



## Synopsis

# Barriers to and outcomes of unspecified kidney donation in the UK: BOUnD, a mixed-methods study

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## Plain language summary

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## Plain language summary

In the United Kingdom, donating a kidney to a stranger (known as unspecified or altruistic donation), was clarified in the Human Tissue Act 2006. The numbers increased rapidly, leading to a major impact on kidney transplantation, both through donations to a single individual and through the national United Kingdom Living Kidney Sharing Scheme, where chains of transplants are initiated. Patients who would otherwise not easily obtain a transplant have benefited in particular. Despite this, some evidence of negative attitudes by healthcare professionals still exists, along with concerns about the justification of unspecified donation.

The Barriers and Outcomes in Unspecified Donation study was a large, mixed-methods study that aimed to assess the barriers to and outcomes of unspecified donation. The study comprised three main arms, considering the following questions:

1. What do healthcare professionals think about the practice?
2. What are the physical and psychosocial outcomes after unspecified donation?
3. What is the economic benefit (if any) of unspecified donation?

The first question was answered through a questionnaire study of 153 healthcare professionals from every United Kingdom transplant centre and 59 semistructured interviews. We found that there was broad support for unspecified donation, but that uncertainty existed among healthcare professionals over age limits for younger donor candidates and the timing of psychological assessment. The need for consistency across the country, and further training, was emphasised. Indeed, we found wide variations in the proportion of donors who did not proceed to donate.

To answer the second and third questions, we recruited 837 donors, both 'conventional' donors (aka specified donors, who know their recipient) and unspecified donors, to a prospective questionnaire study. Sequential questionnaires were completed by 373 donors over four time points (two before and two after donation) across a 12-month period. Thirty-five participants underwent semistructured interviews. We found that unspecified donors had equivalent physical and psychosocial outcomes to 'conventional' (specified) donors, and did not regret donation, but did experience some negative attitudes. Finally, we found that unspecified donation was no more expensive than 'conventional' donation, and that a small increase in donation rates would save significant sums for the National Health Service. Those not proceeding to donation expressed differing needs with respect to how this news was communicated and how people were subsequently followed up, especially those with new medical diagnoses.