

# The Lighthouse Medical Practice

## Privacy Notice - Research

### Patient information and health and care research

All NHS organisations (including Health & Social Care in Northern Ireland) are expected to participate and support health and care research. The Health Research Authority and government departments in Northern Ireland, Scotland and Wales set standards for NHS organisations to make sure they protect your privacy and comply with the law when they are involved in research. Our [research ethics committees](#) review research studies to make sure that the research uses of data about you are in the public interest, and meet ethical standards.

Health and care research may be exploring prevention, diagnosis or treatment of disease, which includes health and social factors in any disease area. Research may be sponsored by companies developing new medicines or medical devices, NHS organisations, universities or medical research charities. The research sponsor decides what information will be collected for the study and how it will be used.

Health and care research should serve the public interest, which means that research sponsors have to demonstrate that their research serves the interests of society as a whole. They do this by following the [UK Policy Framework for Health and Social Care Research](#). They also have to have a legal basis for any use of personally-identifiable information.

### How patient information may be used for research

When you agree to take part in a research study, the sponsor will collect the minimum personally-identifiable information needed for the purposes of the research project. Information about you will be used in the ways needed to conduct and analyse the research study. NHS organisations may keep a copy of the information collected about you. Depending on the needs of the study, the information that is passed to the research sponsor may include personal data that could identify you. You can find out more about the use of patient information for the study you are taking part in from the research team or the study sponsor. You can find out who the study sponsor is from the information you were given when you agreed to take part in the study.

For some research studies, you may be asked to provide information about your health to the research team, for example in a questionnaire. Sometimes information about you will be collected for research at the same time as for your clinical care, for example when a blood test is taken. In other cases, information may be copied from your health records. Information from your health records may be linked to information from other places such as central NHS records, or information about you collected by other organisations. You will be told about this when you agree to take part in the study.

### Keeping information for future research

Information about you that is collected during a research study may be kept securely to be used in future research in any disease area, including research looking at social and economic factors affecting health. This may include combining it with information about you held by other health or government organisations such as [NHS Digital](#). Usually the information is combined together by matching information that has the same [NHS number](#). Doing this makes maximum use of the information you have provided and allows researchers to discover more.

Researchers may not be able to specify all the possible future uses of the information they keep. It could include providing the information to other researchers from NHS organisations, universities or companies developing new treatments or care. Wherever this happens it will be done under strict legal agreements. The information about you will be depersonalised wherever possible so that you cannot be identified. Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.

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On rare occasions NHS organisations may provide researchers with confidential patient information from your health records when we are not able to seek your agreement to take part in the study, for example because the number of patients involved is too large or the NHS organisation no longer has your contact details. Researchers must have special approval before they can do this.

### Your choices about health and care research

If you are asked about taking part in research, usually someone in the care team looking after you will contact you. People in your care team may look at your health records to check whether you are suitable to take part in a research study, before asking you whether you are interested or sending you a letter on behalf of the researcher.

In some hospitals and GP practices, you may have the opportunity to sign up to a register to hear about suitable research studies that you could take part in. If you agree to this, then research nurses, researchers or administrative staff authorised by the organisation may look at your health records to see if you are suitable for any research studies.

It's important for you to be aware that if you are taking part in research, or information about you is used for research, your rights to access, change or move information about you are limited. This is because researchers need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from a study, the sponsor will keep the information about you that it has already obtained. They may also keep information from research indefinitely.

If you would like to find out more about why and how patient data is used in research, please visit the [Understanding Patient Data website](https://understandingpatientdata.org.uk/what-you-need-know).

<https://understandingpatientdata.org.uk/what-you-need-know>

1) <b>Data Controller</b> contact details	The Lighthouse Medical Practice 6 College Road Eastbourne East Sussex BN21 4HY
2) <b>Data Protection Officer</b> contact details	Dr Tim Caroe The Lighthouse Medical Practice 6 College Road Eastbourne East Sussex BN21 4HY
3) <b>Purpose</b> of the sharing	Medical research.
4) <b>Lawful basis</b> for processing or sharing	Identifiable data will be shared with researchers either with explicit consent or, where the law allows, without consent. The lawful justifications are;  Article 6(1)(a) “the data subject has given consent to the processing of his or her personal data for one or more specific purposes”

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	<p>or</p> <p>Article 6(1)(e) may apply “necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller”</p> <p>And in addition there are three possible Article 9 justifications.</p> <p>Article 9(2)(a) – ‘the data subject has given explicit consent...’</p> <p>or</p> <p>Article 9(2)(j) – ‘processing is necessary for... scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member States law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and interests of the data subject’.</p> <p>or</p> <p>Article 9(2)(h) – ‘processing is necessary for the purpose of preventative...medicine...the provision of health or social care or treatment or the management of health or social care systems and services...’</p>
<p><b>6) Rights to object</b></p>	<p>In England you can register your choice to opt out via the <a href="#">NHS website</a> . If you do choose to opt out you can still agree to take part in any research study you want to, without affecting your ability to opt out of other research. You can also change your choice about opting out at any time.</p> <p>You do not have to consent to your data being used for research. You can change your mind and withdraw your consent at any time. Contact the Data Controller or the practice.</p>
<p><b>7) Right to access and correct</b></p>	<p>You have the right to access any identifiable data that is being shared and have any inaccuracies corrected.</p>
<p><b>8) Retention period</b></p>	<p>The data will be retained for the period as specified in the specific research protocol(s).</p>
<p><b>9) Right to Complain.</b></p>	<p>If you wish to raise a complaint on how any research organisation has handled your personal data, you can contact the relevant Data Protection Officer who will investigate the matter. If you are not satisfied with their response or believe they are processing your personal data in a way that is not lawful you can complain to the <a href="#">Information Commissioner’s Office (ICO)</a>. You can use this link <a href="https://ico.org.uk/global/contact-us/">https://ico.org.uk/global/contact-us/</a> or calling their helpline Tel: 0303 123 1113 (local rate) or 01625 545 745 (national rate) There are National Offices for Scotland, Northern Ireland and Wales, (see ICO website)</p>