

Breaking down organ donation borders

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Breaking down organ donation borders: Revisiting “opt out” residency requirements in the UK

Clinical Ethics

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Abstract

All four UK nations have, in recent years, introduced “opt out” organ donation systems. Whilst these systems are largely similar, they operate independently. A key feature of each policy is a residency requirement, stipulating that opt out may only apply where the deceased had been ordinarily resident *in that nation* for at least 12 months. A resident of Scotland who dies in England, for example, would not fall under opt out. Public awareness is the underlying reasoning for such stipulations. A residency requirement was appropriate when Wales was the only UK nation with an opt out system, but, I suggest, the continued imposition of intra-UK borders on organ donation is unjustified now that all four nations operate the same policy. Further, it has the potential to limit organ donation. There is a need for all four systems to be amended to allow for UK-wide applicability, such that providing the deceased was ordinarily resident *in the UK*, they can fall under opt out in any of the four nations. I argue that such an amendment is ethically justified – continuing to satisfy the public awareness criterion – and practically straightforward. In doing so, I emphasise that my proposed amendment should extend only to the four UK nations, stopping short of the Crown Dependencies even though they also operate opt out systems for organ donation.

Keywords

Organ donation, Organ transplantation, Consent

Introduction

Over the last decade, all four UK nations have introduced so-called “opt out” systems for organ donation (also referred to as “deemed consent” or “deemed authorisation”) in a bid to alleviate the shortage of organs for transplantation. Wales moved first, implementing its system in 2015, then Northern Ireland was last to follow suit in 2023 (with some gentle encouragement from Westminster). Whilst they exist as four separate systems, the opt out policies of the four UK nations are largely similar, with the other three copying much of the earlier Welsh system.

A key feature of Wales’ approach to opt out, which can now be found in the other three nations, is the stipulation of two groups of “excepted adults”. That is, opt out does not apply to any adult who either (a) was not ordinarily resident in Wales for at least 12 months immediately before their death,^a or (b) lacked capacity to understand the opt out system and its implications for a significant period before dying.^b Ultimately, these exceptions exist for reasons of public awareness as a core justification for an opt out policy. Individuals that fall into one of these two groups might be said to be less likely than the general population

to be aware of the move to an opt out system and their options to make their wishes known. Certainly, one might question how accurate an assumption that is, but it is at least the reasoning employed.

My focus in this paper is on the first of the two exceptions – the residency requirement. This is now to be found in the respective legislation of England,^c Scotland,^d and Northern Ireland.^e All three followed the example of Wales, tweaking it such that the opt out systems of those other three nations are applicable only to their own residents. That the reach of Wales’ opt out policy was limited to those living in Wales made sense at the time the system was implemented. It was the only opt out system in the UK, with the other three nations still operating express consent. As such, it would not be reasonable to

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assume that those resident elsewhere in the UK would be aware of the system, nor would it be straightforwardly defensible for the system to apply to someone from another jurisdiction where a different system operates. However, now that all four nations have moved to opt out, I suggest that the narrow definition of these residency requirements is unnecessary (in its current framing) and is potentially limiting opportunities for organ donation that would be entirely ethically justifiable. I present a case for the four UK nations to amend their opt out legislation for UK-wide applicability, alongside necessary changes to public awareness efforts to ensure the continued ethical justification of the systems.

Opt out residency requirements

The Human Transplantation (Wales) Act 2013 (HTWA 2013) – the legislation by which Wales introduced its opt out system for organ donation – stipulates that an adult is excepted on the basis of residency as follows:

‘an adult who has died and who had not been ordinarily resident in Wales for a period of at least 12 months immediately before dying’^f

Throughout the UK, the same framing is to be found. In England, under the Human Tissue Act 2004;^g in Scotland, under the Human Tissue (Scotland) Act 2006;^h in Northern Ireland, under the Human Tissue Act 2004.ⁱ Of note, these acts were amended to introduce opt out, whereas Wales passed the HTWA 2013 as a standalone statute – hence 2004 and 2006 being long before the implementation of opt out. The only difference in the residency requirement to note is that whilst Wales, England, and Northern Ireland define “adult” as someone aged 18 or over, in Scotland the system is applicable to anyone from the age of 16.^j

At their core, the purpose of these residency requirements relates to public awareness. That is, requiring someone to reside within a country for the opt out system to apply to them means that included persons are, in theory, exposed to any public information campaigns relating to the system. There are, of course, various factors that might mean such information never reaches a person, but at least the idea is that their residing within the country makes it more likely they will be aware of the opt out system than a resident of a neighbouring country. This public awareness grounding was made apparent during the passage of the HTWA 2013, with the Welsh Government clarifying that ‘[t]he soft opt-out system will only apply to those people who live in and die in Wales, who have had enough time to understand the law and have had an opportunity to opt out, if that is their wish’ (para 24).¹ There may have also been a question of the Welsh Parliament’s legislative competence with regard to imposing an opt out system on those ordinarily resident in other UK nations,² and perhaps even

consideration of the potential media controversy if opt out had been applied to someone not ordinarily resident in Wales, but public awareness was the focus during the legislative process. Indeed, this is why the public awareness duty aligns with the residency requirement, with both being annual^k – to ensure that anyone who falls under the remit of opt out after having moved to Wales has been through at least one public awareness cycle. This same logic was applied in a proposed amendment during debates surrounding England’s opt out system, with Lord McColl of Dulwich having (unsuccessfully) sought to introduce an annual public awareness duty in England,³ arguing:

‘we must be aware of all the people coming into England each year from other jurisdictions. Crucially, the awareness-raising and advertising provision set out in my amendment is made in the existing Welsh legislation but is missing from the [Organ Donation (Deemed Consent)] Bill’.⁴

The importance of public awareness to the defensibility of opt out systems has been consistently reiterated throughout the literature. First of Price’s four criteria for an ethically justifiable system is that ‘individuals are aware of the issue being posed and the significance of opting out or remaining silent’ (p. 137).⁵ Saunders, too, stresses the need for it to be ‘clearly communicated to all involved that this is how their silence will be interpreted’ if an opt out system is to be considered as entailing valid consent (p. 71).⁶ This speaks to the central feature of consent as informed (in addition to being given voluntarily by an individual with the requisite capacity – hence there also being a capacity requirement within the opt out systems^l), and the importance societies place on requiring that people understand what may happen to their body in certain circumstances.

Given this importance of public awareness, the residency requirements may be said to be more effective in some UK nations than in others. This relates to the extent of broader public awareness efforts made, which is variable. In particular, how the relevant legislation is framed to (not) require certain key aspects of public awareness. England is certainly the worst system in this respect, having not included any explicit ministerial duties that relate to public awareness. It is the only one of the four not to do so, with the other three requiring annual public information campaigns – thus relating directly to the length of the residency requirements.^m Further, the English system was introduced at the height of the COVID-19 pandemic which raises further questions of dedication to widespread awareness.^{7,8}

There is a question, then, as to whether sufficient levels of public awareness have been achieved, even in the three UK nations where there are statutory duties. Whilst policymakers clearly consider their approach adequate, there is no widely recognised public awareness bar for the justifiability

of an opt out system against which the systems can be assessed. Further, means of measuring levels of public awareness – such as surveys – are not wholly reliable. The sorts of people we might anticipate being less likely to be aware of the change to opt out are similarly unlikely to have engaged with a survey. That is not to say that there is no benefit to gauging public awareness through survey methods, but any findings must be considered with caution.

Despite this unanswered question as to the sufficiency of public awareness, for the purposes of this article, I am considering the public awareness criterion to be met by the UK systems. Any argument that this criterion is *not* met ultimately acts to discredit the policy as a whole given its roots in public awareness as central to the “consent” element, whereas I am concerned with a finer point of logical consistency across the systems. Thus, my discussion remains relevant notwithstanding the defensibility of opt out as an overarching policy – we ought still to explore the specific constructions of these systems.

Policy alignment and unnecessary borders

When Wales first introduced opt out, being the only UK nation with such a system made the current framing of the residency requirement necessary. This is the reality where a policy such as opt out is introduced in a devolved or federal setting, as a straightforward citizenship or permanent residency requirement – as found in the opt out systems of countries such as Singapore⁸ – cannot be relied upon to distinguish in the detail required. The addition of the residency requirement in Wales was, then, a recognition of territorial extent, removing the risk of complications around the HTWA 2013 affecting residents of other nations (whether within the UK or beyond). For the system to be justifiable from the public awareness standpoint, those resident elsewhere in the UK had to be excluded as it would not be reasonable to consider them to be aware of the Welsh system – less reasonable still to consider them to be aware that it would apply to them if they were to die in Wales. Further, should residents of other UK nations be aware and want to act, they may justifiably have been confused as to how they would record their objection to the policy of another nation applying to them. The residency requirement, then, was critical to the defensibility of the new policy which would, at the time, set Wales apart from the rest of the UK.

The same logic could also be applied to the English opt out system when it was second to be introduced in 2020. Perhaps even to the Scottish legislation shortly after, although less convincingly. But by the time Northern Ireland passed its opt out legislation in 2022, the UK was set to have opt out in all four nations. The need for the residency requirement in its current form was, thereby, removed. By its current form, I mean that each of the four UK nations has the residency requirement set “locally”;

opt out in Wales is only applicable to those ordinarily resident in Wales, opt out in England is only applicable to those ordinarily resident in England, and so on. Assuming the effectiveness of public awareness efforts in all four nations – which, for the purposes of this discussion, I take to be satisfactory – we can consider any UK resident of 12 months or more to be justifiably within the remit of one of the four opt out systems (that of the nation which they reside in). Then, given the clear similarities between the four systems, such that they borrow exact wording for many elements, it is a small step to consider UK residents as justifiably within the remit of opt out *throughout the UK*. As such, there is a case for the residency requirements of each nation to be amended. Not removed, but amended. This amendment ought to focus on the localised aspect, replacing the name of the respective nation with “UK”. Doing so would increase the reach of all four systems without undermining the importance of public awareness to the residency requirement.

Now that Wales is no longer an outlier on this matter of policy, broadening the residency requirement in this way would still satisfy the public awareness justification. Consider someone who is ordinarily resident in Scotland who dies on a visit to Wales. Within Scotland, they would fall within the reach of the Scottish opt out system (assuming no other exceptions apply). The public awareness campaigns in Scotland would (hopefully) have reached them, such that they are aware of the opt out system, how it could affect them, and what they must do depending on their views. If this person had not chosen to opt out of the Scottish system, it would apply and, had they died in Scotland, the process potentially culminating in donation would have begun. With the current framing of the residency requirements, that this person died in Wales would prevent opt out applying to them – the Scottish system they were ordinarily within does not apply in Wales, and the Welsh system does not apply to them as someone not ordinarily resident in Wales.⁹ This is an unnecessary exclusion of a potential organ donor. The public awareness justification no longer exists as the person was aware of such an opt out system, even if it was formally under a separate piece of legislation. That all four nations operate the same opt out system means there is no longer a risk of someone entirely unfamiliar with the policy has their organs transplanted without their explicit consent.¹⁰

It is also feasible that many UK residents already assume that opt out applies UK-wide in the way I am proposing. Despite devolution, people in the UK do not frequently think of the four nations as quite so distinct. This is especially true of health matters given the operation of the NHS throughout the UK. Certainly, this caused some confusion during the COVID-19 pandemic when residents of devolved nations were receiving information on restrictions applicable to them as well as England, whether by watching a news channel broadcast from London or from social

media. It is also common nowadays for people to live their lives across borders within the UK. The Codes of Practice themselves acknowledge this, such as the Welsh Code discussing the residency of an individual who works in Cardiff but lives in Bristol (para 55).⁹ Indeed, potential donors who live across UK borders have already been excluded from opt out in Wales based on the residency requirement; in the period from implementation to September 2017, '18 [potential donors] were flagged as not being resident in Wales – some of these cases were from English border counties, such as Shropshire, so a Welsh hospital will sometimes have been the closest location' (p. 47).¹⁰

Of course, it would be essential for public information surrounding opt out to be amended in light of my proposed amendment. There would need to be clear messaging on the UK-wide applicability to avoid the change appearing in any way covert. But this is nothing hugely onerous as existing campaigns can simply be edited. Even if it were somewhat onerous, it would still be justified in overcoming issues of potential donors lost to an unnecessarily cautious approach to the residency requirement.

Beyond the continued satisfaction of the public awareness justification, the practical considerations associated with this proposed amendment are relatively straightforward. Much of the UK's organ donation and transplantation structure is already joined up through NHS Blood and Transplant. My proposed amendment would, then, alleviate some administrative burden. Each UK nation separately operating its residency requirement requires the Specialist Nurse – Organ Donation (SNOD) to determine which nation the deceased was ordinarily resident in. Whilst perhaps only slightly, it would be more straightforward for the SNOD to simply confirm that the deceased had been ordinarily resident somewhere in the UK, perhaps even considering information such as citizenship and permanent residency as in other countries. That would remove the need for discussions around whether it is appropriate to consider the person who lives in Bristol but works in Cardiff ordinarily resident in Wales – instead it could be confirmed that they are ordinarily resident *in the UK*.

There is also already a centralised NHS Organ Donor Register, maintained by NHS Blood and Transplant.¹¹ This covers the entirety of the UK, enabling all NHS hospitals to access any recorded decision by the deceased before proceeding under opt out. As such, we need not be concerned that a hospital in Northern Ireland would not be able to confirm whether a deceased ordinarily resident in England had opted out, for example. These systems are already in place, resulting in no significant practical barriers to my proposed amendment.

I earlier noted that the Scottish system is applicable to anyone aged 16 or over, whereas the rest of the UK treats 18 as the age someone becomes an adult for the purposes of opt out. Justification of my proposed amendment has thus far rested significantly on the four systems being

almost identical. This matter of age is one of the things that prevents the systems being identical and thus may be perceived as an obstacle to this UK-wide application of the residency requirement. Broadening the residency requirement in the way I have thus far proposed would introduce the possibility of a 16- or 17-year-old from Wales, England, or Northern Ireland who dies in Scotland having their organs transplanted under opt out. This is problematic in terms of the public awareness justification as any information they would have received in their home nation would have stated 18 as the age of applicability, so they would not expect to be affected yet.

Whilst this would only conceivably affect a very small number of people, if any, it would still undermine the ethical defensibility of the policy (and the amendment in particular). Though it is an issue that is very simply overcome by qualifying my proposed amendment where it is applied in Scotland. That is, err on the side of caution in treating 18 as the age for opt out to apply in Scotland – thus matching the other UK nations – *unless* the deceased is confirmed as ordinarily resident in Scotland. This would only be required of the Scottish system, as we need not be concerned with the reverse issue. A 16- or 17-year-old from Scotland who dies in Wales, England, or Northern Ireland being excluded from opt out despite having been informed that opt out under the Scottish system would apply to them does not undermine the public awareness justification because under all of the systems opt out being lawful does not mean that donation definitely takes place. Essentially, excluding someone is easier to justify than including them, as the systems fundamentally view exclusion as a safety net that protects against undermining the autonomy of citizens. Thus, the 16- or 17-year-old from Scotland who dies in Wales, England, or Northern Ireland would still be able to donate under express consent with their parents provided this consent on their behalf – something that, in practice, would happen under opt out anyway.

The only remaining objection one might have is that, in the event one of the four nations should choose to return to an opt in system (or, indeed, to any procurement approach other than opt out), this would muddy the ethical waters where those hard borders have been removed. Essentially, the justification for the borders would return as it existed when only Wales operated an opt out system (i.e. the absence of public awareness leaving people aware that opt out will affect them). This objection falls away rather quickly in highlighting that, quite simply, in the event of one nation changing its system the other three could amend theirs to account for the discrepancy. If Scotland,⁹ for example, were to return to an opt in system, Wales, England, and Northern Ireland could all amend their opt out legislation so that it does not apply to anyone ordinarily resident in Scotland. This may have a disproportionate impact on donation rates in that a cautious approach would likely be taken with some individuals whose

ordinary residence is not immediately apparent. Though this is justified in appropriately respecting the autonomy of those who are not clearly ordinarily resident in one of the opt out nations.

One final practical point to acknowledge relates to the role of the family in organ donation decisions. Even where the law considers there to be valid consent under an opt out system, the deceased's family are necessarily involved in discussions to provide important medical and social background information (para 117).^{8,9} The law does not permit the so-called family veto, but relevant guidance documents recognise the importance of the family supporting any donation decision such that where they do object it is ill-advised to proceed (para 118).⁹ If the family must be engaged with anyway, one might argue that the residency requirement is not particularly relevant. Whilst I would not necessarily disagree with this position, any objection on this basis is more so an objection to the policy of opt out in general rather than to the matter of amended residency requirements. Again, it remains important to examine the particulars of the UK's opt out systems even if one questions the utility of the policy as a whole. If we are to take it that the opt out systems act as more encouraging for the family to permit donation (para 113),⁹ as is the hope behind them, then my suggestion holds.

What of the Crown Dependencies?

Opt out organ donation is also an approach followed in the Crown Dependencies. Such systems are already in operation in Jersey⁸ and Guernsey,¹ with the Isle of Man having set things in motion with a view to implementing opt out in the near future.¹¹ Given my proposed amendment in the UK, one might suggest that it be extended to incorporate the Crown Dependencies – or, at least for now, Jersey and Guernsey.

Both Jersey and Guernsey have opt out systems much the same as the UK nations, including the same residency requirements.¹² We might, then, say that the same cross-border public awareness situation applies as across the UK – no one would find themselves unexpectedly under a system of opt out. Concerning practical aspects, the NHS Organ Donor Register also includes the Crown Dependencies, thereby setting aside any concerns about significant administrative burden in establishing a joint system. However, there are reasons why we should not – at least not at this stage – look to extend my proposed amendment this far.

Even if they remain true to some extent, the arguments in favour of my proposed amendment across the UK are weaker where the Crown Dependencies are concerned. Whilst it is reasonable to consider UK citizens as thinking opt out would apply across the country, this is less convincing a position in relation to the Crown Dependencies. Their level of independence from the UK is significant, the relationship primarily concerning defence and

international relations.¹² As such, even though the NHS Organ Donor Register includes the Crown Dependencies, it would not be reasonable to assume people realise this, nor is it realistic to think people would expect the UK and Crown Dependencies to operate a collective opt out system in the way a UK-wide system would be expected amongst citizens of the four UK nations. Evidence of this is the 2017 Jersey Opinions & Lifestyle Survey, which found that 20% of Jersey residents who are not on the NHS Organ Donor Register have not joined it for the reason that they did not realise that they, as Jersey residents, were able to (p. 26).¹³ Naturally, public awareness initiatives around opt out could incorporate clarity of messaging on things like this, but it remains true that the Crown Dependencies are not as joined up with the UK as the UK nations are with each other. As such, whilst there may be *some* justification for extending this amendment to include the Crown Dependencies, I will stop short of endorsing it with quite the confidence I do within the UK.

Conclusion

It is my contention that the current framing of the residency requirements found in all four UK opt out systems is unnecessary and has the potential to limit organ donation. The need for strict application of the devolved borders as inclusion criteria is not required now that all four UK nations operate opt out systems – Wales is not alone in its policy now, so concerns over public awareness of opt out operating across UK borders no longer stand. This remains true as long as all four nations maintain their opt out systems, the necessity of hard devolved borders in organ procurement arising again in the event that policy variation returns. Importantly, though, I note that amending the systems as I have suggested is a matter of ensuring greater logical consistency; it is not necessarily an endorsement of opt out as a good policy choice as I recognise there remain weaknesses with its central premise, some of which intersect with the residency requirement.

As such, I have presented the case for amending these residency requirements to incorporate UK-wide applicability. A further stipulation would be necessary in amending the Scottish system, specifying that UK-wide applicability is only true of those aged 18 or over – the current Scottish inclusion of 16- and 17-year olds remaining under the purview of a stricter devolved border. Nonetheless, whilst some of these policy similarities hold true of the Crown Dependencies, such that there might be a case for extending my proposed amendment to incorporate Jersey, Guernsey, and the Isle of Man, there is not a strong enough justification for doing so at this stage.


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Data availability statement

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

Notes

- a. S.5(3)(a) Human Transplantation (Wales) Act 2013.
- b. S.5(3)(b) Human Transplantation (Wales) Act 2013.
- c. S.3(9)(a) Human Tissue Act 2004, as amended by s.1(5) Organ Donation (Deemed Consent) Act 2019.
- d. S.6D(2)(a) Human Tissue (Scotland) Act 2006, as amended by s.7(2) Human Tissue (Authorisation) (Scotland) Act 2019.
- e. S.3(9A)(a) Human Tissue Act 2004, as amended by s.1(4) Organ and Tissue Donation (Deemed Consent) Act (Northern Ireland) 2022.
- g. S.5(3)(a) Human Transplantation (Wales) Act 2013.
- h. S.3(9)(a) Human Tissue Act 2004, as amended by s.1(5) Organ Donation (Deemed Consent) Act 2019.
- i. S.6D(2)(a) Human Tissue (Scotland) Act 2006, as amended by s.7(2) Human Tissue (Authorisation) (Scotland) Act 2019.
- j. S.3(9A)(a) Human Tissue Act 2004, as amended by s.1(4) Organ and Tissue Donation (Deemed Consent) Act (Northern Ireland) 2022.
- k. This difference does need to be considered in light of my suggestion of alignment and will be revisited shortly.
- l. SS.2(2) and 5(3)(a) Human Transplantation (Wales) Act 2013.
- m. S.5(3)(b) Human Transplantation (Wales) Act 2013.
- n. S.2(2) Human Transplantation (Wales) Act 2013; s.1(2) Human Tissue (Scotland) Act 2006, as amended by s.2(3) Human Tissue (Authorisation) (Scotland) Act 2019; s.15(3) Health (Miscellaneous Provisions) Act (Northern Ireland) 2016, as amended by s.1(7) Organ and Tissue Donation (Deemed Consent) Act (Northern Ireland) 2022.
- o. SS.4(2)(b) and 4(3) Human Organ Transplant Act 1987 [Singapore].
- p. I have specified “not ordinarily resident in Wales” rather than “ordinarily resident in Scotland” as, theoretically, someone could be considered ordinarily resident in more than one UK nation. The likelihood of this happening in practice is perhaps small, but someone who splits their time between, say, two UK nations may be considered ordinarily resident in both for the purposes of opt out – it would be at the discretion of the SNOD. But this would certainly not apply to someone on a short-term visit.
- q. Or, at least, no more risk than there is of this happening under the current system.
- r. This is purely for the sake of argument. I in no way suggest Scotland is more likely than any other UK nation to turn its back on opt out at some point.
- s. I cite here only the Welsh Code of Practice for brevity, but the same guidance is to be found in relation to the other opt out systems of the UK.

- t. Human Transplantation and Anatomy (Jersey) Law 2018.
- u. Human Tissue and Transplantation (Bailiwick of Guernsey) Law 2020.
- v. Human Tissue and Organ Donation Act 2021.
- w. S.5(3)(a) Human Transplantation and Anatomy (Jersey) Law 2018; s.24(1)(b) and s.24(3) Human Tissue and Transplantation (Bailiwick of Guernsey) Law 2020. I will set aside the Isle of Man for now as its system is not yet implemented. Nonetheless, it should be noted that the same residency requirement features under s.10(11)(a) Human Tissue and Organ Donation Act 2021.

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