**Structured Abstract**

*Summary of Background data*

Unspecified kidney donation (UKD) describes living donation of a kidney to a stranger. The practice is playing an increasingly important role within the transplant programme in the United Kingdom, where these donors are commonly used to trigger a chain of transplants; thereby amplifying the benefit derived from their donation. The initial reluctance to accept UKD was in part due to uncertainty about donor motivations and whether the practice was morally and ethically acceptable.

*Objectives*

This article provides an overview of UKD and answers common questions regarding the ethical considerations, clinical assessment and how UKD kidneys are used in order to maximise utility. Existing literature on outcomes after UKD are also discussed, along with current controversies.

*Conclusions*

We believe UKD is an ethically acceptable practice which should continue to grow, despite its controversies. In our experience, these donors are primarily motivated by a desire to help others and utilisation of their kidney as part of a sharing scheme means that many more people seek to benefit from their very generous donation.

# Donating a Kidney to a Stranger: A Review of the Benefits and Controversies of Unspecified Kidney Donation

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Running head: A review of Unspecified Kidney Donation

## INTRODUCTION

For individuals with end-stage kidney disease a transplant is the only way of removing the need for renal replacement therapy. Countries differ in their laws, degrees of public engagement and financial investment in transplantation and support either or both living and deceased donation to varying degrees. A living donor kidney transplant~~ation~~ results in ~~better survival rates relative to dialysis, and~~ longer graft survival than a transplant from a deceased donor [1]. The term 'unspecified kidney donation' (UKD) (also known as 'altruistic' and 'non-directed donation') describes living donation of a kidney to a stranger [2]. Despite a lack of international consensus on the ethical and legal aspects of UKD, it has become an established practice in the United Kingdom (UK) and in the United States of America (USA), whilst remaining illegal in many countries across the world. ~~The practice also~~ It is making an increasingly significant contribution to the number of transplants generated through the UK Living Kidney Sharing Scheme (UKLKSS) and consequently plays a significant role in reducing waiting times for patients on the kidney transplant waiting list.

~~Despite its healthcare benefits and controversies, UKD is rarely discussed outside the transplant community.~~ The initial reluctance to accept UKD was in part due to uncertainty about donor motivations ~~what would motivate someone to accept the risks of major surgery in the interest of a complete stranger~~, and whether the desire to donate to a stranger ~~so~~ was psychopathological. Whilst increased clinical experience has significantly attenuated these fears, they have not yet been completely allayed [3].

## ETHICAL CONSIDERATIONS

For some clinicians, UKD is a logical extension of specified kidney donation (SKD), where a family member or friend is the donor. The common ethical hurdle for all living donation is that

in addition to contravening the primary principle ~~of medical practice~~ to 'first do no harm', it goes one step further ~~and places those~~ by placing harms and risks of surgery upon an otherwise healthy person for the benefit of someone else. The case for SKD is easier to argue because the recipient is known to the donor and it is not simply the harms to the potential donor and the benefits to the recipient that must be considered, but additionally the relative harms of not proceeding with living donation. For example, ~~it may be argued that~~ a parent ~~will~~ may experience greater harm from the death or continued suffering of their child than from the harms and risks of surgery to themselves. With respect to UKD, the ethical issues are further complicated by the absence of a relationship between donor and recipient. The potential benefits to the donor from the act of donation become more abstract and may draw on more general ethical obligations to do good, or to maximise overall utility when deciding how to behave.

We believe UKD is an ethically acceptable practice which should continue to grow, despite its controversies. ~~Evidence suggests that~~ In our experience, unspecified kidney donors (UKDrs) are primarily motivated by a desire to help someone in need; ~~with~~ the donation making little difference to them directly, but a significant difference to someone else [4]. The desire to donate is frequently in keeping with similarly benevolent behaviours elsewhere in the donor's life and ~~the choice to donate~~ appears to be a natural extension of their self-identity and sense of social responsibility [5]. These beliefs and characteristics may help to address some of the theoretical ethical concerns with the concept of UKD: their settled and stable preferences speak to the issue of whether UKDrs are likely to be appropriately autonomous; they appear to be consistently well motivated and virtuous; and, their apparently systematic approach to maximising benefits seems consistent with some form of utilitarianism.

## BECOMING AN UNSPECIFIED KIDNEY DONOR IN THE UNITED KINGDOM

Guidelines published by the British Transplantation Society (BTS) and Renal Association (RA) require that all living kidney donors undergo rigorous assessment [3]. The physical components are identical for unspecified and specified kidney donors (SKDrs) and determine whether an individual is fit enough to survive surgery, whether the kidney is suitable for transplantation and whether the donor's remaining kidney is likely to provide sufficient life-long renal function. After completion of standard tests potential donors are assessed by a nephrologist and a transplant surgeon before discussion at a multidisciplinary team meeting. Finally, the individual is interviewed by an Independent Assessor who is appointed and trained by the Human Tissue Authority to ensure that the legal requirements have been met and that no reward is being sought or offered, and ~~that there is~~ no coercion. The assessment of UKDrs and SKDrs does differ in the requirement for a formal mental health assessment, which is recommended for all UKDrs, ~~whereas it~~ but is optional for SKDrs [3]. ~~This is based on a consensus among mental health clinicians working within the field of transplantation and the format and justification for this is outlined in the BTS/RA Guidelines.~~

## MAXIMISING THE UTILISATION OF UNSPECIFIED DONOR KIDNEYS

Since 2018 all UKDr kidneys are directed towards the UKLKSS, provided that there is no compatible higher priority patient on the national transplant waiting list. The UKLKSS facilitates transplants between blood group and human leucocyte antigen (HLA) incompatible SKD donor-recipient pairs by exchanging kidneys with one or more other donor-recipient pairs or compatible pairs that seek a ~~. Compatible pairs may also register to achieve a~~ better HLA or age matched transplant. Donors and recipients are characterised by their demographic and clinical data prior to being entered into the scheme and optimal combinations of transplants are identified quarterly between the registered pairs using computer software.

UKDrs are used within the UKLKSS to trigger a chain of transplants (called 'altruistic donor chains') between two or more incompatible donor-recipient pairs (Figure 1). The remaining organ from the donor at the end of the chain is then allocated to a recipient on the national transplant list according to national allocation criteria. Incorporating UKDrs into the UKLKSS maximises the benefit derived from each donation by increasing the number of transplants it facilitates. For example, 89 UKDrs donated between April 2017 and April 2018, resulting in a total of 138 transplants. ~~This was possible due to 33 UKDrs (37.1%) being entered into donor chains, resulting in 82 transplants~~ [6]. The nature of the UKLKSS is such that it typically includes individuals who are more difficult to transplant and therefore provides opportunities for individuals ~~to have a living donor transplant~~ who otherwise may never receive a transplant ~~would never receive one~~ (i.e. due to immunological complexity), as well as increasing opportunities for all patients on the national transplant list. Due to the level of organisation required, sharing schemes such as these are likely only to be possible in countries with established transplant programmes. We are in favour of utilising UKDr kidneys in this way as it maximises the benefits of UKD with minimal additional risk.

## OUTCOMES AFTER UNSPECIFIED KIDNEY DONATION

Although there is a paucity of research, available evidence suggests that physical outcomes for UKDrs and SKDrs are comparable~~, despite UKDrs being on average 10 years older~~ [4]. Donors' psychological outcomes are also broadly similar, with little regret [4]. Some UKDrs report an increase in self-esteem and feel that donation became a positive emotional anchor that was referred to in times of difficulty [5 7]. UKDrs and SKDrs do differ significantly in levels of perceived social support [8], with UKDrs feeling less supported by family and friends. Lack of

support for donation and strong family objections have been anecdotally cited as reasons for withdrawing from the donation process.

The BTS/RA guidelines state that UKDrs and their intended recipients must remain unknown to each other prior to surgery, however anonymity may be broken post-transplant with the consent of all parties, who initially communicate through the transplant centres. UKDrs have different views on anonymity, but evidence suggests that the majority would like to receive some communication [4]. An issue of concern for both donors and the transplant community is the potential long-term detrimental effect of receiving news of a graft failure or death of the recipient [9].

**CONTROVERSIES**

Given the success of UKD programmes in the UK and USA, we do not consider the overall practice to be controversial. Current controversies relate to UKDrs who wish to donate another organ (such as a liver lobe), those who are terminally ill and those who are very young. Transplant professionals have raised concerns for young people coming forward as ~~potential~~ UKDrs, in particular those aged 18-25, questioning whether they possess sufficient maturity, life experience and wisdom to donate and whether there is greater potential for regret. Some UKDrs offering other organs to ~~have also come forward to offer a lobe of their liver to an~~ unspecified recipients have also caused concern, predominantly due to~~; the motivating factor being the desire to replicate the positive experience of donating a kidney. Concerns for this practice include~~ the additional risks associated with living donor liver surgery and the implication of complications on individuals with only one kidney.

Another issue within the UK are the broad differences in UKD rates across the country, ~~UK vary broadly~~ with currently over 50% of donations take place within just 5 out of 23 transplant centres [6]. ~~, some of which have otherwise relatively small living donor programmes. A concern amongst former UKDrs is that~~ UKDrs have highlighted some negative attitudes held by transplant professionals towards UKD (such as an assumption of psychopathological motives) and have expressed concerns that these may be prolonging the time it takes for them to donate or prohibiting some ~~potential donors from proceeding~~ individuals from donating. ~~The degree of variability in the numbers of UKDrs across the UK~~ These issues warrant~~s~~ empirical investigation and a national prospective multicentre study of UKD in the UK is currently underway ~~and aims~~ to address some of these issues [10].

## CONCLUSIONS

UKD is becoming increasingly routine in the UK, despite some continuing controversy. The utilisation of UKDrs within UKLKSS amplifies the benefits of this extraordinary gift given by well-motivated individuals who wish to help someone in need. ~~Similarly to specified donors, UKDrs are an invaluable asset to the kidney transplantation programme and make a significant contribution towards reducing the waiting list. Given the concerns that surround UKD,~~ The concerns surrounding UKD are understandable due to its unique nature and prospective studies that address these are necessary to support the wider transplant community to develop the programme with confidence for the benefit of potential donors and recipients.

## ACKNOWLEDGEMENTS

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## References

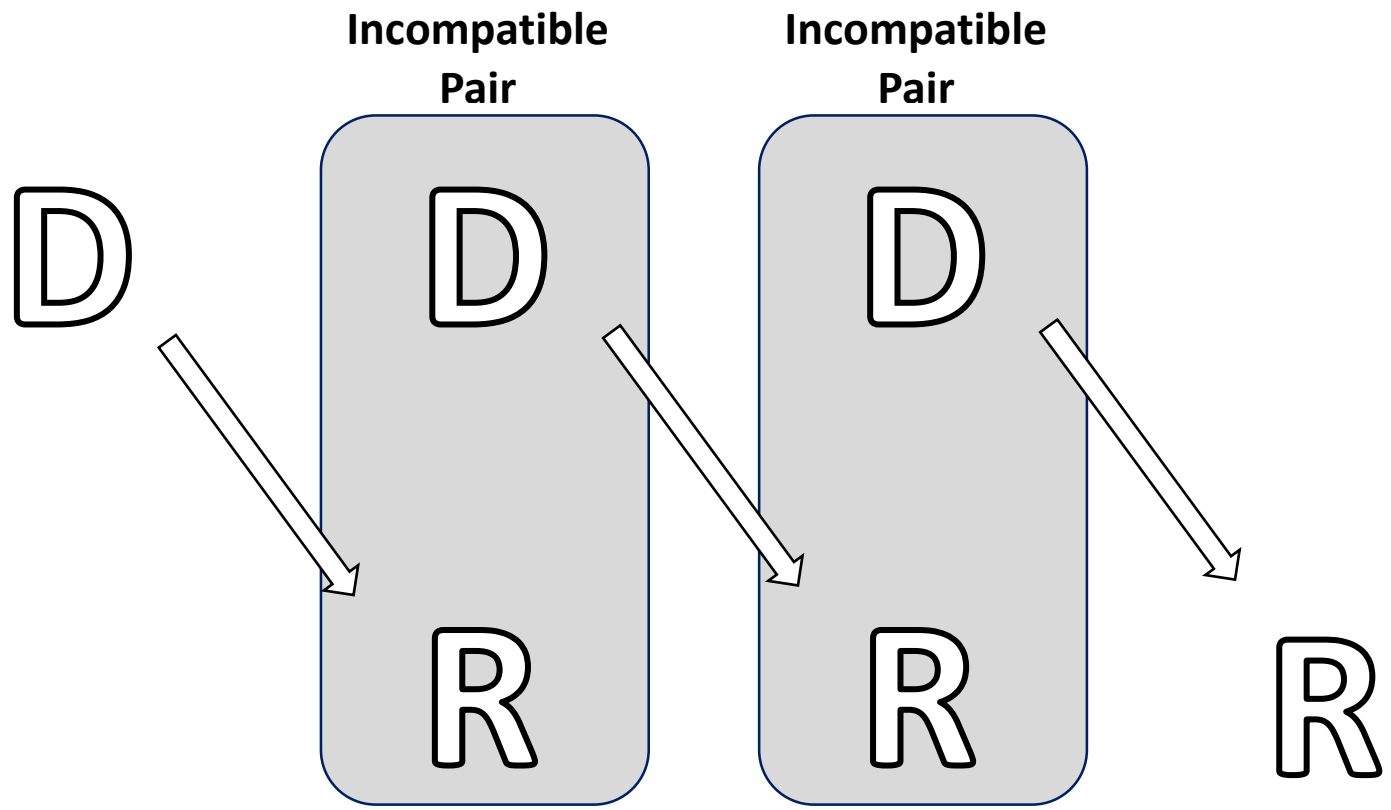

1. Barnett N, Mamode N. Kidney transplantation. *Surgery* 2011;29(7):330-35. doi: http://dx.doi.org/10.1016/j.mpsur.2011.04.002
2. Dor FJ, Massey EK, Frunza M, et al. New classification of ELPAT for living organ donation. *Transplantation* 2011;91(9):935-8.
3. British Transplantation Society and Renal Association. Guidelines for Living Donor Kidney Transplantation. Fourth ed, 2018.
4. Maple H, Chilcot J, Burnapp L, et al. Motivations, outcomes, and characteristics of unspecified (nondirected altruistic) kidney donors in the United Kingdom. *Transplantation* 2014;98(11):1182-9. doi: 10.1097/tp.0000000000000340 [published Online First: 2014/08/08]
5. Clarke A, Mitchell A, Abraham C. Understanding donation experiences of unspecified (altruistic) kidney donors. *Br J Health Psychol* 2014;19(2):393-408. doi: 10.1111/bjhp.12048 [published Online First: 2013/05/23]
6. NHS Blood and Transplant. Organ Donation and Transplantation Activity Report 2017/18. 2018
7. Tong A, Craig JC, Wong G, et al. "It was just an unconditional gift." self reflections of non-directed living kidney donors. *Clinical Transplantation* 2012;26(4):589-99. doi: http://dx.doi.org/10.1111/j.1399-0012.2011.01578.x
8. Jacobs CL, Roman D, Garvey C, et al. Twenty-two nondirected kidney donors: An update on a single center's experience. *American Journal of Transplantation* 2004;4(7):1110-16. doi: 10.1111/j.1600-6143.2004.00478.x
9. Mamode N, Lennerling A, Citterio F, et al. Anonymity and Live-Donor Transplantation: An ELPAT View. *Transplantation* 2013;95(4):536-41. doi: 10.1097/TP.0b013e31827e31f7
10. Gare R, Gogalniceanu P, Maple H, et al. Understanding barriers and outcomes of unspecified (non-directed altruistic) kidney donation from both professional's and patient's perspectives: research protocol for a national multicentre mixed-methods prospective cohort study. *BMJ open* 2017;7(9):e015971. doi: 10.1136/bmjopen-2017-015971 [published Online First: 2017/09/25]

**FIGURE LEGENDS**

Figure 1: Donation as part of an ‘Altruistic Donor Chain’ (ADC)

Figure

**Figure 1: Donation as part of an 'Altruistic Donor Chain' (ADC)**




Altruistic donor chains are created when a UKD donates to a recipient who has an incompatible living donor. That recipient's donor then donates to another recipient, and so on. The chain is terminated when a final living donor donates to an individual on the transplant waiting list. In the example above, an altruistic donor chain results in 3 transplants from 1 UKD.