

May 2004

Workgroup on Quality
National Committee on Vital and Health Statistics

Measuring Health Care Quality: Obstacles and Opportunities

Contents

Executive Summary	2
Summary Matrix	5
1. Introduction	12
2. The Quality Workgroup Initiative	13
Project Goal and approach	13
Overview of findings	17
3. Specific Findings and Candidate Recommendations	24
Assessing health care and health outcomes	24
Reducing disparities in health and health care	33
Building the data and information infrastructure to support quality	35
Balancing patients' interests in quality and confidentiality	41
4. Relevant Private and Public Sector Initiatives	43
5. Next Steps for the Quality Workgroup	51

Appendix: Panel topics, dates and panelists

EXECUTIVE SUMMARY

Efforts to improve health care in the United States can succeed only when those working toward that goal are equipped with accurate, complete and timely information on important health care processes and outcomes. This precondition of quality health care has been the focus of a lengthy study by the National Committee on Vital and Health Statistics (NCVHS), the statutory public advisory body on the information needs underlying health policy. The Committee offers the present report as a summary of its findings and candidate recommendations, and as a platform for a new stage of consultation and collaboration in which it hopes to engage key stakeholders in determining how best to move forward.

The Quality Workgroup Initiative

The National Committee established the Quality Workgroup (QWG) in 1998 to take the lead in the Committee's work on health data issues affecting quality measurement and improvement. The Workgroup organized 17 panel presentations over a four-year period, enabling the Committee to talk with more than 40 experts about the challenges of developing health care quality measures, implementing quality measurement and improvement projects, and using comparative performance data to drive quality improvement. This report is based on the testimony of those experts.

Findings and Candidate Recommendations

The Committee has organized its findings and candidate recommendations into four priority areas that emerged as themes in the testimony. The areas, which relate closely to HHS Strategic Objectives, are:

Assessing and improving health care and health outcomes: The objectives in this area are to make it possible to collect clinical measures of health care and health status by increasing the range and specificity of currently collected administrative data, as well as standardizing data collection for patient and population surveys.

Reducing disparities in health and health care for minority populations: The findings in this area concern the collection of data on the race, ethnicity and primary language of insurance beneficiaries and patients. The objective is to enable quality meas-

urement, reporting and tracking of health care for people in racial and ethnic minorities, toward the ultimate goal of eliminating health disparities among racial and ethnic groups.

Building the data infrastructure to support quality assessment and improve-

ment: The objectives in this area are to accelerate the development and use of the national health information infrastructure and to facilitate quality measurement through improved data coding standards, record linkage and exchange, and standard functionality requirements for electronic health records.

Balancing patients' interests in privacy protection and protection of their health

and safety: The objective in this area is to optimize the balance between protecting the privacy of personal health information and the goals of care coordination and management and of quality assessment and improvement.

The strategic focus of the candidate recommendations varies; some target existing health data systems, while others target evolving systems such as the electronic health record or personal health record. All of them come with implementation options to be considered by, and in consultation with, key stakeholders.

Next Steps and Relevant Public and Private Sector Initiatives

The Committee has tried to take into account the extensive work that has taken place in recent years on the national health information infrastructure and health data standards. Section 4 of the report outlines promising public- and private-sector initiatives that are expected to affect health data systems and could facilitate implementation of candidate recommendations. The candidate recommendations now move to the agendas of the relevant NCVHS subcommittees and workgroups for prioritization and future action. Under the leadership of these groups, the Committee looks forward to expanded discussions with stakeholders to determine the most effective and efficient ways to move forward.

Summary Matrix

For each of the priority areas described above, the following Summary Matrix outlines the findings on specific data needs and the relevant NCVHS subcommittees and work-groups. The other matrix columns indicate, for each data need, 1) the strategic focus of the candidate recommendation, 2) the Committee's candidate recommendation, 3) potential options for addressing it, and 4) relevant public and private sector initiatives.

**NCVHS Quality Work Group Report
Summary Recommendations Matrix**

Priority Area / (Relevant NCVHS Subcommittee and/or Work- group)	Data Need (Data Gap and/or Reporting Obstacle)	Strategic Focus †	Candidate Recommendation	Potential Options to be Considered	Relevant Public & Private Sector Initiatives
Assessing Health Care and Health Outcomes (S & S/QWG)	Selected Laboratory Test Results	Existing Data Systems	1. Create a mechanism for reporting selected inpatient and outpatient labo- ratory results in a standard transac- tion.	Consider revising NUBC & NUCC data- sets; ANSI X12N 837I & P; Claims Attach- ment Standard; or de- velop a new standard transaction	Connecting for Health; Consoli- dated Health Infor- matics Initiative (CHII); ASTM Conti- nuity of Care Record (CCR); HL7 Clinical Document Architec- ture (CDA); Con- sumer-Purchaser Disclosure Project (C/PDP); Public Health Data Stan- dards Consortium (PHDSC)
	Selected Vital Signs & Objective Data	Existing Data Systems	2. Create a mechanism for reporting selected vital signs and objective data measurements for inpatient encounters and outpatient visits in a standard transaction.	Consider revising NUCC & NUBC data- sets; ANSI X12N 837P & I; Claims Attach- ment Standard; or de- velop a new standard transaction	Connecting for Health; PHDSC; CHII; CCR; CDA; C/PDP
	Discharge Di- agnosis Modi- fier/Flag for “Present at admission”	Existing Data Systems	3. Facilitate the reporting of a diagnosis modifier to flag diagnoses that were present on admission on secondary di- agnosis fields in all inpatient claims transactions.	Consider modifying the UB '04 and revis- ing the ANSI X12N 837I Implementation Guide	PHDSC; C/PDP

Priority Area / (Relevant NCVHS Subcommittee and/or Work- group)	Data Need (Data Gap and/or Reporting Obstacle)	Strategic Focus †	Candidate Recommendation	Potential Options to be Considered	Relevant Public & Private Sector Initiatives
(S & S/QWG)	Operating Physician Identifier Code	Existing Data Systems	4. Modify the usage instructions for the existing data element for Operating Physician such that it is a required data element for the <i>principal</i> inpatient procedure.	Consider revising the ANSI X12N 837I Implementation Guide	PHDSC; CCR; CDA; C/PDP
	BOTH Dates <u>and</u> Times for Admissions & Procedures	Existing Data Systems	5. Modify the requirements for reporting Admission Date/Time and <i>selected</i> Procedure Dates/Times on Institutional claims transactions.	Consider revising the NUBC coding instructions and/or the ANSI X12N 837I Implementation Guide	PHDSC; C/PDP
	Episode start & end dates for services billed using Global Procedure Codes	Existing Data Systems	6. Encourage payers to modify billing instructions to providers to align procedure start and end dates with services included in selected global procedure codes in standard HIPAA claims transactions.	Modify CMS billing instructions; work toward consensus among state Medicaid agencies on their billing instructions; and encourage private payers to adopt similar provisions.	PHDSC; CCR; CDA; C/PDP
	Functional Status Codes	Existing and Evolving Data Systems	7. Review the available options for coding patients' functional status in EHRs & other clinical data sets and recommend standard approaches. Conduct the research recommended by NCVHS in 2001 and CHI in 2003, as endorsed by NCVHS.	Consider adopting ICF, SNOMED CT, and/or LOINC	CHI; NCVHS 2001 report and January, 2004 NCVHS letter to the Secretary
			8. Create a mechanism for reporting functional status codes in a standard transaction	Consider revising NUCC & NUBC datasets; ANSI X12N 837P & I; Claims Attachment; or develop new standard transaction	CDA; PHDSC

Priority Area / (Relevant NCVHS Subcommittee and/or Work- group)	Data Need (Data Gap and/or Reporting Obstacle)	Strategic Focus †	Candidate Recommendation	Potential Options to be Considered	Relevant Public & Private Sector Initiatives
Assessing Health Care and Health Outcomes (Populations/ QWG)	Adequate benchmarking data for states & metropolitan areas and racial & ethnic sub- populations	Existing Data Systems	9. Develop survey sampling approaches that can assure the availability of adequate benchmarking data at the state and metropolitan area levels and for racial and ethnic sub- populations.	Targeted sampling; pe- riodic augments; oth- ers TBD	HHS Data Council
	Standard Survey Items	Existing Data Systems	10. Standardize currently inconsistent items that are used to report the same measure of quality (e.g., immunization and screening rates) across federal surveys. Coordinate with states and private sector quality measurement/ oversight organizations on the adoption of common items across federal, state and private sector surveys.	Work through the QuICC and the Na- tional Quality Forum to adopt standard sur- vey items where feasi- ble.	IOM, National Quality Forum
Reducing Disparities in Quality (S & S/ Populations)	Data on Race & Ethnicity of all enrollees	Existing Data Systems	11. Modify existing mechanisms for re- porting race & ethnicity of subscribers <i>and</i> dependents on the HIPAA enroll- ment transaction.	Consider revising the ANSI X12N 834 Im- plementation Guide	IOM; PHDSC

Priority Area / (Relevant NCVHS Subcommittee and/or Work- group)	Data Need (Data Gap and/or Reporting Obstacle)	Strategic Focus †	Candidate Recommendation	Potential Options to be Considered	Relevant Public & Private Sector Initiatives
Reducing Disparities in Quality (S & S/ Populations)	Data on Race & Ethnicity of patients	Existing Data Systems	12. Investigate how best to capture race & ethnicity on a standard provider transaction.	Consider revising NUCC & NUBC data- sets and ANSI X12N 837P & I to report race & ethnicity on all 837I claims and on 837P claims containing a CPT E&M code for a <i>new</i> patient service; add race and ethnicity to the Claims Attach- ment Standard; or de- velop a new standard transaction.	CCR; CDA; IOM; PHDSC
	Data on Primary Lan- guage of all enrollees	Existing Data Systems	13. Modify existing mechanisms for re- porting the primary language of both subscribers <i>and</i> dependents on the HIPAA enrollment transaction.	Consider revising the ANSI X12N 834 Im- plementation Guide	PHDSC
Building the Data Infrastructure to Support Quality Improvement (S & S/NHII WG)	Standard Clinical Terminologies	Evolving Data Systems	14. Adopt standard clinical terminol- ogies, including a crosswalk or meta- thesaurus of clinical synonyms that can be used to consistently identify and describe clinical conditions, proce- dures, treatments and outcomes across EHRs, administrative transactions and provider and patient surveys.	Reference the PMRI letter to HHS.	CHII; EHR Collabo- rative; IOM Health Quality Initiative; eHealth Initiative; Public-Private Col- laborative for Pub- lic Health; CCR; CDA

Priority Area / (Relevant NCVHS Subcommittee and/or Work- group)	Data Need (Data Gap and/or Reporting Obstacle)	Strategic Focus †	Candidate Recommendation	Potential Options to be Considered	Relevant Public & Private Sector Initiatives
Building the Data Infrastructure to Support Quality Improvement (S & S/NHII WG)	Common Vocabulary for Patients	Evolving Data Systems	15. Promote the identification of lay synonyms for standard clinical terms that are easily comprehensible to patients of different cultures and educational attainment. Include these lay terms in the meta-thesaurus of clinical synonyms to facilitate their use in personal health records and patient surveys.	Ask the NLM to develop a crosswalk of lay terminologies for existing clinical terminologies that are important for patients in managing their own care or acting as caregiver	Connecting for Health
	Expanded Diagnosis Coding Standard	Existing Data Systems	16. Adopt ICD 10-CM for coding and classification of diagnoses and health conditions in administrative transactions.	Reference the 11/04 NCVHS letter to HHS and add the quality context as further impetus for adoption of ICD-10-CM	
	Crosswalk of standard procedure codes across care settings	Existing Data Systems	17. Create a mechanism for efficiently mapping procedure codes across current and proposed HIPAA standard coding systems to facilitate querying and aggregating procedure information across care settings.	Ask the NLM to develop an electronic crosswalk or meta-thesaurus of clinical terminologies for procedures and their associated clinical codes	eHealth Initiative; Public-Private Col- laboration
	Clinical Decision Support functionality in EHRs	Evolving Data Systems	18. Standard functionality requirements for electronic health records should include clinical decision support to facilitate planning and delivery of evidence-based care to individual patients and groups.	Work through HL-7 and the EHR Collaborative to promote standard functionality	EHR Collaborative

Priority Area / (Relevant NCVHS Subcommittee and/or Work-group)	Data Need (Data Gap and/or Reporting Obstacle)	Strategic Focus †	Candidate Recommendation	Potential Options to be Considered	Relevant Public & Private Sector Initiatives
Building the Data Infrastructure to Support Quality Improvement (S & S/NHII WG)	Standards for Data content and Reporting functionality in EHRs	Evolving Data Systems	19. EHRs should employ uniform data standards for core content and data storage formats to facilitate population health surveillance and reporting functions.	Work through ASTM, HL-7 and the EHR Collaborative to promote standard functionality	CHII; CCR; CDA; EHR Collaborative
	Interoperability of EHRs and standard formats for selected record extracts from EHRs	Evolving Data Systems	20. Promote standards for interoperability of electronic clinical data systems and EHRs and adopt a core set of output record formats that EHRs should be capable of exporting and importing to support care coordination and QA/QI.	ASTM Continuity of Care Record (CCR); HL7 Clinical Document Architecture (CDA); others to be identified or developed	CHII; CCR; CDA; eHealth Initiative; IOM Health Quality Initiative; Bridges to Excellence; Public-Private Collaboration; EHR Collaborative; HIPAA; CMS' Quality Initiative
Building the Data Infrastructure to Support Quality Improvement (S & S/ NHII WG/Privacy & Confidentiality)	Standard Provider Identifier	Evolving Data Systems	21. HHS should recommend the adoption of the NPI as a consistent provider identifier, not only in administrative transactions, but <i>also</i> in clinical data systems, EHRs, provider surveys, and clinical record and reporting formats. HHS should implement this recommendation within all federally funded health information systems.	ASTM E31; HL7 RIM; CCR	CHII; CCR; CDA; eHealth Initiative; Public-Private Collaboration; HIPAA

Priority Area / (Relevant NCVHS Subcommittee and/or Work-group)	Data Need (Data Gap and/or Reporting Obstacle)	Strategic Focus †	Candidate Recommendation	Potential Options to be Considered	Relevant Public & Private Sector Initiatives
Building the Data Infrastructure to Support Quality Improvement (S & S/ NHII WG/Privacy & Confidentiality)	Voluntary Standard Patient Identifier/ Identifier Logic	Existing Data Systems	22. Develop a voluntary, standardized Patient Identifier or Patient Identifier logic that, when authorized by the patient, can be used to link healthcare records for the same patient across payers, providers and care settings.	Create a mechanism(s) for patients to request a standard personal identifier and/or agree to the application of standard logic for assigning a unique ID based on existing PHI	CHII; CCR; CDA; Bridges to Excellence; eHealth Initiative; Public-Private Collaboration
Balancing Patients' Interests (Privacy & Confidentiality)	Impediments to record access & linkage for coordination of care and QA/QI	Existing Data Systems	23. Examine privacy protections under existing federal laws that inhibit access to and linkage of patient records across payers, providers and care settings for purposes of care coordination and management and quality assessment and improvement. Revise and/or clarify current regulations to reduce obstacles while effectively balancing the best interests of patients and populations.	Consider possible Addendum to OCR Guidance	CCR; CDA; C/PDP; Bridges to Excellence; eHealth Initiative; Public-Private Collaboration; Connecting for Health; PHDSC; HIPAA;

†Some recommendations are targeted for Existing Data Systems such as HIPAA administrative transactions and/or HL-7 message formats commonly used in clinical information systems, while others are targeted for Evolving Data Systems such as Electronic Health Records (EHRs) or Personal Health Records.

1. INTRODUCTION

This report from the National Committee on Vital and Health Statistics (NCVHS) comes at a time of intense national attention to health care quality and a host of high-profile initiatives to improve it. None of these efforts can succeed, however, without solid information well beyond what is currently available. As the recently released National Healthcare Quality Report and others attest, gaps in data collection and limitations on data sharing continue to be serious impediments to knowing exactly what is going on in health care and how it can be improved.

As one of its responsibilities as the statutory public advisory body on the information needs underlying health policy, NCVHS advises the Secretary of Health and Human Services on quality measurement. The Committee established the Quality Workgroup (QWG) in June 1998, when the U.S. was riveted by a crisis in health care quality. Since then, the Workgroup has monitored and advised on national initiatives and led the full Committee in investigating quality measurement issues. Over a four-year period, the Committee heard from more than 40 experts, in 17 panels, about the challenges of developing health care quality measures, implementing quality measurement and improvement projects, and using comparative performance data to drive quality improvement. (Details about the hearings are in the Appendix.)

This report is based on the testimony of those experts. After concluding the information-gathering phase, the QWG summarized the key data issues raised by the panels, clarified priorities in the light of current developments, and crafted a broad set of candidate recommendations for closing gaps, for referral to the agendas of relevant NCVHS subcommittees and workgroups.

The process of translating findings into candidate recommendations has been both interesting and challenging because of the extensive activity around health care quality, the health information infrastructure and standards that have emerged since the project began. The Committee has taken pains to take this activity into account, and it plans additional efforts to draw those responsible for advances in data standards and the health information infrastructure more fully into the quality improvement main-

stream in ways that are compatible with other initiatives. The Designated Standards Maintenance Organizations (DSMOs) will be key partners, joining others from industry and government.

The Committee sees implementation as an evolving and collaborative process. While some improvements are envisioned for existing data systems and might be accomplished in relatively short order, others are evolutionary in nature and must wait for the adoption of electronic health records and other system changes. This report is intended to help shape the direction of change so that maximum use can be made of available information at every stage to ensure Americans the best possible health care and health.

The following pages begin by describing the QWG's approach to its initiative and summarizing its findings about priority areas and crosscutting data issues. Section 3 presents the Committee's specific findings and candidate recommendations in the four priority areas: 1) assessing health care and health outcomes, 2) reducing disparities in health and health care, 3) building the data and information infrastructure to support quality, and 4) balancing patients' interests in quality and confidentiality. (The findings are articulated first, followed by the relevant candidate recommendation[s].) Section 4 surveys current initiatives the Committee believes will help fill quality measurement data gaps and remove reporting obstacles, including several projects of the National Committee itself. (The matrix in the Executive Summary summarizes the data needs, candidate recommendations and complementary initiatives.) Section 5 outlines the QWG's planned next steps.

2. THE QUALITY WORKGROUP INITIATIVE

Project Goal and Approach

As noted, the principal goal of the report is to identify specific data needs and the actions that could improve both the data and systems capabilities needed to support quality assessment and improvement in health care. In so doing, the Committee hopes to engage public and private stakeholder organizations in initiating those actions. The

principal focus of the Committee's explorations into data needs and gaps, and information infrastructure requirements, has been on care delivered in hospital and office or clinic settings. This focus was chosen for two reasons. First, the preponderance of care is delivered in those settings. Second, these settings lack separate data collection streams for documenting health and functional status to support quality assessment, such as the MDS in nursing homes and OASIS in home health care. However, many of the candidate recommendations propose changes to standard HIPAA transactions that are employed in all health care settings and that will, therefore, enhance quality assessment and improvement capabilities in these other settings as well.

From the outset, the Committee's study of quality measurement issues interacted both with major external initiatives and with complementary NCVHS activities. The Workgroup was launched close on the heels of the publication of *Quality First: Better Health Care for All Americans*, the final report of the President's Advisory Commission on Consumer Protection and Quality in Health Care. The Advisory Commission report set out a number of recommendations for enhancing quality measurement and improvement capabilities that depend upon a strong health data and information infrastructure. The Workgroup decided it would initially focus on identifying the key data gaps and barriers that were likely to hinder the implementation of "data-dependent" Advisory Commission recommendations, and that it would offer its own suggestions for reducing or eliminating these data gaps and barriers.

In its August 1998 letter to then Secretary Shalala, NCVHS supported the recommendations of the President's Advisory Commission and articulated a number of key areas in which it proposed to further those ends. The QWG focused its efforts in three specific areas:

- Evaluating the adequacy of existing data on which to base quality measurement priorities and recommending improvements to current data collection and/or reporting initiatives;
- Identifying important data content gaps with respect to quality measurement and offering recommendations for resolving them in future releases of claims, enrollment, pharmacy or other administrative transaction standards or in the electronic health record (EHR); and

- Identifying policy and infrastructure barriers to implementing data collection, data linkage and data exchange for care management, coordination of care, and quality assessment and improvement and offering recommendations for reducing policy barriers and strengthening the data and information infrastructure to support these activities.

Through the efforts of other Subcommittees and Workgroups, NCVHS either undertook or supported additional initiatives for the elimination of gaps and barriers to quality assessment and improvement. These included:

- Improving data quality through facilitating the adoption of the EHR and monitoring adoption of administrative simplification standards;
- Facilitating data linkage through the adoption of national identifiers;
- Recommending standards for minimum data content, output formats for data exchange, and core functionality of an EHR to support quality measurement and improvement; and
- Reducing the measurement burden on providers by recommending the adoption of standard data collection formats for clinical and administrative data necessary to report quality measures.

Given the sizable number of concurrent initiatives within NCVHS that were highly relevant to quality measurement and improvement, the Workgroup determined that the best way to obtain input from the field and maximize the cross-fertilization of these various NCVHS initiatives was to conduct most of its information gathering through panel sessions conducted within the context of full NCVHS Committee meetings. The QWG organized 16 full Committee panels and two separate hearings over a 4-year period, in addition to drawing from previous testimony to the full Committee on related data issues.

Additionally, QWG members participated in several key initiatives of the NCVHS Populations Subcommittee with the specific goal of eliciting input on quality measurement issues relevant to these initiatives. These addressed the areas of Medicaid-Managed Care data requirements; functional status measurement; collection and reporting of Race/Ethnicity data; and surveillance and data reporting for populations in the Insu-

lar Areas and Territories. Individual members of the QWG also brought the quality measurement perspective to the development of the Vision for 21st Century Health Statistics and the NHII Report, and to the Committee's recommendations to the Office of Civil Rights on the proposed HIPAA Privacy Rule and its subsequent modifications. The QWG also leveraged the ongoing work of other NCVHS Subcommittees and identified and proposed additional avenues, outlined in the candidate recommendations below, for strengthening current quality assessment and improvement capabilities.

The QWG sought broad input from both the public and private sectors to identify important gaps in existing data collection mechanisms and systems, as well as barriers to accessing and using data for quality assessment and improvement. It sought to propose options for addressing data gaps and improving the data infrastructure needed to support meaningful, valid, cost-effective and broadly representative quality measurements and timely quality improvement initiatives.

During the course of the QWG's work, the Department of Health and Human Services articulated its strategic five-year objectives, several of which had direct bearing on these goals and helped to facilitate the QWG's efforts through related governmental initiatives and public-private partnerships. These objectives included the following:

- Objective 3.4** Eliminate racial and ethnic health disparities
- Objective 5.1** Reduce medical errors
- Objective 5.2** Increase the appropriate use of effective health care services by medical providers
- Objective 5.3** Increase consumer and patient use of health care quality information
- Objective 5.4** Improve consumer and patient protections
- Objective 5.5** Accelerate the development and use of an electronic health information infrastructure

In pursuit of its objectives, HHS commissioned studies by the Institute of Medicine that further elaborated the need for better data and systems to assess and improve quality, recommended initiatives to meet that need, and discussed the public sector's role in leading them. The QWG kept abreast of the many new public and private sector

activities in the area of quality measurement and reporting. It organized panel presentations on such major initiatives as the Institute of Medicine reports emanating from its Quality of Health Care in America activities; the activities of the HHS Quality Inter-agency Coordinating Committee and the National Quality Forum; the strategic goals and projects of key accrediting bodies; and the development of the National Healthcare Quality Report (NHQR) and the National Healthcare Disparities Report by the Agency for Healthcare Research and Quality (AHRQ).

Either through panel testimony organized by the QWG or reference to other NCVHS testimony and recommendations, the QWG considered all data sources used in quality measurement. These sources include vital statistics systems, national surveys, several types of administrative transaction records (both traditional and electronic medical records), and new, emerging, patient-held records.

Overview Of Findings

Priority Areas of Focus

Several common themes emerged through public testimony and reviews of relevant public documents regarding data gaps and barriers to quality assessment and improvement. These themes fall into four broad categories, which provide the structure for the Committee's findings and candidate recommendations. They are:

- *Assessing and improving health care and health outcomes*
- *Reducing disparities in health and health care for minority populations*
- *Building the data infrastructure to support quality assessment and improvement*
- *Balancing patients' interests in privacy protection and protection of their health and safety*

Assessing and Improving Health Care and Health Outcomes

The IOM reports *To Err is Human* and *Crossing the Quality Chasm* document the alarming extent of quality problems in this country and the compelling need to overhaul our health care delivery system if we want to improve quality of care. HHS Objectives 5.1 and 5.2 address the need to “reduce medical errors” and “increase the appropriate use of effective health care services by medical providers.” The first steps in re-

ducing errors and improving the quality of health care delivery are problem identification and root cause analysis, two data-dependent activities. Likewise, determining whether or not interventions have led to real improvement requires re-measurement. A frequently cited rule of quality improvement is that “you can’t manage what you can’t measure.” But the current health information infrastructure makes quality measurement limited, costly, and burdensome.

The recent *National Healthcare Quality Report* documents wide variation in health outcomes among states, health plans and hospitals as well as in the extent to which health care reflects recommended clinical guidelines. These variations in care, coupled with recent evidence on the impact of public reporting on quality performance measures, suggest an important role for consumer information about quality as a force in driving healthcare professionals and organizations to improve. Consumers need information at the local level, about individual clinicians, medical groups, hospitals and other care facilities if public reporting on quality performance is to be effective. The collection of such information is extremely inefficient and costly in many care settings, due to lack of automation or limitations in data content, coding and retrieval mechanisms in many computerized information systems.

HHS Objective 5.3 focuses on increasing patient and consumer use of quality information; but first, that information must be made available to them and it must be relevant to their needs and concerns. In line with another IOM report, *Leadership by Example*, CMS has taken the lead in requiring most facility-based organizations to measure and publicly report on important, uniform quality indicators. It also is working with the physician community to develop similar measures. Still, the current portfolio of measures is limited in addressing consumers’ needs and interests.

The diffusion of pay for performance initiatives by many private sector payers, as well as the recent entry of CMS into this realm, creates financial incentives for provider groups and facilities to invest in information technology solutions to both measure and improve quality of care. These initiatives also fuel the demand for quality measurement at the provider level by those paying the bills. Low-cost, efficient data collection, storage and retrieval systems are needed to both minimize the costs of quality meas-

urement and maximize the scope of consumer-relevant measures that can be easily obtained and reported.

Throughout the testimony taken during the QWG initiative, data content gaps in administrative systems and limited functionality for population-based assessment in existing clinical data systems were the most commonly cited limitations, especially for health outcomes assessment. Health outcomes include both clinical outcomes (mortality, morbidity, physiologic measurements, etc.) and functional status. They are considered by some experts to be the best measures of the quality of health care.

Testimony from quality professionals lauded the potential of computerized clinical information systems while lamenting the limited adoption of integrated EHRs. Much of the testimony focused on the standard administrative transactions defined under HIPAA, as these transaction records are currently the most widely available and cost-effective sources of healthcare data. Measures based on administrative data are more readily scalable, since they can be created and reported at the provider, organization or payer level with little or no difference in the cost of measurement.

The adoption of computerized medical records, pharmacy order entry systems and clinical laboratory and radiology information systems should enable the capture of more complete, accurate, specific and timely clinical information in an even more cost-effective manner in the future. However, the diffusion of these technologies into provider practices has been slow and uneven. Administrative claims/encounter transactions represent an attractive short-term option for capturing additional data elements that represent important health care processes and/or health outcomes, while continuing to pursue the benefits of EHRs and a robust national health information infrastructure.

Reducing Disparities in Health and Health Care

A recent IOM report, *Unequal Treatment*, has documented many disparities in the quality of care received by racial and ethnic minority and other disadvantaged subpopulations. Unfortunately, the range of studies available to draw on for this report was limited by the lack of socio-demographic data in many existing healthcare data-

sets. Without adequate information on patient and population characteristics, such as race, ethnicity, primary language, education and income, it is nearly impossible to assess whether the quality of care is distributed equitably across a population. Yet these focused studies make it abundantly clear that it is not.

Eliminating these disparities first requires uncovering them—in every medical office, hospital, nursing home and health plan. Yet the failure in these settings to systematically collect, in easily retrievable form, data on race, ethnicity, primary language, education and other important sociodemographic characteristics of patients makes such discovery difficult and limits efforts to identify and eliminate disparities. Most provider organizations will not be willing to invest in programs or processes that have been shown to reduce or eliminate disparities in the absence of data showing that they, in fact, have the problem these interventions purport to solve.

HHS Objective 3.4 is to eliminate racial and ethnic disparities. Only the routine collection of data on race, ethnicity and primary language, in consistent and retrievable form, will focus attention and resources on finding and eliminating the types of disparities cited in *Unequal Treatment*.

Building the Data and Information Infrastructure to Support Quality

The recent NCVHS report, *Information for Health: Building the National Health Information Infrastructure*, cites the many potential health and cost benefits of provider investment in information technology to support quality improvement in health care delivery. Additional financial incentives for such investments continue to emerge from both public and private sector payers. HHS Objective 5.5 is to accelerate the development and use of an electronic health information infrastructure, and the activities of the Consolidated Health Informatics Initiative are effective forces for achieving progress in this area. Provider investment in clinical information technology has rapidly accelerated in recent months; however, the lack of clinical data standards, core functionality requirements for EHRs and interoperability standards has impeded this progress.

Other data standardization issues identified in testimony as impeding quality measurement still remain in three areas:

- **Data coding standards:** Assuring consistency in coding of diagnoses, procedures and other health care services rendered to patients, regardless of care setting.
- **Record linkage and exchange:** Enabling communication, coordination of care and measurement and accountability for quality of care across providers and care settings.
- **Standard functionality requirements for electronic health records:** Supporting effective care management, population health assessment and quality measurement and reporting.

Balancing Patients' Interests in Quality and Confidentiality

Given the dependence of quality improvement on information, a delicate balance must be struck when weighing the potential risks to the confidentiality of a patient's personal health information against the potential risks to that person's health as a result of poor quality of care. While the Office of Civil Rights put tremendous effort into developing a valuable guidance document for covered entities and others to facilitate their compliance with the HIPAA Privacy Rule, some issues still remain unclear.

Most providers have access only to data on the services they provide and payers have access to data only on the services they cover. This places serious limitations on the ability of either stakeholder to assess the quality of care their patients and/or insureds received; each has access to only a piece of the picture.

In particular, there remains considerable confusion within the provider and payer communities about the sharing of individuals' personal health information between payers and providers in situations where a patient may no longer be covered by a given payer or receiving care from a given provider, or when a patient's relevant clinical history predates their relationship with a given payer or provider. Likewise, when multiple payers cover different types of services, yet each is held accountable for overall quality of care, limitations to data-sharing among payers can lead to measurements

that are not fairly representative of payer or provider performance and can lead to misdirection of scarce improvement resources and/or mislead consumers.

One area cited in testimony to NCVHS is the fragmentation of information on patients receiving behavioral health services through carve-out programs. For example, the carve-out behavioral health service vendor generally does not have access to pharmacy claims for identifying problems in medication compliance, while the primary care physician may be unaware that a patient is taking an antidepressant that could potentially interact with other recommended treatments. Confusion such as this is hampering efforts to provide, measure and improve quality of care.

Cross-cutting Data Issues

Data quality issues represented a common theme among those testifying on data needs for quality measurement and improvement in all four priority areas. Data quality issues can be broadly categorized as follows:

Availability of the needed data

Data gaps represent an area of major concern to multiple stakeholders and encompass a diverse array of data elements. Some data elements necessary to assess and improve quality of care are simply not available to those responsible for quality measurement and improvement activities both within and outside payer and/or care delivery organizations. These data gaps are attributed to a number of different factors, including the burden of data collection; technology barriers to data collection; legal and/or technical barriers to sharing data among multiple clinicians or organizations involved in delivering or managing the care of a patient; and differing priorities among suppliers and users of the data

Completeness of the available data

Data completeness refers both to the completion or documentation rates for existing data elements within a record and to the completeness of records in a dataset (e.g., whether all visits are captured or only those made to a particular site). Some data

elements that can be collected and reported under existing processes and electronic standards are not routinely collected, transmitted and/or stored for future analysis. Data completeness problems were cited in the testimony in connection with medical records, administrative transaction data and survey data. The implementation of HIPAA administrative transaction standards during the course of this QWG initiative and the acceleration of EDI use by providers and payers have improved the completeness of data capture for those elements that are required under the standard; however, some key data elements needed for quality assessment and improvement have been designated as *not used* or the conditions under which they are required are too restrictive.

Accuracy of the available data

Certain types of data have been more prone to errors and inaccuracies, either intentional or unintentional. Administrative data are prone to accuracy issues to a greater extent than medical record information. Problems with the accuracy of *procedure* coding in administrative transactions appear to be rare. The exception is global procedure codes, some of which encompass pre- or post-operative services that either occurred outside the specified procedure dates or were not actually delivered. The accuracy of *diagnosis* coding in administrative claims/encounter transactions, in contrast, is a frequently cited problem. Those testifying felt this was related both to the limitations of paper-based data collection systems, such as encounter forms or “super-bills,” and the lack of documentation incentives under capitation and other payment mechanisms.

For example, one comparison of health plan claims with state-mandated discharge records for the same inpatient episode found that the discharge records reported to the state showed significantly higher percentages of discharges with more than three discharge diagnoses and a higher average number of discharge diagnoses than in the claims submitted to the health plan. This disparity was attributed to both per diem and percent of charge-based payment mechanisms, which, unlike DRGs, offered no incentive for complete coding of co-morbid diagnoses.

Timeliness of the available data

In the absence of electronic data interchange or universal EDI participation rates, lags in administrative data submission and processing have in the past rendered some types of data unusable for time-sensitive quality improvement purposes. The implementation of HIPAA transaction standards during the period encompassing the QWG's deliberations has greatly increased EDI participation. Likewise, the recent acceleration in adoption of EHRs and CPOE systems has greatly reduced the lag times between the occurrence of healthcare events or orders and the availability of relevant clinical information for decision support and records of those events for quality assessment and improvement. In some cases, these information technologies have enabled real- or close to real-time availability of data for intervening to reduce potential medical errors, improve patient compliance with medications and notify providers and/or patients of needed follow-up care. Efforts to incent greater adoption of these information technologies are now part of the federal agenda for improving quality of care.

3. SPECIFIC FINDINGS AND CANDIDATE RECOMMENDATIONS

Assessing Health Care and Health Outcomes

Despite the undisputed influence of many factors unrelated to health care (age, gender, environment, genetics, behavior, etc.), health outcomes represent the quality measures most salient to consumers, as well as to many purchasers of health benefit plans. Sophisticated risk adjustment methods have been developed to account for many of the important predisposing factors when measuring and reporting publicly on health outcomes. Risk adjustment, however, depends in large part upon the completeness, accuracy and specificity of diagnosis, procedure and medication codes on which such methods are based. Each of these aspects of coding can be problematic.

Laboratory values and vital signs represent proximate clinical outcomes, the measurement of which requires clinical information that is often available only through chart abstraction. Risk adjustment of clinical outcomes such as complication or mortality rates also can depend upon the availability of physiologic measurements (e.g., kidney function in diabetics, peak flow measurements for asthmatics, ejection fraction

for heart failure), which themselves can serve as proximate outcomes. Some important health outcomes for priority health conditions can be ascertained through vital signs and/or objective data, such as blood pressure and weight. Vital signs and most laboratory and radiology test results are currently not available in claim transaction records, and the claims attachment standard has not yet been finalized. Administrative transactions represent a short-term option for capturing the additional data elements necessary to determine these important health outcomes. The inclusion of these data elements will require either revisions to existing HIPAA standards and implementation guides or the development of a new standard transaction.

Candidate recommendation 1: Test Results

- *Create a mechanism for reporting selected inpatient and outpatient laboratory results in a standard transaction.*

Focus on tests that represent important clinical outcomes for the priority health conditions identified by the IOM report, *Priority Areas for National Action: Transforming Health Care Quality* (2003). Work with AHRQ and the National Quality Forum to identify these clinical outcomes and associated laboratory test codes.

Candidate recommendation 2: Vital Signs/Objective Data

- *Create a mechanism for reporting selected vital signs (e.g., blood pressure) and objective data measurements (height/weight and Body Mass Index) on inpatient encounters and outpatient visits in a standard transaction.*

Focus on measurements that represent important clinical outcomes for the priority health conditions identified in the aforementioned IOM report. Work with AHRQ and the National Quality Forum to identify these clinical outcomes and with the appropriate DSMOs and Medical Code Set Developers to assign appropriate procedure codes and data elements for these measurements.



Diagnosis Modifiers can help to differentiate pre-existing conditions from those that may have been the result of medical errors or ineffective processes of care. Severity indicators and flags for whether a diagnosis was present on admission are examples of

diagnosis modifiers. Procedure coding systems, such as CPT, have long recognized the value of modifiers for defining the context and elucidating critical details that are needed to interpret what care was delivered under what circumstances, and to bill appropriately for that care.

Nosocomial infections and medical errors can often lead to the development of preventable complications or co-morbidities among hospitalized patients. However, the presence of discharge diagnosis codes for these conditions can be alternately interpreted as indicators of patient casemix/severity of illness or as signifying a potential problem in the care that a patient received. A flag that can distinguish those conditions that were present on admission from those that developed during the course of hospitalization can permit the identification of potential problems in the care process that need improvement, while also serving as an important data element for risk/severity adjustment. The 837 institutional claim standard supports such a flag, but it is not used in the current Implementation Guide. There is experience collecting this information in New York and California hospital discharge systems, where it has proven valuable for both risk adjustment and outcomes assessment.

Examples of modifiers that were cited as potentially helpful:

- A modifier for hospital discharge diagnoses to indicate whether the condition was present on admission or developed during the inpatient stay would enable the identification of potentially preventable complications and/or morbidities.
- A modifier to indicate the severity of a diagnostic condition, using established severity classifications or staging criteria, such as those developed by medical professional societies for asthma, coronary artery disease and cancer.

Candidate recommendation 3: Secondary Admission Diagnosis Flag

- *Facilitate the reporting of a diagnosis modifier to flag diagnoses that were present on admission on secondary diagnosis fields in all inpatient claims transactions.*

Documenting the **provider rendering a specific inpatient service/procedure** is critical to identifying providers with the necessary experience and expertise to produce improved health outcomes and also to targeting quality improvement interventions when instances of poor quality are found. Transparency and accountability in health care demand that it is possible to determine the responsibility for care that is, or should be, delivered to a population or individual.

Here again, administrative transactions represent a reasonable vehicle for capturing information about the provider who rendered a specific service or procedure to a patient. The professional claim transaction already provides for the capture of the rendering provider for a specific procedure code on the claim detail record, but while the institutional claim transaction includes a data element to capture the surgeon's identifier, in the case of an operative procedure, the current Implementation Guide designates the Operating Physician data element as "Not Used."

Outside of an integrated, electronic medical record, the clinician who reads a particular radiological exam or performs a procedure in an institutional setting can only be identified through linkage of a professional claim with the respective institutional claim. While most states mandate the submission of institutional claims/discharge records for public use in de-identified form, the submission of professional claims data is generally not required. Thus, this linkage cannot occur and the rendering provider cannot be identified or held accountable, except within the context of an integrated delivery system or health plan. The continued development of the NHII will help to improve data exchange capabilities outside of these contexts; however, a short-term solution is also needed.

The reporting of the data element for the Operating Physician who performed the Principal Procedure within the institutional claim transaction would greatly enhance the transparency of and accountability for care and create incentives for quality improvement. It will also help to identify surgeons who meet volume thresholds for surgical procedures where the risk of mortality is relatively high and where the surgeon's experience in performing a procedure and the mortality rate for that procedure are highly correlated.

Candidate recommendation 4: Operating Physician

- *Require the existing data element for Operating Physician to be reported for the principal inpatient procedure.*



Service Dates/Times are important data elements for assessing the timeliness of care. Few quality measures currently exist for timeliness of care, which was identified in the IOM's *Quality Chasm* report as an important aspect of health care quality. Several data issues around assessing the timeliness of service delivery were highlighted in panel testimony, in each case relating to the use of administrative data for measuring timeliness of care. First, timeliness measures are often defined based on recommended follow-up intervals for clinical procedures or outcomes that are not routinely captured in claims (e.g., abnormal test results). By reporting test results for laboratory or radiology tests that represent key clinical indicators of quality as recommended above, this issue can be at least partially addressed.

A second data issue is that the dates and times associated with the delivery of certain services either are not captured at all in administrative data or are coded incompletely or inappropriately within the context of an episode of care. In the case of institutional care, several important quality measures are dependent upon time intervals between events (e.g., administration of thrombolytic agents in the ER; administration of prophylactic antibiotics prior to surgery and discontinuation post-surgery). These quality measures are needed because there are important negative health consequences associated with delays in administering certain therapeutic procedures. While the institutional claim transaction standard includes data elements for both Admission Date/Time and for Procedure Date/Time, the instructions in the current Implementation Guide for this transaction does not indicate *both* date *and* time as required elements. While it may be impractical, costly and burdensome to require date and time for every procedure, requiring these data elements for a subset of specified procedures that relate to nationally endorsed quality measures is both feasible and consistent with evolving documentation practices in most hospitals.

Candidate recommendation 5: Dates and Times for Admission and Procedures

- *Modify the requirements for reporting the Admission Date/Time and Procedure Date/Time data elements to include both date and time for Admission and for selected Procedures on the Institutional Claim transaction. Encourage NQF and others to identify the procedures for which these data elements would be required.*

∅

Global Procedure Codes for many surgical and obstetrical procedures have made it simpler for providers to bill for a package of services provided within a defined episode of care, but have led to problems in evaluating the quality of care delivered within such episodes. The coding rules for service dates applicable to the specific services included within these care episodes have not been sufficiently defined to permit the identification of start and end dates for care episodes.

One example cited in testimony is the inability to measure either the timeliness of initiating prenatal care or the timeliness of receiving postpartum care, both of which depend upon using the date of the first prenatal visit as the service start date and the postpartum visit date as the service end date for a global episode of obstetrical care. While a separate data element exists to track the start date for prenatal care, common practice is to submit claims for obstetrical care using the inpatient admission and discharge dates as the starting and ending service dates, despite the broader description of the care episode included under the global CPT code. HEDIS® chart reviews revealed that, on average, close to 15 percent of obstetrical patients in health plans had not received post-partum care at eight weeks following their delivery despite submission of a claim containing a global code that included payment for this visit.

Candidate recommendation 6: Episode Start and End Dates for Global Procedure Codes

- *Encourage payers to modify their billing instructions to providers to align procedure start and end dates with services included in selected global procedure codes in standard HIPAA claims transactions.*

∅

Functional status is another important health outcome and is considered by many quality experts to be among the best measures of the quality of health care received by patients. It is a key element in evaluating a patient's quality of life. NCVHS is already on record as recommending the inclusion of functional status as a core data element and the use of an appropriate coding system for ascertaining a patient's functional status at key points within a care episode. The NCVHS recommended in its 2001 report on *Classifying and Reporting Functional Status* that HHS support research into the feasibility and appropriateness of implementing the ICF to capture functional status on administrative transactions. Since that time, the CHII has explored the government's need for classifying and coding functional status in clinical records and other data collection mechanisms (e.g. MDS, OASIS, FIM, etc.), as well as administrative transactions, and recommended that the scope of such research be broadened to include SNOMED-CT and other sources of disability terms within the UMLS Meta-Thesaurus. Functional status has also been measured using patient surveys (e.g. NHIS), but these are often expensive to implement and can suffer from non-response bias, particularly among the functionally impaired, as well as inconsistencies in terminology. In January 2004, the NCVHS endorsed the recommendations of the CHII and this report lends further support for the adoption of the Committee's recommendations on functional status.

Functional status is best measured in the context of care episodes, and claim/ encounter data represent the most efficient mechanism for capturing functional status at the time of a visit or discharge. Doing so would require the implementation of a data element for functional status on the HIPAA claim/encounter transaction and the adoption of a standard codeset for this data element. .

Candidate recommendation 7: Functional Status Coding

- *Review the available options for coding patients' functional status in administrative transactions, EHRs & other clinical data sets and recommend standard approaches.*

Conduct the research recommended by the 2001 NCVHS report and by CHII as endorsed by NCVHS in its January 2004 letter to the Secretary.

Candidate recommendation 8: Functional Status Reporting

- *Create a mechanism for reporting functional status codes in a standard transaction.*



The lack of **adequate benchmarking data for states, major metropolitan areas and racial & ethnic sub-populations** is impeding quality improvement. Benchmarking data are used to identify quality problems and to track progress in improving quality and eliminating disparities in care.

Many important health outcomes are best reported by patients (e.g., functional status, pain levels and symptom relief), and surveys are often the most appropriate measurement tools for assessing these types of health outcomes. Patient surveys can also be a better source of some types of clinical process measures (e.g., advice to quit smoking, education about self-testing or self care management tasks) than medical records. Federal surveys frequently reveal problems in care and/or sub-optimal health outcomes. However, quality problems identified in national surveys are less compelling than those identified at the state, local and institutional levels in promoting financial investments in quality improvement.

Actionable results of quality measurement activities are critical to the development of quality improvement and error prevention strategies. The absence of state or local data on which to make the case for such investments creates a burden on local entities to collect their own data, often at greater expense and with uneven implementation. Likewise, inadequate survey sampling for some minority populations has impeded the identification of health disparities and disparities in care, and deferred or delayed investment in quality improvement efforts for minority populations. Recently, in a letter to the Secretary, NCVHS urged adoption of recommendations made in a General Accounting Office report to Congress, that DHHS should take steps to insure the adequacy of federal data in this area. The Committee recommended developing a long-term strategic plan for addressing data needs for racial and ethnic minorities, increased sample sizes for surveys of minority groups, targeted surveys using methods that would allow direct comparison with national data, and expanded access to such data. If implemented, these initiatives would significantly improve our ability to iden-

tify, target and track deficiencies in health and healthcare among small, geographically dispersed racial and ethnic groups.

Candidate recommendation 9: Adequate Benchmarking Data

- *Develop survey-sampling approaches that can assure the availability of adequate benchmarking data at the state and metropolitan area levels and for racial and ethnic sub-populations.*

Focus on national surveys that provide source data for quality measures that relate to the priority health conditions identified by the IOM and/or are included in either the National Healthcare Quality Report, the National Health Disparities Report or other federal reports, such as Health United States, that track progress on Healthy People 2010 goals.



Standardization issues in data collection for patient and population surveys limit the ability to leverage data collected via different public and private sector survey tools that purport to measure the same care process or health outcome. As a result, each survey effort demands larger sample frames than might otherwise be needed and data cannot easily be pooled or stratified across surveys to examine care at a more detailed sub-population or organizational level.

While the Administrative Simplification provisions of HIPAA have gone a long way toward standardizing the content and format of administrative transactions, similar standards do not exist for items in many patient and population surveys that collect information about the same health care services and/or outcomes. Patients can receive multiple surveys from different sponsors regarding the same health care event(s) but using different sampling approaches, measure constructs, survey questions, measurement scales and scoring methodologies. Even within the public sector, questions about the same event or service can have different wording, scales and scoring methods.

One success story in resolving such inconsistencies was the standardization of

the consumer-reported measure of flu immunization across the HIS, MCBS, BRFSS and CAHPS surveys that were developed by different federal health agencies. Other survey items could benefit from similar standardization.

While different sample frames are often necessary to address differing purposes, the use of commonly worded questionnaire items and response scales could greatly improve the usefulness of public sector surveys for quality measurement and could serve as a basis for items included in private sector surveys.

Candidate recommendation 10: Standard Survey Items for the Same Quality Measures

- *Standardize currently inconsistent items that are used to report the same measure of quality (e.g., immunization and screening rates, functional status) across federal surveys. Coordinate with states and private sector quality measurement/oversight organizations on the adoption of common items across federal, state and private sector surveys.*

Focus efforts on crosscutting quality measures and measures for the priority health conditions identified by the aforementioned IOM report. In particular, focus on quality measures that are included or planned in current and future National Healthcare Quality and National Health Disparities Reports and in key federal reports used for tracking progress on Healthy People 2010 goals.



Reducing Disparities in Health and Health Care

Race and ethnicity are particularly important demographic factors for quality assessment and improvement, as health insurance coverage does not appear to reduce disparities due to these factors to the same extent it does for differences in income or education.

It is important to be able to identify improvement opportunities and to target interventions appropriately. Some racial and ethnic groups are at a disproportionate risk of developing certain health conditions, as well as at risk of poorer outcomes. Effective

interventions to reduce disparities rely on the ability to identify those subpopulations at the greatest risk for poor outcomes and to target them for outreach and preventive care programs.

Furthermore, providers' perceptions of a patient's race and ethnicity have been demonstrated to affect their use of diagnostic and therapeutic interventions, often to the detriment of quality. As a result, these factors can be important determinants of health outcome, often due to health care providers' responses to patients' race and/or ethnicity rather than to any genetic predisposition.

Thus, it is important to understand *both* how clinicians perceive the race/ethnicity of patients and how patients self-identify their race and ethnicity. The addition of race and ethnicity for both subscribers and dependents to the HIPAA standard enrollment transaction is one mechanism for capturing *self-reported* race and ethnicity for a broad segment of the population. *Provider-reported* race and ethnicity could be captured on standard claim transactions; the data elements currently are included in the institutional transaction standard but are allowed only in the Institutional Reporting Guide, not the HIPAA Implementation Guide used for claims. Even if this were changed, it would affect only the inpatient population, which represents only a small percentage of the population using health care services in a given time period. One possible strategy for broadening the population base for which race and ethnicity are captured, while minimizing the reporting burden on professional claims, would be to condition the reporting of race and ethnicity on outpatient visits to visits by new patients, based on CPT-4 Evaluation and Management codes.

Candidate recommendation 11: Race/Ethnicity Data for all Insureds

- *Modify existing mechanisms for reporting race & ethnicity of subscribers and dependents on the HIPAA enrollment transaction.*

Candidate recommendation 12: Race/Ethnicity Data for Patients

- *Investigate how best to capture race & ethnicity on a standard provider transaction.*

Communicating with patients in their **primary language** has been shown to produce better diagnosis and treatment decisions and to improve the likelihood that patients will understand and adhere to medical advice. Likewise, informational outreach efforts by payers to assure that beneficiaries know how to access covered services and patient education initiatives to foster effective self-management practices in preventive and chronic illness care rely on the ability to communicate effectively with members and patients in their preferred language. Thus, knowing a patient's primary language is a key factor in facilitating effective communication strategies, which, in turn, can affect a patient's compliance with their treatment plan and improve health outcome.

Candidate recommendation 13: Primary Language

- *Modify existing mechanisms for reporting the primary language of both subscribers and dependents on the HIPAA enrollment transaction.*



Building the Data and Information Infrastructure to Support Quality

The need for **common clinical terminologies** for EHRs has been identified as an important concern for both sharing clinical information among caregivers and using this information to measure quality of care. The Department of Health and Human Services has recently licensed SNOMED CT for use in the United States, and the Veterans Administration has recently announced an initiative to standardize terminologies across medical record systems within the VA delivery system. This example of federal leadership is to be applauded. However, such solutions need to be rapidly diffused into the private sector for major benefits to be realized. Further, the problem may take on new proportions as we move toward patient-held records where lay terminologies need to be considered if patients are to fully realize the benefits of such integrated, accessible records.

Candidate recommendation 14: Standard Clinical Terminologies

- *Adopt standard clinical terminologies, including a “crosswalk” or meta-thesaurus of clinical synonyms that can be used to consistently identify and describe clinical conditions, procedures, treatments and outcomes across electronic health records, administrative data and provider and patient surveys.*

Candidate recommendation 15: Common Patient Vocabulary

- *Promote the identification of lay terms that represent synonyms for standard clinical terms and that are easily comprehensible to patients of different cultures and educational attainment. Include these lay terminologies in the “crosswalk” or meta-thesaurus of clinical synonyms described above.*



The **adoption of ICD-10-CM** would help with the capture of more specific clinical information on disease severity, including complications, co-morbidities and risk factors. ICD-9-CM has exhausted the available codes for some health conditions, resulting in the assignment of new conditions and/or new manifestations of existing diseases to the “catch-all” category of *not elsewhere classified* within the most closely related disorder.

Risk adjustment also depends upon the adequacy of diagnosis coding systems for capturing relevant patient behavioral risks, such as smoking history, lack of exercise or poor dietary habits, all of which are more specifically defined in ICD-10-CM. Most other industrialized nations have already transitioned to ICD-10, requiring a painstaking crosswalk of diagnosis codes to make international comparisons of health system performance.

ICD-10-CM will address the current inadequacy of ICD-9-CM for expanding the clinical codes used to describe the various manifestations of diseases, health conditions and health risk behaviors. It will also provide greater specificity for ascertaining severity of disease for risk/severity adjustment of health outcomes and will enable international comparisons of quality of care and the sharing of best practices among nations that have adopted ICD-10.

In a November 5, 2003, letter to the Secretary, NCVHS recommended that the Department of Health and Human Services “initiate the regulatory process for the concurrent adoption of ICD-10-CM and ICD-10-PCS.”

Candidate recommendation 16: Expansion of Standard Clinical Codes for Diagnoses

- *Adopt ICD-10-CM for coding and classification of diagnosis and health conditions in administrative transactions.*



Inconsistent **coding of clinical procedures** across different care settings complicates the measurement of quality across the continuum of care. Even with the significant advances achieved through the adoption of standard administrative transactions under HIPAA, the persistence of different coding systems for procedures across the professional and institutional claims transactions creates formidable obstacles to the linkage, integration and aggregation of patient data across care settings. The proposed adoption of SNOMED-CT for EHRs will add to the difficulty. The multi-axial structures of both SNOMED-CT and ICD-10-PCS, add a layer of complexity to the aggregation of procedure data, although such aggregation can be accomplished in an electronic environment. Aggregation of procedure data based on CPT-4 and HCPCS procedure codes is even more difficult, due to the non-hierarchical structure of these coding systems. In addition, issues were raised in testimony about the measurement problems created by the routine deletion of CPT-4 and HCPCS codes, which complicates the identification of patients having procedures during a time period that spans or includes multiple years as well as the trending of procedure rates over time.

Aggregation of procedure data, based on *any* of the existing and proposed HIPAA standard procedure coding systems, would be greatly facilitated through the availability of a mechanism, such as an electronic crosswalk, for mapping these procedure codes across coding systems. Likewise, the use of such a crosswalk would greatly enhance the capability to identify patients who received the same or similar procedures for the purposes of measuring, monitoring/trending and improving quality of care.

The Uniform Medical Language System can facilitate the mapping of information about clinical procedures that are represented by different codes depending on the site of care or the type of electronic record (clinical or administrative). However, UMLS does not resolve the problem of inconsistent terminologies. As referenced more broadly in candidate recommendation 14, the development of common terminologies for procedures in clinical records that can be mapped to procedure codes used in administrative transactions would help to address this shortcoming.

Candidate recommendation 17: Mapping of Standard Clinical Codes for Procedures

- *Create a mechanism for efficiently mapping procedure codes across current and proposed HIPAA standard coding systems to facilitate querying and aggregating procedure information across care settings.*



Core functionality requirements for electronic health records should include functions that support population-based quality assessment and improvement as well as direct patient care. EHRs have tremendous capabilities to improve patient care and prevent medical errors through the incorporation of clinical decision support. They also have the potential to assist clinicians in population health management.

While most EHRs have extensive functionality to filter, sort and display a given patient's clinical information, few have strong capabilities for population-based analyses. Case-finding query capabilities and standard record formats for exporting patient data are important for generating population and disease registries, important functions for care management, quality measurement and quality improvement.

Candidate recommendation 18: Clinical Decision Support

- *Standard functionality requirements for electronic health records should include clinical decision support (e.g. guideline-driven data entry templates, reminders, prompts, and alerts), to facilitate the planning and delivery of evidence-based care to individual patients and groups.*

Candidate recommendation 19: Population-based query and reporting

- *EHRs should employ uniform data standards for core content and data storage formats to facilitate population health surveillance and reporting functions.*
- *EHRs should include functionality that “Supports continuous quality improvement, utilization review, risk management, and performance monitoring.”¹*



The lack of standards for **systems interoperability and data comparability** hinders the ability to integrate and interpret clinical data consistently across caregivers who may use different and incompatible EHRs. It also has delayed the adoption of EHRs by clinicians who are concerned that their chosen EHR will be incompatible with other record systems (e.g., their affiliated hospital) with which they wish to link in order to maximize the completeness of their patient records and the utility of their EHR system.

Likewise, the lack of **common record formats** for sharing relevant clinical information among caregivers could make it more difficult to do so under incompatible EHR systems than under traditional paper records. One example of such a record format, the Continuity of Care Record (CCR), has been developed through the collaboration of several medical professional associations and ASTM. This particular record format accommodates the sharing of core elements of a patient’s medical history (e.g. allergies, immunizations, active medications, active problem list, etc.) among caregivers. Adoption of the HL7 Clinical Document Architecture would also promote the exchange of clinical information among responsible parties.

Candidate recommendation 20: Interoperability of Clinical Data Systems

- *Develop standards for interoperability of electronic clinical data systems and EHRs and adopt a core set of output record formats that EHRs should be capable of exporting and importing to support care coordination and QA/QI.*



¹ HIMSS Electronic Health Record Definitional Model, Version 1.0, page 6, June 2003. www.himss.org.

Standard identifiers for patients and providers were identified as among the most important data elements required for linking patient records (11/99). Whether the capture of health outcomes is accomplished through administrative data and/or computerized patient records, the potential for improving quality measurement will still rely upon adequate record linkage capabilities, which depend heavily on the use of standard identifiers.

Consistent provider identifiers are needed for linking and aggregating performance data at the individual clinician, group or facility levels and for establishing accountability for processes and outcomes of care. The NPI, while only mandated for HIPAA administrative transactions, can serve this purpose for clinical data systems and provider surveys as well.

Candidate recommendation 21: Standard Provider Identifiers

- *HHS should recommend the adoption of the NPI as a consistent provider identifier in clinical data systems, EHRs, provider surveys and clinical record and reporting formats, as well as in HIPAA transactions. HHS should implement this recommendation within all federally funded health information systems.*

∞

Plans for a **unique patient identifier** have been sidelined, primarily due to privacy and confidentiality concerns. The need for this identifier was recognized in the HIPAA legislation passed in 1996, and that need persists today. The full benefits of administrative simplification will not be realized until standard patient identifiers are established. The lack of a unique patient identifier seriously limits the linkage of clinical records across care settings and health plans and impedes the identification and analysis of care episodes that span settings, providers or health benefit coverage arrangements. It also impedes electronic data exchange among clinicians who share responsibility for a patient's care and with patients in the context of a Personal Health Record.

Record linkage is necessary to obtain a complete picture of the quality of care a patient receives, since different providers in different care settings under different insurance mechanisms that utilize different insured or patient identifiers may render the various elements of recommended care. The recent trend toward greater vertical integration of health care systems, with shared information systems, can help to address this weakness, but greater data-sharing among caregivers and mechanisms for linking data across providers and care settings is needed to address the fragmentation problem. Some states have implemented comprehensive reporting requirements that permit the collection and linkage of data across providers and payers within a state. However, delays in the adoption of standard identifiers for patients and providers hamper record linkage.

Candidate recommendation 22: Voluntary Patient Identifier or Identifier Logic

- *Develop a voluntary, standardized Patient Identifier or Patient Identifier logic that, when authorized by the patient, can be used to link healthcare records for the same patient across payers, providers and care settings.*

∞

Balancing Patients' Interests in Quality and Confidentiality

Current misunderstandings about the HIPAA Privacy regulations foster a conservatism that may lead to even further reluctance to share health information about patients among caregivers and between caregivers and health plans.

As an example, health plans are expected by their accrediting body to assure that patients receive appropriate preventive care. While the measures that are used to determine a health plan's compliance with this requirement over the previous year look at care for individuals who were enrolled in the plan as of December 31st and who had been enrolled for at least one year, assessing compliance with preventive care guidelines frequently requires looking back in a patient's record for more than one year to determine if the service was provided within the recommended interval. Compliance

with screening guidelines for colorectal cancer requires a look back of 5 to 10 years, potentially encompassing periods during which the patient may not have been enrolled in that health plan. Similarly, the actual measurement of a patient's care during the previous year may not be initiated until 3 or 4 months into the following year, an interval during which the patient may have terminated their coverage with that health plan. Providers are often reluctant to provide clinical information for the period preceding the patient's coverage in that health plan and may refuse to provide *any* information for patients who are no longer enrolled in the plan.

Conversely, if a patient has remained with the plan and is found to be overdue for a particular preventive service, the plan may be reluctant to provide that information to the patient's primary care physician (PCP) if uncertain whether that doctor is still the patient's physician of record. With many physicians turning to health plans to help them populate the condition-specific patient registries that have been demonstrated to improve care management and health outcomes, plans' concerns about potentially sharing data with a physician who may no longer be the patient's PCP could severely constrain the implementation of an important quality improvement tool.

This problem impacts quality measurement, and can also negatively impact the quality of health care itself. Given the current malpractice climate and concerns over public accountability, providers and health plans could be caught in a "catch-22" whereby they're denied access to complete information about the services an individual has received or needs, yet held liable if that individual fails to receive recommended care in a timely manner.

Candidate recommendation 23: Clarify Privacy Protections

- *Examine privacy protections under existing federal law that inhibit access to and linkage of patient records across payers, providers and care settings for the purposes of care coordination and management and quality assessment and improvement. Revise and/or clarify current regulations to reduce these obstacles, while effectively balancing the best interests of patients and populations.*

∞

4. RELEVANT PRIVATE AND PUBLIC SECTOR INITIATIVES

A number of initiatives that are ongoing, planned, or recently completed, operating in both the public and private sectors, can affect health data systems in a manner that would facilitate implementation of the candidate recommendations laid out in this report. This section touches on a number of these. While the list is certainly not complete, it includes activities that are currently the most promising. While all quality-assessment initiatives, such as those required or promoted by organizations such as NCQA, JCAHO, NQF, FAACT and LEAPFROG, support the case for improved data for quality measurement, particular emphasis has been given to those initiatives that not only depend on secondary or administrative data for their initiative but also are actively working to improve the quality of those data. These activities are listed in roughly chronological order, starting with short-term and very current activities, followed by those that are more long-term. Relevant initiatives are also included in the Summary Matrix in the Executive Summary.

Institute of Medicine (IOM) Health Care Quality Initiative

As noted earlier, the IOM's Committee on Quality Health Care in America has undertaken an initiative to identify and describe the challenges to the nation's health care quality and to recommend changes to address those challenges. To date, the Institute (in conjunction with work by other IOM Committees) has completed and released at least seven separate studies, many of which speak directly to the issues raised in the present report. *To Err is Human* and *Crossing the Quality Chasm* have already been described in detail. In addition to these, two other reports focus on improving the information and communications technology infrastructure to improve the safety, quality and efficiency of care. They are *Fostering Rapid Advances in Health Care: Learning from System Demonstrations* (2002) and *Key Capabilities of an Electronic Health Record* (2003).

The latter report, *Key Capabilities*, was requested by DHHS, which charged the IOM with development of an EHR functional model by identifying core care delivery-related functionalities. Health Level 7 (HL7) will further specify these functionalities and incorporate them into the model. The report recommends that the EHR should include

certain critical data items, including medical and nursing diagnoses, a medication list, allergies, demographics, clinical narratives and laboratory test results, both current and past. Also recommended is the use of standardized clinical terminologies to facilitate real-time monitoring and feedback of provider performance, particularly when this entails data summarization across multiple and diverse sources.

Consolidated Health Informatics Initiative

The Consolidated Health Informatics (CHI) initiative is part of the 2002 e-Gov Strategy which uses improved Internet-based technology to make it easier and more cost-effective for citizens and businesses to interact with the government. The CHI initiative is establishing a portfolio of existing clinical vocabularies and messaging standards enabling federal agencies to build interoperable federal health data systems; participating federal agencies include Health and Human Services (HHS), Veterans Affairs (VA), Department of Defense (DOD), Social Security Administration (SSA), General Services Administration (GSA) and National Institute of Science and Technology (NIST).

In March, 2003, HHS, DOD and VA announced the first set of uniform standards for the electronic exchange of clinical health information to be adopted across the federal government; these standards are 1) HL7 messaging standards for activities such as order entry, scheduling, and admission/discharge/transfer of patients; 2) Laboratory Logical Observation Identifier Name Codes (LOINC) to standardize the electronic exchange of clinical laboratory results; 3) Institute of Electrical and Electronics Engineers 1073 (IEEE 1073) connectivity standards to facilitate telehealth as well as other activities; 4) Digital Imaging Communications in Medicine (DICOM) standards for transmission of images and other diagnostic information between devices; and 5) National Council for Prescription Drug Programs (NCPDP) standards for retail pharmacy transactions. Work groups were deployed to develop recommendations for nineteen additional domains, including medications, diagnosis/problem lists, demographics, population health, and history and physical. Reports were produced on all nineteen domains, although in some cases the CHI recommendation was not to adopt a standard at this time. The NCVHS commented on all of the reports in three letters to the Secretary (September and November 2003 and January, 2004) and concurred with the

CHI recommendations, endorsing formal government adoption where appropriate. These standards will further a number of the topics addressed by this report, including vital signs (history and physical), race/ethnicity (demographics), test results, and diagnosis modifiers (diagnosis/problem list).

Continuity of Care Record (CCR) Data Standards

The Continuity of Care Record is a proposed XML document standard for minimum data needed to ensure access to a patient's information across several care settings. A draft proposal for a CCR standard was released in December, 2003, by the American Society for Testing and Materials (ASTM) International, the Health Information Management and Systems Society (HIMSS), the American Academy of Family Physicians (AAFP) and the Massachusetts Medical Society (MMS). The standard covers seven categories of mandatory data elements, including patient-identifying information, insurance and financial information, advanced directives, patient health status, care documentation and recommendations for care (care plan). The health status element includes vital signs, lab results, procedures/assessments, including procedure time and provider, and diagnoses, problems and conditions, including date of onset and status; these correspond to candidate recommendations of this report. In addition, while the CCR is not meant as a substitute for an EHR, it is one component of a comprehensive electronic medical record standard, currently being developed by HL7 and HIMSS.

Consumer/Purchaser Disclosure Project

The Consumer/Purchaser Disclosure Project is a coalition of consumer, labor and purchaser organizations that is working to develop a set of standardized performance measures for hospitals, providers and treatments. An initial set of standardized hospital quality measures has now been adopted by the National Quality Forum (NQF) and the Centers for Medicare and Medicaid Services (CMS); CMS has also begun work on a standardized hospital patient experience survey. A proposal has been presented to the National Uniform Billing Committee (NUBC) to add six data elements to the standard hospital bill for inpatient services (UB-04); these elements represent information that the Disclosure Project believes are essential to crafting more performance-sensitive provider payment methods. They include a number of the data elements recom-

mended by this report: a flag for each secondary diagnosis, indicating whether the condition was present on admission; a unique physician identifier for each coded procedure; vital signs recorded at presentation; key lab values; and time of day of admission, discharge and each procedure.

Bridges to Excellence

Bridges to Excellence (BTE), is based on the recommendations issued by the IOM report *Crossing the Quality Chasm*. In that report, the IOM encourages realignment of payment for care as an incentive for higher quality of care (pay for performance) and investment in clinical information technology to prevent medical errors, improve clinical decision-making and facilitate accountability for quality. One of the BTE programs, currently underway with funding from the Robert Wood Johnson Foundation and implemented by the National Committee for Quality Assurance (NCQA), MedStat and Michael Pine and Associates, Inc., is called Physician Office Link. **Physician Office Link** enables physician office sites to qualify for financial bonuses based on their implementation of specific office-based processes to reduce errors and increase quality; processes focus heavily on the development of electronic clinical data systems that have been shown to improve patient care.

eHealth Initiative

Public and private entities are collaborating through the eHealth Initiative to drive improvement in the quality, safety, and cost-effectiveness of health care through information. The Initiative operates through broad membership including accrediting groups and quality improvement organizations; employers and purchasers; health systems, hospitals, and physician organizations; payers; public health; academia; and standards organizations. One of its strategic priorities is to lay the foundation for an interconnected, electronic health information infrastructure by promoting the adoption of clinical data standards and interoperability. The activities of the Initiative include: 1) the adoption of interoperable systems and standards to facilitate the use of information technology in health and healthcare; and 2) the adoption and alignment of incentives to promote an interoperable, interconnected electronic health information infrastructure.

Public-Private Sector Collaboration for Public Health

Launched by the eHealth Initiative in November 2002, this Collaboration brought together public health, providers and standards organizations to develop and implement strategies for reporting public health data using interoperable standards, to promote and accelerate an interconnected, electronic health information infrastructure.

Connecting for Health

Connecting for Health is a public/private initiative that was convened by the Markle Foundation in late 2002 as an outgrowth and broadening of the Public-Private Sector Collaboration for Public Health. The work of Connecting for Health is organized via three Working Groups, operating in the areas of standardization, privacy and security, and personal health.

The Data Standards Working Group has developed and established consensus on a core set of data and communication standards and protocols for the sharing of health-care information. It has drafted three HL-7 implementation guides, focusing on: 1) standardized reporting of clinical microbiology data; 2) standardized reporting of limited information about reasons for health care encounter (chief complaint); and 3) standardized laboratory, pharmacy and supply order messaging, which could include a broad spectrum of diagnostic testing and clinical observations, including vital signs. In September 2002, the Steering Group, which exercises oversight over the three Working Groups, agreed on the voluntary adoption of these data standards and communication protocols. The U.S. Government announced its adoption of HL-7 messaging standards in March of 2003.

In addition, the Personal Health Working Group identified the essential characteristics of a personal health record, and Connecting for Health announced formation of the Healthcare Collaborative Network (HCN), a demonstration project that brings together major health care systems and hospitals, federal health agencies (Centers for Disease Control and Prevention, Centers for Medicare and Medicaid Services), and healthcare IT suppliers, to show how electronic communications can help patients receive neces-

sary and timely medical treatment and guard against medical errors, incorrect prescriptions and adverse drug events.

Electronic Health Record (EHR) Collaborative

The EHR Collaborative brings together provider organizations, payers, accrediting organizations, IT suppliers and managers, and public sector agencies, including public health. The Collaborative focuses on advancing the adoption of information standards for healthcare. Most recently, it has employed its resources to facilitate a series of open forum meetings to gather feedback on the EHR functionality standards being developed by HL7, in response to the IOM Report *Key Capabilities of an Electronic Health Record* (see above). The proposed HL7 EHR functionality standard is currently being voted on. DHHS expects to have a model record (EHR) ready in 2004.

Public Health Data Standards Consortium (PHDSC)

The Consortium was founded in 1998, to examine the implications of HIPAA for public health practice and health services research. During the intervening years, the Consortium has represented these two groups in a variety of data standards-setting processes, including the National Uniform Billing Committee and the National Uniform Claims Committee (standards setting groups for institutional and provider health care claims, respectively), HL7, and X12.

The Consortium continues in the forefront of public sector initiatives to improve the quality of health care data in support of public health goals, including improved healthcare quality and population health. Recently, the Consortium convened an Ad Hoc Task Force to bring public health and research perspectives to the effort to develop the HL7 functional model for the EHR.

Current initiatives by the Consortium include maintenance and promotion of the Health Care Service: Data Reporting Guide, which provides a national standard, based on the HIPAA-compliant 837 institutional claim standard, for institutional health care service information (hospital discharge registry data), in support of quality measurement, community assessment, surveillance and other comparative studies. The Guide includes some of the data items recommended by the present report and required by

many states for their hospital discharge registries, but not by HIPAA for electronic filing of an institutional claim. These data items include race/ethnicity and secondary admission diagnosis flag.

In addition, the Consortium is working with the National Center for Health Statistics and the National Association for Public Health Statistics and Information Systems on a standard for electronic exchange of vital records data, a critical source of outcomes and quality of care data. The Consortium also is supporting the standardized collection and management of data within public health categorical domains and data integration between domains (e.g., external cause-of-injury data; environmental and clinical data related to childhood lead poisoning; immunization records; and communicable disease data, among others).

CMS Quality Initiative

In November 2001, HHS Secretary Thompson announced the Quality Initiative, the Department's commitment to assure quality health care for all Americans through accountability and public disclosure. The primary objectives for the Quality Initiative are to (a) empower consumers with quality of care information to make more informed decisions about their health care, and (b) stimulate and support providers and clinicians to improve the quality of health care. In accord with Secretary Thompson's commitment, CMS launched the CMS Quality Initiative nationally in 2002; one component is the Physician Focused Quality Initiative, to better assess the quality of care for key illnesses and clinical conditions and support clinicians in providing appropriate treatment of those conditions. This Initiative includes the Doctor's Office Quality (DOQ) Project, the Doctor's Office Quality Information Technology (DOQ-IT) Project and several demonstration projects, including the Care Management Performance Demonstration, a pay-for-performance pilot to promote adoption and use of health information technology by physicians. This and other pay-for-performance projects (such as Bridges to Excellence) help make the business case for investment in improved data infrastructure, to improve both clinical decision-making, care management and quality assessment capacity. The DOQ-IT Project is currently considering ways to encourage adoption of provider office-based IT systems and provider-to-provider electronic data transmission, to improve the quality of care, particularly for

patients with chronic disease; this supports the concept of interoperable electronic clinical data systems and standardized core output record formats (Candidate recommendation 20).

American Medical Association: Performance Measures Advisory Group

The American Medical Association (AMA) CPT coding system for reporting medical services and procedures has recently been expanded to include Category II CPT codes. These are supplemental tracking codes used for performance measurement, and are overseen by the Performance Measures Advisory Group (PMAG), an advisory body to the CPT Editorial Panel. The PMAG plays an important role in promulgating these codes, which are necessary to support the type of administrative data-dependent quality reporting required by CMS' DOQ Project, among others.

Health Insurance Portability and Accountability Act (HIPAA)

As “rollout” of the regulations mandated under HIPAA continues, the rules for administrative transaction standards and the Privacy Rule have now been implemented and speak directly to several of this report’s candidate recommendations. In addition, in February 2002, NCVHS issued recommendations for PMRI message format standards. In 2003, DHHS Secretary Thompson announced that those standards would be adopted by the federal government as part of the federal government’s eGov initiative, within the context of the National Health Information Infrastructure (NHII). In November 2003, NCVHS made recommendations for PMRI terminology standards, consistent with the work of the Consolidated Health Informatics Initiative described earlier. In January 2004, DHHS announced the National Provider Identifier (NPI) standard for use in HIPAA transactions. Broad adoption of the NPI for administrative transactions will facilitate expansion of this standard identifier to clinical data systems, as proposed in Candidate recommendation 21.

5. NEXT STEPS FOR THE NCVHS QUALITY WORKGROUP

As a federal advisory body, the National Committee on Vital and Health Statistics has historically contributed to the evolution of health information policy by identifying broad trends, convening and working collaboratively with key stakeholders, and encouraging convergence among potentially complementary efforts. The Committee intends to work in the same manner toward needed improvements in health care quality measurement.

As noted, the findings presented in this report summarize the experience and insights of a broad range of experts in the health care quality field. Strong input from the purchaser/payer community, whose increased interest in quality is an important trend, is also reflected. The candidate recommendations that have been put forward to address specific data needs now become part of the agendas of the relevant NCVHS subcommittees and workgroups, for prioritization and future action.

The next critical step is to solicit stakeholders' views on the achievability and value of each one. The process will include hearings and other interactions through which stakeholders and experts will be asked to share their views and expertise with the Committee. For example, the Quality Workgroup will conduct a hearing in June on the first eight candidate recommendations and plans to co-sponsor hearings with the Subcommittee on Populations later in 2004 on the collection of race and ethnicity data and survey approaches, following up on candidate recommendations 9 through 13. In addition, input will be needed to ascertain the most effective and efficient ways to align the data needs for measures used for improvement within clinical care settings with those used by payers for evaluation and those used by consumers and patients facing healthcare decisions. The Committee attaches priority to encouraging a convergence between those working toward data standards and a strong health information infrastructure and those working to improve quality measurement and health care delivery and outcomes.

Finally, the Workgroup will watch with interest the many complementary initiatives outlined in the previous section, and it will continue to advise the Secretary on the HHS strategic objectives related to health quality measurement and improvement.

APPENDIX

Presentations

to the National Committee on Vital and Health Statistics on Data Needs for Quality Measurement and Improvement

1996 through 2002*

July 25, 2002: Workgroup on Quality Hearing, National Healthcare Quality

Report

- Walter Suarez, National Association of Health Data Organizations
- David Bergman, FACCT/Child and Adolescent Health Measurement Initiative
- Jerod Loeb, JCAHO
- Paul Conlon, American Hospital Association
- Jim Mortimer, Midwest Business Group on Health

June 26, 2002: Measuring quality of mental health/substance abuse services

- Eric Goplerud, SAMHSA
- Mady Chalk, CSAT
- Phillip Renner, NCQA
- Constance Horgan, Washington Circle Group
- Sue Eisen, Boston University for the ECHO Survey Research Team
- Pamela Greenberg, American Managed Behavioral Healthcare Association (AMBHA)
- Suzan Lumpkin, Magellan/AMBHA
- Vijay Ganju, NASMHPD Research Institution

December 12, 2001: Safety Initiatives

Public/Private Sector Safety Initiatives

- Jim Battles, AHRQ
- Noel Eldridge, Veterans Administration
- Janet Corrigan, IOM
- Alan Vaida, Institute for Safe Medication Practices [Susan: this is a Private Sector organization that has partnered with the FDA in sharing data on medication errors—you could list it here or under the next heading]

Private Sector Safety Initiatives

- Suzanne Delbanco, The Leapfrog Group

June 27-28, 2001

1. **Racial and Ethnic Minorities**
 - Carolyn Clancy, AHRQ
 - Olivia Carter-Pokras, HHS Office of Minority Health
 - David Nerenz, Michigan State University
2. **Patient Safety Task Force**
 - Gregg Meyer, AHRQ
3. **National Quality Forum and IOM National Quality Report**
 - Kenneth Kizer, National Quality Forum
 - Janet Corrigan, IOM
 - Thomas Reilly, AHRQ

September 19-20, 2000: Briefings on Quality of Care Data Issues

- Margarita Hurtado, IOM

February 23-24, 2000: IOM Report and AHRQ Response

- Janet Corrigan, IOM
- Gregg Meyer, AHRQ

January 24, 2000: Subcommittee on Populations Hearings on Functional Status Assessment, Panels on Functional Status and Health Status Measurement

- Robert L. Kane, University of Minnesota
- Donald Lollar, CDC
- Nancy Whitelaw, The National Council on the Aging
- Gretchen Swanson, Western University of Health Sciences
- Jinnet Fowles, HealthSystem Minnesota
- Margaret Stineman, University of Pennsylvania
- Ruth Stein, Albert Einstein College of Medicine
- Alice Kroliczak, HRSA
- Gerry Hendershot, NCHS
- Paul Placek, NCHS
- Allan Meyers, Boston University

November 3, 1999: Workgroup on Quality hearing (breakout session)

1. **Limitations in existing data sources for health plans and medical groups**
 - Elizabeth McGlynn, RAND Corporation
 - Joshua Seidman, NCQA
2. **Experiences with data limitations in California; current initiatives around data improvement**
 - Richard Dixon, The Lewin Group
 - Mark Smith, California Health Care Foundation

3. Issues of data or design limitations in developing measures for use across populations or in health care delivery systems

- Carolyn Cocotas, Performance Measures Coordinating Council
- Joshua Seidman, NCQA
- Steve Clauser, HCFA

June 23-24, 1999: Panel, Data for Measuring Quality of Care

- Gregg Meyer, AHRQ
- Steve Clauser, HCFA
- Nancy Peterson, VA

June 23, 1999: Panel, Collection of Race/Ethnicity Data on HIPAA Transactions

- Jerry O'Keefe, NAHDO/MA Div. of Health Care Finance & Policy
- Anne Elixhauser, AHCPR
- Jinnet Fowles, HealthSystems Minnesota
- Paul Cheng, Union Health Center
- J. Emilio Carrillo, NY Hospital Community Health Plan
- Anthony Knettel, ERISA Industry Committee (ERIC)
- Violet Woo, Office of Minority Health
- Ed Woo, Office of the General Counsel
- Nancy Krieger, Harvard School of Public Health

January 22, 1999: Subcommittee on Populations Hearings on Data and Quality Issues in Post-Acute Care

- Robert L. Kane, University of Minnesota
- Korbin Liu, Urban Institute
- Andrew Kramer, University of Colorado
- Arthur Webb, Village Care, NY
- Henry Ireys, Johns Hopkins University
- David Zimmerman, University of Wisconsin
- Sue Nonemaker, Health Care Financing Administration, DHHS
- Karl Kilgore, Integrative Health Services
- Lee Hargraves, The Picker Institute

September 15-16, 1998: Update Following the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry

- Nancy Foster, AHCPR

June 16-17, 1998 (Creation of Workgroup on Quality of Care)

1. Auditing Quality of HEDIS data

- Paul Elstein, HCFA

2. Comments on Quality Commission Final Report

- Barbara Starfield, NCVHS and Johns Hopkins School of Public Health
- Kathryn Coltin, NCVHS and Harvard Pilgrim Health Care

April 15, 1998: Subcommittee on Populations, Boston, MA

1. Quality of Care and Medicaid Data Panel

- Carol Tobias, Medicaid Working Group
 - Diane Flanders, MA Division of Medical Assistance
 - Bruce Landon, Harvard Medical School
 - Representative Harriet Chandler, Joint Committee on Health Care of the MA Legislature
2. Policy, Data and Quality: State Perspective Panel, MA Division of Medical Assistance
- Mary Beth Fiske
 - Anthony Ascitutto
 - Marjorie Porell

March 4, 1998

1. **President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry**
 - Richard Sorian, Deputy Director, President's Advisory Commission
2. **Data Quality Issues**
 - Kathryn Coltin, NCVHS and Harvard Pilgrim Health Care
 - Paul Elstein, HCFA
 - James Tierney, NCQA
 - Arnold Milstein, Pacific Business Group on Health

February 10, 1998: Subcommittee on Populations, Arizona AHCCS Program, Medicaid Managed Care Project

Quality Indicators Panel

- Juman Abujbara, MD
- Susan Cypert
- Alan Schafer

January 13, 1998: Subcommittee on Populations, Hearings on Data Needs for Monitoring Performance in Medicaid Managed Care

1. Legislative, Consumer and Advocacy Panel
 - Robert Griss, Center on Disability and Health
 - Rep. Lee Greenfield, Chair, Human Service Finance Division, Minnesota
 - Chery Fish-Parcham, Families USA
2. State Panel
 - Nancy Clarke, Oregon
 - Lori Ranbom, Ohio
 - Bob Brewer, Nebraska
3. Health Plan Panel
 - Kathryn Coltin, NCVHS and Harvard Pilgrim Health Care
 - Donald Umlaw, Health Partners of Arizona
 - Eileen Peterson, United Health Care
 - Michael Collins, University of Maryland, Baltimore

November 14-15, 1996: Research, Public Health, and Quality Assurance Panel

- Margaret Van Amringe, JCAHO
- Margaret O’Kane, NCQA
- Korbin Liu, Urban Institute
- Mark Epstein, National Association of Health Data Organizations

** (All presentations were to the full Committee unless otherwise indicated.)*