

request-52283-0c247456@whatdotheyknow.com

Our ref: PD/KH/190974

Dear Mr Rawlins

Re: Information request

I am writing regarding your request for information dated the 19th November.

We are able to provide the following information in response to your request.

1. Donor Demographics

As stated in the leaflet 'Your Information – A Guide For Donors', the purpose of comparing the blood donor database with other databases would be to improve the accuracy of our own records, and to keep them up to date, thereby enabling us to contact donors for the primary purpose of inviting them to donation sessions. There is no fixed rule for when such data transfers might occur, as it depends on the availability of a suitable reference database and the means to effect a reliable update. When active, the process involved matching of NHSBT records with central NHS records, and flagging of the latter for all matches found. Thereafter, changes to the central records (address, or the death of the patient) would be transmitted to NHSBT as it occurred. This was an extension of the primary functionality of the link, which was to provide a means for people to enrol as blood donors at the point of registering or re-registering with a GP.

The mechanism for updating addresses on existing donor records is currently deactivated, because of issues arising from data quality and insufficient validation on upload. Even before it was deactivated, the address updating mechanism was switched off on request for individual donors.

The central NHS databases referred to are the NHAIS (formerly Exeter Systems) and not the PDS nor its predecessor, the NHS Strategic Tracing Service. The assumption was that the new address supplied from the NHAIS would always be more up to date than that held by NHSBT because the message was triggered when a patient notified his or her GP of a change of address on moving house.

- a. As per the above, the NHAIS record was regarded as the gold standard in these transactions.

- b. Once the link between records was established, the interface involved a one-way flow of data only. There was never any updating of central records with data from NHSBT.
- c. Not applicable, see above.
- d. No.
- e. Not applicable as the PDS is not involved.
- f. Not applicable as the PDS is not involved.
- g. Our terminology is in fact more accurate, as the individual NHAIS databases are not nationally accessible. The wording was also designed to accommodate the possibility of developing other solutions such as links to NSTS or PDS, which to date has not happened.
- h. On manual registration of any new donor, the facility exists to check their address against the public version of the Electoral Roll, as an aid to input accuracy.

During 2009, an extract of records of donors whose mailings had been returned to us as undeliverable was submitted for matching by Experian against their own records, and those of the Royal Mail National Change of Address database.

- i. See above; the project with Experian was governed by a contract defining their role as data processor on NHSBT's behalf.

2. Blood Donor Online (BDO)

- a. The Government Gateway is the responsibility of the Cabinet Office's e-Delivery Team. Atos Origin has been the major supplier.
- b. NHSBT uses the Government Gateway for account management only. When a donor authenticates, we pass the details to GG which responds with a session ticket if the authentication is successful. Logging on to BDO does not give access to any of the 'state organisations' with which the donor may also be enrolled - they would have to log in again to those. Logging in with a GG account on any system other than BDO will not give access to BDO.
- c. Yes. Blood Donor Online is a user interface to the donor's record on the NHSBT blood donor database.
- d. No/not applicable

- e. No/not applicable
- f. Not at present. NHSBT uses GG only for authentication services. We host Blood Donor Online ourselves and communicate with GG only at the login step of the session. Our infrastructure is not geared to handle the volume of BDO accounts.
- g. We do not hold the precise information you request, but in the last 12 months there have been 32,271 unique users of BDO, and 76,987 in total. There are 1.375 active donors on our database.

3. Use of donated blood for research and development work

- a. A mixture of both, depending on the circumstances.
- b. NHSBT has in the past obtained legal advice and endorsement from the Information Commissioner's Office to the effect that data that relates to a donation, such as its fate, rather than directly to its donor, does not constitute personal data within the meaning of the Data Protection Act 1998. Such data therefore does not fall within the ambit of the Act's Subject Access provisions. Where research projects involve testing whose results might be of interest to the donors, these are commonly performed anonymously so that there is no potential for providing results. Where donor-identifiable projects are undertaken, these will be with full informed consent, the terms of which will depend on the nature of the project.

4. Smallpox Vaccination

Although wild smallpox has been eliminated there are still a few laboratories working with smallpox virus including some in this country. Thus workers in these laboratories and their contacts may still be vaccinated against smallpox. It is a live vaccine and as such may present a risk to a patient if blood is taken from a recently vaccinated donor. This is because many of the patients who receive blood have a very poor or no immune system.

This question is asked verbally as we hope that it can soon be removed from the question schedule, and so incorporating it on the stationery would not be desirable or cost-effective.

It is asked of all donors at present.

5. Organ Donor Register

The Organ Donor Register is founded on the opt-in system as currently enshrined in UK legislation. There is no need to opt out as this is the default

in the absence of opting in. If an individual has concerns that next of kin may consent to donation after death, contrary to his or her wishes, that individual should ensure that friends and family know their views and provide assurance that their wishes will be respected. We encourage everyone to discuss their wishes with family whether they wish to donate or not.

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If you have any queries about this letter, please contact me. Please remember to quote the reference number above in any future communications. In addition if I can be of any further assistance in any other way please do not hesitate to contact me.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Andrew Pearce', with a long horizontal flourish extending to the right.

Andrew Pearce
Head of Donor Advocacy

E-mail: customer.services@nbs.nhs.uk

If you are unhappy with the service you have received in relation to your request and wish to make a complaint or request an review of our decision, you should write to: Head of Donor Advocacy, NHS Blood and Transplant, Colindale Avenue, Colindale, London, NW9 5BG (Email: customer.services@nhsbt.nhs.uk).

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by NHS Blood and Transplant (NHSBT). The Information Commissioner can be contacted at: The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF.