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Collector: Web Link 1 (Web Link) Started: Tuesday, September 23, 2014 1:37:52 AM Last Modified: Tuesday, September 23, 2014 1:46:18 AM Time Spent: 00:08:25 IP Address: 82.29.173.33		

Q1: The overarching purpose of my proposal is to move from the current opt-in system to a soft opt-out system of organ donation. Do you support this move? Please indicate "yes/no/undecided" and explain the reasons for your response.

Yes,

Please give your reasons for your response: However, it is crucial to emphasise that other countries who have much higher donor registration rates have achieved this not simply through a change to opt-out alone. There are many other important variables that influence national donor registration rates. It is vital that the general public are supportive of such a change and are well informed regarding the concepts of brain death and organ retrieval processes. Brazil adopted a presumed consent law in 1997, with opt-out denoted by a note on an ID card or driving licence. The law had to be repealed in 1998, principally because of mistrust of government and accusations of body snatching. The UK organ donor task force felt that although a system of presumed consent in Spain had been followed by a rise in organ donation, that rise was not thought to be down to the switch, but rather down to better public awareness of donation and confidence in doctors. They believed that there was a significant danger of presumed consent eroding patients' trust in doctors and put potential donors off. In my opinion, in the last few years, Scotland has done an excellent job in raising public awareness of the issue and that the time is now right to consider a move to opt-out. In 2008, the UK organ task force found little evidence that presumed consent would increase the number of organs available for transplant. However, we have just completed an investigation of organ donation rates in opt-in and opt-out consent systems in 48 countries across a 13-year period. We controlled for many potentially important confounding variables in our analyses and found that deceased donor rates (per-million population) were significantly higher in opt-out (average = 14.24) than opt-in consent countries (average = 9.98). (Shepherd L, O'Carroll RE and Ferguson E, An international comparison of deceased and living organ donation/transplant rates in opt-in and opt-out systems: a panel study. BMC Medicine (2014, in press).

Q2: 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?

The rise in organ donor registrations over the last few years demonstrates the significant positive impact of public education and awareness campaigns.

Q3: I believe the role of the family should be limited to being consulted on whether they are aware of any (unregistered) objection by the deceased rather than asking for their consent. Do you agree? Please indicate "yes/no/undecided" and explain the reasons for your response.

Yes,

Please give reasons for your response:
However, I think one needs to recognise the potentially difficult situation that clinical teams may face when a very distressed family strongly opposes the donation. Strategies for handling these difficult situations need to be well thought through and planned.

Q4: Do you think an individual should be able to appoint a proxy to make the final decision regarding transplantation on their behalf? Please indicate "yes/no/undecided" and explain the reasons for your response.

Yes,

Please give reasons for your response:
It could be the case that an individual is very happy to donate, but that their loved one is much less comfortable with the prospect, and that donation may cause significant distress in the surviving loved one. In such a scenario, if both parties agree, it seems sensible to allow the proxy to make the final decision.

Q5: My proposal is that only adults should be automatically opted-in to be a donor. Younger persons would have to register to be a donor, by themselves or with parental consent as they currently do. This approach is I believe the best way to safeguard children and young people. Do you agree? Please indicate "yes/no/undecided" and explain the reasons for your response.

Yes

Q6: Do you agree the age limit for an adult should be set at 16 years old? Please indicate "yes/no/undecided" and explain the reasons for your response.

Yes

Q7: Do you agree the soft opt-out system should apply to people who have been resident in Scotland for a minimum period of 1 year prior to their death? Please indicate "yes/no/undecided" and explain the reasons for your response.

Yes

Q8: If you answered no to the above how long, if any, should this period of residency last before they become subject to the soft opt-out system? Would this residency need to be for a continuous period?

Respondent skipped this question

Q9: Do you think 6 months is a long enough period to run a campaign prior to change over?

No. For the reasons outlined in 1, for this change to succeed it is essential that the general public are well educated, trusting and supportive. It is vital that a high profile and adequately funded public relations campaign is run for at least 12 months in order to build public trust and confidence in the change. Also, the process for opting-out must be highly publicised and made as simple and easy as possible. It should be possible via a number of different avenues, (e.g. text, phone, on-line etc., as is the case for opting-in at present.

Q10: What is your assessment of the likely financial implications (if any) of the proposed Bill to you or your organisation? What (if any) other significant financial implications are likely to arise?

I am not competent to answer this question.

Q11: Is the proposed Bill likely to have any substantial positive or negative implications for equality? If it is likely to have a substantial negative implication, how might this be minimised or avoided?

It is possible that members of some ethnic groups will be more likely to opt-out than others. I am not sure how this can be minimised.

Q12: Do you have any other comments on or suggestions relevant to the proposal?

No

PAGE 3: Contact Details

Q13: If you wish your response, or any part of it, to be treated as anonymous and/or confidential, please check the appropriate box. If not, then please go to question 14.

Respondent skipped this question

Q14: Thank you for completing this survey. Please provide your name and contact details below.

- Name
- Company
- Address
- Address 2
- City/Town
- State/Province
- ZIP/Postal Code
- Country
- Email Address

