

Storage of human organs prompts three inquiries

Richard Woodman *London*

The clinical negligence lawyer Michael Redfern QC is to chair the independent inquiry into the mass storage of human organs at the Alder Hey Royal Liverpool Children's Hospital, the government has announced.

The other panel members are Jean Keeling, consultant in paediatric pathology at the Royal Sick Children's Hospital in Edinburgh, and Liz Powell, chief officer at Liverpool Central and Southern Community Health Council.

The inquiry will look into the circumstances surrounding the removal and retention of human tissues, determine to what extent the Human Tissue Act 1961 was complied with, and examine professional practice, including what information was given to the children's parents. The findings and recommendations will be published after being sent to the health secretary, Alan Milburn, by the end of March 2000.

Last month's internal hospi-



Michael Redfern QC will chair inquiry

tal inquiry report by consultant paediatric pathologist Stephen Gould said the extent of organ retention between 1988 and 1995 was "far more than would normally be expected."

An estimated 2000 to 2500 pots filled with organs had been stored in a laboratory cellar following postmortem examinations at the hospital. The count included 767 brains, 611 hearts, 773 thoracic organs, and 787 sets of abdominal organs, including sometimes the gonads.

Although initially regarded as unusual, organ retention became the "accepted norm" because of the department's new status under Dick van Velzen, Britain's first professor of fetal and infant pathology at Liverpool from 1988 to 1995, who has since been reported to the General Medical Council.

Many clinicians would also have been "very aware of heart retention," but it was "highly unlikely" that this would have been specifically discussed with parents at the time of consent, the report added.

Meanwhile, the chief medical officer for England, Liam Donaldson, has given more details of his separate investigation into the scale of organ retention generally, which is expected to report by September.

In a news release, he said he would specifically comment on the practices undertaken at the Walton Centre for Neurology and Neurosurgery, Liverpool, following confirmation that the centre had retained some brains and spinal cords from patients.

"When my investigations are concluded I will be using the findings together with the outcome of the Alder Hey inquiry, as well as an interim report from the Bristol inquiry, to draw up comprehensive advice for the secretary of state on this whole subject. □

Court sanctions use of anonymised patient data

Tessa Richards *BMJ*

The English Court of Appeal has overturned a High Court ruling made last May that the use of anonymised patient data breached confidentiality. The successful challenge, mounted by Source Informatics, the Association of the British Pharmaceutical Industry, the General Medical Council, the Medical Research Council, and the National Pharmaceutical Association against the Department of Health, has been welcomed by epidemiological research workers.

"What this means," said Michael Langman, professor of medicine at Birmingham University and one of many signatories to a letter flagging up the importance of research on non-identifiable patients (*BMJ* 1999;319:1366), "is that it will now be possible, subject to getting ethical approval, to carry out important epidemiological and genetic research and to carry out large drug safety studies, which are an integral part to monitoring drug safety in man."

The General Practice Research Database, run by the Medicines Control Agency, and the UK primary care database, formerly owned by Source Informatics but now owned by IMS Health, a commercial company that supplies information to pharmaceutical companies, are huge and unique sources of information. The data held by IMS Health alone, the smaller of the two databanks, are on two million patients.

In the original High Court ruling (28 May 1999) Justice Latham concluded that the holders of anonymised patient information held a duty of confidentiality to the patients.

It is this ruling that has been overturned by the appeal court judgment (21 December 1999). The new ruling says that the use of such information does not involve a breach of confidentiality and therefore it is not necessary to consider whether implied consent has been given □

German prosecutor investigates the removal of dead babies' organs

Déirdre Tilmann Mahkorn *Bergisch Gladbach*

Owing to a major television report dealing with the allegedly illegal removal of organs in post-mortem examinations, the public prosecutor of the German city of Münster has now started an investigation.

Just before Christmas, the political programme *Panorama* reported that Münster based pathologists had removed organs from at least 41 babies for the benefit of a study concerning the sudden infant death syndrome without fully informing the bereaved parents.

In 33 cases the parents of the babies concerned had signed a consent form that explicitly stated that a postmortem examination may also entail the removal

of tissue samples.

Very few consent forms, however, mentioned the permanent removal of complete organs. This fact in particular was the main focus of criticism voiced by the spokesperson of a self help group for the parents of children whose deaths had been attributed to the sudden infant death syndrome.

The lack of a national uniform consent form is one of the major issues, which pathologists are now planning to tackle. So far, a couple from Cologne has reclaimed the heart of their child who died from the sudden infant death syndrome and on whom a postmortem examination was performed.

In Germany the legal situation of the removal of tissue and organ material remains unclear. There is no federal law dealing with the issue of postmortem examinations, and different localities have different laws. In Berlin and Saxony, for example, a post-mortem examination can be carried out only if the deceased gave consent before death or if the relatives give consent.

Postmortem examinations are performed in only about 1% of deaths, down from 5.6% in 1985. In the sudden infant death syndrome, as with any case where the cause of death is unclear, the performance of a postmortem examination is mandatory. Pathologists do not need the permission of relatives to perform such an examination.

It is generally accepted, however, that for ethical reasons it is the right of relatives to be informed. The public prosecutor is now investigating whether any offence has been committed. □