

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

Developed in Collaboration With the American Academy of Pediatrics, Association of European Paediatric Cardiologists, Child Health Corporation of America, Congenital Cardiac Anesthesia Society, Congenital Heart Surgeons' Society, International Society for Nomenclature of Paediatric and Congenital Heart Disease, National Association of Children's Hospitals and Related Institutions,* and The Society of Thoracic Surgeons*

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Preamble

The American College of Cardiology (ACC) and the American Heart Association (AHA) support their members' goal to improve the care of patients with cardiovascular disease through professional education, research, and development of guidelines and standards and by fostering policies that support optimal patient outcomes. The ACC and AHA recognize the importance of the use of clinical data standards for patient management, assessment of outcomes, and conduct of research, and the importance of defining the processes and outcomes of clinical care, whether in randomized trials, observational studies, registries, or quality improvement initiatives.

Clinical data standards strive to define and standardize data relevant to clinical concepts, with the primary goal of facilitating uniform data collection by providing a platform of clinical terms with corresponding definitions and data elements. Broad agreement on a common vocabulary with reliable definitions used by all is vital to pool and/or compare data across clinical trials to promote interoperability with

electronic health records (EHRs) and to assess the applicability of research to clinical practice. The ultimate purpose of clinical data standards is to contribute to the infrastructure necessary to accomplish the ACC's mission of fostering optimal cardiovascular care and disease prevention and the AHA's mission of building healthier lives, free of cardiovascular diseases and stroke.

The specific goals of clinical data standards are:

1. To establish a consistent, interoperable, and universal clinical vocabulary as a foundation for both clinical care and clinical research, including clinical trials
2. To promote the ubiquitous use of EHRs and facilitate the exchange of data across systems through harmonized, standardized definitions of key data elements
3. To facilitate the further development of clinical registries, quality and performance improvement programs, outcomes evaluations, and clinical research, including the comparison of results within and across these initiatives

The key elements and definitions are intended to facilitate the consistent, accurate, and reproducible capture of clinical concepts; standardize the terminology used to describe cardiovascular diseases and procedures; create a data environment conducive to the assessment of patient management and outcomes for quality and performance improvement and clinical and translational research; and increase opportunities for sharing data across disparate data sources. The ACC/AHA Task Force on Clinical Data Standards (Task Force) selects cardiovascular conditions and procedures that will benefit from creation of a standard dataset. Subject matter experts are selected to examine/consider existing standards and develop a comprehensive, yet not exhaustive, standard dataset. When a data collection effort is undertaken, only a subset of the elements contained in a clinical data standards listing may be needed, or conversely, users may want to consider whether it may be necessary to collect some elements not listed. For example, in the setting of a randomized clinical trial of a new drug, additional information would likely be required regarding study procedures and drug therapies.

The ACC and AHA recognize that there are other national efforts to establish clinical data standards, and every attempt is made to harmonize newly published standards with existing standards. Writing committees are instructed to consider adopting or adapting existing nationally and internationally recognized data standards if the definitions and characteristics are useful and applicable to the set under development. In addition, the ACC and AHA are committed to continually expanding their portfolio of data standards and will create new standards and update existing standards as needed to maintain their currency and promote harmonization with other standards as health information technology and clinical practice evolve.

The Health Insurance Portability and Accountability Act privacy regulations, which went into effect in April 2003, have heightened all practitioners' awareness of our professional commitment to safeguard our patients' privacy. The Health Insurance Portability and Accountability Act privacy

regulations¹ specify which information elements are considered “protected health information.” These elements may not be disclosed to third parties (including registries and research studies) without the patient’s written permission. Protected health information may be included in databases used for healthcare operations under a data use agreement. Research studies using protected health information must be reviewed by an institutional review board or a privacy board.

We have included identifying information in all clinical data standards to facilitate uniform collection of these elements when appropriate. For example, a longitudinal clinic database may contain these elements because access is restricted to the patient’s caregivers. Conversely, registries may not contain protected health information unless each patient grants specific permission. These fields are indicated as protected health information in the data standards.

In clinical care, caregivers communicate with each other through a common vocabulary. In an analogous fashion, the integrity of clinical research depends on firm adherence to prespecified procedures for patient enrollment and follow-up; these procedures are guaranteed through careful attention to definitions enumerated in the study protocol, case report forms, and clinical event committee charters. When data elements and definitions are standardized across studies, comparison, pooled analysis, and meta-analysis are enabled, thus deepening our understanding of individual studies.

The recent development of quality performance measurement initiatives, particularly those for which the comparison of providers is an implicit or explicit aim, has further raised awareness about the importance of data standards. Indeed, a wide audience, including nonmedical professionals such as payers, regulators, and consumers, may draw conclusions about care and outcomes. To understand and compare care patterns and outcomes, the data elements that characterize them must be clearly defined, consistently used, and properly interpreted.

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1. Introduction

This document creates the first extensive data dictionary, with data elements and definitions, specifically for use in the outpatient—or ambulatory—domain of pediatric and congenital cardiology. It is 1 of 16 domains of mutual interest identified in pediatric cardiology and congenital cardiac disease necessary to build a framework that enables the goal of interoperable data exchange to occur. The other domains include: congenital heart defect nomenclature, adult congenital heart disease, critical care, cardiomyopathy, cardiac transplantation, pulmonary hypertension, congenital cardiac surgery, echocardiography, diagnostic and interventional catheterization, exercise stress testing and physiology, electrophysiology, cardiac magnetic resonance imaging, fetal physiology, perfusion, and cardiac anesthesia. The reason that this domain was chosen first was that there are other nascent data dictionaries that capture, or at least overlap with, other domains in our field. However, outpatient cardiology previously has had limited, if any, attention to its data structure, despite the fact that patients spend the vast majority of their life in this area of care.

The need for a master set of data elements and definitions is of topical interest for the pediatric and congenital heart disease clinician where data sharing is critical to identify best practices, develop evidence-based guidelines, and determine statistical significance in our patient populations. There is a wide range of disease processes across a relatively small set of patients in pediatric and congenital heart disease; this fact is in contrast to adult cardiac disease where there is a large population of patients who experience a more homogenous set of disease processes. In a year, a cardiac center in adult medicine is likely to treat thousands of patients who present with one of only a few disease processes. Adult cardiac medicine has successfully built clinical decision support tools, established data registries, and achieved data pooling because of the large distribution of patients across these disease processes, and because there are common data standards. There are limited large-scale observational data that can be used for evidence-based decisions and for cardiac research in outpatients with pediatric and congenital heart disease.² Getting to outcome measures in pediatric cardiology and cardiac surgery is challenging; attaining evidence-based decision-making has been challenging, if not even more challenging, although groups such as the Pediatric Heart Network and the National Pediatric Cardiology Quality Improvement Collaborative³ have been breaking down this barrier. There are many obstacles within standardizing and sharing data in pediatric cardiac surgery—including variation in surgical techniques and skills, variations in perioperative care, variation in underlying anatomy, adequate risk stratification, nonavailability of natural history of unoperated patients in the present era, and insufficient patient numbers—from which to draw statistically significant conclusions.⁴

Pediatric and congenital cardiology and cardiovascular surgery comprise a wholly separate set of diagnoses and procedures compared with those of adult cardiology. Pediatric and congenital cardiac care begins at fetal cardiology through congenital as well as acquired pediatric cardiac disease, leads up to and through adult congenital cardiac disease states, and also incorporates some aspects of adult cardiac care. Several efforts to list congenital cardiac disease, surgical interventions, and complications have been accomplished over the past 15 years including efforts from the Association for European Paediatric and Congenital Cardiology, The Society of Thoracic Surgeons, and the European Association for Cardio-Thoracic Surgery. The combination of the data elements published by the Association for European Paediatric and Congenital Cardiology with the set of data elements created by The Society of Thoracic Surgeons and European Association for Cardio-Thoracic Surgery⁵ to give the IPCCC (International Paediatric and Congenital Cardiac Code) was a historic effort in delineating and mapping the various nomenclatures used in the field. Common nomenclature serves as an important linkage across clinical data registries and for EHR data warehousing. Specifically, a number of terms used in this data dictionary harmonize with the living document that is the IPCCC. The IPCCC has not determined the details of all of the terms and definitions associated with the ambulatory environment. Thus, further harmonization will be important as this work progresses.

At this juncture, evidence-based guidelines for the inpatient and outpatient care of children with congenital heart disease are generally lacking, and pediatric cardiologists are often “on their own” when trying to deliver the best quality of care to these children. Compounding this problem, there are often insufficient patients at any one heart center to accumulate sufficient evidence to define optimal patient care. Clinical outcome measures to determine the effect of inpatient and outpatient care are evolving slowly, and there is no universal standardized clinical record to monitor a patient’s course, long-term outcomes, and comorbidities or quality-of-life indicators. Collaborative multi-institutional efforts are required to improve the quality of care for children with congenital heart disease; several have already begun, including the IMPACT (Improving Pediatric and Adult Congenital Treatments) registry, the Pediatric Heart Network and the National Pediatric Cardiology Quality Improvement Collaborative. Clinical data registries, which use data for comparative benchmarking, translational research, and quality improvement, have provided a useful model to improve care and to measure clinical outcomes. Many of these societal and multi-institutional database registries exist in the specialty fields of pediatric and congenital heart disease. Much of our work in defining the minimum data set for the pediatric and congenital heart disease patient will be through “harmonization” and identification of gaps and overlaps in these already existing registries. The multiple societal registries and multi-institutional clinical data registries will provide much of the foundation elements to the data dictionary as needed for the pediatric and congenital heart disease patient. The Multi-Societal Database Committee for Pediatric and Congenital Heart Disease began some of this work in developing strategies to link registries and databases. This committee was established in 2005 with the goal of providing the infrastructure, spanning geographic and subspecialty boundaries, and creating collaboration between healthcare professional interested in the analysis of outcomes of treatments provided to patients with congenital cardiac disease. Through a supplemental document published in *Cardiology in the Young*⁵ and a series of annual meetings, this committee offers definitions as standards across the multiple registries in pediatric and congenital heart disease. There are >36 organizations and professional societies that are invited and participate in these meetings and activities. Many of these organizations and societies provide these proceedings or meeting agenda topics to their respective clinical boards. As a result, many of the clinical registries in pediatric and congenital heart disease share clinical nomenclature for disease classification and procedural coding.

We use the term “EHR” as not only referring to the generic concept of such computer-based systems, but includes the idea that a patient’s medical information and discrete data capture may be stored in multiple systems, with clinical data standards enabling the appearance of a single repository. One of the greatest inefficiencies of the current approach to measuring clinical quality indicators and clinical and translational research is the absence of a unifying infrastructure with streamlined, one-time data collection, common data terms, and cooperative use of data shared

among institutions and researchers. Clinical quality outcomes assessment and research processes typically occur as independent, parallel endeavors. For example, clinical evaluation findings and management decisions, with accompanying test results, can be documented in a clinic note, dictated into a letter for communication with others, coded for reimbursement, keyed into multiple web-based systems for quality reporting, regulatory activities, and clinical trials, and later be extracted from patient records to support additional clinical or research needs. If uniform data standards and terms supported by an EHR and across all these disparate systems were in place, the data could be captured once in the clinical workflow and be made available to all stakeholders. The current writing committee understands that the entry of information into the EHR is performed by numerous medical personnel, many of whom are not trained in the skills of accurately and consistently entering data in a structured fashion. This data entry is a fundamental source of data error within the EHR. Nevertheless, the hope is to leverage this data by creating structured elements and definitions that can be incorporated into the EHR, and thus used in the future in a routine manner.

Taking a holistic view of the terminologies used in the care of cardiac diseases, we look to the “ACCF/AHA 2011 Key Data Elements and Definitions of a Base Cardiovascular Vocabulary for Electronic Health Records”⁶ as our guide in thinking about how our field approaches this requirement. However, there is need to create a separate data set for pediatric and congenital disease patients. Children have unique developmental needs and their parent-caregivers have informational needs that are different from those of adults. Pharmacodynamic and metabolic factors make processes in pediatric patients different than in adults. During early childhood, a child is more likely to have multiple visits to the physician’s office, and children see multiple specialists throughout childhood. Thus, there are indeed many characteristics of pediatric care that differ from adult care. In addition to the adult and pediatric differences in medical care, there is also difference both in respective EHR design and in respective data collection points. And, these characteristics often need to be captured differently in EHR systems so that pediatricians and specialty providers benefit from the automation of clinical and developmental child health information.

We therefore suggest the need to compile through the EHR the collective-comparative needs of the many clinical, medical, and surgical domains in the care of pediatric and congenital heart disease patients. Our approach takes us from cardiology clinic to cardiac diagnostic imaging to interventional to cardiac critical care to cardiac care programs. Within each of these domains, we present the cohort perspective and/or clinical prevalence, the presence of current data registry and/or “shareability” of clinical data, and outline of future directions. We see this plan as a first step toward achieving EHR data exchange for the continuity of clinical care of the pediatric and congenital heart disease patient. As for future steps, we see the need for aligning the ACC and AHA pediatric data set to the adult data set and for aligning the ACC and AHA pediatric data set to US

Meaningful Use data standards. To do so, immediate next steps for the Task Force will involve further mapping of existing clinical data registries and clinical domain needs to better understand issues around common data standards, overlaps, and gaps in data content.

2. Methodology

2.1. Writing Committee Composition

The Task Force selected a writing committee chair and facilitated the selection of members for the writing committee. The writing committee consisted of 31 individuals who are experts in cardiovascular medicine, HER technologies, and medical informatics, and included representation from pediatric and congenital cardiovascular medicine and surgery.

2.2. Relationships With Industry and Other Entities

The Task Force makes every effort to avoid actual or potential conflicts of interest that might arise as a result of an outside relationship or a personal, professional, or business interest of any member of the writing committee. Specifically, all members of the writing committee are required to complete and submit a disclosure form showing all such relationships that could be perceived as real or potential conflicts of interest. These statements are reviewed by the Task Force and updated when changes occur. Authors' and peer reviewers' relationships with industry and other entities pertinent to this data standards document are disclosed in Appendixes 1 and 2, respectively. In addition, for complete transparency, the disclosure information of each writing committee member—including relationships not pertinent to this document—is available as an [online supplement](#). The work of the writing committee was supported exclusively by the ACC and AHA without commercial support. Writing committee members volunteered their time for this effort. Meetings of the writing committee were confidential and attended only by committee members and staff.

2.3. Development of Terminology Concepts

The terminology for this document has been derived from 2 primary sources. The first was a set of data elements created by the chair of this writing committee for use specifically in an outpatient clinical practice that could be scalable for use. The second comes from the International Society for Nomenclature of Paediatric and Congenital Heart Disease that initially created a set of data elements to make the IPCCC more complete. However, it had not specifically included definitions. These 2 source documents were then harmonized and divided into smaller sections, consistent with the typical method of documentation within the medical record. These smaller sections included the history of the present illness, risk factors, the past medical history, the physical examination, and common cardiac diagnoses. Our subject matter experts then reviewed and refined these data elements and definitions to derive a data dictionary that would be complete for the majority of patients seen in the outpatient setting.

2.4. Consensus Development

The Task Force established the writing committee according to the processes described in the Task Force's methodology statement.⁷ The responsibility of the writing committee was to review and refine the list of the candidate terms identified for ambulatory EHR for pediatric and congenital cardiology, and to harmonize the attributes and other informatics formalisms required to attain interoperability of the terms. The writing committee's work was accomplished through series of teleconferences and extensive e-mail correspondences. The vetted set of terminology resulted in the tabular data elements and definitions in Appendixes 3-7.⁸⁻³⁷

2.5. Relation to Other Standards

The writing committee reviewed the "ACCF/AHA 2011 Key Data Elements and Definitions of a Base Cardiovascular Vocabulary for Electronic Health Records"⁶ along with available published ACC/AHA clinical data standards. Key sources such as the National Cancer Institute Enterprise Vocabulary Services,³⁸ the Logical Observation Identifiers Names and Codes (LOINC),³⁹ and the Clinical Data Interchange Standards Consortium (CDISC)⁴⁰ were also reviewed. Most existing published definitions were adopted, and a few were adjusted to eliminate verbiage and improve definitions. New definitions were also proposed by the writing committee for terminology that needed to be defined. Through this consensus work, the writing committee anticipates that this vocabulary set will facilitate uniform adoption of these terms by the various clinical, research, and EHR communities.

2.6. Peer Review and Public Review

This document—"2017 AHA/ACC Key Data Elements and Definitions for Ambulatory Electronic Health Records in Pediatric and Congenital Cardiology"—was reviewed by official reviewers nominated by the ACC and AHA. To increase its applicability further, the document was posted on the ACC website for a 30-day public comment period from July 22, 2016, to August 22, 2016. This document was approved for publication by the ACC Board of Trustees on May 25, 2017, by the AHA Science Advisory and Coordinating Committee on June 7, 2017, and by the AHA Executive Committee on June 30, 2017. The writing committee anticipates that these data standards will require review and updating in the same manner as other published clinical practice guidelines, performance measures, and appropriate use criteria. The writing committee will therefore review the set of data elements periodically, beginning with the first anniversary of publication of the standards, to ascertain whether modifications should be considered.

3. Data Elements and Definitions

The writing committee identified pediatric and congenital terms for EHRs. This document outlines these terms in Appendixes 3-7:

1. History of Present Illness
2. Risk Factors
3. Past Medical History

4. Physical Examination
5. Common Cardiac Diagnoses

3.1. History of Present Illness

The history of the present illness is the portion of the clinical evaluation that brings the patient into the physician's office for assessment. It can be an initial visit or for follow-up after either observation or intervention. The content and degree of documentation in this section is what drives the remainder of the examination as well as the assessment and the decision-making process, and thus heavily influences subsequent reimbursement. Almost all medical and surgical specialties have a set of typical or frequently seen diagnoses. This section helps to organize historical factors required to correctly assess these diagnoses.

3.2. Risk Factors

The concept of risk factors includes those issues that may exist in the patient, arise in the patient, or be conferred by family history that increase the risk of further cardiac disease or complications associated with the heart.

3.3. Past Medical History

Information gathered in the past medical history section has an important part in the evaluation of the patient as it gives the background of medical and surgical conditions against which the present illness exists. A patient with a negative past medical history may be evaluated differently from that of a patient who presents in the context of multiple complex set of medical and/or surgical problems. Ensuring appropriate delineation of these problems is vital.

3.4. Physical Examination

The physical examination in cardiology can be one of the most diagnostic patient evaluations, giving information that can lead directly to a diagnosis, or at least to a relatively narrow differential diagnosis. Similarly, the combination of descriptors used to document the examination can communicate a clear picture of the cardiac assessment to another provider.

3.5. Common Cardiac Diagnoses

As mentioned previously, these "typically seen" diagnoses are specific to the practice of pediatric cardiology, specifically in the outpatient setting. These are in addition to the large variety of congenital cardiac defects, arrhythmias, and other pathologic processes that will be further delineated and defined in subsequent documents.

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KEY WORDS: AHA Scientific Statements ■ congenital heart disease ■ electronic health records ■ pediatrics

Appendix 1. Author Relationships With Industry and Other Entities (Relevant)—2017 AHA/ACC Key Data Elements and Definitions for Ambulatory Electronic Health Records in Pediatric and Congenital Cardiology

Name	Employment	Consultant	Speaker	Ownership/ Partnership/ Principal	Research	Institutional, Organizational, or Other Financial Benefit	Expert Witness
Jeffrey R. Boris, Chair	Children's Hospital of Philadelphia— Clinical Professor of Pediatrics, Division of Cardiology	None	None	None	None	None	None
Marie J. Béland	Montreal Children's Hospital	None	None	None	None	None	None
Lisa J. Bergensen	Boston Children's Hospital—Associate in Cardiology	None	None	None	None	None	None
Steven D. Colan	Boston Children's Hospital—Director of Clinical Research, Cardiology	None	None	None	None	None	None
Joanna Dangel	Medical University of Warsaw—Professor of Pediatric Cardiology	None	None	None	None	None	None
Curtis J. Daniels	Nationwide Children's—Director Adolescent and Adult Congenital Heart Disease	None	None	None	None	None	None
Christopher Davis	Rady Children's Hospital San Diego —Director, Cardiopulmonary Exercise Laboratory	None	None	None	None	None	None
Allen D. Everett	Johns Hopkins All Children's Hospital— Director of the Pediatric Proteome Center	None	None	None	None	None	None
Rodney Franklin	Royal Brompton Hospital—Consultant Paediatric Cardiologist	None	None	None	None	None	None
J. William Gaynor	Children's Hospital of Philadelphia— Director, Fetal Neuroprotection and Neuroplasticity Program	None	None	None	None	None	None
Darryl T. Gray	Agency for Healthcare Research and Quality —Medical Officer	None	None	None	None	None	None
Jennifer C. Hirsch- Romano	University of Michigan—Associate Director, Pediatric Cardiothoracic Intensive Care Unit	None	None	None	None	None	None
Jeffrey P. Jacobs	Johns Hopkins All Children's Hospital— Chief, Division of Cardiovascular Surgery	None	None	None	None	None	None
Marshall Jacobs	Johns Hopkins Cardiac Surgery—Director, Pediatric Cardiac Surgery Outcomes Research	None	None	None	None	None	None
Howard Jeffries	Seattle Children's Hospital—Medical Director, Clinical Effectiveness	None	None	None	None	None	None
Otto Nils Krogmann	Klinik Für Kinderkardiologie	None	None	None	None	None	None
Edwin A. Lomotan	Agency for Healthcare Research and Quality—Medical Officer	None	None	None	None	None	None
Leo Lopez	Nicklaus Children's Hospital—Medical Director, Noninvasive Cardiac Imaging	None	None	None	None	None	None
Ariane Marelli	McGill University Health Centre—Associate Professor of Medicine	None	None	None	None	None	None
Gerard R. Martin	Children's National Health System— Medical Director of Global Health	None	None	None	None	None	None
G. Paul Matherne	University of Virginia Children's Hospital— Associate Chief Medical Officer	None	None	None	None	None	None
Constantine Mavroudis	Johns Hopkins Children's Heart Surgery— Site Director	None	None	None	None	None	None

(Continued)

Appendix 1. Continued

Name	Employment	Consultant	Speaker	Ownership/ Partnership/ Principal	Research	Institutional, Organizational, or Other Financial Benefit	Expert Witness
Ken McCardle	Mount Sinai Health System—Senior Director, Clinical Operations	None	None	None	None	None	None
Gail D. Pearson	National Heart, Lung, and Blood Institute—Director, Adult and Pediatric Cardiac Research Program	None	None	None	None	None	None
Geoffrey Rosenthal	University of Maryland—Director, Children’s Heart Program	None	None	None	None	None	None
John S. Scott	Office of the Assistant Secretary of Defense, Health Affairs—Program Director, Clinical Informatics Policy	None	None	None	None	None	None
Gerald A. Serwer	C.S. Mott Children’s Hospital—Professor, Pediatrics	None	None	None	None	None	None
Stephen S. Seslar	Seattle Children’s Hospital—Associate Professor, Pediatric Cardiology	None	None	None	None	None	None
Robert Shaddy	Chief Professor -Children’s Hospital of Philadelphia	None	None	None	None	None	None
Timothy Slesnick	Emory University School of Medicine—Assistant Professor of Pediatrics	None	None	None	None	None	None
David F. Vener	Texas Children’s Hospital—Associate Professor, Pediatrics and Anesthesiology	None	None	None	None	None	None
Henry L. Walters III	Children’s Hospital of Michigan—Chief, Cardiovascular Surgery	None	None	None	None	None	None
Paul M. Weinberg	Children’s Hospital of Philadelphia—Director, Cardiac Registry	None	None	None	None	None	None

This table represents the relationships of committee members with industry and other entities that were determined to be relevant to this document. These relationships were reviewed and updated in conjunction with all meetings and/or conference calls of the writing committee during the document development process. The table does not necessarily reflect relationships with industry at the time of publication. A person is deemed to have a significant interest in a business if the interest represents ownership of $\geq 5\%$ of the voting stock or share of the business entity, or ownership of $\geq \$5000$ of the fair market value of the business entity; or if funds received by the person from the business entity exceed 5% of the person’s gross income for the previous year. Relationships that exist with no financial benefit are also included for the purpose of transparency. Relationships in this table are modest unless otherwise noted. Please refer to <http://www.acc.org/guidelines/about-guidelines-and-clinical-documents/relationships-with-industry-policy> for definitions of disclosure categories or additional information about the ACC Disclosure Policy for Writing Committees.

ACC indicates American College of Cardiology; and AHA, American Heart Association.

Appendix 2. Reviewer Relationships With Industry and Other Entities—2017 AHA/ACC Key Data Elements and Definitions for Ambulatory Electronic Health Records in Pediatric and Congenital Cardiology

Name	Representation	Employment	Consultant	Speaker	Ownership/ Partnership/ Principal	Research	Institutional, Organizational, or Other Financial Benefit	Expert Witness
Geetha Raghuvver	ACC Board of Governors	Professor of Pediatrics— University of Missouri – Kansas City School of Medicine	None	None	None	None	None	None
David Kao	AHA Official Reviewer	Assistant Professor of Medicine— University of Colorado, Division of Cardiology	None	None	None	None	None	None
Michael A. Kutcher	Task Force Lead Reviewer	Professor of Cardiology— Wake Forest Baptist Health	None	None	None	None	None	None
Robert H. Beekman	Content Reviewer	Professor of Pediatric Cardiology— Children’s Hospital Medical Center of Cincinnati Ohio	None	None	None	None	None	None
Michele Grenier	Content Reviewer	Professor of Pediatrics—University of Mississippi Medical Center	None	None	None	None	None	None
Michael Nihil	Content Reviewer	Pediatric Cardiology— Baylor St. Luke’s Medical Center	None	None	None	None	None	None

This table represents the relationships of reviewers with industry and other entities that were disclosed at the time of peer review, including those not deemed to be relevant to this document. The table does not necessarily reflect relationships with industry at the time of publication. A person is deemed to have a significant interest in a business if the interest represents ownership of $\geq 5\%$ of the voting stock or share of the business entity, or ownership of $\geq \$5000$ of the fair market value of the business entity; or if funds received by the person from the business entity exceed 5% of the person’s gross income for the previous year. Relationships that exist with no financial benefit are also included for the purpose of transparency. Relationships in this table are modest unless otherwise noted. Names are listed in alphabetical order within each category of review. Please refer to <http://www.acc.org/guidelines/about-guidelines-and-clinical-documents/relationships-with-industry-policy> for definitions of disclosure categories or additional information about the ACC/AHA Disclosure Policy for Writing Committees.

ACC indicates American College of Cardiology; and AHA, American Heart Association.

Appendix 3. History of Present Illness

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
Chief Complaint							
Chief Complaint	The primary reason for a patient visit to a healthcare provider.		<ul style="list-style-type: none"> • Murmur • Palpitations • Chest pain • Dizziness • Syncope • Cyanosis • Screening for cardiac condition • Dyspnea • Others 			NCI Thesaurus ¹⁰	
			Murmur	An auscultated finding describing a series of audible vibrations of varying intensity (loudness), frequency (pitch), quality, configuration, and duration created by turbulent blood flow in the heart or surrounding vessels.			
			Palpitations	An unpleasant sensation of irregular and/or forceful beating of the heart.		NCI Thesaurus ¹⁰	NCI Code: C37999
			Chest pain	Discomfort felt in the upper abdomen, thorax, neck, or shoulders.			
			Dizziness	A sensation of lightheadedness, unsteadiness, turning, spinning, or rocking.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C37943
			Syncope	Sudden loss of consciousness with loss of postural tone, not related to anesthesia with spontaneous recovery as reported by patient or observer. Patient may experience syncope when supine.		ACC/AHA/HRS 2006 Key Data Elements and Definitions for Electrophysiological Studies and Procedures ¹²	
			Cyanosis	A bluish or purplish discoloration of the skin and mucous membranes resulting from a reduced concentration of oxygenated hemoglobin in the blood.		NCI Thesaurus ¹⁰	
			Screening for cardiac condition	Evaluation of relevant coexisting conditions (eg, T21, XO, Marfan, cleft palate, family history).			
			Other				

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
Chief Complaint – Timing							
Chief Complaint – Onset	Time interval from onset/recognition of “chief complaint” to present		Integer field Units	Number corresponding to time since onset. Appropriate time units for reported period, including days, weeks, months, or years.			
Chief Complaint – Periodicity	Recurrence at regular intervals of time of the chief complaint.		Intermittent Continuous	Periodically stopping and starting. Continuously present.		NCI Thesaurus ¹⁰	NCI Code: C71325
Chief Complaint – Frequency	The number of occurrences of a periodic process in a unit of time.		Multiple times/day Daily Weekly Monthly Other	More than once per day. Occurs on average once per day. Occurs once to several times per week. Occurs once to several times per month.			
Chief Complaint – Time of Day	The time of day the chief complaint typically occurs.		Morning Midday	The first part or period of the day, extending from dawn, or from midnight, to noon. The middle of the day; noon or the time centering around noon.			

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
Chief Complaint – Duration							
Chief Complaint – Duration	The length of time the chief complaint occurs.		Afternoon Evening Night Unknown	The time from noon until evening; pertaining to the latter part of the day. The latter part of the day and early part of the night; the period from sunset to bedtime. The period of darkness between sunset and sunrise.			
Chief Complaint – Severity							
Severity	The intensity of the chief complaint as perceived by the patient.		Integer field Units	Number corresponding to the duration. Appropriate time units for reported duration.			
			Integer 0–10	Verbal 0–10 Scale as appropriate patient's developmental stage.			
			Integer 0–5	Wong-Baker FACES Scale: 5-point visual analog scale as appropriate for patient's developmental stage.		Adapted from Wong DL, Baker CM. Pain in children: comparison of assessment scales. <i>Pediatr Nurs.</i> 1988;14:9–17 ³³	
			Integer 0–10	Infant Behavioral FLACC Scale: 0-10-point scale based in caregiver's observation of infant's behavior.		Adapted from Merkel SI, Voepel-Lewis T, Shayevitz JR, et al. The FLACC: a behavioral scale for scoring postoperative pain in young children. <i>Pediatr Nurs.</i> 1997;23:293–7 ²²	
Chief Complaint – Context							
Intercurrent Illness Present	Presence of other illnesses at the time the chief complaint started.		<ul style="list-style-type: none"> • Yes • No • Unknown 				
			Yes	The patient was unwell at the time the chief complaint was manifested.			

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
Prior Evaluation	In clinical medicine, assessment of the patient for the purposes of forming a diagnosis and plan of treatment, before the current chief complaint.		No	The patient was in her/his usual state of health when the chief complaint was manifested.			
			Unknown	Whether the patient experience an intercurrent illness at the time the chief complaint became manifest is unknown.			
			<ul style="list-style-type: none"> • Yes • No • Unknown 				
			Yes	The patient has undergone previous subspecialty evaluation for the same chief complaint.			
			No	The patient has not undergone previous subspecialty evaluation for the same chief complaint.			
			Unknown	It is unknown if the patient has undergone previous subspecialty evaluation for the same chief complaint.			
Prior Evaluation: Location	Location of the institution where chief complaint was previously evaluated.		Text field				This term may facilitate obtaining old records regarding this chief complaint.
Prior Evaluation: Date	Date of assessment of the patient for the purposes of forming a diagnosis and plan of treatment, before the current chief complaint.		Date/time			Adapted from Jonas WB. Mosby's Dictionary of Complementary and Alternative Medicine. St. Louis, MO: Mosby/Elsevier; 2005 ¹⁷	
Prior Evaluation: Tests Performed	Tests performed as part of the previous evaluation of chief complaint.						

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
			ECG	The record produced by the variations in electrical potential caused by electrical activity of the heart muscle and detected at the body surface, as a method for studying the action of the heart muscle.			
			Echocardiogram	The recording of the position and motion of the heart walls or internal structures of the heart by the echo obtained from beams of the ultrasonic waves directed through the chest wall.			
			Exercise stress test	A graded test to measure an individual's heart rate and oxygen intake while undergoing strenuous physical exercise, as on a treadmill.			
			Cardiac MRI	A noninvasive medical imaging technology using magnetic field and radio waves to evaluate the heart's anatomy and function for detection and monitoring of cardiac diseases.			
			Cardiac CT	A noninvasive medical imaging technology that uses x-ray procedure with the aid of computer to generate cross-sectional images of the heart.			
			Cardiac catheterization	Passage of a small catheter through a vein or artery in an arm or leg or the neck and into the heart, permitting the securing of blood samples, determination of intracardiac pressure, and detection of cardiac anomalies.			
			EP study/EP test	An invasive procedure that tests the electrical conduction system of the heart to assess the electrical activity and conduction pathways of the heart.		Thomas KE, Zimetbaum PJ. Electrophysiology study: indications and interpretations. In: Van G-X, Kowey PR, eds. Management of Cardiac Arrhythmias. 2nd ed. New York, NY: Humana Press (Springer Science+Business Media, LLC); 2011:123-40 ³¹	
Prior Evaluation: Diagnosis	Diagnosis given based on the previous evaluation of the chief complaint.						
Prior Evaluation: Previous Therapies	Treatment recommendations from previous evaluation of the chief complaint.						

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
			Medications	A drug or substance used to treat a medical condition.			
			Interventional catheterization	The performance of a cardiac catheterization with the intent of making a modification to the structures of the heart or surrounding vessels.			
			Catheter ablation/radiofrequency ablation/cryoablation	Catheter ablation is an invasive procedure used to remove or terminate a faulty electrical pathway from sections of the hearts of those who are prone to developing cardiac arrhythmias such as atrial fibrillation, atrial flutter, SVT and Wolff-Parkinson-White syndrome.			
			Cardiac surgery	The surgical treatment of diseases affecting the heart and blood vessels inside the thorax.			
Dietary: Routine Caffeine Intake	The quantities of caffeine, a central nervous system stimulant, found in coffee, tea and other foods and beverages, taken in and utilized by the body.		<ul style="list-style-type: none"> • Yes • No • Unknown 				
			Yes	Intake of caffeine routinely occurring as frequently as at least every other day.			
			No	No routine caffeine, or infrequent caffeine, intake.			
Dietary: Caloric Intake	Caloric intake based on age, BSA and comorbid conditions.		Unknown				
			<ul style="list-style-type: none"> • Adequate • Inadequate • Excessive • Unknown 				
			Adequate caloric intake	Sufficient caloric intake per day.			
			Inadequate caloric intake	Deficient caloric intake per day.			
			Excessive caloric intake	Caloric intake is more than what is required per day.			
			Unknown				

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
Dietary: Fluid Intake	The quantities of liquid taken in and used by the body.		<ul style="list-style-type: none"> • Adequate • Inadequate • Unknown 	Qualitative state of being sufficient for a specific purpose.			
			Adequate	Qualitative state of being sufficient for a specific purpose.			
			Inadequate	Qualitative state of not being sufficient for a specific purpose.			
			Unknown				
Dietary: Salt Intake	The quantities of sodium chloride (or common salt) taken in and used by the body.		<ul style="list-style-type: none"> • Adequate • Inadequate • Excessive • Unknown 				
			Adequate	Qualitative state of being sufficient for a specific purpose.			
			Inadequate	Qualitative state of not being sufficient for a specific purpose.			
			Excessive	Qualitative state of being too much for a specific purpose.			
			Unknown				
History of Trauma	Chief complaint is caused by traumatic event.		<ul style="list-style-type: none"> • Yes • No • Unknown 				
			Yes				
			No				
			Unknown				
Witnessed	Chief complaint witnessed or seen by bystander.		<ul style="list-style-type: none"> • Yes • No • Unknown 				
			Yes				
			No				
			Unknown				

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
Chief Complaint – Associated Signs and Symptoms							
Associated Symptoms	Symptoms and signs present with the chief complaint.		<ul style="list-style-type: none"> • Bowel incontinence • Bladder incontinence • Carpal spasm • Chest pain • Cough • Cyanosis • Diaphoresis • Dizziness • Dyspnea • Fatigue with feeding • Faceplant • Headache • Hyperventilation • Lethargy • Loss of consciousness • Nausea • Numbness/tingling • Pallor • Palpitation • Postictal confusion • Rash • Seizure activity • Sensation of heat or cold • Sleep disturbance • Syncope • Tongue biting • None 				For chief complaint of syncope, need to be able to specify prodromal, during or following syncopal event as a modifier of this term.

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
Bowel incontinence	Inability to control the escape of stool from the rectum.		Bowel incontinence	Inability to control the escape of stool from the rectum.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C78498
Bladder incontinence	Inability to control the flow of urine from the bladder.		Bladder incontinence	Inability to control the flow of urine from the bladder.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C78497
Carpal spasm	A spasmodic contraction of the muscles of the hands, especially the wrists, such as during alkalosis or tetany.		Carpal spasm	A spasmodic contraction of the muscles of the hands, especially the wrists, such as during alkalosis or tetany.			
Chest pain	Discomfort felt in the upper abdomen, thorax, neck, or shoulders.		Chest pain	Discomfort felt in the upper abdomen, thorax, neck, or shoulders.			
Cough	A sudden, often repetitive, spasmodic contraction of the thoracic cavity, resulting in violent release of air from the lungs, and usually accompanied by a distinctive sound.		Cough	A sudden, often repetitive, spasmodic contraction of the thoracic cavity, resulting in violent release of air from the lungs, and usually accompanied by a distinctive sound.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C37935
Cyanosis	A bluish or purplish discoloration of the skin and mucous membranes resulting from a reduced amount of oxygenated hemoglobin in the blood.		Cyanosis	A bluish or purplish discoloration of the skin and mucous membranes resulting from a reduced amount of oxygenated hemoglobin in the blood.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C26737
Diaphoresis	Indicator to signify the presence of the symptom of excessive sweating.		Diaphoresis	Indicator to signify the presence of the symptom of excessive sweating.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C35051
Dizziness	A sensation of lightheadedness, unsteadiness, turning, spinning, or rocking.		Dizziness	A sensation of lightheadedness, unsteadiness, turning, spinning, or rocking.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C37943
Dyspnea	An uncomfortable sensation of difficulty breathing. It may present as an acute or chronic sign of an underlying respiratory or heart disorder.		Dyspnea	An uncomfortable sensation of difficulty breathing. It may present as an acute or chronic sign of an underlying respiratory or heart disorder.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C2998
Fatigue with feeding	A state of increased discomfort and decreased efficiency due to prolonged or excessive exertion during the taking of food.		Fatigue with feeding	A state of increased discomfort and decreased efficiency due to prolonged or excessive exertion during the taking of food.			
Faceplant	A type of syncope in which there is no attempt to protect oneself from the effects of the fall.		Faceplant	A type of syncope in which there is no attempt to protect oneself from the effects of the fall.			
Headache	Pain in various parts of the head, not confined to the area of distribution of any nerve.		Headache	Pain in various parts of the head, not confined to the area of distribution of any nerve.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C34661
Hyperventilation	Abnormally prolonged, rapid, and deep breathing.		Hyperventilation	Abnormally prolonged, rapid, and deep breathing.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C50590
Lethargy	Experience of decreased consciousness characterized by mental and physical inertness.		Lethargy	Experience of decreased consciousness characterized by mental and physical inertness.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C78416
Loss of consciousness	A level of awareness that can be described as consistently not responsive to stimuli.		Loss of consciousness	A level of awareness that can be described as consistently not responsive to stimuli.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C50635

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
Nausea			Nausea	The sensation that one is about to vomit.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C3258
Numbness/tingling			Numbness/tingling	(1) The loss of the sensation of feeling in an area of the body. AND/OR (2) A sensation as of repetitive pin pricks, caused by cold or by striking a nerve, or because of various diseases of the central or peripheral nervous system.		NCI Thesaurus ¹⁰	NCI Thesaurus Code(s): (1): C34857; (2): C50771
Pallor			Pallor	An unusual or extreme paleness, state of decreased skin coloration.			
Palpitations			Palpitations	An unpleasant sensation of irregular and/or forceful beating of the heart.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C37999
Pedal spasm			Pedal spasm	A spasmodic contraction of the muscles of the feet, especially the ankles, such as during alkalosis or tetany.			
Postictal confusion			Postictal confusion	Period of confusion post seizure in which the patient does not respond appropriately although appearing "awake."			
Rash			Rash	Any change in the skin which affects its appearance or texture. A rash may be localized to one part of the body, or affect all the skin. Rashes may cause the skin to change color, itch, become warm, bumpy, dry, cracked, or blistered, swell and may be painful.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C39594
Seizure			Seizure	Sudden, involuntary skeletal muscular contractions of cerebral or brain stem origin.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C2962
Sensation of cold			Sensation of cold	An internal feeling of being cooler without a concomitant change in the ambient environment.			
Sensation of heat			Sensation of heat	An internal feeling of being warmer without a concomitant change in the ambient environment.			

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
			Sleep disturbance	An interruption, departure, or divergence from that which is considered normal in sleep.			
			Syncope	Sudden loss of consciousness with loss of postural tone, not related to anesthesia with spontaneous recovery as reported by patient or observer. Patient may experience syncope when supine.		ACC/AHA/HRS 2006 Key Data Elements and Definitions for Electrophysiological Studies and Procedures ¹²	
			Tongue-biting	Clamping of the teeth on the tongue, as can accompany a seizure.			
			None	No associated symptoms/signs present.			
Chief Complaint – Modifying Factors							
Exacerbating Factors	Factors causing the chief complaint to worsen.		<ul style="list-style-type: none"> • Caffeine intake • Change to upright position • Crying/emotion • Defecation • Exercise • Hair brushing • Hot weather • Hot bath • Inspiration • Intercurrent illness • Leaning forward • Menses • Micturition • Movement • Noxious stimuli • Pain • Palpitation • Prolonged standing • Startle • Stretching • Supine position • Swimming • Other • None 				

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
Caffeine intake			Caffeine intake	Intake of caffeine routinely occurring as frequently as at least every other day.			
Change to upright position			Change to upright position	The state of going from a supine or seated position to a standing position.			
Increased emotional state			Increased emotional state	A state of mental excitement, characterized by alteration of feeling tone and by physiological and behavioral changes.			
Defecation			Defecation	The evacuation of fecal matter from the rectum.			
Exercise			Exercise	Performance of physical exertion for improvement of health or correction of physical deformity.			
Hair brushing			Hair brushing	The use of an implement, consisting of bristles, attached to a handle to groom hair.			
Hot weather			Hot weather	Increased ambient temperature.			
Hot bath/shower			Hot bath/shower	Bathing with water that has an extremely elevated temperature.			
Inspiration			Inspiration	The drawing of air into the lungs.			
Intercurrent illness			Intercurrent illness	A disease occurring during the course of another disease with which it has no connection.			
Leaning forward			Leaning forward	Tilting the upper body so that the head and chest extends beyond the waist.			
Menses			Menses	The monthly flow of blood from the female genital tract.			
Micturition			Micturition	Urination, the act of emptying the bladder of urine.			
Movement			Movement	An act of moving; motion.			
Noxious stimulus			Noxious stimulus	Hurtful, injurious, pernicious agent that produces a reaction in a receptor or tissue.			
Pain			Pain	A feeling of distress, suffering, or agony, caused by stimulation of specialized nerve endings.			
Palpation			Palpation	The act of feeling with the hand.			
Prolonged standing			Prolonged standing	The state of being in an upright position continuing for a time greater than what would be considered normal.			
Startle			Startle	To make a quick involuntary movement as in alarm, surprise, or fright.			

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
Alleviating Factors	Factors making the chief complaint better.		Stretching	An activity that elongates shortened soft-tissue structures and thereby increases flexibility.			
			Supine position	Lying with the face upward or on the dorsal surface.			
			Swimming	Propel the body through the water by using the limbs.			
			Other				
			None				
			• Antacid medications				
			• Inspiration				
			• Isometric counter-measures				
			• Leaning forward				
			• NSAID medications				
• Pressure							
• Rest							
• Supine position							
• None							
Antacid medication			Oral therapeutic agent that counteracts acidity.				
Inspiration			The drawing of air into the lungs.				
Isometric counter-measures			Grasping one's hands in the midline and pushing them away from each other with tensed muscles OR leg crossing plus tensing of leg, abdominal, and buttock muscles.	Adapted from Brignole M, Croci F, Menozzi C, et al. Isometric arm counter-pressure maneuvers to abort impending vasovagal syncope. J Am Coll Cardiol. 2002;40:2053-9 ¹¹ AND from Krediet CTP, van Dijk N, Linzer M, et al. Management of vasovagal syncope: controlling or aborting faints by leg crossing and muscle tensing. Circulation. 2002;106:1684-9 ¹⁹			

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping	
			Leaning forward	Tilting the upper body so that the head and chest extends forward of the waist.				
			NSAID medications	A medication from the category of the NSAIDs.				
			Pressure	Continuous physical force exerted on an object by something in contact with it.				
			Rest	Repose after exertion.				
			Supine position	Lying with the face upward or on the dorsal surface.				
			None					
Chief Complaint – Other Data Qualifiers								
Location of Chest Pain	The location of chest pain.		<ul style="list-style-type: none"> • Sternum • Sternal border • Midclavicular line • Intercostal space • Epigastrium • Anterior axillary line 					
			Sternum (lower, mid, upper)	Location is in the middle of the anterior wall of the thorax, bounded by the clavicles, above, and with the cartilages of the first seven ribs, along the sides.				
			Sternal border (left lower/mid/upper; right lower/mid/upper)	Location is along the lateral edge of the sternum.				
			Midclavicular line (right/left)	Location is along an imaginary vertical line on the chest originating from the midpoint of a clavicle.				
			Intercostal space (right/left, 2/3/4/5)	Location is in the area defined by a superior rib margin and an inferior rib margin.				
		Epigastrium	The upper and middle region of the abdomen, located within the sternal angle.					
		Anterior axillary line (right/left)	Location is along an imaginary vertical line that descends along the lateral aspect of the chest wall originating from the armpit.					

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping	
Radiation of Chest Pain	The part of the body to which the chest pain radiates.		<ul style="list-style-type: none"> • None • Left arm • Neck • Back • Abdomen • Sternum • Sternal border • Midclavicular line • Anterior axillary line • Other 					
			None	The chest pain does not radiate.				
			Left arm	The chest pain radiates to the left arm.				
			Neck	The chest pain radiates to the neck.				
			Back	The chest pain radiates to the back.				
			Abdomen	The chest pain radiates to the abdomen.				
			Sternum (lower, mid, upper)	Location is in the middle of the anterior wall of the thorax, bounded by the clavicles, above, and with the cartilages of the first seven ribs, along the sides.				
			Sternal border (left lower/mid/upper; right lower/mid/upper)	Location is along the lateral edge of the sternum.				
			Midclavicular line (right/left)	Location is along an imaginary vertical line on the chest originating from the midpoint of a clavicle.				
			Anterior axillary line (right/left)	Location is along an imaginary vertical line that descends along the lateral aspect of the chest wall originating from the armpit.				
Quality of Chest Pain	The characteristics of chest pain as described by the patient.		Other	The chest pain radiates to an area not specified.				
			<ul style="list-style-type: none"> • Sharp pain • Dull pain • Burning pain • Tearing pain • Pressure pain 					

(Continued)

Appendix 3. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Values	Permissible Value Definitions	Parent Field	Source of Definition	Mapping
			Sharp pain	A sensation of a stabbing feeling.			
			Dull pain	A sensation of mild or blunted discomfort.			
			Burning pain	A sensation of an intense discomfort, similar to that experience as a result of a thermal burn, distinct from sharp, stabbing or aching, often related to nerves, used, sometimes to describe gastric or esophageal pain.			
			Tearing pain	A sensation of a sharp, lacerating, intense, discomfort, sometimes used to describe the pain felt during an aortic dissection.			
			Pressure pain	A sensation of an object creating physical force.			
Quality of Palpitations	The characteristics of the palpitations as described by the patient.		<ul style="list-style-type: none"> • Skipped/early heartbeats • Forceful heartbeats • Racing heartbeats 				
			Skipped/early heartbeats	The sensation of an isolated cardiac contraction occurring prior to the normal or regular rhythm.			
			Forceful heartbeats	The sensation of an isolated cardiac contraction occurring with greater strength than that of a typical or normal contraction.			
			Racing heartbeats	The sensation of an abnormally rapid heart rate.			
Activity Associated With Chief Complaint	Associated activity when chief complaint occurs or that induces onset of the chief complaint.		<ul style="list-style-type: none"> • At rest • During exercise • After exercise • No pattern 				
			At rest	Chief complaint typically occurs at rest.			
			During exercise	Chief complaint typically occurs during exercise.			
			After Exercise	Chief complaint typically occurs on conclusion of exercise.			
			No pattern	Chief complaint occurs both at rest and with exercise.			

CT indicates computed tomography; ECG, electrocardiogram; EP, electrophysiology; MRI, magnetic resonance imaging; NCI, National Cancer Institute; and SVT, supraventricular tachycardia.

Appendix 4. Risk Factors

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
History of CHD							
History of CHD	Any abnormality of cardiac structure or function present at birth.		<ul style="list-style-type: none"> • Yes • No • Unknown 				
Age Diagnosed	The age of the patient when CHD was diagnosed.		Yes No Unknown				
Presenting Finding	The presenting findings of CHD.		Age	In days, weeks, months, or years.			
			Murmur	An auscultated finding describing a series of audible vibrations of varying intensity (loudness), frequency (pitch), quality, configuration, and duration created by turbulent blood flow in the heart or surrounding vessels.			
			Cyanosis	A bluish or purplish discoloration of the skin and mucous membranes resulting from a reduced amount of oxygenated hemoglobin in the blood.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C26737
			Respiratory distress	A pathological increase in the effort and frequency of breathing movements.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C27165
			Fatigue	A state of exhaustion usually caused by various etiologies such as a period of mental or bodily activity, sleep deprivation, medications, chronic disease, or other factors.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C3036
			Failure to thrive	Weight below the third to fifth percentile or a decrease in the percentile rank of two major growth parameters in a short period.			
			Multiple anomalies	Presence of multiple congenital malformations.			
			Family history of CHD	Having a first-degree or first- and second-degree relative with a history of CHD.			
			Other				

(Continued)

Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
Intervention(s)	The treatment the patient had for CHD.		<ul style="list-style-type: none"> • Medications • Infective endocarditis prophylaxis • Cardiac catheterization • Interventional catheterization • Surgery 	A drug or substance used to treat a medical condition.			
			Medications	The giving of antibiotic therapy for the prevention of endocarditis.			
			IE prophylaxis	Passage of a small catheter through a vein in an arm or leg or the neck and into the heart, permitting the securing of blood samples, determination of intracardiac pressure, and detection of cardiac anomalies.			
			Cardiac catheterization	The performance of a cardiac catheterization with the intent of making a modification to the structures of the heart or surrounding vessels.			
			Interventional catheterization	The surgical treatment of diseases affecting the heart and blood vessels inside the thorax.			
			Cardiac surgery				
			<ul style="list-style-type: none"> • Duchenne • Becker • No • Unknown 			NCI Thesaurus ¹⁰	NCI Thesaurus Code: C101216
Myopathy	A nontraumatic and nonneoplastic disease of the muscles.		Duchenne	An X-linked genetic disorder caused by a mutation in the dystrophin gene characterized by early onset, rapidly progressive skeletal muscle weakness and atrophy initially involving the lower extremities that eventually affect the entire body including respiratory and cardiac muscles.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C75482
			Becker	An X-linked genetic disorder caused by a mutation in the dystrophin gene characterized by onset in late childhood or adults of slowly progressive skeletal muscle weakness and atrophy initially involving the lower extremities that may eventually affect the entire body including respiratory and cardiac muscles.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C84587

(Continued)

Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
Other Muscular Dystrophies and Storage Diseases That Lead to Cardiomyopathies			No				
			Unknown				
			<ul style="list-style-type: none"> • Limb girdle dystrophy • Myotonic dystrophy • Mitochondrial • Ox/Phos • Glycogen storage disorder • Fatty acid oxidation disorder • None • Unknown 				
			Limb girdle dystrophy	A group of muscular dystrophies due to mutations in a variety of genes, predominantly affecting the proximal muscles of the arms and legs.			
			Myotonic dystrophy	An inherited progressive disorder affecting the muscles.			
			Mitochondrial	Muscular dystrophy secondary to a mitochondrial disorder.			
			Ox/Phos	Muscular dystrophy secondary to a genetic defect that interferes with oxidative phosphorylation frequently associated with severe neurologic abnormalities.			
			Glycogen storage disorder	Myopathy secondary to glycogen accumulation related to an enzymatic deficiency or absence.			
			Fatty acid oxidation disorder	Myopathy secondary to a genetic defect in fatty acid metabolism.			
			None				
		Unknown					

(Continued)

Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
Kawasaki's Disease							
Kawasaki Disease	Kawasaki disease is an acute self-limited vasculitis of childhood that is characterized by fever, bilateral nonexudative conjunctivitis, erythema of the lips and oral mucosa, changes in the extremities, rash, and cervical lymphadenopathy.		Yes No Unknown			McCordle BW, Rowley AH, Newburger JW, et al. Diagnosis, treatment, and long-term management of Kawasaki disease: a scientific statement for health professionals from the American Heart Association. <i>Circulation</i> . 2017;135:e927-99 ²¹	
Symptom Onset	Date of the first onset of the symptoms of Kawasaki disease.		Date	mm-dd-yyyy			
Age When First Noted	The age of the patient when the symptoms of Kawasaki disease were first noted.		Integer	Age in days, weeks, months, or years.			
Symptoms	The symptoms of Kawasaki disease that the patient had.		Fever Rash Conjunctivitis Cheilitis	The elevation of the body's temperature above the upper limit of normal, usually taken as 37.7°C. Any change in the skin which affects its appearance or texture. The rash in Kawasaki disease can be polymorphous and typically includes the groin. Inflammation of the conjunctivae of the eye. The conjunctivitis of Kawasaki disease is nonexudative and spares the limbus. An inflammatory process affecting the lips.		NCI Thesaurus ¹⁰ NCI Thesaurus ¹⁰ NCI Thesaurus ¹⁰ NCI Thesaurus ¹⁰	NCI Thesaurus Code: C3038 NCI Thesaurus Code: C39594 NCI Thesaurus Code: C34504 NCI Thesaurus Code: C7954

(Continued)

Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
			Strawberry tongue	The pathological finding of the tongue in which the tongue has an appearance of a strawberry.		NCI Thesaurus ¹⁰	Specifically, there is an anterior cervical lymph node with Kawasaki disease. If there are shotty or multiple nodes involved, it is typically felt to not be consistent with Kawasaki disease. NCI Thesaurus Code: C50764
			Lymphadenopathy	A clinical finding indicating that a lymph node is enlarged. The lymphadenopathy of Kawasaki disease is a single anterior cervical lymph node.			
			Arthralgia	Pain in a joint.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C50464
			Erythema of the palms and/or soles	Red discoloration of the skin caused by infectious agents, drug hypersensitivity, or underlying diseases.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C26901
			Edema of the palms and/or soles	Accumulation of an excessive amount of watery fluid in cells or intercellular tissues.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C3002
			Desquamation	Peeling of the skin that typically starts at the tips of the fingers/toes.			
			Labile affect	Emotional instability characterized by rapid and dramatic mood swings.			
			Abdominal pain	The sensation of discomfort in the abdominal region.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C26682
			Dehydration	A condition resulting from the excessive loss of water from the body.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C26740
			Gallbladder hydrops	Enlargement of the gallbladder secondary to prolonged obstruction of the cystic duct that is non-obstructive.			

(Continued)

Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping		
Kawasaki Z- Score Classification	Classification for the size of aneurysm in Kawasaki disease.		<ul style="list-style-type: none"> No involvement Dilatation only Small aneurysm Medium aneurysm Large or giant aneurysm 			McCordle BW, Rowley AH, Newburger JW, et al. Diagnosis, treatment, and long-term management of Kawasaki disease: a scientific statement from the American Heart Association. <i>Circulation</i> . 2017;135:e927-99 ²¹			
Laboratory Findings for Kawasaki Disease	The laboratory findings indicating diagnosis of Kawasaki disease. The criteria for incomplete Kawasaki disease are: 1) Elevated ESR or CRP 2) Sterile pyuria 3) Anemia 4) Decreased albumin 5) Elevated alanine aminotransferase 6) Leukocytosis 7) Thrombocytosis		No involvement	Always <2 mm					
			Dilatation only	From 2 to 2.5 mm; or if initially <2, a decrease in Z score during follow-up ≥ 1					
			Small aneurysm	≥ 2.5 to <5 mm					
			Medium aneurysm	≥ 5 to <10 mm					
			Large or giant aneurysm	≥ 10 , or absolute dimension ≥ 8 mm					
			Platelet count	The determination of the number of platelets in a blood sample, usually expressed as platelets per milliliter of whole blood.				NCI Thesaurus ¹⁰	NCI Thesaurus Code: C51951
			ESR	A quantitative measurement of the distance that red blood cells travel in 1 hour in a sample of unclotted blood.				NCI Thesaurus ¹⁰	NCI Thesaurus Code: C74611
CRP	A quantitative measurement of the amount of CRP, an inflammatory marker, in the blood, expressed as milligrams per liter.								

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Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
			Sterile pyuria	The presence of leukocytes in the urine without evidence of an infection.			
			WBC	Concentration of leukocytes in the peripheral blood stream, expressed as WBCs per milliliter of whole blood.			
			Hemoglobin	Concentration of hemoglobin in the peripheral blood stream, expressed as grams per deciliter.			
			Alanine aminotransferase	The concentration of alanine aminotransferase, a liver enzyme, in the blood, expressed in units per liter.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C74954
Intervention for Kawasaki Disease	Whether treatment was given for Kawasaki disease.		Yes				
			No				
Intervention for Kawasaki Disease, Timing	The timing of treatment given to patient from the onset of the initial symptoms of Kawasaki disease.		<10 days within the onset of initial symptoms				
			>10 days within the onset of initial symptoms				
Intervention for Kawasaki Disease, Medication(s)	The medications given to the patient for treatment of Kawasaki disease. If known, dosage should also be indicated.		IVIg	Pooled immunoglobulins given parenterally. In Kawasaki disease, given as 2 g/kg of body weight.			
			Aspirin	Acetyl salicylic acid given orally as 80–100 mg/kg body weight per day, divided QID through the first 36 hours of IVIG therapy, then 3–5 mg/kg body weight daily until 6 to 8 weeks after the onset of Kawasaki disease.			

(Continued)

Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
			Coumadin	An anticoagulant used to prevent thrombosis and thromboembolism that inhibits vitamin K epoxide reductase.			
			Other	Includes ticlopidine, clopidogrel, abciximab, steroids, infliximab.			
Intervention for Kawasaki Disease, Response	The patient's response to treatment of Kawasaki disease.		<ul style="list-style-type: none"> • Yes • No 				
Intervention for Kawasaki Disease, Type of Response	The type of treatment patient received for Kawasaki disease.		<ul style="list-style-type: none"> • Resolution of findings • Relapse • Retreatment 				
			Resolution of findings				
			Relapse				
			Retreatment				
Intervention for Kawasaki Disease, Medications	Medications used for the treatment of Kawasaki disease.		<ul style="list-style-type: none"> • IVIG • Steroids • Infliximab • Other 				
			IVIG				
			Steroids				
			Infliximab				
			Other				
Intervention for Kawasaki Disease, Sequelae	Outcomes or findings after treatment of Kawasaki disease.		<ul style="list-style-type: none"> • None • Relapse • Coronary artery aneurysm • Coronary artery ectasia • Angina • MI • Gangrene 				

(Continued)

Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
			None				
			Relapse	The return of a disease after a period of remission.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C38155
			Coronary artery aneurysm	Focal dilation of a coronary artery secondary to arterial wall weakening.			
			Coronary artery ectasia	Diffuse dilation of coronary artery segment.			
			Angina	A heart condition marked by paroxysms of chest pain due to reduced oxygen to the heart.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C51221
			MI	Gross necrosis of the myocardium, as a result of interruption of the blood supply to the area, as in coronary thrombosis.		2014 ACC/AHA Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials ¹⁶	NCI Thesaurus Code: C27996
			Gangrene	Death of tissue, usually in considerable mass and generally associated with loss of vascular (nutritive) supply and followed by bacterial invasion and putrefaction.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C50573
Rheumatic Fever							
Rheumatic Fever	An inflammatory disorder that follows infection with group A streptococcus. It affects the heart, joints, and subcutaneous tissues. It is manifested with pericarditis, heart murmur, congestive heart failure, polyarthritis, subcutaneous nodules, and erythema marginatum.		<ul style="list-style-type: none"> • Yes • No • Unknown 			NCI Thesaurus ¹⁰	NCI Thesaurus Code: C34984
Onset	Date of the first onset of rheumatic fever.		Date	mm-dd-yyyy			
Age When First Symptoms Occurred	The age of the patient when first symptoms of rheumatic fever occurred.		Integer	Age in years			

(Continued)

Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping			
Symptoms	The symptoms of rheumatic fever that the patient had.		Carditis	Inflammation of the heart or its surroundings.						
			Polyarthritits	Type of arthritis that involves ≥5 joints simultaneously, and usually associated with autoimmune conditions.						
			Subcutaneous nodules	Firm lump under the skin.						
			Rash	Any change in the skin that affects its appearance or texture. The rash associated with rheumatic fever is erythema marginatum, a pruritic rash characterized by pink rings on the trunk and inner surfaces of the extremities.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C39594			
			Sydenham's chorea	A neurologic disorder characterized by smooth involuntary, uncoordinated movements affecting especially the hands, feet, and face.						
			Evidence of previous streptococcus infection	The presence of a positive anti-Streptolysin-O or anti-DNase B, demonstrating that the patient was previously infected with <i>Streptococcus</i> .						
			Previous acute rheumatic fever or rheumatic heart disease	Prior history of rheumatic fever or rheumatic heart disease.			NCI Thesaurus ¹⁰	NCI Thesaurus Code: C34984		
			Family history of rheumatic fever/ rheumatic heart disease	The presence of a first-degree family member with a history of rheumatic fever or rheumatic heart disease.						
			Minor Criteria for Rheumatic Fever	Minor symptom criteria for rheumatic disease include fever, arthralgia, elevated ESR levels, elevated CRP levels, elevated WBC levels, prolonged PR interval.		• Yes				
						• No				
Intervention for Rheumatic Fever	The type of treatment the patient received for rheumatic fever.		<ul style="list-style-type: none"> • Bed rest • Medication • Interventional catheterization • Cardiac surgery 							

(Continued)

Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
			Bed rest	Restriction of a patient's activity, either partially or completely.			
			Medication	A drug product that contains one or more active and/or inactive ingredients; it is intended to treat, prevent or alleviate the symptoms of disease. This term does not refer to the individual ingredients that make up the product.			
			Interventional catheterization	The performance of a cardiac catheterization with the intent of making a modification to the structures of the heart or surrounding vessels.			
			Cardiac surgery	The surgical treatment of disease affecting the heart and blood vessels within the thorax.			
		Pharmacological Therapy for Rheumatic Fever		<ul style="list-style-type: none"> • Aspirin • Steroids • Anticongestive medications • Penicillin • Other 			Use RxNorm code mapping for definition of medications
		Surgical Intervention for Rheumatic Fever		<ul style="list-style-type: none"> • Valvuloplasty • Valve replacement 			
Other Risk Factors							
Family History of Heart Disease	The presence of heart disease in a first-degree family member.		<ul style="list-style-type: none"> • Cardiomyopathy • Coronary artery disease • CHD • Long QTc • Marfan Syndrome • Ehlers-Danlos syndrome • Sudden death/SIDS • SADS • Others 				

(Continued)

Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
Cardiomyopathy	A disease of the heart muscle or myocardium proper.					NCI Thesaurus ¹⁰	NCI Thesaurus Code: C34830
CAD	Indicate if the patient has/had any direct blood relatives (ie, parents, siblings, children) who have had any of the following diagnosed at age <55 y for male relatives or <65 y for female relatives: <ul style="list-style-type: none"> • Coronary artery disease (ie, angina, previous CABG or PCI) • MI • Sudden cardiac death without obvious cause. If the patient is adopted or the family history is unavailable, code "No." <p>Yes/No/Null.</p>					STS Registry v2.70 ²⁹	
CHD	The presence of a heart defect that is present at birth.					NCI Thesaurus ¹⁰	NCI Thesaurus Code: C95834
Long QTc	Disorder characterized by prolongation of the heart rate corrected QT interval that predisposes to ventricular arrhythmias and sudden death. As calculated by the Bazett formula.						
Marfan syndrome	A genetic syndrome inherited as an autosomal dominant trait. It is caused by mutations in the FBN1 gene. It is characterized by tall stature, elongated extremities, mitral valve prolapse, aortic dilatation, aortic dissection, and subluxation of the lens. Diagnosis is made based on the 2010 Revised Ghent Nosology for Marfan syndrome. ⁴¹					NCI Thesaurus ¹⁰	NCI Thesaurus Code: C34807
Ehlers-Danlos syndrome	A group of inherited connective tissue disorders characterized by loose and fragile skin and joint hypermobility.					Adapted from NCI Thesaurus ¹⁰	NCI Thesaurus Code: C34568
Sudden death/SIDS	Unexpected death in infancy which remains unexplained following autopsy, review of the medical history, and investigation of the death circumstances and death scene.					NCI Thesaurus ¹⁰	NCI Thesaurus Code: C85173
SADS	Unexpected sudden cardiac death secondary to a genetic condition that lowers the threshold for lethal arrhythmia. This includes Brugada syndrome, catecholaminergic polymorphic ventricular tachycardia, long QT syndrome, short QT syndrome, Timothy syndrome, and Wolff-Parkinson-White syndrome.						

(Continued)

Appendix 4. Continued

Terminology Concept	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
Abnormal Cardiac Study	History of abnormal cardiac study.		Others <ul style="list-style-type: none"> • ECG • Echocardiogram • Chest x-ray • Holter monitor • Event monitor • Other 				
			ECG	A procedure that records the electrical current in the heart in the form of a continuous strip graph.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C38053
			Echocardiogram	A test that uses high-frequency sound waves (ultrasound) to create an image of the heart.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C16525
			Chest x-ray	A radiographic examination of the chest.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C38103
			Holter monitor	An ambulatory electrocardiographic technique that records a continuous electrocardiographic rhythm pattern for ≥24 h to detect heart arrhythmias.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C38064
			Event monitor	An ambulatory electrocardiography technique that intermittently records the electrical rhythm of the heart on demand or automatically			
			Other <ul style="list-style-type: none"> • Primary pulmonary hypertension • Secondary pulmonary hypertension 			NCI Thesaurus ¹⁰	NCI Thesaurus Code: C3120
Pulmonary Hypertension	Increased pressure within the pulmonary circulation due to lung or heart disorder.		Primary pulmonary hypertension	Type of pulmonary hypertension that is not caused by any other disease or condition.			
			Secondary pulmonary hypertension	Type of pulmonary hypertension that is caused by an underlying condition.			
Failure to Gain Weight/Thrive	History of failure to gain weight.		• Yes • No				

CABG indicates coronary artery bypass graft; CAD, coronary artery disease; CHD, congenital heart disease; CRP, C-reactive protein; ESR, erythrocyte sedimentation rate; IE, infective endocarditis; IVIG, intravenous immunoglobulin; MI, myocardial infarction; NCI, National Cancer Institute; PCI, percutaneous coronary intervention; SADS, sudden arrhythmic death syndrome; SIDS, sudden infant death syndrome; and WBC, white blood cell.

Appendix 5. Past Medical History

Data Element	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
Birth							
Gestation	The period of fetal development in the uterus from the start of conception until its birth.		<ul style="list-style-type: none"> • Term • Preterm • Postterm 			NCI Thesaurus ¹⁰	NCI Thesaurus Code: C92804
			Term	Gestation is ≥ 37 wk using best estimated due date.			
			Preterm	Gestation that is < 37 wk and 0 days' gestational age.			
			Postterm	Gestation lasts ≥ 42 wk.			
Gestational Complications	A difficulty or problem that occurs during intrauterine development that can jeopardize the health of the fetus.		<ul style="list-style-type: none"> • Yes • No • Unknown 				
Neonatal Complications	A problem that occurs at or just after delivery of an infant that can jeopardize the health of the infant.		<ul style="list-style-type: none"> • Yes • No • Unknown 				
Review of Systems							
Review of Systems							
			Dermatological	Normal or abnormal clinical findings related to the skin.			
			Endocrine	Normal or abnormal clinical findings related to the collection of tissues capable of secreting hormones.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C41064
			Gastrointestinal	Normal or abnormal findings related to the stomach and intestines.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C13359
			Hematological	Normal or abnormal findings related to abnormalities of the synthesis of hemoglobin, and/or the mechanisms of coagulation.		NCI Thesaurus ¹⁰	NCI Thesaurus Code(s): (1): C26323; (2): C17837
			Hemoglobinopathy	Normal or abnormal findings related to the structural alterations of a globin chain within the hemoglobin molecule.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C3092

(Continued)

Appendix 5. Continued

Data Element	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
			Musculoskeletal	Normal or abnormal findings related to the musculoskeletal system.			
			Neurologic	Normal or abnormal findings related to the nervous system.			
			Developmental	Normal or abnormal findings related to physical, emotional, behavioral, or social development.			
			Otolaryngological	Normal or abnormal findings related to disorders of the ear, nose, and throat.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C16943
			Psychiatric	Normal or abnormal findings related to mental health.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C17026
			Respiratory	Normal or abnormal findings related to the respiratory system.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C25656
			Rheumatological	Normal or abnormal findings related to diseases and disorders of the connective tissues.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C17099
Syndrome							
Syndrome	Genetic anomalies and collections of malformations that are known to cluster together that can be associated with congenital heart defects.						
			Trisomy-13	A chromosomal abnormality consisting of the presence of part or all of a third copy of chromosome 13 in somatic cells.		Adapted from NCI Thesaurus ¹⁰	NCI Thesaurus Code: C36529
			Trisomy-18	A chromosomal abnormality consisting of the presence of part of all of a third copy of chromosome 18 in somatic cells.		Adapted from NCI Thesaurus ¹⁰	NCI Thesaurus Code: C36626
			Trisomy-21	A chromosomal abnormality consisting of the presence of part or all of a third copy of chromosome 21 in somatic cells.		Adapted from NCI Thesaurus ¹⁰	NCI Thesaurus Code: C43224
			Turner syndrome	A chromosomal abnormality occurring in phenotypic females, characterized by the absence of a part or all of one of the sex chromosomes.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C26900
			Loeys-Dietz syndrome	A genetic syndrome characterized by a rare autosomal dominant syndrome caused by mutations in the <i>TGFBR1</i> or <i>TGFBR2</i> genes. It is characterized by aortic dilation and dissection, vascular tortuosity, hypertelorism, bifid uvula, scoliosis, and pectus deformities.		Loeys BL, Dietz HC, Braverman AC, et al. The revised Ghent nosology for the Marfan syndrome. <i>J Med Genet.</i> 2010;47:476–85 ³⁷	

(Continued)

Appendix 5. Continued

Data Element	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
		Noonan syndrome	A genetic syndrome caused by mutations in the <i>PTPN11</i> gene (>50% of the cases) or less frequently mutations in the <i>SOS1</i> , <i>RAF1</i> , or <i>KRAS</i> genes. It is characterized by short stature, webbed neck, hypertelorism, low-set ears, deafness, and thrombocytopenia or abnormal platelet function.			NCI Thesaurus ¹⁰	NCI Thesaurus Code: C34854
		Williams syndrome	A genetic syndrome caused by multiple gene deletions from a region of chromosome 7, including the deletion of <i>CLIP2</i> , <i>ELN</i> , <i>GTF2I</i> , <i>GTF2IRD1</i> , and <i>LIMK1</i> genes. It is characterized by distinctive facial appearance (elfin facies), mild-to-moderate mental developmental delay, cheerfulness, cardiovascular abnormalities and infantile hypercalcemia.			NCI Thesaurus ¹⁰	NCI Thesaurus Code: C85232
		22q11 deletion (DiGeorge syndrome, Shprintzen syndrome, FACES, CATCH-22)	A congenital anomaly characterized by partial deletion of the short arm of chromosome 22.			NCI Thesaurus ¹⁰	NCI Thesaurus Code: C2989
		Marfan syndrome	A genetic syndrome inherited as an autosomal dominant trait. It is caused by mutations in the <i>FBN1</i> gene. It is characterized by tall stature, elongated extremities, mitral valve prolapse, aortic dilatation, aortic dissection, and subluxation of the lens. Diagnosis is made based on the 2010 Revised Ghent Nosology for Marfan syndrome. ⁴¹				
		VACTERL association	An association of congenital birth defects that includes vertebral abnormalities, anal atresia, cardiac abnormalities, tracheo-esophageal fistula, renal abnormalities, and limb abnormalities.			NCI Thesaurus ¹⁰	NCI Thesaurus Code: C99105
		CHARGE association	A genetic syndrome characterized by autosomal dominant mutations in the <i>CHD7</i> gene. The term CHARGE is an acronym for the following unusual congenital abnormalities that are associated with this syndrome: coloboma of the eye, heart defects, choanal atresia, growth and developmental delay, genital, and ear abnormalities.			Adapted from NCI Thesaurus ¹⁰	NCI Thesaurus Code: C75100

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Appendix 5. Continued

Data Element	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
			Fetal alcohol syndrome	A syndrome that can develop in infants whose mothers consumed alcohol during pregnancy. Manifestations of this syndrome include low birth weight, failure to thrive, developmental defects, organ dysfunction, mental deficiencies, behavioral problems, and poor motor coordination.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C84713
			Ehlers-Danlos syndrome	A group of inherited connective tissue disorders characterized by loose and fragile skin and joint hypermobility.		Adapted from NCI Thesaurus ¹⁰	NCI Thesaurus Code: C34568
			Osteogenesis imperfecta	A group of usually autosomal dominant inherited disorders characterized by defective synthesis of collagen type I resulting in defective collagen formation. It is characterized by brittle and easily fractured bones.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C26837
			Glycogen storage disease	An inherited metabolic disorder characterized either by defects in glycogen synthesis or defects in the breaking down of glycogen. It results either in the creation of abnormal forms of glycogen or accumulation of glycogen in the tissues.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C61272
			Mucopolysaccharidosis	A group of autosomal recessive or X-linked inherited lysosomal storage disorders affecting the metabolism of mucopolysaccharides, resulting in the accumulation of mucopolysaccharides in the body. Signs and symptoms include organomegaly, mental developmental delay, abnormal skeletal development, heart disorders, hearing loss, and central nervous system deficiencies.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C61259
			Tuberous sclerosis	Hereditary disease characterized by seizures, intracerebral tumors, cardiac tumors, developmental delay, and skin and ocular lesions.			
			Other				
			Unknown				

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Appendix 5. Continued

Data Element	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
Noncardiac Surgical History	Surgeries or interventions performed in the patient that do not involve the heart, but are commonly seen in patients who have complex congenital heart disease.		<ul style="list-style-type: none"> • No • Unknown • Tonsillectomy • Adenoidectomy • Bilateral myringotomies with tube placement • Herniorrhaphy • Cleft palate repair • Dental extraction • Spinal fusion • Gastrostomy/fundoplication • Fundoplication • Central venous catheter • Ventriculoperitoneal shunt • Ladd's or other malrotation procedures • Other 				
			No				
			Unknown				
			Tonsillectomy	Surgical removal of the tonsils.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C51679
			Adenoidectomy	Surgical removal of the pharyngeal tonsils (adenoids).		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C51697
			Bilateral myringotomies with tube placement	Also known as placement of pressure equalization tubes, used for treatment of chronic or recurrent otitis media.			
			Herniorrhaphy	Surgical repair of a hernia (eg, inguinal, abdominal).			
			Cleft palate repair	Surgery to repair a cleft palate.			
			Dental extraction	Removal of ≥1 teeth.			
			Spinal fusion	Surgical procedure in which ≥1 parts of the spine are joined together.			
			Gastrostomy/fundoplication	Creation of an opening between the stomach and the outside of the body.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C52006

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Appendix 5. Continued

Data Element	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
			Fundoplication	A therapeutic surgical procedure to treat gastroesophageal reflux disease and hiatus hernia. It involves the wrapping of the fundus of the stomach around the lower esophagus to strengthen the lower esophageal sphincter.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C91834
			Central venous catheter	A tube surgically placed into a blood vessel for the purpose of giving intravenous fluid and drugs or for obtaining blood samples.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C17612
			Ventriculoperitoneal shunt	Surgical procedure in which a tube is placed in one of the ventricles of the brain and whose other end is placed in the abdomen to relieve hydrocephalus			
			Ladd's or other malrotation procedures	Surgical procedure performed to alleviate intestinal malrotation.			
			Other				
Medications	A drug or substance used to treat a medical condition.		<ul style="list-style-type: none"> • Yes • No • Unknown 				
	The following information for medications should be collected: Name, dose, frequency, route, and concentration.						
Allergic Reaction	A hypersensitivity reaction triggered by exposure to a previously encountered foreign substance to which the individual has formed antibodies.		<ul style="list-style-type: none"> • Medication • Fish • Others • None • Unknown • CHD 			NICHD ⁴¹	

(Continued)

Appendix 5. Continued

Data Element	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
<p>Family History of Cardiovascular Disease and Cardiovascular Disease Risk Factors</p>			<ul style="list-style-type: none"> • CAD • CABG • PCI • MI • Hypertension • Hyperlipidemia • Sudden cardiac death • Stroke • Arrhythmia • Syncope • Other chronic diseases • Unknown 	<p>The presence of a heart defect that is present at birth.</p>		<p>NCI Thesaurus¹⁰</p>	<p>NCI Thesaurus Code: C95834</p>
			<p>CAD</p>	<p>Narrowing of the coronary arteries due to fatty deposits inside the arterial walls. The diagnostic criteria may include documented history of any of the following: documented coronary artery stenosis $\geq 50\%$ (by cardiac catheterization or other modality of direct imaging of the coronary arteries); previous coronary artery bypass graft (CABG), previous percutaneous coronary intervention (PCI), previous myocardial infarction.</p>		<p>2014 ACC/AHA Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials¹⁶</p>	
			<p>CABG</p>	<p>A procedure performed to bypass partially or completely occluded coronary arteries with veins and/or arteries harvested from elsewhere in the body, thereby improving the blood supply to the coronary circulation supplying the myocardium (heart muscle).</p>		<p>2014 ACC/AHA Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials¹⁶</p>	
			<p>PCI</p>	<p>PCI is the placement of an angioplasty guide wire, balloon, or other device (eg, stent, atherectomy, brachytherapy, or thrombectomy catheter) into a native coronary artery or CABG for the purpose of mechanical coronary revascularization. The assessment of coronary lesion severity via intravascular ultrasound, coronary flow reserve, or fractional flow reserve is not considered to be a PCI procedure.</p>		<p>2014 ACC/AHA Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials¹⁶</p>	

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Appendix 5. Continued

Data Element	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
MI				Clinical syndrome where there is evidence of myocardial necrosis in a clinical setting consistent with myocardial ischemia.		2014 ACC/AHA Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials ⁶	
Hypertension				Pathological increase in blood pressure; a repeatedly elevated blood pressure exceeding 140/90 mm Hg.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C3117
Hyperlipidemia				Elevated levels of lipids in the blood.		NCI Thesaurus ¹⁰	NCI Thesaurus Code: C34707
Sudden cardiac death				Death that occurs unexpectedly, and not within 30 days of an acute MI.		2014 ACC/AHA Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials ⁶	
Stroke				An acute episode of focal or global neurological dysfunction caused by presumed brain, spinal cord, or retinal vascular injury as a result of hemorrhage or infarction but with insufficient information to allow categorization as ischemic or hemorrhagic.		Kernan WN, Ovbiagele B, Black HR, et al. Guidelines for the prevention of stroke in patients with stroke and transient ischemic attack: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. Stroke. 2014;45:2160–236 ¹⁸	
Arrhythmia				An electrocardiographic finding of an atypical cardiac rhythm resulting from a cardiac pathologic process.			
Syncope				Sudden loss of consciousness with spontaneous recovery.			
Other chronic diseases							
Unknown							
Social History							
Living Arrangement	Other persons who live with the patient at home.						Check all that apply.

(Continued)

Appendix 5. Continued

Data Element	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping
			Lives with mother				
			Lives with father				
			Lives with step-mother				
			Lives with step-father				
			Lives with partner/spouse				
			Lives with aunt				
			Lives with uncle				
			Lives with foster parent				
			Living with sibling				
			Living with legal guardian other than above				
			Living alone				
Siblings			<ul style="list-style-type: none"> • Yes • No • Other 				
Education	Highest education attained.		<ul style="list-style-type: none"> • Grade school completion • High school completion • College • Graduate studies • 504 plan • IEP 				
			Grade school completion	Completed the first 6 or 8 grades of education.		NCI Thesaurus ¹⁰	
			High school completion	Completed secondary education through 12th or 13th grade as required by the school system.		NCI Thesaurus ¹⁰	
			College	Completion of education at an institution of higher education created to educate and grant degrees; often a part of a university.		NCI Thesaurus ¹⁰	
			Graduate studies	Completion of a program of study of at least the full-time equivalent of ≥1 academic years of work beyond the bachelor's degree.			
			504 plan	A plan created under section 504 for children with disabilities identified under the law to allow for accommodations for the child to be able to achieve academic success in primary or secondary school.			

(Continued)

Appendix 5. Continued

Data Element	Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Source of Definition	Mapping	
Employment	The state of being engaged in an activity or services for wages or salary.		IEP	Individualized education plan in primary and secondary school.				
			<ul style="list-style-type: none"> • Full-time • Part-time • No 			NCI Thesaurus ¹⁰		
			Full-time	Employed for a standard number of hours of working time, at least 50% or 20 h/wk.			NCI Thesaurus ¹⁰	
			Part-time	Employment involving less than the standard or customary working time.			NCI Thesaurus ¹⁰	
Alcohol Use	Current or previous use by the patient of any alcohol.		No					
			<ul style="list-style-type: none"> • Yes • No • Unknown 				Data element is for patient.	
Tobacco Use	Current or previous use of any tobacco product including cigarettes, cigars, pipes, and chewing tobacco. (Captured as smoking status.)		<ul style="list-style-type: none"> • Current every day smoker • Current some day smoker • Former smoker • Never smoker • Smoker, current status unknown • Unknown if ever smoked • Heavy tobacco smoker • Light tobacco smoker 			HealthIT.gov Meaningful Use Definition & Objectives ¹⁵		
			Current every day smoker					
			Current some day smoker					
			Former smoker					
			Never smoker					
			Smoker, current status unknown					
			Unknown if ever smoked					
			Heavy tobacco smoker					
			Light tobacco smoker					
			<ul style="list-style-type: none"> • Yes • No • Unknown 				World Health Organization ³⁴	

CABG indicates coronary artery bypass graft; CAD, coronary artery disease; CHD, congenital heart disease; IEP, individualized education plan; NCI, National Cancer Institute; NICHD, National Institute of Child Health and Human Development; MI, myocardial infarction; and PCI, percutaneous coronary intervention.

Appendix 6. Physical Examination

A. Vital Signs

Terminology Concept	Concept Definition	Suggested Data Element	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Vital Signs – Weight	A measurement that describes the vertical force exerted by a mass of the patient as a result of gravity.	Weight	Numeric, in kg	0.2–500			
Vital Signs – Height	A measurement that describes the vertical measurement or distance from the base, or bottom, of the patient, to the top of the patient; this can be taken as the dimension of extension of a patient who cannot stand.	Height	Numeric, in cm	10–230			
Vital Signs – BMI	A measurement that is used to indicate the body fat an individual is carrying based on the ratio of weight to height as measured in kilograms per square meters.	BMI	Numeric, in kg/m ²				
Vital Signs – BSA	A measurement that indicates overall patient size incorporating one of several different accepted equations, as measured in square meters.	BSA	Numeric, in m ²				
Vital Signs – RABP	A measurement that describes the pressure of the circulating blood against the walls of the blood vessels. Measurement is taken from the right arm.	RABP, displayed as systolic pressure over diastolic pressure	Numeric, in mmHg				
Vital Signs – Other Extremity Blood Pressure	A measurement that describes the pressure of the circulating blood against the walls of the blood vessels. Measurement is taken from extremities other than the right arm.	Other extremity blood pressure	Numeric, in mmHg				
Vital Signs – Body Temperature	A measurement that describes the amount of heat inside the body.	Temperature	Numeric, in Fahrenheit or Celsius	95–107 degrees, for Fahrenheit 35–41.7 degrees for Celsius			
Vital Signs – Heart Rate	A measurement that describes the frequency of rate of contractions of the systemic (often left) ventricle measured within a unit time.	Heart rate	Numeric, in beats per minute	0–300			
Vital Signs – Respiratory Rate	A measurement that describes the rate of breathing (inhalation and exhalation) measured within a unit time.	Respiratory rate	Numeric, in breaths per minute	0–100			
Vital Signs – Oxygen Saturation	A measurement that describes the determination of oxygen-hemoglobin saturation of blood.	Oxygen saturation	Numeric, in %	20–100			

BMI indicates body mass index; BSA, body surface area; BP, blood pressure, mmHg, millimeter mercury; and RA, right arm.

Appendix 6. Continued

B. Cardiac Examination

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings	
Cardiac Examination – Anterior Chest Inspection	Inspection of the region of the anterior surface of the chest and epigastric area.	Anterior chest inspection	<ul style="list-style-type: none"> • Normal • Symmetric • Asymmetry • Hyperactive • Sternotomy scar • Thoracotomy scar • Pectus excavatum • Pectus carinatum 	Inspection of the region of the anterior surface of the chest and epigastric areas that reveals a normally shaped thorax, free from any infection, other form of disease or malformation or asymmetry; and a point of maximal impulse (apical impulse) that is a single outward impulse, usually located inside the mid clavicular point at the intercostal space 5.				
			Normal	Inspection of the region of the anterior surface of the chest and epigastric areas that reveals an approximate correspondence of form and constituent configuration on opposite sides of a vertical central dividing line.				
			Symmetric	Inspection of the region of the anterior surface of the chest and epigastric areas that reveals disparate configuration on opposite sides of a vertical central dividing line.				
			Asymmetry	Inspection of the region of the anterior surface of the chest and epigastric areas that reveals a highly or excessively active or hyperkinetic apical impulse				
			Hyperactive	Replacement of destroyed tissue by fibrous tissue due to a surgical procedure where a vertical in-line incision is made along the sternum, after which the sternum itself is divided.				
			Sternotomy scar					

(Continued)

Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Cardiac Examination – Precordium, Palpation	Palpation of the part of the chest wall that is located anterior to the heart.		Thoracotomy scar	Replacement of destroyed tissue by fibrous tissue due to a surgical procedure where an incision (cut) was made into the chest wall to the left or to the right of the midline.		Schlantz RC, Hurst JW. Examination of the Precordium: Inspection and Palpation. Examination of the Heart, Part 3. Dallas, TX: American Heart Association; 1990 ⁴⁶	
			Pectus excavatum	A clinical finding in which there is depression of the sternum visible on examination of the chest.			
			Pectus carinatum	A clinical finding in which there is protuberance of the sternum visible on examination of the chest.			
			<ul style="list-style-type: none"> • Normal • Hyperdynamic • Thrill • Lift or heave • Tap • Palpable heart sound • PMI 				
			Normal	A clinical finding in which palpation of the chest wall anterior to the heart reveals normal location and characteristic of the right ventricular and apical impulses without other palpable impulses.			
			Hyperdynamic	A clinical finding in which palpation of the precordium reveals a hyperkinetic cardiac impulse with increased amplitude and forcefulness.		Schlantz RC, Hurst JW. Examination of the Precordium: Inspection and Palpation. Examination of the Heart, Part 3. Dallas, TX: American Heart Association; 1990 ⁴⁶	

(Continued)

Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
			Thrill	A clinical finding in which humming vibration; accompanying a loud, harsh or rumbling murmur felt during palpation of the precordium or over the blood vessels.		Otto CM, Bonow RO. Valvular heart disease. In: Bonow RO, Mann DL, Zipes DP, et al, eds. Braunwald's Heart Disease: A Textbook of Cardiovascular Medicine. 9th ed. Philadelphia, PA: Elsevier Health Sciences; 2011:1468-5 ³⁶	
			Lift or heave	A clinical finding in which there is an abnormally increased and sustained systolic pulsation found on palpation of the chest wall over the heart, including over a ventricle or the pulmonary artery area. This is typically associated with increased blood volume or pressure in the associated chamber.		Schlant RC, Hurst JW. Examination of the Precordium: Inspection and Palpation. Examination of the Heart, Part 3. Dallas, TX: American Heart Association; 1990 ³⁶	
			Tap	A clinical finding in which there is an abnormally increased and localized brief pulsation found on palpation of the chest wall over the heart, typically associated with ventricular hypertrophy or increased intraventricular pressure.			
			Palpable heart sound	A clinical finding in which a heart sound is felt during palpation of the chest wall.			
			PMI	A clinical finding demonstrating the pulsation associated with the contraction of the systemic ventricle. Typically associated with the apex of the heart.		Schlant RC, Hurst JW. Examination of the Precordium: Inspection and Palpation. Examination of the Heart, Part 3. Dallas, TX: American Heart Association; 1990 ³⁶	
Cardiac Examination – PMI Type			<ul style="list-style-type: none"> • Normal • Abnormally displaced • Abnormally located 				

(Continued)

Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Cardiac Examination – Heart Sounds	Auditory vibrations of varying intensity (loudness), frequency (pitch), quality, and duration noted during auscultation of the thorax as part of the examination of the cardiovascular system.	Heart sounds	Normal	A clinical finding in which the PMI is located in the midclavicular line, fifth intercostal space.			
			Abnormally displaced	A clinical finding in which the PMI is located lateral to the anticipated position in the left midclavicular clavicular line, fifth intercostal space.			
			Abnormally located	A clinical finding in which the PMI is located in a place other than the left anterior chest.			
			<ul style="list-style-type: none"> • S1 • S2 • S3 • S4 • Summation gallop • Systolic click • Opening snap • Rub • Whoop • Knock • Murmur 				
			S1	An auscultated finding describing the heart sound that occurs with ventricular systole and is produced mainly by closure of the atrioventricular valves, signifying the first heart sound.			
			S2	An auscultated finding describing the heart sound that signifies the beginning of diastole and is caused by closure of the semilunar valves, signifying the second heart sound.			
			S3	An auscultated finding describing a low-frequency sound that follows A2 in early diastole and corresponds with the first phase of rapid ventricular filling, signifying the third heart sound. It is normal in children and young adults, but abnormal in others.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷	

(Continued)

Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
S4			An auscultated finding that describes a low-frequency sound, heard late in diastole just before S1, caused by forceful atrial contractions, signifying the fourth heart sound. It is typically abnormal, except in highly trained athletes and the elderly.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷		
Summation gallop			An auscultated finding in which S3 and S4 fuse, during tachycardia or a prolonged PR interval or both.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷		
Systolic click			An auscultated finding describing a sharp, high-frequency sound heard during auscultation of the thorax caused by valvar prolapse or stenosis.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷		
Opening snap			An auscultated finding describing a crisp, sharp sound that can be heard in the midprecordial location, caused by thickening and deformity of the atrioventricular valve.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷		
Rub			An auscultated finding describing high or medium pitched and scratchy sound, generated by inflammation of the pericardial sac.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷		
Whoop			An auscultated finding describing a loud musical or sonorous vibratory systolic murmur that may be heard in patients with atrioventricular valve prolapse.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷		

(Continued)

Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Cardiac Examination – Heart Sounds, S1 Types	An auscultated finding describing the heart sound that occurs with ventricular systole and is produced mainly by closure of the atrioventricular valves, signifying the first heart sound.		Knock	An auscultated finding describing an early diastolic banging sound associated with pericardial constriction.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷	
			Murmur	An auscultated finding describing a series of audible vibrations of varying intensity (loudness), frequency (pitch), quality, configuration, and duration created by turbulent blood flow in the heart or surrounding vessels.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷	
			<ul style="list-style-type: none"> • Normally split S1 • Abnormal S1 • Widened split S1 • Reverse split S1 • Soft S1 • Loud S1 • Single S1 				
			Normally split S1	Auscultated finding in which there is appropriate splitting between the closure sounds of the atrioventricular valve.			
			Abnormal S1	An auscultated finding in which the components of the first heart sound are not normal.			
			Widened split S1	An auscultated finding in which the mitral and tricuspid closure sounds are wider apart in time than normal.			
			Reverse split S1	An auscultated finding in which the tricuspid valve closure sound occurs before the mitral closure sound.			
			Soft S1	An auscultated finding in which the sounds comprising the first heart sound are quieter than normal.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷	

(Continued)

Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Cardiac Examination – Heart Sounds, S2 Types	An auscultated finding describing the heart sound that signifies the beginning of diastole and is caused by closure of the semilunar valves, signifying the second heart sound.		Loud S1	An auscultated finding in which the sounds comprising the first heart sound are louder than normal.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷	
			Single S1	An auscultated finding in which the atrioventricular valve closure sounds occur so close together as to sound single.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷	
			<ul style="list-style-type: none"> • Normally split S2 • Abnormal S2 • Fixed split S2 • Widely split S2 • Reverse split S2 • Single S2 • Loud P2 (pulmonary component) of S2 				
			Normally split S2	An auscultated finding in which the semilunar valve closure sounds occur close together without occurring simultaneously and vary with respiration.		Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 ²⁷	
			Abnormal S2	An auscultated finding in which the semilunar valve closure sounds are not normal.			
			Fixed split S2	An auscultated finding in which the semilunar valve closure sounds do not vary with respiration.			
			Widely split S2	An auscultated finding in which the semilunar valve closure sounds occur further apart in time than normal.		The Stanford Medicine 25. Cardiac second heart sounds. Available at: http://stanfordmedicine25.stanford.edu/the25/cardiac.html ³⁰	

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Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Cardiac Examination – Heart Sounds, Location (Including Murmurs)			Reverse split S2	An auscultated finding in which the pulmonic valve closure sound occurs prior to the aortic valve closure sound.			
			Single S2	An auscultated finding in which the semilunar valve closure sounds occur simultaneously.			
			Loud P2 (pulmonary component) of S2	An auscultated finding in which the pulmonary valve closure sound is louder than normal.			
			<ul style="list-style-type: none"> • Apex • Left lower sternal border • Left middle sternal border • Left upper sternal border • Right upper sternal border 				
			Apex	The location on the precordium that corresponds to the location of the blunt extremity of the heart formed by the left ventricle.		Stedman's Medical Dictionary, 28th ed. Baltimore, MD: Wolters Kluwer; 2006 ⁸	
			Left lower sternal border	The location on the precordium that corresponds to the tricuspid region, between the fifth, and sixth intercostal spaces at the left sternal border; LLSB.		Tavel ME. Cardiac auscultation. A glorious past—but does it have a future? Circulation. 1996;93:1250–3 ³⁸	
			Left middle sternal border	The location on the precordium that corresponds to the region between the third and fifth intercostal spaces at the left sternal border.		See above.	
			Left upper sternal border	The location on the precordium that corresponds to the pulmonic region, between the second and third intercostal spaces at the left sternal border.		Tavel ME. Cardiac auscultation. A glorious past—but does it have a future? Circulation. 1996;93:1250–3 ³⁸	See above.

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Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Cardiac Examination – Heart Sounds, Phase of Murmur			Right upper sternal border	The location on the precordium that corresponds to the aortic region, between the second and third intercostal spaces at the right sternal border.		Tavel ME. Cardiac auscultation. A glorious past—but does it have a future? <i>Circulation</i> . 1996;93:1250–3 ²⁸	
			<ul style="list-style-type: none"> • Right middle sternal border • Right lower sternal border • Right lung field/right chest • Left lung field/left chest • Left anterior axillary line • Left axilla • Right anterior axillary line • Right axilla • Back • Infraclavicular, left • Infraclavicular, right • Systolic • Diastolic • Continuous • Continuous with diastolic spillover • Ejection systolic murmur 				
			Right middle sternal border	The location on the precordium that corresponds to the region between the third and fifth intercostal spaces at the right sternal border.			
			Right lower sternal border	The location on the precordium that corresponds to the region between the fifth, and sixth intercostal spaces at the right sternal border.			

(Continued)

Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
			Right lung field/right chest	The location on the thorax that corresponds to the location of the pleural apices, middle and lower or base, posteriorly, laterally and anteriorly of the right lung, covered during auscultation.		Adapted from YourDictionary. Lung-fields definition. Available at: http://www.yourdictionary.com/lung-fields ³⁵ AND Chandrasekar A. Auscultation of lungs - method of exam. Loyola University Medical Education Network. Available at: http://www.meddean.luc.edu/lumen/meded/medicine/pulmonar/pd/pstep29.htm ¹³	
			Left lung field/left chest	The location on the thorax that corresponds to the location of the pleural apices, middle and lower or base, posteriorly, laterally and anteriorly of the left lung, covered during auscultation.	Lung part [for lung field] Entire lung and left lung structure [for entire left lung]	Adapted from YourDictionary. Lung-fields definition. Available at: http://www.yourdictionary.com/lung-fields ³⁵ AND Chandrasekar A. Auscultation of lungs - method of exam. Loyola University Medical Education Network. Available at: http://www.meddean.luc.edu/lumen/meded/medicine/pulmonar/pd/pstep29.htm ¹³	
			Left anterior axillary line	The location on the thorax delineated by a coronal line on the anterior torso marked by the anterior axillary fold on the left side.	Trunk structure and vertical reference line OR Entire axillary region and structure of left axillary region		
			Left axilla	The location on the thorax delineated by a pyramid-shaped space forming the underside of the shoulder between the upper arm and the side of the chest on the left side.	Entire axillary region and structure of left axillary region	Mosby, Inc. Mosby's Dictionary of Medicine, Nursing & Health Professions. St. Louis, MO: Mosby/Elsevier; 2009 ²³	

(Continued)

Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
			Right anterior axillary line	The location on the thorax delineated by a coronal line on the anterior torso marked by the anterior axillary fold on the right side.	Trunk structure and vertical reference line OR Entire axillary region and structure of right axillary region		
			Right axilla	The location on the thorax delineated by a pyramid-shaped space forming the underside of the shoulder between the upper arm and the side of the chest on the right side.	Entire axillary region and structure of right axillary region		
			Back	The location on the thorax that describes the posterior portion of the trunk of the human body between the neck and the pelvis; the dorsum.	Back structure, including back of neck		
			Infraclavicular, left	The location that describes the anterior portion of the thorax directly below the left clavicle.	Thoracic structure		
			Infraclavicular, right	The location that describes the anterior portion of the thorax directly below the right clavicle.	Thoracic structure		
			Systolic	The phase of time during ventricular ejection in which the semilunar valve(s) are open.	Heart murmur, categorized by timing		
			Diastolic	The phase of time between ventricular ejection, in which the semilunar valve(s) are closed.	Heart murmur, categorized by timing		
			Continuous	The phase of time encompassing both systole and diastole.	Heart murmur, categorized by duration, and heart murmur, categorized by timing	Fang J, O'Gara P. The history and physical examination: evidence-based approach. In: Libby PP, Bonow RO, Mann DL, et al, eds. Braunwald's Heart Disease: A Textbook of Cardiovascular Medicine. 8th ed. Philadelphia, PA: Elsevier Science; 2008:138-9 ⁴	
			Continuous with diastolic spillover	The phase of time encompassing systole and the early part of diastole.			

(Continued)

Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Cardiac Examination – Heart Sounds, Systolic Murmur Types			Ejection systolic murmur	An auscultated finding of a heart murmur heard predominantly in midsystole, when ejection volume and velocity of blood flow are at their maximum; it is produced by ejection of blood into the pulmonary artery and aorta. Typically crescendo-decrescendo.	Midsystolic murmur		
			<ul style="list-style-type: none"> • Short • Medium • Long • Pansystolic/holosystolic • Early systolic • Midsystolic • Late systolic • Early diastolic • Mididiastolic • Late diastolic 				
			Short	A brief length of time after onset of a valve closure sound.	Heart murmur, categorized by duration		
			Medium	A medium length of time after a valve closure sound.			
			Long	An extended length of time after a valve closure sound.	Heart murmur, categorized by duration		
			Pansystolic/holosystolic	A length of time occupying the entire systolic interval, from first to second heart sounds.	Systolic murmur		
			Early systolic	A period of time describing the early portion of the ventricular ejection phase.			
			Midsystolic	A period of time describing the middle portion of the ventricular ejection phase.	Systolic murmur	Walker HK, Hall WD, Hurst JW. Clinical Methods: The History, Physical, and Laboratory Examinations. 3rd ed. Boston, MA: Butterworths; 1990 ³²	

(Continued)

Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings		
Cardiac Examination – Heart Sounds, Timing			Late systolic	A period of time describing the last half of the ventricular ejection phase. This may or may not extend to the second heart sound.	Cardiac feature	Walker HK, Hall WD, Hurst JW. <i>Clinical Methods: The History, Physical, and Laboratory Examinations</i> . 3rd ed. Boston, MA: Butterworths; 1990 ³²			
			<ul style="list-style-type: none"> • Middiastolic • Late diastolic • To and fro or systolic-diastolic murmur 						
			Middiastolic	A period of time describing the middle portion of the ventricular filling phase.					
			Late diastolic	A period of time describing the last half of the ventricular filling phase. This may or may not extend to the first heart sound.					
			To and fro or systolic-diastolic murmur	An auscultated finding associated with the accentuation of a heart murmur during both ventricular ejection and ventricular filling phases.				Sarkar A. <i>Bedside Cardiology</i> . New Delhi, India: Jaypee Brothers Medical Publishers (P) Ltd; 2012 ²⁵	
			<ul style="list-style-type: none"> • High frequency • Medium frequency • Low frequency 						
Cardiac Examination – Heart Sounds, Pitch			High frequency	An auscultated finding in which a heart sound is heard only with the diaphragm of the stethoscope.	Frequencies and general adjectival modifier				
			Medium frequency	An auscultated finding in which a heart sound with both the diaphragm and the bell of the stethoscope.	Frequencies				
			Low frequency	An auscultated finding in which a heart sound only with the bell of the stethoscope.	Frequencies and general adjectival modifier				

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Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Cardiac Examination – Heart Sounds, Grade			<ul style="list-style-type: none"> • Grade I • Grade II • Grade III • Grade IV • Grade V • Grade VI 	<p>An auscultated finding that is very soft or intermittently heard.</p> <p>An auscultated finding that is as loud as the breath sounds.</p> <p>An auscultated finding that is louder than the breath sounds.</p> <p>An auscultated finding that is louder than the breath sounds in the presence of a palpated thrill.</p> <p>An auscultated finding that is heard with the stethoscope on a 45-degree angle OR on its side in the presence of a palpated thrill.</p> <p>An auscultated finding that is heard with the stethoscope off of the chest wall OR with the naked ear.</p>			
Cardiac Examination – Heart Sounds, Murmurs, Characteristic			<ul style="list-style-type: none"> • Vibratory • Blowing • Harsh • Multifrequency • Squeaky • Machinery • Nonspecific 	<p>An auditory quality with a distinct groaning, croaking, buzzing or twanging quality.</p> <p>An auditory quality similar to the sound of a person blowing air.</p>	<p>Heart murmur, categorized by quality</p> <p>Heart murmur, categorized by quality</p>	<p>The American Heritage Medical Dictionary. Boston, MA: Houghton Mifflin Company; 2007⁹</p>	

(Continued)

Appendix 6. Continued
B. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
			Harsh	An auditory quality in which flow sounds to be highly turbulent.	Heart murmur quality, harsh	McConnell ME, Adkins SB 3rd, Hammon DW. Heart murmurs in pediatric patients: when do you refer? Am Fam Physician. 1999;60:558-64. ²⁰	
			Multifrequency	An auditory quality in which multiple frequencies are heard either simultaneously or in rapid succession.			
			Squeaky	An auditory quality in which the turbulence is brief and noted with the diaphragm of the stethoscope only.			
			Machinery	An auditory quality in which turbulence sounds similar to the workings of an industrial machine.			
			Nonspecific	An auditory quality in which there are no recognizable characteristics to describe the turbulent sound.			

AHA indicates American Heart Association; and PMI, point of maximum impulse.

Appendix 6. Continued
C. Extracardiac Examination

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
General Examination							
General Appearance			<ul style="list-style-type: none"> Well perfused Poorly perfused 				
			Well perfused	A clinical finding in which there is sufficient blood flow to the core and extremities.			
			Poorly perfused	A clinical condition in which there is insufficient blood flow to the core or to the extremities.			
Skin Examination	Examination of the skin on physical examination.	Extremity appearance	<ul style="list-style-type: none"> Normal Pallor Flushing Diaphoresis 				
			Normal	A clinical description of the skin in which there is appropriate color and perfusion.			
			Pallor	A clinical finding in which there appears to be a loss of color and/or perfusion, or a white appearance.			
			Flushing	A clinical finding in which there is reddening of the skin, typically with increased perfusion.			
			Diaphoresis	A clinical finding in which there is excessive or unpredictable sweating.			
Examination of the Abdomen							
Abdominal Examination – Auscultation	Abdominal findings on auscultation.		<ul style="list-style-type: none"> No abdominal bruits Abdominal bruits 				
			No abdominal bruits	A clinical finding in which there is absence of vascular sounds heard over major arteries in the abdomen.			

(Continued)

Appendix 6. Continued
C. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Abdominal Examination – Palpation	Abdominal findings on palpation.		Abdominal bruits	A clinical finding in which there is the presence of turbulent vascular sounds heard over one or more major arteries in the abdomen.		Walker HK, Hall WD, Hurst JW. Clinical Methods: The History, Physical, and Laboratory Examinations. 3rd ed. Boston, MA: Butterworths; 1990 ³²	
			<ul style="list-style-type: none"> • Normal • Hepatomegaly • Splenomegaly 				
Abdominal Inspection			Normal	A clinical finding in which there is no organomegaly or masses found on palpating the abdomen.			
			Hepatomegaly	A clinical finding in which the liver is found to be enlarged on abdominal palpation.			
			Splenomegaly	A clinical finding in which the spleen is found to be enlarged on abdominal palpation.			
			<ul style="list-style-type: none"> • Normal • Protuberant • Scaphoid 				
Examination of the Genitalia	Examination findings of the external genitalia on physical examination.		Normal	A clinical finding in which there are no abnormal findings on visual inspection of the abdomen.			
			Protuberant	A clinical finding in which there is unusual or prominent convexity of the abdomen on visual inspection.			
			Scaphoid	A clinical finding in which the anterior abdominal wall is sunken or has a concave appearance on visual inspection.			
Genital Examination – External Genitalia			<ul style="list-style-type: none"> • Normal • Edematous scrotum 				

(Continued)

Appendix 6. Continued
C. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
			Normal	A clinical finding in which the male external genitalia demonstrate no anomalies or abnormal findings on visual inspection.			
			Edematous scrotum	A clinical finding in which the scrotal skin is found to have become taut due to excessive fluid as noted on visual inspection.			
Examination of the Extremities							
Examination of Extremities – Appearance	Examination findings on the appearance of extremities on physical examination.	Extremity appearance	<ul style="list-style-type: none"> • Normal • Cyanosis • Clubbing • Edema 				
			Normal	A clinical finding in which the extremities demonstrate no anomalies of appearance or color.			
			Cyanosis	A clinical finding in which the skin is noted to have a bluish cast due to an increased concentration of deoxyhemoglobin in cutaneous blood vessels on visual inspection.			
			Clubbing	A clinical finding in which the distal phalanx of each finger appears rounded and bulbous, the nail plate is more convex, and the angle between the plate and the proximal nail fold appears increased to ≥ 180 degrees on visual inspection.			
			Edema	A clinical finding in which there is the accumulation of excessive fluid in the interstitial spaces, and appears as swelling on visual inspection.			

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Appendix 6. Continued
C. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Examination of the Extremities – Capillary Refill Time	The capillary nail refill test, also called the nail blanch test, is performed on the nail beds as an indicator of tissue perfusion (the amount of blood flow to tissue) and dehydration.	Capillary refill time (in seconds)	<ul style="list-style-type: none"> Normal Delayed 	<p>A clinical finding in which a capillary nail refill test returns to pink color in <2 seconds after pressure is removed.</p> <p>A clinical finding in which a capillary nail refill test returns to pink color in >2 seconds after pressure is removed.</p>			
			<p>Normal</p> <p>Delayed</p>				
Examination of Extremities – Pulses, Amplitude			<ul style="list-style-type: none"> 0 (absent) 1+ (decreased) 2+ (normal) 3+ (increased) 4+ (water hammer or markedly increased) 				
			0 (absent)	A clinical finding in which palpation of a pulse demonstrates no upstroke or amplitude.			
			1+ (decreased)	A clinical finding in which palpation of a pulse demonstrates a diminished upstroke and/or amplitude.			
			2+ (normal)	A clinical finding in which palpation of the pulse demonstrates appropriate upstroke, amplitude, and decay.			
			3+ (increased)	A clinical finding in which palpation of the pulse demonstrates a significantly increased upstroke and/or amplitude.			

(Continued)

Appendix 6. Continued
C. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Examination of Extremities – Pulses, Location			4+ (water hammer or markedly increased)	A clinical finding in which palpation of the pulse demonstrates a significantly increased upstroke, amplitude, and rapid decay.			
			<ul style="list-style-type: none"> • Brachial • Ulnar • Radial • Femoral • Dorsalis pedis • Posterior tibial • Carotid • Abdominal aorta 				
			Brachial	The artery of the upper arm, whose pulse can be palpated on the inner surface of the upper arm between the bodies of the biceps and triceps muscles.			
			Ulnar	The artery of the lower arm that supplies the medial part of the anterior compartment of the forearm, wrist and hand, the superficial structures of the central palm and most of the palmar and distal dorsal aspects of the fingers, whose pulse can be palpated on the flexor surface of the wrist medially.			
			Radial	The artery of the lower arm that supplies muscles of lateral portions of both the anterior and posterior compartment of the forearm, lateral aspect of the wrist, skin of the dorsum hand and proximal portions of digits, and deep muscles of pain whose pulsations can be palpated on the flexor surface of the wrist laterally.			

(Continued)

Appendix 6. Continued
C. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
			Femoral	The artery of the groin that supplies the lower extremity, including the anterior and anteromedial surfaces of the thigh, whose pulse is palpable below the inguinal ligament, midway between the anterior superior iliac spine and the symphysis pubis.			
			Dorsalis pedis	The artery of the foot that supplies the muscles on the dorsum of the foot whose pulses can be palpated on the dorsum of the foot just lateral to the extensor tendon of the big toe.			
			Posterior tibial	The artery of the foot that supplies the posterior and lateral compartment of the leg whose pulses can be palpated as it passes behind the medial malleolus of the ankle.			
			Carotid	The artery of the neck that arises from the aortic arch and terminates in the external and internal carotid arteries whose pulse can be palpated just medial to the sternocleidomastoid muscle.			
			Abdominal aorta	The lower part of the aorta in the abdomen prior to its bifurcation to the iliac arteries, whose pulse can be palpated at the level of the umbilicus.			

(Continued)

Appendix 6. Continued
C. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Examination of Extremities – Radial-Femoral Lag	Delay between the upstroke of the right radial pulse and a femoral pulse. Presence indicates coarctation of the aorta.		<ul style="list-style-type: none"> • Absent • Present 	A radial-femoral lag (or brachial-femoral lag or delay) is not present.		OSCE Skills. Peripheral vascular (PVS) examination. Available at: http://www.osceskills.com/e-learning/subjects/peripheral-vascular-examination/ ²⁴	
			Present	A radial-femoral lag (or brachial-femoral lag or delay) is a finding on physical examination when palpation of both the radial and femoral pulses on one side of the body at the same time, reveals a delay, suggesting the presence of coarctation of the aorta.		OSCE Skills. Peripheral vascular (PVS) examination. Available at: http://www.osceskills.com/e-learning/subjects/peripheral-vascular-examination/ ²⁴	

Appendix 7. Common Cardiac Diagnoses

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Murmur			<ul style="list-style-type: none"> Innocent murmur Pathologic murmur Still's murmur Venous hum Innocent pulmonary systolic murmur Carotid bruit Physiologic pulmonary artery stenosis Mammary souffle 				
			Innocent murmur	A clinical finding in which turbulent flow is noted by auscultation that is not associated with any structural cardiac defects.			
			Pathologic murmur	A clinical finding in which turbulent flow is noted by auscultation that is associated with a structural cardiac defect.			
			Still's murmur	An innocent murmur with a medium pitched, vibratory character heard at the apex, left lower sternal border, left middle sternal border, and right upper sternal border that disappears or becomes quieter and localizes to the left lower sternal border on upright position.			
			Venous hum	An innocent murmur with a medium pitched, blowing character with diastolic accentuation heard at the right or left upper sternal border that disappears with jugular venous compression or supine position.			
			Innocent pulmonary systolic murmur	An innocent murmur with a medium pitched, harsh character heard at the left middle and left upper sternal border that disappears with upright position.			
			Carotid bruit	An innocent murmur with a medium pitched, harsh character heard at the right or left upper sternal border, supraclavicular region, or anterior portion of the lower neck that disappears with bilateral shoulder hyperextension.			
			Physiologic pulmonary artery stenosis	An innocent murmur with a medium or high pitched, blowing character heard at the left middle sternal border that can also be heard at the same volume across the precordium and back that does not disappear with maneuvers but is only heard in infants <6 mo of age.			
			Mammary souffle	An innocent murmur with a medium or high pitched, blowing character with continuous flow with systolic accentuation heard over or above the breasts that disappears with compression of the breast tissue.			

(Continued)

Appendix 7. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Hypotension and Syncope			<ul style="list-style-type: none"> • Syncope • Syncope with exertion • Arrhythmic syncope • Syncope due to acquired heart lesion • Syncope due to congenital heart lesion • Syncope due to pulmonary hypertension • Neurally mediated/neurocardiogenic syncope • Vasodepressor syncope • Cardinhibitory syncope • Situational syncope • Carotid sinus syncope • Syncope due to migraine • Drug-induced syncope • Psychogenic syncope • Dysautonomia • Familial dysautonomia (Riley-Day, hereditary sensory and autonomic neuropathy type III) • Neurogenic orthostatic hypotension (multiple system atrophy, Shy-Drager syndrome) • Postural orthostatic tachycardia syndrome • Hypotension • Hypotension due to cardiac dysfunction • Hypotension due to drug • Orthostatic intolerance • Chronic orthostatic intolerance • Dizziness 				

(Continued)

Appendix 7. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Syncope			Syncope	A condition in which there is a sudden, brief loss of consciousness associated with loss of postural tone from which there is spontaneous recovery.			
Syncope with exertion			Syncope with exertion	A condition in which syncope occurs either during or after physical activity.			
Arrhythmogenic syncope			Arrhythmogenic syncope	A condition in which syncope occurs due to an arrhythmia.			
Syncope due to acquired heart lesion			Syncope due to acquired heart lesion	A condition in which syncope occurs due to a disease process of the heart with which the patient was not born.			
Syncope due to congenital heart lesion			Syncope due to congenital heart lesion	A condition in which syncope occurs due to a disease process of the heart with which the patient was born.			
Syncope due to pulmonary hypertension			Syncope due to pulmonary hypertension	A condition in which syncope occurs associated with a sudden and severe increase in pulmonary vascular resistance.			
Neurally mediated/neurocardiogenic syncope			Neurally mediated/neurocardiogenic syncope	A condition in which syncope occurs due to a brief imbalance of the autonomic nervous system.			
Vasodepressor syncope			Vasodepressor syncope	A condition in which neurally mediated syncope occurs in which the blood pressure falls and the heart rate increases.			
Cardioinhibitory syncope			Cardioinhibitory syncope	A condition in which neurally mediated syncope occurs in which the blood pressure falls and heart rate falls.			
Situational syncope			Situational syncope	A condition in which neurally mediated syncope occurs due to a specific circumstance, such as micturition, defecation, coughing, or traction of the hair.			
Carotid sinus syncope			Carotid sinus syncope	A condition in which neurally mediated syncope occurs due to massage of the carotid body.			
Syncope due to migraine			Syncope due to migraine	A condition in which syncope occurs associated with the occurrence of cerebral vasospasm.			
Drug-induced syncope			Drug-induced syncope	A condition in which syncope occurs due to the ingestion or administration of a chemical substance.			
Psychogenic syncope			Psychogenic syncope	A condition in which syncope occurs due to a conversion disorder.			
Dysautonomia			Dysautonomia	A condition in which there is a severe imbalance in the autonomic nervous system.			
Familial dysautonomia (Riley-Day syndrome, hereditary sensory and autonomic neuropathy type III)			Familial dysautonomia (Riley-Day syndrome, hereditary sensory and autonomic neuropathy type III)	A dysautonomia due to a genetic disorder associated with an abnormality of the sensory and autonomic nerves, decreased sensation of pain and decreased production of tears.			
Neurogenic orthostatic hypotension (multiple system atrophy, Shy-Drager syndrome)			Neurogenic orthostatic hypotension (multiple system atrophy, Shy-Drager syndrome)	A condition in which there is neurologic degeneration, postural tachycardia, and muscular rigidity.			

(Continued)

Appendix 7. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
			Postural orthostatic tachycardia syndrome	A type of chronic orthostatic intolerance lasting ≥ 3 months associated with excessive upright tachycardia in the absence of orthostatic hypotension, plus a constellation of typically daily symptoms that may include lightheadedness, dizziness, nausea, dyspnea, diaphoresis, headache, fatigue and other symptoms of autonomic dysfunction. Excessive tachycardia is defined by present consensus as a heart rate increase of at least 30 beats/min in adults (40 beats/min for adolescents), or a heart rate > 120 beats/min, within 10 min of upright tilt table testing.			
			Hypotension	A condition in which the blood pressure is less than the below the fifth percentile or below 2 standard deviations of the mean for age and sex.			
			Hypotension due to cardiac dysfunction	A condition in which there is hypotension because of inadequate pumping function of the heart.			
			Hypotension due to drug	A condition in which there is hypotension because of the effects of a medication or other substance.			
			Orthostatic intolerance	A condition in which there is the presence of ≥ 1 symptoms (eg, dizziness, lightheadedness, nausea, dyspnea, vision change) occurring specifically when assuming or maintaining upright position and resolving in the seated or supine position.			
			Chronic orthostatic intolerance	A condition in which there is orthostatic intolerance lasting for at least 3 mo with associated functional impairment.			
			Dizziness	A condition in which the sensation of lightheadedness or a feeling of movement within the head occurs.			
Chest Pain and Angina			<ul style="list-style-type: none"> • Chest pain • Noncardiac chest pain • Angina pectoris • Stable angina • Unstable angina • Prinzmetal angina • Microvascular angina (Syndrome X) • Musculoskeletal chest pain 				

(Continued)

Appendix 7. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
			<ul style="list-style-type: none"> Musculoskeletal chest pain due to costochondral junction syndrome (Tietze) Musculoskeletal chest pain due to costochondritis Musculoskeletal chest pain due to rib injury Musculoskeletal chest pain due to slipping rib syndrome Musculoskeletal chest pain due to sternal injury Musculoskeletal chest pain due to intercostal myofascial injury Musculoskeletal chest pain due to myositis Musculoskeletal chest pain due to myositis: enterovirus epidemic myalgia (pleurodynia) (Bornholm) Musculoskeletal chest pain: psychogenic Musculoskeletal chest pain: psychogenic with dysfunctional breathing (hyperventilation) Musculoskeletal chest pain: idiopathic/precordial catch syndrome (Texidor's twinge) 				
			Chest pain	Discomfort felt in the upper abdomen, thorax, neck, or shoulders.			
			Noncardiac chest pain	A condition in which there is chest pain that is not due to a cardiac etiology.			
			Angina pectoris	A condition in which there is severe chest pain due to myocardial ischemia.			
			Stable angina	A condition in which there is angina pectoris that occurs predictably with increasing amounts of stress or activity, resolves with cessation of activity, and has been present for ≥ 4 wks.			
			Unstable angina	A condition in which there is angina pectoris that occurs without stress or activity, or with decreasing stress or activity compared with stable angina, and has been present for < 2 wks.			

(Continued)

Appendix 7. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
			Prinzmetal angina	A condition in which there is angina pectoris due to spasm of the coronary artery.			
			Microvascular angina (Syndrome X)	A condition in which there is angina pectoris due to occlusion of the smaller coronary arteries.			
			Musculoskeletal chest pain	A condition in which there is chest pain due to an etiology in the structures making up the chest wall.			
			Musculoskeletal chest pain due to costochondral junction syndrome (Tietze)	A condition in which there is musculoskeletal chest pain associated with localized inflammation of at ≥ 1 joints between the rib and the costal cartilage.			
			Musculoskeletal chest pain due to costochondritis	A condition in which there is musculoskeletal chest pain associated with inflammation of ≥ 1 ribs and/or cartilages.			
			Musculoskeletal chest pain due to rib injury	A condition in which there is musculoskeletal chest pain secondary to trauma to ≥ 1 ribs.			
			Musculoskeletal chest pain due to slipping rib syndrome	A condition in which there is musculoskeletal chest pain associated with ≥ 1 ribs subluxing from the joint.			
			Musculoskeletal chest pain due to sternal injury	A condition in which there is musculoskeletal chest pain secondary to trauma to the sternum.			
			Musculoskeletal chest pain due to intercostal myofascial injury	A condition in which there is musculoskeletal chest pain secondary to trauma to the connective tissues between the ribs.			
			Musculoskeletal chest pain due to myositis	A condition in which there is musculoskeletal chest pain secondary to inflammation of the muscle tissue.			
			Musculoskeletal chest pain due to myositis: enterovirus epidemic myalgia (pleurodynia) (Bornholm)	A condition in which there is myositis secondary to an infectious etiology.			
			Musculoskeletal chest pain: psychogenic	A condition in which there is the sensation of musculoskeletal chest pain due to a conversion disorder.			
			Musculoskeletal chest pain psychogenic: with dysfunctional breathing (hyperventilation)	A condition in which there is musculoskeletal chest pain associated with inappropriate hyperventilation or tachypnea.			
			Musculoskeletal chest pain: idiopathic/precordial catch syndrome (Texidor's twinge)	A condition in which there is musculoskeletal chest pain characterized by brief, sharp discomfort associated with inspiration.			

(Continued)

Appendix 7. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
<p>Other Common Clinical Findings Noted During the Evaluation for Cardiac Disease</p>			<ul style="list-style-type: none"> • Symptomatic • Asymptomatic • Hypoxemia • Normal saturation • Desaturation • Heart failure • Cardiomegaly • Dyspnea • Tachypnea • Hyperpnea • Stridor • Wheezing • Coughing • Hemoptysis • Epistaxis • Poor feeding • Anorexia nervosa • Failure to thrive • Hypercyanotic spell • Palpitations • Irregular heart beat • Ascites • Fatigue (lassitude) • Delayed developmental milestones • Headache • Decreased exercise tolerance • Acrocyanosis • Breath-holding spell • Simple breath-holding spell • Complex breath-holding spell • Pallid breath-holding spell • Cyanotic breath-holding spell 				

(Continued)

Appendix 7. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
			Symptomatic	A clinical description in which a patient demonstrates evidence of ≥ 1 clinical finding suggestive of underlying pathology.			
			Asymptomatic	A clinical description in which a patient does not demonstrate evidence of clinical findings to suggest underlying pathology.			
			Hypoxemia	A clinical finding in which the arterial oxygen tension is lower than the normal range.			
			Normal saturation	A clinical finding in which the percentage of filled hemoglobin binding sites for oxygen is within the normal range.			
			Desaturation	A clinical finding in which the percentage of filled hemoglobin binding sites for oxygen is lower than the normal level.			
			Heart failure	A clinical condition in which the function of the heart is inadequate to meet the metabolic needs of the body.			
			Cardiomegaly	A clinical finding in which the heart is noted to be larger than normal.			
			Dyspnea	A clinical finding in which there is labored breathing.			
			Tachypnea	A clinical finding in which there is rapid breathing.			
			Hyperpnea	A clinical finding in which there is deeper breathing than normal.			
			Stridor	A clinical finding in which there is loud or harsh inspiratory noise associated with obstruction of the upper airway.			
			Wheezing	A clinical finding in which there is a raspy high-pitched whistling sound noted on expiration or inspiration associated with obstruction of the lower airways.			
			Coughing	A clinical finding in which there is forceful expulsion of air with a harsh sound.			
			Hemoptysis	A clinical finding in which blood is coughed up from the lungs.			
			Epistaxis	A clinical finding in which there is bleeding from the nose.			
			Poor feeding	A clinical finding in which a patient does not or is not able to take in food in normal amounts.			
			Anorexia nervosa	A clinical disorder in which a patient has an emotional abnormality characterized by an obsessive desire to lose weight by refusing to eat.			
			Failure to thrive	A clinical condition in which a patient has insufficient weight gain.			
			Hypercyanotic spell	A clinical finding in which a patient has profound cyanosis associated with hyperpnea; classically associated with tetralogy of Fallot.			

(Continued)

Appendix 7. Continued

Terminology Concept	Concept Definition	Suggested Data Element Label	Permissible Value	Permissible Value Definition	Parent Field	Sources	Mappings
Palpitations				A clinical historical feature in which there is the sensation of the heart beating abnormally in rate, rhythm, or force.			
Irregular heart beat				A clinical finding in which the rhythm of the heart is noted to be abnormal.			
Ascites				A clinical finding in which there is accumulation of interstitial fluid in the peritoneal cavity.			
Fatigue (lassitude)				A clinical historical feature in which there is extreme tiredness.			
Delayed developmental milestones				A clinical finding in which there is a failure to achieve expected mental or physical milestones for age.			
Headache				A clinical historical feature in which there is continuous pain in the head.			
Decreased exercise tolerance				A clinical finding in which there is inability to perform increased physical activity compared with normal levels for self or for age.			
Acrocyanosis				A clinical finding in which there is a bluish coloration noted in the distal portions of the extremities.			
Breath-holding spell				A clinical condition in which there is a brief involuntary cessation of breathing at end-expiration in response to emotional or painful stimulus seen in infants, toddlers, and children.			
Simple breath-holding spell				A clinical condition in which there is a breath-holding spell without syncope.			
Complex breath-holding spell				A clinical condition in which there is a breath-holding spell associated with syncope.			
Pallid breath-holding spell				A clinical condition in which there is a breath-holding spell associated with pale appearance.			
Cyanotic breath-holding spell				A clinical condition in which there is a breath-holding spell associated with cyanotic appearance.			

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

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Name	Employment	Consultant	Speaker	Ownership/ Partnership/ Principal	Research	Institutional, Organizational, or Other Financial Benefit	Expert Witness
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Lisa J. Bergensen	Boston Children’s Hospital— Associate in Cardiology	None	None	None	None	None	None
Steven D. Colan	Boston Children’s Hospital— Director of Clinical Research, Cardiology	None	None	None	None	None	None
Joanna Dangel	Medical University of Warsaw— Professor of Pediatric Cardiology	None	None	None	None	None	None
Curtis J. Daniels	Nationwide Children’s— Director	None	None	None	None	• ABIM	None

Name	Employment	Consultant	Speaker	Ownership/ Partnership/ Principal	Research	Institutional, Organizational, or Other Financial Benefit	Expert Witness
Robert Shaddy	Chief Professor - Children's Hospital of Philadelphia	None	None	None	None	None	None
Timothy Slesnick	Emory University School of Medicine—Assistant Professor of Pediatrics	None	None	None	None	None	None
David F. Vener	Texas Children's Hospital—Associate Professor, Pediatrics and Anesthesiology	None	None	None	None	None	None
Henry L. Walters III	Children's Hospital of Michigan—Chief, Cardiovascular Surgery	None	None	None	None	None	None
Paul M. Weinberg	Children's Hospital of Philadelphia—Director, Cardiac Registry	None	None	None	None	None	None

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