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## **CONSULTATION ON INTRODUCING 'OPT-OUT' CONSENT FOR ORGAN AND TISSUE DONATION IN ENGLAND**

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**Response from Humanists UK, February 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 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, we 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.

### **RESPONSE TO CONSULTATION QUESTIONS**

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

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

We believe that a single simple system for record decisions is the best way to implement an 'opt-out' system. In the event of a death, medical professions have one single register to consult for an opt out. This will reduce the risk of confusion, delays or contradiction over a person's wishes and sets a clear framework by which people can understand how the organ donation process works. In many cases, the medical decision over whether organ donation can take place is time-sensitive. Allowing additional ways to store an opt out decision, such as in their will, at a GP surgery, or through family consent, will involve delays to the process as each of these methods would have to be checked. This could result in organs no longer being useful for donation thus defeating the whole purpose of an opt-out system.

If there is only one way in which to record a decision, the public information campaign accompanying the change could then focus on more pressing matters such as the lack

of knowledge about the process of organ donation, the need to increase donation rates, and the importance of communicating organ donation wishes with family and loved ones.

Although we believe that a single system is required to store decisions, we feel it is important that this system is accessible to all, including those with physical and mental disabilities. Therefore, the Department of Health should consider whether methods other than online or phone registration should be used for people who would struggle to access these methods, such as paper registration forms or whether guardians and carers can register wishes on behalf of charges who might not be able to access the register themselves.

## **2. What do you think are the advantages or disadvantages of including personal information on someone's organ donation decision?**

There are several advantages to recording personal information in addition to whether the person has opted out of donation. One advantage to the current system is that it allows donors to specify if there are certain organs or tissues that they are not willing to donate. Although the opt-out system is designed to maximise the number of organs available, this does not mean that donors are necessarily willing to donate all of their organs. This might encourage potential donors with specific requirements not to opt out entirely. The system should allow people to opt -out for parts or organs as well as for the whole body. This could be done simply through the Organ Donation Register and could be checked alongside opt-out status upon death.

Secondly, a person may have religious beliefs that whilst not prohibiting organ donation, do specify how the body should be handled after death. Specifically, the Jehovah's Witness community are not opposed to organ donation, but to blood donation. Therefore, they would require blood to be removed from an organ before transplantation. Although this is a relatively small community, recording personal information such as this would mean that they would be less likely to opt out.

Finally, for evaluation and monitoring purposes, it would be advantageous to record the reason why people opt out. This information could be useful in assessing the success of the new system and the effective planning of public awareness campaigns. This could be done easily by adding an optional question to the Organ Donor Register when a person selects to opt out.

## **3. How can we make people more aware of the new rules on organ donation?**

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 the system change, including hard-hitting radio and television adverts, on transport advertising spaces, and

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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

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 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, NHS Blood and Transfusion 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 England.

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 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

A change in system is likely to result in more people choosing, passively or otherwise, to become donors. Polling conducted by the British Medical Association in 2017 shows that 66% of people are willing to donate some or all of their organs after death; however, only 39% have signed up to the current opt-in register. Therefore, if the law was to change, it would result in more people who wish to become donors actually fulfilling this wish. Additionally, only 6% of people in Wales have chosen to opt out of the system since its introduction. This is less than was initially estimated, and suggests that there is no correlation between a change to an opt-out system and more people choosing not to donate. It is therefore likely to be the case that the increased attention placed on organ donation as an issue that would accompany any change in the law encourages people to discuss their views and seek to donate. Ultimately, we are in favour of organ donation, and as an opt-out system is more efficient in enabling organs to become available, we support its introduction unreservedly.

#### **5. If the law changes, people would be considered willing to be an organ donor unless they have opted out. Do you think this change could have a negative 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 negatively 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

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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>

exception. The followers of Shintoism often object to donation because they believe that a body should not be injured in any way after death. However, there are very few Shinto followers in the UK: the 2011 census records only 1,075 individuals.<sup>4</sup> The change in the system should not negatively 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 in England 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.

Overall, the majority of the English population supports organ donation and the introduction of an opt-out system with as many as 8 in 10 people being in favour. 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.

## **6. 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 (please give details).

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

## **7. 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.

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

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

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.

**8. Which of the following should not be included in the proposed new rules about organ donation?**

- people who lack capacity
- visitors to England
- people living in England for less than 12 months (for example, students from overseas, armed forces personnel)

**Are there any other groups you think should not be included? Please say why you think this.**

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 England and those living in England 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. Those entering the country for periods of less than 12 months should have the option to opt in to the register for the duration of their stay in the country, either as part of the process of applying for a visa or by specifically applying to the register. However, it is imperative that data-sharing takes place with the Welsh, Scottish, and Northern Irish organ donation registers, so that wishes can be shared across the four 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.

## **9. 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 England 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

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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

presumed consent, the kidney transplant rate increased by 86%.<sup>13</sup> A similar increase in England would be life-changing as between March 2016 and March 2017, 256 people died either waiting for a kidney transplant or shortly after one.<sup>14</sup> As of January 2018, 5,080 people are still waiting for a kidney transplant in the UK.<sup>15</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>16</sup> There were 104 donors in the 21-month period following the new rules compared to 101 in a similar period beforehand.<sup>17</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 efficacy on the part of the opt-out system. Further time is needed before the data from Wales can be conclusively analysed. However, the greater size of the English population means the impact of the opt-out system would almost certainly be more significant in England than it was in Wales.

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>18</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>19</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>20</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>21</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 England and should be implemented in the near future.

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

<sup>14</sup><https://www.organdonation.nhs.uk/news-and-campaigns/news/waiting-time-to-kidney-transplant-down-18-but-shortage-of-donors-still-costing-lives/>

<sup>15</sup> NHSBT figures

<sup>16</sup><https://www.theguardian.com/society/2016/sep/04/wales-deemed-consent-organ-donation-system-promising-results>

<sup>17</sup> Young et al. (2017) *Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report*

<sup>18</sup> Ibid.

<sup>19</sup> Ibid.

<sup>20</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>21</sup> Young et al. (2017) *Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report*



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>22</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.

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.

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<sup>22</sup> Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (Oxford University Press, 1979); Raanan Gillon, *Philosophical Medical Ethics* (John Wiley & Sons, 1986)

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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