Notice of meeting of
Health Overview & Scrutiny Committee

To: Councillors Funnell (Chair), Wiseman (Vice-Chair), Boyce, Cuthbertson, Doughty, Fitzpatrick and Hodgson

Date: Wednesday, 14 December 2011

Time: 4.30 pm

Venue: The Guildhall, York

A G E N D A

1. Declarations of Interest (Pages 3 - 4)
At this point Members are asked to declare any personal or prejudicial interests they may have in the business on this agenda. A list of general personal interests previously declared are attached.

2. Minutes (Pages 5 - 14)
To approve and sign the minutes of the meeting held on 21 September 2011.

3. Public Participation
At this point in the meeting, members of the public who have registered their wish to speak regarding an item on the agenda or an issue within the Committee's remit can do so. The deadline for registering is **Tuesday 13 December 2011** at **5:00 pm**.

4. Update from Yorkshire Ambulance Service on Ambulance Complaints Service (Pages 15 - 16)
This report from the Ambulance Service's Service and Quality Improvement Manager informs the Committee on the number of complaints received into Yorkshire Ambulance Service (YAS) as a year to date position.

5. **2011/12 Second Quarter Financial & Performance Monitoring Report - Adult Social Services** (Pages 17 - 22)

This report analyses the latest performance for 2011/12 and forecasts the financial outturn position by reference to the service plan and budgets for all of the relevant services falling under the responsibility of the Director of Adults, Children and Education.

6. **Summary & Outcomes Report - Joint Health Overview & Scrutiny Committee's Response to the Consultation on Children's Congenital Cardiac Surgery** (Pages 23 - 198)

The purpose of this report is to summarise the background to the consultation, the main issues identified by the Joint Health Overview and Scrutiny Committee (HOSC) and the recommendations put forward to the Joint Committee of Primary Care Trusts (JCPCT).

NB: Annex B of the report will only be available online due to its size.

7. **Briefing for City of York Health Overview and Scrutiny Committee on proposals to create an urgent care centre** (Pages 199 - 234)

The purpose of this paper is to provide the Committee with information about the proposals to create an urgent care centre for the York area.

8. **Local Health Watch York: Progress Update** (Pages 235 - 242)

This report updates the Committee on the progression from LINks (Local Involvement Networks) to Local HealthWatch by October 2012.

9. Update on Carer's Review (Pages 243 - 372)

The Health Overview Scrutiny Committee (HOSC) completed a Carer's Review in 2010/11. The Committee recommended that the Cabinet Member for Health & Social Services should receive an annual report updating the Carers Strategy and that the same report should be submitted to the Health Overview & Scrutiny Committee. The report was submitted to the Cabinet Member 22 November 2011.This report's purpose is to update the Committee.

10. The Local Account for Adult Social Care 2011 (Pages 373 - 454)

This report introduces the Local Account for Adult Social Care 2011.

11. Update Report-End of Life Care Review (Pages 455 - 462)

This report updates the Committee on progress made in relation to their review on End of Life Care. It details outcomes of an informal meeting held on 13th October 2011 where the aim was to begin to scope and timetable the review. It also sets out further developments since that date.

12. Work Plan 2011-12 (Pages 463 - 464)

Members are asked to review the Committee's Work Plan for 2011-12.

13. Urgent Business

Any other business which the Chair considers urgent under the Local Government Act 1972

Democracy Officer

Name- Judith Betts
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For more information about any of the following please contact the Democracy Officer responsible for servicing this meeting

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Agenda Annex

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Scrutiny Committees

The purpose of all scrutiny and ad-hoc scrutiny committees appointed by the Council is to:

- Monitor the performance and effectiveness of services;
- Review existing policies and assist in the development of new ones, as necessary; and
- Monitor best value continuous service improvement plans

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Agenda Item 1

HEALTH OVERVIEW AND SCRUTINY COMMITTEE

Agenda item I: Declarations of interest.

Please state any amendments you have to your declarations of interest:

Councillor Boyce	Mother in receipt of Care Services
Councillor Doughty	Volunteers for York and District Mind and partner also works for this charity.
Councillor Funnell	Member of the General Pharmaceutical Council Member of York LINks Pharmacy Group Trustee of York CVS
Councillor Hodgson	Previously worked at York Hospital
Councillor Wiseman	Public Member of York Hospitals NHS Foundation Trust Member of the Adoption Panel and Consultation Meetings with looked after children “Show Me That I Matter”

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City of York Council	Committee Minutes
MEETING	HEALTH OVERVIEW & SCRUTINY COMMITTEE
DATE	21 SEPTEMBER 2011
PRESENT	COUNCILLORS FUNNELL (CHAIR), WISEMAN (VICE-CHAIR), BOYCE, CUTHBERTSON, DOUGHTY, FITZPATRICK AND HODGSON
IN ATTENDANCE	VINCE LARVIN – YORKSHIRE AMBULANCE SERVICE (YAS) HELEN HUGILL – YAS MARK INMAN – YAS EILEEN WOOD – YAS MICHELE MORAN – LEEDS PARTNERSHIP NHS FOUNDATION TRUST ALAN ROSE – YORK TEACHING HOSPITAL NHS FOUNDATION TRUST JOHN YATES – OLDER PEOPLE'S ASSEMBLY PAUL MURPHY – CYC ADAM GRAY – CYC RICHARD HARTLE – CYC KATHY CLARK - CYC

13. DECLARATIONS OF INTEREST

Members were invited to declare at this point in the meeting any personal or prejudicial interests they might have in the business on the agenda. Members requested the following amendments and additions to the standing interests already declared:

Councillor Funnell – addition of member of York LINks Pharmacy Working Group.

Councillor Boyce – remove references to employed by the Alzheimer's Society, York and trustee of York Carers' Centre as she was no longer involved with either body.

14. MINUTES

RESOLVED: That the minutes of meetings of the Health Scrutiny Committee held on 20 June and 6

July 2011 be approved and signed by the Chair as correct records.

15. PUBLIC PARTICIPATION

It was reported that there had been one registration to speak at the meeting under the Council's Public Participation Scheme.

A representative of the Older People's Assembly (OPA) made representations in relation to two agenda items, item 5 – Terms of Reference for the Health and Wellbeing Board and item 6 – HealthWatch Procurement Monitoring Report. In relation to the first item he pointed out that the functioning of the Health and Wellbeing Board would rely on the breadth and expertise of its sub-committees', their professional knowledge and their ability to maintain a strong public and patient focus. He asked what action was being taken to ensure that the Board did not just become another council committee?

Regarding item 6, he stated that he regretted that no representative from LINks was attending the meeting as the success of York LINks had largely been due to the effort, knowledge and expertise of three paid members of staff. He asked what security of employment, if any, would these staff have following the transfer to Healthwatch?

The Chair confirmed that the points had been noted and would be considered as part of these agenda items later in the meeting.

16. 2011/12 FIRST QUARTER FINANCIAL MONITORING AND PERFORMANCE MONITORING REPORT - ADULT SOCIAL SERVICES

Consideration was given to a report which set out the latest performance and budget for 2011/12 and forecast the outturn position by reference to the service plan and budgets for all the relevant services falling under the responsibility of the Director of Adults, Children and Education.

It was confirmed that the budget was again reporting early financial pressures of £1,017k, the main factors being a greater number of referrals than anticipated in Independent Residential and Nursing Care together with increased take up of Direct Payments. There had also been delays in letting the reablement

contract and reconsideration of other care service options which had resulted in the full savings not being achieved in Elderly People's Homes.

Officers confirmed that the directorate were also assessing the 2012/13 savings proposals which could be brought forward and reviewing commissioning budgets and developments with a view to identifying one off savings to be made during the current year.

The report went on to examine Quarter 1 performance and it was noted that of the 13 reported indicators 7 were meeting or exceeding the Q1 targets.

Members questioned a number of points in relation to the budget including:

- Request for further details of the indicators which had fallen short of their targets. Officers confirmed that delayed discharges had improved since last year however it was hoped that new structures in Community Services and the Foundation Trust together with additional investment would ensure faster response times.
- Effect on services of holding vacant posts. Officers confirmed that this was mainly on the provider side but that no services were ever at a staffing level where they were unsafe.
- Details of the number of reviews carried out in relation to placing adults with learning disabilities in settled accommodation. Officers pointed out that the reviews usually peaked towards the end of the year which ensured that this target could be met. It was also confirmed that CYC was nationally a better performer in this area.

RESOLVED: That the report be received and noted.

REASON: To update the Committee on the latest financial and performance position for 2011/12.

17. TERMS OF REFERENCE FOR HEALTH AND WELL BEING BOARD

Members considered a report which set out progress towards the establishment of a shadow Health and Wellbeing Board for York to meet the requirements of the White Paper Equity and

Excellence: Liberating the NHS and the Health and Social Care Bill 2011.

The Committee were reminded that local authorities would have a new, direct accountability for health improvement, and that the public health function would transfer from the PCT's in 2013. As a pathfinder area York would be expected to have many of the components in place in shadow form by April 2012 and this was being overseen by a multi-agency Transition Board. Details of the functions of the new Health and Wellbeing Board, a statutory partnership set up as a sub-committee of the Council, were also set out in the report.

Consultation with partners had been undertaken on the provisional recommendations of the Transition Board details of which would be considered by Cabinet at its meeting on 4 October 2011. The key principles to be considered were:

- The size of the Health and Wellbeing Board.
- Whether to include provider representatives on the Board.
- The Board's strategic positioning.

Officers confirmed that, subsequent to publication of the Scrutiny Committee report, the Cabinet report had been updated following receipt of additional comments. During the course of the consultation the following changes had been suggested in relation to Board membership:

- Elected members should be increased from 1 to 3, made up of the Leader, a relevant portfolio holder and an opposition spokesperson.
- The Board should be chaired by the Leader of the Council or his/her nominee.
- Representation from the Clinical Commissioning Group should be increased to 2 doctors.

A plan showing the diagrammatic relationship between the various bodies was circulated to members at the meeting (a copy of which has been attached as an annex to the agenda).

Members were then asked for their comments on the draft proposals for consideration by the Cabinet at their meeting. The following points were raised:

- The Board appeared to be well represented by health professionals; however a balance was required to ensure that there was promotion of a healthy lifestyle. It was confirmed that the Board could call in providers to provide

evidence and/or assist with their work but that, if required, Board membership could be adjusted prior to April 2012.

- Members confirmed that the proposals were a very positive and ambitious move forward.
- Board progress would be kept under observation to ensure that it was open and inclusive and to monitor the various relationships.

Officers confirmed that progress on the Board's establishment would be included in the Committee's work plan and that the speaker's earlier comments would be taken into consideration.

Following further discussion it was

RESOLVED: That the Committee note the progress made towards establishing a shadow Health and Wellbeing Board for York.

REASON: To keep the Committee up dated with establishing a shadow Health and Wellbeing Board.

18. HEALTHWATCH PROCUREMENT MONITORING REPORT

Members received an update on the progression from LINks (Local Involvement Networks) to Local HealthWatch by October 2012.

The overarching intention of Local HealthWatch was to provide a single point of contact, connecting people to the right NHS and social care advice and advocacy services, and helping people to find information that would enable them to choose the services they needed and required.

It was reported that a recent bid had given York's HealthWatch pathfinder status which presented an opportunity for scoping and planning to test some of the proposed new functions. It was noted that HealthWatch whilst retaining the most successful elements of the current LINks function would be different and distinct from LINks and that discussions had already been held on the commissioning process.

Officers confirmed that they were still awaiting clarification on certain points including further details on signposting and funding.

In answer to the question raised in respect of the future employment of LINks staff it was confirmed that these staff were employed by the host, North Bank Forum but that this was unfortunately not within this Committee's remit.

Members made a number of points and questioned various aspects of the report including:

- Local authority commissioning of NHS complaints advocacy.
- Complaints monitoring.
- Noted that monitoring of standards would now be undertaken.
- Concerns that the complaints service should be properly resourced and independent.
- Details of public consultation and the need to engage the public with simpler access to services.

Officers confirmed that a further update would be provided at the Committee's next meeting.

RESOLVED: That the latest progress report towards establishing HealthWatch be received and noted.

REASON: To keep the Committee informed of the progress towards establishing HealthWatch.

19. UPDATE FROM COUNCILLOR WISEMAN ON THE REGIONAL JOINT SCRUTINY COMMITTEE INVESTIGATING THE PROPOSED CHANGES TO CHILDREN'S CARDIAC SERVICES

The Committee were updated in respect of the NHS review of how it delivered congenital heart services to children in England and Wales. It was reported that Children's Cardiac Services were currently delivered in 11 centres across England and that it was expected that the review would recommend the reduction of the number of centres offering these procedures and creating fewer but larger centres to deliver them. The proposals had detailed 4 options, with only one of these suggesting the retention of children's congenital heart surgery in Leeds.

Members were reminded that Councillor Wiseman had been nominated as the CYC representative to attend meetings of the Joint Health Overview and Scrutiny Committee (Yorkshire and

the Humber). This committee had been appointed to consider and respond to the proposed reconfiguration of Children's Congenital Heart Services in England with the committee being given until 5 October 2011 to respond to the proposals. Cllr Wiseman confirmed that input had been sought from the Joint Committee of Primary Care Trusts (JCPCT) which had unfortunately, to date, not been forthcoming.

Copies of the following papers were circulated for members' information (these documents have been included as an annex to the agenda for this meeting):

- Background to the review.
- Report from the Joint Health Overview and Scrutiny Committee.
- Details of the four options that the public would be consulted on.

It was confirmed that representatives from the JCPCT had again been invited to the Joint Scrutiny Committee meeting due to take place the following day in Leeds to present the response to previous questions together with any further questions identified by members of the Joint Committee.

Councillor Wiseman confirmed that, following the meeting in Leeds, she would update Members on the outcome by email.

RESOLVED: That the verbal update be received and noted.

REASON: To keep Members updated on the NHS review of the delivery of congenital heart services to children in England and Wales.

20. END OF LIFE CARE REVIEW - REPORT AND TOPIC ASSESSMENT FORM

Members considered a report which presented them with a Topic Assessment Form which briefly outlined the proposed scrutiny review on End of Life Care ('Do Not Resuscitate' (DNR) Forms – Their Use and Effectiveness').

The Scrutiny Officer requested members to complete Annex A, the Topic Assessment Form, attached to the report, in order to scope and timetable the review to enable it to proceed and to consider whether the review should be undertaken by the whole Committee or by a smaller Task Group.

The Scrutiny Officer also updated that the End of Life Care form was entitled the DNACPR Do Not Attempt Cardio Pulmonary Resuscitation form rather than DNR.

In answer to members' questions the Scrutiny Officer outlined the reason for the topic and remit of the review. She confirmed that members had agreed to a short review for this topic but pointed out that this would not preclude further scrutiny work in this area.

Following further discussion it was

RESOLVED: i) That the scrutiny review be undertaken by the full Health Scrutiny Committee.

ii) That the Scrutiny Officer be requested to email suggested dates for the first meeting for members' to complete Annex A, scope and timetable the review.

iii) That the Scrutiny Topic Assessment Form be circulated by email to members for drafting and comment for consideration and final completion at the meeting. [1.]

REASON: In order to progress this topic to review.

Action Required
1. Email form and suggested dates to Members. TW

21. UPDATE FROM YORKSHIRE AMBULANCE SERVICE ON ARTICLE THAT APPEARED IN THE PRESS ON 1 SEPTEMBER 2011

The following representatives from the Yorkshire Ambulance Service attended the meeting to discuss an article published in The Press on 1 September 2011 entitled 'Ambulance Complaints Increase'.

- The Locality Director North and East Yorkshire
- Acting Head of Operations
- Service and Quality Improvement Manager and
- Locality Manager Patient Transport Services

The Ambulance Service representatives thanked members for inviting them to attend the meeting to enable them to put the contents of the article and figures into context.

The Locality Director North and East Yorkshire explained that the complaints figures, referred to in the article, related to accident and emergency and non emergency work and represented complaints received by the whole Trust not just North Yorkshire. He pointed out that the figures included comments and concerns both written and verbal which were all logged on their database which not all other trusts necessarily did. Service users were actively encouraged to comment on the services they received with comment cards being carried by the patient transport vehicles and with this being rolled out to all accident and emergency vehicles.

The Acting Head of Operations went on to put the figures into context. He pointed out that the NHS Information Service website referred to receipt of 600 written complaints with North Yorkshire receiving no written complaints regarding the emergency services during the year. It was pointed out that North Yorkshire had a much higher level of compliments than the rest of the service with them receiving 1 compliment per 8 members of staff.

The Service and Quality Improvement Manager referred to the recent online tool which allowed patients to complete a survey regarding their experiences.

The Locality Manager Patient Transport Services confirmed that there had been a rise in complaints in respect of the patient transport service and online bookings. She confirmed that the call centre was in the process of remodelling with additional resources being allocated to the patient self booking service and with 90% of calls now being answered within 30 seconds. It was anticipated that there would now be a decline in complaints relating to this service.

Members went on to question a number of points including:

- Accident and emergency turn round time and resulting knock on effects on service. Confirmation that systems had been put in place to overcome this with a target of 80% turn round in 25 minutes which they were making good progress towards.

- Ambulance equipment checks. Confirmation that the CQC inspection had confirmed that all servicing and cleanliness of ambulances and ambulance stations were in order.
- Staff complaints system.
- Complaint levels for the current year.

The Chair thanked the representatives for their attendance and thorough explanation in respect the concerns raised.

RESOLVED: That the Yorkshire Ambulance Service be requested to return to the Committee's November meeting to provide an update on the complaints figures.

REASON: To continue to update the Committee on the work of the Ambulance Service.

22. WORK PLAN 2011/12

Consideration was given to the Committee's work plan for 2011/12.

RESOLVED: That the draft work plan for 2011/12 be received and noted subject to the addition of the following:

- January 2012 - Health and Wellbeing Board update
- November 2011 – Performance update from the Yorkshire Ambulance Service

REASON: In order to provide the Committee with a work programme for future meetings.

CLLR C FUNNELL, Chair
[The meeting started at 5.00 pm and finished at 7.05 pm].

Agenda Item 4

Yorkshire Ambulance Service NHS
NHS Trust

Update Summary on Ambulance Service Complaints

1. PURPOSE/AIM

1.1 The purpose of this report is to provide information on the number of complaints received into Yorkshire Ambulance Service (YAS) as a year to date position.

2. COMPLAINTS/CONCERNS UPDATE

2.1 The number of complaints and concerns received in 2011/12 are similar to those received over the same period as the previous year.

2.2

	Period				
	2010/2011	2011/2012			
	Full year	Q1	Q2	Q3	Q4
No. Complaints received	67	17	24		
No. Concerns received*	1552	375	367		
Compliments	793	198	194		

* To include PALS concerns, informal complaints and negative feedback, as collected

2.3 The Emergency Service received 171 complaints during Q2 in 2011/12 which equates to 0.1% of the activity for this service.

2.4 The Patient Transport Service (PTS) received 219 complaints during Q2 in 2011/12 which equates to 0.09% of the activity for this service.

3. FUTURE CHANGES

3.1 Complaints representatives from every England Ambulance Trust met in January 2011 to agree the type of complaints/concerns that should be included in all future reporting. From April this year, YAS is now being benchmarked with other ambulance services with nationally agreed reporting criteria.

3.2 The nationally agreed reporting criteria has only been agreed between Ambulance Services and therefore may differ with other NHS Trusts.

3.3 East Midlands Ambulance Service (EMAS) has agreed to co-ordinate the collection of this data on behalf of all Ambulance Trusts. An update is expected imminently but is not available for this report.

4. SUMMARY

4.1 YAS views receiving complaints as not always a negative, as it gives us the opportunity to learn about how our service is perceived and experienced so that we can learn lessons and where necessary, make changes.

4.2 YAS is actively seeking the views of its Service Users and is currently displaying posters on vehicles and in Emergency Departments encouraging patients to provide feedback via our online survey. YAS is also retrospectively contacting patients who have used the Emergency Service and using the feedback to identify service improvements required.

Helen Hugill
Service and Quality Improvement Manager

Health Overview & Scrutiny Committee **14 December 2011**

Report of the Director of Adults, Children & Education

2011/12 SECOND QUARTER FINANCIAL & PERFORMANCE MONITORING REPORT – ADULT SOCIAL SERVICES

Summary

1 This report analyses the latest performance for 2011/12 and forecasts the financial outturn position by reference to the service plan and budgets for all of the relevant services falling under the responsibility of the Director of Adults, Children and Education.

Financial Analysis

2 The Adult Social Services budget is reporting financial pressures of £1,374k (2.8% of the £48,411k net budget) where pressures that have been evident in previous years related to demand for care still remain. The main contributory factors are:

i) A greater number of referrals than anticipated in Independent Residential & Nursing Care (£828k) and a continued increase above forecast level in the number of customers taking up Direct Payments (£630k), along with a significant pressure in External Homecare primarily related to Learning Disability customers with additional pressures relating to children in transit betweens children's and adults services (£929k).

ii) In terms of Business Change, there have been delays on two workstreams. In Homecare, there have been delays in letting the reablement contract and reconsideration of other care services options (£666k); and in EPHs, implementation delays mean that the full saving is unlikely to be achieved (£270k).

3 However, mitigating actions have already been identified to help reduce these pressures. A significant number of vacant posts are being held whilst the Business Change workstreams continue (£891k); and delays in two Supported Living schemes (£250k).

4 As well as the vacancy freeze outlined above, and a moratorium on non essential expenditure, the directorate is also assessing 2012/13 savings proposals that could be brought forward, as well as reviewing commissioning budgets and new customer/scheme developments with a view to identifying additional one-off savings for 2011/12.

Performance Analysis

5. Performance in Quarter 2 shows 6 of the 14 reported indicators meeting or exceeding the Q2 targets and a further 7 indicators, while falling short of Q2 targets, are within tolerance levels set. 1 indicator has fallen below tolerance and has been reported as red.

Code	Description of PI	11/12				
			Qtr 1	Qtr 2	Qtr 3	**Year End**
A&S1C (NPI 130)	Customers & Carers receiving Self Directed Support (Direct Payments and Individual Budgets)	Target	25.0%	29.0%	33.0%	**37.0%**
		Actual	25.7%	28.1%		
A&S1C REGIONAL	Customers & Carers receiving Self Directed Support (Direct Payments and Individual Budgets)	Target	-	-	-	**TBC**
		Actual	-	64.1%	-	
A&S1G (NPI 145)	Adults with learning disabilities in settled accommodation	Target	16.8%	33.5%	50.3%	**67.0%**
		Actual	13.0%	30.6%		
A&S1E (NPI 146)	Adults with learning disabilities in employment	Target	1.4%	2.9%	4.3%	**5.7%**
		Actual	2.1%	3.8%		
Delayed Discharges 1	Average weekly number of CYC Acute delayed discharges	Target	7.90	7.90	7.90	**7.90**
		Actual	10.08	8.64		

A&SNPI 132	Timeliness of social care assessment	Target	70.0%	70.0%	70.0%	**70.0%**
		Actual	62.7%	62.0%		
A&SNPI 133	Timeliness of social care packages	Target	90.0%	90.0%	90.0%	**90.0%**
		Actual	91.2%	89.9%		
A&S NPI35	Carers receiving needs assessment or review and a specific carer's service, or advice and information	Target	6.4%	12.8%	19.2%	**25.6%**
		Actual	8.1%	13.1%		
A&S NPI36	People supported to live independently through social services (all ages)	Target	4292	4316	4340	**4364**
		Actual	4363	4325		
A&SD39	Statement of Needs	Target	96.0%	96.0%	96.0%	**96.0%**
		Actual	95.2%	95.9%		
A&SD40	All services Reviews	Target	32.5%	55.0%	77.5%	**90.0%**
		Actual	35.6%	56.4%		
A&SD54a	Equipment - 7 days - Excluding Telecare	Target	96.0%	96.0%	96.0%	**96.0%**
		Actual	93.9%	95.7%		
RAP A6	Assessments missing Ethnicity	Target	5.0%	5.0%	5.0%	**5.0%**
		Actual	8.5%	7.7%		
RAP P4	Services missing Ethnicity	Target	5.0%	5.0%	5.0%	**5.0%**
		Actual	4.5%	4.4%		

6. *A&S1C Customers & Carers receiving Self Directed Support (Direct Payments and Individual Budgets)* which shows the delivery of personal budgets in year continues to rise steadily. The working definition of this indicator is being looked at nationally, and the end of year target of 37.0% represents a significant challenge as under the current definition we continue to count service users ineligible for Managed Budgets or Direct Payments in the denominator. Work in the region has identified an alternative and more accurate measure which is now being used to benchmark locally and is reported in the matrix as *A&S1C REGIONAL*. This change will be recommended as part of the DH Zero Based Review of all indicators. Customers in receipt of personal budgets continues to rise (currently 28.11%) but has fallen just short of the Q2 target. Actions

are being taken to re-invigorate progress, including a new hospital review process which will ensure that people discharged into Social Care will be eligible for review and a personal budget.

7. *Average weekly number of CYC Acute delayed discharges* has fallen to 8.64 from over 10 in the previous quarter, and compared to 9.38 at the same period last year which indicates and improving situation. Further analysis shows the average weekly number of reimbursable delays, which reflect the number of people delayed is below last year, while the bed days calculation is higher. This shows that while fewer people are being delayed, it is, on average, for a longer period than in 2010/11.

8. Timeliness of social care assessment is now at 61.9%, which is below the target of 70% and lower than last year. Performance in this area has been affected by the process of clearing waiting lists which have been reduced (from 196 in August to 108 by the end of September). The effect has been to introduce a number of new assessments which are out of time. It is envisaged that this performance will continue to decline until the waiting lists are cleared. The timeliness of social care packages is just below target levels 89.9% which is better than 85.4% last year.

9. Despite overall Timeliness of social care assessment being significantly low in Q2, Telecare and warden call assessments are running for September was 100%. Timeliness of social care packages however continues to rise and was just short of 97% of packages required in Q2 delivered on time.

10. *Assessments missing Ethnicity* has been reported as outside of tolerance, however work to reduce this has been effective in Q2, and new processes introduced as part of the locality redesign and data cleansing activity is likely to bring this back on target in the next quarter.

Council Plan

10. The information included in this report demonstrates progress on achieving the council's corporate strategy (2009-12) and the priorities set out within it.

Implications

11. The financial implications are covered within the main body of the report. There are no significant human resources, equalities, legal, information technology, property or crime & disorder implications arising from this report.

Risk Management

12 The overall directorate budget is under significant pressure. This is particularly acute within Adult Social Services budgets. On going work within the directorate may identify some efficiency savings in services that could be used to offset these cost pressures before the end of the financial year. It will also be important to understand the level of investment needed to hit performance targets and meet rising demand for key statutory services. Managing within the approved budget for 2011/12 is therefore going to be extremely difficult and the management team will continue to review expenditure across the directorate.

Recommendations

13 As this report is for information only there are no specific recommendations.

Reason: To update the committee on the latest financial and performance position for 2011/12.

Contact Details

Authors:	**Chief Officer Responsible for the report:**
Richard Hartle Head of Finance *Tel No. 554225*	Peter Dwyer Director of Adults, Children and Education
Mike Richardson Performance & Improvement Manager *Tel No. 554355*	**Report Approved** *Y* **Date** *17 November 2011*

Specialist Implications Officer(s) None

Wards Affected: *List wards or tick box to indicate all* **All** *Y*

For further information please contact the author of the report

Background Papers
2011-12 Finance and Performance Monitor 2, Cabinet 1 November 2011
Annexes
None

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Health Overview & Scrutiny Committee 14 December 2011

Report of the Assistant Director Governance & ICT

Summary & Outcomes Report - Joint Health Overview & Scrutiny Committee's Response to the Consultation on Children's Congenital Cardiac Surgery

Summary

1. The purpose of this report is to summarise the background to the consultation, the main issues identified by the Joint Health Overview and Scrutiny Committee (HOSC) and the recommendations put forward to the Joint Committee of Primary Care Trusts (JCPCT).

Background Information

2. In 2008 the NHS Medical Director requested a review of Children's Congenital Heart Services in England. The aim of the review was to develop and bring forward recommendations for a *Safe and Sustainable* national service that had:

- Better results in surgical centres with fewer deaths and complications following surgery
- Better, more accessible assessment services and follow up treatment delivered within regional and local networks
- Reduced waiting times and fewer cancelled operations
- Improved communication between parents/guardians and all of the services in the network that see their child
- Better training for surgeons and their teams to ensure the service is sustainable for the future
- A trained workforce of experts in the care and treatment of children and young people with congenital heart disease
- Surgical centres at the forefront of modern working practices and new technologies that are leaders in research and development

- A network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network

3. On behalf of the ten Specialised Commissioning Groups in England and their constituent local Primary Care Trusts, the Safe and Sustainable Review Team (at NHS Specialised Services) managed the review process and this had involved:

   - Engaging with partners across the country to understand what works well at the moment and what needs to be changed
   - Developing standards – in partnership with the public, NHS staff and their associations – that surgical centres must meet in the future
   - Developing a network model of care to help strengthen local cardiology services
   - An independent expert panel assessment of each of the current surgical centres against the standards
   - The consideration of a number of potential configuration options against other criteria, including access, travel times and population.

4. At the JCPCT meeting held on 16th February 2011, the following recommendations and options for consultation were presented and agreed:

   - Development of Congenital Heart Networks across England that would comprise all of the NHS services that provide care to children with Congenital Heart Disease and their families, from antenatal screening through to the transition to adult services
   - Implementation of new clinical standards that must be met by all NHS hospitals designated to provide heart surgery for children
   - Implementation of new systems for the analysis and reporting of mortality and morbidity data relating to treatments for children with congenital heart disease
   - A reduction in the number of NHS hospitals in England that provide heart surgery for children from the current 11 hospitals to 6 or 7 hospitals in the belief that only larger surgical centres can achieve true quality ad excellence
   - The options for the number and location of hospitals that provide children's heart surgical services in the future are;

Option A: Seven surgical centres at: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Glenfield Hospital, Leicester • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[1]	**Option B: Seven surgical centres at:** • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • Southampton General Hospital • 2 centres in London
Option C: Six Surgical Centres at: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London	**Option D: Six surgical centres at:** • Leeds General Infirmary • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London

5. Formal public consultation on the proposed changes took place between 1st March 2011 and 1st July 2011, whilst Health Overview and Scrutiny Committees were given an extended deadline of 5th October 2011 to respond to the proposals.

6. In March 2011, on behalf of 15 local authorities across Yorkshire and the Humber, a Joint Health Overview & Scrutiny Committee (HOSC) was formed and became the statutory body responsible for responding to the consultation on the 'Review of Children's Congenital Cardiac Services in England' along with the associated reconfiguration proposals. This Committee was administered by

[1] The preferred two London centres in the four options are Evelina Children's Hospital and Great Ormond Street Hospital for Children

Leeds City Council and City of York Council's representative on the Committee was Councillor Wiseman.[2]

7. In considering the review documentation and the proposals set out in the Safe and Sustainable Consultation Document: *A new vision for Children's Congenital Heart Services in England (March 2011),* the Joint HOSC considered a range of evidence and heard from a number of key stakeholders as summarised in the paragraphs below prior to producing their final report.

Summary of Issues Highlighted in the Final Report

8. In summary, the view of the Joint HOSC is that any future model of designated paediatric congenital cardiac surgical centres that does not include a centre in Leeds will have a disproportionately negative impact on the children and families across Yorkshire and the Humber.

9. This view, as identified in the full final report, is specifically based on the evidence considered in relation to:

- Co-location of services
- Caseloads
- Population density
- Vulnerable groups
- Travel and access to services
- Costs to the NHS
- The impact on children, families and friends
- Established congenital cardiac networks
- Adults with congenital cardiac disease
- Views of the people of the Yorkshire & Humber Region

10. Whilst focusing on the needs of the children and families across Yorkshire and the Humber and the retention of services in the region, the Joint HOSC also identified potential negative impacts of alternative proposals in other parts of the country. As such, and as detailed in the report, the Joint HOSC were mindful not to shift any similar disadvantages to other areas of the country that were identified in Options A to C of the proposals (see table above).

[2] Councillor Fraser, prior to May 2011

11. The specific recommendations included in the final report and put forward to the JCPCT are attached at **Annex A** to this report.

Identified Concerns

12. During the inquiry, the Joint HOSC identified some specific concerns in relation to the consultation process and the availability of a range of information. Specifically the Joint HOSC highlighted concerns in relation to the availability of:

- The detailed breakdown of assessment scores for surgical centres produced by the Independent Expert Panel (chaired by Sir Ian Kennedy) – which subsequently have seemingly been used as a proxy for quality at current surgical centres.
- A finalised Health Impact Assessment report
- A detailed breakdown of information on the likely impacts on identified vulnerable groups across Yorkshire and the Humber referred to in the Health Impact Assessment (interim report)
- The Price Waterhouse Coopers report that tested the assumed patient travel flows under each of the four options presented for public consultation
- Additional work undertaken around capacity across surgical centres
- Detailed financial calculations and assumptions

13. Members of the Joint HOSC also highlighted serious concern and disappointment with the JCPCT's general reluctance to adequately engage with the Joint HOSC during its inquiry.

14. In early October 2011 the Joint HOSC presented its consultation response to the proposals and issued a formal report to the Joint Committee of Primary Care Trusts (JCPCT), the decision making body, for consideration. A copy of the Joint HOSC's full final report can be found at **Annex B** to this report (available online only due to its size). Agendas and Minutes relating to the meetings of the Joint HOSC can be found on Leeds City Council's website via the following link:

http://democracy.leeds.gov.uk/ieListMeetings.aspx?CId=793&Year=2011

15. It is expected that, in line with current Department of Health guidance[3], a formal response (by the JCPCT) to the Joint HOSC's report will be received and available by the middle of November 2011.

16. It should be noted that, notwithstanding any response to the Joint HOSC's report from the JCPCT, a formal decision by the JCPCT on the preferred option was not expected until mid-December at the earliest. However, this deadline may well change due to a successful legal challenge from the Royal Brompton Hospital (RBH) in London. RBH applied for a judicial review in relation to several elements of the consultation but only one was upheld.

17. The Honourable Mr. Justice Owen found that the JCPCT's process for assessing the RBH's compliance with the standards relating to 'research and innovation' (which was found to be 'poor') was flawed, stating that '*…the failure to meet the RBH Trust's legitimate expectation as to the use to which the information provided in response to the self-assessment Template, and the likely consequential effect upon the assessment of 'Quality' in the inter London centre scoring, rendered the consultation process unfair to the Trust, the unfairness being of such a magnitude as to lead to the conclusion that the process went radically wrong.'*

18. In conclusion, the Honourable Mr. Justice Owen's judgement was that '*…the consultation exercise was unlawful, and must therefore be quashed.*'

19. The JCPCT is understood to be appealing against this decision: If unsuccessful on appeal or the JCPCT decides to hold a further public consultation (because an appeal would take too long) then the decision on the preferred option would be delayed. However, if successful on appeal, it is still unlikely that the final decision on the preferred option will be made by mid-December 2011, due to the timescales associated with the necessary court proceedings. Nonetheless, the JCPCT has indicated that they intend to make a final and binding decision by spring 2012.

Consultation

20. This report is for information only.

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[3] Where an overview and scrutiny committee request a response from the NHS body to which it has reported, the NHS body shall respond to the request within 28 days.
(*Overview and Scrutiny of Health – Guidance: Department of Health (July 2003))*

Options

21. This report is for information only and as such there are no options. However the Committee are asked to nominate a new representative to sit on the Regional Joint HOSC.

Analysis

22. This report is for information only. A full analysis and discussion of the Safe and Sustainable consultation documentation was carried out by the Joint HOSC and is set out in their full report.

23. Members may be aware that Councillor Wiseman, the current representative on Regional Joint HOSC is standing down from the Health Overview & Scrutiny Committee in York. She will be taking up a place on the Health & Well Being Board. This means that York's place on the Regional Joint HOSC will be vacant as of 8th December 2011[4].

24. The Committee are advised to nominate a new representative to sit on the Regional Joint HOSC. It is important that the voice of York's Health Overview & Scrutiny Committee continues to be heard in relation to the proposed changes to children's cardiac services. The next meeting of the Regional Joint HOSC is scheduled for Monday 19th December 2011 at 9.30am and will be held in Leeds Civic Hall. The nominated representative from this Committee is requested to make themselves available to attend.

Council Plan 2011-2015

25. This report details the written response of the Joint HOSC to a national consultation regarding the provision of Children's Congenital Cardiac Services. It is not directly linked to the five priorities the Council has set.

Implications

26. This report is for information only and as such there are no implications associated with the recommendations within it.

Risk Management

27. There are no risks associated with the recommendations within this report.

[4] Subject to approval at the Full Council meeting on 8th December 2011

Recommendations

28. Members are asked to:

- Note the report
- Nominate a representative to sit on the Regional Joint HOSC

Reason: To keep the Committee informed of the work of the Joint HOSC in relation to the proposed changes to children's cardiac services.

Contact Details

Author:	**Chief Officer Responsible for the report:**
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Report Approved ✓ **Date** 01.12.2011

Specialist Implications Officer(s) None

Wards Affected: **All** ☐

For further information please contact the author of the report

Background Papers:
None

Annexes

Annex A Summary of Recommendations
Annex B Final Report (online only)

Annex A

Summary of Recommendations

Principal Recommendation 1:

In order to meet the needs and growing demand of the 5.5 million people living in the Yorkshire and Humber region, the surgical congenital cardiac unit currently provided by Leeds Teaching Hospitals NHS Trust must be retained and included in any future configuration of paediatric congenital cardiac surgical centres.

Principal Recommendation 2:

Based on the matters outlined in this report we recommend the following 8-centre configuration model:

- **Leeds General Infirmary**
- **Alder Hey Children's Hospital, Liverpool**
- **Birmingham Children's Hospital**
- **Bristol Royal Hospital for Children**
- **Freeman Hospital, Newcastle**
- **Southampton General Hospital**
- **2 centres in London**

Recommendation 3:

Given the significant benefits to the patient and their families of genuinely co-locating relevant services, we believe genuine co-location should receive greater recognition and weighting when determining future service provision.

Recommendation 4:

Given one element of the review is to ensure more care is delivered closer to home, population density should be a key consideration in the configuration of future provision.

Recommendation 5:

Adult cardiac services and the overall number of congenital cardiac surgical procedures carried out should be considered within the scope of this review and used to help determine the future configuration of surgical centres. As a minimum there should be a moratorium on any decision to designate children's cardiac surgical centres until the review of the adult congenital cardiac services is completed and the two can be considered together.

JOINT HEALTH C . . . . V AND SCRUTINY COMMITTEE (YORKSHIRE AND HUMBER)

REVIEW OF CHILDREN'S CONGENITAL CARDIAC SERVICES

FINAL REPORT

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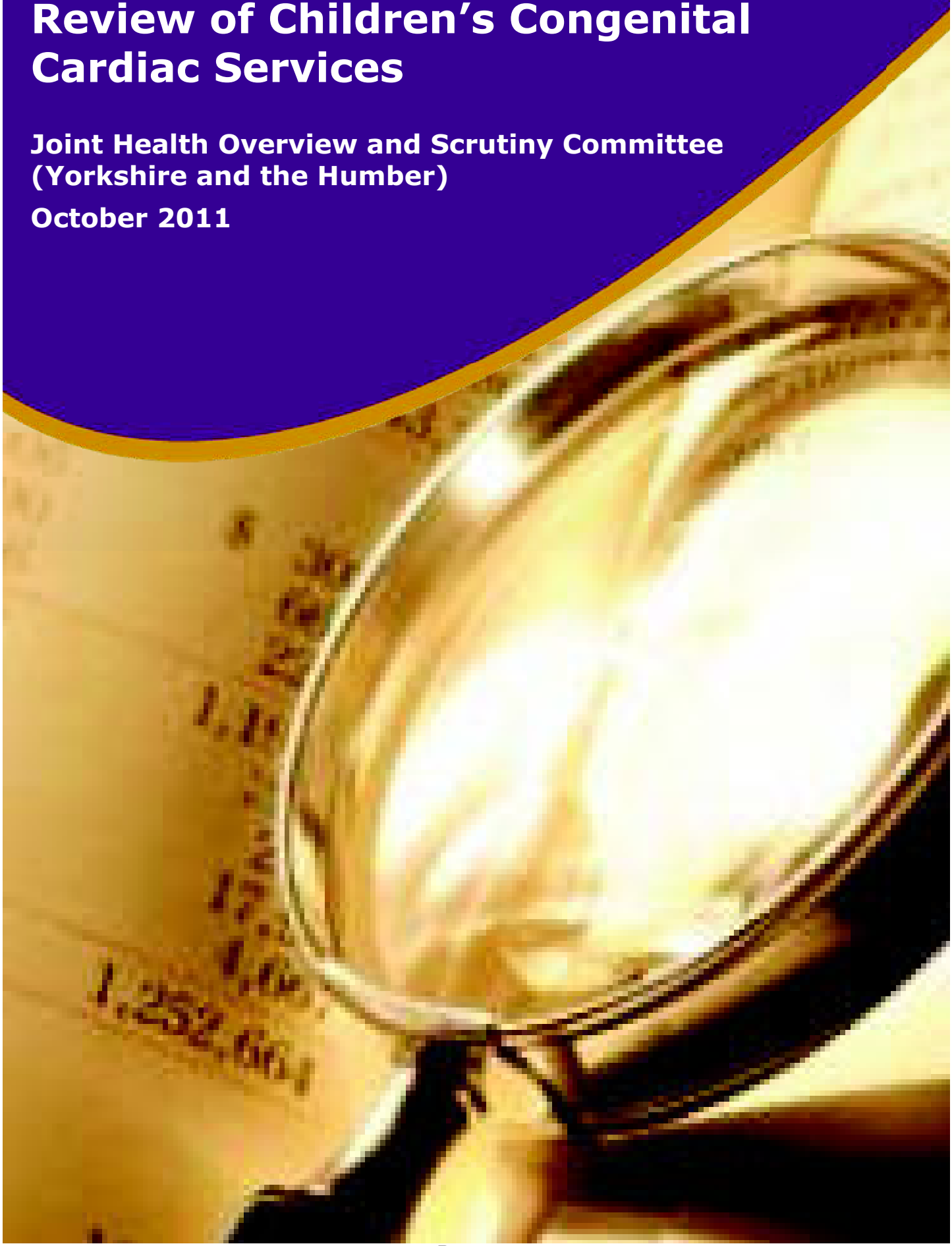
Scrutiny Inquiry Report

Review of Children's Congenital Cardiac Services

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

October 2011



Foreword

I am pleased to present the report of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), following its inquiry into the review of Children's Congenital Cardiac Services in England and the associated proposals.

I believe **this report and its recommendations send a clear and powerful message** to both the national review team and the Joint Committee of Primary Care Trusts (JCPCT) – as the decision-making body. That message is **that children and families across Yorkshire and the Humber will be disproportionately disadvantaged if the current surgical centre in Leeds is not retained in any future service model**.

It is worth emphasising that **over 600,000 people across Yorkshire and the Humber signed a petition – the largest petition of its kind in the United Kingdom** – supporting the retention of the current surgical centre at Leeds Children's Hospital. I and other members of the joint committee firmly believe that the level of support for the petition **demonstrates the strength and depth of feeling across the region** and that this public voice needs to be listened to.

However, while focusing on the needs of children and families across Yorkshire and the Humber and the retention of services in our region, the joint committee has been aware of the potential negative impacts of alternative proposals in other parts of the country. As such, and as detailed in the report, we have been mindful not to simply attempt to passport to other parts of the country the disproportionate disadvantages we have identified in three of the four service models presented for public consultation.

This report reflects the considerable time and effort of all the members of the Yorkshire and Humber Joint Committee – both past and present. I am extremely grateful for the enthusiasm and commitment of my colleagues on the joint committee and feel this report demonstrates the considered approach we have taken.

In formulating this report the joint committee considered a wide range of evidence – and wanted to consider additional information that was not made available. The joint committee heard from a variety of witnesses – most of whom willingly accepted the invitation to meet and share their knowledge and experience of the issues under consideration. While the joint committee is extremely grateful to all those who have contributed to this inquiry, I would like to specifically recognise the input of the following:

- Cathy Edwards and Matthew Day from the Specialised Commissioning Group (Yorkshire and the Humber);

Foreword

- Stacey Hunter and her staff at Leeds Teaching Hospitals NHS Trust (LTHT);
- Mr Kevin Watterson , Dr. John Thomson and other clinicians at LTHT;
- The families who shared their experience of the excellent treatment and facilities provided at the current surgical centre at Leeds Children's Hospital; and,
- Sharon Cheng from the Children's Heart Surgery Fund

Details of the information we have considered and the people we have spoken and listened to are outlined in the report. However, it is worth highlighting that the joint committee remains disappointed with the JCPCT and its general reluctance to adequately engage with us during our inquiry.

It would not have been possible to complete our inquiry and produce this report without the support and dedication of all those involved. On behalf of the joint committee, I would like to thank the scrutiny support officers from all the participating authorities who have provided assistance throughout this inquiry, but I would like to reserve special thanks to Steven Courtney and Andy Booth at Leeds City Council for their tireless efforts.

Finally, I must re-emphasise that all of the joint committee's work supports the view that retaining the current surgical centre at Leeds is in the best interests of the children and families of this region. As a joint committee representing the 15 top-tier Yorkshire and the Humber local authorities and a population in excess of 5.5 million, we trust that – alongside the considerable public feeling displayed by children and families across the region – our findings and recommendations will be respected and given full and proper consideration by the Chair and members of the JCPCT**.**

Councillor Lisa Mulherin
Chair, Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Cardiac patient and nurse on the cardiac surgical unit at Leeds Children's Hospital

Introduction

1. This report is provided on behalf of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – a committee specifically formed to consider the outcome and subsequent proposals of the national review of children's congenital cardiac services, alongside the implications for the region. The Committee's membership included a single representative from each of the 15 local authorities with health scrutiny powers across Yorkshire and the Humber, namely:

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

2. The **background and scope of the inquiry that underpins this report is detailed in Appendix 1**.

Conclusions and Recommendations

Overview

3. As the Joint Health Overview and Scrutiny Committee for Yorkshire and the Humber, we represent the 15 top-tier authorities and the 5.5 million residents from across the region.

4. Throughout this inquiry, we have sought to consider a wide range of evidence and engage with a number of key stakeholders to help in our consideration of the proposals set out in the public consultation document 'Safe and Sustainable: A new vision for Children's Congenital Cardiac Service' published in March 2011.

5. Regrettably, we have not been able to consider all the information we identified as being necessary to conclude our review, prior to our 5 October 2011 deadline imposed by the review team. Some of that information was not available due to the timing of some additional work commissioned during the consultation period, while we were also denied access to other information we believe to be relevant. We feel very strongly that such information should have been made available for public scrutiny prior to any decision on the future configuration of designated surgical centres and believe it is in the public interest to do so.

6. We are stunned by the contempt displayed towards the legitimate public scrutiny of the review and its proposals. The dismissive response to many of our requests for information – to help us consider the proposals, the evidence-base and the implications for children and families across Yorkshire and the Humber – has been inexcusable. Once again, our detailed views and findings in this regard are outlined elsewhere in this report.

7. Nonetheless, this report has been compiled based on the evidence and information available to us at the time of writing. We reserve the right to add further comment and recommendations as and when the outstanding information we have requested or any other relevant details become available.

8. Fundamentally, **we strongly believe that any future model of designated paediatric congenital cardiac surgical centres that does not include a centre in Leeds will have a disproportionately negative impact on the children and families across Yorkshire and the Humber.** This belief is specifically based on the evidence we have considered in relation to:

   - Co-location of services;
   - Caseloads;
   - Population density;
   - Vulnerable groups;
   - Travel and access to services;

Conclusions and Recommendations

- Costs to the NHS
- The impact on children, families and friends;
- Established congenital cardiac networks;
- Adults with congenital cardiac disease;
- Views of the people of the Yorkshire and Humber region

9. We have serious concerns regarding some aspects of the review process and the subsequent consultation. We will explore all of these issues in more detail elsewhere in the report.

10. We believe that the Leeds Children's Hospital provides the most comprehensive range of clinical services for children with congenital heart problems. These services include foetal cardiology, maternity, neonatal, all inpatient children's specialities and adult congenital services, and are supported by a Paediatric Intensive Care Unit (PICU) with 24/7 Consultant Intensivist support and dedicated psychology and specialist nurse input. There are 41 rooms available for use by families who wish to be resident at the hospital and this includes a purpose built 22 bedded facility which is managed by the Sick Children's Trust.

11. It is clear that the review process to date has determined that the services provided by Leeds Teaching Hospitals NHS Trust (in common with those in the other remaining nine congenital cardiac surgical centres) are 'safe'. We have also been advised that the latest national data which compares outcomes across centres (provided via the national audit database (Central Cardiac Audit Database (CCAD)) has recently been published. This confirms that the outcomes for congenital cardiac patients in Leeds are consistent with the rest of the UK. As such, **as all centres are considered safe we believe that the real focus of this review and our response to it should be around the sustainability of these services for the future**.

12. With a 3-surgeon team, the Leeds surgical centre delivered 316 cardiac surgical procedures for children in 2009/10 – the 3rd highest number of procedures outside of London – which accounts for approximately 8% of the total national caseload. In 2010/11 the Leeds surgical centre delivered 336 cardiac surgical procedures for children, and a further 56 cardiac surgical procedures for adults. This equates to a total of 392 cardiac surgical procedures.

13. As democratically elected representatives of Yorkshire and the Humber, we believe it is imperative to retain a children's congenital cardiac surgical centre in Leeds. Based on what we have heard about the current unit and the operation of the very strong network, we do not believe that de-classifying the current surgical centre at Leeds would be in the interests of local children and families or the local health services, and that **any future configuration that**

Conclusions and Recommendations

does not include a surgical centre in Leeds will disproportionately disadvantage children and families across this region.

14. The argument for retaining the surgical centre in Leeds is, in many ways, underpinned by an extract from an opening statement published in the public consultation document. In summary, the statement (taken from the Guardian newspaper (dated 28 April 2010) and supported by a number of Presidents of various professional medical organisations) relates to the need for NHS changes to be driven by clinical evidence and we believe it is crucial to highlight the following extract:

    'Patients may indeed have to travel further for some specialist care, but if it is significantly better care then we believe that centralisation is justified'.

15. From the evidence we have considered, we believe that without the retention of the Leeds surgical centre, **three of the four proposals (Options A-C) will deliver a significantly worse patient experience for children and families across Yorkshire and the Humber** for the following reasons:
    - The range of interdependent surgical services, maternity and neonatal services are not co-located at any of the alternative surgical centres available to Yorkshire and the Humber patients and their families;
    - Considerable additional journey times and travel costs, and associated increased accommodation, childcare and living expense costs and increasing the stress and strain on family life at an already difficult time;
    - Fragmentation of the already well established, very strong network across the region.

16. Therefore, we believe children and families across Yorkshire and the Humber will not receive significantly better care if the Leeds unit is not retained as part of any future configuration of surgical centres.

17. In considering the best interests of children and families across Yorkshire and the Humber, alongside local health services, we believe it is our duty to highlight this matter publicly. We believe it is also our duty to draw this to the attention of the Joint Committee of Primary Care Trusts (JCPCT), prior to any decision on the future model for children's congenital cardiac services, by making the following recommendation:

Conclusions and Recommendations

Principal Recommendation 1:
In order to meet the needs and growing demand of the 5.5 million people living in the Yorkshire and Humber region, the surgical congenital cardiac unit currently provided by Leeds Teaching Hospitals NHS Trust must be retained and included in any future configuration of paediatric congenital cardiac surgical centres.

An alternative reconfiguration option

18. It is our view that the interests of children and families across Yorkshire and the Humber are best served by retaining the Leeds centre in any future configuration. However, we fully acknowledge that the proposals put forward in the consultation document are a result of an ongoing *national* review. As such, in considering the proposals and available evidence, we have also tried to reflect on the potential implications in other parts of England. In doing so we put forward our second principal recommendation to the JCPCT, which proposes an alternative model for the configuration of designated surgical centres.

Principal Recommendation 2: Based on the matters outlined in this report we recommend the following 8-centre configuration model:

- **Leeds General Infirmary**
- **Alder Hey Children's Hospital, Liverpool**
- **Birmingham Children's Hospital**
- **Bristol Royal Hospital for Children**
- **Freeman Hospital, Newcastle**
- **Southampton General Hospital**
- **2 centres in London**

19. In presenting the remainder of our report and further justification for our principal recommendations, we have set out our findings and additional recommendations under the following areas:

- Issues for children and families across Yorkshire and the Humber
- An alternative reconfiguration option
- Concerns and lessons to be learned

Conclusions and Recommendations

Issues for children and families across Yorkshire and the Humber

Co-location of services

20. It is widely acknowledged that the co-location of services brings about huge benefits for children and adults with interdependent conditions. The issue of co-location is considered in the consultation document and uses the definition described by the Framework of Critical Inter-Dependencies. In this, a number of service areas are described as having '*an amber relationship*', which is described as a '*…relationship under some circumstances, requiring varying levels of access and contact between specialists, but not necessarily co-location…'*

21. As such, co-location in this context is defined as meaning either:
    - location on the same hospital site; or
    - location in other neighbouring hospitals if specialist opinion and intervention were available within the same parameters as if services were on the same site.

22. We have heard on a number of occasions that the review of Children's Congenital Cardiac Services has its roots in the findings and recommendations arising from the Bristol Royal Infirmary Inquiry report (often referred to as the Kennedy Report (2001)). Indeed this is included in the NHS Medical Director's opening remarks within the public consultation document. We have considered some aspects of the recommendations made by Sir Ian Kennedy in that report and were particularly struck by recommendation 178, which states:

    'Children's acute hospital services should ideally be located in a children's hospital, which should be as close as possible to an acute general hospital. This should be the preferred model for the future.'

23. As such, we believe that the definition of 'co-location of services' appears to be loosely interpreted in the options considered in this current review. **We would argue that the public would generally consider co-location to mean just that – services co-located on a single site**. We believe that including centres where such services may be located over multiple hospital sites within that definition of co-location is misleading and disingenuous.

24. Currently in Leeds, children from across Yorkshire and the Humber access surgical and interdependent services in a children's hospital within an acute general hospital (Leeds General Infirmary) on one hospital site.

Conclusions and Recommendations

25. All children's acute services are *genuinely co-located* in Leeds alongside maternity services, which is essential for the wellbeing of mother and baby if cardiac interventions are required at birth. We believe that co-location of services in this way can significantly reduce the potential negative impacts associated with the separation of the mother and baby immediately after birth.

26. We considered evidence (attached at Appendix 2)presented by Dr. Sara Matley (Consultant Clinical Psychologist at Leeds Teaching Hospitals NHS Trust) on how the bond established between children and parents is crucial to a child's development – which can affect physical growth, as well as emotional and cognitive development and wellbeing. We do not believe this has received any significant consideration during this review, and specifically when defining co-location. **We believe that this review should place greater importance on the life-long wellbeing of children and their families than is currently evident.**

27. Reducing the likelihood of mother and child being separated immediately after birth (where the child could be transferred to another hospital for surgery) would help to minimise the unnecessary stress on the baby, mother and family. Having maternity services and children's congenital cardiac surgery on one site is invaluable to families. As such, we endorse the following comment from the Yorkshire and Humber Congenital Cardiac Network in response to the public consultation:

> ***"As a network, our view is that the gold standard for care would be delivery in a maternity unit with tertiary neonatal care on the same site as the cardiac unit, to avoid any unnecessary delay in treatment. The parents in our region currently have this choice, so Options A, B and C would be viewed by parents in our region as a retrograde step."***

28. We understand that of the other surgical centres considered within the review, only one other centre delivers all such services on one site – that being Southampton General Hospital.

29. We are advised that, through its statement issued in February 2011, it is the view of the British Congenital Cardiac Association (BCCA) that the gold standard of co-location in terms of children's congenital cardiac services equates to the co-location of foetal, maternity, neonatal services, Paediatric Intensive Care (PICU), children's inpatient services and Adult Congenital Cardiac services on a single hospital site. The statement is presented below:

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"It has become increasingly clear throughout this review that paediatric cardiac surgery cannot be considered in isolation and that numerous inter-dependencies between key clinical services (from fetus to adult) must be reflected in the final decision. The BCCA welcomes the recognition by the review that the linking of paediatric and adult cardiac services is integral to providing high quality care. It is important that the centres designated to provide paediatric cardiac surgery must be equipped to deal with all of the needs of increasingly complex patients. For these services at each centre to remain sustainable in the long term, co-location of key clinical services on one site is essential."

30. This standard of provision is currently provided by the service at LTHT. We have been advised that there has been a significant amount of reconfiguration work at LTHT (and at considerable public expense) to be able to deliver the gold standard of care described above.

31. Leeds Children's Hospital provides the most comprehensive range of clinical services for children with congenital heart problems, including foetal cardiology, maternity, neonatal, all inpatient children's specialities and adult congenital services. These are supported by a Paediatric Intensive Care Unit (PICU) with 24/7 Consultant Intensivist support and dedicated psychology and specialist nurse input. There are 41 rooms available for use by families who wish to be resident at the hospital and this includes a purpose built 22 bedded facility which is managed by the Sick Children's Trust.

32. **We believe that through its comprehensive co-location of clinical services, the Leeds Children's Hospital achieves the gold standard in children's congenital cardiac care and co-location of inter-dependent services**.

33. We have been advised by the Yorkshire and Humber Congenital Cardiac Board (the regional network body) that options without a surgical centre in Leeds will offer inferior co-location of services for patients and families from Yorkshire and the Humber. This will have a detrimental impact on the access and experience for patients compared to the current service in Leeds.

34. Furthermore, we have been advised that in Leeds the same surgeons treat children and adults on the same site and there is continuity of care for patients from childhood through into adulthood. As such, we believe that adult cardiac surgery would be adversely affected by any future model that does not retain the current cardiac surgical centre in Leeds. However, this matter is considered in more detail elsewhere in the report.

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Recommendation 3:
Given the significant benefits to the patient and their families of genuinely co-locating relevant services, we believe genuine co-location should receive greater recognition and weighting when determining future service provision.

Caseloads

35. The case for a minimum of 400 and an optimum of 500 surgical procedures in a 4-surgeon surgical centre is a cornerstone of the proposals set out in the consultation document. However, based on the 6 or 7 surgical centre models proposed, the current national activity detailed in the consultation document (3,600 surgical procedures) equates to an average of 600 or 514 surgical procedures per surgical centre. We understand that, inevitably, designated surgical centres across the country will not deliver 'an average' number of procedures, we feel this provides a useful proxy measure.

36. On this basis, it seems rather odd that on one hand an optimum number of procedures is presented and then on the other hand the same consultation document outlines two 6-centre options – which will deliver an average number of procedures 20% in excess of the optimum level. As such, **we believe that any current surgical centre that only featured in a 6-centre model, such as Leeds, has been severely disadvantaged during the consultation period**. In addition, the consultation document also sets out a national projection of around 4,000 procedures by 2025 – which would equate to an average of approximately 670 and 570 paediatric cardiac surgical procedures per surgical centre under the proposed 6-centre and 7-centre models, respectively.

37. Given one of the main aims of the review is to deliver sustainable arrangements for the provision of children's congenital cardiac services, we would question the methodology that proposes future configuration models that are likely to deliver an average number of procedures in excess of the stated optimum number.

38. The consultation document reports that with a 3-surgeon team, the Leeds surgical centre delivered 316 cardiac surgical procedures for children in 2009/10 – the 3rd highest number of procedures outside of London. This accounts for approximately 8% of the total national caseload. In 2010/11 the Leeds surgical centre delivered 336 cardiac surgical procedures for children, and a further 56 cardiac surgical procedures for adults. This equates to a total of 392 cardiac surgical procedures. Given the level of surgical activity at the Leeds centre, we are intrigued by the comments of the Chair of the JCPCT in

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response to one of our requests for additional information, which described the Leeds surgical centre as having '*a relatively low caseload'* – which we believe is clearly not the case.

39. We believe the response from the Chair of the JCPCT is at odds with details contained in the Expert Panel Report, which reported '*Waiting lists at the Trust are long*'. Furthermore, we believe the view of the Expert Panel suggests demand for services at the Leeds surgical centre is outstripping current capacity. We explored this matter further and were advised the Trust had been actively trying to recruit a fourth surgeon for some time but had been hampered in this recruitment by the uncertainties surrounding the future of the surgical centre pending the outcome of this review. We were also advised that the recruitment process was continuing and interviews were due to be held on 7 December 2011.

40. While it is clear that Leeds Teaching Hospitals NHS Trust (LTHT)has reached a level of surgical activity approaching 400 procedures per year (children and adults combined) with only 3 surgeons, we believe surgical activity would have been far in excess of this level if a fourth surgeon were already in post. We can only speculate on the impact this may have had on the options put forward for public consultation and the inclusion of the Leeds surgical centre in more options.

41. We also believe that the impact on other services has not received sufficient consideration in the process to date. For example, we have been advised that were Leeds not to be retained as a designated surgical centre, the Trust would be unable to perform paediatric interventional cardiology procedures without a cardiac surgeon on standby. We were advised that this is a growing area of activity and currently approximately 550 such procedures are performed annually in Leeds. However, we understand that such cardiac interventions are not included as part of the overall surgical activity figures for individual centres, and we do not believe there has been sufficient consideration in this regard to date.

42. Nonetheless, as it is clear that the review process to date has determined that the services provided by LTHT are 'safe', **we believe it would be irrational not to retain a designated surgical centre in Yorkshire and the Humber currently undertaking this level of activity with the associated local demand for services.**

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Population density

43. We have already stated that the population of Yorkshire and the Humber is in the region of 5.5 million people. However, it should be recognised that a total population of around 14 million people are within a 2-hour drive of the current surgical centre at Leeds. In planning the delivery of NHS services and to help ensure we make best use of public resources, it would seem logical to ensure that specialist surgical centres are located within areas of higher population and demand. The British Congenital Cardiac Association's (BCCA) view is that:

> **"The quality of service is key and where possible, the location of units providing paediatric cardiac surgery should reflect the distribution of the population to minimise disruption and strain on families."**

44. In the evidence submitted to our committee, Michael Dugher MP for Barnsley East stated:

> **"Population density must be taken into consideration in health planning and if it is based on this principle, all of the problems due to reconfiguration, such as extra distance and extra cost for individual families, are minimised because you move the doctors to the patients, not the patients to the doctors."**

45. Similar views were expressed during the course of our inquiry and through the Director of Public Health at Kirklees Council, we were advised that Yorkshire and the Humber has double the child population of the North East region, and is growing much faster. Within this, the BME population is growing fastest. As such, **we believe the logic of having designated surgical centres that reflect the distribution of the population cannot be refuted**.

46. We also believe that population density has been a significant consideration in identifying other centres as part of each of the consultation options put forward, including the surgical centres in Liverpool, Bristol, Birmingham and the need for two centres in London.

47. In terms of the sustainability of the networks that this review is hoping to achieve, we were advised that it will be more difficult to deliver care closer to home and share expertise, if the surgeons are more remotely located from their patients and the staff in the district children's cardiology centres.

Recommendation 4:
Given one element of the review is to ensure more care is delivered closer to home, population density should be a key consideration in the configuration of future provision.

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Vulnerable Groups

48. We sought additional, and in our view essential, information on the vulnerable groups highlighted in the Health Impact Assessment (HIA) Interim Report. Notwithstanding the interim status of the HIA report, this presented the following information in terms of vulnerable groups:

    - *Children (under 16s) who are the primary recipient of the services under review and, therefore, most sensitive to service changes;*
    - *People who experience socio-economic deprivation;*
    - *People from Asian ethnic groups, particularly those with an Indian, Pakistani, Bangladeshi and other Indian subcontinent heritage;*
    - *Mothers who smoke during pregnancy; and*
    - *Mothers who are obese during pregnancy;*

    These groups are defined as vulnerable groups because they are more likely to need the services under review and, are most likely to experience disproportionate impacts.

49. The report states that there are currently 2745 patients in vulnerable postcode districts, and sets out the likely travel and access impacts on vulnerable groups / postcode districts (based on current patient activity) under each of the proposed options (A-D).

50. We requested further information about how this analysis related specifically to children and families across Yorkshire and the Humber, but this information was not forthcoming. In his response to our request denying access to this information, the Safe and Sustainable Programme Director, stated:

    "Mott MacDonald have been commissioned to report on the Health Impact Assessment in a way that is transparent and equitable… I would not wish to influence the robust process they have undertaken by requesting the methodology is changed by singling out a particular area for analysis. Similarly, it would not be appropriate for me to ask them to release the data to one interested party, particularly as some stakeholders have already submitted their final response to consultation and would not have had the opportunity to take this data into account when formulating their responses."

51. As with a number of other reasonable requests for information, this unsatisfactory response denies access to information that we believe would support the arguments we are making that children and families across Yorkshire and the Humber will be disproportionately disadvantaged by any future configuration that does not retain the Leeds surgical centre.

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52. We would contend that other Overview and Scrutiny Committees (OSCs) have not sought this information because their populations are not being disadvantaged to the same extent in the proposals put forward. All OSCs have had the opportunity to seek this information should they wish to have done so. **We do not believe there is any legitimate reason why this information was not made available to us. We believe it is not in the best interests of the public to withhold such information as it undermines confidence in the process and potentially the outcome of the review.**

53. We believe that Yorkshire and the Humber has a significant concentration of vulnerable groups, including a large South Asian population in Kirklees, Bradford and Leeds who we know are more susceptible to congenital cardiac conditions. Issues associated with consultation with families from these communities are detailed elsewhere in this report.

54. We are also concerned that the needs of people in areas with high levels of deprivation e.g. Hull (ranked 10th out of 326 local authorities in the Indices of Deprivation in England 2010), Bradford (ranked 26th) and Doncaster (ranked 39th) have not been sufficiently taken into account in drawing up the options that went out to consultation.

55. We have also seen evidence from the 2001 Census that a high proportion of households in our region do not have access to a car or van, including 44% of households in Hull, 36% in Sheffield and 34% in Leeds. Across the region an average of 30% of households do not have access to their own private transport which significantly affects their journey times and travel costs to access hospital services already but which will be significantly exacerbated if the Leeds centre is not retained. A summary of this information is detailed in Appendix 3.

56. As such, and as previously stated we do not believe that children and families from across Yorkshire and the Humber will receive significantly better care should the surgical centre at Leeds not be retained in the future.

57. Our attempts to obtain relevant information on the potential impacts on vulnerable groups across Yorkshire and the Humber will continue. As such, once again we reserve the right to add further comment and recommendations should the information we have requested be forthcoming.

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Travel and access to services

58. The patient flows predicted under options A-C presented in the consultation document, alongside supporting information considered by the JCPCT, suggest patient travel patterns from the Yorkshire and Humber region that do not appear to match local knowledge. We believe this has also been highlighted by the Yorkshire and the Humber Specialised Commissioning Group (YHSCG), which (in part) resulted in the commissioning of additional work around testing the assumptions of patient flows under each of the proposed reconfiguration options.

59. While we welcomed this additional review work and testing of assumptions, we cannot understand why more detailed analysis was not undertaken prior to the options for consultation being identified and issued for public consultation. We also remain frustrated that such information will not be available for public scrutiny until after our 5 October 2011 deadline, despite previously being advised that the details would be available in August 2011. Here again we must reserve the right to comment as and when the Price-Waterhouse Coopers (PwC) report is published.

60. Notwithstanding the availability of this additional assessment work, we firmly believe this will be highly significant and is likely to be a considerable factor in determining whether or not proposed designated centres are likely to attract sufficient patient volumes in order to undertake the suggested minimum number of 400 - 500 surgical procedures per centre. Furthermore, such information will also help to identify and determine whether proposed surgical centres are at risk of being destabilised by an increase in patient numbers above and beyond the planned capacity. As such, we believe the importance of such information cannot be over emphasised.

61. We believe it is clear from the information considered that children and families from across Yorkshire and the Humber will be disproportionately and consistently disadvantaged in terms of access and travel times under three (options A-C) of the four options presented. This is reinforced by the details presented in Mott MacDonald's Health Impact Assessment (Interim Report).

62. Patient and family access to the proposed surgical centres should be a key consideration in determining the future configuration model. In this regard, we believe the current surgical centre in Leeds has excellent transport links to and from the city. This includes the motorway and road network (including access to the M1, M62 and A1(M)), the rail network (including direct access to the high speed East Coast mainline and the Transpennine rail route) and access by air via Leeds-Bradford. It is unclear how such factors have been factored into the review process to date.

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63. Furthermore, we have been denied access to a more detailed breakdown of the likely affects on vulnerable groups across Yorkshire and the Humber. As such, it is difficult to state the likely impacts with any degree of certainty. Nevertheless, **we believe that extending travel times and the complexity of journeys for patients across Yorkshire and the Humber is likely to place additional strain on children and families at what will already be a particularly stressful time**. In our view this is both unreasonable and unnecessary.

64. In terms of access and journey times, the public consultation document suggests that '…there is a minimal impact on journey times for most families…' for each of the reconfiguration options (Options A-D). The public consultation document seeks to demonstrate this by way of the overall percentage of the population likely to experience an increase in travel time in excess of 1½ hours.

65. However, as part of our inquiry, we received evidence from Embrace – which is the United Kingdom's first combined infant and children's transport service, which undertakes neonatal transfers alongside paediatric retrievals for the 23 hospitals across Yorkshire and the Humber, including four tertiary neonatal units and two paediatric intensive care units. We were advised that Embrace had sought to assess the potential impact of each of the four options by modelling the transfer activity undertaken by Embrace during 2010/11. We were further advised that this comprised a total of 224 transfers with a cardiac diagnosis, and there were up to 188 children within the current surgical centre at Leeds that may have needed to be transferred out under some of the options proposed.

66. The outcome of this work is very striking and once again highlights the disproportionate impact that three of the four options (Options A-C) would have on children and families across Yorkshire and the Humber. This impact assessment suggests that **between 53% and 73% of the 2010/11 Yorkshire and the Humber transfers could be in excess of the additional 1½ hours highlighted in the review – in comparison to the national figures of between 3.6% and 6.2%.**

67. Furthermore, any reconfiguration option that does not include the Leeds surgical centre is likely to see more than a four-fold increase in the mileage covered by the region's transfer and retrieval service – as detailed elsewhere in this report.

68. Additionally, care closer to home is described as one of the five key principals that has driven the review – except where surgery and other interventional procedures are necessary. However, we believe these aspects are crucial and

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key elements of service and should not be disassociated from the principle of care closer to home.

69. As such, it is clear that the proposed options A-C would significantly affect the ability of children and families across Yorkshire and the Humber to access surgical and other interventional procedures as close to their home as possible. Indeed, options A-C would require the region's children and families to by-pass their nearest centre (in Leeds) in order to access services outside of the region in Newcastle, Liverpool, Leicester or Birmingham.

70. However, we recognise that should the surgical centre at Leeds be retained at the expense of the one currently located in Newcastle (i.e. Option D), children and families from across the North East of England (albeit potentially fewer in number) could be subject to similar issues around travel and access to services. We also believe that similar issues may arise should the current surgical centre in Southampton not be retained.

Costs to NHS

71. Notwithstanding the potential impacts on children and families, the impact assessment work undertaken by Embrace also highlighted the significant impact of Options A-C on the transfer and retrieval service itself. This summarised in the table below:

Option	Transfers and repatriation	Total mileage	Total time
Option D	336	29,396 miles	681 hrs.
Option A	618	133,267 miles	2,633 hrs.
Option B or C	618	139,271 miles	2,866 hrs.

72. We were advised that while increases in the number of out of region transfers were likely with the retention of the Leeds surgical centre, it is clear from the above details that **the impact of options A-C could be exponential** in terms of the increase in transportation and retrieval activity across Yorkshire and the Humber – **resulting in over 80% increase in the number of transfer or retrieval journeys, over 100,000 additional miles and over 2000 additional work hours**.

73. We were advised that the most realistic model to address this resultant increase in activity would need further investment in Embrace, through an increase in the number of teams (driver, nurse and doctor) available to the service, alongside an increase in the number of ambulances and essential equipment. While there has not been any detailed assessment of the increase in expenditure for these services, it is clear that **any option that does not**

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retain the current surgical centre at Leeds, will result in very significant increases in transportation and retrieval costs for the NHS, as well as families of patients, across this region.

74. We believe the overall financial implications associated with the model of care proposed by this review are likely to be very significant – both in terms of establishing new arrangements and the on-going delivery of the proposed model of care. The above details help provide some sense of the scale of likely financial implications (albeit restricted to the transfer and retrieval service provided across Yorkshire and the Humber). However from the responses we have received to the questions we have asked, we believe that to date **there has been insufficient consideration of the financial implications.** We also believe that the level of detail publicly available in this regard has been inadequate.

75. Nevertheless, during our discussion with the Yorkshire and Humber representative of the JCPCT in late September 2011, it was highlighted that, **'…the new configuration would inevitably cost more…**' and may provide **'…a worse service for some patients and their families…'** We queried the likely level of the cost increase and, while we were not provided with any detailed analysis, we understand this is likely to be a significant increase with no additional funding likely to be forthcoming. As such, we believe that under Options A-C, **children and families across Yorkshire and the Humber will not only endure a significantly worse patient experience, but this will also be at considerable greater expense to the population across this region**.

The impact on children, families and friends

76. It seems clear to members of our committee that the significant impact that any future reconfiguration of these services would have on home and family life has been given very little consideration. Indeed in his response to our concerns about the disproportionate impact that removing the Leeds centre would have on children and families in our region, dated 16 September 2011, the Chair of the JCPCT makes no reference at all to the impact on the wellbeing of the families of patients. The response also ignores the benefits to be gained in terms of aiding recovery from ensuring that patients can be visited by friends and family whilst they are in hospital and the need for a parent who is at the bedside to have some respite whilst the other parent, grandparents, friends or other family members are visiting.

77. Furthermore, the same letter goes on to state that the financial impact of the reconfiguration falls outside the scope of this Review. Given that we already know that all of the surgical centres being reviewed are safe and that we are

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therefore looking for a sustainable model for the future, we cannot state strongly enough that minimising the negative financial impact and emotional strain on families in this region is of fundamental importance.

78. Extending the journeys families have to make also significantly impacts upon their household budgets. We were advised that a parent of a child having to travel from Grimsby to Newcastle by train would have to pay a £70 return train ticket. This cost would be repeated for every visit and given the distance and journey times involved would also be likely to incur accommodation costs, additional living expenses, additional childcare costs for siblings at home and place additional strain on any parent trying to continue to work and visit their ill child.

79. It should also be noted that we have received evidence from parents and grandparents who have emphasised that they would not have been able to support their child or grandchild in hospital as they have done if they were obliged to travel much further than they already do. They stated that they would not be able to visit after work or bring siblings to visit after school if their child or grandchild was in a hospital much further away.

80. The impact on family life, including the impact on siblings at home, has been a key concern throughout our inquiry. We have heard, first hand, about the delicate balancing that parents must strike between supporting a sick child, providing continuity for a child or children at home and maintaining employment. Such issues are difficult enough, without the additional difficultly associated with having to access a surgical centre outside of the region. Such matters are highlighted in the response we received from Julian Smith, MP for Skipton and Ripon, which includes the following statements:

    '…Lois and her husband spent months at her daughter's bedside in Leeds…'

    '…without the ward being there he would have had to make some fairly tough choices between family commitments and continuous employment.'

81. In addition, when we visited the centre in the Leeds Children's Hospital we also saw firsthand the facilities that are available to older children and teenagers who are recovering from surgery, which enable friends to visit and support their recovery. While similar facilities may be available in other centres, should the surgical centre in Leeds not be retained, we believe the reality of the situation would be that **the practicalities and costs associated with visiting friends recovering in surgical centres outside this region would be prohibitive for older children and teenagers across Yorkshire and the Humber**.

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Established congenital cardiac networks

82. At our meeting in late September 2011, we were advised by the then Yorkshire and Humber representative on the JCPCT that the importance and strength of network arrangements are crucial to the future success, or otherwise, of the proposed changes and future configuration of designated surgical centres.

83. We had previously heard from the Yorkshire and Humber Congenital Cardiac Network manager, who presented the Congenital Cardiac Services Strategy (2011) developed by the Yorkshire and Humber Congenital Cardiac Network. We heard how the strategy had been developed to describe how services are arranged and delivered to meet the needs of both children (from birth) and adults with congenital cardiac conditions. We were also advised that by considering the needs of both children and adults, the network represented the only one of its type nationally.

84. We have been advised that the network model developed across Yorkshire and the Humber has helped form the blueprint for future network arrangements. We are also aware that as part of the assessment of surgical centres, the Yorkshire and Humber Network was judged as **'very strong'**, while others have described the network as 'exemplary', whilst recognising the need for continuous improvement and refinement.

85. However, in order to better inform our understanding of the relative strengths of all existing networks (as detailed in the Expert Panel report (December 2010)), we requested details of the breakdown in assessment scores. Regrettably, once again we were denied access to this information – on the basis that the JCPCT had not received or considered such detail. Once again, we reserve the right to comment further when and if this detail is eventually made available.

86. However, while the Expert Panel report (December 2010) identifies some areas of non-compliance as far as the Yorkshire and Humber network is concerned, we have also heard some contrary evidence in this regard, as detailed in the table below:

Nature of non-compliance	**Alternative evidence**
Telemedicine within the network is weak; however this may be due to the geography of the region	It is recognised that telemedicine is a specific area of development for the Yorkshire and Humber network in common with most, if not all the other current surgical centres across the country.

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Nature of non-compliance	Alternative evidence
The panel felt that clinical governance needs to improve within the network.	No specific details have been provided. At our meeting in September 2011, the Yorkshire and Humber representative on the JCPCT confirmed that there was 'no case to answer' in this regard.
There is no lead transition nurse within the network	At our meeting in September 2011, we were advised that this is factually incorrect and that, as part of its site visit in Leeds, the expert panel was introduced to the transition nurse.

87. Without access to the detailed breakdown in scores, it is difficult to assess the impact of factual inaccuracies on the overall scoring of individual centres and, therefore, on the range of potential options considered.

88. In addition, we have been advised that Leeds Teaching Hospitals NHS Trust did not receive the detailed scoring of the Expert Panel following the site visit and was given very limited opportunity to comment an the Panel's findings, and correct any factual inaccuracies, prior to publication. We are concerned that, seemingly, the review process did not allow existing surgical centres to comment on such aspects.

89. We have been advised that establishing a robust and fully functioning network can take years to embed. Therefore, given the critical role of all networks in the success or failure of future arrangements, **we believe it is completely illogical that three of the four proposed options would see the break-up and fragmentation of the existing very strong network arrangements across Yorkshire and the Humber.** We believe that in the review process to date, the strength of networks has not been given an appropriate level of consideration, or sufficient importance or weighting attached to existing structures. We believe this severely disadvantages the children and families of Yorkshire and the Humber.

Adults with congenital cardiac disease

90. We are aware that the minimum number of surgical procedures, within designated centres and those undertaken by individual surgeons, are a cornerstone to the proposals put forward. We note the rationale behind the minimum numbers, but remain to be convinced by the clinical evidence used to support the number of procedures presented in the proposals.

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91. We understand that the NHS is reviewing the provision of congenital cardiac services via two separate but related reviews and that the process for the designation of adult congenital services will proceed in 2011. This will include reference to the separate standards that have been developed by a separate expert group which were published in 2009. In preparing this report, it should be noted that we have not sought to consider these service standards.

92. As previously stated, we have been advised that in Leeds the same surgeons treat children and adults on the same site and there is continuity of care for patients from childhood through into adulthood. We also understand that elsewhere in the country, other surgeons also treat both children and adult congenital cardiac patients.

93. We received evidence that Adult congenital heart surgery is currently spread across 21 hospitals, many without the expertise and regular experience of operating on congenital heart problems. This is clearly not safe or sustainable.

94. We understand that when reviewing any service, it is necessary to define the scope of the review. We also understand that this can be a complex exercise in itself. Nonetheless, we believe that the consideration of children's and adult's congenital cardiac services as two separate reviews is too simplistic an approach and represents an artificial separation of existing clinical practice.

95. We firmly believe that on a similar basis to the sustainability issues put forward in the children's congenital cardiac services consultation document, and **by considering adult congenital services separately, the outcome from the children's congenital cardiac services review will almost certainly pre-determine the outcome of the adult's services review.**

96. Adult congenital heart patients at the Leeds Centre have also made their views clear that they feel disenfranchised by the fact that their service is not being consulted upon jointly with the children's service in this review.

97. Furthermore, by considering the number of paediatric and adult cardiac surgical procedures in totality, we believe this provides a completely different landscape and, in our view, would significantly affect the number of surgical centres required across the country. We learnt that there were 859 adult congenital heart surgical procedures carried out across the country last year. Enough to justify retaining another two centres if the suggested minimum number of 400 surgical procedures is applied.

98. As previously stated, we understand that with three surgeons in post, 392 surgical procedures (adults and children combined) were undertaken last year at the current surgical centre in Leeds.

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99. Although we have not been provided with any detailed projections, we are advised that the adult population requiring cardiac surgery in the future is likely to rise significantly in the coming years and, at some point in the future, may actually rise higher than the number of surgical procedures undertaken on children. This is in part due to the advances in this field of medicine and the increase in survival rates for children into adulthood.

100. As such, simply by continuing to treat patient numbers arising in Yorkshire and the Humber, we would question whether in reality there are indeed any sustainability issues around the surgical centre in Leeds. Similar considerations may also be true for other areas.

101. We understand that similar concerns around the exclusion of the number of adult procedures have been raised by other professional bodies. We understand that concerns have been raised both in terms of absolute patient numbers and also around pre-determination. Such concerns appear to remain unaddressed.

Recommendation 5:
Adult cardiac services and the overall number of congenital cardiac surgical procedures carried out should be considered within the scope of this review and used to help determine the future configuration of surgical centres. As a minimum there should be a moratorium on any decision to designate children's cardiac surgical centres until the review of the adult congenital cardiac services is completed and the two can be considered together.

The views of the people of the Yorkshire and Humber region

102. Over 600,000 people in the Yorkshire and Humber region signed a petition supporting the retention of the surgical centre at the Leeds Children's Hospital. We firmly believe their voice needs to be listened to. All of our work on this inquiry supports their view that retaining the Leeds centre is in the best interests of the children and families of this region.

103. We have heard evidence that well motivated parents of children with congenital heart problems struggled with the consultation response form and evidence that the response forms and associated consultation document were not translated into ethnic minority languages, e.g. Urdu, until the final 5 weeks of the 4 month consultation.

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104. Given the difficulties that even well motivated and more vulnerable groups experienced with the formal public consultation **we trust that the largest petition of its kind in the United Kingdom will be received with respect and given the proper consideration it's signatories expected when adding their support to the Leeds centre.**

105. As such, we pressed for a response from the JCPCT in terms of how it would weight the petition received. In a response dated 27 September 2011, the Safe and Sustainable Programme Director advised that:

> **'It will be for the JCPCT members to determine the weight that it applies to petitions – and all other types of evidence submitted during public consultation...'**

106. We trust the JCPCT will give significantly greater consideration and weighting to public opinion expressed through the petition from this region than is perhaps otherwise suggested by this response.

An alternative reconfiguration option

107. We have already outlined our proposed alternative reconfiguration option for consideration by the JCPCT. However, we believe it is important to highlight that our rationale for putting forward the 8-surgical centre model, detailed in Principal Recommendation 2, is based on the following matters:

- Co-location of services;
- Travel and access to services; and,
- Caseloads and the number of adults with congenital cardiac disease.

Co-location of services

108. It is widely acknowledged that the co-location of services brings about huge benefits for children and adults with interdependent conditions.

109. As detailed earlier in this report, the review of Children's Congenital Cardiac Services has its roots in the findings and recommendations arising from the Bristol Royal Infirmary Inquiry report (often referred to as the Kennedy Report (2001)). We have considered some aspects of the recommendations made in that report and were particularly struck by recommendation 178, which states:

> ***'Children's acute hospital services should ideally be located in a children's hospital, which should be as close as possible to an acute general hospital. This should be the preferred model for the future.'***

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110. However, we believe that the definition of 'co-location of services' within this review has been loosely interpreted in drawing up the options put forward for public consultation. The term co-location should be used to describe just that – services co-located on a single site, and we believe greater emphasis should be placed on those surgical centres capable of offering services on that basis.

Travel and access to services

111. As previously highlighted, the patient flows predicted under options A-C presented in the consultation document, alongside supporting information considered by the JCPCT, suggest patient travel patterns from the Yorkshire and Humber region that do not appear to match local knowledge.

112. While we welcomed the additional review work and testing of assumptions, we cannot understand why more detailed analysis was not undertaken prior to the proposed options being identified and issued for public consultation. Notwithstanding the availability of this additional assessment work, we firmly believe this will be highly significant and is likely to be a considerable factor in determining whether or not proposed designated centres are likely to attract sufficient patient volumes in order to undertake the suggested minimum number of 400 - 500 surgical procedures per centre.

113. Furthermore, such information will also help to identify and determine whether proposed surgical centres are at risk of being destabilised by an increase in patient numbers above and beyond the planned capacity.

114. In lieu of any evidence to the contrary, we believe that children and families from across Yorkshire and the Humber will be disproportionately and consistently disadvantaged in terms of access and travel times under three (options A-C) of the four options presented. This is reinforced by the details presented in Mott MacDonald's Health Impact Assessment (Interim Report).

115. We believe that extending travel times and the complexity of journeys for patients across Yorkshire and the Humber is likely to place additional strain on children and families at what will already be a particularly stressful time, which we believe to be both unreasonable and unnecessary.

116. We have previously outlined the impact assessment work undertaken by Embrace, which highlighted the disproportionate impact that options A-C would have on children and families across Yorkshire and the Humber. This suggested that between 53% and 73% of the 2010/11 Yorkshire and the Humber transfers could be in excess of the additional 1½ hours highlighted in the review – in comparison to the national figures of between 3.6% and 6.2%. It

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also highlighted that any reconfiguration option that does not include the Leeds surgical centre is likely to see more than a four-fold increase in the mileage covered by the region's transfer and retrieval service.

117. Nonetheless, we recognise that should the surgical centre at Leeds be retained at the expense of the one currently located in Newcastle (i.e. Option D), children and families from across the North East of England (albeit potentially fewer in number) could be subject to similar issues around travel and access to services. We also believe that similar travel and access to services issues may arise should the current surgical centre in Southampton not be retained. For these reasons, we have proposed the retention of the current surgical centres at Leeds, Newcastle and Southampton as part of an 8-surgical centre model.

Caseloads and the number of adults with congenital cardiac disease

118. The minimum number of surgical procedures, both within designated surgical centres and those undertaken by individual surgeons, are a cornerstone to the proposals put forward. While we note the rationale behind the minimum number of procedures presented in the proposals, we remain to be convinced by the clinical evidence used to support and justify the minimum number of procedures.

119. Notwithstanding the suggested minimum number of surgical procedures, we are aware that the NHS is also reviewing the provision of adult congenital cardiac services and the process for designating surgical centres will proceed during 2011. However, we understand that in many cases, the same surgeons treat both children and adults and there is often continuity of care for patients from childhood through into adulthood.

120. We are advised that the adult population requiring cardiac surgery in the future is likely to rise significantly in the coming years and, at some point in the future, may actually rise higher than the number of surgical procedures undertaken on children. This is in part due to the advances in this field of medicine and the increase in survival rates for children into adulthood.

121. We received evidence that adult congenital heart surgery is currently spread across 21 hospitals, many without the expertise and regular experience of operating on congenital heart problems. While this is clearly not safe or sustainable, we also learnt that there were 859 adult congenital heart surgical procedures carried out across the country last year. Using the rationale applied in relation to the review of children's congenital cardiac services, the current volume of adult patients would be enough to justify retaining two centres.

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122. We believe that the consideration of children's and adult's congenital cardiac services as two separate reviews is too simplistic an approach and represents an artificial separation of existing clinical practice. Furthermore, by considering the number of paediatric and adult cardiac surgical procedures in totality, we believe this provides a completely different landscape and, in our view, would significantly affect the number of surgical centres required across the country and would support the 8-centre model proposed.

123. The public consultation document sets out a national projection of around 4,000 procedures by 2025 – which would equate to an average of approximately 670 paediatric cardiac surgical procedures per surgical centre under a 6-centre model and 570 paediatric cardiac surgical procedures per surgical centre under a 7-centre model. This is far in excess of the optimum 400-500 surgical procedures put forward elsewhere in the same consultation document. We feel this represents further evidence to support the 8-centre model proposed.

Concerns and lessons to be learned

124. Throughout this inquiry, we have sought to consider a wide range of evidence and engage with a number of key stakeholders to help in our consideration of the proposals set out in the public consultation document '*Safe and Sustainable: A new vision for Children's Congenital Cardiac Service'* published in March 2011. Elsewhere in the report we have already outlined some of our concerns regarding the proposals and the proposed configuration of designated surgical centres.

125. We have also already outlined some of our concerns on a range of other matters, however for ease of reference we have outlined these below:

Review assumptions

<u>Patient flows</u>

126. Options A-C suggest patient travel patterns from the Yorkshire and Humber region that do not match local knowledge. This has also been highlighted by the Yorkshire and the Humber Specialised Commissioning Group (YHSCG), which (in part) resulted in the commissioning of additional work around testing the assumptions of patient flows under each of the proposed reconfiguration options.

127. As previously stated, while we welcomed this additional review work, we cannot understand why more detailed analysis was not undertaken prior to the options for consultation being identified and issued for public consultation. We understand that the additional assessment work will have a significant focus on

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areas across Yorkshire and the Humber, with 8 (out of 18) postcode areas identified for more detailed analysis and testing.

128. Nonetheless, we remain frustrated that such information will not be available for public scrutiny until after our 5 October 2011 deadline, despite previously being advised that the details would be available in August 2011. As previously stated we must reserve the right to comment as and when the Price-Waterhouse Coopers (PwC) report is published.

Presumed capacity

129. We understand that the review has worked on a stated capacity of 600 surgical procedure per annum at Leeds Teaching Hospitals NHS Trust. We have been advised that this is factually incorrect and at no time has the Trust stated this to be the case. We understand that some additional work commissioned by the JCPCT around surgical capacity is currently ongoing and therefore is not available to us for comment. Again, we reserve the right to comment on this aspect once this has been completed and becomes available.

The number of surgical centres and patient numbers

130. Based on the proposed 6 or 7 surgical centre models, the current national activity (3,600 surgical procedures) equates to an average of 600 or 514 surgical procedures per surgical centre.

131. It seems rather odd that on one hand an optimum number of procedures is presented and then on the other hand the same consultation document outlines two 6-centre options – which will deliver an average number of procedures 20% in excess of the optimum level. **We believe that any current surgical centre that only features in a 6-centre model, such as Leeds, has been severely disadvantaged during the consultation period**.

132. The consultation document also sets out a national projection of around 4,000 procedures by 2025 – which would equate to an average of approximately 670 and 570 paediatric cardiac surgical procedures per surgical centre under the proposed 6-centre and 7-centre models, respectively. Given one of the main aims of the review is to deliver sustainable arrangements for the provision of children's congenital cardiac services, we would question the methodology that proposes future configuration models that are likely to deliver an average number of procedures far in excess of the stated optimum number.

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Adult congenital cardiac surgery would be reviewed separately

133. Throughout our inquiry, there has been significant concern expressed that the review to date has solely focused on congenital cardiac services for children, when in reality it is not uncommon for the same surgeons to treat both children and adults on the same surgical site. As we have already outlined, during 2010/11 the Leeds surgical centre delivered 336 cardiac surgical procedures for children, and a further 56 cardiac surgical procedures for adults. This equates to a total of 392 cardiac surgical procedures.

134. While it is clear that Leeds Teaching Hospitals NHS Trust (LTHT)has reached a level of surgical activity approaching 400 procedures per year (children and adults combined) with only 3 surgeons, we believe surgical activity would have been far in excess of this level if a fourth surgeon were already in post. The impact of similar considerations on other surgical centres is not clear. However, what is clear is that **the 859 adult congenital heart surgical procedures carried out across the country last year would be enough to justify retaining another two surgical centres, if the suggested minimum number of 400 surgical procedures were to be applied**.

135. We believe that considering children's and adult's congenital cardiac services as two separate reviews is too simplistic an approach, representing an artificial separation of existing clinical practice. We also fail to see how the outcome of the review of children's congenital cardiac services can do anything other than pre-determine the outcome of the review of adult's congenital cardiac services.

136. Considering both children's and adult's congenital cardiac services in one review would also have given the adult patients the opportunity to have their views equally heard.

137. We understand that similar concerns around the exclusion of the number of adult procedures have been raised by other professional bodies. We believe that, as yet, these concerns have failed to be adequately addressed.

Review process, governance and transparency

138. To date, we believe there have been a number of fundamental flaws within the review process, its governance and transparency, that must be drawn to the attention of the JCPCT.

139. The consultation document outlines the process behind the proposed changes. This includes development of the proposed national quality standards and model of care, which summarises work undertaken by the Children's Heart Federation. When we questioned the review team regarding this work, we were referred to the Children's Heart Federation. As our concerns were unable to be

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addressed directly, we would question how robustly the JCPCT has considered the information prior to its inclusion with in the consultation document.

Accountability

140. As a Joint Health Overview and Scrutiny Committee (HOSC), we were established as the statutory scrutiny body for Yorkshire and the Humber to consider and respond to the review proposals – representing the 15 top-tier local authorities and a population in excess of 5.5 million. Therefore, not only do we form a key and legitimate part of the democratic process, we also form part of the current statutory arrangements for public accountability within the NHS.

141. As detailed elsewhere in our report, we have been keen to formally engage with the JCPCT as part of our consideration of the proposals and the associated methodology. The former Chair of the Joint HOSC formally raised this matter in April 2011. This was subsequently pursued by the new Chair in August 2011, in the form of two written requests formally inviting a JCPCT representative at attend our meeting on 2 September 2011. This invitation was declined.

142. Subsequent invitations to attend resulted in the offer of attendance on 22 September 2011. This was accepted, only for the expected decision maker not to arrive on the morning of the meeting. The decision maker did eventually attend the committee on the afternoon of the 22 September 2011 but only when issued with a demand to do so.

143. As democratically elected representatives, all members of the Joint HOSC act in the best interest of the communities we represent and take this responsibility very seriously. Three of the four currently proposed options around the reconfiguration of designated surgical centres are likely to have very significant implications for the children and families across our region. It is important therefore that representatives of those communities are afforded the opportunity to question, scrutinise and interrogate the available evidence and appropriately hold decision-makers to account.

144. To help ensure consideration of a broad base of evidence, at its meeting on 2 September 2011, the Joint HOSC formally considered recently published reports by Ipsos MORI on the outcome of public consultation and a Health Impact Assessment report produced by Mott MacDonald.

145. In line with recognised good practice, and as outlined elsewhere in our report, representatives from both organisations were invited to attend our meeting to present their reports and address any questions of the committee. Unfortunately, following discussions with the Safe and Sustainable review team, both organisations declined the invitation to attend as it was not usual practice

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and/or it was felt inappropriate to accept invitations to individual HOSC meetings, as this could lead to an inconsistent approach across different regions.

146. As such, we were left in a position where neither the report commissioners nor the report authors (for the Health Impact Assessment and report on the Public Consultation) were in attendance to present the reports or address any questions from the committee.

147. We took exception to this and made it clear that we believe that a failure to engage with us on the part of the JCPCT demonstrates contempt for local democracy, and has increased cynicism and a lack of confidence in the review process.

Scoring

148. As part of the process for assessing current surgical centres, we have been advised that initially panel members separately assessed each centre in April 2010, based on consideration of a written self-assessment form completed by each centre. The panel then visited each centre between May and June 2010, meeting staff, parents, carers and patients. Panel members took account of what they heard and saw on each centre visit by re-assessing and discussing the initial scores to reach a consensus score for each of the relevant factors.

149. However, while the overall assessment scores are publicly available in the consultation document (page 82) and observations (by way of the Independent Expert Panel Report (December 2010)), the detailed breakdown of those assessment scores have not been made publicly available. We also understand that the assessment scores have not been made available to individual centres – despite requests for that information.

150. We feel very strongly that information such as this should have been made available for public scrutiny prior to any decision on the future configuration of designated surgical centres and believe it is in the public interest to do so

Fair comparisons

151. We do not believe that all existing surgical centres have been considered on the same basis.

152. As outlined elsewhere in this report, we feel that population density in the Yorkshire and the Humber region should have been considered on the same basis as Birmingham, Bristol, Liverpool and the requirement for 2 surgical centres in London, which feature in all four options.

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153. Furthermore, there is a range of co-located paediatric services available at the Leeds Children's Hospital, alongside maternity and other co-located services and specialisms based on the same site at Leeds General Infirmary. Such service configurations have been described as the 'gold standard' for future service provision, yet it appears not to have received sufficient weighting in the case for Leeds.

154. The Yorkshire and Humber region's cardiac network which has operated since 2005 and has been recognised as being "exemplar". The future network model proposed in the consultation document is again described as the 'gold standard' for the future service delivery model, yet three of the four options put forward for consultation would see the fragmentation of the unique and exemplary cardiac network currently in operation in our region.

Consistency of application of criteria

155. Option B includes centres not predicted to achieve the minimum of 400 procedures. As such, we question the consistency of application of the volume criteria which is supposed to underpin the short-listing process.

156. We also question the emphasis that is being placed on nationally commissioned specialist services currently being carried out in certain hospitals in some parts of the country, which seem to outweigh the consideration being given to centres of population in other parts of the country.

Financial calculations and assumptions

157. During our discussion with the Yorkshire and Humber representative of the JCPCT in late September 2011, it was highlighted that, **'…the new configuration would inevitably cost more…**' and may provide **'…a worse service for some patients and their families…'** We queried the likely level of the cost increase and, while we were not provided with any detailed analysis, we understand this is likely to be a significant increase with no additional funding likely to be forthcoming.

158. We have been advised that in terms of the increase in transportation and retrieval activity across Yorkshire and the Humber, increases in the number of out of region transfers are likely under each of the four proposed options, however **the impact of options A-C could be exponential – resulting in over 80% increase in the number of transfer or retrieval journeys, over 100,000 additional miles and over 2000 additional work hours**.

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159. The most realistic model to address this resultant increase in activity would need further investment, through an increase in the number of transport teams (driver, nurse and doctor), alongside an increase in the number of ambulances and other essential equipment. We understand that there has not been any detailed assessment of the increase in expenditure for these services, however it is clear that **any option that does not retain the current surgical centre at Leeds, will result in very significant increases in transportation and retrieval costs for the NHS, as well as families of patients, across this region**.

160. We believe that under Options A-C, **children and families across Yorkshire and the Humber will not only endure a significantly worse patient experience, but this will also be at considerable greater expense to the population across this region**.

161. We believe the overall financial implications associated with the model of care proposed by this review are likely to be very significant – both in terms of establishing new arrangements and the on-going delivery of the proposed model of care. However from the responses we have received to our questions, we believe that to date **there has been insufficient consideration of the financial implications.** We also believe that the level of detail publicly available in this regard has been inadequate.

Scope

162. We raised concerns regarding the scope of the review and the exclusion of similar services delivered in Scotland. We were advised that the scope of the review was limited to services in England and Wales. However it was also highlighted that a small number of cases that flow from Scotland and Northern Ireland to English surgical centres had been taken into account as part of the review.

163. While we recognise that the children's heart surgical unit is Glasgow is part of the Scottish devolved administration's responsibility, we believe that more effort should have been made to include all UK surgical centres within the scope of the review, as this may have had an impact on the potential patient flow, particularly for centres in the North of England.

164. In addition, while services delivered in Scotland have been deemed outside the scope of this review, we note the reference within the consultation document to the existing cardiology centre at Edinburgh and the support this provides to the nearby surgical centre, presumably in Newcastle. Therefore we believe that within the review process, some consideration has been given to some of the services currently delivered in Scotland. Notwithstanding the Scottish devolved administration's responsibility mentioned above, we question the rationale for excluding services delivered in Scotland from the scope of this review.

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Availability of information

165. We have not been able to consider all the information we identified as being necessary to conclude our review, prior to the 5 October 2011 deadline imposed by the review team.

166. Some of that information was not available due to the timing of additional work commissioned during the consultation period. We were also denied access to other information we believe to be relevant, and **it remains unclear on what grounds access to that information has been denied**. We feel very strongly that such information should have been made available for public scrutiny prior to any decision on the future configuration of designated surgical centres and believe it is in the public interest to do so.

167. We have attempted to highlight our concerns throughout the consultation process, and have already raised a number of matters with both the national review team and directly with the Chair of the JCPCT. However we remain seriously concerned that not all relevant information was available to us and other key stakeholders prior to the response deadlines. This information includes:

- The detailed breakdown of assessment scores for surgical centres produced by the Independent Expert Panel (chaired by Sir Ian Kennedy);
- A finalised Health Impact Assessment report;
- The Price Waterhouse Coopers report that tested the assumed patient travel flows under each of the four options presented for public consultation;
- Additional work undertaken around capacity across surgical centres;
- Detailed financial calculations and assumptions.

168. We are also extremely concerned that **the Joint Committee of Primary Care Trusts (JCPCT) failed to adequately engage with us during the consultation period**. Early in the process we highlighted our desire to engage with the JCPCT (as the decision-making body), to discuss the proposals, highlight our concerns and inform the production of this report. Details of our requests are presented at Appendix 4. However, we did not secure the attendance until very late in the process and less than 10-working days prior to our submission deadline. **We believe this type of approach is not in the spirit of open, transparent and accountable decision-making,** and serves only to undermine public confidence in the planning and delivery of local health services. We trust this approach will not be repeated in any future consultations.

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169. We are also concerned that we have been unable to engage with two independent third party organisations, namely Ipsos MORI and Mott MacDonald, that authored key reports. While the reports have been available to us for consideration, we feel it is good practice that the author(s) of any report considered by the committee should be available to present and discuss the reports if invited to do so. We extended an invitation to both Ipsos MORI and Mott MacDonald in this regard, which was subsequently declined.

170. We understand that both organisations declined our invitation based on advice given by the national review team. We believe that such advice is wholly inappropriate and once again is not in the spirit of open, transparent and accountable decision-making.

171. We also sought additional, and in our view essential, information highlighted in the Health Impact Assessment (HIA) Interim Report. Notwithstanding the interim status of the HIA report, this presented the following information in terms of vulnerable groups:

- *Children (under 16s) who are the primary recipient of the services under review and, therefore, most sensitive to service changes;*
- *People who experience socio-economic deprivation;*
- *People from Asian ethnic groups, particularly those with an Indian, Pakistani, Bangladeshi and other Indian subcontinent heritage;*
- *Mothers who smoke during pregnancy; and*
- *Mothers who are obese during pregnancy;*

These groups are defined as vulnerable groups because they are more likely to need the services under review and, are most likely to experience disproportionate impacts.

172. The report states there are currently 2745 patients in vulnerable postcode districts, and sets out the likely travel and access impacts on vulnerable groups / postcode districts (based on current patient activity) under each of the proposed options (A-D).

173. We requested further information about how this analysis related specifically to children and families across Yorkshire and the Humber, but this information was not forthcoming. In the response denying access to this information, the Safe and Sustainable Programme Director, stated:

> *"Mott MacDonald have been commissioned to report on the Health Impact Assessment in a way that is transparent and equitable… I would not wish to influence the robust process they have undertaken by requesting the methodology is changed by singling out a particular area for analysis.*

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Similarly, it would not be appropriate for me to ask them to release the data to one interested party, particularly as some stakeholders have already submitted their final response to consultation and would not have had the opportunity to take this data into account when formulating their responses."

174. We believe this is an unsatisfactory response that denies legitimate access to information we believe to be crucial when considering the impact on children and families in this region. All Overview and Scrutiny Committees have had the same opportunity to seek similar information should they wish to have done so, as such **we do not believe there is any legitimate reason why this information was not made available to us.**

175. Overall, we have been astounded by the contempt displayed towards the legitimate public scrutiny of the review and its proposals. The dismissive response to many of our requests for information – to help us consider the proposals, the evidence-base and the implications for children and families across Yorkshire and the Humber – has been inexcusable.

Nationally Commissioned Services – Heart transplantation, ECMO and Complex Tracheal Surgery.

176. As set out in the consultation documents, an expert panel was appointed to consider the delivery of the three nationally commissioned services and advise the JCPCT accordingly. The consultation document also sets out the conclusions of the expert panel, including the view that 'the optimum is to maintain Nationally Commissioned Services in their current locations if possible.'

177. At our meeting on 22 September 2011 and as set out in the consultation document, we were advised that, in common with all other current providers of children's cardiac surgery in England (who were not currently providers of nationally commissioned services) Leeds Teaching Hospitals NHS Trust (LTHT) were invited to express an interest in providing one or more of the three nationally commissioned services. LTHT expressed an interest in providing all three services and we were provided with details of those submissions.

178. We were advised by LTHT that the Trust was given 16 working days (13 April 2010 to 7 May 2010) to complete and submit the proforma and accompanying evidence, and understand that very limited feedback has been provided by the expert panel.

179. We were also advised that the assessment of the potential to deliver these services was undertaken solely through consideration of the completed proforma and accompanying evidence by an expert panel. This is supported by

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the details outlined in Appendix 2 of the consultation document. As such, we understand that assessments did not include any site visits and/or interviewing of potential providers.

180. LTHT acknowledged the likelihood that any centre not currently providing these services would need to expand and develop some of the necessary skills / resource. However, we were also advised that without having any specific feedback regarding its submission, it was difficult for the Trust to explain or convey why the expert panel was not confident that the Trust had demonstrated it had the appropriate skills and infrastructure to deliver such services in the future.

181. We had been previously advised by LTHT that, of the three nationally commissioned services, delivery of ECMO specifically would be the easiest to implement – particularly given that such interventions become necessary when undertaking many cardiac surgical procedures, albeit for a relatively short period of time. However, we were subsequently advised that the Trust already had trained perfusionists, surgeons, nurses in theatres and on Intensive Therapy Unit (ITU) who have the necessary skills to deliver the service. As such, expanding and developing such areas would not be prohibitive to the delivery of the service – particularly given the anticipated implementation phase of the review (approximately 12 months).

182. The consultation document details the scoring of the expert panel (against a maximum of 30) and presents these by way of a 'league table' for each of the nationally commissioned services. These league tables also includes current providers of each service – with each provider being awarded the maximum score of 30. However, the available information does not suggest that current providers were required to provide any details associated with their provision against the six assessment areas and, therefore, seemingly not subject to the same assessment process. In our view, to award any centre a maximum score, without any assessment (or description of such assessment) is not good practice and wholly inappropriate. This suggests there are no areas for improvement within a centre currently delivering a nationally commissioned services.

183. Based on the information available to us, we are concerned that:

- the process for considering the potential delivery of nationally commissioned services across all providers (including current providers) has not been consistent,
- the process for considering the potential delivery of nationally commissioned services has not been sufficiently robust, and has essentially been a paper based assessment.

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- potential providers were not given sufficient time to complete and return the necessary documentation.
- the future delivery of nationally commissioned services has seemingly proven to be a fundamental factor in drawing up the consultation options. However, these services do not appear to have been considered sufficiently important to be included in the initial self-assessment.
- LTHT has never been provided with the detail of the expert panel's assessment or been given access to the scores / rationale as to why the expert panel was not confident that such services could be provided by the Trust.

184. As such, we would question the appropriateness of the methodology and approach employed for considering the future delivery of nationally commissioned services, and query the relative significance of delivering such services and the associated timing within the overall review.

Training

185. As part of our inquiry, we questioned the degree to which the impact on training future surgeons, cardiologists and other medical/ nursing staff had been factored into the review. In response the Safe and Sustainable Programme Director advised that *'…the JCPCT recognises that improved training processes will need to be put in place for clinical staff…'* and that the independent expert panel, chaired by Professor Sir Ian Kennedy, concluded that *'…the succession planning for surgeons must be a key consideration for the future delivery of paediatric cardiac service.'* The response concluded *'…this is an issue for the implementation phase of the review rather than the assessment phase.'* We were further advised that ***'The 'track record for training new doctors' has not fed into the assessment of the current centres.'***

186. We were advised by a Leeds Teaching Hospitals NHS Trust clinician that in its 'teaching hospital' role, the Trust provides a range of student placements in a wide range of roles and over a number of different disciplines. While the Trust does not deliver any formal training for cardiothoracic surgeons, it was outlined that 3 trainee cardiologists are in post in the Trust at any one time.

187. We were further advised that the Trust had been instrumental in developing a regional training model for general paediatricians to develop and extend their knowledge around cardiology. It seems likely that this would be lost if the current surgical centre at Leeds was not retained in the future configuration of designated surgical centres.

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188. While the full impact of the likely training requirements are not yet known, **we believe a regional training and development programme will be an essential element in the delivery of the proposed network model of care.**

189. We believe this aspect has received insufficient consideration to date, and are concerned that Leeds Teaching Hospitals NHS Trust's role in developing a regional training model does not appear to have been given any weighting in this review.

Public consultation

190. As part of the public consultation process, we understand that it has been stated on numerous occasions that the JCPCT is open-minded in terms of the future reconfiguration of designated surgical centres, and will consider any alternative models put forward that have not already considered.

191. While we welcome this suggestion, the public consultation document clearly states that **'Based on 11 centres there are 2047 possible different ways to configure the service.'** The consultation document then describes the various stages of the options assessment process, including establishing a shortlist of viable options and scoring of the viable reconfiguration options identified – which leads to the formation of the four configuration options identified for public consultation. Assuming the 2047 possible permutations and the options assessment process are robust, we fail to see how the public consultation process will deliver any alternative models that have not already been considered and dismissed.

192. As such, we question how open-minded the JCPCT will be and how the public consultation can be described as being '*…at a time where the policy decision can be influenced*'.

193. During our inquiry our attention was drawn to the accessibility of the consultation questionnaire, which was identified as the primary source to gather public opinion on the proposals. We heard from different sources that the questionnaire was complex and not user friendly – referring to a public consultation document in excess of 230 pages in length. While we appreciate that the subject matter is complex and covers a number of different, albeit related issues, we question the logic behind the approach used. Concern was also expressed that a significant emphasis was placed on completing the questionnaire on-line. **We believe that a public consultation exercise should aim to encourage participation, make information accessible and allow people to contribute in a way which is convenient and meaningful to them – not those responsible for analysing responses**.

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194. We would also question the role of the JCPCT in agreeing a communications plan that failed to identify particular BME communities within the plans for public consultation at the outset – particularly when it is already known that members of some of those communities are more likely to need to access congenital cardiac services. It was suggested to us that members of the JCPCT raised concerns in this regard but were advised **'…it was too late…'** to do anything about. The timing of such concerns and the origin of the associated advice are unclear, however this seems a wholly inappropriate manner in which to address concerns raised by the decision-making body.

195. We have already expressed our concern regarding the comments from the Safe and Sustainable Programme Director in relation to the weighting likely to be given to public petition, who advised that:

> **'It will be for the JCPCT members to determine the weight that it applies to petitions – and all other types of evidence submitted during public consultation – when it meets to consider the responses to consultation.'**

196. We trust the JCPCT will give significantly greater consideration and weighting to public opinion expressed through the petition from this region than is suggested by this response.

197. We also considered a number of Council motions from a number of authorities across the region. In the main, these were directed at the Secretary of State for Health and for many authorities we were provided with the response received. What is striking is that while the responses more often than not make reference to the on-going public consultation, the Council motions do not appear to have passed to Ipsos MORI for inclusion within the consultation report. We believe this demonstrates a disconnection between different part of the NHS. As such, the council motion details are presented at Appendix 5 for consideration.

Engagement with Black and Minority Ethnic (BME) communities

198. We understand that children and families from the Indian sub-continent in particular are more likely to require children's congenital heart services. There is a significant population of BME communities of Kashmiri, Pakistani and other Indian sub-continent communities across Yorkshire and the Humber who ought to have been better engaged in this consultation from the outset.

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199. Engagement of these communities received insufficient attention across Yorkshire and the Humber. Translated information was not available until the final 5 weeks of the 4 month public consultation process.

200. As local authorities strive to maintain stronger and thriving local communities, it is important that public sector agencies work together to ensure active engagement across all communities. We do not feel that this public consultation sufficiently addressed this aspect of involvement and engagement.

Consultation with the Joint Health Overview and Scrutiny Committee (HOSC)

201. To help the Joint HOSC produce a fully informed report/response, it has been essential to gather and consider a wide range of data/ evidence. This specifically includes consideration of the local data and impacts. The level of detail required was not readily available when the proposals were first published and the detail that was subsequently made available has taken time to gather and analyse. The result of which served to severely limit the timeframe for the Joint HOSC to meet to consider the local data and impacts.

202. Concerns were raised about the timing of public consultation and involvement of HOSCs in November 2010, when it first emerged that the original timetable for consultation was likely to be delayed. Hence, following local elections, the inevitable changes to the membership of the Joint HOSC has had a significant impact on the meaningful involvement of the committee during the whole of the reported '7-month consultation period'. It should be recognised that as a result of the public consultation's proximity to local council elections – which resulted in a significant change in membership (over 50%) – the Joint HOSC was unable to arrange further meetings until after the close of pubic consultation on 1 July 2011.

203. Nonetheless, throughout this inquiry, we have sought to consider a wide range of evidence and engage with a number of key stakeholders to help in our consideration of the proposals. The range of evidence considered has included information produced by constituent authorities of the Joint HOSC. These details are presented at Appendix 6.

204. Regrettably, we have not been able to consider all the information we identified as being necessary to conclude our review, prior to our 5 October 2011 deadline imposed by the review team. Some of that information was not available due to the timing of some additional work commissioned by the JCPCT during the consultation period, while we have also been denied access to other information we believe to be relevant. **We feel very strongly that such information should have been made available for public scrutiny prior**

Conclusions and Recommendations

to any decision on the future configuration of designated surgical centres and believe it is in the public interest to do so.

205. We are stunned by the contempt displayed towards the legitimate public scrutiny of the review and its proposals. The dismissive response to many of our requests for information – to help us consider the proposals, the evidence-base and the implications for children and families across Yorkshire and the Humber – has been inexcusable.

206. Nonetheless, we welcome the suggestion that the Centre for Public Scrutiny (CfPS) will be involved as part of the 'lessons learned' activity associated with this review and we look forward to being actively involved and contributing to this process.

Summary of Evidence

Monitoring arrangements

Standard arrangements for monitoring the outcome of the recommendations will apply.

Decision-makers to whom the recommendations are addressed will be asked to submit a formal response to the report and its recommendations, as required under current legislation.

The Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) will then determine any further monitoring of the recommendations.

Reports and Publications Submitted

14 March 2011

- Safe and Sustainable - A new vision for Children's Congenital Heart Services in England: Consultation Document (March 2011)
- Safe and Sustainable - Congenital Heart Services in England: Briefing 2 (Spring 2011)
- Safe and Sustainable – A New Vision for Children's Congenial Heart Services in England – Presentation Slides prepared by Cathy Edwards, Director of Yorkshire and Humber Specialised Commissioning Group

29 March 2011

- Reconfiguration of Children's Congenital Heart Services in England – initial response from Leeds Teaching Hospitals NHS Trust
- Projected/ estimated population flows under each of the 4 consultation options
- Frequently asked questions (FAQs) and the associated responses available from the Safe and Sustainable website
- A letter from the Leader of Leeds City Council

2 September 2011

- JCPCT Update: correspondence
- Health Impact Assessment: Interim Report (Mott MacDonald)
- Report of the public consultation (Ipsos Mori)
- Regional Congenital Cardiac Network Strategy (March 2011)
- Congenital Cardiac Network Board: Response to the Safe and Sustainable Review of Children's Congenital Cardiac Services in England (June 2011)
- Yorkshire and the Humber Regional Impact Assessment (Specialised Commissioning Group)
- Leeds Teaching Hospitals NHS Trust: Formal response to the 'Safe and Sustainable - A New Vision for Children's Congenital Heart Services in England – Consultation Document'

Summary of Evidence

Reports and Publications Submitted (continued)

2 September 2011 (cont.)

- Adult Congenital Heart Disease (ACHD) in Yorkshire and the Humber: A briefing document
- Adult Congenital Heart Disease – a commissioning guide for services (May 2006)
- Neonatal time critical cardiac transfers in the Yorkshire and Humber region: S Oruganti et al
- Bonding and attachment in CHD babies and young children: Leeds Teaching Hospitals NHS Trust
- Regional Infant and Children's Transport Service: Impact assessment
- Written submissions from the following Hospital Trusts:
  - Airedale NHS Foundation Trust
  - Alder Hey Children's NHS Foundation Trust
  - Harrogate and District NHS Foundation Trust
  - Northern Lincolnshire and Goole Hospitals NHS Foundation Trust
  - Sheffield Children's NHS Foundation Trust
- Children's Heart Surgery Fund – report on regional engagement activity
- Feedback from the following local authorities:
  - Kirklees Council
  - Leeds City Council
  - North East Lincolnshire Council
  - North Lincolnshire Council
  - North Yorkshire County Council
  - Rotherham Council,
  - Wakefield Council.

19 September 2011

- JCPCT: correspondence and written response to questions

22 September 2011

- JCPCT: correspondence and written response to questions
- Additional information from Leeds Teaching Hospitals NHS Trust
- Details (and associated correspondence) of Council motions from the following authorities across Yorkshire and the Humber:
  - City of York Council – 7 April 2011
  - East Riding of Yorkshire Council – 27 July 2011
  - Harrogate Borough Council – 13 April 2011
  - Kirklees Council – 23 March 2011
  - Leeds City Council – 6 April 2011 and 14 September 2011
  - Rotherham Council – 27 July 2011
  - Sheffield City Council – 6 July 2011
  - Wakefield Council – 30 March 2011

Summary of Evidence

Reports and Publications Submitted (continued)

22 September 2011 (continued)

- Comments from the following Members of Parliament (Yorkshire and the Humber):
  - Julian Smith MP (Skipton and Ripon)*
  - Michael Dugher MP (Barnsley East)*
- Additional information from Leeds Teaching Hospitals NHS Trust

29 September 2011

- Children's Heart Federation – details of survey work undertaken
- Feedback from the following local authorities:
  - City of Bradford MDC
  - East Riding of Yorkshire Council
- Comments from the following Members of Parliament (Yorkshire and the Humber):
  - Hilary Benn (Leeds Central)*
  - Rosie Winterton (Doncaster Central)*

4 October 2011

- Comments from the following Members of Parliament (Yorkshire and the Humber):
  - Austin Mitchell MP (Great Grimsby)*

Other reports and evidence considered

- Bristol Royal Infirmary Inquiry Final Report: Section Two – Recommendations
- Code of Practice on Consultation (HM Government (July 2008))
- Final Report: The relationship between volume and outcome in Paediatric Cardiac Surgery – a literature review for the National Apecialised Commissioning Group (September 2009)
- Safe and Sustainable: Review of Children's Congenital Cardiac Services in England: Pre-consultation business case
- Safe and Sustainable: Review of Children's Congenital Cardiac Services in England: Report of Independent Expert Panel Chaired by Professor Sir Ian Kennedy (December 2010)
- Safe and Sustainable: Review of Children's Congenital Cardiac Services in England: Response form (March 2011)

** Comments provided are attached at Appendix 8*

Summary of Evidence

Witnesses Heard

- Dr Mike Blackburn (Paediatric Cardiologist), Leeds Teaching Hospitals NHS Trust
- Maggie Boyle (Chief Executive), Leeds Teaching Hospitals NHS Trust
- Elspeth Brown (Consultant Cardiologist), Leeds Teaching Hospitals NHS Trust
- Lois Brown (Parent)
- Andy Buck (Chief Executive), NHS South Yorkshire and Bassetlaw
- Dr Derek Burke (Medical Director), Sheffield Children's NHS Foundation Trust
- Ailsa Claire (Yorkshire and the Humber representative), Joint Committee of Primary Care Trusts
- Sharon Cheng (Charity Director), Children's Heart Surgery Fund (CHSF)
- Alison Conchie (Children's Services Business Manager), Leeds Teaching Hospitals NHS Trust
- Dr Mark Darowski (Paediatric Intensivist), Leeds Teaching Hospitals NHS Trust
- Matthew Day (Specialty Registrar in Public Health), Specialised Commissioning Group (Yorkshire and the Humber)
- Cathy Edwards (Director), Specialised Commissioning Group (Yorkshire and the Humber)
- Dr Steve Hancock (Lead Paediatric Consultant), Embrace, Sheffield Children's NHS Foundation Trust
- Stacey Hunter (Divisional General Manager (Leeds Children's Hospital)), Leeds Teaching Hospitals NHS Trust
- Judith Huntley (Cardiac Nurse), Leeds Teaching Hospitals NHS Trust
- Ruth Lund (Yorkshire and Humber Congenital Cardiac Network Manager), Specialised Commissioning Group (Yorkshire and the Humber)
- Karl Milner (Director of Communications),Leeds Teaching Hospitals NHS Trust
- Liz Murch (Clinical Nurse Manager), Embrace and Paediatric Critical Care, Sheffield Children's NHS Foundation Trust
- Dr Kevin Smith (Medical Adviser), Specialised Commissioning Group (Yorkshire and the Humber)
- Dr John Thomson (Consultant Cardiologist), Leeds Teaching Hospitals NHS Trust
- Kevin Watterson (Paediatric Cardiac Surgeon), Leeds Teaching Hospitals NHS Trust and Children's Heart Surgery Fund (CHSF) Trustee
- Debra Wheeler (Children's Services Directorate Manager), Leeds Teaching Hospitals NHS Trust

Please note: *The above details do not reflect any engagement with parents or parent groups undertaken by individual members of the committee, outside of the formal meeting arrangements and organised site visits.*

Summary of Evidence

Dates of Scrutiny

12 January 2011	–	Health Overview and Scrutiny Committees - Yorkshire and the Humber Network meeting: Briefing meeting
14 March 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 1 – outline of proposals
29 March 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 2 – evidence gathering
29 March 2011	–	Site visit, Leeds Children's Hospital: Discussions with staff and parents
18 July 2011	–	Health Overview and Scrutiny Committees - Yorkshire and the Humber Network meeting: Briefing meeting (new members)
22 August 2011	–	Site visit, Leeds Children's Hospital: Discussions with staff, parents and other family members
2 September 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 3 – evidence gathering
19 September 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 4 – evidence gathering
22 September 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 5 – evidence gathering
29 September 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 6 – evidence gathering. Initial draft report
4 October 2011	–	Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – Session 7 evidence gathering. Final draft report

Please note: *The above details do not reflect the local engagement work undertaken by individual members of the committee, outside of the formal meeting arrangements and organised site visits.*

Appendix 1: Background and Scope

Background

1. In 2008, in response to concerns raised by clinicians and parent groups, the NHS Medical Director requested a review of Children's Congenital Heart Services in England. The aim of the review was to develop and bring forward recommendations for a *Safe and Sustainable* national service that has:

   - Better results in surgical centres with fewer deaths and complications following surgery.
   - Better, more accessible assessment services and follow up treatment delivered within regional and local networks.
   - Reduced waiting times and fewer cancelled operations.
   - Improved communication between parents/ guardians and all of the services in the network that see their child.
   - Better training for surgeons and their teams to ensure the service is sustainable for the future.
   - A trained workforce of experts in the care and treatment of children and young people with congenital heart disease.
   - Surgical centres at the forefront of modern working practices and new technologies that are leaders in research and development.
   - A network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network.

2. Since that time, on behalf of the ten Specialised Commissioning Groups in England, and their constituent local Primary Care Trusts, the *Safe and Sustainable* review team (at NHS Specialised Services) has managed the review process, which has involved:

   - Engaging with partners across the country to understand what works well at the moment and what needs to be changed.
   - Developing standards – in partnership with the public, NHS staff and their associations – that surgical centres must meet in the future.
   - Developing a network model of care to help strengthen local cardiology services.
   - An independent expert panel assessment of each of the current surgical centres against the standards.
   - The consideration of a number of potential configuration options against other criteria including access, travel times and population.

3. In August 2009, the first 'Safe and Sustainable' newsletter was published. This set out the aims and objectives of the review programme, and outlined how the children's cardiac surgery programme would be developed in England. This was the first information about the national review provided to a range of stakeholders, including local authority Health Overview and Scrutiny Committees.

Appendix 1: Background and Scope

4. Subsequent newsletters were published in November 2009, May 2010, December 2010 and most recently in August 2011.

5. In April 2010, a 'Need for Change' document, endorsed by the relevant professional bodies and patients associations, was published, which highlighted the following issues:

   - Children's heart surgery is becoming increasingly complex.
   - Services have developed on an ad hoc basis; there is a need for a planned approach for England and Wales.
   - Surgical expertise (31 surgeons) is spread too thinly over 11 surgical centres.
   - Some centres are reliant on one or two surgeons and cannot deliver a safe 24 hour emergency service.
   - Smaller centres are vulnerable to sudden and unplanned closure.
   - Current arrangements are inequitable as there is too much variation in the expertise available from centres.
   - Fewer surgical centres are needed to ensure that surgical and medical teams are seeing a sufficient number of children to maintain and develop their specialist skills.
   - Available research evidence identifies a relationship between higher-volume surgical centres and better clinical outcomes.
   - Having a larger and varied caseload means larger centres are best placed to recruit and retain new surgeons and plan for the future.
   - The delivery of non-surgical cardiology care for children in local hospitals is inconsistent; strong leadership is required from surgical centres to develop expertise through regional and local networks.
   - Increasing the national pool of surgeons is not the answer, as this would result in surgeons performing fewer surgical procedures and increase the risk of occasional surgical practice.

6. In January 2011, the Regional Health Scrutiny Network (Yorkshire and the Humber) received a briefing from the Director of the Specialised Commissioning Group (Yorkshire and the Humber) on the review process and associated timescales. This was provided in the run up to the meeting of the Joint Committee of Primary Care Trusts (JCPCT) in February 2011.

7. The meeting of the JCPCT took place on 16 February 2011, where the following recommendations and options for consultation were presented and agreed:

   - Development of Congenital Heart Networks across England that would comprise all of the NHS services that provide care to children with Congenital Heart Disease and their families, from antenatal screening through to the transition to adult services.

Appendix 1: Background and Scope

- Implementation of new clinical standards that must be met by all NHS hospitals designated to provide heart surgery for children.
- Implementation of new systems for the analysis and reporting of mortality and morbidity data relating to treatments for children with Congenital Heart Disease.
- A reduction in the number of NHS hospitals in England that provide heart surgery for children from the current 11 hospitals to 6 or 7 hospitals in the belief that only larger surgical centres can achieve true quality and excellence.
- The options for the number and location of hospitals that provide children's heart surgical services in the future are presented:

Option A: Seven surgical centres: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Glenfield Hospital, Leicester • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[1]	**Option B: Seven surgical centres:** • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • Southampton General Hospital • 2 centres in London[1]
Option C: Six surgical centres: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[1]	**Option D: Six surgical centres:** • Leeds General Infirmary • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[1]

8. At the same meeting of the JCPCT, it was agreed that public consultation on the proposals would commence on 28 February 2011, running until 1 July 2011.

[1] *The preferred two London centres in each of the four options are Evelina Children s Hospital and Great Ormond Street Hospital for Children*

Appendix 1: Background and Scope

Scope of the Inquiry

9. Forming a joint health overview and scrutiny committee, to consider the reconfiguration of health services covering the whole of the Yorkshire and the Humber region, is an extraordinary and previously unprecedented requirement. The coordination of this work should not be underestimated and we are extremely grateful to the network of scrutiny support officers for their continued efforts in this regard.

10. At our first meeting in March 2011[2], we considered and agreed the terms of reference for our work as a formal joint committee. The full terms of reference are presented at Annex 1, however these can be summarised as considering:
    - The review process and formulation of options presented for consultation;
    - The projected improvements in patient outcomes and experience;
    - The likely impact on children and their families (in the short, medium and longer-term), in particular in terms of access to services and travel times;
    - The views of local service users and/or their representatives;
    - The potential implications and impact on the health economy and the economy in general, on a local and regional basis; and,
    - Any other pertinent matters that arise as part of the our inquiry.

11. At our second meeting in March 2011, we considered how we might gather the necessary evidence to help us form an objective view of the proposals and agreed an outline action plan. We kept our actions under review as our inquiry progressed, therefore the outline action plan was indicative rather than completely definitive of our overall approach.

12. A brief outline of our meetings is provided within the main body of the report. Nevertheless, it should be recognised that due to the timing of the consultation and the close proximity of local elections the Joint HOSC was unable to arrange further meetings until after the close of pubic consultation on 1 July 2011.

13. It should be noted that the outcome of the local elections resulted in a significant change in membership (over 50%) of the Joint HOSC. This, almost inevitable change to the membership of the Joint HOSC, has had a significant impact on the meaningful involvement of the committee during the whole of the reported '7-month consultation period' for Health Overview and Scrutiny Committees. Details in the change in membership are outlined in the Terms of Reference attached at Annex 1.

[2] Revisions to the Terms of Reference were agreed at the meeting held on 2 September 2011.

Appendix 1:
Background and Scope

14. It should also be noted that concerns about the timing of public consultation and involvement of HOSCs were raised in November 2010, when it first emerged that the original timetable for consultation was likely to be delayed.

15. As part of our inquiry, many members of the committee took the opportunity to visit the current surgical centre in Leeds and the additional facilities on offer. In addition, a number of members met with children and families within their own local authority boundary to hear first hand of their experience of the current services and any concerns around the proposed changes. This vital information from service users informed a number of the Joint HOSC's discussions and is reflected in the inquiry report and its recommendations.

Appendix 1:
Background and Scope

Annex 1

JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (YORKSHIRE AND THE HUMBER)

REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND

TERMS OF REFERENCE[3]

1.0 Introduction and background

1.1 Children's heart surgery is an increasingly complex procedure that demands great technical skill and expertise from surgeons and their teams. In the Yorkshire and the Humber region, Leeds Teaching Hospitals NHS Trust currently offers the only surgical centre that provides children's heart surgery services. Following the local reconfiguration of hospital services, these services are delivered at the Children's Hospital, located within Leeds General Infirmary (LGI).

1.2 In 2008, in response to concerns raised by clinicians and parent groups, the NHS Medical Director requested a review of Children's Congenital Heart Services in England. Concerns had been raised that some centres were not performing enough surgical procedures to maintain and develop their specialist skills, and some centres did not have enough surgeons to guarantee a safe 24/7 service. There was also some concern that the NHS is too reliant on other countries to train the next generation of children's heart surgeons.

1.3 As such, the aim of the review was to develop and bring forward recommendations for a *Safe and Sustainable* national service that has:

- Better results in surgical centres with fewer deaths and complications following surgery
- Better, more accessible assessment services and follow up treatment delivered within regional and local networks
- Reduced waiting times and fewer cancelled operations
- Improved communication between parents/ guardians and all of the services in the network that see their child
- Better training for surgeons and their teams to ensure the service is sustainable for the future
- A trained workforce of experts in the care and treatment of children and young people with congenital heart disease

[3] As amended on 2 September 2011

Appendix 1: Background and Scope

- Surgical centres at the forefront of modern working practices and new technologies that are leaders in research and development
- A network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network

1.4 On behalf of the ten Specialised Commissioning Groups in England, and their constituent local Primary Care Trusts, the *Safe and Sustainable* review team (at NHS Specialised Services) has managed the review process. This has involved:

- Engaging with partners across the country to understand what works well at the moment and what needs to be changed
- Developing standards – in partnership with the public, NHS staff and their associations – that surgical centres must meet in the future
- Developing a network model of care to help strengthen local cardiology services
- An independent expert panel assessment of each of the current surgical centres against the standards
- The consideration of a number of potential configuration options against other criteria including access, travel times and population.

1.5 At the Joint Committee of Primary Care Trusts (JCPCT) meeting held on 16 February 2011, the review team reported an overwhelming feeling that the time for change is long overdue. At that meeting the JCPCT was presented with the following recommendations:

- Development of Congenital Heart Networks across England that would comprise all of the NHS services that provide care to children with Congenital Heart Disease and their families, from antenatal screening through to the transition to adult services.
- Implementation of new clinical standards that must be met by all NHS hospitals designated to provide heart surgery for children.
- Implementation of new systems for the analysis and reporting of mortality and morbidity data relating to treatments for children with Congenital Heart Disease.
- A reduction in the number of NHS hospitals in England that provide heart surgery for children from the current 11 hospitals to 6 or 7 hospitals in the belief that only larger surgical centres can achieve true quality and excellence.
- The options for the number and location of hospitals that provide children's heart surgical services in the future are:

Appendix 1: Background and Scope

Option A: Seven surgical centres: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Glenfield Hospital, Leicester • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[4]	**Option B: Seven surgical centres:** • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • Southampton General Hospital • 2 centres in London[4]
Option C: Six surgical centres: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[4]	**Option D: Six surgical centres:** • Leeds General Infirmary • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[4]

1.6 Having analysed the available information, the JCPCT agreed that the above options should form the basis of public consultation – commencing on 28 February 2011 and running until 1 July 2011.

2.0 Purpose and scope of the inquiry

2.1 The purpose of the joint scrutiny inquiry is to make an assessment of, and where appropriate, make recommendations on the potential options to reconfigure the delivery of Children's Congenital Heart Services in England.

2.2 In receiving the identified options, the Joint Health Overview and Scrutiny Committee (HOSC) will consider the likely implications across the Yorkshire and Humber region. This will include consideration of the:

- Review process and formulation of options presented for consultation;
- Projected improvements in patient outcomes and experience;
- Likely impact on children and their families (in the short, medium and longer-term), in particular in terms of access to services and travel times;
- Views of local service users and/or their representatives;

[4] *The preferred two London centres in each of the four options are Evelina Children s Hospital and Great Ormond Street Hospital for Children*

Appendix 1: Background and Scope

- Potential implications and impact on the health economy and the economy in general, on a local and regional basis;
- Any other pertinent matters that arise as part of the Committee's inquiry.

2.3 Consideration will also be given to the arrangements for consulting on the proposals and a view given regarding the adequacy of such arrangements.

2.4 The work of the joint HOSC will, as far as practicable, be undertaken to reflect the general principles set out in the Joint Health Scrutiny Protocol (Yorkshire and the Humber).

2.5 The joint HOSC intends to provide a timely and positive contribution to the public consultation on the proposals.

3.0 Comments from participating Health Overview and Scrutiny Committees

3.1 In the development of these terms of reference, comments from constituent and participating local authority health overview and scrutiny committees (HOSCs) have been taken into account.

4.0 Timetable for the inquiry and submission of evidence

4.1 The joint scrutiny inquiry will commence in March 2010.

4.2 As part of the public consultation on the future of Children's Congenital Heart Services in England, Health Overview and Scrutiny Committees have been given until 5 October 2011 to respond to the proposals.

4.3 As such, the likelihood is that any report/ recommendations will need to be finalised and agreed by the end of September 2011.

5.0 Membership and arrangements for the Joint HOSC

5.1 Membership and arrangements for the joint HOSC shall be in accordance with the Joint Health Scrutiny Protocol (Yorkshire and the Humber).

5.2 Following individual decisions and nominations from constituent local authorities, the membership of the Joint HOSC will be:

- Barnsley MBC – Cllr. Jen Worton replacing Cllr. Janice Hancock
- Bradford MDC – Cllr. Mike Gibbons replacing Cllr. Elaine Byrom
- Calderdale Council – Cllr. Ruth Goldthorpe
- City of York Council – Cllr. Sian Wiseman replacing Cllr. Sandy Fraser
- Doncaster MBC – Cllr. Tony Revill replacing Cllr. Georgina Mullis
- East Riding of Yorkshire Council – Cllr. Barbara Hall
- Hull City Council – Cllr. Danny Brown replacing Cllr. John Hewitt

Appendix 1: Background and Scope

- Kirklees Council – Cllr. Liz Smaje
- Leeds City Council – Cllr. Lisa Mulherin (Chair) replacing Cllr. Mark Dobson (Chair)
- North East Lincolnshire Council – Cllr. Karl Wilson replacing Cllr. Peggy Elliot
- North Lincolnshire Council – Cllr. Jean Bromby replacing Cllr. Trevor Barker
- North Yorkshire County Council – Cllr. Jim Clark
- Rotherham MBC – Cllr. Shaukat Ali
- Sheffield City Council – Cllr. Ian Saunders
- Wakefield Council – Cllr. Betty Rhodes

5.3 As the administering authority, attendance of substitute/ alternate members will be in accordance with Leeds City Council's Scrutiny Procedural Rules.

6.0 Witnesses

6.1 The following organisations (including appropriate representatives) and witnesses have been identified as possible contributors to this joint inquiry:

- Parents and/or service user representatives
- Specialised Commissioning Group (Yorkshire and the Humber)
- Leeds Teaching Hospitals NHS Trust
- Appropriate professionals and/or professional bodies
- Primary Care Trusts (Yorkshire and the Humber)
- Yorkshire Ambulance Service (YAS) and/or other patient transport organisations
- Local GPs and/or their representative body
- Local Members of Parliament
- Local Authority representatives

6.2 The Joint HOSC will seek to identify and receive all relevant contributions, using a variety of methods to gather information. As such, the Joint HOSC will aim to keep the list of witnesses under review throughout the joint inquiry.

7.0 Monitoring arrangements

7.1 Following completion of the joint scrutiny inquiry and the publication of the consultation response and/or recommendations, a response from the appropriate NHS body (or bodies) receiving the report, will be requested within 28 working days and subsequently considered by the joint HOSC as soon as practicable.

Appendix 1: Background and Scope

7.2 Any other monitoring arrangements agreed by the joint HOSC will be included in the final report.

8.0 Measures of success

8.1 The Joint HOSC will seek to respond to the consultation proposals in an appropriate manner, and publish realistic and practical recommendations, as appropriate. However, how the joint HOSC will deem whether its work has been successful in making a difference to local people will be identified as the joint inquiry progresses and discussions take place. Such information will be detailed in the joint committee's final report.

Appendix 2: Bonding and attachment

CHD Bonding & Attachment: Dr Sara Matley, Consultant Clinical Psychologist, LTHT

Bonding and attachment in CHD babies and young children

For babies and young children, care and development are strongly linked, and the bond between baby and parent or carer is crucial to the growth and development of the child – affecting physical growth as well as emotional and cognitive development and wellbeing.

Children's earliest experiences shape how their brains develop, which in turn determines future health and wellbeing. Very young children need secure and consistent relationships with other people in order to thrive, learn and adapt to their surroundings and this may also impact their ability to form good future relationships.

Research indicates that attachment aids children to develop physically, emotionally, socially and morally. Good, secure attachments enable children to cope with change and stress, cope with separation and loss, become independent and develop future relationships.

A care giver's ability to respond to, and stimulate a baby is influenced by the degree of attunement with the baby, and this serves to buffer his or her physiological, as well as emotional and behavioral responses to stress.

Attunement between mother and child is directly affected by the maternal-infant bond, which in turn is shaped by prenatal and perinatal events. Among the complex factors that influence bonding at birth are the mother's attitude toward the pregnancy and her perception of available support systems, her experience of procedures e.g echocardiograms, her perception of stress during pregnancy, and separation (Mead, 2004)

The sensitive period

One of the most important perinatal periods affecting bonding are the interactions in the hours and weeks following birth. Classic work by Klaus & Kennell, 1970 indicated the harm caused to the mother-infant relationship and as a result of research such as this there has been significant changes in practice in neonatal care, from a system which routinely separated mothers from newborn infants to a family centered approach which maximises contact and promotes bonding.

An emerging literature suggests that maternal distress in the prenatal and perinatal period may adversely affect development. Factors such as maternal stress, depression, perceived social support, and parenting stress are identified in the literature as risk factors. There is a growing literature indicating that perinatal maternal adjustment is associated with children's longer term emotional and behavioural functioning. (Anhalt et al, 2007)

Appendix 2: Bonding and attachment

Disruption to bonding

Separation in early life is associated with a reduction in maternal-infant attunement. The impact of maternal-infant separation during the sensitive period may permanently alter emotional relationships.

Many hospital procedures carried out to decrease perinatal health risks may pose a challenge to bonding. For example, bonding can be jeopardized when a child is separated because of illness, when placed in an intensive care nursery, when placed in an incubator, or when the mother is anesthetised at delivery (Madrid & Pennington, 2000).

Events such as these which affect the ability of the mother to meet the needs of her infant shape the capacity of the newborn to tolerate stress. Events occurring during labour and delivery that may affect the mother or the infant's ability to bond include early separation, pain in the mother or infant, the use of medication such as anesthesia, and anxiety. Maternal-infant separation following cesarean sections is common and appears to have a negative impact upon the quality of maternal-infant interactions. Separation from baby is found to be the most difficult aspect for mothers when their child is hospitalised. Parents can often feel excluded (Wigert et al, 2006).

Feldmen et al (1999) studied of maternal bonding under differing conditions of proximity, separation and potential loss, found that separation of a mother from its newborn baby due to hospitalization initially led to increased anxiety and stress in the mother. However prolonged separation due to hospitalization resulted in a decrease in preoccupation with the child and a poor attachment.

Leeds Early Intervention approach

There is a body of evidence that suggests children with chronic illnesses are at greater risk than other, healthy children of developing emotional and behavioural difficulties (Eiser, 1990). Rautava et al (2003) completed a longitudinal study of the impact of hospitalization of a newborn on families and found those who had been separated from their baby due to medical need reported higher levels of behavioural problems at age 3yrs which indicated long lasting effects of early separation. Locally, our own research looking at the incident of behavioural problems in children with Congenital Heart Defects shows significantly higher rates of behavioral problems than would be found in a healthy comparison group (Matley, 1997). Disruption to bonding and attachment play a major role in the development of longer term difficulties.

In an attempt to ameliorate longer term problems the support offered in Leeds is targeted at early and proactive interventions, which aim to support prospective parents from antenatal diagnosis through to delivery, and longer term care thereafter. This enables good working relationships to be developed and a continuity of care, which fosters trust and communication.

Appendix 2: Bonding and attachment

The benefits of having all Maternity, Neonatal and Paediatric Cardiac Surgery services upon one site, allows for a continuity of care and effective communication between all the teams involved in the care of both mother and baby.

The risks and length of maternal separation can be avoided or considerably reduced because all care can be provided on one site. Accommodation for newly delivered mothers is available on the ward so attachment and bonding can be fostered. Breast feeding, which can enhance bonding, is also encouraged and facilitated by well trained staff and good provision of facilities and equipment.

Emotional support is provided by all the team, and more specific help can be gained from the Cardiac Nurse Specialist team and the integrated Psychology and Counselling service available on the children's ward. The emotional support offered is aimed at bolstering parents' resilience and encouraging personal coping strategies. This work will often compliment the support of family members who are local enough to visit and perhaps share some of the caring responsibilities, and emotional stress.

As a Psychology team we see a number of families who have experienced the trauma of a very unexpected, and perhaps abrupt separation from their baby due to an undiagnosed problem. Much of this work focuses on helping parents to 'grieve' for the loss of a normal birth experience and early interactions, as well as helping them make sense to the trauma they have experienced.

We have also seen a number of parents who have experienced separation from their child, being left behind in a peripheral hospital, as experiencing extreme anxiety and trauma symptoms. These experiences further hinder their ability to bond with their babies.

With the increasing antenatal CHD detection rate and the expert fetal cardiology service available at Leeds, the opportunities to prepare parents, co-ordinate care with the other relevant onsite services, provide counselling and support from the very earliest of days all aims to reduce the risk of stress, anxiety, depression and separation, which in turn is aimed at fostering bonding and attachment, with the longer term goal of reducing the risks of behavioural and emotional problems for children and families in the future. Co-location of Maternity, Neonatal & Cardiac Surgery is essential to continue this unique proactive, early intervention approach to care.

Case Study

L was a young mother whose baby was diagnosed antenatally with complex congenital heart disease. During sessions with a Psychologist L reported a number of worries about the child's future and how this would impact upon her husband and two small children. L's greatest worry however was about being separated from her baby. This upset the mother a great deal and part of the preparation work we did involved visiting the ward so that she could picture where her daughter would be.

Appendix 2: Bonding and attachment

L was terrified that her child might die without any family around her; it was very important for her that either she or her husband be there when this happened. As the child was critically ill when she was born, there was a good chance that the child may die without her family around her, if the mother was separated from the child. The father was in a difficult position of wanting to support the mother after the birth, but also wanting to be around the baby when she was born.

Care for mother and baby was co-ordinated and arrangements made for L to deliver in Leeds, and her husband and children to be accommodated in Eckersley House, the family accommodation.

L's baby did die, but surrounded by her family once they had the chance to say goodbye. A move to care provided in a standalone heart unit would mean that maternity services would not be located in the same hospital as the cardiac surgery would have been devastating for this family. It would have increased the mother's fear, risk of future emotional & psychological difficulties and the possibility that her child would die without her being there.

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Appendix 3: Indices of Deprivation in England (2010)

- Table 1 provides the local authority summary of the indices of deprivation (ranked out of 326). North Yorkshire is broken down into the seven borough/district councils. This shows that Scarborough has a higher level of deprivation, compared to other areas in North Yorkshire.

TABLE 1

Indices of deprivation 2010 - local authority summary

A rank of 326 is least deprived, a rank of 1 is most deprived.

	Average Score	Rank of Average Score
Barnsley	28.55	47
Bradford	32.58	26
Calderdale	23.18	105
Doncaster	29.76	39
East Riding of Yorkshire	14.97	202
Kingston upon Hull, City of	37.53	10
Kirklees	25.23	77
Leeds	25.83	68
North East Lincolnshire	29.3	46
North Lincolnshire	21.75	120
Rotherham	28.12	53
Sheffield	27.39	56
Wakefield	25.87	67
York	12.93	234
Craven	12.13	246
Hambleton	10.97	264
Harrogate	10.28	282
Richmondshire	11.18	261
Ryedale	13.91	213
Scarborough	24.75	85
Selby	12.93	235

Source: Indices of Deprivation 2010, Communities and Local Government 2011

Appendix 3: Indices of Deprivation in England (2010)

- Table 2 shows the county summary (ranked out of 149) and has an overall figure for North Yorkshire

TABLE 2

Indices of Deprivation 2010 - County summary

A rank of 149 is least deprived, a rank of 1 is most deprived.

Indice of Deprivation 2010 - County summary		
	Average Score	Rank of Average Score
Barnsley	28.55	40
Bradford	32.58	24
Calderdale	23.18	75
Doncaster	29.76	33
East Riding of Yorkshire	14.97	122
Kingston upon Hull	37.53	10
Kirklees	25.23	62
Leeds	25.83	55
North East Lincolnshire	29.30	39
North Lincolnshire	21.75	83
North Yorkshire	13.97	129
Rotherham	28.12	45
Sheffield	27.39	47
Wakefield	25.87	54
York	12.93	131
Source: Indices of Deprivation 2010, Communities and Local Government 2011		

Appendix 3:
2001 Census details

- Table 3 shows the information on households with no cars or vans. Although the source is the 2001 census, this is the most recent information available.

TABLE 3

2001 Census - Cars and Vans

	All Households	Households with no cars or vans	
	Count	Count	Percentage
Barnsley	92165	29633	32.15
Bradford	180246	58592	32.51
Calderdale	80937	25111	31.03
Doncaster	118699	36391	30.66
East Riding of Yorkshire	131084	26536	20.24
Kingston upon Hull, City of	104288	45720	43.84
Kirklees	159031	47059	29.59
Leeds	301614	103987	34.48
North East Lincolnshire	66054	21895	33.15
North Lincolnshire	64014	15122	23.62
Rotherham	102279	30374	29.7
Sheffield	217622	77605	35.66
Wakefield	132212	40465	30.61
York	76920	21008	27.31
North Yorkshire	237583	46398	19.53
Total	2064748	625896	30.31

Source: 2001 Census, Cars and Vans, Neighbourhood Statistics, Office for National Statistics, © Crown Copyright 2003

Appendix 4:
Letters to the JCPCT and review team

Councillor Mark Dobson
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Our ref MD/smc
Date 14 April 2011

Mr. Jeremy Glyde, Programme Director
Safe and Sustainable Programme
NHS Specialised Commissioning Team
2nd floor, Southside
105 Victoria Street
London SW1E 6QT

Dear Mr. Glyde,

Re: Review of Children s Congenital Heart Services in England

Thank you for your recent communication (8 April 2011), highlighting concerns associated with comments attributable to Leeds Teaching Hospitals NHS Trust (LTHT). I have sought a response to these concerns from the Trust's Chief Executive, Ms. Maggie Boyle.

As you are undoubtedly aware, the 15 local authorities (with Health Scrutiny responsibilities) across the Yorkshire and Humber Region have established a Joint Health Overview and Scrutiny Committee (HOSC) to consider the proposals of this national review and provide a consultation response in this regard. As such, I will share your communication with other members of the Joint HOSC, alongside any response from LTHT.

I understand that Steven Courtney (Principle Scrutiny Adviser to Leeds City Council's Scrutiny Board (Health) and the Joint HOSC) has already been in contact with you, advising of the current progress and future work of the Joint HOSC. As such, I will not repeat the content of that communication, other than perhaps to re-emphasis the following points:

Cont./

Appendix 4: Letters to the JCPCT and review team

Involvement of Safe and Sustainable the JCPCT in the work of the Joint HOSC

Members of the Joint HOSC are keen to meet with appropriate representatives and would therefore wish to formally invite you (as Programme Director), along with the Chair of the JCPCT (Sir Neil McKay) and the Yorkshire and Humber SCG representative on the JCPCT (Ms. Ailsa Claire) to contribute to a future meeting (or meetings) of the Joint HOSC in this region. The main purpose of this attendance being to help the Joint HOSC consider in more detail the:

- Review process and formulation of options presented for consultation;
- Projected improvements in patient outcomes and experience; and,
- Likely impact on children and their families (in the short, medium and longer-term), in particular in terms of access to services and travel times.

I would appreciate your cooperation in this regard and trust you will provide details of availability as a matter of urgency.

Consultation process and associated timescales

Members of the Joint HOSC were concerned about the general accessibility of the proposals, given:

(a) The length and complexity of the consultation document (which exceeds 230 pages);
(b) That a summary document had not been provided; and
(c) The accessibility of the consultation questions

The Joint HOSC also expressed significant concern regarding the timing of the consultation, its proximity to local elections and the impact of purdah. There was a strongly held view that this demonstrated a lack of appreciation (or regard for) local democracy and the potential impact on the work (and membership) of a Joint HOSC.

As you are already aware, one of the outcomes of the Joint HOSC meeting held on 29 March 2011, was to formally seek a three month extension to the consultation period. In part, this is to allow the Joint HOSC to complete its work and issue its report and any recommendations. A report to this effect is currently being prepared and will be formally directed to the JCPCT in the near future.

I trust you appreciate that, as democratically elected representatives of local communities, the overall health and wellbeing of all citizens across the Yorkshire and Humber region is without question an underlying consideration for all local councillors. Nonetheless, I think it is worth reinforcing that this is not only a cornerstone of the work of the Joint HOSC but its primary purpose when considering the proposals put forward. Furthermore, the consultation document detailing the proposed changes states, '*We would like to hear from anyone with a view on the future of congenital heart services* . This is precisely one of the aims of the Joint HOSC – in order to help inform its view and any recommendations it may put forward.

Cont./

Appendix 4: Letters to the JCPCT and review team

In addition, as Chair of the Joint HOSC and as an advocate of openness and transparency, I will be working hard to ensure that we seek as wide a range of views as possible and that the vast majority of the committee's work is undertaken in public. Undoubtedly, this is likely to attract local media interest – particularly during a period of a public consultation and engagement. As such, I make no apologies for the range of views that may be expressed as part of the scrutiny process and which may be subsequently reported – even where some of those views may be unpalatable and seen as unhelpful to the review team and/or the JCPCT.

Finally, I hope you take the opportunity to engage with the Health Scrutiny process in this region and look forward to receiving your response in the very near future.

Yours sincerely

Councillor Mark Dobson
Chair, Scrutiny Board (Health)

cc Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)
Cathy Edwards, Director – Specialised Commissioning Group (Yorkshire and the Humber)

Appendix 4:
Letters to the JCPCT and review team

Councillor Lisa Mulherin
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Date 22 August 2011

Sir Neil McKay (Chair, JCPCT)
NHS Specialised Services
Safe and Sustainable Programme
2nd Floor, Southside
105 Victoria Street
London
SW1E 6QT

Dear Sir Neil,

Re: Children s Congenital Cardiac Services Review Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

As Chair of the Yorkshire and Humber Joint Health Overview and Scrutiny Committee (HOSC) considering the proposed reconfiguration of Children's Congenital Cardiac Services and the potential impact on children and families across the region, I am writing to express our frustration that the outcome of the additional work to test assumptions around patient flows will not be available for HOSCs to consider prior to the 5 October 2011 consultation deadline: This is a vital source of evidence that warrants detailed consideration to help the Joint HOSC prepare a more fully informed consultation response and it is unacceptable that this will not be available to us.

I also note with some concern that this information will not be publicly available until after the JCPCT has made a decision on the reconfiguration proposals – a situation that is quite astounding and certainly not in the spirit of open and transparent decision-making.

At our next meeting on 2 September 2011, and in the absence of the PwC report, the Joint HOSC will be considering patient flow details provided in the regional impact assessment prepared by the SCG, alongside an impact assessment produced by EMBRACE – the regional body responsible for delivering a dedicated paediatric transport service.

Cont./

Appendix 4: Letters to the JCPCT and review team

With this in mind, I would like to take this opportunity to invite you and/or Ailsa Claire, in your respective roles within the formal decision-making body, to attend this meeting to provide an update on the work of the JCPCT and to address questions on the role of the JCPCT within the review process to date. This will also provide an opportunity for you to hear first hand the details presented by EMBRACE.

I appreciate that this formal invitation to attend on 2 September 2011 may be relatively short notice; however the former Chair of the Joint HOSC first outlined the committee's intentions to involve appropriate representatives of the JCPCT and the Safe and Sustainable Team in April 2011 (copy enclosed). Despite the apparent lack of a formal response to that letter, I trust the content of this letter will have previously been communicated to you.

I look forward to hearing from you in the very near future. However, please do not hesitate to contact me should you have any queries and/or need any additional information.

Yours sincerely

Councillor Lisa Mulherin
Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and the Humber

Enc.

cc Jeremy Glyde, Safe and Sustainable Programme Director (NHS Specialised Services)
Ailsa Claire, Chair (Yorkshire and the Humber Specialised Commissioning Group)
Cathy Edwards, Director (Yorkshire and the Humber Specialised Commissioning Group)
All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

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Date 26 August 2011

Sir Neil McKay (Chair, JCPCT)
NHS Specialised Services
Safe and Sustainable Programme
2nd Floor, Southside
105 Victoria Street
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Dear Sir Neil,

Re: Children s Congenital Cardiac Services Review Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Thank you for your response, dated 26 August 2011.

I note your comments regarding regional SCGs being best placed to represent the NHS at local scrutiny committees to speak to this review and am sorry that you will be unable to attend the meeting on 2 September 2011.

As you may be aware, for some time the Joint HOSC has worked very closely with Cathy Edwards (as Director of Yorkshire and the Humber SCG) at different stages during the review process. Cathy has attended a number of meetings – both formal committee meetings and briefing sessions, and I am sure all members of the Joint HOSC (both past and present) are grateful for Cathy's input into the regional scrutiny process.

That said, I would like to reiterate the desire of the Joint HOSC to formally engage with the JCPCT directly – as the decision-making body – and invite a representative from its membership to attend next week's meeting. As outlined in my previous letter, the purpose being to provide an update on the work of the JCPCT, address any questions raised, and to hear first hand any comments and/or concerns raised by the Joint HOSC.

Cont./

Appendix 4: Letters to the JCPCT and review team

Despite Cathy already attending for a separate item on next week's agenda, I would respectfully remind you that Cathy is neither part of the JCPCT, nor part of the secretariat supporting the decision-making process.

Finally, I would like to take this opportunity to remind you that, in considering and responding to the review proposals, the Joint HOSC is acting as the statutory scrutiny body for Yorkshire and the Humber – representing the 15 top-tier local authorities and a population of 5.5 million. As such, I hope you will reconsider the invitation previously extended and ensure that the JCPCT is appropriately represented at next week's meeting.

Please contact me should you have any queries and/or need any additional information, otherwise I look forward to hearing from you in due course.

Yours sincerely

Councillor Lisa Mulherin
Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and the Humber

cc Jeremy Glyde, Safe and Sustainable Programme Director (NHS Specialised Services)
Ailsa Claire, Chair (Yorkshire and the Humber Specialised Commissioning Group)
Cathy Edwards, Director (Yorkshire and the Humber Specialised Commissioning Group)
All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Appendix 4:
Letters to the JCPCT and review team

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Date 7 September 2011

Sir Neil McKay (Chair, JCPCT)
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2nd Floor, Southside
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Dear Sir Neil,

Re: Children s Congenital Cardiac Services Review Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Further to the meeting of the Joint Health Overview and Scrutiny Committee (HOSC) on 2 September 2011 and our related correspondence beforehand, on behalf of the Joint HOSC, I must advise you of the anger and frustration of the Committee members that the JCPCT has yet to formally engage with the Joint HOSC, despite a number of written requests to do so.

Members of the Joint HOSC feel it is imperative for there to be some direct input from the JCPCT (as the appropriate NHS decision-making body), in order to inform our response to the proposals around the future provision and configuration of Children's Congenital Cardiac Services. As previously outlined, in considering and responding to the proposals, the Joint HOSC is acting as the statutory scrutiny body for Yorkshire and the Humber – representing the 15 top-tier local authorities and a population in excess of 5.5 million.

The frustrations expressed by members of the Joint HOSC are by no means any reflection on the input and support provided to date by Cathy Edwards (Director, Yorkshire and the Humber SCG) – which has been extremely helpful and of high quality. There are however some aspects of the Joint HOSC's inquiry and specific questions that need to be addressed by those on the decision-making body.

Cont./

Appendix 4: Letters to the JCPCT and review team

As all of the units that went out to consultation are recognised as being safe, and there seems to be a reluctance (at best) to engage directly with us, there is a growing cynicism within the Committee about the way in which the four options that went out to consultation were drawn up.

As such, we formally request written responses to the following questions which Committee members had wished to put to you or any other JCPCT member at our meeting last week:

(1) Why was the Leeds unit not included in all four options on the grounds of population density in the Yorkshire and the Humber region, on the same basis that the units at Birmingham, Bristol, Liverpool and the 2 London centres, which feature in all four options?

(2) Why isn't the genuine co-location of paediatric services provided at the Leeds Children's Hospital, alongside maternity services and other co-located services and specialisms on the same site at Leeds General Infirmary given greater weighting? Such service configurations have been described as the 'gold standard' for future service provision, yet it appears not to have been given sufficient weighting in the case for Leeds.

(3) Why isn't the "exemplar" cardiac network which has operated in the Yorkshire and Humber region since 2005 given greater weighting in the drawing up of the four options? The future network model proposed in the consultation document is again described as the 'gold standard' for the future service delivery model, yet three of the four options put forward would see the fragmentation of this unique and exemplary cardiac network.

(4) Why doesn't the Leeds unit feature in more of the four options put forward given that all surgical centres are theoretically capable of delivering the nationally commissioned Extra Corporeal Membrane Oxygenation (ECMO) service?

(5) Why isn't travel and access to the Leeds unit given a higher weighting given the excellent transport links to the city by motorway and road network (including access to the M1, M62 and A1(M)), the rail network (including direct access to the high speed East Coast mainline and the Transpennine rail route) and access by air via the Leeds-Bradford airport? Almost 14 million people are within a two hour travelling distance of the Leeds unit.

(6) We are keen to understand in more detail the relative strengths and weaknesses of each surgical centre. We therefore request the detailed breakdown of the assessment scores determined by the Independent Assessment Panel, Chaired by Sir Ian Kennedy (referred to on page 82 of the consultation documents).

Cont./

Appendix 4: Letters to the JCPCT and review team

(7) How has the potential impact of the proposed reconfiguration of surgical centres on families, including the additional stress, costs and travelling times, been taken into account within the review process to date?

(8) Why have congenital cardiac services for adults been excluded from the review when, in some cases, the same surgeons undertake the surgical procedures?

(9) We have heard that more children with congenital cardiac conditions are surviving into adulthood, which suggests an overall increase in surgical procedures (for children and adults), which is likely to be beyond the 3600 surgical procedures quoted in the consultation document:

(a) As such, what would be the overall impact of combining the number of adult congenital heart surgery procedures with those performed on children, i.e. how many procedures are currently undertaken by the same surgeons and what are the future projections?

(b) How would this impact on the overall number of designated surgical centres needed to ensure a safe and sustainable service for the future?

(c) What would be the affect on the current and projected level of procedures for each of the existing designated centres?

(10) How has the impact on other interdependent hospital services and their potential future sustainability been taken into account within the review process to date?

(11) The Government's Code of Practice on Consultation (published July 2008) sets out seven consultation criteria: Please outline how the recent public consultation process meets each criterion.

(12) What specific arrangements have been put in place to consult with families in Northern Ireland?

(13) How have ambulance services (relevant to the affected patient populations) been engaged with in the review process – particularly in relation to drawing up the projected patient flows and associated travel times?

(14) How has the impact on training future surgeons, cardiologists and other medical/ nursing staff been factored into the review?

(15) What are the training records of each of the current surgical centres and how have these been taken into account in drawing up the proposals?

Cont./

Appendix 4: Letters to the JCPCT and review team

(16) Why have services provided in Scotland been excluded from the scope of the review, when the availability and access to such services may have a specific impact for children and families across the North of England and potentially Northern Ireland?

(17) Please confirm whether or not a similar review around the provision of congenital heart services for children, is currently being undertaken in Scotland. Please also confirm any associated timescales and outline how the outcomes from each review will inform service delivery for the future

Bearing in mind the 5 October 2011 deadline for the Joint HOSC to formally submit its response to this review, the Joint HOSC is proposing to hold a further meeting to consider this matter on **19 September 2011**, and we feel it is imperative that detailed responses to the above questions are available for consideration at that meeting. As such, **I would be pleased to receive your written response within 5 working days**.

Furthermore, I would request your attendance and that of any other member of the JCPCT (as you feel appropriate) at the above meeting, which is due to commence at 10:00am in Leeds Civic Hall. Please be aware that I believe previous requests for your attendance at meetings of the Joint HOSC have been legitimate and form part of the accountability framework for the NHS – set out in Section 38 of the Local Government Act 2000 and clarified in the Overview and Scrutiny of Health Guidance (Department of Health, July 2003).

Please contact me should you have any queries and/or need any additional information, otherwise I look forward to hearing from you in the very near future.

Yours sincerely

Councillor Lisa Mulherin
Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and the Humber

cc All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)
Jeremy Glyde, Safe and Sustainable Programme Director (NHS Specialised Services)
Ailsa Claire, Chair (Yorkshire and the Humber Specialised Commissioning Group)
Cathy Edwards, Director (Yorkshire and the Humber Specialised Commissioning Group)
Rt Hon Andrew Lansley MP, Secretary of State for Health
All Members of Parliament (Yorkshire and the Humber)

Appendix 4:
Letters to the JCPCT and review team

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Your ref
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Date 22nd September 2011
12:00 noon

NHS Yorkshire and the Humber
(Headquarters)
Blenheim House
West One, Duncombe Street
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Dear Ms Claire,

Re Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) 22 September 2011

The Yorkshire and Humber Regional Joint HOSC meeting this morning was convened around your availability to attend as the Yorkshire representative of the JCPCT. The Committee was advised at the start of its meeting that Andy Buck was attending in your place. With every respect to Mr Buck he is not a representative of the JCPCT, he has made it clear to our Committee this morning that he has not been briefed by you on this matter and that he has not attended previous JCPCT meetings. He has no official capacity to represent the JCPCT today.

Mr Buck has offered to listen to what we have to say and to take away any questions he cannot answer and ensure that we will be given those answers in writing. At the eleventh hour in the process this is simply not acceptable.

We have repeatedly asked for a JCPCT member to attend our meetings. We first asked for the availability of a JCPCT member to attend our meeting five months ago. We were finally advised that you would be available to attend a meeting this morning at one week's notice.

Cont./

Appendix 4: Letters to the JCPCT and review team

We were not given any apology for your failure to attend today and were not given any prior warning that you would not be attending.

The committee demand your attendance on behalf of the JCPCT as agreed today. We require you to attend before 2:00pm today. I need not remind you that the NHS has a statutory duty to comply with the Committee s request for attendance.

We intend to make our views clear about this latest incident and the contempt with which the Joint HOSC for this region and the democratically elected representatives of 5.5 million people have been treated by the JCPCT. This has further undermined our confidence in the process of the Safe and Sustainable Review.

Yours sincerely

Councillor Lisa Mulherin
Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and the Humber

cc All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Appendix 5: Council motions across Yorkshire and the Humber

City of York Council 7 April 2011

'There are 11 children s heart surgery units in England, but the NHS is proposing under its 'Safe and Sustainable review to reduce this to 6 or 7 specialist hubs undertaking 400 operations per year; and,

The choice facing the NHS review team will be to retain either the Children s Heart Surgery Unit at Leeds General Infirmary or the unit at Newcastle to serve the north; and,

Leeds serves a major population catchments area of 14 million people in Yorkshire and the Humber, Lincolnshire and North Derbyshire, has the capacity to expand and has centralised the whole of its children s services operations on one site; and,

Leeds General Infirmary is at the forefront of work on inherited cardiac conditions and is much valued for providing safe, high quality children s heart surgery;

Council asks Members to join with local MPs and community groups to express all-party support for keeping open the Children s Heart Unit at Leeds General Infirmary and asks the Chief Executive to write to the Department of Health to ask for the retention of the Leeds Children s Heart Unit as the centre best placed to serve as the specialist hub for the needs of young cardiac patients in Yorkshire and the north of England.

Response attached at Appendix 7.

East Riding of Yorkshire 27 July 2011

'That this Council supports the retention of the Children s Cardiac Surgery Services at Leeds as the unit serves a region of population of almost 14 million people and Leeds General Infirmary is ideally placed to deliver services as it does now, to people living throughout Yorkshire and the Humber, Lincolnshire and the North Midlands.

Harrogate Borough Council 13 April 2011

'This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary and notes with concern the Unit s limited inclusion in the NHS proposals for the national reconfiguration of Children s cardiac Surgery.

The Services provided at present are an important and essential part of health services available to residents of Harrogate District.

The Council requests that the Chief Executive writes to the Secretary of State for Health in order to call for the retention of the vitally important surgical services in Leeds.

Letter and response attached at Appendix 7.

Appendix 5: Council motions across Yorkshire and the Humber

Kirklees Council 23 March 2011

"This Council notes with concern the potential closure of the Children s Heart Surgery Unit at Leeds General Infirmary, as a result of the Department of Health s 'Safe and Sustainable' review of Children s Heart Surgery Units.

The closure of the Leeds Unit, which serves a large population centre, will have a severe impact on Yorkshire families, including those living in Kirklees, and would mean that parents with sick children would have to travel to Newcastle, Liverpool or Leicester, to receive the essential treatment currently provided in Leeds. This will cause extreme difficulty as a result of the distances families will have to travel, at a time of high anxiety about their child s health.

This Council recognises that a Joint Health Scrutiny Committee is currently meeting to fully consider the proposals for children s congenital cardiac surgery services. Whilst not wishing to predetermine the findings of that review, nevertheless this Council wishes to express serious concerns about the impacts of removing services
from the Leeds area. These concerns to be forwarded in a letter to the Department of Health with copies to all MP s within the Kirklees area.

This Council also requests that representations be made on behalf of the Council as part of the Department of Health s consultation exercise in support of the retention of the Leeds Children s Heart Surgery Unit."

Report back to Council (including letter and response) attached at Appendix 7.

Leeds City Council 6 April 2011

'This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary, and notes with concern the unit s limited inclusion in NHS proposals for the national reconfiguration of children s cardiac surgery services.

This Council requests that the Chief Executive write to the Secretary of State for Health in order to call for the retention of these vitally important surgical services in Leeds. It also recognises the ongoing efforts of Leeds MPs to lobby the Secretary of State to the same effect.

Letter and response attached at Appendix 7.

Appendix 5: Council motions across Yorkshire and the Humber

Leeds City Council 14 September 2011

'That this Council notes with concern the ongoing discussions regarding the proposed reconfiguration of children s cardiac surgery services and the devastating effect this could have on the Yorkshire Heart Centre at Leeds General Infirmary and the families of this region.

The Council supports the demands of the cross party Joint Health Overview and Scrutiny Committee for Yorkshire and Humber for the Government to re-examine the way in which the decision is being made and ensure that the democratic process is not being ignored.

Council therefore urges the government to confirm that all available information will be examined before a decision is made which could force parents from Yorkshire to travel hundreds of miles should their children need cardiac treatment.

Rotherham Metropolitan Borough Council 27 July 2011

'This Council recognises the expertise in Children s Cardiac Services which has been built up by the Leeds Teaching Hospitals NHS Trust (LTHT) based at Leeds General Infirmary (LGI). LTHT also supports outreach clinics at Rotherham Foundation Trust (RFT) which are used by approximately 300 children each year:

The Council wishes to register its opposition and serious concerns at the potential loss of the Children s Cardiac Unit in Leeds which would have a devastating impact on those children requiring the specialist services provided by the facility.

The Council resolves to work with all relevant stakeholders to campaign to retain specialist children s cardiac surgery in the region and to inform the Secretary of State for Health of our views.

Sheffield City Council 6 July 2011

That this Council

- *(a) notes the NHS Safe and Sustainable Review into the way that children s congenital heart surgery services should be provided in the future*
- *(b) is concerned by the likely closure of the surgical centre at Leeds General Infirmary (LGI) as the only such unit in the Yorkshire and Humber region*
- *(c) is also concerned by the implications of this likely closure for critically ill children and their families in Sheffield who use this service*
- *(d) resolves to continue to raise the profile of this issue locally to make the people of Sheffield aware of the knock-on effect of this closure*
- *(e) fully supports maintaining the paediatric cardiac surgery unit at the LGI for the continued benefit of sick children and their families in Sheffield*

Appendix 5: Council motions across Yorkshire and the Humber

Wakefield Metropolitan District Council 30 March 2011

Letter attached (dated 15 April 2011). We were advised that no response had been received.

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Kirklees COUNCIL

Regional Joint Health Overview Scrutiny Committee
Children s Congenital Heart Services

FEEDBACK FROM PUBLIC CONSULTATION IN KIRKLEES

Background

Kirklees Council arranged two drop-in sessions for members of the public in May 2011 – one was held in Huddersfield and one held in Dewsbury. These sessions were publicised in the local press, on Kirklees Scrutiny's Twitter account, and on Kirklees Scrutiny's Facebook page. Eight people attended and shared their stories – all expressed concern about the potential loss of the unit in Leeds.

Two letters were also received.

Cllr Elizabeth Smaje, the Council's representative on the Regional Joint HOSC, also held a meeting with Dr Sara Matley from the Children's Heart Surgery Fund on 20 June 2011.

Key Themes

A number of key themes and messages emerged from the discussions, and these are set out below:

- **Pre-Natal Scans**

  Concern was expressed that congenital cardiac conditions were not always picked up during pre-natal scans. Several of those who attended had been aware of other serious health issues, for example, gastrological, and had therefore given birth at Leeds General Infirmary as they have units for other paediatric specialisms. Cardiac surgery was often then needed very quickly on a seriously ill baby.

- **Co-location of Services**

  The centralisation of children's hospital services at Leeds General Infirmary ensures that a wide range of paediatric services are co-located on the same site. A child can therefore have access to various specialists simultaneously and not need to be moved between sites. Concern was expressed that this would not be available at Liverpool or Newcastle.

  There was also concern that maternity services in both Liverpool and Newcastle are on different hospital sites from the children's heart unit, which could see mother and baby separated shortly after birth. In Leeds, both services are co-located on the same hospital site.

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- **Number of Procedures**

  Concern was expressed that the projected number of procedures that would be carried out by a unit in Leeds did not take into consideration that population growth in the Yorkshire and Humber region is exceeding the national average.

  There was also concern that adult procedures had not been accounted for. There are an increasing number of people with congenital heart conditions surviving into adulthood and they are also operated on by the same surgeons, as they are specialists in congenital heart problems.

- **Travel Distance**

  Concern was expressed that the additional travelling time for Kirklees' residents to Liverpool or Newcastle could have significant adverse consequences. There was concern about rush hour traffic on the M62, M1 and A1 and the impact this would have on travel times. Concern was also expressed about the assumption of which postcode areas would attend which of the alternative hospitals and that a situation could arise where Liverpool was overwhelmed and Newcastle was unable to meet the minimum number of procedures.

- **Ambulance Service**

  Concern was expressed about the ability of Yorkshire Ambulance Service, and Embrace, to manage an increased number of neonatal, perinatal and paediatric transfers of critically ill children. Concern was expressed that the air ambulance did not fly in the dark and that it could also be grounded when foggy.

- **Impact on Paediatric Intensive Care Beds**

  In Yorkshire and Humber, Leeds and Sheffield provide the regional paediatric intensive care units and paediatric cardiac intensive care units. Dr Matley advised that the beds within the units are used flexibly and therefore the loss of 8 paediatric cardiac intensive care beds would impact across the region.

- **Staffing**

  Concern was expressed that there was an assumption consultants from the Leeds unit would take up positions at Newcastle or Liverpool if Leeds were to close. Newcastle currently has 2 consultants and Leeds has 3 and are looking to recruit a fourth. There was concern that consultants may not wish to relocate to Newcastle and that if a unit was located there and Leeds closed, there may be a period of time when there were insufficient surgeons available across the north of England.

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- **Affordability**

  A number of parents were concerned about the costs they would incur if procedures were carried out at Liverpool or Newcastle. Expenses such as: travel, accommodation, and food were raised. It was recognised that the Children's Heart Surgery Fund in Leeds give assistance to families by providing nearby accommodation, helping with expenses, and providing kitchen facilities so parents can prepare their own food rather than incurring the expense of eating out. It was not known if similar facilities were available in Liverpool or Newcastle. There was particular concern about parents on low incomes.

- **Family Life**

  Many of those attending spoke about the impact on their family life of supporting a critically ill child through serious surgery. Several mentioned their other children and their needs, and the conflict they had faced in supporting the child in hospital but also being a parent to other children. Children were often kept in hospital for several weeks following surgery, and parents needed to be able to shuttle back and forward. Parents were often very reliant on assistance from their wider families and friends, which they felt would not be as easy if further distances had to be travelled.

- **Engagement Events**

  Those attending had been unhappy with the quality of engagement events at the Armouries, and did not feel that the correct people were presenting the information. They were also dissatisfied that there appeared to be a 'done deal'.

  It was commented that those in attendance were predominantly white, middle class, and articulate people. A suggestion was made that engagement with mosques, for example, could have helped to reach a wider number of people.

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Kirklees COUNCIL

Regional Joint Health Overview Scrutiny Committee
Children s Congenital Heart Services

INFORMATION PROVIDED BY KIRKLEES COUNCIL S DIRECTOR OF PUBLIC HEALTH

Background

Cllr Elizabeth Smaje, the Council's representative on the Regional Joint HOSC, sought clarification from Dr Judith Hooper, Director of Public Health for Kirklees Council, on the likely impact on infant mortality in Kirklees, if children's cardiac provision was to be moved further away.

The following comments were received:

- The infant mortality rate is unlikely to be affected if children's heart surgical services are further away. Evidence suggests that pooling surgical expertise into fewer larger centres ensures they perform the necessary number of procedures a year to maintain and develop their expertise. This results in better outcomes.

- The child does not need to reach a surgical centre in the shortest possible time but the specialist intensive care retrieval teams should get to these children, and stabilise them correctly so that surgery can then be carried out in the best possible circumstances. A letter by Dr Ian Jenkins (the immediate past president of the Paediatric intensive Care Society) describes this http://www.specialisedservices.nhs.uk/news/view/32

- The distance from home and travel to centres further away could have an impact on the parents and siblings. Newcastle is one of the sites proposed as a centre. Yorkshire & Humber has double the child population of the North East region, and is growing much faster. Within this, the BME population is growing fastest. The Pakistani population has more congenital abnormalities and cardiac abnormalities form a significant proportion of these. (In Kirklees almost a quarter of the infant deaths due to congenital abnormalities (2006-8) had cardiac abnormalities observed at time of birth. In addition a small proportion who died of other causes had cardiac abnormalities observed at time of birth and there may also be those cardiac problems picked up some time after birth). The Pakistani population has large families and is more deprived, so a disproportionately high burden is placed on these families by imposing additional travel. However the number of major heart operations needed by a child should be small and much of the rest of the care can be delivered nearer home by networks built around the specialist centre.

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Some children with congenital heart disease will have other complex service and care needs. There may be issues around cardiac surgery being at a separate centre from where other care needed by the child is provided e.g. in Liverpool cardiac would be at Alder Hey and maternity at Liverpool Women's. Newcastle services are actually spread over 3 sites, whilst Leeds is on a single site. The importance of such co-location is not easy to quantify. More information may be available in the impact assessment.

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Regional Joint Health Overview Scrutiny Committee
Children s Congenital Cardiac Services

Kirklees Joint Strategic Needs Assessment 2010 Information on Vulnerable Groups identified by Health Impact Assessment: Interim Report

In the Health Impact Assessment: Interim Report, published August 2011, information was outlined on the population groups that will be disproportionately affected by reconfiguration proposals due to their higher susceptibility of experiencing congenital heart disease and, therefore, needing children's heart surgery services.

The population groups identified included:

- People who experience socio-economic deprivation;
- People from Asian ethnic groups, particularly those with an Indian, Pakistani, Bangladeshi and other Indian subcontinent heritage;
- Mothers who smoke during pregnancy;
- Mothers who are obese during pregnancy.

The Joint Strategic Needs Assessment for Kirklees 2010, published July 2011, provides the following data relevant to these population groups:

Socio-economic deprivation

The Index of Deprivation 2007 identified Kirklees as one of the 50 most deprived local authorities in England for both the income and employment domains – Kirklees is ranked 12th worst in England. More than 70,000 people (about 1 in 6) were classed as income deprived and 27% of the Kirklees population live in the top 20% of most deprived areas, nationally.

Asian ethnic groups

Over 1 in 8 people are of south Asian origin, Pakistani and Indian primarily. Over 1 in 3 young people in the north of Kirklees are of south Asian origin, especially in Dewsbury and Batley.

Smoking during pregnancy

19% of white women smoke during pregnancy – with variations from 33% in Dewsbury to 7% in Denby Dale & Kirkburton (17% national average). No south Asian women said they smoked during pregnancy and this led to a figure of 10% of all women who smoked during pregnancy.

49% of 130 teenage mothers enrolled in the Kirklees Family Nurse Partnership programmes smoked at enrolment with 38% continuing to smoke in their 36th week of pregnancy.

Obesity during pregnancy

48% of mothers were at least overweight, especially Pakistani origin mothers (60%). Obesity was worse in north Kirklees with 23% of mothers obese

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Kirklees COUNCIL

Regional Joint Health Overview Scrutiny Committee - Children s Congenital Cardiac Services

Assumptions have been made by the Safe and Sustainable Team on the patient flows that would arise from each of the proposed configurations of surgical centres. In the event of Options A, B or C being agreed, it is anticipated that the postcode flows within the Kirklees boundary would be as follows: BD to Liverpool; HD to Liverpool; and WF to Newcastle.

Analysis of each of the postcode areas has been undertaken, and it is acknowledged that for patients with an HD or BD postcode, Liverpool would be the natural destination if Option D was not selected. However, the analysis shows that for patients with a WF postcode, Newcastle would not be the natural destination, with travel times nearly double that of Liverpool. This would therefore affect the assumed numbers of patients that would attend each hospital.

	By Car (source: google maps)			By Public Transport (source: transportdirect.info)		
	To Leeds General Infirmary	To Newcastle Freeman Hospital	To Alder Hey Children s Hospital	To Leeds General Infirmary	To Newcastle Freeman Hospital	To Alder Hey Children s Hospital
HD1 Central Huddersfield	31 mins	2 hrs 21 mins	1 hr 6 mins	41 mins	3 hrs 32 mins	2 hrs 6 mins
HD9 Rural Huddersfield (Holmfirth)	44 mins	2 hrs 33 mins	1 hr 19 mins	1 hr 25 mins	4 hrs 5 mins	2 hrs 46 mins
WF12 Dewsbury	25 mins	2 hrs 8 mins	1 hr 15 mins	34 mins	4 hrs 9 mins	2 hrs 18 mins
WF17 Batley	21 mins	2 hrs 8 mins	1 hr 18 mins	40 mins	4 hrs 10 mins	2 hrs 31 mins
BD11 Birkenshaw	18 mins	2 hrs 10 mins	1 hr 10 mins	37 mins	2 hrs 46 mins	3 hrs 4 mins
BD19 Cleckheaton	19 mins	2 hrs 9 mins	1 hr 8 mins	46 mins	3 hrs 5 mins	2 hrs 55 mins

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Kirklees COUNCIL

Regional Joint Health Overview Scrutiny Committee
Children s Congenital Heart Services

VISIT TO LEEDS CHILDREN S HEART SURGERY UNIT, LEEDS GENERAL INFIRMARY

On 22 August 2011, Cllr Smaje (Kirklees representative on the Joint HOSC) visited the Children's Heart Surgery Unit at Leeds General Infirmary. Cllr Mulherin from Leeds Council was also present on the visit. Stacey Hunter, Divisional General Manager for Children's Services, and Karl Milner, Executive Director – External Relations, accompanied the visit.

During the visit, Cllr Smaje and Cllr Mulherin spoke with staff in the Children's Heart Surgery Unit, and they raised a number of issues:

- Travelling time to Newcastle or Liverpool if the Leeds unit were to close.
- Continuity of care – many patients had been attending the unit since they were small babies.
- Siblings at home – parents facing difficult situations if siblings were at school.
- Travel costs – many patients seek assistance with travel expenses already.
- Co-location with other services.

Cllr Smaje and Cllr Mulherin also spoke with the grandmother of a young patient on the Children's Heart Unit. She explained that she travelled by public transport 3 or 4 times a week to Leeds General Infirmary to help provide her daughter with a short break. She had been undertaking this journey for the last 7 weeks. She was concerned that this would not be possible if she had to travel to Liverpool or Newcastle.

Concerns raised by Leeds Teaching Hospitals Trust during the visit:

- The decision not to include the number of adult procedures and cardiac interventions within the figures. Intervention cardiology is a growing area and around 550 paediatric interventions are undertaken a year – 200 pacemaker/defibrillator; 200 structural; 150 a combination of the two. The Trust advised that the cardiologists undertaking intervention procedures had stated that they would not undertake them without a cardiac surgeon on standby, as this would not be safe.

- The lack of an evidence base for the 400 procedures figure – it is argued that some surgeons will not undertake as many procedures due to the complexity of the surgery they undertake, however they will still be undertaking a sufficient number to sustain competency. There is no evidence linking the number of procedures to clinical outcomes.

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- 17 outreach clinics are run by Leeds, which are attended by sonographers. Around half of these are surgical clinics, which would not continue if Leeds was to close. Leeds did not believe that surgeons would be able to run outreach clinics from Newcastle or Liverpool into the Yorkshire & Humber region, as they would need to be in theatre or on site, and not considerable distances from the hospital.

- Concern was expressed about the separation of obstetrics and cardiology. The Trust have undertaken work in hospitals around the region to ensure that scans can be undertaken in more local settings so that patients do not have to always travel to Leeds.

- The impact on other services, for example, the kidney service. This is hard to quantify, but cannot be ignored.

- The number of paediatric intensive care cots would be reduced by approximately 6-8, as the funding will not be available.

- Leeds is the biggest teaching hospital in the country but would be unable to train in this speciality.

- Concern was expressed about recruitment of high quality staff. It was felt that the most experienced cardiac consultants and cardiac anaesthetists would be drawn to the hospitals where surgery was being performed.

- Concern was expressed that many patients did not just have to attend the hospital once for the procedure, but attended regular appointments. It was estimated that the majority of patients who are maintaining their condition will attend the hospital once every 3 months; a smaller number whose condition was stable would attend the hospital once every 6 months for a check-up. Following a procedure, monthly check ups would be put in place. Liaison nurses are in regular contact with patients, by phone calls where necessary.

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NORTH LINCOLNSHIRE COUNCIL PEOPLE SCRUTINY PANEL

Response to the Consultation on "Safe and Sustainable: A New Vision for Children's Congenital Heart Services in England".

1. INTRODUCTION

1.1 As democratically elected members and statutory co-optees, North Lincolnshire Council's People Scrutiny Panel welcomes the opportunity to comment on this consultation in our role as representatives of the community.

2. THE PANEL S RESPONSE

2.1 The People Scrutiny Panel agrees with the general principle of reducing the number of specialist surgical units in England. We believe that there is clear clinical evidence that health outcomes will improve as units are staffed by a minimum of 4 consultant cardiac surgeons and the number of procedures rises to the 500 per year benchmark. This will also enable 24/7/365 cover and a full consultant-led clinical response to any emergency.

2.2 The panel has fully considered each of the options and considers that Option D provides the most appropriate model, both for the residents of North Lincolnshire, the wider region and the whole of England and Wales. This is based on a number of considerations that are set out below.

3 DEMOGRAPHICS AND GEOGRAPHY

3.1 Clearly, Leeds is a geographically central city, with excellent transportation links via the M1, A1 and M62 for a vast area of the North of England. Yorkshire and the Humber has a population more than twice as large as the North East (5.5m compared to 2.6m) and Leeds is accessible to a population of 13.8m within a 2-hour drive (2.8m in the North-East).

3.2 There is also a relatively large Asian population across the region; proportionally, these communities are likely to have a greater demand for these services than the wider population. The consultation document (page 204) acknowledges that "projected birth rates may be higher for some ethnic community groups." This is in the context of a projected birth rate in the Yorkshire and Humber region that is double the national average to 2015.

3.3 The Emerging Findings from the Health Impact Assessment also acknowledges that mothers who are obese or who smoke throughout pregnancy are also at increased risk of their children requiring access to cardiac surgery. These are particularly challenging issues within North Lincolnshire, with smoking in pregnancy and obesity in the worst-performing quartile in the country.

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4. CLINICAL OUTCOMES, CLINICAL NETWORKS AND MATERNITY

4.1 Like others, the panel has concerns around the specific scoring and weighting system used by Sir Ian Kennedy and his team. Whilst we would agree that the quality of clinical outcomes is the most important consideration, the methodology used by the team has not been released, despite numerous requests. Despite this, (excluding John Radcliffe Hospital) the review acknowledges that "all options got between 95% and 100% of the maximum score" and the review recommended that all options should be "awarded equal score against the quality criteria on the basis that the assessment panel scored individual centres against the standards and did not produce comparative scores".

4.2 The existing Clinical Network in the Yorkshire and Humber area is, rightly, held in very high regard nationally. The scrutiny panel has significant concerns regarding the viability and effectiveness of non-surgical lifelong support delivered from Leeds for patients and their families in the region, if an option other than D was agreed on. Consultants would naturally gravitate to the specialist centres in Liverpool, Newcastle and/or Leicester. This would either lead to lengthy travelling times for consultants providing outreach or clinics in this area (thus reducing the number of procedures undertaken), an increased need for ill babies and children to travel long distances, or a damaging reduction in local services.

4.3 Finally, a pregnant woman from North Lincolnshire with a foetus with serious cardiac problems could potentially have to deliver in Newcastle, Liverpool, Leicester, before being transferred to the local Cardiac Centre. Clearly, this would be an unhelpful and stressful pathway. Similarly, the loss of a surgical unit at Leeds would require lengthy travelling for many children in need of the existing cardiac catheter intervention service in Leeds. Indeed, families would potentially have to drive past Leeds to travel on to Liverpool or Newcastle.

5. TRAVEL AND ACCESS

5.1 As alluded to in 3.1, a key consideration should be to ask the fewest possible number of patients to travel the least possible distance. The local catchment area is far larger and contains far more people than the other options set out.

5.2 We acknowledge that, if Option D is chosen, other people from outside the area would have to travel. However, the numbers would be fewer, and we have particular concerns about the impact that the requirement to travel for a disproportionate number of families, possibly with more than one child, will have. The panel would also ask why no consideration has been given to liaising with the Scottish Government and colleagues North of the border to allow patients from the North of England to access the specialist centre at Yorkhill in Glasgow.

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6. CO-LOCATION OF FACILITIES

6.1 Leeds is one of only two sites in the country to have co-location of all key specialisms on one site, including maternity (see 4.3) and intensive care (PICU). If an option other than D goes ahead, patients and families from North Lincolnshire would potentially see a more fragmented service than they have done previously. Referral and follow-up arrangements for many procedures are not yet formulated so cannot be supported.

7. THE LANSLEY TESTS

7.1 In May 2010, the Secretary of State set out four key tests that would be central to any proposal in the Health Service going ahead. In response to these, we are assured that the proposals are focussed on improving patient outcomes and are based on sound clinical evidence. As this is not a service commissioned by GPs, the second test is largely irrelevant. The third test states that a proposal must genuinely promote choice for patients. In many ways, this is contrary to the aims of improving clinical outcomes through centralisation, so the test must consider how proportionate the impact is likely to be to local populations. In that context, we cannot say that this test has been met, as any option other than D would have a *disproportionate* effect on local people, because of the larger population base and demographics of this area, as described in Paragraph 3. We find it worrying that a full Health Impact Assessment is yet to be completed, despite the public consultation having ended. As such, we have some concerns around the fullness of the consultation carried out (test 4). Whilst the panel is aware of the numerous events undertaken by the review team, including feeding into the joint regional scrutiny committee, many families remain outside of the consultation process.

8. CONCLUSION

8.1 To conclude, after a full consideration of the evidence, the scrutiny panel recommends that Option D is adopted and implemented. This is based on clinical outcomes and the future viability of follow-up, outreach and support arrangements, demographic considerations, co-locality, and the potentially disproportionate effect on children and their families from North Lincolnshire and the wider region.

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North Yorkshire County Council
Chief Executive's Group

County Councillor Jim Clark
(Harrogate Harlow Division) 74 Green Lane
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North Yorkshire
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16 June 2011

Cathy Edwards
Director - Yorkshire & the Humber Specialised Commissioning Group
Hillder House
Gawber Road
BARNSLEY S75 2PY

Dear Cathy

Children s Congenital Heart Services

At the meeting of the North Yorkshire Scrutiny of Health Committee on 8 April 2011 we considered the consultation document on the proposed changes to Children's Congenital Heart Services. In view of what we feel are the special circumstances facing North Yorkshire in looking towards both Leeds and Newcastle as regional centres for this service we supported Option D but with the inclusion of Newcastle – in effect an "Option E".

On the basis of the information available to the Committee and using Option D as the starting point, patient flows under a new Option E would be:

	Option D	Option E
London	1,482	1,482
Birmingham	660	660
Bristol	420	420
Leeds	636	380 *
Liverpool	400	389 **
Newcastle		267 ***

* 636 - Carlisle (27) - Durham (26) - Darlington (31) - Newcastle Upon Tyne (97) - Sunderland (22) - Berwick on Tweed (2) - Middlesbrough (51).
** 400 - Lancaster (11).
*** Carlisle (27) + Durham (26) + Darlington (31) + Newcastle Upon Tyne (97) + Sunderland (22) + Berwick on Tweed (2) + Middlesbrough (51) + Lancaster (11).

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In reaching this view we were mindful of the need for consultants to build up specialist expertise and that putting in place a critical mass in a fewer number of locations will lead nationally to a service which is sustainable in the long term. But we feel these factors must be tempered by the need to take into account geographical considerations and the risks to children being transported large distances. For instance, if Leeds were to close, a child born with a congenital heart defect in Hull faces a journey of 144 miles to the Freeman Hospital in Newcastle, a child from Wakefield faces a journey of 111 miles and a child from Leeds faces a journey of 99 miles. These are also huge distances for the relatives and guardians wanting to visit children.

In terms of building viable units at both Newcastle and Leeds we feel there are a number of other factors that could be explored.

Firstly with regard to Newcastle if the possibility of directing some patients to Newcastle from the Scottish borders is explored and if the fact that Newcastle provides children's heart transplant surgery is fully taken into account, we feel there could sufficient case in favour of that unit being retained. With regard to Leeds we feel it is essential that its regional population is taken into account. For instance, between 2011 and 2033 the number of children up to 9 years of age in the region is planned to increase from 623,500 to 696,100 - an increase of 11.6%. This would bridge the shortfall. We also feel the centre's accessibility, its co-location of children's and adult cardiac surgery on one site and the strength of the clinical network that has been established for paediatric congenital heart disease must be given sufficient weighting so the service is not lost.

Secondly we feel there is still a debate taking place across the NHS about whether or not the 400 threshold figure is actually a robust figure and also whether or not the scoring methodology underpinning the options sufficiently takes into account all relevant factors. Unfortunately because the consultation with overview and scrutiny committees is only taking place at a regional level we have not had the opportunity to examine these issues in detail.

Against this background we feel there are sufficient uncertainties to suggest that in actual fact that case for retaining all 3 centres in the North is more finely balanced than first appears. We strongly urge, therefore, that before any final decision is made on this matter the scoring methodology, the threshold figure of 400 and the inherent risks in transporting seriously ill children across large distances are reviewed to ensure all relevant factors and options for the service are fully explored. We need to be reassured.

On behalf North Yorkshire Scrutiny of Health Committee I would be grateful if you would take these points into consideration when reaching your final decision. As a member of the Yorkshire and Humber Joint Committee I hope to have an opportunity to discuss these issues in more detail at its next meeting.

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Finally for ease of reference for the recipients of this letter the actual consultation document on the review of Children's Congenital Heart Services can be accessed via the link below:

http://www.specialisedservices.nhs.uk/safe_sustainable/public-consultation-2011

Yours sincerely

County Councillor Jim Clark

Chair: North Yorkshire County Council Scrutiny of Health Committee
Copy to: See attached circulation list
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Robert Goodwill MP
Nigel Adams MP
Julian Smith MP
Julian Sturdy MP
All Chief Executives of Borough/District Councils in North Yorkshire
Sue Cornick, Associate Director - North East Specialised Commissioning Team
Chair of Yorkshire & Humber Joint Committee (C/o: Steven Courtney, Principal Scrutiny Advisor, Leeds City Council)
Chair of the North East Joint Committee (C/o: Peter Mennear, Scrutiny Officer, Stockton Borough Council)
Jayne Brown, Chief Executive – NHS North Yorkshire and York

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ROTHERHAM BOROUGH COUNCIL REPORT

Meeting:	**Children and Young People's Scrutiny Panel**
Date:	**14 July 2011**
Title:	**Update: specialist children s heart surgery; consultation**
Directorate:	**Chief Executive s All wards**

Summary

Safe and Sustainable – the NHS review into the future of children's congenital heart services in England proposed to change the current service model. Health Overview and Scrutiny Committees are being consulted as part of the statutory consultation process. This report updates members of the Health Select Commission of developments.

Recommendations

That the Health Select Commission:

a. agrees that the nominated members from the former Children and Young People's Scrutiny Panel continue in their role for the duration of this review;

b. comments on the report and refers any concerns issues regarding the review of children s cardiac services to the Rotherham Council representative on the Regional Health Overview and Scrutiny Committee;

c. notes the Cabinet response to the consultation;

d. receives further updates of progress.

Proposals and Details

The proposals set out in Safe and Sustainable - A New Vision for Children's Congenital Heart Services in England consultation document, are the outcome of a national review process. The four month public consultation period closed on July 1st 2011.

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In summary, it is proposed that the reconfigured Congenital Heart Networks across England that would comprise all of the NHS services that provide care to children with Congenital Heart Disease and their families, from antenatal screening through to the transition to adult services. However, in doing this there will be a reduction in the number of NHS hospitals in England that provide heart surgery for children from the current 11 hospitals to 6 or 7 hospitals in the belief that only larger surgical centres can achieve true quality and excellence.

Safe and Sustainable consulted on the following areas:

- Standards of care: proposed national quality standards of care to be applied consistently across the country
- Congenital heart networks: development of networks to coordinate care and ensure more local provision (e.g. assessment, ongoing care)
- The options: the number and location of hospitals that provide children heart surgical services in the future
- Better Monitoring: improvements for analysis and reporting of mortality and morbidity data

The options for the number and location of hospitals that provide children's heart surgical services in the future are:

Option A: Seven surgical centres at: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Glenfield Hospital, Leicester • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[5]	**Option B: Seven surgical centres at:** • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • Southampton General Hospital • 2 centres in London[1]
Option C: Six surgical centres at: • Freeman Hospital, Newcastle • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[1]	**Option D: Six surgical centres at:** • Leeds General Infirmary • Alder Hey Children's Hospital, Liverpool • Birmingham Children's Hospital • Bristol Royal Hospital for Children • 2 centres in London[1]

[5] *The preferred two London centres in the four options are Evelina Children s Hospital and Great Ormond Street Hospital for Children*

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Currently Rotherham children with serious congenital heart problems are referred to Leeds Teaching Hospital Trust for treatment, based at Leeds General Infirmary. LTHT also supports outreach clinics at Rotherham Foundation Trust (RFT). Colleagues from RFT estimate that approximately 300 children use the clinic in Rotherham per year.

Leeds only features in 1 of the four options for service configuration. If closed, it is proposed that Rotherham children and families will receive services from one of the following: Newcastle, Birmingham or Leicester. Alternative proposals for configuration of services can be put forward.

Health Overview and Scrutiny Committee Involvement

Health Overview and Scrutiny Committees[6] are being consulted as part of the statutory consultation process and because it affects more than one Local Authority area, this is being coordinated in Yorkshire and Humber through a Joint Committee (chaired by a Member from Leeds City Council). There has been two meetings of the Joint Committee to date (minutes and papers are available on-line). Further meetings are planned with various representatives from health bodies and patients parents groups from across the region to gather evidence to inform the Committee s formal response to the consultation. Information is also being sought by the Committee in respect of patient flow and a health impact assessment of the proposals on the region s population. This information is expected shortly.

It should be noted that the period for Joint Health Overview and Scrutiny Committees to respond to the consultation has been extended to October 5, 2011.

The former Children and Young People's Scrutiny Panel (in its health scrutiny role) nominated one member from Rotherham Council (Cllr Shaukat Ali) to be part of this joint committee. The Children and Young People's Scrutiny Panel also formed a small member working group consisting of Cllrs Ali, Falvey and Sims to inform Rotherham s input to the process.

All Council Members have been previously contacted by email for their views on the proposals. These have been used to inform questions to witnesses and lines of inquiry. It is suggested that any further comments concerns from the Health Select Commission are referred to the member working group for Cllr Ali to raise with the regional committee. Further updates of progress will be submitted to this committee in due course.

[6] Under Rotherham's previous overview and scrutiny arrangements, health scrutiny responsibilities were delegated to the former Children and Young People's Scrutiny Panel if they relate to children's health matters

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As the members of the working group are familiar with the issues and have undertaken considerable work meeting with parents, MPs and local clinicians, it is proposed to continue with these arrangements for the duration of the review.

Local Discussions

Given the complexity and sensitivity of the issue, the working group held an initial meeting with colleagues from Rotherham Foundation Trust and NHS Rotherham to discuss how the proposals may impact upon local services.

In particular, concerns have been raised about the following:–

- access to facilities for Rotherham children and families, particularly in emergency or acute situations;
- sustainability of local clinics;
- retention and future development of specialist skills;
- sustainability of intensive care facility at Leeds Teaching Hospital Trust should it no longer be a specialist facility.

A further meeting was held with local parents of children with congenital heart diseases who have accessed services in Leeds. Whilst many of the concerns reflected the views of clinicians, further questions were asked about:

- lengthy 'blue light' journeys across busy road networks;
- support networks for children and their carers and increased disruption and costs, particularly for families on low incomes, if services are re-located;
- collocation of services and whether sufficient emphasis had been placed on the benefits of this in the review;
- transition to adult services.

The working group also met with local MPs to inform them of the health scrutiny process and share information. In addition, the views of Youth Cabinet were sought. Their concerns mirrored many of the issues previously raised.

Considerable media interest has been generated both locally and nationally. The local press has been contacted by Cllr Ali to seek the public s views on the proposals. In addition, a regional charity, the Children s Heart Surgery Fund has held a number of meetings throughout the Yorkshire and Humber region, including Rotherham.

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Discussions have also taken place with other South Yorkshire Health Scrutiny support to ascertain any joint areas of concern to feed into the regional consultation.

Cabinet Response

The Cabinet has responded separately to the consultation, opposing the closure of Leeds as a surgical centre. The response is attached as Appendix A

Finance

There are no financial implications directly related to this report.

Background Papers and Consultation

Safe and Sustainable - A New Vision for Children's Congenital Heart Services in England: Consultation Document
http://www.specialisedservices.nhs.uk/document/safe-sustainable-a-new-vision-children-s-congenital-heart-services-in-england-consultation-document
Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)
14th March, 2011: http://democracy.leeds.gov.uk/ieListDocuments.aspx?MId=5146&x=1
29th March, 2011:
http://democracy.leeds.gov.uk/ieListDocuments.aspx?CId=793&MId=5149&Ver=4

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ROTHERHAM BOROUGH COUNCIL CONSULTATION RESPONSE

Thank you for the opportunity to respond to the "Safe and Sustainable Review of Children's Cardiac Services".

1. **In making a response, we fully endorse the principles outlined in the consultation.**

   - Children - The need of the child comes first in all considerations
   - Quality
   - Equity
   - Personal service
   - Close to families' homes where possible

We have specific comments in respect of proximity to families' home (outlined under the headings of blue light transfers; support networks and financial considerations)

2. **Do you agree or disagree with the statement that Without change there is a risk that in the future some children s congenital cardiac services may become neither safe nor sustainable ?**

We would support the above statement. However, we would urge the retention of Leeds Teaching Hospital Trust as a surgical centre as we believe that it meets the above conditions and has the capacity to improve its service.

3. **To what extent do you support or oppose the national standards within each of these seven key themes?**

We would support the seven key themes

4. **To what extent do you support or oppose the proposal to increase the role of paediatricians with expertise in cardiology in District Children s Cardiology Services across England?**

see 6

5. **To what extent do you support or oppose the proposal that current surgical units that are not designated for surgery in the future become Children s Cardiology Centres?**

We would support this aim. However, should Leeds not be chosen as an option, we have concerns whether the proposed Cardiology Centre would be sustainable in the long term, particularly in respect of retaining and developing specialist staff to support this service.

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6. To what extent do you support or oppose the proposal to develop Congenital Heart Networks across England?

We are pleased that the review calls for the strengthening of local heart networks and includes proposals to increase the roles of paediatricians locally. We already have a foundation for this work. Indeed, both parents and local clinicians value the access to regular clinics run locally by Leeds Cardiology staff, including transition nurses, in conjunction with the Rotherham based paediatric team. We are aware that Rotherham clinicians have developed greater degrees of specialism as a result of their collaboration with the Leeds centre, leading to better services for some of the most vulnerable children and young people in Rotherham.

We believe that this is a blue-print that should be rolled out elsewhere. We are not persuaded that this excellent service would be replicated to the same standard should Leeds not be the chosen option.

7. To what extent do you support or oppose:

- The need for 24/7 care in each of the Specialist Surgical Centres?
- The proposal that, in the future, interventional cardiology should be provided only by designated Specialist Surgical Centres

We would support the above aims.

Additional Comments

However, in responding we would also like to make some specific observations that we do not believe have been addressed in the Safe and Sustainable review.

Population

Services should be located in proximity to the population. Currently, Leeds has almost 14 million people within a two hour drive of its hospital. Newcastle has far fewer, with less than three million. Whilst population density appears to be a qualifying factor for hospitals in Liverpool and Birmingham; this standard does not appear to have been applied to the selection of Leeds as an option.

Blue-light transfer

Because of the proximity of the motorway and public transports network, the journey to Leeds is relatively simple for patients in Rotherham. Should services relocate to Newcastle or other centres, babies and children in our area would have much greater transfer times to travel. This would not only be the case for specialist heart procedures but also for related procedures in order to ensure heart specialists are on hand in case of a medical emergency. In addition, Newcastle is not well served by a motorway network.

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Feedback from local parents all stress that transfers time are critical; having experienced the emergency transport of their children to Leeds for life-saving treatment they have articulated their concerns about whether longer blue light journeys to the other proposed centres would lead to the same positive outcomes. We share their concerns that a blue light journey of three hours plus on a busy road network is neither safe nor sustainable.

Local parents have expressed existing concerns about blue light services and the availability of specialist equipment to support very sick children being transferred. With journey times being lengthened, both parents and specialist staff based at our local hospital believe that patient safety will be compromised. Parents were not reassured at recent consultation events that sufficient consideration has been given to these issues. Given the potential of longer journey times, we share the view that safe transfer cannot be assured under these circumstance.

Co-location

We do not believe that sufficient consideration has been given in the scoring to the co-location of services in Leeds. We are aware that local parents attending Leeds consider co-location to be a positive factor in their child's care and as such its provision is a great reassurance to them. Local clinicians also cite the significance of co-location; be it in terms of better access to specialisms; minimising disruption and blue-light transfers; continuity of care and smooth transition to adult services; and minimising disruption and stress of parents and carers. We are aware that some of the other options do not have these benefits.

We are aware that local parents attach great value to the services in Leeds; not only in terms of medical care and expertise but also to the support it gives to children and carers in very difficult circumstances. This applied across the team from surgical staff, cardiac nurses or access to counselling services. Basic accommodation is available on site in Leeds, allowing parents to be close to their child whilst undergoing surgery. It is important that such facilities remain available to support parents or carers.

Transition

With the increasing numbers of children with congenital heart defects surviving into adulthood, it is critical that adult services are also safe and sustainable. Given the services are inter-linked, with often the same surgeons performing both adult and paediatric interventions, if Leeds were to close as a surgical centre would the adult service be viable? We do not believe that this issue has been given consideration.

Intensive Care

We are concerned that the closure of Leeds would lead to significant reductions in children's intensive care capacity. This will mean that some children needing intensive care may have to receive care outside of our region or put additional pressure on intensive care beds provided at the other specialist children's hospital locally.

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Support Networks

The impact on families, including other siblings, should not be underestimated. Local parents and clinicians spoke of the practical support given to parents or carers by their own families whilst their child was awaiting or undergoing treatment. At present Leeds is accessible via car or public transport, however, if the service was relocated, there was a widespread view that it would be difficult for their families to maintain the same level of support because they would have travel much further distances. They were concerned that this would be difficult if a round-trip of several hours was required, potentially adding to an already stressful and distressing situation.

Examples were given of existing difficulties of getting time-off work to attend appointments and having to use leave entitlements. This may be compounded if more time off was needed to travel greater distances.

We are aware that the impact on parents who do not have access to their own transport is considerable. Currently a journey to Leeds by public transport can involve up to three changes, plus a short walk (often with buggy) to the LTHT. This can often take over two hours. It is envisaged that the journey to any of the other centres on public transport would add between 2 -3 hours to the trip. On weekends or out of hours this would be more difficult. This is without taking costs into consideration.

Financial consideration

Yorkshire and Humber has a higher proportion of families on low income families. We envisaged the cost of journeys for Rotherham families would increase if Leeds were no longer the specialist centres. Whilst we are aware that claims can be made for some travel costs, the overall cost of journeys/ overnight stays and other associated costs could be substantial.

Impact on ethnic minority communities

We have serious concerns that the proposed closure of Leeds as a surgical centre would have a disproportionate impact on ethnic minority communities as our region is home to a greater number of these families who are also disproportionately higher users of this unit.

In conclusion, any decision to close Leeds as a surgical centre would not best serve the interests of some of the most sick and vulnerable children in Rotherham.

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Report to Regional Health Overview Scrutiny Committee
August 2011

Report of: Councillor Ian Saunders
Sheffield City Council Member representative on the Regional Health Overview & Scrutiny Committee

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Subject: Sheffield City Council response to the *Safe* and *Sustainable* Review of Children's Congenital Cardiac Services in England

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Author of Report: David Molloy, Scrutiny Policy Officer, Sheffield City Council

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Summary:
This report outlines the key concerns of Sheffield City Council in response to the *Safe* and *Sustainable* review's proposals for the reconfiguration of children's congenital cardiac surgery services in England.

Type of item: The report author should tick the appropriate box

Reviewing of existing policy	
Informing the development of new policy	
Statutory consultation	**X**
Performance / budget monitoring report	
Cabinet request for scrutiny	
Full Council request for scrutiny	
Community Assembly request for scrutiny	
Call-in of Cabinet decision	
Briefing paper for the Scrutiny Committee	
Other	

The Scrutiny Committee is being asked to:
Note the concerns of Sheffield City Council to the *Safe* and *Sustainable* proposals and consider these as part of the regional response to the proposals

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Background Papers:
Safe and Sustainable: Review of Children's Congenital Cardiac Services in England

Category of Report: OPEN

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Report of the Sheffield City Council Member Representative on the Regional Health Overview Scrutiny Committee

Sheffield City Council response to the Safe and Sustainable Review of Children s Congenital Cardiac Services in England

1. Introduction

1.1 This report sets out the key concerns of Sheffield City Council in response to the Safe and Sustainable Review's proposals for the reconfiguration of children's congenital cardiac surgery services in England.

2. The rationale for a national review

2.1 There are currently 11 children's heart surgery centres in England. The Leeds Teaching Hospitals NHS Trust is the only centre based in the Yorkshire & Humber region.

2.2 Experts have become concerned that smaller centres are not sustainable in the future and cannot provide the best possible care. It has also been claimed that services have developed on an ad-hoc basis and, as a result, the current care pathway does not deliver the best possible care for children and their families.

2.3 The intention behind the review is to ensure that national standards are met and that the best service is delivered.

2.4 Of the 11 heart surgery centres in England some have fewer than 4 paediatric surgeons. This means that in some centres there will be times when a surgeon is not available to deal with routine cases or emergencies.

2.5 The review states the need for each centre having enough surgeons to meet the day-to-day demands of each centre. These include:

- Being on call for emergencies
- Undertaking ward rounds
- Running outpatient clinics
- Training
- Annual leave

2.6 Smaller centres may not see the same volume and variety of caseload that colleagues in a larger centre will inevitably see. A significant risk of smaller centres with fewer staff is that there may be times when cardiac surgery teams are not available. This can lead to:

- A lack of 24/7 care
- Small case loads
- Occasional practice
- Cancelled operations
- Low availability of staff in emergencies

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2.7 The new standards require a minimum of 4 surgeons in each centre, each performing a minimum number of surgical procedures each year to maintain their expert skills. Experts agree that surgeons should be performing 100 to 125 procedures per year. This suggests that each centre should be performing 400 to 500 procedures a year.

2.8 The 2001 Kennedy public enquiry into the deaths at the Bristol Royal Infirmary recommended that quality standards be developed for children's heart surgery centres and that there be fewer, larger centres of expertise. The 2003 Munro Review also recommended fewer centres, but this recommendation was not implemented. The Summit of Experts (2006) concluded that the current configuration of child heart surgery services was unsustainable and called for fewer centres. Moreover, the Royal College of Surgeons 2007 report, 'Delivering a First Class Service', also called for fewer, larger cardiac surgery centres. In addition, The National Clinical Advisory Team (2010) reviewed the *Safe* and *Sustainable* case for change and endorsed the need for fewer cardiac surgery centres.

2.9 A range of other professional organisations have expressed support for the rationale for change including: Royal College of Surgeons; Royal College of Nursing; Society of Cardiothoracic Surgery in Great Britain and Ireland; Royal College of Paediatrics & Child Health; British Congenital Cardiac Association; Children's Heart Federation; Specialised Healthcare Alliance; and, the Paediatric Intensive Care Society Council.

2.10 The review will lead to fewer, larger centres of excellence providing children's heart surgery. Each centre will have a minimum of 4 consultant congenital cardiac surgeons. Each centre will also have enough doctors and nurses to provide 24/7 care for children and parents. There will be a minimum of 400 paediatric heart surgeries per centre each year. Tertiary surgical centres will provide clinical leadership throughout their networks. The changes will also mean better training for surgeons and their teams to ensure the long-term sustainability of the service.

2.11 The review has stipulated that the location of children's heart surgery centres cannot be 'local' to all people in England. However, the review does stipulate that services that don't involve surgery or interventional procedures can be provided more locally.

2.12 The vision is a network of linked hospitals working together, pooling expertise and experience to ensure the best results for children and young people. The new model aims to deliver better and more consistent care for children and young people with heart disease. Continual review will ensure the service provides the best care and support for parents and their children. The new service will strengthen the delivery of assessment and follow-up care in local hospitals so that children and families do not have to travel long distances. Current surgical centres that are not recommended for designation under the *Safe* and *Sustainable* review will become specialist paediatric cardiology centres, though not providing interventional services. A network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network. Under the new standards, the roles of Paediatrics with an interest in Cardiology and cardiac Liaison Teams will be strengthened to ensure expert care is delivered at a local level.

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2.13 The principles of the *Safe* and *Sustainable* review are

- The NHS must provide only the very highest standards of care for children and their families, regardless of where they live or which hospital provides their care
- Centres should provide care that is based around the needs of the child and the family, including transition to adult services
- All relevant treatment other than surgery, including follow-up, should be provided as locally as possible to the family
- Clinical standards should be agreed and met by all centres
- The review is not a cost-cutting or bureaucratic exercise

2.14 The new model of care aims to deliver better and more consistent care for children and young people with congenital heart disease. The key points to be emphasised on the new model of care include:

- The outcome of Safe and Sustainable is NOT to close existing centres. Centres that are not designated for surgery will continue to provide non-interventional specialist paediatric cardiology services
- It is envisaged that there will be a number of managed cardiology networks across England
- The model of care seeks to strengthen the delivery of assessment and follow-up services in local hospitals so that children and families have easy access to local services and do not have to travel long distances to the tertiary surgical centres for non-interventional work.

2.15 The benefits for children and families of the new model of care include:

- Improved clinical outcomes
- Improved access: local diagnostic services and follow-up treatments; 24/7 care; and, surgical centres with expertise in complex procedures
- Stronger communication between services and parents: specialist liaison nurses and network collaboration
- Larger and stronger clinical teams: more sustainable; improved training and learning; a sufficient volume and range of operations; joint operating; and, improved recruitment and retention

3. The Sheffield perspective: key concerns

3.1 Sheffield City Council's Children & Young People Scrutiny Committee nominated Councillor Ian Saunders as Sheffield's representative to the Yorkshire & Humber Regional Health Overview & Scrutiny Committee. This regional committee has been scrutinising the proposals in the *Safe* and *Sustainable* review and will be submitting its own regional written response to the proposals.

3.2 Based on extensive work that has been undertaken in Sheffield on these proposals, there are a number of key concerns about the potential closure of the paediatric cardiology surgery centre at Leeds Teaching Hospitals NHS Trust. These include the manner in which the *Safe* and *Sustainable* review has been carried out, along with the potential impact of the Leeds closure on children, parents and their wider families in Sheffield.

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Key areas of concern

Flaws of the review

3.3 During our investigations, we are concerned about the manner in which the *Safe* and *Sustainable* review has been carried out. In our opinion, there are a number of flaws in the review process. These include:

- The lack of thoroughness throughout the process: we are concerned that the Health Impact Assessment was not completed before the final options for consultation were presented. We would stress how important it is for all information being made available for any serious consultation with service users and professionals to take place. Other areas of concern in this regard relate to the lack of engagement with Black Minority and Ethnic Groups and the fact that no Equality Impact Assessment has been undertaken.

- The lack of consideration given to children moving through to adulthood: in our discussions with senior practitioners in Sheffield, they have referred to the absolute focus of the review on children with congenital heart conditions. What has been lacking in this review, in the eyes of professionals, is the lack of attention paid by the review in the transition to adulthood. In the opinion of these professionals, it is a fatal error of the review to fail to consider this transition from childhood to adulthood.

- The importance attached in the review to surgical centres that have Extracorporeal Membrane Oxygenation (ECMO) facilities, such as The Freeman Hospital, Newcastle-upon-Tyne: there has been a great deal of importance attached in the Safe and Sustainable review to this facility being available in a number of hospitals across the UK. However, from our conversations with health professionals, whilst the importance of having these facilities is acknowledged, there is concern that the ability of hospitals to undertake this technique has been overplayed in the review. It is our understanding that ECMO facilities are generic skills that can be transferred to other hospitals across the country. We are therefore concerned that these skills have been overemphasised in the review which has placed certain hospitals that have such facilities, at an advantage over hospitals that do not. It is also worth noting that the LGI perform mini-ECMO with every operation.

Patient flow assumptions and the issue of choice

3.4 There are a number of concerns about the projected patient flows in the *Safe and Sustainable* review report. The 'Options for Consultation' section of the report (pages 88-91) sets out the 'network' that Sheffield would become part of, and where Sheffield children with serious cardiac defects would be referred on to for surgery as part of this network. For each of the options set out in the report, it is presumed that Sheffield children would be referred on to:

- Option A – Leicester Network
- Option B – Birmingham Network

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- Option C – Newcastle Network
- Option D – Leeds Network

3.5 Nonetheless, these 'future potential networks' are based on the assumption that individual hospitals will willingly refer their patients to the surgical centres within their respective networks. Based on our conversations with Sheffield Children's Hospital, the City Council are concerned about these assumptions and believe that they are flawed. It is our understanding that it is (and will continue to be) the decision of individual hospitals where they refer their patients on to for paediatric surgery. In the case of Sheffield Children's Hospital, it is understandable that they will refer their paediatric patients to surgical centres where they believe the best outcomes will be delivered. In the case of Sheffield Children's Hospital, if the Leeds surgical centre were to close they would refer their paediatric patients on to Birmingham as this is where they believe that the best outcomes for their patients would be achieved. **It would not be the intention of Sheffield Children s Hospital to refer their paediatric patients on to Leicester or Newcastle as set out in Options A and C.**

3.6 Sheffield Children's Hospital are more than happy with the service that they receive from Leeds General Infirmary for their paediatric patients. The Children's Hospital have been referring to Leeds for approximately 9 years. Before this, they used to refer their paediatric patients to Leicester for heart surgery. However, Sheffield Children's Hospital were not particularly happy with the outcomes at Leicester and decided to switch their referrals to Leeds. The *Safe* and *Sustainable* review therefore raises wider questions about the issue of hospital 'choice'.

3.7 The choice of individual hospitals to refer their paediatric patients to the surgical centre of their choice is an issue that Sheffield City Council believes has been overlooked in the *Safe* and *Sustainable* review report. What also appears to have been overlooked in the review is the issue of patient 'choice' in the wider NHS constitution. As far as the City Council understands, hospitals would become part of a wider network whereby patients with serious cardiac defects would be referred to the cardiac surgery centre within this network. This raises questions, however, about where the choice of patients and their families lies in having surgery at centres that suit their specific circumstances.

3.8 An additional concern is the accuracy of the patient flow figures used in the review. It is not clear to us which postcodes have been used in assessing the flow of patients from Sheffield into the Leeds Teaching Hospital. We are also not clear which areas of Sheffield this covers as there are a number of areas outside the city which have Sheffield (S) postcodes including North Derbyshire and Chesterfield. We welcome the additional work that Pricewaterhouse Coopers have been commissioned to do into this crucial area of work.

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Impact on children, parents and their families

3.9 It is clear that the closure of the paediatric cardiac surgical centre at Leeds General Infirmary will have a significant impact on sick children, parents and families across Sheffield.

3.10 These 'impact' concerns relate primarily to two key areas. Firstly, there is the significant increase in transport times for families in Sheffield with children that have cardiac defects. During interviews, parents and their wider family members have informed us that they feel reassured that an emergency journey to Leeds General Infirmary for cardiac surgery on their child is approximately 45-60 minutes journey time from Sheffield. Should the Leeds cardiac surgery centre close as part of the *Safe* and *Sustainable* review, there will be a significant increased travel times for families in Sheffield taking their children for cardiac surgery to either Birmingham or Newcastle in particular, as set in Options B and C.

3.11 In addition, there is also an increased financial cost implication for families in Sheffield were the Leeds centre to close. For families with children that have serious cardiac defects that requires surgery, there is the increased cost of food and accommodation when their child is in hospital in another part of the country outside the Yorkshire and Humber region. In their interviews, parents told us that whilst Leeds General Infirmary is a reasonable travel away from Sheffield, the advantage of the current arrangement is that they can be with their children whilst they are awaiting heart surgery (or are recovering from heart surgery) and juggle their family arrangements around so that this works for them. For example, their partner can continue to work and wider family members can look after other children within the family. Furthermore, family life can be juggled around so that parents can take a break from being with their sick child and the stresses that are inevitably involved with this. If the Leeds centre were to close, and parents were required to travel to either Birmingham or Newcastle for their children to have surgical treatment, then the options for maintaining a relatively stable family life during this period will be diminished.

3.12 In short, it is the view of Sheffield City Council that the potential closure of the paediatric cardiac surgery centre at Leeds General Infirmary will have a significant 'knock-on' impact on children with cardiac defects, their parents and wider families. It is the view of health professionals across the city, in our conversation with them, that the Yorkshire and Humber region has a large enough population and successful paediatric surgical service at Leeds General Infirmary to justify keeping the centre open. There appears to be some irrationality in the largest geographical region in England not having its own paediatric cardiac surgical unit. In our conversations with senior health professionals, they have emphasised the central health planning principle of moving health services to the general population. Based on these conversations, it is the opinion of Sheffield City Council that the *Safe* and *Sustainable* review appears to have forgotten this key principle of effective health planning.

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The unique selling point of Leeds Teaching Hospitals NHS Trust

3.13 It is clear that the paediatric cardiac surgery centre at Leeds General Infirmary has a number of 'unique selling points'. These all add to the significant added value of maintaining the centre in the Yorkshire and Humber region. At present, patients enjoy a single site paediatric centre at LGI for in-patient care with feotal and adolescent/congenital heart disease services also on-site and out-patient follow-up delivered locally in district general hospitals around the region. Excellence in modern specialist care demands multidisciplinary care with other paediatric specialities being immediately available on site and not semi-available across a city. The modern provision of cardiac care for children and young people demands a well-developed clinical and managerial network such as the Yorkshire, Humber and North Trent Paediatric Cardiology Network working collaboratively with the team at LGI as it does so presently. It is therefore somewhat ironic that the Safe and Sustainable Review is aiming to replicate the LGI model across the country yet proposes to exclude the LGI as a specialist surgical centre.

3.14 Furthermore, it is evident that the paediatric cardiac surgical centre at LGI meets the essential criteria behind the *Safe* and *Sustainable* Review, including:

- Quality – there is no question about the high quality care that children receive at the LGI paediatric cardiac surgical centre. In our interviews, parents had nothing but praise for the staff and quality of care that their child received
- The NHS must plan and deliver care that is based around the needs of the child – services and facilities must be designed and delivered around a child's basic needs. The unique advantage of the centre at LGI is that services are truly co-located with neonatal and paediatric services. This means that services are designed around the needs of children, being based on a single site centre. Having centres for cardiac surgery co-located to general paediatric services is also advised by the British Congenital Cardiac Association (BCCA).

3.15 The *Safe* and *Sustainable* review refers to LGI currently having 3 cardiac paediatric surgeons and in 2010 the centre performed 316 procedures. This is obviously short of the minimum 400 procedures that the review recommends in terms of sustainability. Nonetheless, in our conversations with the cardiac paediatric team at Leeds General Infirmary have said that based on future population projections and some minor changes to referral patterns this number would be expected to exceed 400 procedures per annum. There also appear to be strong demographic reasons for retaining the surgical centre in Leeds, as the table below indicates.

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	Current population (m)	Population over past decade (-)	Projected population for 2028 (m)
Yorkshire & Humber	5.5	+ 5.7%	6.1
North East	2.6	- 3.6%	2.8

The knock-on impact

3.16 Sheffield City Council are also concerned to note that the potential closure of the paediatric cardiac surgery centre at Leeds General Infirmary will have a significant 'knock-on' impact on the wider regional network, which has been built up over a number of years. It has been suggested that the closure of the Leeds surgical unit could lead to the loss of the substantial support network that has been built around this such as the network of cardiologists and specialised nurses which has been held up as an exemplar model in modern day practice. In our discussion with Sheffield health professionals, it is their view that it is illusionary to divorce surgery from cardiology.

3.17 Sheffield, and the Yorkshire and Humber region more generally, currently benefits from the 'Embrace Transport Service', located near junction 37 of the M1. The service provides a 24 hours a day, 7 days a week critical care transport service for critically ill neonatal and paediatric patients in the Yorkshire and Humber region. The location of the service means that it can respond quickly to referrals from clinicians throughout the region. Whilst recognising the significance of having this service located in, and serving, the region, it is our view that this has, in some ways, gone against the case for the children's surgical centres at the LGI to remain open in the review. What has without doubt been overlooked in the *Safe* and *Sustainable* review is the huge increase in workload for the Embrace Transportation Service that the closure of the surgical centre at the LGI bring.

4. What does this mean for the people of Sheffield?

4.1 The potential closure of the paediatric cardiology surgery centre at the Leeds Teaching Hospital NHS Trust will have a significant impact on children in Sheffield with cardiac problems. This will also, inevitably, have a significant knock-on impact on their parents and wider families. There is a common misconception that Sheffield Children's Hospital provides all relevant services to children and young people, including those with serious cardiac defects. This, of course, is not the case. Whilst Sheffield Children's Hospital has its own Cardiology Unit, those children in the Sheffield region who require cardiac surgery have this at Leeds Teaching Hospital NHS Trust.

Appendix 6:
Local authority information

5. Recommendation

5.1 The Committee are recommended to note the contents of the report along with the key concerns of the potential closure of the Leeds' facility from a Sheffield perspective, and consider these as part of the regional response to the proposals.

Appendix 6:
Local authority information

Councillor Lisa Mulherin
Chair, Scrutiny Board
(Health and Wellbeing and Adult Social Care)
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Civic Hall
LEEDS LS1 1UR

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Civic Hall Tel. 0113 39 51411
Civic Fax 0113 24 78889
Your ref
Our ref LM/SMC
Date 29 June 2011

Freepost RSLT-SRLZ-JYYY
Safe and Sustainable
Ipsos MORI
Research Services House
Elmgrove Road
Harrow
HA1 2QG

Dear Sirs,

Review of Children s Congenital Cardiac Services in England initial response

In January 2011, the Regional Health Scrutiny Network (Yorkshire and the Humber) received a briefing from the Director of the Yorkshire and the Humber Specialised Commissioning Group (YHSCG) on the review of Children's Congenital Cardiac Services process and associated timescales. This was provided in the run up to the meeting of the Joint Committee of Primary Care Trusts (JCPCT) on 16 February 2011.

Following the February meeting of the JCPCT and subsequent announcements about proposed reconfiguration of Children's Congenital Cardiac Services in England, the regional network established a formal joint health overview and scrutiny committee (JOSC) to consider those proposals on behalf of the 15 local authority Health Overview and Scrutiny Committees covering the whole of the Yorkshire and the Humber region. It should be noted that this is an extraordinary and unprecedented requirement in terms of NHS service reconfigurations and the coordination of this work should not be underestimated.

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Appendix 6:
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At its first meeting in March 2011, the JOSC agreed its terms of reference: These can be summarised as considering:

- The review process and formulation of options presented for consultation;
- The projected improvements in patient outcomes and experience;
- The likely impact on children and their families (in the short, medium and longer-term), in particular in terms of access to services and travel times;
- The views of local service users and/or their representatives;
- The potential implications and impact on the health economy and the economy in general, on a local and regional basis; and,
- Any other pertinent matters that arise as part of the inquiry, and we are extremely grateful to the network of scrutiny support officers for their continued efforts in this regard.

To date, the JOSC has formally received and considered evidence from YHSCG and Leeds Teaching Hospitals NHS Trust (LTHT). However, as a result of the public consultation's proximity to local council elections – which resulted in a significant change in membership (over 50%) – the JOSC has been unable to arrange any further meetings until after the close of pubic consultation on 1 July 2011. However, we were previously advised that the deadline for HOSCs to respond to the proposals had been extended until October 2011 – which was subsequently confirmed by the national team's statement regarding consultation with HOSCs dated 20 May 2011.

I am reliably informed that concerns were raised about the timing of public consultation and involvement of HOSCs in November 2010, when it first emerged that the original timetable for consultation was likely to be delayed, given the inevitable changes to membership of HOSCs immediately after the local elections and the impact this would have on the meaningful involvement with HOSC's during this time.

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

To help the JOSC produce a fully informed report/response, it is essential that it gathers and considers a wide range of data/ evidence. This specifically includes consideration of the local data and impacts. The level of detail required was not readily available when the proposals were first published and has taken time to gather and analyse. The result of which served to severely limit the timeframe for the JOSC to meet to consider the local data and impacts and then provide an informed and more detailed response by the public consultation deadline.

A response from the JOSC will follow ahead of the October 2011 deadline.

However, I would like to make the following personal observations on the reconfiguration options put forward in the public consultation document:

Cont./

Appendix 6:
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Co-location of services

It is widely acknowledged that the co-location of services brings about huge benefits for children and adults with interdependent conditions. Currently in Leeds, children from across the region access surgical and interdependent services **on one hospital site**. However, the definition of 'co-location of services' appears to be loosely interpreted in the options being considered under "Safe and Sustainable" to include centres where such services may be located over multiple hospital sites. I would argue that the public would consider co-location to mean a single site.

All children's acute services are *genuinely co-located* in Leeds alongside maternity services (which is essential for the wellbeing of mother and baby if cardiac interventions are required at birth). Reducing the likelihood of mother and child being separated immediately after birth (where the child would be transferred to another hospital for surgery) would help to minimise the unnecessary stress on the mother and family. Having maternity services and children's congenital cardiac surgery on one site is invaluable to families across the region at the start of a child's life.

I would add that adult cardiac surgery would also be adversely affected by any move away from children's congenital hear surgery in Leeds, where the same surgeons treat children and adults on the same site and there is continuity of care for patients from childhood through into adulthood.

Patient flows, travel and access

The patient flows predicted under options A-C suggest patient travel patterns from the Yorkshire and Humber region that do not appear to match local knowledge.

I welcome the additional review work that is now being undertaken around travel patterns, but I find it frustrating that more detailed analysis and testing of assumptions was not undertaken prior to the options for consultation being identified, as the impact will be significant in determining whether or not designated centres are likely to attract sufficient patient volumes in order to undertake the suggested minimum number of 400 - 500 surgical procedures per centre.

Extending travel times and the complexity of journeys for patients across the Yorkshire Region places an additional strain on patients and their families at what will already be a particularly stressful time.

Engagement with Black and Minority Ethnic (BME) communities

I understand that families from the Indian sub-continent in particular are more likely to require children's congenital heart services. There is a significant population of BME communities of Kashmiri, Pakistani and other Indian sub-continent communities in the Leeds City Region who ought to have been better engaged in this consultation from the outset.

Cont./

Appendix 6:
Local authority information

I believe their engagement received insufficient attention and translated information was not readily available early enough in the process.

As local authorities strive to maintain stronger and thriving local communities, it is important that public sector agencies work together to ensure active engagement across all communities. I do not feel that this public consultation sufficiently addressed this aspect of involvement and engagement.

Level of surgical activity

The case for a minimum of 400 procedures per designated surgical centre is a cornerstone of the case for change and underpins the assessment of options. Having recently received the activity data for 2010/11, it is worthy of note that Leeds Teaching Hospitals Trust undertook 342 surgical procedures with 3 surgeons during this time. This represents the 3rd highest number of procedures outside of London. With the review process already determining that the services provided by LTHT are 'safe', it would appear nonsensical not to retain a designated centre in Yorkshire and the Humber that is currently undertaking this level of activity.

In addition, as Option B includes centres not predicted to achieve the minimum of 400 procedures, I would question the consistency of application of the volume criteria which is supposed to underpin the process, when Option B is presented as a valid option for consultation.

One final note is that I would question the emphasis that is being placed on certain nationally commissioned specialist services currently being carried out in certain hospitals in some parts of the country, which seem to outweigh the consideration being given to centres of population in other parts of the country.

I trust these comments will be helpful and look forward to submitting the report of the JOSC (Yorkshire and the Humber) later in the year.

Yours sincerely

Councillor Lisa Mulherin
Chair, Scrutiny Board (Health and Wellbeing and Adult Social Care), Leeds City Council and Chair, Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

cc All members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)
Cathy Edwards (Director, Yorkshire and the Humber Specialised Commissioning Group)

Appendix 6: Local authority information

Information provided by Leeds City Council:

An analysis of the **Index of Multiple Deprivation (IMD) 2010** shows that **Leeds now has:**

- 25 SOAs (5.3%) in the most deprived 3% on the national scale (covering an approximate population of 40,600)
- 92 SOAs (19.3%) in the most deprived 10% on the national scale (covering an approximate population of 150,000)
- 136 SOAs (28.6%) in the most deprived 20% on the national scale (covering an approximate population of 225,600)
- The most deprived SOA in the city is ranked 114 on the national scale (Spencer Place, Bankside Street, Shepherds Lane)
- The least deprived is ranked 32,105 (Cookridge, Moseley Woods)
- Gipton & Harehills is the only ward with 100% of its SOAs ranked in the most deprived 20%
- 9 wards have 50% or more of their SOAs ranked in the most deprived 20%

Comparison with the 2007 IMD

The initial analysis suggests an overall worsening position when compared to the rest of the country with the majority of SOAs in Leeds seeing their ranking fall. Of the 476 SOAs in Leeds:

- 154 have seen an improvement in their IMD ranking
- 322 have seen their ranking fall

In 2007 Leeds had 22 SOAs that were ranked in the most deprived 3% nationally, this number has risen to 25 on the new IMD.

In 2007 Leeds had 95 SOAs that were ranked in the most deprived 10% on the national scale. On the new 2010 IMD Leeds has 92 SOAs in this bracket. 8 SOAs from the 2007 IMD have now moved out of the 10% bracket but there are 5 SOAs which are now ranked in the most deprived 10% and were not previously in this bracket.

The 5 SOAs which are now in the 10% bracket and were not previously are:

Ref number	Area Includes	Ward	2007 Rank	2010 Rank
E01011389	Woodnook Drive, Silk Mills	Weetwood	3701	2802
E01011723	Langbars, Braytons, Eastwoods	Crossgates & Whinmoor	3497	2810
E01011726	Gamble Lane, Tong Drive, Stonecliffes, Hall Lane	Farnley & Wortley	4383	2869
E01011476	Brooms, Nesfields	Middleton Park	4041	2983
E01011656	Boggart Hill Dr, Barncroft Rd, Ramshead Dr, Monkswood Hill	Killingbeck & Seacroft	3922	3140

Appendix 6:
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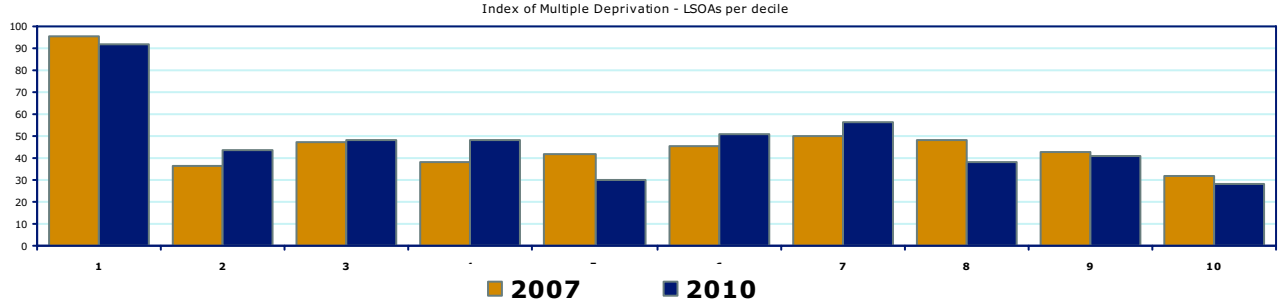
Index of Multiple Deprivation Ward Rankings

Ward	SOA's	Lowest Ranked LSOA	Highest Ranked LSOA	LSOAs ranked in top 10% 2007	LSOAs ranked in top 10% 2010	LSOA Change in Ward	LSOAs ranked in top 20% 2007	LSOAs ranked in top 20% 2010	LSOA Change in Ward
Adel & Wharfedale	12	**5164**	32105	0	0	◄ 0	0	1	▲ 1
Alwoodley	14	**2034**	30743	2	2	◄ 0	3	3	◄ 0
Ardsley & Robin Hood	12	7085	31122	0	0	◄ 0	0	0	◄ 0
Armley	16	**932**	14118	5	5	◄ 0	10	10	◄ 0
Beeston & Holbeck	14	**1282**	11992	6	5	▼ 1	7	7	◄ 0
Bramley & Stanningley	16	**1568**	21233	4	3	▼ 1	6	6	◄ 0
Burmantofts & Richmond Hill	16	**260**	8773	13	12	▼ 1	14	14	◄ 0
Calverley & Farsley	14	6627	29894	0	0	◄ 0	0	0	◄ 0
Chapel Allerton	13	**122**	27800	6	6	◄ 0	7	7	◄ 0
City & Hunslet	12	**398**	14894	9	9	◄ 0	9	11	▲ 2
Cross Gates & Whinmoor	15	**2810**	24851	1	1	◄ 0	5	5	◄ 0
Farnley & Wortley	16	**1136**	20071	5	5	◄ 0	7	8	▲ 1
Garforth & Swillington	13	13537	29541	0	0	◄ 0	0	0	◄ 0
Gipton & Harehills	16	**114**	**3735**	14	13	▼ 1	16	16	◄ 0
Guiseley & Rawdon	16	7119	31695	0	0	◄ 0	0	0	◄ 0
Harewood	13	17349	30921	0	0	◄ 0	0	0	◄ 0
Headingley	14	7278	21486	0	0	◄ 0	0	0	◄ 0
Horsforth	14	10199	31665	0	0	◄ 0	0	0	◄ 0
Hyde Park & Woodhouse	13	**2619**	17486	2	1	▼ 1	4	4	◄ 0
Killingbeck & Seacroft	17	**120**	17668	10	10	◄ 0	14	14	◄ 0
Kippax & Methley	14	7080	27210	0	0	◄ 0	0	0	◄ 0
Kirkstall	14	**860**	17100	1	1	◄ 0	4	4	◄ 0
Middleton Park	17	**300**	12685	11	12	▲ 1	13	13	◄ 0
Moortown	14	**2727**	28997	1	1	◄ 0	2	2	◄ 0
Morley North	14	8499	29555	0	0	◄ 0	0	0	◄ 0
Morley South	14	**5127**	23361	0	0	◄ 0	0	2	▲ 2
Otley & Yeadon	13	7525	29587	0	0	◄ 0	0	0	◄ 0
Pudsey	15	**3320**	24210	0	0	◄ 0	2	1	▼ 1
Rothwell	15	**4990**	22755	0	0	◄ 0	1	1	◄ 0
Roundhay	17	**2325**	29047	1	1	◄ 0	1	1	◄ 0
Temple Newsam	13	**348**	27927	4	4	◄ 0	4	4	◄ 0
Weetwood	16	**2802**	24366	0	1	▲ 1	2	2	◄ 0
Wetherby	14	12439	32061	0	0	◄ 0	0	0	◄ 0

1-974 = Ranked in worst 3% **975-3248** = Ranked in worst 10% **3248-6496** = Ranked in worst 20%
▼ 1 = decrease of LSOAs in 10/20% margin ▲ 1 = increase of LSOAs in 10/20% margin



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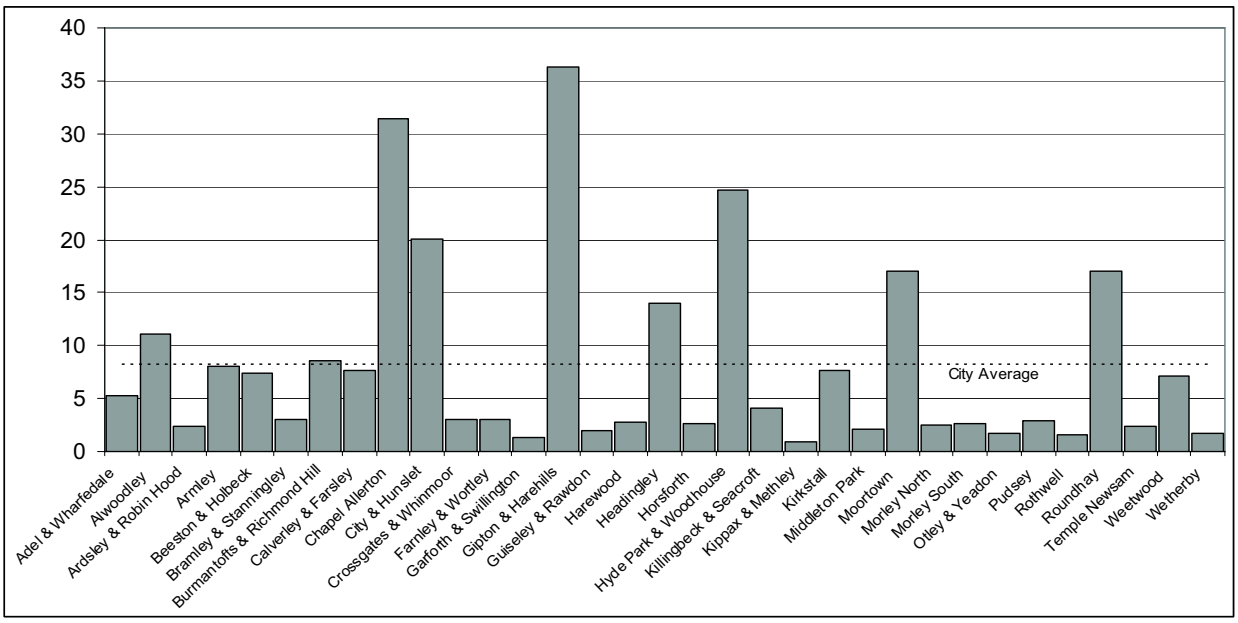
Leeds and its communities

Black and Minority Ethnic (BME) Communities

At the time of the 2001 Census there were almost 78,000 people from BME communities living in Leeds (10.8% of the total resident population). Geographic analysis of the Census data has shown how BME communities are concentrated in particular geographic areas of the city:



- Almost one-third of the city's BME population live in just three wards: Gipton & Harehills, Chapel Allerton and Hyde Park & Woodhouse.
- People from BME communities account for over 40% of the resident population in Gipton & Harehills, in Chapel Allerton 36.5% and in Hyde Park & Woodhouse 31.4%.
- Over a quarter of the Pakistani population lives in Gipton & Harehills.
- The vast majority (85%) of the city's Bangladeshi community is concentrated in three wards: Gipton & Harehills, City & Hunslet and Chapel Allerton.
- Over half (55%) of the city's Black-Caribbean community live in three wards: Gipton & Harehills, Chapel Allerton and Hyde Park & Woodhouse.

In 2009 the Office for National Statistics (ONS) produced some updated information on the numbers of people from BME communities. While this is only available at the city level, it shows that in Leeds:

- The BME population has increased from 77,900 in 2001 to 137,200 in 2009 (representing a 76% increase)

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- BME communities now account for 17.4% of the resident population (from 10.9% in 2001)
- The largest BME groups in the city are the Pakistani and Indian communities with 22,500 (49% increase from 2001) and 20,700 (67% increase from 2001) people respectively
- The "Other White" category has seen the biggest increase in numbers from 10,700 in 2001 to 25,600 in 2009 (139% increase from 2001) many of who will be migrant workers
- Black African, Bangladeshi, Black African / White, Other Asian, and Other Ethnic groups have all seen their numbers more than double

	2001		2009		Change
	Numbers	Rates	Numbers	Rates	
White	*656,900*	*91.8*	*683,400*	*86.8*	*26,500*
White British	637,700	89.1%	650,500	82.6%	12,800
White Irish	8,600	1.2%	7,300	0.9%	-1,300
Other White	10,700	1.5%	25,600	3.2%	14,900
Mixed Heritage	*9.800*	*1.4*	*18,800*	*2.0*	*6,000*
Black Caribbean & White	4,600	0.6%	5,400	0.7%	800
Black African & White	900	0.1%	2,000	0.3%	1,100
Asian & White	2,500	0.3%	5,000	0.6%	2,500
Other Mixed	1,800	0.3%	3,300	0.4%	1,500
Asian or Asian British	*32,400*	*4.5*	*54,500*	*6.9*	*22,100*
Indian	12,400	1.7%	20,700	2.6%	8,300
Pakistani	15,100	2.1%	22,500	2.9%	7,400
Bangladeshi	2,500	0.3%	5,200	0.7%	2,700
Other Asian	2,400	0.3%	6,100	0.8%	3,700
Black or Black British	*10,400*	*1.5*	*19,800*	*2.5*	*9,400*
Black or Black Caribbean	6,700	0.9%	7,700	1.0%	1,000
Black African	2,500	0.3%	10,400	1.3%	7,900
Other Black	1,200	0.2%	1,700	0.2%	500
Other Ethnic Group	*6,000*	*0.8*	*14,200*	*1.8*	*8,200*
Chinese	3,500	0.5%	5,200	0.7%	1,700
Other	2,600	0.4%	9,000	1.1%	6,400
All people	715,600		787,700		72,100

Analysis of the ONS data shows that migration (both internal and international) continues to be a major influence on our population growth. Data on new migrant communities is fragmented – but it is estimated that in 2009 between 6,500 and 10,500 new migrants (who will stay for more than 12 months) arrived in Leeds.

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Information provided by North East Lincolnshire Council:

> *The Grimsby Telegraph published articles in April and May and asked local residents for their support, by completing coupons published in the newspaper. 117 responses were received in support of retaining the unit at Leeds with 39 responses citing cost of travel/distance to travel as their reason/ concern, and 21 responses identifying increased risk to patients as the primary issue.*

A schedule, providing complete details (i.e. names and addresses) has been provided and was made available to members of the Joint HOSC on request.

Information provided by Wakefield Council:

Wakefield's position:

- Broadly in line with other respondents
- Council debated proposals in March 2011 – supported option D with the retention of Leeds
- Social Care & Health OSC discussed on 21 April 2011-10-06 Member of the public attended Committee to express concerns (supported by written submissions from other members of the public, all supportive of Leeds – concerns expressed in line with other respondents
- Committee's main concerns are:
    a. The review process – concerns that the Health Impact Assessment was not available
    b. Focus on children through to adulthood not given sufficient consideration
    c. Insufficient and flawed consideration of patient flows
    d. Impact on children, parents and families
    e. Level of surgical activity – evidence not conclusive
    f. Affordability – not sufficiently considered
    g. **Disappointment that Joint Health Scrutiny Committee is not seeking common ground with Newcastle on a collaborative response that seeks to promote the vested interests of both whilst upholding the principles of the review. In other words jointly proposing that Leeds <u>and</u> Newcastle are retained in any configuration (as suggested by North Yorkshire).**

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Information provided by City of Bradford MDC:

On 15 September 2011, the Health Overview and Scrutiny Committee– **resolved:**

1. *That, having given this matter much consideration, from the options proposed within the consultation, the Committee unanimously endorses Option D and recommends this as the option to be taken forward.*

2. *In reaching its decision the Committee are mindful that there has been a severe lack of critical information being presented in a timely manner. Dependant on information yet to be submitted it is possible that a further Children's Heart Surgical Centre may be required to meet demand.*

3. *That the Committee notes with extreme dismay that only a few days will be available to the Joint Health Overview and Scrutiny Committee (Yorkshire and Humber) to make its recommendations once it has received information requested from the Joint Committee of Primary Care Trusts*

Information provided by East Riding of Yorkshire Council

On 13 September 2011, the Health, Care and Wellbeing Overview and Scrutiny Committee – **resolved:**

That the Sub-Committee support the retention of children's cardiac surgery services at Leeds General Infirmary to deliver children's cardiac surgery services.

Appendix 7:
Motions of Councils – associated correspondence

Details of the correspondence (sent and received) and reports referred to in Appendix 5.

From the Rt Hon Andrew Lansley CBE MP
Secretary of State for Health

Department of Health

POC1_613235

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 3000
Mb-sofs@dh.gsi.gov.uk

Kersten England
Chief Executive
City of York Council
The Guildhall
York
YO1 9QN

24 MAY 2011

Dear Kersten,

Thank you for your letter dated 21 April about retaining the Children's Heart Surgery Unit at Leeds General Infirmary.

I have taken note of your concerns. However, the *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups that commission specialised services, such as children's heart surgery, across England. I have, however, been following its progress.

The reasons they are carrying out the review are to improve services for patients in terms of safety, sustainability, outcomes and excellence of care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years about the risks posed by the unsustainable nature of having smaller surgical centres.

The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease. From my knowledge of the process, it appears to me that it has been very much clinically driven.

I would like to reiterate that no decision has yet been made on the location of children's heart surgery units. The proposed options for

children's congenital heart services are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. This is an open consultation and it is not pre- determined. The Joint Committee of Primary Care Trusts, overseeing the consultation, will consider an independent analysis of the consultation responses, reports from overview and scrutiny committees, and a health impact assessment. The Committee is expected to make a decision in Autumn 2011.

I would like to encourage you and other members of the City of York Council to respond to the consultation. I understand that there are public consultation events during the four-month consultation period. More information about the events and consultation can be found at: http://www.specialisedservices.nhs.uk/safe_sustainable/public-consultation-2011

Yours sincerely,

ANDREW LANSLEY CBE

Harrogate BOROUGH COUNCIL

Working for you

Mr T Riordan
Chief Executive
Leeds City Council
3rd Floor
Civic Hall
LEEDS LS1 1UR

Our Ref CE/LAN
Your Ref
Date 13 May 2011

Dear Tom

Children's Cardiac Services in Yorkshire And The Humber

Thank you for your letter of 5 May 2011 concerning the national review of Children's Cardiac Services and the options included within that review for consultation purposes.

This matter has already been considered by the Council in the form of the following Notice of Motion presented to its meeting held on 13 April 2011:-

"This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary and notes with concern the Unit's limited inclusion in NHS proposals for the national reconfiguration of Children's Cardiac Surgery Services.

The Services provided at present are an important and essential part of health services available to residents of Harrogate District.

The Council requests that the Chief Executive writes to the Secretary of State for Health in order to call for the retention of the vitally important surgical services in Leeds".

In debating the issue, the Council shared the City's concern over the potential loss of the Children's Cardiac Unit and the impact both locally and regionally of this. Members also discussed the transfer times and network issues to which you refer, were cardiac services to be sited in Newcastle and also the personal consequences of this in terms of children's care and the additional burden for families faced with commuting during a period of already intense pressure and stress.

I am pleased to say that the Council supported the motion unanimously, and I have now written to the Secretary of State for Health calling for the retention of Children's Cardiac Services in Leeds in line with the requirements of the approved motion.

I will of course keep you informed of progress.

Yours sincerely

Wallace Sampson
Chief Executive
chiefexecutive@harrogate.gov.uk

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Harrogate BOROUGH COUNCIL

Working for you

Mr A Lansley CBE MP
Secretary of State for Health
Richmond House
79 Whitehall
LONDON
SW1A 2NS

Our Ref CE/LAN
Your Ref
Date 13 May 2011

Dear Mr Lansley

Children's Cardiac Services in Yorkshire and the Humber

The extensive national review of Children's Cardiac Services across England has put forward four options for consultation aiming to consolidate Children's Cardiac Services into six or seven locations. As you are aware, Children's Cardiac Services are currently provided in Yorkshire and the Humber by the Leeds Teaching Hospitals NHS Trust. I understand that the National Review Team assessed all Children's Cardiac Services, including Leeds to be "safe". However, retaining the Leeds provision is only one of the four options being put forward in the public consultation. The preferred option places Children's Cardiac Services in Newcastle, Liverpool, Birmingham, Leicester, Bristol and two sites in London.

This region benefits from a comprehensive range of co-located services for adults and children, with Leeds being the only centre in the North of England to fulfil every child and adult inter-dependency. Leeds has pioneered clinical networks in this area and the majority of regional work has been adopted as national guidelines.

In response to the consultation exercise and concerns over the potential loss of Children's Cardiac Services, the Council, at its meeting held on 13 April 2011, considered the following Notice of Motion:-

"This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary and notes with concern the Unit's limited inclusion in NHS proposals for the national reconfiguration of children's cardiac surgery services.

The Services provided at present are an important and essential part of health services available to residents of Harrogate District.

The Council requests that the Chief Executive writes to the Secretary of State for Health in order to call for the retention of the vitally important surgical services in Leeds".

In debating the motion, Members of the Council were conscious of the great number of children and families within the Harrogate District, the region and from other parts of the country benefiting from the expertise held by the Leeds Teaching Hospitals NHS Trust.

Continued ...

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www.harrogate.gov.uk

Council also raised concern over the transfer times, were such services to be lost in favour of Newcastle and the additional anxiety and stress that would be faced by families and their children in commuting to Newcastle, a city itself not well served by a motorway network.

Following debate, the motion was unanimously approved by all Members of the Council and in accordance with its wishes I am, therefore, calling for the retention of these vitally important surgical services in Leeds.

Yours sincerely

Wallace Sampson
Chief Executive
chiefexecutive@harrogate.gov.uk

From the Rt Hon Simon Burns MP
Minister of State for Health

DH Department of Health

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 4850

Your Ref: CE/LAN

PO00000616648

Mr Wallace Sampson
Chief Executive
Harrogate Borough Council
Council Offices
Crescent Gardens
Harrogate HG1 2SG

Dear Mr Sampson

06 JUN 2011

Thank you for your letter of 13 May to Andrew Lansley on behalf of Harrogate Borough Council about the children's cardiac surgery unit at Leeds General Infirmary. I am replying as the Minister responsible for this policy area.

The *Safe and Sustainable* review of paediatric cardiac surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups that commission specialised services, such as paediatric cardiac surgery, across England. The Department of Health has been following its progress.

The *Safe and Sustainable* review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years about the risks posed by the unsustainable nature of having smaller surgical units. The aim of *Safe and Sustainable* is to ensure that paediatric cardiac surgery services in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease, as have the proposed service standards.

I understand the Council's concern about the provision of continuity of care. Clinicians working in the service and their professional associations have identified the quality benefits of working in larger surgical centres, carrying out a larger numbers of procedures. This is not incompatible with maintaining continuity of care, such as a child continuing to see the same surgeon over their lifetime. A concentration of expertise facilitates research into the different

techniques and thus encourages sharing of best practice. More importantly, though, it ensures better cover in an emergency and less need for transfer of children between centres.

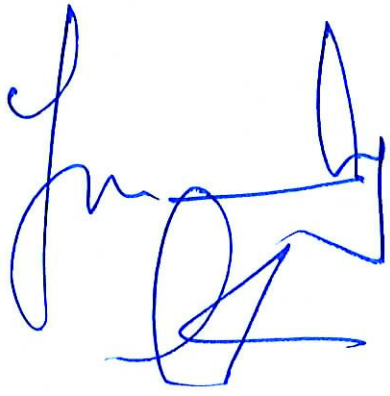
I am advised that travel times analysis has been used in the development of the options. There is a minimal impact on journey times for most families for the four options that are being consulted on. However, many children do not have access to the routine follow-up care service locally at present and have to travel longer distances unnecessarily to receive this care from a surgical unit. The proposed model of care will ensure that all children have access to a paediatrician with expertise in cardiology locally and that all follow-up routine care is provided closer to patients' homes.

I would like to highlight that there are no proposals to close any of the units. Surgery may cease at some units in the future but the aim is that these units will continue to provide specialist, non-interventional paediatric cardiac services for their local populations.

No decision has yet been made on the location of paediatric cardiac surgery units. Patients and the public have the opportunity to make their views known during the formal public consultation process, which closes on 1 July. The Joint Committee of Primary Care Trusts, which is overseeing the consultation, will consider an independent analysis of the consultation responses, reports from overview and scrutiny committees, and a health impact assessment. The Committee is expected to make a decision this autumn.

I would like to encourage you to respond to the consultation. More information about the consultation can be found at www.specialisedservices.nhs.uk by following the links.

I hope this reply is helpful.



SIMON BURNS

Kirklees COUNCIL

Name of meeting: **Annual Council**

Date: **25 May 2011**

Title of report: **Leeds Children's Heart Surgery Unit at Leeds General Infirmary and Adopted by Council**

Is it likely to result in spending or saving 250k or more, or to have a significant effect on two or more electoral wards?	**No**
Is it in the Council s Forward Plan?	**No**
Is it eligible for call in by Scrutiny?	**Not applicable - item for information only**
Date signed off by Director name **Is it signed off by the Director of Resources?** **Is it signed off by the Acting Assistant Director - Legal Governance?**	**16 May 2011, David Smith, Director of Resources** **No financial implications** **No legal implications**
Cabinet member portfolio	**Not applicable**

Electoral wards affected and ward councillors consulted: **Not applicable**

Public or private: **Public**

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1. Purpose of report

For Council to note the response from the Department of Health to the Council's Motion on Leeds Children's Heart Surgery Unit.

2. Key points

Council, at its meeting on 23 March 2011, approved and adopted the following Motion:-

"This Council notes with concern the potential closure of the Children s Heart Surgery Unit at Leeds General Infirmary, as a result of the

Department of Health s 'Safe and Sustainable' review of Children s Heart Surgery Units.

The closure of the Leeds Unit, which serves a large population centre, will have a severe impact on Yorkshire families, including those living in Kirklees, and would mean that parents with sick children would have to travel to Newcastle, Liverpool or Leicester, to receive the essential treatment currently provided in Leeds. This will cause extreme difficulty as a result of the distances families will have to travel, at a time of high anxiety about their child s health.

This Council recognises that a Joint Health Scrutiny Committee is currently meeting to fully consider the proposals for children s congenital cardiac surgery services. Whilst not wishing to pre-determine the findings of that review, nevertheless this Council wishes to express serious concerns about the impacts of removing services from the Leeds area. These concerns to be forwarded in a letter to the Department of Health with copies to all MP s within the Kirklees area.

This Council also requests that representations be made on behalf of the Council as part of the Department of Health s consultation exercise in support of the retention of the Leeds Children s Heart Surgery Unit."

A response to the Motion has been received from the Department of Health, as set out below:-

Thank you for your letter of 25 March to Andrew Lansley about the Children's Heart Surgery unit at Leeds General Infirmary. I have been asked to reply.

The *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups which commission specialised services, such as children's heart surgery, across England.

The purpose of the review is to improve services for patients in terms of safety, sustainability, better outcomes and excellent care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years around the risks posed by the unsustainable nature of having smaller surgical centres. The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease.

I am advised that travel times analysis has been used in the development of the options. There is a minimal impact on journey times for most families for the four options that are being consulted on. Many children, however, do not have access to the routine follow-up care service locally at present and have to travel longer distances unnecessarily to receive this care from a surgical unit. The

proposed model of care will ensure that all children have access to a paediatrician with expertise in cardiology locally and that all follow-up routine care is provided closer to patients' homes.

No decision has yet been taken on the location of children's heart surgery services. The proposed options for children's heart surgery units are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. The Joint Committee of Primary Care Trusts, which is overseeing the consultation, will consider an independent analysis of the consultation responses, reports from Overview and Scrutiny Committees, and a health impact assessment. The Committee is expected to make a decision this autumn.

I would like to encourage you to respond to the consultation. I understand that there are public consultation events during the four-month consultation period, including two in Leeds on Tuesday 10 May at the Royal Armouries Museum. More information on these events and the consultation can be found at www.specialisedservices.nhs.uk by following the links.

I hope this reply is helpful.

3. Implications for the Council

None applicable to this report.

4. Consultees and their opinions

Not applicable.

5. Officer recommendations and reasons

That Council notes the response, which is for information only.

6. Cabinet portfolio holder recommendation

Not applicable.

7. Next steps

None applicable to this report.

8. Contact officer and relevant papers

Adrian Johnson: 01484 221712
Email: adrian.johnson kirklees.gov.uk

Background Papers: Letter dated 14 April 2011 from the Department of Health.

9. Assistant director responsible

Vanessa Redfern, Legal, Governance and Monitoring

DOC871A (160511)

Kirklees COUNCIL

Legal and Governance
Second Floor, Civic Centre 3
Huddersfield HD1 2TG

Tel: 01484 221712
Fax: 01484 221707

adrian.johnson@kirklees.gov.uk

www.kirklees.gov.uk

Please ask for: Adrian Johnson

Our Ref: MAJ/PAW/DOC838A

25 March 2011

Andrew Lansey CBE MP
Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
London SW1A 2NS

Dear Secretary of State

Resolution Passed by Kirklees Council in relation to Leeds Children's Heart Surgery Unit - Leeds General Infirmary (LGI)

At a meeting of the Kirklees Council held on 23 March 2011 the following resolution was passed:-

"This Council notes with concern the potential closure of the Children's Heart Surgery Unit at Leeds General Infirmary, as a result of the Department of Health's 'Safe and Sustainable' review of Children's Heart Surgery Units.

The closure of the Leeds Unit, which serves a large population centre, will have a severe impact on Yorkshire families, including those living in Kirklees, and would mean that parents with sick children would have to travel to Newcastle, Liverpool or Leicester, to receive the essential treatment currently provided in Leeds. This will cause extreme difficulty as a result of the distances families will have to travel, at a time of high anxiety about their child's health.

This Council recognises that a Joint Health Scrutiny Committee is currently meeting to fully consider the proposals for children's congenital cardiac surgery services. Whilst not wishing to pre-determine the findings of that review, nevertheless this Council wishes to express serious concerns about the impacts of removing services from the Leeds area. These concerns to be forwarded in a letter to the Department of Health with copies to all MP's within the Kirklees area.

This Council also requests that representations be made on behalf of the Council as part of the Department of Health's consultation exercise in support of the retention of the Leeds Children's Heart Surgery Unit."

Our Ref: MAJ/PAW/DOC838A

- 2 -

I would welcome your response in due course in order that I may report back to the Council accordingly.

As requested by the Council resolution I am copying this letter to Kirklees Members of Parliament.

Yours faithfully

Adrian Johnson
Governance Officer

c.c. Michael R Wood MP, House of Commons, London SW1A 0AA
Jason McCartney, House of Commons, London SW1A 0AA
Simon Reevell MP, House of Commons, London SW1A 0AA
Barry J Sheerman MP, House of Commons, London SW1A 0AA
Mary Creagh MP, House of Commons, London SW1A 0AA

Your ref: MAJ/PAW/DOC838A

Our ref: TO00000605259

Department of Health
Richmond House
79 Whitehall
London
SW1A 2NS
Tel: 020 7210 4850

Mr Adrian Johnson
Legal and Governance
Kirklees Council
Second Floor
Civic Centre 3
Huddersfield
HD1 2TG

14 April 2011

Dear Mr Johnson,

Thank you for your letter of 25 March to Andrew Lansley about the Children's Heart Surgery unit at Leeds General Infirmary. I have been asked to reply.

The *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups which commission specialised services, such as children's heart surgery, across England.

The purpose of the review is to improve services for patients in terms of safety, sustainability, better outcomes and excellent care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years around the risks posed by the unsustainable nature of having smaller surgical centres. The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease.

I am advised that travel times analysis has been used in the development of the options. There is a minimal impact on journey times for most families for the four options that are being consulted on. Many children, however, do not have access to the routine follow-up care service locally at present and have to travel longer distances unnecessarily to receive this care from a surgical unit. The

proposed model of care will ensure that all children have access to a paediatrician with expertise in cardiology locally and that all follow-up routine care is provided closer to patients' homes.

No decision has yet been taken on the location of children's heart surgery services. The proposed options for children's heart surgery units are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. The Joint Committee of Primary Care Trusts, which is overseeing the consultation, will consider an independent analysis of the consultation responses, reports from Overview and Scrutiny Committees, and a health impact assessment. The Committee is expected to make a decision this autumn.

I would like to encourage you to respond to the consultation. I understand that there are public consultation events during the four-month consultation period, including two in Leeds on Tuesday 10 May at the Royal Armouries Museum. More information on these events and the consultation can be found at www.specialisedservices.nhs.uk by following the links.

I hope this reply is helpful.

Yours sincerely,

Daniel Nebel
Customer Service Centre

Andrew Lansley CBE MP
Secretary of State
Department of Health
Richmond House
79 Whitehall
London SW1A 2NS

Tom Riordan
Chief Executive
3rd Floor
Civic Hall
Leeds LS1 1UR

Tel: 0113 247 4554
Minicom: 0113 247 4000
Fax: 0113 247 4870
tom.riordan leeds.gov.uk

Our reference: **let188/TR/MW**

13 April 2011

RESOLUTION OF LEEDS CITY COUNCIL

I write to inform you that Leeds City Council at a meeting of the Full Council on 6th April 2011 passed the following resolution:

This Council supports the excellent work of the Yorkshire Heart Centre at Leeds General Infirmary, and notes with concern the unit s limited inclusion in NHS proposals for the national reconfiguration of children s cardiac surgery services.

This Council requests that the Chief Executive write to the Secretary of State for Health in order to call for the retention of these vitally important surgical services in Leeds. It also recognises the ongoing efforts of Leeds MPs to lobby the Secretary of State to the same effect.

I would be grateful if you could consider the views of Leeds City Council as expressed in the resolution.

Tom Riordan
Chief Executive

From the Rt Hon Andrew Lansley CBE MP
Secretary of State for Health

DH Department of Health

POC1_611755

Your Ref: let188/TR/MW

MR. T. RIORDAN
25 MAY 2011
CHIEF EXECUTIVE

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 3000
Mb-sofs@dh.gsi.gov.uk

Tom Riordan
Chief Executive
Leeds City Council
3rd Floor
Civic Hall
Leeds LS1 1UR

Also cc to Andy Nash → Group Leaders.

24 MAY 2011

Dear Tom,

Thank you for your letter dated 13 April about retaining the Children's Heart Surgery Unit at Leeds General Infirmary. Councillor Terry Grayshon also wrote to me on 28th April 2011 about this. I have also replied to his letter.

I have taken note of your concerns. However, the *Safe and Sustainable* review of children's heart surgery units in England is being carried out within the NHS by the National Specialised Commissioning Team on behalf of the ten regional groups that commission specialised services, such as children's heart surgery, across England. I have, however, been following its progress.

The reasons they are carrying out the review are to improve services for patients in terms of safety, sustainability, outcomes and excellence of care for children. The review was instigated as a result of increasing concerns held by surgeons, other clinicians and NHS commissioners over a number of years about the risks posed by the unsustainable nature of having smaller surgical centres.

The aim of *Safe and Sustainable* is to ensure that children's heart surgery units in England deliver the very highest standard of care for children and their families well into the future. The development of the proposed model of care has been led by many clinicians directly involved in the care and treatment of children with congenital heart disease. From my

knowledge of the process, it appears to me that it has been very much clinically driven.

I would like to reiterate that no decision has yet been made on the location of children's heart surgery units. The proposed options for children's congenital heart services are currently being consulted on. Patients and the public have the opportunity to make their views known during the formal public consultation process which closes on 1 July. This is an open consultation and it is not pre- determined. The Joint Committee of Primary Care Trusts, overseeing the consultation, will consider an independent analysis of the consultation responses, reports from overview and scrutiny committees, and a health impact assessment. The Committee is expected to make a decision in Autumn 2011.

I would like to encourage you and other members of Leeds City Council to respond to the consultation. I understand that there are public consultation events during the four-month consultation period. More information about the events and consultation can be found at: http://www.specialisedservices.nhs.uk/safe_sustainable/public-consultation-2011

Yours ever,

ANDREW LANSLEY CBE

Copy of letter from Wakefield Metropolitan District Council

Rt Hon Andrew Lansley, MP
Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
London
SW12A 2NL

15 April 2011

Dear Mr Lansley

CHILDREN S CONGENITAL HEART SERVICES NHS CONSULTATION

I write in response to the NHS public consultation on the way children s congenital heart services should be provided in the future. The Council of the City of Wakefield at its meeting held on 30 March 2011, debated the issues arising from the consultation document with particular regard to the excellent services currently provided at Leeds General Infirmary.

Members of Council in debating the options for reconfiguring the services noted that the current service provided at Leeds General Infirmary only featured in one option, option D.

Members of Council were unanimously of the view that should any other option be pursued which would result in the closure of the Leeds Specialist Unit, there would be a huge gap in provision from Birmingham or Leicester in the south, Newcastle in the north and Liverpool to the west. The implications of such a decision would mean children from Yorkshire, North Derbyshire and Northern Lincolnshire having to travel long distances for treatment putting additional strain and costs on families. Council was also concerned that as specialism s were lost in the region, there would also be an adverse impact on adult cardiology services.

Members noted that Leeds General Infirmary was at the forefront of work on inherited cardiac conditions holding an excellent record for providing safe, high quality children s heart services. The centralised unit operating from a single site at the Leeds General Infirmary, currently serves a population of some 5.5 million people in the Yorkshire, North Derbyshire and Lincolnshire regions which is one of the highest population coverage s of all units in England.

The Council respectfully asks that there concerns and support to retain specialist children s congenital heart services at Leeds General Infirmary are taken into account as part of the consultation and decision making processes and that a favourable outcome will result.

Yours sincerely

Councillor Peter Box, CBE
Executive Leader
Wakefield Metropolitan District Council

Appendix 8:
Comments from Members of Parliament

Comments received from Members of Parliament (Yorkshire and the Humber) referred to in the Summary of Evidence section of the report.

JULIAN SMITH MP
Skipton & Ripon

HOUSE OF COMMONS
LONDON SW1A 0AA

Cllr Lisa Mulherin
Chair
Joint Health Overview and Scrutiny Committee
3rd Floor (East)
Civic Hall
Leeds LS1 1UR

Our ref: SR4596

12 September 2011

Dear Cllr Mulherin,

Please find attached Mr Smith's response to the consultation which sets out his view on the reconfiguration of Children's Congenital Cardiac Services. I hope this is helpful in advance of your meeting on Monday 19 September.

With best wishes.

Yours sincerely,

STEPHEN NAYLOR
Office of Julian Smith MP

Tel: 020 7219 7145 · Email: julian.smith.mp@parliament.uk · Website: www.juliansmithmp.com

Sir Neil McKay CBE
Chair of the Joint Committee of Primary Care Trusts
NHS
2-4 Victoria House
Capital Park, Fulbourn
Cambridge CB21 5XB

Our ref: SR4397

1 June 2011

Dear Sir Neil,

As we are approaching the end of the Safe and Sustainable public consultation on the future of children's congenital heart services, I wanted to set out my views following meetings, discussions and research into the proposals being set out.

I believe strongly that the Children's Heart Surgery Unit at the Leeds General Infirmary should be retained.

There have been many compelling human stories told to me over recent months from constituents across the Skipton and Ripon constituency.

Lois Brown, from Cononley, has been one of the leaders of the campaign. Her three-year-old daughter Amelie was born with a heart defect and Lois and her husband spent months at her daughter's bedside in Leeds. They say Amelie would not have survived without the Leeds unit.

[redacted] eldest daughter had major heart surgery at the Leeds General Infirmary about four years ago. He says that he practically lived there for about six weeks, travelling back and forth to work in Skipton every day. Without the surgery, he says his daughter would not have lived and without the ward being there he would have had to make some fairly tough choices between family commitments and continuous employment.

I have also spoken to parents in Ripon who credit the Leeds unit with saving their child's life, a mum from near Addingham wrote to me to tell me of their experiences and why they think the unit is so valuable and doctors from across North Yorkshire who believe having children's heart surgery in Yorkshire is essential to the care of very sick children.

However, I know that in a review like this those stories, no matter how emotional or compelling, are not enough. The review will be examining facts and figures, medical data and medical views. From all my research, discussions and enquiries I believe the case for keeping the Children's Heart Surgery unit in Leeds is equally compelling.

The Leeds General Infirmary is in the middle of one of the densest population areas of the country. 14 million people are within two hours travel time including the five and a half million people in the Yorkshire and the Humber region. It encompassed both the urban areas of West and South Yorkshire and the more rural parts of North Yorkshire, including my constituency. One of the concerns expressed to me is that getting to another unit – be it Newcastle or Leicester or Liverpool - from somewhere like

the Yorkshire Dales or Nidderdale would mean significantly increased travel times, especially for those parents who have to rely on public transport.

The Leeds unit has the capacity to expand and is also part of the Leeds General Infirmary Leeds General Infirmary. This means it is the only unit to have true co-location - all the specialist services required by the Children's Heart Surgery Unit in one place. This is a huge asset for healthcare, for doctors and nurses, for children and for parents. I believe this important element has been underplayed in the current review process.

Another key element is the multiracial mix of Yorkshire's population. No account has been made of the Asian community of Yorkshire and the fact that doctors have told me that children of Asian parents are more susceptible to heart conditions.

There have also been concerns raised with me about the consultation process itself. Parents and campaigners have not been happy with the public meetings that have been held and some have raised issues regarding the criteria being used to make the decisions.

I have no doubt that there are passionate views around the future of any children's heart surgery unit. However, the case for the facility in Leeds is compelling and overwhelming. It has an excellent record for providing safe, high quality children's heart surgery, a dense population with some parts of that population more predisposed to heart conditions and high quality transport links to the north, south, east and west by road and rail.

The Leeds Children's Heart Surgery Unit is an excellent facility for the whole of Yorkshire and the whole of the North of England. I hope you will ensure it has a strong future.

Due to the huge public interest in this consultation, I am releasing this letter to the media.

Yours sincerely,

JULIAN SMITH MP

cc Rt Hon Andrew Lansley MP, Secretary of State for Health
cc Kevin McAleese, North Yorkshire and York Primary Care Trust Chairman
cc Jayne Brown, North Yorkshire and York Primary Care Trust Chief Executive
cc Alisa Claire, Yorkshire and The Humber Specialised Commissioning Group

HOUSE OF COMMONS
LONDON SW1A 0AA

Jeremy Glyde
Safe and Sustainable Programme Director
NHS Specialised Services
2nd Floor
Southside
105 Victoria Street
London
SW1E 6QT

28th June 2011

Dear Mr Glyde,

Re: Listen to Barnsley – Save Leeds Children's Heart Unit

In response to the 'Safe' and Sustainable' Service Review into the future of children's heart services, on behalf of my constituents I would like to press the case for retaining the service at Leeds General Infirmary.

My constituents and I have been determined to fully participate in this consultation and there has been a lively debate across the local media in Barnsley, plus the issue has been discussed at a range of local meetings, including most recently at a formal round table I held in Hoyland in my constituency. Attending this meeting was Kevin Watterson, Heart Surgeon and Sara Matley, Consultant Clinical Psychologist, both Trustees of the Children's Heart Surgery Fund, as well as a number of former patients whose lives had been saved thanks to the brilliance of the clinicians and the care they received at the Leeds General Infirmary.

So my submission to your consultation is one that is rooted in real peoples' lives and real peoples' experiences. I believe that their evidence makes for a powerful and overwhelming case for retaining a Children's Heart Service in Leeds. Please listen to those Barnsley residents who have made their strong feelings known throughout this submission.

We all want better outcomes for children with congenital heart disease and the highest quality national children's heart service. I am fully aware that the aim of this Review is to drive up the quality of treatment and I understand the principles that lie behind favouring a reduction in the number of units to create hubs of excellence and pool surgical expertise. It is right that decisions are made that improve the service on a clinical basis. However, these decisions must also be made in consultation with patients, their families and staff and on the basis of other relevant facts such as population size, travel times and the need to ensure patients have proper family support during their care in hospital.

Barnsley Office: West Bank House, West Street, Hoyland, Barnsley S74 9EE
Tel: 01226 743483 Email: michael.dugher.mp@parliament.uk
Web: www.michaeldugher.co.uk

A locally delivered service

One of the five principles that guided the Review was the need for a locally delivered service where possible. The significance of this cannot be underestimated and the actual location of the services and the impact on travel times is one of the most important things to get right in this Review.

- Nearly 14 million people are within 2 hours' travel time of the Leeds General Infirmary and its location means it can accommodate patients from outside the current catchment area via some of the UK's major transport links, such as the M1, A1, M62, East Coast, TransPennine and Cross Country rail network.

- The Unit at Leeds covers a population of 5.5 million people in Yorkshire & Humber, Lincolnshire and North Derbyshire regions – covering one of the highest populations of all the Units in England. Newcastle by contrast has a population coverage of 2.6 million. Population density must be taken into consideration in health planning and if it is based on this principle, all of the problems due to reconfiguration, such as extra distance and extra cost for individual families, are minimised because you move the doctors to the patients, not the patients to the doctors.

- The birth rate is growing above the national average in Yorkshire and Humber – in other areas it is falling. Population growth predictions for 2028 put Yorkshire and Humber at 6.1 million and Newcastle at 2.8 million (half the national projection growth rate). With about 1 baby in every 133 births being born with congenital heart disease – it makes sense for services to be based where they will be more babies.

- Heart surgeons and intensive care doctors have said that increased travelling time is not good for children and their families, especially in the case of emergency surgery where it could prove fatal.

"My family has had cause to appreciate first-hand the value of its predecessor, at Killinbeck after our daughter was born with a heart condition 28 years ago. The expertise of the unit and its closeness to our home did much to ensure she is alive today....Whatever the reasons made for closure, there is one fundamental reason why the unit must stay open: IT IS SIMPLY TOO FAR TO TRANSPORT A VERY SICK CHILD FROM OUR REGION TO EITHER NEWCASTLE OR LIVERPOOL" [redacted] *Barnsley*

"With heart disease in children, one of the more noticeable signs seen is how rapidly and often that child can become very seriously ill. On 4 occasions in his life, Bradley collapsed and had stopped breathing. On one occasion Bradley had to be rushed to LGI from Barnsley (30 minutes by ambulance) after his heart went into SVT (Supra Ventricular Tachycardia). It is a medical fact that if SVT is not reversed within 1 hour of onset then full heart block and death quickly follows. It took a specialist unit like that at LGI to revert Bradley's deformed heart back to a normal rhythm. The new proposed alternative, Newcastle Upon Tyne, is hours further away, and will be way too late to save any child with specialist needs from any such emergency" John and [redacted]*, Cudworth*

- A local service means that families are able to rely on external practical and emotional support from family and friends who are close at hand. The length of time a child is in hospital can vary from a couple of days to many months. Therefore, the impact on organising childcare for siblings and continuing to work will be enormous if parents have to travel a significantly greater distance to visit their child. Some patients receive treatment from the time they are born right up until teenage years – the ability for friends to visit the patient on a regular basis has a morale boosting effect and should not be underestimated.

"Having to travel, should the LGI, close will greatly affect siblings and other family members who will then be unable to visit heart children during their stay in hospital. Visits from siblings and family members is proven to help the recovery of the patient and boost moral during very upsetting and scary times"
[redacted], *Cudworth*

"If children have to go to Newcastle for their treatment, an after work commute to see their children would be virtually impossible"
[redacted] *Darfield*

"This is a vital service and serves a very wide area. Families will have long journeys and great inconvenience if this Centre closes. My own son had a heart echo scan when he was only a few days old and this could prove to be a great hardship for families in the future if they have to travel great distances"
[redacted] *Great Houghton*

The service at Leeds General Infirmary also has a strong case in the other five principles that guided the review:

The need of the child comes first in all considerations
The dedicated staff at the Leeds General Infirmary ensure that the necessity to fulfil the needs of all the children attending their Unit is paramount when making decisions about treatment and care. If this Unit closes, sick children will have to get used to a new environment, with new staff. For many children surgery is not a once in lifetime event but something many have to endure many times and the upheaval of travel and new environments is an added burden. Some families may have to think about moving house in order to be nearer a Unit and this would have a huge impact on family life.

"It is a nice hospital where it's a lot like being at home and everyone comes to see me which makes me feel much, much better". [redacted] *aged 9*

Leeds offers a well established lifespan psychological support service with four members of staff. At other Units, the service is less established or not as well provided for. I have been told that Newcastle, for example, only has a part time psychologist limited to transplant patients.

Quality

The Paediatric Cardiac Service at Leeds General Infirmary extends from pre-natal diagnosis to the treatment of congenital heart disease in adults. It has an excellent record of providing safe, high quality surgery. Staff at Leeds have fears that removing surgery will dismantle the rest of the high quality service and lead to a loss in expertise as it becomes harder to retain and attract high quality staff. Leeds General Infirmary is at the forefront of work on inherited cardiac conditions – this expertise should not be lost.

"At the present time we have an excellent service from Leeds General Infirmary that is the hub of the best developed cardiac network in the UK. This network has been adopted as a blueprint of how cardiac services within the country should be run" Child Health Advisory Group for Yorkshire Region

"My Grandson was not expected to survive more than 5 minutes from birth. He spent his first 3 months from birth in LGI and had his first double heart bypass. His second bypass was just over a year ago and now he is aged 9 years, attends Carlton Primary School and is a good swimmer. Many thanks to LGI" [redacted] *Cudworth*

High Standards

Leeds General Infirmary is one of only two centres in the UK (the other is Southampton) which has co-location of children services on one site (cardiac surgery, cardiology and all paediatric services) and as such meets the requirements of the Department of Health's Critical Interdependencies report *Commissioning safe and sustainable specialised paediatric services - a framework" (2008).* The British Congenital Cardiac Association (BCCA), a leading support organisation of the Safe and Sustainable Review, released a statement on 18 February that said: 'For these services at each centre to remain sustainable in the long term, co-location of key clinical services on one site is essential.' Other Units are stand-alone sites and as such do not offer the same level of service. This could mean children have to travel to various locations for treatment instead of one.

"If a child is born in a District Hospital, they have a short transfer to Leeds for assessment and if it is felt the problem is not surgical they can continue to be looked after in the tertiary centre. If the future, it would mean a long transfer to either Newcastle, Liverpool or Birmingham for assessment...These hospitals are likely not to be sited at the same place as neonatal and paediatric services and therefore may require a further transfer. These transfers will provide a significant financial burden...and more importantly, pose a significant patient safety issue" Child Health Advisory Group for Yorkshire Region

"I was born with a rare form of heart disease. I was instantly transferred to Killingbeck Children's Heart Hospital – now Killingbeck Ward in the Cardiac Unit of Leeds General Infirmary - there parents felt their children were getting the right specialist treatment and it was closer to their homes to be able to visit their children after work"
[redacted], *Darfield*

A personal service

Feedback from patients and families shows that they receive first class personal service throughout their treatment pathway with support from the Children's Heart Surgery Fund.

Patient Choice is important here too - if patients from Leeds, Yorkshire and the Humber choose to go to Liverpool because it is closer and more convenient to go to there from Yorkshire rather than travel to Newcastle, then it is likely that the Unit at Newcastle will not achieve the minimum 400 cases a year required by the Review.

In addition to all the points above, I have been told that there are significant factual inaccuracies contained in the report by the assessment panel that visited the Unit in Leeds and that there was no opportunity given to address these prior to the publication of the consultation. It appears for example, that Liverpool was given extra scoring due to its high population density, but Leeds was not, despite having a higher population density within a two hour drive.

I am extremely concerned about the impact on my constituents and other families in Yorkshire & the Humber region should the Leeds Unit be closed. It would leave a huge geographical gap in provision and as a result, the nearly 300 families which are currently supported each year would face huge logistical difficulties and increased costs to travel substantial distances at a time of great anxiety about their child's health.

Whichever Units are chosen, there must be steps taken to provide help with additional travel and accommodation costs that will be incurred as a result of this policy to reduce the overall number of Units. I would like to see measures put in place to support families who will have to make increased journey times and who will have no option but to stay overnight as a result. No matter which option is decided upon, families will need additional support, particularly those from areas like Barnsley, who for socio-economic reasons will find it harder to travel longer distances.

We all want better outcomes for children with congenital heart disease and I believe that the children's heart surgery unit at Leeds General Infirmary is ideally placed to act as one of the hubs of excellence. In terms of quality of service, ease of access and the size of population, it is clear that the Unit at Leeds should to be retained as the major centre serving the North Midlands, Yorkshire and the North East. As one person put to me - bring the doctors to the patients, not the other way round.

I am grateful for your consideration and look forward to your response.

Yours sincerely,

Michael Dugher

Michael Dugher MP
Member of Parliament for Barnsley East

Rt Hon Hilary Benn
MP for Leeds Central
House of Commons
London SW1A OAA

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H of C (tel) 0207 2195770
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20th September 2011

Cllr Lisa Mulherin
Chair, Scrutiny Board
(Health and Wellbeing and
Adult Social Care)
3rd Floor East
Civic Hall
Leeds LS1 1UR

Dear Lisa

Many thanks for your letter of the 8th September about the Children's Congenital Cardiac Services Review. As you will be aware, we have as the region's MPs made a number of representations to government and to Sir Neil McKay about the review in support of the LGI unit.

I very much support the points that you made in your letters to Andrew Lansley and Neil Mckay, and I look forward to continuing to work with you as we seek to make sure that the Leeds unit remains open.

Best wishes

Yours sincerely

Rt Hon Hilary Benn
MP for Leeds Central

Cc Rt Hon Andrew Lansley, Secretary of State for Health
Sir Neil McKay, Chair of Joint Committee of Primary Care Trusts

BERWICK, Ann

From: BERWICK, Ann
Sent: 20 September 2011 16:43
To: 'lisa.mulherin@leeds.gov.uk'
Subject: Children's Congenital Cardiac Services Review

Dear Cllr. Mulherin

Thank you for your letter of 8 September regarding the Children's Congenital Cardiac Services Review, enclosing a copy of a letter you have sent to the Secretary of State for Health. I am extremely supportive of the points that you have made in your letter to the Secretary of State. I made a number of representations both individually and together with other Yorkshire and the Humber MPs and will continue to do so, so please do let me know if you feel there is anything further I need to do at this stage with regard to the letter you have sent to the Secretary of State.

Yours sincerely,

Rt Hon Rosie Winterton
MP for Doncaster Central
Tel 01302 326297

Austin Mitchell MP
House of Commons
London
SW1A 0AA
0207 219 4559

Ms Lisa Mulherin
Chair, Scrutiny Board
(Health and Wellbeing and Adult Social Care)
3rd Floor (East)
Civic Hall
Leeds LS1 1UR

Monday 3rd October 2011

Dear Lisa,

I write to express the strongest possible support for the case Leeds is putting up for the retention of its Children's Congenital Cardiac Services.

The issue is of vital importance to my area, North East Lincolnshire, our children's unit at Diana Princess of Wales Hospital, and to children and parents in the whole of South Humberside.

The basic reason is the quality and the service children receive from Leeds and the fact that visits there can also be combined with other services at Leeds. I also have to emphasise that we are a somewhat isolated area and that if Leeds were closed and the children and parents forced to travel to Newcastle the increased travel, costs, and extra time involved would be a considerable barrier.

There is a substantial population here on both banks of the Humber who do not seem to have been given sufficient weight in the proposal to look at only four options. This looks to me to have been heavily and unreasonably weighted against Leeds.

If Leeds is closed my constituents would be amongst the worst affected. I am not prepared to see this inflicted on Grimsby and North East Lincolnshire by what looks to be an act of administrative convenience which causes real damage to the people I represent.

I've made my views known to the minister and to the health authorities. I hope that these will not be ignored.

Yours sincerely,

Austin Mitchell MP

Harrogate and District NHS Foundation Trust

York Teaching Hospital NHS Foundation Trust

NHS North Yorkshire and York

Briefing for City of York Health Overview and Scrutiny Committee on proposals to create an urgent care centre

Executive summary

It is often the case that people are unsure of where they should go to access healthcare, particularly if they have a minor illness or injury, or become ill outside of normal working hours.

An Emergency and Urgent Care Board has been established comprising expert representatives from across the York healthcare community with the aim of designing and delivering an integrated urgent care centre for the York area.

The proposed urgent care centre, which will be located at York Hospital adjacent to the emergency department, will create a single point for people to access care for minor illness or injury.

Under the current system, this group of patients attend the NHS walk in centre on Monkgate, the emergency department at York Hospital, or the GP out of hours service. By integrating these services into a single centre, and relocating the walk in centre from Monkgate to the emergency department at York Hospital, patients will be able to access the right care from the right healthcare professional at the right time. If needed, they will also be able to access the range of specialist support services at the hospital. Health services will also benefit from more streamlined patient pathways, and by separating minor illness and injury from the main emergency department, the emergency department staff will be able to focus their efforts on the most seriously ill patients.

A significant amount of work has been undertaken to design an improved service that will best meet patients' needs, whilst offering the most effective use of the resources available. Through a programme of patient and public engagement work, the views of people who use the service have been sought throughout the project and have been key to designing how such care will be delivered in the future.

The proposals for the redesign have also been supported by commissioners (NHS North Yorkshire and York and Vale of York Clinical Commissioning Group) and local patient representatives including Foundation Trust governors and York Local Involvement Network (LINk) members.

This paper outlines the rationale for creating an urgent care centre, how key stakeholders have been fully engaged in developing the proposals, and how the relocation of the walk in centre will be communicated to patients and the public. It also includes information about the current service provision at both the walk in centre and the emergency department, as well as clinical evidence to support the proposals.

The purpose of this paper is to provide the Overview and Scrutiny Committee with information about the proposals and the planned engagement and communication work. The Emergency and Urgent Care Board would like the Overview and Scrutiny Committee to note the plans for the integrated urgent care centre and to approve the plans for communicating the changes to patients and the public.

1. Introduction

The multi-agency Emergency and Urgent Care Board has been established to look at how a fully-integrated unscheduled and urgent care service can be delivered in York. The aim of the project is the integration of urgent care services and the redesign of the way minor illness and injury are treated in the emergency department in order to continue to improve the quality and delivery of emergency care to patients in the York community.

A key part of this work is the proposal to relocate the NHS walk in centre from Monkgate to York Hospital's emergency department. This would provide the important first step in a programme of work to deliver integrated urgent and unscheduled care.

The purpose of this paper is to provide the Health Overview and Scrutiny Committee with information about the project and the work completed to date, and to give the Committee assurance in relation to the planned programme of focused public engagement and communications around the relocation of the walk in centre.

2. Background

The NHS offers a wide variety of services and knowing how and where to access the most appropriate care can often be confusing for patients, especially when they become unwell outside of usual working hours.

It has long been thought that the organisation of urgent care services in York could be improved, and that fragmentation of care under the current system should be addressed. This requires the adoption of a ‘whole systems approach’ to ensure the integration of services.

Currently, patients can access the following services for advice and treatment:

- Their GP practice
- The GP out of hours service
- NHS Direct
- NHS walk in centre at Monkgate
- York Hospital’s emergency department
- 999 ambulance services

Discussions have been ongoing with NHS North Yorkshire and York (the commissioners of these services) since January 2011 to deliver a fully integrated unscheduled care service for patients with minor injury and illness who attend York Hospital’s emergency department.

Under Transforming Community Services, the management of the walk in centre on Monkgate in York was transferred to Harrogate and District NHS Foundation Trust. Local agreement was reached to consult staff at the NHS walk in centre on transferring their employment to York Teaching Hospital NHS Foundation Trust, with a view to relocating the walk in centre to the York Hospital site in the longer term.

At present, patients in York Hospital’s emergency department with minor illness and injury are seen and treated in the same space and by the same team as the ‘major’ patients (i.e. those with a serious medical condition or serious injury). By streaming patients with minor illness and injury to an urgent care centre within the emergency department, the space in the main emergency department will be used solely by the ‘major’ patients. This will enable the emergency department team to better co-ordinate care and concentrate resources for these patients which will help reduce waits and improve patient experience for this group.

In addition, the new national quality indicators for the emergency department place a greater focus on the importance of early, meaningful assessment by a clinical decision maker, and on improving the experience for all patients attending the department.

The delivery of an urgent care centre will have an impact on the flow and experience of patients in the ‘major’ side of the emergency department, as well as providing a more streamlined service for patients with minor illness and injury.

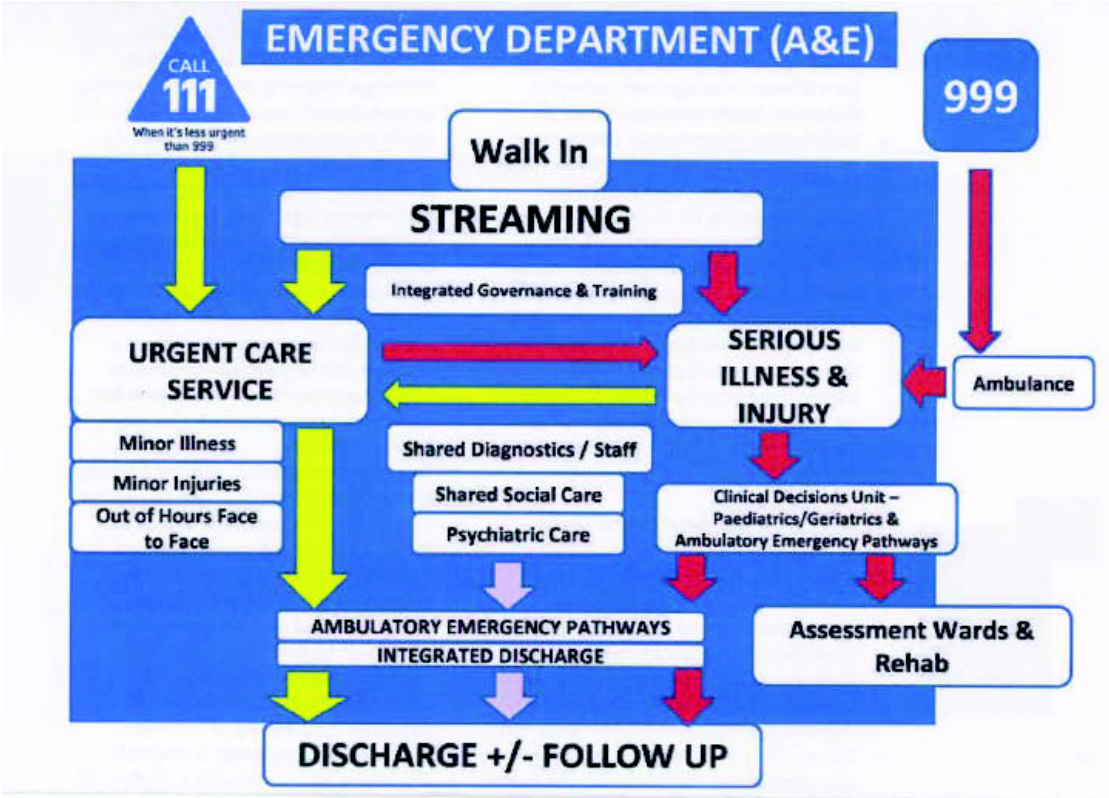
Two steering groups (major and minor) were set up as sub-groups of the Emergency and Urgent Care Board. The minors steering group considered a number of options for how the urgent care centre could be delivered and agreed a proposal to develop a model of care incorporating the walk in centre function, that would be delivered from the York emergency department to form an integrated urgent care service co-located with primary care out of hours services.

Assessment of attendances shows that a significant proportion of patients with minor illness or injury can equally be managed by primary or secondary care. By integrating existing services and redesigning urgent care functions the aim is to provide services that are best placed to meet patients' needs within the resources available to the healthcare community.

3. What would the proposed new service look like?

The Emergency and Urgent Care Board has several sub-groups that have worked to develop proposals for how the urgent care centre would operate. The detail of the proposed model was finalised at a rapid improvement event held between 10-13 October 2011.

The recently published guidance document from the GP Centre for Commissioning: Guidance for commissioning integrated urgent and emergency care - A whole system approach (Author: Dr Agnelo Fernandes) includes the following diagram illustrating patient flow in the proposed new system:



(Patient flow diagram taken from Guidance for commissioning integrated urgent and emergency care - A whole system approach, p.71)

The proposed pathway for the York urgent care centre is in appendix A. This will include the cohort of patients that currently attend the walk in centre. Patients from the walk in centre and the emergency department minor injury and illness patients will be the cohort of patients who will access the newly-formed urgent care centre. The outcome of the rapid improvement event was to agree the flow of patients through the urgent care centre. The approach will be measured and reviewed, testing the flow.

Space to accommodate the urgent care centre will be made available through the relocation of the orthopaedic outpatient clinic, adjacent to the emergency department. The orthopaedic outpatient clinic has relocated as part of the launch of the Musculoskeletal Clinical Assessment, Triage and Treatment Service.

4. The impact on patients now and in the future

The urgent care centre will provide quality care for patients with minor injury and illness by offering access to the right health care professional, in the right setting, at the right time. It will be flexible to adapt to future needs.

It is not always clear to patients which service they should choose. A single access service for the walk in centre and the emergency department will enable patients who have emergency and urgent care needs to access the

service in a single place and the service will then enable to patients to be directed to the right pathway to meet their needs. This will happen at the point that patients access the service, rather than in separate locations as is currently the case. Being sited at York Hospital gives better access to support such as X-ray and other diagnostic services, providing a more streamlined service for patients.

Under the current system, some patients are transferred from the walk in centre to another service, including the emergency department.

The urgent care centre has been designed with improving the patient experience at the centre of the model, and patients' views have been sought throughout the process.

The diagram in appendix B shows the areas that patients value and find important. This information was collated through an observation study in the emergency department, the standpoint questionnaire in the waiting area, and queries to the patient advice and liaison service and complaints. Key areas include:

- A single point of access for minor injury and illness in York's emergency department
- To be seen by the right person, at the right time and in the right setting to meet patients' needs

York Hospital has increased the availability of parking on site following the opening of the multi-storey car park, and is served by good public transport links.

This model also provides the opportunity to make much-needed improvements to the environment, which will be of benefit to both patients and staff.

5. Clinical evidence to support the proposals

The proposals have been developed by doctors and other clinicians from across the local health community, including York Hospital, GP out of hours service, Yorkshire Ambulance Service and GPs from the local clinical commissioning group.

The walk in centre has previously been located in the emergency department during bank holiday periods, giving an indication of how this might work on a more permanent basis. This has demonstrated that patients and local residents can cope with this change even when there is relatively low-key publicity, and when the relocation is only for a short period.

Allowing the service to be fully integrated into an urgent care centre would help streamline these patients and ensure they are directed to the most appropriate pathway for their needs.

A pilot has been carried out to test the impact of having a GP working within the emergency department. The project ran on weekdays for five weeks and a total of 604 patients were seen (an average of three patients per hour). This is the same throughput as the walk in centre, where nurses see and treat a similar cohort of presenting conditions.
The GP pilot demonstrated that patients' needs can be met in a 'see and treat' model where a senior decision maker with the right skills to see the patients is at the front of the service.

The clinical evidence for a fully integrated model was further supported by the publication in August 2011 of the GP Centre for Commissioning document: Guidance for commissioning integrated urgent and emergency care - A whole system approach (Author: Dr Agnelo Fernandes). The document states that: "Several benefits are associated with integrated ED (A and E) and UCC, including the ability to serve a complex itinerant inner-city population; better management of demand from patients who "vote with their feet" and utilise the secondary care facilities as their walk in centre; and a more flexible utilisation of workforce across the services to match risk and demand." (Guidance for commissioning integrated urgent and emergency care - A whole system approach, p. 69).

The rationale for the drive to develop an urgent care centre was also confirmed by the rapid improvement event, as follows:

- There is currently a duplication of services
- There is duplication in the skills of staff working in the services
- Patients with 'minor' complaints are seen in a poor environment in the emergency department
- Some steps in the current processes do not add value for patients
- The lack of space creates issues of privacy, dignity and confidentiality
- Often long waiting times
- Lack of space has prevented the redesign of services
- Problems in the minors service impact on the majors service
- The environment for children does not meet the standard we aspire to

The rapid improvement event also demonstrated a consensus that the clinicians with the right skills to see and diagnose patients presenting with minor injury and illness were emergency nurse practitioners or walk in centre nurse practitioners, GPs, or emergency department medics (either a consultant, middle grade, or registrar).

6. Overview of the services

Emergency department, York Hospital:
The emergency department in York has around 73,000 attendances per year (around 200 per day). Of this total attendance, 52,000 are classified and minor injury or illness (24,000 attendances are for minor illness and 28,000 are for minor injury). Attendances are increasing by 3 per cent each year, mainly in the injury and illness category.

The department is open 24 hours a day, seven days a week. It is staffed by a mix of nurses and nurse practitioners, medical staff, occupational therapists, physiotherapists, social workers (Rapid Assessment Team), healthcare assistants, reception and admin staff, and is supported by access to other specialists within the hospital.

Performance is consistently above the national quality indicator of 95 per cent of patients seen, treated and discharged or admitted within four hours.

Walk in centre, Monkgate:
The walk in centre sees 18,500 patients per year. This figure is reducing by 1,000 attendances per year.

It is a nurse-led service running from 8am – 6pm, seven days a week. The nursing staff are minor illness and injury trained and there are twelve nurse prescribers. Patients are seen in chronological order of arrival other than those indicated by ‘red flag’ conditions.

The breakdown of attendances and the age profile of patients for both the walk in centre and the emergency department are included in appendix C.

7. Communications and engagement:

a. How walk in centre and emergency department staff have been involved

Staff from the emergency department and the walk in centre have been involved in the work throughout the project.

Nursing and administration staff from the emergency department and the walk in centre are members of the minors steering group and have been involved in shaping the progress of work. These representatives also attended the rapid improvement event.

Other staff in the emergency department receive feedback via the morning meetings, the senior staff meeting, the senior nurse meeting, and the emergency department directorate meeting. There are also posters outlining

the redesign proposals in the emergency department staff room and on the poster board in the emergency department seminar room. Staff are able to contribute via a suggestion box in the emergency department staff room.

Walk in centre staff receive updates and information via the walk in centre representatives and at staff meetings. The emergency department directorate manager has also attended meetings at the walk in centre to share information about the project. Posters outlining the redesign proposals are displayed in the walk in centre staff room.

Other stakeholders who will be affected by the work are also represented on the Emergency and Urgent Care Board and in the sub-groups. These include GP out of hours, Vale of York Clinical Commissioning Group, Yorkshire Ambulance Service, PCT commissioners, and mental health services. A list of Emergency and Urgent Care Board members is included in appendix D.

b. Outcome of consultation with walk in centre staff

The walk in centre staff transferred their employment to York Teaching Hospital NHS Foundation Trust on 1 November 2011 following a formal consultation exercise. Part of this consultation included discussions around the potential relocation of the walk in centre.

c. Patient and public engagement

A communications and engagement plan has been developed (see appendix E).

A significant programme of patient and public involvement work has already been undertaken.

There is a dedicated sub-group of the Emergency and Urgent Care Board leading on communications and engagement, consisting of communications leads and patient and public involvement leads and representatives from the partner organisations represented on the Board. A further group has been working specifically on patient and public involvement, developing plans and carrying out projects including observations in the emergency department and focus groups. Representatives from York Hospital's Council of Governors and members of York LINk are included in this group.

An electronic survey point was installed in the waiting are of the emergency department to capture patients' experience.

Local LINk members and Foundation Trust governors carried out observations in the emergency department using a specially-designed

observation tool. The tool was developed using an experience-based design approach.

People who had recently visited the emergency department were also recruited to take part in focus groups.

Key feedback from all of these approaches was around the environment (including the reception area), and information about waiting times.

An example of where the input of LINks and Governors has directly affected the redesign plans is around changes to the design and location of the reception area, with the changes that are being proposed reflecting feedback gathered through the observation work.

The full feedback from all of these approaches has been fed into the design of the urgent care centre and the redesign of the emergency department environment. A focus group approach and discussions with stakeholders will take place over the plans to relocate the walk in centre in order to identify and address any issues.

The communications activity will be delivered in two phases. The first phase will centre on informing and engaging people on the walk in centre relocation.

The second phase will be a broader piece of work to give people the knowledge to make informed choices when accessing services. A social marketing campaign will be developed, both to inform public about the urgent care centre and also to direct people to most appropriate service for their needs in a bid to address the increasing trend of attendances to the emergency department and to improve the use of primary care facilities.

This will help to manage the pressure facing the emergency department and will also improve services for patients. It will draw on existing campaigns (e.g. Choose Well) and will employ a social marketing approach to help influence behaviour change.

d. Assurance of plans

The Emergency and Urgent Care Board is assured that a robust communications and engagement plan is in place, and that the relocation of the walk in centre does not constitute a significant change in service so as to warrant full formal public consultation, and that any delay to potential improvements would be detrimental to the service.

As the plans are to relocate the service, the ‘walk in’ facility for people with minor illness and injury will continue to be provided, and the service will be enhanced through its integration into an urgent care centre.

In terms of access, the centre would be located a similar distance from the city centre, and less than a mile from its current location on Monkgate. There is ample parking available for patients on the York Hospital site, and free parking is available for people attending the emergency department.

NHS North of England (the Strategic Health Authority) is aware of the proposals and the communications and engagement plans.

Foundation Trust governors and members of the York LINk have been involved in the observation work. Governors can continue to play a key role in this engagement as they have a link role between the Trust and its communities. A supporting statement from York LINk is at appendix F.

The York LINk members and Foundation Trust Governors who carried out the observation study asked at their last meeting to return once the new urgent care service is in place in order to carry out a similar study.

GPs have been involved throughout the work and are supportive of the proposals, as are the main service commissioners (NHS North Yorkshire and York). The Vale of York Clinical Commissioning Group has been represented on the Board and in the sub-groups and has had a key role in shaping the design of the service. A supporting letter from the group is at appendix G. A supporting statement from the York Local Medical Committee is at appendix H.

8. Potential issues

As well as the walk in centre, the building on Monkgate houses a number of public facing and administrative services and teams.
This includes:

- The district nurse referral team (an admin team that handles calls/enquiries for the district nurses)
- The GP out of hours call centre
- Dental
- Sexual health
- Fast response
- Minster Health
- PMS Homeless service
- Smoking cessation (external service)
- TB Clinic (external service)

The plans to relocate the walk in centre do not affect any of these services, and they will continue to operate from their current location.

There is also a potential issue around car parking. Access and availability are much better on the hospital site than at the current Monkgate site, however the way the spaces directly outside the emergency department are used was raised as an issue by the focus groups. This issue, including giving permits to people who are using the emergency department so that they can park free of charge, will be addressed as part of the redesign work.

Concerns have been raised about security at the Monkgate site once the walk in centre relocates. NHS North Yorkshire and York is carrying out a risk and security review which will include the arrangements at Monkgate.

A further issue is that a small number of people collect their continence products from the walk in centre reception. Arrangements are being made so that these individuals can collect their products from either Clifton Health Centre, Clementhorpe Health Centre, or Tang Hall Clinic (whichever is most convenient for them). Staff collecting continence products for people in residential homes will be able to collect from Cornlands Road Clinic reception.

9. Next steps

The final recommendation to relocate the walk in centre was taken by the Emergency and Urgent Care Board in April 2011.

The Board commissioned the rapid improvement event to detail how the model of an urgent care centre would work, including patient flows and staff working within the centre. This followed six months of intensive data gathering and working with key stakeholders to develop potential clinical models to support the relocation of the walk in centre to the emergency department. This work was lead by the minors steering group.

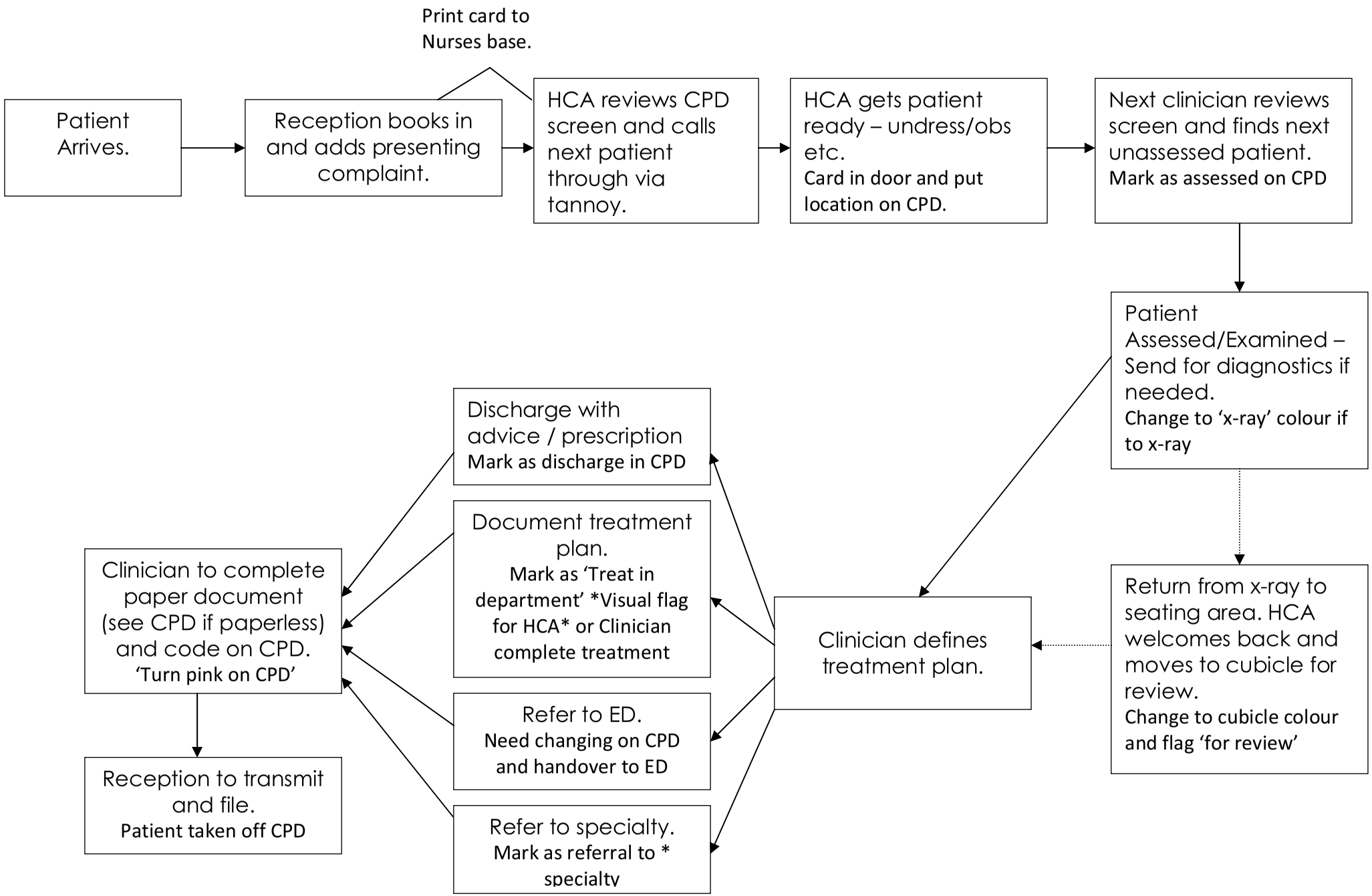
This work and the recommendations were then ratified by the Emergency and Urgent Care Board on 3 November 2011.

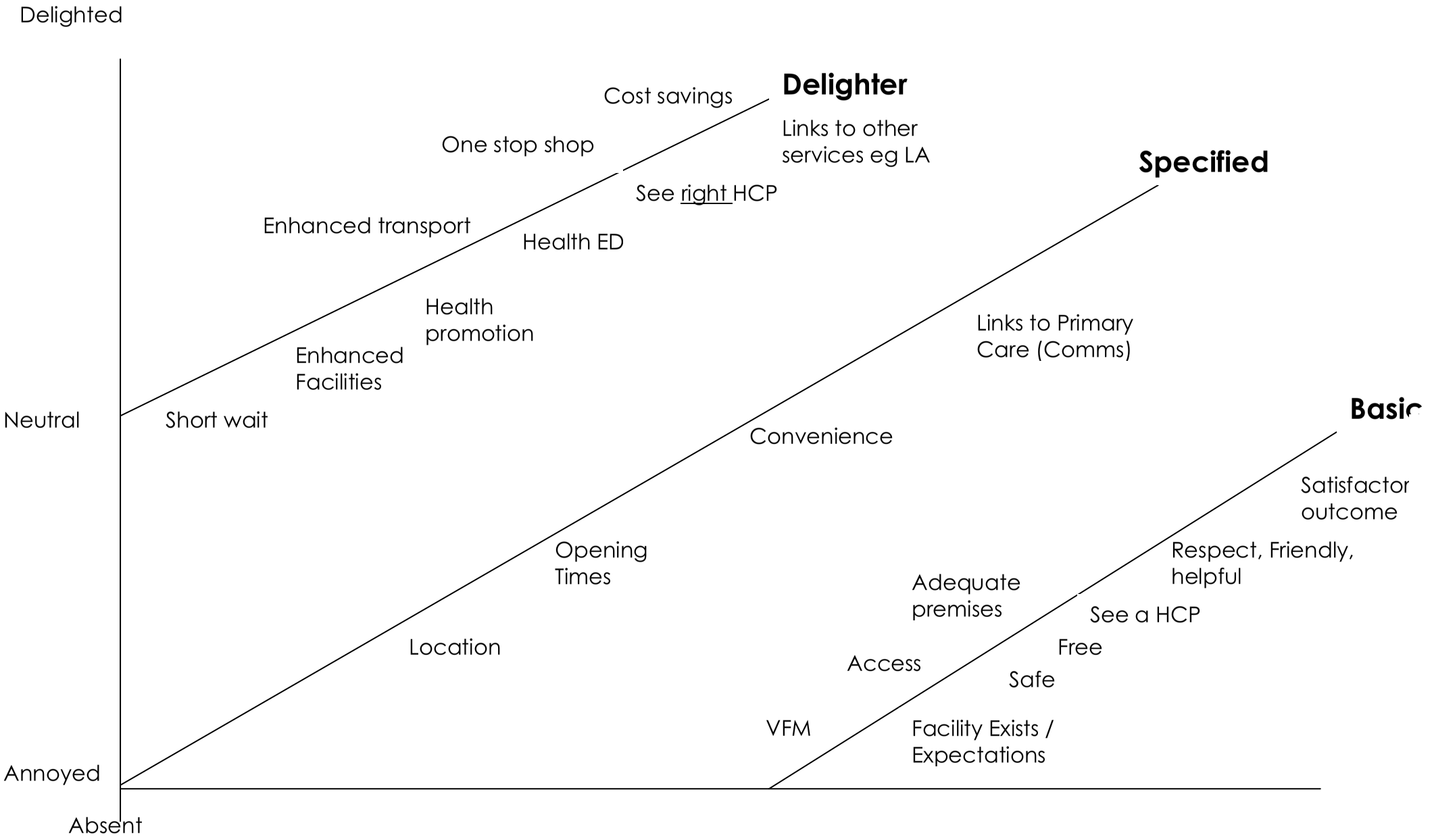
Final approval will be taken to NHS North Yorkshire and York's Board and to Vale of York Clinical Commissioning Group and the York Clinical Steering Board.

The Emergency and Urgent Care Board is satisfied that sufficient plans are in place to engage and inform the relevant stakeholders about the move and how it will affect them. The Board will write to the Health Overview and Scrutiny Committee in six months' time to update them as to progress with the work and any issues around patient and public involvement, and any

feedback gathered during the course of the project. Representatives from the Emergency and Urgent Care Board will attend a future meeting at the Committee's request.

APPENDIX A: Patient pathway for Urgent Care Centre





APPENDIX B: What do patients value and find important?

Appendix C:
Breakdown of attendances (emergency department)

Audit group	Financial year				
	2006/07	2007/08	2008/09	2009/10	2010/11
Gr 1: ED minor illness	46,505	46,265	47,398	49,589	23,639
Gr 2: minor injury	-	-	-	-	28,466
Gr 2: med eld and med paeds ED majors	12,983	13,468	13,029	15,377	14,930
Gr 3; med, eld & med paeds GP referrals admitted via ED	2,622	2,862	3,583	2,879	2,635
Gr 4; all surg specialities	3,417	3,868	4,137	3,374	3,575
Gr 5: clinical exceptions	102	87	139	267	343
Grand total	**65,893**	**70,732**	**68,316**	**71,488**	**73,593**

Age profile for attendances (emergency department – all attendances, Jan – Sept 2011)

Count of A&E	Month/Yr									
Age Group	1/2011	2/2011	3/2011	4/2011	5/2011	6/2011	7/2011	8/2011	9/2011	Grand Total
0-4	466	475	475	528	427	430	423	417	418	4,059
5-9	178	198	272	299	258	255	248	234	236	2,178
10-14	309	283	482	336	410	362	377	245	385	3,189
15-19	508	507	571	461	577	447	500	421	503	4,495
20-24	617	593	679	595	692	582	622	564	614	5,558
25-29	380	371	412	381	405	441	442	405	393	3,630
30-34	355	330	334	345	400	334	378	428	336	3,240
35-39	290	284	322	370	326	352	357	369	346	3,016
40-44	397	334	343	354	411	372	373	362	330	3,276
45-49	322	286	366	352	359	369	358	381	366	3,159
50-54	305	259	304	311	319	294	289	326	323	2,730
55-59	256	190	234	271	288	233	253	279	251	2,255
60-64	279	241	285	305	285	316	283	286	279	2,559
65-69	237	194	209	246	211	259	249	228	226	2,059
70-74	207	191	241	232	253	250	231	265	220	2,090
75-79	250	254	270	246	282	230	232	266	250	2,280
80-84	229	233	248	262	282	255	251	260	241	2,261
85-89	266	214	221	209	259	212	225	191	200	1,997
90-94	113	92	113	104	110	103	104	97	103	939
95-99	34	25	26	33	36	32	27	34	36	283
100-104	6	4	9	3	7	8	4	1	4	46
Grand Total	6,004	5,558	6,416	6,243	6,597	6,136	6,226	6,059	6,060	55,299

Age profile for attendances (emergency department – minor injury and illness, Jan – Sept 2011)

Count of Atts	Month/Yr									
Age Group	1/2011	2/2011	3/2011	4/2011	5/2011	6/2011	7/2011	8/2011	9/2011	Grand Total
0-4	362	383	398	454	375	377	370	348	348	3,415
5-9	155	176	246	281	243	236	220	213	210	1,980
10-14	271	249	438	314	373	335	349	216	358	2,903
15-19	424	445	499	411	508	389	441	369	420	3,906
20-24	499	507	581	510	603	505	542	473	515	4,735
25-29	315	311	358	317	342	380	367	352	336	3,078
30-34	261	250	276	296	324	271	304	357	275	2,614
35-39	214	221	257	289	268	287	279	305	276	2,396
40-44	291	249	255	285	341	298	294	275	253	2,541
45-49	226	203	271	243	267	274	277	290	267	2,318
50-54	217	177	205	218	244	217	201	234	231	1,944
55-59	161	115	157	191	194	159	175	187	173	1,512
60-64	132	131	152	193	197	192	189	179	169	1,534
65-69	108	112	101	145	128	153	128	140	126	1,141
70-74	103	89	116	121	136	125	122	134	108	1,054
75-79	102	104	116	111	130	109	108	135	107	1,022
80-84	66	87	89	93	117	99	105	113	95	864
85-89	81	68	68	77	103	84	81	79	70	711
90-94	30	32	29	41	42	13	30	32	35	284
95-99	7	7	6	12	11	8	6	13	12	82
100-104		1	3	1	2	2				9
Grand Total	4,025	3,917	4,621	4,603	4,948	4,513	4,588	4,444	4,384	40,043

Number of attendances and age profile for attendances (walk in centre – Jan – Oct 2011)

Age Group	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Grand Total
0-4	133	131	128	143	117	101	104	108	89	121	1175
5-9	34	56	55	62	46	36	59	59	33	60	500
10-14	39	26	35	43	44	39	69	57	34	30	416
15-19	182	215	195	169	174	160	153	180	175	280	1883
20-24	331	296	394	317	353	346	288	305	273	343	3246
25-29	181	163	196	181	175	183	176	159	158	197	1769
30-34	112	92	122	114	110	129	131	137	121	103	1171
35-39	90	80	70	86	85	77	123	93	94	105	903
40-44	84	95	97	137	112	92	115	118	84	94	1028
45-49	79	74	69	92	91	90	96	110	93	85	879
50-54	67	68	58	99	97	58	81	86	76	88	778
55-59	56	39	50	97	65	74	80	68	58	64	651
60-64	60	43	62	69	65	82	93	82	92	61	709
65-69	21	29	35	48	60	59	39	48	54	59	452
70-74	39	26	35	60	45	42	41	44	38	31	401
75-79	13	10	25	31	36	30	35	44	36	32	292
80-84	6	7	9	34	22	19	16	26	25	5	169
85-89	5	5	7	5	8	12	17	19	8	10	96
90-94	1	6	1	4	1		3	7	2	1	26
95-99	1			1		1	1	1			5
100-104					1						1
Unknown		1	2		2	6	1	3		1	16
Grand Total	1534	1462	1645	1792	1709	1636	1721	1754	1543	1770	16566

Appendix D:
Emergency and Urgent Care Board membership

Name	Role/organisation
Andrew Bertram	Director of Finance & Deputy Chief Executive, York Teaching Hospital NHS Foundation Trust (Chair)
Lucy Brown	Head of Communications, York Teaching Hospital NHS Foundation Trust
Dr Steve Crane	Consultant (Emergency Medicine), York Teaching Hospital NHS Foundation Trust
Mr Tony Gibbon	Consultant (Orthopaedics), York Teaching Hospital NHS Foundation Trust
Kaye Grannon	Walk-In Centre Service Manager
Dr David Hayward	GP
Dr Mike Holmes	Clinical Lead, Doctors Out of Hours
Becky Hoskins	Corporate Matron, York Teaching Hospital NHS Foundation Trust
Vince Larvin	Assistant Director of Operations, Yorkshire Ambulance Service
Mandy McGale	Associate Director of Operations, York Teaching Hospital NHS Foundation Trust
Louise Parker	Improvement Manager, York Teaching Hospital NHS Foundation Trust
Rachel Potts	Locality Director, Vale of York, NHS North Yorkshire and York
Steve Reed	Directorate Manager (Emergency Department), York Teaching Hospital NHS Foundation Trust
Dr Donald Richardson	Clinical Director (General & Acute Medicine) York Teaching Hospital NHS Foundation Trust
Sue Rushbrook	Director, Systems and Network

	Services, York Teaching Hospital NHS Foundation Trust
Jill Wilford	Acting Matron (Emergency Department), York Teaching Hospital NHS Foundation Trust
Mr Mike Williams	Clinical Director (Emergency Medicine), York Teaching Hospital NHS Foundation Trust

APPENDIX E

Emergency and Urgent Care Board
Communications and engagement strategy

1. Background

Plans are in place to relocate the NHS walk in centre to York Hospital. This is the first step in a programme of work to deliver integrated urgent and unscheduled care. This strategy outlines how an integrated approach to communications will ensure consistency of communication and engagement across all stakeholder groups.

The communications activity will be delivered in two phases.

The first phase will focus on raising awareness of the relocation of the walk in centre. The second phase will be a broad awareness raising/information sharing campaign around which services the urgent care centre will provide and to support people in making informed decisions when accessing care. This will link in with existing campaigns such as Choose Well and the winter health campaign. Alongside this a targeted social marketing campaign will be developed. This will focus specifically on a particular user group, identified through the patient and public involvement work and data analysis of users.

2. Communications objectives

- Ensure appropriate and effective communications and engagement mechanisms are in place to support the work
- Ensure that the key messages are communicated effectively to all stakeholders
- Support the Emergency and Urgent Care Board in gaining buy-in from key opinion formers (e.g. MPs, LINks, local media)
- Ensure that staff receive timely information about the work, and, where possible, are informed first about changes affecting them
- Proactively manage media relations around the relocation of the walk in centre and the establishment of the urgent care centre
- Ensure the appropriate level of engagement and, where necessary, consultation takes place with relevant stakeholders
- Increase public awareness and understanding of the services that are available and when they should be accessed
- Influence behaviour change among identified groups through a targeted programme of communications activity
- Secure positive and supportive media coverage of the work

- Ensure key messages are aligned with other campaigns (e.g. Choose Well)

3. Key messages

- The walk in centre is moving to the emergency department at York Hospital to form part of the new urgent care centre
- The urgent care centre will provide quality care for patients with minor injury and illness by offering access to the right health care professional, in the right setting, at the right time
- This is an example of local NHS organisations working together to design services that best meet patients' needs whilst offering the most effective use of resources
- This is an important part of our integration with community services and bringing together the separate elements of urgent and unscheduled care
- Feedback from patients, public and staff has been sought throughout the project and their views have influenced the design of the service

4. Key milestones

Milestone	**Date**
Walk in centre transfers from community and mental health service to Harrogate Foundation Trust	1 April 2011
Emergency and urgent care board established	April 2011
Consultation with walk in centre staff on relocation begins	1 October 2011
Rapid improvement event to finalise pathway and environment redesign proposals	10 – 13 October 2011
Consultation with walk in centre staff ends	1 November 2011
Proposals for urgent care centre approved by Emergency And Urgent Care Board	3 November 2011
Chair and deputy chair of York Health Overview And Scrutiny Committee briefed	3 November 2011
Members of Emergency And Urgent Care Board attend	30 November 2011

Overview And Scrutiny Committee meeting – decision taken on formal public consultation	
Orthopaedic outpatients clinic moves out of emergency department space	7 November 2011 (first clinics held at new location)
Capital works in emergency department completed	Tbc
Walk in centre closes	Tbc (dependent on decision by OSC re formal public consultation)
Urgent care centre becomes operational	Tbc (dependent on decision by OSC re formal public consultation)

5. Stakeholder analysis

A full list of stakeholders is at appendix 1. Different stakeholders require different levels of communication and engagement depending on their level of interest and influence. Not all stakeholders require the same level and frequency of communication so efforts can be focussed in particular priority areas. Identifying and segmenting stakeholders according to their communications needs also helps avoid the risk of inadequate communication, or providing inconsistent communication between stakeholders in the same group.
Stakeholders have been grouped using an influencer matrix (see appendix 2), measuring their communications requirements in terms of both their level of interest in the work and their influence in terms of public opinion. Using this approach, stakeholders have been grouped into four potential categories:

- Key players
- Active consultation
- Keep informed
- Monitor

i. Key players:
These are a priority as they have the most interest in the outcome of the project and the most influence in terms of swaying public opinion about the work. It is important to engage them, give them accurate, timely information and gain their support whilst giving them the mechanisms to ask questions and air concerns.

These have been identified as:

- City of York Council's Health Overview and Scrutiny Committee
- Commissioners (NHS North Yorkshire and York)
- GP commissioners (Vale of York Clinical Commissioning Group)
- GP out of hours (managed by Harrogate and District NHS Foundation Trust)
- LMC
- Staff (emergency department/walk in centre)
- Yorkshire Ambulance Service

ii. Active consultation:
These stakeholders have a high level of influence but may have lower levels of interest. It is essential to engage with them over the process and they need to be proactively kept informed.

These have been identified as:

- Local residents (Near WIC)
- York LINk
- Mental Health Trust (Leeds Partnerships NHS Foundation Trust)
- Foundation Trust Governors

iii. Keep informed:
Due to their role it is important to put in place mechanisms to keep these stakeholders up to date with what is happening. They have low levels of influence and do not require proactive engagement, however they should be monitored and the approach changed should they become influencers or opinion formers.

These have been identified as:

- Patients/general public
- Local authority (including social services and education)
- Local MPs (Nigel Adams – Selby & Ainsty, Hugh Bayley –York Central, Julian Sturdy - York Outer, Ann McIntosh – Thirsk & Malton)
- NHS Yorkshire and the Humber
- Pharmacies (including Healthcare at Home on York Hospital site)
- Trade union representatives
- York Carers' Forum
- Foundation Trust members
- Patient support and advocacy groups (e.g. York Older People's Assembly)
- York Tourist Board
- Local taxi firms who may be booked to take people to walk in centre

iv. Monitor:

This group of stakeholders are not a priority in terms of communication around the work, however they will be kept informed where appropriate through existing communication links.
These have been identified as:

- North Yorkshire Police
- Monitor (Foundation Trust Regulator)
- Care Quality Commission
- Neighbouring NHS Trusts
- York CVS
- Volunteers (Friends of York Hospitals)
- Contractors and suppliers
- York Wheels

6. Overview of tactics

The tactics for communicating with each broad group are outlined in this section. A working 'action plan' giving dates for delivery of each of the elements will be developed, with progress to be monitored by the communications and engagement sub-group of the Emergency and Urgent Care Board and reported back to the Board. Much of the detail, in particular planned completion dates, is yet to be finalised and is dependent on the outcome of the Health Overview and Scrutiny Committee's decision around formal consultation. The activity will also depend on the outcome of the market research which will inform the social media campaign – the specific target audiences need to be determined before the campaign can be designed and implemented.

Media relations:

- Media releases to key local media
- Letter for publication on letters page of local papers
- Radio and TV features – case studies needed (or possible 'day in the life'-type feature)
- Weekly health feature (York Press)
- Launch event/'moving party' media opportunity
- Reactive media handling lines needed

Above the line:

- Advert/advertorial in local paper(s)
- Advert in Local Link magazine (York)
- Consider other advertising opportunities (e.g. bus stops, toilet doors, sides of buses, billboards etc)

Stakeholder engagement:

- Page in Your Voice (City of York Council's residents' newsletter)
- Letter to GP practices
- Core copy for reproducing in stakeholder newsletters
- Briefing to York Health Overview and Scrutiny Committee
- Briefing to York LINk
- Updates to York Hospital's Council of Governors
- Foundation Trust members' newsletter
- Public meetings (attendance when invited to LINk meetings, forums etc, or where appropriate, organising meetings on behalf of the Trust)
- Hotels/B&Bs sent information via York Tourist Board to enable them to signpost tourists to the walk in centre

Patient and public involvement:

- Focus groups with people who have experienced the emergency department
- Observation tool – 24 hour observation of emergency department
- Standpoint questionnaire in emergency department waiting area
- Dedicated information stand at York Trust's open day
- Attendance at local events (e.g. York Fifty Plus festival, freshers week events)
- Attend meetings/give presentations to patient groups/communities of interest (for example the York Older People's Assembly and other voluntary sector groups) to inform them of the plans and ensure they can voice any concerns.

Internal communications and staff engagement:

- Staff briefings
- Posters in staff rooms (walk in centre and emergency department)
- Update in team brief (York trust staff and community-based staff)
- core copy for featuring in staff newsletters
- display in York Hospital main entrance (high footfall: patients, visitors and staff)
- updates on intranet sites
- screensaver

Social marketing:
The tactics used will be dependent on the target audience identified through the analysis of users of the walk in centre and emergency department. Tactics will be chosen that most effectively reach the specific audience.

E-comms/new media/social media:

- information on York Trust, PCT website
- online 'countdown tool' (XX days until the move)

- Choose Well app
- Possible tie-in with local media using twitter

Other tactics to consider:

- Posters to GP practices, walk in centre, emergency department, pharmacies, libraries, gyms, supermarkets, hotels, B&Bs etc
- posters to large local employers for displaying in staff areas
- audit of where information about the walk in centre features (e.g. directories, online and print) – these will need to be systematically updated
- large banner outside walk in centre and emergency department advertising moving date

7. Formal consultation (public/staff)

Formal public consultation will take place when the changes proposed are a substantial development or variation for current service provision or are required by Monitor. Any consultation process will be in line with the legal requirements on NHS bodies to consult with the public, patients, advisory and user groups, health overview and scrutiny committees as detailed in part 242 (formerly section 11 of the Health and Social Care Act 2001) of the consolidated NHS Act 2006.

The City of York Council's Health Overview and Scrutiny Committee will be consulted on the requirement for full public consultation. Informal consultation and public engagement will continue as outlined in this plan.

Governors can play a key role in this informal consultation and engagement as they have a link role between the Trust and its communities.

Staff will be consulted on changes that have a direct, significant impact on them. This consultation would follow HR legislation and guidance.

8. Risks and challenges

If focussed public engagement cannot be demonstrated, then formal public consultation may be required. This will delay the move of the walk in centre, and there will cost implications to carrying out such a consultation exercise.

It is important that the messages around what the urgent care centre is for are carefully thought out in the second phase of the communications activity, to manage public expectation about what the centre will offer.

9. Resources

Communications activity will be delivered by York Teaching Hospital NHS Foundation Trust's communications team, in partnership with communications leads from partner organisations. A budget will need to be identified for materials to support the campaign, for example, graphic design costs, print, and advertising.

10. Evaluation

The effectiveness of the plan will be evaluated to enable the approach to be refined if necessary as the work progresses and to inform future communications activity. Methods will include:

- Patient experience surveys
- Analysis of media coverage
- Web traffic – traffic to site following publicity
- Feedback on NHS Choices
- A change in the 'type' of attendances in the emergency department (fewer inappropriate users)

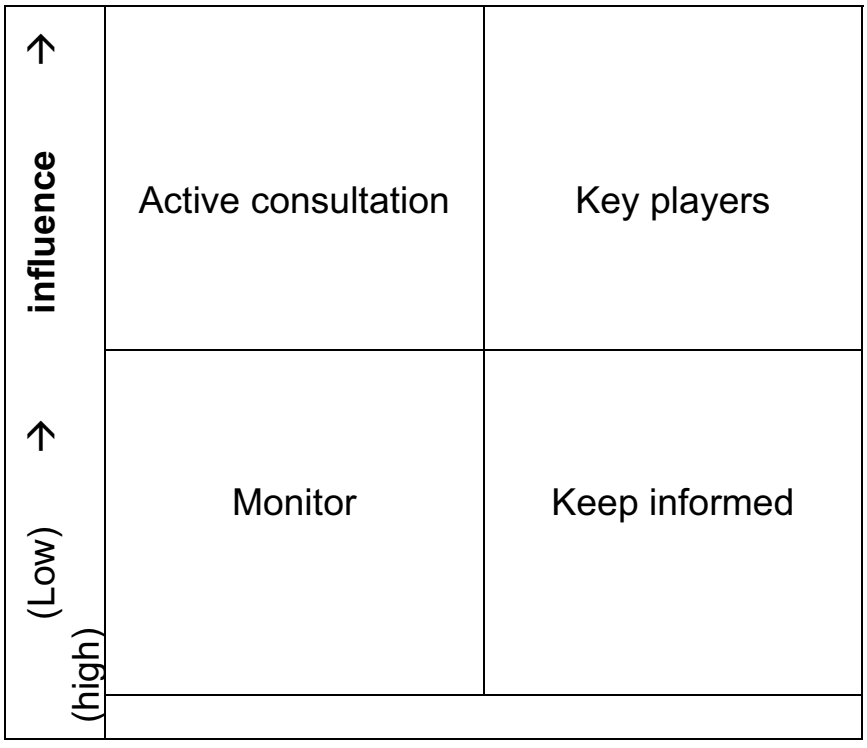
Appendices:

Appendix 1:
Stakeholder list

- Patients (current and future)
- Public
- Volunteers (our own plus FOYH etc)
- GPs and practice managers
- Current and future staff
- Carers
- Neighbouring NHS Trusts (Harrogate and District NHS Foundation Trust, Yorkshire Ambulance Service)
- Strategic Health Authority (NHS Yorkshire and the Humber)
- Commissioners (NHS North Yorkshire and York, GP commissioning groups)
- Voluntary organisations
- Community Groups
- Local Authority including Social Services and Education
- Local MPs (Anne McIntosh, Julian Sturdy, Hugh Bayley, Nigel Adams)
- Media (key players: York Press, Yorkshire Post, Malton Gazette and Herald, Selby Times, Selby Post, BBC Look North, ITV Calendar, BBC Radio York, Minster FM)
- Trade union representatives
- Foundation Trust Governors
- HYMS
- Universities
- Local schools and colleges
- Contactors and suppliers
- Professional bodies
- Royal Colleges, deaneries
- Overview and Scrutiny Committee (City of York)
- CQC
- Monitor

- FTN/NHS Confederation
- Foundation Trust members (current and future)
- LINks groups
- Patient support and advocacy groups (York Older People's Assembly)
- Pharmacists
- GP surgeries
- York Tourist Board/B&Bs/hotels

Appendix 2:
Influencer matrix



	(Low) → **interest** → (high)

Appendix F:
Statement of support form York LINk

Comments from Jane Perger, Vice Chair of York LINk

York Link has welcomed the opportunity to work alongside the governors of York Hospital as representatives of the residents of York on the project.
We welcome the approach of bringing patient representatives and the hospital governors into this early stage of the redesign of the ED and proposed transfer of the Walk-in Centre.

Having spent time observing the staff at work over a period of time, we would like to compliment them highly on how they manage with the current layout. The redesign will enhance patient experience and enable staff to perform their role more efficiently. We understand that integrating the walk-in department and ED will prevent duplication and hopefully provide a more streamlined service.

We look forward to working with the hospital on this project in the future.

APPENDIX G: Letter of support from VOYCCG

Senior Partner
Dr P F Faller

GP Partners
Dr E V Fowler
Dr S Young
Dr D Hayward
Dr W F Laughey
Dr M A Holmes
Dr G M Towler
Dr F S Scott
Dr N J Jackson
Dr K P Anderson
Dr A J Gilmore
Dr S Blades
Dr J R Read

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Managing Partner
Mr J J McEvoy

GP Associates
Dr E O Watts
Dr A J Smart
Dr C Dickson
Dr L K Barker
Dr J A Oakland
Dr M Pickard
Dr S Osborne

Head of Nursing
Mrs J M Smith

17th November 2011

Dear Sirs,

I am writing in my capacity as development board member for the Vale of York Clinical Commissioning group (VOYCCg).

OSC will hear the case for the relocation of York Walk in Centre (WIC) to York Hospital Foundation Trust (YHFT) on 30th November 2011.

The relocation of the WIC forms part of a significant reconfiguration of urgent care services in York. We have been involved in this project for the last 8 months. This involves a redesign of part of the Emergency department at York Hospital and the development of a new care pathway which will better meet the needs of local residents.

Part of this pathway will see an experienced Primary Care physician working in the Emergency department in a new Urgent Care Centre. This will enable patients to be seen by an appropriate health care professional at the right time and we feel will offer a more joined up service for patients attending Accident and Emergency.

The development of the Urgent Care Centre is an important part of the PCTs Quality Improvement Prevention and Productivity (QIPP) programme and also is in line with recent

Royal College of General Practitioners guidance on integrating urgent care.

We strongly support the relocation of the WIC to YHFT. It forms a vital part of the new care pathway and we feel gives added value for York residents who need medical care in this setting.

Yours Sincerely,
Dr David Hayward

APPENDIX F – Statement of support From The York Local Medical Committee

The Division is generally supportive of the relocation and holds the view that this will improve service to patients. General Practitioners should be an integral part of the team involved in the triage and treatment of patients. Division members expressed this view at a recent informal meeting with Mark Hayes and Rachel Potts.

I have kept this comment brief in view of today's deadline for the report but would be happy to discuss this with you if that would be helpful.

Fred Faller
(Chair Selby and York Division of YORLMC Ltd)

Health Overview and Scrutiny Committee 14 December 2011

Local HealthWatch York : Progress Update

Summary

1. To update the Health OSC on the progression from LINks (Local Involvement Networks) to Local HealthWatch by October 2012.

Background

2. Local Involvement Networks (LINks) were established through the Local Government and Public Involvement Act 2007. They are independent community-based networks of organisations and individuals committed to strengthening and widening the influence of patients and the public in the planning, provision and improvement of health and social care services.

3. LINk's main powers and responsibilities are to monitor services by entering and viewing, and to gather the views and experiences of the community about their local services - and make those views known to those responsible for commissioning, providing, managing or scrutinising those services.

4. Since its establishment in York in April 2008 the York LINk has supported the development of a proactive Steering Group which is made up of volunteer representatives from both individuals and local voluntary sector organisations which reflect the make-up of the local community as a whole.

5. Since April 2008 York LINk has promoted an identifiable local brand and implemented a creative approach to community engagement and participation, particularly through the use of LINk Ward Representatives who are responsible for promoting involvement at a ward level to ensure that the views of communities are firmly embedded in the design, delivery and review of services.

6. Over the last thee years York LINk has also produced a series of reports around issues such as End of Life Care, Dental Services and Carer's Rights which gather together an analysis of key issues and the views of local people in order to make recommendations to health and social care commissioners.

Local HealthWatch

7. HealthWatch will be the new consumer champion for both health and social care. It will exist in two distinct forms - Local HealthWatch and, nationally, HealthWatch England.

8. Local HealthWatch will evolve from the existing Local Involvement Networks (LINks), continuing their work alongside some additional functions. This includes signposting people to useful information about health and social care services. From April 2013 Local HealthWatch will also signpost to, or directly provide, an advocacy service for people with complaints about NHS services.

9. The overarching intention of Local HealthWatch is to provide a single point of contact, by connecting people to the right NHS and social care advice and advocacy services, and by helping people to find information that will enable them to choose the services they need and require.

10. Local HealthWatch bodies will be independent organisations (e.g. Community Interest Companies; Industrial and Provident Societies, Charities, Companies Limited by Guarantee etc).

11. Local authorities will commission Local HealthWatch with the freedom to decide how to do this. From April 2013 local authorities will commission NHS complaints advocacy from any suitable provider, including local HealthWatch, and the service will be accessed through local HealthWatch.

12. Local HealthWatch will have a seat on the new Health and Wellbeing boards to ensure consumer voice is integral to health and social care decision making.

HealthWatch Pathfinder Status

13. City of York Council, in partnership with York LINk, recently submitted a successful bid to the Department of Health to become a HealthWatch Pathfinder for the 2011-2012 financial year.

14. Pathfinder status presents an opportunity for scoping and planning - to begin to test the some of the proposed new functions for Local HealthWatch and allow partners to move towards an agreed, effective and appropriate model for the City. It also provides a small amount of funding for networking/dissemination with other HealthWatch Pathfinder areas.

15. Pathfinder status also allows an opportunity to review and evaluate the effectiveness of existing relationships between the LINk and key healthcare providers in the City, and to develop new models and mechanisms of engagement in the future.

16. It is important to note that HealthWatch involves far more than a change of brand or title and, whilst retaining the most successful elements of the current LINks function, will be different and distinct from LINks.

17. The existing LINks function will continue until Local HealthWatch is formally established in October 2012. A LINks workplan has been drawn up for the 2011-12 financial year. Key LINks priorities over the forthcoming year include producing reports and recommendations around access to food in hospital and service provision for older people in York.

Consultation

18. As part of York's HealthWatch Pathfinder a Stakeholder Event (to gauge initial interest in the concept of Local HealthWatch and discuss potential delivery models) was held in July. The event was attended by over 20 partner organisations in the City and the wider sub region. Early feedback has indicated a keen interest in Local HealthWatch and its potential impact.

19. During the feedback session it was clear that there was a consensus about many of the principles for a local HealthWatch, these were:
    - HealthWatch should have good knowledge and understanding of the needs and existing work and services in York.
    - Local expertise and knowledge should be preserved.
    - HealthWatch needs to be clearly independent of City of York Council and other statutory providers.
    - HealthWatch should be representative of all needs and support people through all clinical pathways.

- HealthWatch needs to have clear lead ownership and accountability.
- HealthWatch must be accessible to all.

20. Since the conference a group comprised of representatives from NYYPCT Public Health and PALS teams , CYC Neighbourhood Management Unit, Strategy and Development Team and Adult Social Care Commissioning Team have met to discuss the commissioning process for York HealthWatch.

21. The group has held discussions around a number of key issues and next steps that need to be taken as follows:

    - To adopt a formal procurement process to select an independent organisation(s) to deliver Local HealthWatch in York from October 2012 onwards.
    - To initiate the HealthWatch procurement process by November 2011.
    - To hold further consultation events, enabling Citywide partners to have input into the commissioning process and to comment on service specification design.

22. A further City-wide consultation event is now due to take place on 6th December 2011 at the Bar Convent, York. The event will provide an update on the latest national developments and will offer an opportunity for all partners to comment on the outline commissioning proposals for HealthWatch in York.

Options

23. This report is for information only report, there are no specific options for members to decide upon.

Analysis

24. Please see above.

Council Plan 2011-15

25. The establishment of Local HealthWatch in York will make a direct contribution to the following specific outcomes listed in the draft City of York Council Plan:

- Improved volunteering infrastructure in place to support increasing numbers of residents to give up their time for the benefit of the community
- Increased participation of the voluntary sector, mutuals and not-for-profit organisations in the delivery of service provision

Implications

- **Financial**

26. Local HealthWatch will be financed through three separate strands of funding as follows:

    - Existing government funding to Local Authorities to support the current LINks function will be rolled forward into HealthWatch.
    - Monies provided for the current 'signposting element' of PCT PALS teams will be transferred across to local authority budgets from October 2012.
    - Monies for NHS Complaints Advocacy will be transferred to local authorities in April 2013.

27. It should be noted that while an indicative sum of money will be provided to City of York Council under each of the above headings, none of these monies will be ringfenced i.e. they will be paid to City of York Council as part of various Adult Social Care formula grants.

28. City of York Council has the discretion allocate all these monies to Local HealthWatch, or allocate some of the funding to other health and social care priorities.

Department of Health (DoH) Funding Consultation

29. The DoH is currently seeking views on options around the distribution of monies for the **signposting** and **complaints advocacy** elements of HealthWatch – principally whether to allocate funding to local authorities based upon their population size population or level of 'adult social care need'.

30. Through the current proposal CYC would receive around £90,000 per annum to commission HealthWatch signposting services if this

were based upon population size, and only £70,000 per annum based on an adult social care need formula.

31. In the case of complaints advocacy, CYC would receive £56,000 per annum based on population size, and £44,000 based on adult social care need.

32. City of York Council and partners have recommended that the NHS Transition Board respond to the Government consultation, indicating their preference for the allocation of HealthWatch commissioning monies based upon population size.

33. This recommendation has been made on the basis that York has a high proportion of 'self-funders' i.e. individuals who are funders of their own care needs. As a preventative, signposting service the ethos of Local HealthWatch should be to support these individuals and users of adult social care services in equal measure.

- **Human Resources (HR)**

34. There are no human resource implications

- **Equalities**

35. Establishing a successful Local HealthWatch in York will enable the targeting of support towards activities which contribute towards all the equality outcomes set out in the draft Council Plan. It will be a requirement of the successful organisation(s) delivering Local HealthWatch to demonstrate and evidence their commitment to equal opportunities in the work of their organisations, in line with the Equalities Act 2010.

- **Legal**

36. There are no legal implications

- **Crime and Disorder**

37. There are no crime and disorder implications

- **Information Technology (IT)**

38. There are no information technology implications

- **Property**

39. There are no property implications

- **Other**

40. There are no other implications

Risk Management

41. There are risks of challenge to the validity of City of York Council's procurement and commissioning process if a HealthWatch contract is let without full and proper consulation with City wide partners. The thorough consultation processes that will be followed through the HealthWatch Pathfinder process will mitigate this risk.

Recommendations

42. Members are asked to note the report and the latest progress towards establishing HealthWatch. A further update will be provided at the next Health OSC meeting.

Contact Details

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Adam Gray Senior Partnership Support Officer (VCS) Neighbourhood Management Unit Directorate of Communities and Neighbourhoods	**Sally Burns** Director of Communities and Neighbourhoods
Tel. 551053	**Report Approved** ✓ **Date** *5 December 2011* **Kate Bowers** Head of Neighbourhood Management
	Report Approved ✓ **Date** *5 December 2011*

Specialist Implications Officer(s) n/a

Wards Affected: **All** X

For further information please contact the author of the report

Background Papers: N/A

Health Overview Scrutiny Committee **14 December 2011**

Report of the Carers Strategy Manager, ACE, on behalf of the Carers Strategy Group

Annual Update on the Carers Strategy

Update on the Implementation of the Recommendations Arising from the Carer's Review

Six monthly Report in Relation to the Indicators being Monitored in Relation to Carers

Summary

1. The Health Overview Scrutiny Committee (HOSC) completed a Carer's Review in 2010/11. The Committee recommended that the Cabinet Member for Health & Social Services should receive an annual report updating the Carers Strategy and that the same report should be submitted to the Health Overview & Scrutiny Committee. The report was submitted to the Cabinet Member 22 November 2011.

2. This report's purpose is to update the Committee.

Background

3. In November 2010 the Committee appointed a Task Group of three members. The task group worked with ACE officers: Head of Commissioning and Partnerships and Carers Strategy Manager. Informal and formal meetings were held, as well as a public event to gather evidence.

4. The Review agreed the following aim and objectives:

Aim: To promote the valuable work done by carers and to improve the way City of York Council and its key partners identify carers and ensure they have access to information and the support available.

Key objectives:

i to raise awareness of carers

ii to improve access to information for carers

5. The review was completed in April 2011.

6. The Carers Strategy Group is a partnership of statutory and voluntary agencies and carer representatives which oversees the implementation of York Strategy for Carers. The Strategy has been refreshed in 2011, incorporating the recommendations of the Carer's Review. The Strategy (Annex 1) was agreed by ACE DMT on 6 October and includes a summary of progress 2009–2011 and an action plan for 2011–15.

Consultation

7. The HOSC Carer's Review included a consultation event in January 2011 and in total 34 people contributed their views.

8. York Strategy for Carers 2011–15 was developed by the multi-agency partnership and includes a summary of information from a number of consultations with carers during 2010–11 (see Annex 2).

9. These included a meeting held with carers in August 2010 in order to respond to the refresh of the National Strategy. In addition, in September 2010 York LINks held a Public Information and Awareness Event on Carers Rights, and in January 2011 York Carers Centre received 183 responses to its user survey.

10. Some of the key messages from carers are as follows:
    - "protect the carers and the cared for is protected"
    - the importance of supporting the carer's physical health and mental wellbeing
    - the importance of short breaks
    - given that people do not always identify themselves as a carer it is important that key professionals, especially GPs are able to identify carers
    - 95% of carers consulted by York Carers Centre felt that leaflets in the Carers Information Pack were useful and relevant
    - young carers need specialist support in schools and further education

Carers Strategy Update

11. York Strategy for Carers 2011-2015 includes a summary of progress (p21–27) which is attached as Annex 3. A significant number of achievements have been made in working to support carers in York. There is also a range of work that still needs to be done which is summarised in the Action Plan 2011-2015 (p28-33) attached as Annex 4.

12. Some of the achievements and outstanding work are listed below.

Achievements

- The Carers Information Pack is annually updated and additional fact sheets developed as needed.
- York Carers Centre is established as an independent organisation and focal point for information provision and signposting.
- York Carers Centre led the development of two e-learning carer awareness training tools which were launched in June 2011.
- York now has three active and well established carer led forums: York Carers Forum (adult carers); CANDI (parent carers); Young Carers Revolution (young carers).
- City of York Council's Library Service worked actively with York Carers Centre during Carers Week 2011 to distribute information and raise carer awareness.
- The Flexible Carer Support Scheme continued to provide an increased number of direct payments to support and sustain carers in their caring role, with 680 carers being supported in 2010/11.
- York Carers Centre's Employment Education and Training service provides a specialist service supporting carers with training, work and related issues.
- NHS North Yorkshire and York included carers' issues in the principles for the Admissions and Discharge Policies for all Acute Trusts to follow.
- York Carers Centre has contacted all GPs surgeries in York distributing information and organised 13 awareness raising sessions.
- York Carers Centre's Young Carers Service continues to work with York schools to raise awareness and increase the school based support available for young carers.

- Young Carers Revolution (the young carers forum) has produced a DVD which is recognised as an excellent awareness raising tool and has been promoted locally and nationally.

What still needs to be done:

- Effectively provide information in public places which is accessible to people who may not recognise themselves as carers.
- Reduce the length of the waiting list for Carers Assessments of Need.
- Roll out information about carers' employment rights to employees and employers in York.
- Engage with the new NHS commissioning bodies as they develop, to promote carers issues.
- Set up a Young Carers task group.
- Implement the Common Assessment Framework (CAF) as the assessment tool for young carers.

Update of the Implementation of the Recommendations Arising from the Carer's Review

13. Feedback on the specific recommendations is recorded in Annex 5.

14. The Carers Strategy Group has a small number of task groups. Some of the recommendations of the Carer's Review come under the remit of these groups:

Carers Health Steering Group

15. The Carers Health Steering Group has provided the Action Plan which summarises the work it undertakes (Annex 6). NHS North Yorkshire and York promotes good practice in primary care and acute trusts. The responsibility for implementation of innovative approaches and carer awareness training rests with provider organisations.

16. The Dementia Pathway demonstrates good practice as a care pathway which incorporates carers issues in the 'Map of Medicine' (Annex 7), as does the Levels of Care model and project (Annex 8).

Carers Information Group

17. This group has a small Task Group and a wider Reference Group. The group annually produces the Carers Information Pack which is regularly updated and new fact sheets are under development. In response to the recommendation:

> '*the Multi-Agency Carer's Strategy Group identifies where it would be helpful to provide public information about what it means to be a carer*'

18. The group is currently producing a post card to send to carers with the winter edition of York Carers Centre's newsletter, to consult about the places where carers feel information should be available. In addition, promotional information for people who do not recognise themselves as carers is under consideration.

19. Two e-learning carer awareness tools were launched in summer 2011, one about young carers and the other about adult carers. The Carers Information Group is overseeing work to promote the tools in partnership with CYC ACE's Workforce Development Unit and those in local health agencies.

Six-monthly Report in Relation to the Indicators being Monitored in Relation to Carers

20. NHS North Yorkshire and York would like clarification about the 'quality indicators' being referred to.

Options

21. Whilst there are no specific options associated with the recommendations within this report Members are asked to consider the following:

- With regard to Annex 5 Members may choose to do one, some or all of the suggestions below:
    - Sign off those recommendations where implementation has been completed
    - Request further updates to clarify any outstanding recommendations.

- With regard to Recommendation A(iii) and Recommendation F arising from the Carer's Review give consideration to adding further reports to their workplan.

Analysis

22. The Committee are asked to consider the update at Annex 5 and decide which recommendations, if any, to sign off as complete. Members should also consider whether they would like to add a further report to their workplan to update them on any recommendations they have been unable to sign off at today's meeting.

23. In addition to this Members may wish to consider adding two further reports to their work plan for future consideration. Recommendation A (iii) asks that a written report be provided to the Health Overview & Scrutiny Committee on a six monthly basis in relation to quality indicators that are being monitored in respect of carers. Members should consider adding this to their work plan at an appropriate time. The update on this particular recommendation (Annex 5 refers) asks that the Committee give clarity to NHS North Yorkshire & York about the 'quality indicators' being referred to. Members are advised to provide this clarity at today's meeting in order that a clear focus can be given to future reports.

24. In accordance with Recommendation F of the Carer's Review, an Annual Update on the Carer's Strategy in York should be added to the Committee's workplan. Members are asked to consider making this addition to their workplan.

Council Plan 2011-15

25. Carers are York residents, or are supporting York residents and as such are affected by all the five key priorities in The Council Plan 2011–15. However, the actions and projects under 'protect vulnerable people' are of particular significance in providing services and support to sustain carers in their caring role.

Implications

Financial

26. All of the actions will be accommodated within existing budgets.

Equalities

27. An Equalities Impact Assessment has been completed for York Strategy for Carers 2011-15.

28. The actions arising are:

- Continue to improve accessibility of information for carers and key workers and improve identification of 'hidden' carers.
- Ensure information about carers' ethnicity is appropriately recorded by City of York Council, York Carers Centre and all Carers Strategy partner organisations to inform future service planning.
- Use existing contact mechanisms with BME, multi-faith and multi-cultural groups to identify the numbers of carers from BME communities and take appropriate action.
- Monitor the progress City of York Council makes in implementing the 'Carer Friendly Employer Chartermark' Action Plan.

Other

29. There are no implications relating to Human Resources, Legal, Crime and Disorder, Information Technology or Property arising from this report.

Risk Management

30. As the report is for information, no risks arise directly from this report. In a broader sense, however, failure to recognise the importance of carers could lead to the Council failing to comply with its statutory duties under the Equalities legislation, and to additional costs falling on social care budgets.

Recommendations

31. HOSC is invited to receive the report, note its contents, and comment as appropriate; specifically they are asked to:

- Sign off any completed recommendations arising from the Carer's Review
- Add a further update report to their work plan for any outstanding recommendations
- Add a report to their workplan in relation to the quality indicators that are being monitored in respect of carers (Recommendation A(iii) of the review refers

- Give clarity to NHS North Yorkshire & York as to which quality indicators Recommendation A(iii) of the review is referring to

- Add an annual update report on the Carer's Strategy in York to their workplan in accordance with Recommendation F arising from the Carer's Review.

Reason: To comply with the recommendations of the Health Overview and Scrutiny Committee and to highlight the importance of the work of Carers in accordance with the council's Corporate Strategy.

Contact Details

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Report Approved ✓ **Date** *7 November 2011*

Pete Dwyer
Director of Adults, Children and Education

Report Approved ✓ **Date** *7 November 2011*

Specialist Implications Officer(s)

Wards Affected: **All** ✓

For further information please contact the author of the report

Background Papers:

Annexes:

Annex 1: York Strategy for Carers 2011-15

Annex 2: What Carers in York have told us

Annex 3: Summary of Progress July 2011

Annex 4: York Carers Strategy Action Plan 2011–2015

Annex 5: Feedback on Carer's Review recommendations November 2011

Annex 6: Carers Health Steering Group Action Plan

Annex 7: Dementia Pathway 'Map of Medicine'

Annex 8: Levels of Care model and project

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NHS
North Yorkshire and York

CITY OF YORK COUNCIL

York Strategy for Carers

2011 – 2015

York Carers Centre

YORK CARERS FORUM
yorkcarersforum@tiscali.co.uk

CANDI

Young Carers Revolution

YORK STRATEGY FOR CARERS 2011 - 2015

Contents

Appendices

1. Why carers matter

Many of us will be carers at some point in our lives. It is a role that can creep up gradually and for some it can be a life long role. For others it can come unexpectedly and suddenly following a crisis. Supporting carers is in all our interests.

Who are carers?
'A carer is someone who, unpaid, looks after or supports a relative, friend or neighbour who is ill, disabled, frail or in need of emotional support'.

Facts

- There are 6 million carers in the UK.
- Over 1 million carers provide more than 50 hours care per week.
- An estimated 37% of these carers are new to caring every year.
- 58% of carers are women and 42% men.
- Women have a 50% chance of becoming a carer before they are 59.

'Facts about carers' Carers UK, June 2009.

The impact of caring

Carers make a significant contribution in providing health and community care to relatives, friends and neighbours. The impact of caring varies depending on individual circumstances, however it is known that those caring for long hours each week are more likely **not** to be in good health. Caring can also have a financial impact and one in eight workers in the UK combine work with caring responsibilities. [1]

Carers are from all walks of life and all backgrounds. Some carers can face particular disadvantage and we may know little about them. These carers are often called 'hidden carers'. They can be 'hidden' due to the circumstances of the person they care for, or their cultural background. For example, carers of people with mental ill health or substance misuse can find it hard to access support.

Equality and social inclusion

Some carers may be less likely to access appropriate information and support. The City of York Council's 'Equality Action Group' provided feedback about the Carers Strategy in 2010 [2] identifying carers who need specific support:

- People with sensory impairments
- Carers with learning disabilities
- Carers from black and minority ethnic communities
- Lesbian, gay, bisexual and transgender (LGBT) carers
- Travellers
- Carers with mental health problems
- Older carers

[1] Carers UK (June 2009) *Fact about carers*
[2] City of York Council, Equality Action Group (February 2010) *Help us get it right day: feedback report.*

In order to achieve greater equality in supporting all carers, specific approaches should be adopted to reach carers who are currently unknown.

2. National Picture

All public bodies are engaged in a time of major and unprecedented change in responding to the challenges following the Comprehensive Spending Review of 2010, and the new legislative requirements affecting health, social care and many other aspects of local government.

Carers Strategy

'*Recognised, valued and supported: next steps for the Carers Strategy'* was published by the Coalition Government in November 2010 to outline current priorities for the ten year vision set out in the Carers Strategy of 2008. [3]

Social care

The Coalition Programme committed the Government to reforming the system of social care in England. *A Vision for Adult Social Care: Capable Communities and Active Citizens*[4] was published in 2010 and is one a number of key documents[5] which sets out principles and required actions. The Government plans to publish the Social Care Reform Bill in spring 2012. This follows the Law Commission's review of adult social care legislation and the Dilnot Commission's work on the funding of care and support.

Health

The Health and Social Care Bill was published in January 2011. The Bill provides for significant changes to the health service. This includes the abolition of Strategic Health Authorities and Primary Care Trusts, the transfer of commissioning responsibilities to GPs and the transfer of responsibilities for public health to local authorities.

Performance framework

The national requirements for health and social care are in a process of change. The government describes a vision moving away from top-down performance management, to sector-led improvement and local accountability. New outcomes frameworks for both health and social care have been published in 2010/11, however these have not yet been implemented.

Equality Act 2010

This Act introduces nine 'protected characteristics' replacing what were known as the six equality strands:

---

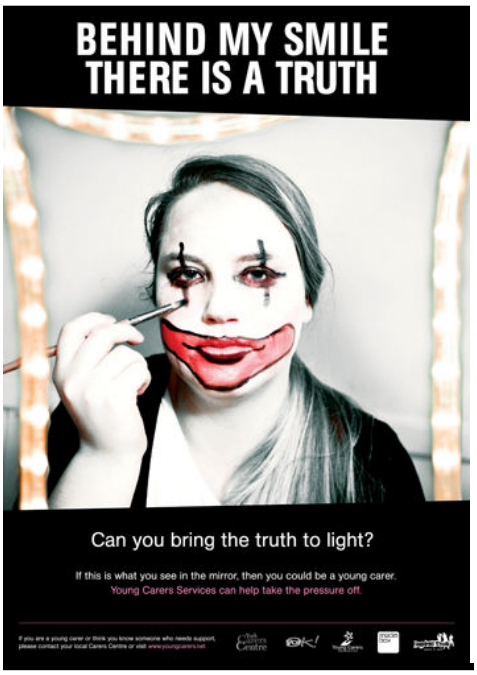
[3] HM Government (2010) *Recognised, valued and supported: next steps for the Carers Strategy;* HM Government (2008) *Carers at the heart of 21st-century families and communities: A caring system on your side, a life of your own.*

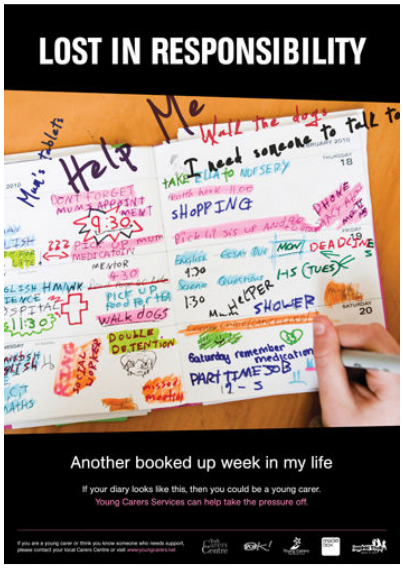
[4] Department of Health (2010) *A Vision for Adult Social Care*

[5] Department of Health (2010)*Think Local, Act Personal ;* Department of Health (2010) *Transparency in Outcomes :a framework for quality in adult social cares*

- Age
- Disability
- Gender reassignments
- Race
- Religion or belief
- Sex
- Sexual orientation
- Marriage and civil partnership
- Pregnancy and maternity

The Act also strengthens the protection of carers against harassment and discrimination at work and in the provision of goods and services. This is because a carer is now counted as being 'associated' with someone who is already protected by the law because of their age or disability.[6]





(Campaign Images produced by Young Carers Revolution 2010)

[6] Government Equalities Office leaflet (2010) *Equality Act 2010: What do I need to know as a carer?*

3. Local picture

Carers in York

Carers in York (2001)	Numbers	%
Total population	181,094	100%
Total population of unpaid carers	17,009	9%

[7]

Carers make up over 9% of the population in York. The 2001 census records 342 young carers aged 8 –17 years in York, which is likely to be an underestimate, as other research suggests there are as many as 1,600.

An estimate based on the increase in population suggests there were 18,676 adult carers in York in 2010.

Hours of care provided by carers (2001)	Numbers	%
Total population of unpaid carers	17,009	100%
Care provided 1 - 19 hours per week	12,478	73%
care provided 20 - 49 hours per week	1,520	9%
Care provided over 50 hours per week	3,011	18%

[8]

Analysis of the 2001 census indicates that 21% of carers caring for 50 hours a week are likely to be in poor health. This is double the percentage of people who are not caring. [9]

Population and demographic change

York's population is rising. A total population of 181,094 was recorded in the 2001 census. The population is predicted to be 202,400 in 2011. A total of 89% of York's population is 'White British', with the BME population rising from 4.9% in 2001 to 11% in 2009. [10]

[7] 2001 Census
[8] 2001 Census
[9] Carers UK, (2004) *In Poor Health: the impact of caring on health.*
[10] City of York Council, Business Intelligence Hub Highlight Report July 2011

Older people
There is a significant growth in the population of older people. The Council reported in 2006 an expected 31% growth in the population of older people over 65 in the following 15 years and an estimated 700 additional older people with dementia.[11] This highlights the associated increase in mental health and physical and sensory needs as the population ages. It is expected that there will be an increase in both the number of older people being supported by carers, as well as the number of older carers. It is likely that more people will become 'mutual carers' where two or more people, each experiencing ill health or disability, will care for each other.

Strategic planning
Without Walls is the name of a group of people who have worked together since 2003 to jointly develop a shared vision for the city. The Partnership is made up of representatives of public, voluntary and business organisations in York. They have developed a '*Strategy for York'*, which sets out the long-term vision for the local area based on what matters most to people. In addition, they have also developed a '*City Plan*' that focuses on a small number of priorities that are critical to address in the next four years to secure York's future.

Partners of the Without Walls Partnership all agreed to include the ambitions of the 'Strategy for York' and 'City Plan' into their own plans and strategies. City of York Council have produced a plan for 2011 – 2015 describing priorities and actions that will be taken to deliver our contribution towards the 'Strategy for York' and 'City Plan'.

Joint Strategic Needs Assessment
This aims to provide a comprehensive analysis of current and future needs in relation to the health and wellbeing of children and adults in the City and to inform future planning and commissioning decisions. The 2010 Assessment included a section about carers which referenced the Carers Strategy Action Plan. The production of a revised Assessment is underway, overseen by the Shadow Health and Wellbeing Board.

Carers Strategy Group
The Carers Strategy Group is a partnership of people from statutory and voluntary organisations as well as carer representatives from the carer led forums. The group meets every three months to monitor progress with the Carers Strategy Action Plan. The group is coordinated by City of York Council's Adults, Children and Education directorate and is working towards increasing carer awareness at all levels of strategic planning.

[11] City of York Council (2007) *City of York Commissioning Strategy for Older People 2006 - 2021*

Funding

York Carers Strategy Group supports partnership working between health and social care agencies in the commissioning and provision of services.

City of York Council dedicates funding from the Area Based Grant and NHS North Yorkshire and York uses funding from its core budget to support carers in the following ways:

- Strategic support and direct payments for carers.
- Services commissioned specifically for carers.
- Respite and sitting services.
- Through support provided to the cared for person which allows carers to take a break.
- Specialist services for example Community Mental Health Services that provide advice and support to carers.

As part of the National Strategy refresh the government announced that it is including £400m over four years in PCT allocations and potentially GP consortia subsequently, to spend on supporting carers. This funding is an indicative amount and is included in the PCTs baseline budget and in many cases is already committed against the current service provision. Therefore there is no new separate allocation specifically for Carers on top of the 'core' funding for PCTs.

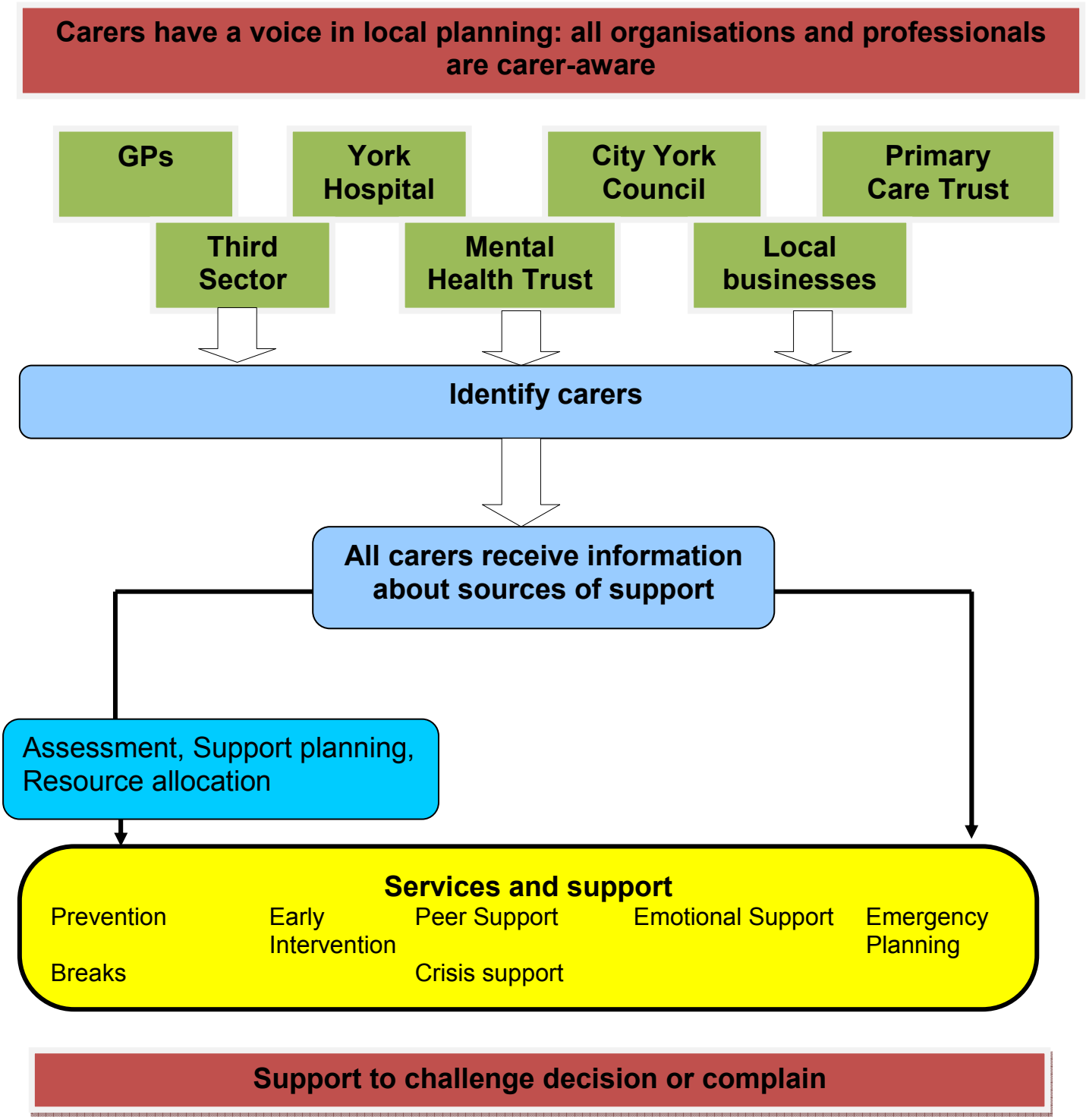
4. Vision and Outcomes Framework

Our vision in York is to work towards developing a local community where carers' needs are identified and supported by all public services and other organisations in the City. In short: 'Carers are everybody's business'.

Carers should be respected and acknowledged. Each carer has a unique perspective, alongside skills and knowledge gained through the experience of caring.

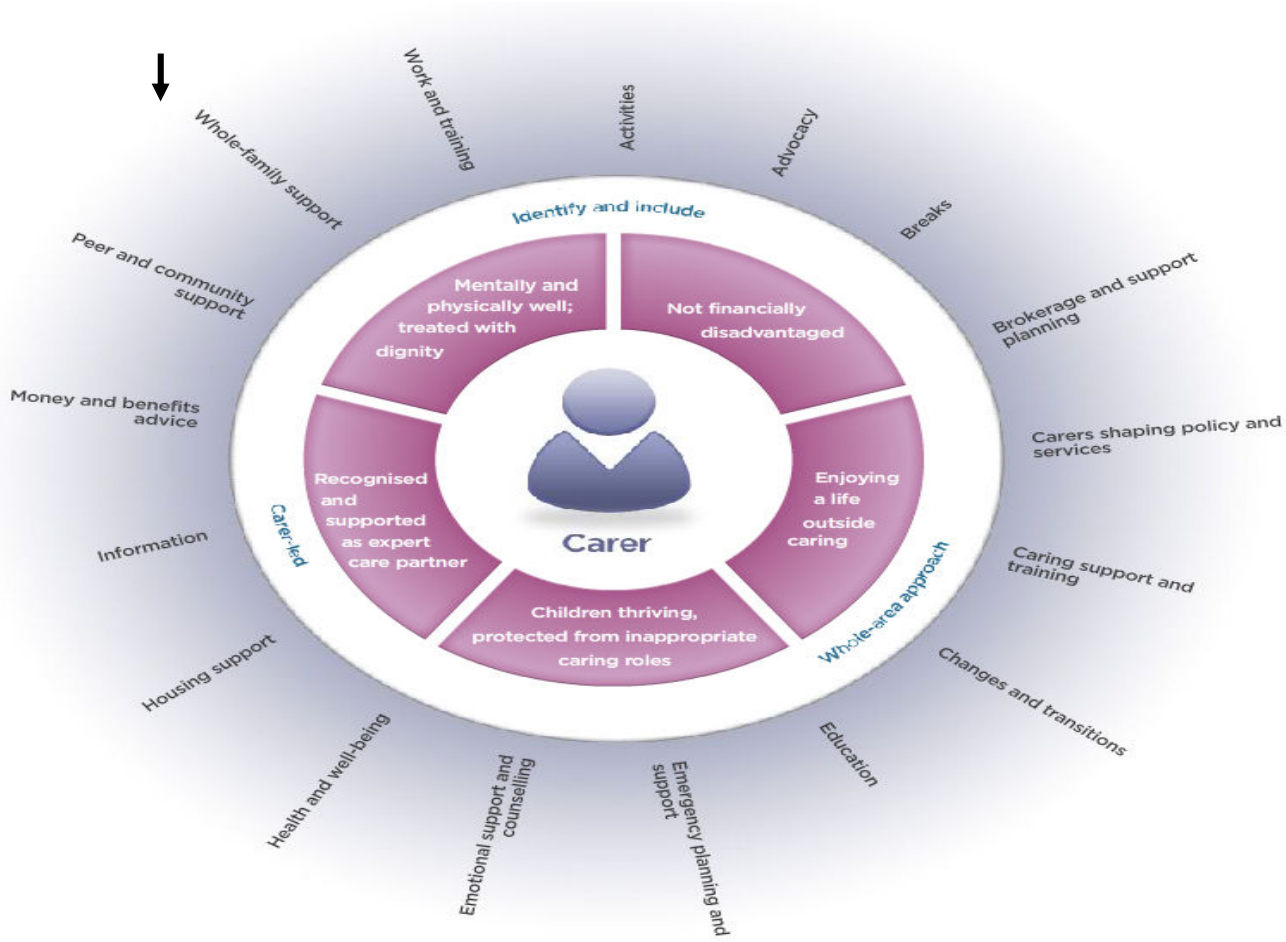
Care pathway for carers support

This has been drafted as a guide for all agencies. The chart below shows how we can work towards making sure carers are always recognised and directed to sources of support .



Outcomes framework

The 'Carers Hub' [12] is a resource developed by the Princess Royal Trust for Carers. It is a model of comprehensive carer support based on the outcomes of the refreshed National Strategy.



The carer is at the centre of the hub. The five outcomes are in the inner section and are universal ambitions for carers. These ambitions underpin the work of York Strategy for Carers.

The middle band states the overarching values:

- 'Identify and include' – we must make sure we reach all carers including those most at risk of being overlooked.

- 'Carer-led' – services and support should be individually tailored, and carers should be part of planning and strategic forums.

- 'Whole-area approach' – effective whole area planning is needed to make sure carers' specific needs are met.

[12] http://www.carershub.org

We will use the Carers Hub to help us plan work required to implement the carers strategy in the future.

5. Achievements and what we still need to do

Recognised and supported as expert care partners

What we have achieved

Information
York Carers Centre is now an established local independent charity and a focal point for information and advice.

Carers shaping policy
There are three active carer led forums in York helping to make sure carers voices are heard: CANDI, York Carers Forum and Young Carers Revolution.

Carer Awareness Training
Regionally funded training held for library staff, workers in primary care health settings and those undertaking Carers Assessments of Need.

Carers Assessments
City of York Council's social work teams have skilled Carers Support Workers carrying out carer assessments.

Carer awareness raising
York Carers Centre led the development of the Young Carer and Adult Carer e-learning tools.

Personalisation
Regional conference on personalisation hosted by York Carers Centre, February 2011.

Young adults carers
York Carers Centre successfully provides specialist support to young adult carers aged 18 and over.

Personalisation
York Carers Forum has worked with City of York Council to inform carers about personalisation.

City of York Council Health Overview Scrutiny Committee
Review successfully undertaken 2010/11 focusing on carer identification and information.

Integrated services and better coordination
A 'Care Pathway for carers support' has been drafted. Initial discussions have taken place about some of the implications for City of York Council's adult social care services.

York LINk review
Review completed and recommendations made spring 2011.

Development work at York Carers Centre
Lead agency in work to develop services for Young Carers, whole family support and expanded to incorporate a specialist service for carers affected by substance misuse.

What we still need to do

- Ensure all Carers Strategy partners adopt the 'Care Pathway for carers support'.
- Set up a robust system for update and distribution of accessible information for carers.
- Identify and display information for carers in key places in York.
- Provide public information in these 'key places' which is accessible to people who may not recognise themselves as 'carers'.
- Establish the potential 'trigger points' for carer recognition, so carers can be identified earlier.
- Involve GPs in the provision of information to carers.
- Ensure Adult Social Services provide a coordinated approach to assessment for the 'whole family'.
- Reduce length of waiting list for Carers Assessment of Need.
- Include carer awareness raising in all workforce development strategies.
- Map carer involvement in local health and social care planning networks with attention to the development of Healthwatch.
- Review carer involvement.
- Ensure information about carers ethnicity is appropriately recorded by City of York Council and York Carers Centre to inform future service planning.
- Scope the work needed to identify the numbers of carers from BME communities and assess their needs.
- Ensure City of York Council reviews its equalities framework enabling carers to become part of all equality and inclusion work.

Enjoying a life outside caring

What we have achieved

Carers Discount Card
York Carers Centre launched a free discount card for carers supported by 50 local businesses.

Carers Emergency Card Scheme
Over 400 carers of all ages registered. Launched for Young Carers.

Carers Breaks- York Carers Forum
In response to feedback from carers, new monthly Art and Craft sessions established in addition to monthly social meetings with massages provided; coach trips trialled- enabling carers to take a break with the person they care for; events during carers week.

Flexible Carer Support Scheme
Direct payments received by 600 carers in 2009/10 and 680 carers in 2010/11 to support and sustain caring role.

Young adult carers
York Carers Centre supported 44 young adult carers in 2010/11 with 14 new carers joining. Monthly pub quiz and cinema groups.

Carer Breaks and Promoting Social Networking - York Carers Centre
Art classes, card making, special events and massage sessions support over 200 carers annually aiming to promote well-being and reduce social isolation.

Telecare *
Small pilot scheme offered 3 months free trial of equipment to carers 2010/11.

* see footnote[13]

[13] **"Telecare is the continuous, automatic and remote monitoring of real time emergencies and lifestyle changes over time in order to manage the risks associated with independent living." It can provide people with electronic equipment such as community alarm systems or falls sensors which makes it possible to live independently and also call for help when needed.**

What we still need to do

- Set up a clear framework for provision of breaks for carers which links to self directed support and personalisation.
- Audit existing services and support.
- Agree the concept of what a carers break is.
- Ensure learning from the report of the National Demonstrator Sites is incorporated into future local plans.
- Pursue roll out of Carers Emergency Card to parent carers.
- Ensure telecare services are accessible to carers.

The Carers' Quilt in St Nicholas's Chapel, York Minster


YORK CARERS FORUM

Not financially disadvantaged

What we have achieved

Employment
York Carers Centre Employment Education and Training service supported carers with writing CVs, training, volunteering, becoming 'work ready'. Work with employers to support carers to stay in work.

Benefits uptake
York Carers Centre achieved an increase of £77,000 in welfare benefits uptake during a ten month period in 2011/11.

York Explore training courses
York Carers Centre has established links with York Library Service to help carers access free courses on computer skills and managing finances.

York Carers Centre – laptops
Funding obtained providing 30 carers with laptops enabling access to digital services to reduce social isolation, access job searches and online shopping, and increase networks.

Young adult carers
York Carers Centre supported 2 young carers to volunteer abroad and provided support to others to enable access to higher education.

What we still need to do

- Audit benefits advice services available to carers.
- Improve the availability of financial information and advice to young people aged 16+.
- Ensure carers can access financial advice when the cared for enters residential care and at end of life.
- Ensure City of York Council implements the action plan linked to the 'Carers Friendly Employer' chartermark.
- Develop links and engage with local businesses.
- Ensure information about carers' employment rights is available to employees and employers in York.

Mentally and physically well and treated with dignity

What we have achieved

GP surgeries
York Carers Centre has contacted all GP surgeries in York and distributed information, organised 13 awareness raising sessions for surgery staff and held 13 advice sessions at one GP surgery.

Back care support and training for carers
Proposal developed for 2 year training package utilising new non recurrent DH funding.

Self health checklist
This has been piloted and the feedback is positive. It supports carers to identify their own health needs and acts as a prompt for discussion with their GP practice.

Admissions and Discharge Policy
NHS North Yorkshire and York included carers issues in the principles for the Admissions and Discharge Policies for all Acute Trusts to follow.

Drug and Alcohol Misuse
NHS North Yorkshire and York arranged for the Carers Centre staff to access training on support for carers of those with Substance misuse and alcohol misuse.

Dementia Care Pathway
Carers issues have been included in to the Dementia Map of Medicine to prompt primary care to consider the needs of carers and supportive mechanisms such as the Emergency Carers Card.

End of life
York Carers Forum has worked with York Hospital to ensure carers are recognised, supported and included in the End of Life Pathway.

What we still need to do

- Health commissioners and providers ensure greater consistency around identifying and addressing the needs of carers.
- Health commissioners monitor work towards ensuring that all care pathways provide guidance on the information and advice carers will need.
- To engage with the new NHS Commissioning bodies (Clinical Commissioning Groups) as they develop, to promote carer issues and build on existing work in Primary, Community and Acute Care.

Children thriving, protected from inappropriate caring roles and supported in their caring roles

What we have achieved

Supporting schools
York Carers Centre's Young Carers Service started dedicated work with schools in 2009.

Whole family working
York Carers Centre secured funding for a specialist one year post 2010/11 offering direct support to families and work to support strategic change.

Strategy
City of York Council has identified a lead officer for young carers. A task group has been established to plan and implement actions.

Carers Assessments for Young Carers
A Task Group has begun work to implement young carer assessments in York using the Common Assessment Framework.

Young Carers Forum
Ongoing meetings of Young Carers Revolution have started, leadership of the group has been established and new members attended a meeting in April 2011. DVD promoted locally and nationally. York MP Julian Sturdy praised work of Forum in speech in House of Commons.

Young Carers Service
Support for 95 young carers in 2010/11 and 38 new carers joined due mainly to increased awareness in schools.

Young Carers Awareness Raising
Young Carers Revolution (YCR) DVD promoted locally and nationally. York MPs attended YCR meetings. YCR received standing ovation at No Wrong Doors Conference 2010. Links made with Youth Parliament. Best Community Project in York and Volunteer award in London received.

Breaks for young carers
Monthly sessions held for 3 different age groups, 286 sessions of one to one support, 50 separate activities and 36 groups sessions provided by Young Carers Service 2010/11.

Good practice in schools
Staff at Millthorpe School have been supported to run support groups for young carers. Lessons held at All Saints School for year 11 students to raise awareness re young carers. Feedback from Huntington school deputy head confirms that student and teacher awareness about young carers has increased as a result of work by Young Carers Service.

What we still need to do

- Support the development of the Young Carers task group and action plan.

- Implement the Common Assessment Framework (CAF) as the assessment tool for Young Carers Assessment.

- Ensure all adult services assessment processes and paperwork includes identification of young carers.

- Develop work in schools which identifies the support needs of young carers and ensures this support is made available.

- Young Carers Task Group to consider York LINk report (March 2011) recommendation: 'Young carers should be given help to get home access to computers'.

6. Priorities

The Carers Strategy Group agreed the following priorities for the renewed Strategy Action Plan at its meeting in July 2011:

- **Develop work with partner agencies which reaches unknown carers and provides appropriate responses.**
- **Increase access to information for carers and key workers in 'key places'.**
- **Raise carer awareness amongst GPs and all workers in health settings.**
- **Engage with the Clinical Commissioning Group for Vale of York to raise awareness of the support needs of carers.**
- **Ensure the need to provide support for carers is included in all work at a strategic level.**
- **Implement the young carers assessment of need.**

York Carers Forum outing to Yorkshire Lavender (Terrington) – 7th July 2011

APPENDIX 1

Progress summary July 2011

York Carers Strategy Action Plan - Key priorities and targets 2009 - 2011

National Strategic Outcome One ***Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.***			
	Outcome	**Local priority**	**Achievements: July 2011**
1A	**Information**: Carers will have easy access to accurate information and advice	• Provision of easily accessible information and signposting	• Carers Information Pack produced and annually updated • York Carers Centre developing as focal point for information • York Carers Centre, CANDI, York Carers Forum, Young Carers Revolution and City of York Council websites provide information for carers

1B	**Carer identification:** Carers will be recognised and valued for their unique role in supporting the cared for person	• Increase identification of carers in Primary Care (see 4C)	• York Carers Centre contacted all GP surgeries and distributed information in 2010/11 • City of York Council Health Overview Scrutiny Committee completed a carer review in spring 2011 focussing on carer identification
1C	**Young Adult Carers:** Carers will have easy access to accurate information and advice	• Establishment of support for young adult carers aged 18 years + by York Carers Centre	• York Carers Centre provides regular ongoing support to 44 young adults (July 2011)
1D	**Integrated services:** Services and information will be provided in a coordinated way across and within agencies	• Closer joint working and partnerships between health, social care and the third sector • Awareness raising for professionals	• Draft 'Care Pathway for Carers Support' presented to Carers Strategy Group April 2011 • E learning carer awareness raising tools re 'Young Carers' and 'Adult Carers' launched May/June 2011

1E	**Personalised services:** Carers will have access to a range of flexible services that meet their individual needs	• Carer Assessment of Need • Common Assessment Framework *(NB not implemented for adults in York)* • Personal budgets	• Continued increase in numbers of separate carer assessment and review completed (673 in 09/10 and 857 in 10/11) • Carer's role acknowledged in assessment questionnaire for cared for person's personal budget
1F	**Carer involvement:** Carers will be involved in planning and monitoring the services they receive	• Training for carers – Living for Learning • Carer involvement	• One Living for Learning course held in 2009 • Three active carer led forums established and offered ongoing support

National Strategic Outcome Two ***Carers will be able to have a life of their own alongside their caring role***			
	Outcome	**Local priority**	**Achievements**
2A	**Break provision:** Carers should have access to a range of flexible breaks	• Joint plans with NYYPCT re new money for breaks • Review current breaks provision • Personal budgets to enable carers to take breaks	• Breaks review presented to Carers Strategy Group April 2010 • Continued increase in numbers of carers benefiting from Flexible Carer Support Scheme (600 in 09/10 and 680 in 10/11)
2B	**Emergency Card Scheme:** Carers should be better equipped to deal with a crisis and have peace of mind	• Emergency Card Scheme	• Card scheme well established for adults, now includes young carers
2C	**Technology:** Carers should have access to a range of services and support	• Telecare	• Small scheme to promote benefits of telecare for carers completed in 10/11

2D	**Housing, Leisure and Transport:** Carers should have access to a range of services and support	• Discount card scheme	• Carers with Carers Emergency Card and those in receipt of Carers Allowance can access discounts at City of York Council leisure classes and swimming pools • York Carers Centre launched a discount card for carers in December 2010 involving 50 local businesses

National Strategic Outcome Three ***Carers will be financially supported so that they are not forced into financial hardship by their caring role***			
	Outcome	**Local priority**	**Acheivements**
3A	**Income:** Carers should have access to benefits advice	• Welfare benefits advice	• York Carers Centre continues to increase uptake of benefits for carers.
3B	**Employment:** Carers should have access to employment support and vocational training	• Ensure carers in employment are supported • Encourage carer aware employment practice • Make local links with new 'care partnership managers' at Jobcentre Plus	• York Carers Centre Employment Education and Training service established. • York Carers Centre works with employers • City of York Council awarded a Carer Friendly Employer charter mark • Care Partnership Manager a member of Carers Strategy Group

National Strategic Outcome Four ***Carers will be supported to stay mentally and physically well and treated with dignity***			
	Outcome	**Local priority**	**Achievements**
4A	**Prevention:** Carers should have access to appropriate medical advice, and support about their own health needs	• Self-health checklist distribution and evaluation	• Check list piloted and distributed • Business case for back care support for carers compiled and short term development work planned • Need to give advice to carers on moving and handling included in principles for Admissions and Discharge policies circulated to Acute Trusts

4B	**NHS:** Carers needs should be addressed in hospital admission and discharge procedures		• NHS North Yorkshire and York included carers issues in the principles for the Admissions and Discharge Policies for all Acute Trusts • Health passport piloted for Neurology patients includes pages about carers. • York Carers Forum worked with York Hospital to ensure carer recognition at End of Life Pathway

4C	**Primary Care and GPs:** Primary care professionals should identify carers ensuring appropriate support, signposting and referrals	• Update GP resource pack (*Decision made not continue with pack)* • Develop work to improve carer identification and signposting in primary care settings	• York Carers Centre contacted all GP surgeries in York and distributed promotional information • Carer issues included in Dementia Map of Medicine to prompt support of carers
4D	**Emotional Support:** Carers should have support to maintain their well being and reduce stress		

National Strategic Outcome Five ***Children and young people will be protected from inappropriate caring and have the support they need to learn, develop, and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes*.** *(Every Child Matters outcomes: be healthy, stay safe, enjoy and achieve, make a positive contribution, achieve economic well-being)*			
	Outcome	**Local priority**	
5A	**Universal services:** Children will have the support they need to learn develop and thrive	• Support schools in York to support young carers	• York Carers Centre began dedicated work with York Schools in 2009 • Young Carers Revolution produced and publicised a range of carer awareness raising tools
5B	**Targeted support for young carers:** Young carers will be able to make a positive contribution and have their views respected	• Set up a Young Carers Forum	• Young Carers Revolution established as York's carer led forum for young carers

5C	**Whole family support:** Children and young people will be protected from inappropriate caring		• York Carers Centre secured funding for a specialist one year post 2010/11 offering direct support to families and work to support strategic change which enabled the development of the e learning carer awareness raising tools.

York Carers Strategy Action Plan 2011 - 2015

Appendix 2

National Strategic Outcome One ***Recognised and supported as expert care partners***		
	Outcome	**What we need to do**
	Information: Carers will have wider access to accurate information and advice available through a range of communication methods	• Set up a robust system for update and distribution of accessible information for carers, including electronic distribution methods • Decide which are the 'key places' in York where carers information should be available • Develop and distribute public information which is accessible to people who may not recognise themselves as 'carers' • Involve GPs in the provision of information to carers
	Carer identification: Carers will be recognised and valued for their unique role in supporting the cared for person	• Enable professionals to effectively identify carers. • Include carer awareness raising in all workforce development strategies

	Integrated services: Services and information will be provided in a coordinated way across and within agencies	• Ensure all Carers Strategy partners adopt the 'Care Pathway for carers support'
	Personalised services: Carers will have access to a range of flexible services that meet their individual needs	• Adult and Children's Social Services to provide a coordinated approach to assessment for the 'whole family' • City of York Council will reduce length of waiting list for Carers Assessment of Need
	Carer involvement: Carers will be involved in planning and monitoring the services they receive	• Review and increase carer involvement and take appropriate action • Map carer involvement in local health and social care planning networks with attention to the development of Healthwatch

	Equality and social inclusion: All carers will be able to access services and support.	• Ensure information about carers ethnicity is appropriately recorded by City of York Council, York Carers Centre and all Carers Strategy partner organisations to inform future service planning • Use existing contact mechanisms with BME, multi-faith and multi-cultural groups to identify the numbers of carers from BME communities and take appropriate action • City of York Council to review its equalities framework to ensure carers become part of all equality and inclusion work

National Strategic Outcome Two ***Enjoying a life outside caring***		
	Outcome	**What we need to do**
	Break provision: Ensure carers have access to a range of flexible breaks	• Set up a clear framework for provision of breaks for carers which links to self directed support and personalisation • Audit existing services and support • Agree and promote the concept of what a carers break is • Research and adopt good practice • Roll out the Carers Emergency Card to parent carers

	Technology: Ensure carers have access to a range of services and support	• Provide accessible telecare services to adults
National Strategic Outcome Three ***Not financially disadvantaged***		
	Outcome	**What we need to do**
	Income: Ensure carers have access to benefits and financial advice	• Audit current benefits advice services available to carers • Ensure carers can access financial advice when the cared for enters residential care and at end of life

	Employment: Carers should have access to employment support and vocational training	• Monitor City of York Council's implementation of the action plan linked to the 'Carers Friendly Employer' charter mark • Develop links with local businesses • Roll out information about carers employment rights to employees and employers in York

National Strategic Outcome Four ***Mentally and physically well; treated with dignity***		
	Outcome	**What we need to do**
	Prevention: Carers should have access to appropriate medical advice, and support about their own health needs **NHS:** Carers needs should be addressed in hospital admission and discharge procedures **Primary Care and GPs:** Primary care professionals should identify carers ensuring appropriate support, signposting and referrals **Emotional Support:** Carers should have support to maintain their well being an reduce stress	• Health commissioners and providers ensure greater consistency around identifying and addressing the needs of carers • Health commissioners will work towards ensuring that all care pathways provide guidance on the information and advice carers will need • To engage with the new NHS Commissioning bodies (Clinical Commissioning Groups) as they develop to promote carers issues and build on existing work in Primary, Community and Acute Care

National Strategic Outcome Five ***Children thriving, protected from inappropriate caring roles***		
	Outcome	**What we need to do**
	Universal services: Children have access to the support they need to learn, develop and thrive	• Set up the Young Carers task group and action plan • Ongoing development of the work now established in schools which supports young carers • Task group to consider York LINk report (March 2011) recommendation: 'Young carers should be given help to get home access to computers'
	Whole family support: Children and young people are protected from inappropriate caring. Young adults have access to appropriate advice in relation to their transition into adulthood.	• Implement the Common Assessment Framework (CAF) as the assessment tool for Young Carers Assessment. • Ensure adult services identify young carers in their assessment processes and paperwork • Ensure effective sources of advice are available to young carers aged 16-18+

Appendix 3

What carers in York have told us?

National Strategy refresh session – York 2010
25 people attended a consultation meeting on 16th August 2010.
16 were carers, of whom 4 were young carers. Three other carers returned written responses. Nine workers/professionals attended of whom all had specialist roles to support unpaid carers. Carers discussed what the priorities for services and support to carers should be.

KEY MESSAGES (from final discussion at meeting)

"Don't let money rule it, sometimes have to spend a bit to create a lot."

Do not cut services to carers. Carers save money, and are value for money. Protect the carers, and the cared for is protected.

"These services are our rights."

Personalisation and respite is a complex issue.

Third sector equals value for money.

Short breaks are a priority.

Emergency support at short notice.

Development of personal budgets and support to maintain them.

Identification of carers in schools, GPs, hospital and hospital discharge.

Training by carers in carer awareness for professionals/workers.

Carers Allowance: increase and change the rules.

Young Carers need specialist support and support in schools and Further Education.

Carers own health.

Quotes from carers

Peer Support

"The only things that have worked well for me is when I have spoken to other carers….they were the ones who put me on to things that helped me. I would love to say "serviceland" helped me but I can't."

"Enabling parent/carers to speak to other parent/carers. People listen and learn best from people that know what they mean without having to explain."

Health and Well-being

"One of the most important outcomes of the strategy. If the carer doesn't have support and attention to their physical needs then there would be two people in need of care."

"For me, the most important priority for the carer strategy is to ensure both the mental and physical well-being of the carer…..in the long term, funds targeted at ensuring carers are mentally and physically able to continue in their supporting roles will pay huge dividends by avoiding significant costs when things go wrong."

"Emotional support for carers would be very welcome as it is badly needed. The only emotional support I have ever received in my caring role, has come from other carers. Funding carer led support groups should be a priority."

Health Overview Scrutiny Report 2011
In November 2010 the City of York Council's Health Overview Scrutiny Committee set up a Task Group to carry out a Carer's Scrutiny Review.

Aim: to promote the valuable work done by carers and to improve the way City of York Council and its key partners identify carers and ensure they have access to information and the support available.

Key objectives:
1) To raise awareness of carers
2) To improve access to information for carers

20 carers and 10 care workers contributed information in person or via a questionnaire.

Analysis of information from the Public Event and questionnaires

The importance of early identification of carers
Key professionals, especially GPs need to be aware of carers from an early stage and identify them as soon as possible.

Recognising you are a carer
People do not always immediately recognise themselves as a carer. Steps need to be taken to encourage early carer self-identification so that the right information can be provided at the right time. Carer needs to have access to information immediately that they recognise themselves as a carer.

"Many comments were received (at the public event and in returned questionnaires) that recognising that you are a carer was a gradual process, however it often became very clear at a point of crisis (such as hospital admission or diagnosis or a particular condition.)"

Provision of Information
Information would need to be proportionate to the needs of each individual carer.

Carers own needs
Comments at the public event were backed up by questionnaires that identified that frequently more support is given to patients/customers than to carers. This meant that the carer's health often suffered as a consequence and carer didn't always get enough time to spend on their own needs especially if they were caring for more than one person.

York LINk Report 2011

The LINk Steering Group held a Public Information and Awareness Event on Carers Rights on September 8th 2010. Evidence about services for carers in York was provided by a total of 48 individuals and York Carers Centre staff.

Recommendations from "Report on Carers Rights – March 2011" were made on the following themes:

Young Carers

- City of York Council to help fund York Carers Centre to promote young carers awareness in schools
- Implementation of a Young Carers Card Scheme and funding for York Carers Centre for a young carers event
- GPs should keep a record of young carers
- City of York Council provide support to help young carers to find ways of funding home computers

Employment

- City of York Council organise support and advice to help carers combat discrimination in the workplace
- Local organisations to offer work experiencing placements to carers

Parent carers

- City of York Council should improve access for disabled children to social services
- Jointly commissioned (by NHS North Yorkshire and York and City of York Council) posts to help parent carers liaise with community, social services and health services

City of York Council

- Congratulations to City of York Council for the amount of support provided for carers and carer organisations and request that high standards are maintained.

Carers Assessments

- Increased resources from City of York Council to reduce waiting times for Carers Assessments

GPs

- GP surgeries in York should adopt the model used in Somerset called the Carers Champions Scheme, with training delivered by York Carers Centre and York Carers Forum.

York Carers Centre Survey 2011

In January 2011 York Carers Centre sent out a survey to 650 adult carers registered on its database. In total 183 surveys were returned: a response rate of 28%. The following is a summary of feedback from carers.

To view the full survey results go to:
http://www.yorkcarerscentre.co.uk/content/carers-survey-2011

Current services

- 47% of carers heard about York Carers Centre from a social worker or carer support worker.
- 13% of carers heard about York Carers Centre from their GP surgery.
- 57% of carers responded that one of the reasons they initially contacted the Centre was to find information about services, and 42% to register for the Carers Emergency Card.
- 58% of carers usually contact the Centre by phone.
- 94% of carers felt able to speak to someone at the Centre at a convenient time.
- 95% of carers fed back very positively about all aspects of home visits from Centre workers.
- 88% of carers agreed that information in York Carers Centre newsletter was useful and relevant.
- 95% of carers felt that leaflets in the Carers Information Pack were useful and relevant.
- 79% of carers agreed that York Carers Centre helps them with the stresses of being a carer.

What carers would like to see in the future

- 80% of carers would like to have regular advice surgeries in their local area.
- 74% of carers felt if would be useful to have a telephone helpline for emotional support.

Appendix 4

Carers Scrutiny Review March 2011 – summary of recommendations

City of York Council Health Overview Scrutiny Committee Carers Review Task Group met between December 2010 and March 2011.
For further details and the full final report see:
http://democracy.york.gov.uk/ieListDocuments.aspx?CId=718&MId=6313&Ver=4

Carers Scrutiny Review March 2011 – summary of recommendations

To raise awareness of carers:

- Health commissioners and providers ensure that there is greater consistency around how carers are identified and once identified their needs addressed.
- That the Multi-Agency Carer's Strategy Group identifies where it would be helpful to provide public information about what it means to be a carer and how to access support to enable carers to identify themselves earlier.
- That City of York Council reviews its Equalities Framework to ensure that carers become an integral part of all equality and inclusion work.

To improve access to information for carers

- That health commissioners ensure that all care pathways provide guidance on the information and advice carers will need.
- That Adult Social Services develop a clear pathway, which provides an integrated approach to assessment for the whole family.
- To continue to promote carer awareness an annual update on the Carers Strategy for York be presented to the Heath Overview and Scrutiny Committee and thereafter to the Executive Member for Health and Adult Social Services.

York Strategy for Carers

Compiled and agreed by York Carers Strategy Group August 2011.

For more information contact:

Frances Perry
Carers Strategy Manager
City of York Council

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Email **frances.perry@york.gov.uk**

Acknowledgements

Thanks to Young Carers Revolution for the campaign images page 5 and 19, to see their campaign please visit www.youngcarersrevolution.wordpress.com

Thanks to York Carers Forum for photos page 14 and 20.

Other photos from local and national library sources.

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"One of the most important outcomes of the strategy. If the carer doesn't have support and attention to their physical needs then there would be two people in need of care."

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	Outcome	**Local priority**	**Achievements: July 2011**
1A	**Information**: Carers will have easy access to accurate information and advice	• Provision of easily accessible information and signposting	• Carers Information Pack produced and annually updated • York Carers Centre developing as focal point for information • York Carers Centre, CANDI, York Carers Forum, Young Carers Revolution and City of York Council websites provide information for carers
1B	**Carer identification:** Carers will be recognised and valued for their unique role in supporting the cared for person	• Increase identification of carers in Primary Care (see 4C)	• York Carers Centre contacted all GP surgeries and distributed information in 2010/11 • City of York Council Health Overview Scrutiny Committee completed a carer review in spring 2011 focussing on carer identification

1C	**Young Adult Carers:** Carers will have easy access to accurate information and advice	• Establishment of support for young adult carers aged 18 years + by York Carers Centre	• York Carers Centre provides regular ongoing support to 44 young adults (July 2011)
1D	**Integrated services:** Services and information will be provided in a coordinated way across and within agencies	• Closer joint working and partnerships between health, social care and the third sector • Awareness raising for professionals	• Draft 'Care Pathway for Carers Support' presented to Carers Strategy Group April 2011 • E learning carer awareness raising tools re 'Young Carers' and 'Adult Carers' launched May/June 2011
1E	**Personalised services:** Carers will have access to a range of flexible services that meet their individual needs	• Carer Assessment of Need • Common Assessment Framework *(NB not implemented for adults in York)* • Personal budgets	• Continued increase in numbers of separate carer assessment and review completed (673 in 09/10 and 857 in 10/11) • Carer's role acknowledged in assessment questionnaire for cared for person's personal budget
1F	**Carer involvement:** Carers will be involved in planning and monitoring the services they receive	• Training for carers – Living for Learning • Carer involvement	• One Living for Learning course held in 2009 • Three active carer led forums established and offered ongoing support

National Strategic Outcome Two ***Carers will be able to have a life of their own alongside their caring role***			
	Outcome	**Local priority**	**Achievements**
2A	**Break provision:** Carers should have access to a range of flexible breaks	• Joint plans with NYYPCT re new money for breaks • Review current breaks provision • Personal budgets to enable carers to take breaks	• Breaks review presented to Carers Strategy Group April 2010 • Continued increase in numbers of carers benefiting from Flexible Carer Support Scheme (600 in 09/10 and 680 in 10/11)
2B	**Emergency Card Scheme:** Carers should be better equipped to deal with a crisis and have peace of mind	• Emergency Card Scheme	• Card scheme well established for adults, now includes young carers
2C	**Technology:** Carers should have access to a range of services and support	• Telecare	• Small scheme to promote benefits of telecare for carers completed in 10/11

2D	**Housing, Leisure and Transport:** Carers should have access to a range of services and support	• Discount card scheme	• Carers with Carers Emergency Card and those in receipt of Carers Allowance can access discounts at City of York Council leisure classes and swimming pools • York Carers Centre launched a discount card for carers in December 2010 involving 50 local businesses

National Strategic Outcome Three ***Carers will be financially supported so that they are not forced into financial hardship by their caring role***			
	Outcome	**Local priority**	**Acheivements**
3A	**Income:** Carers should have access to benefits advice	• Welfare benefits advice	• York Carers Centre continues to increase uptake of benefits for carers.
3B	**Employment:** Carers should have access to employment support and vocational training	• Ensure carers in employment are supported • Encourage carer aware employment practice • Make local links with new 'care partnership managers' at Jobcentre Plus	• York Carers Centre Employment Education and Training service established. • York Carers Centre works with employers • City of York Council awarded a Carer Friendly Employer charter mark • Care Partnership Manager a member of Carers Strategy Group

National Strategic Outcome Four ***Carers will be supported to stay mentally and physically well and treated with dignity***			
	Outcome	**Local priority**	**Achievements**
4A	**Prevention:** Carers should have access to appropriate medical advice, and support about their own health needs	• Self-health checklist distribution and evaluation	• Check list piloted and distributed • Business case for back care support for carers compiled and short term development work planned • Need to give advice to carers on moving and handling included in principles for Admissions and Discharge policies circulated to Acute Trusts
4B	**NHS:** Carers needs should be addressed in hospital admission and discharge procedures		• NHS North Yorkshire and York included carers issues in the principles for the Admissions and Discharge Policies for all Acute Trusts • Health passport piloted for Neurology patients includes pages about carers. • York Carers Forum worked with York Hospital to ensure carer recognition at End of Life Pathway

4C	**Primary Care and GPs:** Primary care professionals should identify carers ensuring appropriate support, signposting and referrals	• Update GP resource pack (*Decision made not continue with pack)* • Develop work to improve carer identification and signposting in primary care settings	• York Carers Centre contacted all GP surgeries in York and distributed promotional information • Carer issues included in Dementia Map of Medicine to prompt support of carers
4D	**Emotional Support:** Carers should have support to maintain their well being and reduce stress		

National Strategic Outcome Five ***Children and young people will be protected from inappropriate caring and have the support they need to learn, develop, and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes*.** *(Every Child Matters outcomes: be healthy, stay safe, enjoy and achieve, make a positive contribution, achieve economic well-being)*			
	Outcome	**Local priority**	
5A	**Universal services:** Children will have the support they need to learn develop and thrive	• Support schools in York to support young carers	• York Carers Centre began dedicated work with York Schools in 2009 • Young Carers Revolution produced and publicised a range of carer awareness raising tools
5B	**Targeted support for young carers:** Young carers will be able to make a positive contribution and have their views respected	• Set up a Young Carers Forum	• Young Carers Revolution established as York's carer led forum for young carers

5C	**Whole family support:** Children and young people will be protected from inappropriate caring		• York Carers Centre secured funding for a specialist one year post 2010/11 offering direct support to families and work to support strategic change which enabled the development of the e learning carer awareness raising tools.

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Annex 4

York Carers Strategy Action Plan 2011 - 2015

National Strategic Outcome One ***Recognised and supported as expert care partners***		
	Outcome	**What we need to do**
	Information: Carers will have wider access to accurate information and advice available through a range of communication methods	• Set up a robust system for update and distribution of accessible information for carers, including electronic distribution methods • Decide which are the 'key places' in York where carers information should be available • Develop and distribute public information which is accessible to people who may not recognise themselves as 'carers' • Involve GPs in the provision of information to carers
	Carer identification: Carers will be recognised and valued for their unique role in supporting the cared for person	• Enable professionals to effectively identify carers. • Include carer awareness raising in all workforce development strategies
	Integrated services: Services and information will be provided in a coordinated way across and within agencies	• Ensure all Carers Strategy partners adopt the 'Care Pathway for carers support'

	Personalised services: Carers will have access to a range of flexible services that meet their individual needs	• Adult and Children's Social Services to provide a coordinated approach to assessment for the 'whole family' • City of York Council will reduce length of waiting list for Carers Assessment of Need
	Carer involvement: Carers will be involved in planning and monitoring the services they receive	• Review and increase carer involvement and take appropriate action • Map carer involvement in local health and social care planning networks with attention to the development of Healthwatch
	Equality and social inclusion: All carers will be able to access services and support.	• Ensure information about carers ethnicity is appropriately recorded by City of York Council, York Carers Centre and all Carers Strategy partner organisations to inform future service planning • Use existing contact mechanisms with BME, multi-faith and multi-cultural groups to identify the numbers of carers from BME communities and take appropriate action • City of York Council to review its equalities framework to ensure carers become part of all equality and inclusion work

National Strategic Outcome Two ***Enjoying a life outside caring***		
	Outcome	**What we need to do**
	Break provision: Ensure carers have access to a range of flexible breaks	• Set up a clear framework for provision of breaks for carers which links to self directed support and personalisation • Audit existing services and support • Agree and promote the concept of what a carers break is • Research and adopt good practice • Roll out the Carers Emergency Card to parent carers
	Technology: Ensure carers have access to a range of services and support	• Provide accessible telecare services to adults

National Strategic Outcome Three ***Not financially disadvantaged***		
	Outcome	**What we need to do**
	Income: Ensure carers have access to benefits and financial advice	• Audit current benefits advice services available to carers • Ensure carers can access financial advice when the cared for enters residential care and at end of life
	Employment: Carers should have access to employment support and vocational training	• Monitor City of York Council's implementation of the action plan linked to the 'Carers Friendly Employer' charter mark • Develop links with local businesses • Roll out information about carers employment rights to employees and employers in York

National Strategic Outcome Four *Mentally and physically well; treated with dignity*		
	Outcome	**What we need to do**
	Prevention: Carers should have access to appropriate medical advice, and support about their own health needs **NHS:** Carers needs should be addressed in hospital admission and discharge procedures **Primary Care and GPs:** Primary care professionals should identify carers ensuring appropriate support, signposting and referrals **Emotional Support:** Carers should have support to maintain their well being an reduce stress	• Health commissioners and providers ensure greater consistency around identifying and addressing the needs of carers • Health commissioners will work towards ensuring that all care pathways provide guidance on the information and advice carers will need • To engage with the new NHS Commissioning bodies (Clinical Commissioning Groups) as they develop to promote carers issues and build on existing work in Primary, Community and Acute Care

National Strategic Outcome Five ***Children thriving, protected from inappropriate caring roles***		
	Outcome	**What we need to do**
	Universal services: Children have access to the support they need to learn, develop and thrive	• Set up the Young Carers task group and action plan • Ongoing development of the work now established in schools which supports young carers • Task group to consider York LINk report (March 2011) recommendation: 'Young carers should be given help to get home access to computers'
	Whole family support: Children and young people are protected from inappropriate caring. Young adults have access to appropriate advice in relation to their transition into adulthood.	• Implement the Common Assessment Framework (CAF) as the assessment tool for Young Carers Assessment. • Ensure adult services identify young carers in their assessment processes and paperwork • Ensure effective sources of advice are available to young carers aged 16-18+

Board & Topic		Recommendation of the Scrutiny Committee	Executive/Comments & Recommendations of 26th April 2011	Update on Recommendations as of November 2011
Health Overview & Scrutiny Committee - Carer's Review	**A**	That Health Commissioners and providers ensure that there is greater consistency around how carers are identified and once identified their needs addressed. This would need to include:	Agree subject to assessment of training budgets and accepting that the Council can advise the Hospital Trust but that they are the body charged with responsibilities for activities in the hospital.	The Carers Health Steering Group is a task group of the Carers Strategy Group and works to implement the attached Action Plan (Annex 6).
	i	Training in carer awareness for all health professionals and allied staff		NHS North Yorkshire and York promotes good practice in primary care and acute trusts. The responsibility to deliver training rests with provider organisations.

Board & Topic		Recommendation of the Scrutiny Committee	Executive/Comments & Recommendations of 26th April 2011	Update on Recommendations as of November 2011
	ii	That the hospital looks at extending the innovative approaches they have been piloting and embedding these into standard practices for all admissions and discharges		NHS North Yorkshire and York included carer issues in admissions and discharge principles. The responsibility for implementation rests with the Acute Trust.
	iii	That a written report be provided to the Health Overview & Scrutiny Committee on a six monthly basis in relation to quality indicators that are being monitored in respect of carers		NHS North Yorkshire and York would like clarification about the 'quality indicators' being referred to.

Board & Topic		Recommendation of the Scrutiny Committee	Executive/Comments & Recommendations of 26th April 2011	Update on Recommendations as of November 2011
	B	That the Multi-Agency Carer's Strategy Group identifies where it would be helpful to provide public information about what it means to be a carer and how to access support to enable carers to identify themselves earlier:	Agree	The Carers Information Group: 1 Produces, updates and develops the Carers Information Pack. 2 Is producing a postcard to consult with carers about their views about where information should be available. 3 Is developing promotional information for people who do not necessarily recognise themselves as carers.
	i	Where places are identified carer awareness training should be made available for key workers		The Carers Information Group is planning work to promote the carer awareness e-learning tools with Workforce Development Units in health and social care and other partner organisations.

Board & Topic		Recommendation of the Scrutiny Committee	Executive/Comments & Recommendations of 26th April 2011	Update on Recommendations as of November 2011
	C	That City of York Council reviews its Equalities Framework to ensure that carers become an integral part of all equality and inclusion work and this to include:	Agree that CYC review its Equalities Framework and takes to the next meeting of the Equalities Advisory Group the proposal that a carer representative be invited to join	The revised template (June 2011) for all Equalities Impact Assessments includes 'Carers of older and disabled people' as an additional 'Protected Characteristic'.
	i	Inviting a carer representative to become a member of the Equalities Advisory Group		York Carers Forum are involved in the work of the Equality Advisory Group and carer representatives are attending meetings.

Board & Topic		Recommendation of the Scrutiny Committee	Executive/Comments & Recommendations of 26th April 2011	Update on Recommendations as of November 2011
	D	That health commissioners ensure that all care pathways provide guidance on the information and advice carers will need regarding specific medical conditions as well as sign-posting them to support and advice. This will need to address what the impact might be on:	Agree	Carers issues are incorporated in each individual care pathway as they are developed. Good practice examples include the Dementia Pathway where carers issues are included in the 'Map of Medicine' (Annex 7) and in the Levels of Care model and project (Annex 8).
	i	the Carer		
	ii	The family as a whole		
	iii	**The cared for person**		

Board & Topic		Recommendation of the Scrutiny Committee	Executive/Comments & Recommendations of 26th April 2011	Update on Recommendations as of November 2011
	E	That Adult Social Services develop a clear pathway, which provides an integrated approach to assessment for the whole family whilst recognising the individual needs within the family and the impact of caring on the carer	Agree	1 ACE's new Adult Assessment and Safeguarding process includes in its principles *'Carer awareness is an integral part of the process for all staff and all teams. Staff and teams should maintain a focus on carers at every point in the process.' 2* Work to combine support planning processes for customers and carers has been agreed. 3 A review of the Flexible Carer Support Scheme which provides direct payments to support carers is underway, aiming to improve efficiency and effectiveness in delivering support to carers within the resources we have.4 The lead officer for Young Carers is currently working with Adult Services Group Manager to establish how young carers can best be identified by Adult Social Services.

Board & Topic		Recommendation of the Scrutiny Committee	Executive/Comments & Recommendations of 26th April 2011	Update on Recommendations as of November 2011
	F	To continue to promote carer awareness, an annual update on the Carer's Strategy for York be presented to the Health Overview & Scrutiny Committee and thereafter to the Cabinet member for Health & Adult Social Services	Agree that the Cabinet Member for Health & Social Services should receive an annual report updating the Carer's Strategy and that the same report should be submitted to the Health Overview & Scrutiny Committee	The annual report updating the Carers Strategy is included in the main report.

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Carers Health Steering Group
Annex 6
York Carers Strategy Action Plan 2009 - 12 Review of Progress

National Strategic Outcome Four **Carers will be supported to stay mentally and physically well and treated with dignity (Targets agreed by Carers Health Steering Group)**					
	Outcome	**Local priority**	**Target 2011-15**	**Key achievements**	**Outstanding**
4A	**Prevention:** Carers should have access to appropriate medical advice, and support about their own health needs	1. Self-health checklist distribution and evaluation	1.Update and identify funding for reprint. Distribution by March 2012	1. Carers Forum and Carers Centre updated, distributed and received feedback.	1.Agreement needed on next steps. Meeting Aug 15th .
		2. To learn from the national demonstrator sites and adapt action plan if appropriate.	2. Carer leads to report any findings at future meeting	2. CYC Carers lead offered to do a brief report on findings and feedback	2.CYC Carers lead to feedback at next meeting
		3. Explore opportunities for Back care training.	3. Funding identified and offered by March 2012.	3. Discussions held at Strategy group as to possibility of using reablement non recurrent funding for a 2 (?) year project	3.York Programme Board to agree to funding.

		4. Ensure advice on lifting and handling given to carers on discharge of cared for person from Hospital. 5. Ensure carers issues are considered as part of the levels of Care as it develops	4. Included in discharge policy by September 2011. 5. Carers issues included in the service specification for the levels of care by December 2011.	4. Included in the principles for Admissions and Discharge policies and circulated to all Acute Trusts. 5.Draft service specification complete	4.Need confirmation from York Acute Trust they are signed up to the principles. 5.Need agreement and sign off and implementation
4B	NHS: **Carers needs should be addressed in hospital admission and discharge procedures** including mental health	1.To include recommendations of ADASS report 'Carers as Partners in Hospital Discharge' in discharge policy and contracts for acute care http://www.adass.org.uk/index.php?option=com_content&view=article&id=504&Itemid=386 2. To pilot the Carers Passport within YDFT, evaluate and recommend roll out if shown to be successful	1. Inclusion in discharge policies and contracts by September 2011 for implementation from April 2012 2. Pilot to take start by Dec 2010 Recommendations completed by April 2012	1. Included in the principles for Admissions and Discharge policies and circulated to all Acute Trusts. 2. Need update from YDFT	1. Need confirmation from York Acute Trust they are signed up to the principles. 2. YDFT to feed back at next meeting in Aug

4C	**Primary Care and GPs:** Primary care professionals should identify carers ensuring appropriate support, signposting and referrals, **including those supporting people with mental health problems.**	1. Promote carers issues with GP practices by utilising the Royal College of GPs action guide for GPs and their teams. 2. Utilise opportunities for input to GP and community staff training and development events to raise carers issues. 3. People with mental health problems receiving support from Primary Care Services: ensure their carers receive appropriate support.	1.Distribute amended action guide to all GP practices by March 2012 2. Input to training for primary care staff as opportunities arise 3. Raise issues with York Mental Health Modernisation and Partnership Board Health by January 2012 . Explore use of Mental Health Support Line	1. 2. 3. E-mail sent to chair of MH Modernisation and Partnership Board to request agenda item at future meeting to discuss.	1. Discussions with CCG rep to agree best approach to distribute guidance. 2. Discussions with CCG rep to identify opportunities to include Carers issues in training. 3. Await response from MH Board.

		4. Adapt the Royal College of Psychiatrists /Princess Royal Trust for Carers Checklist for Psychiatrists – working in partnership with carers, to promote with CMHT / Geriatricians	4. Distribute amended checklist by March March 2012.	4.	4. Discussions to be held between NHS Commissioners and MH providers and Acute Trust to identify current practice and option of checklist.
4D	**Emotional Support:** Carers should have support to maintain their well being and reduce stress	1. Audit support and services available to carers. Identify gaps in provision and consider options. 2. Support for ex-carers to tie in with End of Life Strategy	1. Audit completed by March 2012 2. Develop end of life recommendations for supporting carers	1. Lack of capacity to undertake this at present 2.	1. 2. Links to be made with York / Selby End of Life Strategy Group.

4E	**Young Carers**	Carers Health Steering Group and Outcome Five lead to address how the health needs of young carers can be meet, and action accordingly. Priorities identified: 1. Emotional support and CAMHS 2. Raise awareness of GPs through Young Carers Revolution DVD 3. Staying healthy – self health checklist for young carers.	1. TBC 2. TBC 3. TBC		Carers Health Steering Group / Outcome 5 lead.

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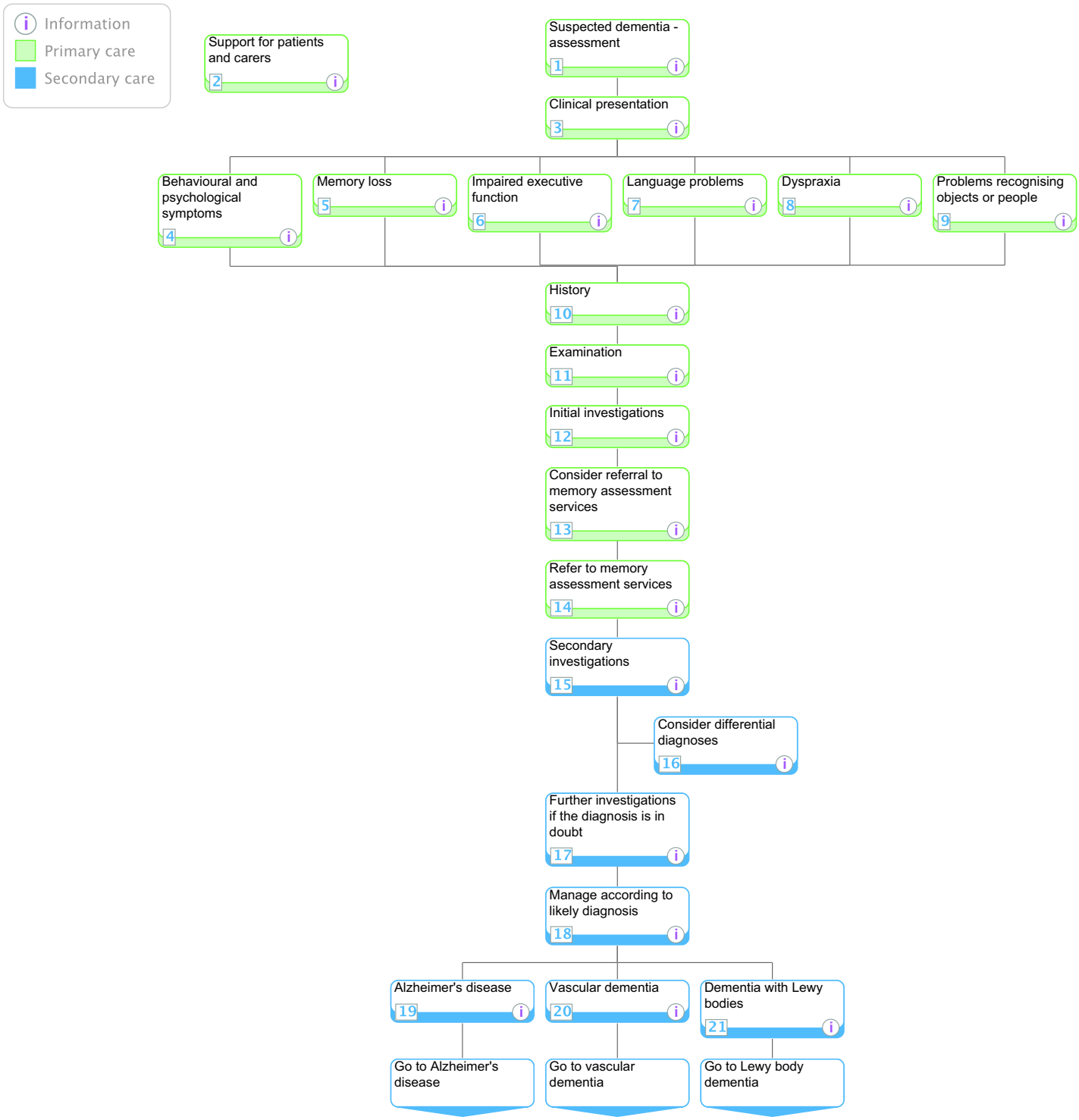
Dementia - assessment - DRAF

Mental Health > Other > Dementia - DRAFT



Locally reviewed: Due for review: Printed on: 03-Aug-2010

IMPORTANT NOTE
Locally reviewed refers to the date of completion of the most recent review process for a pathway. All pathways are reviewed regularly every twelve months, and on an ad hoc basis if required. Due for review refers to the date after which the pathway on this page is no longer valid for use. Pathways should be reviewed before the due for review date is reached.

Dementia - assessment - DRAF

1 Suspected dementia - assessment

Quick info:

Scope:

- diagnosis of Alzheimer's disease, vascular dementia and dementia with Lewy bodies
- information on treatment to reduce cognitive, behavioural and psychological symptoms in adults

Out of scope:

- frontotemporal dementia (Pick's disease) and dementia due to other medical causes (eg. HIV, Parkinson's disease, head trauma) or substance abuse

Definition:

- dementia is a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function
- there is a decline in activities of daily living and impairment in social function
- there are different causes of dementia, the most common three being:
  - Alzheimer's disease:
    - characterised by gradual and progressive onset of cognitive impairment, including memory loss and leading to a decline in daily and social function
  - vascular dementia (due to small vessel disease or multiple infarcts and often co-occurring with other vascular risk factors)
  - dementia with Lewy bodies is characterised by:
    - impairment of executive function
    - parkinsonism
    - visuospatial dysfunction
    - fluctuation
    - visual hallucinations

Prevalence:

- dementia is principally a disease of the elderly affecting:
  - 6% of people over age 65 years
  - 30% of people over age 90 years
- Alzheimer's disease and vascular dementia are the most common forms of dementia
- Alzheimer's disease accounts for more than 60-65% of the cases of dementia
- dementia with Lewy bodies accounts for up to 15% of dementia in the elderly

Risk factors:

- causes of Alzheimer's and dementia with Lewy bodies are not fully understood
- risk factors for Alzheimer's disease include:
  - genetic
  - older age
  - female gender
  - head trauma
  - hypertension
  - cholesterol
  - obesity
  - diabetes
  - atrial fibrillation
  - smoking
  - past history of depression
- vascular dementia is related to stroke and cardiovascular risk factors (older age, smoking, diabetes, hyperlipidaemia, hypertension)

Prognosis:

- Alzheimer's disease is often difficult to diagnose in the early stages due to an insidious onset followed by a progressive decline in cerebral function
- people with Alzheimer's disease have an average life expectancy after diagnosis of approximately 8-10 years
- vascular dementia often follows a stepwise, fluctuating course although the onset can be gradual in those with subcortical ischaemic vascular dementia
- most people with dementia will eventually require assistance to perform even simple tasks

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

Warner J, Butler R, Arya P. Dementia. Clin Evid 2004; 1361-90.

Scottish Intercollegiate Guidelines Network (SIGN). Management of patients with dementia. Clinical Guideline 86. Edinburgh: SIGN; 2006.

2 Support for patients and carers

Quick info:

Hambleton & Richmondshire

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-H&R-CarerSupport.pdf

Selby

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-Selby-CarerSupport.pdf

Contact number for details of North Yorkshire Carer's Emergency Card - 0845 872 7374

York

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-Y-CarerSupport.pdf

3 Clinical presentation

Quick info:

North Yorkshire Carer's Assessment: Adult Community Services Assessment Line - 0845 034 9410

Selby Only

Selby Carers' Centre gives support and do carer's assessment. Unit 18, Ousegate, Selby YO8 4NN. Tel: 01757 292532. E-mail: selbycarers@wilfward.org.uk. Web: www.wilfward.org.uk

York Only

York Carer's Centre can signpost people to appropriate support and services for carers, including information on Carer's Assessments of Need, the Carer's Emergency Card and practical respite support. York Carer's Centre, 17 Priory Street, York YO1 6ET. Tel: 01904 715490

A Quick Guide to Services for Carers:

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-Y-QuGdCarers.pdf

Carer's Assessment of Need: If you provide regular and substantive care for someone, you can have a carer's assessment to discuss the help you need. It is an opportunity to talk about your caring role. City of York Council undertakes the assessment and will look at the support available from a range of organisations. A small fund has been set up to provide flexible support for carers of adults to sustain them in their caring role. Please contact: Initial Assessment and Safeguarding Team, P O Box 402, 10-12 George Hudson Street, York YO1 6ZE. Tel: 01904 555111

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-Y-CarerAssmnt.pdf

Carer's Emergency Card: is a partnership between York Carers Centre and City of York Warden Call Service. The scheme is free, has open access and allows carers to register an emergency plan. If an unplanned situation or emergency happens, the person they care for will not be left at risk. Carers are given an emergency carer's card which alerts other people to the fact that they are a carer. Tel: 01904 715490

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-Y-CarerEmgCrdLft.pdf

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-Y-CarerEmCdforContacts.pdf

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-Y-CarerEmgCrdRegFm.pdf

Age Concern provides advice, information and practical help for older people over 60 and their carers, including benefits advice, community befriending and support services. The "In Safe Hands" scheme provides short breaks for carers of older people, including those with dementia. Tel: 01904 627995

Crossroads provides practical help and short breaks for carers, including carers of people with dementia. Tel: 01904 790200

National Guidance

- dementia is suggested by an impairment in two or more cognitive functions, such as memory, possibly with behavioural alteration, and the subsequent decline in the ability to carry out activities of daily living and normal social interaction
- diagnosis of dementia is determined by:
  - the presence of memory loss and at least one of the following:
    - apraxia
    - agnosia (problems recognising objects or people)
    - aphasia (impaired language comprehension and/or speech difficulties)
    - impaired executive function
  - deterioration from person's previous level of functioning and significant effect upon their daily life
  - not explained by other systemic causes or psychiatric illness
- mild cognitive impairment (MCI) is determined by impairment in one or more cognitive domains not associated with activities of daily living or social function
- healthcare staff should consider referring people who show signs of MCI for assessment by memory assessment services to aid early identification of dementia – more than 50% of people with MCI later develop dementia

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.

National Institute for Health and Clinical Excellence (NICE). Dementia: Supporting people with dementia and their carers in health and social care. CG42. London: NICE; 2006.

4 Behavioural and psychological symptoms

Quick info:

- dementia can present with psychiatric symptoms such as:
  - depression
  - delusions
  - disinhibition
  - apathy

5 Memory loss

Quick info:

- short- and long-term memory loss is a characteristic feature of dementia and a required characteristic for diagnosis
- short-term memory is usually affected to a greater extent than long-term memory which is characteristic only late in the course of dementia

Worried About Your Memory leaflet:

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-WAYMLft.pdf

References:

American Academy of Neurology (AAN). Practice parameter: diagnosis of dementia (an evidence-based review). St. Paul, MN: AAN; 2001.

Alberta Clinical Practice Guidelines Program. Cognitive impairment: Dementia. Diagnosis to management. Edmonton: Alberta Medical Association; 2005.

Alberta Clinical Practice Guidelines Program. Cognitive impairment: Is this dementia? Symptoms to diagnosis. Edmonton: Alberta Medical Association; 2005.

American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

6 Impaired executive function

Quick info:

- deterioration in ability to plan, initiate, judge, carry out and stop complex behavioural tasks is commonly observed

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.

7 Language problems

Quick info:

- deterioration in language comprehension and speech (aphasia) is a common feature of dementia

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.

8 Dyspraxia

Quick info:

- despite intact comprehension, sensory faculties and motor abilities, people with dementia often exhibit deterioration in execution of motor activities, eg. dressing oneself

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.

9 Problems recognising objects or people

Quick info:

- deterioration in ability to recognise objects or people despite intact sensory function (agnosia) is a feature

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.

10 History

Quick info:

History:

- ideally ask the patient questions and then speak either together or separately with a family member or carer who is able to provide additional information
- assess onset and progression of dementia symptoms
- medical history, including current health and medication
- check for:

- depression
- acute onset indicating confusional state

- consider non-cognitive effects:
  - affective symptoms
  - behavioural or personality change
  - psychosis
  - disinhibition
  - feelings of restlessness or agitation
  - aggressive behaviour
  - patterns and triggers of agitated behaviour
- consider other mental health disorders, eg. sleep disturbance, vivid or physically acted out dreams (REM sleep disorder), suicidal ideation, psychoses (hallucinations and delusions)
- consider comorbid physical illness which may impact on cognition
- physical symptoms such as movement disorders
- social status
- risk (suicide risk, potential for violence, neglect and abuse, risk of falls)
- consider any medication that may adversely affect cognitive functioning
- enquire about driving, continence and alcohol consumption

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

McGonigal-Kenney ML, Schutte DL. Non-pharmacologic management of agitated behaviors in persons with Alzheimer disease and other chronic dementing illnesses. University of Iowa Gerontological Nursing Interventions Research Center. Iowa City, IA; 2004.

Scottish Intercollegiate Guidelines Network (SIGN). Management of patients with dementia. Clinical Guideline 86. Edinburgh: SIGN; 2006.

11 Examination

Quick info:

Examination: (examination criteria below mandatory prior to referral to secondary care):

- perform mental state examination using a standardised instrument to assess cognitive function such as the Mini Mental State Examination (MMSE):
  - when interpreting test results consider, where possible, the patient's educational level and prior capacity, and any sensory impairment or other comorbidity that may be affecting performance
- assess hearing and vision and ensure patients are using reading glasses if necessary when carrying out tests like MMSE
- perform a full physical examination considering any differential causes
- use DSM-IV, ICD-10 or other specific criteria for diagnosis, eg. NINCDS-ADRDA, NINDS-AIREN, International Consensus criteria for dementia with Lewy bodies

Consider:

- other standardised testing or rating scales, including those for mood, memory and cognitive functioning, eg. Addenbrooke's Cognitive Examination may improve initial cognitive testing
- directly observing behaviour, eg. consider observing patient imitating putting on a shirt, waving goodbye, brushing teeth etc. to test for apraxia
- assessing reports from informants (eg. carers) through interview
- if vascular dementia is suspected, look for other signs of vascular disease (check peripheral pulse, listen for carotid bruit, consider carotid doppler)
- normal neurology or non-localised findings which may be associated with Alzheimer's disease
- focal neurology associated with vascular dementia, parkinsonism associated with dementia with Lewy bodies

Also assess:

- carers (coping, knowledge, physical and mental health, relationship to patient)

- decision making capacity and identify surrogate decision maker in a sensitive way
- as far as possible, the cultural values and norms of the family to ensure that care is tailored sensitively

North Yorkshire Carer's Assessment: Adult Community Services Assessment Line - 0845 034 9410

Selby Only

Selby Carers' Centre gives support and do carer's assessment. Unit 18, Ousegate, Selby YO8 4NN. Tel: 01757 292532. E-mail: selbycarers@wilfward.org.uk. Web: www.wilfward.org.uk

York Only

York Carer's Centre can signpost people to appropriate support and services for carers, including information on Carer's Assessments of Need, the Carer's Emergency Card and practical respite support. York Carer's Centre, 17 Priory Street, York YO1 6ET. Tel: 01904 715490

A Quick Guide to Services for Carers:

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-Y-QuGdCarers.pdf

Carer's Assessment of Need: If you provide regular and substantive care for someone, you can have a carer's assessment to discuss the help you need. It is an opportunity to talk about your caring role. City of York Council undertakes the assessment and will look at the support available from a range of organisations. A small fund has been set up to provide flexible support for carers of adults to sustain them in their caring role. Please contact: Initial Assessment and Safeguarding Team, P O Box 402, 10-12 George Hudson Street, York YO1 6ZE. Tel: 01904 555111

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-Y-CarerAssmnt.pdf

Carer's Emergency Card: is a partnership between York Carers Centre and City of York Warden Call Service. The scheme is free, has open access and allows carers to register an emergency plan. If an unplanned situation or emergency happens, the person they care for will not be left at risk. Carers are given an emergency carer's card which alerts other people to the fact that they are a carer. Tel: 01904 715490 - See node 2 for details

Age Concern provides advice, information and practical help for older people over 60 and their carers, including benefits advice, community befriending and support services. The "In Safe Hands" scheme provides short breaks for carers of older people, including those with dementia. Tel: 01904 627995

Crossroads provides practical help and short breaks for carers, including carers of people with dementia. Tel: 01904 790200

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

McGonigal-Kenney ML, Schutte DL. Non-pharmacologic management of agitated behaviors in persons with Alzheimer disease and other chronic dementing illnesses. University of Iowa Gerontological Nursing Interventions Research Center. Iowa City, IA; 2004.

Scottish Intercollegiate Guidelines Network (SIGN). Management of patients with dementia. Clinical Guideline 86. Edinburgh: SIGN; 2006.

National Institute for Health and Clinical Excellence (NICE). Dementia: Supporting people with dementia and their carers in health and social care. CG42. London: NICE; 2006.

12 Initial investigations

Quick info:

Perform a basic dementia screen at the time of presentation, including:

- full blood count
- ESR, CRP, Lipid profile
- urea, electrolytes and creatinine
- glucose
- liver function
- calcium
- serum vitamin B12 and folate levels
- thyroid function tests

Consider performing:

- midstream urine test if considering acute confusional state
- chest X-ray or electrocardiogram if pulse is <60 or serious cardiovascular history

Consider screening for comorbidities, such as:

- depression

- syphilis or HIV – not routinely indicated; only perform if there is clinical suspicion

Unusual presentations, particularly in young people, may indicate rare disease, eg. tumours, frontotemporal dementia or normal pressure hydrocephalus.

Refer to memory assessment services for appropriate further investigations.

Refer patients with memory problems of uncertain significance to memory assessment services.

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

American Academy of Neurology (AAN). Practice parameter: diagnosis of dementia (an evidence-based review). St. Paul, MN: AAN; 2001.

American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.

Scottish Intercollegiate Guidelines Network (SIGN). Management of patients with dementia. Clinical Guideline 86. Edinburgh: SIGN; 2006.

National Institute for Health and Clinical Excellence (NICE). Dementia: Supporting people with dementia and their carers in health and social care. CG42. London: NICE; 2006.

13 Consider referral to memory assessment services

Quick info:

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-Dep-guide.pdf

14 Refer to memory assessment services

Quick info:

Hambleton & Richmondshire

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-H&R-refcon.pdf

Selby & York

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-S&Y-refcon.pdf

15 Secondary investigations

Quick info:

Perform:

- non-contrast magnetic resonance image (MRI) or CT scan (MRI is the preferred modality for the assessment of dementia, but CT can be used):
  - for diagnostic evaluation
  - to exclude other cerebral pathologies
  - to help establish the subtype diagnosis
- request view of temporal lobe in CT scan
- carry out comprehensive assessment (as detailed in the history and examination node), including further neuropsychological assessment carried out by a specialist at secondary care level

Reference:

National Institute for Health and Clinical Excellence (NICE). Dementia: Supporting people with dementia and their carers in health and social care. CG42. London: NICE; 2006.

16 Consider differential diagnoses

Quick info:

Consider differential diagnoses and comorbidities at the time of diagnosis and at regular intervals subsequently, such as:

- depression

- psychosis or schizophrenia
- delirium
- amnestic disorder
- head trauma
- substance abuse

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.

Scottish Intercollegiate Guidelines Network (SIGN). Management of patients with dementia. Clinical Guideline 86. Edinburgh: SIGN; 2006.

17 Further investigations if the diagnosis is in doubt

Quick info:

- if the diagnosis is in doubt, HMPAO single photon emission CT scan (SPECT) may be used to help differentiate Alzheimer's disease from frontotemporal dementia and vascular dementia
- consider FDG positron emission tomography (FDG PET) if HMPAO SPECT is not available
- FP-CIT SPECT is the preferred imaging modality if dementia with Lewy bodies is suspected
- HMPAO SPECT is not helpful in people with Down's syndrome
- cerebrospinal fluid examination should be used if Creutzfeld-Jakob disease or other form of rapidly progressive dementia is suspected
- electroencephalography is not recommended as a routine investigation in people with dementia
- electroencephalography can be considered if a diagnosis of delirium, frontotemporal dementia or Creutzfeld-Jakob disease is suspected or in the assessment of seizure disorder in those with dementia
- brain biopsy should only be considered in highly selected people whose dementia is thought to be a potentially reversible condition that cannot be diagnosed in any other way

Reference:

National Institute for Health and Clinical Excellence (NICE). Dementia: Supporting people with dementia and their carers in health and social care. CG42. London: NICE; 2006.

18 Manage according to likely diagnosis

Quick info:

- delirium, delusions and depression can complicate diagnosis of dementia
- diagnosis of particular type of dementia must be according to standard diagnostic criteria and should be made in a specialist centre by appropriately trained professionals
- many cases of dementia may have mixed pathology (particularly Alzheimer's and vascular dementia); such cases should be managed according to the condition that is thought to be the predominant cause

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.

National Institute for Health and Clinical Excellence (NICE). Dementia: Supporting people with dementia and their carers in health and social care. CG42. London: NICE; 2006.

19 Alzheimer's disease

Quick info:

- memory loss and disturbance in executive functioning in the presence of at least one of the following:
-
  - aphasia
  - apraxia
  - agnosia
- characterised by gradual onset and continuing cognitive decline
- effect upon the person's social and daily functioning
- other causes of dementia are excluded, eg.:
  - central nervous system conditions
  - systemic disease
  - substance abuse
- diagnosis of Alzheimer's disease is primarily based on clinical features and after excluding other systemic and brain disorders that could account for the cognitive impairment
- the preferred diagnostic criteria (as recommended by the National Institute for Health and Clinical Excellence [NICE]) are the NINCDS/ADRDA; alternatively the DSM-IV and ICD-10 may be used

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-WhatisAlzheimers.pdf

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-WhatisDementia.pdf

References:

American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.

Scottish Intercollegiate Guidelines Network (SIGN). Management of patients with dementia. Clinical Guideline 86. Edinburgh: SIGN; 2006.

20 Vascular dementia

Quick info:

- memory loss and at least one of the following:
  - aphasia
  - apraxia
  - agnosia; or
  - disturbance in executive functioning
- memory is variably affected
- the main cognitive effects are in attentional dysfunction, executive dysfunction and slowed information processing
- a gradual progression can occur in subcortical disease
- effect upon social and daily function
- no other systemic or psychiatric cause
- associated with cerebrovascular disease
- typically more abrupt onset – often stepwise, fluctuating decline in function
- usually a temporal relationship between vascular disease and dementia symptoms
- evidence of current and older lesions should be detectable on CT scan and magnetic resonance image (MRI)
- focal neurological signs (gait anomalies, hemiparesis, etc.)
- compatible history, eg. presence of risk factors, past transient ischaemic attack (TIA) or cerebrovascular accident (CVA), associated ECG changes
- the preferred diagnostic criteria (as recommended by the National Institute for Health and Clinical Excellence [NICE]) are the NINDS-AIREN; alternatively the DSM-IV and ICD-10 may be used

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-WhatisVascD.pdf

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-WhatisDementia.pdf

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.

American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.
Scottish Intercollegiate Guidelines Network (SIGN). Management of patients with dementia. Clinical Guideline 86. Edinburgh: SIGN; 2006.

21 Dementia with Lewy bodies

Quick info:

- memory loss and at least one of the following:
  - aphasia
  - apraxia
  - agnosia; or
  - disturbance in executive functioning
- progressive cognitive decline, particularly affecting visuospatial and executive functioning combined with:
  - fluctuation
  - cognition and parkinsonism
  - recurrent and persistent visual hallucinations
- no other systemic or psychiatric cause
- similar progressive decline as in Alzheimer's but with parkinsonian features (eg. bradykinesia, tremor) and prominent psychotic symptoms (visual hallucinations, delusions)
- marked sensitivity to extrapyramidal adverse effects of antipsychotic medication
- neuroleptic sensitivity
- REM sleep behaviour disorder
- may be history of repetitive falls and syncope
- the preferred diagnostic criteria (as recommended by the National Institute for Health and Clinical Excellence[NICE]) are the International Consensus Criteria for Dementia with Lewy Bodies

http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/
http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-WhatisDwithLewyBodies.pdf
http://www.nyypct.nhs.uk/AdviceInformation/ReferralToolkit/_MoM_docs/Dem-WhatisDementia.pdf

References:

American Psychiatric Association (APA). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. Arlington, VA: APA; 1997.
American Psychiatric Association (APA). Diagnostic and statistical manual of mental disorders. 4th edn (DSM-IV). Arlington, VA: APA; 2006.
Scottish Intercollegiate Guidelines Network (SIGN). Management of patients with dementia. Clinical Guideline 86. Edinburgh: SIGN; 2006.

Dementia - assessment - DRAF

Key Dates

Due for review:
Locally reviewed: , by
Updated: 05-May-2010

Annex 8

SERVICE SPECIFICATION

Service	**Levels of Care (levels 2 – 4)**
Commissioner Lead	
Provider Lead	
Period	

Specification Version Control			
Version	**Date**	**Lead**	**Significant Changes**
1	25/05/2011	AB	
2	10/07/2011	AB	Amended following consultation period
3	08/08/2011	AB	Further amendments following consultation
4	11/08/2011	AB	Amendments agreed at LOC Steering Group meeting

1. Purpose

1.1 Aims

'Levels of Care' is a service model that determines the most clinically suitable placement based on the provision of high quality care in settings that are most appropriate to people's needs via an integrated approach between health and social care organisations Its specific aims are to:

Deliver services to people who would otherwise face unnecessary prolonged hospital stays within agreed timescales.
Maximise independence and enable service users to resume living at home safely in a time efficient manner
Provide multi-disciplinary, seamless care closer to a person's home, reducing avoidable hospital admission and avoiding delays in discharge and reducing avoidable nursing and residential care admissions
Incorporate cross-professional and cross-provider working and improving health and social care outcomes
Provide a system that is flexible enough to meet individual service user

needs, focusing on pro-active care co-ordination, supported self-care, prevention so patients achieve optimum outcomes and health education aiming to reduce relapse and hospital admissions.
Provide improved service user experiences.
Provide more cost effective care.
Focus on a preventative agenda aimed at maximising independence and reducing reliance/delaying need for longer term health and social care services.

1.2 Evidence Base

The White Paper 'Our Health, Our Care, Our Say: A New Direction for Community Services' (DH 2006) describes opportunities to provide care differently, out of hospital, in communities and people's homes, where they can access safe and convenient care. Intermediate care guidance (DH 2001) and National Services Frameworks for older people and long term conditions also provide evidence for Levels of Care type service provision. These indicated a requirement for a new layer of care between primary and specialist services, which would provide integrated services to:

- ✓ Promote faster recovery from illness.
- ✓ Prevent unnecessary acute hospital admissions.
- ✓ Support timely discharge.
- ✓ Maximise independent living.

They also indicated that this type of care could:

- ✓ Be targeted at people who would otherwise face unnecessary prolonged hospital stays.
- ✓ Be provided on the basis of a comprehensive holistic assessment, resulting in a structured individual care plan that involves active treatment and rehabilitation.
- ✓ Be designed to maximise independence and to enable individuals to remain or resume living at home.
- ✓ Involve short term interventions, typically lasting no more than 6 weeks and frequently as little as 1-2 weeks or less.
- ✓ Involve cross-professional working, within the framework of the single assessment process, a single professional record and shared protocols.

MCAP (Medical Care Appropriateness Protocols) based audits undertaken during 2010/2011 indicated that a number of patients were occupying a hospital bed when they were deemed medically fit to be discharged to a community based health/social care service.

The NHS Improvement Plan (DH 2004) places emphasis on the ability of the NHS to care for people in the community, calling for 'fewer emergency admissions which cause anxiety for patients and are a poor use of hospital resources'.

The report 'Getting the Basics Right' (DH 2007) summarised the observation of 14 projects in five healthcare communities. The aim of their work was to identify the conditions that had to be met to enable shifts in care. The factors affecting the ability to bring about shifts in care were identified as:

- Receptive organisational and policy contexts in which shifts were attempted.
- Organisational leadership and sponsorship of service improvement.
- Action to overcome cultural barriers to change and improvement.
- Sufficient time to make shifts, particularly during a period of organisational change.
- Arrangements for sustaining shifts and scaling them up, including developing business cases and specifications.

The Kings Fund (Sigh and Ham 2005) indicated that systems in which care co-ordination is a central component tend to be associated with lower costs, as well as better outcomes and higher patient satisfaction.

'Where next for the NHS reforms?' (Kings Fund, 2011) indicated that the NHS is faced with the major challenges of using resources more efficiently and of meeting the needs of an ageing population in which chronic medical conditions are increasingly prevalent. It indicated that the key task is to implement a new model of care in which clinicians work together more closely to meet the needs of people and to co-ordinate services. This model of integrated care should focus much more on preventing ill health, supporting self care, enhancing primary care, providing care in people's homes and the community, and increasing the co-ordination between primary care teams and specialists and between health and social care.

1.3 General Overview

The Levels of Care model addresses the major challenge of using resources more efficiently whilst meeting the needs of an increasingly ageing local population in which chronic conditions are increasingly prevalent. It is a model in which professionals and clinicians from health and social care organisations work together more closely together to meet the needs of the population and to co-ordinate services. Thus moving beyond fragmentation between providers and services to effective co-ordination around the needs of the community.

There are fours levels within this model namely:

Level 1: Acute Care

The aim of this level is to arrest or control and illness, injury or condition.

Level 2: Sub Acute Care

A step-up or step-down treatment which further refines a care plan whilst managing co-occurring conditions when the primary complaint has been arrested or controlled, or is stable.

Level 3: Intermediate Care (facility based)

A step-up or step down unit in a care environment with intermittent input from a range of health professionals. Will either initiate or finish a course of treatment where the frequency or complexity cannot be managed in the home or where the service user has problems with activities of daily living, including transfer, mobility and safety and which cannot be addressed by home-based support.

Level 4: Intermediate Care (home based)

A service to assess, initiate, maintain or complete a course of treatment that requires supervision but where the individual can be supported at home.

For the purposes of this specification we will be dealing with Levels 2 to 4.

1.4 Objectives

Deliver a pathway of care across all levels to ensure seamless, risk managed care, with reduced duplication of assessment and diagnostics and enhanced communication.

Increased integrated working between health and social care to deliver the levels of care pathway.

Provision of an integrated, jointly appointed and singularly managed, multi-skilled community team delivering robust health and social care outcomes and high levels of service user satisfaction.

Increase the prevention of unnecessary admissions (including readmissions) to hospital of people in crisis, who could safely be looked after elsewhere within the levels of care pathway.

To facilitate the timely discharge of service users from any of the services within the levels of care pathway (e.g. from hospital for those who no longer

require acute medical intervention).

Implementation of a robust system to measure the performance within the levels of care pathway, meeting commissioner performance monitoring requirements.

Work towards developing the capability to share service user level data between health and social care.

The levels of care pathway will be flexible enough to incorporate any future technological innovations.

Any care planning should have, as its ultimate aim, to get people in their own home as soon as possible i.e. get people back to optimum health in order to assist them towards independent living over a short period of time.

Implementation of a single assessment process and use of individualised care plans thus developing the capability to share data at an individual level between health and social care organisations. In developing this process the feasibility of developing an electronic care plan will be considered.

Accurate recording for individual outcomes to show improvement in individual quality of life following involvement of the Levels of Care service

Reduction of unnecessary handover/contacts with separate health and social care staff

Improved support for carers to carry out their caring role effectively

1.5 Expected Outcomes

Improved access to services throughout the levels of care pathway through the delivery of seamless care and services at the appropriate time, place and by the most appropriate professional(s).

Enhanced level of clinical and social care outcome for individuals through implementation of seamless, risk managed levels of care pathway, reduced duplication of assessment, diagnostics and the sharing of information, facilitating the delivery of efficient and effective services.

An increased number of people remaining in their own home and maintaining their independence

Enhanced service user and carer experience, satisfaction and quality of life both through being healthier and spending less time in hospital; this through a process of delivering proactive approaches focussed on providing individuals with the knowledge and skills to facilitate self-care, well-being and promote independence.

Deliver high standards relating to speed of response to identified need.

Reduction in admissions to acute settings.

Reduction in length of stay in acute settings through an improvement in patient throughput.

Reduction in current levels of acute bed base.
Reduction in the number of people being admitted to residential/nursing care from a hospital setting.
Increase in the number of older people with mental health problems, including dementia, receiving appropriate care, reablement and support to live at home.
Increased independence and therefore reduced allocated care hours through provision of technologies like telecare/telehealth.
To facilitate fast track for people who wish to die at home.
Increase of early hospital release days due to installation of minor adaptations, reduction in trip hazards and/or installation of telecare/telehealth equipment.

2. Scope

2.1 Service Description

Level 2

A step up or step down unit (ideally in a community setting) to further refine a treatment plan whilst managing co-occurring conditions when the primary complaint has been arrested, controlled or is stable.

Rehabilitation goal is to restore as much function as possible and to either discharge to home or transfer the service user to a lower level of care.

Palliative care goal is to support patient to achieve their preferred place of care and death

Diagnostics should be available onsite or easily accessible on demand.

For people who are sufficiently medical stable and therefore do not require consultant care input two or three times a week but do require skilled nursing and/or therapy input on a relatively intensive basis, and regular medical input and / or more specialist rehabilitation. This may be provided in community hospitals or in identified sub-acute wards on acute hospital sites.

Essential criteria: Service users medically stable
Service user requires medical review every 2 – 3 days
Nursing intervention at least 4 hourly

Clear pathways and protocols for stepping up or down care
Staffed to recommended levels
Clear leadership and lines of responsibility
Multi-disciplinary teams and meetings to discuss the care of the individual
Access to specialist care and advice where needed

Level 3

A step up or step down unit to initiate or finish a course of treatment where the frequency or complexity cannot be managed in the home (usually greater than 3 visits a day and/or high level therapy problems requiring equipment, resources and facilities), or where the service user has problems with activities of daily living, including transfer, mobility and safety.

Rehabilitation objective is to initiate, maintain and complete a programme of therapy so the service user can return home with maximum functional capability.

For people who no longer require skilled nursing input above the level that can be provided by a community team, but do require an ongoing period of recuperation or rehabilitation, which is not necessarily a social care need, and whose care needs and / or personal circumstances mean that they cannot yet be supported at home. These are care-led beds, with nursing and therapy input from the community team as in level 4.

Level 3 will be delivered by an integrated health and social care community team based in the community with clear links to other pathways, processes and organisations (this team will also cover Level 4).

Essential criteria: Service user requires low level of nursing input.
Care level same as level 4 but cannot be managed via home-based support.
Medical care to be provided by primary care when required.
Interventions to be provided by OT's, physiotherapists or therapist technician once or twice per day.
Health or social care needs that can be delivered by a multi-skilled team.

Level 4

Level 4 service aims to initiate, maintain or complete a course of treatment that requires supervision, but where a person can be safely supported at home. The goal being to maximise independence whilst minimising dependency on ongoing

services. Provision will be accessed through a central point and be home based. It will include a rapid response element within a maximum timescale of 2 hours, depending on the level of urgency. Service users will receive a single assessment by a trusted assessor, who will communicate effectively with all colleagues to provide a service for that individual as required. Level 4 will deliver home based care and palliative care, and provide in reach support to intermediate care beds and sub acute care.

The commissioning intention for Level 4 is to secure the provision of a comprehensive range of integrated services in the community focused on promoting self-care, rehabilitation and independent living e.g. from small therapeutic interventions to intensive support from multi-disciplinary teams.

As with Level 3 there will be an integrated health and social care community team based in the community with clear links to other pathways, processes and organisations

Essential criteria: Care level same as Level 3 but where support needs can be met in the home environment.
Individual monitoring infrequent (e.g three times a week or up to three times a day)
Staffing ratios dependent on individual service user need, and capability of the individual and their carer.

2.2 Accessibility/acceptability

The service will be provided to adults over the age of 18 and are subject to the commissioning responsibility of xxxxxxxx Commissioning Consortium.

2.3 Whole System Relationships

Levels of Care cannot work in isolation and must work with partners to deliver safe, effective and clear pathways. Partners will include:

Primary Care
Secondary Care
Social Care
Community Services
Voluntary Sector
Nursing Homes
Residential Care

Mental Health
Hospices
Other services as appropriate

2.4 Interdependencies

The service works in collaboration with all health and social care professional agencies through the assessment and care provision processes, from referral to and discharge from the service. There will be robust links to voluntary agencies and support groups for those concerned and their carers. The delivery of services is also dependent on good IT links between different services to allow sharing and using of information as required and to provide the necessary monitoring and outcomes data This ensures that each individual receives the most appropriate care in order to get them back to optimum health and assisting them towards independent living.

2.5 Relevant Clinical Networks and Screening Programmes

The Levels of Care Service will be expected to provide information to national networks as appropriate. It will be expected to provide support, expert opinion and information to relevant local networks and also to keep updated on information coming out of networks either through attendance at relevant meetings or via some other agreed route..

2.6 Sub-contractors

It is not expected that sub-contracting will be required in relation to the Levels of Care provision. However should sub-contracting be required, this will be in agreement with the commissioners and the service will ensure that full and relevant information is provided.

3. Service Delivery

3.1 Service Model

The overall model is illustrated in Appendix 1.

Level 2

Level 2 will require a facility based model that can provide either step up or step

down care or direct referral. It will assist people who are medically stable in an acute setting, by providing a short term rehabilitation intervention designed to enable a timely co-ordinated discharge from a hospital-based setting. The objective will be to improve an individual's level of independence/recovery/daily functional ability to enable them to be stepped down to levels 3 or 4 or be discharged home (the palliative care pathway will result in patients achieving their preferred place of care and death). Essentially this will be achieved through refining existing treatment plans, whilst managing co-occurring conditions when the primary complaint has either been arrested, controlled or is stable.

There will be a rehabilitative element within the model i.e. to restore as much function as possible and also to transfer the individual concerned to a lower level (either 3 or 4) when it is expedient to do so.

The core elements of this level will be:

- Access to the same skill set and knowledge base as acute care (including diagnostics).
- Balanced skill mix with availability of the following staffing elements:
  - ✓ Consultant
  - ✓ GP with Special Interest in care of the elderly
  - ✓ Nursing (including nurse prescribers)
  - ✓ Links to Social Care (to assist in the achievement of discharge goals in a timely manner
  - ✓ Therapy:
    - Occupational Therapy
    - Physiotherapy
    - Speech & Language Therapy
    - Dietetics
  - ✓ Generic Support
- Diagnostics, available on site or easily accessible on demand:
  - ✓ X-ray
  - ✓ ECG
  - ✓ Echo
- Patient Transport
- Pharmacy
- Estate that includes facilities:
  - ✓ Bedded ward(s)
  - ✓ Laundry
  - ✓ Catering
  - ✓ Portering
  - ✓ Domestic services
  - ✓ Equipment including:

- Profiling beds
- Hoists
- Piped oxygen
- Resuscitation

In addition to the core elements the team would also require access to the following areas of expertise:

- Primary Care including:
  - ✓ GPs
  - ✓ Practice Nurses

- Mental Health including:
  - ✓ Psychiatry
  - ✓ Psychology

- Community Services including:
  - ✓ Community Matrons
  - ✓ Case Management
  - ✓ Community/District Nursing leading palliative care
  - ✓ Carers Support
  - ✓ Falls Assessment
  - ✓ Social Care Assessment

- Specialisms including:
  - ✓ Tissue viability
  - ✓ Specialist Palliative Care in all settings
  - ✓ Continence management

Levels 3 and 4

The expected outcomes from levels 3 and 4 are consistent i.e. to support the transition of an individual from intermediate care to home, by offering a short period of rehabilitation then to regain sufficient physical functioning and confidence to live independently at home. Consequently there will be a requirement to develop a fully integrated health and social care community team with a single point of contact. This team would provide both step up and step down. It will be based on the working practices of the existing:

Fast Response Team;
Community Virtual Wards;
Rapid Assessment Team;

Reablement Service.

The aim of the team will be to deliver rehabilitation, reablement, intermediate care and support palliative care packages in the community in order to avoid unnecessary hospital, residential and nursing home admission and facilitate discharge by enabling people to be supported in the community.

The core elements of the integrated health and social care team would be:

- Single Point of Access

- Assessment requiring access to:
  - ✓ Nursing
  - ✓ Palliative Care
  - ✓ Occupational Therapy
  - ✓ Physiotherapy
  - ✓ Care Management
  - ✓ Telecare/telehealth

- Reablement requiring access to:
  - ✓ Social Care assessment and reablement service provision
  - ✓ Nursing
  - ✓ Occupational Therapy
  - ✓ Physiotherapy
  - ✓ Generic Practitioners
  - ✓ Equipment, including telecare (as and when required)
  - ✓ Rehabilitation facilities
  - ✓ Information about local voluntary sector and universal services

In addition to the core elements the team would also require access to the following areas of expertise:

- Primary Care including:
  - ✓ GPs
  - ✓ Practice Nurses

- Mental Health including:
  - ✓ Psychiatry
  - ✓ Psychology
  - ✓ Nursing

- Secondary Care including:
  - ✓ Geriatrics

- ✓ Dietetics
- ✓ Diagnostics

- Community Services including:
  - ✓ Community Matrons
  - ✓ Case Management
  - ✓ Community Nursing/District Nursing to lead palliative care provision in the community
  - ✓ Carers Support
  - ✓ Falls Assessment

- Specialisms including:
  - ✓ Tissue viability
    Specialist Palliative Care in all settings .

- Voluntary Sector service provision including:
  - Home from Hospital services
  - Carers services
  - Dementia services

The responsibilities and requirements of the team will include:

- Bed management in relation to health and non health level 3 beds in the community.
- Training to provide a basic knowledge regarding the management of dementia.
- Training for generic assistants in the reablement of neurological conditions would be provided.
- Support the implementation of Telecare and Telehealth initiatives.
- Signposting to voluntary sector and universal services
- Delivery of standards of care as defined in national and locally agreed guidance.
- Making onward referral and seeking specialist advice as necessary
- Ensuring carers have sufficient support and training
- Planning an exit strategy for each individual, ensuring they and and their carers understand whne and why support is coming to an end and how to reconnect with services if need arises.
- Ensuring individuals are involved in decisions about their care
- Conducting satisfaction reviews and auditing of service provision on at lleast an annual basis
- Provide support and cover to ensure continual professional development

3.2 Care Pathways

The Levels of Care pathway will be agreed with commissioners and will indicate the meeting of the objectives highlighted in section 1.4.

3.3 Workforce

Staff will be trained to an appropriate level to carry out the required functions in order to achieve the objectives, confidently and competently. This will include:

Safeguarding
Dementia
Carer awareness
Diversity and equality
Lasting Powers of Attorney
DOLS
Mental Capacity Act
Understanding of complaints process and PALS services
Nursing home services
Continuing care requirements

This is not an exhaustive list but an indication of the range of activities.

4. Referral, Access and Acceptance Criteria

4.1 Geographic coverage/boundaries

The service is open to all those subject to the commissioning responsibilities of the xxxxxxx Consortia and over the age of 18.

4.2 Location(s) of Service Delivery

To be determined

4.3 Days/Hours of operation

The expectation would be that this team would operate 24/7 on a flexible

basis in order to meet demand

4.4 Referral criteria & sources

It is not possible to produce a definitive list of service users or types of presenting conditions but, as a guide Levels of Care will support the outcomes identified in Section 1.5.

Those providing the Levels of Care service will ensure all individuals presenting are accepted for triage and assessment. Access will be through a single point of entry based on explicit and specific referral criteria (that has been approved by the commissioners) and promoted to referral sources in primary, secondary and community care.

Referrals will be received from a range of sources including:

- ✓ Self referral
- ✓ Primary Care
- ✓ Community services
- ✓ Acute services
- ✓ Out of Hours service
- ✓ Carer or relative (if known by the service)
- ✓ Social services
- ✓ Specialist Nursing
- ✓ Nursing/Residential homes
- ✓ Mental Health Services
- ✓ Voluntary Sector

Referrals to the various levels will be for a time limited period (based on agreement with the commissioners), mainly for the reason of avoiding unnecessary or prolonged hospital, residential or nursing home admission or to facilitate rehabilitation on a step-up or step down basis.

The key element as to whether or not and individual meets the criteria for the Levels of Care Service will be the assessed level of risk of further deterioration without prompt and/or timely intervention, or an indication that an improvement in function could be achieved thus reducing dependency on care and promoting independence. This will be determined through the triage and assessment process.

4.5 Referral route

Individuals who meet the referral criteria will be accepted via a single point of

referral

The service will, where necessary, return to the referrer any referral that does not meet the explicit and specific referral criteria and/or is not sufficiently comprehensive to determine this. The service will need to signpost if self-referral takes place.

If necessary the service will facilitate access to specialist services as an onward referral

4.6 Exclusion Criteria

Individuals who:

- Require acute care.
- Do not meet the referral criteria indicated in section 4.4
- Are under the age of 18.
- Not subject to the commissioning responsibilities of xxxxxx Commissioning Consortium.

4.7 Response time and prioritisation

All urgent referrals will be telephoned and triaged within 4 hours of receipt of referral. All routine referrals to be triaged within 1 working day.

Triage will indicate if the individual is appropriate for the Levels of Care service and indicate which level is preferred. The provision of the service will ensure that, wherever possible, prioritisation is in line with the following:

- ✓ An acute admission is avoided/early discharge is facilitated.
- ✓ Level 2 or 3 bed access is achieved if required.

4.8 Record keeping and communication

The collation of data will be in accordance to an agreed minimum data set with the commissioners.

Where required multi-disciplinary meetings will take place to discuss individual's requirements/outcomes.

5. Discharge Criteria & Planning

Discussions with the individual around discharge planning will begin at the commencement of treatment and will continue throughout the episode of care. Individual Care plans which include discharge planning will be utilised throughout treatment.

The Levels of Care service will ensure:

- Discharge arrangements take into account the needs of the individual concerned, their family and carer(s).
- A proactive approach to discharge planning to avoid delayed discharges within the service, this to include an expected date of discharge being identified once the individual enters the service.
- A robust discharge policy is in place and available to all Levels of Care staff to ensure best and consistent practice.
- On discharge information will be provided about who to contact if service is required in the future, as well as signposts to other services.

6. Self-Care and Service User and Carer Information

The Levels of Care service will ensure that:

- ✓ Self-care and self-management of an individual's condition is a key priority/outcome of the intervention.
- ✓ Relevant information will be provided as required. It will be in a format accessible for the individual concerned in order for them to gain knowledge and understanding of their condition, thus enabling them to make informed choices for care and treatment.
- ✓ Appropriate support is given to both individuals concerned and carers to facilitate and promote self/care/management.
- ✓ Promotion of user and carer involvement in the planning, delivery of care and services will be undertaken.
- ✓ Where applicable all individuals are given the opportunity to access appropriate self-management training e.g. Expert Patient programme.
- ✓ All individuals and their carers will be given clear information regarding the aims and objectives of the Levels of Care service, what they can expect to receive, discharge processes, other services they may wish to access (e.g. voluntary sector) and how to utilise the complaints process.
- ✓ Carers should have the choice to be involved with the individual's care plan and rehabilitation, with consent of the individual (or in line with the Mental Capacity Act).

The levels of care service will ensure that it actively encourages communication and engagement between themselves and key stakeholders and demonstrate that feedback from those concerned is used to inform service redesign.delivery. The minimum requirement of this should include:

- ✓ Surveys/questionnaires of those using the Levels of Care service
- ✓ Carer surveys/questionnaires
- ✓ GP survey/questionnaires
- ✓ Routine contracting/perfvormance meetings with commissioners.

7. Quality and Performance Indicators	*Quality and Performance Indicator(s)*	*Threshold*	*Method of Measurement*	*Consequence of Breach*
HCAI Control				
Service User Experience				
Improving Service Users & Carers Experience				
Unplanned admissions				
Reducing Inequalities				
Reducing Barriers				
Improving Productivity				
Access				
Personalised Care Planning				
Outcomes				
Additional Measures for Block Contracts:-				
Staff turnover rates				

Sickness levels				
Agency and bank spend				
Contacts per FTE				

8. Activity

Activity Performance Indicators	*Threshold*	*Method of measurement*	*Consequence of breach*

Activity Plan

The Levels of Care service will ensure that activity data is provided to meet the agreed performance monitoring requirements as agreed with commissioners.

The service will provide activity and performance information both as a total for the whole service and also broken down by its individual components. This will in line with contract requirements as agreed with the commissioners.

9. Continual Service Improvement Plan

Future performance targets and thresholds will be agreed with commissioners and will be based on the establishment of baseline targets.

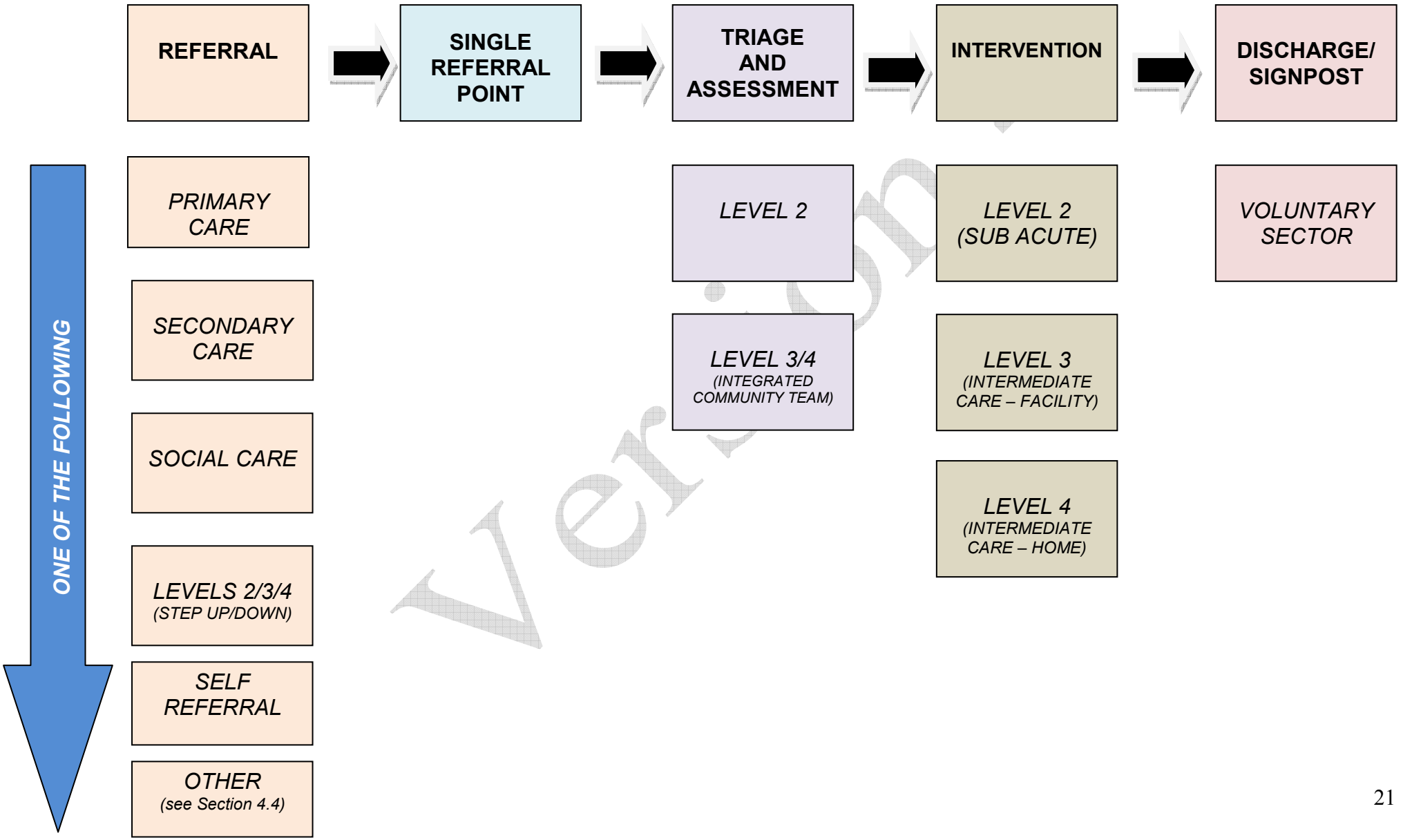
10. Prices & Costs

To be determined

10.1 Price

Provider(s) to provide a schedule of costs for each level based on this specification.

Appendix 1: High Level Model of proposed Levels of Care Service



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Health Overview & Scrutiny Committee 14 December 2011

Report of the Director of Adults, Children & Education

The Local Account for Adult Social Care 2011

Summary

1. This report introduces the Local Account for Adult Social Care 2011. Members are asked to:

   a. comment on the content of the Local Account ahead of its approval by the Cabinet Member for Health, Housing and Adult Social Services at her meeting on 20 December 2011

   b. note the performance and improvements described in the Local Account for 2010/2011 information

   c. note the areas for development and improvement for the coming year

Background

2. As of 2011/12, the Care Quality Commission (CQC) has stopped its regulatory assessment of councils and resultant Annual Performance Assessment, with councils moving instead to a more sector-led assessment process.

3. The Department of Health Document, *Transparency in outcomes: a framework for adult social care* establishes the concept of a Local Account created by councils to describe quality and outcomes in adult social care.

4. The Promoting Excellence in Councils' Adults Social Care Programme Board, which is made up of representatives from ADASS, Local Government Group, CQC and the Department of Health requested that all councils consider producing a local account during 2011/12 by December 2011.

5. While the content and format of the Local Account is not defined, the account has to be comprehensive and contain enough detail so that service users and members of the public see the evidence and data underpinning the analysis where they wish. It also aims to be accessible to allow service users, carers and the wider public to comment on our plans and priorities.

6. In York we propose that the Local Account for 2011 will be made available through the council website in this comprehensive version, with printed copies being made available on request. There will also be an Easy Read version, and a shorter summary, both available online to promote accessibility.

Council Plan 2011-2015

7. The content of the Local Account has direct contribution to within the priority of Protecting Vulnerable People as described in the council plan for 2011-15. Within that priority it specifically supports and evidences local action around:

   improving care facilities to support people with specialist needs

   investment in services to support people in the community, including telecare and reablement provision

   safeguarding adults and promoting independence through individual budgets.

Implications

Equalities

8. The Local Account has to be accessible and as such advice and guidance in the production of an Easy read version of the document will be sought through Equality Officers.

Other

9. There are no implications relating to financial, HR, ICT, crime and disorder, property or legal issues arising from this report.

Recommendations

10. Health Overview and Scrutiny Committee are asked to:

    a. comment on the content of the Local Account ahead of its approval by the Cabinet Member for Health, Housing and Adult Social Services at her meeting on 20 December 2011

    b. note the performance and improvements described in the Local Account for 2010/2011 information

    c. note the areas for development and improvement for the coming year

Contact Details

Author:

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Peter Dwyer
Director of Adults, Children and Education

Report Approved	✓	**Date**	*17 November 2011*

Wards Affected:	**All**	✓

For further information please contact the author of the report

Annexes

Annex 1 - Local Account City of York Council 2011

Annex 2 - Local Account Graphs & Analysis 2011

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ANNEX 1

City of York Council – ACE Directorate

Local Account for Adult Social Care

Achievements and Priorities in Adults Services

Adults, Children & Education Directorate

account (*n,)*
1. a verbal or **written report**, description, or narration of some occurrence, event, etc.
2. an explanation of conduct, ***esp. one made to someone in authority***
3. ground; basis; consideration: ***on this account, on account of***
4. importance, consequence, or value ***of significant account***
5. assessment; judgment
6. profit or advantage: ***to turn an idea to account***
7. on behalf of another; as in the phrase **on your account**

2011

Comprehensive Version

Table of Contents

Introduction to the Local Account 2010-11

I am pleased to welcome you to the City of York Local Account for Adult Social Care for 2010-11. I hope that you find it engaging informative and accurate.

We work ever more closely with our partners to deliver the best possible outcomes social care users, their families and carers and have taken many of the opportunities to work with health community leaders to commission and deliver integrated health and social care services across the city. We are working to establish the new Heath and Wellbeing Board underpinned by a Joint Strategic Needs Assessment and Health and Wellbeing Strategy which drives the nature of action and delivery to provide the best possible health and wellbeing for the citizens of York.

We have made significant improvements in the past year, redesigning services to meet increased need and using the skills of our staff to deliver high quality services in a time of great change. We remain committed to continued performance improvement through the development of our staff, and the processes and systems which support them. There is no question that, along with all public services, we continue to face substantial financial challenges but we remain committed even in that context to protecting vital front line services.

This Local Account has been built around improving outcomes for people in the city, and we believe that we have set ourselves some challenging goals for the next year. However, it is vitally important that we stay in touch with what service users, carers and their families see as important, and that we can always be responsive to these needs. To that end, the Local Account is also asking for your views on our performance and our priorities. Please take the opportunity to comment and feedback on the content of this document and add your voice to shape the priorities for the future of services in York.

Pete Dwyer
Director of Adults, Children and Education

About this document:

A Local Account should allow members of the public to:

- understand the work we have done, and the priorities for the year ahead
- see evidence for the statements we have made, and the reasons why actions or decisions have been taken
- access supporting data; see trends and comparisons in activities which support better customer outcomes
- have the opportunity to comment and feedback on the content either directly or as part of wider consultation processes

The account has to be comprehensive and contain enough detail so that service users and members of the public see the evidence and data where they wish. It also aims to be accessible and interactive to allow service users, carers and the wider public to comment on our plans and priorities. In order that we can achieve this, along with graphs & analysis against out key performance indicators, the Local Account will be published in three versions:

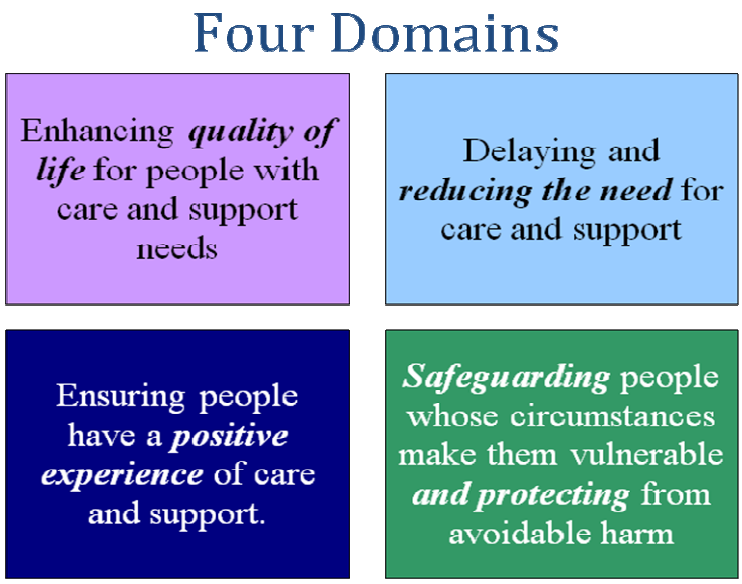
- **The Comprehensive Version:** a data and analysis rich narrative document available at **sampleurl1.york.gov.uk**
- **The Accessible Version**: a shorter, easy read version of the account available at **sampleurl2.york.gov.uk**
- **The Interactive Version:** an executive summary version of the account available online
  available at **sampleurl3.york.gov.uk**

This is the Comprehensive Version

How to Use this Document:

This document describes the work and priorities for adults social care in terms of **Domains**, **Outcomes** and **Measures.**

Domains express a broad policy for our services; that is the direction that we want to take the services in for the benefit the users and carers who access them. There are four Domains which describe the aims of our services.



Each of these **Domains** breaks down into a number of **Outcomes** which describe what things should look like for people in York. The **Measures** will evidence how well we are doing by looking at the data and information we have gathered.

Based on how we are doing in all these areas, we will set out our **Priorities** for the year ahead. As part of the Local Account for Adults Services we will also be inviting comment and feedback which, along with our other strategic plans and commitments, we will use to shape the direction future priorities for adults social care in the City of York.

Worked Example:

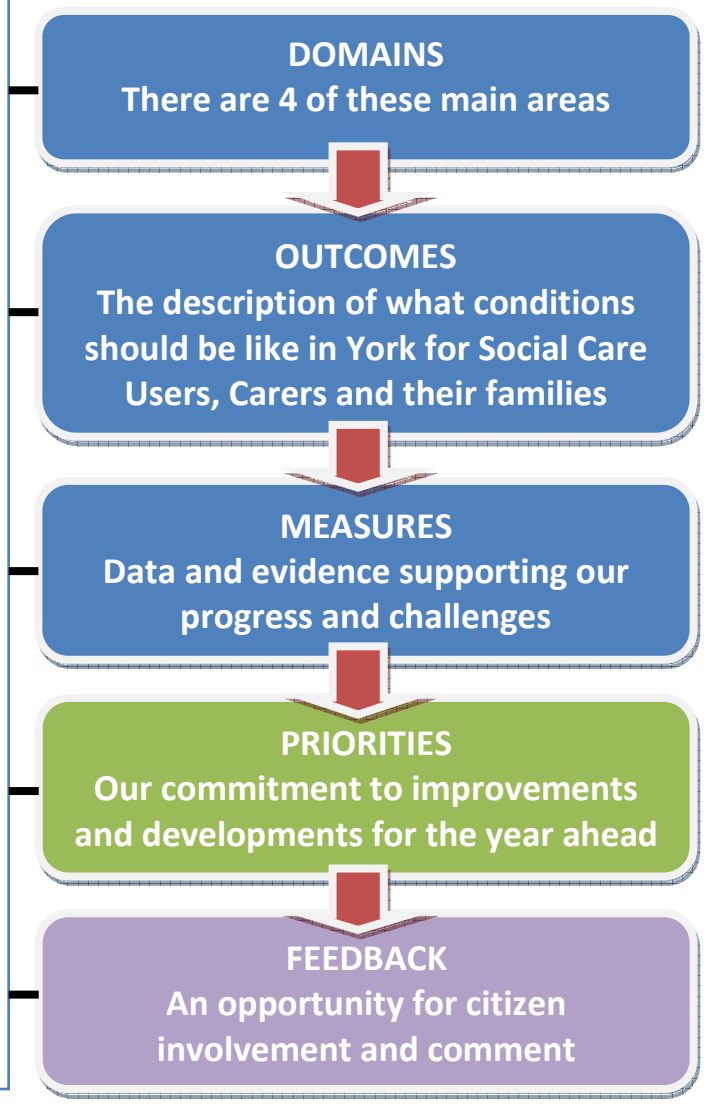
It is a policy that the work we do *Delays and Reduces the need for Care and Support*. This describes the **Domain**. In this case it describes Domain 2 - Reducing the Need.

This describes the **Outcomes** we want to see in order to achieve the aims of the Domain. The account will describe the services and support we have put in place to ensure we are making these conditions a reality.

We will publish that available that we use **Measures**. These are available through the *Graphs & Analysis* document which accompanies the Local Account.

The Local Account will then outline **Priority** areas which we will take forward over the coming year, alongside our partners in the city and across the county.

The Local Account will offer an opportunity for feedback and challenge and to contribute to the direction and Priorities for the future.



York's Specific Challenges:

York is a growing city. Continued growth in the population and the fact that people are living longer raises specific challenges for the provision of social care. The majority of people accessing social care in the city are those who are living with a disability, or who need care and support as they age.

In 2010 the population of York was calculated as 202,400 which was 11.7% more than the 2001 census population, and works out as twice the national average increase of 5.6%. The population rises varies greatly across age groups but can be seen very clearly in the older people age groups.

Between 2001 and 2010 the over 60 age group has risen from 39,400 to 44,887 in the city, which works out as a 14% increase, and it is predicted to rise further to 52,600 by 2021. Overall that equates to a 34% rise in this age group since 2001.

The over 80 group has risen by from 8,100 to 10,047, a 24% rise, between 2001 and 2010. The over 80 age group and is predicted to rise further to 13,100 by 2021, that's a 62% rise since 2001.

Between 2002 and 2010 there has been a 24% rise in people claiming disability living allowance, which is just above the regional rate of 23%, although less than the national rate of 31%. Those claiming incapacity benefit or severe disablement allowance claimants however, have decreased by 31% in the same period.

To meet these and other challenges for York, and to ensure that this is done in partnership with our health colleagues, we will be producing a new **Joint Strategic Needs Assessment (JSNA**) in 2012.

The purpose of the JSNA is to provide a comprehensive analysis of the local health and wellbeing needs of children, adults, older people, geographic and vulnerable groups. It comprises a mix of quantitative and qualitative data and will inform the development of the local health and well being strategy and in

turn, together with other key strategies and plans, will inform priorities and commissioning decisions across the city.

This Local Account and the feedback we receive will be used to shape future JSNAs, and in its turn, the findings from the JSNA will be reflected in future Local Accounts. This way we can be sure that social care and health are working together to deliver the best outcomes for York.

Working within a Financial Context

2010/11 Outturn

The Adult Social Services overspend was primarily due to an increased demand for care services above that provided for in the approved budget. The main contributory factors include; the fact that more people opted to take Direct Payments than anticipated as the personalisation of services was rolled out; a greater than anticipated number of referrals for independent residential and nursing; and a reduction in the level of income generated in elderly persons homes (EPHs).

2011/12 projection

In Adult Social Services, the pressures above that have been evident in previous years relating to demand for care still remain. There have also been delays on two major projects; in Home care, there have been delays in letting the reablement contract and reconsideration of other care services options, and in EPHs, implementation delays mean that the full saving expected in 2011/12 is unlikely to be achieved.

2012/13 and beyond

There will be continued pressure on budgets as the care demographic profile continues to increase and funding remains tight in these straitened economic times. The intention of helping people remain at home where possible will be met through the expansion of the reablement service. There is also a project underway looking at the care provided in our EPHs to increase the provision for those with dementia and higher dependency needs.

There is a wider national discussion taking place on care provision and how it is funded following the findings of the Dilnot Commission. This talks of such things as capping individuals' contribution to their care, maintaining universal disability benefits and having consistent access to services nationwide etc. The government are set to respond in a white paper due out in Spring 2012 and this could significantly impact on the directorate's financial position.

Personal health budgets and the reconfiguration of the health service may also have an effect on adult social care finance as the agenda to integrate services and realise efficiencies gathers pace.

The outlook is challenging from a financial perspective but has highlighted the need to do something quickly about the future financial pressure building from an ageing population.

Quality & Contract Monitoring

Quality of service provision for our customers is of upmost importance. We understand the moral and legal accountability for the duty of care and quality of the service and operate a framework of effective contract monitoring and quality assurance to fulfil our duties and responsibilities. We operate the complimentary processes of contract monitoring and quality assurance stay in touch with both providers' and customers' concerns and identify how any required improvements can be made.

Contract monitoring ensures that both the council and the provider are working together to provide the best support possible for people and work in partnership with providers to continuously improve the standard of care.

Quality assurance works across in house and external providers and regularly reviews aspects of services to ensure the support provided is of good quality, safe, efficient and effective.

We work to identify any areas of concern arising from these processes and deliver appropriate actions to address those concerns quickly.

Domain 1: Quality of Life

We want to ensure that the people of York who use services and their carers enjoy a high **quality of life**. We believe that this means:

Delivering High Quality Support and Information so that people are be able to live their own lives to the full and helped to achieve the things which matter to them by getting high quality support and information.

Supporting Carers so that they are helped balance their caring roles while maintaining their desired quality of life.

Delivering the Personalisation Agenda to ensure that people are given the opportunity to manage their own social care support as much as they wish, so that are in control of what, how and when this support is delivered to match their own personal needs.

Supporting People so that people with social care needs are supported to maintain a family and social life and contribute to community life, avoiding loneliness or isolation and find employment when they want to.

Looking back, this is what we said we would do in our 2010 assessment:

We will make a self-assisted assessment based tool available online to increase the access for people in self assessing their needs.

Residents living within the City of York Council area now have access to an online supported self assessment, which is helping to provide more choice and more control to residents who wish to find items to help themselves with daily tasks but need professional advice. It can be found at **https://www.equip-yourself-york.org.uk/smartassist/york**

We will continue the work with local providers and stakeholders in developing market capacity to increase the choice for people in the city to an ever widening range of support.

Meetings with provider forums and the voluntary sector have identified the need for support to develop options further for customers. Support has been

provided to the CVS to work with its members to develop a collaborative working and self directed support forum, to look at how capacity can be increased within the sector. We have worked with partners to look at a consortium approach to support planning and further work with providers will focus on support planning opportunities alongside care management colleagues. We have established framework agreements with home care providers which are outcome based, and give customers the chance to agree how their support will be delivered.

We will progress our transformation of services to self-directed support and deliver control of personal support and hit our targets by March 2011.
At the end of March 2011 we had achieved a figure of 24.9% against our nationally set target of 30% all our customers receiving Self Directed Support. We intend to stretch our targets to 37% for the year 2011/12.

Under the council's agenda for preparing to meet the needs of an increasing population of older people we will produce a profile of York older citizens to inform further actions and improvements against the World Health Organisation Global Age Friendly City Guide and other national and regional reports. *Work in this area has progressed well through the last year and has identified a number of key priorities: keeping the ageing population issue on everyone's agenda, promoting a more positive attitude towards ageing and older people in York, engaging better with York's ageing population and engaging with the voluntary sector to help deliver on this agenda. We agreed a Joint Vision for Older People with health partners in July 2010.*

We would work with York Contact Centre developing prompts and scripts to help them identify more carers and signpost these people to appropriate support. *Work with the Carers Contact Centre has continued throughout the year although specific work on these scripts has not yet been completed.*

Outcome 1.1 - Delivering high quality support and information

We understand our duty to provide information advice and support whether

you receive services directly from the council, whether you pay for these yourself or with your personal budget.

On the end of the telephone we have the adult social care initial assessment team, who are a dedicated team of trained staff ready to help people who require information, advice and signposting, or an assessment of their social care needs, whether routine or urgent. Team members complete social care assessments and deal with any referrals concerning safeguarding vulnerable adults.

Our online Information is available from the City of York Council website, and contains a wealth of information for services users, their carers and their families in many areas of health and social care. We offer advice and information for carers, and for people with learning disabilities, mental health problems or physical disability including how to access specialist services and such as blue badge and green badge parking permits, helpline and specialist equipment.

We offer a range of information and help for those looking to access home care and support services for people who may need extra help to live in their own home or extra care and support such as warden call, access to community or day centres in the city, mobile meals or residential care and we have a mental health support line provides telephone based support and information to people aged 18 and over who experience mental health problems.

For those people wishing to find out about health services we have general advice on accessing doctors, GPs' and hospitals, as well as information, advice and support if you go into, or come out of hospital.

We work with North Yorkshire County Council to provide an Emergency Duty Team which can be contacted outside office hours only, including weekends and bank holidays, on 0845 034 9417. The service is available to everyone living in York and to people who normally live elsewhere but who are staying temporarily in or visiting the area. The team will provide you with help and

advice and deal with emergencies over the phone.

Outcome 1.2 - Supporting carers

We know that Carers make a significant contribution in providing health and community care to relatives, friends and neighbours. Our vision in York is to work towards developing a local community where carers' needs are identified and supported by all public services and other organisations in the City. In short: "Carers are everybody's business". Carers should be respected and acknowledged as each carer has a unique perspective, alongside skills and knowledge gained through the experience of caring.

We have worked with our partners across the city to provide exclusive benefits for carers such as the free **Carers Discount Card** which was launched by York Carers Centre supported by 50 local businesses and a **Carers Emergency Card Scheme** which has been taken up by over 400 carers of all ages.

We run the **Flexible Carer Support Scheme** which provided direct payments to over 600 carers in 2009/10 and 680 carers in 2010/11 to support and sustain caring role. We offer support through **Carers Breaks,** a vital opportunity for carers to have a short break to refresh and re-energise them.

During a survey carried out of customers who had received a flexible carers support grant, 96% told us that having the grant had helped them in sustaining their role as a carer, and in getting the support the needed. This is what some of them said:

"It costs £12 a time so I can pay for ironing monthly. This takes the pressure off"

"A great help. It has made the difference between being able to afford to run the car and not"

"The grant gave me self confidence to be able to learn to use facilities for getting information"

Outcome 1.3- Delivering the personalisation agenda

Personalisation is about making sure that when people have to access social care support, people are still able to live as they wish, confident that services are of high quality, are safe and promote their own individual needs for independence, wellbeing and dignity.

Personal budgets are a new way of giving you control over your care and support. This is what is commonly known as "self-directed support". This lets you plan how you want your social care and support managed. It gives you more choice and control over the support you need. You have the choice to be more involved in deciding what support is arranged, and who is going to do what. It gives you the opportunity for more flexibility with your social care funding.

How to get a personal budget Since August 2010 we have re-organised our teams to make it as simple as possible for people with support needs and their carers to access a personal budget by completing their own personal needs questionnaire, supported by a care manager. Following this, and dependent on the types of need, a budget will be calculated and you will have an idea of exactly how much money your allocation might be, right from the start. Working together we will then help you come up with a support plan, which will focus on how you want to live your life, making sure you can use the resources available to help you achieve those goals which will also take into account the needs of your carers.

Outcome 1.4 - Supporting people

All directorates and services in City of York Council aim to be fair and inclusive. To do this we ensure that we challenge all forms of unfairness and value diversity. We want our communities to be self-confident, health places and this means reduce social, economic and educational disadvantage.

The York Fairness Commission has been set up to look into how to make the city **a fairer and more equal place to live and work**. Its aim is to set forward a

vision for York that can inform, influence and inspire the council and others, including the public and local employers, to lead by example and work for change that will improve the quality of life in York for us all. The Commission will focus on **social and economic inequalities** of income, education and occupation that create divides between citizens, and which are harmful to everybody's health and wellbeing. The results of the commission's work will be used to influence the council's budget decisions and the work of its partners, to create a fairer York for all its residents

We want to see people who use social care services involved in our community and helping us make decisions.

Since 2001 York has had a lively Valuing People Partnership Board which sets out to make sure that all people with learning disabilities have equal access to all services and facilities, including people with complex support needs and those from minority ethnic backgrounds. The group works in partnership with other organisations in York to understand the whole picture in the city and identify gaps and opportunities and responds to both local and national requests for action/information that will help to improve the lives of people with learning disabilities. The Board is co-chaired by one independent person and one person with a learning disability.

There are five priority groups, each with a lead person and a co-lead who is a person with a learning disability or is a family carer. There are priority groups for: health; housing; personalisation; what people do in the day, on an evening and on a weekend; and involving everyone to make it happen. The priority groups have written action plans for the period 2009 to 2012. The work of the priority groups is reported to and monitored by the Partnership Board.

We fund a self advocacy service to provide support to people with learning disabilities to take an active and valued part in our Valuing People Partnership Board (including support to the co-chair, who is a service user). We also have service users and carer representatives on our key stakeholder groups including the York Mental Health Partnership and Modernisation Board, Supporting People Consultation Groups and the York Dementia Working Party.

We have also funded the development of a user led organisation, York Independent Living Network, and they are hosting five forum events this year for anyone with a disability, including hard to reach groups, on a variety of topics alongside the continued funding of a range of advocacy services.

We want to see more disabled people and those with mental health needs in employment. **We work with Future Prospects' Supported Employment Service** and **The Blueberry Academy team** which are organisations that support and assist disabled people and people with health issues with all aspects of training and employment to help people realise their potential to gain sustainable paid employment. The team of learning and work advisers, job coaches and mentors give individualised information, advice and guidance and help arrange the relevant support and back-up a person needs to achieve success.

The Community Recovery Team is a team of health and social care workers dedicated to supporting inclusion and recovery for people who have experience Mental Health problems. By using community facilities trainees are supported by a mentor and facilitators, backed up with personalised training packages and plans. The training received is transferable, not just helping people return to work in a supported way and increasing skills and confidence and support recovery.

1.5 Measures - How well are we doing?

We have established a number of measures to help us see how well we are working to achieve some of these outcomes. More detail on these is available in the annex to this document, entitled ***Local Account for Adult Social Care Analysis of Indicators & Targets.***

To measure the overall **social care-related quality of life**, we use the responses we received to the Social Care Survey. The social care related quality of life score for an individual is a composite measure using responses to questions from the ASCS covering eight domains (control, dignity, personal care, food

and drink, safety, occupation, social participation and accommodation). Our overall score is shown in *Graph 1 of the Analysis of Indicators & Targets document and places York above its comparator group and the national average. Detailed responses to the question can be found in the adult social care survey section of the document.*

We are working to enable **people to manage their own support as much as they wish**, so that are in control of what, how and when support is delivered to match their needs. This is measured through the provision of self directed support. Under the current published measures York is performing below that of the average in England, and the comparator groups delivering personal budgets to 24.9% of all social care customers, however, when measuring in year, and using only those people who qualify for a personal budget, rather than all customers known to the authority, our performance was 47.5%. **It is our intention to use this more accurate and reflective measure in the future.**

To measure our commitment to **increasing the proportion of service users in employment and preventing social isolation** we measure the proportion of adults with learning disabilities in paid employment and the *proportion of adults with learning disabilities who live in their own home or with their family (settled accommodation), Graphs 4 & 5 of the Analysis of Indicators & Targets document .* Our performance in these areas exceeds both the national average and comparator groups in these areas.

We intend to enhance further enhance the measures in this Domain to include:

the proportion of people who use services who have control over their daily life

carer-reported quality of life measured through a carers survey

1.6 Quality of life: our priorities for the coming year

Enable self funders to access financial advice by January 2012.

Undertake a flexible carers support scheme grant survey and a carers' survey to look at the best way of distributing funds to make the most impact on carers' lives and wellbeing. To run an "easy read" version of these in order that carers with learning disabilities can contribute and shape the future of the services.

Further promote self assessments.

To promote personal budgets and proactively discuss the financial options with customer right from the first contact. To improve our systems to help deliver information and advice about self directed support.

We intend to make QA reports available to all on request eg The 2010/11 Residential Care Homes and Home Care QA reports to be styled in an appropriate format to circulate to survey responders, prospective residents/relatives, customers and other professionals

We shall be carrying out a survey of customers of our assessment and personalisation service in 2012 to obtain feedback on their experience and quality of: personalised support, assessment and support planning, individual budgets, self assessment, achievement of outcomes.

Domain 2: Delaying and Reducing Need

We want to ensure that the people of York who use services and their carers are supported in **delaying and reducing the need for services and maintaining their independence** by:

Preventing Illness and Dependency by ensuring that everybody has the opportunity to have the best health and wellbeing throughout their life, and can access support and information to help them manage their care needs.

Earlier diagnosis, intervention and reablement mean that people and their carers are less dependent on intensive services.

Delivering Timely and Appropriate Support by ensuring that, when people develop care needs, the support they receive takes place in the most appropriate setting, and enables them to regain their independence.

Looking back, this is what we said we would do in our 2010 assessment:

We will reduce levels of delayed discharges from hospital care and improved access to intermediate care provision. *Delayed discharges had continued to rise during 2010/11. An extensive analysis of the causes showed a large increase in the number of referrals from the hospital as more people are able to go home earlier. Work to improve the pathway of people being discharged is ongoing, and as part of our commitment to reduce delays we are redesigning services in 2011/12 and have set ourselves targets to return to 2009 levels.*

We will focus on more complex telecare packages targeting those people with higher levels of need to retain their independence. *The service continues to receive an average of 55 new referrals every month and we expect this to increase when the Intensive Support Service begins and the telecare team become an integrated part of the reablement processes.*

We will commission the new extra care scheme at Auden Court with housing

colleagues and York Housing Association. *The first extra care project in York has been launched in the spring of 2011, providing 41 apartments for over-55s who are paying for care. Auden House offers professional on-site support for older people, allowing them greater independence while still having the peace of mind that comes with knowing people are nearby.*

Outcome 2.1 - Preventing illness and dependency

The 2010 Joint Strategic Needs Assessment (JSNA) was commissioned by the Director of Adults, Children and Education and the Associate Director of Public Health/Locality Director. The purpose of the JSNA is to provide a comprehensive analysis of the local health and wellbeing needs of children, adults, older people, geographic and vulnerable groups. It comprises a mix of quantitative and qualitative data and will inform the development of the local health and well being strategy and in turn inform priorities and commissioning decisions. The JSNA will incorporate the following dimensions:

Population level analysis of the city to ensure that appropriate services are available to suit the age; gender; ethnicity; and vulnerable groups. The JSNA will incorporate an analysis of **social and place**: community wellbeing; economy & income; environment; education; housing; crime & disorder and

Lifestyle determinants of health: such as physical activity; healthy eating; alcohol and drug misuse; smoking; health improvement interventions. There will be a view of overall wellbeing; measured by life expectancy & mortality; disability; mental health; cardiovascular health, cancers & respiratory health.

Colleagues working in clinical health alongside staff from children's and adults social care, managers of specialist services and special interest groups will be invited to participate to give their views on service access and use, and be invited to offer their perspectives of the services and the issues being presented in the city.

Outcome 2.2 - Earlier diagnosis, intervention and reablement

Our Reablement works with the majority of people discharged from hospital where additional support is needed. It times its first visit for when people have returned home puts in support to see them through the initial six weeks of recovery. Through this period the support will be gradually reduced as customer recovers. Our staff go out on this first visit and ask people what they see as important to them, and plan the support around their needs and wishes.

Other 'traditional' home care services enable people to stay at home by supporting people with just the tasks they struggle with. **Reablement works specifically to get people back to their earlier level of independence, or near to it.** They can work with the customer to identify what is important to them and work towards it. Support will then withdraw or reduce so people do not become overly dependent upon it.

A survey undertaken of people over 65 who had been discharged from hospital to rehabilitation services during the period October–December 2010 found that:

94 % of those surveyed were happy at the time of discharge with the decisions made about the care and support they were to receive after leaving hospital

54% said they were given something in writing (a care or support plan) which detailed how you were going to be supported and enabled to continue living at home

89% felt that they got the support/service that they were expecting

77% said that it made their level of independence better

91% said they were happy with the support they had received from social services since their last stay in hospital

Our rapidly developing programme of telecare and warden call services

support people with deteriorating health or reduced independence to stay in their own homes for as long as possible. Customers can have the security to remain at home and these services provide their families much needed reassurance (sometimes they are able to 'listen in' and monitor themselves). "Just checking" services can be used to see what people are doing at home and so know what support needs to be put in.

Outcome 2.3 - Delivering timely and appropriate support

The council work with health colleagues to ensure the quality and effectiveness of hospital discharge arrangements through regular meeting. In these meetings the performance of timely and appropriate discharges from York District Hospital is monitored. This is a forum where concerns related to poor quality discharge arrangements and/or lack of co ordination of services can be raised and resolved.

The department is contributing towards the work initiated by the acute trust and PCT looking at 'levels of care'. This will result in closer partnerships and integrated working with community health services and colleagues in the acute trust and enable more people to be treated in the community and at home.

In times of particular pressure resources can become stretched. As in previous years six 'winter pressure beds' are being established in one of York's residential homes. This will enable 'step down' facilities to be available for patients who need further recuperation and rehabilitation but who don't require acute, higher level care. In addition extra resource has been made available by the acute trust for the purchase of more care manager or social work hours which will enable timely assessment and discharge over the winter months. In cases of intense pressure fortnightly co-ordinated up dates by PCT/Acute Trust and CYC are in place to monitor winter pressures.

Customers/patients in the community with long term needs are supported through services commissioned by social care. Multi-agency support is provided by community nursing services, community matrons, physiotherapy

and occupational therapy services. Specialist renal social workers and a neuro-social worker offer support to patients who may have inpatient stays or clinic attendance but need support to live in their own homes between these episodes.

The continuing health care assessment process is well developed in York, the work being closely co-ordinated between specialist care managers who focus exclusively on continuing health assessments and their health colleagues working in the nursing assessment team at Malton. This arrangement enables timely assessments and funding decisions to take place for patients who may have chronic and enduring conditions.

2.4 Measures - How well are we doing?

Our performance detailing the *Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital* into reablement / rehabilitation services (Graph 6) shows that York is showing a high percentage of people remaining at home following reablement.

Delayed transfers of care from hospital, and those which are attributable to adult social care have risen over the past three years. The number of acute delayed transfers of care attributable to adult social care aged 65 or over, rose from 4 to 11 per 100,000 population. This rise is more than double the England rate of 4 and the comparator group rate of 5 per 100,000 population. Average days of acute delay per week attributable to ASC rose to 32.8 from 9.3 in York between 2007-08 to 2009-10. This failing performance is being addressed through partnership working, improved systems and challenging targets for 2012.

2.5 Delaying and reducing needs: our priorities for the coming year

To extend links into the voluntary sector especially for people who will not require formal ongoing support, to minimise social isolation and encourage continued independence.

Reduce the levels of delayed transfers of care from hospital in the city from 2010-11 rates.

To support the development of community health capacity to deliver 'step down' care and make links to ensure this works in partnership with our reablement service.

Increase the capacity of our reablement service through a tender exercise with the independent sector.

Domain 3: Positive Experience

We want to ensure that the people of York who use services and their carers have a **positive experience of social care** whenever and wherever they access it. We believe that this means:

Maintaining Quality and Service to ensure that people who use social care and their carers are satisfied with their experience of care and support services.

Involving Carers to ensure that they feel that they are respected as equal partners throughout the care process.

Being Transparent about Services and Care so that people know what choices are available to them locally, what they are entitled to, and who to contact when they need help.

Maintaining Dignity and Respect to make sure that people, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual.

Looking back, this is what we said we would do in our 2010 assessment:

We would implement a 'Customer Services Blueprint' ensuring a first class, single point of contact. Customer service in the future will be owned and delivered by a single service within our organisation. *Our initial Assessment and Safeguarding Team went live in 2010 and has been acting as a single point of contact for social care contact in York.*

We will continue to keep people informed about changes and developments in the services and seek their views to shape the delivery of social care. *Consultation for the major areas of change in the city...*

The Mental Health Partnership Board will improve engagement of service

users in service development through a 'Bright Ideas Group' and consultation with services users and current services. This will be tracked through the Board's work plan, and will be reported in an annual report on the Board's achievements. *The Bright Ideas Group consists of experienced and proactive members who draw on their practical knowledge of service delivery in York and good practice in other areas of the country to seed pragmatic and innovative ideas and ways of working into day to day delivery. The group's mandate from Partnership and Modernisation Board was to "think big and think differently". Its report was published in March 2011.*

We will be expanding the older people's signposting service to include outreach for hard to reach and minority groups and include monitoring of this through contract reviews. *There is further work required to develop the partnership between the signposting service provider and YREN (York Racial Equality Network). Further development work is under way between all parties and the council and it is hoped that awareness of the service will be made more widely available to minority groups within the community in 2011-12.*

Developing joint council and PCT commissioning structures to support our drive to deliver integrated and outcome focused health and social care services. *The integrated commissioning service arm of Adults, Children and Education was newly established in Autumn 2011 as part of the organisational review following the creation of the Directorate of Adults, Children and Education. The intention is to create a cohesive commissioning arm across the full range of council-funded services for children and adults. The service arm is also the key interface with the NHS and will play a key part in establishing the new mechanisms and structures that will emerge from the coalition government's health reforms. Ultimately, the hope is that commissioning will be "integrated" not just within the council, but across its partners in the NHS as well.*

Support the development of more personalised care, through new home care contracts, link to regional market development work stream and work with residential and nursing homes. *As part of the re-commissioning of locality*

home contracts and framework agreements, an outcomes based service specification was introduced in November 2010. The specification focuses on personalised support and monitoring of outcomes enabling customers to maximise their independence, and give them choice and control over how and when their service is delivered to them. The quality audit undertaken in Residential & Nursing Care in 2010 focused on personalisation within care homes and will provide a "benchmark" to monitor providers against in 2011-12.

Progress with our review of residential homes in the city. The review has been progressing during 2010/11 and into 2011/12. It is expected that the conclusions will be made by members before the end of 2011/12 based on the consultation exercises undertaken in the year.

Outcome 3.1 - Maintaining quality and service

A rolling quality assurance programme covers all service areas over a 2-year period, and a lively programme of customer consultation is carried out to support service reviews and to monitor and improve services on the basis of customer feedback. The 2010-12 programme included surveys of the following customer groups:

Residential care residents, relatives , other professionals and staff (to support a service review); home care customers; sheltered housing with extra care/supporting people; intermediate care services; telecare/warden call; learning disabilities customer review satisfaction survey.

As part of the national annual adult social care survey we asked 982 out of 5033 customers about the quality of our service. Of the 655 customers who responded, 91% were either satisfied or very satisfied with the care and support services they received. The outcomes of the survey are published in the local press and the national/council's comparison report is available on the internet. Customers taking part in the survey are provided with a copy of the report on request.

All quality assurance material and reports can be produced on request in any

format the customer requires i.e. other languages, bold print etc. Survey tools and reports are automatically made available in accessible version as appropriate to customers who are elderly, disabled or have a learning disability so they can read and self complete as they prefer. Signers, interpreters and advocates are used when required.

Outcome 3.2 - Involving carers

Carers Strategy Group: The Carers Strategy Group is a partnership of people from statutory and voluntary organisations as well as carer representatives from the carer led forums. The group meets every three months to monitor progress with the Carers Strategy Action Plan. The group is co-ordinated by City of York Council's Adults, Children and Education directorate and is working towards increasing carer awareness at all levels of strategic planning.

York Carers Strategy Group supports partnership working between health and social care agencies in the commissioning and provision of services. City of York Council dedicates funding from the area based grant and NHS North Yorkshire and York uses funding from its core budget to support carers through strategic support and direct payments for carers, commissioning services specifically for carers, funding respite and sitting services and through support provided to the cared for person which allows carers to take a break. There are also other specialist services for example community mental health services that provide advice and support to carers.

Carers shaping policy: There are three active carer led forums in York helping to make sure carers voices are heard: CANDI, York Carers Forum and Young Carers Revolution. To support Integrated services and better coordination, a "Care Pathway for carers support has been drafted and initial discussions have taken place about some of the implications for City of York Council's adult social care services. There has been Carer Awareness Training held for library staff, workers in primary care health settings and those undertaking carers assessments of need. And York Carers Centre led the development of the

young carer and adult Carer e-learning tools.

Outcome 3.3 - Being transparent about services and care

Accredited Provider lists are published on the Council's web site which includes links to recent CQC inspection reports and the latest CQC published rating. The council maintain accredited provider lists which are available to both public and care management colleagues and is looking at enhancing its quality assurance framework for providers with an option for this being made available to the public in the future.

The council has produced specific 'easy read' fact sheets on our website about the personalisation agenda and self directed support. We are also intending to redevelop the adult social care section of our council website to make it more accessible and easier to use.

This information is available to everyone, regardless of how they are funded. Our website contains an OT self assessment tool, which enables people to complete a self assessment form on line in order to identify equipment that may be suitable for them (if required) and suppliers of this equipment. We are also intending to redevelop the adult social care section of our council website to make it more accessible and easier to use which will include a wide range of information on services across the city which self funders will be able to access.

How this Shapes Services: Quality Assurance consultation programmes undertaken since 2009 have highlighted that the majority of residents in the council's residential homes did not like food prepared for them by the hospital. They asked for better quality, home cooked food. During 2010, there was a phased re-introduction of food cooked by their own chef on the premises in each of the homes. A subsequent survey has shown that the vast majority of residents feel there has been a great improvement in quality and choice. These were some of their comments:

"It's smashing, no complaints"

"Before it came from the hospital but now we have a cook and it's very good"

"Since hospital food it's fantastic. We get more variety"

During 2010 we surveyed a sample of sheltered housing with extra care residents. They told us that organised activities were limited. As a result activities have been increase and volunteer activity workers from CVS have been recruited to help. A survey of residents in this year's programme will be used to check whether they are satisfied with the outcome of these improvements.

Following a survey of warden call/telecare customers, because of the variation in information given by customers on the frequency of system checks, the service has reviewed its procedures and is planning to introduce two monthly calls by a dedicated team to establish a consistent approach for customers' peace of mind.

3.4 Maintaining dignity and respect

How does the council work with the PCT to ensure that people and their carers have their wishes respected and are treated with dignity?

Care homes and care services have been involved with the roll-out of local protocols on 'Do Not Attempt to Resuscitate' which will ensure that the known wishes of residents are respected at the end of their lives.

Staff in all council-run homes have received Dignity in Care training. The effectiveness of this has been followed up by a survey of 50% of the home's residents and a sample of their relatives, friends and other professional plus staff. When asked if they felt they were always cared for in a courteous and considerate way 100% said 'yes' in five of the homes, with 61– 92% responding 'yes' in the other homes and staff in general were spoken very highly of for the way they treated residents and supported relatives.

The 2010 home care services survey also focussed on whether we were meeting the NHS Dignity in Care standards and **all of the council's home care teams scored 100% for always treating customers with dignity and respect.**

For front line staff, any issues are dealt with through their line management and supervision. The 2010 residential care services survey, which focussed on the Dignity in Care standards, found that the majority of residents felt their individual homes rated well in these areas. In response to asking how they felt they achieved the appropriate treatment of residents, they said recruiting the right staff, good training, understanding the residents and good teamwork. The vast majority were confident about reporting poor practice and how.

Our staff are well aware of the importance of maintaining dignity in care, and these were some of the things they said about how the residents should be treated:

> *"Understanding residents needs. Good communication and teamwork."*
>
> *"We all are very professional and have regular training on dignity awareness."*
>
> *"We always try to involve customers in our conversations. We try to involve them in care planning, we have behavioural management plans in place to follow." (from a staff member of the LD respite unit)*

All surveys conducted by social services monitor and promote dignity and respect, choice, inclusion and the right to expect the highest quality service. Customers with learning difficulties, memory loss etc are given exactly the same opportunity to contribute their views and raise concerns. This has been clearly demonstrated in the 2010/11 residential care survey with lively, useful feedback being provided by our respite learning disability customers as well as the residents of our EMI units.

3.5 Measures – How well are we doing?

In the adult social care survey for 2010-11 we asked about the overall satisfaction of people who use services with their care and support. **We found that the overwhelming majority were satisfied to some degree**, and in the top two selected answers. 30% of respondents said they were extremely satisfied and 35% were very satisfied (*ASC Q1, Graphs and Analysis Document*).

We also asked whether people who use services and carers who found it easy to find information about support. **More than three quarters said the found it easy to find information**, with 29% reporting it very easy to find and 49% saying it was fairly easy to find.

We intend to supplement these measures in the coming year with:

A measure to gauge the overall satisfaction of carers with social services, ensuring people know what choices are available to them locally, what they are entitled to, and who to contact when they need help.

To ensure that carers feel that they are respected as equal partners throughout the care process we will be looking to ask about carers who report that they have been included or consulted in discussions about the person they care for.

3.6 Positive experience: our priorities for the coming year

Following the completion of a major consultation exercise within the residential services, one of the recommended outcomes is to have a quality champion within the service to secure ownership of quality and to facilitate the sharing of good practice between teams.

A carers' survey is being carried out in 2011 which will provide benchmarks for the national survey in 2013. 5% of carers and 20% of carers of people with learning disabilities are to be targeted. We will specifically ask carers whether they feel they have been involved as much as they wanted to be in discussions about the support or services

provided to the person they care for.

We shall be carrying out a survey of relatives who are willing to talk to us about their relative's end of life care within the council's residential care homes as part of the 2012/13 quality assurance programme.

The results of the consultation on the proposed major changes in our residential care homes will drive our transformation programme.

Domain 4: Safeguarding

We want to ensure that the people of York circumstances make them vulnerable are **Safe and Protected from Harm.** We believe that this means:

helping everyone enjoy physical safety and feel secure

working to ensure that people are free from physical and emotional abuse, harassment, neglect and self-harm

protecting people as far as possible from avoidable harm, disease and injuries

supporting people to plan ahead and have the freedom to manage risks the way that they wish

Looking back, this is what we said we would do in our 2010 assessment:

We will recruit an independent chair of the Safeguarding Board. This will ensure the chairing of the Board is undertaken in a professional, fair and consistent way without possibility of compromise for the agencies involved
This has been achieved. The independent chair has been appointed and is in post.

We will ensure feedback mechanisms are in place to any agencies involved in safeguarding processes. This will ensure that the information given by those customers and others who are part of the safeguarding process influences the policies, procedures and practice of those working in this area.
Progress has been made towards achieving this. All agencies receive feedback on every safeguarding concern made to the council. We also meet with agencies to look at particular issues relating to their organisation and the safeguarding issues for their customers. We are undertaking quality assurance work with our customers and will use the information we gain from this to inform the development of our safeguarding practice.

Outcome 4.1 - Helping everyone enjoy physical safety and feel secure

The council works with partners through York Safeguarding Adults Board.

The members are signed up to a implementing a multi agency policy which makes it clear that safeguarding is everybody's business. We commission training for the independent and voluntary sector to promote this message and to let them know how to alert and refer safeguarding concerns. We routinely monitor where these alerts come from. Information to the public about safeguarding is provided through our website.

We have strong governance arrangements and reporting processes in place to monitor the effectiveness of arrangement. We report to the council and to York Safeguarding Adults Board. This provides scrutiny from both our peers and those elected by the people of York, and the annual report has been published and is available online. York Safeguarding Adults Board provides the partnership approach to implementing the recommendations within it. We are undertaking work to ensure that those who have been through safeguarding processes have their voice heard and that we learn from this experience.

We are currently reviewing our protocols as the lead agency to improve the pathway for our partner colleagues to refer safeguarding concerns to us. We continue to routinely monitor where our referrals come from and work with referring agencies to ensure these pathways work.

All agencies are aware of the safeguarding procedures and are signed up to the multi-agency policy. We have a dedicated Safeguarding Manager who as a matter of routine ensures that all safeguarding referrers receive advice consistent with these procedures. Problems with the implementation of procedures that cannot be resolved at an operational level are progressed through York Safeguarding Adults Board. We collect data regarding the source of our safeguarding alerts. We meet regularly with our partner agencies who alert us to safeguarding concerns. We have also held meeting regarding developing safeguarding responses for hard to reach groups.

To ensure we learn from any serious incidents and case reviews, the council runs a safeguarding practice group at which lessons learned and national and local developments are shared with those responsible for running safeguarding investigations. We recognise the many shared areas of interest and practice between safeguarding children and safeguarding adults work. Work is underway to share learning and practice which will influence the development of our strategic approach to investigations and the practice of those running

them.

We produce a leaflet for the public to let everyone know how to report an incident of abuse. There is a single point of contact we provide for all referrals and a variety of means for people to contact us including email, fax and telephone. We have a safeguarding website which includes guidance on how to report abuse and a standard form.

Outcome 4.2 - Working to ensure that people are free from physical and emotional abuse, harassment, neglect and self-harm

We ensure that people's rights to equal access and consideration of cultural, religious and spiritual needs are considered in assessments and support planning as we routinely conduct equality impact assessments on changes in policy we make within the council. Our care management documentation prompts our staff to consider cultural, religious and spiritual needs. Our approach to personalisation means that we are encouraging people to identify their own support needs and outcomes in theses areas which we will help them to meet.

We continue to develop our focus on human rights through training such as safeguarding and mental capacity. We work closely with our contracting colleagues to focusing on human rights issues with providers. This includes working on improvement planning with providers to improve their understanding and practice with regard to human rights and issues of discrimination.

Outcome 4.3 - Protecting people as far as possible from avoidable harm, disease and injuries

We have procedures in place to deal with evidence of poor practice in our own staff through competence and disciplinary policies. Regular supervision and PDR processes are in place to pick up on such evidence. Our management team works to identify potential areas of poor practice and rectify through a variety of responses including training, staff development changes in processes. Our safeguarding procedures provide a response where there is evidence of poor practice that might lead to serious harm.

4.4 Measures – How well are we doing?

In this year's Adults Social Care Survey we asked people about their feelings of safety and security. The proportion of people using social care services who feel safe and secure. Neatly two thirds of respondents said they felt as safe as they would like to feel, while 32% said they felt adequately safe, but not as safe as they would like.

We would like to supplement these measures with additional indicators that show:

the proportion of referrals to adult safeguarding services which are repeat referrals

the safety and security of carers

4.5 Safeguarding: our priorities for the coming year

Establish a stand alone *Safeguarding Adults Team* with staff members whose dedicated role is to investigate abuse.

Develop the pathway with our providers so that we know that all safeguarding referrals are dealt with in a consistent manner.

Improve our safeguarding processes, including learning from safeguarding children's services, to provider better guidance to those investigating alleged abuse and those managing these cases.

Work through York Safeguarding Adults Board to develop a "York Picture" to inform safeguarding priorities for partners across the city.

Comments and Feedback

5.1 Comments and feedback

Have your say!

We encourage feedback on all our activity and services, positive or negative it helps us to address problems and shape the services for the future. With specific reference to this document we would like to know:

Do you agree with the priorities we have set for ourselves for the coming year? What would you add or remove?

Are there any other areas of adult social care you feel we should focus on as a priority?

Have you found the Local Account easy to access and understand? What changes would you like to see in the future?

Please also feel free to comment on any aspect of adults social care in York.

Please make it clear whether you are a service user, a carer, a family member, or other interested party.

We will incorporate these views in our planning and preparation of next years local account, the Joint Strategic Needs Assessment for the city, and where applicable notify our partners of these issues. You are welcome to contact us by post or email.

Adults Children & Education (ACE)
10-12 George Hudson Street
York
YO1 6ZE

By email:

haveyoursay@york.gov.uk

Annex 2

City of York Council – ACE Directorate

Local Account for Adult Social Care

Analysis of Indicators & Targets

Adults, Children & Education Directorate.

account (*n,)*
1. a verbal or written report, description, or narration of some occurrence, event, etc.
2. an explanation of conduct, ***esp. one made to someone in authority***
3. ground; basis; consideration: ***on this account, on account of***
4. importance, consequence, or value ***of significant account***
5. assessment; judgment
6. profit or advantage: ***to turn an idea to account***
7. on behalf of another; as in the phrase **on your account**

2011

GRAPHS & ANALYSIS

Contents

About this document:

A Local Account should allow members of the public to:

Understand the work we have done, and the priorities for the year ahead;

See evidence for the statements we have made, and the reasons why actions or decisions have been taken;

Access supporting data; see trends and comparisons in activities which support better customer outcomes,

Have the opportunity to comment and feedback on the content either directly or as part of wider consultation processes.

The account has been published in three versions.

The Comprehensive Version: a data and analysis rich narrative document.
available at **sampleurl1.york.gov.uk**

The Accessible Version: a shorter, easy read version of the account.
available at **sampleurl2.york.gov.uk**

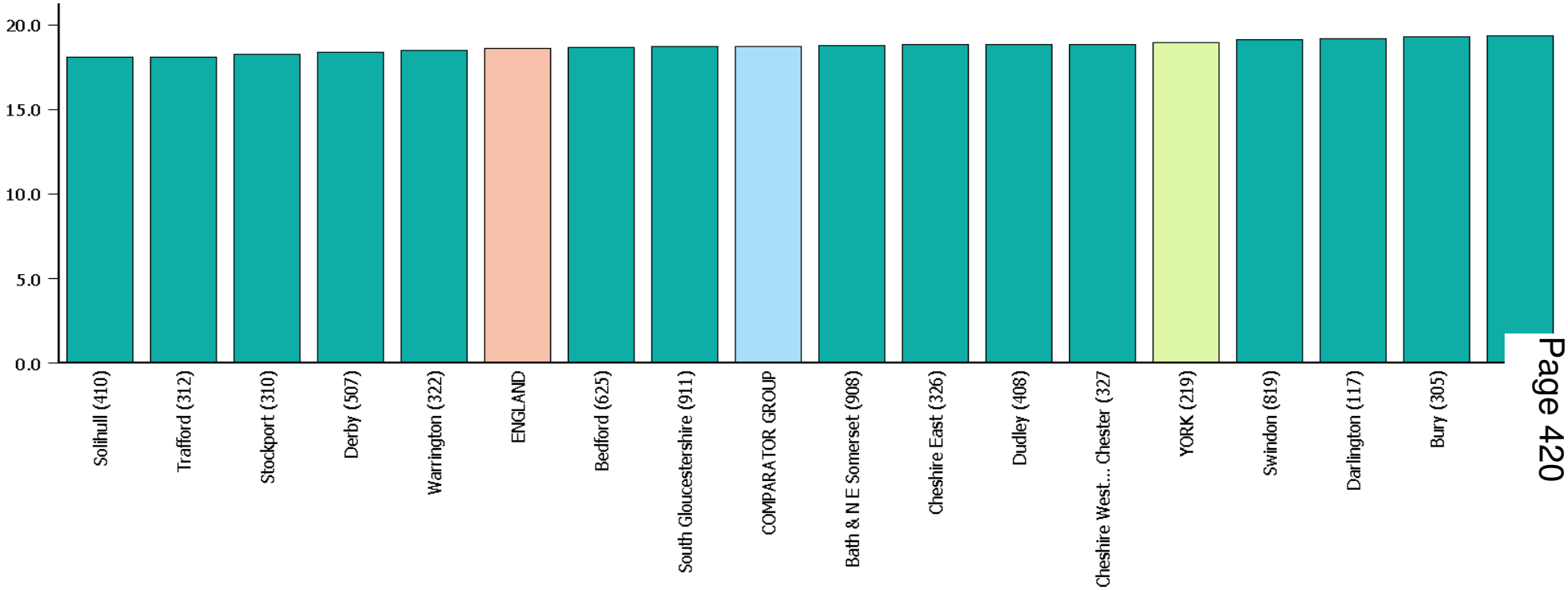
The Interactive Version: an executive summary version of the account available online available at **sampleurl3.york.gov.uk**

A single document showing an analysis of our performance will accompany all three versions called the GRAPHS & ANALYSIS document.

This is the GRAPHS & ANALYSIS Document which accompanies all the versions.

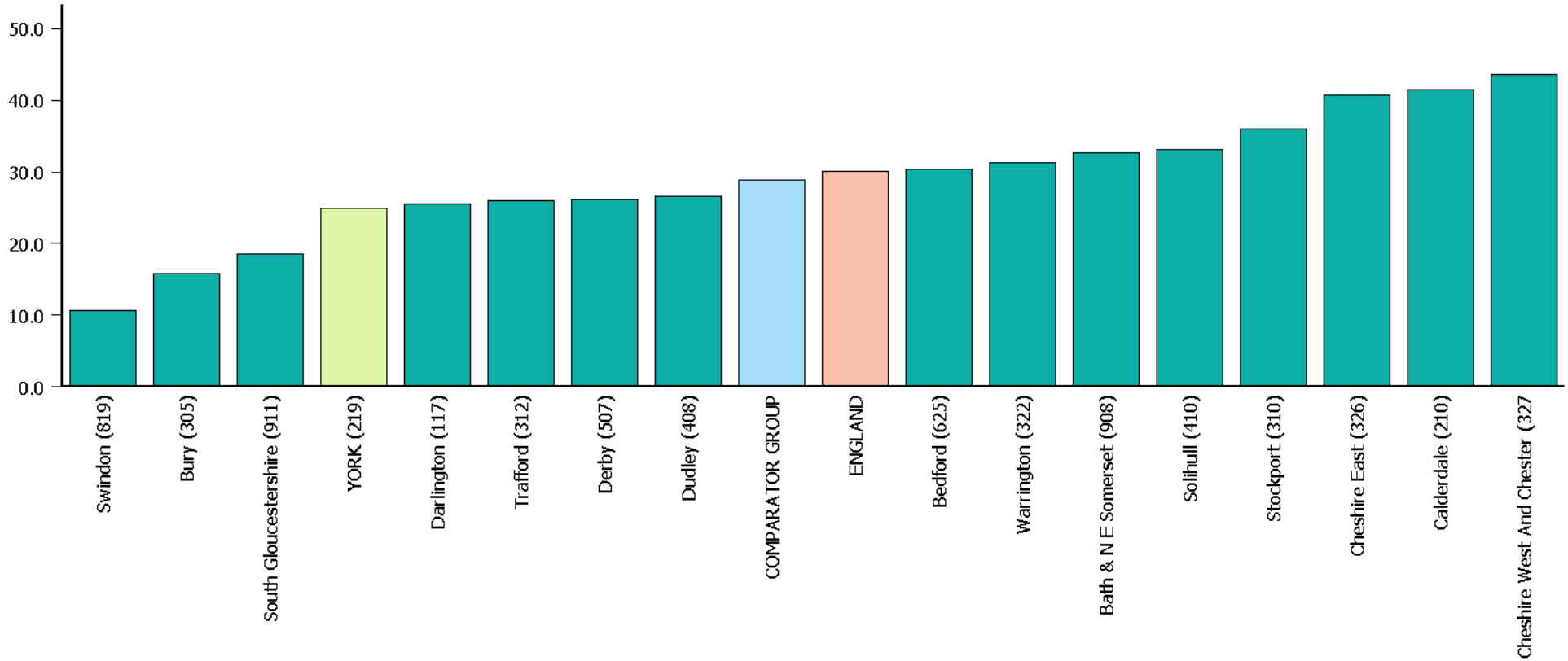
National Returns Data Sets.

Graph1: Self reported experience of social care users (expressed as a score out of 24), 2010-11



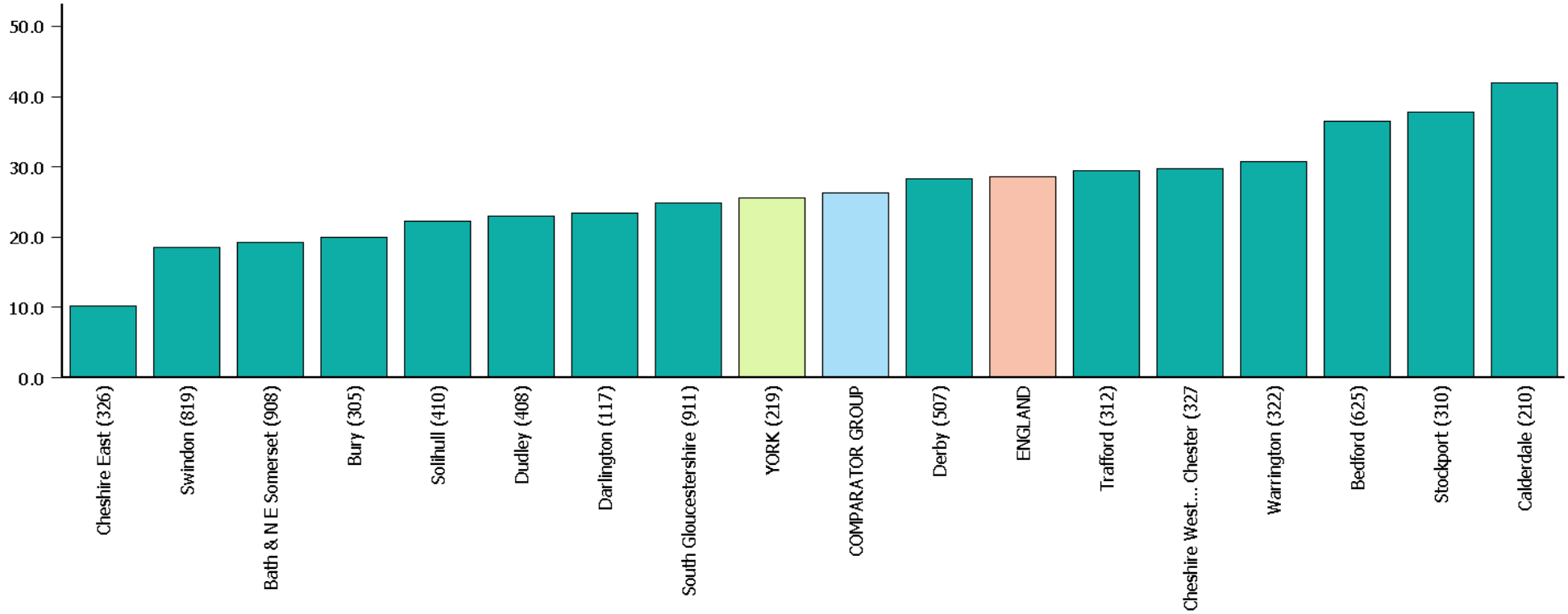
COMPARATOR GROUP	18.1	18.5	18.8	19.0	19.4
ENGLAND	17.4	18.3	18.6	19.0	19.7

Graph 2: Proportion of people using social care who receive self directed support, and those receiving direct payments



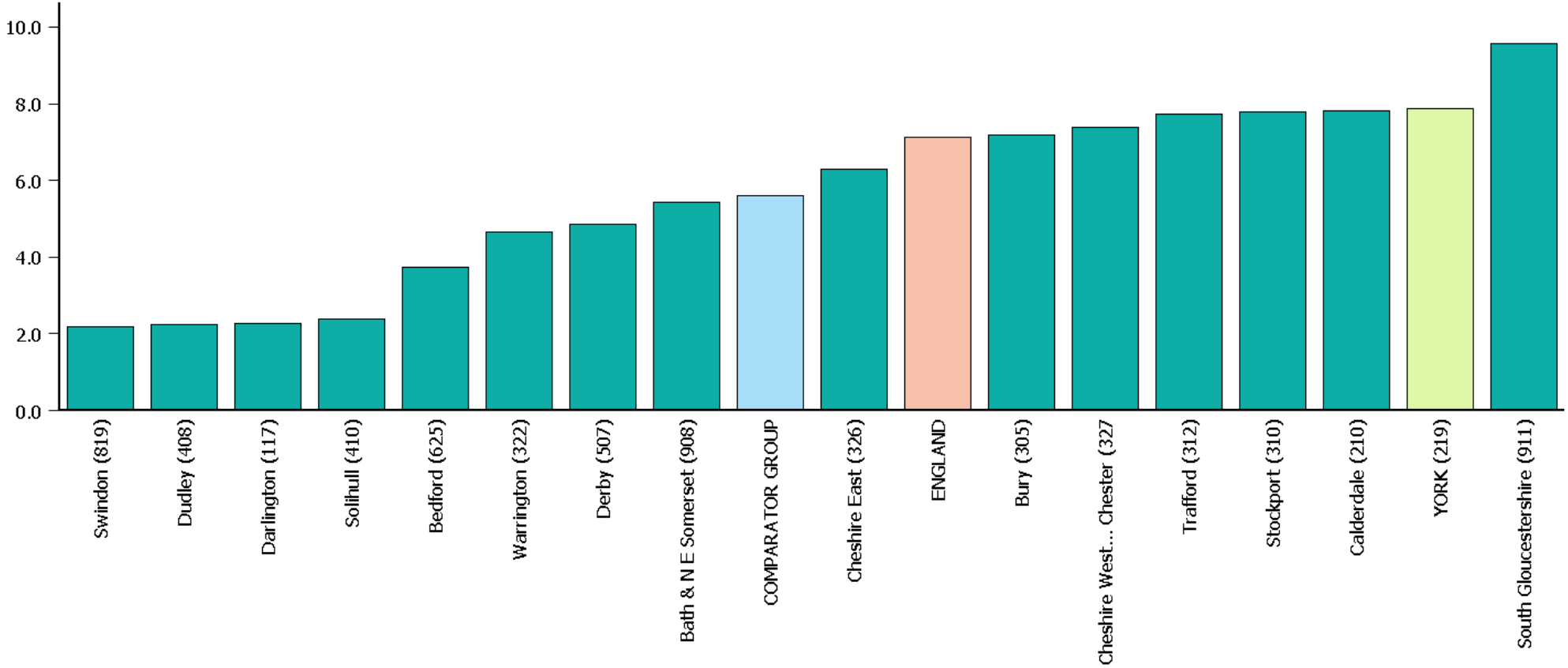
Comparator	Minimum	25th Percentile	Average	75th Percentile	Maximum
YORK (219)	.	.	24.9	.	.
COMPARATOR GROUP	10.6	25.2	28.9	34.6	43.5
ENGLAND	4.0	22.1	30.1	35.2	98.5

Graph 3: Carers receiving needs assessment or review and a specific carer's service, advice or information (expressed as a percentage), 2010-11



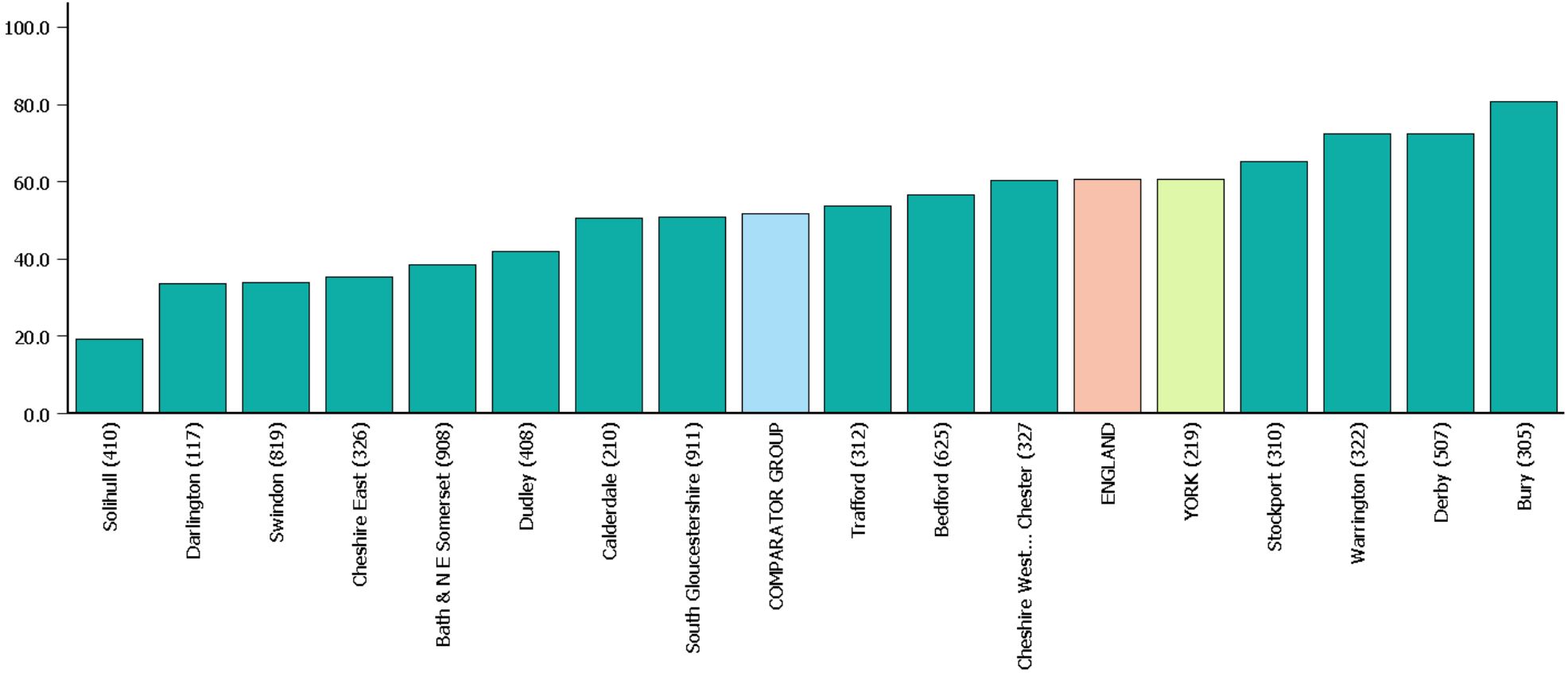
Comparator	Minimum	25th Percentile	Average	75th Percentile	Maximum
YORK (219)	.	.	25.5	.	.
COMPARATOR GROUP	10.2	21.1	26.4	30.2	41.9
ENGLAND	8.4	22.3	28.7	33.0	60.2

Graph 4. Proportion of adults with learning disabilities in paid employment:



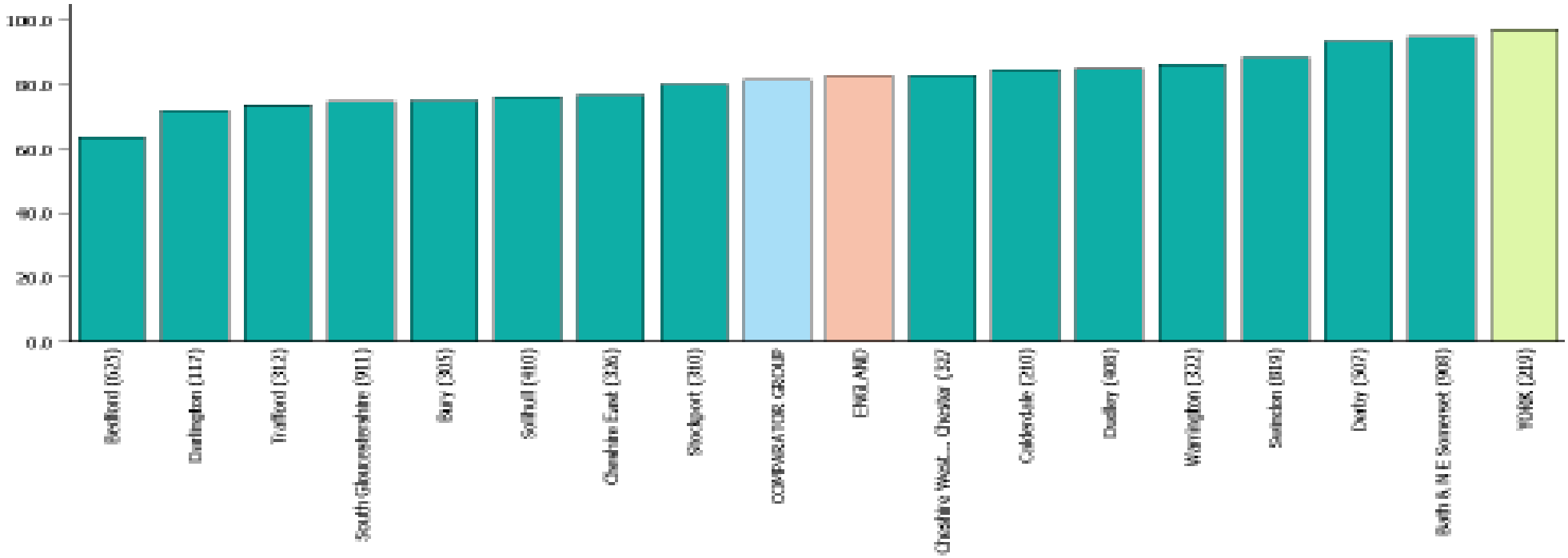
Comparator	Minimum	25th Percentile	Average	75th Percentile	Maximum
YORK (219)	.	.	7.9	.	.
COMPARATOR GROUP	2.2	3.1	5.6	7.8	9.6
ENGLAND	0.0	4.1	7.1	9.0	30.8

Graph 5. Proportion of adults with learning disabilities in settled accommodation



Comparator	Minimum	25th Percentile	Average	75th Percentile	Maximum
YORK (219)	.	.	60.6	.	.
COMPARATOR GROUP	19.3	36.9	51.6	62.8	80.8
ENGLAND	19.3	51.5	60.6	70.2	100.0

Graph 6. Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services



Comparator	Minimum	25th Percentile	Average	75th Percentile	Maximum
YORK (219)	.	.	97.1	.	.
COMPARATOR GROUP	63.4	74.9	81.6	87.2	97.1
ENGLAND	44.9	78.5	83.1	88.8	100.0

Adults Social Care Survey (ASCS) 2011

Background & methodology

Each year local authorities are required to compile and submit a number of statistics to the Department of Health concerning social care services provided by Social Services Departments. This year, the Adult Social Care Survey replaced the old user experience survey programme (PSS survey). The survey includes all eligible service users who were in receipt of a service on 30th September2010. This included service users who were in their own home, residential care, nursing care, extra care housing and sheltered accommodation who have received services funded by Social Services.

Postal questionnaires were sent out towards the end of January 2011 to 982 eligible customers selected at random. Two separate reminders were sent out in February 2011. Following two reminder letters, a total of 655 customers completed a survey. This gives an excellent response rate of 67%.

Data-processing was carried out by an independent research agency. The report was written by the CYC Business Intelligence Team.

Statistical reliability explained

Based on statistical rules, the overall results from this survey are accurate to within +/- 3.6% at the 95% confidence level. This means that if the exact same survey was carried out 100 times, 95 out of 100 times the results would not be more or less than 3.6% from the figures in this report. *This level is superior to the accepted industry standard of +/- 5%.*

The statistical accuracy of results at sub-level will vary. As a guide, a base size of 400 will have an accuracy level of +/- 4.7% at the 95% confidence level, 250 at +/- 6.0% and 100 at +/- 9.7%.

This report shows the figures for respondents who gave a definite response to each question so base sizes will vary where there are questions that have not been completed. Where responses do not add up to 100%, this is due to multiple coding (respondents could choose more than one option) or computer rounding.

Profile Sample from the Survey

655 People Completed the Survey.

84% of People completing the survey we over 55 years old.

Of the remaining 17%, 13% were between 35 and 74 years old, and 4% were 18 to 34 years old.

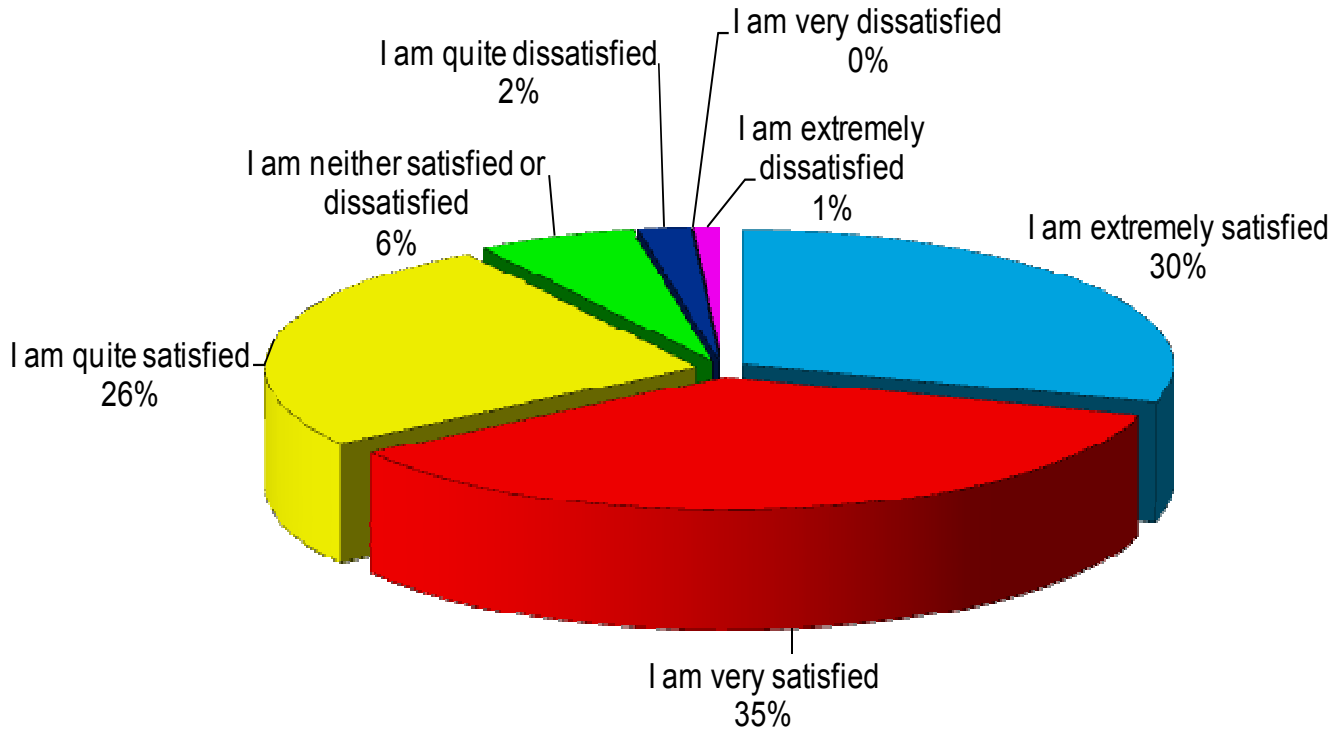
72% of respondents described themselves as having a physical disability, frailty or sensory impairment.

10% had a Learning Disability.

5% had Mental Health problems.

13% described themselves as “other” vulnerable people.

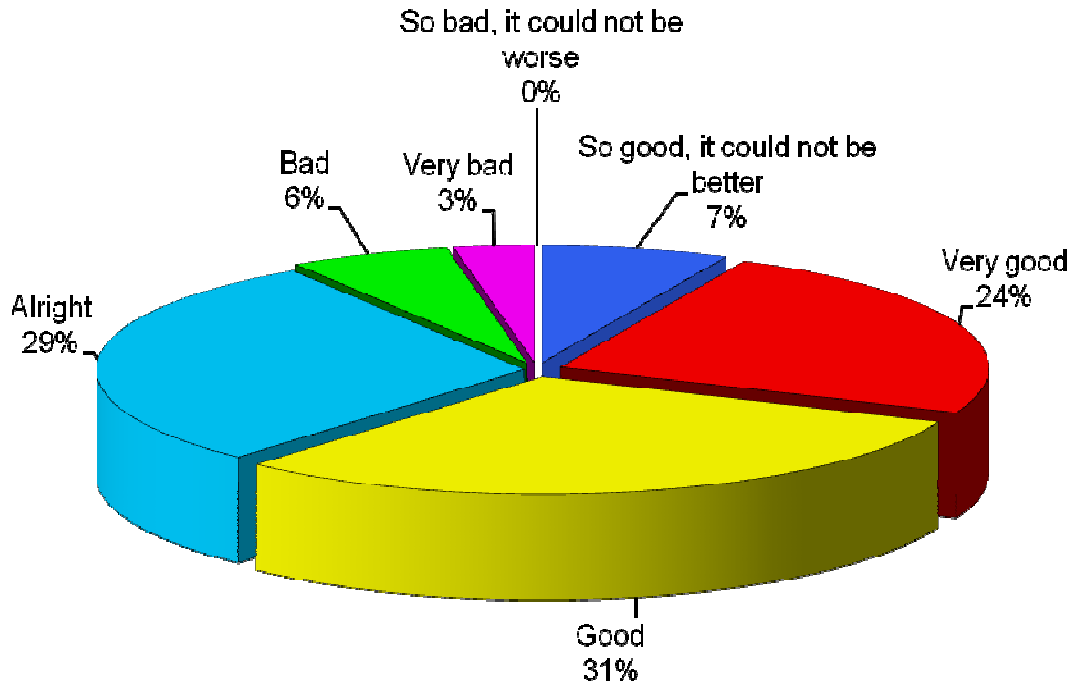
ASCS Q1: Overall, how satisfied are you with the care and support services you receive?



The overwhelming majority of the sample are satisfied to some degree with care and support services (91%).

Base: all respondents who answered the question (n= 499)

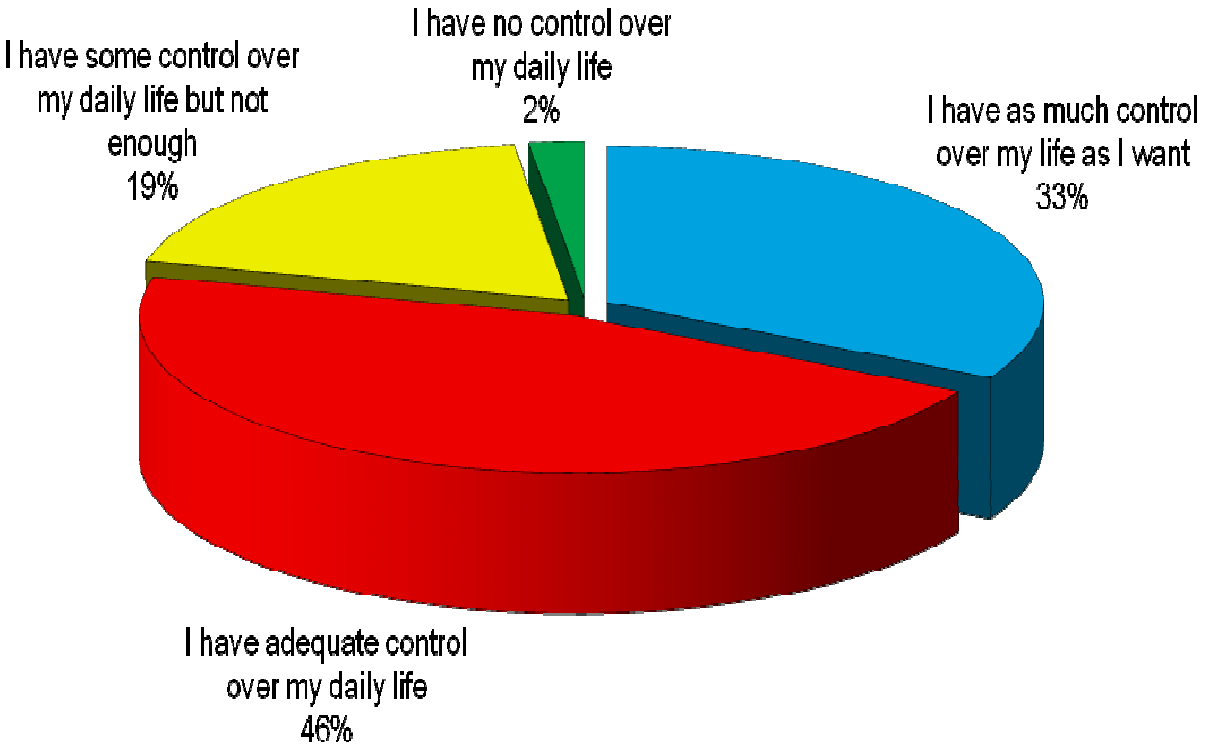
ASCS Q2: Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?



Nearly two-thirds (62%) of the sample regard their health as good, whilst a further 29% believe it to be alright.

Base: all respondents who answered the question (n= 521)

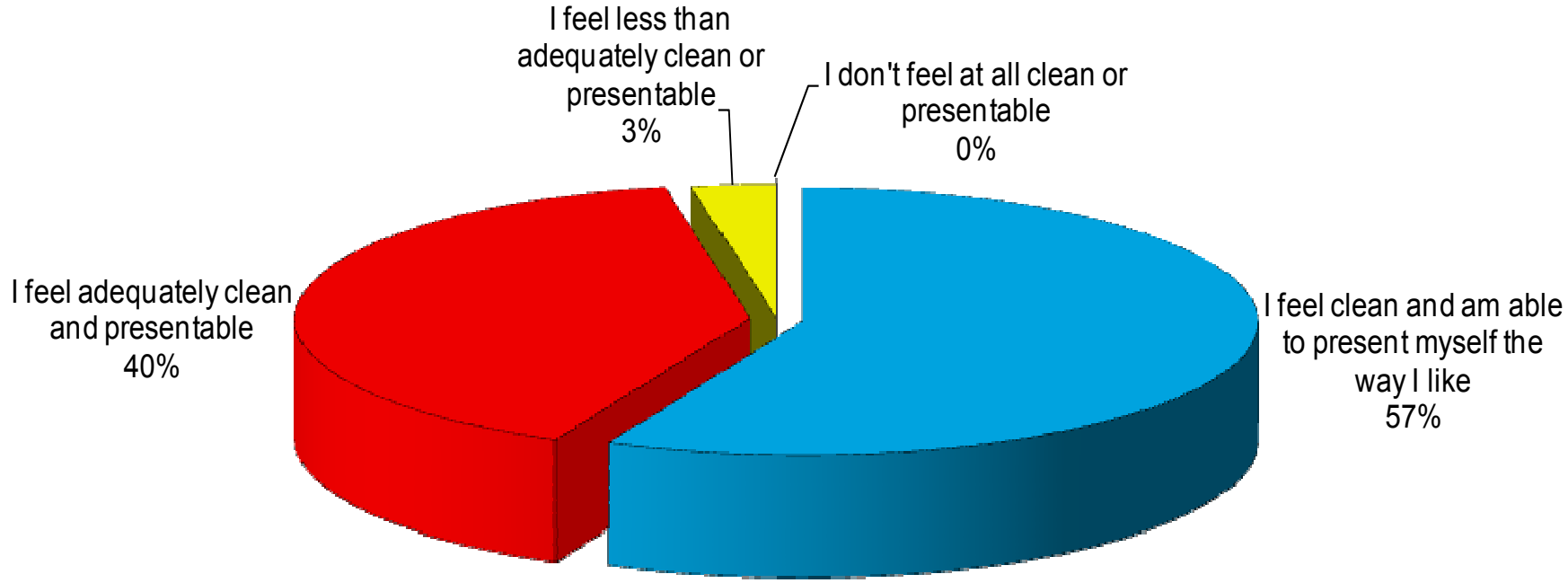
ASCS Q3: Which of the following statements best describes how much control you have over your daily life?



Respondents were more likely to say they have adequate control over their life, with nearly half (46%) saying this.

Base: all respondents who answered the question (n= 521)

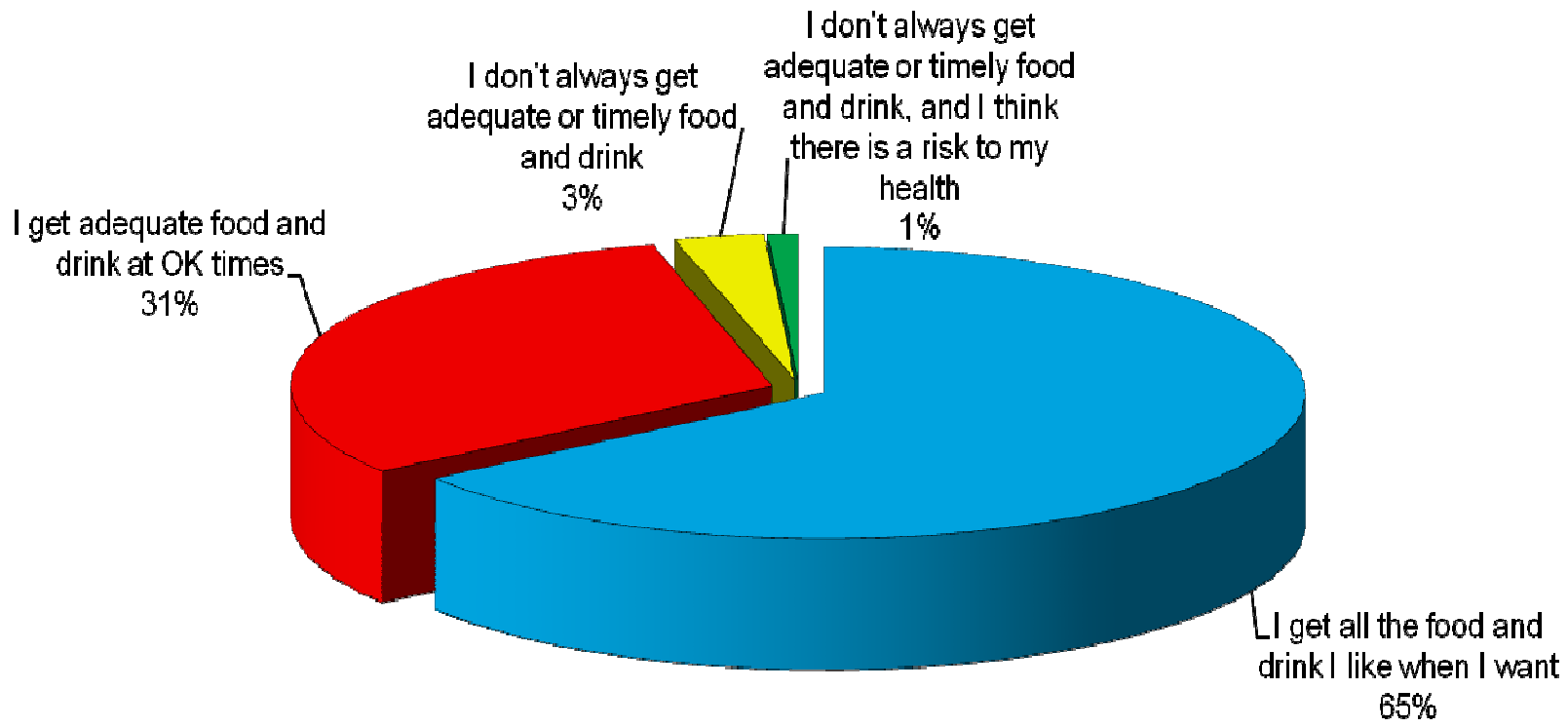
ASCS Q4: Thinking about your personal care, by which we mean being clean and presentable in appearance, which of the following statements best describes your situation?



More than half (57%) of the respondents said they feel clean and able to present themselves the way they like, whilst a further 40% said they feel adequately clean and presentable.

Base: all respondents who answered the question (n= 521)

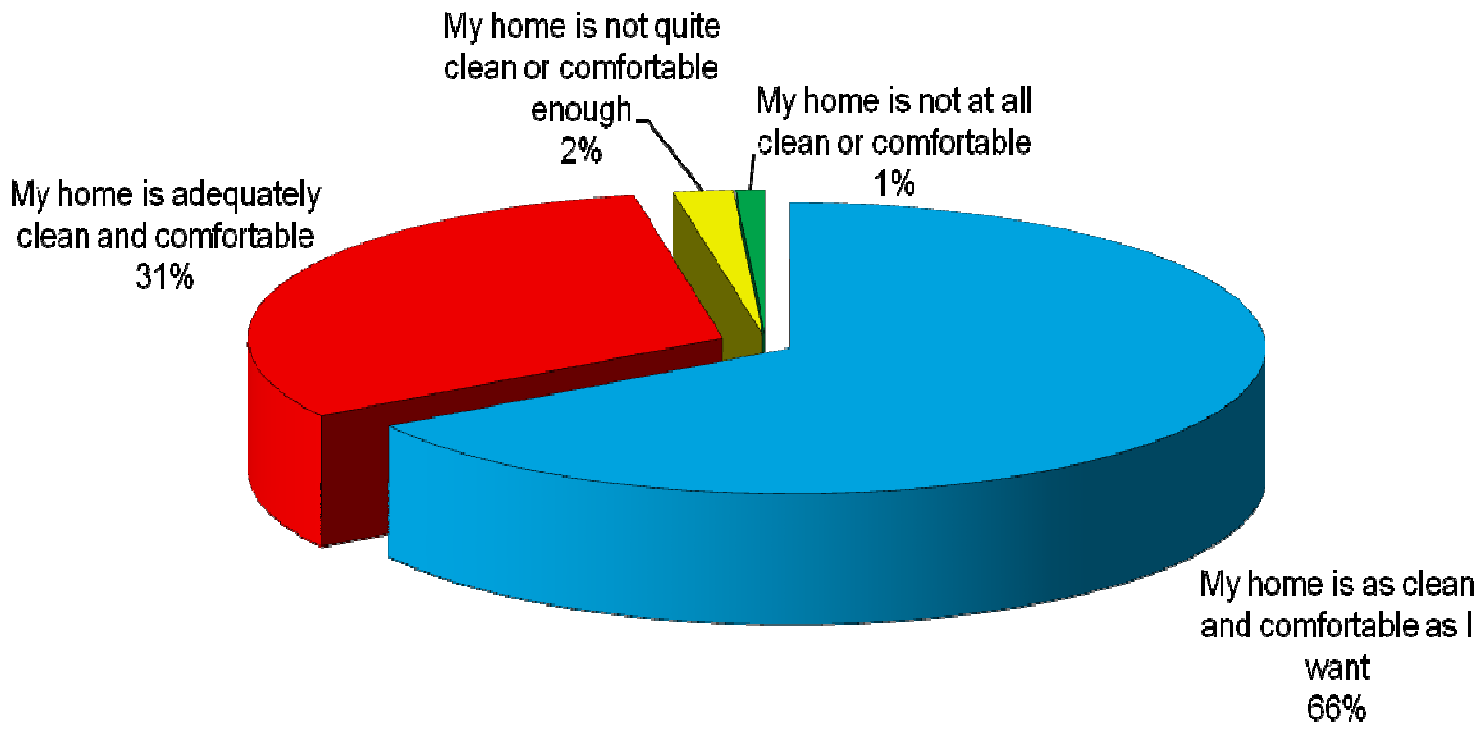
ASCS Q5: Thinking about the food and drink you get, which of the following statements best describes your situation?



Respondents were more likely to say they get all the food and drink they would like when they want, with two-thirds (65%) saying this. A further 31% said they get adequate food and drink at okay times.

Base: all respondents who answered the question (n= 518)

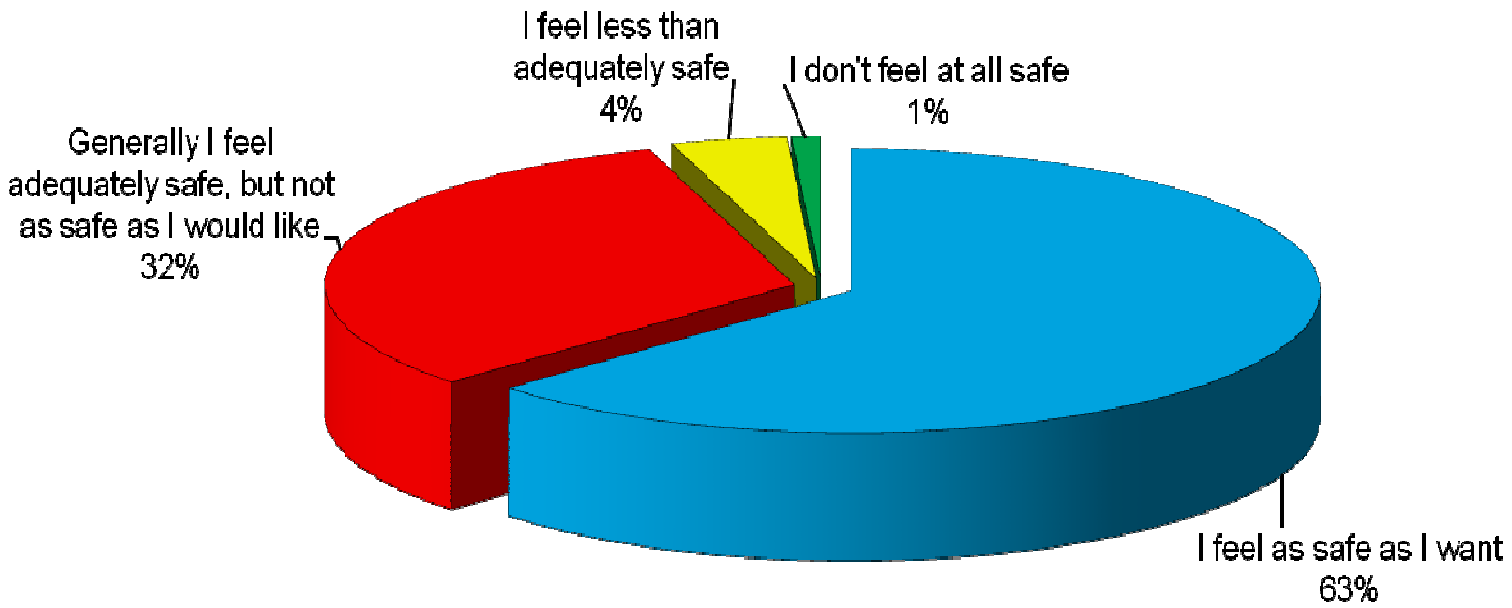
ASCS Q6: Which of the following statements best describes how clean and comfortable your home is?



The overwhelming majority of the sample are satisfied with the cleanliness and comfort of their home, with 97% saying it is at least adequately clean and comfortable.

Base: all respondents who answered the question (n= 520)

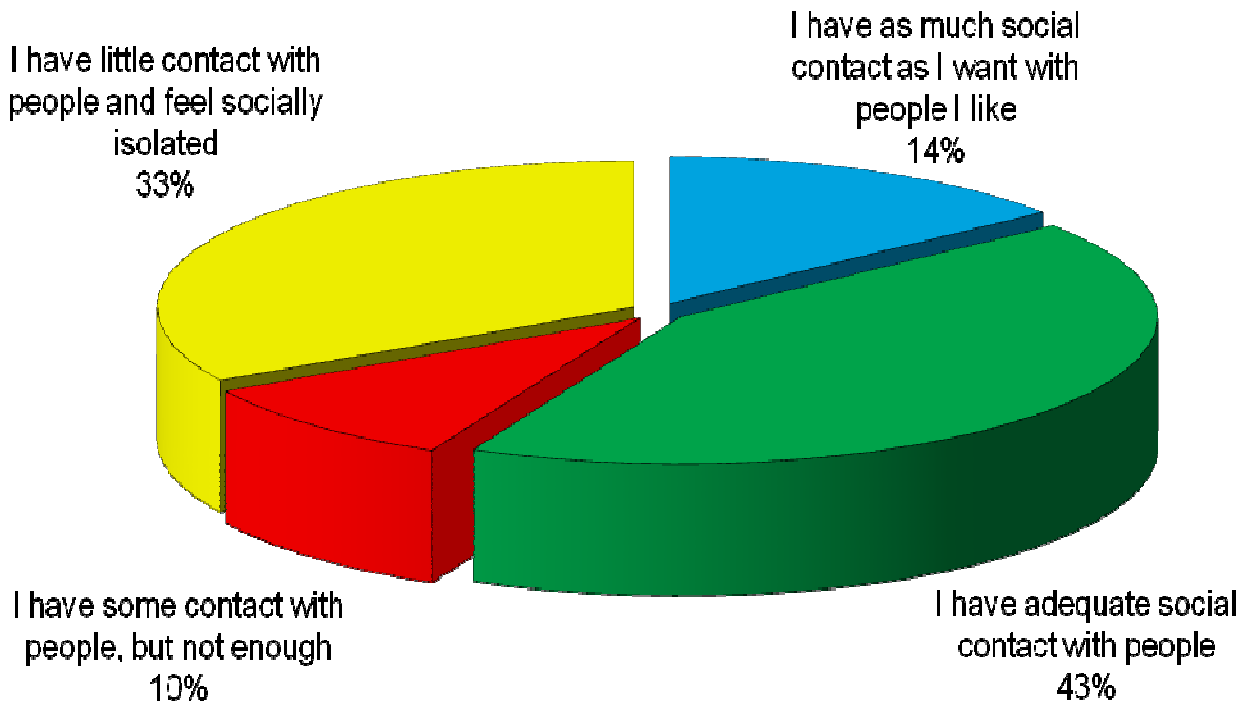
ASCS Q7: Which of the following statements best describes how safe you feel?



Nearly two-thirds (63%) of the respondents say they feel as safe as they would like, whilst 32% feel adequately safe, but not as much as they would like.

Base: all respondents who answered the question (n= 513)

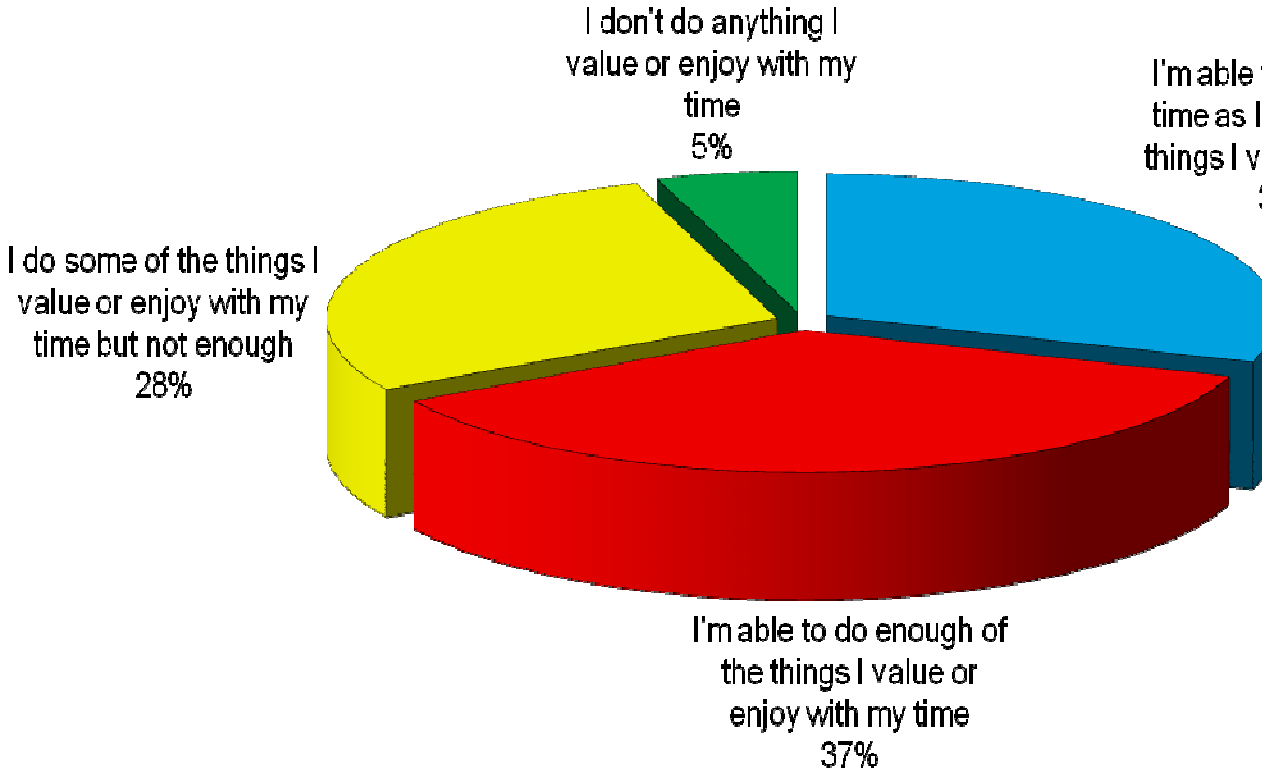
ASCS Q8: Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?



Over half (57%) of the sample have at least adequate social contact with people they like. However a third (33%) have only a small amount of social contact and feel isolated.

Base: all respondents who answered the question (n= 513)

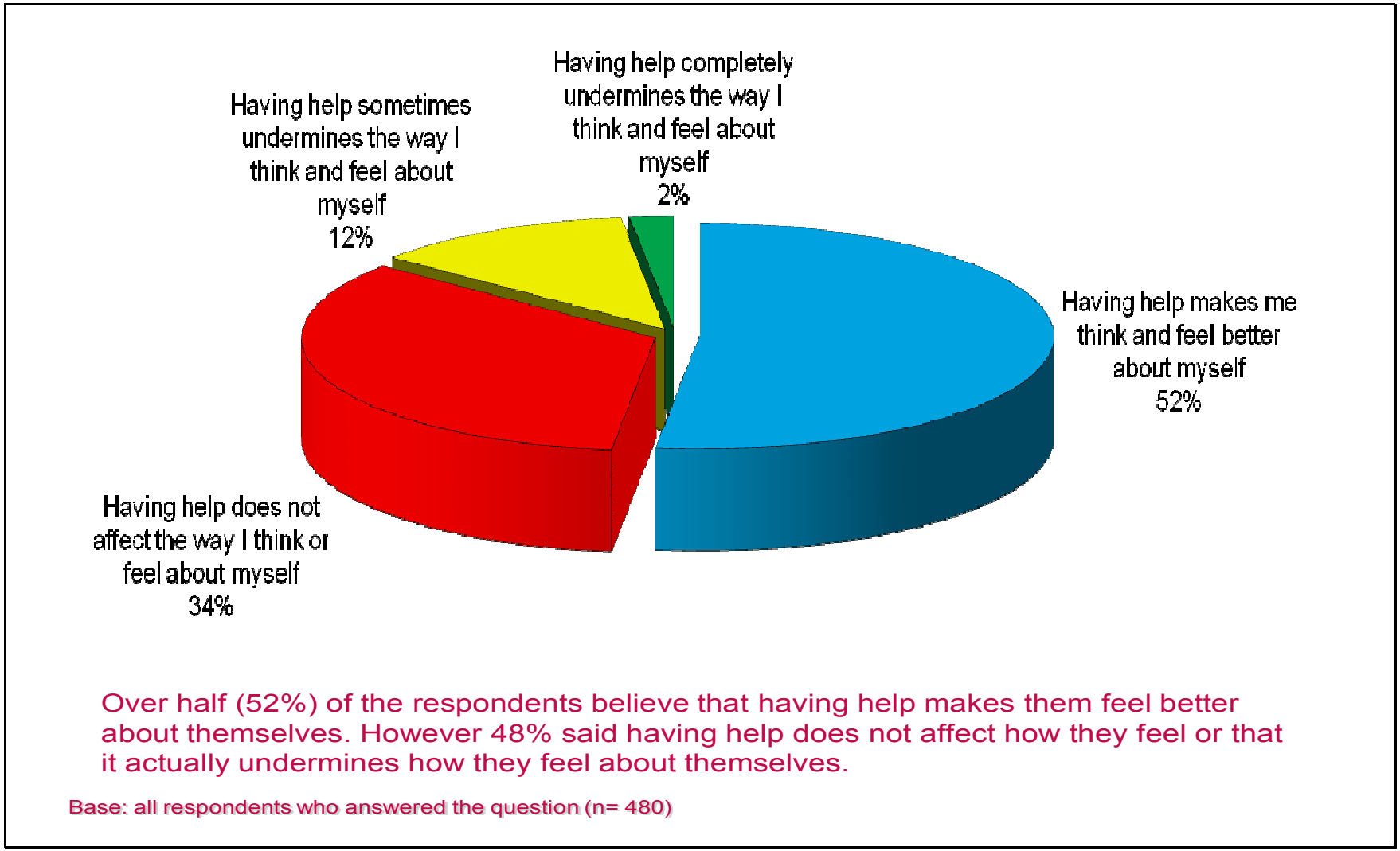
ASCS Q9: Which of the following statements best describes how you spend your time?



Two-thirds (67%) of respondents claim that they are able to do enough of the things they value and enjoy.

Base: all respondents who answered the question (n= 500)

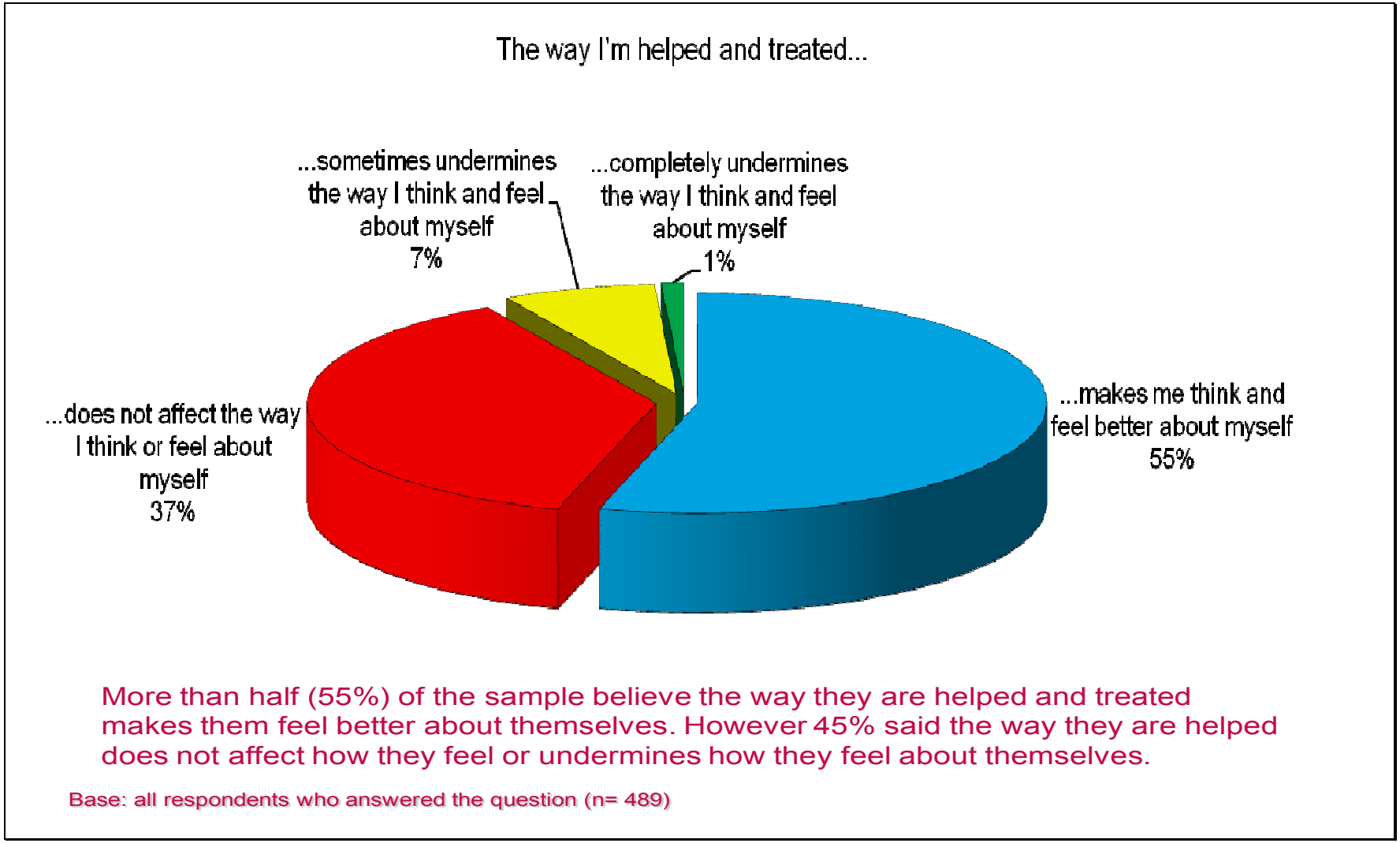
ASCS Q10: Which of these statements best describes how having help to do things makes you think and feel about yourself?



Over half (52%) of the respondents believe that having help makes them feel better about themselves. However 48% said having help does not affect how they feel or that it actually undermines how they feel about themselves.

Base: all respondents who answered the question (n= 480)

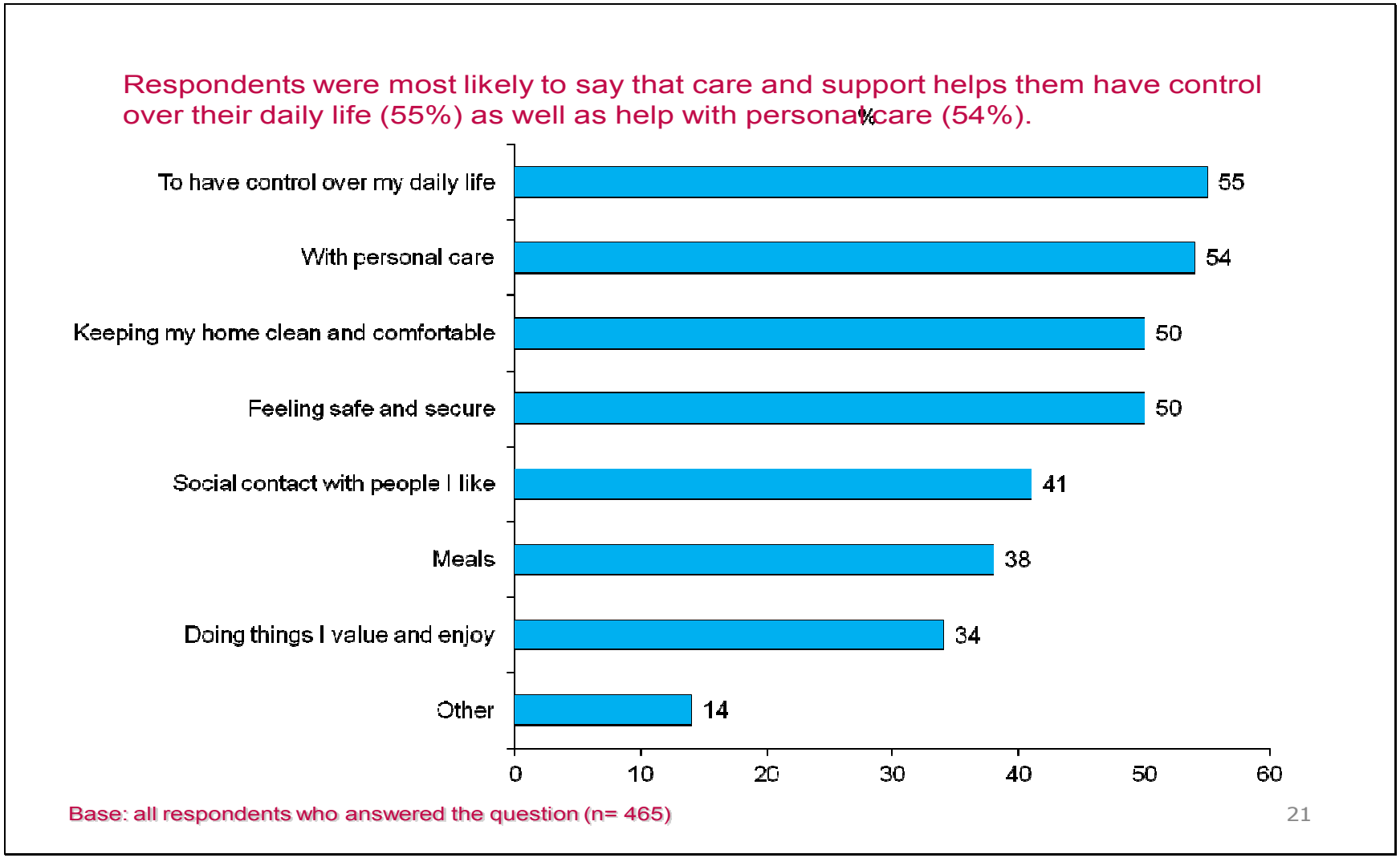
ASCS Q11: Thinking about the way you are helped and treated, and how that makes you think and feel about yourself, which of these statements best describes your situation?



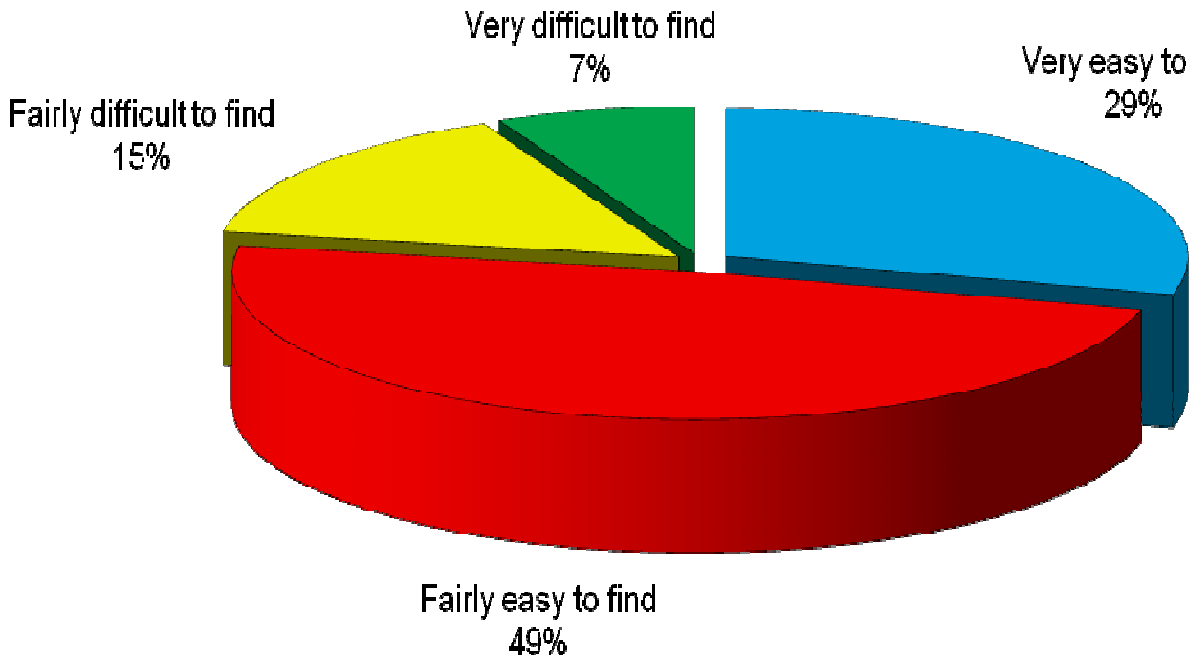
More than half (55%) of the sample believe the way they are helped and treated makes them feel better about themselves. However 45% said the way they are helped does not affect how they feel or undermines how they feel about themselves.

Base: all respondents who answered the question (n= 489)

ASCS Q12: In what ways do care and support services help you?



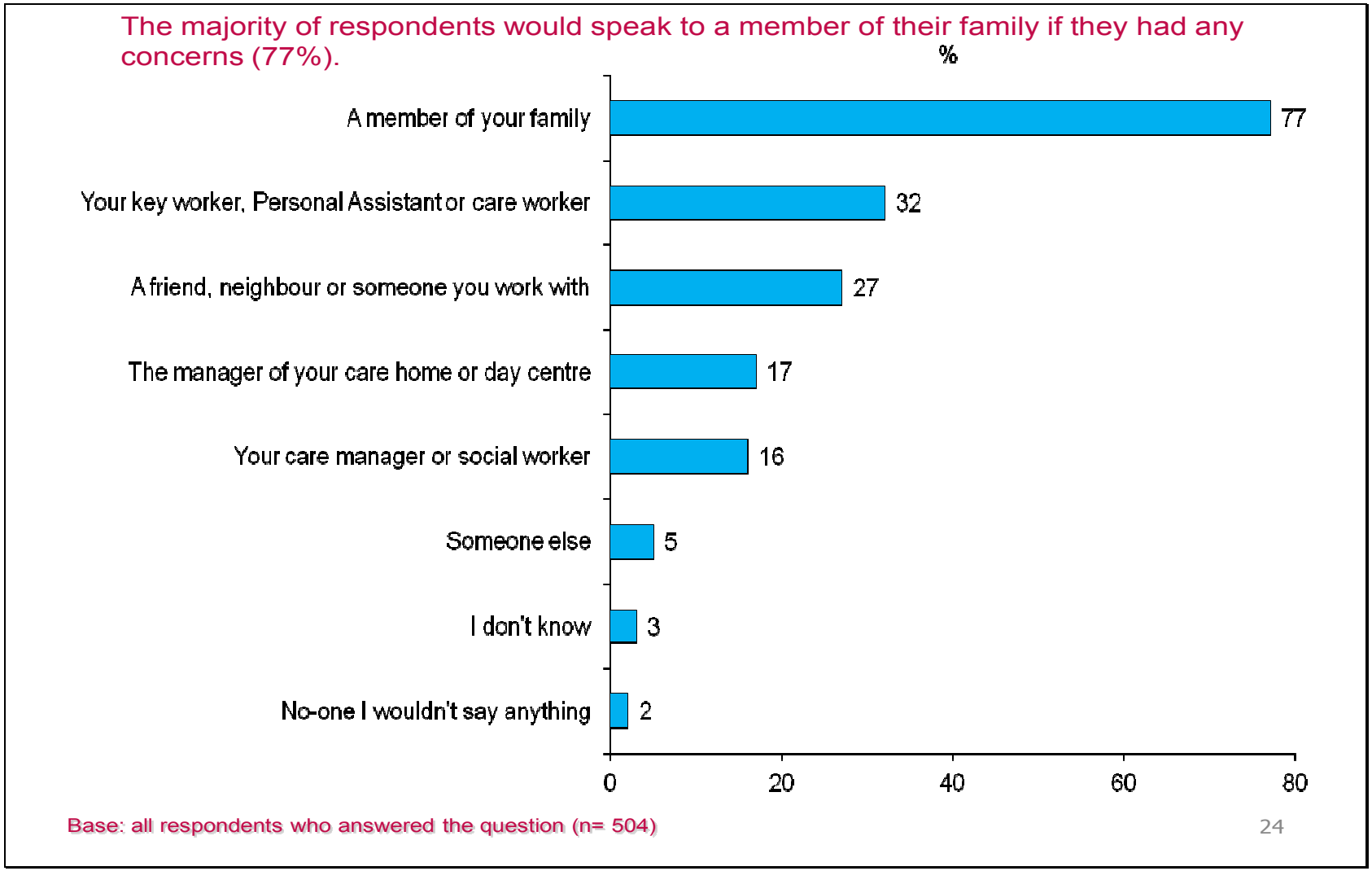
ASCS Q13: In the past year, have you found it easy or difficult to find information and advice about support, services or benefits?



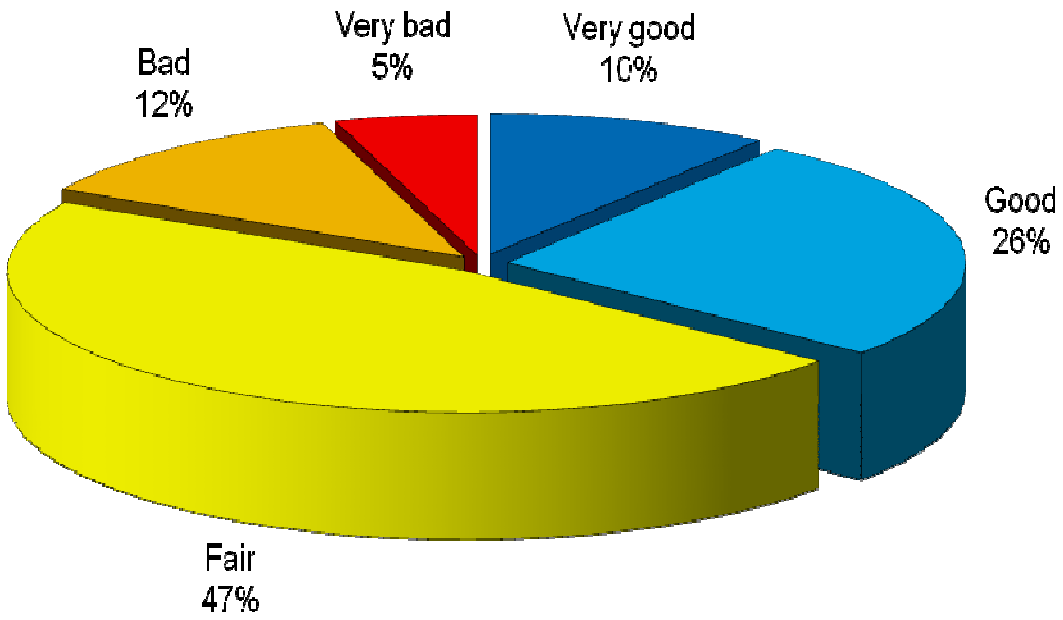
More than three-quarters (78%) of the sample said overall they found it easy to find information about services and support, with the majority of these individuals saying it was fairly easy (49%).

Base: all respondents who answered the question (n= 502)

ASCS Q14: Thinking about the care and support you receive, if you felt unsafe or were worried about something that had happened to you, who would you talk to?



SCS Q15: How is your health in general?



More than a third (36%) of the sample describe their health as good, whilst a further 47% describe it as fair. The remaining 17% of the sample believe their health to be bad.

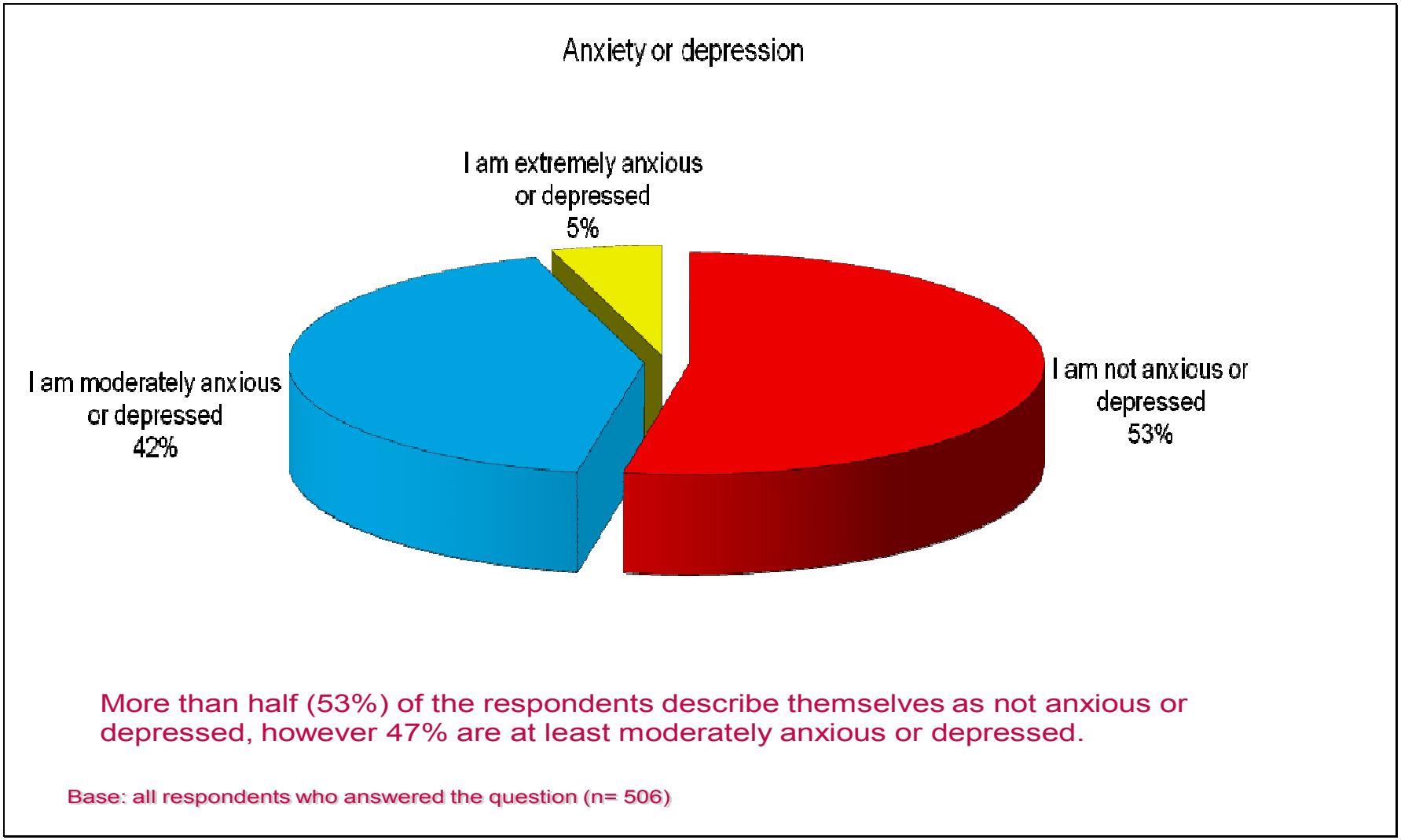
Base: all respondents who answered the question (n= 516)

ASCS Q16 (a): Please indicate which statements best describe your own health state today.

When asked to describe their state of health more than half report to have moderate pain or discomfort (60%), whilst 13% describe having extreme pain or discomfort.

Base: all respondents who answered the question (n= 506)

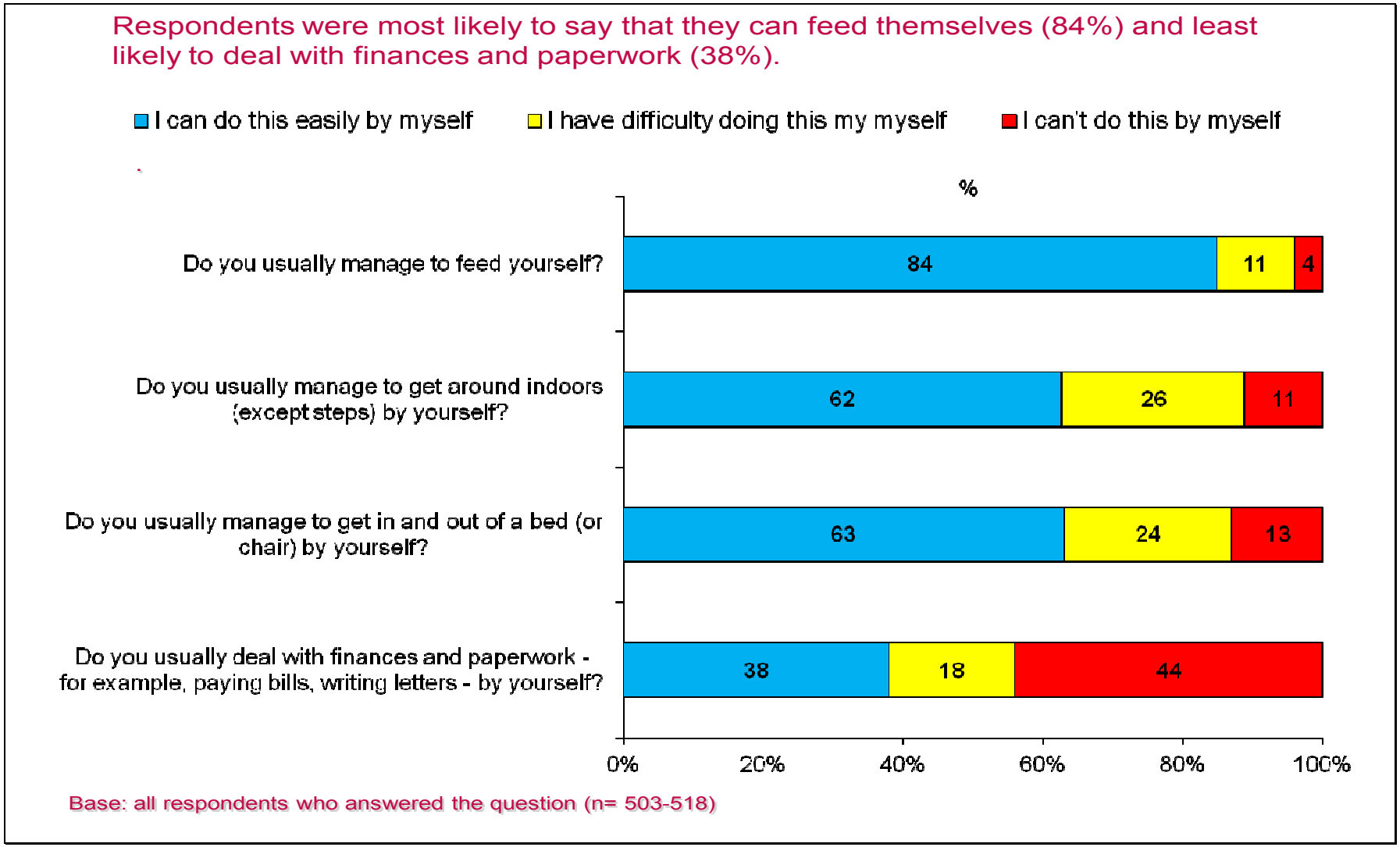
ASCS Q16 (b): Please indicate which statements best describe your own health state today.



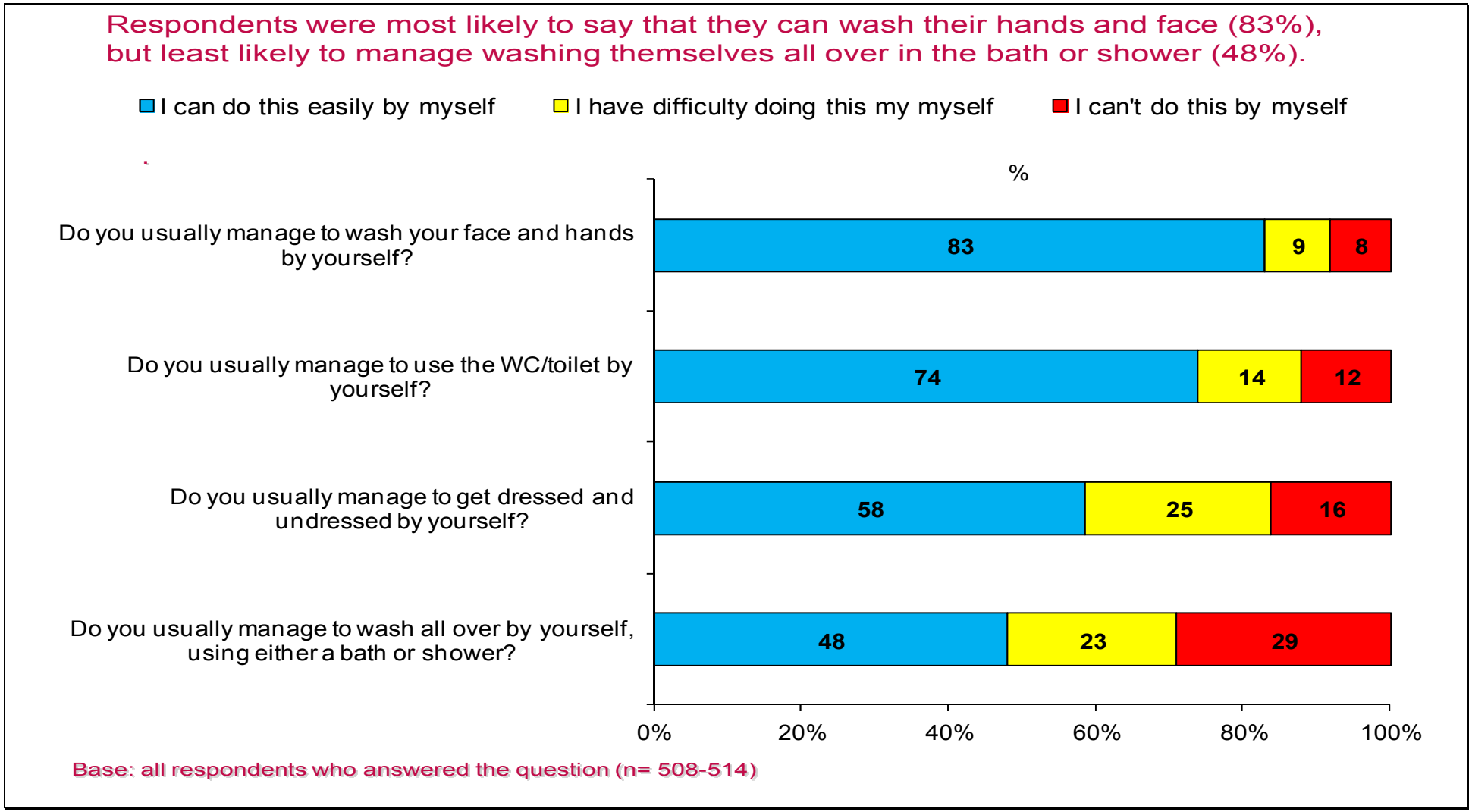
More than half (53%) of the respondents describe themselves as not anxious or depressed, however 47% are at least moderately anxious or depressed.

Base: all respondents who answered the question (n= 506)

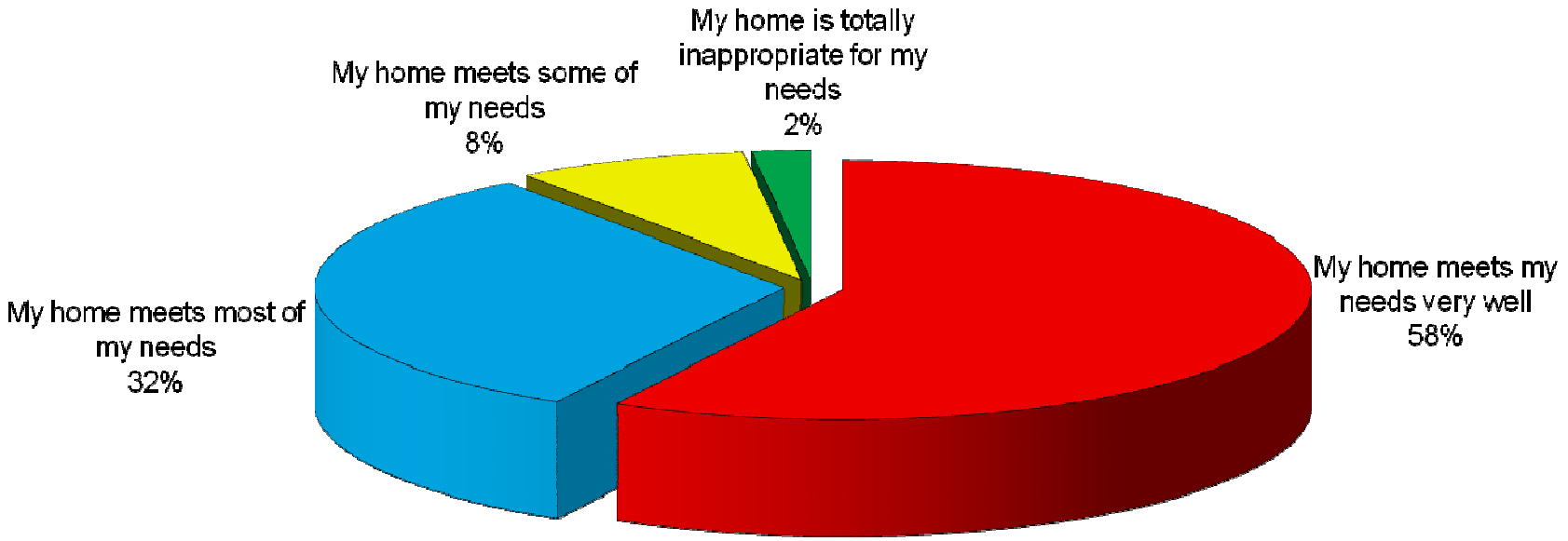
ASCS Q17: Please place a tick in the box that best describes your abilities for each of the following questions



ASCS Q18: Please place a tick in the box that best describes your abilities for each of the following questions



ASCS Q19: How well do you think your home is designed to meet your needs?



More than half (58%) of the sample believe their home meets their needs very well, whilst a further 40% said it at least meets some of their needs.

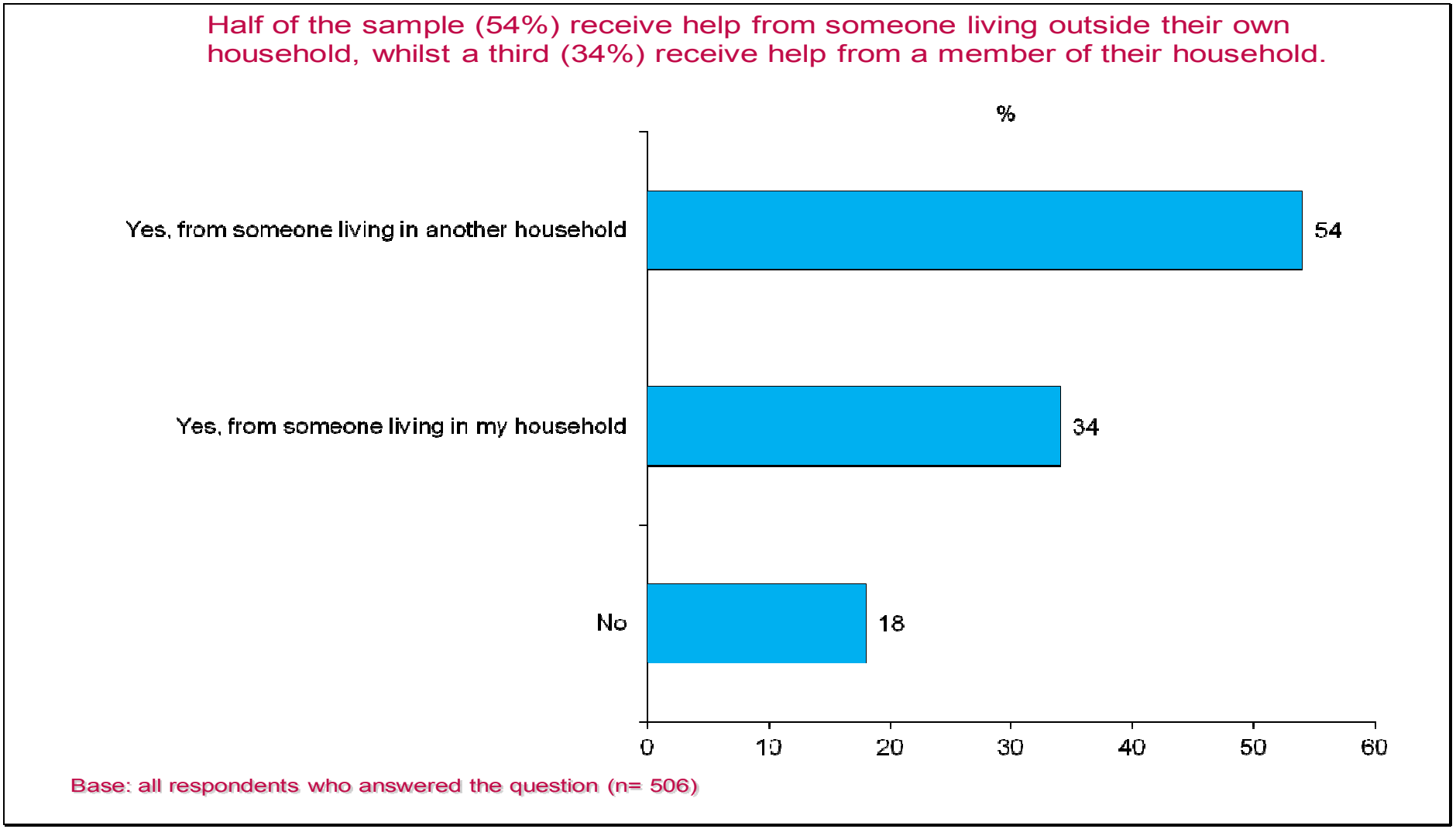
Base: all respondents who answered the question (n= 514)

ASCS Q20: Thinking about getting around outside of your home, which of the following statements best describes your present situation?

Around a third (36%) of the sample believe they can get to all places they want in their local area, whilst 28% said they find it hard at times and 20% are unable to get to the places they want in their local area.

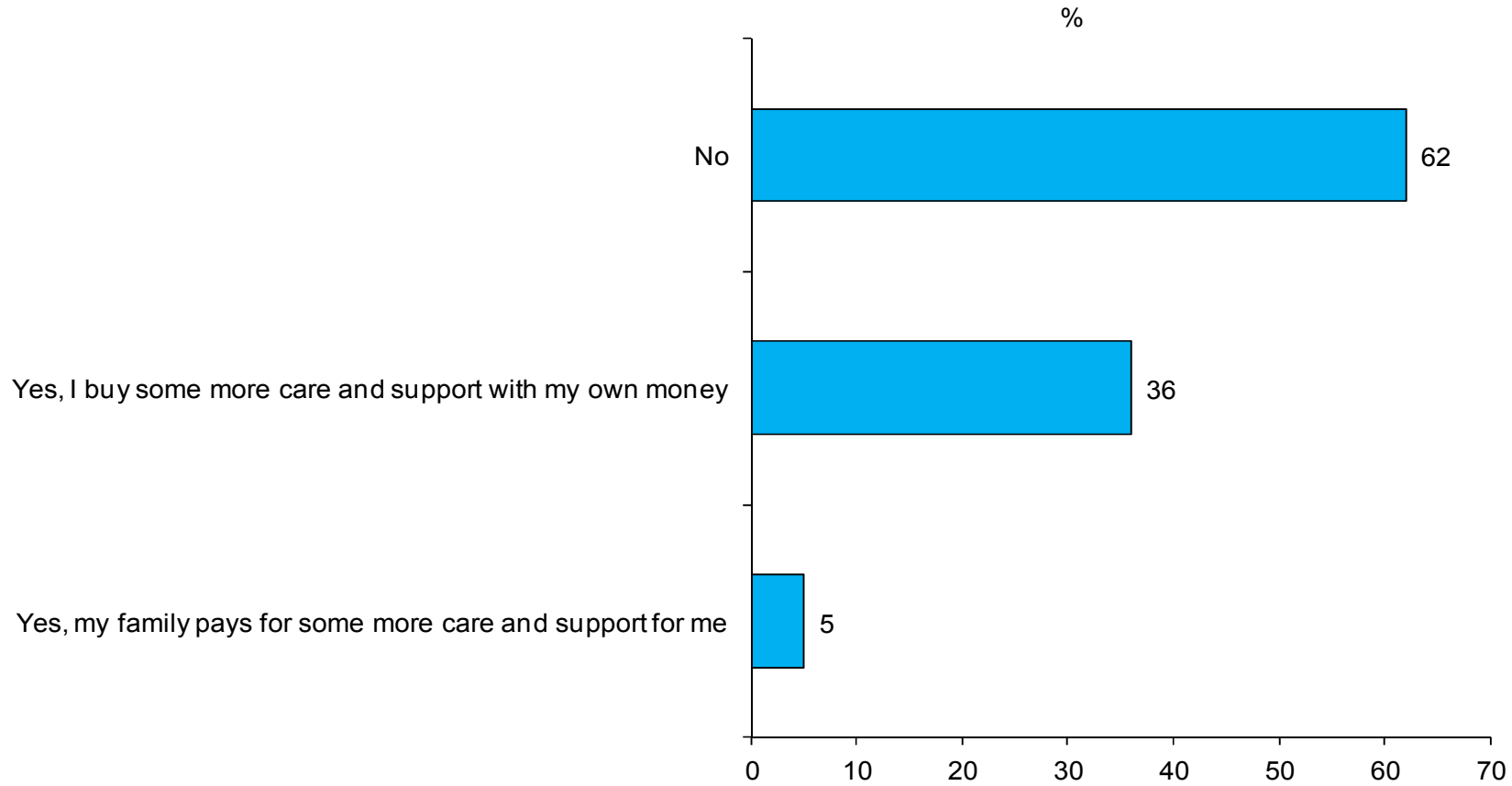
Base: all respondents who answered the question (n= 502)

ASCS Q21: Do you receive any practical help on a regular basis from your husband/wife, partner, friends, neighbours or family members?



ASCS Q22: Do you buy any additional care or support privately or pay more to 'top up' your care and support?

More than half (62%) of the sample do not pay for any additional care or support, whilst 36% do pay for more support with their own money.



Base: all respondents who answered the question (n= 482)

Notes on Graphs.

Data for 2010-11 is provisional. Please note that the England figures currently displayed on the Standard Reports are an average of the indicator values for all councils, as opposed to the sum of all the council numerators over the sum of all the council denominators.

Comparator Groups are based on the CIPFA "nearest neighbour methodology" which makes it possible to identify councils with like demographic features. This data is calculated from the submitted values from 15 other councils with the most similar "nearest neighbour profile". NB: These groups are not necessarily the same as the family groups used by other inspectorates or council departments.

Sources for data which are not from the survey will be references. The CYC analysis and graphing pre-dates that of the DH, and uses partially completed surveys as well as responses to easy read survey. This means that there are minor discrepancies between local graphs and published DH data.

The author acknowledges that the data contained within charts and tables featured in this report in respect of the former National Indicator set are sourced from *NASCIS, The website of the Health and Social Care Information Centre.*

Useful Links.

The Adult Social Care Outcomes Framework - Handbook of definitions:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_128362

Personal Social Services Adult Social Care Survey, England - Provisional 2010-11: http://www.ic.nhs.uk/statistics-and-data-collections/social-care/user-surveys/personal-social-services-adult-social-care-survey-england--provisional-2010-11

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Health Overview & Scrutiny Committee **14 December 2011**

Report of the Assistant Director Governance & ICT

Update Report – End of Life Care Review *'The Use & Effectiveness of DNACPR[1] forms'*

Summary

1. This report updates the Committee on progress made in relation to their review on End of Life Care. It details outcomes of an informal meeting held on 13th October 2011 where the aim was to begin to scope and timetable the review. It also sets out further developments since that date.

Background

2. At a scrutiny work planning event held on 25th July 2011 it was agreed that the Health Overview and Scrutiny Committee would do some review work around End of Life Care. This led to a workshop being held on 31st August 2011 between Members of the Committee and a variety of stakeholders to agree a focus for the review. Discussions led to the focus being agreed as the 'use and effectiveness of DNACPR forms'.

3. At a full meeting of the Health Overview and Scrutiny Committee on 21st September Members deferred an item to clarify the scope and timetable to the review and the matter was subsequently considered at an informal meeting on 13th October.

Outcomes from 13th October meeting

4. At the meeting on 13th October Members completed the Scrutiny Topic Assessment Form and this is now attached at **Annex A** for information. The completed Topic Registration Form acts as the scope for the review and sets out information on who the

[1] Do Not Attempt Cardiopulmonary Resuscitation

Committee will consult and the kind of information they will want to receive.

5. In addition to this the Committee agreed that they would potentially hold two evidence gathering meetings as follows:

   Monday 28th November - 9am to 12 noon
   Monday 5th December – 2pm to 5pm

6. The Members of the Committee who attended on 13th October agreed to undertake some preliminary evidence gathering via the internet/telephone based on the information in **Annex A**. It was also agreed that those present at that meeting would contact various organisations with a view to making initial contact and inviting them to attend one of the two meeting dates that had been set aside for evidence gathering (detailed in **Paragraph 5** of this report). Once the initial contact has been made then formal invitations to give evidence would be sent.

   Further developments

7. However, since then it has come to light that the original dates set were not practical for many of the key health partners to attend. In addition to this further discussions with the Chair highlighted the need for the Committee to receive some background information on DNACPR forms prior to gathering evidence from key health partners in relation to how they use the forms.

8. In light of this a further informal meeting of the Committee has been arranged for Wednesday 21st December at 1pm to consider background information on DNACPR forms that will be provided by NHS North Yorkshire & York.

Consultation

9. Various health organisations and partners would be asked to give evidence as part of the review; these are detailed in **Annex A** to this report.

Options

10. Members are asked to note the contents of this report.

Analysis

11. Members are asked to note the contents of the report and the additional meeting date of 21st December 2011.

12. It is envisaged that once the Committee have received the background information from NHS North Yorkshire & York they will be in a better position to agree a line of questioning for future evidence gathering sessions and to agree a timeline for the rest of the review.

Council Plan 2011-2015

13. This report is linked with the 'Protect Vulnerable People' theme of the Council Plan in particular the key outcome:

    'There will be a focus on independence and greater choice and control over their lives for vulnerable people'.

Implications

14. There are no financial, human resources, legal or other implications associated with the recommendations in this report. Implications may arise as the review progresses and these will be addressed accordingly.

Risk Management

15. There are no known risks associated with the recommendations within this report.

Recommendations

Members are asked to note the contents of this report.

Reason: To progress this review

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Report Approved ✓ **Date** 01.12.2011

Specialist Implications Officer(s) None

Wards Affected: **All** ✓

For further information please contact the author of the report

Background Papers:

None

Annexes

Annex A Completed Scrutiny Topic Assessment Form

Annex A

SCRUTINY TOPIC ASSESSMENT FORM FOR COUNCILLORS
'ONE PAGE STRATEGY'

What is the broad topic area?

End of Life Care

What is the specific topic area?

'Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Forms – Their Use and Effectiveness'

Ambitions for the review:

To try and ensure that patients* wishes and instructions are acted upon by health professionals and carers at the end of life, especially in terms of ensuring that instructions in relation to information on DNACPR forms is up to date and adhered to when required.

*Adults aged 16 & over

(For completion by the relevant Overview & Scrutiny Committee)

Does it have a potential impact on one or more sections of the Population? **Yes** [X] **No** [ ]

Is it a corporate priority or concern to the council's partners? **Yes** [X] **No** [ ]

Will the review add value? And lead to effective outcomes?[1] **Yes** [X] **No** [ ]

Will the review duplicate other work? [2] **Yes** [ ] **No** [x]

Is it timely, and do we have the resources? **Yes** [x] **No** [ ]

If the answer is 'Yes' to all of the above questions (bar the duplication question), then the Committee may decide to proceed with the review. To decide how best to carry out the review, the Committee will need to agree the following:

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[1] The review topic is a sub-set of a very broad issue. It will increase the chances of having effective outcomes for more residents.

[2] The review will complement rather than duplicate other work by narrowing in on a sub-set where there are some known problems/concerns

Annex A

1) Who and how shall we consult?

Questions to Ask

To clarify what the DNACPR form is, how the form works, who recognises the form
To understand & clarify the difference between a DNACPR form and a living will
To understand what variants there are to the DNACPR form, if any
To understand how the form came into being
To understand what is happening now and why it is happening
To find out how many DNACPR forms are not adhered to & why (statistical rather than specific information)
To understand how clearly the scheme is set up
To understand the opinions/guidance & advice of professional organisations in relation to this form
To investigate how things can be improved and who can help with any suggested improvements

Who to Consult
(either via face to face discussions, written correspondence or internet/telephone research)

NHS North Yorkshire, York & GP Commissioners, District Nurses
Individual GPS *(target 2 practices)*
Yorkshire Ambulance Service
York Teaching Hospital NHS Foundation Trust
Independent Care Group
York Link
St Leonard's Hospice
City of York Council Adult Social Services
Carers
Voluntary Sector (Age UK, McMillan, local Stroke Association, Older People's assembly)
General Medical Council (GMC), British Medical Association (BMA) for any ethical guidance on DNACPR forms *(internet/telephone research to look at measurement against gold standard/national standards/local standards)*
National Hospice & Palliative Care website
Patient opinion websites

2) Do we need any experts/specialists? (internal/external)*?*

See list above

To 'advertise' the review with CVS & Links to try and encourage people to come and talk to the Committee

3) What other help do we need? E.g. training/development/resources

Apart from the information detailed above the following is required to give a whole picture of the situation:

To revisit the LINk report on End of Life Care Services and the recommendations contained within it (28th August 2009)

4) How long should it take?

The whole review should be complete by the end of the municipal year.

Next meetings will be to gather evidence and will take place as follows with venue to be confirmed:

Monday 28th November 9am to 12 noon
Monday 5th December 2pm to 5pm

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Health Overview & Scrutiny Committee Work Plan 2011/2012

Meeting Date	Work Programme
14th December 2011 (postponed from 30th November 2011)	1. Update from Yorkshire Ambulance Service on Complaints Service 2. Quarterly Financial & Performance Monitoring Reports 3. Regional Joint Scrutiny Committee's Final Report in relation to Proposed Changes to the Provision of Children's Cardiac Surgery 4. Report - Proposed Changes at the Walk In Centre 5. Health Watch Procurement Monitoring Report 6. Update Report on Carer's Review *(the report will include; an Update on the Implementation of the Recommendations Arising from the Carer's Review, Six Monthly Report in Relation to the Indicators being Monitored in Relation to Cares and an annual update report on the Carer's Strategy for York)* 7. The Local Account for Adult Social Care 8. Update on the End of Life Care Review (The Use & Effectiveness of DNACPR Forms) 9. Work Plan
18th January 2012	1. Update on the Implementation of the Recommendations Arising from the Childhood Obesity Scrutiny Review 2. Health Watch Procurement Monitoring Report 3. Update on Dementia Strategy Action Plan 4. Update on the Shadow Health & Well Being Board 5. Briefing from Leeds Partnership Foundation Trust on Proposed Changes to the Mental Health Service *(Verbal Update)* 6. Ward Redesign at Bootham Park Hospital 7. Work Plan
14th March 2012	1. Quarterly Financial & Performance Monitoring Reports 2. Health Watch Procurement Monitoring Report 3. Work Plan

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