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Running title: Critical review of patient information

Title: Patient information about Living Donor Kidney Transplantation across UK renal units: a critical review

Abstract

Background: Patient information about living donor kidney transplantation is used to supplement conversations between health professionals, people with advanced kidney disease and potential kidney donors. It is not known if information is designed to support decision making about renal replacement options or if it helps people discuss living kidney donation with family and friends.

Objective: Critical review of resources used in outpatient kidney consultations to support patients' decision-making about living kidney donor transplantation.

Design: Mixed methods including an audit questionnaire and critical analysis of patient information leaflets.

Participants & measurements: All kidney transplant centres and renal units in United Kingdom received a questionnaire to elicit by whom, how and when information about living kidney donation is delivered. Copies of leaflets were requested. A coding frame was utilised to produce a quality score for each leaflet.

Results: Thirty-nine (54%) units participated. Patients discussed living donor kidney transplantation with nephrologists (100%), living donor nurse (94%), transplant co-ordinator (94%) and pre-dialysis nurse (86%). Twenty-three leaflets were provided and reviewed, mean quality scores for inclusion of information known to support shared decision-making was m= 2.82 out of 10 (range 0-6, S.D.=1.53). Readability scores indicated they were 'fairly difficult to read' (M = 56.3 S.D.=9.4, range 0-100). Few included cultural and faith information. Two leaflets were designed to facilitate conversations with others about donation.

Running title: Critical review of patient information

Conclusions: Leaflets are unlikely to adequately support decision making between options and discussions about donation. Services writing and updating patient leaflets may benefit from our 6 principles to guide their development.

Keywords: advanced kidney disease, decision making, kidney transplant, living donor kidney transplantation, patient information.

Introduction:

In the United Kingdom (UK), living donor kidney transplantation (LDKT) is established as providing superior outcomes for people with advanced kidney disease (AKD) compared to deceased donor kidney transplantation (DDKT) and dialysis. LDKT offers an opportunity to plan for transplant without the necessity of dialysis, which provides both improved patient outcomes and is economically beneficial for healthcare services (Laupacis et al., 1996, Tonelli et al., 2011). Living Donor Kidney Transplantation is associated shorter hospital admissions, improved life expectancy and graft survival compared to deceased donor kidney transplantation (DDKT); and better quality of life and self-reported health status compared to DDKT and long-term dialysis (Terasaki et al., 1995, Kerr et al., 2012, Rodrigue et al., 2015, Bailey, 2016).

Whilst LDKT has numerous benefits for people with AKD, it is a complex decision involving various ethical and emotional considerations, in part because it necessitates input from a living kidney donor. To ensure that the donation process is entirely voluntary, kidney health professionals rely on people with AKD to initiate conversations with friends and family about considering kidney donation. People with AKD report that they find it difficult to initiate these conversations, lack the required knowledge of the procedure to discuss it with potential donors, and feel guilty and fearful about raising the subject (Kranenberg et al., 2007, Barnieh et al., 2011, Ahmed et al., 2021). Furthermore, decisions about LDKT are not made in isolation. People who are unable to find a donor, do not meet the eligibility criteria, or who find that their transplant is no longer able to sustain their health and quality of life, face additional decisions about deceased donor transplantation and dialysis. People making decisions about LDKT therefore require knowledge of all other renal replacement therapy options available to them.

Literature review:

United Kingdom kidney guidelines recommend disease and treatment information is designed to support people to make decisions and be available in different formats (National Renal Services Framework, 2004, Isnard Bagnis et al., 2015, NICE, 2018). Patient information in the form of leaflets, is used to supplement conversations between kidney professionals and people with AKD (Winterbottom et al., 2007, Isnard Bagnis et al., 2015, Van Den Bosch et al., 2015, Winterbottom et al., 2020). Given that health professionals are unable to talk directly to potential living kidney donors during the initial stages of the process, patient information leaflets may serve to bridge the gap between health professional and potential donor by facilitating conversations between potential recipients and potential donors as well as educating, preparing about treatment options and assisting both parties to make decisions about LDKT. Approximately one quarter of people with AKD have a limited ability to read, appraise and act upon health information (Taylor et al., 2017). Given the need for people with AKD to assess and communicate health information to potential donors, it is perhaps not surprising that people with limited 'health literacy' are less likely to receive a kidney transplant (Taylor et al, 2019). People from ethnic minorities also report lower health literacy levels and express uncertainty about their religion's and faith's stance on donation (Wong, 2010, Ismail et al, 2012). This may in part explain why this population is less likely to receive a timely transplant, yet there are more people from ethnic minorities with kidney disease (NHS Blood & Transplant, 2019).

Good quality patient information about LDKT must be be relevant, accurate, balanced, evidence based, comprehensive, accessible, and up to date (Coulter et al., 1998, Winterbottom et al., 2007, Treadgold & Grant 2014, Winterbottom et al., 2020). Further, information needs to be written and presented in a way that makes it easy to understand, includes visual aids and diagrams to help understanding, be readable, contain culturally sensitive information, be available in different languages and signpost to the same information for different audiences (College et al., 2008; Treadgold & Grant 2014).

Previous reviews have identified that patient information leaflets supporting people making dialysis and conservative management decisions are not designed in a way that supports kidney policy recommendations or patient information standards. They do not meet acceptable levels for readability, do not present treatment information in a balanced way, and are not written in ways known to support decision making (Winterbottom et al 2007, 2020). It is not known if information provided by kidney services about LDKT is able to support people with AKD to choose between renal replacement options or help people discuss living kidney donation with their family and friends. This study describes a critical review of the resources UK renal staff use when providing information about living donor kidney transplantation to people with advanced kidney disease in outpatient kidney consultations.

Methods

Design: Mixed methods survey of current practice, including an audit questionnaire and critical analysis of patient information in the form of leaflets about LDKT used by UK renal services. The questionnaire did not require ethical approval and was registered on a renal audit database.

Sample: All 71 UK renal units (identified from the Renal Registry 22nd Annual Report, 2020), NHS Blood & Transplant website, and four renal charities (Kidney Research UK, National Kidney Federation, Kidney Care UK and the National Black, Asian, Mixed Race, and Minority Ethnic Transplant Alliance), were eligible for participation. Patient information leaflets were included if they contained information about LDKT, were aimed at potential donors or recipients. Patient information leaflets focussing on deceased donor kidney transplantation, exchange programmes, altruistic donation, capacity and decision making, COVID-19 specific information, general information about chronic kidney disease, and Human Tissue Authority information were excluded.

Materials: An audit questionnaire was designed (Winterbottom et al., 2007, 2020) for staff to complete, which elicited details about by whom, how and when different types of information about LDKT is delivered, satisfaction with patient information leaflets and preferred method of communication about LDKT, availability of leaflets in different languages, inclusion of culturally specific information, and access to local translation services. Leaflets provided to supplement out-patient clinical encounters involving discussions about LDKT were requested. An invitation letter was developed to accompany the questionnaire. For the critical analysis of the patient information leaflets, a coding framework was developed with reference to renal policy guidelines (British Transplantation Society Guidelines, 2018, National Services Framework, 2004), previous critical analyses of dialysis modality and conservative management leaflets (Winterbottom et al, 2007, 2020; Morony et al.,2015), patient informed decision making standards (Bekker et al, 1999; Charnock et al., 1999, Joseph-Williams et al, 2014, Stacey et al., 2017) and patient information guidance (Flesch 1948; Ley,1988; Duman, 2013). The coding frame was piloted on 5 leaflets and the final version applied to each of the leaflets, eliciting the following content: 1) leaflet descriptors and purpose, 2) general information about AKD, description of LDKT, e.g. how to begin the process, description of donor andrecipient, requirements and contraindications for donation, purpose of treatment, ethical issues, 3) description of donor workup program, e.g. phases and details of testing, what happens if approved or not approved, other treatment options, 4) consequences of treatment, e.g. quality of life, impact on lifestyle issues, psychological issues, maintaining contact with renal services, health insurance, risks and success rates, 5) culturally sensitive information e.g., principles of different faiths, message from faith leaders, transplantation rates and waiting times by ethnicity, language/translation issues, geographical issues, information available in other languages 6) general leaflet format (16 items), 7) balance and biasing components (6 items), and 8) shared decision making components and communication prompts (10 items). All items scored '1' if described in the leaflet, '0' if not; total scores were calculated for sections 6-8 by adding up the scoring of items in each section to produce a quality score out of 16, 6 and 10 respectively. A minority of items in section 8 were reversed scored where the exclusion of certain information scored '1'. The Flesch Readability Ease Formula was applied to leaflets (0–100; difficult–easy to comprehend, Flesch, 1948), to provide a measure of how easy the information is to understand. Interpretation of the scores was aided by reference to newspapers to provide a comparable text with similar level of difficulty (Ley & Florio, 1996).

Procedure: *A web-based version of the audit questionnaire was emailed to n=24 centres where kidney transplantation surgery is conducted, via the Living Kidney Donor Network. This yielded a poor response (n=4). Subsequently all 71 renal units were sent the audit questionnaire via the postal service, addressed to the 'kidney transplant co-ordinator'* Respondents returned the questionnaire, and copies of the leaflets used to supplement conversations about LDKT, in a reply paid envelope. One reminder questionnaire was posted after two weeks, and an email was sent to remaining units one month after the written reminder. Information about LDKT available on 3 UK renal charity websites were included in the analysis. See Figure 1 for flow diagram of study recruitment.

Analysis: Coding frame score data were managed using the Statistical Package for the Social Sciences (SPSS, version 27, Chicago, IL, USA). Frequency and descriptive data summarized the responses from the questionnaire and leaflets' content analysis.

Results

Audit of renal service practice

Thirty-nine (54%) units returned the audit questionnaire (Figure 1) from England (n=29), Wales (n=2), Scotland (n= 4), and Northern Ireland (n=4). Units provide patients with an opportunity to discuss LDKT with various kidney health professionals: a nephrologist (100%), living donor nurse (94%), transplant co-ordinator (94%) and pre-dialysis nurse (86%). Respondents reported fewer opportunities to discuss LDKT with a clinical psychologist (52%), primary care practitioner (13%) and social worker (3%). One-to-one consultations are supplemented with information supplied in a variety of different formats. Most commonly patient information leaflets (97%) are provided and posted to patients prior to the consultation (69%). Staff are satisfied with the leaflets they provide (M=5.84, range 3-7, S.D.=1.15). Reasons for their ratings included, positive feedback from patients, and a belief that the information was comprehensive; but some felt that the leaflets were too lengthy. Respondents were not able to specify the languages, other than English, that their information was available in, however they reported that locally produced information (29%), and NHS Blood & Transplant information (48%) is available in additional languages. Twenty-two (56%) renal units have access to interpretation services routinely, and these are easy to access (M=5.14 out of 7, range 1-7, S.D.=1.67).

Two thirds of services also recommend websites (67%) and half provide the opportunity for patients to meet other patients with AKD (51%). Other opportunities to learn about LDKT include: attending an open day or group seminar (41%), receiving a home visit (28%), watching a DVD (15%), Transplant TV (7%), decision aid (7%), and audio information (5%). Almost two-thirds of respondents (62%) stated that supplementary information was provided by a transplant assessment nurse, a 'pre-dialysis' nurse within a low clearance clinic or a live donor nurse. All staff reported that their preferred method of communicating with patients was via face-to-face contact. They reported that this helped to build rapport, involves families in discussions, provides the opportunity to ask questions, and that leaflets alone were not enough to engage people to talk to their friends and family about donation.

<insert Figure 1 about here>

Critical analysis of patient information leaflets

Twenty-three different leaflets were identified to support people making decisions about LDKT (Table 1). Leaflets were developed by a variety of different organisations; 9 were locally produced by renal services. Sixteen of the leaflets were supplied by renal units, 6 were sourced from kidney charity websites, and 1 from a healthcare service website. Three of the leaflets were used by more than one renal service (Table 1). Leaflets varied considerably in length; containing 11 pages on average (range 2–55; SD = 11.6). Readability scores indicated that leaflets were ‘fairly difficult to read’ and understanding the text was equivalent to reading the ‘Guardian’ or ‘Daily Telegraph’ newspapers (M = 56.2 out of 100, range 35.0-74.6, S.D.=9.2, Flesch,1948, Ley & Florio 1996; Table 1).

Most leaflets did not explicitly state their purpose; they were all judged to inform people about, and/or prepare them for LDKT. Three leaflets explicitly stated they were designed to help people make decisions about donation, two leaflets were designed to help people have conversations with friends and family, and two provided spaces for potential donors and recipients to record their progress through the transplantation process. Leaflets were aimed at either potential donors (n=13) or recipients (n=10). The average quality score for general presentation of information was 7.9 out of 16 (range 4-12, s.d.=2.3), indicating that they included some techniques known to promote health literacy and facilitate decision making by reducing cognitive load. All were written in the present tense and included clear headings. Most were an appropriate font size (87%) and length (78%) and included short paragraphs (83%) and bullet points (65%). Few leaflets referenced other sources of the same information (26%) or included a glossary (13%) or diagrams (13%). Leaflets aimed at potential donors (m=8.8 s.d.=1.9) scored higher than those written for recipients for the general presentation of information (m=6.8, s.d.=2.4; F(1,21)=4.7, p=0.0).

Inclusion of illness and treatment specific information

People with AKD are often unable to distinguish between the symptoms of their kidney disease and those of ageing and other illnesses. This makes it difficult to recognise the necessity to plan ahead and make changes to their kidney care management (Winterbottom et al., 2014). A limited number of leaflets described LDKT within the context of a worsening chronic disease. For example, few included a description of what happens when the kidneys fail (13%), provided an explanation of AKD (4%), stages of kidney disease (4%), consequences of kidney failure (4%), symptoms (4%) or risk factors (4%). Whilst leaflets provided a description of LDKT (65%) few explained that the aim of LDKT is to improve quality of life (30%), relieve symptoms of kidney disease (4%), and protect and maintain kidney function (4%). Providing general information about chronic kidney disease, being explicit about identifying and managing symptoms, and the use of decision maps, can help people to ‘see’ how treatment decisions fit in within the context of their illness and understand why it is important to make decisions about the future management of their illness. Providing basic information about advanced kidney disease to potential donors may aid understanding of the necessity to donate a kidney. Leaflets aimed at recipients were more likely to include illness specific information.

Most leaflets focussed on preparing people for LDKT by providing information about how to commence the transplantation process (87%). Almost all leaflets also described the donor workup program (96%), with detailed reference to phase 1 (61%), phase 2 (52%), and 'final steps' (52%), and pre-assessment tests such as blood group (74%) and tissue type matching (65%), referral to psychological services (39%), and the donor health questionnaire (22%). Living donor kidney transplantation has both short- and long-term impact on donor and recipients lifestyle and to make an informed decision, people require information about all of the treatment options and their consequences. Leaflets mentioned deceased donor kidney transplantation (70%), dialysis (65%) and paired donation (52%) as available treatment options, few mentioned conservative management (4%). Some post-treatment information was included such as: recovery after the operation (61%), life expectancy (57%), risks after the operation (48%), transplant failure (26%), and death (22%). Almost two thirds of leaflets mentioned non-medical aspects of life after donation (61%) and associated treatment burden: maintaining regular contact with renal services (52%), impact on finances (52%), time off work (52%), continued use of medication (44%), work (39%), mental health (30%), pregnancy (30%), the cost of health insurance (26%), family life (17%), driving (13%), holidays (13%), sport (9%), and sex life (9%). Leaflets designed for potential donors included more information about preparation for the procedure and the short- and long-term consequences of LDKT.

Inclusion of culturally specific information

One leaflet focussed specifically on LDKT for Hindu communities. Few leaflets mentioned longer waiting times for ethnic minority groups (17%), or statistics on transplantation rates by ethnicity (4%). There were references to geographical issues between donor and recipients (13%), principles of difference faiths (9%), a general discussion of cultural issues around LDKT

(9%), or a message from the local or national faith leader (4%), in a small proportion of leaflets. A minority of leaflets referred to information being available in different languages (13%) or discussed the use of an interpreter (4%).

Inclusion of components to support decision making and discussions between donor and recipient.

The average quality score for leaflets was 2.8 out of 10 (range 0-6, s.d.=1.5). Approximately one third explicitly mentioned the decision to be made (39%) and included advice on how to make the decision (39%). Few included components known to support decision making, such as references to supporting scientific evidence (9%), a sponsorship or conflict of interest statement (4%) and prompts or space asking people to think what is important in their life or what like and dislike about treatments (9%). No leaflets included a visual representation of the pros and cons, a balanced presentation of potential harms and benefits of treatment information or included information in ways known to assist people in making decisions such as comparison tables, timelines of the decision or values elicitation exercises, to help people assimilate treatment information with their own values. Approximately one third included narratives by patients or health professionals (35%) which may impact on people's ability to make an unbiased decision. Information was judged to be somewhat balanced, scoring on average 3.2 out of 6 (range 1-5, s.d.=0.9). Most leaflets were written from an objective viewpoint (91%), most did not include value terms (74%), and leaflets were more likely to present risk figures numerically (65%) rather than verbally (35%), which improves risk interpretation. There was no difference in the decision making quality score (F(1,21)=1.7, p=0.2) or quality score for balanced information between recipient and donor leaflets (F(1,21)=0.1, p=0.7). Leaflets encouraged people to discuss donation with friends, family and/or health professionals (78%) and provided information about the 'next steps' after a discussion had taken place (70%). One leaflet (4%) included suggestions of questions to encourage people to discussion of donation, one suggested techniques to help people discuss donation. Two leaflets (9%) encouraged people to write down information they wished to discuss with others, one was not directed at people having discussions with potential donors, but for recording information along the transplant pathway.

Discussion

This study provides an overview of how just over half of all UK renal services support people with advanced kidney disease making decisions about living donor kidney transplantation (see Figure 2). Staff most value being able to speak to people about donation and all services provide information verbally with input from multi-disciplinary team members, primarily physicians and nurses (van den Bosch et al., 2015). United Kingdom kidney services meet renal policy guidance by providing their patients with information in a variety of different formats (NSF, 2004, NICE, 2018). This may help boost people's understanding of treatment information including those with low health literacy (Treagold & Grant, 2014). Most commonly, patient information leaflets are used to supplement conversations about LDKT and are aimed at potential donors and recipients separately. Potential donors may have different information needs to people with AKD, this perceived difference is reflected in discrepancies in the type of information included between leaflets. Providing comprehensive information about the illness context and consequences of the treatment option for both parties can increase understanding of the necessity to donate and improve shared decision making (Joseph-Williams et al, 2014).

Staff reported that they were satisfied with the leaflets they provide, and that this is often posted prior to the consultation, suggesting they recognise the importance of written information in preparing people for, and enhancing discussions around LDKT (Winterbottom et al., 2007, 2020).

Our critical analysis of patient information leaflets suggests that it is provided by those working within UK renal transplant services is not structured in a way that provides optimal support for people making decisions about LDKT and for those discussing LDKT with their family and friends, including those from ethnic minorities and people with lower health literacy (Winterbottom et al., 2007, 2020). Patient decision aids should be considered for supporting people with AKD deciding between renal replacement options (NICE Guidelines, 2021). Patient decision aids encourage people to become active participants in healthcare decisions. They present comprehensive, evidence-based, balanced information about all available treatment options and their consequences. They are explicit about the decision, present information in a way which is easy to understand and encourage people to make preference-based decisions by considering what is important to them and trade-off their values against the rigours of each treatment option (Stacey et al., 2017, Bekker et al., 1999, Fagerlin et al, 2003). The National Institute for Health and Care Excellence (NICE)-accredited patient decision aids for people making decisions about dialysis and conservative care options exist and use of these resources across services demonstrates best practice and reduces inequity in practice (NICE, 2021).

Decision making about renal replacement options is complex, involving multiple education sessions with input from multiple stakeholders. The deliberation of options usually occurs over a protracted period of time, when few symptoms from the illness are recognised or experienced (Loiselle et al, 2016). It is likely that people will require different types of information at different points in their illness and this is reflected in the numerous complex interventions developed, addressing different aspects of the decision problem. These include patient decision aids where LDKT is presented alongside dialysis, deceased donor transplantation and conservative management options (Ameling et al., 2012, Patzer et al., 2016), interventions to improve communication between recipients and donors (Garonzik-Wang et al. 2012, Kumar et al., 2016), information aids (National Kidney Foundation 2016), educational aids (Ismail et al., 2014, Rodrigue et al., 2014, Waterman et al., 2014,), and interventions targeting specific ethnic populations (Arriola et al., 2014, Gordon et al, 2016). The majority of these interventions have been developed in the United States, and to our knowledge, none of these are used in UK renal settings or focus on South Asian populations, and only one focusses on a Muslim population, the second largest religion in the UK (ONS, 2019, Padela et al, 2021, for reviews see: Gander et al, 2017 and Hunt et al, 2018). Our team is undertaking further research to understand the complex context within which decisions about LDKT take place within UK renal settings to determine the most effective ways to support people making decisions about LDKT, particularly for individuals from the South Asian population (Winterbottom et al, accepted for publication). Considerable health inequalities exist for access to LDKT, people from ethnic minorities are more likely to have kidney disease but spend longer on the waiting list and are less likely to receive a kidney (NHS Blood and Transplant, 2019). Staff reported that they had good access to translators to support discussions with people who do not speak English. The written information we reviewed included little culturally sensitive content. It seems unlikely that these 23 leaflets are able to support people who require clarification on specific religious and cultural information. Almost half of all audit respondents were aware of the faith-based information publicly available, however our review of this information suggests that it is directed towards deceased organ donation (NHS Blood and Transplant https://www.organdonation.nhs.uk/helping-you-to-decide/your-faith-and-beliefs/). It may be that staff place more emphasis on providing information verbally to non-English speakers, rely on family members of non-English speaking people to translate written information, or that they verbally signpost people to the NHS Blood & Transplant information, and our questionnaire did not capture this.

Strengths and weaknesses of the critical review

We received a good questionnaire response rate from units of different sizes in diverse geographical areas and included a range of leaflets developed by a variety of organisations, two of which were used across nine services. Whilst there is 'other' additional information available in the public domain, we provided an overview of written resources currently used by kidney services and that which is available on 4 leading UK kidney charity and the NHS Blood & Transplant website. Some units provide people with more than one leaflet, it is not known if some of the leaflets were meant to be read as part of a suite of resources covering different aspects of the treatment option, this may have biased our scoring system. We addressed our audit questionnaire to 'transplant co-ordinators' and captured a service point where some of the written information assumed people had decided to pursue LDKT. LDKT treatment information may also be included at an earlier stage in patient education about treatment options (Winterbottom et al., 2007). This may explain why comprehensive information about other treatment options was not included in the leaflets we reviewed.

Implications for clinical practice

The audit highlights the inequity in access to information and considerable variation in how kidney services educate and inform people about LDKT options, reflecting the lack of standardised guidance on delivery of such services (van den Bosch et al., 2015). The variability in the quality and amount of patient information leaflets is likely to introduce bias into people's decision making and reinforces this variation in practice. Services that are writing and updating their patient information may benefit from considering our 6 principles to help guide their development, so that they adequately meet service and patient need for people making shared decisions about LDKT and other renal replacement options (See Table 2).

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Table 1: Resources used by renal services to support LDKT decision making (n=23)

ID	Developer	Year publication (review date)	Title (Number of units using the leaflet)	Stakeholder	Flesch readability score
1	Charity	-	Living donor kidney transplantation – patient information (1)	donor	67.9
2	Renal service	2017 (2020)	Renal Living Donor Transplantation – information for potential living donors (1)	donor	50.5
3	Healthcare service	2020	Information about becoming a living kidney donor (1)	donor	58.7
4	Charity	2017	Making Possible A Gift of Life. Living Organ Donation and Transplant for Hindu Communities (0)	donor	61.1
5	Charity	-	Receiving a Kidney – what to expect (1)	recipient	51.6
6	Charity	-	Donating a Kidney – what to expect (2)	donor	67.7
7	Healthcare service	-	Living donor kidney transplantation and raising the subject with family and friends (0)	recipient	61.9
8	Charity	-	Frequently Asked Questions about Kidney Transplant – Patient Information (0)	recipient	74.6
9	Renal service	-	Transplant Information Pack – Book 1 (1)	recipient	63.8
10	Healthcare service	2020	Could I be a Living Donor (1)	donor	54.7
11	Renal Service	2015	Information about Living donor kidney transplantation – information for the recipient (1)	recipient	50.9
12	Renal Services	2015	Information for Potential Living Kidney Donors (1)	donor	56.8
13	Healthcare service	-	Could I be a Living Kidney Donor? (5)	donor	46.0

14	Pharmaceutical company	2020	Gift of Life Living Kidney Donor Your Questions Answered (4)	donor	42.4
15	Charity	(2019)	Transplantation Series a (0)	recipient	60.8
16	Charity	-	Living Donor Information (0)	donor	53.8
17	Charity	(2019)	Transplantation Series b (0)	recipient	70.5
18	Renal Services	2017	Information for potential Living Kidney Donors (1)	donor	52.9
19	Renal Services	2020	Your Guide to Kidney Transplantation Options (1)	recipients	35.0
20	Renal services	2010 (2019)	Living Kidney Donors – An Introduction (1)	donor	48.0
21	Renal services	2020	Patient Information Booklet – Living donor kidney transplantation (1)	donor	54.4
22	Renal services	-	Kidney Transplantation Guide Information For You (1)	recipient	53.9
23	Healthcare Service	-	Let's talk about the benefits of receiving a kidney from a living donor (0)	recipient	54.0

Table 2: Six principles to guide the development of patient information in renal services.

1 Establish the purpose of the patient information	
Rationale:	The content and design of patient information is dependent on its function. Information designed to support decision making requires additional components to that which is designed to educate and prepare people about options.
Further reading:	O'Cathain, Croot, Sworn et al. (2019) Taxonomy of approaches to developing interventions to improve health: a systematic methods overview. Pilot and Feasibility Studies, 5:41. Winterbottom A., Conner M. & Mooney A. et al. (2007) Evaluating the quality of patient information provided by Renal Units across the UK. Nephrology, Dialysis & Transplantation, *22,* 2291–2296.
2 Consider whether patient information currently exists in practice	
Rationale:	Use of existing patient information promotes best practice and discourages duplication of effort.
Further reading:	National Institute for Health and care Excellence (NICE) directory of NICE endorsed patient decision aids (https://www.nice.org.uk/about/what-we-do/into-practice/endorsement) Ottawa Hospital Research Institute (OHRI) Patient Decision Aid Inventory (https://decisionaid.ohri.ca/azinvent.php)
3 Use evidence-based guidelines for patient information development	
Rationale:	Use of established guidance during the developmental process improves the quality of patient information.
Further reading:	Stacey D, Volk RJ, for the IPDAS evidence update (2021) The International Patient Decision Aid Standards (IPDAS) Collaboration: Evidence Update 2.0. Medical Decision Making, 41, 729-733. Joseph-Williams N, Newcombe R, Politi M. et al. (2014). Toward minimum standards for certifying patient decision aids: a modified Delphi consensus process. Medical Decision Making, 34, 699–710. Treadgold P & Grant C. (2014) Evidence Review: what does good health information look like? Patient Information Forum, London, UK.
4 Assess the demographics of the local renal population	
Rationale:	Differences in age, cognitive decline, ethnicity and health literacy may impact on people's ability to understand patient information. Consider how this will inform leaflet content, format, and structure.

Further reading:	Marsay S (2017) DCB1605 Accessible Information: Implementation Guidance v1.1, NHS England. Morony S, Flynn M, McCaffery KJ, et al. (2015) Readability of written materials for CKD patients: a systematic review. American Journal of Kidney Disease, 65, 842–850. Taylor DM, Fraser SDS, Bradley JA, et al. (2017) A Systematic Review of the Prevalence and Associations of Limited Health Literacy in CKD. Clin J Am Soc Nephrol. 12(7):1070-1084.
5 Explore the context within which patient information will be provided	
Rationale:	Consider how, when and by whom patient information will be used in clinical practice. Staff may have training needs to support people making decisions about LDKT.
Further reading:	Combes G, Sein K and Allen K. (2017). How does pre-dialysis education need to change? Findings from a qualitative study with staff and patients. BMC Nephrology 18:334. Joseph-Williams N, Abhyankar P, Boland L. et al. (2021) What Works in Implementing Patient Decision Aids in Routine Clinical Settings? A Rapid Realist Review and Update from the International Patient Decision Aid Standards Collaboration. Medical Decision Making. 41, 907-937.
6 Consider how to share patient information across services	
Rationale:	Sharing patient information via different media, including online databases, quality assessment websites, clinical study groups, conference, social media, and word of mouth, promotes best practice and reduces variation in practice.
Further reading:	National Institute for Health and Care Excellence (NICE, 2021) Shared Decision Making Guidelines [NG197] https://www.nice.org.uk/guidance/ng197

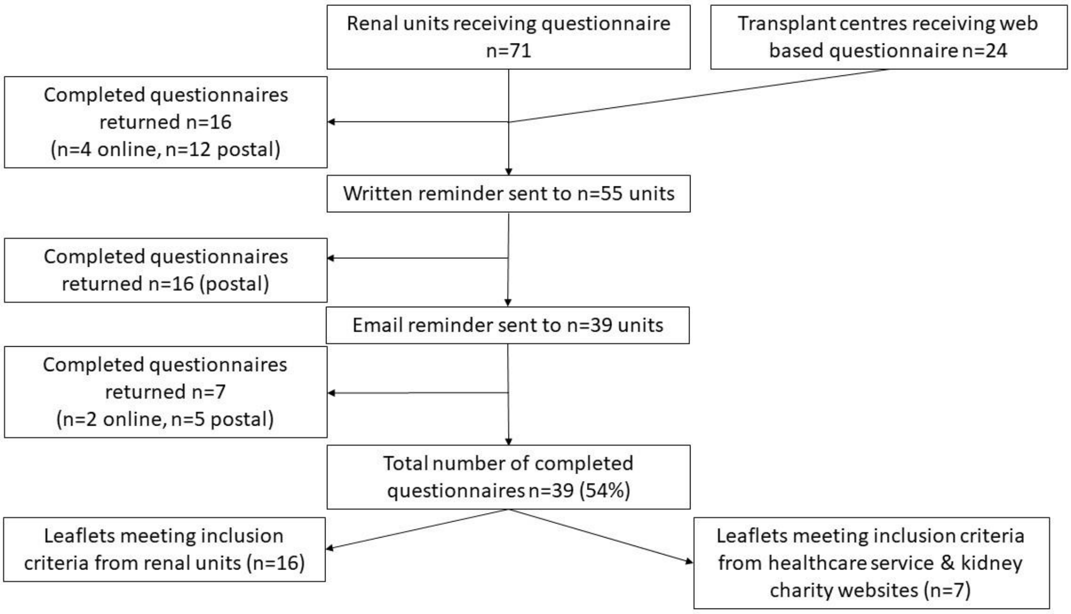
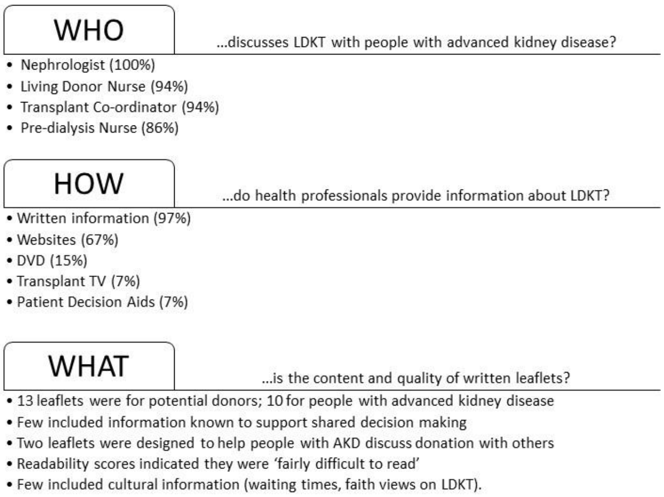


Figure 1: Flow diagram of study recruitment

Figure 2: summary of study findings



WHO ...discusses LDKT with people with advanced kidney disease?

- Nephrologist (100%)
- Living Donor Nurse (94%)
- Transplant Co-ordinator (94%)
- Pre-dialysis Nurse (86%)

HOW ...do health professionals provide information about LDKT?

- Written information (97%)
- Websites (67%)
- DVD (15%)
- Transplant TV (7%)
- Patient Decision Aids (7%)

WHAT ...is the content and quality of written leaflets?

- 13 leaflets were for potential donors; 10 for people with advanced kidney disease
- Few included information known to support shared decision making
- Two leaflets were designed to help people with AKD discuss donation with others
- Readability scores indicated they were ‘fairly difficult to read’
- Few included cultural information (waiting times, faith views on LDKT).