Transplantation (Authorisation of Removal of Organs etc.) (Scotland) Bill

Royal College of General Practitioners

The Royal College of General Practitioners (RCGP) is the academic organisation in the UK for general practitioners. Its aim is to encourage and maintain the highest standards of general medical practice and act as the ‘voice’ of general practitioners on education, training and issues around standards of care for patients.

The College in Scotland came into existence in 1953 (one year after the UK College), when a Scottish Council was created to take forward the College’s interests within the Scottish Health Service. We currently represent over 5100 GP members and Associates in Training throughout Scotland. In addition to a base in Edinburgh, the College in Scotland is represented through five regional faculty offices in Edinburgh, Aberdeen, Inverness, Dundee and Glasgow.

1. Do you support the Bill?

RCGP Scotland supports the aim of the legislation to increase the number of organs available for transplantation in Scotland. With only 41% of eligible people signed up, reliance on the current opt-in system places a significant responsibility on relatives to provide consent after death and there is often a dilemma in respecting relatives’ requests over the previous consent of the deceased patient. RCGP Scotland anticipates that this should be addressed to some extent by the terms outlined in the amendments to the Bill. Although it is acknowledged that it is not the only reason for better donor numbers, international evidence suggests that an ‘opt-out’ system increases organ donation. Recent surveys on public opinion in Scotland would appear to support amendment to the current legislation to increase the number of organ donors. RCGP Scotland is also confident that the consultation has generated sufficient public support to outweigh concerns that the patients’ right to decision may potentially be removed by a “soft” opt-out approach.

RCGP Scotland seeks to encourage patient enablement and to facilitate patients in taking responsibility for their own care and a “soft” opt-out does offer the opportunity during the awareness raising activity, to campaign for a culture in which people are encouraged to actively opt in by registering as a donor, rather than the inactivity which defaults to opting in. This also has the benefit of reducing the burden on gaining authority by operation of law.

RCGP Scotland does have significant concern regarding the shorter term financial implications for the NHS and anticipated implementation costs of £8 million to change the system, in the current climate of critically stretched resources. With significant under spend in General Practice to meet the current needs of the ageing population.
population and increasing numbers of patients with multiple long term conditions, the needs and cost to the health service of patients waiting for organ donation and the decision on the right time to address the problem of donors needs to be placed in the context of the immediate needs for the whole population of patients in Scotland. However, RCGP Scotland fully supports the benefits to patients requiring organ transplant and the resulting longer term health gain is not in question.

2. **Do you think the Bill (if enacted) would achieve its aim of increasing the number of organs and tissue made available for transplantation in Scotland? Please provide an explanation for your answer.**

This is supported by the experiences of implementing an opt-out system in other countries. However, with the proposed change to a "soft" opt-out with the retention of an ‘opt-in’ option, we would anticipate that an ‘opt-in’ by default or the option to appoint a proxy will in fact reduce the number of people on the donor register in the knowledge that that there will in fact be no need to register to be considered a willing donor. Without active campaigning to encourage donor registration as described above in question 1, this is seen as a likely fairly rapid transition to a full opt-out system.

The increase in organ donations in the UK since 2006 has been attributed to improvements in the organ donation systems recommended by the Organ Donation Taskforce. It is therefore anticipated that the raised public awareness achieved by a campaign to inform the public and health care professionals of the amendment in legislation to a “soft” opt-out system would in itself, by the very nature of promoting organ donation, further improve the number of organs and tissues made available for donation.

3. **Do you support the proposal of appointing a proxy? Please provide an explanation for your answer**

In theory this offers an alternative option to actively opting in or out and allows individuals to appoint one person to make the decision and avoid potential family conflict after death. On this basis, RCGP Scotland supports this in principle, however, it is difficult to predict how frequently this option will actually be taken or in what circumstances and RCGP would offer some caution as to whether there is sufficient clarity laid out in the terms of this Bill in how this will be interpreted and managed in practice within the legislative framework. We would seek further clarity for GPs in counseling patients and relatives about how this option will be operated and to the advantages and disadvantages of opting for this route.
4. Do you have any comments on the role of “authorised investigating persons” as provided for in the Bill?

The responsibility to ensure the criteria are met at each step before the authority by ‘operation of law’ is applied appears to be clearly set out in the terms of the Bill. In supporting the change to the legislation, RCGP Scotland would encourage that the proposed awareness raising campaign directs sufficient attention to ensuring the confidence of the public that the amended legislation does provide safety nets to decisions made in this way which protect individuals from decisions which are potentially biased towards the recipient of an organ and which do take into account the interests of the donor and the impact for management plans for end of life care.

5. Is there anything in the Bill you would change? If yes, please provide more details.

Ethical questions have been raised as to the level of informed consent for opting in to date, on the basis of whether the information on the processes surrounding organ donation is sufficiently explicit and available at the point of giving consent. While it is recognised that many people choose not to seek further information about organ donation, in order to encourage and promote positive opting in (which in future may be reached by defaulting on ‘opt-out’) with ethically sound informed consent, RCGP Scotland would like to see more provision in the Bill for ensuring clear information is made available at the point of the opt in process and also where there is active opting out.

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