



SHARING YOUR NHS PATIENT DATA

Sharing your data for your own individual care

Information sharing in the NHS is subject to rigorous regulation and governance to ensure your full identifiable and personal medical data is kept confidential and only ever seen by carefully vetted doctors, nurses and administrative staff responsible for overseeing your care.

With the development of information technology the NHS will increasingly be sharing key information from your GP medical notes with Out of Hours GP Services, Hospital A&E Units, Community Hospitals, Community Nurses, all of whom may at various times in your life be looking after you. Sharing information can improve both the quality and safety of care you receive, and in some cases can be vital in making life-saving decisions about your treatment.

There are currently two different elements of sharing NHS patient information

- SCR = The NHS Summary Care Record
- EDSM = The Enhanced Data Sharing Model

SCR = NHS Summary Care Record

The NHS Summary Care Record was introduced many years ago to help deliver better and safer care; it contains basic information about:

- Any allergies you may have,
- Unexpected reactions to medications, and
- Any prescriptions you have recently received.

The intention of the SCR is to help clinicians in Hospital A&E Departments and GP “Out of Hours” health services to give you safe, timely and effective treatment. Clinicians are only allowed to access your SCR record if they are authorised to do so and, even then, only if you give your express permission. You will be asked if healthcare staff can look at your Summary Care Record every time they need to, unless it is an emergency, for instance if you are unconscious. You can refuse if you think access is unnecessary.

Over time, health professionals treating you may add details about any health problems and summaries of your care. Every time further information is added to your record, you will be asked if you agree (explicit consent).

Patients under 16 years have an NHS Summary Care Record created for them, so if you are the parent or guardian of a child please either make this information available to them or decide and act on their behalf.

EDSM = Enhanced Data Sharing Model “SystemOne”

The database and software used to store your GP health record is called “SystemOne”. It is a very secure national system used by over 2000 GP practices and 4800 NHS organisations including GP out of hour’s services, children’s services, community services and some hospitals. The system gives your GP the facility to share your record with other health providers who are involved in your care, for example the local Community Nurses who may look after you when you leave hospital or become housebound. Allowing your GP to share your record in the “SystemOne” database helps to deliver better and safer care for you. It is the policy of all local GP practices to automatically opt registered patients into “SystemOne” sharing unless they expressly decline. Those patients who choose to decline are able to determine if their data is “shared out” and/or “shared in”.

Sharing OUT controls whether information recorded at our GP practice can be shared with other health care providers.

Sharing IN determines whether or not our GP practice can view information in your record that has been entered by other services who are providing care for you or who may provide care for you in the future (*that you have consented to share out*).

Sharing your data for purposes not related to your individual care

Your confidential patient information can be used for research and planning, unless you have chosen to opt out. You are able to make or change your decision at any time. Most of the time, anonymised data is used for research and planning, so your confidential patient information isn't always needed. If you DO opt out, data that does not identify you may still be used.

Your confidential patient information provides numerous benefits. It is used in research to find cures and better treatments for diseases like diabetes and cancer, or can be used to plan health and care services more effectively. With your data, the NHS is better able to develop and improve health and care services for the future, which helps to improve health and social care for you and your family.

The NHS collects health and care data from all NHS organisations, trusts and local authorities, and also from private organisations, such as private hospitals providing NHS funded care. Research bodies and organisations can request access to this data. For further information: <https://www.nhs.uk/using-the-nhs/about-the-nhs/your-health-records/>

There are very strict rules on how your data can and cannot be used, and you have clear data rights. Access to confidential patient information will not be given for marketing purposes or insurance purposes - unless you specifically request this. Protection of your confidential patient information is taken very seriously and is looked after in accordance with good practice and the law.

Every organisation that provides health and care services will take every step to:

- ensure data remains secure
- use anonymised data whenever possible
- use confidential patient information to benefit health and care
- not use confidential patient information for marketing or insurance purposes (unless you specifically request this)
- make it clear why and how data is being used respect your decision if you decide to opt out
- only use information about you when allowed by the law

All NHS organisations must provide information on the type of data they collect and how it is used. Data release registers are published by NHS Digital and Public Health England, showing records of the data they have shared with other organisations.

Manage your choices

Sharing your data for purposes not related to your individual care

Online: <https://www.nhs.uk/your-nhs-data-matters/>

Use this service to request that your confidential patient information is not used beyond your own individual care.

Telephone: 0300 303 5678 Open: 9am to 5pm Monday to Friday (excluding bank holidays).

You may contact the NHS Digital Contact Centre to verify your identity and discuss your data sharing choices. We may be able to guide you through the online service or set a choice on your behalf.

Parents or legal guardians may also set and manage a choice on behalf of their child under the age of 13. You can set and manage a choice on behalf of another individual, who is unable to manage their choice independently, for example if you have power of attorney.

If you decide to opt out, this will be respected and applied by NHS Digital and Public Health England. These organisations collect, process and release health and adult social care data on a national basis. Your decision will also be respected and applied by all other organisations that are responsible for health and care information by March 2020. An opt-out will only apply to the health and care system in England and does not apply to your health data where you have accessed health or care services outside of England, such as in Scotland and Wales. If you choose to opt out, your data may still be used during some specific situations, for example, during an epidemic where there might be a risk to the health of other people.

For more information on where opt outs do not apply visit: <https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/where-opt-outs-dont-apply/>



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Please complete the form below to detail your personal decisions regarding the aspects of NHS patient data sharing for health care purposes. It is very important you sign this form to say that you understand and accept the risks to your personal health care if you do decide to opt out of SCR or EDSM. Hand the completed form in to Reception, who will scan this form into your NHS GP Medical Records and enter the appropriate computer codes.

GP Practice	Fremington Medical Centre
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Patient's FULL NAME	
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Patient's DATE OF BIRTH	
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1. SCR - NHS SUMMARY CARE RECORD

Please tick only one box.

- Express consent for medication, allergies and adverse reactions only
- Express consent for medication, allergies, adverse reactions & additional info (recommended)
- Express dissent – Patient does not want a summary care record and fully understands the risks involved with this decision

2. EDSM – ENHANCED DATA SHARING MODEL “SystemOne”

Sharing Out – Do you consent to the sharing of data recorded by your GP practice with other organisations that may care for you?

- YES share data with other organisations (recommended)
- NO do NOT share any data recorded by my GP Practice; I fully accept the risks associated with this decision

Sharing In – Do you consent to your GP Practice viewing data that is recorded at other organisations and care services that may care for you?

- Consent Given (recommended)
- Consent Refused; I fully accept the risks associated with this decision

Patient's FULL SIGNATURE		DATE	
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