

# Highlights from this issue

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## Consent and the opt-out scheme of organ donation

This journal has a long tradition of promoting reasoned debate on key questions in medical ethics. In this and future issues, we hope to continue this tradition by introducing a new type of article. Feature articles will provide a longer, in-depth discussion of an original ethical idea or argument, or of an important empirical finding. These articles will be accompanied by several short commentaries by leading experts in the area who will offer their critical perspective on the article, followed by a brief reply by the author.

Our first such debate is a lively exchange on organ donation. In his feature article, Ben Saunders offers a new argument for an 'opt-out' scheme for organ procurement (*see page 69, Editor's choice*). The idea of an opt-out scheme has of course been defended before. But Saunders claims that the common understanding (and defence) of this system in terms of 'presumed consent' is mistaken. After reminding us that our primary concern should be to save more lives, not to increase people's opportunities to be virtuous or altruistic, Saunders argues that consent needs to be understood as an action, not a mental attitude such as intention, and therefore not something that can be simply presumed. But the relevant action can be implicit, signified, for example, by failure to register one's objection against the background of a system of social conventions such as those associated with an opt-out scheme. Against such a background, failure to register one's objection amounts to *implicit* consent—whether or not it expresses one's *intention* to consent. Familiar worries about presumed consent, such as that consent must be given and cannot be simply presumed, thus no longer present a problem to the opt-out scheme.

Jurgen De Wispelaere and Timothy Wilkinson offer forceful commentaries on Saunders' proposal. De Wispelaere (*see page 73*) doubts that we can really understand the notion of consent without any reference to what individuals want. De Wispelaere's main objection, however, is that Saunders has not really provided good grounds for adopting an opt-out

scheme. He rejects the idea that we should prefer such a scheme on consequentialist grounds, and argues that the question must ultimately be settled by reference to what we believe consent is meant to protect. In addition, De Wispelaere points out that, in most countries, it is effectively the next of kin who donate the organs of their loved ones. He thinks that the existence of a de facto family veto makes the case for an opt-out scheme weaker, because on such a scheme it would be harder for family members to determine what a deceased relative really wanted.

Wilkinson's commentary (*see page 74*) asks whether Saunders' proposal would be an improvement both with respect to its adequacy as a consent procedure and as a way to increase the supply of organs. He registers doubts on both counts. Wilkinson agrees that tacit consent can be genuine consent. But he argues that it has to be easy and costless to express dissent, and he thinks that Saunders has not done enough to show that his proposal meets this condition. Wilkinson joins De Wispelaere in thinking that the de facto role that families currently play in organ donation decisions presents a serious challenge to Saunders' proposal. If the proposal means that families will be sidelined, this will lead to a backlash that is likely to reduce organ supply. If families will retain their veto power, then in effect all the proposal adds is a formal opt-out, which again can be expected to reduce, not increase, the supply.

In his reply (*see page 75*), Saunders suggests that we need to distinguish the question of family involvement from the question of whether positive opt-in is superior to the mere absence of opting out. But he admits that it is hard to be confident that his proposal will increase the supply of organs, and that the current role that families play in the process may present a problem in this respect. Saunders argues, however, that there are good grounds for adopting an opt-out scheme *even* if it will not increase the organ supply. This is because he thinks it is fairer to place the burden of registration on those who do not donate, and because an explicit opt-out option can better protect individuals against families later

consenting to the use of their organs against their wishes.

## Letting the doctor decide

In recent decades, much emphasis has been given to patient autonomy, and there is now a consensus in medical ethics that medical decision-making should be patient-centred. Yet several studies suggest that many patients, nevertheless, prefer that clinical decisions be taken by their doctors. A study by Grace Chung and colleagues (*see page 77*) aimed to clarify this apparent tension, and to identify predictors of patients' preference for entrusting doctors with decision-making. This study is based on a survey of internal medicine patients at the University of Chicago Medical School. Interestingly, nearly all the participants wanted doctors to offer them choices and to take their opinion into account; yet, around two out of three also preferred that decisions be ultimately made by their doctors. This preference was more strongly associated—although the effect size was relatively small—with patients who were older, less educated, male and healthier.

## Academic freedom and global health

Donald Evans (*see page 98*) argues that, in a context of massive global inequality, a key role of universities is to guarantee the independent pursuit and dissemination of knowledge. Preserving academic freedom, however, is in tension with the growing influence of market forces and the context of economic stringency in which universities now operate. Evans highlights three overlapping ways in which this tension presents a serious threat to global health: the privatisation, commercialisation and instrumentalisation of knowledge, he believes, erode academic freedom and have negative effects on research programmes, the conduct of research, and the deployment of research results. Evans argues that, as a first step towards addressing this problem, the institutions that benefit from the sale of knowledge should set aside a proportion of their earnings to support freely available research on public

goods relevant to the majority of the world's population that is currently denied a decent quality of life.

### Problems in research ethics

Psychosurgery has a rather unpleasant history. But recent advances in our understanding of the brain and of the neural circuitry underlying psychiatric disorders have led to a revival of interest in the use of neurosurgery in the treatment of psychopathology. Unlike the discredited psychosurgery of the past, deep brain stimulation (DBS) is a highly focused, adjustable and reversible form of surgery which is used in highly selective patient populations. Yet DBS still raises numerous ethical questions. One important set of challenges arises in connection with informed consent of psychiatric patients who enrol in clinical trials involving DBS. Eligibility for such surgical intervention involves meeting highly stringent selection criteria—not only severity and chronicity, but also failure of conventional forms of therapy. Focusing in particular on risk analysis, patient autonomy, voluntariness and the duty of the clinical/researcher, Nir Lipsman and

colleagues (*see page 107*) argue that the traditional conceptualisation of research consent may be inadequate in this unique context, and they suggest better ways to ethically obtain consent for such clinical trials.

A very different set of questions in research ethics arise in the context of longitudinal studies where, because repeated contact with participating subjects is necessary, the aims of research can seem to be in tension with the need to protect privacy and confidentiality. Vladimir Carli and colleagues (*see page 127*) outline a solution to this problem that respects privacy yet ensures effective linkage of data to individual participants in a repeated measures design. Their proposed procedure involves collecting anonymous repeated measurements via email ('ARME') using two separate one-way communication systems through ad hoc email accounts and a secure website.

### Being systematic about reasons

Systematic reviews of empirical research aim to offer comprehensive, minimally biased surveys of the relevant studies in an area, and are widely used in guiding

policy-making and clinical decisions. Systematic reviews can provide non-experts with a reliable picture of the state of the art and of points of consensus and disagreement in complex areas of empirical research. However, successful policy and clinical decision-making require accurate empirical input and sound normative guidance. In particular, it requires identifying the reasons and values that support or oppose each of the available options. It is thus somewhat strange that the idea of a systematic review of ethical argument and debate has so far received so little attention. Daniel Strech and Neema Sofaer (*see page 121*) have performed the important service of suggesting how to go about preparing such a 'systematic review of reasons'. Such reviews, they point out, would identify the relevant reasons more reliably than more informal sampling of the literature and thus help improve decision-making. Strech and Sofaer offer prescriptions for setting the specific review question, identifying the relevant literature, and adapting the presentation of the results to appropriate target audiences. As they admit, their model has limitations. But I hope that others will follow their lead.