

## Consent 4 transplantation: A single centre retrospective cohort analysis of transplant decision-making in adult kidney patients who lack capacity

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### Introduction

The Supreme Court rulings *Aintree* (2013), and *Montgomery* (2015), mark the transition in medicine from paternalism to individualism concerning information provision, consent and “best interests” assessment. A comprehensive ethical and legal framework governs decisions for living donors who lack capacity as set out by the HTA. To date however, there has been little enquiry into decision-making in recipients who lack capacity. We examined our local consent procedure and practice for determining ‘best interests’ in kidney transplant recipients who were deemed to lack capacity and considered ways to improve our service.

### Methods

A retrospective cohort analysis of adult kidney patients who were identified as lacking capacity and transplanted January 2000 - April 2019. Electronic and paper records were interrogated including original consent forms. Outcomes included patient and graft survival.

### Results

We identified n=10 patients labelled as lacking capacity transplanted between January 2000 and April 2019, n=8 (80%) of which happened between 2015-2019. Mean age 36 years (range 18-59). In n=8, the disorder of the mind resulting in incapacity was learning disability (LD), 1 cerebrovascular disease and 1 degenerative metabolic disease. n=9 were on dialysis at the time of transplantation (n=1 pre-emptive failing transplant), mean 37 months on dialysis prior to transplant. n=4 had been transplanted previously. Six transplants were from living donors (n=5 related n=1 altruistic non-directed, and n=4 deceased donors (n=3 DCD and n=1 DBD). Only n=5 had a formal ‘best-interests’ meeting documented during work up however, all had been discussed at multi-disciplinary (MDT) meetings (either live donor or complex recipients). Psychology input was documented pre-transplant in one case. Themes from pre-transplant work up included - consideration of marginal / high-risk donors, communication, and transport. n=7 original consent forms were reviewed (3 missing from paper records). All consent forms examined were “consent 4” forms and completed by surgeons (3 consultants, 3 SPR/clinical fellows and 1 core trainee). Second signatories were present in n=5 and n=1 neither signatory were consultants. For all the next of kin or family had signed to confirm they were consulted. Themes identified from the best-interests assessment on consent forms were- improved quality of life and increased survival. Only one form referenced the patient’s preferences.

Outcomes- n=9 are alive with functioning grafts - mean creatinine 144 (range 45 -290) and follow up 59 months (range 10-241). One patient died with a functioning graft 18 years post-transplant.

### Discussion

Changes in the law, improved advocacy for, and attitudes towards people with LD and cognitive impairment is resulting in more patients who lack capacity being proposed as recipients. All our recipients had positive outcomes from transplantation however our analysis highlights some of the distinct considerations in such cases. Identified improvements to local practice include the development of a structured assessment of patients thought to lack capacity being proposed for transplantation. What is clear from the case law is that the emphasis on patient preferences for competent patients should be extended to patients who lack capacity. In future best interests decisions will be incomplete without these preferences being considered.