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978-1-107-00860-1 - 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.

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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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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

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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

Acknowledgements

I would like to thank many colleagues, fellow travellers and friends, who challenged, inspired and supported me through the writing of this book. First, I would like to thank Lisa Bortolotti and Iain Law. Together we are co-founders of the Birmingham ‘Health and Happiness’ Research Cluster (www.birmingham.ac.uk/schools/ptr/departments/philosophy/research/healthandhappiness.aspx). This book, like so much of my work over the last decade, has been enriched by working closely with these inspirational colleagues who are intimidatingly clever and unfailingly kind: an amazing combination. I would like to mention others connected to the Health and Happiness group to whom I am very grateful, including, Angus Dawson, David Hunter, Marie Fox, Sheelagh McGuinness, Yujin Nagasawa, Jonathan Reinartz, Jussi Suikkanen, Jeremy Williams with special mention of Jean McHale who it has been a pleasure talking to and collaborating with, and whose views on biobanks have given me more than a little pause for thought! In addition to those I have already mentioned at Birmingham I would also like to thank Helen Beebee, who has been an unfailingly supportive colleague and is a valued friend, as well as the rest of the philosophy department, particularly Darragh Byrne, Nick Effingham and Joss Walker. Others I would like to thank at the University of Birmingham are Lynne Brydon, Leslie Brubaker, Luis Cabrera, Francesca Carnivalli, David Cheetham, Deryn Guest, Charlotte Hempel, Paul Jackson, Heather Marquette, Nicola Smith, Martin Stringer, Michael Taylor and Isabel Wollaston; and particular thanks must go to my Head of College, Michael Whitby, who supported the last six months of writing by giving me “buy-out” from undergraduate teaching. The final, and by far the most important, thank you to colleagues from Birmingham is to Sean Cordell. Sean worked with me on my last funded project on the ethics and governance of biobanks and was invaluable as a research assistant in completing this project. His reassurance, persistence and support were essential to finishing this book. In particular, I have to give him special thanks for doing the referencing and bibliography: a challenge for me as a

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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.

I would also like to thank my family – my connected others – Gillian my mother and Dominic my brother. In them I am very lucky and their support is hugely appreciated as too is the support of Simon and Laura who provided a writing oasis. My final thanks go to my husband Matthew. My connected other in terms of our common commitment to striving for common and public goods, which are every bit as important as personal preferences. I thank him for his intellectual strength, for his refusal to compromise excellence, and for his belief in academic endeavour as an essential contribution to making the world a better place. Thanks as well, of course, go to our amazing and wonderful daughter, Clara: our little bit of perfection!