Who owns human tissue? Part 2

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The Royal College of Pathologists of Australasia is auditing and developing a position statement on the practice of retaining tissue at (and other than at) autopsy, partly in response to major public concern following two recent UK cases.[1] Professor Skene describes these cases, which directly address the issue of ownership of human tissue, and puts forward six proposals for Australian law. Dr Nisselle explains the delicate balance that must be struck between patients' rights and the public good.

I reported in *Medicine Today*, just two months ago, on a woman's application to the Supreme Court of Western Australia to gain access to tissue removed from a deceased man during surgery and preserved in paraffin wax in a pathology laboratory (*Roche v. Douglas* [2000] WASC 146).[2] She wanted to have the tissue DNA-tested to prove that she was the man's daughter so that she could share in his estate. The Master of the Court recognised that the stored tissue was property, so the court had jurisdiction to make an order for it to be DNA-tested (and he ordered that the test be done). However, he said that 'it [was] not necessary for [him] to determine who holds the proprietary interest in the tissue', that is, who owns it.

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It was only a matter of time until the ownership issue arose more specifically. Now, it has, in two UK cases recently reported in *The Times*.

Two reports in 'The Times'

On 10 November 2000, *The Times* reported that '[four] families of dead children whose organs were removed or kept without their permission have begun legal action against the hospital where they died [the Diana, Princess of Wales Hospital in Birmingham]'.[3] The solicitor in this case is apparently acting in 30 cases. One of the parents is reported to have said that she commenced the legal proceedings to expose the hospital's 'arrogance' in removing her daughter's organs without her consent.

Then, on 14 November 2000, another report in *The Times* concerned fetuses retained by a hospital after stillbirths and terminations of pregnancy.[4] The fetuses were reportedly sent to Alder Hey Hospital, Merseyside, by other hospitals in the area in the late 1980s and early 1990s for postmortem examinations. A spokesman for the group representing the parents of the Alder Hey babies, Pity 2, is reported to have said, 'some of these fetuses are from stillbirths and miscarriages, which means they were wanted and I'm sure parents would have no idea they would end up in a hospital store'.

The difference between these cases and the West Australian case is that the parents are claiming not only access to the stored tissue but also a type of ownership. They apparently, although this is not clear from the newspaper reports – want the tissue or fetuses to be returned to them for disposal – or not to be retained by the hospitals. If these UK cases reach a court, the judge or judges will not be able to avoid the ultimate issue of who owns the stored tissue.

What should the law be?

It is interesting to speculate what decision an Australian court might – or should – make, if confronted with a similar issue. Courts have said, consistently, both in England and in Australia, that dead bodies are not property and cannot be owned. Executors (and the parents of a child) have been held entitled to possession of the corpse for the purpose of burial but this did not entail the right to retrieve tissue that was not needed for burial. Further, ownership of stored tissue taken for surgical procedures, autopsy and the like is conceptually different from ownership of corpses (whole bodies).

It seems to me that there are good reasons for the law to recognise ownership in the person or institution that holds the tissue, provided it has been taken and stored lawfully. However, as indicated by *Roche v. Douglas*, other people may have rights in relation to the tissue, such as a right to seek access to it for the purpose of checking its accuracy, determining their own genetic status and obtaining evidence for legal proceedings. The lawfulness of the initial taking of the tissue will then become imperative.

Ownership of human tissue: my proposals for Australian law

- If tissue is removed with lawful authority, the body removing it owns it. That is not the case if it was removed unlawfully – for example, without statutory authority or the express or implied authority of the person concerned (the donor).
- The donor (or the next of kin) has no legal right to have the tissue returned or destroyed.
- The hospital or laboratory must use the tissue for the purpose for which it was taken. If it proposes to do, or has done, otherwise, the donor should be entitled to a legal remedy (injunction or damages) but not the return or disposal of the tissue.
- If a commercial product is developed from the tissue, the donor is not entitled to share in the profits but should have a remedy (injunction or damages) if he or she did not authorise that use of the tissue.
- People who need to obtain access to their own stored tissue should have a legal right to do so; the law will ultimately support such a right in the same way as it does for publicly held medical records and is likely, ultimately, to do for privately held records.
- People may also have a legal right to access the stored tissue of other people, for example, to gain information that is necessary for their own health care, or for other legitimate reasons, for example, to gain evidence for a legal claim (as in *Roche v. Douglas* [2000] WASC 146).

The lawful taking of tissue

Where tissue is removed for autopsy, as in the English cases, lawfulness depends on compliance with the relevant legislation. In Australia, tissue may be lawfully removed for postmortem examination without consent from the donor or the next of kin if the body is within the jurisdiction of the Coroner.

An Australian hospital in the position of the two English hospitals described in *The Times* could argue that the initial removal of the tissue was lawful and that it is entitled to retain the tissue for the authorised purpose – namely to do the postmortem examination. This might require the tissue to be retained beyond the first tests but that would be a matter for argument.

If the hospital proposed to use the tissue for another purpose, not associated with the postmortem examination, then the next of kin might have legitimate grounds for legal action to prevent that use or to obtain compensation after the unlawful use. But I do not believe that they would, or should, be entitled to demand that the tissue be returned or destroyed.

The issue of bailment

In suggesting this approach to ownership of stored tissue, I reject the conceptualisation of 'bailment' as the basis on which tissue is taken and held by hospitals and laboratories. A bailment implies that the person concerned, or a legal representative, is entitled to demand its return or destruction.

I also reject the notion that the tissue is owned by the donor which is implicit in the *Genetic Privacy and Non-Discrimination Bill 1998* (Cwlth). One must take account of a donor's argument that the tissue belongs to him or her since it came from the person's body. But that argument can be met by the requirement that the tissue can be used only for the purpose for which it was lawfully taken. Also, the presumption of ownership could be varied by agreement between the parties.

Six proposals

My proposals for the development of Australian law are set out in the box.

They fit neatly with existing judicial statements, recognising that it is theft to remove a blood sample after a blood alcohol test;[5] that blood products are goods under the *Trade Practices Act 1974* (Cwlth);[6] and the principles of patent law permitting property interests in biological substances.

They also avoid difficult legal issues that might arise from regarding stored tissue as owned by the donor. For example:

- would it be part of the donor's estate, passing to a beneficiary by will or on intestacy (death without a will or with a will that does not dispose entirely of one' property)?
- would the hospital have to obtain the donor's consent before disposing of the tissue?

Series editor's comment

Call for a balancing Act

The ownership of human tissue is a problem that cries out for a statutory solution – that is, legislation. Leaving it to be sorted out by the civil courts, through actions brought under Common Law will be costly and take, possibly, many years before a decisive determination is achieved.

Professor Skene's proposals try to achieve a balance between patients' rights and practicality. This balance already exists in a range of statutory solutions to what could be problems at Common Law. For example, in many jurisdictions, an accused cannot be compelled to give evidence (because of what Rumpole fondly called the 'Golden Thread of British Justice' – the presumption of innocence). It is for the Crown to prove guilt, not the accused to prove innocence. So, if you cannot be forced to give testimony, why is it that you can be forced to give up your breath for preliminary breath alcohol testing or your blood for blood alcohol testing after an

accident? Technically, you cannot be forced to do either but substantial penalties attach to refusal and 'adverse inference' will also be attached – that is, it will be assumed that you refused because you were over the limit.

Why is this so? Because public order and public good requires that the roads be made safe. Parliament can decide, by statute, to override a civil right for the preservation of the public good. Where that takes us can be a slippery slide – there were arguments, sound arguments, in favour of the Australia Card but it was shot down by those who said the counter arguments, centred on liberty and privacy, had more force than the arguments in favour.

Some scenarios

So yes, it is true that your gall bladder (uterus, kidney) is your gall bladder (uterus, kidney). It is personal rather than public property – so long as it is within you. While your car mechanic is not automatically entitled to keep any part he takes out of your car, for the orderly management of a health system and for the greater good of the community, your gall bladder (uterus, kidney) may need to be treated differently from your carburettor.

Certainly, viewing a corpse (be it an adult, child, stillbirth or miscarriage) and having the 'closure' of burial can be of great psychological benefit to family and partners. While this is becoming routine practice in many areas there are some circumstances where the law intervenes – for example, some religions forbid autopsies but if a cause of death cannot be certified, the Coroner can override the family's wishes and order an autopsy.

Then, there was the case of the man whose spleen required removal who found out some years later that it had been kept and used to develop a cell line. Was he entitled to a proprietary interest in the commercial development that used his spleen? Well, it was argued that the spleen was useless until transformed into a commercial development by the skill of others.[7]

Looked at another way, a surrogate mother may receive payment to compensate her for the pregnancy, labour and childbirth. But if her adopted progeny is educated at the expense of the rearing parents, is the surrogate mother entitled to share the income ultimately earned by the product of her womb?

The last word

Ah, it's the stuff of late night discussions, over many ports – the difficulty is that you solve the problem but then can't remember the solution through next morning's mental fog! Flippancy aside, although Professor Skene's proposals do raise major philosophical and moral issues, pragmatism must ultimately prevail. We need a set of working rules to guide us – and that's a matter for parliament, not the courts. MT

References

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