

**National Clinical Congenital Heart Disease Audit**  
**RESEARCH COMMITTEE**  
**TERMS OF REFERENCE**

## **National Congenital Heart Disease Audit**

### **TERMS OF REFERENCE**

#### **1. TITLE**

National Congenital Heart Disease Audit Research Committee

#### **2. INTRODUCTION**

The National Congenital Heart Disease Audit (NCHDA) Research Committee is to advise and promote research using the NCHDA database. These terms of reference set out the membership, structure of partnerships, decision-making and accountability, workplan and performance management, confidentiality and the arrangements for the conduct of business of the committee.

#### **3. PURPOSE**

The role of the committee is to promote the use of NCHDA data in high quality research projects that have the ultimate aim of improving patient care. The group are responsible for appraising research applications requesting access to NCHDA data and overseeing and collaborating on projects using audit data. The group will develop a research agenda for the audit, including submitting grant applications, commissioning or carrying out analysis, and preparing papers for publication as required.

The NCHDA research committee is represented on the NCHDA Steering group and NICOR Research Executive.

#### **4. MEMBERSHIP**

##### **4.1. The Chairperson**

The Chairperson is appointed by the NCHDA Steering Committee. Their responsibilities include:

- Inviting specialists to attend meetings when required by the committee;
- Guiding the meeting according to the agenda and time available;
- Ensuring all discussion items end with a decision, action or definite outcome; and
- Review and approve the draft minutes before distribution
- Report (or nominate a representative) on NCHDA research activity and related issues to the NICOR Research Executive

The committee will appoint a deputy Chairperson, to undertake the Chairperson's responsibilities in their absence. The deputy Chairperson will report back to the Chairperson.

##### **4.2. The minute-taker**

The NCHDA project manager will be responsible for supporting the Chair in the management of NCHDA business. Responsibilities include:

- Scheduling meetings and notifying committee members;
- Prepare agendas and issuing notices for meetings, and ensuring all necessary documents requiring discussion or comment are attached to the agenda;
- Distributing the agenda and associated papers seven working days prior to any meeting;
- Taking notes of proceedings and prepare minutes of the meeting;
- Brief minutes and action points arising from the meetings to be written and circulated within 7 working days of the meeting
- The minutes shall be checked by the Chairperson and accepted by committee members as a true and accurate record at the commencement of the next meeting.

#### 4.3. Qualification of membership

All members are appointed by the NCHDA Steering Committee. All members must have demonstrable expertise/experience in research as a key requirement. Membership must include representatives from the following groups:

- NCHDA Clinical Lead
- NCHDA Lead for Research
- 3 members of the NCHDA Steering Committee
- NICOR analyst/methodologist
- NICOR data manager
- 2 surgical representatives from The Society for Cardiothoracic Surgery
- 2 cardiology representatives from the BCCA
- Patient/lay representation

Membership is for a term of 3 years unless members terminate their membership or cease to represent their respective stakeholder group.

Member	Position	Committee role	End of membership
Rodney Franklin	Consultant Paediatric Cardiologist, Royal Brompton Hospital	Chair	2016
David Barron	Consultant Congenital Cardiac Surgeon, Birmingham Children's Hospital	Chair of SCTS congenital subcommittee	2016
Kate Brown	Consultant Paediatric Cardiac Intensivist, Great Ormond Street Hospital	Clinical Lead for NCHDA Research	2016
Kate English	Consultant Adult Congenital Cardiologist, Leeds General	ACHD BCCA representative	?2016

	<b>Infirmary</b>		
<b>Andreas Hoschtitzky</b>	<b>Consultant Congenital Surgeon, Manchester Royal Infirmary</b>	<b>SCTS representative</b>	<b>2016</b>
<b>Serban Stoica</b>	<b>Consultant Congenital Cardiac Surgeon, Bristol Children's Hospital</b>	<b>SCTS representative</b>	<b>2016</b>
<b>Chuck McLean</b>	<b>Consultant Congenital Cardiac Surgeon, Royal Hospital for Sick Children, Glasgow</b>	<b>Database lead of SCTS congenital subcommittee</b>	<b>2016</b>
<b>Robin Martin</b>	<b>Consultant Paediatric Cardiologist, Bristol Children's Hospital</b>	<b>BCCA President</b>	<b>2015</b>
<b>Andrew Tometzki</b>	<b>Consultant Paediatric Cardiologist, Bristol Children's Hospital</b>	<b>BCCA Congenital Cardiology representative</b>	<b>2017</b>
<b>Alan Magee</b>	<b>Consultant Paediatric Cardiologist, Southampton General Hospital</b>	<b>BCCA representative</b>	<b>?2015</b>
<b>Thomas Witter</b>	<b>Database Manager, Evelina Children's Hospital</b>	<b>Elected Congenital Cardiology Database Managers' representative</b>	<b>2016</b>
<b>Tbc</b>	<b>Lay representation</b>	<b>P&amp; P</b>	<b>2-3 years</b>
<b>David Cunningham</b>	<b>Senior Strategist</b>	<b>NICOR</b>	<b>End of employment/ change of role</b>
<b>Owen Nicholas</b>	<b>Senior Analyst &amp; Statistician</b>	<b>NICOR</b>	<b>End of employment/ change of role</b>
<b>Anthony Bradley</b>	<b>NCHDA Project Manager</b>	<b>NICOR</b>	<b>End of employment/ change of role</b>

#### 4.4. Quorum membership

A quorum is necessary for the transaction of business. The following members (or their deputies) must be present before a meeting can proceed:

- The Chair of the Steering Committee, or their nominated deputy
- SCTS and BCCA representatives
- A surgical and interventional representative?
- NICOR Senior Analyst/statistician



Other members will be required to attend a minimum of 75 % of all meetings

#### **4.5. Invitees**

Internal or external persons may be invited to attend meetings at the request of the Chairperson on behalf of the committee to provide advice and assistance where necessary. It may not be necessary for an invitee to attend the whole meeting and may be requested to leave the meeting at any time by the Chairperson.

#### **4.6. End of membership**

Committee members will cease to be a member of the committee if they:

- Resign from the committee
- Fail to attend three consecutive meetings
- Resign from their employment
- Breach confidentiality

### **5. STRUCTURE OF PARTNERSHIPS**

The NCHDA Research Committee reports to the NICOR Research Executive and the NCHDA Steering Committee.

### **6. DECISION-MAKING AND ACCOUNTABILITY**

A quorum is necessary for the transaction of business. The NCHDA Research Committee is accountable to the NCHDA Steering Committee.

### **7. WORKPLAN AND PERFORMANCE MANAGEMENT**

Overall, NCHDA is responsible for advising and supporting all research activity relating to NCHDA data.

Specifically this includes:

- Input into the annual analysis requirements and analysis plan
- Appraising internal and external application to use audit data
- Overseeing and collaborating on projects using audit data
- Supporting the delivery of research related contracted deliverables

During the project lifecycle the Research Committee has the authority to co-opt additional member(s) to the Project Team to perform research related task(s) which may be under the project plan in order to meet deliverables. Depending on the scale of the task(s) some of these may be undertaken by the Project Manager.

### **8. CONFIDENTIALITY**

The business of the NCHDA Research Committee is not confidential, although the Chair reserves the right to censor sensitive information from published minutes in exceptional circumstances. In these circumstances the notes will document that a closed item was discussed.

At times the group will deal with sensitive information and all members will be required to work in accordance with NICOR and HQIP Standard Operating Procedures and Policies, paying particular regard to governance and confidentiality. These include but are not limited to:

- NICOR Outlier policy
- NICOR Data sharing policy and associated agreements
- HQIP Standard Reporting procedure
- HQIP Contract Review Process

## **9. ARRANGEMENTS FOR THE CONDUCT OF BUSINESS**

In addition to the ways of working highlighted within the roles of the Chairperson and minute-taker, the following apply:

### **9.1. Frequency of meetings**

Meetings will be held on a quarterly basis. In the interim, applications can be reviewed via on-line discussion.

### **9.2. Duration of meetings**

The meeting will be scheduled for 2 hours.

### **9.3. Location of meetings**

Meetings will normally take place in London apart from March meetings which will be held alongside the SCTS annual conference location.

## **10. REVIEW OF THE TERMS OF REFERENCE**

The terms of reference and membership shall be reviewed annually from the date of approval to ensure the committee continues to be fit for purpose. They may be altered to meet the current needs of all committee members, with agreement of the Chair and the majority of members.

## **11. TERMS OF REFERENCE – AGREEMENT**

The terms of reference of the National Congenital heart Disease Audit Research Committee have been:

Reviewed: June 10<sup>th</sup> 2014

Agreed: June 10<sup>th</sup> 2014

Date for review: April 2015