
Documentation submitted by NHS Blood and Transplant to Professor Sir Gordon Duff's Independent Review

Various scripts and briefing papers used in handling the error

Briefing – organ donor registrations via the Driver and Vehicle Licensing Agency (DVLA) (1)

Briefing – organ donor registrations via the Driver and Vehicle Licensing Agency (DVLA) (2)

RM outline script for speaking to donor families affected

Briefing – organ donor registrations via the Driver and Vehicle Licensing Agency (DVLA)

Introduction

This briefing outlines an issue which has arisen relating to the recording of wishes by people joining the NHS Organ Donor Register (ODR) via driving licence application forms. It has been provided to key stakeholders involved in organ donation and transplantation.

Summary of issue

- The Driver and Vehicle Licensing Agency (DVLA) has a 'tick-box' on driving licence application forms, which allows people to join the NHS Organ Donor Register (ODR) at the same time as applying for their licence.
- The DVLA scheme is a major source of registrations, accounting for around 8 million of the 17 million people currently signed up to the NHS ODR. Applicants can choose whether they wish to donate all of their organs, or tick boxes to specify individual organs such as the heart or lungs.
- Only 13 per cent of those who register on the ODR via the DVLA express a preference to donate specific organs (i.e. most people tick 'all organs')
- NHSBT recently identified a processing error in one of our systems, which is used to process information received from the DVLA. This error has resulted in the wishes of some people who had specified they wanted to donate specific organs being recorded incorrectly. Our investigation has established that this issue dates back to 1st January 1999.
- We have checked and ensured that the error has not affected any of the other sources of donors to the register.
- As soon as we had pinpointed the issue, we suspended the use of information regarding preferences from affected records in the discussions with donor families, and quarantined any new registrations from DVLA
- We have now identified that approximately 812,000 records may have been affected, representing just under five per cent of the 17 million on the ODR. Of these, 444,000 are in the process of being corrected electronically, and a carefully controlled process has begun to do this. However, there remain 368,000 people whose preferences are not clear. We will therefore be writing to all of these donors, asking them to confirm their preferences.
- Our investigation has also revealed that since this error occurred a small proportion of people who registered to donate specific organs via the DVLA scheme have died and become organ donors. Although they had all recorded their wish to save lives through organ donation, the donor transplant co-ordinators initiated discussions with some of their families based on the wishes recorded incorrectly on the NHS ODR. We have reviewed all of these records, and are in the process of contacting the families of those donors early this week. We are offering a full apology, an explanation, and provision of as much support as individual families need, including referral to a counselling service.
- It is important to note that all affected donors had definitely indicated their wish to become an organ donors, and that no organs were removed without the written endorsement of the donor's family or next of kin.

- DH has announced an independent review into what happened, and we will of course co-operate fully with this to ensure that lessons are learned.

Media interest

This issue is now the subject of media interest, and you may be approached to comment. Whilst any views expressed are clearly a matter for each individual and organisation, for reference NHSBT will be using the following key messages with the media:

- A processing error has been identified, which has meant the wishes of a number of people who joined the NHS Organ Donor Register via driving licence application forms were recorded incorrectly. This is an issue within NHSBT; DVLA are NOT implicated in this error.
- As soon as this issue came to light, NHSBT began a thorough investigation and the source of the problem was identified. It has now been corrected to ensure that future registrations are accurately recorded.
- We can reassure people that no data has been lost at any stage, and no other routes to join the NHS Organ Donor Register have been affected.
- As a small proportion of these potential donors did donate after their death, we are contacting their families to explain that there may have been a discrepancy with the information we were holding in relation to their preference and to apologise for any distress this causes.
- Organ donation never goes ahead without the full support of donor families. The eventual decision about which organs are suitable for donation is made by healthcare professionals after someone has died, taking account of the cause of death, their detailed medical history and in consultation with relatives.
- Patients rely on the generosity of organ donors, and it is incredibly important that people continue to sign up as donors and discuss their wishes with their families.

11 April 2010

Briefing – organ donor registrations via the Driver and Vehicle Licensing Agency (DVLA)

Introduction

This briefing outlines an issue which has arisen relating to the recording of wishes by people joining the NHS Organ Donor Register (ODR) via driving licence application forms. It has been provided to key stakeholders involved in organ donation and transplantation.

Summary of issue

- The Driver and Vehicle Licensing Agency (DVLA) has a 'tick-box' on driving licence application forms, which allows people to join the NHS Organ Donor Register (ODR) at the same time as applying for their licence.
- The DVLA scheme is a major source of registrations, accounting for around 8 million of the 17 million people currently signed up to the NHS ODR. Applicants can choose whether they wish to donate all of their organs, or tick boxes to specify individual organs such as the heart or lungs.
- Only 13 per cent of those who register on the ODR via the DVLA express a preference to donate specific organs (i.e. most people tick 'all organs')
- NHSBT recently identified a processing error in one of our systems, which is used to process information received from the DVLA. This error has resulted in the wishes of some people who had specified they wanted to donate specific organs being recorded incorrectly. Our investigation has established that this issue dates back to 1st January 1999.
- We have checked and ensured that the error has not affected any of the other sources of donors to the register.
- As soon as we had pinpointed the issue, we suspended the use of information regarding preferences from affected records in the discussions with donor families, and quarantined any new registrations from DVLA
- We have now identified that approximately 800,000 records may have been affected, representing just under five per cent of the 17 million on the ODR. Of these, 500,000 have been corrected electronically and we are writing to around 300,000 people to ask them to confirm their preferences.
- Our investigation has also revealed that since this error occurred, a small proportion of people who registered to donate specific organs via the DVLA scheme have died and become organ donors. Although they had all recorded their wish to save lives through organ donation, the donor transplant co-ordinators initiated discussions with some of their families based on the wishes recorded incorrectly on the NHS ODR. We have reviewed all of these records and found that 25 donors were affected by this error. We are in the process of contacting the families of these donors to explain the issue and to offer a full apology and referral to a counselling service if required.
- It is important to note that all affected donors had definitely indicated their wish to become an organ donors, and that no organs were removed without the written endorsement of the donor's family or next of kin.
- DH has announced an independent review into what happened, and we will of course co-operate fully with this to ensure that lessons are learned.

Actions taken and key points to note

- A processing error has been identified, which has meant the wishes of a number of people who joined the NHS Organ Donor Register via driving licence application forms were recorded incorrectly. This is an issue within NHSBT; DVLA are NOT implicated in this error.
- As soon as this issue came to light, NHSBT began a thorough investigation and the source of the problem was identified. It has now been corrected to ensure that future registrations are accurately recorded.
- We can reassure people that no data has been lost at any stage, and no other routes to join the NHS Organ Donor Register have been affected.
- As a small proportion of these potential donors did donate after their death, we are contacting their families to explain that there may have been a discrepancy with the information we were holding in relation to their preference and to apologise for any distress this causes.
- Organ donation never goes ahead without the full support of donor families. The eventual decision about which organs are suitable for donation is made by healthcare professionals after someone has died, taking account of the cause of death, their detailed medical history and in consultation with relatives.
- Patients rely on the generosity of organ donors, and it is incredibly important that people continue to sign up as donors and discuss their wishes with their families.

26 April 2010

RM outline script for speaking to donor families affected

State who you are, you are calling back as arranged.

I've now had the opportunity to look at your relatives (state relationship i.e. husband) notes and I'm now in a position to tell you that the wishes of your (relative) were not held in an accurate record at the time of their death. And that therefore the information we may have given you at the time of their death was incorrect.

I can reassure you that there is absolutely no suggestion that NAME () did not want to be a donor or that they had been incorrectly added to the organ donor register – essentially what the error Identified means is that we believe there has been an incorrect recording of specific organs or tissue on the Organ Donation Register.

So what does this mean?

We have compared NAME'S () original registration through the DVLA driving license form and checked this against the record that was held in the Organ Donor Register at the time of their death.

Specific script relating to individual cases

The registration completed by NAME () shows that he/she wished to donate . Through the programming error, this was however recorded as .

This means NAME has donated his/her when he/she wished to donate his/her .

We are deeply sorry for this error and for the upset and confusion this may cause to you and your family and wholeheartedly apologise.

I'm sure you may want to take some time to consider and think about what I've said and possibly talk this over with your family. I'd be more than willing to speak to you again or arrange for someone to come and meet you if you would prefer - at a time convenient to you . (If immediately take up this offer – seek to make arrangements in keeping with their wishes).

Do you have any immediate questions that you would like to ask?

Inform caller – I will confirm the information we have just discussed in writing.

Confirm what follow up arrangements have been agreed? (i.e. further call, face to face, letter)