

## **Data Provision Notice**

## Patient Objections Management For General Practices in England

Note: This notice replaces the previous version and now supports organisations which are not compliant with the General Practice Extraction Service (GPES)



# We are the trusted national provider of high-quality information, data and IT systems for health and social care

## www.hscic.gov.uk enquiries@hscic.gov.uk



#### **Executive Summary**

The NHS Constitution states "You have the right to request that your confidential information is not used beyond your own care and treatment and to have your objections considered". To support this patients are able to register objections with their general practice to either prevent their identifiable data being released outside of the GP Practice (known as a Type 1 objection) or to prevent their identifiable data from any health and social care setting being released by the HSCIC for purposes other than direct patient care, (known as a Type 2 objection).

The HSCIC has been directed by the Department of Health to collect aggregate and patient level data relating to patient objections from all general practices in England including health and justice organisations with registered patients, and Ministry of Defence (MoD) service medical units under section 254 of the Health and Social Care Act 2012. This data is required in order for the HSCIC to respect patients' wishes by upholding the objection for any data released outside of the HSCIC for purposes beyond their direct care, and to monitor the levels of uptake and withdrawal of both Type 1 and Type 2 patient objections.

Information Asset Owner: Dave Roberts, Head of Primary Care

Strategy

Version: V2.0

Date of publication: 27/05/2016

## **Document Management**

## **Revision History**

| Version | Date     | Summary of Changes  |
|---------|----------|---|
| 1.0     | 19/10/15 | 1 <sup>st</sup> Publication   |
| 2.0     | 27/05/16 | Updated to include NON GPES sites, including Health and Justice Organisations with registered patients, and Ministry of Defence (MoD) Service Medical Units |

## **Contents**

|   | _  |    |
|---|----|----|
| Background  | 5  |    |
| Purpose of the collection   | 5  |    |
| Benefits of the collection  | 6  |    |
| Legal basis for the collection, handling, publication and dissemination | 6  |    |
| Persons consulted   | 6  |    |
| Scope of the collection   | 6  |    |
| Form of the collection  | 7  |    |
| Manner of the collection  | 8  |    |
| Period of the collection  | 9  |    |
| Further Information and Support   | 9  |    |
| Burden of the collection  | 9  |    |
| Steps taken by HSCIC to minimise the burden of collection               |    | 9  |
| Detailed burden assessment findings                                     |    | 10 |
| Assessed costs  |    | 10 |
| Burden Advice and Assessment Service recommendations                    |    |    |
| Help us to identify inappropriate collections                           | 10 |    |

## **Background**

The Health and Social Care Act 2012 (the Act) gives the Health and Social Care Information Centre (HSCIC) statutory powers, under section 259(1), to require data from health or social care bodies or organisations who provide health or adult social care in England, where it has been Directed to establish an information system by the Department of Health (DH) (on behalf of the Secretary of State) or NHS England.

When a Direction is received, the HSCIC can issue a Data Provision Notice to the appropriate providers of the required data which are then legally required, under section 259(5) of the Act, to provide the data in the form and manner specified below.

## Purpose of the collection

The <u>NHS Constitution</u> states "You have the right to request that your confidential information is not used beyond your own care and treatment and to have your objections considered".

The HSCIC is committed to supporting a patient's wishes in respect of sharing confidential information. The HSCIC "Guide to confidentiality in health and social care" states that:

- Patients can object to information about them leaving a general practice in identifiable form for purposes other than direct care, so confidential information about them will not be shared. This is referred to throughout this documentation as a Type 1 objection.
- Patients can object to information about them leaving the HSCIC in identifiable form, so confidential information about them will not be sent to anyone by the HSCIC other than for purposes of direct care. This is referred to throughout this documentation as a Type 2 objection.

The HSCIC has been directed by the Department of Health to collect aggregate and patient identifiable data relating to patient objections from all general practices in England under section 254 of the Act.

The collection of aggregate data will be used to honour the commitment, made in response to the recommendations of the <u>2013 Caldicott Review</u>, that HSCIC would monitor the rate of objections made by patients to the sharing of information. Information collected on the number of Type 1 objections made and withdrawn in each GP Practice will also inform the independent review of consent and opt-outs which is being led by the Care Quality Commission, with support from Dame Fiona Caldicott.

This collection is required in order for the HSCIC to:

- 1. Monitor the levels of patient uptake and withdrawal of both Type 1 and Type 2 patient objection this will be aggregate data.
- 2. Respect a patient's wishes by upholding patient Type 2 objections (or the withdrawal of Type 2 objections) this will be patient identifiable data.

Details of Type 1 objections will not be collected at patient level.

The patient identifiable data collected for Type 2 objections will be used internally by the HSCIC to prevent patient identifiable data from being released outside of the HSCIC for purposes beyond their direct care – it will not be published or released.

An <u>Information Governance Assessment</u> has been undertaken as part of the approval for this extraction by the <u>GPES Independent Advisory Group (IAG)</u> on <u>13 February 2014</u>.

### Benefits of the collection

• Patients and care recipients will have their right to object to their information being shared for purposes beyond their direct care respected by HSCIC in line with the NHS Constitution.

## Legal basis for the collection, handling, publication and dissemination

- The HSCIC has been directed by the Secretary of State for Health in exercise of the powers conferred by sections 254(1) and (6), 262(5), 274(2) and 304(9), (10) and (12) of (the Act), and regulation 32 of the National Institute for Health and Care Excellence (Constitution and Functions) and the Health and Social Care Information Centre (Functions) Regulations 2013.
- In accordance with section 254(5) of the Act, the Secretary of State has consulted the Health and Social Care Information Centre before giving these Directions.
- This information is required by the HSCIC under section 259(1) of the Act. In line with section 259(5) of the Act, all general practices in England must comply with the requirement and provide information to the HSCIC in the form, manner and period specified in this Data Provision Notice.
- This Notice is issued in accordance with the <u>procedure published</u> as part of the HSCIC duty under section 259(8).
- The data to be processed includes patient identifiable data which is deemed to be personal
  and as such requires fair processing under the Data Protection Act 1998. Details of how the
  HSCIC will meet the requirements of fair processing are published on the <u>HSCIC Personal</u>
  information choices website.

#### **Persons consulted**

Following receipt of a direction to establish a system to collect Patient Objections Management data the HSCIC has, as required under section 258 of the Act, consulted with the following persons:

Co-chairs of the Joint General Practice Information Technology Committee (JGPITC), who
were content with this collection, on behalf of their members.

## Scope of the collection

Under section 259(1) of the Act, this Notice is served in accordance with the procedure published as part of the HSCIC duty under section 259(8) on the following persons:

 All general practices in England including Health and Justice Organisations and Ministry of Defence (MoD) Service Medical Units

Under section 259(5) of the Act the organisation types specified above must comply with the form, manner and period requirements below.

#### Form of the collection

This requirement relates to the extraction of patient identifiable and aggregate patient objections data that is routinely recorded on GP systems as part of the normal interaction between patients and GPs or other staff authorised to update the clinical system.

#### **Aggregate data**

The following aggregate counts will be collected for each GP practice to allow the HSCIC to monitor Type 1 and Type 2 objections:

- The total number of patients registered at each general practice.
- The number of patients registered at each general practice who have currently recorded a Type 1 objection.
- The number of patients registered at each general practice who have currently recorded a Type 1 withdrawn objection.
- The number of patients registered at each general practice who have currently recorded a Type 2 objection.
- The number of patients registered at each general practice who have currently recorded a Type 2 withdrawn objection.

#### Patient identifiable data

The following patient identifiable data will be collected from each GP practice to allow the HSCIC to uphold Type 2 patient objections in relation to data that is disclosed.

Where a patient has objected or has withdrawn their objection to their patient identifiable data leaving the HSCIC (i.e. a Type 2 objection), the following data items will be extracted for each patient with a Type 2 objection code:

| Data item     | Purpose  |
|---------------|--|
| NHS Number    | This will be used by the HSCIC to identify if there is a matching NHS Number within any identifiable data they plan to disclose. |
| Code          | The HSCIC requires the following objection codes:  |
|               | Dissent from disclosure of personal confidential data by Health and Social Care Information Centre; or                           |
|               | Dissent withdrawn from disclosure of personal confidential data by Health and Social Care Information Centre.                    |
| Recorded Date | The date the objection code and/or withdrawal of objection code  |

| was recorded on a patient's general practice record. |
|--|
|  |

A full history of Type 2 objection codes will be extracted so the HSCIC can ensure that the latest status is always applied and that patient wishes are respected.

Patients are able to register their objections to the sharing of their data with their GP Practice and this will be recorded on GP systems using the codes listed below:

| Known as: | Description  | READ2 | CTV3  | SNOMED CT       |
|-----------|--|-------|-------|-----------------|
| Type 1    | Dissent from secondary use of general practitioner patient identifiable data                                 | 9Nu0. | XaZ89 | 827241000000103 |
|           | Dissent withdrawn for secondary use of general practitioner patient identifiable data                        | 9Nu1. | XaZ8A | 827261000000102 |
| Type 2    | Dissent from disclosure of personal confidential data by Health and Social Care Information Centre           | 9Nu4. | XaaVL | 881561000000100 |
|           | Dissent withdrawn from disclosure of personal confidential data by Health and Social Care Information Centre | 9Nu5. | XaaVM | 881581000000109 |

Full details of the data to be collected can be found in the <u>Patient Objections Customer Requirement Summary</u>.

### Manner of the collection

Data will be securely extracted via either the General Practice Extraction Service (GPES) or the HSCIC Secure Electronic File Transfer (SEFT) system for non-GPES sites, and processed by the HSCIC. Sites <u>must</u> use GPES where they are able to do so.

#### **GPES Enabled Sites**

General Practices using GPES will receive a message from HSCIC to participate in the data collection which is called 'Patient Objections Management'.

This will appear as a service offer in the message centre of the Calculating Quality Reporting Service (CQRS) system. General Practices <u>must</u> select "Yes" when they see the message asking to accept the service. They will then see a message confirming that they have accepted the CQRS service and are participating in collections for the service.

This will be a one off activity for GPES enabled sites. Extracts will be taken automatically each month without further intervention.

Further details on GPES can be found on the <u>HSCIC General Practice (GP) collections webpage</u>.

#### **Non-GPES Sites**

Sites not using GPES will receive an email with instructions for how to register for the HSCIC's SEFT system. Sites <u>must</u> provide the registration information specified in this email in order to allow them to submit the data.

These sites will also receive an attachment of a single Microsoft Excel template (in the form or an XLS or XLSX file), with two worksheets, one for patient identifiable data and one for aggregate data as defined in "Form of the Collection" above. Sites <u>must</u> complete these worksheets and return to the HSCIC via SEFT on a monthly basis. An Open Document Spreadsheet (.ods) version of the template is available from the HSCIC upon request.

#### Period of the collection

Data was collected for the first time in December 2015 and will be collected every month until the collection is replaced by a new patient data sharing preferences model recommended by Dame Fiona Caldicott and accepted by the Secretary of State. If a new model is not in place before March 2017 the existing data collection service will be reviewed. The <a href="HSCIC GP Collections Service">HSCIC GP Collections Service</a> Bulletins will specify the data collection dates.

## **Further Information and Support**

Further Information about this collection and the mechanism for collecting this data are available below:

HSCIC GP Collections service – for more information on the data collection dates and participation.

If you have any queries in relation to the Patient Objections Management collection, please contact the HSCIC Contact Centre via <a href="mailto:enquiries@hscic.gov.uk">enquiries@hscic.gov.uk</a> with 'Patient Objections Management Data Provision Notice' in the subject line, or telephone 0300 303 5678.

#### Burden of the collection

#### Steps taken by HSCIC to minimise the burden of collection

The HSCIC has sought to minimise the burden on general practices by using existing data extract technology, rather than requesting information in another format which may be more burdensome to process.

In seeking to minimise the burden it imposes on others, in line with sections 253(2a) and 265(3) of the Act, the HSCIC has an assessment process to validate and challenge the level of burden incurred through introducing new information standards, collections and extractions.

This assessment is carried out by the Burden Advice and Assessment Service (BAAS) who carry out a Detailed Burden Assessment (DBA) and report findings and recommendations, as part of the overarching <u>Standardisation Committee for Care Information (SCCI) process</u>. The SCCI Committee oversees the development, assurance and acceptance of information standards, data collections and data extractions for the health and social care system in England.

#### **Detailed burden assessment findings**

This collection uses the GPES system, which imposes minimal burden on General Practices. Information required is routinely collected and recorded in GP systems as part of the ongoing interaction between GPs and their patients.

A survey of subject matter experts was considered sufficient to assess the burden for providers of data.

No concerns were raised by the BAAS survey.

BAAS maintains and publishes a <u>central register</u> of assessed data collections and extractions, including burden assessment detail relating to all national collections. Further information about the collection and estimated costs can be viewed from this register.

#### **Assessed costs**

The associated burden is noted below:

|              |         | Based upon 7,800 GP Practices  |
|--------------|---------|--|
| Burden £     | £126.7k | 2 minutes per GP * 1 (one-off) (approx. £47,330 in total across all GPES sites)  |
|              |         | 30 minutes per GP Practice Manager * 12 (monthly) (approx. £79,356 in total across all non-GPES GP sites)                                    |
| Set Up Costs | £59.0k  | Includes costs for GP System Suppliers and the Health and Social Care Information Centre (HSCIC)   |
| Other Costs  | £194.0k | Are on a per annum basis and include ongoing costs for GP System Suppliers and the HSCIC to extract and process the patient objections data. |
| Total costs  | £379.7k |  |

#### **Burden Advice and Assessment Service recommendations**

The burden of this collection should be reviewed 12 months after the initial extraction.

## Help us to identify inappropriate collections

The HSCIC BAAS offers a Collection Referral Service which is a simple and confidential way to allow data providers to refer data collections they feel would benefit from further scrutiny.

Visit the BAAS website for more details and information on how to <u>refer a collection</u>.

For further information

www.hscic.gov.uk

0300 303 5678

enquiries@hscic.gov.uk

Copyright © 2016 Health and Social Care Information Centre.

Under the <u>Open Government Licence</u> you are encouraged to use and re-use the publicly accessible information in this notice free of charge. Re-use includes copying, issuing copies to the public, publishing, broadcasting and translating into other languages and its subsequent use in commercial or non-commercial enterprise.