



Health Care Data

101

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Introduction

This informational guide introduces non-health sector professionals to health care data. This guide answers questions such as:

- Who collects and uses health care data?
- What are some common types of health care data?
- How is health care data stored and what systems are used to store it?
- What are typical uses of health care data?
- How can different organizations access health care data?
- What data are available in my local community?

Data from the health care sector is essential to understanding and improving individual health. This data can inform the planning and development of population-level programs and policies in many sectors.

Our nation's understanding of the factors that shape health is expanding beyond the health care sector to include social determinants and environmental conditions. Organizations in other sectors such as public health, community development, and human services are increasingly interested in accessing and analyzing health care data. Entities from community-based organizations to research institutions are exploring how to harness, link and analyze various datasets to understand and address the myriad factors that have an impact on health.

Understanding what information is considered traditional health care data and how to access it is an important foundational step to sharing data across sectors. Integrating health care data with data from other sectors is essential for telling a complete story of a community's well-being and for a holistic view of individual health. Frequently, collaborators don't know what information is contained within health care data or how to access it.

The ways that health care data are stored, shared, standardized, and regulated varies greatly across communities, agencies, health systems, and providers, creating a non-uniform and constantly changing landscape. Understanding the scope, power and limitations of health care data can be daunting, but is a critical starting point in creating data-driven improvement initiatives.

The Data Across Sectors for Health (DASH) National Program Office developed this guide to provide an overview of common terms used when discussing health care data to promote a shared vocabulary across sectors. Given the diversity and complexity in health care data systems, this guide serves as a starting point for non-health sector professionals who want to further investigate the health care data available in their local communities. It is not an exhaustive list, but hopefully can serve as a reference for those who are new to using health care data.

ABOUT DATA ACROSS SECTORS FOR HEALTH (DASH)

DASH, led by the Illinois Public Health Institute in partnership with the Michigan Public Health Institute with support from the Robert Wood Johnson Foundation, aims to align health care, public health, and other sectors to systematically compile, share, and use data to understand factors that influence health and develop more effective interventions and policies. Learn more at dashconnect.org.



Key Takeaways

Fundamentals for non-health sector professionals on using health care data:

1. Health care data sets are an important source of information for understanding health disparities and addressing health inequities in patient populations.
2. Most health care data captures information about services that individual patients receive during encounters with the health care system. It may lack information about whether these services led to a specific set of desired health outcomes.
3. Health care data is often formatted differently across various organizations, leading to issues exchanging data, interpreting shared data, and matching patient records across systems.
4. Partnering with existing collaborative efforts or neutral data intermediaries can create a pathway for accessing restricted data sets. When requesting data, be specific about the data fields needed and the intended use of the data.
5. Protected health information like electronic health record data is regulated by the Health Insurance Portability and Accountability Act (HIPAA), but there may be other types of data that can serve your needs or a work around that can be developed. Be flexible and enter the data sharing process with an open mind.

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PART 1

Health Care Data Basics



Key Stakeholders in Health Care Data Collection and Use

The most common creators and users of health care data are listed below. Stakeholders may be part of more than one group.

- **Patients/Consumers:** Patients may access health data from many sources in order to make informed decisions as consumers. They also share personal health information with other stakeholders on this list. Through wearable technology, they may also generate health data.
- **Health Care Providers and Delivery Systems:** Hospitals, hospital systems, physicians, physician networks, health clinics, home health, nursing homes, hospices, pharmacies, etc. that provide a range of health care services.
- **Suppliers:** Pharmaceutical companies, medical device manufactures, information technology vendors, etc. that supply goods and services to the health care system.
- **Public Health Professionals:** Local, state, and federal health departments and agencies that are responsible and accountable for the nation's health.

Health is influenced by a wide variety of determinants, from an individual's social condition and environment to the health care services they receive.

- **Health Plans and Payers:** Insurance companies, health plans, managed care organizations, employers, government and other entities that provide or arrange for payment of certain health care services.

Common Types of Health Care Data

Health is influenced by a wide variety of determinants, from an individual's social condition and environment to the health care services they receive. While social and environmental factors are powerful determinants of health, health care data provides specific and measurable insights into community and population health interventions. Data is collected about both health conditions and related factors (health data) and services provided (health care data).

Some typical types of health care data are grouped below according to the stakeholders who typically create or use the data, but it is important to note that there is wide variation in whether or not these data are available in one's local community, city, county, or state. Some types of data may fall under more than one category and may be available either at an individual or aggregate level. Each type of data can support multi-sector initiatives.

INDIVIDUAL DATA

- Information that identifies an individual and their health conditions and services is often protected by HIPAA privacy laws at the state and federal level and is called protected health information (PHI). Technological innovations have made accurately collecting, storing and sharing this type of data easier than ever. While individuals have some access to their individual information, often there is a fee for medical records requests.



- Personal devices that automatically track blood pressure, heartbeat, sleep, and physical activity levels, along with programs that can store information about doctor visits, prescriptions and other health information has created an explosion of granular health data that exists outside of the health care system and the associated protections.

PROVIDER DATA

Health care providers typically collect PHI to help identify and track services and outcomes of treatment offered to individuals. This data may be privacy-protected, but often can be de-identified, aggregated, and shared to respond to population-level health trends. Some common types are described below:

- **Demographics:** In the health care sector, demographic information can include personally identifiable information such as name, date of birth, address, and account or medical record numbers, and descriptive information such as race, gender, income level, educational status, nativity, immigration status, and housing status. Together with diagnostics, this often constitutes federal and state health benefits *eligibility* data from programs like Medicare (public insurance for adults over age 65 or disabled persons managed on the federal level) and Medicaid (state managed public insurance for low-income persons).
- **Diagnoses:** A description of the health status of an individual, typically used to describe a variation from normal (i.e. “healthy”) to a presence of disease, infection, or injury, and often includes a prognosis or information on the severity of the condition.
- **Procedures:** Procedures describe the medical interventions or services a medical professional provides to a patient (as opposed to what a patient might do on doctor's orders).
- **Screening tests, laboratory information, and radiology data:** This data can include the types of tests ordered, dates of service, lab and other test results, and pictures such as ultrasound or x-ray images.
- **Medication prescriptions and adherence data:** Information on prescribed medications including drug name, dosage, if the prescription was filled and picked up by the patient, and compliance with prescribed medications over time.

- **Instructions/referrals:** Information on patient education provided, general instructions to the patient, referrals for care to other providers (e.g. specialists), referrals to other health resources (e.g. exercise programs), or referrals to social services.
- **Narrative/qualitative case notes:** Written notes by the provider that can include the patient's reason for a visit, health status, general impressions, and other qualitative or observational information.

INFORMATION COLLECTED AND USED BY HEALTH CARE SYSTEMS AND PAYERS

Health care data are also collected and aggregated beyond the individual, often at the provider, medical center, and health system level, or by payers such as Medicare, Medicaid, and private insurers. This data may be helpful in understanding and addressing health disparities in patient populations.

- **Health system/community capacity:** Numerical counts of staff, supplies, or other resources available within a medical center or community, such as the number of hospital beds or the number of specialists.
- **Health care quality:** Information on provider, medical center, or health plan performance on measures of safety and quality of care, such as the percentage of women who received mammograms, the percentage of hospital-acquired infections, surgical mortality rates, diabetics receiving appropriate management and many more as developed and applied by various governing bodies (see [Appendix B](#)).
- **Health care utilization:** Information on the services people receive, where they go for these services, and how efficiently these services are provided, such as the number of primary care physician visits per 1,000 people, the number of hospital discharges, or the average wait time to see a physician.

- **Health care spending/costs:** Information on health care spending, such as reimbursement rates and average spending by condition. While the term “cost” is often used, there is disagreement on how to calculate and allocate health care costs.
- **Claims:** Claims are formal requests to insurance companies for coverage or compensation. Claims contain information on patient diagnoses, procedures and tests conducted, dates of services, costs, and where services were rendered.
- **Eligibility:** Demographic information, such as household size, income, and residency is collected to determine what services will be covered for individuals. Often, different service providers will have outdated and siloed information technology systems that collect this data, leading to multiple eligibility determinations that are needed for various services.
- **Administrative data:** Much of the above data is often collected for operational purposes and is categorized more broadly as administrative data. See [Appendix A](#) for publicly available datasets that contain administrative data.

INFORMATION COLLECTED OR USED BY PUBLIC HEALTH PRACTITIONERS

The public health sector has several levels of jurisdiction, from local to global, including the World Health Organization and the Centers for Disease Control and Prevention. The public health sector includes city, state, county, and local health departments. Not all communities have health departments at all of these levels; much of the variation is due to public health funding and infrastructure created, regulated, or determined at the state-level.

Data used by public health practitioners comes from a variety of systems. Public health practitioners aggregate and analyze data typically for a specified place-based population. Some of the information collected and used by local health departments and federal health agencies is described below.

- **Vital Statistics:** Birth, marriage, divorce and death records from various government agencies.
- **Health system utilization data:** Patient-level and facility-level information on health care services available and used over time to track trends.

STRUCTURED DATA VS. UNSTRUCTURED DATA

Structured data is collected and stored in a highly organized and often standardized format.

Unstructured data is stored as free text or images typically found within the medical record such as progress reports, clinical notes, and radiology images.

- **Surveillance Data:** Information on reported immunizations and certain diseases such as HIV, hepatitis C, blood lead levels, and measles. Local and state health departments use surveillance systems and disease-specific registries to track certain conditions and report to the National Notifiable Disease Surveillance System. Providers may also be required to submit “case reports” that include information about patients’ risk factors, specific diseases, symptoms, diagnostic results and treatment information. Some electronic health record systems create registries that contain surveillance data.
- **Population-level health outcomes:** Information about different public health indicators such as vital statistics, cause-specific mortality, prevalence and incidence rates, life expectancy, and quality of life. These data are usually extrapolated from reportable conditions or other population-level surveillance efforts and/or estimates drawn from population-based surveys. Public health departments make these available in a variety of ways (see [“Tips for Accessing Health Care Data”](#)).

Health Care Data Formats

Health care data such as diagnoses, procedures and test results are stored and displayed in one of the following formats.

STRUCTURED DATA

Structured data is information collected and stored in a highly organized and often standardized format. Structured data is important because it allows for comparison and aggregation of data elements across patients, providers, payers and health systems. With health care data, structured data are typically stored as alphanumeric codes or prefixed lists of terms.

Different organizations regulate each of these data standards at the organizational, industry, or national level, and they are subject to change over time to keep pace with business and regulatory requirements. Health care stakeholders are inconsistent with how data standards are applied, leading to issues with exchanging data across systems and interpreting shared data. Creating and maintaining a cohesive, national system is part of an ongoing national conversation. See [Appendix C](#) for a list of structured data formats commonly used for health care data.

UNSTRUCTURED DATA

Information stored as free text or images such as progress reports, clinical observations, and radiology images is usually stored in the medical record as unstructured data, making aggregation and cross-system comparisons difficult. When measured by volume, the majority of health care data are stored in this format. This information can be used for individual care coordination efforts or to create aggregate or standardized data sets through manual extraction. Recent advances in natural language processing are beginning to create new pathways to collect and interpret unstructured data.

Where Health Care Data is Stored

ELECTRONIC HEALTH OR MEDICAL RECORD (EHR OR EMR) DATA SYSTEMS

An electronic health record (EHR), also commonly referred to as an electronic medical record (EMR), is simply a digital version of a patient's medical record, or chart, that includes both structured and unstructured data. Clinical information is entered by health providers into systems at the practice level. An EHR can include a patient's medical history, health assessments, diagnoses, treatments, clinical observations, immunization records, imaging reports, lab results, and more. Many EMRs run reports on the data stored within them based on different domains such as diagnoses, procedures, or dates of services rendered. However, extracting details can be a difficult and manual processing is required for some data types like radiological images or faxed lab results.



Also, given that each provider or health system maintains their own customized EHR system from hundreds of possible base products, individuals may have multiple EHR records associated with them, each formatted slightly differently, creating data quality issues. This can be problematic when trying to get a complete picture of an individual who has different records across systems.

CLAIMS PROCESSING SYSTEMS

Data created for eligibility determinations and billing purposes is typically standardized data such as X12, ICD-10, CPT, HCPCs and LOINC codes (see [Appendix C](#)). Each health care payer, including private insurers, Medicare, and Medicaid collects “claims” and other data as described earlier. While claims data contains a wealth of information on a person's health status, it does not contain the full medical record, lacking the unstructured, free text data and detailed demographic data. Additionally, claims data are proprietary to the payer and since a person may change health insurance plans many times throughout their lifetime, this presents challenges to understanding a patient's full medical history.

PRACTICE MANAGEMENT SYSTEMS

Irrespective of the presence or absence of an EHR system, health care facilities may also have a practice management system for storing demographic data on patients, tracking the services that they receive and viewing insurance claims data. Practice management systems often contain information about the cost of services provided and the amount of revenue generated. HIPAA requires structured data and processing rules when these systems electronically exchange information with payer systems.

PHARMACY DATA SYSTEMS

Pharmacies typically collect data on drugs, prescriptions, prescribers, patients, and billing, which is shared with payers and/or health care delivery systems. This data uses NDC and RxNorm codes.

PUBLIC HEALTH DEPARTMENTS

Public health departments collect many types of information as described above and can make it available in a variety of ways. Surveillance systems, disease registries, and outcomes reports are sometimes available by request. Many health departments operate “dashboards” or public information portals with open data that is accessible to local communities.

STATE HEALTH CARE DATABASES

Nearly all states maintain some type of system for collecting data about health care services statewide. Some states may collect discharge data directly from hospitals or delegate entities to create reporting systems for various types of encounters. Some states have databases that store medical, dental, and pharmacy claims from multiple public and private insurers called All Payer Claims Databases (APCDs). To find out if your state has an APCD, go to <https://www.apcdcouncil.org/state/map>. The [National Association of Health Data Organizations](#) has more general information about the way states collect data, although state-specific information is limited to members.

Connected Health Information Systems

HEALTH INFORMATION EXCHANGES

Health Information Exchange (HIE) refers to infrastructure that enables the electronic transfer of health information across different health record systems. This system may allow a provider, such as a primary care physician, to send health information securely to a specialist. It may also allow a provider to search for a patient in order to pull their medical record from another hospital system. HIE is also often used to refer to entities that provide this infrastructure, or services related to health information. Master Patient Indexes enable HIEs to match patients records across multiple systems, ensuring individual patient data is accurate and consistent.

HIEs evolved from health care systems' need to securely send a variety of health data amongst providers in different locations. Although some states have an officially endorsed HIE or a state-designated entity, some private entities developed proprietary HIEs independently to address their specific

business needs. National standards or requirements are not mandated for health information exchange beyond privacy/security and administrative transactions, so each HIE is different. Any or all of the types of health care data discussed earlier in this report can be part of an HIE. HIEs may differ in functionality, client base, or stage of development. The data architecture can differ as well. Sometimes the disparate data are transferred to a centralized database and other times the data remain in their original databases and a connection is forged between them.

While HIEs are a potentially rich source of health care data, HIEs do not exist in every city or state and the form and governance of HIEs varies from place to place. There is no comprehensive updated list of HIEs. A national trade association, [Strategic Health Information Exchange Collaborative](#), has an interactive map of their membership, and some states, like Minnesota, regulate HIE and have publicly available lists. Hospitals or the provider community may be the best resource to learn whether an area has robust HIE.


INTEGRATED DATA SYSTEMS

Integrated Data Systems (IDS) share state- and/or local-level administrative agency data across sectors such as education, health, justice, and social services. The first IDS in America was started in the 1970's in South Carolina. By the 1990's, other states, local government agencies, academic institutions, and community organizations followed the example led by South Carolina and created their own IDS. Each IDS contains different information such as workforce, education, health, court, and housing data, depending on which organizations are part of the partnership. IDS can be used to monitor and evaluate services and programs, coordinate services across sectors, and develop and test innovative interventions.



PART 2

Tips for Accessing Health Care Data



Determine what health care data is essential to your project and where it can be found in your community

Determining exactly what type of health care data you need and what is available to you can help maintain focus on the project goals instead of the interim step of accessing or sharing data. Health care data systems can vary significantly by community, making it essential to research what systems exist in your local setting.

Upon discovering local health care data systems, determine the specific data that are stored to better determine how you can use the data and possible limitations that exist. For instance, does the database contain claims data or data for a specific sub-population, such as Medicaid participants? Examining existing data sources also means evaluating the data for quality, completeness, and relevance for your intended uses. Considering the data owner's capacity to respond, ask for data dictionaries, tracking systems, data collection methods, and data validity and reliability.

Data requests should clearly delineate exactly what data you would like to access, specifically noting the data fields and definitions. Present the particular questions that you hope the data can help answer instead of a general inquiry to see what data they have available. This strategy will help to provide a concrete inquiry for their response and demonstrate the specific intended use of the data. Next, confirm that your organization has the appropriate infrastructure to securely handle the data that may be shared.

Protected health information (PHI), like EHR data, is regulated by HIPAA, but there may be other types of data available that can serve your needs. See [Appendix C](#) for tools to help determine whether to use PHI and the required processes involved. Written security procedures and confidentiality agreements can help alleviate some data security concerns. Ensure that your staff has the ability to clean and analyze the data, which can ease trust concerns as well as illustrate that your team will not require extensive technical assistance from the health care data owner.

Build multi-sector partnerships

Identifying health care data organizations and systems in your community can be a challenge, but partnerships with payers, academic institutions, health departments, and other state or local government agencies can bring knowledge of the local public health and health care landscape. Identify existing community collaborations and partnerships within your community and build upon those. Partnering with existing collaborative efforts or data intermediaries can create a pathway your organization to access de-identified or restricted data sets. The partnering agency can act as a neutral intermediary between your organization and the health database organization, allowing for the secure transfer of data.



start by learning about the community health improvement process and opportunities to get involved. Public health departments complete and update community health improvement plans (often addressing “HealthyPeople 2020”) to qualify for accreditation or funding. Community health needs assessments (CHNA) and implementation strategies are required of tax-exempt hospitals as a result of the Patient Protection and Affordable Care Act. To forge relationships with health care, you may meet interested parties through the CHNA. This [list of national health IT conferences](#) also provides a starting point for networking with health care professionals.

Building collaborations can be time-consuming, particularly when trying to bridge sectors that might have little in common other than being a part of a geographic community. Every sector uses their own language to talk about their work, so creating a common language is an important step to set a common vision before specific projects are realized.

Explore the value of your proposed project

Consider specific short and long-term goals that you intend to achieve using the data and align them with each collaborating organizations’ (or desired collaborator’s) goals. For example, consider how your project will benefit each organization through reduced costs or access to data that help them achieve their organizational mission or leverage additional funding. Engaging leadership from all partner organizations from the beginning can help ensure goals and actions to reach these goals are aligned. Meaningfully engaging persons with lived experience is increasingly recognized as a foundation for effective community engagement and the creation of authentic community collaborations. Also, consider implementing a program evaluation plan to show how success will be measured through cost savings, lives saved, or other indicators.

RESOURCES FOR BUILDING PARTNERSHIPS

- [BUILD Health Challenge Report on Partnering with Hospitals/Health Systems](#)
- [Environmental Scans from DASH and AcademyHealth](#)
- [CDC Community Health Improvement Navigator](#)
- [Practical Playbook Building Partnerships](#)

Within public health and health care, build relationships with staff at different levels, including data analysts, population health managers, epidemiologists, community benefits directors, administrators, care managers, and others. For public health,

Identifying the specific ways in which the data will be used can help build buy-in from stakeholders. Telling a story with specific uses for the proposed data set or system can help with visualizing the project. This activity can help to overcome some of the barriers mentioned above.

Learn to navigate the rules, regulations, and policies surrounding health care data sharing

The legal restraints surrounding health care data sharing can be complex and may require legal counsel. However, instead of assuming HIPAA will prevent your project from moving forward, fully investigate if your initiative is allowable or a work around can

be developed. Enter the data sharing process with an open mind and be flexible to solutions that are different than your original proposals. Consider researching state and federal regulations of the data and propose solutions to allow for data sharing while remaining compliant with regulations.

Privacy concerns may be alleviated by removing identifying data elements from the dataset or aggregating data so no one individual can be recognized. Many agencies have their own Institutional Review Boards (IRBs) that will require you submit a proposal to gain access to certain data sources, at which time they will ask you to explicitly describe your research purpose, design, data transfer and storage security protocols, deliverables, and dissemination plan. To learn more about HIPAA regulations, see the [Additional Resources](#) section.

Connect with your Peers

All In: Data for Community Health is a learning network of communities across the country that are testing exciting new ways to transform health through multi-sector partnerships to share data.

LEARN MORE ONLINE

Visit the website at:

www.allindata.org

Join the *All In* online community at:

allin.healthdoers.org

All In: Data for Community Health is a learning collaborative that helps communities build capacity to address the social determinants of health through multi-sector collaborations working to share data. *All In* is led by [five partner initiatives](#), including DASH, who joined forces to coordinate technical assistance for communities, foster dialogue across sites, and cultivate peer-to-peer activities for those tackling common challenges. Collectively, *All In* includes 60+ local collaborations. Join the *All In* online community to learn how others are using health care data and connect with professionals dedicated to improving community health through multi-sector data sharing.

Publicly Available Data Resources

There are thousands of publicly available datasets that contain health care data. Organizations across the country are aggregating datasets or creating tools to investigate the wealth of data available. Below is a small selection of datasets and websites that can help access local level health care information.

[CDC WONDER](#): An online interactive data query system with many national vital health statistics datasets (births and deaths) along with others on health conditions including AIDS, cancer, STD morbidity, vaccine adverse events, with data available at the county level.

[Community Health Status Indicators to Combat Obesity, Heart Disease and Cancer](#): This dataset contains over 200 measures including cause mortality rates, life expectancy, birth information, drug use, depression, immunizations, nutrition and exercise, and preventative services on the county level.

[County Health Rankings and Roadmaps](#): This website contains measures, rankings, and maps at the county level of health indicators related to length and quality of life, health behaviors, clinical care providers, social and economic factors, and the physical environment. These visualizations come from a variety of sources and can provide insights into where health information is stored.

[Community Commons](#): This website houses a large variety of data from different sectors such as health, economics, education and the environment. Each dataset provides information on where the data was accessed from and an interactive map to visualize the data at the state, county, census tract, or other level. Furthermore, users can create and publish their own data maps to the website.

ADDITIONAL DATA SETS

[500 Cities Project](#): A collection of health data indicators with modeled estimates down to the census-tract level for the 497 largest cities in the U.S. and the largest cities in Vermont, West Virginia, and Wyoming.

[CDC WISQARS](#): An online data query system with data on injuries, violent deaths, and costs with some information available down to the county-level.

[Healthdata.gov](#): A collection of government agencies' datasets from the national to city level.

[State Health Facts](#): A website providing state-level data on many indicators relating to health status, coverage, cost, and insurance.

[Agency for Healthcare Research and Quality \(AHRQ\)](#): Datasets related to health care utilization, quality, and spending.

[Substance Abuse and Mental Health Services Administration \(SAMHSA\)](#): Datasets related to mental/behavioral health and substance abuse.

[Center for Medicare and Medicaid Services \(CMS\)](#): Datasets related to specific programs such as Medicare and Medicaid, health care spending, and other topics.

[Dartmouth Atlas](#): Data on health care resources and their allocation throughout the U.S. with datasets at various geographic levels from national to state to city to hospital level.

[Catalog of Administrative Data Sets](#): J-PAL, global research center working to reduce poverty by ensuring that policy is informed by scientific evidence, has compiled a catalog of various types of administrative data sets available, including sectors beyond health.

Health Care Data Standards and Regulatory Agencies

[The U.S. Department of Health and Human Services \(HHS\)](#): A cabinet level department of the federal government focused on protecting the health and well-being of Americans. Below are some of the agencies within HHS that help to carry out that mission.

[Centers for Disease Control and Prevention \(CDC\)](#): An agency that works to prevent and control diseases, injury, and disability and improve health and quality of life.

[Center for Medicare and Medicaid Services \(CMS\)](#): The agency that manages the Medicare and Medicaid programs including eligibility requirements, services covered, and reimbursement.

[Agency for Healthcare Research and Quality \(AHRQ\)](#): An agency responsible for generating and spreading evidence that makes health care safer, higher quality, equitable, and more affordable.

[National Institutes of Health \(NIH\)](#): An agency responsible for biomedical and public health research.

[Food and Drug Administration \(FDA\)](#): An agency tasked with ensuring the safety and efficacy of pharmaceutical drugs, medical products, food, cosmetics, and biological products.

[Office of the National Coordinator for Health Information Technology \(ONC\)](#): The principal federal entity charged with coordination of nationwide efforts to implement and use the most advanced health information technology and the electronic exchange of health information.

[X12](#): Chartered by the American National Standards Institute to create standards for electronic data exchange (historically referred to as EDI, or Electronic Data Interchange). This body creates standards mandated by HIPAA.

[The World Health Organization](#): Created and maintains the International Classification of Diseases (ICD). Most member states use this classification for reporting mortality data, while the U.S. has adapted it for use in standardizing health data for billing purposes.

[Joint Commission: Accreditation, Health Care, Certification](#): An independent, not-for-profit organization that accredits and certifies nearly 21,000 health care organizations and programs in the U.S.

[The National Committee for Quality Assurance \(NCQA\)](#): A private not-for-profit organization in the U.S. that works to improve health care quality through the administration of evidence-based standards, measures, programs, and accreditation.

[Health Level Seven International \(HL7\)](#): A not-for-profit organization that provides a comprehensive framework and related standards for the exchange, integration, sharing, and retrieval of electronic health information.

Health and health care data formats

ICD-10. (International Statistical Classification of Diseases and Related Health Problems-10): Alphanumeric codes used in the United States to document patient diagnoses and procedures since October 2015. Prior to then, ICD-9 codes were used. A universal cross-walk to convert ICD-9 to ICD-10 codes does not exist. These codes are typically used for billing. **Example:** J11.1 is the ICD-10 diagnosis code for influenza due to unidentified influenza virus with other respiratory manifestations. B030ZZZ is the procedure code for an MRI of the brain.

CPT. (Current Procedural Terminology): Codes used to document medical procedures and services that are typically used for billing. **Example:** 42820 is the CPT code for a tonsillectomy on a person under the age of 12.

HCPCS Level II. (Health care Common Procedure Coding System): Five-character alphanumeric codes for medical supplies and equipment and non-physician services that are typically used for billing. **Example:** E0114 is the code for a pair of non-wood crutches.

CARCs and RARCs. (Claim Adjustment Reason Codes and Remittance Advice Remark Codes): Codes added to processed claims to provide information that explains any payment adjustments.

LOINC. (Logical Observation Identifiers Names and Codes): Codes for laboratory and clinical results typically used by laboratories and for billing. **Example:** 5792-2 is the code for testing glucose in urine using a strip.

SNOMED-CT. (Systematized Nomenclature of Medicine-Clinical Terms): Clinical terminology lists using controlled vocabularies that are typically used for a patient's problem lists, or list of symptoms or diseases, within a medical record.

RxNorm: Normalized terminology for drugs typically used by pharmacies.

NDC. (National Drug Code): Ten digit codes that describes the drug, dose, strength, route, and packaging typically used by pharmacies. **Example:** 0009-0029-01 is the code for 0.25 mg tablets of Xanax for oral use in a 100-tablet bottle.

HIPAA Transactions: Some administrative health care transactions are required to be structured according to standards set by independent organizations when being sent electronically (see the table below). The transactions are often referred to by their number(s), so for example "270/271" refers to eligibility query and response.

APPENDIX C

Continued

TRANSACTION	STANDARDS ORG - NAME
Eligibility for a health plan (Health Care Eligibility Benefit: Inquiry and Response)	ASC X12 – 270/271
Health Care Claim Status: Request and Response	ASC X12 – 276/277
Referral Certification and Authorization (Health Care Services Review – Request for Review and Response)	ASC X12 – 278
Health Care Services Notification and Acknowledgment	ASC X12 – 278
Health Plan Premium Payments (Payroll Deducted and Other Group Premium Payment for Insurance Products)	ASC X12 – 820
Enrollment/Disenrollment in a Health Plan (Benefit Enrollment and Maintenance)	ASC X12 – 834
Health Care Claim: Payment/Advice (ERA – Electronic Remittance Advice)	ASC X12 – 835
Health Care Electronic Funds Transfer (EFT)	NACHA CCD+ Addenda
Health Care Claims or equivalent encounter information: Professional, Institutional and Dental	ASC X12 – 837(P), (I), (D)
Coordination of Benefits: Professional, Institutional and Dental	ASC X12 – 837(P), (I), (D)
Retail Pharmacy Claim, pharmacy supplies, eligibility, coordination of benefits & professional services	NCPDP D.0 & ASC x12 – 837(P)
Health Care Claims Attachment	TBA

ADDITIONAL RESOURCES

[Accountable Communities for Health Data Sharing Toolkit](#): A toolkit outlining parameters for framing your community's current data sharing maturity and providing resources to assist with various aspects of data sharing.

[All-Payers Claim Databases \(APCD\)](#): The website of the APCD Council, a learning collaborative of government, private, non-profit, and academic organizations focused on improving the development and deployment of state-based APCDs.

[Community Engagement Around Health Data](#): A guide from Urban Institute with resources for organizing community events around the 500 Cities data.

[Connecting Communities with Data](#): A practical guide from the Minnesota Department of Health for using electronic health record data to support community health.

[Health and Community Indicator Measures](#): A report describes the landscape of online health and community indicators platforms to inform strategic planning.

[Health Data Tools and Statistics](#): A comprehensive list of population health data sources.

[Health Information Exchanges \(HIE\)](#): HIE resources and tools from the Healthcare Information and Management Systems Society (HIMSS).

[HIPAA Regulations](#): Information about HIPAA regulations on the U.S. Department of Health and Human Services (HHS) website.

[Integrated Data Systems \(IDS\)](#): Background information about how and why IDSs are used from Actionable Intelligence for Social Policy (AISP).

[National Neighborhood Indicators Partnership \(NNIP\)](#): A collaborative effort by the Urban Institute and local partners to further the development and use of neighborhood information systems in local policymaking and community building.

[Network for Public Health Law](#): A free network providing assistance, resources and training to public health officials, practitioners, advocates and attorneys so that they can make full use of the law as a tool to improve health outcomes.

[Social Interventions Research and Evaluation Network \(SIREN\)](#): A network dedicated to catalyzing and disseminating high-quality research that advances efforts to address social determinants of health in health care settings.

[Using Electronic Health Data to Improve Community Health](#): A report jointly released by the de Beaumont Foundation and Johns Hopkins University providing a framework for requesting electronic health data from hospitals and health systems.