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# The human capacity to reflect and decide: Bioethics and the reconfiguration of the research subject in the British biomedical sciences

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## Abstract

This article examines how a fundamental element of the British bioethical assemblage – the literature on informed consent published between 1980 and 2000, a period when bioethics became a powerful force in the UK – has influenced contemporary understandings of the research subject. Drawing on Foucault, the article argues that this corpus of texts has created a sphere of possibilities in which research subjects can imagine themselves as human beings who reflect and decide whether they want to participate in medical experimentation. In particular, it shows how the narratives found in these texts portray relationships between researchers and their human subjects as ‘paternalistic’, and calls for their replacement by new, more ethical relationships characterized by both ‘dialogue’ and ‘respect’ and articulated around subjects who can ‘think and take decisions’. It also discusses the different strategies – using patient information sheets, a list of possible questions and invitations to take time to reflect – which the bioethical literature has developed in order to realise these new, ethical relationships. As the article suggests, these narratives and strategies provide researchers and research subjects with models and examples of how to interact with each other that are very different from the ones that prevailed before the emergence of bioethics.

## Keywords

bioethics, biomedicine, biomedical research ethics, identity, research subject, subjectivity

The assemblage of philosophical concepts, ethical guidelines, medical law experts and research ethics committees that makes up bioethics has become increasingly influential and ubiquitous of late (Jasanoff, 2005; Petryna, 2009; Reubi, 2010; Salter and Salter, 2007). First articulated in the 1960s and 1970s by a small network of American and British

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doctors, patient activists, lawyers and philosophers concerned about the way modern medicine was developing, this assemblage has been embraced and expanded over the past few decades by a growing number of actors in the West and beyond. Universities, hospitals, funding agencies, medical associations, patient groups, governments, international organizations and pharmaceutical companies have all progressively adopted and further elaborated the rationalities and practices characteristic of bioethics (Cooter, 2000; Fox and Swazey, 2008; Sunder Rajan, 2007). The articulation and extensive adoption of this bioethical apparatus has brought into being a new way to govern biomedical research defined by complex ethical frameworks and a concern to protect human life and dignity from the dangers of modern medicine (Booth, 1993; Busby, 2006; Hazelgrove, 2002; Petersen, 2005).

The present article explores a fundamental part of the bioethical assemblage and the new governance of medical research it has helped to create: the vast corpus of texts that discuss and promote the principle of informed consent; a principle that requires all scientists who carry out research on human subjects to inform them and obtain their permission beforehand (Corrigan, 2003; O'Neill, 2002; Wolpe, 1998). More specifically, it examines how this literature on informed consent has reconfigured the figure of the research subject in the UK, one of the countries where bioethics was first articulated (Whong-Barr, 2003). Drawing on Foucault and others (Foucault, 2008; Hacking, 2002; Rose, 2007), the article argues that the narratives, strategies and procedures contained in this corpus of texts have created a sphere of possibilities in which research subjects can understand themselves and act as human beings who reflect and decide whether they want to participate in a study. The article shows, in particular, how the narratives in the literature on informed consent portray relationships between researchers and their human subjects as 'paternalistic', and calls for their replacement by relationships characterized by both 'dialogue' and 'respect' and articulated around subjects who can 'think and take decisions'. It also shows the different strategies and procedures such as the use of patient information sheets and communication techniques, which this literature has developed in order to realize these new, ethical relationships. As I suggest in this article, these narratives, strategies and procedures provide both researchers and research subjects with descriptions and models of how to think and interact; models with which they can identify and emulate. These descriptions and models, I further suggest, are very different from the ones that prevailed until the 1960s and 1970s. Indeed, in the governance of biomedicine prior to the rise of bioethics, the research subject was generally portrayed as a citizen who, in the name of society and the common good, was expected to give his or her body as material for experimentation whenever physicians deemed it necessary (Bolton, 2008; Reubi, 2009).

The argument presented in this article contributes to the sociological and anthropological literature on bioethics. For the most part, this literature has examined the bioethical assemblage in order to expose its failures and shortcomings: the bureaucratic nature of bioethics that stifles democratic debate and public engagement (Holden and Demeritt, 2008; Jasanoff, 2005); the powerlessness of bioethics to prevent the pharmaceutical industry from exploiting those most at risk (Sunder Rajan, 2007; Waldby and Mitchell, 2006); and the inability of bioethics to take into account the intricacies of the social and cultural milieus in which it is deployed (Corrigan, 2003; Geissler, 2005). In this article, I take a different approach. Instead of emphasizing the failures of bioethics, I draw attention to its productive nature by examining how the literature on informed consent helps constitute new ways to imagine the subject of medical experimentation (see also Lupton, 1997).

I start by sketching the development of the bioethical governance of medical research in the UK and unpacking the notion of the bioethical literature on informed consent. I then show how this literature has brought into being a new figure of the research subject: a human being able to reflect and decide whether he or she wants to be experimented upon.

## The British bioethical assemblage

As alluded to above, bioethics is understood here as a vast assemblage or apparatus characterized by a multitude of heterogeneous elements, including: guidelines and instruction manuals on how to conduct research ethically; intellectual concepts such as paternalism, dignity and respect; official reports on the moral aspects of human experimentation; the political will to protect human beings against the dangers inherent to medicine; research ethics committees; textbooks on informed consent; experts and research centres specializing in medical law and ethics; material devices such as information sheets and consent forms; and national bioethics commissions (Reubi, 2010; see also Collier and Ong, 2005; Rabinow and Rose, 2003).<sup>1</sup> In the UK, the development of such an assemblage and its progressive transformation of the governance of biomedical science started in the 1960s and can be divided into three periods (Reubi, 2009).

The initial period, which stretches from the early 1960s to the late 1970s, is when many of the elements that make up the bioethical apparatus were first articulated and assembled. This period was characterized by an increasing desire to question modern medicine and its perceived authority (Cooter, 2000; O'Neill, 2002; Whong-Barr, 2003; Wilson, 2011a, 2012). Challenges came from a variety of sources: feminists contesting doctors' control of women's bodies and sexualities; patient and civil liberties groups opposing medical power; anti-psychiatry activists denouncing the mistreatment of mental health patients; intellectuals inspired by Ivan Illich's critique of modern medicine; doctors anxious about the rising abuses in human experimentation; and Christian theorists wary about the pre-eminence of science and medicine in contemporary thinking. Another feature of this early period was the demands made by American funding agencies that the British researchers whom they financed adhere to the ethical principles that were being developed in the USA (Hedgecoe, 2009). These different challenges and demands led to the creation of the UK's first association for the promotion of bioethics (Institute of Medical Ethics), the launch of the first journal in the field (*Journal of Medical Ethics*) and the publication of the first books on the topic (for example, Campbell, 1972; Pappworth, 1969). They also contributed to the framing of medical research as a danger for human beings, the application of notions such as paternalism and informed consent to the field of medicine, and the establishment of the country's first research ethics committees. However, while these developments were critical in shaping today's bioethical assemblage, the influence of the latter on the governance of medical research remained limited during this period, with most doctors hostile to its rationalities and practices (Hazelgrove, 2002).

It was not until the second period, which stretches from the early 1980s to the late 1990s, that the bioethical apparatus markedly expanded and transformed the governance of medical research in the UK (Booth, 1993; Hazelgrove, 2002; Wilson, 2011a). This development was due, in large part, to the heated public debates on embryo research taking place at the time (Mulkay, 1997; Wilson, 2011a). It was also due to the predominance at the time of neo-liberal theories of rule in the UK. Indeed, the importance given in bioethics to the right

of research subjects to decide what to do with their bodies resonated with neo-liberalism's emphasis on individual choice and responsibility (Cooter, 2000; Waldby and Mitchell, 2006). Furthermore, bioethicists' aspirations to regulate medicine combined well with the Thatcher government's critique of professional power and demand for public accountability (Wilson, 2011a, 2012). These different influences led to the establishment of research centres on bioethics such as the Centre for Medical Law and Ethics at King's College London; the insertion of bioethics in the national medical curriculum; the creation of the Nuffield Council on Bioethics, the British equivalent to a national ethics commission; the multiplication of scholarly texts on medical law and ethics; the increase of research ethics committees which had now become mandatory; and the setting up of new monitoring mechanisms such as the Human Fertilisation and Embryology Authority. They also led to the adoption of bioethical rationalities and practices by most of the country's institutions involved in medical research. These institutions included: Royal medical colleges such as the Royal College of Physicians; funding agencies such as the Medical Research Council; the Department of Health; the British Medical Association; hospitals and universities; patients groups such as Consumers for Ethics in Research; and the Association of the British Pharmaceutical Industry. All of these institutions published ethical guidelines and instruction manuals for medical researchers and set up expert committees to examine particular moral issues related to human experimentation (Reubi, 2009: chapter 4).

The third and last period, which spans the first decade of the 21st century, has seen the consolidation and improvement of the bioethical assemblage, which had been put in place during the 1980s through the 1990s. The scandals linked to the retention of human organs and tissues at Alder Hey and other UK hospitals at the turn of the new millennium were an important factor in the transition to this latest period (Busby, 2006; Seale et al., 2006; Wilson, 2011b). It led to the development of yet more ethical guidelines for medical research and the adoption of new monitoring mechanisms such as the Human Tissue Authority. Another factor for the consolidation and improvement of the UK's bioethical apparatus was public concern about developments in new fields of medical research such as genomics and stem cell research (Petersen, 2005; Salter and Jones, 2005; Tutton and Corrigan, 2004). To assuage these concerns, the ethical knowledge, procedures and mechanisms developed during the earlier periods were adapted and extended to these new fields of research.

The articulation of the British bioethical apparatus and its extensive adoption by organizations involved in research over the past 50 years have led to a fundamental transformation of the way biomedical science is problematized and governed in the UK (Booth, 1993; Busby, 2006; O'Neill, 2002; Wilson, 2011b). Before the development of bioethics, the governance of biomedical science was characterized by an enthusiasm for medical progress and scientific freedom (Porter, 1999: chapters 20, 21; Weindling, 2006: chapter 17). Physicians were encouraged to conduct research and left free to decide which experiments were right to pursue for ensuring human health and happiness. It was thought that their inherent 'integrity' and 'good character' would prevent them from any wrongdoings (Bolton, 2009: chapter 2; Hazelgrove, 2002). Today, in contrast, medical research is often deemed to be dangerous for human beings and the governance of biomedical science is dominated by a desire to protect human life and dignity against this danger (Armstrong, 2007; Stevens, 2000). The typical response to this perceived danger is to set up ethical frameworks. These frameworks are increasingly complex combinations of: written, ethical codes regulating the way medical research should be done; formal procedures for

researchers to complete before carrying out investigations; detailed instruction manuals explaining how researchers should implement the codes; and monitoring mechanisms such as research ethics committees that ensure that ethical principles are respected (Jasanoff, 2005; Salter and Salter, 2007).

### *The bioethical literature on informed consent, 1980–2000*

A fundamental part of the British bioethical assemblage and the new governance of medical research it has helped to bring into being is the literature on informed consent (Corrigan, 2003; O'Neill, 2002). As explained earlier, this literature is a large corpus of texts that discuss and promote the principle of informed consent: a principle that obliges scientists to inform and obtain the consent of research subjects about their participation in an investigation. These texts not only determine what is meant by informed consent or explain why its adoption is critical. They also develop procedures and mechanisms to operationalize and ensure the effective implementation of this fundamental principle of research ethics. While literature on informed consent has been published regularly from the 1960s to the present, my focus is on texts published between 1980 and 2000. Indeed, given the vast amount of literature on the subject published over the years, such a focus is necessary in order to have a reasonably sized and homogenous corpus of texts to analyse. The decision to focus on the period between 1980 and 2000 is based on two reasons. First, as mentioned above, this period corresponds to the time when bioethics became an established and influential force in the UK. Second, both the meaning of and the technologies to operationalize the principle of informed consent became fixed during this period. In comparison, the literature on informed consent published in the 1960s and 1970s is small and rather heterogeneous, while the literature on informed consent in the 2000s does not vary much from the canon established in the 1980s and 1990s.

The bioethical literature on informed consent published between 1980 and 2000 is large and varied. First, it comprises scholarly books and articles authored by specialists in medical law and ethics that discuss the concept of informed consent (for example, Byrne, 1983; Campbell et al., 1992; Faulder, 1985; Kennedy, 1988; Warnock, 1998). Second, it includes reports produced by expert committees on bioethics that examine specific moral problems pertaining to medical research (for example, Medical Research Council, 1991; Nicholson, 1986; Nuffield Council on Bioethics, 1995; Royal College of Physicians, 1990b; Warnock, 1985). Third and last, this literature also comprises guidelines, instruction manuals and information leaflets published by institutions involved in medical research that lay out for both scientists and their human subjects how investigations should be conducted (for example, British Medical Association, 1995; Consumers for Ethics in Research, 1994; Department of Health, 1991; General Medical Council, 1998; Royal College of Physicians, 1984). It is worth noting that, although these texts are very different in kind, they are remarkably homogenous in their understanding of informed consent. There are different reasons for this. First, many of these texts are either authored by or drafted in consultation with one or more members of the small network of British experts in medical law and ethics. Second, many of these texts reference and borrow from each other, sometimes word for word. Third, most of them are influenced by the notion of informed consent used in the USA, which was progressively becoming the accepted international canon (see Salter and Salter, 2007).

## The figure of the research subject before bioethics

Before the emergence of bioethics, the dominant figure of the research subject for the British public was the citizen who, in the name of the common good, was expected to give his or her body for experimentation whenever physicians thought it necessary (Bolton, 2008: chapter 4; Reubi, 2009: chapter 3). This conception of the subject was in keeping with the prevailing logic of rule at the time built around notions of ‘social solidarity’ and ‘welfarism’ (Miller and Rose, 2008). Within this logic, political subjects were conceptualized as citizens with rights granted by the welfare state to social protection against deprivation, ignorance and disease in return for the citizen’s duty to actively contribute to the good of society. In relation to health more specifically, citizens were entitled to protection against disease by the National Health Service, and expected, in return, to support research and thus contribute to medical progress. A good illustration of this pre-bioethical understanding of the research subject can be found in a book entitled *The Gift Relationship*, written in the late 1960s by Richard Titmuss, a professor of social administration at the London School of Economics and an important figure in the post-war governance of medicine and health in the UK (Fontaine, 2002). In this book, Titmuss argued that:

[Citizens] are expected to behave as givers ... [and offer their bodies as] research material for experimentation and the testing of new drugs and other diagnostic and therapeutic measures. ... [Citizens’] willingness to be ‘taught on’ and to give of themselves is presumed; it is taken for granted in the name of research, the advancement of medical science, society’s need for doctors ... and ultimately for the good of all. (Titmuss, 1997 [1970]: 280–281)

The relationship between this research subject conceptualized as citizen and the physician was built on the notions of ‘scientific authority’, ‘gentlemanly conduct’ and ‘trust’ (Bolton, 2009: chapter 3; Hazelgrove, 2002; Weindling, 2006: chapter 17). The doctor was conceived as an expert whose duty was to use his or her technical knowledge to ensure medical progress and, thereby, the good for all in society. As such, he or she had both the responsibility and authority to determine what experiments should be carried out and which subjects should be included. The doctor was not just conceived of as an expert but also as a gentleman whose inherent integrity and good character prevented him or her from any wrongdoings. Both this scientific expertise and gentlemanly behaviour was deemed to contribute to the trust that citizens can and should invest in the judgments of physicians in relation to medical research. While not unheard of, notions of consent and ethical guidelines made little sense to this pre-bioethical understanding of research subjects and their relationships with doctors. Indeed, it was thought that such notions could only hamper medical and social progress by curbing scientific freedom and undermining trust.

## A new figure of the research subject

As noted earlier, I argue that the literature on informed consent published between 1980 and 2000 brought into being a new figure of the research subject that differs markedly from the one that dominated before the emergence of bioethics. This new figure of the subject of biomedical experimentation is a human being capable of reflecting and deciding whether he or she wants to participate in medical research. To substantiate this claim, I explore in

the remainder of the article two elements found in the bioethical literature. First, I analyse the narratives that describe existing relationships between researchers and research subjects as ‘paternalistic’ and call for their replacement by new, more ethical relationships. Second, I analyse the strategies and procedures through which texts on informed consent seek to realize the new, more ethical relationships they advocate. I suggest that these narratives, strategies and procedures generate a ‘sphere of possibilities’ in which subjects of medical research can understand themselves as persons who think and choose whether they want to be experimented upon (Hacking, 2002). Indeed, these narratives, strategies and procedures provide research subjects with models and illustrations of how to act in the experimental setting that they can adopt and follow.

Before having a closer look at these different narratives, strategies and procedures, it is important to clarify what is meant by the ‘sphere of possibilities’ that is generated by the bioethical literature. To say that this corpus of texts creates the possibility for people to imagine themselves and to act as this new sort of research subject does not imply, of course, that they will effectively do so. As ethnographers have demonstrated at length, they often do not (see, for example, Corrigan, 2003; Hoeyer, 2007). However, it is fair to say that the new bioethical figure of the research subject is one possible way of imagining this subject that has become increasingly predominant in recent years. There are many reasons for this predominance. One is the ascendancy of the advanced liberal logic of governance in the UK since the early 1980s. The subject of governance that is favoured by this logic is the active and enterprising individual who realizes him or herself through acts of choice (Miller and Rose, 2008). There is no doubt that the way the new bioethical figure of the research subject resonates with this advanced liberal subject has given the former added authority (Cooter, 2000; Waldby and Mitchell, 2006; Wilson, 2011b). Another reason for the predominance of the bioethics model of the research subject is the fact that most of the institutions active in medical research in the UK have adopted and actively promote compliance with the principle of informed consent (Booth, 1993; Busby, 2006; Hazelgrove, 2002). A further reason is the lack of any alternative model of the research subject that could challenge the monopoly enjoyed by the one brought into being by bioethics (O’Neill, 2002).

## **Narratives about the relationship between researchers and research subjects**

The literature on informed consent abounds with ‘narratives’ about the relationship between researchers and research subjects (White, 1987, 2010).<sup>2</sup> These narratives comprise two main types of account. The first is an account of existing relationships between medical scientists and research subjects. This account represents these relationships as ‘paternalistic’, condemns them for perpetuating an understanding of the subject as ‘passive and incompetent’ and calls for their replacement with new, more ethical relationships. The second is an account of these new, more ethical researcher–researched relationships. It includes a description of the research subject who ‘thinks and takes decisions’ – a subject that these new relationships both presuppose and enable. It also includes a description of two of the most characteristic features of these new relationships advocated by the literature on informed consent: ‘dialogue’ and ‘respect’.

### 'Doctors must abandon paternalistic attitudes'

Texts on informed consent repeatedly portray relationships between researchers and research subjects in the UK as 'paternalistic' (for example, Campbell et al., 1992: 17–21; Faulder, 1985: 1–6; Kennedy, 1988: chapter 2). According to these texts, a relationship is paternalistic when the investigator (doctor) has the sole prerogative to decide whether a subject (patient or healthy volunteer) should take part in a research project. In such a relationship, the physician–investigator has to decide what he or she thinks is best for the subject, irrespective of the subject's wishes. As the bioethical literature suggests, this decision can result in withholding information from or telling lies to the subject. A typical illustration of this way of representing things can be found in *Philosophical Medical Ethics*, a bioethics textbook published in 1986 by Raanan Gillon. Gillon, who was the president of the Institute of Medical Ethics and editor of the *Journal of Medical Ethics* for most of the 1980–1990s, argues that 'paternalism' occurs when doctors 'do [what is] best for one's patients' even if this means 'doing things against their immediate wishes', 'not consulting them' or even 'deceiving them' (Gillon, 1986: 67–68). Similarly, John Harris, an important figure of British bioethics and co-founder of the Centre for Social Ethics and Policy in Manchester, asserts in his 1985 book *The Value of Life* that:

Paternalism is the belief that it can be right to order the lives of others for their own good, irrespective of their wishes or judgments. The characteristic cry of the paternalist is 'Don't do that, it isn't good for you' ... [Paternalism might involve] deliberately deceiving [the patient] ... or knowingly giving only partial information'. (Harris, 1985: 194, 198)

The literature on informed consent did not only portray existing researcher–researched relationships as paternalistic, it also suggested that doctors will generally try to justify paternalism by pointing out that they have a superior medical knowledge to that of research subjects. So, for example, Sheila McLean, a legal scholar at the University of Glasgow's Institute of Law and Ethics, explained in *A Patient's Right to Know* that: the paternalistic 'model assumes that the patient lacks the technical ability to make medical decisions and their expertise justified the doctors making decisions on the patients' behalf' (McLean, 1989: 4). Likewise, Carolyn Faulder, a feminist activist working at King's College's Centre for Medical Law and Ethics, explained in *Whose Body Is It? The Troubling Issue of Informed Consent* that:

Doctors generally say that they must [decide for their patients] because their skills and experience give them the advantage of superior knowledge. ... Patients have [to] put themselves into their hands precisely because they possess these skills and they [must therefore] rely on their doctors to choose the best [solution for them]. (Faulder, 1985: 28)

Unsurprisingly, paternalism is deemed to be problematic in bioethical texts because it overlooks research subjects' capacity to reflect and decide about their own bodies. As John Harris explains in *The Value of Life*: paternalism 'involves treating the [research subject] as incompetent' and 'denies his control over his own life and moral destiny' (Harris, 1985: 194). Indeed, 'where the [research subject] is misinformed, or only told part of the truth', 'his capacity to make the best choices he can will be undermined' (Harris, 1995: 198).

Given paternalism's problematic nature, the bioethical literature argues that paternalistic relationships should be replaced by new, more ethical relationships articulated around the notion of informed consent. For example, Alastair Campbell, co-founder of the *Journal of Medical Ethics* and author of the UK's first bioethics textbook, argues in *Medical Ethics* that 'the old paternalistic attitude must be rejected' and replaced by 'a different model of the medical relationship' (Campbell et al., 1992: 18, 21; 1997: 19, 22). Likewise, Ian Kennedy, co-founder of both King's College Centre for Medical Law and Ethics and the Nuffield Council on Bioethics, explains in *Unmasking Medicine* that 'we must challenge the power which doctors exert', 'take responsibility for our lives' and create 'a new relationship between doctor and patient' (Kennedy, 1981: 167). Even the generally conservative Medical Research Council explains in a report on *The Ethical Conduct of Research on Children* that 'it can no longer be assumed that the patient should be solely guided by the judgment of his medical attendant' as such a position is now 'seriously out of line with contemporary thinking' (Medical Research Council, 1991: 21; see also Medical Research Council, 1992: 7).

It is possible to question how accurate it is to portray relationships between biomedical researchers and their subjects before the emergence of bioethics as paternalistic. A response to such questioning would be to say that, while paternalism captures some aspects of that relationship, such as the key role given to scientists for deciding which experiments should be done and how they are to be performed, it overlooks others, such as the notions of citizenship and gentlemanly conduct. Another, better response would be to say that the bioethical literature uses paternalism as a rhetorical rather than a historically accurate description of relationships between doctors and patients. In other words, paternalism is a rhetorical device for this literature. It enables proponents of bioethics to problematize the relationship between the researcher and research subject relationship by portraying it in a negative light: full of deception and lies and contemptuous of people's wishes. By doing so, they open up a space for intervention and reform of the unsatisfactory relationships that currently exist between physicians and their research subjects.

### **'A being able to think, act and communicate'**

The literature on informed consent is also replete with accounts of the new, more ethical relationship that should replace the paternalistic one currently in place. These accounts contain a description of the research subject that this new, ethical relationship both presupposes and enables: a 'human being' or 'person' who is 'able to think, act and communicate'. For example, Gillon's (1986: 50, 60) *Philosophical Medical Ethics* describes research subjects as 'persons' with a 'capacity to think, decide and act'. Campbell makes a similar point in his *Medical Ethics*, portraying patients as 'persons' who 'have their own opinions and aims in life' and who will 'act intelligently in most of things they do' (Campbell et al., 1992: 9; 1997: 9). Likewise, Mary Warnock, an important actor in the bioethical governance of medical research in the UK, explains in an article on informed consent that a research subject should be treated as 'a human' with a 'power of understanding [and] making serious decisions' (Warnock, 1998: 1003). The same idea can be found in one of the British Medical Association's (1995: 66) guide on consent: research subjects have a 'capacity' to 'understand ... [and use] information ... to arrive at a choice'.

The accounts of this new, more ethical relationship that are found in bioethical texts also include a description of two of its key characteristics. The first one is the way the relationship is structured as 'a dialogue' between medical scientists and potential research candidates. It is assumed that potential candidates generally lack the technical knowledge required to decide whether or not to participate in an experiment. As Carolyn Faulder (1985: 35) explains, they are 'usually ignorant about the basic medical facts'. The aim of the dialogue with the scientists is to allow the candidates to obtain the necessary knowledge about the proposed research so that they can decide whether or not they want to take part. As Campbell (1992: 9; 1997: 9) explains, research subjects must 'be given information ... in order to act intelligently'. He further explains that this should be achieved through 'a respectful and broadly rational dialogue between doctor and [research subject]' that 'combines the [latter's] values with the [former's] expertise' (p. 9). Similarly, the General Medical Council argues in its guide on *Seeking Patients' Consent* that 'effective communication is the key to enabling [research subjects] to make informed decisions' and that an 'open, helpful dialogue ... leads to clarity of ... understanding' (General Medical Council, 1998: paragraph 3).

The second key characteristic of this new, ethical relationship is the way it is permeated by a desire to 'respect' the choices of potential research subjects even when these seem unwise. John Harris (1985: 194–195), for example, argues that doctors should always show 'respect for the wishes' of the research subjects even when they 'appear to be self-destructive'. Carolyn Faulder (1985: 25) makes a similar point when she explains that doctors have to 'respect the right' of potential research candidates 'to make choices' even if these choices seem 'unwise or irresponsible'. Similarly, the General Medical Council (1998: paragraphs 1 and 19) asserts that '[d]octors ... must respect patient's autonomy – their right to decide whether or not to undergo any medical intervention even where a refusal may result in harm to themselves or their own death, ... [even] if a patient's choice appears irrational.'

It is interesting to note here that, according to the literature on informed consent, research candidates have no right to remain in ignorance about an investigation in which they participate. Similarly, they have no right to 'choose not to choose' whether or not they want to participate in a research project. John Harris (1985: 208), for example, argues that 'it is doubtful whether there can be any right to remain in ignorance'. Indeed, for him, doctors should 'remedy where possible both the defects of reasoning and of information which militate against the individual's capacity [to reflect and decide]', even if this means 'contravening the wishes of the agent [not to know]' (1985: 213). Similarly, the General Medical Council explains that 'no-one may make decisions on behalf of a competent adult' (1998: paragraph 11). This means that when 'patients ask [doctors] to make decisions on their behalf' and 'insist they do not want to know' about the research, doctors 'should explain [to] them the importance of knowing' and 'still provide [them with] basic information' (paragraph 11). Such statements are rather ironic, given the emphasis that the bioethical literature places on the notion of choice. They also show that proponents of bioethics are well aware that the figure of the human being capable to think and decide will not necessarily be happily embraced by everyone and that it will sometimes need to be forced onto people.

More importantly for the argument presented here is that these bioethical narratives help to make it possible for research subjects to imagine themselves as persons who can

reflect and decide whether to participate in medical research. Indeed, through its depiction and moral condemnation of paternalistic relationships, the literature on informed consent offers them a detailed account of what should *not* happen between an investigator and his or her human subjects. In particular, it tells them that an investigator should never decide for his or her research subjects and should certainly not lie to, or otherwise deceive, them. Similarly, the bioethical literature's account of dialogic and respectful relationships provides scientists and research subjects with a model of how to behave and interact with each other. More specifically, it shows investigators how they should discuss the proposed experiment with their human subjects and how they need to respect the latter's decisions, irrespective of how reasonable they might seem. It also shows research subjects how they can reflect about what has been discussed and decide, in accordance with their own values and aims in life, what they want to do.

## Technologies of dialogue

As noted earlier, the literature on informed consent has developed a variety of strategies and procedures to make relationships between researchers and their human subjects more ethical. In order to achieve this, some of these strategies and procedures seek to generate a dialogue between the investigator and the research subjects. In this section, I explore the three most significant of these 'technologies of dialogue': patient information sheets; communication techniques; and lists of suggested questions about biomedical research (Miller and Rose, 2008).<sup>3</sup>

### *The patient information sheet*

The patient information sheet (PIS) is one of the most significant technologies of dialogue discussed in bioethical texts. A PIS is a printed handout that scientists give to potential research subjects, and which informs them about the research. In the 1980s, these handouts simply outlined the purpose of the study, the procedures involved and the possible risks and benefits. A good example is the Royal College of Physicians' *Guidelines on the Practice of Ethics Committees in Medical Research*, first published in 1984 and regularly updated since then. These guidelines suggest that an investigation 'should be the subject of an explanatory document setting out [its] purpose, the procedures, the risks [and] the benefits' (Royal College of Physicians, 1984: 12; also see Royal College of Physicians, 1990a: 20–21; 1996: 30–32). More recently, patient information sheets have included information about insurance coverage in reaction to the perceived dangers associated with the growing clinical trials industry (Petryna, 2009). So, for example, in its guidelines on medical experiments with volunteers, the Association of the British Pharmaceutical Industry (1988: 8) suggests that the details about the 'insurance cover' should 'be considered for inclusion in [the information] document' (see also Royal College of Physicians 1990a: 21; 1996: 32). Another late addition to the PIS, this time in reaction to the 1990 John Moore case in California, has been information about financial arrangements. A good illustration can be found in a report on research ethics committees written by Julia Neuberger, a member of the Human Fertilisation and Embryology Authority and chairperson of the Patient's Association. According to her, 'all good information sheets ...

should say something about the finances' and whether the research will bring 'financial benefit to the researchers' (Neuberger, 1992: 40).

Texts on informed consent present the PIS as a means to support and improve the dialogue and exchange of information between the researcher and the research subject. As Consumers for Ethics in Research (1994: 1), a London-based charity founded in 1989 to promote biomedical research ethics, explains, 'written leaflets can help people' to 'discuss the research more fully and clearly'. Likewise, in a report on *Medical Research on Children*, the Institute of Medical Ethics suggests that the PIS is a means 'to achieve better communication between doctor and patient' (Nicholson, 1986: 218). One of the reasons, according to the bioethical literature, is that written information allows research subjects to more easily comprehend and retain the oral explanations they are given. In the same report, for example, the Institute of Medical Ethics argues that using an information sheet increases 'the proportion of the information offered that is retained' following a discussion between researcher and research subject (Nicholson, 1986: 221). Similarly, in a pamphlet on the PIS, Consumers for Ethics in Research (1994: 1) asserts that written leaflets help people 'understand and remember researchers' spoken information'.

Another reason given in the literature on informed consent for why the PIS improves communication is because it enables research subjects to resume their discussion with and ask additional questions to the investigators whenever they want. Indeed, as suggested in the Royal College of Physicians' (1996: 32) *Guidelines*, 'information sheets should clearly state the name, address and telephone number of the investigator'. This, as Carolyn Faulder (1985: 115) explains, should make it clear to the research subject 'that she can resume the dialogue at any time' and 'ask more questions as they occur to her'. Similarly, Consumers for Ethics in Research (1994: 15) argue that 'a researcher's name and phone number should be on the [information] leaflet' so that research subjects can 'contact [him or her] if they have any questions or problems'.

### *Communication techniques*

The bioethical literature recommends many techniques for communicating with research participants. As with the PIS, the aim of these techniques is to improve communication between researchers and research subjects by ensuring that the latter give the former 'comprehensible' information. For example, the Royal College of Physicians (1990b: 16) recommends that explanations about the proposed study 'should be couched in easily comprehensible terms'. The Institute of Medical Ethics similarly advises that such information should be 'readily comprehensible' (Nicholson, 1986: 221). This stress on comprehensibility derives from the assumption that doctors speak a technical language that is unintelligible to laypersons. As Faulder (1985: 35) argues, medical 'expertise generates its own jargon' and opens a 'communication gap' between investigators and research subjects. Likewise, Consumers for Ethics in Research (1994: 4) assert that 'scientific language' is 'likely to confuse, worry or distress' research subjects and to 'prevent knowledge from being shared more fairly through society'.

To ensure that the information provided by the researcher is comprehensible to research subjects, texts on informed consent suggest a series of communication techniques. One is to use non-technical, simple, easy writing. Consumers for Ethics in Research (1994: 4), for instance, recommends the use of 'plain English' – a style of writing that favours:

Short words, sentences and paragraphs; only one or two main ideas per sentence; requests rather than commands; the active voice (we will book) rather than the passive voice (appointments will be booked); a personal approach (we, you, your baby) rather than the impersonal (they, those, he or she); [and] specific details (4 weeks) rather than vague ones (lengthier interval monitoring). (Consumers for Ethics in Research, 1994: 6)

Another communication technique used to ensure comprehension is to 'provide [information] in manageable amounts ... over a period of time' and perhaps to 'repeat it' (General Medical Council, 1998: 13). A further technique is to 'speak at the right volume and speed' and, 'if necessary, accompany speech with slightly exaggerated gestures or facial expressions' (British Medical Association, 1995: 14). Likewise, communication is facilitated by creating 'the right environment' where 'the lighting is soft and indirect, but sufficiently bright for easy eye contact and interpretation of expression' (British Medical Association, 1995: 18).

### *Lists of suggested questions*

Another technology of dialogue recommended in the bioethical literature is lists of suggested questions about medical research. The aim of these lists is to stimulate discussion between researchers and research subjects by suggesting a series of topics related to the proposed investigation. Some of these lists offer research subjects a series of questions to ask investigators. A typical example is the list contained in the leaflet *Medical Research and You: What You Need to Think About* published and widely distributed by Consumers for Ethics in Research:

Here are some questions you may want to ask before you sign [a consent form]: How was I chosen? What will happen to me? ... How often will this happen, or for how long? Will it hurt? What are the possible side effects of the research? How long will the research take? Will I have to make extra visits to the hospital, or stay in longer? Will my fares or expenses to and from appointments be paid? What kind of care will I have if I do not take part in the research? ... If you are pregnant, how might the research affect your baby? What is the research for? ... Who is sponsoring the research? (Consumers for Ethics in Research, 1993: 1)

Other lists suggest a series of issues for researchers to discuss with subjects. In her report on research ethics committees, for example, Julia Neuberger recommends that researchers use the following 'Consent Checklist for Investigators':

Have you given an oral explanation to the subject, including: This is a research project? Participation is voluntary? The aims of the project? The likely duration of the subject's involvement? The expected benefits to the subject and/or others? The expected nature of the drug or device being tested? ... What risks, inconvenience, discomfort or distress may reasonably be anticipated for this patient? That the refusal to participate may be given without reasons and will not affect the care which will be given to the subject? ... What compensation arrangements are available? Whom to contact in an emergency and how? (Neuberger, 1992: 40)

In addition to containing lists of topics and questions, texts on informed consent strongly urge researchers to encourage dialogue. For instance, a report on research with patients by

the Royal College of Physicians (1990b: 17) advises researchers that research subjects should always be ‘invit[ed] to ask more information’. Likewise, the Association of the British Pharmaceutical Industry (1988: 8) recommends that investigators should ‘give the volunteer the opportunity to question him on any points felt by the volunteer to require qualification’. Similarly, Peter Byrne (1983: 30), a bioethicist at King’s College’s Centre for Medical Law and Ethics, suggests that doctors should ‘make a reasonable effort to listen and to explain’.

Like the narratives examined earlier, these different technologies of dialogue help to generate a sphere of possibilities in which research subjects can imagine themselves and act as human beings who communicate, think and choose. Indeed, the action of handing over a PIS with written explanations about a proposed study can only encourage the investigator and research subject to discuss the latter’s participation in the study. Likewise, communication techniques provide investigators and their research subjects with detailed illustrations of how they should communicate with each other, from speaking slowly and using short sentences to ensuring that the lighting is bright enough for easy eye contact. In the same way, invitations to query researchers, including lists of possible questions about medical research, offer human subjects tangible examples of how to respond to a request to participate in a study.

## **Technologies of respect**

The literature on informed consent has developed numerous technologies to ensure that investigators respect the choices made by research subjects. In this section, I explore two of the most important of these ‘technologies of respect’: recommendations to take time to reflect and instructions not to coerce and manipulate (Miller and Rose, 2008).

### *Time to reflect*

Recommendations for potential research candidates to take their time to reflect before deciding whether or not to take part in a study are commonly found in bioethical texts. These recommendations take different forms. Some are directly addressed to the research subject. For example, in its information leaflets on biomedical research, Consumers for Ethics in Research (1994: 16) advises potential candidates that ‘no one should rush you into having something you would rather not have’; you should ‘take your time to think’; you do not ‘have to decide at once’. Other recommendations are addressed to researchers. For example, the Royal College of Physicians (1990b: 17) advises that ‘[i]t is unreasonable to ask a patient to agree on the spot to take part in research which either involves more than minimal risk or involves extended inconvenience or discomfort. Time should be allowed for the patient to consider the position [and] to read the Information Sheet in unhurried circumstances.’

The amount of time that should be allowed varies according to the complexity of the information and the severity of the risks. When the study is complex and/or the risks are great, the bioethical literature generally recommends at least 1 day for reflection. For instance, the General Medical Council (1998: paragraph 13) advises doctors to ‘allow patients sufficient time’, ‘especially where the information is complex or the severity of the risks are great’. Similarly, the Royal College of Physicians’ suggest that:

The time required for [reflection] will depend on what seems appropriate in the circumstances. For research which is low risk or undemanding it might, for example, be quite acceptable for a patient attending a hospital clinic ... to have a cup of tea and to reach a decision within a few minutes. In other circumstances it might seem appropriate for the decision to be declared at a different visit on a different day. (Royal College of Physicians, 1990b: 17)

This time for reflection should ensure that researchers respect and do not hamper the research candidate's ability to make a free decision. As the Institute of Medical Ethics explains in a report on research on children:

The difficulties in ensuring voluntariness ... [are] subtle ... One form of persuasion ... may be the demand that a decision be made straight away, generally for the pragmatic reason that the researcher is busy. ... The provision of a period of time for reflection by [potential research subjects] would greatly assist them in coming to a freely given decision with which [they are] happy. ... There are therefore good reasons for suggesting that ... there should in general be a gap of at least one day between the giving of information and the requesting of consent. ... This procedure is suggested as being the most likely to obtain a free ... consent. (Nicholson, 1986: 222–223)

### *Abstaining from coercion and manipulation*

Another commonly recommended technology of respect is instructions to avoid coercing or manipulating people into becoming research subjects. A good illustration is the Royal College of Physicians' (1986: 5) stipulation that 'there should be no coercion, overt or covert, of anyone to volunteer for research'. Another example is the General Medical Council's (1998: paragraph 16) directive that doctors 'must not put pressure on anyone to take part in research'. As with recommendations to allow time for reflection, the aim of such instructions is to ensure that researchers respect and do not hinder the ability of potential subjects to freely decide to participate. As Carolyn Faulder (1985: 128) explains in her book on informed consent and medical research, '[o]ur bodies belong to us. ... We alone must decide whether we wish to loan our bodies to the cause of medical research. No one has the right to influence, deceive or manipulate us into making a decision which is against our own best wishes for ourselves.'

These instructions to avoid coercion and manipulation are often further specified through a series of additional recommendations. One such recommendation is to provide 'honest' and 'objective' accounts of the proposed study to potential research subjects. For example, the General Medical Council (1998: paragraph 9) reminds researchers that they 'must respond honestly' and 'as accurately and objectively as possible' to 'any questions the [research participant] raises'. Another of these additional recommendations is to avoid financially rewarding participants, as it interferes with their ability to freely decide. As the Royal College of Physicians (1990b: 27) argues:

Where a patient incurs personal expense as a consequence of participation in research it is of course proper that he should be reimbursed for that expenditure ... [However] additional payments to patients ... are generally undesirable ... [In particular,] payments should not be such as to persuade patients to volunteer against their better judgement.

Similarly, in its report on human tissue research, the Nuffield Council on Bioethics (1995: 50) suggests that monetary rewards for giving human tissue should be avoided, as they ‘may obstruct rather than secure genuine consent’. Yet another of these additional recommendations is to be particularly careful when using subjects such as prisoners and mentally ill people who are deemed especially vulnerable to coercion or manipulation. For example, the Royal College of Physicians (1996: 39; cf. also: 1984: 16; 1990a: 29) stipulates that ‘[t]he quality of the consent of candidate subjects who are junior or subordinate members of a hierarchically-structured group or are prisoners requires careful consideration [as their] willingness to volunteer may be unduly influenced by the expectation of adventitious benefits’.

As with the narratives and technologies of dialogue analysed earlier, technologies of respect make it possible for research subjects to imagine themselves as persons who can reflect and freely choose whether or not to participate in a particular experiment. Indeed, recommendations to take time and think before deciding to participate in a study offer research subjects a concrete example of how they should react when confronted with an invitation to take part in an experiment. Similarly, the instructions to avoid coercion and manipulation provide both scientists and research subjects with a detailed model of how an investigator should behave when conducting research on human beings. It tells them, in particular, that potential subjects should be presented with objective information and not be offered financial rewards. It also tells them that vulnerable subjects such as prisoners should never be asked to participate in a study.

## Conclusion

As already mentioned, existing historical and sociological studies have extensively documented the progressive articulation of what I have termed the British bioethical assemblage (Hazelgrove, 2002; Hedgecoe, 2009; Wilson, 2011a, 2012). This research has shown how a variety of developments, from the rise of feminism and neo-liberalism to the protracted debates about embryo research, have led to the elaboration of the concepts, guidelines, experts, committees and reports that make up bioethics today. Existing historical and sociological studies have also convincingly argued that the governance of British medical research has been transformed by the emergence of this bioethical assemblage, especially from the 1980s onwards (Booth, 1993; O’Neill, 2002; Petersen, 2005; Wilson, 2011b). They have shown, in particular, how bioethics has helped to shift the governance of biomedical research from scientific freedom and enthusiasm for medical progress to complex ethical regulatory frameworks and a will to protect human life and dignity against the dangers of science.

Building on this research, I explored in this article how a fundamental element of the British bioethical apparatus – the literature on informed consent published between 1980 and 2000, a period when bioethics became a powerful force in the UK – has influenced contemporary understandings of the research subject. Drawing on the work of Michel Foucault, I argued that this literature has brought into being a new figure of the research subject: a human being capable of reflecting and deciding whether he or she wants to partake in medical research. As the article showed, this figure is markedly different from the one that was prevalent before the ascendancy of bioethics: a citizen who was expected

to sacrifice, for the greater social good, his or her body, yielding it as material for experimentation whenever physicians deemed it necessary (Bolton, 2008; Reubi, 2009).

To substantiate this argument, I explored two aspects of the literature on informed consent. First, I examined the narratives on relationships between researchers and research subjects contained in this literature. My analysis showed how they portray existing researcher–researched relationships as ‘paternalistic’ and call for their replacement with new, more ethical relationships characterized by both ‘dialogue’ and ‘respect’, and articulated around the idea that research subjects can ‘think and take decisions’. Second, I analysed some of the most significant technologies of government discussed in bioethical texts such as patient information sheets, lists of questions and suggestions to take time to reflect. This examination showed how these technologies seek both to generate an open conversation between researchers and research subjects and to ensure that the former do not interfere in the latter’s decision-making.

These different narratives and technologies, I suggested, have created the possibility for research subjects to imagine themselves as persons who can reflect and decide whether to be experimented upon (see Hacking, 2002). Indeed, these narratives and technologies provide both researchers and potential subjects with detailed descriptions of what should not happen in the experimental situation. They also offer models and examples of how investigators and their human subjects should interact with each other. Of course, researchers and research subjects may fail to adopt these models or emulate these examples, but the narratives and technologies provide them with the possibility to do so. This possibility, I suggested, was not available to such an extent before the rise of bioethics.

By demonstrating how the British bioethical apparatus has produced a new understanding of the research subject, this article has also sought to show a different side of bioethics from the one generally portrayed by social scientists. The latter usually understand their role as exposing the dark side of bioethics and debunking its shortcomings and failures. In contrast, the aim of the present article has been to draw our attention to the productive nature of bioethics. Its aim was to show how important it is for social scientists to start taking seriously the knowledge, experts and practices that make up bioethics and to understand how they have reconfigured and shaped the way we think and act today.

## Notes

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1. Thus understood, bioethics is not limited to the intellectual work of academic philosophers interested in the moral aspects of biomedicine or the official reports produced by national bioethics committees. It also encompasses the more mundane work of hospital research ethics committees when they decide whether or not to approve a specific research proposal, to the ethical guidelines

- and instruction manuals for researchers drafted by funding bodies and medical associations, and the undergraduate courses on medical law and ethics run by medical schools.
2. According to White (2010: 274), a narrative is not 'a neutral medium in which events, whether imaginary or real, can be represented with perfect transparency', but is instead 'an expression in discourse of a distinct mode of experiencing and thinking about the world, its structure and its processes'. Used in a variety of contexts from religious thought and literary fiction to historical scholarship, a narrative is 'a story with well-marked beginning, middle and end phases', 'formal coherency' and 'a plot [through] which the events contained in the account are endowed with a meaning' (White 1987: 2, 9 and 21). More importantly for us, perhaps, is the way this story is eminently 'moral' and 'moralizing': 'the weight of meaning of the events recounted [in the narrative] is thrown forward into a future just beyond the immediate present, a future fraught with moral judgement' (White, 1987: 21–25).
  3. Both the notion of 'technologies of dialogue' and that of 'technologies of respect', which I develop later in the article, draw on Miller and Rose's (2008) concept of 'technologies of government'. According to Miller and Rose (2008: 32), these technologies are 'humble and mundane mechanisms' – techniques of notation and calculation, surveys, presentational forms such as tables, instruction manuals, standardized procedures, and professional vocabularies – 'through which authorities [seek] to shape, normalise and instrumentalise the conduct, thought decisions and aspirations of others in order to achieve the objectives they consider desirable'. As such, these technologies are an essential part of the activity of ruling; they 'make it possible to govern' (Miller and Rose, 2008: 32).

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