HEALTH SCRUTINY PANEL
25 MARCH 2015
OSCAR NOTTINGHAM
REPORT OF HEAD OF DEMOCRATIC SERVICES

1. Purpose

1.1 To receive a brief overview of the work of OSCAR Nottingham, to help identify whether further scrutiny is required.

2. Action required

2.1 The Panel is asked to use the information provided to decide whether further scrutiny could add value and influence any of the issues raised.

3. Background information

3.1 OSCAR Nottingham was started by a group of concerned parents of young Sickle Cell sufferers who struggled to find information, overcome difficulties, and find people who could understand their needs. It became a Registered Charity in 1983 and currently it aims to support Sickle Cell and Thalassaemia sufferers of all ages, and their families, with their social, financial and welfare needs.

3.2 Sickle cell disease (SCD) is a serious inherited blood disorder where the red blood cells, which carry oxygen around the body, develop abnormally, and can change shape, ie they can become sickle shaped instead of the normal doughnut shape. This causes episodes of pain and other symptoms, including chest infections and anaemia. Crises (sickling) can cause long-term complications, including damage to organs and joints, and strokes. Certain conditions can trigger crises, for example cold, infection, dehydration or low oxygen. In the UK, about 12,500 people have SCD. It is more common in people whose family origins are African, African-Caribbean, Asian or Mediterranean. It is rare in people of North European origin. On average, 1 in 2,400 babies born in England have SCD, but rates are much higher in some urban areas.[1]

3.3 Thalassaemia is a group of inherited blood disorders where the haemoglobin is abnormal. The affected red blood cells are unable to function normally, which leads to anaemia. Consequences can be mild to very serious, for example, requiring frequent blood transfusions and the risk of heart failure. Anyone may carry a thalassaemia gene. Alpha thalassaemia is a blood disorder that occurs worldwide. It's particularly common in Southeast Asia, and also affects people of Mediterranean, North African, Middle Eastern, Indian and Asian origin. In England, beta thalassaemia major is thought to affect around 1,000 people, with an estimated 214,000 carriers. It most commonly affects people of Cypriot, Indian, Pakistani, Bangladeshi and Chinese origin. In the UK, 8 out of 10 babies born with BTM have parents of Indian, Pakistani or Bangladeshi ancestry.[2]

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[1] www.patient.co.uk
[2] www.nhs.uk

3.4 Craig Galpin, Education and Awareness Officer, Nottingham City Clinical Commissioning Group will provide an overview of the work of the charity OSCAR Nottingham, to provide members of the Panel with an insight to its work and to enable them to decide whether any further scrutiny is necessary.

4. List of attached information

4.1 **Appendix 1** – Sickle Cell Disorder and Thalassaemia Major Report, March 2015.

5. Background papers, other than published works or those disclosing exempt or confidential information

None

6. Published documents referred to in compiling this report

http://oscarnottingham.org/Index.aspx
www.patient.co.uk
www.nhs.uk

7. Wards affected

All

8. Contact information

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