



## Privacy Notice

### Introduction

Our research participants are very important to us and we are constantly striving to improve the service they receive, through looking at the ways we work and ensuring our staff are highly trained. As a Trust we encourage research which allows us to offer our patients the latest technologies, techniques and medicines – and attract and retain our enviable team of more than 15,000 highly skilled staff.

We are one of the biggest and busiest NHS Trusts in the country, serving the one million residents of Leicester, Leicestershire and Rutland – and increasingly specialist services over a much wider area. Our nationally and internationally-renowned specialist treatment and services in cardio-respiratory diseases, Extra Corporeal Membrane Oxygenation (ECMO), cancer and renal disorders reach a further two to three million patients from the rest of the country.

Spread over the General, Glenfield and Royal Infirmary hospitals, we also have our very own Children's Hospital and work closely with partners at the University of Leicester and De Montfort University providing world-class teaching to nurture, train and develop the next generation of doctors, nurses and other healthcare professionals, many of whom go on to spend their working lives with us.

Our Heart centre at the Glenfield hospital continues to lead the way in developing new and innovative research and techniques, such as surgery with a Robotic Arm, TAVI (Trans-Catheter Aortic Valve Insertion) and the use of the suture less valve in heart surgery. It has also become one of the world's busiest ECMO centres and the only hospital in the UK to provide ECMO therapy for both adults and children.

Our purpose is to provide 'Caring at Its Best' by living a set of values created by our staff that embody who we are and what we are here to do. They are:

- We focus on what matters most
- We treat others how we would like to be treated
- We are passionate and creative in our work
- We do what we say we are going to do
- We are one team and we are best when we work together

Our service users are at the heart of all we do and we believe that 'Caring at its Best' is not just about



the treatments and services we provide, but about giving everyone who interacts with the hospital the best possible experience. That is why we are proud to be part of the NHS and we are proud to be Leicester's Hospitals.

This privacy notice lets you know what happens to any personal data that you give to us, or any that we may collect from or about you.

This privacy notice applies to personal information processed by or on behalf of the Trust. This Notice explains:

- Who we are, how we use your information and who our Data Protection Officer (DPO) is
- What kinds of personal information about you we process
- What the legal grounds for our processing of your personal information are (including when we share it with others)
- What you should do if your personal information changes
- How long we retain your personal information
- What your rights under data protection law are

The EU General Data Protection Regulation (EU GDPR) became law on 24 May 2016 and later replaced by UK GDPR on 14<sup>th</sup> October 2020 as a result of UK exit from EU. This is a single UK-wide regulation on the protection of confidential and sensitive information. It entered into force in the UK on the 25 May 2018, repealing the Data Protection Act (1998).

For the purpose of applicable data protection legislation (including but not limited to the General Data Protection Regulation (Regulation (UK) 2020/679) (the "GDPR"), and the Data Protection Act 2018 (currently in Bill format before Parliament).

University Hospitals of Leicester NHS Trust is a registered "Data Controller", Information Commissioner Office (ICO) registration number Z7882087. We collect and process personal information about you. This notice explains how we use and share your information. Information may be collected in the following formats - paper, online, telephone, email, CCTV or by a member of our staff, or one of our partners.

We will continually review and update this privacy notice to reflect changes in our services and feedback from service users, as well as to comply with changes in the law. When such changes occur, we will revise the "last updated" date as documented in the version control section.



## Why we collect information about you

We need information about you so that we can contact you to share opportunities about research in which you may be interested in taking part.

We may collect further information about you at the point of entry into a research study to give you the best possible care. For every study you enter you will be given detailed information in the patient information sheet and consent process about:

- what data we will need to collect,
- why we need to collect it,
- how it will be used,
- who we may need to share it with, and
- how it will be stored and/or destroyed

We may not be able to recruit you to a study unless we have enough information about you.

For processing to be lawful under the UK General Data Protection Regulation ( UK GDPR) we need to identify a legal basis before we can process personal data. These are often referred to as the 'lawful basis for processing'.

The identified legal basis for University Hospitals of Leicester NHS Trust to process healthcare data is: '6(1)(e) – Processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.'

The type of data we process (health data) is known as a 'special category data'. The identified legal basis for University Hospitals of Leicester NHS Foundation Trust to process healthcare data is:

'9(2)(h) Necessary for the purposes of preventative or occupational medicine, for medical diagnosis, the provision of health or social care or treatment or management of health or social care systems and services, carried out by or under supervision of health professionals who in the circumstances owes a duty of confidentiality under and enactment of rule of law'.

This is the lawful basis for processing the health data that we collect to provide care directly to each patient, and the data that we collect for managing and planning our services to you.

## What information we collect about you

For the purposes of Leicester's Research Registry, we will only collect minimal data about you. This comprises:



- Your email address
- Your location
- Whether you are over 18

In addition, you may choose to tell us about any health conditions you are interested in. We will not presume that you have any health conditions, and this is an optional field so you may choose not to answer.

If you consent to enter a research study, additional information may be collected about you. The information we collect will be specific to that study and you will be informed of this before you decide to take part.

### **What are the different types of data?**

According to the UK General Data Protection Regulation, personal data means any information relating to an identified or identifiable natural person. An identifiable person may be someone who can be identified directly or indirectly.

Sensitive Personal Data relates to information concerning a data subject's racial or ethnic origin, political opinions, religious beliefs, trade union activities, physical or mental health, sexual life or details of criminal offences.

Pseudonymised data takes the most identifying fields within a database and replaces them with artificial identifiers or pseudonyms. For example, a name is replaced with a unique number.

Pseudonymised data is not the same as anonymised data. When data has been pseudonymised it still retains a level of details in the replaced data that should allow tracking back of the data to its original state.

Anonymisation is the process of turning data into a form which does not identify individuals and where identification is not likely to take place. This allows for a much wider use of the information as it changes it from personal data to statistical data. Where possible, University Hospitals of Leicester NHS Trust uses and shares anonymised data instead of identifiable data to protect the confidentiality of the subjects involved while still being able to plan services.

For the purposes of Leicester's Research Registry, we will only collect your email address, approximate location and whether you are 18 years or above.

If you decide to enter a research study, we may also collect the following, depending on the research study:



Personal demographic details including your name, address, date of birth, and phone number for:

- identifying you, to ensure we have the right person to treat
- planning our services in your local area
- to contact you regarding appointments and feedback via text messages (you can opt out of this if you like by contacting us, following opt out instructions in the message or informing staff when you attend an appointment)

### **Sensitive information: health data and diagnostic data**

This information is taken so that we can offer you the best care available and tailor it to your needs. It is kept securely and only those with a need to see it are allowed access.

We may share information regarding your health with other agencies and organisations, including other healthcare providers. This work is completed in accordance with Data Protection law, and where possible will either have had any information that identifies you removed, or with your consent.

You will be fully informed of the types of information we will collect, and why we will collect it before you consent to any research study, the details of which will be included in the patient information sheet and consent process and are unique to each study.

### **Closed Circuit Television (CCTV) /surveillance**

If you come into one of our research facilities, we have installed CCTV systems in some of our premises that are used by members of the public, for the purposes of public and staff safety and crime prevention and detection. CCTV is also installed on the outside of some of our buildings for the purposes of monitoring building security and crime prevention and detection.

Images captured by CCTV will not be kept for longer than necessary. However, on occasions there may be a need to keep images for longer, for example where a crime is being investigated. We operate CCTV and disclose to relevant agencies, such as the Police, in accordance with the codes of practice and safeguards issued by the Information Commissioner.

### **How long will we store your information?**

For the purposes of Leicester's Research Registry, we will contact you on an annual basis to ask you if you would like to remain on our registry. If you do not respond, or choose to withdraw your consent, your data will be permanently deleted from our digital register. No paper copies of the database will be retained or stored.



If you later consent to enter a research study, the length of time your data will be stored will vary according to the protocol for each study. You will be fully informed of the amount of time your information will be stored in the patient information sheet and consent process.

### **Why we collect information about ethnicity**

We do not collect information about your ethnicity for the purposes of Leicester's Research Registry. If you later consent to enter a research study, we may collect information about your ethnicity in accordance with the study protocol, which is an ethically approved 'manual' for how the study will be carried out. You will be informed about this through the patient information sheet and consent process before you agree to take part.

### **How we use your information**

We will use the information you provide in a manner that conforms to the UK General Data Protection Regulation and which is supported by the Data Protection Act 2018. We will endeavour to keep your information accurate and up to date and not keep it for longer than is necessary.

The data you have provided for Leicester's Research Registry will not be used for any other purpose than to share opportunities for you to participate in research run by University Hospitals of Leicester NHS Trust and its partners.

If you later choose to enter a research study, we will process the information you give to the study team for the following purposes:

- Staff caring for you have accurate and up to date information to help them decide the best possible care and treatment needed for you
- We can contact you in relation to your care and treatment
- Information is available should you need another form of care, for example if you are referred to a specialist or another part of the NHS
- There is a good basis for looking back and assessing the type and quality of care you have received
- Your concerns can be properly investigated should you need to complain

### **How your information is used for other purposes**

In addition to supporting the care you receive; your information may also be used to help us:

- Look after the health of the general public



- Review the care we provide to ensure it is of the highest standard
- Teach and train health care professionals (if you do not want your information to be used in this way, please let us know. It will not affect your treatment in any way)
- Conduct research approved by the Local Research Ethics Committee (your personal details will not be disclosed outside of the Trust without your consent)
- Conduct audits to assess and improve the effectiveness of our services
- Investigate complaints, legal claims or untoward incidents
- Make sure our services can meet patient needs in the future
- Prepare statistics on NHS performance
- Ensure treatments and services meet the needs of local communities
- Monitor the way public money is spent

If you do not want certain information recorded or shared with others, please talk to the person in charge of the research study you have chosen to take part in. There are however some aspects of your care which we are obliged to record.

### **Is any information transferred outside the European Economic Area**

Information given to us for the purposes of Leicester's Research Registry will not be transferred outside the European Economic Area.

If you later choose to be part of a research study, we may transfer your personal information to countries outside the UK if our research partners are outside of Europe, but this will be with your full consent and based on the stringent Data Protection assurances provided by the research partner who will be expected to sign a data sharing agreement with us. If you are outside the UK and would like to see a copy of your records, please request these through the Access To Your Records section of this web site: <https://www.leicestershospitals.nhs.uk/patients/patient-and-visitor-services/health-and-medical-records/>

### **How we protect your information**

We understand the personal and sensitive nature of your information. In addition to the UK General Data Protection Regulation (UK GDPR) and Data Protection Act 2018 (DPA18) everyone working for the NHS is subject to the Common Law Duty of Confidence. Staff are required to protect your information under the NHS Confidentiality Code of Conduct and must inform you how your information will be used and allow you to decide if and how your information can be shared.

We may use external companies to process personal information such as for archiving or destruction of data. These organisations will be bound by contractual agreement to ensure information is kept confidential and secure in compliance with the UK GDPR/DPA18.



## Who else might see your information?

You may be receiving care from other people as well as the NHS so we may be required to share your information with them for example with:

- Other healthcare professionals e.g., doctors, nurses, ambulance services
- Partner organisations who contribute to your long term care e.g., GPs, social services, private sector providers
- Other services e.g., cancer registries, complaints, auditing, research purposes etc. (anonymised/pseudonymised or your consent will be sought)

We may also need to share your information for other purposes for example with (please note this list is not exhaustive):

- Carers/guardians with parental responsibilities
- Carers/guardians without parental responsibility (subject to explicit consent, unless data is anonymous)
- Disclosure to NHS managers and the Department of Health for the purposes of planning, commissioning, managing and auditing healthcare services
- Disclosure to bodies with statutory investigative powers – e.g., the Care Quality Commission, the GMC, the Audit Commission, the Health Service Ombudsman, the Health Research Authority, the Medicines and Healthcare products Regulatory Agency
- Disclosure, where necessary and appropriate, to non-statutory investigations – e.g., Members of Parliament
- Disclosure, where necessary and appropriate, to government departments other than the Department of Health
- Disclosure to solicitors, to the police, to the courts (including a Coroner's court), and to tribunals and enquiries
- Disclosure to the media (the minimum necessary disclosure subject to explicit consent)

We may therefore need to share your information with these individuals to ensure the best possible care is provided. We will only ever pass information about you if they have a genuine need for it, on a need to know basis, if there is a court order, there is a statutory power to share patient data or we have your consent. We will not disclose your information to a third party unless there are exceptional circumstances, such as when the health and safety of others is at risk or if the law requires us to pass on such information.

## Information sharing in the NHS

Information sharing can help to improve the quality of care and treatment, but it must be governed by the legal and ethical framework that protects the interests of service users.



The Trust co-ordinates the sharing of information through the use of official Information Sharing Agreements to ensure that data is handled in accordance with the framework. This framework ensures that the responsibilities of the owner of the data (Controller) and the party processing the data (Processor) are set out, what will happen in the event of a confidentiality breach and who takes responsibility for this.

### **Patient control of information**

You may want to prevent confidential information about you from being shared or used for any purpose other than providing your care. You have a right to opt-out of the NHS or other organisations using your information. If you wish to do this please contact the Trust via the contact details highlighted below:

Data Protection Officer- Saiful Choudhury

Email: [Saiful.Choudhury@uhl-tr.nhs.uk](mailto:Saiful.Choudhury@uhl-tr.nhs.uk)

We do however need to remind you that we may not be able to provide you with a service or be able to undertake the appropriate care needed unless we have enough information about you, or your permission to use that information.

### **Your rights**

#### **Correcting inaccurate information**

We have a duty to ensure your information is accurate and up to date to make certain we have the correct contact and treatment details about you. If your information is not accurate and up-to-date, you can ask us to correct the record. If we agree that the information is inaccurate or incomplete, it will be corrected. If we do not agree that the information is inaccurate, we will ensure that a note is made in the record of the point you have drawn to the organisation's attention. If you wish to have any inaccurate information altered, please [click here](#) to contact the Patient Information and Liaison Service:

<https://www.leicestershospitals.nhs.uk/patients/patient-welfare/patient-information-and-liaison-service/>

#### **Accessing your information held by University Hospitals of Leicester NHS Trust**

You have the right to see or be given a copy of personal data held about you. To gain access to your information you will need to make a Subject Access Request (SAR) to the Trust. Requests should be addressed to the Trust and we will aim to respond to your request within one month from receipt of your request. For more information please [click here](#):

<https://www.leicestershospitals.nhs.uk/patients/patient-and-visitor-services/health-and-medical-records/>



## Freedom of Information Requests (FOI)

The Freedom of Information Act (2000) gives every Individual the right to request information held by the Trust that is deemed to be in the public interest. Your request for information must be made in writing and you are entitled to a response within 20 working days. For more details on submitting a Freedom of Information request please click

<https://www.leicestershospitals.nhs.uk/aboutus/freedom-of-information/>

## Complaints

Although we work hard to offer high standards of service and care, things can sometimes go wrong. Should this happen, we will do all that we can to put things right for you and to make sure that the same thing does not happen again. If you would like to know more information on complaints or wish to make a complaint, please click here:

<https://www.leicestershospitals.nhs.uk/patients/patient-welfare/patient-information-and-liaison-service/>

Should you have any concerns about how your information is to be used having read this Privacy Notice, you wish to request the notice in another accessible format or if you do not wish your information to be shared by University Hospitals of Leicester NHS Trust then please contact the Trust here:

<https://www.leicestershospitals.nhs.uk/patients/patient-welfare/patient-information-and-liaison-service/> or email: [pils@uhl-tr.nhs.uk](mailto:pils@uhl-tr.nhs.uk)

The NHS is introducing a tool so that people can opt out of their confidential patient information being used for reasons other than their individual care and treatment. This service is available through NHS Digital – National Data Opt-Out programme. Further details can be found at the following link –

<https://digital.nhs.uk/services/national-data-opt-out-programme>

There may be circumstances where we are legally obliged to share your personal data with other third parties, for reasons such as safeguarding purposes or a court order. In such cases you will not be able to opt out of data sharing.

If you are not happy with our responses and have exhausted all the avenues in the University Hospitals of Leicester NHS Foundation Trust's process and wish to take your complaint to an independent body, you can do this by contacting the Information Commissioner's Office.

## COVID-19 Update



The health and social care system is going to face significant pressures in the coming months due to the COVID-19 outbreak. Staff will need to work in different ways from usual and we want to ensure they can focus on responding to these events.

The Secretary of State for Health and Social Care has Directed NHS Digital to collect and analyse data from providers and other organisations involved in managing the COVID-19 response and then disseminate information and analysis to other bodies for the purpose of planning and managing the response. NHS England and NHS Improvement have been given legal notice to support the processing and sharing of information to help the COVID-19 response under Health Service Control of Patient Information Regulations 2002.

Individual healthcare organisations, arm's length Bodies (except NHS Digital and NHS England and NHS Improvement which have been separately notified) and local authorities have now also been given legal notice under the same regulations to support the processing and sharing of information to help the COVID-19 response. This is to ensure that confidential patient information can be used and shared appropriately and lawfully for purposes related to the COVID-19 response. The Notice is attached. This notice applies to:

- all providers of healthcare
- all GP practices
- all Department of Health and Social Care arm's length bodies
- local authorities

Under COPI Regulations 2002, processing means:

- the recording and holding of information
- the retrieval, alignment and combination of information
- the organisation, adaption or alteration of information
- the blocking, erasure and destruction of information

It also includes the dissemination of information to other organisations that require it for the same purposes.

The Notice includes a non-exhaustive list of COVID-19 related purposes, and the effect of the Notice is that any processing which is undertaken in pursuance of those purposes will be deemed lawful irrespective of any limitations which the common law duty of confidentiality would ordinarily impose. This is, however, subject to some specific caveats as set out in the COPI Regulations themselves. These include that organisations' use of the information in question is limited to that which is



necessary for the particular purpose, and further that as far as is reasonably practical individual identifiers are removed to the extent that they are not required for the purpose.

These Notices have been reviewed on 30 September 2020 and have been extended until further notice.

Data controllers are still required to comply with relevant and appropriate data protection standards and to ensure within reason that they operate within statutory and regulatory boundaries. The UK General Data Protection Regulation (UK GDPR) allows health data to be used as long as one of the conditions under both Art. 6 and Art. 9 are met. There are conditions under both Articles that can be relied on for the sharing of health and care data – including, under Article 6, pursuance of an organisation's public tasks and, under Article 9, 'the care and treatment of patients' and 'public health'. We would expect any organisation to disseminate information within legal requirements set out under UK GDPR.

### **Contact information and further advice**

If you would like to know more about how we use your information, require information in any accessible format or language or if (for any reason) you do not wish to have your information used in any of the ways described, please contact:

Data Protection Officer- Saiful Choudhury

Email: [Saiful.Choudhury@uhl-tr.nhs.uk](mailto:Saiful.Choudhury@uhl-tr.nhs.uk)

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

The Information Commissioner

Wycliffe House

Water Lane

Wilmslow

Cheshire SK9 5AF

Telephone number 0845 306 060 or 01625 545 745

Website: [www.ico.org.uk](http://www.ico.org.uk)