

Tom Leveridge  
Scrutiny Office  
States Greffe  
Morier House  
St Helier  
Jersey JE1 1DD

West End Donor Centre  
26 Margaret Street  
London  
W1W 8NB

Sent via e-mail to: [t.leveridge@gov.je](mailto:t.leveridge@gov.je)

7<sup>th</sup> March 2018

Dear Mr Leveridge,

## Jersey Organ Donation Review

I am writing in response to the letter from Deputy R J Renouf (Chairman of the Health and Social Security Scrutiny Panel) to my colleague Louise Davey, seeking information regarding organ donation and transplantation. This letter has been passed to me for a response, as I am currently leading work with NHSBT to support the various Government initiatives to introduce an opt out system for organ donation.

To respond to the queries in the order in which they are raised:

1. *Copies of questions that the next of kin of potential organ donors are asked*

Guidance on the discussion with the next of kin regarding the potential for organ donation, including the questions that should be asked, is available at the following sections of the Organ Donation and Transplantation website:

- <http://www.odt.nhs.uk/deceased-donation/best-practice-guidance/consent-and-authorisation/>
- <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/1581/approaching-the-families-of-potential-organ-donors.pdf>

Guidance on the questions to be asked once consent for donation is in place is provided in the enclosed document 'FRM4211'.

2. *What information is stored on the Organ Donor Register?*

The following data is stored on the Register:

- Title
- First Name\*
- Other Name
- Last Name\*
- Preferred Name
- Date of Birth\*
- Sex\* (male, female, other, prefer not to say, transgender)

- Ethnicity
  - Religion
  - Address\*
  - Postcode\*
  - Telephone
  - Mobile
  - Email
  - Donation decision: 'Opt-in', 'Opt-out' or 'Nominate a representative'
  - Donation choices (which organs/tissue they would like to consent to donate):  
Kidneys, Heart, Liver, Corneas, Lungs, Pancreas, Small Bowel, Tissue
  - Withdrawal reason and date (for those that have previously registered and subsequently decided to withdraw from the register)
  - Unique Identification Number(s)
    - NHS Number (English, Welsh, NI residents)
    - CHI Number (Scottish residents),
    - DVLA Number
    - DVANI Number (Northern Ireland residents)
    - Death Status
    - Date of death
- (\* Indicates Manatory Fields)

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.

3. *Who has overall responsibility for the Organ Donor Register?*

The Chief Executive of NHS Blood and Transplant, Ian Trenholm, has overall responsibility for the Organ Donor Register.

The Head of the Organ Donor Register, Alex Hudson, also has Information Governance responsibility and is the Information Asset Owner for the Register within NHS Blood and Transplant.

4. *Where is the Register stored?*

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 NHSBT server.

5. *How is the Register maintained?*

There are a number of approaches for ensuring the Register is effectively maintained:

- The ICT support and maintenance of the Register is provided by a Third Party Supplier (Northgate Public Services).
- The general operational service, such as identifying and addressing any potential conflicts in data and responding to requests for the establishment of nominated representatives for organ donation, is provided by a team

within the Organ Donation and Transplantation Directorate within NHS Blood and Transplant.

- The Register's website is maintained by the Digital Team within the Communications Directorate of NHS Blood and Transplant.
- Work to raise awareness of the Register and campaigns/ marketing activity falls within the responsibility of the Communications Directorate of NHS Blood and Transplant.

6. *Who has access to the Register?*

The following people have access to the Organ Donor Register:

- 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.

7. *On what basis can the Register be amended?*

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, their representatives. For example, individuals can request an amendment – such as a change of surname or decision about which organs they want to donate – by inputting data to the Organ Donor Register website or calling the Organ Donor Line. The teams will amend data on the Register in line with their request.

8. *What happens if an individual changes their mind?*

They are able to amend their registration decision (opt-in, opt-out) and/or their individual organ preferences via the website, by calling the 24/7 Organ Donor Line or make an amendment request in writing. Individuals have the right to access their own data and to be forgotten.

9. *Can a legal representative amend a donor's choice on their behalf?*

Yes - there is a process to nominate an appointed representative to act on behalf of an individual regarding recording decisions on the Register. A parent can also amend the decision of a child under the age of 12.

10. *Are there any internal supervision and compliance procedures around the Register?*

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.

*11. Is there independent oversight of the Register?*

The Register is subject to internal audits, which are currently overseen by Price Waterhouse Cooper (PWC)

*12. How does the process for triggering different teams from across the UK work in practice?*

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 (further data on this process is available at: <http://www.odt.nhs.uk/transplantation/tools-policies-and-guidance/policies-and-guidance/>).

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.

*13. Are there any guidelines which apply to clinicians setting out how they should act in cases where organ donation is seen as a possibility? Could we provide a copy of these guidelines?*

Best practice guidance on organ donation has been published by the General Medical Council, the UK Donation Ethics Committee and NICE. The ODT website contains details regarding best practice in identifying, referring and caring for potential organ donors. This is available at: <http://www.odt.nhs.uk/deceased-donation/best-practice-guidance/donor-identification-and-referral/>.

There is also best practice in consent. This is available at:

<http://www.odt.nhs.uk/deceased-donation/best-practice-guidance/consent-and-authorisation/>

I hope that this has addressed your queries. Please do not hesitate to contact me if you require any further information (telephone: 07525299064; email: [Claire.williment@nhsbt.nhs.uk](mailto:Claire.williment@nhsbt.nhs.uk)). You may also find it helpful to look at the Organ Donation and Transplantation website ([www.odt.nhs.uk](http://www.odt.nhs.uk)), which contains a wealth of information regarding the organ donation, retrieval and transplant process.

Yours sincerely,

A handwritten signature in cursive script that reads "Claire Williment".

Claire Williment  
*Head of Opt Out Development*

ODT Donor Number 

# ***Patient Assessment Form***

## **Directions for completion**

- 1 This form must be completed in **black or dark blue ink** by the Specialist Nurse – Organ Donation (SNOD)/Nurse Practitioner (NP)/Assistant Nurse Practitioner (ANP)/Tissue Transplant Co-ordinator and signed where required.
- 2 The original copy should be retained by the **SNOD/NP/ANP/Tissue Co-ordinator** for the donor file.
- 3 A copy should be made for the patient's medical records.
- 4 In the event of organ and tissue donation, a legible copy should be sent to the relevant **Tissue Establishment**, where required.

**NOTE:** The term patient is used throughout the form to refer to the potential donor.

ODT Donor Number

**PATIENT INFORMATION**

Patient's Forename(s) <small>Please print</small>	Patient's Surname <small>Please print</small>
Donating Hospital	
Hospital Number	Cause of Death
NHS/CHI Number	
Date of Birth (dd/mm/yyyy)	Occupation

**INTERVIEWEE INFORMATION**

Information discussed with	
Name <small>Please print</small>	Relationship <small>Please print</small>

**For patients under the age of 18 months or those who have been breast-fed in the last 12 months the mother is required to answer these questions with regard to both her own and her child's health.**

**For children:** has your child been breast-fed in the past 12 months?      Yes       No       Unknown

**NOTE:** for all patients under the age of 18 months and any baby or child who has been breast-fed in the last 12 months, a blood sample is required from the mother of the patient.

**For ALL female patients between 13 and 53 years of age: Is there a possibility that your relative could be pregnant?**      Yes       No       Unknown

**GENERAL HEALTH INFORMATION**

1. Did your relative visit a general practitioner in the last two years?      Yes       No       Unknown

If YES, give details

2. Was your relative currently seeing or waiting to see a general practitioner or any other healthcare professional?      Yes       No       Unknown

If YES, give details

3 a) Did your relative have diabetes?      Yes       No       Unknown

If YES, were they on insulin?      Yes       No       Unknown

3 b) Is there a family history of diabetes?      Yes       No       Unknown

If YES, is it insulin-dependent diabetes?      Yes       No       Unknown

4. Did your relative take regular medication?      Yes       No       Unknown

If YES, give details

ODT Donor Number

## GENERAL HEALTH INFORMATION

5. Did your relative ever undergo any investigations for cancer or were they ever diagnosed with cancer? Yes  No  Unknown

If YES, give details

6. Did your relative recently suffer from significant weight loss? Yes  No  Unknown

If YES, give details

7. Did your relative ever suffer from any bone, joint, skin or heart disease? Yes  No  Unknown

If YES, give details

8. Did your relative have a history of eye disease or undergo eye surgery or laser treatment? Yes  No  Unknown

If YES, give details

9. Did your relative ever have any operations? **If NO go to question 12** Yes  No  Unknown

If YES, give details

10. a) Did your relative ever have any surgery on the brain or spine? Yes  No  Unknown

If YES, give details

10. b) If YES, was this before 1993? Yes  No  Unknown

Give details including date

11. Did your relative ever have an organ or tissue transplant? Yes  No  Unknown

If YES, give details including date

12. Was your relative ever told not to donate blood? Yes  No  Unknown

If YES, give details of where, when and the reason



ODT Donor Number **GENERAL HEALTH INFORMATION**

13. Did your relative receive a transfusion of blood or blood product(s) at any time? Yes  No  Unknown

If YES, give details including where, when and reason for transfusion

14. Did your relative suffer from recent memory loss, confusion or unsteady gait? Yes  No  Unknown

If YES, any reasons for this?

15. Did your relative suffer from any type of brain disease such as Parkinson or Alzheimer? Yes  No  Unknown

If YES, give details

16. Did your relative have a family history of prion disease, such as CJD, or were they ever told that they were at risk of prion disease? Yes  No  Unknown

If YES, give details

17. Did your relative ever receive human pituitary extracts, e.g. growth hormones, fertility treatment or test injections for hormone imbalance? Yes  No  Unknown

If YES, give details including dates

18. Did your relative suffer from any chronic or autoimmune illness or disease of unknown cause? Yes  No  Unknown

If YES, give details

19. Did your relative ever have hepatitis, jaundice or liver disease? Yes  No  Unknown

If YES, give dates, diagnosis, treatment and location

20. Did your relative ever have any other significant infection? Yes  No  Unknown

If YES, give details, and any treatment received

ODT Donor Number

## RECENT HISTORY

21. Did your relative have any signs of recent infection, e.g. colds, flu, fever, night sweats, swollen glands, diarrhoea, vomiting or skin rash? Yes  No  Unknown

If YES, please specify dates, symptoms, diagnosis, and treatment

22. Did your relative come into contact with an individual with an infectious disease recently or have any immunisations within the last 8 weeks? Yes  No  Unknown

If YES, give details

23. Did your relative have any acupuncture, tattooing, body piercing, botox, injections or cosmetic treatments that involve piercing the skin in the last 4 months? Yes  No  Unknown

If YES, give details including where and when

24. In the last 12 months has your relative been bitten by or been in close contact with a bat anywhere in the world, or been bitten by any other animal whilst abroad? Yes  No  Unknown

If YES, give details of incident, circumstances, animal, place, dates, and treatment.

## TRAVEL HISTORY

25. In the last 12 months did your relative go outside the UK (including business trips)? Yes  No  Unknown

If YES, give details of dates and destinations visited

26. Was your relative born outside the UK or have they ever lived or stayed outside the UK for a continuous period of 6 months or more? Yes  No  Unknown

If YES, give details of dates visit/return and destinations

27. Did your relative ever have malaria or an unexplained fever which they could have picked up whilst abroad? Yes  No  Unknown

If YES, give date of fever/illness, places visited, duration and dates

28. a) Did your relative ever go to Central America, Mexico or South America for a continuous period of 4 weeks or more? Yes  No  Unknown

If YES, give details of dates, places (rural/urban areas), nature of visit

28. b) Was your relative's mother born in Central America, Mexico or South America? Yes  No  Unknown

If YES, give details of date and place

ODT Donor Number

## BEHAVIOURAL RISK ASSESSMENT

29. Did your relative

(a) Consume alcohol?

Yes  No  Unknown

If YES, what and how much?

(b) Smoke tobacco or any other substance?

Yes  No  Unknown

If YES, give details

30. Is it possible that any of the following apply to your relative?

(a) Was, or may have been infected with HIV, hepatitis B or C, or HTLV?

Yes  No  Unknown

(b) Has ever injected, or been injected, with non-prescription drugs, including body-building drugs, even if it was a long time ago or only once?

Yes  No  Unknown

(c) Been in prison or a juvenile detention centre for more than 3 consecutive days in the last 12 months? **NB This excludes those who have been in a police cell for <96 hours**

Yes  No  Unknown

31. Was your relative ever sexually active?

**If no, go to question 33.** If yes, is it possible that your relative:

(a) Was ever given payment for sex with money or drugs?

Yes  No  Unknown

(b) Ever had a sexually transmitted disease?

Yes  No  Unknown

Yes  No  Unknown

If YES, give details

32. Was your relative sexually active in the last 12 months?

Yes  No  Unknown

**If no, go to question 33.** If yes, is it possible that in the last 12 months your relative had sex with:

(a) *(for male patients only)* another man?

Yes  No  Unknown

(b) *(for female patients only)* a man who has had sex with another man?

Yes  No  Unknown

(c) Anyone who is HIV or HTLV positive?

Yes  No  Unknown

(d) Anyone who has Hepatitis B or C?

Yes  No  Unknown

(e) Anyone who had a sexually transmitted disease?

Yes  No  Unknown

(f) Anyone who has ever been given payment for sex with money or drugs?

Yes  No  Unknown

(g) Anyone who has ever injected drugs?

Yes  No  Unknown

(h) Anyone who may ever have had sex in any part of the world where AIDS/HIV is very common (this includes most countries in Africa)?

Yes  No  Unknown

33. Having answered all the previous questions, is there anyone else who you think may provide more information?

Yes  No

If YES, please specify





ODT Donor Number

Does a haemodilution calculation need to be carried out? Yes  No  Reason

A haemodilution calculation must be performed if the patient has:

1. Been transfused with blood or blood products.
2. Received infusions of synthetic colloids and/or crystalloids following blood loss\*.

**A - If the donor has received blood products/components, a pre-transfusion sample must be sought irrespective of volume of blood or blood product. This sample must be submitted for microbiological characterisation of the donor.**

**B - If haemodilution calculation is  $\geq 50\%$ , a pre-dilution sample must be sought.**

If pre-transfusion or pre-dilution samples can not be found, the Microbiology laboratory and all recipient centres/ tissue establishments must be informed and this documented.

\* Decision on significance of blood loss should be discussed with clinical ITU team and made on a case by case basis.

**CALCULATION FOR PLASMA DILUTION continued**

**CRYSTALLOID INFUSED:**

INTERVAL PRIOR TO SAMPLING	VOLUME INFUSED (ml)	% RETAINED	VOLUME RETAINED (ml)
> 24 HOURS		0	None
2-24 HOURS		25	
1-2 HOURS		50	
<1 HOUR		75	
<b>TOTAL CRYSTALLOID RETAINED:</b>			

**BLOOD/COLLOID INFUSED:**

INTERVAL PRIOR TO SAMPLING	VOLUME INFUSED (ml)	% RETAINED	VOLUME RETAINED (ml)
24-48 HOURS		100 (Blood) 50 (Colloid)	
0-24 HOURS		100	
<b>TOTAL BLOOD/COLLOID RETAINED:</b>			

Patient weight - _____ <b>ESTIMATED TOTAL BLOOD VOLUME:</b> 70ml per kilogram of body weight 50ml per kilogram of body weight in ICU	<b>% HAEMODILUTION</b> <b>(CRYSTALLOID RETAINED+ BLOOD/COLLOID RETAINED) X 100</b> <b>BLOOD VOLUME</b>
---	--

**ACCEPT (<49%)/REJECT ( $\geq 50\%$ )**

Signature of health care professional obtaining information  Please print name

Date of interview         Time of interview