An Integrated Cardiovascular System (ICVS):
Cardiac Rhythm Management

A proposal for the UCLP Academic Health Sciences Network (AHSN)
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Introduction

Heart rhythm disorders represent a major cause of morbidity and mortality. One common example is atrial fibrillation (AF) which may result in symptoms and increases the risk of stroke. Ventricular arrhythmias are also common, particularly in patients with other heart disease, and can lead to sudden death. The past 20 years have seen huge developments in the field of cardiac rhythm management with new therapies, including anticoagulants, devices and ablation, producing demonstrable reductions in the morbidity and death underpinned by robust randomised controlled trial data.

Over the past decade, a number of reports have raised the national profile of arrhythmia conditions in the NHS. In March 2005, chapter eight of the national service framework (NSF) for coronary heart disease focussed on the issue of arrhythmias & sudden cardiac death highlighted the high prevalence of these. A key aim of the document was to develop NHS systems that:

- provide guidance on making the initial diagnosis and on management by readily accessible approved algorithms;
- improve access to a higher level of expertise by development of rapid access multidisciplinary arrhythmia and/or blackouts clinics;
- focus education on key carers;
- improve access to diagnostics at all stages; and
- improve acquisition, storage and availability of clinical information such as ECGs and audit of all interventions.

Our group has been at the forefront of the development and adoption of these new therapies & has an international profile in cardiac rhythm management (CRM). However, we know that within our population there remains a great need to identify patients at risk and deliver both simple and complex therapy appropriately and at an early stage. One example is the very low rates of appropriate prescription of anticoagulants for prevention of stroke in AF in the proposed academic health sciences network (AHSN).

We believe that the AHSN offers the opportunity to fully integrate primary, secondary and tertiary care for arrhythmia disorders, thus ensuring early diagnosis, prevention and treatment of cardiac arrhythmia and their complications.

Current CRM service provision for patients in UCLP AHSN

1. Tertiary Care

At present tertiary care is delivered at 5 sites within the AHSN. Three of these centres (UCLH, Barts Health and Basildon) provide a full range of adult arrhythmia services; Great Ormond St has a complex paediatric arrhythmia service. Further sub-speciality inherited arrhythmia and cardiomyopathy services are offered at the Heart Hospital and Barts while the Heart Hospital is the only centre to offer Grown Up Congenital Heart disease arrhythmia services.
In addition, there is now a successful complex device service at the Royal Free Hospital as well as some smaller units providing standard elective pacemaker implantation and follow up.

Our CRM group has the strongest research output in the UK with studies supported by funding from national research agencies (MRC, BHF, Welcome Trust) cardiovascular charities (BHF, Heart UK) and the European Commission.

Although much of our work is delivered to our local population, we are also recognised national referral centres for complex arrhythmia work particularly for AF, VT and inherited arrhythmia. We are also the first region in the country to offer a 24/7 on call EP service.

2. Secondary care
The arrhythmia services have developed a close integration and collaboration with the district general hospitals in the region. As a result there are specialist arrhythmia clinics in all of the hospitals in the region that have been willing to accommodate such clinics. This is supplemented by ward rounds and teaching sessions of general cardiologists.

3. Primary care
At present there are a limited number of specialist clinics run in primary care. Nurse led primary care arrhythmia services have been very successful in identifying patients, delivering therapy and reducing referral to secondary and tertiary care in our sector. The UCLP initiative offers an opportunity to develop these services and improve care.

Current clinical and research collaborations within UCLP AHSN

Specialised Cardiovascular Services & Interdisciplinary Teams
The CRM group works in collaboration with a number of other services in across the UCLP network to provide support services to patients with arrhythmias. These include the Inherited Cardiovascular Disease Service (ICC), UCLH Grown Up Congenital Heart Disease Unit (High Risk Pregnancy service), structural heart disease services, interventional cardiology, heart failure service, cardiothoracic surgery.

The CRM group also participate in Heart Failure MDTs to determine optimal device prescription and programming for heart failure management as well as Cardiology-Stroke MDTs to identify suitable candidates for Left Atrial Appendage Occlusion devices in patients unable to receive anticoagulants.

Patient Charities
The CRM group work very closely with the charitable sector to provide medical and educational support to patients and carers throughout the UK. There are strong links between the Arrhythmia Alliance & the AF Association. Examples of joint initiatives include the production of patient information booklets and videos that are distributed nationally (Arrhythmia Alliance, AF Association, Cardiomyopathy Association and The British Heart
Foundation). We have recognised that patient input is critical to forming services that are relevant to patients and that engaging patients is critical to the influence and formation of national healthcare policy.

The Key Priorities for Cardiac Rhythm Management (CRM) within UCLP AHSN

The mission statement of the UCLP CRM team is to reduce morbidity and mortality associated with cardiac rhythm disorders by:

a) early diagnosis of cardiac arrhythmia
b) prevention of cardiac arrhythmia and/or the associated morbidity/mortality
c) early treatment of cardiac arrhythmia
d) using research to develop innovative treatment strategies leading to wealth creation

There are 5 key clinical priorities where CRM can significantly improve quality of life and reduce mortality in the 6.5 million UCLP population:

A. **Tachycardia management** including early diagnosis and treatment of Atrial Fibrillation to prevent strokes & hospitalisations.
B. **Rapid Assessment of Syncope**
C. **Implantation** of Pacemakers, Cardiac Defibrillators (ICD) and Resynchronisation Devices (CRT) to prevent sudden death and hospitalisations for Heart Failure
D. **UCLP sector wide 24/7 heart rhythm centres** delivering specialist care of life threatening cardiac arrhythmia (complete heart block and ventricular arrhythmia)
E. **Remote Monitoring of devices** for outpatient follow-up to reduce hospital admissions/attendances

Proposal for a UCLP AHSN Arrhythmia Service

Establishment of a unified research and clinical network within the UCLP AHSN presents an opportunity to build a unique healthcare system for the full spectrum of arrhythmia conditions. Clinical services for heart rhythm disorders will be provided according to the strategic goals of UCLP including an emphasis on standards of excellence for clinical practice, education and research. The AHSN provides a mechanism for ensuring healthcare delivery from primary care through to tertiary care facilitating the patient’s journey through the system. The arrhythmia service intends to use this opportunity to integrate and deliver specialist care as close to primary care as possible.

A new care network for patients with Heart Rhythm Disorders

Although cardiac arrhythmias are common there are large inconstencies in patient diagnosis and management. This applies especially to the commonest arrhythmia –AF which is frequently silent until it presents in the context of a stroke. The challenge therefore is to provide the highest standards of care for all patients integrating screening, early diagnosis and optimal patient centered management.
We propose to consolidate the four existing Electrophysiology centres (UCLH, BLT, Essex Heart Centre and GOS) by developing common operating procedures and informatics, multidisciplinary teams that work across sites, and collaborative appointments. This will create one of the largest centres of excellence for CRM in the world and will form the basis for large scale research programmes. The fact that this involves a minimum of four geographically separate units as coordinating centres means that this will, for the moment, be a virtual centre. However the CRM group recognises the obvious benefits of co-location of some units and the financial, clinical and academic benefits this brings.

We also propose a new strategy for delivery of Electrophysiology services at a local level. This will involve the delivery of specialist arrhythmia services in primary care by arrhythmia nurse specialists employed by the CRM centres and under consultant supervision. This model has been successfully pioneered within the CRM group providing screening, diagnosis and treatment of AF with only 12% of patients requiring referral to secondary or tertiary care. Priorities would be the development of AHSN wide screening programme for AF in high risk patients identified by existing computer algorithms (e.g. GRASP-AF). These patients would then be reviewed by specialist nurses and GPs and appropriately anticoagulated within primary care thus reducing stroke rates in the AHSN. This strategy would deliver a 20% increase in the anticoagulation uptake of high risk AF patients within the AHSN and a corresponding stroke reduction within 4 years its establishment.

Bespoke patient treatment algorithms will ensure that treatment occurs within primary care whenever possible and that patients in whom this is not possible are referred promptly to secondary/tertiary centres for intervention (e.g. cardioversion, pacemaker implantation, ablation) could be achieved in a timely manner. Local multidisciplinary meetings would be established between GPs and specialist arrhythmia nurses. Electrophysiology Consultants would be integral to this management pathway by being responsible for developing uniform patient care algorithms (in collaboration with primary care physician leaders) and providing email consultations. This would serve to break down the current delays in referral and therapeutic intervention. This strategy will not only give patients access to specialist care but also reduce costs associated with unnecessary hospital referrals and investigation.

In order to meet the need for the population served by UCLP, we propose a network in which the tertiary centres (Barts, UCLH, Essex Heart Centre) act as a virtual hub for a number of satellite arrhythmia services based in primary & secondary care. The CRM group will share personnel, clinical and research governance frameworks, standard operating procedures and informatics systems. All patients reviewed at the satellites will be registered centrally and will have access to the core arrhythmia centres. Our aim will be to maximise care local to the patient, making it necessary for them to travel to one of the tertiary centres only for highly specialised investigation (e.g. family screening of inherited arrhythmia) or treatment (e.g. catheter ablation).

The costs involved in the additional staff (e.g. primary care arrhythmia nurses) would be offset by reductions in stroke, inappropriate investigations, avoid delays in secondary and tertiary care referral (interpretation of the 24 hour tapes are often inaccurate and trigger unnecessary referrals or patients are referred to general cardiologists who then refer them
to EP thus adding an extra step in the patient journey) and unnecessary procedures (e.g. D.C. cardioversion). All these approaches will be subject to audit to identify optimal strategies.

**How will this model be applied to the 5 Key Clinical Priorities?**

**A. Tachycardia Management**

The main five major categories of arrhythmias relevant to this document are:

- **Atrial Fibrillation**
- **Other Supraventricular arrhythmias**
- **Ventricular arrhythmias** occurring in structural heart disease. The management of common aetiologies (ischaemic heart disease) is covered by current NICE guidance. However rare forms of cardiomyopathy require more specialist care within the world leading centres we represent.
- **Inherited Arrhythmia syndromes** caused by mutations in cardiac ion channels which can result in ventricular arrhythmia and sudden death.
- **Arrhythmias due to Grown-Up Congenital Heart (GUCH) Disease.**

**Atrial Fibrillation & Thromboembolic Stroke**

Atrial fibrillation (AF) is the most common sustained cardiac arrhythmia in the UK [BHF, 2004]. Both AF and AF related illness cost the NHS over £2.2 billion each year affecting nearly 2% of the population-between 100,000 and 200,000 people in the UK develop AF every 12 months. For 2008, it was calculated that AF accounted for 5.7 million days in hospital beds costing over £1.8 billion.

A devastating complication of AF is stroke. People with AF have a five-fold greater risk of stroke and thromboembolism than those without [NICE, 2006] and yet only 18% currently receive thromboprophylaxis. The incidence of stroke attributable to AF increases from 1.5% in people 50–59 years of age to 23.5% in people 80–89 years of age [NICE, 2006]. The majority of these strokes occur in those with silent AF who are not anticoagulated. This represents a major opportunity to intervene utilising integrated screening and prevention programmes. Preventing 1 stroke would save £15,000/year and it is estimated that 1000 patients need to be treated to prevent 31 strokes a year- ie. NNT=32/yr to prevent 1 stroke/year. In Tower Hamlets alone it is estimated from GP registers that 50% of patients who should be on anticoagulants are actually not receiving these drugs offering a huge potential for the AHSN to impact on this morbidity.

The CRM group will improve identification and treatment of AF by employing specialist arrhythmia nurses who will serve a network of general practices. They will be tasked with assisting with the setting up of screening programs to run alongside hypertension screening and be responsible for applying algorithms pioneered within the CRM group for diagnosis confirmation and treatment.
The AHSN CRM target for AF will be to increase appropriate anticoagulation prescription by 10% in the first four years of the AHSN.

**Other Supraventricular Arrhythmias**

The estimated prevalence of paroxysmal supraventricular tachycardia (PSVT) is 2.25 per 1000.(3). The overall incidence of atrial flutter is 0.088%; 58% of these patients also have AF. Atrial flutter alone is seen in 0.037%.

The establishment of curative ablation for SVT and atrial flutter means that the morbidity and hospitalisations arising from these arrhythmias can be avoided. The challenge remains to identify these patients (especially atrial flutter which like AF can also be silent and has the same risk of stroke as AF) and ensure optimal therapy is delivered promptly as these conditions have significant medical and cost implications.

The CRM group has developed a world first in SVT treatment with a strategy which is currently being validated in randomised trials in collaboration with London Ambulance. This allows patients presenting acutely with SVT to be diagnosed, treated and discharged by the paramedics without transportation to hospital. They can then be reviewed and offered definitive treatment in rapid access arrhythmia clinics in primary or secondary care.

**Ventricular Arrhythmias**

Sudden cardiac arrest claims around 50-100 lives per 100 000 population every year in the United States and Europe accounting for more than 5% of overall mortality. It remains a considerable burden on communities and health systems.

A shockable rhythm (ie: VT/VF) underlies up to half of the arrests and in the majority the culprit aetiology is either an acute ischaemic event or preceding ventricular dysfunction. The latter patients can be identified by screening and offered prophylactic ICD implantation based on NICE guidance. Similarly survivors of cardiac arrest can be protected by an ICD if a reversible cause is not identified. The CRM group will develop formal links with colleagues in heart attack centres and heart failure services to ensure that all patients who may benefit, will be offered ICD or cardiac resynchronisation.

**Inherited Arrhythmia syndromes**

Our units have established inherited CV disease clinics where patients are screened and managed (as part of the ICVD service). The commonest ion channelopathies account for approx 1/2500 of the population and usually manifest in teenage years or middle age. Sudden death & arrhythmic events can be prevented by medication (eg. Beta blockers) or implantation of an ICD in eligible candidates.

The CRM group will consolidate inherited arrhythmia syndrome management across the sector. This service will focus on improving identification of patients at high risk and genetic guided therapy.

**Arrhythmias due to Inherited Cardiomyopathies and GUCH.**

The arrhythmias due to cardiomyopathy principally encompass atrial fibrillation and ventricular tachycardia/VF. Optimal management requires a combined approach between
the ICVD physicians and electrophysiologists. A significant proportion of cardiomyopathy patients require device therapies (ICDs, CRT) and catheter ablation may be employed to treat arrhythmias resistant to medical therapy. The GUCH patients require integrated care with catheter ablation improving outcomes due to atrial arrhythmias in this population who are prone to atrial tachycardias and atrial flutter. These highly specialised services will remain centred in tertiary care.

Table 1:

Estimates for numbers of people with commonest arrhythmia disorders & inherited arrhythmia disorders/arrhythmogenic cardiomyopathies resident in the UCLP Network.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Population Prevalence</th>
<th>Estimated prevalent cases UCLP AHSN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atrial Fibrillation</td>
<td>20/1000</td>
<td>130,000</td>
</tr>
<tr>
<td>SVT</td>
<td>2.25/1000</td>
<td>14,600</td>
</tr>
<tr>
<td>Atrial Flutter</td>
<td>3/1000</td>
<td>19500</td>
</tr>
<tr>
<td>ICD 1’ and 2’Implantation Rate</td>
<td>75/1000,000</td>
<td>490</td>
</tr>
<tr>
<td>Arrhythmogenic right ventricular cardiomyopathy</td>
<td>1 in 1000 to 1 in 10,000</td>
<td>600-6000</td>
</tr>
<tr>
<td>Long QT syndrome</td>
<td>1 in 5000</td>
<td>1200</td>
</tr>
<tr>
<td>Hypertrophic cardiomyopathy</td>
<td>1 in 500</td>
<td>13000</td>
</tr>
<tr>
<td>Dilated cardiomyopathy</td>
<td>1 in 2500</td>
<td>2400</td>
</tr>
<tr>
<td>Brugada Syndrome</td>
<td>1 in 5000</td>
<td>1200</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>188,340</td>
</tr>
</tbody>
</table>

B. Rapid Assessment of Arrhythmia, Syncope/Transient Loss of Consciousness (T-LOC)

Syncope accounts for 3% of hospital attendances and 6% of acute medical admissions. At least 10% of these events result in fractures. In the elderly, it most frequently presents as “falls” with amnesia after the collapse. The average length of stay for hospital admission is 3.9 days costing £70million/year to the NHS. These patients can be risk stratified according to ESC T-LOC guidance and cost-effective diagnostic and management pathways are established utilising implantable loop recorders when indicated. Rapid, efficient assessment of these patients to identify cardiac causes requires fully integrated primary and secondary care pathways to minimise future events and prevent sudden death from bradycardia or ventricular arrhythmia.

The CRM group will identify and investigate patients at risk of arrhythmia related syncope within primary care with the help of specialist nurses running rapid access
arrhythmia/syncope clinics. Intervention when needed will then be arranged between nurses and their supervising CRM consultant in secondary or tertiary care where appropriate.

The AHSN CRM target will be an increase in bradycardia device implantation from 560/million to 620/million over the first 4 years (national target 700/million not achieved by any region in the UK).

C. Device Therapy (Pacemakers, ICDs, Cardiac Resynchronisation)

Even though a number of randomised controlled trials of CRT & primary/secondary prevention ICD studies have demonstrated benefit for these devices, there is still an important unmet need. There is significant under diagnosis of heart failure in the UCLP population & patients with heart failure who meet criteria for CRT implantation to reduce mortality & hospitalisation are not recognised in the community. This also applies to patients with previous myocardial infarction and severely impaired LV function who are potential candidates for ICD prophylaxis as well as large numbers of elderly patients with subclinical conduction disease and chronotropic incompetence who would benefit from simple pacemaker implantation to reduce syncope and improve exercise tolerance. Indeed it is recognised that device implant rates in the UK are less than 50% of those in Germany and the USA due to lack of eligible patient identification in the community. Such patients could be identified utilising the resources of UCLP GP databases and referral networks and referred accordingly to their local arrhythmia centre.

The AHSN CRM target will be to increase CRT implant rates to equal or exceed the national target (at present over the AHSN as a whole the implant rate is below the national target).

D. UCLP Sector Wide Emergency Arrhythmia Management

The CRM group have already established a 24h emergency pacemaker implantation & Ventricular Tachycardia service to ensure prompt management of life threatening arrhythmia. This involves permanent pacemaker implantation for irreversible bradyarrhythmia, avoiding the long hospital stays and complications associated with temporary pacing. For ventricular arrhythmia patients- expert ICD programming & VT ablation are offered 24/7.

In order to make this available to the entire UCLP population the CRM group will collaborate to reconfigure referral pathways with ambulance and accident and emergency services triaging and transferring patients to “Arrhythmia Emergency Centres”.

The AHSN target will be to demonstrate significant reductions in hospital stay and morbidity in this patient group achieved through prompt definitive treatment.

E. Remote Device Monitoring

The exponential increase in pacemaker, ICD and CRT implantation is already placing an increasing burden on healthcare resources in terms of patient follow-up and generator/lead replacements. This trend is set to continue. The advent of remote monitoring of device
function and remote physiological monitoring (e.g., lung impedance and respiratory rate in heart failure) will mean that patients can be managed at home by their cardiologist without the cost and burden of repeated hospital visits both for the patient and staff involved. The CRM group are currently using the data provided by these devices for early identification of heart failure and changing drug therapy to avoid admission to heart failure applying treatment algorithms. However, the potential of remote follow-up to reduce hospital admission and complications from devices remains unfulfilled. The advent of remote programming, anticipated within the next 2-3 years, would provide further opportunity to lower hospital admissions and limit patient journeys to hospital pacing clinics and therefore increase patient quality of life.

*The AHSN target will be to demonstrate reductions in heart failure and device complication-related hospital admissions.*

### Other Opportunities arising from the UCLP CRM Service

#### Enhanced Research Collaborations

The CRM group has agreed to uniform patient pathways including common policies for referral, investigation and treatment. This means that a unique health care system will be developed encompassing large numbers of patients within a clearly defined geographical area managed using commonly agreed strategies. This approach will facilitate the inclusion of all arrhythmia patients in research projects including biobanking, randomised controlled trials and large scale outcomes research.

There are also synergies between the internationally recognised expertise in arrhythmia & cardiovascular disease at UCL and developing research programmes within the BLT NIHR Cardiovascular Biomedical Research Unit and the Heart Centre at Charterhouse Square. Opportunities for integrated research programmes relevant to the CRM theme include molecular cardiology, advanced cardiac imaging, cardiovascular genetics, stem cell biology, pharmacology, cardiovascular epidemiology and large-scale trials of novel treatment strategies. Many of these programmes are in development but the AHSN funding and infrastructure will create an unprecedented platform to realise a world-class internationally competitive programme. The recent incorporation of the Institute of Cardiovascular Science (ICS) into the new Faculty of Population Health Sciences at UCL offers opportunities for outcomes research and health economic analysis, while the recently developed partnership between UCL and Yale University presents revolutionary opportunities for genomic research and novel engineering solutions in the field.

#### Education and Training

Increasing demand for arrhythmia services over the next 5-10 years will generate a need for greater awareness and training for health care professionals. Our CRM group have already
trained a significant proportion of the new consultant electrophysiologists in the country. The union of existing services across UCLP AHSN will create a critical mass of clinical activity and expertise that can be used to support comprehensive quality training and education. A major function of the new Electrophysiology AHSN will be the development of an educational programme based on regular courses, small group teaching and remote learning using state of the art telemedicine and conferencing facilities. An important part of this will be focused on the education and support of specialist arrhythmia nurses and GPs. Part of this education plan will be to define established training programmes for all nurses working within the CRM group. This will allow them to switch between different sectors, for example allowing ward or catheter lab nurses to move to primary care and vice versa thus enhancing career choices and improving recruitment and retention.

Patient and family education will also be a key part of our strategy so that patients and their families can make informed decisions made about their care.

**Wealth Creation**

**Technology research and development**
Despite major therapeutic advances, arrhythmias still represent a substantial unmet need for therapeutic innovations. The CRM group has strong links with Industry and undertake both phase 1 technology evaluation and randomised controlled trials of CRM technologies including devices (ICDs, lead technologies) & ablation energy sources. These collaborations are set to expand with the establishment of the Yale-UCL “first in man” technology development programme. We have pioneered multicentre randomised controlled trials of arrhythmia technologies (SMARTAF, PVAC) and established a European Registry of Subcutaneous ICD implantation (EFFORTLESS). An important factor in this relationship has been the volume of patients managed by the individual groups. However, as a single CRM group within the AHSN, the scale of clinical activity that this proposal envisages provides an internationally unique infrastructure for the identification of novel therapeutic targets, randomised clinical trials and population scale outcomes research. Existing research pipelines in genomics, proteomics and outcomes research will be scaled up to support the basic science necessary in the translation of novel therapies into clinical practice. This CRM programme complements recent UCLP endorsed innovations such as the BHF Research Excellence bid for Centre for Therapeutic Innovation.

**Intellectual property**
We plan to use the patient pathways, clinician education programs and clinical research publications to create a brand for the AHSN. This brand and the materials will be exported as consultancy and training packages to other regions of the world with the assistance of industry and UK department of trade and industry.