

# DEPARTMENT OF HEALTH CONSULTATION: INTRODUCTION OF A STATUTORY OPT-OUT SYSTEM FOR ORGAN DONATION

Response from Northern Ireland Humanists,  
February 2021



## ABOUT NORTHERN IRELAND HUMANISTS

Northern Ireland Humanists is a part of 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 100,000 members and supporters and over 100 members of the All-Party Parliamentary Humanist Group.

Humanists UK has campaigned over the last two decades for the introduction of opt-out organ donation across the UK and crown dependencies. In 2008, we submitted evidence to a House of Lords inquiry into organ donation, were consulted by the Organ Donation Taskforce and gave oral evidence to the Welsh Assembly Health, Wellbeing, and Local Government Committee Inquiry into Presumed Consent for Organ Donation. We worked with the UK Government on the introduction of opt-out organ donation in England, including sitting on the NHS Blood and Transplant organ donation campaign advisory panel. We briefed MPs and peers in favour of the Organ Donation (Deemed Consent) Act 2019 and submitted evidence to consultations held by the Governments of the Isle of Man, Guernsey, and Jersey into opt-out systems.

**I am responding: an organisation**

## SUMMARY OF RESPONSE

We support opt-out organ donation because humanists do not believe that respect for the dead constitutes any reason to object to allowing a deceased person's organs being used to help others, except when the deceased has expressed a contrary wish. The advantages of an opt-out system to increase willingness to donate and thereby the number of organs available for transplant have been well-illustrated in existing research in other UK and European jurisdictions that have opt-out systems already in place.

## RESPONSE TO CONSULTATION QUESTIONS

**Q5. To what extent do you agree that opt-out legislation should NOT apply to children (those under 18 years) and that the donation decision should be made by those with parental responsibility? Rate your agreement with this statement.**

Disagree

We believe an opt-out system should be based on the principle that the potential donor is of sound mind, capable in ordinary circumstances of making medical decisions, and has been given the opportunity and relevant information to decide if they wish to opt out or not. As to whether children should be excluded, in certain parts of the UK, such as England, a child of 16 can register with the Organ Donor Register under the current system and, therefore, is deemed capable of making this decision independently.



We recommend the age limit is lowered to 16 and young people are educated at school about organ donation options. For children below this age, those who are regarded as Gillick competent should continue to be able to opt in to donate, with parents or guardians able to make decisions about donation for their children where they have not reached this level of competence.

**Q6. Do you think that any of the following people should be exempt from deemed consent for organ donation and the family should provide that consent? (please tick all those that apply)**

Agree

- Adults who lack capacity
- Visitors, including cross-border workers from ROI & tourists to Northern Ireland
- People who are only temporarily resident in Northern Ireland (e.g. students from overseas or ROI, overseas Armed Forces personnel), people on work placements from overseas or ROI
- People whose identity is unknown

Similarly to our answer in question five, we believe an opt-out system is premised upon potential donors being given the opportunity and adequate information to decide if they wish to donate or not. Therefore, we agree that adults who lack the capacity to consent and people whose identity is unknown should be excluded from any new legislation concerning deemed consent. Similarly, visitors to Northern Ireland and those temporarily residing here for less than 12 months should be exempt as they may be unfamiliar with the opt-out system. Their organs should not be donated unless they have expressed a clear wish to do so or their families have given express consent. Those entering the country for periods of less than 12 months should be given 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 applying to the register, perhaps via leaflets at ports of entry. However, these opt-ins should apply across the United Kingdom and the data should be shared with the Welsh, Scottish, and English organ donation registers.

Disagree

- Prisoners

We believe prisoners should not be exempt from deemed consent. Prisoners over the age of 16 can easily be informed of organ donation options and given adequate resources to be able to opt out should they wish to do so. There is no reason for them to be excluded from the deemed consent provision.

We do not think that any other groups merit exclusion from the proposed deemed consent provision.

**Q7. To what extent do you agree that, in situations where there is a known decision to donate recorded on the NHS Organ Donor Register, the family should always be asked about the last known organ donation decision of their loved one, to ensure it's still accurate?**



Neither agree nor disagree

We support the introduction of a 'soft opt-out' system of deemed consent similar to the systems in England and Wales. As such, we believe that in some circumstances consulting the families of potential organ donors is still relevant.

However, we do not support family members being able to override the deceased's wishes. The role of the family is to be a source of information about the intentions of the deceased, not themselves be decision-makers in the donation process. The family should be consulted to establish if they have evidence that the last known wishes of the deceased are different from what is on the register.

Otherwise, this is deeply unfair to the donor, runs counter to the principle of informed consent, 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 opposition to donation, preventing many lives from being saved.<sup>1</sup> 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's wishes. We sought the views of Richard Norman, Professor Emeritus of Moral Philosophy at the University of Kent and a 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 an 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

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<sup>1</sup> *Together for Health: Organ Donation Annual Report 2017*, Welsh Government, (2017):  
<https://gov.wales/sites/default/files/publications/2018-07/organ-donation-annual-report-2017.pdf>



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 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, whether 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.'

**Q8. To what extent do you agree that, in situations where there is no known organ donation decision, the family should always be asked about whether their loved one would have objected to organ donation?**

Agree

Similarly to our response to question seven, we believe in this circumstance consulting the families of potential organ donors is appropriate. Specifically, if a family member of the deceased has



evidence that the individual was opposed to donating their organs, but that they failed to actively opt out prior to their death, then that evidence should be given weight in the decision.

**Q9. Which of the following statements best summarises how the introduction of opt-out legislation would influence your support for donation of a loved one's organs and/or tissues?**

I currently support organ donation and would continue to do so

We currently support organ donation and would continue to do so after a statutory opt-out system was implemented. Since its introduction, only 6% of people in Wales have chosen to opt out.<sup>2</sup> This is less than initially estimated and suggests that there is no correlation between a change to an opt-out system and more people choosing not to donate. Therefore it is likely to be the case that the increased attention placed on organ donation that would accompany the change to an opt-out system would encourage 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.

**Q11. To what extent do you agree that the donation of organs and tissues for research purposes should be excluded from statutory opt-out and the family approached for express consent?**

Agree

Where consent has not been stipulated by the deceased to donate their organs for research purposes, we support express consent being required. Thus, family members are approached in this decision as sources of information for the deceased's last known wishes.

**Q12. To what extent do you agree that people's faith or beliefs should continue to be taken into consideration as part of the donation discussion after any move to an opt-out system?**

Agree

We strongly believe in and defend the right to freedom of religion or belief. Therefore, we agree that a person's religion or belief should be taken into consideration following any move to an opt-out system. We propose a system similar to England, whereby upon completion of the registration process, persons can state that their religion or beliefs are important to them in making this decision. Family members may also be consulted about the consonance of organ donation with the deceased's faith, beliefs, and practices. Within this system, specialist donation nurses discuss with family members how donation might proceed in line with the deceased's stated wishes, share information with family members relevant faith or belief statements, discuss whether the organ

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<sup>2</sup> Westminster Hall Deb, (13 July 2017), 'Organ Donation: Opt-out System' Volume 627. <https://hansard.parliament.uk/commons/2017-07-13/debates/17071358000002/OrganDonationOpt-OutSystem>



donation and retrieval process might need to be adapted to respect the deceased's faith or belief, and offer support to the family by contacting religious authorities or pastoral carers if desired.

**Q13. What do you think is the most important and effective activity for raising awareness of the law change? (please select no more than 3)**

- TV, radio
- Out of home advertising (e.g. posters on public transport, billboards etc.)

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>3</sup>

Such campaigns need to be run extensively in the run-up to the system change, including hard-hitting radio and television adverts, posters 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 system in Wales suggested that an advert needs to be seen seven times for the message to be adequately conveyed.<sup>4</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 it came into force.<sup>5</sup> We have been told informally by NHS Blood and Transport that 80% of people in England are now aware of the changes, nine months after the new law came into force. Therefore we support a year-long advertising campaign across Northern Ireland aimed at increasing awareness such as those used before the law changes in England and Wales.<sup>6</sup> Going forward, the Department of Education should seek to introduce the topic of organ donation into the school curriculum.

If the wishes of the deceased concerning their body are to be recognised, including which organs potential donors may or may not want to donate, those wishes need to be well informed. 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.

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<sup>3</sup> Mossialos, E., Costa-Font, J. & Rudisill, C. *Does organ donation legislation affect individuals' willingness to donate their own or their relative's organs? Evidence from European Union survey data.* BMC Health Serv Res 8, 48. 2008. <https://doi.org/10.1186/1472-6963-8-48>

<sup>4</sup> BBC News, *Organ donation law awareness campaign "huge challenge"*, 2015. <http://www.bbc.co.uk/news/uk-wales-politics-34019713>

<sup>5</sup> Young et al. *Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report*, Welsh Government, 2015 <https://gov.wales/sites/default/files/statistics-and-research/2019-05/evaluation-human-transplantation-wales-act-impact.pdf>

<sup>6</sup> NHS Blood and Transplant, *Organ donation law change awareness campaign launches* <https://www.nhsbt.nhs.uk/news/pass-it-on-campaign/>





**Q14. If you have any other comments or views you would like to express in relation to the proposed opt-out legislation, please comment below.**

We strongly believe that an opt-out organ donation system would be a beneficial and popular measure in Northern Ireland. 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>7</sup> A report by Mossialos *et al* 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>8</sup> This was echoed by a more recent report by Bilgel *et al* 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>9</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>10</sup> Similarly, in Spain, after the first decade of presumed consent, there was an increase of 142%.<sup>11</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>12</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 obtained.<sup>13</sup> While the overall increase in the 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.

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

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<sup>7</sup> Melissa Palmer, *Opt-out systems of organ donation: International evidence review* Welsh Government, 44, 2012. <https://gov.wales/sites/default/files/statistics-and-research/2019-08/121203optoutorgandonationsummaryen.pdf>

<sup>8</sup> Mossialos, E., Costa-Font, J. & Rudisill, C. *Does organ donation legislation affect individuals' willingness to donate their own or their relative's organs? Evidence from European Union survey data.* BMC Health Serv Res 8, 48. 2008. <https://doi.org/10.1186/1472-6963-8-48>

<sup>9</sup> Bilgel F, *The impact of presumed consent laws and institutions on deceased organ donation.* Euro Journal Health Econ. Feb;13(1):29-38. 2012. <https://pubmed.ncbi.nlm.nih.gov/20848298/>

<sup>10</sup> Gnant et al., *The impact of the presumed consent law and a decentralized organ procurement system on organ donation: Quadruplication in the number of organ donors.* 1991. Transplantation Proceedings <https://repository.library.georgetown.edu/handle/10822/746526>

<sup>11</sup> Matesantz and Miranda, *Organ Donation for Transplantation – the Spanish Model.* Madrid, Spain: Grupo Aula Medica 2000 <https://pubmed.ncbi.nlm.nih.gov/10382976/>

<sup>12</sup> Michielson, P., *Presumed consent to organ donation: 10 years' experience in Belgium.* J. R. Soc Med 1996 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1296026/>

<sup>13</sup> Steven Morris, 'Welsh 'deemed consent' organ donation system shows promising results' *The Guardian*, 2016 <https://www.theguardian.com/society/2016/sep/04/wales-deemed-consent-organ-donation-system-promising-results>



percentage who opted out was lower than had been anticipated.<sup>14</sup> Crucially, there was also an increase in families consenting to the donation of the organs of their relatives from 44% in 2014 to 65% in 2017.<sup>15</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* 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>16</sup> A change in Northern Ireland's law, especially if it were accompanied by a robust public information campaign, would prompt a decrease in families refusing to consent to organ donation, just 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 of the public conducted 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>17</sup> We therefore believe the introduction of an opt-out system of organ donation has the potential to bring a wide range of benefits to Northern Ireland and should be implemented soon.

More recently, an early examination of organ donation rates since a soft opt-out system was implemented in Wales in 2015 indicates an increase in registered donors, fewer instances of family refusals and more living donations.<sup>18</sup> Further, in exploring the impact of deceased organ donation rates in a comparative study between England and Wales, Madden *et al* found significant increases in organ donation consent in Wales following the opt-out system implementation relative to England (pre England's change in organ donation law).<sup>19</sup> Due to the disruption to NHS services caused by the coronavirus pandemic, it has not been possible to gather reliable data on the effectiveness of the law change in England since its introduction in May 2020.

Aside from the empirical evidence that opt-out systems increase the availability of organs for transplant, the ethical evidence also favours this change. We sought the views of Richard Norman, Professor Emeritus of Moral Philosophy at the University of Kent and a Patron of Humanists UK, on this question also. He told us:

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<sup>14</sup> Young et al., *Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report*, Welsh Government, 2017

<https://gov.wales/sites/default/files/statistics-and-research/2019-05/evaluation-human-transplantation-wales-act-impact.pdf>

<sup>15</sup> *Ibid.*

<sup>16</sup> Mossialos, E., Costa-Font, J. & Rudisill, C. *Does organ donation legislation affect individuals' willingness to donate their own or their relative's organs? Evidence from European Union survey data*. BMC Health Serv Res 8, 48. 2008. <https://doi.org/10.1186/1472-6963-8-48>

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

<https://gov.wales/sites/default/files/statistics-and-research/2019-05/evaluation-human-transplantation-wales-act-impact.pdf>

<sup>18</sup> Noyes J, McLaughlin L, Morgan K, et al, *Short-term impact of introducing a soft opt-out organ donation system in Wales: before and after study*, BMJ Open (2019) <https://bmjopen.bmj.com/content/9/4/e025159>

<sup>19</sup> Madden et al., *The effect on consent rates for deceased organ donation in Wales after the introduction of an opt-out system*. Association of Anaesthetists. (2020) <https://associationofanaesthetists-publications.onlinelibrary.wiley.com/doi/full/10.1111/anae.15055>





'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 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 adequately 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.'

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<sup>20</sup> Tom Beauchamp and James Childress, *Principles of Biomedical Ethics* (Oxford University Press, 1979) <https://jme.bmj.com/content/28/5/332.2>; Raanan Gillon, *Philosophical Medical Ethics* (John Wiley & Sons, 1986). <https://www.jstor.org/stable/3750643?seq=1>



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