

Liverpool study wants to find out about the experiences of South Asian and African-Caribbean families who were asked to donate their relative's organs after their death

Current UK policy on organ donation and transplantation singles out the 'problem' of low donation from South Asian and African-Caribbean communities in the UK. This is due, in part, to large numbers of individuals from these communities being on transplant waiting lists as a result of high rates of chronic disease, like diabetes; and the relatively low levels of donated organs from these communities. The Department of Health (2008) plans to tackle this issue through research and educational campaigns targeted at African-Caribbean and South Asian communities, to find the best way to 'promote awareness and understanding of donation' and encourage an informed response to requests for families to donate their relative's organs after their death.

However, there is a problem with this approach in that existing organ donation rates among South Asian and African-Caribbean communities are often explained as a problem of 'culture'. This has led to a range of simplistic assumptions being made about these communities. In addition, by explaining 'culture' as often no more than peoples' attitudes to organ donation, policy-makers are placing responsibility for the organ shortage at the door of these communities, rather than also looking at the wider social and institutional factors which have a role to play. In response to this misrepresentation of the issue, a PhD research study is taking place in the division of Public Health at The University of Liverpool. The study is looking at the experiences of individuals and families from African-Caribbean or South Asian ethnic backgrounds who were asked to donate their relative's organs after their death in hospital. The Liverpool study is **not** about trying to get more people to donate organs. Rather, it aims to understand peoples' experiences of being asked to donate their relative's organs, and the reasons for their decision. To do this, the researcher, Jessie Cooper, is looking to speak to South Asian/Asian British and African-Caribbean/Black British non-donor (said 'no' to organ donation) **and** donor families or individuals from the North-West of England. She will also be interviewing health professionals who were involved in asking families to donate. The study aims to map out a more relevant understanding of the subject of organ donation in relation to Minority Ethnic communities by taking into account peoples' experiences and their everyday lives, as well as looking at the general political, social, institutional, and organisational aspects of organ donation.

Call for volunteers to take part in the study

If you were asked about organ donation after your relative's death, and if you are from a South Asian/Asian British or African-Caribbean/Black British ethnic background living in the North-West of England, would you be willing to discuss your experiences with us? We are looking for people who decided not to donate their relative's organs, as well as people who consented to donation. The experiences of both donor and non-donor families and individuals are equally important to us. All participation would be fully confidential and anonymous. The interviews will be participant directed, meaning that there are no set questions: you talk to the researcher about your experiences in your

own words. We would also like to talk to any members of the community who are interested in discussing this subject.

If you are interested in taking part in the study, or are generally interested in discussing the research, you can find out more by calling Jessie Cooper on: 0151 794 5272 or emailing her at jessie21@liv.ac.uk. Any help would be hugely appreciated. The study is being fully supervised by Dr. Ciara Kierans, who is an experienced researcher in this area.