

**WRITTEN QUESTION TO H.M. ATTORNEY GENERAL
BY SENATOR S.C. FERGUSON
ANSWER TO BE TABLED ON MONDAY 25th NOVEMBER 2019**

Question

1. Will H.M. Attorney General explain the legal basis for the States to remove organs from deceased people?
2. Do friends or relatives have authority to permit a deceased person's organs to be donated, given that they do not 'own' the deceased person's body; or is it the case that an individual must give authority, on the basis of a witnessed signature, for their organs to be donated after they have died?
3. In which legal enactment is it provided that the deceased person's medical practitioner must hold the information to demonstrate that the deceased person had given permission for their organs to be donated?
4. Given that patient information is currently held by N.H.S. Wales, is it permissible under the rules of G.D.P.R. to transfer private information to a third party, such as N.H.S. Wales, particularly in the absence of signed permission?

Answer

1. Transplantation activity involving the body of a deceased person, including the removal from the body of organs for donation purposes, is governed by the Human Transplantation and Anatomy (Jersey) Law 2018. The 2018 Law provides that a person may lawfully carry on a transplantation activity with express or deemed consent¹. The provision of each such consent, and exceptions to the giving of consent, is governed by express provision made therein². The carrying out of a transplantation activity without consent - express or deemed - is a criminal offence³.
2. To answer the question first about the manner in which an individual must give their consent for organ donation, the 2018 Law simply provides that the authority on which a transplantation activity may be carried out is the provision of 'express consent' or 'deemed consent'⁴ –
 - a. The 2018 Law does not prescribe the form in which express consent must be provided. It says only that the consent is to be provided or given⁵.
 - b. In the case of 'deemed consent'⁶, which would become relevant where the deceased had not opted or been able to make an express decision as to consent, the 2018 Law enables that consent to be deemed, subject to a number of conditions. Those conditions include that the deceased person is not an excepted person⁷ or a young person⁸ – in which case express consent to a transplantation activity is always required – and where another stated exception in the 2018

¹ Article 3(1).

² As to express consent, see Article 4, 5, 6, and 7. As to deemed consent, see Article 4 and 9.

³ Article 11(1).

⁴ Article 3(1) enables a transplantation activity to be carried on on the basis of express or deemed consent.

⁵ See, for example, Article 4(3) dealing with 'consent' in which the Law simply says that "*express consent is required*" and the table set out in that Article talks only of "*the adult's consent*" or the "*consent of the person or persons appointed* [to make the decision as to consent on his or her behalf]".

⁶ See Article 4(2).

⁷ The excepted persons are adults who had died but were not ordinarily resident in Jersey for a period of 12 months before dying (Article 5(3)(a)) and an adult who lacked the capacity before dying to understand the notion that consent to a transplantation activity could be deemed to have been given (Article 5(3)(b)).

⁸ See Article 6 which requires express consent in the case of young persons (ie persons under the age of 18).

Law does not apply, such as where the deceased person had decided not to consent to a transplantation activity, in other words, they had ‘opted out’ from the deemed consent system⁹.

The 2018 Law does not go further in prescribing the form in which express consent, or a decision not to consent, must be provided. In practice, the established means of providing consent to organ donation is through registration on the Organ Donation Register, and that Register now permits the registration of opt-out decisions also, though that would not prevent consent or an opt-out decision being evidenced by other means. The Senator will recall that the States made provision enabling the registration of express and opt-out decisions on the Organ Donation Register in the Human Transplantation and Anatomy (Jersey) Regulations 2019.

In ‘deemed consent’ cases, there are other practical and medical factors which will determine whether ‘deemed consent’, though established in accordance with the 2018 Law, will result in an actual organ donation. Those are matters of medical policy and practice on which the Health Minister or specialist medical practitioners would need to advise.

As regards the first part of this question, as to the authority of friends and relatives, to permit a deceased person’s body to be donated, the 2018 Law makes provision in this regard. In cases for which express consent is required under the 2018 Law, for example –

- a. where an adult has died and had not made an express decision as to a transplantation activity but had appointed one or more persons under the 2018 Law¹⁰ to deal with the issue of consent, the 2018 Law permits those appointed persons to provide consent to organ donation on behalf of the deceased¹¹. The Senator is referred to Article 8 of the 2018 Law for further detail as to the appointment of such persons.
- b. In a case where a deceased person had appointed a person to make such a decision, but at the time of death that appointed person is not available to give consent, the 2018 Law permits a person who stands in a qualifying relationship to the deceased to give consent to organ donation on behalf of the deceased¹². A person in a ‘qualifying relationship’ includes, among others, the deceased’s spouse, civil partner, certain extended family members and friends of long-standing¹³.

In the case of young persons, the 2018 Law permits those with parental responsibility or those standing in a qualifying relationship to the child to provide consent to organ donation in certain circumstances¹⁴. Those cases are set out in Article 6 of the 2018 Law.

The 2018 Law also makes express provision as to the cases in which a qualifying relation may *object* to consent being deemed in the case of a deceased person who had neither made an express decision as to organ donation nor a decision to ‘opt-out’. Provision is made for objections to deemed consent in Article 4(2)(c) of the 2018 Law.

3. The question asks whether registered medical practitioners, specifically general practitioners, in Jersey are required by law to keep a record of either the express consent or ‘opt-out’ decisions of Jersey residents, where made, for the purposes of the 2018 Law. There is no provision of this nature in the 2018 Law.
4. The Senator’s question seeks to ascertain if it is compatible with data protection legislation for NHS Blood and Transplant Service, which is responsible for maintaining the Organ Donation Register in the UK, to make available information, provided to it by members of the public in registering a decision as

⁹ See Article 4(2)(a). The other exceptions are listed in Article 4(2)(b) and (c).

¹⁰ See under Article 8.

¹¹ See Article 4(2)(b) and Case 3 in Table 1 set out in Article 4, in the case of adults who are not excepted persons. See Article 5(2), (5) and Case 2 in Table 2 set out in Article 5 in the case of adults who are excepted persons.

¹² See Article 4(2)(b) and Case 4 in Table 1 set out in Article 4 in the case of adults who are not excepted persons. See Article 5(2), (5) and Case 3 in Table 2 in Article 5 in the case of adults who are excepted persons.

¹³ See list of qualifying relationships set out in Article 1(3).

¹⁴ See Article 6 and the cases listed in Table 3 in Article 6.

to organ donation, to third parties, which I have taken to mean medical practitioners working at hospitals, such as the General Hospital.

There is no processing of personal data, in the context of organ donation activities, by authorities in Jersey, and so Jersey data protection legislation is not directly relevant. Rather, in the case of a Jersey resident registering their decision as to organ donation on the Organ Donation Register, that process involves the consensual submission of personal data by Jersey residents to NHSBT for the specific purpose of registration on the Organ Donation Register and processing for related purposes. In that regard, applicants who wish to register on the Organ Donation Register, through the NHSBT website, are required to read and agree a privacy statement – that privacy statement can be found at www.nhsbt.nhs.uk/privacy.

This privacy statement makes it clear that NHSBT will collect and process certain personal data and that handling of personal data is regulated by the General Data Protection Regulation and the Data Protection Act 1998. It is made clear that the majority of NHSBT's data processing is necessary under Article 6(e) and 9(h) of the GDPR - provisions which in turn have been reflected in the Data Protection Act 1998 - which allows NHSBT, as a public authority, to process personal data for the performance of its task or in the public interest and for the provision of health care. Permitting access by local authority hospital practitioners, including those at the Jersey General Hospital, for the purposes of organ donation enquiries by medical practitioners on the death of a person, would come within these permitted exceptions.