
STATES OF GUERNSEY ORGAN DONATION SCHEME CONSULTATION

Response from Channel Islands Humanists, March 2018

ABOUT CHANNEL ISLANDS HUMANISTS AND HUMANISTS UK

Channel Islands Humanists is a section of Humanists UK. We want a tolerant world where rational thinking and kindness prevail. We work to support lasting change for a better society, championing ideas for the one life we have. Our work helps people be happier and more fulfilled, and by bringing non-religious people together we help them develop their own views and an understanding of the world around them. Founded in 1896, Humanists UK is trusted by over 65,000 members and supporters to promote humanism. Through our ceremonies, pastoral support, education services, and campaigning work, we advance free thinking and freedom of choice so everyone can live in a fair and equal society.

In 2008, Humanists UK made a submission to a House of Lords inquiry into organ donation, was consulted by the Organ Donation Taskforce, and gave oral evidence to the Welsh Assembly Government Committee Inquiry into Presumed Consent for Organ Donation, recommending that the UK adopt a presumed consent 'opt-out' organ donor scheme to replace the current 'opt-in' scheme. In 2010, Humanists UK wrote a leaflet about humanist perspectives on organ donation for the NHS England Blood and Transplant section to add to their existing series of leaflets explaining organ donation from a variety of viewpoints and principles. These leaflets encourage people to think about organ donation and consider some of the issues and benefits involved. More recently, Humanists UK has been working with the UK Government on the organ donation consultation currently taking place with respect to England, including having met with the UK Department of Health and Social Care about the matter and having responded to the consultation along with Richard Norman, Professor Emeritus of Moral Philosophy at the University of Kent. We have also worked with Professor Norman on our response to this consultation - reflecting our unique interdisciplinary expertise between medical ethics and the law.

Response to consultation questions

1. Do you think Guernsey should

Move to a soft opt-out model, as proposed

2. If Guernsey moved to a soft opt-out organ donation model, would this affect your decision about organ donation?

Yes - it would make me want to become an organ donor after my death

3. If an opt-out system comes into force we need to make sure that everyone understands how the system has changed. We would like to know what you think the best ways of telling people what the changes are, so they can decide what they want to do.

The evidence suggests that public information campaigns substantially increase

the number of organs donated and the willingness of people to donate both their own and the organs of their relatives. Mossialos et al (2008) found that 'awareness of regulation increases the odds of being willing to donate one's own organs by 91 percent and those of a relative by 74 percent'.¹

Such campaigns need to be run extensively in the run-up to the system change, including hard-hitting radio and television adverts, on transport advertising spaces, and a series of roadshows and public events across the island. Evidence put forward by Bethan Lewis of Cardiff-based Brighter Comms in the run-up to the introduction of the system in Wales suggested that an advert needs to be seen 7 times in order for the message to be adequately conveyed.² These measures were very successful in Wales with polling showing 74% of people being aware of the changes to the system by February 2016, three months after the opt-out system came into force.³ Going forward, information packs on how the opt-out system works should be produced for inclusion in the curriculum for Personal, Social, Health, and Economic Education (PSHE) and Citizenship for schools on the island.

It must also be recognised that the wishes of the deceased with respect to their body, including not donating organs, will be respected. Therefore, there needs to be an in-depth understanding of the changes proposed among the public. We believe that it is important that the Government conducts a thorough public information campaign that informs people not only of the new regulations and of the vital need for more organs, but also of the need to discuss organ donation with family members and to formally opt out if they do not wish to donate their organs.

4. If someone is going to die and it is possible for them to donate their organs, medical staff always talk to their family or long-standing friend to find out if they wanted to be a donor. In many cases, families find it easier to support organ donation if they know it was what their loved one wanted. If an opt-out model is adopted, and someone has died and they have not opted out of organ donation, should their family be able to make the final decision?

Other (please specify)

We support the introduction of a 'soft opt-out' system of presumed consent in Guernsey. As such, we believe that in some circumstances consulting the families of potential organ donors is still relevant. Specifically, if a family member of the deceased has evidence that the individual was opposed to donating their organs, but that they were unable to actively opt-out prior to their death, then that evidence should be given weight in the decision. However, we do not support family members being able to override the deceased wishes. The family should only have the final decision to prevent donation if they have evidence that that was indeed the wishes of the deceased.

¹ Mossialos et al (2008). 'Does organ donation legislation affect individuals' willingness to donate their own or their relative's organs? Evidence from European Union survey data'. *BMC Health Services Research* 8:48

² <http://www.bbc.co.uk/news/uk-wales-politics-34019713>

³ <http://organdonationwales.org/News/75per-cent-aware?lang=en>

5. Do you think someone's family should be able to decide if their organs are donated, it is different to the decision they made when they were alive?

No - someone's family should never be able to make a different decision about organ donation

Can you explain more about why you think this?

Although we are in favour of family involvement in certain organ donation cases, we do not believe family members should dictate the decision of whether organs are donated if it means overriding the wishes of the potential donor. This is deeply unfair to the donor and has been proven to negatively impact the number of organ donations that take place. In Wales, in the year 2016-7, there were 21 instances of families rejecting the donation of a relative's organs, although the deceased had not expressed an opposition to donation, preventing many lives from being saved.⁴ Our position therefore is that any change in the law should ensure that the wishes of the deceased are the prime consideration in whether a donation goes ahead.

There is an ethical problem with allowing family members to override the deceased wishes. We sought the views of Richard Norman, Professor Emeritus of Moral Philosophy at the University of Kent and Patron of Humanists UK, on this question. He told us:

It is worth looking more closely at the idea of 'informed consent' in an attempt to clarify why and how it applies in this case. Why, it might be asked, should a person's wishes be respected once they are dead? How can your autonomy carry any moral weight if you are no longer alive to exercise it? Why should it matter to you what happens to your body after you have died?

One answer which may seem attractive is an appeal to the concept of ownership. I own my body, it might be said, my body organs are my property, they belong to me, and hence I have a right to say what should be done with them after I have died. Such a right is then being thought of as a right of bequest, of inheritance. I have a right to decide what should happen to my property after my death and who should inherit it, other people have a duty to respect my decisions, and that includes my decision about what should be done with my body.

The language of 'ownership' does indeed often feature in discussions of these matters. It is, however, debatable whether such language adequately captures the nature of the relation between a person and his/her body. If my relation to my body is the relation of owner to property, this seems to imply that I am something separate and distinct from my body - some kind of disembodied self or spirit. It can be argued that a more appropriate way of putting it would be to say that I am my body - not with the implication that I am no more than a physical object, but in the sense that I am, by my very nature, an embodied being. In reaction against the Cartesian tradition, many philosophers have convincingly argued that my body is my way of being in the world. It is as

⁴ <http://gov.wales/newsroom/health-and-social-services/2017/171204report/?lang=en>

an embodied being that I find my way around the world and come to understand it, that I relate to other persons, and that I have a sense of my own identity.

It can be argued that this way of thinking about the relation between a person and her/his body makes better sense of our ideas about the treatment of the body after death. If the body is thought of as an object previously owned by the dead person, then it would seem to follow that if the dead person had no particular wishes about how their body should be treated, it becomes an unowned object and there would in principle be nothing wrong with treating it as a piece of garbage to be thrown on a scrap heap. But a dead body is not just abandoned property, a left-over object. It is a dead person, and as such deserving of respect. That is why, in all cultures, whatever religious or non-religious, it is seen as wrong to dishonour or disrespect the bodies of the dead.

If, then, the respect due to a dead body is the respect owed to a person, it should entail also a respect for the wishes of that person when he/she was alive. Arguably, we have here a stronger basis for the application of the value of autonomy and the principle of informed consent than is provided simply by the idea of ownership.

It is also a sound ethical basis for the version of a 'soft opt-out' system which we support. As stated above, we would wish to see strict limits to the scope for consultation of relatives of the dead person. If other family members have good reason to think that the deceased would have wanted to opt out of organ donation despite never actually having done so, that can properly be seen as relevant in ascertaining the deceased's wishes and respecting their autonomy. The wishes of family members should not, however, be allowed to override the wishes or even the presumed consent of the deceased. Allowing them to do so would represent a lack of respect for the deceased as a person.

In the 1960s, when organ transplants and in particular the first heart transplants were receiving wide publicity, the broadcaster Malcolm Muggeridge, a recent convert to Catholicism, denounced the new life-saving procedures on the grounds that they disrespected the human body and treated human beings as just 'collections of spare parts'. The opposite is in fact the case. In respecting people's willingness to donate their organs after their death, we are respecting the status of the dead body as a dead person, and respecting their capacity as a moral agent to go on doing good in the world after their death.

6. Which of the following groups should not be included in the proposed new rules regarding organ donation?

People who lack capacity

Visitors to Guernsey

People living in Guernsey for less than 12 months

Are there any other groups you think should be included? Please say why.

We believe an opt-out system is premised on the principle that the potential donor has been given an opportunity to decide if they do not wish to donate. Therefore, we agree that adults who lack the capacity to consent to organ donation should be excluded from any new legislation concerning organ donation, as should visitors to Guernsey and those living in Guernsey for less than 12 months, who are unfamiliar or unable to access the Organ Donor Register. Their organs should not be donated unless they have expressed a clear wish to donate their organs or their families have given consent. However, it is imperative that data-sharing takes place with the Welsh, English, Scottish, and Northern Irish organ donation registers, so that wishes can be shared across all jurisdictions.

We do not think that any other groups merit exclusion from the new rules about organ donation. On the question of whether children should be excluded, in certain parts of the UK, a child of 16 is able, under the current system, to register with the Organ Donor Register. We recommend that the age limit is lowered to 16 and young people are routinely educated at school about this. For children below this age, those who are regarded as Gillick competent should still be able to opt in (and again this should be taught about at school) to donation and parents/carers should still be able to make decisions about the donation for their children under this age. They should routinely be asked their wishes at the appropriate time.

For more details, information and evidence, contact Humanists UK:

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