

Submission from the British Humanist Association (BHA): Proposals for Legislation on Organ and Tissue Donation: A Welsh Government White Paper



About the BHA

The British Humanist Association (BHA) is the national charity working on behalf of non-religious people who seek to live ethical and fulfilling lives on the basis of reason and humanity. We promote Humanism, support and represent the non-religious, and promote a secular state and equal treatment in law and policy of everyone, regardless of religion or belief. Founded in 1896, we have around 30,000 members and supporters, and over 70 local and special interest affiliates.

The BHA advocates an ethical, evidenced based approach to public-policy making, and campaigns on a wide range of bio-ethical issues from the use of homeopathy to assisted dying. In April 2008, the BHA gave evidence on the subject of organ donation to the Welsh Assembly Government's Health, Wellbeing and Local Government Committee.

The BHA's view on organ donation

We support medical advances for the improvement of human health and wellbeing. Humanists do not believe that respect for the dead constitutes any reason to object to allowing deceased humans' organs to be used to help others, except when the deceased has expressed a contrary wish.

We believe that better public education about organ donation and transplantation is essential, and that policy actions at both state and European levels are needed in order to increase the number of organ transplants and so save more lives. We are concerned that the low number of organs donated across Europe is contributing to unnecessary suffering, a large number of unnecessary deaths and to a market in organs and even trafficking in human beings for the purpose of removing organs.

The UK operates an 'opt-in' donor scheme where people have to register themselves. However, it is often the case that those who would be happy to donate their organs fail to register or have never discussed the matter with their friends and family, so medical staff and close relatives may not be aware of their consent to help others after their deaths. This contributes to the low number of organs available.

The [British Medical Association has suggested a 'soft' system of 'presumed consent'](#), whereby organ donation (for those over the age of 16) would be the default position, but individuals could opt-out while alive. Next of kin would be informed after death that the individual had not opted out and asked if they are aware of any unregistered objection: this would make their decision easier than at present. If not, organs could be transplanted. We support this proposal, accompanied by a public information and education campaign. We support campaigns to encourage the public to discuss their wishes for the end of life, including organ donation, in advance.

The White Paper on Proposals on Proposals for Legislation on Organ and Tissue Donation

We welcome this opportunity to contribute to the Welsh Government's consultation on introducing a soft opt-out system, and we have responded to the consultation questions below.

The BHA is firmly supportive of the intentions of the Welsh Government to introduce a soft system of presumed consent where the views of family members are taken into account. However, the BHA

also considers the lack of public education about organ donation and transplantation as a major factor in the relatively low levels of donation. Ideally, we would like to see change across the UK to a system of presumed consent for organ donation for transplantation, not only in Wales.

Consultation Questions

Persons who will be included in the soft opt-out system

Question 1

The White Paper sets out individuals must have lived in Wales for a sufficient period of time before being included within the soft opt-out system

a) What factors should be taken into account when determining whether an individual 'lives in Wales'?

The BHA does not hold an established position on the question of determining residency as it lies outside our expertise. However, we agree with the principle that the soft opt-out system should only apply to Welsh residents who have lived in the country for a sufficient period to be acquainted with the proposed system, and register their objection to donating if they should wish. This is important because an introduction of a presumed consent system in Wales would be accompanied by a full and comprehensive education and awareness raising programme that residents in other parts of the UK may have no access to and therefore may not be suitably informed as to make a choice on whether to opt out or not.

b) What should that period of time be?

See above

Question 2 Do you agree discussions between clinicians and family in the event of an individual's death, will identify and safeguard those who lack capacity? Yes No

Comments

No comment

Question 3 Do you agree that the soft opt-out system for Wales should only apply to persons aged 18 years and over? If not, why? Yes

Comments

We agree that the opt-out system should apply to individuals who are capable of holding fully informed and considered views on the subject. We support the BMA's position where people over the age of 16 should be included in the opt-out system.

However, if there are good pragmatic reasons for initially having a minimum age of 18 in the proposed Welsh system we would support that, but urge the Welsh Government to keep the age limit under review and in light of any future evidence or sound reasoning for a reduction in that age limit.

Question 4 Do you agree with the retention of the existing Organ Donor Register to be operated in conjunction with the soft opt-out system? Yes

Comments

We agree that the Organ Donor Register should be operated in conjunction with the soft opt-out system, as we believe all measures possible should be taken to maximise the incidences of donation.

Without access to the ODR, when residents of Wales die in another part of the United Kingdom that does not operate an opt-out system, they will not have had the opportunity to express their consent, and consequently there might be a lesser chance of their organs being used.

Additionally, the need for retaining an ODR can be demonstrated in the hypothetical example of an individual who is strongly in favour of donating her organs on her death, but whose next of kin is opposed to organ donation. Without an opportunity to have made a clear statement of intent, such as registration on the ODR, the wishes of the deceased may not be adequately represented.

The operation of the soft opt-out system for Wales

Question 5

a) In relation to the record keeping options for the soft opt-out system, which do you prefer (see paragraph 56 of the White Paper)? Option A Option B Option C Option D

Comments

The BHA does not hold a specific policy in terms of the record keeping options for the soft opt-out system. We would support any system that most effectively captures the intentions of members of the public, and crucially allows medical staff to make quick and informed decisions.

b) Are there other options you feel would provide an effective and secure system? Comments

No comment

Question 6 What is the role of the family in safeguarding the wishes of the deceased? Comments

Our policy position on organ donation is based on the humanist principle that individuals should have the right to live by their own personal values and the freedom to make decisions about their own lives, as long as these do not result in harm to others or to the general aim of minimising suffering and advancing human happiness. Protecting individual autonomy is therefore of great concern to humanists.

The presumed consent system seems better able to protect the wishes of someone who had not opted-out, even if the relatives themselves have strong views against organ transplantation, because the individual should have been given good enough information to make an informed choice when she was alive and the presumed consent should usually be taken as paramount.

This is not to say that relatives' views should never be taken into account. We support the British Medical Association's 'soft' system of presumed consent where relatives would not be asked to consent to donation (as in the present system), but would be told that the individual had not opted out and would be asked if they are aware of any unregistered objection¹. We believe that this would help decrease the number of objections from relatives.

While humanists do not consider the removal of organs in order to save the life of another a disrespectful act, we appreciate that the appropriateness of sometimes taking into account the views of close relatives. If the removal of organs would cause grieving family members further anguish and distress then it would not seem appropriate to the organs of the deceased, even if they had not stated their objection to becoming an organ donor.

¹ 1 British Medical Association (2007) 'Organ donation – presumed consent for organ donation', July 2011. http://www.bma.org.uk/ethics/organ_transplantation_donation/organdonationbrief.jsp

Implementation

Question 7 How can the Welsh Government ensure that the public awareness campaign is effective? Comments

No comment

Equality Impact Assessment

Question 8

The Welsh Government would welcome your views on the potential impact of the proposed soft opt-out system for the:

- a) Welsh Language,
- b) race,
- c) faith,
- d) disability,
- e) age,
- f) sexual orientation,
- g) gender, gender reassignment,
- h) marriage or civil partnership:

Comments

The BHA strongly objects to the use of the term 'faith' being used as short hand to cover the religion or belief characteristic. Using the term faith automatically excludes non-religious people from consideration. Moreover, the term 'religion or belief' is the legal term as defined in the Equality Act 2010 and is therefore the appropriate term to use. The inclusive term 'religion or belief' recognises that challenging unfair or unlawful discrimination against non-religious people, such as humanists, is just as important as challenging unfair or unlawful discrimination against religious people. Excluding non-religious people by using 'faith' rather than 'religion or belief' suggests that non-religious beliefs are not as important to individuals as religious beliefs. We strongly urge that the term 'faith' is replaced by 'religion or belief' in any equalities work undertaken by the Welsh Government.

Other issues

Question 9 We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them. Comments:

Naomi Phillips
Head of Public Affairs
07540 257101
020 7079 3585
naomi@humanism.org.uk
www.humanism.org.uk

January 2012