

CARE.DATA GUIDE FOR GP PRACTICES

Introduction

This guide is intended to support GP practices in:

- Understanding the care.data service
- Raising patient awareness of how confidential data will be used by the care.data service
- Understanding what to do if a patient objects

What is care.data?

The NHS is changing and services are being restructured. These reforms will impact upon the way that clinical data are collected, shared and analysed. Under the powers of the Health and Social Care Act 2012 (HSCA), the Health and Social Care Information Centre (HSCIC) can, under certain circumstances¹, **require** Personal Confidential Data (PCD) from GP practices without seeking patient consent. One of the first initiatives using these new powers is the care.data service². This service has been commissioned by NHS England and will be delivered by the HSCIC. The HSCIC is England's central authoritative source of health and social care information (see FAQ 1 for further information).

Care.data will make increased use of information from medical records with the intention of improving healthcare, for example by ensuring that timely and accurate data are made available to NHS commissioners and providers so that they can better design integrated services for patients. In the future, approved researchers may also benefit. The HSCIC will link PCD extracted from GP systems with PCD from other health and social care settings.

The BMA supports the use of patient data for secondary purposes, including commissioning, and recognises the importance of greater transparency and more intelligent use of data to improve the quality of care delivered to patients. Achieving these aims must not undermine existing high standards of confidentiality.

NHS England has made a commitment that personal confidential data will not be shared unless there is a legal basis or an overriding public interest in disclosure.

What data will be extracted?

The dataset to be extracted from GP systems for the care.data service includes personal confidential data such as referrals, all NHS prescriptions and other clinical data. Identifiers (DOB, postcode, NHS number and gender) are required by the HSCIC to link the GP data with PCD from other care settings, e.g. hospitals, in order to analyse patient care across pathways. Free text will not be extracted for care.data. A technical specification has been published which provides full details of the data to be extracted³. The extraction will be on a monthly basis, prospective from April 2013, using the General Practice Extraction Service (GPES)⁴. Once linked, the data will be stored at the HSCIC in a secure environment with the highest standards of information governance and technical expertise to protect the data.

The dataset has been considered by a clinical informatics expert group, which included representatives from the British Medical Association (BMA) and the Royal College of General Practitioners (RCGP). The group was satisfied that the dataset seemed appropriate for commissioning. Any future changes to the dataset or to scope will be subject to review by the group and GP practices will be informed of any alterations. The care.data proposal was also reviewed and approved by the GPES Independent Advisory Group (IAG)⁵.

What data flows can a patient object to?

Care.data is one of a number of flows of PCD from GP practices. Some disclosures of PCD are well established (e.g. for health research that is in the public interest and has special approval under section 251 of the NHS Act 2006).

Patients have the right to object to any extraction of PCD from the GP practice unless there is (a) a statutory duty to share information, (b) a court order or (c) an overriding public interest in disclosure. The Secretary of State for Health, however, has given a commitment that, for extractions of PCD from GP records that are to be sent to the HSCIC, patient objections will be respected⁶.

In addition to controlling whether PCD flows from the GP practice to the HSCIC, patients have a right to object to PCD from any health and social care setting (e.g. hospital data) leaving the HSCIC. In general, such data will only be made available to accredited third parties in anonymised, pseudonymised or aggregated form. PCD may flow from the HSCIC where there is a legal basis, for example to researchers or commissioners who have section 251 approval, however patients can object to this as indicated below.

Recording a patient objection

GPs are best placed to manage patients' objections in relation to how PCD are processed. GPs can control the extraction of such PCD by entering appropriate codes into the GP record.

The default position for all patients is that PCD will leave the practice where there is a legal basis; i.e. under the powers of the HSCA or a section 251 approval. **No codes need to be entered in the record, these extracts will happen automatically.**

Where a patient objects, GPs should use the following codes to record the objection:

- **Prevent PCD leaving the GP practice** – where a patient objects to PCD leaving the GP practice use the **'Dissent from secondary use of GP patient identifiable data'** code (Read v2: 9Nu0 or CTV3: XaZ89 or SNOMED CT 827241000000103).
- **Prevent PCD leaving the HSCIC** – where a patient wishes to prevent PCD gathered from any health and social care setting from leaving the HSCIC use the **'Dissent from disclosure of personal confidential data by Health and Social Care Information Centre'** code (Read v2: 9Nu4 or CTV3: XaaVL or SNOMED CT 8815610 00000100).

Patients can change their minds and reverse a previous objection in which case the following codes should be used:

- **Remove the block on PCD leaving the GP practice** by using the **'Withdraw dissent from secondary use of GP patient identifiable data'** code (Read v2: 9Nu1 or CTV3: XaZ8A or SNOMED CT 827261000000102).
- **Remove the block on PCD leaving the HSCIC** by using the **'Dissent withdrawn from disclosure of personal confidential data by Health and Social Care Information Centre'** code (Read v2: 9Nu5 or CTV3: XaaVM or SNOMED CT 8815810 00000109).

By recording both objection codes, a patient will prevent PCD from leaving the GP practice AND prevent PCD from other health and social care settings from leaving the HSCIC (see FAQ 22).

If a patient trusts the HSCIC to receive PCD from the GP practice, so that it can be linked and used for commissioning or research in a pseudonymised form, but is concerned about PCD leaving the HSCIC then only the code which prevents PCD leaving the HSCIC should be used. This code will prevent PCD from all health and social care settings *leaving* the HSCIC. It should be noted that in this scenario, PCD will flow from the GP practice to the HSCIC. It will not prevent PCD flowing from the GP practice to other accredited third parties where there is section 251 approval. In all cases PCD will only flow where there is a legal basis. If a patient objects to disclosure of PCD for secondary uses by the GP as well as by the HSCIC, then both codes must be added.

As anonymised data, such as QOF data, are not PCD, they will not be affected by these codes. Anonymised data will flow to and from the HSCIC for all patients.

The BMA, RCGP, NHS England and HSCIC have developed a leaflet that should be made available to patients and a poster that must be displayed in the GP practice. Information should also be included on the practice website, in e-bulletins and patient newsletters to raise patient awareness so that the fair processing requirements of the Data Protection Act 1998 are met. A set of FAQs to help answer patients' queries has been produced and is available at www.england.nhs.uk/caredata. It is important that patients' wishes are respected both in terms of those who wish to object and those who wish for data to be used to benefit future healthcare. The HSCIC will record the numbers of patient objections made at each practice. Where there appears to be an abnormal number of objections, the BMA and NHS England will explore with practices why this might be occurring (e.g. due to any misunderstandings or coding errors).

Further Information

A list of FAQs is available at: <http://bma.org.uk/practical-support-at-work/ethics/confidentiality-and-health-records/care-data>

If you have any remaining questions you can contact the HSCIC Contact Centre, who are acting as a helpline for GPs, by calling 0845 300 6016 or emailing enquiries@hscic.gov.uk quoting 'care.data – GP' in the subject line. If you have patient queries that aren't covered by the materials or FAQs that you need help answering please contact the HSCIC contact centre for support.

1 When directed to do so by the Secretary of State for Health, NHS England or when receiving a mandatory request from CQC, NICE or Monitor.

2 Everyone Counts: Planning for Patients 2013/14 (<http://www.england.nhs.uk/everyonecounts/>)

3 <http://www.england.nhs.uk/wp-content/uploads/2013/05/ces-tech-spec-gp-extract.pdf>

4 <http://www.hscic.gov.uk/gpes>.

5 Any updates to content or scope will be published on the HSCIC website at: <http://www.hscic.gov.uk/article/1858/GPES-Independent-Advisory-Group>.

6 A patient can inform their GP of their wishes to object and this should be recorded – there is no need for the patient to demonstrate damage or distress.