

Plain English explanation

This practice participates in research. We will only agree to participate in any project if there is an agreed clearly defined reason for the research that is likely to benefit healthcare and patients. Such proposals will normally have a consent process, ethics committee approval, and will be in line with the principles of Article 89(1) of GDPR.

Research organisations do not usually approach patients directly but will ask us to make contact with suitable patients to seek their consent. Occasionally research can be authorised under law without the need to obtain consent. This is known as the section 251 arrangement¹. We may also use your medical records to carry out research within the practice.

We share information with the following medical research organisations with your explicit consent or when the law allows: NIHR Clinical Research Network North East and North Cumbria

You have the right to object to your identifiable information being used or shared for medical research purposes. Please speak to the practice if you wish to object.

1) Data Controller	Dr Jon Levick Jonlevick@nhs.net 01207 560206
2) Data Protection Officer	Catherine McBride Catherine.mcbride3@nhs.net 01207 560206
3) Purpose of the sharing	Medical research.
4) Lawful basis 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” or 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” And in addition there are three possible Article 9 justifications. Article 9(2)(a) – ‘the data subject has given explicit consent...’

	<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>We will also recognise your rights established under UK case law collectively known as the “Common Law Duty of Confidentiality”²</p>
<p>5) Recipient or categories of recipients of the shared data</p>	<p>The data will be shared with NIHR Clinical Research Network North East and North Cumbria</p>
<p>6) Rights to object</p>	<p>You do not have to consent to your data being used for research. If you have consented to your data being used in research you can change your mind and withdraw your consent at any time. Contact the Data Controller or the practice. We will normally comply with any request.</p>
<p>7) Right to access and correct</p>	<p>You have the right to access any identifiable data that is being shared and have any inaccuracies corrected.</p>
<p>8) Retention period</p>	<p>The data will be retained for the period as specified in the specific research protocol(s).</p>
<p>9) Right to Complain.</p>	<p>You have the right to complain to the Information Commissioner’s Office, you can use this link https://ico.org.uk/global/contact-us/</p> <p>or calling their helpline Tel: 0303 123 1113 (local rate) or 01625 545 745 (national rate)</p> <p>There are National Offices for Scotland, Northern Ireland and Wales, (see ICO website)</p>

1, Section 251 and the NHS Act, Health Research Authority.

<https://www.dropbox.com/s/sekq3trav2s58xw/Official%20Section%20251%20guidance%20Health%20Research%20Authority.pdf?dl=0>

2 “Common Law Duty of Confidentiality”, common law is not written out in one document like an Act of Parliament. It is a form of law based on previous court cases decided by judges; hence, it is also referred to as 'judge-made' or case law. The law is applied by reference to those previous cases, so common law is also said to be based on precedent.

The general position is that if information is given in circumstances where it is expected that a duty of confidence applies, that information cannot normally be disclosed without the information provider's consent.

In practice, this means that all patient information, whether held on paper, computer, visually or audio recorded, or held in the memory of the professional, must not normally be disclosed without the consent of the patient. It is irrelevant how old the patient is or what the state of their mental health is; the duty still applies.

Three circumstances making disclosure of confidential information lawful are:

- where the individual to whom the information relates has consented;
- where disclosure is in the public interest; and
- where there is a legal duty to do so, for example a court order.