States of Jersey
States Assembly

États de Jersey
Assemblée des États

Health and Social Security Scrutiny Panel

Organ Donation Review

Presented to the States on 27th March 2018

S.R.3/2018

CONTENTS

Executive Summary

Organ donors provide a vital service to society by saving and improving the lives of thousands of people each year across the UK. The Minister for Health and Social Services' aim to increase the number of potential organ donors in Jersey is commendable.

Organ donation is an emotive and personal issue. The move from an opt-in to an opt-out system means that appropriate safeguards are required to protect vulnerable groups and also to provide those people, who do not want to donate their organs, with a means of opting out. Based on the evidence we have received as part of our review, we are satisfied that the Minister's opt-out proposals provide these protections.

The main change that will result from the opt-out system is how the family of a potential organ donor is approached for consent. Losing a loved one is an extremely distressing and emotional time. 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 loved one's organs can be donated.

It is clear that adopting an opt-out approach will not in itself increase organ donation. The evidence suggests that this must be accompanied by other measures, not least an increase in public awareness. A high profile and sustained public awareness campaign must accompany the introduction of this legislation to ensure that more lives can be saved and enhanced through organ donation. This will also make it more likely that families will discuss this important matter long before the situation ever arises.

Key Findings

KEY FINDING 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%).

KEY FINDING 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.

KEY FINDING 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.

KEY FINDING 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.

KEY FINDING 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.

KEY FINDING 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.

KEY FINDING 7: In light of the draft Law, it is important that families discuss their choice with regard to organ donation.

KEY FINDING 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.

KEY FINDING 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.

KEY FINDING 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.

KEY FINDING 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.

KEY FINDING 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.

Recommendations

RECOMMENDATION 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.

RECOMMENDATION 2: The Minister should bring forward regulations to the States to provide a means for people to opt-out of organ donation.

RECOMMENDATION 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.

RECOMMENDATION 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.

RECOMMENDATION 5: Wales spent five 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.

Introduction

1. On 27th February 2018, Senator Andrew Green, the Minister for Health and Social Services (the Minister) lodged the Draft Human Transplantation and Anatomy (Jersey) Law 201- (the draft Law) (P.57/2018).[1]

2. The draft Law introduces a new organ donation system known as deemed or presumed consent. This is also referred to as an opt-out as opposed to an opt-in system.

3. On 12th February 2018, we launched a review into the Minister's plans in anticipation of the draft Law being lodged. The aim of our review was to understand how the new opt-out system would work in practice and ensure appropriate safeguards were in place to protect vulnerable people.

4. We were keen to ensure that the public's views and opinions on an opt-out organ donation system were considered and addressed by the Minister. We received 5 questions via Twitter, some of which were put directly to the Minister. We received 12 written submissions and held 3 public hearings with a range of stakeholders. All written and oral evidence can be found on our website.[2] We are grateful to all those who contributed to our review.

5. Chapter 1 of the report explains what is meant by organ donation and explores the difference between an opt-in and an opt-out system. It looks at the experience of other jurisdictions and examines the rationale for moving from one system to the other. Chapters 2, 3 and 4 explore the implications of the new system for the organ donor register, clinical practice and vulnerable parties respectively. It looks in detail at the relationship between clinical staff and families or next of kin during organ donation. Finally, Chapter 5 examines the transitionary arrangements that the Minister has said he will put in place.

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[1] States of Jersey, Draft Human Transplantation and Anatomy (Jersey) Law 201-, P.57/2018

[2] www.scrutiny.gov.je

Chapter 1: Organ donation

Opt-in organ donation

6. Organ donation involves giving an organ to someone who needs a transplant. Transplants can save or enhance the lives of other people.[3] We heard this directly from Mr Neil MacLachlan, Consultant Obstetrician/Gynaecologist and Founder of the Jersey Love Hearts Appeal. He told us how his daughter's life had been saved after receiving a heart transplant and that since then she had had "12 years of fantastic life".[4]

7. Donation can be made by living donors (this was outside the scope of this review) or after a person's death.

8. Jersey is part of the UK National Health Service's Blood and Transplant Service (NHS-BT) for the purposes of organ donation. NHS-BT supports patients, donors and their families throughout the donation and transplantation process.

9. Jersey, like England, currently operates an informed consent or opt-in organ donation system. In order for organs to be donated there needs to be explicit consent in place. This can be done by the individual whilst they are alive by signing the NHS Organ Donor Register (ODR or the Register) or telling a relative or close friend about their decision. If they have not signed on to the ODR then their family can consent after they die.

10. A recent poll undertaken in Jersey showed that 75 per cent of people would want an organ transplant if they needed one. It also showed that 55 per cent of people would want their organs to be used to treat others when they die.[5]

11. Despite these high numbers, only 14 per cent of adults were on the Register (compared to 38 per cent in the UK). Of those not on the Register, 40 per cent said they had not got round to it and 21 per cent were not sure how to sign the Register.

KEY FINDING 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%).

KEY FINDING 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.

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[3] NHS Blood and Transplant, What is organ donation? (accessed March 2018)
[4] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.22
[5] States of Jersey, Statistics Unit, Jersey Opinions and Lifestyle Survey Report 2017

Opt-out organ donation

12. The draft Law lodged by the Minister proposes moving from an opt-in system with informed consent to an opt-out system where consent is presumed or deemed. Under the plans, most people in Jersey would be presumed to be willing to donate their organs on their death, unless they have signed up to a register stating that they do not want that to happen.

13. Reaction to the opt-out approach varied. The Very Reverend Mike Keirle, Dean of Jersey said that “I absolutely support the opt-out process for organ donation except in the case of minors, where a parental/guardian decision would need to be made with a set age for this to happen”.[6] Monsignor Nicholas France, the Catholic Dean of Jersey said “While I fully appreciate the value of organ donation, I believe it should be our free choice and not something imposed”.[7] Guy de Faye wrote to us and expressed his opposition to the Minister’s proposals including, for example, “allowing a government authority to assume "ownership" of bodies” in the "life support phase" of existence”.[8]

14. Mr MacLachlan said:

> *“[…] I was trying to think why Jersey should do it, to make this jump, and I think because we are so low on the registration rate that the potential to do good would be greater than if you were in England where you already have 36 per cent registered. So because we have such a difficult primary healthcare system and driving licences and everything else, I think the gain could be greater because 13 per cent, and if we are going to continue to use organs from Britain then I think it beholds us really to do a little bit more. I mean it just does not look very good and I think there has to be a big, big drive on education and do not make this look threatening, you know: “We want you to understand why this law is coming in.” So hopefully that will happen and I think if we could get in front of England that is a little feather in Jersey’s cap.”*[9]

15. When asked about why he was introducing a new opt-out organ donation system, the Minister said it was to make more organs available for transplant and to encourage families to talk about organ donation before the situation arises. He told us:

> *“I think primarily to ensure that as many organs as possible are available for transplant. It does not mean every organ will be taken or used but, as you know, we have a very low uptake of people opting in at the present time and that is primarily, if my information is correct, because people have not got round to it, not because they have got a problem with it.*
>
> *[…] if I had a second objective it is to get people to talk about it when it is less traumatic, so when they are not faced with the loved one at end of life where they are, for the first time, maybe thinking about organ donation; it had never been discussed. I want those conversations to take place years, hopefully, in advance so that people know what their family wants as well as the fact that they can choose. If they do not want to they can choose to*

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[6] Very Reverend Mike Keirle
[7] Monsignor Nicholas France
[8] Guy de Faye
[9] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.22

> *opt-out, so I want to bring those conversations forward much earlier so people can really discuss it. […].”*[10]

16. Several other jurisdictions already have explicit opt-out laws. These include, for example, Austria, Belgium, the Czech Republic, Finland, France, Greece, Hungary, Israel, Italy, Luxembourg, Norway, Poland, Slovenia, Spain, Sweden and Turkey.

17. The Welsh Government has recently implemented an opt-out system. Patricia Vernon MBE, Head of Healthcare Quality Legislation, Welsh Government told us about the Welsh system:

> *“[…] the legislation in Wales introduced the concept of “deemed consent”. This means that people over the age of 18 are regarded as having no objection to organ donation after death, unless they have expressly stated otherwise. There are some important safeguards in the new law to exclude children, people who lack capacity and those who have not lived in Wales for 12 months or more, from having their consent deemed. In those cases, family members in a qualifying relationship may make the decision on their behalf.”*[11]

18. In January 2017, the Minister said in relation to the Welsh initiative that he was adopting a “watch and learn approach”.[12] When asked what has happened in Wales that triggered the Minister to bring forwards legislation in Jersey, the Minister replied:

> *“Basically that they judged their system to be successful, that while they have not had massive amounts of transplants taking place as a result of it there has been an improvement. The evidence is that these conversations have taken place, and I met with the Minister for Health for Wales, whose name escapes me at the moment, and discussed directly with her face to face the benefits that they have seen over the last year. So I took that watching brief. I waited that year until they came back with their report, and then we went out and did our own survey to see if the community were minded the same way as I was. I would argue that that has come back very clearly that they are.”*[13]

19. Commenting on the Welsh experience Mr MacLachlan added:

> *“So the Welsh system has been in, I think it will be 3 years this year, and what has been interesting is initially there was no significant increase in donation rates, there were more people dying who were prepared to give their organs, but there was not much of a change to begin with. Recently I think they are beginning to start to see an increase in the number of organs that are being used, so they are now using more organs.*
>
> *[…] what Wales have done is they have just said: “Well, Spain did it, all these other countries with good rates do it, so let us try to copy that.” That is what they have done.*
>
> *In Spain it took about 10 years before they started to see really significant rises, so it would be wrong to criticise the Welsh for massive success*

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[10] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.2
[11] Patricia Vernon MBE
[12] States of Jersey, Draft Human Transplantation and Anatomy (Jersey) Law 201-, P.57/2018, p.19
[13] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.8

> *because you would not expect that. This is going to take a while to bed in. […]*
>
> *So I think it is too early; I think there is a lot of interest. It is beginning to climb now and I would imagine, over the next 10 years, you will see. Wales now is up to around about 24 per million of population, it is much higher than the U.K. generally, so already it has shown some improvement.”*[14]

20. In addition to Wales, the Scottish Government has indicated that it will implement an opt-out system and the UK Government is currently consulting on a similar system. There is also a Private Members Bill on this matter which has government support and has reached Committee stage.[15] Guernsey is also considering implementing an opt-out system.

21. A Commons Library Briefing Paper, published in February 2018, provided an overview of a number of reviews of the evidence on moving to an opt-out system of consent for organ donation. All the reviews reached similar conclusions:

- There was an association between higher donation rates and an opt-out system (as demonstrated in figure 1);
- It was not possible to say that an opt-out system alone would lead to an increase in rates;
- Several other factors are likely to play a part in affecting organ donation rates, such as organisation and infrastructure of the organ donation service, public awareness and investment in health care; and
- Opt-out systems are unlikely to reduce organ donation.[16]

22. Mr MacLachlan emphasised the point that the change to an opt-out approach should be accompanied with other measures:

> “[…] the general feeling is that it is not just the opt-out system, it is what goes with it, it is all the I.T.U. beds, it is the specialist nurses, it is the society thinking: “Do you know what, I am not going to throw my organs in a dustbin, I am going to give them to someone, let us do something *good.”*[17]

KEY FINDING 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.

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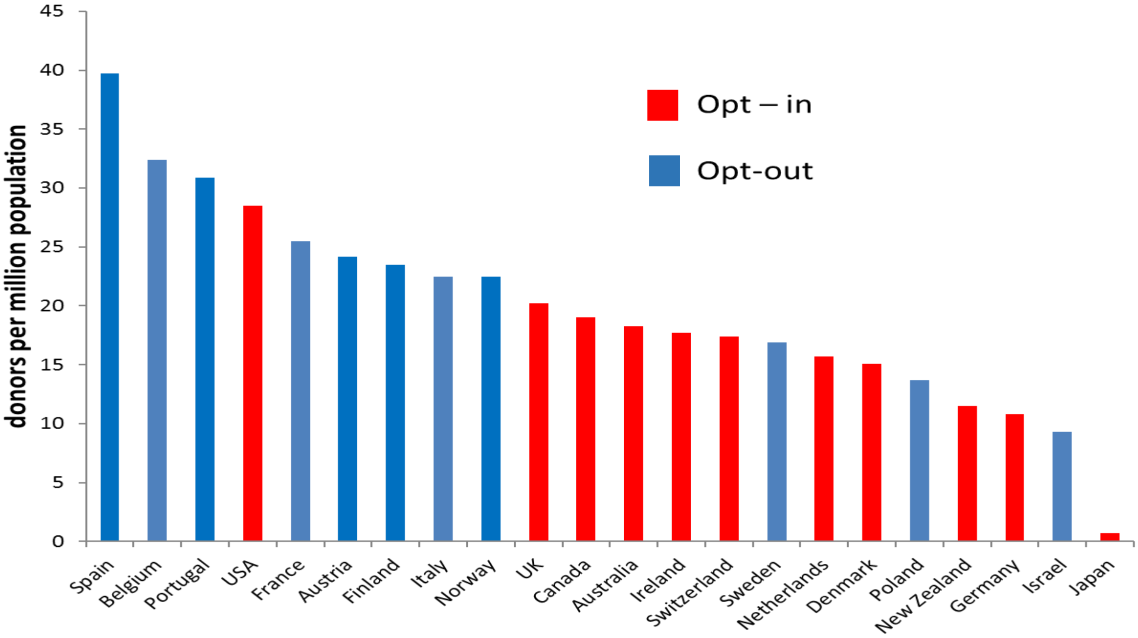
[14] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.14

[15] House of Commons, Organ Donation (Deemed Consent) Bill 2017-19 (accessed March 2018)

[16] House of Commons Library Briefing Paper, The Organ Donation (Deemed Consent) Bill 2017-19, 21 February 2018

[17] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.13

Figure 1: International Donation Rates: relationship with legal framework for consent



Source: NHS Blood and Transplant

Chapter 2: Organ donor register

The NHS Register

23. The NHS Organ Donor Register (the Register) is a confidential list of people who want to record their decision to donate their organs and/or tissue. The Register along with the National Transplant Register is managed by the NHS Blood and Transplant (NHS-BT) service in the UK. By using the two registers NHS-BT is able to match donors to people who are waiting for a transplant.

24. As Jersey is part of NHS-BT for the purposes of organ donation, people in Jersey are able to register an organ donation decision on the Register.[18]

25. Ms Vernon highlighted to us that it was not a legal requirement to sign the register. It is just the easiest and most visible way of recording a decision:

> *"[…] it is not a legal requirement to record an organ donation decision on the Organ Donor Register, since it is possible to make a decision verbally, or in writing, however the Organ Donor Register is the easiest and most visible way of recording a decision. At the time of death, the Organ Donor Register will be checked in the first instance to see if there is a recorded decision. If there is not, then the person's family will be asked if they know of a decision which was given verbally during the person's lifetime."*[19]

26. When someone signs up to the Register a number of personal details are taken and recorded including, for example, a person's name, date of birth, sex, ethnicity, religion, contact details and donation decision.[20][21]

27. Claire Williment, Head of Opt Out Development at NHS-BT told us about the accountability and governance arrangements of the register:

> *"The Chief Executive of NHS Blood and Transplant has overall responsibility for the Organ Donation Register. The Head of the Organ Donor Register also has Information Governance responsibility and is the Information Asset Owner for the Register within NHS Blood and Transplant. The Organ Donor Register complies with the requirements set out in the Human Tissue Act, the Data Protection Act and from May 2018, the General Data Protection Regulations.*
>
> *NHS Blood and Transplant also has established reporting systems from the ODR to internal Clinical Governance, Quality and Information Governance standards. An internal performance report is made available to the Executive Team within NHS Blood and Transplant. The Register is subject to internal audits, which are currently overseen by Price Waterhouse Cooper (PWC)."*[22]

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[18] Patricia Vernon MBE
[19] Patricia Vernon MBE
[20] Claire Williment
[21] It should be noted that the data regarding ethnicity and religion are not made available to the operational teams at the point of determining the recorded decision of a potential organ donor.
[22] Claire Williment

28. Ms Williment told us that the Register is stored within the EU on the Microsoft Azure Cloud (Republic of Ireland and Netherlands). A copy of the Register is also stored on an NHS-BT server. Technical maintenance of the Register is provided by a Third Party Supplier and operational maintenance (such as identifying and addressing potential conflicts in data) is carried out by a team within the Organ Donation and Transplantation Directorate in NHS-BT.

29. Only a limited number of people have access to the Register. These include:

- **Specialist Nurses for Organ Donation and Tissue Donation Nurses** employed by NHS Blood and Transplant access the Register to determine if the potential donor had recorded a decision.
- **Administrative teams within NHS Blood and Transplant**. This includes the teams responsible for ensuring the Organ Donor Register data is accurate. It also includes the ODT Hub Operations team, who are responsible for liaising with the Specialist Nurses for Organ Donation.
- **Staff working within the Organ Donor Line team**, who respond to calls from the general public wanting to record a decision on the Organ Donor Register. This is provided by a third party contact centre – TelePerformance.

30. If a person changes their mind about organ donation or wants to update their personal details in some way they can do so via the NHS organ donation website, by calling the 24/7 Organ Donation Line or in writing. Data on the register can be amended by members of the ODR and Organ Donor Line teams, in line with requests from the individuals concerned or, where appropriate, a nominated representative. Individuals also have the right to access their own data and to be forgotten.[23]

Registering in Jersey

31. In addition to signing up to the NHS Organ Donor Register, since 2015 it was intended that Jersey residents should be able to sign up to the Register (and to choose which organs they would be prepared to donate) when applying for a Jersey driving licence. The driving licence application form was amended to include a section inviting applications to record their decision. At this time, there was no data sharing agreement between NHS-BT and Jersey DVLA or the Comité des Connétables.

32. Each parochial authority (the Connétable) is responsible for issuing driving licences to their Parish residents. The parishes maintain a single database which holds information about all driving licences issued to Jersey residents. The Chairman of the Comité des Connétables, Connétable Len Norman told us that, “NHS-BT proposed a method for data transfer but the required testing, and budgetary constraints imposed on NHS-BT, has delayed its introduction”.[24]

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[23] Claire Williment
[24] Comité des Connétables 1

33. There are currently 14,720 people who have indicated their desire to register as a donor through a driving licence application but whose decision has not been transferred on to the Register maintained by NHS-BT. 12,900 of these are active driving licences. Connétables Norman explained the figures in his letter:

> *"The number of active licences where the driver has consented to organ donation is currently 12,900 but this may well include persons who have registered separately with NHS-BT – until the data transfer it is impossible to ascertain the degree of duplication. The total number of drivers who have consented to organ donation (this includes licences which are not active) is 14,720 – there can be a number of reasons why a licence will no longer be active including if a person has moved away from Jersey and exchanged their licence in another country; the licence has expired and has not been renewed or the person is deceased."*[25]

34. As of 16 February 2018 there were 12,418 people in Jersey (12%) known to be on the NHS Register. In a scenario where there are no duplications between these registrations and the people who have consented through their driving licence applications, the number of Jersey residents who have consented to organ donation could be closer to between 25,318 and 27,138 people (24% and 26%).

35. Connétable Norman told us that the Comité des Connétables had not informed these people that their decision had not been recorded on the Register.[26]

36. The Minister confirmed that he was aware of the situation and expressed his "disappointment".[27] Connétable Norman also said that the "situation is far from satisfactory".[28]

37. We heard from a family member of a potential organ donor who had experienced distress as a result of this situation. Person A (who has been anonymised to protect his identity) told us:

> *"What we were prepared for was he was quite willing for his organs to be donated. He had made this note previously and one of the things that came to light when he filled in his driving licence he had put in where there is an area there to ask you. This had been sent in but it appears that where it is administered from the Town Hall that it had not been sent to the central register. That, as I found, very strange."*[29]

38. Mr MacLachlan, Founder of the Jersey Love Hearts Appeal, who was involved in promoting the use of driving licence applications to increase organ donor registrations said:

> *"[…] we tried very hard to get the driving licences sorted and sadly, not through Jersey's fault, but through a transfer of data problem, that has not been successful. It is too clunky. It is too costly for the number of donors*

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[25] Comité des Connétables 2
[26] Comité des Connétables 2
[27] Minister for Health and Social Services
[28] Comité des Connétables 2
[29] Public hearing with next of kin, 1 March 2018, p.2

> *probably. I do not think it is something that ... they have so many issues in the N.H.S. (National Health Service) transplant area that spending a lot of money transferring data from our driving licences to suck in that data is, I think, quite difficult. I do not know the logistics. We thought it had been done. But I do not think it has […].”*[30]

39. Connétable Norman said that the Comité hoped to transfer the data it had collected so far in the next few months.[31]

40. In light of the problems it had experienced, NHS-BT's proposals for future registration and the Minister's proposals to change the law, the Comité told us that it was considering removing this option from Jersey driving licence applications:

> *“In late 2017 NHS-BT proposed that, as the main route for new organ donor registrations, the Jersey process should link to the NHS-BT website rather than continue to process data. This has the benefit that issues such as General Data Protection Regulation (GDPR), organ preference updates and other governance issues are controlled via a single NHS-BT-led route.*
>
> *In light of this proposed change, together with the Minister for Health and Social Services proposal of an opt-out system, it is likely that the opt-in option will be removed from Jersey driving licence applications in the future. The online driving licence application process could provide the applicant with a link to the NHS-BT main register. Paper applications might include NHS-BT leaflets encouraging applications to sign up to the register online.”*[32]

41. Responding to this issue, Ms Williment:

> *“Jersey residents have always been able to register to donate their organs on the NHS Organ Donor Register directly with NHS Blood and Transplant and we encourage them to continue to do so. We do not have an arrangement with the authorities in Jersey to handle data collected and collated by them, but we do appreciate their support for the cause of organ donation. We are working constructively with the Jersey authorities to ensure that any information they have collected is uploaded to the Organ Donor Register under appropriate data sharing arrangements. Anyone wishing to register for organ donation can do so via www.organdonation.nhs.uk or the Organ Donor Line on 0300 123 23 23.”*[33]

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[30] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.5

[31] Comité des Connétables 2; States of Jersey, Official Report, Monday 19 March 2018

[32] Comité des Connétables 1

[33] Email correspondence

KEY FINDING 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.

RECOMMENDATION 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.

Adapting to an opt-out system

42. Ms Vernon told us that decisions about how the NHS Organ Donor Register should be modified to take account of an opt-out system were made when Wales moved to this new system:

> *"[…] there is only one single register. It was decided early in the project that having more than one "list" of organ donation decisions would be too risky, and that all recorded decisions should be available on the same register. In practical terms this means that there is only one register to check in the event of organ donation being a possibility."*[34]

43. The Minister agreed that having more than one register was risky:

> *"The last thing you want is a Jersey register and a U.K. register or Welsh register and a Scottish register because that is not efficient and it is highly risky, might I say, because you might miss things."*[35]

44. Ms Vernon, explained how the Register was modified to take account of the change to the Welsh organ donation system:

> *"As part of the implementation of the new legislation in Wales, the UK Organ Donor Register was redeveloped to enable it to record all decisions in relation to organ donation. This means that decisions to be a donor (opt-in) or decisions not to be a donor (opt-out) are held in one single place.*
>
> *The new Organ Donor Register can also accommodate the details of up to two appointed representatives. This facility was provided because some people might want to involve another person in the decision, for example a religious leader.*
>
> *The Organ Donor Register will only hold one active registration at a time and the latest recorded decision on the Organ Donor Register is the one which is acted upon. Should other parts of the UK decide to move to a*

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[34] Patricia Vernon MBE

[35] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.9 & 10

> *system of deemed consent, the new Organ Donor Register has been developed with sufficient capacity to allow for such a change.*
>
> *[…] One common misconception is that moving to a deemed consent system means that everyone is automatically added to the Organ Donor Register, but this is not the case. Consent is only deemed in the absence of an express decision, either recorded on the Organ Donor Register by the individual, or expressed verbally during life and conveyed via the family after death."*[36]

Opting out in Jersey

45. Mark Richardson, Assistant Director of Policy, Communications and Ministerial Support at the Health Department, said that the Department would have to look into how someone in Jersey would notify their organ donation preference under an opt-out system. However, he indicated that they would do this through the NHS Organ Donor Register:

> *"I think that is something that we need to look into going forward, but I mean my understanding is at the moment, for example, you can phone or do it online. I am on the register and I rang them up to check I was. You can also do it online, I understand. The difference will be that obviously under the new arrangement, if it is accepted, that people will also be able to opt-out and make sure that is put across and recorded on the register as well."*[37]

46. The draft Law currently includes a provision so that consent of an adult is deemed to be given for organ donation unless the adult has decided not to consent before their death.[38] The draft Law allows the Minister to make regulations in the future for the registration of express consent, or express refusal to consent to organ donation.[39] However, there is no provision in the draft Law which requires the Minister to have to make this available.

47. Frank Le Gros, Legal Adviser at the Law Officers Department explained how the Law was currently drafted:

> *"I think the law, as it is drafted, is quite clear on the effect of the opt-out. Article 4 talks about consent in the case of adults. Article 4(2) says: "Consent is deemed" unless one of a series of things happens, and the first one is that: "A decision of the adult not to consent to the specified activity was in force immediately before his death." Then Article 19(2)(d) says that: "The States may bring forward regulations making provision for the registration of express refusal to consent."*
>
> *[…] There is no mechanism in the law itself. The law allows the States to bring regulations to provide systems for recording opt-in and opt-out. The effect of someone opting out is reflected in the law in Article 4(2). The regulations will elaborate, flesh out, the mechanisms for registering that opt-out, but the right place for the opt-out elements to be reflected in law is*

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[36] Patricia Vernon MBE

[37] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.10

[38] States of Jersey, Draft Human Transplantation and Anatomy (Jersey) Law 201-, P.57/2018, p.39 & 40

[39] States of Jersey, Draft Human Transplantation and Anatomy (Jersey) Law 201-, P.57/2018, p.50

> *in the impact of an opt-out on the consents system. That is in Article 4(2)(a).”*[40]

48. Mr Le Gros continued:

> *“[…] As the law stands, it perfectly supports bringing in and putting in place a very detailed system for organ donation for opting in and opting out and registering those decisions and elaborating in finite detail about how those systems will work. If you do not put that in regulations you have to put it in the law. If you have split of provisions in the law and in the regulations about how the system mechanisms and systems work then there is a case to say that the law is not accessible and clear to people who use it because they have to look at 2 different sources. So there is an argument for putting it in regulations but I think that is as much as I can say from a legal perspective. The rest is ultimately a policy decision.”*[41]

49. When asked why there was no obligation for the Minister to bring forwards a mechanism for opt-out in the primary legislation, the Minister said:

> *“I think you are making the assumption that if the States pass this, this will become law as soon as it has been to Privy Council, and that is not the case. There is a fairly significant sum of money there available to run a proper campaign, while accepting what Frank says about having to bring the regulations forward. But there will be a proper campaign. So I cannot see the Appointed Day Act […] coming forward for 9 months to a year because that education, that campaign, those systems need to be in place.”*[42]

50. Mr Le Gros added:

> *“[…] my understanding is that the reason why there is going to be a space of a year between passing the law and bringing the law into force, is to enable these mechanisms to be developed. The importance in developing these mechanisms is consulting with people who use them, so clinicians and members of the public who will be organ donors and making sure the systems are in place. That is why it is not appropriate to spell out in the law how those mechanisms could work. But if, for example, you wanted to change that mechanism, you would have to change the law. The law would have to go to Privy Council, it would have to come back and be subject to States debate.”*[43]

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[40] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.10 & 14
[41] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.14 & 15
[42] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.11
[43] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.14

KEY FINDING 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.

KEY FINDING 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.

KEY FINDING 7: In light of the draft Law, it is important that families discuss their choice with regard to organ donation.

RECOMMENDATION 2: The Minister should bring forward regulations to the States to provide a means for people to opt-out of organ donation.

Chapter 3: Clinical practice

The process of organ donation

51. Ms Williment from the NHS-BT service summarised the clinical process in relation to organ donation:

> *"Clinicians in Intensive Care are responsible for referring potential donors to NHS Blood and Transplant. Once a referral is made, a Specialist Nurse for Organ Donation (SNOD) is mobilised to the hospital to determine the donation potential. If donation is a possibility, the SNOD will determine if any decision is recorded on the Organ Donor Register and approach the family to discuss donation. Once consent is given, the ODT Hub Operations team offers the organs for transplantation, in line with nationally agreed offering protocols […].*
>
> *Once organs have been accepted, the ODT Hub Operations team mobilise a Cardiothoracic and/or Abdominal National Organ Retrieval Service (NORS) team to retrieve the organs. The NORS team also undertakes a range of checks during the retrieval process to assess the quality of the organs for transplantation. They will alert the relevant transplant unit if there are any concerns to agree whether the retrieval should proceed. In some cases, a Unit that had originally accepted the organ may then decline it. In these circumstances, the organ is re-offered through the ODT Hub Operations Team on a fast-track basis.*
>
> *Once the organs have been agreed as suitable for transplantation, the ODT Hub Operations team organises the transportation of the organs to the relevant Transplant Units. The NORS team packs the organs ready for transportation and the ODT Hub Operations team alerts the Unit when they have been despatched."*[44]

52. Sam North, Acting Clinical Manager for the Intensive Care Unit and High Dependency Care at Jersey's General Hospital said to us that there was a Transplant Committee in the Hospital that was made up of a range of clinicians from Jersey and NHS-BT. The aim of the Committee is to examine practices relating to organ donation in Jersey.[45]

53. Ms North explained that there were two types of organ donation: those following circulatory death (referred to as donation after circulatory death or DCD) and those following brain stem death (referred to as donation after brain stem death of DBD). Ms North said that, "the general treatment of a patient, regardless of which route of organ donation they go down, is no different."[46]

54. Ms North explained the clinical process for organ donation following circulatory death:

> *"[…] the patient, if they go down what we call "the non-heart-beating route", which is D.C.D. (donation after circulatory death) donation, what happens in these patients, these are the patients who may have had a massive stroke, who are going to make a very poor prognosis and the*

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[44] Claire Williment
[45] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.43 & 44
[46] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.24

> *decision with the family then is, that treatment is withdrawn on the grounds of futility.*
>
> *They will often go to the anaesthetic room and the patient will be with their family and they will have their breathing tube removed and the family will be allowed to stay with that patient for a certain amount of time, often up to 2 hours, and if the patient passes away within that 2-hour timeframe they will then be taken to the operating theatre where the surgeons are there ready to retrieve the organs. That sounds like a very sort of whistle stop tour but it is all in conjunction with the family.*
>
> *The family are aware of the situation; that they have to die within a certain timeframe because obviously what happens is, once that breathing tube is removed the patient may have a slow decline and that would, ultimately, mean that the organs have been deprived of oxygen for a longer amount of time. […]*
>
> *[…] once the breathing tube is removed, the patient would be declared dead by a doctor; they would have their heart listened to in the same way as if they were to die anywhere else within the hospital, or the home. They would be ... what we call asystolic. They would be declared dead and then they would be taken through to the operating theatre.*
>
> *[…] If they do not die, they come up to the Intensive Care Unit and we look after them as we would any other end of life patient but organ donation cannot happen because the organs have been without oxygen for so long.*
>
> *[…] The family are all completely aware of this. They are told that there is a certain timeframe and a lot of families will often still push for donation because at that point they really want some kind of good to come out of their situation.”*[47]

55. Ms North then explained the clinical process for organ donation following brain stem death:

> *“The other kind of organ donation is a bit more complex, which is the brainstem dead donors. So these are people who suffered a catastrophic brain injury in which there is no brain activity left.*
>
> *In order to declare that, 2 doctors have to do what is called brainstem testing, which is they test the cranial nerves, 2 separate doctors at 2 separate times, and the time of death is then documented on their death certificate at the time of the first set of tests. So for a relative to come in to see their loved one’s heart beating, their chest going up and down, but being told that they are dead is a very difficult concept ... but these patients are legally dead by the term of brainstem death, okay? So they are legally dead. So they would remain with us in the Intensive Care Unit and they would be supported because the family have given consent for organ donation.*
>
> *When the time to go down to the operating theatre comes they would go down to the operating theatre, straight into the operating theatre because they are legally classed as ... they have already passed away based on*

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[47] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.24

> *the time of death when they had those special tests. There was no brain activity left.*
>
> *[…] they are legally dead. They feel no pain. There was no consciousness in their brain anymore. They are dead. Then the operation does take place there and then […] an anaesthetist would still be with the patient and at the time when they cross-clamp the aorta, which is one of the big vessels from the heart, the anaesthetist would then step back and the team would carry on. But for a lay person, and even for healthcare professionals, to understand brainstem death is a very difficult concept but what it does is a series of tests, which test all neurological criteria.*
>
> *Once they are deemed as "no longer alive" their time of death is put on their death certificate but to someone to walk into an intensive care unit you would presume that they were still alive because you can see their heart tracing and their chest moving up and down but there is nothing neurologically."*[48]

56. Ms North finally explained what happens if the organs are not successfully transplanted:

> *"So when a relative is asked about organ donation they consent to research. If they want to consent to research they can. The overarching principle of organ donations is organs are only ever taken for the purposes of donation but, for the reason I spoke about before, you may have an organ that is not viable by the time it gets to the recipient or the recipient is too unwell to receive that organ the organ would be then ... obviously it cannot be put back in so it would be disposed of as per the hospital policy from where it lands, unless the family have consented to research, and it would be entered into a research pool.*
>
> *The family would typically have consented to the research and are told all this during the process that in the event that they cannot be donated this is what the options are and many families will go for research as opposed to disposal. The families are then told on the day or even by the time it gets to the other side that the organ unfortunately was not able to be transplanted."*[49]

57. Ms North said that the current clinical practice in Jersey would not change as a result of the Ministers proposals to introduce an opt-out organ donation system:

> *"Though from my point of view ... the notification systems would be the same. The patients are going still to be notified ... the doctors will still be notifying the teams in the U.K. in the same way as we do now. We do not check the register here. So if a patient comes up in the Intensive Care Unit and they are, unfortunately, at the end of their life we then make those telephone calls to the UK-based specialist nurses who then check the register.*
>
> *So from a Jersey point of view, I do not think our system could be anything different. The care that the patient will still receive will be the same and if the UK nurses deemed that that patient could be a potential donor they*

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[48] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.25 & 26
[49] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.36

> *would make the necessary arrangements to come over and talk to the family.'*[50]

KEY FINDING 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.

Engaging with next of kin

58. Arguably the biggest change that will result from moving from an opt-in to an opt-out system will focus around the relationship between clinical staff and the families or next of kin of potential organ donors – especially how families are approached to discuss the potential for organ donation.

59. It is worth noting that consent in some form will still be required. This was emphasised by Mr MacLachlan and by Mr Le Gros who pointed out that:

> *"[…] it is a criminal offence under the law to deal with a deceased body with transplant activity in the absence of consent. So if that adds reassurance to those who are concerned about how their bodies might be dealt with and ensuring that those involved with the system comply with those requirements then the law is supported with specific criminal offences."*[51]

60. The NHS-BT Organ Donation and Transplant Activity Report 2016/17 stated that the number of deceased organ donors had increased because of improved collaboration between donors and their families, a host of clinicians working in different parts of the NHS and finally the transplant recipient and their family.[52]

61. The NHS-BT Activity Report stated that, "despite this encouraging progress, opportunities for donation continue to be missed". The report highlighted "family refusal" as the biggest obstacle:

> "Transplantation depends on clinicians recognising the potential for organ donation and still this does not always happen, particularly when donation after circulatory death is a possibility. However, it is family refusal that represents our biggest obstacle and as such our most important opportunity to further increase the number of transplants.*"*[53]

62. This is demonstrated in figure 2 which shows that opportunities for organ donation are lost around the family approach and consent stages. Figure 2 was explained in detail by Mr. Neil MacLachlan:

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[50] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.16

[51] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.15; Public hearing with the Minister for Health and Social Services, 13 March 2018, p.31

[52] NHS Blood and Transplant, Organ Donation and Transplantation Activity Report 2016/17, p.5

[53] NHS Blood and Transplant, Organ Donation and Transplantation Activity Report 2016/17, p.5

> *“The blue line is for donors after brain death. So if you follow it along where it says 28 per cent, so we can see that 28 per cent of possible donors are not brain stem tested. Too busy, intensive care, slipped my mind, so you lose 28 per cent of potential donors just by not doing brain stem testing.*
>
> *If you then go along, you lose another 4 per cent because of contraindications, H.I.V. (human immunodeficiency virus), something that they just cannot do it.*
>
> *Then 7 per cent of those are lost because there is no approach to the family, so that is where you need your specialist nurses.*
>
> *But then the big bit is 35 per cent are then lost because of failure of consent. So that is not 35 per cent of the original chunk but 35 per cent at that stage of the remaining donors. […].”*[54]

63. The NHS-BT Activity Report said that there were two main ways that family refusal could be addressed:

> *“Family refusal very often reflects the understandable difficulties that families face when losing a loved one, and there are two ways in which they can be addressed. First of all, family refusal is less likely when the possibility of donation is raised by trained requestors - specialist nurses for organ donation. However there are still occasions when this does not happen and when donation is raised by clinical staff who have had little training in this most delicate of tasks.*
>
> *Secondly, we know that families are much more likely to support donation when the individual’s decision is known beforehand. Discussing our end of life decision with those closest to us will ease the burden they face and make it more likely that our wishes are respected. […].”*[55]

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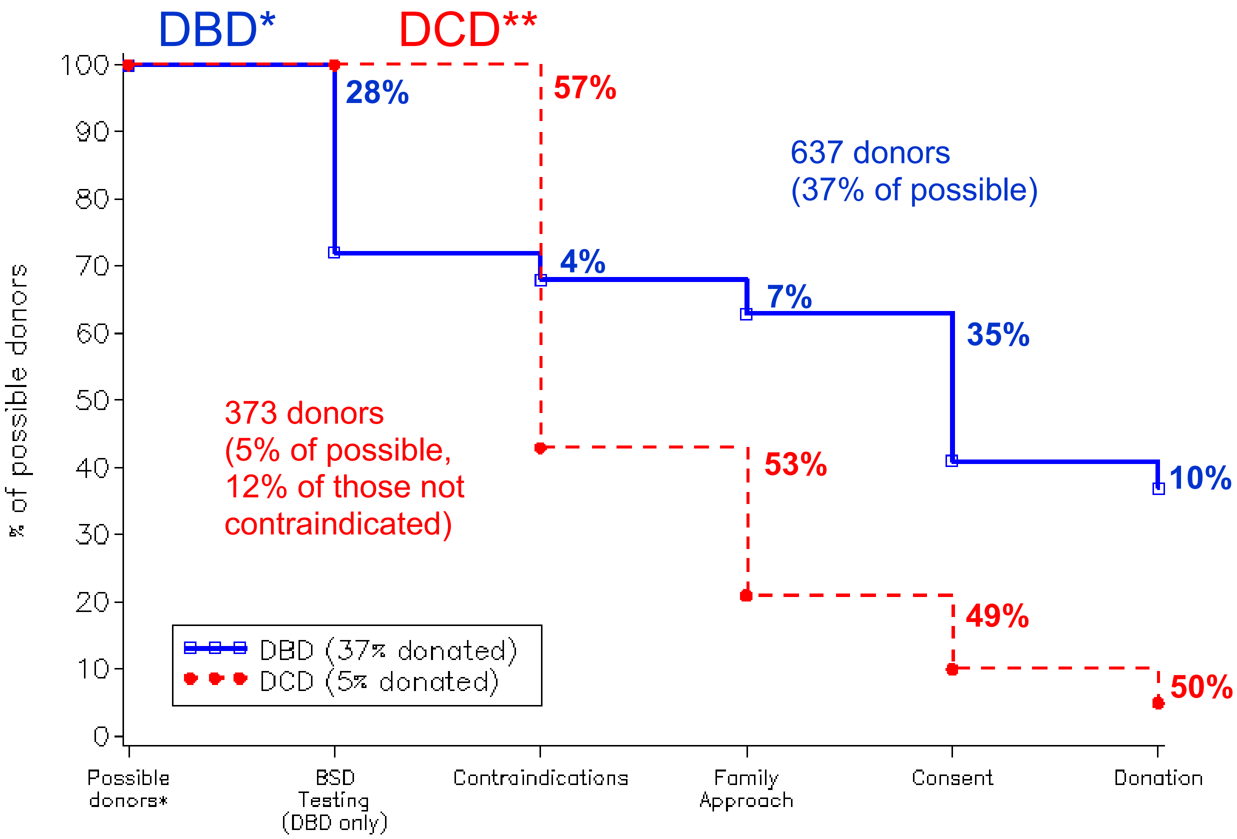
[54] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.9

[55] NHS Blood and Transplant, Organ Donation and Transplantation Activity Report 2016/17, p.5

Figure 2: Where are opportunities lost pre-donation (2010/2011)?



* DBD – possible donors meeting criteria for neurological testing

** DCD – possible donors not confirmed dead by neurological criteria where imminent death anticipated and treatment withdrawn

Source: Mr MacLachlan

The role of specialist nurses

64. The NHS-BT website sets out the role of Specialist Nurses for Organ Donation (SNODs):

> *"[They] support potential donor families and the operational processes of organ donation. The specialist nurse receives detailed training in communication and family support, especially in the end of life wishes conversations. This training enables the specialist nurse to explore the individual's decision or the families wishes, providing specific donation information tailored to the individual case. Involving the specialist nurse from the initial end of life care discussions enables a relationship between the family and specialist nurse to develop and for the specialist nurse to better support the family through the end of life care process."*[56]

65. Ms North emphasised that SNODs "are introduced to the family as end of life specialists because that is what their ultimate role is. Regardless of whether organ donation goes ahead they are there to support the family through that end of life

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[56] NHS Blood and Transplant, Role of Specialist Nurse (accessed March 2018)

process." She said that "those nurses will stay until the bitter end to support that family through a difficult time."[57] This includes, for example, ensuring that after surgery the body is treated with dignity and respect.[58]

66. Ms North said that SNODs are "specially trained in that area to have those sensitive conversations with the family at that distressing time":

> *"[…] you go on an intensive training course, which is about 3 to 4 weeks and that is all about the discussion surrounding how to have those sensitive conversations and that, as far as I am aware, is still the same now. The specialist nurses go through a period of supervised practice before they are left on their own to discuss things with the family."*[59]

67. Ms North explained that SNODs tend to be successful in the role because of their communication skills:

> *"I think, broadly speaking, the reason that those specialist nurses got those jobs is based on their communications skills and I would say that, from my experience, that I have never really experienced any bad or insensitive conversations."*[60]

68. Ms North highlighted that consent rates were much higher when a SNOD was involved in the family approach than a doctor:

> *"It is 29 per cent for a doctor ... if the doctor was to approach a family about organ donation. It goes up to 76 per cent if a specialist nurse is involved (DBD death) [12% and 64% respectively for DCD] and that is often because they have the skills and the information for that family at that time and often the questions from the family are things like the timeframes involved, what could they donate, will this affect the funeral arrangements, which is where the specialist nurse steps in."*[61]

69. Despite the success of SNODs at increasing consent rates among families for organ donation, we heard from a family member of an organ donor based in Jersey, known as Person A, who described being "confronted" with an NHS nurse in Jersey's General Hospital as "disturbing".[62] He also described the questioning associated with organ donation as "intense". To try and avoid this situation, Person A suggested that there should be a liaison officer to engage the family before the process starts and then to help the family through the process.[63]

70. Ms North agreed that the questions were "private and invasive" but were "handled in a sensitive manner". The questions ranged from: a person's sexual history and whether they have had any sexual intercourse with someone of the same sex; whether they have travelled to any countries where HIV (Human Immunodeficiency Virus) and AIDS (acquired immunodeficiency syndrome) are prevalent; and whether they had used intravenous drugs. Ms North said that these questions had to be asked to assess the

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[57] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.16 & 17
[58] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.22 & 23
[59] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.20
[60] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.20
[61] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.19
[62] Public hearing with next of kin, 1 March 2018, p.2
[63] Public hearing with next of kin, 1 March 2018, p.3

likelihood that the patient is carrying any blood borne diseases. Ms North emphasised that these questions are asked to everyone regardless of their age.[64] These are also the same questions asked when someone gives blood.[65]

71. When we put the suggestion of having a liaison officer in Jersey to support families of organ donors to the Minister, he responded by saying that he would prefer to have a SNOD:

> *"I would prefer to have somebody who does this all the time that is current and up to date coming in with the right support locally than somebody who rarely does it, who may not even be in the Island when the event occurred, I would rather have - and that is no disrespect to whoever that person might be - someone who was up to date, does it all the time, understands the situation of today, not 5 weeks ago or 5 months ago."*[66]

72. Ms North added that there is no training on island for specialist nurses:

> *"There is no training on Island for specialist nurses because we do not have someone in that post but nurses in an Intensive Care Unit naturally are equipped to deal with sensitive conversations although some may not feel as comfortable having organ donation conversations and that is often due to the fact that they do not know the full information so they do not want to give the family information that is untrue at that sensitive time."*[67]

73. However, these issues were challenged by Mr MacLachlan who said that "there was no reason why some [Jersey] nurses could not be trained". He said that these nurses would be separate from the clinical team caring for the person but may work on another ward. He also said that it would be possible for them to maintain their skills by engaging with SNOD groups in the UK. He cautioned that you would "not want to change the current system if it is going to be an inferior one" but he concluded by suggesting that local nurses could be supported by UK SNODs until they had built up enough relevant experience.[68]

Knowing an individual's decision

74. In a presentation submitted by Mr MacLachlan, it emphasised that consent from families is much higher when families know their loved one wanted to donate:

> *"Unless someone has registered with the Register or carries a donor card, their family and those close to them may not know their views on organ donation when they die'. When their loved one's wishes are unknown, and faced with a decision at a time when they are feeling vulnerable and distressed, 46% of families choose to donate their organs. The remaining 54%, with 'nothing-to-go-on' may feel that the safest course of action for them is to refuse permission for donation.*
>
> *In contrast, when families know their loved one wanted to donate - for example either via the NHS Organ Donor Register or via a previous*

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[64] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.18 & 21
[65] A copy of the questions asked can be found in the evidence from Claire Williment
[66] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.18 & 21
[67] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.21
[68] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.10 & 11 & 15

> *discussion with their loved one about organ donation - their consent rate is 88%."*[69]

75. When speaking to us, Mr MacLachlan underlined this point by saying:

> *"So lack of consent is a really big issue and what is really important about this point is that if you know someone is on the register or you have had the conversation around the breakfast table, and you know that in their mind that is what they want, then consent rates go right up. You are 70, 80 per cent consenting, but if you do not know because they are not on the register and you have not ever had that slightly miserable conversation, then you do not know and family consent rates then are very high."*[70]

76. This seem to be supported anecdotally by a family member of an organ donor based in Jersey, known as Person A. Person A said that he and his family were prepared to think about organ donation because they knew their loved one was "quite willing for his organs to be donated" because he had signed up to the organ donor register via his driving licence.[71]

77. Some witnesses highlighted that this approach also works when someone does not want to donate their organs. The Minister said, for example:

> *"I would if I felt that way, speak to my GP as well and I would also tell my family members. That is what we want; those conversations to take place. Equally, if someone is very keen that their organs be used when they pass away I would argue that they should do the same, have those conversations, make sure their G.P. knows."*[72]

KEY FINDING 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.

RECOMMENDATION 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.

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[69] Mr MacLachlan 1
[70] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.9
[71] Public hearing with next of kin, 1 March 2018, p.2 & 4
[72] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.31

Chapter 4: Protecting vulnerable groups

Protections in the draft Law

78. The draft Law sets out a number of protections for vulnerable, or at risks, groups. Express consent is required for:

- A young person;[73]
- An adult who has died and who had not been ordinarily resident in Jersey for a period of at least 12 months immediately before dying; and
- An adult who has died and for a significant period before dying lacked capacity to understand the notion that consent to a specified activity can be deemed to have been given.[74]

79. Mr Le Gros set out the protections provided by the draft Law:

> *"So the deemed consent system will not apply to what are considered to be excepted persons. That is Article 5 of the law. So those are people who lack capacity to understand the notion of deemed consent for a significant period before dying. Those adults who have not been an ordinary resident in Jersey for 12 months immediately before dying and then if you look at Article 6 that provides that deemed consent does not apply to young persons. So in each of those cases express consent to the transplant activity is required."*[75]

80. These protections are in line with the protections set out in Welsh legislation on organ donation.[76]

Establishing next of kin

81. We heard from a person, known as Person B to protect her identity, who thought that she was next of kin to her loved one. She told us that she and her boyfriend had changed their medical records in the hospital to reflect this. However, when her boyfriend was admitted to hospital, transferred to intensive care and was then considered to be a potential organ donor, Person B discovered that she was not the next of kin. She said:

> *"My issue was ... I absolutely support organ donation but I think the thing that people need to know is you can have your next of kinship revoked.*
> *[…]*

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[73] For the purposes of the Law a young person is competent to deal with the issue of consent if the young person is 16 years of age or over and it would appear to a reasonable person that the young person has sufficient understanding to make an informed decision on that issue. A young person is not competent to deal with the issue of consent if the young person is under 16 years of age.

[74] States of Jersey, Draft Human Transplantation and Anatomy (Jersey) Law 201-, P.57/2018, p.41 & 42

[75] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.32

[76] Human Transplantation (Wales) Act 2013

> *I asked my partner, and a month before […] we were in hospital and […] we changed our medical records, so he was my next of kin and I was his. That is what I thought it was. […]*
>
> *[…] we were in the hospital and I was in A&E and then […] got moved to intensive care. The doctor who, luckily, I knew, came out to me and he said […] the parents are next of kin but they have said you can go in. […] At the time I did not really understand what that meant because I was so stressed.*
>
> *I would not ever have stopped them being next of kin because they were his parents and I believe that is the right thing for families to do. However, […] I do not think anybody else in the world knows that you can have your next of kinship revoked.*
>
> *So when I spoke to the Viscount about it, he said: "Yes, that is a fact. It can happen and it happens quite a lot." I have heard of 2 other people that have had this situation. […]*
>
> *So I think that really needs looking into because I think maybe if everyone does the scheme, when they get their paperwork sorted it needs to be absolutely clarified about the law, about the next of kinship."*[77]

82. Person B said that she supported the new system on the proviso that people were educated about the next of kin issue:

> *"I think it is a great system but under the proviso that lots of education is given and something about next of kinship. I do not know whether that has to be a legal thing or what. But I put it out to my friends: "I am going to do this, does anybody have any views on it?" Different people have been concerned about the age range that this scheme would cover."*[78]

83. Mr Le Gros set out what provision was made in the Law for determining next of kin:

> *"[…] if you look at Article 1(3) of the law there is a list of people who are regarded as being in a qualifying relationship to the deceased and it gives what might be considered a sort of table, an order, hierarchy, and you have a friend of longstanding included there. So someone like girlfriends or boyfriends their views could be taken into account by clinicians. There is not a definition of what a friend of longstanding means. To do so would be almost impossible in terms of reflecting every case so it is something which would be taken on a case by case basis. These are decisions which clinicians are quite capable of making in terms of understanding whose views are relevant when the time comes."*[79]

84. Ms Karen Stephen-Dalton, Assistant Law Draftsman said that there was "no order of priority" in the provisions in the Law, so the decision about who ultimately qualified as next of kin would have to be made at the time.[80]

85. Ms North set out how next of kin was determined from a clinical perspective:

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[77] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.7
[78] Public hearing with next of kin, 1 March 2018, p.12
[79] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.27
[80] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.28

> *"It is not as clear-cut as "this is the hierarchy" because you could have someone who has been your friend for 25 years but you have absolutely no contact with your parents so that almost puts this hierarchy completely out because you are asking the people who know you the least to make decisions about you. If those kind of situations come up it is not a simple case of just thinking of: Who is on this piece of paper?" You would often go to the G.P. (general practitioner) notes, talk to the G.P. "Have they ever said who they want as their next of kin on their notes?" You will often speak to the broader family. It is not just one set of information. If you are getting to the point where you are having to go to a friend of longstanding you have exhausted all other options before you get to that point. There is a huge amount of detective work that goes on to make sure that the person that you are asking is the right person."*[81]

86. Ms North told us that if you had two family members with differing views, organ donation would not take place:

> *"If you have got 2 people who are at completely opposite ends of the spectrum, ... organ donation would not go ahead based on the fact that the family could not come to an agreed decision because what that would do would ultimately leave one part of the family even more bereaved than they would if something was going ahead but it would also have damaged the organ donation procedure because you were taking organs from somebody who did not agree. So that has never ever happened in my role and I would say that that again comes down to the role of the specialist nurses who are able to tackle those often common misconceptions about why the family do not want it to happen. Often by informing, giving them all the information that they need, they are able to actually come to the decision that: "Yes, this what they all want as a family" or: "No, this is not what they all want as a family" and taking account of the thoughts and feelings of the deceased as well."*[82]

87. Ms North added that this would not change under the new system:

> *"That would be no different to what we currently do now. If the family cannot come to an agreement about what the correct course is regardless of whether that person is on the register or not, organ donation will not happen."*[83]

KEY FINDING 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.

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[81] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.28
[82] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.29
[83] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.29

Chapter 5: Transitionary arrangements

Awareness-raising

88. Mark Richardson from the Health Department told us when the law would likely come into force:

> *"What we would hope is, if I may, is we would be looking at a date for the law to come in and it would be something like 1st July 2019. So obviously it has got to get through the States in April then we give a bit of time. So that is what we will be looking at. About 1st July 2019."*[84]

89. The reason for the delay in enacting the Law is set out in the report accompanying the draft Law which states:

> *"If the States agree to the change in the Law to give effect to a deemed consent approach to organ donation then a high-profile awareness-raising campaign will take place over the year before the new Law takes effect. This would give time to inform Islanders of the change and explain clearly the choices that are available with regard to registering an organ donation decision (opting in or out) and the implications of not registering a decision, where an individual's consent can be deemed. The campaign would be designed to ensure that as many people as possible think about organ donation.*
>
> *We would need to work with our colleagues at NHS Blood and Transplant (NHS-BT) – the body that provides a blood and transplantation service to the NHS – to ensure that the registration process was straightforward and that the process for opting out and opting in was clear and easy to access. This might involve registering online or by phone as well as information on how individuals add or remove their names if they wish. Those who had already opted in and on the current register would be treated as having made an opt-in decision unless they chose to change their mind."*[85]

90. Tom Innes, Communications Manager at the Health Department set out the options available to the Department to promote the new Law:

> *"I think it was mentioned earlier about the onus being on Government to ensure this. It is not a question of doing a public notice and having a website that people need to look out and find out about this.*
>
> *The Government needs to be more proactive in making sure the information is not forced upon people but it is very apparent to them and a leaflet drop to all households is very much part of that.*
>
> *The leaflet that will be printed would also be available in appropriate places, libraries, G.P. surgeries, Parish Halls; those sorts of things, where people would expect to find them.*
>
> *We would also use the media. The media are interested in this. It has been covered quite extensively since the Minister first put it forward. Social media; which can also be boosted with a small financial sponsorship.*

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[84] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.35
[85] States of Jersey, Draft Human Transplantation and Anatomy (Jersey) Law 201-, P.57/2018, p.8

> *There are also other advertising routes and maybe some routes less travelled such as refuse trucks, branded buses, banners on roadsides. Anything that will alert people to this and direct them towards information and how to opt-out or in."*[86]

91. The Minister told us that £20,000 had been set aside for this communication work.[87] Mr MacLachlan stated in his written evidence that, in 2015, Wales "spent £3.4 million on a publicity campaign that has seen every house hold in Wales receiving a leaflet through their door, as well as TV adverts, supermarket roadshows and "flashmobs" at Cardiff train station".[88]

92. We received a submission from Sergio da Silva who was concerned that non-English speaking parts of the population might not know about the Minister's plans.[89] When we raised with point with the Minister, he confirmed that any communications would be translated into other languages.[90]

93. Ms Vernon told us what they did when an opt-out system was implemented in Wales:

> *"We carried out a two year communications campaign prior to the new law coming into force to enable Welsh people to decide whether they wanted to opt-out of having their consent deemed.*
>
> *There were also several work streams supporting the practical application of the legislation, such as guidance and training, subordinate legislation, for example in relation to excluded materials and work with NHS Blood and Transplant on the redevelopment of the Organ Donor Register."*[91]

94. Rob Sainsbury, Director of Jersey's General Hospital reflected on his experience of working in Wales:

> *"I think it is fair to say that the experience in Wales was very media intensive. It became part of a national debate. So there is a formal approach in terms of getting the messages and the information out there. There is something about an intuitive debate as well so that people can ask the questions, so they have to think about those options in terms of being able to have an interactive discussion about questions that people might have. This is very important."*[92]

95. Mr MacLachlan said that he thought the Law would likely "make everyone talk about [organ donation].[93] He warned that if the State does not take the public with it, the Law could backfire:

> *"If you do not this could seriously backfire. You could end up with fewer organs because if you do not take the public with you they are going to say: "The State is not going to take my organs." You have to explain to*

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[86] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.35
[87] Minister for Health and Social Services
[88] Mr MacLachlan
[89] Sergio da Silva
[90] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.41
[91] Patricia Vernon MBE
[92] Public hearing with the Minister for Health and Social Services, 13 March 2018, p.36
[93] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.15

> *people what this is about otherwise you can seriously have an own goal here."*[94]

96. Mr MacLachlan highlighted a number of other things that could be done to promote organ donation. He held up the work done in Spain (which has an opt-out system and high rates of organ donation) to publicise and promote organ donation:

> *"If you have an N.T.O. (National Transplant Organisation) like they do in Spain, that has done their work, you go to Madrid there is a coach in the square with the transplant organisation on it and people go and sit in the seats on the coach and talk about donation; if they want to sign they can sign."*[95]

97. Mr MacLachlan also raised the possibility of promoting organ donation in schools. He told us that NHS-BT have existing lessons "which you can plug in to the school curriculum".[96] He suggested that there should be a memorial in Jersey for those people and families who have donated.[97]

KEY FINDING 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.

KEY FINDING 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.

RECOMMENDATION 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.

RECOMMENDATION 5: Wales spent five 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.

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[94] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.8
[95] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.11
[96] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.14
[97] Public hearing with Mr Neil MacLachlan, 13 March 2018, p.16

Appendix

Panel membership

Deputy Richard Renouf, Chairman

Deputy Geoff Southern, Vice-Chairman [did not participate in this review]

Deputy Terry McDonald

Deputy Jackie Hilton

Senator Sarah Ferguson

Terms of Reference

1. Asses the objectives in seeking to move from an opt-in to an opt-out system
2. Evaluate the effectiveness of other opt-out systems in other jurisdictions and understand whether the same experience is likely to be replicated in Jersey
3. Understand how the proposed new system would work in practice and comment on its suitability, including proposed arrangements to support family members of potential organ donors
4. Ensure that the proposed new system has appropriate safeguards in place to protect vulnerable parties (e.g. families, children, migrant workers etc.)
5. Understand how the proposed new system would be introduced and to understand what transitionary arrangements would be required

Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the Panel's website: www.scrutiny.gov.je.

Wednesday 28 February 2018

Person A; Person B [held in private and anonymised]

Monday 5 March 2018

Senator A. Green MBE, Minister for Health and Social Services; **Mr. F. Le Gros**, Legal Adviser, Law Officers Department; **Ms. K. Stephen-Dalton**, Assistant Law Draftsman, Chief

Ministers Department; **Mr. M. Richardson**, Assistant Director, Policy, Communications and Ministerial Support, Department for Health and Social Services; **Mr. T. Innes**, Communications Manager, Department for Health and Social Services; **Ms. S. North**, Acting Clinical Manager I.C.U. (Intensive Care Unit)/H.D.C. (High Dependency Care), General Hospital; **Mr. R. Sainsbury**, Hospital Director, General Hospital

Tuesday 13 March 2018

Mr N. MacLachlan, Consultant Obstetrician/Gynaecologist and Founder of the Jersey Love Hearts Appeal

Published written evidence

The following written evidence was received and can be viewed on the Panel's website: www.scrutiny.gov.je.

The Dean of Jersey

Catholic Dean in Jersey

Claire Williment

Comité des Connétables 1

Comité des Connétables 2

Guy de Faye

Minister for Health and Social Services

Mr Neil MacLachlan 1

Mr Neil MacLachlan 2

Mr Neil MacLachlan 3

Patricia Vernon MBE

Sergio da Silva

The twitter questions we received as part of the review are also available to view on the Panel's website: www.scrutiny.gov.je.