HEALTH AND WELLBEING BOARD

4 June 2013

Title: Health & Wellbeing Strategy Priority: Sickle Cell Disease and Thalassaemia	
Report of the Vice-Chair of the Health & Wellbeing Board	
Open Report	**For Information**
Wards Affected: ALL	**Key Decision:** No
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Sponsor:
Dr W Mohi, Chair of Barking and Dagenham Clinical Commissioning Group

Summary:
The Health and Wellbeing Strategy 2012-15 has prioritised sickle cell services as an area for improvement and integration in 2013. The CCG is leading on the development of a community sickle cell service which will be provided by BHRUT for the Barking and Dagenham, Redbridge and Havering CCGs. The first community site will be based at Barking Community Hospital, with an anticipated start date of June 2013.

The prevalence of sickle cell disease has increased significantly over the last five years and BHRUT manages approximately 5% of the national burden of disease. Approximately half the BHRUT caseload is for Barking and Dagenham patients - Barking and Dagenham has the highest carrier rates of any borough in the country, with the exception of Lewisham which is equivalent.

Joint meetings with BHRUT and CCG commissioners have been established to work through the phased implementation of the service and a community service is expected to operate at Barking Hospital from June 2013.

Recommendation(s)

The Health and Wellbeing Board is asked to note the project and make any comments on this briefing.

Reason(s)

To agree the key design principles and ensure that the project has appropriate planning and support to deliver its key milestones by April 2014.

1. Introduction

1.1. In February 2012, the Health and Adult Services Select Committee (HASSC) considered a report from Dr Ian Grant, Consultant Haematologist BHRUT, on sickle cell disease in Barking and Dagenham. HASSC agreed to ask the Health and Wellbeing Board to consider prioritising sickle cell services, given the rapid growth in demand and the impact of the disease within the next Health and Wellbeing Strategy.

1.2. The Health and Wellbeing Strategy 2012-2015 prioritises sickle cell services as an area for improvement and integration of services in 2013. The key deliverable for this priority is the establishment of a community service for people living with sickle cell disease by May 2013, with the primary outcome being a reduction in A&E attendances for sickle cell disease.

1.3. The CCG is the lead partner for this initiative and in collaboration with Havering and Redbridge CCGs, has commissioned a community sickle cell service from BHRUT as part of the 13/14 contract.

1.4. This paper describes the need and demand for services locally and the progress made in implementing a community service. Partners are invited to comment on the contribution that they could make to improving the health and wellbeing of this population.

2. Background

2.1. Sickle cell is the fastest growing genetically inherited condition in the UK affecting over 1 in 2,000 births and over 10,000 adults living with the condition in the UK. About 0.15% of African Americans are homozygous for sickle cell disease and 8% have the sickle cell trait.

2.2. Sickle cell disease is a life-long disease, with significant morbidity and mortality. The median age of death for people with sickle cell disease is 50 years for men and 55 years for women. Pulmonary complications are the most common cause of death accounting for 28% of all deaths. Complications that result in hospital admission include vaso-occlusive crisis, infection and acute chest syndrome

2.3. Sickle cell disease and trait have been becoming progressively more visible amongst the population of Barking and Dagenham. Given the emergent diversity of the population and increased prevalence of sickle cell disease the capacity of the current services to meet increasing demands has been reviewed.

3. Local need and demand for services

3.1. The changing ethnic demographic of the local population across Barking and Dagenham, Havering and Redbridge has been dramatic; between 2001 and 2012 the estimated proportion of the population identifying as Black African has trebled in Barking and Dagenham and Havering and increased by one and a half times in

Redbridge. It is estimated that just over 6% of the population in 2012 across the three boroughs are identified as Black African.

3.2. The prevalence of sickle cell disease has increased significantly in the last five years. There are around 15,000 people with sickle cell disease in the UK, most of whom are resident in London and the caseload at BHRUT is around 800, which represents approximately 5% of the national burden of disease. In 2012, BHRUT had 156 adults and 170 children registered with Barking and Dagenham GPs on their caseload (50% of total caseload). The number of patients registered with the service at BHRUT has risen by 10% between 2009 and April 2012.

3.3. In Barking and Dagenham, 1 in 297 babies born are affected by significant haemoglobinopathy and Barking and Dagenham has the highest carrier rates of any borough in the country.

3.4. The table below highlights the total number of sickle cell outpatient appointments and A&E attendances for Barking and Dagenham patients in 2011/12.

	Total activity 11/12	**Total cost 11/12**
Outpatient attendances	2,775	£491,991
A&E admissions	244	£354,295

3.5 In addition to health support required for this population, there is also a need for significant psychological, social and welfare support.

4. National Guidelines and Peer Review

4.1. There is a growing body of national guidance and policy relating to sickle cell disease, this includes:

- National guidelines for adults living with sickle cell disease (2008)
- National guidelines for children living with sickle cell disease (2010)
- A sickle crisis (2008)

4.2 Sickle cell disease is explicitly mentioned in the National Service Framework for children and young people and there is also NICE guidance relating to the management of sickle cell crisis.

4.3 There is a national programme of peer service reviews and in February 2013 the national peer review team assessed the service at BHRUT. The review team found a high level of engagement between commissioners, public health and the service and evidence of good practice. It was noted that there was a potential unmet need and that the community aspect of care was inadequate.

4.4 People living with haemoglobinopathy require multi-disciplinary support in acute and maintenance periods. They should have a baseline and annual review and have regular blood tests, medication reviews, immunisation and psychological support

and counselling. At the point of diagnosis, they and their families may need additional support and counselling.

4.5 BHRUT has three haematologists with a special interest in sickle cell disease. Paediatric and adult outpatient and inpatient services are able to deliver all aspects of care and treatment for people affected with sickle cell disease. Universal antenatal screening was introduced in 2003, and couples who could have a child with sickle cell disease are counselled.

4.6 Barking & Dagenham, Havering and Redbridge Clinical Commissioning Groups (BHR CCGs) have commissioned BHRUT to establish a community sickle cell service across Barking and Dagenham, Havering and Redbridge. The community service is enhancement of the specialised haemoglobinopathy service currently provided by BHRUT.

5 Management of sickle cell disease

5.1 It will be a nurse led service supported by Consultant Haematologist from BHRUT and this community service will provide direct face to face contact and support through community based drop in and programmed clinics in the three boroughs, in addition to telephone support for professionals and patients.

5.2 It will provide seamless care between community and hospital and help provide social, psychological, counselling and medical care in the community, thus preventing hospital admissions. The local defined outcomes that the BHR CCGs have commissioned from BHRUT for this service are to:

- Reduce A&E repeat attendances
- Reduced Hospital Admissions
- Reduced length of hospital stay
- Improve care and management of patients with long term conditions
- Patient satisfaction and treatment compliance
- Improve care pathways for sickle cell disease in the community
- Reduce acute spend for sickle cell patients

5.3 The first community site will be in Barking and Dagenham, as this borough has a larger proportion of patients with sickle cell disease, with the intention for roll out in Redbridge and Havering. Until the community service is up and running, patients are seen on the Queen's Site.

6 Current Progress and next steps

6.1 Joint meetings with BHRUT and CCG commissioners have been established to work through the phased implementation of the service. To date, the following progress has been made and timelines agreed:

- BHRUT has recruited a lead nurse for the community sickle cell service, with a start date of 10th May 2013.

- Recruitment of the remaining nursing and supportive posts has been completed and the full team will be in post by August 2013.
- Barking Hospital has been identified as the first community site and a site visit with BHRUT and commissioners is planned for Monday 13th May 2013.
- The service will offer initially 1 session per week with the intention to increase to 2 sessions per week at Barking Hospital; iIt is anticipated this service at Barking Hospital will be up and operational by June 2013.
- The other two sites within Redbridge and Havering boroughs, in addition to the frequency of these clinics is yet to be determined and will require input from the commissioners.
- Full implementation of the community nurse-led sickle cell service is planned for September 2013.
- LBBD adult social care will align social work support to the local clinic as it becomes established in Barking & Dagenham ensuring there is good access to information, advice and care and support if required.
- Consideration will be given to how access to housing advice can be improved.

6.2 It is proposed that the monitoring of the delivery plan and outcomes for the sickle cell community service is devolved to the Integrated Care Subgroup of the Health and Wellbeing Board.

7 Mandatory Implications

7.1 JSNA

The Joint Strategic Needs Assessment highlights that 'sickle cell disease and trait have been becoming progressively more visible amongst the populations of outer North East London, most notably in Barking and Dagenham'. Historical activity at BHRUT in 2009 highlighted a case load of 256 in Barking and Dagenham compared to 96 in Havering and 133 in Redbridge. The estimated case load for Barking and Dagenham in 2011 was 366.

7.2 Health & Wellbeing Strategy

Priority 3 under Theme 3 (Improvement) of the Health and Wellbeing Strategy outlines that in 2012/13 work will be undertaken to look into improving the care for those living with sickle cell and thalassaemia.

7.3 Integration

Whilst the commissioning of a community service has been driven by health needs associated with demographic changes, there is the opportunity to consider how

social care, housing services and the local sickle cell thalassaemia support group may support the service once it is established.

7.4 Financial Implications

Funding to commission a community sickle cell service has been approved by the CCG in the commissioning plan for 2013/14.

Implications completed by: Martin Sheldon, Chief Finance Officer, CCG/ONEL

8 Housing Implications

Consultation with the Housing Service has taken place during the development of this report.

Our approach to sickle cell disease is essentially one of prevention and we aim to ensure that any housing advice or solution conforms to three preventative criteria: that the home is dry, warm and accessible. Any individual will be assessed according to their housing need and the impact of sickle cell disease on their day to day life.

We aim to ensure that the home is dry and free from damp and that adequate space is provided. We aim to ensure that the home is warm and energy efficient. We also aim to ensure that the home is accessible, especially that we prioritise homes that are on ground or lower floors. Decent housing is essential to maintain the health and quality of life of those with sickle cell disease. The Housing Strategy Service is keen to further develop a position on sickle cell disease (and thalassaemia) and is happy to engage with the Health and Well Being Board on this issue.

Implications completed by: James Goddard, Group Manager Housing Strategy, LBBD

9 Discussion

9.1 It is suggested that Board discussion focuses on:

- The potential of all partners to contribute to health and wellbeing plans for this population of people with sickle cell disease.
- How the Board will be assured of the impact of the proposals.