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## **ORGAN DONATION (ISLE OF MAN) BILL 2018**

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### **Response from Humanists UK, April 2018**

#### **ABOUT HUMANISTS UK**

At 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, we are trusted to promote humanism by over 65,000 members and supporters and over 100 members of the All Party Parliamentary Humanist Group. 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**

##### **What is your name?**

Rachel Taggart-Ryan

##### **What is your email address?**

[rachel@humanism.org.uk](mailto:rachel@humanism.org.uk)

##### **Are you responding on behalf of an organisation?**

Yes

If yes, please tell us which organisation

Humanists UK

##### **Are you resident in the Isle of Man?**

No

## May we publish your response?

Yes, you can publish my response in full

### 1. Are you a registered organ donor?

Yes

### 2. Have you had experience of any part of the process of organ donation? For example, have you or a family member received or donated an organ. Please tell us of any previous experience of organ donation

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, we 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.

In 2018, we met with civil servants from the Department for Health and Social Care to support the adoption of an opt-out system in England. We submitted a response to the subsequent consultation in conjunction with Professor Richard Norman, Professor of Moral Philosophy at the University of Kent. We have also submitted response to the recent consultation in support of the adoption of an opt-out organ donation system the Crown Dependency of Guernsey.

### 3. Have you ever discussed organ donation with family members / other next of kin?

Yes

### 4. Do you have any ideas or suggestions about how the Isle of Man Government could encourage more people to register as organ donors?

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'.<sup>1</sup>

Such campaigns need to be run extensively in the run-up to a change in system or in a concentrated period annually, including hard-hitting radio and television adverts, on transport advertising spaces, and a series of roadshows and public events across the country. Evidence put forward by Bethan Lewis of Cardiff-based Brighter Comms in the run-up to the introduction of the opt-out

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<sup>1</sup> 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

system in Wales suggested that an advert needs to be seen 7 times in order for the message to be adequately conveyed.<sup>2</sup> 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.<sup>3</sup> Going forward, UK NHS Organ Donor Register should produce information packs on how the opt-out system works for inclusion in the curriculum for Personal, Social, Health, and Economic Education (PSHE) for schools in the Isle of Man.

**5. Do you think people should have more ways to record a decision about organ and tissue donation?**

The NHS Organ Donor Register online  
No - you should only be able to record your decision directly onto the NHS Organ Donor Register online or on the phone

**6. For the purposes of organ donation do you think that the cut-off date for being regarded as a child should be 16 or 18?**

16

In certain parts of the UK, a child of 16 is able, under the current system, to register with the Organ Donor register. We believe that a child of this age is capable of making an informed decision about their wishes for their own body if 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.

**7. If the law changes, would this affect your decision about organ donation?**

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

**8. Do you think this change could have any particular impact on people from some religious groups or ethnic backgrounds?**

No.

The principle of opt-out in conjunction with a public awareness campaign means that no-one, whether from a particular religious or ethnic group, should be impacted by a change in the system. Those from religious groups who object to organ donation because of their beliefs can simply opt out. There is no requirement for them to even state their reason for doing so. In reality, very few religious groups object to organ donation. Most religious authorities either believe it is a matter for the individual's conscience or encourage adherents to donate. We are only aware of one possible exception. The followers of Shintoism often object to donation because they believe that a body should not be injured in any way after death. The Isle of Man 2016 census did not contain a religious

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

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

belief question, however it is unlikely that there are many shinto followers on the island. The 2011 UK census records only 1,075 individuals on the mainland.<sup>4</sup>The change in the system should not impact upon Shinto followers if steps are taken to make the community aware that they can opt out.

In terms of ethnicity, generally speaking, the new rules regarding organ donation would benefit people from minority ethnic backgrounds, rather than negatively impacting them. The evidence suggests that people from black and Asian backgrounds are underrepresented on the organ donor register, resulting in an average six months longer wait for an organ for patients from those backgrounds. As such, an increase in the number of organs donated would have a positive impact upon the waiting time. Additionally, the change in legislation and the campaigning surrounding it would raise awareness of organ donation as an issue which could help overcome the lack of knowledge concerning organ donation that the National Black, Asian and Minority Ethnic Transplant Alliance has labelled one of their 'main challenges'.<sup>5</sup> Again, we are aware of one possible minority ethnic group that would be an exception to this. The Roma are a distinct ethnic group who are generally opposed to organ donation because of their specific beliefs about the afterlife which involve the body remaining whole. The change in the system should not negatively impact upon members of the Roma community if steps are taken to make the community aware that they can opt out.

The new legislation in Wales has had little impact on religious communities, as while the 2011 census recorded that 60.3% of people in Wales held a religious belief, only 6% had opted out of the organ donor register by June 2017.<sup>6</sup> We do not believe that this change in law will have a negative impact on religious groups or people of ethnic backgrounds. There is no prior research to suggest that this will be the case.

**9. If the law changes and someone has died, and they have not opted out of organ donation, should their family be able to make the final decision?**

Other - If other, please specify

Humanists UK supports the introduction of a 'soft opt-out' system of presumed consent. 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.

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

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<sup>4</sup> <http://www.brin.ac.uk/2012/census-2011-any-other-religion/>

<sup>5</sup> <http://www.nbta-uk.org.uk/2017/10/more-organ-donation-needed-from-black-communities/>

<sup>6</sup> [https://en.wikipedia.org/wiki/Religion\\_in\\_Wales](https://en.wikipedia.org/wiki/Religion_in_Wales); Young et al. (2017) *Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report*

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

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 known wishes of the potential donor. Families should only be able to override where they know that the wishes of the donor are different what is presumed. Otherwise, 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.<sup>7</sup> 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 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.

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<sup>7</sup> <http://gov.wales/newsroom/health-and-social-services/2017/171204report/?lang=en>

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.

**11. If the Isle of Man moves to an opt-out system, should any of the following groups NOT be included in presumed consent?**

Children under 16 years old

People who lack capacity to consent

Visitors to the Island unless registered elsewhere

People living on the Island for less than 12 months unless registered elsewhere

Are there any other groups you think should not be included? Please tell us which groups and why you think this.

No

**12. Do you agree that Section 19 covers the topics that should be included in this code?**

Yes

**13. Please tell us about any opinions or evidence you have about opting out of organ donation.**

We strongly believe that an opt-out organ donation system would be beneficial for the Isle of Man and would welcome a change from the current law. The advantages of an opt-out system are well-illustrated in existing research. Six separate 'methodologically robust' studies have shown that opt-out organ donation policies are associated with higher rates of organ donation.<sup>8</sup> A report by Mossialos et al (2008) concluded that 'countries with a presumed consent policy had respondents with a higher willingness to donate their own organs as well as those of a relative'.<sup>9</sup> This was echoed by a more recent report by Bilgel et al. (2012) which analysed data from 24 countries and found that there was an 18% increase in organ donation rates in areas with presumed consent legislation.<sup>10</sup>

In many countries in Europe, the introduction of presumed consent was followed by an increase in the rate of organ donation. In Austria, in the eight years after presumed consent was made legal in 1982, the rate of organ donation quadrupled.<sup>11</sup> Similarly, in Spain, after the first decade of presumed consent there were 33.6 people donating per million people which represented an increase of 142%.<sup>12</sup> Opt-out systems improve the long-term rate of organ donation and in some countries there have been more immediately beneficial effects. In Belgium, in the two years following the introduction of presumed consent, the kidney transplant rate increased by 86%.<sup>13</sup>

In Wales, after the opt-out system was introduced in 2015, there was an increase in organ donors. In the first six months, 32 of the 60 organs transplanted came from patients whose consent was presumed and might otherwise have not been donated.<sup>14</sup> There were 104 donors in the 21-month period following the new rules compared to 101 in a similar period beforehand.<sup>15</sup> While the overall increase in number of donors was small, this is attributable to a shortage of eligible donors as opposed to any lack of

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<sup>8</sup> Palmer (2012). 'Opt-out systems of organ donation: International evidence review'

<sup>9</sup> 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

<sup>10</sup> Bilgel et al. (2012) 'The impact of presumed consent laws and institutions on deceased organ donation.' *European Journal of Health Economics* 13(1): 29-38

<sup>11</sup> Gnant et al. (1991) 'The impact of the presumed consent law and a decentralized organ procurement system on organ donation: Quadruplication in the number of organ donors'. *Transplantation Proceedings*

<sup>12</sup> Matesantz and Miranda (2000) *Organ Donation for Transplantation—the Spanish Model*. Madrid, Spain: Grupo Aula Medica

<sup>13</sup> Michielson (1996) 'Presumed consent to organ donation: 10 years' experience in Belgium'. *J. R. Soc Med*

<sup>14</sup><https://www.theguardian.com/society/2016/sep/04/wales-deemed-consent-organ-donation-system-promising-results>

<sup>15</sup> Young et al. (2017) *Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report*

efficacy on the part of the opt-out system. Further time is needed before the data from Wales can be conclusively analysed.

Where implemented, opt-out systems for organ donation have generally proved popular. In Wales, a year after the opt-out law was introduced, 71% of the Welsh public approved of the change, and the percentage who opted out was lower than had been estimated.<sup>16</sup> Crucially, there was also an increase in families consenting to the donation of the organs of their relatives from 44.4% in 2014 to 64.5% in 2017.<sup>17</sup> The refusal of family members to donate the organs of a relative, sometimes because of ignorance of the wishes of their relative, is currently a barrier to increasing the number of organ donors. Mossialos et al. (2008) found that people were much more willing to donate their own organs than those of a relative and concluded that 'decision making about organ donation by relatives of the deceased' might well have 'a downward impact on organ supply'.<sup>18</sup> A change in English law, especially if it was accompanied by a robust public information campaign, would likely prompt a decrease in families refusing to consent to organ donation as has occurred in Wales. It could also achieve the goal of raising awareness of the importance of people communicating their wishes regarding organ donation to their relatives. Whilst before 2015, surveys conducted of the general public in Wales indicated that around 40% had spoken to family members about their organ donation wishes, this had grown to 51% by March 2017.<sup>19</sup> As such, we believe the introduction of an opt-out system of organ donation has the potential to bring a wide range of benefits to the Isle of Man and should be implemented in the near future.

Aside from the empirical evidence that opt-out systems increase the availability of organs for transplant, the ethical evidence also favour this change. Again, 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:

When thinking about the ethics of an organ donation opt-out system it may be helpful to refer to the four principles of medical ethics which were originally proposed by Beauchamp and Childress and have gained wide acceptance as a shared ethical framework: the values of beneficence, non-maleficence, autonomy, and justice.<sup>20</sup> The principle of beneficence – of doing good – is clearly relevant. A change from an opt-in to an opt-out system has the potential to save human lives and thereby contribute significantly to the promotion of human happiness and well-being.

That is not, by itself, enough to settle the ethical issue. However great the amount of good that can be done, it is not normally acceptable to achieve this by using some people, against their wishes, for the good of others. That is why the value of autonomy is equally important, and why the requirement of informed consent is deeply embedded in the principles and practice of medical ethics.

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<sup>16</sup> Ibid.

<sup>17</sup> Ibid.

<sup>18</sup> 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

<sup>19</sup> Young et al. (2017) *Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report*

<sup>20</sup> Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (Oxford University Press, 1979); Raanan Gillon, *Philosophical Medical Ethics* (John Wiley & Sons, 1986)



In the present case, the requirement of informed consent would appear to be neutral as between an opt-in system and an opt-out system. In either system, people are enabled to give or withhold their consent to having their bodily organs used for a transplant operation – provided, that is, the ‘presumed consent’ in an opt-out system really is informed consent. In practice this means that all reasonable efforts must be made to publicise the system and ensure that everyone is properly informed of their right to opt out. If such arrangements are in place, it can plausibly be maintained that an opt-out system respects the principle of autonomy.

The change from an opt-in to an opt-out system is therefore not a rejection of the value of autonomy, but simply a change in the default position. There are, in addition, good reasons for thinking that ‘presumed consent’ should be the default position:

- If there is a strong moral case, other things being equal, for using the organs of a dead person to provide life-saving treatment for another human being, it is reasonable that the default position should reflect the strength of that moral case.
- It is reasonable that the default position should reflect the prevailing moral consensus. In our society the consensus is clearly in favour of organ donation.
- If some individuals object to having their organs used in this way, their objection is likely to be based on some distinctive religious doctrine or belief system. People who hold such beliefs are likely also to be aware of the need to exercise their right to opt out.

It would seem, then, that the principle of beneficence furnishes a good reason for changing to an opt-out system, and that the principle of autonomy does not furnish any objection to making such a change.

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

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**Richy Thompson**  
**Director of Public Affairs and Policy**  
**0781 5589 636**  
**020 7324 3072**  
[richy@humanists.uk](mailto:richy@humanists.uk)  
[humanists.uk](http://humanists.uk)

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