



Department  
of Health

Freedom of Information Team  
Department of Health  
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SW1A 2NS

[FreedomofInformation@](#) **GRO-C**

JJ Evans

request-403774-4c8f1c5e@ **GRO-C**

1 September 2017

Annex A: DH response to initial request dated 10 May 2017  
Annex B: Request for internal review 20 June 2017

Dear Mr Evans,

**FREEDOM OF INFORMATION ACT (FOIA): INTERNAL REVIEW  
CASE REFERENCE IR 1083997**

You originally wrote to the Department of Health (the DH) on 27 April 2017 requesting the number of haemophilia patients, according to the National Haemophilia Database, who acquired hepatitis C or HIV through treatment for haemophilia, and how many of those patients had subsequently died from conditions attributed to hepatitis C or HIV. We responded to you on 10 May 2017 (FOI 1083997) stating that DH does not hold the requested information referring you to UK Haemophilia Centre Doctors' Organisation (UKHCDO) database - <http://www.ukhcdo.org>.

A copy of our response, including the full text of your request is at Annex A.

You subsequently emailed DH on 20 June 2017 requesting an internal review into the handling of your original request. A copy of your email is at Annex B.

The purpose of an internal review is to assess how your FOI request was handled in the first instance and to determine whether the original decision given to you was correct. This is an independent review as I was not involved in the original decision.

I have discussed your request with the team which has the relevant policy responsibility related to this case. DH's Research and Development Directorate has confirmed that this information is not held by DH and, although DH provided the funds to set up the National Haemophilia Database which is run and hosted by the UKHCDO, the database is no longer funded by DH.

The United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) is required by the Department Of Health to collect data, but does not hold the data itself as it is kept in the National Haemophilia Database, which is located in Manchester. You may wish to use the information request form on the National Haemophilia Database website to ask for the specific information you are seeking.

Conclusion

After careful consideration I am satisfied that the initial response you received was fully compliant with the FOIA.

The review is now complete.

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by the Department. The ICO can be contacted at:

The Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF

Yours sincerely

HARISH SEHDEV  
*Deputy Head of Freedom of Information*  
*Department of Health*

## Annex A DH response to initial request

10 May 2017

Dear JJ Evans

### Freedom of Information Request Reference FOI-1083997

Thank you for your request dated 27 April 2017 in which you asked the Department of Health (DH):

*“Please can you tell me how many Haemophilia patients (According to the National Haemophilia Database) have been CONFIRMED as having either Hepatitis C or HIV infection acquired through their Haemophilia treatment.  
In addition please can you tell me how many Haemophilia patients have died (According to the National Haemophilia Database) from conditions attributed to Hepatitis C infection acquired from Haemophilia treatment.  
In addition please can you tell me how many Haemophilia patients have died (According to the National Haemophilia Database) from conditions attributed to HIV / AIDS infection acquired from Haemophilia treatment.”*

Your request has been handled under the Freedom of Information Act (FOIA).

The DH does not hold the information you requested. This is because we are not the appropriate authority to contact on this subject. You may wish to contact UK Haemophilia Centre Doctors' Organisation- <http://www.ukhcd.org/> who may hold the information you require on the *National Haemophilia Database* (NHD) that they host. In addition NHD publishes reports on its website and has an information request form for specific information requests so you may wish to use that to seek any additional information.

If you are not satisfied with the handling of your request, you have the right to appeal by asking for an internal review. This should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to the address at the top of this letter, or the email address at the end of this letter.

Please remember to quote the reference number above in any future communications. If you are not content with the outcome of your internal review, you may complain directly to the Information Commissioner (ICO) who may decide to investigate your concerns. Generally, the ICO cannot make a decision unless you have already appealed our original response, and received our internal review response. The ICO will not usually investigate concerns where there has been an undue delay in bringing it to their attention. You should raise your concerns with them within three months of your last meaningful contact with us.

The ICO can be contacted at:  
The Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

<https://ico.org.uk/concerns/>

Yours sincerely,

**Annex B: Request for internal review**

From: JJ Evans [mailto:request-403774-4c8f1c5e@GRO-C]  
Sent: 20 June 2017 16:21  
To: FreedomofInformation  
Subject: Re: Freedom of Information request - Haemophilia Patient Death Numbers

Dear Department of Health,

Thank you for your reply on 10th May to my FOI Request (Your ref: FOI 1083997). In your reply you advised that I contact the UKHCDO / NHD for this information. I have done this however the Manager of the NHD (Bruce Cowen) has not provided the information and has advised me that as a Charity the UKHCDO are not obliged to provide it.

I find it most concerning that this would be the case when the UKHCDO is required by the Department of Health to collect this data in the first place. This is clearly Public Information that is being collected on behalf of a Public Body and then withheld.

The information I originally requested relates to an issue, which as you may be aware, is alleged by many, including Politicians to have been subject to a "cover-up". My experience in getting at this information so far is not helping to quash those allegations.

This event is the greatest loss of life in the UK in modern times and the exact figures should be published, when they are clearly held, by the NHD, who have collected this data as requested/required by the Department of Health. Not based on "modeling" or guess-work, but on the exact information held by the NHD.

Your response states that "we are not the appropriate authority to contact on this subject", but the UKHCDO website states that "The UKHCDO is required by the Department of Health to collect data" (<http://www.ukhcd.org/nhd/>) and have subsequently made it clear to me that they do not intend to provide this information.

It cannot be the case that the Department of Health hides behind a "Charity" in order to prevent Public Information garnered through the NHS from being released. I would again request the following information below. If the information is not forthcoming I would like to request an Internal Review under Section 45 of the FOI Act and I will file a complaint with the ICO and my MP.

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Please can you tell me how many Haemophilia patients (According to the National Haemophilia Database) have been CONFIRMED as having either Hepatitis C or HIV infection acquired through their Haemophilia treatment.

In addition please can you tell me how many Haemophilia patients have died (According to the National Haemophilia Database) from conditions attributed to Hepatitis C infection acquired from Haemophilia treatment.

In addition please can you tell me how many Haemophilia patients have died (According to the National Haemophilia Database) from conditions attributed to HIV / AIDS infection acquired from Haemophilia treatment.

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Yours faithfully,  
JJ Evans