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Part I

Setting the scene

1 A principled and pragmatic approach to organ shortage

Anne-Maree Farrell, David Price and Muireann Quigley

Ethical and legal issues concerning organ donation and transplantation have been the subject of much controversy and debate in many countries, especially over the last twenty years.[1] Technological developments in the field have opened up the possibility of transplanting an increasing number of human organs to those in need. The number of organs available for transplantation, however, has not kept pace with such developments. In the United Kingdom (UK) alone, the gap is widening between the number of persons on the national waiting list for organs and the number of available organs, with 7,980 persons on the active national waiting list as of the end of the financial year 2009–10 and approximately 1,000 people dying each year for want of a solid organ transplant.[2] Not only are transplant waiting times increasing in general (primarily for kidneys), but rates of development of end-stage organ failure and disease are continuing to increase, most notably amongst black and ethnic minority populations.

Whilst the number of solid organ transplants performed in the UK continues to rise, this masks two crucial and revealing trends. First, annually the number of living donors now exceeds the number of deceased donors with respect to kidneys, which itself generates accusations that too much reliance is being placed on living donors as sources for organs. The number of living donors has increased in the last decade from 338 in 1999–2000 to 1,032 in 2009–10, a more than 300 per cent rise.[3] Second, the volume of heart-beating, brain (stem) dead donors has steadily declined during this period, from 744 in 1999–2000 to 623 in 2009–10. This figure has, however, been more than compensated for by a large rise in the number of non-heart-beating donors (otherwise referred to as ‘donors

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[1] D. Price, *Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework* (Cambridge University Press, 2009); *Legal and Ethical Aspects of Organ Transplantation* (Cambridge University Press, 2000).

[2] NHS Blood and Transplant, www.uktransplant.org.uk/ukt/statistics/latest_statistics/latest_statistics.jsp.

[3] *Ibid.*

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after cardiac/circulatory death') from 33 to 336 in the same period.[4] Although the number of such donors has historically been modest, they now account for more than a third of all deceased organ donors in the UK. Multi-organ retrieval is less common in the latter context (many are 'kidney-only' retrievals), and thoracic non-heart-beating donations are a relatively recent development, therefore heart-beating rather than non-heart-beating donors are generally still viewed as the optimal source of organs for transplant.[5] Indeed, some still consider organs from non-heart-beating donors to be 'marginal'.[6]

Numbers of heart-beating donors have reduced as a result of fewer younger people dying of severe head injury or catastrophic cerebrovascular events, such as road-traffic accidents. Changes in the diagnosis and management of severe brain injuries also now result in fewer critically ill patients fulfilling brain stem death testing criteria. The general decline in heart-beating donation represents a major problem with regard to addressing the problem of organ shortage. These trends are not just confined to the UK, but can be observed in most other countries with developed organ donation and transplantation systems. To a very significant extent, all such countries are in some form of crisis in terms of meeting the demand for organs, and those working in the field all largely share common concerns, anxieties and issues.

The organ-shortage crisis has recently led to the issue of organ donation assuming a prominent place on the political agenda at both national and European Union (EU) levels. The government in the UK established an Organ Donation Taskforce to examine a range of options to address the problem. In its first report, published in 2008, it set out a series of recommendations to address organ shortage in the UK, but within the existing legal and policy framework. In this report, the UK Organ Donation Taskforce stated that three key organisational issues needed to be addressed within the structure of the national health system if there was to be a significant increase in the rate of organ donation:

1. donor identification and referral;
2. donor co-ordination; and
3. organ retrieval arrangements.

Most importantly, there needed to be clear political leadership and commitment to addressing these issues in order to achieve the desired result.[7] A Clinical Director for Transplantation has now been appointed to, inter alia, implement the Taskforce's fourteen recommendations

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[4] *Ibid.* [5] See Chapter 9. [6] See Chapter 7.

[7] Department of Health, *Organs for Transplants: A Report from the Organ Donation Taskforce* (London: Department of Health, 2008), pp. 3–19.

(principally relating to resourcing, systems and infrastructural factors),[8] which it is claimed will lead to a 50 per cent increase in organ donation within a five-year timespan.[9]

In addition, the previous Prime Minister, the Rt Hon. Gordon Brown, and the Chief Medical Officer for England both lent their support to calls for a presumed consent (opt-out) regime to replace the current opt-in arrangements in place in relation to organ donation.[10] This led to the Taskforce being reconvened and reconstituted to consider the issue. In late 2008, it advised that such a measure should not be considered at the present time, but should be revisited after five years if organ donation rates had not significantly improved by that time. Such calls for reform by senior government figures point to the severity of the crisis, notwithstanding the bitter legacy of organ retention scandals in the UK,[11] which led to consent becoming the centrepiece of a newly established legislative regime dealing with the use of human material, including organs.[12]

At EU level, the European Commission has recently recognised the importance and urgency of addressing ethical and legal issues concerning organ transplantation and shortage on a supranational basis. This led the Commission to publish an action plan setting out how it proposes to address the issue,[13] which was accompanied by a legislative proposal (Directive) to establish an EU-wide risk regulation regime in the field.[14] The Directive has now been adopted at EU level, and implementation is required by Member States by 27 August 2012.[15] In reviewing recent developments in EU organ donation and transplantation, the House of

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[8] Department of Health, 'Government announces appointment of new national clinical director for transplant' (3 April 2008), http://nds/coi.gov.uk/Content/Detail.asp?ReleaseID=364434&NewsAreaID=2.

[9] Department of Health, *Organs for Transplants*, p. 3.

[10] Department of Health, *2006 Annual Report of the Chief Medical Officer: on the State of Public Health* (London: Department of Health, 2007), p. 33; the former Prime Minister, the Rt Hon. Gordon Brown, 'Organs can help us make a difference', *Daily Telegraph*, 14 January 2008.

[11] M. Brazier, 'Retained organs: ethics and humanity', *Legal Studies*, 22 (2002), 550–69.

[12] D. Price, 'The Human Tissue Act 2004', *Modern Law Review*, 68 (2005), 798–821. The new legislative regime for the UK is set out in two pieces of legislation, namely the Human Tissue Act 2004 and the Human Tissue (Scotland) Act 2006.

[13] Commission of the European Communities, *Action Plan on Organ Donation and Transplantation (2009–2015): Strengthened Cooperation between Member States* (COM (2008) 819/3, Brussels, 8 December 2008).

[14] *Ibid.*; Proposal for a Directive of the European Parliament and of the Council on standards of quality and safety of human organs intended for transplantation (COM(2008) 818 final, Brussels, 8 December 2008).

[15] Directive 2010/45/EU of the European Parliament and of the Council of 7 July 2010 on standards of quality and safety of human organs intended for transplantation (OJ L 207, 6 August 2010), in particular Article 31(1).

Lords EU Select Committee recognised the benefit to be gained from concerted cross-border action to address organ shortage of the type envisaged by the Commission, provided that such action did not become administratively burdensome in practice and did not inhibit the application of expert clinical judgement and informed patient choice.[16]

Various reasons have been offered to explain the shortage of organs. In terms of potential donors, public surveys and published academic research reveal a high level of public support for organ donation in general terms. When faced with the decision to donate a family member's organs, however, the reality has been somewhat different, with high rates of refusal. It has also been suggested that healthcare professionals involved in organ transplantation have failed to be sufficiently proactive in approaching potential donors and/or their families, and appropriate infrastructures and training in the field have been lacking in terms of promoting organ donation.[17] In the UK, consideration has been given recently to the identification of 'clinical triggers' that would immediately result in automatic notification of potential donors to transplantation agencies, as takes place in the United States (USA); however, such proposals have yet to be implemented. In addition, the 'gift relationship' which has been used to provide the ethical underpinning for the system of organ donation and transplantation has been criticised for failing to encourage sufficient numbers of individuals and their families to donate.[18]

Consideration has been given to a range of policy options to address supply and demand issues in organ transplantation, including:

1. the establishment of commercial market or monopsonistic schemes for organs;[19]

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[16] House of Lords European Union Committee, *Increasing the Supply of Donor Organs within the European Union*, 17th Report of Session 2007–08, Volume 1: Report, HL Paper 123–I (London: The Stationery Office, 2008).

[17] T. Burroughs, B. Hong, D. Kappel and B. Freedman, 'The stability of family decisions to consent or refuse organ donation: would you do it again?', *Psychosomatic Medicine*, 60 (1998), 156–62; T. Long, M. Sque and S. Payne, 'Information sharing: its impact on donor and nondonor families' experience in the hospital', *Progress in Transplantation*, 16 (2006), 144–9; M. Sque, S. Payne and J. Macleod Clark, 'Gift of life or sacrifice? Key discourses to understanding organ donor families' decision-making', *Mortality*, 11 (2006), 117–32.

[18] M. Sque and S. Payne, 'Gift exchange theory: a critique in relation to organ transplantation', *Journal of Advanced Nursing*, 19 (1994), 45–51; L. Siminoff and K. Chillag, 'The fallacy of the "gift of life"', *The Hastings Center Report*, 29 (1999), 34–41; J. Childress, 'The failure to give: reducing barriers to organ donation', *Kennedy Institute of Ethics Journal*, 11 (2001), 1–16.

[19] L. Cohen, 'A futures market in cadaveric organs: would it work?', *Transplantation Proceedings*, 1 (1993), 60–1; C. Erin and J. Harris, 'A monopsonistic market – or how to buy and sell human organs, tissues and cells ethically' in I. Robinson (ed.), *Life and Death under High Technology Medicine* (Manchester University Press in association with the Fullbright Commission, London, 1994), pp. 134–53.

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2. the expanded use and range of organs from living donors;[20]
3. the adoption of the 'Spanish model' to facilitate optimum institutional arrangements for organ donation;[21]
4. the implementation of presumed consent (opt-out) regimes for organ donation;[22]
5. the need for revised allocation criteria;[23] and
6. the implementation of supranational (regulatory) regimes to facilitate best practice and organ exchange.[24]

Given the current prominence of issues relating to organ donation and transplantation on the political agenda at both national and international levels, this book is both timely and innovative for a number of reasons. First, there is an urgent need for critical, informed and up-to-date analysis of such developments by those with the requisite academic and practical expertise. Second, there is a need to focus on strategies to increase organ donation that are likely to succeed in the short to medium term. The editors seek to move away from examining longstanding and unresolved ethical, religious and cultural conflict and controversy over issues in organ donation and transplantation, with the aim of identifying coherent and innovative solutions for addressing organ shortage. Such solutions should be principled yet pragmatic in approach, and capable of being implemented in a timely fashion in order to facilitate an increase in organ donation, primarily in the UK, but with potential application beyond this national context.

There are a number of reasons for focusing on the UK. First, it has a particularly low rate of deceased organ donation, when compared to many of its European neighbours.[25] There is a need to understand why

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[20] A. Garwood-Gowers, *Living Donor Organ Transplantation: Key Legal and Ethical Issues* (Aldershot: Ashgate, 1999); M. Abecassis, M. Adams, P. Adams *et al.*, 'Consensus statement on the live organ donor', *Journal of the American Medical Association*, 284 (2000), 2919–26.

[21] J. Martínez, J. López, A. Martin *et al.*, 'Organ donation and family decision-making within the Spanish donation system', *Social Science and Medicine*, 53 (2001), 405–21.

[22] I. Kennedy, R. Sells, A. Daar *et al.*, 'The case for "presumed consent" in organ donation', *Lancet*, 351 (1998), 1650–2; J. Radcliffe-Richards, A. Daar, R. Guttmann *et al.*, 'The case for allowing kidney sales', *Lancet*, 351 (1998), 1950–2; R. Gimbel, M. Strosberg, S. Lehrman *et al.*, 'Presumed consent and other predictors of cadaveric organ donation in Europe', *Progress in Transplantation*, 13 (2003), 17–23.

[23] J. Childress, 'Putting patients first in organ allocation', *Cambridge Quarterly of Healthcare Ethics*, 10 (2001), 365–76.

[24] A. Farrell, 'Adding value? EU governance of organ donation and transplantation', *European Journal of Health Law*, 17 (2010), 51–79.

[25] Commission of the European Communities, Commission staff working document: accompanying document to the Communication from the Commission to the European Parliament and the Council: organ donation and transplantation: policy actions at EU level: summary of the Impact Assessment (SEC(2007) 705, Brussels, 30 May 2007).

this situation has developed, and whether a way forward can be found to redress it. Second, the UK is not alone in having to deal with a shortage of organs and, therefore, an examination of what may be done to address the issue is likely to have relevance beyond this national context. Third, the inspiration for this book derives from a seminar series funded by the UK's Economic and Social Research Council (ESRC) which ran for a period of eighteen months between October 2006 and March 2008. It brought together a diverse range of participants from various academic and practitioner backgrounds to examine the issue of organ shortage, with a particular focus on the UK context. The majority of the contributors to the book participated in the seminar series. Those contributors whose brief is to examine how the issue of organ shortage has been addressed elsewhere (e.g. in other European countries and in North America) will also focus on what can be learned from the approaches taken in their own national settings to inform UK policy-making on the issue.

The chapters in this book all examine ethical, legal and social concerns regarding the shortage of organs for transplantation. As a result, a diverse range of issues is examined within individual chapters. In Part I, the chapter by Margaret Brazier and John Harris sets the scene by reviewing long-running ethical and legal controversies in debates about organ donation and transplantation, where they have often sat on opposing sides. Notwithstanding their differences, however, they both agree on the end to be achieved – more organs need to be made available for transplantation. With this in mind, they propose a way forward towards ethical compromise in order to facilitate the achievement of this desired end, which may in turn enable others to develop realistic and pragmatic options for increasing the number of donated organs for transplantation.

Part II groups together a series of chapters which focus on issues which have not been fully addressed in UK government policy-making and initiatives in relation to increasing organ donation. In Chapter 3, Gurch Randhawa tackles an historically neglected issue in discussions on organ shortage, namely how it impacts upon particular ethnic or minority groups. He draws on a case study of South Asian and Afro-Caribbean groups in the UK, who suffer from a higher rate of renal failure than the Caucasian population and are disproportionately represented on UK organ transplant waiting lists, but who are also relatively less frequent organ donors. Indeed, rates of family refusal of donation amongst these populations are considerably higher than in the general population. Professor Randhawa emphasises the need to stimulate higher rates of organ donation amongst these populations at the same time as developing disease prevention strategies for avoiding organ failure. However, he also draws attention to the need for further research in many areas, exploring

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attitudes, treatment compliance, and referral, as well as socioeconomic and religious factors.

The next two chapters deal with the need for better education about organ donation and transplantation processes. These chapters show that we cannot draw and rely on the simplistic conclusion that more and better public education on its own is likely to be a panacea. Drawing on public engagement of science theories, Mairi Levitt argues in Chapter 4 that public education initiatives in the field of organ donation need to be integrated into a more complete account of why organ transplantation is needed. With this in mind, more attention needs to be paid to the context in which decision-making about donation will ultimately be made. In addition, she questions the supply-focused nature of current education initiatives which allow the public rather than the government to be blamed for any failure to meet the demand for organs. In Chapter 5, Magi Sque and Tracy Long-Sutehall examine the reasons behind the high rate of refusal on the part of families when asked to donate organs from deceased family members. They recognise that the families of potential donors are critical to the organ donation process, but argue that they need to be recognised as bereaved individuals above all else, and be properly supported by staff educated in dealing with bereaved persons. The authors discuss families' concerns about the donation process itself, as well as its consequences. They argue that, if the rate of organ donation is to increase, then there is an urgent need for better understanding of the social processes that are part of the organ donation process. Decision-making in the context of a bereaved family is multifaceted and multidimensional. Awareness of what is actually involved in the process should be made clear through suitable education mechanisms, so that if the issue of organ donation is raised at the bedside of a dying relative, it is neither foreign nor intimidating to the grieving family.

Part III examines some of the key issues around which ethical and medical conflict have arisen in the context of organ donation and transplantation, as well as strategies that could potentially be employed to address such conflict. In Chapter 6, Muireann Quigley provides an ethical perspective on the issue of incentivisation in organ donation. She considers general ethical issues surrounding the use of individual and institutional incentives to try and increase rates of organ donation. She argues that we need to accept that the essential purpose of incentives is to alter the decision-making process and to tip the balance in favour of donation. This, however, does not in itself render unethical the use of certain incentives. In accepting the need for incentives to act as encouragement to individuals or their families, she further argues that there is a need to let go of the idea that donations ought only to be motivated by altruistic

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ideals. This chapter briefly considers the creation of incentives, recently introduced in Israel, to donate by enhancing the likelihood of receipt of an organ in the event that one is needed. She warns that the widespread implementation of any incentive scheme, however, would need to be subject to ongoing empirical evaluation in order to determine whether or not it would actually achieve an increase in the supply of organs for transplantation, and whether it would result in any distorting or adverse effects. Following on from this contribution, Antonia Cronin observes in Chapter 7 that the shortage of organs means that it is not always possible to find the 'ideal' donor and, in light of this, examines the use of marginal donors in organ transplantation. Informed by her professional experience as a transplant clinician, she reviews the available empirical research on the use of such donors and assesses the outcomes resulting from the use of their organs in transplantation. She analyses the ethics involved in making decisions to use marginal donors and argues that what may have appeared at the outset to be a muddled compromise in addressing the problem of organ shortage has in fact legitimate utility in the absence of current real alternatives. In making such an argument, however, she points out that the resort to the use of marginal donors draws attention to the need for full consideration to be given to policy measures relating to organ donation which could substantially increase the supply of organs in the first place.

In Chapter 8, Phil Dyer and Sheelagh McGuinness examine the issue of organ allocation. An overview of the evolution of the allocation system in the UK and its current criteria is provided, as well as an analysis of its benefits and its shortcomings. The overview is informed by Phil Dyer's long-term involvement in transplantation medicine, both as a scientist and as a participant on relevant professional representative bodies. The authors provide an illuminating account of the medical and biological constraints within which such a system operates. They analyse critically the background assumptions implicit in the criteria used, arguing that allocation decisions cannot be made on purely medical or scientific grounds. For example, they argue that whilst justice is an important factor in allocation, benefit and utility must also be weighed in the balance to optimise each donation. In Chapter 9, John Coggon and Paul Murphy examine some of the difficult issues faced by intensive care clinicians when involved in decision-making about the care of patients who may potentially become organ donors. In this regard, Paul Murphy brings his extensive practical experience as a senior intensivist to bear on the subject matter examined. Specifically, the authors consider legal and ethical concerns regarding ante-mortem interventions that may facilitate posthumous organ donation. While they concede that greater ethical and legal clarity is

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needed in this area, they argue that where a patient's values support deceased donation, measures aimed at optimising the chances of successful organ transplantation will not contravene physicians' duties toward their patients. The authors show that a broad interpretation of the concept of best interests as understood in English common law, embracing as it does a plurality of values, supports this position.

Part IV focuses on best practices and current initiatives in organ donation and transplantation processes in a number of other Western countries. The overarching aim of this Part is to provide country case-study examples which could potentially be drawn upon and/or adapted for use in other countries to increase organ donation. In Chapter 10, Mónica Navarro-Michel examines the 'Spanish Model', which has enjoyed spectacular success in recent years in terms of increasing the rate of deceased organ donation both in Spain and in other countries which have adopted the model. She provides an overview of how the model works in practice, in conjunction with the legally mandated opt-out system for organ donation which operates in Spain. She considers whether the legal framework is a key factor in the substantial increase in the rate of organ donation in Spain, but goes on to argue that what was crucial to the success of the Spanish Model was the implementation of institutional and organisational reforms to the organ donation and transplantation system, rather than the law on its own. In order to illuminate which elements of the model can potentially lead to success, she examines the case studies of Italy (e.g. Tuscany), Australia and Latin America, which have adopted some of the key elements of the Spanish Model. She concludes by considering whether any, and if so which, aspects of the Spanish Model could usefully be transferred and implemented in the UK context.

In Chapter 11, Salla Lötjönen and Nils Persson examine kidney organ donation and transplantation processes in a discrete regional area – the Nordic countries – comprised of Denmark, Finland, Iceland, Norway and Sweden. Nils Persson's expertise and professional experience as a transplant surgeon inform the analysis. The authors trace the history of organ donation and transplantation processes and legislation in each of these countries. They argue that despite the organisational commitment towards a regional approach, and a generally homogenous population in the Nordic countries, national sociocultural, medical and legal differences prevail, resulting in differing rates of both living and deceased organ donation as between the countries. They analyse the reasons for these disparities, particularly in relation to the use of living organ donors, and assess the usefulness of a regionally based approach.

Chapters 12 and 13 focus on recent experiences in North America. In the first of these chapters, Linda Wright and Diego Silva provide an