

Privacy Notice – Practice

Version:	Review date:	Edited by:	Approved by:	Comments:
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1 Introduction

1.1 Policy statement

NHS Digital collects information with the purpose of improving health and care for everyone. The information collected is used to:1

- Run the health service
- Manage epidemics
- Plan for the future
- Research health conditions, diseases and treatments

1.2 Principles

NHS Digital is a data controller and has a legal duty, in line with the UK General Data Protection Regulation (UK GDPR), to explain why it is using patient data and what data is being used. Similarly, Hadrian Primary Care Alliance (HPCA) has a duty to advise patients of the purpose of personal data and the methods by which patient personal data will be processed.

1.3 Status

The organisation aims to design and implement policies and procedures that meet the diverse needs of our service and workforce, ensuring that none are placed at a disadvantage over others, in accordance with the <u>Equality Act 2010</u>. Consideration has been given to the impact this policy might have with regard to the individual protected characteristics of those to whom it applies.

This document and any procedures contained within it are non-contractual and may be modified or withdrawn at any time. For the avoidance of doubt, it does not form part of your contract of employment.

1.4 Training and support

The organisation will provide guidance and support to help those to whom it applies to understand their rights and responsibilities under this policy. Additional support will be provided to managers and supervisors to enable them to deal more effectively with matters arising from this policy.

¹ NHS Digital – How we look after your health and care information



2 Scope

2.1 Who it applies to

This document applies to all employees of the organisation and other individuals performing functions in relation to the organisation such as agency workers, locums and contractors.

Furthermore, it applies to clinicians who may or may not be employed by the organisation but who are working under the Additional Roles Reimbursement Scheme (ARRS).²

2.2 Why and how it applies to them

Everyone should be aware of the practice privacy notice and be able to advise patients, their relatives and carers what information is collected, how that information may be used and with whom the organisation will share that information.

The first principle of data protection is that personal data must be processed fairly and lawfully. Being transparent and providing accessible information to patients about how their personal data is used is a key element of the UK General Data Protection Regulation.

3 Definition of terms

3.1 Privacy notice

A statement that discloses some or all of the ways in which the organisation gathers, uses, discloses and manages a patient's data. It fulfils a legal requirement to protect a patient's privacy.

3.2 Data Protection Act 2018 (DPA18)

The <u>Data Protection Act</u> (DPA18) will ensure continuity by putting in place the same data protection regime in UK law pre- and post-Brexit.

3.3 Information Commissioner's Office (ICO)³

The UK's independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals

3.4 General Data Protection Regulation (GDPR)⁴

The GDPR replaced the Data Protection Directive 95/46/EC and was designed to harmonise data privacy laws across Europe, to protect and empower all EU citizens'

² Network DES Contract specification 2021/22

³ ICO

⁴ GDPR



data privacy and to reshape the way in which organisations across the region approach data privacy.

The GPDR came into effect in May 2018.

Post-Brexit, in January 2021, the GDPR became formally known as UK GDPR and was incorporated within the <u>Data Protection Act 2018</u> (DPA 18) at Chapter 2.

Throughout the remainder of this notice, GDPR is known as UK GDPR.

3.5 Data controller

The entity that determines the purposes, conditions and means of the processing of personal data

3.6 Data subject

A natural person whose personal data is processed by a controller or processor

4 Compliance with regulations

4.1 UK GDPR

In accordance with the UK GDPR, this organisation will ensure that information provided to subjects about how their data is processed will be:

- Concise, transparent, intelligible and easily accessible
- Written in clear and plain language, particularly if addressed to a child
- Free of charge

4.2 Article 5 compliance

In accordance with Article 5 of the UK GDPR, this organisation will ensure that any personal data is:

- Processed lawfully, fairly and in a transparent manner in relation to the data subject
- Collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes
- Adequate, relevant and limited to what is necessary in relation to the purposes for which it is processed
- Accurate and, where necessary, kept up to date; every reasonable step must be taken to ensure that personal data that is inaccurate, having regard to the purposes for which it is processed, is erased or rectified without delay
- Kept in a form that permits the identification of data subjects for no longer than is necessary for the purposes for which the personal data is processed



 Processed in a manner that ensures appropriate security of the personal data, including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage by using appropriate technical or organisational measures

Article 5 also stipulates that the controller shall be responsible for, and be able to demonstrate compliance with, the above.

4.3 Communicating privacy information

At HPCA, the organisation's privacy notice is displayed on our website, through signage in the waiting room and in writing during patient registration. We will:

- Inform patients how their data will be used and for what purpose
- Allow patients to opt out of sharing their data, should they so wish

4.4 What data will be collected?

At HPCA, the following data will be collected:

- Patient details (name, date of birth, NHS number)
- Address and NOK information
- Medical notes (paper and electronic)
- Details of treatment and care, including medications
- Results of tests (pathology, X-ray, etc.)
- Any other pertinent information

4.5 National data opt-out programme

The national data opt-out programme introduced in May 2018 affords patients the opportunity to make an informed choice about whether they wish their confidential patient information to be used just for their individual care and treatment or also used for research and planning purposes.⁵

Whilst several start dates have been discussed, following consultation with the BMA and RCGP, DHSC have confirmed in a letter⁶ dated 19th July 2021 that there is now no specific start date for this programme for health and care organisations to comply with the national data opt and will now commit to uploading any data only when the following has been established:

- The ability to delete data if patients choose to opt-out of sharing their GP data with NHS Digital, even if this is after their data has been uploaded
- The backlog of opt-outs has been fully cleared
- A Trusted Research Environment has been developed and implemented in NHS Digital
- Patients have been made more aware of the scheme through a campaign of

⁵ NHS Digital National data opt-out programme

⁶ DHSC letter dated 19 Jul 21



engagement and communication.

Patients who wish to opt out of data collection can register a national data opt out and <u>no longer</u> need to register a Type 1 opt-out by 1st September as previously decreed.

4.6 Opting out

DHSC advise that the opting out system will be simplified to allow the patient to change their opt out status at any time. They have additionally advised that:

- Patients do not need to register a Type 1 opt-out by 1st September to ensure their GP data will not be uploaded
- NHS Digital will create the technical means to allow GP data that has
 previously been uploaded to the system via the GPDPR collection to be
 deleted when someone registers a Type 1 opt-out
- The plan to retire Type 1 opt-outs will be deferred for at least 12 months while DHSC establish the new arrangements. Type 1 opt-outs will not be implemented without further consultation with the RCGP, the BMA and the National Data Guardian

Given these changes, there is no longer any urgency to process Type 1 opt-outs specifically for GPDPR in order for patients to opt-out.

What remains is that patients still cannot register for the national data opt out programme via their own GP but will continue to choose to opt out by using one of the following:

- Online service Patients registering need to know their NHS number or their postcode as registered at their GP practice
- Telephone service 0300 303 5678 which is open Monday to Friday between 0900 and 1700
- NHS App for use by patients aged 13 and over (95% of surgeries are now connected to the NHS App). The app can be downloaded from the App Store or Google play
- "Print and post" registration form
- Coupled with the application form, photocopies of proof of the applicant's name (e.g., passport, UK driving licence etc.) and address (e.g., utility bill, payslip etc.) need to be sent to:

NHS PO Box 884 LEEDS LS1 9TZ

Note: It can take up to 14 days to process the form upon receipt



4.7 Patients in secure settings

Patients in the detained and secure estate who want to register a national data optout need a healthcare professional to fill in a <u>proxy form</u> on their behalf. The following <u>information and guidance on proxy forms</u> details who can complete it and how it should be filled in.

The national data opt-out information is held centrally on the NHS Spine and will not be updated in the SystmOne prison module so you will not see the national data opt-out in the patient's record.

Further reading can be sought from NHS Digital.

5 General practice data for planning and research data collection

5.1 About

The new General Practice Data for Planning and Research Data Collection (GPDPR)⁷ is a data collection to help the NHS to improve health and care services for everyone by collecting patient data that can be used to do this.

The GPGPR is designed to assist the NHS to:

- Monitor the long-term safety and effectiveness of care
- Plan how to deliver better health and care services
- Prevent the spread of infectious diseases
- Identify new treatments and medicines through health research

5.2 Data sharing

Data may be shared from GP medical records for:

- Any living patient registered at a GP practice in England when the collection started – this includes children and adults
- Any patient who died after this data sharing started and was previously registered at a GP practice in England when the data collection started

NHS Digital will not share the patient's name or demographic details. Any other data that could directly identify the patient will be replaced with unique codes which are produced by de-identification software before the data is shared with NHS Digital. This includes:

•	NHS	num	ber

•	General	Practice	Local	Patient	Number	•

⁷ GPDPR



- Full postcode
- Date of birth

This process is called pseudonymisation and means that no one will be able to directly identify the patient in the data.

It should be noted that NHS Digital will be able to use the same software to convert the unique codes back to data that could directly identify the patient in certain circumstances and where there is a valid legal reason.

NHS Digital has the ability to do this.

5.3 What information can and cannot be shared

NHS Digital will collect structured and coded data from patient medical records including:

- Data about diagnoses, symptoms, observations, test results, medications, allergies, immunisations, referrals, recalls and appointments including information about physical, mental and sexual health
- Data on sex, ethnicity and sexual orientation
- Data about staff who have treated patients

NHS Digital will not collect:

- Name and address (except for postcode, protected in a unique coded form)
- Written notes (free text) such as the details of conversations with doctors and nurses
- Images, letters and documents
- Coded data that is not needed due to its age for example medication, referral and appointment data that is over 10 years old
- Coded data that GPs are not permitted to share by law for example certain codes about IVF treatment and certain information about gender reassignment

5.4 Opting out

Patients who do not want their identifiable patient data to be shared for purposes except their own care can opt-out by registering a Type 1 Opt-out or a national data opt-out (NDO-O) or both. NHS Digital will not collect any patient data for patients who have already registered a Type 1 Opt-out in line with current policy.

a. Type 1 Opt-out

A Type 1 Opt-out is used to opt out of NHS Digital collecting a patient's data.



If patients do not want their patient data shared with NHS Digital for the purposes of planning or research, they can register a Type 1 Opt-out with the GP practice. Patients can register a Type 1 Opt-out at any time and additionally may reverse their decision at any time by withdrawing their Type 1 Opt-out.

If a patient registers a Type 1 Opt-out after the collection has started, no more of the patient's data will be shared with NHS Digital. They will however still hold the patient data that was shared before the Type 1 Opt-out was registered.

If patients have previously registered a Type 1 Opt-out and they would like to withdraw this, they can also use the form to do this. The form can be sent by post or email to the GP organisation or the patient can call 0300 303 5678 for a form to be sent out to them.

b. National data opt-out (NDO-O)

NDO-O is opting out of NHS Digital sharing your data.

Once established, the NDO-O will also apply to any confidential patient information shared by the GP practice with other organisations for purposes other than a patient's individual care. It will not apply to this data being shared by GP practices with NHS Digital as it is a legal requirement for this organisation to share this data with NHS Digital and the NDO-O does not apply where there is a legal requirement to share data.

5.5 Available resources

The following resources are available for staff at HPCA:

- National Data Guardian for Health and Care review of data security, consent and opt outs
- National data opt out data protection impact assessment
- National data opt out training
- Compliance with the national data opt out
- Guidance for health and care staff
- Supporting your patients information and resources
- Information for GP practices*
- Understanding the national data opt out

As detailed above, this is now incorrect as this has been superseded by the DHSC letter dated 19th July 2021.

Further information is available within the National data opt out guidance

^{*}At the time of publishing this notice, the link to the NHS Digital webpage relating to information for GP practices still advises that practices must comply with NDO-O by 30th September 2021.



6 Further information

6.1 Privacy notice checklists

The ICO has provided a privacy notice checklist that can be used to support the writing of the organisation's privacy notice. The checklist can be found by following this link.

6.2 Privacy notice template

A privacy notice template can be found at Annex A.

It is recognised that the type and style of privacy notices may vary. However this privacy notice template has been reviewed as appropriate by a current Data Protection Officer. It is acknowledged to be extensive and covers all eventualities that may occur around information governance.

6.3 Notifications for patients

Annex B – Social media/website information update

Annex C – Text messaging and telephone message Information

Annex D - Staff opt out guidance

6.4 e-Learning

All staff must complete Data Security Awareness training annually in line with the Data Security and Protection Toolkit. HPCA will using the Data Security Awareness Training at e-Learning for Health.

7 Summary

It is the responsibility of all staff at HPCA to ensure that patients understand what information is held about them and how this information may be used.

Furthermore, the organisation must adhere to the DPA18 and the UK GDPR to ensure compliance with extant legal rules and legislative acts.



Annex A - Practice privacy notice

As a registered patient, [Insert organisation name] has a legal duty to explain how we use any personal information we collect about you at the organisation. We collect records about your health and the treatment you receive in both electronic and paper format.

Why do we have to provide this privacy notice?

We are required to provide you with this privacy notice by law. It provides information about how we use the personal and healthcare information we collect, store and hold about you. If you have any questions about this privacy notice or are unclear about how we process or use your personal information, or have any other issue regarding your personal and healthcare information, then please contact our Data Protection Officer [insert DPO name and contact details].

The main things the law says we must tell you about what we do with your personal data are:

- We must let you know why we collect personal and healthcare information about you
- We must let you know how we use any personal and/or healthcare information we hold about you
- · We need to inform you in respect of what we do with it
- We need to tell you about who we share it with or pass it on to and why
- We need to let you know how long we can keep it for

What is a privacy notice?

A privacy notice (or 'fair processing notice') explains the information we collect about our patients and how it is used. Being open and providing clear information to patients about how an organisation uses their personal data is an essential requirement of the new UK General Data Protection Regulations (UK GDPR).

Under the UK GDPR, we must process personal data in a fair and lawful manner. This applies to everything that is done with patient's personal information. This means that the organisation must:

Have lawful and appropriate reasons for the use or collection of personal data



- Not use the data in a way that may cause harm to the individuals (e.g., improper sharing of their information with third parties)
- Be open about how the data will be used and provide appropriate privacy notices when collecting personal data
- · Handle personal data in line with the appropriate legislation and guidance
- Not use the collected data inappropriately or unlawfully

What is fair processing?

Personal data must be processed in a fair manner – the UK GDPR says that information should be treated as being obtained fairly if it is provided by a person who is legally authorised or required to provide it. Fair processing means that the organisation has to be clear and open with people about how their information is used.

[insert organisation name] manages patient information in accordance with existing laws and with guidance from organisations that govern the provision of healthcare in England such as the Department of Health and the General Medical Council.

We are committed to protecting your privacy and will only use information collected lawfully in accordance with:

- UK General Data Protection Regulations 2016
- Data Protection Act 2018
- Human Rights Act 1998
- Common Law Duty of Confidentiality
- Health and Social Care Act 2012
- NHS Codes of Confidentiality and Information Security
- Information: To Share or Not to Share Review

This means ensuring that your personal confidential data (PCD) is handled clearly and transparently and in a reasonably expected way.



The Health and Social Care Act 2012 changed the way that personal confidential data is processed so it is important that our patients are aware of and understand these changes and that you have an opportunity to object and know how to do so.

The healthcare professionals who provide you with care maintain records about your health and any NHS treatment or care you have received (e.g., NHS Hospital Trust, GP surgery, walk-in clinic, etc.). These records help to provide you with the best possible healthcare.

NHS health records may be processed electronically, on paper or a mixture of both and we use a combination of working practices and technology to ensure that your information is kept confidential and secure.

Who is the data controller?

[insert organisation name] is registered as a data controller under the Data Protection Act 2018. Our registration number is [add number] and our registration can be viewed online in the public register at http://www.ico.gov.uk. This means we are responsible for handling your personal and healthcare information and collecting and storing it appropriately when you are seen by us as a patient.

We may also process your information for a particular purpose and therefore we may also be data processors. The purposes for which we use your information are set out in this privacy notice.

What type of information do we collect about you?

Information held by this organisation may include the following:

- Your contact details (such as your name, address and email address)
- Details and contact numbers of your next of kin
- Your age range, gender, ethnicity
- Details in relation to your medical history
- The reason for your visit to the organisation



- Any contact the organisation and/or your practice has had with you including appointments (emergency or scheduled), clinic visits, etc.
- Notes and reports about your health, details of diagnosis and consultations with our GPs and other health professionals within the healthcare environment involved in your direct healthcare
- Details about the treatment and care received
- Results of investigations such as laboratory tests, x-rays, etc.
- Relevant information from other health professionals, relatives or those who care for you
- Recordings of telephone conversations between yourself and the organisation

Information collected about you from others

We collect and hold data for the purpose of providing healthcare services to our patients and we will ensure that the information is kept confidential. However, we can disclose personal information if:

- It is required by law
- You provide your consent either implicitly for the sake of your own care or explicitly for other purposes
- · It is justified to be in the public interest

To ensure you receive the best possible care, your records are used to enable the care you receive. Information held about you may be used to help protect the health of the public and to help us to manage the NHS.

Information may be used for clinical audit purposes to monitor the quality of services provided, may be held centrally and may used for statistical purposes. Where we do this, we ensure that patient records cannot be identified.

Sometimes your information may be requested to be used for clinical research purposes – the organisation will always endeavour to gain your consent before releasing the information.



Improvements in information technology are also making it possible for us to share data with other healthcare providers with the objective of providing you with better care. You can choose to withdraw your consent to your data being used in this way. When the organisation is about to participate in any new data-sharing scheme, we will make patients aware by displaying prominent notices and on our website at least four weeks before the scheme is due to start. We will also explain clearly what you have to do to 'opt-out' of each new scheme.

A patient can object to their personal information being shared with other healthcare providers but if this limits the treatment that you can receive then the doctor will explain this to you at the time.

What is special category data?

The law states that personal information about your health falls into a special category of information because it is extremely sensitive. Reasons that may entitle us to use and process your information may be as follows:

Public interest	Where we may need to handle your personal information when it is considered to be in the public interest. For example, when there is an outbreak of a specific disease and we need to contact you for treatment or we need to pass your information to relevant organisations to ensure you receive advice and/or treatment
Consent	When you have given us consent
Vital interest	If you are incapable of giving consent and we have to use your information to protect your vital interests (e.g., if you have had an accident and you need emergency treatment)
Defending a claim	If we need your information to defend a legal claim against us by you or by another party
Providing you with medical care	Where we need your information to provide you with medical and healthcare services



The legal justification for collecting and using your information

The law says we need a legal basis to handle your personal and healthcare information.

Contract	We have a contract to deliver healthcare services to you. This contract provides that we are under a legal obligation to ensure that we deliver medical and healthcare services to the public.
Consent	Sometimes we also rely on the fact that you give us consent to use your personal and healthcare information so that we can take care of your healthcare needs. Please note that you have the right to withdraw consent at any time if you no longer wish to receive services from us.
Necessary care	Providing you with the appropriate healthcare where necessary The law refers to this as 'protecting your vital interests' where you may be in a position not to be able to consent.
Law	Sometimes the law obliges us to provide your information to an organisation

How do we use your information?

Your data is collected for the purpose of providing direct patient care; however, we are able to disclose this information if it is required by law, if you give consent or if it is justified in the public interest.



In order to comply with its legal obligations, this organisation may have to send data to NHS Digital when directed by the Secretary of State for Health under the <u>Health and Social Care Act 2012</u>. Additionally, we may have to contribute to national clinical audits and will send the data that is required by NHS Digital as the law allows. This may include demographic data, such as date of birth, and information about your health which is recorded in coded form; for example, the clinical code for diabetes or high blood pressure.

Under the General Data Protection Regulation, we will be lawfully using your information in accordance with:

- Article 6, (e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller
- Article 9, (h) processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working
 capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social
 care systems

Who can we provide your personal information to and why?

Whenever you use a health or care service, such as attending the local hospital or using the district nursing service, clinical information about you is collected to help ensure you get the best possible care and treatment. This information may be passed to other approved organisations where there is a legal basis to do so, to help with planning services, improving care, researching to develop new treatments and preventing illness. All of this helps in providing better care to you and your family and future generations.

However, as explained in this privacy notice, confidential information about your health and care is only used in this way as allowed by law and would never be used for any other purpose without your clear and explicit consent.

We may pass your personal information on to the following people or organisations because these organisations may require your information to assist them in the provision of your direct healthcare needs. It therefore may be important for them to be able to access your information in order to ensure they may deliver their services to you:

- Hospital professionals (such as doctors, consultants, nurses etc.)
- Other GPs/doctors
- Primary Care Networks
- NHS Trusts/Foundation Trusts/Specialist Trusts



- NHS Commissioning Support Units
- NHS England (NHSE) and NHS Digital (NHSD)
- Multi-agency Safeguarding Hub (MASH)
- Independent contractors such as dentists, opticians, pharmacists
- Any other person who is involved in providing services related to your general healthcare including mental health professionals
- Private sector providers including pharmaceutical companies to allow for the provision of medical equipment, dressings, hosiery etc.
- Voluntary sector providers
- Ambulance Trusts
- Integrated Care Systems
- Clinical Commissioning Groups
- Local authority
- Social care services
- Education services
- Other 'data processors', e.g., Diabetes UK

You will be informed who your data will be shared with and in some cases asked for explicit consent for this to happen when this is required.

Who may we provide your information to:

- For the purposes of complying with the law, e.g., the police
- Anyone you have given your consent to, to view or receive your record, or part of your record. If you give another person or organisation consent to access your record, we will need to contact you to verify your consent before we release that record. It is important that you are clear and understand how much and what aspects of your record you give consent to be disclosed
- Computer systems we operate a clinical computer system on which NHS staff record information securely. This information can then be shared with other clinicians so that everyone caring for you is fully informed about your medical history including allergies and medication. We will make information available to our partner organisations (above) unless you have declined data sharing to ensure you receive appropriate and safe care. Wherever possible, staff will ask your consent before your information is viewed.



• Extended access – we provide extended access services to our patients so that you can access medical services outside of our normal working hours. To provide you with this service, we have formal arrangements in place with the Clinical Commissioning Group whereby certain key 'hubs' offer this service for you as a patient to access outside of our opening hours.

This means those key 'hubs' will have to have access to your medical record to be able to offer you the service. Please note to ensure that those hubs comply with the law and to protect the use of your information, we have very robust data sharing agreements and other clear arrangements in place to ensure your data is always protected and used for those purposes only [amend as appropriate]

• Data extraction by the Clinical Commissioning Group – the Clinical Commissioning Group at times extracts medical information about you but the information we pass to them via our computer systems cannot identify you to them

This information only refers to you by way of a code that only your own practice can identify (it is pseudo-anonymised). This therefore protects you from anyone who may have access to this information at the Clinical Commissioning Group from ever identifying you as a result of seeing the medical information and we will never give them the information that would enable them to do this [amend as appropriate]

Your rights as a patient

The law gives you certain rights to your personal and healthcare information that we hold as set out below:

Access and Subject Access Requests

You have a right under the Data Protection legislation to request access to view or to obtain copies of what information the organisation holds about you and to have it amended should it be inaccurate. To request this, you need to do the following:

- Your request should be made to [insert name and contact details within the organisation]
- o For information from a hospital or other Trust/NHS organisation you should write directly to them



	 There is no charge to have a copy of the information held about you. However, we may, in some limited and exceptional circumstances, have to make an administrative charge for any extra copies if the information requested is excessive, complex or repetitive We are required to provide you with information within one month. We would ask therefore that any requests you make are in writing and it is made clear to us what and how much information you require You will need to give adequate information (for example full name, address, date of birth, NHS number and details of your request) so that your identity can be verified and your records located
Correction	We want to make sure that your personal information is accurate and up to date. You may ask us to correct any information you think is inaccurate. It is especially important that you make sure you tell us if your contact details including your mobile phone number have changed
Removal	You have the right to ask for your information to be removed. However, if we require this information to assist us in providing you with appropriate medical services and diagnosis for your healthcare, then removal may not be possible
Objection	We cannot share your information with anyone else for a purpose that is not directly related to your health, e.g., medical research, educational purposes etc.
Transfer	You have the right to request that your personal and/or healthcare information is transferred, in an electronic form (or other form), to another organisation but we will require your clear consent to be able to do this.

How long do we keep your personal information?



We are required under UK law to keep your information and data for the full retention periods as specified by the NHS Records Management Code of Practice for health and social care and national archives requirements.

More information on records retention can be found online at: NHSX – Records Management Code of Practice 2020.

Where do we store your information electronically?

All the personal data we process is processed by our staff in the UK. However, for the purposes of IT hosting and maintenance this information may be located on servers within the European Union.

No third parties have access to your personal data unless the law allows them to do so and appropriate safeguards have been put in place such as a data processor as above. We have data protection processes in place to oversee the effective and secure processing of your personal and/or special category data.

[insert organisation name] uses a clinical system provided by a data processor called EMIS/SystmOnline [amend as appropriate]. With effect from 10 June 2019, EMIS/SystmOnline [amend as appropriate] started storing the organisation's EMIS web data in a highly secure, third party cloud hosted environment, namely Amazon Web Services ('AWS').

Data does remain in the UK and will be fully encrypted both in transit and at rest. In doing this, there will be no change to the control of access to your data and the hosted service provider will not have any access to the decryption keys. AWS is one of the world's largest cloud companies, already supporting numerous public sector clients (including the NHS), and it offers the highest levels of security and support.

Maintaining your confidentiality and accessing your records

We are committed to protecting your privacy and will only use information collected lawfully in accordance with the UK General Data Protection Regulations (which is overseen by the Information Commissioner's Office), Human Rights Act, the Common Law Duty of Confidentiality and the NHS Codes of Confidentiality and Security. Every staff member who works for an NHS organisation has a legal obligation to maintain the confidentiality of patient information.

All of our staff, contractors and locums receive appropriate and regular training to ensure they are aware of their personal responsibilities and have legal and contractual obligations to uphold confidentiality, enforceable through disciplinary procedures. Only a limited number of



authorised staff have access to personal information where it is appropriate to their role and this is strictly on a need-to-know basis. If a sub-contractor acts as a data processor for [insert organisation name], an appropriate contract (Article 24-28) will be established for the processing of your information.

We maintain our duty of confidentiality to you at all times. We will only ever use or pass on information about you if others involved in your care have a genuine need for it. We will not disclose your information to any third party without your permission unless there are exceptional circumstances (i.e., life or death situations) or where the law requires information to be passed on and/or in accordance with the information sharing principle following Dame Fiona Caldicott's information sharing review (Information to share or not to share) where "The duty to share information can be as important as the duty to protect patient confidentiality." This means that health and social care professionals should have the confidence to share information in the best interests of their patients within the framework set out by the Caldicott principles.

Our organisational policy is to respect the privacy of our patients, their families and our staff and to maintain compliance with the UK General Data Protection Regulation (UK GDPR) and all UK specific data protection requirements. Our policy is to ensure all personal data related to our patients will be protected.

In certain circumstances you may have the right to withdraw your consent to the processing of data. Please contact the organisation in writing if you wish to withdraw your consent. In some circumstances we may need to store your data after your consent has been withdrawn to comply with a legislative requirement.

Sharing your information without consent

We will normally ask you for your consent but there are times when we may be required by law to share your information without your consent, for example:

- Where there is a serious risk of harm or abuse to you or other people
- Safeguarding matters and investigations
- Where a serious crime, such as assault, is being investigated or where it could be prevented
- Notification of new births



- Where we encounter infectious diseases that may endanger the safety of others, such as meningitis or measles (but not HIV/AIDS)
- Where a formal court order has been issued
- Where there is a legal requirement, for example if you had committed a road traffic offence.

Third party processors

To enable us to deliver the best possible services, we will share data (where required) with other NHS bodies such as hospitals. In addition, the organisation will use carefully selected third party service providers. When we use a third-party service provider to process data on our behalf then we will always have an appropriate agreement in place to ensure that they keep the data secure, that they do not use or share information other than in accordance with our instructions and that they are operating appropriately. Examples of functions that may be carried out by third parties include:

- Companies that provide IT services and support, including our core clinical systems, systems that manage patient facing services (such as our website and service accessible through the same), data hosting service providers, systems that facilitate appointment bookings or electronic prescription services and document management services etc.
- Further details regarding specific third-party processors can be supplied on request to the data protection officer as below.

Third parties mentioned on your medical record

Sometimes we record information about third parties mentioned by you to us during any consultation. We are under an obligation to make sure we also protect that third party's rights as an individual and to ensure that references to them that may breach their rights to confidentiality are removed before we send any information to any other party including yourself. Third parties can include spouses, partners and other family members.

Anonymised information



Sometimes we may provide information about you in an anonymised form. If we do so, then none of the information we provide to any other party will identify you as an individual and cannot be traced back to you.

Audit

Auditing of clinical notes is done by [insert organisation name] as part of their commitment to the effective management of healthcare whilst acting as a data processor.

Article 9.2.h is applicable to the management of healthcare services and "permits processing necessary for the purposes of medical diagnosis, provision of healthcare and treatment, provision of social care and the management of healthcare systems or services or social care systems or services." No consent is required to audit clinical notes for this purpose.

Furthermore, compliance with Article 9(2)(h) requires that certain safeguards are met. The processing must be undertaken by or under the responsibility of a professional subject to the obligation of professional secrecy or by another person who is subject to an obligation of secrecy.

Auditing clinical management is no different to a multi-disciplinary team meeting discussion whereby management is reviewed and agreed. It would be realistically impossible to require consent for every patient reviewed that is unnecessary.

It is also prudent to audit under Health and Social Care Act 2008 (Regulated Activities) Regulations 2014: Regulation 17: Good Governance.

GP connect service

The GP connect service allows authorised clinical staff at NHS 111 to seamlessly access our clinical system and book directly on behalf of a patient. This means that, should you call NHS 111 and the clinician believes you need an appointment, the clinician will access available appointment slots only (through GP Connect) and book you in. This will save you time as you will not need to contact the organisation directly for an appointment.

We will not be sharing any of your data and we will only allow NHS 111 to see available appointment slots. They will not even have access to your record. However, NHS 111 will share any relevant data with us but you will be made aware of this. This will help in knowing what treatment/service/help you may require.

Invoice validation



Your information may be shared if you have received treatment to determine which Clinical Commissioning Group (CCG) is responsible for paying for your treatment. This information may include your name, address and treatment date. All of this information is held securely and confidentially; it will not be used for any other purpose or shared with any third parties.

NHS health checks

Cohorts of our patients aged 40-74 not previously diagnosed with cardiovascular disease are eligible to be invited for an NHS Health Check. Nobody outside the healthcare team in [insert organisation name] will see confidential information about you during the invitation process.

Patient communication

As we are obliged to protect any confidential information we hold about you, it is imperative that you let us know immediately if you change any of your contact details.

We may contact you using SMS texting to your mobile phone should we need to notify you about appointments and other services that we provide to you involving your direct care. This is to ensure we are sure we are contacting you and not another person. As this is operated on an 'opt out' basis we will assume that you have given us permission to contact you via SMS if you have provided your mobile telephone number. Please let the organisation know if you wish to opt out of this SMS service. We may also contact you using the email address you have provided to us.

Primary care networks

The objective of primary care networks (PCNs) is for group practices together to create more collaborative workforces that ease the pressure of GPs, leaving them better able to focus on patient care. All areas within England are covered by a PCN.



Primary Care Networks form a key building block of the NHS long-term plan. Bringing general practices together to work at scale has been a policy priority for some years for a range of reasons including improving the ability of practices to recruit and retain staff, to manage financial and estates pressures, to provide a wider range of services to patients and to integrate with the wider health and care system more easily.

All GP practices have come together in geographical networks covering populations of approximately 30–50,000 patients to take advantage of additional funding attached to the GP contract. This size is consistent with the size of the primary care homes that exist in many places in the country but are much smaller than most GP federations.

This means that [insert organisation name] may share your information with other practices within the Primary Care Network to provide you with your care and treatment.

Risk stratification

Risk stratification is a mechanism used to identify and subsequently manage those patients deemed as being at high risk of requiring urgent or emergency care. Usually this includes patients with long-term conditions, e.g., cancer. Your information is collected by a number of sources including [insert organisation name]. This information is processed electronically and given a risk score which is relayed to your GP who can then decide on any necessary actions to ensure that you receive the most appropriate care.

Safeguarding

The organisation is dedicated to ensuring that the principles and duties of safeguarding adults and children are consistently and conscientiously applied with the wellbeing of all at the heart of what we do.

Our legal basis for processing for UK General Data Protection Regulation (UK GDPR) purposes is:

• Article 6(1)(e) '...exercise of official authority...'.

For the processing of special categories data, the basis is:

• Article 9(2)(b) – 'processing is necessary for the purposes of carrying out the obligations and exercising specific rights of the controller or of the data subject in the field of employment and social security and social protection law...'



Safeguarding information such as referrals to safeguarding teams is retained by [insert organisation name] when handling a safeguarding concern or incident. We may share information accordingly to ensure a duty of care and investigation as required with other partners such as local authorities, the police or healthcare professionals (i.e., the mental health team).

Shared care

To support your care and improve the sharing of relevant information to our partner organisations (as above) when they are involved in looking after you, we will share information to other systems. You can opt out of this sharing of your records with our partners at any time if this sharing is based on your consent.

Telephone system

Our telephone system records all telephone calls. Recordings are retained for up to three years and are used periodically for the purposes of seeking clarification where there is a dispute as to what was said and for staff training. Access to these recordings is restricted to named senior staff [amend as appropriate].

Opt-outs

National opt-out facility

This is used by the NHS, local authorities, university and hospital researchers, medical colleges and pharmaceutical companies researching new treatments.

You can choose to opt out of sharing your confidential patient information for research and planning. There may still be times when your confidential patient information is used; for example, during an epidemic where there might be a risk to you or to other people's health. You can also still consent to take part in a specific research project.



Your confidential patient information will still be used for your individual care. Choosing to opt out will not affect your care and treatment. You will still be invited for screening services such as screening for bowel cancer.

You do not need to do anything if you are happy about how your confidential patient information is used.

If you do not want your confidential patient information to be used for research and planning, you can choose to opt out by using one of the following:

- Online service patients registering need to know their NHS number or their postcode as registered at their GP practice
- Telephone service 0300 303 5678 which is open Monday to Friday between 0900 and 1700
- NHS App for use by patients aged 13 and over (95% of surgeries are now connected to the NHS App). The app can be downloaded from the App Store or Google play
- "Print and post" registration form: https://assets.nhs.uk/prod/documents/Manage_your_choice_1.1.pdf
 - Photocopies of proof of applicant's name (e.g., passport, UK driving licence etc.) and address (e.g., utility bill, payslip etc.) need to be sent with the application. It can take up to 14 days to process the form once it arrives at NHS, PO Box 884, Leeds, LS1 9TZ.
- Getting a healthcare professional to assist patients in prison or other secure settings to register an opt-out choice. For patients detained in such settings, guidance is available on NHS Digital and a proxy form is available to assist in registration.

Note: Unfortunately, the national data opt-out cannot be applied by this organisation.

General Practice Data for Planning and Research opt out (GPDPR)

The NHS needs data about the patients it treats to plan and deliver its services and to ensure that the care and treatment provided is safe and effective. The General Practice Data for Planning and Research data collection will help the NHS to improve health and care services for everyone by collecting patient data that can be used to do this. For example, patient data can help the NHS to:

Monitor the long-term safety and effectiveness of care



- Plan how to deliver better health and care services.
- Prevent the spread of infectious diseases
- Identify new treatments and medicines through health research

GP practices already share patient data for these purposes but this new data collection will be more efficient and effective. This means that GPs can get on with looking after their patients and NHS Digital can provide controlled access to patient data to the NHS and other organisations who need to use it, to improve health and care for everyone.

Contributing to research projects will benefit us all as better and safer treatments are introduced more quickly and effectively without compromising your privacy and confidentiality.

NHS Digital has engaged with the <u>British Medical Association (BMA)</u>, <u>Royal College of GPs (RCGP)</u> and the <u>National Data Guardian (NDG)</u> to ensure relevant safeguards are in place for patients and GP practices.

What patient data is shared about you with NHS Digital?

The collection date is still to be confirmed, although when it has been, patient data will be collected from GP medical records about:

- Any living patient registered at a GP practice in England when the collection started this includes children and adults
- Any patient who died after the data collection started and was previously registered at a GP practice in England when the data collection started

They will not collect your name or where you live. Any other data that could directly identify you, for example NHS number, General Practice Local Patient Number, postcode and date of birth, is replaced with unique codes that are produced by de-identification software before the data is shared with NHS Digital.



This process is called pseudonymisation and means that no one will be able to directly identify you from the data. The diagram below helps to explain what this means. The diagram below helps to explain what this means and using the terms in the diagram, the data we share would be described as de-personalised.



Image provided by Understanding Patient Data under licence.

The data collected by NHS Digital

We will share structured and coded data from GP medical records that is needed for specific health and social care purposes as explained above.

Data that directly identifies you as an individual patient, including your NHS number, General Practice Local Patient Number, postcode, date of birth and if relevant date of death, is replaced with unique codes produced by de-identification software before it is sent to NHS Digital. This means that no one will be able to directly identify you in the data.

NHS Digital will collect:



- Data on your sex, ethnicity, and sexual orientation
- Clinical codes and data about diagnoses, symptoms, observations, test results, medications, allergies, immunisations, referrals and recalls and appointments including information about your physical, mental, and sexual health
- Data about the staff who have treated you

More detailed information about the patient data collected is contained within the <u>Data Provision Noticed issued to GP practices</u>.

NHS Digital will not collect:

- Your name and address (except for your postcode in unique coded form)
- Written notes (free text) such as the details of conversations with doctors and nurses
- Images, letters and documents
- Coded data that is not needed due to its age for example medication, referral and appointment data that is over 10 years old
- Coded data that GPs are not permitted to share by law for example certain codes about IVF treatment and certain information about gender re-assignment

NHS Digital legal basis for collecting, analysing and sharing patient data

When NHS Digital collects, analyses, publishes and shares patient data, there are strict laws in place that it must follow. Under the UK General Data Protection Regulation (UK GDPR), this includes explaining to patients what legal provisions apply under UK GDPR that allows it to process patient data. The UK GDPR protects everyone's data.

NHS Digital has been directed by the Secretary of State for Health and Social Care under the <u>General Practice Data for Planning and Research Directions 2021</u> to collect and analyse data from GP practices for health and social care purposes including policy, planning,



commissioning, public health and research purposes. NHS Digital is the controller of the patient data collected and analysed under the GDPR jointly with the Secretary of State for Health and Social Care.

All GP practices in England are legally required to share data with NHS Digital for this purpose under the <u>Health and Social Care Act 2012</u> (2012 Act). More information about this requirement is contained in the <u>Data Provision Notice</u> issued by NHS Digital to GP practices.

NHS Digital has various powers to publish anonymous statistical data and to share patient data under sections 260 and 261 of the 2012 Act. It also has powers to share data under other Acts, for example the <u>Statistics and Registration Service Act 2007</u>.

Regulation 3 of the <u>Health Service (Control of Patient Information)</u> Regulations 2002 (COPI) also allows confidential patient information to be used and shared appropriately and lawfully in a public health emergency. The Secretary of State has issued legal notices under COPI (COPI Notices) requiring NHS Digital, NHS England and Improvement, arm's-length bodies (such as Public Health England), local authorities, NHS trusts, clinical commissioning groups and GP practices to share confidential patient information to respond to the COVID-19 outbreak. Any information used or shared during the COVID-19 outbreak will be limited to the period of the outbreak unless there is another legal basis to use confidential patient information.

How NHS Digital uses patient data

NHS Digital will analyse and link the patient data we collect with other patient data we hold to create national data sets and for data quality purposes. NHS Digital will be able to use the de-identification software to convert the unique codes back to data that could directly identify patients in certain circumstances for these purposes, where this is necessary and where there is a valid legal reason. There are strict internal approvals which need to be in place before NHS Digital can do this and this will be subject to independent scrutiny and oversight by the Independent Group Advising on the Release of Data (IGARD).

These national data sets are analysed and used by NHS Digital to produce national statistics and management information including public dashboards about health and social care which are published. NHS Digital never publish any patient data that could identify any individual. All data they publish is anonymous statistical data.

For more information about data NHS Digital publish see <u>Data and Information</u> and <u>Data Dashboards</u>.

Who does NHS Digital share patient data with?



All data that is shared by NHS Digital is subject to robust rules relating to privacy, security and confidentiality and only the minimum amount of data necessary to achieve the relevant health and social care purpose will be shared.

All requests to access patient data from this collection, other than anonymous aggregate statistical data, will be assessed by NHS Digital's <u>Data Access Request Service</u> to make sure that organisations have a legal basis to use the data and that it will be used safely, securely and appropriately.

These requests for access to patient data will also be subject to independent scrutiny and oversight by the <u>Independent Group Advising on the Release of Data (IGARD)</u>. Organisations approved to use this data will be required to enter into a data sharing agreement with NHS Digital regulating the use of the data.

There are several organisations that are likely to need access to different elements of patient data from the General Practice Data for Planning and Research collection. These include but may not be limited to:

- The Department of Health and Social Care and its executive agencies including Public Health England and other government departments
- NHS England and NHS Improvement
- Primary care networks (PCNs), clinical commissioning groups (CCGs) and integrated care organisations (ICOs)
- Local authorities
- Research organisations including universities, charities, clinical research organisations that run clinical trials and pharmaceutical companies

If the request is approved, the data will either be made available within a secure data access environment within the NHS Digital infrastructure or, where the needs of the recipient cannot be met this way, as a direct dissemination of data. NHS Digital plan to reduce the amount of data being processed outside central, secure data environments and increase the data it makes available to be accessed via its secure data access environment.



Data will always be shared in the uniquely coded form (de-personalised data in the diagram above) unless in the circumstances of any specific request it is necessary for it to be provided in an identifiable form (personally identifiable data in the diagram above), for example, when express patient consent has been given to a researcher to link patient data from the General Practice for Planning and Research collection to data the researcher has already obtained from the patient. It is therefore possible for NHS Digital to convert the unique codes back to data that could directly identify patients in certain circumstances, and where there is a valid legal reason which permits this without breaching the common law duty of confidentiality. This would include:

- Where the data is needed by a health professional for the patient's own care and treatment
- Where the patient has expressly consented to this, for example to participate in a clinical trial
- Where there is a legal obligation, for example where there are COPI Notices
- Where approval has been provided by the <u>Health Research Authority</u> or the Secretary of State with support from the <u>Confidentiality Advisory Group (CAG)</u> under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 (COPI) this is sometimes known as a 'section 251 approval'

This would mean that the data was personally identifiable in the diagram above. Re-identification of the data would only take place following approval of the specific request through the Data Access Request Service and subject to independent assurance by IGARD and consultation with the Professional Advisory Group which is made up of representatives from the BMA and the RCGP. If patients have registered a national data opt-out this would be applied in accordance with the national data opt-out policy before any identifiable patient data (personally identifiable data in the diagram above) about the patient was shared.

Details of who NHS Digital have shared data with, in what form and for what purposes are published on their data release register.

Where does NHS digital store patient data?

NHS Digital only stores and processes patient data for this data collection within the United Kingdom (UK). Fully anonymous data (that does not allow patients to be directly or indirectly identified), for example statistical data that is published, may be stored and processed outside of the UK.



Some of the NHS Digital processors may process patient data outside of the UK. If they do, they will always ensure that the transfer outside of the UK complies with data protection laws.

What to do if you have any questions

Should you have any questions about our privacy policy or the information we hold about you, you can:

- 1. Contact the organisation via email at [insert email address]. GP practices are data controllers for the data they hold about their patients⁸
- 2. Write to the data protection officer at [insert organisation address]
- 3. Ask to speak to the practice manager [insert name] or their deputy [insert name]

The data protection officer (DPO) for [insert organisation name] is [insert name]

Objections or complaints

In the unlikely event that you are unhappy with any element of our data-processing methods, do please contact the practice manager [insert name] at [insert organisation address] in the first instance. If you feel that we have not addressed your concern appropriately, you have the right to lodge a complaint with the ICO. For further details, visit <u>ico.gov.uk</u> and select "Raising a concern" or telephone: 0303 123 1113.

The Information Commissioner's Office is the regulator for the General Data Processing Regulations and offers independent advice and guidance on the law and personal data including your rights and how to access your personal information.

Changes to our privacy policy

We regularly review our privacy policy and any updates will be published on our website, in our newsletter and on posters to reflect the changes. This policy is to be reviewed [insert review date].

⁸ BMA GPs as data controllers under the GDPR



Annex B - Social media/website information

Using your health data for planning and research

The new General Practice Data for Planning and Research Data Collection (GPDPR) is coming. This data collection will help the NHS to improve health and care services for everyone by collecting patient data that can be used to do this.

The GPDPR is designed to help the NHS to:

- · Monitor the long-term safety and effectiveness of care
- Plan how to deliver better health and care services
- Prevent the spread of infectious diseases
- Identify new treatments and medicines through health research

You can decide whether you wish to have your information extracted and there are two main options available to you.

Option 1:

Type 1 Opt Out applies at organisational level and means that your medical record is not extracted from the organisation for any purpose other than for direct patient care. You can opt out at any time, however you should opt out before the beginning of September to ensure your data is not extracted for this purpose. Opting out after this date will mean that no further extractions will be taken from your medical record.

Further information is available here.

Option 2:

Type 2 Opt Out allows data to be extracted by NHS Digital for their lawful purposes but they cannot share this information with anyone else for research and planning purposes. You can opt out at any time.

Further information is available here.

How do you opt out?

Type 1 – You need to contact the practice by phone, email or post to let us know that you wish to opt out.

Type 2 – you need to inform NHS Digital. Unfortunately, this cannot be done by the practice for you. You can do this by any of the following methods:



- Online service You will need to know your NHS number or your postcode as registered at your GP practice via https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/
- Telephone service 0300 303 5678 which is open Monday to Friday between 0900 and 1700
- NHS App For use by patients aged 13 and over (95% of surgeries are now connected to the NHS App). The app can be downloaded from the App Store or Google play
- "Print and post" registration form: https://assets.nhs.uk/prod/documents/Manage_your_choice_1.1.pdf
 - Photocopies of proof of the applicant's name (e.g., passport, UK driving licence etc.) and address (e.g., utility bill, payslip etc.) need to be sent with the application.

It can take up to 14 days to process the form once it arrives at National Data Opt Out, Contact Centre, NHS Digital, HM Government, 7 and 8 Wellington Place, Leeds, LS1 4AP.



Annex C – Patient text messaging and telephone message templates

Text message content template

You can opt out of your health information being shared with NHS Digital for planning and research before the commencement date. For more information, please visit https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/ to find out more.

Patient information for website template

The way in which patient data gathering is done by NHS Digital is changing. There is currently a lot of information online and in the news about your choices and opting out of these collections. You can opt out of your GP record being shared with NHS Digital for planning and research and this should be done before the commencement date.

For more information, please visit our privacy notice at [insert link to practice privacy notice] to find out more.

Email response template

Thank you for your email regarding the sharing of patient data and being able to opt out of these collections. The NHS Digital GP Data extraction is a legally required activity for this practice; however, you do have a right to opt out of the sharing of your data for research and planning purposes.

NHS Digital provides a detailed guide for patients on how the information it extracts is used and how you can opt out. This can be found at https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research

Please be aware that there are two types of opt out:

Type 1 - applies at organisational level and means that the patient's medical record is not extracted from the organisation for any purpose other than for direct patient care.

Type 2 - allows data to be extracted by NHS Digital for its lawful purposes but it cannot share this information with anyone else for research and planning purposes.

If you wish to apply Type 1 Opt Out, please let us know and we will apply this locally to your clinical record. This will mean you data is not extracted on or after the commencement date.

If you wish to apply Type 2 National Data Opt Out you must do this directly with NHS Digital. You can do this in any of the following ways:



- Online service Patients registering need to know their NHS number or their postcode as registered at their GP practice via https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/
- Telephone service 0300 303 5678 which is open Monday to Friday between 0900 and 1700.
- NHS App For use by patients aged 13 and over (95% of surgeries are now connected to the NHS App). The app can be downloaded from the App Store or Google play.
- "Print and post" registration form: https://assets.nhs.uk/prod/documents/Manage_your_choice_1.1.pdf
 - Photocopies of proof of applicant's name (e.g., passport, UK driving licence etc.) and address (e.g., utility bill, payslip etc.) need to be sent with the application. It can take up to 14 days to process the form once it arrives at National Data Opt Out, Contact Centre, NHS Digital, HM Government, 7 and 8 Wellington Place, Leeds, LS1 4AP.

Telephone message template

We have received numerous enquiries about patient data being extracted by NHS Digital to be used for research and planning. You, as a patient, have the right to opt out of your information being used in this way.

Extensive information about this process can be found by visiting our website [give website address] or, if you do not have internet access, please speak with a member of our reception team who will be very happy to explain this to you.



Annex D – Organisational staff opt out guidance

This guidance is provided to all staff who may be required to respond to queries about the current data opt-outs available.

Who is NHS Digital?

- NHS Digital is the national information and technology partner for the health and care system
- It provides information and data to the health service so that it can plan
 effectively and monitor progress, create and maintain the technological
 infrastructure that keeps the health service running and links systems
 together to provide seamless care and develops information standards that
 improve the way different parts of the system communicate
- NHS Digital is the national custodian for health and care data in England and has responsibility for standardising, collecting, analysing, publishing and sharing data and information from across the health and social care system, including general practice

What does it do with the data it collects?

- Patient data collected from general practice is needed to support a wide variety of research and analysis to help run and improve health and care services. Whilst the data collected in other care settings such as hospitals is valuable in understanding and improving specific services, it is the patient data in general practice that helps NHS Digital to understand whether the health and care system as a whole is working for patients.
- Research the long term impact of coronavirus on the population
- Analyse healthcare inequalities
- Research and develop cures for serious illnesses

What type of data does NHS Digital extract from the organisation?

- Diagnoses and symptoms
- Observations
- Test results
- Medications
- Allergies and immunisations
- Referrals, recalls and appointments
- The patient's sex, ethnicity and sexual orientation
- Data about staff who have treated the patient

If a patient wishes to opt out of data sharing, there are two types of optout:



- Type 1 applies at organisational level and means that the patient's medical record is not extracted from the organisation for any purpose other than for direct patient care.
- Type 2 allows data to be extracted by NHS Digital for its lawful purposes but it cannot share this information with anyone else for research and planning purposes.

How does a patient opt out?

- **Type 1** the patient must inform the practice of their decision and this is coded at the practice locally to their clinical record.
- **Type 2** the patient must do this themselves with NHS Digital. Unfortunately, this cannot be done by the organisation. The patient can do this by:
 - Online service Patients registering need to know their NHS number or their postcode as registered at their GP practice via https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/
 - Telephone service 0300 303 5678 which is open Monday to Friday between 0900 and 1700.
 - NHS App For use by patients aged 13 and over (95% of surgeries are now connected to the NHS App). The app can be downloaded from the App Store or Google play
 - "Print and post" registration form:
 https://assets.nhs.uk/prod/documents/Manage_your_choice_1.1.pdf
 - Photocopies of proof of applicant's name (e.g., passport, UK driving licence etc.) and address (e.g., utility bill, payslip etc.) need to be sent with the application. It can take up to 14 days to process the form once it arrives at National Data Opt Out, Contact Centre, NHS Digital, HM Government, 7 and 8 Wellington Place, Leeds, LS1 4AP.
 - Getting a healthcare professional to assist patients in prison or other secure settings to register an opt-out choice. For patients detained in such settings, guidance is available on NHS Digital and a proxy form is available to assist in registration.

Coding the patient record

If the patient wishes to **opt out** – use code 827241000000103 Dissent from secondary use of general practitioner patient identifiable data (finding)

If the patient wishes to **opt in** – use code 827261000000102 Dissent withdrawn for secondary use of general practitioner