



Our ref: NIC-242402-P9S4R

7<sup>th</sup> February 2014

Dear Dr Bhatia,

**Re: Information Request – Freedom of Information Act (FOIA) 2000**

I can confirm that the Health and Social Care Information Centre (HSCIC) has considered your query dated the 13<sup>th</sup> January 2014.

***I would be grateful if you would clarify just one point about how the data that you hold is processed after GP uploads.***

***Your [previous response](#) made it clear that uploaded GP data held by the HSCIC as part of care.data would be retrospectively anonymised in cases where an individual opts-out after extraction has taken place, i.e. when the 9Nu0 code is added to their GP record. In such circumstances, no further information would be uploaded from that patient's GP record to the HSCIC (as a primary care dataset).***

***Please could you kindly tell me:***

- Does this action result in retrospective anonymisation of ALL the data relating to that patient as held in the "Primary Care / HES Non relational database", or just the GP data part of it (leaving the HES component unaffected)?***
- Will the "retrospectively anonymised" GP data be unlinked and removed completely from the Primary Care / HES Non relational database (i.e. the CES database), leaving just identifiable HES data, or will it remain in the database, associated in some way with the matching HES data (in which case I would be unclear as to how it could be regarded as anonymised)?***

There has been a change in policy in relation to retrospective anonymisation since our response to your Freedom of Information request dated 9 September 2013.

The initial policy decision relating to retrospective anonymisation was taken in recognition of the short timescales between patients being informed about the programme and the first planned extraction of data from GP surgeries.

Since this decision was taken, the first planned extraction of data has been postponed to allow a national awareness-raising campaign to take place, thus giving citizens more time to register their objections.

At a national level, the awareness-raising includes:

- A patient leaflet about information sharing sent to every household in England during January 2014**
- A dedicated patient information line, which will be available from 6th January until 31st March 2014 to respond to questions from patients. Please note that the patient line will not be able to record objections**

- Resources and guidance that we have developed nationally including patient materials and FAQs
- If required, arrangements for GPs to receive additional materials including Braille and easy read and audio versions
- Social media activities
- Digital media. For example, there are dedicated patient support pages on the NHS Choices website, including a lead article on the front page that signposts citizens to information ([www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/caredata.aspx](http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/caredata.aspx)). The site receives over 20 million hits a month. There are also dedicated pages on the HSCIC website ([www.hscic.gov.uk/patientconf](http://www.hscic.gov.uk/patientconf))
- Discussion with national patient groups, charity and voluntary sector organisations to enable cascade of messages through their regular and social media channels
- Information about care.data provided to 350,000 charities and voluntary groups who have been asked to cascade the information to their members
- National media coverage for example articles in the Observer, the Guardian, and the Independent and radio interviews

Regional awareness-raising includes:

- Extensive regional media coverage with over 100 articles on regional news websites
- Proactive focus on specialist regional events aimed at area teams, CCGs and others who helped provide local support to practices
- Additional awareness raising with the public through regional communications teams

Following discussion with the Department of Health, an objection will now be applied from the time at which it is made. The HSCIC will not anonymise data retrospectively where an objection is registered with a GP practice following an extraction of data.

- ***Could you confirm that no further identifiable GP primary care dataset uploads will take place with respect to such a patient who has opted-out (9Nu0) subsequent to the first extraction?***

Where patients have registered an objection to the disclosure of their personal confidential data from GP practices, this will be respected in all but exceptional circumstances.

The circumstances when an objection would be overridden are very rare and relate to specific legal requirements. Further details can be found in question 23 of the Frequently Asked Questions for GPs available at [www.england.nhs.uk/caredata](http://www.england.nhs.uk/caredata)

In line with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the HSCIC website.

I trust you are satisfied with our response to your request for information. However, if you are not satisfied, you may request a review from a suitably qualified member of staff not involved in the initial query, via the [enquiries@hscic.gov.uk](mailto:enquiries@hscic.gov.uk) e mail address or by post at the above postal address.

I will assume that your request to the organisation is now closed.

Yours sincerely,

**James Smith**  
**Higher Information Governance Officer**

Further information about your right to complain under the Freedom of Information Act is available from the Information Commissioner's Office, Wilmslow, Cheshire, and on The Information Commissioner's website [www.ico.gov.uk](http://www.ico.gov.uk).

The Health and Social Care Information Centre values customer feedback and would appreciate a moment of your time to respond to our Freedom of Information (FOI) Survey to let us know about your experience. Please access the survey through this link

[https://www.surveymonkey.com/s/HSCIC\\_FOI\\_Feedback](https://www.surveymonkey.com/s/HSCIC_FOI_Feedback)