



**GROWN UP CONGENITAL HEART  
PATIENTS ASSOCIATION**

**SPECIALIST GUCH CENTRES  
IN ENGLAND**

**SEPTEMBER 2007**

## **Introduction**

The GUCH Patients Association (GUCHPA) is often asked, "Where should I go for medical care?" Despite the various hospital claims to have the necessary special expertise and facilities to help GUCH patients, patients have often reported lack of satisfaction or successful outcome and their wish for referral elsewhere. Understandably patients are sent by practitioner to the local hospital and cardiologist, the GP having little or no understanding that there is something special, rare or even demanding about their patient's needs. Patients report that they are frequently met with little understanding of their basic condition. The Department of Health cannot provide the answer to this question.

The needs for these patients, particularly involving better information, was recognised by the British Cardiac Society in 1992 and produced in September 2002 a report titled "Grown-Up Congenital Heart (GUCH) Disease: Current Needs and Provisions of Service for Adolescents and Adults with Congenital Heart Disease in the UK".

This report which was followed in 2006 by a guide published by the Department of Health titled "A commissioning guide for services for young people and Grown Ups with Congenital Heart Disease (GUCH)" recognised that there were two levels of care, specialist and local. A specialist centre was distinct in having cardiac surgery for GUCH patients.

The trustees of GUCHPA considered that they must be fully informed about the current status of available medical facilities for GUCH patients and should be fully aware of the content of the claimed specialist centres. Now that there is sufficient consensus over the definition and requirements of a specialist centre, it has been thought appropriate to examine the contents of the centres and the service levels.

## **Specialist GUCH Centres**

This term is agreed upon. What is less clear is how to determine which units are truly specialist centres providing the necessary services.

The NHS GUCH Guide states as a requirement: "All adults with congenital heart disease whatever the level of complexity are seen by an "expert" from a specialist centre at least once and receive a written care plan." GUCHPA considers it important to define which centres are specialist and ideally to know who is an expert consultant in GUCH medicine (and surgery).

GUCHPA does not accept that a GUCH specialist is one who practices GUCH cardiology, either paediatric or adult, and does occasional outpatient clinics, interventions or operations. The Royal College of Physicians Cardiology Specialist Advisory Committee has produced a training module for the advanced sub-speciality of GUCH which should have been completed before a consultant can be considered a GUCH specialist. This currently entails two years high intensity training by a specialist GUCH team.

This definition however can obviously only apply to newer consultants and there are consultants who can be considered specialist if they have for the last five years spent in excess of 50% of their time working exclusively with GUCH patients within an established GUCH service including the peri and post operative management of cardiac surgical cases.

## **Survey**

The document was designed and based upon the requirements of a specialist centre as stated within the two documents mentioned (British Cardiac Society Report 2002 and Department of Health GUCH Guide 2006). It was sent to known GUCH consultants or the Head of Cardiology in hospitals either known to or claiming to have a specialist centre service. Surveys were designed with input from patient representatives and medical members of the Trust Board. Comprehensive

suggestions from Southampton General Hospital GUCH Unit were also added and taken into account. A copy of the final survey is included in Appendix A.

Comments from the first survey distribution, negative and positive were taken into account and reflected in the second survey. On return of the surveys, the data was reviewed by two members of the Trust Board, one GUCH consultant and one patient. Where answers were not clear, not reflective of the facts as known or not responded to, further enquiries were made and where necessary direct contact was made with the appropriate consultant. Some checks were made on the stated facts although this was not a complete audit.

The survey enabled a categorisation of the level of service and the degree of specialist expertise available. The main aim was to provide a simple statement as to whether the hospital complied or did not comply with the requirements considered necessary by GUCHPA for a specialist centre.

## **Basic Data**

Both the NHS GUCH Guide and the British Cardiac Society report require specialist centres to have cardiac surgical expertise for GUCH patients. It is considered that GUCH surgical activity should include more than 30 surgical cases per annum for our purposes, though ideally a GUCH cardiosurgical specialist centre should include 50 surgical cases per annum. The numbers are small, interventional therapy is taking over many surgical cases and this minimum number is likely to change.

The most up to date available data (2004-2005) was obtained from the Central Cardiac Audit Database (CCAD) to determine whether there was sufficient practice to enable the term "expert" to be applied to GUCH centres.

## **Definitions**

The centres surveyed are categorised as either "COMPLY" or "NOT COMPLY".

### **COMPLY**

Whilst this does not necessarily mean that the centre has the full resources which a specialist centre is deemed to need by the two reports mentioned, it does mean that it has enough of the services for us to consider it to be able to offer a service level deemed to be specialist.

We have also included what we believe the centre is in particular need of, despite us still believing that they are capable of being considered a specialist centre.

### **NOT COMPLY**

Means that we do not consider they have enough of the required resources to enable them to be considered, yet, a specialist centre. By implication it means that should they obtain the resources which we consider they are lacking then they would be considered to comply.

We have also included in this category those centres where we are unsure whether particular resources are there or not and have detailed those concerns. If we are able to confirm one way or another on that doubt we will change the entry.

## Results

<b>CENTRE</b>	<b>OUTCOME</b>	<b>NOTES</b>
<b>BIRMINGHAM</b> UNIVERSITY HOSP	COMPLY	No dedicated inpatient area CCAD: 49
<b>BRISTOL</b> ROYAL INFIRMARY	COMPLY	No EP separate to Consultants No dedicated inpatient area No GUCH trained cardiac pathologist CCAD: 42
<b>LEEDS</b> GENERAL	COMPLY	No dedicated inpatient area No GUCH trained cardiac pathologist No 24 hour point of reference CCAD: 47
<b>LEICESTER</b> GLENFIELD	NOT COMPLY	Not two FTE GUCH Consultant Card. No dedicated inpatient area No GUCH trained cardiac pathologist CCAD: 32 <b>Comment:</b> Not 2 FTE Consultants
<b>LONDON</b> ROYAL BROMPTON	COMPLY	Not in multi-disciplined environment CCAD: 116
<b>LONDON</b> HEART	COMPLY	No dedicated inpatient area Not in multi-disciplined environment No linked clinical psychologist service No linked social worker service CCAD: 55
<b>LONDON</b> ST THOMAS'S	NOT COMPLY	Not two FTE GUCH Consultant Card. No dedicated inpatient area Minimal link with GUCHPA CCAD: 7 <b>Comment:</b> Surgical numbers too low and not 2 FTE Consultants
<b>MANCHESTER</b> ROYAL INFIRMARY	NOT COMPLY	Not two FTE GUCH Consultant Card. No dedicated inpatient area MRI not on site CCAD: not recorded <b>Comment:</b> Needs to COMPLY as soon as possible - NW needs this centre
<b>NEWCASTLE</b> FREEMAN	NOT COMPLY	Not two FTE GUCH Consultant Card. No dedicated inpatient area CCAD: 45 <b>Comment:</b> Needs to COMPLY as soon as possible – NE needs this centre
<b>OXFORD</b> RADCLIFFE	NOT COMPLY	Not two FTE GUCH Consultant Card No GUCH nurse specialist No dedicated inpatient area No link with GUCHPA CCAD; 19 <b>Comment:</b> Surgical numbers too low, not 2 FTE Consultants and no GUCH nurse.
<b>SOUTHAMPTON</b> GENERAL	COMPLY	No dedicated inpatient area No linked clinical psychologist service CCAD: 53

## **Commentary**

Nearly all those determined as complying need to address some issues. Only one has an established and appropriate in-patient area.

Where they do not comply matters should also be considered geographically. In the NE (Newcastle) and NW (Manchester) the investment needs to be put in to bring them up to the full resources required to fully comply as soon as possible.

There must be doubt over whether resources would be better used if redirected from others non-complying such as Oxford and St Thomas's where geographical considerations are less relevant.

Sensible investment decisions are required to achieve a consolidation of the service for a national service model. We do not believe the number of specialist centres should increase.

It is important for us to address other areas now both in terms of units and geography.

There are units that are not specialist centres but do have an "expert", others provide a more local service, mainly outpatient, and it is important that these be retained for the benefit of the patients who might find travel on a regular basis difficult.

There is also a need for the services in Scotland, Wales and Northern Ireland to be surveyed.

This report will be available on the website [www.guch.org.uk](http://www.guch.org.uk) and will be updated as our determination of the centres alters and increases.

## **Patient Perspective**

It is important that GUCH patients are given simple and understandable information without the need for interpretation. It is also important that just because a centre does not have the resources when compared to another but is still able to be considered a centre with an "expert" that we do not give out the wrong message by mistake.

Therefore from a patient perspective based upon the returns and apparent experience the centres where they will find an "expert" or GUCH specialist are as follows:

Birmingham – University Hospital  
Bristol – Royal Infirmary  
Leeds – General Hospital  
Leicester – Glenfield Hospital  
London – Brompton  
London – Heart  
London – St Thomas's  
Manchester – Royal Infirmary  
Newcastle – Freeman Hospital  
Southampton – General Hospital

To that list can be added centres which are not specialist GUCH centres but what might be called a local GUCH centre with an "expert" or GUCH specialist who would liaise with an appropriate specialist centre when necessary which are:

Liverpool – Broadgreen Hospital  
Norwich – Norfolk & Norwich Hospital  
Plymouth – Derriford Hospital

It should be safe for GUCH patients to presume that by attending one of these centres they will still receive a proper care plan.

A separate document, Appendix B, detailing the contact details for all these will be made available for GUCH patients.

GUCHPA

## APPENDIX A



### PATIENTS ASSOCIATION

#### GUCH SPECIALIST CENTRE – RESOURCE MEASUREMENT

##### UNIT: X

ITEM	COMPLIANCE	MARKING
Two or more Cardiologists with specialist training in GUCH. One to have experience in interventional techniques other than coronary angioplasty unless a Paediatric Cardiologist is available and competent to undertake intervention in GUCH patient.		Full time GUCH = 16 Part time = 8 Minimal = 4 Max: 48  0
Two or more cardiac surgeons trained and practising in adult and paediatric surgery. (Unit must have min 50 complex cases per annum).		@ 16, max 32  0
A clinical GUCH nurse specialist.		Full time GUCH = 8 Part time = 4 Minimal = 2 Max 16  0
Specialist outpatient service		Comp 8, partial 4  0
An EP with training and experience of arrhythmias in congenital as well as acquired heart disease, pacemaker technology, ablation technology, and defibrillator implantation.		Comp 8, partial 4  0
ITU with relevant experience		Comp 8, partial 4  0
Two or more cardiac anaesthetists with specific interest and experience in congenital cardiac malformations in adolescents and adults.		Comp 8, partial 4  0
A dedicated ward area for GUCH patients with appropriate extra facilities.		Comp 8, partial 4  0
ECHO Cardiologist		Comp on site 8, offsite 6 partial 2  0
MRI Cardiologist		Comp on site 8, offsite 6 partial 2  0
Dental advice and a clinical service for dental surgery should be available, but not necessarily on site.		Comp on site 6, offsite 4 partial 2  0
A formal link with a named obstetrician/obstetric team to allow the centralisation of expertise in management of pregnancy in “at risk” patients.		Comp on site 6, offsite 4 partial 2  0
Close links with other specialist departments, including genetics, endocrinology, respiratory medicine, neurology and surgery, ideally on site.		Comp on site 6, offsite 4 partial 2  0
Liaison with the GUCH Patients Association.		Comp 4, partial 2  0
Database for GUCH and liaison with national databases.		Comp 4, partial 2  0
A cardiac pathologist with interest in congenital cardiac malformations.		Comp 4, partial 2  0

Ideally located in an adult medical environment with multidisciplinary specialist provision.		Comp 4, partial 2 0
Shared care protocols with local GUCH centres and GPs. May include outreach clinics.		Comp 4, partial 2 0
Provide a 24-hour point of reference for local GUCH centres, tertiary centres etc.		Comp 4, partial 2 0
Teaching and training including for technicians and also post-graduate education.		Comp 4, partial 2 0
Collaborate with other specialist and local GUCH centres to ensure national audit.		Comp 4, partial 2 0
Committed to research and development and provide an environment where research can be carried out.		Comp 4, partial 2 0
An association/connection to a transplant centre.		Comp on site 4 offsite 2 0
<b>Additional specialists:</b>		
Physiotherapist		Comp 4, partial 2 0
Dietician		Comp 4, partial 2 0
Clinical psychologist (with specific GUCH sessions)		Comp (specific) 4, partial 2 0
Social worker (dedicated or partial)		Comp (dedicated) 4, partial 2 0
<b>TOTAL</b>		(Max 226) 00

## APPENDIX B



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### Hospitals in England recognised by the Association for the diagnosis of GUCH patients

- **NHS GUCH Guide states it is important that “All adults with congenital heart disease whatever the level of complexity are seen by an expert from a specialist centre at least once and receive a written care plan.”;**
- **It is best if patients are referred to a centre by a GP or other doctor but if this is proving difficult they should phone the centre themselves;**
- **The resources of hospitals differ and we have relied upon information provided by them. (Private patients are also welcome).**

#### **Birmingham - University Hospital**

Edgbaston Birmingham B15 2TH  
0121 627 2959 or 0121 627 2870  
Dr S Thorne, Dr P Clift

#### **Bristol Royal Infirmary**

Bristol Royal Infirmary  
Dolphin House Bristol BS2 8HW  
0117 3420483 or  
Nurse Specialist 0117 3420463  
Dr G Stuart, Dr R Martin, Dr M Turner

#### **Leeds General Hospital**

Great George Street Leeds LS1 3EX  
Liaison Nurse: 0113 3928154  
New patients: 0113 3928184  
Dr K English, Dr J Thompson,  
Dr M Blackburn, Dr J Gibbs.

#### **Leicester - Glenfield Hospital**

Groby Road Leicester LE3 9QP  
0116 256 3904 or 0116 256 3082  
Dr F Bu'Lock, Dr R Leanlage, Dr M Khan

#### **Liverpool - Broadgreen Hospital**

Thomas Drive Liverpool L14 3LB  
0151 288 4811  
Dr I Peart, Dr D Kitchener

#### **London – Brompton Hospital**

Sydney Street London SW3 6NP  
020 7351 8602  
Prof M Gatzoulis, Dr M Mullen, Dr L Swan

#### **London – Guy's St Thomas's**

Cardiothoracic Unit 6th Floor East Wing  
St. Thomas' Lambeth Palace Rd SE1 7EH  
020 7188 1090  
Dr C Head, Dr E Rosenthal

#### **London – Heart Hospital**

16 – 18 Westmoreland Street  
London W1M 8PH  
GUCH Office 020 7573 8808  
In emergency ask for on call GUCH Registrar  
Prof J Deanfield, Dr S Cullen, Dr F Walker

#### **Manchester Royal Infirmary**

Oxford Road Manchester M13 9WL  
0161 276 4143  
Dr V Mahadavan, Dr B Clarke, Dr L Cotter,  
Dr N Malaya

#### **Newcastle – Freeman Hospital**

High Heaton Newcastle Upon Tyne NE7 7DN  
0191 233 6161 or  
Nurse Specialist 0191 244 8990  
Dr J O'Sullivan, Dr M Chaudhari

#### **Norwich – Norfolk & Norwich Hospital**

Colney Lane, Norwich NR4 7UZ  
01603 289666 or  
Nurse Specialist 01603 287002  
Dr L Freeman

#### **Plymouth – Derriford Hospital**

Derriford, Plymouth PL6 8DH  
01752 792661  
Dr A Marshall

#### **Southampton General Hospital**

Wessex Cardiac Unit  
Tremona Road Southampton SO16 6YD  
02380 777222  
Dr A Salmon, Dr G Veldtman,  
Dr J Gnanapragasam, Dr J Vettukattil  
Liaison Nurse: Bleep 1481

