or the topic of study, rather than the method by which it is studied. For example, an analysis of the legislation relating to the removal of anonymity from gamete donors, and its relation to the ethical framework behind that move (if any), would count as 'bioethics'; whereas a similar analysis of legislation relating to gambling would not. A sociological analysis of the notion of autonomy in clinical decision-making would probably count as bioethics; but an analysis of the notion of autonomy in corporate decision-making would not.

Given this, one cannot decree that bioethical study must incorporate an empirical element. Rather, we can say that bioethics is a wide and varied field, which seeks to analyse, illuminate, or offer a solution to a variety of ethical issues, in a number of different ways—all of which might properly be counted as bioethics, but none of which are clearly delineated by a specific method, approach or discipline. One such approach is empirical bioethics, and although the nature, usefulness, or indeed the novelty, of this approach remains controversial, it seems to be an approach with a future.

Empirical bioethics is in itself a wide and varied field, and trying to define it as a distinct discipline or method is difficult because of its sheer breadth of scope. Nevertheless, empirical approaches to bioethics share a recognition of the impact and influence which empirical data can exert on normative bioethical questions. However, as Ives notes in his editorial to this special edition, the way in which this is approached will depend very much on what one is trying to achieve. It is clear from the articles presented here that there are many ways of 'doing' empirical bioethics, and it is arguably up to the reader to decide for him or herself which approaches work and which do not, in light of their specific aims.

A number of theoretical approaches to empirical bioethics have been conceived. The most prominent of these include 'Critical Bioethics' [7] and the model of 'Integrated Ethics' advocated by van der Scheer and Widdershoven [15] and Molewijk et al. [9]. At the same time commentators have also put forward a taxonomy and critique of the ways in which empirical data has informed bioethics in the past (for example, see [4, 10, 15]). Nonetheless, there has been a tendency to keep the empirical and the ethical separate, allocating each a specific role, rather than attempting to achieve a synthesis. Ashcroft [2] notes that this kind of separation of the empirical and the ethical is often manifest in arguments formulated as an hypothetical imperative. The bioethicist makes the proposition: 'if P then X', and empirical data are cited as evidence that P.

This latter approach is sometimes criticised for not being a true marriage or integration of empirical and philosophical methods, but its appeal in bioethics is clear. Supporting ethical propositions with empirical data seems to offer a sure footing in the often shifting ground of ethical discourse. Harris [5] has pointed out the nebulous concepts and ineffectual ethical reasoning incorporated in many of the European legal pronouncements against reproductive cloning. Similar problems abound in other areas of bioethical concern. Ethical arguments and judgements are notoriously subjective, and unamenable to proof.

Contextualising normative claims in an empirical framework seems to offer a way through these difficulties: a possibility of demonstrable answers to at least some of the questions which surround ethical issues. It is no surprise to find that Harris [6] claims that the safety consideration is “the one decent argument against cloning” (p. 109). Concerns about harm can be articulated, projected, quantified and—arguably—*proven empirically* in a way that concepts such as dignity cannot.

Taking the hypothetical imperative, then, one might say ‘If reproductive cloning is harmful, then it is unethical.’ If the bioethicist can use empirical data to prove that it is *not* harmful, seemingly the ethical point has been proven—and in a way which does not rely on any religious, emotional or deontological reasoning.

However, perhaps precisely because of its affinity with science, and its ease of integration with a utilitarian, as opposed to a deontological, moral framework, there is a risk that this kind of appeal to empirical data makes one lazy, as if it replaced the need for moral argument altogether. An illustration of this tendency can be seen in the ongoing debate over the controversial ‘need for a father’ component of the Human Fertilisation and Embryology (HFE) Act 1990.

A heated debate has erupted around this clause. On one side are those who believe there to be an intrinsic moral value in the heterosexual two parent family setup. On the other are those who place an intrinsic moral value in the principle of non-discrimination. Yet very few of those involved in this particular debate are willing to engage on these terms. Rather, the entire debate has drifted off into a quasi empirical and utilitarian dispute. In these circumstances, empirical claims can become an anodyne substitute for moral deliberation. More worryingly, the idea that the empirical focus can provide an easy solution appears to be illusory.

Those who are in favour of the ‘need for a father’ clause can and do bolster their claims with all manner of empirical data demonstrating that the children of single parents are more likely to struggle at school and suffer from a number of other social problems [1, 14]. It has also been suggested that the input of a father specifically is beneficial or even essential to a child’s wellbeing (for example, see [3]). But those who disagree can also cite a wealth of other data that seem to cast doubt on these findings [8, 11].

Both sides purport to share a relatively uncontentious moral belief about the importance of preventing harm to children. If the welfare of the child is really the fundamental ethical concern here, then in the face of evidence that a particular circumstance ‘C’ is not harmful to a child one should cease to object to ‘C’. If this does not happen, it seems clear that the empirical claim in that argument was not doing any of the work it claimed to be doing. Rather, it was simply a way of defending a moral position without actually having to confess to holding a particular moral view.

There is also the problem of what to do when the data are evenly balanced, or inconclusive. The answer, of course, depends in part on the real role of empirical data in these arguments. If it is genuinely functioning as the factual base that determines how the moral goal is achieved (the welfare of the child), then the answer is to reserve judgement and, like a true Pyrrhonian, acknowledge that we simply do not yet know and therefore cannot say, with any authority, whether or not a child ‘needs a father’, at least on empirical grounds.

It seems plausible that neither side in this debate is really motivated by simple utilitarian concerns. Even if fatherless children were not disadvantaged in any way, some of those who oppose the removal of the clause would still do so, on the grounds that the moral value of fathers is not dependent on its connection with good outcomes for children. Likewise, those who uphold the liberal non-discriminatory approach might accept demonstrably bad outcomes for children in some circumstances. For example, being born into impoverished circumstances is one of the most reliable predictors of suboptimal outcomes for children, in terms of social, educational and physical wellbeing [10]. Nevertheless, few argue for proscriptive legislation to prevent these births.

As Clackson notes in her paper in this special edition, problems can arise when the deontological component of moral reasoning is not addressed. Perhaps this is a particular danger for empirical bioethics: the affinity between empirical data and consequentialist ethics is undeniable. Yet, while throwing empirical data at a moral dispute does not always yield fruitful answers, interacting with empirical research, and conducting such research, can be a vital part of bioethics. What is required is a considered and critical use of empirical data, and a degree of reflexivity in establishing the purpose of such data in each new piece of research.

Establishing the role and relevance of empirical data to bioethical questions is likely to be an ongoing challenge for those involved in this field. The value of empirical bioethics, like any tool, depends on the sensitivity and skill of those who use it. Each of the five papers included in this special edition can be read as being a response to that challenge. Collectively they demonstrate not just sensitivity and skill, but a variety of ways in which empirical data and observation can be used to inform illuminating and thought-provoking research in bioethics. It is to a short discussion of each of these papers that we now turn.

Rachel Crockett

Rachel Crockett’s paper addresses one of the fundamental difficulties in the relationship between science, social science and bioethics. The development of screening techniques to identify diseases and pathologies at an early stage—perhaps even simply to identify those at risk, before they actually contract the condition—is often widely hailed as a tool beneficial to society in general and to individuals. However, clearly, offering this kind of service to the public will not produce the looked-for economic and health benefits if people do not put themselves forward for these programmes. Uptake of screening has not always been of the level anticipated. Why is this?

Neither science nor ethics can fully answer this question: what is needed is engagement with the people who are involved and an analysis of their motivations.

Crockett's paper reveals the complexity of some of the underlying ethical assumptions about screening programmes in the abstract when they are put into action. Current bioethical norms emphasise the importance of free and informed consent as part of the broader ethical principle of respect for autonomy; people are expected to make their own decisions based on accurate and unbiased information.

In the context of screening programmes this means providing data on the negative aspects of screening, as well as the positive. But, as Crockett observes, different demographics approach screening in different ways. A paternalistic approach toward encouraging the public to participate in screening programmes might focus on the benefits of screening, framed in a context of personal and social responsibility. Reconfiguring this framework in line with a more autonomy-enhancing model, based on information and personal choice, may mean that fewer of those who are most at risk are identified. Thus, the benefits—and burdens—accrue to the 'worried well', while the worst off continue to be disadvantaged, and health inequalities may even be exacerbated.

Crockett's empirical research demonstrates the degree to which people may place differing levels of importance on the 'goods' that screening has to offer. These differences cannot necessarily be resolved by providing further information: the rift goes deeper than this. What is at issue here is a fundamental dichotomy of values. Screening programmes are supposed (by those who implement them, and those who use them) to yield certain benefits. But those who choose not to use them do not perceive these benefits to outweigh the immediate risks and burdens.

In this piece of research the importance, as well as the limitations, of empirical research are thrown into sharp relief. Empirical research demonstrates that this dichotomy of perception exists, but it cannot tell us how to act on this. Is it more important to address health inequalities, perhaps by adopting a more coercive or paternalistic approach? Or should we accept the value of autonomous decisions, and recognise that perceptions of the good will differ according to one's social standing and cultural perspectives? The answers to these *ethical* questions are hugely important. If we accept that the value placed on long-term health outcomes is relative, and resign ourselves to the fact that those most at risk will not benefit from non-directive screening programmes, the efficacy of those programmes themselves comes into question, along with the further ethical consideration of whether they are a suitable way of expending resources.

Saffron Clackson

Clackson's paper deals with some of the same issues as Crockett's (namely questions about paternalism and equitable healthcare distribution), but she starts from a theoretical perspective, while Crockett's empirical data are her main focus. Clackson examines Ronald Dworkin's conception of prudence in decision-making for healthcare insurance. Dworkin's concern is based on an observation that healthcare spending in the US seems to be neither rational nor just. He aims to devise a framework for decision-making that would remedy these problems, based on the choices of idealised agents who would have fully accurate information.

One of the attractive aspects of Dworkin's philosophy is its non-judgmental and democratic approach. He seems to eschew laying down deontological precepts by which people should lead their lives, basing his arguments on quasi-empirical speculations about what people *really would* do given certain idealised circumstances.

Yet Clackson observes that despite the weight Dworkin gives to recognising individuals' values and choices, his system is nevertheless paternalistic. That is, he believes that some people's choices might actually still be wrong even if they had access to all the relevant information and were not constrained by economic circumstances. Dworkin's theory of just distribution rests on the idea that people *ought* to choose on the basis of self-interest even if this is not how they would actually behave in real life. Given this, it is less obvious what purpose Dworkin's idealisations serve. In specifying what people ought to choose, his system begins to look rather prescriptive.

Clackson suggests that this apparent paternalism springs in part from a misguided assumption about the degree to which people are purely self-serving. If people make choices which do not coincide with what Dworkin thinks is the 'right' option, this may be because his beliefs about what motivates—or ought to motivate—people is misguided. Clackson cites empirical studies which support her claim that people do not invariably place their own interests above those of others. People's feelings and motivations in the real world are more complex, and less 'purely' self-interested than those of Dworkin's idealised agents. Sometimes our choices might be altruistic. Not only does Dworkin's theory not allow for this—it seems to treat it as a logical error.

Clackson has identified an interesting ambiguity in Dworkin's argument. When he describes his idealised agent as being self-interested, is he making a normative or an empirical claim? If the latter, it is—according to the evidence Clackson cites—plain wrong. If the former, his theory looks prescriptive and paternalistic, as well as being at odds with the intuitive ethical weight we tend to give altruistic motivations.

Perhaps what Dworkin was trying to achieve was a kind of hybrid claim partway between the normative and the empirical. That is, he may not be suggesting that people *do* make decisions on the basis of self-interest, and he may not be making the normative claim that they *ought* to do so. But he might be suggesting that healthcare insurance choices should be made *as though they would* do so. Yet if this is the case, it needs to be clear why we should adopt such an attitude, especially given that, as Clackson notes, Dworkin's system gives little scope for the degree to which people are motivated by deontological as well as consequential moral concerns.

Adèle Langlois

Langlois' article on South African and Kenyan perspectives on the UNESCO Universal Declaration on Bioethics and Human Rights is a study of the dynamic between universal bioethical instruments and grassroots bioethics regulation. Writing from an international relations perspective, Langlois' concern is not to examine philosophically the relationship between universal moral principles (at an international level) and pluralistic moral reasoning (at a national level); but rather to engage in a pragmatic study of “broad (bioethical) principles negotiated at an international level and their subsequent adaptation to national level policy and practice.”

This might be described as an empirical study *of* bioethics—an endeavour to study and understand the processes involved in bioethics discourse. The article is essentially a study of the way in which guidelines devised to operate universally are adopted at a local level and adapted to suit the needs of a particular community. Understanding this process is fundamental to bioethics research and teaching, given that traditional models of bioethics (dominated by philosophical approaches) tend to start with general abstract principles and then seek to apply those principles to particular cases. By studying the process by which the general is applied to the particular, it may be possible to evaluate the efficacy of such an approach. If, when applied at a local, particular level, a global, general principle has to be altered, then why bother with the general in the first place?

Langlois focuses on two key areas. First, she examines the ways in which universal principles are incorporated into national practice in Kenya and South Africa. Second, she seeks to identify whether the UNESCO declaration adds value to this process of national decision-making. She suggests that the challenge of implementing such statements in the framework of national policy lies in adapting them to suit the particular social and economic context of the country in question. A large and all-encompassing instrument such as the UNESCO declaration can thus only be effective if it is accompanied by capacity-building programmes to ensure that those to whom it intends to speak are aware of it and of what it can offer.

This exploration speaks to a wide audience. It will be of interest to those who are concerned with the particular issues surrounding bioethics regulation in Africa. It will also be relevant to those working in policy related areas who wish to appreciate the kinds of process involved in the translation of international guidelines to national and local instruments. It also speaks more generally to the bioethicist who might want to understand how general principles are adapted to suit particular needs, and if they are then this might challenge traditional philosophical approaches to bioethics. Although Langlois is keen to distance herself from more general philosophical questions—concerning universal as opposed to pluralist moral reasoning—it is also clear that this kind of work has a role to play within that debate.

Mikey Dunn

Like Langlois, Dunn is concerned to establish how a legal framework, based at least in part on ethical principles, actually functions in practice. He uses his first-hand experience as a support worker to assess the relationship of fit between the statutory regulation of substitute decision-making put forward in the Mental Capacity Act (2005) (MCA) and the nature of substitute decision-making on the ground. The MCA regulation depends, Dunn suggests, on conceptualising substitute decisions as individual, discrete interventions. These are presumed to be associated with clear and expected outcomes, and to be open to objective justification through reference to a best interests checklist. This conceptualisation is supposed to be applicable to all substitute decisions that are made.

On the ground, however, Dunn found that not every kind of substitute decision could be accommodated by this approach. Long-term decisions about life plans and healthcare interventions fitted it well, but *everyday* decisions, such as what clothes a resident would wear, did not. Mundane or routine matters could not easily be passed into discrete decisions. Most importantly, Dunn found that attempting to approach *all* decisions in this way was incompatible with the provision of good care. Everyday decisions did not correspond neatly to best interests checklists. Instead, substitute decisions in this context naturally arose out of shared experiences and were embedded in ongoing interactions between the substitute decision-makers and the residents.

Dunn found that there were two distinct forms of substitute decision-making, and only one of these—long-term, or strategic decision-making—was in line with the formalised best interests approach of the MCA and its Code of Practice. ‘Relational’ substitute decision-making for everyday matters was, Dunn claims, *inconsistent* with the legal and ethical framework of the MCA. The implication seems to be that relational substitute decision-making is not an activity which can be supported in the legislative framework, and that we therefore need to provide an alternative normative framework for it. Dunn suggests that an ethics of care perspective could provide such a framework.

This special edition illustrates the variety of ways in which empirical research can inform ethical debate. Dunn’s approach involves a re-examination of legal and ethical concepts through empirical findings. He argues for a re-examination of the substitute decision-making concept on the basis of how he, as a support worker, found himself making substitute decisions. This analysis is concerned not simply with highlighting discrepancies between the law and the ground, but with *defending* practices on the ground where these discrepancies arise.

Where legal frameworks are too stringent, or too narrowly conceived, important aspects of good practice may be lost if they are not recognised. Tan et al. [13] detected a problem of this kind in the proposal to make a lack of legal decision-making capacity a necessary criterion for the coercive treatment of those with mental health problems. They argue on the basis of an interview study that the concept of legal capacity is not sensitive to all the relevant decision-making problems in patients with anorexia nervosa. The impact of a capacity approach, by implication, would be to make it illegal to treat patients whom we have a moral obligation to treat.

In the case of Dunn’s research, the practice under threat is allowing relational aspects of care to inform the substitute decisions which are made for a person who lacks capacity. Relational substitute decision-making—alongside strategic substitute decision-making—is arguably integral to providing good care. Yet because it is incompletely recognised by the new legal framework, it cannot be endorsed and properly regulated. Dunn’s work highlights this danger; in bringing together the descriptive and the normative in this way, his research is a model of the new empirical bioethics.

Timothy James

As with several of the contributions to this special edition, Timothy James' article concerns differences in bioethical theory and practice, in this case juxtaposing the bioethics of judicial decisions with the bioethics of academia. James distinguishes between the definitive and 'real life' deliberations of the law court and the hypothetical discussions of the philosophy department. He begins by briefly exploring the relationship between law and ethics, before outlining differences in the purposes, training and methods of judges and philosophers and the ways in which these impact on how bioethical questions are answered in legal practice.

The rights and wrongs of ethically complex medical dilemmas, in practical terms, are often finally determined by judges, as in recent cases concerning treatment withdrawal, conjoined twins and embryo implantation. This is a major distinction between the court and the classroom. Academic ethicists are under no obligation to reach a definite answer; they are at liberty to debate bioethical questions *ad infinitum*. Judicial decisions, on the other hand, must be conclusive, and they have major consequences for the lives of real (or potentially real) people. James writes, "In cases involving the life and death of real individuals it may be hard for a judge to reach logically impeccable but painful and perhaps counter-intuitive conclusions."

Given this, he asks whether it is appropriate for judges to take philosophical debate into consideration in their decision-making. Both judges and philosophers use case comparisons to aid their conclusions. The difference lies in the nature of the cases employed. Judges extrapolate primarily from previous rulings, whilst philosophers favour 'thought experiments'. Judges are concerned with the authority of law, with legitimacy and consistency, and therefore James argues that reliability may be a more important test of their decisions than validity, as derived from the authority of reason.

James concludes his article by discussing the role of courts in law-making. While in theory, judges merely interpret pre-existing law, in practice they are able to come to the answer they consider most appropriate, "socially, politically or even ethically," by manipulating past principle and precedent. James suggests that a deeper examination of such judicial practice in difficult medical cases might enable philosophical bioethicists to better understand and find common ground with legal reasoning. This in turn could offer a further opportunity to gauge the role and relevance of an empirical approach at the intersection of law and ethics.

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