# NHS Lothian DataLoch Privacy Notice

#### 1. About DataLoch

DataLoch is a data service that has been developed in partnership by the University of Edinburgh and NHS Lothian. Further NHS Boards and Local Authorities in South-East Scotland will join our partnership in the future to ensure the benefits of our work extend to the entire region.

The DataLoch team believes that putting data at the centre of responses to health and care system challenges is critical to improving services through research, innovation and planning. Our approach will lead to better decision-making, research, and support for colleagues on the front line. We will do this by:

- bringing together health and social care data for the South-East Scotland region.
- working with experts in health and social care to understand and improve this data; and
- providing safe access to data for researchers.

**Please note:** DataLoch hosts and processes personal data from both patients (routinely collected health and social care data used for research, hosted within NHS Lothian) and applicants (researcher application data, public enquiries and newsletter subscribers, hosted within the University of Edinburgh).

NHS Lothian is responsible (and the Data Controller) for patient data processed as part of DataLoch. The University of Edinburgh is responsible for research applicant data, public enquiries, and DataLoch newsletter subscriptions. (For details about personal data processed within the University of Edinburgh visit the University of Edinburgh DataLoch Privacy Notice.)

The rest of this privacy notice relates solely to patient data for which NHS Lothian is responsible.

#### 2. About NHS Lothian

NHS Lothian is a public organisation created in Scotland under section 2 of the National Health Service (Scotland) Act 1978 (the **NHS Act 1978**). It is one of the organisations which form part of NHS Scotland (**NHSS**). For clarity, we/our are used in this Data Protection Notice to refer to NHS Lothian with respect to our role in the DataLoch partnership.

# 3. About the personal information we use

In relation to DataLoch we use personal information on different groups of individuals including:

- Patients
- Staff
- Contractors
- Suppliers
- Complainants, enquirers
- Professional experts and consultants

The personal information we use includes information that identifies you like your name, address, date of birth and postcode in addition to sensitive personal data, including information about racial or ethnic origin, genetic data, and health. In addition, religious or philosophical beliefs, as well as sex life or sexual orientation, may be inferred from free-text clinical notes.

#### 4. Our purposes for using personal information

#### **NHS Lothian**

Under the NHS Act 1978, NHS Lothian has the statutory responsibility to provide or arrange for the provision of a range of health care, health improvement and health protection services. We are given these tasks so that we can help to promote the improvement of the physical and mental health of the people of NHS Lothian and assist in operating a comprehensive and integrated national health service in Scotland.

We use personal information to enable us to provide and improve healthcare services for patients and within research processes, including the DataLoch service.

#### **DataLoch**

In common with the rest of the UK, the South-East Scotland region is facing a number of major health and social care challenges. These include: an ageing population; increasing numbers of people living with long-term and often multiple conditions; delays in hospital discharge; and ever-increasing costs of medicines. Meeting such challenges requires new innovative solutions.

DataLoch supports the delivery of our duties by bringing together key health and social care data will allow a holistic data-driven approach to the prevention and treatment of different conditions, as well as the provision of health and social care services more broadly. There is the possibility for greater proactive (rather than reactive) health and social care for the region's residents.

# 5. Our legal basis for using personal information

NHS Lothian, as Data Controller, is required to have a legal basis when using personal information. NHS Lothian considers that performance of our tasks and functions are in the public interest.

DataLoch processes personal information for research purposes and service planning, management and improvement. So, when using personal information within DataLoch,

our legal basis is that its use is necessary for the performance of a task carried out in the public interest, or in the exercise of official authority vested in us. Additionally, the legal basis for processing data within DataLoch is that the use is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes, with appropriate safeguards in place and exemptions relating to this UK GDPR lawful processing.

## 6. Who provides the personal information

When you do not provide information directly to us, we receive it from other individuals and organisations involved in the delivery of health and care services in Scotland. These include other NHS Boards and primary care contractors such as GPs, dentists, pharmacists, opticians, other public bodies (e.g. Local Authorities) and suppliers of goods and services. DataLoch processes the above data for the research purposes as outlined by UK GDPR and the Data Protection Act 2018.

# 7. Sharing personal information with others

Depending on the situation, where necessary we will share appropriate, relevant and proportionate personal information in compliance with the law.

# 8. Transferring personal information abroad

Personal health information is not routinely transferred overseas in relation to DataLoch. Agreement would be required in line with research approvals.

#### 9. Retention periods of the information we hold

Within NHS Lothian, we keep personal information as set out in the Scottish Government Records Management: Health and Social Care Code of Practice (Scotland) 2020. The NHS Code of Practice sets out minimum retention periods for information, including personal information, held in different types of records including personal health records and administrative records. As directed by the Scottish Government in the Records Management Code of Practice, we maintain a retention schedule as part of our Records Management Policy detailing the minimum retention period for the information and procedures for the safe disposal of personal information.

Data will not be held for longer than the research purposes require it.

# 10. How we protect personal information

NHS Lothian take care to ensure your personal information is only accessible to authorised people. Staff have a legal and contractual duty to keep personal health information secure and confidential.

The following security measures are in place to protect personal information as part of DataLoch including:

- All staff undertake mandatory training in Data Protection and IT Security
- Compliance with NHS Scotland Information Security Policy
- Organisational policies and procedures on the safe handling of personal information
- Access controls and audits of electronic systems
- All researchers seeking access to data are required to sign a user agreement (contract) and provide evidence of data protection and confidentiality training

## 11. Your rights

This section contains a description of your data protection rights in relation to NHS Lothian-controlled data that is processed by DataLoch.

Data processed within DataLoch is controlled by NHS Lothian, and in the future other data sources. In responding to requests, the DataLoch team is required to refer to the Data Controllers.

# The processing of data within DataLoch will be subject to:

# The right to be informed

NHS Lothian must explain how we use your personal information. We use a number of ways to communicate how personal information is used, including:

- This Data Protection Notice
- The DataLoch website
- Programme of engagement

#### The right of access

You have the right to access your own personal information.

This right includes making you aware of what information we hold along with the opportunity to satisfy you that we are using your information fairly and legally.

You have the right to obtain:

- Confirmation that your personal information is being held or used by us
- Access to your personal information
- Additional information about how we use your personal information

Although we must provide this information free of charge, if your request is considered unfounded or excessive, or if you request the same information more than once, we may charge a reasonable fee.

If you would like to access your personal information, you can do this by submitting a written request.

Access the form on our <u>Requests for Personal Information</u> page. Please complete and return to:

Email: <a href="mailto:loth.datalochig@nhs.scot">loth.datalochig@nhs.scot</a>

## The right to rectification

If the personal information we hold about you is inaccurate or incomplete you have the right to have this corrected.

If it is agreed that your personal information is inaccurate or incomplete, we will aim to amend your records accordingly, normally within one month, or within two months where the request is complex. However, we will contact you as quickly as possible to explain this further if the need to extend our timescales applies to your request. Unless there is a risk to patient safety, we can restrict access to your records to ensure that the inaccurate or incomplete information is not used until amended.

If for any reason we have shared your information with anyone else, for example for a research project, it will not be possible to update individual information in those copies of the information.

If on consideration of your request NHS Lothian does not consider the personal information to be inaccurate then we may add a comment to your record stating your concerns about the information. If this is case, we will contact you within one month to explain our reasons for this.

If you are unhappy about how NHS Lothian has responded to your request for rectification, we will provide you with information on how you can complain to the Information Commissioner's Office, or how to take legal action.

#### The right to object

As NHS Lothian is processing your personal information for the purpose of the performance of a task carried out in the public interest, you have the right to object to the processing and also seek that further processing of your personal information is restricted. Please be aware that if NHS Lothian can demonstrate compelling legitimate grounds for processing your personal information, then your right will not be upheld.

#### Other rights

There are other rights under current Data Protection Law however these rights only apply in certain circumstances. For further information on these rights please visit ico.org.uk/for-the-public.

#### The right to complain

NHS Lothian employ a Data Protection Officer to check that we handle personal

information in a way that meets data protection law. If you are unhappy with the way in which we use your personal information, please tell our Data Protection Officer using the contact details below.

Data Protection Officer Information Governance Woodlands House 74 Canaan Lane Edinburgh EH9 2TB Phone – 0131 465 5444

Email: Loth.DPO@nhs.scot

You also have the right to complain about how we use your personal information to the Information Commissioner's Office (ICO). Details about this are on their website at <a href="https://www.ico.org.uk">www.ico.org.uk</a>.

#### 12. NHS Lothian

For further information regarding NHS Lothian please go to the <a href="NHS Lothian Data">NHS Lothian Data</a>
Protection Notice

# 13. The University of Edinburgh

For further information regarding University of Edinburgh please go to the University of Edinburgh DataLoch Privacy Notice.