

# FREQUENTLY ASKED QUESTIONS CARE.DATA GUIDE FOR GP PRACTICES

## 1. What is the Health and Social Care Information Centre?

The **Health and Social Care Information Centre** (HSCIC) is England's central, authoritative source of health and social care information. The Health and Social Care Act 2012 (HSCA) empowered the HSCIC to require providers of NHS care to send it confidential data in limited circumstances i.e. when directed to do so by the Secretary of State for Health, NHS England or when receiving a mandatory request from the Care Quality Commission (CQC), NICE or Monitor. The HSCIC will process the confidential data in a secure environment and can only release confidential data where there is a legal basis.

## 2. What is care.data?

NHS England has described the care.data service as: '...a new, modern data system for the NHS in England. Known as *care.data*, its purpose will be to provide timely, accurate information to citizens, clinicians and commissioners about the treatments and care provided by the NHS. The aims of the care.data programme are six-fold: first, to support patients' choice; second, to advance customer services; third, to promote greater transparency; fourth, to improve outcomes; fifth, to increase accountability; and finally to drive economic growth by making England the default location for world-class health services research. The underlying data within care.data will all be collected routinely as part of the care process. For the first time, these data will be linked for patients nationwide along their entire continuum of health and social care.' The intention is to expand **Hospital Episodes Statistics (HES)** to form Care Episode Statistics (CES) by incorporating and linking data across all care settings. One of the first components is the inclusion within CES of primary care data.

## 3. What is the General Practice Extraction Service (GPES)?

GPES is the national primary care data extraction service managed by the HSCIC. GPES is capable of obtaining information from all GP practices in England for specific and approved purposes. GPES is the tool used by the HSCIC to extract data and therefore will be the default system by which GPs disclose data to the HSCIC for care.data. GPs can choose to use another system provided that this is acceptable to the HSCIC.

## 4. What is Personal Confidential Data (PCD)?

This term describes personal information about identifiable individuals who are owed a duty of confidentiality i.e. the information was given 'in confidence' and should be kept private or secret unless there is a legal basis or overriding public interest for disclosure. It includes information about deceased as well as living individuals.

## 5. What data will GP practices be required to provide for care.data?

The data to be extracted from GP systems for care.data includes information such as family history, vaccinations, diagnoses, referrals, biological values (such as blood pressure, BMI and cholesterol with QOF exceptions codes) and all NHS prescriptions. Identifiers (DOB, postcode, NHS number and gender) are required to link the GP data with PCD from other care settings in order to analyse patient care across pathways. Free text will not be included for care.data. A full list of the data to be extracted is available in the **care.data GP extract – technical specification document**.

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). 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.

In addition, the GPES Independent Advisory Group (IAG) has approved the proposal. Further information on the IAG, including its membership, is available on the [Health and Social Care Information Centre website](#).

## 6. What do I need to do to ensure patients know about care.data and have the chance to object before their data is extracted?

The BMA, NHS England, RCGP and HSCIC have jointly produced a leaflet to inform patients about these changes. This should be made available to patients in the practice waiting room. You should also make information available on your website and in any regular patient communication, such as e-bulletins and patient newsletters.

In addition, a poster is provided which must be displayed prominently within the practice. Other routine communications to patients can also be used to raise awareness, for example, providing the leaflet with repeat prescriptions, including information in mailings for screening programmes or sending copies out with routine practice communications to patients.

GPs should ensure that practice staff are aware of these changes. Staff should be able to respond to queries from patients and direct them to the patient FAQs or the leaflet for further information. This is important in terms of meeting fair processing responsibilities under the Data Protection Act 1998 (DPA).

## 7. Where can I get extra copies of leaflets and materials from?

Visit [www.england.nhs.uk/caredata](http://www.england.nhs.uk/caredata) where you can order extra copies to be delivered to your practices directly. You can also download a pdf of the leaflet to put on your practice website.

## 8. Who covers the cost for us to provide patients with materials?

The awareness raising materials have been funded by NHS England.

## 9. What other awareness raising is taking place to ensure patients are aware?

Additional awareness raising is taking place led by NHS England. This includes:

- A range of resources such as a toolkit for practices which includes a how to guide, a template press release for local tailoring, GP and patient FAQs, advice and guidance for staff and patients, leaflets and posters
- Proactive focus on specialist regional events which are scheduled to take place in September. Events aimed at area teams, CCGs and others who in turn can help provide local support to practices
- Continued dialogue with early implementer practices throughout the first phase of testing to share learning and case study examples of good practice which will be incorporated into on-line resources
- Call off arrangements for additional materials including Braille, easy read and audio versions
- Additional awareness raising with the public through regional communications teams
- Social and digital media: dedicated web support pages for patients and for professionals; use of central social media channels
- Discussion with national patient groups, charity and voluntary sector organisations to enable cascade of messages through their regular and social media channels
- A publically accessible privacy impact assessment which will make reference to this work. This is a requirement of the HSCIC.

## 10. When will the data extraction begin?

The extraction is scheduled for the autumn, approximately 8 weeks from the time that you receive these materials. You will be notified by your system supplier of the exact date for the extraction. All staff in your practice authorised to use GPES must have completed the online training package before running the extraction. Details of the training are available at: <http://www.hscic.gov.uk/gpestraining>

## 11. Why is there an 8 week timetable for us to make our patients aware?

We discussed the timetable with the Information Commissioner's Office and agreed that 8 weeks was a reasonable amount of time to make patients aware of the changes in advance of the extraction of data provided that efforts have been made to make patients aware as detailed in FAQ 6.

**12. Can practices opt out of care.data extractions?**

No. The HSCA gives the HSCIC the power to require the information and GPs are legally obliged to comply with that requirement.

**13. How do these extractions comply with the Data Protection Act/GMC guidance?**

The HSCA creates a statutory obligation for GP practices to disclose information to the HSCIC in certain circumstances, for example to comply with a requirement for PCD from NHS England. Where there is a rule of law that requires a person to provide information (as the HSCA does), data controllers do not have discretion as to whether or not to comply with that requirement (section 35 of the DPA). Although the duty to disclose is a legal requirement, GPs have collected the data and as data controllers retain some responsibilities under the DPA; most relevant for care.data is the requirement to comply with the fair processing requirements. This means they need to inform patients of which data they are required to share with the HSCIC and they should also provide details of how patients can raise objections (i.e. by speaking to practice staff and having the objection recorded on their medical record).

Guidance on confidentiality from the GMC is clear that doctors must disclose information to satisfy a statutory requirement. As the HSCA creates a statutory obligation to disclose PCD, GPs will not be in breach of GMC guidance for disclosing PCD in this case. They will be in breach of the statutory requirement if they don't disclose PCD.

**14. Is the GP the data controller once the data has been disclosed to the HSCIC?**

The GP remains the data controller for the purposes they are using the data; the HSCIC will be the data controller for the data for the purposes for which they are processing and will be obliged to comply with the DPA principles. Therefore if the HSCIC shares PCD with others, where there is a legal basis for so doing, it is solely the HSCIC's responsibility to inform patients who they are sharing the information with and why.

**15. If the practice is the data controller why can't they prevent disclosure if they feel they are unable to fulfil their obligations under the Data Protection Act?**

GP practices have dual responsibilities; under the Health and Social Care Act there is a statutory obligation to disclose the data and under the DPA there is a statutory obligation to undertake fair processing. GP practices must meet both obligations.

**16. Can patients object to the disclosure of PCD from GP practices to the HSCIC?**

Yes. As set out in the **NHS Constitution**, individuals have a right to object to the disclosure of PCD and a right to have any reasonable objections respected. The Secretary of State for Health has also given a commitment that in relation to data held in GP records, individuals' objections to disclosure to the HSCIC will be respected other than in exceptional circumstances (e.g. in the event of a civil emergency see FAQ 18). A patient can inform their GP of their wishes to object – there is no need for the patient to demonstrate damage or distress. Section 10 of the DPA does not apply; the right to object has been implemented as a constitutional rather than legal right.

**17. What Read code do I need to use to stop the PCD of a patient who has objected from leaving the 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).

**18. Will recording an objection prevent all PCD for that patient from leaving the GP practice?**

No, although the circumstances when an objection would be overridden are very rare and these are in relation to specific legal requirements.

In relation to disclosures to and from the HSCIC, there may be exceptional circumstances, in accordance with the law, where patients' objections are overridden for example, where there is a civil emergency. Separate to care.data and disclosures to the HSCIC, there are already a limited number of circumstances when the law requires disclosure of certain PCD, regardless of whether a patient has objected. An example of a legal requirement to disclose PCD is public health legislation which is designed to control the spread of infectious diseases. A court order also requires disclosure of PCD.

In addition to the legal requirements to disclose PCD, doctors are permitted to make disclosures, without patient consent and even where a patient has objected, when it is in the public interest. For example, when the police are investigating a murder and may require information about an individual patient. These decisions, made on a case by case basis, must balance the duty of confidentiality owed to the patient and the broader public interest in a confidential health service with the benefits which may arise from the disclosure. Disclosures in the

public interest are made where it is judged that the disclosure is essential to prevent a serious and imminent threat to public health or to national security, to protect individuals or society from serious harm or to prevent or detect a serious crime.

These exceptions mean that it would be misleading to inform a patient that entering a code in their GP record will prevent all PCD leaving the GP practice.

#### 19. **Can patients prevent data from other healthcare settings flowing to the HSCIC?**

Not at present though we are working towards this aim. The BMA, the RCGP, NHS England and the HSCIC believe that patients should be able to restrict the flow of PCD from any healthcare setting (such as hospitals), into the HSCIC, though at present this is not feasible. PCD can only flow, however, where there is a legal basis for example, HES have flowed to the HSCIC for many years with approval under section 251 of the NHS Act 2006 (see FAQ 35).

As an important first step towards this aim, we are introducing codes to allow patients to limit flows of PCD from their GP practice to the HSCIC. In addition patients can also prevent flows of PCD, from any healthcare setting, from leaving the HSCIC.

#### 20. **Can patients object to PCD leaving the HSCIC?**

Yes. Where a patient objects to PCD leaving the HSCIC, the GP should enter the relevant code into the GP record. This will prevent PCD from any setting leaving the HSCIC.

#### 21. **What Read code do I need to use to stop PCD leaving the HSCIC for a patient who has objected to this?**

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)

#### 22. **If patients object to both data leaving the GP practice and the HSCIC how will the HSCIC identify the patient to action the objection of data flowing from the HSCIC?**

If both objection codes are applied to a patient's record then it is necessary for the patient's NHS number to flow from the GP practice to the HSCIC so that the patient's objection to information leaving the HSCIC can be actioned. The HSCIC needs the NHS number in order for them to apply the objection to the data they already hold. No other information which identifies the patient will flow to the HSCIC from the practice.

#### 23. **Do I have to enter a reason for an objection?**

No. GP practices should record patients' objections using the appropriate code as detailed in the **care.data guide for GP practices**. The BMA and NHS England will review data on the number of patient objections per practice. 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.

#### 24. **Shouldn't patients opt-in to care.data?**

The HSCA empowers the HSCIC to require providers to send it confidential data when it is directed to collect this data. The Act also overrides the requirement under the common law duty of confidentiality to seek patient consent. Whilst there is a public interest in confidential data being used for the benefit of the health service, the BMA and NHS England have agreed that the Secretary of State for Health and NHS England will not instruct the HSCIC to extract PCD on any patients who have lodged an objection to the use of PCD.

#### 25. **Why isn't there a form for patients to fill in?**

The HSCA overrides the common law duty of confidentiality requirement to seek patient consent for the disclosure of data to the HSCIC. This is not therefore a dissent/opt out process so no form is required. A practice is free to choose how they wish to work with their patients to capture their wishes and can use a form if they wish.

**26. Shouldn't patients have a greater number of choices to allow them to object to specific uses of their GP data?**

Ideally the BMA, RCGP, NHS England and the HSCIC would like patients to have more choices. However, we see the agreement for a patient to object to flows of their GP PCD as an important first step. We hope that this arrangement will raise awareness amongst both healthcare professionals and patients about how confidential data are used for purposes beyond direct care. Before introducing any additional options for patients, the BMA, RCGP, NHS England and the HSCIC will assess the impact upon GP practices, patients and the health service.

**27. Can someone stop their identifiable data being used by the HSCIC after it has already been sent, for example, if they don't lodge their objection in time?**

If a person does not lodge their objection before PCD is extracted, patients can still notify their GP of their objection and ask the HSCIC to anonymise the PCD that has already been transferred so that patient cannot be subsequently identified.

**28. How will PCD be linked in the HSCIC?**

NHS England aims to expand HES by 'incorporating and linking individual-level care data across all care settings'. This will be known as CES. The first stage will be to include extracts from GP systems into CES which, once linked, will then be pseudonymised. This process of linking the data is automated.

Identifiers (such as NHS number, DOB, gender and postcode) are held separately from the GP clinical data within the HSCIC. Data is linked, for example to HES data using these patient identifiers by means of an algorithm. This methodology has been developed to maximise the match rate but minimise the risk of false positive matches; where necessary the algorithm is altered to improve match rates i.e. where the quality of the data may be poor.

**29. Why can't patients object to anonymised data flows?**

Data which are anonymised are not subject to a duty of confidentiality and are not considered to be personal data for the terms of the DPA. The public good which can be achieved through the use of anonymous data is considered to outweigh the potential harms associated with the use of anonymised data.

**30. What happens if a patient has opted out of the Summary Care Record?**

The Summary Care Record (SCR) opt out codes are different and will not prevent disclosure of PCD to the HSCIC. The SCR and care.data are different and therefore you cannot assume that an objection to one should automatically apply to the other. If a patient has objected to the SCR and objects to disclosure of PCD for secondary uses, new codes in line with this guidance should be recorded as well.

GPs may be aware of certain patients who are likely to have concerns about privacy. A GP practice may choose to email, phone or talk to patients over time about care.data and data sharing if they think that it is likely that a patient may have concerns. This will not necessarily be limited to those who have opted out of the SCR but those who the practice is aware of having concerns in the past.

**31. What is CPRD and will the objection codes apply to CPRD?**

The Clinical Practice Research Datalink (CPRD) is the new English NHS observational data and interventional research service, jointly funded by the NHS National Institute for Health Research (NIHR) and the Medicines and Healthcare products Regulatory Agency (MHRA). CPRD services are designed to maximise the way anonymised NHS clinical data can be linked to enable many types of observational research and deliver research outputs that are beneficial to improving and safeguarding public health. Further information is available [here](#).

The objection codes will apply to any flows of PCD from GP practices for secondary purposes so they will apply to CPRD.

**32. What is the guidance for patients who have no capacity to make decisions for themselves, can carers decide on their behalf?**

An individual with a Lasting Power of Attorney for health and welfare can object on behalf of a patient who lacks capacity. If a carer or relative who does not hold a Lasting Power of Attorney raises specific concerns with you, then you should make a decision based on an assessment of the patient's best interests, taking into account the views of the carer/relative.

**33. Can a parent/guardian of a child make the decision on their behalf?**

Where a child lacks competence an individual with parental responsibility may make a decision on behalf of the child. If the child is competent then they should make the decision.

**34. Will NHS England be able to access PCD?**

NHS England does not have powers itself to require confidential data from providers, only to instruct the HSCIC to do so. NHS England would need to seek special approval under section 251 of the NHS Act 2006 if it required confidential information. As with any section 251 application, such a request would need to be considered and approved by the independent Confidentiality Advisory Group (CAG). NHS England has made a commitment that PCD will not be shared without explicit consent unless there is a legal basis or an overriding public interest in disclosure.

**35. What is section 251 approval?**

Under section 251 of the NHS Act 2006, regulations are in place, which allow the common law duty of confidentiality to be set aside for specific medical purposes when it is in the interests of patients or the wider public and it is impractical to obtain consent

and it is not possible to use anonymised data. This is often referred to as seeking 'section 251 approval'. The circumstances in which section 251 approval may be granted cover essential NHS activity and important medical research. Further information is available on the [Health Research Authority website](#). This includes a [register](#) of approved applications.

**36. We are having technical difficulties with our N3 connection, can we postpone the data extract until these are fixed?**

You will need to contact the N3 technical team to ensure that your practice is up and running by the time the extract takes place.

**37. Who do I contact if I have further questions?**

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](mailto:enquiries@hscic.gov.uk) quoting 'care.data – GP' in the subject line.

Further information is also available in the form of a toolkit which is an information resource for GP practices. This is available [here](#).