

## Sikh and muslim perspectives on kidney transplantation.

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### Background

Kidney transplantation offers patients with end stage renal disease (ESRD) better survival when compared to dialysis for those who are well enough to undergo the procedure. Typically, ethnic minorities experience longer waiting times on transplant lists in comparison to Caucasian patients. It is believed that this inequality stems from a particularly high need for kidney transplantation combined with a low rate of deceased donation among black, Asian and minority ethnic (BAME) groups. This is in addition to blood group and tissue incompatibility with the majority of donors who, in the UK, are of Caucasian origin.

Despite the documented benefits live kidney donor transplantation (LKDT) rates are low, and decreasing, among UK BAME communities. Research indicates that ethnic minorities experience a number of barriers to LDKT; notably, patients' reluctance to initiate conversations about LDKT and insufficient information about donation and surgery.

This work was the first phase of a larger project aiming to increase the visibility of LDKT among BAME communities by producing, testing and piloting a video-based intervention about LDKT in these communities in the United Kingdom. This initial phase of the project scoped the views and perspectives around LDKT of members of the BAME community.

### Methods

Three focus groups were held during December 2018 and January 2019. They were stratified by religion and experience. They included Sikh and Muslim donors and recipients of both live and deceased transplanted kidneys. The focus groups were recorded, transcribed verbatim and data was analysed thematically.

### Results

- Religious issues. For both Muslim and Sikh groups it was important that organ donation and transplantation was commensurate with their religious beliefs. It was much easier for Sikh participants to align transplantation with their religious beliefs than for Muslim participants.
- Lack of knowledge within the community. There was a general lack of understanding about transplantation within both Muslim and Sikh communities and this reduced the offer and uptake of LDKT. There was however, the possibility of utilising extended family, some of whom lived overseas, within these communities to participate in LDKT once knowledge about this process was improved, thereby increasing the pool of potential live donors.
- Timing. Both recipients and donors required time to come to terms with their role in the LDKT process. Being on the national deceased waiting list appeared to inhibit consideration of live donation.
- Identification with transplantation. Participants needed to be able to identify with transplantation as an option for them and their cultural groups specifically. Being able to do this more easily would assist them in coming to a decision about transplantation in a more timely manner. This would entail having community members or religious leaders delivering information about transplantation.

## Discussion

This work has highlighted the complexity of information giving and decision making within BAME communities. Whilst some issues are unique to these communities, some are applicable to many transplant donors and recipients irrespective of cultural group. The next stage of the project is to develop an appropriate video-based tool to address these highlighted issues within these BAME communities.