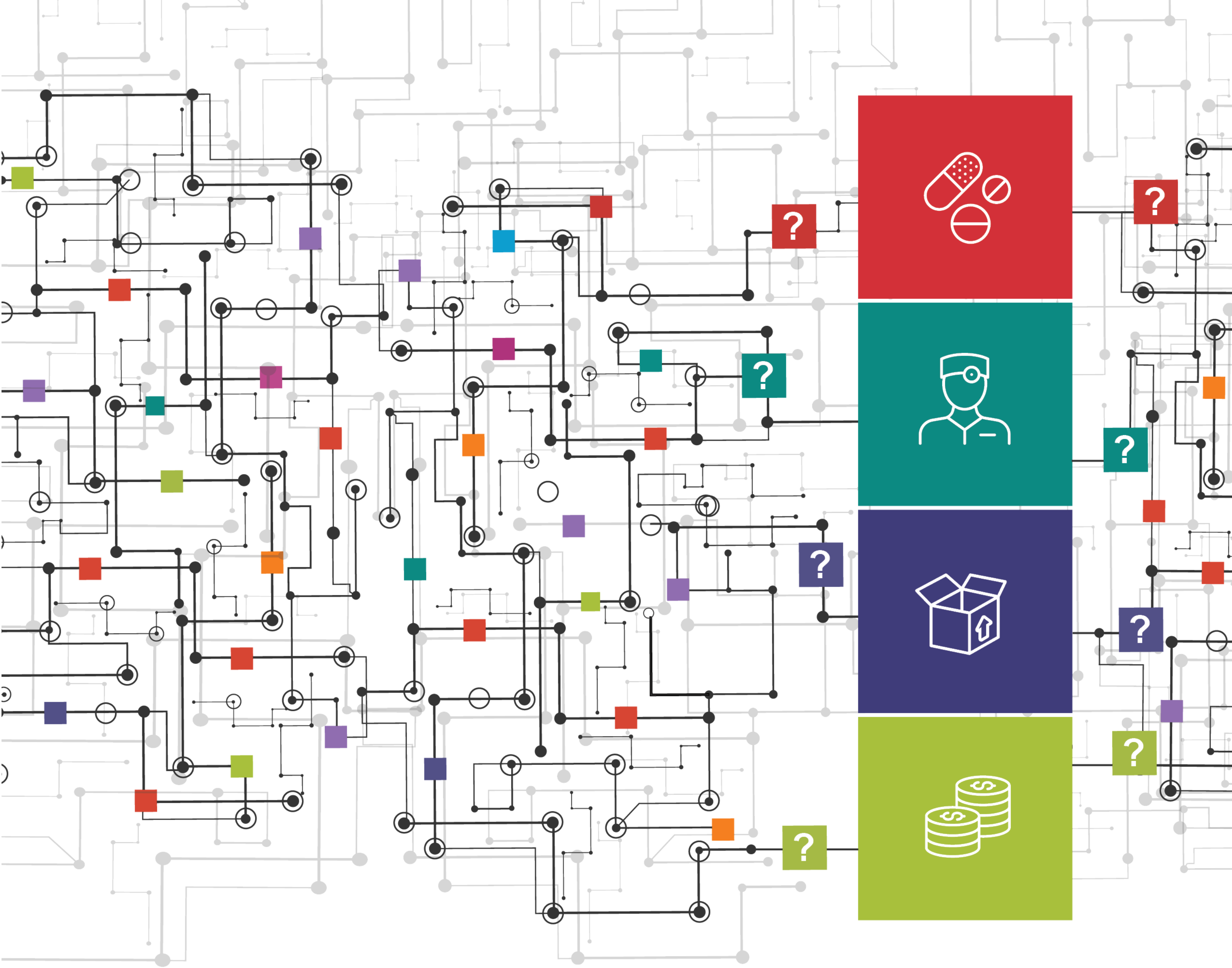

Questions as an Organizing Framework for Health Information Systems

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MEASURE Evaluation

Questions as an Organizing Framework

for Health Information Systems

James C. Thomas, MPH, PhD, MEASURE Evaluation, University of North Carolina at Chapel Hill

Manish Kumar, MPH, MEASURE Evaluation, University of North Carolina at Chapel Hill

MEASURE Evaluation
Carolina Population Center
University of North Carolina at Chapel Hill
123 West Franklin Street, Suite 330
Chapel Hill, NC 27516 USA
Phone: +1 919-445-9350
measure@unc.edu
www.measureevaluation.org

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INTRODUCTION

A country's health services are guided by an information system that reveals which health services are most needed and where. Among its many uses, a health information system (HIS) can show which programs are effective, and it can help a country coordinate with neighboring countries in combatting an epidemic that crosses their borders. The flow of data used for these purposes resembles a vast watershed that gives rise to a river—unconnected rivulets that coalesce together to form increasingly large flows. Individual data elements originate in a wide variety of institutions and settings. The data collectors add counts of individual patients or vials of medicine into aggregate numbers and send them to district, provincial, and national offices. The reach of an HIS is broad, ideally extending into any place where people are living. It is composed of subsystems designed to focus on components as disparate as patient diagnoses and the availability of hospital beds. Each subsystem has its own paper forms for data collection or, increasingly, its own digital system for data collection, storage, and analysis. [1]

It is difficult to see an HIS as a whole or to understand it due to its complexity. This obscures which components most need strengthening and compromises the coordination and collaboration essential to establishing a strong HIS. A framework that shows how the parts fit together and function toward a larger purpose can lessen the confusion. A variety of frameworks has been proposed in the last 10 years or so to serve this purpose. In this paper we describe those frameworks, identify their limitations, and propose a new framework that is more informative and helpful. The frameworks previously proposed were based on a set of systems, a means of informing programs, and levels of health system governance. The system we propose is based on questions that an HIS needs to address.

Systems as an organizing framework

The information systems that compose an HIS include electronic health records (EHR), a health management information system (HMIS), a routine health information system (RHIS), and a community health information system (CHIS).

According to the Institute of Medicine (IOM), an EHR informs patient care delivery, patient self-management, and the management of health service finances and administration. [2] Meanwhile, the Center for Medicare and Medicaid Services (CMMS) defines an EHR as an "electronic version of a patient's medical history, that is maintained by the provider over time, and may include all of the key administrative clinical data relevant to that persons care under a particular provider, including demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data and radiology report." [3] Financial and administrative data are mentioned in the IOM definition, but the CMMS definition refers only to administrative data.

The PubMed Medical Subject Heading (MeSH) definition is institutionally broader and not constrained to a single facility. According to the MeSH definition, an EHR consists of "[m]edia that facilitate transportability of pertinent information concerning a patient's illness across varied providers and geographic locations. Some versions include direct linkages to online consumer health information that is relevant to the health conditions and treatments related to a specific patient."[4] Some refer to this trans-facility system as a CHIS. One group, for example, defined a CHIS as "an integrated, patient-centric, web-based application that assists all stakeholders in healthcare management."[5]

HMIS, RHIS, and HIS are terms that are sometimes used interchangeably. [6] For instance, terms such as HMIS, RHIS, management information system, or even HIS have been associated with health service data sources. [7] The WHO differentiates between HIS and HMIS, asserting that an HIS is focused on both population-based and institution-based data sources while an HMIS is focused on facility-based health resource records. [7] Others, however, describe an HMIS as a tool that can help improve the quality of healthcare services, [8] a definition that seems to combine elements of health services and their management.

The 2017 Broadband Commission Report on Digital Health used a combined term: HIS/HMIS. They defined it as "a term encompassing all types of paper and digitized data in the health system including, for example, diagnostic images, laboratory, clinical and pharmaceutical records, system administration data, and relevant demographic and other personal data." They added that "the term electronic HIS (eHIS) is sometimes used to refer specifically to digitized data."[9].

The Technical Report 14639-1:2012 (en) [10] of the International Organization for Standardization defines a health information system as a "system that combines vital and health statistical data from multiple sources to derive information and make decisions about the health needs, health resources, costs, uses, and outcomes of healthcare." While this definition focuses on numerical data characterizing the health of a population and the factors that influence its health, it does not include health resources data.

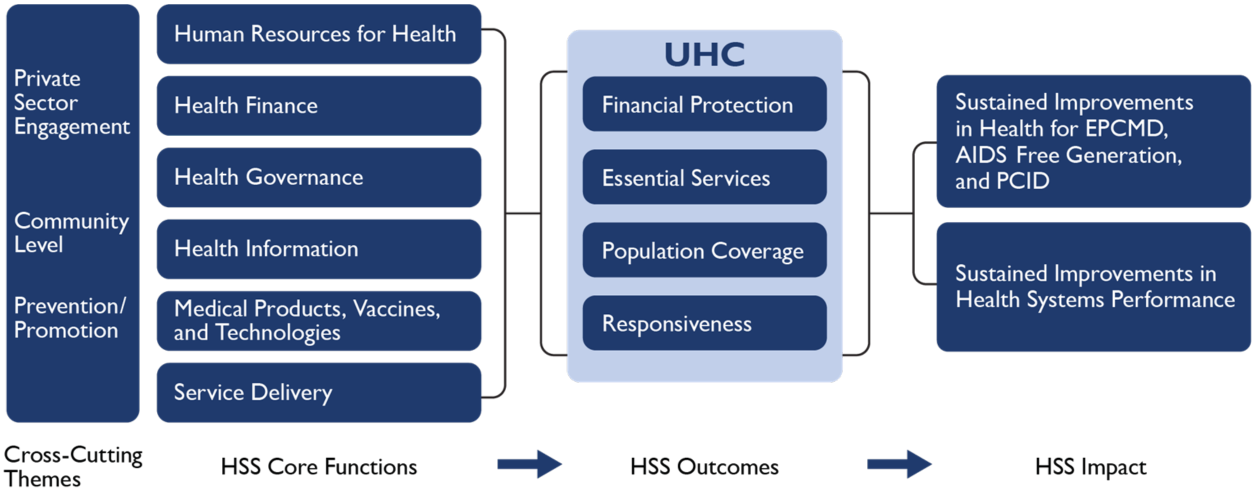
The MeSH system defines HIS as "a system for the collection and/or processing of data from various sources, and using the information for policy making and management of health services."[11] It could be paper-based or electronic. This definition identifies two essential purposes of an HIS: (1) to support health policy formulation, and (2) to manage healthcare services delivered by health workers at different facilities.

Even though the terms EHR, HIMS, RHIS, and CHIS are commonly used to describe elements of an HIS, there is no global consensus as to their meaning, their elements, or even their purposes. Rather than clarify how an HIS works and how its parts fit together, these terms introduce more confusion. Moreover, they do not include some types of information that commonly inform policymakers about the health of the population and the allocation of resources needed. In particular, none of the systems includes *ad hoc* studies and program evaluations.

Programs as an organizing framework

In its "Vision for Health System Strengthening," the U.S. Agency for International Development (USAID) described how the components of a health system work together towards the Agency's long-term goals: ending preventable child and maternal deaths (EPCMD), an AIDS-free generation (AFG), and protecting communities from infectious diseases (PCID) (Figure 1). [12] This framework addresses health services rather than health *information* services, but each of the core functions listed generates data for an HIS and is informed by data. Thus, it describes at a high level the types of data needed in an HIS.

Figure 1. The USAID framing of the core functions of health system strengthening [12]

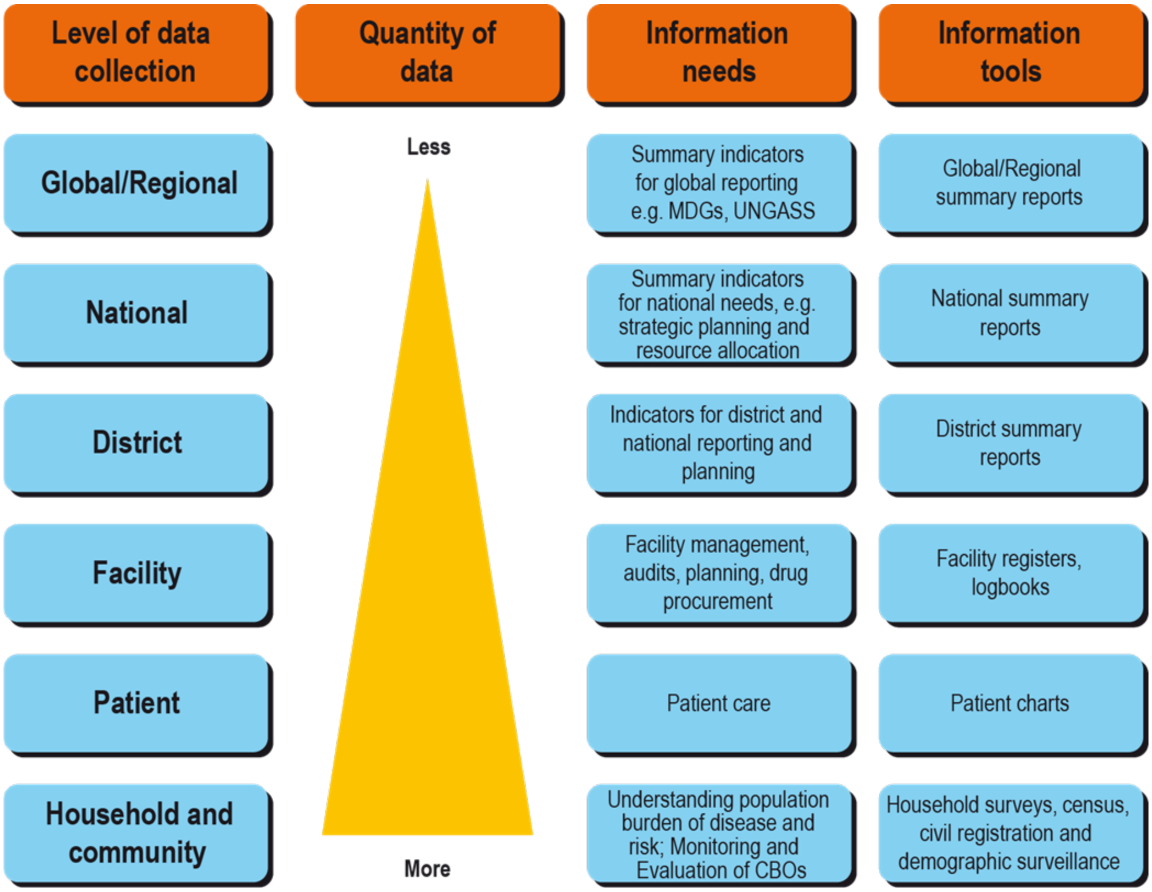


It is likely that this unifying framework started with the various USAID programs and worked backwards to indicate how they relate to the broader goal of universal healthcare (UHC) and the various components of a health system. As such, it is more a framework for USAID health programs than for an HIS, and it provides minimal insight into how an HIS works. Such a framework is susceptible to changes within the Agency. Since the publication of the HSS diagram, the names of each of the three USAID programs have changed. Name changes often reflect additional changes within the program. Although the programs are likely still tied to the goal of universal healthcare, their shifting nature makes them a poor anchor for an HIS framework. Moreover, a USAID program perspective is likely to be perceived by a country as an externally imposed priority, which would not engender ownership by the country.

Governance levels as an organizing framework

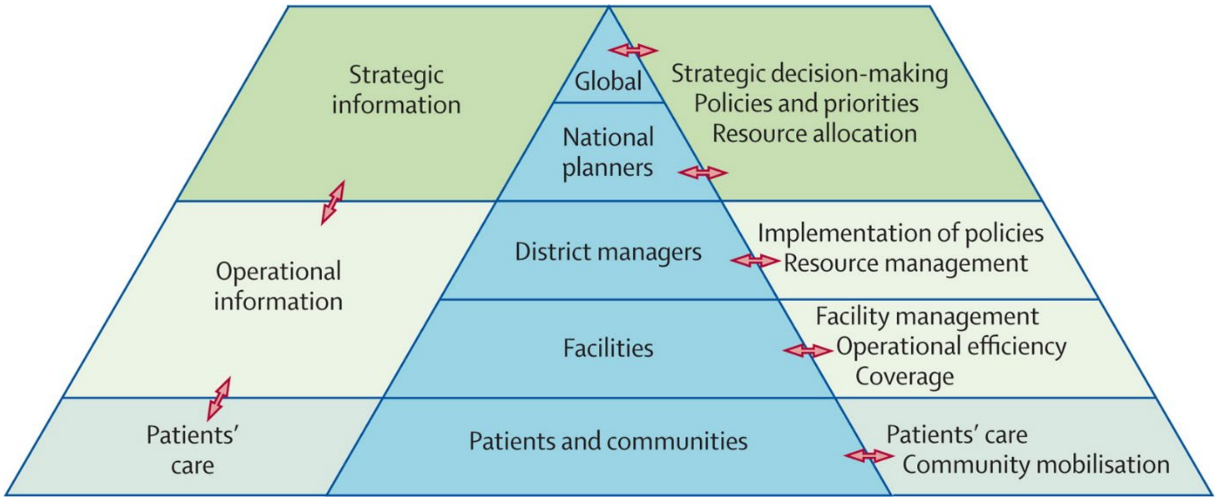
The Health Metrics Network (HMN), which existed temporarily within the World Health Organization, developed an HIS framework aimed at portraying how information needs vary by several levels of society and their governance: the household and community, the patient, the facility, the district, the nation, and global and regional coordination (Figure 2). [13] Many of the principles in the HMN framework also appeared in an information pyramid proposed by AbouZahr (Figure 3). [14] In addition to the levels of governance, the pyramid indicated three categories of information use: for patient care, operational management, and strategic planning.

Figure 2. Health Metrics Network framing of a health information system according to the information needs and tools at different levels of society and governance [13]



Level of data collection	Quantity of data	Information needs	Information tools
Global/Regional	Less	Summary indicators for global reporting e.g. MDGs, UNGASS	Global/Regional summary reports
National		Summary indicators for national needs, e.g. strategic planning and resource allocation	National summary reports
District		Indicators for district and national reporting and planning	District summary reports
Facility		Facility management, audits, planning, drug procurement	Facility registers, logbooks
Patient		Patient care	Patient charts
Household and community	More	Understanding population burden of disease and risk; Monitoring and Evaluation of CBOs	Household surveys, census, civil registration and demographic surveillance

Figure 3. The framing of a health information system according to the categories of information and their uses at different levels of society and governance [14]



The HMN framework and the HIS pyramid both underscore that a country's health information needs span from the individual patient to the national population. To this end, some data are at the individual level, primarily informing patient care, while other data are aggregated and less detailed but provide perspectives on a population. While it is true that different levels of government have different questions, simply noting this falls short of identifying the data elements that each needs and how they relate to each other. These frameworks are, thus, more conceptual than practical.

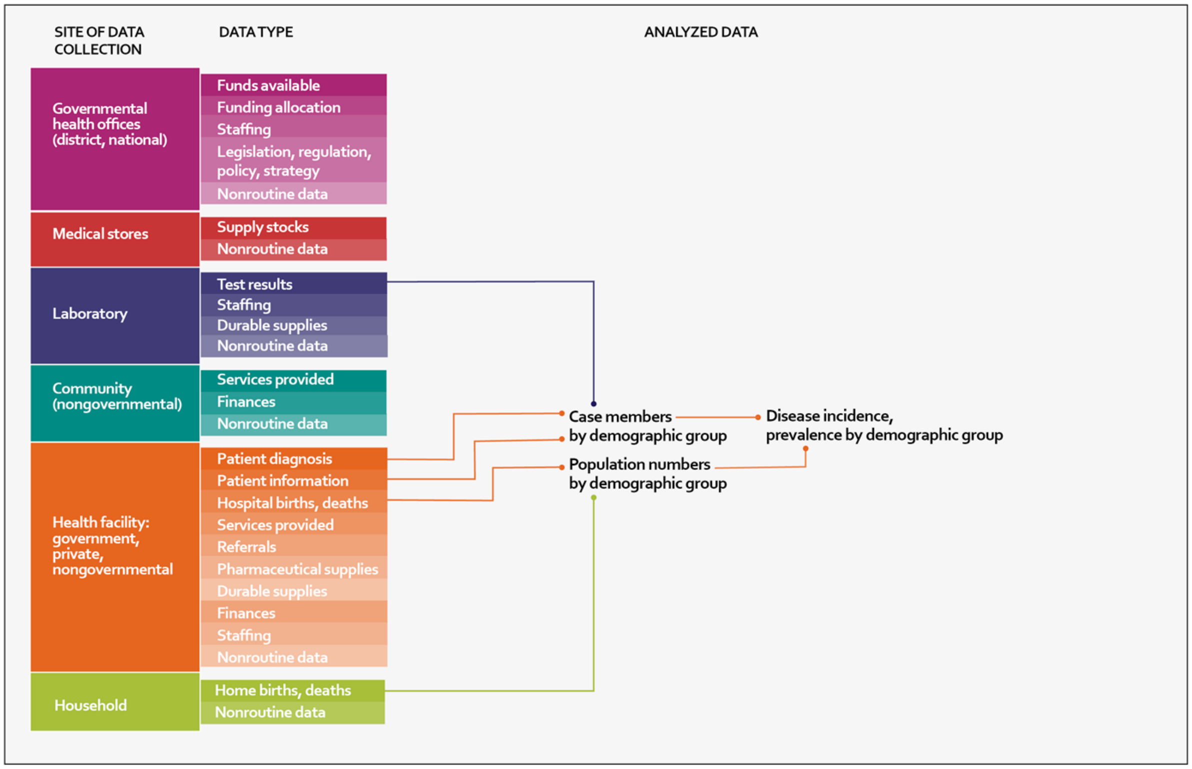
Questions as an organizing framework

The three frameworks described above do not inform the types of data to collect, how they work together, and toward which purposes. We believe that a framework based on the questions being asked meets these criteria. The questions will vary according to the setting or the level of governance. In a clinic, for example, a common question would be, "How many patients are presenting with symptoms of malaria each month?" A district office would be interested in the aggregate number of cases reported from all diagnosing facilities and whether the stores of antimalarial medications will be adequate for the anticipated number of cases.

Once stakeholders pose a question, they search for data that can answer it. The question is not limited by specifying the information systems from which it can draw. In the example of the district health office, above, an answer to the question of the number of monthly cases would come from data originating in several EHRs as they contribute data to a district RHIS. Meanwhile the information on the adequacy of the stores would be answered through a logistics management information system (LMIS), a system that has utility for important questions but, for reasons that are not entirely clear, is sometimes excluded from the list of systems composing an HIS.

The question-based framework we propose consists of three elements: the sites of data collection, the data types each site commonly generates, and the types of information that data analysis can yield (Figure 4). The types we list are intended as an example; a given country can modify the types of data available at the sites according to the national practices. In our example, data routinely collected at the household level include births and deaths, typically collected by the census or community health workers. A household survey would be a type of nonroutine data that can also contribute to an HIS and decisions about the allocation of resources. In our framework, we include the possibility of such nonroutine data in every location where data are collected.

Figure 4. The data sources, data types, and data analyses needed to answer the question "What are our population health priorities?"



In a health facility, whether run by the government, a private company, or a nongovernmental organization (NGO), common types of data routinely collected relate to the patient (e.g., diagnosis, demographic information, birth, death), services provided, supplies used (e.g., pharmaceuticals and durable supplies, such as beds), and operations (e.g., finances and staffing).

Community services in our example are those provided outside of a clinic or a home. They might include health education to groups. The data routinely collected in such a setting could include the services provided and their cost to the providers. Laboratories, whether in a clinic, hospital, or freestanding, routinely collect data on test results, staffing, and supplies such as reagents and centrifuges. Medical stores, where pharmaceuticals are stored after manufacture and before being sent to a service provider, keep track of stock.

The district and national government health offices receive data from the sites mentioned above, but they also generate data of their own. Within the HIS, they are uniquely aware of the funds made available through the national budget, the funds spent and in reserve, leadership staff positions filled and open, and national health policies, regulations, and strategies.

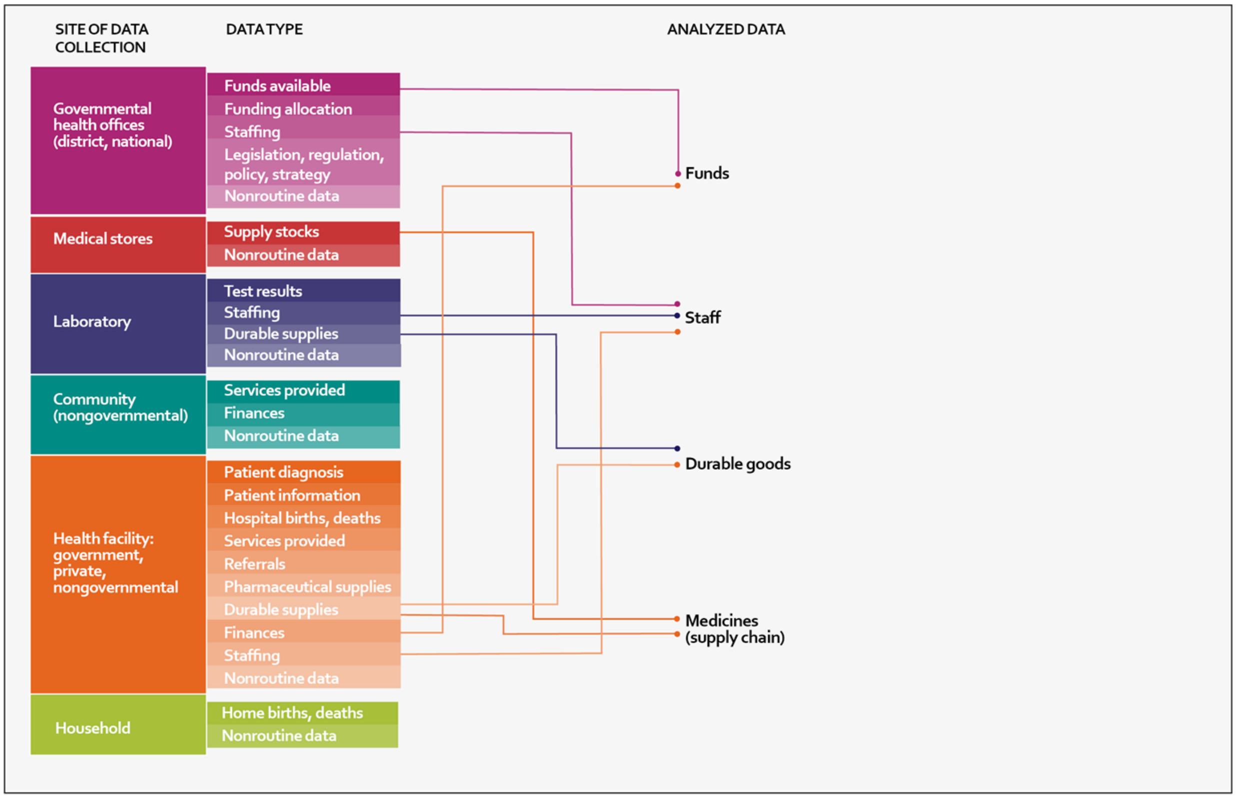
Data analyses to answer questions

This array of data, collected at sites ranging from the household to the Ministry of Health offices, provides the ability to answer a range of questions critical to guiding a population's health services. Each question will require data from a variety of sources, and for each question the sources will differ. Moreover, the questions will differ at the various levels of governance, from the clinic to the national Ministry of Health. At the national level, four critical questions are: (1) What are our population health priorities, based on the occurrence of various health outcomes? (2) What resources do we have to address our priorities? (3) Are we using our resources efficiently (which relies on financial data in the system)? (4) Are we making progress on our priorities, based on disease trends, program evaluations, and compliance with national priorities? We present diagrams of data types used and data analyses to answer these four questions (Figures 4-7).

An answer to the question "What are our health priorities?" (see Figure 4) will draw upon laboratory test results, patient diagnoses in clinical settings, and information about the patient's sex, age, and place of residence. Dividing these numbers by the numbers of people in a population, drawn from household census and vital statistics on births and deaths, yields disease incidence and prevalence, which enable comparisons and the identification of high incidence groups in the country.

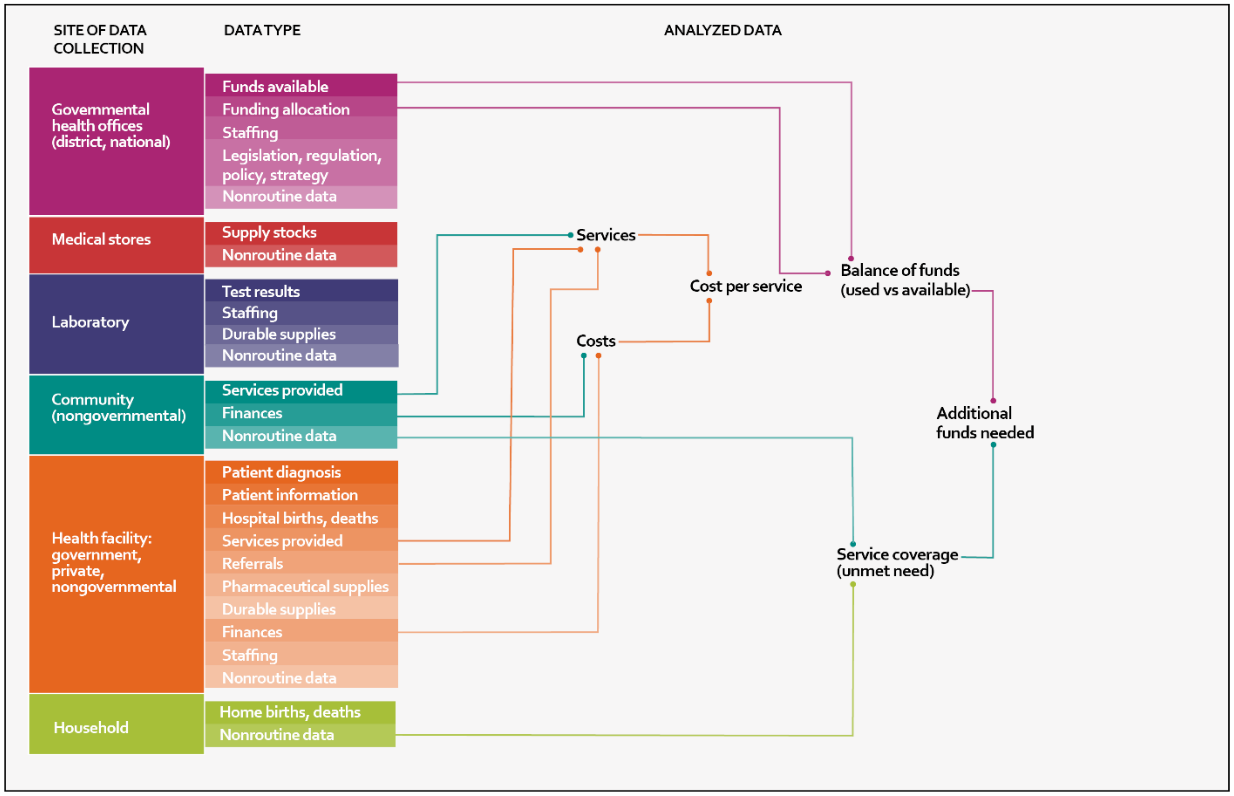
An answer to the question "What resources do we have to address our priorities?" (see Figure 5) will draw upon financial data from the health facilities and higher levels of government; staffing data from health facilities, laboratories, and government health offices; durable goods data from health facilities and laboratories; and medicine supplies in medical stores and health facilities. Combined with information on the patterns of occurrence, and thus health resource needs by population group and region, policymakers can strategically allocate the resources.

Figure 5. The data sources, data types, and data analyses needed to answer the question “What resources do we have to address our health priorities?”



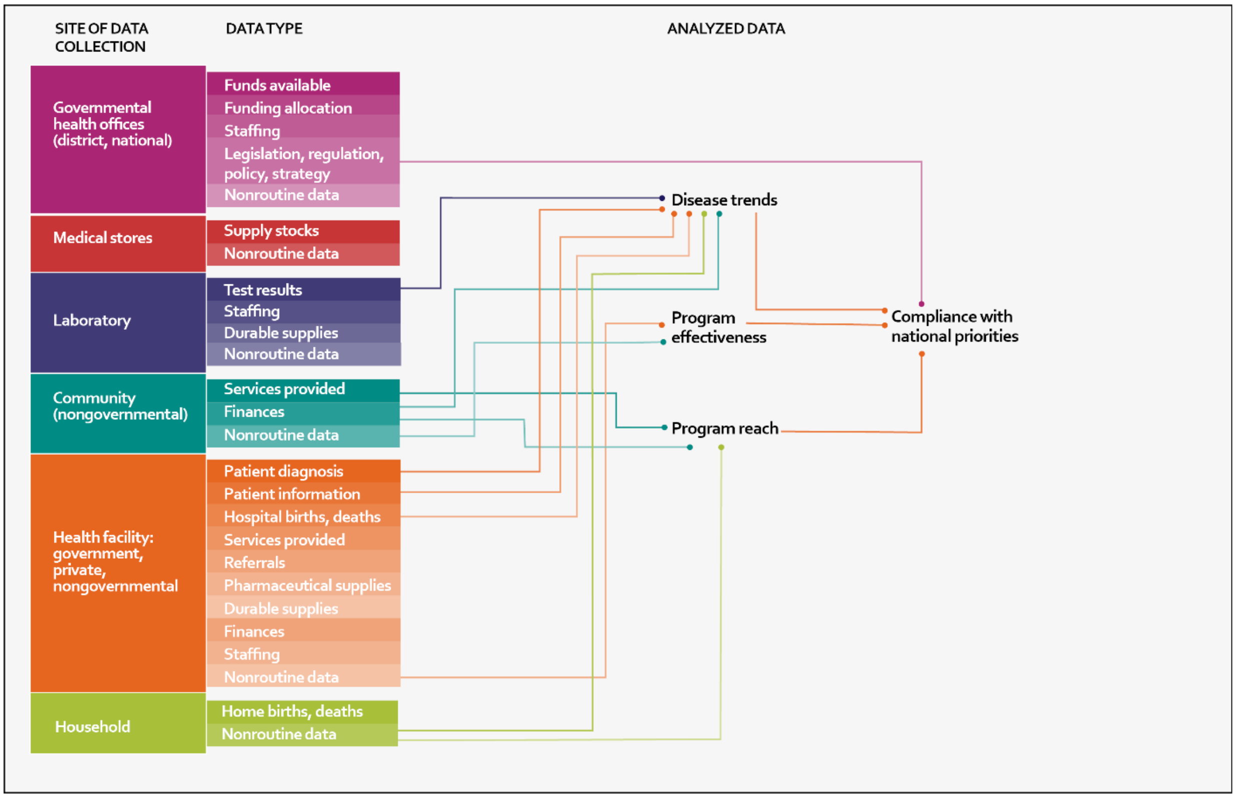
Resources are almost always scarce and expensive. Decisions about which resources to use in what situations need to be informed by the resource or service cost and the total amount of funds available (see Figure 6). With data on services provided and their respective costs, one can calculate the average cost per service. This measure, in turn, can be multiplied by the number of people needing the service. Data on budgets and expenditures from administrative offices at the district and national level will indicate the balance of funds available. When contrasted with estimates of the percentage of the population reached with the services, a ministry can quantify and advocate for any additional funds needed to extend services to those currently unreached.

Figure 6. The data sources, data types, and data analyses needed to answer the question "Are we using resources efficiently?"



The fourth critical question (Figure 7) is whether the resources deployed and the programs implemented are having the intended effect on the health outcome. Are the rates declining? If not, is it because too few have been reached or because the service itself is ineffective? At a still higher administrative level, the analysis of disease trends, program effectiveness, and program reach will enable a ministry to assess whether a policy and its programs are achieving national priorities and goals.

Figure 7. The data sources, data types, and data analyses needed to answer the question "Are we making progress?"



The advantages of a question-based framework

The question-based framework we propose simultaneously provides a consistent terminology and adaptability to a variety of governance settings. It sidesteps the inconsistent definitions of systems, such as of HMIS and RHIS, by referring instead to the data elements that can find a place in one, both, or none of those systems. The framework addresses questions that are of central importance to the country (or other governance level), rather than programs directed by a donor. And it provides needed practical detail to the frameworks based on levels of governance.

A framework that maintains consistent elements for all levels of governance but accommodates a variety of questions at each level reflects what has been called a "federated" health information architecture. [15] A federated system "has the potential to improve HIS efficiency; provide flexibility for local innovation; cater to the diverse information needs of healthcare providers, program managers and policymakers; and encourage data-based decision-making."

The description of data collection sites, data types, and data analyses provides a level of specificity between concepts and technical detail that allows those who are not information technologists to see what the system is composed of and what its purposes are. Moreover, it allows those who focus on a particular component—a stream of data, if you will—to see how their part contributes to the larger watershed, if the lack of any data types prevents their stream from being more useful, or if adjustments to systems or capacity building are needed to make better use of data collected. This perspective can provide a sense of meaning to their work and facilitate ownership of the system, along with a will to maintain and improve it.

Unfortunately, many current HIS have not been guided by the questions they need to answer. Instead, they have grown out of an impulse to collect and digitize readily accessible data or meet administrative and management needs. The availability of these data—collected without a vision for the broader purpose—is then often followed by a search for the questions they can answer. Too often, they cannot answer some of the most basic or important questions. Putting the cart before the horse in this way can result in an inefficient and non-useful HIS. The inefficiency includes the time of many personnel to collect data that cannot be used. Starting with the end in mind—the questions that need to be answered—can minimize this and also prevent the urge to manipulate data to conform to pre-determined answers.

Using the framework

The questions and HIS diagrams we provide here are examples. To be of practical use to a particular country, the data types and where they are collected will need to reflect the systems of that country. But to facilitate discussions about the HIS across the levels of governance within the country, we believe it would be most helpful to keep a country's list of data types and sources consistent for each level of governance and each question.

While adapting some elements to local systems, a country can also benefit from adhering to common definitions of particular data items. For example, to coordinate efforts to control an epidemic affecting several neighboring countries, the countries would benefit from a shared definition of signs and symptoms indicating infection. An inability to compare across countries might reveal one country's lack of best practices or the need to strengthen data collection in one of the site systems.

The number of questions that can be asked of a health care system is virtually limitless. As we have seen, each question requires particular types of data. Questions that focus on a narrow issue often require information that is not commonly collected. For example, asking, "What proportion of the population has an easily accessible health facility?" might require asking each patient attending a clinic about the distance they traveled or asking each household about their nearest health facility. With each new data type, the burden of data collection increases. When the data collectors are also service providers, at a certain point the burden of data collection can become too great, which can hurt, rather than help, the health system by slowing the delivery of services or reducing the number of patients that can be seen in a day. A question-based framework is not the cause of this problem. Rather a question-based framework can make explicit the number of questions that are being asked and facilitate discussion among stakeholders about the relative priorities of the questions and alternative means of obtaining answers. Just as an HIS guides population health services, so a question-based HIS framework can guide the structure and uses of the HIS.

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Carolina Population Center
University of North Carolina at Chapel Hill
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Phone: +1 919-445-9350
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