Original Article

Re-moralising medicine: The bioethical thought collective and the regulation of the body in British medical research

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Abstract The way in which the scientific and medical use of the human body is problematised and governed in the United Kingdom was radically reconfigured over the last 30 years, changing from a logic of rule articulated around 'supply' and 'solidarity' to one construed around 'ethics'. Drawing on the work of Ludwik Fleck and others, this article argues that one of the reasons for this reconfiguration was the existence and influence of a network of philosophers, doctors and lawyers who sought, from the 1960s onwards, to re-moralise medicine: the bioethical thought collective. The article first describes the collective's membership and organisation, focusing in particular on the form of the interdisciplinary expert committee. It also describes some of the knowledge and practices that make up the community's thought style, such as its moral concern about modern medicine and the notions of respect for persons and informed consent. The article then shows how these organisational forms, knowledge and practices that characterise the collective have shaped the government of human tissue research over the last 15 years. By highlighting the important role played by expert networks and knowledge, the article makes an original contribution to the sociology of the ethical government of biomedical science.
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Over the course of the last 30 years, the way in which the medical and scientific use of the human body is problematised and governed in the United Kingdom has been progressively reconfigured (Booth, 1993; Hazelgrove, 2002; Reubi, 2012).[1] Up to the 1970s, the use of human tissue in medical research was usually seen as a 'problem of supply'. The concern for the architects of the

British welfare state was to ensure that researchers had sufficient supplies of human body parts to advance medical knowledge and thus bring health and happiness to all citizens. The solution, unsurprisingly perhaps, was a strategy in keeping with the then dominant logic of rule centred on social solidarity: the gift relationship (Burchell *et al*, 1991; Fontaine, 2002; Miller and Rose, 2008; Dean, 2010). This strategy was articulated around the figure of the citizen who, encouraged through publicity campaigns, gave his or her body to medical science for the good of all and who, in return, was taken care of by society. Today, in contrast, the medical and scientific use of the body is generally understood as a 'problem of ethics'. The concern, for regulators in the early twenty-first century Britain, is to soothe the public anxieties and moral unease associated with the possible implications and misuses of new scientific developments such as stem cell research and genetic databases. The typical way to do this is to set up regulatory frameworks to ensure that the use of the body in hospitals, tissue banks and research institutions is done ethically (Jasanoff, 2005; Petersen, 2005; Salter and Jones, 2005; Busby, 2006).

Drawing on the work of Fleck (1979) and others (Hass, 1992; Hacking, 2002; Mirowski and Plehwe, 2009), I argue in this article that one of the reasons for the reconfiguration of the way in which we govern the medical use of the body has been the existence and influence of what I term the bioethical thought collective – a network of philosophers, doctors, social scientists and lawyers who have sought, from the 1970s onwards, to re-moralise medicine. The article first describes the collective's membership, organisation and thought style, focusing on the period between the 1970s, when the collective first emerged, and the 1990s, when the collective became really influential. It then shows how the bioethical thought collective has, from the mid-1990s onwards, influenced the reconfiguration of the way in which we govern the medical use of the human body. By emphasising the importance of networks of expertise and knowledge in making today's regulation of human tissue research, the article offers an original contribution to the sociological literature on the ethical governance of the life sciences. Indeed, the explanations for the recent transformation of how the medical use of the body is governed that can be found in this literature tend to stress the role played by neo-liberal theories of rule and the politics of legitimation conducted by government and the medical profession (for example, Cooter, 2000; Jasanoff, 2005; Petersen, 2005; Waldby and Mitchell, 2006).

Before discussing the bioethical thought collective and how it has influenced the way in which we currently govern the medical use of the body, the article spends some time describing the recent reconfiguration of the regulation of human tissue research.

Reconfiguring the logic of rule: From 'supply' and 'solidarity' to 'ethics'

Until the 1970s, the way to govern the collection of human tissues for medical and scientific purposes was articulated around notions of 'supply' and 'solidarity'. As mentioned earlier, the concern for the managers of the British welfare state was to ensure that researchers had sufficient supplies of human tissue to advance medical knowledge and thus bring health and happiness to all. The post-war period was a time characterised by a fervent enthusiasm for modern medicine, which was understood to be a critical vector of progress and prosperity (Porter, 1999: Chapter 21; Le Fanu, 2000). Medical research, it was thought, had to be supported and facilitated through excellent infrastructures, generous funding, scientific freedom and a sufficient supply of human tissue (Booth, 1993). Codes of ethics to regulate research had no place – they were deemed to be an unnecessary obstacle to medical progress (Hazelgrove, 2002; Weindling, 2006: Chapter 17).[2] The parliamentary debates that led to the adoption of the United Kingdom's first *Human Tissue Act* in 1961 provide a good illustration of this then predominant way of thinking. The aim of the *Act* was, as the Government's spokeswoman explained in Parliament, to remove any legal obstacles to the medical use of human tissues so as to allow 'the progress of research' for 'the benefit of the living' (Hansard, 1961a, pp. 1231–1235). Interestingly, none of the Members of Parliament present disagreed. In particular, they did not seem to think that the scientific use of the human body entailed any dangers and did certainly not conceive it as a 'problem of ethics.' On the contrary, most interveners expressed enthusiasm for the 'wonders of modern science' and their 'benefit for humanity' (Hansard, 1961a, p. 1240, 1961b, p. 841).

The way in which the architects of the post-war British welfare state generally sought to ensure that researchers had sufficient supplies of human tissue was by using a strategy that chimed with the then predominant mode of government centred on social solidarity: the gift relationship (Burchell *et al*, 1991; Fontaine, 2002; Miller and Rose, 2008; Dean, 2010). This strategy was articulated around the figure of the citizen who gives his or her body to medical science for the good of all and who, in return, is taken care of by society (Busby, 2006; Bolton, 2008; Reubi, 2012). Richard Titmuss's (1970)*The Gift Relationship* is probably the best and most famous example of this way of conceiving things. In this book, which sought to defend welfarism at a time when it was coming under increasing attack from neo-liberal think-tanks around the country, Titmuss (1997 [1970], p. 283) argued that citizens should be altruistic and 'behave as givers'. This, in his mind, included putting oneself forward as 'material for experimentation', so as to ensure 'the advancement of medical

science' and 'the good of all patients' (ibid., pp. 280–283). Such a gift, he continued, should be 'characterised by complete, disinterested, spontaneous altruism' together with 'some expectation and assurance that a return gift [will] be received [from society] at some future time' (ibid., p. 140). Of course, Titmuss was well aware that such citizens did not necessarily exist as such; one had, he argued, to 'actualise [people's] social and moral potentialities' and 'foster altruism' through education and publicity campaigns (ibid., pp. 59 and 306).

In contrast to this logic of rule articulated around 'supply' and 'solidarity', the currently predominant way to govern the medical use of the body is centred on the notion of 'ethics'.[3] The main concern for regulators over the last few years has been to address the ethical issues arising from human tissue research, including the commercialisation of the human body; the implications of stem cell research; the possible misuse of the personal information generated by genetic databases; and the collection and use of human organs and tissues by pathologists (Tutton and Corrigan, 2004; Jasanoff, 2005; Busby, 2006; Seale *et al*, 2006). The purpose, when addressing these ethical issues, has been to soothe the anxiety that they generate among the British population and avoid them fuelling the public mistrust towards medicine that has developed in the United Kingdom over the last 40 years (Porter, 1999; Le Fanu, 2000; Petersen, 2005). One of the earliest illustrations of this new way of thinking is a report published by the Nuffield Council on Bioethics in 1995. The aim of the report was, according to its authors, to 'deal with the ethical questions raised by the medical and scientific use of human tissue', such as 'the commercialisation of the human body' (1995, pp. ii and 12). This was important because of the 'increasing public concern' generated by these questions (ibid., p. 123). Another good example of this new way of problematising and governing the human body is the Medical Research Council's (MRC) first guidelines on human tissue research, which were published in 2001. The authors explained that 'general principles that could govern the use of all human biological material in research' were necessary, given the 'widespread concern about … ethical issues relating to genetic research' (2001, p. 1).

The way in which regulators have sought to solve these different ethical issues and soothe associated public anxieties has been to set up regulatory frameworks to ensure that the medical and scientific use of the body is done ethically (Jasanoff, 2005; Petersen, 2005; Salter and Jones, 2005). Over the last 10 years, the government, regulatory bodies, funding agencies, professional organisations and research centres have all adopted such frameworks. One significant example is the new 2004 *Human Tissue Act* – a completely revised *Act*, which replaces the earlier 1961 version. Other examples include: the Medical Research Council's (2001) *Operational and Ethical Guidelines on*

Human Tissue and Biological Samples for Use in Research; the Royal College of Pathologists' (2001) *Guidelines for Handling 'Surplus' and Archival Material from Human Biological Samples*; the Chief Medical Officer's (2001) *Removal, Retention and Use of Human Organs and Tissue*; the Department of Health's (2003) *The Use of Human Organs and Tissues;* the Human Tissue Authority's (2006b) *Code of Practice on the Removal, Storage and Disposal of Human Organs and Tissue*; the UK Biobank's (2006) *Ethics and Governance Framework*; and the Royal College of Physicians' (2007) *Guidelines on the Practice of Ethics Committees in Medical Research with Human Participants*.

These different regulatory frameworks are generally articulated around two main elements. The first one is guidelines about how research on human tissue should be conducted. They comprise: rules about the accepted levels of risk or harm for those providing their bodily tissues (for example, Department of Health, 2003, p. 6); rules about the scientific quality of the research (for example, Royal College of Physicians, 2007, pp. 10 and 36–38); rules about the acquisition, storage and disposal of human tissues (for example, MRC, 2001, pp. 18–20); rules about what should be done with the personal information gained from human tissues (for example, UK Biobank, 2006, pp. 5–11); and rules about informed consent (for example, Royal College of Pathologists, 2001: Sections 1–2; Human Tissue Authority, 2006a). The second element around which these regulatory frameworks are built is institutions that monitor whether existing guidelines for the medical use of the body are effectively being observed by researchers. One such institution is research ethics committees that have to assess and approve any proposed investigation using human tissue before it can be carried out (for example, Royal College of Physicians, 2007, pp. 4–16). Another such institution is the Human Tissue Authority (2006a), a regulatory agency that ensures that research centres using human tissue abide by the existing guidelines through a system of licensing and inspection.

The sociological literature on the ethical governance of the biomedical sciences has put forward a couple of explanations for this recent reconfiguration of the way in which we regulate the medical use of the body. One group of scholars has argued that the current bioethical regulation of human tissue research is due to the predominance of neo-liberal theories of rule in the United Kingdom today (for example, Cooter, 2000; Waldby and Mitchell, 2006). According to them, a logic of rule articulated around ethics became prevalent because, unlike a logic centred on social solidarity, it combined well with some of neo-liberalism's core tenets. In particular, they point out that today's ethical regulation of human tissue research with its strong emphasis on informed consent shared a common commitment to individual choice with neo-liberal theories of rule. Another group of scholars have argued that the way in which we currently regulate human tissue research is the result of a 'politics of

legitimation' (for example, Jasanoff, 2005; Petersen, 2005; Salter and Jones, 2005; Busby, 2006; Seale *et al*, 2006). They show how there is an increasing distrust for and anxiety associated with the medical sciences among the British public. This, they argue, is due to both recent scientific advances like the development of stem cell research and the elaboration of a national genetic database (UK Biobank) and highly publicised scandals about the illegal collections of human organs and tissues in British hospitals at the turn of the twenty-first century. These authors show how, concerned about the damage that this public mistrust might have for science, the government, the medical profession and the life sciences industry have tried to rebuild the legitimacy of the biomedical sciences. To do so, these three groups have established new bodies (for example, Human Genetics Commission) or mandated existing ones (for example, House of Lords; Nuffield Council on Bioethics) to report on the possible ethical implications of these scientific advances. They have also set up commissions of enquiry to look into the illegal collections of organs and tissues assembled in British hospitals (for example, the Bristol Royal Infirmary Inquiry; the Royal Liverpool Children Inquiry; the Retained Organ Commission), and advocated for the adoption of the 2004 *Human Tissue Act* and the other regulatory frameworks listed above.

The bioethical thought collective

Building on these findings, the present article argues that another complementary reason for the recent reconfiguration of the way in which we govern the medical use of human tissue is the development and influence of the bioethical thought collective. The notion of the bioethical thought collective draws on the work of Fleck (1979) and others (Hass, 1992; Hacking, 2002; Mirowski and Plehwe, 2009). According to these authors, 'thought collectives' are communities or networks of professionals with a recognised expertise in a specific domain. What makes these networks distinctive is that their members, who can come from a variety of backgrounds and disciplines, develop and share a same 'style of thinking' – a grid of intelligibility and action that allows the network's members to represent, analyse and intervene upon a particular reality, which comprises linguistic expressions, theories, values, beliefs, problems, explanations, organisational forms and practices. As these authors suggest, such epistemic communities have played a key role in the generation of many of the scientific and political truths that prevail today. Following these authors, the bioethical thought collective is best characterised as a British-based network of philosophers, lawyers, social scientists and doctors whose purpose is to re-moralise medicine. For the members of this network, modern medicine

is a cause for concern and both doctors and researchers have to be guided and, sometimes, limited. Their aim is to provide this guidance and re-organise medicine around the notion of respect for persons through a combination of research, policy recommendations and public discussions.

The development of the bioethical thought collective began in the 1970s (Cooter, 2000; O'Neill, 2002). This period saw the establishment of the first organisation for the promotion of bioethics, the London-based Institute of Medical Ethics (IME) and the first academic research centre on bioethics, the Centre of Medical Law and Ethics (CMLE) at King's College London. It also saw the launch of the first journal in the field, the *Journal of Medical Ethics* (*JME*), as well as the publication of the first books and articles on the topic (for example, Campbell, 1972, 1977; Dunstan, 1974; Kennedy, 1976). The collective grew markedly over the 1980s and 1990s, becoming increasingly influential in the regulation of the biomedical sciences as the century drew to a close (Wilson, 2011, 2012). During these two decades, new research centres were opened (for example, Centre for Social Ethics and Policy (CSEP), University of Manchester; Centre for Contemporary Ethical Studies, Keele University), new journals were launched (for example, *Bioethics; Cambridge Quarterly in Healthcare Ethics*) and a plethora of new articles and books were published (for example, Kennedy, 1981; Dunstan and Seller, 1983; Harris, 1985; Gillon, 1986; Brazier, 1987; Warnock, 1987; Brazier and Lobjoit, 1991; Campbell *et al*, 1992; Neuberger, 1992; Kennedy and Grubb, 1994; O'Neill, 1996; Warnock, 1998). It is also during this time that many of the concepts, forms and practices developed by the collective were adopted by most British organisations involved in biomedical research. Indeed, the Department of Health, the Royal College of Physicians (RCP), funding agencies like the MRC, the British Medical Association and the Association of the British Pharmaceutical Association all issued ethical guidelines and set up expert committees like the Nuffield Council on Bioethics (Reubi, 2012). Similarly, universities and hospitals around the country introduced undergraduate courses on medical ethics and set up research ethics committees (Whong-Barr, 2003; Hedgecoe, 2009).

In the period between the early 1970s and late 1990s, the collective's membership was characterised by its interdisciplinarity and stability. Many of the network's members did not have any training in the medical sciences. They were philosophers, theologians, lawyers, social scientists and others usually working for academic institutions and interested in applying their knowledge to the field of medicine. Examples comprise: theologian Alastair V. Campbell, first editor of JME and author of the earliest book on medical ethics in the United Kingdom: *Moral Issues in Medicine*; philosopher Ranaan Gillon, professor of medical ethics at Imperial College, former editor of the JME and president of the IME; theologian Gordon R. Dunstan, senior ethicist of the Church of England

and co-founder of the CMLE; Oxford philosopher Mary Warnock, chair of the Warnock Committee on Human Fertilisation and Embryology; lawyer Ian Kennedy, author of numerous books on medical law and ethics, including *The Unmasking of Medicine*, and co-founder of both the CMLE and the Nuffield Council on Bioethics; philosopher John Harris, author of *The Value of Life* and co-founder of the Manchester CSEP; feminist and CMLE member Carolyn Faulder; lawyer Margaret Brazier, author of the often re-edited textbook *Medicine, Patients and the Law,* co-founder of the CSEP and member of the Nuffield Council on Bioethics; and Cambridge philosopher Onora O'Neill, co-founder of the Nuffield Council on Bioethics. In addition to these 'lay' members, the collective also comprised doctors and life scientists concerned with the ethical dimensions of medicine. Examples include figures like Douglas Black, one-time president of the IME and founder of the RCP's Committee on Ethical Issues in Medicine; and Anne McLaren, a Cambridge embryologist who sat on the Warnock Committee and a founding member of the Nuffield Council on Bioethics.

In the 25 years or so following its emergence, the collective was organised around three main institutional forms. The first one was the professional association and is best illustrated by the already mentioned IME. Founded in 1975, the IME defined itself as an independent association for the promotion of medical ethics (Whong-Barr, 2003). It carried out its mandate by running public conferences on ethical issues and publishing two journals: the *IME Bulletin* and the *JME*. The second key institutional form was the academic research centre. Two good examples are the CMLE founded by Ian Kennedy, Gordon Dunstan and others at King's College London in 1978 and the CSEP established by John Harris and Margaret Brazier at the University of Manchester in 1987. Scholars working at these centres carried out enquiries into and published books and articles about aspects of medicine deemed to be ethically problematic (for example,Kennedy, 1981; Dunstan and Seller, 1983; Harris, 1985; Warnock, 1987; Brazier and Lobjoit, 1991; Campbell *et al*, 1992; O'Neill, 1996). They also taught medical ethics to medical undergraduates and ran masters programmes in the upcoming field of bioethics. The third and last main institutional form was the interdisciplinary expert committee. The most famous example is certainly the Nuffield Council on Bioethics (2000b), founded in 1991 by Ian Kennedy, Onora O'Neill, Anne MacLaren and others with funds from the Nuffield Foundation, the MRC and the Wellcome Trust. But there are many other examples, including: the IME's Working Group on the Ethics of Clinical Research Investigations on Children; the RCP's Committee on Ethical Issues in Medicine; the MRC's Working Parties on Research on Children and Research on the Mentally Incapacitated; and the Department of Health's Committee on the Research Use of Fetuses. All these committees share two characteristics.

They all have an interdisciplinary membership drawn from medicine, philosophy, theology, social science and law. And they all have as their mandate to identify and examine ethical issues related to modern medicine and to make policy recommendations on how to address them.

A key element of the collective's style of thinking between the early 1970s and the late 1990s was the belief that biomedical science had become a cause for concern. This belief which, interestingly, echoed the British public's growing dissatisfaction with modern medicine and distrust towards biomedical scientists (Porter, 1999: Chapter 21; Le Fanu, 2000) was a necessary foundation for the expert network's plan to re-moralise medicine. Indeed, if medicine was not a problem, there was no *reason d'être* for the collective's research and policy recommendations. There are many examples of this problematisation of biomedical science in the writings of the collective. Alastair Cambpell's piece on *Establishing Ethical Priorities in Medicine* published in the *British Medical Journal* in 1977 is one such case:

> In his celebrated attack on the 'medicalisation of life' Ivan Illich has suggested that [modern medicine] causes more damage to health than it brings benefit to mankind …. The focus of his attack seems to me entirely correct. It is now essential that we ask some basic questions about the task and place of medical care within society as a whole. (Campbell, 1977, p. 818)

Another illustration of the bioethical thought collective's dissatisfaction about modern medicine is Ian Kennedy's 1980 Reith Lectures entitled *The Unmasking of Medicine*:

> My view can be stated briefly. Modern medicine has taken the wrong path. An inappropriate form of medicine has been created, in large part by doctors and medical scientists … I will go further. The nature of modern medicine makes it positively deleterious to the health and well-being of the population …. [We] have hitched our wagon to the wrong star, scientific medicine. (Kennedy, 1981, pp. 26 and 50)

Similarly, Warnock, in an article arguing for the establishment of a national bioethics commission, explained that:

> After the last war there was a cliché to the effect that man's scientific knowledge had outstripped his moral sense. At the time it was uttered in the context of the physical sciences. The bomb had, rightly, frightened us all. Now that same cliché is more and more to be heard in the context of the biological sciences. We must take it seriously. (Warnock, 1988, p. 1627)

It is important to note that, for the members of the bioethical network, the problem with medicine was identified as a 'moral' or 'ethical' problem. Again, this comes across in the writings of the collective. Alastair Campbell (1972: Chapter 6), for instance, used the terms 'moral dilemmas' and 'ethical issues' to refer to his concerns with biomedical science. Likewise, Mary Warnock (1988, p. 1626) used the expression 'ethical problems' to discuss her worries about medicine. The aspects of the biomedical sciences that the collective deemed to be of moral concern were multiple, and ranged from organ transplantation and electroshock therapy to end-of-life issues and truth telling (Whong-Barr, 2003). Among these different aspects that were deemed to be problematic, medical research figured prominently, not the least because of the key role it played in modern medicine and its growing volume (Booth, 1993). The types of research that were of particular concern to members of the bioethical expert network included: clinical trials, because of their ever-increasing numbers, and the potential physical and psychological harm they can cause to human participants (for example, Faulder, 1985; Royal College of Physicians, 1986; cf. also Petryna, 2009); research on groups deemed to be especially vulnerable to abuse, like children and the mentally incapacitated (for example, Nicholson, 1986; Royal College of Physicians, 1990; Medical Research Council, 1991); research on human embryos, because of the fears of scientists meddling with reproduction and selective eugenics (for example, Kennedy, 1984; Warnock, 1985; cf. also Mulkay, 1997); and research on foetuses, because of the anxieties of women being encouraged to abort in the name of scientific progress (for example, Committee on the Research Use of Fetuses, 1989).

Another, central element of the collective's style of thinking between the early 1970s and the late 1990s was the moral principle that persons should always be treated with respect. Indeed, it was around this principle of respect for persons that the bioethical thought collective sought to re-moralise medicine. For the members of the bioethical network, this principle meant that doctors and scientists should show at all times a certain 'concern' or 'sensitivity' in their dealings with their patients or research subjects. For instance, John Harris (1985, p. 193) exhorted physicians to show 'concern for the welfare' and 'respect the wishes' of their patients. Similarly, Mary Warnock (1983, p. 248) recommended that scientists should treat their research subjects with 'sensitivity'. Often, members of the collective expressed this obligation to show respect as a Kantian interdiction for doctors to treat their patients or research subjects as 'a mean to an end' or 'a thing'. Ian Kennedy (1984, p. 6), for example, argued that 'many would see [it as] a fundamental principle [that medical researchers] may not use humans as means to an end, but must respect them as ends in themselves'. Likewise, CMLE member Carolyn Faulder

(1985, p. 23) explained that doctors should always 'regard patients as persons rather than objects or things'.

For the collective, an important way through which the principle of respect for persons was to be realised was the notion of informed consent, which requires scientists willing to conduct research on human subjects to adequately inform them about the investigation and to obtain their permission before carrying it out. Indeed, a fundamental characteristic of personhood is the capacity to reason, value and decide; by informing potential participants about the investigation and asking whether they are willing to be involved, scientists acknowledge and respect both their capacity to reflect and choose and their personhood. A good illustration of this way of thinking can be found in the writings of Ranaan Gillon:

> Willing rational agency, … the ability to think combined with self awareness over time [is] the essence of personhood.(Gillon, 1986, p. 50) Respect for persons … requires adequately informed consent from the subject before [any] research can be performed.(Gillon, 1989, p. 4)

Alastair Campbell and his colleagues make a very similar point in their often reprinted textbook on *Medical Ethics*:

> Respect for Persons: … Patients have their own opinions and aims in life, which require them to act intelligently in most of the things they do. But in order to act intelligently, patients must … be given information, … be allowed to think about what is being said … [and] make up their own minds.(Campbell *et al*, 1992, p. 9)

Until the 1960–1970s, the notion of informed consent had no place in British medicine and research; indeed, most doctors and scientists had probably never heard of it (Hazelgrove, 2002; Weindling, 2006). The work of the bioethical thought collective had an important role in introducing and advancing the notion of informed consent in Britain from the 1970s onwards (O'Neill, 2002; Mold, 2011; Wilson, 2012).[4] Indeed, its members wrote many books and articles that sought to determine what informed consent exactly meant and explain why it was critical to make medicine ethical again. Examples include Gordon Dunstan and Mary Seller's *Consent in Medicine*, Carolyn Faulder's *Whose Body Is It Anyway? The Troubling Issue of Informed Consent* and Mary Warnock's *Informed Consent: A Publisher's Duty*. Members of the collective also participated in the redaction of reports, manuals and guidelines that devised strategies and procedures – patient information sheets; clear and comprehensible language; signed consent forms – to ensure informed consent's effective implementation (for example, Nicholson, 1986; Royal College of Physicians, 1990; British Medical Association, 1995).

Of course, to say that the bioethical thought collective shared a common style of thinking does not imply that there were no disagreements between its members. On the contrary, there were some important differences of opinion between them – which is perhaps not surprising given the strong personalities and different disciplinary backgrounds that made up the collective. One example is the dispute about the definition of personhood. For some members of the collective, only entities that have the capacity to reason, value and decide could be identified as persons (for example, Harris, 1985; Gillon, 1986). Such an understanding meant that embryos and foetuses, for example, were not due any respect. Others had a more inclusive understanding of personhood, arguing that it encompassed any entity that was, biologically speaking, part of the species *Homo sapiens* (for example, Warnock, 1983; Kennedy, 1984). Another example of disagreement is the difference of views about the exact scope of the concept of informed consent. For most members of the collective, the respect of this concept was absolutely critical (for example, Kennedy, 1981; Harris, 1985; Faulder, 1985; Warnock, 1998). Indeed, it was so critical that, according to them, research subjects had no right to remain in ignorance or ask doctors to decide for them (Reubi, 2012). In contrast, other members like Onora O'Neill (1996; 2002), while agreeing that informed consent was important, sought to limit its scope by arguing that one should leave some place for trust in the doctor–patient relationship.

Finally, it is also important to note that the articulation of the bioethical thought collective did not take place in a vacuum but was very much influenced by the wider changes and developments taking place at that time in the United Kingdom.[5] One of these was the growing anxiety about the way in which modern medicine was progressing and the mounting challenges to medical authority within British society from the 1960s onwards (Porter 1999, Chapter 21; Le Fanu, 2000). This was driven by a range of factors: scandals such as the prescription of thalidomide to pregnant women and the excesses in human experimentation in British hospitals revealed by Maurice Pappworth in his 1967 pamphlet *Human Guinea Pigs*; philosophical critiques of modern medicine such as Ivan Illich's 1976 *Limits to Medicine*; feminists contesting doctors' control over women's bodies and sexualities; patient groups like the Patient Association and the College for Health campaigning for the right of patients to decide about their treatment; anti-psychiatry activists denouncing the mistreatment of patients; and Christian thinkers wary about the pre-eminence of scientific training in medical education and eager to teach students about morals and society (Cooter, 2000; Hazelgrove, 2002; Whong-Barr, 2003; Mold, 2010; Wilson, 2012). There is little doubt that this important development in British society encouraged and shaped the making of the bioethical thought collective: scandals and philosophical critiques fed into the collective's concern

about modern medicine, with many of its members explicitly referring to them in their writings (for example, Campbell 1972; Campbell 1977; Kennedy 1981); some of the collective's members such as Carolyn Faulder and Julia Neuberger were also active in feminist groups and patient organisations with which the collective shared many principles like that of informed consent (O'Neill, 2002; Mold, 2011); and several members of the collective were theologians such as Alastair Campbell and Gordon Dunstan, while the IME was established as the successor of the London Medical Group, a student organisation created in 1963 by the Christian Student Movement to engage future doctors with medical humanities and society (Whong-Barr, 2003).

The bioethical thought collective was further spurred and influenced by another two pivotal developments in British society. The first one was the rise to power of the Conservative party in 1979. As Duncan Wilson (2011; 2012) shows, the bioethical thought collective's ambition to re-moralise medicine through ethical frameworks dovetailed with the Conservative desire to restrict the power of the professions, medicine included, and make them accountable to the public. These shared aspirations certainly helped to bolster the bioethical thought collective's influence, with the Conservative governments of the 1980s and 1990s supporting both the creation of bioethical expert committees like the Warnock and Polkinghorne Committees and the adoption of ethical frameworks for medical research, like the Department of Health's (1991) guidelines on research ethics committees (for example, Warnock, 1985; Committee on the Research Use of Fetuses, 1989). The second pivotal development was the public debates about human embryo research in the 1980s. These often heated debates caused medical researchers to progressively embrace the idea of ethical oversight, which they had hitherto opposed (Hazelgrove, 2002). Indeed, confronted with the prospect of a complete ban on embryo research as advocated by an increasing popular pro-life Christian lobby, these researchers began to see the attraction of ethical frameworks that would allow experimentation at certain clearly defined conditions (Mulkay, 1997). There is little doubt that this shift, which led to funding agencies and medical organisations like the MRC and the RCP establishing bioethics expert groups and issuing ethical guidelines, further strengthened the position of the bioethical thought collective in the United Kingdom (Reubi, 2012).

The collective's influence in the reconfiguration of human tissue research regulation

The remainder of the article shows how the bioethical thought collective has, from the 1990s onwards, influenced the recent reconfiguration of the way in

which we govern the medical use of the body. To do so, it starts by describing the important role that some of the collective's organisational forms and experts have played in the regulation of human tissue research over the last 15 years. Then it shows how some of the collective's key concepts have been incorporated into the way human tissue research is governed today.

Some of the collective's organisational forms and experts have had a key role in the regulation of the use of the body in medical research over the last 15 years. First, interdisciplinary expert committees, a form that is characteristic of the way in which the bioethical network is organised, have had an important role in the reconfiguration of the government of human tissue research. The best example is, perhaps, the Nuffield Council on Bioethics itself. Indeed, the Nuffield Council on Bioethics (1995; 2000a) was the first to examine and report on the ethical issues associated with the medical use of the body in the United Kingdom; it also studied, later on, the moral problems generated by stem cell research. There are many other examples. One is the working group that, in the late 1990s, scrutinised and drafted guidelines about the ethical aspects of human tissue research for the MRC (2001). As other interdisciplinary expert committees, the group comprised: doctors involved in medical ethics, like professor of psychiatry and founding member of the Nuffield Council on Bioethics, Eve Johnston; philosophers concerned about medicine, such as Len Doyal, professor of medical ethics and member of the British Medical Association's Ethics Committee; and medical lawyers like Andrew Grubb, co-author with Ian Kennedy of a textbook on medical law and member of the RCP's Committee on Ethical Issues in Medicine. Another example is the UK Biobank Ethics and Governance Council. Established by the Wellcome Trust together with the MRC, the Council's mandate is to examine ethical issues related to the UK Biobank project and, if necessary, adapt the bank's *Ethics and Governance Framework* accordingly. Like the MRC working group, the Council's membership comprises lawyers like professor of medical jurisprudence Graeme Laurie, philosophers like professor of ethics Heather Widdows and doctors like professor of medicine and member of the *JME*'s editorial board Roger Higgs.

Second, many of the collective's experts that were discussed earlier have been involved in the reconfiguration of the way in which we govern the medical use of the human body. An excellent example is bioethics pioneer Alastair Campbell. He has played an important role in the problematisation and regulation of human tissue research in the United Kingdom. He has helped drafting the Nuffield Council on Bioethics' (2000a) report on the ethical aspects of stem cell research. He has also, as Vice Chair of the Retained Organs Commission, examined the moral issues associated with the collection and use

of organs and tissues by pathologists. Furthermore, he has participated in the writing of the UK Biobank's regulatory framework as Chairman of its Ethics and Governance Council. Another good illustration is lawyer Ian Kennedy, another pioneer of the bioethics collective. Like Campbell, Kennedy has played a critical role in the regulation of the scientific and medical use of the body. He co-authored the Nuffield Council on Bioethics' (1995) report on human tissue research and was also the Chair of the Bristol Children Infirmary Inquiry, which examined the ethical aspects of the collection and storage of human organs and tissues by pathologists. There are many further examples, including: Margaret Brazier (who was chair of the Retained Organs Commission with Campbell), Anne McLaren (who co-authored the Nuffield Council on Bioethics report on stem cell research with Campbell) and Onora O'Neill (who co-authored with Ian Kennedy the Nuffield Council on Bioethics' report on human tissue research).

Another indication of the bioethical thought collective's influence on the reconfiguration of the regulation of human tissue research is how some of its key notions have been incorporated into the way in which we govern the medical use of the body today. First, the principle of respect for persons, which was developed by and is characteristic of the bioethical thought collective, has become critical to the way in which the medical use of the body is problematised and regulated today. A good illustration is the MRC's (2001, p. 6) *Operational and Ethical Guidelines on Human Tissue and Biological Samples for Use in Research*, which explains that 'an important principle underlying the use of any human material for research should be respect for the human body and for the known wishes of the donor of the material'. Similarly, the Department of Health's (2003, p. 5) guidelines on the collection and use of human tissue for research state that one of the 'general principles' that governs the medical use of tissue is that 'the human body and its parts should be treated with respect'. Another good example is the HTA's *Code of Practice on the Removal, Storage and Disposal of Human Organs and Tissues*. The code asserts that scientists collecting and using human body parts have to 'respect' people's decisions not to give their bodies to medical research (2006, p. 8). It also orders scientists to dispose of the human tissue left over after research 'with respect' and, in particular, not to throw it away together with other clinical waste (ibid., p. 17).

Second, the notion of informed consent that the collective's experts helped develop and introduce in the United Kingdom has become a central tenet of the way in which the medical use of the body is regulated today (O'Neill, 2002; Corrigan, 2003; Petersen, 2005). The new 2004 *Human Tissue Act* is probably the best example. While the notion of informed consent was absent of the 1961 version of the *Act*, it is at the heart of the 2004 one. The HTA, which was

created by the *Act* and whose mandate is to offer guidance on and ensure the application of the *Act*, explains in its *Code of Practice on Consent* that:

> At the heart of the *Act* lies the need to obtain consent for the removal, storage and use of human tissue or organs and the storage and use of whole bodies … . The *Act* requires consent for the removal, storage and use of human tissue.(Human Tissue Authority, 2006a, p. 6)

Another example is the MRC's *Operational and Ethical Guidelines on Human Tissue and Biological Samples for Use in Research*, which state that informed consent is a key principle for human tissue research:

> Key principles: … . Informed consent is required from the donor whenever a new sample is taken … for research. Donors should understand what the sample is to be used for and how the results of the research might impact on their interests. Consent must also be obtained for storage and potential future use of samples.(MRC, 2001, p. 3)

Conclusion

The article started by describing how the way in which the medical and scientific use of the human body is problematised and governed in the United Kingdom has been radically reconfigured during the last 30 years. As it explained, the logic of rule that predominated until the 1970s was articulated around supply and solidarity. The problem for the administrator of the welfare state was to ensure that researchers had enough human tissues to carry out research and advance medical knowledge. The solution was to encourage citizens to be altruistic and give their bodies to science for the good of society. In contrast, the logic of rule that dominates today is centred on ethics. The concern for the regulator in the twenty-first century is to address the ethical issues associated with human tissue research and appease the public anxieties they generate. Generally, the answer is to set up regulatory frameworks to ensure that the use of the human body by scientists is done ethically.

The sociological literature on the ethical governance of biomedical science offers a couple of explanations – neo-liberalism and politics of legitimation – as to why such a radical reconfiguration took place (for example, Salter and Jones, 2005; Petersen, 2005; Waldby and Mitchell, 2006). Building on these findings, this article argued that another complementary reason for this reconfiguration has been the existence and influence of the bioethical thought collective. To substantiate this claim, the article first described this collective, focusing on the period from the 1970s, when the collective first emerged, to the 1990s, when it become influential in the United Kingdom. Drawing on Ludwik Fleck (1979),

the article characterised the collective as a network of philosophers, lawyers and doctors whose plan was to re-moralise medicine and who were organised around different forms such as the interdisciplinary expert committee. It also showed how the collective's style of reasoning was shaped by a belief that medical research had become a cause for moral concern and needed to be rearranged around two associated notions developed by the collective: respect for persons and informed consent. The article then showed how the collective has, from the 1990s onwards, influenced the recent reconfiguration of the way in which we govern the medical use of the human body. It described, in particular, how the collective's model of the interdisciplinary expert committee and its experts had a key role in the regulation of human tissue research over the last 15 years. It also described how the collective's notions of respect for persons and informed consent have been incorporated into the way in which we administer research on human tissue today.

By showing the influence of the bioethical thought collective in the development of today's government of human tissue research, this article builds on the work of authors like Hass (1992), Mirowski and Plehwe (2009). These authors have convincingly argued that epistemic communities and knowledge play a central role in the articulation of many of the political regimes of truth that prevail today. They have showed how such networks and their expertise, from international human rights NGOs and discourses to neo-liberal think-tank and theories, have shaped the way in which we currently govern economic and social life. This article demonstrates that the same is true in relation to the government of the biomedical sciences and invites researchers who study this field to pay more attention to the role of moral expert networks, and the knowledge and practices that they have developed.

About the Author

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Notes

1 This development is not exclusive to the United Kingdom. It has been taking place in most countries in the Western world and, more recently, beyond (Jasanoff, 2005; Petryna, 2009; Reubi, 2010).

2 In the United Kingdom, there were calls for the adoption of ethical codes regulating human experimentation from the 1960s onwards. The first such codes to be adopted include: the Medical Research Council's 1963 *Responsibility in Investigations on Human Subjects*; the Association of the British Pharmaceutical Industry's 1977 *Guidelines for Preclinical and Clinical Testing of New Medicinal Products Part 2 – Investigations in man*; and the Royal College of Physicians' *Guidelines on the Practice of Ethics Committees in Medical Research*. The *Nuremberg Code* remained largely unknown in the United Kingdom until the 1960s and was never deemed to be relevant for British researchers; the same is true about the World Medical Association's 1964 *Helsinki Declaration*. There was no ethical code that specifically addressed the use of human tissue in research until the late 1990s (Cooter, 2000; Hazelgrove, 2002; Weindling, 2006).

3 Of course, questions of supply and the technique of the gift are still present today. But they have become notions of secondary importance and have been subsumed under the new way of thinking about the medical use of the human body articulated around ethics and respect (Tutton, 2004; Busby, 2006).

4 The notion of informed consent had had an already long history before it was picked up, further elaborated and promoted by British bioethicists and medical lawyers from the 1970s onwards. Interestingly, one of the first articulations of the notion of informed consent was done in Germany in the late nineteenth and early twentieth centuries (Vollmann and Winau, 1996). It was this German version of the notion of informed consent, which had been codified by the Ministry of Interior of the German Reich in its 1931 *Guidelines for New Therapy and Human Experimentation*, that was later used and further developed by the American, British, and French officials who drafted the *Nuremberg Code* after World War Two (Weindling, 2006).

5 An important *foreign* influence on the making of the British bioethical thought collective was the rapid emergence and institutionalisation of bioethics in the United States from the 1970s onwards (Jonsen, 1998; Stevens, 2000). To start with, American funding agencies quickly began to demand from British scientists whom they financed that they respect the ethical principles and procedures that were being developed in the United States (Hedgecoe, 2009). Furthermore, several members of the British bioethics thought collective such as Ian Kennedy, Onora O'Neill, and Julia Neuberger spent time in North American universities learning about and working on bioethics.

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