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## **EDITORIAL IV**

## Will the UK ever reach international levels of organ donation?

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The phrase used by pathologists to describe their domain, 'This is the place where death delights to serve the living'. can now be applied equally well to the transplant operating theatre. Although transplantation may occur from living donors, it is frequently from the tragedy of untimely death that it becomes possible to give another person a new life through the gift of donated organs or tissues. A complex and tightly linked set of processes, transplantation, has effectively become routine in many countries as a result of research and development in basic science, pharmacotherapeutics, clinical practice, and ethics. However, persisting and substantial international variations in donation and transplantation rates<sup>2</sup> suggest that organizational and behavioural factors are equally important, and these require systematic investigation. In response to low donation rates in the UK, in 2006 the government set up the UK Organ Donation Taskforce, with broad representation from key groups.

# The impact of the UK Taskforce on Organ Donation

The Taskforce's report was published<sup>3</sup> in January 2008 and its recommendations were adopted by all four UK Departments of Health. An increase in donation rates of 50% within 5 years was proposed as a target. Implementation became the responsibility of the National Programme Delivery Board for Organ Donation, the funding for which ended this year. Continued responsibility now rests with UK National Health Service Blood and Transplant (NHSBT). Since the Taskforce report, there has been a transformation in the organization of organ donation, with an increase of 25% in donations, but the interpretation of these changes is complex. The decline in donations after brain-stem death has halted and has probably been reversed (5% increase), the preceding increase in donations after circulatory death has accelerated (87% since 2007/8), and live donations are up 9% since 2008/9. Since 2009/10, organ transplants have increased 1%, but the majority are renal transplants. However, the previous marked decrease in cardiac transplants is starting to recover. The age and incidence of obesity of donors have

also increased.<sup>4</sup> How should we interpret these outcomes so far?

As detailed by Murphy and Smith<sup>5</sup> in this issue, the Taskforce made 14 recommendations to improve the situation in the UK. These included the introduction of a nationally integrated transplant service, clarification of legal and ethical issues, optimization of best practice (now done through the appointment of clinical leads and specialist nurses in organ donation in each hospital), 'embedding' donor transplant coordinators (DTCs) within intensive care units, and making donation a routine part of end-of-life (EoL) care discussions. This last element was translated into a minimum requirement that DTCs should be notified of all patients with catastrophic neurological injury in whom treatment is to be withdrawn, and that tests of brain stem function (with or without the use of clinical 'triggers' for referral to the DTC) should be applied to all patients in whom brain-stem death was possible, regardless of likely donation status. This has now appeared as a CQUIN (Commissioning for Quality and Innovation) developed by the West Midlands Strategic Health Authority<sup>6</sup> with anticipated values (dependent on hospital activity) in the region of £120 000-£317 000, funding which will be lost to hospitals which do not meet agreed targets on donation processes and outcomes. The intended aim of these various measures is to 'normalize' organ donation, to decrease variability in the practice of intensive care physicians, and to improve conversion rates by maximizing potential donor identification, family consent, physiological support, and organ retrieval. Quality improvement has now become performance management.

## Can we increase the rate of consent?

It is likely that these measures will have some effect, but it may not solely be the effect intended. Anecdotal evidence from local audits suggest that many of the 'potential' donors who did not undergo tests of brain stem function either did not satisfy the preconditions for testing or had a contraindication to donation, or family refusal. This latter element is the main step-down in potential donor

'conversion'. Family consent rates are currently around 65%; if this was to increase to 85%, then most of the Taskforce's objectives would be met. It is clear, therefore, that improving consent rates must be a key ambition, and this probably requires a multifaceted approach, including training clinical staff and providing a supportive environment and changing public attitudes to donation, particularly in some cultural groups. Collaborative requesting has not been found to improve consent rates, suggesting that if donor coordinators are the answer, then we may need to rephrase the question. Alternatively, once the organ donor register is more mature, the UK Donation Ethics Committee might perhaps consider contingent transplantation, in which those willing to give would be prioritized in organ allocation, as has been implemented in Israel.

## **Building trust**

In a proportion (as yet unknown) of 'missed' potential donors, the cause may be failure by the responsible intensive care specialist to consider donation and the need for testing. Deliberate obstruction, for example, by a clinician with personal difficulties with the concept of brain death or donation, would be wholly unacceptable, since the individual should ensure that the care of the potential donor was handed over to a colleague. However, a much more likely scenario is that potential donors were not identified because of pressures of work and the desire of the specialist to focus on helping the family. Intensive care physicians have a very direct, highly concentrated, and special relationship with patients and families in the context of EoL care. Intensive care unit (ICU) consultants must build a trusting, fiduciary relationship with the family within hours or days, the sort of which a traditional family doctor might develop over a lifetime. This process of establishing trust is essential to help families come to terms with an impending death. To do this we have to focus first on the patient, and second on the family. Anything which might disturb this rather fragile relationship could also make it very difficult to manage the process of treatment withdrawal and a 'decent death', which has the potential to cause a lifetime of burdensome regrets for the family. This is why the subject area is so sensitive. In contrast, organ donation benefits future (as yet unknown) patients and so extends our fiduciary duty from the patient and family to society as a whole. This conceptual shift can make those involved to feel that they are required to commoditize the patient as a community resource, instead of being focused solely on the needs and feelings of the family.

There are two potential solutions to this problem. The first and most powerful is accurate data. We need prospective research to test the clinical triggers for identifying potential donors combined with ethnographic research<sup>9</sup> exploring staff attitudes and behaviours in a limited number of clinical settings using a prospective stepped cluster design. This would allow us to determine at the same time the clinical utility of the triggers, and reasons for non-testing, which

would in turn direct attention towards clinical decisionsupport and behavioural interventions. The second potential approach relating to EoL care was proposed at the start of the Programme Board's work, but was not adopted; it may now be too late.

## End-of-life care: a missed opportunity?

The Organ Donation Taskforce report placed donation appropriately within the envelope of EoL care, but did not adequately explore what this might mean at the bedside. Instead of proposing organ donation 'champions' and 'embedded' DTCs, we could have appointed clinical leaders in EoL care hospital-wide and ICU-located, whose remit would also include donation, and who could have brought added value both to the Taskforce's work and the GMC's guidance on EoL care. 10 Given that 20% of intensive care patients die in the ICU and a further 10% die before hospital discharge, 11 ICU staff already possess considerable expertise in palliative care and bereavement management. Moreover, since many unresolved complaints about UK hospitals involve deficiencies in (non-ICU) ward care around the time of death, 12 it seems sensible to develop systems-wide structures and processes to assist staff with EoL care, while at the same time providing donation as a tool for bereavement mitigation for the family. Local donation committees should give detailed and considered thought to enhancing their role in EoL care, not just organ donation. It is possible that this change in perspective and accompanying attitudes would improve consent rates more effectively than a process focused solely on donation which includes financial incentives based on 'conversion' rates and organ acquisition rates. For example, the higher donation rates in Spain, where there is presumed consent, could also in part be attributable to the fact the DTCs are usually intensive care specialists and anaesthetists<sup>13</sup> with the authority of experience across the spectrum of EoL care, organ donation, and transplantation. Australia has also appointed full-time ICU specialists in each major hospital as donor coordinators, and has seen a marked increase in donation rates.

## Alternative pathways of care

An alternative approach is to admit patients to ICU who have donor potential but who would in other circumstances be denied admission on the basis of futility. This practice occurs in Spain where coronary care units are often incorporated within ICU, and where DTCs are usually intensive care specialists. Whether locally arranged financial incentives for coordinators represent a conflict of interest in bridging these two roles is unknown. Patients' prior wishes in this respect could be determined during advance care planning discussions; another example of how organ donation could be better subordinated within EoL care. Three pathways are possible for patients admitted to ICU solely for their donation potential: donation after circulatory arrest, organ system support until they satisfy the criteria for neurological determination of



death, or continued survival for variable periods in varying states of impaired consciousness or declining organ function. The legality, ethics, and impact of such an approach require further consideration, particularly in the resource-constrained context of UK intensive care provision. It is also likely that resource constraints are part of the explanation for international variations in donation rates: 5.1% of all deaths in England involve ICU management, compared with 17.2% in the USA. These represent 10.1% of hospital deaths in England and 47.1% in the USA. There is, therefore, much greater opportunity to identify potential donors in the controlled environment of ICUs in better-resourced countries.

## **New challenges**

Donation after circulatory death (DCD) represents a new challenge to ICU clinicians. In the context of controlled DCD, once the potential donor has been identified and consent obtained, the process of death and organ retrieval must be focused on donor optimization.<sup>16</sup> Donor optimization is an area requiring improvement in ICU practice in all circumstances, but in the context of DCD, it means that the processes we have developed for permitting a peaceful death in the ICU must now take place in an environment which allows rapid intervention to optimize organ retrieval, for example, the operating theatre. Consensus guidance<sup>17</sup> from the Intensive Care Society, British Transplant Society, and NHSBT is helpful in this respect, emphasizing the need to standardize comfort care, the practice of tracheal extubation, and clarity in discussions with the family in terms of managing expectations and satisfying the patient's presumed or stated wishes.

### The future

It is currently unclear whether or how the Taskforce's proposed target of a 50% increase in donations over 5 years will be achieved. It takes time to change systems and behaviour, and we need data to justify specific interventions within their clinical context. The work of the Taskforce and its subsequent embodiments has contributed substantially to a better understanding and more harmonious relationships between the transplant community and intensive care. The context of interventions deserves closer examination in future research linking structures, processes, and outcomes. The UK has the fewest ICU beds of all developed Western countries<sup>18</sup> (0.35 ICU beds and 16.4 donors per million population), and is frequently compared with Spain (0.82 beds and 32 donors) and the USA (2 beds and 25.6 donors). Intensive care is often perceived as the pinch-point for delivering viable donors; if the ratio of organ donors to ICU beds were a valid metric, UK intensive care would be the most efficient of the three (46.8, 39, and 12.8, respectively).

<u>Woody Allen defined confidence as 'what you have before you understand the problem'.</u> A key task of NHSBT has been to provide increasingly reliable data about

donation and transplant outcomes. This now needs to be accompanied by collaborative research into organizational and behavioural factors so that we can develop effective interventions to increase donation and transplantation rates by improving our care of the donor, the donor's family, and the transplant recipients. The acquisition of specialty status for intensive care medicine brings with it the need to take personal responsibility for this ambition through application of best practice and visible local leadership supported by national professional bodies. The three organizations represented by the authors—the Faculty of Intensive Care Medicine, the Royal College of Anaesthetists and the Intensive Care Society—are fully committed to this task.

#### **Declaration of interests**

J.B. is the Dean of the Faculty of Intensive Care Medicine, B.T. is the President of the Intensive Care Society, and P.N. is the President of the Royal College of Anaesthetists. The views expressed in this commentary are the authors' own.

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