NHS National Services Scotland

REVIEW OF CHILDREN'S CONGENITAL CARDIAC SERVICES AT ROYAL HOSPITAL FOR SICK CHILDREN (YORKHILL), GLASGOW

REPORT OF THE INDEPENDENT EXPERT PANEL CHAIRED BY PROFESSOR SIR IAN KENNEDY

FEBRUARY 2012

Background and Context

In 2010 an expert group of children's heart doctors, lay representatives and NHS commissioners developed a set of quality standards against which paediatric congenital cardiac surgical units in England were assessed by an independent expert panel under the auspices of the *Safe and Sustainable* review. The standards had been endorsed by the relevant professional associations in the United Kingdom including the British Congenital Cardiac Association, the Society for Cardiothoracic Surgery of Great Britain and Ireland and the Royal College of Paediatrics and Child Health, as well as national heart charities such as the Children's Heart Federation. The standards are included as Appendix A to this report.

Although the service at the Royal Hospital for Sick Children at Yorkhill in Glasgow ('the Hospital') is not subject to the review of services in England, an expert panel was asked by the devolved administration in Scotland to assess the paediatric congenital cardiac surgical unit at the Hospital. The terms of reference required the panel to assess the service against compliance with the *Safe and Sustainable* standards. The process was in part objective, in so far as it drew together relevant data, and subjective in that it called for the judgment of experts as to the extent to which the facts put before them demonstrated compliance with the standards.

The unanimous judgments arrived at by the panel are set out in this document.

Purpose of this document

The panel sought to assess the Hospital's current compliance with the *Safe and Sustainable* standards, the Hospital's development plans to meet the standards where gaps in compliance were identified and the Hospital's development plans to meet the standards if activity were to increase to 400 surgical procedures per year or more.

In accordance with the terms of reference it was not the panel's role to assess how the Hospital compared to surgical centres in England. Rather, the panel assessed the extent to which the Hospital itself demonstrated compliance with the standards in so far as they relate to paediatric cardiac surgical services and paediatric interventional cardiology services.

Under each core requirement, a summary of the key areas where actions are required to comply with the standards is provided.

Assessment visit

The assessment visit took place on 3 November 2011.

The panel received and reviewed the Hospital's written submission, including documentary evidence provided by the Hospital, prior to the assessment visit taking place.

During the assessment visit the panel toured the facilities at the Hospital and received a presentation from the congenital cardiac service team.

The panel met a broad range of staff, including surgeons, cardiologists, intensivists, nurses and members of the management team. The panel also met patient and parent representatives.

There were opportunities for the assessment panel to question the staff and patient and parent representatives throughout the day and for evidence to be submitted to the panel.

The panel scored the Hospital against each of the core standards using the following scoring criteria:

Score	Definition
R	▪ **Inadequate**: No evidence to assure panel members
O	▪ **Poor**: Limited evidence supplied
A	▪ **Acceptable**: Evidence supplied is adequate, but some questions remain unanswered or incomplete
G	▪ **Good**: Evidence supplied is good, and the panel are assured that the centre has a good grasp of the issues
B	▪ **Excellent**: Evidence is exemplary

Assessment Panel

Professor Sir Ian Kennedy (Chair)

Professor Sir Ian Kennedy chaired the public inquiry into the care of children receiving heart surgery at the Bristol Royal Infirmary between 1984 and 1995. His landmark 'Kennedy Report' in 2001 highlighted fundamental flaws in the planning, delivery and management of paediatric cardiac surgical services, and it made a number of recommendations around safety, medical competency and public involvement relevant to the NHS as a whole. He was Chair of the Healthcare Commission from 2003 to 2009, after which he became Chair of the Kings Fund inquiry into the quality of general practice in England. In 2009 he became Chairman of the Independent Parliamentary Standards Authority.

Dr Michael Godman

Dr Godman is a retired Consultant Paediatric Cardiologist. He worked in the Royal Hospital for Sick Children in Edinburgh until 1999, during which time he was also a Senior Lecturer in the Department of Child Life and Health, and the Medical Director for the hospital. He was nominated to the panel by the British Congenital Cardiac Association.

Dr Ian Jenkins

Dr Jenkins is a Consultant in Paediatric Intensive Care and Cardiac Anaesthesia at the Bristol Royal Children's Hospital. He is the Immediate Past President of the Paediatric Intensive Care Society and was also co-opted onto the Councils of the Association of Paediatric Anaesthetists of Great Britain and Ireland (2007-2011) and the Intensive Care Society (2010 -2011). He chaired the working party writing the new Standards for the Care of Critically Ill Children, published in 2010.

Dr David Mabin

Dr Mabin is a Consultant Paediatrician with expertise in paediatric cardiology at the Royal Devon & Exeter NHS Foundation Trust. He is the Convenor for Paediatric Cardiology at the Royal College of Paediatrics and Child Health. He also sits on the British Congenital Cardiac Association Council and is Clinical Sub-Dean at the Peninsula Medical School in Exeter.

Mr James Monro

Mr Monro was a Consultant Congenital Cardiac Surgeon in the NHS until 2004. He was President of the Society of Cardiothoracic Surgeons of Great Britain and Ireland from 2000-2002, President of the European Association for Cardiothoracic Surgery in 2003 and 2004 and a founding Chairman of the EACS Congenital Cardiac Surgical Committee. He was co-chairman of the committee which produced the "Report of the Paediatric and Congenital Cardiac Services Review Group" in 2003.

Julia Stallibrass MBE

For the last 20 years Julia Stallibrass has worked in the NHS in various public health and commissioning roles, most recently as Head of Specialised Services Commissioning in the National Specialised Commissioning Team. She has also worked for the Department of Health where she was the policy lead for commissioning specialised services. Whilst at the Department of Health she produced the Carter Report on the 'Review of Commissioning Arrangements for Specialised Services'. She retired in 2009 and in that year she received an MBE for services to the NHS.

Sharon Stower

Sharon is an Independent Nursing and Healthcare Consultant and founder and Managing Director of Sharon Stower Consultancy Ltd. Her current work involves undertaking service reviews in health care environments advising on health care issues and legal nurse expert work. She was a former Director of Nursing and Service Improvement at Doncaster and Bassetlaw Hospitals NHS Foundation Trust. Sharon was nominated to the panel by the Royal College of Nursing.

Maria Von Hildebrand

Maria von Hildebrand has been working in patient and public involvement since 1995. She is the founder of Constructive Dialogue for Clinical Accountability, a national charity set up in partnership with patients, the public and clinicians. The objective of her work has been to improve the information exchange between health care professionals and patients, to ensure there is knowledge transfer and shared responsibility for the process of informed consent resulting in improved quality and safety outcomes for public benefit.

Declarations of Interest

No conflicts of interest have been declared.

Dr Godman, Dr Jenkins, Dr Mabin and Mr Monro all know clinicians at the Hospital in a professional capacity.

Dr Godman worked as a Consultant Paediatric Cardiologist at Edinburgh Royal Hospital for Sick Children until his retirement in 1999.

1. SUMMARY OBSERVATIONS AND COMMENTS

Introduction

The panel had significant concerns about important aspects of the service in the surgical unit and in the broader congenital heart network. Of most concern was a lack of leadership and coherent team working. Also of concern was a sense that the provision of paediatric intensive care may be unsafe if critical staffing problems are not addressed.

Strategy and vision

The panel felt that whilst the Hospital had a vision that included proposals and development plans, these tended to be aspirational; it was not always clear how these plans would be implemented, and who would lead them.

This was typified with the Hospital's ambition to develop the research programme. Whilst the ambition was evident, this was not supported by a robust research strategy and there was insufficient staff capacity and resource to undertake an extensive research programme.

Leadership

The panel was left with an impression that the senior leadership team were not operating as a cohesive team and that there was a lack of clear strategic leadership.

This was evidenced in part by the fact that there was almost no Board-level presence during the assessment visit, and it was not clear how the paediatric cardiac surgery service was integrated with the Hospital Board's broader strategic objectives.

This view was reinforced by the panel's observation that there was a poor working relationship between members of the cardiology and surgical teams.

Commissioning arrangements

The commissioning arrangements for paediatric cardiac surgery and related services were fragmented and confusing.

This had made planning and investment a significant challenge for the Hospital.

Patient engagement

Parents and patients whom the panel met demonstrated strong support for the service and indicated excellent relationships with staff which had led to a high degree of trust between patients and staff; however patients and parents did not appear to be actively involved in decision-making.

The panel identified several opportunities for increasing patient and parent involvement, for example: identifying critical success factors and developing the ‘transition to adult’ service.

Network arrangements

The panel recognised the challenges of the large geographical area and the dispersed population in managing the network.

The Hospital had excellent telemedicine arrangements within the network; however other aspects of the network were under-developed.

In particular the panel felt that there was an emphasis on centrally provided care. This was exemplified by the lack of coherent protocols within the network and the fact that services such as those provided by liaison nurses and transition nurses were not available within the network.

Staffing and capacity

There were significant concerns over the staffing and capacity levels within the paediatric intensive care unit (PICU), which had been exacerbated by the recent departure of two PICU consultants. The panel was also of the view that Hypolplastic Left Heart Surgery had been introduced without sufficient consideration of the pressures that this would bring to PICU.

The panel was of the view that urgent remedial action is required in PICU to prevent care from becoming unsafe.

The panel's key findings and deliberations are described in detail under each of the core requirements.

	Compliance	Gaps in Compliance	Final Score
Aims, business strategy and strategic priorities	▪ The Hospital referred to a business plan; however this was not supported by a robust strategy or financial information.	▪ The mechanism for commissioning paediatric cardiac services and related services was unclear and confusing and had led to disjointed service provision. ▪ The panel felt that leadership within both the Hospital generally and in paediatric congenital cardiac surgical services was poor as there was no clear leadership structure; there appeared to be a lack of cohesion between the senior team members.	Poor
IT and estates strategy	▪ Implementation of telemedicine, both within the Hospital and the network was good, and there was an awareness of where there were current gaps in provision, and the reason these may exist, such as Paisley and Elgin. ▪ A good technician-led echocardiogram service was present throughout the hospital. ▪ The Hospital's estates strategy was predicated on the move to the Southern General site in 2015, and the plans for this transfer had been well developed with Hospital staff.	▪ The panel noted that whilst HeartSuite had been implemented elsewhere in the Hospital, it had not been implemented within the network. ▪ Whilst the Hospital's estates strategy was predicated on the transfer of services to the Southern General Site in 2015, it was not clear what the Hospital will do to develop and maintain the existing estate until then.	Good
Contribution to key objectives	▪ The Hospital provided a clear description of its key objectives; however it was not always evident how the Hospital Board would achieve these objectives.	▪ The panel felt that the Hospital Board had not displayed a good track record of how it had achieved its key objectives for paediatric cardiac services in the 12 year period since the merger of Glasgow and Edinburgh paediatric cardiac services.	Acceptable

		▪ The panel expressed concerns over the degree of leadership in achieving the Hospital's key objectives.	
Service delivery arrangements, including networks and major contracts	▪ The Hospital outlined clear, comprehensive service delivery arrangements; however the panel felt that there were some gaps in these.	▪ The service development plans appeared to be heavily focused on the medical workforce and made insufficient reference to other staffing groups, including nurses. ▪ There was limited explicit reference to cardiac surgery in the service delivery arrangements. ▪ Plans for the network appeared aspirational; it was not clear how these would be implemented.	Acceptable
Main stakeholder groups	▪ The Hospital identified a broad range of stakeholders; however these were largely 'inwards' facing and represented different staff groups within the Hospital.	▪ The Hospital did not identify patients and parents or DGHs within the network as key stakeholders.	Poor
Critical success factors for delivering plans and Main internal and external factors upon which successful delivery is dependent upon	▪ The Hospital identified a range of critical success factors, including sources of investment, as a major external factor. ▪ Succession planning was identified as a potential concern, and the Hospital indicated a strategy for addressing this.	▪ The Hospital indicated an awareness of concerns relating to PICU capacity, and it was unclear how these concerns would be addressed. ▪ There was insufficient engagement of patients and parents in identifying critical success factors; this was exemplified by the bi-annual survey, which suggested a low level of patient involvement in service planning. ▪ The panel felt that concentrating on the transfer to the new hospital in 2015 may have caused the Hospital to reduce their focus on considering critical success factors.	Acceptable

	Compliance	Gaps in Compliance	Final Score
Main constraints and risks	▪ The Hospital demonstrated an awareness of constraints and risks.	▪ Where the Hospital identified constraints and risks, they often did not identify possible remedial actions.	Acceptable
High level strategic and operational benefits	▪ The Hospital gave a sound description of the benefits that they would seek to extract from their plans; however it was not always clear how these would be achieved, or who would lead the delivery of these.	▪ The Hospital did not sufficiently describe any benefits within the network.	Acceptable
Opportunities for innovative working	▪ The development of the Advanced Nurse Practitioner role was deemed as innovative. ▪ The Hospital had been groundbreaking in its implementation of telemedicine within the network, however the telemedicine technology was not, in itself, innovative.	▪ Whilst the Hospital described several new working practices, these were often not innovative practices as they had already been implemented in other organisations in the UK. An example of this was the recent introduction of Hypoplastic Left Heart surgery by the Hospital.	Poor
Learning, development and growth	▪ The Hospital benefited from shared learning from other UK providers, and this was exemplified by the introduction of Hypoplastic Left Heart surgery to the Hospital through training from other UK centres. ▪ The Hospital had a strong learning culture. ▪ Advanced Nurse Practitioners had been provided with training opportunities in Liverpool ▪ Training for physiologists appeared strong.	▪ There was a limited description of the training opportunities for other non-medical staffing groups. It is crucial that training be made available for all workforce groups.	Good

2. STRENGTH OF NETWORK

Summary

In the Scottish network there is a single paediatric cardiac surgical unit (in Glasgow) that has a relationship with the main non-interventional cardiology service in Edinburgh and with a number of district general hospitals. The network in Scotland has unique challenges due to geography and population dispersal. The panel recognised these challenges but did not consider that the challenges preclude providing a well managed, coordinated and effective network.

In the panel's opinion the network was generally under-developed; there was poor evidence of clinical leadership across the network and limited evidence of the benefits that a network model of care could bring to the treatment and management of children in Scotland with congenital heart disease. The Hospital did not demonstrate an appropriate understanding of how networks could work or the benefits of a networked approach; rather the Hospital's approach was based on a model of 'command and control'.

	Compliance Strength of Network	Gaps in Compliance	Final Score
Current achievement against the core standards A1, A2, A5, A7, A8, A13, A24, A25 and B3	▪ Telemedicine was present throughout the network, and the necessity of telemedicine, based on the challenging geographical circumstances, was recognised.	▪ The Hospital had an informal relationship with DGHs in the network, predicated on strong personal relationships. ▪ The Hospital failed to meet several of the standards, including: ▪ active leadership of the network; ▪ formal protocols agreed with the network; ▪ a nominated nurse leader; ▪ multi disciplinary working across the network.	Poor
Development plans/ risks to meeting standards A1, A2, A5, A7, A8, A13, A24, A25 and B3 (if not all ready achieving)	▪ The Hospital demonstrated clear proposals for the network which are currently awaiting approval.	▪ The panel felt that the £50,000 available for funding administrative support for the network was insufficient in developing the network, as dedicated clinical leadership is also necessary. ▪ The implementation plan for delivering the proposals for the network was unclear.	Poor
Impact on standards A1, A2, A5, A7, A8, A13, A24, A25 and B3 if activity increases to 400 procedures per year and any additional development that would be necessary if activity increased	▪ The panel felt that the proposals for the network were valid if activity increased to 400 procedures or more.	▪ It was unclear what the implications of extending the geography of the network would have on the network. For example, there may be a requirement to recruit additional staff if the network expands further, and this had not been recognised in the proposals for the network.	Poor

Core Standard	Actions to achieve compliance (Strength of Network)
A1	▪ Develop protocols for care, treatment, transition and referrals within the network. ▪ Monitor performance against protocols within the network. ▪ Undertake audits within the network.
A2	▪ Consult with DGHs in the network in designing models of care.
A5	▪ Appoint a dedicated lead nurse who works wholly within paediatric cardiac services.
A7	▪ Develop relationships with other Specialised Surgical Centres.
A8	▪ Develop a managed network for paediatric congenital heart services that includes formal protocols. ▪ Ensure DGHs within the network are signed up to these protocols.
A13	▪ Ensure all protocols are developed with DGHs within the network, with patients and with parents. ▪ Formally document all protocols.
A24	▪ Develop pathways of care that include referral, treatment and transition with DGHs in the network.
A25	▪ Include arrangements for multi disciplinary care in the network care pathways.
B3	▪ Include arrangements for foetal medicine services in the network care pathways.

3. STAFFING AND ACTIVITY

Summary

The standards stipulate a minimum of 4 full-time consultant congenital cardiac surgeons in a congenital cardiac surgical unit based largely on a need for a safe and sustainable surgical rota that can be delivered around the clock. In order to avoid occasional surgical practice the standards also stipulate that each surgeon should be performing a minimum of 100 paediatric congenital surgical procedures a year, and ideally a minimum of 125 such procedures a year. The Hospital failed to meet several of these standards giving rise to serious concerns amongst panel members about the sustainability of the service overall.

The Hospital had 3 surgeons, which impeded an ability to deliver a safe surgical rota around the clock as required by the standards. Work was not evenly distributed between the surgeons which led the panel to express concerns over sustainability. One surgeon performed around 140 paediatric surgical procedures per year, meeting the critical mass proposed by the standards, whereas the other two surgeons fell considerably short at around 70 paediatric surgical procedures each per year.

The Hospital had also identified the need to recruit a further two intensivist consultants to increase the numbers to 10 consultants. The panel noted with significant concern that there was an acknowledgment by Hospital staff that this may still leave the PICU stretched to a degree that maybe unsafe.

	Compliance Staffing and Activity	Gaps in Compliance	Final Score
Current achievement against the core standards C4, C5, C6, C7, C9, C11 and F2	▪ Theatres and wards were staffed to sufficient capacity subject to the 'gaps in compliance' observed by the panel.	▪ The Hospital failed to meet several of the standards including: ▪ 4 surgeons; ▪ minimum of 7 wte cardiac liaison nurses; ▪ a dedicated lead cardiac nurse. ▪ The Hospital had 3 surgeons; however work was not evenly distributed between these surgeons. One surgeon undertook approximately 140 procedures per year whilst the other two surgeons each undertook approximately 70 procedures per year. ▪ The panel also raised concerns regarding the number of intensivists and PICU nurses. ▪ The panel was told that there had been a relatively recent reduction in the number of cardiac liaison nurses, and the panel observed little evidence of plans to rectify this by increasing the number of nurses to meet the standards.	Inadequate
Development plans/ risks to meeting standards C4, C5, C6, C7, C9, C11 and F2 (if not all ready achieving)	▪ The Hospital had identified a need to recruit an additional (fifth) cardiologist and has a business case for the post.	▪ The Hospital had identified the need to recruit a further 2 intensivist consultants to increase the numbers to 10 consultants; however there was a recognition by Hospital staff – and endorsed by the panel - that this may still leave the PICU stretched. In any event there were concerns over an inability to recruit additional intensivist capacity. ▪ The Hospital had attempted to recruit an additional cardiologist, however this was unsuccessful. ▪ There was limited evidence of robust plans to increase the number of cardiac liaison nurses.	Poor

		▪ The panel felt that the Hospital held a view that the cardiac liaison nurses must be based in Glasgow, when they can in fact be based within a hospital in the network. In the panel's opinion this demonstrated a lack of understanding and appreciation of the benefits of a network approach, which ultimately was to the detriment of care for children and their families. ▪ The Hospital had not identified any plans to increase their PICU nursing workforce.	
Impact on standards C4, C5, C6, C7, C9, C11 and F2 if activity increases to 400 procedures per year and any additional development that would be necessary if activity increased	▪ The panel recognised that there were credible plans to increase the workforce, however there was no clear process for achieving these plans.	▪ There were concerns over recruitment for some posts. ▪ The Hospital had not indicated plans to increase all areas of the workforce where there were deficiencies, such as PICU nursing.	Poor

Core Standard	Actions to achieve compliance (Staffing and Activity)
C4	▪ *The panel was unable to make recommendations that would address the concerns around sustainability and the need to provide a safe surgical rota around the clock in the absence of four full time consultant congenital cardiac surgeons. It must be for Commissioners and Hospital management to identify the implications of non-compliance with the standards and how non-compliance with the standards may be addressed to ensure safety and sustainability.* ▪ Ensure that activity is appropriately distributed between the surgeons in so far as it can be achieved within the constraints of a relatively low surgical caseload. ▪ Ensure appropriate mentoring arrangements are in place when recruiting any additional surgeons.
C9	▪ Provide sufficient medical and nursing staff for continuous emergency cover around the clock. ▪ Consider whether current staffing levels in PICU are sufficient to provide a compliant rota and recruit as required.
C11	▪ Review establishment levels in PICU and recruit nursing and medical staff to ensure sufficient capacity in PICU. This has become even more important with the introduction of surgery for Hypoplastic Left Heart Syndrome.
F2	▪ Ensure each patient has a named specialised nurse. ▪ Recruit additional specialised nurses to ensure sufficient capacity. ▪ Increase the number of cardiac liaison nurses working across the network..

4. INTERDEPENDENT SERVICES

Summary

The panel noted that the standards for interdependent services were met, and that all critically interdependent services were co-located. The panel noted that maternity, neonatology and foetal medicine were co-located as stipulated and defined in the standards.

	Compliance Interdependent Services	Gaps in Compliance	Final Score
Current achievement against the core standards C12-21, C64 and C65	▪ All critically interdependent services were co-located.		Excellent
Development plans/ risks to meeting standards C12-21, C64 and C65 (if not all ready achieving)	▪ All critically interdependent services were co-located. ▪ Once services are transferred to the Southern General site, maternity and children's services will be co-located on one site.		Excellent
Impact on standards C12-21, C64 and C65 if activity increases to 400 procedures per year and any additional development that would be necessary if activity increased	▪ All critically interdependent services were co-located. ▪ Once services are transferred to the Southern General site, maternity and children's services will be co-located on one site.	▪ Whilst all critically interdependent services were currently co-located, the Hospital had not indicated to what extent capacity for interdependent services would need to be increased should activity increase to 400 procedures per year or more.	Good

Standards C64 and C65 were reviewed under Facilities and Capabilities, and not under Interdependent Services.

5. FACILITIES AND CAPACITY

Summary

The panel had strong concerns that current staffing levels in the paediatric intensive care unit may be unsafe and are certainly not sustainable. The panel noted that these concerns were also shared by key Hospital staff interviewed on the day. Although there was some evidence of plans to address this problem by increasing the workforce, the panel members considered that the plans described to them would still leave significant risks in the service even if implemented. The panel recommends that urgent remedial action be taken.

	Compliance Facilities and Capacity	Gaps in Compliance	Final Score
Current achievement against the core standards C64, C65 and F6	▪ There was currently good capacity for parents and families to stay at the hospital. This included a Ronald McDonald House. ▪ Current PICU provision indicated a larger proportion of beds per capita of population than the rest of the UK; however not all of these beds were staffed.	▪ The panel felt that nurse staffing levels in PICU may not currently be safe and were certainly not sustainable, and this had led to low resilience, in particular because there was not separate or bespoke staff for emergency retrievals. The introduction of Hypoplastic Left Heart surgery had further increased pressure on PICU capacity to a degree that is unsustainable and may become unsafe. ▪ The panel noted that the PICU would be stretched even with 10 consultants; at the time of the visit there were only 8; a 1 in 4 on call rota covering 22 beds was deemed insufficient. ▪ The Hospital had moved to a 'Hospital @ Night' model, which tended to lead to a more junior, less specialised skills mix on call. ▪ The Hospital did not provide quiet rooms in all relevant care areas, including out patients.	Poor
Development plans/ risks to meeting standards C64, C65 and F6 (if not all ready achieving)	▪ The Hospital had developed plans to increase their workforce, for instance there were plans to recruit a clinical psychologist. ▪ The Hospital had funding to recruit 2 more PICU consultants.	▪ There must be immediate action to fill the 2 consultant PICU vacancies; even then Hospital staff acknowledged that this would leave the PICU stretched to an unacceptable and unsustainable level. ▪ The panel had concerns that whilst plans to increase the workforce were in place, the Hospital had not demonstrated a commitment to apply funding.	Poor
Impact on standards C64, C65 and F6 if activity increases to 400 procedures per year and any additional development that would be necessary if activity increased	▪ The Hospital had indicated good relationships with Caledonian University, which would be beneficial in recruiting additional nurses.	▪ There were concerns that the Hospital may not be able to recruit additional staff.	Poor

Core Standard	Actions to achieve compliance (Facilities and Capacity)
C64	▪ Remedy staffing capacity in PICU as a matter of urgency. ▪ Recruit additional consultant and nursing cover as required.
F6	▪ Ensure the provision of quiet rooms in all relevant care areas, including out patients.

6. AGE APPROPRIATE CARE (TRANSITION TO ADULT SERVICES)

Summary

Although there is no requirement for children's congenital heart services to be co-located with adult congenital heart services, a seamless transition from child to adult services is essential. It is at the transition stage that adolescents are at risk of 'falling out' of the system and being 'lost to medical follow up'. Overall, the panel members were of the opinion that transition arrangements were poor.

	Compliance Age Appropriate Care	Gaps in Compliance	Final Score
Current achievement against the core standards D1- D8		▪ Although the panel was presented with a transition policy, there was little evidence of compliance with the standards. ▪ There was only one nurse-led clinic per month. ▪ There were no dedicated beds for adolescents, although cubicles were made available for adolescents where possible. ▪ There was insufficient staff for transition working in the network.	Poor
Development plans/ risks to meeting standards D1- D8 (if not all ready achieving)	▪ The Hospital was moving from a one-off clinic for transition to a period of transition from the age of 14 onwards. ▪ There were plans to recruit clinical psychologists, and the Hospital reported that funding had been identified.	▪ There were no plans to develop transition capacity within the network. ▪ The panel raised concerns that there was little active patient involvement or engagement in developing plans for transition and ensuring care was age appropriate.	Poor
Impact on standards D1- D8 if activity increases to 400 procedures per year and any additional development that would be necessary if activity increased		▪ The concerns over transition within the network remain valid if activity increased to 400 procedures or more. ▪ The need to develop plans for transition will remain valid if activity increases to 400 procedures or more.	Poor

Core Standard	Actions to achieve compliance (Age Appropriate Care)
D1	▪ Develop a comprehensive approach to transition, in partnership with adult congenital heart disease services, including, where appropriate, provision within the network.
D3	▪ Recruit a dedicated transition nurse.
D4	▪ Provide ongoing review of care management plans. ▪ Undertake audit to ensure compliance with the standard.
D6	▪ Recruit additional clinical psychologists to ensure psychological support is made available to all patients, parents and families.
D7	▪ Provide a dedicated area and facilities for adolescents. ▪ Ensure plans for transition exist within the network as well as the designated surgical centre in partnership with adult congenital heart disease services

7. INFORMATION AND CHOICE

Summary

Whilst patients and parents were provided with good quality, accessible information about the care they would be receiving in a range of formats there were some deficits under standards relating to information and choice. This was particularly notable in the allocation of specific staff groups, such as cardiac liaison nurses and clinical psychologists, as they were not always accessible to patients and parents at key points in the care pathway, particularly at the point of decision-making.

	Compliance Information and Choice	Gaps in Compliance	Final Score
Current achievement against the core standards E1- E14	▪ The consent process was undertaken in advance, using a two stage approach. ▪ Nurse support was available during the consent process. ▪ Information was made available in several different formats including books and pamphlets. ▪ Details of out of hour contacts were made available to all patients and families.	▪ Clinical psychologists were not available at the point of decision-making, as there was a week's wait to access an appointment. ▪ There is no evident culture of informing parents of how to obtain second opinions although there was evidence of referrals to England for complex cases. ▪ Whilst patients and families indicated a strong degree of approval for the care provided by the nurses and doctors, they did not appear to be actively involved in decision-making.	Acceptable
Development plans/ risks to meeting standards E1-E14 (if not all ready achieving)	▪ The Hospital demonstrated good compliance against several of the standards including E2, E3, E5, E6-10, and there were plans for achieving compliance with other standards, such as E4. These plans were at times weak and it was not always evident how achievable these would be, for instance there were concerns over funding for cardiac liaison nurses.	▪ The Hospital did not demonstrate an understanding of the role of some staff groups, such as cardiac liaison nurses.	Poor

	Compliance Information and Choice	Gaps in Compliance	Final Score
Impact on standards E1-E14 if activity increases to 400 procedures per year and any additional development that would be necessary if activity increased		▪ The concerns over the role and use of cardiac liaison nurses remain valid if activity increases to 400 procedures or more. ▪ The need to develop plans remains valid whether or not activity increases to 400 procedures or more.	Poor

Core Standard	Actions to achieve compliance (Information and Choice)
E1	▪ Enable and encourage patients and parents to actively take part in the decision-making process.
E4	▪ Recruit sufficient clinical psychologist capacity to ensure all patients, parents and families have access to clinical psychology support during the decision-making process.
E11	▪ Formalise in protocols, and routinely communicate to patients and parents, the option of a second opinion at another Specialised Surgical Centre.

8. ENSURING EXCELLENT CARE

Summary

The panel felt that the Hospital broadly met the standards relating to governance arrangements. Otherwise the panel felt that the plans relating to 'ensuring excellent care' were aspirational. Whilst the Hospital described an ambitious research programme, the panel felt that the capacity and capability to deliver it was not apparent.

	Compliance Ensuring Excellent Care	Gaps in Compliance	Final Score
Current achievement against the core standards G1, G4 and G12	▪ The Hospital demonstrated a good track record with regard to audit. ▪ The Hospital had clinical governance arrangements in place. ▪ The Hospital had a clear, multi disciplinary management structure in place. ▪ The Hospital used mentoring for junior staff.	▪ Whilst the Hospital indicated a strong appetite for research, this appeared aspirational as there was no research strategy, and staff had limited capacity available for undertaking research.	Poor
Development plans/ risks to meeting standards G1, G4 and G12 (if not all ready achieving)		▪ The Hospital demonstrated commendable aspirations with regard to research; however this was not encapsulated in a strategy.	Poor
Impact on standards G1, G4 and G12 if activity increases to 400 procedures per year and any additional development that would be necessary if activity increased		▪ The concerns over ensuring excellent care, particularly with regard to implementing the plans for research remain valid if activity increases to 400 procedures or more. ▪ The need to develop plans for ensuring excellent care will remain valid if activity increases to 400 procedures or more.	Poor

Core Standard	Actions to achieve compliance (Ensuring Excellent Care)
G12	▪ Develop a coherent research strategy, outlining all major research areas and indicating opportunities for working in partnership with other centres. ▪ Ensure sufficient capacity and resources exist to implement the research strategy, including dedicated time in work plans for clinicians to undertake research.