**SUPPLEMENTAL MATERIAL**

**Supplemental Table S1.** Search strings employed in the literature databases

|  |
| --- |
| **PubMed Search**  (“Heart Defects, Congenital”[Mesh] OR "congenital heart"[All Fields] OR "congenital cardiac"[All Fields] OR "heart defects"[All Fields]) AND (“adult” [MeSH] OR “adult” [Title/Abstract] OR “young adult” [Mesh] OR “young adult” [Title/Abstract]) AND (Cohort Studies[Title/Abstract] OR Population[Title/Abstract] OR Follow-Up[Title/Abstract] OR Studies[All Fields]) AND (Epidemiology[All Fields] OR Prevalence[All Fields] OR time factors[All Fields] OR trends[All Fields] OR incidence[All Fields]) AND (Outcome[All Fields] OR mortality[All Fields] OR Prognosis[All Fields] OR Survival[All Fields]) AND (Disease Management[All Fields] OR Treatment[All Fields] OR outcome[All Fields] OR intervention[All Fields]) AND (public health[All Fields] OR policy[All Fields] OR resources[All Fields])  Filters English, and 18+, publication date from 01/01/2006 to 31/12/2015 |
| **EmbaseSearch**  (congenital and (heart or cardiac) and (defect or disease or anomaly or lesions) and (adult or adulthood)).ab. and (public health or national health or healthsystem or health system or health service or healthcare or health care or health program or information system or administrative database or medical records or discharge or insurance or Nationwide or inpatient or policy or resources or cost). |

**Supplemental Table S2.** Selected studies characteristics

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **First author** | **Data source name** | **Study design** | **Availability of a detailed CHD definition**  **(coding used)** | **Study population**  **-CHD lesions**  **-specific issues**  **-subcategories of CHD** | **Age of inclusion (years)** | **Control group or standardization** | **Study years** |
| Marelli [51](#_ENREF_51) | The Québec CHD Database | Descriptive study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -All patients diagnosed for CHD (not only hospitalized)  -Severe/other CHD lesions | All ages\* | No control population | 1985-2000 |
| Gurvitz [13](#_ENREF_13) | The California OSHPD | Cross sectional study | N/A  (ICD-9-CM) | -All CHD lesions  -Hospitalized  -Complex/non-complex CHD | 12-44 | Non-pregnant, non-CHD | 2000-2003 |
| Mackie [4](#_ENREF_4) | The Québec CHD Database | Cross sectional study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -All patients diagnosed for CHD (not only hospitalized)  -Severe/other CHD lesions | ≥18 and alive in 1996 | The general Quebec adult population over this time period (for age- and gender-adjusted rates) | 1996-2000 |
| Billett [52](#_ENREF_52) | -The Hospital Episode Statistics (HES) database And  -The Office for National Statistics | Descriptive study | -N/A (ICD-10)  And  - ✓  (ICD-9, ICD-10) | -All CHD lesions  -Hospitalized | All ages\* | No control population  Age-standardized rates (calculated using the European Standard population) | 1994-2004 |
| Chan [53](#_ENREF_53) | Hong Kong Health Authority’s Clinical Data Analysis and Reporting System (CDARS) | Descriptive study | N/A  (ICD-9-CM) | -Marfan syndrome  -Hospitalized | All ages\* | No control population | 1997-2006 |
| Karamlou [54](#_ENREF_54) | Nationwide Inpatient Sample | Descriptive study | ✓  ICD-9-CM | -ASD/PFOs  -Hospitalized for ASD closure (surgical or transcatheter) | All ages\* | No control population Population-normalized procedure rates obtained from US Census data | 1988-2005 |
| Opotowsky [14](#_ENREF_14) | Nationwide Inpatient Sample | Cross sectional study | ✓  ICD-9 | -ASD/PFOs  -Hospitalized for percutaneous ASD closure | ≥20 | No control population  Sampling weights to produce nationally representative estimates | 2001-2005 |
| Opotowsky [5](#_ENREF_5) | Nationwide Inpatient Sample | Descriptive study | ✓  ICD-9 | -All CHD lesions  -Hospitalized  -Simple/complex CHD | ≥18 | No control population  Sampling weights to produce nationally representative estimates | 1998-2005 |
| Patel [36](#_ENREF_36) | United Network for Organ Sharing | Cohort study | N/A | -All CHD lesions  -Primary heart transplant recipients | >17 | Non-CHD adult heart transplant recipients | 1987-2006 |
| Bouchardy [64](#_ENREF_64) | The Québec CHD Database | Cohort study and case-cohort study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -Atrial arrhythmias  -Severe/other CHD lesions | ≥18 | 1:1 matching to non–atrial arrhythmia controls (on age, sex, CHD severity and calendar time) | 1988-2005 |
| Karamlou [38](#_ENREF_38) | United Network for Organ Sharing | Cohort study | N/A | -All CHD lesions  -Isolated heart transplant recipients | 18-45 | Non-CHD adult heart transplant recipients | 1990-2008 |
| Karamlou [15](#_ENREF_15) | Nationwide Inpatient Sample | Cross sectional study | ✓  ICD-9 | -All CHD lesions  -Hospitalized for an open-heart or thoracic aortic operations | ≥18 | No control population  Sampling weights to produce nationally representative estimates | 1988-2003 |
| Khairy [39](#_ENREF_39) | The Québec CHD Database | Cohort study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -All patients diagnosed for CHD (not only hospitalized)  -Severe/other CHD lesions | All ages\* (alive or born after July 1987) | No control population | 1987-2005 |
| Bernier [37](#_ENREF_37) | The Québec CHD Database | Cohort study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -Atrial arrhythmias  -Right/left-sided lesions | ≥18 | No control population  Comparison between right- and left-sided lesions patients | 1988-2005 |
| Ionescu [58](#_ENREF_58) | The Québec CHD Database | Time-series study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -History of cardiac surgical operation  -Severe/other CHD lesions | All ages\* | No control population  Comparison between adults and children | 1988-2005 |
| Gilboa [55](#_ENREF_55) | Multiple cause of death public-use data files | Descriptive study | ✓  ICD-10 | -All CHD lesions  -Deaths | All ages\* | No control population | 1999-2006 |
| Kim [17](#_ENREF_17) | Pediatric Health Information System | Cross-sectional study | ✓  ICD-9-CM | -All CHD lesions  -Hospitalized for congenital heart surgery procedure | 18-49 | No control population | 2000-2008 |
| Rodriguez [18](#_ENREF_18) | Nationwide Inpatient Sample | Cross sectional study | ✓  ICD-9 | -Septal defects (ASD, VSD, AVSD)  -Hospitalized | ≥18 | No control population  Sampling weights to produce nationally representative estimates | 2007 |
| Lowe [63](#_ENREF_63) | The Québec CHD Database | Cohort study and matched cohort study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -pulmonary hypertension (primary or secondary PH)  -Severe/shunts/valvular/other CHD lesions | ≥18 | 1:1 matching to non–PH controls (on age, CHD lesion, and calendar time) | 1990-2005 |
| Afilalo [66](#_ENREF_66) | The Québec CHD Database | Cohort study (case-control for sensitivity analysis) | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -All patients diagnosed for CHD (not only hospitalized)  -Severe/shunts/valvular lesions | ≥65 | No control population  Comparison between patients with severe, shunt, and valvular lesions | 1990-2005 |
| Kim [16](#_ENREF_16) | Pediatric Health Information System | Cross-sectional study | ✓  ICD-9-CM | -All CHD lesions  -Hospitalized for congenital heart surgery procedure | 18-49 | No control population  a. Comparison between high and low resource use admissions  b. Comparison between adults and children | 2000-2008 |
| Opotowsky [20](#_ENREF_20) | Nationwide  Inpatient Sample | Cross sectional study | ✓  ICD-9 | -All CHD lesions  -Women hospitalisation for childbirth  -Simple/complex/unclassified CHD lesions | All ages\* | Women without CHD | 1998-2007 |
| Roifman [65](#_ENREF_65) | The Québec CHD Database | Cohort study and case-control study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -Aortic coarctation and VSD  -All patients diagnosed for coarctation or VSD (not only hospitalized) | ≥18 | Comparison between aortic coarctation and VSD populations | 1988-2005 |
| Karamlou [19](#_ENREF_19) | Nationwide  Inpatient Sample | Cross sectional study | N/A | -All CHD lesions  -Recipients undergoing heart transplantation  -Univentricular/biventricular anatomy | ≥14 | No control population  Comparison between univentricular versus biventricular anatomy | 1993-2007 |
| Baraona [21](#_ENREF_21) | Nationwide  Inpatient Sample | Cross sectional study | ✓  ICD-9 | -AVSD, VSD, tetralogy of Fallot, patent ductus arteriosus  -Hospitalized  -With or without Down Syndrome | 18-64 | No control population  Comparison between with and without Down Syndrome | 1998-2009 |
| Kotowycz [40](#_ENREF_40) | The Québec CHD Database | Cohort study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -ASD  -ASD closures (surgical or transcatheter) | 18-75 | No control population  Comparison between surgical closure and transcatheter closure | 1988-2005 |
| Krieger [24](#_ENREF_24) | Nationwide  Inpatient Sample | Cross sectional study | ✓  ICD-9 | -Single ventricle i.e. tricuspid atresia, hypoplastic left heart syndrome, common ventricle  -Hospitalized | 18–49 | a. Non-CHD hospitalized patients  b. Tetralogy of Fallot hospitalized patients | 1998-2009 |
| Maxwell [62](#_ENREF_62) | Nationwide  Inpatient Sample | Matched cohort study | ✓  ICD-9-CM | -All CHD lesions  -Hospitalized | ≥18 | 1:4 matching to the general population (on age, sex, race, year, elective or urgent or emergency procedure, comorbidity score, primary procedure code) | 2002-2009 |
| Collins [22](#_ENREF_22) | Pediatric Health Information System | Cross-sectional study | ✓  ICD-9 | -Single ventricle i.e. tricuspid atresia, hypoplastic left heart syndrome, common ventricle  -Hospitalized  -Anatomical subtype (tricuspid atresia, hypoplastic left heart syndrome, common ventricle) | ≥18 | No control population  Comparison according to the anatomical subtype | 2004-2011 |
| Rodriguez [25](#_ENREF_25) | Nationwide  Inpatient Sample | Cross sectional study | ✓  ICD-9 (supplemental files) | -All CHD lesions  -Hospitalized for heart failure | ≥18 | No control population  Comparison between with and without heart failure | 2007 |
| Gelow [23](#_ENREF_23) | United Network for Organ Sharing | Cross-sectional study | N/A | -All CHD lesions  -Listed for primary heart transplant | ≥18 | Non-CHD adult listed for primary heart transplant | 1985-2010 |
| Collins [26](#_ENREF_26) | Pediatric Health Information System | Cross-sectional study | ✓  ICD-9 | -Single ventricle i.e. tricuspid atresia, hypoplastic left heart syndrome, common ventricle  -Hospitalized patients with cardiac arrhythmia  -Anatomical subtype (tricuspid atresia, hypoplastic left heart syndrome, common ventricle) | ≥18 | No control population | 2004-2011 |
| Mylotte [41](#_ENREF_41) | The Québec CHD Database | Cohort study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -ASD  -ASD closures (surgical or transcatheter) | 18 -75 | No control population  Comparison between surgical closure and transcatheter closure | 1988-2005 |
| Mylotte [8](#_ENREF_8) | The Québec CHD Database | Time series, case-control study and cohort study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -All patients diagnosed for CHD (not only hospitalized)  -Severe/other CHD lesions | 18-65 | No control population | 1990-2005 |
| Nyboe [61](#_ENREF_61) | The Danish Public Registries (incl. Danish National Patient Registry) | Matched-cohort study | ✓  ICD8 until 1993 then ICD-10 | -ASD  -All patients diagnosed after age 18 for ASD (not only hospitalized) | ≥18 at time of diagnosis | 1:10 matching to the general population (on sex and birth year) | 1977-2009  (follow-up until 2011) |
| Marelli [3](#_ENREF_3) | The Québec CHD Database | Descriptive study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -All patients diagnosed for CHD (not only hospitalized)  -Severe/other CHD lesions | All ages\* | No control population  Comparison between adults and children, between severe and other CHD lesions | 1983-2010 |
| Maxwell [57](#_ENREF_57) | The California OSHPD Ambulatory Surgery Database | Descriptive study | ✓  (ICD-9-CM) | -All CHD lesions  -Outpatient surgical encounters  -no subcategory | All ages\* | No control population  Comparison between adults and children | 2005-2011 |
| Lin [6](#_ENREF_6) | Taiwan’s National Health Insurance Research Database | Matched cohort study | ✓  ICD-9-CM | -All CHD lesions  -Diagnosed for major cardiovascular adverse events  -Cyanotic/non-cyanotic CHD, also with and without history of surgical treatment | ≥18 | Non CHD population matched on age, sex,  and residential area | 2000-2003 (follow-up until 2010) |
| Lu [56](#_ENREF_56) | California State Inpatient Databases | Descriptive study | ✓  (ICD-9-CM) | -All CHD lesions  -Hospitalized  -PFO/ASD only or not | 10-29 | Non-ACHD hospitalized patients | 2005-2009 |
| Bhatt [27](#_ENREF_27) | Nationwide Inpatient Sample | Cross-sectional study | ✓  ICD-9-CM | -All CHD lesions  -Hospitalized for congenital heart surgical procedure  -Surgical complexity | 18–49 | No control population | 2005-2009 |
| Hassan [43](#_ENREF_43) | Nationwide Inpatient Sample | Cohort study | ✓  ICD-9-CM | -Marfan syndrome  -Women’ hospitalisation for childbirth | N/A | Delivery hospitalizations of women without Marfan syndrome | 2003-2010 |
| Lee [45](#_ENREF_45) | Taiwan’s National Health Insurance Research Database | Cohort study | ✓  ICD-9-CM | -All CHD lesions  -Newly diagnosed CHD patients | All ages\* | No control population  Standardized incidence ratios (sex, age at CHD diagnosis, and follow-up period) | 1998-2006 (follow-up until December 2007) |
| Hayward [30](#_ENREF_30) | The California OSHPD | Cross sectional study | ✓  (ICD-9-CM) | -All CHD lesions  -Hospitalized for PM or ICD implantation  -Complex/ non-complex CHD | ≥18 | Non-ACHD patients undergoing PM or ICD implantation | 2005-2011 |
| Wu [48](#_ENREF_48) | Taiwan’s National Health Insurance Research Database | Cohort study | ✓  ICD-9-CM | -Tetralogy of Fallot  -All patients diagnosed for Tetralogy of Fallot (not only hospitalized) | All ages\* | No control population | 2000-2010 |
| Maxell [46](#_ENREF_46) | Nationwide  Inpatient Sample | Cohort study | ✓  ICD-9 | -All CHD lesions  -Hospitalized with an electrophysiology procedure | ≥18 | Non-CHD patient hospitalized with an electrophysiology procedure | 1998-2011 |
| Nyboe [60](#_ENREF_60) | The Danish Public Registries (incl. Danish National Patient Registry) | Matched-cohort study | ✓  ICD8 until 1993 then ICD-10 | -ASD  -All patients diagnosed after age 18 for ASD (not only hospitalized)  -Closed (transcatheter, surgical)/unclosed ASD | ≥18 at time of diagnosis | 1:10 matching to the general population (on sex and birth year) | 1977-2009 |
| Singh [32](#_ENREF_32) | Nationwide  Inpatient Sample | Cross-sectional study | ✓  ICD-9 | -ASD/PFOs  -Hospitalized for percutaneous ASD closure | >18 | No control population | 2001-2010 |
| Fernandes [29](#_ENREF_29) | The California OSHPD | Cross sectional study | ✓  (ICD-9-CM) | -All CHD lesions except VSD associated with MI, congenital aortic stenosis or regurgitation or pulmonary valve stenosis  -Hospitalized for ACHD surgery  -Simple, moderate, complex CHD | 21-65 | No control population  Comparison between specialized and non-specialized centers | 2000-2011 |
| Thompson [34](#_ENREF_34) | Nationwide Inpatient Sample | Cross-sectional study | ✓  ICD-9-CM | -All CHD lesions  -Women’ hospitalisation for childbirth | N/A | Non-CHD women | 2000-2010 |
| Tabtabai [33](#_ENREF_33) | Nationwide  Inpatient Sample | Cross-sectional study | ✓  ICD-9 | -Single ventricle i.e. tricuspid atresia, hypoplastic left heart syndrome, common ventricle  -Hospitalized | >14 | No control population  a. Comparison between with and without heart failure  b. Comparison with Tetralogy of Fallot | 2000-2011 |
| Chen [42](#_ENREF_42) | Taiwan’s National Health Insurance Research Database | Cohort study (with and without propensity score matching) | N/A  ICD-9 | -ASD  -Hospitalized for ASD closure (surgical or transcatheter) | ≥18 | Surgical ASD closure patients matched 1:2 with transcatheter ASD closure patients (using propensity score) | 2004-2011 |
| Wu [47](#_ENREF_47) | Taiwan’s National Health Insurance Research Database | Cohort study | ✓  ICD-9-CM | -Aortic coarctation  -All patients diagnosed for coarctation (not only hospitalized)  -Age groups | <60 | No control population  Comparison between aortic coarctation and non-coarctation CHD patients | 2000-2010 |
| Bhatt [28](#_ENREF_28) | Nationwide  Inpatient Sample | Cross sectional study | ✓  ICD-9 | -Aortic coarctation  -Hospitalized for tanscatheter endovascular  stenting of coarctation | ≥18 | No control population  Comparison according to hospital volume | 2000-2011 |
| Seckeler [31](#_ENREF_31) | University Health System  Consortium Clinical Database Resource Manager database | Cross-sectional study | ✓  ICD-9 | -Single ventricle i.e. tricuspid atresia, hypoplastic left heart syndrome, common ventricle  -Hospitalized for noncardiac conditions  -age groups | 18-40 | Non-CHD hospitalized patients (age-matched) | 2011-2014 |
| Lanz [44](#_ENREF_44) | The Québec CHD Database | Cohort study (with and without propensity score matching) and case-control study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -Hospitalized for stroke (ischemic or hemorrhagic)  -Severe/other CHD lesions | 18-64 | 1:40 matching to non-stroke controls (on calendar time and age) | 1998-2010 |
| Beausejour Ladouceur [35](#_ENREF_35) | The Québec CHD Database | Cross sectional study | ✓  algorithm using ICD-9 codes, specific CHD procedures, physician | -All CHD lesions  -Exposed to ≥1 low-dose ionizing radiation-emitting cardiac imaging  -Severe/other CHD lesions | All ages\* | No control population | 1990-2005 |
| Islam [50](#_ENREF_50) | Discharge Abstract Database of the Canadian Institute for Health Information | Cohort study | ✓  ICD-9 and ICD-10 | -All CHD lesions  -Hospitalized  -Simple/moderate/complex CHD | All ages\* | No control population | 2003-2012 |
| Videbæk [59](#_ENREF_59) | The Danish Public Registries (including Danish National Patient Registry) | Matched cohort study | ✓  ICD8 until 1993 then ICD-10 | -Simple CHD i.e. isolated ASD, patent ductus arteriosus, VSD with normal pulmonary vascular resistance, or mild pulmonary stenosis  -All patients diagnosed for simple CHD (not only hospitalized) | 0-15 at time of diagnosis | 1:10 matching to the general population (on sex and birth year) | 1963-2012 (from age 15) |
| Islam [49](#_ENREF_49) | Discharge Abstract Database of the Canadian Institute for Health Information | Cohort study | ✓  ICD-9 and ICD-10 | All CHD lesions  -Hospitalized  -Simple/moderate/complex CHD | All ages\* | No control population | 2003-2013 |

\*all ages included but specific conclusions for adults

N/A not available

ACHD, adult with congenital heart disease; ASD, atrial septal defect; AVSD, Atrioventricular Septal Defect; CHD, Congenital Heart Disease; ICD-x-CM, International Classification of Diseases xth revision Clinical Modification; ICD, implantable cardiac defibrillator; MI, myocardial infarction; OSHPD, Office of Statewide Health Planning and Development; PH, pulmonary hypertension; PM, Pace-maker; PFO, permanent foramen ovale; VSD, Ventricular Septal Defect

**Supplemental Table S3.** Study objectives and endpoints

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| First author | Resource utilization | Adverse events or post procedural complications | Temporal trends | Cost | Demography | Pattern of care | Specific clinical issues | Mortality | Transition or transfer | Population at risk | Comparison between 2 procedures | Detailed objectives |
| Marelli [51](#_ENREF_51) | No | No | ✓ | No | ✓ | No | No | No | No | No | No | To measure the observed prevalence, age, and proportions of adults relative to children with CHD in the general population from 1985 to 2000 |
| Gurvitz [13](#_ENREF_13) | No | No | No | No | No | ✓ | No | No | ✓ | No | No | To evaluate hospitalization patterns (e.g. admission source, access to care, primary insurance source, regionalization) of CHD patients surrounding the transition from adolescence to adulthood |
| Mackie [4](#_ENREF_4) | ✓ | No | No | No | No | No | No | No | No | No | No | To describe the use of general health care resources in ACHD and to examine the impact of CHD severity on resource utilization |
| Billett [52](#_ENREF_52) | No | No | ✓ | No | No | No | No | ✓ | No | No | No | To ascertain time trends in rates of hospital admission, operations, in-hospital case fatality and general mortality for CHD in England and Wales |
| Chan [53](#_ENREF_53) | No | No | No | No | ✓ | No | No | ✓ | No | ✓ | No | To examine the demographics of patients with Marfan syndrome admitted to Hong Kong hospitals from 1997 to 2006 |
| Karamlou [54](#_ENREF_54) | No | No | ✓ | No | No | ✓ | No | ✓ | No | No | ✓ | To determine nationwide trends in the use of percutaneous compared with surgical ASD closure and their respective outcomes over an 18-year period |
| Opotowsky [14](#_ENREF_14) | ✓ | ✓ | No | No | No | ✓ | No | No | No | No | No | To describe complications after percutaneous PFO/ASD closure focusing on the relationship between hospital annual procedural volume and the risk of adverse events |
| Opotowsky [5](#_ENREF_5) | ✓ | No | ✓ | ✓ | No | No | No | No | No | No | No | To define the epidemiology of hospitalizations for ACHD in the US |
| Patel [36](#_ENREF_36) | No | No | No | No | No | No | No | ✓ | No | ✓ | No | To analyze early and late survival and predictors of death after heart transplantation for ACHD |
| Bouchardy [64](#_ENREF_64) | No | No | No | No | No | No | ✓ | ✓ | No | No | No | -To determine the overall prevalence of atrial arrhythmias in ACHD in 2005  -To estimate age-related lifetime risk of developing atrial arrhythmias  -To compare adverse outcomes (mortality, morbidity, need for cardiac interventions) in individuals with and without atrial arrhythmias |
| Karamlou [38](#_ENREF_38) | No | No | ✓ | No | No | No | ✓ | ✓ | No | ✓ | No | To investigate outcomes and risk factors for mortality and retransplantation among ACHD compared with adult recipients |
| Karamlou [15](#_ENREF_15) | No | No | ✓ | No | No | ✓ | No | ✓ | No | No | No | To determine the ideal clinical environment (type of hospital, children’s specialty hospital versus general hospital, congenital heart surgeon or non-congenital heart surgeon) for ACHD patients that would reduce in-hospital mortality |
| Khairy [39](#_ENREF_39) | No | No | ✓ | No | No | No | No | ✓ | No | No | No | To characterize temporal trends in all-cause mortality in patients with CHD |
| Bernier [37](#_ENREF_37) | No | No | No | No | No | No | ✓ | ✓ | No | No | No | To compare the lifetime prevalence of atrial arrhythmias in patients with right- versus left-sided CHD and their effect on the prognosis |
| Ionescu [58](#_ENREF_58) | No | No | ✓ | No | No | No | ✓ | No | No | No | No | -To describe the changes in CHD surgical operations volume in children and adults over the past 18 years  -To investigate the relationship between changes in the cardiac surgical operations volumes and changes in the size and age-severity distribution of the CHD population |
| Gilboa [55](#_ENREF_55) | No | No | ✓ | No | No | No | No | ✓ | No | No | No | -To examine temporal trends in mortality from CHD from 1999 to 2006  -To explore differences in CHD mortality by race-ethnicity |
| Kim [17](#_ENREF_17) | No | No | No | No | No | ✓ | No | ✓ | No | No | No | -To characterize ACHD surgery admissions in free-standing pediatric hospitals  -To identify adjusted risk factors associated with inpatient mortality  after ACHD surgery  -To examine the extent to which adult versus total (pediatric and adult) congenital heart surgery volume is associated with adult in-hospital mortality |
| Rodriguez [18](#_ENREF_18) | ✓ | No | No | No | No | No | No | ✓ | No | No | No | To assess hospitalizations for septal defects in ACHD and risk factors associated with significant morbidity and mortality |
| Lowe [63](#_ENREF_63) | ✓ | No | No | No | No | No | ✓ | ✓ | No | No | No | To assess the impact of the diagnosis of pulmonary hypertension on mortality, morbidity, and health services utilization in an ACHD population |
| Afilalo [66](#_ENREF_66) | No | No | ✓ | No | ✓ | No | No | ✓ | No | ✓ | No | To measure the prevalence, disease burden, and determinants of mortality in geriatric ACHD |
| Kim [16](#_ENREF_16) | ✓ | No | ✓ | ✓ | No | ✓ | No | ✓ | No | No | No | -To examine the pattern and proportion of resources consumed by adults who undergo CHD surgery in free-standing pediatric hospitals  -To explore the association of high resource use with in-hospital death and length of stay during ACHD surgery admissions  -To identify risk factors for high resource use among ACHD surgery admissions in pediatric hospitals |
| Opotowsky [20](#_ENREF_20) | ✓ | No | No | No | No | No | ✓ | ✓ | No | No | No | To define the epidemiology of adverse cardiovascular events among women with CHD hospitalized for childbirth in the US |
| Roifman [65](#_ENREF_65) | No | No | No | No | No | No | ✓ | No | No | ✓ | No | -To describe the prevalence of CAD among adults with CoA  -To determine whether CoA is an independent predictor of CAD or premature CAD |
| Karamlou [19](#_ENREF_19) | No | No | ✓ | No | No | No | No | ✓ | No | No | No | To investigate changes in case mix over time, univentricular versus biventricular status, and the effect of univentricular anatomy on death after heart transplantation among ACHD recipients |
| Baraona [21](#_ENREF_21) | ✓ | No | ✓ | No | No | No | No | ✓ | No | ✓ | No | To describe the epidemiology of hospitalizations in adults with Down syndrome and CHD in the US |
| Kotowycz [40](#_ENREF_40) | ✓ | ✓ | ✓ | No | No | No | No | ✓ | No | ✓ | ✓ | To assess the comparative effectiveness and long-term safety of transcatheter versus surgical closure of secundum ASD in adults |
| Krieger [24](#_ENREF_24) | ✓ | No | ✓ | No | No | No | ✓ | No | No | ✓ | No | To determine whether hospitalized patients with a single ventricle diagnosis have higher rates of nonalcoholic cirrhosis than patients without CHD |
| Maxwell [62](#_ENREF_62) | ✓ | No | ✓ | No | No | No | No | ✓ | No | No | No | To examine perioperative outcomes (morbidity and mortality) among ACHD patients undergoing major noncardiac surgery |
| Collins [22](#_ENREF_22) | ✓ | No | ✓ | ✓ | No | No | No | No | No | ✓ | No | -To characterize trends in pediatric hospital utilization by adults with single ventricle  -To determine if the anatomic subtypes of single ventricle affect the distribution of comorbid medical conditions  -To determine the impact of the comorbid conditions on health care costs |
| Rodriguez [25](#_ENREF_25) | ✓ | No | No | No | No | No | ✓ | ✓ | No | No | No | To assess national prevalence, morbidities, and risk factors for mortality during hospitalizations among ACHD with heart failure |
| Gelow [23](#_ENREF_23) | No | No | ✓ | No | No | No | ✓ | No | No | No | No | To determine the relationship between ventricular assist devices implantation and successful transplantation among ACHD patients listed for heart transplants |
| Collins [26](#_ENREF_26) | ✓ | No | ✓ | ✓ | No | No | No | No | No | ✓ | No | -To characterize trends in pediatric hospital utilization by adults with single ventricle and cardiac arrhythmias  -To determine if the anatomic subtypes of single ventricle affect the distribution of cardiac arrhythmias  -To determine the impact of cardiac arrhythmias on comorbid conditions and health care costs |
| Mylotte [41](#_ENREF_41) | No | No | No | ✓ | No | No | No | No | No | No | No | To compare the long-term cost effectiveness of transcatheter and surgical closure of secundum ASD in adults |
| Mylotte [8](#_ENREF_8) | ✓ | No | ✓ | No | No | ✓ | No | ✓ | No | No | No | To examine the impact of specialized care on ACHD patient mortality |
| Nyboe [61](#_ENREF_61) | No | No | No | No | No | No | ✓ | ✓ | No | No | No | -To compare the risk of pneumonia in the general population with the risk of pneumonia in adult patients with unclosed ASD, ASD closed by surgery or with a transcatheter technique  -To examine pneumonia-related mortality of adult patients with ASD |
| Marelli [3](#_ENREF_3) | No | No | ✓ | No | ✓ | No | No | No | No | No | No | -To estimate the lifetime prevalence of CHD  -To compare the number of adults to the number of children with CHD in the Quebec population from 2000 to 2010  -To estimate the change in prevalence of severe CHD in adults compared with children |
| Maxwell [57](#_ENREF_57) | No | No | No | No | No | ✓ | No | No | No | No | No | -To determine the proportion of adults and children with CHD who undergo surgery in CHD centers  -To compare proximity to CHD centers among those who receive care at specialized centers and those who do not |
| Lin [6](#_ENREF_6) | No | No | No | No | No | No | ✓ | ✓ | No | No | No | To identify the long-term major adverse cardiovascular events in ACHD patients in Taiwan |
| Lu [56](#_ENREF_56) | ✓ | No | No | ✓ | No | ✓ | No | No | ✓ | No | No | To examine how hospitalization and costs change among CHD patients as they transition from adolescence (10-19 years) to young adulthood (20-29 years) |
| Bhatt [27](#_ENREF_27) | ✓ | No | No | ✓ | No | ✓ | No | ✓ | No | No | No | -To examine resource use during adult congenital heart surgical admissions in adult hospitals  -To determine the association of high resource use with mortality, and identify risk factors for high resource use |
| Hassan [43](#_ENREF_43) | ✓ | No | No | No | No | No | ✓ | ✓ | No | ✓ | No | To evaluate pregnancy and cardiovascular outcomes in pregnant women with Marfan Syndrome |
| Lee [45](#_ENREF_45) | No | No | No | No | No | No | ✓ | No | No | No | No | To explore the association of CHD with malignancies and examine the risk factors for the development of cancer after a diagnosis of CHD |
| Hayward [30](#_ENREF_30) | No | ✓ | No | No | No | ✓ | No | No | No | No | No | To compare pacemaker and ICD implantation complication rates between adults with and those without CHD |
| Wu [48](#_ENREF_48) | No | No | ✓ | No | No | No | ✓ | ✓ | No | ✓ | No | To investigate the long-term outcomes of tetralogy of Fallot patients and their current medical needs, particularly when focusing on arrhythmia events |
| Maxell [46](#_ENREF_46) | ✓ | ✓ | ✓ | ✓ | No | ✓ | No | ✓ | No | No | No | To determine whether ACHD undergoing catheter-based electrophysiology procedures have an increased risk for complications compared with adults without CHD |
| Nyboe [60](#_ENREF_60) | No | No | No | No | No | No | ✓ | ✓ | No | No | No | To estimate the risk of atrial fibrillation and stroke and the impact of closure in patients with ASD compared with a general population cohort |
| Singh [32](#_ENREF_32) | ✓ | No | ✓ | ✓ | No | ✓ | No | ✓ | No | No | No | To evaluate current trends in the utilization of ASD/PFO closure in adults and investigate the effect of annual hospital volume on in-hospital outcomes |
| Fernandes [29](#_ENREF_29) | No | No | ✓ | No | No | ✓ | No | No | No | No | No | -To determine the proportion of ACHD surgery performed at specialty ACHD centers  -To identify factors associated with ACHD surgery being performed outside of specialty centers |
| Thompson [34](#_ENREF_34) | ✓ | No | ✓ | No | ✓ | No | ✓ | ✓ | No | ✓ | No | To estimate nationwide trends in the prevalence of maternal CHD and determine whether women with CHD are more likely than women without maternal CHD to have medical and obstetric complications |
| Tabtabai [33](#_ENREF_33) | ✓ | No | ✓ | ✓ | No | ✓ | ✓ | ✓ | No | ✓ | No | To assess trends in the population rate of single ventricle admissions, reasons for hospitalization, rate of heart failure, and associated outcomes and resource utilization in adult hospitals in the US |
| Chen [42](#_ENREF_42) | No | ✓ | ✓ | No | No | No | No | ✓ | No | No | ✓ | To compare the long-term outcomes and the incidence of major cardiovascular complications after surgical and transcatheter ASD closure |
| Wu [47](#_ENREF_47) | No | No | No | No | No | No | ✓ | No | No | ✓ | No | To estimate the risk of hypertension and stroke among patients aged <60 years with simple CoA |
| Bhatt [28](#_ENREF_28) | ✓ | ✓ | No | ✓ | No | ✓ | No | No | No | No | No | To analyze the relation of hospital volumes to the outcomes of stenting in adults with CoA |
| Seckeler [31](#_ENREF_31) | ✓ | No | No | ✓ | No | No | No | ✓ | No | ✓ | No | To compare health care resource utilization of adults with single ventricle and adults without any CHD who were hospitalized for noncardiac diagnoses in the US |
| Lanz [44](#_ENREF_44) | No | No | No | No | No | No | ✓ | No | No | ✓ | No | -To estimate the incidence rate and cumulative risk of stroke in ACHD  -To compare the risk of stroke in ACHD with the general adult population  -To identify the strongest predictors of stroke in patients with ACHD |
| Beausejour Ladouceur [35](#_ENREF_35) | No | No | ✓ | No | No | No | No | No | No | No | No | To determine exposure to Low Dose Ionizing Radiation-related cardiac imaging and therapeutic procedures in children and adults with CHD |
| Islam [50](#_ENREF_50) | ✓ | No | ✓ | No | ✓ | No | No | No | No | No | No | -To determine temporal changes in the hospitalization rate among CHD patients in Canada  -To determine temporal changes in length of hospital stay, overall and among specific patient subgroups and to identify predictors of length of stay>14 days |
| Videbæk [59](#_ENREF_59) | No | No | No | No | No | No | No | ✓ | No | No | No | To examine mortality and cardiovascular morbidity in patients diagnosed with simple CHD from 1963 to 1973 and compare them with a general population cohort |
| Islam [49](#_ENREF_49) | ✓ | No | No | No | No | No | No | No | No | No | No | -To assess the readmission rate of patients with CHD in Canada between 2003 and 2013  -To identify risk factors for 1-month hospital readmission |

ACHD, adult with congenital heart disease; ASD, atrial septal defect; CAD: coronary artery disease; CHD, Congenital Heart Disease; CoA: Aortic coarctation; ICD, implantable cardiac defibrillator; PFO, permanent foramen ovale

**Supplemental Figure S1.** PRISMA flow chart of search, inclusion and exclusion screening, and accepted studies of the review

Records retrieved from electronic database searching

N=2,217

PubMed search (n=2,012)

Embase search (n=205)

Duplicates removed

n=29

Records screened on the basis of title and abstract

N=2,188

Records excluded

N=1,991

Records selected based on title and abstract

N=197

Full-text publications excluded

N=148

Full-text publications assessed for eligibility

N=207

Publications included in the review

N=59

Records identified after searching the reference lists of yielded publications

N=10

**Supplemental Figure S2.** Distribution of publications according to the geographical origin of the data source used

**Supplemental Results.** Detailed description of the most recently used administrative health databases

**The Quebec CHD Database (Canada)**

The first published article on ACHD using administrative health databases came from the Quebec CHD Database. In Quebec, Canada’s second largest province, a unique healthcare number is assigned to all individuals at birth that is used to track all diagnoses and health services rendered and systematically recorded until death. The Quebec CHD database was created by merging information on all patients with a CHD diagnosis from the province’s three administration databases: the physicians’ services and drug claims database (Régie de l’Assurance Maladie du Québec), the hospital discharges summary database (Med-Echo), and the Quebec Health Insurance Board and Death Registry. Thus, the Quebec CHD Database is CHD-specific and do not contain non-CHD population. Patients were identified with CHD if they had at least one diagnostic code for CHD and/or a CHD-specific surgical procedure. Diagnostic algorithms were developed to optimize extraction of valid CHD diagnoses, cross-referencing diagnoses and procedures from multiple sources and using provider codes to select diagnoses made by certain specialists only. Thus, the Quebec CHD Database captures demographics, vital statistics data, diagnoses coded with the International Classification of Diseases, 9th Revision (ICD-9) and 10th Revision (ICD-10; as of 2006) as well as procedure codes and in and outpatient health services used throughout a patient’s life in Quebec since 1983. As physician remuneration is based on these claims, there is a strong incentive to divulge all professional activities.

**Danish population-based registers for health research (Denmark)**

Thygesen et al. presented in a supplement of the *Scandinavian Journal of Public Health* the wide range of Danish registers and register-based researches.1 Using a unique personal identification number assigned to every inhabitant since 1968 (Civil Personal Registration, CPR number, which is ID number in Denmark), it is possible to link data from one or more registers or from other sources with register-based information at an individual level for decades. The Danish National Health Service provides tax-supported health care for all inhabitants, guarantees free access to general practitioners and hospitals, and refunds a variable proportion of the prescription medication costs. The Danish National Patient Registry was established in 1977, and 99.4% of all discharges from Danish medical hospitals are recorded there.2 Recorded information includes the CPR number, dates of hospital admission and discharge, all surgical or other therapeutic procedures performed, and up to 20 discharge diagnoses, coded according to the ICD-8 before 1994 and ICD-10 later. Data on vital status including date of birth, date of emigration, and date of death for all Danish residents since 1968 are available through linkage with the Danish Civil Registration System.3 Since 1995, it also contains information on outpatient contacts but outpatient diagnoses are not registered. Danish National Prescription Registry comprises all prescription drugs redeemed from Danish community pharmacies since 1994. It has been used in 2 of the selected articles to specify a diagnosis: prescription of antibiotic as an indicator of infections4 and prescription for anticoagulation and antiarrhythmic medicine as an indicator of atrial fibrillation.5

Denmark also constituted an original CHD register, *The Danish Register of Congenital Heart Disease*. CHD patients diagnosed between 1963 and 1974 were identified based on review of medical records in all Danish pediatric and medical departments by an experienced pediatric cardiologist, H. B. Laursen.6 Thereafter, this registry was implemented by data from the Danish National Patients Register through the CPR from the Danish Civil Registration System7 to constitute a comprehensive CHD database.

**The National Health Insurance Research Database (Taiwan)**

In Taiwan, the national cohort of CHD patients was retrieved from the National Health Insurance Research Database (NHIRD) released by the Taiwan National Health Research Institute. The NHIRD, which was established in 1995, enrolls up to 99% Taiwan’s population (about 23 million in 2012) and the insurance reimburses all clinical managements and procedures. The NHIRD also records all the medical data from inpatient care to outpatient clinics and all the basic data of the beneficiaries such as date of birth, dates of visits, sex, type of admission or outpatient clinic visit as well as the hospital’s characteristics, diagnosis and treatment codes, reimbursement fees, and survival status at discharge. Diagnostic information is based on the ICD-9, Clinical Modification (ICD-9-CM). To avoid the error from a tentative diagnosis, only those who received outpatient visits more than twice or admission under the CHD-specific diagnosis were considered as CHD patients.

**The Nationwide Inpatient Sample (United States)**

The NIS is managed under the Healthcare Cost and Utilization Project (HCUP) sponsored by the Agency for Healthcare Research and Quality (AHRQ). The NIS is the largest publicly available all-payer inpatient care database in the United States including data on approximately 7 to 8 million discharges per year from approximately 1,000 hospitals in now 48 states. The database is a stratified, cross-sectional sample that includes approximately 20% of all community (non-federal, short-term, general, and specialty) hospital discharges in the United States. Until 2012, the sampling protocol was such that when a hospital was chosen, all discharges from that hospital for the selected time period were included. The NIS contains admission data including patient demographics (age, sex, race), procedure codes and ICD-9-CM diagnoses including comorbidities, admission source, length of stay, discharge status (discharged to home, rehabilitation facility, nursing facility, or inpatient death), expected payment source, total billed hospital charges, estimated costs, and specific hospital characteristics. ICD-9-CM codes for CHD are used to identify the ACHD population. Data from the NIS are available from 1988 through 2013, which allows analysis of trends over time. To ensure representativity, the NIS was stratified by geographical region, hospital bed size, teaching status, urban versus rural location, and hospital ownership. Sampling weights provide national estimates so that cases in the NIS can be used to produce estimates of the entire national hospitalized population. The NIS does not follow patients after discharge or does not link multiple hospitalizations of the same patient. The unit of analysis is hospitalization.

Starting with database year 2012, the Nationwide Inpatient Sample was replaced with the National Inpatient Sample. The National Inpatient Sample uses a redesigned sampling method and contains a sample of all discharges rather than hospitals. The National Inpatient Sample hasn’t been used yet for ACHD purpose.

In fact, the NIS is based on the data collection efforts of participating States (HCUP Partners) that maintain statewide data systems. The state-level entities that create state-specific hospital discharge databases voluntarily share their files with AHRQ through a public-private partnership, and these files become part of HCUP. The California OSHPD is one of the HCUP Partners and its database was extensively used as such in several articles in this review.8-12 The California OSHPD provides data from 97% of non-federal hospitals in California.

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