

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 extract 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. 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 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. 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 (no humans will view the PCD).

The HSCIC has provided the following technical description of the process:

The GP patient identifiers are held separately within the HSCIC from the clinical data from the GPES extract for care.data. Likewise, the HES patient identifiers are held separately from the clinical HES data. The clinical elements of the data sets are associated with the correct patient using the record number in the case of GP data (care.data extract) and a pseudonym (the HES ID) in the case of the HES data.

Data are linked using the patient identifiers by means of an algorithm which uses combinations of NHS Number, DOB, gender and postcode. This methodology has been developed over the years in light of the data quality 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 data quality may be poor. Once a match has been ascertained the HES ID is attached to the GP clinical data via the GP record number and the GP patient identifiers are then discarded.

7. Can patients object to the disclosure of data 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 8). 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 Data Protection Act 1998 (DPA) does not apply; the right to object has been implemented as a constitutional rather than legal right.

8. Will recording an objection prevent all PCD 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.

9. 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 [professional guidance](#). 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.

10. 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 and NHS England believe that patients should be able to restrict the flow of PCD from any healthcare setting (such as hospital), into the HSCIC, though at present this is not technically possible. 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 22).

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. As a second step, patients will be able to prevent flows of PCD, from any healthcare setting, from leaving the HSCIC.

11. Can patients object to PCD leaving the HSCIC?

Yes, under section 10 of the DPA, patients have a right to object to any processing of PCD by the HSCIC, which causes them damage or distress. Patients can contact the HSCIC who will be required to consider and respond to this objection. Patients can use their section 10 rights now, however in the future the process will be made easier with the introduction of a new objection code, which will allow patients to ask their GP to prevent PCD being disclosed from the HSCIC rather than having to contact the HSCIC. Patients do not have to demonstrate damage or distress in order to have this code added to their record.

12. When will the code which prevents PCD leaving the HSCIC be available?

The BMA and NHS England will inform GP practices when the code is available. This code will act as a flag in the HSCIC and will ensure that no PCD, from any healthcare provider or setting will leave the HSCIC by recording an objection at the GP practice.

As this code covers flows of PCD from all healthcare providers and settings, it is more technically challenging to implement. The BMA is working with the HSCIC and NHS England to enable this code as soon as possible.

13. What should I do if a patient wishes to prevent PCD flows from the HSCIC before the code is available?

If a patient objects to PCD leaving the HSCIC, we recommend that you make a list of these patients so that you can add the new code in the records of these individuals at a later date. Patients should be informed that their request will not be immediate but will be actioned in the future. In the meantime, patients can contact the HSCIC using their right to object to the processing under section 10 of the DPA. Although the organisation does not necessarily have to cease processing they must consider and respond to the objection.

14. 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.

15. 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. Alternatively they can contact the HSCIC directly and raise their objection.

16. Shouldn't patients opt-in to care.data?

The HSCA empowers the HSCIC to require providers to send it confidential data in limited circumstances. 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.

17. 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 and NHS England would like patients to have more choices. However, we see the agreement for a patient to object to flows of their GP data 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.

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

The 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.

19. 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.

20. 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.

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.

21. 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 share the data with others it is solely their responsibility to inform patients who they are sharing it with and why.

22. What is section 251 approval?

Under section 251 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.

23. 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 personal confidential data will not be shared without explicit consent unless there is a legal basis or an overriding public interest in disclosure.

24. Where can I refer patients to for further information?

The BMA, NHS England and RCGP have produced a leaflet for patients, which practices should make available to inform patients about these changes as well as a poster that should be displayed within the practice.

You should also make information available on your website and in any regular patient communication, such as e-bulletins and patient newsletters. 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 DPA.

Further engagement activity is planned with a number of patient, voluntary and charity groups, including key research organisations, to support awareness around the programme. The HSCIC will be required to make reference to this work in their privacy notice which will be publically accessible.

25. 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 quoting 'care.data – GP' in the subject line.