Access to and availability of LDKT in the UK

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Outline of talk

• What do we mean by access?
• Is access to LDKT equal and fair in the UK?
  • Who is disadvantaged?
  • Why?
• Focus on socioeconomic deprivation
• Interventions
Access to living-donor kidney transplantation

For people to be able to access a living-donor kidney transplant they need

i) the opportunity
Opportunity

- AVAILABLE
- AFFORDABLE
- ACCEPTABLE
- ADEQUATE SUPPLY
Access to living-donor kidney transplantation

For people to be able to access a living-donor kidney transplant they need

i) the opportunity

AND

ii) the means
Do all kidney patients have equal access to living-donor kidney transplantation?
Do all kidney patients have equal access to living-donor kidney transplantation?
Where you live matters...
Living donor kidney transplant rates (pmp) by recipient country/Strategic Health Authority of residence

Source: Annual Report on Kidney Transplantation 2017/18, NHS Blood and Transplant
Adult Living donor kidney transplants (pmp) in the UK, 1 April 2017 - 31 March 2018

Source: Annual Report on Living Donor Kidney Transplantation 2017/18, NHS Blood and Transplant
Why does access vary across centres?

• Variation in acceptance of living donors
• Variation in process – work up
• Variation in clinical population
• Clinician attitude to LDKT?
• Healthcare staff and system capacity?

Arunachalam C et al. NDT 2013;28(7): 1952-60
Who you are matters...
Socioeconomic position

Age group
- 18 - 34
- 35 - 49
- 50 - 64
- 65 - 75

Ethnicity
- White
- Asian
- Black
- Other

Civil Status
- Married
- Divorced
- Single

Qualifications
- Higher
- Secondary
- None

Car ownership
- Yes
- No

Home ownership
- Yes
- No

Country
- N. Ireland
- England
- Wales
- Scotland

Odds Ratio [95% CI]

1 [reference]
0.34 [0.25 - 0.46]
0.19 [0.14 - 0.27]
0.11 [0.08 - 0.17]
0.55 [0.39 - 0.77]
0.64 [0.42 - 0.99]
0.46 [0.19 - 1.11]
1 [reference]
0.63 [0.46 - 0.88]
0.77 [0.58 - 1.02]
1 [reference]
0.76 [0.59 - 0.97]
0.55 [0.42 - 0.74]
1 [reference]
0.51 [0.37 - 0.72]
1 [reference]
0.65 [0.49 - 0.85]
1 [reference]
0.31 [0.18 - 0.53]
0.27 [0.13 - 0.50]
0.22 [0.12 - 0.41]
If you are older, more deprived, or from a non-white ethnic group you are less likely to get a living-donor kidney transplant...
If you are older, more deprived, or from a non-white ethnic group you are less likely to get a living-donor kidney transplant...

BUT WHY?
How do age, socioeconomic deprivation and ethnicity affect these steps?

- Number of potential donors?
- Donor knowledge?
- Donor willingness?
- Donors ability to attend work up?
- Donor withdrawal?
- Donor health?
- Duration of work up?
- Doctor sign off?

Pool of potential donors → Those with whom donation is discussed → Those agreeing to work-up → Donors fit for donation

Knowledge about LDKTs?
Attitudes towards LDKTs?
Confidence speaking to possible donors?
Willingness to accept an offer?
People with kidney disease

Potential donors

Healthcare workers

Healthcare system
If you are more deprived you are less likely to get a living-donor kidney transplant... **WHY?**
Socioeconomic deprivation

• The social and economic disadvantage of an individual or group relative to others in society.

• More than just a lack of money.
Measures of socioeconomic deprivation

- Incorporates some assessment of social standing and assets:
  - Education, occupation, employment, income, housing tenure, household amenities, car ownership
  - Individual level vs area level e.g. Index of Multiple Deprivation

The English Indices of Deprivation 2015
ATTOM study

Those agreeing to work-up

Donors fit for donation

"Deprived donors more likely to have high BMIs and health problems."

"Deprived donors more likely to drop out of work up."
Study Design and Methods

- Multicentre prospective cohort study
- 7 renal units in England and Wales
  - Bristol
  - Cambridge
  - Cardiff
  - Newcastle
  - Stoke
  - Preston
  - Swansea
- Data were collected on all individuals who started living kidney donor assessment between 01/08/14 and 31/1/16
805 potential donors

112 actual donors

Were socioeconomically deprived donors more likely to be unfit for donation?

No

| Potential donor characteristic | Least deprived | | | | | | Most deprived | p value |
|-------------------------------|---------------|---|---|---|---|---|---|---|---|
| Median BMI (kg/m²) (IQR)      | 26.3 (5.9)    | 26.8 (5.5) | 26.9 (6.7) | 26.8 (5.3) | 27.6 (8.5) | 0.1 |
| Active comorbidity             |               |               |               |               |               |     |
| • 0                            | 95 (64.6)     | 121 (74.2)   | 97 (71.9)    | 79 (61.7)    | 127 (72.6)  | 0.41 |
| • 1                            | 41 (27.9)     | 36 (22.1)    | 31 (23.0)    | 36 (28.1)    | 35 (20.0)   |     |
| • 2                            | 9 (6.1)       | 6 (3.7)      | 6 (4.4)      | 10 (7.8)     | 10 (5.7)    |     |
| • 3 or more                    | 2 (1.4)       | 0            | 1 (0.7)      | 3 (2.3)      | 3 (1.7)     |     |

Were socioeconomically deprived donors less likely to donate?

No

Log regression analysis: likelihood (OR) of donating, per +1 IMD quintile, p value for linear trend 0.12

Were socioeconomically deprived donors more likely to drop out?

No

Log regression analysis: likelihood (OR) of withdrawal, per +1 IMD quintile, p value for linear trend 0.11

Those agreeing to work-up

Donors fit for donation

Those with whom donation is discussed

Pool of potential donors

No apparent barriers to donation that were related to socioeconomic deprivation.
Those agreeing to work-up

Donors fit for donation

Those with whom donation is discussed

Pool of potential donors
Higher socioeconomic deprivation group

Four important barriers:

- Passivity – lack of advocacy

“I went into it a bit blind and I just went with the flow, what people were telling me to do. I didn’t look it up anything, I didn’t take charge of my – I didn’t take charge of anything really. I let people do it for me because I was scared and I didn’t really want to know any details.”

(F, 41-50, IMD quintile 5)
Higher socioeconomic deprivation group

Four themes:

• Passivity – lack of advocacy

• Disempowerment in clinical encounters

“We never discussed having a living donor…I don't think there was ever a discussion—there was never a discussion of having a live donation.”

(Female, 31-40 years, IMD quintile 4)
Higher socioeconomic deprivation group

Four themes:

• Passivity – lack of advocacy
• Disempowerment in clinical encounters
• Lack of social support from potential donors
Lack of social support

“…my mum’s family was quite large but I never really had much to do with them…”
(Female, 61-70, IMD quintile 4)
Higher socioeconomic deprivation group

Four themes:

• Passivity – lack of advocacy
• Disempowerment in clinical encounters
• Lack of social support from potential donors
• Short-term health focus

“I knew you could have transplants...but ... I wasn’t really thinking about- I just thought of what was going to go on now ... I’m the sort of person that doesn’t think five years ahead. I don’t even try and think a year ahead. I think within the next couple of months, whatever. My whole life has been basically not thinking too far ahead.” (Male, 41-50, IMD quintile 5)
Higher socioeconomic deprivation group

Four themes:

• Passivity – lack of advocacy
• Disempowerment in clinical encounters
• Lack of social support from potential donors
• Short-term health focus

Exploring Differences in Transplant Type

Many people with kidney failure want to receive a transplant. We are trying to understand whether certain factors explain why some people get a living donor transplant from a friend or relative, and why some people get a transplant from someone who has died.

If you do not want to answer a question, please just leave it blank.

If you would like help completing the questionnaire, please contact Research Nurse Ann-Marie O’Sullivan 01223 348232 or access the questionnaire online:

https://tinyurl.com/kidney-transplants

We are very grateful for your time.
Questionnaire study

- Asked patients about:
  - The number of people in family
  - Whether family members were suitable
  - Transplant knowledge
  - Beliefs about living kidney donation and transplantation
  - Social support
  - Patient activation
    - ‘the knowledge, skills and confidence’ they have in managing their own health

Study Design and Methods

• Based at 14 renal units in the UK
  • Belfast, Bristol, Birmingham, Cambridge, Guy’s and St Thomas’, Imperial, Leicester, Manchester, Newcastle, Nottingham, Oxford, Sheffield, St Georges, St Helier
• Adults transplanted between 1/4/13 and 31/3/17.
• 1239 questionnaires returned
• Logistic regression and mediation analyses
Findings

- LDKT associated with higher levels of:
  - Transplant knowledge
    - Unpublished data redacted
  - Patient activation
    - Unpublished data redacted
  - Perceived social support
    - Unpublished data redacted
  - Health literacy
    - Taylor D et al, KI 2019, in press
More deprived people:

- Lack knowledge about LDKTs.
- Lack the skills and confidence to pursue a LDKT.
- Feel disempowered and don’t feel engaged in treatment decision making by clinicians.
- Don’t think people close to them would want to donate.
Socioeconomic deprivation → Reduced access to LDKT
Socioeconomic deprivation

- Lack of transplant knowledge
- Low levels of health literacy
- Lack of skills and confidence
- Perceive low levels of social support

Reduced access to LDKT
People who are deprived have the opportunity but not the means to access to a LDKT
What next?
Overcoming barriers
Socioeconomic deprivation

Lack of transplant knowledge

Low levels of health literacy

Lack of skills and confidence

Perceive low levels of social support

Reduced access to LDKT
The ASK trial: improving AccesS to living-donor Kidney transplantation
The ASK trial: improving Access to living-donor Kidney transplantation

Due to start later in 2019
Equal care doesn’t mean equal access
BAME

Reduced access to LDKT
Older age

Reduced access to LDKT

?
Interventions desperately needed...

...but we need to understand the barriers before we can overcome them.
What are the barriers in your units?
What are the barriers in your units?

How do you know?
Importance of understanding your local picture

• Be prepared to find your assumptions are wrong
• Bristol example – clinicians thought we were ‘converting’ approximately 30%-50% of our potential donors to actual donation – it was actually 17%
• BMI wasn’t a barrier specific to people who are deprived
What are the barriers to overcoming these barriers?