

## Briefing for the Public Petitions Committee

**Petition Number:** [PE1453](#)

**Main Petitioner:** Caroline Wilson on behalf of The Evening Times & Kidney Research UK (Scotland)

**Subject:** Opt for Life

Calls on the Scottish Parliament to urge the Scottish Government to introduce an opt-out system of organ donation in Scotland to help save more lives.

### BACKGROUND

This Petition calls for a change to legislation governing the approach to organ donation in Scotland, with a move from an “opt-in” to an “opt out” system in Scotland. The change involves replacing the current opt-in system (where an individual actively expresses their choice to donate organs or tissue by joining the organ donor register) with an opt-out system (where the individual is required to explicitly make it known while they are alive that they are not in favour of their organs being used for transplant when they die). The key difference is an opt-in system involves an individual expressly stating a wish that their organs and tissue be used for transplant on their death. On the other hand, an opt-out system assumes that organs and tissue are available for transplant unless there is a specific instruction to the contrary. The Petitioner argues that moving to an opt-out system would increase the availability of organs for transplant.

Organ donation is devolved and governed through the Human Tissue (Scotland) Act 2006 (asp 4). The equivalent legislation in other parts of the UK is the Human Tissue Act 2004 (c. 30). To date the law across the UK has maintained the opt-in system for cadaveric<sup>1</sup> organ donation<sup>2</sup>; although Wales is currently progressing a Bill that would introduce an opt-out system<sup>3</sup>.

There are different ways that opt-out and opt-in systems work in practice. Most commonly either approach can work in a ‘soft’ or ‘hard’ form. Soft opt-in and opt-out systems usually mean the family has a say in the final decision about organ donation at the time of the person’s death. Under opt-in this means that even if someone wishes their organs to be donated on their death, if the family object, the family’s wishes will be respected. Similarly, a soft opt-out system would involve consulting with the family to capture any unregistered objection, with scope not to proceed if

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<sup>1</sup> “Cadaveric organ transplant” (as opposed to living transplant) refers to the transplant of organs or tissue that takes place at the time of the individual’s death.

<sup>2</sup> Payne, J (2008) Organ Donation. SPICe briefing. Available [here](#)

<sup>3</sup> Welsh Government (2012) “Draft Human Transplantation (Wales) Bill”. Available [here](#)

this would cause severe distress to the family. Where hard opt-out or opt in systems are in place, the declaration of the person when they were alive is final and there is no role for the family in the decision about organ donation at the time of the individual's death.<sup>4</sup>

## The Ethics of Organ Donation

The decisions each country makes regarding its approach to organ donation involve a complex range of ethical, legal, medical, organisational and societal components. The fundamental dilemma lies in concurrently respecting the views and rights of the potential donor and obtaining organs in an efficient manner. Different countries employ different systems to maximise organ procurement (Rithalia et al, 2008<sup>5</sup>). In the UK at present, the fundamental principle framing organ donation is that organs are donated actively, freely, voluntarily and unconditionally, using a soft opt-in system.

The proposal being put forward in Wales - and that is also promoted by the British Medical Association for the whole of the UK – is to move to a soft opt-out system. The UK Organ Donation Taskforce (ODT) established by the UK Government to identify barriers to organ donation, explored issues that may have a bearing on donation rates and recommended action to increase organ donation within current legal frameworks. This group suggested 14 recommendations that, if acted upon, could increase donation rates by 50 per cent within 5 years.<sup>6</sup>

The taskforce explored the question of whether the UK should introduce an opt-out system for organ donation.<sup>7</sup> This report noted that countries with an opt-out system tend to have higher organ donation rates. However, “presumed consent alone does not explain the variation in organ donation rates between different countries, many other factors affect donation rates” (p.4). The expert working groups considering the legal and ethical implications of introducing an opt-out system advised that there was no fundamental legal or ethical barrier to the introduction of a soft opt-out system with relevant safeguards in place. However, the taskforce found considerable evidence that there were downsides to introducing such a system. These included:

- Health professionals raising concerns about the potential for damage to the vital relationship of trust between clinicians caring for people at the end of life, the patients and their families.
- Recipients of organs stressed a need to know that the organs donated were given freely by donors and their families – the gift relationship is stressed as highly important to those who receive organs by donation.
- Support from the public and patients' groups for informed consent highlighted concern that assumed consent by silence belongs to a more paternalistic era.

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<sup>4</sup> There is some discussion of this in the BMA (2012) report: [Building on Progress: Where next for organ donation policy in the UK?](#)

<sup>5</sup> Supporting evidence to the Organ Donation Taskforce. Available [here](#) Appendix 1 lists the systems in place in different countries as this was found in 2007/8. As this paper was published in 2008, some countries may have since changed their approach to organ donation.

<sup>6</sup> Organ Donation Taskforce (2008) Organs for Transplant: a report from the Organ Donation Taskforce. Available [here](#)

<sup>7</sup> Organ Donation Taskforce (2008) The potential impact of an opt out system for organ donation in the UK: an independent report from the Organ Donation Taskforce. Available [here](#)

Some felt that an opt-out system would be dehumanising given current healthcare practices shifting towards greater choice and responsiveness.

The taskforce argued that a move to an opt-out system, while potentially offering real benefits, carried significant risk if not introduced carefully and with due consideration to the concerns of those against this system. The 14 recommendations made by the taskforce were intended to offer a mechanism for increasing organ donation without the need to move to an opt-out system. After a period of five years, the taskforce recommended that progress be reviewed, at which point the option of opt-out could be considered again if necessary.

## **Current Campaigns**

This Petition has emerged as a result of the [Evening Times](#) campaign calling for an opt-out system for organ donation in Scotland. The campaign is based on the premise that a move to an opt-out system would greatly increase the availability of healthy donor organs. Alongside this, NHS Greater Glasgow and Clyde are also currently running a campaign – [Respect My Dying Wish](#) – which focuses on promoting the NHS organ donor register and, more importantly, encouraging people to let their family members know their wishes with regard to organ donation on their death. The website notes that families are always consulted about organ and tissue donation; if the family refuses to allow donation, the donation will not go ahead. In practice, only four out of 10 families allow organ donation when they don't know their loved one's wishes. This figure rises to nine out of 10 when the family know this is what their loved one wanted.

The Scottish Government has run annual organ donation campaigns since 2007 with the aim of raising awareness of organ donation and encouraging people to join the NHS Organ Donor Register. Public Health Minister Michael Matheson launched the 2012/13 campaign on 29 October 2012. The main message of this campaign is to get people talking about organ donation, to make their wishes known to their family and friends and encourage sign-up to the register. A new Scottish campaign website has been launched to support the campaign

## **SCOTTISH GOVERNMENT ACTION**

The Scottish Government accepted the findings of the UK organ donation taskforce report. The then Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon MSP, stated after the publication of the report that, as a result of the recommendations of the UK taskforce report, opt-out was not being considered in Scotland. That said, the plan would be to formally reconsider this decision, in line with the taskforce's recommendation, in five years' time (in 2013).<sup>8</sup>

## **SCOTTISH PARLIAMENT ACTION**

In the current Parliamentary session, a Motion (S4M-04418) was debated in the Chamber on 1 November 2012 on a move to a system of presumed consent (opt-out) in Scotland. The Official Report from this debate can be found [here](#).

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<sup>8</sup> Scottish Government Press Release "Human Organ Donation" November 2008. Available [here](#)

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7 November 2012

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