

## Investigating reasons for ethnic inequity in living donor kidney transplantation in the UK: a mixed-methods analysis of a multicentre questionnaire-based study

**Dr Katie Wong**<sup>1,2</sup>, Dr Fergus Caskey<sup>1,2</sup>, Dr Amanda Owen-Smith<sup>1</sup>, Dr Stephanie MacNeill<sup>1</sup>, Dr Charles Tomson<sup>3</sup>, Mr Frank Dor<sup>4</sup>, Dr Pippa Bailey<sup>1,2</sup>

<sup>1</sup>University Of Bristol, Bristol, United Kingdom, <sup>2</sup>Southmead Hospital, Bristol, UK, <sup>3</sup>The Newcastle upon Tyne Hospitals NHS Foundation Trust, , UK, <sup>4</sup>Imperial College Healthcare NHS Trust, , UK

### Background

A living-donor kidney transplant is one of the best treatments for kidney failure, yet in the UK there is evidence of ethnic inequity in access. We designed this questionnaire-based mixed-methods study to investigate the patient-reported reasons that family members of Black, Asian and Minority Ethnic group (BAME) individuals were not able to become living kidney donors.

### Method:

This questionnaire-based case-control study included 14 UK hospitals. Participants were adults transplanted between 1/4/13-31/3/17. Participants provided data on all relatives aged >18 years who could have been potential living kidney donors. Participants were asked for the reasons why relatives could not donate: individuals were asked to tick all options that applied from a list of reasons (Age; Health; Weight; Location; Financial/Cost; Job; Blood group; No-one to care for them after donation) and a box was provided for free-text entries following the option 'Other-please give details'. Multivariable logistic regression was used to analyse the association between the likelihood of selecting each reason for non-donation and participant ethnicity (binary variable White versus BAME). 56/171 BAME respondents provided free-text responses and all were analysed. Qualitative responses were analysed using thematic analysis.

### Results:

1,240 questionnaires were returned from 3,103 patients (40% response). There was strong evidence that after adjustment for potential confounders sex, age and socioeconomic position, BAME individuals were more likely than White respondents to indicate that family members lived too far away to donate (adjusted odds ratio (aOR) 3.14 [95% Confidence Interval (CI) 2.10-4.70]), were prevented from donating by financial concerns (aOR 2.25 [95% CI 1.49-3.39]), were not able to take time off work (aOR 2.05 [95% CI 1.36-3.09]), and were not the right blood group (aOR 1.47 [95% CI 1.12-1.94]). Four qualitative themes were identified from free-text responses from BAME participants: a)Burden of disease within the family b)'Unorthodox' religious beliefs c)Specific geographical concerns (healthcare provision, visa difficulties) and d)Knowledge handling. The theme 'Knowledge Handling' incorporated three subthemes: i)Need for more detailed knowledge, ii)Protected disclosure of health status, and iii)Recipient assumptions about potential donor knowledge.

### Conclusion:

We have identified multiple barriers to living kidney donation in the UK BAME population, which should be further investigated and addressed. BAME transplant recipients were more likely to report that potential donors were not the right blood group: work should be undertaken to ascertain if this reflects true ABO-incompatibility or misunderstanding. Potential donors living outside the UK is a major barrier, related to

difficulties with accessing visas and concerns about a specific country's healthcare system's capacity for longer-term post-donation care. The financial barriers reported may disproportionately affect overseas donors who, although entitled to reimbursement for travel, accommodation and visa costs, may incur large "up-front" costs which may be prohibitive. No respondents reported that a major religion's position on living donation was a barrier to donation. However, there were several references to family members holding beliefs described as 'distorted' religious beliefs: this highlights the need to understand the beliefs of potential donors who belong to non-mainstream religions, which may be out of the remit of denominational faith leaders.