<table>
<thead>
<tr>
<th>Title:</th>
<th>Sickle Cell Disease in Barking and Dagenham</th>
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Report of the Corporate Director of Adult and Community Services

<table>
<thead>
<tr>
<th>Open</th>
<th>For Information</th>
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<tbody>
<tr>
<td>Wards Affected: NONE</td>
<td>Key Decision: NO</td>
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</tbody>
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Matthew Cole, Public Health

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Summary:
On 5 November 2013 Members requested that Dr Ian Grant (Consultant Haemotologist, BHRUT) returns to the HASSC to report on the development of sickle cell services locally.

Dr Grant will be giving a presentation at the meeting. The report overleaf is produced by Public Health and sets the scene, in terms of background and demographics, for members to discuss with Dr Grant developments in sickle cell services.

Recommendation(s)
Members of the Health and Adult Services Select Committee are recommended to:
1. Note this report in preparation for receiving Dr Grant’s presentation.
1. **Sickle Cell Disease**

1.1. Sickle cell disease is the fastest growing genetically inherited condition in the UK affecting around 10,000 people. Sickle cell disease and sickle cell trait have been becoming progressively more visible amongst the populations of outer north east London (ONEL), most notably in Barking and Dagenham. This reflects the growing ethnic diversity of the population and the fact it now affects over 1 in 2,000 live births\(^1\).

1.2. Sickle cell disease describes a group of conditions caused by the 'sickle' mutation of the haemoglobin molecule (Hb). Hb is responsible for transporting oxygen in the red blood cells of humans, and the sickle mutation reduces the ability of the red blood cell to carry oxygen.

1.3. Clinically significant sickle cell disease is a result of individuals inheriting the sickle gene from both parents or a sickle gene and another specific variant. Sickle cell carrier status, also sometimes called sickle cell trait, occurs when individuals only inherit one sickle gene; carriers rarely have clinical symptoms except in extremis and so rarely are aware they carry the gene unless screened.

1.4. Sickle cell disease is more common amongst individuals from Africa, the Mediterranean, the Middle East, parts of India, the Caribbean and South and Central America. Prevalence of the sickle cell gene is generally higher in areas with a history of malaria and this is because sickle cell trait protects against malaria.

1.5. Sickle cell disease can cause deformed blood cells to clog up small blood vessels starving the surrounding tissue of oxygen which may lead to organ damage. Other presentations include overwhelming sepsis, acute chest syndrome, priapism, lung disease, recurrent chronic leg ulceration, visual loss and stroke\(^2\). Sickle cell disease can also lead to premature death and the median age of death for men with sickle cell disease is 42yrs and for women is 48yrs\(^3\).

1.6. National standards have been published for health services for adults and children with sickle cell disease in 2008 and 2010. The aim of sickle cell disease management is to improve survival and reduce the frequency, duration and severity of painful crises and other complications. This involves prophylaxis through immunisation, drug treatment and in some cases blood transfusion, lifestyle support and management, psychological and social/welfare support.

2. **Prevalence in Barking and Dagenham**

2.1. The demographic profile of outer north east London has been evolving over the last ten years and the increasing ethnic diversity is reflected in the growth in the case load of patients living with and affected by sickle cell disease.

2.2. Estimated demand was modeled using the generic North East London prevalence estimate of 2.18 significant conditions\(^4\) per 1,000 babies screened\(^5\) applied to the GLA 2011 population estimated for the ONEL boroughs\(^6\). The estimated number of

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\(^1\) Sickle cell disease in childhood: Standards and guidelines for clinical care. 2nd Ed. Oct. 2010. NHS Screening Programmes. p5

\(^2\) Standards for the clinical care of adults with sickle cell disease in the UK. Sickle Cell Society. 2008. p16


\(^4\) Significant conditions comprise the following results: FS, FSC, FS other and FE (F, foetal haemoglobin; S, S haemoglobin; C, C haemoglobin; E, E haemoglobin).


\(^6\) GLA 2005 extrapolations for 2011 population
patients with clinically significant sickle cell disease is 1,366 patients in the ONEL boroughs.

<table>
<thead>
<tr>
<th>Borough</th>
<th>Projected New Births</th>
<th>Estimated Case Load</th>
<th>Projected 1 to 8 yrs</th>
<th>Estimated Case Load</th>
<th>Projected 19 to 74 yrs</th>
<th>Estimated Case Load</th>
<th>Total Estimated Case Load</th>
</tr>
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<tbody>
<tr>
<td>Barking &amp; Dagenham</td>
<td>3,724</td>
<td>8.1</td>
<td>45,722</td>
<td>99.7</td>
<td>116,546</td>
<td>258.4</td>
<td>366.2</td>
</tr>
<tr>
<td>Havering</td>
<td>2,836</td>
<td>6.2</td>
<td>48,569</td>
<td>105.9</td>
<td>163,416</td>
<td>356.2</td>
<td>468.3</td>
</tr>
<tr>
<td>Redbridge</td>
<td>4,196</td>
<td>9.1</td>
<td>60,531</td>
<td>132.0</td>
<td>179,089</td>
<td>390.4</td>
<td>531.5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>10,756</strong></td>
<td><strong>23.4</strong></td>
<td><strong>154,822</strong></td>
<td><strong>337.5</strong></td>
<td><strong>461,051</strong></td>
<td><strong>1005.1</strong></td>
<td><strong>1366.1</strong></td>
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</tbody>
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Table 1 shows the estimated case load of sickle cell patients broken down into age groups in the ONEL.

2.3. In 2010 the service at BHRUT saw 14 live births to women with sickle cell disease. These women are seen in a joint consultant haematologist/obstetric clinic and reviewed monthly for the first two trimesters and then fortnightly in the third trimester and weekly as they approach full term.

3. Developments in Sickle Cell Services

3.1. The 2010/11 QIPP plan for Barking and Dagenham identified the need to undertake focused work to explore the potential for sickle cell disease community services in the Barking, Havering and Redbridge University Hospital NHS Trust healthcare economy. This was because of the growing case load of patients registered with Sickle Cell Disease at BHRUT which reflects the changing populations in Barking and Dagenham, Havering and Redbridge.

3.2. A review was undertaken by the Barking and Dagenham Public Health Team, which reported in December 2010 and recommended that a tariff based community service was commissioned to buffer the acute costs of the growing demand and meet the national guidance of best practice, the review also recommended a block contract for ante-natal screening and support.

3.3. Currently the three boroughs, Barking and Dagenham, Havering and Redbridge spend around £240K on outpatient services for patients with sickle cell disease and around £290K on admissions at Barking, Havering and Redbridge University Hospital NHS Trust.

3.4. More information including services available to local people can be found in the Barking and Dagenham Joint Strategic needs assessment (JSNA): [http://www.barkinganddagenhamjsna.org.uk/Pages/jsnahome.aspx](http://www.barkinganddagenhamjsna.org.uk/Pages/jsnahome.aspx)