

## **Isle of Man Organ Donor consultation on an opt-out / deemed consent system**

On the 29<sup>th</sup> March 2018, following leave to introduce a Private Member's Bill, a consultation was launched on the proposed introduction of an "opt-out" or deemed consent system of organ donation.

This was to make sure that the island's population, and any professional bodies involved, had ample opportunity to comment and to help decide whether to create a new system, or stay with the existing "opt-in" organ donation system. The consultation ran for 12 weeks.

The aim of these proposed changes was set out as:

- Increase the numbers of people who would donate their organs after their death; and
- An easy opt out method for those who did not want to donate organs after their death.

97% of replies were from island residents

99% of replies were from private individuals

28% said "you can publish my response in full"

54% said "you can publish my response anonymously"

18% did not want their response to be published

### **Q1. We asked: Are you a registered organ donor?**

57% who responded were registered on the UK NHS register

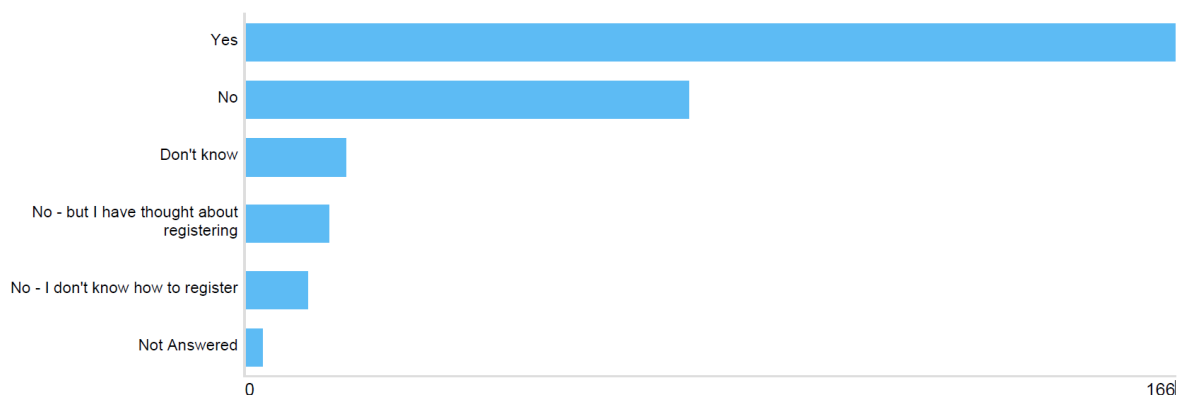
27% who responded were not registered on the UK NHS register

6% didn't know or couldn't remember if they had registered

5% were not registered but had thought about it

4% didn't know how to register

1% did not reply



**Q2. We asked: Have you had any experience of the organ donation process?**

89% Yes

11% No

You replied:

*"A close friend's son became a donor when he died as a teenager following a brain hemorrhage"*

*"My mother passed away while on the transplant list for a liver. A friend has received an organ."*

*"I work in healthcare and have cared for transplant patients. I have also dealt with families who have lost a love one and are deciding about whether to consent to organ donation."*

*"I received a liver transplant in 2008"*

*"After two "false starts" my brother received a transplant. I am so grateful to the donor for the gift it gave him to be with us and to see his children grow and to meet his grandchildren".*

*"We weren't able to fulfill my brothers wish to donate his organs, as he was killed in a racing incident."*

*"My daughter died 2 years ago and it was her wish and ours to donate her organs. The organ donation team were fantastic through the whole process explaining everything and were very respectful and sympathetic. It has helped us so much to know her death has not been in vain. She has given life to others."*

*"My daughter in law is awaiting a lung transplant"*

*"I have a family member who is on the transplant waiting list"*

The responses reflected a range of very personal experiences and we are very grateful to people who shared them. It is clear that the consultation attracted many people who had had firsthand experience of transplants or the issues affecting donors and recipients.

**Q3. We asked: Have you ever discussed organ donation with family members / other next of kin?**

88% who responded had discussed donation with their family or next of kin

11% had not discussed donation with family or next of kin

1% did not reply



**Q4. We asked: Do you have any ideas or suggestions on how the IOM government could encourage more people to register as organ donors?**

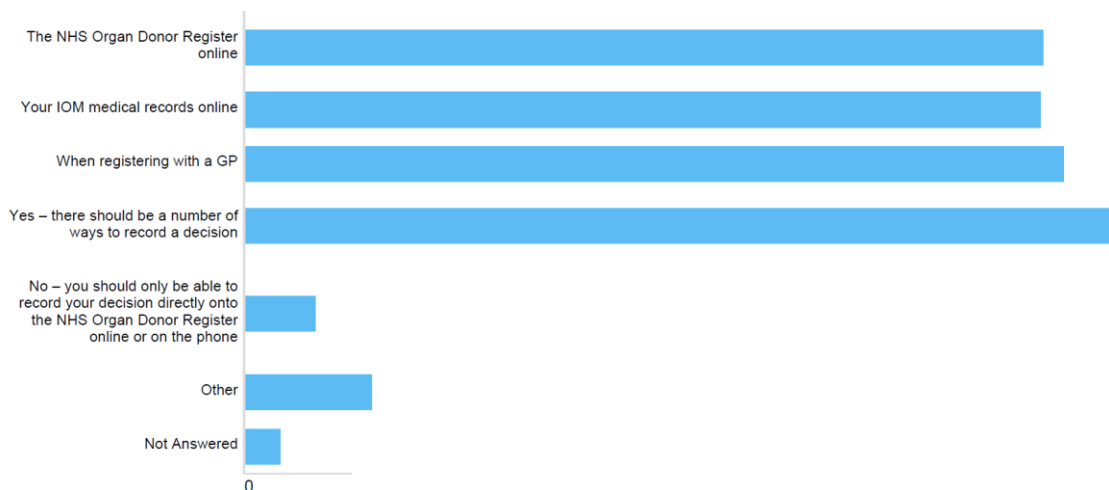
*“Promote the number of lives saved/changed on the Island through organ donation. Ideally by getting those involved on both sides involved (if willing).”*

*“I believe that everybody should automatically be registered as an organ donor. People should have the right to opt out if they wish.”*

The evidence suggests that public information campaigns substantially increase the number of organs donated and the willingness of people to donate both their own and the organs of their relatives. Mossialos et al (2008) found that ‘awareness of regulation increases the odds of being willing to donate one’s own organs by 91 percent and those of a relative by 74 percent’.

**Q5. We asked: Do you think people should have more ways to record a decision about organ and tissue donation?**

- 69% NHS register
- 69% IOM medical records on line
- 71% when registering with a GP
- 76% There should be a number of ways to register your decision
- 6% There should be a number of ways to register
- 11% Other
- 3% Did not answer



Since this consultation was launched it is clear that the most streamlined and effective way of registering your “opt-in” or “opt out” decision will be on the UK NHS organ donor register. People suggested there should be as many ways to register as possible but in practice this may lead to delay while all the different records were checked and to possible confusion if different decisions were recorded. The UK NHS register provides a one stop shop to quickly determine the wishes of the donor.

**Q6. We asked: For the purposes of organ donation do you think the cutoff date for being a child should be 16 or 18?**

Age of consent:

65% Thought the age of 16 was the correct age of consent

33% Thought the age of 18 was the correct age of consent

2% Did not wish to make a comment

You said:

*“A 16 year old should have a say in what happens to their body after death.”*

This would be consistent with the legal age for other activities on the Isle of Man, such as voting.

*“At 16 a person can fully appreciate the importance of providing life-saving help to others.”*

*“Children can be very socially aware and I think by 16 they are able to make an informed decision.”*

*“On the Island you can drive from 16, actively taking the lives of yourself and others into your hands every day. If you are mature enough to operate a vehicle, you are mature enough to have agency over your own body, during life and after death.”*

Other respondents had different views:

*“I don't feel anyone under 18 can give full consent.”*

*“I agree with 18 in line with other noted ages of consent.”*

*“It is a very grey area in legal terms between 16 and 18 years of age and with most not knowing what to do today never mind what to do with their body when they die.”*

**Q7. We asked: If the law was changed would this affect your decision about organ donation?**

65% would not change their decision

15% said it would make them want to become a donor

20% said it would make them opt out of being a donor

This is an interesting response. There are 6,200 people on the island already on the NHS organ donation register out of a population of about 84,000. The results of this question suggest that only a minority would actively opt out of the proposed new system allowing many more organs to potentially become available for transplant.

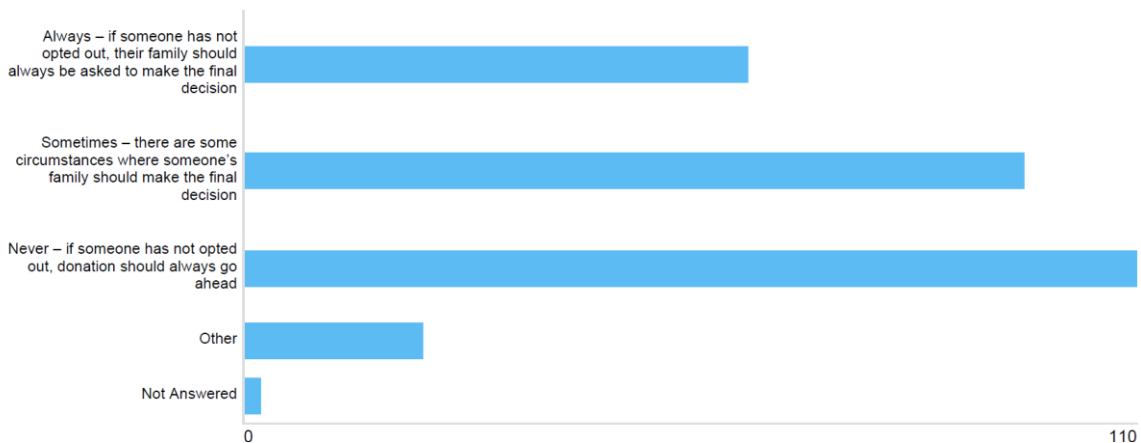
**Q8. We asked: Do you think this change could have any particular impact on people from some religious groups or ethnic backgrounds?**

- 46% Yes it would make a difference
- 28% No it would not make a difference
- 24% Don't know
- 2% Did not answer

Some religions may not support organ donation or actively discourage it and such points of view would be recognised and respected under the proposed opt-out system.

**Q9. We asked: If the law changes and someone has died, and they have not opted out of organ donation should their family be able to make the final decision?**

- 21% Always
- 33% Sometimes
- 38% Never
- 8% Other



You said:

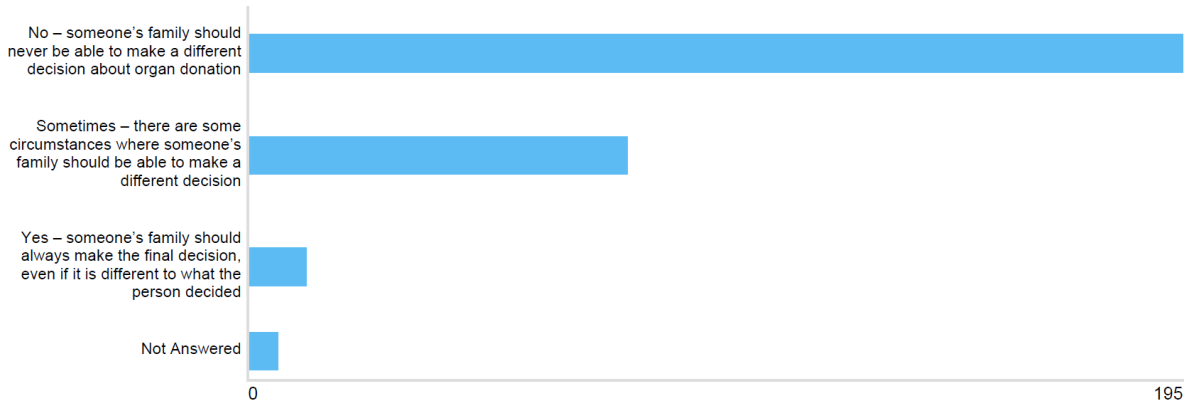
*“Yes as a courtesy family members should be advised that organ donation will take place.”*

*“Sometimes – there are some circumstances where someone’s family should make the final decision.”*

*“This would depend on how well the changes (ie you have to opt out) have been in the public knowledge.”*

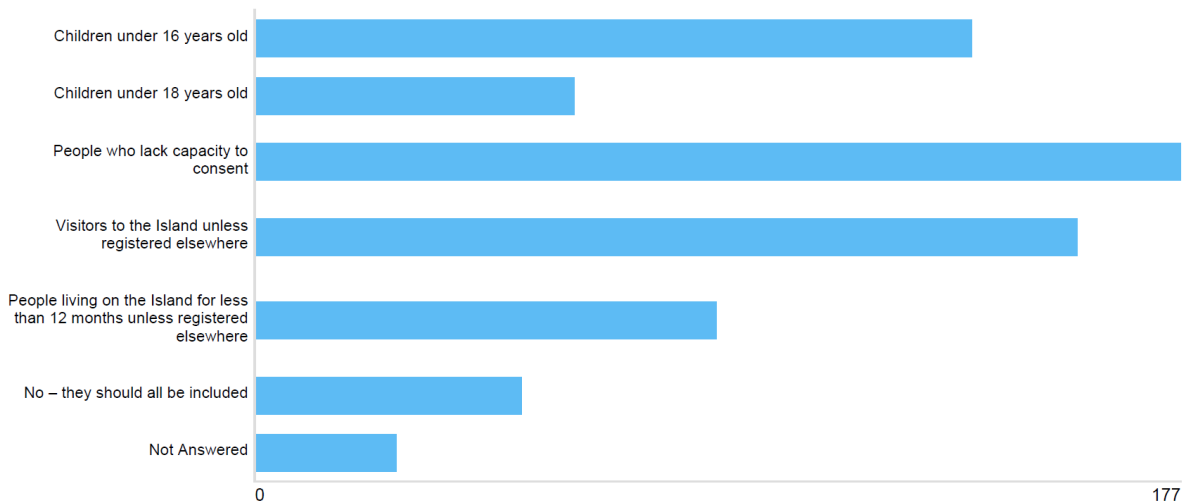
**Q10. We asked: Do you think someone’s family should be able to decide if their organs are donated if it is different to the decision they made when they were alive?**

67% No  
 27% Sometimes  
 4% Yes  
 2% did not answer



**Q11. We asked: If the IOM moves to an opt-out system should any of the following groups not be included in presumed consent?**

47% Children under 16  
 21% Children under 18  
 61% People who lack capacity to consent  
 54% Visitors to the Island unless registered elsewhere  
 30% people living on the Island for less than twelve months unless registered elsewhere  
 18% No they should all be included  
 9% Did not answer



**Q12. We asked: Do you agree that section 19 of the bill covers all the topics that should be included in the code of practice?**

82% Yes

7% No

11% did not answer

You said:

*“The code of practice should be made available to everyone, not just those interested. The opt out process automatically enrolls almost everyone into the donor system so everyone must be able to see if all those involved in the process are abiding by the code. The code should also include all administration staff as well as medical personnel.”*

*“There should be a reference and parity with the UK bill, not least to ensure that our practices may lead to organs being refused if different.”*

*“2 c and e cover communication, but there should be an additional provision making clear the responsibility to ensure suitably trained staff are made available to carry out these communications”.*

**Q13. We asked: Please tell us about any opinions you have about opting out of organ donation.**

*“Anything that can be done to increase the availability of organs for donation is GOOD!”*

*“I would imagine that an opt-out system would increase the consent rate and therefore the number of transplants. It could be argued that this will put an increased strain on Health Service resources.”*

*“I understand certain religions etc. believe you must retain all your body in order to access their ‘heaven’ or similar. I think this should be respected but I do believe it is down to the individual to opt out themselves.”*

*“Opting out system will increase the number of transplants. It will stop the awkward question being asked by the medics at a difficult time and relatives having to make that decision.”*

*“This is a hugely bad, wrong proposal and should never go ahead”*

*“I believe organ donation is very important and is something most of the population ‘never get round to’ although most would probably agree to donate their organs upon death. Therefore, I think there are probably a great many opportunities for organ donation that get missed. I believe an opt-out system would identify the people who are strongly against their organs being donated and encourage them to register as a no. I do believe this would increase the number of organs that become available and could be life changing.”*

*“Personally I think switching to an opt-out system would be beneficial to our society: it’d very likely increase the number of available organs and therefore successful transplants, saving lives.”*

*“I looked into this topic a couple of years ago when Wales moved to an opt out system and think this is something we should have done a long time ago, tried and tested there and seems to have increased donations which is really good news. In time it will become the norm and by changing the law that will help this happen.”*

## **Conclusion**

There was a good response to the consultation with the majority of people having personal experience of organ donation in a variety of ways. Whilst a minority opposed any changes to the present opt-in system, the majority of people who responded were supportive of change as they saw it would enable more organs to become available for donation and help tackle some of the long waiting lists which exist for patients requiring transplants.

Whilst this may be seen as a small sample the results are very similar to those of opinion polls in the UK.

A recent survey of 2,000 people by the British Heart Foundation (BHF) found that 74% of people are in favour of a system where people are registered as a potential donor unless they stated otherwise.

### **If an opt-out system was adopted how would an Isle of Man system work?**

Before changing to an “opt-out” system, there would be an extensive, high profile campaign to inform the public about the changes. It would aim to encourage people to consider, and discuss with their next of kin, their personal wishes about organ donation in the event of their death.

People would be able to register their decision to “opt-in” or “opt-out” on the UK NHS organ donor register.

Once implemented, if someone over the age of 16 were to die and donation is a possibility, their decision on the UK NHS organ donor register, by law will be checked. If the individual has “opted out” then donation could not proceed.

As an extra safeguard, if the individual had not registered their decision on the UK NHS organ donor register, family members would be asked if they were aware of any unregistered objection. If the relatives were not aware of any objection, then they would be informed that donation would proceed.

If the donor had opted in the relatives would be informed of those wishes and donation would proceed if the organs were deemed viable.