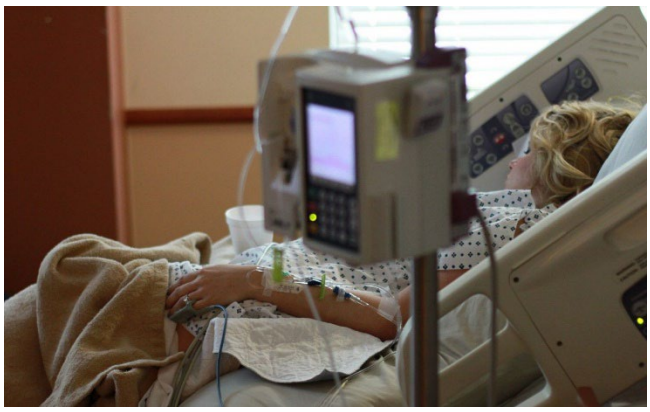
UK Parliament POST

POSTNOTE

Number 641 April 2021

Living organ donation



Living organ donation leads to better patient outcomes and is more cost-effective than deceased organ donation but it carries potential risks to the donor. This POSTnote describes the scale and nature of living organ donation in the UK and analyses ethical considerations, existing barriers and policies set out to increase living donor activity.

Overview

- In the past 20 years, living organ donations performed in the UK have trebled, accounting for 35% of transplants in 2019.
- Kidneys are the main organ donated by living donors. The UK Living Kidney Sharing Scheme is world leading for maximising the number of living donations.
- Health inequalities are prevalent in living organ donation and originate from interacting factors such as ethnicity and socio-economic deprivation.
- Opportunities to increase living organ donation include engaging with communities and improving health education.
- The next NHS Blood and Transplant organ donation strategy is due to be published in Spring 2021.

Background

Despite the total number of organ donors increasing by 56% over the past decade, organ supply still does not meet demand in the UK.[1] Between April 2019 and March 2020 there were over 6,000 patients registered on the transplant waiting list, of which 88% were in need of a kidney or liver.[1] In this time, 1,118 of them died or became ineligible for transplantation while waiting.[2] Living organ donation (LOD) refers to the donation of an organ (such as a kidney or a lobe of the liver) from a living donor. It provides an alternative to receiving an organ from a deceased donor (PN 441). It offers better patient outcomes and a more cost-effective approach compared with deceased donation, but carries potential risks for the donors.[3–5] In 2019, LOD accounted for 35% of all transplant activity in the UK.[3,6] The number of living organ donors has trebled in the past 20 years, stabilising at around 1,000 donors per year.[1,7]

To increase the rates of consent for deceased donation, England introduced an opt-out system in May 2020 following the Organ Donation (Deemed Consent) Act 2019.[8] This means all adults in England are now considered to have agreed to be an organ and tissue donor when they die unless they have recorded a decision not to donate.[8,9] However, the deceased's relatives can override this if they provide evidence that the deceased did not wish to become a donor.[10,11] There is a complex regulatory framework with different policies across the devolved nations (Box 1). Wales was the first UK nation to switch to an opt-out system. Evidence suggests that deceased-donor consent rates in Wales have increased significantly since this change.[12–14] However, this is not reflected in a rise in eligible donors overall, as their organs may not be healthy enough to be donated.[12] A longer period of time is needed to draw further conclusions, though research comparing countries with opt-in versus opt-out systems suggest no significant difference in deceased donation or transplant activity.[15,16]

Rate of living organ donation

A living-donor transplant (LDT) is a surgical procedure to remove an organ, or portion of an organ, from a living person and implant it in another person whose organ is no longer functioning properly.[6] The organ most frequently donated by a living person is a kidney.[17,18] In 2019/20, 98% of LDTs in the UK were kidney transplants whilst the remaining 2% were liver transplants.[18,19] Despite similarities in laws and requirements, these procedures have differing levels of associated risks.

Living liver donation

Liver disease is one of the biggest causes of death in the UK.[20,21] Liver transplant is the only cure for liver failure as no device can replace liver function long-term.[20,22] In 2019/20, 981 people received a liver transplant from a deceased donor across the seven liver transplant centres in the UK.[23] As of March

The Parliamentary Office of Science and Technology, Westminster, London SW1A 0AA
02072192840 **post@parliament.uk** **parliament.uk/post** **@POST_UK**

2020, there were 446 patients waiting for a liver.[23] The average waiting time for a deceased donor liver was 4.5 months.[19,24]

Living–Donor Liver Transplants (LDLTs)
A living donor can donate one of the four lobes of their liver.[22] LDLTs are associated with comparable outcomes to deceased donor transplants, but operations are likely to take place at an earlier stage of disease progression in the recipient.[19,25] In 2019/20, there were 22 LDLTs in the UK, 16 of which were adult-to-child.[23] These are more common as a smaller amount of liver is needed to provide a child with full liver function.[26] Risks to both donor and recipient are significantly higher for adult-to-adult than adult-to-child transplants as more liver must be removed, and the liver will fail if insufficient mass of liver is transplanted.[26] Donor mortality rate increases from 1 in 1,000 to 1 in 200 with donations of a larger lobe of liver.[27]

Box 1: Regulatory bodies and legislations

Regulatory bodies and legal framework
Transplants performed in the UK from living donors must comply with the requirements of the relevant legislation (Human Tissue Act 2004 for England, Wales and Northern Ireland, and the Human Tissue (Scotland) Act 2006).[28,29] The Human Tissue Authority (HTA) is the regulator responsible for assessing all applications for living organ donation in the UK and granting licences to the transplant centres performing living organ donation.[30] For an application to be granted HTA approval, the donor must give consent freely and there must be no reward attached to the donation.[31] Consent for the removal of organs from living donors must comply with the requirements of the Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 in England, Wales and Northern Ireland.[32,33] The Human Tissue (Scotland) Act 2006 sets out requirements in Scotland in which the word 'authorisation' is used rather than 'consent'.[19,28,33]

Deceased donation: legislation in devolved nations
Each of the devolved nations has different legislation surrounding deceased organ donations.
- **Wales** introduced an opt-out system in 2015 following the Human Transplantation (Wales) Act 2013.[34]
- **Scotland** approved the Human Tissue (Authorisation) (Scotland) Act in 2019, which introduced an opt-out system in March 2021.[35]
- **Northern Ireland** retains an opt-in system in which individuals need to record their decision to become deceased donors. A public consultation on changing to an opt-out system closed in February 2021.[36]

Living kidney donation

In 2018, NHS England estimated that around 3 million people in the UK had Chronic Kidney Disease (CKD).[37,38] CKD progresses to kidney failure in 1 in 50 patients and requires therapies to replace kidney function.[39] This can be achieved through dialysis but the best option for eligible patients is a transplant from a living or deceased donor.[40] An individual can lead a healthy life with only one functioning kidney, though the risks involved with donation, such as surgery (including a 1 in 3,000 risk of death) and long-term complications, must be considered (see below).[41] There are 24 kidney transplant centres in the UK and, in 2019/20, 2,577 patients received a kidney from 1,506 deceased donors.[42] As of March 2020, there were 4,960 patients waiting for a kidney.[42] The average waiting time for a deceased-donor kidney transplant (DDKT) was 2.5–3 years.[43] In 2019/20, 1,001 patients received a kidney from a living donor.[42]

Advantages of Living Donor Kidney Transplant (LDKT)
LDKT has the highest survival rates at 10 years post-operation at 89%; for DDKT the figure is 77% and for dialysis is 44%.[3,4,44] Compared with DDKT, LDKT allows for better preparation as it offers patients a planned procedure, often with shorter hospital stays and quicker recovery times.[45] 40% of LDKTs are performed before a patient requires dialysis compared with 12% for DDKTs.[45] Due to the better outcomes of LDKTs and subsequent reduction in hospital visits, LDKTs are also the most cost-effective treatment for kidney failure on the NHS.[5,46] LDKTs save the NHS up to £25,800 per year post-operation when compared with dialysis.[5]

A transplanted kidney from a living-donor can last for over 40 years, though the average time is around 27 years.[46] In comparison, kidneys from DDKTs are functional for 15 years on average and patients are more likely to require several transplants in their lifetime.[47] Within 10 years, 18% of LDKTs are likely to fail, compared with 24% for DDKTs.[3] These patients will require another transplant and LDKTs offer better outcomes than DDKTs for any subsequent kidney transplants.[46]

Routes to living organ donation

NHS Blood and Transplant (NHSBT) is responsible for matching and allocating donated living organs via multiple routes:[48,49]
- **Directed donation.** A person donates an organ to a specific individual with whom they have a genetic or pre-existing relationship (a family member or friend).
- **Directed altruistic donation.** A person donates an organ to a specific individual with whom there is no prior evidence of genetic or pre-existing relationship. For example, donation to someone they met through social media.
- **Non-Directed Altruistic Donation (NDAD).** A person donates an organ to a complete stranger either on the NHS waiting list or in the UK Living Kidney Sharing Scheme (Box 2) to initiate a chain of transplants.
- **Paired/pooled donation.** When a potential donor/recipient pair are not compatible, they can be matched with another pair in the same situation. For example, if Donor 1 (D1) wants to donate to Recipient 1 (R1) and Donor 2 (D2) wants to donate to Recipient 2 (R2) but both couples are incompatible, they could be paired. Then, if D1 is compatible with R2 and D2 compatible with R1, donor organs can be swapped between recipients. When two pairs are involved, this is known as paired donation. When more pairs are involved in the swap, this is known as pooled donation. NDADs can kickstart a chain of transplants with one or two pairs in the middle and ending with a recipient on the transplant list. In 2019/20, 95 NDADs led to 146 patients receiving a kidney in this way (Box 2).[42]

Matching donors and recipients

Suitably matching donors and recipients is a key factor for successful transplantation. For a donor and recipient to be matched, they must meet a set of strict criteria that are determined through medical tests and consultation with a multi-disciplinary transplant team. Patients will be added to the national waiting list while they are searching for a living donor.

The internet (including social media and matching websites) is an emerging and controversial route to find living donors.

Criteria for living donor suitability

Once a potential donor has volunteered to be considered they must first undergo multiple tests to ensure that they are healthy enough (physically and psychologically) to donate.[50] This takes into account factors such as any existing or past medical conditions (for example high blood pressure, diabetes, obesity, hepatitis, cancer) and age.[50,51] The HTA evaluates donor understanding and their free and voluntary consent through an independent interview (Box 1).[33]

Compatibility

Donors are also assessed for their compatibility to their intended recipient through multiple processes.[52] The main criteria are blood type and the type of protein markers present on the surface of their organs (known as Human Leucocyte Antigens or HLAs).[53,54] As both are inherited from one's parents, donation within families often results in good compatibility.[52] After any transplant, medication is used to suppress the recipient's immune response to the donated organ, reducing the likelihood of rejection and prolonging transplant survival.[55]

Roughly 1 in 3 donor/recipient pairs are incompatible but, in some cases, incompatibility may be overcome through a treatment known as desensitisation.[56,57] This requires further medication to suppress the recipient's immune response.[58–60] Given that success rates are lower than when suitably matched, the UK Living Kidney Sharing Scheme (Box 2) is the preferred option for unsuitably matched kidney donations.[59,56,58,61]

Box 2: UK Living Kidney Sharing Scheme

The UK Living Kidney Sharing Scheme is a programme administered by NHSBT that enables kidneys from living donors throughout the UK to be 'swapped' for the benefit of patients waiting for a transplant.[62] Every 3 months, an algorithm finds the best combinations of recipients and donors that have agreed to join a paired/pooled scheme for donation.[62–65] Non-directed altruistic donation can begin a chain of donations, resulting in a patient on the national waiting list also receiving a donation from a living donor.[66] The scheme is anonymous and confidential, so people do not know who their donor or recipient is.[64,65] The UK's Living Kidney Sharing Scheme has enabled over 1,200 transplants since its inception in 2007.[64,66,67]

Timescales and logistics of matching

Assessments can take considerable time and require a multidisciplinary team of specialists (including clinicians, nurses psychiatrists and psychologists) to examine different aspects of donor health and suitability.[68] Current targets aim for evaluations to be completed within 18 weeks, but in 2016 the average timeframe was 10 months.[26,69] In 2010, a transplant centre in Northern Ireland implemented a streamlined one-day assessment process to perform all the medical tests in a single hospital visit.[70] This has been reported, among others, as a key factor in the large and sustained increase observed in living donation rates in Northern Ireland.[70]

Waiting lists

Patients requiring a transplant are added to the NHS national waiting list. Searching for or assessing living donor options does not affect a person's position on the list.[71] The majority of patients on this list will receive a donation from a deceased donor, although in some cases patients on the national kidney waiting list can benefit from the UK Living Kidney Sharing Scheme (Box 2).[72]

Altruistic donation and the internet

Many stakeholders expected the use of the internet to increase the number of directed altruistic donations but expressed concerns around associated ethical challenges.[73] These include altruistic donors potentially choosing themselves the 'most deserving' recipient or a rise in transplant tourism (Box 3).[74] In the UK, it is legal to place an advertisement seeking a living donor providing there is no reward, payment or material advantage to the donor. NHSBT and the HTA both offer guidance to donors and recipients who intend to place such an advertisement to ensure these laws are adhered to.[75–78] There are two main routes that may be used to find donors online:

- **Social media** may be used to find potential altruistic donors but this is rarely done in the UK.[79] Because of logistical difficulties, transplant centres are not obliged to consider all potential donors who come forward from these methods. However, there have been occasions where multiple donors have come forward through social media and those not matched to their desired recipient chose instead to donate to a stranger through non-directed altruistic donation.[79]
- **Matching websites** are accessible in the UK but are not yet accepted by the NHS as a valid route for finding a donor due to concerns over ethical challenges (see above).[76] There are 458 UK-based registered users on the most popular US matching site, which claims to meet NHS guidelines concerning zero fees and website regulation.[80,81]

Further ethical considerations

Donor risks and autonomy

A few academics debate whether the risks introduced to an otherwise healthy donor present a conflict with a doctor's obligation to cause no harm. LOD is allowed only when donor risks are outweighed by the benefits to the recipient and to wider society (through reduced numbers on the waiting list and a healthier population).[82–84] LDKTs are not associated with excess donor mortality, kidney failure or other diseases during 10 years of follow-up.[85,86] However, surgery carries risks that cannot be eliminated (see above).[17,83,86] Individual autonomy is key for a donor's decision-making and motivation to donate.[87–89] Despite the lack of physical benefit for donors, many describe a psychological gain in knowing that their decision has transformed someone else's life.[17,83,90] Donating can also improve a donor's quality of life.[91] For example, if the donor is the carer of the recipient, fewer dialysis appointments would result in more free time for both.[91]

Promotion of living organ donation

There are some concerns about actively promoting LOD within society (for instance through promotional materials) and whether it is justified.[74] Some believe doctors should only provide balanced and impartial information about a patient's options.[83] The majority of the medical community consider promotional materials to be a means of informing individuals and increasing awareness of LOD rather than endorsing it.[92,93] Given donors can only consent after discussing all the

implications of LOD with medical specialists and following independent assessment by the HTA, donor free will is arguably protected.[48]

Box 3: Transplant tourism

The World Health Organization defines transplant tourism as obtaining an organ through overseas transplantation by means that contravene the regulatory frameworks of one's own country.[94,95] It is a worldwide legal, ethical and economic issue.[94] Evaluating the scale of this phenomenon is difficult as it relies on people voluntarily declaring it to the authorities.[96]

- According to NHSBT, 395 UK residents travelled abroad to receive a kidney transplant and subsequently returned to the UK for further care between 2000–2016.[97] 60% of these received a kidney from an unrelated or unspecified living donor.[97]
- Patients may return to the UK requiring further care if their transplant is not performed to adequate standards, putting extra strain on the NHS.[98,99]
- Without the HTA being able to assess both donor and recipient before transplantation, evaluations may not be as rigorous and questions arise about the ethics, consent and motives for such procedures.[100]

Transplant tourism is believed to be a major driver for forced organ harvesting worldwide (CDP 2019-0069).[101–103] Organisations such as Doctors Against Forced Organ Harvesting have campaigned for tighter regulation of such practice.[104] In January 2020, a Private Members' Bill was introduced in the House of Lords to amend the Human Tissue Act 2004 to make organs sourced abroad liable to the same scrutiny as those sourced in the UK.[105,106]

Health inequalities in living organ donation

The NHS defines health inequalities as unfair and avoidable differences in health across the population, and between different groups within society.[107] They arise from a range of interacting factors (such as ethnicity or socio-economic background) and affect different aspects of LOD.[107]

Living organ donation and minority ethnic groups

Risk factors associated with chronic kidney and liver disease are more common amongst certain minority ethnic groups, which make them more likely to need a transplant.[108–112] For example, type 2 diabetes (which can lead to CKD) is six times more likely in South Asian communities and three times more likely in African and African-Caribbean communities than in White people.[113]According to NHSBT, there were 1,909 people from Black Asian and minority ethnic (BAME) communities actively waiting for an organ transplant as of February 2020.[114] This is the highest number for 5 years and accounted for 32% of the national waiting list, despite minority ethnic communities representing only 13% of the UK population.[112,114–116] Although matching donors and recipients from different backgrounds is possible, for many the best match will come from a donor of the same ethnic background as they are more likely to have matching blood groups and tissue types.[117] According to NHSBT, donation rates from BAME communities are lower than from White people.[118] In 2019/20, 9.7% of LDTs were from Asian donors, 4.1% from Black donors and 4.3% from other ethnicities.[112] The number of deceased BAME donors has increased over the past 5 years from 80 to 121 annually while the number of BAME living donors has remained fixed between 140–160 annually.[112] Uncertainty around religious permissibility and lack of trust in health professionals are two of the biggest attitudinal barriers to LOD amongst these communities.[119,120]

Living organ donation and socio-economic status

Individuals from socioeconomically deprived groups are more likely to have CKD and to require a transplant.[121,122] However, they are less than half as likely to receive LKDTs compared with less deprived populations.[123–126] There is no direct financial cost to an individual receiving or donating an organ.[127,128] Travel and accommodation costs along with loss of earnings are reimbursed to ensure donors are not financially worse off because of donation.[127,128] The factors deterring these communities from living donation are often not financial difficulties or location.[123] Barriers include lack of awareness and knowledge of LOD schemes, reduced patient empowerment and perceived lack of social support from family and friends.[123]

Public awareness and opinion

According to a 2020 NHSBT survey of 1,800 UK adults, over half (58%) of respondents were aware of living kidney donation.[129] When asked whether they would consider becoming a kidney donor, the majority (66%) agreed. Of these, 91% would consider donating to a family member while 48% would consider donating to a friend and 21% to a stranger.[129] All major stakeholders (such as clinicians, researchers and patient-focused charities) agree that promoting public awareness of organ donation, including the laws and regulations surrounding it, is crucial to increasing the number of donations and overall benefits for society.[84,88,130–133,134,135]

Strategies to increase living organ donation

An Organ Donation Taskforce was established in 2006 to identify barriers to both deceased and living organ donation.[7,136] In 2010, a UK-wide review of the LDKT programme led to the development of the 2010–2014 NHSBT UK Strategy for LDKT.[137] Its main goal was to improve LDT activity to 18 per million people (pmp), which it achieved.[138] The Living Donor Kidney Transplantation Strategy 2020 was published in 2014 with the aim to reach LDT activity of 26 pmp by 2020. However, according to the NHSBT data, LDT fell just below 16 pmp in 2019.[138] Reasons for this may include an increase in deceased donations.[79] The new 10-year strategy for Organ Donation and Transplantation in the UK is due to be published in spring 2021.

Initiatives to tackle health inequalities

The NHSBT strategy set out a series of initiatives to increase the number of living organ donors from minority ethnic groups and socio-economically deprived communities. For example, a 2017 NHSBT campaign to target BAME communities included investing into the National BAME Transplant Alliance to address myths about LODs through trusted community organisations.[109,139–141] The Faith and Organ Donation Action Plan also promoted dialogue about LOD between faith leaders and their communities.[141] Another more recent project includes specialist visits to a patient's home to nurture conversation with friends and family about transplantation and living kidney donation.[142,143] After being shown to reduce disparities in living donor activity in countries such as the US and the Netherlands, these methods are currently being trialled in the UK.[144,145]

References

1. Organ Donation and Transplantation Activity Report 2019/20. Section 2 Overview of Organ Donation and Transplantation.
2. Organ Donation and Transplantation Activity Report 2019/20. Section 1 Summary of Donor and Transplant Activity.
3. Organ Donation and Transplantation Activity Report 2019/20. Section 11 Survival Rates Following Transplantation.
4. What are Survival Rates for Patients on Dialysis? - Renal Fellow Network.
5. Cost-effectiveness of transplantation. NHS Blood and Transplant.
6. Living Donor Kidney Transplantation 2020: A UK Strategy.
7. Organs for Transplants A report from the Organ Donation Taskforce 2008. 66.
8. Organ Donation (Deemed Consent) Act 2019.
9. What is the opt out system? (Excluded groups include people under 18, people who have lived in England for less than 12 months and those who lack capacity to understand the change in law). *NHS Organ Donation*.
10. Consent for organ and tissue donation after death| Royal College of Nursing. *The Royal College of Nursing*.
11. HTA Code of Practice F Part Two - Deceased Organ and Tissue Donation.
12. Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report.
13. Noyes, J. *et al.* Short-term impact of introducing a soft opt-out organ donation system in Wales: before and after study. *Open Access*, 9.
14. Madden, S. *et al.* (2020). The effect on consent rates for deceased organ donation in Wales after the introduction of an opt-out system. *Anaesthesia*, Vol 75, 1146–1152.
15. Arshad, A. (2019). Comparison of organ donation and transplantation rates between opt-out and opt-in systems. *Clin. Investig.*, 8.
16. Rieu, R. (2010). The potential impact of an opt-out system for organ donation in the UK. *J. Med. Ethics*, Vol 36, 534–538.
17. British Transplant Society Guidelines for Living Donor Kidney Transplantation June 2018.
18. Organ Donation and Transplantation Activity Report 2019/20. Section 3 Organ Donation Activity.
19. Could I be a living liver donor? NHS Blood and Transplant.
20. British Liver Trust Liver Disease Crisis. *British Liver Trust*.
21. Deaths registered in England and Wales - Office for National Statistics.
22. NHS Blood and Transplant Liver. *Organ transplantation*.
23. Organ Donation and Transplantation Activity Report 2019/20. Section 8 Liver Activity.
24. NHS Blood and Transplant: Liver Transplant Report 2019/20.
25. Live Donor Liver Transplantation - King's College Hospital, NHS Foundation Trust.
26. British Transplantation Society Living Donor Liver Transplantation Guidelines.
27. NHS Blood and Transplant Living donor liver transplant. *nhsbt.nhs.uk*.
28. Human Tissue (Scotland) Act 2006. Statute Law Database.
29. Human Tissue Authority Human Tissue Act 2004. *hta.gov.uk*.
30. Human Tissue Authority Organ donation and transplantation. *hta.gov.uk*.
31. HTA Code of Practice F Part One - Living Organ Donation.
32. The Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006. Queen's Printer of Acts of Parliament.
33. Human Tissue Authority Living organ donation: Legal Framework. *hta.gov.uk*.
34. Human Transplantation (Wales) Act 2013. Queen's Printer of Acts of Parliament.
35. Human Tissue (Authorisation) (Scotland) Act 2019.
36. (2020). Public Consultation Document on the introduction of a statutory opt-out system for organ donation for Northern Ireland | Department of Health. *Health*.
37. BMJ Best Practice, Chronic kidney disease, bestpractice.bmj.com.
38. Kidney Care UK Facts and Stats. *www.kidneycareuk.org*.
39. Kerr, M. Chronic Kidney Disease in England: The Human and Financial Cost. 44.
40. Vanholder, R. *et al.* (2017). Reducing the costs of chronic kidney disease while delivering quality health care: a call to action. *Nat. Rev. Nephrol.*, Vol 13, 393–409. Nature Publishing Group.
41. Become a living donor. *NHS Organ Donation*.
42. Organ Donation and Transplantation Activity Report 2019/20. Section 5 Kidney Activity.
43. (2017). Kidney transplant - Waiting list. *nhs.uk*.
44. Steenkamp, R. *et al.* (2015). UK Renal Registry 17th Annual Report: Chapter 5 Survival and Cause of Death in UK Adult Patients on Renal Replacement Therapy in 2013: National and Centre-specific Analyses. *Nephron*, Vol 129, 99–129.
45. Sharma, V. *et al.* (2019). Living donor kidney transplantation: often a missed opportunity. *Br. J. Gen. Pract.*, Vol 69, 428–429. British Journal of General Practice.
46. Bellini, M. I. *et al.* (2020). Living Donor Kidney Transplantation Improves Graft and Recipient Survival in Patients with Multiple Kidney Transplants. *J. Clin. Med.*, Vol 9,
47. American Kidney Fund Deceased donor transplant. *kidneyfund.org*.
48. Human Tissue Authority Roles of the HTA and NHSBT. *hta.gov.uk*.
49. Human Tissue Authority Types of living organ donation. *hta.gov.uk*.
50. (2015). General Information on Living Donation. *National Kidney Foundation*.
51. NHS Blood and Transplant Kidney donor health considerations. *organdonation.nhs.uk*.
52. Great Ormond Street Hospital for Children Tissue typing for kidney donation. *gosh.nhs.uk*.
53. Kidney Offering Scheme. *ODT Clinical - NHS Blood and Transplant*.
54. Anthony Nolan HLA typing and matching guidelines. *anthonynolan.org*.
55. The Renal Association (2010). Clinical Practice Guidelines. Vol 5th Edition,
56. Süsal, C. *et al.* (2017). Desensitization and survival in kidney transplant recipients. *Nat. Rev. Nephrol.*, Vol 13, 196–198. Nature Publishing Group.
57. Sethi, S. *et al.* (2017). Desensitization: Overcoming the Immunologic Barriers to Transplantation. *J. Immunol. Res.*, Vol 2017,
58. Guy's and St Thomas' NHS Foundation Blood group incompatible kidney transplant. *guysandstthomas.nhs.uk*.
59. Patient Information - Incompatible Living Kidney Donation. Renal Transplant Department, East and North Herefordshire NHS Trust.
60. Barnett, A. N. R. *et al.* (2014). Tailored desensitization strategies in ABO blood group antibody incompatible renal transplantation. *Transpl. Int. Off. J. Eur. Soc. Organ Transplant.*, Vol 27, 187–196.
61. Pankhurst, L. *et al.* (2017). The UK National Registry of ABO and HLA Antibody Incompatible Renal Transplantation: Pretransplant Factors Associated With Outcome in 879 Transplants. *Transplant. Direct*, Vol 3,

62. NHS Blood and Transplant: UK Living Kidney Sharing Scheme.
63. Imperial College London How UK Living Kidney Sharing Schemes mean more patients can receive life-changing transplants. *www.imperial.nhs.uk*.
64. UK's living kidney sharing scheme hits 1000th transplant milestone. *NHS Organ Donation*.
65. Manlove, D. (2018). How Operational Research Helps Kidney Patients in the UK. *Impact*, Vol 2018, 16–19. Taylor & Francis.
66. Ferrari, P. *et al.* (2015). Kidney paired donation: principles, protocols and programs. *Nephrol. Dial. Transplant.*, Vol 30, 1276–1285.
67. Biró, P. *et al.* (2019). Building Kidney Exchange Programmes in Europe—An Overview of Exchange Practice and Activities. *Transplantation*, Vol 103, 1514–1522.
68. British Transplantation Society Living-Donor Kidney Transplantation Guidelines 4th Edition.
69. Bailey, P. K. *et al.* (2017). A multicenter cohort study of potential living kidney donors provides predictors of living kidney donation and non-donation. *Kidney Int.*, Vol 92, 1249–1260.
70. Graham, J. M. *et al.* (2018). The Adoption of a One-Day Donor Assessment Model in a Living Kidney Donor Transplant Program: A Quality Improvement Project. *Am. J. Kidney Dis. Off. J. Natl. Kidney Found.*, Vol 71, 209–215.
71. (2016). The Kidney Transplant Waitlist – What You Need to Know. *National Kidney Foundation*.
72. Kidney Care UK Transplantation. *kidneycareuk.org*.
73. Give a Kidney Past and future of altruistic kidney donation. *Give a Kidney*.
74. Moorlock, G. (2015). Directed altruistic living donation: what is wrong with the beauty contest? *J. Med. Ethics*, Vol 41, 875–879. Institute of Medical Ethics.
75. Organ donation social media. *NHS Blood and Transplant*.
76. Human Tissue Authority Living organ donation matching websites and social media. *hta.gov.uk*.
77. Appealing for a kidney on social media if you or someone you know needs a transplant - NHSBT.
78. Responding to an appeal on social media - NHSBT.
79. NHSBT, Personal Communication.
80. Matching Donors. *matchingdonors.co.uk/*.
81. MatchingDonors.com, Personal Communication.
82. Donating a Kidney to a Stranger: A Review of the Benefits and Controversies of Unspecified Kidney Donation | Ovid.
83. Glannon, W. Is it unethical for doctors to encourage healthy adults to donate a kidney to a stranger?
84. Institute of Medicine (2006). Organ Donation: Opportunities for Action. The National Academies Press.
85. Krishnan, N. *et al.* (2020). Comparison of Medium-term Outcomes of Living Kidney Donors With Longitudinal Healthy Control in the United Kingdom. *Transplantation*, Vol 104, e65–e74.
86. Kiberd, B. A. *et al.* (2017). Lifetime risks of kidney donation: a medical decision analysis. *BMJ Open*, Vol 7, e016490. British Medical Journal Publishing Group.
87. Affairs, A. C. on E. and J. (2012). AMA Code of Medical Ethics' Opinions on Organ Transplantation. *AMA J. Ethics*, Vol 14, 204–214. American Medical Association.
88. King, M. (2018). A Moral Framework for Living Donor Transplantation. *Journal of Medical Ethics blog*.
89. Wilkinson, T. M. Living Donor Organ Transplantation. *Ethics and the Acquisition of Organs*. Oxford University Press.
90. Clarke, A. *et al.* (2014). Understanding donation experiences of unspecified (altruistic) kidney donors. *Br. J. Health Psychol.*, Vol 19, 393–408.
91. (2019). 5 Big Benefits of Living Donation for the Donor. *National Kidney Foundation*.
92. NHS Blood and Transplant Organ donation campaigns. *organdonation.nhs.uk*.
93. Burnapp, L. *et al.* (2020). Raising awareness of unspecified living kidney donation: an ELPAT* view. *Clin. Kidney J.*, Vol 13, 159–165.
94. WHO | The state of the international organ trade: a provisional picture based on integration of available information. *WHO*. World Health Organization.
95. Broumand, B. *et al.* (2017). New Definition of Transplant Tourism. *Int. J. Organ Transplant. Med.*, Vol 8, 49–51.
96. Gonzalez, J. *et al.* (2020). Organ Trafficking and Migration: A Bibliometric Analysis of an Untold Story. *Int. J. Environ. Res. Public. Health*, Vol 17,
97. Preventing Organ Trafficking and Transplant Tourism in the UK - NHSBT.
98. Krishnan, N. *et al.* (2010). Organ Trafficking for Live Donor Kidney Transplantation in Indoasians Resident in the West Midlands: High Activity and Poor Outcomes. *Transplantation*, Vol 89, 1456–1461.
99. Akoh, J. A. (2012). Key issues in transplant tourism. *World J. Transplant.*, Vol 2, 9–18.
100. Report on the legislation regarding donation and transplantation of organs from living donors in eleven european countries.
101. Danovitch, G. M. *et al.* (2013). Organ Trafficking and Transplant Tourism: The Role of Global Professional Ethical Standards—The 2008 Declaration of Istanbul. *Transplantation*, Vol 95, 1306–1312.
102. DAFOH Short Report (May 2020) – Doctors Against Forced Organ Harvesting (DAFOH).
103. Lunn, J. *et al.* (2021). Forced live organ extraction in China.
104. Doctors Against Forced Organ Harvesting (DAFOH) – Promoting Ethics in Medicine.
105. Organ Tourism and Cadavers on Display Bill [HL] - Parliamentary Bills - UK Parliament.
106. News, E. (2020). Lord Hunt's All Party Amendment on Forced Organ Harvesting in China – Targeting Falun Gong, Uighurs, Political and Religious Dissidents – Debated In Parliament. Peers Demand That The Government Acts. *The International Coalition to End Transplant Abuse in China*.
107. NHS England » Definitions for Health Inequalities.
108. (2019). BAME Organ Donation: Why aren't there more donors? *London City Hall*.
109. Campaign to increase black and Asian organ donors - NHSBT 2017/18.
110. Schofield, P. *et al.* (2011). Ethnic differences in blood pressure monitoring and control in south east London. *Br. J. Gen. Pract.*, Vol 61, e190–e196.
111. Health and social care directorate Quality standards and indicators Briefing paper - NICE.
112. Organ Donation and Transplantation data for Black, Asian and Minority Ethnic (BAME) communities. Report for 2019/2020. NHS Blood and Transplantation.
113. Diabetes UK (2019) Us, diabetes and a lot of facts and stats.
114. Record number of people from BAME backgrounds receiving lifesaving organs. *NHS Blood and Transplant*.
115. Ethnicity and religion statistics. *Institute of Race Relations*.
116. Race Disparity Audit Ethnicity facts and figures. *gov.uk*.
117. Organ donation and ethnicity. *NHS Organ Donation*.
118. London Assembly Health Committee - Bame Donor Report.
119. Morgan, M. *et al.* (2016). Increasing the acceptability and rates of organ donation among minority ethnic groups: a programme of observational and evaluative research on Donation, Transplantation and Ethnicity (DonaTE). NIHR Journals Library.

120. Wong, K. *et al.* (2020). Investigating Ethnic Disparity in Living-Donor Kidney Transplantation in the UK: Patient-Identified Reasons for Non-Donation among Family Members. *J. Clin. Med.*, Vol 9, 3751.
121. Rees, D. M. *et al.* Why are people who are socially deprived more likely to develop CKD than those who are not? 49.
122. Bailey, P. (2017). Socioeconomic deprivation and renal transplant: a literature review. *J. Kidney Care*, Vol 2, 6–13. Mark Allen Group.
123. Bailey, P. K. *et al.* (2016). Socioeconomic deprivation and barriers to live-donor kidney transplantation: a qualitative study of deceased-donor kidney transplant recipients. *BMJ Open*, Vol 6, e010605. British Medical Journal Publishing Group.
124. Hossain, M. P. *et al.* (2012). Social deprivation and prevalence of chronic kidney disease in the UK: workload implications for primary care. *QJM Mon. J. Assoc. Physicians*, Vol 105, 167–175.
125. Udayaraj, U. P. *et al.* (2010). Socio-economic status, ethnicity and geographical variations in acceptance rates for renal replacement therapy in England and Wales: an ecological study. *J. Epidemiol. Community Health*, Vol 64, 535–541.
126. Udayaraj, U. *et al.* (2012). Social deprivation, ethnicity, and uptake of living kidney donor transplantation in the United Kingdom. *Transplantation*, Vol 93, 610–616.
127. Policy Reimbursement of Expenses for Living Donors Updated August 2018.
128. Bailey, P. K. *et al.* (2016). What factors explain the association between socioeconomic deprivation and reduced likelihood of live-donor kidney transplantation? A questionnaire-based pilot case-control study. *BMJ Open*, Vol 6, e012132. British Medical Journal Publishing Group.
129. Kantar (2020). Organ Donation Attitudinal Tracker Wave 9, NHSBT (June 2020).
130. Smith, S. G. *et al.* (2013). Skill set or mind set? Associations between health literacy, patient activation and health. *PloS One*, Vol 8, e74373.
131. Taylor, D. M. *et al.* (2019). Limited health literacy is associated with reduced access to kidney transplantation. *Kidney Int.*, Vol 95, 1244–1252. Elsevier.
132. Taylor, D. M. *et al.* (2017). Education, health literacy, and inequity in access to transplantation: findings from the ATTOM cohort study. *The Lancet*, Vol 390, S88.
133. Schumacher, K. J. *et al.* (2020). Survey of Patient's Experience of Altruistic Nondirected Kidney Donation. *Saudi J. Kidney Dis. Transplant.*, Vol 31, 739.
134. Parsons, J. A. *et al.* (2020). A global pandemic is not a good time to introduce 'opt-out' for organ donation. *Med. Law Int.*, Vol 20, 155–166. SAGE Publications Ltd.
135. Busting the myths around opt-out organ donation. *The Nuffield Council on Bioethics*.
136. Working Together to Save Lives The Organ Donation Taskforce Implementation Programme's Final Report, 2011. *GOV.UK*.
137. Burnapp, L. Living Donor Transplantation The National Picture.
138. IRODaT - International Registry on Organ Donation and Transplantation.
139. Why black, Asian and minority ethnic donors are needed. *NHS Blood and Transplant*.
140. Living Transplant Initiative - Increasing living kidney donations among some BAME communities. NBTA.
141. Role of Religion in Organ Donation-Development of the United Kingdom Faith and Organ Donation Action Plan | Elsevier Enhanced Reader.
142. (2020). The ASK Trial - Trial Information Sheet.
143. ISRCTN registry ASK: Improving access to kidney transplantation.
144. Steenaart, E. *et al.* (2019). The effectiveness of an interactive organ donation education intervention for Dutch lower-educated students: a cluster randomized controlled trial. *Trials*, Vol 20, 643.
145. National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Health Sciences Policy; Committee on Issues in Organ Donor Intervention Research; Liverman CT, Domnitz S, Childress JF, (2017). Opportunities for Organ Donor Intervention Research: Saving Lives by Improving the Quality and Quantity of Organs for Transplantation. National Academies Press (US).