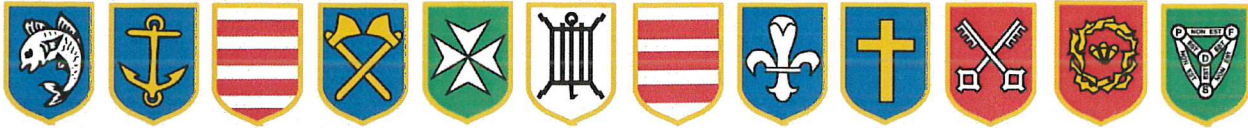


Comité des Connétables



Deputy R J Renouf
Chairman, Health and Social Security Scrutiny Panel
Scrutiny Office
States Greffe
Morier House
St Helier
JE1 1DD

Our ref: LN/srdeg/25

14 March 2018

Dear Richard

Organ donation review

I am responding to your letter dated 6 March 2018 and the additional questions below regarding how someone's preference for organ donation is managed through the Jersey Driving Licence application process.

- 1. Since 2015, when Jersey driving licence applications included an option to register as an organ donor, how many people have indicated that they wish to be organ donors?*
- 2. Have individual Parishes or the Comité des Connétable informed applicants, who have indicated that they wish to donate their organs, that they have not been placed onto the NHS organ donor register?*
- 3. Why has the fact that this data has not been transferred to the NHS organ donation register been made public?*
- 4. What are the specific reasons as to why this data has not been transferred to the NHS organ donation register?*

As explained in my email of 5 March 2018, the Comité des Connétables was approached by representatives of The Love Hearts Appeal (a Jersey charity that promotes organ donation) in November 2013 asking whether applications for driving licences could include an option to register as an organ donor. The Comité was sympathetic to the request and after consultation, including with the NHS Blood and Transplant Service (NHSBT), the Comité, with the support of the (then) Minister for Transport and Technical Services, amended the driving licence application form so that an applicant might sign up to the register.

A new stock of the application form was due to be ordered and although the process for the transfer of the data had not been confirmed with NHSBT there seemed every likelihood that this would be finalised within a short period of time so the addition of the organ donor question was included in the new stock of application forms. The option therefore first appeared on driving licence application forms in 2015.

The data transfer method proposed was an automatic feed. Despite regular contact with NHSBT through 2015 to establish the development of the automated data feed, the provision of an internal testing resource was an issue for NHSBT and due to the number of ongoing projects they were unable to secure this; a change freeze through to January 2016 resulted in further delays. As an interim measure a non-automatic transfer was considered but again NHSBT resource issues meant the request was rejected due to other business priorities. NHSBT have gone through a period of transformation and the IT resource is shared across the business.

In early 2017 NHSBT advised that it would not be possible for them to consider taking on new ODR Access Partners at this time as they were currently undergoing a significant ICT Transformation and as such resources required to support new access partners for the Organ Donor Register was not currently available.

During 2017 the situation was reviewed with senior officers of the Transplantation Support Services at NHSBT who proposed that the main route to new registrations should be the NHSBT website. This would mean work would cease on the ongoing sharing of data with Jersey no longer processing this data. It would also mean that issues such as GDPR, organ preference updates and other governance issues are controlled via a single NHSBT-led route (NHSBT will be able to provide analysis of registrations via this route, should this be required). In addition NHSBT will be provided with a full dataset of the information already held. The Jersey driving licence application form will need to be amended so that information is no longer gathered.

At this time the Minister for Health and Social Services has also been actively investigating the opt-out scheme which has now been proposed in the draft Human Transplantation and Anatomy (Jersey) Law P.57/2018.

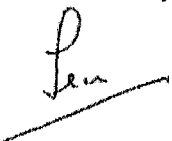
Removing the option to register from the driving licence application process requires a lead in time as it will include removing the organ donor option from the application form - this will require the approval of the Minister for Infrastructure and restocking parishes with the new forms. This work is in hand and we would hope can be completed in the next couple of months.

Discussion has therefore been ongoing with NHSBT but, ultimately, it has not been possible yet to transfer the data though we hope this will be achieved in the next few months. The situation is far from satisfactory and we should, indeed, have taken steps sooner to inform applicants of the delay in transferring their wishes to NHSBT.

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 NHSBT – until the data transfer it is impossible to ascertain the degree of duplication. The total number 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 the 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.

Relevant correspondence between the Comité, NHSBT, Health etc. is being collated and will be provided shortly.

Yours sincerely



Len Norman
Chairman