An Ethical Force Program™ *Consensus Report*

Improving Communication—Improving Care

How health care organizations can ensure effective, patient-centered communication
with people from diverse populations

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Every organization in a health care system must communicate complex information to a wide range of people. Communicating complex information clearly and effectively is a challenge, but it is critical for ethical, high-quality health care. Many people who read or hear standard health information do not fully understand it. In the United States today:

■ More than 22 million people speak English less than "very well."

■ More than 34 million people were born in another country.

■ More than 95 million people have literacy levels below what they need to understand even basic written health information, such as how often to take a medicine.

Many leaders of organizations throughout the health care system understand that cultural beliefs and values, linguistic diversity, literacy levels and other issues can affect the quality of health care communication. And poor quality communication can affect health outcomes and the long-term success of health care businesses.

Taking a patient-centered approach to health care communication can help an organization's staff and leaders learn about the communication needs of the individuals and groups they serve. A patient-centered approach will also help an organization find the right ways to meet these needs. *Patient-centered communication is respectful of and responsive to a health care user's needs, beliefs, values and preferences.* Defined in this way, patient-centered communication is not just about patient-doctor conversations, it is an element of any ethical, high-quality health care interaction *(see Box)*.

The goal of this report is to help health care organizations communicate better. To do this, the report describes why communication is important and how an organization can take steps to ensure good communication. Organizational performance is separated into six main areas and three subareas. Within organizations, quality improvement efforts to promote patient-centered communication could focus on any or all of these interrelated areas.

Example: Patient-Centered Communication

A Puerto Rican man was hospitalized in an intensive care unit on a ventilator. His prognosis was very poor and his family was asked whether he would want to be removed from the ventilator. This already difficult decision was made even more complex because his family included almost 40 people, half of whom spoke English and half of whom spoke only Spanish. Both family groups were having a hard time understanding what was going on and the non-English speakers did not fully trust that the English-speaking family members were telling them the whole story.

Before the situation got out of control, however, one of the patient's nurses contacted the hospital's Cross-Cultural Communication Department. Outreach workers and interpreters worked with clinical staff to explain the situation to the family in both languages and in clear, simple terms that everyone could understand. Each family group designated a spokesperson who could ask questions, express concerns and contribute to the final decision. When the final decision was made, all the family members agreed that it was the right one.

Patient-centered communication is not just about patient-doctor interactions. In this case, a hospital used community and professional resources, and verbal, written and nonverbal communication that focused on the cultural, linguistic and emotional needs of the family, to reach a patient-centered health care decision.

1. *Understand your organization's commitment.* An organization should routinely examine its commitment, capacity and efforts to meet the communication needs of the populations it serves, including leadership involvement; mission, goals and strategies; policies and programs; budget allocations; and workforce values.

2. *Collect information.* An organization should use standardized qualitative and quantitative collection methods and uniform coding systems to gather valid, reliable information for understanding the demographics and communication needs of the populations it serves.

3. *Engage communities.* An organization should make demonstrable, proactive efforts to understand and reach out to the communities it serves, including establishing relationships with community groups and developing opportunities for community members to participate in shaping organizational policies.

4. *Develop workforce.* An organization should ensure that the structure and capability of its workforce meets the communication needs of the populations it serves, including by employing and training a workforce that reflects and appreciates the diversity of these populations.

5. *Engage individuals.* An organization should help its workforce engage all individuals, including those from vulnerable populations, through interpersonal communication that effectively elicits health needs, beliefs and expectations; builds trust; and conveys information that is understandable and empowering.

    5a. *Socio-cultural context.* An organization should create an environment that is respectful to populations with diverse backgrounds; this includes helping its workforce understand socio-cultural factors that affect health beliefs and the ability to interact with the health care system.

    5b. *Language.* An organization should determine what language assistance is required to communicate effectively with the populations it serves, make this assistance easily available and train its workforce to access and use language assistance resources.

    5c. *Health literacy.* An organization should consider the health literacy level of its current and potential populations and use this information to develop a strategy for the clear communication of medical information verbally, in writing and using other media.

6. *Evaluate performance.* An organization should regularly monitor its performance with regard to each of the prior content areas using structure, process and outcome measures, and make appropriate adjustments on the basis of these evaluations.

This report lists a number of specific, measurable expectations for performance in each of these areas. Organizations can use these performance expectations as a framework for evaluating performance and a guide for quality improvement in patient-centered communication.

Each individual performance expectation is designed so that almost any organization can meet it.

Although each expectation is met by some health care organizations, few organizations currently meet all of the expectations. Communication is a complex topic and this report addresses many different aspects of communication. Organizations should use the report as a map to identify areas of strength and weakness and to help focus resources on the areas most in need of improvement.

In the next phase of its work on patient-centered communication, the Ethical Force Program is field testing an organizational self-assessment toolkit. The toolkit is based on the performance expectations listed in this consensus report and will provide organizations with specific recommendations for where to focus quality improvement initiatives.

Which Organizations?

The performance expectations in this report are meant to be relevant to a wide variety of organizations involved in health care. Most will be directly applicable to hospitals, physician practices, pharmacies, health plans and other providers. But several should also be relevant to government agencies, patient advocacy groups, employers and other health plan purchasers, groups concerned about community health such as senior centers, YMCAs, and faith-based organizations, and commercial or noncommercial providers of health information, such as health information Web sites. Each of these organizations has a responsibility to provide its audience with clear, understandable information about health care.

Even organizations that do not directly serve "patients" can use patient-centered concepts to guide communication with customers, enrollees or employees, all of whom are potential patients. For example, an employer that offers health insurance can improve communication about health insurance options, disease prevention, healthy lifestyles and other topics by using an approach that solicits feedback from the intended audience and considers the audience's needs, beliefs, values and preferences.

Which Populations?

Clear communication is always important in health care, to every individual and population. However, in certain cases, specific communication challenges are regularly encountered and can be identified. These challenges make some individuals and populations more vulnerable to gaps in effective communication. This report describes why communicating effectively about health care relies on understanding three factors—the audience's culture, language, and health literacy skills. Populations whose members have limited or no English proficiency, a culture that is not well understood by personnel in the organization and/or limited health literacy skills are referred to as "communication-vulnerable" populations. The report provides specific expectations for addressing potential communication gaps with these populations *(see especially Content Areas 5a: Socio-Cultural Context, 5b: Language, 5c: Health Literacy)*.

The Ethical Force Program™ was initiated in 1997 to improve health care by advancing ethical behavior among all participants in the health care system. It is a collaborative research program directed by an Oversight Body of 21 leaders from organizations representing the major stakeholders in the health care system. Among other activities, the program uses a standardized, consensus-building process to create self-assessment toolkits that are practical, inexpensive and ready-to-use. These toolkits are based on consensus reports, such as this one, and they are designed to help health care organizations evaluate internal climate and target quality improvement efforts in specific domains that are critical to ethical, high-quality health care. For more, see *www.EthicalForce.org*

ACGME	Accreditation Council for Graduate Medical Education
ACP	American College of Physicians
ADA	Americans with Disabilities Act
AHA	American Hospital Association
AHIP	America's Health Insurance Plans
AHRQ	Agency for Health Care Research and Quality
AMA	American Medical Association
AMA CEJA	American Medical Association Council on Ethical and Judicial Affairs
AMAF	American Medical Association Foundation
ANA	American Nurses Association
APhA	American Pharmacists Association
ASHP	American Society of Health-System Pharmacists
ATSDR	Agency for Toxic Substances and Disease Registry
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CDC	Centers for Disease Control and Prevention
CHIA	California Healthcare Interpreters Association
CLAS	Culturally and Linguistically Appropriate Services
CMS	Centers for Medicare and Medicaid Services
CMWF	The Commonwealth Fund
EFOB	Ethical Force Program Oversight Body
HEDIS	Health Plan Employer Data and Information Set
HRET	Health Research and Educational Trust
IOM	Institute of Medicine
IRB	Institutional Review Board
Joint Commission	Joint Commission on Accreditation of Healthcare Organizations
LEP	Limited English Proficient
MMIA	Massachusetts Medical Interpreters Association

NBGH	National Business Group on Health
NCCC	National Center for Cultural Competence
NCES	National Center for Education Statistics
NCHS	National Center for Health Statistics
NCIHC	National Council on Interpreting in Health Care
NCI	National Cancer Institute
NCQA	National Committee for Quality Assurance
NHeLP	National Health Law Program
NICHQ	National Initiative for Children's Healthcare Quality
NPHHI	National Public Hospital and Health Institute
NQF	National Quality Forum
NRC	National Research Council
QISMC	Quality Improvement System for Managed Care
REALM	Rapid Estimate of Adult Literacy in Medicine
SCHIP	State Children's Health Insurance Program
TOFHLA	Test of Functional Health Literacy in Adults
U.S. DHHS	U.S. Department of Health and Human Services
U.S. DHHS HRSA	U.S. Department of Health and Human Services Health Resources and Services Administration
U.S. DHHS OCR	U.S. Department of Health and Human Services Office for Civil Rights
U.S. DHHS OMH	U.S. Department of Health and Human Services Office of Minority Health
U.S. DOJ	U.S. Department of Justice

Introduction

Patient-centered communication is important to ethical, high-quality health care. This report explains why. It also provides a framework and a set of expectations for health care organizations that want to assess their performance and design quality improvement initiatives around patient-centered communication.

It is often easy to see the link between effective communication and high-quality health care (Stewart 1995, Roter and Hall 1993). Patient satisfaction increases when communication is clear, understandable and respectful (Morales et al. 2006, Beach et al. 2005, Wanzer et al. 2004, Williams et al.1998b). Gaps or lapses in communication between health care professionals and patients, or among health care professionals, can lead to medical errors and unexpected outcomes (Hughes et al. 2005, Wilson et al. 2005, Forster 2005, Poon et al. 2004, Woolf 2004, Gandhi 2000). Patients who understand medication and treatment instructions are more likely to adhere to therapy and return for follow-up care (Jacobs et al. 2004, DiMatteo 1994). And, as self-management of complex chronic illness becomes more important to health care, effective communication becomes more important to long-term health outcomes (Ashton et al. 2003, Williams et al. 2002).

In addition, ethical health care is built around relationships. Relationships in health care often hold special

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> **In Summary:** The goal of this report is to set out specific expectations for the ethical actions of health care organizations that will promote patient-centered communication.
>
> - Ethical health care means that all people have opportunities to participate in making decisions about their own health and receive appropriate, high-quality care.
>
> - Patient-centered communication is respectful of and responsive to a person or population's needs, beliefs, values and preferences.
>
> - Patient-centered communication contributes to ethical, high-quality health care because it helps ensure that people have the information they need to make informed decisions and take part in their own care.

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meaning, beyond just provider-consumer interactions. This is, in part, because of the personal nature of many health care communications (Hall et al. 2001, Veatch 1991). When health care professionals and patients cannot communicate effectively, the health care relationship suffers.

- Ineffective or disrespectful communication prevents patients from participating in decisions that affect their well-being.

- The right to informed consent depends on effective communication of complex information.

- Trust in health care relies on clear communication (Thom 2000).

- Shared decision making, a promising model for effective patient-clinician relations, requires good communication (Charles et al. 2003).

- Respect for patients, sometimes in very vulnerable situations, drives ethical standards that call for truth telling and patient involvement in decisions about their own care (AMA Opinions 8.12, 8.121, 10.01).

For all of these reasons, patient-centered communication is not only a key to high-quality health care, but it is critical to the ethical quality of health care *(see also Appendix B: Ethics and Patient-Centered Communication)*.

Focus populations. This report focuses on populations that have an elevated risk of experiencing communication gaps *(see definitions below)* when they interact with health care organizations that are not attuned to their communication needs. Common examples include populations whose members have limited or no English proficiency, a culture that is not well understood by personnel in the organization and/or limited health literacy skills.

- The Institute of Medicine and others have found that one important root cause of unequal treatment and outcomes among minority populations is ineffective communication (Taylor and Lurie 2004, IOM 2003).

- Because of the link between effective communication and quality care, it follows that these populations suffer from health care disparities (Morales et al. 2006, AHRQ 2004, Freimuth and Quinn 2004, Johnson et al. 2004).

When an issue—like patient-centered communication—is of great importance to the ethical quality of health care, the Ethical Force Program™ believes the issue should be carefully studied, standard expectations for performance developed, and tools for self-assessment and monitoring of health care organizations made available. This report achieves the first two of these three goals. It also provides a framework that the Ethical Force Program will use to create a self-assessment toolkit (the third goal) during the next phase of it its work on patient-centered communication.

Defining Key Terms

For purposes of this report we have adopted the following definitions.

Communication gaps: Instances of misunderstanding between a health care organization or a health care professional and the individual or population they are serving. This can happen because the communication is unclear or too complex, if one party is distracted, when the communication is in a language unknown or otherwise inappropriate, or for many other reasons. Communication gaps can occur when communication is written, verbal or of another type.

Communication-vulnerable populations: Populations at risk of experiencing communication gaps. Communicating effectively about health care relies on understanding three factors—the audience's culture, language, and health literacy skills. Therefore, populations whose members have limited or no English proficiency, a culture that is not well understood by personnel in an organization and/or limited health literacy skills should be considered communication-vulnerable.

Health care organizations: Any organization that plays a role in the provision, coordination or financing of health care. Many such organizations are direct providers of clinical care, but others provide health-related services such as insurance, pharmaceuticals, other health care products or other forms of customer care. In addition, many of this report's expectations are relevant to organizations that develop educational and informational materials for patients, such as federal agencies (e.g., the National Institutes of Health, the Centers for Disease Control and Prevention), state governments and commercial or noncommercial providers of health information (e.g., health information Web sites).

Health literacy: The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions (IOM 2004a, Selden et al. 2000).

Patient-centered communication: Communication that is respectful of and responsive to a health care user's needs, beliefs, values and preferences. Any communication that affects health care users can be patient-centered, including oral, written and nonverbal communications between individuals and practitioners, individuals and health care organizations, and between and among health care practitioners and health care organizations (*See Appendix A: What is Patient-Centered Communication?*).

Socio-cultural context: The combined force of a person or population's culture, background and socio-economic status. Culture is defined as "the thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious or social groups" (U.S. DHHS OMH 2001).

Background: The Ethical Force Program

Ethical standards in health care are important because caring for people's health is not only a large and diverse business, it is a moral enterprise that requires the trust of the individuals and populations served (Wynia 1999). As health care becomes increasingly complex, with more and more stakeholders involved, its ethics become more challenging too. Today, each participant in health care delivery is strongly affected by the ethical standards of many other participants. If we hope to build and maintain trust in the system as a whole, its various stakeholders must work together to develop shared ethical standards, clear expectations of ethical performance, and methods of ensuring accountability to these performance expectations. The purpose of the Ethical Force Program is to accomplish these challenging tasks.

The Ethical Force Program was created, in part, because medical ethics alone cannot guarantee high-quality health care. Medical ethics exist to ensure the trustworthiness of health care professionals, so that even the most vulnerable patients know their best interests and preferences will be respected. For this reason, medical ethics commonly focuses on the relationship between patients and health care professionals. Today, however, health professionals such as doctors and nurses must work together with managers, suppliers, purchasers, public health agencies, patient

groups, health plans, hospitals, pharmacies and many other stakeholders. With these sets of relationships growing in complexity, health care is increasingly the work of organizations and systems of care as well as of individuals (IOM 2001, ACGME 1999). Although the patient-clinician relationship is as important as ever to effective and respectful health care, this complex web of relationships can have a big impact on professional ethics and the care of patients. While the ethics of clinical care remain important, so too are the ethics of business, public health and other types of organizations. In many cases the ethical standards of these various stakeholders and organizations align, but in some cases they may conflict.

This means that the ethical standards of health care professionals are no longer, by themselves, sufficient to ensure the trustworthiness of the entire health care system. For example, a physician's traditional promise of confidentiality would be meaningless in the modern health care system—in which computerized information is common—if it were not supported by broader ethical (and sometimes legal) expectations regarding confidential information. It is only when many stakeholders, including hospitals, health plans and purchasers, all agree to adhere to clear, shared ethical standards for confidentiality that the physician's traditional Hippocratic promise to protect confidential patient information can be made and kept.

The trustworthiness of the health care system today demands that every stakeholder be accountable to others in the health care community around a set of shared ethical expectations. The Ethical Force Program was created by a broad group of health care stakeholders based on this belief (Wynia 1999, Emanuel and Emanuel 1996). Since 1997, the program has developed a method for moving toward such accountability, one ethical domain at a time.

Ethics and Performance Measurement

The Ethical Force Program hopes health care organizations will assess their ethical performance in the same way they assess performance in other areas. For this reason, the Ethical Force Program is organized as, and uses the terminology of, a performance measurement program.

The program uses a stepwise process for performance measure development, which is explained in more detail below. The process begins by identifying and defining a specific *domain of ethics* that should be addressed by participants through-

out the health care system. A framework for assessing the domain is then created by dividing the domain into relevant content areas. Content areas are aspects of the domain that should be considered for an ethical assessment. Next, within each content area, specific *measurable expectations* for performance are described. Both the content areas and the performance expectations within them are developed using a rigorous consensus process that involves the Oversight Body for the Ethical Force Program *(see Appendix E)*, a national Expert Advisory Panel appointed by the Oversight Body *(see Appendix F)*, and multiple outside reviewers. By following these steps, the Ethical Force Program hopes to ensure that its expectations are important, feasible to address and, unless specifically noted, applicable to all organizations that play a role in health care. Future stages of development for this project will include the creation and field testing of self-assessment tools that will help organizations evaluate their performance against the expectations listed in this report *(see Tables 1-6)*.

When the Ethical Force Program was created, its first task was to select core domains of health care ethics for assessment (Berkman et al. 2000, Berkman et al. 1998). The first ethical domain addressed by the program was protecting the privacy and confidentiality of identifiable health care information. The consensus report on this issue, *Protecting Identifiable Health Care Informational Privacy,* was released in 2001, and an organizational self-assessment toolkit for this domain is now available (EFOB 2001, Wynia et al. 2001, see www.EthicalForce.org). The second ethical domain addressed by the program was fair health care coverage decisions (EFOB 2004, Wynia et al. 2004). The consensus report on this issue, *Ensuring Fairness in Health Care Coverage Decisions*, was released in 2004. A brochure is also available to help patients understand how decisions about health care coverage are made, including the roles of practitioners, employers and health plans. In addition, Ethical Force Program staff are developing a casebook of challenging coverage decisions to give human resources professionals and business owners guidance when making difficult health care coverage decisions. The current report on patient-centered communication for vulnerable populations is the third in this series of consensus reports addressing a variety of domains of health care ethics.

The Stages of the Ethical Force Process

The Ethical Force Program uses a three-stage process for developing performance measures in domains of ethics (Figure 1, Wynia 1999). This report is the result of the first stage, where the Ethical Force Oversight Body:

■ Selects a particular domain of ethics for performance measure development,

■ Works in an iterative process to develop a framework and expectations for assessing the domain, and

■ Presents its consensus on some concrete steps that organizations can take to assess and improve performance (Figure 2).

STAGE I

Select a domain and develop consensus on specific expectations for ethical action

STAGE II

Develop testable performance measures based on consensus expectations from STAGE I

STAGE III

Field test performance measures and disseminate those that are valid, reliable and feasible to use

Figure 1

Development of the Consensus Report

Oversight Body

1. Selects domain of ethics to address

2. Appoints expert advisory panel

Expert Advisory Panel

3. Reviews literature and research on the domain

4. Suggests measurement framework (i.e., creates content areas)

5. Reviews and comments on measurement framework

6. Approves content areas

7. Suggests measurable expectations within content areas

8. Reviews and comments on measurable expectations within content areas

9. Approves measurable expectations

10. Disseminates discussion document for public comment

11. Reviews comments and incorporates into final consensus report

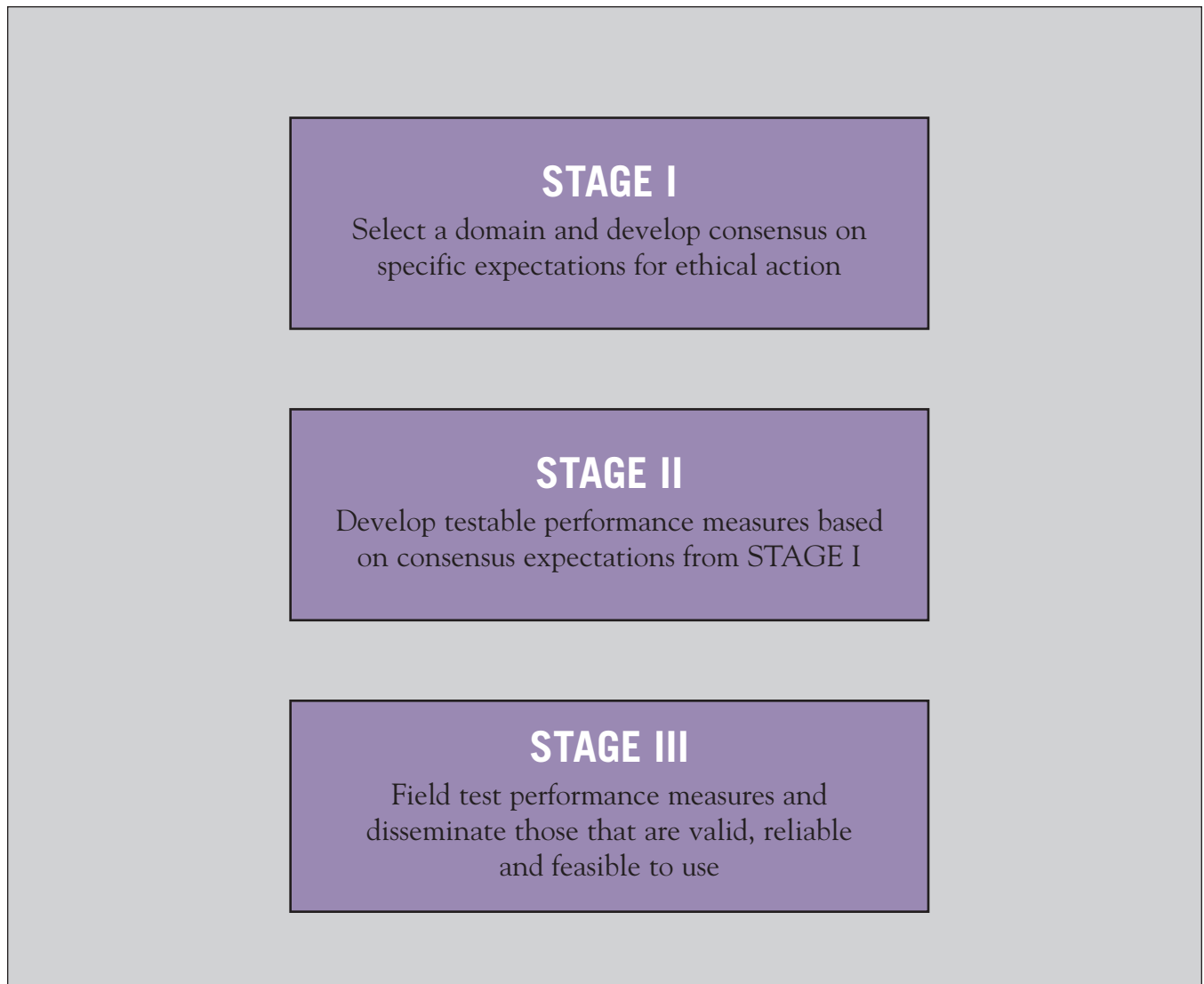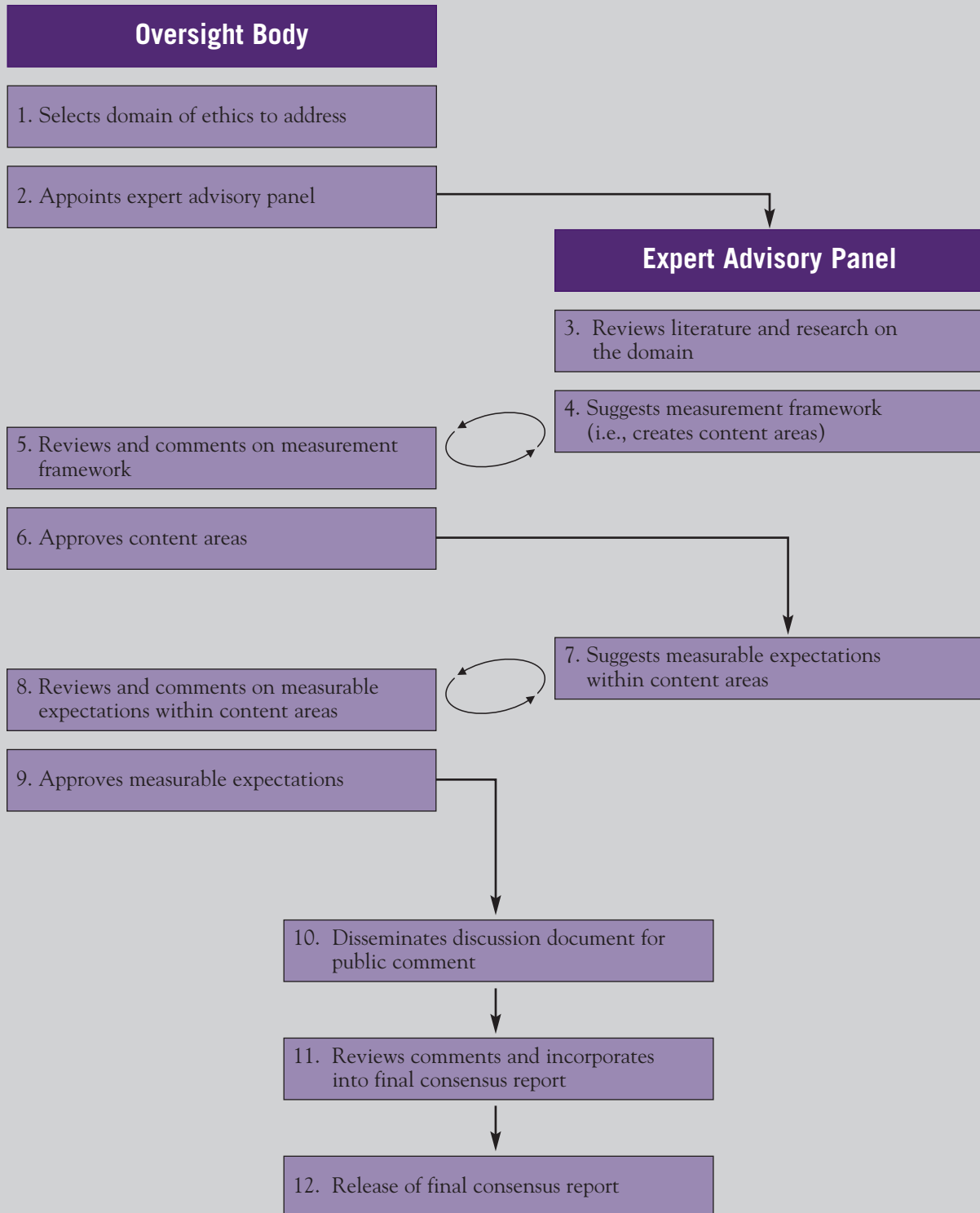12. Release of final consensus report

Figure 2

Once the Ethical Force Program's Oversight Body selected "patient-centered communication for vulnerable populations" as a domain, it appointed a national Expert Advisory Panel on patient-centered communication to assist in developing this report *(see Appendix F)*. The panel's first charge was to review existing ethical norms and performance standards for patient-centered communication *(see Appendix D: Regulations and Standards)*. This review was then used by the panel to recommend reasonable content areas that would provide a framework for assessment. These content areas were carefully reviewed, revised and approved by the Oversight Body, which considered if all the areas being addressed were important and if any relevant considerations were being ignored. This review process included the use of numerical rating scales (from 1 to 10) to assess each content area on its overall importance and relevance to patient-centered communication. Areas with low scores (mean < 7) were reviewed, and then either revised or eliminated during meetings of the Oversight Body. This formal review process is designed to ensure the content validity of the overall performance measurement framework (Litwin 1995).

Nine content areas (six main areas and three subareas) were ultimately approved by the Oversight Body. This provided a working framework for the next stage: development of measurable expectations for performance. For this stage, the Expert Advisory Panel identified many potentially measurable expectations within each content area. "Performance expectations" are specific expectations for action that can be measured within organizations in a valid, reliable and feasible way.

For example, Content Area 1 is entitled, "Understand your organization's commitment." The specific performance expectations in this area outline how an organization should demonstrate that patient-centered communication is a priority for its leaders and workforce members. For example, one measurable expectation is that "the organization commits identifiable resources (funds, personnel) to ensuring effective communication with communication-vulnerable populations" (expectation 2.0). Without specifying the amount or types of resources that should be committed, which will vary in different organizations, this expectation is realistic to achieve and it is measurable. In addition to ensuring that communication initiatives are discussed during budget-setting processes, an important reason for this particular expectation is that organizations must be able to identify and track the resources allocated to

specific communication initiatives to measure investment (and return on investment).

The Expert Advisory Panel and the Ethical Force Oversight Body systematically reviewed each proposed expectation for its overall importance, feasibility of implementation and potential for measurement. In this review process, each Oversight Body member gave each item numeric grades (from 1 to 10) for its importance, feasibility, and measurability. Those items receiving low scores (mean score < 7) in any of these three categories were reviewed, and then either revised or eliminated.

This grading process was repeated three times over a period of a year-and-a-half. Revisions were made along the way to reach consensus. During this process, the Expert Advisory Panel met in person three times and conducted numerous e-mail communications. The Oversight Body also met in person three times, each time making recommendations for revisions. In addition, this report was circulated to a group of more than 100 external reviewers from across the health care system. These reviewers received draft versions of the report via e-mail and provided significant feedback about the value of the framework and the feasibility of meeting the expectations.

Following release of this report, the performance expectations listed in each content area will be used to create a self-assessment toolkit (Figure 1). The toolkit will include survey items for patients, clinicians and other workforce members, site review criteria and policy review criteria. In addition, implementation and interpretation guides will be created to help organizations use the toolkit for self-assessment, peer review, report card projects and other quality assessment and improvement projects (Wynia 1999). All parts of the toolkit will be field tested before being released for widespread use.

Challenges of Measuring Ethics Quality

Today, public demands, regulation, technological advances and financial pressures have generated a lot of interest in tools to measure the quality of health care. Though most health care quality measures address customer service (such as waiting times) or technical competence (such as operative outcomes or frequency of using screening tests), the Ethical Force Program believes that an organization's ethical climate is also important to health care quality (Wynia 1999, Wolf 1994, Donabedian 1993).

Measuring whether an organization meets or exceeds ethical expectations for patient-centered communication is both valuable and difficult. Communication is required for almost every aspect of health care and being patient-centered requires consideration of a diverse range of needs, beliefs, values and preferences. Ethical standards in health care are based on a combination of business, professional, public health and personal ethics. Patients, clinicians, insurers and others all have a set of ethical standards that influence their actions and their views on acceptable interactions and outcomes. As with other domains of ethics quality, and many other facets of heath care quality, there is no "gold standard" for measuring the quality of patient-centered communication (Wynia 1999). In areas of performance measurement where no gold standard exists, quality measures must focus on measuring adherence to basic norms, use of procedures to ensure quality improvement and appropriate attention to important and complex issues, and organizational progress toward aspirational goals (Wynia 1999).

Basic norms. When addressing a new ethical issue, the Ethical Force Program always begins with a review of the literature. This helps determine how the issue (patient-centered communication) is, or should be, understood and fostered by organizations. During the review, themes that are repeated across several sources are considered basic, accepted norms and used as the starting point for development of performance expectations *(see Appendix D: Regulations and Standards)*.

Procedures and processes. Other expectations in the report are based on procedural issues and process measures. An organization's communication strategies should vary according to its populations' needs, beliefs, priorities and resources. This makes it difficult to create a single list of strategies that should always, or never, be followed. Instead, an organization should have ethical processes and procedures for adapting its communication strategies to meet the needs of specific populations.

Aspirational goals. Within the performance expectations, there are a few goals that organizations should aspire to meet. These goals are important, but reviewers tend to give them low grades for feasibility of implementation and measurement. Aspirational goals are often discussed in the descriptions of the content areas, but only rarely appear as actual performance expectations within each content area.

A Framework for Self-Assessment and Performance Improvement

This report proposes six main content areas and three subareas for assessment of patient-centered communication. In summary, to assess and improve patient-centered communication for vulnerable populations, health care leaders and decision makers should:

1. Understand your organization's commitment,

2. Collect information,

3. Engage communities,

4. Develop workforce,

5. Engage individuals, by considering

   5a. Socio-cultural context,

   5b. Language, and

   5c. Health literacy, and finally

6. Evaluate performance.

The areas are not listed in order of importance, but in the order they might logically be considered during a quality improvement process. Note that the last content area calls for an organization to evaluate its performance. Information from this evaluation can be used to develop or renew a quality improvement agenda for patient-centered communication. It can also be used to restart the quality improvement cycle by again assessing the organization's commitment in light of the information it has gathered and any changes that are made.

Limitations of the Framework

It is important to be realistic about what this consensus report can accomplish. First, the expectations for patient-centered communication in this report cannot guarantee high quality. Even if all the expectations are met, they are neither exhaustive nor specific enough for any one organization to be sure they have closed all possible communication gaps. In addition, it is theoretically possible for an organization to simulate adherence to ethical standards while not addressing a systemic communication problem *(see Appendix B: Ethics and Patient-Centered Communication)*. In this regard, it is important to recognize that no set of expectations or measures can provide an ironclad guarantee of truly ethical actions.

Any set of measures can be "gamed." Our hope and expectation, however, is that organizations will embrace this framework and measure their performance with good intentions and integrity.

Legal and Regulatory Limitations

In identifying content areas and performance expectations for this report, the Ethical Force Program's Oversight Body recognizes that organizations also need to meet various federal, state, local and other regulations *(see Appendix D: Regulations and Standards)*. For example, several laws require organizations to provide interpretation services.
In many cases, these laws and regulations are intended to improve communication *(for example, the Culturally and Linguistically Appropriate Services—CLAS—standards)*.
However there may be times when regulations or mandates conflict with an organization's plan for improving patient-centered communication. While we are not aware of any instances where the expectations we list conflict with the law, if such cases exist, organizations and individuals should obey the law. Nevertheless, we also believe that health care professionals have an ethical obligation to seek changes to laws when such changes would improve health care (AMA 2004a, Wynia 2004, Wynia et al.1999).

The Evolving Health Care System

The Ethical Force Program recognizes that the health care system will continue to evolve. For example, in 2006, key health care organizations include hospitals, physician practices, pharmacies, health plans, employers (acting as health plan purchasers), and federal and state governments (acting as purchasers, regulators, providers, and sources of information). Over time, these entities may change. For instance, the role individuals play in choosing their health care insurance has been increasing. We have worked to provide expectations for patient-centered communication that are measurable in the current system, yet flexible enough to adapt as the health care system evolves.

Realistic Expectations

Not all participants in today's health care system are meeting all of the expectations we list. Indeed, this work would be unnecessary if they were. However, we know that several organizations are meeting or exceeding many of the expectations listed, and we suspect that some organizations meet all the expectations. We hope this means that the performance expectations are realistic. Some organizations— in particular small group practices or solo practitioners— may feel that it is impossible to implement or live up to some of the expectations listed in this document. In many cases, this will be because the report is written for organizations, rather than individuals. While some expectations, such as assigning tasks to committees, are more appropriate for larger organizations, most of the recommendations can still be adapted to very small groups. Each content area includes implementation notes for addressing the listed performance expectations. When necessary, these notes provide some suggestions for adapting the expectations.

Questions and Answers About
Patient-Centered Communication,
Ethics Quality and Organizational
Self-Assessment

Is communication important in health care?

Yes, communication is fundamental to health care (Flach 2004, IOM 2003, IOM 2002, Safran et al. 2001, Gordon et al. 1995, Stewart 1995, Roter and Hall 1993). To achieve positive health outcomes, health care professionals and other stakeholders must be able to communicate with the people and populations they serve about disease prevention, treatment plans and options, risks and benefits, medication instructions, and other topics related to effective health care.

National organizations have identified health care communication as an essential element of public health and a core component of the health care system. For example, Healthy People 2010 has included health communication not only as one of its focus areas, but indicated that it also affects each of its 10 leading health indicators (Public Health Foundation 1999). The Joint Commission on Accreditation of Health Care Organizations, the National Committee for Quality Assurance and others have developed standards that require health care organizations to recognize individuals' right to and their need for effective communication *(see Appendix D: Regulations and Standards, Joint Commission 2004, NCQA 2004)*. Finally, the National Quality Forum has listed communication as both a practice for improving patient safety as well as a national priority for health care quality measurement and reporting (NQF 2004, 2003).

What is patient-centered communication?

The patient-centered approach to communication is widely recognized as a valuable strategy for building relationships with individuals and improving the quality of care provided by physicians and other health care professionals (Epstein et al. 2005, Taylor and Lurie 2004, IOM 2001, Mead and Bower 2000, Laine and Davidoff 1996). Patient-centeredness has been defined as a "moral philosophy with three core values:

■ Considering individuals' needs, wants, perspectives and individual experiences;

■ Offering individuals opportunities to provide input into and participate in their care; and

■ Enhancing partnership and understanding in the patient-physician relationship" (Epstein et al. 2005).

As it applies to communication, being patient-centered requires skills to obtain information from individuals about their specific preferences, needs and values; relationship-building skills for making connections and building trust with individuals; partnering skills for making decisions and solving problems together with individuals; and counseling skills (Cooper and Roter 2003). It has been shown that using these communication skills during health care encounters improves satisfaction, compliance and adherence to treatment regimes, provision of preventive services, and clinical outcomes. (Beach et al. 2005, Flach et al. 2004, Stewart 1995)

More details on the ways in which patient-centered communication has been defined by others, as well as some of the choices we made in using the term for this report, are provided by Mary Catherine Beach, MD, MPH in a review essay that is included as an appendix to this report *(see Appendix A: What is Patient-Centered Communication?)*.

What is the role of health care organizations in promoting patient-centered communication?

While patient-centered communication is typically viewed as an element of interactions between clinicians and patients, this report explores the benefits of integrating patient-centered communication into the relationships a health care organization has with the populations it serves. In *Crossing the Quality Chasm*, the Institute of Medicine recommends that health care systems become more patient-centered to help individuals have more control over their own health care (IOM 2001). The report notes that "systems must be designed to serve the needs of patients, and to ensure that they are fully informed, retain control and participate in care delivery whenever possible, and receive care that is respectful of their values and preferences."

Health care operates in systems, with many different organizations playing key roles. This means every organization that is part of the health care system needs to think about how it communicates with the populations it serves. For example, what information does the organization need to communicate and how do people use information from the organization? This includes communication that takes place between individuals and populations and their employers, health plans, hospitals, clinics, pharmacies, and other sources of health-related information.

As described in this consensus report, there is much that organizations can and should do to promote and assess patient-centered communication. Organizational activities include population-based communication initiatives, training individual members of the workforce, monitoring patients' communication needs and experiences, creating policies that foster patient-centered communication, and much more. Activities such as these are best done at an organizational level, but they can each affect an individual practitioner's ability to provide patient-centered communication. Organizations must play a key role if we are to ensure patient-centered communication throughout the health care system.

Is patient-centered communication important to all stakeholder organizations in health care?

Every organization that plays a role in health care should work to communicate effectively with all the populations it serves. Patient-centered communication is one strategy for making health care communication more relevant and understandable to patients, and thus more effective. (Fiscella et al. 2004, U.S. DHHS HRSA 2003, Safran et al. 1998, Williams et al. 1998b, Stewart 1995).

It is worth noting that many organizations with an important role in health care do not have patients. For these organizations, there is still value in using patient-centered concepts to guide communication with customers, enrollees, employees, clients, etc. (all of whom are potential patients). For example, communication about health insurance options, disease prevention, healthy lifestyles, and many other topics can be improved by using an approach that solicits feedback from the intended audience and considers the audience's needs, beliefs, values and preferences in shaping and delivering the message.

One goal of this report is to help all organizations that play a role in the health care system assess and improve how they communicate with the populations they serve. The expectations in this report can be applied to a wide variety of organizations, including hospitals, physician practices, pharmacies, health plans, government agencies, patient advocacy groups, employers and other health plan purchasers, groups concerned about community health such as senior centers, YMCAs, and faith-based organizations, and commercial or noncommercial providers of health information (e.g., health information Web sites). Each of these organizations has a responsibility to provide its audience with clear, understandable information about health care.

In Summary: This consensus report outlines expectations that a health care organization should be able to meet in its efforts to identify and bridge gaps in communication between the organization as a whole, its workforce, and the populations it serves. These gaps can result in the organization providing inadequate communication to certain population groups, which can lead to poor health outcomes, health care disparities, and long-term problems for the health care organization *(see Appendix C: The "Case" for Patient-Centered Communication)*.

Which organizations? Many organizations interested in this report will be direct providers of clinical care, but others will provide health-related services such as insurance, pharmaceuticals, other health care products, or other forms of customer care. Some of the report's expectations are relevant to organizations that develop educational and informational materials for patients, such as federal agencies (e.g., the National Institutes of Health, the Centers for Disease Control and Prevention), state governments and commercial or noncommercial providers of health information (e.g., health information Web sites).

Which populations? We focus on ways an organization can improve how it interacts with, and meets the needs of, populations at risk of experiencing communication gaps. These "communication-vulnerable populations" include those whose members have limited or no English proficiency, a culture that is not well understood by personnel in the organization and/or limited health literacy skills.

The performance expectations outlined in the tables throughout this report are written using generic language intentionally, so that they can be applied to any health care organization. In many cases, it will be straightforward for organizations to determine how to address the expectations on their own. In some cases, specific guidance to help certain types of organizations interpret and meet the expectations is provided in the implementation notes.

Where should an organization begin?

Few organizations, regardless of size or type, will already be meeting all of the expectations in this consensus report. Communication is a complex topic and the expectations address many different aspects of communication. An organization should use the report and its lists of performance expectations as a guide to identify which areas of patient-centered communication represent the organization's strengths and weaknesses. An organization can then begin taking steps to address some of the expectations that are most relevant and feasible to address in its situation.

The content areas in the report are not listed in order of importance, but in the order they might logically be considered during a quality improvement process. Many organizations will already meet some of the expectations. In this case, an organization might choose to identify and focus on those content areas and performance expectations it has not yet addressed. Other organizations might need to start at the very beginning.

To begin, every organization should consider its general climate and its current policies and activities. If the organization already places a high value on effective communication and, in particular, on meeting the communication needs of the vulnerable populations its serves, then it should be well prepared to move forward and meet the performance expectations in the remaining content areas. But if an organization's climate is less focused on effective communication and meeting the needs of vulnerable populations, it may have to begin by building organizational support for focusing on patient-centered communication with these groups.

The last content area recommends that an organization evaluate its performance. The process of quality improvement is a cycle. The goal of evaluating and reevaluating performance over time is to help an organization understand if and how it is succeeding in meeting the

expectations it addresses. An organization should take what it learns from evaluations and use the information to go back and fine tune its efforts to promote patient-centered communication.

What is the link between ethics and patient-centered communication?

Health care organizations hold unique ethical obligations. Though profitability may be an important motivation, health care organizations are expected to meet the health care needs faced by the communities that surround them (Pijnenburg and Gordijn 2005, Wilmot 2000, Emanuel 2000). This expectation creates a social covenant between health care organizations and their communities. Sometimes the covenant is explicit, such as when a hospital's mission statement contains specific goals for meeting the health care needs of local populations; other times the terms of the covenant are implied. One tool that health care organizations use to fulfill their social covenants and meet their ethical obligations is patient-centered communication.

Patient-centered communication is vital for health care organizations to provide ethical, high-quality care. The ethical importance of patient-centered communication is reflected in several professional codes, guidelines and standards for health care organizations (*see Appendix D: Regulations and Standards*). These codes, guidelines and standards each argue that health care organizations have specific ethical obligations related to communication. Ethical obligations that relate to patient-centered communication fit into three broad themes: health care organizations must maintain and protect health care users' autonomy; health care organizations must assure quality care; and health care organizations must maintain equity among health care users. None of these obligations may be fully achieved without patient-centered communication.

Autonomy. Communication that is respectful of and responsive to patients' preferences, needs and values is the mechanism that health care practitioners use to discover patients' autonomous preferences so that they may act on them. Without patient-centered communication, the individuals being served are taken out of the loop, leaving practitioners to assume or guess their needs and preferences. In such a situation, autonomy is not possible.

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Quality. Patient-centered communication helps identify areas where communication-vulnerable populations receive lower-quality care and helps practitioners find ways to improve the care they deliver. Patient-centered communication increases trust in the health care system and opens it to traditionally underserved communities. This may dramatically improve the access to and quality of care that members of these communities receive.

Equity. Patient-centered communication can help health care organizations ensure equity among individuals with different communication needs. For example, to communicate about health care, some individuals need interpreter services or documents that have been translated into clear, nontechnical language. Without patient-centered communication, individuals from communication-vulnerable groups may experience communication gaps that result in their receiving a lower quality of care than those from other less vulnerable groups.

More detailed information on the links between ethics and patient-centered communication can be found in *Appendix B: Ethics and Patient-Centered Communication.*

Why is patient-centered communication especially important to certain populations?

While the patient-centered approach to communication is a valuable way to improve relationships and interactions with all populations that an organization serves, it is particularly useful for communicating with populations that may be at risk for experiencing communication gaps. Communicating effectively about health care relies on understanding three factors—the audience's culture, language, and health literacy skills. Therefore, populations whose members have limited or no English proficiency, a culture that is not well understood by personnel in the organization and/or limited health literacy skills are referred to as "communication-vulnerable" populations.[i]

There is substantial evidence of these populations experiencing gaps in health care communication. For example:

■ *Socio-cultural context.* Socio-cultural context affects how illness is discussed and treated, the level of participation individuals have during health care encounters, whether or not individuals can access sufficient health care information to actively participate in their health care (for example, using the Internet), and whether or not individuals have sufficient trust in the organization and its workforce to communicate fully (Napoles-Springer et al. 2005, Cooper and Roter 2003). *See Chapter 8.*

■ *Language.* Individuals with limited English proficiency are less likely to understand the health information they receive, less likely to receive preventive care and screenings, and more likely to misunderstand treatment and medication instructions (Jacobs et al. 2005, Jacobs et al. 2004, Andrulis et al. 2002). *See Chapter 9.*

■ *Health literacy.* Individuals with limited health literacy have poorer health status and self-reported health, less knowledge and understanding of their health and medical conditions, limited understanding and use of preventive services, decreased adherence rates, and increased hospitalizations and health care costs (Schwartzberg et al. 2005, Berkman et al. 2004, IOM 2004, Andrus and Roth 2002, AMA 1999, Williams et al. 1998a). *See Chapter 10.*

As a result of these types of gaps in communication, some populations are at risk for misunderstanding, mistrust, nonadherence and other health care problems (Cooper et al. 2003, IOM 2003). Gaps in communication can lead to medical errors, increased costs and overall poor quality health care (Bernstein 2005, Jacobs 2004, Schillinger 2004, Flores et al. 2003, IOM 2003, AHRQ 2001). Thus, communication gaps have a negative impact on health outcomes and may be a root cause of some health care disparities (Jacobs et al. 2005, Berkman et al. 2004, Taylor and Lurie 2004, IOM 2003, Fiscella et al. 2002, Schillinger et al. 2002, Schneider 2002).

For all of these reasons, this report puts a special focus on the communication needs of these especially vulnerable populations. Throughout the report we call these groups "communication-vulnerable populations," since their specific vulnerability is to miscommunication and its adverse effects.

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i Communication-vulnerable population groups are at risk for inadequate communication, but they are capable of making medical decisions. Determining if an individual is capable of making medical decisions is not the focus of this report, though communicating with patients who lack decision-making capacity can pose substantial challenges. Decision-making capacity is a legal determination, which is made based on medical evidence. While it is not the topic of the report, individuals who lack capacity to make medical decisions for themselves (such as those with delirium or advanced dementia, for example) still deserve and can benefit from respectful and clear communication.

Content Area 1.

Understand Your Organization's Commitment

An organization should routinely examine its commitment, capacity and efforts to meet the communication needs of the populations it serves, including leadership involvement; mission, goals, and strategies; policies and programs; budget allocations; and workforce values.

> Quick tips:
>
> Take time at meetings to talk about communication policies and projects.
>
> Make sure workforce members know who to talk to about communication questions or problems.

Communication is fundamental to health care (IOM 2003, IOM 2002, National Cancer Institute 2001, Gordon et al. 1995, Stewart 1995, Roter and Hall 1993). Every organization that is part of the health care system needs to think about how it communicates with the populations it serves. For example, what information does the organization need to communicate and how do people use information from the organization? People look to their employers and health plans for information about health care insurance, coverage choices and wellness programs. They often expect hospitals and clinics to provide information on disease prevention, chronic care management, and treatment options. For information on medication instructions, individuals ask their physicians or nurses, but they also get information from pharmacies, pharmaceutical companies, and from health information Web sites. All of these different types of organizations must consider how they communicate with individuals and populations about health care.

To start, every type of organization needs to first determine if its internal climate promotes good, patient-centered communication. An organization's internal climate reflects leadership commitment and attitudes, workforce values and investments, organizational history, financial concerns, external political and regulatory forces and other factors (Schein 1992). This climate has a strong influence on how an organization operates and responds to different situations.

To see if organizational climate is focused on patient-centered communication, leaders should:

- Look at guiding documents, policies and procedures. Making goals for patient-centered communication a part of mission, vision and values statements provides a reference for workforce members and serves as evidence of the organization's ideals and priorities.

- Consider their own attitudes and behaviors. For workforce members to see the importance of patient-centered communication, leaders must set the example by demonstrating good communication, highlighting communication goals, and providing funds for initiatives that improve communication (NPHHI 2004, IOM 2001).

- Find out what messages are reinforced. Workforce members pick up on the messages they hear at new employee orientation, mandatory group meetings, and other events. They should know why patient-centered communication is important and be encouraged to participate in opportunities to enhance these communication skills.

Understanding how patient-centered communication fits its priorities is especially important for organizations that serve or encounter populations that are more vulnerable to communication gaps. Communication gaps can mean an organization provides ineffective communications or inadequate information to certain populations and, more importantly, can lead to patient safety violations and medical errors. For example, reported anecdotes as well as research studies have shown that individuals with limited English proficiency or limited health literacy skills may be at increased risk of misunderstanding medication instructions, misunderstanding informed consent discussions, and experiencing serious or adverse events while hospitalized

> A population can be vulnerable to communication gaps if its members have limited or no English proficiency, a culture that is not well understood by personnel in the organization and/or limited health literacy skills (Freimuth and Quinn 2004, Lillie-Blanton et al. 2003, Gordon et al. 1995).

(Bernstein 2005, Cohen et al. 2005, Fulton and Nelson 2005, Thomas 2005, Underwood 2005, Wilson et al. 2005a, Andrulis et al. 2002, Betancourt and Jacobs 2000, Gandhi et al. 2000). Within certain populations, communication gaps can impair health outcomes and lead to health disparities. Throughout this report, populations that may experience these types of communication gaps are referred to as "communication-vulnerable populations."

Example: Leadership Support of Patient-Centered Communication

Patient-centered communication fits well with the mission and values at WakeMed Health and Hospitals (Raleigh, NC), and leaders have taken many steps to make sure the hospital's workforce members know it is a priority. For example a senior vice president discusses culture and communication during new employee orientation, language and culture issues are woven into workforce training sessions, and bilingual workforce members are actively recruited.

What Should an Organization Do?

Each of the following considerations is important for understanding an organization's climate and commitment. Some of these issues are addressed in more detail in later sections of the report.

Leadership commitment: Within an organization, leaders should make patient-centered communication an organizational priority and should bring attention to the importance of meeting the communication needs of relevant vulnerable populations.

- Leaders should recognize that patient-centered communication can help an organization meet its business goals—for example, by improving public image and loyalty to the organization, increasing market share with certain populations, enhancing employee morale and promoting cost-effective care *(see also Appendix C: The "Case")*.

- Leaders should oversee communication campaigns, partnerships and other efforts. They should also be accountable for initiatives that help target audiences understand the information they receive.

- Leaders should recognize that communication crosses all disciplines. Managers from all relevant departments (e.g., clinical staff, human resources, workforce development, marketing, customer/patient relations, risk management) should be recruited to participate in communication initiatives.

- Leaders should set up a chain of accountability that includes ongoing participation by senior and other leadership on committees and boards that monitor whether an organization's communications policies and activities are up-to-date, clear to workforce members, and consistently implemented.

- Leaders should allocate funds for patient-centered communication, report on these issues to their governing board(s), interact with the local community, and offer opportunities for relevant workforce members to enhance their communication skills and knowledge.

Policy documents: An organization should examine the policies it has in place to promote effective communication.

- Core governance documents such as mission and vision statements, performance goals, and strategic plans should establish a commitment to patient-centered communication and emphasize meeting the communication needs of vulnerable populations.

- An organization should review the policies that guide how workforce members communicate with each other. Lapses in communication between workforce members or departments within an organization often affect how information about health care is communicated to the individuals and populations they serve.

Information systems and other resources: Information systems should be in place to collect and track information on individuals' communication needs. In addition, workforce members should be trained on how to collect information reliably and consistently.

- Examples of important information to collect include the language an individual speaks, whether an interpreter is needed, and other information that might affect health care communication, such as cultural, and in some cases religious, background.

■ An organization's human resource infrastructure can be strengthened by providing training opportunities and communication tools to encourage workforce members to improve their communication skills and knowledge.

■ An organization can assess what values it conveys to its workforce members by reviewing the training priorities and curricula it offers and promotes.

More on collecting information and training workforce members is provided throughout the report, especially in *Content Area 2: Collect Information and Content Area 4: Develop Workforce*.

Continuous evaluation: An organization should consider how it is viewed by the populations it currently and potentially serves. This type of feedback is the best way to see if an organization is on the right track in terms of meeting communication needs, respecting individuals, effectively conveying information and providing high-quality care, regardless of population characteristics. More on meeting communication goals and evaluating performance is provided throughout the report, especially in *Content Area 6: Evaluate Performance*.

Limitations and Barriers

Patient-centered communication can, and often should, be a part of an organization's quality initiatives. But investments in improving communication must be balanced against other needs, including the other needs of communication-vulnerable populations and the needs of other populations. Establishing performance goals and allocating financial and human resources to develop an effective communication infrastructure can divert resources from other efforts and other populations, some of which may have economic and social power within an organization.

■ Leaders must make the case that allocating resources for patient-centered communication efforts that target vulnerable populations is both the right thing to do and will result in improvements that benefit all populations over time *(see also Appendix C: The "Case")*.

Some organizations have specialized missions and the leaders may not think their primary population includes enough communication-vulnerable individuals for a special focus (e.g., certain specialty hospitals, or small businesses with primarily well educated employees).

■ Keep in mind the range of ways a population can be vulnerable to ineffective health care communication. Aging populations, for example, may have health care needs that change faster than their health literacy skills can adapt.

■ Recognize that the skills for good patient-centered communication with communication-vulnerable populations can be used to improve communication with all populations.

Performance Expectations: Table 1

This table lists specific performance expectations that an organization should be able to meet in its efforts to identify and bridge gaps in communication. All organizations will not be able to meet every expectation right away. Some expectations might be goals to strive for over time.

See the box on page 23 for more information on applying the expectations in the table.

		Expectation
1.0		The organization's written strategic and operational plans address identifying and appropriately meeting the communication needs of communication-vulnerable populations.
2.0		The organization commits identifiable resources (funds, personnel) to ensuring effective communication with communication-vulnerable populations.
3.0		The organization's business plan has measurable indicators of success that address care for communication-vulnerable populations.
	3.1	The Board of Trustees receives regular reports on how the organization cares for communication-vulnerable populations.
	3.2	A senior executive's portfolio includes monitoring and improving care for communication-vulnerable populations.
4.0		The organization has policies that address the communication needs of communication-vulnerable populations and that place these needs in the context of other organizational needs and priorities.
5.0		As part of its charge, every relevant committee within the organization considers how its decisions and actions affect the needs of communication-vulnerable populations.
	5.1	At least one individual or committee has as one of its charges a focus on addressing the specific needs of communication-vulnerable populations.
	5.2	The organization has a strategy for disseminating and integrating relevant information about meeting the needs of communication-vulnerable populations across its workforce and committees.
6.0		The organization's workforce is knowledgeable about organizational policies and procedures for communicating with communication-vulnerable populations and how these apply to their work.
	6.1	The workforce is knowledgeable about leadership commitment.
	6.2	The workforce knows, or has access to information outlining, the primary contact person or office for interpretation services, workforce development, communication training and other relevant communication issues.

Implementation Notes:

1.0: These plans should address the role of community partnering, interpreter services and document translation, health literacy, cross-cultural training, etc. The plans should also include performance indicators and assignment of workforce and leadership accountability.

3.2: This does not have to be a new senior executive position; an existing leader may have care for communication-vulnerable populations as part of his or her management portfolio.

4.0: Communication should be integral to many organizational efforts including patient safety, quality improvement and meeting accreditation requirements. Policies should take into account existing federal, state and local regulations that may apply to certain populations. This includes monitoring changes in regulations that affect communication polices and strategies.

5.0: Many of an organization's committees will consider issues that are affected by communication, such as informed consent, patient safety, quality improvement and development of educational and informational messages and materials. For example, hospital ethics committees and Institutional Review Boards often discuss whether patients understand educational materials and receive effective communication leading to valid informed consent.

5.1: A committee that meets this description may have various titles and charges, for example "diversity committee," "cross-cultural care committee," "patient or employee relations committee," or "community health committee."

For a small organization that cannot maintain a standing committee, it may be possible to work with other larger organizations in the area or at least to have one member of its workforce who is responsible for working with specific populations to determine communication needs.

5.2: Patient-centered communication often requires effective communication within an organization and between different parts of an organization. An organization should make sure all its committees know about relevant discussions and decisions of other committees, especially those on how the organization meets the needs of its communication-vulnerable populations.

Selected Resources:

Agency for Healthcare Research and Quality. Oral, Linguistic, and Culturally Competent Services: Guides for Managed Care Plans. Washington, DC; 2003. *www.ahrq.gov/about/cods/cultcomp.htm*

National Public Hospital and Health Institute. Serving Diverse Communities in Hospitals and Health Systems. Washington, DC: National Public Hospital and Health Institute; 2004. *www.naph.org/Content/ContentGroups/Publications1/MON2004_6_OMH.pdf*

U.S. Department of Health and Human Services Health Resources and Services Administration, Center for Health Services Financing and Managed Care and the Office of Minority Health. Cross-Cultural Communication in Health Care: Building Organizational Capacity. Washington, DC; 2003. *www.hrsa.gov/reimbursement/broadcast/default.htm*

Content Area 2.
Collect Information

An organization should use standardized qualitative and quantitative collection methods and uniform coding systems to gather valid, reliable information for understanding the demographics and communication needs of the populations it serves.

Quick tips:

Look up census data and ask local elementary schools for enrollment information.

Talk to the people you serve about common and unmet communication needs.

Communication can only be patient-centered if an organization knows what populations it is, and should be, serving. By collecting information from and about its populations, an organization can address specific communication needs and barriers and develop appropriate communication plans and strategies. All organizations that play a role in the health care system, including health care delivery organizations, pharmacies, health insurance plans, employers and others, should collect information to improve communication.

An organization should collect two levels of information about the populations its serves, individual-level information and community-level information.

Information collected from individuals can help an organization adjust specific communication services, programs and resources to the needs of individuals and populations.

■ This includes basic information on an individual's race, ethnicity and primary language. It may also include information about an individual's health beliefs and value system, health literacy and other relevant information.

■ Qualitative information collected with individual interviews, feedback cards, Web sites, help lines and other methods also can help an organization identify local concerns and specific areas where individuals need more communication services or assistance.

Information collected from communities can guide strategic planning processes and help an organization identify if there are populations in its community that need to be engaged.

This includes information about languages spoken in the community, general literacy and health literacy levels and other communication needs.

If information is collected only from individuals already interacting with an organization, an organization may neglect entire populations that it has not successfully engaged, but that may need care or other services. This neglect would represent a missed opportunity in many cases, and a potential threat in others. For instance, if a hospital is failing to meet the communication needs of a specific racial or ethnic population, and as a result the majority of the population avoids receiving care at that hospital, the hospital is both missing an opportunity and subjecting itself to a potential legal threat *(see also Appendix C: The "Case")*.

Example: Get Demographic Information at Low Cost by Contacting Local Groups

Staff members at University of Virginia Health Systems (Charlottesville, VA) contact the local school districts to find out what languages are spoken by students currently enrolled in the public school system. Other hospitals gather information about cultural origins of the community, and new groups in the community, by asking the local United Way, senior centers, faith-based organizations, post office or police department.

What Should an Organization Do?

Individual-level information: An organization should standardize how workforce members collect and store information they get from individuals (AHIP 2005, HRET 2004). An organization that adopts a single standardized protocol for entering, storing and accessing information will have an accurate, effective tool for determining language and communication needs, tracking quality indicators and health outcomes for specific populations, and informing quality improvement efforts.

■ Most hospitals (78 percent) collect information on their patients' race, ethnicity and primary language, but the collection is not standardized and often the information is not shared, even among different departments of a single hospital (HRET 2004).

- Information is often collected repeatedly, possibly confusing and alienating patients and producing information that is neither consistent nor accessible across an organization.

Implementing or improving information collection strategies requires that systems be in place to store the information in a way that is both secure and accessible to authorized individuals throughout an organization. For example, in a medical practice, the workforce members responsible for scheduling interpreters should be able to access information on language assistance needs before a patient arrives for an appointment. As a result of the Health Information Portability and Accountability Act of 1996, tools and resources are available to provide guidance on privacy concerns and solutions related to information collection and storage within certain health care organizations, including health plans, hospitals and physician practices *(see, for example, the Ethical Force Program's Consensus Report on Health Care Informational Privacy, Wynia et al. 2001)*.

An organization should support efforts to collect information in an accurate and consistent way.

- Leaders should provide policy, operational and financial support and they should be kept up-to-date on the information collected.

- Workforce members should be trained on how to collect information about race, ethnicity and primary language from individuals, how to input this information, and how to answer questions about why this information is collected.

- There should be a strategy for categorizing the many individuals who identify with multiple races or ethnicities.

To help individuals understand and become comfortable with the idea of providing information on their race, ethnicity and primary language, an organization should develop an education strategy that explains why the information is being collected, what information individuals will be asked to provide and how the information will be used (Baker et al. 2005).

In addition to general information on race, ethnicity and primary language that should be collected from every person, an organization should use interviews, surveys and focus groups to collect more detailed information on health concerns, beliefs and unmet communication needs.

- Ask individuals what their specific communication needs are, how well these needs are being met, and whether there are ways they can be better served.

- Ask individuals if the information and educational materials they receive are understandable.

Community-level information: An organization should work with community groups to find out the languages spoken in the community, the range of general literacy and health literacy levels, and other common communication needs. For an organization that has no reliable system for collecting individual-level information, using community-level information is one way to predict individual needs until effective information collection systems are in place.

- Sources of this information include the U.S. Census Bureau, local public health departments, senior centers, faith-based organizations, post offices, police departments and community groups such as the United Way.

- The most up-to-date information on community demographics is often available from local school districts.

- Online tools, such as the Pfizer health literacy prevalence calculator (Pfizer Clear Health Communication Initiative), can help estimate local health literacy levels.

Partnering with other organizations in the community to develop shared information collection methods is one way that smaller organizations, such as small employers or medical practices, can keep costs down. This helps especially if the same populations are being served by multiple partners. Partners also can work together to educate populations about information collection efforts.

An organization can compare its community information to individual-level information to see if there are populations in the community that are not using the organization and its services.

- All organizations should be aware of local populations and be generally equipped to communicate with them and provide care if needed.

- Even an organization with a specialized mission that does not typically serve the entire population of a geographic community (such as specialty hospitals, military facilities or national institutions and networks) may be required to step in if there is an epidemic, emergency or other unforeseen event.

Limitations and Barriers

An organization might have several concerns about the feasibility of financing and implementing comprehensive information collection strategies. These include beliefs that: there is no good way to collect the information, especially from communication-vulnerable populations; collecting the information might cost too much; it might be illegal to collect certain information; the information collected might not be accurate or kept confidential or it might be used in a negative way to discriminate against individuals or populations (AHIP 2005, HRET 2004, National Research Council Committee on National Statistics 2004).

Some of these concerns are valid—in particular, that financial and human resources are needed to develop an information collection system and to train workforce members to use the system. However, having an information collection system that can be used throughout an organization to collect, share and track information about communication-vulnerable populations is important for many reasons, even beyond improving communication. Leaders can develop budgets and strategic plans that incorporate the financial and human resources required to establish new systems or improve systems already in use, but only if they see its importance.

To address legal concerns, a health care organization needs to build awareness about federal and local regulations regarding information collection (*see also Appendix C: The "Case"*).

- Many organizations are required to collect information on the race, ethnicity and language needs of individuals being served to comply with Title VI of the Civil Rights Act of 1964, the Hill-Burton Act, the Emergency Medical Treatment and Active Labor Act, Medicare, Medicaid, and other Executive Orders and federal policies (*for more detailed information on federal regulations, see* www.lep.gov) (Summit 2001).

- Only six states (California, Maryland, New Hampshire, New Jersey, New York, Pennsylvania) have some limited restrictions on how health plans and other health care organizations collect information on race and ethnicity.

- Even in theses six states, these restrictions apply only to the application process, not to the collection of information from current enrollees or about eligible populations for broader strategic planning at an organizational level (AHIP 2005, NHeLP 2005).

Performance Expectations: Table 2

This table lists specific performance expectations that an organization should be able to meet in its efforts to identify and bridge gaps in communication. All organizations will not be able to meet every expectation right away. Some expectations might be goals to strive for over time.

See the box on page 23 for more information on applying the expectations in the table.

		Expectation
1.0		Relevant organizational leaders understand the legal regulations, state and national requirements, and other implications of collecting, storing, accessing and using information about the communication needs of individuals and populations.
2.0		The organization has standardized methods for collecting information about the race/ethnicity of individuals they serve.
	2.1	When possible, information on an individual's race and ethnicity is collected directly from the individual.
3.0		The organization ensures that information on how individuals need to communicate is collected, including…
	3.1	Primary language.
	3.2	Whether an interpreter or other form of language assistance is needed.
4.0		The organization collects population-level information about its communication-vulnerable populations and their communication needs.
	4.1	The organization works with community and advocacy groups that serve its community to collect information about new and emerging racial, ethnic and language populations.
	4.2	The organization collects information on the general literacy and health literacy levels of the populations it serves.
5.0		The organization uses a standardized format for storing and accessing information about communication needs across the organization.
	5.1	Information on the communication needs of individuals is accessible and understandable to relevant members of the workforce.
	5.2	Information on the communication needs of populations is available to leaders for short and long-term planning.
6.0		The organization cross-links demographic information with clinical quality measures.

Implementation Notes

2.0: This information can be collected and categorized in a number of ways. For example, at minimum hospitals and health plans should collect information on an individual's race and ethnicity based on the guidelines provided by the U.S. Office of Management and Budget. If possible, an organization should collect more detailed information in response to its populations.

An organization that serves seemingly homogeneous populations (e.g., Hispanic and Latino populations) might also benefit from collecting information on dialect, language fluency, country of origin and acculturation (NRC 2004). This information can help an organization identify differences in communication needs. Information on how long individuals have lived in a community also might be important, since it can reflect familiarity with how to access resources and available services.

2.1: An organization should consider developing campaigns to educate its populations on why collecting information about race, ethnicity and primary language can improve the quality of health care. In particular, these educational campaigns should address fears of discrimination, especially if these fears are prevalent within the populations served.

3.0: Relevant members of the workforce should be trained to elicit information from individuals on whether they have particular communication needs stemming from their language, culture, education or literacy level, religion or other factors.

■ For example, individuals can have specific beliefs about advance directives; they might not want to know the results of certain medical tests; or they might prefer that a particular family member serve as a primary communicator. Forms should have space to note such individual beliefs or preferences about communication *(see also Content Area 5a: Socio-Cultural Context)*.

3.1: In some cases an individual's primary language might not be his or her preferred language for health care interactions. Information should be collected on primary language for both written and oral communication *(see also Content Area 5b: Language)* (Brach et al. 2005).

3.2: *See also Content Area 5b: Language*.

4.0: Beyond collecting information about the populations it actually serves, an organization should collect information about any other populations that are eligible to be served.

4.1: An organization should use representatives of community, advocacy and specialty groups as sources of information on changes in the populations it currently serves or should serve *(see also Content Area 3: Engage Communities)*.

4.2: It is typically not feasible or appropriate for a health care organization to measure the health literacy levels of all the individuals it serves (Schwartzberg et al. 2005). However, there are ways for an organization to collect information about health literacy levels on a population level *(see also Content Area 5c: Health Literacy)*.

5.0: This will make it easier to cross-link and analyze information from different areas of an organization and during different stages of individual encounters. It will also assist an organization in comparing information collected at the individual level with information collected at the community level. For purposes of information security and individual privacy, an organization should consider methods for encoding and deidentifying the information it stores.

5.1: When making information on communication needs accessible to relevant workforce members, an organization also should consider related privacy issues (Wynia et al. 2001).

6.0: Cross-linking information on demographics and communication needs with information on perceptions, health outcomes and health care quality, allows an organization to isolate any issues affecting certain populations that need to be further researched or addressed.

Selected Resources

America's Health Insurance Plans. More Health Insurance Plans Addressing Gaps in Health Care Experienced by Minorities in U.S. Washington, DC: America's Health Insurance Plans; 2004. *www.ahip.net/content/ pressrelease.aspx?docid=112*

America's Health Insurance Plans. Tools to Address Disparities in Health: Data as Building Blocks for Change. Washington, DC: America's Health Insurance Plans; May 2005.

Health Research and Educational Trust. Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals. New York: The Commonwealth Fund; May 2004. *www.cmwf.org/ publications/publications_show.htm?doc_id=225959*

Health Research and Educational Trust. A Toolkit for Collecting Race, Ethnicity, and Primary Language Information from Patients. Chicago, IL: Health Research and Educational Trust; 2005. *www.hretdisparities.org/ hretdisparities/index.jsp*

Summit Health Institute for Research and Education and National Health Law Program. Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices. New York: The Commonwealth Fund; 2001. *www.cmwf.org/ publications/publications_show.htm?doc_id=221295*

National Center for Education Statistics (NCES). National Assessment of Adult Literacy: A first look at the literacy of America's adults in the 21st century. Washington, DC: National Center for Education Statistics; 2005. *http://nces.ed.gov/naal/*

Pfizer Clear Health Communication Initiative. Improving Health Literacy: Prevalence Calculator. *www.pfizerhealthliteracy.org/calculator.html*

U.S. Census Bureau American FactFinder. *http://factfinder.census.gov/home/saff/main.html?_lang=en*

Content Area 3.
Engage Communities

An organization should make demonstrable, proactive efforts to understand and reach out to the communities it serves, including establishing relationships with community groups and developing opportunities for community members to participate in shaping organizational policies.

Quick tips:

Invite community members to serve on advisory boards.

Provide an accessible contact person for community members who have questions, praise or complaints.

Improving health outcomes in the 21st century is increasingly dependent on systemwide efforts to improve health care access, disease prevention and the promotion of healthy lifestyles. Leading causes of death in the United States in 2004 included heart disease, cancers, stroke, and chronic lower respiratory disease, each of which often result from or are made more severe by health behaviors such as improper dietary habits, lack of physical activity or smoking (National Center for Health Statistics 2004). Managing chronic diseases is also increasingly important as the population ages and people with chronic illness survive longer. Health professionals and organizations can influence these trends by helping the people they serve understand how specific behaviors affect their health and that of their families and communities. While some of this information can be conveyed during individual clinical encounters and in the materials provided by hospitals, clinics, health plans, pharmacies and others, changing a population's beliefs and behaviors requires communication efforts at the community level (Goode 2001, U.S. DHHS 2000).

Communities are often defined by geographic boundaries, but they can also be defined by race, ethnicity, primary language, immigration history, past experiences, social roles, beliefs and values, educational and economic status, or other affinities and factors. Health professionals form a community, as do police officers, school children, employees of a firm and so on. Because of this complexity, community engagement in health care is a broad set of activities—"the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues that affect the well-being of those people" (CDC and ATSDR 1997).

Community engagement allows an organization to interact with individuals, their families and support structures, well beyond the few opportunities when the individuals encounter the organization as patients, customers or enrollees.

■ Engaging community entities such as radio stations, faith-based organizations, schools, adult education groups and supermarkets, provides a wide range of opportunities to present health messages in gradual, nonthreatening ways.

■ Receiving information about disease management from an employee assistance program or having a religious leader reinforce advice about healthy lifestyles can help individuals incorporate desired changes into their lives more easily and consistently.

■ Engaging communities may be the most effective strategy for addressing aspects of good health that lie outside the direct reach of health care delivery organizations.

A community is "a framework for living rather than [merely] a political jurisdiction—a complex network of people, institutions, shared interests, locality, and a sense of psychological belonging" (Goode 2001, Warren 1978).

For some populations, the primary trusted source of health information will be a leader or group in the community that is not a direct provider of clinical care. This situation is probably most common when the population has difficulty understanding, or is not targeted to receive, standard health care messages.

■ Every community has leaders and groups it relies on for trusted information.

■ A health care organization should identify these sources and work with them to help clarify community priorities and to convey information back to community members about disease prevention, health promotion and available health care resources.

- By doing this, an organization can begin to overcome mistrust, misunderstanding or apathy that sometimes characterizes the relationship between communication-vulnerable populations and the health care system (NPHHI 2004).

> **Example: Partnering with Local Organizations for Community Outreach**
>
> Workforce members from the Community Outreach and Interpreter Services department at Caritas Good Samaritan Medical Center (Brockton, MA) visit elementary schools during parent-teacher conferences to help enroll children in health plans; they regularly go to local festivals, religious services, and even laundromats to do health care outreach; and they help local Councils on Aging with interpretation at blood pressure and other screening events. The manager of the department also sits on the boards of the local rotary club, hospice and community college.

What Should an Organization Do?

An organization should be proactive in understanding the populations it serves, the communities these populations live in, and the locally available health care resources. An organization should make its workforce members aware of the resources that individuals are likely to have because this can affect what health recommendations the individuals will and will not be able to follow.

An organization can build understanding through active dialogue with the groups that are vital to the community's social fabric. An organization should have a standing body (e.g., community liaison committee) that includes senior managers and has the authority to set internal goals for community partnerships.

- This body should ensure the organization sends consistent messages to the community and always has identifiable and accessible points-of-contact.

- The body should be directly accountable to senior leaders to guarantee consistent support for community partnering activities.

- A smaller organization that is unable to maintain a standing body might commit a single workforce member to this role or partner with local organizations to form a shared body.

- Members of the body should approach individuals who have a role in improving the community's health and who can serve as effective partners and allies, including representatives of government agencies, local businesses, not-for-profit organizations, adult education organizations and religious groups (Public Health Foundation 1999).

Optimal partners will be those most familiar with the resources available in the community and the resources that community members need. An organization can identify and integrate partners continuously, but the relationships should be built on reciprocal trust, respect, shared objectives and recognition of mutual benefits.

An organization and its partners should assess the key health needs and issues in the communities they serve; they should establish what health outcomes are desired and achievable; and they should assign responsibility for reaching goals (Minkler 1990). Together they should identify needs and anticipate long- and short-term investments to assure their needs are met.

An organization should educate the community about initiatives and resources as well as gather information from the community about its need for specific programs, barriers to receiving sufficient health care, and resources the community has available. If an organization and its partners identify barriers to patient-centered communication that cannot be resolved on a local level, they should identify ways to work together to advocate for policy and regulatory changes.

An organization should include members of relevant communities in its strategic planning processes (NICHQ 2005). This will ensure that each community's values and needs are considered as the organization prioritizes programs, needs assessments, educational programming and outreach activities. Community partners can help craft messages that will reach individuals and will have a positive impact on their own health.

Limitations and Barriers

Addressing community needs can take a lot of resources. In some cases, an organization might have to make difficult decisions about which community needs receive limited resources. Balancing the use of limited resources is always challenging and it requires information about what needs exist. When all of a community's needs cannot be met, it is critical to engage the community in setting priorities.

Occasionally, community desires for services might actually be at odds with professional standards of medical care.

- In extreme cases, an organization could produce worse health outcomes as a result of being attentive to unconventional community demands.

- In such situations, careful balancing is required to avoid breaches of professional standards of care while maintaining community engagement.

For an organization without a track record of reaching out to local communities, it can be difficult initially to convince community groups to join and contribute to a long-term partnership. In this situation, the organization might have to begin by partnering with a few receptive groups. Working with these groups can establish its commitment to the community and lead to additional relationships over time.

Performance Expectations: Table 3

This table lists specific performance expectations that an organization should be able to meet in its efforts to identify and bridge gaps in communication. All organizations will not be able to meet every expectation right away. Some expectations might be goals to strive for over time.

		Expectation
1.0		The organization has a written plan for engaging the communities it serves to achieve effective health care communication, especially the communities' communication-vulnerable populations.
	1.1	The organization involves representatives of the communication-vulnerable populations it serves in its planning processes.
	1.2	The organization has written criteria outlining the types of activities that should be communicated to and reviewed by its communities.
	1.3	The organization has a strategy for obtaining community feedback on the effectiveness and impact of its activities to improve communication.
2.0		The organization has a point-of-contact (person or office) that is accessible to community members to help address communication needs.
3.0		The organization has an individual or committee charged with developing and maintaining ties to community partners.
	3.1	The organization works with its community partners to facilitate communication outside of clinical encounters, emphasizing the needs of communication-vulnerable populations.
	3.2	The organization and its community partners work together to identify resources, services and assets available within the community to aid in communicating about health and health care, especially for communication-vulnerable populations.

Implementation Notes

1.0: This plan might be a section of an organization's larger strategic or operational plan, or it might be a separate document. It need not be long or complicated to be useful. It should address relevant communication-vulnerable populations; strategies for working with communities to achieve communication goals; and measurable indicators of success.

1.1: When possible, representatives of the predominant communication-vulnerable populations being served should be involved in an organization's planning and quality improvement processes (e.g., via advisory boards, committee participation and/or focus groups).

■ Appropriate representatives may come from community organizations (e.g., faith-based organizations, community centers, senior centers, adult education groups, libraries, etc.) or from patient groups (e.g., diabetes associations, cancer support groups, etc.)

■ Leaders from local government and business groups who are familiar with community resources and the public health infrastructure may be effective partners to help establish and invest in short- and long-term goals.

■ Recruit members for community advisory boards by disseminating invitation letters to those who have contacted the organization about communication needs, either met or unmet (COSMOS 2003).

1.2: Examples of activities that have an impact on the communities of communication-vulnerable populations and that should be developed with community feedback include:

■ Creating and disseminating new strategic plans.

■ Creating a new educational campaign.

■ Developing a new language access program or new interpreter program. In this case it is especially important to involve the populations that speak the target languages.

1.3: A health care organization should develop a way to get feedback from communities about communication needs and barriers and, more specifically, on communication programs, projects and educational materials as they are being developed (for example, holding community roundtables or focus groups). Surveys that are appropriately translated and developed at the proper health and general literacy levels also may be of value, though many surveys do not achieve satisfactory response rates, especially among communication-vulnerable populations.

2.0: Having a consistent point-of-contact for communication initiatives (and, for that matter, any community initiative) will help establish and maintain long-term, productive relationships.

3.0: Different types of organizations are addressing this issue in uniquely appropriate ways. For example, hospitals often have a community advisory board specifically to serve this function. Other committees often include members of the community to provide feedback and build support. Health plans sometimes invite enrollees to participate on a variety of committees along with plan administrators and practitioners. Purchasers might include employee representatives on committees that inform decisions about health care benefits (Wynia et al. 2004).

3.1: A health care organization should work with community partners to bring health care communication and education to communication-vulnerable individuals in the community. This can be done via health fairs, seminars, school visits, displays at libraries or senior centers, partnerships with faith-based organizations or other outreach activities.

■ Health fairs and other activities should include both organizational and community staffing and development. For instance, an activity might be sponsored by an organization and staffed by community members as well as by its professional workforce members.

■ Community groups and faith-based organizations can help address health literacy by sponsoring talks and seminars on health promotion, disease prevention and managing chronic conditions.

■ Community members, either as employees or volunteers, can be involved in projects to facilitate community members' use of an organization. An example of such a project is the Native American Patient Navigator Program, cosponsored by the National Cancer Institute's Center to Reduce Cancer Health Disparities and the Northwest Portland Area Indian Health Board (Swan 2004).

■ Communication strategies should use technology to help bridge communication gaps that separate many populations from sources of health and health care information. In addition to traditional outreach mechanisms, such as radio or television, innovative uses of beepers, the Internet, and cellular phone text features can provide individualized messages, such as chronic care reminders.

When necessary, organizations should also work together with health care and community partners to advocate for policy and regulatory changes to improve patient-centered communication, especially on behalf of communication-vulnerable populations that often have few advocates and little political influence.

3.2: Neither health care organizations nor community groups alone are likely to be able to provide communica-tion-vulnerable populations with services to meet all their communication needs. By working together to share resources and develop referral relationships, each partner can convey information and respond to the communication needs of communication-vulnerable populations more effectively, both within and outside of individual clinical encounters.

Large health care organizations such as national health plans, managed care organizations, pharmacy chains, and major employers can form partnerships to disseminate information at a broad level. They can also partner with local groups to target specific populations. Good examples include the Spanish language health awareness campaigns led by the media company Univision Communications Inc., or the cross-cultural disease-specific awareness campaigns developed by national groups such as the American Heart Association (American Heart Association, Univision 2003).

A smaller organization that does not have the resources to create and test novel initiatives can still work within its communities to communicate local messages and build trust among its populations. In addition, organizations of all sizes might consider working with or through local offices of larger national groups to take advantage of educational materials and national campaigns that have already been created.

Selected Resources

Administration on Aging. Achieving Cultural Competence: A Guidebook for Providers of Services to Older Americans and Their Families. Washington, DC: US Department of Health and Human Services; 2001. *www.aoa.gov/prof/adddiv/cultural/CC-guidebook.pdf*

CDC/ATSDR Committee on Community Engagement. Principles of community engagement. Atlanta, GA: Centers for Disease Control and Prevention, Public Health Practice Program Office; 1997. *www.cdc.gov/phppo/pce/index.htm*

Economic and Social Research Institute. Community Voices: Lessons for National Health Policy. Washington, DC: Economic and Social Research Institute; 2004. *www.wkkf.org/Pubs/Health/Lessons_for_National_Health_Policy_00250_03762.pdf*

Goode T. Policy Brief 4: Engaging communities to realize the vision of one hundred percent access and zero health disparities: a culturally competent approach. Washington, DC: National Center for Cultural Competence, Georgetown University Center for Child & Human Development; 2001. *http://gucchd.georgetown.edu/nccc/documents/ncccpolicy4.pdf*

Content Area 4.
Develop Workforce

An organization should ensure that the structure and capability of its workforce meets the communication needs of the populations it serves, including by employing and training a workforce that reflects and appreciates the diversity of these populations.

Quick tips:

Use local colleges and community groups to help recruit staff from your community.

Provide tips on improving communication skills during meetings/trainings.

To provide the highest quality care, every health care organization must make sure its workforce can communicate health care information and elicit information from individuals in a way that is understandable, accessible and sensitive to individual needs, beliefs and preferences.

■ An organization should maintain a workforce that reflects the diversity of the populations it serves.

■ An organization should take steps to make sure its workforce members, at all levels, respect the populations they serve and can communicate effectively.

An organization's workforce includes its full- and part-time employees, contract employees, consultants, volunteers and students. While each of these groups can have different roles within the organization, all must be aware of the organization's commitment to effective communication.

There are many reasons why a diverse workforce can improve communication about health and health care. A diverse workforce will have a range of experiences and ideas that contribute to information sharing, development of innovative approaches to communication, and the ability to respond quickly to changing communication needs (Powe and Cooper 2004, Sullivan Commission 2004). Having a diverse workforce is especially important for an organization that serves populations from multiple language, cultural, educational, and socio-economic backgrounds. When individuals encounter workforce members that they can relate to, they may share more information and be more receptive to the information they receive.

Racial and ethnic minority patients are more likely to choose physicians with backgrounds similar to theirs, are more satisfied in racially concordant patient-physician relationships, and view the quality of their heath care more favorably when their physician has a similar background to theirs (IOM 2004b, Cooper et al. 2003, Laveist and Nuru-Jeter 2002, Cooper-Patrick et al. 1999).

Many health care organizations will have a hard time building a workforce that reflects the populations it serves. Today, the pool of health care professionals does not represent the diversity of individuals in the United States. For example, over 25 percent of the United States population is African American, Hispanic American or American Indian; but only 9 percent of nurses and 6 percent of physicians come from these groups (Sullivan Commission 2004).

■ A health care organization must train workforce members in the skills and resources they need to communicate with individuals from any background (Karliner et al. 2004).

■ This requires ongoing efforts to reinforce that workforce members should communicate in clear and simple terms, identify and track communication needs and preferences, access and work with interpreters and be aware and respectful of cultural differences.

Example: Training Should Be Flexible and Frequently Reinforced

Leaders at Woodhull Medical and Mental Health Center (Brooklyn, NY) recognize that workforce training requires multiple approaches that are creative, accessible and flexible. They suggest keeping training sessions short (under 1 hour) and offering them at multiple times or as a series; creating computer-based training; using a town hall meeting format (offered once in the morning and again in the afternoon); making some trainings voluntary and others mandatory; and maintaining a video and resource library for use by departments for specific training needs.

What Should an Organization Do?

To maintain a capable workforce with good communication skills, an organization should plan workforce development for all stages of the work cycle—recruitment, training and retention. This should include steps to improve workforce satisfaction and opportunities for advancement. As part of the strategic planning process, an organization should set feasible goals for workforce diversity and training (Thomas 2004). Strategies to meet these goals should include suggestions from community members on how to attract qualified people from the community to open positions. A senior leader should be responsible for progress toward workforce and training goals (Henault 2004).

Recruit: An organization should recruit workforce members to meet its current and potential populations' demands for language assistance and other services.

- Help students experience what it is like to work in a health care organization by setting up internships and other training models in collaboration with local schools and colleges.

- Collaborate with local educational institutions, professional associations, trade organizations, and labor and social service agencies to advertise positions.

- If appropriate, make a proportion of first contact or customer service positions bilingual.

- Create incentives to attract individuals with particular language skills into the workforce. This might include structuring pay scales to include modest pay differentials for employees with desired language or communication skills.

Train: An organization should conduct regular training sessions to improve the ability of relevant workforce members to communicate with diverse populations. This might include how to:

- Communicate professionally in unfamiliar or difficult situations, access language assistance services, work with interpreters, negotiate across religious and cultural beliefs, determine an individual's preferred level of autonomy, and make sure individuals understand the health information they are given (U.S. DHHS HRSA 2005, Karliner et al. 2004, Makoul 2001, Clark et al. 1999, Roter and Hall 1993).

- Communicate consistently with coworkers about an individual's care or other services.

- Communicate understandably with individuals about routine issues, such as treatments or insurance coverage or in emergencies, such as during an evacuation.

Training opportunities should help workforce members reflect on the ways their personal health-related values, biases and beliefs influence how they view and interact with others. Meeting long-term training goals requires organizations to integrate and reinforce key messages. Thus, information about the role and importance of good communication should be presented in a range of flexible and accessible formats (i.e., as part of new employee training, mandatory and voluntary training, informal peer-to-peer training, seminars and online training modules.)

If an organization's mission includes training health care workers for other areas of the community or health care system (as in academic medical centers, for example), there should be a strategy to effectively provide trainees with the skills to communicate across cultures, languages and health literacy levels. There should also be a plan for transitioning trainees to their new positions.

Retain: For workforce members who want a career at the organization and have good communication skills, there should be a plan for retention and advancement. An organization should:

- Make salaries and benefits competitive with similar organizations in the community and appropriate to the roles that the workforce members play in the organization.

- Give workforce members opportunities to work with mentors. Mentors help workforce members integrate across the organization, develop skills such as negotiation and communication, and build leadership qualities such as respect and empathy.

- Establish educational partnerships with local institutions, regular training and certification opportunities, and tuition reimbursement programs.

Assess: An organization should conduct regular (generally at least annual) assessments of how well it achieves its goals for workforce training and diversity. It can do this by:

- Comparing the demographics of its workforce and leadership to quantitative goals and to the demographics of the populations it serves.

- Regularly assessing workforce members on communication skills.

Assessments should be done department by department and job class by job class, to make sure no area is neglected and that workforce members' skills are appropriate to each level and sector. As indicated by the assessments, an organization should adjust its training strategies and schedules to ensure workforce members receive training on the skills they need and will use.

Limitations and Barriers

It is often difficult for an organization to develop a workforce that can meet all the communication needs of its populations. An organization has to decide how specific to make diversity goals. Goals should be realistic and based on the availability of qualified candidates both now and in the future. Health care organizations should play a role in expanding the pool of qualified applicants.

An organization also should be aware of the burdens that might be placed on workforce members who are more capable of communicating with specific individuals and populations.

- Workforce members who are expected to serve as interpreters should have this duty listed on their job description.

- They should also receive appropriate interpreter training and a clear explanation of different situations in which they may be asked to interpret.

- Leaders should consider providing guidance for specific communication roles. For example, workforce members/contractors who work only as trained medical interpreters; bilingual staff members who are trained to do medical interpretation in addition to their primary job; bilingual staff members who provide services in multiple languages but do not perform medical interpretation; and staff members who are not fluent but can speak a few words of one or more languages (*see also Content Area 5b: Language*).

Finally, individuals who encounter workforce members from their culture or country of origin might occasionally expect favors or special treatment from these workforce members. An organization should make workforce members aware of this potential and train them on what to do and how to communicate if it occurs.

An Ethical Force Program™ Consensus Report

Performance Expectations: Table 4

This table lists specific performance expectations that an organization should be able to meet in its efforts to identify and bridge gaps in communication. All organizations will not be able to meet every expectation right away. Some expectations might be goals to strive for over time.

		Expectation
1.0		The organization has a written plan that includes goals and policies for maintaining a workforce that meets the needs of the populations it serves—especially its communication-vulnerable populations.
	1.1	The plan addresses developing a workforce with members from diverse backgrounds.
	1.2	The plan addresses training members of the workforce on communication skills.
	1.3	The organization monitors achievement of the plan's goals, assesses the effectiveness of the plan's policies and updates the plan as necessary.
2.0		Within its workforce, the organization cultivates an atmosphere of respect, both among members of the workforce and for the individuals they serve.
3.0		The organization partners with educational institutions and other community organizations to achieve workforce goals and enhance services, especially for communication-vulnerable populations.
4.0		The organization trains its workforce on how to communicate, especially with individuals from communication-vulnerable populations.
	4.1	The organization provides financial support for communication training.
	4.2	Training for each job classification is based on the needs and responsibilities of workforce members in that classification.
	4.3	Relevant members of the workforce are trained on topics and skills including: a. The importance of effective communication to health care. b. The organization's communication policies, including how to access interpreters and translated materials. c. How to work with an interpreter and use available language services. d. Procedures for collecting information from individuals on primary language and communication method. e. Exploring one's own cultural background and the cultural backgrounds of individuals and populations served. f. How to communicate in clear and simple terms. g. Ways to identify and respond to individuals' desired levels of autonomy. h. How to elicit individuals' needs, beliefs and values, and health care preferences. i. Techniques to check if individuals understand information that is provided.
	4.4	The organization evaluates the relevance and effectiveness of communication training and responds with adjustments that address the unmet needs of its workforce.
5.0		The organization recognizes or rewards individuals and departments that are working to improve patient-centered communication.

Implementation Notes

1.0: The plan should describe how the organization recruits, trains and maintains a qualified workforce across all levels of the organization. The plan should assign accountability and authority for meeting the goals it outlines. An organization's workforce includes its full- and part-time employees, contract employees, consultants, volunteers, students, etc.

1.1: This does not mean the number of workforce members must be proportional to the number of individuals who speak a particular language or come from a particular background, but it does mean a workforce that is:

■ Representative and respectful of, and can communicate with, the populations it serves

■ Trained to communicate across cultures, languages and health literacy levels

Developing a workforce with members from diverse backgrounds improves an organization's ability to communicate and interact with its communication-vulnerable populations by:

■ Broadening the perspectives from which the organization can draw when it needs to respond to changing populations.

■ Creating a welcoming environment in which communication-vulnerable populations will feel comfortable communicating.

■ Supporting a learning environment where members of the workforce can use each others' experiences to develop and refine effective communication strategies.

1.2: Workforce members should be trained to refer individuals to appropriate resources, such as heath educators and community health workers.

1.3: Plans should be routinely reassessed and revised according to new information about performance *(see also Content Area 6: Evaluate Performance)*.

3.0: This might include working with primary and secondary schools to introduce health care careers to students; partnering with colleges and universities to create internship and training programs; and working with communication-vulnerable populations to help attract individuals to the health care professions as potential career options.

4.0: For workforce members who have frequent contact with the populations being served (patients, enrollees, customers, employees), this training may be more extensive than for other workforce members. However, all workforce members should at least receive an orientation.

Information about the role and importance of good communication should be presented in a range of flexible and accessible formats (e.g., as part of new employee training, mandatory and voluntary training, informal peer-to-peer training, seminars, online training modules, etc.).

■ Communication training does not have to be long or demanding, and can be integrated into various existing training sessions, meetings and other events.

■ Training should be consistent, using recognized teaching tools. If new tools/curricula are being used, then these should be carefully evaluated.

■ Senior leadership should be involved in training programs.

■ Training should help workforce members reflect on the ways their personal health-related values, biases and beliefs influence their interaction with others.

Online training modules have been developed by the Office of Minority Health and the Manhattan Cross Cultural Group (U.S. DHHS OMH, Critical Measures). Some training programs are also available in VHS or CD-ROM formats (American Academy of Family Physicians, Grainger-Monsen and Haslett 2003).

4.1: Examples of financial support include paying for members of the workforce to attend training sessions, bringing in trainers to conduct workshops, or having one or more members of the workforce complete a train-the-trainer program to bring information/training back to the organization. An organization will need to make sessions accessible by providing them at multiple times and by planning for human resources coverage to allow staggered attendance.

4.2: Training curricula should be based on what workforce members need to know to do their jobs. Communication roles can range from routine discussions about health and health care to provision of evacuation information during emergencies. In all cases, an organization should have a method for assessing whether it is providing its workforce with the training it needs. This assessment should include talking to workforce members.

4.3: Training should avoid simplistic generalizations that can lead to stereotyping of individuals from communication-vulnerable populations. Training should emphasize sensitivity to variations within populations as well as among populations, including individual variations in beliefs, expectations and preferred modes of communication. Training should help all members of the workforce develop the knowledge and skills needed to explore these variations during the course of care or service.

a: The first goal of training is to help workforce members understand that effective communication is integral to building trusting relationships, ensuring health care quality and meeting safety requirements.

b, c: Relevant members of the workforce should be trained on the importance of using trained, qualified medical interpreters. They should learn about the types of interpretation services that are available, how to access these services and how to work with an interpreter.

d: In particular, workforce members need to know how to respond to questions about why information about race, ethnicity and primary language is collected.

e: Role playing exercises are one strategy to help familiarize practitioners and other workforce members with their own beliefs and values and those of the individuals and populations they serve. They can also prepare the workforce to communicate in unfamiliar or difficult situations.

f: *See also Content Area 5c: Health Literacy.*

g, h: Workforce training should include suggestions on how to elicit an individual's health-related needs, beliefs and values, preferences, and preferred level of autonomy and how to structure interactions to respect each of these issues.

i: For example, training workforce members to use the "teach back" method can improve communication and understanding with the individuals they serve *(see also Content Area 5c: Health Literacy)*.

Selected Resources

American Academy on Communication in Healthcare
www.aachonline.org/

The Association of Professional Chaplains
www.professionalchaplains.org/

American Medical Association Foundation. Health Literacy: Help Your Patients Understand. Chicago: AMA Press; Oct 2003. *www.ama-assn.org/ama/pub/category/8115.html*

Bayer Institute for Health Care Communication
www.bayerinstitute.org/index.php

The Center for the Health Professions. Strategies for Improving the Diversity of the Health Professions. The California Endowment; Aug 2003. *www.futurehealth.ucsf.edu/pdf_files/StrategiesforImproving FINAL.pdf*

Community Catalyst. The Color of Medicine: Strategies for Increasing Diversity in the U.S. Physician Workforce. Washington, DC: WK Kellogg Foundation, The Robert Wood Johnson Foundation, and The Henry J. Kaiser Family Foundation; Apr 2002. *www.communitycatalyst.org/resource.php?doc_id=325*

Doak LG and Doak CC, ed. The Pfizer Principles for Clear Health Communication. Pfizer Clear Health Communication Initiative; 2003-2004. *www.pfizerhealthliteracy.com/improving.html*

Gilbert MJ, ed. A Manager's Guide to Cultural Competence Education for Health Care Professionals. The California Endowment; 2003. *www.calendow.org/reference/publications/cultural_competence.stm*

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Institute for Diversity in Health Management
www.diversityconnection.org/

Institute of Medicine Committee on Institutional and
Policy-Level Strategies for Increasing the Diversity of the
U.S. Health Care Workforce. In the Nation's Compelling
Interest: Ensuring Diversity in the Health Care Workforce.
Washington, DC: National Academy Press; 2004.
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Strategies for Leadership. Does Your Hospital Reflect the
Community It Serves? Diversity and Cultural Proficiency
Assessment Tool for Leaders. Chicago: American Hospital
Association; 2004.*www.diversityconnection.org/
userdocs/uploads/5_leadership_ifd.pdf*

The Sullivan Commission on Diversity in the Healthcare
Workforce. Missing Persons: Minorities in the Health
Professions. Washington, DC: The Sullivan Commission;
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documents/Sullivan_Final_Report_000.pdf*

U.S. Department of Health and Human Services Health
Resources and Services Administration. Transforming the
face of health professions through cultural and linguistic
competence education: The role of the HRSA Centers of
Excellence. Washington, DC; 2005.

Content Area 5.
Engage Individuals

An organization should help its workforce engage all individuals, including those from vulnerable populations, through interpersonal communication that effectively elicits health needs, beliefs and expectations; builds trust; and conveys information that is understandable and empowering.

Quick tips:

Ask the people you serve how they need to receive health-related information.

Make sure people know whom to ask when they need help making decisions or have questions about their health care.

In its report, "Crossing the Quality Chasm", the Institute of Medicine recommends that the U.S. health care system become more patient-centered to help individuals actively participate in their own health care (IOM 2001). The report noted that "systems must be designed to serve the needs of patients, and to ensure that they are fully informed, retain control and participate in care delivery whenever possible, and receive care that is respectful of their values and preferences." For this type of system to work, all individuals must feel confident that they have the knowledge and ability to participate. This means every health care organization—including hospitals, physician practices, pharmacies, health plans and others—must commit to engaging all the individuals it serves.

An organization should encourage individuals to take responsibility for their own health, to participate in making health care decisions and to set goals for their health care.

- To be engaged in their own health care, individuals need accurate information that they can understand and use.

- Individuals should feel comfortable asking questions. They should not have to struggle to learn about preventive measures, tests, treatments or other services they may need (Green 2004, Laine and Davidoff 1996).

- For individuals with varying levels of health literacy, limited English proficiency, or who may come from diverse cultural backgrounds—that is, communication-vulnerable populations—failure to receive health

information in ways they can understand and use may be a significant barrier to becoming engaged in their health care.

Communication. Good interpersonal communication between patients and their health care practitioners often determines patient perceptions, trust in the physician, patient loyalty, adherence to treatment schedules and overall positive health outcomes (IOM 2003, Safran et al. 2001, Clark et al. 1999, Gordon et al.1995, Stewart 1995, Roter and Hall 1993, Kaplan et al. 1989).

- Only with good communication and information exchange can health care professionals and the individuals they serve bridge the gap between lay and professional views of medical conditions and health care treatments (Ashton et al. 2003).

- It is important for a health care organization to communicate with individuals in ways that are accessible, understandable, compassionate and encouraging (AMA 2004a, AHA 2003, ASHP 1999, National Business Group on Health).

Informed consent requires good communication. Informed consent is not a signature on a form; it is a process that applies to all health care interactions. To get valid informed consent, health care professionals—whether delivering care, services or products—must engage individuals in a discussion about risks, benefits and alternatives. This interaction is central to informed consent, regardless of whether a form, video, computer program, or other resource is used to help someone provide the information.

Trust. Engagement requires shared trust between individuals and the professionals and organizations they rely upon for health care.

- For example, lack of trust can prompt patients to question their physicians' decisions and seek information on their own. Research has shown that good communication is related to more trust and that patients who trust their physicians benefit from an improved therapeutic bond and better healing (Safran et al. 1998, Thom 1997).

- Trust is a fundamental element of the medical profession, and maintaining trust should be a focal point of physician practices, hospitals, health plans, pharmacies and the health care system overall.

Due to personal experiences, cultural biases and other factors, some individuals can have more or less trust than others (Siminoff et al. 2004, Boulware et al. 2002, Minniefield et al. 2001, Blackhall et al. 1999, Freedman 1998, Yuen et al. 1998, Gamble 1997, Hauser et al. 1997).

- Workforce members should recognize the role of mutual trust in patient (or customer, enrollee, employee) engagement.

- Workforce members should understand the importance of good communication to building trusting relationships.

- Workforce members should be aware of and sensitive to cultural and language differences and the impact of mistrust on an individual's ability and willingness to communicate effectively.

Additional information is provided in the next three content areas on communicating across cultures, languages and health literacy levels.

Example: Using Group Settings to Reach Individuals

San Francisco General Hospital uses group health care visits to engage patients in their own care. For example, diabetes groups bring patients together once a month for group education, discussion, and clinical check-ins. Each session has a set discussion agenda, but it is often replaced with what patients want to talk about. Patients that participate are often low income, indigent, or homeless, and many lack trust in the health care system and are challenged to perform their self-care. Each month, patients create their own action plans that focus on what is important to them and what they feel they can achieve to improve their health.

What Should an Organization Do?

An organization should help individuals become informed and engaged in their own health care.

- Ask individuals how they prefer to receive information and communicate about health care.

A health care delivery organization can promote patient-centered communication by training its clinicians to use narrative medicine. With narrative medicine, a clinician gets a fuller understanding of an individual's health care needs by having the individual describe his or her health concern, condition or experience as a story. The information and emotion conveyed by the story is then used as part of the medical evaluation (Charon 2004, DasGupta and Charon 2004).

- This is especially important for individuals who require language assistance, including those who are deaf or hearing-impaired.

- This information should be included in individuals' files or records and made accessible to relevant workforce members (*see also Content Area 2: Collect Information*).

An organization should make sure its workforce members, at all levels, have the time, training, cultural awareness and resources available to effectively communicate with individuals from diverse backgrounds and with a range of communication needs. Professional workforce members, in particular, need sufficient time with each individual to build relationships; they need language services available when necessary; and they need to have organizational support to address individual needs, beliefs and expectations once they are determined.

It is important for an organization to train professional workforce members to talk to individuals about decision-making roles.

- Some individuals will want to make their own decisions, while some will want to make decisions in collaboration with their families.

- Some individuals might be more comfortable deferring to their physician or another health care professional to guide their health care decisions—this too can be patient-centered, if it is based on the patient's needs, beliefs, values and preferences.

To help individuals make decisions about their health care, an organization should develop and offer shared decision-making programs (Wilson et al. 2005b, O'Connor et al. 2003, O'Connor et al. 1999a, O'Conner et al. 1999b, Research Triangle Institute 1997). With more knowledge about their options and conditions, individuals can experience less conflict about decisions and feel more comfortable taking active roles in decision making (O'Conner 1999b).

Finally, an organization should offer opportunities for individuals to provide feedback about their care and unmet needs. This can be done via perception surveys, interviews, focus groups, comment boxes, telephone numbers or e-mail addresses. Advocacy or ombudsman programs can also help an organization learn about individuals' needs and expectations.

Example: Helping Individuals Participate in Their Own Care

The Lance Armstrong Foundation provides the "LIVESTRONG™ Survivorship Notebook" free of charge to cancer patients. The notebook provides education, cancer survivors' stories, resources for engaging the health care system, and a place for patients to take notes on their cancer care. It is designed to be portable so that patients can bring it to appointments and use it during all their interactions with the health care system.

Limitations and Barriers

For patient-centered communication to work, an organization must accommodate individuals with different levels of interest in engagement and personal control over their health care.

- Many individuals today want to expand the lines of communication between themselves and the organizations providing and financing their health care. These individuals will often engage quickly and play an active role in their health care by asking questions and conducting their own research.

- Other individuals might hesitate to take this active role, perhaps due to mistrust, fear, or because they do not understand complex medical information. Health care professionals should strive to engage these individuals and address their concerns.

- Some might truly prefer a more passive role, which relies on their physicians or other health care professionals as their primary source of information, advice and even decision making.

Some individuals prefer to remain less engaged in health care decisions for legitimate reasons, including their culture, religion, age, or background and other experiences *(see also Content Area 5a: Socio-Cultural Context)*. An organization should generally respect these reasons. However, organizations and workforce members should avoid making assumptions about what individuals know or what they want based on generalizations, or stereotypes, about an individual's background. A health care organization should train its workforce members to engage individuals according to each individual's preferences.

- As an organization focuses on patient-centeredness and emphasizes the roles individuals should play in their own health care, it is important that individuals who choose to remain less engaged are not harmed as a result of this choice (Thomson et al. 2001).

Finally, a health care organization needs a strategy for deciding whether or how to accommodate unusual communication preferences.

- In certain cases, meeting the needs or preferences of one individual will infringe on the rights of another.

- For example, a patient might request that only workforce members of a particular gender, race or cultural background attend to them.

While some requests might be easy to accommodate, others will be more difficult. Some might even contradict existing policies or laws (such as those regarding nondiscrimination) or set a bad precedent. Such accommodations should be considered carefully to ensure that, while an organization maintains flexibility, it does not neglect the needs of other individuals and workforce members. The process for making these types of decisions should be carefully documented.

Performance Expectations: Table 5

This table lists specific performance expectations that an organization should be able to meet in its efforts to identify and bridge gaps in communication. All organizations will not be able to meet every expectation right away. Some expectations might be goals to strive for over time.

See the box on page 23 for more information on applying the expectations in the table.

		Expectation
1.0		The organization promotes the importance of effective communication to building trusting relationships and emphasizes how closing communication gaps due to socio-cultural, language and health literacy issues can improve health outcomes.
2.0		The organization has programs to help communication-vulnerable populations navigate the health care system to appropriately use health care resources.
3.0		The organization helps its workforce members communicate with individuals about how decisions are made and their role in shared decision making with respect to treatment choices and health care goals.
4.0		The organization helps individuals make decisions by providing them with information about their health and health care that is timely, sufficient, understandable, usable and, when appropriate, confidential.
5.0		The organization helps its workforce provide guidance for individuals on self-care, disease prevention, treatments, or other health care services.
6.0		Individuals have and are aware of opportunities to provide the health care organization with feedback.
	6.1	Perception of care surveys are translated into languages spoken and read by the communication-vulnerable populations served, and are in culturally appropriate formats.
	6.2	The organization considers the length, complexity and format of surveys being given to communication-vulnerable populations in relation to standardized levels of health literacy.
	6.3	Focus groups are convened on a regular basis to get feedback on the perceptions of care and communication needs of communication-vulnerable populations.
7.0		Workforce surveys and focus groups are conducted on a regular basis to learn about attitudes and understanding of methods for effective communication.
8.0		The organization works with its professional staff to structure services in a way that allows sufficient time for effective communication and relationship building with individuals from communication-vulnerable populations during health care encounters.

Implementation Notes

1.0: Workforce members must understand that positive health outcomes rely on good communication.

■ Bridging communication gaps can help an organization address mistrust, nonadherence, and other factors that influence health outcomes.

■ Workforce members must also recognize the role of mutual trust. Trust is linked to communication and often influences how actively individuals participate in their health care.

2.0: Community members can serve as health system navigators. Navigator programs are designed to facilitate interactions within an organization by using trusted intermediaries from the community. Navigators might help individuals arrange transportation to an appointment, coordinate babysitting, find their way around different departments in an organization, and so on *(see also Content Area 3: Engage Communities, specifically expectation 3.1)* (Patient Navigator, Outreach, and Chronic Disease Prevention Act of 2005, Breast Cancer Demonstration Project 2002, Farber et al. 2002).

3.0: An organization's workforce members (including clinical staff, human resources representatives, advocates, board certified chaplains, etc.) should talk to individuals about establishing decision-making roles. Most individuals prefer to be involved in their own medical decisions, though some prefer to have their physicians or family members make their decisions for them. To effectively communicate with individuals from communication-vulnerable populations, workforce members must be aware of who will be involved in decision-making processes.

4.0: To become engaged in their own health care, individuals need accurate information about their health and health care. This information needs to be available in appropriate languages, at a sufficiently broad health literacy level, and it must be presented in a way that is respectful of individuals' cultures.

6.0: Examples of ways an organization can provide individuals with opportunities for feedback include perception of care surveys or focus groups, 1-800 numbers, comment boxes, and e-mail addresses. When possible, an organization should acknowledge and respond to comments, especially when concerns are raised. If an organization receives a very high volume of feedback, it should develop a way to prioritize those that require immediate response.

6.2: Survey development should take into account variability in individuals' health literacy levels. This includes written surveys, phone surveys and other survey formats. Determination of the appropriate health literacy level for each survey should be based on information available as to the general literacy of the populations that an organization regularly serves *(see also Content Areas 2: Collect Information and 5c: Health Literacy)*.

6.3: Individuals from communication-vulnerable populations often will not fill out or return written surveys. Therefore, an organization should use other methods, such as focus groups, to reach out to individuals from these populations.

Selected Resources

Institute of Medicine Committee on Communication for Behavior Change in the 21st Century: Improving the Health of Diverse Populations. Speaking of Health: Assessing Health Communication Strategies for Diverse Populations. Washington, DC: National Academy Press; 2002. *www.nap.edu/openbook/0309072719/html/*

Joint Commission on Accreditation of Health Care Organizations. Speak Up™ Campaign. *www.jcaho.org/accredited+organizations/speak+up/speak+up+initiatives.htm*

The Lance Armstrong Foundation. LIVESTRONG™ Survivorship Notebook. Austin, TX: The Lance Armstrong Foundation. *www.livestrong.org*

Levin SJ, Like RC, Gottlieb JE. ETHNIC: a framework for culturally competent clinical practice. In Appendix: Useful clinical interviewing mnemonics. Patient Care 34(9):188-9.

Makoul G. Essential elements of communication in medical encounters: the Kalamazoo consensus statement. Bayer-Fetzer Conference on Physician-Patient Communication in Medical Education. Acad Med. 2001 Apr;76(4):390-3. *www.fp.ucalgary.ca/ose/Essential Elements.pdf*

Content Area 5a.
Socio-Cultural Context

An organization should create an environment that is respectful to populations with diverse backgrounds; this includes helping its workforce understand socio-cultural factors that affect health beliefs and the ability to interact with the health care system.

> Quick tips:
>
> Find out if the people you serve can relate to your educational and informational materials.
>
> Talk to the people you serve about how their beliefs and values affect their health care decisions.

Everyone has a socio-cultural context that shapes his or her health-related beliefs, values and practices. The uniqueness of a person's socio-cultural context stems from a range of factors, including race, ethnicity, religion, experience, socio-economic status and education level (IOM 2003). To communicate well with individuals, a health care organization must:

- Recognize the impact of socio-cultural context on how individuals communicate, interact with the health care system and make health care decisions (Napoles-Springer 2005, AHA 2003, ASHP 1997, AMA Policy 65.977, National Business Group on Health).

- Help its workforce members understand their own socio-cultural contexts and the impact these might have on communicating and negotiating with individuals who have different backgrounds, beliefs and values.

- Consider how efforts such as strategic planning and workforce training can improve cultural awareness, responsiveness and overall communication.

Within the National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS standards), culture is defined as "the thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious or social groups" (U.S. DHHS OMH 2001). Together, culture, level of education, socio-economic status and other characteristics form a person's socio-cultural context. Socio-cultural context influences how people understand their health—including their views on sources of illness, effective treatments and prevention (Anderson et al. 2003). When communicating about

health and health care, an organization must be aware of the day-to-day concerns of the individuals it serves. For example, it is important to take into account things like the foods people eat, the activities they engage in, the images and environments they can relate to, and the family members that make up their support systems and decision-making structures (Betancourt 2004).

If workforce members do not have the training and resources necessary to communicate effectively across socio-cultural contexts, the individuals they serve (whether patients, customers, enrollees or employees) can feel that they are not understood or respected and might be less likely to ask questions, trust treatment recommendations and adhere to prescribed regimens (Betancourt 2004, Betancourt et al. 2002, Beach and Roter 2000).

> Organizations that train workforce members to communicate openly and respectfully with individuals from diverse backgrounds have more success in helping these individuals achieve health care goals. Even critical, difficult health care decisions are made more smoothly (Johnson et al. 2004, Beach and Roter 2000).

Every encounter between an individual and a health care organization is unique because it is a function of so many socio-cultural factors. When all of these factors are considered, it becomes impossible to identify, let alone prescribe, any specific set of rules for interacting with individuals from one group or another.

The best strategy is to encourage a learning attitude with open communication and discussion among individuals, families and workforce members to convey information, negotiate options, make decisions and achieve solutions.

What Should an Organization Do?

A health care organization should create an environment where the individuals it serves and its workforce members from different socio-cultural backgrounds feel comfortable communicating. Specific attention should be given to the institution's atmosphere and physical surroundings. For example, an organization might consider how individuals are addressed by the organization and its workforce members, the images included in written materials, and service hours (office, customer service, care delivery, etc.).

An organization should encourage its workforce members to know what populations live in the communities they serve and to watch for changes in these communities.

- An organization should provide regular training to help workforce members understand the importance of socio-cultural issues in good health care.

- Rather than imply that everything about a given culture can be learned in one session, an organization should use training programs that provide strategies for approaching cross-cultural interactions without stereotypes.

- Training programs can be short and can be combined with other training events.

With the right resources and training, workforce members can develop the confidence to work with individuals from any culture or background. More information on workforce training is included in *Content Area 4: Develop Workforce*.

Limitations and Barriers

During cultural diversity training, workforce members sometimes learn about specific practices or beliefs that can make groups different from each other. Because there are so many complex factors that influence socio-cultural context, simply listing common differences between racial or ethnic groups is rarely a good training strategy.

- Assuming that all individuals from a given social or cultural group follow a particular set of beliefs or behaviors ignores the importance of individual differences.

- This can lead to stereotyping and potentially disrespectful generalizations.

- An organization must instead train workforce members to respond to individuals' needs by carefully asking questions, listening to the answers and eliciting views on health and illness (Brach and Fraser 2000).

This limitation does not ignore those instances when there are data showing that specific populations have increased risk or susceptibility to particular diseases or conditions. Clinical risks based on race are very rough tools, but at the moment they are sometimes the best available data to help inform screening decisions. In these cases, individual characteristics should be considered in the context of known population data.

Finally, respecting individuals from diverse backgrounds does not mean health care professionals have to ignore professionally defined standards of medical practice.

- If an individual's beliefs are contrary to medical science, health care professionals should not simply accept decisions based on these beliefs out of respect for cultural difference.

- Health care professionals should explore the basis for an individual's decisions when they are contrary to medical advice. It is important to make sure that rejection of a professional's advice does not result from misunderstanding or mistrust of medical information.

- While individuals have a right to reject medical advice, medical professionals have an obligation to help individuals fully understand their options.

Performance Expectations: Table 5a

This table lists specific performance expectations that an organization should be able to meet in its efforts to identify and bridge gaps in communication. All organizations will not be able to meet every expectation right away. Some expectations might be goals to strive for over time.

See the box on page 23 for more information on applying the expectations in the table.

	Expectation
1.0	The organization creates a physical environment that facilitates communication by fostering a feeling of welcome and comfort for individuals from communication-vulnerable populations.
2.0	The organization prepares its workforce members to communicate with individuals from communication-vulnerable populations they are likely to encounter.
3.0	The organization enables relevant members of its workforce to engage individuals in conversations about their understanding of their health, health care, conditions and treatments.
4.0	The organization has a protocol for identifying and responding to members of its workforce who communicate with individuals in ways that lack respect, compassion or socio-cultural sensitivity.
5.0	The organization ensures that relevant workforce members are aware of and can convey information to individuals about health care resources available in the organization and in the community.
6.0	The organization's scheduling of communication and educational events are sensitive to relevant religious and cultural observances.

Implementation Notes

1.0: An organization should consider:

- Accessibility of the office, both transportation to the office and accommodations for individuals with disabilities or limited mobility.

- Service hours (office, customer service, care delivery, etc.).

- Flexibility in policies and procedures—for example, pharmacies that partner with local delivery services.

- Consideration of how workforce members answer the phone or address individuals.

In particular, a care delivery organization should consider:

- Providing a private place for families to communicate with patients and caregivers.

- Providing access to spiritual and religious leaders and facilities to accommodate the needs of these religions (such as ceremonies or other requests).

- Adjusting protocols and rules to meet the needs of visitors from particular cultures.

- The garments patients are given and the cultural appropriateness of food choices.

This is a partial list of considerations an organization might use to foster a sense of comfort that can encourage effective communication (Lumetra 2002, Andrulis et al. 2001). Additional ideas can be found in the following suggested resources.

2.0: In addition to training on issues noted in *Content Area 4: Develop Workforce*, an organization should provide its workforce members with information on what languages, cultures and religions are common within the populations it serves.

3.0: An organization can enable and facilitate conversations by providing training, funding and time to encourage effective communication.

Engaging individuals in this area can include encouraging appropriate members of the workforce to ask relevant questions about an individual's life outside the health care

system, including their ability to obtain medication and travel to appointments, their family and community support network, and how those support structures influence their decisions.

4.0: An organization should have progressive steps that include recognizing, retraining, mentoring and, when appropriate, disciplining workforce members who demonstrate problems communicating with respect and compassion.

5.0: Some individuals may be unable to pay for their prescriptions, unable to find transportation to the organization, or have other logistical concerns about health care, insurance, etc. An organization should familiarize its workforce with the resources available to address these issues, and provide the information and materials needed to effectively communicate about these resources.

6.0: Communication and educational programs should be scheduled to avoid conflicts with religious and cultural observances. Shared celebrations of cultural events, when appropriate, can help create a welcoming environment.

Selected Resources

Betancourt JR, Green AR, Carrillo JE. Cultural Competence in Health Care: Emerging Frameworks and Practical Approaches. New York, NY: The Commonwealth Fund; 2002. *www.cmwf.org/usr_doc/betancourt_culturalcompetence_576.pdf*

Cross Cultural Health Care Program
www.xculture.org/

DiversityRx. Resources for Cross Cultural Health Care www.diversityrx.org/

Ethnomed
http://ethnomed.org

Georgetown University National Center for Cultural Competence *http://gucchd.georgetown.edu/nccc/*

Lumetra. The Cultural Competence Self-Assessment Protocol for Managed Care Organizations. Centers for Medicare & Medicaid Services; 2002. *www.lumetra.com/healthplans/doc/HP_CulturalCompetencyTool.pdf*

Adapted from The Cultural Competence Self-Assessment Protocol for Hospital Systems developed by Andrulis DP, Delbanco T, Avakian L, Shaw-Taylor Y; 2001. *http://erc.msh.org/provider/andrulis.pdf*

National Initiative for Children's Healthcare Quality. Improving Cultural Competency in Children's Health Care: Expanding Perspectives. Cambridge, MA: NICHQ; 2005.

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Content Area 5b.
Language

An organization should determine what language assistance is required to communicate effectively with the populations it serves, make this assistance easily available and train its workforce to access and use language assistance resources.

Quick tips:

Make sure workforce members know how to contact an interpreter when they need one.

Provide important documents in the languages you encounter most often.

Everyone who enters the health care system should be able to expect a certain level of communication based on one of the core rights of ethical health care: informed consent.

- Individuals should always be respected and should be asked to give informed consent for any medical interventions they receive.

- A health care professional should be responsible for explaining, in a way the individual can understand, the risks, benefits and alternatives to any interventions being considered.

- Individuals must be given the information and opportunities they need to make decisions about their own health (AMA 2004a, AHA 2003, Beauchamp and Childress 2001, ASHP 1999, ASHP 1997, AMA Policy 10.01, AMA Policy 170.986, NBGH).

These expectations are valid regardless of the individual's ability to speak or understand English.

The idea of informed consent clearly applies to health care practitioners and delivery organizations, but it is also relevant to pharmacies, health plans, purchasers and others. Each of these organizations has an ethical obligation to communicate clearly and transparently about the risks and benefits of any services or products it offers and its role in the health care system *(see Ensuring Fairness in Health Care Coverage Decisions, EFOB 2004)*.

In addition to ethical reasons for providing understandable communication, there are also several U.S. laws and regulations that require health care organizations to provide language assistance to individuals who have limited English proficiency. These laws and regulations are intended to

ensure equal, nondiscriminatory access to public programs and health care services. Such laws include Title VI of the Civil Rights Act of 1964, the Emergency Medical Treatment and Active Labor Act, the Hill-Burton Act, Medicaid, Medicare, State Children's Health Insurance Program (SCHIP) and Executive Order 13166: Improving Access to Services for Persons with Limited English Proficiency (NHeLP 2004, Perkins et al. 2003). In addition, several state laws also require health care organizations to offer language assistance (Perkins 2006).

Any person or organization that expects individuals to rely on them, directly or indirectly, for the information they need to make health care decisions, has ethical obligations based on the right to informed consent. This obligation requires that information be provided at a level and in a language that individuals can understand *(see also Appendix B)*.

There are currently 22 million people in the United States who speak English less than "very well" (U.S. Census Bureau American Community Survey 2004). As this number grows, language assistance services will become more and more important to good health care.

Safety. When an organization provides effective language assistance, individuals are better able to ask questions, explain symptoms, understand instructions, and provide informed consent (Morales et al. 2006, Andrulis et al. 2002, Hablamos Juntos 2001).

Quality. When an organization provides effective language assistance, individuals are more likely to visit physicians for preventive care, fill prescriptions and adhere to treatment regimes, and have their confidentiality protected (Andrulis et al. 2004, Jacobs et al. 2004, IOM 2003).

Over 25 percent of individuals with limited English proficiency who do not have an interpreter say that they do not understand their medication instructions. This is compared to only 2 percent of individuals who get an interpreter or who do not need one (Andrulis et al. 2002).

Preparedness. When an organization has a reliable system for providing language assistance it can respond more quickly to emergency situations such as epidemics or other disasters where rapid communication to diverse populations can be essential.

> Example: Emerging Sources of Support for Interpretation Services
>
> Some U.S. health plans recognize the importance of language assistance to providing high-quality health care. These have begun 1) collecting data on members' languages, 2) recruiting and identifying bilingual staff and physicians, 3) organizing and financing interpreter services, and 4) educating members and physicians about how to receive language assistance services (Brach et al. 2006, Brach et al. 2005).

What Should an Organization Do?

Health care professionals from across the country report that they have difficulty providing high-quality health care to individuals with limited English proficiency. This is because it is hard to communicate across languages and there is not enough funding for language assistance services (IOM 2003, Kaiser 2001).[i]

Despite these sometimes formidable barriers, a health care organization should communicate with individuals in a language that they can understand. To do this, an organization first needs to determine when and how health communication takes place (AHRQ and CMS 2003).

■ An organization should document which workforce members might communicate with individuals or populations that need language assistance, the types of communication typically used, and the communication resources these workforce members need.

■ It is important to include communication over the phone and in person, during business hours and after-hours/weekends, and in emergency and nonemergency situations. This should include verbal and written communications with both individuals and populations.

In a perfect world, individuals would be matched with physicians, customer service representatives, and other workforce members who are qualified to communicate with them in their primary languages. Since this is often impossible, an organization should provide language assistance, including interpretation and translation for the languages most common in its populations.

■ Every health care organization should have someone whose primary job is managing language assistance.

> Keep in mind that some adults who have limited or no English proficiency may have low levels of health literacy in their own language (Gazmararian et al. 1999, Williams et al. 1995). For more information, *see Content Area 5c: Health Literacy.*

Interpretation: Individuals who need to communicate in a language other than English should have access to trained, competent interpreters when they interact with a health care organization. Interactions can include everything from scheduling an appointment and visiting a physician to getting the proper prescription from a pharmacy, arranging payments, and calling a health plan's customer service line. Interpreters can be provided in person, accessed over the phone, or provided through video conferencing.

Medical interpretation should be done only by someone who has been trained and tested on their language and interpretation skills. This can be a trained, competent professional interpreter or a bilingual workforce member.

Trained, competent professional interpreters (either in person or over the phone) always should be used when the topic of communication is technical or involves discussion of important decisions, risks and benefits, treatment plans and instructions, end-of-life, or informed consent. These interpreters can be employees of the organization or they can be contractors.

Bilingual workforce members may be appropriate interpreters in an emergency, if there are no trained, competent professional medical interpreters for the required language available, or when the information being interpreted is nonclinical or administrative, such as scheduling or "wayfinding" (i.e., providing directions or other nonmedical instructions).

Bilingual workforce members should only provide medical interpretation if they have been assessed on their language skills and their ability to interpret, trained to interpret,

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i Note that 51 percent of providers believed patients did not adhere to treatment because of culture or language; 56 percent reported no cultural competency training (IOM 2003, pgs 71-72).

and understand that they may only interpret to the extent they are qualified and able (U.S. DHHS OCR 2003).[ii] If bilingual workforce members find that interpretation duties are interfering with their regular work, an organization may need to examine and expand its other language assistance options.

It is important that everyone who serves as an interpreter receive training to clarify their responsibilities and to ensure professional and ethical conduct. Interpreters should be trained on validated curricula and standards, and they should be capable of interpreting with accuracy, confidentiality, impartiality and neutrality (NCIHC 2005, 2004, 2002, CHIA 2002, MMIA 1995).

Training should help interpreters understand the ways their personal health-related values, biases and beliefs influence how they interact with others.

> Neutrality allows both sides to communicate without an interpreter influencing the course of communication or treatment. Advocating on behalf of one party or the other may have a negative effect on information transfer.

- Interpreters should know that the individuals they are interpreting for may have varying degrees of health literacy and might not understand—even if they appear to—many medical terms or technical instructions.

- Some medical terms do not have a direct translation into other languages and will require additional explanation.

- Most interpreters are not trained to assess an individual's level of understanding, but they must feel comfortable making any concerns about an individual's understanding known to the workforce member for whom they are interpreting.

Unless an individual specifically requests an exception, people who should not be used as interpreters include untrained bilingual workforce members and an individual's friends or family members. It is especially poor practice to use children under the age of eighteen as interpreters. Among other problems with this practice, children are unlikely to understand medical terminology and they should not be put in positions of authority over adults (Burke 2005, NHeLP 2004 pg. 45).

- Negative outcomes of having these "stand-ins" interpret include omission of information, improperly interpreted concepts, and editorialized information (Flores et al. 2003).

- Other consequences include potential embarrassment to all the individuals involved and confidentiality violations.

- An organization may put itself at legal risk if it relies on an untrained interpreter who makes an error with clinical consequences (Flores et al. 2003).

If an individual wants to use a family member or friend to interpret, an organization should strongly consider having its own interpreter present to observe and assist if needed. A trained, competent interpreter can confirm that the interpretation is accurate and complete, and they can provide assistance with medical terminology or other issues if the family member or friend needs it. Some organizations ask that individuals sign a waiver of their right to a trained, competent interpreter provided free by the organization (Youdelman and Perkins 2005). At minimum, an organization should document in writing when an individual declines the use of a trained, competent interpreter.

A health care organization should also clarify the language assistance roles of two other categories of workforce members.

Bilingual workforce members. Workforce members who provide services directly in an individual's primary language should be assessed on their language skills and informed of any limitations to the duties and services they are qualified to perform. This category may include physicians, nurses, social workers, pharmacists, financial counselors, receptionists or others. In some cases, these workforce members may have excellent vocabulary and written skills, but accents may limit how well they can be understood.

Basic speakers. Workforce members with limited skills in particular languages may occasionally speak to individuals in these languages. These workforce members should be encouraged to improve their skills, but they should be clear on when it is appropriate for them to use their basic skills (e.g., for providing comfort, very basic information, or navigation).

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ii "[Health care organizations] should be aware that competency requires more than self-identification as bilingual. Some bilingual staff and community volunteers, for instance, may be able to communicate effectively in a different language when communicating information directly in that language, but not be competent to interpret in and out of English. Likewise, they may not be able to perform written translations" (U.S. DHHS OCR 2003).

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Regardless of their language ability, workforce members at all levels should be trained to access and work with interpreters. This is important because at some point they may encounter an individual who does not speak any of the languages in which they are proficient.

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Example: Recognizing Interpreters as Specialists on the Professional Team

At WakeMed Health and Hospitals (Raleigh, NC) there is a strong emphasis on improving the language skills of bilingual workforce members. For example, they are reimbursed for language classes and they can participate in immersion programs. These staff members are tested on their language skills and they conduct many interactions on their own. However, they will stop an encounter to bring in a staff medical interpreter if they feel like the encounter is progressing beyond their language skills. This is seen as calling in a specialist to help with the encounter.

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Translation: An organization should provide written educational and notification materials in the languages commonly spoken by its populations. The most important documents to translate include those that individuals must follow on their own and those that provide information about important medical decisions.

- For example, commonly translated documents include application forms, consent forms, notifications of rights and responsibilities, discharge instructions, material about specific chronic conditions, and medication or treatment instructions (Sharif et al. 2006, U.S. DHHS OMH 2001).[iii]

Directly translating a document from one language into another often changes some of the document's meaning. Instead, important documents should be originally created in each necessary language. This helps to ensure that the documents accurately convey the concepts and ideas in the required languages. If it is not feasible to create original documents in target languages, documents should be translated from English by a professional translator, proofread, and then reviewed for accuracy and clarity by another qualified source.

- All translated documents should be "field tested" with representatives of the relevant non-English speaking populations to check for accuracy and understandability

- All written materials, no matter what language, should be reviewed to make sure they are clear to individuals with limited health literacy *(see Content Area 5c: Health Literacy)*.

Signs: Ideally, everywhere a sign in English provides information or directions, there should also be a sign with the same information in an organization's other common languages. However, if an organization serves populations that speak many languages, signs with every relevant language will be impossible to read.

- Some organizations have installed kiosks at entry points that provide pamphlets, instructions and maps in commonly spoken languages.

- An organization can also use symbols to replace text.

Symbols are beneficial because they also work for individuals with limited literacy or health literacy skills. Many groups are doing research to determine what types of signs and way-finding methods work best (see the Hablamos Juntos Web page at *www.hablamosjuntos.org*). An organization should evaluate different strategies to determine which best meet its needs.

Limitations and Barriers

An organization may face several limitations as it tries to provide language assistance. The main limitations fall into three categories: financial, time and quality.

Financial. For many organizations, financial constraints are the primary limitation to providing individuals with effective language assistance. In particular, this is common among small organizations and those that serve very linguistically diverse populations. While some federal assistance is available, only 13 states currently offer Medicaid reimbursement for language assistance (NHeLP 2005).[iv] For most of these states, Medicaid reimbursement

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iii Excerpt from CLAS #7: "It is important to translate materials that are essential to patients/consumers accessing and making educated decisions about health care. Examples of relevant patient-related materials include applications, consent forms, and medical or treatment instructions; however, health care organizations should consult Office for Civil Rights guidance on Title VI for more information on what the Office considers to be 'vital' documents that are particularly important to ensure translation" (65 FR 52762-52774, August 30, 2000).

iv Hawaii, Idaho, Kansas, Massachusetts, Maine, Minnesota, Montana, New Hampshire, Utah, Vermont, and Washington. Texas and Virginia are initiating pilot projects in 2006.

covers outpatient, fee-for-service care, but not inpatient hospital care. Medicare does not currently reimburse for language services and most private insurance plans do not pay for language assistance.

- Organizations throughout the health care system should work together to make recommendations on, and advocate for, appropriate reimbursement for these necessary health care services.

For an organization with minimal financial flexibility, providing language assistance often requires innovative solutions. For example, some organizations are partnering with other health care stakeholders in served communities to form language assistance cooperatives. Other organizations are using information technology to make interpreters available even if they are not on site, and many are advocating within individual states for increased funding for language assistance (Youdelman and Perkins 2005, NHeLP 2004, *www.hablamosjuntos.org*).

Time. An organization is also limited if it cannot provide language assistance in a timely manner. If health care professionals have to wait a long time for language assistance they may resort to alternative, less safe arrangements. An organization should develop effective ways to identify, in advance, what language assistance individuals might need. For example, some organizations maintain databases that track language and communication needs. To make

language assistance easily accessible, it is helpful for an organization to have a single phone or beeper number that workforce members can use to access interpreters or other language assistance.

Some clinicians worry that using interpreters makes patient encounters longer than if they do not use interpreters. In most cases, the encounters without interpreters are shorter because less information is exchanged. An organization should train clinicians on the clinical value of using trained, qualified interpreters and the clinical and legal risks of not using them when needed. In general, once clinicians begin using trained, qualified interpreters the experience is enough to convince them to stop using untrained workforce members, family members or friends.

Quality. Many organizations have a hard time identifying and recruiting trained, qualified interpreters. Although national standards for health care interpreters were released in 2005, only Washington state has an established certification program (Bancroft 2005, NCIHC 2005, NHeLP 2004). Until certification becomes more common, an organization should work with well established consulting, training, interpreting, and translation associations and companies to find interpreters that have completed recognized trainings (such as the Cross Cultural Health Care Program's Bridging the Gap training course) and to customize language assistance strategies (NCIHC 2005, 2004, 2002, CHIA 2002, MMIA 1995).

Performance Expectations: Table 5b

This table lists specific performance expectations that an organization should be able to meet in its efforts to identify and bridge gaps in communication. All organizations will not be able to meet every expectation right away. Some expectations might be goals to strive for over time.

See the box on page 23 for more information on applying the expectations in the table.

		Plans, Policies, Procedures
1.0		The organization has policies and strategies in place to identify and address the need for language assistance in at least the following three situations.
	1.1	When a significant segment of a relevant population speaks a language other than English.
	1.2	When a smaller segment (e.g., a few percent) of a relevant population speaks a language other than English.
	1.3	When an individual speaks a language rarely encountered by the organization.
2.0		The organization has a written plan for coordinating interpretation services and monitoring their quality.
	2.1	The plan addresses funding for interpretation services.
	2.2	The plan indicates modes of interpretation that are provided and situations when each will be used.

| | 2.3 | The plan assigns responsibility to a particular workforce member(s) for arranging interpretation services when needed. |

Plans, Policies, Procedures

3.0		The organization has policies that govern the use of bilingual workforce members as interpreters and service providers.
	3.1	The organization ensures that bilingual workforce members who serve as interpreters know what duties they are expected and authorized to perform and the limits of these duties.
	3.2	The organization ensures that bilingual workforce members who serve as interpreters are trained, tested and regularly assessed on the level of services they may be called upon to perform.
4.0		The organization has policies to determine when to develop materials in non-English languages and when to translate materials.
	4.1	Policies address funding for document creation and translation.

Monitoring Language Needs

5.0		The organization has a system to track an individual's need for language assistance.
	5.1	When an individual schedules an appointment, the workforce member making the appointment determines whether an interpreter is needed and in what language.
	5.2	An individual's charts, records, or database entries include information on primary language and whether an interpreter is needed or requested.
	5.3	Language need information is summarized and reviewed annually to determine whether changes should be made to the language assistance programs offered.

Services and Utilization

6.0		Workforce members routinely inform non-English speaking individuals of their rights to interpretation and translation services.
	6.1	Notices indicating the right to use an interpreter, free of charge, are posted in reception areas or provided to individuals in their primary language.
	6.2	Outreach into the community is conducted to ensure that individuals from communication-vulnerable populations are aware of the organization's ability to communicate with them.
7.0		The organization disseminates information to individuals and populations about the benefits of using trained and tested medical interpreters rather than family members or friends for interpretation.
8.0		The organization maintains copies of its main educational and notification documents in languages read by a significant portion of the individuals it serves.
	8.1	Translations from English are independently evaluated and checked for accuracy.
	8.2	Translated materials are readily accessible to individuals (patients, customers, enrollees, employees) and workforce members, who need them.
	8.3	There is a mechanism for members of the workforce to request translation of documents.
9.0		The organization has understandable signage.

Plans, Policies, Procedures: Implementation Notes

1.0: An organization should have a written plan for each of the listed situations. Workforce members should be trained on this plan. An organization should also have a way of evaluating how effectively it is addressing each of these situations.

1.3: Health care delivery organizations can use "I speak…" cards/posters or other mechanisms to identify rare languages (*www.usdoj.gov/crt/cor/Pubs/ISpeakCards.pdf*). Many telephonic interpretation services provide language identification.

- For situations when the individual cannot read or their language cannot be identified, symbol cards may provide temporary assistance.

- Another, more technologically advanced alternative is the use of computer software to facilitate basic interactions across languages (e.g., The MedBridge System, *www.ino-com.com/solutions/solutions.html*).

2.0: For a small organization, the written plan can be a brief description of procedures. A larger organization may require longer, more detailed documents. The key is for an organization's leaders and workforce members to think specifically about the needs of their communication-vulnerable populations and how they will meet these needs.

An organization should ensure the competency of its interpreters. This can be done by partnering with an organization that provides trained, tested medical interpreters or by conducting its own assessment and training programs.

- If interpreter services are outsourced an organization should form strong relationships with the interpreters and provide education on the organization's culture, what resources are available and how to access them.

2.1: By law, if an organization accepts federal funds, interpretation must be provided at no cost to individuals requiring the assistance (NHeLP 2004).

Some health plans currently finance interpreter services for their enrollees. Health plan purchaser organizations should include or consider the costs and benefits of interpreter services when selecting benefits packages for their employees (Brach et al. 2005).

2.2: Interpreters should be available to individuals at all points of contact with the organization. For example, during in-person and telephone encounters; during normal business hours and after-hours/weekends; and during emergency, inpatient and outpatient encounters.

- When it is not feasible to provide face-to-face interpretation, an organization should provide interpreters over the phone, using videoconferencing or other technologies.

Some individuals may have social or cultural reservations against using interpreters.

- An organization should be aware of the risks of allowing friends and family members to serve as interpreters, including problems with confidentiality, health literacy, and the risk that they may not communicate key aspects of information to a parent or elder, etc.

- An organization should document when individuals decline the services of a trained medical interpreter.

3.0: An organization should have policies that specify the roles and responsibilities of:

- Workforce members working solely as medical interpreters.

- Bilingual workforce members who are capable of and trained in interpreting.

- Bilingual workforce members who do not interpret but provide services in individuals' primary languages (this category may include workforce members with excellent vocabulary and written skills, but whose accents may limit how well they can be understood).

- Workforce members who are not fluent in particular languages but occasionally speak to individuals in these languages.

3.1: Interpretation should be included in the job descriptions and performance evaluations for bilingual workforce members performing these duties.

3.2: Bilingual workforce members who serve as interpreters should be trained, tested and regularly assessed to ensure they can provide competent medical interpretation and are proficient in medical terminology.

4.0: An organization should have long-term strategic goals for document translation. An organization should consider when and how documents will be developed in particular languages, when and how documents will be translated, and how documents will accessed by workforce members and the populations being served.

Monitoring Language Needs: Implementation Notes

5.0: *See also Content Area 2: Collect Information, specifically expectation 3.0.*

5.2: An organization should document when individuals need interpreters; when they request interpreters; when they use in-person, phone, or other interpretation; and how long individuals wait for interpreters *(see also Content Areas 2: Collect Information and 6: Evaluate Performance)*.

Services and Utilization Implementation: Notes

6.2: An organization should be able to identify specific steps it has taken to reach out into its community, especially to connect with communication-vulnerable populations.

7.0: Individuals who are hesitant to use medical interpreters may not understand that language assistance is free of charge or may think requesting an interpreter will result in a long wait time.

- Within its communities, an organization should address common misconceptions about using medical interpreters and work to build awareness of the benefits.

- When individuals do not want to use medical interpreters, workforce members should engage the individuals to find out their reasons and explain the benefits.

In particular, an organization should have a policy against using minors as medical interpreters. "Extra caution should be exercised when the LEP [limited English proficient] person chooses to use a minor as the interpreter. While the LEP [limited English proficient] person's decision should be respected, there may be additional issues of competency, confidentiality, or conflict of interest when the choice involves using children as interpreters." (U.S. DHHS OCR 2003).

8.0: Depending on the type of organization, educational and notification documents that require translation might include: information on health promotion and disease prevention for specific chronic and acute conditions, notifications, application forms, menus, prescriptions and medication instructions, informed consent forms, advance directives, pre- and post-procedure instructions, referral information, and any discharge and treatment instructions.

8.1: Translated documents should always be reviewed for accuracy and field tested with the relevant populations. Review should include having a qualified, trusted source, independent of the translator, verify the accuracy and understandability of the documents.

8.3: There should be a process for submitting requests for translation if a member of the workforce recognizes a need.

9.0: If an organization serves populations that speak many languages, signs with every language will be impossible to read. Many groups are doing research on effective signs and "way-finding" methods. For example, *see the Hablamos Juntos Web page on "Signs that Work" (www.hablamosjuntos.org).*

Selected Resources

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California Healthcare Interpreting Association *http://chia.ws/pages/index.php*

California Primary Care Association. Providing Health Care to Limited English Proficient Patients: A Manual of Promising Practices. *www.cpca.org/resources/research/pdf/PPGuide.pdf*

The Cross Cultural Health Care Program. Bridging the Gap: Interpreter Training. *www.xculture.org/training/overview/interpreter/programs.html*

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Content Area 5c.
Health Literacy

An organization should consider the health literacy level of its current and potential populations and use this information to develop a strategy for the clear communication of medical information verbally, in writing and using other media.

Quick tips

Research the level of literacy and health literacy in the populations your organization serves.

Ask the audience to review early versions of documents to make sure they are clear and easy to read.

Many individuals, whether they speak English or not, do not understand the health information they receive from their physicians, their hospitals, their health plans or their employers.

■ Over 95 million people living in the United States (43 percent of adults) have literacy levels below what they need to understand most health information (NCES 2005, Schwartzberg et al. 2005, IOM 2004a, Kirsch et al. 1993).

■ When health care professionals and organizations communicate, the information is often complex and technical. This means even adults who read and write well might not understand much of it (IOM 2004a, Schwartzberg et al. 2005, Wallace and Lennon 2004, Williams et al. 2002, Williams et al. 1995).[v]

Literacy is an individual's ability to read and write. Health literacy is "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (IOM 2004a, Selden et al. 2000).

Certain vulnerable groups, such as older adults, individuals with fewer years of formal education, and individuals with limited English proficiency are more likely to have inadequate or marginal health literacy (NCES 2005, Paasche-Orlow et al. 2005, Schwartzberg et al. 2005, Gazmararian et al. 1999, Williams et al. 1998a, Williams et al. 1995). Limited health literacy is an especially serious problem for aging populations—a projected 40 million Americans by 2010. These populations often have multiple chronic conditions such as hypertension and diabetes that require consistent medication and self-monitoring (Parker et al. 2003).

If a health care organization wants to improve quality, safety, informed consent, and shared decision making, it must help individuals understand and process health care information (Berkman et al. 2004, IOM 2004a, Parker et al. 2003, Osborne 2001b).

■ Individuals with limited health literacy skills might not understand simple prescription instructions, self-care guidelines or even the importance of managing chronic conditions (Gazmararian et al. 2003, Schillinger et al. 2002, Gazmararian et al. 1999, Williams et al. 1998a).

■ As a result, individuals with limited health literacy skills have increased rates of hospitalization, suffer from poorer health outcomes, and have more avoidable health care expenditures than individuals with stronger health literacy skills (Howard et al. 2005, Schwartzberg et al. 2005, Wolf et al. 2005, IOM 2004a, Baker et al. 2002, Williams et al. 2002, Baker et al. 1998).

A health care organization should create or adopt materials that present information clearly. This will make it easier for individuals to understand their health conditions, their rights and responsibilities, and their part in providing informed consent. An organization should also make sure its workforce members are trained to communicate in clear, simple terms. They should confirm that individuals understand instructions, have the information they need, and can follow treatment plans (AMA 2004a, AHA 2003, Schillinger et al. 2003, Youmans and Schillinger 2003, ASHP 1997, AMA Policy 160.931).

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v For a discussion of the distinctions between literacy and health literacy, see Chapter 1 of Schwartzberg et al. 2005.

What Should an Organization Do?

An organization should work to create an environment where everyone feels they can ask questions (Osborne 2006, AMAF 2003). Many patients, especially those with limited literacy or health literacy skills, are embarrassed to ask questions or admit when they do not understand something. One of the first steps in meeting a population's health literacy needs, is to help individuals admit when they need help or have questions. For example, body language, tone of voice, and visual reminders ("Ask Me 3" posters, "Ask me, I can help" buttons) can encourage individuals to ask questions (Osborne 2006, AMAF 2003, Partnership for Clear Health Communication).

A health care organization should provide the populations it serves with clear and understandable information. It should also help individuals recognize when they are not receiving or understanding as much information as they want or need.

- An organization should train its clinical workforce members to observe patient behavior for signs of limited health literacy or misunderstanding.

- An organization should train workforce members to help individuals get the information they need to make informed decisions (Rosenthal et al. 2004).

- Trained workforce members should be available, in person and over the phone, to help individuals if they are unsure how to fill out administrative forms or how to interpret instructions, directions, signs or other information or education materials.

Health Literacy. A health care organization should not try to measure or track the health literacy level of every individual it serves (Schwartzberg et al. 2005). Instead, an organization should gather information about health literacy at a population level. The Pfizer Clear Health Communication Initiative has an online calculator that estimates the percent of individuals in a population who might have limited health literacy skills based on population percentages, including age, race and ethnicity, English language proficiency and Medicaid status. Alternatively, an organization can estimate health literacy levels by administering the Rapid Estimate of Adult Literacy in Medicine (REALM) or the short version of the Test of Functional Health Literacy in Adults (TOFHLA) to a sample of individuals (Schwartzberg et al. 2005, Baker et al. 1999, Parker et al. 1995, Williams et al. 1995, Davis et al. 1993, Davis et al. 1991). This type of research, when performed strategically, can help validate an organization's estimates of its populations' health literacy ranges.

General Literacy. General literacy levels or educational attainment, while not perfect methods for estimating health literacy, are often used as rough indicators of health literacy. An organization can learn about the range of general literacy and education levels in relevant populations using information from the U.S. Census Bureau (U.S. Census Bureau American Factfinder), community-based organizations, local school districts and public health departments.

There are several reasons why an organization should document the general literacy and health literacy levels in its populations.

- When leaders and workforce members know the prevalence of limited literacy and health literacy in their own populations, they often become more supportive of initiatives that address individuals' literacy and health literacy needs.

- Literacy and health literacy data can help an organization identify especially vulnerable groups, such as recent immigrants *(see also Content Area 2: Collect Information)*.

Most individuals, even those who are very health literate, prefer to receive health information that is clear and straightforward. For this reason, an organization should create education and notification documents, Web sites, media messages and other communications that are understandable to the broadest audience possible (IOM 2004a, Schwartzberg et al. 2005).

An organization should use a variety of methods to communicate in an understandable way.

- For example, an organization might use illustrated information, audio tapes/CDs, videos, graphics, multimedia tools, computer-based programs and other creative strategies.

- However, the effectiveness of some of these strategies may be limited by individuals' access to, or comfort level with, technology (Osborne 2004, Williams et al. 2002).

- One optimal scenario would be for an organization to provide access to assisting technologies, such as educational DVD-ROMs, when individuals are on site and workforce members are available to answer questions.

Example: Starting Small to Build Support for Health Literacy Initiatives

The Iowa Health System uses the Institute for Healthcare Improvement's rapid-cycle model for quality improvement to test possible interventions for addressing health literacy. In one case, a few physicians were asked to use the "teach back" method with the last patient they saw before lunch and their last patient of the day. These physicians found that using the "teach back" method didn't make encounters longer, but it did help them use their time more effectively.

Limitations and Barriers

It is often difficult to communicate health care information in a way that is clear and understandable. Health care messages, and the health care system itself, are often too complex for simple explanations. By trying to simplify complex health information, it is possible to create new, unintended messages that are no longer accurate or that do not convey the original key points.

- When an organization and its workforce members use plain language, it is important to make sure the information is also correct and complete.

- To check if information and educational materials contain the right messages, work with adult education teachers and classes and field test materials with the appropriate audiences.

Individuals with limited literacy or health literacy skills might not admit when they do not understand something. A health care organization should train its workforce members to look for indirect clues that an individual is having a problem reading a form or brochure or understanding a conversation or instruction. For example, some clues might be if individuals leave important sections of forms blank or if they say "I forgot my eyeglasses," "I'll read it later," or "I trust you, I don't need to read it…" If workforce members identify a possible problem, they can then provide assistance in a nonthreatening way.

Performance Expectations: Table 5c

This table lists specific performance expectations that an organization should be able to meet in its efforts to identify and bridge gaps in communication. All organizations will not be able to meet every expectation right away. Some expectations might be goals to strive for over time.

See the box on page 23 for more information on applying the expectations in the table.

		Expectation
1.0		The organization is familiar with the range of general literacy levels within the populations it serves.
2.0		The organization creates an environment where individuals at all literacy and health literacy levels feel respected and where questions are encouraged.
	2.1	The organization ensures its workforce is available and receptive to answering questions and helping individuals complete forms and interact with the health care system.
3.0		The organization provides educational and notification materials—written, audio and visual—at literacy and health literacy levels that reach as many individuals as possible.
	3.1	Forms request the minimum information that is necessary.
4.0		The organization regularly assesses educational and notification materials to ensure they are understandable to individuals at a broad range of literacy and health literacy levels.
	4.1	The organization has individuals from relevant populations review its materials to ensure they are understandable.
	4.2	The organization asks its workforce if it has received feedback on the understandability and clarity of materials.
5.0		The organization requires its workforce to implement proven techniques (i.e., "teach back") to ensure individuals understand the information they receive.
6.0		The organization uses a variety of strategies to communicate with individuals that may have limited literacy or health literacy skills.
	6.1	Signage can be understood by individuals with limited literacy or health literacy skills, including using pictorial representations as appropriate.
7.0		The organization works with the populations it serves and community organizations to help improve health literacy.

Implementation Notes

1.0: An organization will not be able to, and should not, measure the health literacy level of every individual in the populations it serves. Instead, it should collect information on the range of educational attainment and general literacy among its populations (U.S. Census Bureau American Community Survey, local school districts, etc.).

In addition to gathering information on the general literacy of the populations it serves, an organization can use online resources and research tools to estimate its populations' health literacy.

- The Pfizer Clear Health Communication Initiative has an online calculator that estimates the percent of individuals who might have limited health literacy based on population percentages, including age, race and ethnicity, English proficiency and Medicaid status.

- An organization can also estimate its populations' health literacy by administering the Rapid Estimate of Adult Literacy in Medicine (REALM) or the short version of the Test of Functional Health Literacy in Adults (TOFHLA) to a sample of individuals (Schwartzberg et al. 2005, Parker et al. 1995, Williams et al. 1995, Davis et al. 1993, Davis et al. 1991).

2.0: For example, an organization should:

- Create a shame-free environment where individuals are not intimidated to participate (AMAF 2003).

- Train all workforce members, from customer service to clinicians, to be effective communicators across the health literacy spectrum *(see also Content Area 4: Develop Workforce)*.

- Help individuals understand and use health care resources.

- Evaluate signs, audio announcements, written materials, workforce demeanor and other elements of the environment to make sure they are welcoming to individuals who might have limited health literacy skills.

3.0: Examples include: information on organizational policies (such as privacy policies), information on health promotion and disease prevention, consent forms, disease-specific informational brochures, billing notices, discharge instructions, prescription instructions, patient rights documents, and many other types of documents.

- Incorporating graphic elements and simple pictures into these documents has been shown to improve understanding and retention of information for all individuals, not just those with limited literacy and health literacy skills (Osborne 1999).

4.0: This should be done for written materials as well as audio and visual formats. Individuals with limited health literacy skills will not understand audio or visual materials if they use technical words or assume a high baseline level of knowledge.

- Materials for English and non-English speaking/reading populations as well as deaf, hearing-impaired, and blind populations should be reviewed for clarity and understandability.

If an individual cannot make his or her own decisions, then communications must be understandable to surrogate decision makers, family, friends or other caregivers.

4.1: This should include review by representatives of an organization's main language and cultural groups (Osborne 2005, Osborne 2001a).

5.0: One proven strategy is the "teach back" (also "repeat back" or "show me") method, which checks for understanding by asking individuals to repeat back how they understand a situation or a set of instructions (NQF 2005, Schillinger et al. 2003). Workforce training should include how to use this and other techniques for clear communication and to assess understanding *(see also Content Area 4: Develop Workforce)*.

6.0: For example, an organization might use illustrated information, graphics, videos, multimedia tools, computer-based programs and other creative strategies to convey information in an understandable way. However, the application of some of these strategies may be limited by individuals' access to, or comfort level with, technology.

6.1: Signs and maps used by health care organizations are often difficult to understand and use. An organization should assess the usability of its navigation tools and make sure there are always workforce members available to answer questions *(see also Content Area 5b: Language) (Rudd 2004, Osborne 2001c)*.

7.0: In addition to making communication as universally understandable as possible, a health care organization should also work with community partners to improve health literacy. For example, an organization can work with school districts, faith-based organizations, adult education

groups, and senior centers to coordinate educational sessions, seminars, workshops and other learning opportunities on health care topics of interest to communities.

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Content Area 6.
Evaluate Performance

An organization should regularly monitor its performance with regard to each of the prior content areas using structure, process and outcome measures, and make appropriate adjustments on the basis of these evaluations.

Quick tips:

Include a few questions about communication on both patient and workforce surveys.

Assign someone to track how often complaints and errors can be traced to communication issues.

A health care organization that is committed to continuous improvement and meeting the changing needs of its populations must regularly evaluate its efforts to communicate with the populations it serves. After considering each of the content areas in this report, and taking steps to achieve the performance expectations, an organization will need to assess its progress toward strategic goals. It will also need to identify areas and tasks that require additional resources and focus. The best way to do this is by using standard, consistent measures to monitor the impact an organization's procedures, training programs, educational tools, initiatives and interventions have on organizational performance, including improved communication and health outcomes (IOM 2002).

"A comprehensive set of measures or indicators tied to patient/customer and organizational performance requirements represents a clear basis for aligning all processes with your organization's goals" (Baldrige National Quality Program Health Care Criteria for Performance Excellence, Baldrige 2006).

Performance evaluation is important to all programs and initiatives in an organization. In many cases procedures for performance evaluation will already be in place and must simply be adjusted to assess communication with relevant vulnerable populations. Whether new or existing mechanisms are used for ongoing evaluation, an organization should make sure all measures are well tested and validated.

- Adopt standardized sets of clinical measures developed or endorsed by established groups such as the Hospital Quality Alliance, the American Medical Association's Physician Consortium for Performance Improvement and the National Quality Forum.

- Adhere to accreditation standards, such as those of the Joint Commission on Accreditation of Healthcare Organizations and the National Committee for Quality Assurance.

- Effective measures allow an organization to report its performance across the populations it serves and to compare its own performance over time and in relation to other organizations.

There are some reasons why relatively few organizations currently report communication performance and how it relates to clinical outcome measures.

- Many health care organizations do not or cannot yet evaluate how well they care for specific vulnerable populations. This would require an organization to collect demographic information and then link the information to clinical outcome measures *(see also Content Area 2: Collect Information)*.

- In most cases organizations do not yet evaluate the quality of individual clinical encounters, which is where many key communications take place.

- Few organizations measure communication quality at any level. Primarily, this is because communication assessment strategies are only recently being tested, though some seem to provide reliable information (Epstein et al. 2005, Fiscella et al. 2004, Epstein and Hundert 2002).

Despite the early stage of measurement in this area, an organization can reinforce its commitment to effective communication and build trust by conducting regular self-assessments. These assessments should include feedback from patients (or customers, enrollees, employees) and workforce members and should result in actions that address gaps that are identified. If individuals and communities see that their feedback is valued and used to guide improvements, they will be more likely to become engaged, continue participating, and take a more active role in managing their own health.

What Should an Organization Do?

To evaluate its performance in a consistent, meaningful way, a health care organization needs to adopt standard performance measures. An organization should conduct regular internal assessments using these measures. In cases where standard measures of organizational performance have not yet been developed, an organization should identify some initial measures that have been tested and proven to be preliminarily effective. For example, several academic research groups have developed assessment tools to evaluate organizational cultural competence (Andrulis et al. 2001, National Center for Cultural Competence).

Written evaluations. Many organizations use standard written surveys to get basic information on patient (or customer, enrollee, employee) perceptions. Examples include Picker Patient Care Surveys and Press Ganey Patient Satisfaction Surveys.

- When using standard evaluation tools, an organization should recognize that many have not been designed to get feedback from individuals with diverse cultural backgrounds, little or no English proficiency, or limited health literacy skills.

Interviews and focus groups. An organization should include focus groups and interviews as part of its performance measurement strategy. These can provide a more accurate and detailed evaluation of the perceptions of all the populations it serves.

- Ask individuals if they understand the information they receive and if they believe they are being heard by the organization's workforce members.

- Evaluate changes in a population's knowledge about their health. For example, ask individuals with diabetes about maintaining their blood glucose levels to assess communication and education about diabetes self-care.

Workforce evaluations. An organization should also use surveys, interviews, and focus groups to track the experiences of its workforce. In particular, it should ask if workforce members feel they have the time, training and resources to communicate well with the individuals they serve.

> To find out if an organization's climate encourages patient-centered communication, there should be continuous open and honest dialogue between leaders, workforce members, relevant communities and the individuals being served.

Community evaluations. An organization should ask its partners, both within the community and the health care system, if it is meeting their communication needs. This can be done with interviews or focus groups and will help maintain long-term external relationships (*see also Content Area 3: Engage Communities*)

External evaluations. For some types of organizations—including hospitals and health plans—independent, outside evaluations are important indicators of performance. This includes evaluations conducted by the Joint Commission on Accreditation of Healthcare Organizations, the National Committee for Quality Assurance, and URAC.

During internal assessments, an organization should examine how its policies and performance compare to federal and state legal requirements. It should also determine if progress has been made toward meeting strategic goals.

- An organization should evaluate organizational structure and processes that are meant to improve communication as well as communication and clinical outcomes.

- An organization should compare the results of qualitative and quantitative evaluations.

- An organization should choose appropriate information management tools, train workforce members to conduct and participate in evaluations, and have proper supervision over the evaluations.

- The results of evaluations should be maintained in a database that allows an organization to track the results of its efforts over time.

Ideally, an organization should link its communication performance measures, demographic data, and health outcome measures. Such linkages allow organizations to track changes in health outcomes, stratified by population, and identify programs and interventions that have a positive or negative impact on specific populations.

To assess how well patient-centered communication is implemented in clinical settings, a variety of measures are currently being developed and validated. Among the techniques that are proving to be effective and accurate indicators of communication performance are use of unannounced standardized patients, observation and evaluation by a supervisor, in-person interviews with patients and families, satisfaction and perception of care surveys, and peer evaluation (Epstein et al. 2005, Fiscella et al. 2004, Epstein and Hundert 2002).

An organization should report the findings from its evaluations to all relevant stakeholders, including its leadership, workforce, local partners, and the individuals and populations it serves.

■ Many organizations collect data and conduct evaluations that never result in visible change or improvement.

■ Reporting on the results of evaluations and using them to make improvements will help build support for initiatives and ongoing evaluations at all levels of an organization.

■ As part of reporting, an organization may decide to hold workshops or town hall meetings to generate ideas for addressing, solving and learning from any issues that arise.

To complete the feedback loop, an organization should integrate the findings from its evaluations into strategies for better addressing each of the content areas in this consensus report. To promote buy-in, this integration of findings should be done in a way that involves leadership, workforce members, patient (customer, enrollee, employee) representatives and the community.

Limitations and Barriers

Some organizations are very concerned about the costs associated with comprehensive evaluations as well as the costs for new/improved data and information systems that can integrate clinical performance and other data. These concerns must be balanced with the understanding that an organization will only be able to make informed decisions—about business, quality and safety—if it has valid information about an effort's overall costs and impact on health outcomes.

Most health care organizations already have some outcome assessment and quality improvement protocols in place.

Adding validated measures of communication to these existing protocols will allow an organization to track the effectiveness of efforts to improve communication over time.

It will also allow an organization to see how its communication strategies relate to resource allocation, patient perceptions, workforce perceptions, and health outcomes.

The result will be a strong foundation for evidence-based judgments about budget and strategic planning.

Performance Expectations: Table 6

This table lists specific performance expectations that an organization should be able to meet in its efforts to identify and bridge gaps in communication. All organizations will not be able to meet every expectation right away. Some expectations might be goals to strive for over time.

See the box on page 23 for more information on applying the expectations in the table.

		Expectation
1.0		The organization conducts an annual self-evaluation of progress toward meeting written strategic goals and other quantitative targets related to communication with communication-vulnerable populations.
	1.1	Self-evaluation includes standardized measures of clinical performance and health outcomes, stratified by race, ethnicity, primary language and/or other relevant demographic indicators of potential communication-vulnerable populations.
	1.2	Regular evaluations include talking to workforce members, community liaisons and individuals from communication-vulnerable populations about both positive and negative aspects of the organization's communication programs and strategies.
2.0		The organization integrates questions about communication into both patient (customer, enrollee, employee) perception of care surveys and workforce surveys.
	2.1	All surveys are provided in languages and formats and at a health literacy level that allow the surveys to be understood and completed easily by respondents.
3.0		The organization tracks the number and focus of communication oriented grievances and complaints submitted by its workforce, community members and individuals from communication-vulnerable populations.
4.0		The organization tracks its language assistance programs by monitoring: how often individuals need language assistance; request assistance; use in-person, phone or other assistance; how long they wait for assistance; and perceptions of the assistance from both the user and provider.
5.0		Results of all evaluations are shared with the organization's senior leadership.
6.0		The organization produces an annual report to outline progress and areas for targeted improvement in patient-centered communication.
7.0		The organization evaluates how well members of its workforce communicate during one-on-one encounters with individuals.
8.0		The organization responds to the results of evaluations by having leaders, workforce members, community members and individuals from the populations it serves work together to develop solutions and make changes to plans, policies, procedures and educational programs.

Implementation Notes

1.0: Each of the previous content areas outline a number of actions, policies and goals that an organization should include in its strategic planning. Many organizations will also have quantitative goals for communication in place as part of quality improvement and accreditation processes, compliance with federal and state regulations, and for other reasons.

Annually monitoring how well an organization meets these goals and adheres to these policies will help identify performance gaps and areas for improvement, areas that lack or have excess resources, and individuals or sectors of the organization that should be recognized for achievements.

1.1: An organization should be able to link the results of its overall self-evaluation processes with the results of individual performance evaluations conducted by its Human Resources department.

1.2: Discussions can occur informally, one-on-one, or in groups (including focus groups or other community meetings). To determine if feedback differs based on how it is gathered, information from these discussions should be compared to the findings from workforce and patient (customer, enrollee, employee) perception surveys and other feedback.

2.0: Ideally, items on these surveys should address each of the preceding content areas as well as general items to assess the effectiveness of communication programs and strategies.

4.0: One goal of tracking language assistance is to determine how often individuals require language assistance but do not receive it. *See also Content Areas 2: Collect Information and 5b: Language, for details on some of the related information an organization should collect and analyze.*

6.0: The annual report should be circulated to an organization's executive board, leadership, relevant committees, workforce and community groups, and be made available to the public. In some instances, confidential self-evaluation and opportunities to respond are appropriate prior to public release of information in a report.

7.0: An organization should have a strategy for conducting these evaluations. It should also announce how often they take place.

For example, standardized patients or "secret shoppers" can be helpful to evaluate communication performance. Outside of health care delivery organizations, it may be useful to use software that monitors customer service or other phone calls.

For clinical encounters, promising evaluation techniques include unannounced standardized patients, observation and evaluation by supervisors, in-person interviews with individuals and families, and peer evaluation (Schirmer et al. 2005).

8.0: After responding to its evaluations, an organization should restart the process outlined in this report with *Content Area 1: Understand Your Organization's Commitment.* The entire process is intended to be circular and self-reinforcing. Each subsequent round of self-evaluation is expected to lead to better understanding and increasingly effective interventions.

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What is Patient-Centered Communication?

Mary Catherine Beach, MD, MPH

Patient-centered medicine is a term originally coined by Balint in 1969 to express the belief that each patient "has to be understood as a unique human-being" (Balint 1969). Since its inception, the concept has evolved and expanded, such that today almost no one would deny that health care ought to be patient-centered (IOM 2001). Despite the general endorsement of patient-centeredness within the medical community, there is considerable ambiguity in its definition and use across settings. The purpose of this paper is to clarify dimensions of patient-centered care, and of patient-centered communication in particular, in order to specify the scope of the Ethical Force Program's Patient-Centered Communication Initiative.

To better understand what patient-centeredness is, it is instructive to consider what it is not. Although patient-centeredness has been critiqued for its potential to be viewed as an excessively individualistic model of care, the patient-centered framework does not necessarily assume that an individual's preferences override the needs of a population, or that the patient's family and community are not important to consider in addition to the patient themselves. Because of the number of ways patient-centeredness has been construed, there is more than one model of care that can be regarded as antithetical to patient-centeredness. Some have contrasted patient-centered medicine with care that is directed primarily at combating disease, or illness-oriented medicine (Balint 1969). Others have argued that patient-centeredness is at one end of a continuum, with "doctor-centeredness" at the opposite end (Byne and Long 1976). Still others have identified medical paternalism as the opposite of patient-centeredness, because it may fail to acknowledge the preferences, needs, and values of individual patients (Laine and Davidoff 1996). Finally, patient-centeredness has also been described in contrast to a purely technical or biomedical model of care, where the physician is seen merely as the technician who delivers interventions and performs procedures (Engel 2001). In short, it is fair to say that any of these alternative conceptions of patient-physician interactive styles are not patient-centered, and that patient-centeredness could be envisioned as a strategy to correct for all of these tendencies in medicine simultaneously.

Patient-centered care has been broadly defined as "care that is respectful of and responsive to individual patient preferences, needs, and values" (IOM 2001). Patient-centeredness is not limited to communication; it may also include other aspects of care such as convenience of office hours, ability to get appointments in a timely fashion, being seen on time for appointments, attention to physical comfort, and having services near one's place of residence. As communication is integral to health care, patient-centered communication is an important part, though perhaps a narrower subset, of patient-centered care. Patient-centered communication, thus, may be defined as *communication* that is respectful of and responsive to individual patient preferences, needs, and values. There are many modes of communication in health care settings, and Figure 3 depicts the conceptual relationship between patient-centered care and a sampling of the types of communications that may be patient-centered.

Of the many modes of communication occurring in health care, face-to-face communication between patients and practitioners has received the most attention and is most well described in terms of its patient-centered features. Rather early in the evolution of the concept of patient-centered medicine, Lipkin et al. describe the "patient-centered interview," as one which "approaches the patient as a unique human being with his own story to tell, promotes trust and confidence, clarifies and characterizes the patient's symptoms and concerns, generates and tests many hypotheses that may include biological and psychosocial dimensions of illness, and creates the basis for an ongoing relationship" (Lipkin et al. 1984). According to Lipkin, practitioners who are patient-centered tend to have specific knowledge, attitudes and skills. Examples of the knowledge that patient-centered practitioners might have are the ability to name seven ways to characterize a symptom, define countertransference, and identify different types of interview questions. Examples of the attitudes that patient-centered practitioners may have are unconditional positive patient regard, willingness to join with patients as partners, and respect for patient autonomy and individuality. Examples of the skills that patient-centered practitioners might demonstrate are the ability to elicit a patient's "story" of illness, express interest and commitment to patients, and overcome barriers to communication (Lipkin et al. 1984).

More recently, in an effort to summarize the volume of literature which describe the features of patient-centered encounters between patients and practitioners, Mead and Bower developed a conceptual framework that includes five dimensions (Mead and Bower 2000). They are: 1) adopting the biopsychosocial perspective (as opposed to a perspective that is narrowly biomedical); 2) understanding the patient as a person in his or her own right, not merely as a body with an illness; 3) sharing power and responsibility between the doctor and the patient; 4) building a therapeutic alliance—a relationship that is both instrumentally and intrinsically valuable; and 5) understanding the doctor as a person, not merely as a skilled technician (Mead and Bower 2000). Mead and Bower themselves suggest that there is uncertainty in how best to operationalize and balance these concepts, however these five basic dimensions are representative of the literature on patient-centeredness within patient-practitioner encounters.
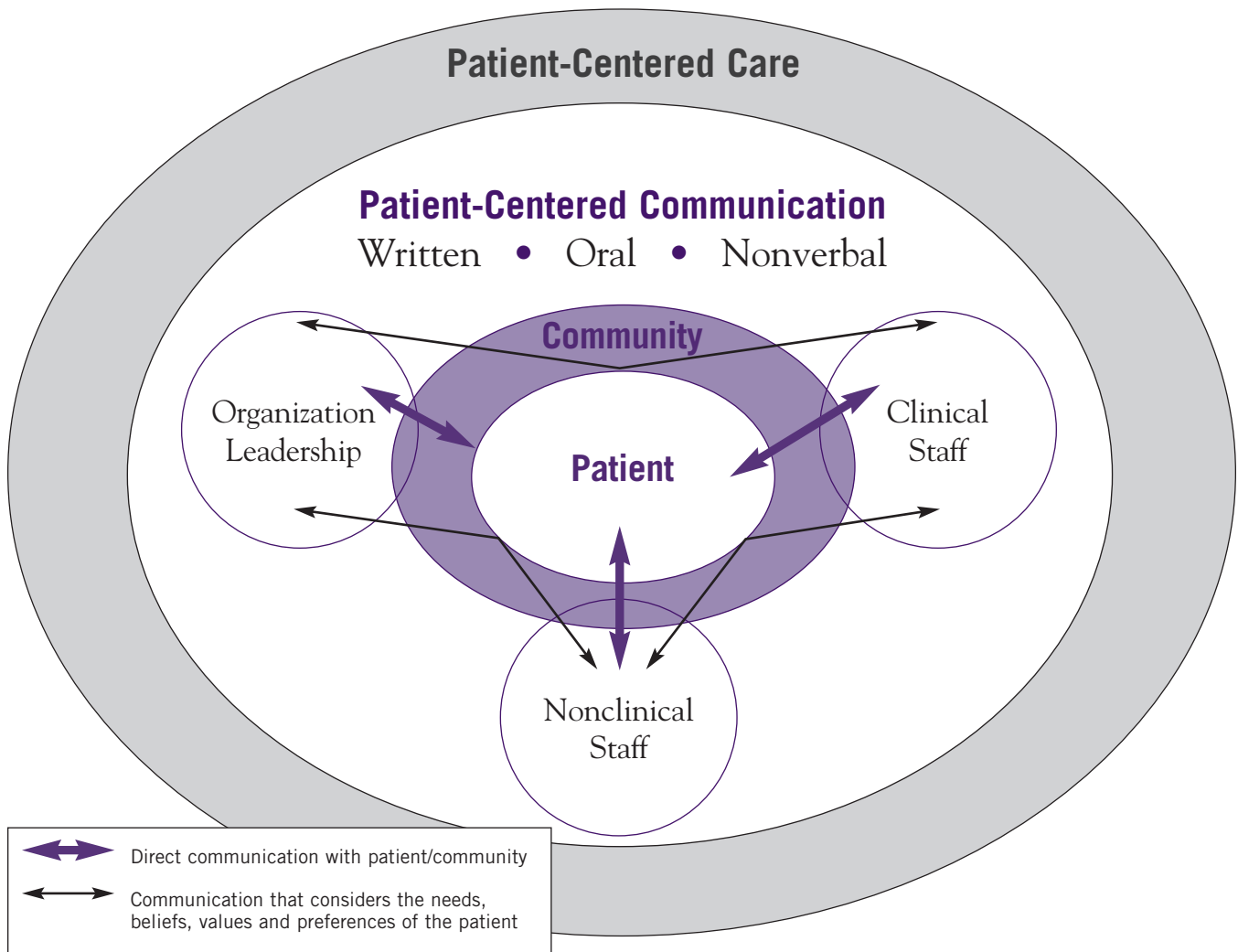
In addition to the communication that occurs between patients and practitioners in face-to-face encounters, there are other modes of communication that may be patient-centered (*see Figure 3*). Patients may experience patient-centered communication when attempting to interface with the health system, including nonclinical staff and organizational leadership. For example, patients may have the ability to e-mail their practitioners if they prefer, to interact effectively with nurse/triage systems and pharmacy call centers, and receive timely returned phone calls. Written communication from a health care organization to a patient, such as signage, appointment reminders and patient education materials, may also be patient-centered to the extent that they meet patients' needs, are written in a way that patients can understand, and enhance patients' understanding and ability to participate in medical care. Also, practitioners communicate with each other, with nonclinical staff and with organizational leadership in ways that may or may not be patient-centered. For example, different members of the health care team may communicate and contribute their different perspectives (e.g. nurse-physician, physician-pharmacist, physical therapist-nurse, generalist-specialist, etc.) to ensure that patients' values and preferences are honored. While these interactions do not always directly involve the patient, the communication that occurs between health professionals may be considered patient-centered to the extent that the patient's interests are the focus of that communication. Finally, some of this communication undoubtedly involves the patients' community, of which the practitioners, nonclinical staff and organizational leadership may be a part.

Finally, although patient-centered communication is typically thought of as communication that is aligned to meet the needs of individual patients, it is also appropriate to think about patient-centered communication, especially from an organizational perspective, as communication aligned to meet the needs of populations of patients. Therefore, facilitation of patient-centered communication within organizations must include policies and practices that are responsive to the communication needs and preferences of the populations of patients served by the organization.

Conclusion

The Ethical Force Program's Patient-Centered Communication Initiative is focused on communication, which is a specific part of providing patient centered care. Patient-centered communication is any communication that is respectful of and responsive to individual patient preferences, needs and values. This includes all modes of communication (e.g., written or verbal) and all participants in health care (e.g., communication within and between patients, practitioners, and health care organizations). The aim of policies and practices that promote patient-centered communication should be to enhance the health of patients by improving the relationships between patients, practitioners and the organizations within which they interact.

Figure 3. Conceptual Framework for Patient-Centeredness in Health Care

Patient-Centered Care

Patient-Centered Communication
Written • Oral • Nonverbal

Community

Organization Leadership

Patient

Clinical Staff

Nonclinical Staff

Direct communication with patient/community

Communication that considers the needs, beliefs, values and preferences of the patient

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Ethics and Patient-Centered Communication
Jeff Jarosch, MA and Fritz Allhoff, PhD

Health care organizations hold unique ethical obligations. Though profitability may be an important motivation, health care organizations are expected to strive to meet the health care needs of the communities they serve (Pijneneburg and Gordijn 2005, Wilmot 2000, Emanuel 2000). This expectation creates a social covenant between health care organizations and their communities. Sometimes the covenant is explicit, such as when a hospital's mission statement contains specific goals for meeting patients' communication and other needs, and sometimes it is implied. One tool that health care organizations use to fulfill their social covenants and meet their ethical obligations is patient-centered communication.

Patient-centered communication is communication that is respectful of and responsive to patients' preferences, needs and values. Any communication that affects patients can be patient-centered, including oral, written and nonverbal communications between patients and practitioners, patients and health care organizations, and between and among health care practitioners and health care organizations. Patient-centered communication is vital for health care organizations to provide ethical, high-quality care. The ethical importance of patient-centered communication is reflected in several professional codes, guidelines, and standards for health care organizations. This examination of patient-centered communication and ethics is complemented by business and other related arguments for patient-centered communication (*see Appendix C: The "Case"*).

The documents used here to explore ethics and patient-centered communication include:

■ The Joint Commission on Accreditation of Healthcare Organizations Standards for Hospitals, Ambulatory, Behavioral Health, Long Term Care, and Home Care (Joint Commission 2004)

■ The American Hospital Association "Ethical Conduct for Health Care Institutions" (AHA 1992)

■ The American Medical Association "Principles of Medical Ethics" (AMA 2004)

■ The American Nurses Association "Code of Ethics for Nurses" (ANA 2001)

■ The American Pharmacists Association "Code of Ethics for Pharmacists" (APhA 1994)

■ The Institute of Medicine Report, "Crossing the Quality Chasm: A New Health System for the 21st Century" (IOM 2001)

■ The Institute of Medicine Report, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care" (IOM 2003)

■ The Office of Minority Health "National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care" (U.S. DHHS OMH 2001)

These documents were created by a wide variety of groups representing various health-related interests. Ideas about ethics in health care that appear across all these documents are likely to represent an ethical consensus among health care organizations.

These codes, guidelines and standards each argue that health care organizations and providers have specific ethical obligations related to patient-centered communication. These ethical obligations that relate to patient-centered communication fit into three broad themes:

■ Health care organizations must maintain and protect the autonomy of health care users.

■ Health care organizations must assure quality care.

■ Health care organizations must maintain equity among health care users.

None of these ethical obligations can be fully achieved without patient-centered communication.

The first ethical obligation, to maintain the autonomy of health care users, is central to any ethical examination of patient-centered communication. Each of the documents described here addresses the importance of patient autonomy in some way. According to the American Hospital Association "Ethical Conduct for Health Care Institutions," "policies and practices must respect and promote the patient's responsibility for decision making" (AHA 1992). The "Code of Ethics for Nurses" requires that nurses respect patient self-determination and autonomy (ANA 2001). The American Medical Association "Principles of Medical Ethics" and the "Code of Ethics for Pharmacists," similarly argue that physicians and pharma-

cists must respect patients' dignity and autonomy (AMA 2004; APhA 1994). "Crossing the Quality Chasm" suggests that the patient must be the "source of control" in order to improve the quality of care in the United States (IOM 2001).

There is agreement within the health care system that maintaining health care users' autonomy and recognizing autonomous patients' preferences, needs and values is vital to providing ethical health care. This ethical obligation cannot be met without patient-centered communication. Communication that is respectful of and responsive to health care users' preferences, needs and values is the mechanism that health care practitioners use to discover patients' preferences so that they may act on them. Without patient-centered communication, patients and clients are taken out of the loop, leaving practitioners to assume or guess their needs and preferences. In such a situation, autonomy is simply impossible.

Several of the documents above focus on the ethical obligation to maintain patients' autonomy with specific regard to health care users' cultures and linguistic backgrounds. The American Hospital Association "Ethical Conduct for Health Care Institutions" states that "health care institutions should assure that the psychological, social, spiritual and physical needs and cultural beliefs and practices of patients and families are respected" (AHA 1992). The CLAS standards address issues of language and communication directly, stating that "Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable, and respectful care that is provided in a manner compatible with their cultural health beliefs and preferred language" (U.S. DHHS OMH 2001). The Institute of Medicine Report, *Unequal Treatment,* argues that health care providers must be educated to respect and interact with patients from any culture (IOM 2003). It is not possible for a health care organization or a health care practitioner to respect and accommodate patients' cultural and linguistic background without communicating with them in a way that is responsive to their preferences, needs and values.

Of special note is that health care organizations must take extra care when communicating with individuals from cultures in which autonomy itself is not as strong a value as it tends to be in Western cultures. In some cultures (and in some families in every culture) health care decisions are not so much made autonomously by individual patients as they are made collectively within the family. Health care organizations should be alert to recognize and honor such

cultural or personal preferences. To do so is not disrespectful of patient autonomy; it is within the rights of autonomous persons to share decision-making authority about their health care with anyone they choose—including their family, doctor, religious leader or simply a friend.

The second ethical obligation of health care organizations, reflected in the codes, guidelines and standards examined here, is that health care organizations must assure quality care. Each of the documents explicitly addresses obligations regarding quality and argues that health care organizations must provide all health care users with care that meets recognized quality standards. Patient-centered communication is at the heart of this ethical obligation because it is vital to assuring and improving quality for communication-vulnerable groups *(data to support this assertion are reviewed in Appendix C: The "Case")*. The use of patient-centered communication can expose areas where communication-vulnerable groups receive low-quality care and allow practitioners to find ways to improve their care. Furthermore, if health care organizations and practitioners communicate with patients and clients in a way that is responsive to their preferences, needs, beliefs and values, patients are more likely to receive appropriate care and are more likely to return for more care in the future. Patient-centered communication increases trust in the health care system and opens it to traditionally underserved communities. This may dramatically improve the access to and quality of the care members of these communities receive.

The third ethical obligation of health care organizations, to maintain equity among health care users, is also well reflected in the documents examined here. The "Code of Ethics for Pharmacists" states that "when health resources are allocated, a pharmacist is fair and equitable, balancing the needs of patients and society" (APhA 1994). The Institute of Medicine report on quality states that health care organizations should be equitable, "providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status" (IOM 2001). Communication barriers, whether culture, language or literacy-related, are personal characteristics that can vary dramatically from patient to patient. Patient-centered communication is a method that health care organizations can use to ensure equity among individuals facing varying communication challenges. For instance, to communicate effectively with practitioners, health care users from communication-vulnerable groups often require interpretation or documents that have been translated into clear and simple language. Without these

types of patient-centered communication services and interventions, these patients will be more likely to experience communication gaps. Communication gaps include when a practitioner misunderstands or discounts specific concerns about a treatment or medication, when an informed consent discussion does not achieve full informed consent, or when a patient leaves a health care encounter without understanding treatment, follow-up, or medication instructions. Without patient-centered communication, equity is not possible. This is because individuals from communication-vulnerable groups can experience communication gaps, which might result in their receiving a lower quality of care than those from other, less vulnerable groups.

This set of ethical responsibilities—to promote and respect autonomy, assure quality of care, and deliver equitable care—establishes an ethical case for the importance of patient-centered communication in health care. It is no accident that these responsibilities are in line with the basic ethical principles laid out in the Belmont Report on the ethical conduct of research on human subjects (The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). These core ethical principles, usually spelled out as autonomy, beneficence and justice, form a comprehensive, consensus-based ethical framework for how to care for any person in a situation of vulnerability.

As clear and consistent as these three responsibilities may seem, there are times when patient-centered communication can uncover previously unnoticed ethical dilemmas. This can be especially problematic when the three responsibilities examined here come into conflict with each other. For instance, through patient-centered communication, a physician might discover that an individual holds a value or belief that is causing him/her to make decisions that might have a negative impact on his/her health (such as a personal belief in faith healing that is leading to nonadherence to prescribed medications). In this situation, the responsibility to maintain individuals' autonomy comes into conflict with the responsibility to provide quality care. Should the physician respect the patient's autonomy and allow him or her to make a decision that could result in a poor health outcome, or attempt to persuade, or coerce, the patient into taking a different course, perhaps sacrificing some degree of autonomy? In most cases, physicians can educate such patients on the facts of a condition, clearing up any misconceptions; but if the patient's decision rests on values that differ from the

physician's, not a misunderstanding, then autonomy must generally be respected.

Resource limits also create ethical dilemmas in addressing the communication needs of vulnerable populations. As a result of resource limits, the responsibility to provide patient-centered communication to all health care users (equity) can come into conflict with the responsibility to assure a high quality of care. As an extreme example, a health care organization might decide to use its resources only to serve those health care users with whom practitioners can easily communicate. As a result, the patients served might receive high-quality care, but at the expense of having some patients locked out of the system (i.e., inequity). However, most health care organizations have a responsibility to serve all members of their communities, so they cannot pick and choose whom to serve based on communication skills. In other words, health care organizations' ethical responsibilities require them to meet vulnerable populations' needs, even if the organization must commit additional resources to do so.

So how much of an organization's resources should be devoted to meeting the communication needs of vulnerable populations? When resources spent on improving communication come from a limited pool, arguments over balancing communication needs with other needs are inevitable. Indeed, limited resources can at times cause communication-vulnerable populations to receive lower-quality care than other groups. But this inequity in quality of care is a reason that organizations should seek ways to provide patient-centered communication effectively and efficiently, not an argument for denying communication-vulnerable groups access to care. In short, in the face of resource limits, ethical health care organizations must make a good-faith effort to provide equal access to high-quality health care for all populations.

Until this point, we have examined ethical arguments for patient-centered communication that are reflected in eight prominent documents that discuss the ethical responsibilities of health care organizations. This strategy relies largely upon the ethical method of principalism, establishing an ethical basis for action based on specific rules, or principles (e.g., autonomy, beneficence and justice). But principalism is just one approach to moral philosophy. Other ethical and philosophical movements and methods, including utilitarianism and deontology, can provide additional ethical bases for patient-centered communication.

Very briefly, according to utilitarianism the right action (or practice) is the one, out of the available possibilities, that maximizes aggregate happiness, or "utility." Through effective communication, health care organizations will be better able to ascertain the preferences, needs and values of individuals and populations, and will consequently be able to provide treatment that is consistent with these preferences, needs and values. Patients will derive more satisfaction from treatments that are consistent with their preferences, needs and values than from treatments inconsistent with these. Put simply, through patient-centered communication health care organizations make the individuals and populations they serve happier *(and healthier, Appendix C: The "Case)*. Those who have the most to gain from patient-centered communication are those for whom communication is most difficult to begin with—suggesting that special efforts to address the needs of these populations will bring the most additional "utility." *As discussed in Appendix A*, health care organizations can also benefit from patient-centered communication in a wide variety of ways. Individual patients, patient populations, and health care organizations all can derive utility from patient-centered communication. Finally, it is reasonable to suggest that widespread progress in patient-centered communication could improve the way that society views health care and lessen any public mistrust or cynicism about health care systems. Taken together, these factors all suggest that utilitarianism supports efforts to promote patient-centered communication, especially efforts to address the communication needs of vulnerable populations.

Deontology is the study of rights and duties. Under deontology, rights and duties cannot be violated even if doing so would contribute to aggregate happiness. There are many versions of deontology, but most of these share a central core that will be familiar from the discussion of principles above. Owing to Immanuel Kant, most deontological ethical theories hold that all humans are morally required to respect the autonomy of other persons (Reich 1995). So a central question that deontology poses with regard to patient-centered communication is: what is the relationship between patient-centered communication and autonomy? If patient-centered communication is sensitive to autonomy, then it is a moral good. (Or, alternatively, if the absence of patient-centered communication interferes with autonomy, then patient-centered communication must be considered a moral good.) We have already established that patient-centered communication is vital to maintain patient autonomy. Thus, patient-centered communication is a moral good for the deontologist.

Conclusion

These extremely brief summaries of a principalist approach, a utilitarian approach and a deontological approach to the ethics of patient-centered communication are remarkable for the degree to which all support its ethical importance. Clearly patient-centered communication is vital to ethical health care. The principalist argument, in particular, is reflected in a number of key ethical codes, guidelines, and standards that strongly support the ethical consensus that health care organization must take steps to foster and promote patient-centered care.

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The Case for Promoting Patient-Centered Communication in Health Care Organizations

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Abstract

Assessing and improving patient-centered communication, as recommended in this report, will take resources— including money, time and personnel. In most health care organizations, all of these are in short supply. This section provides some of the business, legal and financial reasons why any health care organization—including hospitals, physician practices, pharmacies, health plans and others— should consider using limited resources to improve communication with vulnerable populations.

The reasons are separated into two categories: business opportunities, if leaders create and support patient-centered communication initiatives, and business risks, if leaders neglect the importance of effective communication across cultures, languages and health literacy levels.

Research and real-world experience show that taking steps to improve patient-centered communication can provide a health care organization with valuable opportunities to:

- Strengthen the commitment to its mission and high-quality care

- Improve consumer loyalty, retention and public image

- Increase market share

- Enhance employee morale

- Promote cost-effective care

- Solidify a leadership position and unite the workforce around a strong vision

On the other hand, failing to ensure effective communication is known to carry significant risks for health care organizations, including:

- Legal and regulatory risks, such as lawsuits related to inadequate informed consent, violations of federal laws (e.g., Title VI and the Americans with Disabilities Act), inconstancy with the Culturally and Linguistically Appropriate Services (CLAS) standards and inability to meet the accrediting and regulatory standards of the Joint Commission on Accreditation of Healthcare Organizations (Joint Commission) or other organizations.

- Poor communication is widely believed to be the number one cause of medical errors.

- Ineffective communication leads to ineffective care, including lower adherence to therapies, worse health outcomes and delivery of unnecessary diagnostic services.

Overall, there are a number of compelling business reasons to make sure vulnerable populations have opportunities to engage in and receive effective health care communication. Taken together, these reasons suggest that increasing attention and resources should be targeted toward monitoring and improving patient-centered communication.

Introduction

Arguing for patient-centered communication on business grounds might seem unnecessary, given the strong moral and ethical case for promoting patient-centered communication described in Appendix B. However, while health care ethics demand good communication, spending resources on improving communication might not seem to be immediately financially rewarding for a health care business. Even if an organization's leaders recognize that good communication improves quality of care, a simple quality improvement argument might not be enough to convince some decision makers.

Blumenthal and Ferris suggest that improving the quality of health care has a positive impact on society. The rewards they list include "realizing the professional aspirations of health professionals, improving public health, fostering social solidarity, and increasing the pride of Americans in their health care system and their society" (Blumenthal and Ferris 2004). Unfortunately, others have found that there is not a strong "business case" for improving quality in the current American health care system (Kilpatrick et al. 2005, Balit and Dyer 2004, Leatherman et al. 2003, Brach and Fraser 2002). For health care delivery organizations, that must devote resources to improving quality, the financial rewards for doing so are often ambiguous, delayed or wholly unrealized (Blumenthal and Ferris 2004, NCQA 2001a). As a result, many experts believe that purchasers of health care will need to develop

and use incentives that specifically require organizations to meet quality standards, such as linking payments to demonstrated quality improvements (ACP 2005, AMA Policy 450.947, Bodenheimer et al. 2005, Bailit and Dyer 2004). This means there is a need to create, rather than simply recognize, a business case for many quality improvements in health care.

While these arguments present a discouraging picture for quality improvement in general, there are some situations when it is much easier to outline a "business case" for allocating resources to improve quality in specific areas. This includes improvements that address miscommunications and gaps in communication (Weinstock 2003, Goode et al. 2001). Good business practices in health care, especially over the long run, strongly support improvements to make communication more effective and patient-centered. More specifically, the case for patient-centered communication rests on both the business opportunities that come from creating and supporting patient-centered communication initiatives and the business risks of neglecting the importance of effective communication across cultures, languages and health literacy levels.

Business Opportunities of Patient-Centered Communication

Many health care professionals prefer not to think of health care in a traditional business model, with sellers and buyers (customers). But whether or not health care could or should operate in a "free market," health care can draw some lessons from traditional business models. Good businesses, including good health care organizations, are mission-focused and attentive to the needs of those in the consumer role, whether they be patients, customers, enrollees or employees. And a good business will take advantage of opportunities for investments that will promote long-term success and growth.

Over the long term, investments in improving communication with vulnerable populations have the potential to:

- Strengthen an organization's commitment to its mission and a high quality of care

- Improve consumer loyalty, retention and public image

- Increase market share

- Enhance employee morale

- Promote cost-effective care

- Solidify a leadership position and unite the workforce around a strong vision

Strengthen the Mission

Improving patient health is the core mission for many, if not all, health care organizations (Ozar et al. 2001). Since patient health is improved with effective communication, or, alternatively, is put at risk through ineffective communication (Forster et al. 2003; Huntington and Kuhn 2003, Forster et al. 2002, Beckman et al. 1994), efforts to improve communication will serve this core mission. In addition, the traditional primary duty for physicians and health care organizations is to act in the best interests of the patients they serve. Since protecting the interests of patients cannot be done without understanding what those interests are, effective communication is required to fulfill a "patients-first" mission.

But what are the business rewards of activities that strengthen an organization's mission?

Evidence suggests that a strong mission is one of the key factors to long-term business success. For instance, in their landmark study of corporate culture and best business practices, "Built to Last: Successful Habits of Visionary Companies," James Collins and Jerry Porras identified the characteristics of some of the world's premier companies (Collins and Porras 1997). The authors compared eighteen elite companies with their still successful but generally second-ranking counterparts. A strong organizational vision, or "core ideology," was the distinguishing characteristic of stellar companies, and an important element of general achievement and longevity in business. Those companies whose actions were guided by a set of essential values and "a sense of purpose beyond making money" tended to be more profitable and successful than corporations whose primary goal appeared to be maximizing income.

Collins and Porras show that good business practices ultimately demand the "prioritization of mission over profit motives." As a result, expenditures on patient-centered communication that are carried out because they are mission-focused, even if they are not immediately or directly reimbursed, may contribute to the long-term survival and success of a health care business.

Improve Quality of Care

Providing high-quality care is a common core value for health care organizations. Recent discussions about how to improve quality in health care highlight the importance of patient-centered care and effective communication with vulnerable populations.

In its influential report "Crossing the Quality Chasm: A New Health System for the 21st Century," the Institute of Medicine (IOM) identified six areas for improving the health care system to enhance quality (IOM 2001). One of these six areas is the provision of "patient-centered" care, which the IOM defines as care that is "respectful of and responsive to individual patient preferences, needs and values in a way that ensures that patient values guide all clinical decisions." Another is "equitable care" that "does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location and socioeconomic status." In other words, high-quality care must be patient-centered and equitably provided to all populations served. Therefore, if quality is important to an organization then improving patient-centered communication for vulnerable populations must also be important.

An abundance of anecdotal information and a growing body of formal research suggest that good communication with patients makes history-taking and diagnosis easier and minimizes both overuse and underuse of health care services (Bernstein 2005, Jackson 2005, Thomas 2005, Jacobs et al. 2004, Ashton et al. 2003, Flores et al. 2003, Lee et al. 2002, Elderkin-Thompson et al. 2001, Salimbene 2001, Hornberger et al. 1997, Baker et al. 1996a,b). In addition, effective communication can lead to improved quality through reducing delays in care, and improving adherence and use of preventive services (Jacobs et al. 2004).

During a series of recent site visits to hospitals, the Ethical Force Program learned of instances where inadequate communication led to expensive workups for minor (or nonexistent) problems, near-miss errors related to misdiagnosis, and frequent misunderstandings leading to patient nonadherence and failures to follow up (Ethical Force Program 2005, Hedges-Greising and Hasnain-Wynia 2005). Overall, effective communication can lead to better treatment for patients as well as time and resource savings for health care organizations.

Enhance Consumer Loyalty, Retention, Appropriate Utilization and Public Image

Strong consumer relations are important to organizations that provide health care services. Because health care is so important to patients, and so closely tied to emotions, individuals with good experiences can be an important source of referrals, repeat business and a positive public image. The opposite is also true. If a few patients have bad experiences, they can influence many others. Demonstrating patient-oriented values and promoting patient-centered communication can strengthen a health care organization's community ties, improve its reputation and solidify its consumer base. A loyal consumer base helps organizations avoid costly problems, such as high turnover, low utilization rates and unused capacity.

In addition, an organization's public image is a powerful resource and a strong contributor to its financial success. An organization with a reputation for providing high-quality services that meet the needs of its community will attract qualified workforce members who share a similar commitment to excellence in patient care. Such a reputation is also an asset within the community. It serves as a foundation when an organization needs community approval and cooperation for institutional changes (such as public financing for new construction or obtaining a "Certificate of Need" for new equipment or services). Finally, a strong reputation for public service can help lessen damage to an organization's image in the event of an adverse event. A respected, trusted organization can maintain its community relationships and withstand negative publicity. While the organization might still be held accountable (publicly or legally) for medical errors or other missteps, it can maintain its competitive advantage if the public feels it contributes to the community and overall is responsive to community needs and concerns.

Increase Market Share

An organization's visible efforts to make communication more patient-centered and effective can bring immediate benefits in some highly competitive markets. These efforts will both improve the organization's reputation and differentiate it from competitor organizations.

Minority groups represent a rapidly expanding and sometimes overlooked customer base. The U.S. Census Bureau estimates that four of ten Americans will belong to a racial or ethnic minority by 2030 (U.S. Census 2000). Yet while minority populations represent a growing segment of the health care market, some organizational leaders still perceive that these patients are now, and always will be, more expensive and riskier to treat (Brach and Fraser 2002). But for those with a deeper understanding of health care markets, this shortsightedness on the part of the competition represents a business opportunity (Stevenson et al. 2002). During recent site visits to hospitals, for example, the Ethical Force Program found that hospital leaders who recognize minority populations as a viable consumer segment can increase their organization's market share and succeed (Fogaren 2005). Recent immigrant populations, which may be uninsured or underinsured, over time tend to get insurance and become "paying customers." Some will even become community and business leaders—and hospital donors. As a result, organizations that make early efforts to reach out to these new arrivals can develop a remarkably loyal customer base.

Enhance Workforce and Stakeholder Morale

The importance of good workforce morale is a lesson many successful businesses have learned. Good morale is defined as "the spirits of a person or group as exhibited by confidence, cheerfulness, discipline, and willingness to perform assigned tasks" (American Heritage Dictionary 2000). Good morale, or esprit de corps, motivates employees and other workers to be successful and loyal.

Initiatives that focus on helping vulnerable populations can inspire workforce members, limit cynicism, build pride in the workplace, and create "an internal culture that promotes quality and excellence" (Balit and Dyer 2004). How might focusing on patient-centered communication build strong workforce morale? First, initiatives in patient-centered communication tend to involve many different workforce members in a united quality improvement effort. To be successful, patient-centered communication must occur throughout an organization—across divisions, job types, and service lines. Second, communication initiatives often encourage staff members to learn from their patients, patient communities and each other. These initiatives often start with planners collecting information from staff members about what barriers they face in communicating

with patients and in communicating across the organization. Collecting and sharing data sometimes leads to a gradual shift in attitude that can be very healthy for organizational culture. For example, developing a "learning culture" will benefit related efforts to reduce errors and promote clinical quality improvement. Third, training workforce members to address specific communication issues will provide lessons on improving general communication skills. Relationships between employees, including within and between management and employees, may also improve as overall communication skills improve. Finally, patient-centered communication initiatives can provide leadership with chances to reward excellence in care, tangibly underscoring the organization's commitment to its mission.

Promote Cost-Effective Care

In some cases, patient-centered communication strategies can help organizations deliver more cost-effective care. For example, a health care organization can limit costs if it understands the needs of its communities and patients enough to provide the most appropriate, focused services (Hornberger et al. 1997). Outreach and prevention programs that include effective communication strategies as part of their protocols are more successful at encouraging patients to visit clinics for screenings and adopt healthy lifestyles (Jacobs et al. 2004).

Solidify Leadership Position

Health care leaders can demonstrate and reinforce their leadership positions by launching new initiatives that staff and community members view as inspirational and widely beneficial. The Ethical Force Program saw this repeatedly during site visits to eight hospitals that are developing innovative ways to meet the communication needs of diverse patient populations (Ethical Force Program 2005). Leaders and managers set a clear moral compass for their organizations and gain the loyalty and admiration of employees when they model ethical behavior, reward the ethical behavior of others, engage staff members in shared projects with high moral purpose (as well as business benefits), and demonstrate a willingness to learn and evolve.

The Risks of Ineffective Communication

Despite the business opportunities that have been outlined, there are many cases when health care organizations see little or no short-term direct financial gain from improved communications with vulnerable populations. It can take considerable resources, in the short term, to address communication gaps. For instance, it can be expensive to implement interpreter services, which are rarely reimbursed to the level of their immediate costs (Albert 2004, Hawryluk 2002). And some of the populations that are most at risk for communication gaps are poor and uninsured or underinsured (Doty 2003, CMWF 2001). As a result, activities that attract these patients for care might seem to present an initial fiscal risk to a health care organization.

On the other hand, most leaders know that ignoring vulnerable populations is not a realistic solution for the long-term. And there are significant costs associated with knowingly providing ineffective communication. Thus, there may be a business case for making improvements in communication if the real or potential costs associated with failing to address communication gaps are greater than the costs of acting to improve communication.

For health care organizations that fail to address communication gaps, there are at least three major risks including:

- Legal and regulatory violations, inconsistency with standards and inability to meet accrediting requirements

- Vulnerability to medical errors and resulting lawsuits

- Providing ineffective care, including delivery of unnecessary diagnostic services and experiencing lower adherence to therapies and worse health outcomes

Legal Obligations

Informed Consent

For physicians and other health professionals, ethical and legal obligations require the informed consent of patients for most medical care (the primary exception being in emergencies). Ethically, informed consent derives from respect for persons and the ethical principle of autonomy.

Legally, informed consent is rooted in the concept of self-determination, by which competent patients have the right to control what happens to their bodies when seeking health care services. The goal of the informed consent process is to make sure that competent, fully-informed patients are aware of their diagnosis, prognosis, treatment and procedure options as well as the associated risks and benefits (Meisel and Kuczewski 1996). Many legal cases have reinforced that health professionals, and the organizations where they work, must provide an effective informed consent process that supports the decision-making role of the patient.[i]

A stark example occurred recently, when a health system in Florida paid $3.8 million in an out-of-court settlement to 5,000 pregnant women who complained that a consent form was "unreadable." The women successfully argued that:

> *a complex and difficult to understand informed consent document is conducive to a coercive atmosphere. The document itself is coercive, intentionally or not, when it is unduly long, complex and incomprehensible. This type of document sends a message… that [patients] have no meaningful role on the process because it is something that can be understood only by people with greater knowledge than they possess* (Hochhauser 2005).

The consent form they were complaining about had three pages of single-spaced type, written at the 14th-grade level. Institutional review boards (IRBs) on average recommend that informed consent forms for research be written at the 8th-grade level (Paasche-Orlow et al. 2003) and federal agencies and research departments commonly recommend a 6th- through 8th-grade reading level (Hochhauser 2005).

Civil Rights and Antidiscrimination Laws

Beyond informed consent requirements, hospitals, health plans, pharmacies, physician groups and other provider organizations have additional legal obligations with regard to communication. Almost all health care organizations must comply with Title VI of the Civil Rights Act of 1964. This act prohibits discrimination on the basis of race, color or national origin (U.S. DOJ 1998). It has been interpreted by the courts and federal agencies to require that health care organizations provide equally high quality care to patients who do and do not speak English.[ii] According

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i A few examples include Johnson v. Kokemoor, 199 Wis. 2d 615, 631, 545 NW2d 495 (1996); Cobbs v. Grant, 8 Cal. 3d 229, 502 P.2d 1, 104 Cal. Rptr. 505 (Cal. 1972); Wuerz v. Huffaker, 42 S.W.3d 652 (Mo.App. E.D. 2001); Wilkerson v. Mid-America Cardiology, 908 S.W.2d 691 (Mo.App. W.D. Jul 25, 1995)

ii 42 U.S.C. § 2000d. See also 45 C.F.R. § 80 et seq., Lau v. Nichols, 414 U.S. 563 (1974)

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to the National Health Law Program, "The federal Department of Health and Human Services and the courts have applied this statute to protect national origin minorities who do not speak English well. Thus, recipients of federal funding must take reasonable steps to ensure that people with limited English proficiency have meaningful access to their programs and services" (NHeLP 2004).

The Office for Civil Rights policy states, "Services denied, delayed or provided under adverse circumstances have serious and sometimes life-threatening consequences for an LEP [limited English proficient] person and generally will constitute discrimination on the basis of national origin, in violation of Title VI" (U.S. DHHS OCR 2003). Furthermore, organizations do not need to discriminate intentionally to be in violation of Title VI. So-called "neutral" polices and practices that have the effect of limiting access to programs and services according to national origin are also against the law. The Office for Civil Rights has investigated and counseled a large number of health and social service organizations over the past 30 years to ensure Title VI compliance (U.S. DHHS OCR 1999).

In addition, Titles II and III of the Americans with Disabilities Act (ADA) prohibit discrimination against individuals with disabilities in public services and public accommodations (DOJ ADA 2006). And under Section 504 of the Rehabilitation Act, all health care organizations that receive federal payments (such as Medicare payments) must ensure that their services are accessible to persons with disabilities. Since some disabilities, such as deafness, lead to communication barriers, federal laws require that health care organizations make effective accommodations for these populations.

Costs of failing to comply with Title VI of the Civil Rights Act and the provisions of the ADA and Rehabilitation Act can be high. Health care organizations that do not communicate effectively with limited English proficient (LEP) patients can lose federal funding and, as a result of a public investigation, may lose standing in the community. Recently, private actions taken by patients against provider organizations have further illustrated the responsibility of health care businesses to provide equal access to federally funded programs (U.S. DHHS OCR 2003). For example, a 2005 civil rights complaint was filed against several New York hospitals for lack of adequate interpretation services (Bernstein 2005).

Regulatory Obligations

The CLAS Standards

In March 2001, the U.S. Office of Minority Health published its final report on national standards for Culturally and Linguistically Appropriate Services in health care (U.S. DHHS OMH 2001). This report identifies 14 individual guidelines (commonly referred to as the CLAS standards). While most CLAS standards are recommendations and not mandates, they have become an increasingly important reference point in the ongoing quality and health disparities dialogue. Standards 4-7 on provision of language assistance services, which are derived from Title VI obligations, are considered to be legally required *(see also Appendix D: Regulations and Standards)*.

Accreditation and Other Requirements

For hospitals and other health care organizations, the Joint Commission has, since 1951, developed and enforced standards through its accreditation process. Requirements for Joint Commission accreditation have increasingly emphasized cultural and linguistic competence. Its standards largely reflect the CLAS standards *(see also Appendix D: Regulations and Standards)*.

For health plans, the National Committee for Quality Assurance (NCQA) accreditation requirements evaluate if effective communication practices are in place for vulnerable patient populations (see also Appendix D: Regulations and Standards). NCQA uses the Health Plan Employer Data and Information Set (HEDIS) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS) as part of its accreditation process. HEDIS is a set of standardized performance measures jointly developed by public and private purchasing organizations, consumers and unions. HEDIS currently requests information about language diversity of Medicaid membership and in the past has requested information about availability of language interpretation services (NCQA 2006, 2001). CAHPS measures health plan performance from the patient's point of view and includes several questions about patient-centered communication and satisfaction with physician communication (AHRQ 2005).

Finally, public purchasers, such as Medicare and Medicaid, have been active in encouraging quality measurement through the development of standards such as the Quality Improvement System for Managed Care (QISMC). These,

too, contain provisions designed explicitly to "ensure that services are provided in a linguistically and culturally appropriate manner" (Brach and Fraser 2002). Recently, Centers for Medicare and Medicaid Services pay-for-performance initiatives have raised the possibility of Medicare payments being linked to performance on CAHPS measures, which would add a further incentive for providers to ensure effective patient-centered communication.

Avoiding Medical Errors, Other Adverse Events and Lawsuits

Studies suggest that miscommunication is a common underlying cause of diagnostic and treatment errors in medicine (Woolf et al. 2004). In fact, according to the Joint Commission, communication errors are the most common root cause of sentinel events (i.e., serious medical errors, Joint Commission 2005). For vulnerable populations, communication problems are likely to be especially prominent causes of medical errors (Thomas 2005, Youdelman and Perkins 2005, Peota 2004, AMA 1999). Among individuals with limited English proficiency, significant interpretation errors are more common when ad hoc interpreters, such as friends or family members, are used (Flores et al. 2003). Health care leaders recognize that a single communication error can lead to significant costs, including legal, compensation and reputation costs (Jacobs et al. 2004, Andrulis et al. 2002).

In addition, good patient-centered communication can help establish trust and rapport with patients, families and communities. Most medical errors do not result in lawsuits (Brennan et al. 2004, Andrews et al. 1997). A considerable body of research suggests that lawsuits arise from bad outcomes in combination with the error of "insensitive handling and poor communication after the incident" (Huntington and Kuhn 2003, Forster et al. 2002, Levinson et al. 1997, Beckman et al.1994, Vincent et al. 1994, Hickson et al. 1992).

Research on the causes of malpractice claims has led to a movement that promotes open communication, and even apologies, in the wake of medical errors. This movement advocates removing apologies from use in litigation. Proponents of this movement recommend full disclosure and open communication after medical errors as a means to reduce liability costs. There is mounting evidence that being honest and open about medical errors saves money.

For instance, after creating a more open disclosure policy, "[t]he University of Michigan Health System saw legal costs drop to $1 million annually, down from the $3 million it used to spend" (Albert 2005). The Veterans Administration Healthcare System has also documented successful implementation of a proactive disclosure program (Kraman and Hamm 1999).

> The Sorry Works! Coalition is a collaborative program launched by patients, lawyers, doctors, industry executives and administrators that is designed to improve physician-patient communication *(www.sorryworks.net)*.

In sum, it is likely that programs to improve communication will have positive effects on malpractice liability, both by avoiding errors in the first place and by reducing liability risk when errors occur.

Conclusion

Health care experts have suggested that the business case for improving quality in health care is generally weak. But this is not the case for efforts to improve patient-centered communication for vulnerable populations. In fact, there are a number of very compelling business reasons to invest in ensuring effective communication throughout health care. Organizations that commit to improving quality through the implementation of patient-centered communication strategies should be rewarded with greater patient satisfaction, less enrollee turnover, and more word-of-mouth referrals. This can lead to the organization securing a competitive advantage for the future. In addition, failure to address communication gaps can be very costly. Taken together, these reasons suggest that increasing attention and resources should be targeted toward monitoring and improving patient-centered communication.

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Regulations and Standards Related to
Consensus Report Expectations

The expectations in this consensus report are supported by a variety of guidelines and standards, including some legal, regulatory and accreditation requirements. In this appendix we provide a brief summary of the primary standards and requirements that organizations must address, as they relate to the topics and expectations within the report. This summary is not comprehensive. Many organizations and individuals whose work informed the consensus expectations in this report are not mentioned here, but are instead referenced throughout the body of the report.

- The sources and primary audiences for these regulations and standards are listed on pages 138-139.

Content Area 1: Understand Your Organization's Commitment

Title VI of the Civil Rights Act of 1964

Prohibits organizations that receive federal funding from discriminating against individuals on the basis of race, color or national origin—this is interpreted to include discrimination on the basis of English proficiency.

U.S. Department of Health and Human Services Office for Civil Rights Title VI Guidance

"The development and maintenance of a periodically updated written plan on language assistance for limited English proficient persons for use by a recipient's employees who serve or interact with the public could be an appropriate and cost-effective means of documenting compliance with Title VI and providing a framework for the provision of timely and reasonable language assistance."

According to the guidance, the plan should:

- Identify limited English proficient persons who need language assistance.
- Include information on how language assistance will be provided.
- Outline what staff should be trained on the organization's plan and how they will be trained and evaluated on provision of language assistance.
- Indicate how the organization will notify limited English proficient persons that language assistance is available.

"Effective plans [for provision of language assistance] set clear goals and establish management accountability."

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS)

Health care organizations should develop, implement and promote a written strategic plan that outlines clear goals, policies, operational plans and management accountability oversight mechanisms to provide culturally and linguistically appropriate services (standard 8).

Joint Commission on Accreditation of Healthcare Organizations (Joint Commission)

The Joint Commission requires the organizations it accredits (hospital, ambulatory, long term care, behavioral health and home care) to demonstrate effective communication. This includes:

- Leadership accountability for timely transmission of information within the organization

- Effective communication across the organization, as well as with external organizations and the populations it serves
- Dissemination of mission, goals, plans, policies, and other governance documents to all staff

Organizations are assessed on compliance with applicable laws and regulations, short and long-term planning activities, and leadership effectiveness and competence to fulfill their organizations' missions. The Joint Commission does not specify that strategic planning activities must result in written plans that outline how organizations ensure high-quality patient-centered communication with diverse patient populations.

Applicable Standards:

Standard LD.2.10: An individual or designee(s) is responsible for operating the organization according to the authority conferred by governance.

Standard LD.2.20: Each organizational program, service or department has effective leadership.

Standard.LD.3.10: The leaders engage in both short-term and long-term planning.

Standard LD.3.60: Communication is effective throughout the organization.

Standard LD.3.80: The leaders provide for adequate space, equipment and resources.

Standard LD.3.120: The leaders plan for and support the provision and coordination of patient education activities.

Standard LD.4.10: The leaders set expectations, plan, and manage processes to measure, assess and improve the organization's governance, management, clinical and support activities.

Standard LD.4.50: The leaders set performance improvement priorities and identify how the organization adjusts priorities in response to unusual or urgent events.

URAC Standards
- **Core**
- **Case Management (CM)**
- **Health Plan and Health Network**

Core 3: The organization (a) maintains and complies written policies and procedures that govern all aspects of its operations; and (b) maintains a master list of all such policies and procedures.

Core 27: The organization, as part of its quality management program, provides written documentations.

Core 34: The organization follows marketing and communication practices that include: (a) mechanisms to clearly and accurately communicate information about services to consumer and clients; and (b) safeguards against misrepresentations about the organization's services.

Core 38: Access to Services. The organization establishes standards to assure that consumers and clients can obtain services.

CM 1: The case management program's description and/or written policies and procedures include a definition of case management consistent with these standards and provide information on: (a) the types of consumers served; (b) the delivery of case management services; and (c) staff qualifications.

CM 12: The organization establishes and implements policies to promote the autonomy of consumers and support consumer and family decision making.

Health Plan and Health Network Standard P-NM 1—Scope of Services

The organization defines the scope of its services with respect to: (a) the types of health care services offered within the provider network; (b) the geographic area served by the provider network; and (c) populations served by the provider network.

Health Plan and Health Network Standard P-NM 2—Provider Network Access and Availability

The organization establishes goals, measures actual performance in comparison to those goals, and makes improvements where necessary for the provider network regarding: (a) access to care; and (b) availability of providers to provide care to consumers.

Content Area 2: Collect Information

Federal Laws and Regulations (NHeLP 2004, Summit 2001)

Many health care organizations are required by law to collect information on the race, ethnicity, and language needs of the individuals and populations served, or eligible to be served, by the organizations to comply with:

- Title VI of the Civil Rights Act of 1964

- The Hill-Burton Act

- The Emergency Medical Treatment and Active Labor Act

- Medicare and Medicaid

- Other Executive Orders and federal policies

Although anecdotal reports continue to circulate among administrators that collecting demographic data may be illegal, only six states (California, Maryland, New Hampshire, New Jersey, New York, Pennsylvania) have any restrictions on how health plans and other health care organizations collect information on race and ethnicity. These restrictions apply only to the application process, not to collection of information from enrollees or about eligible populations for broader strategic planning at the organizational level.

U.S. Department of Health and Human Services Office for Civil Rights Title VI Guidance

To comply with Title VI, the Office for Civil Rights instructs organizations to:

- assess "the number or proportion of limited English proficient individuals eligible to be served or encountered and the frequency of encounters."

Adhering to Title VI also requires organizations to identify the specific language needs of individuals who interact with the organization.

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS)

Health care organizations should ensure that data on the individual patient's/consumer's race, ethnicity, and spoken and written language are collected in health records, integrated into the organization's management information systems, and periodically updated (standard 10).

Health care organizations should maintain a current demographic, cultural and epidemiological profile of the community, as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area (standard 11).

Joint Commission on Accreditation of Healthcare Organizations (Joint Commission)

Standard IM.6.20: Records contain [patient/resident/client]-specific information, as appropriate, to the care, treatment and services provided.

- More specific requirements for what information must be collected and when it must be collected vary by the organization being accredited (hospital, ambulatory, long term care, behavioral health, and home care). Examples of information that must be collected include cultural and religious practices, spiritual orientation, ability to hear and speak and predominant language.

Standard PC.2.20: The organization defines in writing the data and information gathered during assessment and reassessment.

Standard IM.6.60: The organization can provide access to all relevant information from a patient's record when needed for use in patient care, treatment and services.

Beginning on January 1, 2006,

Standard IM.6.20 requires "hospitals to collect information on the language and communication needs of patients. Specifically, the standard requires that each medical record contain, as applicable, the patient's language and communication needs, in addition to the patient's name, gender, address, date of birth and authorized representative, if any."

URAC Standards
- **Core**
- **Consumer Education and Support (CES)**
- **Case Management (CM)**

Core 36: The organization implements a mechanism to collect or obtain information about consumer satisfaction with services provided by the organization.

CES 17: Consumer Feedback Mechanism. The organization has processes to: (a) collect consumer feedback about communication, education and support; and (b) analyze feedback (including analysis by relevant subpopulations) to identify trends and opportunities for improvement.

CM 1: The case management program's description and/or written policies and procedures include a definition of case management consistent with these Standards and provide information on (a) the types of consumers served and (b) the delivery of case management services.

The National Committee for Quality Assurance (NCQA)

Standard on Culturally Competent Care (QI Element A, Cultural Needs and Preferences): The organization assesses the cultural, ethnic, racial and linguistic needs of its members and adjusts the availability of practitioners within its network if necessary.

The Health Plan Employer Data and Information Set (HEDIS)

For the HEDIS performance measures, managed care organizations are required to report on the diversity of individuals enrolled in Medicaid, including the number and percent of Medicaid members by race/ethnicity, Hispanic origin and spoken language.

The National Quality Forum (NQF)

NQF encourages the standardized collection and classification of race and ethnicity data. To improve health care quality for minority patients:

"Support and awareness should be built to improve race and ethnicity data collection practices in quality measurement efforts among health care organizations and the public."

It also recommends nationally standardized performance measures designed around and analyzed for disparities (NQF 2002).

Content Area 3: Engage Communities

U.S. Department of Health and Human Services Office for Civil Rights Title VI Guidance

Organizations should provide notice of language assistance services in a language limited English proficient individuals will understand. Examples of how this might be done include

- "Working with community-based organizations and other stakeholders to inform limited English proficient individuals of the recipients' services, including the availability of language assistance services."

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS)

Health care organizations should develop participatory, collaborative partnerships with communities and utilize a variety of formal and informal mechanisms to facilitate community and patient/consumer involvement in designing and implementing CLAS-related activities (standard 12).

Health care organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS standards and to provide public notice in their communities about the availability of this information (standard 14).

Joint Commission on Accreditation of Healthcare Organizations (Joint Commission)

Standard LD.3.30 Hospitals: Hospital demonstrates commitment to its community by providing essential services in a timely manner.

URAC Health Plan and Health Network Standards

Standard P-NM 6—Participating Provider Representation

The organization develops and implements a formal strategy to ensure that the perspective of participating providers is represented in provider network management processes, with an emphasis on: (a) participation by nonemployee participating providers on committees that address clinical and provider payment policies; and (b) representation of the types of providers that most frequently provide services to consumers.

The National Quality Forum (NQF)

"Community-based intermediaries should be utilized to develop and disseminate health care quality information to minority consumers."

This includes consideration of the message format so it is understandable to individuals with low literacy and limited English proficiency. (NQF 2002)

Essential Public Health Services (CDC 1994)

The Essential Services encourage stakeholders in the health care system to create and actively participate in partnerships, between schools, faith communities, work sites, health care organizations and professionals and others, to widely disseminate information and work together to improve health and health care.

- Essential Service #3: Inform, educate and empower people about health issues.
- Essential Service #4: Mobilize community partnerships to identify and solve health problems.

Content Area 4: Develop Workforce

U.S. Department of Health and Human Services Office for Civil Rights Title VI Guidance

This guidance instructs organizations to identify staff who need training, develop a strategy for staff training, and a method for evaluating the outcomes of staff training.

- The guidance also states that "staff should know their obligations to provide meaningful access to information and services for limited English proficient persons."

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS)

Health care organizations should implement strategies to recruit, retain and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the service area (standard 2).

Health care organizations should ensure that staff at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery (standard 3).

Joint Commission on Accreditation of Healthcare Organizations (Joint Commission)

The Joint Commission requires organizations to have a staffing plan that ensures a qualified and competent workforce that can fulfill the organization's mission, however it does not require inclusion of diversity goals.

Standard HR.1.10: The organization provides an adequate number and mix of staff that are consistent with the organization's staffing plan.

Standard HR.1.20: The organization has a process to ensure that a person's qualifications are consistent with his or her job responsibilities.

Standard HR.2.10: Orientation provides initial job training and information.

Standard HR.2.30: Ongoing education, including in-services, training, and other activities, maintains and improves competence.

Standard LD.3.70: The leaders define the required qualifications and competence of those staff who provide care, treatment and services, and recommend a sufficient number of qualified and competent staff to provide care, treatment and services.

URAC Standards
- **Core**
- **Case Management (CM)**

Core 13: The organization has written job descriptions for staff.

Core 14: Staff meets qualifications as outlined in written job descriptions.

Core 15: The organization implements a policy to (a) verify the current licensure and credentials of licensed or certified personnel/consultants upon hire; and (b) implement corrective action in response to adverse changes in licensure or certification status.

Core 16: The organization has a training program.

Core 17: Staff Operational Tools and Support. The organization provides staff with: (a) written operational policies and procedures appropriate to their jobs; and (b) clinical decision support tools as appropriate.

Core 33: Financial Incentives Policy. If the organization has a system for reimbursement, bonuses or incentives to staff or health care providers based directly on consumer utilization of health care services, then the organization implements mechanisms addressing how the organization will ensure that consumer health care is not compromised.

CM 1: The case management program's description and/or written policies and procedures include a definition of case management consistent with these Standards and provide information on: (a) the types of consumers served; (b) the delivery of case management services; and (c) staff qualifications.

CM 8: The organization encourages professional development among case managers through: (a) providing the experience/knowledge needed to apply for professional certification; (b) education regarding the quality management program; (c) membership in or attendance at meetings of relevant professional organizations; and (d) education in cultural diversity appropriate to the populations served.

National Committee for Quality Assurance (NCQA)

Standard on Culturally Competent Care (QI Element A, Cultural Needs and Preferences): The organization assesses the cultural, ethnic, racial and linguistic needs of its members and adjusts the availability of practitioners within its network if necessary.

The Health Plan Employer Data and Information Set (HEDIS)

Managed care organizations must report the number of practitioners and member services staff who provide services to Medicaid and Medicare enrollees in languages other than English.

Essential Public Health Services (CDC 1994)

Essential Service #8 Assure a Competent Public and Personal Health Care Workforce.

Among other things, this service includes education, training and assessment of personnel (including volunteers and other lay community health workers) to meet community needs for public and personal health services.

Content Area 5: Engage Individuals

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS)

Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language (standard 1).

Joint Commission on Accreditation of Healthcare Organizations (Joint Commission)

Standard RI.2.30: [Patients/Residents/Clients] are involved in decisions about care, treatment and services provided.

Standard RI.2.40: Informed consent is obtained.

Standard RI.2.100: Organization respects the [patient's/resident's/client's] right to and need for effective communication.

Standard PC 6.10: The patient receives education and training specific to the patient's needs and appropriate to the care, treatment and services provided.

Standard PC 6.30: The patient receives education and training specific to the patient's abilities as appropriate to the care, treatment and services provided by the hospital. This standard requires that content be "presented in an understandable manner" and that the individuals' comprehension be evaluated.

Standard LD.3.20 [Patients/Residents/Clients] with comparable needs receive the same standard of care, treatment and services throughout the organization.

URAC Standards
- **Core**
- **Consumer Education and Support (CES)**

Core 35: Communication Plan. The organization implements a communication plan to inform consumers and clients of their rights and responsibilities, including: (a) how to obtain services; and (b) their rights to submit a grievance or appeal, and how to do so.

CES 2: Further Pre-Enrollment Consumer Information Requirements. The information made available to potential enrollees under CES 1 includes: (a) data about member satisfaction with services provided by the organization; (b) condition-specific criteria for benefits coverage; (c) descriptions of the processes the organization uses to provide information and support to consumers: i. for whom English is not their primary language; ii. from different cultural backgrounds; and iii. with special needs, such as cognitive or physical impairments.

CES 4: Post-Enrollment Communication with Consumers. Upon enrollment, the organization informs consumers about available information resources and assistance.

CES 14: Cultural Sensitivity Communication Requirement Information is presented and delivered in ways that are sensitive to the diversity of the organization's enrollment, including: (a) literacy levels; (b) language differences; (c) cultural differences; and (d) cognitive and/or physical impairment.

CM 12: The organization establishes and implements policies to promote the autonomy of consumers and support consumer and family decision making. Such policies address: (a) the process by which consumers are informed of choices regarding services; (b) the right of consumers to have input into the case management plan; (c) the right of consumers to refuse treatment or services, including case management services and the implications of such refusal relating to benefits eligibility and/or health outcomes; (d) the use of end-of-life and advance care directives by the organization, as applicable; (e) the right of consumers to obtain information regarding the organization's criteria for case closure; (f) the right of consumers to receive notification and a rationale when case management services are changed or terminated; and alternative approaches when the consumer and/or family is unable to fully participate in the assessment phase.

Consumer Assessment of Healthcare Providers ans Systems (CAHPS) 2.0H

Adult survey questions address whether patients feel doctors and other health providers:
- Treat them with courtesy and respect (Q27, 31).
- Listen carefully to them (Q29).
- Communicate with them effectively (in person, over the phone, in writing) (Q30, 39, 41).

Child survey questions ask parents whether they feel doctors and other health providers:
- Effectively communicate with them (answer questions, provide information, discuss concerns—Q41, Q42, Q43).
- Effectively involve them in decision making (provide information about choices, risks and benefits, discuss preferences—Q45, Q46, Q47, Q48).

Content Area 5a: Socio-Cultural Context

Title VI of the Civil Rights Act of 1964

"No person in the United States shall, on the ground of race, color or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS)

Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language (standard 1).

Health care organizations should ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing and resolving cross-cultural conflicts or complaints by patients/consumers (standard 13).

Joint Commission on Accreditation of Healthcare Organizations (Joint Commission)

The Joint Commission requires hospitals to have a procedure for conflict resolution, although it does not specify any cultural or linguistic requirements.

Standard RI.2.120: The hospital addressed the resolution of complaints from patients and their families.

Standard RI.2.80: The organization addresses the wishes of the [patient/resident/client] relating to end-of-life decisions.

Standard RI.2.220 (LTC only): Residents receive care that respects their personal values, beliefs, cultural and spiritual preferences, and lifelong patterns of living.

Standard LD.3.20: [Patients/residents/clients]with comparable needs receive the same standard of care, treatment and services throughout the organization.

URAC Standards
- **Consumer Education and Support (CES)**

  CES 2: Further Pre-Enrollment Consumer Information Requirements. The information made available to potential enrollees under CES 1 includes: (a) data about member satisfaction with services provided by the organization; (b) condition-specific criteria for benefits coverage; (c) descriptions of the processes the organization uses to provide information and support to consumers: i. for whom English is not their primary language; ii. from different cultural backgrounds; and iii. with special needs, such as cognitive or physical impairments.

  CES 14: Cultural Sensitivity Communication Requirements. Information is presented and delivered in ways that are sensitive to the diversity of the organization's enrollment, including: (a) literacy levels; (b) language differences; (c) cultural differences; and (d) cognitive and/or physical impairment.

National Committee for Quality Assurance (NCQA)

> Standard on Culturally Competent Care (QI Element A, Cultural Needs and Preferences): The organization assesses the cultural, ethnic, racial and linguistic needs of its members and adjusts the availability of practitioners within its network if necessary.

Content Area 5b: Language

Federal Laws and Regulations
(NHeLP 2005, NHeLP 2004, Summit 2001)

> Several federal laws and regulations require organizations to provide language assistance for individuals with limited English proficiency:
>
> - Title VI of the Civil Rights Act of 1964
> - Hill-Burton Act
> - Emergency Medical Treatment and Active Labor Act
> - State Children's Health Insurance Program (SCHIP)
> - Medicare and Medicaid
> - Other Executive Orders and federal policies
>
> Within these are requirements that organizations provide individuals with access to information, services and programs regardless of their ability to speak or understand English. This includes making interpreters, bilingual staff, translated materials and other language assistance services available at no cost to the individuals being served.

U.S. Department of Health and Human Services Office for Civil Rights Title VI Guidance

> To meet the requirements of Title VI, the Office for Civil Rights recommends that organizations develop a plan for language assistance that includes the following information:
>
> - Types of language services available
> - How staff can obtain those services
> - How to respond to limited English proficient callers
> - How to respond to written communications from limited English proficient persons
> - How to respond to limited English proficient persons who have in-person contact with recipient staff
> - How to ensure competency of interpreters and translation services

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS)

> Health care organizations should ensure that patient/consumers receive from all staff members effective, understandable and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language (standard 1).

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Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation (standard 4).

Health care organizations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their right to receive language assistance services (standard 5).

Health care organizations must assure the competence of language assistance provided to limited English proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/consumer) (standard 6).

Health care organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area (standard 7).

Joint Commission on Accreditation of Healthcare Organizations (Joint Commission)

Standard PC 6.10: The patient receives education and training specific to the patient's needs and appropriate to the care, treatment and services provided.

Standard PC 6.30: The patient receives education and training specific to the patient's abilities as appropriate to the care, treatment and services provided by the hospital. This standard requires that content be "presented in an understandable manner" and that the individuals' comprehension be evaluated.

Standard RI.2.10: The organization respects the rights of [patients/residents/clients].

Standard RI.2.20: Patients receive information about their rights.

Standard RI.2.100: Organization respects the [patient's/resident's/client's] right to and need for effective communication.

- EP.2 Written information provided is appropriate to the age, understanding, and as appropriate to the population serviced, the language of the [patient/resident/client].
- EP.3 Organization facilitates provision of interpretation (including translation services) as necessary.
- EP.4 Organization addresses needs of those with vision, speech, hearing, language and cognitive impairments.

Standard LD.1.30: The organization complies with applicable law and regulation.

Standard LD.3.20. [Patients/Residents/Clients] with comparable needs receive the same standard of care, treatment and services throughout the organization.

URAC Standards
- **Consumer Education and Support (CES)**

CES 2: Further Pre-Enrollment Consumer Information Requirements. The information made available to potential enrollees under CES 1 includes: (a) data about member satisfaction with services provided by the organization; (b) condition-specific criteria for benefits coverage; (c) descriptions of the processes the organization uses to provide information and support to consumers: i. for whom English is not their primary language; ii. from different cultural backgrounds; and iii. with special needs, such as cognitive or physical impairments.

CES 14: Cultural Sensitivity Communication Requirements. Information is presented and delivered in ways that are sensitive to the diversity of the organization's enrollment, including: (a) literacy levels; (b) language differences; (c) cultural differences; and (d) cognitive and/or physical impairment.

National Committee for Quality Assurance (NCQA)

Standard on Language Access Services (RR4 Element B, Translation Services): The organization provides translation services within its member services telephone function based on the linguistic needs of its members.

Consumer Assessment of Healthcare Providers and Systems (CAHPS) 2.OH

Individuals are asked to report on whether they understand the explanations and information they receive from their doctors and health care providers, both written and oral. *See Content Area 5: Engage Individuals*.

The Health Plan Employer Data and Information Set (HEDIS)

Organizations must track and report the availability of language interpretation services provided to Medicaid and Medicare enrollees.

National Quality Forum (NQF)

Safe Practice 10: Voluntary consensus standard on informed consent. Calls for health care providers to "ask each patient or legal surrogate to recount, or 'teach back,' what he or she has been told during the informed consent discussion." (NQF 2003)

Among other recommendations, this standard calls for health care providers to use consent forms written in the language of the patient, and to provide interpreters when needed.

National Council on Interpreting in Health Care (NCIHC)

National Standards of Practice for Interpreters in Health Care. Standards cover accuracy, confidentiality, impartiality, respect, cultural awareness, role boundaries, professionalism, professional development and advocacy.

Content Area 5c: Health Literacy

Institute of Medicine (IOM) Priority Areas for National Action

Self-Management/Health Literacy. "Public and private entities should systematically provide educational programs and interventions that aim to boost patients' skills and confidence in managing and assessing their health problems. With a higher level of health literacy, more people also would have the skills to understand and act on health care information." (IOM 2003)

This is included as a cross-cutting area that impacts each of the other priority areas, asthma, diabetes, hypertension, immunization, etc.

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS)

The first CLAS standard emphasizes that health care information be understandable to the individuals who receive it, however there is no mandate for the use of plain language materials.

Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language (standard 1).

Joint Commission on Accreditation of Healthcare Organizations (Joint Commission)

Standard RI 2.100: Organization respects the [patient's/resident's/client's] right to and need for effective communication.

Standard PC 6.10: The patient receives education and training specific to the patient's needs and appropriate to the care, treatment and services provided.

Standard PC 6.30: The patient receives education and training specific to the patient's abilities as appropriate to the care, treatment, and services provided by the hospital. This standard requires that content be "presented in an understandable manner" and that the individuals' comprehension be evaluated.

Standard LD.3.20 [Patients/Residents/Clients] with comparable needs receive the same standard of care, treatment, and services throughout the organization.

URAC Standards
Consumer Education and Support (CES)

CES 13: Health Literacy Communication. The organization has a process to provide information.

CES 14: Cultural Sensitivity Communication Requirements. Information is presented and delivered in ways that are sensitive to the diversity of the organization's enrollment, including: (a) literacy levels; (b) language differences; (c) cultural differences; and (d) cognitive and/or physical impairment.

Consumer Assessment of Healthcare Providers and Systems (CAHPS) 2.0H

Individuals are asked if doctors and other health care providers explain things in a way they can understand, if they can understand written materials, and whether they experience problems with paperwork. *See Content Area 5: Engage Individuals.*

Agency for Health Care Research and Quality (AHRQ 2001)

Health literacy is addressed as one of 11 patient safety practices that were the most highly rated (of the 79 practices reviewed in detail) in terms of strength of the evidence supporting more widespread implementation.

- "Asking that patients recall and restate what they have been told during the informed consent process."

Safe Practice 10: Voluntary consensus standard regarding informed consent. Calls for health care providers to "ask each patient or legal surrogate to recount, or 'teach back,' what he or she has been told during the informed consent discussion" (NQF 2003).

Among other recommendations, this standard call for health care providers:

To use consent forms written in simple sentences

To engage patients in a full dialogue about the proceedings for which they provide consent

To assist visually or hearing-impaired and low-literacy patients with interpretation and reading

Content Area 6: Evaluate Performance

U.S. Department of Health and Human Services Office for Civil Rights Title VI Guidance

An organization's plan for provision of language assistance services "would likely include a process for [monitoring] its implementation of its plan and for updating its plan as necessary." Organizations may want to consider changes in:

- Current limited English proficient populations in service area or population affected or encountered
- Frequency of encounters with limited English proficient language groups
- Nature and importance of activities to limited English proficient persons
- Availability of resources, including technological advances and sources of additional resources, and the costs imposed
- Whether existing assistance is meeting the needs of limited English proficient persons
- Whether staff knows and understands the language assistance plan and how to implement it
- Whether identified sources for assistance are still available and viable

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS)

Health care organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction assessments and outcomes-based evaluations (standard 9).

Joint Commission on Accreditation of Healthcare Organizations (Joint Commission)

While it does not specify evaluation of communication performance, the Joint Commission does require organizations to collect data and monitor overall performance.

Standard PI.1.10: The organization collects data to monitor its performance.

EP.3: (For hospitals) this includes using data on individuals' perceptions of care, treatment, and services to improve patient safety and the ability to meet individuals' needs and expectations.

Organizations are also required to monitor the competence of the workforce.

Standard HR.3.10: Competence to perform job responsibilities is assessed, demonstrated and maintained.

URAC Standards
- **Core**
- **Consumer Education and Support (CES)**
- **Health Plan and Health Network**

Core 18: The organization maintains a formal assessment program for individual staff members that include an annual performance appraisal.

Core 22: The organization maintains a quality management program that promotes objective and systematic monitoring and evaluation of consumer and client service and health care services.

Core 27: Quality Management Documentation. The organization, as part of its quality management program, provides written documentation of: (a) ongoing monitoring for compliance with URAC Standards; (b) objectives and approaches utilized in the monitoring and evaluation of activities; (c) identification of key indicators and measures of consumer and client service, which may include clinical care, complaint rates, and adverse events; (d) the implementation of action plans to improve or correct identified problems; (e) the mechanisms to communicate the results of such activities to staff; (f) the mechanisms to communicate the results of such activities to the governing body or to corporate management; and (g) tracking and trending of data related to consumer and client service and health care services.

Core 37: Consumer satisfaction results are shared with the Quality Management Committee

Core 39: Access to Services Monitoring. The organization defines and monitors its performance with respect to the requirements established under Core 38 and, as appropriate, acts to improve access to services.

Core 40: Access to Services Reporting. Information about the ability of consumers to access services is reported to the Quality Management Committee.

Core 41: The organization maintains a system to receive and respond in a timely manner to complaints and, when appropriate, inform consumers of their rights to submit an appeal.

CES 17: Consumer Feedback Mechanism. The organization has processes to: (a) collect consumer feedback about communication, education, and support; and (b) analyze feedback (including analysis by relevant subpopulations) to identify trends and opportunities for improvement.

CES 18: Consumer Feedback Quality Management. The organization reports the data collected under CES 17 to a quality management committee.

CES 19: Consumer Outreach Measurement. The organization has a process to measure the results of its consumer outreach efforts with regard to: (a)consumer understanding of information; and (b) the impact of outreach efforts on consumer behavior.

Health Plan and Health Network Standard P-NM 2—Provider Network Access and Availability

The organization establishes goals, measures actual performance in comparison to those goals, and makes improvements where necessary for the provider network regarding: (a) access to care; and (b) availability of providers to provide care to consumers.

The National Quality Forum (NQF)

NQF calls for uniform evaluation of performance for underserved populations across all nationally standardized measures. It has endorsed standards that call for a cross-cutting focus on vulnerable populations to reduce disparities in health and health care as the highest national priority for health care quality measures and reporting (NQF 2004).

Source of Guidelines, Standards, Requirements / Primary Audiences

Title VI of the Civil Rights Act of 1964

Applicable to all recipients of federal financial assistance. Includes organizations providing services to Medicare, Medicaid and State Children's Health Insurance Program (SCHIP) enrollees (U.S. DHHS OCR 2003, NHelp 2004).

U.S. Department of Health and Human Services Office for Civil Rights Title VI Guidance

National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS). For voluntary adoption by health care organizations. Also intended for use by policymakers, accreditation and credentialing agencies, purchasers, patients, advocates, educators (U.S. DHHS OMH 2001).

Agency for Health Care Research and Quality (AHRQ)
Making Health Care Safer

Policy makers, researchers, health care organizations and providers.

Institute of Medicine (IOM) Priority Areas for National Action

Organizations and individuals involved in provision and financing of health care.

Joint Commission on Accreditation of Healthcare Organizations

All accredited organizations unless specifically noted: hospitals, ambulatory, long term care, behavioral health and home care.

An Ethical Force Program™ Consensus Report

URAC

• **Core Standards, Version 1.1**
• **Accreditation Program Guide for Case Management Standards, Version 2.0**
• **Consumer Education and Support Standards, Version 1.0**
• **Health Plan and Health Network Standards**

>Core organizational quality standards apply to several accreditation programs: health plan, health network, utilization management, workers comp utilization management, case management, disease management, independent review, credentials verification organization, health call center, claims processing and consumer education and support.

The National Committee for Quality Assurance (NCQA)

The Health Plan Employer Data and Information Set (HEDIS)

>Managed care plans

Consumer Assessment of Healthcare Providers and Systems (CAHPS)

>Healthcare Providers and Systems

>• Formerly the Consumer Assessment of Health Plan Surveys

The National Quality Forum (NQF)

>Groups involved in health care quality measurement and reporting.

Essential Public Health Services

>State and local public health systems.

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Title VI of the Civil Rights Act of 1964, 42 USC §§ 2000d, section 601.

U.S. Department of Health and Human Services Office for Civil Rights (U.S. DHHS OCR). Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons. Washington, DC: OCR; Aug 2003. *http://www.hhs.gov/ocr/lep/revisedlep.html* (accessed Sep 26, 2005).

U.S. Department of Health and Human Services' Office of Minority Health (U.S. DHHS OMH). Final Report: National Standards for Culturally and Linguistically Appropriate Services in Health Care. Washington, DC: OCR; Mar 2001. *http://www.omhrc.gov/templates/content.aspx?ID=87* (accessed Feb 1, 2006)

Members of the Ethical Force Program
Oversight Body 2004-2006

APPENDIX E

The Ethical Force Program's Expert Advisory Panel on Patient-Centered Communication