



The Organ Scandal That Shaped Law

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In 2001, two contrasting news stories were prominent in the UK media for several weeks. One involved parents who discovered that parts of their children had been removed after death without consent and stored for research purposes.¹ The other concerned parents of seriously ill children in urgent need of a transplant, appealing for organ donors to come forward.² These two news stories capture some of the issues attached to organ donation.

The scandal

Prior to 1999, the general UK public was blissfully unaware that Bristol Royal Infirmary and the Royal Liverpool Children's Hospital (Alder Hey) within the National Health Service (NHS) were retaining and storing dead children's body parts and organs without consent from the family. On some occasions, parents were misled as to what they were consenting to, or, where they agreed to a post-mortem subject to certain conditions, these conditions were sometimes ignored. According to authors Margaret Brazier and Emma Cave:

*"In some cases infants were literally stripped of all their organs and what was returned to their families was an 'empty shell'. In a horrifying number of cases, organs and tissue retained were simply stored. They were put to no good use. In some instances, the whole foetus or still born infant was kept and stored in pots."*³

What sparked the inquiry? In 1992, an infant girl named Samantha Rickard died during open-heart surgery at Bristol Royal Infirmary. Four years later, her mother requested for the medical records upon learning of the high mortality rates for children's heart surgery at the hospital. From the medical records, she discovered that her daughter's heart was retained without her knowledge.⁴

To investigate the matter, the family set up an action group and held a press conference to inform the public of the hospital's practice. This then drew attention to the massive number of hearts retained at Alder Hey. In

¹ BBC News, "Organ scandal background" (29 January 2001) <http://news.bbc.co.uk/2/hi/1136723.stm>
² J Herring, "Medical Law and Ethics" (7th Ed, Oxford University Press, 2018)
³ M Brazier and E Cave, *Medicines, Patients and the Law* (6th Ed, Manchester University Press, 2016) at 547
⁴ *The Guardian* (18 May 2003) <https://www.theguardian.com/society/2003/may/18/observermagazine.theobserver>



January 2001, the Redfern report, detailing the removal and retention of thousands of children's organs, was released. In early 2003, Alder Hey and the victims' families reached an out-of-court settlement for £5 million.⁵

UK's Human Tissue Act 2004

Following the organ scandals, Parliament passed the Human Tissue Act 2004 with the objective of providing "*a consistent legislative framework for issues relating to whole body donation and the taking, storage and use of human organs and tissue*".⁶ The 2004 Act makes consent the fundamental principle underpinning the lawful storage and use of human bodies, body parts, organs and tissue and the removal of material from the bodies of deceased persons and "*is intended to achieve a balance between the rights and expectations of individuals and families, and broader considerations, such as the importance of research, education, training, pathology and public health surveillance to the population as a whole*".⁷

Malaysia's Human Tissues Act 1974

Although Malaysia has the Human Tissues Act 1974, it is very brief and only provides for "*the use of parts of human bodies of deceased persons for therapeutic purposes and for purposes of medical education and research*". Hence, the 1974 Act covers only donors who are deceased and not living donors. Furthermore, the lack of definition to the phrase "*tissue*", "*therapeutic purposes*" as well as "*person lawfully in possession of the body*" leaves the provision open. Given the lack of explicit rules or regulations in the 1974 Act, the guidelines issued by the Malaysian Medical Council (MMC) titled "Organ Transplantation" in Guideline 006/2006 is to be read together with the 1974 Act. It is the author's view that there is a pressing need for Parliament to pass legislation that will also protect the rights of potential live donors.

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⁵ *Liverpool Echo*, "Timeline: how the Alder Hey scandal broke" (9 May 2013) <http://www.liverpooecho.co.uk/news/liverpool-news/timeline-how-thealder-hey-scandal-3489864>
⁶ Explanatory Notes to the Human Tissue Bill (Session 2003-04) <https://publications.parliament.uk/pa/cm200304/cmbills/009/en/04009x--.htm>
⁷ *Ibid.*