

## HEALTH SELECT COMMISSION

**Venue: Town Hall, Moorgate  
Street, Rotherham S60  
2TH**

**Date: Thursday, 12th July, 2012**

**Time: 9.30 a.m.**

### A G E N D A

1. To determine whether the following items should be considered under the categories suggested in accordance with Part 1 of Schedule 12A (as amended March 2006) to the Local Government Act 1972
2. To determine any item the Chairman is of the opinion should be considered later in the agenda as a matter of urgency
3. Apologies for Absence
4. Declarations of Interest
5. Questions from members of the public and the press
6. Communications
7. Minutes of previous meeting (Pages 1 - 6)
8. Health and Wellbeing Board (Pages 7 - 11)  
- minutes of meeting held on 6<sup>th</sup> June, 2012
9. Health and Wellbeing Strategy. (Pages 12 - 26)
10. Autistic Spectrum Disorder. (Pages 27 - 31)
11. Adult Congenital Heart Disease Services Review. (Pages 32 - 53)
12. Date and Time of Future Meetings:-  
-Thursdays at 9.30 a.m.  
13<sup>th</sup> September, 2012  
25<sup>th</sup> October  
6<sup>th</sup> December  
24<sup>th</sup> January, 2013  
7<sup>th</sup> March  
18<sup>th</sup> April

**HEALTH SELECT COMMISSION**  
**Thursday, 31st May, 2012**

Present:- Councillor Steele (in the Chair); Councillors Barron, Beaumont, Burton, Dalton, Goult, Hoddinott, Kaye, Roche and Wootton.

Councillor Wyatt was in attendance at the invitation of the Chair.

Apologies for absence were received from Councillor Middleton, Richardson, Scholey, Victoria and Wells.

**1. DECLARATIONS OF INTEREST**

There were no declarations of interest made at the meeting.

**2. QUESTIONS FROM MEMBERS OF THE PUBLIC AND THE PRESS**

There were no members of the public or the press present at the meeting.

**3. COMMUNICATIONS**

The Chairman reported that a sponsorship form was being passed around for anyone wishing to sponsor representatives of Speak Up for a 26 mile walk.

It was also reported that an e-mail had been sent to Members with regard to the NICE Public Health Draft Guidance on Obesity. The Chairman and Vice-Chair had met and discussed putting forward positive comments.

Resolved:- (1) That the Chairman and Vice-Chair submit a positive response on behalf of the Select Commission.

(2) That a copy of the response be circulated to Select Commission Members.

**4. MINUTES OF PREVIOUS MEETING**

The minutes of the previous meeting held on 19<sup>th</sup> April, 2012, were noted.

**5. HEALTH AND WELLBEING BOARD**

Councillor Wyatt, Cabinet Member for Health and Wellbeing, gave the following update:-

- The next Board meeting was on 6<sup>th</sup> June, the main item of business being the draft Health and Wellbeing Strategy. It would then be considered by Cabinet in June and be in place for the Clinical Commissioning Group (CCG) authorisation
- The CCG was undertaking examination of a number of documents in advance of the authorisation. There would also be a recruitment exercise for a Chief Officer for the CCG and other HR issues with regard to existing NHS staff

- HealthWatch was an extremely complicated issue. It was Rotherham's plan to have HealthWatch operating by October, 2012
- John Wilderspin, Department of Health, Health and Wellbeing Boards Implementation, had written stating he wished to visit Rotherham to look for examples of good practice. He wanted to attend a Board meeting to meet Board members, discuss the relationship between Select Commission, CCG and the wider health community

Discussion ensued with the following comments made/highlighted:-

- The Council's Audit Committee had considered the differing Risk Assessment arrangements between the NHS and Council. The Committee had recommended that there be named officers who were responsible for Risk Assessment and work to draw the 2 closer together
- There was a well established NHS Audit Committee
- Audit and governance, certainly in respect of CCG Audit Group, was 1 of the major documents which had to pass the test in order to achieve authorisation as well as having to demonstrate the strong working relationships between all the agencies in particular the Local Authority and Health
- The Local Authority Audit Committee Chair also chaired the Joint Audit Committee Group

Councillor Wyatt was thanked for his update.

## **6. WORK PROGRAMME 2012-13**

The Chair presented the proposed work programme for 2012/13. In pulling together the programme, there needed to be a retrospective look at what had been achieved in 2011/12 with any outstanding issues carried forward. The main focus included development area projects with the Centre for Public Scrutiny and a review of Continuing Healthcare.

Discussions had already taken place with the Cabinet, Strategic Leadership Team and Select Commission Chairs to identify some strategic priorities for the work programme that would involve joint working across both the Executive and Select Commissions which included:-

- Fuel Poverty
- 11 most Deprived Areas
- Troubled Families
- Welfare Reform
- Role of local Members in their Communities
- Reducing Health Inequalities
- Special Educational Needs and announced Legislative Changes

At its meeting on 25<sup>th</sup> May, 2012, the Overview and Management Board had requested that a joint review of the Health and Improving Lives Select Commissions take place on Autistic Spectrum Disorder.

3A

The review into Continuing Health Care was continuing and hoped to be completed by the end of July.

The Chair asked for suggestions from Members bearing in mind the restricted staffing resources that were now available:-

- Waiting times – operations, A&E – monitor trends
- Access to Health Services
- Sexual Health Services
- Commissioning
- Discharge Policy

Resolved:- That the Chairman and Vice-Chair report the above to the Overview and Management Board.

## 7. TOBACCO PLAIN PACKAGING CONSULTATION

Alison Iliff, Public Health Specialist, presented the consultation by the Department of Health on Standardised Packaging of Tobacco Products that would close on 10<sup>th</sup> July, 2012.

The purpose of the consultation was to seek the views of interested people, businesses and organisations on a policy initiative that would require the packaging of tobacco products to be standardised, the aim being to improve public health by reducing the use of tobacco. Any actions to take further policy action on tobacco packaging would be taken only after full consideration was given to consultation responses, evidence and other relevant information. Legislation would be required if it was decided to pursue a policy.

The following points were highlighted:-

- Standardised packaging was currently not in place anywhere in the world; Australia had passed Legislation and would come into effect as from 1<sup>st</sup> December, 2012
- The Government wanted to consult on whether the public felt it was a good idea, whether they felt it would reduce smoking/the uptake of smoking in young people and prevent relapses from those who had quit
- The Tobacco Control Alliance had responded to the consultation based on the template response produced by ASH (Action on Smoking and Health). However, the Alliance had felt it needed to question and comment on the evidence review that accompanied the consultation
- Although the Alliance supported the standardised approach, it felt manufacturers would find other ways to promote their product. It was suggested that Legislation should be considered to prevent the tobacco industry undermining the plain packaging
- A number of research studies had been undertaken giving standardised packets of cigarettes to smokers of all age groups with the results showing it would reduce the use of tobacco products. However, standardised packaging was not in place anywhere in the world and the

studies had not been able to replicate the fact that if everyone had a standardised package would it matter? Would it actually stop people smoking if there was no difference between all the packaging? The Alliance felt this had not been addressed or recognised and was a weakness

- Standardised packaging would take away the misunderstanding regarding the differing strengths of different cigarettes
- Plain packaging would not distract from the health warning but it should be larger type?
- The Alliance did not have anyone with the expertise in trade and competition law so had only responded based on what it had read
- The Alliance did not believe there would be any detrimental effect in the short term to packaging manufacturers as it would still need to be produced and manufactured. Longer term, if the Policy was introduced and succeeded in the way it was intended, then smoking would reduce and there would be an impact
- All cigarette packets contained an invisible embedded marking that Trading Standards and HRMC could detect with hand held devices. The marking would still be in place in plain packaging and, therefore, identification of counterfeit products should not be any less easy or more difficult than at present
- Cigarettes purchased abroad and then sold them on and duty tax avoided would be much easier to identify until Europe adopted the standardised packaging

Consideration was given to the consultation questions and the Tobacco Control Alliance's response as follows:-

**Question 1 Which option do you favour?**

Require standardised packaging of tobacco products together with an additional publicity campaign

**Question 2 If standardised tobacco packaging were to be introduced would you agree with the approach set out in paragraphs 4.6 and 4.7 of the consultation?**

Yes - as per Alliance response.

**Question 3 Do you believe that standardised tobacco packaging would contribute to improving public health over and above existing tobacco control measures?**

Yes - as per Alliance response.

**Question 4 Do you believe that standardised packaging of tobacco products has the potential to:-**

**4a Reduce the appeal of tobacco products to consumers?**

Yes. As per Alliance response plus Legislation to prevent advertising on clothes etc. or the effect of standardised packaging would be negated.

**Question 4b Increase the effectiveness of health warnings on the packaging of tobacco products?**

Yes - As per Alliance response.

**Question 4c Reduce the ability of tobacco packaging to mislead consumers about the harmful effects of smoking?**

Yes - as per Alliance response.

**Question 4d Affect the tobacco-related attitudes, beliefs, intentions and behaviours of children and young people?**

Yes - as per Alliance response.

**Question 5 Do you believe that requiring standardised tobacco packaging would have trade or competition implications?**

No - as per Alliance response plus wish to see trends reduce.

**Question 6 Do you believe that requiring standardised tobacco packaging would have legal implications?**

No - as per Alliance response.

**Question 7 Do you believe that requiring standardised tobacco packaging would have costs or benefits for manufacturers, including tobacco and packaging manufacturers?**

Yes - as per Alliance response.

**Question 8 Do you believe that requiring standardised tobacco packaging would have costs or benefits for retailers?**

Yes - as per Alliance response.

**Question 9 Do you believe that requiring standardised tobacco packaging would increase the supply of, or demand for, illicit tobacco or non-duty-paid tobacco in the United Kingdom?**

Yes. Harder to distinguish - a hologram to show it was an illegal product.

**Question 10 People travelling from abroad may bring tobacco bought in another country back into the United Kingdom for their own consumption, subject to United Kingdom customs regulations. This is known as 'cross-border shopping'. Do you believe that requiring standardised tobacco packaging would have an impact on cross-border shopping?**

No - as per Alliance response.

**Question 11 Do you believe that requiring standardised tobacco packaging would have any other unintended consequences?**

No - as per Alliance response.

**Question 12 Do you believe that requiring standardised tobacco packaging should apply to cigarettes only or to cigarettes and hand-rolling tobacco?**

Both cigarettes and hand-rolling tobacco.

**Question 13 Do you believe that requiring standardised packaging would contribute to reducing health inequalities and/or help us fulfil our duties under the Equality Act 2010?**

As per Alliance response.

**Question 14 Any comments**

**Question 15 Further comments on tobacco packaging that you wish to bring to our attention**

As per Alliance response

Resolved:- That a response be made on behalf of the Select Commission on the lines indicated above.

**8. REPRESENTATION ON WORKING GROUPS/PANELS**

Resolved:- That the Select Commission's representatives for the 2012/13 Municipal Year be as follows:-

Health, Welfare and Safety Panel  
Councillor Wootton  
Councillor Dalton (substitute)

Recycling Group  
Councillor Beaumont

**9. DATE AND TIME OF FUTURE MEETING:-**

Resolved:- That the next meeting be held on Thursday, 12<sup>th</sup> July, 2012 commencing at 9.30 a.m.

**HEALTH AND WELLBEING BOARD**  
**6th June, 2012**

Present:-

**Members**

Councillor Wyatt  
Tom Cray  
Councillor Doyle  
Chris Edwards  
Ian Jerrams  
Councillor Lakin

**in the Chair**

Strategic Director, Neighbourhoods and Adult Services  
Cabinet Member, Adult Social Care  
Chief Operating Officer, CCG/NHSR  
RDaSH  
Cabinet Member, Children, Young People and Families  
Services

Dr. David Polkinghorn  
Dr. John Radford  
Joyce Thacker  
Janet Wheatley

CCG  
Director of Public Health  
Strategic Director CYPS  
VAR

**Officers:-**

Tracy Holmes  
Shona McFarlane  
Jason Page  
Chrissy Wright  
Dawn Mitchell

Communications, RMBC  
Director of Health and Wellbeing, NAS  
CCG  
Strategic Commissioning Manager, Resources  
Democratic Services

Apologies for absence were received from Karl Battersby, Christine Boswell, Phil Foster, Matt Gladstone and Martin Kimber.

**S1. MINUTES OF PREVIOUS MEETING**

Agreed:- That the minutes be approved as a true record.

**S2. JOINT HEALTH AND WELLBEING STRATEGY**

The Board considered the circulated draft Joint Health and Wellbeing Strategy. An officer group had been established to support the Board's work programme particularly development of the Strategy and had supported the 2 stakeholder workshops.

At the first workshop, held on 26<sup>th</sup> March, Board members and partners had been presented with the headlines from the Joint Strategic Needs Assessment along with the outcomes from the local health inequalities consultation. 5 strategic themes had been agreed which would form the basis of the local Strategy:-

- Prevention and early intervention
- Expectations and aspirations
- Dependence to independence
- Healthy lifestyles
- Long term conditions
- Poverty



The officer group had then developed the themes into strategic outcomes which presented a desired state for what Rotherham should look like in 3 years.

The second workshop held on 11<sup>th</sup> April provided an opportunity for partners to agree the 'outcomes' and wording and used then to consider appropriate actions which would be required over the next 3 years to bring about step changes to reduce health inequalities in Rotherham.

If supported by the Board, the Strategy would then be considered by Cabinet for adoption as Council Policy and by the CCG to inform the authorisation process for the Rotherham Clinical Commissioning Group.

Discussion ensued as follows:-

- Consultation - Press release emphasising that it was a draft Strategy - included on partners' websites
- The document would satisfy requirements for the CCG authorisation process
- Voluntary and community sector would be very interested in the actions and how they could be involved

Agreed:- (1) That the draft Joint Health and Wellbeing Strategy be agreed and submitted to the Cabinet for recommendation to Council for adoption as Policy.

(2) That all partner agencies post the document on their respective websites.

(3) That the document be proof read by an appropriate organisation to ensure it was readable by all sectors of the community.

(4) That any comments on the document be forwarded to Kate Green.

(5) That consultation takes place including a consultation event, liaison to take place with LINKs

(6) That Tracy Holmes arrange for a press release to be issued.

### **S3. CLINICAL COMMISSIONING GROUP AUTHORISATION**

Chris Edwards, CCG/NHSR reported that there were 212 CCGs in England split into 4 "waves" between the end of July and September, 2012, for the authorisation process. The first wave contained 40 of which Rotherham was 1.

The CCG had submitted all its documentation in accordance with the deadline and had received 363 feedbacks. In September there would be a visit from the Commissioning Board followed by communication in October as to whether it had been authorised. If successful, the CCG would be operating formally from 1<sup>st</sup> April, 2013.

Rotherham was well ahead of other CCGs.

Chris thanked everyone who had been involved so far.

Agreed:- (1) That the report be noted.

(2) That the CCG constitution, once authorised, be submitted to the Board for information together with a list of the appropriate policies and procedures.

(3) That a presentation be made to a future Board meeting on the CCG.

**(JANET WHEATLEY DECLARED A PERSONAL INTEREST IN THE FOLLOWING 2 ITEMS)**

**S4. UPDATE ON HEALTHWATCH**

The Board received, for information, the latest LGiU Policy Briefing on HealthWatch issued 14<sup>th</sup> May, 2012.

It gave an overview of the Legislation and the practicalities of HealthWatch England and Local HealthWatch.

The Care Quality Commission had indicated that HealthWatch England would be set up in October, 2012, and, following representations from local authorities and LINKs, the start date for Local HealthWatch had been put back from April, 2012 to April, 2013.

The Act imposed a duty on upper tier and unitary local authorities to contract with a Local Health Watch organisation for the involvement of local people in the commissioning, provision and scrutiny of health and social services. These arrangements should include reporting arrangements to HealthWatch England. The Act also made provision for contractual arrangements between local authorities and Local HealthWatch which must be a social enterprise.

Local HealthWatch organisations must produce an annual report on their activities and finance and had regard to any guidance from the Secretary of State in preparing the reports.

Health and Wellbeing Boards were required to have a representative of Local HealthWatch amongst their members.

The Government currently allocated £27M each year to local authorities for LINKs through the Local Government Formula Grant. In 2012/13 an additional £3.2M would be made available to support start-up costs for Local HealthWatch. In 2013/14 the current £27M for LINKs would become funding for Local HealthWatch organisations each year. Additional funding would also be made available to local authorities from 2013/14 to support both the information function that Local HealthWatch would have and also for commissioning NHS Complaints Advocacy.

Agreed:- That the briefing be noted.

**S5. ROTHERHAM HEALTH WATCH**

Chrissy Wright submitted proposals for the preferred option for an organisational model for Rotherham's HealthWatch.

Local authorities were responsible for commissioning and procuring an efficient and effective Local HealthWatch organisation by 1<sup>st</sup> April, 2013. It was intended that a formal procurement approach be undertaken given the range of functions for HealthWatch.

Once the preferred provider had been appointed, the annual programme of work would be developed in partnership with Health Watch Rotherham (HWR) in line with the Health and Wellbeing Board priorities.

The options for the organisational model were:-

1. a contract with the 1 provider to deliver all HealthWatch functions – this could be a social enterprise
- 2 a contract with the 1 provider who may sub-contract to other organisations to deliver certain elements of HealthWatch – this could be a social enterprise
3. a contract with a consortium arrangement who had experience of providing specialist functions
4. a contract with a number of different providers with specialist knowledge but they were required to work in partnership to deliver the local HealthWatch brand
5. a contract with a specific provider. This could be LINKs (grant in aid could be provided) or a group of other people within the community

The benefits of working with 1 provider, as per either option 1 or 2, were improved partnership working, customers able to access 1 provider easily and ease of contract monitoring and management.

The report also set out a detailed timeline for the commissioning of HealthWatch Rotherham.

The Health and Social Care Act 2012 included the provision that the NHS Complaints Advocacy Service must be commissioned by the local authority, either as part of the specification or the local HealthWatch contract, or as a separate contract with another organisation. The proposals were currently being discussed with NHSR.

Discussion ensued on the report:-

- Disappointment expressed at the delay in the implementation date. It was hoped that once the contract had been awarded that Rotherham may be able to accelerate the start date
- Rotherham was ahead of others in the region in setting up HealthWatch
- The tendering process must meet EU procurement rules in terms of the timeline for evaluation and awarding of the contract
- Desire for it to be driven by raising the consumer and patient voice improving the experience of patients and service users
- Consultation was to take place with key stakeholders on the model and specification
- Specification would include voice and influence of children and young people
- Possible TUPE implications – to be built into the tendering process

Agreed:- (1) That the Board's preferred organisational model options be 1 and 2.

(2) That a further report be submitted once the consultation on the organisational model and specification had been completed.

(3) That the Board supports the inclusion of the NHS Complaints Advocacy Service and that a further report be submitted thereon.

(4) That the minimum and maximum level of funding available and activities set out in the action plan be noted.

(5) That the Board supports the commencement of Rotherham HealthWatch as soon as practicable.

#### **S6. COMMUNICATIONS**

The Chairman reported that John Wilderspin, Department of Health, Health and Wellbeing Boards Implementation, had written to him stating he wished to visit Rotherham to look for examples of good practice. He wanted to attend a Board meeting to meet Board members, discuss the relationship between Select Commission, CCG and the wider health community.

The Chairman had invited him to either the July or September meeting.

#### **S7. DATE OF FUTURE MEETINGS 2012/13**

Agreed:- That meetings of the Health and Wellbeing Board be held on Wednesdays commencing at 1.00 p.m. in the Rotherham Town Hall during 2012/13 as follows:-

11<sup>th</sup> July, 2012  
5<sup>th</sup> September  
24<sup>th</sup> October  
28<sup>th</sup> November  
16<sup>th</sup> January, 2013  
27<sup>th</sup> February  
10<sup>th</sup> April

1.	<b>Meeting:</b>	Health Select Commission
2.	<b>Date:</b>	12 July 2012
3.	<b>Title:</b>	Joint Health and Wellbeing Strategy
4.	<b>Directorate:</b>	Resources

## 5. Summary

Scrutiny members have been presented with a range of information over the previous 12 months, in relation to the proposals within the Health and Social Care Act and how these are being implemented in Rotherham. These changes include the establishment of the Health and Wellbeing Board, which has now been in shadow form locally since September 2011, and the development of a local Joint Health and Wellbeing Strategy. The purpose of the Health and Wellbeing Strategy is to be the high-level, strategic plan for the Health and Wellbeing Board, which all partners are expected to sign up to.

This report presents the Joint Health and Wellbeing Strategy for Rotherham. It describes the process which has taken place to develop the strategy and the thinking behind the strategic priorities and subsequent actions which form the basis of the document. Health Select Commission members are asked to consider these priorities and actions and comment on the overall theme of the strategy and consider whether this feels right for Rotherham, based on what is known from the Joint Strategic Needs Assessment, Health Inequalities consultation and other local intelligence.

## 6. Recommendations

**That Health Select Commission members:**

- **Note the strategy and the process by which it has been developed**
- **Note the priorities and actions set out in the strategy and consider whether:**
  1. **these are the right priorities for Rotherham to focus on?**
  2. **these are the right actions to deliver these priorities?**
  3. **the three year actions are in the right order of priority?**

## 7. Background

To achieve improved health and wellbeing outcomes for local communities, there needs to be increased joint working between the NHS and local authority, and high quality local leadership through the Health and Wellbeing Board (HWBB) is an essential foundation of this. HWBBs will be seen as a tool to improve joint working by bringing together key commissioners and increasing local democratic engagement alongside increased public and user engagement. Publishing a local Joint Strategic Needs Assessment (JSNA) and Joint Health and Wellbeing Strategy (JHWS) will be a duty of the HWBB from April 2013, when Boards take on their statutory responsibilities, although earlier development of this will ensure we are appropriately placed to tackle the huge health challenges that face Rotherham.

Joint Health and Wellbeing Strategies (JHWS) take the important step from assessing local needs and assets, which have been published in the Joint Strategic Needs Assessment (JSNA) to collectively addressing the underlying determinants of health and wellbeing.

Draft guidance for developing JHWS has been published and this describes a set of values that should underpin good health and wellbeing strategies:

- JSNAs and Strategies should form the basis for local decisions that drive service change such as investment and disinvestment according to people's local needs and engagement with the local community
- Strategies should set shared priorities based on evidence of greatest need and set out a clear rationale for the locally agreed priorities
- Strategies should inform commissioning decisions across local services for health and social care, but should also be used to influence the commissioning of local services beyond health and care to make a real impact upon the wider determinants of health
- Strategies should provide a unique opportunity to explore local issues that single organisations have not managed to tackle on their own
- Strategies should not try to solve everything, but take a strategic overview of how to address the key issues identified in the JSNA, including tackling the worst inequalities
- Strategies should concentrate on an achievable amount – prioritisation is difficult but important to maximise resources and focus on issues where greatest outcomes can be achieved
- Strategies should address issues through joint working across the local system

The strategy presented here is the Rotherham HWBBs response to the requirement to produce a joint strategy, which has been set out in the Health and Social Care Act.

## 8. Proposals and Details

The JHWS for Rotherham sets out the key priorities that the local HWBB will deliver over the next three years to improve the health and wellbeing of Rotherham people.

The strategy presents a shared commitment to reduce health inequalities locally. It will be used to guide all agencies in Rotherham in developing commissioning priorities and

plans and in tackling the major public health and wellbeing challenges present in our communities.

The strategy will sit within a set of documents which demonstrate the journey from gathering data, to understanding whether we are achieving our goals, these include:

- Joint Strategic Needs Assessment: our intelligence
- Health and Wellbeing Strategy: our vision and how we will achieve this
- Commissioning plans: funding and leadership
- Performance management framework: evaluating success.

The priorities and actions within the strategy have been developed through consultation with the public and key stakeholders across Rotherham. This has been done through a series of consultation events, stakeholder workshops and an officer task group.

### ***JSNA and Health Inequalities Consultation***

The Rotherham JSNA was refreshed throughout 2011/12 and provides a comprehensive set of data and intelligence for health and wellbeing issues and needs locally. Public consultation on the JSNA took place during this time which involved a series of events with key groups and organisations. The final revised document has been presented across the council, including a presentation at the Health Select Commission in and the final document has been presented to scrutiny members previously.

At the end of 2011 the local authority and NHS Rotherham undertook a joint consultation with the public, looking at health inequalities issues and how these affected local people. The findings of this consultation exercise were presented at a Rotherham Health Summit in December 2011 and been used to supplement the JSNA findings in deciding Health and Wellbeing priorities.

### ***Health and Wellbeing Officer Group***

Following agreement at the HWBB meeting in February, an officer group was established to support the work programme for the Board, in particular the development of the JHWS. This group was made up of officers from RMBC commissioning, policy and performance, colleagues from public health (NHS Rotherham) and the Clinical Commissioning Group (CCG), and chaired by the lead strategic director for health and wellbeing.

The officer group have supported and overseen two stakeholder workshops and have met regularly since March to develop the strategy.

### ***Stakeholder Workshop 1 – 26 March***

The purpose of the workshop was:

- For partners to agree the findings of the JSNA and its impact upon each organisation
- For partners to discuss and agree a 'shortlist' of strategic priorities over the next three years for consideration by the Health and Wellbeing Board
- For partners to agree a list of five strategic outcomes for the HWB to consider and agree

HWBB members and partners were presented with the headlines from the JSNA along with the outcomes from the local health inequalities consultation. Using this information, five strategic themes were agreed as an outcome of this first workshop which would form the basis of the local strategy, they were as follows:

1. Prevention and early intervention
2. Expectations and aspirations
3. Dependence to independence
4. Healthy Lifestyles
5. Long-term conditions
6. Poverty

Using these themes, the officer group developed them into 'strategic outcomes' which presented a desired state for what Rotherham should look like in three years.

### ***HWBB Workshop 2 – 11 April***

The second workshop provided an opportunity for partners to agree the 'outcomes' and wording used and use these to consider appropriate actions which would be required over the next three years to bring about step changes to reduce health inequalities in Rotherham.

The agreed 'outcomes' and final step changes are presented in the strategy attached as appendix A.

### **8.1 The Rotherham Strategy**

The strategy presents the high-level plan for the HWBB. The document provides a clear picture of what we intend to do in Rotherham, it includes:

- The problem – why we need a strategy
- What we want to achieve – our vision and strategic outcomes
- What we will do – tackle the big issues presented in the JSNA
- How we will do it – specific actions which will bring about step changes over three years and who will be responsible for doing this

A life stage framework has been agreed as the basis of the strategy, subsequent action and performance monitoring. The life stages include:

- Starting well (age 0-3)
- Developing well (age 4-24)
- Working and living well (age 25-54)
- Ageing well (age 65+)

The document demonstrates how these life stages map across the five agreed outcomes and this has been presented in a matrix showing the lead and supporting agency for each area.

### ***Commissioning Plans and Monitoring Success***

The strategy is a high-level plan for the HWBB with a number of strategic priorities and outcomes, it does not include all of the detail in relation to specific areas of work that need to happen in tackling the health and wellbeing challenges in Rotherham. This detail will be developed in the commissioning and action plans for services across the borough; including social care, public health and the NHS, as well as other local



services that impact on people's health and wellbeing. This strategy will inform local commissioning decisions and those developing commissioning plans will need to give the strategy due regard.

In order to understand whether we have been successful with this strategy, a performance management framework is being developed, which will map key indicators across the lifestage framework. This will be used to demonstrate whether we are achieving improvements for each of the big issues and the strategic outcomes of the strategy.

Future JSNAs and Index of Multiple Deprivation 2016 will also demonstrate whether the strategy has had an impact on reducing health inequalities and deprivation.

### **8.2 Next Steps**

The Health and Wellbeing Board and Cabinet have approved the draft strategy. The strategy will now be presented to the public and stakeholders for comment and feedback on whether the priorities and actions are right for Rotherham, based on the information in the JSNA and other intelligence already gathered.

This feedback and public involvement will be done through a series of events and engagement activity with the voluntary and community sector, stakeholders and the public. Feedback and comments from the Health Select Commission will form part of this activity.

The strategy will also be used to inform the authorisation process for the Rotherham Clinical Commissioning Group which is currently taking place.

## **9. Finance**

There are no direct financial implications in relation to the content of this report.

## **10. Risks and Uncertainties**

Having a jointly agreed strategy in place is essential to guide the work of the HWBB and ensure the key priorities are delivered on.

To effectively inform commissioning plans of all agencies there needs to be 'buy-in' from everyone involved and each agency needs to see where they fit into the bigger picture.

## **11. Policy and Performance Agenda Implications**

The details in this report directly relate to the development of a local health and wellbeing strategy, which will be a requirement of the HWBB to publish from April 2013, although earlier implementation will ensure we are appropriately placed to tackle health issues locally and the CCG can seek authorisation.

Health Overview and Scrutiny will have a role in ensuring the priorities and outcomes of the strategy are being delivered and that activity put in place to address these health and wellbeing challenges are achieving results.

## 12. Background Papers and Consultation

Rotherham JSNA 2011

[http://www.rotherham.gov.uk/info/10016/council\\_documents/2102/joint\\_strategic\\_needs\\_assessment\\_2011](http://www.rotherham.gov.uk/info/10016/council_documents/2102/joint_strategic_needs_assessment_2011)

Rotherham Draft Joint Health and Wellbeing Strategy 2012-15 (attached)

## 13. Contacts

### **Cllr Ken Wyatt**

Cabinet Member for Health and Wellbeing  
RMBC

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Rotherham Borough

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Joint Health and Wellbeing Strategy  
2012 – 2015



## Introduction

**The Rotherham Health and Wellbeing Strategy sets out the key priorities that the local Health and Wellbeing Board will deliver over the next three years to improve the health and wellbeing of Rotherham people.**

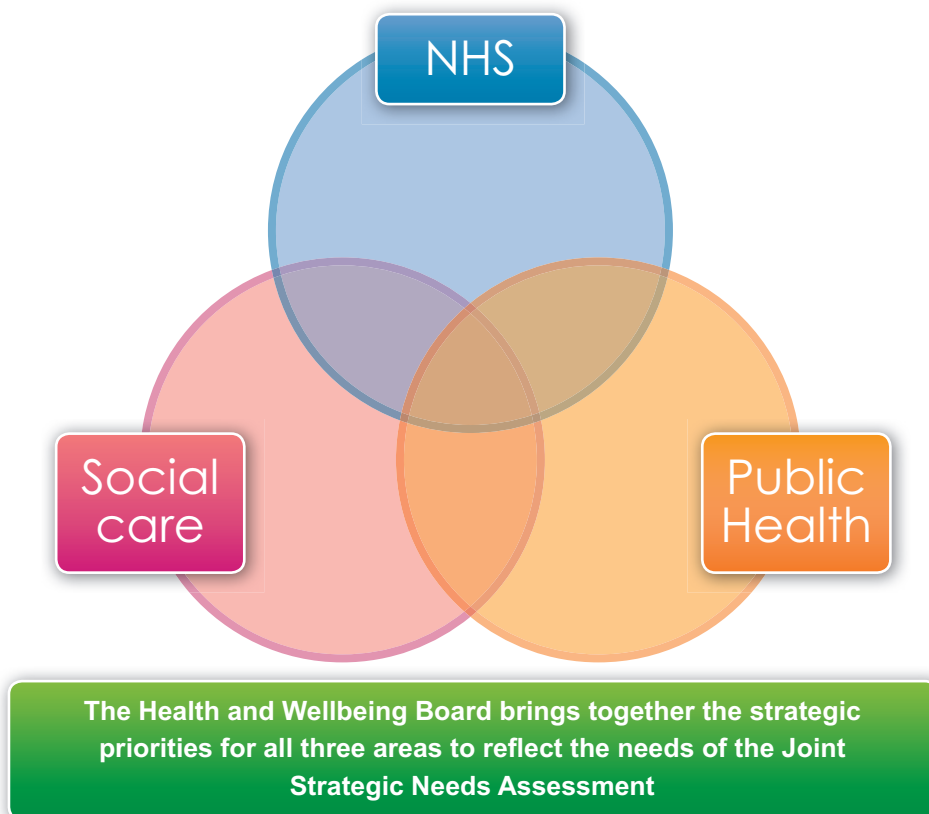
The document brings together the things that impact on people's health and wellbeing into a single, high-level framework. The strategy will be used to guide all agencies in Rotherham in developing commissioning priorities and plans in tackling the major public health and wellbeing challenges present in our communities. The document presents a shared commitment to ensure all Rotherham individuals and families are able to make positive choices to improve their physical, mental health and wellbeing, as well as helping to build strong communities. The strategy should also ensure that public services do everything we can to address the root causes of ill-health.

This strategy will sit within a set of documents which demonstrate the journey from gathering data, to understanding whether we are achieving our goals, these include:

- *Joint Strategic Needs Assessment: our intelligence*
- *Health and Wellbeing Strategy: our vision and how we will achieve this*
- *Commissioning plans: funding and leadership*
- *Performance management framework: evaluating success.*

### Integrating Health and Social Care

There are obvious benefits from bringing together planning, funding, and delivery of health and social care. This is demonstrated through the publication of three frameworks of outcomes for the NHS, public health and adult social care. The diagram below shows how these frameworks overlap and how the Health and Wellbeing Board, and their joint priorities presented in this strategy, sit within the centre of this.





# Why we need a strategy

## Health Inequalities

Deprivation in Rotherham is higher than average and increasing. According to the Index of Multiple Deprivation in 2007, Rotherham ranked 68th most deprived district in England.

In 2010 we had moved to 53rd. Rotherham still ranks amongst the top 20% most deprived districts nationally. The biggest causes of deprivation in Rotherham remain Education and Skills, Health and Disability and Employment. Life expectancy is lower the England average, but there is also a large gap between the least and most deprived areas in the borough; 9.9 years for men and 5.9 for women. Health inequalities in Rotherham are generally worse than the England average and our statistical neighbours.

(source: Health Profile 2011, DH)

The Marmot Review of Health Inequalities *'Fair Society, Healthy Lives'* provides evidence that there is a bigger impact on the health for those living in deprivation. The review suggests that there needs to be a focus across different backgrounds as well as across the life course, with appropriate levels of help given to people from different backgrounds to reduce inequalities. It also presents the positive impact of employment for the health and wellbeing of working age people, particularly for an individual's mental health and wellbeing.

## Life Course Framework

The Health and Wellbeing Board have agreed a life course framework, which has been adapted from the Marmot life course. The diagram below shows how the life course for this strategy links to the key points in people's lives:



## Our Joint Strategic Needs Assessment

The Joint Strategic Needs Assessment (JSNA) takes a comprehensive look at the health and social care needs of Rotherham. We refreshed and published our JSNA at the end of 2011, using factual information and evidence to identify needs.

Our JSNA has told us that the main determinants of health inequalities include deprivation and worklessness, attainment and skills, low birth-weight, infant mortality and mental health, as well as lifestyle factors such as poor diet, obesity, smoking and alcohol use, teenage pregnancy and low levels of physical activity. It also highlighted the ongoing concerns relating to the increased demands due to the ageing population and caring responsibilities, as well Rotherham's population is becoming more diverse and this poses challenges for service delivery.



## Health Inequalities Consultation

To ensure that we fully understand the needs and demands of our local population, we have undertaken a comprehensive consultation on health inequalities with local people. This identified five themes: increased cost of living, quality health services, having the skills for life, Rotherham communities' assets and the look and feel of Rotherham, with an overarching theme of the raising aspirations of Rotherham people and communities.

The most common issues raised included:

- *Families felt challenges in their daily lives led to difficulties in prioritisation and a lack of long-term planning.*
- *Many felt trapped in a cycle of poverty with little prospect of escape.*
- *People felt that young people had poor skills for life and work.*
- *A welfare culture of dependency had become the norm for some people, which was also reflected in rising concerns about welfare reform and expected reductions in benefit.*
- *Low aspirations and expectations were evident across all age groups.*
- *There was little common identity in Rotherham, mainly in the outer areas of the Borough.*
- *Black and Minority Ethnic people still faced discrimination and negative perceptions from services.*
- *Older people often felt isolated and unsafe but also offered untapped potential to help others*
- *People identified the skills they had to offer, but found the opportunity to use them difficult to find.*
- *People want clear, direct and simple messages on health to encourage people to make changes.*

## What we want to achieve

### Our Vision:

**To improve health and reduce health inequalities across the whole of Rotherham.**

### Our 'Strategic Outcomes'

The Health and Wellbeing Board have agreed six areas of priority and associated outcomes for the strategy, which represent a desired state for what we want Rotherham to look like in three years:

- PE Priority 1 - Prevention and early intervention**  
Outcome: Rotherham people will get help early to stay healthy and increase their independence.
- EA Priority 2 - Expectations and aspirations**  
Outcome: The expectations and aspirations of Rotherham people will be understood and matched by services that are delivered to borough-wide standards, tailored to an individual's personal circumstances.
- DI Priority 3 - Dependence to independence**  
Outcome: Rotherham people will increasingly identify their own needs and choose solutions that are best suited to their personal circumstances.



**HL Priority 4 - Healthy lifestyles**  
 Outcome: People in Rotherham will be aware of health risks and be able to take up opportunities to adopt healthy lifestyles.

**Lc Priority 5 - Long-term conditions**  
 Outcome: Rotherham people will be able to manage long-term conditions so that they are able to enjoy the best quality of life.

**PT Priority 6 - Poverty**  
 Outcome: Reduce poverty in disadvantaged areas through policies that enable people to fully participate in everyday social activities and the creation of more opportunities to gain skills and employment.

## What we will do - tackle the 'Big Issues'

The Health and Wellbeing Board will prioritise and tackle the 'big issues' highlighted by the JSNA and health inequalities consultation, these are:

<b>Starting Well</b>	<ul style="list-style-type: none"> <li>• <i>Low birthweight &amp; high infant mortality</i></li> <li>• <i>High smoking rates in pregnancy</i></li> <li>• <i>Low breastfeeding rates</i></li> <li>• <i>High teenage conceptions</i></li> <li>• <i>High obesity rates</i></li> </ul>
<b>Developing Well</b>	<ul style="list-style-type: none"> <li>• <i>Low attainment, skills and aspirations</i></li> <li>• <i>Low levels of physical activity</i></li> <li>• <i>High levels of lifestyle risks – alcohol, smoking, substance misuse, obesity</i></li> <li>• <i>High rates of teenage pregnancy</i></li> <li>• <i>High rates of emotional, behavioural or attention deficit disorders</i></li> <li>• <i>High emergency admissions</i></li> <li>• <i>Meeting the needs of increasingly diverse minority ethnic and migrant communities</i></li> </ul>
<b>Living and Working Well</b>	<ul style="list-style-type: none"> <li>• <i>High levels of lifestyle risks – smoking, alcohol, diet, obesity</i></li> <li>• <i>High levels of worklessness and benefit culture</i></li> <li>• <i>Low levels of physical activity</i></li> <li>• <i>Low qualification and skill levels</i></li> <li>• <i>High levels of depression and anxiety</i></li> <li>• <i>High deprivation and rising fuel poverty</i></li> <li>• <i>High rates of disability</i></li> <li>• <i>Increasing need for carer support</i></li> <li>• <i>Meeting the needs of increasingly diverse minority ethnic and migrant communities</i></li> </ul>
<b>Ageing Well</b>	<ul style="list-style-type: none"> <li>• <i>Increase in age related conditions such as; dementia, mobility &amp; hearing impairment, diabetes, falls</i></li> <li>• <i>High levels of depression</i></li> <li>• <i>Low levels of physical activity</i></li> <li>• <i>Rising number of older &amp; disabled people living alone &amp; feeling isolated</i></li> <li>• <i>Ageing carers and growing care gap</i></li> <li>• <i>High pensioner poverty and rising fuel poverty</i></li> <li>• <i>High demand for acute care</i></li> <li>• <i>High levels of lifestyle risks – smoking, alcohol, diet, obesity</i></li> </ul>



# How we will do it

To help us achieve an improvement in health and wellbeing we have agreed a set of actions that will bring about step changes to reduce health inequalities in Rotherham.

These are presented in order of priority for what we want to achieve over the next three years, noting that some of the actions will impact on others and therefore need to happen first.

## Year one

- 1 We will coordinate a planned shift of resources from high dependency services to early intervention and prevention.
- 2 We will provide much clearer information about the standards people should expect and demand.
- 3 We will change the culture of staff from simply 'doing' things for people to looking for ways of prolonging independence and promoting self care.
- 4 We will work together to understand our community assets; identifying what and where they are across the borough and how we use them effectively.
- 5 We will adopt a coordinated approach to managing people with long-term conditions.
- 6 We will make an overarching commitment to reducing health inequalities, particularly in areas suffering from a concentration of disadvantage.

## Strategic Outcome

- DI PE
- EA
- DI
- HL
- LC
- PT

## We will also ask the Rotherham Partnership:

To look at new ways of assisting those disengaged from the labour market to improve their skills and readiness for work.

To ensure that strategies to tackle poverty don't just focus on the most disadvantaged, but there is action across the borough to avoid poverty worsening.

To consider how we can actively work with every household in deprived areas to maximise benefit take-up of every person.

- DI PT
- PT
- PT





**Year two**

- 7 We will focus on motivating people to change behaviours and design our campaigns around prevention and early intervention.
- 8 We will train all people who work towards reducing health inequalities to respond to the circumstances of individual people and the local community.
- 9 We will seek out the community champions and support them with appropriate resources, to take action and organise activities.
- 10 We will identify a common approach to risk profiling for all services and organisations.
- 11 We will develop a common approach to data sharing so we can provide better support across agencies and put in place a long-term plan for the life of the individual.

**Strategic Outcome**



**Year three**

- 12 Services will be delivered in the right place at the right time by the right professional.
- 13 We will ensure all our workforce routinely prompt, help and signpost people to key services and programmes.
- 14 We will develop the concept of “reablement”, stepping up and stepping down, to a much wider range of professionals and services.
- 15 We will use the health and wellbeing strategy to influence local planning and transport services to help us promote healthy lifestyles.
- 16 We will ensure all agencies work together to make transitions between services for those with long term conditions seamless and smooth.



**Year three onwards**

- 17 We will develop a joint approach to maximise the use of assistive technology to benefit people.
- 18 We will co-produce with Rotherham people the way services are delivered to communities facing challenging conditions.
- 19 We will properly enable people to become independent and celebrate independence.
- 20 We will promote active leisure and ensure those who wish to are able to access affordable, accessible leisure centres and activities.
- 21 We will work jointly to review our eligibility criteria thresholds and ensure we are able to escalate and de-escalate people through services as their needs change.





### Linking the life stages with our strategic outcomes

Bringing about improvement in health and wellbeing is incredibly challenging and we see the need to drive actions forward. We have therefore identified a lead professional who will be accountable for each outcome and life stage. The table shows the lead agency, but also who will need to provide the main supporting and advising role for each area.

	Prevention & Early Intervention	Expectations & Aspirations	Dependence to Independence	Healthy Lifestyles Independence	Long-term Conditions	Poverty
<b>Starting Well</b>	Led by Public Health Supported by CCG, CYPS	Led by CYPS Supported by CCG Advised by PH	Led by CYPS Supported by CCG	Led by PH Supported by CCG & CYPS	Led by CYPS Supported by CCG Advised by PH	Advised by All
<b>Developing Well</b>	Led by CYPS Supported by CCG & PH	Led by CYPS Supported by CCG Advised by PH	Led by CYPS Supported by CCG	Led by PH Supported by CCG & CYPS	Led by CYPS Supported by CCG Advised by PH	Advised by All
<b>Living and Working Well</b>	Led by Public Health Supported by CCG & AS Advised by CYPS	Led by AS Supported by CCG Advised by PH	Led by AS Supported by CCG	Led by PH Supported by CCG & AS	Led by CCG Supported by AS Advised by PH	Advised by All
<b>Ageing Well</b>	Led by AS Supported by CCG & PH	Led by AS Supported by CCG Advised by PH	Lead by AS Supported by CCG	Led by PH Supported by CCG & AS	Led by AS Supported by CCG Advised by PH	Advised by All

AS = Adult Services      CYPH = Children and Young People Services  
 PH = Public Health      CCG = Clinical Commissioning Group

Having agreed leads and support will ensure a coordinated approach across all the life stages. This will help us to work towards breaking the 'cycle' of poor health. We see that we cannot simply shift our resources to 'Starting Well' to prevent poor health, but we need to address the determinants of health at each life stage to ensure young people do not become unhealthy adults and adults do not become unhealthy older people.

## What Next?

In order to meet the strategic objectives and outcomes we will require a picture of assets and services that we have available across Rotherham. Continuing to develop this will ensure it provides a clear and comprehensive picture of how services in Rotherham are delivered to meet need, based on the Joint Strategic Needs Assessment.

### Commissioning Plans

We will use this strategy to inform commissioning plans for all health and wellbeing partner agencies; including public health, NHS and social care. Commissioning plans will identify who will do the work to help us achieve our goals.

### Performance Management Framework

In order to understand whether we have been successful, we will develop a performance management framework using the life stage and strategic outcomes matrix. This will include key indicators from each of the national outcomes frameworks, along with any local measures, which will demonstrate whether we are achieving improvements for each of the big issues, and ultimately our strategic outcomes.



Future Joint Strategic Needs Assessments and the Index of Multiple Deprivation 2016 will also demonstrate whether this strategy has had an impact on deprivation and health inequalities, in line with the national average.

### **Reviewing the Strategy**

The strategy presented here is a three year plan and we will formally review it annually. Over the course of the three years we will continue to build up a much clearer picture of the needs of our population; through our Joint Strategic Needs Assessment, as well as how we commission services. We will also use local people and future developments such as Healthwatch, to help us understand our population needs and how services are actually delivered. This annual review process will help us recognise how well we are doing and show if we are off track and allow us to change direction as needed.

Rotherham people will remain at the centre of the strategy and a continued consultation plan will ensure that the strategy remains focused on listening to the views and improving the health of all Rotherham people.

**[www.rotherham.nhs.uk](http://www.rotherham.nhs.uk)**

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<b>ROTHERHAM BOROUGH COUNCIL – REPORT TO MEMBERS</b>
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<b>1.</b>	<b>Meeting:</b>	<b>Health Select Commission</b>
<b>2.</b>	<b>Date:</b>	<b>12<sup>th</sup> July 2012</b>
<b>3.</b>	<b>Title:</b>	<b>Autism Spectrum Conditions - Update</b>
<b>4.</b>	<b>Directorate:</b>	<b>Children and Young People's Services</b>

### **5. Summary**

This paper describes the recent work of the Autism Spectrum Conditions (ASC) Strategy Group in Rotherham's Children and Young People's Service. It reflects their commitment to:

- Recognise the complexity of the autism spectrum.
- Develop the services that work to help young people with ASC to support and remain close to their families and local community.
- Develop resource and provision to meet the needs of children and young people who experience ASC.
- Develop the understanding of 'Personalisation, Pupil Progress and Mainstreaming'.
- Engage with families and children with ASC to produce outcomes reflecting corporate agenda.
- Develop monitoring and quality control mechanisms to ensure value for money.

The purpose of the work is to raise the attainment of all Rotherham's children and young people.

### **6. Recommendations**

**That the Health Select Commission notes the activities undertaken to address issues raise and improve services.**

The following are the main recommendations:

1. That the report be received and its contents noted.
2. The further work take place on:
  - Closer alignment with Health in an attempt to achieve increased compatibility with CYPS/Health records.
  - Work to review and monitor the Identification, Assessment and Intervention Plans relating to Autism Spectrum Condition (ASC).
  - Revisit the eligibility criteria for the Children's Disability Team and Adult Services.

- Contribute to the ASC Scrutiny Review that is planned to recommence shortly.
- Increasing school/college staff knowledge of the Autism Spectrum Condition.
- Link the Children Services' Policy to the Adults with Autism Plan with regard to transition and Adult Services.
- Ensure Value for Money and the link to Dedicated Schools Grant expenditure.
- Roll out the Parent and Child Charter across the town's schools and services.
- Develop the targeted work around Demand Avoidance.

3. That a further report be submitted to the Cabinet.

## **7. Proposals and Details**

Rotherham Council has made a vast difference to the children and young people who experience ASC. There has been a thoughtful and planned response taking into account the competing needs on the community response. A number of officers over the years have carefully planned the strategic and operational response to support children and young people who experience Autism Spectrum Condition.

In the seven decades since autism was categorised the results of research and clinical work have led to the broadening range of the autistic spectrum from the profound austerity of severe autism, to the subtle communication difficulties found in aspects of Asperger's Syndrome.

Children and young people with Autistic Spectrum Condition have impairments in social interaction, verbal and non-verbal communication and imagination, this is often labelled 'the triad of impairment'. These traits are often accompanied by a narrow range of interests, activities and behaviour patterns which are often pursued rigidly sometimes to a point of obsession.

Often described as the invisible disability, autism is a complex lifelong developmental impairment; the range of autistic conditions is diverse and remains largely misunderstood. There has been some excellent work in Rotherham on the inclusion of children with ASC in their local mainstream school.

The Autism Strategy Group defines its work in four broad areas of activity:

- Services and Provision around ASC.
- Continued Professional Development.
- Diagnosis and Assessment Procedures.
- Involvement and Parents/Childs Voice and Influence.

The purpose of this work is to raise the attainment and improve life long experiences of children and young people with ASC. In order to do this effectively we must listen to the children and families and ensure their voice has influence on policy.

The Autism Strategy Group meets on a termly basis and receives information on previously commissioned work from each of the four major subgroups.

Recent work has highlighted a number of issues (June 2012):

- We have a number of children and young people with a diagnosis of ASC. At the moment approximately 1:60 in the 0-19 age range have a diagnosis and this is well above the regional and national range (1246 as at June 2012). This is a key area for further discussion.
- The families in Rotherham told us the following:
  - a. We need to do more to support families and children at home. This should include the development of an agreed entitlement for children and families following a diagnosis.
  - b. Our schools are not always well enough informed re ASC. We should pursue the Autism Friendly Schools Award, increase the practical and physical support to establish ASC friendly rooms and enable teaching staff in our schools. This would be an opportunity to use the expertise and resources in the SEN Special School Sector.
  - c. We need to develop trust and confidence at times of transition:
    - Entry to School/Early Years Settings
    - Foundation – Year 1
    - Year 6 – Year 7
    - Year 11 – Year 13
    - Year 14 - College
- Schools need additional support to develop teaching skills and learning objectives. 'Across the Board' practices in schools should be adapted regarding display, storage issues and the use of software to produce a range of communication symbols.
- All strategic developments relating to services for ASC children and families should be in greater partnership.
- The ASC Strategy Group has a clear remit and established terms of reference within the DfE response to the Green Paper.
- The policy of children's services and adult services relating to ASC should be closer aligned.

During the year the ASC Strategy Group have focused on the following activities to improve services that I would like to draw to your attention:

- Development of closer links with National Autistic Society – Local/National activity.
- Significant impact by Head Teacher of Milton to Kilnhurst & Swinton Resources.
- Discussions have taken place re a Joint Venture: Milton – Swinton – Dearne Valley College : re Post-16 provision.

- Identification of pressure point re Young Persons Learning Agency and Freeman College – requests for specialist placement.
- Discussions with The Robert Ogden School re Person Centred Reviews/Review processes.
- Commentary on the NICE guidelines re Autism.
- Multi agency launch of “Think Autism” and drop-in sessions for parents.
- Published the “Need to Know” Campaign – Autism/Mental Health.
- Autism Communication Team has been involved in the DSG Value for Money review.
- Members Scrutiny review re-launched.
- Adult Services have prepared a paper on Adults with Autism that has been discussed with Children’s Services.
- Continuation of the Chat & Chill Youth Club.
- Use of Aiming High to enhance short break facilities for Children and Young People who experience ASC.
- Greater understanding of ASC with children and young people who are looked after by the Local Authority.
- Project work around Pathological Demand Avoidance continues.

## **8. Finance**

There are at this stage no new financial demands being highlighted.

## **9. Risks and Uncertainties**

We must continue to improve our knowledge and understanding of ASC, listen to parents, carers and the young people themselves. It is vital to link the developments around ASC to Aiming High for Disabled Children, Transitions to Adulthood, Early Intervention and Positive Outcomes for Pupils. This will result in our children achieving their potential.

## **10. Policy and Performance Agenda Implications**

There is a need to support the children, young people and their families around the disability of Autism Spectrum Condition. As a community we have to ensure that we continue to develop our strategic thinking and appropriate use of resources to this local demand. We must ensure that the work undertaken has critical value and impacts on our community, to this end we must continue to place Autism as a priority of the work of both the Children and Young People’s Service and the delivery of an integrated CAMHS Strategy.

It is also important to ensure that the policy and practice of Children and Young People’s Service is aligned with that of the Adult Services.

## **11. Background Papers and Consultation**

This paper draws from the ASC papers taken to Members in April 2009, June 2010 and October 2011.

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**Telephone:** 01709 822579



<b>ROTHERHAM BOROUGH COUNCIL - REPORT TO MEMBERS</b>
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<b>1. Meeting:</b>	Health Select Commission
<b>2. Date:</b>	12 July 2012
<b>3. Title:</b>	NHS Adult Heart Disease Services Review
<b>4. Directorate:</b>	Resources

### **5. Summary**

The NHS has undertaken a national review of services for people with congenital heart disease. The paper attached outlines how the review has been undertaken and a proposed model for improving the way in which services are delivered.

Feedback is being sought by the NHS on this document and their proposed model. Health Select Commission members are asked to consider the potential changes which have been suggested and provide comments to be included in a formal scrutiny response by the deadline 27 July 2012.

### **6. Recommendations**

**That Health Select Commission members:**

- **Consider and comment on the proposals set out in the NHS document and agree a formal response to be submitted by 27 July**

## **7. Background**

More people are now living with adult congenital heart disease (ACHD) than ever before in England. In a report by the NHS it has been suggested that provision and quality of services varies dependent on where someone lives.

The NHS has therefore undertaken a review of these services nationally to address these issues and ensure everyone receives a high standard of care.

The report attached outlines how the review has been undertaken and sets out a proposed model for services for people ACHD.

The NHS are asking for feedback on these proposed changes from anyone with a particular interest, to ensure they are able to develop a service that meets the needs of the public and delivers the best care for everyone.

Members of the Health Select Commission are asked to consider this document and the proposals and bring any comments/feedback to the meeting to include in a formal response on behalf of the Commission.

## **8. Finance**

There are no direct financial implications associated with this report.

## **10. Risks and Uncertainties**

The NHS is seeking views from any interested party. This is an opportunity for the Health Select Commission to influence their decisions and ensure that what is eventually put in place is reflective of what the public need and want.

## **11. Background Papers and Consultation**

Improving everyday life for adults with congenital heart disease: a review into NHS services (report attached)

## **13. Contacts**

### **Kate Green**

Policy and Scrutiny Officer

RMBC, Resources

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**Improving everyday life for adults  
with congenital heart disease**

A review into NHS services - we want your views

# Foreword

There are now more adults living with congenital heart disease in England than ever before and the number is growing each year. Congenital heart disease can affect all areas of a person's life and those living with the condition need very specialist advice, support and care. In this country specialist care for adult congenital heart disease (ACHD) has not always developed in a planned and systematic way and excellent service provision is not always available everywhere. There are examples of very good practice in some areas but we need to make sure that this quality is available to all, regardless of where they live. We want to ensure that every patient with this condition receives a world class standard of care.

The NHS has been speaking to patients, their families, clinicians, NHS staff and commissioners. It is clear that there is a disparity in the way services are provided across the country. Some patients have said that they receive excellent care but many feel that things could be better. Some patients have said access to specialist ACHD care and clear advice about living with their condition has been lacking.

We want to change this. It is important that we enable all adults living with this lifelong condition to live their lives to the full, reassured by the fact they have the best possible care available to them.

With the full support of NHS commissioners (in charge of organising services), those involved in reviewing services have been working with a group of expert clinicians, professional organisations and ACHD patient representatives to assess the specialist services currently provided and explore how excellent care can be provided across England. We believe care should be organised within coherent networks covering the entire country and that those providing services should meet minimum standards to ensure the best quality care in the future.

The NHS wants to hear from all of you – patients, families, carers, clinicians and anyone else with a particular interest – to ensure we develop a service that meets your needs and delivers the best care for all.

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**Professor Sir Roger Boyle CBE**  
Chair, ACHD Advisory Group

Former National Director for  
Heart Disease and Stroke

## ABOUT THIS DOCUMENT

This document sets out the challenges faced by adults with congenital heart disease and areas for improvement identified so far in the review process. Pages 4 to 6 set out what patients have told us about what it is like to live with the condition every day.

We have been working closely with an expert group of clinicians, patients and commissioners (the ACHD Advisory Group) to identify areas for improvement and to develop a model of how ACHD services could be organised in the future. On pages 9 to 14 we summarise this proposed network model of care and the draft minimum standards (draft national designation standards) which we believe would help the NHS deliver excellent care in the future.

**We would like to know if you agree with the potential improvements we are suggesting. Please share your views by Friday 27<sup>th</sup> July. Pages 16 to 17 describe how you can get involved and have your say on the future of ACHD services.**

## WHAT IS ACHD?

Adult congenital heart disease affects people aged 16 and over living with a heart defect that developed in the womb and was present at birth. The condition is relatively rare, affecting 1 in 133 people. Congenital heart disease is sometimes diagnosed in the womb, but often it is not identified until after birth, or may even remain undetected until adulthood.

Thanks to medical advancements over the last few decades most people born with congenital heart disease now survive into adulthood, so there is a growing population of adults in this country living with the condition. Major heart operations are most commonly carried out during childhood. People with congenital heart disease will need ongoing care throughout their lives from services that specialise in the needs of adults.

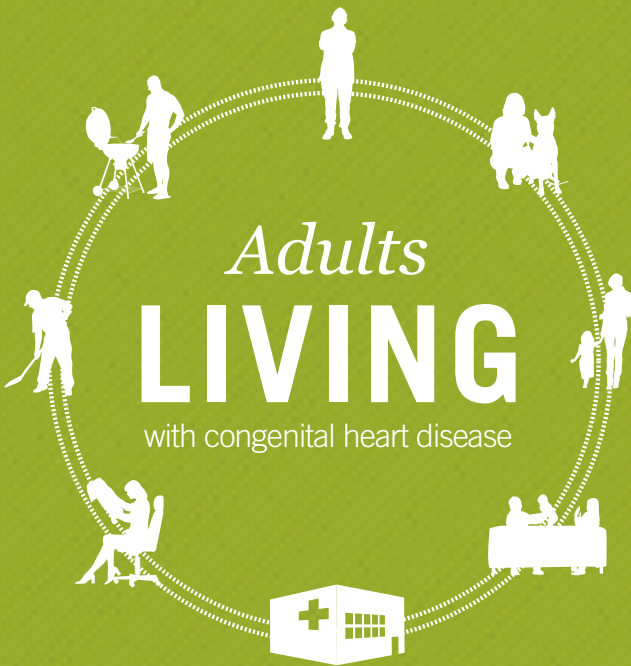
## THE REVIEW

This review into adult congenital heart services is separate to the *Safe and Sustainable* review of children's congenital heart services. Although there are obvious connections between both patient groups, the support needs of adults and children with congenital heart disease are different. For instance, whilst many children with congenital heart disease require surgical and interventional care, significantly fewer adult patients require surgery. All adults with congenital heart disease do however need ongoing expert care and support and as you will see in this document many patients have emphasised this.

While this review will take the outcome of *Safe and Sustainable* into account, ACHD services will be subject to an in-depth objective review process and consultation before any decisions are made on the future configuration of services.



# Life as an adult with congenital heart disease



## GROWING UP

People with ACHD have told us that the transition between children and adult services is often the hardest part about growing up and can span several years. Doctors have described how teenagers with congenital heart disease are often at more risk of emergency hospital admissions and deteriorations in their health, as well as psychological problems, in some cases leading to feelings of isolation.

Services should be age appropriate and take into account the different needs of patients across different age groups and cultures. Those with ACHD need accessible, clear and seamless transition arrangements in place so that they can move into adult life with reassurance that the care they receive will be responsive to their changing needs.



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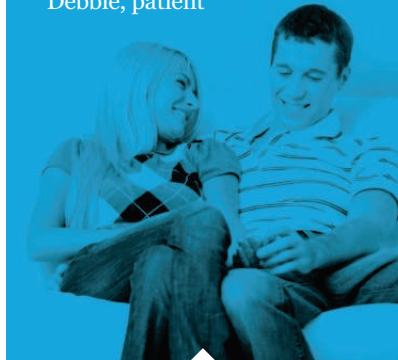
*Transition was one of the most difficult periods for me. You often feel so isolated and I didn't really have anyone when I was growing up to support me psychologically through the process.*

Susan, patient

”

*“It will be hard work physically and emotionally but like most women I want to have children as it’s a natural thing to want. We will just see if I am able to cope with it when the time is right.”*

Debbie, patient



Continued on Page 6



**EDUCATION, WORKING AND SOCIAL LIFE**

There are aspects of life many people take for granted, such as going to school, holding down a job and socialising with friends. People with ACHD often have very complex conditions that require regular follow-up care, which can have a significant impact on every aspect of their lives.

Those with ACHD in full time education may require regular time away from school, college or university, which can be very disruptive. Patients have told us that when coming out of education and entering working life the demands of regular employment can be very challenging. A readily available, comprehensive service which includes access to ACHD experts and occupational therapists would help adults with ACHD to address the additional challenges they face in their everyday life.



**SEX, RELATIONSHIPS AND BUILDING A FAMILY**

Living with ACHD means that when those with the condition have new sexual partners, they often need to consider the implications on their heart and overall health. For some women with ACHD conditions it is perfectly safe to have children and raise a family. However, for others, the risks of complications associated with getting pregnant and giving birth are significant. For those women, pregnancy requires careful assessment and monitoring as their heart condition, combined with the physical stresses of pregnancy, can present very real health risks.

Unplanned pregnancy can be extremely serious for some women with congenital heart disease and the contraceptive pill needs to be carefully prescribed.

The NHS should provide adults with congenital heart disease with advice and support tailored to individuals’ needs to guide them through the process and help them understand the potential complications.



**LOOKING AFTER YOUR BODY AND HEART**

Keeping active and maintaining a healthy diet is vital to the long term health of people with ACHD. Being over or underweight can put significant strain on the heart. For most individuals with ACHD regular, moderate exercise is encouraged but it is important that they receive expert advice on sensible activities that will not put too much strain on their heart.

Dental hygiene is very important, as conditions such as gum disease may result in bacterial infections which can damage heart valves and cause complications. People are also advised of the possible risks of infection posed by simply getting their ears pierced or getting a tattoo.

People with ACHD should have access to the right advice to enable them to make informed lifestyle choices.

*“I have always wanted to be a nurse and still now would like to be however I know this isn’t possible as I get far too tired and being on my feet running round in that type of job wouldn’t be suitable for me.”*

Debbie, patient



*“When growing up I experienced issues around Games sessions at school. I was told that I was not able to compete or participate in many of these sessions. It felt like there was a lack of knowledge around my condition”*

Janet, patient



*“There is a need for appropriate psychological and emotional support. The emotional impact of living with congenital heart disease generally begins pre-birth. Therefore a cradle to grave approach in providing emotional support should be given to individuals and family members.”*

Wendy, patient



### GROWING OLDER

As we age, secondary conditions can develop including acquired heart disease (such as coronary artery disease), diabetes, arthritis and dementia, and for those with ACHD this can present new and complex challenges.

With a growing ACHD population we need to ensure that specialist care is available to deal with these complications and the impact it will have on an individual’s heart. Services should be carefully designed to take account of the development of acquired heart disease and the increasing level of other medical conditions associated with ageing.

“

*As I have grown older I’ve had to visit hospital more often with other health complications. I want to be able to have full trust in the care that I receive and know that staff understand my condition.*

Susan, patient

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### EMOTIONAL WELLBEING AND COUNSELLING

Living with congenital heart disease can impact on a person’s wellbeing and happiness. Many people have told us that they often feel anxious and find it hard to come to terms with their condition and the limitations it places on their lives.

A patient’s experience doesn’t just constitute surgery and physical care. People have told us that proper mental and psychological support can have a very positive effect.

Specialist psychological support and counselling should be regularly available to those with ACHD who need help to come to terms with the condition and understand it better.





# Why improve things?

People with congenital heart disease need specialist care and the NHS has a duty to ensure that these needs are adequately met.

## TRANSITION FROM CHILDREN'S SERVICES

At present, many transition services are inadequate and people are often lost in the system during the process. This means people either don't ever see an adult congenital specialist or are left to make their own enquiries on follow up care.

## UNPLANNED AND INCONSISTENT PROVISION

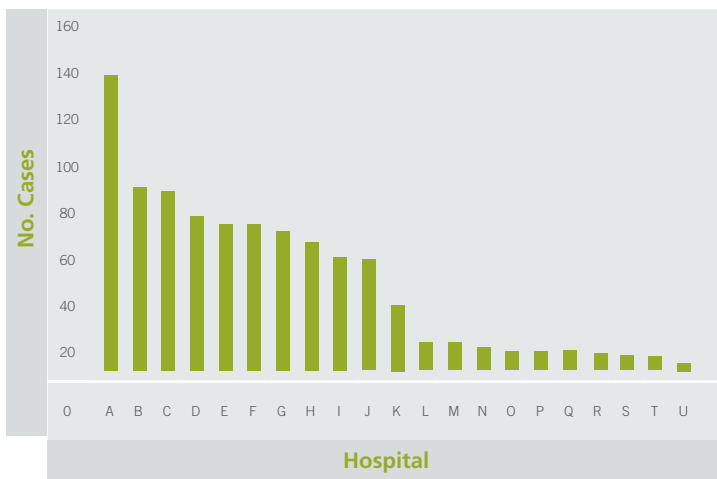
Specialist ACHD services have developed in an unplanned way in some parts of the country. People have told us that access to specialist ACHD care is not consistent and there are few areas where formal networks are in place. In some areas of the country people have access to certain ACHD services which are not always available in other areas. Services are not always joined up and people tell us that the lack of communication and clear referral pathways can be frustrating.

## LOW PROCEDURE NUMBERS

Some hospitals are carrying out just a handful of surgical procedures on adults with congenital heart disease. This is known as 'occasional practice' and means that some clinicians may not be carrying out enough procedures to develop their skills and

## 2010/11 ACHD Cardiac Surgery Activity By Hospital

(data from the Central Cardiac Audit Database, Feb 2012 – anonymised)



This graph shows the variation in the number of cases performed by 21 hospitals currently providing ACHD surgery

continually improve outcomes for patients. The graph shows the wide range in the number of procedures taking place across the country. (Please note that not all centres performing ACHD surgery submit data to the Central Cardiac Audit Database).

## MONITORING QUALITY

Experts agree that the care and ongoing support that patients receive need to be monitored more effectively through better data collection and reporting on patient outcomes. We are aware that currently a significant amount of information is not submitted to the national audit by some hospitals caring for people with ACHD.

## CAPACITY

There has been an increase in demand for specialist ACHD services which will continue to rise as the population living with this condition grows. We want to ensure services are being managed effectively and people with ACHD are seen within appropriate timescales. Clinicians need to have reasonable workloads to allow them to spend enough time with their patients so they always get the care they need.

## NETWORKED SERVICES

Current services have developed in an ad hoc way which means that some adults with ACHD do not have access to all the services they need. People with ACHD often require care from other parts of the NHS. Women with ACHD may need maternity care and as they age people with ACHD may develop secondary health conditions. The specialists caring for these patients need to work together to ensure care is appropriate to the patient's need. Integrated care pathways need to be established in all areas with links to other associated services and the highly specialised national services such as transplant surgery.

## DEVELOPING EXPERT SKILLS

Clinicians have told us that the training of staff for the growing ACHD population has not developed in a planned or systematic way. Surgical procedures and treatments for ACHD patients are very complex and specialist training is required. It has been suggested by some secondary care cardiologists themselves that the ACHD patients they currently care for would be better cared for within a specialist ACHD service.

# Ensuring excellent care for adults with ACHD

We should ensure that all patients get a service that is excellent. Ongoing care needs to be geographically convenient and part of a strong and dependable patient support network. By reshaping services we will improve access to care, develop strong networks of care and better meet the demands of a growing ACHD population.

## HOW SHOULD SERVICES BE ORGANISED?

The ACHD Advisory Group has developed a proposed model of organising care in the future and draft national designation standards that centres would need to comply with to ensure excellence in the future.

We believe services should be organised within a network of care, built around three levels of specialist ACHD expertise. The ACHD Specialist Centre would lead the network, working closely with ACHD Intermediate Centres and ACHD Local Centres to deliver excellent care at a local level.

Clear referral pathways between the different ACHD centres and defined relationships with children's heart services and non-cardiac services would allow patients to access the care they need seamlessly. Centres would carefully monitor patient outcomes and submit data to the national audit process.

## THE ACHD NETWORK

The three types of centres would form networks of ACHD care, with leadership provided by the Specialist Centre. There would be clearly defined policies and pathways established within each network and working links to other types of specialised care, such as obstetrics, transplantation services and palliative care.

### YOUR THOUGHTS

We are very keen to hear your views on the proposed model for organising care in the future.



**ACHD LOCAL CENTRES**

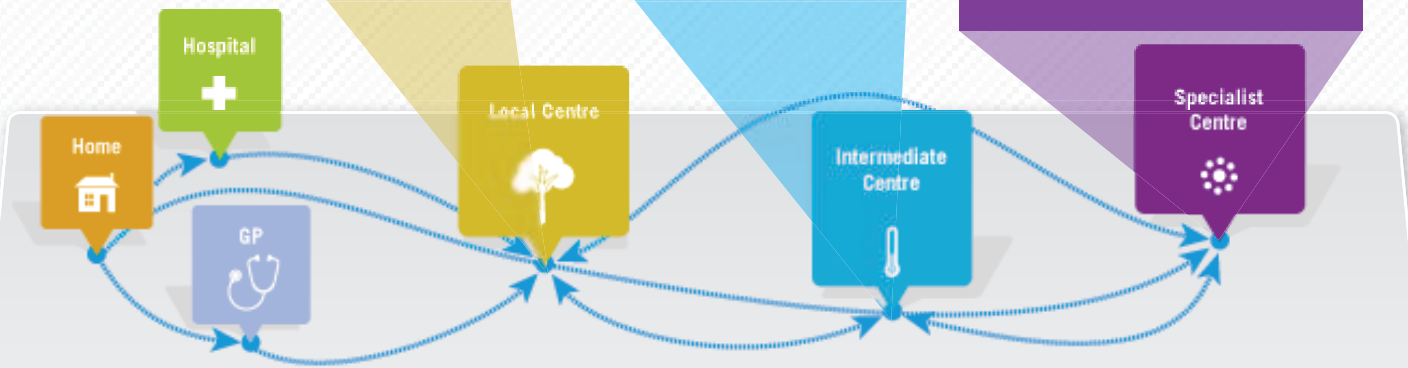
will be responsible for the ongoing provision of an ACHD patient's care including regular check-ups and monitoring.

**ACHD INTERMEDIATE CENTRES**

will be responsible for specific areas of heart health management that do not require surgical support. Specialist cardiologists, nurses and other clinicians will deliver ongoing care and a range of imaging and diagnostic procedures.

**ACHD SPECIALIST CENTRES**

will be responsible for leading the networks of care and undertaking all interventions including surgery and therapeutic catheterisation. All ACHD interventions will be carried out at these specialist centres by specialist ACHD surgeons and cardiologists. Concentrating interventional expertise into these specialist centres will improve patient outcomes and remove the risk of occasional practice at other hospitals.



**WHAT HAPPENS TO YOUNG PEOPLE DURING TRANSITION?**

The young adult's pathway between children's congenital heart services and ACHD services will be managed by specialist-led transfer clinics.

ACHD model of care	ACHD Local Centres	ACHD Intermediate Centres	ACHD Specialist Centres
Surgery			
Hybrid procedures (surgery and interventional catheterisation)			
Lead pathways to other highly specialised services			
Interventional cardiology			
Complex electrophysiology			
High risk pregnancy			
Cardiology (Specialist ACHD Cardiologist input)			
Simple electrophysiology			
Management of pregnancy			
Cardiologists with an interest in ACHD			
Ongoing care			
Assessment and diagnosis			

## WHAT SHOULD FUTURE SERVICES LOOK LIKE?

### BUILDING BETTER NETWORKS OF EXPERTISE

Specialist Centres would need to provide leadership to all the services within their network and ensure that patients receive world class ongoing care.

- Surgical expertise should be concentrated in a smaller number of specialist centres. Specialist centres should be responsible for supporting local hospitals in providing ongoing care for patients.
- Patients should be able to receive expert ongoing care from clinicians at a local hospital in the area in which they live. Cardiologists at local hospitals need the support of ACHD specialists.
- The network needs to be robust and sustainable to ensure that women with congenital heart disease receive specialist pre- and post-natal support.

*“The availability of specialist expertise for women with ACHD before, during and after pregnancy is essential to ensure these women make informed choices and have access to the very best multidisciplinary care. The Royal College of Obstetricians and Gynaecologists welcomes this review and supports the proposals to develop networks of specialist adult congenital cardiac care.”*

Professor Catherine Nelson-Piercy, Royal College of Obstetricians and Gynaecologists



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*Adults with congenital heart disease face many challenges - among them the need for informed integrated care with advice from specialist teams. Much more needs to be done to ensure that those who move from childhood to adulthood with heart disease receive the co-ordinated and specialist care that they require. The proposed regional congenital heart networks will ensure that hospital cardiologists know where to seek advice both from local ACHD centres as well as specialist centres.*

Professor Keith Fox, British Cardiovascular Society

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- As they age people with ACHD suffer the same burden of acquired diseases as the general population. Expert ACHD clinicians need to be readily available to advise non ACHD health professionals involved in the delivery of care. For example a patient with ACHD and acquired coronary heart disease may be managed by general cardiothoracic surgeons, or require joint working from both general and ACHD surgeons.
- Effective liaison between specialist ACHD centres and other specialist health services is needed e.g. pulmonary hypertension, genetics and transplantation services.

“

*Adults with congenital heart disease need holistic, multidisciplinary care. The Association of Cardiothoracic Anaesthetists supports this review, particularly the proposal to develop networks of specialist care which will ensure all patients have access to specialist ACHD anaesthetists for surgical procedures.*

Dr Ravi Gill, Association of Cardiothoracic Anaesthetists

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### GREATER ACCESS TO SPECIALIST CARE

People with ACHD need access to specialist care. All patients, including those with less complex needs, should have the opportunity to be seen at least once by a specialist.

- To ensure that care is provided to people with ACHD in the most effective way there is a need for all specialist centres to have formally constructed multidisciplinary teams of cardiologists, cardiac surgeons, interventional radiologists, anaesthetists and intensivists.

### CONCENTRATING SURGICAL EXPERTISE IN SPECIALIST CENTRES

All adults with congenital heart disease should be able to access excellent, world class standards of surgical care that is consistent across the country.

- There is strong advice from clinicians that operations and interventions should only be performed by congenital heart specialists who are part of a recognised team, have appropriate training and experience, and carry out a minimum number of procedures per year including complex surgery. It is important for clinicians to carry out enough procedures each year to be able to maintain and develop specialised skills.



Continued on Page 12

## APPROPRIATE CARE CLOSER TO HOME

It is important that patients are able to access excellent ongoing care as close to home as possible.

- Patients should be able to access ongoing care at their local hospital where trained staff are able to provide expert care for their condition, without the need for regular journeys to a specialist centre.
- Patients need to have a robust care plan in place. GPs should have access to all relevant information about a patient's condition to ensure they receive the most appropriate care.
- In the case of a non-cardiac medical or surgical emergency, arrangements should be in place for the specialist congenital cardiology team to advise the clinician in the local hospital who is responsible for the patient's care.
- Families need to have better access to accommodation near specialist centres. Adults with ACHD who also have learning difficulties may be more dependent on their family and carers so adequate accommodation should be available.

## IMPROVING REFERRAL PROCESSES AND PATIENT PATHWAYS

Clear pathways for patient care, including investigation, treatment and follow up should be standardised throughout the country. Patients need a more co-ordinated service that recognises that congenital heart disease is a lifelong condition which affects people's quality of life.

- Stronger networks with clear protocols will ensure that patients are referred appropriately and in a timely manner. Patients should be supported throughout by their ACHD Specialist Nurse.
- Local hospitals are not equipped to deal with the more complex needs of an individual with ACHD and should refer patients to specialist centres for specialist advice and treatment.

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*The British Heart Foundation fully supports the aims of this review. All adults living with congenital heart disease should have access to highly specialised care. Services for adults with this lifelong condition need to improve and care should be consistent across the country irrespective of where a person lives.*

Dr Mike Knapton, British Heart Foundation



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## IMPROVING THE TRANSITION FROM CHILDREN TO ADULT SERVICES

Improving the transition from children to adult services is critical to providing high quality care.

- Relationships between GPs, local hospitals and specialist centres should be better organised to ensure that transition is smooth and efficient.
- It is proposed that specialist transition clinics are put in place to ensure that transition is effectively co-ordinated and uninterrupted and that patients are referred on to the appropriate specialist services.

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*As more and more children born with heart conditions reach their teenage years and adulthood, preparing them for these critical parts of their lives is vital. Part of that preparation is ensuring that they are at the centre of their care moving forward. These standards, and the model of care, are a vital step forward in ensuring that this happens.*

Paul Willgoss, Children's Heart Federation and ACHD patient



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*This review and the proposal to develop strong networks of specialist ACHD care is welcomed by the BACCNA. Clearly defined roles and pathways should enable specialist ACHD nurse practitioners to provide more effective care throughout the network.*

Sheena Vernon, British Association of Congenital Cardiac Nursing for Adults



## INFORMATION AND COMMUNICATION

A successful network of care requires good communication between GPs, ACHD centres, local hospitals and the wider patient support network.

- The growing ACHD population has resulted in some ACHD Nurse Specialists being overworked and sometimes unable to respond to and care for the needs of patients. People with ACHD should have access to a named nurse in order to ensure that patients receive better communication, co-ordination and advice.
- There should be better support and access to information for partners, families and carers, and improved guidance about where they can access specialist advice.
- Information from specialists should be delivered to patients or GPs in a timely manner without delays.
- Centres need to be more proactive in publicising the wealth of information and support available from patient groups, such as the GUCH Patients Association, the British Heart Foundation and the Children's Heart Federation.
- Around 47% of people with Down's Syndrome are born with congenital heart defects. It is vital that people with ACHD with learning difficulties receive information and are communicated with in a way that they will understand. There is also a need for these patients to have access to appropriate emotional support to help them understand their condition better.

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*Patients with ACHD have complex needs and require specialist, co-ordinated care throughout their lives. To deliver the best quality care nurses and other clinicians need to work within strong networks of specialist and supporting services, with access to appropriate training and information. The Royal College of Nursing fully backs this review and the proposals to develop networks of specialist ACHD services throughout the country.*

Dr Peter Carter, Royal College of Nursing



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*“The standard of my overall care is good, but I have sometimes found the communication aspects of the overall process poor. Communication between local hospitals, specialist centres and GPs needs to improve.”*

Janet, patient



# The review process and next steps

## WHO IS CONDUCTING THE REVIEW?

The National Specialised Commissioning Team, part of NHS Specialised Services, is carrying out the review and has convened an ACHD Advisory Group to provide expert advice. The ACHD Advisory Group includes ACHD patient representatives, clinicians and representatives from professional associations. The ACHD Advisory Group has developed draft national designation standards which build on work carried out by a separate expert group in 2009.

The draft national designation standards can be found at: [www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease](http://www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease)

An independent group of experts will visit hospitals looking to provide ACHD services in the future as part of an assessment of their ability to meet the draft national designation standards. No decisions have been made and at this stage we are seeking your views to help inform the development of the draft national designation standards.

Next year a decision making group will publish options on how to improve services for people with ACHD and we will hold a formal period of public consultation to ensure everyone has the opportunity to contribute their views.

## TIMELINE FOR THE REVIEW

2011

July 2011 - April 2012

Working with professionals, patients and commissioners to develop a proposed model of care and draft national designation standards

May 2012 - July 2012

Engaging with patients and their families, NHS staff, clinicians and other groups on the draft national designation standards

Autumn 2012

Reviewing feedback from patients and clinicians and revising draft national designation standards

Winter 2012 - Spring 2013

ACHD centres will be visited by an independent group of experts and scored against their ability to meet the draft national designation standards

Development of different options for how ACHD services might be organised in the future

Summer - Autumn 2013

National public consultation on the options for how ACHD services might be organised in the future

End of 2013

A decision on the future of ACHD services to be made

2014

2014

Improvements to ACHD services to be implemented

## HOW CAN YOU HAVE YOUR SAY?

### WE WANT TO HEAR YOUR VIEWS ON:

- ❓ What do you think of our proposed model of organising care into networks of specialist centres, intermediate centres and local centres with links to non-cardiac care?
- ❓ Do you have any comments on the draft national designation standards?
- ❓ What other improvements can be made to the way the NHS organises care for people with ACHD?

### HAVE YOUR SAY ON THIS REVIEW:

- ✔ **To download** the draft national designation standards and to find out more about the review go to <http://www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease>

### YOU CAN SUBMIT YOUR VIEWS BY:

✉ **Letter:** Christy Rowley

NHS Specialised Commissioning Team  
2<sup>nd</sup> floor, Southside, 105 Victoria Street  
London SW1E 6QT

@ **Email:** [adultheart@nsscg.nhs.uk](mailto:adultheart@nsscg.nhs.uk)


**In person:** We are holding a number of regional workshops for patients and people working with adults with congenital heart disease. If you would like to attend please contact the communications team on 020 7025 7520 for more details.

Please provide your comments  
by **Friday 27<sup>th</sup> July 2012**



**CONTACT US:**

- Easy-read and large print versions of this document are available and other formats and languages can be provided on request.
- To request a copy or for further details on the engagement process please contact the NHS Specialised Services communications team on

 **Tel:** 020 7025 7520

 **Email:** [nhsspecialisedservices@grayling.com](mailto:nhsspecialisedservices@grayling.com)

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*As patients we spend our entire lives in close contact with the NHS and have a clear idea of how we would like services to be delivered. It is vital that people with congenital heart disease take this opportunity to help shape the future of their service.*

Michael Cumper,  
Grown Up Congenital Heart  
Patients' Association



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# Any questions?

Please find answers to common questions below.



## Q Why are you reviewing services for adults with congenital heart disease?

**A** This review is designed to deliver improvements in the quality of treatment and care for adults with congenital heart disease. A review of services for children with congenital heart disease was initiated in 2008. Evidence shows that the number of adults with congenital heart disease is increasing as those with the condition are living longer. It is clear that the service needs to be developed to evolve with this trend. It is also apparent from feedback that we have received from clinicians and patients that the current service needs to be improved as it is not currently well provided in some parts of the country. There are no predetermined outcomes; at this stage we are gathering views from you and other patients on how the current service can be improved for adults living with congenital heart disease.

## Q Does the review cover the whole of the UK?

**A** The review only covers ACHD services in England. Services are designated separately in Wales, Scotland and Northern Ireland. However patients in Wales, Scotland and Northern Ireland may use English specialist services (tertiary services). Representatives from Scotland and Wales sit on the Advisory Group as observers.

## Q Who is carrying out the review of ACHD services?

**A** The review is being carried out by the National Specialised Commissioning Team (NSCT), part of NHS Specialised Services, and is advised by the ACHD Advisory Group. The NSCT is responsible for commissioning over sixty highly specialised services, often for very small numbers of people.

## Q Who sits on the ACHD Advisory Group?

**A** The Group is chaired by Professor Sir Roger Boyle, former National Director of Heart Disease and Stroke. The Group is made up of clinical professionals with a variety of expertise relevant to the needs of people with ACHD, NHS commissioners and patient representatives. The Group is advisory, and it will not play any part in making decisions on the future shape of services. More information about the members of the Advisory Group can be found here: <http://www.specialisedservices.nhs.uk/info/adults-with-congenital-heart-disease>

## Q Will I get a chance to have my say on the future of adult congenital heart services?

**A** Yes. We are very keen to hear from as many people as possible on how the current service can be improved and also what currently works well. A series of engagement events will be taking place in May and July 2012 and will be open to patients and people working with adults with congenital heart disease. We aim to hold a national public consultation on the proposals for improving the service in 2013.

**Q Who will make the decision on the future of ACHD services?**

**A** We are currently gathering views and evidence so that we can best shape the improvements that need to be made. We will publicise information about the decision making process throughout the course of the review.

**Q When will any changes be implemented?**

**A** Any changes to adult congenital heart services are expected to be made in 2014.

**Q Will the proposed networks of ACHD care be aligned with the networks of care for children's heart services?**

**A** The review will consider how adult networks may align with the children's networks that will be agreed by *Safe and Sustainable*. Services for adult congenital cardiac care will be designed around the specific and unique needs of adults and there will be clearly defined working relationships between specialist ACHD and children's congenital cardiac services. A dedicated transition process will manage the pathway of young adults between the two services.

## Organisations involved in the review



BRITISH CONGENITAL CARDIAC ASSOCIATION



Royal College of  
Obstetricians and Gynaecologists  
Bringing to life the best in women's health care



British Cardiovascular Society



Royal College of Nursing®

