

The World Database for Pediatric and Congenital Heart Surgery: Use of an International Congenital Database in South Korea

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More than a decade has elapsed since the historic inaugural meeting of the World Society for Pediatric and Congenital Heart Surgery (WSPCHS). The leaders and participants of this event were motivated and inspired by the prospect of a new era of global communication in the field of congenital heart disease. Their mission, galvanized by the ratification of the society's constitution, directed new members to promulgate efforts to "promote the highest quality of comprehensive cardiac care to all patients with congenital heart disease across the globe," with a message that would be realized for decades to come [1]. Cardiovascular disease remains the second leading cause of premature death in the Republic of Korea [2], and congenital cardiac surgical programs continue to develop and grow accordingly. Already, approximately 3,000 congenital cardiac operations are conducted each year by 28 active congenital heart surgeons throughout the country. As the 14 institutions with active congenital heart programs are located in major urban centers (Table 1), efforts to create more regional cardiac centers will surely lead

Table 1. Congenital cardiac programs in South Korea

Congenital cardiac programs
Asan Medical Center
Chonnam National University Hospital
Chungnam National University Hospital
Ewha Womans University Mokdong Hospital
Gachon University Gil Medical Center
Keimyung University Dongsan Medical Center
Korea University Ansan Hospital
Kyungpook National University Hospital
Pusan National University Yangsan Hospital
Samsung Medical Center
Sejong General Hospital
Seoul National University Children's Hospital
Seoul St. Mary's Hospital
Severance Cardiovascular Hospital

to an increase in case volume as surgical options become more readily accessible to rural populations. As with other countries, a national database to provide quality improvement tools and the ability to track long-term outcomes is critical for the evolution of congenital cardiac surgery in the Republic of Korea.

Received: July 12, 2017, Revised: August 16, 2017, Accepted: August 16, 2017, Published online: February 5, 2018

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Form name	Data to be entered
Institutional practice details	Information detailing the institution's congenital cardiac surgical practice (e.g., annual case volume, population and region served, number of congenital heart surgeons)
Demographics	Patient information (e.g., patient name, gender, date of birth)
Preoperative	Preoperative details of patient history (e.g., prior cardiac operations, chromosomal or syndromic abnormalities, preoperative risk factors)
Surgery	Surgical data (e.g., height and weight at surgery, bypass time, cross-clamp time)
Discharge	Complication and discharge information (e.g., reoperations required, nature of postoperative complications)
Follow-up	Data from 1 year post-index operation (e.g., readmission required, reoperation required, patient status)
Death	Details of death (e.g., date of death, cause of death, autopsy findings)

The World Database for Pediatric and Congenital Heart Surgery (WDPCHS) is strategically positioned to effortlessly provide such a service to all congenital cardiac surgical programs in the Republic of Korea. The WDPCHS possesses the tools to function as a national resource for such efforts with a modest expenditure of resources from individual institutions.

The history of the WDPCHS began during the Fourth Scientific Session of the 2014 WSPCHS annual meeting in São Paulo, Brazil. A town hall meeting was convened to evaluate the need for and to explore the possibility of establishing a global database that would be available to all members of the Society. After much debate and consideration, a committee was established to advance, with the support of the society, a database that would collect vital information, allowing all centers, including those flourishing in the Republic of Korea, to benchmark their outcomes and progress in providing surgical care to children with congenital heart disease. It was expected that a large number of centers in all regions of the world, regardless of their economic conditions, would benefit from the quality assessment tools provided and supported by an international consortium of congenital cardiac surgical programs. As programs grow and evolve within the Republic of Korea, this data-sharing model will provide critical information to aid in the effort to constantly assess and improve quality, ultimately ensuring that every child suffering from congenital heart disease receives the best possible cardiac care.

The WSPCHS was fortunate to retain the services of the James and John Kirklin Institute for Research in Surgical Outcomes at the University of Alabama at Birmingham. Under the leadership of James K.

Kirklin, this institute and its precursor organization have been and continue to be responsible for the creation and maintenance of both nationally and internationally-acclaimed clinical databases [3]. With the experience of this institute and invaluable input from multiple international experts in the fields of both congenital heart disease and database development, a global platform for information exchange was created and adjudicated by members of the society. The WDPCHS went live on January 1, 2017, following an extensive period of planning focused on determining the appropriate variables to collect, creating a design that can be applied on a global scale regardless of socioeconomic status, and engaging in strategies to encourage international participation.

The WDPCHS is designed to produce meaningful performance and quality analyses of surgical outcomes that extend beyond immediate hospital survival, capturing important morbidities and mortalities for up to a year postoperatively. By utilizing standardized terms and definitions developed and adjudicated by several national and international expert organizations, the database has embraced a common language, communication, and assessment of congenital cardiac practices across the globe. In order to provide individual centers adequately detailed outcome analyses while remaining cognizant of limited financial and personnel resources, variables were selected to provide the greatest opportunity to evaluate programmatic deficiencies and to implement necessary improvements in preoperative selection, intraoperative performance, and postoperative management. Institutions will be able to confidentially compare their center-specific data to regional, national, and international aggregate data, allowing the identi-

fication and implementation of quality improvement strategies. Table 2 illustrates the organization of the database and the types of information that are being collected. Institutional practice data are collected in sufficient detail to facilitate the creation of an international registry of congenital cardiac centers. The information collected in this category includes annual center case volumes, the number of congenital cardiac surgeons actively practicing at the center, the geographic region served, the population served, the number of other institutions within the geographic region, and a description of the services provided. The surgery form requires the input of only 19 variables. Several of these variables, such as the primary cardiac procedure and cardiac diagnosis, are organized into easy-to-navigate drop-down menus with categories reflecting routine clinical practice. These variables, including prior cardiac operations, preoperative risk factors, weight, cardiopulmonary bypass time, and intraoperative complications, were chosen by international experts in the field of congenital cardiac surgery to reliably represent the operative conduct of a surgical program. The collection of follow-up information on readmission, morbidities, and mortalities for up to a year postoperatively is a distinguishing feature that separates this database from others. This longitudinal follow-up will provide for the first time a global picture of longitudinal care beyond the immediate postoperative period.

Data quality is critical, and excessive data collection may lead to the dilution of efficient and effective analysis, increased expenditure of valuable resources, and loss of enthusiasm from participating members [4]. For these reasons, surgical procedures are assigned to 1 of 2 categories within the database. This 2-tiered system was created to allow for both the input of detailed data for a pre-selected group of surgical procedures and the collection of a limited number of variables for all cardiac operations performed (Table 3). The additional follow-up data cover important morbidities, readmission for interventions related to the index surgical procedure, and mortality for up to 1 year postoperatively. Importantly, the database will maintain the flexibility to incorporate additional procedures in the tier I category as centers gain experience with the database and come to recognize its value, both for quality assurance and research.

Table 3. Tier I procedures

Procedure name
Ventricular septal defect repair
Atrioventricular septal defect repair
Coarctation repair
PAPVC repair
TAPVC repair
Glenn/Hemi-Fontan procedure
Fontan procedure
Tetralogy of Fallot repair
Arterial switch operation
Ebstein's anomaly repair
Truncus arteriosus repair
Modified Norwood procedure
HLHS biventricular repair

PAPVC, partial anomalous pulmonary venous connection; TAPVC, total anomalous pulmonary venous connection; HLHS, hypoplastic left heart syndrome.

To advance its societal mission, the WSPCHS has made this global quality improvement program available to its members free of charge. WSPCHS members from programs that lack sufficient resources and facilities to undertake sophisticated outcome analyses or whose country does not presently have a national database will particularly benefit from this endeavor. By establishing the World Database, the WSPCHS is taking an essential step in the process of global improvement of care for children with congenital heart disease. In the longer term, we anticipate that the inclusion of more data in a global database will enable more accurate risk adjustment than is possible using national registries. The World Society invites all institutions in the Republic of Korea to fully participate in this important initiative. More detailed information concerning the WDPCHS can be found at <http://www.uab.edu/medicine/wdpchs/>.

Conflict of interest

No potential conflict of interest relevant to this article was reported.

Comments from editorials

I read with much interest the manuscript titled "The World Database for Pediatric and Congenital Heart Surgery". This is a very timely and concise re-

view raising attention to the world database of congenital cardiac surgery. I think the manuscript can be published in our journal as it is.

However, I would like to add a comment as a congenital cardiac surgeon in Korea. In the 1st paragraph, the author mentioned "Cardiovascular disease remains the second leading cause of premature death in the Republic of Korea [2], and congenital cardiac surgical programs continue to develop and grow accordingly.", which provides a somewhat weak basis of the need for world database in Korea. Some Korean surgeons would not agree with that point of view although the cited statistics are true. Korea ranked 11th place in 'life expectancy at birth' http://gamapserver.who.int/gho/interactive_charts/mbd/life_expectancy/atlas.html and 3rd place in 'healthy life expectancy at birth' http://gamapserver.who.int/gho/interactive_charts/mbd/hale_1/atlas.html according to WHO 2015 data. The mortality of congenital heart surgery in Korea seems around 2.5-3.4% between 2007 and 2011 (<http://kctvs.inforang.com/data/html/CHD2009.pdf>). In my opinion, the necessity for larger scale database lies on that point. We don't have any

national database for CHD and even can't find any simple collection of surgical results since 2012 although some Korean surgeons may claim good results from their own data and our society provides good health care.

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References

1. Kirklin JK, St Louis JD. *Databases in pediatric cardiac surgery: a nexus of opportunity and obligation*. World J Pediatr Congenit Heart Surg 2016;7:675-6.
2. World Health Organization. *2014/2015 World Health Organization data for the Republic of Korea* [Internet]. Geneva: World Health Organization; 2014 [cited 2017 Jul 6]. Available from: http://www.who.int/nmh/countries/kor_en.pdf?ua=1.
3. Vener DF, Gaies M, Jacobs JP, Pasquali SK. *Clinical databases and registries in congenital and pediatric cardiac surgery, cardiology, critical care, and anesthesiology worldwide*. World J Pediatr Congenit Heart Surg 2017;8: 77-87.
4. Jacobs JP, Wernovsky G, Elliott MJ. *Analysis of outcomes for congenital cardiac disease: can we do better?* Cardiol Young 2007;17 Suppl 2:145-58.