Information Commissioner's Office

Upholding information rights

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Data Protection Act 1998
Undertaking follow-up

NHS Digital
ICO Reference: ENF0605979

On 16 December 2016 the Information Commissioner's Office (ICO) conducted a follow-up assessment of the actions taken by NHS Digital (formerly known as HSCIC) in relation to the undertaking it signed on 19 April 2016.

The objective of the follow-up is to provide the ICO with a level of assurance that the agreed undertaking requirements have been appropriately implemented. We believe that appropriate implementation of the undertaking requirements will mitigate the identified risks and support compliance with the Data Protection Act 1998.

The follow-up assessment consisted of a desk based review of the documentary evidence NHS Digital supplied to demonstrate the action it had taken in respect of the undertaking requirements. This included:

- Data Provision Notice. Patient Objections Management. For General Practices in England. Version 2.0 Notified 27/05/2016
- Patient Objections Bespoke Solutions Requirements
- Patient Objections System use guide
- Patient Objections Policy
- Contact results exceptions spreadsheets for recipients of data.

The review demonstrated that:

a/ NHS Digital has taken appropriate steps and put plans in place to address the requirements of the undertaking and to mitigate the risks highlighted.

NHS Digital confirmed that it has taken the following steps:

1. HSCIC should establish and operate a system to process and uphold Type 2 objections, in accordance with the Direction from the Secretary of State.

NHS Digital has established and currently operates a system to process and uphold Type 2 objections. This was done by directing GPs to supply the necessary data via the General Practice Extraction Service or HSCIC Secure Electronic File Transfer system. Internal technological systems have been developed to receive, record and manage these patient objections around a central Patient Objections System. Organisational processes have been developed for NHS Digital staff to be aware of, and correctly use, the Central Patient Objections System where their work makes this necessary. Auditable information is recorded for these processes and the policies are due for regular review. Specific roles, (such as Information Asset Owners,) have been identified as responsible for aspects of the system and such individuals have received appropriate guidance. A steering group and system user group have been established as part of ongoing monitoring to ensure continued compliance.

3. HSCIC should ensure measures are put in place so that any patients who have previously registered a Type 2 objection, or patients who register a Type 2 objection in future, are provided with clear fair processing information that enables them to understand how the Type 2 objection will be applied and how their data will be used.

NHS Digital has updated the fair processing information on its website to describe and explain Type 1 and Type 2 objections to patients. The NHS Choices website has also been updated to include clear information on objections and contains referral links to more information on the NHS Digital website relating to objections. Additionally awareness about objections was relayed via the external relations manager to selected external organisations who regularly offer advice to patients who contacted them.

4. HSCIC should contact recipients of data sets it provided in the period January 2014 – April 2016 (where Type 2 objections can be processed and upheld in accordance with the Direction) and make them aware that the datasets may include records relating to patients who have chosen to opt out. HSCIC should do this within three months.

Using its Data Access Release team and Data Release Register NHS Digital was able to identify the recipients of data sets provided between January 2014 and April 2016 that were likely to contain records of patients who had registered a Type 2 objection and not covered by an exemption. A letter was sent on 19 July 2016; (the day after the three months described in the undertaking expired,) informing the recipient that the dataset may include records as described above. Further contact was made if a

recipient did not confirm receipt of the original correspondence. This was done by letter or telephone as appropriate. As of 19 October 2016 it was reported that all recipients had been successfully contacted.

5. HSCIC should contact recipients of data sets it provided in the period January 2014 – April 2016 (which included patient data where Type 2 objections can be processed and upheld in accordance with the Direction) and where the agreement allowed the recipient to onwardly disseminate the data, to make them aware that this data should no longer be disseminated further. HSCIC should do this within three months.

It was identified that four data sharing agreements included provision to onwardly disseminate data. The circumstances of each were examined in detail and found that for each for different reasons no action was required in relation to the undertaking requirement.

6. HSCIC should contact recipients of data sets it provided in the period January 2014 – April 2016 (which included patient data where Type 2 objections can be processed and upheld in accordance with the Direction) to inform them that, where possible, the data sets should be destroyed or deleted and replaced with a new data set, which reflects patient opt outs, provided by HSCIC in its place. Whether it is possible to destroy or delete the data will depend on whether or not it has already been processed and used, such as in a research study or as part of business intelligence information made available to a Trust. HSCIC will collect and retain a certificate of destruction where it is possible for data to be destroyed or deleted.

As part of contacting the recipients of the relevant data sets as previously mentioned, NHS Digital advised that where possible the data sets should be destroyed / deleted. A log of destruction certificates has been kept where they have been provided to NHS Digital and requests for replacement data sets are being processed if appropriate.

7. HSCIC should revisit the matter of objections following the completion of the National Data Guardian review and consider whether its systems and processes can be modified to allow the Type 2 objection to be applied in circumstances where this is not currently possible.

NHS Digital has stated that they have examined the National Data Guardian's (NDG) review of data security, consent and opt-outs published 6 July 2016. NHS Digital reports that for the systems identified where it is currently accepted as not possible to apply

the Type 2 objections the review does not change this situation. The NDG review does not recommending any changes to existing arrangements pending a full consultation on the proposed new consent/opt-out model. NHS Digital has undertaken that the systems identified will be examined again following the publication of the response by the Secretary of State to the NDG review as there may be proposals made regarding legislative changes that impact the situation.

b/ NHS Digital has taken appropriate steps and put plans in place to address some of the requirements of the undertaking, however further work needs to be completed by 18 April 2017 to fully address the agreed actions.

In particular NHS Digital confirmed that it has taken the following steps:

2. HSCIC should ensure measures are put in place so that any patients affected by this incident can be made aware that it is possible that their personal data has been shared with third parties against their wishes. This process should be completed within six months.

NHS Digital has, as well as relying on the press coverage regarding the incident to raise awareness, had published relevant information to the NHS Choices website on the right to opt-out of identifying information of patients being shared beyond their GP practice or NHS Digital. It has produced standard wording that was sent to all GP practices asking for the information be made available to patients. It also provided the same to both Healthwatch England and the Patients Association and requested they disseminate it throughout their organisations to aid in informing patients.

However the requirement to make patient's affected by the incident aware that their personal information has been shared with third parties against their wishes has not been fulfilled. The wording used on the NHS Choices website is "The HSCIC has started to uphold type 2 objections from 29 April 2016" it does not make clear that there was sharing carried out prior to the date where objections made were not being honoured. There is an assumption that while mentioning that sharing occurs, and the objections will be honoured from 29 April 2016, the reader will know that prior to this date even though they had objected, that objection was not honoured and sharing took place. Is must be considered if it is a reasonable assumption that the average individual would know that the delay caused inappropriate sharing. While correspondence to GPs and third party organisations is more detailed there is no evidence that any did pass on the information

to patients, or that GPs made it available to returning patients who attended their surgeries.

NHS Digital should take further action:

- To make it clear by amending published material that type 2 objections received prior to 29 April 2016 were not honoured prior to this date and so information was shared incorrectly from January 2014.
- To assess the effectiveness of the program of distributing material to GPs and other organisations to raise patient awareness of the failure honour received objections.

If NHS Digital confirms its agreement to take the recommended steps, the ICO is satisfied that regulatory action will not be necessary at this stage.

Date Issued: 06 January 2017

Addendum

NHS Digital has agreed to implement the two recommendations suggested in b/ relating to patient awareness of the failure to honour received objections.

The changes to the text of the NHS website at http://content.digital.nhs.uk/yourinfo have already been completed.

NHS Digital has described measures they intend to take to assess the effectiveness of the program of distributing material to GPs and other organisations. The ICO considers that these measures as stated will be satisfactory.

Date: 07 February 2017