

## Scottish Council on Human Bioethics

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### Consultation response to Scottish Executive – Health Department

## Consultation Paper on the Human Tissue (Scotland) Bill and Issues Relating to Adults with Incapacity

The **Scottish Council on Human Bioethics** (SCHB) is an independent, non-partisan, non-religious registered Scottish charity composed of doctors, lawyers, psychologists, ethicists and other professionals from disciplines associated with medical ethics. The principles to which the Scottish Council on Human Bioethics subscribe are set out in the **United Nations Universal Declaration of Human Rights** which was adopted and proclaimed by the UN General Assembly by resolution 217A (III) on 10 December 1948.

The SCHB is very grateful to the Health Department of the Scottish Executive for this opportunity to respond to the consultation on the **Consultation Paper on the Human Tissue (Scotland) Bill and Issues Relating to Adults with Incapacity**. It welcomes the Department's intent to promote public consultation, understanding and discussion on this topic.

In addressing the consultation, the SCHB has formulated the following responses (not all questions have been answered):

### A. Adults with Incapacity: Deceased Donors

#### A.1. Authorisation during the lifetime of the adult with incapacity

**Question 1: Is there any reason why the authorisation arrangements proposed for adults in general by the Bill should not apply to adults with incapacity, provided they had the capacity to make that decision at the time they started to carry an organ donor card or put their name on the NHS Organ Donor Register?**

The SCHB is of the opinion that there are no reasons why the authorisation arrangements proposed for adults in general by the Bill should not apply to adults with incapacity, provided they had the capacity to make that decision at the time they started to carry an organ donor card or put their name on the NHS Organ Donor Register. However, this would depend on the amount of time between the loss of capacity and the removal of organs. Persons with capacity sometimes change their minds with time in addition to circumstances and can then act according to their new wishes. Persons who have lost capacity cannot.

**Question 2: Does the fact that the adult may subsequently lose capacity, and therefore the capacity to withdraw an existing authorisation, raise any separate issues?**

Persons with capacity sometimes change their minds with time in addition to circumstances and can then act according to their new wishes. Persons who have lost capacity cannot.

**Question 3: Should the Bill be used to put beyond doubt in future the issue of a welfare attorney or guardian's powers to give authorisation for the donation of body parts after the adult's death, where the adult with incapacity was known to have expressed a view as regards donation before losing capacity? If this should be possible, what proof, if any, should the welfare attorney or guardian be expected to provide of the donation wishes of the adult with incapacity?**

The Bill should be used to put beyond doubt in future the issue of a welfare attorney or guardian's powers to give authorisation for the donation of body parts after the adult's death, where the adult with incapacity was known to have expressed a view as regards donation before losing capacity. This could be done through a signed letter or a statement made before two witnesses. However this may then be equivalent to a form of self-authorisation.

#### A.2. Authorisation after the death of the adult with incapacity

If someone had lacked capacity for many years prior to their death, it could be argued that the passage of time might invalidate any knowledge the nearest relative might have of the wishes of the adult. This situation could, of course, arise in relation to any adult, where the only conversation as to the use of body parts after death might have taken place 20 or more years before death occurred. It might be argued that the significant difference with adults with incapacity is that they would

not have been able to change their minds, either by making their revised views known to their nearest relative, or by themselves withdrawing their existing written authorisation, as is open to an adult to do at any time under section 6(2)(b) of the Bill.

**Question 4: Does the fact that an adult who has lacked capacity for many years prior to death unduly prejudice the incapable adult, contrary to the spirit of the 2000 Act, when compared to any capable adult, as regards the opportunity to change their mind about donation?**

**Should the length of time an adult has lacked capacity render invalid any wishes in favour of donation which they had expressed while they still had capacity? If so, what would the appropriate length of time be?**

The SCHB agrees that the fact that an adult has lacked capacity for many years prior to death does unduly prejudice the incapable adult, contrary to the spirit of the 2000 Act, when compared to any capable adult, as regards the opportunity to change their mind about donation.

**Question 5: Is there any problem with the role of the nearest relative of an adult with incapacity in respect of the fact that the nearest relative could in theory authorise the donation of body parts from a person who was an adult when they died but had never had capacity in life to express any wishes on the subject themselves?**

The SCHB is of the view that this is a difficult situation. It agrees that an adult who has never had capacity might be placed in the same situation as a child who died under 12 years of age according to Section 11 of the proposed Bill in that the adult's views will not have been taken into account by his or her nearest relative in making the decision after death. However, the SCHB is of the opinion that the nearest relative of the adult who has never had capacity is probably the person best placed to make a decision in relation to authorising donation after death.

## **B. Adults with Incapacity: Living Donors**

**Question 6: Are consultees generally in favour of the prohibition of the removal of organs, parts of organs and non-regenerative tissue from a living adult with incapacity for the purpose of transplantation to another person? If not, should consideration be given to making the position in Scotland consistent with that proposed for the rest of the UK, ie a mechanism should be put in place to allow the Human Tissue Authority to consider the donation of organs, parts of organs or non-regenerative tissue by a living adult with incapacity?**

It is the view of the SCHB that the removal of organs, parts of organs and non-regenerative tissue from a living adult with incapacity for the purpose of transplantation to another person should be prohibited.

In addition the SCHB is of the opinion that the Human Tissue (Scotland) Bill should ensure that it complies to the following Council of Europe legislation:

*A. Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin [1]*

*B. Convention on Human Rights and Biomedicine [2]*

In Chapter VI (Organ and tissue removal from living donors for transplantation purposes) of this European Convention it is stated that:

*Article 20 – Protection of persons not able to consent to organ removal*

- 1. No organ or tissue removal may be carried out on a person who does not have the capacity to consent under Article 5.*
- 2. Exceptionally and under the protective conditions prescribed by law, the removal of regenerative tissue from a person who does not have the capacity to consent may be authorised provided the following conditions are met:*
  - i. there is no compatible donor available who has the capacity to consent;*
  - ii. the recipient is a brother or sister of the donor;*

- iii. *the donation must have the potential to be life-saving for the recipient;*
- iv. *the authorisation provided for under paragraphs 2 and 3 of Article 6 has been given specifically and in writing, in accordance with the law and with the approval of the competent body;*
- v. *the potential donor concerned does not object.*

Moreover, as with the Hague Convention on the International Protection of Adults [3], the SCHB would like to see the United Kingdom ratify, as soon as possible, the above Council of Europe legal instruments on behalf of Scotland.

**Question 7: Do you agree that it should be possible for adults with incapacity to donate regenerative tissue, subject to independent scrutiny of each case?**

The SCHB agrees that it should be possible for adults with incapacity to donate regenerative tissue, subject to independent scrutiny of each case.

**Question 8: Should adults with incapacity be able to donate regenerative tissue only to close family members, or should non-directed donation also be open to them?**

The SCHB is of the opinion that the Human Tissue (Scotland) Bill should ensure that it complies to the following Council of Europe legislation:

*Convention on Human Rights and Biomedicine [4]*

In Chapter VI (Organ and tissue removal from living donors for transplantation purposes) of this European Convention it is stated that:

*Article 20 – Protection of persons not able to consent to organ removal*

1. *No organ or tissue removal may be carried out on a person who does not have the capacity to consent under Article 5.*
2. *Exceptionally and under the protective conditions prescribed by law, the removal of regenerative tissue from a person who does not have the capacity to consent may be authorised provided the following conditions are met:*
  - i. *there is no compatible donor available who has the capacity to consent;*
  - ii. *the recipient is a brother or sister of the donor;*
  - iii. *the donation must have the potential to be life-saving for the recipient;*
  - iv. *the authorisation provided for under paragraphs 2 and 3 of Article 6 has been given specifically and in writing, in accordance with the law and with the approval of the competent body;*
  - v. *the potential donor concerned does not object.*

Moreover, as with the Hague Convention on the International Protection of Adults [5], the SCHB would like to see the United Kingdom ratify, as soon as possible, the above Council of Europe legal instruments on behalf of Scotland.

**Question 9: If the donation of regenerative tissue from an adult with incapacity is to be possible, should the case by case scrutiny be provided:**

**(a) by conferring a function on the Scottish Ministers so that they can refer cases to the Human Tissue Authority, as will happen in the rest of the UK; or**

**(b) by adapting the protections in relation to research which are already incorporated in the Adults with Incapacity (Scotland) Act 2000, including an appeal provision?**

**In the latter case, should there be a provision that such tissue could not be removed unless there was no donor with capacity who was a suitable match?**

The SCHB is of the opinion that the donation of regenerative tissue from an adult with incapacity should only be possible,

when scrutiny is provided by conferring a function on the Scottish Ministers so that they can refer cases to the Human Tissue Authority, as will happen in the rest of the UK.

## Post-Mortem Examinations and Anatomical Examinations under the Anatomy Act 1984

### Question 10: Is there any reason why the authorisation arrangements proposed for adults in general in relation to decisions relating to post-mortem examinations or the Anatomy Act 1984 should not apply to adults with incapacity?

Post-Mortem examinations should be carried out when the cause of death is not understood and where it may reasonable benefit research into the condition afflicting the person, in order to advance science and help others who may be suffering the same condition.

#### Other Issues

The SCHB is of the opinion that the Human Tissue (Scotland) Bill should ensure that it complies to the following Council of Europe legislation:

*A. Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin [6]*

*B. Convention on Human Rights and Biomedicine [7]*

Moreover, as with the Hague Convention on the International Protection of Adults [8], the SCHB would like to see the United Kingdom ratify, as soon as possible, the above Council of Europe legal instruments on behalf of Scotland.

1. Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin, <http://conventions.coe.int/Treaty/en/Treaties/Word/186.doc> - Adopted on 24 January 2002 but has not yet entered into force - Legally binding if ratified by a country - The United Kingdom has not signed nor ratified this additional Protocol

2. Convention on Human Rights and Biomedicine, <http://conventions.coe.int/Treaty/en/Treaties/Word/164.doc> - Entered into force on 1 December 1999 - Legally binding if ratified by a country - The United Kingdom has not signed nor ratified this Convention

3. Convention on the International Protection of Adults, [http://www.hcch.net/index\\_en.php?act=conventions.text&cid=71](http://www.hcch.net/index_en.php?act=conventions.text&cid=71) - Legally binding if ratified by a country - Adopted on 13 January 2000 but has not yet entered into force - The United Kingdom has ratified the Convention on 5 November 2003 (but for Scotland only) - <http://www.scotland.gov.uk/health/mentalhealthlaw/millan/Report/rnhs-37.asp>

4. Convention on Human Rights and Biomedicine, <http://conventions.coe.int/Treaty/en/Treaties/Word/164.doc> - Entered into force on 1 December 1999 - Legally binding if ratified by a country - The United Kingdom has not signed nor ratified this Convention

5. Convention on the International Protection of Adults, [http://www.hcch.net/index\\_en.php?act=conventions.text&cid=71](http://www.hcch.net/index_en.php?act=conventions.text&cid=71) - Legally binding if ratified by a country - Adopted on 13 January 2000 but has not yet entered into force - The United Kingdom has ratified the Convention on 5 November 2003 (but for Scotland only) - <http://www.scotland.gov.uk/health/mentalhealthlaw/millan/Report/rnhs-37.asp>

6. Additional Protocol to the Convention on Human Rights and Biomedicine concerning Transplantation of Organs and Tissues of Human Origin, <http://conventions.coe.int/Treaty/en/Treaties/Word/186.doc> - Adopted on 24 January 2002 but has not yet entered into force - Legally binding if ratified by a country - The United Kingdom has not signed nor ratified this additional Protocol

7. Convention on Human Rights and Biomedicine, <http://conventions.coe.int/Treaty/en/Treaties/Word/164.doc> - Entered into force on 1 December 1999 - Legally binding if ratified by a country - The United Kingdom has not signed nor ratified this Convention

8. Convention on the International Protection of Adults, [http://www.hcch.net/index\\_en.php?act=conventions.text&cid=71](http://www.hcch.net/index_en.php?act=conventions.text&cid=71) - Legally binding if ratified by a country - Adopted on 13 January 2000 but has not yet entered into force - The United Kingdom has ratified the Convention on 5 November 2003 (but for Scotland only) - <http://www.scotland.gov.uk/health/mentalhealthlaw/millan/Report/rnhs-37.asp>