

Kidney Research UK Response to the proposed Organ and Tissue Donation (Scotland) Bill (Anne McTaggart MSP)

24th September 2014

Background

Kidney Research UK is the leading charity dedicated to funding research into the causes, treatment and prevention of kidney disease. Transplantation remains the most effective current treatment for renal failure and a significant part of our research portfolio is dedicated to improving the success of kidney transplants. We have an agreed position on the issue of presumed consent, which is expanded in the response below. More recently, our supporters in Scotland have been very active in supporting the campaign to bring this issue to debate.

We have consolidated our response under Question 2 of the Consultation:

How essential is it to change the law (from an opt-in to a soft opt-out system) in order to achieve the intended benefits (increased transplant rates, reduced waiting lists)? Are there other (non-legislative) measures that could achieve similar outcomes without the need for legislation?

Kidney Research UK welcomes this consultation and its aims to raise transplant rates and reduce waiting times. We appreciate the work that has been done by yourself, our supporters based in Scotland, the Scottish Government and the Scottish Transplant Group to encourage more organ donations.

The Welsh Government's decision to implement its own soft opt-out represents an important case study, which we will be following very closely. Of course, even if a change in legislation were to take place in Scotland, it would not provide a magic bullet in isolation. Low donation and transplantation rates are a symptom of wider problems, which require several long-term solutions.

Infrastructure and clinical practice

Even under the current legislation, we know that more organs could be used for transplantation. Sometimes people die in circumstances where timely organ retrieval is very difficult, although we note the programme recently started in Edinburgh to address this (Taking Organ Transplantation to 2020, NHSBT). For controlled deaths however, the NHSBT 2020 strategy addresses a number of areas where infrastructure and clinical practice need to improve to increase the number of transplantations. Sufficient attention and urgency is needed here to ensure any increase in potential donors is not wasted.

The need for more research

More research is also vital to shorten the waiting list and make more of every donation opportunity. Kidney Research UK has been funding research in this

field for some time, but we want to see a step change in making transplanted kidneys work better and last longer. The “Making Every Kidney Count” appeal, launched recently, aims to raise £3 million to accelerate research into graft viability, reducing rejection, increasing the life of transplanted organs and ultimately making more donated kidneys available.

Family consent

Encouraging a cultural change around organ donation and transplantation requires a long term plan which could help overcome one of the main barriers to organ donation: family consent. Your proposal makes it clear that families could object if they thought the deceased had an unrecorded objection. In practice however, this will be hard to manage where the family itself objects. At the time of loss, health care professionals have a duty of care to the grieving family. It would be hard to imagine circumstances where their wishes would be dismissed, especially where such a move would cause serious emotional stress. If presumed consent were to be passed then, a substantial period of initial public engagement, and ongoing awareness after a change in legislation, would be needed to ensure family consent issues did not undermine the objective of the change.

Attitudes to organ donation

Indeed, stigma and religious obstacles to organ donation currently lead to very low numbers of donors, and high rates of objection from families after death, especially among Black, Asian and Minority Ethnic (BAME) communities, which are in turn at higher risk of illnesses such as kidney disease and thus are over represented on the organ waiting list. Recognising the difficulty in raising awareness and getting people involved in organ donation among BAME communities, Kidney Research UK deployed its tailored approach called the ‘Peer Educator’ (PE) programme, which has brought excellent results both in terms of raising the number of people registered on the Organ Donation Register (ODR) and encouraging people in BAME communities to talk about the issue.

To date, the PE programme has driven over 2,000 new registrations onto the ODR. The key behind PEs’ success in improving community awareness on the issue lies with the PEs themselves. By recruiting ‘peers’ from the same ethnic minority community, Kidney Research UK makes sure that the right cultural and religious issues are addressed. The aim is long-term behavioural change. A current project is running in Glasgow and the West of Scotland, in partnership with the Scottish Government.