



Our ref: NIC-264897-W0G6X

15th May 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 request for information dated 14 April 2014 which stated:

I am very grateful for your previous FOI response concerning anonymisation of uploaded GP care.data

<https://www.whatdotheyknow.com/request/202364/response/505779/attach/2/NIC%20257306%20Y3R4J%20Final%20FOI%20Response.pdf>

My understanding from your reply is that citizens *will* be able to request anonymisation of their uploaded GP care.data information.

I would be very grateful if you would provide me with the following further information:

**** Please could you tell me which of the uploaded core patient GP data fields (NHSNumber, Date of Birth, Gender, PostCode, Ethnicity Code, Registration Status, Registration Date, De-Registration Date, Date of Death) would be deleted/blanked upon anonymisation***

**** Please could you tell me if the resulting anonymised GP data would be completely "unlinked" from its corresponding HES record?***

**** Please could you tell me (yes/no/we haven't decided yet) whether citizens will be able to request that their uploaded GP care.data is deleted, and not just anonymised?***

The HSCIC does not hold any documentation as outlined above.

The HSCIC has yet to take a formal decision on whether patient data would be anonymised or deleted and the process that will be used to facilitate this. We expect this decision to be made by the end of August, before the first extraction of data begins to arrive at the HSCIC. However, we are still working through the plans and timescales for this.

We hope to align this with the work we are currently doing to review the existing 'Withdrawal of Consent to the Processing of Personal Information for Secondary Care Purposes' form and related processes.

If a patient requests that their uploaded GP care.data is anonymised, but does NOT request their GP to add the 9Nu0 read code to their record, what happens then? Would that result in the following?

**** their identifiable GP dataset would continue to be uploaded to the HSCIC on a regular, monthly, basis and would be anonymised at the HSCIC***

Yes but as per earlier response the decision as to whether the data is deleted or anonymised has not been taken.

*** no combined/linked GP-HES data (i.e. CES data) could be released to organisations, in any format (since the uploaded and anonymised GP data is no longer linked to HES data)**

Yes

*** uploaded GP data could then only ever be released to organisations in an aggregate or anonymised format (i.e. could not be released to organisations in a pseudonymised or clearly identifiable format)**

Yes, as per earlier response if the decision is taken to anonymise the data then the data could only be released in aggregate or anonymised form.

I would also be grateful if you would also kindly provide me with the following information, in respect of citizens whom have neither opted out via 9Nu0 nor requested that their uploaded GP care.data, or their HES record, are anonymised:

*** When citizens die, what will happen to their uploaded GP care.data?**

The data previously collected from primary care will continue to be held by the HSCIC. When the status of the patient record is changed at the GP Practice, no further new flows of data will occur for that citizen.

What happens to their HES record?

The data previously collected from hospitals and collated in the form of Hospital Episode Statistics will continue to be held by the HSCIC.

Could either continue to be used for data releases, in any format?

Yes, the data previously collected could continue to be released.

*** When citizens are formally deregistered from their English GP surgery, for whatever reason, and until such time as they register with a new English GP surgery, what will happen to their uploaded GP care.data?**

The data previously collected from primary care will continue to be held by the HSCIC. When the status of the patient record is changed at the previous GP Practice no further new flows of data will occur for that citizen, until such time as they register at a new GP Practice.

What happens to their HES record?

The data previously collected from hospitals will continue to be held by the HSCIC. If a patient attends for hospital treatment in any part of England, activity data e.g. about their attendance, outpatient appointment, diagnosis and/or treatment will continue to be recorded and submitted as part of the Commissioning Data Sets and will therefore continue to be collected within HES.

Could either continue to be used for data releases, in any format?

Yes, the data previously collected could continue to be released.

And what happens if they never re-register with an English GP surgery (e.g. they emigrate)?

The data previously collected from primary care will continue to be held by the HSCIC. When the status of the patient record is changed at the GP Practice to indicate they are no longer registered then no further new flows of data will occur for that citizen. The data previously collected could continue to be released.

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 hope that 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 email address or by post at the above address.

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

Yours sincerely

Julie Shippen
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.

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