

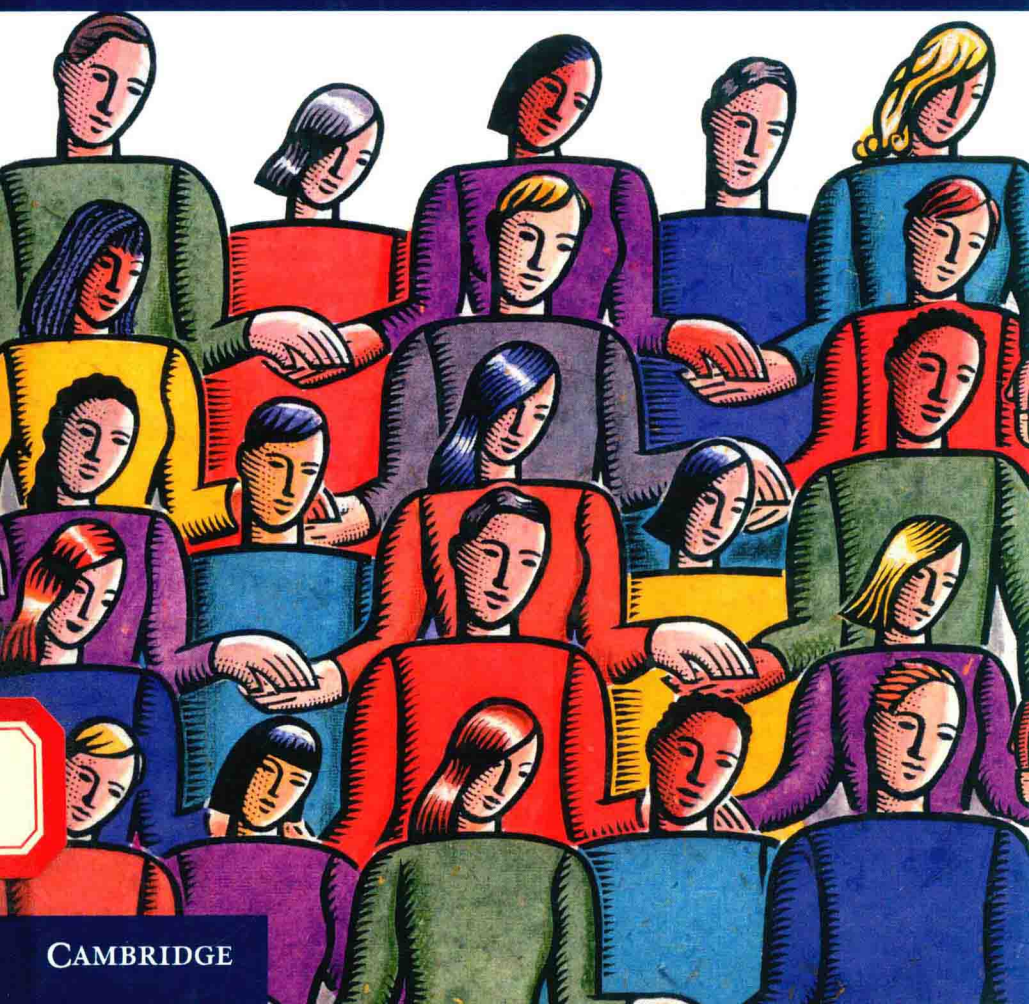
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Bioethics and Law

The Connected Self

The Ethics and Governance of the
Genetic Individual

Heather Widdows



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The Connected Self

Currently, the ethics infrastructure – from medical and scientific training to the scrutiny of ethics committees – focuses on trying to reform informed consent to do a job which it is simply not capable of doing. Consent, or choice, is not an effective ethical tool in public ethics and is particularly problematic in the governance of genetics. Heather Widdows suggests using alternative and additional ethical tools, and argues that if individuals are to flourish it is necessary to recognise and respect communal and public goods as well as individual goods. To do this she suggests a two-step process – the ‘ethical toolbox’. First the harms and goods of the particular situation are assessed and then appropriate practices are put in place to protect goods and prevent harms. This debate speaks to core concerns of contemporary public ethics and suggests a means to identify and prioritise public and common goods.

Heather Widdows is a professor in the philosophy department at the University of Birmingham, where she teaches moral philosophy, bioethics, global ethics and health and happiness.

This series of books was founded by Cambridge University Press with Alexander McCall Smith as its first editor in 2003. It focuses on the law's complex and troubled relationship with medicine across both the developed and the developing world. In the past twenty years, we have seen in many countries increasing resort to the courts by dissatisfied patients and a growing use of the courts to attempt to resolve intractable ethical dilemmas. At the same time, legislatures across the world have struggled to address the questions posed by both the successes and failures of modern medicine, while international organisations such as the WHO and UNESCO now regularly address issues of medical law.

It follows that we would expect ethical and policy questions to be integral to the analysis of the legal issues discussed in this series. The series responds to the high profile of medical law in universities, in legal and medical practice, as well as in public and political affairs. We seek to reflect the evidence that many major health-related policy debates in the UK, Europe and the international community over the past two decades have involved a strong medical law dimension. With that in mind, we seek to address how legal analysis might have a trans-jurisdictional and international relevance. Organ retention, embryonic stem cell research, physician assisted suicide and the allocation of resources to fund health care are but a few examples among many. The emphasis of this series is thus on matters of public concern and/or practical significance. We look for books that could make a difference to the development of medical law and enhance the role of medico-legal debate in policy circles. That is not to say that we lack interest in the important theoretical dimensions of the subject, but we aim to ensure that theoretical debate is grounded in the realities of how the law does and should interact with medicine and health care.

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For Matthew

Preface

A brief word about the background of this book is required. Addressing the challenge that genetics presents to traditional medical and bioethical frameworks has been an obsession of mine since my first academic position as a post-doc on a European project which focused on the ethics of genetics, reproduction and research ethics.¹ I went on later to run my own project on property in tangible and intangible information in an age where there is profit in previously unprofitable “waste” products of human tissue.² The collaborations with project partners and project contributions have been particularly valuable in negotiating the complex topic of genetic governance, especially in terms of engagement with lawyers and scientists. Genetic governance requires input from many disciplines if the issues are to be understood and navigated. In 2007 I became a member of the Ethics and Governance Council (EGC) of UK Biobank, and undoubtedly my most important contribution in practical terms is the work I have done with fellow council members in advising on practice and policy for this new endeavour. This work has informed the many publications I have written on this topic. Importantly, the views I express here are personal. They are not the views of UK Biobank or of the EGC, but my own. And, while my understanding has clearly been informed by my work on the EGC, nothing in this book comes from any special knowledge: all discussion about UK Biobank comes from publicly available material. To date, I have written eleven papers and chapters on the ownership and governance of genetic information and have also edited a collection already published in this series on *The Governance of Genetic Information* (Cordell, Widdows et al. 2011; Widdows 2007; 2009a; 2009b; 2011a; 2011b; 2012; Widdows and Bullock 2011; Widdows and Cordell 2010;

¹ TEMPE Project (Teaching Ethics: Materials for Practitioner Education), an EC funded project which ran 2000–2002. The project final report can be found at: http://ec.europa.eu/research/biosociety/pdf/qlg6_1999_00353_finalreport.pdf

² PropEur (Property Regulation in European Science, Ethics and Law). Project SAS6-CT-2003–510239. Summary abstract can be found at: ftp://ftp.cordis.europa.eu/pub/science-society/docs/overview_society_contracts.pdf

2011a; 2011b; Widdows and Mullen 2009). My latest work has been focused on the more specific topic of the ethics of biobanking and I have recently collaborated in a project where I ran a theme on the ethics of biobanking.³ This culminated in the production of a Special Issue of *Health Care Analysis*, edited with Sean Cordell, on this topic (Widdows and Cordell 2011b). This book brings together and develops themes which are embryonic in many of these papers, for instance, concerns about property and the body, as well as worries about false pictures of the self in the bioethical framework (concerns which connect to my wider work on virtue theory). However, the book is far more than a collection of the insights in these earlier papers. It is a new and extensive argument. It argues that the genetic self is the connected self and, accordingly, that much of current ethics is wholly ineffective. It proposes ways forward and argues that the recognition and protection of public and common goods is essential for any effective ethics and governance.

³ Tiss.EU (Evaluation of Legislation and Related Guidelines on the Procurement, Storage and Transfer of Human Tissues and Cells in the European Union) www.tisseu.uni-hannover.de

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dyslexic. So with heartfelt thanks and all good wishes for the future – thank you Sean.

I would like to thank those I have collaborated with from across disciplines on various projects and publications connected to genetic governance. Including, and notably the series editors, Graeme Laurie, Margaret Brazier and Richard Ashcroft, whose support and encouragement in this project and in my life generally I am very grateful for and which has been a source of strength to me. In addition I would like to thank my colleagues on the Ethics and Governance Council of UK Biobank. Those who have served with me are Andrea Cook, Erica Haimes, Roger Higgs, Ian Hughes, Anneke Lucassen, Roger Moore, Hilary Newiss, Martin Richards, Sally Smith, Chris Wild, Jonathan Hewitt, Tracey Phillips, Andrew Russell, Margaret Shotter and Paolo Vineis. Particular thanks to Roger Brownsword, Graeme Laurie (again) and Adrienne Hunt, and to Alastair Campbell, Jo Sumner and Tara Camm – who persuaded me to apply to be a member of the EGC.

Thanks also to Donna Dickenson (who got me into applied ethics from “pure” theory in the first place), and to all the partners I have worked with on European Projects, including Itziar Alkorta, Ruth Chadwick, Aitziber Emaldi, Tina Garanis-Papadatos, Nils Hoppe, Christian Lenk, Pekka Louhiala, Ruud ter Meulen, Paul Oldham, Peter Sykora and Urban Wiesing. And to my wonderful researchers on various projects, Caroline Mullen, Dita Wickins-Drazilova and Sean Cordell (again – he deserves double thanks). Others who have inspired me, either in person or in their work, and who deserve thanks are David Archard, Bob Brecher (who spent time editing beyond the call of duty – yet again), Andrew Edgar, Hille Haker, John Harris, Martha Nussbaum, Onora O’Neill, Fiona MacCallum, Neil Manson, Anne Phillips, Sigrid Stercx and Steve Wilkinson.

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Introduction

The genetic self is the connected self. This claim underpins the key argument of this book, that our current ethical frameworks are flawed and actually offer little ethical protection. In fact, so limited is the dominant choice model of ethics that too often there are no effective safeguards in operation at all. If these arguments are correct, then current ethics and governance mechanisms and practices need to be transformed; and not only those of bioethics. Most obviously, systems of governance which present individual rights and goods in conflict with group goods and which promote individual rights at the expense of common and public goods need to be rethought. Mechanisms to prioritise and protect key public, common and social goods, which benefit all individuals, need to be devised and implemented with urgency if injustices are to be avoided and redressed.

The issues which *The Connected Self* addresses are important beyond genetic ethics and governance. They matter in debates about security and environmental ethics, and in all debates where there is controversy about how to balance individual and group goods.¹ It is based on the conviction that if individuals are to flourish it is necessary to recognise and respect communal and public goods as well as individual goods. The book argues that a first step in implementing appropriate ethics is to identify what harms and goods are at stake in any given situation. After this, appropriate practices can be put in place to protect relevant goods and prevent harms. This two-step process is the “ethical toolbox”. This argument speaks to core concerns of contemporary public ethics and the ethical toolbox provides a means to identify and prioritise public and common goods.

How to balance such rights and goods is at the core of contemporary debates about the proper units of ethical concern (whether individuals or different types of groups), and ethical priorities. Group and public goods

¹ The security and environmental debates discuss how much individual choice can and should be curtailed. Parallels with the environmental debate will be used throughout to illustrate and clarify.

are at the heart of adequate genetic governance: for, if groups do not feature in the ethical framework then certain types of injustice are at worst invisible and at best parasitical (and secondary) to individual concerns. These conceptual concerns regarding groups and their goods speak directly to the practice and policy concerns of genetic governance: from the structure of ethical frameworks to political concerns regarding what counts as participation; to questions of ownership rights and decision-making powers in genetic governance; to traditional bioethical concerns regarding what counts as harm in research. This is because the framework which is adopted, and what *counts* as goods and harms, determines the practices which are put into place. This book proposes a framework which recognises the needs of both individuals and groups, and different types of groups, and explores the possibilities and potential problems involved in implementing such a framework. How debates about genetic governance are resolved impacts upon governance more generally and influences how individuals are envisaged and constructed in the private and public spheres.

While this book focuses on bioethics, and particularly on genetic governance, it resonates with the public ethics and governance debates more broadly and advocates frameworks of ethics and governance which respect and promote public goods and social capital and which enhance solidarity and trust. Such mechanisms fit with the claim that the genetic self is the connected self, since philosophical pictures of the self connect to the type of governance and policy which is constructed. Philosophical arguments about the nature of the self are far from “academic”, especially when that word is used – oddly – to mean “irrelevant” or “unconnected to reality”. In fact, philosophical views are fundamental in shaping ethical and policy claims, and in turn, policy and practice embed and ingrain dominant philosophical models. This book suggests that underlying the current dominant, and problematic, governance model is a particular philosophical picture, one of the individual as an isolated and separate, choosing self. By contrast it argues instead that a more accurate and representative model is one that presents the self in relationship, connected to significant others and wider communities and embedded in a particular context. This philosophical claim is supported by genetics – and philosophical theory provides a way to conceptualise the connected self which genetics requires.

The book begins with philosophical pictures of the connected self. It argues that these underlying pictures of the self are assumed in policy and practice and fundamentally affect the ethics and governance frameworks which are possible. However, one does not have to accept the philosophical claims to accept the ethical conclusions. But while policy makers might wish to focus on the ethical conclusions alone, only in the context

of the philosophical debate is the strength of current models properly explained. Only if one understands that the underlying pictures of the self have a huge influence on the systems which are actually put in place can one recognise and negotiate these and so make better policy likely. Thus this work is intended to be of use to both philosophers and non-philosophers. Moreover, it is hoped it will change policy and practice. Genetic governance is obviously a multi-disciplinary concern, of importance to philosophers, lawyers, scientists and policy makers. In this regard it sits well in the context of current applied ethics, particularly global ethics, where the interdependence of theory and practice is well recognised (Widdows 2012).

Too often in genetic ethics and governance the influence of the underlying philosophical pictures is neglected. This omission makes critique of current models harder, as criticisms tend to address the symptoms rather than the cause. It is no good attempting to recognise the rights of third parties in practice if one can conceive of individuals only as separate and isolated selves. For conception of the individual self as discrete from all others readily gives rise to the view that respecting individual rights should be the primary – and often the only – goal of ethics and governance. This leads to a picture of the individual in conflict with other individuals and with the community as a whole. A connected view suggests that individuals are related to and caring for other individuals, and are connected to, and embedded in, the community. This does not mean that there is never tension between individuals, and between individuals and the community, but there is not constant conflict. This book begins with an examination of the philosophical understandings of the self. It shows how these have played out in the theory of bioethics and sets out the consequences in practice. It shows that philosophical claims do matter, and matter significantly, and that changing philosophical pictures is essential to changing policy and practice.

The claims of the connected self

The Connected Self presents a new argument, and admittedly a controversial one. If the argument of this book is correct, and current ethical frameworks fail to respect the connected nature of the genetic self, then essentially current dominant ethical frameworks provide little and, in some cases, effectively no ethical protection. While this book builds on and utilises discussions and claims of previous work, the argument and claims of this book represent a comprehensive new argument which begins with critiquing pictures of the self and ends with suggesting a new ethical framework for genetic governance and one which is

potentially useful for governance more broadly.² The argument of *The Connected Self* is built up gradually step by step. It first argues that a philosophically realistic picture of the self is not the isolated choosing self so common to much post-enlightenment philosophy. It then shows how a false philosophical picture of the self underlies bioethics, and that this has resulted in a narrow choice model of ethics. Because this is built on a false model of the self the practices of bioethics are flawed, they are unable to protect connected others and common and group goods and therefore ultimately to protect individuals. It argues that this is particularly true in the genetic era, as genetic material and information is *shared* and *identifying*. Having set out the problem it then proceeds to seek better models. Ultimately it proposes the “ethical toolbox”. The ethical toolbox is a two fold procedure. Its first stage – and possibly the most important – is an analysis stage, which identifies and prioritises the goods which should be protected and the harms which should be avoided in any given situation. The second stage is fitting appropriate ethical tools to these harms and goods, beginning with the most significant. The ethical toolbox is easily implemented, it is reflexive and it is responsive. It protects the connected self and, because it is built on better philosophical pictures of the self, results in a framework which contributes to social capital and engenders trust.

The structure of the connected self

To make this argument the book begins, in Chapters 1 and 2, by assessing the picture of the self which underpins today’s ethical frameworks, particularly bioethical frameworks. It argues that the picture of an isolated, individual, choosing self is a false one which is unrepresentative of the human person. It draws on philosophical critiques of the post-enlightenment, liberal individual, particularly those of feminism and virtue ethics. It goes on to show how this false picture of the self has been taken to extremes in bioethics, resulting in the adoption of the flawed individual choice model. The problems with this model are set out in general in Chapter 2, before moving in Chapter 3 to the core claim of the book, that the genetic self is the connected self. The claim that the genetic self is the connected self is built on two key features of genetic information – that genetic information is both *shared* and *identifying*. While these features of genetic information are widely recognised the consequences of these for ethics and governance frameworks have not yet been sufficiently recognised. In particular, the

² My previous work on this topic is detailed in the Foreword.

profound challenge that the *shared* and *identifying* nature of genetic information presents for *the* primary bioethical ethical practice of informed consent has not been addressed.

The book proceeds to look at the areas in which there have been attempts in bioethics to produce frameworks which address the failures of the individual choice model, and it maps the ‘communal turn’ in bioethics. Following this two of the most prominent alternative models of genetic governance, those of benefit sharing and trust, are considered. In the final chapters a new approach is suggested. This approach begins, in Chapter 8, by proposing a mechanism by which the significant goods and harms of any circumstance can be recognised; part 1 of the ethical toolbox. Unlike the individual choice model the ethical toolbox recognises the whole range of goods and harms: a necessary first step in any adequate effective ethics and governance framework. Once such harms and goods have been identified then appropriate ethical practices can be applied in the situation to protect the important goods and prevent the potential harms. This is the second stage of the ethical toolbox: the application of current, new and alternative practices. The advantage of the ethical toolbox, in addition to the fact that it recognises the connected nature of the genetic self, is that it provides a means to address the worst failures of the dominant individual choice model, while not asserting an equally restrictive “one-size-fits-all” model of ethics. Furthermore, and importantly for ethics and governance more generally, it has additional benefits in that it is likely to contribute to social capital and to trust and so will enhance public goods.