Increasing the acceptability and rates of organ donation among minority ethnic groups: a programme of observational and evaluative research on Donation, Transplantation and Ethnicity (DonaTE)

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Plain English summary

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Nearly three-quarters of all transplants in the UK use organs donated by someone who has died and who had registered as an organ donor and/or their families have consented to donation. However, black (mainly African and Caribbean origin) and South Asian (Indian, Pakistani and Bangladeshi origin) groups have both a relatively high need for transplantation (mainly kidney transplantation) and a relatively low donation rate. This limits the availability of well-matched organs, thus substantially increasing waiting times for transplantation with implications for quality of life and survival.

This research aimed to understand why donation rates are relatively low among black and South Asian communities in the UK and to identify the characteristics of effective community campaigns and hospital interventions. It involved three phases:

- The community phase identified the ways in which faith or cultural beliefs often served as barriers to donation. Campaigns that were most effective in addressing these issues were characterised by delivery in familiar community settings, a strong interpersonal element, presented by trained lay individuals from the community.
- The hospital phase identified worries and uncertainties for staff that reduced competence and confidence in communication and providing support to families from minority ethnic groups.
- The development of a training package for intensive care unit staff was informed by the community and hospital studies and aims to enhance confidence and competence in supporting families from minority ethnic groups. The digital versatile disk is available at www.youtube.com/watch?v=ueaR6XYkeVM&feature=youtu.be.
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