Supplementary information and late items for Scrutiny Board (Health and Well-being and Adult Social Care) on 28 March 2014

Pages 1-4: Agenda item 7 - NHS Specialised Services and Consultation on Proposed Changes to Specific Service Changes – Submission by Leeds Teaching Hospitals NHS Trust

Pages 5-30: Agenda item 10 - To consider a report from the Head of Scrutiny and Member Development presenting information in relation to the UK Strategy for Rare Diseases, NHS England's associated Statement of Intent and the link to specialised services.

Pages 31-44: Agenda item 11 - To consider a report from the Head of Scrutiny and Member Development seeking nomination of a member from within its membership (subject to Full Council agreement) to sit on the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to the new review of Congenital Heart Disease services.

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

28th March

Background briefing on Leeds Teaching Hospitals Specialised Services

Overview

- Specialised services are those which are clinically complex and often require support from specialist clinicians across a range of disciplines. They are typically commissioned for populations greater than 1 million, and are often high cost & low volume. Examples include specialised cancer services, specialised children's services, renal dialysis, and transplantation.
- The Trust is the largest provider of specialised services within Yorkshire and the Humber region, both in terms of range of services provided and the overall volume and cost.
- Since April 2013 NHS England (NHSE) has been responsible for commissioning specialised services, using funding top-sliced nationally from clinical commissioning group (CCG) allocations.
- For all providers in Yorkshire & the Humber, the NHSE specialised commissioner is the South Yorkshire Area Team. For LTHT the 2013/14 specialised services contract is forecast to be £394m (45%) out of a total LTHT NHS patient care income of £863m
- Although not part of specialised services, secondary dental & screening services and offender health are also directly contracted by NHS England, in this case by West Yorkshire Area Team.
- Leeds City Council now contracts for sexual health services as part of the Public Health directorate.
- Other secondary health services are contracted by CCGs on behalf of their local populations.
- NHS funding is allocated in the same way to both specialised services and CCGs, with the same efficiency & growth assumptions. The rate of cost inflation has historically been higher in specialised services, especially around the growth of new high cost drug treatments or other new health technologies. This creates a significant cost pressure for specialised services contracts.

NHS England's approach

- NHS England's approach is to move towards nationally consistent commissioning policies and service standards, supported through consistently applied ways of classifying and paying for services, and of monitoring the quality of services using clinical dashboards.
- The policy intention is to concentrate expertise in fewer centres and only commission services from those who can best meet the required standards. This was re-emphasised by Sir David Nicholson, the outgoing NHS England Chief Executive, in recent media interviews.
- There is strong clinical evidence to demonstrate that outcomes for patients are better where expertise is centralised.

- Appendix 1 identifies the major specialised services provided by LTHT with their approximate 2013/14 value.
- Inevitably, any attempt to “cut the cake” between national & local commissioners means that many patient pathways cross commissioning boundaries, with both CCG and Area Teams being responsible for funding parts of the pathway e.g. diagnostic & rehabilitation phases may fall within CCG allocations, whilst only the main treatment itself may be specialised. This means that CCGs and Area Teams need to work together to ensure seamless care pathways.
- NHSE has developed service specifications for each specialised service. These are minimum quality standards that all providers must meet. In future NHSE will only contract with providers who meet the service specification in full. This is expected to reduce the numbers of providers for many specialised services. These specifications have been developed nationally by clinical reference groups and these continue to be updated and refined.
- NHS England has also developed more detailed national commissioning policies for specific specialised treatments, including newly developed services.
- During 2013/14 all providers assessed their compliance with national specialised service specifications and came to agreement with NHSE as to whether they could achieve compliance on a service by service basis, providing action plans to deliver this where possible (derogation). For those services where NHSE was not confident that providers could achieve compliance, or where there was no obvious regional centre, priority areas for service review and potential reconfiguration have been identified. This includes burn care, complex obesity services, some complex gynaecology and infectious disease services.
- The Trust is making progress to achieve full compliance for all services it provides and to work with specialist commissioners to support the reconfiguration of services across the region.
- NHSE is intending to publish the results of the compliance work conducted soon, in the context of developing future service strategy. The Trust has received information which confirms that its existing compliance status compares well with that of other major centres in the region.

Major Service Changes in 2013/14

The first year of the new specialised services commissioning arrangements has seen a number of major changes which have been challenging both for both Trust & Area Team:-

- Designation of LGI as the Major Trauma Centre for West Yorkshire, doubling the numbers of major trauma cases brought direct to LGI rather than to surrounding District Hospitals (value £8m)
- Growth in adult liver transplants of nearly 40% (£2.5m) following changes in national catchment areas for allocating donors to transplant centres. Leeds previously had among the longest liver transplant waiting times in the UK, which improved access to donor organs is helping to alleviate.
- Growth in high cost drugs and devices of £17m or 20%. £7m of this was accounted for by just 2 drugs.
- Transfer of vascular surgery from Mid-Yorkshire (£0.6m in 2013/14, £1.5m full year)

APPENDIX 1	
Leeds Teaching Hospitals: Specialised Services 2013/14	
Service	**Value 2013/14**
	£M
Highly Specialised Services (up to 10-15 Providers nationally)	
Adult & Paediatric Liver Transplants	9
Paediatric Liver Disease	3
Paroxysmal Nocturnal Haemoglobinuria (PNH)	29
Primary Cilliary Dyskinesia (PCD)	1
	42
Specialised (up to 50 Providers nationally)	
Adult Cardio Respiratory Services	27
Adult Neurosciences	32
Specialist Orthopaedics	4
Specialised Children's Services	43
Specialised Digestive Diseases	2
Specialised Head & Neck Surgery	3
Cancer Services	55
Trauma & Related Services	18
Renal & Non-Transplant Liver Services	18
Critical Care (Adults, Neonates & Childrens)	50
Clinical Genetics Services	7
Specialist Rehabilitation Servces	5
High Cost Drugs & Devices	75
Quality Payments (CQUINS)	8
Other	4
	352
Total South Yorkshire Area Team Specialised	**394**

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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):	☐ Yes	☒ No
Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☒ No
Is the decision eligible for Call-In?	☐ Yes	☒ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	☐ Yes	☒ 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 papers[1]

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.

UK STRATEGY FOR RARE DISEASES - COMMITMENTS

(lead organisation as of February 2014)

Number	Commitment	Organisations leading on action in England (seeking contributions from other organisations as appropriate)
1	Strengthen the mechanisms and opportunities for meaningful and sustained patient involvement in rare disease service provision and research, recognising patient groups as key partners – including in the development of the four country plans to implement the Strategy.	All relevant organisations in line with their remit
2	Improve awareness amongst service providers and others of the effects that rare diseases can have on a person's education, family, social relationships and ability to work.	All relevant organisations in line with their remit
3	Encourage effective and timely liaison between the NHS and other public service providers, and encourage providers to consider the effects of rare diseases on people's lives when they are developing and managing services.	NHS England
4	Make sure that patients and their families have a say in decisions about treatment and in the planning, evaluation and monitoring of services.	NHS England
5	Consider how to give all patients with a rare disease clear and timely information about: their condition and its development; treatment and therapy options; practical support.	NHS England
6	Improve access for patients (or where appropriate their parents or guardians) to their personal data.	NHS England
7	Support patients to register on databases, where these exist.	Public Health England/NHS England

Number	Commitment	Organisations leading on action in England (seeking contributions from other organisations as appropriate)
8	Help patients to contribute to research and other activity related to rare diseases.	NHS England/National Institute for Health Research
9	Continue to work with the UK National Screening Committee to ensure that the potential role of screening in achieving earlier diagnosis is appropriately considered in the assessment of all potential new national screening programmes and proposed extensions to existing programmes.	DH/UK National Screening Committee
10	Initiate action to ensure carrier testing approved by the appropriate commissioning bodies, where the associated molecular tests are evaluated and recommended by UKGTN, is accessible for at risk relatives.	NHS England
11	Work to achieve reduced times for diagnosis of rare diseases, whilst acknowledging that more needs to be done to ensure that undiagnosed patients have appropriate access to coordinated care e.g. to help disabled children who are thought to have a genetic syndrome or condition that science has not yet identified.	NHS England

Number	Commitment	Organisations leading on action in England (seeking contributions from other organisations as appropriate)
12	Work with the NHS and clinicians to establish appropriate diagnostic pathways which are accessible to, and understood by, professionals and patients, by — establishing clear, easily accessible and effective pathways between primary care, secondary care, regional centres and specialist clinical centres, as appropriate — putting protocols in place to identify patients with no diagnosis, ensuring that a lack of diagnosis does not create a barrier to treatment — drawing on patients' ability to help inform decisions about referral and diagnosis — creating effective clinical networks to support this process — making high quality diagnostic tests accessible through common, clinically agreed systems or pathway — embedding appropriate information in national data systems including measuring equity of access to molecular tests to maintain UKGTN diagnostic studies	NHS England
13	Ensure that there are appropriate procedures for evaluating the costs and benefits of treatments for patients.	NICE
14	Where appropriate, support the availability of computerised prompts to help GPs diagnose a rare disease when a rare disease has not previously been considered.	NHS England
15	Improve education and awareness of rare diseases across the healthcare professions, including: — involving patients in the development of training programmes — encouraging medical, nursing and associated health professionals to get hands-on experience in specialist clinics — ensuring awareness of methods and clinical techniques used in differential diagnosis.	Health Education England

Number	Commitment	Organisations leading on action in England (seeking contributions from other organisations as appropriate)
16	Monitor the development of ICD-11 in preparation for its adoption.	All relevant organisations in line with their remit
17	Work with colleagues in Europe on the development of the European Orphanet coding system and considering the adoption of Orphanet coding and nomenclature.	NHS England
18	Standardise data collection, building upon existing NHS data standards, and develop standards where they do not exist, increasing the reliability of information for use inproviding or commissioning care.	NHS England is currently in discussion with relevant agencies to establish responsibility
19	Explore options to improve the link between existing patient data and electronic health records.	NHS England is currently in discussion with relevant agencies to establish responsibility
20	Assess the potential for rare disease databases where they do not exist.	Department of Health
21	Agree international standards, building on existing NHS standards.	NHS England
22	Support international links to UK databases and build on the work of current funded programmes that aim to link rare disease research internationally.	NHS England

Number	Commitment	Organisations leading on action in England (seeking contributions from other organisations as appropriate)
23	Continue to develop service specifications for rare diseases. This will include country specific care pathways and a 'generic' care pathway that sets out best practice that can be applied to all patients with rare diseases in the UK (particularly where there are no disease specific pathways). The generic care pathway will include: — an appropriate care plan for all patients with a rare disease — clearly stated principles around the standards of care which patients with a rare disease can expect, including patients with no diagnosis — the development of seamless pathways for transition, from childhood to adolescence, and on to adulthood and older age — access criteria and measures of quality and outcomes	NHS England
24	Agree that specialist clinical centres should as a minimum standard: — have a sufficient caseload to build recognised expertise — where possible, not depend on a single clinician — coordinate care — arrange for coordinated transition from children's to adults' services — involve people with rare conditions, and their families and carers — support research activity — ensure their expertise is available to families and their healthcare teams	NHS England
25	Ensure that the relationship between the specialist clinical centres and science and research is explained to and understood and put into practice by: practitioners delivering local health and social care; the research community; industry; academia.	NHS England/Department of Health
26	Set out clearly the connections to and communications with specialist clinical centres in molecular diagnostics and other forms of diagnostic support.	NHS England/Department of Health

Number	Commitment	Organisations leading on action in England (seeking contributions from other organisations as appropriate)
27	Ensure that specialist clinical centres are as concerned with research as with health and social care support, and that they develop networks that provide professional to professional dialogue and collaboration across a wide range of experts, including internationally (especially for those conditions that are ultra-rare).	NHS England/Department of Health
28	Work with international partners wherever possible and develop UK-wide criteria for centres to become part of an expert reference network to increase the flow of information between patients and professionals in a range of disciplines.	NHS England
29	Improve systems to record genetic and other relevant information accurately to record the incidence and prevalence of disease and support service planning and international planning.	Public Health England/NHS England
30	Identify how they can change systems to hold information about rare diseases, including information about the uptake of treatments.	NHS England
31	Look at how the 4 UK countries develop, change or expand information systems to capture, connect and analyse data about clinical and social care pathways.	Department of Health
32	Work together to identify a selection of the rare diseases most suited to the development of best-care pathways and propose other rare diseases for possible pathway development, taking on board the needs of patients and carers and the challenges faced during delivery of the first set of pathways.	NHS England
33	Examine how they can encourage service providers to involve patients in research and to ensure appropriate funding for excess treatment costs for research in rare diseases.	NHS England

Number	Commitment	Organisations leading on action in England (seeking contributions from other organisations as appropriate)
34	Make better use of online applications to give patients information about their condition so that they can develop a personalised care path plan with their clinical and social care team.	NHS England
35	Use portals to connect patients and relatives to enhance research participation and, where appropriate, promote self-enrolment to approved research studies with online consenting, self-reporting and use of social media.	Department of Health/NHS England
36	Encourage patient groups to get involved with regulatory bodies.	Department of Health
37	Help patient organisations and community engagement events develop more formal partnerships with the NHS research-active organisations.	NHS England/National Institute for Health Research
38	Explore the feasibility of the UK Clinical Trials Gateway including experimental medicine trials for rare diseases to provide information for patients and their families about research trials.	National Institute for Health Research
39	Work with the research community, regulators, providers of NHS services and research funders to develop risk-proportional permission systems.	Health Research Authority
40	Encourage researchers to use current guidance to produce generic participant information leaflets and consent forms and participate in future guidance reviews.	Health Research Authority
41	Promote good practice and the use of systems which facilitate a consistent and streamlined process to local NHS permissions of publically, charitably and commercially funded research with an aim to reduce timescales.	National Institute for Health Research

Number	Commitment	Organisations leading on action in England (seeking contributions from other organisations as appropriate)
42	Begin and complete next generation sequencing (NGS) demonstration projects to: evaluate their usefulness, acceptability and cost-effectiveness; develop effective health economic assessments (for example through Health Technology assessments) and similar initiatives.	UK Genetic Testing Network/NICE
43	Evaluate different NGS platform configurations, for example: — NGS for clinical condition-specific sets of genes (such as 100–200 of the 22,000 genes — whole exome sequencing (2% of the entire genome) — whole genome sequencing	UK Genetic Testing Network/NHS England/NICE
44	Support the introduction of NGS into mainstream NHS diagnostic pathways, underpinned by appropriate clinical bioinformatics, including clinical bioinformatics hubs supported by high performance computing centres, where appropriate.	NHS England/Health Education England
45	Ensure that training and education are available to the NHS workforce, highlighting the importance of NGS to all aspects of rare disease care, including support for evidence based local counselling for patients and their relatives who receive NGS results.	Health Education England/NHS England/Genomics England Limited
46	Work with industry to set priorities and determine how best to support research into rare diseases and promote research collaboration.	National Institute for Health Research
47	Support initiatives to facilitate engagement between patients, clinical care teams, researchers and industry wherever practical.	NHS England/National Institute for Health Research
48	Set out the benefits of collaboration (besides producing specific treatments) for all stakeholders.	NHS England/National Institute for Health Research

Number	Commitment	Organisations leading on action in England (seeking contributions from other organisations as appropriate)
49	Continue to build a cohesive infrastructure for implementation and coordination of rare disease research in the NHS.	National Institute for Health Research
50	Encourage major research funders to use current structures to coordinate strategic funding initiatives in rare diseases.	Department of Health [through its membership of the Office for Strategic Coordination of Health Research (OSCHR) Board and the UK Clinical Research Collaboration (UKCRC)]
51	Improve engagement between key stakeholders, including: — patients and relatives — main funding providers — healthcare commissioners — NHS hospitals and specialist care units — industry (pharmaceutical, biotechnology, IT, diagnostics)	NHS England/National Institute for Health Research

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NHS England

UK Strategy for Rare Diseases

NHS England Statement of Intent

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Publications Gateway Reference:	**01208**
Document Purpose	Guidance
Document Name	UK Strategy for Rare Diseases - NHS England Statement of Intent
Author	NHS England
Publication Date	26 February 2014
Target Audience	Patients and public
Additional Circulation List	
Description	This document sets out how NHS England will play its part in delivering the UK Strategy for Rare Diseases in England. A more detailed plan will be built into the five year strategy, for specialised services, currently being developed by NHS England.
Cross Reference	UK Strategy for Rare Diseases
Superseded Docs (if applicable)	N/A
Action Required	N/A
Timing / Deadlines (if applicable)	**N/A**
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UK STRATEGY FOR RARE DISEASES

NHS ENGLAND STATEMENT OF INTENT

INTRODUCTION

The government has issued a UK Strategy for Rare Diseases, containing 51 commitments (labelled 'C') which all four countries of the UK have agreed to achieve by 2020.

The present document sets out how NHS England will play its part in delivering those commitments.

EMPOWERING THOSE AFFECTED BY RARE DISEASES

C1. Strengthen the mechanisms and opportunities for meaningful and sustained patient involvement in rare disease service provision and research, recognising patient groups as key partners – including in the development of the four country plans to implement the Strategy.

There is always more that can be done but patient involvement is a strong theme in the way that NHS England organises its business. Specific to specialised services, there is patient representation on the 75 Clinical Reference Groups that agree service policies and specifications, and also on the Rare Disease Advisory Group.

NHS England will strengthen its relationship with patient representatives by inviting all patient representatives on Clinical Reference Groups, on an annual basis, to suggest ways in which NHS England can improve and build upon patient involvement in rare disease service provision in a meaningful and sustained way.

Each Clinical Reference Group will ensure involvement and appropriate engagement with patient organisations for rare diseases that fall within their remit.

The Rare Diseases Advisory Group will be charged with ensuring communication is carried out in a structured and systematic way. Responsibilities will include: collating information, communicating responses and circulating an action plan if necessary.

C2. Improve awareness amongst service providers and others of the effects that rare diseases can have on a person's education, family, social relationships and ability to work.

This improved awareness can come from close involvement of patients in service planning and delivery, as noted above.

C3. Encourage effective and timely liaison between the NHS and other public service providers, and encourage providers to consider the effects of rare diseases on people's lives when they are developing and managing services.

Care for patients with rare diseases, whenever possible, will be provided holistically and should include consideration of the patient's and their family's non-medical needs. All agencies involved in the care of the patient should work in an integrated way to design a pathway for patients that crosses organisational boundaries.

This should also apply to services provided across geographical boundaries and NHS England will continue to work with counterparts in the UK, including the National Services Division in Scotland, the Welsh Health Specialised Services Committee in Wales and the Health and Social Care Board in Northern Ireland to ensure patients with rare conditions can access appropriate treatment across the UK.

NHS England will also work with counterparts in Europe; this has been made possible by the EU Directive on cross-border healthcare which grants a fundamental right to all European Economic Area (EEA) citizens to access healthcare services in the EEA.

The Rare Diseases Advisory Group is best suited to oversee this work by NHS England. NHS England will report to Rare Diseases Advisory Group on the progress of cross border work on an annual basis.

C4. Make sure that patients and their families have a say in decisions about treatment and in the planning, evaluation and monitoring of services.

As indicated above in commitment 1, patients are already at the heart of planning, monitoring and evaluating services for rare disease through their membership of the Clinical Reference Groups and Rare Diseases Advisory Group. NHS England will empower patient representatives on Clinical Reference Groups through measures outlined in commitment 1 to make sure that membership is an active, contributing membership.

C5. Consider how to give all patients with a rare disease clear and timely information about: their condition and its development; treatment and therapy options; practical support.

It is already best practice for clinical teams to offer this information to patients, and the question of whether the information is clear and timely is routinely monitored in patient experience surveys.

All NHS England service specifications will be available on the NHS England website and will link to other reliable sources of information and any details of relevant patient organisations. Provider Trusts will be encouraged to provide information about their specialised services on their own websites.

C6. Improve access for patients (or where appropriate their parents or guardians) to their personal data.

We plan to improve access for patients to their own data in two ways. Firstly, to encourage the good practice of copying to patients all clinic letters. Secondly, by encouraging the use (subject to proper procurement) of systems such as MySpace and Patient Knows Best which allow patients to access their own data.

C7. Support patients to register on databases, where these exist.

Public Health England have indicated an intent to develop a national rare disease register. NHS England will play its part in helping to ensure data flows into that register.

Information regarding registries will be achieved through commitment 5.

C8. Help patients to contribute to research and other activity related to rare diseases.

NHS England will work with other key organisations, including the Department of Health and through the UK Rare Diseases Stakeholder Forum, to deliver this commitment.

NHS England will also contribute through its requirement that expert centres are research active (see commitment 24).

IDENTIFYING & PREVENTING RARE DISEASES

C9. Continue to work with the UK National Screening Committee to ensure that the potential role of screening in achieving earlier diagnosis is appropriately considered in the assessment of all potential new national screening programmes and proposed extensions to existing programmes.

The UK National Screening Committee has primary responsibility for this commitment. NHS England will contribute actively as required.

C10. Initiate action to ensure carrier testing approved by the appropriate commissioning bodies, where the associated molecular tests are evaluated and recommended by UKGTN, is accessible for at risk relatives.

The recommendations of the UK Genetic Testing Network will be considered by NHS England and subject to available resources, incorporated into services specifications.

DIAGNOSIS & EARLY INTERVENTION

C11. Work to achieve reduced times for diagnosis of rare diseases, whilst acknowledging that more needs to be done to ensure that undiagnosed patients have appropriate access to coordinated care to help disabled children who are thought to have a genetic syndrome or condition that science has not yet identified.

Implementation of this commitment will be achieved in part through the mechanisms set out in commitment 12 and 23.

We will also develop a working group to identify the problems associated with the diagnosis of rare diseases. The working group will report back, within 12 months, on the ways in which NHS England can improve diagnosis and early intervention. This working group will initially be a sub group within the Rare Diseases Advisory Group with the intention of broader membership.

C12. Work with the NHS and clinicians to establish appropriate diagnostic pathways which are accessible to, and understood by, professionals and patients, by:

- ***establishing clear, easily accessible and effective pathways between primary care, secondary care, regional centres and specialist clinical centres, as appropriate***
- ***putting protocols in place to identify patients with no diagnosis, ensuring that a lack of diagnosis does not create a barrier to treatment***
- ***drawing on patients' ability to help inform decisions about referral and diagnosis***
- ***creating effective clinical networks to support this process***
- ***making high quality diagnostic tests accessible through common, clinically agreed systems or pathway***
- ***embedding appropriate information in national data systems including measuring equity of access to molecular tests to maintain UKGTN diagnostic studies.***

This commitment will be achieved primarily through the Rare Disease Annex for all service specifications, which all Clinical Reference Groups must consider when commissioning specialised services. The Rare Disease Annex will incorporate all points listed above. Effective clinical networks will also be delivered through commitment 26 and 27.

The Rare Diseases Advisory Group has been tasked to oversee the effectiveness of the Rare Disease Annex. NHS England will provide the necessary information to allow the Rare Diseases Advisory Group to carry out monitoring duties.

C13. Ensure that there are appropriate procedures for evaluating the costs and benefits of treatments for patients.

NHS England will collaborate closely with the National Institute for Health and Care Excellence (NICE) in the formal appraisal of technologies, including the newly established evaluations committee for highly specialised technologies. NHS England's internal procedures for evaluating the costs and benefits of treatment will, where appropriate, take account of the specific needs of patients with rare disease. These evaluations will be publicly available for scrutiny.

C14. Where appropriate, support the availability of computerised prompts to help GPs diagnose a rare disease when a rare disease has not previously been considered

Expert systems show great promise as a tool to help early recognition of rare disease. This technology is however not yet fully developed. NHS England will support piloting and evaluation where appropriate.

C15. Improve education and awareness of rare diseases across the healthcare professions, including:

- ***involving patients in the development of training programmes***
- ***encouraging medical, nursing and associated health professionals to get hands-on experience in specialist clinics***
- ***ensuring awareness of methods and clinical techniques used in differential diagnosis***

NHS England will provide appropriate support to those leading on the delivery of this commitment

C16. Monitor the development of ICD-11 in preparation for its adoption

The strategic intent of NHS England is to adopt SNOMED CT as its standard coding system. SNOMED CT is interoperable with ICD 10, and will be with ICD 11 when developed.

C17. Work with colleagues in Europe on the development of the European Orphanet coding system and considering the adoption of Orphanet coding and nomenclature

NHS England will deliver this commitment and we are currently investigating appropriate methods to do so.

C18. Standardise data collection, building upon existing NHS data standards, and develop standards where they do not exist, increasing the reliability of information for use in providing or commissioning care
NHS England is currently in discussion with relevant agencies in order to establish responsibility for this commitment.

C19. Explore options to improve the link between existing patient data and electronic health records

NHS England is currently in discussion with relevant agencies in order to establish responsibility for this commitment.

C20. Assess the potential for rare disease databases where they do not exist

As noted in commitment 7, Public Health England have indicated an intent to develop a national rare disease register which will cover every patient in England with a rare disease. NHS England will play its part in helping to ensure data flows into that register.

C21. Agree international standards, building on existing NHS standards

NHS England is represented on the international body which governs health data standards, the *International Health Terminology Standards* Development *Organisation*. We will build on this platform to deliver this commitment.

C22. Support international links to UK databases and build on the work of current funded programmes that aim to link rare disease research internationally

NHS England will deliver this commitment and we are currently investigating appropriate methods to do so.

COORDINATION OF CARE

C23. Continue to develop service specifications for rare diseases. This will include country specific care pathways and a 'generic' care pathway that sets out best practice that can be applied to all patients with rare diseases in the UK (particularly where there are no disease specific pathways). The generic care pathway will include:

- ***an appropriate care plan for all patients with a rare disease***
- ***clearly stated principles around the standards of care which patients with a rare disease can expect, including patients with no diagnosis***

- ***the development of seamless pathways for transition, from childhood to adolescence, and on to adulthood and older age***
- ***access criteria and measures of quality and outcomes***

As noted in commitments 3 and 12 NHS England will develop a Rare Disease Annex that will apply to all service specifications and will incorporate the requirements listed above. It will also incorporate an assurance that every patient will be made aware of who is responsible for providing their care. Provisions for patients with undiagnosed conditions will also be made.

C24. Agree that specialist clinical centres should as a minimum standard:

- ***have a sufficient caseload to build recognised expertise***
- ***where possible, not depend on a single clinician***
- ***coordinate care***
- ***arrange for coordinated transition from children's to adults' services***
- ***involve people with rare conditions, and their families and carers***
- ***support research activity***
- ***ensure their expertise is available to families and their healthcare teams***

NHS England will reflect these requirements in the Rare Disease Annex which will apply to centres providing specialist care for rare diseases.

C25. Ensure that the relationship between the specialist clinical centres and science and research is explained and understood and put into practice by: practitioners delivering local health and social care; the research community; industry; academia

NHS England will work with other key organisations, including the Department of Health and through the UK Rare Diseases Stakeholder Forum, to deliver this commitment.

We will encourage specialist centres to make appropriate links to research networks and centres.

C26. Set out clearly the connections to and communications with specialist clinical centres in molecular diagnostics and other forms of diagnostic support

NHS England will work with other key organisations, including the Department of Health and through the UK Rare Diseases Stakeholder Forum, to deliver this commitment.

C27. Ensure that specialist clinical centres are as concerned with research as with health and social care support, and that they develop networks that provide professional to- professional dialogue and collaboration across a wide range of experts, including internationally (especially for those conditions that are ultrarare)

NHS England will work with other key organisations, including the Department of Health and through the UK Rare Diseases Stakeholder Forum, to deliver this commitment.

C28. Work with international partners wherever possible and develop UK-wide criteria for centres to become part of an expert reference network to increase the flow of information between patients and professionals in a range of disciplines

The European Commission is developing a system for Europe-wide networks of expert reference centres, and is likely to develop, for each network, disease specific criteria. Within England the general criteria for centres will be as set out in commitment 23 above, and developed more specifically in the Rare Disease Annex.

C29. Improve systems to record genetic and other relevant information accurately to record the incidence and prevalence of disease and support service planning and international planning

This benefit will flow from the establishment of a national register for rare disease – see commitment (C) 7 above.

C30. Identify how they can change systems to hold information about rare diseases, including information about the uptake of treatments

The main limitation at present is the lack of a good coding system for rare disease. SNOMED CT overcomes this limitation – see commitment 16.

THE ROLE OF RESEARCH

C31. Look at how the 4 UK countries develop, change or expand information systems to capture, connect and analyse data about clinical and social care pathways

NHS England will work with other key organisations, including the Department of Health and through the UK Rare Diseases Stakeholder Forum, to deliver this commitment.

C32. Work together to identify a selection of the rare diseases most suited to the development of best-care pathways and propose other rare diseases for possible pathway development, taking on board the needs of patients and carers and the challenges faced during delivery of the first set of pathways

NHS England will carry out a priority setting exercise to identify the most suitable pathway development; this will involve patient groups.

C33. Examine how they can encourage service providers to involve patients in research and to ensure appropriate funding for excess treatment costs for research in rare diseases

The NHS Standard Contract makes reference to excess treatment costs and we are producing a research resource kit for commissioners.

NHS England will also support existing projects that encourage the increased involvement of patients in research design and participation in clinical trials.

C34. Make better use of online applications to give patients information about their condition so that they can develop a personalised care path plan with their clinical and social care team

NHS England will deliver this commitment and we are currently investigating appropriate methods to do so.

C35. Use portals to connect patients and relatives to enhance research participation and, where appropriate, promote self-enrolment to approved research studies with online consenting, self-reporting and use of social media

NHS England will work with other key organisations, including the Department of Health and through the UK Rare Diseases Stakeholder Forum, to deliver this commitment.

C36. Encourage patient groups to get involved with regulatory bodies

NHS England will provide appropriate support to those leading on the delivery of this commitment.

C37. Help patient organisations and community engagement events develop more formal partnerships with the NHS research-active organisations

NHS England will work with other key organisations, including the Department of Health and through the UK Rare Diseases Stakeholder Forum, to deliver this commitment.

C38. Explore the feasibility of the UK Clinical Trials Gateway including experimental medicine trials for rare diseases to provide information for patients and their families about research trials

NHS England will provide appropriate support to those leading on the delivery of this commitment.

C39. Work with the research community, regulators, providers of NHS services and research funders to develop risk-proportional permission systems

NHS England will provide appropriate support to those leading on the delivery of this commitment.

C40. Encourage researchers to use current guidance to produce generic participant information leaflets and consent forms and participate in future guidance reviews.

NHS England will provide appropriate support to those leading on the delivery of this commitment.

C41. Promote good practice and the use of systems which facilitate a consistent and streamlined process to local NHS permissions of publically, charitably and commercially funded research with an aim to reduce timescales.

NHS England will provide appropriate support to those leading on the delivery of this commitment.

C42. Begin and complete next generation sequencing (NGS) demonstration projects to: evaluate their usefulness, acceptability and cost-effectiveness; develop effective health economic assessments (for example through Health Technology Assessments) and similar initiatives

NHS England will provide appropriate support to those leading on the delivery of this commitment.

C43. Evaluate different NGS platform configurations, for example:

- ***NGS for clinical condition-specific sets of genes (such as 100–200 of the***
- ***22,000 genes***
- ***whole exome sequencing (2% of the entire genome)***
- ***whole genome sequencing***

NHS England will work with other key organisations, including the Department of Health and through the UK Rare Diseases Stakeholder Forum, to deliver this commitment.

C44. Support the introduction of NGS into mainstream NHS diagnostic pathways, underpinned by appropriate clinical bioinformatics, including clinical bioinformatics hubs supported by high performance computing centres, where appropriate

NHS England will provide appropriate support to those leading on the delivery of this commitment.

C45. Ensure that training and education are available to the NHS workforce, highlighting the importance of NGS to all aspects of rare disease care, including support for evidence based local counselling for patients and their relatives who receive NGS results

NHS England will provide appropriate support to those leading on the delivery of this commitment.

C46. Work with industry to set priorities and determine how best to support research into rare diseases and promote research collaboration

NHS England will provide appropriate support to those leading on the delivery of this commitment.

C47. Support initiatives to facilitate engagement between patients, clinical care teams, researchers and industry wherever practical

NHS England will work with other key organisations, including the Department of Health and through the UK Rare Diseases Stakeholder Forum, to deliver this commitment.

C48. Set out the benefits of collaboration (besides producing specific treatments) for all Stakeholders

To deliver this commitment NHS England will work with key stakeholders, including: Industry; patients and relatives; main funding providers; healthcare commissioners; and NHS hospitals and specialist care units to develop a compact.

C49. Continue to build a cohesive infrastructure for implementation and coordination of rare disease research in the NHS

NHS England will provide appropriate support to those leading on the delivery of this commitment.

C50. Encourage major research funders to use current structures to coordinate strategic funding initiatives in rare diseases

NHS England will provide appropriate support to those leading on the delivery of this commitment.

C51. Improve engagement between key stakeholders, including:

a) patients and relatives

b) main funding providers

c) healthcare commissioners

NHS England will work with other key organisations, including the Department of Health and through the UK Rare Diseases Stakeholder Forum, to deliver this commitment.

Report author: Steven Courtney
Tel: 24 74707

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: Joint Health Overview and Scrutiny Committee (Yorkshire and Humber)

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

Summary of main issues

1. At its meeting on 26 March 2014, Council will consider recommendations put forward from the General Purposes Committee at its meeting on 4 March 2014, relating to confirming the mandate of a Joint Health Overview and Scrutiny Committee (Yorkshire and Humber) and delegating relevant functions in relation to the new review of Congenital Heart Disease services.

2. The reports presented to Council and General Purposes Committee are attached to this report.

3. Subject to Full Council agreement, the Scrutiny Board (Health and Wellbeing and Adult Social Care) is asked to nominate a member from within its membership to sit on the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to the new review of Congenital Heart Disease services.

4. Confirmation of the outcome from the Full Council meeting on 26 March 2014 will be provided the meeting.

Recommendations

5. The Scrutiny Board (Health and Wellbeing and Adult Social Care) is asked to note the reports to Council and General Purposes Committee and, subject to Full Council agreement, nominate a member from within its membership to sit on the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to the new review of Congenital Heart Disease services.

1 Background papers[1]

1.1 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.

Report author: E Davenport
Tel: 0113 - 2478408

Report of City Solicitor

Report to Full Council

Date: 26 March 2014

Subject: Recommendations from General Purposes Committee – Joint Health Overview and Scrutiny Committee (Yorkshire and Humber)

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

Summary of main issues

1. This report puts forward recommendations from the General Purposes Committee at its meeting on 4 March 2014, relating to confirming the mandate of a Joint Health Overview and Scrutiny Committee (Yorkshire and Humber) and delegating relevant functions in relation to the new review of Congenital Heart Disease services.

2. Attached to this report is a copy of the report which was considered by the General Purposes Committee.

Recommendations

3. General Purposes Committee recommends to full Council:
   (a)That Council reconfirms its support for the establishment of a Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to NHS England's new review of Congenital Heart Disease services;

   (b)That Council delegates relevant functions, as set out in Appendix 1 of the submitted report to the General Purposes Committee, that shall be exercisable by the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), subject to such terms and conditions therein; and

(c) That Council asks the Scrutiny Board (Health and Wellbeing and Adult Social Care) to nominate a member from within its membership to sit on the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to the new review of Congenital Heart Disease services and, upon nomination, agrees to appoint such member to the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber).

1. Purpose of this report

1.1 To put forward recommendations from the General Purposes Committee, in relation to the Joint Health Overview and Scrutiny Committee (Yorkshire and Humber).

2 Background information

2.1 General Purposes Committee is authorised to make recommendations to full Council about proposals to amend the constitution, and in connection with the discharge of any of its functions.

3 Main issues

3.1 On the 4 March 2014, the City Solicitor submitted a report asking the General Purposes Committee to consider and make recommendations to full Council to reconfirm the mandate previously given by full Council for the establishment of a Joint Health Overview and Scrutiny Committee (Yorkshire and Humber) and subsequently delegate relevant functions in relation to the new review of Congenital Heart Disease services.

3.2 A copy of the report to General Purposes Committee is attached as an appendix to this report.

3.3 General Purposes Committee resolved to make recommendations to full Council as proposed in that report.

4 Corporate Considerations

4.1 Consultation and Engagement

4.1.1 As set out in the attached report.

4.2 Equality and Diversity / Cohesion and Integration

4.2.1 As set out in the attached report.

4.3 Council policies and City Priorities

4.3.1 As set out in the attached report.

4.4 Resources and value for money

4.4.1 As set out in the attached report.

4.5 Legal Implications, Access to Information and Call In

4.5.1 This decision is not subject to call-in. Nor does this report contain any exempt information.

4.6 Risk Management

4.6.1 As set out in the attached report.

5 Conclusions

5.1 As set out in the attached report.

6 Recommendations

6.1 General Purposes Committee recommends to full Council

a) That Council reconfirms its support for the establishment of a Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to NHS England's new review of Congenital Heart Disease services;

b) That Council delegates relevant functions, as set out in Appendix 1 of the submitted report to the General Purposes Committee, that shall be exercisable by the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), subject to such terms and conditions therein; and

c) That Council asks the Scrutiny Board (Health and Wellbeing and Adult Social Care) to nominate a member from within its membership to sit on the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to the new review of Congenital Heart Disease services and, upon nomination, agrees to appoint such member to the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber).

7 Background documents[1]

7.1 None

[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.

Leeds CITY COUNCIL

Report author: Steven Courtney
Tel: 0113 247 4707

Report of the City Solicitor

Report to General Purposes Committee

Date: 4 March 2014

Subject: Reconfirming support for a Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to the new Congenital Heart Disease review

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

Summary of main issues

A Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – JHOSC – was initially established in March 2011 to consider and respond to the proposals arising from the Safe and Sustainable Review of Children's Congenital Cardiac Services in England.

Following a number of concerns raised about the proposals, on 12 June 2013, the Secretary of State for Health accepted in full, the findings and recommendations of the Independent Reconfiguration Panel and called a halt to the Safe and Sustainable Review process.

NHS England subsequently set out its intentions for a new review to consider the whole lifetime pathway of care for people with congenital heart disease (CHD) i.e. covering services to both children and adults.

Following the decision of the Secretary of State for Health to halt the previous review, the joint committee has continued to meet to maintain the momentum of its previous work.

However, as it is likely that the JHOSC will make recommendations to NHS England and other interested parties, which may include the Secretary of State for Health, it is advisable to reconfirm the mandate previously given by council and seek approval of the details set out in Appendix 1 for inclusion within the Council's Constitution.

Recommendations

1. General Purposes Committee is asked to:

   1.1 Note the content and detail presented in this report.

   1.2 Make the following recommendations to full Council:

   (a) That Council reconfirms its support for the establishment of a Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to NHS England's new review of Congenital Heart Disease services.

   (b) That Council delegates relevant functions, as set out in Appendix 1, that shall be exercisable by the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), subject to such terms and conditions therein.

   (c) That Council asks the Scrutiny Board (Health and Wellbeing and Adult Social Care) to nominate a member from within its membership to sit on the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to the new review of Congenital Heart Disease services and, upon nomination, agrees to appoint such member to the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber).

1. Purpose of this report

1.1 To ask the General Purposes Committee to consider and make recommendations to Full Council to reconfirm the mandate previously given by Council for the establishment of a Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) and subsequently delegate relevant functions in relation to the new review of Congenital Heart Disease services.

2. Background information

2.1 A Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – JHOSC – was initially established in March 2011 to consider the Safe and Sustainable Review of Children's Congenital Cardiac Services in England – the associated proposals and the impact on children and families across Yorkshire and the Humber. The JHOSC also acted as the appropriate scrutiny body across Yorkshire and the Humber in providing a response to the proposals and reconfiguration options presented for public consultation.

2.2 For the purpose of considering the Safe and Sustainable Review of Children's Congenital Cardiac Surgery and its impact on children and families across Yorkshire and the Humber, Leeds City Council (LCC) – through its Scrutiny Support Unit – led the process to establish the JHOSC during the second half of 2010. Subsequently, LCC has been supporting the work of the JHOSC since it was formally established in March 2011.

2.3 The membership for the JHOSC was made up of a single representative from each of the following 15 top-tier local authorities (i.e. those with specific health scrutiny powers) across Yorkshire and the Humber:

- Barnsley MBC
- Calderdale Council
- City of Bradford MDC
- City of York Council
- Doncaster MBC
- East Riding of Yorkshire Council
- Hull City Council
- Kirklees Council
- Leeds City Council
- North East Lincolnshire Council
- North Lincolnshire Council
- North Yorkshire County Council
- Rotherham MBC
- Sheffield City Council
- Wakefield Council

2.4 At that time, the terms of reference identified that JHOSC's work would specifically include consideration of the:

- Review process and formulation of options presented for consultation;
- Projected improvements in patient outcomes and experience;
- Likely impact on children and their families (in the short, medium and longer-term), in particular in terms of access to services and travel times;
- Views of local service users and/or their representatives;
- Potential implications and impact on the health economy and the economy in general, on a local and regional basis;
- Any other pertinent matters that arise as part of the Committee's inquiry.

2.5 As the administering authority, arrangements for the JHOSC were made in accordance with Leeds City Council's Scrutiny Procedural Rules.

2.6 Following a decision on the proposed future model of care and designation of surgical centres in July 2012, the JHOSC made a referral to the Secretary of State for Health in November 2012. This referral was made on the basis that the

proposed changes would not be in the best interests of local NHS services and was subsequently passed to the Independent Reconfiguration Panel (IRP) for consideration and advice.

2.7 The IRP's advice and recommendations were set out in its report to the Secretary of State for Health at the end of April 2013. On 12 June 2013, an announcement from the Secretary of State for Health accepted the IRP's report and recommendations in full and called a halt to the Safe and Sustainable Review of Children's Congenital Cardiac Services in England.

2.8 The Secretary of State for Health then invited NHS England – as the new body responsible for commissioning specialised services following the restructuring arrangements across the NHS that came into force from 1 April 2013 – to report how it intended to proceed by the end of July 2013.

3 Main issues

3.1 New review of congenital heart disease (CHD) services

3.1.1 Following the decision of the Secretary of State for Health to halt the previous review, the joint committee has continued to meet to maintain the momentum of its previous work.

3.1.2 At its meeting in September 2013 the JHOSC considered the Secretary of State's decision alongside the report of the Independent Reconfiguration Panel (IRP) and was advised of NHS England's intentions for the new review to consider the whole lifetime pathway of care for people with congenital heart disease (CHD) i.e. covering services to both children and adults.

3.1.3 Members of the JHOSC expressed support for the work of the JHOSC to continue, insofar as it relates to the new CHD review, and specifically highlighted a number of points, including:

- The strength of joint scrutiny arrangements across Yorkshire and the Humber, vis-à-vis the Safe and Sustainable review and proposals, was clearly evident in the Secretary of State's announcement in June 2013.
- That the new CHD review would benefit from similar robust scrutiny arrangements as those in place for the Safe and Sustainable review.
- Concern regarding the likely timescales for the new review and the processes necessary for agreeing revised terms of reference across fifteen constituent local authorities.

3.1.4 It was clarified at that meeting that while it would not be necessary to formally dissolve the JHOSC, in order to place the governance arrangements for the JHOSC on a firmer footing – insofar as its work relates to the new CHD review – the existing terms of reference for the JHOSC would need to be revised to reflect the changed approach and scope of the new review of CHD services. It was also confirmed that any revised terms of reference may then need approval from the constituent local authority members.

3.1.5 Revised terms of reference / an outline work plan associated with the new review of CHD services was agreed by the JHOSC at its meeting in December 2013, and these details are available on request. Nonetheless, as it is likely that the JHOSC will make recommendations to NHS England and other

interested parties, which may include the Secretary of State for Health, it is advisable to reconfirm the mandate previously given by council and approve the details set out in Appendix 1 for inclusion within Section 4 (Joint Arrangements) of the Council's Constitution.

4 Corporate Considerations

Consultation and Engagement

4.1 In September 2013, Members of the JHOSC expressed broad support for the work of the JHOSC to continue insofar as it relates to the new CHD review. Revised draft terms of reference were presented and subsequently agreed at the JHOSC meeting in December 2013.

4.2 Discussions are continuing with other constituent authorities regarding the processes necessary to reconfirm commitment to the refocused work of the JHOSC.

Equality and Diversity/Cohesion and Integration

4.3 There are no specific equality and diversity or cohesion and integration specifically associated with this report. However, although not a decision-making body, as a local authority joint committee the JHOSC will have to have a general regard of public sector equality duties.

4.4 In particular, the JHOSC will consider the impact of any future reconfiguration and future service model proposals on specific populations and communities across Yorkshire and the Humber. This will be alongside the general health and equality impacts arising from the new review and in particular, the comparison with existing provision and service configuration. This was a key feature of the JHOSC's previous work.

Resources and value for money

4.5 As the administering authority, day-to-day support for the work of the JHOSC will continue to be provided through the Council's Scrutiny Support Unit. This has been the case since the JHOSC was established in March 2011 when considering the Safe and Sustainable Review of Children's Congenital Cardiac Services in England.

4.6 However, in recognition of the unprecedented level of support already provided to the work of the JHOSC and a view from its members that the new congenital heart disease services review would benefit from similar robust scrutiny arrangements as those in place for the Safe and Sustainable review, all constituent authorities have been invited to make a small financial contribution of £1000 per authority for the financial year 2014/15.

Legal Implications, Access to Information and Call In

4.7 Under Regulation 30 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013, two or more local authorities may appoint a joint overview and scrutiny committee of those authorities and arrange for relevant functions to be exercisable by the joint committee, subject to such terms and conditions as the authorities may consider appropriate. As the proposed terms of reference below for the JHOSC include discharging the authorities' functions under Regulation 23, this means that the authorities cannot report to the Secretary of State themselves if they are dissatisfied with the consultation on the new review of CHD services or if they consider the proposals are not in the interests of the health service in their areas.

4.8 Where a health body is required to consult with more than one authority in relation to a proposal for a substantial development of the health service or for a substantial variation in the provision of such a service, those authorities must appoint a joint overview and scrutiny committee for those purposes, and the powers to make comments on proposals consulted on, require information, and require witnesses can only be exercised by that joint committee.

4.9 Subject to the matters mentioned in 4.7 and 4.8 above, the usual statutory rules relating to overview and scrutiny committees will apply to the JHOSC.

4.10 This report does not contain any exempt or confidential information and, as the matters contained in this report relate to Council functions, it is not subject to call-in.

Risk Management

4.11 The main risk relates to the timely contribution of the JHOSC's work are part of the new review of CHD services. This risk forms part of the day-to-day support for the work of the JHOSC and will be broadly mitigated through the development of a forward work programme.

5 Conclusions

5.1 The previous work of the JHOSC, insofar as it relates to the Safe and Sustainable Review of Children's Congenital Cardiac Services in England, is well known and has been well documented to date.

5.2 There is clear support from constituent authorities for the work of the JHOSC to continue and for the new review of CHD services to benefit from similar robust scrutiny arrangements as those established for the Safe and Sustainable review.

5.3 As the administering authority, Leeds City Council – through its Scrutiny Support Unit – is committed to continuing to provide day-to-day support for the JHOSC and constituent authorities have been invited to make a relatively small financial contribution for the financial year 2014/15.

5.4 At this relatively early stage in the new CHD review, it is appropriate to provide Council with an opportunity to reconfirm its support for the JHOSC and its refocused terms of reference.

6 Recommendations

6.1 General Purposes Committee is asked to:

6.1.1 Note the content and detail presented in this report.

6.1.2 Make the following recommendations to full Council:

(a) That Council reconfirms its support for the establishment of a Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to NHS England's new review of Congenital Heart Disease services.

(b) That Council delegates relevant functions, as set out in Appendix 1, that shall be exercisable by the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), subject to such terms and conditions therein.

(c) That Council asks the Scrutiny Board (Health and Wellbeing and Adult Social Care) to nominate a member from within its membership to sit on the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to the new review of Congenital Heart Disease services and, upon nomination, agrees to appoint such member to the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber).

7 Background documents[2]

7.1 None used

[2] 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.

SECTION 4 - JOINT ARRANGEMENTS

The **Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)** is a joint committee appointed under Regulation 30 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013/218 and is authorised to discharge the following health overview and scrutiny functions of the authority[3], insofar as they relate to NHS England's new review of Congenital Heart Disease services:

a) To review and scrutinise any matter relating to the planning, provision and operation of the health service in its area, pursuant to Regulation 21 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013

b) To make reports and recommendations on any matter it has reviewed or scrutinised, and request responses to the same pursuant to Regulation 22 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013.

c) To comment on, make recommendations about, or report to the Secretary of State in writing about proposals in respect of which a relevant NHS body or a relevant health service provider is required to consult, pursuant to Regulation 23 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013.

d) To require a relevant NHS body or relevant health service provider to provide such information about the planning, provision and operation of the health service in its area as may be reasonably required in order to discharge its relevant functions, pursuant to Regulation 26 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013.

e) To require any member or employee of a relevant NHS body or relevant health service provider to attend meetings to answer such questions as appear to be necessary for discharging its relevant functions, pursuant to Regulation 27 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013.

Member Authorities:

- Barnsley MBC
- Calderdale Council
- City of Bradford MDC
- City of York Council
- Doncaster MBC
- East Riding of Yorkshire Council
  Hull City Council
- Kirklees Council
- Leeds City Council
- North East Lincolnshire Council
- North Lincolnshire Council
- North Yorkshire County Council
- Rotherham MBC
- Sheffield City Council
  Wakefield Council

Reference to more specific details:
http://democracy.leeds.gov.uk/ieListMeetings.aspx?CId=793&Year=0

[3] In accordance with regulations issued under Section 244 National Health Service Act 2006 (the regulations)