An Integrated Cardiovascular System (ICVS):
Congenital Heart Disease

A proposal for the UCLP Academic Health Sciences Network (AHSN)
February 2013
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Summary

- Adult congenital heart disease (also known as GUCH) is a growing sub-speciality of cardiology which has the potential to be the leading programme in Europe and to be world class.

- Development of life-time congenital heart disease services by the ICVS will catalyse the progress of the overall integrated cardiovascular (ICVS) programme.

- The scale and quality of the service of the ACHD service will provide huge opportunities for education, research and wealth creation.

- Investment now will capitalise on the national reorganisation for ACHD with a potential to create a large single centre for CHD, boosting both activity and funding from specialist commissioning.

Background

Congenital heart disease consists of a group of disorders with abnormal heart structure or function which is present from birth and occurs in 0.8% of all live deliveries.

Over the last 40 years, there has been huge progress in medical and surgical treatment, so that >90% of children with congenital heart disease are now expected to survive into adulthood. This has created a new population of patients, grown up congenital heart (GUCH) or adult congenital heart (ACHD). The adult numbers are growing rapidly and the severity of disorders in these adult survivors is also increasing. Despite treatment in childhood, most adults require specialist long term follow-up and many will need further interventions including cardiac catheterisation and or surgery.

Clinical service design is moving towards integrated programmes to deliver ‘life time care’ of congenital heart disease in congenital heart centres rather than in separate paediatric and adult cardiology units. As the long term outcome of many congenital heart treatments performed in childhood are still unknown, there is a tremendous opportunity for research and at the same time delivering integrated care across the whole pathway, which results in better care for adult patients, while allowing feedback of late outcomes to paediatric cardiology, enabling the development of new and better treatments for the next generation of children.

ICVS / UCLP has the opportunity to become the largest centre for lifetime management of congenital heart disease in Europe, rivalling if not exceeding the best North American centres in size and clinical care quality.
Existing service provision for CHD in UCLP

GOSH is the largest paediatric cardiology unit in the UK, performing ~600 operations per year and ~ 400 interventional catheterisation procedures. In 1997, the ACHD (GUCH) unit opened at the Middlesex Hospital to provide care for GOSH patients after 18 years of age. The service moved to the Heart Hospital in 2003 and its size has grown exponentially, with approximately 6500 patients under active follow-up and approximately 300-400 new patients per year (85% from GOSH, 15% from other sources – appendix 1).

The majority of clinical activity is outpatient based (~3500 patients / yr) with a less frequent need for invasive procedures including catheter interventions (~120 / yr), congenital heart surgery (60-70 / yr), electrophysiology and device interventions (45-50 / yr).

Congenital heart surgery at THH is world class with excellent outcomes (mortality <1%) in a surgical cohort where 60% of surgeries are re-do procedures (31% 2nd operation, 22% 3rd operation). The maternal cardiology service also has excellent outcomes with mortality <0.2% and morbidity of <5% from over 760 deliveries in women with heart disease, 60% of whom have moderate or highly complex heart disease.

Patients ‘graduate’ from GOSH via a transition programme, established in 1998. Adolescents are referred into the transition clinic at 12 years, where they are jointly managed by a GOSH cardiologist, ACHD cardiologist and specialist ACHD nurse, until age 18 years, after which point in time their care is transferred to the Heart Hospital. This programme is a world leader and exemplar of how to ensure continuity of care from childhood to adulthood between specialist services and is the first of its kind in the UK.

Strengths and weaknesses of current ACHD programme

Strengths

- Good links to GOSH with a secure and predictable growing practice
- High profile international leaders amongst senior staff
- Leadership of national policy developments
- World class clinical and research expertise in key areas, e.g. MRI, interventional catheterisation, surgery, pregnancy and heart disease

Weaknesses

- Understaffed at senior, junior and allied health professional level
- Inadequate resources and planning thus far to develop ‘network’ as envisaged in ICVS
- Lack of academic infrastructure to exploit research opportunities
Vision for a congenital heart disease programme

The congenital heart disease programme should be a catalyst for the realisation of an integrated CV system for the AHSN. It should deliver:

- A fully integrated 360 degree service from foetus to child to adult to pregnancy and the next generation, for the whole UCLP community of 6 million as well as national and international referrals.
- A major teaching role in this growing specialist field of cardiology
- Research based on large numbers, innovation and excellence
- Leadership of delivery of the national ACHD service review recommendations for specialist care and a hub and spoke network

We envisage

- A specialist centre for ACHD at ICVS (St Bartholomew's) with a full range of medical and surgical investigation and treatment facilities.
- The existing collaboration with GOSH will be enhanced with seamless transfer of care and formal cost effective pathways.
- Development of ACHD outreach programme to incorporate on site services at UCH, BLT, Newham and L&D.
- Creation of a new network of linked referral centres in the south east to deliver the new national ACHD service framework. This will involve common care pathways, operating procedures, informatics and MDT working across sites with the possibilities for joint appointments. This will ensure that quality of care is at the same excellent standard throughout the network and provide access for all patients to the appropriate level of specialist care and decision making.
Why invest in ACHD now?

- The national ACHD service review is likely to designate ‘congenital centres’ which need to demonstrate joint working with paediatric cardiology units as is already demonstrated and envisaged by the ICVS.

- These specialist centres will be the hubs for a structured referral network, with central funding to the specialist centres, contingent on designation by specialist commissioning.

- The national ACHD review is on-going and it is likely that only two ACHD programmes will be designated in London (one centre North and one South of the Thames), it is therefore essential that UCLP’s programme is of sufficient scale and quality to not only achieve these commissioning standards but to become “The centre for N.Thames”.

- Timely investment in ACHD by the ICVS will attract clinical and academic staff from other centres at risk and potentially create the largest ACHD specialist unit in the UK and Europe.

- Congenital heart disease links three of the four CV centres within the AHSN (UCLH, GOSH and St Bartholomew’s).

- ACHD clinical activity has secure growth projections based on predictable demand from paediatric cardiology, obstetrics and other referral sources.

- Clinical activity underpins many other sub-speciality cardiac activities, such as electrophysiology, imaging, devices/interventional catheterisation and surgery with strong referral activity in these areas.

- Clinical activity links with other UCLP clinical activities including women’s health with rapidly growing maternal/foetal clinics.

- Investment in academic activities would unlock a huge potential output in outcomes research (NICOR), advanced imaging, pulmonary hypertension, novel devices and quality of life assessment. A unique advantage in the ICVS is the expertise in outcomes provided by NICOR at UCL, which hosts the national congenital heart disease registry. A formal plan for investment in a joined up clinical CHD programme would send a powerful signal of academic intent to underpin our application for a BHF research excellence award in March 2013.

The delivery of this ACHD vision will ensure similar integration of other specialist CV services, which are closely linked with ACHD.
Opportunities

- **Improved quality of care across AHSN**
  
  Better accessibility to specialist care and education for local medical professionals.

- **Better Research Collaborations**
  
  The adult CHD patient population under specialist follow-up will increase by encompassing patients from a larger number of centres into a network with common data-sets. Quality control of data will be provided by the “hub”. Outcomes research is an important area for study, potentially changing paediatric surgical techniques which may improve both quality and longevity of life. ACHD patients will also provide a wealth of opportunities for collaborative research for imaging, electrophysiology, clinical pharmacology and novel ‘first in man’ devices.

- **Education and Training**
  
  Health care professionals have an on-going need for education and training (E&T), especially in niche sub-specialties such as ACHD. We currently provide core curriculum ACHD training to the London and East of England Deanery, but there is an opportunity to provide this E&T not only within the network but to capitalise on this need EU and worldwide, via joint fellowships, regular educational conferences, and remote learning. This development will help to establish ACHD within UCLP / AHSN as a leader in education.

- **Wealth creation**
  
  The establishment of the largest centre for CHD in Europe will provide a unique opportunity to deliver and evaluate novel treatments in this growing population of cardiac patients.

CHD has a major track record in innovative device development, which has then been extended to mainstream adult care, e.g. percutaneous valve insertion. Similarly the increasing incidence of arrhythmia, cardiac failure and pulmonary hypertension provides a platform for clinical trials of new drug therapies. This has not been possible up to now because of the fragmentation of both clinical and academic activities, which will be solved by the ICVS.