

STATES OF JERSEY



ORGAN DONATION REVIEW (S.R.3/2018): RESPONSE OF THE MINISTER FOR HEALTH AND SOCIAL SERVICES

**Presented to the States on 10th July 2018
by the Minister for Health and Social Services**

STATES GREFFE

**ORGAN DONATION REVIEW (S.R.3/2018): RESPONSE OF THE MINISTER
FOR HEALTH AND SOCIAL SERVICES**

Ministerial Response to:	S.R.3/2018
Ministerial Response required by:	6th July 2018
Review title:	Organ Donation Review
Scrutiny Panel:	Health and Social Security

FINDINGS

	Findings	Comments
1	Organ donation saves and enhances lives. The percentage of Jersey adults currently on the NHS Organ Donor Register (14%) is markedly lower than the UK (38%).	Agree that organ donation saves lives and can improve the recipient's health and quality of life. The number of Islanders on the NHS Organ Donor Register is disappointing, but should increase with the new approach.
2	A likely reason for the difference between Jersey and the UK is the fact that, in the UK, applicants can join the Register through the driving licence application process, which has not proved possible in Jersey.	Agreed.
3	An opt-out organ donation system is likely to increase the number of potential organ donors, but so far there is little evidence to suggest that it will increase the number of organ donations unless it is accompanied by other measures, such as public awareness campaigns.	Agree that a high-profile public information and awareness-raising campaign is key to making as many people as possible think positively about organ donation while they are fit and well.
4	The Comité des Connétables has not transferred the information regarding the 14,720 people who indicated their desire to register as a donor to the NHS Organ Donor Register. The Comité des Connétables has indicated that the data will be transferred within the next 2 to 3 months.	The Comité des Connétables is working to amend the driving licence application form to remove organ donor registration and to manage the change to the opt-out system, cease collection data and then complete the transfer of data held to NHSBT via a secure data transfer.
5	Changing from an opt-in to an opt-out organ donation system represents a fundamental change to the Island's approach to organ donation. The draft Law does not contain details of the opt-out mechanism.	In response to Scrutiny's comments, the draft Law adopted by the States included an amendment that requires the States, by Regulations, to make provision for the registration of express consent, or a decision not to consent, to a specified activity. This provision is now mandatory rather than discretionary as previously drafted. In practice, it is likely that individuals will register their

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		decision with the NHS Blood and Transplant service, which currently maintains the single UK-wide register that records whether an individual has opted out (or opted in) to organ donation.
6	In the absence of a specific opt-out mechanism, the decision to donate organs will always lie with families or next-of-kin, even if an individual has previously expressed a wish to donate their organs.	Next-of-kin have to give permission for organ donation to proceed, so ultimately donation would not go ahead if the family objected. This is why it is important that individuals let their family know of their wishes in advance, so they are less likely to be overruled.
7	In light of the draft Law, it is important that families discuss their choice with regard to organ donation.	Absolutely. One of the Minister's aims in facilitating a change in approach to organ donation was to encourage Islanders to have the conversation with their families about donating while still fit and well, rather than leaving it until the emotive aftermath of a fatal accident or illness. As the Minister said: 'A few words now can make the difference later on.'
8	Clinical practice associated with the retrieval, transfer and transplantation of organs will not change as a result of moving to an opt-out organ donation system.	Agreed.
9	How families are approached to gain consent to donate a relative's organs will be crucial under the new opt-out system. Ensuring the right people with the appropriate training are available will maximise the chances that a family will consent to their relative's organs being donated.	Agreed. When the possibility of organ donation is identified, a trained specialist nurse in organ donation comes to the Island to oversee arrangements and support the donor's family. These arrangements continue.
10	The protections for vulnerable groups enshrined in the draft Law – including for children, people lacking capacity, and recent arrivals to the Island – are appropriate.	Agreed.
11	A high-profile and sustained public awareness campaign will be essential in ensuring that (a) the public are aware of the change from an opt-in to an opt-out system; and (b) there is an increase in the percentage of persons registering on the NHS Organ Donor Register.	Agreed.

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12	Wales, which recently introduced an opt-out organ donation system, spent roughly £3.4 million on a public information campaign. The Minister is proposing to spend £20,000 in Jersey. This is roughly £1.10 per person in Wales compared to roughly £0.20 per person in Jersey.	Noted (see recommendation 5 overleaf).

RECOMMENDATIONS

	Recommendations	To	Accept/Reject	Comments	Target date of action/ completion
1	The Comité des Connétables should transfer the data it has on applicants' organ donation preference to the NHS Blood and Transplant service within 2 to 3 months. If it is unable to transfer the data it should write to all the people affected, notifying them of the situation and encouraging them to sign the NHS Organ Donor Register directly.	H&SS	Accept	The Minister for Health and Social Services understands that the Comité des Connétables has consulted with the Minister for Infrastructure to amend the driving licence application form to remove organ donor registration; the amended form is being drafted and will be ordered shortly. When this is available, parishes will cease to collect the data, and the Minister has been informed that the parishes will transfer data held to NHSBT via secure data transfer.	End September 2018
2	The Minister should bring forward Regulations to the States to provide a means for people to opt-out of organ donation.	H&SS	Accept	The Law as amended means that Regulations will be brought forward setting out how people can opt out.	Before July 2019
3	Family members and next-of-kin must continue to be treated sensitively, with care and respect, as they will ultimately have the final say on whether their relative's organs can be donated.	H&SS	Accept	This will continue to be the case.	Happening now
4	The Minister should ensure that campaign materials are translated into other languages, especially Portuguese and Polish. The campaign should be ongoing and extend beyond the year prior to the change in the Law.	H&SS	Accept	The importance of these points is recognised.	Before July 2019

	Recommendations	To	Accept/ Reject	Comments	Target date of action/ completion
5	Wales spent 5 times the amount of money per person on a public information campaign. The Minister should consider increasing the budget in light of the experience in Wales and the fact that Jersey is not able to sign people up to the NHS Organ Donor Register via the driving licence application process.	H&SS	Accept	This point is noted. Wales was the first UK jurisdiction to make the change to an opt-out system, so it was to be expected that it would spend more per head on communicating the change to the Public. Thanks to its success, there is now more awareness of organ donation. Being a small island it is easier to communicate with the Island's population. However, if additional funding is required for the publicity and awareness campaign, then the Minister will seek this additional funding.	Before July 2019

CONCLUSION

The Minister expresses his thanks to the Health and Social Security Scrutiny Panel for its report on his plans to introduce a new opt-out/deemed consent organ donation system. In reviewing the draft Law, the Panel raised a number of constructive points in policy and legislative matters, and amendments were made to the Law as a result. The Minister would like to acknowledge Scrutiny's helpful role in reviewing and improving this legislation, which he hopes will make it easier for Islanders to donate their organs and potentially to save more lives.