



## **Guide for East Lancashire Hospitals NHS Trust (ELHT) Service Users on Understanding and Exercising your Rights under the General Data Protection Regulations**

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### 1. What is the General Data Protection Regulations (GDPR)

The GDPR is a long overdue update of current data protection legislation, Data Protection Act 1998. Changes in technology and society in the 19 years since this act was enacted mean that it is long overdue for an update. The developments in technology offer opportunities to collect, use and share health data more efficiently. This will help the care of patients as data can be shared quickly between providers of health and social care services. Improved research should facilitate better treatments in particular for growing epidemic of long term conditions such as diabetes, and chronic obstructive pulmonary disease, ultimately improving the quality, safety, and efficiency of the healthcare systems in the UK.

The General Data Protection Regulations (GDPR), which will apply from 25<sup>th</sup> May 2018, provides rights for citizens to be better informed about the use made of their personal data, and gives clear responsibilities to people and or using personal data.

The GDPR gives patients the clear right as the data subject and sets out obligations for East Lancashire Hospitals NHS Trust (ELHT) to facilitate the exercising of your rights under this regulation. This guide sets out rights of NHS service users under GDPR and what ELHT will do to ensure your rights are safeguarded.

### 2. Terminology

**The GDPR uses some terminology that is important to understand this guide:**

**Personal data** - means any information relating to an identifiable person, whether this person can be identified directly or indirectly. In the guide where it refers to data, it should be interpreted as relating to personal data unless otherwise specified.

**Information** – this is not just written information but relates to videos and pictures as well. So video footage and photographs that meet the definition of personal data is subject to these regulations as well

**Data processing** – this refers to any operation performed on personal data. This includes collection, storage, and adaptation, and retrieval, use of, sharing, disclosure, and restriction of, erasure or destruction of the data.

The GDPR gives an individual the same data protection rights across all countries within the European Union (EU) and European Economic Area. It also guarantees your rights in countries where the EU has checked or made an agreement that similar level of rights for data handling and protection exist.

### 3. Why does ELHT “process” your information and under what legal justification

ELHT collects information about you to enable the provision of healthcare by the Trust, support other agencies involved in providing social and healthcare, collect information for medical and related research, to enable reporting of standards and performance to NHS England and care commissioners, public health and in compliance with legal obligations that ELHT has to as public authority.

The legal justification for ELHT to process your data is that “it 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 (ELHT)”. Additionally since we process some sensitive information about you, which includes your health and treatment information amongst others, we rely on further justification that the processing is necessary for the provision of social and healthcare, treatment or the management of health and social care services.

### 4. What are your rights as individuals?

You have rights under the common law duty of confidentiality. This says that data provided in confidence should not be shared without consent. GDPR will not replace this duty. This requires that ELHT be clear what legal basis is used to set aside this duty and therefore allow the Trust to collect and process your data. This will be achieved by ELHT under GDPR by ensuring it will be transparent about why information is collected, what information is collected and how ELHT processes the information collected.

The GDPR provides the following rights for individuals of which the right to be informed is one of the most important:

Rights	What ELHT has to do	What does it mean for our service users
a) The right to be informed	<p>It has to be transparent about why and what information we collect and “process” your information.</p> <p>ELHT will do this by providing clear privacy notice on its internet site, with posters and leaflet situated at every reception.</p>	<p>So that service users can ensure that personal data is being processed fairly and lawfully, ELHT must provide certain minimum information to you, regarding the contact details for ELHT and the Trust Data Protection Officer, the legal basis for collection of information, what kind of data ELHT will collect, who ELHT will share it with and how long the data will be kept, service user rights to complain and the consequences of users not providing information to ELHT.</p> <p>You can also expect that such information will be provided in a concise, transparent, intelligible and easily accessible form, using clear and plain language.</p>
b) For patient’s data to be processed as long as the person who does the processing is by a person, “subject to legal obligation of professional	Trust will ensure that health care professionals making decisions about processing your information are staff qualified to do so i.e. belong to professional association for example Doctors belong to the BMA and Royal colleges and Nurses belong to the Royal College of Nursing, both which set standards of conduct	This means that healthcare staff and organisations that employ them such as hospitals do not have an obligation to ask for your consent before they can process data collected about you. However, they are bound by all the principles described in Article 5 of the GDPR, “that ensures the exemption from consent is proportionate and limited to what is necessary for the patients’ health and social care.”

Rights	What ELHT has to do	What does it mean for our service users
<p>secrecy”</p>	<p>for their members to follow.</p> <p>These and other ELHT staff who may also be involved in the processing of your data are bound by contractual requirements to abide by data protection regulations and additionally by a common law duty of confidence to your information.</p>	
<p>c) The right of access to information about you as a service user.</p>	<p>ELHT must confirm whether it processes data about you as a service user. If it does then ELHT will first verify your identity and must provide the information free of charge but will charge for further copies of the same information. This right extends to knowing why ELHT hold and process your data, how long the data is held and who it may be shared with.</p>	<p>The service user will normally receive, within a month of making the request in writing, either a reason why ELHT cannot supply this information or a copy of the information in an electronic format. If the request is complex, ELHT may extend the response deadline by a further two months.</p> <p>Access request can be sent to:</p> <p>The Subject Access Request Team, Burnley General Hospital, Casterton Avenue, Burnley, Lancashire. BB10 2PQ.</p> <p>Or by email to: <a href="mailto:SubjectAccessrequest@elht.nhs.uk">SubjectAccessrequest@elht.nhs.uk</a></p>
<p>d) The right to rectification of inaccurate data held about you as a service user.</p>	<p>ELHT has to, without undue delay, rectify any inaccurate personal data held about you, once informed. If the information is inaccurate as it is incomplete, then the ELHT has to ensure the record is completed by including supplementary statement in the relevant record / casenote.</p>	<p>ELHT will, without undue delay, rectify any information we hold about you if it is agreed to be inaccurate or incomplete.</p>
<p>e) The right to erasure of personal data held</p>	<p>ELHT must erase the personal data in question when the data is no longer necessary for the</p>	<p>Once a request for erasure is put to ELHT, your data will be considered for erasure as long as it</p>

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<p>about you as a service user, where there is no compelling or legal reason for its continued processing</p>	<p>purpose the information was collected or if there is no legal grounds for ELHT to “process” the data or withdrawal of consent for data collected using consent as the basis of collection. ELHT will also tell you if it cannot comply with your request. This could be if erasure clashes with ELHT’s legal obligation for the performance of a public interest task or exercise of official authority as a NHS healthcare provider under duties set out by NHS England.</p> <p>If it does comply with your request then ELHT will erase the data within one month of the request. If ELHT has shared your data it will take reasonable steps to ensure that organisations who have received this data will receive notification of erasure.</p>	<p>meets one of the following conditions;</p> <ul style="list-style-type: none"> <li>- Where the data is no longer necessary for the purpose it was collected. This will be set out in the Trust privacy notice.</li> <li>- If ELHT have collected any of your personal data with consent as the basis of collection and then this consent for processing is withdrawn.</li> <li>- If ELHT do not have the legal basis to continue to “process” your data.</li> <li>- If the data was unlawfully “processed”. In breach of the GDPR.</li> <li>- The data has to be erased to meet a legal obligation.</li> <li>- Where data is processed in relation to the offering internet information services (which ELHT does not do anyway).</li> </ul> <p>This right can be used with “right to restriction of processing” as set out in section f below, whilst ELHT considers its decision in response to the request for erasure of data.</p>
<p>f) The right to restrict “processing” of your data</p>	<p>ELHT must restrict the processing of the data in question, if certain criteria apply as set out under “what it means for the service user”, by moving the data or making the data unavailable to all data users and making sure that data cannot be processed further.</p> <p>If ELHT has disclosed the data in question to third parties, then ELHT will inform them, if possible, about the restriction on processing of this data. Although ELHT does not have to inform third parties if it involves disproportionate effort, the Trust do not envisage using this</p>	<p>User can request restriction of processing of data in the following circumstances;</p> <ul style="list-style-type: none"> <li>- Where you want to contest the accuracy of the data.</li> <li>- Where you have objected to the processing of the data and the ELHT are considering whether it can comply or not.</li> <li>- Where the processing is unlawful and you as the data subject or his/her legal representative do not want the data erased.</li> <li>- Where ELHT no longer require the data but the service user or their legal representative require the data to establish, exercise or defend a legal</li> </ul>

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	exemption.	claim
g) The right to data portability	If data about a person is collected based on direct consent or under contractual obligations then ELHT must be able to provide the information in structured and commonly used electronic format, back to the person whose data it is.	<p>You as the service user have the right to receive your personal data if provided by you directly and collected by ELHT on the basis of direct consent or as part of a contract</p> <p>This is not normally expected to apply to ELHT as data will not be collected on the basis of consent or contractual obligation rather it is collected on the basis of public interest.</p>
h) The right to object to “processing” of your data.	<p>Since the legal grounds for collection of your data is based on public interests, ELHT has to abide by this regulation and will offer a clear route for this objection to be communicated to ELHT.</p> <p>If ELHT cannot clearly demonstrate that its compelling legitimate interest override your rights and freedoms or that processing is necessary for the exercise and defence of a legal claim, then it will abide by the objection request and stop processing of the data in question as soon as reasonably possible.</p> <p>ELHT will clearly set out this right in its Privacy Notice.</p>	<p>You as a service user have a right, based on grounds relating to your particular situation, to object to “processing” of your data for which the legal grounds are based on legitimate interest or on the exercise of public interest.</p> <p>There is also the right to object to the processing of your personal data for direct marketing purposes and for the purpose of scientific and historical research and statistics, unless this is carried out for reasons of public interest.</p> <p>The right to object can be done by raising this with Trust Data Protection Officer on; <a href="mailto:lg-issues@elht.nhs.uk">lg-issues@elht.nhs.uk</a></p>
i) Rights relating to automated decision making including profiling.	Currently ELHT does not use automated decision making tools in the provision of care. As technology develops there may be systems that can automatically determine an intervention and deliver this. If this point is reached ELHT will always abide the requirement to have a human check the required intervention and ensure any algorithms used for generating interventions in an automated manner will be fully tested before they are used.	<p>The service user has the right to not be subject to a decision based solely on automated processing of your data including profiling if it produces legal effects and significantly effects you as the service user.</p> <p>The right does not apply if the data in question is collected arising from direct consent from the patient concerned. The right will always apply where it concerns children.</p> <p>So decisions about your health will always be subject to human intervention and checking by appropriate clinicians.</p>
j) The right to be told about a data breach involving	ELHT will tell you if the Trust has suffered data protection breach which is likely to or has resulted	The effected service user will receive notification in writing of any breach resulting in high risks (e.g. fraud or identity theft). This

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<p>your data, where this breach is likely to result in a high risk to your rights and freedoms.</p>	<p>in high risks to your rights and freedoms, without undue delay. ELHT will also have to report this to the Information Commissioner’s Office within 72 hours of the breach happening.</p>	<p>will give the opportunity to mitigate any adverse effect as soon as possible and reduce the degree of harm.</p> <p>The notification will include the name and contact details for the Trust Data Protection Officer, a description of the likely consequences of the data breach and a description of the measures taken by ELHT to deal with the breach and measures taken to mitigate any adverse effects of the breach.</p> <p>If the breach effects a large number of patients then ELHT may not be able to write out to all concerned as it may involve a disproportionate effort. In this case ELHT will use the media to get the message out as quickly and widely as possible.</p>
<p>k) Rights for Children(person aged under 16 years) to be protected as they are recognised as especially vulnerable natural persons in the new General Data Protection Regulation</p>	<p>ELHT will ensure Privacy Notices as set out in section k above. (The Right to be informed), are clear and designed with a child’s understanding in mind. ELHT will also ensure any reliance that is not based on direct consent to justify processing children’s data is backed up with a careful and documented consideration of whether a child’s interests override those of ELHT. The Trust will also comply with any further guidance and rules regarding children’s information processing as they are published by the UK government and the Information Commissioner’s Office.</p>	<p>There will be no change for the service users as the provision of healthcare for children is provided under specific GDPR provisions as set out in the introduction, section 2. Additionally there will be no barriers to processing of children’s information if there is child safeguarding issue or to ensure the prevention of harm to children. This is in line with current data protection practice.</p>
<p>l) Rights under other data regulations and laws the NHS is subject to</p>	<p>ELHT must abide by other UK legislation concerning the protection and use of personal information including:</p> <ul style="list-style-type: none"> <li>• Digital Economy Act 2017</li> </ul>	<p>The service user can expect ELHT to abide by the GDPR and other legislation and guidance when processing your information as Trust service users.</p> <p>This means processing user information as</p>

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	<ul style="list-style-type: none"> <li>• Human Rights Act 1998 (article 8)</li> <li>• The Freedom of Information Act 2000</li> <li>• The Children Act 1989</li> <li>• The Children Act 2004</li> <li>• National Health Service Act 1977 (S 251)</li> <li>• Health Act 1999</li> <li>• The Adoption and Children Act 2002</li> <li>• Health and Social Services Act 2000</li> <li>• Human fertilisation and Embryology Act 2001(sc25)</li> <li>• Health and Social Care Act 2012</li> </ul> <p>Note there are other acts which have an impact on data protection which ELHT will consider when making decision on what data to process and in particular when to share information and when not to. The full list will be set out in the Trust Privacy Notice.</p>	<p>required by legislation.</p> <p>So for example NHS Act 1977, section 251 allows NHS to share data for central reporting and for public health purposes amongst other purposes.</p> <p>The Children Act 2004 requires the Trust to put the interest of the child first in any decision made about data processing. It places a duty places a duty “ to co-operate in promoting the wellbeing of children and young people and to make arrangements to safeguard and promote the welfare of children”</p> <p>This means, for example, data will be shared with other agencies including the police if child safeguarding issue is involved</p>
<p>m)The right to lodge a complaint with the Trust or the Information Commissioner’s Office(ICO) and the right to judicial remedy</p>	<p>ELHT will promptly deal with any complaint or query about a data protection issue.</p> <p>This can be done by raising this with Trust Data Protection Officer on; <a href="mailto:lg-issues@elht.nhs.uk">lg-issues@elht.nhs.uk</a> or</p> <p>Tel 01254734488. Or filling in the complaint form on the Trust internet site; <a href="http://www.elht.nhs.uk/contact-us/">http://www.elht.nhs.uk/contact-us/</a></p> <p>You can expect a response to your query within one month of the request.</p> <p>The ICO can be contacted on the following link:</p>	<p>ELHT will deal with complaints and questions promptly and provide advice as how to escalate the complaint, if you are unhappy with our response.</p> <p>The GDPR also sets out the right to have your case heard by the Courts and if the courts deem it appropriate receive compensation.</p>

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	<a href="https://ico.org.uk/global/contact-us">https://ico.org.uk/global/contact-us</a> or Tel 0303 123 1113	

## 5. What (if any) are the limitations to these rights

There are some potential restrictions on these rights under GDPR. The GDPR allows the UK government to legislate to restrict the scope and applicability of the rights set out in the table above. The restrictions allow the processing of service user data without meeting the principles of fair, lawful and transparent processing. Additionally there are restrictions on the rights, set out above of; transparency, rectification, erasure, notification, data portability, right to object, automated decision making (including profiling) and right to be informed of a breach.

The circumstances in which exemption can be invoked are restricted but relevant ones for the NHS include; children safeguarding, prevention detection of crime, for the protection of legal proceedings, where it undermines the protection of person who the data relates to or the rights and freedoms of others and for the prevention, investigation, detection and prosecution of breaches of ethics by regulated professions such as British Medical Association and the Royal college of Nursing amongst others.

## 6. Who to contact to exercise your rights?

If you think that any of your rights under the GDPR are not being respected or adhered to by ELHT, please contact the Office of Data Protection Officer. Please contact:

**Data Protection Officer,  
East Lancashire Hospitals NHS Trust  
Royal Blackburn Hospital  
Haslingden Road  
Blackburn  
Lancashire  
BB3 2PQ**

Or email the Trust Data Protection Officer on; [lg-issues@elht.nhs.uk](mailto:lg-issues@elht.nhs.uk) or Tel 01254 734488.

Or by filling in the complaint form on the Trust internet site:

<http://www.elht.nhs.uk/contact-us/>