Review of Paediatric Cardiac Services by the Education, Children & Young People Scrutiny Panel.

1. What services are available to Portsmouth HOSP residents?

There are 11 surgical centres in England. Since 2005, most Portsmouth residents use Southampton University Hospitals Trust (SUHT). Alternatively there are three in London (Great Ormond Street, Royal Brompton & Harefield and Guys & St Thomas.

Queen Alexandra Hospital, Cosham.
Paediatric services available to Portsmouth children:

1. General paediatric outpatient assessment for minor cardiac problems.
2. Children's emergency department
3. Local availability of outpatient assessment by a Generalist Paediatrician with an expertise in cardiology (PEC).
4. Visiting specialist outreach clinics by cardiologists from Southampton with a local PEC.
5. Inpatient medical therapy and/or pre cardiac surgery care for patients selected by SGH as suitable for DGH care at PHT
6. The following non-invasive cardiac investigations:
    - Chest radiograph
    - Electrocardiogram
    - Ambulatory electrocardiogram
    - Cardiac event recording electrocardiogram
    - Exercise electrocardiogram
    - Ambulatory BP monitoring
    - Home oxygen saturation monitoring
    - Paediatric echocardiography (by PEC)
    - Adolescent echocardiography (by cardiac echocardiography technicians)

7. The following multi-disciplinary support services:
    - Children's community nursing
    - Neonatal community nursing
    - Other speciality support as necessary (genetics, development, psychology).

Southampton General Hospital – a tertiary (surgical) centre.

1. Paediatric cardiac surgery (this forms one quarter of all cardiac surgery performed).
2. Specialist outpatient clinics
3. Specialist day case services
4. Specialist cardiac intervention, surgery, pre operative and post operative care.
5. Cardiac liaison nursing support

2. **How well used are these services?**

On average a Primary Care Trust is likely to have only 20 children each year requiring heart surgery. Between six and eight in every 1,000 children born in the UK are likely to have Coronary Heart Disease.[1]

Since 2005, an average of 26.4 patients aged 18 or under per year are diagnosed with cardiac disease in Portsmouth.

Southampton General Hospital.

Nationally, 3,500 paediatric cardiac procedures are carried out a year; 400 of which are done in Southampton General Hospital (11%). Between 14 and 16 hospitals refer patients to Southampton for cardiology procedures including the insertion of a stent (a tube placed in the coronary arteries to keep the arteries open) and other devices. It pioneered this work and carries out the largest volume of congenital procedures (25% of cardiac surgery is congenital).

Patients undergoing cardiac procedures stay in hospital for the shortest time possible. Most patients with stents have the operation in the morning and return home that evening. More complex operations require the patient to stay in a specialist Intensive Treatment Unit for several days.

Patients are referred to the appropriate hospital depending on the nature of the operation and the expertise of the surgeons. However, only Great Ormond Street Hospital carries out heart transplants.

Often infants with cardiac conditions suffer from other conditions aswell. All the consultants involved will be involved in the discussions about treatment. The heart problems are normally dealt with first. All paediatric specialities are provided for at Southampton General Hospital.

The Primary Care Trust that covers Southampton is looking at eradicating duplication of paediatric services that are provided both in the community and at the hospital. However, the level of these services will be increased to reinforce its position as a tertiary provider. 130 consultants will have paediatric interest and there will be 200 paediatric beds. The Chief Executive explained that he felt paediatric services had a bright future because of the increase in demand as the population grows.

Southampton General Hospital has been described as exemplary in training and education, the management of paediatric intensive care and the standards on most of its wards by an independent review of the 11 centres that carry out children's heart surgery which was led by Professor Sir Ian Kennedy. In this review it was ranked the second best performing centre nationally for its quality of outcome, environment, team working, culture and

[1] http://www.specialisedservices.nhs.uk/library/30/Learning_from_Bristol_The_Report_of_the_Public_Inquiry_into_childrens_heart_surgery_at_the_Bristol_Royal_Infirmary_1984_1995_The_Kennedy_Report_1.pdf

parent involvement. Since the 1970s it has been in the top hospitals for survival rates and has never been investigated for mortality rates. The decision to operate is taken at a joint conference. If a mortality does occur, the case is discussed thoroughly to see if lessons could be learnt. There is a good culture of openness where staff feel able to discuss freely all aspects of treatment.

Parents are prepared to travel to get the best for their children and most procedures are planned. Patients in need of urgent surgery are diagnosed and stabilised at their nearest hospital and then collected by staff from Southampton General Hospital either by plane (for those in the Channel islands) helicopter or ferry (for those on the Isle of Wight) or road (for those on the mainland as far afield as Oxford, Worthing and Plymouth).

3. **What is the cost of providing these services and how are these paid for?**
NHS Portsmouth spent £432,722 on commissioning paediatric cardiac services in 2009/10. Between 2005 and November 2010 it spent £1,886,698. Southampton General Hospital took 90 patients from Oxford cardiology unit when it closed last year at a cost of between £3.5 and £4m. Most cases cost approximately £10,000.

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4. **What are the main causes of paediatric cardiac conditions and are they preventable?**
The reasons for cardiac problems are varied and could be congenital due to faulty genes or growth-related issues resulting in:
   - Defective tubes that feed into the heart.
   - A transposed heart.
   - Defective valves.
   - Tears or gaps between the chambers

Coronary Heart Disease.

The severity of the abnormality which constitutes the Coronary Heart Disease (CHD) can vary enormously. For some children (approximately 50%) it will be relatively mild and may even heal spontaneously as the child develops. For the others, a surgical procedure will almost certainly be necessary to enable them to have a good chance of growing into adulthood. At the extreme, some babies with very severe abnormalities may die within days if they do not have medical and surgical treatment. Some, sadly, are beyond treatment and die.

The care and treatment of children with CHD includes, but is not confined to, hospital care. Very often healthcare professionals who work in the community, such as GPs, health visitors and midwives, district nurses, physiotherapists and social workers, may contribute to their care.

There is a link between prematurity and cardiac problems.

Women who had heart surgery in childhood are now having children.

Congenital structural heart disease

Congenital structural heart disease is the largest group of pathological cardiac conditions. The overall incidence is 8 per 1,000 live births overall (for Portsmouth Hospitals Trust catchment this would be approximately 50 patients per year).

The risk factors for these conditions include genetic and syndromic abnormalities, and in-utero exposures including certain drugs, alcohol, rubella infection and maternal gestational diabetes.

Measures to prevent these exposures are widely known and in place within public health and primary care.

Antenatal screening will identify babies with the most serious forms of congenital heart disease and may result in termination of the pregnancy.

Acquired heart disease

Acquired heart disease (including inflammatory and infective diseases and intrinsic heart muscle abnormalities) is less predictable but is estimated to represent around 20 new patients per year.

The main causes include infective and post infective triggers and genetic factors. It is extremely rare for there to be a toxic exposure (such as alcohol, in contrast to adult patients).

These conditions are not normally preventable.

The role of screening all children for heart muscle abnormalities is not established as a suitable prevention strategy for sudden cardiac death secondary to this cause.

Rhythm disturbances, palpitations, chest pain, collapse

Patients referred to PHT with these conditions are common (estimated to be in the region of 50-70 patients per year).

The specialist investigation of these complaints in childhood is important, although only 20-30% may have significant associated pathology.

Murmurs

Murmurs are a common finding in childhood occurring in 5-6/10 children under the age of 10 years. Not all murmurs require specialist cardiology assessment as they may be recognised by the GP or paediatrician as 'innocent murmurs' with no associated structural or functional heart disease.

Specialist assessment for definitive exclusion of congenital heart disease is requested when features of the murmur are not characteristic for an innocent murmur. This group represents a significant proportion of the referrals to the

paediatric cardiac service at Portsmouth Hospitals Trust. It is not possible to prevent murmurs.

Ischaemic heart disease
Although the majority of adult heart disease represents a tiny proportion of paediatric heart disease and is rarely seen. When seen this is associated with congenital or inflammatory heart disease, the usual preventative measures for adult ischaemic heart disease do not apply.

5. **Are paediatric cardiac services included sufficiently in the prevention programmes for General Cardio Vascular Disease?**
Prevention for paediatric cardiac disease is not specifically addressed in the general cardio vascular disease programme.

Smoking during pregnancy. A lot of work is being carried in the city to reduce the number of mothers smoking during pregnancy.

Identification.
There is no specific ante-natal screening programme for heart defects. A nuchal fold scan (for Down syndrome) is carried out at 12 and again at 20 weeks. If risk factors for the baby are identified e.g. there is a family history of congenital heart disease or the mother's lifestyle is risky (due to alcohol or drug taking) the mother will be referred to a specialist clinic and closely monitored.

There is a policy for screening for congenital cardiac disease in newborn babies, through the physical examination of newborn babies and the 6-8 week examination. Most babies with cardiac problems are identified in the first 24 to 48 hours after birth and many murmurs are picked up at the 6-8 week examination.

The age of the mother can mean that the baby is predisposed to many problems including Down syndrome. There are more obstetric risks for very young and older mothers. The average age of the first time mother is 28-29.

Often infants with cardiac conditions also suffer from other conditions as well. All the consultants involved will be involved in the discussions about treatment. The heart problems are normally dealt with first. All paediatric specialities are provided for at Southampton General Hospital.

There is a lot of work carried out in schools and with parents to improve lifestyle choices and therefore reduce obesity and acquired heart disease in adulthood. This is not relevant to this review as paediatric cardiac problems are congenital due to faulty genes or growth-related issues.

The issue of children's weight is currently a topic of much national debate and will have implications for later prevention of adult ischaemic disease. Few types of paediatric cardiac disease are related to prevention programmes

(e.g. rubella immunisation, adequate recognition and treatment of streptococcal throat infection).

6. **Are such programmes adequately staffed with dedicated leads for paediatric cardiac services?**
   As noted in the previous section, this is not relevant to this review as paediatric cardiac problems are congenital due to faulty genes or growth-related issues.

7. **Has the transition to adult services been adequately considered?**
   Infants often require further surgery throughout their lives. There are very close working relationships between adult and paediatric cardiologists with joint clinics being held to ensure continuity for the transition from children's to adults' services.

   Southampton offers a service for patients with congenital heart disease from foetal to adult life (one of only a few such centres in the UK). The huge majority of patients are followed throughout their life by the SGH team and when they reach adolescence will transition to the specialist SGH adult congenital service.

8. **How is multi-agency partnership involved?**
   Through local Paediatricians with an expertise in cardiology, Southampton General Hospitals team and Primary Care.

9. **What is the current consultation looking at?**
   The National Specialised Commissioning Team leads the Joint Committee of Primary Care Trusts' Safe and Sustainable review of children's congenital heart services in England and Wales.

   The 2001 Kennedy public inquiry in to the deaths at Bristol Royal Infirmary recommended that quality standards should be developed and fewer, larger centres of expertise configured. The Monro Review (2003), Summit of experts (2006), Royal College of Surgeons (2007) report 'Delivering a first class service and the national clinical advisory team's (2010) review of the safe and sustainable case for change all call for fewer children's cardiac surgery centres. This will lead to better results because of the regular operations being carried out and the consequent specialist skills of the surgeons. The current 11 centres have been reviewed using the following criteria:

   - The quality of clinical services
   - The ability of each centre to meet the proposed clinical standards in the future (a minimum of four surgeons and adequate other medical staff to ensure cover for emergencies and 400 procedures carried out a year to ensure the upkeep of specialist skills
   - Analysis of access and travel times.
   - The outcome of a health impact assessment.
   - Clinical networks.

- Impact on other services.
- Workforce implications.
- Public consultation.
- Affordability.

The Panel publish its proposals for reconfiguration on 16 February 2011. It is expected that this will include reducing the number of centres that provide paediatric cardiac services and a new network model of care that would facilitate the delivery of all non-surgical and non-interventional paediatric cardiology care as locally as possible. The current tertiary centres will either remain as Tertiary (Surgical) Centres and continue to carry out cardiac surgery or will become Children's Cardiology Centres (CCCs).

The Health Overview & Scrutiny Panels will be asked to provide their responses to the proposals by early March 2011 and the decision for the reconfiguration of services will be taken in April. The changes are expected to be implemented in 2013.

The most likely model for the future of cardiac services within PHT is that it will represent a Paediatric Cardiology Periphery Service (PCPS) which is described as follows in the Safe and Sustainable Paediatric Cardiac Service Standards document of March 2010: *The PCPS will have close working relationships with Tertiary Centre and CCCs and with their local hospitals in close proximity. The team will include a consultant paediatrician with expertise in cardiology, and there will be a named consultant paediatric cardiologist from the tertiary centre or CCC so that combined paediatric cardiology clinics are held regularly at the PCPS. They will accept referrals for children suspected of having congenital heart disease from local hospitals, general practitioners, community paediatricians and others involved in primary care and they will also perform inpatient (including neonatal) and outpatient non-invasive diagnostic procedures and ongoing management of children with congenial heart disease.*

10. How will this affect our region?

It is likely that the number of centres would be reduced to one in our region.

11. What support is in place for parents of children with paediatric cardiac conditions?

The charity Wessex Heartbeat supports patients with cardiac problems (adults and children) by providing information, support and free accommodation in two houses very close to Southampton General Hospital for families of patients. The specialist cardiac liaison nurses in the ward offer practical advice to families.

The team liaison nurses at Southampton General Hospital in the ward offer practical advice to families.

Condition specific support groups (e.g. Max appeal for families who have children with 22q11 deletion/ VCFS/ D George syndrome which often affects the heart).

Tertiary centre parents support group at Southampton General Hospital.

Specialist Cardiac Liaison Support

Community children's nursing support

Local PEC support.

A summary of the Education, Children & Young People Scrutiny Panel's visit to Southampton General Hospital on 17 February is attached to this report as appendix 1.

Conclusions.

1. Southampton General Hospital was described as an exemplar hospital in training and education, the management of paediatric intensive care and the standards on most of its wards by an independent review of the 11 centres that carry out children's heart surgery which was led by Professor Sir Ian Kennedy. In this review it was ranked the second best performing centre for its quality of outcome, environment, team working, culture and parent involvement.

2. It has the lowest mortality rate in the country for mixed Intensive Care Units.

3. The closure of this surgical centre would mean a loss of facilities and experience. During this review, the Panel has heard that staff do not necessarily transfer to the nearest centre. Its closure would also mean an increase in costs to families from Portsmouth and surrounding areas who would have to travel further to a surgical centre. This would be particularly felt by families in the Channel Islands.

Recommendation.

The Education, Children & Young People Scrutiny Panel recommends that the Health Overview & Scrutiny Panel ask the Cabinet to write to the NHS Specialist Services to express the Council's support of option B in its Safe Sustainable Review of paediatric cardiac services.