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Hackney College  
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N1 6LP

Date 01st November 2016

Email: [foi@homerton.nhs.uk](mailto:foi@homerton.nhs.uk)

Dear Sir or Madam,

**Ref: FOI 2819**

Thank you for your recent Freedom of Information request regarding.

The Trust can provide the following information:

**A. The number of patients diagnosed with genetic haemochromatosis who have been provided with genetic testing for haemochromatosis and/or genetic counselling in relation to their condition.**

Period of 1<sup>st</sup> Jan 2015 to 31<sup>st</sup> Dec 2015.

We had 40 requests for Haemochromatosis Gene Analysis.

14 requests were not performed (either previous result or unsuitable sample)

26 were screened; 10 had no mutations in either gene – i.e. Negative, 7 had a heterozygous mutation in one gene only – i.e. Haemochromatosis is unlikely but there could be genetic implications, 7 had a homozygous mutation in the p.C282Y gene – i.e. risk of iron overload, 2 had a compound heterozygous mutation in both genes – i.e. are at risk of Haemochromatosis

**B. The number of marriage or civil partners of patients diagnosed with genetic haemochromatosis who have been provided with genetic testing for haemochromatosis and/or genetic counselling in relation to their partners' condition.**

This data is not held. We advise patients to encourage partner and family testing but the tests are not linked to maintain confidentiality.

**C. The number of siblings of patients diagnosed with genetic haemochromatosis who have been provided with genetic testing for haemochromatosis and/or genetic counselling in relation to their sibling's condition.**

Same as above.

**D. A copy of your protocol or pathway applicable to the provision of genetic testing/counselling for families of patients diagnosed with genetic haemochromatosis.**

No Trust protocol exists and the management of haemochromatosis patient is as per national guidelines.

If you have any queries about this response please contact the information governance manager at [foi@homerton.nhs.uk](mailto:foi@homerton.nhs.uk) , in the first instance. If following that, you still have any concerns, you may contact the Information Commissioner either by letter, FOI/EIR Complaints resolution, Wycliffe House, Water Lane, Wilmslow, Cheshire SM9 5AF, or by email [www.informationcommissioner.gov.uk](http://www.informationcommissioner.gov.uk) to take them further.

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Yours sincerely

Mohamed Uddin  
FoI Administrator

Mike Dunne  
Information Governance Manager