

Opting out of waiting list deaths

The future of organ donation in the
United Kingdom



POLYGEIA

STUDENTS SHAPING GLOBAL HEALTH POLICY

Contributors

Lead Author: Chidera Ota

Lead Editor: Dr David Neal

Design: Ali Abdaal

February 2017

Contents

Executive Summary	4
Introduction & Context	6
Systems Abroad	8
The Potential of Opt-out in the UK	10
The Impact of Opt-out	15
Conclusion	18
References	19

1 Executive Summary

This report presents research collated and reviewed with two fundamental goals in mind: to understand and to present in simple terms, the current problems with the UK organ donation system; and to analyse to what extent an 'opt-out' donation system might solve the problems.

The nature of the problem can be so simply stated that it is in danger of being perpetually underappreciated: over 1000 people every year die or have to be removed from the organ waiting list. This is because there are not currently enough donors to meet the need for transplants. Such is the scale of many of today's pressing health issues that 1000 might have failed to impress a sense of urgency at a Global Health Think Tank. Of course for each member of our national community who makes up that thousand every year, and for their families, the importance of the issue is infinite. If there is a solution that would not come at too great a cost to society, we must seek it.

In Wales, a form of 'opt-out' system, in which all are presumed donors unless registering otherwise, was introduced in 2016. France introduced such a system in 2017. In Spain this system has been in place for decades. Such a system has been talked about in the UK but until now, no government has made the effort to seriously consider and facilitate implementation.

In this report we demonstrate the seriousness of ongoing failure to implement this policy.

Research from the NHS suggests that around half of the population would like to donate their organs after death. Only 16% definitely would not want to donate. Yet less than 40% of the population is registered as an organ donor. Our approach had been to model how these numbers might determine the availability of organs under an opt out system. Based on published data from NHS Blood and Transplant, the models show that even if only the 50% definitely in favour all became registered under opt out, virtually no one in the UK would die waiting for an organ transplant.

The ability to end deaths on the organ transplant waiting list is therefore within the scope of an opt-out system, even if on the most limited scenario, no one is newly persuaded to donate.

The costs associated with implementing an opt-out system primarily relate to doing so in an ethically sound manner. The biggest investment would be in publicising the change to allow people the opportunity to register opting out of that is their choice. However, the economic benefits for society of investing in organ transplantation have been well documented so this investment should provide a sound return.

Polygeia is calling on the Government to introduce a white paper on adopting an opt out organ donation system before the end of this Parliament. The time for waiting is over. It is time to act.

2 Introduction & Context

At this moment in time there are over 6000 people in the UK on the transplant waiting list [1]; people with life threatening conditions, for which the only solution is an organ transplant. However, the average waiting time is 233 days, and in the 2015-2016 financial year, 466 patients died waiting. A further 881 were removed from the waiting list entirely; this often occurs due to deterioration in health so severe that a transplant operation may no longer be tolerated.[2] It is clear that work needs to be done in order to decrease waiting times, and the number of patients who die on the waiting list, by increasing the number of transplant operations taking place. Here we will explore whether increasing the number of organ donations made is a feasible solution.

Currently, in order to become a potential organ donor, you must register to do so. There are a few opportunities to do this, such as when applying for a passport or an Oyster card. [3] However, outside of these opportunities, registration requires a conscious effort, allowing the lack of visibility and information on why and how to donate organs to impact the number of transplants available. The impact of this opt-in system becomes clear when the results of a 2015 survey by the NHS Blood and Transplant service are considered.

‘When asked ‘Do you want to donate your organs after death’ 50% of all respondents answered yes, 16% no, 11% never thought about it and 23% don’t know.’ [4]

The results of this survey show that only 16% of the population are definite in not wanting to donate their organs, yet in January 2016 only 34% of the population were registered to donate.[3] Given this disparity, an opt-out system could potentially be more representative of the wishes of the population as a whole than the state of the current opt-in system.

In an opt-out system, all people are considered to be potential organ donors, unless they have actively chosen to be taken off the organ donation register. This is a system that has been implemented successfully in multiple countries, including Spain and France. It is also being debated in the Netherlands, and closer to home, has been introduced in Wales. This report explores the benefits and limitations of such a system within the United Kingdom, and how such a system could be implemented. In particular, we model the impact of an opt out system on the number of organs available for transplant and the number of people dying whilst waiting for organs.

3 Systems Abroad

In December 2015, Wales changed from an opt –in system to a new opt-out system, in which patients who haven’t registered a decision to opt-in or opt-out of organ donation ‘will be treated as having no objection to being an organ donor.’[5] This change was championed by the Welsh Labour led government, and sparked criticism from the Welsh Conservative party and the church in Wales.

The change was immediately followed by a ‘rush’ of people to opt out, as reported by The Guardian, with a swift increase from 15,000 to 86,000 people choosing opt out the following the publicity on the change in legislation.[6] However, despite some negative press, Wales saw an increase to 31 donations in the 6 months following the change, compared to the 23 and 21 people who donated organs in the same time period in 2014 and 2013, respectively, a 35% increase.[7]

The Welsh change in system was inspired in part by the success of the switch to ‘opt out’ in Spain, initiated in 1979. This change is credited for Spain’s status as the country with the highest number of organ donors per million population. However, the success of the organ donation programme in Spain cannot be explained wholly by its opt-out basis.

This is clear given that in 1989, 10 years after the change in legislation, donation rates in Spain were still incredibly similar to those in the UK.[8] It was at this point that what has become known as the ‘Spanish Model’ was implemented, and the rate of organ donation began to slowly rise to the numbers we see now.

The Spanish model focuses on improving of transplant coordination, between donors and recipients, and putting systems in place to ensure any viable organs are matched, and transported efficiently. There is also a focus on improving the dissemination of information on the importance of, and arrangement of, organ donation. This has helped to reduce the ‘refusal rate’: the rate at which the family of the deceased refuse the use of organs of their relative, a legal loophole that allows relatives to overrule the decision of the deceased.[9] This rate is currently 9% in Spain, small in comparison to 43% in the UK.[10]

Looking at the systems in place for organ donation in Wales and Spain, it seems clear that changing to an ‘opt-out’ system, whilst maybe not sufficient entirely in itself to improve transplant rates and reduce waiting times and deaths, can be an important starting point. This example also highlights that it is important to strengthen other aspects of organ donation, to ensure all opportunities for organ donation are fully utilized.

4 The Potential of Opt-out in the UK

The United Kingdom is far behind several countries in Europe, and the United States in deceased organ donation rates, and as a result, there has been much discussion in how to improve this, including around whether an ‘opt-out’ system would be an appropriate solution.

As recently as April 2016, the British Medical Association called for a ‘soft’ opt-out system, similar to that piloted in Wales, in which, unless person has stated opposing wishes, it is assumed they consent to being an organ donor after death.[11] This is a ‘soft’ system, as there is room for objection from family members as an extra ‘safeguard’, to ensure the patient’s wishes are met. This change is likely to be better received than a ‘hard’ opt-out option, in which there is little room for the family to convey the donor’s personal wishes if they feel they are not represented by their registration status.

With regard to introducing an ‘opt-out’ system in the UK there are legal and ethical considerations, alongside considering the political influence needed to manoeuvre such a change. We will consider these in turn below.

Ethical Considerations

An understandable concern with the implementation of an opt-out system is the impact on the autonomy of patients. ‘Respect for autonomy’ is one of the four major ethical principles, originally developed by Beauchamp and Childress, that are used to provide a moral framework in which healthcare is delivered. There have been suggestions that switching to an opt out system will create opportunity for organs to be taken from patients who have not left the organ donation register, but do not wish to have organs removed after death, violating their right to autonomy.[12] However, it is important to consider that in our current system, there are patients who wish to donate organs, but may not have registered to become organ donors before death, creating a similar moral conundrum.

It is also important to consider another two of the four core principles of medical ethics:

- o Beneficence - to act in the best interest of a patient
- o Justice - to ensure benefits, risks and costs are distributed fairly

Bearing the first of these in mind, it seems morally right to work in a ‘opt out’ system, in order to ensure that we work in the best interests of patients requiring organ transplants, by ensuring as many useful organs as possible are removed from patients after they die.

With regard to ‘justice’, and the utilitarian approach of the National Health Service (NHS), again there is a strong ethical argument for an ‘opt-out’ system, considering the huge benefit donated organs can make to the thousands of patients on waiting lists (alongside their family and friends).

In order to ensure that organ donation remains as ethical as possible, it is therefore important to ensure that people feel their autonomy is respected. One way to do this is to ensure that all people are well educated about the organ donation system, what it means to be within an ‘opt out’ system, and how remove themselves from the organ donation list, if they so wish. Offering a ‘soft’ opt out option, in which a patient’s family can also object to organ donation on their behalf, could also reduce the chance of a patient’s autonomy being ignored, though there is a risk that family members may themselves ignore a relative’s choices; something that education on organ donation could help avoid. Nevertheless, by providing people with the ability to easily opt out of organ donation, and also improving our donation system to ensure the maximum number of patients receive organs they need, we will certainly be moving towards a more ethically sound organ donation system, that is supported by the principles upon which the National Health Service and the NHS Blood and Transplant service were founded.

Implementation

As discussed, there are many factors that must be considered when implementing a new opt-out organ donation system. One of great importance, is the role of political will in implementing changes in the NHS. In Wales, the decision to introduce an opt out system was first greatly hindered by, and then strongly bolstered by, the government. It was following the National Assembly for Wales Election in 2011, in which three parties of four, including the winning Labour party, included introducing an opt-out organ donation system in their manifestos, that formal actions taken to implement the change began. [13]

Given the similarities in the way the government impacts on the NHS in the rest of the UK, it follows that, in order to introduce an opt-out system, it is necessary to have at least one, if not all major political parties on board.

Another important factor considered above, and by the Welsh Government, was the need to publicise and disseminate information about the change to the organ donation system, to the populace it would affect. In Wales, this was dealt with by allowing a delay from when the Human Transplantation Act bill was passed, in 2013, to when the bill was allowed to take effect, in 2015. A similar delay would be useful in the United Kingdom, to allow information to be spread across the region.

The publicity would need to use multimedia, such as newspapers, television, and the internet, whilst also having tactics in place to ensure marginalised groups are reached, such as the elderly or homeless. One way of doing this would be to have adverts on buses, bus stops, or in GP practices: places most of the population will observe over a few years.

It will be important not only to advertise changes, but to encourage discussion of organ donation amongst peers, and family. As mentioned before, the UK has a very high refusal rate in comparison to other countries, such as Spain, and within a soft opt-out system, family members will still be able to refuse organ donation on their relative's behalf. Publicity that aims to normalise organ donation, and make people more open about their views, with regard to donating, is incredibly important to ensure that their family members are aware of, and respectful of, their relatives' wishes. This may help to reduce the organ donation refusal rate.

A final consideration to make would be to look at the long term management of an opt-out system, paying particular attention to the ways in which the Spanish healthcare system moulded around this change. It is important to have a long term plan, that will allow an improvement in all services surrounding organ transplantation, including collection and storage of organs, identification of potential donors to be, and allocation and transport of organs to donees. This organisation is crucial to the success of any organ donation system, but will be particularly important in ensuring the increased number of organ donations are dealt with efficiently. [9]

5 The Impact of Opt-out

In 2015-2016, 1347 people died on, or were removed from, the transplant waiting list, at a point when only 34% of the British population were registered on our organ donor register, resulting in a total of 3519 transplants.

Looking at the welsh pilot of an 'opt-out' system, with an 35% increase in donations, we feel this is a realistic example, that can be used to model what may happen if the the rest of UK switch to on 'opt-out' organ register, given the similarities between the two healthcare systems.[7] If we were to see a similar rise in organ donors in the uk, this could result in up over 1,200 more organ transplants in the UK.

Had the number of people on our current organ donation register been more representative of the 50% of the population who are definitely willing to donate organs [4], the number of deceased organ donors would have risen by (an estimated) 642 people. Given each donor on average produce at least two organ transplants each[14], this could have resulted in a drop of around 1284 patients from the transplant waiting list, almost accounting for all of those who died waiting. In other words, even if under an opt out system, only those who currently state that they definitely want to donate but have not actively registered went on to donate, virtually no one would die waiting for an organ transplant.

However, if we were to switch to an opt out register and find that only the 16% that have stated definitively that they would not want to donate their organs would opt out, that could result in a reduction of around 4000 to 5000 patients from the transplant waiting list, which currently sits at around 6500. Up to 75% of those requiring organ transplants would get one within 12 months.

These models and their interpretation are based on a number of assumptions. These include: that each patient on the waiting list requires only one transplant, that organs from newly registered donors would become available at the same rate as those currently on the register, and that on average there would be the same rate of tissue-type matching between the new donor pool and those on the transplant waiting list.

Nonetheless, these models clearly illustrate just how powerfully a change to an opt out system could affect the lives of thousands of people who are currently waiting for organ transplants, and who may not survive long enough to receive one in our current system.

Economic Impact

A thorough and detailed analysis of the economic impact of increasing the availability of organs for transplant is beyond the scope of this report. However, the potential for an opt-out organ donation register to benefit the health system financially, and indeed benefit the wider economy, deserve mentioning/research. NHS West Midlands Specialised Commissioning Team has previously reported that an increase in organ donation by 50%, could save the NHS £200,000,000 per annum.[15] Indeed, in our model above, if all members of the public, except those that actively oppose organ donation, were on the organ donation register, this would represent a 50% increase.

To give a more specific example of how organ donation saves money, patients with kidney failure, who require regular dialysis, cost, on average, £30,800 per patient, per year - requiring around 3% of the NHS budget. If, instead, a patient was treated with a kidney transplant, this would cost £17,000 for the transplant operation, plus £5,000 per year for immunosuppressive drugs, to ensure the donated organ is accepted into a donees body. This would result in over 80% cost saving per patient per year, following their operation.[16] While it is important not to reduce this issue to finance, this is a significant sum of money, that could be spent elsewhere to help a struggling healthcare system.

6 Conclusion

Given the magnitude of the possible benefits of changing to an opt-out system, we think it is imperative that the NHS and government begin work on implementing this switch as soon as possible. In the meantime, we call on everyone in the UK to consider and to register their organ donation preference. Our report shows that together, we have the power to end deaths on the organ transplant waiting list.

Every day's delay marks the death of a human being - a mother, a father, a son or a daughter. Surely then, the time to act is now.

References

1. https://nhsbtdbe.blob.core.windows.net/umbraco-assets/1067/united_kingdom.pdf
2. http://www.odt.nhs.uk/pdf/activity-report/summary_of_transplant_activity.pdf
3. <http://www.standard.co.uk/news/london/transport-users-who-apply-for-oyster-card-online-given-opportunity-to-become-organ-donors-9850458.html>
4. <https://www.organdonation.nhs.uk/news-and-campaigns/news/national-transplant-week/>
5. <https://www.organdonation.nhs.uk/register-to-donate/more-information-about-your-choices/more-information-about-refusing-organ-donation/>
6. <https://www.theguardian.com/society/2015/dec/01/wales-switches-to-organ-donation-opt-out>
7. <https://www.theguardian.com/society/2016/jun/14/wales-deemed-consent-organ-donations-increase-transplants>
8. Fabre J, Murphy P, Matesanz R: Presumed consent: a distraction in the quest for increasing rates of organ donation. *BMJ*. 2012, 341: c4973-10.1136/bmj.c4973.
9. Matesanz R: Factors influencing the adaptation of the Spanish Model of organ donation. *Transpl Int*. 2003, 16: 736-741. 10.1111/j.1432-2277.2003.tb00233.x.
10. Rieu, R. (2010). The potential impact of an opt-out system for organ donation in the UK. *Journal of Medical Ethics*, 36(9), pp.534-538.

References

11. <https://www.bma.org.uk/collective-voice/policy-and-research/ethics/organ-donation>
12. <http://theconversation.com/the-ethics-of-opt-out-organs-17711>
13. Proposals for Legislation on Organ and Tissue Donation: A Welsh Government White Paper. Welsh Government. 8 November 2011.
14. <https://www.organdonation.nhs.uk/news-and-campaigns/news/highest-number-of-organ-transplants-ever-across-uk-but-many-families-still-say-no-to-donation/>
15. Poyntz K; Lusuardi R; Price A. West Midlands Specialised Commissioning Team, Organs for transplant: An analysis of the current costs of the NHS transplant programme;the cost of alternative medical treatments and the impact of increasing organ donation. October 2010.
16. <http://www.kidney.org.uk/archives/news-archive-2/campaigns-transplantation-trans-cost-effect/>