

PE1453/I

Chief Medical Officer and Public Health Directorate

SCOTTISH TRANSPLANT GROUP

Prof John Forsythe,
Lead Clinician for Organ Donation and Transplantation (Scotland)

PA 0131 242 1715 Email -john.forsythe@luht.scot.nhs.uk



Andrew Howlett
Assistant Clerk to the Public Petitions Committee
T3.40
The Scottish Parliament
Edinburgh
EH99 1SP



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Dear Mr Howlett

CONSIDERATION OF PETITION PE1453: OPT OUT SYSTEM OF ORGAN DONATION

Thank you for your email of 19 December to my colleagues Gareth Brown and Pamela Niven offering the Scottish Transplant Group (STG) the opportunity to submit comments on Petition PE1453.

The STG is aware that this petition has been prompted by the Glasgow Evening Times, which has been campaigning on this issue for some time and would like to state at the outset that we are very grateful to the paper for all it has done to raise awareness on issues of organ donation and transplantation.

Your email arrived after the December meeting of the STG, therefore members were contacted by email and offered the opportunity to respond individually. Five members responded with an additional three members stating they had already contributed to their organisation's own responses to the Committee (NHS Blood and Transplant and NHS Tayside).

The responses from STG members can be summarised as follows:

Respondent 1 (Clinician). Not supportive of a move to an opt out system. Strongly supportive of any moves which will improve organ donation and transplantation or which raise awareness of the issue with the public. Is not convinced that opt out would deliver more organ donors or transplants than could be achieved within the current legislative system. Thinks a soft opt out system will continue to rely on consent from relatives as is the case in the current opt in system. Thinks there is more that can be done to increase donor and transplant numbers by improving conversion of potential to actual donors; by increasing the number of intensive care beds; by continuing to promote and enhance the role of specialist nurses and clinical leads for organ donation; in assessing organ viability and prolonging graft life; and looking at allocation of organs in particular extended criteria or "marginal" organs.

Respondent 2 (Clinician). Supportive of a move to opt out but ranked it low in the list of priorities required to drive up donation and transplant rates

Respondent 3 (Clinician). Not convinced that a move to opt out would drive up donation and transplantation rates. Strongly supportive of continuing to improve the organ donation infrastructure in Scotland (and the UK). Encouraged that organ and tissue donation has continued to rise year on year since the implementation of the organ donation taskforce recommendations and considers that it is too early to judge that current work being undertaken has not been successful.

Respondent 4 (Patient representative). Considers that “a detailed review” of opt-out is merited. As the recipient of an organ, endorsed the principle that organ donation is a gift freely and voluntarily given but does not believe that that position would change under an opt out system. Commented that there is the potential for some harrowing views being expressed in the press and cites specifically the testimony of a relative whose grandchild was involved in the Alder Hey incident during a radio interview on organ donation. Pointed out that stories like this can sometimes make far more (negative) impact than genuine good news stories can create (positive) impact. Expressed concern that under the current opt in system relatives can overturn the wishes of the potential organ donor.

Respondent 5 (Clinician). Not convinced that a move to opt out would bring about the improvement claimed in the petition and considers that it is the changes to the infrastructure and changing the culture of organ donation within society and the profession which are more important. Feels that Scotland is already beginning to show this. Considers that the European countries with the highest levels of deceased donation and who have shown most improvement in recent years (Spain, Portugal and Croatia) have done so because of infrastructure changes and not legislative change. Cites examples where donation levels have dropped following a change to opt out (Brazil, Chile). Thinks current infrastructure and culture change work in Scotland should continue and feels that one of the main areas to address is increasing the rate of authorisation where the individual had in life, not expressed a wish regarding organ donation. Mentioned concern from some patient groups and certainly from many of the faith groups that even a soft opt out is not acceptable. Feels that there would be significant financial cost in moving to this system as well as cross-border issues. Thinks there would be some merit in watching what happens in Wales and determining the impact before going down that route.

As there has not been time for the STG to come to a collective view, the responses above reflect the views of the individual respondents concerned, and not the STG as a whole.

As the Committee will be aware, the remit of the STG is to give advice and make recommendations to the Scottish Government on matters relating to organ and tissue donation and transplantation. Membership of the group consists of a representative of each Scottish transplant unit, a physician associated with each type of transplant, NHS Blood and Transplant’s (NHSBT) Regional Manager for Scotland, an intensivist nominated by the Scottish Intensive Care Society, the Nursing Director of National Services Division (who commission transplant services for Scotland), the Director of Tissue Services at the Scottish National Blood Transfusion Services, the Medical Director and Director of Organ Donation at NHSBT, the Chair of the UK Transitional Steering Group, a donor family representative, three transplant recipients and representatives of the Scottish Government Health Directorates.

In addition to giving advice and making recommendations to the Scottish Government, in January 2008, the Cabinet Secretary for Health & Wellbeing asked the Group to take on the task of overseeing the implementation in Scotland of the recommendations from the first report of the Organ Donation Taskforce.

Over the last few years we have supported the ongoing work to improve donation rates in Scotland. Additional funding for more specialist nurses in organ donation and the appointment of clinical leads for organ donation in each large hospital in Scotland along with the establishment of Board donation committees and the strengthening of the system of organ retrieval have made a large contribution to driving up donor numbers and transplant operations.

The STG strongly supports the ongoing advertising and publicity campaigns designed to encourage people to sign up to the NHS Organ Donor Register and, most importantly, to make those closest to them aware of their wishes. It's heartening to note that over 2 million people in Scotland (over 40% of the population) now have their names on the Register. This is the highest percentage of any part of the UK. The STG firmly believes this is money well spent, since donation depends in many cases on the family and clinicians being clear that they're fulfilling someone's express wishes.

All of this activity is designed to make organ donation a usual event within Scotland, and we are starting to see results. Last year, 2011-12 saw the highest ever number of deceased donors in Scotland, 81 compared to 67 in 2010-11. These donation figures mean that, in Scotland, we have already achieved the 50% increase that the UK Organ Donation Taskforce thought would be possible by 2013. This in turn has meant that a record number of 342 transplant operations were undertaken in 2011-12 compared to 301 in 2010-11. I'm pleased to report that 2012-13 is on track to deliver a further rise in donor numbers.

While all of this is good news, we realise that there is much more which can be done and are also implementing a number of other initiatives such as specialist communication training for organ donation professionals and the promotion of organ donation within emergency medicine departments.

If the committee would like to see the individual responses sent by STG members, STG secretariat would be happy to seek their permission for these to be provided.

Yours sincerely

Professor John Forsythe
Chair of STG and Lead Clinician for Organ Donation and Transplantation