

Addressing health inequalities in living donation: learning from research

UK LKD Network meeting April 2024

Chairs: Lisa Burnapp and Gurch Randhawa



Blood and Transplant

Aim of session

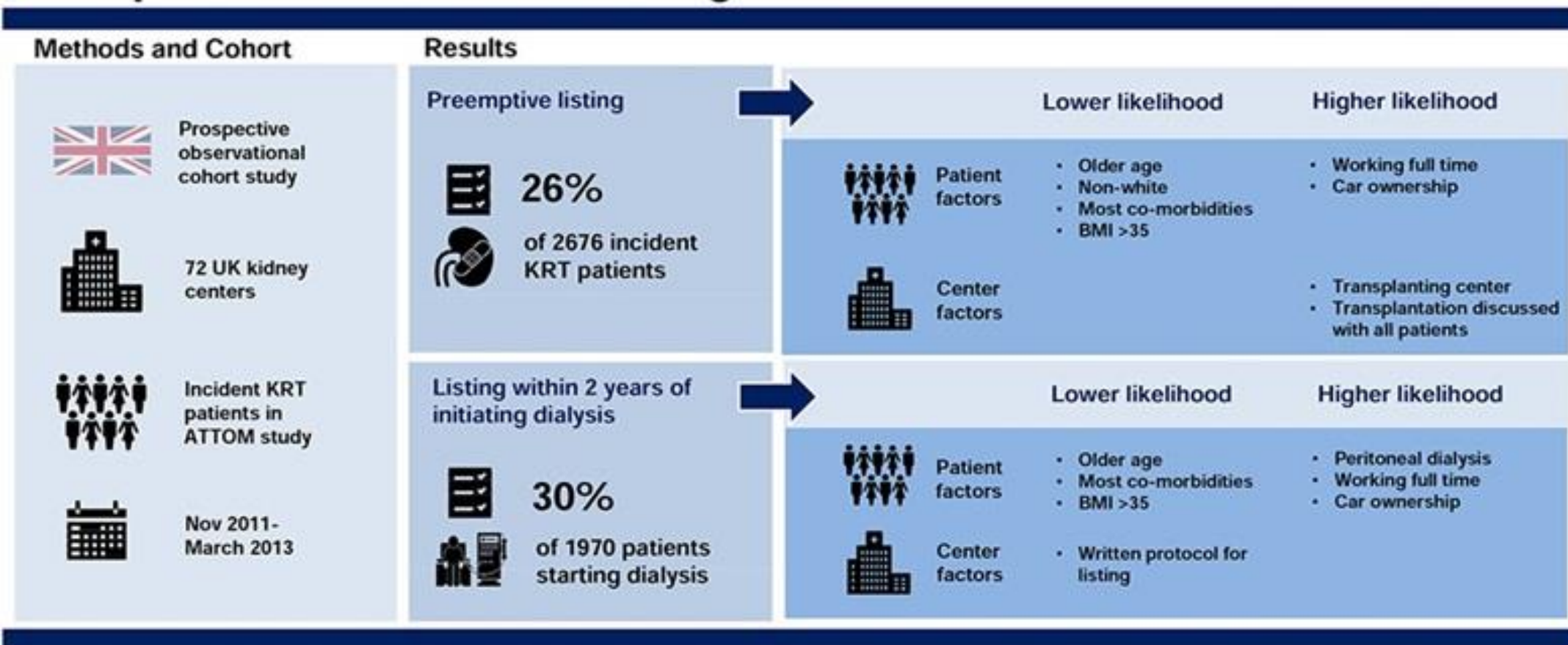
- Current state of equity in LDKT
- What's behind the variation in equity
- Needs assessment in underserved groups
- Your thoughts

How are we doing for equity of access to LDKT in the UK

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Is there inequity in access to kidney transplantation in the United Kingdom?



Conclusion Patient case-mix accounts for most of the inter-center variation seen in access to transplantation in the UK. Socioeconomic inequity exists despite having a universal healthcare system.

Rishi Pruthi, Matthew Robb, Gabriel Oniscu, Charles Tomson, et al. *Inequity in Access to Transplantation in the UK: A Prospective Observational Cohort Study*. CJASN doi: 10.2215/CJN.11460919. Visual Abstract by Beatrice Concepcion, MD.

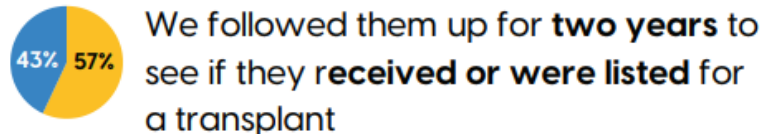
6%–33% for preemptive listing and 25%–40% for listing after starting dialysis

Differences in access to the kidney transplant waiting list in the UK








WHO DID WE INCLUDE?



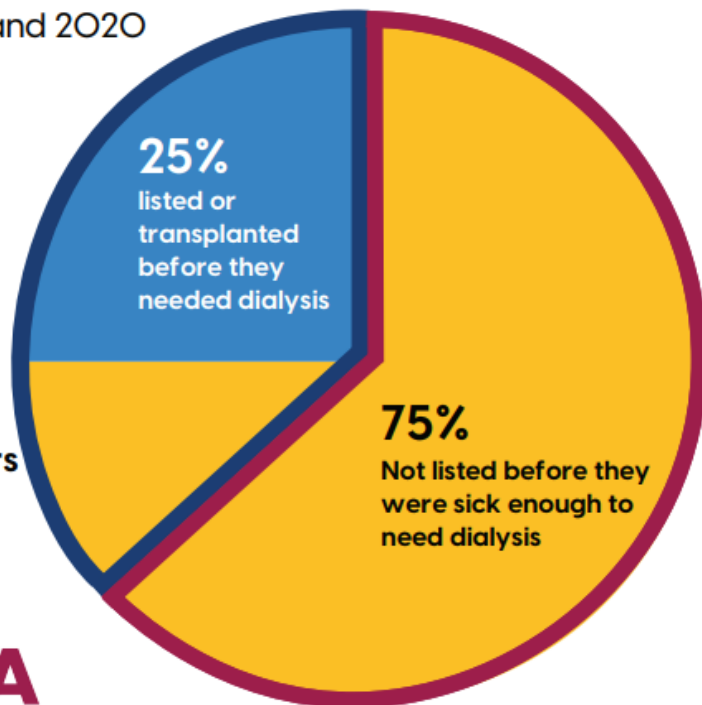
WHAT HAPPENED TO THEM IN 2 YEARS?



WHAT DIFFERENCES DID WE FIND BETWEEN THE PEOPLE WHO WERE LISTED AND THE PEOPLE WHO WERE NOT?

-  Males and females were **equally** likely to be listed
-  Patients with diabetes were **less likely** to be listed
-  Asian people were **more likely** to be listed
-  Black people were **less likely** to be listed
-  Patients who lived in more deprived areas were **less likely** to be listed
-  Patients treated in transplant centres were **more likely** to be listed than those in non-transplant centres
-  Which centre a patient was treated at appeared to affect how likely they were to be listed

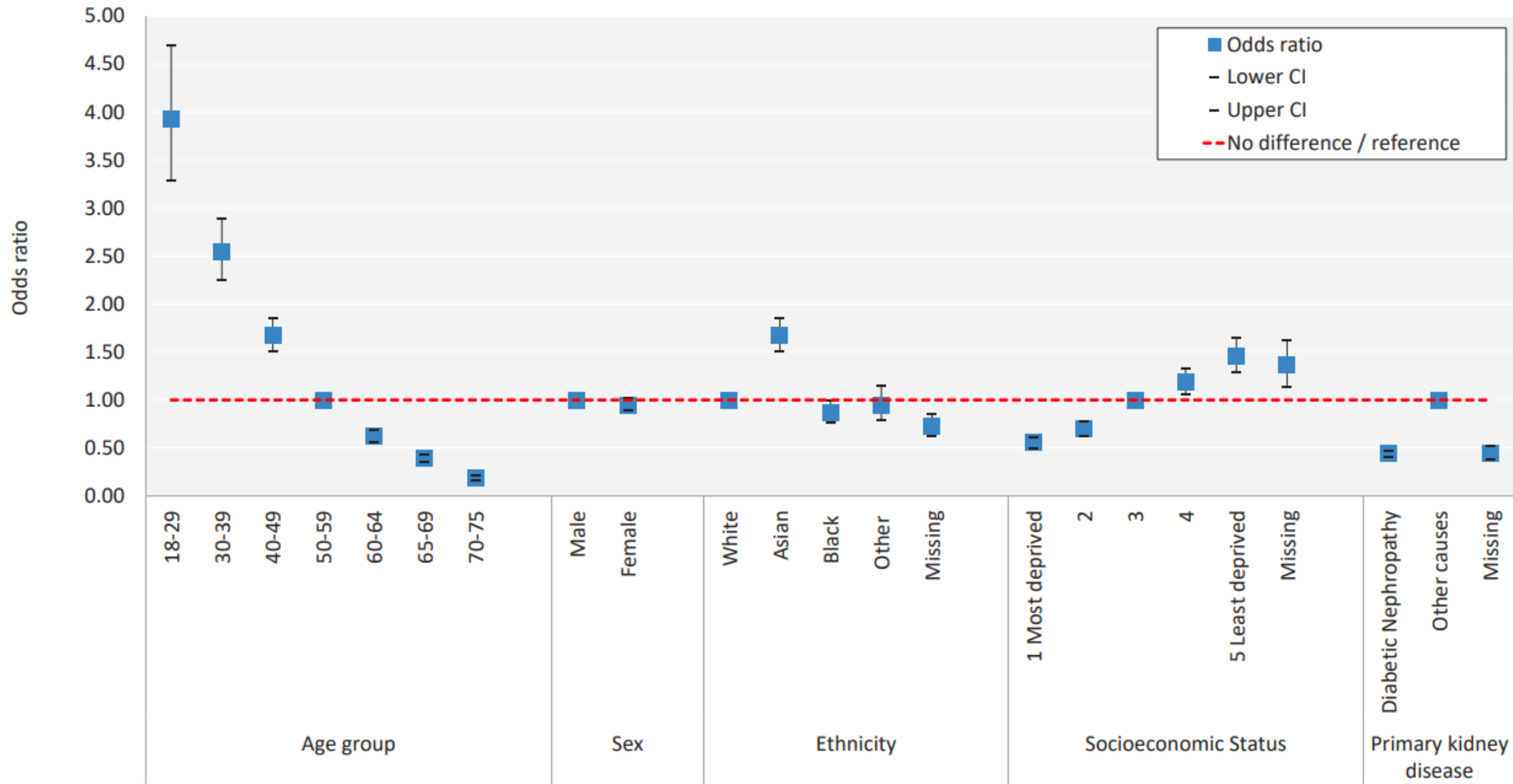
43%
listed or
transplanted
within 2 years



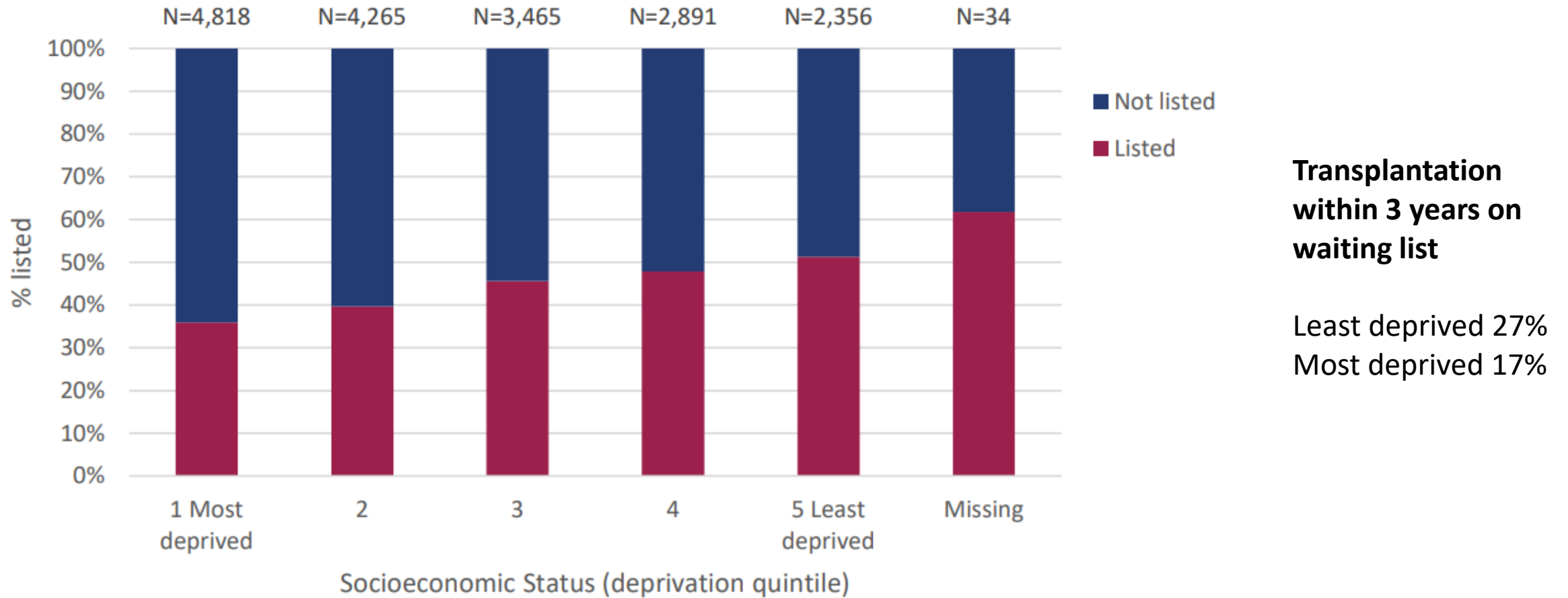
57%
not listed or
transplanted
within 2 years

WHAT NEXT?

We need to do more research to understand these differences. We want to find out how to improve things so that everyone has equal access to the transplant waiting list.



Socioeconomic status



51% of patients who lived in the most affluent areas were listed (deceased donor waiting list) within 2 years of starting KRT, compared to only 36% of patients who lived in most deprived areas



Sex and Gender Differences in Kidney Transplantation



Men have faster progression of CKD



Women are less likely to be listed



Men get transplanted more often



Men have higher incidence of ESKD



Women wait longer once listed

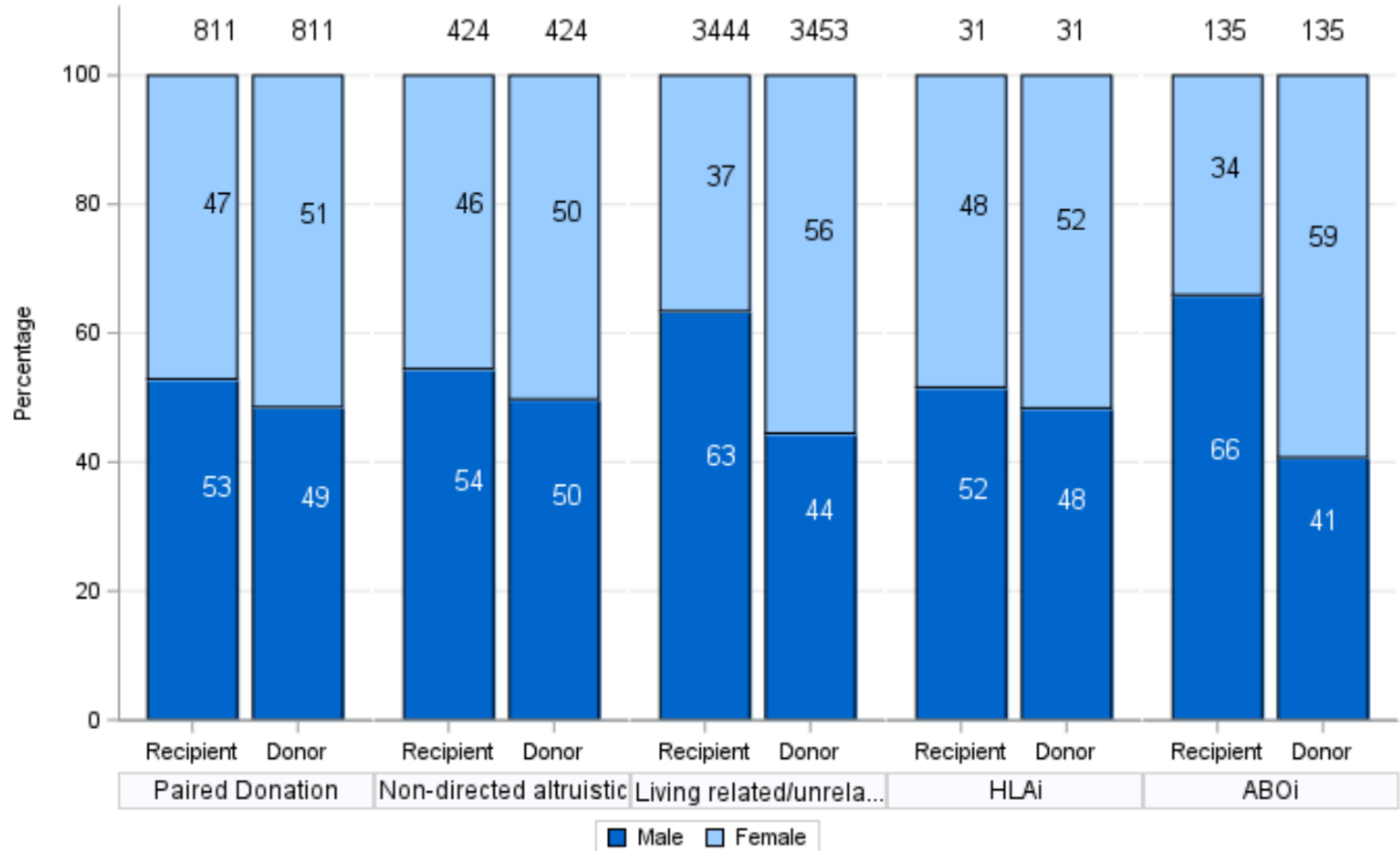


Women donate more (kidneys) than they receive

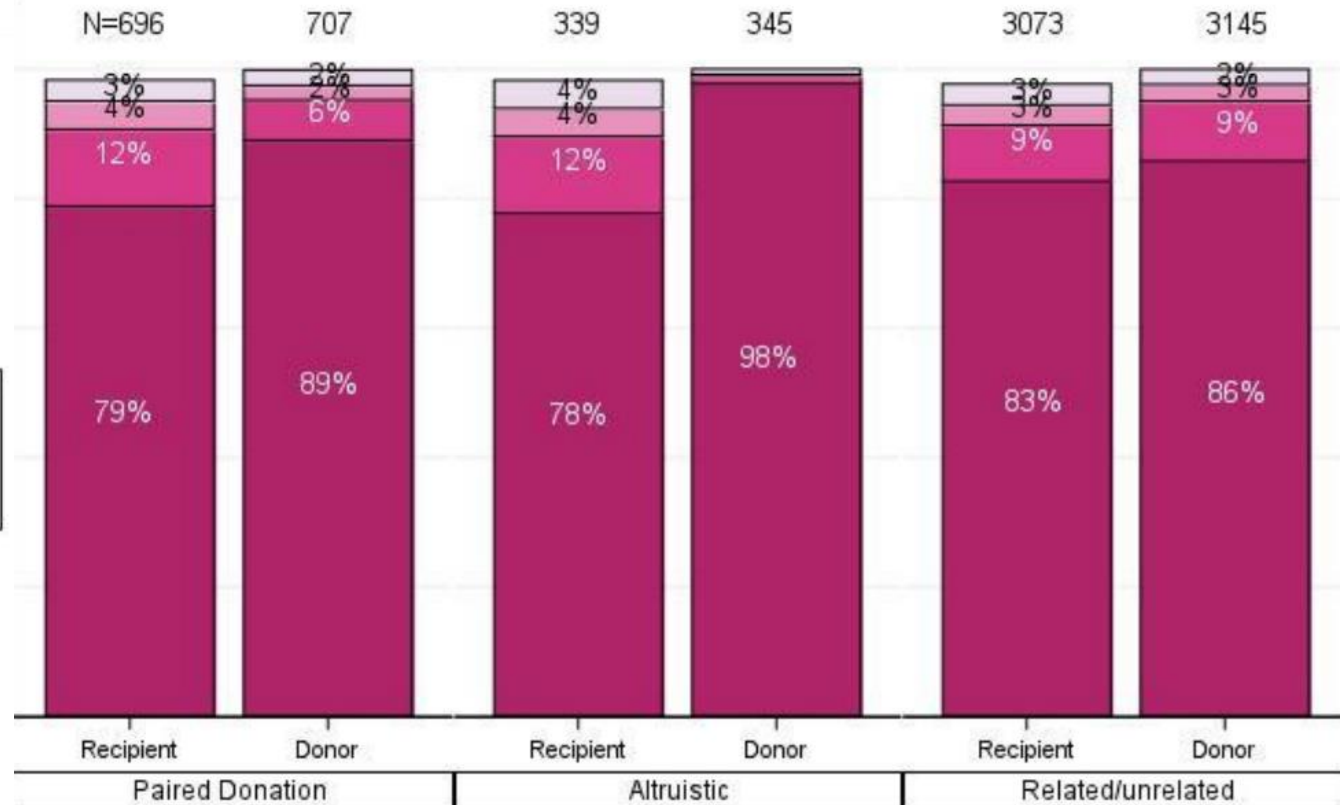
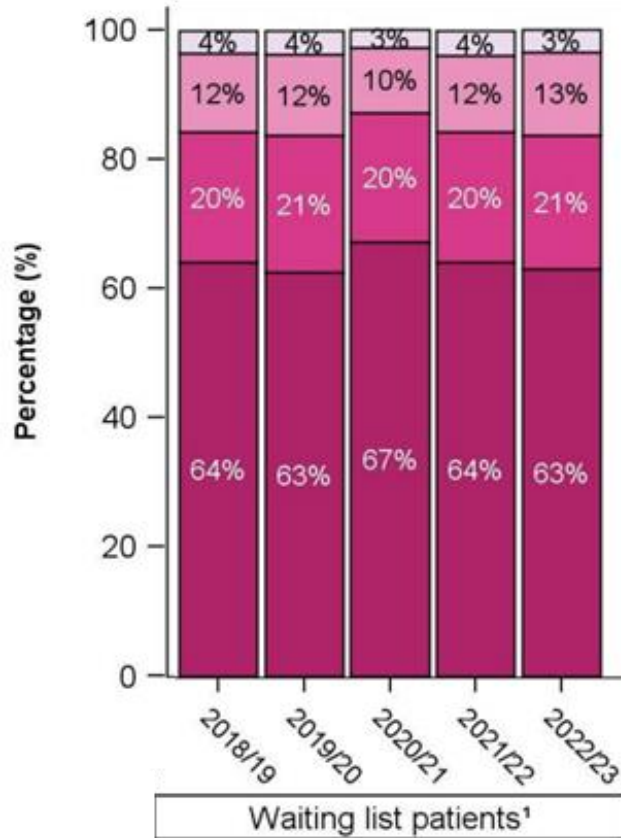
[Sex and gender disparities in access and outcomes in kidney transplantation \(rcpath.org\)](http://rcpath.org)

Access to LDKT

Sex differences 2017-23



Ethnicity – waiting list & LDKT (2018-23)

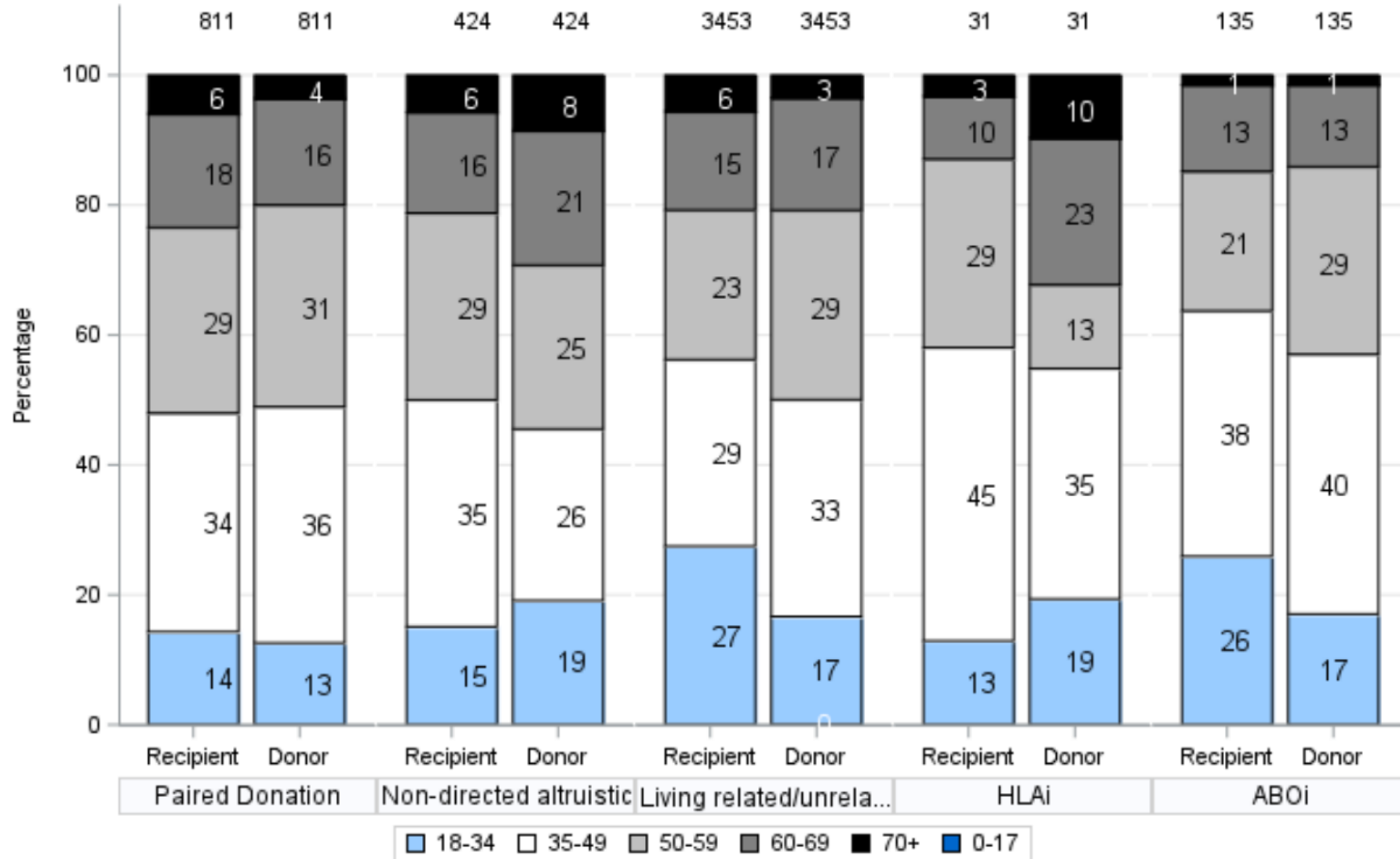


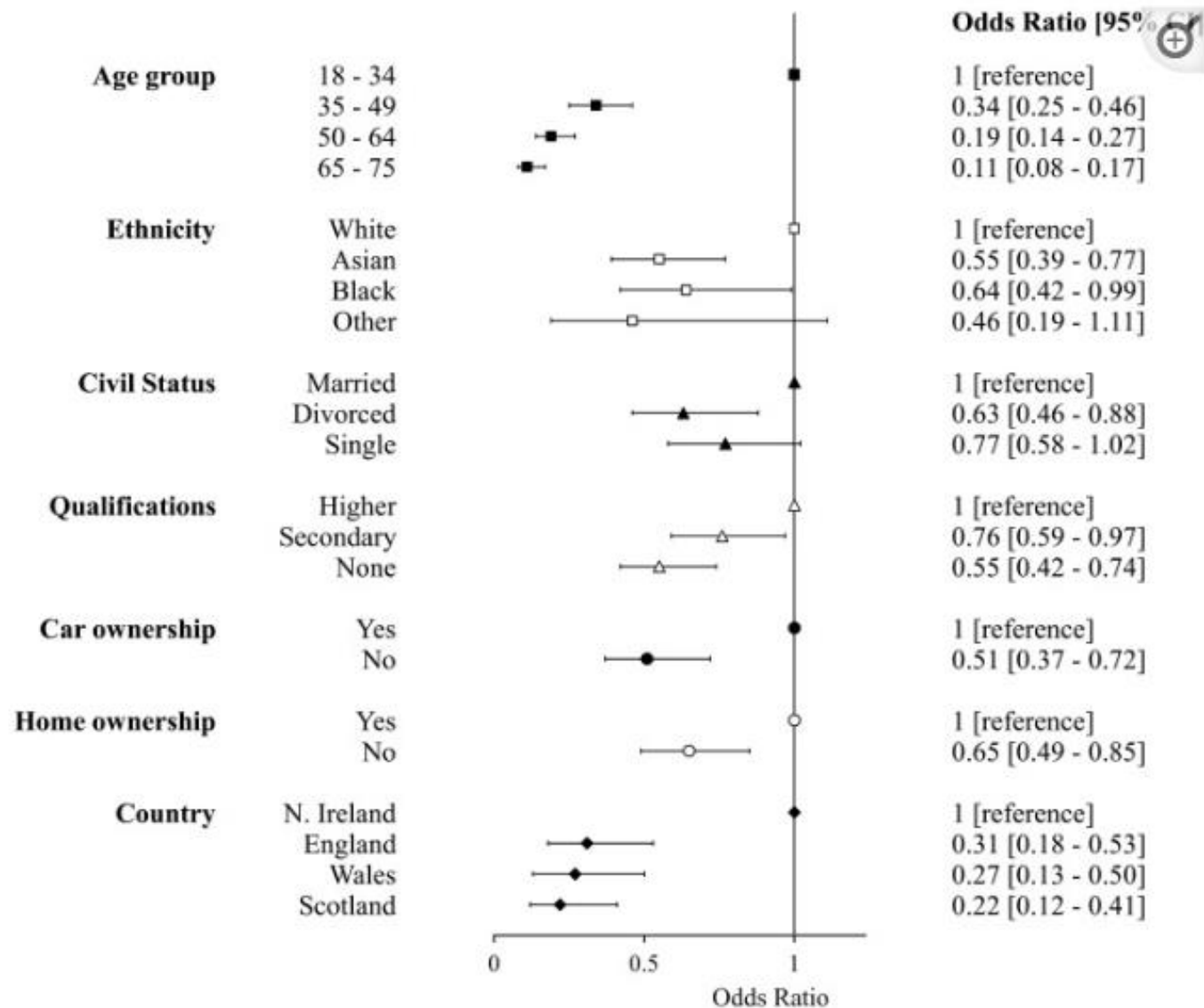
33.3%

19.2%

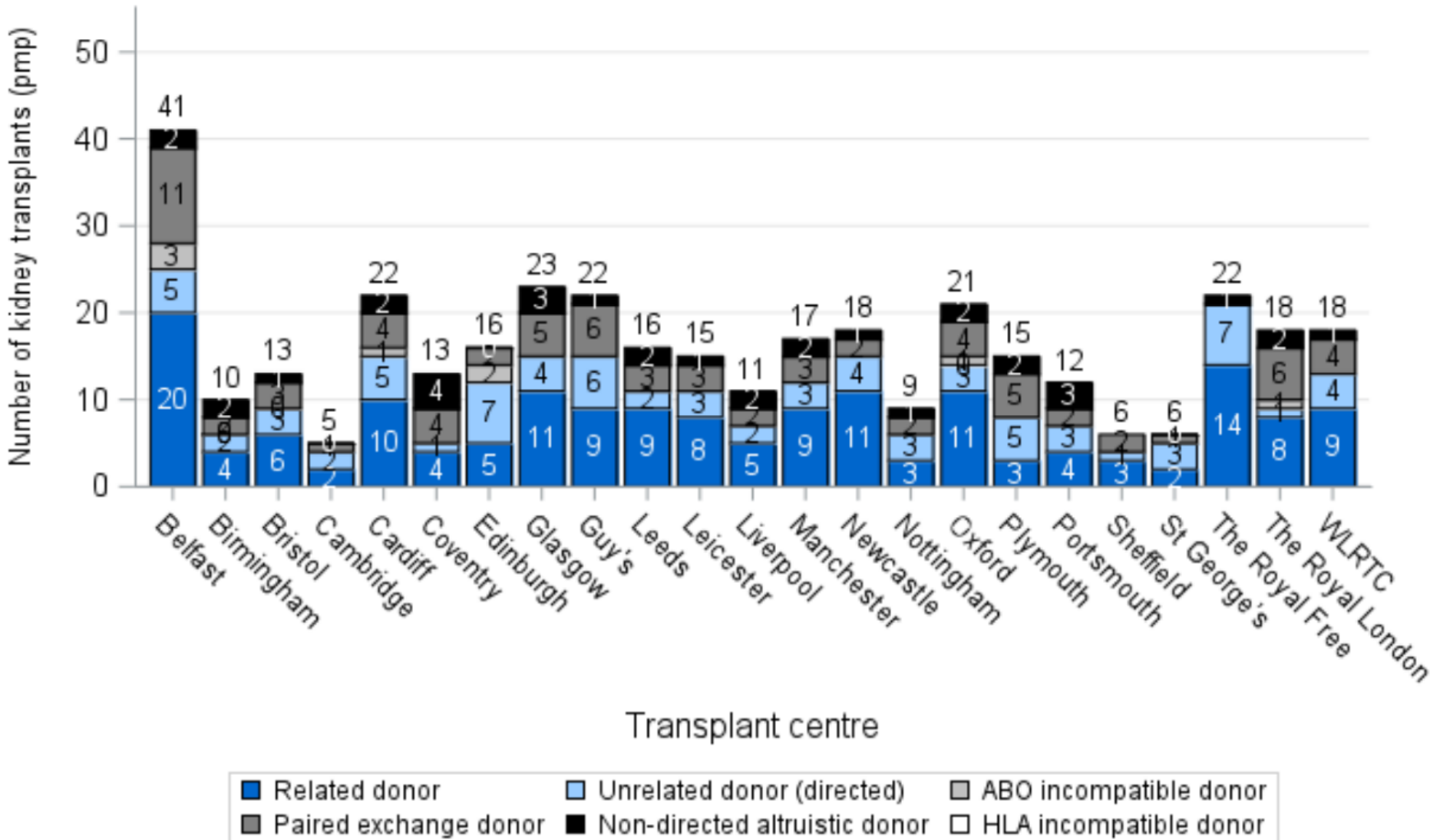
LDKT increased but 8% fall in ethnic minority living donors

Age 2017-23

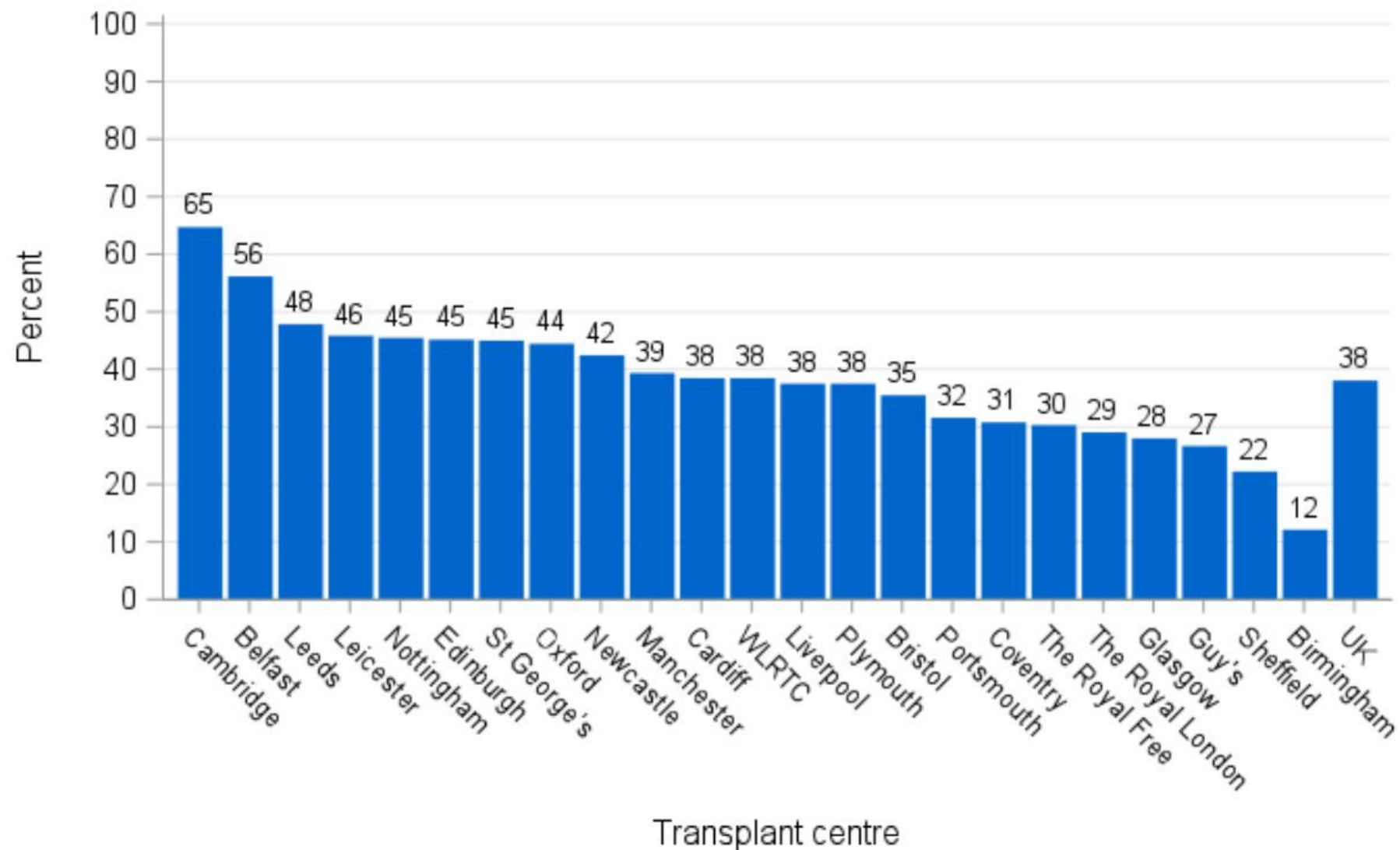




Unit variation (pmp) 2022-23



Pre-emptive LDKT (2022-23)



Summary

- Significant difference in equity to access / timely access to LDKT
- Social determinants of health playing key role and likely to be worse for individuals with intersectional (multiple characteristics)

What is behind the variable equity – understanding our processes and population we serve

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**The Leeds
Teaching Hospitals**
NHS Trust

Our processes

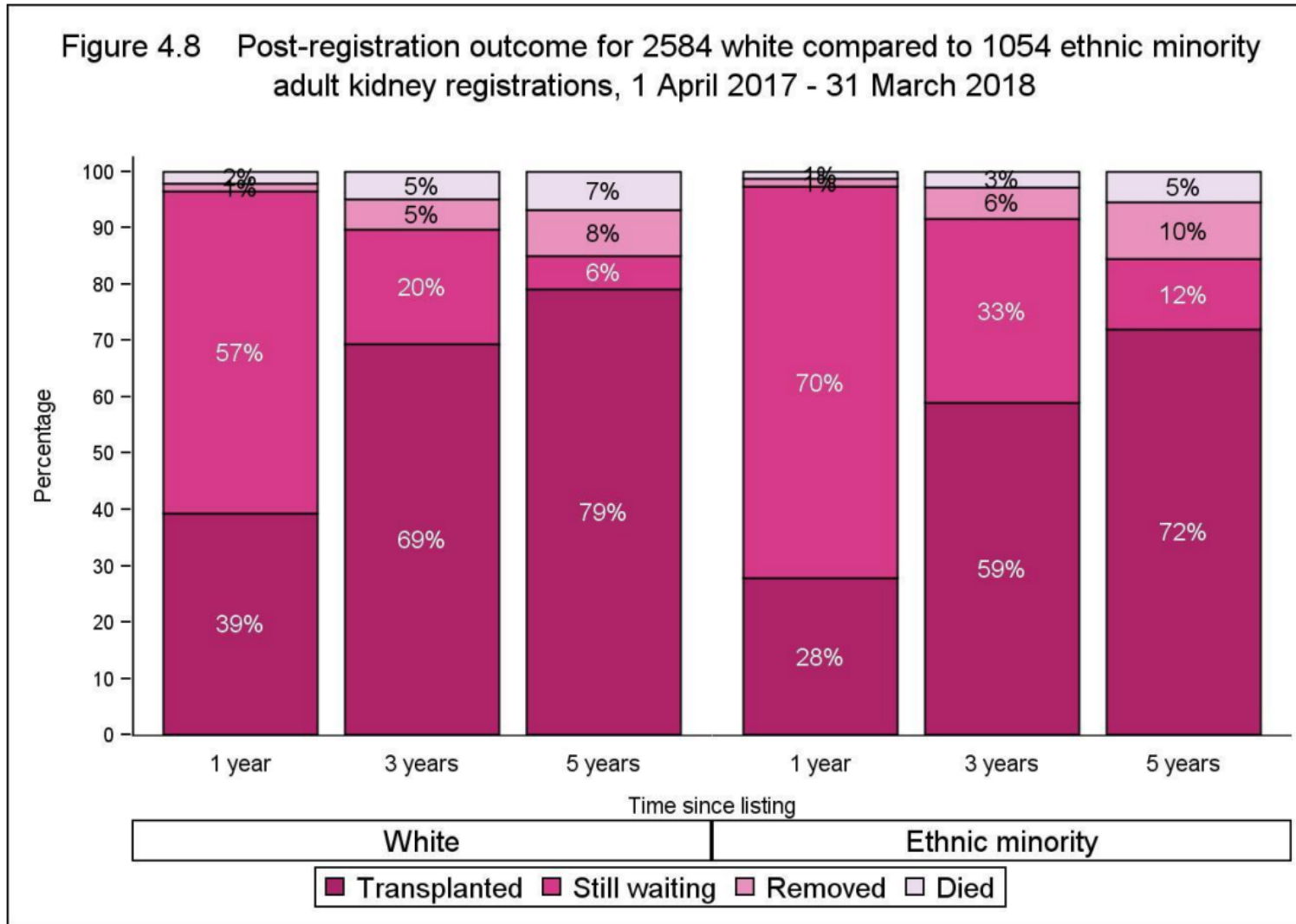


Late referral
Poor education
Lack of cohesion

David Van Dellen WJT
2021



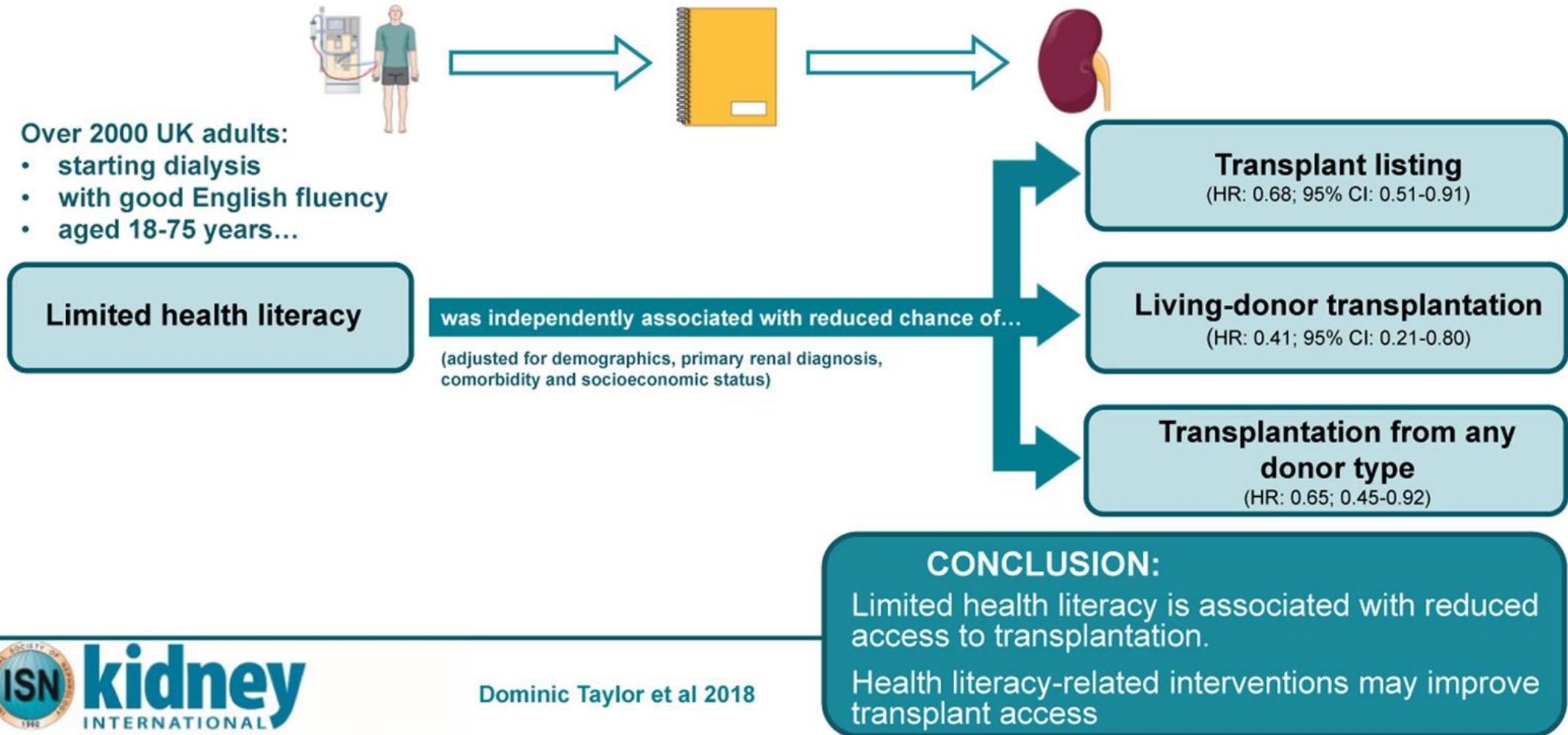
Why timely access and LDKT important



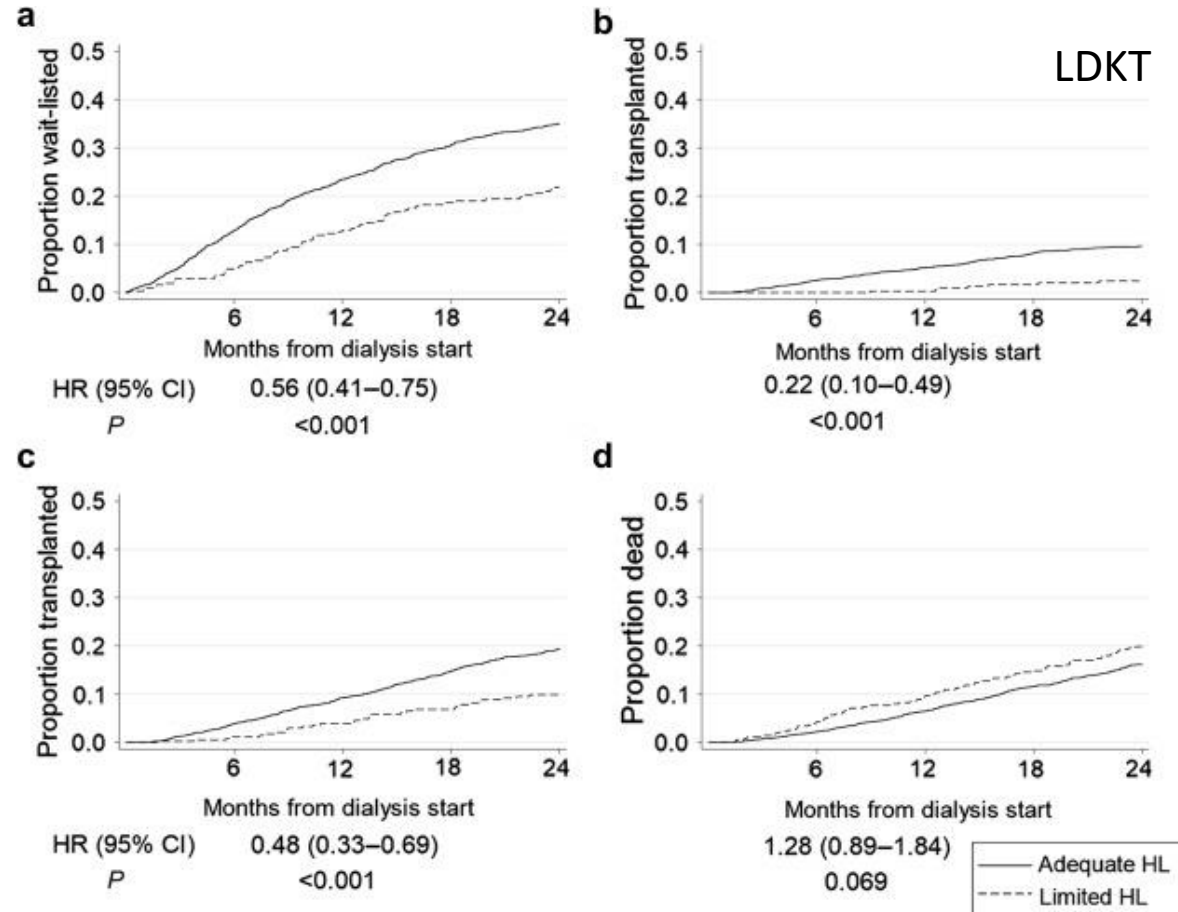
UK national audit – information leaflet

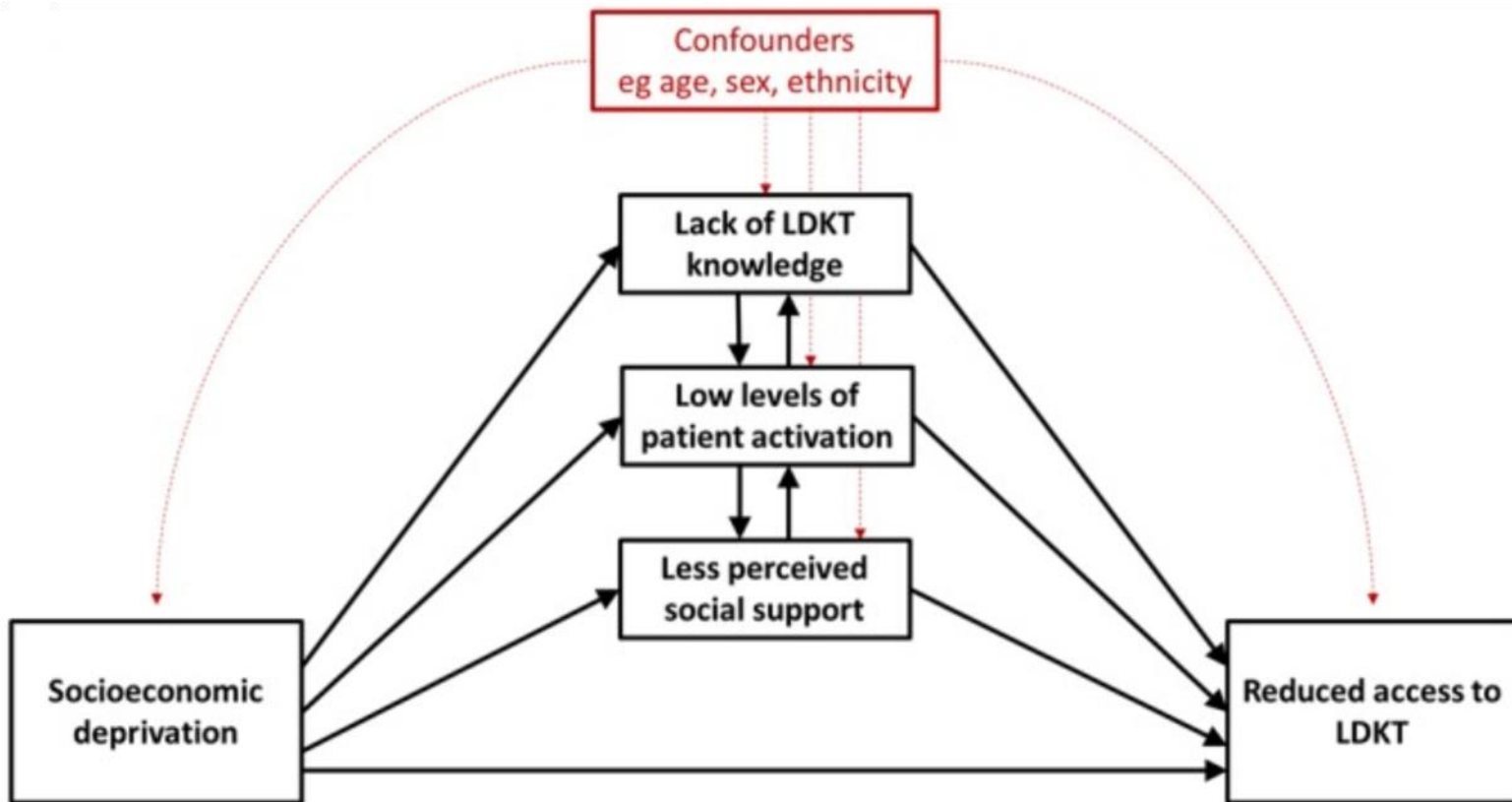
- Twenty-three leaflets were provided and reviewed, mean quality scores for **inclusion of information** known to support shared decision-making was $m = 2.82$ out of 10 (range = 0–6, $SD = 1.53$).
- **Readability scores** indicated they were ‘fairly difficult to read’ ($M = 56.3$, range = 0–100, $SD = 9.4$).
- Few included cultural and faith information.
- Two leaflets were designed to facilitate conversations with others about donation.

Limited health literacy is associated with reduced access to kidney transplantation



Health literacy





Higher income
Education

Better knowledge,
activation and social
support

Mediated about
50% of LDKT

Inter-sectionality

- Found sex and ethnicity
- But not SE and other confounders

But small proportion of ethnic minority (171 of 1240), thus might not be transferrable

Why family members were perceived by kidney patients as unsuitable as living kidney donors

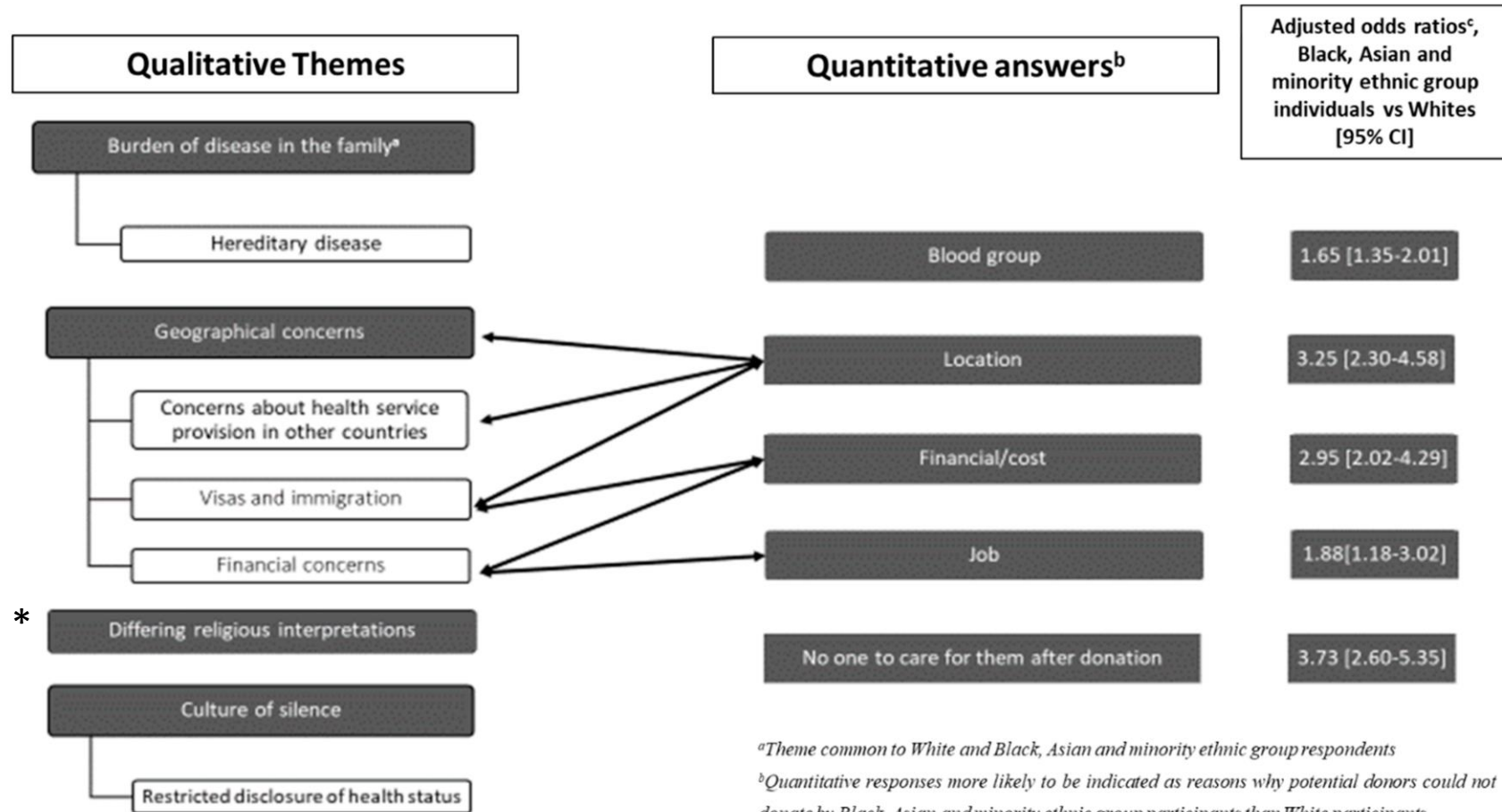
Reported Reason Potential Donor not Suitable for Donation	White <i>n</i> = 1027, <i>n</i> (%)	Black, Asian and Minority Ethnic Group <i>n</i> = <i>n</i> (%)	White vs. Black, Asian and Minority Ethnic Group Chi ² <i>p</i> -Value
Age—too old or too young to donate	562 (54.8)	94 (55.0)	0.96
Health—not healthy enough to donate	648 (63.2)	109 (63.7)	0.88
Weight—too over or underweight to donate	152 (14.8)	30 (17.5)	0.36
Location—they live too far away to be able to donate	188 (18.3)	72 (42.1)	<0.001
Financial/cost—the financial impact of donation would be too much	98 (9.6)	40 (23.4)	<0.001
Job—not able to take the time off work to donate	106 (10.3)	29 (17.0)	<0.001
Blood group—not the right blood group to donate	199 (19.4)	51 (29.8)	0.002
No-one to care for them after donation	63 (6.1)	32 (18.7)	<0.001

all individuals who received kidney transplants between 1/4/13 and 31/3/17, stratified by LDKT/DDKT

notes

- All transplant recipients (40% return rate)
- Most participants had not asked any of their relatives to donate (n = 848/1181, 71.8%).
- In total, 81.8% (n = 973/1189) reported that one or more relative had offered to donate, with 85.6% of these actually starting donor assessment (representing 14.4% attrition).
- Questionnaire (English language)

Logistics and concerns

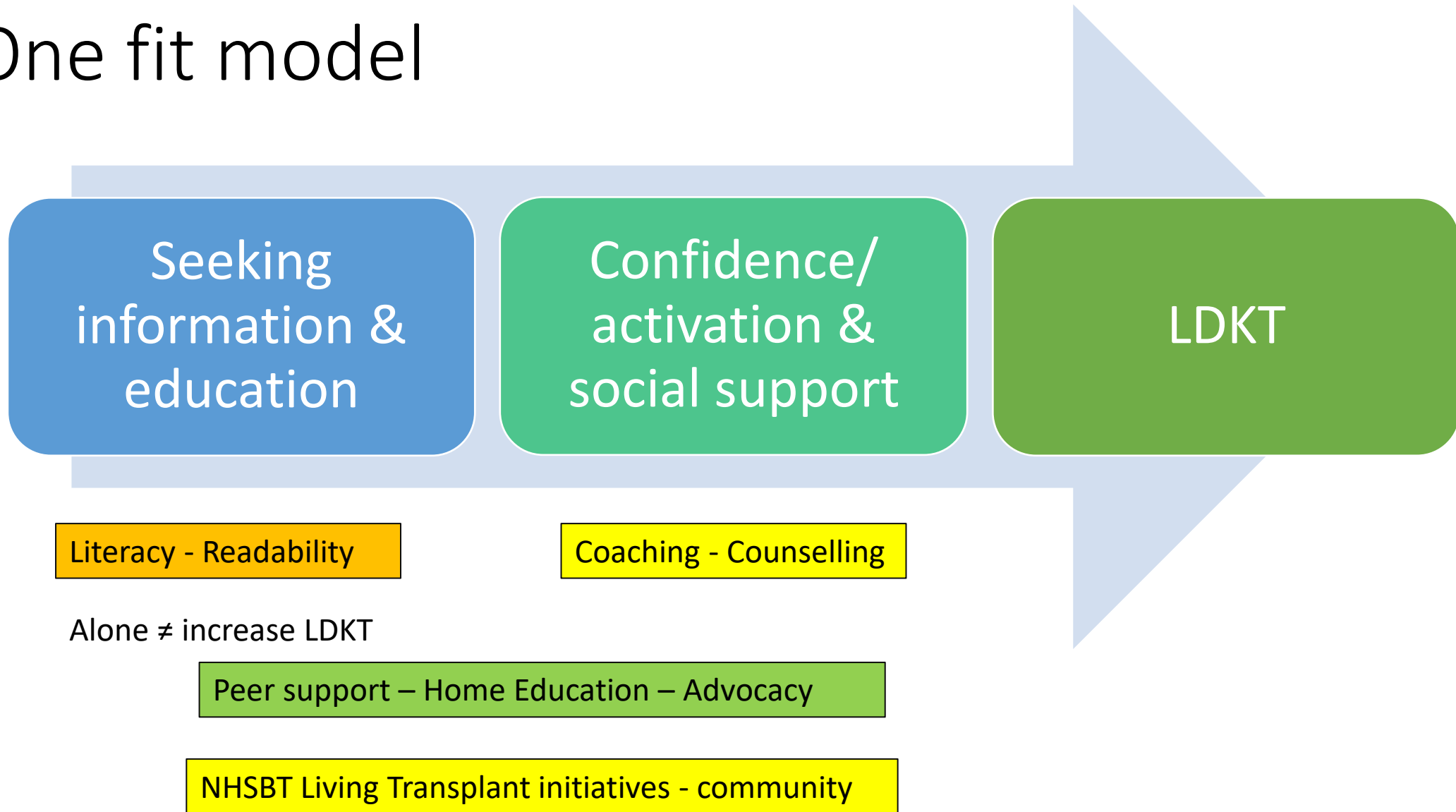


^aTheme common to White and Black, Asian and minority ethnic group respondents

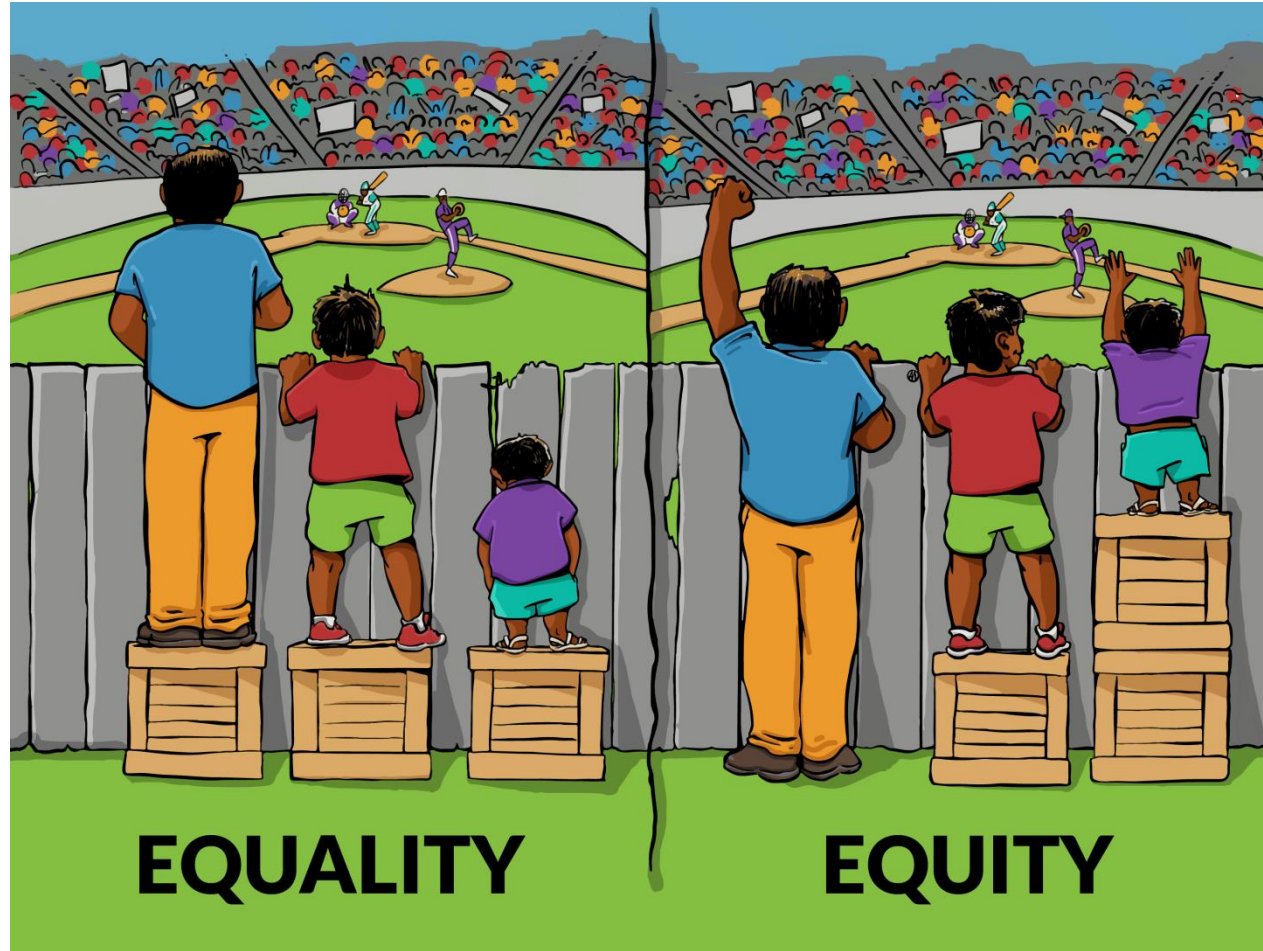
^bQuantitative responses more likely to be indicated as reasons why potential donors could not donate by Black, Asian and minority ethnic group participants than White participants

^cAdjusted for age and sex

One fit model



Solution – more resources?



The ASK trial: complex multicomponent intervention

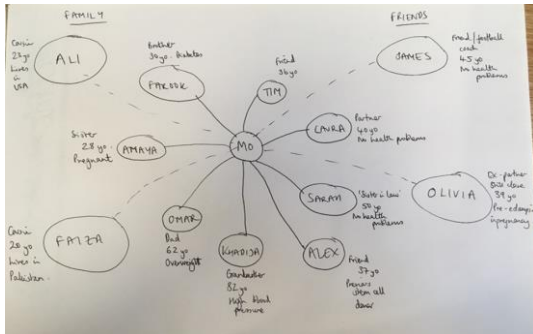
- a two-arm, parallel group, pragmatic individually-randomised controlled feasibility trial (n=62) of a complex multicomponent intervention to improve AccesS to Kidney transplantation

Intervention

1. One-to-one meeting with LDKT specialist

- Discuss LDKT, their family members' awareness of their kidney disease, and potential donor candidacy.

- Sociogram



2. Written outreach to family and friends

3. Home-based family engagement and education



- Introduction to healthy kidneys
- Kidney disease
- Dialysis
- Transplantation
- Living donor kidney transplants
- Living kidney donation
- How people can find out more

A) Is the intervention acceptable and deliverable? B) Is an RCT possible?

Participant inclusion criteria

1. English-speaking adults (age ≥ 18 years)
2. Individuals active on the UK Kidney Transplant only waiting list
3. Individuals who do not have any potential living kidney donors currently undergoing surgical assessment for donation

Equality and diversity of participation

Variable	Eligible n=300	Invited n=183	Participants n=62	Non- participants n=121
Sex - number female (%)	95 (32)	56 (31)	18 (29)	38 (31)
Age group n (%)				
≤25 years	4 (1)	1 (1)	0	1 (1)
26-45 years	74 (25)	43 (23)	16 (26)	27 (22)
46-65 years	163 (54)	102 (56)	32 (52)	70 (60)
>65 years	59 (20)	37 (20)	14 (23)	23 (19)
Socioeconomic position				
EIMD decile ≤ 5 (most deprived) n (%)	154 (51)	97 (53)	30 (48)	67 (55)
Ethnicity - Participants from Black, Asian, Other ethnic groups n (%)	66 (22)	43 (23)	17 (27)	26 (21)

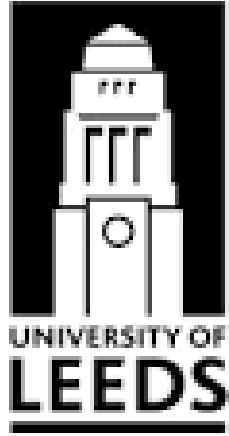
Results



- The feasibility trial was not powered to determine intervention effectiveness, but findings inform the sample-size calculation for the effectiveness RCT.
 - 28% of intervention arm had donors in assessment vs. 10% in usual care arm.
 - 6% of intervention arm have received a LDKT vs. 0% in usual care arm.

Summary – Our processes and our patients!

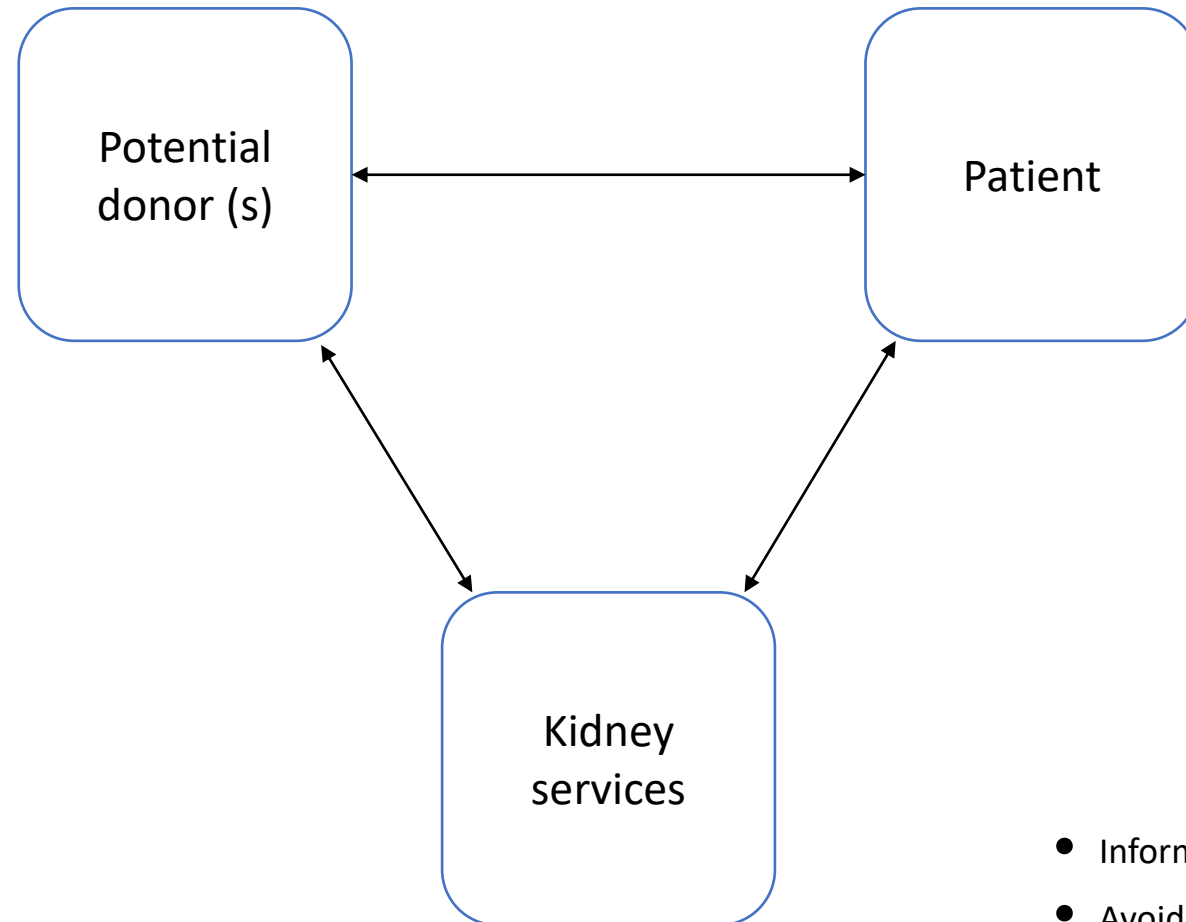




LDKT in underserved groups – Research to clinical practice

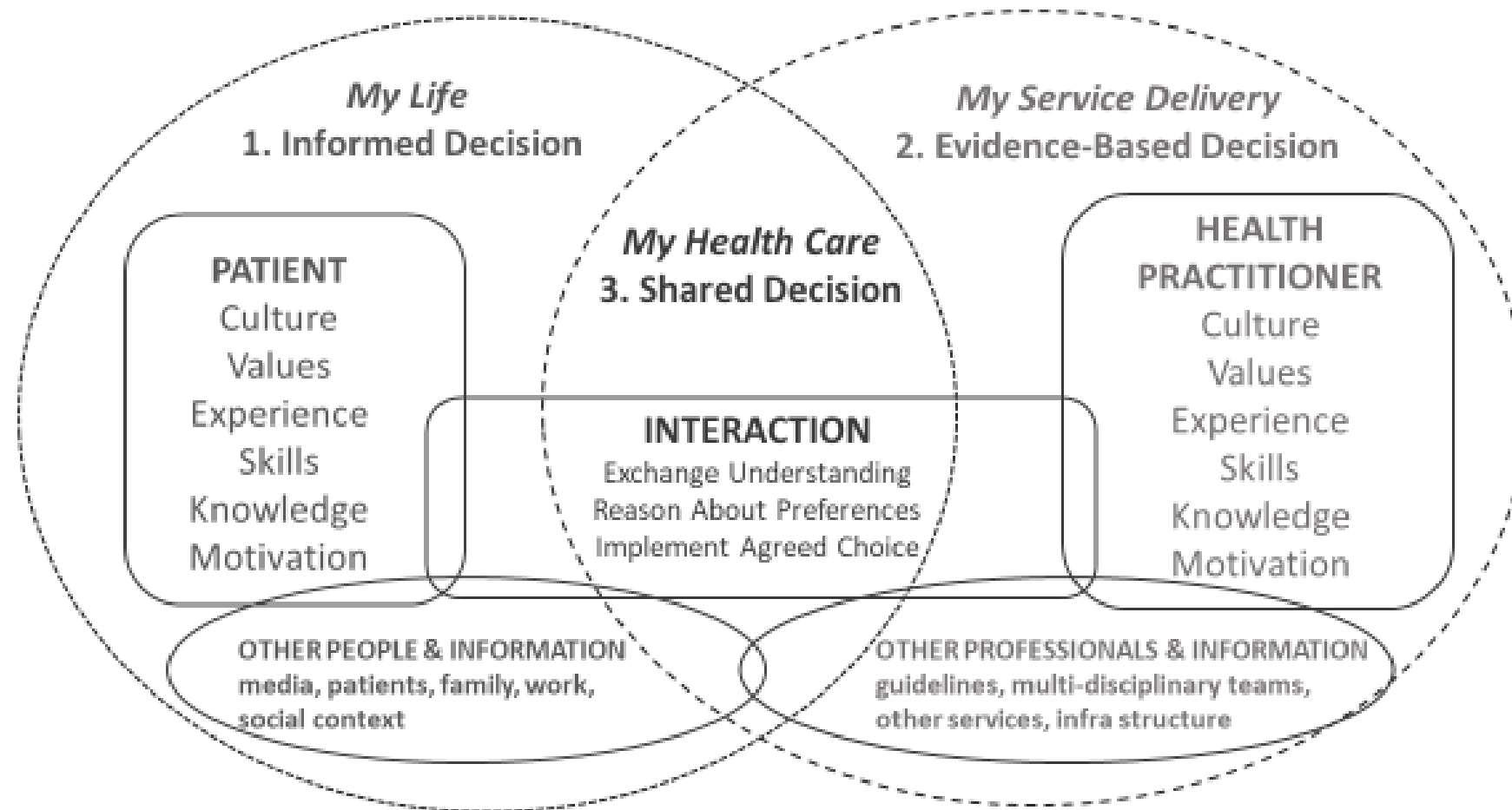
Dr Ahmed Ahmed
Nephrologist, LTHT

LDKT decision making



- Information- decision making support
- Avoiding coercion/ ensuring voluntary donation

Making Informed Decisions Individually and Together (MIND-IT) Framework: Multiple-Stakeholder Decision Maker Roles in Healthcare (©Bekker 2015).



First published in Breckenridge et al, Nephrol Dial Transplant. 2015. [10.1093/ndt/gfv209](https://doi.org/10.1093/ndt/gfv209)

Aim

- Understand patients' decisional needs around LDKT
- Under- researched & under-served groups
- Inform interventions to improve LDKT

Minority ethnic groups
Women
Socially deprived



Studies

1. People with AKD – The underserved/Under-represented in research

- Minority ethnic groups- Non- English speaking
- Socially disadvantaged
- Women

2. Healthcare professionals supporting patient decision making

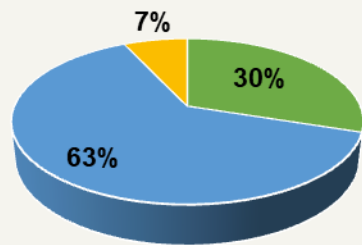
- Transplant coordinators
- Transplant surgeons
- Nephrologists

- Decisional needs
- Inform service provision
- Guide interventions

Methods

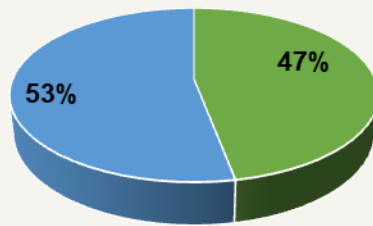
- Semi-structured interviews (N = 30 patients and 19 staff)
- Two renal centres
- Purposive sampling
- Thematic analysis [Braun & Clarke 2006, 2022](#)

Ethnicity



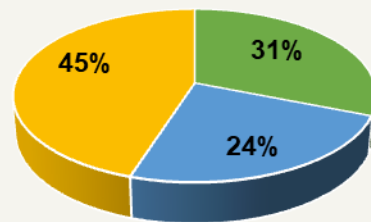
■ White ■ S Asian ■ Black

Gender



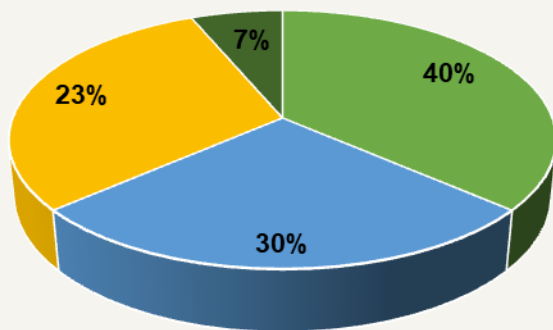
■ Male ■ Female

RRT



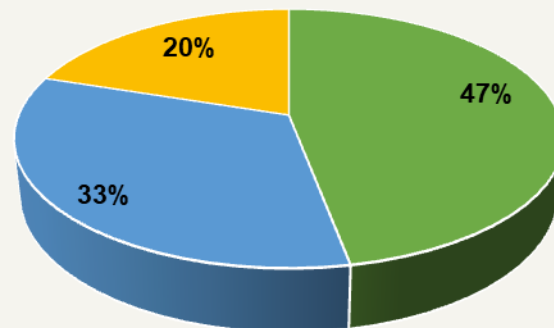
■ LDKT ■ DDKT ■ Waiting list

Education



■ School ■ College
■ University ■ Higher studies

IMD Deprivation Decile



■ (1-3) ■ (4-7) ■ (8-10)

Themes..

KNOWLEDGE

- Benefits of LDKT
- Health implications for donors
- Financial and logistical support.

FAMILY AND SOCIAL MATTERS

- Donor-recipient relationship
- Guilt
- Fear of isolation and concerns about future

DELIBERATION AND VALIDATION

- Religion & fate
- Cultural norms
- Meet others Tx recipients
- Financial and health risks

Patient-facing materials

- Readability & Language
- Content (Culture, faith and transplantation)

Deliberation and validation

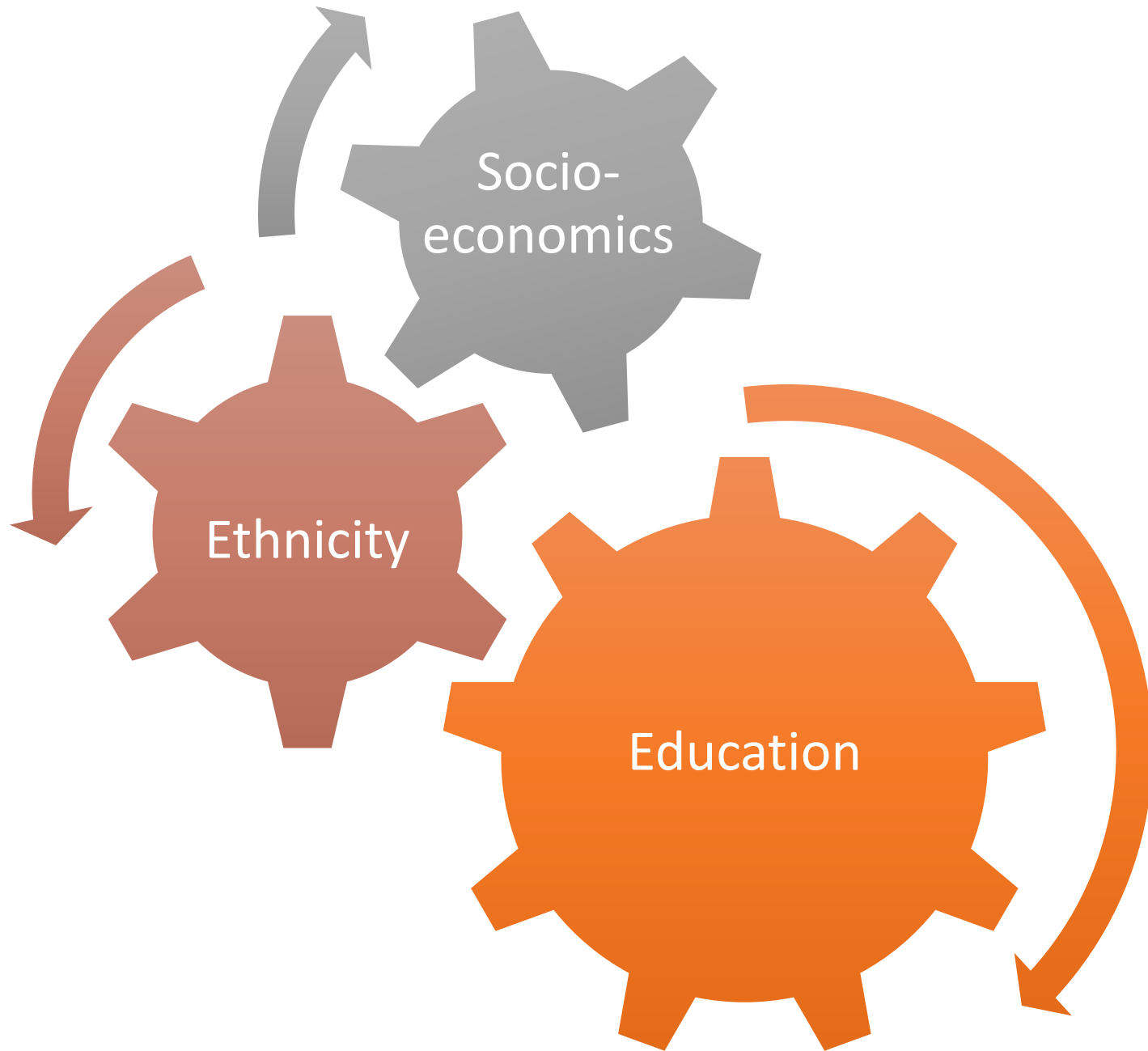
Interpreted as: "I am not sure if I am allowed to have kidney from non-Muslim person, I don't know if I will accept"

52 M, South Asian, School, Urdu

Interpreted as: "This is my fate (Referring to dialysis), I just thank God that my children are ok, I just have to be thankful to God and do my treatments"

Interpreted as "I am there to look after my family, I don't want my kids to sacrifice for me, if it was the opposite I will give them kidney because this how it should be, not the other way around".

"53 F, South Asian, School, Urdu, Waiting list"



Inter-sectional
of demographic
characteristics

Intersectionality

"I am not sure if I am allowed to have kidney from non-Muslim person, I don't know if I will accept"

52 M, South Asian, Waiting list, Urdu speaking, School, IMD 2

VS

"I know that my religion allow me to have kidney transplant, but I know some of our community might not agree"

44 F, South Asian, LDKT, English speaking, University degree, IMD 9

"When people knew I have kidney problem some of them stopped even visiting us. I don't want my son to go through this"

54 M, South Asian, waiting list, Urdu speaking, School

IMD 3

VS

"I don't have a problem myself, but I think people from my community wouldn't want to ask others for kidney, I don't think it is acceptable".

31 M, South Asian, English speaking, Post-grad degree, Waiting list, IMD 8

Interpreted as "I don't know how long people wait, but I don't care, I just do my treatment and wait for my turn"

53 F, South Asian, Waiting list, Urdu speaking, School, IMD 1

VS

I was told that I will not get matching kidney easily and I have to wait more than three years on dialysis, that's when I started thinking seriously about talking to my family in Zambia"

60 M, Black African, English speaking, University, LDKT, IMD 7

Decisional needs of people from minority ethnic groups around living donor kidney transplantation: A UK healthcare professionals' perspective

Purpose

To understand kidney healthcare professionals' perspectives on the needs of people with kidney failure making decisions about living kidney donation (LDKT)



Methods

Semi-structured interviews in 2 renal centres



Sample (n=19)

Transplant-coordinators (n=8)
Nephrologists (n=7)
Transplant surgeons (n=3)
Specialist nurses (n=1)

Decisional needs

People with advanced kidney disease



Knowledge



Religion & culture



Risk perception

Patient information resources



Suitability of patient-facing resources



Timing and setting of education

Kidney healthcare professionals



Language barriers



Staff diversity



Trusted personnel



Cultural awareness

Recommendations

For centres with >20% minority ethnic patient groups, we suggest:

1. Review current information resources to ensure suitability with non-English speakers and those with poor health literacy
2. Use educational events and community platforms to improve understanding and engagement about LDKT
3. Appoint a living donor co-ordinator in transplant referring centres
4. Enhance ethnic diversity of the front-line Staff
5. Provide and maintain diversity and cultural awareness staff training
6. Further research to develop decision support interventions that adequately support people from ethnic minority groups

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¹Leeds Teaching Hospitals NHS Trust, ²University of Leeds, ³Bradford Teaching Hospitals NHS Foundation Trust, United Kingdom

Key messages

- D-M needs (and how to meets them) can vary
- Barriers are not set at one level but rather multi-faceted
- No “one size fits all” solution- Seek holistic approach
- Resources needs to be adapted to suit under-served groups, those with combined factors (ethnicity, education, language barriers)



Setting

Transplant listing clinic

Have you approached friends and/or family members and spoken to them about kidney transplantation?

YES

NO

Have (any of) your potential donors been in touch with the hospital to start the donation process?

YES

YES

NO

Explore if further support and information required

NO

Research study

Exploratory questions and if barrier identified and support accepted by recipient

NO

Revisit in 6/12 (CNS or Consultant in charge of patient)

YES

Questions to patient

Barriers - Can you tell me why you haven't spoken to anyone about donation

Potential responses

Don't know how to start the conversation

Fears and guilt around asking donation

Unsure about the LDKT

Financial/logistical concerns

Religious/cultural

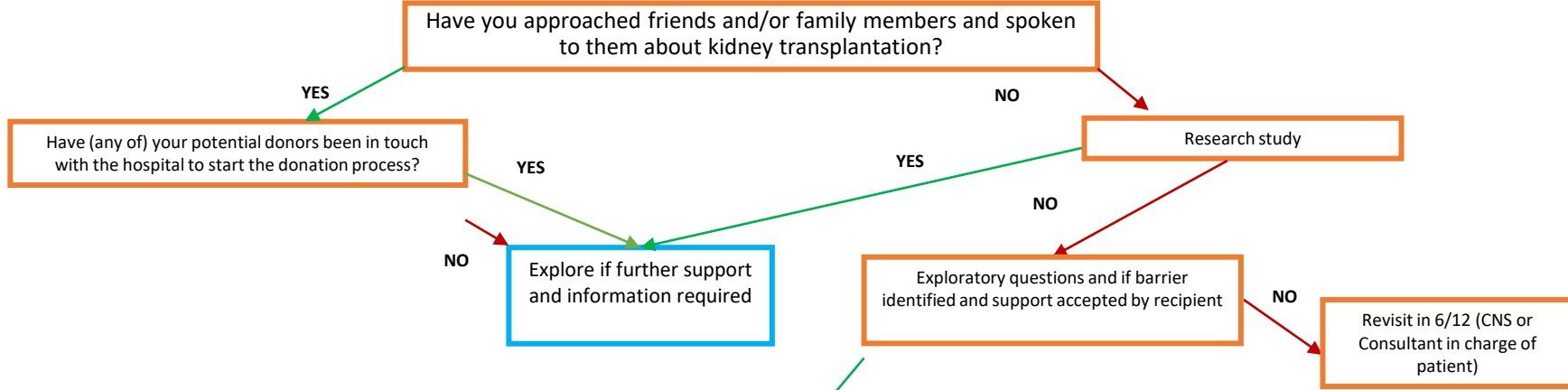
Other

Possible Supporting services and resources



Plenary discussion

- What new resources do we need?
- How can these be delivered?
- What other changes in service provision can be made to achieve a sustainable equity to all.



Questions to patient

Barriers - Can you tell me why you haven't spoken to anyone about donation

Potential responses

- Don't know how to start the conversation
- Fears and guilt around asking donation
- Unsure about the LDKT
- Financial/logistical concerns
- Religious/cultural
- Other

Supporting services and resources

- Difficult Conversations Booklet to support conversations
- 1 to 1 coaching
- Counselling
- Further face to face discussion
- Booklet
- Website
- KCUK or NKF information

Additional checks/points to consider

- Peer Support
- Describe the purpose, referral process and waiting times
- Check if family members/others are required at the meeting
- Check preference for language/ability to read/understand English