

PE1453/F

Minister for Public Health

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Public Petitions Committee
T3.40
The Scottish Parliament
Edinburgh
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Dear David

CONSIDERATION OF PETITION PE1453: OPT OUT SYSTEM OF ORGAN DONATION

Thank you for your clerk's letter of 13 December seeking the views of the Scottish Government on petition PE1453 on proposals to move to a system of opt-out for organ donation. The Committee has asked three specific questions, and I address each of these below. Firstly however, it is worth saying that I am aware that this petition has been prompted by the Glasgow Evening Times, which has been campaigning on this issue for some time. I am very grateful to the paper for all it has done to raise awareness on issues of organ donation and transplantation. My comments below should not be taken to mean I do not support the very good campaigning work the paper has recently undertaken. I recently met with the Editor of Evening Times to discuss their campaign and their support for opt out.

What previous approaches have proved to be successful, or unsuccessful, in increasing levels of organ donation?

Over the last five years our activity has been informed primarily by the work of the UK Organ Donation Taskforce (ODTF), which published its report in 2008¹. (The ODTF also separately looked at opt out and published a report in 2008².) The Taskforce set out 14 recommendations which were intended to increase organ donation by 50% over 5 years. Scotland has worked hard to meet this target by:

- Delivering national annual awareness raising campaigns, and producing new information materials about the Human Tissue (Scotland) Act 2006;
- Establishing donation committees in each NHS Board;
- Establishing Clinical Leads for Organ Donation in each of our main hospitals;
- Strengthening the network of donor transplant co-ordinators, by appointing 7 additional co-ordinators;

¹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082122

² http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_090312

- Funding a radical revision of the Organ Donation Teaching Resource Pack for use in secondary schools.

Additionally, the former Cabinet Secretary agreed to the implementation of further measures in Scotland, recognising that Scotland started at a lower rate of donation than the other UK countries. These measures included the setting up of a communications course for those dealing with bereaved relatives around the time of request for authorisation, and consideration of a programme of category II donation after circulatory death (see below), as practiced in Spain. The former Cabinet Secretary reserved the right to return to the issue of opt out should the pace of improvement in organ donation slow down. In fact, significant success has been seen, including:

- Scotland now has the UK's highest percentage of residents signed up to the NHS Organ Donor Register – over 41% of population compared to the UK average of 31%.
- 2011-12 saw the highest ever number (346) transplant operations undertaken on Scottish recipients, and 2012-13 looks on track to increase again.
- 2011-12 saw the highest ever number (81) of organ donors in Scotland, and 2012-13 looks on track to increase again to around 90 donors.
- Scotland has achieved a 50% increase in donations in four years – meeting the Taskforce target one year early.

What steps are currently being taken, or considered, to increase levels of organ donation?

There is still more work to be done in Scotland and a number of pieces of work are underway:

- In the next month a new pilot of Masstricht category II donation after circulatory death (DCD) will be launched in the city of Edinburgh. This will allow individuals who have a witnessed cardiac arrest in the street, and for whom, all efforts to revive and resuscitate fail, to become organ donors if they have previously expressed a wish to do so. Although common elsewhere in Europe, this will be the first recent such pilot in the UK.
- We are continuing to run annual and high profile awareness raising campaigns – and we are the only part of the UK that has done so over the last five years. This year we launched a new Scottish website which allows people to sign up to the NHS Organ Donor Register direct. In November alone the campaign led to over 20,000 new Scottish registrations.

In early 2013 we will publish a new Scottish plan for donation and transplantation, under the umbrella of a new UK-wide strategy. This will identify the priority areas of work we will take forward which we believe will meaningfully increase the number of donated organs in Scotland, including, but not limited to:

- Work to reduce the rates of family refusals. Although family consent is not required if an individual has authorised the use of their organs for transplantation we do not currently retrieve organs if there is not family support to do so. We know that family consent is highest when Specialist Nurses in Organ Donation (SNODs) make the approach to the family. We will work to ensure that SNODs are involved in all approaches to families;
- Streamlining the process of organ offering and retrieval – there are instances of families withdrawing or refusing consent because the process is too lengthy or trying.

Although there is a need to ensure the appropriate clinical procedures are followed we believe we can streamline the process to minimise withdrawals of consent; and

- Work to hold NHS Boards to account for missed referrals. We know that there are instances of Boards not referring a potential donor to the SNODs for assessment – even in cases where an individual is already on the NHS Organ Donor Register. We will work with the NHS Boards and NHSBT to minimise such missed opportunities.

Do you have any other views on what the petition seeks?

The Scottish Government does not currently support opt-out for the following reasons:

- There is no guarantee that opt out would lead to many more organs being available. In order to become a donor, individuals have to die in specific circumstances – normally within intensive care (although there are some exceptions). Only around 1% of all deaths in Scotland occur in circumstances which allow donation to proceed. Opt out will not change that. (Indeed, it is worth noting that the Welsh Government has also recently made clear that there is no guarantee that opt out legislation will lead to more organs being made available³.)
- It is not clear that opt-out systems have led to higher donation rates in other countries. A systematic review of opt out systems⁴ *did* find some evidence of association between opt out and higher donation rates, however this was only an association. Other associations were also identified that, in some cases, were stronger than opt-out (including road traffic accidents, health infrastructure, and wealth). The review said: “...it cannot be inferred...that the introduction of presumed consent legislation per se leads to an increase in donation rates” and “Presumed consent alone is unlikely to explain the variation in organ donation rates between different countries”.
- There are clear exceptions to the association between opt out and higher donation rates - USA has consistently high donation rates without opt out; Sweden has had opt out since 1996 but continues to have low rates of donation. Spain has amongst the best donation rates, but although it had opt out since 1979 it was only a decade later, after infrastructure change, that donor rates began to rise.
- Opt out will increase the numbers on NHS Organ Donor Register, however it is worth keeping in mind that you do not have to be on the register in order to donate. In Scotland all potential donors – whether on the register or not – should be considered for donation, and the potential for donation discussed with families, who can consent even if the deceased was not on the register. When this system works – and I recognise we are currently missing some potential donors – all possible donors will be captured.
- Parts of Scotland already have very high levels of deceased donation – on a par with the best performing countries – without opt out. NHS Lothian’s deceased donation rate in 2011-12 was 34.7 per million population (pmp), and NHS Tayside was 29.8pmp. This compares with rates of 32.0pmp and 30.7pmp in Spain and Croatia respectively. There is no reason why some other Boards in Scotland can’t also reach these rates.
- The petition is correct to refer to high levels of support for organ donation, but that is not a direct read across to support for opt out. A recent Welsh attitudes survey⁵ found only 49% were in favour of opt out. 22% were against opt out and 21% needed more information to decide. With the introduction of opt out there is a risk that we may turn

³ <http://www.bbc.co.uk/news/uk-wales-politics-20583179>

⁴ Carried out by the University of York for the Organ Donation Task Force in 2008.

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_090295.pdf

⁵ <http://wales.gov.uk/docs/caecd/research/121019organdonationen.pdf>

some individuals, who are generally positive about organ donation, into people who are more wary of issues to do with organ donation and transplantation simply because their views are assumed.

- In their work on opt out, the Organ Donation Taskforce also found that a proportion of clinicians were concerned about a move to opt out. Some intensive care staff in particular feared that a move to opt out would make critical care more difficult and could lead to some intensive care practitioners opting out of participation in donation programmes entirely. There is not unanimous support for opt out amongst clinicians in Scotland.

My priority is to continue to increase the number of organs available for donation in Scotland. We have been doing that very successfully without opt out over the last five years, and I believe we can continue to increase donation rates by focussing on the strategies which will have the biggest impact – those outlined above, and those we will set out in more detail later in 2013.

I have copied this letter to Andrew Howlett, your clerk.

MICHAEL MATHESON