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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This document was approved by the American College of Cardiology Board of Trustees on May 25, 2017, the American Heart Association Science Advisory and Coordinating Committee on June 7, 2017, and the American Heart Association Executive Committee on June 30, 2017.


This article is copublished in Circulation: Cardiovascular Quality and Outcomes.

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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 regulations (1) 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.

Biykem Bozkurt, MD, PhD, FACC, FAHA
Chair, ACC/AHA Task Force on Clinical Data Standards

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, at least overlap with, other domains in our field. However, outpatient cardiology previously 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 homogeneous 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 Collaborative (3) 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 Surgery (5) 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 U.S. 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 Appendices 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 IPCCCC 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 to 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 to 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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KEYWORDS ACC/AHA Clinical Data Standards, electronic health records, congenital heart disease, pediatrics
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2017 AHA/ACC KEY DATA ELEMENTS AND DEFINITIONS FOR AMBULATORY ELECTRONIC HEALTH RECORDS IN PEDIATRIC AND CONGENITAL CARDIOLOGY

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<th>Name</th>
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<tr>
<td>Edwin A. Lomotan</td>
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<td>Leo Lopez</td>
<td>Nicklaus Children's Hospital—Medical Director, Noninvasive Cardiac Imaging</td>
<td>None</td>
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<tr>
<td>Ariane Marelli</td>
<td>McGill University Health Centre—Associate Professor of Medicine</td>
<td>None</td>
<td>None</td>
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<td>None</td>
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<tr>
<td>Gerard R. Martin</td>
<td>Children's National Health System—Medical Director of Global Health</td>
<td>None</td>
<td>None</td>
<td>None</td>
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<tr>
<td>G. Paul Matherne</td>
<td>University of Virginia Children's Hospital—Associate Chief Medical Officer</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
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<tr>
<td>Constantine Mavroudis</td>
<td>Johns Hopkins Children's Heart Surgery—Site Director</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
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<tr>
<td>Ken McCardle</td>
<td>Mount Sinai Health System—Senior Director, Clinical Operations</td>
<td>None</td>
<td>None</td>
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<tr>
<td>Gail D. Pearson</td>
<td>National Heart, Lung, and Blood Institute—Director, Adult and Pediatric Cardiac Research Program</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Geoffrey Rosenthal</td>
<td>University of Maryland—Director, Children's Heart Program</td>
<td>None</td>
<td>None</td>
<td>None</td>
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Continued on the next page
APPENDIX 1. CONTINUED

<table>
<thead>
<tr>
<th>Name</th>
<th>Employment</th>
<th>Consultant</th>
<th>Speaker</th>
<th>Ownership/Partnership/Principal</th>
<th>Research</th>
<th>Institutional, Organizational, or Other Financial Benefit</th>
<th>Expert Witness</th>
</tr>
</thead>
<tbody>
<tr>
<td>John S. Scott</td>
<td>Office of the Assistant Secretary of Defense, Health Affairs–Program Director, Clinical Informatics Policy</td>
<td>None</td>
<td>None</td>
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<tr>
<td>Gerald A. Serwer</td>
<td>C.S. Mott Children’s Hospital–Professor, Pediatrics</td>
<td>None</td>
<td>None</td>
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<tr>
<td>Stephen S. Seslar</td>
<td>Seattle Children’s Hospital–Associate Professor, Pediatric Cardiology</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
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</tr>
<tr>
<td>Robert Shaddy</td>
<td>Chief Professor-Children’s Hospital of Philadelphia</td>
<td>None</td>
<td>None</td>
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<tr>
<td>Timothy Slesnick</td>
<td>Emory University School of Medicine—Assistant Professor of Pediatrics</td>
<td>None</td>
<td>None</td>
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<tr>
<td>David F. Vener</td>
<td>Texas Children’s Hospital–Associate Professor, Pediatrics and Anesthesiology</td>
<td>None</td>
<td>None</td>
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<tr>
<td>Henry L. Walters III</td>
<td>Children’s Hospital of Michigan–Chief, Cardiovascular Surgery</td>
<td>None</td>
<td>None</td>
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<tr>
<td>Paul M. Weinberg</td>
<td>Children’s Hospital of Philadelphia—Director, Cardiac Registry</td>
<td>None</td>
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<td>None</td>
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</tbody>
</table>

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 ≥5% of the voting stock or share of the business entity, or ownership of ≥$5,000 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

<table>
<thead>
<tr>
<th>Name</th>
<th>Representation</th>
<th>Employment</th>
<th>Consultant</th>
<th>Speaker</th>
<th>Ownership/Partnership/Principal</th>
<th>Research</th>
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<tbody>
<tr>
<td>Geetha Raghuveer</td>
<td>ACC Board of Governors</td>
<td>Professor of Pediatrics—University of Missouri–Kansas City School of Medicine</td>
<td>None</td>
<td>None</td>
<td>None</td>
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<tr>
<td>David Kao</td>
<td>AHA Official Reviewer</td>
<td>Assistant Professor of Medicine—University of Colorado, Division of Cardiology</td>
<td>None</td>
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<td>None</td>
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</tr>
<tr>
<td>Michael A. Kutcher</td>
<td>Task Force Lead Reviewer</td>
<td>Professor of Cardiology—Wake Forest Baptist Health</td>
<td>None</td>
<td>None</td>
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<tr>
<td>Robert H. Beekman</td>
<td>Content Reviewer</td>
<td>Professor of Pediatric Cardiology—Children’s Hospital Medical Center of Cincinnati Ohio</td>
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<tr>
<td>Michele Grenier</td>
<td>Content Reviewer</td>
<td>Professor of Pediatrics—University of Mississippi Medical Center</td>
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<tr>
<td>Michael NIHil</td>
<td>Content Reviewer</td>
<td>Pediatric Cardiology—Baylor St. Luke’s Medical Center</td>
<td>None</td>
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</table>

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 ≥5% of the voting stock or share of the business entity, or ownership of ≥$5,000 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

<table>
<thead>
<tr>
<th>Terminology Concept</th>
<th>Suggested Data Element</th>
<th>Permissible Values</th>
<th>Permissible Value Definitions</th>
<th>Parent Field</th>
<th>Source of Definition Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chief Complaint</td>
<td></td>
<td>Murmur</td>
<td>An auscultated finding</td>
<td>NCI Thesaurus (10)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Palpitations</td>
<td>describing a series of audible vibrations of varying intensity</td>
<td>NCI Thesaurus (10)</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Chest pain</td>
<td>loudness), frequency (pitch),</td>
<td>NCI Code: C37999</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dizziness</td>
<td>quality, configuration, and</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Syncope</td>
<td>duration created by turbulent</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cyanosis</td>
<td>blood flow in the heart or</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Screening for</td>
<td>surrounding vessels.</td>
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<tr>
<td></td>
<td></td>
<td>cardiac condition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dyspnea</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Others</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Murmur</td>
<td>An unpleasant sensation of</td>
<td>NCI Thesaurus (10)</td>
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<tr>
<td></td>
<td></td>
<td>Palpitations</td>
<td>irregular and/or forceful</td>
<td>NCI Code: C37999</td>
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<tr>
<td></td>
<td></td>
<td>Chest pain</td>
<td>beating of the heart.</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Dizziness</td>
<td>A sensation of lightheadedness,</td>
<td>NCI Thesaurus (10)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Syncope</td>
<td>unsteadiness, turning,</td>
<td>NCI Thesaurus Code: C37943</td>
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<tr>
<td></td>
<td></td>
<td>Cyanosis</td>
<td>spinning, or rocking.</td>
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<tr>
<td></td>
<td></td>
<td>Screening for</td>
<td>Sudden loss of consciousness</td>
<td>ACC/AHA/HRS 2006 Key Data Elements and Definitions for Electrophysiological Studies and Procedures (12)</td>
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<tr>
<td></td>
<td></td>
<td>cardiac condition</td>
<td>with loss of postural tone,</td>
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<td></td>
<td></td>
<td></td>
<td>not related to anesthesia</td>
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<td></td>
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<td>with spontaneous recovery</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>as reported by patient or</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>observer. Patient may</td>
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<td></td>
<td></td>
<td></td>
<td>experience syncope when</td>
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<td></td>
<td></td>
<td></td>
<td>supine.</td>
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<td></td>
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<td>Murmur</td>
<td>A bluish or purplish</td>
<td>NCI Thesaurus (10)</td>
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<td>Palpitations</td>
<td>discoloration of the skin</td>
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<td></td>
<td></td>
<td>Chest pain</td>
<td>and mucous membranes</td>
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<tr>
<td></td>
<td></td>
<td>Dizziness</td>
<td>resulting from a reduced</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Syncope</td>
<td>concentration of oxygenated</td>
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<td></td>
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<tr>
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<td>hemoglobin in the blood.</td>
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<td>Screening for</td>
<td>Evaluation of relevant</td>
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<tr>
<td></td>
<td></td>
<td>cardiac condition</td>
<td>coexisting conditions (e.g., T21,</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>XO, Marfan, cleft palate,</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>family history).</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Other</td>
<td></td>
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#### Chief Complaint - Timing

<table>
<thead>
<tr>
<th>Chief Complaint - Onset</th>
<th>Time interval from onset/recognition of &quot;chief complaint&quot; to present</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Integer field Number corresponding to time since onset.</td>
</tr>
<tr>
<td></td>
<td>Units Appropriate time units for reported period, including days,</td>
</tr>
<tr>
<td></td>
<td>weeks, months, or years.</td>
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#### Chief Complaint - Periodicity

<table>
<thead>
<tr>
<th>Chief Complaint - Periodicity</th>
<th>Recurrence at regular intervals of time of the chief complaint.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intermittent</td>
<td>Periodically stopping and starting.</td>
</tr>
<tr>
<td>Continuous</td>
<td>Continuously present.</td>
</tr>
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</table>

*Continued on the next page*
## Terminology

<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
<th>Suggested Data Element</th>
<th>Permissible Values</th>
<th>Permissible Value Definitions</th>
<th>Parent Field</th>
<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chief Complaint - Frequency</strong></td>
<td>The number of occurrences of a periodic process in a unit of time.</td>
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<tr>
<td></td>
<td>Multiple times/day</td>
<td>More than once per day.</td>
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<tr>
<td></td>
<td>Daily</td>
<td>Occurs on average once per day.</td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td>Weekly</td>
<td>Occurs once to several times per week.</td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td>Monthly</td>
<td>Occurs once to several times per month.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| **Chief Complaint - Time of Day** | The time of day the chief complaint typically occurs. | | | | | |
| | Morning | The first part or period of the day, extending from dawn, or from midnight, to noon. | | | | |
| | Midday | The middle of the day; noon or the time centering around noon. | | | | |
| | Afternoon | The time from noon until evening; pertaining to the latter part of the day. | | | | |
| | Evening | The latter part of the day and early part of the night; the period from sunset to bedtime. | | | | |
| | Night | The period of darkness between sunset and sunrise. | | | | |
| | Unknown | | | | | |

| **Chief Complaint - Duration** | The length of time the chief complaint occurs. | | | | | |
| | Integer field | Number corresponding to the duration. | | | | |
| | Units | Appropriate time units for reported duration. | | | | |

| **Chief Complaint - Severity** | The intensity of the chief complaint as perceived by the patient. | | | | | |
| | 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. | | | | |
| | Integer 0-10 | Infant Behavioral FLACC Scale: 0-10-point scale based in caregiver's observation of infant's behavior. | | | | |


# APPENDIX 3. CONTINUED

<table>
<thead>
<tr>
<th>Terminology Concept</th>
<th>Definition</th>
<th>Suggested Data Element</th>
<th>Permissible Values</th>
<th>Permissible Value Definitions</th>
<th>Parent Field</th>
<th>Source of Definition Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Chief Complaint - Context</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercurrent Illness Present</td>
<td>Presence of other illnesses at the time the chief complaint started.</td>
<td></td>
<td>Yes</td>
<td>The patient was unwell at the time the chief complaint was manifested.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
<td>The patient was in her/his usual state of health when the chief complaint was manifested.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Unknown</td>
<td>Whether the patient experienced an intercurrent illness at the time the chief complaint became manifest is unknown.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prior Evaluation</td>
<td>In clinical medicine, assessment of the patient for the purposes of forming a diagnosis and plan of treatment, before the current chief complaint.</td>
<td></td>
<td>Yes</td>
<td>The patient has undergone previous subspecialty evaluation for the same chief complaint.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No</td>
<td>The patient has not undergone previous subspecialty evaluation for the same chief complaint.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Unknown</td>
<td>It is unknown if the patient has undergone previous subspecialty evaluation for the same chief complaint.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 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

### Prior Evaluation: Tests Performed
- Tests performed as part of the previous evaluation of chief complaint.
- 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.

Continued on the next page
## APPENDIX 3. CONTINUED

<table>
<thead>
<tr>
<th>Terminology Concept</th>
<th>Definition</th>
<th>Suggested Data Element</th>
<th>Permissible Values</th>
<th>Permissible Value Definitions</th>
<th>Parent Field</th>
<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise stress test</td>
<td>A graded test to measure an individual’s heart rate and oxygen intake while undergoing strenuous physical exercise, as on a treadmill.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiac MRI</td>
<td>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.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiac CT</td>
<td>A noninvasive medical imaging technology that uses x-ray procedure with the aid of computer to generate cross-sectional images of the heart.</td>
<td></td>
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</tr>
<tr>
<td>Cardiac catheterization</td>
<td>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.</td>
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<tr>
<td>EP study/EP test</td>
<td>An invasive procedure that tests the electrical conduction system of the heart to assess the electrical activity and conduction pathways of the heart.</td>
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</tr>
<tr>
<td>Prior Evaluation: Diagnosis</td>
<td>Diagnosis given based on the previous evaluation of the chief complaint.</td>
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<tr>
<td>Prior Evaluation: Previous Therapies</td>
<td>Treatment recommendations from previous evaluation of the chief complaint.</td>
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<tr>
<td>Medications</td>
<td>A drug or substance used to treat a medical condition.</td>
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<tr>
<td>Interventional catheterization</td>
<td>The performance of a cardiac catheterization with the intent of making a modification to the structures of the heart or surrounding vessels.</td>
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</tr>
<tr>
<td>Catheter ablation/ radiofrequency ablation/cryoablation</td>
<td>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.</td>
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<td></td>
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</tr>
<tr>
<td>Cardiac surgery</td>
<td>The surgical treatment of diseases affecting the heart and blood vessels inside the thorax.</td>
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</tbody>
</table>

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### APPENDIX 3. CONTINUED

<table>
<thead>
<tr>
<th>Terminology Concept</th>
<th>Definition</th>
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<th>Permissible Value Definitions</th>
<th>Parent Field</th>
<th>Source of Definition Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietary: Routine Caffeine Intake</td>
<td>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.</td>
<td>Yes</td>
<td>Yes</td>
<td>Intake of caffeine routinely occurring as frequently as at least every other day.</td>
<td>No</td>
<td>Unknown</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No</td>
<td>No</td>
<td></td>
<td>Unknown</td>
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<td></td>
<td></td>
<td>Unknown</td>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dietary: Caloric Intake</td>
<td>Caloric intake based on age, BSA and comorbid conditions.</td>
<td>Yes</td>
<td>Adequate</td>
<td>Adequate caloric intake Sufficient caloric intake per day.</td>
<td>Inadequate</td>
<td>Inadequate caloric intake Deficient caloric intake per day.</td>
</tr>
<tr>
<td>Dietary: Fluid Intake</td>
<td>The quantities of liquid taken in and used by the body.</td>
<td>Yes</td>
<td>Adequate</td>
<td>Adequate Qualitative state of being sufficient for a specific purpose.</td>
<td>Inadequate</td>
<td>Inadequate Qualitative state of not being sufficient for a specific purpose.</td>
</tr>
<tr>
<td>Dietary: Salt Intake</td>
<td>The quantities of sodium chloride (or common salt) taken in and used by the body.</td>
<td>Yes</td>
<td>Adequate</td>
<td>Adequate Qualitative state of being sufficient for a specific purpose.</td>
<td>Inadequate</td>
<td>Inadequate Qualitative state of not being sufficient for a specific purpose.</td>
</tr>
<tr>
<td>History of Trauma</td>
<td>Chief complaint is caused by traumatic event.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Witnessed</td>
<td>Chief complaint witnessed or seen by bystander.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

Continued on the next page
### Chief Complaint - Associated Signs and Symptoms

<table>
<thead>
<tr>
<th>Terminology Concept</th>
<th>Definition</th>
<th>Suggested Data Element</th>
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<th>Parent Field</th>
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</tr>
</thead>
</table>
| Associated Symptoms | Symptoms and signs present with the chief complaint. | - Bowel incontinence  
- Bladder incontinence  
- Carpal spasm  
- Chest pain  
- Cough  
- Cyanosis  
- Diaphoresis  
- Dizziness  
- Dyspnea  
- Fatigue with feeding  
- Face plant  
- 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. | NCI Thesaurus (10) | NCI Thesaurus Code: C78498 |

**Bowel incontinence**

Inability to control the escape of stool from the rectum.

**Bladder incontinence**

Inability to control the flow of urine from the bladder.

**Carpal spasm**

A spasmodic contraction of the muscles of the hands, especially the wrists, such as during alkaliosis or tetany.

**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.

**Cyanosis**

A bluish or purplish discoloration of the skin and mucous membranes resulting from a reduced amount of oxygenated hemoglobin in the blood.

**Diaphoresis**

Indicator to signify the presence of the symptom of excessive sweating.

**Dizziness**

A sensation of lightheadedness, unsteadiness, turning, spinning, or rocking.

Continued on the next page
<table>
<thead>
<tr>
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<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyspnea</td>
<td>An uncomfortable sensation of difficulty breathing. It may present as an acute or chronic sign of an underlying respiratory or heart disorder.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C2998</td>
<td></td>
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</tr>
<tr>
<td>Fatigue with feeding</td>
<td>A state of increased discomfort and decreased efficiency due to prolonged or excessive exertion during the taking of food.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C34661</td>
<td></td>
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</tr>
<tr>
<td>Faceplant</td>
<td>A type of syncope in which there is no attempt to protect oneself from the effects of the fall.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C50590</td>
<td></td>
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</tr>
<tr>
<td>Headache</td>
<td>Pain in various parts of the head, not confined to the area of distribution of any nerve.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C78416</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Hyperventilation</td>
<td>Abnormally prolonged, rapid, and deep breathing.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C30635</td>
<td></td>
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</tr>
<tr>
<td>Lethargy</td>
<td>Experience of decreased consciousness characterized by mental and physical inertia.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C3258</td>
<td></td>
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</tr>
<tr>
<td>Loss of consciousness</td>
<td>A level of awareness that can be described as consistently not responsive to stimuli.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C39594</td>
<td></td>
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</tr>
<tr>
<td>Nausea</td>
<td>The sensation that one is about to vomit.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C2962</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Numbness/tingling</td>
<td>(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.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C34857; (2): C50771</td>
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</tr>
<tr>
<td>Pallor</td>
<td>An unusual or extreme paleness, state of decreased skin coloration.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C39999</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Palpitations</td>
<td>An unpleasant sensation of irregular and/or forceful beating of the heart.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C2962</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Pedal spasm</td>
<td>A spasmodic contraction of the muscles of the feet, especially the ankles, such as during alkalosis or tetany.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C2962</td>
<td></td>
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</tr>
<tr>
<td>Postictal confusion</td>
<td>Period of confusion post seizure in which the patient does not respond appropriately although appearing “awake”.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C39994</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Rash</td>
<td>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.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C2962</td>
<td></td>
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</tr>
<tr>
<td>Seizure</td>
<td>Sudden, involuntary skeletal muscular contractions of cerebral or brain stem origin.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C2962</td>
<td></td>
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</tr>
<tr>
<td>Sensation of cold</td>
<td>An internal feeling of being cooler without a concomitant change in the ambient environment.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C2962</td>
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</tbody>
</table>

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<tr>
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<th>Source of Definition Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensation of heat</td>
<td>An internal feeling of being warmer without a concomitant change in the ambient environment.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Sleep disturbance</td>
<td>An interruption, departure, or divergence from that which is considered normal in sleep.</td>
<td></td>
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</tr>
<tr>
<td>Syncope</td>
<td>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.</td>
<td>ACC/AHA/HRS 2006 Key Data Elements and Definitions for Electrophysiological Studies and Procedures (12)</td>
<td></td>
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</tr>
<tr>
<td>Tongue-biting</td>
<td>Clamping of the teeth on the tongue, as can accompany a seizure.</td>
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</tr>
<tr>
<td>None</td>
<td>No associated symptoms/signs present.</td>
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</tr>
</tbody>
</table>

**Chief Complaint - Modifying Factors**

**Exacerbating Factors**

Factors causing the chief complaint to worsen.

- 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

Caffeine intake

Intake of caffeine routinely occurring as frequently as at least every other day.

Change to upright position

The state of going from a supine or seated position to a standing position.

Increased emotional state

A state of mental excitement, characterized by alteration of feeling tone and by physiological and behavioral changes.

Defecation

The evacuation of fecal matter from the rectum.

Exercise

Performance of physical exertion for improvement of health or correction of physical deformity.

Hair brushing

The use of an implement, consisting of bristles, attached to a handle to groom hair.
<table>
<thead>
<tr>
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<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hot weather</td>
<td>Increased ambient temperature.</td>
<td></td>
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</tr>
<tr>
<td>Hot bath/shower</td>
<td>Bathing with water that has an extremely elevated temperature.</td>
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<td></td>
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</tr>
<tr>
<td>Inspiration</td>
<td>The drawing of air into the lungs.</td>
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<tr>
<td>Intercurrent illness</td>
<td>A disease occurring during the course of another disease with which it has no connection.</td>
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<td></td>
</tr>
<tr>
<td>Leaning forward</td>
<td>Tilting the upper body so that the head and chest extends beyond the waist.</td>
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<tr>
<td>Menses</td>
<td>The monthly flow of blood from the female genital tract.</td>
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</tr>
<tr>
<td>Micturition</td>
<td>Urination, the act of emptying the bladder of urine.</td>
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<tr>
<td>Movement</td>
<td>An act of moving; motion.</td>
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<tr>
<td>Noxious stimulus</td>
<td>Hurtful, injurious, pernicious agent that produces a reaction in a receptor or tissue.</td>
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<tr>
<td>Pain</td>
<td>A feeling of distress, suffering, or agony, caused by stimulation of specialized nerve endings.</td>
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</tr>
<tr>
<td>Palpation</td>
<td>The act of feeling with the hand.</td>
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</tr>
<tr>
<td>Prolonged standing</td>
<td>The state of being in an upright position continuing for a time greater than what would be considered normal.</td>
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<tr>
<td>Startle</td>
<td>To make a quick involuntary movement as in alarm, surprise, or fright.</td>
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<tr>
<td>Stretching</td>
<td>An activity that elongates shortened soft-tissue structures and thereby increases flexibility.</td>
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<tr>
<td>Supine position</td>
<td>Lying with the face upward or on the dorsal surface.</td>
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<tr>
<td>Swimming</td>
<td>Propel the body through the water by using the limbs.</td>
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</tbody>
</table>

**Other**

None

**Alleviating Factors**

Factors making the chief complaint better.

- Antacid medications
- Inspiration
- Isometric countermeasures
- 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 countermeasures

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.


### 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.

### Chief Complaint - Other Data Qualifiers

#### Location of Chest Pain

The location of chest pain.

- **Sternum**
- **Sternal border**
- **Midclavicular line**
- **Intercostal space**
- **Epigastrium**
- **Anterior axillary line**

<table>
<thead>
<tr>
<th>Sternum (lower, mid, upper)</th>
<th>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.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sternal border (left lower/mid/upper; right lower/mid/upper)</td>
<td>Location is along the lateral edge of the sternum.</td>
</tr>
<tr>
<td>Middiavicular line (right/left)</td>
<td>Location is along an imaginary vertical line on the chest originating from the midpoint of a clavicle.</td>
</tr>
<tr>
<td>Intercostal space (right/left, 2/3/4/5)</td>
<td>Location is in the area defined by a superior rib margin and an inferior rib margin.</td>
</tr>
<tr>
<td>Epigastrium</td>
<td>The upper and middle region of the abdomen, located within the sternal angle.</td>
</tr>
<tr>
<td>Anterior axillary line (right/left)</td>
<td>Location is along an imaginary vertical line that descends along the lateral aspect of the chest wall originating from the armpit.</td>
</tr>
</tbody>
</table>
### Radiation of Chest Pain

The part of the body to where the chest pain radiates.

<table>
<thead>
<tr>
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<th>Permissible Value Definitions</th>
<th>Parent Field</th>
<th>Source of Definition Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>The chest pain does not radiate.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left arm</td>
<td>The chest pain radiates to the left arm.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neck</td>
<td>The chest pain radiates to the neck.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Back</td>
<td>The chest pain radiates to the back.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abdomen</td>
<td>The chest pain radiates to the abdomen.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sternum (lower, mid, upper)</td>
<td>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.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sternal border (left lower/mid/upper; right lower/mid/upper)</td>
<td>Location is along the lateral edge of the sternum.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middiavicular line (right/left)</td>
<td>Location is along an imaginary vertical line on the chest originating from the midpoint of a clavicle.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anterior axillary line (right/left)</td>
<td>Location is along an imaginary vertical line that descends along the lateral aspect of the chest wall originating from the arm pit.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>The chest pain radiates to an area not specified.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Quality of Chest Pain

The characteristics of chest pain as described by the patient.

<table>
<thead>
<tr>
<th>Suggested Data Element</th>
<th>Permissible Values</th>
<th>Permissible Value Definitions</th>
<th>Parent Field</th>
<th>Source of Definition Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharp pain</td>
<td>A sensation of a stabbing feeling.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dull pain</td>
<td>A sensation of mild or blunted discomfort.</td>
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</tr>
<tr>
<td>Burning pain</td>
<td>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.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Tearing pain</td>
<td>A sensation of a sharp, lacerating, intense, discomfort, sometimes used to describe the pain felt during an aortic dissection.</td>
<td></td>
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</tr>
<tr>
<td>Pressure pain</td>
<td>A sensation of an object creating physical force.</td>
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</table>
### APPENDIX 3. CONTINUED

<table>
<thead>
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<th>Terminology Concept</th>
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<th>Permissible Value</th>
<th>Permissible Value Definitions</th>
<th>Parent Field</th>
<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Palpitations</td>
<td>The characteristics of the palpitations as described by the patient.</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Skipped/early heartbeats</td>
<td>The sensation of an isolated cardiac contraction occurring prior to the normal or regular rhythm.</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Forceful heartbeats</td>
<td>The sensation of an isolated cardiac contraction occurring with greater strength than that of a typical or normal contraction.</td>
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<tr>
<td></td>
<td></td>
<td>Racing heartbeats</td>
<td>The sensation of an abnormally rapid heart rate.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Activity Associated With Chief Complaint</td>
<td>Associated activity when chief complaint occurs or that induces onset of the chief complaint.</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>At rest</td>
<td>Chief complaint typically occurs at rest.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>During exercise</td>
<td>Chief complaint typically occurs during exercise.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>After exercise</td>
<td>Chief complaint typically occurs on conclusion of exercise.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>No pattern</td>
<td>Chief complaint occurs both at rest and with exercise.</td>
<td></td>
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</tr>
</tbody>
</table>

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

### APPENDIX 4. RISK FACTORS

<table>
<thead>
<tr>
<th>Terminology Concept</th>
<th>Definition</th>
<th>Suggested Data Element</th>
<th>Permissible Value</th>
<th>Permissible Value Definitions</th>
<th>Parent Field</th>
<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of CHD</td>
<td>Any abnormality of cardiac structure or function present at birth.</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>No</td>
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<tr>
<td></td>
<td></td>
<td>Unknown</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Age Diagnosed</td>
<td>The age of the patient when CHD was diagnosed.</td>
<td>Age</td>
<td></td>
<td>In days, weeks, months, or years.</td>
<td></td>
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</tr>
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</table>

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### APPENDIX 4. CONTINUED

<table>
<thead>
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<th>Terminology Concept</th>
<th>Definition</th>
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<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presenting Finding</td>
<td>The presenting findings of CHD.</td>
<td>murmurs</td>
<td>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.</td>
<td>NCI Thesaurus (10) NCI Thesaurus Code: C26737</td>
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<tr>
<td>Cyanosis</td>
<td>A bluish or purplish discoloration of the skin and mucous membranes resulting from a reduced amount of oxygenated hemoglobin in the blood.</td>
<td>cyanosis</td>
<td>NCI Thesaurus (10) NCI Thesaurus Code: C27165</td>
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<td></td>
</tr>
<tr>
<td>Respiratory distress</td>
<td>A pathological increase in the effort and frequency of breathing movements.</td>
<td>respiratory distress</td>
<td>NCI Thesaurus (10) NCI Thesaurus Code: C27165</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>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.</td>
<td>fatigue</td>
<td>NCI Thesaurus (10) NCI Thesaurus Code: C3036</td>
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</tr>
<tr>
<td>Failure to thrive</td>
<td>Weight below the third to fifth percentile or a decrease in the percentile rank of two major growth parameters in a short period.</td>
<td>failure to thrive</td>
<td>NCI Thesaurus (10) NCI Thesaurus Code: C27165</td>
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<tr>
<td>Multiple anomalies</td>
<td>Presence of multiple congenital malformations.</td>
<td>multiple anomalies</td>
<td>NCI Thesaurus (10) NCI Thesaurus Code: C27165</td>
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</tr>
<tr>
<td>Family history of CHD</td>
<td>Having a first-degree or first- and second-degree relative with a history of CHD.</td>
<td>family history of CHD</td>
<td>NCI Thesaurus (10) NCI Thesaurus Code: C27165</td>
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<tr>
<td>Other</td>
<td>The treatment the patient had for CHD.</td>
<td>intervention(s)</td>
<td>Medications, Infective endocarditis prophylaxis, Cardiac catheterization, Interventional catheterization, Surgery</td>
<td>NCI Thesaurus (10) NCI Thesaurus Code: C27165</td>
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<tr>
<td>Medications</td>
<td>A drug or substance used to treat a medical condition.</td>
<td>medications</td>
<td>IE prophylaxis</td>
<td>NCI Thesaurus (10) NCI Thesaurus Code: C27165</td>
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<tr>
<td>IE prophylaxis</td>
<td>The giving of antibiotic therapy for the prevention of endocarditis.</td>
<td>IE prophylaxis</td>
<td>NCI Thesaurus (10) NCI Thesaurus Code: C27165</td>
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</thead>
<tbody>
<tr>
<td>Cardiac catheterization</td>
<td>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.</td>
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<tr>
<td>Interventional catheterization</td>
<td>The performance of a cardiac catheterization with the intent of making a modification to the structures of the heart or surrounding vessels.</td>
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<tr>
<td>Cardiac surgery</td>
<td>The surgical treatment of diseases affecting the heart and blood vessels inside the thorax.</td>
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<tr>
<td>Myopathy</td>
<td>A nontraumatic and nonneoplastic disease of the muscles.</td>
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<tr>
<td>Duchenne</td>
<td>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.</td>
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<tr>
<td>Becker</td>
<td>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.</td>
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<tr>
<td>No</td>
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<tr>
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<th>Source of Definition</th>
<th>Mapping</th>
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</thead>
<tbody>
<tr>
<td>Other Muscular Dystrophies and Storage Diseases That Lead to Cardiomyopathies</td>
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<td></td>
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<tr>
<td>Limb girdle dystrophy</td>
<td>A group of muscular dystrophies due to mutations in a variety of genes, predominantly affecting the proximal muscles of the arms and legs.</td>
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<tr>
<td>Myotonic dystrophy</td>
<td>An inherited progressive disorder affecting the muscles.</td>
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</tr>
<tr>
<td>Mitochondrial</td>
<td>Muscular dystrophy secondary to a mitochondrial disorder.</td>
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<tr>
<td>Ox/Phos</td>
<td>Muscular dystrophy secondary to a genetic defect that interferes with oxidative phosphorylation frequently associated with severe neurologic abnormalities.</td>
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<tr>
<td>Glycogen storage disorder</td>
<td>Myopathy secondary to glycogen accumulation related to an enzymatic deficiency or absence.</td>
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<tr>
<td>Fatty acid oxidation disorder</td>
<td>Myopathy secondary to a genetic defect in fatty acid metabolism.</td>
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<tr>
<td>None</td>
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<tr>
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</table>

**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.


<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
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<tbody>
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<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Symptom Onset</strong></td>
<td>Date of the first onset of the symptoms of Kawasaki disease.</td>
<td>Date</td>
<td>mm-dd-yyyy</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td><strong>Age When First Noted</strong></td>
<td>The age of the patient when the symptoms of Kawasaki disease were first noted.</td>
<td>Integer</td>
<td>Age in days, weeks, months, or years.</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td><strong>Symptoms</strong></td>
<td>The symptoms of Kawasaki disease that the patient had.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Fever</td>
<td>The elevation of the body’s temperature above the upper limit of normal, usually taken as 37.7°C.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C3038</td>
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<tr>
<td></td>
<td>Rash</td>
<td>Any change in the skin which affects its appearance or texture. The rash in Kawasaki disease can be polymorphous and typically includes the groin.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C39594</td>
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</tr>
<tr>
<td></td>
<td>Conjunctivitis</td>
<td>Inflammation of the conjunctiva of the eye. The conjunctivitis of Kawasaki disease is nonexudative and spares the limbus.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C34504</td>
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<tr>
<td></td>
<td>Cheilitis</td>
<td>An inflammatory process affecting the lips.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C7954</td>
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<tr>
<td></td>
<td>Strawberry tongue</td>
<td>The pathological finding of the tongue in which the tongue has an appearance of a strawberry.</td>
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<tr>
<td></td>
<td>Lymphadenopathy</td>
<td>A clinical finding indicating that a lymph node is enlarged. The lymphadenopathy of Kawasaki disease is a single anterior cervical lymph node.</td>
<td>NCI Thesaurus (10)</td>
<td>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</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Arthralgia</td>
<td>Pain in a joint.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C50464</td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Erythema of the palms and/or soles</td>
<td>Red discoloration of the skin caused by infectious agents, drug hypersensitivity, or underlying diseases.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C26901</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Edema of the palms and/or soles</td>
<td>Accumulation of an excessive amount of watery fluid in cells or intercellular tissues.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C3002</td>
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<thead>
<tr>
<th>Terminology Concept</th>
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<th>Parent Field</th>
<th>Source of Definition Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Desquamation</td>
<td>Peeling of the skin that typically starts at the tips of the fingers/toes.</td>
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<tr>
<td>Labile affect</td>
<td>Emotional instability characterized by rapid and dramatic mood swings.</td>
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</tr>
<tr>
<td>Abdominal pain</td>
<td>The sensation of discomfort in the abdominal region.</td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C26682</td>
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<tr>
<td>Dehydration</td>
<td>A condition resulting from the excessive loss of water from the body.</td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C26740</td>
<td></td>
<td></td>
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<tr>
<td>Gallbladder hydrops</td>
<td>Enlargement of the gallbladder secondary to prolonged obstruction of the cystic duct that is non-obstructive.</td>
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</table>

#### Kawasaki Z-Score Classification

- Classification for the size of aneurysm in Kawasaki disease.
  - No involvement
  - Dilatation only
  - Small aneurysm
  - Medium aneurysm
  - Large or giant aneurysm


<table>
<thead>
<tr>
<th>Classification</th>
<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Source of Definition Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>No involvement</td>
<td>Always &lt; 2 mm</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dilatation only</td>
<td>From 2 to 2.5 mm, or if initially &lt; 2, a decrease in Z score during follow-up ≥1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small aneurysm</td>
<td>≥2.5 to &lt; 5 mm</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medium aneurysm</td>
<td>≥5 to &lt; 10 mm</td>
<td></td>
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<tr>
<td>Large or giant aneurysm</td>
<td>≥10, or absolute dimension ≥8 mm</td>
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</tbody>
</table>

#### 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

<table>
<thead>
<tr>
<th>Laboratory Finding</th>
<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Source of Definition Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Platelet count</td>
<td>The determination of the number of platelets in a blood sample, usually expressed as platelets per milliliter of whole blood.</td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C51951</td>
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### Terminology

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<th>Source of Definition</th>
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</tr>
</thead>
<tbody>
<tr>
<td>ESR</td>
<td>A quantitative measurement of the distance that red blood cells travel in 1 hour in a sample of unclotted blood.</td>
<td></td>
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<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus</td>
<td>Code: C74611</td>
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<tr>
<td>CRP</td>
<td>A quantitative measurement of the amount of CRP, an inflammatory marker, in the blood, expressed as milligrams per liter.</td>
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<td></td>
</tr>
<tr>
<td>Sterile pyuria</td>
<td>The presence of leukocytes in the urine without evidence of an infection.</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WBC</td>
<td>Concentration of leukocytes in the peripheral blood stream, expressed as WBCs per milliliter of whole blood.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hemoglobin</td>
<td>Concentration of hemoglobin in the peripheral blood stream, expressed as grams per deciliter.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alanine</td>
<td>The concentration of alanine aminotransferase, a liver enzyme, in the blood, expressed in units per liter.</td>
<td></td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus</td>
<td>Code: C74954</td>
<td></td>
</tr>
</tbody>
</table>

### Intervention for Kawasaki Disease

- **Whether treatment was given for Kawasaki disease.**
  - **Yes**
  - **No**

#### Timing

- **<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.

<table>
<thead>
<tr>
<th>Medication(s)</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>IVIG</td>
<td>Pooled immunoglobulins given parenterally. In Kawasaki disease, given as 2 g/kg of body weight.</td>
</tr>
<tr>
<td>Aspirin</td>
<td>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.</td>
</tr>
<tr>
<td>Terminology Concept</td>
<td>Suggested Data Element</td>
</tr>
<tr>
<td>---------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Coumadin</td>
<td>An anticoagulant used to prevent thrombosis and thromboembolism that inhibits vitamin K epoxide reductase.</td>
</tr>
<tr>
<td>Other</td>
<td>Includes ticlopidine, clopidogrel, abciximab, steroids, infliximab.</td>
</tr>
<tr>
<td>Intervention for Kawasaki Disease, Response</td>
<td>The patient's response to treatment of Kawasaki disease.</td>
</tr>
<tr>
<td>Intervention for Kawasaki Disease, Type of Response</td>
<td>The type of treatment patient received for Kawasaki disease.</td>
</tr>
<tr>
<td>Intervention for Kawasaki Disease, Medications</td>
<td>Medications used for the treatment of Kawasaki disease.</td>
</tr>
<tr>
<td>Intervention for Kawasaki Disease, Sequelae</td>
<td>Outcomes or findings after treatment of Kawasaki disease.</td>
</tr>
<tr>
<td>Relapse</td>
<td>The return of a disease after a period of remission.</td>
</tr>
<tr>
<td>Coronary artery aneurysm</td>
<td>Focal dilation of a coronary artery secondary to arterial wall weakening.</td>
</tr>
<tr>
<td>Coronary artery ectasia</td>
<td>Diffuse dilation of coronary artery segment.</td>
</tr>
<tr>
<td>Angina</td>
<td>A heart condition marked by paroxysms of chest pain due to reduced oxygen to the heart.</td>
</tr>
<tr>
<td>MI</td>
<td>Gross necrosis of the myocardium, as a result of interruption of the blood supply to the area, as in coronary thrombosis.</td>
</tr>
<tr>
<td>Gangrene</td>
<td>Death of tissue, usually in considerable mass and generally associated with loss of vascular (nutritive) supply and followed by bacterial invasion and putrefaction.</td>
</tr>
</tbody>
</table>
### Terminology

<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
<th>Suggested Data Element</th>
<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Source of Definition Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rheumatic Fever</td>
<td>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.</td>
<td>Yes</td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C34984</td>
<td></td>
</tr>
</tbody>
</table>

### Onset

<table>
<thead>
<tr>
<th>Date of the first onset of rheumatic fever.</th>
<th>mm-dd-yyyy</th>
</tr>
</thead>
</table>

### Age When First Symptoms Occurred

The age of the patient when first symptoms of rheumatic fever occurred.

<table>
<thead>
<tr>
<th>Integer</th>
<th>Age in years</th>
</tr>
</thead>
</table>

### Symptoms

The symptoms of rheumatic fever that the patient had.

<table>
<thead>
<tr>
<th>Carditis</th>
<th>Inflammation of the heart or its surroundings.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Polyarthritis</td>
<td>Type of arthritis that involves ≥5 joints simultaneously, and usually associated with autoimmune conditions.</td>
</tr>
<tr>
<td>Subcutaneous nodules</td>
<td>Firm lump under the skin.</td>
</tr>
<tr>
<td>Rash</td>
<td>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.</td>
</tr>
<tr>
<td>Sydenham's chorea</td>
<td>A neurologic disorder characterized by smooth involuntary, uncoordinated movements affecting especially the hands, feet, and face.</td>
</tr>
<tr>
<td>Evidence of previous streptococcus infection</td>
<td>The presence of a positive anti-Streptolysin-O or anti-DNase B, demonstrating that the patient was previously infected with Streptococcus.</td>
</tr>
<tr>
<td>Previous acute rheumatic fever or rheumatic heart disease</td>
<td>Prior history of rheumatic fever or rheumatic heart disease.</td>
</tr>
<tr>
<td>Family history of rheumatic fever/ rheumatic heart disease</td>
<td>The presence of a first-degree family member with a history of rheumatic fever or rheumatic heart disease.</td>
</tr>
</tbody>
</table>
### Minor Criteria for Rheumatic Fever

<table>
<thead>
<tr>
<th>Terminology Concept</th>
<th>Definition</th>
<th>Suggested Data Element</th>
<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minor Criteria for Rheumatic Fever</td>
<td>Minor symptom criteria for rheumatic disease include fever, arthralgia, elevated ESR levels, elevated CRP levels, elevated WBC levels, prolonged PR interval.</td>
<td></td>
<td>Yes</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Intervention for Rheumatic Fever</th>
<th>The type of treatment the patient received for rheumatic fever.</th>
<th>Bed rest</th>
<th>Medication</th>
<th>Interventional catheterization</th>
<th>Cardiac surgery</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed rest</td>
<td>Restriction of a patient's activity, either partially or completely.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Medication</td>
<td>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.</td>
<td></td>
<td></td>
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<tr>
<td>Interventional catheterization</td>
<td>The performance of a cardiac catheterization with the intent of making a modification to the structures of the heart or surrounding vessels.</td>
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</tr>
<tr>
<td>Cardiac surgery</td>
<td>The surgical treatment of disease affecting the heart and blood vessels within the thorax.</td>
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<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Medication for Rheumatic Fever</th>
<th>Pharmacological Therapy for Rheumatic Fever</th>
<th>Aspirin</th>
<th>Steroids</th>
<th>Anticongestive medications</th>
<th>Penicillin</th>
<th>Other</th>
<th>Use RxNorm code mapping for definition of medications</th>
</tr>
</thead>
</table>

| Surgery for Rheumatic Fever | Surgical Intervention for Rheumatic Fever | Valvuloplasty | Valve replacement | | | | |

### Other Risk Factors

<table>
<thead>
<tr>
<th>Family History of Heart Disease</th>
<th>The presence of heart disease in a first-degree family member.</th>
<th>Cardiomyopathy</th>
<th>Coronary artery disease</th>
<th>CHD</th>
<th>Long QTc</th>
<th>Marfan Syndrome</th>
<th>Ehlers-Danlos syndrome</th>
<th>Sudden death/SIDS</th>
<th>SADS</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiomyopathy</td>
<td>A disease of the heart muscle or myocardium proper.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C34830</td>
<td></td>
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Continued on the next page
### Terminology

<table>
<thead>
<tr>
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<th>Mapping</th>
</tr>
</thead>
</table>
| CAD     | Indicate if the patient has/had any direct blood relatives (i.e., parents, siblings, children) who have had any of the following diagnosed at age <55 y for male relatives or <65 y for female relatives:  
- Coronary artery disease (i.e., 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.” Yes/No/Null. | STS Registry v2.70 (29) |
<p>| 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 |</p>
<table>
<thead>
<tr>
<th>Terminology Concept</th>
<th>Definition</th>
<th>Suggested Data Element</th>
<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>SADS</td>
<td>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.</td>
<td>Others</td>
<td>Abnormal Cardiac Study</td>
<td>History of abnormal cardiac study.</td>
<td>ECG</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C38053</td>
</tr>
<tr>
<td>ECG</td>
<td>A procedure that records the electrical current in the heart in the form of a continuous strip graph.</td>
<td>NCI Thesaurus (10)</td>
<td>Echocardiogram</td>
<td>A test that uses high-frequency sound waves (ultrasound) to create an image of the heart.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C16525</td>
<td></td>
</tr>
<tr>
<td>Chest x-ray</td>
<td>A radiographic examination of the chest.</td>
<td>NCI Thesaurus (10)</td>
<td>Holter monitor</td>
<td>An ambulatory electrocardiographic technique that records a continuous electrocardiographic rhythm pattern for ≥24 h to detect heart arrhythmias.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C38103</td>
<td></td>
</tr>
<tr>
<td>Event monitor</td>
<td>An ambulatory electrocardiography technique that intermittently records the electrical rhythm of the heart on demand or automatically</td>
<td>NCI Thesaurus (10)</td>
<td>Other</td>
<td>Increased pressure within the pulmonary circulation due to lung or heart disorder.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C3120</td>
<td></td>
</tr>
<tr>
<td>Primary pulmonary hypertension</td>
<td>Type of pulmonary hypertension that is not caused by any other disease or condition.</td>
<td>NCI Thesaurus (10)</td>
<td>Secondary pulmonary hypertension</td>
<td>Type of pulmonary hypertension that is caused by an underlying condition.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C3120</td>
<td></td>
</tr>
<tr>
<td>Failure to Gain Weight/Thrive</td>
<td>History of failure to gain weight.</td>
<td>Yes</td>
<td>No</td>
<td>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 arrhythmia death syndrome; SIDS, sudden infant death syndrome; and WBC, white blood cell.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## APPENDIX 5. PAST MEDICAL HISTORY

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Definition</th>
<th>Suggested Data Element</th>
<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gestation</td>
<td>The period of fetal development in the uterus from the start of conception until its birth.</td>
<td>Term, Preterm, Postterm</td>
<td>Term</td>
<td>Gestation is ≥37 wk using best estimated due date.</td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td>C92804</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Preterm</td>
<td>Gestation that is &lt;37 wk and 0 days' gestational age.</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Postterm</td>
<td>Gestation lasts ≥42 wk.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gestational Complications</td>
<td>A difficulty or problem that occurs during intrauterine development that can jeopardize the health of the fetus.</td>
<td>Yes, No, Unknown</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neonatal Complications</td>
<td>A problem that occurs at or just after delivery of an infant that can jeopardize the health of the infant.</td>
<td>Yes, No, Unknown</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review of Systems</td>
<td>Dermatological</td>
<td>Normal or abnormal clinical findings related to the skin.</td>
<td>Dermatological</td>
<td>NCI Thesaurus (10)</td>
<td></td>
<td>NCI Thesaurus Code: C41064</td>
<td></td>
</tr>
<tr>
<td>Review of Systems</td>
<td>Endocrine</td>
<td>Normal or abnormal clinical findings related to the collection of tissues capable of secreting hormones.</td>
<td>Endocrine</td>
<td>NCI Thesaurus (10)</td>
<td></td>
<td>NCI Thesaurus Code: C13359</td>
<td></td>
</tr>
<tr>
<td>Review of Systems</td>
<td>Gastrointestinal</td>
<td>Normal or abnormal findings related to the stomach and intestines.</td>
<td>Gastrointestinal</td>
<td>NCI Thesaurus (10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review of Systems</td>
<td>Hematological</td>
<td>Normal or abnormal findings related to abnormalities of the synthesis of hemoglobin, and/or the mechanisms of coagulation.</td>
<td>Hematological</td>
<td>NCI Thesaurus (10)</td>
<td></td>
<td>NCI Thesaurus Code(s): (1): C26323; (2): C17837</td>
<td></td>
</tr>
<tr>
<td>Review of Systems</td>
<td>Hemoglobinopathy</td>
<td>Normal or abnormal findings related to the structural alterations of a globin chain within the hemoglobin molecule.</td>
<td>Hemoglobinopathy</td>
<td>NCI Thesaurus (10)</td>
<td></td>
<td>NCI Thesaurus Code: C3092</td>
<td></td>
</tr>
<tr>
<td>Review of Systems</td>
<td>Musculoskeletal</td>
<td>Normal or abnormal findings related to the musculoskeletal system.</td>
<td>Musculoskeletal</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review of Systems</td>
<td>Neurologic</td>
<td>Normal or abnormal findings related to the nervous system.</td>
<td>Neurologic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review of Systems</td>
<td>Developmental</td>
<td>Normal or abnormal findings related to physical, emotional, behavioral, or social development.</td>
<td>Developmental</td>
<td>NCI Thesaurus (10)</td>
<td></td>
<td>NCI Thesaurus Code: C16943</td>
<td></td>
</tr>
<tr>
<td>Review of Systems</td>
<td>Otolaryngological</td>
<td>Normal or abnormal findings related to disorders of the ear, nose, and throat.</td>
<td>Otolaryngological</td>
<td>NCI Thesaurus (10)</td>
<td></td>
<td>NCI Thesaurus Code: C17026</td>
<td></td>
</tr>
<tr>
<td>Review of Systems</td>
<td>Psychiatric</td>
<td>Normal or abnormal findings related to mental health.</td>
<td>Psychiatric</td>
<td>NCI Thesaurus (10)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Continued on the next page
### APPENDIX 5. CONTINUED

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Definition</th>
<th>Suggested Data Element</th>
<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory</td>
<td>Normal or abnormal findings related to the respiratory system.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C25656</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rheumatological</td>
<td>Normal or abnormal findings related to diseases and disorders of the connective tissues.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C17099</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 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 TGFBR1 or TGFBR2 genes. It is characterized by aortic dilation and dissection, vascular tortuosity, hypertelorism, bifid uvula, scoliosis, and pectus deformities.

- **Noonan syndrome**
  A genetic syndrome caused by mutations in the PTPN11 gene (<50% of the cases) or less frequently mutations in the SOS1, RAF1, or KRAS 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
## APPENDIX 5. CONTINUED

<table>
<thead>
<tr>
<th>Data Element</th>
<th>Definition</th>
<th>Suggested Data Element</th>
<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Williams syndrome</td>
<td>A genetic syndrome caused by multiple gene deletions from a region of chromosome 7, including the deletion of <em>CLIP2, ELN, GTF2I, GTF2IRD1</em>, and <em>LIMK1</em> genes. It is characterized by distinctive facial appearance (elfin facies), mild-to-moderate mental developmental delay, cheerfulness, cardiovascular abnormalities and infantile hypercalcemia.</td>
<td></td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C85232</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22q11 deletion (DiGeorge syndrome, Shprintzen syndrome, FACES, CATCH-22)</td>
<td>A congenital anomaly characterized by partial deletion of the short arm of chromosome 22.</td>
<td></td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C2989</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marfan syndrome</td>
<td>A genetic syndrome inherited as an autosomal dominant trait. It is caused by mutations in the <em>FBN1</em> 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).</td>
<td></td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>VACTERL association</td>
<td>An association of congenital birth defects that includes vertebral abnormalities, anal atresia, cardiac abnormalities, tracheoesophageal fistula, renal abnormalities, and limb abnormalities.</td>
<td></td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C99105</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHARGE association</td>
<td>A genetic syndrome characterized by autosomal dominant mutations in the <em>CHD7</em> 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.</td>
<td></td>
<td></td>
<td>Adapted from NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C75100</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fetal alcohol syndrome</td>
<td>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.</td>
<td></td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C84713</td>
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<th>Data Element</th>
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<th>Parent Field</th>
<th>Source of Definition</th>
<th>Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ehlers-Danlos syndrome</td>
<td>A group of inherited connective tissue disorders characterized by loose and fragile skin and joint hypermobility.</td>
<td>Adapted from NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C34568</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Osteogenesis imperfecta</td>
<td>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.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C26837</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glycogen storage disease</td>
<td>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.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C61272</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mucopolysaccharidosis</td>
<td>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.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C61259</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tuberous sclerosis</td>
<td>Hereditary disease characterized by seizures, intracerebral tumors, cardiac tumors, developmental delay, and skin and ocular lesions.</td>
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<tr>
<td>Other</td>
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</tr>
<tr>
<td>Unknown</td>
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<th>Source of Definition</th>
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</thead>
<tbody>
<tr>
<td>Noncardiac Surgical History</td>
<td>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.</td>
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<tr>
<td></td>
<td>No</td>
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<td></td>
<td>Unknown</td>
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</tr>
<tr>
<td></td>
<td>Tonsillectomy</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C51679</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Adenoidectomy</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C51697</td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Bilateral myringotomies with tube placement</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Herniorrhaphy</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C51679</td>
<td></td>
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<tr>
<td></td>
<td>Cleft palate repair</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Dental extraction</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Spinal fusion</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C51679</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gastrostomy/fundoplication</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C51679</td>
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<td></td>
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<tr>
<td></td>
<td>Fundoplication</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C51679</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Central venous catheter</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C51679</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ventriculoperitoneal shunt</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C51679</td>
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<tr>
<td>Ladd's or other malrotation procedures</td>
<td>Surgical procedure performed to alleviate intestinal malrotation.</td>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medications</td>
<td>A drug or substance used to treat a medical condition. The following information for medications should be collected: Name, dose, frequency, route, and concentration.</td>
<td>Yes</td>
<td>No</td>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allergic Reaction</td>
<td>A hypersensitivity reaction triggered by exposure to a previously encountered foreign substance to which the individual has formed antibodies.</td>
<td>Medication</td>
<td>Fish</td>
<td>Others</td>
<td>Unknown</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family History of Cardiovascular Disease and Cardiovascular Disease Risk Factors</td>
<td>CHD</td>
<td>CHD</td>
<td>CAD</td>
<td>CABG</td>
<td>PCI</td>
<td>MI</td>
<td>Hypertension</td>
</tr>
<tr>
<td>CHD</td>
<td>The presence of a heart defect that is present at birth.</td>
<td>NCI Thesaurus (10)</td>
<td>NCI Thesaurus Code: C95834</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>CAD</td>
<td>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.</td>
<td>2014 ACC/AHA Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials (16)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>CABG</td>
<td>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).</td>
<td>2014 ACC/AHA Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials (16)</td>
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<th>Source of Definition Mapping</th>
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</thead>
<tbody>
<tr>
<td>PCI</td>
<td>PCI is the placement of an angioplasty guide wire, balloon, or other device (e.g., 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.</td>
<td>PCI</td>
<td>2014 ACC/AHA</td>
<td>Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials (16)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MI</td>
<td>Clinical syndrome where there is evidence of myocardial necrosis in a clinical setting consistent with myocardial ischemia.</td>
<td>MI</td>
<td>2014 ACC/AHA</td>
<td>Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials (16)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>Pathological increase in blood pressure; a repeatedly elevated blood pressure exceeding 140/90 mm Hg.</td>
<td>Hypertension</td>
<td>NCI Thesaurus</td>
<td>NCI Thesaurus Code: C3117</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hyperlipidemia</td>
<td>Elevated levels of lipids in the blood.</td>
<td>Hyperlipidemia</td>
<td>NCI Thesaurus</td>
<td>NCI Thesaurus Code: C34707</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sudden cardiac death</td>
<td>Death that occurs unexpectedly, and not within 30 days of an acute MI.</td>
<td>Sudden cardiac death</td>
<td>2014 ACC/AHA</td>
<td>Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials (16)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke</td>
<td>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.</td>
<td>Stroke</td>
<td>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)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arrhythmia</td>
<td>An electrocardiographic finding of an atypical cardiac rhythm resulting from a cardiac pathologic process.</td>
<td>Arrhythmia</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Syncope</td>
<td>Sudden loss of consciousness with spontaneous recovery.</td>
<td>Syncope</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Other chronic diseases</td>
<td></td>
<td>Other chronic diseases</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
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<td>Unknown</td>
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<tbody>
<tr>
<td><strong>Social History</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Living Arrangement</td>
<td>Other persons who live with the patient at home.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lives with mother</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Lives with father</td>
<td></td>
<td></td>
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<tr>
<td>Lives with step-mother</td>
<td></td>
<td></td>
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<tr>
<td>Lives with step-father</td>
<td></td>
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<tr>
<td>Lives with partner/spouse</td>
<td></td>
<td></td>
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<tr>
<td>Lives with aunt</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Lives with uncle</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Lives with foster parent</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Living with sibling</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Living with legal guardian other than above</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td><strong>Siblings</strong></td>
<td>Yes, No, Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>Highest education attained.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Grade school completion</td>
<td>Completed the first 6 or 8 grades of education.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>High school completion</td>
<td>Completed secondary education through 12th or 13th grade as required by the school system.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>College</td>
<td>Completion of education at an institution of higher education created to educate and grant degrees; often a part of a university.</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate studies</td>
<td>Completion of a program of study of at least the full-time equivalent of ≥1 academic years of work beyond the bachelor's degree.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>504 plan</td>
<td>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.</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>IEP</td>
<td>Individualized education plan in primary and secondary school.</td>
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<th>Source of Definition</th>
<th>Mapping</th>
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<tbody>
<tr>
<td><strong>Employment</strong></td>
<td>The state of being engaged in an activity or services for wages or salary.</td>
<td>- Full-time</td>
<td></td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>- Part-time</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>- No</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Full-time</td>
<td>Employed for a standard number of hours of working time, at least 50% or 20 h/wk.</td>
<td></td>
<td></td>
<td></td>
<td>NCI Thesaurus (10)</td>
<td></td>
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</tr>
<tr>
<td>Part-time</td>
<td>Employment involving less than the standard or customary working time.</td>
<td></td>
<td></td>
<td></td>
<td>NCI Thesaurus (10)</td>
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<td></td>
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<tr>
<td>No</td>
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<tr>
<td><strong>Alcohol Use</strong></td>
<td>Current or previous use by the patient of any alcohol.</td>
<td>- Yes</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>- No</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td>- Unknown</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Tobacco Use</strong></td>
<td>Current or previous use of any tobacco product including cigarettes, cigars, pipes, and chewing tobacco. (Captured as smoking status.)</td>
<td>- Current every day smoker</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td>- Current some day smoker</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>- Former smoker</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Never smoker</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>- Smoker, current status unknown</td>
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<tr>
<td></td>
<td></td>
<td>- Unknown if ever smoked</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>- Heavy tobacco smoker</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>- Light tobacco smoker</td>
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<td></td>
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<tr>
<td>Current every day smoker</td>
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<tr>
<td>Current some day smoker</td>
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<tr>
<td>Former smoker</td>
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<td></td>
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</tr>
<tr>
<td>Never smoker</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Smoker, current status unknown</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Unknown if ever smoked</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Heavy tobacco smoker</td>
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<tr>
<td>Light tobacco smoker</td>
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<td></td>
</tr>
<tr>
<td><strong>Illicit Drug Use</strong></td>
<td>The nonmedical use of chemicals that are prohibited by international law.</td>
<td>- Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>- No</td>
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<td></td>
<td></td>
<td>- Unknown</td>
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<tr>
<td><strong>World Health Organization (34)</strong></td>
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### Terminology Concept

<table>
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<tr>
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<th>Parent Field</th>
<th>Sources</th>
<th>Mappings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vital Signs - Weight</td>
<td>A measurement that describes the vertical force exerted by a mass of the patient as a result of gravity.</td>
<td>Weight</td>
<td>Numeric, in kg</td>
<td>0.2-500</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vital Signs – Height</td>
<td>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.</td>
<td>Height</td>
<td>Numeric, in cm</td>
<td>10-230</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vital Signs – BMI</td>
<td>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.</td>
<td>BMI</td>
<td>Numeric, in kg/m²</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vital Signs – BSA</td>
<td>A measurement that indicates overall patient size incorporating one of several different accepted equations, as measured in square meters.</td>
<td>BSA</td>
<td>Numeric, in m²</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vital Signs – RABP</td>
<td>A measurement that describes the pressure of the circulating blood against the walls of the blood vessels. Measurement is taken from the right arm.</td>
<td>RABP, displayed as systolic pressure over diastolic pressure</td>
<td>Numeric, in mm Hg</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vital Signs – Other Extremity Blood Pressure</td>
<td>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.</td>
<td>Other extremity blood pressure</td>
<td>Numeric, in mm Hg</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vital Signs – Body Temperature</td>
<td>A measurement that describes the amount of heat inside the body.</td>
<td>Temperature</td>
<td>Numeric, in Fahrenheit or Celsius</td>
<td>95-107 degrees, for Fahrenheit 35-41.7 degrees for Celsius</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vital Signs – Heart Rate</td>
<td>A measurement that describes the frequency of rate of contractions of the systemic (often left) ventricle measured within a unit time.</td>
<td>Heart rate</td>
<td>Numeric, in beats per minute</td>
<td>0-300</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vital Signs – Respiratory Rate</td>
<td>A measurement that describes the rate of breathing (inhalation and exhalation) measured within a unit time.</td>
<td>Respiratory rate</td>
<td>Numeric, in breaths per minute</td>
<td>0-100</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vital Signs – Oxygen Saturation</td>
<td>A measurement that describes the determination of oxygen-hemoglobin saturation of blood.</td>
<td>Oxygen saturation</td>
<td>Numeric, in %</td>
<td>20-100</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Terminology Concept</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Cardiac Examination - Anterior Chest Inspection</td>
<td>Inspection of the region of the anterior surface of the chest and epigastric area.</td>
<td>Anterior chest inspection</td>
<td>Normal</td>
<td>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.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Symmetric</td>
<td>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.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Asymmetry</td>
<td>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.</td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Hyperactive</td>
<td>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</td>
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<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Sternotomy scar</td>
<td>Replacement of destroyed tissue by fibrous tissue due to a surgical procedure where a vertical incision is made along the sternum, after which the sternum itself is divided.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Thoracotomy scar</td>
<td>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.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Terminology Concept</td>
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</tr>
<tr>
<td>Pectus excavatum</td>
<td>A clinical finding in which there is depression of the sternum visible on examination of the chest.</td>
<td></td>
<td></td>
<td></td>
<td>Schlant RC, Hurst JW. Examination of the Precordium: Inspection and Palpation. Examination of the Heart, Part 3. Dallas, TX: American Heart Association; 1990 (26)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pectus carinatum</td>
<td>A clinical finding in which there is protuberance of the sternum visible on examination of the chest.</td>
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</tbody>
</table>

**Cardiac Examination** — Palpation of the part of the chest wall that is located anterior to the heart.

- 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. | | | | Schlant RC, Hurst JW. Examination of the Precordium: Inspection and Palpation. Examination of the Heart, Part 3. Dallas, TX: American Heart Association; 1990 (26) | |
| Hyperdynamic | A clinical finding in which palpation of the precordium reveals a hyperkinetic cardiac impulse with increased amplitude and forcefulness. | | | | | |
| 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 (26) | |
| 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. | | | | | |

Continued on the next page
### Terminology

<table>
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<tr>
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<th>Parent Field</th>
<th>Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palpable heart sound</td>
<td>A clinical finding in which a heart sound is felt during palpation of the chest wall.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Schlant RC, Hurst JW. Examination of the Precordium: Inspection and Palpation. Examination of the Heart, Part 3. Dallas, TX: American Heart Association; 1990 (26)</td>
</tr>
<tr>
<td>PMI</td>
<td>A clinical finding demonstrating the pulsation associated with the contraction of the systemic ventricle. Typically associated with the apex of the heart.</td>
<td></td>
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</tr>
</tbody>
</table>

### Cardiac Examination – PMI Type

- **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 line, fifth intercostal space.

- **Abnormally located**
  - A clinical finding in which the PMI is located in a place other than the left anterior chest.

### Cardiac Examination – Heart Sounds

<table>
<thead>
<tr>
<th>Heart sounds</th>
<th>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.</th>
</tr>
</thead>
<tbody>
<tr>
<td>- S1</td>
<td>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.</td>
</tr>
<tr>
<td>- S2</td>
<td>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.</td>
</tr>
<tr>
<td>- S3</td>
<td>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.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>S4</td>
<td>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.</td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Summation gallop</td>
<td>An auscultated finding in which S3 and S4 fuse, during tachycardia or a prolonged PR interval or both.</td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Systolic click</td>
<td>An auscultated finding describing a sharp, high-frequency sound heard during auscultation of the thorax caused by valvar prolapse or stenosis.</td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Opening snap</td>
<td>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.</td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rub</td>
<td>An auscultated finding describing high or medium pitched and scratchy sound, generated by inflammation of the pericardial sac.</td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Whoop</td>
<td>An auscultated finding describing a loud musical or sonorous vibratory systolic murmur that may be heard in patients with atrioventricular valve prolapse.</td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Murmur</td>
<td>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.</td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
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</tbody>
</table>

**Cardiac Examination – Heart Sounds, S1 Types**

- 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.
<table>
<thead>
<tr>
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<th>Parent Field</th>
<th>Sources</th>
<th>Mappings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abnormal S1</td>
<td>An auscultated finding in which the components of the first heart sound are not normal.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
</tr>
<tr>
<td>Widened split S1</td>
<td>An auscultated finding in which the mitral and tricuspid closure sounds are wider apart in time than normal.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
</tr>
<tr>
<td>Reverse split S1</td>
<td>An auscultated finding in which the tricuspid valve closure sound occurs before the mitral closure sound.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
</tr>
<tr>
<td>Soft S1</td>
<td>An auscultated finding in which the sounds comprising the first heart sound are quieter than normal.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
</tr>
<tr>
<td>Loud S1</td>
<td>An auscultated finding in which the sounds comprising the first heart sound are louder than normal.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
</tr>
<tr>
<td>Single S1</td>
<td>An auscultated finding in which the atrioventricular valve closure sounds occur so close together as to sound single.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
</tr>
</tbody>
</table>

**Cardiac Examination – Heart Sounds, S2 Types**

- Normally split S2
- Abnormal S2
- Fixed split S2
- Widely split S2
- Reverse split S2
- Single S2
- Loud P2 (pulmonary component) of S2

<table>
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<tr>
<th>Permissible Value</th>
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<th>Sources</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Normally split S2</td>
<td>An auscultated finding in which the semilunar valve closure sounds occur close together without occurring simultaneously and vary with respiration.</td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Abnormal S2</td>
<td>An auscultated finding in which the semilunar valve closure sounds are not normal.</td>
<td>Shaver JA, Leonard JJ, Leon DF. Auscultation of the Heart. Examination of the Heart, Part 4. Dallas, TX: American Heart Association; 1990 (27)</td>
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</tr>
</thead>
<tbody>
<tr>
<td>Widely split S2</td>
<td>An auscultated finding in which the semilunar valve closure sounds occur further apart in time than normal.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>The Stanford Medicine 25. Cardiac second heart sounds. Available at: <a href="http://stanfordmedicine25.stanford.edu/the25/cardiac.html">http://stanfordmedicine25.stanford.edu/the25/cardiac.html</a> (30)</td>
<td></td>
</tr>
<tr>
<td>Reverse split S2</td>
<td>An auscultated finding in which the pulmonic valve closure sound occurs prior to the aortic valve closure sound.</td>
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<tr>
<td>Single S2</td>
<td>An auscultated finding in which the semilunar valve closure sounds occur simultaneously.</td>
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<tr>
<td>Loud P2 (pulmonary component) of S2</td>
<td>An auscultated finding in which the pulmonary valve closure sound is louder than normal.</td>
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</tbody>
</table>

### Cardiac Examination - Heart Sounds, Location (Including Murmurs)

- **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; LLB. (Tavel ME. Cardiac auscultation. A glorious past—but does it have a future? Circulation. 1996;93:1250-3 (28))
- **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. See above. (Tavel ME. Cardiac auscultation. A glorious past—but does it have a future? Circulation. 1996;93:1250-3 (28))
- **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? Circulation. 1996;93:1250-3 (28))

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</tr>
</thead>
<tbody>
<tr>
<td><strong>Cardiac Examination - Heart Sounds, Phase of Murmur</strong></td>
<td></td>
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</tr>
<tr>
<td>Right middle sternal border</td>
<td>The location on the precordium that corresponds to the region between the third and fifth intercostal spaces at the right sternal border.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Right lower sternal border</td>
<td>The location on the precordium that corresponds to the region between the fifth, and sixth intercostal spaces at the right sternal border.</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Right lung field/right chest</td>
<td>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.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Chandrasekar A. Auscultation of lungs - method of exam. Loyola University Medical Education Network. Available at: <a href="http://www.meddean.luc.edu/lumen/meded/medicine/pulmonar/pd/pstep29.htm">http://www.meddean.luc.edu/lumen/meded/medicine/pulmonar/pd/pstep29.htm</a> (13)</td>
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<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Sources</th>
<th>Mappings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Left anterior axillary line</td>
<td>The location on the thorax delineated by a coronal line on the anterior torso marked by the anterior axillary fold on the left side.</td>
<td></td>
<td></td>
<td></td>
<td>Trunk structure and vertical reference line OR Entire axillary region and structure of left axillary region</td>
<td>Mosby, Inc. Mosby's Dictionary of Medicine, Nursing &amp; Health Professions. St. Louis, MO: Mosby/Elsevier; 2009 (23)</td>
<td></td>
</tr>
<tr>
<td>Left axilla</td>
<td>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.</td>
<td></td>
<td></td>
<td></td>
<td>Entire axillary region and structure of left axillary region</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right anterior axillary line</td>
<td>The location on the thorax delineated by a coronal line on the anterior torso marked by the anterior axillary fold on the right side.</td>
<td></td>
<td></td>
<td></td>
<td>Trunk structure and vertical reference line OR Entire axillary region and structure of right axillary region</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right axilla</td>
<td>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.</td>
<td></td>
<td></td>
<td></td>
<td>Entire axillary region and structure of right axillary region</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Back</td>
<td>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.</td>
<td></td>
<td></td>
<td></td>
<td>Back structure, including back of neck</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infraclavicular, left</td>
<td>The location that describes the anterior portion of the thorax directly below the left clavicle.</td>
<td></td>
<td></td>
<td></td>
<td>Thoracic structure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infraclavicular, right</td>
<td>The location that describes the anterior portion of the thorax directly below the right clavicle.</td>
<td></td>
<td></td>
<td></td>
<td>Thoracic structure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systolic</td>
<td>The phase of time during ventricular ejection in which the semilunar valve(s) are open.</td>
<td></td>
<td></td>
<td></td>
<td>Heart murmur, categorized by timing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diastolic</td>
<td>The phase of time between ventricular ejection, in which the semilunar valve(s) are closed.</td>
<td></td>
<td></td>
<td></td>
<td>Heart murmur, categorized by timing</td>
<td></td>
<td></td>
</tr>
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</table>
### Terminology

<table>
<thead>
<tr>
<th>Concept</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continuous with diastolic spillover</td>
<td>The phase of time encompassing systole and the early part of diastole.</td>
</tr>
<tr>
<td>Ejection systolic murmur</td>
<td>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.</td>
</tr>
</tbody>
</table>

### Cardiac Examination – Heart Sounds, Systolic Murmur Types

- Short
- Medium
- Long
- Pansystolic/holosystolic
- Early systolic
- Midsystolic
- Late systolic
- Early diastolic
- Middiastolic
- Late diastolic

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
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<tbody>
<tr>
<td>Short</td>
<td>A brief length of time after onset of a valve closure sound. Heart murmur, categorized by duration</td>
</tr>
<tr>
<td>Medium</td>
<td>A medium length of time after a valve closure sound.</td>
</tr>
<tr>
<td>Long</td>
<td>An extended length of time after a valve closure sound. Heart murmur, categorized by duration</td>
</tr>
<tr>
<td>Pansystolic/holosystolic</td>
<td>A length of time occupying the entire systolic interval, from first to second heart sounds. Systolic murmur</td>
</tr>
<tr>
<td>Early systolic</td>
<td>A period of time describing the early portion of the ventricular ejection phase.</td>
</tr>
<tr>
<td>Midsystolic</td>
<td>A period of time describing the middle portion of the ventricular ejection phase. Systolic murmur</td>
</tr>
<tr>
<td>Late systolic</td>
<td>A period of time describing the last half of the ventricular ejection phase. This may or may not extend to the second heart sound.</td>
</tr>
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### Terminology

<table>
<thead>
<tr>
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<tr>
<td>Middiastolic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Late diastolic</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To and fro or systolic-diastolic murmur</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Middiastolic</td>
<td>A period of time describing the middle portion of the ventricular filling phase.</td>
<td></td>
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</tr>
<tr>
<td>Late diastolic</td>
<td>A period of time describing the last half of the ventricular filling phase. This may or may not extend to the first heart sound.</td>
<td></td>
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</tr>
<tr>
<td>To and fro or systolic-diastolic murmur</td>
<td>An auscultated finding associated with the accentuation of a heart murmur during both ventricular ejection and ventricular filling phases.</td>
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<td></td>
<td></td>
<td></td>
<td>Sarkar A. Bedside Cardiology. New Delhi, India: Jaypee Brothers Medical Publishers (P) Ltd; 2012 (25)</td>
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</table>

| **Cardiac Examination – Heart Sounds, Pitch** | | | | | |
| High frequency | | | | | |
| Medium frequency | | | | | |
| Low frequency | | | | | |
| 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 | | | |

| **Cardiac Examination – Heart Sounds, Grade** | | | | | |
| Grade I | | | | | |
| Grade II | | | | | |
| Grade III | | | | | |
| Grade IV | | | | | |
| Grade V | | | | | |
| Grade VI | | | | | |
| Grade I | An auscultated finding that is very soft or intermittently heard. | | | | |
| Grade II | An auscultated finding that is as loud as the breath sounds. | | | | |
| Grade III | An auscultated finding that is louder than the breath sounds. | | | | |
| Grade IV | An auscultated finding that is louder than the breath sounds in the presence of a palpated thrill. | | | | |

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### Terminology Concept

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<tbody>
<tr>
<td>Grade V</td>
<td></td>
<td>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.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Grade VI</td>
<td></td>
<td>An auscultated finding that is heard with the stethoscope off of the chest wall OR with the naked ear.</td>
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#### Cardiac Examination – Heart Sounds, Murmurs, Characteristic

- Vibratory
- Blowing
- Harsh
- Multifrequency
- Squeaky
- Machinery
- Nonspecific

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<th>Characteristic</th>
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<tr>
<td>Multifrequency</td>
<td>An auditory quality in which multiple frequencies are heard either simultaneously or in rapid succession.</td>
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</tr>
<tr>
<td>Squeaky</td>
<td>An auditory quality in which the turbulence is brief and noted with the diaphragm of the stethoscope only.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Machinery</td>
<td>An auditory quality in which turbulence sounds similar to the workings of an industrial machine.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nonspecific</td>
<td>An auditory quality in which there are no recognizable characteristics to describe the turbulent sound.</td>
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</table>

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

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<tr>
<td>General Appearance</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Well perfused</td>
<td>Well perfused</td>
<td>A clinical finding in which there is sufficient blood flow to the core and extremities.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poorly perfused</td>
<td>Poorly perfused</td>
<td>A clinical condition in which there is insufficient blood flow to the core or to the extremities.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin Examination</td>
<td>Examination of the skin on physical examination.</td>
<td>Extremity appearance</td>
<td>Normal</td>
<td>Normal</td>
<td>A clinical description of the skin in which there is appropriate color and perfusion.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Pallor</td>
<td>Pallor</td>
<td>A clinical finding in which there appears to be a loss of color and/or perfusion, or a white appearance.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Flushing</td>
<td>Flushing</td>
<td>A clinical finding in which there is reddening of the skin, typically with increased perfusion.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Diaphoresis</td>
<td>Diaphoresis</td>
<td>A clinical finding in which there is excessive or unpredictable sweating.</td>
<td></td>
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<tr>
<td>Examination of the Abdomen</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Abdominal Examination - Auscultation</td>
<td>Abdominal findings on auscultation.</td>
<td>No abdominal bruits</td>
<td>No abdominal bruits</td>
<td>No abdominal bruits</td>
<td>A clinical finding in which there is absence of vascular sounds heard over major arteries in the abdomen.</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Abdominal bruits</td>
<td>Abdominal bruits</td>
<td>A clinical finding in which there is the presence of turbulent vascular sounds heard over one or more major arteries in the abdomen.</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Hepatomegaly</td>
<td>Hepatomegaly</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Splenomegaly</td>
<td>Splenomegaly</td>
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### APPENDIX 6. CONTINUED

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<th>Parent Field</th>
<th>Sources</th>
<th>Mappings</th>
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<tbody>
<tr>
<td>Abdominal Inspection</td>
<td>Normal</td>
<td>A clinical finding in which there is no organomegaly or masses found on palpating the abdomen.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hepatomegaly</td>
<td>A clinical finding in which the liver is found to be enlarged on abdominal palpation.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Splenomegaly</td>
<td>A clinical finding in which the spleen is found to be enlarged on abdominal palpation.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Normal</td>
<td>A clinical finding in which there are no abnormal findings on visual inspection of the abdomen.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Protuberant</td>
<td>A clinical finding in which there is unusual or prominent convexity of the abdomen on visual inspection.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Scaphoid</td>
<td>A clinical finding in which the anterior abdominal wall is sunken or has a concave appearance on visual inspection.</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

#### Examination of the Genitalia

- **Genital Examination – External Genitalia**
  - Examination findings of the external genitalia on physical examination.
  - Normal
  - Edematous scrotum
  - 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
  - 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.
<table>
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<tr>
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<th>Mappings</th>
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</thead>
<tbody>
<tr>
<td>Clubbing</td>
<td>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.</td>
<td></td>
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</tr>
<tr>
<td>Edema</td>
<td>A clinical finding in which there is the accumulation of excessive fluid in the interstitial spaces, and appears as swelling on visual inspection.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Examination of the Extremities - Capillary Refill Time</td>
<td>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.</td>
<td>Capillary refill time (in seconds)</td>
<td>Normal</td>
<td>A clinical finding in which a capillary nail refill test returns to pink color in &lt;2 seconds after pressure is removed.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Delayed</td>
<td></td>
<td>A clinical finding in which a capillary nail refill test returns to pink color in &gt;2 seconds after pressure is removed.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Examination of the Extremities - Pulses, Amplitude</td>
<td></td>
<td>0 (absent)</td>
<td>A clinical finding in which palpation of a pulse demonstrates no upstroke or amplitude.</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>1+ (decreased)</td>
<td>A clinical finding in which palpation of a pulse demonstrates a diminished upstroke and/or amplitude.</td>
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<tr>
<td></td>
<td></td>
<td>2+ (normal)</td>
<td>A clinical finding in which palpation of the pulse demonstrates appropriate upstroke, amplitude, and decay.</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>3+ (increased)</td>
<td>A clinical finding in which palpation of the pulse demonstrates a significantly increased upstroke and/or amplitude.</td>
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<tr>
<td></td>
<td></td>
<td>4+ (water hammer or markedly increased)</td>
<td>A clinical finding in which palpation of the pulse demonstrates a significantly increased upstroke, amplitude, and rapid decay.</td>
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<tbody>
<tr>
<td>Examination of Extremities – Pulses, Location</td>
<td></td>
<td></td>
<td>Brachial, Ulnar, Radial, Femoral, Dorsalis pedis, Posterior tibial, Carotid, Abdominal aorta</td>
<td></td>
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</tr>
<tr>
<td>Brachial</td>
<td>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.</td>
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</tr>
<tr>
<td>Ulnar</td>
<td>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.</td>
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<tr>
<td>Radial</td>
<td>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 dorsal hand and proximal portions of digits, and deep muscles of pain whose pulsations can be palpated on the flexor surface of the wrist laterally.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Femoral</td>
<td>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.</td>
<td></td>
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<tr>
<td>Dorsalis pedis</td>
<td>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.</td>
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</tr>
<tr>
<td>Posterior tibial</td>
<td>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.</td>
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<tr>
<td>Carotid</td>
<td>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.</td>
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</tr>
<tr>
<td>Abdominal aorta</td>
<td>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.</td>
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</tr>
<tr>
<td>Examination of Extremities – Radial-Femoral Lag</td>
<td>Delay between the upstroke of the right radial pulse and a femoral pulse. Presence indicates coarctation of the aorta.</td>
<td>□ Absent □ Present</td>
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</tr>
<tr>
<td></td>
<td>Absent</td>
<td>A radial-femoral lag (or brachial-femoral lag or delay) is not present.</td>
<td></td>
<td></td>
<td>OSCE Skills. Peripheral vascular (PVS) examination. Available at: <a href="http://www.osceskills.com/e-learning/subjects/peripheral-vascular-examination/">http://www.osceskills.com/e-learning/subjects/peripheral-vascular-examination/</a> (24)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Present</td>
<td>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.</td>
<td></td>
<td></td>
<td>OSCE Skills. Peripheral vascular (PVS) examination. Available at: <a href="http://www.osceskills.com/e-learning/subjects/peripheral-vascular-examination/">http://www.osceskills.com/e-learning/subjects/peripheral-vascular-examination/</a> (24)</td>
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</table>
### APPENDIX 7. COMMON CARDIAC DIAGNOSES

<table>
<thead>
<tr>
<th>Terminology Concept</th>
<th>Suggested Data Element Label</th>
<th>Permissible Value Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Murmur</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Innocent murmur</td>
<td></td>
<td>A clinical finding in which turbulent flow is noted by auscultation that is not associated with any structural cardiac defects.</td>
</tr>
<tr>
<td>Pathologic murmur</td>
<td></td>
<td>A clinical finding in which turbulent flow is noted by auscultation that is associated with a structural cardiac defect.</td>
</tr>
<tr>
<td>Still's murmur</td>
<td></td>
<td>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.</td>
</tr>
<tr>
<td>Venous hum</td>
<td></td>
<td>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.</td>
</tr>
<tr>
<td>Innocent pulmonary systolic murmur</td>
<td></td>
<td>An innocent murmur with a medium pitched, harsh character heard at the left middle and left upper sternal border that disappears with upright position.</td>
</tr>
<tr>
<td>Carotid bruit</td>
<td></td>
<td>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.</td>
</tr>
<tr>
<td>Physiologic pulmonary artery stenosis</td>
<td></td>
<td>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 &lt; 6 mo of age.</td>
</tr>
<tr>
<td>Mammary souffle</td>
<td></td>
<td>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.</td>
</tr>
</tbody>
</table>
APPENDIX 7. CONTINUED

<table>
<thead>
<tr>
<th>Terminology and Syncope</th>
<th>Suggested Data Element Label</th>
<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Sources</th>
<th>Mappings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Syncope</td>
<td></td>
<td>A condition in which there is a sudden, brief loss of consciousness associated with loss of postural tone from which there is spontaneous recovery.</td>
<td></td>
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</tr>
<tr>
<td>Syncope with exertion</td>
<td></td>
<td>A condition in which syncope occurs either during or after physical activity.</td>
<td></td>
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</tr>
<tr>
<td>Arrhythmogenic syncope</td>
<td></td>
<td>A condition in which syncope occurs due to an arrhythmia.</td>
<td></td>
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</tr>
<tr>
<td>Syncope due to acquired heart lesion</td>
<td></td>
<td>A condition in which syncope occurs due to a disease process of the heart with which the patient was not born.</td>
<td></td>
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</tr>
<tr>
<td>Syncope due to congenital heart lesion</td>
<td></td>
<td>A condition in which syncope occurs due to a disease process of the heart with which the patient was born.</td>
<td></td>
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</tr>
<tr>
<td>Syncope due to pulmonary hypertension</td>
<td></td>
<td>A condition in which syncope occurs associated with a sudden and severe increase in pulmonary vascular resistance.</td>
<td></td>
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</tr>
<tr>
<td>Neurally mediated/ neurocardiogenic syncope</td>
<td></td>
<td>A condition in which syncope occurs due to a brief imbalance of the autonomic nervous system.</td>
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</tr>
<tr>
<td>Vasodepressor syncope</td>
<td></td>
<td>A condition in which synaptically mediated syncope occurs in which the blood pressure falls and the heart rate increases.</td>
<td></td>
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</tr>
<tr>
<td>Cardioinhibitory syncope</td>
<td></td>
<td>A condition in which synaptically mediated syncope occurs in which the blood pressure falls and heart rate falls.</td>
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</tr>
<tr>
<td>Situational syncope</td>
<td></td>
<td>A condition in which synaptically mediated syncope occurs due to a specific circumstance, such as micturition, defecation, coughing, or traction of the hair.</td>
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</tbody>
</table>

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<table>
<thead>
<tr>
<th>Terminology Concept</th>
<th>Concept Definition</th>
<th>Suggested Data Element Label</th>
<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Sources</th>
<th>Mappings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carotid sinus syncope</td>
<td>A condition in which neurally mediated syncope occurs due to massage of the carotid body.</td>
<td></td>
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<tr>
<td>Syncope due to migraine</td>
<td>A condition in which syncope occurs associated with the occurrence of cerebral vasospasm.</td>
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</tr>
<tr>
<td>Drug-induced syncope</td>
<td>A condition in which syncope occurs due to the ingestion or administration of a chemical substance.</td>
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<tr>
<td>Psychogenic syncope</td>
<td>A condition in which syncope occurs due to a conversion disorder.</td>
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</tr>
<tr>
<td>Dysautonomia</td>
<td>A condition in which there is a severe imbalance in the autonomic nervous system.</td>
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</tr>
<tr>
<td>Familial dysautonomia (Riley-Day syndrome, hereditary sensory and autonomic neuropathy type III)</td>
<td>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.</td>
<td></td>
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<tr>
<td>Neurogenic orthostatic hypotension (multiple system atrophy, Shy-Drager syndrome)</td>
<td>A condition in which there is neurologic degeneration, postural tachycardia, and muscular rigidity.</td>
<td></td>
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</tr>
<tr>
<td>Postural orthostatic tachycardia syndrome</td>
<td>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 &gt;120 beats/min, within 10 min of upright tilt table testing.</td>
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<tr>
<td>Hypotension</td>
<td>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.</td>
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<tr>
<td>Hypotension due to cardiac dysfunction</td>
<td>A condition in which there is hypotension because of inadequate pumping function of the heart.</td>
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<tr>
<td>Hypotension due to drug</td>
<td>A condition in which there is hypotension because of the effects of a medication or other substance.</td>
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<tr>
<td>Orthostatic intolerance</td>
<td>A condition in which there is the presence of ≥1 symptoms (e.g., dizziness, lightheadedness, nausea, dyspnea, vision change) occurring specifically when assuming or maintaining upright position and resolving in the seated or supine position.</td>
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<tr>
<td>Chronic orthostatic intolerance</td>
<td>A condition in which there is orthostatic intolerance lasting for at least 3 mo with associated functional impairment.</td>
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<tr>
<td>Dizziness</td>
<td>A condition in which the sensation of lightheadedness or a feeling of movement within the head occurs.</td>
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</table>
### Chest Pain and Angina

<table>
<thead>
<tr>
<th>Terminology</th>
<th>Concept</th>
<th>Definition</th>
<th>Permissible Value</th>
<th>Permissible Value Definition</th>
<th>Parent Field</th>
<th>Sources</th>
<th>Mappings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest pain</td>
<td></td>
<td></td>
<td>Discomfort felt in the upper abdomen, thorax, neck, or shoulders.</td>
<td></td>
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</tr>
<tr>
<td>Noncardiac chest pain</td>
<td></td>
<td>A condition in which there is chest pain that is not due to a cardiac etiology.</td>
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</tr>
<tr>
<td>Angina pectoris</td>
<td></td>
<td>A condition in which there is severe chest pain due to myocardial ischemia.</td>
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</tr>
<tr>
<td>Stable angina</td>
<td></td>
<td>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.</td>
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<tr>
<td>Unstable angina</td>
<td></td>
<td>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 &lt;2 wks.</td>
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<tr>
<td>Prinzmetal angina</td>
<td></td>
<td>A condition in which there is angina pectoris due to spasm of the coronary artery.</td>
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</tbody>
</table>

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### Terminology

<table>
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<tr>
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<th>Sources</th>
<th>Mappings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Microvascular angina (Syndrome X)</td>
<td></td>
<td>A condition in which there is angina pectoris due to occlusion of the smaller coronary arteries.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Musculoskeletal chest pain</td>
<td></td>
<td>A condition in which there is chest pain due to an etiology in the structures making up the chest wall.</td>
<td></td>
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</tr>
<tr>
<td>Musculoskeletal chest pain due to costochondral junction syndrome (Tietze)</td>
<td></td>
<td>A condition in which there is musculoskeletal chest pain associated with localized inflammation of at ≥1 joints between the rib and the costal cartilage.</td>
<td></td>
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</tr>
<tr>
<td>Musculoskeletal chest pain due to costochondritis</td>
<td></td>
<td>A condition in which there is musculoskeletal chest pain associated with inflammation of ≥1 ribs and/or cartilages.</td>
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</tr>
<tr>
<td>Musculoskeletal chest pain due to rib injury</td>
<td></td>
<td>A condition in which there is musculoskeletal chest pain secondary to trauma to ≥1 ribs.</td>
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<tr>
<td>Musculoskeletal chest pain due to slipping rib syndrome</td>
<td></td>
<td>A condition in which there is musculoskeletal chest pain associated with ≥1 ribs subluxing from the joint.</td>
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</tr>
<tr>
<td>Musculoskeletal chest pain due to sternal injury</td>
<td></td>
<td>A condition in which there is musculoskeletal chest pain secondary to trauma to the sternum.</td>
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</tr>
<tr>
<td>Musculoskeletal chest pain due to intercostal myofascial injury</td>
<td></td>
<td>A condition in which there is musculoskeletal chest pain secondary to trauma to the connective tissues between the ribs.</td>
<td></td>
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</tr>
<tr>
<td>Musculoskeletal chest pain due to myositis</td>
<td></td>
<td>A condition in which there is musculoskeletal chest pain secondary to inflammation of the muscle tissue.</td>
<td></td>
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</tr>
<tr>
<td>Musculoskeletal chest pain due to myositis: enterovirus epidemic myalgia (pleurodynia) (Bornholm)</td>
<td></td>
<td>A condition in which there is myositis secondary to an infectious etiology.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Musculoskeletal chest pain: psychogenic</td>
<td></td>
<td>A condition in which there is the sensation of musculoskeletal chest pain due to a conversion disorder.</td>
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</tr>
<tr>
<td>Musculoskeletal chest pain psychogenic with dysfunctional breathing (hyperventilation)</td>
<td></td>
<td>A condition in which there is musculoskeletal chest pain associated with inappropriate hyperpnea or tachypnea.</td>
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</tr>
<tr>
<td>Musculoskeletal chest pain: idiopathic/precordial catch syndrome (Texidor's twinge)</td>
<td></td>
<td>A condition in which there is musculoskeletal chest pain characterized by brief, sharp discomfort associated with inspiration.</td>
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</tbody>
</table>
## APPENDIX 7. CONTINUED

<table>
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<tr>
<th>Terminology Concept</th>
<th>Concept Definition</th>
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<th>Sources</th>
<th>Mappings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Symptomatic</td>
<td>A clinical description in which a patient demonstrates evidence of ≥1 clinical finding suggestive of underlying pathology.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Common</td>
<td></td>
<td></td>
<td>Asymptomatic</td>
<td>A clinical description in which a patient does not demonstrate evidence of clinical findings to suggest underlying pathology.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical</td>
<td></td>
<td></td>
<td>Hypoxemia</td>
<td>A clinical finding in which the arterial oxygen tension is lower than the normal range.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Findings</td>
<td></td>
<td></td>
<td>Normal saturation</td>
<td>A clinical finding in which the percentage of filled hemoglobin binding sites for oxygen is within the normal range.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Noted During</td>
<td></td>
<td></td>
<td>Desaturation</td>
<td>A clinical finding in which the percentage of filled hemoglobin binding sites for oxygen is lower than the normal level.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>the Evaluation</td>
<td></td>
<td></td>
<td>Heart failure</td>
<td>A clinical condition in which the function of the heart is inadequate to meet the metabolic needs of the body.</td>
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<tr>
<td>for Cardiac</td>
<td></td>
<td></td>
<td>Cardiomegaly</td>
<td>A clinical finding in which the heart is noted to be larger than normal.</td>
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</tr>
<tr>
<td>Disease</td>
<td></td>
<td></td>
<td>Dyspnea</td>
<td>A clinical finding in which there is labored breathing.</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Tachypnea</td>
<td>A clinical finding in which there is rapid breathing.</td>
<td></td>
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</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Tachypnea</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Hyperpnea</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Stridor</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Wheezing</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Coughing</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Hemoptysis</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Epistaxis</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Poor feeding</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Anorexia nervosa</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Failure to thrive</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Hypercyanotic spell</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Palpitations</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Irregular heart beat</td>
<td>A clinical finding in which there is rapid breathing.</td>
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<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td>Acute</td>
<td>A clinical finding in which there is rapid breathing.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
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<th>Sources</th>
<th>Mappings</th>
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<td>Hyperpnea</td>
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<td>A clinical finding in which there is deeper breathing than normal.</td>
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<tr>
<td>Stridor</td>
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<td>A clinical finding in which there is loud or harsh inspiratory noise associated with obstruction of the upper airway.</td>
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<tr>
<td>Wheezing</td>
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<td>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.</td>
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<td>Coughing</td>
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<td>Hemoptysis</td>
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<td>A clinical finding in which blood is coughed up from the lungs.</td>
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<td>Epistaxis</td>
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<td>A clinical finding in which there is bleeding from the nose.</td>
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<td>Poor feeding</td>
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<td>A clinical finding in which a patient does not or is not able to take in food in normal amounts.</td>
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<tr>
<td>Anorexia nervosa</td>
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<td>A clinical disorder in which a patient has an emotional abnormality characterized by an obsessive desire to lose weight by refusing to eat.</td>
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<tr>
<td>Failure to thrive</td>
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<td>A clinical condition in which a patient has insufficient weight gain.</td>
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<td>Hypercyanotic spell</td>
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<td>A clinical finding in which a patient has profound cyanosis associated with hyperpnea; classically associated with tetralogy of Fallot.</td>
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<td>Palpitations</td>
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<td>Irregular heart beat</td>
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<tr>
<td>Ascites</td>
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<tr>
<td>Fatigue (lassitude)</td>
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<td>A clinical historical feature in which there is extreme tiredness.</td>
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<tr>
<td>Headache</td>
<td></td>
<td>A clinical historical feature in which there is continuous pain in the head.</td>
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<td>Decreased exercise tolerance</td>
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<td>A clinical finding in which there is inability to perform increased physical activity compared with normal levels for self or for age.</td>
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<td>Acrocyanosis</td>
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<td>Breath-holding spell</td>
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<td>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.</td>
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### APPENDIX 7. CONTINUED

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