

Privacy Notice – Universal Care Plan

How your information is used

Health and social care professionals involved in your care need access to your Universal Care Plan (UCP) to provide you with safe, effective, and timely care.

Your UCP is accessed through the Better UCP platform. This enables the health and social care professionals involved in your care to view and update relevant information so they can respond appropriately to your individual needs. Professionals will only see and edit the information that is necessary for them to carry out their specific role.

Sharing information for sickle cell disease

If you have been diagnosed with sickle cell disease, certain personal and clinical information from your UCP may be securely shared with the National Disease Registration Service (NDRS). This information is used to support public health monitoring, service planning, and research aimed at improving care standards and outcomes for people living with sickle cell disease.

All information shared with the NDRS is handled confidentially, accessed only by authorised personnel, and transferred using secure government arrangements.

Your rights

You have a right to object to the sharing of your information in these circumstances. However, in some cases we have a legal duty to use and share information to ensure you receive safe care and to meet our statutory obligations.

Information Required Under the UK General Data Protection Regulation (UK GDPR).

Under the UK GDPR, we are required to provide you with the following information

1) Controller contact details	NHS South West London CCG 120 the Broadway Wimbledon London SW19 1RH
2) Data Protection Officer contact details	If you wish to contact your local Data Protection Officer, please email our UCP helpdesk on ucp.helpdesk@swlondon.nhs.uk alongside your post code so we can direct your query to your local officer.

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<p>3) Purpose of the processing</p>	<p>Your personal data is processed to support the delivery of direct Care.</p> <p>Direct care refers to care provided specifically to you as an individual. When you are referred to another service (such as a referral to a specialist in a hospital), relevant and necessary information about your health, circumstances, and care needs may be shared with other healthcare professionals. This enables them to provide the most appropriate advice, investigations, treatments, therapies and care.</p> <p>Health and Social care professionals also need to access and update your UCP so they can provide responsive and coordinated care, particularly in urgent and emergency situations.</p> <p>Where applicable, information shared with the NDRS supports:</p> <ul style="list-style-type: none">• Public health monitoring,• Service planning,• Research and quality improvement• National collection of disease-specific data for sickle cell disease,
<p>4) Lawful basis for processing</p>	<p>The processing of personal data in the delivery of direct care and related administrative purpose is carried out in accordance with Article 6 and 9 conditions of the UK GDPR: which permit the use of personal information and specific- category data for healthcare provision and compliance with legal obligations.</p>

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	<p><i>Article 6(1)(e) ‘...necessary for the performance of a task carried out in the public interest or in the exercise of official authority...’.</i></p> <p><i>Article 9(2)(h) ‘necessary for the purposes of preventative 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...’</i></p> <p>We will also recognise your rights established under UK case law collectively known as the “Common Law Duty of Confidentiality” *</p> <p>Data sharing to the NDRS is conducted under the Health and Social Care Act 2012, Section 251 provisions, and associated regulations.</p>
<p>5) Recipient or categories of recipients of the processed data</p>	<p>Your information may be shared with Health and Social care professionals and relevant support staff involved in your care. This includes staff working in:</p> <ul style="list-style-type: none"> • NHS organisations • Hospitals, • Diagnostic and treatment centers • Community and social care services <p>Information is shared only where necessary to support your personal care and is accessed through secure systems</p>
<p>6) Rights to object</p>	<p>You have the right, under Article 21 of the UK GDPR, to object to some or all of your personal information being processed and shared, including where information is shared with the National Disease Registration Service (NDRS).</p> <p>You may contact the Data Controller:</p> <ul style="list-style-type: none"> • Raise an objection, • Request further information, • Opt out of specific data sharing, where appropriate <p>Please note that this is a right to raise an objection, not an absolute right to prevent processing. In some circumstances, we may still need to use or share your information to comply with legal obligations or to ensure safe and effective care. Where possible, your preferences will be are respected</p> <p>The NDRS opt out is different from the National Data Opt Out (NDOO) https://digital.nhs.uk/services/national-data-opt-out.</p> <p>If a patient has registered a NDOO:</p> <ul style="list-style-type: none"> • NDRS is still able to collect their data because the NDOO does not apply where an organisation has a legal obligation to collect confidential patient information. NDRS's legal obligation is the National Disease Registries Directions 2021 https://digital.nhs.uk/ndrs/data/national-disease-register-service-directions. • For any data that NDRS shares with other organisations through NHS England's Data Access Request Service

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	<p>patients opt-outs are applied in line with the National Data Opt-Out Policy https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document</p>
7) Right to access and correct	<p>You have the right to:</p> <ul style="list-style-type: none">• Request access to the personal data held about you• Ask for any inaccurate information or incomplete information to be corrected. <p>There is no general right to have accurate medical records deleted, unless ordered by a Court of Law.</p>
8) Retention period	<p>Your information will be retained in line with the law and national guidance. https://transform.england.nhs.uk/information-governance/guidance/records-management-code/ is</p> <p>You may also contact NHS South West London or your local Integrated Care Board for more details about retention times.</p>
9) Right to Complain.	<p>If you have a concern about how your personal data is being used, you have the right to complain to the Information Commissioner's Office (ICO), you can use this link https://ico.org.uk/global/contact-us/</p> <p>or calling their helpline Tel: 0303 123 1113 (local rate) or 01625 545 745 (national rate)</p> <p>The ICO has National Offices in Scotland, Northern Ireland and Wales. Further details are available on the ICO website</p>

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Confidentiality

“Common Law Duty of Confidentiality”. The Common Law Duty of Confidentiality is not set out in a single written document like an Act of Parliament. Instead, it is based on decisions made by the courts over time. This means it is often referred to as 'judge-made' or case law. The law is applied by reference to those previous cases, so common law is also said to be based on precedent.

Under common law, information provided in circumstances where it is expected that a duty of confidence applies; that information cannot normally be disclosed without the consent of the person who provided it.

In health care this means that all patient information is confidential, regardless of the format in which it is held. This includes information that is:

- Written on paper
- Stored electronically
- Recorded visually or through audio
- Held in the memory of a health or care professional

The duty of confidentiality applied to all patients irrespective of their age or mental capacity

When confidential information may be shared lawfully

Confidential patient information may be disclosed lawfully under common law in the following circumstances:

1. **With the individual's consent** – The person whom the information relates has given their consent for it to be shared
2. **In the public interest** - Disclosure is necessary to prevent serious harm to the individual or others, or to protect public safety
3. **Where there is a legal obligation** – Disclosure is required by law, for example where there is a court order or statutory requirement.

Where disclosure occurs, only the minimum necessary information will be shared, and it will be handled in accordance with professional, ethical, and legal standards.