Organ Shortage: Ethics, Law and Pragmatism

Organ shortage is an ongoing problem in many countries. The needless death and suffering which have resulted necessitate an investigation into potential solutions. This examination of contemporary ethical means, both practical and policy-oriented, of reducing the shortfall in organs draws on the experiences of a range of countries. The authors focus on the resolution and negotiation of ethical conflict, examine systems approaches such as the ‘Spanish Model’ and the US Breakthrough Collaboratives, evaluate policy proposals relating to incentives, presumed consent and modifications regarding end-of-life care, and examine the greatly increased use of (non-heart-beating) donors suffering circulatory death, as well as living donors. The proposed strategies and solutions are capable not only of resolving the UK’s own organ-shortage crisis, but of being implemented in other countries grappling with how to address the growing gap between supply and demand for organs.

Dr Anne-Maree Farrell is Senior Lecturer in Law at the Centre for Social Ethics and Policy and the Institute for Science Ethics and Innovation, School of Law, University of Manchester.

Professor David Price is Professor of Medical Law at Leicester De Montfort Law School, De Montfort University.

Dr Muireann Quigley is Lecturer in Bioethics at the Centre for Social Ethics and Policy and the Institute for Science Ethics and Innovation, School of Law, University of Manchester.
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 the 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. Organ retention, embryonic stem cell research, physician assisted suicide and the allocation of resources to fund healthcare 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 healthcare.

**General Editors**
Professor Margaret Brazier, *University of Manchester,*
Professor Graeme Laurie, *University of Edinburgh*

**Editorial Advisory Board**
Professor Richard Ashcroft, *Queen Mary, University of London,*
Professor Martin Bobrow, *University of Cambridge,*
Dr Alexander Morgan Capron, *Director, Ethics and Health, World Health Organization, Geneva,*
Professor Jim Childress, *University of Virginia,*
Professor Ruth Chadwick, *Cardiff Law School,*
Dame Ruth Deech, *University of Oxford,*
Professor John Keown, *Georgetown University, Washington, DC,*
Dr Kathy Liddell, *University of Cambridge,*
Professor Alexander McCall Smith, *University of Edinburgh,*
Professor Dr Mónica Navarro-Michel, *University of Barcelona*
Marcus Radetzki, Marian Radetzki and Niklas Juth  *Genes and Insurance: Ethical, Legal and Economic Issues*
Ruth Macklin  Double Standards in Medical Research in Developing Countries
Donna Dickenson  Property in the Body: Feminist Perspectives
Matti Häyry, Ruth Chadwick, Vilhjálmur Árnason, Gardar Árnason  The Ethics and Governance of Human Genetic Databases: European Perspectives
Ken Mason  The Troubled Pregnancy: Legal Wrongs and Rights in Reproduction
Daniel Sperling  Posthumous Interests: Legal and Ethical Perspectives
Keith Syrett  Law, Legitimacy and the Rationing of Health Care
Alastair Maclean  Autonomy, Informed Consent and the Law: A Relational Change
Heather Widdows and Caroline Mullen  The Governance of Genetic Information: Who Decides?
David Price  Human Tissue in Transplantation and Research
Matti Häyry  Rationality and the Genetic Challenge: Making People Better?
Anne-Maree Farrell, David Price and Muireann Quigley  Organ Shortage: Ethics, Law and Pragmatism
Contents

List of figures  ix
List of tables  x
Contributors  xi
Acknowledgements  xviii
List of abbreviations  xix
Table of cases  xxi
Table of legislation  xxii

Part I Setting the scene  1

1 A principled and pragmatic approach to organ shortage  3
   ANNE-MAREE FARRELL, DAVID PRICE AND MUIREANN QUIGLEY

2 Does ethical controversy cost lives?  15
   MARGARET BRAZIER AND JOHN HARRIS

Part II Current issues affecting organ shortage  35

3 Organ donation and transplantation: meeting the needs of a multi-ethnic and multi-faith UK population  37
   GURCH RANDHAWA

4 Educating the public to encourage organ donation?  52
   MAIRI LEWITT

5 Bereavement, decision-making and the family in organ donation  67
   MAGI SQUE AND TRACY LONG-SUITEHALL

Part III Strategies for addressing organ shortage  87

6 Incentivising organ donation  89
   MUIREANN QUIGLEY
Contents

7 Making the margins mainstream: strategies to maximise the donor pool 104
ANTONIA CRONIN

8 The allocation of organs: the need for fairness and transparency 122
PHIL DYER AND SHEELAGH MCGUINNESS

9 Ante-mortem issues affecting deceased donation: an ethico-legal perspective 136
JOHN COGGON AND PAUL MURPHY

Part IV Comparative perspectives 149

10 Institutional organisation and transplanting the ‘Spanish Model’ 151
MONICA NAVARRO-MICHEL

11 Kidney donation: lessons from the Nordic countries 171
SALLA LÖTJÖNEN AND NILS H. PERSSON

12 Organ donation and transplantation: the Canadian experience 185
LINDA WRIGHT AND DIEGO S. SILVA

13 Systematic increases in organ donation: the United States experience 195
ALEXANDRA K. GLAZIER

Part V Current reform and future challenges 213

14 Negotiating change: organ donation in the United Kingdom 215
BOBBIE FARSIDES

15 Addressing organ shortage in the European Union: getting the balance right 227
ANNE-MAREE FARRELL

16 Promoting organ donation: challenges for the future 245
DAVID PRICE

Bibliography 269
Index 296
Figures

5.1 Interlocking Model of Bereavement Services  
11.1 Deceased donors (per million inhabitants):  
   1993–2008  
11.4 Patients admitted to the kidney waiting list, waiting for donation and deceased while waiting in 2008 (per million inhabitants)  
13.1 Example of kidney paired donation exchange
Tables

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1</td>
<td>Patients listed (active or suspended) for an organ transplant in the UK as at 31 December 2008, by ethnic origin and organ</td>
<td>40</td>
</tr>
<tr>
<td>3.2</td>
<td>Percentage of individuals registered (including suspended) on the list for a kidney (including kidney/pancreas) transplant in the UK as at 31 December 2008, by age decade and ethnic origin</td>
<td>41</td>
</tr>
<tr>
<td>3.3</td>
<td>Number registered on the list for a liver transplant in the UK as at 31 December 2008, by age decade and ethnic origin</td>
<td>41</td>
</tr>
<tr>
<td>3.4</td>
<td>Kidney donors in the UK, 2006–2008, by donor type and ethnic origin</td>
<td>42</td>
</tr>
<tr>
<td>3.5</td>
<td>Time actively registered on the list for a kidney transplant in the UK</td>
<td>42</td>
</tr>
<tr>
<td>3.6</td>
<td>Patients dying in 2006 whilst listed for a transplant</td>
<td>42</td>
</tr>
<tr>
<td>12.1</td>
<td>Waiting times for transplants by Canadian province 2008</td>
<td>186</td>
</tr>
</tbody>
</table>
Contributors

MARGARET BRAZIER is Professor of Law at the Centre for Social Ethics and Policy and the Institute for Science Ethics and Innovation at the University of Manchester. She is a Fellow of the UK Academy of Medical Sciences and is currently Editor-in-Chief of the Medical Law Review. Her research expertise lies in the area of medical jurisprudence, particularly involving issues relating to consent and autonomy, reproductive medicine, the role of the criminal law in healthcare and the donation and use of body parts. Recent publications include: ‘Respecting the living means respecting the dead too’, Oxford Journal of Legal Studies, 28 (2008) and ‘Human(s) (as) medicine(s)’ in First Do No Harm: Law and Ethics in Health Care (2006).

JOHN COGGON is Research Fellow in the Institute for Science Ethics and Innovation at the University of Manchester. He is an International Associate Editor of the Journal of Bioethical Inquiry and a member of the ethics committee of the British Medical Journal. His research expertise lies broadly within the area of health law and ethics, with particular interests in legitimate decision-making, autonomy, best interests, end-of-life issues, analysis and application of theoretical constructs, public health law and ethics. Recent publications include: ‘Doing what’s best: organ donation and intensive care’ in Ethics and Law in Critical Care (2010) and ‘Best interests and potential organ donors’, British Medical Journal, 336 (2008).

ANTONIA CRONIN is a Consultant Nephrologist at the NIHR Biomedical Research Centre, Guy’s and St. Thomas’ NHS Foundation Trust, and Honorary Clinical Research Consultant, MRC Centre for Transplantation, King’s College London. She is also currently Chair of the Ethics Committee of the British Transplantation Society and Honorary Research Fellow, Institute for Science Ethics and Innovation, University of Manchester. Her research interests focus on ethico-legal issues involved in tissue and organ donation, clinical

PHIL DYER is a Consultant Clinical Scientist at the Scottish National Blood Transfusion Service, Royal Infirmary of Edinburgh, and Honorary Professor in Transplantation Science, University of Manchester. He is a Fellow of the Royal College of Pathologists, and co-founded the British Society for Histocompatibility and Immunogenetics. Professor Dyer was President of the British Transplantation Society from 2002 to 2005. He has served on a number of committees, including the ethics committee of the Royal College of Pathologists, and was a member of the Human Tissue Working Group on the Human Tissue Act from 2004 to 2005. His research interests include organ and stem cell transplantation, the outcomes of clinical transplantation, pharmacoimmunogenetics, and organ allocation. He has published widely in the areas of organ and tissue transplantation.

ANNE-MAREE FARRELL is Senior Lecturer in Law at the Centre for Social Ethics and Policy and the Institute for Science Ethics and Innovation, University of Manchester. Dr Farrell’s research expertise lies broadly within the area of health law, with a particular interest in governance and regulation of human material such as organs, tissue and blood at European and global levels. Recent publications include: ‘Adding value? EU governance of organ donation and transplantation’, European Journal of Health Law, 17 (2010) and ‘Time for change: the need for a pragmatic approach to addressing organ shortage in the UK’, Clinical Ethics, 3 (2008).

BOBBIE FARSIDES is Professor of Clinical and Biomedical Ethics at Brighton and Sussex Medical School, University of Sussex, and Visiting Professor at the Centre for Biomedicine and Social Science, King’s College London. She is a Member of the UK Donation Ethics Committee, and was a Member of the UK Organ Donation Taskforce from 2008 to 2009 and Specialist Advisor to the House of Lords European Sub-Committee which conducted an inquiry into policy action on organ donation and transplantation at EU level. Her research interests are broadly focused on examining the experiences of healthcare
practitioners and scientists operating in ethically contested areas of modern biomedicine. She was the lead author for the UK Organ Donation Taskforce’s Ethics Sub-Group’s Report: The Potential Impact of an Opt Out System for Organ Donation in the UK (2008).

ALEXANDRA K. GLAZIER is Vice-President and General Counsel of the New England Organ Bank, and Adjunct Professor of Law at Boston University. She is also a Member of the US Department of Health and Human Services Advisory Committee for Organ Transplantation and the Vice-Chair of the Ethics Committee, United Network for Organ Sharing (UNOS). Her research interests are focused on legal, policy and legislative issues related to organ donation and transplantation. Recent publications include: ‘Regulatory face-off: what agency should oversee face transplantation?’, American Journal of Transplantation, 8 (2008), and ‘Organ donation and dual advocacy’, New England Journal of Medicine, 358 (2008).

JOHN HARRIS is Lord Alliance Professor of Bioethics and Director of the Institute for Science, Ethics and Innovation, University of Manchester. He is a Fellow of the UK Academy of Medical Sciences, and a Member of both the UK Human Genetics Commission and the Ethics Committee of the British Medical Association. He was one of the founding Directors of the International Association of Bioethics and is currently Editor-in-Chief of the Journal of Medical Ethics. His research expertise and interests include ethics and policy dimensions of genetics, biotechnology, organ donation and transplantation, embryo experimentation, stem cells, genetic and other enhancement and disability issues. Recent publications include: ‘Time to move to presumed consent for organ donation’, British Medical Journal, 340 (2010) and ‘Organ procurement – dead interests, living needs’, Journal of Medical Ethics, 29 (2003).

MAIRI LEVITT is Head of the Department of Philosophy at Lancaster University. She has an academic and research background in social science and religious studies. Since 1993 she has been engaged in multi-disciplinary research on the ethical and social implications of genetics and medical technologies. Her research projects, in a variety of subject areas, have involved public engagement work with the general public, young people and stakeholders, and a critical perspective on the way health policy and information is communicated. Her most recent research has included children and the national DNA database, ‘criminal genes’ and public policy, and perspectives on the roles of nature and nurture in human development.
TRACY LONG-SUTEHALL is Senior Research Fellow in the School of Health Sciences, University of Southampton. Her research focuses on a range of issues concerning organ donation and transplantation, and currently involves examining the reasons why family members decline tissue donation, and how nurses facilitate end-of-life care in critical care settings. Recent publications include: ‘What does a diagnosis of brain death mean to family members approached about organ donation: a review of the literature’, Progress in Transplantation, 18 (2008), and ‘Conflict rationalization: how family members cope with a diagnosis of brain stem death’, Social Science & Medicine, 67 (2008).

SALLA LÖTJÖNEN is Senior Advisor, Legislative Affairs, Ministry of Justice, Helsinki, and Adjunct Lecturer in Medical and Biolaw at the University of Helsinki. Dr Lötjönen’s research expertise is in the area of medical law, medical research, research ethics and family law. Relevant publications include: ‘Biopankit’ (‘Biobanks’) in Bio-oikeus lääketieteessä (Biolaw in Medicine) (2006) and ‘Ihmisperäisten biologisten näytteiden käyttö lääketieteellisessä tutkimuksessa’ (‘The Use of Biological Samples in Medical Research’), Lakimies (2005).

SHEELAGH McGUINNESS is Lecturer in Ethics and Law at the Centre for Professional Ethics, Keele University. Her research expertise lies in the inter-relationship between medical law, bioethics and public policy. She has particular research interests in human reproduction, religious beliefs and medical law, transgender medicine, organ donation, and research ethics. Recent publications include: ‘Respecting the living means respecting the dead too’, Oxford Journal of Legal Studies, 28 (2008).

PAUL MURPHY is Consultant in Neuroanaesthesia and Critical Care at The General Infirmary, Leeds. He is also National Clinical Lead for Organ Donation, NHS Blood and Transplant. His research interests focus on the epidemiology of deceased organ donation in the UK, ethico-legal issues involved in deceased organ donation and donation after cardiac death. Recent publications include: ‘Controlled non-heart beating organ donation: neither the whole solution nor a step too far’, Anaesthesia, 63 (2008), and ‘Best interests and potential organ donors’, British Medical Journal, 336 (2008).

MÓNICA NAVARRO-MICHEL is Reader in Law at the University of Barcelona. Dr Navarro-Michel’s research expertise is in the area of medical law, with a particular focus on issues of consent, organ transplantation and assisted reproduction. Most of her research has been published in Spanish; recent English-language publications

**NILS H. PERSSON** is Associate Professor and Senior Surgeon in the Department of Nephrology and Transplantation, Skåne University Hospital, Malmö. His research and professional expertise is in organ donation and kidney transplantation, with a particular focus on expanded/marginal donors and allocation strategies. Publications include articles on the potential for organ donation in Sweden in relation to ICU deaths, marginal donors and informed consent in kidney transplantation, and public perceptions of xenotransplantation.

**DAVID PRICE** is Professor of Medical Law at De Montfort University, Leicester. His research expertise lies within the areas of the use of human tissue for medical and scientific applications, physician-assisted dying and the withholding and withdrawal of life-sustaining medical treatment. He was a Member of the UK Organ Donation Taskforce from 2008 to 2009 and is currently a Member of the Nuffield Council on Bioethics Working Party on Human Bodies in Medicine and Research. Recent publications include *Human Tissue for Transplantation and Research: A Model Legal and Ethical Framework*, (Cambridge University Press, 2009) and he was Editor of *Organ and Tissue Transplantation* (2006) which includes a substantial Introduction by him.

**MUIREANN QUIGLEY** is Lecturer in Bioethics at the Centre for Social Ethics and Policy and the Institute for Science Ethics and Innovation at the University of Manchester. Her research focuses on the ethics of organ transplantation, reproduction and reproductive technologies, justice and responsibility in healthcare, and stem cells and rights (specifically property rights in the human body and its parts). Recent publications include: ‘Best interests and potential organ donors’, *British Medical Journal, 336* (2008), and ‘The organs crisis and the Spanish model: theoretical versus pragmatic considerations’, *Journal of Medical Ethics, 34* (2008).

**GURCH RANDHAWA** is Professor of Diversity in Public Health and Director of the Institute for Health Research, University of Bedfordshire. He was a member of the UK Department of Health’s Organ Donation Taskforce from 2008 to 2009. As part of the work of the Taskforce, he was Chair of the Social and Cultural Working Group. He is currently Chair of the Department of Health’s End of Life Care in Advanced Kidney Disease project. He is also Chair of the NHS Luton; Member of the UK Donation Ethics Committee; and a Non-Executive Director for the University of Bedfordshire.
Director of the Human Tissue Authority. Professor Randhawa’s research expertise lies in the examination of diabetes, kidney disease, transplantation and end-of-life care amongst minority ethnic groups. Key publications in the area of organ donation and transplantation include: ‘Faith leaders united in their support for organ donation – findings from the Organ Donation Taskforce’s study of attitudes of UK faith and belief group leaders to an opt-out system’, Transplant International, 23 (2010); and ‘Utilising faith communities in the UK to promote the organ donation debate: the views of UK faith leaders’, Journal of Diversity in Health and Care, 7 (2010).

DIEGO S. SILVA is a Doctoral Candidate at the Dalla Lana School of Public Health, University of Toronto, and a member of the Collaborative Program in Bioethics at the Joint Centre for Bioethics. His research interests focus on organ donation and transplantation, public health and mental health, and include the moral implications of policy and practice. Recent publications include: ‘Incentives for organ donation: Israel’s novel approach’, Lancet, 375 (2010) and ‘Of altruists and egoists: living anonymous donors’ in Organ Transplantation: Ethical, Legal and Psychosocial Aspects (2008).

MAGI SQUE is Professor of Clinical Practice and Innovation at the School of Health and Wellbeing, Centre for Health and Social Care Improvement, University of Wolverhampton and The Royal Wolverhampton NHS Hospitals Trust. She currently acts as an advisor to the UK Department of Health on organ donation, and is a Member of its Research Commissioning Project Group. Her other research interests are focused on bereavement, life-limiting illness, social constructions and concepts of the dying and the dead body, the role of relatives and significant others in illness (particularly life-limiting trajectories), and the nature and quality of support given to them. She is currently International Chair of the European Platform’s (ELPAT) Deceased Donation Working Group based at Erasmus University Medical Center. Recent publications include: Organ and Tissue Donation: an Evidence Base for Practice (2007) and ‘Why relatives do not donate organs for transplants: “sacrifice” or “gift of life”?’ Journal of Advanced Nursing, 61 (2008).

LINDA WRIGHT is Director of Bioethics at the University Health Network in Toronto. She is also Assistant Professor in the Department of Surgery and a member of the Joint Centre for Bioethics at the University of Toronto. Her research expertise lies in examining ethical issues that arise in the area of organ donation and
Acknowledgements

This book has its origins in a five-part seminar series, *Transplantation and the Organ Deficit in the UK: Pragmatic Solutions to Ethical Controversy*, which was funded by the UK Economic and Social Research Council (ESRC) between 2006 and 2008 (RES-451-25-4341), and we gratefully acknowledge its support. The seminar series brought together a multidisciplinary and international group of ethicists, lawyers, clinicians, scientists, sociologists and patient advocates who all had interests and expertise in the field of organ donation and transplantation. All participants in the seminar series were particularly interested in finding a principled and pragmatic way forward in order to address the problems created by the ongoing shortage of organs both in the UK and beyond. It proved to be a highly stimulating series of seminars, which challenged participants to examine alternative and creative ways in which this issue could be addressed. The seminar series coincided with a period of heightened policy activity and reform of organ donation and transplantation processes at both UK and EU levels, and several participants also consulted and/or advised on such processes. We would like to thank the participants in the seminar series, many of whom are contributors to this book, for their thought-provoking insights and lively exchange of ideas, as well as for the rapport that developed between us as a result.

We would also like to acknowledge the support we have received from Cambridge University Press in the preparation and completion of the book, in particular from Finola O’Sullivan, Brenda Burke, Richard Woodham and Jo Breeze – it has been much appreciated.

Anne-Maree Farrell would like to thank Ron, Tom and the Peek-Farrell family for their support and patience during the completion of this project. David Price wishes to offer his heartfelt thanks to Arlene. Muireann Quigley would like to thank Brian Willis, who always supports and believes in her.

The editors would like to especially thank Margot Brazier for her encouragement and support in relation to the seminar series, as well as in the preparation of this book.
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABOi</td>
<td>ABO blood group incompatible</td>
</tr>
<tr>
<td>ACE</td>
<td>angiotensin converting enzyme</td>
</tr>
<tr>
<td>AIDS</td>
<td>acquired immune deficiency syndrome</td>
</tr>
<tr>
<td>AIT</td>
<td>antibody incompatible living donor renal transplantation</td>
</tr>
<tr>
<td>ATR</td>
<td>angiotensin receptor blockers</td>
</tr>
<tr>
<td>BBSRC</td>
<td>Biotechnology and Biological Sciences Research Council (UK)</td>
</tr>
<tr>
<td>BME</td>
<td>black and minority ethnic</td>
</tr>
<tr>
<td>CCDT</td>
<td>Canadian Council for Donation and Transplantation</td>
</tr>
<tr>
<td>DCD</td>
<td>donation after cardiac death</td>
</tr>
<tr>
<td>DMV</td>
<td>Department of Motor Vehicles (USA)</td>
</tr>
<tr>
<td>DSA</td>
<td>donor specific antibody</td>
</tr>
<tr>
<td>ECD</td>
<td>expanded criteria donor</td>
</tr>
<tr>
<td>ESRF</td>
<td>end-stage renal failure</td>
</tr>
<tr>
<td>EU</td>
<td>European Union</td>
</tr>
<tr>
<td>HIV</td>
<td>human immunodeficiency virus</td>
</tr>
<tr>
<td>HLA</td>
<td>human leukocyte antigen</td>
</tr>
<tr>
<td>HLAI</td>
<td>human leukocyte antigen incompatible</td>
</tr>
<tr>
<td>HLH</td>
<td>haemophagocytic lymphohistiocytosis</td>
</tr>
<tr>
<td>HTA</td>
<td>Human Tissue Authority (UK)</td>
</tr>
<tr>
<td>ICU</td>
<td>intensive care unit</td>
</tr>
<tr>
<td>KPD</td>
<td>kidney paired donation</td>
</tr>
<tr>
<td>LDT</td>
<td>living donor organ transplantation</td>
</tr>
<tr>
<td>MHC</td>
<td>major histocompatibility complex</td>
</tr>
<tr>
<td>NCCUSL</td>
<td>National Conference of Commissioners of Uniform State Laws (USA)</td>
</tr>
<tr>
<td>NDFC</td>
<td>National Donor Family Council (USA)</td>
</tr>
<tr>
<td>NHBD</td>
<td>non-heart-beating donors</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service (UK)</td>
</tr>
<tr>
<td>NHSBT</td>
<td>National Health Service Blood and Transplant (UK)</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Description</td>
</tr>
<tr>
<td>---------------</td>
<td>-----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>NHSBT-ODT</td>
<td>National Health Service Blood and Transplant – Organ Donation and Transplantation Directorate (UK)</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Clinical Excellence (UK)</td>
</tr>
<tr>
<td>NOTA</td>
<td>National Organ Transplant Act (USA)</td>
</tr>
<tr>
<td>NSF</td>
<td>National Service Framework (UK)</td>
</tr>
<tr>
<td>OMC</td>
<td>Open Method of Co-ordination (EU)</td>
</tr>
<tr>
<td>ONT</td>
<td>Organización Nacional de Trasplantes (Spain)</td>
</tr>
<tr>
<td>OPO</td>
<td>Organ Procurement Organization (USA)</td>
</tr>
<tr>
<td>PDA</td>
<td>Potential Donor Audit (UK)</td>
</tr>
<tr>
<td>PGD</td>
<td>pre-implantation genetic diagnosis</td>
</tr>
<tr>
<td>PMP</td>
<td>per million population</td>
</tr>
<tr>
<td>QOF</td>
<td>Quality and Outcomes Framework (UK)</td>
</tr>
<tr>
<td>RCIDT</td>
<td>Red/Consejo Iberoamericano de Donación y Trasplante (Latin America)</td>
</tr>
<tr>
<td>RRT</td>
<td>renal replacement therapy</td>
</tr>
<tr>
<td>UAGA</td>
<td>Uniform Anatomical Gift Act (USA)</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>USA</td>
<td>United States</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
<tr>
<td><a href="http://www.cambridge.org">www.cambridge.org</a></td>
<td>© in this web service Cambridge University Press</td>
</tr>
<tr>
<td>978-0-521-19899-8 - Organ Shortage: Ethics, Law and Pragmatism</td>
<td></td>
</tr>
<tr>
<td>Anne-Maree Farrell, David Price and Muireann Quigley</td>
<td></td>
</tr>
<tr>
<td>Frontmatter</td>
<td>More information</td>
</tr>
</tbody>
</table>
### Table of cases

#### England and Wales

- Felthouse v. Bindley (1862) CB(NS) 869
- R v. Sussex Justices, ex parte McCarthy [1924] 1 KB 256
- Cassidy v. Ministry of Health [1951] 2 KB 343
- Barnett v. Chelsea & Kensington Hospital Management Committee [1969] 1 QB 428
- Collins v. Wilcock [1984] 1 WLR 1172, 1178 (CA)
- Re F (mental patient: sterilisation) [1990] 2 AC 1
- Re A (A Minor) [1992] 3 Med LR 303
- Re Y (mental patient: bone marrow donation) [1997] 2 WLR 556
- Re A (medical sterilisation: male sterilisation) [2000] 1 FCR 193
- Re S (adult patient: sterilisation) [2001] Fam 15
- R (on the application of N) v. M and others [2003] 1 WLR 562
- Burke v. General Medical Council [2005] EWCA Civ 1003
- Ahsan v. University Hospitals of Leicester NHS Trust [2007] PIQR P19

#### United States

- Schembre v. Mid America Transplant Ass’n, 135 SW 3d 527 (Mo. App. 2004)
### Table of legislation

#### Canada

<table>
<thead>
<tr>
<th>Act</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Constitution Act, 1867 30 &amp; 31 Victoria, c. 3. (UK)</td>
<td></td>
</tr>
<tr>
<td>Human Tissue Gift Act, R.S.S. 1978</td>
<td></td>
</tr>
<tr>
<td>Criminal Code, R.S.C. 1985</td>
<td></td>
</tr>
<tr>
<td>Canada Health Act, R.S.C. 1985</td>
<td></td>
</tr>
<tr>
<td>Food and Drug Act, R.S.C. 1985</td>
<td></td>
</tr>
<tr>
<td>Human Tissue Gift Act, C.C.S.M. 1987</td>
<td></td>
</tr>
<tr>
<td>Human Tissue Act, R.S.N.W.T. 1988</td>
<td></td>
</tr>
<tr>
<td>Human Tissue Donation Act, R.S.P.E.I. 1988</td>
<td></td>
</tr>
<tr>
<td>Human Tissue Gift Act, R.S.N.S. 1989</td>
<td></td>
</tr>
<tr>
<td>Human Tissue Act, R.S.N.L. 1990</td>
<td></td>
</tr>
<tr>
<td>Trillium Gift of Life Network Act, R.S.O. 1990</td>
<td></td>
</tr>
<tr>
<td>Civil Code of Quebec, S.Q. 1991</td>
<td></td>
</tr>
<tr>
<td>Human Tissue Gift Act, R.S.B.C. 1996</td>
<td></td>
</tr>
<tr>
<td>Human Tissue Gift Act, R.S.A. 2000</td>
<td></td>
</tr>
<tr>
<td>Human Tissue Gift Act, R.S.Y. 2002</td>
<td></td>
</tr>
<tr>
<td>Human Tissue Gift Act, S.N.B. 2004</td>
<td></td>
</tr>
</tbody>
</table>

#### Council of Europe


#### European Union


Italy

Law 91/1999, 1 April, on the retrieval and transplantation of organs and tissues (Legge 91/1999, 1 Aprile, di disposizioni in materia di prelievi e di trapianti di organi e di tessuti)

Nordic countries

Act relating to Transplantation, Hospital Autopsies and the Donation of Bodies (Lov om transplantasjon, sykehusobduksjon og avgivelse av lik m.m.), Nr. 6 of Statutes, 9 February 1973

Act on Transplantation (Lag om transplantation m.m.), Nr. 831 of Statutes, 8 June 1995

Regulations and General Guidelines by the Swedish National Board of Health and Welfare (Socialstyrelsens föreskrifter och allmänna råd) 1997:4, Removal of organs and tissue for organ transplantation and other medical purposes (Organ-och vävnadstagning för transplantation eller för annat medicinsk ändamål)

Governmental Bill to amend the Act on the Medical Use of Human Organs and Tissues Nr. 93 of 2000

Health Act (Sundhedsloven), Nr. 546 of Statutes, 24 June 2005, Part IV, Chapter 12

Governmental Bill to amend the Act on the Medical Use of Human Organs and Tissues Nr. 276 of 2009

Act on the Medical Use of Human Organs and Tissues (Laki ihmisen elimien ja kudoksien lääketieteellisestä käytöstä) Nr. 101 of Statutes, 2 February 2001 (as amended up until June 2010)

Spain

Law 30/1979, 27 October, on organ extraction and transplant (Ley 30/1979, de 27 de octubre, sobre extracciòn y trasplante de órganos)
Royal Decree 426/1980, 22 February, on organ extraction and transplant (Real Decreto 426/1980, de 22 de febrero, sobre extracción y trasplantes de órganos) (abolished by Royal Decree 2070/1999)

Law 29/1980, 21 June, on clinical autopsies (Ley 29/1980, de 21 de junio, por la que se regulan las autopsias clínicas)

Royal Decree 2230/1982, 18 June, on clinical autopsies (Real Decreto 2230/1982, de 18 de junio, por el que se regulan las autopsias clínicas)

Law 35/1988, 22 November, on human assisted reproduction techniques (Ley 35/1988, de 22 de noviembre, de regulación de las técnicas de reproducción asistida humana) (abolished by Law 14/2006)

Law 42/1988, 28 December, on donation and use of human embryos and foetuses, or their cells, tissues and organs (Ley 42/1988, de 28 de diciembre, de donación y utilización de embriones y fetos humanos o de sus células, tejidos u órganos) (abolished by Law 14/2007)

Royal Decree 2070/1999, 30 December, which regulates the activities of procurement and clinical use of human organs and territorial co-ordination in matters of organ and tissue donation and transplantation (Real Decreto 2070/1999, de 30 de diciembre, por el que se regulan las actividades de obtención y utilización clínica de órganos humanos y la coordinación territorial en materia de donación y trasplante de órganos y tejidos)

Civil Law of Criminal Procedure, 2000 (Ley de Enjuiciamiento Civil, 2000)

Law 41/2002, 14 November, on patients’ autonomy, and rights and obligations with regard to information and documentation (Ley 41/2002, de 14 de noviembre, básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación básica)

Royal Decree 1088/2005, 16 September, on the technical requirements and necessary conditions for blood donation and regulation of blood transfusion centres and services (Real Decreto 1088/2005, de 16 de septiembre, por el que se establecen los requisitos técnicos y condiciones mínimas de la hemodonación y de los centros y servicios de transfusión)

Law 14/2006, 26 May, on human assisted reproduction techniques (Ley 14/2006, de 26 de mayo, reguladora de las técnicas de reproducción asistida humana)

Royal Decree 1301/2006, 10 November, which establishes rules for quality and security for donation, obtaining, evaluating, processing, preserving, storing and distributing human cells and tissues, and rules on co-ordination and functioning for human use (Real Decreto 1301/2006, de 10 de noviembre, por el que se establecen las normas de calidad y seguridad para la donación, la obtención, la evaluación, el procesamiento, la preservación, el almacenamiento y la distribución de células y tejidos humanos
y se aprueban las normas de coordinación y funcionamiento para su uso en humanos

Law 14/2007, 3 July, on biomedical research (Ley 14/2007, de 3 de julio, de investigación biomédica)

Royal Decree 1825/2009, 27 November, which approves the statutes of the ONT (Real Decreto 1825/2009, de 27 de noviembre, por el que se aprueba el estatuto de la Organización Nacional de Trasplantes)

United Kingdom

Anatomy Act 1832
Human Organs Transplant Act 1989
Adults with Incapacity (Scotland) Act 2000
Human Tissue Act 2004
Mental Capacity Act 2005
Human Tissue (Scotland) Act 2006

United States

Uniform Anatomical Gift Act (1968)
UNOS Bylaws, 23 March 2007

Recommendations

Council of Europe

Council of Europe, Recommendation Rec (2005) 11 of the Committee of Ministers to Member States on the role and training of professionals responsible for organ donation (transplant donor co-ordinators) (adopted 15 June 2005)

Latin America

Recommendation Rec RCIDT 2005 (2) on the role and training of professionals responsible for organ donation (transplant donor co-ordinators)
Recommendation Rec RCIDT 2005 (3) on the functions and responsibilities of a national transplant organisation