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

Letters

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Blood and Transplant

Fox Den Road
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Bristol
BS34 8RR

Tel: 0117 975 7575
Fax: 0117 975 7577
www.nhsbt.nhs.uk

Date

Dear NAME

I am writing to you regarding the organ/tissue donation which your late relative NAME made on DATE. Firstly I would like to say thank you once again to NAME and all his/her family members for this donation.

You may remember that his/her wishes as recorded on the Organ Donor Register were discussed with you at the time when hospital staff talked to you about organ (and/or tissue) donation. We have recently identified a technical error within the Register which has affected a very small number of donors, and we believe that the donation made by your relative / NAME may be one of those affected.

In order to verify this and to explain the issue to you in more detail, I would be very grateful if you would contact us as soon as possible on 0300 123 1205. This line will be operating at the following times this week:

Monday 12th April: 12 noon – 10pm

Tuesday 13th April: 9am – 9pm

Wednesday 14th April: 9am – 9pm

Thursday 15th April: 9am – 9pm

Friday 16th April: 9am – 5pm

I realise that contacting you about this may cause distress and I would like to reassure you that there is no doubt that NAME joined the Organ Donor Register and recorded his/her wish to donate organs. However, we would like to talk to you and answer your questions at the earliest opportunity, and so will also try to contact you by telephone using the telephone number held in our records.

Yours Sincerely

Sally Johnson

Director of Organ Donation

NHS Blood and Transplant

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Date

Dear NAME

Following your discussion with (DTC NAME) regarding the NHS Organ Donor Register (ODR), I am writing to provide a written account of the issue, and to provide you with contact details should you have any further queries in relation to this matter.

As the Chief Executive at NHS Blood and Transplant, the organisation now responsible for organ (and tissue) donation in the United Kingdom, firstly I would like to sincerely re-state our gratitude to NAME and all his/her family members for the donation made on DATE.

You may remember that his/her wishes as recorded on the Organ Donor Register were discussed with you at the time when hospital staff talked to you about organ (and/or tissue) donation. The register held details of which organs he/she had indicated a wish to donate. As you know, we have recently rechecked this record and unfortunately discovered that (one/some of) their preferences for organ donation was/were incorrect.

We are absolutely certain that NAME did join the register and recorded his/her wish to donate organs. In the discussion we had with you, however, we indicated that he/she wished to donate (A, B, C, and D). Having verified the information provided to the register, we now know that in fact he/she had listed (A, B, and E) but not (C). In the event, you very kindly agreed that C could be donated, but we realise that you might not have agreed to this if you had been aware that NAME had not specifically stated a wish to donate this organ. We are extremely sorry for this error and apologise unreservedly for any distress this has caused.

A number of records on the Organ Donor Register were affected by this error and a small number of the affected registrants went on to donate organs. This was caused by a processing error with one of our systems, which has now been corrected. When we discovered the problem we knew that although contacting you may cause upset, the right thing to do was to tell you about it.

Although you have already discussed this with NAME, I appreciate that you will probably want to reflect on the information that has been provided and possibly discuss this further. Please contact my office using the details below if you would like to arrange a time for me to call you back.

We have also arranged for an Organ Donation Support Service telephone line to be set up. If you would find it helpful to access this counselling service, please call 0800 680 0646. Please note that calls to this number are only free from landlines.

Yours sincerely

Lynda Hamlyn
Chief Executive



Blood and Transplant

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Date:

Dear NAME

I am writing regarding the NHS Organ Donor Register (ODR), the UK register that holds the records of people who have expressed a wish to donate organs after death.

Our records show that you joined the ODR, or updated your registration, via the Driver and Vehicle Licensing Agency (DVLA) when you completed a form related to your driving license. We are extremely grateful to you for taking this step to save lives and show your support for organ donation.

When you joined the register you filled in a form indicating which organs you wished to donate. Unfortunately, we have discovered a possible discrepancy with a number of ODR records that came via the DVLA. This problem is due to a processing error with one of our systems that has now been corrected. Responsibility for this lies with NHS Blood and Transplant and not the DVLA.

In the majority of cases, we expect the information held to be accurate. To be certain of this we are writing to everyone who may be affected to ask them to check their details. Please be assured that there has been no misrecording of the fact that you joined the register, and no loss of data.

Below you will find the contact details and donation preferences that we currently hold for you. Please could you check to ensure this accurately reflects your wishes.

Name:

Date of Birth:

Address:

Donation wishes:

I would be very grateful if you would contact us to either confirm that the above is correct, or to amend the record if it is not an accurate record of your wishes.

If this IS correct, please use one of the below methods to contact us to confirm this:

Call the NHSBT Organ Donor Records Helpline on 0300 123 99 99

Email:

Write to us at:

FREEPOST RRZK-SHUX-SBCK
NHS Blood and Transplant
Fox Den Road
Stoke Gifford
Bristol
BS34 8RR

If the above record IS NOT accurate, please contact us using one of the below methods to amend it:

Call the NHSBT Organ Donor Records Helpline on 0300 123 99 99

Visit www.organdonation.nhs.uk/amend

Write to us at:

FREEPOST RRZK-SHUX-SBCK
NHS Blood and Transplant
Fox Den Road
Stoke Gifford
Bristol
BS34 8RR

Please accept my apologies for any inconvenience this error causes, and my sincere thanks again for your commitment to saving lives through organ donation. With three people dying in the UK every day because of a lack of organs for transplant, we are encouraging more and more people to make the important decision to register. We ask those already on the ODR to discuss their wishes with their families and to spread the important message about organ donation.

Yours sincerely,

Sally Johnson

Director of Organ Donation and Transplantation

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To all DTCs and Duty Office Staff

Dear Colleague

Incorrect Data on the Organ Donor Register

It will have been obvious to many of you that we have not been able to provide the usual information service with regard to the Organ Donor Register since early March while we have been investigating the problems that arose in 1999.

We have been very careful during this period to make sure you could not give out incorrect information to any potential donor family but unfortunately we could not tell you what was happening. There were two reasons for this: firstly we needed to understand what the problem was and which records were affected and secondly we thought it was important to make sure that the first people to be told would be the affected donor families. Unfortunately the information was given to the press before we could contact the families but we are now doing this as a matter of urgency.

We have taken legal advice which gives answers to two key questions

1. What's the legal position if a donor did not indicate whether he or she wanted to donate the organ used for transplantation? Is this legal position the same in Scotland?

Our legal advice confirms that where a person has not specifically given consent (England and Wales) or authorisation (Scotland) for a particular organ to be donated, then consent/authorisation given by the person's nearest relative is valid, even in circumstances where there may have been some confusion as to what the expressed wishes of the deceased were.

2. Isn't this a breach of the Human Tissue Act?

Our legal advice indicates that consent/authorisation for use of specific organs given by the person's nearest relative is valid under the act.

Where we are able to, we are correcting the miscoded records. We will then write to those members of the Organ Donor Register whose donation preferences are unclear (up to 368,000 people) and we have set up a call centre to check and amend the register. Our aim is quickly to improve the accuracy of the register.

All this work does not alter the fact that the register needs to be reworked so it matches the best of modern databases. Before this incident we had already scheduled this work as a priority for this year's work plan: we will take this work forward later in the year, learning the lessons from this difficult time.

I know you will be concerned about the impact on the public's confidence in organ donation and the Organ Donor Register: it is too early to assess whether this has been affected but we will be doing our utmost to continue to promote the importance of donation.

Yours sincerely

Sally Johnson

Director of Organ Donation and Transplantation

Draft email – Partner organisations

Dear (Name)

As Boots are a long term and highly valued supporter of the Organ Donor Register (ODR), I wanted to write personally following media coverage over the weekend highlighting the fact that NHS Blood and Transplant is investigating a technical error in recording information on the register. The error has led to a number of ODR registrations being incorrectly recorded, where registrants had registered through the Driver and Vehicle Licensing Agency (DVLA) and where they indicated a preference to donate specific organs.

I would like to first take the opportunity to assure you that this problem does not affect people who have registered solely through the Boots Advantage Card scheme, and let you know that in the process of our investigations we have carried out tests on the data feeds from the Boots Advantage Card. We are confident that this error is confined to the data feed from the DVLA.

Unlike the tick box scheme on the Boots Advantage Card, when joining the ODR through the DVLA people are given the opportunity to tick either 'any of my organs and tissue' or specify their organ preferences. Most people (87%) who join through the DVLA choose 'any of my organs or tissues', however a small number do specify those organs they would be willing to donate. It is this group of people who have been affected.

We have, of course, taken this issue extremely seriously and carried out a thorough investigation to establish and correct the source of the problem. As soon as we had identified the issue, we suspended the use of information regarding preferences from affected records in the discussions with donor families, and temporarily stopped any new registrations from the 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 number of affected registrants have died and become organ donors. This has meant that the preferences quoted by health professionals to relatives when organ donation became a possibility may have been subject to error, however no donation took place without consultation with and written endorsement of the donor's family or next of kin. Our first priority is to contact the family members of all of these affected donors to inform them of the error and apologise unreservedly for any distress it causes.

I will contact you again with further updates as our work to correct all affected registrations progresses. In the interim I wanted to assure you that this has not affected the Boots Advantage Card data feed and that no data has been lost or compromised. Our Chief Executive, Lynda Hamlyn will be writing to Alex Gourlay in due course.

Best wishes

Draft email – Group 1 Stakeholders

Dear Colleague,

I am writing to you regarding an issue related to the Organ Donor Register (ODR) that has been covered in the media. You may have heard that NHS Blood and Transplant is investigating a processing error that has led to a number of ODR registrations being incorrectly recorded, where registrants had registered through the Driver and Vehicle Licensing Agency (DVLA) and where they indicated a preference to donate specific organs.

I enclose a briefing which summarises the issue, together with actions NHSBT has taken; and the key points which we are highlighting in our responses to media enquiries.

There is clearly a risk that as a result of this issue, public confidence in the NHS ODR may be affected. It is therefore extremely important to us that key individuals and organisations who share our goal of increasing the number of organs for transplant in the UK have access to clear and accurate information, and are confident in the action we have taken. Our first priority is to contact the families of the small number of organ donors that have been affected by this issue, to explain it to them in detail, answer their questions and apologise unreservedly for any distress that is caused. This is scheduled for early this week,

We hope that this information reassures you that we are taking this matter very seriously and have taken appropriate steps to correct the error. A full independent inquiry will be carried out to assess how this occurred and what lessons can be learned.

I will contact you again as needed to provide further updates on this issue.

Yours sincerely,

(JN, SJ, LW, LH)

Draft email – Supporters

Dear

As a highly valued supporter of the Organ Donor Register (ODR), I wanted to write personally following media coverage over the weekend highlighting the fact that NHS Blood and Transplant is investigating a technical error in recording information on the register. The error has led to a number of ODR registrations being incorrectly recorded, where registrants had registered through the Driver and Vehicle Licensing Agency (DVLA) and where they indicated a preference to donate specific organs.

I would like to first take the opportunity to assure you that we are confident that this error is confined to the data feed from the DVLA.

When joining the ODR through the DVLA people are given the opportunity to tick either 'any of my organs and tissue' or specify their organ preferences. Most people (87%) who join through the DVLA choose 'any of my organs or tissues', however a small number do specify those organs they would be willing to donate. It is this group of people who have been affected.

We have, of course, taken this issue extremely seriously and carried out a thorough investigation to establish and correct the source of the problem. As soon as we had identified the issue, we suspended the use of information regarding preferences from affected records in the discussions with donor families, and temporarily stopped any new registrations from the 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 number of affected registrants have died and become organ donors. This has meant that the preferences quoted by health professionals to relatives when organ donation became a possibility may have been subject to error, however no donation took place without consultation with and written endorsement of the donor's family or next of kin. Our first priority is to contact the family members of all of these affected donors to inform them of the error and apologise unreservedly for any distress it causes.

I will contact you again with further updates as our work to correct all affected registrations progresses.

Draft email – Group 2 charities

Dear

As a key organisation that works closely with NHS Blood and Transplant (NHSBT) to encourage more people to sign up as organ donors, I am writing to you regarding an issue related to the Organ Donor Register (ODR) that has been covered in the media this weekend.

You may have heard that NHS Blood and Transplant is investigating a processing error that has led to a number of ODR registrations being incorrectly recorded, where registrants had registered through the Driver and Vehicle Licensing Agency (DVLA) and where they indicated a preference to donate specific organs. The error has occurred within our system and therefore responsibility for correcting it lies with NHSBT and not the DVLA.

Firstly I would like to reassure you that nobody has been registered as an organ donor against their wishes, no data has been lost at any stage, and no other routes to join the NHS Organ Donor Register have been affected. We are taking this error extremely seriously and have completed a thorough investigation to identify the source of the problem. It has now been corrected to ensure that future registrations are accurately recorded.

We have identified that approximately 812,000 records may have been affected, representing just under five per cent of the 17 million records 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 number of these affected registrants did donate after their death. Our first priority is to contact their families as a matter of urgency 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.

There is clearly a risk that as a result of this issue, public confidence in the NHS ODR as means of recording wishes about organ donation may be affected. It is therefore extremely important to us that that key individuals and organisations who share our goal of increasing the number of organs for patients have access to clear and accurate information, and are confident in the action we have taken.

I very much hope that we can rely on your continuing support in promoting the vital message that organ donation saves lives. As you know, 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.

Yours sincerely

Draft letter – Group 2 professional bodies

Dear

As a professional body with a strong interest in organ donation and transplantation, I am writing to you regarding the issue related to the Organ Donor Register (ODR) that has been covered in the media this weekend.

You may have heard that NHS Blood and Transplant is investigating a processing error that has led to a number of ODR registrations being incorrectly recorded, where registrants had registered through the Driver and Vehicle Licensing Agency (DVLA) and where they indicated a preference to donate specific organs. The error has occurred within our system and therefore responsibility for correcting it lies with NHSBT and not the DVLA.

Firstly I would like to reassure you that nobody has been registered as an organ donor against their wishes, no data has been lost at any stage, and no other routes to join the NHS Organ Donor Register have been affected. We are taking this error extremely seriously and have completed a thorough investigation to identify the source of the problem. It has now been corrected to ensure that future registrations are accurately recorded.

We have identified that approximately 812,000 records may have been affected, representing just under five per cent of the 17 million records 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 number of these affected registrants did donate after their death. Our first priority is to contact their families as a matter of urgency 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.

There is clearly a risk that as a result of this issue, public confidence in the NHS ODR as means of recording wishes about organ donation may be affected. It is therefore extremely important to us that that key individuals and organisations who share our goal of increasing the number of organs for transplant in the UK have access to clear and accurate information, and are confident in the action we have taken.

I very much hope that we can rely on your continuing support in promoting the vital message that organ donation saves lives. If you have any questions in the interim, please do not hesitate to contact me.

Yours sincerely

Sally Johnson