

Why surgical patients do not donate tissue for commercial research: review of records

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The tissue bank at Peterborough Hospitals NHS Trust provides a legal, ethical, and safe supply of human tissue mainly to the commercial biomedical and pharmaceutical sectors. A trained research nurse interviews surgical patients, and, with consent, tissue surplus to diagnostic needs is collected and supplied to clients.^{1 2}

We expected that commercial use of tissue might deter some patients from donating.¹ We did the study primarily to find out why patients declined to donate tissue and whether involvement of commercial companies was an influencing factor. Other reviews of patient attitudes in this area have not concentrated on the commercial aspects of research.^{3 4}

Participants, methods, and results

Preoperative interviews lasting between 15 and 30 minutes on the ward or sometimes in the clinic were done by a research nurse with patients. Verbal and written information about the tissue bank was given. The process of getting consent emphasised the commercial nature of the proposed research,² and every effort was made to ensure that patients did not feel obliged to donate and were not coerced. Parents chose whether to consent on behalf of their children.

We reviewed records of consecutive nurse-patient interviews between 1 October 1998 and 31 August 2002 and recorded reasons why patients refused to donate tissue.

In 3140 preoperative interviews, 38 (1.2%) patients refused to allow their tissue to be used for commercial research. Only two patients cited commercial involvement as the main reason for refusal. Other reasons included the incidents at Alder Hey and Bristol (two patients), extreme anxiety (two patients), and perceived lack of time to make a decision (two patients). Four patients were generally uncomfortable about donation. Another four patients had problems understanding because of their culture or language, and three patients were generally hostile to hospital staff. The remaining individual patients refused because of fear of compromising diagnosis, objection to disclosure of medical history, fear the surgeon would take extra tissue, fear that anonymity would not be upheld, spiritual reasons, or emotional attachment to the organ to be removed. One patient withdrew consent on the morning of surgery after having signed the previous afternoon and one patient was too depressed to make a decision. A further two patients were undecided at the end of the interview and were encouraged to decline. For the five remaining patients, no specific reasons were recorded.

Comment

When patients have adequate information, donating surgically removed human tissue to biomedical research in the commercial sector is not a contentious

issue. The consent process is facilitated by face to face interviews with a trained nurse.⁵

Publicity over retention of organs and tissue after death occurred during the study period, including the fact that thymus tissue removed during paediatric thoracic surgery had been sold to a pharmaceutical company.² When the topic is discussed, our experience reinforces the view that patients perceive research using tissue from living people as fundamentally different from using tissue from dead people.²

Patients awaiting surgery are often pleased and even grateful to have been given an opportunity to play a part in research, which could in the future possibly benefit other people including their family.⁴ A minority of patients will always be hostile, difficult to communicate with, or apprehensive about forthcoming surgery and will choose not to donate tissue.

Contributions: ALJ did interviews. Both authors designed the study, collated the results, and wrote the paper. CW is guarantor. **Funding:** Both authors are employed by the NHS. Cost of tissue acquisition is recovered by agreements and contracts between Peterborough Hospitals NHS Trust and commercial and academic clients.

Competing interests: Peterborough Hospitals NHS Trust and commercial and academic clients could gain financially from research using human tissue. AJ and CW have received expenses and occasional fees from presentations. CW is a member of the medical advisory board of Pathlore (Pathlore took on responsibility for tissue processing for the tissue bank in December 2002 in a public-private partnership with Peterborough Hospitals NHS Trust) and has done paid consultancy work for Capio group, Pharmagene, Celltech, and Medical Solutions (member of the ethics committee and share and warrant holder). CW has received travel sponsorship to a meeting in the United States from GlaxoSmithKline. CW presented this work at the CNIO Tumour Bank Meeting, Madrid, Spain, 13th December 2002.

Ethical approval: Peterborough Research Ethics Committee, January 1999, P96/3.

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Endpiece

Penalised

Growing old is like being increasingly penalised for a crime you haven't committed.

Anthony Powell, English author (1905-2000)

Fred Charatan, retired geriatric physician, Florida