

Access to and availability of LDKT in the UK

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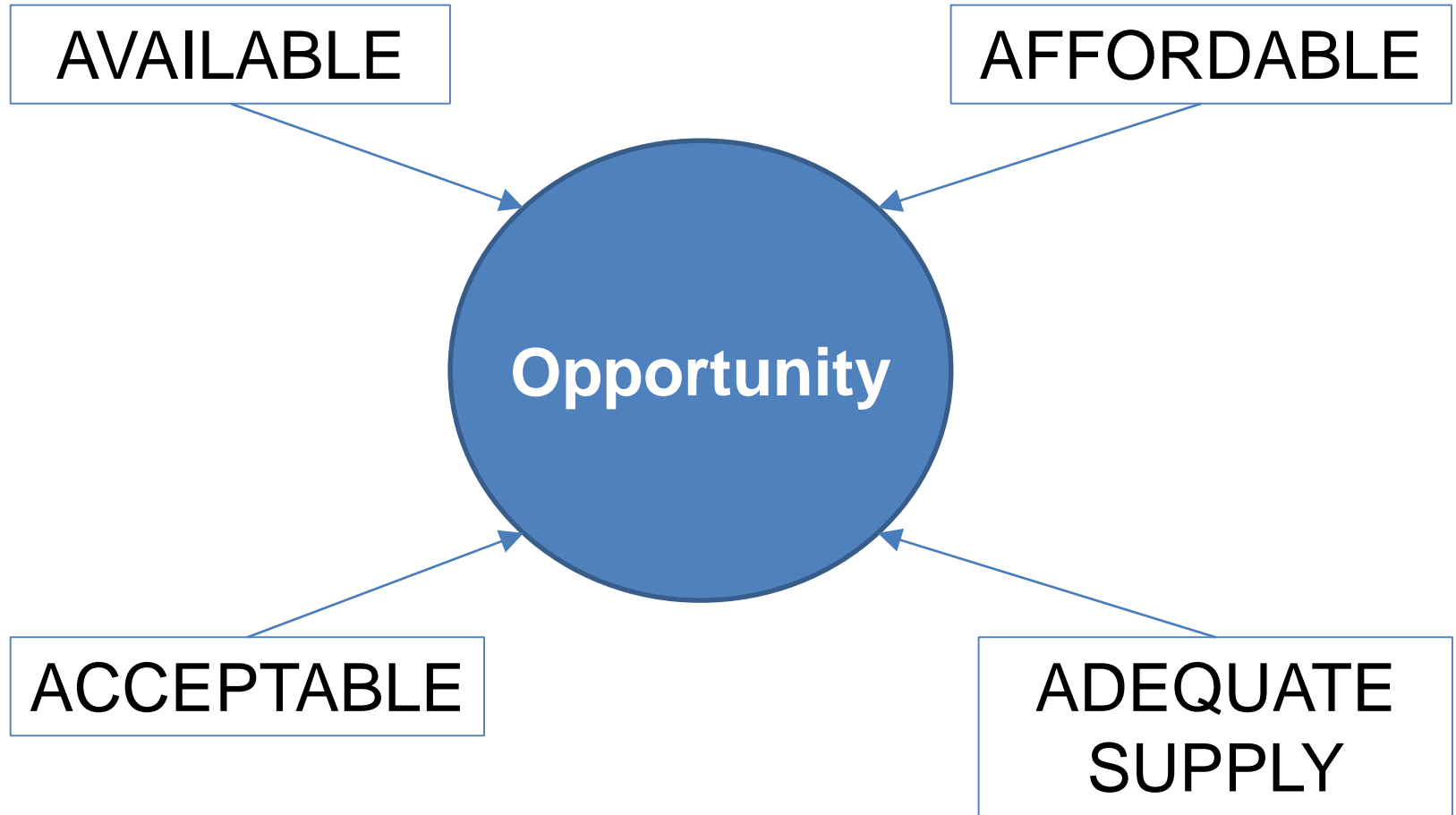
Outline of talk

- 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



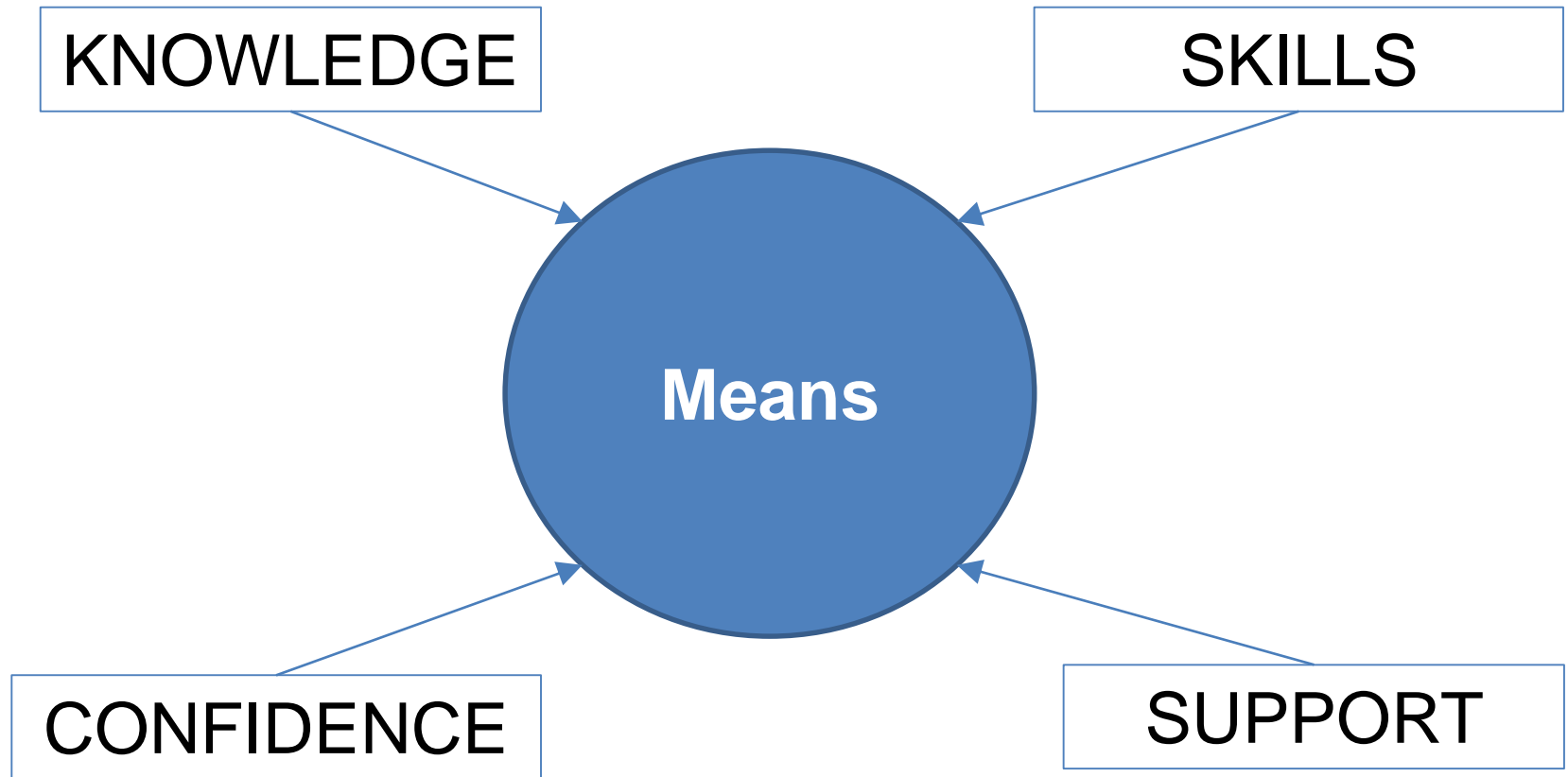
Access to living-donor kidney transplantation

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

i) the opportunity

AND

ii) the means



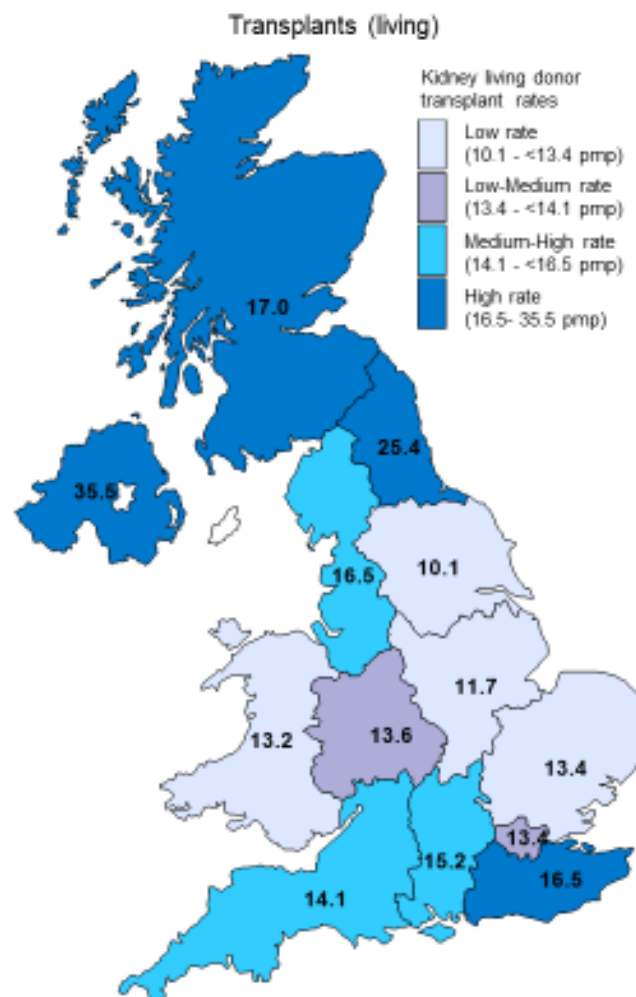
Do all kidney patients have equal access
to living-donor kidney transplantation?

Do all kidney patients have equal access to living-donor kidney transplantation?

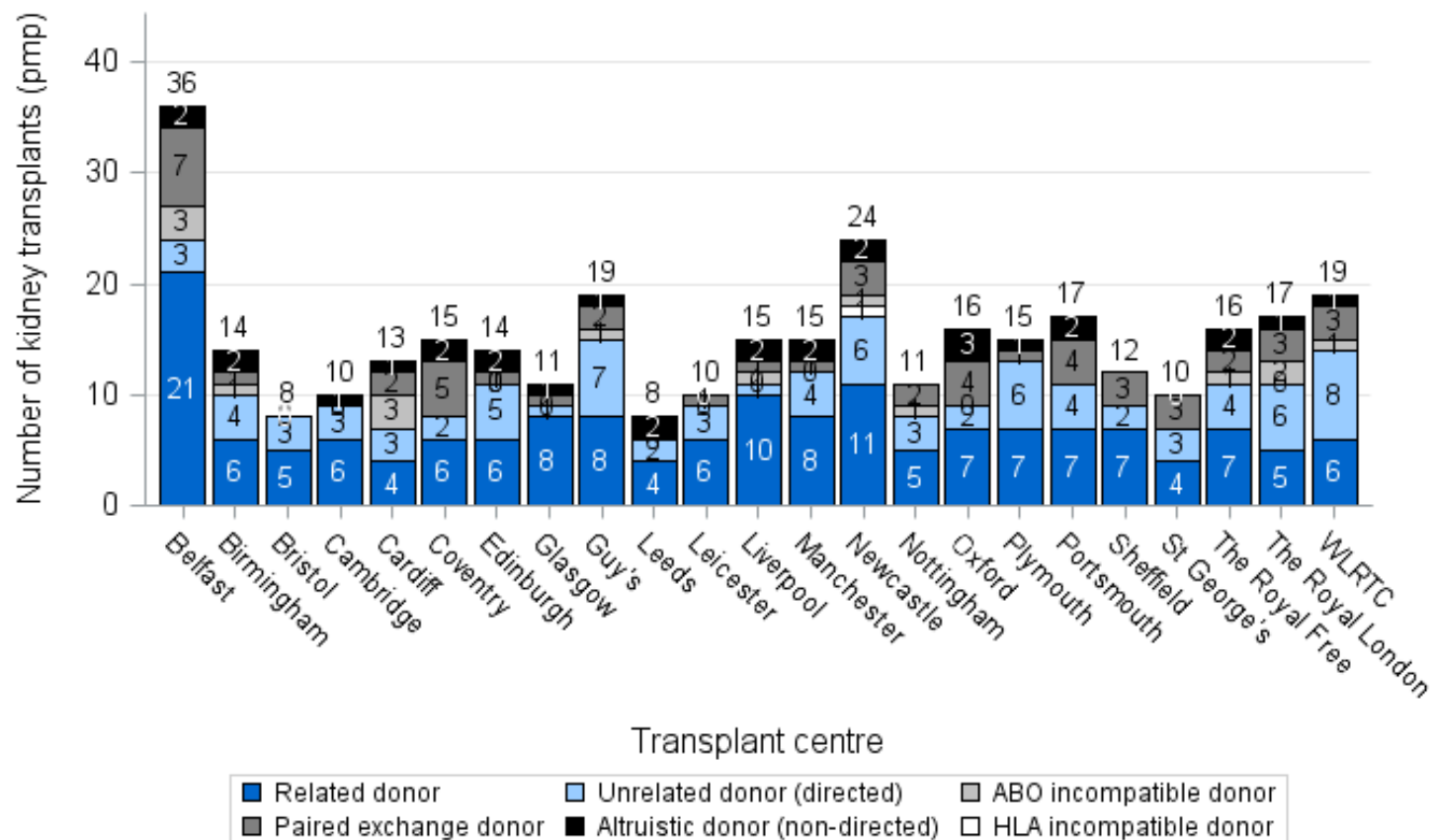


Where you live matters...

Living donor kidney transplant rates (pmp) by recipient country/Strategic Health Authority of residence



Adult Living donor kidney transplants (pmp) in the UK, 1 April 2017 - 31 March 2018

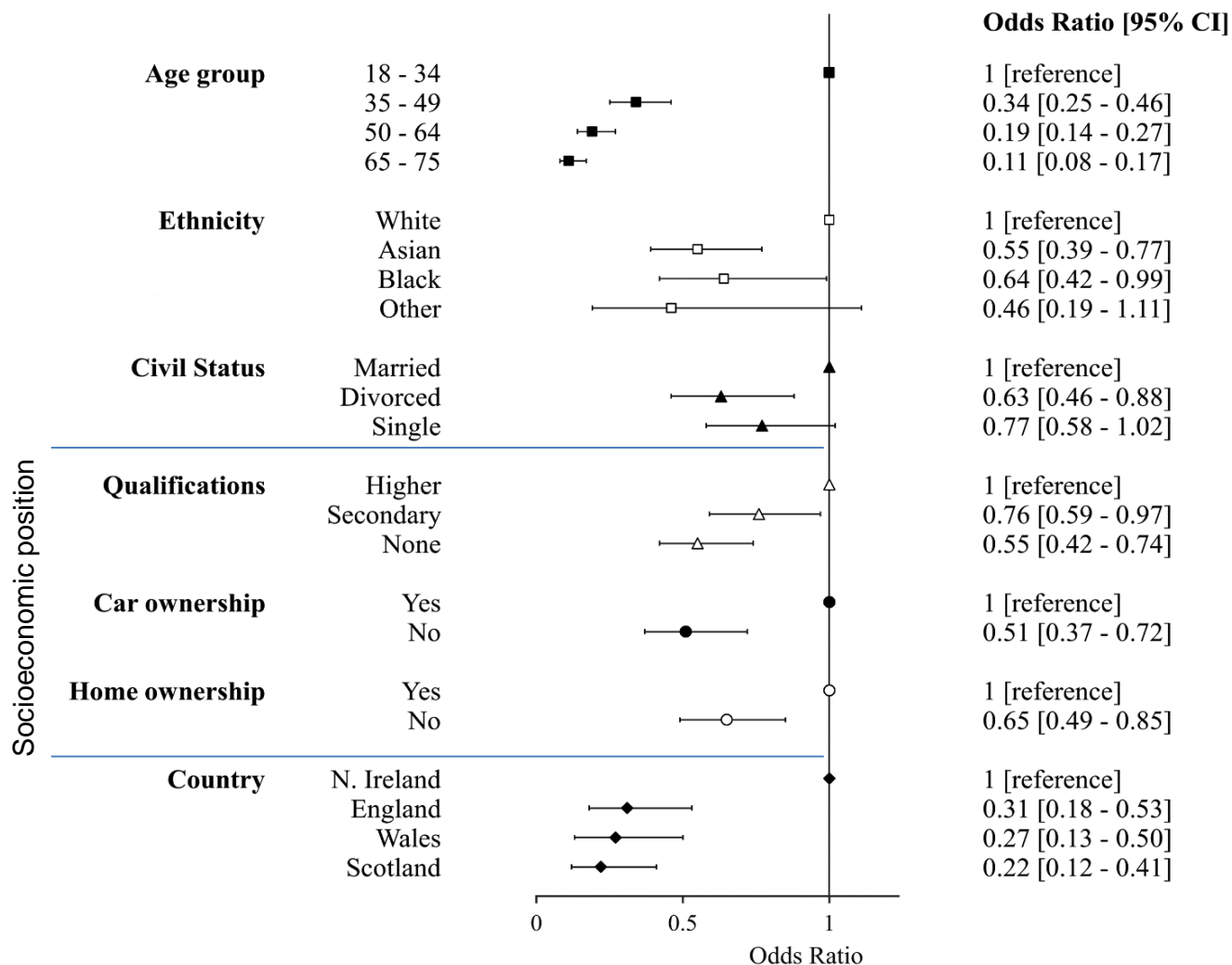


Why does access vary across centres?

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

Who you are matters...

ATTOM study



AGE



SOCIOECONOMIC POSITION



ETHNICITY



If you are older, more deprived, or from a non-white ethnic group you are less likely to get a living-donor kidney transplant...

AGE



SOCIOECONOMIC POSITION



ETHNICITY

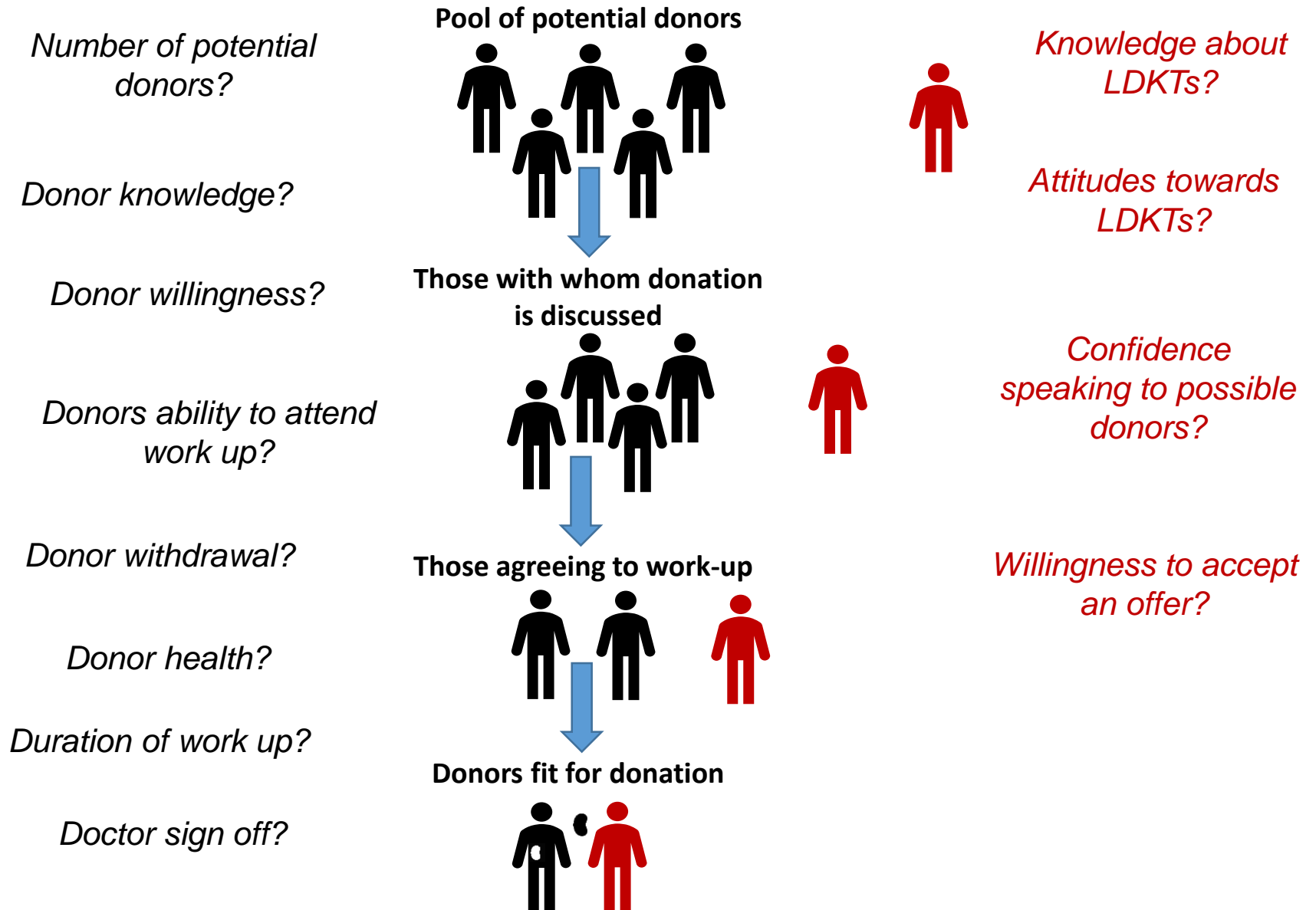


If you are older, more deprived, or from a non-white ethnic group you are less likely to get a living-donor kidney transplant...

BUT WHY?



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



A diagram consisting of four concentric red circles. The text is arranged in layers from the center outwards: 'People with kidney disease' in the center, followed by 'Potential donors', 'Healthcare workers', and 'Healthcare system' in the outermost ring.

Healthcare system

Healthcare workers

Potential donors

People with
kidney disease

AGE



SOCIOECONOMIC POSITION



ETHNICITY



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.

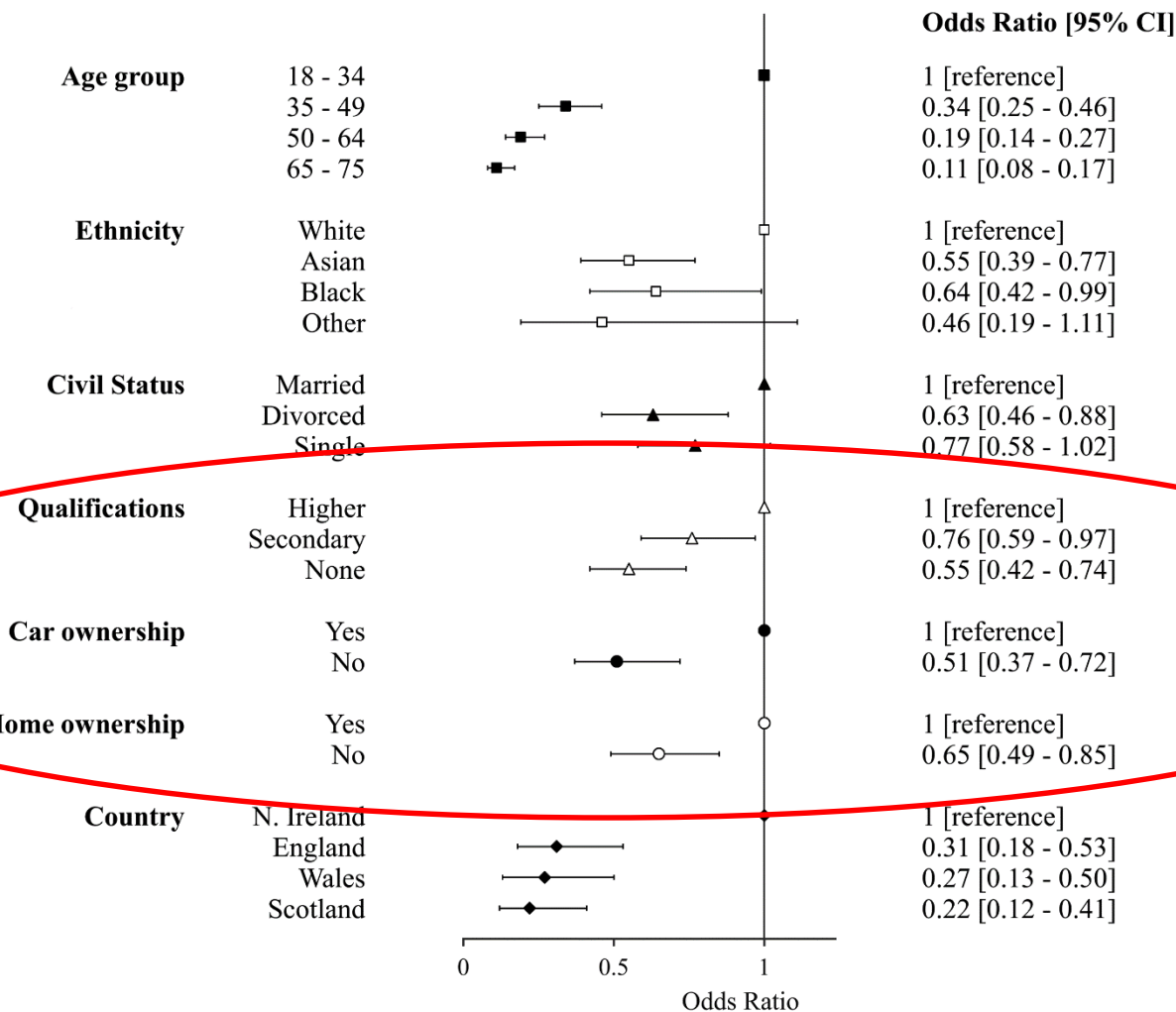


Measures of socioeconomic deprivation

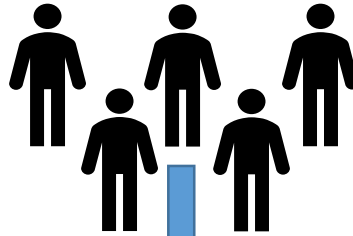
- Incorporates some assessment of social standing and assets:
 - Education, occupation, employment, income, housing tenure, household amenities, car ownership
 - Individual level vs area level e.g. Index of Multiple Deprivation



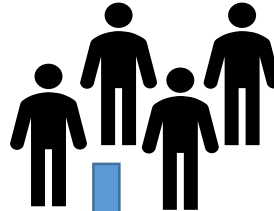
ATTOM study



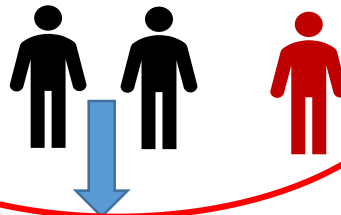
Pool of potential donors



Those with whom donation
is discussed



Those agreeing to work-up



Donors fit for donation



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

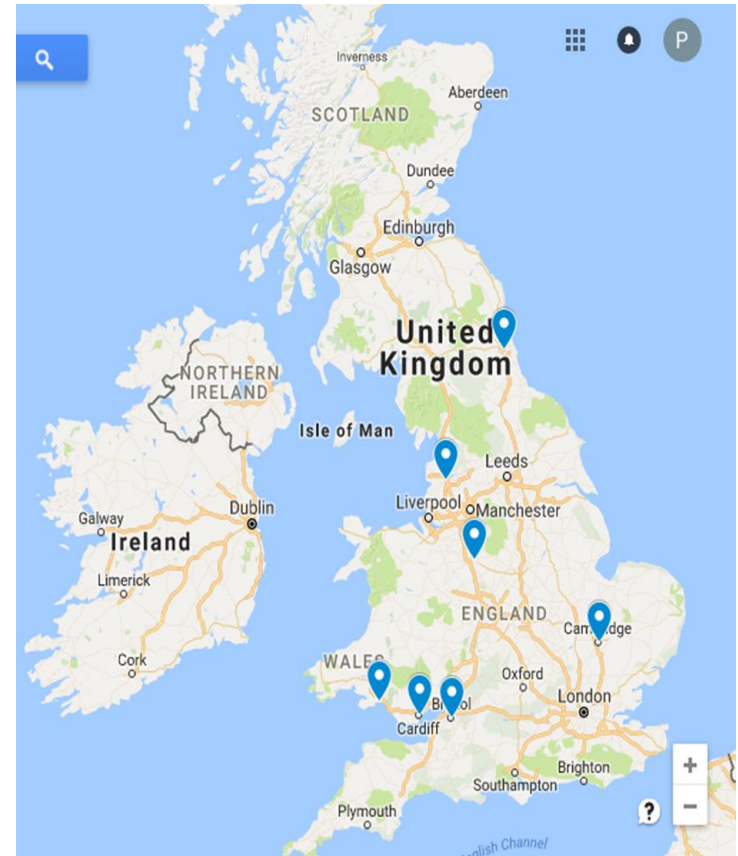


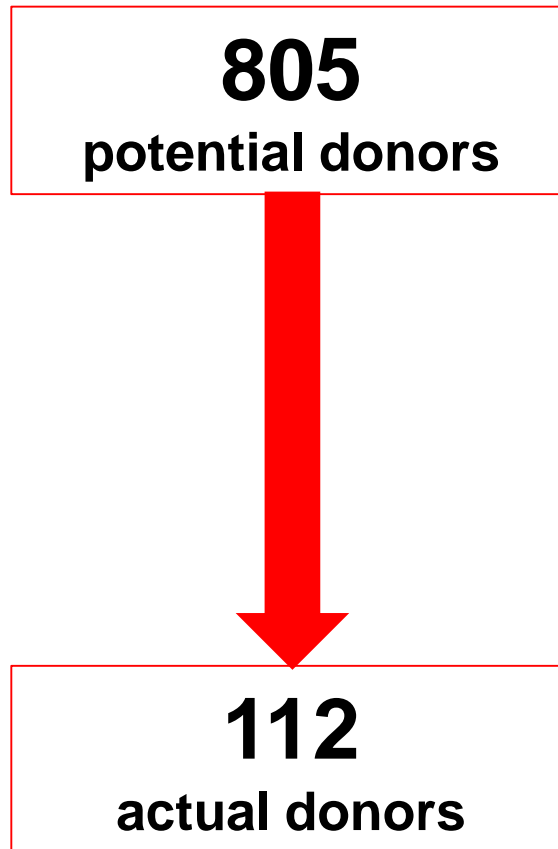
“Deprived donors
more likely to drop
out of work up.”



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





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

No



Potential donor characteristic	Least deprived				Most deprived	p value
Median BMI (kg/m ²) (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



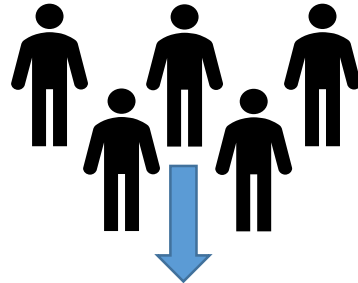
Were socioeconomically deprived donors more likely to drop out?

No

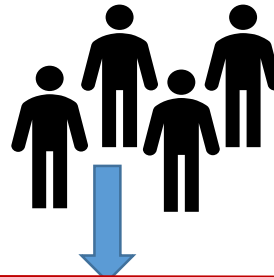
Log regression analysis: likelihood (OR) of withdrawal, per +1 IMD quintile, p value for linear trend 0.11



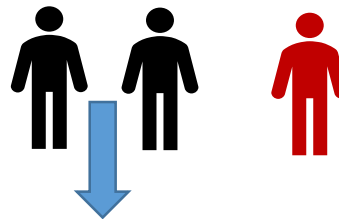
Pool of potential donors



Those with whom donation
is discussed



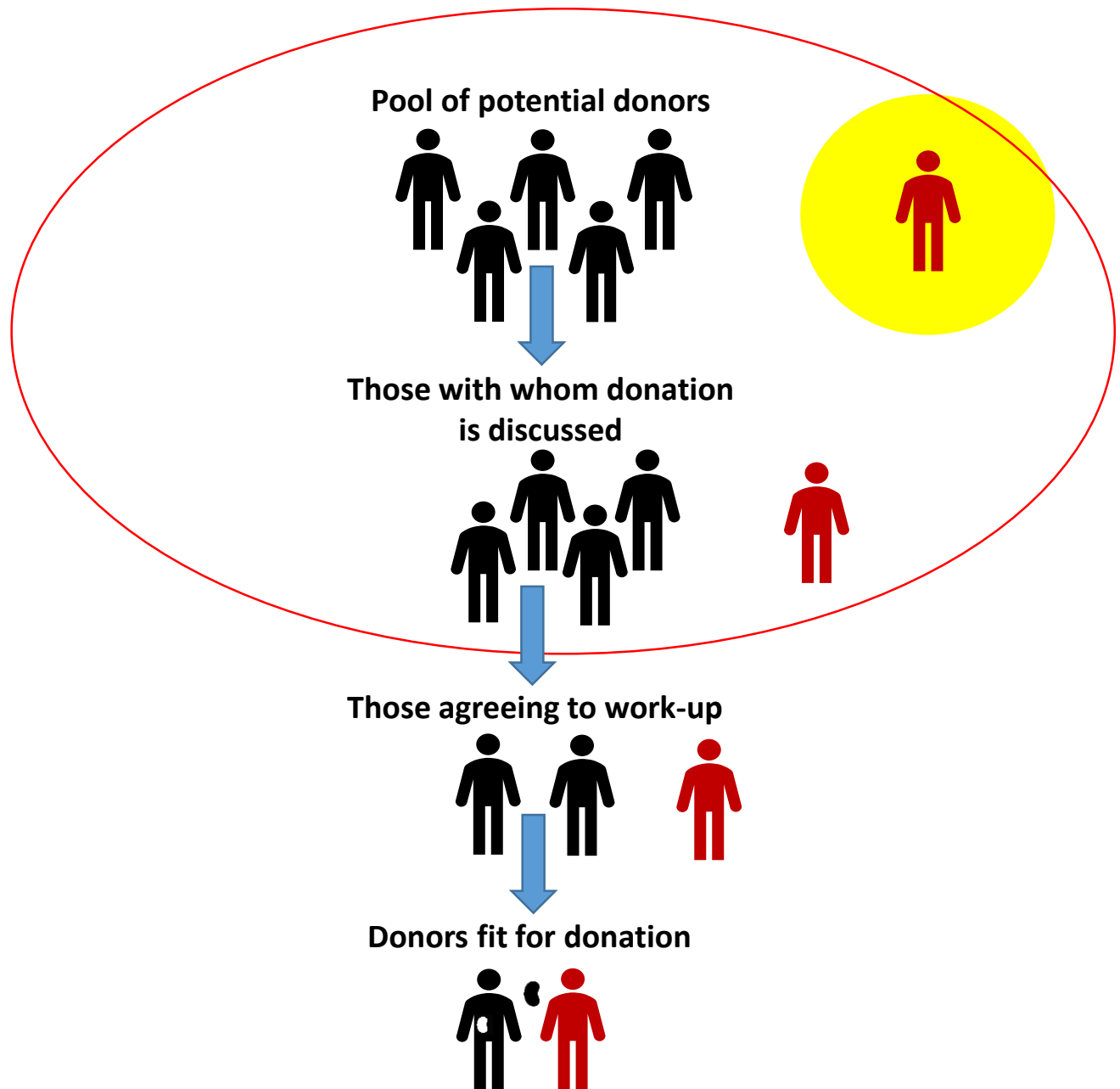
Those agreeing to work-up



Donors fit for donation




No apparent barriers to
donation that were related
to socioeconomic
deprivation.



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 discuss—
there was never a discussion of
having a live donation.”***

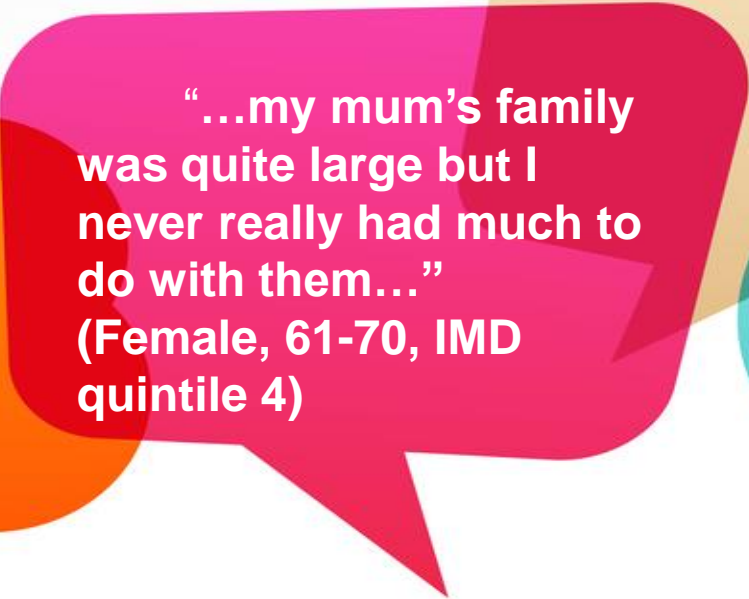
***(Female, 31-40 years,
IMD quintile 4)***

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

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.

Section C: Social support

This section is made up of a list of statements, each of which may or may not be true about you. For each statement tick 'definitely true' if you are sure it is true about you, or tick 'probably true' if you think it is true but are not absolutely certain. Similarly, you should tick 'definitely false' if you are sure the statement is false, or 'probably false' if you think it is false but are not absolutely certain.

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

When you are answering these questions, please think about your current situation.

1. If I wanted to go on a trip for a day (for example, to the beach or to the countryside), I would have a hard time finding someone to go with me.

Definitely false ☐ Probably false ☐ Probably true ☐ Definitely true ☐

2. I feel that there is no one I can share my most private worries and fears with.

Definitely false ☐ Probably false ☐ Probably true ☐ Definitely true ☐

3. If I were sick, I could easily find someone to help me with my daily chores.

Definitely false ☐ Probably false ☐ Probably true ☐ Definitely true ☐

4. There is someone I can turn to for advice about handling problems with my family.

Definitely false ☐ Probably false ☐ Probably true ☐ Definitely true ☐

5. If I decide one afternoon that I would like to go to the cinema that evening, I could easily find someone to go with me.

Definitely false ☐ Probably false ☐ Probably true ☐ Definitely true ☐

6. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.

Definitely false ☐ Probably false ☐ Probably true ☐ Definitely true ☐

7. I don't often get invited to do things with others.

Definitely false ☐ Probably false ☐ Probably true ☐ Definitely true ☐

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

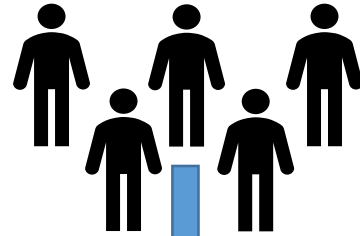
- Based at 14 renal units in the UK
 - Belfast, Bristol, Birmingham, Cambridge, Guy's and St Thomas', Imperial, Leicester, Manchester, Newcastle, Nottingham, Oxford, Sheffield, St Georges, St Helier
- Adults transplanted between 1/4/13 and 31/3/17.
- 1239 questionnaires returned
- Logistic regression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

- 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

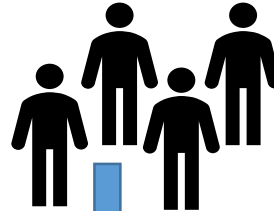
More deprived people:

- 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.

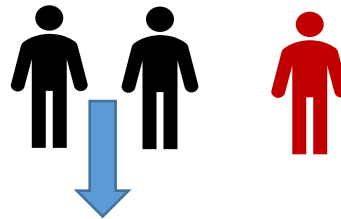
Pool of potential donors



Those with whom donation is discussed



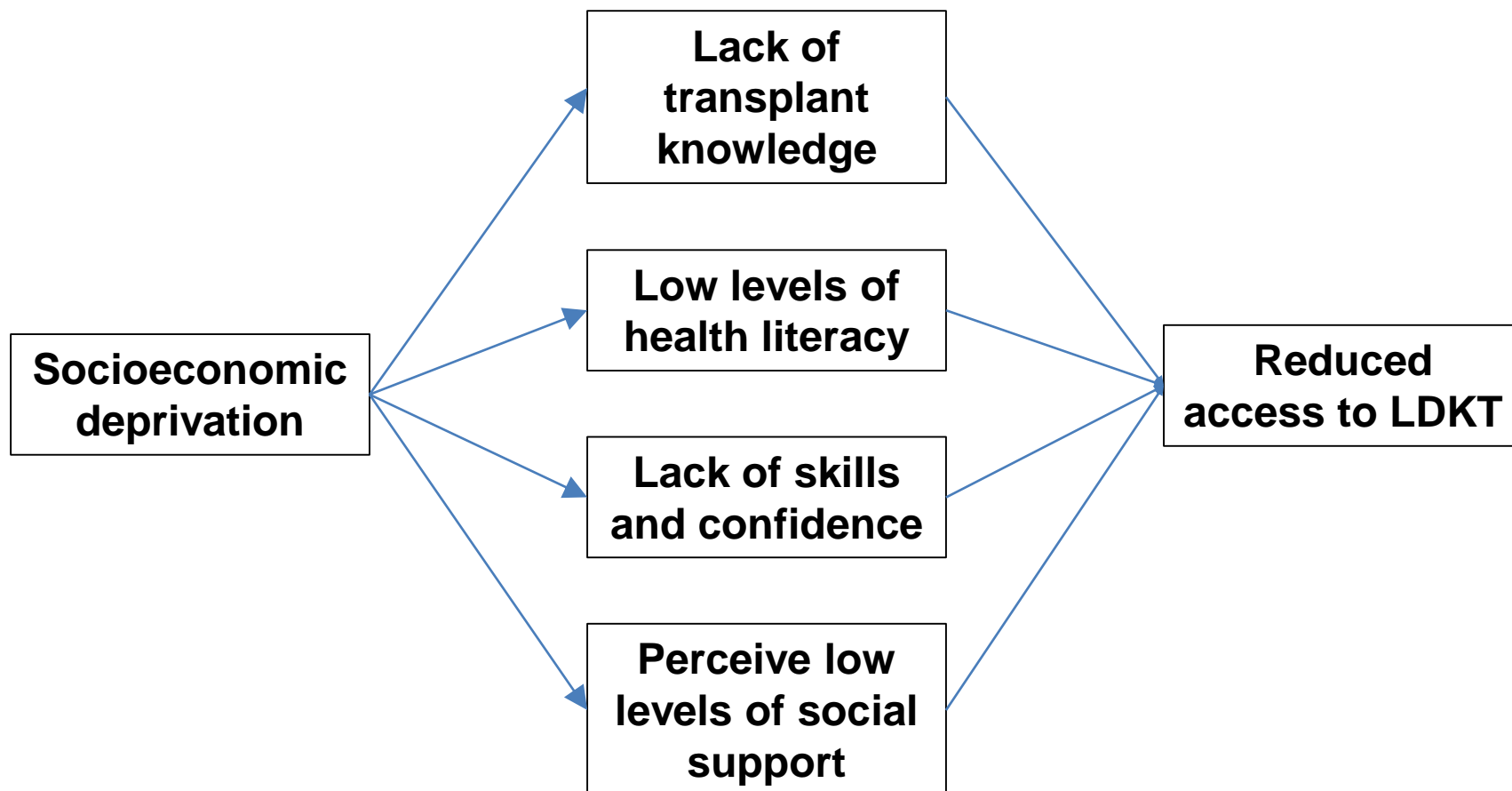
Those agreeing to work-up



Donors fit for donation





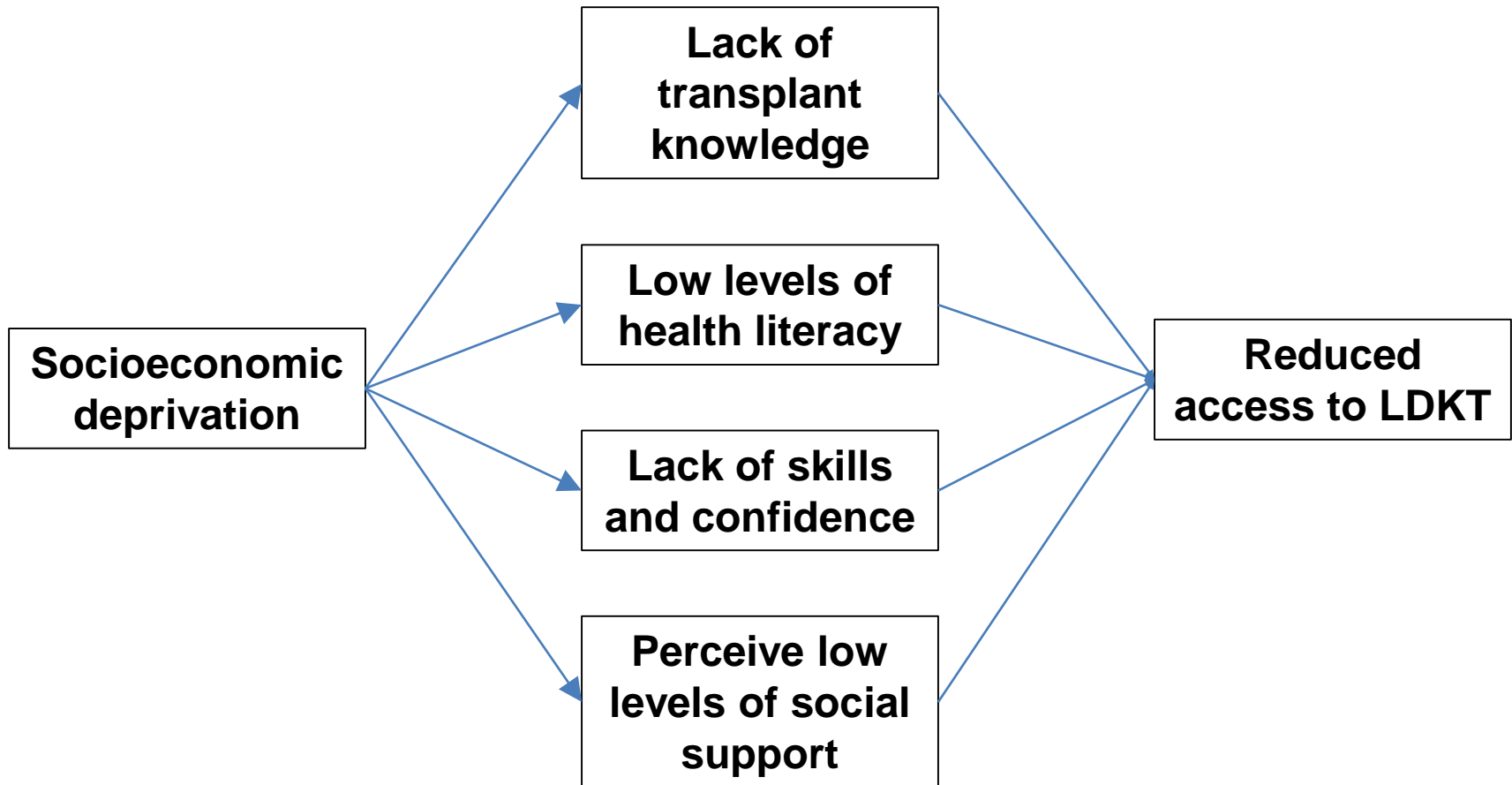


People who are deprived have the opportunity
but not the means to access to a LDKT

What next?



Overcoming barriers





The ASK trial:

improving **A**cces**S** to living-donor **K**idney transplantation



Erasmus MC
Universitair Medisch Centrum Rotterdam





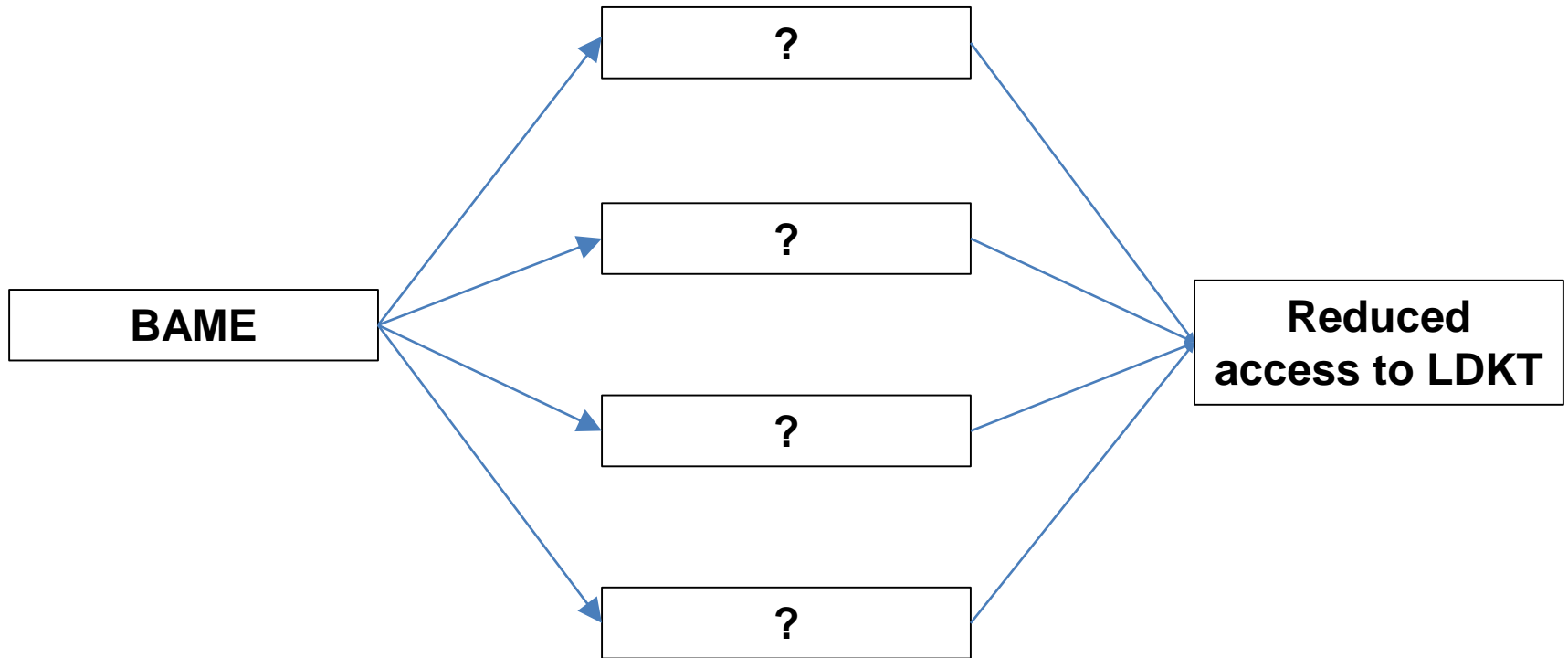
The ASK trial:

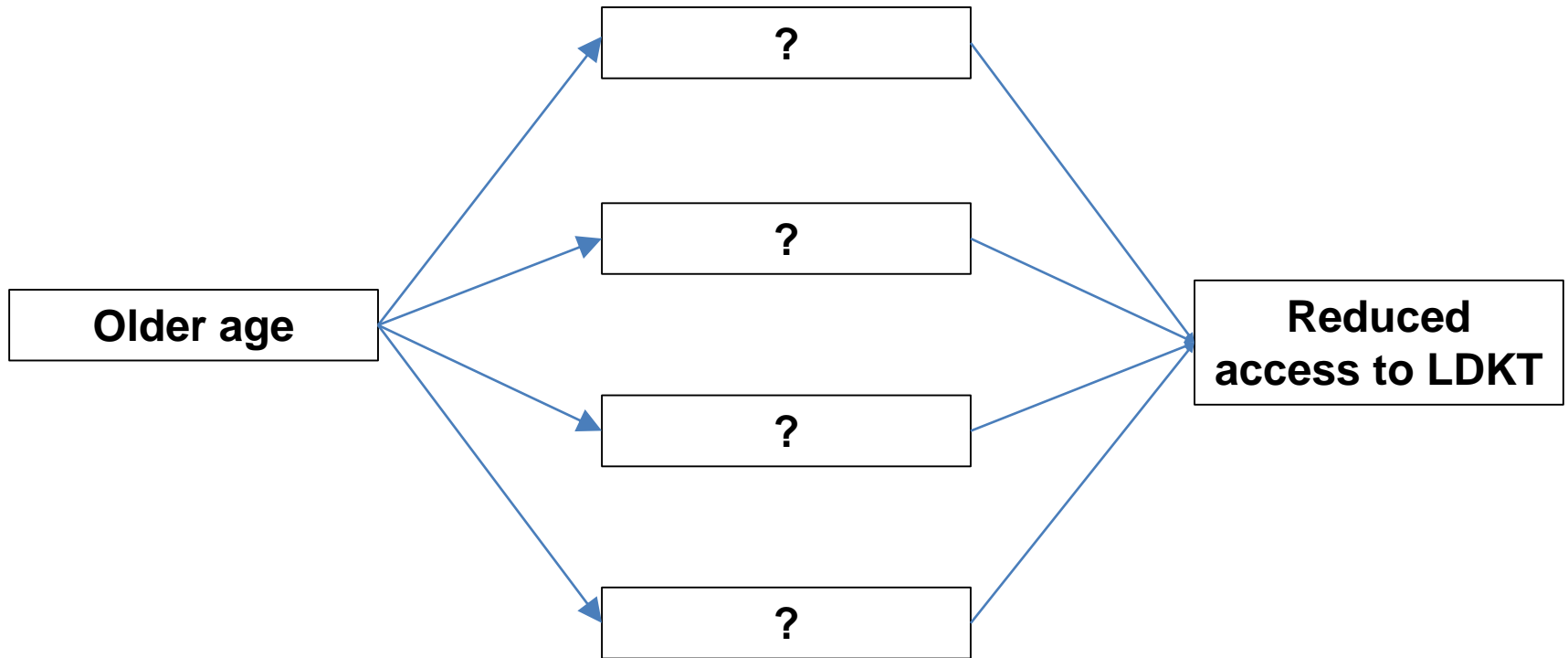
improving **A**cces**S** to living-donor **K**idney transplantation

Due to start later in 2019



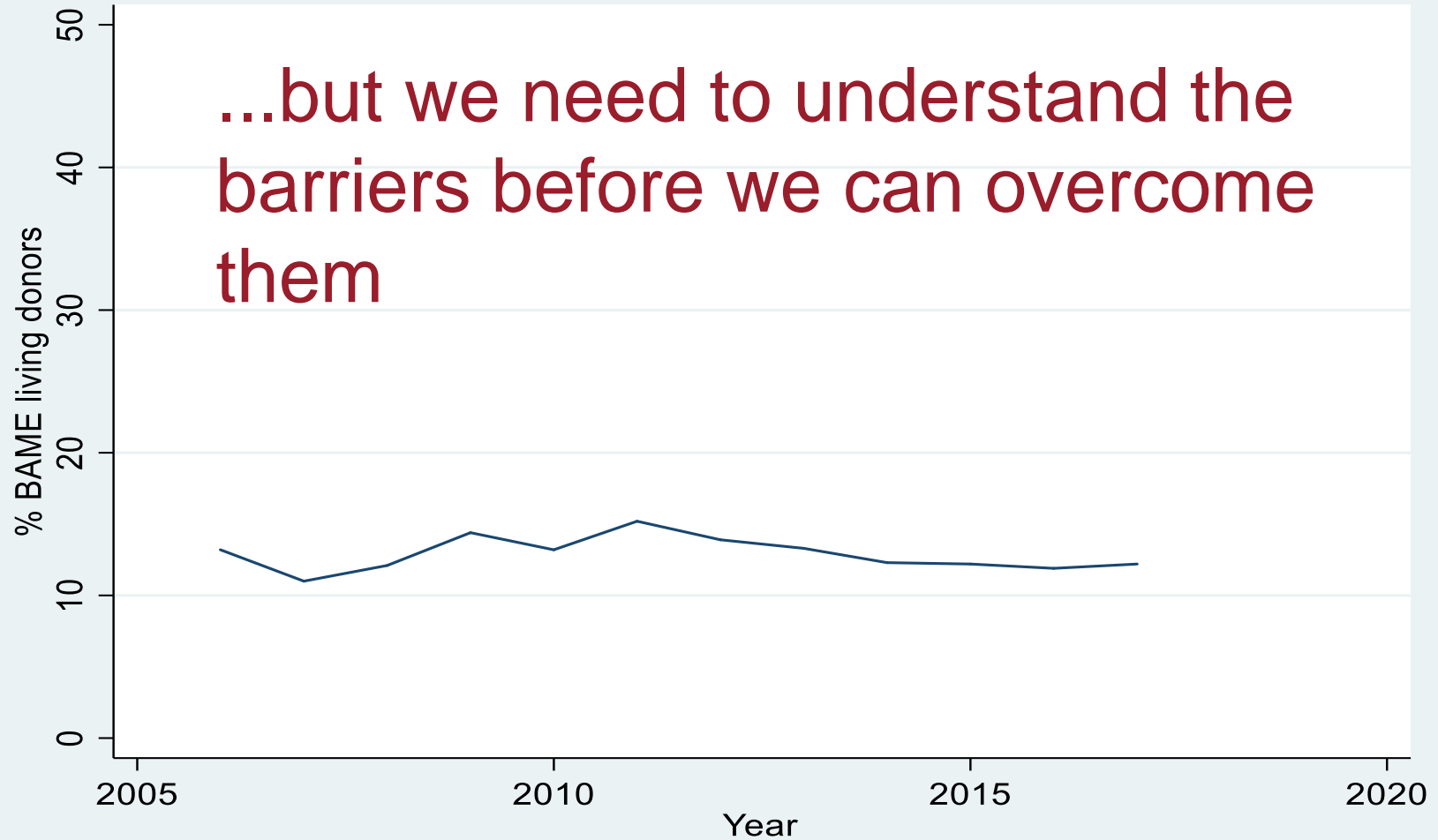
Equal care doesn't mean equal access





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?