

**THE STATES OF DELIBERATION**  
**of the**  
**ISLAND OF GUERNSEY**

**COMMITTEE FOR HEALTH & SOCIAL CARE**

**ORGAN DONATION- INTRODUCTION OF A 'SOFT' OPT OUT SCHEME**

The States are asked to decide:

Whether, after consideration of the Policy Letter entitled 'Organ Donation- Introduction of a 'Soft' Opt Out Scheme', dated 4<sup>th</sup> October 2018, they are of the opinion:

1. To approve the introduction of an organ donation scheme based on 'deemed consent' subject to the safeguards and exemptions set out in this Policy Letter;
2. To direct the preparation of such legislation as may be necessary to give effect to their above decision.

The above Propositions have been submitted to Her Majesty's Procureur for advice on any legal or constitutional implications in accordance with Rule 4(1) of the Rules of Procedure of the States of Deliberation and their Committees.

**THE STATES OF DELIBERATION**  
**of the**  
**ISLAND OF GUERNSEY**

**COMMITTEE FOR HEALTH & SOCIAL CARE**

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The Presiding Officer  
States of Guernsey  
Royal Court House  
St Peter Port

4<sup>th</sup> October 2018

Dear Sir

**1. Executive Summary**

- 1.1 This Policy Letter recommends that Guernsey moves from the current system of organ donation where individuals, or their families on their behalf, need to actively consent to donation taking place to a scheme based on 'deemed consent'. Under the proposed scheme to be established through legislation, subject to the appropriate safeguards and exemptions, people would be deemed to consent to donating their organs unless they actively opt out. This will assist the majority of Islanders who are happy to donate their organs and tissues when they die while at the same time respecting the decisions of those who do not wish to donate.
- 1.2 Organ donation saves and transforms lives but hundreds of people die every year in the UK while waiting for an organ transplant. While many people express support for organ donation, very many have not formally registered their views. Not surprisingly, many people only realise the importance of organ donation when they become exposed to it. While moving to a deemed consent model for organ donation is unlikely to lead to a marked increase in donations given the size of Guernsey's population and the limited circumstances when donation is potentially possible, by symbolically moving the default position the proposals will reinforce the positive view of organ donation and may increase the likelihood of organ donation when the situation arises. A single organ donor can potentially save or enhance the lives of up to nine individuals.
- 1.3 Guernsey is part of a UK wide organ donation and transplant system and across the United Kingdom, steps are being taken to move to an opt-out model. Wales introduced "deemed consent" in December 2015 and the Scottish Government published on 11<sup>th</sup> June 2018 the Human Tissue (Authorisation) (Scotland) Bill which includes provision for a "deemed authorisation system." Within England, the results of a public consultation is due for publication shortly. Separately, a Private Member's

Bill in support of “presumed consent” for organ donation is currently progressing through Parliament. Earlier this year, Jersey approved their Human Transplantation and Anatomy (Jersey) Law 2018 by some 44 votes to 1 which will introduce a soft opt out scheme and the Isle of Man launched a consultation in March of this year on an “opt out” system.

1.4 This Policy Letter recommends the drafting of legislation which will establish within Guernsey an organ donation scheme where:-

- People will be considered willing to be an organ donor unless they decide to opt-out
- Family members will retain a role in confirming decisions
- It is easy for people to register their decision on organ and tissue donation
- Safeguards and exemptions exist for certain groups.

## **2. What is Organ Donation?**

2.1 Organ donation is where organs are removed from one person – a donor – to be transplanted into a person who needs a new organ - the recipient. A single donor can save the lives of up to nine people. Donors who have just died may donate their kidneys, liver, heart, lungs, pancreas and small bowel. In addition, it is possible for tissue to be donated, for example eyes, heart valves, bones and skin. Under both the opt-in and opt-out schemes described below, it is possible to consent to the donation of some organs/tissue and not others.

2.2 Less than one percent of people die in circumstances where it is possible for them to be an organ donor. To donate, death must occur in hospital, typically in Intensive Care, and even then there may be medical or legal reasons why organ donation is not possible. This means that where someone dies in circumstances where organ donation is an option it is especially important that steps are taken to support organ donation.

2.3 Organ donation is managed through NHS Blood and Transplant (NHSBT). In order to maximise the chances of donation being successful, a national transplant waiting list is maintained by the NHSBT which carefully matches organs to the recipient, considering factors such as blood group, age, weight and the tissue type of the donor and potential recipient. Donated organs may go to people in any part of the UK network.

2.4 2016/2017 figures from the NHSBT show that 1,413 deceased donors donated 4,741 organs. Despite a 2% increase in the number of donated organs from the previous year, as at March 2017 there were 6,388 patients on the active transplant list and a further 3,357 who were temporarily suspended from the active list as they were unfit or otherwise unavailable for transplantation. During 2016/2017, 470 patients died while awaiting a transplant on the active/suspended list or within a year of being removed. A further 875 individuals were removed from the list because they were too ill for surgery. There is a particular shortage of donated organs for certain

ethnic groups, with individuals from a black or Asian background waiting on average six months longer for a matched donor.

### **3. How does Organ Donation work in Guernsey currently?**

- 3.1 Currently organ donation is based on an opt-in system governed by the provisions of the Human Tissue (Bailiwick of Guernsey) Law, 1981. In summary, individuals may consent to donating some or all of their organs by expressing a view in their lifetime, typically through registration on the Organ Donation Register (the number who do so is low around 13%) or telling a family member. If such a decision has not been made, the individual's family may be asked to give consent.
- 3.2 For organ donation to proceed, the support of the donor's family is necessary. While consent rates have increased over recent years, figures from the UK indicate that where a patient has not expressed their wishes surrounding donation, the current family consent rate is 46.7%. This rises significantly to 91% where the patient's wish to donate is known. Unfortunately, very many individuals do not talk to their families about their wishes.
- 3.3 In circumstances where someone has died, or is dying, in circumstances where organ donation may be an option, a designated Specialist Nurse for Organ Donation will check if the patient has authorised organ donation and a sensitive discussion will take place with the patient's family. If the family is supportive of donation, a series of clinical checks are made to assess the feasibility of donation. At all times, the clinical team caring for the patient remains focused on ensuring the patient is comfortable and their needs are met. Continued support is provided to the donor's family.
- 3.4 Where a decision is made to proceed with donation, a specialist team of surgeons travel from the UK to retrieve the organs. Following the retrieval, the organs are carefully stored and transported to the hospital(s) where a separate team of surgeons will carry out the transplant(s).

### **4. Deemed Consent Organ Donation**

- 4.1 The model of organ donation being proposed by the Committee is termed 'deemed (or presumed) consent'. In such a system, the default legal position would shift from one where organ donation needs specific consent to one where adults are deemed to have given their consent unless they specifically opt-out. Individuals would still be able to express their wishes regarding specific organs.
- 4.2 Under this model, in circumstances where someone has died or is dying in circumstances where organ donation may be an option:-
  - If the person has opted-out, no donation would proceed.
  - If the person has opted-in, their family would be informed and with their co-operation the viability of donation would be examined.

- If the person had not registered any decision, they would be deemed to have consented to donation. Family or friends would be asked if the individual had expressed any objections to organ donation. If they had not, the assumption would be that donation could proceed. If, however, it was apparent donation may distress the family and may lead to them potentially refusing to provide the background information necessary to safeguard the quality and safety of donated organs, then donation would not proceed. Similarly, where it was not possible to contact family or friends, donation would not proceed as it would not be possible to obtain important information about the deceased person's lifestyle and medical history.

4.3 Deemed consent would not apply for a limited number of groups, those under 18, those not ordinarily resident in Guernsey for the last 12 months and those without capacity. In these circumstances express consent would be required from an appropriate person for donation to proceed. Express consent would be needed for:-

- Anyone under the age of 18, either from the parent or guardian if the child is under 16 or from the young person themselves if they are 16 or 17 and have sufficient understanding to make an informed decision. If a 16 or 17 year old did not give express consent in their lifetime, their parents or guardians would be able to provide express consent upon their death.
- Anyone who, for a period of time before their death, did not have the mental capacity to understand the choices regarding organ donation due to cognitive impairment. Express consent would be required from their family or someone appointed on their behalf to make such decision. New capacity legislation is a priority for the Committee and it is very much anticipated that this will be in place to inform the drafting of any new legislation regarding organ donation.
- Anyone who has not been ordinarily resident in Guernsey for 12 months. In common with the approach adopted in Wales and Jersey, it is proposed that a minimum residency criteria be introduced in order to safeguard people who have only been resident for a short time and might be unaware of the arrangements and the opportunity to opt-out. In these cases, efforts would be made to check whether they had opted-in and, if applicable, to contact their next of kin regarding medical checks and authority to proceed.

4.4 In all cases, notwithstanding the move to deemed consent, families would retain a key role in the donation process. The inclusion of a donor's family means this approach is often termed a soft opt-out system, contrasting to a hard opt-out where family views are not taken into account and organs may be removed from any individual who has not registered to opt-out. This means that the scheme further accommodates individuals who may object to organ donation due to religious or moral reasons. Donation would not proceed where the family indicate their loved one did not want to be a donor or where proceeding is likely to cause the family severe distress or lead to conflict. The intention would be that under the new arrangements there would be increased encouragement for families to discuss their wishes.

- 4.5 Any Law drafted would only apply in Guernsey or the Bailiwick in the event that agreement is reached with Alderney and Sark in relation to a Bailiwick wide Law (see paragraphs 6.3. and 6.4 below). Guernsey residents (or Bailiwick residents in the event of Bailiwick wide legislation) who die in other jurisdictions would not be deemed to have consented. If, for example, someone died in the UK, having been sent to a tertiary centre for treatment which proves unsuccessful, and they are a potential donor, checks would be made of the Organ Donation Register. If they had opted-in, staff would approach their next of kin about their suitability as a donor and if they had not made a choice, the family would be approached to consider giving consent.
- 4.6 In any move to an opt-out consent model, it is important that individuals are aware of the change and are able to simply and clearly make and record their decision. Should the proposals be approved by the Assembly, prior to any legislation being introduced, there would be a high-profile awareness campaign explaining the changes, the choices available to Islanders and the respective implications. This would be designed to encourage people to think about, and discuss with their families, organ donation and would be funded within the Committee's existing resources. All providers in the future Partnership of Purpose will have a role to play in raising awareness and prompting discussion in the spirit of making every contact count.
- 4.7 In conjunction with NHSBT, arrangements will be put in place to ensure that simple and clear processes are in place for Islanders to register their wishes. Opportunities to combine efforts with Jersey will be explored and individuals would be able to expressly appoint someone to make decisions on their behalf after their death.
- 4.8 In common with practice in other jurisdictions, the Committee recommends that the legislation makes clear that the retrieval and use of organs will only be lawful if carried out by a registered medical practitioner or qualified individual and that anyone carrying out a specified activity (e.g. organ removal) under the proposed system without the required consents and permissions will be guilty of a criminal offence. Additionally, the proposed legislative framework would make clear that the Law will not apply to anything done for purposes of the discharge of the functions of the Law Officers of the Crown or any Bailiwick court relating to the holding of an inquest or a post mortem examination and that the integrity of the Inquest function is not compromised. The Law would repeal the Human Tissue (Bailiwick of Guernsey) Law, 1981.
- 4.9 The proposed new primary legislation would contain ordinance-making powers to support the practical application of the Law. These would include powers to specify additional activities to be covered by the Law in keeping with developing medical opinion and ethics, to provide for special circumstances in which consent may be deemed to have been given and to prescribe the processes surrounding the registration of consent or refusal and consequential and supplementary provisions needed to give effect to a model based on deemed consent and the Law as a whole. In addition, in order to support the operation of the scheme, it is recommended that

the Committee is authorised under the Law to issue Codes of Practice and guidance on the application of Codes for the benefit, for example, of health professionals. These will be issued following consultation with appropriate bodies and persons including health professionals.

## **5. Other Jurisdictions**

- 5.1 Wales was the first jurisdiction in the British Isles to introduce deemed consent, with the Human Transplantation (Wales) Act coming into force in December 2015. Individuals over 18 who live and die in Wales are considered as having consented to donate their organs unless they have registered a wish not to be a donor. The family of the deceased is involved in the process and may object to the donation based on their knowledge of the views of the deceased. A review published in November 2017 in respect of the first two years of the Welsh soft-opt out model concluded that while donations had not increased since the Act's introduction, there had been an increase in the percentage of families giving approval for donation. While a longer time period was necessary in order to draw firm conclusions on the impact of the Law, awareness of and support for the model was found to be high both among the general public and NHS staff albeit that publicity of the law needs to be maintained. Particular recommendations included the need to provide greater clarity regarding the family's role and additional training for NHS staff in respect of how to discuss organ donation with family members.
- 5.2 Following a public consultation in 2017 in which 82% of respondents supported a move to an opt-out system, the Scottish Government published on 11<sup>th</sup> June 2018 the Human Tissue (Authorisation) (Scotland) Bill which includes provision for a "deemed authorisation system." The Bill contains safeguards akin to those which exist in the Welsh Law for those without capacity, those who have lived in Scotland for less than 12 months and children.
- 5.3 In England, a consultation was launched in December 2017 on the introduction of an opt-out consent system. The consultation sought to obtain a range of views on organ donation, how best to honour the wishes of potential donors, how to make registering views as simple as possible, the role of the family and possible safeguards.
- 5.4 Separately, the Organ Donation (Deemed Consent) Bill 2017-2019, a Private Member's Bill seeking to amend the Human Tissue Act 2004 so that where a person in England has not made a decision regarding organ donation, the default position will be that consent will be deemed to have been given is currently proceeding through Parliament. The Bill had its second reading debate on 23<sup>rd</sup> February 2018 and has been committed to a Public Bill Committee. The Government has indicated its support for the Bill and has indicated that if approved, the new system will come into effect in England in spring 2020 allowing a one-year transition period for friends and family to discuss their organ donation preferences.

- 5.5 A 2015 Private Bill in Northern Ireland proposing the introduction of an opt-out organ donation consent was unsuccessful due to opposition from the Committee for Health, Social Services and Public Safety. The Health (Miscellaneous Provisions) Act (Northern Ireland) 2016 subsequently imposed a duty on the Government to promote transplantation and between December 2017 and March 2018, the Northern Irish Department of Health published a consultation on the draft policy for improving organ donation rates without changing the law on consent.
- 5.6 In the 2017 Opinions and Lifestyle Survey, Jersey asked a series of questions in relation to organ donation. This highlighted that while three quarters of adult respondents would accept an organ transplant if needed, people were less inclined to donate their own organs – with over half saying they would, nearly a third not sure and 14% saying they would not. Only a quarter of those who were happy to donate had formally registered on the Organ Donation Register, with many who had not citing that they had not got round to it, were not sure how to, or did not realise that Jersey residents could register. A deemed consent approach to donation was supported by a majority of respondents and in April 2018, the States of Jersey approved the Human Transplantation and Anatomy (Jersey) Law 2018 by some 44 votes to 1. Colleagues in Jersey are currently working with the NHSBT to establish the practical arrangement of a deemed consent approach.
- 5.7 The Isle of Man launched a consultation in March of this year on an opt-out system following a Private Member's Bill. This consultation ran until 8<sup>th</sup> June 2018.
- 5.8 Professional bodies have indicated their support of opt-out schemes. The British Medical Association has for many years actively campaigned for the introduction of an opt-out system believing that this would help in addressing the shortage of organs and, following a consultation earlier this year, the Royal College of Nursing have set out their qualified support for an opt-out system of consent subject to safeguards and resources being in place.

## **6. Consultation**

- 6.1 The Committee undertook a public consultation earlier this year. In summary 80% of the 688 respondents were in favour of the Committee's proposals. Respondents recognised the need for some groups to be excluded from the proposals and a majority of respondents did not believe that families should be able to decide if organ donation takes place if this decision is different to that made by the individual when they were alive.
- 6.2 The Committee specifically consulted the Youth Forum, 100% of Forum Members present voted in favour of moving to a soft opt-out model, with 88% of their Members indicating that such a change would make them want to become an organ donor after their death. The Forum felt that there were circumstances where someone's family should make the final decision and suggested the development of a list of circumstances where this would be appropriate. Their membership gave a series of suggestions in relation to how best to communicate any future changes to young people and



suggestion the inclusion of a session on organ donation within the PHSE curriculum in order that young people can make an informed decision.

6.3 The Committee wrote to the States of Alderney earlier this year in respect of the geographical scope of the scheme. The States of Alderney debated without resolution organ donation in May of this year, prompting public consultation in Alderney. The States of Alderney advised that while there was a relatively limited response to the consultation, a majority of respondents were in favour of a soft opt-out system. In correspondence to the Committee, the Chairman of the Policy & Finance Committee has advised that should the States of Guernsey decide to move to a soft opt-out system, he will recommend that the States of Alderney adopt the same approach.

6.4 Similarly, discussions are ongoing with Sark and their Medical & Emergency Services Committee. While both Islands recognise that the legislation would have, in practical terms, limited bearing on the operational delivery of health and care services within their jurisdiction, both Islands recognise the potential merit of Bailiwick legislation so to cover the deaths of their residents who may die in Guernsey. The Committee therefore intends to work closely with both Islands during the drafting process with the view of proposing a Bailiwick-wide law. In so doing, the Committee would consequentially wish to repeal the Human Tissue (Bailiwick of Guernsey) Law 1981, acknowledging that the provisions in that Law will be reinstated through the proposed Bailiwick wide legislation in a manner premised on a deemed consent model.

## 7. **Conclusion**

7.1 The Committee recommends to the Assembly that Guernsey moves towards an opt-out consent system, complemented by wider initiatives to encourage Islanders to consider organ donation and discuss this with their families.

## 8. **Compliance with Rule 4 of the Rules of Procedure**

8.1 In accordance with Rule 4(1), the Propositions have been submitted to Her Majesty's Procureur for advice on any legal or constitutional implications. She has advised that there is no reason in law why the Propositions should not be put into effect.

8.2 In accordance with Rule 4(4) of the Rules of Procedure of the States of Deliberation and their Committees, it is confirmed that the propositions above have the unanimous support of the Committee.

8.3 In accordance with Rule 4(5), the Propositions relate to the primary duty of the Committee to protect, promote and improve the health and well-being of individuals and the community.

8.4 Also in accordance with Rule 4(5), the Committee consulted with Alderney and Sark in developing these proposals and undertook public consultation.

## **Propositions**

9.1 The States are asked to decide whether, after consideration of this policy letter, they are of the opinion:

1. To approve the introduction of an organ donation scheme based on 'deemed consent' subject to the safeguards and exemptions set out in this Policy Letter;
2. To direct the preparation of such legislation as may be necessary to give effect to their above decision.

Yours faithfully

H J R Soulsby  
President

R H Tooley  
Vice President

R G Prow  
D A Tindall  
E A Yerby

R Allsopp