



PRESIDENT'S ADVISORY COMMISSION ON
Consumer Protection AND
Quality IN THE
Health Care Industry

Appendix A
Consumer Bill of Rights and Responsibilities

Table of Contents

[Executive Summary](#)

[Preamble](#)

[Chapter One: Information Disclosure](#)

[Chapter Two: Choice of Providers and Plans](#)

[Chapter Three: Access to Emergency Services](#)

[Chapter Four: Participation in Treatment Decisions](#)

[Chapter Five: Respect and Nondiscrimination](#)

[Chapter Six: Confidentiality of Health Information](#)

[Chapter Seven: Complaints and Appeals](#)

[Chapter Eight: Consumer Responsibilities](#)

Consumer Bill of Rights and Responsibilities
Executive Summary

The Advisory Commission on Consumer Protection and Quality in the Health Care Industry was appointed by President Clinton on March 26, 1997, to "advise the President on changes occurring in the health care system and recommend measures as may be necessary to promote and assure health care quality and value, and

protect consumers and workers in the health care system." As part of its work, the President asked the Commission to draft a "consumer bill of rights."

The Commission includes 34 members and is co-chaired by The Honorable Alexis M. Herman, Secretary of Labor, and The Honorable Donna E. Shalala, Secretary of Health and Human Services. Its members include individuals from a wide variety of backgrounds including consumers, business, labor, health care providers, health plans, State and local governments, and health care quality experts. The Commission has four Subcommittees: Consumer Rights, Protections, and Responsibilities; Quality Measurement; Creating a Quality Improvement Environment; and Roles and Responsibilities of Public and Private Purchasers and Quality Oversight Organizations. The Commission and its Subcommittees meet monthly in public.

Following is a summary of the eight areas of consumer rights and responsibilities adopted by the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry:

I. Information Disclosure

Consumers have the right to receive accurate, easily understood information and some require assistance in making informed health care decisions about their health plans,¹ professionals, and facilities.

This information should include:

- **Health plans:** Covered benefits, cost-sharing, and procedures for resolving complaints; licensure, certification, and accreditation status; comparable measures of quality and consumer satisfaction; provider network composition; the procedures that govern access to specialists and emergency services; and care management information.
- **Health professionals:** Education and board certification and recertification; years of practice; experience performing certain procedures; and comparable measures of quality and consumer satisfaction.
- **Health care facilities:** Experience in performing certain procedures and services; accreditation status; comparable measures of quality and worker and consumer satisfaction; procedures for resolving complaints; and community benefits provided.

Consumer assistance programs must be carefully structured to promote consumer confidence and to work cooperatively with health plans, providers, payers and regulators. Sponsorship that assures accountability to the interests of consumers and stable, adequate funding are desirable characteristics of such programs.

II. Choice of Providers and Plans

Consumers have the right to a choice of health care providers that is sufficient to ensure access to appropriate high-quality health care.

To ensure such choice, health plans should provide the following:

Provider Network Adequacy: All health plan networks should provide access to sufficient numbers and types of providers to assure that all covered services will be accessible without unreasonable delay -- including access to emergency services 24 hours a day and seven days a week. If a health plan has an insufficient number or type of providers to provide a covered benefit with the appropriate degree of specialization, the plan should ensure that the consumer obtains the benefit outside the network at no greater cost than if the benefit were obtained from participating providers. Plans also should establish and maintain adequate arrangements to ensure reasonable proximity of providers to the business or personal residence of their members.

Access to Qualified Specialists for Women's Health Services: Women should be able to choose a qualified provider offered by a plan -- such as gynecologists, certified nurse midwives, and other qualified health care providers -- for the provision of covered care necessary to provide routine and preventative women's health care services.

Access to Specialists: Consumers with complex or serious medical conditions who require frequent specialty care should have direct access to a qualified specialist of their choice within a plan's network of providers. Authorizations, when required, should be for an adequate number of direct access visits under an approved treatment plan.

Transitional Care: Consumers who are undergoing a course of treatment for a chronic or disabling condition (or who are in the

second or third trimester of a pregnancy) at the time they involuntarily change health plans or at a time when a provider is terminated by a plan for other than cause should be able to continue seeing their current specialty providers for up to 90 days (or through completion of postpartum care) to allow for transition of care. Providers who continue to treat such patients must accept the plan's rates as payment in full, provide all necessary information to the plan for quality assurance purposes, and promptly transfer all medical records with patient authorization during the transition period.

Public and private group purchasers should, wherever feasible, offer consumers a choice of high-quality health insurance products. Small employers should be provided with greater assistance in offering their workers and their families a choice of health plans and products.

III. Access to Emergency Services

Consumers have the right to access emergency health care services when and where the need arises. Health plans should provide payment when a consumer presents to an emergency department with acute symptoms of sufficient severity -- including severe pain -- such that a "prudent layperson" could reasonably expect the absence of medical attention to result in placing that consumer's health in serious jeopardy, serious impairment to bodily functions, or serious dysfunction of any bodily organ or part.

To ensure this right:

- Health plans should educate their members about the availability, location, and appropriate use of emergency and other medical services; cost-sharing provisions for emergency services; and the availability of care outside an emergency department.
- Health plans using a defined network of providers should cover emergency department screening and stabilization services both in network and out of network without prior authorization for use consistent with the prudent layperson standard. Non-network providers and facilities should not bill patients for any charges in excess of health plans' routine payment arrangements.
- Emergency department personnel should contact a patient's primary care provider or health plan, as appropriate, as quickly as possible to

discuss follow-up and post-stabilization care and promote continuity of care.

IV. Participation in Treatment Decisions

Consumers have the right and responsibility to fully participate in all decisions related to their health care. Consumers who are unable to fully participate in treatment decisions have the right to be represented by parents, guardians, family members, or other conservators.

In order to ensure consumers' right and ability to participate in treatment decisions, health care professionals should:

- Provide patients with easily understood information and opportunity to decide among treatment options consistent with the informed consent process. Specifically,
 - Discuss all treatment options with a patient in a culturally competent manner, including the option of no treatment at all.
 - Ensure that persons with disabilities have effective communications with members of the health system in making such decisions.
 - Discuss all current treatments a consumer may be undergoing, including those alternative treatments that are self-administered.
 - Discuss all risks, benefits, and consequences to treatment or nontreatment.
 - Give patients the opportunity to refuse treatment and to express preferences about future treatment decisions.
- Discuss the use of advance directives -- both living wills and durable powers of attorney for health care -- with patients and their designated family members.
- Abide by the decisions made by their patients and/or their designated representatives consistent with the informed consent process.

To facilitate greater communication between patients and providers, health care providers, facilities, and plans should:

- Disclose to consumers factors -- such as methods of compensation, ownership of or interest in health care facilities, or matters of conscience -- that could influence advice or treatment decisions.
- Ensure that provider contracts do not contain any so-called "gag clauses" or other contractual mechanisms that restrict health care

providers' ability to communicate with and advise patients about medically necessary treatment options.

- Be prohibited from penalizing or seeking retribution against health care professionals or other health workers for advocating on behalf of their patients.

V. Respect and Nondiscrimination

Consumers have the right to considerate, respectful care from all members of the health care system at all times and under all circumstances. An environment of mutual respect is essential to maintain a quality health care system.

Consumers must not be discriminated against in the delivery of health care services consistent with the benefits covered in their policy or as required by law based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.

Consumers who are eligible for coverage under the terms and conditions of a health plan or program or as required by law must not be discriminated against in marketing and enrollment practices based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.

VI. Confidentiality of Health Information

Consumers have the right to communicate with health care providers in confidence and to have the confidentiality of their individually identifiable health care information protected. Consumers also have the right to review and copy their own medical records and request amendments to their records.

In order to ensure this right:

- With very few exceptions, individually identifiable health care information can be used without written consent for health purposes only, including the provision of health care, payment for services, peer review, health promotion, disease management, and quality assurance.
- In addition, disclosure of individually identifiable health care information without written consent should be permitted in very

limited circumstances where there is a clear legal basis for doing so. Such reasons include: medical or health care research for which a institutional review board has determined anonymous records will not suffice, investigation of health care fraud, and public health reporting.

- To the maximum feasible extent in all situations, nonidentifiable health care information should be used unless the individual has consented to the disclosure of individually identifiable information. When disclosure is required, no greater amount of information should be disclosed than is necessary to achieve the specific purpose of the disclosure.

VII. Complaints and Appeals

All consumers have the right to a fair and efficient process for resolving differences with their health plans, health care providers, and the institutions that serve them, including a rigorous system of internal review and an independent system of external review.

Internal appeals systems should include:

- Timely written notification of a decision to deny, reduce, or terminate services or deny payment for services. Such notification should include an explanation of the reasons for the decisions and the procedures available for appealing them.
- Resolution of all appeals in a timely manner with expedited consideration for decisions involving emergency or urgent care consistent with time frames consistent with those required by Medicare (i.e., 72 hours).
- A claim review process conducted by health care professionals who are appropriately credentialed with respect to the treatment involved. Reviews should be conducted by individuals who were not involved in the initial decision.
- Written notification of the final determination by the plan of an internal appeal that includes information on the reason for the determination and how a consumer can appeal that decision to an external entity.
- Reasonable processes for resolving consumer complaints about such issues as waiting times, operating hours, the demeanor of health care personnel, and the adequacy of facilities.

External appeals systems should:

- Be available only after consumers have exhausted all internal processes (except in cases of urgently needed care).
- Apply to any decision by a health plan to deny, reduce, or terminate coverage or deny payment for services based on a determination that the treatment is either experimental or investigational in nature; apply when such a decision is based on a determination that such services are not medically necessary and the amount exceeds a significant threshold or the patient's life or health is jeopardized.²
- Be conducted by health care professionals who are appropriately credentialed with respect to the treatment involved and subject to conflict-of-interest prohibitions. Reviews should be conducted by individuals who were not involved in the initial decision.
- Follow a standard of review that promotes evidence-based decisionmaking and relies on objective evidence.
- Resolve all appeals in a timely manner with expedited consideration for decisions involving emergency or urgent care consistent with time frames consistent with those required by Medicare (i.e., 72 hours).

VIII. Consumer Responsibilities

In a health care system that protects consumers' rights, it is reasonable to expect and encourage consumers to assume reasonable responsibilities. Greater individual involvement by consumers in their care increases the likelihood of achieving the best outcomes and helps support a quality improvement, cost-conscious environment. Such responsibilities include:

- Take responsibility for maximizing healthy habits, such as exercising, not smoking, and eating a healthy diet.
- Become involved in specific health care decisions.
- Work collaboratively with health care providers in developing and carrying out agreed-upon treatment plans.
- Disclose relevant information and clearly communicate wants and needs.
- Use the health plan's internal complaint and appeal processes to address concerns that may arise.
- Avoid knowingly spreading disease.
- Recognize the reality of risks and limits of the science of medical care and the human fallibility of the health care professional.

- Be aware of a health care provider's obligation to be reasonably efficient and equitable in providing care to other patients and the community.
- Become knowledgeable about his or her health plan coverage and health plan options (when available) including all covered benefits, limitations, and exclusions, rules regarding use of network providers, coverage and referral rules, appropriate processes to secure additional information, and the process to appeal coverage decisions.
- Show respect for other patients and health workers.
- Make a good-faith effort to meet financial obligations.
- Abide by administrative and operational procedures of health plans, health care providers, and Government health benefit programs.
- Report wrongdoing and fraud to appropriate resources or legal authorities.

Consumer Bill of Rights and Responsibilities

Preamble

American consumers and their families are experiencing an historic transition of the U.S. system of health care financing and delivery. In establishing the Advisory Commission on Consumer Protection and Quality in the Health Care Industry, President Clinton asked that it advise him "on changes occurring in the health care system and recommend such measures as may be necessary to promote and assure health care quality and value, and protect consumers and workers in the health care system." As part of that effort, the President has asked the Commission to draft a Consumer Bill of Rights and Responsibilities.

This Commission includes 34 members from a wide variety of backgrounds including consumers, business, labor, health care providers, health plans, State and local governments, and health care quality experts. We hope our diversity of interests and backgrounds will make our recommendations more valuable to those who consider them.

This is an appropriate time to reexamine and reconsider the methods by which our Nation and the health care industry establish and protect the rights and identify the responsibilities of those people who use the health care system. The Commission believes it is essential to preserve those elements of the emerging system that have

a positive impact on the quality of care as well as the cost and availability of health insurance coverage.

Development of a Consumer Bill of Rights and Responsibilities is an important step forward for all those involved in the health care system. Consumers, health care professionals, administrators of health care facilities, and those who operate health plans will benefit from a clear set of unifying standards. The Consumer Bill of Rights and Responsibilities can help to establish a stronger relationship of trust among consumers, health care professionals, health care institutions, and health plans by helping to sort out the shared responsibilities of each of these participants in a system that promotes quality improvement.

The work of this Commission builds on the efforts of many others. The Commission reviewed dozens of proposals prepared and released by a variety of organizations³ that have addressed the rights, responsibilities, and protection of consumers. We have heard public testimony from dozens of individuals and organizations. We are grateful for their contributions.

The Consumer Bill of Rights and Responsibilities charts a course for the continued enhancement of health systems and processes that serve to protect consumers and ensure quality. While the rights and responsibilities included in this report are intended to apply to all consumers and participants in the health care system, the Commission recognizes that the strength of these protections will grow over time as the capabilities of the health care industry become more sophisticated. Certain portions of the industry will require additional time to make these adjustments, but the Commission intends that the bulk of its recommendations be put in place within the next 3 years.

The Consumer Bill of Rights and Responsibilities was first drafted by the Subcommittee on Consumer Rights, Protections, and Responsibilities. The Subcommittee met in open session on seven separate occasions, and the Commission met six times during that same time period. The Subcommittee considered background papers on each topic, heard public testimony on most topics, and considered two or three drafts of each chapter. At each point in that process, the Subcommittee briefed the full Commission on its work and received feedback on those issues. The Commission also has considered draft chapters and revised drafts reflecting the input of its members. Throughout this process, the Subcommittee and the Commission have operated on a consensus basis that has allowed any member to place an issue before the respective body for consideration. The list of issues was refined to reflect the discussions of the Subcommittee and

the Commission. The final product reflects the areas of overall agreement expressed by Commission members.

Objectives of a Consumer Bill of Rights and Responsibilities

The Consumer Bill of Rights and Responsibilities is intended to accomplish three major goals.

First, to strengthen consumer confidence by assuring the health care system is fair and responsive to consumers' needs, provides consumers with credible and effective mechanisms to address their concerns, and encourages consumers to take an active role in improving and assuring their health.

Second, to reaffirm the importance of a strong relationship between patients and their health care professionals.

Third, to reaffirm the critical role consumers play in safeguarding their own health by establishing both rights and responsibilities for all participants in improving health status.

Guiding Principles for the Consumer Bill of Rights and Responsibilities

The work of the Commission was guided by the following principles:

All consumers are created equal. The work of this Commission in establishing a Bill of Rights and Responsibilities must apply to all consumers. This includes all beneficiaries of such public programs as Medicare, Medicaid, the Department of Veterans Affairs, and the Department of Defense, as well as Federal, State, and local government employees. It also includes all those who have private insurance, including those who purchase their own insurance, those who work for companies that have self-funded health plans, and those who work for companies that purchase insurance for their employees and dependents. And, finally, to the extent possible, these rights should be accorded to those who have no health insurance but use the health care system.

Quality comes first. The first question we asked ourselves in each circumstance was: Will this improve the quality of care and of the system that delivers that care? Sometimes this led us to reject policy options that we believe could hinder the progress our Nation has made

toward a health care system that is focused on improving quality through accountable organized systems.

Preserve what works. There are elements of managed care and of indemnity coverage that must be changed to protect the rights of consumers. But there also are elements of each system that have improved quality and expanded access. We have tried to make sure that we preserve what works while we address areas that can and should be improved.

Costs matter. Although a comprehensive cost-analysis was not performed for this Bill of Rights and Responsibilities, the Commission has sought to balance the need for stronger consumer rights with the need to keep coverage affordable. We recognize that, in some circumstances, rights may create additional costs for employers; health plans; Federal, State, and local governments; and consumers. We also recognize that ultimately consumers can bear these costs in the form of lower wages, higher prices, higher taxes, or reduced benefits in other areas. The Commission believes some components of the Bill of Rights may also enhance the efficiency and effectiveness of the health care marketplace. While these efficiencies cannot be well calculated, they may help to offset some cost increases. The Commission has attempted to weigh these factors carefully and support recommendations that may prompt additional spending in cases where such spending may represent an investment in higher quality health care and better health outcomes.

Goals for Consumer Protection in a Quality-Focused Health Care System

A Consumer Bill of Rights and Responsibilities is, by its nature, a snapshot of what is needed at a particular time. The rights enumerated in this report are intended to move the health care system in a direction that is consistent with a system of health care delivery that is focused on obtaining the highest quality and best outcome for consumers and their families. In that light, the Commission has identified a series of goals for the continued reform of the American health care system that will maximize consumer rights in a system that focuses on quality.

Health coverage is the best consumer protection. A health care system that leaves more than 41 million Americans without health coverage cannot adequately protect the rights of consumers and their families. The fact that so many Americans live day in and day out without the security that health coverage provides is intolerable. Recent trends reported by the U.S. Census Bureau that the number of uninsured Americans rose by one million between 1996 and 1997 are cause for great concern. Moreover, the continued existence of a large group of Americans without health insurance increases the costs paid by those who have insurance as uncovered expenses are shifted to other purchasers. Efforts by Federal and State governments to expand the number of children who are insured are encouraging and should be strengthened. Similar efforts should be extended to other segments of the population so that all Americans are covered.

Consumers faced with catastrophic illness require assistance. Each year, an estimated 1,500 to 2,500 Americans lose their private health insurance coverage because their medical expenses exceed a lifetime limit included in their health insurance policy. Many of these consumers must exhaust their family savings before becoming eligible for Medicaid or other forms of public assistance. This creates a tremendous hardship on these individuals and their families. Employers, health plans, and others should seriously consider taking steps to ease this burden by (1) eliminating or increasing lifetime limits, (2) expanding the use of high-risk pools to provide immediate coverage at the time consumers reach a lifetime limit, or (3) offering supplemental coverage for workers who wish to increase their limits.

Coverage must be made affordable for all consumers, employers, and other purchasers. The recent moderation in health care costs is promising and has been a contributing factor in the slowing of insurance coverage losses. Employers, health plans, and Federal and State governments should be applauded for their efforts to make coverage more affordable for more Americans. Recent projections for 1998 are less favorable. History makes clear that we cannot assume that costs will remain under control without continued cost containment.

Vulnerable groups require special attention. Many consumers are, for reasons beyond their control, more vulnerable than others to losing

their coverage or experiencing significant gaps in their coverage. Individuals with mental or physical disabilities, low-income individuals, children, non-English-speaking consumers, and others require considerable attention by decisionmakers at all levels of the system. Enactment of the Americans with Disabilities Act of 1990, the Health Insurance Portability and Accountability Act of 1996, and the Mental Health Parity Act of 1996 were important steps to protect these consumers. Further steps can and should be taken.

Small purchasers need assistance. The owners of small businesses, the self-employed, and those who purchase insurance in the individual market continue to have great difficulty finding and maintaining affordable health care coverage. For a variety of reasons, insurance premiums are higher for small firms relative to the benefits they are able to purchase, and some small firms are unable to purchase insurance at all. In its final report, the Commission intends to offer several recommendations to help ameliorate some of these effects, including voluntary approaches for expanding insurance pools and for adjusting payment systems to reflect the greater risk inherent in small group and individual markets.

Consumer participation in clinical research. The national investment in clinical research has led to breakthrough advances in diagnosis, prevention, and treatment of illness and disability that have lengthened and improved the quality of life for millions of consumers while also achieving significant cost savings to the health care industry. Consumer participation in clinical research through their inclusion in clinical trials is vitally important not only to continued advancement and innovation in medical care but to the often life-threatening nature of the conditions affecting such consumers. The Commission encourages the ongoing efforts by researchers, health plans, employers, public purchasers, and others to resolve impediments to consumer participation in clinical trials and urges participants to reach agreement on an appropriate sharing of costs and responsibilities related to such trials.

The Commission does not, in this report, speak to the issues of implementation or enforcement of the Consumer Bill of Rights and Responsibilities. The rights enumerated in this report can be achieved in several ways including voluntary actions by health plans, purchasers, facilities, and providers; the effects of market

forces; accreditation processes; as well as State or Federal legislation or regulation. In its final report to the President, the Commission intends to speak to the optimal methods for implementing and enforcing these rights through one or more of these approaches.

Finally, the Commission believes that the American people should have access to health care that is of high quality, evidence-based, safe, free of errors, and is available to all Americans regardless of ability to pay. Progress, over time, will require changes that must be made prudently, realistically, and with due regard to the needs of all stakeholders in the system. This Consumer Bill of Rights and Responsibilities specifies improvements that we believe are achievable now and in the next several years. It acquires even more meaning in the context of a broader overarching commitment to ensure that full access to high-quality health care will eventually be available to all Americans.

Consumer Bill of Rights and Responsibilities

Chapter One

Information Disclosure

Statement of the Right

Consumers have the right to receive accurate, easily understood information and some require assistance in making informed health care decisions about their health plans, professionals and facilities.

This information should include:

- **Health plans:**⁴ Covered benefits, cost-sharing, and procedures for resolving complaints; licensure, certification, and accreditation status; comparable measures of quality and consumer satisfaction; provider network composition; the procedures that govern access to specialists and emergency services; and care management information.
- **Health professionals:** Education and board certification and recertification; years of practice; experience performing certain procedures; and comparable measures of quality and consumer satisfaction.
- **Health care facilities:** Experience in performing certain procedures and services; accreditation status; comparable measures of quality and worker and consumer satisfaction; procedures for resolving complaints; and community benefits provided.

Consumer assistance programs must be carefully structured to promote consumer confidence and to work cooperatively with health plans, providers, payers, and regulators. Sponsorship that assures accountability to the interests of consumers and stable, adequate funding are desirable characteristics of such programs.

Rationale

Value-based purchasing allows consumers to obtain greater value for their health care dollar by seeking higher quality care at the best price. To do this, consumers need accurate, reliable information that will allow them to assess differences in the quality and cost of health benefits plans, the health care providers who treat them, and the facilities and institutions that house them. Active and informed decisionmaking by consumers will improve the performance of the health care system, as providers seek to enhance their quality and reduce their costs in order to be more attractive to value-seeking consumers.

A more basic reason for providing consumers with information is an ethical one. Health plans, facilities, and professionals have an ethical obligation to inform consumers about how their actions can affect the consumer's life and health. Medical ethicists ground this obligation in the principle of respect for individual autonomy and individuals' right to make choices about how they receive medical care (Beauchamp and Childress, 1994).

This chapter provides a description of the types of information on health plans, health professionals, and health care facilities that should be made available to consumers either routinely or upon request. The Commission recognizes that much work remains to be done if all this information is to be readily available and understandable to consumers, specifically:

- **Detailed explanation is needed for certain types of information.** Some types of information are straightforward and require no further definition (e.g., the names, board certification status, and geographic location of primary care providers in a plan's network). Other types of information would benefit from the development of more detailed explanation, such as the care management information on clinical protocols, practice guidelines, and preauthorization and utilization review standards and procedures.
- **Standardized measures are needed for comparative purposes.** For the information intended to support consumer decisions regarding the choice of a health benefits plan, or choice of an individual provider or facility,

standardized definitions will be needed to allow for "apples to apples" comparisons.

- **Ongoing development and promulgation of standardized measurement sets and instruments are needed for assessing satisfaction and quality.** The Commission believes that some of the most important types of information a consumer has a right to receive fall into the categories of consumer satisfaction ratings and clinical quality performance measures for health plans, health care professionals, and facilities. For all consumers to exercise this right, processes must be put in place to create standardized performance measures. In its final report, the Commission intends to address how such a process might be established so as to build on existing efforts, encourage ongoing innovation in quality measurement, and provide the best possible information to consumers at any given time to encourage quality improvement through market-based decisions.
- **Useful and appropriate reporting formats and processes are needed for consumers.** Although the Commission believes that consumers should have access to pertinent information, it recognizes that caution must be taken to provide information to consumers in useful formats (e.g., summary and detailed reports, printed copy, and Internet), at appropriate times (i.e., decision points), with assistance for vulnerable groups (i.e., those who are hearing impaired or non-English speaking). These issues also will be addressed in the Commission's final report.

Consumers should be able to obtain other information upon request as outlined below. Plans, providers, and facilities should inform consumers that such information is available and describe how it can be obtained.

Health Plan Information

Many consumers face a choice of health plans such as an indemnity plan, an HMO, a point-of-service plan, or a preferred provider organization. Consumers' choice of a health plan has a significant impact on consumers' ability to make other choices about facilities, health professionals, and treatment options. Even in cases where consumers do not have a choice of plans, they require information on the plan in which they are enrolled to use the available services effectively.

To the extent that a right to information creates disclosure requirements for health plans, these requirements should apply equally to all types of plans (including indemnity, HMO, PPO, and POS) regardless of sponsor (e.g., such government programs as CHAMPUS, VA, FEHBP, Medicare, and Medicaid and private plans

including fully funded, partially self-funded, or fully self-funded plans). If the specific information required for disclosure does not exist, or is unavailable, the consumer should be informed.

The primary responsibility of providing consumers with health plan information falls upon the plans themselves. In the case of self-insured plans, this responsibility will rest with the plan sponsor unless it is delegated or contracted to a third-party administrator.

Within the category of health plan information, one can discern four principal subcategories of information: (1) benefits, cost-sharing, and dispute resolution; (2) health plan characteristics and performance information; (3) network characteristics; and (4) care management information.

- A. Benefits, Cost-Sharing, and Dispute Resolution.** Consumers should receive the following information about a health benefits plan:
- A general summary of all covered benefits, including:
 - General limits on coverage, including any annual or lifetime limits, as well as limits for specific conditions.
 - Whether preventative services are covered.
 - Whether a drug formulary is used and, if so, how decisions are made pertaining to inclusion of drugs, particularly new drugs (including a process to consider exceptions).
 - How drugs, devices, and procedures are deemed experimental.
 - Enrollee cost-sharing, including employee or beneficiary premium contributions, deductibles, copayments, and coinsurance.
 - Type and extent of dispute resolution procedures available in the event of a dispute.
- B. Health Plan Characteristics and Performance Information.** Consumers joining or considering whether or not to join a health plan should receive information about:
- State licensure status, Federal certification, and private accreditation status (including publicly available reports).
 - Consumer satisfaction measures.
 - Clinical quality performance measures.
 - Service performance measures (e.g., waiting time to obtain an appointment with primary care providers and specialists).
 - Disenrollment rates (adjusted for involuntary disenrollment and other relevant factors).

Additional information that should be made available *upon request* includes:

- Number of years in existence.
- Corporate form of the plan (i.e., public or private; gateway.html or for-profit ownership and management).
- Whether the plan meets requirements (State and Federal) for fiscal solvency.
- Whether the plan meets standards (State, Federal, and private accreditation) that assure confidentiality of medical records and orderly transfer to caregivers.

C. Network Characteristics. It is important to provide consumers with information about the characteristics of the network and the procedures that govern its use. Consumers should receive:

- Aggregate information on the numbers, types, board certification status, and geographic distribution of primary care providers and specialists.
- Detailed list of names, board certification status, and geographic location of all contracting primary care providers; whether they are accepting new patients; language(s) spoken and availability of interpreter services; and whether facilities are accessible to people with disabilities.
- Provider compensation methods, including base payment (e.g., capitation, salary, fee schedule) and additional financial incentives (e.g., bonus, withholds, etc.).
- Rules regarding coverage of out-of-network services, and applicable rates of cost-sharing.
- Information about circumstances under which primary care referral is required to access specialty care.
- Information about what options exist for 24-hour coverage and whether enrollees have access to urgent care centers.

Additional information that should be made available *upon request* includes:

- Detailed list of names, board certification status, and geographic location of all contracting specialists and specialty care centers; whether they are accepting new patients; language(s) spoken and availability of interpreter services; and whether facilities are accessible to people with disabilities.
- Detailed list of names, accreditation status, and geographic location of hospitals, home health agencies, rehabilitation and long-term care

facilities; whether they are accepting new patients; language(s) spoken and availability of interpreter services; and whether they are accessible to people with disabilities.

D. Care Management Information. Information in this category that should be available *upon request* includes:

- Preauthorization and utilization review procedures followed.
- Use of clinical protocols, practice guidelines, and utilization review standards pertinent to a patient's clinical circumstances.
- Whether the plan has special disease management programs or programs for persons with disabilities. (This information should indicate whether these programs are voluntary or mandatory or if a significant benefit differential results.)
- Whether a specific prescription drug is included in a formulary and procedures for considering requests for patient-specific waivers.
- Qualifications of reviewers at the primary and appeals levels.

Health Professional Information

All consumers should receive information on:

- Whether the health professional's ownership or affiliation arrangement with a provider group or institution would make it more likely that a consumer would be referred to particular specialists or facility or receive a particular service.
- How the provider is compensated, including base payment method (e.g., capitation, salary, fee schedule) and types of additional financial incentives (e.g., bonus, withholds).

Consumers should receive *upon request* the following information on health professionals:

- Education, board certification, and recertification status.
- Names of hospitals where physicians have admitting privileges.
- Years of practice as a physician and as a specialist if so identified.
- Experience with performing certain medical or surgical procedures (e.g., volume of care/services delivered), adjusted for case mix and severity.
- Consumer satisfaction measures.
- Clinical quality performance measures.
- Service performance measures.
- Accreditation status (if applicable).

- Corporate form of the practice (i.e., public or private, gateway.html or for-profit, ownership and management, sole proprietorship or group practice).
- The availability of translation or interpretation services for non-English speakers and people with communication disabilities.
- Any cancellation, suspension, or exclusion from participation in Federal programs or sanctions from Federal agencies; any suspension or revocation of medical licensure, Federal controlled substance license, or hospital privileges.

Health Care Facility Information

Consumers should receive the following information from a health care facility:

- Corporate form of the facility (i.e., public or private; gateway.html or for-profit; ownership and management; affiliation with other corporate entities).
- Accreditation status.
- Whether specialty programs meet guidelines established by specialty societies or other appropriate bodies (e.g., whether a cancer treatment center has been approved by the American College of Surgeons, the Association of Community Cancer Centers, or the National Cancer Institute).
- The volume of certain procedures performed at each facility.
- Consumer satisfaction measures.
- Clinical quality performance measures.
- Service performance measures.
- Procedures for registering a complaint and achieving resolution of that complaint.
- The availability of translation or interpretation services for non-English speakers and people with communication disabilities.
- Numbers and credentials of providers of direct patient care (e.g., registered nurses, other licensed providers, and other caregivers).
- Whether the facility's affiliation with a provider network would make it more likely that a consumer would be referred to health professionals or other organizations in that network.
- Whether the facility has been excluded from any Federal health programs (i.e., Medicare or Medicaid).

Consumer Assistance Programs

Initial results indicate that consumer assistance programs support consumer needs for information on health plans, providers, and facilities. A loose patchwork of

consumer assistance services currently exists in the public and private sectors. In the public sector, 14 State or locally based Medicaid programs now have established ombudsmen programs to assist beneficiaries with information needs. Some Medicare beneficiaries and people with chronic health problems have access to consumer assistance services through Information, Counseling, and Assistance (ICA) programs, long-term care ombudsmen programs, and protection and advocacy programs.

In the private sector, health plans often provide consumers with assistance services through customer and member service departments (Oxford Health Plans, 1997; Harvard Pilgrim Health Plan, 1997). Large group purchasers and labor unions often provide their employees with consumer assistance by organizing information on plans, educating employees about their rights, and intervening when employees have complaints about their plans (Darling, 1997).

While there are a number of sources that provide assistance to consumers, most programs target specific subpopulations and have limited funds, and hence provide a limited range of services. There are reasons to believe that consumers and other stakeholders would benefit from greater availability of consumer assistance programs that:

- **Inspire confidence.** Consumers want to know that they will be treated fairly.
- **Provide a safety valve.** Even in the best of systems, there will be individuals who fall through the cracks. Assistance programs provide a resource that can help such individuals resolve problems quickly and efficiently, often bridging communication failures between the consumer and the provider or health plan.
- **Foster collaboration.** Assistance programs should work with the array of available resources to best meet the needs of consumers.

The challenge to crafting assistance programs for health care consumers is to ensure that such programs are not duplicative, but rather that they supplement and complement existing resources.

With regard to consumer assistance, the Commission has not addressed issues of implementation. Specifically, this is not an endorsement or a requirement for any particular form of consumer assistance programs, but lays out desirable characteristics of such programs.

Implications of the Right

Obtaining the information listed above and making it available to consumers will not, by itself, equip consumers with the knowledge and abilities required to act on this information. Discussed below are some basic considerations in making this information useful to consumers and the implications of this for key segments of the health care industry.

- **Information Should Be Useful to Consumers and Cost Effective to Obtain.** Edgman-Levitan and Cleary (1996) have documented that consumers are able to evaluate critical information about quality. However, research on how consumers use information to make decisions suggests that too much information can be overwhelming. In its 1988 assessment of methods for communicating the quality of medical care to consumers, the Office of Technology Assessment's Expert Advisory Panel concluded that "limiting information to only a few indicators of quality will probably be necessary [because] people can consider only a few items at any one time. Information is processed as a unit or chunk -- a person's processing capacity has been estimated as being anywhere from four to seven chunks" (OTA, 1988). Ongoing research must be conducted to determine what is the most effective subset of information that consumers can use. Finally, while consumers clearly have a right to information, it must be understood that there are costs associated with collecting and distributing it. While providing information to consumers generates significant benefits for both the consumers and the health system as a whole, it is not necessarily inexpensive. Recognizing these costs, however, is not an argument for a "bare bones" approach to information disclosure. The failure to provide information also has costs. Well-informed consumers are the bedrock of an efficiently operating market. Without meaningful information, consumers are more likely to make choices that can result in less than optimal outcomes for themselves and there is less incentive for participants to strive for excellence. The challenge is to develop coordinated approaches to information collection and dissemination that will provide consumers the information they need to make decisions without imposing severe burdens on plans and providers.

Investments in Clinical Information Systems and Workforce Education and Training Will Be Needed. Greater investment in automated information systems will be necessary for health plans and providers to satisfy these information disclosure requirements, especially ones pertaining to product, facility, and provider performance and quality. The Commission is currently assessing barriers or impediments to investment in clinical

information systems (e.g., inadequate data collection standards; confidentiality concerns; magnitude of capital investments required) and plans to speak to this issue in its final report. Responding to these increased information demands also has implications for the training and education of the health care workforce. There will be greater demand by health care organizations for individuals with particular technical and analytic skills (e.g., computer programming, engineering, data auditing, and statistics). Ongoing training and continuing education programs for practitioners and other workers whose work involves recording, compiling, or manipulating clinical and administrative data will also be needed to assure the completeness and accuracy of data and adherence to confidentiality safeguards.

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Consumer Bill of Rights and Responsibilities
Chapter Two
Choice of Providers and Plans

Statement of the Right

Consumers have the right to a choice of health care providers that is sufficient to ensure access to appropriate high-quality health care.

To ensure such choice, health plans should provide the following:

Provider Network Adequacy: All health plan networks should provide access to sufficient numbers and types of providers to assure that all covered services will be accessible without unreasonable delay -- including access to emergency services 24 hours a day and seven days a week. If a health plan has an insufficient number or type of providers to provide a covered benefit with the appropriate degree of specialization, the plan should ensure that the consumer obtains the benefit outside the network at no greater cost than if the benefit were obtained from participating providers. Plans also should establish and maintain adequate arrangements to ensure reasonable proximity of providers to the business or personal residence of their members.

Access to Qualified Specialists for Women's Health Services: Women should be able to choose a qualified provider offered by a plan -- such as gynecologists, certified nurse midwives, and other qualified health care providers -- for the provision of covered care necessary to provide routine and preventative women's health care services.

Access to Specialists: Consumers with complex or serious medical conditions who require frequent specialty care should have direct access to a qualified specialist of their choice within a plan's network of providers. Authorizations, when required, should be for an adequate number of direct access visits under an approved treatment plan.

Transitional Care: Consumers who are undergoing a course of treatment for a chronic or disabling condition (or who are in the second or third trimester of a pregnancy) at the time they involuntarily change health plans or at a time when a provider is terminated by a plan for other than cause should be able to continue seeing their current specialty providers for up to 90 days (or through completion of postpartum care) to allow for transition of

care. Providers who continue to treat such patients must accept the plan's rates as payment in full, provide all necessary information to the plan for quality assurance purposes, and promptly transfer all medical records with patient authorization during the transition period.

Public and private group purchasers should, wherever feasible, offer consumers a choice of high-quality health insurance products. Small employers should be provided with greater assistance in offering their workers and their families a choice of health plans and products.

Rationale

The ability of consumers to exercise choice in the health care marketplace is associated with several desirable characteristics of a health care system.

- First, choice is associated with increased consumer satisfaction. In a survey of consumers receiving health care in both indemnity and managed care plans, individuals with a choice of health products report greater satisfaction with their plan and tend to rate both their health insurance product and their individual physicians of higher quality (Davis and Schoen, 1997).
- Second, the ability of consumers to choose among competing products is a hallmark of a healthy marketplace. Individual consumers are responsible for 34 percent of all direct expenditures for health care in the United States (Cowan et al., 1996). As the science of measuring and generating accurate and valid information on the quality of health plans, providers and facilities advances, consumers can wield their purchasing power to create incentives in the marketplace for improvements in health care quality.
- Third, consumers who have a role in the selection of their caregivers are likely to have greater confidence in those practitioners and are, therefore, more likely to seek appropriate care in a more timely fashion and follow agreed-upon care regimens.
- Fourth, having a choice of providers allows consumers to take action to preserve continuity of care within the health care system by selecting products and providers that allow them to continue provider relationships when continuity of care is especially important (e.g., prenatal care, care of individuals with complex chronic or disabling conditions).

Thus, a health care marketplace that promotes satisfied consumers, continuity of care, and continuous improvements in quality requires that an array of choices be available to consumers. Without consumers' ability to have and exercise choice,

greater activities may need to be undertaken by group purchasers and regulators to ensure that the health care marketplace responds appropriately to consumers' health care needs.

Consumer Choice of Health Plans or Products

During the last decade, there has been a marked increase in the number and types of health insurance products available in most geographic markets. Prior to the widespread development of managed care plans, most Americans had limited choice of health insurance products. Indemnity products dominated the market with HMO and PPO products available primarily in certain metropolitan areas. The past 10 years have seen a significant increase of insurance products with the expansion of many health plans into new geographic markets and the development of multiple insurance product lines by indemnity insurers and managed care organizations. As a result, with the exception of sparsely populated areas, most communities now have available HMO, POS, PPO, and indemnity products offering consumers a variety of options in terms of benefits, premiums, copayments, and health care delivery systems.

At the same time, there has been a steady migration from traditional indemnity plans to various managed care products in both the public and private markets. Between 1991 and 1995, the percentage of American workers enrolled in indemnity plans decreased from 59 percent to 35 percent (EBRI, 1997). In 1997, more than 5 million Medicare beneficiaries were enrolled in 336 managed care plans, an increase of more than 100 percent since 1993. Under Medicaid, 13 million, or 35 percent, of all beneficiaries have been enrolled in managed care plans, an increase of more than 170 percent since 1993. The Balanced Budget Act of 1997 will increase those trends by expanding the types of products available to beneficiaries of those two public programs.

Although there is greater choice of health insurance products available in most markets, it is important to note that this choice often is exercised at the level of the group purchaser instead of by individual consumers. Between 1988 and 1997, health plan offerings by moderate- and large-sized employers declined (Gabel, 1997). Those offering three or more plans declined from 35 percent to 32 percent, while those offering only one plan climbed from 41 percent to 44 percent over that period. Notably, the percentage of employees in firms with 200 or more workers who were offered coverage of PPOs and POS plans increased from 12 percent in 1988 to 58 percent in 1997 (Gabel, 1997).

There also is evidence of variation in consumer preferences for various product characteristics. In the Kaiser-AHCPR survey (1996), 70 percent of survey respondents would prefer a high-cost product with a wide range of benefits over a low-cost product with a more limited range of benefits (26 percent). Respondents were more divided over other health product decisions. Fifty-three percent said they would pay more for unrestricted choice of physicians, while 43 percent would opt for a lower-cost product that limited choice to a list of physicians. Forty-six percent would pay more to have direct access to any specialist, whereas more than half (51 percent) would choose a lower-cost plan that requires a visit to the family physician for a referral (Robinson and Brodie, 1997).

The Commission is troubled by the limited choice of insurance products made available to many consumers through their employer group purchasers. Some of the reduction in choice of plan and product has resulted from conscious decisions by employers to select high-quality products at the best price in the market. In other instances, employers may be seeking to minimize administrative costs associated with multiple offerings. Affording consumers greater choice of plans would allow consumers to select the product that best meets their individual preferences and would encourage health plans to be responsive to consumers' expressed needs. However, the Commission recognizes that, for many consumers, the availability of one plan is better than no plan at all.

The Commission was unable to achieve consensus on creating a "right" to a consumer choice of health plan or product but it is determined to find ways to encourage and assist employers and other group purchasers in providing consumers with a meaningful choice of health plans and products. Consumer choice of health plans is important and should be provided whenever possible and in a way that is affordable both to employers and consumers. In its final report, the Commission will address policy options to provide greater choice of health plans and products, including encouraging the development of purchasing coalitions and alliances to assist small employers who encounter the greatest difficulty in offering multiple options.

Consumer Choice of Physicians and Other Health Care Providers

The shift from indemnity coverage to managed care arrangements can affect consumers' choice of physicians and other health care providers. In a 1995 study, 41 percent of managed care enrollees who changed health plans over the prior 3 years also changed physicians (Davis et al., 1995). However, nearly all covered workers can now choose a health plan that covers non-network providers. In some

cases, however, the additional cost of these products or of the option to go out of network effectively puts such choice out of the reach of some consumers.

It also is clear that consumers value some degree of choice of physicians. The 1997 Kaiser/Commonwealth National Health Insurance Survey found that respondents with a choice of physicians registered the highest level of satisfaction with their plans (Davis and Schoen, 1997). A Kaiser-AHCPR survey of consumers identified four reasons why consumers prefer a greater choice of physicians and other health care professionals:

- "So you can see whatever doctor you think is best qualified to treat a particular medical problem" (43 percent);
- "So you can change doctors if you become dissatisfied with the one you're seeing" (24 percent);
- "So you can continue seeing your regular doctor" (20 percent); and,
- "So it's easier to see someone else if your doctor is not available for an appointment" (9 percent).

The most frequently cited reasons speak to consumers' desire to use choice of physicians as a way to obtain quality care. The third is directed toward maintaining relationships with physicians with whom consumers have an existing relationship. In other words, 63 percent of consumers surveyed wanted a choice of physicians so that they can develop and maintain a relationship with a physician they trust to provide them high-quality care.

Therefore, it is important for all health plans and products to maintain an adequate network of physicians and other health care providers, to provide for continuity of care when consumers change plans, and to allow consumers with special health care needs to have adequate choice of physicians and other health care providers. This can lead to higher consumer satisfaction with providers and their health plans without undermining the efforts of provider groups and health plans to develop organized delivery systems.

The Commission's recommendations seek to build on these trends toward providing greater choice by taking several steps to ensure (1) network adequacy; (2) greater access for women to qualified specialists for women's health services; (3) ease of access to specialists for consumers with complex and serious conditions; and (4) greater continuity of care for consumers who enroll in new health plans or see their provider dropped from a plan for other than cause.

Provider Network Adequacy

When appropriately structured, a plan using a network of providers can improve the quality and coordination of care delivered to consumers through careful selection and credentialing of providers and through coordination of care by primary care physicians and those with specialty training. The National Association of Insurance Commissioners (NAIC, 1996) has developed standards for provider network adequacy that have been adopted by several States. The Commission believes universal adoption of these standards will improve both the quality of care and consumers' satisfaction with their health plans and their care. Because of its strong desire to maintain the integrity of health plan networks, the Commission has rejected approaches to mandate the inclusion of providers into networks (i.e., "any willing provider" laws) or to require plans to allow enrollees to go out of plan networks at will (i.e., "freedom of choice" laws).

Access to Specialists

Consumers with ongoing health needs often require regular access to physicians and other health care professionals who are specially trained to serve those needs (Bernstein, Dial, and Smith, 1995). This is especially true of those consumers who have disabling or terminal conditions. In such cases, the traditional "gatekeeper" approach used by some health plans can be an impediment to access to quality care and result in unnecessary inconvenience to consumers. The Commission's recommendations are designed to promote consumers' access to appropriately trained specialists while maintaining the integrity of network models of care. Consumers with complex and serious medical conditions who require frequent specialty care should have direct access to a qualified specialist of their choice within a plan's network of providers. Authorizations, when required, should be for an adequate number of direct access visits under an approved treatment plan.

Access to Qualified Specialists for Women's Health Services

Morbidity and mortality associated with breast cancer, cervical cancer, ovarian cancer, and sexually transmitted diseases in women can be significantly reduced through the provision of preventive and routine gynecological services. The U.S. Preventive Services Task Force has issued recommendations pertaining to the provision of Pap smears, mammograms, and other preventive services for women. Women should be able to choose a qualified provider offered by a plan -- including gynecologists, certified nurse midwives, and other qualified health care providers offered by a plan -- for the provision of routine and preventive women's health care services.

Transitional Care

Finally, consumers who are undergoing an extensive course of treatment (e.g., chemotherapy or prenatal care) at the time they join a new health plan should be able to continue to see their current providers for a period of up to 90 days (or through completion of postpartum care). Similarly, such consumers should be able to continue to see a provider who is terminated from a plan's network for reasons other than cause. Sudden interruption of care can compromise the quality of care and patient outcomes. Continuity of care has been shown to increase the likelihood that patients receive appropriate preventive services (O'Malley et al., 1997).

Appropriately transitioning of care can protect the quality of that care and improve consumers' satisfaction with a new health plan or product. The Commission's recommendations are designed to ease the impact of these transitions from one health insurance product to another and changes in the composition of health plan networks while maintaining the integrity of network models of care. Consumers who are undergoing a course of treatment for a chronic or disabling condition (or who are in the second or third trimester of a pregnancy) at the time they involuntarily change health plans or at a time when a provider is terminated by a plan for other than cause should be able to continue seeing their current specialty providers for up to 90 days (or through completion of postpartum care) to allow for transition of care.

Implications of the Right

Health plans will need to comply with network adequacy standards. Because these changes are primarily to be carried out within existing networks, there should not be a significant increase in costs to health plans or enrollees. Many licensed plans already meet these requirements as laid down by the National Association of Insurance Commissioners (NAIC) in its Managed Care Plan Network Adequacy Model Act. Plans also will need to develop processes to comply with requirements regarding continuity of care and ease of access to specialists within their network of providers.

Consumers will need to exercise their right to choice by using good judgment and providing direct feedback to plans about their level of satisfaction with the network provided for them.

Quality Oversight Organizations will need to incorporate network adequacy standards into their review activities.

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Consumer Bill of Rights and Responsibilities
Chapter Three
Access to Emergency Services

Statement of the Right

Consumers have the right to access emergency health care services when and where the need arises. Health plans should provide payment when a consumer presents to an emergency department with acute symptoms of sufficient severity -- including severe pain -- such that a "prudent layperson" could reasonably expect the absence of medical attention to result in placing that consumer's health in serious jeopardy, serious impairment to bodily functions, or serious dysfunction of any bodily organ or part.

To ensure this right:

- Health plans should educate their members about the availability, location, and appropriate use of emergency and other medical services; cost-sharing provisions for emergency services; and the availability of care outside an emergency department.
- Health plans using a defined network of providers should cover emergency department screening and stabilization services both in network and out of network without prior authorization for use consistent with the prudent layperson standard. Non-network providers and facilities should not bill patients for any charges in excess of health plans' routine payment arrangements.
- Emergency department personnel should contact a patient's primary care provider or health plan, as appropriate, as quickly as possible to discuss follow-up and post-stabilization care and promote continuity of care.

Rationale

In 1995, Americans paid an estimated 96.5 million visits to emergency departments, nearly 37 visits per 100 persons (Stussman, 1997). By tradition, emergency departments (EDs) have handled a spectrum of illness, but have had the primary mission of treating those with acutely serious, even life-threatening, medical conditions. Emergency services can be defined as services that are needed or appear to be needed immediately because of injury or sudden illness that threatens serious impairment of any bodily function, and/or serious dysfunction of any bodily organ or part.

Patients go to the emergency department with nonurgent problems for various reasons. Economic and geographic barriers to other forms of care, the lack of a regular provider, and other factors can and do prompt patients to turn to the emergency department for primary and other nonurgent care. Apart from lack of health insurance coverage, nonfinancial barriers to primary care encourage patients to seek evaluation and treatment in the ED. These include problems with work schedules, access to transportation, and concerns about personal safety (Rask, Williams, Parker, et al., 1994). Physician offices and primary care clinics often have limited hours of operation, while EDs are open 24 hours a day. Medicaid beneficiaries, who have a history of limited access to regular providers, have particularly strong relationships with EDs as the provider of first and last resort. Nonurgent visits to the ED can be costly, contribute to overcrowded waiting rooms, divert resources away from other hospital-based care, and compromise the coordination and continuity of care.

But drawing the line between urgent and nonurgent use of the ED is not an easy decision for providers, health plans, and consumers. Criteria -- both prospective and retrospective -- for appropriate ED use are in many ways inadequate. By one criterion, a patient's ED visit might be deemed appropriate, and by another, not so (Lowe and Bindman, 1997). Health care professionals do not agree among themselves about the need for urgent care among emergency department patients (Gill, Reese, and Diamond, 1996). In a survey of 56 hospital EDs, 5.5 percent of patients initially classified by triage nurses as nonurgent were later admitted to the hospital from the ED (Young, Wagner, Kellerman, et al., 1996). Studies estimate that those presenting with nonurgent problems to the ED range from 6.3 percent (Cunningham, Clancy, and Cohen, et al., 1995) to 54.2 percent (Stussman, 1997) of ED visits.

To better manage care and costs in the ED setting, indemnity and managed care plans use a range of tools that includes requirements for prior authorization and imposition of higher cost-sharing for use of out-of-network emergency departments. A 1989 survey of HMO medical directors found coverage policies for ED use across the HMO industry to be fairly uniform (Kerr, 1989). Unless the condition is life-threatening, patients must obtain prior authorization before seeking emergency care services in 80 percent of the responding HMOs, and 38 percent limited their coverage to the EDs of selected network hospitals. A study undertaken by the Center for Health Policy Studies shows that private indemnity insurers have adopted many of these same practices in their fee-for-service arrangements (PPRC, 1996).

A growing set of State and Federal laws and regulations clarify and protect consumers' access to appropriate emergency services. The Emergency Medical Treatment and Labor Act (EMTALA) requires all Medicare participating hospitals to evaluate whether a patient has an emergency medical condition and, if so, to stabilize the patient. The Balanced Budget Act of 1997 requires health plans participating in Medicare or Medicaid to reimburse for emergency services using a "prudent layperson" standard. Numerous States also have adopted this standard for access to emergency services. The Commission's recommendation seeks to create uniformity in all States.

Implications of the Right

Health care providers. Health care providers will need to work to educate consumers about the appropriate use of emergency department services while working to increase the hours and locations of primary care clinics and other facilities to ease access to such services outside of emergency departments. Emergency department personnel need to make strong efforts to ensure the continuity of care of emergency patients by communicating with patients' primary care providers. Efforts should be made to assist consumers with language, communication, or other barriers.

Health plans. Health plans need to expand consumer education efforts and, when it is within their control, expand hours and location of primary care facilities to facilitate access to such services outside of emergency departments. Plans need to ensure that their coverage and payment policies are consistent with the "prudent layperson" standard.

Consumers. Consumers need to become more familiar with the location and hours of nonemergency care settings and strive to make greater use of such facilities when appropriate. Consumers should communicate with their providers and plans to understand any restrictions on their access to emergency services.

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Consumer Bill of Rights and Responsibilities

Chapter Four

Participation in Treatment Decisions

Statement of the Right

Consumers have the right and responsibility to fully participate in all decisions related to their health care. Consumers who are unable to fully participate in treatment decisions have the right to be represented by parents, guardians, family members, or other conservators.

In order to ensure consumers' right and ability to participate in treatment decisions, health care professionals should:

- Provide patients with easily understood information and opportunity to decide among treatment options consistent with the informed consent process. Specifically,
 - Discuss all treatment options with a patient in a culturally competent manner, including the option of no treatment at all.
 - Ensure that persons with disabilities have effective communications with members of the health system in making such decisions.
 - Discuss all current treatments a consumer may be undergoing, including those alternative treatments that are self-administered.
- Discuss all risks, benefits, and consequences to treatment or nontreatment.
- Give patients the opportunity to refuse treatment and to express preferences about future treatment decisions.
- Discuss the use of advance directives -- both living wills and durable powers of attorney for health care -- with patients and their designated family members.
- Abide by the decisions made by their patients and/or their designated representatives consistent with the informed consent process.

To facilitate greater communication between patients and providers, health care providers, facilities, and plans should:

- Disclose to consumers factors -- such as methods of compensation, ownership of or interest in health care facilities, or matters of conscience -- that could influence advice or treatment decisions.
- Ensure that provider contracts do not contain any so-called "gag clauses" or other contractual mechanisms that restrict health care providers' ability to communicate with and advise patients about medically necessary treatment options.
- Be prohibited from penalizing or seeking retribution against health care professionals or other health workers for advocating on behalf of their patients.

Rationale

Consumers depend on health care professionals to provide them with expert consultation and advice on how to stay healthy or how to cure or palliate their health and medical problems. Unlike many other consumer transactions, the asymmetry of information between consumer and health care provider often is great. Decisionmaking also often occurs at a time of illness, which can undermine the patient's ability to act most effectively in his or her own interest.

Patient and Provider Communication

Relationships between consumers and health care professionals are most rewarding and likely to result in positive outcomes when they are characterized by open communication and active participation of patients in the treatment process. Patient participation in treatment is an essential part of compliance, and compliance improves the effectiveness of care and treatment.

The benefits of patient participation go beyond just the anticipated therapeutic effect of the intervention (Czajkowski and Chesney, 1990). For example, the Coronary Drug Project Research Group (1980), which studied the efficacy and safety of several lipid-lowering drugs, found that even among patients who only took placebos, good adherers had a much lower 5-year mortality rate (15 percent) than did poor adherers (24.6 percent).

Patient participation in treatment decision making also leads to improved satisfaction with care and better quality of life. For example, in a study of patients with early breast cancer, it was found that those who believed they were more responsible for treatment decisions and had more choice of treatment reported higher quality of life than those who perceived themselves as less in control of the treatment decisions (Street and Voigt, 1997).

To participate in decisionmaking about their care, consumers must have complete information about treatment options -- including the alternative of no intervention - - as well as the risks, benefits, and consequences of such options. Yet evidence suggests that clinical practice often falls short of these expectations. A 1988 study of hospitalized patients found that physicians discussed test or treatment rationale in only 43 percent of cases and alternatives in 12 percent of cases (Wu and Pearlman, 1988). Physicians shared with patients information about benefits in 34 percent of cases and risks in 14 percent of cases.

The continued development of communications technologies to help consumers more fully understand their treatment options and to evaluate the potential risks and benefits of treatments should be encouraged, for example, the use of videos to help men with prostate cancer evaluate the risks and benefits of surgery versus a "watchful waiting" strategy (Wennberg, 1995) and to help men with benign prostatic hypertrophy sort out options for treatment (Wagner et al., 1995).

Increasingly, effective communication between providers and patients demands some degree of cultural competence. By the year 2000, nearly one-quarter of the U.S. population will be members of racial or ethnic "minority" groups; this will

grow to 47.5 percent by the middle of the next century. Cultural competence refers to the "demonstrated awareness and integration of three population-specific issues: health-related beliefs and cultural values, disease incidence and prevalence, and treatment efficacy" (Lavizzo-Mourey and Mackenzie, 1996). Effective communication for people with communication disabilities may require health care providers to provide auxiliary aids and services and remove certain communication barriers.

It also is imperative that providers be aware of and comply with their patients' decisions with respect to advance directives. Once a patient makes a decision, the health care team should respect this treatment choice. Yet there is clear evidence that this is not happening in far too many instances. Teno et al. (1995) studied 4,301 patients hospitalized in 6 hospitals and found that physicians often were unaware of their patients' wishes. In 47 percent of cases, physicians reported that they did not know of their patients' expressed desire for a "do not resuscitate" order. In another study focusing on nursing home residents transferred to hospitals, Davis, Southerland, Garrett, et al. (1991) found that medical treatment was consistent with advance directives in 75 percent of the 96 cases studied.

Organizational and Contractual Issues

There are a variety of organizational and contractual factors that also may influence communication between patients and providers. These include financial arrangements and contractual restrictions or sanctions that may inhibit the free exchange of information.

Much attention has focused in recent years on the potential effects of providers' financial incentives on treatment. Methods of compensating physicians can be a powerful mechanism to change provider practice, either to improve the quality of care provided to consumers or to reduce the costs of that care. But poorly designed compensation arrangements also can result in inappropriate use (including both overuse and underuse) and barriers to care.

All methods of compensating physicians and other health care providers create some form of incentive for behavior. Various approaches are used to offset the potential adverse effects of compensation arrangements. For example, fee-for-service systems may use utilization review mechanisms to temper incentives toward overutilization of health care services. Capitation systems may incorporate measures of quality and consumer satisfaction to minimize incentives toward

overutilization. Similarly, salaried arrangements may use bonuses to encourage higher provider productivity and exemplary performance.

In 1996, the Health Care Financing Administration promulgated rules concerning the use of certain types of financial arrangements on behalf of health plans serving Medicare or Medicaid beneficiaries. These rules stipulate that compensation arrangements "may not include any direct or indirect payments to physicians or groups as an inducement to limit or reduce necessary services furnished to an individual enrollee who is covered under the managed care organization's contract." These regulations also require disclosure of information about arrangements that transfer substantial financial risk to the health care provider. If the compensation methods used places the physician or physician group at substantial financial risk, then the health plan must survey enrollees about access and satisfaction with the quality of services, and institute adequate and appropriate stop-loss protections.

In addition to financial incentives, contract rules that restrict providers' ability to advise patients about medically necessary treatment options have been the subject of much concern. Health care providers must be able to advocate for their patients without constraint or fear of reprisal. A report by the General Accounting Office (GAO, 1997) reported: "Of the 529 HMOs in our study, none used contract clauses that specifically restricted physicians from discussing all appropriate medical options with their patients. Two-thirds of responding plans and 60 percent of the contracts submitted had a nondisparagement, nonsolicitation, or confidentiality clause that some physicians might interpret as limiting communication about all treatment options. However, contracts with such business clauses often contained anti-gag language stating that the physician should not misconstrue the contract of a specific provision as restricting medical advice to patients or that the physician should foster open communication." As of mid-1997, 25 States had prohibited the use of such clauses in managed care contracts with physicians and legislation was pending in 23 other States (Health Policy Tracking Service, 1997). In December 1996, HCFA banned the use of gag rules under the Medicare program and in February 1997, HCFA took similar action regarding health plans' participating in Medicaid.

Implications of the Right

Consumers must take a more active part in the treatment decision process. Information can be empowering, but navigating the health care system requires patient effort, from completing advance directives to preparing

questions for an office visit. This requires that the consumer ask questions, understand and give informed consent, and become a full partner in treatment decisions with his or her health care provider.

Health care providers also have the central role in ensuring the patient's participation in treatment decisions, including compliance with informed consent. They will need to improve their skills in providing information about the medical and scientific evidence underlying different treatment options to patients and their families; strive to overcome cultural and language and communication barriers; and keep abreast of the latest and best available treatment options. At the same time, they will need to do a better job of listening to their patients and following their decisions, including the decision to forgo treatment or certain types of treatment. Health care providers should assume this responsibility well before a patient reaches a hospital door. To hold the trust of patients, providers will need to disclose financial incentives that may introduce bias into treatment decisionmaking and to avoid such incentives when the balance is tipped against the patient. To be above any potential bias, providers must avoid self-referral arrangements that can cloud their professional judgment. And, finally, health care providers are and should be the most effective advocates for their patients' rights.

Health care facilities and plans must create and maintain an environment supportive of consumer participation in treatment decisions. In the office practice, this means ensuring adequate visit time for patients and providing support for shared decisionmaking programs when questions about care linger, arise after hours, or require further explanation. Health plans can play a significant role in educating patients on how to get the most out of their visit with a health care provider. They can arrange for translator services for patients and continuing education courses for providers to assure cultural and language competency. By statute, health plans and hospitals have obligations to educate the public about the use of advance directives. As importantly, once advance directives are signed, these documents must become part of the patient's health record and must move with the patient from care setting to care setting. In establishing provider compensation arrangements, health plans and facilities must be vigilant in guarding against the unintended, negative consequences of financial incentives by implementing programs to monitor quality of care and patient satisfaction. The nature of these incentives ought to be disclosed to patients and providers. In contracting with health care providers, plans and facilities

should not restrict the provider's ability to discuss treatment options with the patient and not take reprisal upon the health care provider who serves as patient advocate.

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Consumer Bill of Rights and Responsibilities
Chapter Five
Respect and Nondiscrimination

Statement of the Right

Consumers have the right to considerate, respectful care from all members of the health care system at all times and under all circumstances. An environment of mutual respect is essential to maintain a quality health care system.

Consumers must not be discriminated against in the delivery of health care services consistent with the benefits covered in their policy or as required by law based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.

Consumers who are eligible for coverage under the terms and conditions of a health plan or program or as required by law must not be discriminated against in marketing and enrollment practices based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.

Rationale

Consumers want to be treated with respect and they want to be treated fairly. An environment of mutual respect is essential to maintain a quality health care system. Incidences of discrimination -- real and perceived -- mar the relationship between consumers and their health care professionals, plans, and institutions. Multiple consumer surveys (Levinson et al., 1997; Davis et al., 1995; Edgeman-Levitan and Cleary, 1996) have found that many consumers' complaints about the current health care system have their root in the perception that people believe they are not being treated with respect.

Respect has been defined as recognizing a "person's capacities and perspectives, including his or her right to hold certain views, to make certain choices, and to take certain actions based on personal values and beliefs" (Faden and Beauchamp,

1986). Manifestations of disrespect in the health care setting described by consumers in recent research (Levinson et al., 1997) and interviews include: poor communication with their doctor, feeling rushed or ignored, lack of dignity during examinations, experiencing extensive waiting room delays, receiving inadequate explanations or advice, having inadequate time with the doctor during routine visits, feeling that complaints are not taken seriously by providers, and feeling that providers are more concerned with holding down the cost of medical care than with giving the best medical care. Conversely, consumers defined respectful treatment as that which takes into consideration the values, preferences, and expressed needs of the patient. In addition, consumers wanted providers to communicate well, to be respectful of the patient's time, and to give emotional support to alleviate the patient's fear and anxiety.

In order to extend consumers the respect they deserve, members of the health care industry should strive to:

- Provide consumers with assurances that disrespect or discrimination of any kind is intolerable.
- Provide consumers with information regarding existing laws prohibiting disrespectful or discriminatory treatment.
- Provide consumers with an appropriate amount of time to fully discuss their concerns and questions.
- Provide consumers with reasonable assistance to overcome language (including limited English proficiency), cultural, physical or communication barriers.
- Provide consumers with a timely notice and explanation of changes in fees or billing practices.
- Avoid lengthy delays in seeing a patient; when delays occur, explain why they occurred and, if appropriate, apologize for such delays.

A key element of respectful and fair treatment is protection against discrimination in the delivery of health care services, and in marketing and enrollment, for those eligible for coverage under the terms and conditions of a health plan or program, based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.

Sex. Disparities in medical treatment based on sex have been documented in a number of areas, including: diagnosis and treatment of coronary artery disease (Beery, 1995), kidney transplantation and dialysis, heart transplantation, cardiac catheterization, and diagnosis of lung cancer (AMA

Council on Ethical and Judicial Affairs, 1991). Researchers have found that women are less likely to have diagnostic testing, even when functional disability and risk are higher. Women's complaints are seen as less urgent, and fewer referrals follow as a result of this belief (Tobin et al., 1987). Disparities have also been found in the quality of the doctor-patient relationship. For example, one-quarter of women (compared with 12 percent of men) reported that they have been "talked down to" or "treated like a child by a physician," and 17 percent of women (compared with 7 percent of men) had been told that a medical condition they experienced was "all in their head" (The Commonwealth Fund, 1993; Horton, 1995).

Race, ethnicity, national origin, and religion. Discrimination on the basis of race, ethnicity, national origin, or religion in the provision of health care has also been well documented. There is evidence of disparities in the quality of care, access to health care (because of language or geographic barriers), and the amount of care given to minorities as compared with others (Kahn et al., 1994; Giles et al., 1995; Rosenbaum et al., 1997; Smollar, 1988). In the case of facilities or individuals who accept Federal funds, Federal civil rights statutes prohibit the denial of services; the provision of a different service or services in a different manner from those provided to others; and the segregation of or separate treatment of individuals in any matter related to receiving services (Office of Civil Rights, 1990).

Age. Discrimination against consumers based on their age also occurs in the health care industry including: less aggressive treatment for elderly women with breast cancer and lower than average referral rates for mental health services in older people (Nattinger et al., 1992; Osteen et al., 1992; Ayanian et al., 1993). The Age Discrimination Act of 1972 also prohibits discrimination based on age by any institution or health care provider who accepts Federal funds.

Sexual orientation. Gay and lesbian patients have received reduced care or have been denied care because of their sexual orientation (AAPHR, 1994). Discrimination against gay/lesbian consumers has sometimes been compounded by fears of HIV.

Disability status. There is an extensive history of discrimination against people with disabilities and chronic illnesses that has led to action by Federal and State Government. The Americans with Disabilities Act of 1990 (ADA) prohibits discrimination against individuals with real or perceived

disabilities in employment, public services, public accommodations, communications, and employer-provided health insurance. The Health Insurance Portability and Accountability Act of 1996 prohibits the exclusion of an individual from the group insurance market for more than 12 months based on a preexisting medical condition. The Mental Health Parity Act of 1996 prohibits differential lifetime or annual caps on coverage for physical and mental illnesses in certain situations.

Despite passage of these landmark laws, not all Americans living with disabilities or adverse medical conditions have access to health coverage at a cost they believe is fair or affordable. This is particularly true for consumers attempting to purchase coverage in the individual insurance market. Research into further refinements in the insurance market is needed to assist these individuals. The Commission strongly urges insurers, public and private purchasers, State and Federal Governments, and others to explore all policy options to make health coverage available and affordable to Americans who wish to obtain it, especially those who are living with mental or physical disabilities and chronic illnesses.

Finally, despite recent improvements, many health care facilities remain inaccessible to individuals with disabilities (Savage, 1997). The Commission believes that elimination of physical and communication barriers in health care facilities should be a higher priority for government agencies charged with enforcing the ADA.

Source of payment. The health care system currently is undergoing an historic transformation in which low-income Medicaid beneficiaries are being enrolled into private health plans. While this is a positive development in terms of access for traditionally vulnerable populations to high-quality care, it is almost certain to create additional tensions that could be manifest in discrimination. Providers who agree to accept Medicaid beneficiaries must provide equal access, care, and waiting times to those patients. It will be vitally important for State and Federal agencies to closely monitor the provision of care to Medicaid beneficiaries as they move into new health plans.

Implications of the Right

Consumers will need to be vigilant in reporting instances of discrimination based on the factors discussed in this chapter. Consumers also must extend

the same level of respect to health care providers and others in the health care system that they demand of same. An environment of mutual respect is essential to a healthy relationship between consumers and those who care for them.

Health care professionals and other health workers have the most direct contact with patients and, therefore, have the greatest responsibility to treat health care consumers with respect and to ensure that they do not discriminate. Providers have a responsibility to listen to patients and take their concerns and complaints seriously. Providers also have a responsibility to monitor their treatment of patients to assure they are treated with respect and nondiscrimination and to correct problems when they occur.

Health care facilities that renovate existing facilities or construct new ones must meet a high standard of access in order to avoid discriminating against persons with disabilities. While there is no ADA requirement to "retrofit" existing facilities to make them accessible, there is a responsibility to remove "readily achievable" physical and communication barriers. All health care providers should assess the level of access in their medical facilities and take steps to provide effective communication and unimpeded physical access to the maximum extent possible.

Health plans will need to examine the standards and incentives that exist within their systems that may inadvertently discourage providers from attending to the interpersonal aspects of health care quality that can be manifest as disrespect. Consumers enrolled in health plans with defined networks of providers should have access to their plans' participating providers, without regard to the source of their coverage (e.g., Medicare, Medicaid, employer-sponsored plan).

Quality oversight organizations should utilize tools that allow accurate measurement of dimensions of health care quality that reflect consumer concerns about being treated with respect. Public disclosure of these findings, together with measurements of clinical quality of care, cost, benefit, and other salient information can allow consumers to determine the relative importance they place on such information and make their purchasing decisions accordingly.

Health care worker education and training programs need to recognize and act upon the need for improvements in communication skills by

providers. Receiving inadequate explanations and advice, having inadequate time to receive answers to questions, and failure to attend to the need for emotional support can have adverse consequences on health outcomes (Bame et al., 1993; Patterson et al., 1991; Juncos, 1990). Similarly, education and training programs need to develop and implement course content addressing the significance of cultural attitudes on the effectiveness of health care and the importance of being sensitive to the varying needs of people with disabilities, including those with sensory or cognitive disabilities, who often require auxiliary aids or extra time and plain-language explanation to ensure effective communication. Health plans, hospitals, and other large institutional providers are encouraged to have on-site interpreters for any language population that exceeds a specified standard (e.g., 5 percent or more) and telephone interpreter services for other language minorities. Written material provided to patients should also be translated for the larger linguistic groups.

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Consumer Bill of Rights and Responsibilities
Chapter Six
Confidentiality of Health Information⁵

Statement of the Right

Consumers have the right to communicate with health care providers in confidence and to have the confidentiality of their individually identifiable health care information protected. Consumers also have the right to review and copy their own medical records and request amendments to their records.

In order to ensure this right:

- With very few exceptions, individually identifiable health care information can be used without written consent for health purposes only, including the provision of health care, payment for services, peer review, health promotion, disease management, and quality assurance.
- In addition, disclosure of individually identifiable health care information without written consent should be permitted in very limited circumstances where there is a clear legal basis for doing so. Such reasons include: medical or health care research for which an institutional review board has determined anonymous records will not suffice, investigation of health care fraud, and public health reporting.
- To the maximum feasible extent in all situations, nonidentifiable health care information should be used unless the individual has consented to the disclosure of individually identifiable information. When disclosure is required, no greater amount of information should be disclosed than is necessary to achieve the specific purpose of the disclosure.

Rationale

The legal right to confidentiality of health care information and its essential role in the delivery of quality health care has been recognized by the United States Supreme Court, lower Federal and State courts, and Federal and State lawmakers. Similarly, a health care provider's obligation to protect the confidentiality of health information is universally recognized. The assurance that consumers' health information will remain confidential is "fundamental to effective diagnosis, treatment and healing" (Shalala, 1997).

At the same time, the quality of the health care system also depends on the regular exchange of information between providers, employers, plans, public health authorities, researchers, and other users. The changing structure of the health care system and rapid advances in information technology and medical and health care research have increased the demand for and supply of health information among traditional users such as the treating physician, and new users, such as large networks of providers, information management companies, quality and utilization review committees, and independently contracted service providers. Concerns have been raised that, under the current system of information exchange, various entities can access individually identifiable information without sufficient security safeguards and consent requirements.

Other activities undertaken to improve quality and efficiency may present new risks to the confidentiality of health information. For example, quality oversight activities by plans, providers, accreditation bodies, and regulatory agencies require detailed information about the treatment and benefit status of individual consumers. The growing role of employers in workforce health issues has also contributed to the confidentiality debate.

Congress has made repeated attempts to enact a comprehensive Federal confidentiality law but has, to date, been unsuccessful. The web of protections at the Federal and State level that has evolved in the absence of a comprehensive law leaves many aspects of health information unevenly protected. Specialized Federal protections already exist through statutes that address substance abuse, Medicaid beneficiaries, public health, research, government records, and those living with disabilities.

Several States have enacted comprehensive laws and an effort is currently under way at the National Association of Insurance Commissioners to draft a Protected Health Information Model Act for States. Other safeguards have evolved outside of the legislative arena. Accreditation bodies have incorporated requirements for confidentiality policies and patient consent (JCAHO 1996; NCQA 1997; URAC

1996) and continue to collaborate on security and confidentiality issues (JCAHO/NCQA Joint Session, 1997).

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) required the Secretary of Health and Human Services to submit to the Congress detailed recommendations on: (1) the rights that an individual who is a subject of individually identifiable information should have; (2) the procedures that should be established for the exercise of such rights; and (3) the uses and disclosures of such information that should be authorized or required (Public Law 104-191). On September 11, Health and Human Services Secretary Donna Shalala presented those proposals to the Congress (Shalala, 1997). Under the terms of HIPAA, if Congress fails to enact Federal confidentiality legislation by August 1999, the Secretary of HHS is required to promulgate regulations setting confidentiality standards.

The Secretary recommends a comprehensive Federal confidentiality law that would apply "floor preemption," meaning that the law would require that all States comply with a minimum set of confidentiality requirements but would not preempt stronger State laws.

Section 262 of HIPAA also requires the Secretary of HHS to adopt standards by February 1998 for electronic transmission of financial and administrative health care transactions (including information about claims, eligibility, payment, and injury), unique health identifiers (for individuals, employers, plans, and providers), and security.

The Commission believes that it is essential to establish a comprehensive confidentiality framework and encourages the Congress to move forward expeditiously.

Implications of the Right

Health plans, health providers, employers, and other group purchasers should examine existing confidentiality protections to safeguard against improper use or release of individually identifiable information. The Commission does not intend to impede employers or providers from complying with duties established by law. Health providers, facilities, and plans should develop procedures to ensure that when sensitive services (e.g., mental health, substance abuse, reproductive services, or treatment of sexually transmitted diseases) are involved, standard administrative techniques do not inadvertently disclose information to individuals other

than the patient. This is not intended to create two standards of nondisclosure -- one for sensitive medical conditions and another for all others. It is merely a recognition that there may be high level concern about confidentiality with certain medical conditions by some patients.

Law enforcement officers, researchers, and public health agencies should examine their existing policies to ensure that they access individually identifiable information only when absolutely necessary and provide proper safeguards to assure confidentiality.

Consumers should become more aware of the content of their health records and pay particular attention to requests by providers, plans, employers, or others to gain access to those records.

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Consumer Bill of Rights and Responsibilities

Chapter Seven

Complaints and Appeals

Statement of the Right

All consumers have the right to a fair and efficient process for resolving differences with their health plans, health care providers, and the institutions that serve them, including a rigorous system of internal review and an independent system of external review.

Internal appeals systems should include:

- Timely written notification of a decision to deny, reduce, or terminate services or deny payment for services. Such notification should include an explanation of the reasons for the decisions and the procedures available for appealing them.
- Resolution of all appeals in a timely manner with expedited consideration for decisions involving emergency or urgent care consistent with time frames consistent with those required by Medicare (i.e., 72 hours).
- A claim review process conducted by health care professionals who are appropriately credentialed with respect to the treatment involved. Reviews should be conducted by individuals who were not involved in the initial decision.

- Written notification of the final determination by the plan of an internal appeal that includes information on the reason for the determination and how a consumer can appeal that decision to an external entity.
- Reasonable processes for resolving consumer complaints about such issues as waiting times, operating hours, the demeanor of health care personnel, and the adequacy of facilities.

External appeals systems should:

- Be available only after consumers have exhausted all internal processes (except in cases of urgently needed care).
- Apply to any decision by a health plan to deny, reduce, or terminate coverage or deny payment for services based on a determination that the treatment is either experimental or investigational in nature; apply when such a decision is based on a determination that such services are not medically necessary and the amount exceeds a significant threshold or the patient's life or health is jeopardized.⁶
- Be conducted by health care professionals who are appropriately credentialed with respect to the treatment involved and subject to conflict-of-interest prohibitions. Reviews should be conducted by individuals who were not involved in the initial decision.
- Follow a standard of review that promotes evidence-based decisionmaking and relies on objective evidence.
- Resolve all appeals in a timely manner with expedited consideration for decisions involving emergency or urgent care consistent with time frames consistent with those required by Medicare (i.e., 72 hours).

Rationale

Health care consumers, like other purchasers, have concerns about the service they receive. Unlike other consumers, however, health care consumers have special interests at stake -- the length and quality of their lives. How consumer complaints are addressed has a significant impact on the quality of health services provided and on the satisfaction of consumers with the individuals and institutions that provide them.

Fair and efficient procedures for resolving consumer complaints about their health care serve many purposes. First and foremost, enhanced internal and external review processes will assist consumers in obtaining access to appropriate services in a timely fashion, thus maximizing the likelihood of positive health outcomes.

Second, they can be used to bridge communication gaps between consumers and their health plans and providers, and to provide useful information to all parties regarding effective treatment and consumer needs. Third, the opportunity for consumers to be heard by people whose decisions significantly touch their lives evidences respect for the dignity of consumers as individuals and engenders their respect for the integrity of the institutions that serve them.

Properly structured complaint resolution processes should promote the resolution of consumer concerns as well as support and enhance the overall goal of improving the quality of health care. Internal and external complaint and appeal processes should be:

- Timely.
- Fair to all parties.
- Administratively simple.
- Objective and credible.
- Accessible and understandable to consumers.
- Cost and resource efficient.
- Subject to quality review.

Internal and external complaint and appeal processes should not interfere with communication between consumers and their health care providers. For example, in instances where consumers and their providers agree that a service should be reduced or terminated, no written notification of such decisions is needed. Additionally, health care providers who participate in the complaint and appeal processes on behalf of patients should be free from discrimination or retaliation. Likewise, consumers who file a complaint against a provider or plan should be free from discrimination or retaliation.

For the purposes of this chapter, the following definitions are used for the terms "complaints" and "appeals":

Complaint. A "complaint" is any expression of dissatisfaction to a health plan, provider, or facility by a consumer made orally or in writing. This includes concerns about the operations of providers, insurers, or health plans, such as waiting times, the demeanor of health care personnel, the adequacy of facilities or the respect paid to consumers, and claims regarding the right of the consumer to receive services or receive payment for services previously rendered, including the organization's refusal to provide services the consumer believes he or she is entitled to.

Appeal. An "appeal" is a consumer's request for a health plan, facility, or provider or other body to change an initial decision. An appeal process is a procedure for reconsideration of a specific determination made by a health provider, facility or plan.

Current Resolution Processes

Currently, many different procedures are used by group purchasers, health plans, and provider organizations to respond to consumer complaints. Licensed health plans are subject to numerous State and Federal laws, and many also comply with the standards of private accrediting bodies (e.g., NCQA, 1997; JCAHO, 1996; AAHCC/URAC, 1996). Virtually all private and public health plans provide consumers with some form of complaint resolution process. The Commission does not intend by these recommendations to weaken existing consumer protections. These include:

State Licensed Insurance Products. States traditionally have regulated the benefit structure, solvency, rates, and claims process of indemnity insurance companies doing business in the State. Some State insurance regulations require health insurers doing business in the State to provide certain complaint procedures to enrollees (Abraham, 1990). In addition, all 50 States have laws licensing or governing HMOs doing business in the State separate from their laws regulating indemnity insurance products. Many States' laws are based on the model HMO law drafted by the National Association of Insurance Commissioners (NAIC, 1996), which requires HMOs to establish complaint procedures approved by the State's insurance commissioner. An estimated 30 States have some specified complaint procedures that HMOs must follow and at least 7 States now require an expedited appeal for denials of urgently needed care.

ERISA Plans. All employers offering health benefits to their employees through managed care organizations or traditional indemnity insurers must comply with requirements of the Employee Retirement Income Security Act. ERISA requires private employer-provided health benefit plans to disclose certain information to plan participants, to report information to the Federal government, and to pay benefits that are promised under the plan. ERISA regulations generally require employer health plans to approve or deny claims within 90 days and to approve or deny appeals of claims denials within 60 days. Although ERISA health plans are required to establish and disclose complaint and appeals procedures to participants, and to notify

participants of claims denials, the plans are not required to provide a particular complaint procedure (Butler and Polzer, 1996). An internal reconsideration of denied claims is stipulated but appeals may be decided by the same plan administrators that initially denied the claim. Determinations must be in writing and state specific reasons for the decision.

Medicare. Under the Medicare fee-for-service system, fiscal intermediaries and carriers must provide a two-step internal review and notification of their final decision before a beneficiary is entitled to seek reconsideration from the Social Security Administration's payment division and the Health Care Financing Administration (Kinney, 1996). Medicare provides a graded appeal process that includes a hearing before an administrative law judge and administrative appeals council review for claims under Part A (hospital coverage) if the amount in controversy is more than \$100; and under Part B (physical and outpatient coverage) if the claims are more than \$500. Claims under Part A and Part B for more than \$1,000 are entitled to judicial review.

HMOs that participate in Medicare are required to provide meaningful internal procedures for resolving complaints about the quality of care, untimely provision of care, or the improper demeanor of health care personnel (Stayn, 1994). HMO decisions to deny coverage for certain treatment, referral outside a plan, or reimbursement for emergency or out-of-area care are subject to an external review and administrative appeal. HCFA has contracted with a private organization, the Center for Health Dispute Resolution, to perform these reconsiderations (Richardson, Phillips, and Conley, 1993). After external review, a Medicare beneficiary enrolled in an HMO who is "dissatisfied by reason of his failure to receive any health service to which he believes he is entitled and at no greater charge than he believes he is required to pay" has a right to Social Security administrative review for controversies more than \$100 and judicial review for controversies more than \$1,000.

Medicaid. The Federal Medicaid statute requires State agencies to provide beneficiaries with a fair hearing and an administrative appeal when their eligibility or requests for services are denied or not acted upon within reasonable time. These State agency determinations can be challenged in State court under State administrative procedure acts or in Federal court. In addition, HMOs that contract to serve Medicaid beneficiaries must establish an internal complaint procedure that will resolve disputes promptly. These internal procedures are subject to review and approval by the State.

Medicaid HMO enrollees have the same rights to administrative appeal as do fee-for-service enrollees and no recommendations are made concerning the changing of such rights.

Federal Employees Health Benefit Program. Federal employees and their dependents receive coverage through private insurance carriers, including more than 300 HMOs. Under the FEHBP complaint resolution process, enrollees may bring disputes concerning benefits or services to the Office of Personnel Management for review after asking the plan to reconsider its initial denial and failing to receive a satisfactory reply. OPM seeks to determine whether the enrollee or family member is entitled to the services or supply under the terms of the contract.

Other Approaches. The federal HMO Act requires that to be a "federally qualified HMO," a plan must provide meaningful procedures for hearing and resolving complaints between subscribers and the plan. The written procedures must be easily understood and provided upon request. HMOs are not required to comply with the Act's requirements but may do so to obtain favored status. Other approaches to complaint resolution exist in the Department of Defense's health programs, including the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS).

Implications of the Right

Assuring that all consumers have access to both internal and external processes that satisfy the requirements of this right will require action on virtually every level of the health care industry.

Enhancing Internal Review Systems. Health plans will need to examine their existing internal review systems to assure that consumers receive a timely, understandable notice of decisions to deny, reduce, or terminate treatment or pay claims; notice of the reasons for that determination and of the complaint and appeals procedures available to them; and expedited processes for certain types of cases. While there do not appear to be reliable data indicating how many health plans currently provide internal complaint procedures, most apparently do. Thus, implementation of a general right to file internal complaints, to appeal within a health plan, and to receive a response will not require a majority of health plans to change their current practices significantly. It will be important for quality oversight organizations (State licensure programs, Federal certification programs, and

private accrediting bodies) to assure that their standards and review processes adequately address internal complaint and appeal processes of health plans.

Establishing Independent External Appeals Systems. Additional analysis must be done to identify the most effective and efficient methods of establishing the independent external appeals function. Issues to be considered include: mechanisms for financing the external review system; sponsorship of the external review function; design of review processes to assure evidence-based decisionmaking; qualifications of reviewers; consumer cost-sharing responsibilities (e.g., filing fees); and methods of overseeing and holding external appeals entities accountable. It will also be important to establish an ongoing evaluation mechanism to assess the impact of the external appeals process on access to appropriate services, rates of consumer disputes, litigation rates, consumer satisfaction, and costs. The evaluation mechanism should also assess the impact of certain design characteristics on the effectiveness and efficiency of the external appeals process.

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Consumer Bill of Rights and Responsibilities

Chapter Eight

Consumer Responsibilities

Statement of Responsibilities

In a health care system that protects consumers' rights, it is reasonable to expect and encourage consumers to assume reasonable responsibilities. Greater individual involvement by consumers in their care increases the likelihood of achieving the best outcomes and helps support a quality improvement, cost-conscious environment. Such responsibilities include:

- Take responsibility for maximizing healthy habits, such as exercising, not smoking, and eating a healthy diet.
- Become involved in specific health care decisions.
- Work collaboratively with health care providers in developing and carrying out agreed-upon treatment plans.
- Disclose relevant information and clearly communicate wants and needs.
- Use the health plan's internal complaint and appeal processes to address concerns that may arise.
- Avoid knowingly spreading disease.
- Recognize the reality of risks and limits of the science of medical care and the human fallibility of the health care professional.
- Be aware of a health care provider's obligation to be reasonably efficient and equitable in providing care to other patients and the community.

- Become knowledgeable about his or her health plan coverage and health plan options (when available) including all covered benefits, limitations, and exclusions, rules regarding use of network providers, coverage and referral rules, appropriate processes to secure additional information, and the process to appeal coverage decisions.
- Show respect for other patients and health workers.
- Make a good-faith effort to meet financial obligations.
- Abide by administrative and operational procedures of health plans, health care providers, and Government health benefit programs.
- Report wrongdoing and fraud to appropriate resources or legal authorities.

Rationale

In providing consumers with a set of rights and protections, the Commission believes that individual consumers must assume certain responsibilities. Responsibilities create benefits not only for individual consumers and their families but also for the health care system and society as a whole. Improved health status reduces medical costs for the patient, the payer, and society.

The Commission, however, does not intend to create a link between an individual's conduct in meeting his or her responsibilities and the obligations of plans and providers to provide covered services.

Increased patient responsibility can improve consumers' sense of self-worth. For example, increased responsibility among individuals living with disabilities has resulted in increased independence for that population (Rodwin, 1994; National Health Council, 1995). In fact, this is the principle behind the independent living movement, where people with disabilities live in their homes with personal assistant services rather than in institutions. Individuals report that increased responsibility for their health has led to improved self-esteem and a greater sense of empowerment.

Promoting consumer responsibility is an essential component of the effort toward involving consumers directly in decisionmaking about their health and medical care. Consumers often perceive that the medical professionals who care for them are acting in a condescending or paternalistic manner. They resent being put in a position of dependence and being treated as if they are infantile and object to the presumption that they are incapable of making choices themselves (Rodwin, 1994).

While the Commission believes that consumers must assume certain responsibilities, it also recognizes that reasonable accommodations must be made

for numerous consumers with disabilities. For example, some individuals with physical and mental disabilities require assistance with self care; for some individuals with mental disabilities, noncompliance with treatment regimes is a manifestation of their disability; and some individuals with mental and physical disabilities are unable -- due to their disability -- to clearly communicate their wants and needs and, therefore, rely on the assistance of a designated representative. In each case, the health care system must recognize these issues and accommodate these needs. The Commission also recognizes that there are many other factors, such as occupational hazards, language, and income status, that may pose significant barriers to consumers meeting these responsibilities.

Consumers who are able should take the opportunity to educate themselves with respect to the specifics of their benefit coverage and to learn how to access the health care and services available to them as a result of that coverage. This includes:

- Reading and understanding written information that explains benefit coverage.
- Reading and understanding information that describes health plan processes and procedures to follow when seeking care by a physician, hospital, or other provider.
- Seeking information or clarification of information from the health plan as necessary.
- Using the health plan's processes for addressing complaints or grievances when disputes with providers or health plan procedures arise.

Consumer responsibility is particularly relevant to the broad right to information established in this Consumer Bill of Rights and Responsibilities (see [Chapter One](#)). The Right to Information requires the disclosure of information to consumers either directly or upon request on such things as benefits, cost-sharing, complaints and appeals processes, licensure, accreditation, and performance measures. The Right to Information will improve health outcomes only to the extent that consumers have a choice of health plans and use that information in exercising the choice.

Although there is significant value in promoting the consumers' participation in their own health care by increasing their level of responsibility, it is important to set limits on the amount of responsibility expected. The patient's responsibility to comply with medical advice is limited by the principle of informed consent (Benjamin, 1985). The patient retains the right to choose whether to follow

medical advice or not, as long as he or she is willing to accept the health outcome consequences that may result from noncompliance, and the noncompliance does not adversely affect the public (Brock and Wartman, 1994).

Consumers do not have a duty to be subjected to a treatment regime they have good reason to avoid -- for instance, one whose negative side effects outweigh its benefits (Mayer, 1992), or when excessive medication in an institutional setting is used to "control" residents. Most consumer responsibilities do not extend to those who are incompetent to make decisions, including infants, those who are judged to be mentally incompetent, and comatose patients (Emson, 1995; Mayer, 1992; National Health Council, 1995).

In addition, certain high-risk behaviors (smoking, use of smokeless tobacco, illegal drug use) are addictive and cannot be considered fully under the volitional control of the individual consumer. Caution must be used to avoid "blaming the victim." For example, Bayer (1996) notes that during the history of the AIDS epidemic, "the emphasis on personal responsibility was often associated with condemnation of those whose sexual or drug-using behavior had exposed them to HIV, as well as with calls for invasion of privacy and deprivations of liberty."

Compliance with agreed-upon treatment protocols is a particularly important consumer responsibility. Noncompliance with the taking of medication has particular implications for the health status of consumers. Noncompliance includes taking too much medication, taking medication not prescribed, not taking medication prescribed, altering the prescribed dosage, or altering the time between doses.

Finally, it is important to recognize that while consumers should seek to assume the responsibilities discussed in this report, many factors influence consumers' acceptance of medical advice. Some are related to the health care system itself and others are related to the patient's individual psychology. Imanaka, Araki, et al. (1993) identified patient dissatisfaction with their health care providers and plans as a primary cause of patient noncompliance. Several studies have identified inadequate provider-consumer communication as a contributing factor (Imanaka, 1993; Ross, 1991; Donovan and Blake, 1992; Sluijs, Kok, et al., 1993). This leads to situations where:

- The patient and the prescriber have a different understanding of what the patient is supposed to do.

- The patient lacks information or understanding about the disease, pathology, or symptoms.
- The patient does not understand the correct purpose of the intervention.
- The patient and the health care provider have insufficient time to discuss the full range of issues concerning compliance.

Noncompliant patients also may have underlying psychiatric disorders. Yellowless and Ruffin (1989) found that 40 percent of patients who experience a life-threatening asthma episode have psychiatric disorders. Patients often are trying to balance the requirements of their prescribed medical regimen with other aspects of their life (Donovan and Blake, 1992). Finally, some patients choose not to comply with medical instructions as a way of expressing their attempts to cope with their disease; as a reaction to the way they have been treated by doctors; or as a way of fighting the system by breaking its "symbolic" rules (Ross, 1991).

Implications of the Responsibilities

Consumers will have to play an active role in the treatment and management of their health. Consumers will need to ask more questions of their health care providers, insurers, and institutions. They will need to express their wishes and desires clearly to those who care for them and to their family members in the event of incapacity; this should be done *before* an incapacity occurs. They will need to make sure that they understand a treatment regimen that is prescribed for them before they agree to follow it. Once they have made such an agreement, consumers will need to make every effort to comply and, if they cannot, to notify their provider of their desire or need to change that regimen. Consumers will need to recognize the financial and societal impact of their health care decisions and their health care choices should reflect this consideration.

Health care providers will need to communicate more clearly with their patients and their patients' families about diagnoses, treatment options, and treatment protocols. They will need to make greater efforts to ensure that those matters are clearly understood and agreed to. They will need to work with their patients to ensure that treatment regimens are possible to follow and that changes in treatment are made when possible to meet patients' needs or demands.

Health plans will need to consider ways to encourage greater communication between consumers and health care professionals, including incentives for such communication and acceptance of treatment regimens.

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1. The term "health plans" is used throughout this report and refers broadly to indemnity insurers, managed care organizations (including health maintenance organizations and preferred provider organizations), self-funded employer-sponsored plans, Taft-Hartley trusts, church plans, association plans, State and local government employee programs, and public insurance programs (i.e. Medicare and Medicaid).
 2. The right to external appeals does not apply to denials, reductions, or terminations of coverage or denials of payment for services that are specifically excluded from the consumer's coverage as established by contract.

3. The Commission examined proposals by organizations including: the American Association of Health Plans, the American Association of Retired Persons, the American Hospital Association, the American Medical Association, the Campaign for Health Security, Citizen Action, Families USA, the Health Insurance Association of America, HIP Health Plans, the Health Policy Tracking Service, Kaiser Permanente, Kaiser/Group Health, the Midwest Bioethics Center, the National Association of Insurance Commissioners, the National Committee on Quality Assurance, the National Health Council, the Public Policy and Education Fund of New York, the Service Employees International Union, the Utilization Review Accreditation Committee, and many others.
4. The term "health plan" is used throughout this report and refers broadly to indemnity insurers, managed care organizations (including health maintenance organizations and preferred provider organizations), self-funded employer-sponsored plans, Taft-Hartley trusts, church plans, association plans, State and local government employee programs, and public insurance programs (i.e., Medicare and Medicaid).
5. In the context of this chapter, health care information is defined as "any information, whether oral or recorded, in any form or medium, that is created or received by a health care provider, health plan, public health authority, employer, life insurer, school, university, health care clearinghouse; and relates to the past, present, or future physical or mental health or condition of an individual, the provision of health care to an individual, or the past, present, or future payment for the provision of health care to an individual."
6. The right to external appeals does not apply to denials, reductions, or terminations of coverage or denials of payment for services that are specifically excluded from the consumer's coverage as established by contract.



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