

## **Freedom of Information Act 2000 (FOIA)**

### **Decision notice**

**Date:** 16 February 2022

**Public Authority:** NHS Blood and Transplant  
**Address:** 500 North Bristol Park  
Filton  
Bristol BS34 7QH

#### **Decision (including any steps ordered)**

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1. The complainant has requested information about the organ donor register. NHS Blood and Transplant (NHSBT) advised that it does not hold the specific information requested.
2. The Commissioner's decision is as follows:
  - On the balance of probabilities, NHSBT does not hold recorded information falling within scope of the request and complied with section 1(1)(a) of FOIA.
3. The Commissioner does not require NHSBT to take any corrective steps.

#### **Request and response**

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4. On 13 August 2020 the complainant wrote to NHSBT and requested information in the following terms:

"Please provide the following information under the freedom of information act 2000;

When a person wishes to record a decision on the ODR, one is required to enter three identifying details onto the register;

1. Name

2. DOB
3. Address The following details are entered on a voluntary basis;
4. Gender
5. Title
6. Ethnicity
7. Religion
8. Email address
9. Phone number

The following details 'cannot' be entered onto the register;

- \* National Health Number
- \* National Insurance Number

The first nine aforementioned identifying details are either, not unique, or/and could potentially change. Whereas the National Health Number & National Insurance Number, are unique, and under normal circumstances are not prone to change.

At the margin of the ODR certificate, the NHS advice; "we cannot accept responsibility for inaccuracies where we are not made aware of changes...".

More likely than not, a girl who registered her decision at eighteen, will not remember to record change of last name and address, after her nuptial at thirty!

Similarly, will a middle-aged couple who registered their decisions on the ODR, remember to record change of address, when retiring to a home, decades later?

Most people who have been ordinarily resident in England for 12 calendar months, possess a National Health Number and many also have a NINO.

By linking the ODR with the NHS's general database via the National Health Numbers (similar to how the personal details of a credit/debit card are linked to the card & pin numbers), it will surely not only enhance security, but also prevent many irreversible errors.

If so, please provide all the information and documents held by the NHS relating to;

Why does the NHSBT not make it possible for people to 'voluntarily' record these numbers on the ODR."

5. NHSBT responded on 4 September 2020. It explained why the organ donor register (ODR) does not need individuals to provide their NHS

number at the point of registration. This is to avoid introducing a barrier that could potentially prevent someone from registering, if they did not know their NHS number, for example. NHSBT also explained why the ODR does not need individuals to provide their national insurance (NI) number voluntarily or by any other means. NHSBT provided the complainant with links to more information about NHS numbers and the Scottish equivalent.

6. The complainant requested an internal review on 22 June 2021 and NHSBT provided one on 7 July 2021. It confirmed that it holds no further recorded information relevant to the request.

### **Scope of the case**

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7. The complainant contacted the Commissioner on 9 July 2021 to complain about the way their request for information had been handled.
8. The Commissioner has considered whether, on the balance of probabilities, NHSBT holds the specific information the complainant has requested.

### **Reasons for decision**

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9. Under section 1(1) of the FOIA, anyone who requests information from a public authority is entitled under subsection (a) to be told if the authority holds the information and, under subsection (b), to have the information communicated to them if it is held and is not exempt information.
10. The complainant is seeking information from NHSBT that records the decision not to allow individuals to enter certain information into its ODR voluntarily.
11. The complainant considers that NHSBT holds this information but is deliberately withholding it. They note that many NHS websites and systems request that individuals provide an NHS number or NI number, and that only with the ODR is that not requested, and nor is there an option for providing that information voluntarily.
12. In its submission to the Commissioner, NHSBT has acknowledged that in its original response to the request, it had not confirmed that it does not hold the information the complainant has requested. It has told the Commissioner that, as part of the continuous improvement of its FOIA and Data Protection processes, it has now standardised its FOIA

response letters and confirms to all applicants whether it does or does not hold information.

13. NHSBT has gone on to note that, regarding the general information it gave in its response, it should have advised the complainant that it was providing that information under section 16 of FOIA (advice and assistance). NHSBT says it had sought to explain the rationale for not including NHS numbers or NI numbers on the ODR.
14. As it had explained to the complainant, NHSBT explained to the Commissioner that the NHS number is captured post-registration to the ODR. This is done by linking to services provided by NHS Digital known as the 'Personal Demographics Service' (previously NHS Demographic Batch Service). For Scottish residents the Community Health Index (CHI) number (the NHS number equivalent) is captured by linking to a similar service provided by NHS National Services Scotland known as the Community Health Index Service.
15. Post-registration, the ODR retrieves a registrant's NHS or CHI number, depending on the country of address provided at the point of registration.
16. NHSBT's submission next discusses the searches it undertook for information relevant to the request. It consulted Business Owners and Subject Matter Experts for the ODR, including the Head of ODR who has been in post since 2017. That individual has been responsible for the ODR's operational service delivery and, as such, is NHSBT's Information Asset Owner for the Register. They are integral to key decision making for the ODR.
17. A further conversation also took place with the Accountable Executive responsible for implementing the 2015 ODR replacement project, who was in role towards the end of the design and build phase in 2015. These members of staff were not in post in 2015 when key decisions on the design of the replacement of the ODR may have been made (and potential discussion or decisions about whether or not to allow registrants to key in NHS or NI numbers voluntarily). However, those staff members do have access to (and therefore an understanding of) recorded information about the ODR during that time.
18. The previous Accountable Executive in post during the design and build of the ODR replacement in 2015 has now left NHSBT, but any major decisions were handed over to the new Accountable Executive. That staff member is not aware of any such decision about allowing registrants to voluntarily record their own NHS or NI number being discussed or recorded to date. NHSBT notes that the ODR was entirely rebuilt in 2015 and all data from the previous version was migrated

across. Whilst there was a Head of ODR prior to the replacement build, this member of staff has also now left NHSBT and therefore could not be consulted.

19. NHSBT is, however, satisfied due to the searches and reasoning outlined below that it has been able to retrieve all information relevant to the request. Whilst other staff members across NHSBT may have an awareness and broader understanding of the ODR, they are not directly working in this field and therefore it was not appropriate to consult them about this request. But NHSBT considers that the discussions it has had with relevant staff members have enabled it to understand the wider context of the ODR and the information that is captured from donors.
20. NHSBT has gone on to describe other searches it carried out. It undertook a search and review of the ODR shared areas (F Drive). These store all electronic records relating to the ODR, such as meeting minutes and steering groups where decisions, such as any related to the request, are stored. It is a repository for all up-to-date, version-controlled documents that cover all operational ODR activity prior to and from its replacement build in 2015 to the present day.
21. It has been a known operational practice by the entire ODR Team, both prior to the re-build in 2015 to the present day, that documentation is stored only in the shared areas. Therefore this was a relevant search as any recorded information relating to key decision making would be saved on there. It is for this reason that NHSBT is satisfied that the searches would have captured information relating to the request prior to 2015 even if it has not been able to consult directly with staff working on the ODR at that time.
22. NHSBT has further means to store electronic records, such as SharePoint and NHSBT Controlled Documents Library of its Quality Management System. Whilst it did not actively search these places, the ODR team at present do not use SharePoint for document storing and the Controlled Documents library holds Standard Operating Procedure, Policies, Management Process Descriptions that direct or instruct staff on appropriate behaviour. This material does not outline when, where or why operational decisions are made by NHSBT teams as requested by the complainant. It was therefore not necessary to search either of these two additional electronic stores.
23. NHSBT has confirmed that all the searches it carried out were for electronic data; it was not necessary to undertake searches for paper records because operational decisions, if recorded, would be held electronically. Search terms used for the F Drive included 'NHS number' and 'NI number'.

24. Since the request concerned key operational decisions about the ODR, NHSBT did not consider it appropriate to search personal computers of NHSBT staff. If any decisions which affect the design, build or operations of the ODR are taken, these are made jointly with the ODR team in meetings and/ or steering groups. NHSBT considers that it would therefore not be reasonable for personal computers to hold such information. This is because it would need to be accessed and understood across the entire team to be an effective and implemented business decision. For example, ODR administrators need access to key decisions to answer queries from donors, and architects need access to this information to implement any technical changes. As NHSBT has stated previously, it is also a known practice across the ODR team, that all documentation is to be saved on the F Drive, so it is accessible by all relevant members of staff. Holding information on personal computers would not make practical business sense.
25. NHSBT concludes its submission by advising that business decisions such as the design, build and operations of the ODR would usually be discussed as part of formal team meetings and steering groups. As stated, minutes would then be saved on the F Drive so that all staff follow the same working principles and practices. A decision about including NHS and NI numbers specifically "was not deemed to be a viable decision to be made" and therefore there was no business requirement for this to be recorded.
26. Finally, NHSBT has advised that in more recent correspondence with the complainant, separate from their FOIA request, it has provided a further explanation about the decision making that is the focus of their request.
27. The complainant has told the Commissioner that they consider that NHSBT holds the information they have requested because in 2020 a complaint about this issue was submitted to NHSBT. They consider that since senior NHSBT officers are aware of that complaint there must be a record of why NHSBT decided to "deviate from its standard practice when it comes to the ODR".
28. From a discussion with NHSBT, the Commissioner understands that the complaint referred to here is a complaint about their ODR concern that the complainant submitted to NHSBT on 13 August 2020, on the same day they submitted their request for information on the same matter. NHSBT has explained to the Commissioner that it addressed the complainant's concerns through its response to the FOI request only; it did not progress the related complaint, at that time. As such, the Commissioner is satisfied that at the time of the request NHSBT did not hold any information associated with the complaint that it could have communicated to the complainant in its response to their FOI request.

29. NHSBT has explained to the complainant the rationale behind particular decisions about its ODR and the Commissioner finds that rationale to be entirely credible. He is satisfied that NHSBT has given sufficient thought to the complainant's request; who would be likely to know if any relevant information is held and where any such information would be held. The Commissioner is satisfied too with the searches NHSBT has undertaken, which he considers to have been appropriate and thorough. The Commissioner has therefore decided that, on the balance of probabilities, NHSBT does not hold the requested information and complied with section 1(1)(a) of the FOIA.

## Right of appeal

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30. Either party has the right to appeal against this decision notice to the First-tier Tribunal (Information Rights). Information about the appeals process may be obtained from:

First-tier Tribunal (Information Rights)  
GRC & GRP Tribunals  
PO Box 9300  
LEICESTER  
LE1 8DJ

Tel: 0203 936 8963

Fax: 0870 739 5836

Email: [grc@justice.gov.uk](mailto:grc@justice.gov.uk)

Website: [www.justice.gov.uk/tribunals/general-regulatory-chamber](http://www.justice.gov.uk/tribunals/general-regulatory-chamber)

31. If you wish to appeal against a decision notice, you can obtain information on how to appeal along with the relevant forms from the Information Tribunal website.
32. Any Notice of Appeal should be served on the Tribunal within 28 (calendar) days of the date on which this decision notice is sent.

## Signed

**Cressida Woodall**  
**Senior Case Officer**  
**Information Commissioner's Office**  
**Wycliffe House**  
**Water Lane**  
**Wilmslow**  
**Cheshire**  
**SK9 5AF**