Royal College of Pathologists Lay Advisory Committee

Question 2
Yes, although we recognize that this is very much an individual decision and therefore exceptionally difficult to specify. For example a majority of blood donors do not feel they have the right to specify who should receive their blood. However those same individuals have very different views about donation of bone marrow (for a sibling), an egg for a sister or friend, a living kidney etc From the research perspective we would like to highlight the issue of tissue used for histopathology tests. Currently "excess" tissues removed in a surgical procedure are destroyed at a given time after the histopathology report has been issued. We would propose that these tissues be treated automatically as donated to research (with appropriate opt-out and anonymity safeguards.)

Question 3
Yes. Confidentiality is of particular concern and this is more readily maintained by a living donor. Similarly the use to which bodily material is put is more directly influenced by a living donor

Question 15
The Committee firmly believes that financial gains should not be introduced into the donation process The Committee supports the idea of 'non-financial' acknowledgements of the donors which retains anonymity.

Question 23
The Committee would like to emphasise that we do not know what the future development of medicine holds. Thus restricting the future research use of bodily material based on our current knowledge could compromise this research. We therefore propose an opt-out system such that if an individual wishes to restrict the future use of donated tissues (for research) – they must opt-out, otherwise the decision could be left with the research ethics committees who we consider to be very responsible. The Royal College of Pathology Ethics Committee proposes a single cover-all consent.

Question 26
The Committee recognizes the significance of this question and would like to highlight a potential scenario of dead bodies being ‘nationalised’ for organ donation/retrievals. This should not happen without consent if at all.

Question 30
The Committee is concerned that the scope of the consultation is extremely broad and would propose a focus on the HTA and the use of bodily material in research.

We see a difference between the use of such material for research and for medical treatment. With reference to TOR Objective 1,'To identify and consider the ethical, legal and social implications of transactions involving human bodies and bodily material in medical treatment and research.' we note that there is nothing in the document about confidentiality / anonymity. For example, there has been concern recently around sperm donors' anonymity which has seen a fall in donor numbers. The public are therefore clearly aware of issues around confidentiality / anonymity, and the TOR seems not to address these. With reference to TOR Objective 2,' To consider, with reference to different forms and purposes of donation or volunteering, what limits there should be, if any, on the promotion of donation or volunteering....', we note that there is nothing about the option of withdrawing consent at a later date (whether that consent was given actively i.e. opt-in, or presumed e.g. opt-out.) Within Objective 2 we fully support consideration of: 'the cultural and international perspectives, including regulatory differences'. We believe that some some transplant and organ donation organisations are already working in the international context. However the questions posed seem not to draw on international experience and we are concerned that a UK-centric approach is untenable in the context of free movement within the EU. We hope that the Working Party will be looking at examples of good/different practice in some other countries. For example we know that Belgium has an opt-out system and high donor ratios. The LAC has in the past considered how to increase organ donation after death, and noted the Spanish experience (where one has to opt out of donating) with a much higher donation percentage. This appeared to be directly attributable to much more intensive work with the families immediately after the donor's death.