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*From the Biological Secretary and Vice-President Professor PPG Bateson FRS*

10 June 2002

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Policy Document 16/02

Dear Mr Catling

**Response to the Retained Organs Commission consultation on unclaimed and unidentifiable organs and tissues and a possible regulatory framework**

The Royal Society welcomes the opportunity to comment on the Retained Organs Commission Consultation. We strongly endorse the Commission's view that respectful use of retained organs and tissue, following properly informed consent (in the context of knowledge and understanding of what is involved), is an important outcome for many relatives and families.

Research studies using organs and tissues obtained after death or from surgery are of major significance for the health of people in this country. Such collections of organs and tissues are particularly important for research into new and existing diseases and have shown their worth, for example in helping to diagnose new variant-Creutzfeldt-Jakob Disease. We strongly believe from a research perspective that tissue archives should be maintained indefinitely because we do not know what diseases we will have in the future, and therefore cannot judge now what archived material we will need in future disease diagnosis.

Public confidence has understandably fallen in the wake of the Alder Hey Inquiry and we therefore stress the importance of ensuring clear, informed and appropriate consent. Clear guidance should be produced on the criteria for obtaining permission for patients to give consent for their tissues to be used. It is important to recognise the social good and value of organ donation to society. Without these donations of tissue our ability to understand disease would diminish and this would have a serious and damaging effect on healthcare.

The consultation asked whether it would be helpful to identify and define a new term such as 'human material' to refer to body parts, organs and other substances taken from the body during post mortem examinations. We believe that it would be helpful to find a new term but the definition must be made extremely clear. The term 'human material' is too ephemeral and



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has the potential to create misunderstanding, hence would not be suitable as a replacement term. A new term should show a clear distinction between:

- (a) Organs and body-parts, which people do care about. The definition should include standard tissue blocks (tissues that are embedded usually in paraffin wax) because whole organs or major parts of whole organs may be contained in blocks from premature babies.
- (b) "Human material" that many people probably do not care about (e.g. bodily fluids including blood and other self regenerating materials such as small amounts of skin, hair, teeth and nail clippings along with slides containing minute amounts of material).

The Commission asked whether tissues and organs retained before March 2000 that are either not the subject of any inquiries from family members or are unidentifiable (that is the person from whom the tissues were taken is not identifiable) should be disposed of or retained for teaching and research. This material should be carefully reviewed and retained if useful for teaching or research. In particular the Commission asked if there should be any special consideration given to material of particular historical or scientific significance. Periodic review should form the basis of a mechanism for judging which material should be retained. We would recommend however that the system of periodic review would benefit from a set of common guidelines ensuring that there is systematic organisation of archived tissue thus enabling a more comprehensive catalogue system between institutions. Historical specimens such as brain collections have proved essential in studying recent diseases such as Acquired Immune Deficiency Syndrome (AIDS) and nvCJD and therefore we would advise caution in destroying any material that has already been under consideration.

Finally, the Commission sought views on the establishment of a new formal statutory-based system. The recently introduced appraisal and clinical governance systems within the National Health Service should be able to ensure that best practice guidelines are followed. We recommend however that consideration of a new body be considered if public confidence is not restored through the NHS system.

Please do not hesitate to contact us if you require further information.

Yours Sincerely,

