

NHS England Data Opt-out Data Uses and Disclosures Compendium

This document contains a list of examples of potential uses and disclosures of confidential patient information (CPI) which have been assessed against the [national data opt-out operational policy](#). ([Understanding the national data opt-out](#))

Introduction

This document outlines different data disclosures (and the legal basis under which the data is disclosed) in order to give guidance as to whether the national data opt-out needs to be applied to the data disclosure. These include those disclosures under [section 251 approval](#). Please note that there are a large number of section 251 approvals currently in place. This document does not give a definitive list of all approvals that may apply as some are very specific to data disclosures between a limited number of organisations. However, some section 251 approvals are more generic and relevant to a broader range of organisations. Please also note that unless there is a specific exemption, the national data opt-out will apply to data that is disclosed under a section 251 approval.

If an organisation is in doubt as to the legal basis via which data is being disclosed, they should contact the organisation to whom they are disclosing the data in order to understand the legal basis and the means via which the Common Law Duty of Confidentiality (CLDC) is being addressed.

This document also gives some examples of common types of data disclosure where the national data opt-out does not apply.

The example data disclosures in this document are arranged in sections. However, please note that some data disclosures may be relevant to more than one section and in this case, the most appropriate section has been chosen:

Data disclosures for planning and research purposes: [National Surveys, Audits and Registries, Payments, National disease registers, Population screening, Other planning disclosures](#) (including Risk stratification and Assuring transformation), [Research](#).

Data disclosures to and from specific organisation types: [From GP Practices, To NHS England](#).

Data disclosures where the national data opt-out does not apply: [Individual care, aggregate data and anonymised data](#) as examples. Please note that some data disclosures may be relevant to more than one section above and so may be repeated in different sections. Please also note that section 251 approvals are generally reviewed on an annual basis. The examples presented here are typical examples of where the national data opt-out may apply, however data disclosures that are made with section 251 approval are continually changing as new approvals are added and existing approvals expire.

Summary of S251

National data opt-outs apply to a disclosure when an organisation, for example a research body, confirms they have approval from the Confidentiality Advisory Group (CAG) for the disclosure of confidential patient information held by another organisation responsible for the data (the data controller) such as an NHS Trust.

The CAG approval is also known as a section 251 approval and refers to section 251 of the National Health Service Act 2006 and its current Regulations, the Health Service (Control of Patient Information) Regulations 2002. The NHS Act 2006 and the Regulations enable the common law duty of confidentiality to be temporarily lifted so that confidential patient information can be disclosed without the data controller being in breach of the common law duty of confidentiality.

In practice, this means that the organisation responsible for the information (the data controller) can, if they wish, disclose the information to the data applicant, for example a research body, without being in breach of the common law duty of confidentiality. To be clear - it is only in these cases where opt-outs apply.

Data disclosures to NHS England

When NHS England receives a direction to collect information, a Data Provision Notice (DPN) is issued to the providers of the required data. The DPN provides details of the data collection including the purpose, benefits, how it is intended to collect the information, form, manner, frequency and from which organisations. Any information on governance, legal basis or burden considerations is also included. In addition to publishing the DPN, NHS England seek to inform organisations who are within scope of the notice to provide data. Depending on the remit and method of data collection, organisations may need to take local action in order to comply with the DPN.

Organisations in scope of the DPN are legally required under Section 259 (5) of the Health and Social Care Act 2012 to provide the data set as specified by NHS England and (as it is a statutory requirement) national data opt-outs will not apply. For a full list of these data disclosures please see the NHS England list of [Data Provision Notices](#). Some examples of these data disclosures are outlined below:

Information disclosure	Recipient and Type of Data	Purpose of Disclosure	Legal Basis (how the CLDC is addressed/set aside)	Comments	Do national data opt-outs apply Yes/No
Adult social care data	NHS England Client level adult social care data	To assist Local Government and CCGs in fulfilling their statutory functions	Section 259	For example, functions of local authorities under Part 1 of the Care Act 2014	No
Community services data set	NHS England	To improve patient care	Section 259	Allows community service providers and commissioners to view local and national information from community services.	No
Emergency care data set	NHS England	Commissioning Dataset for emergency care	Section 259	The national data set for emergency care services.	No
Female Genital Mutilation (FGM) data set	NHS England	To support the Department of Health and Social Care's FGM Prevention Programme	Section 259	The programme delivers a digital system to strengthen the safeguarding of girls at risk of FGM across the NHS in England.	No
Out of Area Placements (OAPS) dataset	NHS England. Patient information	To eliminate inappropriate out of areas placements for adult acute inpatients by 2020/21	Section 259		No

Data disclosures from GP practices

The following are generic data disclosures from GP practices including examples of two aggregate data disclosures from GP practices (which are not subject to the national data opt-out).

Information disclosure	Recipient and Type of Data	Purpose of Disclosure	Legal Basis (how the CLDC is addressed/set aside)	Comments	Do national data opt-outs apply Yes/No
Individual GP level Data (previously referred to as GP Metrics or GP Insight Data)	NHS England CPI	Used to report back to GP's on the patients they are the 'usual' GP for	Section 259	Hospital data linkage carried out for one of the indicators. Direct Secretary of State commissioned work.	No
GP Appointments Data	NHS England CPI	Used to support winter planning and other holiday periods	Section 259	Collection of GP appointment data (such as who carried out the appointment, the time/date of the appointment and the type of appointment).	No
GP Contract Services: Quality Outcomes Framework (QOF)	Aggregate data	Data collected in order to pay GP's	Section 259	No identifiable data is collected.	No

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GP Contract Services: Childhood Seasonal Influenza Vaccination data	Aggregate data	Data collected in order to pay GP's	Section 259	No identifiable data is collected. This is one example of many where aggregate data is collected for different vaccinations provided by GPs in order that the GP may be paid for the service.	No
GP2DRS (Diabetic Retinopathy Screening)	NHS England Personal data	To invite 'at risk' patients for screening	Section 259	General Practice to Diabetic Retinopathy Screening (GP2DRS) is a system which automates the sharing of patient information between general practices and local diabetic eye screening programmes. The data is not analysed or accessed by anyone at NHS England and is purely used to identify people who are diabetic and require eye screening.	No
Demographic details for current or ex-smokers	Personal data	Lung cancer screening study	Section 251 (18/CAG/0054)	Data collected for a maximum of 100,000 patients from approximately 600 participating GP practices	Yes
Demographic details for current or ex-smokers	Personal data	Medical research (Yorkshire lung trial)	Section 251 (18/CAG/0038)	Medical research which aims to test targeted Low Dose Computed Tomography (LDCT) scans screening in community settings concentrating on deprived areas of Leeds.	Yes

Data disclosures where the national data opt-out does not apply

This section outlines some typical data disclosures where the national data opt-out will not apply. These include examples where the purpose of the data disclosure is to support individual care, the data is aggregated or anonymised (in line with the Information Commissioner's Office Code of practice on anonymisation), the patient has provided explicit consent and the data disclosure includes patient level data that is not CPI - for example, demographic data only:

Information disclosure	Recipient and Type of Data	Purpose of Disclosure	Legal Basis (how the CLDC is addressed/set aside)	Comments	Do national data opt-outs apply Yes/No
Patient health data for individual care	Social care services CPI	To allow social care services to understand and plan a patient's ongoing healthcare needs	Implied consent (Individual care)	Patient health data is now used across a number of different services in order to provide coherent and joined up individual care for patients.	No
Aggregate patient health data	CCG Aggregate patient data	To assist the CCG in planning future services	N/A	Aggregate patient health data is disclosed from a hospital trust to a CCG in order that the CCG can plan future services for the area that it is responsible for.	No
Anonymised patient health data	CCG Anonymised patient data	To assist the CCG in planning future services	N/A	Patient health data that is anonymised in line with the ICO code of practice on anonymisation is disclosed from a hospital trust to a CCG in order that the CCG can plan future services for the area that it is responsible for.	No

Patient health data for a local research project	Local research organisation CPI	To facilitate research into a specific medical condition	Explicit consent	Clinical personnel involved in the individual care of a cohort of patients approach selected patients in order to ask them to participate in a research project run by a local University department. Where the patient agrees to participate, relevant sections of their medical records are made available to the research team.	No – (on the basis the patient has given specific consent to the use of their data for the purpose specified)
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Research

There are a range of data disclosures for research that rely on section 251 support. The national data opt-out will apply to data disclosures for research that are using section 251 approval to set aside the common law duty of confidentiality unless there is a specific exemption. Please note: There are many different section 251 approvals in place for research purposes. The examples below are a representative example. For more information please see the [Confidentiality Advisory Group registers](#).

Information disclosure	Recipient and Type of Data	Purpose of Disclosure	Legal Basis (how the CLDC is addressed/set aside)	Comments	Do national data opt-outs apply Yes/No
Demographic and clinical details	Dendrite Ltd (acting on behalf of UCLH) CPI	Population of a research database focussing on Waldenstroms Macroglobulinemia (WM)	Section 251 (17/CAG/0107)	Data from hospital trusts relevant to Waldenstroms Macroglobulinaemia (WM). This is a rare blood cancer caused by genetic changes in the cells of the immune system.	Yes

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NHS number	Specific research nurses at St Thomas Hospital	Cardiac arrest research	Section 251 (17/CAG/0151)	The NHS number will be used to enable mortality status to be checked for participants in the trial.	Yes
Access to medical records by research team	University of Cambridge	To improve diagnosis and outcomes for Lewy Body dementia	Section 251 (17/CAG/0188)	Data is obtained from hospital trusts and de-identified before being sent to the University for further analysis.	Yes
Archival tumour block samples and Name, Hospital ID, Date of Birth, Date of Death, Gender	Kingston University (CPI)	Medical research	Section 251 (18/CAG/0043)	Investigating the expression pattern and prognostic significance of HER family and other heterologous receptors in paired primary colorectal cancers and their corresponding metastatic lesions and patient response to treatment.	Yes
Patient medical details including Name, Address, Postcode	Data from GP practices to Leeds Teaching Hospitals NHS Trust and University of Leeds (CPI)	Medical research	Section 251 (18/CAG/0038)	Access to confidential patient information is required in order to establish the cohort of patients who are eligible to participate in the research trial involving smokers and lung cancer.	Yes
Demographic details including name and address and HPV status	University College London (CPI)	Medical research into HPV	Section 251 (18/CAG/0118)	Researchers will access confidential patient information on site at the participating Trusts in order to identify the eligible patients for invitation to the study. This is data provided by Manchester University Hospitals NHS Foundation Trust and London North West Healthcare NHS Trust in order to identify eligible patients for a	Yes

				research study. There is a separate opt-out for this, but it needs to be applied alongside the national data opt-out.	
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National Surveys

This section defines the national surveys that are exempt from the national data opt-out. The examples in this section cover the collection of national survey data.

Information disclosure	Recipient and Type of Data	Purpose of Disclosure	Legal Basis for Disclosure (how the CLDC is addressed/set aside)	Comments	Do national data opt-outs apply Yes/No
National Cancer Patient Experience Survey (CPES)	Quality Health (acting on behalf of NHS England) (CPI)	To support the National cancer patient experience	Section 251	Will continue to operate a separate opt-out mechanism. For further information please see Cancer Patient Experience Survey .	No – Special exemption applies
CQC NHS Patient Survey Programmes	Picker Institute Europe (acting on behalf of the CQC)	To support the CQC Patient Survey Programme	Section 251	Will continue to operate a separate opt-out mechanism. Includes the Maternity services, Community mental health, Adult inpatient, Children and young peoples, Emergency (A+E) department and Availability of patient contact details surveys. For further information please see CQC Surveys .	No – Special exemption applies

Children and Young People's Cancer Patient Experience Survey (CYP)	CPI	To support the National cancer patient experience	Section 251	This survey has been granted a 2 year exemption from the national data opt-out.	No – Special exemption applies
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Clinical audits and registries

The national data opt-out does not apply to local clinical audit. There are a number of national audits and registries where data is disclosed to NHS England on behalf of the Department of Health and Social Care (DHSC) and the Healthcare Quality Improvement Partnership (HQIP). Some of this audit data is collected under the statutory powers granted to NHS England so the national data opt-out does not apply. However, some audit data is collected under section 251 approval, in which case the national data opt-out will apply unless there is a specific exemption. Other audit collections that rely on section 251 approval are also outlined below. The examples in this section cover the collection of audit and registry data.

Information disclosure	Purpose of Disclosure	Legal Basis (how the CLDC is addressed/set aside)	Comments	Do national data opt-outs apply Yes/No
GP Practice Audit of Hypertension (Local Audit)	Practice analysis of Hypertension data	Implied consent (Individual care)	Constitutes individual care and treatment/direct care (optimisation of patient care).	No
Breast and Cosmetic Implant Registry (BCIR)	Supports the implementation of Recommendation 21 of the Keogh Review of the	Directed/Section 259	For further information please see Breast and Cosmetic Implant Registry .	No

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	Regulation of Cosmetic Interventions			
National Diabetes Audits	Measures the effectiveness of diabetes healthcare	Directed/Section 259	For further information please see National Diabetes Audit , National Diabetes Audit and Diabetes Prevention Programme , National Diabetes Foot Care Audit , National Diabetes Inpatient Audit , National Diabetes Inpatient Audit – Harms , National Diabetes Transition Audit and National Pregnancy in Diabetes Audit .	No
Female Genital Mutilation Enhanced Dataset	Supports the DHSC's FGM Prevention Programme	Directed/Section 259	Repository for individual level data collected by healthcare providers in England, including acute hospital providers, mental health providers and GP practices. For further information please see Female Genital Mutilation datasets .	No
Out of Area Placements (OAPs)	To understand progress against the national ambition to eliminate inappropriate OAPs in mental health services for adults in acute inpatient care	Directed/Section 259	For further information please see Out of Area Placements (OAP) .	No
Gastro Intestinal Cancer Audit Programme (GICAP)	Improve the quality of hospital cancer care in England and Wales	Section 251 CAG ECC 1-3(d)/2012)	This programme includes the National Bowel Cancer Audit (NBOCA) & National Oesophago Gastric Cancer Audit (NOGCA) For further information please see National Bowel Cancer Audit (NBOCA) & National Oesophago Gastric Cancer Audit (NOGCA)	Yes

National Clinical Audit of Rheumatoid and Early Inflammatory Arthritis Clinical Audit	Improve the quality of care for patients with Rheumatoid and early inflammatory arthritis (EIA) in England and Wales	Section 251 (18/CAG/0063)	For further information please see National Early inflammatory Arthritis Audit (NEIAA)	Yes
National Adult Community Acquired Pneumonia (CAP) Audit 2018-19	To assess variation in the care of patients hospitalised with pneumonia in the UK	Section 251 (18/CAG/0147)	For further information please see the British Thoracic Society .	Yes
Trauma Audit & Research Network (TARN)	Research	s251 PIAG 3-04(e)/2006	For more info please see Trauma Audit and Research network .	Yes

For further information please see NHS England [Clinical audits and registries](#) and HQIPs [National Clinical Audit Programme](#).

Payment and invoice validation data disclosures between providers and commissioners

There are a number of data disclosures between health and care providers to Controlled Environments for Finance (CEFs) which are linked to a Clinical Commissioning Group (ICB) or Commissioning Support Unit (CSU) and to NHS Shared Business Services (SBS) in support of payment and invoice validation processes.

Information disclosure	Recipient and Type of Data	Purpose of Disclosure	Legal Basis (how the CLDC is addressed/set aside)	Comments	Do national data opt-outs apply Yes/No
Invoice	NHS SBS (no CPI)	Invoice validation between providers and commissioners	N/A	Under NHS England guidelines, CPI should NOT be sent direct to NHS SBS as part of the invoice validation process and NHS SBS will return any CPI sent to them in error. Therefore, national data opt-outs do not apply to such data disclosures.	N/A
Invoice backing data for both contracted and non-contracted activity	Controlled Environments for Finance (CPI)	To enable commissioners to determine if they are the responsible commissioner	Section 251 CAG 7-07(b)/2013 CAG 7-07(c)/2013	All data disclosures to CEFFs are supported by a section 251 approval – CAG 7-07(b)/2013 and CAG 7-07(c)/2013 and have been granted an exemption from national data opt-outs by the Confidentiality Advisory Group. For more information please consult the NHS England “who pays advice” and NHS England Invoice validation webpages .	No – CAG have granted an exemption

National disease registers

The national data opt-out does not apply to data disclosures to the National Cancer Register and the National Congenital Anomaly and Rare Diseases Register.

Information disclosure	Recipient and Type of Data	Purpose of Disclosure	Legal Basis (how the CLDC is addressed/set aside)	Comments	Do national data opt-outs apply Yes/No
Cancer Register	Public Health England CPI	Cancer Register	Section 251 (PIAG 03(a)/2001)	A separate opt-out is in place for this register. For more information please see the National Cancer Registration and Analysis Service	No – Special exemption applies
Congenital Anomaly and Rare Diseases Register	Public Health England CPI	Congenital Anomaly and Rare Diseases Register	Section 251 (CAG 10-02(d)/2015)	A separate opt-out is in place for this register. For more information please see the National Congenital Anomaly and Rare Disease Registration Service	No – Special exemption applies

Population screening

The national data opt-out does not apply to data disclosures for the purpose of allowing participation in [national screening programmes](#) endorsed by the UK National Screening Committee. The National Data Guardian's (NDG) review of data security, consent and opt outs recognised that these are to support a patient's individual care: *"There are some elements of direct care which rely on the processing of data nationally, for example the electronic transfer of prescriptions, screening, immunisation programmes and the Summary Care Record. **The Review heard no evidence to suggest that there should be a change to effective local or national arrangements for sharing information**".*

Information disclosure	Recipient and Type of Data	Purpose of Disclosure	Legal Basis (how the CLDC is addressed/set aside)	Comments	Do national data opt-outs apply Yes/No
NHS Breast, Bowel and Cervical Cancer Screening	Public Health England CPI	NHS Breast, Bowel and Cervical Cancer Screening	Section 251 (15/CAG/0207)	This screening programme continues to operate a separate opt-out mechanism for patients who do not wish to be invited for screening.	No
GP2DRS (Diabetic Retinopathy Screening)	NHS England Personal data	To invite 'at risk' patients for screening	Section 259	General Practice to Diabetic Retinopathy Screening (GP2DRS) is a system which automates the sharing of patient information between general practices and local diabetic eye screening programmes. The data is not analysed or accessed by anyone at NHS England and is purely used to identify people who are diabetic and require eye screening.	No

Other planning disclosures

Other planning data disclosures with section 251 approvals covering risk stratification and assuring transformation:

Information disclosure	Recipient and Type of Data	Purpose of Disclosure	Legal Basis (how the CLDC is addressed/set aside)	Comments	Do national data opt-outs apply Yes/No
Risk stratification	Data processors working on behalf of GP practices CPI	Risk stratification	Section 251 (CAG 7-04(a)/2013)	This applies to a limited number of risk stratification suppliers. For further information please see NHS England – Risk stratification . Also see the national data opt-out policy on risk stratification .	Yes
Confidential patient information about people with learning disabilities and/or autism	NHS England (on behalf of NHS England) CPI	Assuring transformation	Section 251 (CAG 8-02 (a-c)/2014)	These flows continue to operate a separate opt-out mechanism and details of how to opt-out of the Assuring Transformation data collection can be found on the NHS England webpages .	No – Special exemption applies
NHS Number, Hospital number, Date of birth, date of death, Gender, LSOA	Blackpool Teaching Hospitals NHS Foundation Trust	Management of health and care services (to inform the future provision of	Section 251 (17/CAG/0196)	Allows the applicants to collect vital baseline data from across primary, community and acute care setting that will inform the analytics aspects of the transformational project.	Yes

	Community Informatics Team and the Midlands and Lancashire CSU	heart failure care.)			
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