## Telegraph.co.uk

## Organs removed without consent after IT blunder

## Bereaved families will be told that organs were removed from their loved ones without consent after a blunder affecting Britain's donor register.

By Patrick Hennessy and Laura Donnelly Published: 9:30PM BST 10 Apr 2010 - Telegraph.co.ok

The records of 800,000 people were affected by an error that meant their wishes about the use of their organs after death were wrongly recorded.

An investigation has found that 45 of those for whom wrong records were stored have since died – and in approximately 20 cases organs were taken where consent had not been given.

Andy Burnham, the Health Secretary, said today he deeply regretted the distress caused to bereaved families of people whose organs were removed without consent following a huge blunder affecting the UK donor register.

He said: "I want to assure the millions of people on the organ donor register that they can have full confidence that only their accurate information will be discussed with their families, and that their wishes will be respected.

"This has clearly not happened in a small number of cases in the past, and I deeply regret the distress caused to the families.

He added: "I have asked NHS Blood and Transplant to take immediate steps to identify and contact all affected families. This process is under way and will be completed as quickly as possible.

"I have asked Professor Sir Gordon Duff of Sheffield University to carry out a review to find out why this has happened, prevent mistakes like this being made again and ensure all necessary steps are taken to maintain confidence in the organ donor register."

Donors can give permission for any of their organs to be taken, or provide more specific agreements. A glitch in the system more than a decade ago removed the distinctions expressed by people.

Many donors have strong views about what can be taken. Often consent is not given for eyes to be removed, while some people who agree to donate organs are uncomfortable with the idea of their body tissue being used in research.

Joyce Robins, from the pressure group Patient Concern said: "This Government has got an absolutely dreadful record when it comes to data, but it is absolutely horrific that such sensitive details were handled in such a careless way."

The NHS is about to contact approximately 20 families who allowed organs to be taken from their relations after being misinformed about what consent had previously been given.

It is illegal to remove organs without prior consent from the person who died or their next of kin. A view is sought from relations before decisions are taken. In the cases where errors were made, it is understood that families were asked for permission, but their decisions were based on misinformation about the wishes of their relations.

After detecting the fault last year, NHS Blood and Transplant, which holds the organ donation register, was able to correct 400,000 of the flawed records. But 400,000 more people will shortly be contacted to be told that the wrong information may be held about them, and asked to provide consent again.

Until fresh consent is obtained, organs will not be taken from any of those people in the event of death.

The error occurred in 1999, when data held by the Driver and Vehicle Licensing Agency, which includes a request for consent in applications for a driving licence, was transferred to the organ registry.

The mistake came to light when NHS Blood and Transplant (NHSBT) wrote letters to new donors thanking them for joining the register, and outlining what they had agreed to donate. Respondents wrote back to say the information was wrong.

A spokesman for NHS Blood and Transplant, said: "We are taking it very seriously and are urgently investigating the situation."

A Department of Health spokesman said: "NHSBT has made the Department of Health aware that a very small number of donor families, and a small proportion of records may have been affected by a coding error on the Organ Donor Register.

"NHSBT are working hard to identify those affected or their families and will contact them to offer help and support.

"We have been assured by NHSBT that urgent action is underway to correct any miscoding of data and we are monitoring the situation closely.

"Organ donation offers many people the gift of life - those considering signing up to the Organ Donor Register can be reassured that they will not be affected."