Nomenclature for Pediatric and Congenital Cardiac Care: Unification of Clinical and Administrative Nomenclature – The 2021 International Paediatric and Congenital Cardiac Code (IPCCC) and the Eleventh Revision of the International Classification of Diseases (ICD-11)

Jeffrey P. Jacobs, MD, Rodney C. G. Franklin, MD, Marie J. Béland, MD, Diane E. Spicer, BS, PA, Steven D. Colan, MD, Henry L. Walters III, MD, Frédérique Baillard, MD, Lucile Houyel, MD, James D. St. Louis, MD, Leo Lopez, MD, Vera D. Aiello, MD, PhD, J. William Gaynor, MD, Otto N. Kroghmann, MD, Hiromi Kurosawa, MD, Bohdan J. Maruszewski, MD, PhD, Giovanni Stellin, MD, Paul Morris Weinberg, MD, Marshall Lewis Jacobs, MD, Meryl S. Cohen, MD, Jeffrey R. Boris, MD LLC, Jeffrey P. Jacobs, MD

1 Congenital Heart Center, UF Health Shands Hospital, Division of Cardiovascular Surgery, Departments of Surgery and Pediatrics, University of Florida, Gainesville, Florida, United States of America
2 Paediatric Cardiology Department, Royal Brompton & Harefield NHS Trust, London, United Kingdom
3 Division of Paediatric Cardiology, The Montreal Children’s Hospital of the McGill University Health Centre, Montréal, Québec, Canada
4 Johns Hopkins All Children’s Hospital, Johns Hopkins University, Saint Petersburg, Florida, United States of America
5 Department of Cardiology, Boston Children’s Hospital, Harvard University, Boston, Massachusetts, United States of America
6 Cardiovascular Surgery, Children’s Hospital of Michigan, Wayne State University School of Medicine, Detroit, Michigan, United States of America
7 Baillier Henry Pediatric Cardiology, Raleigh, North Carolina, United States of America
8 Duke University, Durham, North Carolina, United States of America
9 Congenital and Pediatric Medico-Surgical Unit, Necker Hospital-M3C, Paris, France
10 Department of Surgery and Pediatrics, Children’s Hospital of Georgia, Augusta University, Augusta, Georgia
11 Lucile Packard Children’s Hospital Stanford, Stanford University School of Medicine, Palo Alto, California, United States of America
12 Heart Institute (InCor), University of São Paulo School of Medicine, São Paulo, Brazil
13 Cardiac Center, Children’s Hospital of Philadelphia, Philadelphia, Pennsylvania, United States of America
14 Pediatric Cardiology-Congenital Heart Disease, Heart Center Duisburg, Duisburg, Germany
15 Cardiovascular Surgery, Tokyo Women’s Medical University, Tokyo, Japan
16 Department for Pediatric and Congenital Heart Surgery, Children’s Memorial Health Institute, Warsaw, Poland
17 Pediatric and Congenital Cardiac Surgical Unit, Department of Cardiothoracic and Vascular Sciences, University of Padova, Padova, Italy
18 Johns Hopkins University, Baltimore, Maryland, United States of America
19 Jeffrey R. Boris, MD LLC, Moyal, Pennsylvania, United States of America
20 All Children’s Hospital, Saint Petersburg, Florida, United States of America
21 Congenital Heart Surgery, Medical City Children’s Hospital, Dallas, Texas, United States of America
22 Cardiology Department, Norfolk and Norwich University Hospital NHS Trust, United Kingdom
23 Terry Heart Institute, Wolfson Children’s Hospital, Jacksonville, Florida, United States of America
24 Department of Paediatrics, Division of Pediatric Cardiology, Seattle Children’s Hospital, University of Washington, Seattle, Washington, United States of America
25 Children’s Heart Clinic of Minneapolis, Minneapolis, Minnesota, United States of America
26 Division of Cardiology, Department of Cardiovascular Medicine, Nemours Cardiac Center at the Alfred I. duPont Hospital for Children, Wilmington, Delaware, United States of America
27 Institute of Cardiovascular Science, University College London, London, United Kingdom
28 Congenital Heart Surgery, Birmingham Women’s and Children’s Foundation Trust Hospital, University of Birmingham, Birmingham, United Kingdom
29 Joe DiMaggio Children’s Hospital Heart Institute, Hollywood, Florida, United States of America
30 Advocate Children’s Heart Institute, Advocate Children’s Hospital, Oak Lawn, Illinois, United States of America
31 Department of Pediatrics, Heart Institute, Cincinnati Children’s Hospital Medical Center, University of Cincinnati College of Medicine, Cincinnati, Ohio, United States of America
32 Heart Centre, First Hospital of Tsinghua University, Beijing, China
33 University College London, London, United Kingdom
34 Peyton Manning Children’s Hospital, Indianapolis, Indiana, United States of America
35 Division of Cardiovascular Surgery, The Montreal Children’s Hospital of the McGill University Health Centre, Montréal, Québec, Canada

Corresponding Author:
Jeffrey P. Jacobs, MD, Congenital Heart Center, UF Health Shands Hospital, Division of Cardiovascular Surgery, Departments of Surgery and Pediatrics, University of Florida, 1600 SW Archer Road, Gainesville, Florida, United States of America.
Emails: jeffjacobbs@msn.com and jeffreyjacobs@ufl.edu
Abstract
Substantial progress has been made in the standardization of nomenclature for paediatric and congenital cardiac care. In 1936, Maude Abbott published her Atlas of Congenital Cardiac Disease, which was the first formal attempt to classify congenital heart disease. The International Paediatric and Congenital Cardiac Code (IPCCC) is now utilized worldwide and has most recently become the paediatric and congenital cardiac component of the Eleventh Revision of the International Classification of Diseases (ICD-11). The most recent publication of the IPCCC was in 2017. This manuscript provides an updated 2021 version of the IPCCC.

The International Society for Nomenclature of Paediatric and Congenital Cardiac Disease (ISNPCHD), in collaboration with the World Health Organization (WHO), developed the paediatric and congenital cardiac nomenclature that is now within the eleventh version of the International Classification of Diseases (ICD-11). This unification of IPCCC and ICD-11 is the IPCCC ICD-11 Nomenclature and is the first time that the clinical nomenclature for paediatric and congenital cardiac care and the administrative nomenclature for paediatric and congenital cardiac care are harmonized. The resultant congenital cardiac component of ICD-11 was increased from 29 congenital cardiac codes in ICD-9 and 73 congenital cardiac codes in ICD-10 to 318 codes submitted by ISNPCHD through 2018 for incorporation into ICD-11. After these 318 terms were incorporated into ICD-11 in 2018, the WHO ICD-11 team added an additional 49 terms, some of which are acceptable legacy terms from ICD-10, while others provide greater granularity than the ISNPCHD thought was originally acceptable. Thus, the total number of paediatric and congenital cardiac terms in ICD-11 is 367. In this manuscript, we describe and review the terminology, hierarchy, and definitions of the IPCCC ICD-11 Nomenclature. This article, therefore, presents a global system of nomenclature for paediatric and congenital cardiac care that unifies clinical and administrative nomenclature.

The members of ISNPCHD realize that the nomenclature published in this manuscript will continue to evolve. The version of the IPCCC that was published in 2017 has evolved and changed, and it is now replaced by this 2021 version. In the future, ISNPCHD will again publish updated versions of IPCCC, as IPCCC continues to evolve.

Keywords
Nomenclature, Database, Pediatric, Congenital heart disease (CHD), pediatric heart disease

Submitted June 26, 2021; Accepted June 29, 2021.

This Article has been copublished in Cardiology in the Young and in the World Journal for Pediatric and Congenital Heart Surgery

Introduction
Substantial progress has been made in the standardization of nomenclature for paediatric and congenital cardiac care. In 1936, Maude Abbott, of McGill University in Montréal, Québec, Canada, published her Atlas of Congenital Cardiac Disease, which was the first formal attempt to classify congenital heart disease. The International Paediatric and Congenital Cardiac Code (IPCCC) is now utilized worldwide and is the paediatric and congenital cardiac component of the Eleventh Revision of the International Classification of Diseases (ICD-11). The most recent publication of the IPCCC was in 2017. This manuscript provides an updated 2021 version of the IPCCC, which is now the paediatric and congenital cardiac component of ICD-11.

Congenital cardiac malformations are the most common types of birth defects. Before the introduction of current diagnostic modalities, such as echocardiography, the estimated incidence of CHD ranged from five to eight per 1000 live births. With improved diagnostic modalities, many more patients with milder forms of CHD can now be identified, so that contemporary estimates of the prevalence of congenital cardiac disease now range from eight to twelve per 1000 live births. About one-quarter of neonates and infants with a congenital cardiac defect undergo surgery or catheter-directed intervention in their first year of life. Survival after surgery for congenital heart defects has increased over the past decade, especially for the most complex operations. The aetiology of this improvement is obviously multifactorial, but the ability to compare and benchmark risk-stratified and risk-adjusted outcomes at individual programs to national and international aggregate benchmarks has certainly facilitated these improved cardiac surgical outcomes over time. This benchmarking and improvement in quality requires standardization of the nomenclature and classification of paediatric and congenital cardiac disease, as described in this manuscript.

This manuscript presents the latest edition of The International Paediatric and Congenital Cardiac Code (IPCCC), which has been integrated into the paediatric and congenital cardiac component of the Eleventh Revision of the International Classification of Diseases (ICD-11). This article will discuss the following topics:

- The International Paediatric and Congenital Cardiac Code (IPCCC)
- The Eleventh Revision of the International Classification of Diseases (ICD-11)
- Clinical Nomenclature versus Administrative Nomenclature
This article will then present the following three Supplemental Tables of *IPCCC ICD-11 Nomenclature for Congenital Cardiac Diagnostic Terms* in the ICD-11 Foundation

- Supplemental Table 1. IPCCC ICD-11 Diagnostic Hierarchy
- Supplemental Table 2. IPCCC ICD-11 Definitions
- Supplemental Table 3. IPCCC ICD-11 Codes

(These three tables are available at the following hyperlink.)

The version of the *IPCCC* that was published by *ISNPCHD* in 2017\(^\text{105}\) has evolved and is now updated with the 2021 version published in this manuscript. In the future, *ISNPCHD* will again publish additional updated versions of *IPCCC*, as *IPCCC* continues to evolve.

**The International Paediatric and Congenital Cardiac Code (IPCCC)**

As already emphasised, the development of classification schemes specific to the congenitally malformed heart began with Maude Abbott’s pioneering work in the early 1900s.\(^\text{1,105}\) Her landmark publication in 1936, entitled “Atlas of Congenital Cardiac Disease”, was the first formal attempt to classify the lesions seen when the heart is congenitally malformed.\(^\text{1,105}\) It was not until the 1990s that efforts were made to create a truly international system of nomenclature and classification to support paediatric and congenital cardiac care. Prior to these efforts of the 1990s, multiple systems of nomenclature and classification were used at hospitals across the world. These various systems of nomenclature were the basis of internal, national, and even international registries and databases of paediatric and congenital cardiac care.\(^\text{105}\)

Aided by advances in information technology that facilitate the exchange of information, two independent international collaborations began in the 1990s, resulting in the publication of two separate international paediatric and congenital cardiac systems of nomenclature and classification:

- The European Paediatric Cardiac Code (EPCC) of The Association for European Paediatric and Congenital Cardiology (AEPC)\(^\text{2,3}\)
- The nomenclature system of the International Congenital Heart Surgery Nomenclature and Database Project of The Society of Thoracic Surgeons (STS) in North America, The European Association for Cardio-Thoracic Surgery (EACTS), and The European Congenital Heart Defects Database of The European Congenital Heart Surgeons Foundation (ECHSF) – (renamed The European Congenital Heart Surgeons Association [ECHSA] in 2003).\(^\text{4-37}\)

During the 1990s, both ECHSF and STS created databases to assess the outcomes of congenital cardiac surgery. Beginning in 1998, EACTS, ECHSA, and STS collaborated to create the International Congenital Heart Surgery Nomenclature and Database Project. As a result of this project, by 2000, a common nomenclature, along with a common core minimal dataset, were adopted by EACTS, ECHSA, and STS, and published in The Annals of Thoracic Surgery as a 372-page free standing Supplement.\(^\text{4-37}\) In parallel, in 1996, the AEPC created a Coding Committee to produce a set of diagnostic and procedural codes that would be acceptable and adopted within both the European paediatric cardiology and European paediatric cardiac surgical communities. As a result of this project, in 2000, the EPCC was published in Cardiology in the Young as a 146-page free standing Supplement.\(^\text{2-3}\)

Both the EPCC and the International Congenital Heart Surgery Nomenclature and Database Project included a comprehensive Long List, with thousands of terms, and a Short List designed to be used as part of a minimum data set for multi-institutional registries and databases. Both Long Lists mapped fully to their respective Short Lists. The nearly simultaneous publication of these two complementary systems of nomenclature led to the problematic situation of having two systems of nomenclature that were to be widely adopted, with the potential risk of duplicate or inaccurate coding within institutions, as well as the potential problem of invalidating multicentric projects owing to confusion between the two systems.\(^\text{105}\)

Hence, on Friday, October 6, 2000, in Frankfurt, Germany, during the meeting of ECHSF prior to the 14th Annual Meeting of EACTS, representatives of the involved Societies met and established The International Nomenclature Committee for Paediatric and Congenital Heart Disease, which was to include representatives of the four societies (AEPC, STS, ECHSF, and EACTS), as well as representatives from the remaining continents of the world – Africa, Asia, Australia (Oceania), and South America.\(^\text{41,42,43,44,45,47,105}\) Over four years later, in January, 2005, The International Nomenclature Committee for Pediatric and Congenital Heart Disease was constituted and legally incorporated as *The International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD)*.

At the meeting in Frankfurt in 2000, an agreement was reached to collaborate and produce a reconciliatory bidirectional map between the two systems of nomenclature. The feasibility of this project was established by the creation of a rule-based bidirectional crossmap between the two Short Lists, using the six-digit coding system already established within the EPCC as the common link between the two nomenclature lexicons. This bidirectional crossmap between the two Short Lists was created and published by The International Working Group for Mapping and Coding of Nomenclatures for Pediatric and Congenital Heart Disease, also known for short as the Nomenclature Working Group (NWG), which was the original committee of The International Nomenclature Committee for Paediatric and Congenital Heart Disease and the subsequent *ISNPCHD*.\(^\text{44,45,47}\)

Over the next 8 years, the NWG met 10 times, over a combined period of 47 days, to achieve the main goal of cross-mapping the two comprehensive Long Lists to create the *IPCCC*, which has two dominant versions.\(^\text{105}\)

- The version of the *IPCCC* derived from the European Paediatric Cardiac Code of AEPC
- The version of the *IPCCC* derived from the International Congenital Heart Surgery Nomenclature and Database Project of EACTS, ECHSA, and STS.
These two versions of the **IPCCC** are crossmapped to each other by means of the six-digit coding system and have the following abbreviated short names:

- EACTS-STS derived version of the IPCCC
- AEPC derived version of the IPCCC

The NWG therefore crossmapped the nomenclature of the International Congenital Heart Surgery Nomenclature and Database Project of EACTS, ECHSA, and STS with the EPCC of AEPC, and thus created the IPCCC, which is available for free download from the internet at [https://IPCCC.net](https://IPCCC.net). Additional systems of nomenclature, for paediatric cardiology and cardiac surgery, which were mapped to the common six-digit code spine, include the Boston-based Fyler codes, and the Canadian nomenclature system. There is also mapping to the ninth and tenth revisions of the International Classification of Diseases (ICD-9, ICD-10), usually in a many to one fashion, given the limitations of these earlier versions of ICD.

Most international databases of patients with paediatric and congenital cardiac disease now use the IPCCC as their foundation. This common nomenclature, the IPCCC, and the common minimum database data set created by the International Congenital Heart Surgery Nomenclature and Database Project, are now utilized by multiple databases and registries of paediatric and congenital cardiac care across the world. The following databases all use the EACTS-STS derived version of the IPCCC:

- The Society of Thoracic Surgeons Congenital Heart Surgery Database (STS CHSD)
- The European Congenital Heart Surgeons Association Congenital Heart Surgery Database (ECHSA CHSD)
- The Japan Congenital Cardiovascular Surgery Database (JCCVSD)
- The World Database for Pediatric and Congenital Heart Surgery (WDPCHS)

Several national and institutional databases in Europe use the AEPC derived version of the IPCCC for collection of data, including:

- Germany,
- the Netherlands, and
- the United Kingdom and Republic of Ireland National Congenital Heart Disease Audit.

For all terms within the two versions of the IPCCC, a unique six-digit code corresponds to a single entity, whether it be a morphological phenotype, procedure, symptom, or genetic syndrome. The mapped terms in each of the two versions are synonymous. By 2013, there were 12,168 terms in the IPCCC Long List version derived from the European Paediatric Cardiac Code, and 17,176 terms in the IPCCC Long List version derived from the International Congenital Heart Surgery and Nomenclature Database Project. These Long Lists include hundreds of qualifiers, some specific, such as anatomical sites, and others generic, such as gradings of severity.

It is primarily the Short Lists, rather than the Long Lists, of the two crossmapped versions of the IPCCC that have been used for analyses of multi-institutional and international outcomes following operations and procedures for patients with congenitally malformed hearts. Over a million patients are now coded with the IPCCC in registries worldwide. Both versions of the IPCCC Short Lists have been used to develop empirical systems for the adjustment of risk following surgical procedures, based on the operation type and comorbidities, for the purposes of quality assurance and quality improvement.

Both risk adjustment systems depend upon the IPCCC for all variables, to ensure a common nomenclature between institutions submitting data, and both perform better than the systems based on the subjective assessment of risk.

The history of ISNPCHD and the development of IPCCC have been previously published. The International Working Group for Mapping and Coding of Nomenclature for Paediatric and Congenital Heart Disease was also known as the Nomenclature Working Group or NWG and was the first committee of The International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD). The initial 12 members of Nomenclature Working Group represented multiple subspecialties and continents:

- Vera Aiello, University of São Paulo Medical School, São Paulo, Brazil
- Marie J. Bélard, The Montreal Children’s Hospital, Montréal, Québec, Canada
- Steven Colan, Boston Children’s Hospital, Boston, Massachusetts, United States of America
- Rodney C. G. Franklin, Royal Brompton & Harefield Hospital NHS Foundation Trust, London, United Kingdom
- J. William Gaynor, The Children’s Hospital of Philadelphia, Philadelphia, Pennsylvania, United States of America
- Jeffrey P. Jacobs, University of Florida, Gainesville, Florida, United States of America
- Otto N. Krogmann, Heart Center Duisburg, Duisburg, Germany
- Hiromi Kurosawa, Tokyo Women’s Medical University, Tokyo, Japan
- Bohdan J. Maruszewski, Children’s Memorial Health Institute, Warsaw, Poland
- Giovanni Stellin, Universita di Padova, Italy
- Christo I. Tchervenkov, The Montreal Children’s Hospital, Montréal, Québec, Canada
- Paul Weinberg, The Children’s Hospital of Philadelphia, Philadelphia, Pennsylvania, United States of America

The Presidents of The International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD) are listed below, along with the terms of their Presidency:

- Martin J. Elliott (2000–2009)
- Christo I. Tchervenkov (2009–2013)
The Eleventh Revision of the International Classification of Diseases (ICD-11)

The history of The International Classification of Diseases (ICD) dates back to the late 1800s (Supplemental Figure 1):

- In 1891, the International Statistical Institute commissioned a committee chaired by Jacques Bertillon (1851–1922), Chief of Statistical Services of the City of Paris, to create what became the Bertillon [International] Classification of Causes of Death, with associated sequential numeric codes.\(^{105}\) Over the following decades, this classification scheme was adopted by many countries in the Americas and Europe, with conferences for revision occurring roughly every 10 years to update the system, which became known as The International Classification of Diseases (ICD).
- In 1893, Bertillon presented the (International) Classification of Causes of Death at the meeting of the International Statistical Institute in Chicago, where it was adopted by several cities and countries.
- In 1898, the American Public Health Association recommended its adoption in North America, and that the classification be revised every 10 years.
- In 1900, the First International Conference to revise the Bertillon Classification of Causes of Death was held in Paris.
- In 1909, non-fatal diseases, in other words, morbidity, were added.
- From 1948 until now, the World Health Organization (WHO) has promoted and managed ICD, starting in 1948 with the sixth revision of the International Classification of Diseases, Injuries and Causes of Death.

According to WHO, “ICD is the foundation for the identification of health trends and statistics globally, and the international standard for reporting diseases and health conditions. It is the diagnostic classification standard for all clinical and research purposes. ICD defines the universe of diseases, disorders, injuries and other related health conditions, listed in a comprehensive, hierarchical fashion” [https://www.who.int/standards/classifications/classification-of-diseases]. The ICD-11 development mission was “To produce an international disease classification that is ready for electronic health records that will serve as a standard for scientific comparability and communication”.\(^{105}\) ICD-11 was officially launched on-line by the WHO in June 2018 and endorsed by the World Health Assembly on 25 May 2019. The WHO states that ICD-11 is to be “The global standard for health data, clinical documentation, and statistical aggregation”, that it is “scientifically up-to-date and designed for use in the digital world with state-of-the art technology to reduce the costs of training and implementation”, and that its “multilingual design facilitates global use” [https://www.who.int/classifications/classification-of-diseases].

Although both the Short Lists and the comprehensive Long Lists of each version of IPCCC have been crossmapped, the two Short Lists emanating from their respective Long-List versions are not the same in terms of structure or content.\(^{105}\) ISNPCHD recognized this disparity, and believed that the creation of a congenital cardiac subset within ICD-11 would accomplish several goals:

- help resolve the differences between the Short List of the EACTS-STS derived version of the IPCCC and the Short List of the AEPC derived version of the IPCCC
- present a single common comprehensive and hierarchical Short List of diagnostic terms that could serve all communities involved with paediatric and congenital cardiac care
- harmonize the administrative nomenclature for paediatric and congenital cardiac care with the clinical nomenclature for paediatric and congenital cardiac care.

Hence, ISNPCHD created, organized, and defined the terms of IPCCC in order to standardize nomenclature for paediatric and congenital cardiac care and promote accurate coding, sharing of information, and analysis of data.\(^{41,42,43,44,45,47,105}\) ISNPCHD believed from the start that the concept of “illustration” of the terms would be very important to advance these goals.\(^{87,88,89,90,93,94,102}\) Concurrent with its involvement in developing ICD-11, as described in detail below, ISNPCHD began creating the IPCCC ICD-11 Congenital Heart Atlas to illustrate the terms listed in the “Structural developmental anomaly of heart or great vessels” section of ICD-11. In addition to the terms, definitions, and data about coding that is published in ICD-11, the IPCCC ICD-11 Congenital Heart Atlas is currently being built to contain drawings, photographs of anatomical specimens, images and videos from various imaging modalities, and intraoperative photographs and videos, all designed to help health care professionals better select the correct designation for the cardiac phenotypes listed in ICD-11. The IPCCC ICD-11 Congenital Heart Atlas will, of course, also fulfill multiple educational purposes. The IPCCC ICD-11 Congenital Heart Atlas will be freely accessible on the ISNPCHD website: [https://IPCCC.net]. The IPCCC ICD-11 Congenital Heart Atlas will also be freely accessible via hyperlinks from:

- Heart University [https://www.heartuniversity.org/], and
- The World University for Pediatric and Congenital Heart Surgery [https://wupchs.education/]
Importantly, ICD-11 incorporates textual definitions. With the creation of ICD-11, for the first time, the revision process moved away from reliance on large meetings of national delegations of health statisticians, wherein those who voiced their opinion strongest would dominate the content of the paper-based output — “decibel” diplomacy. In contrast, the ICD-11 revision process is dependent upon international expert clinicians, with digital curation, the incorporation of wide peer review, and extensive field testing. “ICD-11 has been adopted by the Seventy-second World Health Assembly in May 2019 and comes into effect on 1 January 2022” [https://www.who.int/standards/classifications/classification-of-diseases].

The task of creating ICD-11 was divided into content specific Topic Advisory Groups, with related Working Groups led by Managing Editors and chaired by specialist clinicians with an intentionally wide geographic spread. From 2009 through to 2016, the Managing Editor coordinated a series of meetings, some face-to-face, but mostly teleconferences, beginning with the hierarchical structure and terms within ICD-10, and initially producing an evolving alpha draft. In 2012, a beta draft was published online [https://icd.who.int/dev11/f/en], coinciding with the authoring process moving to a web-based platform for its entire content. The tool allows online global peer review and submission of comments by both the authors and worldwide interested parties in the field-testing stage.

From the start, clinicians involved in the Topic Advisory Groups have been encouraged to enlist the advice of specialist Societies to aid the process, thus ensuring that the content was both up-to-date and had Societal endorsement. This process has resulted in a huge increase in the number of individual terms within ICD-11, with secondary expansion of the hierarchical structure when compared with ICD-10.

In collaboration with WHO, ISNPCHD developed the paediatric and congenital cardiac nomenclature that is now within the eleventh version of the International Classification of Diseases (ICD-11). This unification of IPCCC and ICD-11 is the IPCCC ICD-11 Nomenclature and is the first time that the clinical nomenclature for paediatric and congenital cardiac care and the administrative nomenclature for paediatric and congenital cardiac care have been harmonized. The resultant congenital cardiac component of ICD-11 was increased from 29 CHD diagnostic terms codes in ICD-9 and 73 CHD diagnostic terms in ICD-10 to 318 codes submitted by ISNPCHD through 2018 for incorporation into ICD-11. After these 318 terms were incorporated into ICD-11 in 2018, the WHO ICD-11 team added an additional 49 terms, some of which are acceptable legacy terms from ICD-10, while others provide greater granularity than the ISNPCHD thought was originally acceptable, such as individual codes for the various types of isolated branches of the aortic arch or branches of the aortic arch having an aberrant origin. Thus, the total number of paediatric and congenital cardiac terms in ICD-11 is now 367. (Supplemental Table 1 and Supplemental Table 2 and Supplemental Table 3). Populating ICD-11 by the content-specific Topic Advisory Groups was not always without controversy, with at times, for example, heated and prolonged discussions between the Rare Diseases Topic Advisory Group and several Internal Medicine Topic Advisory Working Groups, including the Cardiovascular Working Group, over the hierarchy and content to be included or excluded. Supplemental Tables 1 and 2 present the diagnostic hierarchy (Supplemental Table 1) and definitions (Supplemental Table 2) of the 318 codes submitted by ISNPCHD to compose the IPCCC ICD-11 Nomenclature, as well as the additional 49 scientifically correct or legacy terms added by the WHO ICD-11 team. As these additional 49 entities have now been added to IPCCC, ISNPCHD has provided the needed definitions for these terms (as presented in Supplemental Table 2). Other legacy and scientifically incorrect terms inserted into the ICD-11 Foundation by the WHO ICD-11 team were judged by ISNPCHD to be obsolete or meaningless. These obsolete or meaningless terms, such as “Transposition of the aorta” and “Accessory heart”, have been highlighted to WHO and have been made ‘obsolete’ within the system, meaning that these terms are retained for legacy purposes but will not be visible nor easily searchable. Supplemental Tables 1, 2, and 3, therefore, present the 367 terms that are part of IPCCC and also the paediatric and congenital cardiac component of ICD-11. Consequently, IPCCC and ICD-11 are a system of nomenclature that will, for the first time ever, harmonize the administrative nomenclature for paediatric and congenital cardiac care with the clinical nomenclature for paediatric and congenital cardiac care. This important goal will be achieved with the implementation of ICD-11.

Another of the aims of WHO for ICD-11 is to have the entirety of ICD-11 translated into different languages. The achievement of this objective will enhance the global uptake and utility of ICD-11 for international comparisons of outcomes and initiatives of quality improvement. Currently WHO list 22 languages which are at least partially complete. Knowing this fact, members of ISNPCHD have already translated the IPCCC ICD-11 Nomenclature into French and Portuguese. ISNPCHD has submitted the French version into ICD-11 via their translation tool platform. Unfortunately, it has become apparent that much of the translation work has been delegated by WHO to national governmental designated translation teams, without input from clinicians. This suboptimal strategy has led to some clinically unusable translations in the field of congenital cardiac care in ICD-11. For example:

- English IPCCC term currently in ICD-11: Double outlet right ventricle with non-committed ventricular septal defect
- ISNPCHD French translation: Ventricule droit avec communication interventriculaire sans relation avec les deux gros vaisseaux
- WHO translation (done without ISNPCHD input): Ventricule droit à double sortie avec anomalie septale ventriculaire à distance
- English equivalent to WHO translation: Double exit right ventricle with ventricular septal anomaly at a distance

An anglophone clinician would probably understand what is meant by Double exit right ventricle”, but clearly “ventricular septal anomaly at a distance” does not convey the same
information as the phrase “non-committed ventricular septal defect”. This suboptimal translation and other similar errors need to be corrected. Fortunately, WHO have recently agreed to facilitate members of the ISNPCHD French translation team to work with the French government translation team to resolve these important issues.

The Foundation Component of ICD-11 (ICD-11 Foundation)

The full ICD-11 content is known as the ICD-11 Foundation, which represents the entire ICD-11 universe, divided into 26 sections, and can be accessed digitally [https://icd.who.int/dev11/f/en/#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f455013390]. The 318 diagnostic terms for CHD that were submitted by ISNPCHD in 2018 reside in the Foundation Component of ICD-11, within the Developmental Anomalies section, with the parent term “Structural developmental anomaly of heart or great vessels”, along with the additional 49 terms added to IPCCC by the WHO ICD-11 team since 2018.

The ICD-11 Mortality and Morbidity Statistics version (ICD-11 MMS)

Another feature of ICD-11 is that it is designed to be explicitly stratified to cater to different users, such as primary care, traditional medicine, and public health, producing so-called linearizations or “Tabular Lists”. The initial and most important overall linearization of ICD-11 was that published in July 2018 as the Mortality and Morbidity Statistics version, known as ICD-11-MMS, with a ‘blue’ website: [https://icd.who.int/browse11/l-m/en], which is separate from the ‘orange’ ICD-11 Foundation website: [https://icd.who.int/dev11/f/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f455013390].

ICD-11-MMS is the nearest equivalent to previous ICD versions. ICD-11-MMS includes a printed copy of top-level terms, and is designed to collect global data at a level of detail sufficient to capture important trends in the causes of death and prevalence of major disease entities. It is also the likely diagnostic coding system that will be used by nations for billing purposes. To achieve this objective, WHO in effect top-sliced the ICD-11 Foundation level content to include relevant higher-level terms, although not always with the input of clinicians. In addition, and consistent with previous ICD versions, the WHO has added two additional generic terms in each subsection of the ICD-11-MMS:

1. “Other specified . . . disease” (Y-codes). For example: LA87.0Y Other specified anomaly of tricuspid valve
2. “Disease . . ., unspecified” (Z-codes), which are equivalent to Not Otherwise Specified (NOS) in previous ICD versions. For example: LA89.Z Functionally univentricular heart, unspecified. Of note is that LA89 itself is the MMS code for Congenital anomaly of tricuspid valve.

Another example of the Y and Z codes is provided below:

1. Other specified . . . disease” (Y-codes). For example: LA87.0Y Other specified anomaly of tricuspid valve
2. “Disease . . . , unspecified” (Z-codes). For example: LA87.0Z Congenital anomaly of tricuspid valve, unspecified. Of note is that LA87.0 itself is the MMS code for Congenital anomaly of tricuspid valve.

These Y and Z codes do not appear in the ICD-11 Foundation. Y and Z codes are unique to the ICD-11-MMS version, as will be described in the following discussion. For example, the term “Straddling tricuspid valve” can be found in ICD-11 Foundation, but is not listed in ICD-11 MMS. If coding with ICD-11 MMS, the code LA87.0Y should be used to indicate that a more specific diagnosis is known.

For CHD, of the 367 paediatric and congenital cardiac terms currently in the ICD-11 Foundation, a subset of 104 terms have been retained and will appear in the ICD-11-MMS linearization. As the ICD-11-MMS is likely to be the first component of ICD-11 to be adopted by countries worldwide, ISNPCHD has created a many-to-one unidirectional map of the CHD ICD-11 Foundation level content to the anticipated 2022 version of the CHD ICD-11-MMS content within Developmental Anomalies (Chapter 20). This many-to-one unidirectional map of the CHD ICD-11 Foundation level content to the CHD ICD-11-MMS is provided in Supplemental Table 3 of this manuscript.

Clinical Nomenclature versus Administrative Nomenclature

Several studies have examined the relative utility of clinical and administrative nomenclature for the evaluation of quality of care for patients undergoing treatment for paediatric and congenital cardiac disease. Evidence from four investigations suggests that the validity of coding of lesions seen in the congenitally malformed heart via the 9th Revision of the International Classification of Diseases (ICD-9) is poor.65,91,122,123

- First, in a series of 373 infants with congenital cardiac defects at Children’s Hospital of Wisconsin, investigators reported that only 52% of the cardiac diagnoses in the medical records had a corresponding code from the ICD-9 in the hospital discharge database.122
- Second, the Hennepin County Medical Center discharge database in Minnesota identified all infants born during 2001 with a code for congenital cardiac disease using ICD-9. A review of these 66 medical records by physicians was able to confirm only 41% of the codes contained in the administrative database from ICD-9.123
- Third, the Metropolitan Atlanta Congenital Defect Program of the Birth Defect Branch of the Centers for Disease Control and Prevention of the United States government carried out surveillance of infants and fetuses with cardiac defects delivered to mothers
residing in Atlanta during the years 1988 through 2003.\textsuperscript{63} These records were reviewed and classified using both administrative coding and the clinical nomenclature used in the Society of Thoracic Surgeons Congenital Heart Surgery Database. This study concluded that analyses based on the codes available in ICD-9 are likely to “have substantial misclassification” of congenital cardiac disease.

Fourth, a study was performed using linked patient data (2004-2010) from the Society of Thoracic Surgeons Congenital Heart Surgery (STS-CHS) Database (clinical registry) and the Pediatric Health Information Systems (PHIS) database (administrative database) from hospitals participating in both in order to evaluate differential coding/classification of operations between datasets and subsequent impact on outcomes assessment.\textsuperscript{91} The cohort included 59,820 patients from 33 centres. There was a greater than 10\% difference in the number of cases identified between data sources for half of the benchmark operations. The negative predictive value (NPV) of the administrative (versus clinical) data was high (98.8\%-99.9\%); the positive predictive value (PPV) was lower (56.7\%-88.0\%). These differences translated into significant differences in outcomes assessment, ranging from an underestimation of mortality associated with truncus arteriosus repair by 25.7\% in the administrative versus clinical data (7.01\% versus 9.43\%; p = 0.001) to an overestimation of mortality associated with ventricular septal defect (VSD) repair by 31.0\% (0.78\% versus 0.60\%; p = 0.1). This study demonstrates differences in case ascertainment between administrative and clinical registry data for children undergoing cardiac operations, which translated into important differences in outcomes assessment.

As discussed below, these challenges and problems persist with the 10th Revision of the International Classification of Diseases (ICD-10). Several potential reasons can explain the poor diagnostic accuracy of administrative databases and codes from ICD-9 and even ICD-10:

- accidental miscoding;
- coding performed by medical records clerks who have never seen the actual patient, in other words, coding performed by personnel not involved in the care of the patient;
- contradictory or poorly described information in the medical record;
- lack of diagnostic specificity for congenital cardiac disease in the codes of ICD-9 or ICD-10
- inadequately trained medical coders.

Although one might anticipate some improvement in diagnostic specificity with the adoption of ICD-10, it is still substantially deficient compared to that currently achieved with the clinical nomenclature used in clinical registries. In this regard, ICD-9 has only 29 congenital cardiac codes while ICD-10 has only 73 congenital cardiac codes. It will not be until there is implementation of the pediatric and congenital cardiac components of ICD-11 that harmonization of clinical and administrative nomenclature will be achieved. The implementation of ICD-11, therefore, will resolve many of these challenging issues.

### Summary

The art and science of outcomes analysis and quality improvement for paediatric and congenital cardiac care continue to evolve. The IPCCC nomenclature is utilized in multi-institutional registries and databases all over the world.\textsuperscript{124,125} In this manuscript, we have presented the 2021 version of IPCCC, a global system of nomenclature for paediatric and congenital cardiac care that unifies clinical and administrative nomenclature.

### Acknowledgements

We thank all members of The International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPNCHD) for their tremendous dedication, leadership, and support of this initiative. We also thank Professor Robert H. Anderson, MD, PhD (Hon) and Professor Richard Van Praagh, MD for their decades of dedication to paediatric and congenital care and advancing the art and science of cardiac morphology and cardiac nomenclature. The creation of The International Paediatric and Congenital Cardiac Code (IPCCC) would not have been possible without their tremendous contributions.

### Financial support:

Over the past two decades, The International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPNCHD) and the creation of The International Paediatric and Congenital Cardiac Code (IPCCC) have been supported by the following organizations listed alphabetically:

- American College of Cardiology, Chicago, Illinois, United States of America
- “Andy Collins for Kids Fund”, Montreal Children’s Hospital Foundation, Montréal, Québec, Canada
- “Angela’s Big Heart for Little Kids Fund”, Montreal Children’s Hospital Foundation, Montréal, Québec, Canada
- Association pour la Recherche en Cardiologie du Fœtus et de l’Enfant, Service de Cardiologie Pédiatrique et de Chirurgie Cardiaque Pédiatrique, Hôpital Necker-Enfants Malades, Paris France
- Boston Children’s Heart Foundation and The Marram and Carpenter Fund, Boston, Massachusetts, United States of America
- Canadian Institutes of Health Research, Canada
- “Cardiac Kids Foundation of Florida” [https://cardiackidsfl.com/], Florida, United States of America
- Council on Cardiovascular Disease in the Young of the American Heart Association, United States of America
- Division of Cardiovascular Surgery, The Montreal Children’s Hospital of the McGill University Health Centre, Montréal, Québec, Canada
- Children’s Mercy Hospital, Kansas City, Missouri, United States of America
Division of Pediatric Cardiology, The Montreal Children’s Hospital of the McGill University Health Centre, Montréal, Québec, Canada

Drs. Ivan and Milka Tchervenkov Endowment Fund, Montreal Children’s Hospital Foundation, Montréal, Québec, Canada

Filiale de Cardiologie Pédriatique et Congénitale de la Société Française de Cardiologie, France

Great Ormond Street Hospital for Children, London, England, United Kingdom

Heart and Stroke Foundation of Canada, Canada

Heart of a Child, Children’s Hospital of Michigan Foundation, Detroit, Michigan, United States of America

Hôpital Marie-Lannelongue - M3C, Paris, France

Japan Research Promotion Society for Cardiovascular Diseases, Japan

Montreal Children’s Hospital Foundation, Montréal, Québec, Canada

Nicklaus Children’s Hospital Heart Program, Miami, Florida, United States of America

Secretaria da Cultura e Governo do Estado do Amazonas, Brazil

Sociedade Brasileira de Cardiologia - Departamento de Cardiologia Pediátrica e Cardiopatias Congênitas, Brazil

The Children’s Heart Foundation [https://www.childrensheartfoundation.org/], United States of America

Tokyo Women’s Medical University, Tokyo, Japan

University of Minnesota, Minneapolis, Minnesota, United States of America

University of Padova, Padova, Italy

Ward Family Heart Center, Children’s Mercy Kansas City, Kansas City, Missouri, United States of America

Jeffrey P. Jacobs, MD

Declaration of Confl cting Interests

None.

Ethical standards:

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

Supplemental Material

Supplemental material for this article is available online

REFERENCES:

1. Abbott ME. Atlas of congenital cardiac disease. New York: The American Heart Association; 1936.
2. Franklin RCG, Anderson RH, Daniëls O, et al. The European Paediatric Cardiac Code. Cardiol Young 1999; 9: 633-657.
3. Association for European Paediatric Cardiology. The European Paediatric Cardiac Code. Cardiol Young 2000; 10 (Suppl 1): 1-146
4. Mavroudis C, Jacobs JP. The International Congenital Heart Surgery Nomenclature and Database Project. The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S1-372.
5. Mavroudis C, Jacobs JP. Congenital Heart Surgery Nomenclature and Database Project: Introduction. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S1.
6. Mavroudis C, Jacobs JP. Congenital Heart Surgery Nomenclature and Database Project: Overview and Minimum Dataset. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S2-S17.
7. Jacobs JP, Quintessenza JA, Burke RP, Mavroudis C. Congenital Heart Surgery Nomenclature and Database Project: Atrial Septal Defect. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S18-S24.
8. Jacobs JP, Burke RP, Quintessenza JA, Mavroudis C. Congenital Heart Surgery Nomenclature and Database Project: Ventricular Septal Defect. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S25-S35.
9. Jacobs JP, Burke RP, Quintessenza JA, Mavroudis C. Congenital Heart Surgery Nomenclature and Database Project: Atrioventricular Canal Defect. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S36-S43.
10. Jacobs JP, Quintessenza JA, Gaynor JW, Burke RP, Mavroudis C. Congenital Heart Surgery Nomenclature and Database Project: Aortopulmonary Window. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S44-S49.
11. Jacobs M. Congenital Heart Surgery Nomenclature and Database Project: Truncus Arteriosus. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S44-S49.
12. Herlong JR, Jaggers JJ, Ungerleider RM. Congenital Heart Surgery Nomenclature and Database Project: Pulmonary Venous Anomalies. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S50-S55.

13. Gaynor JW, Weinberg P, Spray T. Congenital Heart Surgery Nomenclature and Database Project: Systemic Venous Anomalies. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S70-S76.

14. Jacobs M. Congenital Heart Surgery Nomenclature and Database Project: Tetralogy of Fallot. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S83-S96.

15. Lacour-Gayet F. Congenital Heart Surgery Nomenclature and Database Project: Right Ventricular Outflow Tract Obstruction – Intact Ventricular Septum. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S97-S105.

16. Tchervenkov CI, Roy N. Congenital Heart Surgery Nomenclature and Database Project: Pulmonary Atresia – Ventricular Septal Defect. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S106-S117.

17. Dearani JA, Danielson GK. Congenital Heart Surgery Nomenclature and Database Project: Ebstein’s Anomaly and Tricuspid Valve Disease. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S118-S131.

18. Nguyen KH. Congenital Heart Surgery Nomenclature and Database Project: Aortic Valve Disease. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S132-S146.

19. Mitruka SN, Lamberti JJ. Congenital Heart Surgery Nomenclature and Database Project: Mitral Valve Disease. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S147-S163.

20. Ring WS. Congenital Heart Surgery Nomenclature and Database Project: Aortic Aneurysm, Sinus of Valsalva Aneurysm, and Aortic Dissection. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S164-S169.

21. Myers JL, Mehta SM. Congenital Heart Surgery Nomenclature and Database Project: Aortico-Left Ventricular Tunnel. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S170-S179.

22. Delius RE. Congenital Heart Surgery Nomenclature and Database Project: Pediatric Cardiomyopathies and End-Stage Congenital Heart Disease. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S180-S190.

23. Myers JL, Mehta SM. Congenital Heart Surgery Nomenclature and Database Project: Diseases of the Pericardium. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S191-S196.

24. Jacobs M, Mayer JE. Congenital Heart Surgery Nomenclature and Database Project: Single Ventricle. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S205-S235.

25. Jaggers JJ, Cameron DE, Herlong JR, Ungerleider RM. Congenital Heart Surgery Nomenclature and Database Project: Transposition of the Great Arteries. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S217-S240.

26. Wilkinson JL, Cochrane AD, Karl TR. Congenital Heart Surgery Nomenclature and Database Project: Corrected (Discordant)
Transposition of the Great Arteries (and Related Malformations). In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, editors. The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S236-S248.

28. Walters HW III, Mavroudis C, Tchervenkov CI, Jacobs JP, Lacour-Gayet F, Jacobs ML. Congenital Heart Surgery Nomenclature and Database Project: Double Outlet Right Ventricle. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S249-S263.

29. Tchervenkov CI, Walters III HW, Chu VF. Congenital Heart Surgery Nomenclature and Database Project: Double Outlet Left Ventricle. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S264-S269.

30. Dodge-Khatami A, Mavroudis C, Backer CL. Congenital Heart Surgery Nomenclature and Database Project: Anomalies of the Coronary Arteries. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S270-S297.

31. Backer CL, Mavroudis C. Congenital Heart Surgery Nomenclature and Database Project: Patent Ductus Arteriosus, Coarctation of the Aorta, and Interrupted Aortic Arch. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S298-S307.

32. Backer CL, Mavroudis C. Congenital Heart Surgery Nomenclature and Database Project: Vascular Rings, Tracheal Stenosis, and Pectus Excavatum. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S308-S318.

33. Deal BJ, Jacobs JP, Mavroudis C. Congenital Heart Surgery Nomenclature and Database Project: Arrhythmias. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S319-S331.

34. Rocchini AP. Congenital Heart Surgery Nomenclature and Database Project: Therapeutic Cardiac Catheter Interventions. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors).

The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S332-S342.

35. Gaynor JW, Bridges ND, Spray T. Congenital Heart Surgery Nomenclature and Database Project: End-Stage Lung Disease. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S343-S357.

36. Mehta SM, Myers JL. Congenital Heart Surgery Nomenclature and Database Project: Cardiac Tumors. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S358-S368.

37. Joffs C, Sade RM. Congenital Heart Surgery Nomenclature and Database Project: Palliation, Correction, or Repair. In: The Annals of Thoracic Surgery April 2000 Supplement: The International Congenital Heart Surgery Nomenclature and Database Project, Mavroudis Constantine, Jacobs Jeffrey P. MD, (editors). The Annals of Thoracic Surgery April 2000 Supplement, Volume 69 Supplement 4, S369-S372.

38. Lacour-Gayet F, Maruszewski B, Mavroudis C, Jacobs JP, Elliott MJ. Presentation of the International Nomenclature for Congenital Heart Surgery - The Long Way from Nomenclature to Collection of Validated Data at the EACTS. European Journal of Cardiothoracic Surgery, 18(2): 128-135, August 2000.

39. Maruszewski B, Lacour-Gayet F, Elliott MJ, Gaynor JW, Jacobs JP, Jacobs ML, Tchervenkov CI, Kurosawa H, Mavroudis C. Congenital Heart Surgery Nomenclature And Database Project: Update And Proposed Data Harvest. For simultaneous publication: The Annals of Thoracic Surgery 2002, The European Journal of Cardio-thoracic Surgery 2002, and The Jpn J Thorac Cardiovasc Surg 2002. The European Journal of Cardio-thoracic Surgery, 21(1): 47-9, January 2002.

40. Gaynor JW, Jacobs JP, Jacobs ML, Elliott MJ, Lacour-Gayet F, Tchervenkov CI, Maruszewski B, Mavroudis C. Congenital Heart Surgery Nomenclature And Database Project: Update And Proposed Data Harvest. For simultaneous publication: The Annals of Thoracic Surgery 2002, The European Journal of Cardio-thoracic Surgery 2002, and The Jpn J Thorac Cardiovasc Surg 2002. The Annals of Thoracic Surgery, 73(3): 1016-8, March 2002.

41. Franklin RCG, Jacobs JP, Tchervenkov CI, Be?land M. Report from the Executive of The International Working Group for Mapping and Coding of Nomenclatures for Paediatric and Congenital Heart Disease: Bidirectional Crossmap of the Short Lists of the European Paediatric Cardiac Code and the International Congenital Heart Surgery Nomenclature and Database Project. Cardiology in the Young, (Volume 12, Suppl. II) 18-22, September 2002.

42. Franklin RCG, Jacobs JP, Tchervenkov CI, Be?land M. European Paediatric Cardiac Code Short List crossmapped to STS/EACTS Short List with ICD-9 & ICD-10 crossmapping. Cardiology in the Young, (Volume 12, Suppl. II) 23-49, September 2002.

43. Franklin RCG, Jacobs JP, Tchervenkov CI, Be?land M. STS/EACTS Short List mapping to European Paediatric Cardiac Code
Short List with ICD-9 & ICD-10 crossmapping. Cardiology in the Young, (Volume 12, Suppl. II) 50-62, September 2002.

44. Béland M, Jacobs JP, Tchervenkov CI, Franklin RCG. The International Nomenclature Project for Paediatric and Congenital Heart Disease: Report from the Executive of The International Working Group for Mapping and Coding of Nomenclatures for Paediatric and Congenital Heart Disease. Cardiology in the Young, (Volume 12, Issue 5) 425-430, October 2002.

45. Franklin RCG, Jacobs JP, Tchervenkov CI, Béland M. The International Nomenclature Project for Pediatric and Congenital Heart Disease: Bidirectional Crossmap of the Short Lists of the European Paediatric Cardiac Code and the International Congenital Heart Surgery Nomenclature and Database Project. Cardiology in the Young, (Volume 12, Issue 5) 431-435, October 2002.

46. Kurosawa H, Gaynor JW, Jacobs JP, Jacobs ML, Elliott MJ, Lacour-Gayet F, Tchervenkov CI, Maruszewski B, Mavroudis C. Congenital Heart Surgery Nomenclature And Database Project: Update And Proposed Data Harvest. For simultaneous publication: The Annals of Thoracic Surgery 2002, The European Journal of Cardio-thoracic Surgery 2002, and The Jpn J Thorac Cardiovasc Surg 2002. The Jpn J Thorac Cardiovasc Surg, 50(11): 498-501, November 2002.

47. Béland MJ, Franklin RCG, Jacobs JP, Tchervenkov CI, Aiello VD, Colan SD, Gaynor JW, Krogmann ON, Kurosawa H, Maruszewski B, Stellin G, Weinberg PM. Update from The International Working Group for Mapping and Coding of Nomenclatures for Paediatric and Congenital Heart Disease. Cardiology in the Young, 14(2): 225-229, April 2004.

48. Jacobs JP, Mavroudis C, Jacobs ML, Lacour-Gayet FG, Tchervenkov CI, Gaynor JW, Clarke DR, Spray TL, Maruszewski B, Stellin G, Elliott MJ, Dokholyan RS, Peterson ED. Lessons Learned From The Data Analysis Of The Second Harvest (1998-2001) Of The Society Of Thoracic Surgeons (STS) Congenital Heart Surgery Database. The European Journal of Cardio-thoracic Surgery, 26(1): 18-37, July 2004.

49. Jacobs JP, Elliott MJ, Anderson RH, Quintessenza JA, Chai PJ, Morell VO, Botero LM, van Gelder HM, Badhwar V, Kanani M, Cohen GA, Burke RP. Creating a Database with Cardiography and Intra-Operative Imaging. In 2005 Supplement to Cardiology in the Young: Controversies of the Venticulo-Arterial Junctions and Other Topics, Jacobs JP, Wernovsky G, Gaynor JW, Anderson RH, editors. Cardiology in the Young, Volume 15, Supplement 1: 184-189, February 2005.

50. Jacobs JP, Maruszewski B, Tchervenkov CI, Lacour-Gayet FG, Jacobs ML, Clarke DR, Gaynor JW, Spray TL, Stellin G, Elliott MJ, Ebels T, Mavroudis C. Current status of the European Association for Cardio-Thoracic Surgery and the Society of Thoracic Surgeons Congenital Heart Surgery Database. Ann Thorac Surg. 2005 Dec; 80(6): 2278-83; discussion 2283-4.

51. Jacobs JP, Franklin RCG, Jacobs ML, Colan SD, Tchervenkov CI, Maruszewski B, Gaynor JW, Spray TL, Stellin G, Aiello VD, Béland MJ, Krogmann ON, Kurosawa H, Weinberg PM, Elliott MJ, Mavroudis C, Anderson R. Classification of the Functionally Univentricular Heart: Unity from mapped codes. In 2006 Supplement to Cardiology in the Young: Controversies and Challenges in the Management of the Functionally Univentricular Heart, Jacobs JP, Wernovsky G, Gaynor JW, Anderson RH (editors). Cardiology in the Young, Volume 16, Supplement 1: 9-21, February 2006.

52. Jacobs JP, Mavroudis C, Jacobs ML, Maruszewski B, Tchervenkov CI, Lacour-Gayet FG, Clarke DR, Yeh T, Walters H L 3rd, Kurosawa H, Stellin G, Ebels T, Elliott MJ. What is Operative Mortality? Defining Death in a Surgical Registry Database: A Report from the STS Congenital Database Task Force and the Joint EACTS-STS Congenital Database Committee. The Annals of Thoracic Surgery, 81(5): 1937-41, May 2006.

53. Tchervenkov CI, Jacobs JP, Weinberg PM, Aiello VD, Béland MJ, Colan SD, Elliott MJ, Franklin RC, Gaynor JW, Krogmann ON, Kurosawa H, Maruszewski B, Stellin G. The nomenclature, definition and classification of hypoplastic left heart syndrome. Cardiology in the Young, 2006; 16(4): 339-368, August 2006.

54. Tchervenkov CI, Jacobs JP, Weinberg PM, Aiello VD, Béland MJ, Colan SD, Elliott MJ, Franklin RC, Gaynor JW, Krogmann ON, Kurosawa H, Maruszewski B, Stellin G. The nomenclature, definition and classification of discordant atrioventricular connections. In 2006 Supplement to Cardiology in the Young: Controversies and Challenges of the Atrioventricular Junctions and Other Challenges Facing Paediatric Cardiovascular Practitioners and their Patients, Jacobs JP, Wernovsky G, Gaynor JW, Anderson RH (editors). Cardiology in the Young, Volume 16 (Supplement 3): 72-84, September 2006.

55. Jacobs JP, Mavroudis C, Jacobs ML, Maruszewski B, Tchervenkov CI, Lacour-Gayet FG, Clarke DR, Gaynor JW, Spray TL, Kurosawa H, Stellin G, Ebels T, Bacha EA, Walters HL, Elliott MJ. Nomenclature and Databases - The Past, the Present, and the Future: A Primer for the Congenital Heart Surgeon. Pediatr Cardiol. 2007 Apr; 28(2): 105-115. Epub 2007 May 4, May 2007.

56. Jacobs JP, Anderson RH, Weinberg P, Walters III HL, Tchervenkov CI, Del Duca D, Franklin RCG, Aiello VD, Béland MJ, Colan SD, Gaynor JW, Krogmann ON, Kurosawa H, Maruszewski B, Stellin G, Elliott MJ. The nomenclature, definition and classification of cardiac structures in the setting of heterotaxy. In 2007 Supplement to Cardiology in the Young: Controversies and Challenges Facing Paediatric Cardiovascular Practitioners and their Patients, Anderson RH, Jacobs JP, Wernovsky G, editors. Cardiology in the Young, Volume 17, Supplement 2, pages 1-28, doi: 10.1017/S1047951107001138, September 2007.

57. Jacobs JP, Wernovsky G, Elliott MJ. Analysis of Outcomes for Congenital Cardiac Disease: Can We Do Better? In 2007 Supplement to Cardiology in the Young: Controversies and Challenges
Facing Paediatric Cardiovascular Practitioners and their Patients, Jacobs JP, Wernovsky G, Gaynor JW, Anderson RH, editors. Cardiology in the Young, Volume 17, Supplement 2, pages 145-158, doi: 10.1016/S1047-9511(07)00127-8, September 2007.

59. Jacobs JP, Jacobs ML, Mavroudis C, Maruszewski B, Tcherwenkov CI, Lacour-Gayet FG, Clarke DR, Yeh T, Walters HL 3rd, Kurosawa H, Stellin G, Ebels T, Elliott MJ, Vener DF, Barach P, Benavidez OJ, Bacha EA. What is Operative Morbidity? Defining Complications in a Surgical Registry Database: A Report from the STS Congenital Database Task Force and the Joint EACTS-STS Congenital Database Committee. The Annals of Thoracic Surgery; 84: 1416-1421, October 2007.

60. Jacobs JP. (Editor). 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Cardiology in the Young, Volume 18, Supplement S2, pages 1-530, December 9, 2008.

61. Jacobs JP. Introduction – Databases and the assessment of complications associated with the treatment of patients with congenital cardiac disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 1-37, December 9, 2008.

62. Jacobs JP, Jacobs ML, Mavroudis C, Backer CL, Lacour-Gayet FG, Tcherwenkov CI, Franklin RCG, Béland MJ, Jenkins KJ, Walters III H, Bacha EA, Maruszewski B, Kurosawa H, Clarke DR, Gaynor JW, Spray TL, Stellin G, Ebels T, Krogmann ON, Aiello VD, Colan SD, Weinberg P, Giroud JM, Everett A, Wernovsky G, Martin J, Elliott MJ, Edwards FH. Nomenclature and databases for the surgical treatment of congenital cardiac disease – an updated primer and an analysis of opportunities for improvement. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 38-62, December 9, 2008.

63. Franklin RCG, Jacobs JP, Krogmann ON, Béland MJ, Aiello VD, Colan SD, Elliott MJ, Gaynor JW, Kurosawa H, Maruszewski B, Stellin G, Tcherwenkov CI, Walters HL 3rd, Weinberg P, Anderson RH. Nomenclature for congenital and paediatric cardiac disease: Historical perspectives and The International Pediatric and Congenital Cardiac Code. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 70-80, December 9, 2008.

64. Jacobs JP, Benavidez OJ, Bacha EA, Walters HL 3rd, Jacobs ML. The nomenclature of safety and quality of care for patients with congenital cardiac disease: a report of the Society of Thoracic Surgeons Congenital Database Taskforce Subcommittee on Patient Safety. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 81-91, December 9, 2008.

65. Strickland MJ, Richle-Colorusso TJ, Jacobs JP, Reller MD, Mahle WT, Botto LD, Tolbert PE, Jacobs ML, Lacour-Gayet FG, Tcherwenkov CI, Mavroudis C, Correa A. The importance of nomenclature for congenital cardiac disease: implications for research and evaluation. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 92-100, December 9, 2008.

66. Welke KF, Karamlou T, Diggs BS. Databases for assessing the outcomes of the treatment of patients with congenital and paediatric cardiac disease – a comparison of administrative and clinical data. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 137-144, December 9, 2008.

67. Bacha EA, Cooper D, Thiagarajan R, Franklin RCG, Krogmann O, Deal B, Mavroudis C, Shukla A, Yeh T Jr, Barach P, Wessel D, Stellin G, Colan SD. Cardiac complications associated with the treatment of patients with congenital cardiac disease: consensus definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 196-201, December 9, 2008.

68. Deal BJ, Mavroudis C, Jacobs JP, Gevitz M, Backer CL. Arrhythmic complications associated with the treatment of patients with congenital cardiac disease: consensus definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 202-205, December 9, 2008.

69. Shann KG, Giacomuzzi CR, Harness L, Myers GJ, Paugh TA, Mellas N, Groom RC, Gomez D, Thuys CA, Charette K, Ojito JW, Tinius-Juliani J, Calaritis C, McRobb CM, Parpard M,
Chancy T, Bacha E, Cooper DS, Jacobs JP, Likosky DS, on behalf of the International Consortium for Evidence-Based Perfusion. Complications relating to perfusion and extracorporeal circulation associated with the treatment of patients with congenital cardiac disease: Consensus Definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 206-214, December 9, 2008.

70. Cooper DS, Jacobs JP, Chai PJ, Jaggers JJ, Barach P, Beekman III RH, Krogmann O, Manning P. Pulmonary complications associated with the treatment of patients with congenital cardiac disease: consensus definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 215-221, December 9, 2008.

71. Welke KW, Dearani JA, Ghanayem NS, Béland MJ, Shen I, Ebels T. Renal complications associated with the treatment of patients with congenital cardiac disease: consensus definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 222-225, December 9, 2008.

72. Checchia PA, Karamlou T, Maruszewski B, Ohye RG, Bronicki R, Dodge-Khatami A. Haematological and infectious complications associated with the treatment of patients with congenital cardiac disease: consensus definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 226-233, December 9, 2008.

73. Bird GL, Jeffries HE, Licht DJ, Wernovsky G, Weinberg PM, Pizarro C, Stellin G. Neurological complications associated with the treatment of patients with congenital cardiac disease: consensus definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 234-239, December 9, 2008.

74. Ghanayem NS, Dearani JA, Welke KF, Béland MJ, Shen I, Ebels T. Gastrointestinal complications associated with the treatment of patients with congenital cardiac disease: consensus definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 240-244, December 9, 2008.

75. Walters HL 3rd, Jeffries HE, Cohen GA, Klitzner T. Congenital cardiac surgical complications of the integument, vascular system, vascular-line(s), and wounds: consensus definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 245-255, December 9, 2008.

76. Dickerson H, Cooper DS, Checchia PA, Nelson DP. Endocrinal complications associated with the treatment of patients with congenital cardiac disease: consensus definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 256–264, December 9, 2008.

77. Jeffries H, Bird G, Law Y, Wernovsky G, Weinberg P, Pizarro C, Stellin G. Complications related to the transplantation of thoracic organs: consensus definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 265-270, December 9, 2008.

78. Vener DV, Tirotta CF, Andropoulos D, Barach P. Anaesthetic complications associated with the treatment of patients with congenital cardiac disease: consensus definitions from the Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 265–270, December 9, 2008.
79. The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease. Part IV – the dictionary of definitions of complications associated with the treatment of patients with congenital cardiac disease. In: 2008 Cardiology in the Young Supplement: Databases and The Assessment of Complications associated with The Treatment of Patients with Congenital Cardiac Disease, Prepared by: The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease, Jacobs Jeffrey P. MD, (editor). Cardiology in the Young, Volume 18, Issue S2 (Suppl. 2), pp 282-530, December 9, 2008.

80. Jacobs JP, Quintessenza JA, Burke RP, Bleiweis MS, Byrne BJ, Ceithaml EL, DeCampli WM, Giroud JM, Perryman RA, Rosendranz ER, Wolff G, Posner V, Steverson S, Blanchard WB, Schiebler GL. Regional congenital cardiac surgery of outcomes in Florida using The Society of Thoracic Surgeons Congenital Heart Surgery Database. Cardiology in the Young, 2009; 19: 360-369, doi:10.1017/S1047951109009151, (First published online 6 July 2009), August 2009.

81. Giroud Jorge M., Jacobs Jeffrey P., Spicer Diane, Backer Carl, Martin Gerard R., Franklin Rodney C. G., Bélard Marie J., Krogmann Otto N., Aiello Vera D., Colan Steven D., Everett Allen D., William Gaynor J., Kurosawa Hiromi, Maruszewski Bohdan, Stellin Giovanni, Tschervenkov Christo L., Walters Henry L. III, Weinberg Paul, Anderson Robert H., Elliott Martin J. Report From The International Society for Nomenclature of Paediatric and Congenital Heart Disease: Creation of a Visual Encyclopedia Illustrating the Terms and Definitions of the International Pediatric and Congenital Cardiac Code. World Journal for Pediatric and Congenital Heart Surgery October 2010 1: 300-313, doi:10.1177/21501351100979622, October 2010.

82. Bergersen L, Everett AD, Giroud JM, Martin GR, Franklin RC, Bélard MJ, Krogmann ON, Aiello VD, Colan SD, Elliott MJ, Gaynor JW, Kurosawa H, Maruszewski B, Stellin G, Tschervenkov CI, Walters HL, Weinberg P, Jacobs JP. Report from The International Society for Nomenclature of Paediatric and Congenital Heart Disease: Cardiovascular Catheterisation for Congenital and Paediatric Cardiac Disease (Part 1 – Procedural Nomenclature). Cardiology in the Young, 2011 Jun; 21(3): 252-259. Epub 2011 Feb 11. PMID: 21310103.

83. Bergersen L, Giroud JM, Jacobs JP, Franklin RC, Bélard MJ, Krogmann ON, Aiello VD, Colan SD, Elliott MJ, Gaynor JW, Kurosawa H, Maruszewski B, Stellin G, Tschervenkov CI, Walters HL, Weinberg P, Everett AD. Report from The International Society for Nomenclature of Paediatric and Congenital Heart Disease: Cardiovascular Catheterisation for Congenital and Paediatric Cardiac Disease (Part 2 –Nomenclature of Complications associated with Interventional Cardiology). Cardiology in the Young. 2011 Jun; 21(3): 260-5. Epub 2011 Feb 11. PMID: 21310094.

84. Weintraub WS, Karlsberg RP, Tcheng JE, Boris JR, Buxton AE, Dove JT, Fonarow GC, Goldberg LR, Heidenreich P, Hendel RC, Jacobs AK, Lewis W, Mirro MJ, Shahian DM, Hendel RC, Bozkurt B, Jacobs JP, Peterson PN, Roger VL, Smith EE, Tcheng JE, Wang T; American College of Cardiology Foundation; American Heart Association Task Force on Clinical Data Standards. ACCF/AHA 2011 key data elements and definitions of a base cardiovascular vocabulary for electronic health records: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Clinical Data Standards. Circulation. 2011 Jul 5;124(1): 103-23. doi: 10.1161/CIR.0b013e31821cc7f1. Epub 2011 Jun 6. Erratum in: Circulation. 2011 Aug 2;124(5): e174. PMID: 21646493.

85. Weintraub WS, Karlsberg RP, Tcheng JE, Boris JR, Buxton AE, Dove JT, Fonarow GC, Goldberg LR, Heidenreich P, Hendel RC, Jacobs AK, Lewis W, Mirro MJ, Shahian DM. ACCF/AHA 2011 Key Data Elements and Definitions of a Base Cardiovascular Vocabulary for Electronic Health Records: A Report of the American College of Cardiology Foundation/American Heart Association Task Force on Clinical Data Standards. WRITING COMMITTEE MEMBERS: William S. Weintraub, MD, FACC, FAHA, Chair; Ronald P. Karlsberg, MD, FACC, FAHA, Vice-Chair; James E. Tcheng, MD, FACC, Vice-Chair; Jeffrey R. Boris, MD, FACC; Alfred E. Buxton, MD, FACC, FAHA; James T. Dove, MD, MACC; Gregor C. Fonarow, MD, FACC, FAHA; Lee R. Goldberg, MD, MPH, FACC; Paul Heidenreich, MD, FACC, FAHA; Robert C. Hendel, MD, FACC, FAHA; Alice K. Jacobs, MD, FACC, FAHA; William Lewis, MD; Michael J. Mirro, MD, FACC; David M. Shahian, MD, FACC, FAHA. ACCF/AHA TASK FORCE ON CLINICAL DATA STANDARDS: Robert C. Hendel, MD, FACC, FAHA, Chair; Biykem Bozkurt, MD, PhD, FACC; Gregor C. Fonarow, MD, FACC, FAHA; Jeffrey P. Jacobs, MD, FACC; Pamela N. Peterson, MD, FACC, FAHA; Véronique L. Roger, MD, MPH, FACC, FAHA Eric E. Smith, MD, MPH, FAHA; James E. Tcheng, MD, FACC; Tracy Wang, MD, FACC, FAHA; William S. Weintraub, MD, FACC, FAHA. J. Am. Coll. Cardiol. published online June 6, 2011 doi:10.1016/j.jacc.2011.05.001. J Am Coll Cardiol Vol. 58, No. 2, 2011. © 2011 by the American College of Cardiology Foundation and the American Heart Association, Inc. ISSN 0735-1097. Published by Elsevier Inc. doi:10.1016/j.jacc.2011.05.001. July 5, 2011. J Am Coll Cardiol. 2011 Jul 5; 58(2):202-22. Epub 2011 Jun 7. PMID: 21652161.

86. Giroud Jorge M., Jacobs Jeffrey P., Jay Fricker F., Spicer Diane, Backer Carl, Franklin Rodney C. G., Bélard Marie J., Krogmann Otto N., Aiello Vera D., Colan Steven D., Everett Allen D., William Gaynor J., Kurosawa Hiromi, Maruszewski Bohdan, Stellin Giovanni, Tschervenkov Christo L., Walters Henry L. III, Weinberg Paul, Anderson Robert H., Elliott Martin J. Proposal for a Web based “Global Virtual Museum of Congenital Cardiac Pathology”. Progress in Pediatric Cardiology. 2012 Jan; 33(1): 91-97. doi:10.1016/j.ppedcard.2011.12.015. In: Lipshultz Steven E. MD, Barach Paul MD, MPH, Jacobs Jeffrey P. MD, Laussen Peter MBBS (Editors). Progress in Pediatric Cardiology: The Future of Pediatric and Congenital Cardiac Care Special Part 2. 2012 Jan; 33(1):1–101.

87. Giroud JM, Aiello VD, Spicer DE, Anderson RH. The Archiving Working Group of the International Society for Nomenclature of Paediatric and Congenital Heart Disease: A Visual Encyclopedia Illustrating the Terms and Definitions of the International Paediatric and Congenital Cardiac Code. Congenital Cardiology Today. 2012; 10(8): 8-10.

88. Aiello VD, Anderson RH, Giroud JM, Spicer DE. Image of the Month (Aortic valve pathology, Bicuspid and Pulmonary valve...
Matherne GP, Mavroudis C, McCardle K, Pearson GD, Rosenthal G, Scott JS, Serwer GA, Sesar SS, Shaddy R, Slensick T, Vener DF, Walters HL 3rd, Weinberg PM. 2017 AHA/ACC Key Data Elements and Definitions for Ambulatory Electronic Health Records in Pediatric and Congenital Cardiology: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Data Standards. J Am Coll Cardiol. 2017 Aug 22; 70(8): 1029-1095. doi: 10.1016/j.jacc.2017.06.027. Epub 2017 Jul 14. PMID: 28716477.

Franklin RCG, Béland MJ, Colan SD, Walters HL, Aiello VD, Anderson RH, Baillard F, Boris JR, Cohen MS, Gaynor JW, Guleserian KJ, Houyel L, Jacobs ML, Jurasek AL, Krogmann ON, Kurosawa H, Lopez L, Maruszewski BJ, St Louis JD, Seslar SP, Srivastava S, Stellin G, Tchervenkov CI, Weinberg PM, Jacobs JP. Nomenclature for congenital and paediatric cardiac disease: the International Paediatric and Congenital Cardiac Code (IPCCC) and the Eleventh iteration of the International Classification of Diseases (ICD-11). Cardiol Young. 2017 Dec; 27(10): 1872-1938. doi: 10.1017/S1047951117002244. PMID: 29286277.

Lopez L, Houyel L, Colan SD, Anderson RH, Béland MJ, Aiello VD, Baillard F, Cohen MS, Jacobs JP, Kurosawa H, Sanders SP, Walters HL 3rd, Weinberg PM, Boris JR, Cook AC, Crucean A, Everett AD, Gaynor JW, Giroud J, Guleserian KJ, Hughes ML, Jurasek AL, Krogmann ON, Maruszewski BJ, St Louis JD, Seslar SP, Spicer DE, Srivastava S, Stellin G, Tchervenkov CI, Wang L, Franklin RCG. Classification of Ventricular Septal Defects for the Eleventh Iteration of the International Classification of Diseases-Striving for Consensus: A Report from the International Society for Nomenclature of Paediatric and Congenital Heart Disease. Ann Thorac Surg. 2018 Nov; 106(5): 1578-1589. doi: 10.1016/j.athoracsur.2018.06.020. Epub 2018 Jul 19. PMID: 30031844.

Cohen MS, Jacobs JP. In Memoriam: Paul Morris Weinberg, MD. Cardiol Young. 2021 Jan; 31(1): 1-10. doi: 10.1017/S1047951121000123. PMID: 3365588.

Tetter JT, Jacobs JP. Global Leadership in Paediatric and Congenital Cardiac Care: ‘Coding our way to improved care: an interview with Rodney C. G. Franklin, MBBS, MD, FRCP, FRCPCH”. Cardiol Young. 2021 Jan; 31(1): 11-19. doi: 10.1017/S104795112000476X. PMID: 33526161.

Centers for Disease Control and Prevention. Congenital Heart Defects Data and Statistics. Retrieved April 6, 2015, from [http://www.cdc.gov/ncbddd/heartdefects/data.html].

Hoffman JI, Kaplan S. The incidence of congenital heart disease. J Am Coll Cardiol. 2002 Jun 19; 39(12): 1890-900. doi: 10.1016/s0735-1079(02)01886-7. PMID: 12084585.

Hoffman JI, Kaplan S, Libethson RR. Prevalence of congenital heart disease. Am Heart J. 2004 Mar;147(3): 425-39. doi: 10.1016/j.ahj.2003.05.003.PMID: 14999190.

Jie Hoffman. The global burden of congenital heart disease. Cardiovasc J Afr. 2013 May;24(4): 141-5. doi: 10.5830/CVJA-2013-028.PMID: 24217047.

Jacobs JP, He X, Mayer JE Jr, Austin EH 3rd, Quintessenza JA, Karl TR, Vricella L, Mavroudis C, O’Brien SM, Pasquali SK, Hill KD, Husain SA, Overman DM, St Louis JD, Han JM, Shahian DM, Cameron D, Jacobs ML. Mortality Trends in Pediatric and Congenital Heart Surgery: An Analysis of The Society of Thoracic Surgeons Congenital Heart Surgery Database. Ann Thorac Surg. 2016 Oct; 102(4): 1345-52. doi: 10.1016/j.athoracsur.2016.01.071. Epub 2016 Aug 31. PMID: 27590683.

St Louis JD, Kurosawa H, Jonas RA, Sandoval N, Cervantes J, Tchervenkov CI, Jacobs JP, Sakamoto K, Stellin G, Kirklin JK. The World Database for Pediatric and Congenital Heart Surgery: The Dawn of a New Era of Global Communication and Quality Improvement in Congenital Heart Disease. World J Pediatr Congenit Heart Surg. 2017 Sep; 8(5): 597-599. doi: 10.1177/2150135117725458. PMID: 28901228.

O’Brien SM, Clarke DR, Jacobs JP, Jacobs ML, Lacour-Gayet FG, Pizarro C, Welke KF, Maruszewski B, Tobota Z, Miller WJ, Hamilton L, Peterson ED, Mavroudis C, Edwards FH. An empirically based tool for analyzing mortality associated with congenital heart surgery. The Journal of Thoracic and Cardiovascular Surgery, 2009 Nov; 138(5): 1139-53. PMID: 19837218, November 2009.

Jacobs ML, O’Brien SM, Jacobs JP, Mavroudis C, Lacour-Gayet F, Pasquali SK, Welke K, Pizarro C, Tsai F, Clarke DR. An empirically based tool for analyzing morbidity associated with operations for congenital heart disease. J Thorac Cardiovasc Surg. 2013 Apr; 145(4): 1046-1057.e1. doi: 10.1016/j.jtcvs.2012.06.029. Epub 2012 Jul 24. PMID: 22835225.

Crowe S, Brown KL, Pagel C, Muthialu N, Cunningham D, Gibbs J, Bull C, Franklin R, Utey M, Tsang VT. Development of a diagnosis- and procedure-based risk model for 30-day outcome after pediatric cardiac surgery. J Thorac Cardiovasc Surg. 2013 May;145(5): 1270-8. doi: 10.1016/j.jtcvs.2012.06.023. Epub 2012 Jul 18. PMID: 22818122.

Rogers L, Brown KL, Franklin RC, Ambler G, Anderson D, Barron DJ, Crowe S, English K, Stickley J, Tibby S, Tsang V, Utey M, Witter T, Pagel C. Improving Risk Adjustment for Mortality After Pediatric Cardiac Surgery: The UK PRAiS2 Model. Ann Thorac Surg. 2017 Jul;104(1): 211-219. doi: 10.1016/j.athoracsur.2016.12.014. Epub 2017 Mar 18. PMID: 28318513.

Jacobs JP, O’Brien SM, Hill KD, Kumar SR, Austin EH 3rd, Gaynor JW, Gruber PJ, Jonas RA, Pasquali SK, Pizarro C, St Louis JD, Meza J, Thibault D, Shahian DM, Mayer JE Jr, Jacobs ML. Refining The Society of Thoracic Surgeons Congenital Heart Surgery Database Mortality Risk Model With Enhanced Risk Adjustment for Chromosomal Anomalies, Syndromes, and Noncardiac Congenital Anatomic Abnormalities. Ann Thorac Surg. 2019 Aug; 108(2): 558-566. doi: 10.1016/j.athoracsur.2019.01.069. Epub 2019 Mar 7. PMID: 30853592.

Béland MJ, Harris KC, Marelli AJ, Houyel L, Baillard F, Dal-laire F. Improving Quality of Congenital Heart Disease Research in Canada: Standardizing Nomenclature Across Canada. Can J Cardiol. 2018 Dec;34(12): 1674-1676. doi: 10.1016/j.cjca.2018.08.034. Epub 2018 Aug 29. PMID: 30527157.

Aiello VD, Mattos SS. The congenital heart disease diagnosis list for the 11th iteration of the International Classification of
122. Cronk CE, Malloy ME, Pelech AN, et al. Completeness of state administrative databases for surveillance of congenital heart disease. Birth Defects Res A Clin Mol Teratol 2003;67: 597-603.

123. Frohnert BK, Lussky RC, Alms MA, Mendelsohn NJ, Symonik DM, Falken MC. Validity of hospital discharge data for identifying infants with cardiac defects. J Perinatol 2005;25: 737-42.

124. Nomenclature for Pediatric and Congenital Cardiac Care. In: Society of Thoracic Surgeons (STS) Cardiothoracic Surgery E-Book. [https://ebook.sts.org/sts/]: Pediatric and Congenital Cardiac Section. Editor: Jeffrey P. Jacobs, MD. Associate Editors: Erle H. Austin, Carl Lewis Backer, Robert (Jake) D. B. Jaquiss, John Edmund Mayer, James S. Tweddell, Winfield J. Wells. Published by The Society of Thoracic Surgeons. Published July 2021.

125. Databases for Pediatric and Congenital Cardiac Care. In:Society of Thoracic Surgeons (STS) Cardiothoracic Surgery E-Book. [https://ebook.sts.org/sts/]: Pediatric and Congenital Cardiac Section. Editor: Jeffrey P. Jacobs, MD. Associate Editors: Erle H. Austin, Carl Lewis Backer, Robert (Jake) D.B. Jaquiss, John Edmund Mayer, James S. Tweddell, Winfield J. Wells. Published by The Society of Thoracic Surgeons. Published July 2021.