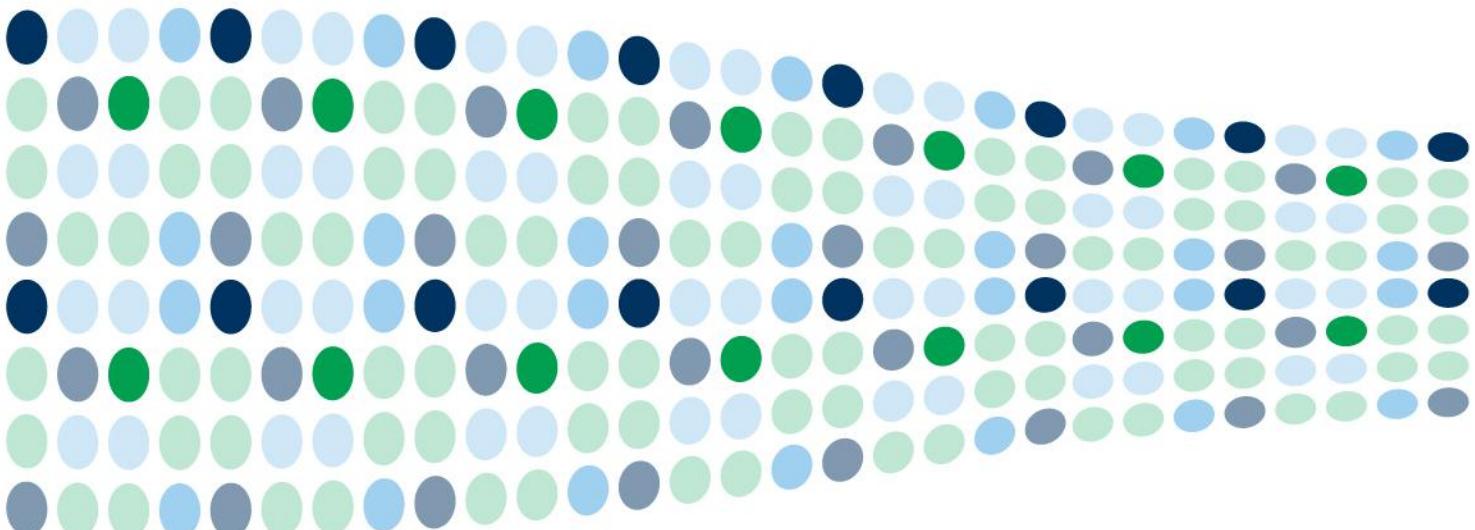


# Review of data releases made by the NHS Information Centre

## Frequently asked questions



## **Review of data releases by the NHS Information Centre Q&A**

### **Overview**

#### **1. What is the Review?**

In March 2014 the HSCIC Board asked Sir Nick Partridge, non-executive director, to lead a review of the data releases made by the HSCIC's predecessor organisation, the NHS Information Centre (NHS IC).

PricewaterhouseCoopers (PwC) were commissioned to undertake the review, which they started on the 10<sup>th</sup> March 2014 and completed on 2<sup>nd</sup> May 2014.

The review examined the arrangements that were in place for the release of data under the NHS IC, and aimed to provide insight and key observations that will allow the HSCIC to learn from its predecessor's experience. This is part of the Board's commitment to openness and transparency.

#### **2. Why was it commissioned?**

The HSCIC commissioned this review because we wanted to understand the systems and processes of the former NHS IC and because we knew that the public had concerns and also wanted to know more. We are committed to being open and transparent and recognise that this is crucial to building a robust organisation which the public trusts.

#### **3. What was the NHS Information Centre?**

The NHS Information Centre (NHS IC) was established in 2005. In March 2012 it reverted to its legal, statutory name, The Health and Social Care Information Centre (HSCIC), to reflect its broader social care responsibilities. It ceased to exist on April 1 2013.

The NHS Information Centre was set up to be England's authoritative, independent source of health and social care information. A major part of its role was to collect data, analyse it and convert it into useful information to help providers improve their services and supports academics, researchers, regulators and policymakers in their work. It also released data to organisations under agreements, which was the main focus of the Review.

#### **4. What time period did the Review cover?**

From when the NHS IC was established, on 1 April 2005; to when it ceased to exist on March 31 2013.

#### **5. What did the Review find?**

The three things we have found out as a result of the review is that the public needs greater openness and reassurance, there must be stricter controls over data use and data users need greater clarity over access.

The report concluded there were significant administrative lapses in recording the release of data. In some cases the decision-making process was unclear and records of decisions incomplete; when handling medical records this is unacceptable.

As a result, Sir Nick has made a series of recommendations. The HSCIC Board has accepted these in full and will agree further actions at its meeting on June 17.

The HSCIC recognises that even though the issues happened in another organisation, it is our responsibility to address these problems. Andy Williams, CEO, has set out a series of actions that will ensure a robust, transparent organisation and build public confidence.

### 6. How is the Review different from the Register?

The HSCIC Register was published for the first time in April 2014 and will be published quarterly. It contains details of all data releases that have been approved and released by the HSCIC since its inception in April 2013. Today's report covers data releases made by the NHS IC from April 1 2005 until 31 March 2013.

The Review also includes information about instances where non-clinical data were issued under the Data Protection Act, in relation to requests from organisations outside the NHS (for instance the police) to assist with tracing individuals.

These releases do not require a data agreement and therefore were not in scope for the original HSCIC Register. However we are committed to transparency and will now provide a quarterly listing of requests for data from police, NCA, UKBA and courts.

### 7. Did the report look at every release made by the NHS IC?

All of the releases made by the NHS IC have been published as an appendix to the report. The review then looked in detail at approximately ten per cent of these releases.

This was to allow PwC to conduct the report quickly and responsively, making the best use of public resources.

The review uses PwC's approved audit sampling methodology, which ensures a random selection and avoids conscious bias or predictability.

### 8. What will the HSCIC do now?

The HSCIC has accepted the Review recommendations and Andy Williams, its new CEO, has developed a series of actions to ensure that the HSCIC develops into a robust and transparent organisation. These include:

- **All data recipients will have to re-apply to the HSCIC in order to continue receiving data.** Should their application be successful after being assessed using the legislation in the new Care Act, they will be issued with a new data sharing agreement. All activity will be centrally logged, monitored and audited and decisions will be published.
- **A new central service** to manage, monitor and audit all data requests and releases – from the point of enquiry to the point of deletion – will be live in July.
- **A strengthened audit function** will be carrying out audits by August. This team will ensure data agreements are adhered to and will halt the flow of data should there be any concerns. If data recipients don't follow their agreements then we will not release any further data to them.
- **Trace requests** will be added to the list of all active data sharing agreements published in the HSCIC quarterly Register.
- **Greater patient and public involvement in the HSCIC and its decision making** will include public and patient representation on our data oversight committee; a communication programme to highlight an individual's right to object to their data flowing to or from the HSCIC; and stakeholder meetings about the new action plan, to gain view about its effectiveness in maintaining secure and trusted information systems..