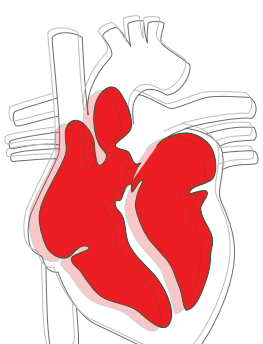
How should human tissue be treated?

"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 hospitals(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

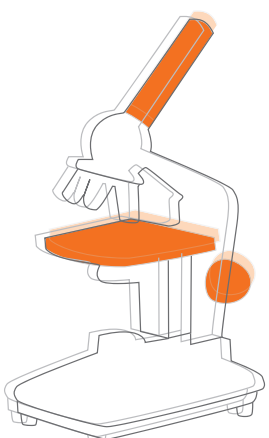
"If someone had asked me, I would have consented, but without asking me, it's just like stealing."

Legislative

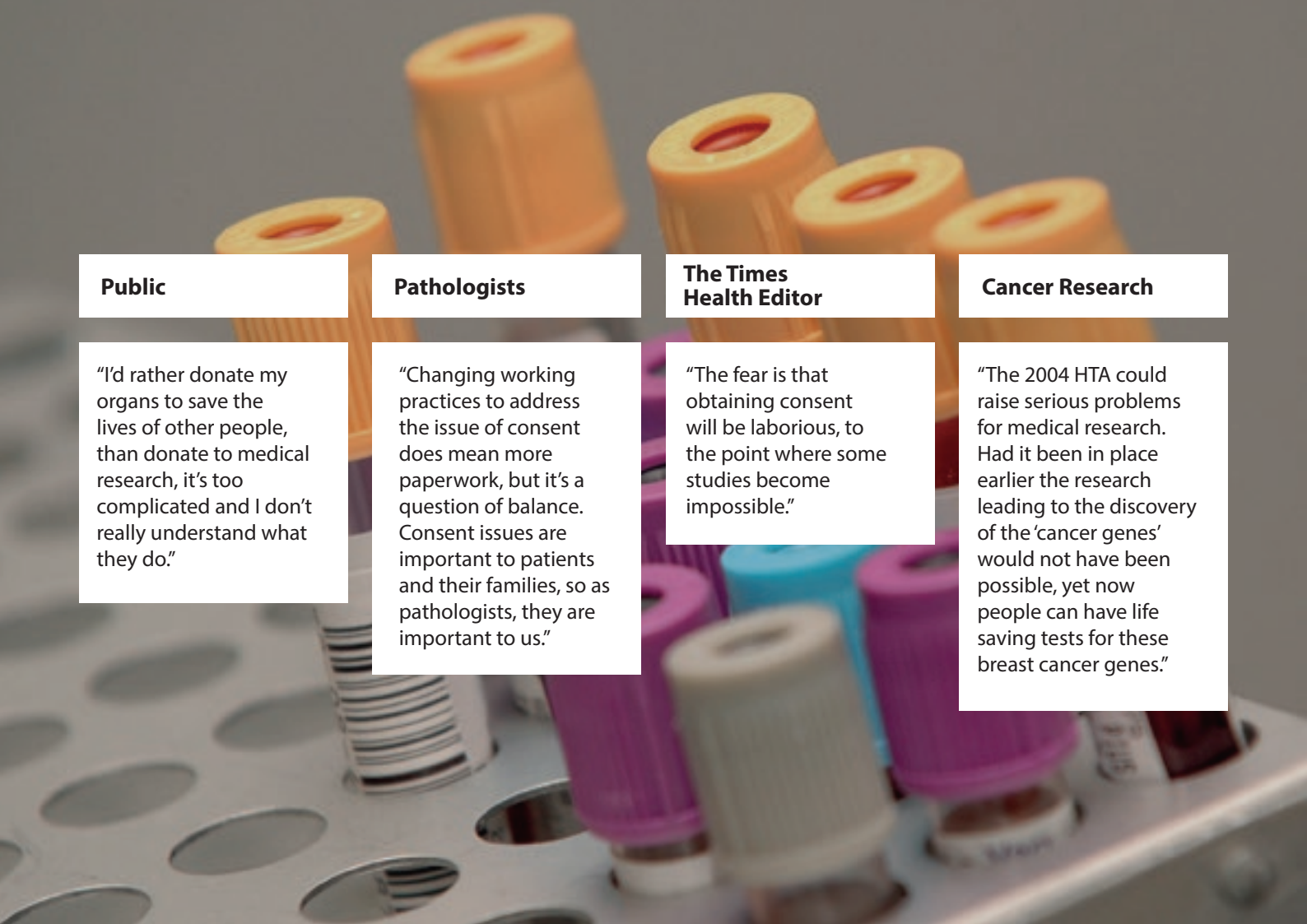
"Doctors removing organs without consent will face sentences of up to three years in prison and unlimited fines. A new Human Tissue Authority will license and inspect premises and enforce a code of conduct."

Whould 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."

Pathologists

"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

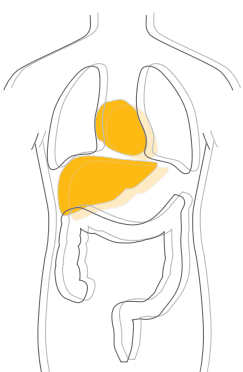
"The fear is that obtaining consent will be laborious, to the point where some studies become impossible."

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?

"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.

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 daughter's life, I wouldn't hesitate."

Patient

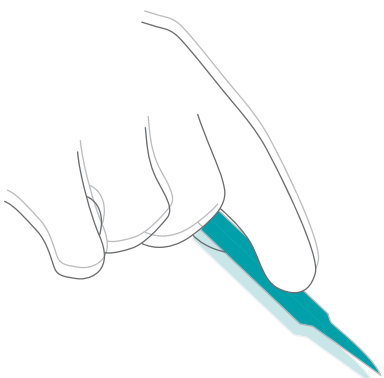
"The living donor sharing scheme brings hope to me and others who are in such desperate need of having a new kidney. This and the possibility of altruistic stranger donation should help to address the shortage of organs available."

Law in England from May 2020

"You can choose to 'opt out' of organ donation after death by registering online. Otherwise it will be assumed you have 'opted in' for organ donation. Your family will be involved in the final decision, so it is important to tell them what you wish to happen. Your faith beliefs will always be respected."

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."

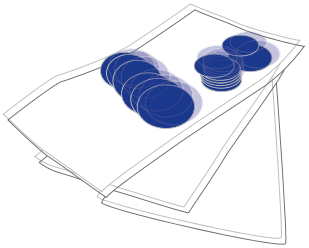
Public

"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."

What should you be given in return for donating your tissue?

"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

Researcher

"Treatment of disease is constantly improving, and many of the developments are based on the findings from research on human tissue. Thus each patient benefits from those patients who donated tissue in the past. I think patients should have a guarantee that all research will be ethical and lawful and should be able to find out what research their tissue was used for and what it discovered. BUT I think payment for each sample would hamper the ongoing progress of research, and so should not be offered."

Pathologist

"For tissue used in transplantation collected in the mortuary, if it can be used to help others and it's not costing bereaved anything, so why should they be paid? For research, pathologists cannot store tissue for very long; blood is usually destroyed in less than a week, solid tissue in a month. So, if it can be used to help others where's the harm in giving it away and it's not costing the bereaved anything, why should they be paid?"

Legal expert*

"Donation means gift, and a gift is given without expectation of reward, whether of money or money's worth. However, the potential donor is entitled to make their own decision about whether to donate, and to sufficient information to help them make that decision. They are entitled to know that their tissue will be used properly and only for the purposes for which they are donating."

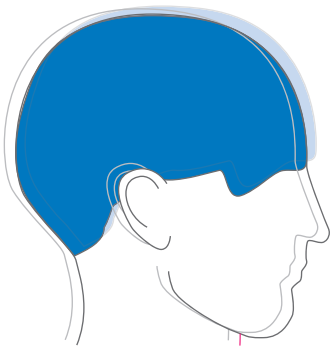
*Lawyer point of view provided by Dr Ruth Stirton, Senior Lecturer in Healthcare Law, University of Sussex

Member of the public

"I think donating tissue should be for altruistic reasons like helping research on new treatments, and not be about personal financial gain for you or for your family."

Whose consent counts?

> The family play a key role in the donation process. The role of the family should be to help establish the decision of the individual with regard to donation.



Source: Human Tissue Authority Code F: Donation of organs and tissue for transplantation 2020.

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."

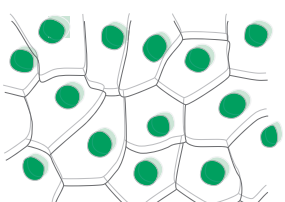
Pathologist

"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."

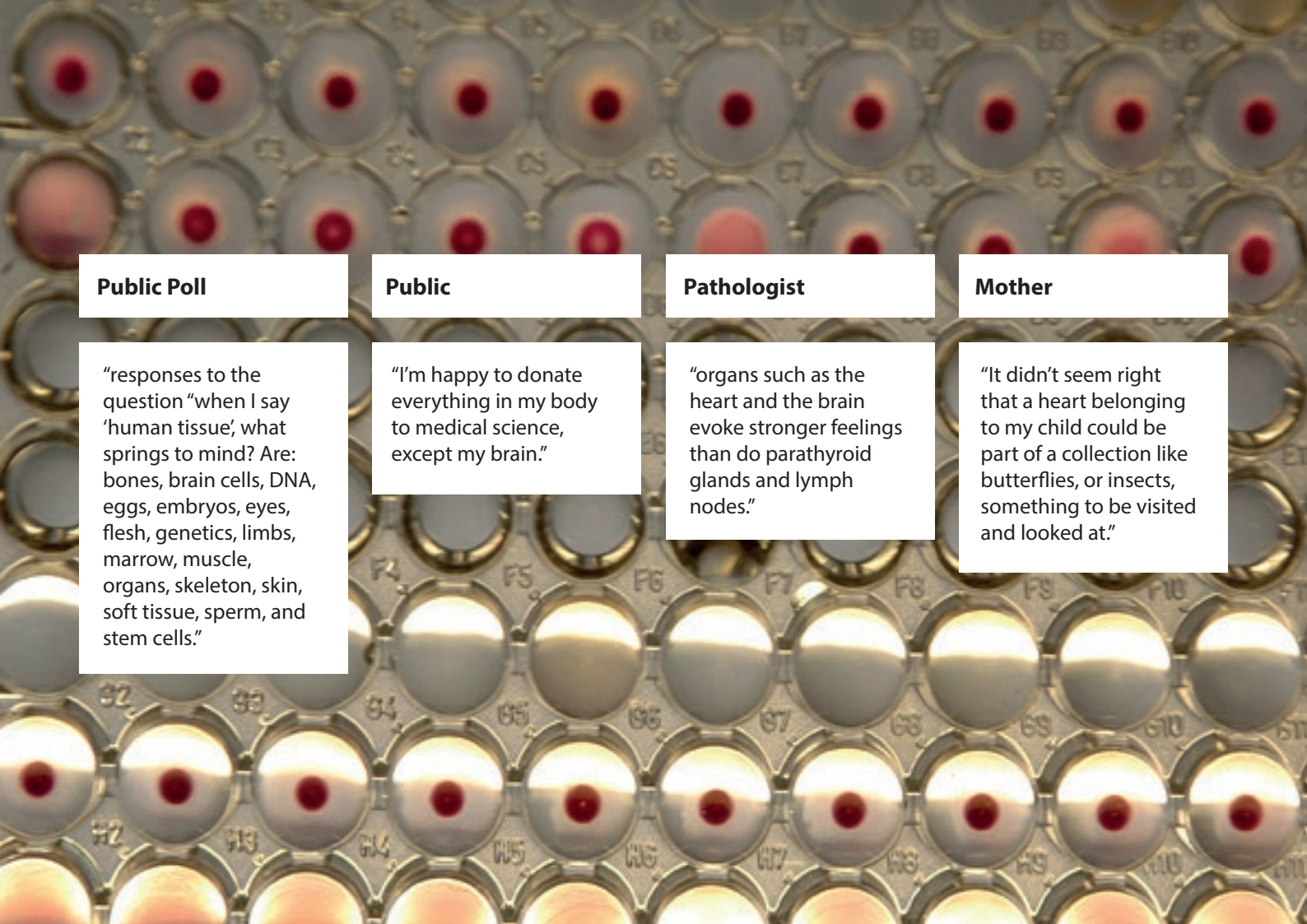
What does ‘human tissue’ mean?



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?

"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."

R. Semple. 2007. The Hunterian Museum.

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."