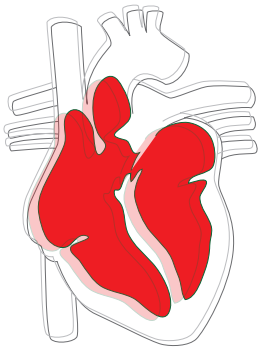
How should human tissue be treated?

> In 1999 a total of 2,080 children's hearts and more than 800 organs from children were kept at Alder Hey Hospital along with 400 foetuses collected from hospital(s) across the region.



http://news.bbc.co.uk/1/hi/health/1136723.stm on 17.09.08

Pathologist

"Consent wasn't an issue with the 1961 Human Tissue Act. Nowadays, people rightly expect control over what happens to their body. The whole pathology profession has embraced change since the 2004 Human Tissue Act."

Mother

"It didn't seem right that a heart belonging to my child could be part of a collection like butterflies, or insects, something to be visited and looked at."

Public

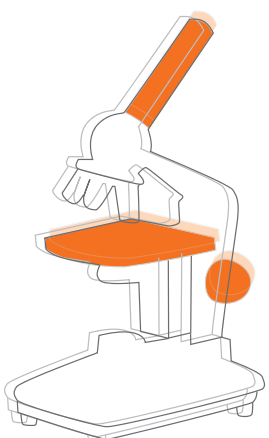
"If someone had asked me, I would have consented, but without asking me, it's just like stealing."

Legislative

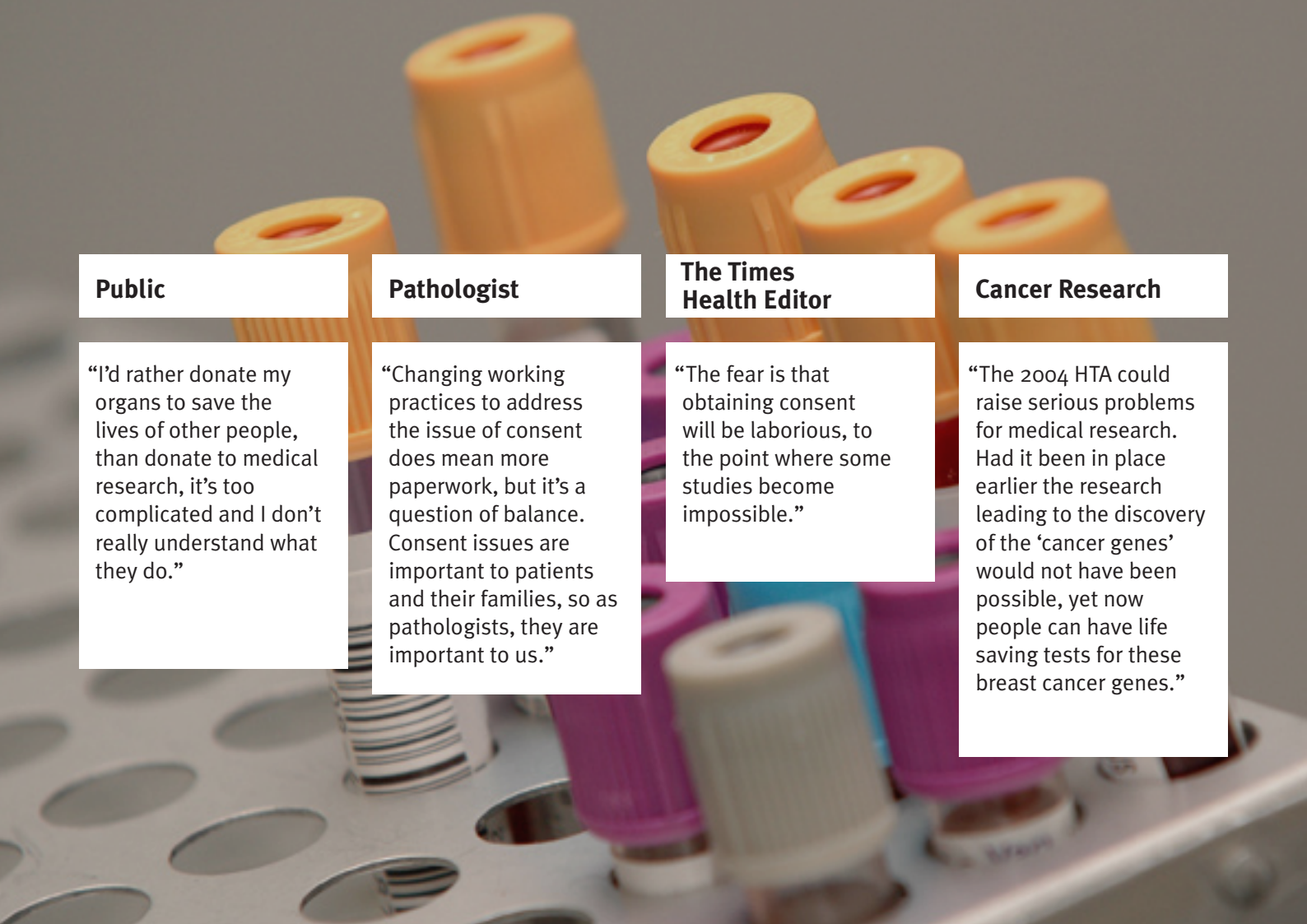
"Doctors removing organs without consent will face sentences of up to three years in prison and unlimited fines. A new Human Tissue Authority will license and inspect premises and enforce a code of conduct."

Should consent be so important?

"Research using human tissue is essential if we are to improve our understanding of cancer and develop more effective cancer treatments."



Professor Alex Markham, Former Chief Executive of Cancer Research UK.
http://www.hta.gov.uk/newsroom/quotes_and_endorsements.cfm on 17.09.08



Public

"I'd rather donate my organs to save the lives of other people, than donate to medical research, it's too complicated and I don't really understand what they do."

Pathologist

"Changing working practices to address the issue of consent does mean more paperwork, but it's a question of balance. Consent issues are important to patients and their families, so as pathologists, they are important to us."

The Times Health Editor

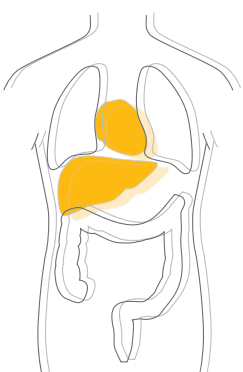
"The fear is that obtaining consent will be laborious, to the point where some studies become impossible."

Cancer Research

"The 2004 HTA could raise serious problems for medical research. Had it been in place earlier the research leading to the discovery of the 'cancer genes' would not have been possible, yet now people can have life saving tests for these breast cancer genes."

What do you think about donation?

"If you're donating your organs, as long as it's going somewhere for the great and good I wouldn't really care. As long as it's doing something rather than just sitting around, or something like that."



Male 16-24, Surbiton.
Ipsos Mori. 2007. Human Tissue Act Stakeholder Evaluation.
http://www.ipsos-mori.com/_assets/polls/2007/pdf/hta.pdf on 17.09.08

Public Poll

"One in six people said they would be certain to donate their body, organ or tissues for medical research, education or transplant purposes."

Public

"In principle I'm against the idea of paying someone for their organs, but if it meant saving my daughters life, I wouldn't hesitate."

Patient

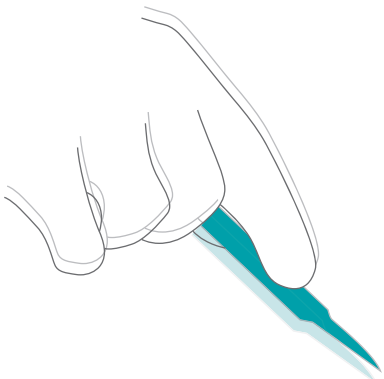
"The HTA brings hope to me and others who are in such desperate need of having a new kidney. This and the possibility of altruistic stranger donation should help to address the shortage of organs available."

British Medical Association

"The BMA would prefer a system where upon their death, patients consent to organ donation is assumed unless specific objections have been made."

Wouldn't your family want to know how you died?

"Without a post-mortem, it is estimated that the cause of death can be wrong in up to 30% of cases."



http://www.nhs.uk/Conditions/Post-mortem/Pages/Why-is-it-necessary.aspx?url=Pages/What-is-it.aspx on 17.09.08

Pathologist

"past practices (keeping patients organs after post mortem) were not necessarily unlawful, but they were increasingly at odds with the expectations and wishes of many grieving families, a practice which is no longer acceptable. Consent is now required for post mortem and tissue retention."

BBC News

"In 1999, in Liverpool, Annette Grimes found that the baby she thought she'd buried whole, 40 years earlier, was buried without his heart, lungs and oesophagus, which had been kept by the hospital following post mortem."

Paediatric pathologist

"In my experience grieving parents are helped by allowing post mortems for their babies and are greatly comforted by knowing the post mortem research will help other families with sick children."

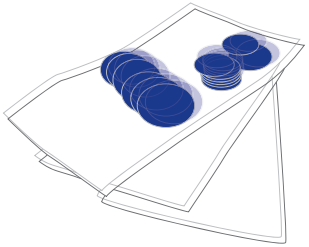
Public

"I don't want to be cut up when I die, because you just don't know what'll happen to your bits and pieces."

Is human tissue for sale?

"Two British hospitals revealed they had given heart tissue, removed from children during live operations, to a pharmaceutical company for research.

Shortly after, both hospitals received cash donations from the company involved."



http://news.bbc.co.uk/1/hi/health/1136723.stm on 17.09.08

Pathologist

"patients must be able to have confidence in the medical research system, we cannot allow this to be undermined by profit making or any kind of 'cash for tissue' practices."

Public

"I want my tissue to be used to help other people, not private drug company profits."

Pathologist

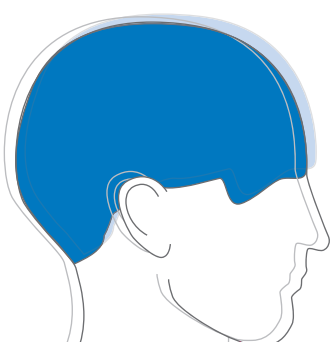
"Once human tissue is removed, it's of not further use to the patient and so much use to us for research, which in turn will help other patients."

Legislative

"Nobody actually has ownership rights in the case of tissue samples."

Whose consent counts?

> A patient can state their wishes about what happens to their body after death. From September 1st, 2006, the wishes of the deceased legally take precedence over those of the family.



Musson R. and Burnapp L. 2006. British Journal of Nursing. 15 (15): 804.

Patient rights activist

"If someone breaks into your house and takes your belongings, it is called stealing. But if someone takes tissues from your body, it is called medical research."

British Medical Association

"The BMA would prefer a system where upon their death, patients consent to organ donation is assumed unless specific objections have been made."

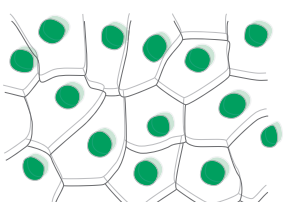
Pathologist

"To remove tissue... without the agreement of the patient would be an assault on the individual and be punishable under other criminal legislation."

Legislative

"To be able to give consent for his or her own tissue, a patient must be 16 years of age or above. Under the age of 16 a patients parent or other legal guardian can give or withhold consent."

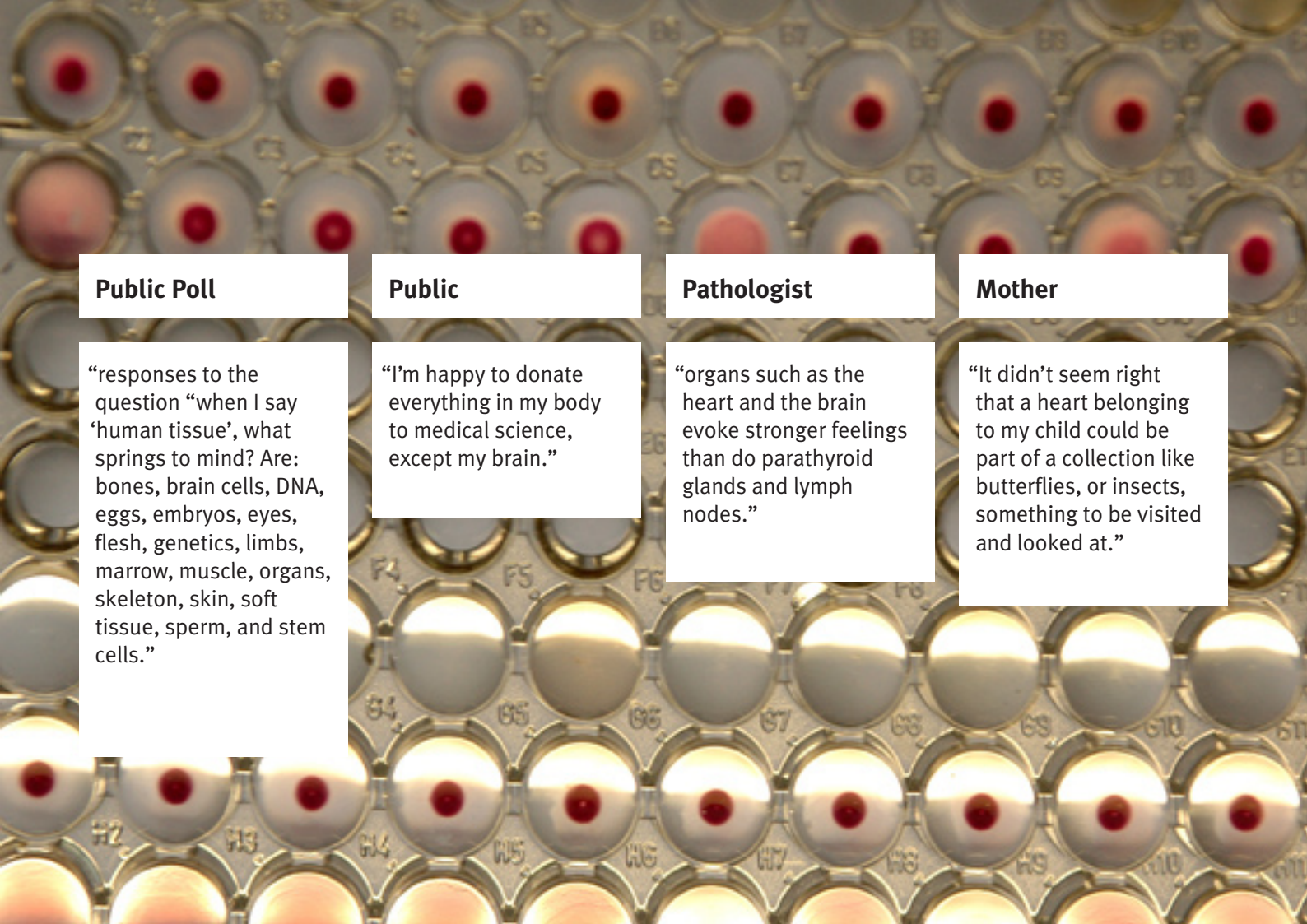
What does ‘human tissue’ mean?



J.C.E. Underwood. 2006. The impact on histopathology practice of new human tissue legislation in the UK. Histopathology. 49: 221-228. p.222.

“Human tissue is ‘material, other than gametes, which consists of or includes human cells’. This Act does not apply to ‘hair and nail from the body of a living person’. HTA 2004

However, [...] the legislation makes no distinction between the heart from a dead child and the urine from a living individual.”



Public Poll

"responses to the question "when I say 'human tissue', what springs to mind? Are: bones, brain cells, DNA, eggs, embryos, eyes, flesh, genetics, limbs, marrow, muscle, organs, skeleton, skin, soft tissue, sperm, and stem cells."

Public

"I'm happy to donate everything in my body to medical science, except my brain."

Pathologist

"organs such as the heart and the brain evoke stronger feelings than do parathyroid glands and lymph nodes."

Mother

"It didn't seem right that a heart belonging to my child could be part of a collection like butterflies, or insects, something to be visited and looked at."

Pathology: Dubious past or ground-breaking progress?

R. Semple. 2007. The Hunterian Museum.

"Charles Byrne (1761-1783) the Irish Giant, made his living at Freak Shows in 18th Century Britain. Aware that anatomists wanted his body for research, his will stated he wanted to be buried at sea in an iron coffin. Three years after his death, the famous anatomist, John Hunter, displayed Byrne's skeleton in his teaching museum, to much acclaim – but against Byrnes expressed wishes."

Medical Historian

"John Hunter was a great man of his time, whose actions, wile morally dubious with hindsight, did advance medical knowledge."

Legislative

"The first legislation to explicitly require consent for use and display of human tissue came into place in 2004."

Public

"I can't believe anyone would do something like this, it's barbaric and totally disgusting".

Pathologist

"This kind of thing, whilst awful, was a product of its time and without it we would not have the benefits of modern medicine."