



Llywodraeth Cymru  
Welsh Government

Deputy R J Renouf  
Chairman  
Health and Social Security Scrutiny Panel  
States of Jersey/États de Jersey  
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Dear Deputy Renouf,

### **Jersey Organ Donation Review**

Thank you for your letter of 19<sup>th</sup> February and for your questions related to the work we did in Wales to prepare for the introduction of a new system of deemed consent to organ donation. We are pleased to offer you whatever help we can.

#### General background

As you know, 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.

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.

## Specific questions

I set out below the answers to your questions (your points are shown in bold italics).

### ***We understand that Wales is part of NHS Blood and Transplant for the purposes of organ donation and that Welsh organ donors are on the NHS Organ Donor Register***

Yes, this is correct. NHS Blood and Transplant (NHSBT) is a Special Health Authority for England and Wales, providing services in relation to blood, tissue and organ donation. Scotland and Northern Ireland also have arrangements in place with NHSBT for organ donation and transplantation.

NHSBT manages the NHS Organ Donor Register and National Transplant Register, which allows them to match donors to people who are waiting for a transplant. The NHS Organ Donor Register is a confidential database for the whole of the UK of people who want to record their decision on organ donation. I understand that people in Jersey are also able to register an organ donation decision on the UK Organ Donor Register.

### ***If someone opted-out of organ donation in Wales, how is this recorded?***

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 system of deemed consent, the new Organ Donor Register has been developed with sufficient capacity to allow for such a change.

I should mention that 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.

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.

### ***How are any entries onto, or changes to, the register authorised? How does someone change their mind? Is a legal representative able to opt out or change the register entry on someone else's behalf?***

A decision can be recorded on the Organ Donor Register quickly and easily by phone or online, either by the person themselves, or by someone acting on their behalf. A person is asked to provide certain personal information which is recorded. The system then sends a letter to the individual to confirm their registration. This not only provides a record of the

decision but also safeguards against malicious or inappropriate registrations. If once registered, an individual changes their mind, they are able to contact NHSBT and amend their registration. This may be done by phone, or online by registering a different decision. Once again, the system would trigger a letter to the individual to confirm the decision. The database records all changes and maintains a registration history.

It is possible for a legal representative or other person to register a decision on behalf of someone else, so long as this represents the views of the individual concerned. This would be tested by organ donation specialist staff during the conversation with the family or the representative, which takes place in all cases where organ donation is a possibility.

***Are there two separate registers as a result of the Welsh opt-out policy? If so, how do the two registers interact?***

As explained above, 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.

***Are there any financial or staffing implications for the Welsh Government in keeping an opt-out register?***

The Welsh Government funded half of the cost of redeveloping the Organ Donor Register, and the other three UK countries funding the remaining half by population share. Ongoing costs are managed within the annual funding provided to NHSBT to manage organ donation services in Wales.

I hope this information is of assistance to you. Please do not hesitate to ask if you require anything further.

Yours sincerely,



**Patricia Vernon, MBE**

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