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REGISTERING ORGAN DONOR PREFERENCES — A THIRD WAY?

Transplantation has been hailed as one of the great advances of modern medicine. However, during the year ending 31 March 2005 in the UK alone, 460 people on the transplant waiting list died before a suitable organ could be found.¹ As of 21 August 2005 there are currently 6298 patients waiting for organ transplants in the UK.² These include 5502 patients requiring kidney transplants, who are currently maintained by dialysis at a total NHS treatment cost of over £110 million a year.² In the UK the current median waiting time for a kidney transplant is 729 days.² Like many great medical advances the impact of transplantation on public health is limited by the available resources. Discussions of how to expand the pool of those donating organs after death tend to be polarised between the relative merits of the extremes of the 'opt in' registry system, as currently used in the UK, versus the 'opt out' presumed consent scheme seen in, for example, Spain. However, the presence of a universal primary care network in the UK suggests a third option, a true census of patients wishes.

Surveys show that around 90% of the UK population would be willing to donate organs after death. Nevertheless, there are only just over 12.5 million people (approximately 21% of the UK population) currently on the NHS Organ Donor Register (ODR).² The reasons for this discrepancy are likely to be multifactorial. The UK Kidney Donor card scheme was introduced in 1971, updated into a multiorgan card in 1981, and the NHS ODR founded in 1994.² There are now multiple routes for an individual to register on this national confidential database. A recent survey by the BBC³ suggested that of those not registered 50% 'had not thought about it' and 30% 'hadn't got around to it'. To allow hundreds of people to die avoidable deaths and hundreds of millions of pounds of NHS money to be wasted every year due to this combination of ignorance and apathy is clearly a public health and policy disaster. A better system for recording individuals wishes after death is a health service priority.

A complete census of patient preferences regarding organ donation could easily be accomplished via the national primary care network and funded through the new GP contract. While already approximately 20% of new registrations to the UK ODR last year came from patients filling in paperwork to

register at a GP practice, GPs are ideally placed to directly ask patients what organ donation preference they would like to be recorded in their medical records. The emphasis would be on simply asking without influencing, and then recording a patient's 'yes/no' response to the question of organ donation. The undecided or concerned need not represent any major additional workload given that these patients can appropriately be referred to excellent nationally available sources of information.² In addition to a record in the practice notes, those patients wishing to be recognised as potential organ donors would have their relevant details automatically transmitted to the national ODR.

The link between registration and organ donation registry is clear. While the National Potential Donor Audit has shown family refusal rates of 40% it is 'essentially unheard of' for a family to refuse consent if the potential donor had previously expressed a preference by registering on the national scheme or carrying a donor card.² Of the approximately 1250 potential cadaveric organ donors in the UK last year, organs were transplanted from only 750.¹ Based on national survey results 1125 would have wished to donate. Registering just a modest 20% of those who express a desire to donate organs after death, but have not yet placed their names on the ODR would likely result, on average each year, in approximately an extra 95 donors giving 265 organs, including 165 kidneys.¹

Given the pressing need for increased organ donation our current system of 'don't ask, maybe tell' has surely outlived its usefulness. The moral and public health imperative is now with policy makers to facilitate primary care physicians directly asking their patients what they would like done with their organs after death. In the meantime, the NHS Organ Donor Line can be reached on 0845 60 60 400.

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