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**INFORMATION NEEDS ASSOCIATED WITH
THE CHANGING ORGANIZATION AND
DELIVERY OF HEALTH CARE:**

**SUMMARY OF PERCEPTIONS,
ACTIVITIES, KEY GAPS, AND PRIORITIES**

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EXECUTIVE SUMMARY

OBJECTIVES AND METHODS

This report summarizes the insights and conclusions drawn during a seven month project to assess unmet needs for supply-side information on the health system. Highlights and key findings of the study are summarized on the next page. The project focused on helping the Department of Health and Human Services (HHS) identify how information needs associated with a changing health care system are perceived by a wide variety of user groups and constituencies, including those representing providers, insurers, purchasers, consumers, and government at various levels. The impetus for the project stems from a wide-spread perception that the health care marketplace is changing rapidly in ways that will require information about changes in the components of the health system and their interrelationships, as well as on the effect of these changes on institutions and public policy objectives. The project is intended to help HHS' Data Council to identify implications for HHS activity, as well as where HHS may have a role in helping to address these issues or support others in addressing them.

The study included two stages of data collection. The first was a broad-based review of perceived gaps, their causes, and the activities generated in response to these perceptions, as identified through interviews with over 50 individuals and a review of relevant literature and Web sites. The second involved obtaining more comprehensive information on a diverse group of 11 entities identified in the first stage as involved in broad-based efforts of interest nationally including the resources and structure of the system, the care process, and the outcomes of that process.

PROJECT CONTEXT

Virtually all those we interviewed expressed a sense of the enormity of change in the marketplace and the span of effects from this change. There is widespread agreement that the serious gaps in "supply side" information on the health system that predated these changes have only grown worse as the system has evolved. These stakeholders recognize the prominent role of market-place strategies in driving change, spurred both by purchasers and by changes in medical practice and technology. They also see considerable instability and geographical diversity in markets. Despite change, fundamental problems, like care for the uninsured, continue, with new problems emerging, like those associated with changes in the physician-patient relationship in a managed care environment. Stakeholders also perceive that emerging provider organizations and managed care models are becoming increasingly complex, with overlapping ownership and contractual linkages among component parts of the health care system. Moreover, provider networks serve diverse managed care products.

PERCEIVED MISMATCHES BETWEEN INFORMATION NEEDS AND AVAILABLE INFORMATION

Historically, the greatest amount of information has been collected on the structure and components of care that define available resources. Less information has been collected on operational

HIGHLIGHTS AND KEY FINDINGS

- HHS's interest in the information needs and associated data gaps created by the rapid transformation of the health system clearly strikes a responsive chord among diverse stakeholders. Our findings show that stakeholders perceive information on the "supply side" of the health system to be very important, with gaps in data serving as a major obstacle to their efforts to serve their constituency, address operational needs, and participate in the policy process.
- We focused on supply side information (i.e. health care suppliers, and insurers and what they report) and identified three types of information: (1) components and structure of the system (that is, the inputs to care), (2) operational process and performance features; and (3) the policy-relevant outcomes of health care delivery.
- We found two major ways in which the current environment has intensified the need for information. First, the growth of managed care and consolidation has generated a heightened demand for information on the structure and linkages in the health care system. Second, the growing interest in accountability, competition and cost containment has heightened the focus on having good operational data on performance or outcomes achieved by health plans and providers for specific populations.
- Stakeholders point to a number of critical questions as illustrative of the kinds of information needed. To answer these questions, there would need to be: (1) better information on health insurers/plans and the arrangements through which providers are linked with plans and integrated systems, and (2) better transaction level data, with appropriate clinical detail and structural links to support analysis of operational performance and outcomes.
- Stakeholders also perceive that national data are not sufficient in today's environment. State and local level data are needed as well. Further, they want data to be flexible enough to support diverse analyses and timely enough to be relevant when the health care system is rapidly changing.
- We identified 23 ongoing efforts within the private sector, states and foundations/research communities to address data gaps and studied 11 of them more comprehensively. Though sponsors of these activities perceive them to be focused on high priority issues, they also perceive significant limitations in the scope of their efforts. These arise because of limited resources, lags in data availability which limit timeliness, and less willingness to provide information in a highly competitive environment with extensive data demands. In addition, quality problems and inconsistencies in available information, combined with a lack of standardization or audit, serve as barriers to enhancing information.

process and performance, particularly in the ambulatory setting, and least has been collected on outcomes of care. However, gaps exist within each of these three types of health information.

Historical Context for Available Information and New Information Needs

Historically, users of information on the health system have relied heavily on private and state-based sources that complement federal efforts. Information on health system components, resources and structures has been maintained separately for health providers and health insurers. The focus has mainly been on information about discrete entities or individual providers rather than their characteristics or relationships with one another. Information on process of care has been based mainly on discharge/encounter level data for institutional services. Data from which outcome measures can be constructed have been highly limited.

We found that many but not all of the information needs and gaps cited in our study have been the focus of attention in previous studies, that preceded the current market changes. These studies include those by the National Committee for Vital and Health Statistics, the Institute of Medicine, the Health Care Financing Administration, and foundations particularly concerned with state data. The existing studies have focused on the inputs and outputs of care rather than on the way these inputs are organized and structured and the effects of these structures--a topic of considerable interest to many of those we spoke with in the private sector. Further, many of the needs identified in earlier studies remain today.

ASSESSING EMERGING ISSUES AND NEEDS

Our respondents provided insights into the kinds of questions that they cannot address well with existing information. We summarize very briefly below this topic, addressed and described more fully in the report.

Health Care Structure. Most current information on the structure of the health care system is oriented toward the counting of the individual types of resources (like providers, facilities, or health plans) that make up the structure. In contrast, our project showed that there is a need for much better information that can be used to assess the adequacy of these resources, changes in them, and the relationships of these resources both to one another and to the existing financing system. For example, who is buying and selling medical practices? What is the right benchmark for medical staffing? What are the characteristics of health plans in different markets? In addition, there is a perception that much more information is needed to support assessing medical practice and training needs, particularly for physicians which tend to account for most existing resources. For example, how many physicians do we really need? Concerns also are widespread over limitations in information on the financing for the health care system and the absence of data on employers. The latter are viewed as increasingly active in driving marketplace change and influencing public policy outcomes.

Operational Process and Performance of Health Care Providers and Plans. There are three types of needs here. The first is a need for better knowledge of the structure of and responsibility for the process of care given the growth of managed care and integrated systems in an increasingly

competitive marketplace. For example, who is actually providing the care, how does a patient reach a provider and what incentives influence the care a provider considers? The second is a need for information to support understanding how structural relationships, like the transfer of risk or growth of technology, influence the process of care. For example, do physicians actually know and understand the contractual provisions that influence their pay? The third is for information that provide insight on the relative efficiency of individual providers or health plans in an increasingly competitive marketplace. For example, what really are the differences in cost or performance between teaching hospitals and others?

Outcomes of Care Delivery. This kind of information has been the least developed historically and is viewed as increasingly valued by those concerned both with assessing the value of care and with understanding its costs and distributional implications. One key issue is how to interpret information on practice when there are no benchmarks or standards for practice. For example, is a caesarian section rate that falls or is below average too high or too low? Simply having outcome information, particularly on a risk-adjusted basis that can be compared across providers or plans, is a problem. Costs as outcome measures, are a second key issue, with current data providing limited insight on the costs of achieving given outcomes or on how capitation or ambulatory care delivery each influence cost. A third key issue is how to interpret current population-based information on access and distribution (like insurance coverage or uncompensated care) in today's market-place. For example, if uncompensated care drops, is this a positive sign that more individuals are insured/able to pay for their own health care or does it mean providers are less willing to see the uninsured?

Cross-Cutting Issues and Needs. Across structure, process, and outcome measures, there are concerns that information needed to address issues at the state and local level are also lacking and that existing data systems have some inherent weaknesses that undercut the utility of information. These include weaknesses in the clinical components of information systems, inconsistencies in data derived from plans built around diverse models, and inconsistencies in the data available centrally about managed care plans regulated differently across insurance systems or states.

Summary List of Key Data Gaps. Table S.1 summarizes the key data gaps that limit the ability of stakeholders to answer the questions they need to answer in today's market. In terms of structure, there is limited and incomplete information on insurance and health plans, as well as on ambulatory and community providers. The limited information on insurance/health plans is a particularly large problem because it complicates the already challenging need to generate better information about how providers in the health care system are linked to one another and with health plans. Getting better information on various facets of these systems was a key need perceived across a variety of stakeholders.

The absence of standardized transaction level data with appropriate clinical content that can be flexibly analyzed and linked to cost and outcomes is a key data gap that serves as a barrier in addressing many of the questions stakeholders have about the process of care and outcomes of the health system.

TABLE S.1

SUMMARY OF DATA GAPS IDENTIFIED FROM THE PERSPECTIVE OF
STAKEHOLDERS OUTSIDE THE FEDERAL GOVERNMENT

STRUCTURE

Component Parts of the Health Care System

- No comprehensive census of health insurance plans or arrangements exists
- Limited information available on community based alternatives to long term care, intermediate models
- Data on ambulatory care and non-physician providers is limited, incomplete, and inconsistent.

Linkages among Parts of the System

- Little information on ownership and/or aggregation of physicians and/or hospitals
- Integration and arrangements (including transfer of risk) between health plans and provider entities and their constituent individual providers not identifiable in data.
- Linkages across the continuum of care not identifiable in data.
- Duplication exists across diverse data collection efforts

PROCESS AND OUTCOMES

- Transaction level information on services which can be linked to individuals, providers, or health plans are often absent
- Clinically relevant data are limited.
- Need the ability to link expenditure data to functional role rather than setting
- More meaningfully categorized expenditure data are needed including out of pocket spending and spending for given outcomes or people

CROSS-CUTTING CONCERNS: GEOGRAPHICAL RELEVANCE AND STRATEGIC FLEXIBILITY

- State specific data are often lacking for all or some states. Data for policy relevant localities (e.g. inner city) is even more limited
- Data need to be adjustable for residence versus service location (especially when areas cross states)
- Data need to support consistent trend analysis but data captured need to be flexibly defined and timely to account for change in the health system
- Data should permit flexible aggregation at different levels (e.g. service level; provider level; patient level; or population level)
- Data need to be capable of being linked to relevant population-based units to support targeted analysis (e.g., individual with a given health problem).

SOURCE: MPR Analysis

EXTENT TO WHICH GAPS ARE BEING ADDRESSED

Through our interviews, we identified a number of efforts initiated in response to concerns about information needs associated with today's evolving marketplace and the data gaps that exist. Many of these are modifications in or expansion to ongoing data collection by associations to develop information needed by their members. Other efforts take the form of independent research funded by states, foundations and other parties to fill the gaps. The 11 efforts selected by HHS for the second phase of our project include ongoing national data collection activities by the American Hospital Association, American Medical Association, American Association of Health Plans, American Association of Homes and Services for the Aging, Association of American Medical Colleges, and National Committee on Quality Assurance, along with selected state and foundation funded efforts.

Table S.2 summarizes the focus of and impetus for the 11 efforts we studied in the second phase of our work and describes their weaknesses. Sponsors of these efforts perceive them to reflect attempts to respond to the priority data gaps they perceive. But they also view these efforts be relatively limited compared with the needs. Limits on the players' authority and resources restrict the amount of information that can be collected and who will provide it. Other barriers to better information include a lack of consistency in definitions used by reporting units and limitations in the willingness to supply information in a highly competitive and demanding marketplace. At least three national associations have recently been forced to make some cuts in their data collection activities in response to budgetary constraints or marketplace concerns, an irony given the heightened demand they perceive for information.

Insights into These Topics for HHS

Despite the diversity of the user community, we found a striking similarity in many of the perceived needs and information gaps. These include considerable shortcomings in the information available on the internal structure and operational process of the health system as it becomes more integrated and complex. There also are concerns about how well performance and outcomes of the system can be measured, either as a whole or for its components. It is clear that stakeholders we interviewed perceive that information on the supply side of the system is very important. Yet in today's environment, there are ironically growing fiscal and proprietary barriers that limit data collection.

A General Role and Need for HHS. Based on the information we obtained, we conclude that private sector stakeholders and states alone cannot address the concerns we identified. In the perception of most of those we spoke with, the private sector does not have the legislative authority inherent in government to require compliance nor the scope of influence needed to capture information that individual constituencies feel they need on the health system and its increasingly complicated organizational arrangements. States are limited both by resources and by the increasing consolidation of the system that limits the utility of state-based information in a context of national purchasing or managed care operations. We conclude the federal government has an important role to play in collaboration with others to address the issues we identified. In particular, the federal government can provide leadership to support collaborative efforts to address problems ill-suited for decentralized action.

TABLE S.2

OVERVIEW OF FOCUS AND PERCEIVED LIMITATIONS OF 11 INITIATIVES

	Impetus/Focus			Perceived Limitations of Efforts ^a			
	Structures & Linkages Among Health System	Process and Performance Measurement	Outcomes	Lack of Standard Definitions For Data Quality	Burden/ Willingness to Provide Data	Timeliness	Cost
National On-Going Efforts							
AAHP	✓	✓		✓	✓		✓
AAHSA		✓	✓	✓		✓	
AAMC	✓	✓	✓	✓		✓	
AHA	✓	✓			✓		✓
AMA	✓	✓			✓		✓
NCQA		✓	✓	✓	✓		✓
Other National Efforts							
Alpha	✓	✓		✓			
NIHCM	✓	✓		✓	✓		
Center	✓	✓					
Other More-focused Efforts							
Florida	✓	✓			✓	✓	✓
Minnesota		✓	✓				

Source: MPR Analysis

^aThe absence of a check does not mean this was not a problem since responses were obtained in an open discussion and some features may not have been mentioned.

The report includes 10 suggestions about what HHS could do to address, in collaboration with others, the key gaps we identified through our work. These suggestions are organized into three main categories.

Addressing Data Gaps on the Structure of Care. The first set of suggestions focus on better information on structure and functional linkages within the health system and their effects on the process of health care delivery. We view these needs as critical and also the most complicated HHS will face because work in this area is relatively undeveloped. We identify four priority areas for attention and suggest some ways of proceeding:

- In collaboration with the NAIC and DOL, HHS should assess current activity focused on developing more consistent and complete census data on health insurance and managed care plans, with a focus on encouraging attention to needs and issues viewed as important by the health policy and research community as this activity unfolds.
- In collaboration with national provider and health plan organizations and associated researchers in and out of government, HHS should determine how to capture meaningful information about linkages across entities in the health system as they form more integrated systems under managed care.
- Review HHS activity to collect provider information across diverse agencies with the objective of deciding change might be desirable in light of market-place change. These are generating growing interest in understanding the linkages across components of the system as well as the components themselves.
- Review current activity to enhance information about purchaser activity in light of needs identified through this project to determine whether current activity is sufficient to meet the needs expressed and if not, what next steps might be desirable.

Addressing Data Gaps on the Process and Outcomes of Care. Our second set of suggestions focus on better information on system operational performance and outcomes. There is considerably more work underway in this area than the previous one both at HHS and elsewhere: The Health Insurance Portability and Accountability Act, in particular, has generated a host of collaborative activity focused on standards for transaction level information. However, while these efforts may promote standardization, they are constrained if data to standardize do not exist. They also may be limited by inherent weaknesses in understanding the structure of the health care system. For example, what is the universe of entities that should be coded and how? We make three suggestions for activities that could prove useful in hastening the speed of change.

- To learn from previous experience, we suggest HHS commission an independent study of the key reasons some high profile prior reports such as those by NCHS committees or IOM have spurred only limited improvements in information systems. The focus should be a practical lessons for the future about how to structure feasible and valuable recommendations and implementation strategies.

- Consult private-sector national associations to determine whether they perceived federal help could be useful such as, for example, in moving forward with NCQA’s recently issued “Roadmap” report on health data systems.
- Similarly, consult with representatives of states, payers, purchasers and others to identify barriers to any additional areas where federal help would be useful. Facilitate communication between these entities and provider and health plan entities on areas of mutual interest in improving performance measures, including developing condition-specific measures on a population basis, tracking care across settings and associating outcomes with costs.

Anticipating Strategic and Other Operational Barriers to Success. Our third and final set of suggestions focus on key strategic or procedural issues that may be impediments to improving information. Two suggestions are:

- HHS may want to assess where it is dependent on information obtained voluntarily through private sector entities and any risks that this may generate in a competitive marketplace.
- Because public-private partnerships appear an increasingly attractive vehicle for mounting successful data initiatives in today’s environment, HHS may want to review the operational issues for government entities joining such arrangements.

The third and final suggestion focuses on the issue of funding as a constraint on data improvements. Our work shows that the funding limitations are a barrier pointed out by all stakeholders interested in enhancing data, particularly in today’s environment. In today’s federal budget climate, it is also an issue for HHS. To identify how best to enhance data given available resources, we suggest that HHS may want to consider convening a “summit” of public and foundation funders to discuss cooperative strategies that might be employed.

In sum, the information needs associated with the changing health system are extensive. Gaps in available information are widely perceived by stakeholders as impeding their ability to effectively serve their constituents. While some activity is underway to improve data and better address gaps, these activities are viewed by their sponsors as severely limited. The federal government can play an important role with stakeholders to better address the current and anticipated future information needs. While data improvement is a long term process and there are many challenges to be faced, stakeholder perceptions suggest some important areas where concrete steps can immediately be taken to begin this process.

I. INTRODUCTION, OBJECTIVES, AND METHODS

KEY POINTS

- **The speed and breadth of change in the health care system, along with budgetary constraints and concerns, generates intense interest in the health care system. Answers to the many questions being raised will require information on new and existing system components, the changing relationships among them, and the effects of the changes on the health care system and individuals.**
- **HHS historically has devoted fewer resources to collecting information on health insurance plans and providers--the “supply” side of the system--than it has devoted to population-based information--the “demand” side. As the health system evolves, the demand for information on the “supply” side is growing and widening, with a variety of public and private stakeholders needing information to support diverse operational concerns.**
- **This project seeks to support the Department of Health and Human Services in identifying key information gaps created by the evolving health care system and in assessing strategic actions to address them.**
- **The report synthesizes information obtained through a two stage process. In the first stage, we reviewed the literature and contacted more than 50 individuals by telephone to discuss their perceptions of health system change. Our discussions focused on information needs and data gaps that health system change has created, along with any activities to fill these gaps. Contacts included representatives of major national associations, providers, insurers, and health plans; state officials; foundation staff; and researchers and policy analysts. We identified 23 efforts to respond to information gaps. In the second stage, we collected comprehensive information on 11 of the 23 efforts.**

A. Rationale For This Work

It could be argued that there is greater instability and change in our health care system today than at any other time in the recent past. The emphasis on market competition is strong among both private and public purchasers. Managed care has become the dominant arrangement both for

delivering and for financing care for privately insured individuals. It is also a growing presence in public programs like Medicaid and Medicare. At the same time, health care providers are consolidating more and more as they affiliate or merge with one another and accept greater risk and/or organizational responsibility for the delivery of care as a provider system affiliated with managed care plans. These trends, along with current budgetary constraints and concerns, are generating intense interest in the health system. Answering the vast range of questions now prompting scrutiny of the health system will require solid information about new and existing system components, the changing relationships among them, and the effects of these changes on institutions and people.

Although the Department of Health and Human Services (HHS) and other federal agencies have historically served as central repositories for population-based information nationwide, especially information from household surveys, HHS devotes many fewer resources to collecting information on health insurance plans and providers--the "supply" side of the system. Although efforts by the states and national entities like the American Medical Association (AMA) and American Hospital Association (AHA) extensively complement federal efforts to collect supply side information, this decentralized structure makes it more difficult to expand the content of supply side information and make it more consistent so that it better serves current needs. By "supply side", we refer here to information on suppliers of health care services including both institutional and individual providers and practitioners, as well as suppliers of health insurance and coverage. The focus is on information produced within the structure, contrasted with the self-reported information typically obtained in population based surveys (i.e. the demand side).

As the supply side of the health care industry evolves and information on this segment of the industry becomes more important, because of market place changes federal policymakers must

consider how these developments affect information needs and how to meet these needs effectively. In addition to its direct role in producing information, HHS plays an important leadership role in the effort to identify perceived gaps in current data and other information collection efforts and to address issues common to information consumers and producers. This role may become increasingly important since changes in the health care market are expanding demand for health system information not just among policymakers but also in the private sector where timely insight on market change and performance is critical to strategic and optimal success.

The purpose of this project is to develop insight into how information needs associated with a changing health system are perceived by a wide variety of user groups and constituencies including those representing providers, insurers, purchasers, consumers and government at various levels. The project also identifies specific activities by a subset of those groups undertaking response to new and evolving health system information needs. With a few exceptions documented in the literature, we focus solely on non-HHS actor perceptions about information needs and their efforts to address these. Insight into these activities will complement HHS's knowledge of its internal and other federal information needs and activities. Together, both sets of information will help HHS policymakers set priorities and develop appropriate collaborative strategies for addressing important gaps that exist or may be arising.

This project is one of several steps HHS is taking to assess the needs for better information on the health care system. The work here, which addresses information needs and gaps relating to the supply side of the health care system, is intended to support HHS's Data Council and to complement other activities in the private sector and in other government bodies. The work also complements HHS's recent survey integration initiative, which focused largely on population-based surveys, that is, the "demand side". Although the supply side encompasses a range of interests, the focus here is

information relevant to the health care system broadly. That is, we focus less on needs for detailed information on individual sectors of the system (e.g., specific kinds of providers, specific federal programs) than on needs for information that cross these areas and provide insight into the system more generally. For example, information pertaining to new business and structural affiliations of providers was an expressed need by various interest groups, including insurers, purchasers, consumers, researchers, and policymakers. In a few areas (e.g., purchaser-related information, expenditures), the needs are not clearly supply- or demand-related. However, we include these areas because they are both frequently overlooked and seen as very important by many of those with whom we spoke. In our view, it is valuable to include them.

B. CONTENT AND METHODS OF THIS PROJECT

This report draws on information obtained through a two-staged process we were asked to use. The first stage involved a relatively broad, but general, review of perceived information gaps and their causes across a broad spectrum of groups. In this stage, we interviewed more than 50 individuals by telephone. Interviewees included representatives of major national associations, providers, insurers, health plans, and beneficiaries; state officials; foundation staff; and researchers and policy analysts. We also selectively reviewed relevant literature and Web sites to obtain additional information on needs and existing work. These sources document (1) perceptions of health system change by various stakeholders, (2) current data systems and where they are weak or otherwise limited, and (3) efforts to fill gaps, and other related material.

In the second stage, we developed more comprehensive information on efforts by a diverse group of 11 entities to respond to information gaps they or their funders perceived. These entities were selected in consultation with staff from the office of the Assistant Secretary for Planning and

Evaluation (ASPE) and the National Center for Health Statistics (NCHS), using a number of criteria to define three priority groupings. The first was for entities engaged in broad and nationally based efforts that would have an ongoing effect on available health information. The second was for entities engaged in priority national efforts that would not necessarily have an ongoing effect, but were still of interest. The third grouping was entities engaged in efforts that were more geographically limited or not ongoing but were still of interest nationally. In this third group, we often limited our selection among entities engaged in somewhat similar activities, such as states. In all groups, we excluded entities engaged in efforts of interest to a narrower audience and set of concerns, as well as certain federal initiatives that would otherwise have been selected had they not already been well known to HHS. Efforts to collect information on these 11 entities focused on understanding the impetus/motivation, content, and perceived strengths and weaknesses of key efforts underway in response to perceived information-related needs. Our efforts included telephone contact typically with several affiliated staff and review of written material.

This paper is intended to address what we learned about specific issues and questions of concern to ASPE. It is not a summary of discrete data collection activities. That is, it synthesizes our insight across a range of information-collection efforts. We describe the context for the project in an overview of health system change and of how information needs are shaped by the responsibilities of diverse groups (Section II). We describe what we learned about the mismatch between information needs of stakeholders and current data systems (Section III). We review what we learned about current efforts to fill gaps and account for limitations with currently available data (Section IV). Finally, we assess the implications of what we learned for priorities and next steps important for HHS to consider as it addresses these issues (Section V). Supplemental material on individual efforts appears in the appendices. Appendix A includes a list of individuals interviewed, Appendix B includes

citations of the most relevant written literature, Appendix C includes a list of the 11 entities and activities studied in more depth, and Appendix D includes a review of previous efforts to identify data gaps.

II. PROJECT CONTEXT: HEALTH SYSTEM CHANGE AND STAKEHOLDER FUNCTIONS

KEY POINTS

- **There is widespread consensus among major private sector health leaders that the health care system is undergoing enormous changes. Change is driven heavily by the active role of large private purchasers in encouraging managed care and competition in an effort to contain costs. The health care system is still in transition and considerable geographic diversity is likely to remain. With health system change, the gaps in supply side data that predated these changes have only grown worse and seriously so.**
- **Information needs of stakeholders both overlap and represent unique functions and responsibilities of diverse groups. Users of data can be thought of in terms of health care suppliers, health care customers, and the regulators/ policymakers at the federal, state and local levels.**
- **Stakeholders' needs for information can be divided into three types: (1) structural information on components of the health care system and their linkages; (2) the process of care, including administrative and clinical performance; and (3) policy relevant information on the effects of structure and process on policy-relevant outcomes and the implications both generally and for distinct constituencies.**

Virtually all those we interviewed expressed a sense of the enormity of change in the marketplace and the span of its effects. There is wide agreement that the serious gaps in supply side data that predated these changes have only grown worse and seriously so. As Joseph Newhouse, chair of the Prospective Payment Assessment Commission, observed in our conversation, “Where isn’t there a data gap?”

The context for this paper is the existing work on changes in the health system. We review these changes, as well as information users and groups, and the current health system information needed to meet the functional responsibilities of the groups. However, while functional responsibilities vary

by user group, we identified many information needs that are common to all groups. Recognizing user perspectives helped us identify in our interviews why groups expressed specific data needs, even when the interviewee did not explicitly describe how their organizations' functional responsibilities fueled their health system data needs and many of the needs served multiple functions and overlapping user communities.

A. Health Care System Change as Viewed by Stakeholders

Important changes in the health care system are being tracked by the Center for Studying Health System Change, established and funded expressly for this purpose by the Robert Wood Johnson Foundation. Center staff recently summarized what they learned in interviews with top leaders in 15 national professional organizations and trade associations about the changes underway in the health system and the efforts of their members to adapt (Corrigan and Ginsburg 1997). We summarize below the major findings they reported.

Center staff identified five themes running through the interviews which they published in *Health Affairs*: (1) large private purchasers heavily influence change by their efforts to slow the rising cost of health care but change also reflects fundamental shifts in medical practice and in the use of technology; (2) the health care system is still in transition, and the considerable geographical diversity in markets is likely to remain; (3) the system simultaneously is experiencing positive change with the growth of managed care and competitive markets (e.g., care coordination and increasing clinical and operational efficiencies) and adverse effects (e.g., siphoning of dollars to investors); (4) the system still faces fundamental problems, such as the large uninsured population, and potential new problems, such as erosion of the clinical foundation of care as reflected in the doctor-patient relationship; and (5) the majority of leaders perceive that reliance on marketplace dynamics should continue, since efforts at federal health reform in their perception failed dismally.

Center staff also reported that different stakeholders have both similar and different concerns. Among purchasers, large employers are much more active than small or medium-size employers in pushing change, and national/regional companies differ from local business coalitions in their interest in practice standardization versus community-based improvements. Purchasers and consumers are frustrated about the limitations in comparative data on health plan performance and outcomes. Insurers and health plans are enthusiastic about managed care's potential value, particularly in forming a clinical information infrastructure to enhance health outcomes. But insurers and plans also feel challenged to develop stable relationships with physicians. Hospital concerns are shaped by the extensive horizontal integration and downsizing occurring in different ways in a variety of markets and industry segments. Academic medical centers are concerned about how core functions (education, research, and patient care) are challenged by the competition introduced by managed care that is reducing the ability to cross-subsidize. Physicians and other provider groups perceive that there is a movement into multi-specialty group practice that is better able to invest in infrastructure and share risk. They also perceive the role of practice management companies to be increasing and they are concerned about the effects of capitation. That is, increasing consolidation within the system is leading to new organizations involved in managing health care as well as arrangements that involve physicians in the risk for the cost of care.

According to Center staff analysis of their interviews, the future system envisioned by leaders includes large national organizations and smaller market players, and insurer- and provider-sponsored entities. The interviews also suggest that there are pressure points throughout the system. These include the uninsured, underinsured, and safety net providers; the elderly and the disabled and how they are integrated into managed care; and the potential erosion of public confidence in the health care system. These pressure points show how system change affects people and entities of different

types and with different policy interests. Demand for information from consumers is perceived to be growing, though serious limitations exist in available information.

The perceptions Center staff identified with association leaders are consistent with prominent academic and popular perceptions elsewhere in the literature. For example, a 1996 *Business and Health* summary of the state of the American health care system highlights the shift from inpatient to ambulatory care settings, the massive economic reconfiguration of the health system as a function of hospital downsizing and emerging oligopolies like Columbia/HCA, and changes in academic medical centers. The summary also includes a managed care perspective arguing for the importance of data to monitor and improve provider performance in a managed care environment (Halvorson in *Business and Health* 1996). The perceptions of Wall Street health security analysts also parallel the perceptions of others. They predict continued rapid growth of managed care and greater development of physician organizations; however, they see hospitals remaining a key and powerful player, with the nonprofit sector continuing to have considerable community-based and political support (Ginsburg and Grossman 1995; Center panel 1997). Miller and Luft (1994), Gold et al. (1995), and Gold and Hurley (1997) highlight the considerable complexity in emerging managed care models and products. For example, managed care plans offer multiple products, their provider networks are structured in complex ways, provider entities are given major responsibility for managed care functions, and there is considerable variation in all of this across markets. Finally, the proliferation of products (e.g., HMOs, PPOs, and point-of-service products) with similar brand names but sometimes different features lead to further confusion and complexity.

Similar trends are perceived to exist outside the acute-care sector. For example, Kane (1995) notes the blurring distinction between home and institutional care and between providers in these two areas. Shaughnessy et al. (1995) observes the growing interest in outcomes and effectiveness of such

care in diverse settings when needs are growing and costs are a concern. Freeman and Trabin (1994) highlight the use of firms that provide “carved-out” managed behavioral health care in contemporary models of managed mental health care delivery. These entities often represent new structures that are influencing patient flow and delivery of care.

B. Where Does the Demand for Information Come From?

For analytical purposes, it is possible to identify and functionally differentiate three key health system user groups: (1) provider and health plan/insurer associations and the suppliers they represent, (2) purchaser and consumer organizations and the customers they represent, and (3) regulators/policymakers. The information needs of these groups share many common features but the uses of information also differ, consistent with differences in function and responsibility for each group. Analytically, three kinds of information needs can be distinguished: (1) structure and components of the health system, (2) operational information on the process of care, and (3) outcome information (including both clinical and policy outcome) to guide policy analysis and representation. The functional categories of data requirements encompass the range of data needs expressed by those we spoke with over the course of the project. The three user types were grouped based on shared perspectives and motivations that drive their information requirements.

Providers and health plans/insurer associations and their members represent suppliers of health care services. They include, for example, the American Medical Association (AMA), American Hospital Association (AHA), Association of American Medical Colleges (AAMC), American Association of Health Plans (AAHP), the American Association of Homes and Services for the Aging (AAMSA) and Health Insurance Association of America (HIAA). These entities also tend to be membership organizations, which need information to support themselves and the needs of their members. In contrast, purchaser and consumer entities such as the American Association of Retired

Persons (AARP), and Pacific Business Group on Health, represent the demand side of the market, that is, the customers. Policymakers and regulators are responsible for defining the “rules of the game” and providing oversight for the market. This diverse group includes federal, state, and local policy-formulating bodies, regulators, and program administrators. We also include here those involved in developing information needed to support these functions, like the National Committee for Quality Assurance (NCQA) or various research or foundation entities.

There is considerable variation within and overlap between each of these user groups (e.g., when government acts as the purchaser for its employees or for public programs). Functional responsibilities also shift over time. For example, the reliance on market-based solutions means that purchasers, through the choices they make, are increasingly, if not always explicitly, influencing health care policy formulation.

The first informational category encompasses functions which directly require structural descriptive information on the components of the health care system. That is, there is the need to know what entities exist, what their characteristics are, and how they are changing. Provider and insurer associations are paid dues to represent a segment of the industry. Hence, they need information to understand their share of the industry and membership base, to project revenue, and to assess potentially desirable changes in their membership eligibility qualifications. For example, with the growth of managed care products, these users would want to know which entities are eligible to join a managed care association and which products and members should be counted for purposes of dues assessment. The suppliers these groups represent need information to identify trends that may affect their strategic decisions as well as to carry out more operating needs (like contracting). Regulators and health policymakers typically need the same kinds of information as provider and insurers on components of the health system, but their focus is on assessing available resources and

entities for whom they are accountable. For example, they would want to know which entities are subject to state insurance oversight. Purchasers and consumers also need information on components of the health system to support their operational needs, as discussed below.

All three entities need operational information on the process of care, particularly information related to performance in both administrative and clinical areas that are relevant to them or their constituency. Provider and insurer associations are expected by their members to provide operational support in terms of measuring and benchmarking performance and developing standardized information such as that used to support clinical practice. For example, members may want to know how their hospitals days per 1,000 covered lives compare to that of peers. Purchaser and consumer organizations are expected to inform or carry out group purchasing activities and help consumers participate more knowledgeably in the system. To do this, they may want to know what choices are available and how each health insurance option performs on such measures as cost, consumer satisfaction, or quality. Regulators and policymakers are expected to monitor performance and provide general oversight. They also have certain regulatory and administrative functions over components of the health system. Therefore, they need enough information to assess and provide feedback on overall performance and improvements. They also need enough information to identify potential problems early on so that steps can be taken to avoid them or to minimize their impact.

All three users are involved in policy analysis to encourage the development of policies that are responsive to the concerns of their particular constituency or interests. The range of policy analysis issues is broad but tends to correspond to understanding the effects of structure and process on policy-relevant outcomes and what both the policy implications and the implications for constituents are. This generates a need for various kinds of information that could be used to assess how constituents will be affected by particular policy options, to support the development of association

positions, or to inform members so that they may position themselves and develop individual positions on issues. For example, has proposed changes in Medicare capitation rates that would reduce rate calculations by the exclusion of indirect payments for graduate medical education. Health plan and provider associations need to know the county-specific impacts of these changes so they can identify effects on markets important to their members; purchasers and consumers are concerned with overall fiscal and geographic impacts specific to their reference population; and government policymakers need information to help them both estimate the budgetary effects of the change overall and assess where to fine tune policy to minimize any adverse short-term impacts of rate reductions.

All these groups also represent and advocate--either for a specific constituency or for their associated public policy body. This representation function differs from policy development in that it is oriented more toward supporting an already formulated position and less toward developing that position. Such support requires information that helps to make the case for the organizations' positions and purpose, including information that would be used to educate policymakers and the public. Such information is needed both at the national level and at the state or locality level where such issues often get considered.

III. PERCEIVED MISMATCHES BETWEEN INFORMATION NEEDS AND AVAILABLE INFORMATION

KEY POINTS

- **Health information needs can be classified into three main types: (1) components and structure of the system (that is, inputs to care), (2) operational process and performance features, and (3) the policy-relevant outcomes of health care delivery. Historically, more information has been collected on structure and resources, with less captured on both operational process and outcomes, particularly in the ambulatory settings. However gaps exist within each of the three major types of health information needs.**
- **Periodic reviews of the adequacy of available information have highlighted data gaps, including some of those we identify here. In particular, these reviews have highlighted the limitations in complete and standardized transaction level information on encounters or services, in the capture of clinically meaningful data elements, and in the development of outcomes information.**
- **What appears new in this evolving environment is: (1) the need for information on the structure of the health system and the linkages among its components; (2) the limitations in process data on operational performance or outcomes and in the ability to link it to particular accountable entities, geographic divisions, subpopulations, or similar health plans/providers; (3) the erosion of transaction or service data due to the growth of managed care and self-insurance; and (4) the increasing concern about data gaps by a wide variety of stakeholders due to the perception of increasingly competitive markets.**
- **Stakeholders identified a number of critical questions they were unable to answer given the absence of better and more complete data. To answer their questions, better information is needed on the ways provider entities are linked to health plans and integrated systems and the arrangements through which these linkages are defined. There also needs to be better transaction and service level data, with appropriate clinical detail and structural links to support analysis of operational performance and outcomes.**
- **National data are not sufficient in today's environment. The stakeholders we interviewed perceive a need for information at the state and local market levels. Further, they want data to be flexible enough to support diverse analyses and timely enough to be relevant when the health care system is changing rapidly.**

The information needs of different users are much the same, and so the same information may meet a variety of functional uses at any given time and across time. We first provide a context for a discussion of new and emerging health system information needs by reviewing the current types and sources of supply side information and how they have been assessed. We then assess current health system issues and outstanding supply side information needs. The information in this section is based on interviews, documents, and other materials reviewed for this project.

Consistent with the earlier discussion, we classify health information needs into three main types: (1) components and structure of the system (that is, inputs to care), (2) operational process and performance features, and (3) the policy relevant outcomes of health care delivery. Historically, the greatest amount of information has been collected on structure and resource issues, with less known about both outcomes and operational process, particularly in the ambulatory care setting. However, gaps exist within each of the three major types of health information needs. To identify such gaps, we subclassify information needs within each category into discrete types of issues or concerns relevant to that category. We also review the issues and needs that cut across categories, and we conclude with a summary of key gaps identified.

A. Historical Context for Available Information and New Information Needs

1. Where Has Information Come From?

Though the health care system is complex, current sources of information correspond to the three types of data needs previously discussed: health resources and structure, (inputs from facilities, providers, insurer/payer coverage vehicles), indicators of the process of care (utilization of discrete services) and--least commonly--outcomes of care (spending, clinical outcomes). Within each data

need category, the information now collected, reflecting the current emphasis in health data, is considerably narrower in scope than current users demand.

As reflected in Table 1, information on health resources and structures is typically divided between health provider and health insurer data. Health provider data are based largely on inventories or files from health care facilities and various types of providers. These files are maintained in federal agencies and in various provider associations. States keep such information on facilities and providers subject to their licensing provisions and sometimes for a broader set of facilities or providers. For the most part, these data relate to discrete entities or individual providers -- information on their characteristics or relationships with one another is limited.

Health agencies or associations have not traditionally been very involved in maintaining data on health insurers and managed care entities. State insurance departments keep such data for insurers or HMOs subject to their licensure requirements. Inventories also are maintained centrally by trade associations and research or consulting firms. Industry data from the Department of Commerce can sometimes provide insight into particular issues of interest.

Information on the process of care is based mainly on discharge/encounter-level data for institutional services (hospital discharges, nursing home stays), with some limited data collection from institutional providers of ambulatory care (outpatient facilities, home health agencies) and--to an even lesser extent--office-based practice. Payers also may have data from claims that can support analysis, though this is much more likely to be the case for public programs (Medicare and, to an extent, Medicaid) than for private insurers. HHS, states, and national provider associations each maintain specific kinds of information. The only information on utilization provided distinctly for individual insurers or payers comes from state filings of utilization and financial information by insurers and HMOs, and from evolving "report card"-type efforts reflected in HEDIS 3.0 reporting.

TABLE 1

ILLUSTRATIVE CURRENT MAJOR SOURCES OF
SUPPLY-SIDE INFORMATION BY TYPE

Federal	Private	State
Health Care Resources - Facilities/Providers		
National Health Provider Inventory	AHA Annual Hospital Survey	Licensure Files
National Home & Hospice Care Survey	AMA Physician Masterfile	
BHP Supply Projections (physicians, nurses)	AAMC Medical Student Data	
BLS Labor Force Data		
Health Care Resources - Insurers/Managed Care Entities		
Department of Commerce Data on Firms	AAHP HMO/PPO Directory InterStudy	HMOs and Insurers Licensed by State
Process and Outcome of Care		
National Hospital Discharge Survey (being modified)	AMA's Socioeconomic Monitoring System	State Hospital Discharge Data
National Ambulatory Medical Care Survey	Proprietary Benchmarking Systems	Ambulatory Data Sets (where they exist)
National Hospital Ambulatory Medical Care Survey	HEDIS 3.0	Insurance Commissioner Filings
National Nursing Home Survey	AHA Annual Hospital Survey	
Medicare and Medicaid Data Systems		
HCFA Analysis of Mortality by Hospital		
SAMHSA Program/Facilities Data		
National Vital Statistics		
National Linked Births/Deaths		
National Health Expenditure Accounts		
Medical Expenditure Panel Survey		

The latter involves aggregate reporting for plans or other entities rather than the development of patient-level databases. Proprietary data of various types are marketed by consulting firms to meet the operational or other needs of purchasers, providers, or health plans, particularly in the interest of benchmarking. However, proprietary data tend to be expensive and not publicly available.

Information on outcomes of the system are quite limited. For the most part, outcomes are derived analytically from process data. The Health Care Financing Administration (HCFA) maintains national health account information with aggregate spending by provider and payer type. The agency has recently expanded the estimates of provider and payer expenditures to the state level. Person-level data on discharges and encounters can support some limited outcomes analysis. Provider data collected as an adjunct to the Medical Expenditure Panel Survey can do the same. Vital statistics data also may be used in outcome studies, as may other population data, all of which are outside the scope of inquiry here.

2. How Good Has the Information Been?

Periodic reviews have been conducted to develop information and/or consensus on the adequacy of available information. Federal data, more than state data, have been subject to review, although there is some information on state data. Reports assessing data collected by private-sector groups are less likely to be publicly available. Most assessments preceded the current marketplace changes and addressed specific kinds of data for which agencies had defined accountability. This limits the comprehensiveness of the scope of the efforts. The most relevant assessments we found are from the periodic reports issued by the National Committee for Vital and Health Statistics (NCVHS), the typically more broad-based and topical studies funded through the Institute of Medicine (IOM), contracted studies of health expenditure accounts, and foundation-funded studies of state health data.

We review each of these briefly below; Appendix D includes a fuller discussion of these historical assessments.

NCVHS Reports. Standing committees established for advising National Center for Health Statistics' (NCHS) data collection activities have issued periodic reports, which tend to be technical in focus. The most relevant is a recent report (US DHHS 1996) recommending a standardized set of health data elements for capturing person- and encounter-level information. The impetus for NCVHS's work is a concern about the administrative burden of inconsistency in data collection and reporting activities and about the confusion generated by lack of standardized health data definitions. NCVHS efforts to develop standardized person- and encounter-level data do not appear to have focused on the impact of the changing marketplace on individual data elements. For example, the payer and charge information included is relatively traditional and fee-for-service based.

Institute of Medicine. The IOM has convened panels to study a number of issues related to health data, one of which we highlight here (See Appendix D for more details and additional studies). With funding from NCHS, the IOM issued a report in 1992 that evaluated NCHS's planned National Health Survey, which would integrate the four health provider surveys with the National Health Interview Survey. The IOM concluded that current systems are uncoordinated and although duplicative at times, they also suffer from important gaps. The IOM cited four areas for priority attention: (1) better insurance claims data, especially for the under-65 population, for the fee-for-service and the prepaid capitated sector; (2) more information on clinical services and physiologic outcomes from medical records; (3) more information from patients (or proxies) on quality of life, health status, and satisfaction with care; and (4) better information on how much is spent (directly and indirectly, including out-of-pocket expenses) on treating particular types of patients. In our view, the IOM recommendations focus mostly on the need for person-level information to support public

policy. They focused less on private sector needs for institutional-level data and data needs of specific health interests. Many of those we spoke with in the private sector wanted more information in the structural arrangements of the health sector on operational performance.

National Health Expenditures. HCFA and others have sponsored work on issues relating the needs for information about health accounts of expenditures. Haber and Newhouse (1991) discuss emerging issues and review existing revisions to the accounts such as to better estimate out-of-pocket spending directly. They also highlight the growing prevalence of vertical integration and managed care, which creates a need for classifications of expenditures that are more responsive to type of service than type of provider. Self-insurance is flagged as a potential threat to the quality and completeness of data on private insurers. Genuardi, Stiller, and Trapnell (1996) consider expenditure data for the prescription drug sector, pointing out changes in the industry with managed care that influence data needs. Ginsburg and Pickereign (1996) assess the policy utility and quality of data used to track health care costs. The authors compare the quality and utility of three kinds of data: provider data on revenues or costs, claims data from insurers, and premium data from employees.

State Data. Long, Marquis, and Rogers (1995) focus on states priorities for state health expenditure data. Gold, Burnbauer, and Chu (1995/1996, 1995) report on a 1994 telephone survey that asked state officials about their perception of data needs and weaknesses. The findings show low levels of policymakers' confidence in the ability to address emerging, but priority, health issues with existing data. Major gaps in data include health expenditures (particularly for expenditures in the private sector and outside of institutions) and on health system and health plan performance. The major barriers to improving the data include funding shortages, lack of comparability across datasets, and the unwillingness of providers and insurers to submit needed data.

B. Assessing Emerging Issues and Needs: Health Care Structure

The structure of the health care system reflects the individual providers as well as how they are organized and linked together as a delivery and financing system, and how well they are linked across the continuum of care. In addition, the number and kinds of physicians in practice reflects the time lag associated between provider training and actual practice. Thus, we include issues associated with planning for needed resources as part of the section on inputs (structure) of care systems. For the same reason, we include issues associated with the available financial resources to support this structure and future training needs (for example, insurance premiums). In discussing these issues, we review their associated information needs and data gaps as viewed from the information obtained in this study.

1. Structure I: Providers, Linkages, Continuum of Care

Most of the current information on the structure of the health system is oriented toward the counting of the individual types of resources (like providers, facilities or health plans) that make up the structure. In contrast, our project showed that there is a need for information that would allow one to interpret the adequacy or change in these resources and to better understand the relationships of these resources both to one another and to the current financing system. (See Table 2 for illustrative questions gathered in the project.)

Physicians and Other Individual Providers. Interest in the structural changes in physician and hospital practice and in how these practices overlap is growing. With respect to resources, for example, those concerned with physicians are interested in understanding how the concept of “doctor” changes as physician practices are bought and group practice grows. In an era of concern about costs and downsizing, there is great interest in knowing the actual bed capacity of the system

TABLE 2

QUESTIONS HIGHLIGHTING DATA GAPS: STAKEHOLDER CONCERNS
ON RESOURCES AND STRUCTURE I

A. Physicians and Other Individual Providers

- Is the nature of a “doctor” changing from entrepreneur to employee--Who is buying and selling practices, with what deals and effects? How is the form of practice changing?
- What is the meaningful bed capacity taking staffing levels into account?
- What is the right benchmark for assessing change in hospital staffing?
- How is the nature of a “hospital” changing as it develops linkages with other parts of the system and what are these linkages (e.g. how many different arrangements do hospitals have with physicians, what types of arrangements).
- What changes are occurring in the nature of retail outlets for pharmaceuticals?
- What is the role of mid-level providers, how is it changing, and how can we describe “other professionals” meaningfully?

B. Linkages Between Providers, Facilities, and Health Plans

- How can we get consistent and meaningful information on the number and characteristics of health plans in different markets?
- What is really driving market level differences in managed care penetration? For example, what role do employer coalitions play?
- How can one assess whether provider networks are “adequate”? What does a staffing ratio mean? What is the capacity of a given system? Is there genuine access? Is red-lining occurring in some low income or minority areas?
- What is the downstream financial risk? How much risk is being transferred from purchaser to plan to provider? Who actively bears the risk and under which arrangements?
- What does ownership in systems really mean (e.g. real systems versus purchased assets, what are affiliations)?
- What should the unit be for accreditation? For example, there are nested entities and many parts in each entity. What is a taxonomy for classifying and which should be used?
- What are the fixed versus variable costs of different structures and what does this imply for consolidation?
- Is there really a trend toward horizontal networking of providers (e.g. particular specialists?)

C. Integration of Acute Care and Long Term Care

- How can we best track the newer kinds of long term care institutions, like assisted living or domiciliary care? What segment of the market are they serving?
- How should we integrate community based care and institutional long term care?
- What are the implications of developing new services like sub-ealite care?

and the best way to assess the “adequacy” of hospital staffing. For example, when workers are being laid off, it would be useful to have information on what a quality though still “lean and mean” system looks like, and on the difference between this and situations that threaten patient care. These kinds of questions, common to providers and policy makers, are hard to answer when existing systems provide limited information on the characteristics of physician practice and the structural features of provider organizations. Similarly, the absence of information linking resources to performance makes interpretation of physician practice difficult.

The competitive marketplace is altering the nature of existing provider relationships as well as the players and their roles. Those representing hospitals, for example, are most interested in understanding how the nature of a “hospital” is changing with the shift from the provision of inpatient services to broader systems of care with potentially more formal physician affiliations. Those representing mid-level providers or “other” professionals want better data on these human resources to understand how their roles are changing. For example, are they being used more or less, and by whom? It is impossible to know this when existing data systems capture only information on individual entities and not what they do, and when the categories and types of information captured are not consistent across providers or settings that may substitute for one another.

Managed care also is changing the provider mix. For example, retail outlets for pharmaceuticals now include larger roles for mail order and managed pharmaceutical practices. This change creates a need to capture more data if users are to continue to get accurate information on the pharmaceutical sector.

Linkages Between Providers, Facilities, and Health Plans. With respect to structure, our interviews revealed that the most pressing need is for better information on the linkages between providers, facilities, and health plans. The existing information in this area is highly limited. One key

gap is the absence of consistent and meaningful information on the number and characteristics of health plans in different markets. While there is some information on HMOs, the information available on other managed care entities is inconsistent, and there is limited information as on which entities serve which markets and to what extent. The absence of such information also makes it difficult to obtain information on other aspects of managed care delivery, which are of key interest. For instance, there is a need for better insight into the adequacy of provider networks when staffing ratios are inadequate and into how to capture, describe, and assess the transfer of risk downstream. The consolidation of providers is also raising other questions. For example, how can structure be understood when parts of the health care system are related to each other through contracts as well as ownership, and through overlapping relationships among associated entities like the hospital, hospital system, and associated physician organizations that may represent primary care physicians, distinct specialties, and other groups? How does one answer such questions when there is often not a list from which to sample, and when it is not clear who can provide what, or when what is provided may be changing over time. We identified some efforts to develop frameworks to support this kind of data collection by researchers like Gloria Bazzoli and Steve Shortell, James Robinson and Harry Castalino, Jeffrey Alexander, and Marsha Gold. However, the activities were at a very early stage and oriented more toward theoretical constructs than ongoing data collection needs.

Integration of Acute and Long-Term Care. The movement to managed care and competition creates the most pressing information needs for the acute care sector. For long-term care, however, developments in the market create a need for a different but analogous kind of information. For instance, most of the historical information on long-term care is specific to institutions. However, the emergence of assisted living facilities and other new types of long-term care, along with a growing emphasis on community-based care, have caused a shift in the marketplace. There is therefore a

pressing need for information on the causes and nature of this shift if we are to address immediate long-term care issues in the appropriate context. In addressing the information needs unique to each sector of care, we must also consider the fact that acute and long-term care are part of the same continuum, and that market forces that shape the former will also affect the latter. For instance, the managed care arrangements that continue to define and redefine the system of acute care will also influence how this type of care is received by people in long-term care. As a result, we can expect there to be a growing need for information on the implications of the relationships between these two systems of care, although this need was not made explicit in our interviews. A key example of the significance of this relationship is the emerging work designed to understand how to construct managed care systems that are sensitive to the chronic care needs of those served by Medicaid. These efforts will require considerably more information than we now have on non-institutional providers of long-term care and their relationships to each other and to the acute care sector.

2. Structure II: Resources -- Training and Financing

Information on resources involves questions and concerns that are central to the development and financing of the system and its components over time (see Table 3 for illustrative issues). Interviewees were especially concerned about training for providers, especially physicians, given the fact that there is already an oversupply nationwide. Many variables that both influence future training needs and the ability to project these needs are not captured well by existing data systems. For example, are physicians responding to economic circumstances by shifting their practice (e.g., from specialty care to primary care), and what does this imply for future physicians and their training needs? Without consistent data on characteristics and content of medical practice, it is difficult to

TABLE 3

QUESTIONS HIGHLIGHTING DATA GAPS: STAKEHOLDER CONCERNS ON
RESOURCES AND STRUCTURE II

A. The Pipeline: Training and Needs*

- What really are physicians doing in their practice versus what they were trained for and how does this affect the needs for training? How are the career paths of physicians with given training changing?
- How many and what kind of providers do we really need?
- How will we know about the amount and kinds of training occurring as it moves toward the ambulatory side of the health care system? How involved are AMCs in ambulatory care delivery?
- How are states paying hospitals for graduate medical education under Medicaid and what are the implications for AMCs with the shift to Medicaid managed care?
- What is the quality and sustainability of curricular innovations under current market conditions?
- What money are states putting toward state supported medical schools (or other health professions) and how much of this is going to meet state needs?
- How can we assess performance of diverse residency programs?
- How are teaching hospitals faring in terms of their three part mission and their ability to finance this? What impact do mergers of community hospitals in the market have on AMCs?

B. Financing of Care

- What are the trends in insurance premiums?
- What role are employers of different types and sizes playing alone or individually to influence the financing and structure of care?
- What is the size of the health care industry and employment base?
- How much are consumers spending out of pocket, is it increasing and why?
- What is the size and nature of interstate transfers in spending?
- How much capital is needed, by who and for what, particularly by those outside equity markets?
- How much are we spending on biomedical research and other forms of nonpersonal health care spending?

*The focus on questions of physical training reflects the current focus of the health care system and could change in the future.

assess this issue. How are primary care training needs and the challenges they create being met in light of the move to ambulatory care-based delivery and training? Do we have systems to even benchmark the extent of these changes? How do we capture outpatient training in different settings and who should collect this information? What do we know about the current providers of training: how is training and funding being influenced by market change? In an era of concern over cost, how can the relative performance of the many different residency programs be assessed? Capturing information on the financing and outputs of medical education has always been complex because of the multiple entities, cross-subsidies, and joint products involved. The limitations these factors create for analysis become more of a concern in the policy environment and for academic medical center operational planning in an era of managed care growth and increased competition.

Concerns about the financing of care are related to gaps in how resource data on the health industry is captured. There is a need for information on the increasingly influential role of employers in the health care system. What are employers doing? What incentives for action are they facing in terms of trends in insurance premiums? There is also a need for information on the role of consumer financing. How much are consumers paying out of pocket, and how and why is this changing? Estimating consumer spending has always been a problem, and it is becoming more complicated as patient spending becomes partly influenced by choices they make among the great variety of health care options that involve variable in- and out-of- network charges. As states grow more dominant in formulating health policy, what interstate transfers in spending exist? What capital needs do providers face for diverse investments, especially when the providers or the intended uses of capital are ill-suited to equity markets? Do we even know how much is spent on biomedical research and other forms of nonpersonal health spending and who is doing the spending? This question may be important if the funding comes from cross-subsidies of patient care that may be tightening.

C. Assessing Issues and Needs: Operational Performance and the Process of Health Care Coverage and Delivery

The issues and needs associated with the process of care can be classified in three categories: (1) better knowledge of the structure of and responsibility for the process of care, (2) the determinants of the process of care, and (3) the efficiency of the process of care both generally and relatively across participants. Table 4 summarizes the key needs and data gaps in these areas as expressed by interviewees.

These issues stem, in part, from a need to understand how the delivery of care is actually structured and who is responsible for it in a system increasingly dominated by managed care and other more integrated systems in a competitive marketplace. Changes such as these are affecting the care that providers can deliver and patients can receive and how much it costs. Each type of provider wants to understand how its segment of the market is being influenced operationally, financially, and philosophically by the changes. Policymakers and consumers share these concerns. For example, who actually chooses the care that is received (the physician, physician group, health plan, or administrators), and how does this factor influence doctor-patient relationships for those participating? Thus, knowing what arrangements are in place and how they influence the process of care is of growing interest to a variety of stakeholders. Another issue is how to assess efficiency in a market in which performance has become more of a concern. These concerns extend beyond general public policy to the specific constituencies that may stand to gain or lose if they are regarded as more or less efficient or a better or worse performer. For example, are teaching hospitals really more costly when their costs are appropriately adjusted for the mix of care and then compared?

Table 4 (pg1)

TABLE 4

QUESTIONS HIGHLIGHTING DATA GAPS: STAKEHOLDER CONCERNS ON
THE PROCESS OF HEALTH CARE COVERAGE AND DELIVERY

A. Structure and Responsibility for Process of Care

- How do consumers actually make decisions in selecting health plans? What information on such issues as medical compensation and effects do consumers want and how do we get it?
- Is there considerable churning across health plans, especially in Medicaid?
- How does managed care really work (e.g. marketing, enrollment and other administrative functions; contracting; medical management and clinical delivery)? How does it vary in different kinds of systems?
- Are provider sponsored plans really clinically integrated and to what extent are they assuming the insurance function as well (or forming consortia with payers)?
- Who is actually delivering care, for example, what role do mid level providers play?
- What are the changing roles of providers in primary and specialty care?
- Is physician use becoming more differentiated between in hospital providers and ambulatory care providers?
- What structures are used in carve-out arrangements and what effects do they really have on the process of care delivery?
- How do we assess if there is a seamless continuum of care in existence?

B. Determinants of Process of Care

- Do physicians and other providers actually know or understand the contractual arrangements under which they function? What effect do these arrangements have on physicians and other providers and how they practice?
- What changes are occurring in how providers and patients communicate?
- How do providers decide on care, for example, what role do practice guidelines or profiling play?
- How does managed care deal specifically with aspects of care, like home health care?

TABLE 4 (*continued*)

- What use is being made of new technologies coming on line?
- At the enterprise level (for example, an integrated system or plan), how can we assess malpractice experience and liability?

C. Efficiency of Process of Care

- Which medical practices perform better, e.g., in terms of productivity or cost-effectiveness so providers get feedback and use it to improve performance?
- What are useful benchmarks for financial, quality, and operational performance?
- Where does managed care actual performance compare against its theoretical potential to enhance coordination of care and preventive activity and to eliminate “fat” (unnecessary care and administrative costs) from the system?
- What are the effects of changes in provider roles and responsibilities in care?
- How do AMCs compare to other hospitals in financial and quality indicators? Similarly, how do other subsets of hospitals, e.g. public hospitals, rural hospitals) or types of providers (for profit versus nonprofit etc) compare?

1. Structure and Responsibility for Process of Care

Existing data systems provide little insight into which health plans even operate, let alone how they do so and what this implies for the various actors in the system. Thus, a high priority for many different entities is information that would shed light on these issues and on what they mean for a diverse variety of functions these entities perform.

For example, if “health plan selection” is a key driver of competitive markets, how do consumers choose, what information do they want and get, what choices do they make, and how stable are their choices? This kind of information affects purchasers/consumers as well as providers and health plans that want to position themselves in the market. The information, typically based on market research, has implications for plans, for example, who want to strategically plan and market their products.

Similarly, there is considerable interest in knowing how managed care actually works both administratively and clinically, how this varies across systems, and how plans and providers interact with one another. There are related concerns for what managed care means for the operation of provider systems. What role do provider-sponsored entities actually play? Are primary care and specialty care roles changing? How do carve-out arrangements in managed care influence the process through which care is delivered and how coordinated is it from the point of view of health systems, the provider, or the participant? Information on all these issues can help entities understand how they and their constituencies may be affected by change or what effects can be anticipated.

2. Determinants of the Process of Care

This set of concerns involves information that would improve the understanding of how the process of care is ultimately determined. Although structural arrangements may be in place, their influence could depend on whether or how they are understood by physicians and other providers,

and on how the providers respond. Structural arrangements may also influence the nature of the provider-patient relationship and process of care. Specific kinds of structural features (e.g., practice guidelines, profiling) are being developed, and there is interest in their effects. Similarly, both consumers with particular health needs and providers focused on serving them are interested in how managed care influences use of provider services. More broadly, there is a concern for knowing the actual use that is made of new technology, since this may influence practice and expenditures. There also is interest in how situations like malpractice can be assessed at the enterprise level rather than just the provider level when managed care and integrated systems are growing. But existing systems do not capture these features of care or the use of particular technologies in a consistent and timely basis.

3. Efficiency in the Process of Care

In a competitive marketplace, provider groups want better information on how they perform relative to their competition. This may be providers like them (e.g., other group practices) or other entities (e.g., academic medical centers or public hospitals). Purchasers also want to compare performance of plans on various measures of financial, quality, or operational performance, as reflected in the development of HEDIS 3.0 and other report-card measures. A variety of stakeholders want to understand how managed care entities perform relative to their theoretical potential to encourage coordination of care, preventative care, clinical integration, and system efficiency. These needs for information require encounters/ transaction-level data at the service level that can be captured consistently across entities and providers, and that can be manipulated to create plan-, provider-, and population-based estimates.

D. Assessing Issues and Needs: Outcomes of Delivery and Policy

Information on outcomes of the health care system have historically been among the least developed. In today's environment, this kind of information is increasingly valued both by those concerned with assessing the value of care and by those concerned with understanding its costs and distributional implications. Table 5 summarizes questions in each of these areas that were raised in our interviews.

1. Appropriateness of Care and Clinical Outcomes

A key set of outcomes-related concerns has to do with how to interpret practice. For example, is a C-section rate too high or too low when it falls or is below average? Some standard for comparison or form of analysis is needed to interpret change. For example, if care processes are subject to strict clinical and utilization management oversight is this appropriate or too restrictive? That is, what is the relationship between care process and outcome? When is medical practice becoming more appropriate or efficient, and when is needed access being denied? Change threatens historical expectations and established practice. Each stakeholder is affected and these effects influence funding streams. Sorting out efficiency from eroding quality becomes critical to a public policy debate involving all stakeholders and a substantial portion of the Gross Domestic Product. Without better and more comprehensive measures of appropriate care and cost-effective care, it will be difficult to address these questions and to separate out individual interests from broader public policy concerns.

Just having outcome information is another concern. What are the outcomes and how much does each cost? How can they be compared on a risk-adjusted basis so health plans or providers can be equitably assessed relative to others? What outcomes do consumers value, and how can this

TABLE 5

QUESTIONS HIGHLIGHTING DATA GAPS: STAKEHOLDER CONCERNS
ON OUTCOMES OF HEALTH CARE DELIVERY

A. Appropriateness of Care and Clinical Outcomes

- Who is controlling the process of care and are the entities doing it doing an appropriate job or are they too restrictive?
- How can we assess changes in performance by distinguishing between effects of changes in medical practice versus access?
- What are the clinical outcomes of care? the risk adjusted outcomes?
- What are the resources that contribute to these outcomes? That is, how much is spent for given outcomes or types of patients or effects?
- How do consumers assess outcomes of care in making decisions, considering appropriateness, cost, perceptions, etc.?

B. Costs of Care

- Is bigger better in terms of the scale of enterprise?
- What resources are devoted to ambulatory care?
- How much is spent on physician care? on provider subgroups?
- To what extent are system savings a one time only savings versus continuing savings? A function of price discounts or real changes in the mix, intensity, or quality of care? Have we now gone beyond the fat to the meat in cutting costs?

C. Population-Based Access and Distribution

- How will we know if people are being squeezed out of the system? For example, what about the homeless? How do we interpret bad debt?
- Can we assume people get needed care once they are insured and affiliated with a provider?
- What is the value (community benefit) of a nonprofit institution or system?
- What is the relationship between managed care and the public health infrastructure?

information be fed into decision-making? Again, consistent and flexible transactions/encounter level data on services is needed to support such studies, and the data have to include, if they are to be useful, those population- and provider-based variables needed for adjustment or manipulation.

2. Costs of Care

There is considerable interest in understanding cost trends, particularly with the shift toward managed care and more ambulatory based delivery using competitive models. Current spending categories provide limited insight on key questions. For example, consolidation is occurring with managed care, but existing systems provide only limited information that can be used to assess whether bigger scale is more efficient. Because spending data has been captured by setting rather than service, there are considerable barriers to assessing the extent of change. The development of capitated systems will make these gaps even larger to the extent that it leads to an erosion of data previously collected centrally to support fee-for-service billing. For example, if one wants to estimate resources devoted to ambulatory care, the fact that resources for hospital outpatient services are included in total hospital spending is a key gap in creating estimates of ambulatory spending. Capitated arrangements may make it more difficult to isolate spending on physicians, an issue of concern to those representing physicians, interested in how much is spent for their services. More generally, there is limited information that could be used to assess the effects of managed care on costs and how this may change over time, since neither costs nor characteristics of managed care are captured on any consistent, comprehensive, or timely basis. While this is a public policy issue, it is also of great concern to both providers or health plans with a stake in particular approaches, and to purchasers who want to “buy right.”

3. Population-Based Information on Access and Distribution

The shifts in the system are generating needs for population-based information about access and distribution. A key concern of a number of groups and individuals we interviewed involves whether one could be confident that existing information would show whether individuals are being squeezed out of the health system. Historically, hospital data on bad debt have been one marker of this event, but what if providers see fewer of such people in a competitive market? Similarly, insurance coverage has often been used as a proxy for potential access, but can we assume people get the care they need once they are insured and affiliated with a provider? What are the effects of differential cost sharing at point of service? How can one assess whether needed care is obtained when it is not clear what care people need? For example, with the growth of consolidation and competition, how can we assess the value of a nonprofit institution or determine the relationship between managed care and the public health infrastructure and how this affects community health? All of these are issues poorly captured in existing data.

E. Cross-Cutting Issues and Needs

A number of information needs expressed by respondents were more general and cut across the specific substantive questions and needs discussed thus far. These needs are reflected in the following questions:

- How do each of the preceding issues translate to individual states? Do states have the data to answer these questions?
- What data should providers be required to report, for example, by state regulators (e.g. NAIC standards)? What data are needed for some functions, such as grievance procedures?

- How can health plans get comparable data across the mix of models included in their network and diverse products so they can compare components in their system and also compare themselves against others (taking into account difference in the levels of illness in the population, and provider structures)?
- What clinical information systems are needed to address purchaser demands?
- How can we get consistent regulatory financial and other data on managed care when they are regulated differently across states and payers?

Each of these issues arises as efforts are made to apply data to the diverse operational needs of the different groups.

F. Summary List of Key Data Gaps

Table 6 summarizes key data gaps by type that stakeholders perceive in today's market. Note that a "data gap" is not synonymous with an "information need". In practice, information needs are met by merging multiple kinds of data to answer a question. Thus, an absent core data element (like transaction and service based information on encounters with appropriate identifiers to link it back to people or health plans can limit the ability to develop information to meet a number of needs. Thus, our focus here on data gaps is to highlight core data elements or kinds of data that are needed to answer many of the kinds of questions stakeholders raise. The first sets are substantive concerns dealing with aspects of the health care system, while the last relate to attributes of useful data.

In terms of structural information, key gaps in information exist with specific components of the system, though the more serious concerns arise from the rapidly evolving and shifting linkages between these components, which influences the process of care. The absence of a comprehensive census of health insurance plans or arrangements or set of identifiers with information or plan characteristics is a key gap since it means there is not effective frame for data collection. Two other

TABLE 6

SUMMARY OF DATA GAPS IDENTIFIED FROM THE PERSPECTIVE OF
STAKEHOLDERS OUTSIDE THE FEDERAL GOVERNMENT

STRUCTURE

Component Parts of the Health Care System

- No comprehensive census of health insurance plans or arrangements exists
- Limited information available on community based alternatives to long term care, intermediatemodels
- Data on ambulatory care and non-physician providers is limited, incomplete, and inconsistent.

Linkages among Parts of the System

- Little information on ownership and/or aggregation of physicians and/or hospitals
- Integration and arrangements (including transfer of risk) between health plans and provider entities and their constituent individual providers not identifiable in data.
- Linkages across the continuum of care not identifiable in data.
- Duplication exists across diverse data collection efforts

PROCESS AND OUTCOMES

- Transaction level information on services which can be linked to individuals, providers, or health plans are often absent
- Clinically relevant data are limited
- Need the ability to link expenditure data to functional role rather than setting
- More meaningfully categorized expenditure data are needed including out of pocket spending and spending for given outcomes or people

CROSS-CUTTING CONCERNS: GEOGRAPHICAL RELEVANCE AND STRATEGIC FLEXIBILITY

- State specific data are often lacking for all or some states. Data for policy relevant localities (e.g. inner city) is even more limited
- Data need to be adjustable for residence versus service location (especially when areas cross states)
- Data need to support consistent trend analysis but data captured need to be flexibly defined and timely to account for change in the health system
- Data should permit flexible aggregation at different levels (e.g. service level; provider level; patient level; or population level)
- Data need to be capable of being linked to relevant population-based units to support targeted analysis (e.g., individual with a given health problem).

SOURCE: MPR Analysis

important gaps involve limitations in data on ambulatory care and nonphysician providers; and information on community-based alternatives to long-term care.

With respect to linkages in the health system, the key gaps appear to be related to the limited information on ownership of provider practice and aggregation of providers as consolidation proceeds. The gaps are also related to the limited information on the arrangements between managed care plans and providers. Information about how components relate across the continuum of care also are limited. Our interviews suggest that gaps are a major concern for private sector stakeholders, as well as others. These concerns also are relatively recent, reflecting changes in the delivery of health care with consolidated and managed care.

In terms of the process of care, the concerns are generally that the available structural information and encounter systems may not provide the kind of understanding needed about how medical practice functions and is determined. This makes it hard to develop good estimates of resource needs and further limits the information available on the efficiency of the care process. Most basically, these needs reflect the broader question of how to obtain process information on how care is delivered and also to better link it with structural information (i.e., on individual providers and systems, including their characteristics). There is a related need for information that could be used to determine how to develop the ability to do standard comparisons based on patient-level information. This effort might involve comparing how care is delivered across in managed care, and fee-for-service sectors. This gap exists for two reasons: (1) there is typically no universal set of transaction or service level information upon which to base analysis especially for the under 65 population and with the growth of managed care; and (2) there are considerable barriers in linking these data to structural data (also absent) about providing plans or other entities.

Like information on the process of care, information on outcomes of care is limited by the absence of both clinically relevant data on performance and the ability to link it to individuals, providers, and health plans. Expenditure data are limited by the categories in which such spending can be assessed and by the absence of meaningful information on both out-of-pocket spending and spending for distinct subpopulations or to achieve given outcomes.

For all kinds of information, there are serious concerns about the absence of data below the national level, that is, for states, markets, and politically relevant localities (such as inner cities). There is also the concern that data is not captured in a way that provides flexibility for analysis that can be adjusted to residence or that allows the data to be aggregated so that it meets diverse needs for information at the provider, patient, and population levels. There is also a concern to establish consistent trends in measurement while remaining flexible and timely to account for change.

IV. EXTENT TO WHICH GAPS ARE BEING ADDRESSED: WHAT WE LEARNED

KEY POINTS

- **There are ongoing efforts within the private sector, states and foundations/research communities to address some of the data gaps stakeholders perceive relative to with the health system. We identified 23 such efforts, focusing on 11 for more intensive study.**
- **The impetus for these efforts stems from stakeholder concerns with limitations in information on the structure, process, and outcomes of the health care system. More specifically, the activities we studied highlight priority concerns about creating better information on the structural linkages among players in the system and their implications; about operational features of arrangements among providers and managed care plans useful in strategic planning and policy development; and about operational performance measures and benchmarks to assess both process and outcomes of care.**
- **Though sponsors of these activities perceive them to be focused on high priority issues, they also perceive significant limitations in the scope of their efforts. These arise because resources are limited, because there are lags in data availability which limits timeliness, and because providers are less willing to provide information in a highly competitive environment with extensive data demands. In addition, quality problems and inconsistencies in the available information, combined with a lack of standardization or audit, serve as barriers.**

Through our interviews, we identified a number of efforts designed to respond to perceived data gaps. Many of these are modifications in or expansions to ongoing data collection by associations to develop information needed by their members. Other efforts take the form of independent research funded by foundations or other parties to fill in the gaps.

Their sponsors perceive these efforts as being relatively limited compared with the needs. Key limitations stem from the limits of players' authority and resources, which restrict the amount and kind of information that can be obtained. Other barriers to better information are grounded in the

lack of consistency in definitions used by reporting units and to challenges related to collecting information in an environment in which the willingness to supply information is limited by market considerations.

A. Focus and Content of Data Collection Efforts

In the first phase, we identified 23 efforts that fell within the scope of our study and into one of three groupings. One grouping is of on-going national efforts, the second is of other national efforts, and the third involves other more limited efforts but still of interest nationally. In the second phase, we obtained more information on 11 of these 23 efforts. Below we review all 23 by grouping and the rationale for the 11 selected. Table 7 summarizes the 11 efforts selected for more intensive study. The table also presents the impetus for their development, the activities underway, and the limitations of the work as perceived by the sponsors.

Of the 23 efforts, the following seven are national and broad-based in scope and will have an ongoing operational effect on data.

- The American Association of Health Plans is redesigning its annual survey to reflect a broader definition of managed care products and needs for more information on operational features of health plans.
- The American Association of Homes and Services for the Aging is helping its members obtain meaningful benchmarks of performance for internal management and other activities.
- The American Hospital Association is redesigning its data collection process to better support an understanding of system integration and managed care.
- The American Medical Association is adding items to surveys in order to better capture physician group and managed care activity.
- The American National Standards Institute is working to enhance operational standardization of claims, employer enrollment, and benefit explanation in operational practice.

TABLE 7

ELEVEN ILLUSTRATIVE EFFORTS TO ADDRESS DATA GAPS: SELECTED ATTRIBUTES

Impetus	Activity	Constraints & Perceived Limitations
Alpha Center		
<p>The changes in the health insurance industry are generating information needs which are hard to address from existing sources. For example, how can the exit from markets be assessed? What is the impact of for profit conversion? The information will be used to assess the changing market, study a subset of individual insurance markets, and assess Medicare reform options.</p>	<p>With funding from RWJF, KFF, and the Anders Foundation, Alpha is trying to develop a national database of health insurers using NAIC- based information along with information on Blues plans and HMOs.</p>	<p>Quality of reported data is poor. Limited data on HMO, small group and individual markets. General limitations with insurer data. Lack of consistency across NAIC reported information.</p>
American Association of Health Plans		
<p>Policy environment generates needs for more information on operational arrangements to support lobbying, clinical activities. Merger of GHAA/AMCRA generated need for comparable information across managed care entities.</p>	<p>Redesign annual HMO survey and associated definitions in collaboration with Harvard. Focus on organizational and delivery aspects of health care plans. Sampling from plans/legal entities within states. Note: financial and utilization information collection has been reduced considerably as part of this shift.</p>	<p>Short time frame to develop survey. Resource limitations preclude PPO sample. Respondent burden concerns will limit length. Focus on health plans provides limited information on other key players (e.g., hospitals, physicians) that define health plan structure.</p>
American Association of Homes and Services for the Aging		
<p>Desire to provide members with meaningful information to benchmark financial, quality and cost performance. Need to help members with internal management needs, and for negotiation and forecasting at the market level.</p>	<p>Worked with Ernst & Young to develop benchmarks for continuing care retirement communities. In 1995, pricing and salary information was also collected. Convene taskforce of members across non-profit continuum to expand and refine benchmarks and definitions.</p>	<p>Lack of standardized definitions for entity type and broadness of individual data elements have limited ability to compare. Lack of timeliness has limited utility. Task force will aim to address common definitional barriers.</p>

TABLE 7 (continued)

Impetus	Activity	Constraints & Perceived Limitations
American Hospital Association		
<p>Market changes require more information on the health systems in which hospitals are embedded, including structural linkages.</p> <p>Policy environment generates a growing need for population based measures and also flexible information systems that can respond to changing needs.</p> <p>Desire to generate revenue through new sources of income and also address member concerns over response burden.</p>	<p>Redesign Annual Survey in 1994 building on joint work with HRET and research community. Items were added to obtain more information on affiliations, participation in managed care and community service.</p> <p>Considerable reductions were made in requests for financing, staffing and facility information. In 1995, the timing of the survey was modified to match hospital's fiscal year to reduce burden.</p> <p>Gather information to identify and profile 500 networks. Published in the AHA Guide and used in research to develop a taxonomy of networks (under AHCPR grant).</p> <p>Create a separate data and information division with the goal of generating revenue producing commercial products.</p>	<p>Limited revenue to support data activity, in part because of how market change has influenced association membership and revenue.</p> <p>Need to limit data requests and burden in response to industry concerns.</p> <p>AHA perceives information on linkages among health system players to be a "huge gap" in information needed to understand the system. They feel their efforts address only a share of the issues and are limited by resource constraints.</p> <p>Network information limited by willingness of systems to provide information because of burden and competitive concerns.</p> <p>Effort at revenue generation will need to be balanced to assure continued credibility with and support from members.</p>
American Medical Association		
<p>Need to understand how market change (consolidation, transformation, new contractual arrangements) will affect physician incentives, independence and income as well as quality of care. Strong interest in understanding who bears financial risk and the implications.</p>	<p>Focus special topics in SMS monitoring system, subject to resource constraints.</p> <p>Census of medical groups expanded items on relationship to HMOs.</p> <p>Joint activity with Hewitt to obtain survey information on physician view of managed care.</p>	<p>General concern that growth of managed care is eroding encounter database. Also concern that more activity is occurring at physician group level, which is hard to capture.</p> <p>Resource constraints which have limited scope of effort (e.g. special topics in SMS)</p> <p>Group practice survey response rates are dropping. Hewitt effort limited by lack of follow up and low response rate.</p>

TABLE 7 (continued)

Impetus	Activity	Constraints & Perceived Limitations
Association of American Medical Colleges		
<p>General need to help members by better tracking what is occurring at teaching hospitals in the context of broader health system change and help members to position themselves internally and in policy debate.</p>	<p>Establish Center for the Assessment and Management of Change in Academic Medicine to analyze impact of market on academic programs and help members adapt. Involves linking various internal & external data for AAMC members. Medical student information to be extended into practice.</p> <p>Acquire clinical-administrative Services Database to establish Sentinel Network for trending performance and outcomes.</p> <p>Online activity to support members.</p>	<p>Definitional limitations.</p> <p>Understanding affiliations of AMCs with clinical enterprises.</p> <p>Inability to capture key health system information needs (e.g. change in primary care practice)</p> <p>Lags in data.</p> <p>On line security.</p> <p>Definitional issues</p>
Center for Studying Health System Change (an RWJF funded center)		
<p>RWJF perceived need to provide timely, objective information on rapid changes in health system and their effect on people at local community as well as national level.</p>	<p>Community Tracking Study of randomly chosen communities, 12 at high intensity study and 48 at low intensity study. Includes site visits (to 12), household, physician, and health system organization surveys.</p> <p>Special projects using existing data and qualitative insights on rapid turn-around basis.</p>	<p>Scope and complexity requires constant context trade-offs of precision and timeliness vs. breadth and depth.</p>
Florida Medical Care System Study (state agency with RWJF grant)		
<p>Generate data to support state-wide health reform by providing objective, comparable information on quality and costs of health plans. As gaps in data identified, they sought to generate information to better understand changes.</p>	<p>Mail survey of physicians about their understanding of arrangements and activities related to managed care.</p> <p>Case studies.</p>	<p>Very long survey and very low response despite active follow-up.</p>

TABLE 7 (continued)

Impetus	Activity	Constraints & Perceived Limitations
Minnesota Health Data Institute (Public-Private Consortium)		
Outgrowth of state health reform effort which highlighted gaps in consumer information, data to monitor performance.	Performance measurement effort to generate survey-based and other performance measures of health plans and providers that consumers and purchasers can use.	
	Electronic data exchange.	
National Committee for Quality Assurance		
Perceived need by purchasers and consumers for performance information to facilitate health plan choice.	HEDIS 3.0, an ongoing effort to develop standardized performance measures for public and private purchasers on a variety of areas. Periodic testing and updates to address outstanding concerns (e.g. chronic care, publicly insured individuals). On line reporting of some measures as well in Quality Compass. (Combines HEDIS, accreditation information on plan specific basis).	Decreased willingness by plans to provide and share information as competition becomes more intense.
Concern over the availability and quality of clinical data from health plans and the willingness of plans to share information	RWJF funded work by NCQA's Committee on Performance Measures to provide a road map for plans to use in anticipating future information system needs.	Absence of active federal role to move audit standards and data sharing forward to benefit the consumer. Measures limited by weaknesses in current clinical and administrative data systems.
National Institute on Health Care Management		
Desire for consolidated resource with state and market level information that could serve as tool in health reform debate.	Develop DataSource (released July 1996), under contract with UCSF. Provide state and MSA data on people, payers providers, and policy variables information. Compiled using contact with over 75 public and private organizations.	Identified a number of by gaps as a result of their activity including: State and local estimates. Limited information on purchasers, contribution, premiums, health plan and provider performance measures.
		Proprietary sources not releasable or, in cases prohibitively expensive.
		Quality and documentation limited across available data.

- The Association of American Medical Colleges is working to make better use of internal and external data to monitor the changing marketplace and its implications for members, and to help members respond to these changes.
- The National Committee on Quality Assurance is developing HEDIS 3.0 to support purchaser and consumer interest in performance information on health plans in order to facilitate choice and to help health plans anticipate information needs so they can reconfigure their systems to generate this information. Because of their national scope and importance, all of these efforts were selected for more intensive review, with the exception of the work by ANSI, which was already familiar and well known to HHS staff.

The second grouping comprises seven national efforts. They are conceptual rather than operationally oriented or are otherwise limited in their periodicity or in other features relevant to providing ongoing national data. Two of these seven are federal efforts that address information needs associated with a changing marketplace. The Agency for Health Care Policy and Research (AHCPR) is both sponsoring research on market forces in managed care and disseminating the result of this research. The NCVHS is working to better standardize data, as described. Like the ANSI work, they were excluded from more intensive review since they are familiar to HHS staff. The other five efforts in this category are:

- The Center for Studying Health System Change, funded by the Robert Wood Johnson Foundation, is conducting the Community Tracking Initiatives, which involves ongoing monitoring of 48 nationally representative communities through household, provider, health plan and other surveys. Twelve of the communities are being studied in more depth through site visits and expanded samples.
- The New Federalism Project at the Urban Institute sponsored by the Annie E. Casey Foundation, the Kellogg Foundation, the Henry J. Kaiser Foundation, and the MacArthur Foundation is working to develop timely state-level tracking of current efforts to decentralize social programs, including analysis of national data, a household survey, and site visits to a subset of states.
- The National Association of Insurance Commission's Health Plan Accountability Workgroup is developing model statutes for states to use in setting standards for managed care plans in the areas of quality, credentialing, utilization review, grievance procedures, and network adequacy. The association is also beginning to

work on data-reporting activities and confidentiality issues associated with information exchange.

- The ALPHA Center is conducting a project to develop a national database on health insurance, supported by funding from the Robert Wood Johnson Foundation's state initiatives program, the Kaiser Family Foundation, and the Anders Foundation. The database will build on state insurance filings under commercial, nonprofit, and HMO authority.
- The National Institute for Health Care Management is conducting a project to develop, under contract with researchers at the University of California at San Francisco, a reference database that synthesizes all the available metropolitan and state-level information in several areas of concern about markets.

Three of these five were studied in more depth. Efforts by the NAIC were excluded since they are familiar to HHS staff and completed efforts are not directly related to information development. The New Federalism Project was excluded because it focuses more on information about federal programs and their effects on people than on the supply side of the health system and its change.

Efforts in the third grouping have potential interest though they are not necessarily national in scope or are otherwise limited. We identified nine such efforts, selecting two for further study in their own right and a third in conjunction with our assessment of the AMA efforts. These three are:

- The state of Florida, supported by a grant from the Robert Wood Johnson Foundation under the state initiatives program, is developing information on the changing marketplace in Florida, including physician arrangements.
- The public-private partnership reflected in the Minnesota Health Data Institute focuses on increasing the availability and accessibility performance information on health plans and providers.
- Hewitt Associates is collaborating with the AMA to survey physicians to assess their satisfaction with managed care.

Another three of the nine efforts in this category involve work by other states to address information needs. All are of interest but were excluded mainly because of resource constraints and because they

are similar to others selected or because they are in somewhat unique environments. These efforts include the Massachusetts' Health Data Consortium, which is focusing on enhancing the availability of standardized data; Maryland's Health Care Access and Cost Commission, which is working to develop both HMO report cards to measure performance and better data from insurers to develop better state expenditure estimates; and Washington State's effort to establish the Foundation for Health Care Quality, a public-private partnership to improve health information network capabilities in the region.

The other three excluded efforts also are interesting but were excluded because they are more familiar to HHS or viewed as sufficiently covered in the first phase. They are RAND's work with states on health expenditure accounts under the Robert Wood Johnson Foundation's state initiatives program; the Foundation for Accountability's work to develop outcome-based quality measures purchasers could use to assess health plans; and the National Association of Health Data Organization's synthesis of state systems for hospital discharge and ambulatory care reporting of encounter-level information.

B. Impetus for Efforts and Their Constraints

Table 8 categorizes the impetus for and the information needs that were the focus of each of the 11 efforts we studied in depth. Also presented are perceived barriers to carrying out the efforts. The 11 efforts can be viewed as spanning the continuum of structure, process, and outcomes of care. More specifically, the impetus for these efforts emphasizes collection of information based on perceived needs (1) to better understand the linkages between players in the health system and what these connections mean for constituencies or public policy; (2) to expand information on insurance and operational arrangements with managed care that would be useful to strategic planning and public policymaking; and (3) to develop performance measures or benchmarks on process or

TABLE 8

OVERVIEW OF FOCUS AND PERCEIVED LIMITATIONS OF 11 INITIATIVES

	Impetus/Focus			Perceived Limitations of Efforts ^a			
	Structures & Linkages Among Health System	Process and Performance Measurement	Outcomes &	Lack of Standard Definitions For Data Quality	Burden/ Willingness to Provide Data	Timeliness	Cost
National On-Going Efforts							
AAHP	✓	✓		✓	✓		✓
AAHSA		✓	✓	✓		✓	
AAMC	✓	✓	✓	✓		✓	
AHA	✓	✓			✓		✓
AMA	✓	✓			✓		✓
NCQA		✓	✓	✓	✓		✓
Other National Efforts							
Alpha	✓	✓		✓			
NIHCM	✓	✓		✓	✓		
Center	✓	✓					
Other More-focused Efforts							
Florida	✓	✓			✓	✓	✓
Minnesota		✓	✓				

Source: MPR Analysis

^aThe absence of a check does not mean this was not a problem since responses were obtained in an open discussion and some features may not have been mentioned.

outcomes that would support the operations of providers, plans, purchasers, consumers, and policymakers. For example, both the AHA and AMA felt limited by having data only on hospitals or physicians, respectively. The AHA wanted to understand how hospitals were consolidating into larger entities and what their contractual arrangements were with physicians and managed care plans. The AMA similarly was concerned that a focus on capturing data at the individual physician level would not provide insight on financial incentives viewed as of critical interest yet negotiated at the level of the physician group. The impetus for these efforts mirror those we identified in phase one interviews and a review of the literature.

Many of the 11 efforts are viewed by their initiators as being limited in different ways, though focused on core concerns. The following major constraints were cited:

- Data gaps and quality problems associated with lack of standardization or audit
- The burden of data collection on providers and plans and a weakening of their willingness to provide data in an increasingly competitive environment
- Lags in data availability, which limit the timeliness of information
- Resource constraints, both in general and in given marketplace activity

It is striking that both the AHA and the AMA have had to cut back on their data collection work in response to budgetary or other constraints, particularly since these national organizations are a major source of information on the health system. It is also striking that the AHA and AAHP have eliminated major data collection activities related to financial information. In an increasingly competitive marketplace, policymakers may want to further consider how much they should or can depend on private organizations to carry out data collection activities, especially when these activities rely on informal agreements and good will.

In addition to these generic kinds of constraints, the 11 entities we interviewed also had some

specific insight into substantive limitations, which might suggest important federal activity. Several groups said their efforts to understand the structure and process through which care is delivered naturally was limited by the limits of the organization's scope. The AAHP focus on health plans limits its ability to obtain information on other key players like hospitals and physicians that are part of those structures. The AMA focus on physicians makes it difficult to obtain information on processes that are increasingly occurring at the group practice level. The focus of the AHA and AAMC on institutional providers limits their ability to generate information about other important changes in the marketplace that affect those institutions (e.g., changes in primary care practice, links between entities other than the hospital).

Groups also expressed concern over their limited ability to influence the availability of basic transaction data used to create performance measures. The AMA, for example, views the erosion of the encounter database coincident with the growth of managed care as a major problem, since it limits the association's ability to describe health care use for the growing population under managed care. NCQA perceives underlying data as such an important issue that it developed a project specifically to help plans anticipate the systems that would be needed in the future. However, the ability of plans to develop these systems requires actions that extend far beyond NCQA's scope and may ultimately require federal intervention, as noted in the NCQA Roadmap (1997). NIHCM's efforts involved steps to compile existing data and thus it illustrates how limited current information is for the end user. UCSF staff found broad-based key gaps, including gaps in purchaser information and health plan performance, in the availability, consistency and comparability of state and local estimates, and in the adequacy of documentation and the public availability of some information maintained for proprietary purposes.

V. IMPLICATIONS FOR HHS AND PRIORITY EFFORTS

KEY POINTS

- **Private sector stakeholders and states alone cannot address fully the concerns we identified. Private sector actors are unable to mobilize sufficient resources and lack influence over components of the system to gather needed information. States can play an important role but they too are resource-constrained. In addition, the increasing consolidation of the health system means that individual state initiatives will fail to address some needs, for example, the interests of purchasers that include multiple states or provider/insurance systems crossing state lines.**
- **We conclude that there is an important federal role in working with the private sector and states to address the information needs created by a rapidly changing health care system. A key contribution of the federal government is to provide a leadership and convening function. We make 10 concrete suggestions for actions that the federal government can take in collaboration with the private sector and states to address priority data gaps and information needs we identified.**

Although the information needs of users are diverse, the similarities in these needs and in perceived gaps in information is striking. There is a perceived lack of information on the internal structure and operations of the health system as it becomes more integrated and complex. There also are concerns over the fact that the ability to measure performance and outcomes for the system as a whole or for its components is seriously limited. It is clear that the stakeholders we interviewed perceive that information on the supply side of the system is very important, even as ironically, the same forces that are creating needs for information are also sometimes limiting the resources and willingness of the private sector to provide such data. What is less apparent is how HHS alone or with others might address these gaps. Also somewhat elusive are the reasons for certain persistent

data limitations despite respected efforts to develop consensus on how to address them.

In this concluding section, we consider what our findings suggest in terms of priorities that HHS may want to consider as it moves to address the issue of information needs in a changing health care environment. We discuss first the issue of an appropriate federal role and then make specific suggestions in three areas.

A. A General Role and Need for HHS

Private sector actors and states alone cannot address the concerns we identified. The private sector lacks the potential for generating legislative authority to require compliance that is inherent in government. Also--and perhaps of greater relevance--the private sector does not perceive itself to have the resources or scope of influence over components and players in the health care system required to collect needed information. States have an important role to play, but resources also limit their activity. Further, the increasing consolidation of the health system means that individual state initiatives cannot address user needs which cross state lines. For example, these include national purchasers that want consistent information for health plans in diverse states or consolidated health systems spanning state lines.

There are a number of reasons for federal leadership in addressing these issues. First, as highlighted in Chapter III.A, the federal government is a major funder of information collection activity on the supply side of the system. While federal spending may here may pale in contrast to the spending on population-based surveys, the federal government remains a major funder of information systems on health care providers and their services. HHS has a fiduciary responsibility to the tax payer and Congress to assure that its efforts are well spent and focused on issues of greatest priority. Second, the current decentralization of authority and involvement in data collection on the health system, complicates the task of addressing data gaps which span multiple governmental jurisdictions

and the defacto scope of influence of diverse private sector constituencies. This creates a need for leadership that is well-suited to the federal government and its potential to collaborate on convening multiple parties. And third, the ERISA pre-emption means that on key issues involving health insurance/health plans, states are often handicapped by their inability to bring in self-funded plans. HHS involvement not only can help bridge this gap but also can encourage a focus on health policy needs when insurance departments and labor address issues of health insurance information.

B. Structural Data Gaps: Suggestions for Action

There is a need for much more information that could be used to describe the health system both in terms of function and in how the relationships of its components are evolving in an era of consolidation, integration, and managed care. The needs in this area correspond to the resource and structural issues we discussed, and to the related concerns about the ability to describe what these changes in functional relationships mean for the process of health care delivery. The perceived need for this kind of information seems relatively recent, and there is both little historical work on which to build and major barriers to progress. For example, some information needs are so “simple” as an inability to even decide which entities should be defined for data capture when both these entities and their linkages are unstable, shifting, and so little documented in the marketplace.

This set of needs is probably the most complicated that HHS will address because work in this area is relatively undeveloped. We suggest that HHS may find it useful to the many focus on four gaps that weaken stakeholders’ ability to understand how the health care system is structured today and how care delivery works.

Census of Insurance/Managed Care Plans/Products. There are large gaps in data on health insurance products nationwide. Collecting information on health insurance has not historically been viewed as a “health system” function. It has been handled through insurance functions, largely at the

state level, and there are many gaps associated with the federal ERISA preemption and with the rapidly evolving managed care marketplace, which has challenged regulators. Working with states, the NAIC has focused closely on the issues of interest here. Federal activity is focused in DOL, which has oversight for ERISA. Yet, the health policy and research community is also interested in this area, since it provides an enumeration set that is important for other kinds of data collection activities and basic structural information that currently is absent.

- **Suggestion #1a.** HHS should meet with NAIC staff and appropriate federal policy makers to discuss the status of ongoing activity and perceived strengths, limits, and needs.
- **Suggestion #1b.** An appropriate HHS role could be to help NAIC and DOL understand the needs of the health policy and research community for these kinds of data and what these needs imply for additional activity or priorities that may differ from the regulatory context. To support this role, HHS could convene an ad-hoc working session with staff from provider, health plan, purchaser, and the regulatory community to identify key concerns and issues.
- **Suggestion #1c.** Follow up this activity with the development of a discussion paper, which reviews the status of current activity in the regulatory arena and the key needs and issues from the perspective of the health policy and research community. Involve regulators in this process and use the document to encourage attention to important health industry, policy, and research needs as systems evolve.

Address Issues in Which the Appropriate “Units” for Data Collection Need to Be Clarified.

There appears to be consensus on the fact that information on individual providers or facilities, and on “health plans” alone is insufficient when the relationships between these entities are varied and complex. Physicians perceive that more functional responsibilities are assumed at the group or physician organization level by large multi-specialty groups, medical IPAs, physical management organizations and other entities. Hospitals perceive the importance of systems of care and point out the complex ways in which these entities relate to their medical staff and others in the provider and health plan community. For example, a given hospital may be part of one or many health care

systems. It could also sponsor an HMO or contract with several HMOs and other managed care entities for a diverse set of products. Each relationship would bring different but overlapping sets of physician affiliations. An individual physician may participate directly in that hospital's HMO, may be part of a group that contracts with other managed care entities, and may be part of a management entity (e.g., an independent practice association) that also contracts with managed care entities. Each of these entities may, in turn, contract with a variety of managed care plans, sometimes directly and sometimes through other entities. Furthermore, many of these relationships are unstable, and the relative importance of different levels of aggregation may vary across and within markets as well as over time. Given this situation, it is not clear how to capture any consistent and universally useful data on these arrangements over time or even at one point in time. Furthermore, the absence of knowledge in this area contributes to difficulties in developing better performance measures.

- **Suggestion #2a.** Convene a working session of individuals and groups who have been struggling with these issues, including AHCPR staff, policy research staff associated with groups including AAHP, AMA, AHA, AAMC and NCQA, and researchers active in developing new frameworks and techniques in this area (such as Jeff Alexander, Steve Shortell/Gloria Bazzoli, Robert Miller/ Hal Luft, Joseph Newhouse, Paul Ginsburg/Robert St. Peter, Bob Hurley/Marsha Gold) to review perceptions of current needs, work in progress upon which to build, and important next steps.
- **Suggestion #2b.** Initiate follow-up efforts to develop both a taxonomy to address these issues and a set of recommendations for national and state data collection priorities in terms that address concerns for the conceptually appropriate units for collecting information and the techniques which need to be used to generate inventories of such units for use by the broad industry, policy, and research communities.
- **Suggestion #2c.** Plan to initiate follow-up activity that appears warranted from the preceding suggestions. At a minimum, information should be disseminated to states or public/private consortiums that would focus on these issues. Potentially, there may be inventories that are best developed at the federal level alone or through a public-private partnership.

Review HHS Provider Information to Decide What Changes Are Desirable in Light of the Changing Marketplace. HHS is involved through a variety of agencies with data collection efforts to count and capture characteristics and process features for certain types of providers/facilities and for various federal programs. In addition to national NCHS surveys, these include diverse and sometimes overlapping or inconsistent data collected by HRSA, SMHSA and other agencies. Given the needs expressed in our interviews, it is not clear that the current HHS structure data collection is the most effective way to focus resources on information needs about the health care system which focus on needs to understand linkages among components as well as the components themselves.

- **Suggestion #3a.** The Data Council should review the status of federal data collection efforts related to capture of health resources and provider information in light of the information in this report. The committee should identify characteristics of the existing system that should be considered fixed, changes that should be assumed to proceed, and the relevant range of activity that should be considered for review.
- **Suggestion #3b.** Consistent with the guidance in Suggestion 2, HHS should commission a technical analysis of strategic options for available resources and solicit input on these options from a variety of public and private constituencies to inform its own decision-making process.

Limitations in Purchaser-Related Information. The absence of information on purchaser activity was a major theme in our interviews. While it is unclear what part of this area should be considered demand side and what part supply side, there is clearly a need for better information on what purchasers offer, how much they pay, what they are doing to influence the health care system and markets, and what this means for public policy.

- **Suggestion #4.** HHS staff should consider current initiatives that affect employers as part of the HHS survey integration project, through other federal agencies, and outside HHS. They should review this report and determine whether the scope of current activity is adequate or whether additional steps need to be taken to address these needs.

C. Process and Outcome Data Gaps: Suggestions for Action

There is a need for better information on system performance and the outputs of care, whether expressed in process or outcome measures, or measured at different levels of aggregation. These include difficulty of obtaining transaction data outside a fee-for-service environment, or in a central location anywhere for the under 65 population, the lack of standardization, and the difficulty of associating performance with specific expenditures or accountable parties.

Unlike the structural data gaps discussed above, the needs have been recognized for some time, and there is ongoing activity that promises to address some of them. A clear illustration is the current extensive work being undertaken by HHS and others to implement the HIPAA of 1996. Yet it is also clear from a review of the historical record that serious barriers have limited past efforts to improve and standardize transaction data to support analysis, and also other features of current systems. Overcoming these gaps is key to the development of improved performance measures and outcome indicators. While efforts around the HIPAA are important opportunities for standardization, their impact will be constrained if data to standardize do not exist or it is not clear what structure of the health care system to code and how.

Learning from the Past. NCHS, the IOM, HCFA, and ANSI have a long history of establishing committees of prominent and talented individuals to propose ways to address the issues related to system performance and outcomes from different vantage points. On a more decentralized basis, NAHDO and NCQA have performed important similar work with states, health plans, and purchasers. The questions is: why are many documented recommendations not acted upon, and what can be done about this? Have the recommendations been flawed, the groups not optimally constituted, the implementation process lacking, or is the process or change just inherently slow? And if it is the latter, what does this imply for realistic policy implementation? The issue here is not

to point fingers. Clearly, there are a number of obstacles that limit implementation and there may also be differences of opinion about how practical or valuable different recommendations or alternative strategies may be. Yet, there is an important opportunity to learn from these past efforts.

- **Suggestion #5.** HHS should commission an independent study to evaluate the process that followed the release of the NCHVS report on standardization, the HCFA expenditure panel chaired by Joe Newhouse, and potentially other efforts. The idea would be to hear the perspectives of a group of diverse stakeholders about the value of recommendations and barriers to implementation or consideration. The purpose of the study would be to identify appropriate lessons for future activity.

Continue the Federal Collaboration with Private-Sector and State Efforts to Develop Performance Measures for Accountable Entities and the Health Care System. There is a great deal of current activity to develop standardized performance measures for provider groups and health plans particularly in response to HIPAA and under HEDIS. Yet these efforts are limited by gaps in data and limitations in data quality, as well as by the effects of the competitive marketplace.

- **Suggestion #6.** HHS staff should meet with NCQA, FAACT, and representatives of appropriate provider and insurer organizations to identify whether current activity addresses key priority needs and where additional federal help could be useful. One starting place for identifying needs could be the recently issued “Roadmap” to health care data prepared by NCQA.
- **Suggestion #7a.** HHS should similarly consult with representatives of states (NAHDO and related members), payers, purchasers, and others to identify where gaps may exist in current efforts and where federal help would be useful.
- **Suggestion #7b.** To encourage communication between user and producer communities, HHS should build on previous work and meet with representatives from both groups to discuss areas in which there may be any mismatches in priorities or unmet needs. One area flagged during our project was the ability to aggregate information to provide estimates for subpopulations, geographically defined resident entities, condition groups, and accountable entities of health plans or providers. Other areas include the inability to associate expenses with particular outcomes or to track care across changing settings of practice.

D. Strategic and Process Issues That May Impede or Enable Efforts

Aside from the substance of the work that is needed, there are certain strategic or procedural constraints that may impede progress. The following three suggestions could enhance the success of efforts and the availability of information.

- **Suggestion #8.** In today's competitive climate, HHS would be wise not to necessarily assume that information available under voluntary private efforts will continue to be available. We were struck by the fact that several groups had eliminated efforts to collect provider data. Historically, provider groups may have stopped collecting data when market changes influenced revenue or when sensitivities of members changed. HHS may want to commission a study to assess where it is dependent on such information, how important the information is, whether there is a need to develop or consider alternatives, or whether an independent capacity should be viewed as important.
- **Suggestion #9.** In today's environment, public-private partnerships to collect data -- such as those developed in states like Minnesota -- are likely to be increasingly important to successful data initiatives. This assumption is incorporated into the suggestions made here. In light of the emerging need for such partnerships, HHS may wish to commission a review of both the operational issues these partnerships create and the experience in states or elsewhere that might inform this effort.
- **Suggestion #10.** HHS should assume that funding will be a constraint for all stakeholders concerned with the issues discussed here. The agency should consider convening a "summit" of public and foundation funders to discuss cooperative strategies that might finance data collection efforts. This is particularly critical, as historical experience suggests that states are severely limited both by the financing available for new data systems and by the resources and authority to attract and support technically proficient staff. Our study suggests that competition also may be reducing resources in the private sector. While more may be invested in data collection, there may be less willingness to engage in data collection for cooperative, as opposed to competitive, concerns. This summit can be a forum for considering not only what partnerships and innovations may be feasible but also the terms on which they may be feasible.

In sum, the information needs associated with the changing health system are extensive. Gaps in available information are widely perceived by stakeholders as impeding their ability to effectively serve their constituents. While some activity is underway to improve data and better address gaps, these activities are viewed by their sponsors as severely limited. The federal government can play an

important role with stakeholders to better address the current and anticipated future information needs. While data improvement is a long term process and there are many challenges to be faced, stakeholder perceptions suggest some important areas where concrete steps can immediately be taken to begin this process.

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APPENDIX A

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APPENDIX B

PHASE ONE BIBLIOGRAPHY

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APPENDIX C

ORGANIZATIONS SELECTED FOR IN-DEPTH STUDY

**ALPHA CENTER
1350 CONNECTICUT AVENUE, NW, SUITE 1100
WASHINGTON, DC 20036
VOICE: (202) 296-1818
FAX: (202) 296-1825
www.ac.org**

**AMERICAN ASSOCIATION OF HEALTH PLANS (AAHP)
1129 20TH STREET, NW
WASHINGTON, DC 20036
VOICE: (202) 778-3200
FAX: (202) 861-1448
www.aahp.org**

**AMERICAN ASSOCIATION OF HOMES AND SERVICES FOR THE AGING
(AAHSA)
901 E STREET, NW, SUITE 500
WASHINGTON, DC 20004-2037
VOICE: (202) 783-2242
FAX: (202) 783-2255
www.aahsa.org**

**AMERICAN HOSPITAL ASSOCIATION (AHA)
ONE NORTH FRANKLIN
CHICAGO, IL 60606-3401
VOICE: (312) 422-3000
FAX: (312) 422-4796**

**AMERICAN MEDICAL ASSOCIATION (AMA)
515 NORTH STATE STREET
CHICAGO, IL 60610
VOICE: (312) 464-5000
FAX: (312) 464-4184
www.ama-assn.org**

**ASSOCIATION OF AMERICAN MEDICAL COLLEGES (AAMC)
2450 N STREET, NW
WASHINGTON, DC 20037-1126
VOICE: (202) 828-0400
FAX: (202) 828-1125
www.aamc.org**

**THE CENTER FOR STUDYING HEALTH SYSTEM CHANGE
600 MARYLAND AVENUE, S.W. , SUITE 550
WASHINGTON, DC 20024
VOICE: (202) 484-5261
FAX: (202) 484-9258**

**FLORIDA AGENCY FOR HEALTH CARE ADMINISTRATION
Medicaid Program Development
P.O. Box 12600
Tallahassee, Florida 32317-2600
Voice: (904) 488-9347
Fax: (904)922-7303**

**MINNESOTA HEALTH DATA INSTITUTE
910 PIPER JAFFRAY PLAZA
444 CEDAR STREET
ST. PAUL, MN 55101
VOICE: (612) 228-4370
FAX: (612) 222-4209**

**NATIONAL COMMITTEE FOR QUALITY ASSURANCE (NCQA)
2000 L STREET, NW, SUITE 500
WASHINGTON, DC 20036
VOICE: (202) 955-3500
FAX: (202) 955-3599
www.ncqa.org**

**NATIONAL INSTITUTE FOR HEALTH CARE MANAGEMENT
(NIHCM DATA SOURCE)
1818 N STREET, NW, SUITE 300
WASHINGTON, DC 20036
VOICE: (202) 296-4426
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APPENDIX D

REVIEWS OF THE ADEQUACY OF AVAILABLE INFORMATION

Periodic reviews have been conducted to develop information and/or consensus on the adequacy of available information. Federal data, more than state data, have been subject to review, although there is some information on state data. Reports assessing data collected by private-sector groups are less likely to be publicly available. Most assessments preceded the current marketplace changes and addressed specific kinds of data for which agencies had defined accountability. This limits the comprehensiveness of the scope of the efforts. The most relevant assessments we found are from the periodic reports issued by the National Committee for Vital and Health Statistics (NCVHS), the typically more broad-based and topical studies funded through the Institute of Medicine (IOM), contracted studies of health expenditure accounts, and foundation-funded studies of state health data.

NCVHS Reports. Standing committees that oversee the National Center for Health Statistics' (NCHS) data collection activities have issued periodic reports, which tend to be technical in focus. The most relevant is a recent report (US DHHS 1996) recommending a standardized set of health data elements for capturing person- and encounter-level information. The set includes 42 elements, 12 of which are person level. Twenty-six elements were viewed as being ready for immediate implementation, 10 as being substantially ready, and the rest as requiring much work. The impetus for NCVHS's work is a concern about the administrative burden of inconsistency in data collection and reporting activities and about the confusion generated by lack of standardized health data definitions. Current and potential uses for the data cited in US DHHS (1996) include:

- Clinical uses (clinical management and continuous quality improvement)
- Payment- and cost-related uses (payment, cost containment, purchasing)
- Management (planning and budgeting, assessing staffing needs, resource allocation, system reform and change)
- Oversight (performance measurement, ensuring access, utilization review, profiling of physician practice patterns, assessing quality and outcomes)

- Technology assessment (need for technology and its effectiveness)
- Public health (surveillance, appraisal of practice)
- Analysis (risk selection and adjustment, building episodes, sample frame development, health services research and epidemiology)
- Consumer information (plan, provider and treatment choice, education)

NCVHS efforts to develop standardized person- and encounter-level data do not appear to have focused on the impact of the changing marketplace on individual data elements. For example, the payer and charge information included is relatively traditional and fee-for-service based.

Institute of Medicine. The IOM has convened panels to study a number of issues related to health data. With funding from NCHS, the IOM issued a report in 1992 that evaluated NCHS's planned National Health Survey, which would integrate the four health provider surveys with the National Health Interview Survey. The IOM concluded that current systems are uncoordinated and although duplicative at times, they also suffer from important gaps. The IOM cited four areas for priority attention: (1) better insurance claims data, especially for the under-65 population, for the fee-for-service and the prepaid capitated sector; (2) more information on clinical services and physiologic outcomes from medical records; (3) more information from patients (or proxies) on quality of life, health status, and satisfaction with care; and (4) better information on how much is spent (directly and indirectly, including out-of-pocket expenses) on treating particular types of patients. The IOM included the user surveys in its 1992 report and considerable external input, but the emphasis was on the needs of current users, typically from the government or research communities. In our view, the focus of the IOM recommendations is the need for person-level information to support public policy rather than the need for institutional-level analysis or the data needs of specific health interests. That is, there is more focus on the inputs and outputs of care than on the organization of resource inputs and processes of care that potentially influence outputs and outcome. In addition, the focus is more

on how well and efficiently the system works for people and less on how it is structured or how entities in it perform or are influenced by change, an area of considerable interest to many of those we spoke with in the private sector. The IOM report includes specific recommendations for reformulating current surveys that are beyond the scope of this paper.

The IOM also has convened other workgroups to focus on issues important to the development of policy-relevant data. In 1995, the IOM issued a report on integrating federal health statistics on children. The summary in the report highlights relevant cross-cutting themes, including the need to link resources and child health outcomes, to assess the effects of state variations in resources and outcomes, and to coordinate efforts across agencies and the public and private sectors. Newachek and Starfield (IOM 1995) developed a paper assessing data needs using the population, the health plan and provider, and health system each as the units of analysis for monitoring health care reform. In their construct, health provider domains include health care services and effectiveness of care. Health system domains include health care resources and health care expenditures. Data issues they flagged for consideration include the comprehensiveness and timeliness of information, meeting descriptive and analytical needs, capacity to assess change, capacity to measure short- and long-term effects of change, provision of adequate geographical detail in measures, capacity to assess outcomes for vulnerable populations, creating flexibility needed to address emerging issues, and integrating efforts of different data developers. The paper concludes by urging that data collection and analysis strategies be jointly considered.

In 1996, the IOM reported on primary care delivery and needs to reorient training. Among its recommendations was a call for better information systems and quality assurance programs for primary care. The IOM also recommended the use of uniform methods and measures to monitor the performance of health care systems and primary care clinicians, careful monitoring by the government of provider supply and federal and state requirements for primary care clinicians, and a national

probability sample database with episode- and population-based information. Standards for data collection were also recommended.

The IOM (1995) also has reported on workforce and educational issues for health services research. It highlighted weaknesses in the supply of researchers with “real world” experience who can support research in the following areas: organization and financing of health care (markets, risk selection, and payment rates), access to health care; practitioner, patient, and consumer behavior; quality of care; clinical evaluation and outcomes research; informatics and clinical decision making; and the health professions workforce, including better ways to forecast, plan, and manage. These areas of noted weakness are ones that relate heavily to the “supply side” of the system.

National Health Accounts. HCFA and others have sponsored work on issues relating the needs for information about health accounts based on expenditures. Haber and Newhouse (1991) reported on an effort to revise the national health expenditure accounts in 1988 as well as efforts proposed in 1990. They also made recommendations for future change that are still relevant today. The paper discusses emerging issues and reviews existing revisions to the accounts to better estimate out-of-pocket spending directly, disaggregate expenses, and reduce errors leading to underestimates and double-counting. It also highlights the growing prevalence of vertical integration and managed care, which creates a need for classifications of expenditures that are more responsive to type of service than type of provider, including a more meaningful definition of “professional services.” Self-insurance is flagged as a potential threat to the quality and completeness of data on private insurers. To support predicting growth in home health spending, the paper also identifies a need to better define and distinguish between the types of home health and personal health services and the use of an expanded provider list to capture information on spending.

In addition to this broad review, there are other, more focused efforts relating to health expenditure data. Genuardi, Stiller, and Trapnell (1996) consider expenditure data for the prescription

drug sector, pointing out the importance of changes in retail outlets with new emerging pharmaceutical suppliers and actors; rebates and other payment changes; and other industry changes such as the growth of generic drugs and managed care. The authors compare estimates based on manufacturer sales, consumer purchasers, and retail sales, and they develop new techniques for estimating the effects of rebates. Ginsburg and Pickereign (1996) assess the policy utility and quality of data used to track health care costs. The authors focus on three kinds of data: provider data on revenues or costs, claims data from insurers, and premium data from employees. They emphasize how these compare in terms of quality and utility, what they tell you, and how they influence the conclusions one draws about costs and trends.

State Data. Long, Marquis, and Rogers (1995) present insight based on conversations with staff from states on priorities for health expenditure data, including why such information is used, what the concepts and components of health expenditure accounts are, and what issues and priorities exist in enhancing information. The issues include the scope of health expenditures: for example, are expenditures restricted to personal health care or does broader public health spending apply? How are interstate transfers to be assessed? Similarly, what should the categories for measuring spending be and what should the units of measurement (including cost shifting) and sources of data be? The authors believe that priority should be given to developing spending data on hospital, physician, other professional services, and prescription drugs to start, with methods that provide information on the flow of funds from payers to these functional uses. They also recommend that estimates be based on residence, and categories be based on services rather than providers. Intermediate and more long-term priorities include expansion of spending estimates to all health services, substate estimates, subpopulation estimates, capital and research spending accounts, and public health spending.

Gold, Burnbauer, and Chu (1995/1996, 1995) report on a 1994 telephone survey that asked state officials about their perception of data needs and weaknesses. In an analysis of data used to support

health care reform, the authors identify major gaps in data on health expenditures (particularly for expenditures in the private sector and outside of institutions) and on health system and health plan performance. The major barriers to improving the data include funding shortages, lack of comparability across datasets, and the unwillingness of providers and insurers to submit needed data. In a related and more general analysis, the authors present information on the low levels of policymakers' confidence in the ability to address emerging, but priority, health issues with existing data. Also discussed is the shakiness of policymakers' confidence in specific kinds of public health data and provider data. Particular weaknesses occur in the following areas: the ability to identify alternative sources of care for clinic users, the effects of clinics on outcomes, and the ability to link data across patients, clinics, or jurisdictions. Also, inpatient data was found to be much better than data on ambulatory care, and data on structure (e.g., counts of providers) was more likely than process data to be available.