

London SDE

London Data Service

Privacy Notice

Contents

1. What is this document about?	2
2. Important Information about the London Data Service	2
2.1 What is the London Data Service?	2
2.2 Why do we process your data?	3
2.3 Which organisations are involved?	3
2.4 What data is used?	3
2.5 Who has access to your data?	4
2.6 What service providers are we using?	4
2.7 Do we make any automated decisions about you?	4
3. What are our lawful bases?	5
3.1 Common law duty of confidentiality	5
4. Technical Information about the London Data Service	5
4.1 How do we collect your data?	5
4.2 How long is your data retained?	6
4.3 Where is your data stored?	6
5. Data sharing	6
5.1 Are we sharing your data?	6
5.2 Is your data transferred to other countries?	6
6. Data Subject Rights	6
6.1 What are your rights?	6
6.2 How can you exercise your rights?	7
6.3 What happens after you submit your request?	7
6.4 Verifying your identity	7
6.5 Our right to refuse to comply with your request or charge a fee	7
7. Can you opt out?	7
8. Making a complaint or raising a concern	9
Appendix A	10

1. What is this document about?

This document is aimed to provide both professionals and patients alike with detailed, yet concise, transparency materials about the London Data Service. It details how the platform works, what information is being used, what the information is being used for, what your rights are and how you can exercise them.

The Sub-national Secure Data Environment ("**SNSDE**") is a programme of work nationally funded by NHS England which involves the creation of 11 NHS-led SNSDEs covering the whole of England, including London. The **London Secure Data Environment ("London SDE")** is under development as part of the wider SNSDE programme.

The London Data Service is an integral part of the London SDE. SDEs are platforms that uphold the highest standards of privacy, security and confidentiality, providing NHS organisations, and in limited circumstances, to approved third-parties, access to patient level data, without allowing the data to be extracted from the environment.

The London SDE is formed by two important components:

- the London Data Service, and
- the London Analytics Platform.

We have a separate Privacy Notice for the London Analytics Platform. If you wish to have more information about that, please find that on this [page](#).

2. Important Information about the London Data Service

2.1 What is the London Data Service?

London has a large, ethnically, and socially diverse population and a world leading setting. The combination of these two elements generates rich, high-quality health and clinical data. However, even to this day, health and care organisations work separately and autonomously when delivering health and care. The different organisations collect data relating to their patients and store it within their internal Electronic Patient Records (EPR), with limited data being shared among themselves. This often prevents health and care professionals from collaborating to provide better care for London patients and hinders the development of lifesaving treatments and interventions to improve patient outcomes.

As part of the London SDE, the London Data Service serves as a system and infrastructure which provides a London-wide solution to:

- pool data from different health and care organisations in London,
- link different records that may exist relating to the same patients,
- transform all the data into the same format and standard,
- store the combined data, and
- make data available to support the delivery and improvement of patient care.

The linked, standardised, and high-quality data will be made available to the health and care organisations for purposes in the public interest and for the purpose of improvement of delivery of health and care to patients in London. The next section explains in detail the public interest purposes for which patient-level data may be processed.

2.2 Why do we process your data?

The London Data Service is a service offered to all health and care providers and local commissioners in the London region. The service we offer serves the following overarching public interest purposes:

- **Supporting the provision of direct and proactive healthcare**, which includes the prevention, investigation and treatment of illness and the alleviation of suffering of individuals, as well as a wide array of population health management programmes.
- **Planning and commissioning of health and care services**, which is understood as the continual process of planning, agreeing, and monitoring and evaluating of health care services.
- **Assessing and improving health and care services**, including service evaluations, developments and audits which all serve the purposes of evaluating current services and identifying areas of improvements and providing insights for decision-makers to consider when establishing or changing services
- **Enabling research**, which is understood as any project undertaken by organisations that contribute data to London Data Service, health and care academic teams or industry partners that attempts to lawfully derive new knowledge to answer or refine relevant questions with scientific methods.

2.3 Which organisations are involved?

The London Data Service itself is not a legal entity and does not hold a legal standing. It is a secure platform established by the health and care organisations that operate in the London region, including:

- Organisations, registered with the Care Quality Commission (CQC) that provide health and care services to the population in London, including General Practices (GP), hospitals, mental health and community providers, and services;
- Local Authorities in London;
- Organisations that commission health and care services from providers, including North East London Integrated Care Board (NEL ICB), South East London Integrated Care Board (SEL ICB), South West London Integrated Care Board (SWL ICB) and West & North London Integrated Care Board (W&NL ICB).

These health and care organisations have collectively decided to contribute data for the creation of the London Data Service. These organisations are also responsible for making all the key decisions about how and why the data ingested into London Data Service may be used and because of that, they are regarded as “Data Controllers” under data protection legislation. The practical operation of the London Data Service is carried out by the North East London Integrated Care Board (NEL ICB) on behalf of all the organisations in the region.

2.4 What data is used?

Patient-level information from the health and care organisations and providers that are part of the London Data Service are collected, including full name, contact details, date of birth, date of death, address, NHS number, ethnicity, race, gender, religion, sexual orientation, marital status as well as details about their health and care and treatment.

2.5 Who has access to your data?

Usually, the data will be processed in an automated manner with no direct human interactions. This is to limit access to the data within London Data Service to the absolute minimum.

There may be extraordinary instances where NEL ICB (acting as the organisation entrusted with hosting London Data Service) needs to have access to the data for purposes of maintaining the service.

Other than that, the infrastructure is set up in a way that ensures complete isolation from outside environment, thus ensuring that neither the health and care providers nor any other third party will have direct access to the data.

2.6 What service providers are we using?

In order to maintain the service, our processor, NEL ICB, is engaging the help of the following organisations for their services:

Service Provider	Reason
Microsoft Limited	Microsoft Azure is used as data storage and management system.
Snowflake Computing UK Limited	Used to build data warehousing and analytics service.
Zendesk	Used for its support desk system with service provision, incident management and support.
Interworks	Used for its Project Management Office support, technical advisory, data engineering and platform services.
Answer Digital Limited	Used for technical advisory, data engineering, analytical and project management services.

NEL ICB has received authorisation from the Data Controllers that are part of the London Data Service to engage the services of the organisations listed above.

2.7 Do we make any automated decisions about you?

No, we do not make any automated decisions about you.

3. What are our lawful bases?

Under the relevant data protection laws (namely the Data Protection Act 2018 and the UK General Data Protection Regulation (“**UK GDPR**”)), a lawful basis is needed in order to lawfully use personal data. It is the obligation of the controller to determine the lawful basis. In our case, this would be each health and care provider and local commissioner who agrees to use and contribute to the London Data Service.

For the London Data Service, the Data Controllers will rely on the following lawful basis:

- **Article 6(1)(e) UK GDPR:** Necessary for the performance of a task carried out in the public interest or in the exercise of official authority.

Personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic and biometric data, health data and data on a person’s sex life and sexual orientation are all considered special category of personal data because they are more sensitive in nature. The data ingested into the London Data Service includes patients’ health data which means that special category of personal data is used. Where special category of personal data is processed, our Data Controllers will be relying on the following lawful bases:

- **Article 9(2)(h) UK GDPR:** Necessary for the provision of health and/or social care, including preventative or occupational medicine;
- **Article 9(2)(i) UK GDPR:** Necessary for reasons of public interest in the area of public health;
- **Article 9(2)(j) UK GDPR:** Necessary for archiving purposes in the public interest, scientific or historical research purposes.

3.1 Common law duty of confidentiality

In addition to the applicable legal bases under the UK GDPR, in February 2025, the London SDE programme received support under Section 251 of the NHS Act 2006 and its current Regulations, the Health Service (Control of Patient Information Regulations 2002), following advice from the Confidentiality Advisory Group (“**CAG**”). This approval allows the London SDE to lawfully receive **confidential** patient-level information from health and care providers in London and from NHS England, and to use this information for various purposes in the public interest, as outlined above in **section 2.2** of this Privacy Notice.

4. Technical Information about the London Data Service

4.1 How do we collect your data?

If you have been to a GP, a hospital, a social care provider or another NHS organisation in London that is part of London Data Service, then data will be extracted from their local records and ingested into London Data Service. You do not need to do anything for this to happen. A

secure method is used, and technical measures are implemented to ensure the safety of your data at every stage of the ingestion process.

4.2 How long is your data retained?

Your data will be retained in line with the [NHS England's Records Management Code of Practice 2023](#) which sets out what people working with, or within, NHS organisations in England need to do to manage records correctly. It is based on current legal requirements and professional codes of best practice. Appendix 2 of the Code contains a detailed retention schedule and sets out how long records should be retained. For more information, please see the code of practice.

4.3 Where is your data stored?

For the London Data Service, Microsoft Azure is primarily used for storage. However, under some circumstances, NEL ICB may use Snowflake Data Cloud for storage as an interim measure where it is instructed to do so by the Data Controllers.

Both Microsoft Azure and Snowflake Data Cloud servers are located in the United Kingdom. They were sub-contracted to provide secure, state-of-the-art data centre facilities and technical infrastructure for the secure storage of data.

5. Data sharing

5.1 Are we sharing your data?

Your data may be shared within the UK. The decision of whether to share or allow access to data is under the responsibility of the Data Controllers of the London Data Service. They will conduct, either independently or jointly, due diligence and assurance processes before each data transfer to ensure that appropriate technical and organisational measures are in place to maintain security and confidentiality of patient data. Only when your health and care provider, or local commissioner agrees to share its data for a specific project, after its due diligence and assurance process, will the data be prepared to be shared and made accessible to approved users. If the Data Controllers decide to share their data, NEL ICB will be instructed to prepare the data accordingly.

5.2 Is your data transferred to other countries?

Your personal data will not be transferred to any other country outside of the UK.

6. Data Subject Rights

6.1 What are your rights?

Under data protection law, you have various rights afforded to you as a data subject. These rights are listed in detail in **Appendix A**.

You can find out more about your rights by visiting the Information Commissioner's Office's website under this [link](#).

6.2 How can you exercise your rights?

You can exercise your rights either verbally or in writing. Please contact us using the details below:

Email:	NELondonicb.oneLondon.opt-out@nhs.net
Address:	OneLondon Service Desk NHS North East London 9 th Floor 20 Churchill Place London E14 5HJ
Phone number:	020 3182 2900 A voicemail service operates 24 hours a day 7 days a week. Please leave a message providing us with your contact name, telephone number and the nature of your request. We will contact you to process your request within office hours (Monday – Friday 09:00 – 17:00)

6.3 What happens after you submit your request?

You will receive communication from us acknowledging the receipt of your request. We will try our best to process your request without undue delay and within one month of receipt. Where we are unable to get back to you within that timeframe, we may extend it by another two months where we are legally allowed to do so. If that is the case, we will inform you as soon as possible about the delay.

6.4 Verifying your identity

We will require you to provide us with additional information so that we can verify your identity. This is solely for us to ensure that we do not disclose your data to the wrong person or to someone who is pretending to be you. Please note that the additional information you provide us will constitute further processing of your personal data.

6.5 Our right to refuse to comply with your request or charge a fee

Usually, we will be happy to comply with your requests without undue delay and free of charge. However, there are certain circumstances where we are legally allowed to refuse to comply or charge a reasonable fee. This will be the case where your request is manifestly unfounded or excessive. If we decide to refuse to comply or charge you a reasonable fee, we will inform you about our decision.

7. Can you opt out?

If you do not wish for your personal information to be used for the purposes of the London Analytics Platform, you can opt out. Opting out means that you inform us that you do not want to participate, and we will take measures to ensure that your personal information is not used.

We offer two different systems for opting out, each tailored to the specific purpose you wish to opt out of.

If you do not want for your personal data to be pseudonymised and then used for **research, planning and service improvement purposes**, you can opt out by...

Online	Via the London Secure Data Environment Data Portal: optout.dataservice.london.nhs.uk
writing to us via email	NELondonicb.oneLondon.opt-out@nhs.net Please use the subject line "Opting-Out of Secondary Purposes" so that we can correctly identify your request.
writing to us via post	OneLondon Service Desk NHS North East London 9 th Floor 20 Churchill Place London E14 5HJ Please title your letter <i>Opting-out for secondary purposes</i> include your name, NHS number, date of birth, address and contact details.
calling us	020 3182 2900 A voicemail service operates 24 hours a day 7 days a week. Please leave a message providing us with your contact name, telephone number and the fact that you would like to opt-out of your data being used for secondary purposes. We will contact you to process your request within office hours (Monday – Friday 09:00 – 17:00)

You can also ask that your data not be shared with services for the individual care that is provided to you. This is likely to have an impact on the information available to NHS services and our partners who are providing your healthcare and should be given careful consideration. If you do not want for your personal data to be used for your **individual care, as well as research, planning and service improvement purposes**, you can inform us by email, postal or telephone methods listed above but please clearly label your request for **Dissent** so we can route your request accordingly.

If you have previously submitted an opt-out form directly to your GP practice so that your personal data is not used for **research, planning and service improvement purposes** (this is called a **Type 1 Opt-Out**), your data will not be pseudonymised and used for these purposes. However, your personal data may still be used and shared for your individual care. For more information on the exercise of Type 1 Opt-Out, please visit the NHS website:

<https://www.nhs.uk/using-the-nhs/about-the-nhs/opt-out-of-sharing-your-health-records/>

If you are experiencing any issues with opting out, please contact us NELondonicb.oneLondon.opt-out@nhs.net and we will be happy to support you.

8. Making a complaint or raising a concern

If you have any concerns, or are unhappy about how your data is being used please get in touch through any of the contact methods below:

Postal Address	OneLondon Service Desk NHS North East London 9 th Floor 20 Churchill Place London E14 5HJ
Phone number	020 3182 2900
Email	NELondonicb.oneLondon.opt-out@nhs.net Please use the subject line "Complaint" so that we can correctly identify your request.

Alternatively, you can raise a concern with the **Information Commissioner's Office (ICO)** who are the UK data protection regulator who will investigate your complaint. Please see the Information Commissioner's website for more details: <https://ico.org.uk/concerns/> The contact details for the ICO are as follows:

Postal Address	Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF
Helpline number	0303 123 1113 (local rate) or 01625 545 745 if you prefer to use a national rate number.
Online	You can also make a complaint or raise a concern via the ICO's website .

Appendix A

Your rights include:

Individual Right	Information about your rights
The right to object	For the purposes of your data in the London Data Service, you have the right to object to the processing of your data.
The right to be informed	You have the right to be informed about how your data is collected and used. This Privacy Notice serves as our transparency material informing you as to how your personal data is used. This Privacy Notice aims to provide you with information in a concise, transparent, intelligible manner which is easily accessible and uses a clear and plain language.
The right of access	You have the right to access and receive a copy of the personal data we hold about you. You can make a subject access request to us for this information. We will provide the information in an accessible, concise and intelligible format, and it will be disclosed in a secure way.
The right of rectification	You have the right to rectify inaccurate personal data which we hold about you.
The right of erasure	In certain circumstances, you have the right to request that we erase the personal data we hold about you. You can only request the personal data is erased where: • it is no longer necessary for the purposes we collected it, • if you provided the information by consent and you withdraw your consent, • we have processed the information unlawfully, • or the erasure is in line with a legal obligation.
The right of restricting processing	In certain circumstances, you have the right to request that we restrict the processing of your data for a period of time. You can only request that the processing of personal data is restricted where: • you are contesting the accuracy of the personal data and it is being verified, • the data has been unlawfully processed, • we no longer need the personal data but you require us to keep it in order to establish, exercise or defend a claim,

The right of data portability	You have the right of data portability, meaning you have the right to receive a copy of your personal data in a structured, commonly used and machine readable format. However, the right of data portability does not apply to the London Data Service, as this right only applies when the data is collected via consent (Article 6(1)(a) UK GDPR) or for the performance of a contract (Article 6(1)(b) UK GDPR). Your health and care providers do not rely on either of these lawful bases to process your personal data for these purposes.
Rights related to automated decision-making including profiling	We do not make any automated decisions or automated profiling about you without any human involvement.