

Privacy Notice Familial Hypercholesterolaemia (FH) Screening Programme

This notice supplements the Norfolk and Norwich University Hospitals Foundation Trust (the Trust) main Patient Privacy Notice which is available on the internet web pages at: <https://www.nnuh.nhs.uk/privacy-notice/>

The reason for providing this notice is to make you aware of how your information will be used in relation to the **Familial Hypercholesterolaemia (FH) Screening Programme** run by the Trust

Please contact us if you have any questions regarding the below.

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| 1) Controller contact details | Norfolk and Norwich University Hospital Colney Lane Norwich NR4 7UY Norfolk and Norwich University Hospitals NHS Foundation Trust (nnuh.nhs.uk) |
| 2) Data Protection Officer contact details | Info.gov@nnuh.nhs.uk |
| 3) Purpose of the processing | <p>The NHS aims to expand access to genetic testing for FH, which causes early heart attacks and affects at least 150,000 people in England. This will enable the diagnosis and treatment of those at genetic risk of sudden cardiac death.</p> <p>The purpose is to screen the population of Norfolk and Waveney for eligibility for genomic testing via Primary Care.</p> <p>This will be done remotely at the FH Hub (Norfolk & Norwich University Hospital) by the Clinical Nurse Specialist for FH who will have access to Eclipse to do the searches.</p> <p>The objective of the FH Project is to increase the identification of FH patients from the current 7% in 2021 to at least 25% by 2024.</p> |
| 4) Lawful basis for processing | <p>The sharing is to support direct care which is covered under the General Data Protection Regulation (GDPR):</p> <ul style="list-style-type: none"> • Article 6(1)(e); ‘necessary... in the exercise of official authority vested in the controller’ the processing is necessary to perform a task in the public interest’ and • Article 9(2)(h) ‘necessary for the purposes of preventative or occupational medicine for the |

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| | <p>assessment of the working capacity of the employee, medical diagnosis, 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'</p> |
| 5) Recipient or categories of recipients of the shared data | <ul style="list-style-type: none"> • Your GP • The data processor and system supplier Prescribing Services Ltd who provide the system, Eclipse used for the screening programme. |
| 6) Rights to object | You have the right to object to this processing of your data and to some or all of the information being shared with the recipients. Contact the Trust or your GP where relevant. |
| 7) Right to access and correct | You have the right to access the data that is being shared and have any inaccuracies corrected. There is no right to have accurate medical records deleted except when ordered by a court of law. |
| 8) Retention period | <p>Screening records will be kept in line with the law and national guidance.</p> <p>Information on how long records can be kept can be found at: https://digital.nhs.uk/article/1202/Records-Management-Code-of-Practice-for-Health-and-Social-Care-2016.</p> |
| 9) Right to Complain | <p>You have the right to complain to the Information Commissioner's Office.</p> <p>You can contact them at this link: https://ico.org.uk/global/contact-us/ or by calling their helpline on 0303 123 1113 (local rate) or 01625 545 745 (national rate).</p> |