

Chapter 1

The “Ethics Job”

Abstract This chapter introduces the aims of the book. The book’s origins lie in a project examining ethical issues in genomics research, as part of a consortium researching into cardiovascular disease. The challenges of working as an “in-house” ethicist on such a project are discussed, as are the importance of debate and dialogue in ethics as well as inter-disciplinary communication. The book aims to help foster such dialogue and to show how philosophical analysis and debate in ethics can help to address emerging ethical challenges. Some of the different ways in which philosophy can contribute to practical ethical issues are illustrated. These include close attention to argument; to the use of key concepts; and to the use of the examples used to advance arguments. The interrelation of abstract theory and experience of concrete situations is also discussed.

1.1 The Role of the “In-house” Ethicist and How This Book Came About

I am a philosopher. In October 2007, I took up a post in the Medical Sciences Division of Oxford University and began work on the “ethics” branch of a scientific research project investigating genetic factors underlying cardiovascular disease. The Procardis consortium includes members from various European countries, including the UK, Italy, Sweden, Germany, and France, and is funded by the European Union. But why is research that aims to help humanity subjected to ethical inquiry? Why do they want someone to “do” ethics then? What was this job exactly?

When I started my post, I did what many other people do in such a position; I read through the large black file about the project that was handed to me, looked back over the job description, and started to wonder what exactly I was meant to be doing. Writing this at the end of my 3-year post, I am still thinking about what exactly such a post of being an “in-house” ethicist required. There are also various tensions inherent in such a post, tensions which could easily give rise to a great deal

of difficulty. This book is a product of thinking through these difficulties, and of my efforts to produce something that might contribute to thinking through the complex issues that I have encountered, issues of both methodology and substance.

One of the features of my particular position in the project was that it was, quite frankly, rather loosely demarcated. Some colleagues who worked in other broadly similar situations have had a more defined role as a member of a team. For example, these colleagues have been involved with obtaining approval for research projects from the relevant research ethics committees; with drafting policy for the conduct of a research project, taking into account particular ethical issues; with looking at how best to obtain adequately informed consent to research from people in difficult circumstances, such as when their child is ill, across language barriers, or where research recruits have little or no prior knowledge of the scientific study of genetics. Some of these colleagues were frequently called over to the scientists’ building to help out on one thing or another.

In contrast, I had no such concrete role. The subjects in the Procardis project were all recruited long before I joined; when they joined, they had read and signed consent forms, and ethics approval for the project and for the recruitment of participants had of course been given. This in fact gave rise to one of the tensions of such a post. Suppose I looked at what had already been done and found it ethically problematic in some respect? In any case, much of this was someone else’s job to check – the job of the various research ethics committees that approved the project and the collection of data in several European countries. In any case, I felt some discomfort at the idea that my role was to tell the scientists that they might be doing something wrong. My job was surely not to act as a kind of soft police force. Besides which my only tools were words: I had no regulatory or institutional power.

It also filled me with great discomfort to think that the role of an “in-house” ethics person might be, even partially, to act as “window dressing”. There is now a great deal of emphasis on ethics in genetics, for reasons I’ll explain in detail in the next chapter. The simple fact then is that *doing ethics* has come to “look good”. Of course, many things which “look good” are good, but not all, and pressures to look good can lead to an unwarranted concern with appearances. Moreover, I consider that the goal-oriented nature of much research funding carries with it a danger that doing good work can be reduced to meeting targets and scoring highly enough in the right sort of categories. The very thought that the “ethics” person might be symbolised as a kind of talisman to indicate lip service to ethical issues was a spur to make sure that I thought carefully about the nature of my role and how to be most effective.

An ethics post attached to a particular consortium gave me a delicate balancing act. On the one hand, I was part of this team: to that extent then, I shared their goals and hoped for their scientific successes; as I got to know the other team members, I liked them. I wasn’t there to “judge” them. But I should surely, as someone concerned with ethical issues of the research, also remain independent, and retain the capacity and the freedom to offer critiques or challenges if I thought it necessary. In many ways, the problem of how to tread this delicate balance between involvement and detachment is one well known from other areas. For instance, the

ethnographer who lives intimately among a group of people in order to document their lives and activities must identify with these people to a sufficient degree to be able to observe and understand; but then would understanding and description be compromised by over-identification, by “going native”? What of the ethnographer who uses the material to publish a work critical of the group of people amongst whom he or she has lived? (Hammersley and Atkinson 1986)

How could I steer a course through such difficulties? My job description required me to run a series of seminars and workshops about ethics across the consortium, although there was little demand for them from the extremely busy scientists. Much of my time was in fact taken up with writing research papers, often in collaboration with colleagues who are social scientists and lawyers and who were working in related areas of the ethics and governance of genetics and of biomedical research more generally. In engaging with the scientists however, I came to consider that there was a strong general need on all sides for further mutual understanding and dialogue between those with different disciplinary backgrounds. There is great scope for building the capacity to think through complex issues in ethics; this would be the answer to my dilemma of how to navigate the demands of my post – by attempting to contribute to the task of interdisciplinary understanding, and, instead of “telling scientists what to do”, to build capacity for individuals to think through complex ethical issues for themselves. The book is a development of that work.

1.2 Research in Genomics

Before going on to describe in more detail what thinking about ethics involves, and what this book in particular will involve, it will be helpful to fill in a little about what research in genomics involves.

1.2.1 *Genetics and Genomics*

Firstly, it is useful to explain the distinction between genetics and genomics. *Genetics* generally refers to a focus on specific genes, for example, specific genes that might be involved in certain diseases such as cystic fibrosis, where one or a few genes are involved. But individuals have about 20–25,000 genes, and well as a great deal more genetic material arranged on their 23 paired chromosomes. *Genomics* refers to the study of large amounts of genetic information, including spanning the whole of the human genome. This book focuses on developments in genomics research, although there are overlaps between ethical issues in genetics and in genomics.

1.2.2 A Genomics Research Project: The Procardis Consortium

The Procardis project can be used as one example of genomics research. The focus of the work is on cardiovascular disease, in particular, looking at people who have suffered from early onset myocardial infarction (heart attack) and comparing them to healthy “controls” (people of a similar age and the same gender but who have not suffered a heart attack) in an attempt to find any genetic differences between these two groups. Because cardiovascular disease is a very common, complex condition, there are a large range of different factors involved in its genesis, including what might be broadly termed environmental factors such as diet, and many complex interacting biological factors, such as blood pressure, blood lipid levels, and a great deal more. There are very likely to be also a large range of genetic factors involved, and it is also likely that each one of these may contribute only a small amount to the overall picture. Because cardiovascular disease is complex, and because each genetic signal is likely to be weak, this also means that many thousands of recruits are needed to get a sufficiently large sample to obtain significant results. The genetic signals that are found to be associated with disease then need to be further investigated to try to understand the underlying biological mechanisms that cause disease or protect against it.

For example, Procardis have investigated links of coronary artery disease with blood levels of C reactive protein (Elliott et al. 2009), blood plasma levels of homocysteine which indicate novel metabolic pathways in need of further investigation (Mälarstig et al. 2009) and genetic associations with the blood lipid Lp(a) lipoprotein, which strongly suggest that genetic variations in this lipid are causally implicated in coronary artery disease (Clarke et al. 2009).

1.2.3 Varieties of Genomics Research

There are a great deal of other genomics research projects underway, many investigating common complex diseases, others investigating less common diseases, many undertaken as part of wider investigations into health. Some involve looking at different reactions individuals have to various drugs. Some projects are part of large biobanks, where large amounts of medical information about large numbers of people are stored for research use over many years. Some involve fairly small numbers of people, for example, individuals suffering from unusual diseases; some involve many thousands, or hundreds of thousands of individuals. Some are located at a particular institute; others are national or often international consortia or large collaborations between many different consortia. Genomics research aims to further our understanding of the biology of health and disease, through understanding the contribution of genetic information to disease, the interaction of genetics and environment, broadly understood, and the interaction of different genes. Hopes for

this research are a better understanding of the biology of disease causation, with eventual hopes for better treatment and diagnosis (Heard et al. 2010).

1.3 Ethical Debate in Genomics

There are in fact a great many questions about ethics and about the regulation of research presented by scientific and technological developments in genetics and genomics. There are questions raised by the uses to which such research findings may be put. There are questions raised by the immense power and detail now seen in the genetic information that it is possible to obtain about individuals, about populations, and about human beings in general. There are questions about protecting the privacy and other interests of research participants, and questions about what might or might not be owed to them. There are questions about how data from genomics research might be shared with other scientists doing similar work.

Besides this issue of what ethical questions there are, there is also the issue of how to go about addressing any such questions. I started this chapter with the statement “I am a philosopher”. One reason for this is that it forms a firm statement of my disciplinary basis; although the ethics work I have been doing might broadly be described by many as falling within the realm of bioethics, bioethics itself typically inhabits a far narrower realm than philosophy. I strongly believe that it is crucial to keep the wider focus of philosophy. There are a whole host of considerations from diverse branches in philosophy that can be brought to bear upon issues in ethics. For example, issues in the philosophy of science can be very pertinent in considering questions in genetics and in medicine: for instance, how we define and think about health and disease. In my own case, work I have done within philosophy of mind, on self-deception, has led me to consider the problems of irrationality that mar much of our thinking and action, especially where ethics is concerned, and to ponder the crucial importance of motivation in ethical reasoning and action. Questions such as these will be raised throughout this book.

Philosophy concerns itself, centrally and self-consciously, with reasoning, evidence, and argument. Of course, all disciplines are concerned with these questions, and are concerned to think critically about their subject matter, but philosophy sets out to think critically about critical thinking – an important aspect of doing philosophy concerns the analysis and dissection of positions and views, in illuminating problems as much as solving them. In teaching philosophy, a large part of what one is doing is teaching the capacity to think things through for oneself. This can be useful for many reasons, including enhancing communication and understanding between those with different disciplinary backgrounds, and for assisting with enriching democratic participation in the public debates and policy discussions on these complex issues. More will be said to emphasise the importance of clear and open debate in medical research later.

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