


Supporting donors: resources, mental health support

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Content

- ▶ Decision support resources / tools
 - ▶ Communication – extended skills / expectation management
 - ▶ Psychological screening and assessment
 - ▶ Psychological support structure for donors
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Organ Donation and Transplantation 2030: Meeting the Need to Increase Living Donors for Kidney Transplantation in the United Kingdom



Blood and Transplant

Background



- 29% of UK's kidney transplant program are living donors.
- Black and minority ethnic (BAME) groups have lower numbers of living donors.
- Further action is required to increase the numbers of living donors in the UK.

The NHSBT Report



- The organ donation and transplantation task force by the NHS Blood and Transplant (NHSBT) published an action plan.
- The NHSBT's aim is to make living donation an expected part of care, where clinically appropriate, for all of society by 2030.

The Action Plan



Government

- Maximize transplant opportunities via UK Living Kidney Sharing Scheme.
- Address health inequalities (e.g., funding recently launched via the Community Investment Programme to enable grass roots organizations to champion organ donation in a culturally relevant way).
- Overcome barriers to donation (including financial) to enable more access to donation.



Transplant Centers

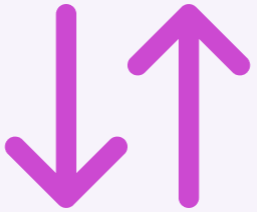
- Improve donor and recipient well-being and experience through better clinical pathways and data quality.
- Remove unnecessary variation in clinical practice by strengthening leadership.
- Recognize donors for their gift of donation through the Living Donor Pin recognition scheme.
- Conduct world-class research to improve donor and recipient outcome.



Community

- Promote awareness among the community, e.g., grass roots organizations like Africa Advocacy, to drive public awareness and engagement in living donation among Black people in the UK & religious leaders to engage their community about the religious stance on living donation.

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Rank the barriers to living kidney donation you find difficult to deal with current resources (1 most difficult to 8 not that difficult)

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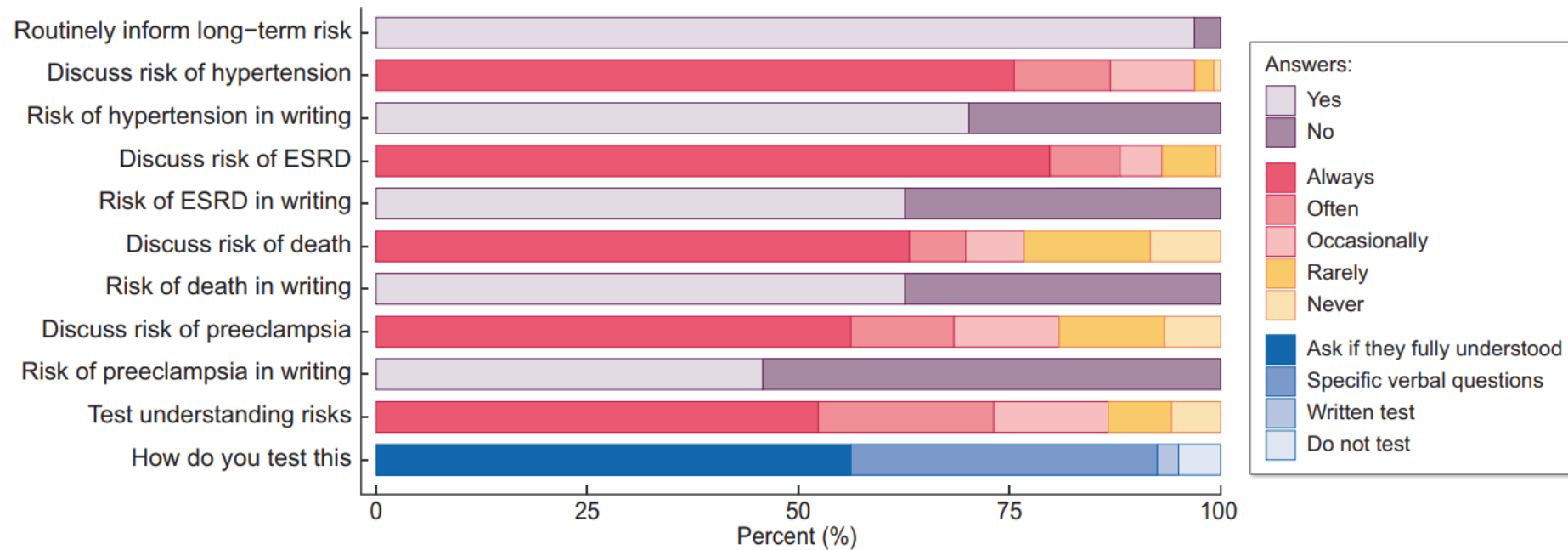
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**What longer term risks do you
inform potential living donors**

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European survey



Long-term risks after kidney donation: how do we inform potential donors? A survey from DESCARTES and EKITA transplantation working groups. NDT 2021

Type of risk	Known estimates
Hypertension	OR 1.25 (1.12–1.39) HR 1.19 (1.01–1.41) Systolic BP mean increase of 5 mmHg
ESRD	HR 11.4 (4.4–29.3) 90/10 000 years versus 14/10 000 years
Gout	HR 1.6 (1.5–6.7)
Preeclampsia	OR 2.4 (1.2–5.0)
Proteinuria	147 mg/day versus 83 mg/day
Left ventricular mass increase	+7 g \pm 10 versus –3 g \pm 8 at 1 year
All-cause mortality	HR 1.3 (1.1–1.5)
Cardiovascular mortality	HR 1.4 (1.03–1.91)

Long-term risks after kidney donation: how do we inform potential donors? A survey from DESCARTES and EKITA transplantation working groups

Decision support tools

Patient information about living donor kidney transplantation across UK renal units: A critical review

Anna Winterbottom PhD, CPsychol ✉ John Stoves MBChB, MD, Shenaz Ahmed PhD, Ahmed Ahmed MBBS, Sunil Daga MBBS, MRCP, PhD

First published: 17 November 2021 | <https://doi.org/10.1111/jorc.12404>

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%)



UK national audit – information leaflet

- 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, $SD = 1.53$).
- **Readability scores** indicated they were ‘fairly difficult to read’ ($M = 56.3$, range = 0–100, $SD = 9.4$).
- Few included cultural and faith information.
- Two leaflets were designed to facilitate conversations with others about donation.




Patient information – Six principles


- ▶ to guide the development of patient information in renal services
 - Establish the purpose of the patient information
 - Consider whether patient information currently exists in practice
 - Use evidence-based guidelines for patient information development
 - Assess the **demographics** of the local renal population
 - Explore the context within which patient information will be provided
 - Consider how to share patient information across services

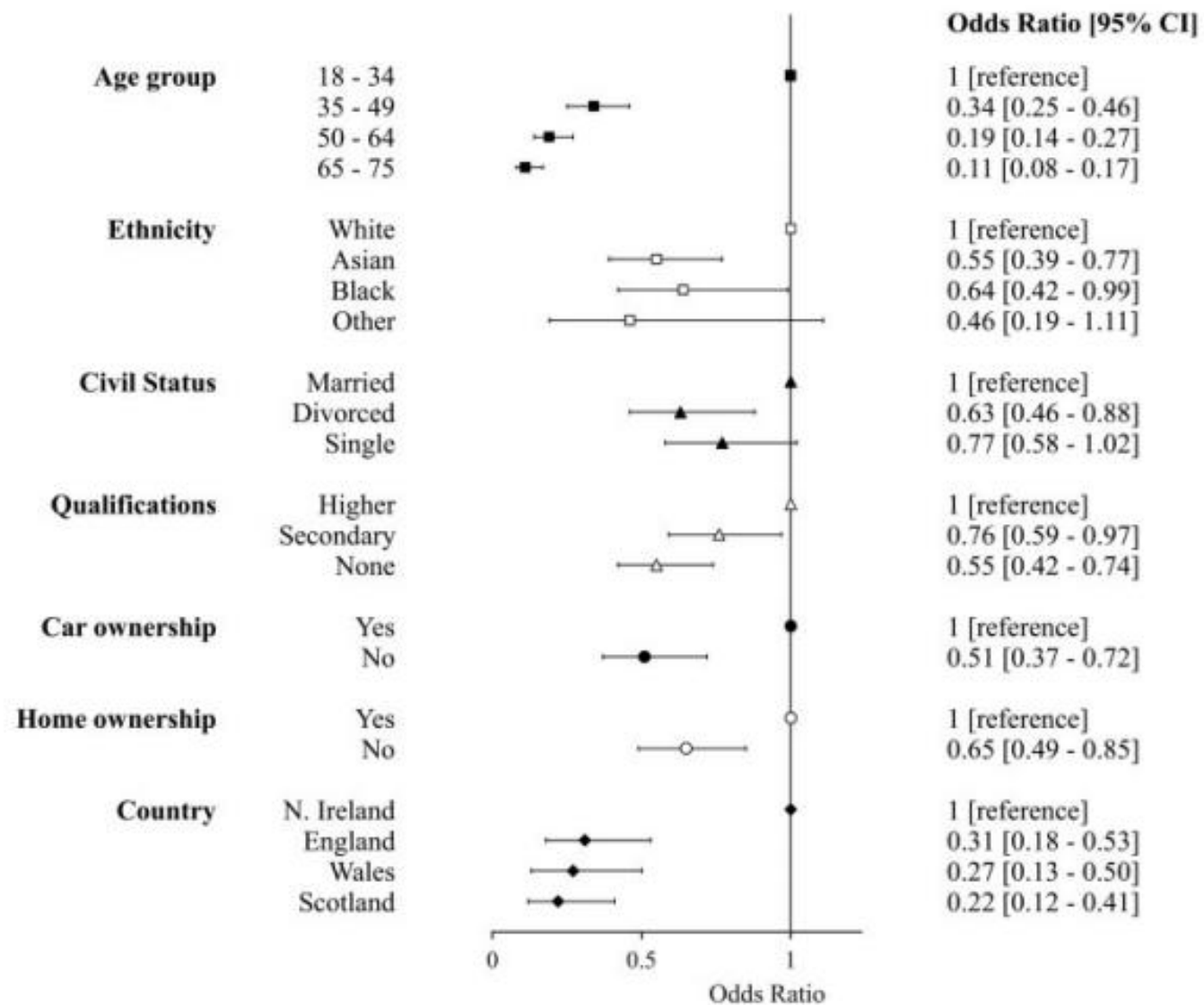


Resources for the underserved groups

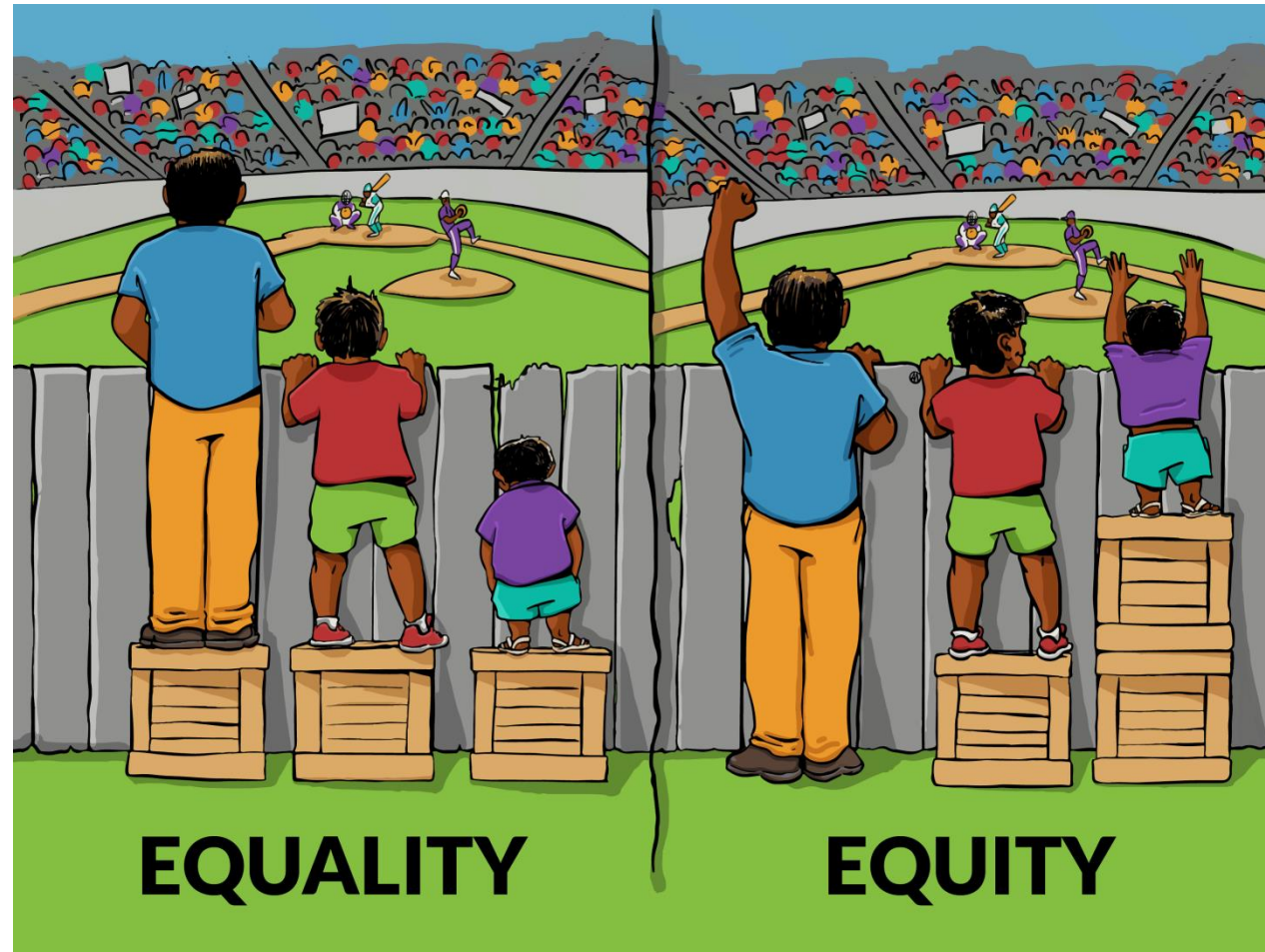
- ▶ definition of ‘underserved’ is highly context-specific;
 - ▶ it will depend on
 - the population,
 - the condition under study,
 - the question
 - the context in which they live (care homes, prison etc.), and
 - the intervention being tested.
- 

Group discussions

- ▶ Who are your underserved group?
 - ▶ Within your tool box of resources, does these meet needs of the underserved group?
 - ▶ What has worked in your services to improve living donation rates?
 - ▶ What would you like to add to your resources and how would you go about developing that?
- 



Solution – more resources?



Solution – tailored resources!

Equality



Equity




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Case study

- ▶ Mr Smith (39 Y) is found medically unsuitable by the MDT. He is very angry and anxious about his son's future and wants to still proceed with living kidney donation. Who should talk to him?
 - Consultant Nephrologist
 - Consultant Transplant surgeon
 - Live Donor Coordinator or equivalent
 - Renal Psychologist or equivalent

Communication

- ▶ How
 - ▶ When
 - ▶ What
 - ▶ Who
- 

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When would you refer / involve a mental health professional in assessing /helping potential living donor?

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Supporting Donors: managing expectations

Longer term consequences of living with one kidney i.e. risk calculator

Normalise experience of donation by sharing experiences of other patients

What will happen in hospital & post-surgery


Post donation dip in mood – baby blues analogy / stress peak & anti-climax

Impact of donation on relationship with recipient & wider family/friends

Sense of indebtedness for the gift



Psychosocial donor screening & assessment

- ▶ Varied practice across UK for psychosocial suitability of LKDs:
anonymous / young / directed
 - ▶ Context - limited access to embedded psychosocial assessors who are suitably trained
 - ▶ Recommend psychosocial screening of young / directed LKDs
 - ▶ Full psychosocial assessment for all anonymous donors
 - ▶ Full psychosocial assessment and intervention for few young / directed
- 

	Red Flag Checklist for Kidney Donor candidates	Answer
1	Does the candidate have unrealistic expectations on living donation?	Y / N
2	Do you have concerns about the candidate's level of commitment?	Y / N
3	Do you have any concerns about motives/reasons for donation?	Y / N
4	Do you have doubts about the mental/cognitive capacity or health literacy of this candidate?	Y / N
5	Is there any evidence that the candidate experiences coercion to donate?	Y / N
6	Are there any unresolved conflicts or major imbalances in the donor-recipient relationship?	Y / N
7	Do you have any concerns about the legality of the donation?	Y / N
8	Do you have any indication that the candidate has a history of, or currently suffers from a psychiatric disorder, or substance abuse?	Y / N
9	Do you have any concerns about the candidate's emotional stability to cope with potential setbacks during and after the donation process?	Y / N
10	Do you have the impression that the candidate lacks knowledge about the consequences of the donation/transplantation procedure and other renal replacement therapies to make a well-considered decision?	Y / N
11	Do you have any concerns about a lack of social support before/after donation?	Y / N
12	Do you have any concerns about the socio-economic situation of the candidate?	Y / N
13	In addition to the information given, are there any non-verbal observations of the candidate that concern you?	Y / N
14	Are there any other reasons to refer the potential donor for further assessment?	Y / N

Psychosocial donor assessment

Recommend EPAT tool for Directed donors

ELPAT Living Organ Donor Psychosocial Assessment Tool (EPAT), Massey et al. (2017)

EPAT covers

- ▶ Decision making process
- ▶ Relationship between recipient & donor
- ▶ Social resources
- ▶ Pressure / coercion
- ▶ Ambivalence
- ▶ Information & risk processing
- ▶ Personal resources
- ▶ Psychopathology
- ▶ Potential implications for donor's job/employability/roles
- ▶ Finances, insurance, follow-up health checks

BTS Guidance for Living Kidney donors 2018

Explore pre-existing issues or those that might impact mental health of donor

Address issues or make recommendations

Full psychosocial ax (EPAT) recommended if concerns about donor suitability

include: active substance misuse

previous or current mental health issues

dependence on prescription medication

self-harm

significant dysfunctional relationships esp between donor/recipient



BTS Guidance for Living Kidney donors 2018

General support provided by Transplant co-ords + peer support / befriending

Tiered approach to psychosocial support & intervention

Explore motivations including coercion / covert pressure, manipulation of familial relationships, & altruism

Discussion of possible problems post transplant to be pre-empted i.e. gift-exchange or indebtedness

Flag possible negatives i.e. fatigue, changes in relationship, lower QoL, overly interested in health of recipient



Anonymous donor psychosocial assessment

- ▶ Psychosocial assessment of all anonymous LKDs recommended although not mandated by HTA
- ▶ Consensus article by Stephen Potts et al.

Journal of Psychosomatic Research, 107 (2018), 26-32



Potts 2018 consensus article

▶ Who

- suitably experienced/qualified mental health worker (psychiatrist/psychologist or other)
- sufficiently familiar with transplantation issues
- embedded/affiliated with transplant service

▶ When – before invasive procedures, after information provided

▶ What – current/previous mental health issues; previous treatment

▶ Purpose – motivation; resilience; expectations; social support; capacity; concurrent life stressors; risk of MH relapse; follow-up options if needed


▶ How – individual interview; third party info; cognitive assessment if required; mental capacity

Psychological support structure for donors

- ▶ Screening / assessment
- ▶ Exploring issues pre listing
- ▶ Unexpected emotional issues post donation
 - medically unexplained symptoms
 - relationship changes
 - tearful / agitated / angry
 - depression / anxiety

1–2 therapy sessions – transplantation experienced/embedded
Referral & GP support

Group discussions – resources

- ▶ What are different types of support structures, the live donor team can access in each region
 - ▶ What works really well at your centre and what are the gaps in your services around psychological support
 - ▶ How will you take this forward
- 

Take home message

