

## 2019-20 ANNUAL REPORT OF THE CODING COMMITTEE (CC) OF THE AEPC

### For planned 54<sup>th</sup> Annual Meeting of the AEPC, Gothenburg, 13-17 May 2020

**Members:** Rodney Franklin (President; RF), Otto Krogmann (Secretary, OK), Lucile Houyel (LH), Nico Blom, Marc Gewillig, Ornella Milanesi, Bohdan Maruszewski (BM), and an AEPC council member: President – Katarina Hanseus (KH) or Secretary General – Ornella Milanesi.

Below are summarised the activities of Coding Committee members in relation to the International Society of Nomenclature for Paediatrics and Congenital Heart Disease (ISNPCHD), its three Working Groups (WG), the International Paediatric and Congenital Cardiac Code (IPCCC), the European Paediatric Cardiac Code (EPCC) Short List, SNOMED-CT, ICD-11 and International Classification of Health Interventions (ICHI) development for 2019-20.

#### 1. IPCCC Long and Short Lists with two dominant versions:

- that promoted and derived from the AEPC Long List
- that promoted and derived from the Society of Thoracic Surgeons and European Association for Cardiothoracic Surgery (STS/EACTS) Long List.

The current AEPC Long and Short List versions are dated April 2020 (v4.1), incorporates ICD-11 related nomenclature changes, whilst the latest STS-EACTS is from June 2018 – both to be available on the ISNPCHD website ([www.ipccc.net](http://www.ipccc.net)), and the CC AEPC website (AEPC version) for free download after signing a copyright statement. Both versions are used in Long and derived Short lists, particularly in Europe (EPCC), Japan and North America, for centre level and national quality control and audit, such as in the UK's National Congenital Heart Disease Audit, where UK and Republic of Ireland congenital cardiovascular outcomes are updated annually:

[https://nicor4.nicor.org.uk/CHD/an\\_paeds.nsf/vwContent/home?Opendocument](https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/home?Opendocument)

#### 2. ISNPCHD and its three working groups: Nomenclature, Definitions and Archiving WGs

ISNPCHD work continues to be conducted by its three WGs. There have been no further meetings since the 21-24<sup>th</sup> February 2019 Montreal, Canada meeting (19<sup>th</sup> NWG / 12<sup>th</sup> DWG / 10<sup>th</sup> AWG meetings). The planned meeting for 13-16<sup>th</sup> June 2020 in Warsaw has been cancelled due to the Covid-19 pandemic, apart from two virtual sessions on 11-12<sup>th</sup> June.

Most work this year has involved the Archiving WG and the ICD-11 linked Atlas for all CHD terms, whilst in parallel liaison with the Pediatric Cardiology Learning Center (PCLC, <https://www.pediatriccardiaclearningcenter.org/>). A Contributor Agreement has recently been signed for web hosting the Atlas between the ISNPCHD and Heart University, which administers the PCLC, including guaranteed free global access to all ISNPCHD content. Justin Tretter leads for the PCLC and Marina Hughes for the ISNPCHD. There has been good progress in producing a template for the web platform to encompass individual lesions using an array of imaging modalities: morphology, echo, CT, MRI, diagrams, intraoperative surgical imaging, etc., each with its own silo and Silo Champion. Morphology content is nearly complete for all lesions. The images with commentaries will link to the ICD-11 Foundation and MMS websites and include IPCCC and ICD-11 codes, definitions and synonyms. The aim is that the Atlas will be complete in time for presentation at 6<sup>th</sup> International Summit of Nomenclature for Paediatric and CHD on 18<sup>th</sup> September 2021 at the next World Congress in Washington DC.

ISNPCHD continues to maintain, develop, update, and preserve the IPCCC, whilst providing ready access to it for the global paediatric and congenital cardiology communities, healthcare industry and governmental agencies.

**3. World Health Organisation, ICD-11 and the ISNPCHD.** The full ISNPCHD authored CHD content is available for use within the Foundation version of ICD-11 (<https://icd.who.int/dev11/f/en/>). This is recommended for AEPC members' use rather than the abbreviated Morbidity & Mortality Statistics (MMS) version of ICD-11, (<https://icd.who.int/dev11/l-m/en>), as the CHD content is limited. Although ICD-11 is technically frozen, proposals for change are welcome either through the ICD proposal platform itself after registration, or by emails to RF. Any proposals, other than typos and minor issues are brought to the monthly teleconferences of the Medical and Scientific Advisory Committee (MSAC, RF a member) to deal with, sending a response directly to proposers. ISNPCHD related WHO work in 2019-20 included:

- Congenital and paediatric cardiology. Although 325 CHD terms and 143 terms relating to acquired and postprocedural CHD heart abnormalities have been incorporated with definitions and synonyms in ICD-11, 94 CHD terms have been added without the knowledge of the ISNPCHD to the Foundation list. Many are legacy or obsolete terms, whilst others add 'legitimate' granularity to the ISNPCHD submissions. Errors and requests to designate certain terms as obsolete have been submitted through the WHO ICD-11

proposal platform (RF) for CHD and also acquired related CHD content. Translation to French was completed last year (LH input) and a Portuguese translation is now being submitted to the WHO.

- Definitions and restructuring of the cardiomyopathy and myocarditis sections to fully encompass paediatric disease, as submitted by RF in 2018, have now been agreed and incorporated by the WHO in the last 6 months.
- **International Classification of Health Interventions (ICHI)**. This project to revise the 1978 International Classification of Procedures in Medicine has just been released as a final Beta Phase in April 2020 (version 3, <https://mitel.dimi.uniud.it/ichi/>). The ICHI scope is wide and includes all forms of interventions, from classic operations through to mental health and rehabilitation. Its novel structure has been challenging to fully map many established CHD procedures: Target (anatomy), Action (procedure to Target), Means (method of Action) and Extension codes (post-coordination). There has been excellent progress after prolonged negotiations between RF and the WHO, with RF submitting over 300 changes to incorporate CHD specific anatomical Target sites and a large number of additional procedures. These were largely accepted in time for version 3. Full ICHI release is scheduled for October 2020, ahead of which further changes are possible, and there will then be an MSAC like process thereafter for updates and improvements.

**5. SNOMED-CT.** Collaboration between the ISNPCHD and SNOMED International, who now manage and own SNOMED-CT (Systematised Nomenclature for Medicine Clinical Terms), re-emerged in early 2019 but slow progress since due to other priorities. Our SNOMED Int link through RF remains Jill Millar (SNOMED Collaboration Lead Consultant). It is still hoped that this will lead to a SNOMED-CT CHD subset incorporating definitions, and 'cleaning up' some of the SNOMED-CT content to reflect current usage and practice.

**6. The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease.** As previously reported, this Committee includes several CC and ISNPCHD members. The 13<sup>th</sup> meeting took place in Atlanta on 5 Oct 2018 with theme: 'How our institution captures all registry data (STS, IMPACT, PC4, PAC3) and the human cost associated?' The 14<sup>th</sup> meeting was planned as a satellite meeting on Wednesday May 13<sup>th</sup> 2020 at the 54<sup>th</sup> AEPC meeting in Gothenburg but due to Covid-19, this has now been delayed a year along with the main meeting – Agenda as planned in Appendix 2.

**8. Coding Committee and AEPC web site.** The website still requires updating to bring up to date with reports and latest versions of IPCCC and EPCC.

The principle goal of the AEPC Coding Committee and the ISNPCHD remains to provide a globally applicable system for paediatric and CHD, with the ability to code scientifically accurate phenotypes and state of the art procedures, using the near-exhaustive directory of terms within the IPCCC and related Short Lists, irrespective of the language or related discipline involved. The work of the DWG and AWG adds quality and clarity to the IPCCC itself and ICD-11 equivalent paediatric and congenital cardiac codes. Working with the PCLC, WHO, SNOMED International, the ACCF/AHA Task Force and Industry will help to ensure these standards are maintained across the spectrum of healthcare for the benefit of our patients.

Respectfully submitted to the CC and AEPC Council.

Dr Rodney Franklin MD FRCP FRCPC  
President of the Coding Committee of the AEPC

54<sup>th</sup> Annual Meeting of the AEPC  
Gothenburg, Sweden, May 2020

## Appendix 1

### **CODING COMMITTEE OF THE AEPC meeting**

**Wednesday May 15<sup>th</sup> 2019 at the 53<sup>rd</sup> Annual Meeting of the AEPC, Seville**

**14.00 – 15.00 hrs**

**Venecia room, 1<sup>st</sup> Floor, Palacio de Congresos y Exposiciones**

### **Minutes**

**Attendance: Rodney Franklin (RF), Lucile Houyel (LH), Otto Krogmann (OK)**

1. Welcome by RF
2. Minutes of last CC meeting, Athens, 10<sup>th</sup> May 2018 approved
3. The overview and update of CC member activities since the 52<sup>nd</sup> AEPC meeting in Athens 2018, as detailed in 2018-19 Annual Report of the Coding Committee to the AEPC Council was shortly reviewed – see report for details.
  - Meetings in Manaus, Brazil (July 2018) and Montreal, Canada (February 2019)
  - ICD-11 and the International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD):
    - Virtual Atlas of ICD-11 CHD terms
    - Translated to French (published, attached) and Portuguese
    - Refinements, ongoing issues: CHD, cardiomyopathy, arrhythmias
  - ICD-11 VSD paper (published, attached)
  - ISNPCHD and International Classification of Health Interventions (ICHI)
4. AEPC web site with respect to Coding Committee needs urgent update as most documents were not migrated to the new AEPC website. OK will try and organize.
1. Any other business:
  - The need for new younger membership of the CC was emphasized.
  - There was again the discussion about the task of the cc of the AEPC as most of the activities is done by the ISNPCHD. Most of the members of the cc are also members of the ISNPCHD.

Adjourn 15.00 h

Respectfully submitted  
Rodney Franklin & Otto Krogmann

AEPC Coding Committee  
May 2019

## Appendix 2

<u>Multi-Societal Database Committee and Cardiac Networks United Symposium: AEPG Gothenburg</u>			
<u>"Collaboration between Multi-Institutional Databases for Quality Improvement"</u>			
<u>Wednesday, May 13, 2019: 08.15-14.45</u>			
Meeting Chairs: Rodney Franklin and Jeff Jacobs			
	<u>Title of Talk</u>	<u>Speaker</u>	<u>Affiliation, City</u>
8.15	<i>Welcome and Summary of Previous Conferences</i>	Jeff Jacobs	Saint Petersburg, Florida
8.30	<i>North American Quality Improvement efforts in Critical Care through PC4 and Cardiac Networks United</i>	Sarah Tabbutt	Exec Director, Pediatric Cardiac Critical Care Consortium, Michigan
8.45	<i>Cardiac Networks United – Quality Improvement through linked databases in North America</i>	Sara Pasquali	Janette Ferrantino Professor of Pediatrics, University of Michigan
9.00	<i>National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC)</i>	Jeff Anderson	Cincinnati, Ohio
9.15	<i>Update on IMPACT linked Quality Improvement initiatives: How we got here and Where we are or should be going</i>	Robert Vincent	Director of ACC IMPACT database, Atlanta
9.30	<i>Learning the patient journey through linking multiple databases: Tetralogy of Fallot and Transposition of the Great Arteries</i>	Christina Pagel	Director, Clinical Operational Research Unit, London
9.45	<i>Discussion of all talks</i>		
<b>10.00: Coffee and refreshment break - 30 mins</b>			
10.30	<i>Ten years experience of the Swedish Registry of Congenital Heart Disease (SWEDCON) - from fetus to GUCH</i>	Gudrun Björkhem	Associate Professor, Lund
10.45	<i>Diagnosis based longitudinal follow up in the German Quality Assurance for Congenital Heart Disease</i>	Sven Dittrich and Alexander Horke	Professor, University of Erlangen-Nuremberg; Hannover Medical School
11.00	<i>Efforts of the Congenital Heart Surgery Society to conduct longitudinal outcomes analysis in the USA</i>	Jim St. Louis	Professor and Director of Surgery, Kansas City, Missouri
11.15	<i>Long-term outcome after paediatric cardiac surgery in Finland</i>	Eero Jokinen	Professor, Helsinki
11.30	<i>Quality Databases in Imaging: the ACC Quality Network and the Intersocietal Accreditation Commission Quality Improvement Tool</i>	Leo Lopez	Medical Director of Echocardiography, Lucile Packard Children's Hospital, Stanford
11.45	<i>Discussion of all talks</i>		
<b>12.00: Lunch - 60 mins</b>			
13.00	<i>Two Decades of Collaboration between The Society of Thoracic Surgeons Congenital Heart Surgery Database and The European Congenital Heart Surgeons Association Congenital Heart Surgery Database</i>	Jeff Jacobs	Saint Petersburg, Florida
13.15	<i>Mortality in children with CHD. Data from Norwegian registries</i>	Henrik Holmstöm	Professor Head of research group PRECISE, Oslo
13.30	<i>Role of the World Society for Pediatric and Congenital Heart Surgery to improve quality across the globe.</i>	Jim St. Louis	Professor and Director of Surgery, Kansas City, Missouri
13.45	<i>Quality Improvement and Public Reporting of CHD outcomes in the United Kingdom</i>	Rodney Franklin	Clinical Lead, UK + Ireland National CHD Audit, London
14.00	<i>Quality Improvement and Public Reporting of CHD outcomes in Pennsylvania</i>	Bill Gaynor	Prof of Surgery, Children's Hospital of Philadelphia, Pennsylvania
14.15-14.45	<i>Discussion of all talks and closing remarks</i>		