



Report of Head of Scrutiny and Member Development

Report to Scrutiny Board (Health and Well-being and Adult Social Care)

Date: 28 March 2014

Subject: The UK Strategy for Rare Diseases and NHS England’s associated Statement of Intent

Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Are there implications for equality and diversity and cohesion and integration?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Is the decision eligible for Call-In?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

1 Purpose of this report

- 1.1 The purpose of this report is to provide information in relation to the UK Strategy for Rare Diseases, NHS England’s associated Statement of Intent and the link to specialised services.
- 1.2 This information provides additional context for Scrutiny Board members as the Board explores the process for developing the national Specialised Services Strategy and the potential implications (nationally, regionally and locally) associated with concentrating expertise in a reduced number of centres.
- 1.3 It also provides additional context as the Scrutiny Board considers and formally responds to consultation around proposed changes to 14 Specialised Service specifications.

2 Background

- 2.1 In November 2013, the Department of Health published the UK Strategy for Rare Diseases, which is available at: www.gov.uk/government/publications/rare-diseases-strategy.
- 2.2 In February 2014, NHS England published its Statement of Intent in response to the UK Strategy for Rare Diseases.

3 Main issues

- 3.1 A summary of the commitments detailed in the UK Strategy for Rare Diseases is appended to this report, along with NHS England’s Statement of Intent.
- 3.2 Representatives from NHS England will be in attendance to outline the link between the UK Strategy for Rare Diseases and specialised services and assist members in considering the details presented.

4 Recommendations

- 4.1 Members of the Scrutiny Board are asked to consider the information presented and identify any specific matters that require further and/or more detailed scrutiny.

5 Background papers¹

- 5.1 None used

¹ The background documents listed in this section are available to download from the Council's website, unless they contain confidential or exempt information. The list of background documents does not include published works.