

Privacy Notice

Background

In Sussex, health and care organisations work in partnership to improve health and care for their citizens. This falls under the umbrella of Sussex Health and Care.

Sussex Health and Care brings together all the health and social care organisations in Sussex, working together to meet the changing needs of all the people who live in our area.

We want to offer better health, better care and to ensure we make the most efficient use of our resources. Further information about Sussex Health and Care can be found on the Website: [Sussex Health and Care](#)

Part of Sussex Health and Care's priorities is to give citizens more joined up care using first class technology and information management systems. The My Health and Care Record provides citizens with the ability to access their health and care information.

Your information, what you need to know

This privacy notice explains why information about you is collected, how that information may be used in the My Health and Care Record, how it is kept safe and confidential, and what your rights are in relation to this.

Why information about you is collected

Health and Care practitioners who provide you with treatment, care or support, are required by law to maintain records about your health, care and any support you have received.

Some of this information plus information that you or others involved in your care may contribute, may be used to create your My Health and Care Record.

Your My Health and Care Record will provide you with information about services (such as appointment times, sign posting to resources) as well as helping you play a more active role in your care or support by viewing, following and contributing to that information. You will have your own access (typically via an app) to your My Health and Care Record.

This will be part of helping us provide everyone with the best and safest possible, care or support.

This information will also be used to help run health and care services efficiently and effectively, including monitoring the quality of services that are provided. Information held about you, within your My Health and Care Record, may be used to help protect the health of the public and to help us manage the NHS and Social Care. In most cases, your data will first be anonymised or pseudonymised when it is to be used for such purposes.

My Health and Care Record keeps your information in digital form. The records will include

basic details about you, such as your name and address. They also contain more sensitive information about your health and well-being, as well as information such as care plans.

What information is in the My Health and Care Record

- Details about you, such as your address, date of birth, NHS Number and next of kin.
- Contacts you have had with health and care services, such as appointments, clinic visits, emergency appointments, etc.
- Notes and reports about your health and well-being, including care plans, allergies, medications and services you receive.
- Details about any care and support you may have had.
- Results of investigations, such as laboratory tests, x-rays, etc.
- Relevant information from other health or care professionals,
- Information you have added about your health and care.
- Where you have given access, relevant information added by your relatives and/or carers.

How your information will be used

Improvements in information technology have made it possible to share data between health and care organisations for the purpose of providing you, your family and your community with better care. The aim of My Health and Care Record is to enable you to become more involved in managing and being a part of decisions about your own care.

Your information is processed by external suppliers who provide the technology, systems and tools (e.g. software and “apps”) that enable you to access and use your My Health and Care Record. My Health and Care Record may be more than one system/tool/app from more than one supplier.

These suppliers act as “Data Processors” on behalf of the organisations supplying the original data (e.g. NHS Hospital Trusts or G.P. Practices). These suppliers are often referred to as Third Party Processors. This information is listed under the section Third Party Data Processors.

Even if you are not using My Health and Care Record at the moment, your information may still be securely shared so it can be activated, without delay, if you choose to do so.

It will be possible for practitioners in other services, who are involved in providing care to you to access the relevant parts of your My Health and Care Record unless you have asked for this not to happen. You may choose to withdraw your permission for personal data being shared for these purposes.

Instructions will be provided to explain what you have to do to ‘opt-out’ of having your data shared within the My Health and Care Record.

If you ‘opt-out’ of your personal information being shared with other providers or with My Health and Care Record, you should discuss this with your healthcare professional to ensure you are aware of any impact on your care provision.

Data from your My Health and Care Record will also be included within the [Sussex Integrated Dataset \(SID\)](#), which is a de-identified linked dataset. The purpose is to evaluate the use of the My Health and Care Record across demographics, help run health and care services efficiently and effectively, improve services and the quality of care and support

evaluation and research. it is not possible for any individuals to be identified from the SID data.

The Legal Basis for using this information

The legal basis under the UK General Data Protection Regulation (GDPR) and UK Data Protection Act 2018 for My Health and Care Record is:

- *Article 6(1)(c) “processing is necessary for compliance with a legal obligation to which the controller is subject.”*
- *Article 9(2)(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 and services on the basis of Union or Member State law or pursuant to contract with a health professional and subject to certain conditions and safeguards;”*

How your information will be kept confidential and safe

Everyone working for the health and social care organisations that use My Health and Care Record are subject to the Common Law Duty of Confidentiality and Data Protection Laws.

All staff in those organisations are expected and under contract to make sure information is kept confidential and receive regular training on how to do this.

Information provided in confidence will only be used for the purposes advised and with agreement given by you, (unless there are other circumstances covered by the law). All staff are required to protect your information, inform you of how your information will be used, and allow you to decide if and how your information can be shared.

The information used for My Health and Care Record hold is kept in secure locations; is protected by appropriate security; and access is restricted to authorised personnel.

All data processors used for My Health and Care Record (those supplying the system and tools) are legally and contractually bound to operate and prove security arrangements are in place where data that could or does identify a person are processed.

The security of the systems and tools used by My Health and Care Record suppliers (Data Processors), will have been checked and approved by an independent group of Information Governance and Security specialists, reporting to the Sussex Health and Care Board, prior to those systems and tools being put into use.

All the organisations involved are committed to protecting your privacy and will only use information collected lawfully in accordance with:

- UK General Data Protection Regulation
- Data Protection Act 2018
- Human Rights Act 1998
- Common Law Duty of Confidentiality
- NHS Codes of Confidentiality and Information Security
- Health and Social Care Act 2015
- And all applicable legislation

Organisations and staff helping you use your My Health and Care Record will maintain their duty of confidentiality to you at all times. They will only ever use or pass on information about you if they reasonably believe that others involved in your care or support have a genuine need for it. They will not disclose your information to any third party without your permission unless there are exceptional circumstances (such as a risk of serious harm to yourself or others) or where the law requires information to be passed on.

Data Retention

Information within your My Health and Care Record will be retained in line with Health and Social Care Records Management Code of Practice. This will be checked and part of the contract terms, and will always meet or exceed any statutory data retention policies that may apply.

Some information may be transferred to other records, such as your hospital record or GP record, in such cases the retention then information becomes part of that record and not My Health and Care Record, so the data retention policy is in line with their record keeping policies (e.g. your GP Practice).

Access to your information

Under the UK GDPR everybody has the right to request access to their data. Under special circumstances, some information may be withheld.

The benefits of My Health and Care Record is you will be able to see information which is held within your record. If you wish to have a copy of the information held within your My Health and Care Record, please contact your healthcare practitioner.

You can also contact the system supplier directly to obtain data held in your My Health and Care Record.

Your right to restrict processing

The NHS Constitution states 'You have a right to request that your personal and confidential information is not used beyond your own care and treatment and to have your objections considered'.

Should you have any concerns about your information, how your information is managed, or wish to opt out of any data collection, please contact your GP, or your healthcare practitioner to discuss how the disclosure of your personal information can be limited. Patients have the right to change their minds and reverse a previous decision.

Third Party Data Processors

The My Health and Care Record in Sussex is powered by the following systems:

- [Patients Know Best \(PKB\)](#): A technology platform, designed to bring together patient data from health and social care providers and the patient's own data, into one secure personal health record.
- [East Sussex Healthcare NHS Trust](#): Are the host organisation under contract for operational processes of the My Health and Care Record.

Data Protection Officer

Should you have any data protection questions or concerns, please ask the health care practitioner most closely involved in your care or contact your healthcare provider's Data Protection Officer for advice.

Notification

The UK GDPR requires organisations to register a notification with the Information Commissioner to describe the purposes for which they process personal and sensitive information.

Complaints

If you have concerns, please contact the health or care provider most closely involved in your care (or follow their organisation's advice), or contact your GP Practice.

For independent advice about data protection, privacy and data-sharing issues, you can contact:

The Information Commissioner
Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF
Phone: **0303 123 1113** Website: www.ico.gov.uk

Further Information

Further information about the way in which organisations use personal information and your rights in that respect, can be found on their individual websites.

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