WEB-BASED RESOURCES FOR RETRIEVING HEALTH POLICY INFORMATION: NLM AND BEYOND

MARJORIE A. CAHN, MA, CATHERINE R. SELDEN, MLS,
AND IONE AUSTON, MLS

ABSTRACT This paper identifies Web-based resources of interest to the health policy community. Both information useful for developing health policy and information about existing health policy are included. Resources described are classified into three major categories: traditional and grey literature, statistical and epidemiological data, and legal and legislative material. National Library of Medicine (NLM) resources include MEDLINE, DIRLINE, HealthSTAR, HSRProj, and HSTAT. In addition, NLM's National Information Center on Health Services Research and Health Care Technology (NICHSR) has a Web page (<http://www.nlm.nih.gov/nichsr/nichsr.html>) that provides an extensive listing of health-policy-related Web sites. Some of the other resources highlighted include those available from the Health Care Financing Administration (HCFA), the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC), the National Committee for Vital and Health Statistics (NCVHS), and the Library of Congress.

HEALTH POLICY INFORMATION DEFINED

Health policy is defined by the National Library of Medicine (NLM) in its controlled vocabulary of Medical Subject Headings (MeSH[®]) as: "Decisions, usually developed by government* policymakers, for determining present and future objectives pertaining to the health care system."¹ NLM's Collection Development

Ms. Cahn is Head and Ms. Selden and Ms. Auston are Librarians at the National Information Center on Health Services Research and Health Care Technology (NICHSR), National Library of Medicine, Bethesda, Maryland.

Correspondence: Marjorie A. Cahn, MA, Head, National Library of Medicine, 8600 Rockville Pike, Building 38, Room 1W22E, Mail Stop 20, Bethesda, MD 20894. (E-mail: CAHN@NLM.NIH.GOV)

*While health policy setting is typically thought of as a government function, in this age of large regional, national, and international health care organizations it is often the case that governmental health policy is refined further at an organizational level. For example, an insurance or managed-care organization may have more restrictive policies

Manual elaborates on this definition by pointing out that integral components of health policy as a subject area are health legislation, regulations and professional guidelines, standards and protocols that regulate health services, public health policy, and health advocacy. The Collection Development Manual subject descriptions are based on a current understanding of the trends in biomedical research and medical practice, and categories in the subject section often are described further in terms of illustrative (not exhaustive) related topics. For health policy, the associated topics listed include biomedical ethics, health economics, health facilities, health professions, health services, and health services research.² Clearly, health policy encompasses very broad areas of information.

Is health policy the same as health policy information? The answer is, yes and no. In some instances, use of the term *health policy information* means literally *information about health policy*. In others, it means instead the *information needed to formulate health policy* or the information on which health policymaking is based. Herein, both information useful for developing and information about existing health policy are included.

HEALTH POLICY INFORMATION KNOWLEDGE BASES AND SEARCH ENGINES

Health policy information knowledge bases and search engines generally may be classified into three major categories: traditional and grey literature, statistical and epidemiological data, and legal and legislative material. However, there is much overlap among these categories. Many of the sources included below provide more than one type of information, but for brevity's sake, they are discussed in only one section.

LITERATURE

NLM has long been a leader in providing access to peer-reviewed literature through its MEDLINE bibliographic database.* MEDLINE covers the fields of medicine, nursing, dentistry, veterinary medicine, the health care system, and the preclinical sciences. It contains bibliographic citations (e.g., authors, title, journal reference) and author abstracts from over 3,800 biomedical journals published in the US and 70 foreign countries and includes over 9 million records

on what services are covered for its members than those the Health Care Financing Administration (HCFA) might cover for Medicare or Medicaid beneficiaries. For purposes of this presentation, both governmental and organizational health policy information are considered.

*Additional information on MEDLINE and all the NLM products and services described here may be accessed at <http://www.nlm.nih.gov>.

TABLE I Summary of National Library of Medicine Free Health Services Research Databases

Database	HealthSTAR	HSRProj	DIRLINE	HSTAT
Contents	Bibliographic citations to health services literature	Citations to health services research in progress	Citations to health services organizations and resources	Full text guideline and technology documents
URL		http://igm.nlm.nih.gov		http://text.nlm.nih.gov

dating to 1966. MEDLINE may be accessed free of charge on the World Wide Web through NLM's Web-based search engines, Internet Grateful Med and PubMed.* It is also widely available from commercial sources.

With the establishment in 1993 of NLM's National Information Center on Health Services Research and Health Care Technology (NICHSR), NLM placed increased emphasis on traditional and grey health policy-related literature. NICHSR's primary goal is to make the results of health services research, including practice guidelines and technology assessments, readily available to health practitioners, health care administrators, health policymakers, and payers and the information professionals who serve these groups. Accordingly, NICHSR supports three NLM databases that provide free access via Internet Grateful Med to citations: to published and fugitive literature in these areas, to research not yet appearing in the literature, and to health services research and policy organizations (Table I).†

HealthSTAR is the on-line bibliographic database that provides access to health services, technology, administration, and research literature. HealthSTAR

*There are different advantages to the two search engines NLM currently makes available to access its literature. PubMed provides free access to MEDLINE, with linkages to publishers' sites for full-text viewing of approximately 100 journals, some by subscription only. PubMed supports search interfaces from simple key words to advanced Boolean expressions, and it has sets of related articles precomputed for each article cited in MEDLINE. The use of MeSH index terms (main topics and subheadings) is supported, as is a clinical query form with built-in search filters for diagnosis, etiology, therapy, and prognosis. Internet Grateful Med provides free access to several NLM databases, including MEDLINE, AIDSLINE, HealthSTAR, AIDSDRUGS, AIDSTRIALS, DIRLINE, HISTLINE, HSRProj, OLDMEDLINE, and SDILINE. It utilizes the full range of MeSH and other controlled vocabularies in its search features, which build on the Unified Medical Language System's Metathesaurus. With Internet Grateful Med, users have the ability to limit searches by language, publication type, age groups, and more using pull-down menus.

†At present, health services research material (and other topic-specific material such as citations on AIDS, space medicine, cancer) resides in separate NLM databases. It is NLM's goal that, in the near future, multiple databases will be integrated into MEDLINE to streamline citation creation and maintenance and to improve ease of retrieval by the user.

became available in 1996 through the merger of two former NLM databases, the HEALTH (Health Planning and Administration) database, initiated in 1978 with the cooperation of the American Hospital Association, and the HSTAR (Health Services/Technology Assessment Research) database, initiated in 1994 by NICHSR. HealthSTAR contains approximately 3 million citations (author; title; reference; procurement source; abstract, if available) to journal articles, monographs, technical reports, meeting abstracts and papers, book chapters, and government documents from 1975 to the present. It includes selected records from NLM's MEDLINE and CATLINE databases, as well as unique records specially indexed for it.

HSRProj, a database of citations to research in progress funded by federal, state, and private grants and contracts became available in 1995. HSRProj is developed in partnership by staff of NLM, the Association for Health Services Research, and the Cecil G. Sheps Center for Health Services Research at the University of North Carolina, Chapel Hill. It includes over 5,000 citations to ongoing or recently completed research funded since 1990. Records provide names of performing and sponsoring agencies, principal investigator, and project period and information about study design, source of the project data, and project description, whenever possible.

The DIRLINE database contains contact points and descriptions (e.g., information on publications, holdings, and services provided) about a wide variety of information resources, including organizations, research resources, projects, databases, and electronic bulletin boards concerned with health and biomedicine. These information resources fall into many categories, including federal, state, and local government agencies; information and referral centers; professional societies; self-help groups and voluntary associations; academic and research institutions and their programs; and information systems and research facilities. DIRLINE has a special subfile covering health services research, including organizations involved with guidelines, technology assessment, and health policy.

Table II provides a summary of selected recent health policy information coverage provided by the four databases described above. Numbers of citations shown are based on subject searches using the MeSH headings for health policy, jurisprudence, and legislation and the MeSH subheadings for statistics and numerical data and epidemiology.

In addition to these bibliographic, research, and organization databases, NICHSR supports HSTAT* (Health Services/Technology Assessment Text), a

*Additional information on HSTAT may be accessed at <http://text.nlm.nih.gov>.

TABLE II Summary of Health Information Coverage in Selected National Library of Medicine Databases

Medical Subject Headings (MeSH) Terms Used for Searches	MEDLINE (1990–1998)	HealthSTAR (1990–1998)	HSRProj (1990–1998)	DIRLINE
Health policy	13,987	20,791	239	122
Statistics and numerical data	64,654	72,970	19	90
Epidemiology	175,304	160,145	346	129
Jurisprudence or legislation	24,405	29,872	5	504

free, full-text, electronic resource for guideline and technology assessment documents (Table I). Developed by NLM's Lister Hill Center, HSTAT provides a table of contents for each document in its collection from which a particular section may be viewed on-line or downloaded. Users also are able to search individual documents, or a user-specified set of documents, by words or phrases to find documents and sections of interest, which may be displayed on-line and downloaded. HSTAT currently includes Agency for Health Care Policy and Research (AHCPR) evidence reports, guideline documents, and technology assessments; National Institutes of Health (NIH) Consensus Development Conference Statements and Technology Assessment Workshop Reports; NIH Clinical Center active research protocols; the US Preventive Services Task Force's Guide to Clinical Preventive Services; AIDS/HIV Treatment Information Service (ATIS) approved guidelines; Substance Abuse and Mental Health Services Administration (SAMHSA) treatment improvement protocols; and a link to the Centers for Disease Control and Prevention's (CDC's) Prevention Guidelines Database. Plans are under way to add the soon-to-be-released Guide to Community Preventive Services to the collection of HSTAT databases. Plans also are under way to link HSTAT to the National Guidelines Clearinghouse* project, currently under development by AHCPR in partnership with the American Medical Association and the American Association of Health Plans.

STATISTICAL AND EPIDEMIOLOGIC DATA

It is beyond the scope of this presentation to list all sources of statistical and epidemiologic data useful in formulating health policy. However, the NICHSR home page† provides links to some of the major data sources. Three of these are

*Additional information on the National Guidelines Clearinghouse, which is expected to become available in fall 1998, may be accessed at <http://www.ahcpr.gov:80/news/press/ngc.htm>.

†Additional information on all the NICHSR products and services described here may be accessed at <http://www.nlm.nih.gov/nichsr/nichsr.html>.

discussed below; others are summarized in Table III. In addition, NICHSR's home page also provides the full text of *Health Statistics Sources*,⁴ by Michael L. Newman of Stanford University. This manual offers selected print and on-line bibliographies and searching tips for users seeking health-related statistical information.

The Health Care Financing Administration (HCFA) is the federal agency that has, since the 1960s, administered the Medicare and Medicaid programs; in 1997, it added to its mission the Child Health Insurance Program (CHIP).^{*} Through these programs, HCFA provides health insurance for tens of millions of aged, poor, young, or specially entitled Americans. HCFA's Office of Research and Demonstrations produces a quarterly serial publication, as well as groups of reports, that provide information on a range of issues in the health care financing field, including findings from research and demonstration projects and statistics on the services provided to these beneficiaries. These include the *Health Care Financing Review*,⁵ research briefs, and extramural research reports. Abstracts from the *Review* dating to spring 1995 and full texts of the briefs and reports are available on-line at <http://www.hcfa.gov/pubforms/ordpub.htm>; citations to them are included in HealthSTAR. The *Review* seeks to improve understanding of HCFA insurance programs and the US health care system by presenting information and analyses on a broad range of health care financing and delivery issues. The *Review* highlights the results of policy-relevant research for a diverse audience that includes policymakers, planners, administrators, insurers, researchers, and health care providers.⁶ HCFA also makes a wide range of statistical information and data available, including annual statistical summaries about beneficiaries, providers, spending, and costs; downloadable public use data files (Table IV); health care indicators based on analysis of recent trends in health care spending; special statistical reports and files on topics such as managed care, immunizations, mammography, enrollment, and diagnosis-related group data; and National Health Expenditures data, including Medicare, Medicaid, private health insurance, and out-of-pocket spending.⁸

The National Center for Health Statistics (NCHS),[†] part of CDC, is the principal US health statistics agency. The mission of NCHS is "to provide statistical information that will guide actions and policies to improve the health of the American people."⁹ NCHS products are listed in their catalogs of electronic products (which

^{*}Additional information on all the HCFA products and services described here may be accessed at <http://www.hcfa.gov>.

[†]Additional information on all the NCHS products and services described here may be accessed at <http://www.cdc.gov/nchswww/>.

TABLE III Selected National Information Center on Health Services Research and Health Care Technology Home Page Links to Health Policy Information Sources

Type	Name
Data sets and data sources	AAMC Clinical Administrative Data Service (CADS) BASIS-32 CDC WONDER Conquest 1.1 HEDIS 3.0 Inter-University Consortium for Political and Social Research (ICPSR) Massachusetts Health Data Consortium, Inc. Minnesota Health Data Institute Registry of State-Level Efforts to Integrate Health Information SAMHSA Statistical Data and Datasets Selected Economic and Demographic Data Extractors SF 36 Health Survey Social Science Data Archives Social Sciences Data Collections, UCSD (University of California, San Diego) Social Science Data Archive at Yale US Census
Epidemiology and health statistics	Bureau of the Census Epidemiology and Biostatistics 1996 Green Book Guide to Locating Health Statistics Falk Library of the Health Sciences Medical Outcomes Trust MEDISTAT New York Department of Health, Information for Researchers WHOSIS
Health policy and health economics	The Alpha Center American Medical Specialty Organization, Inc. Electronic Policy Network Health Administration Resources Health Economics, Places to Go Health Economics, Policy and Medical Outcomes Sources Health Services Information Center (University of Washington) Health Services Research Journal Intergovernmental Health Policy Project Journal of Health Politics, Policy, and the Law MEDWEB: Health Care Policy National Association of Health Data Organizations (NAHDO) National Committee for Quality Assurance (NCQA) National Health Policy Forum (NHPF) RAND Health Program Robert Wood Johnson Foundation and Center for Studying Health System Change Urban Institute Health Policy Center

From ref. 3.

TABLE IV Summary of Health Care Financing Administration Public Use Data Files, by Subject

Subject	File
Providers	End-Stage Renal Disease (ESRD) Renal Provider File ESRD Facility Survey File Provider of Services Listing
Cost limits	Medicare Home Health Agency Cycle 14 Data Set
Payments rates—insti- tutional providers	HCFA Hospital Wage Index Survey File Hospital Wage Indices File PPS SSA/FIPS Metropolitan Statistical Area State and County Crosswalk Reclassified Hospital by Provider File HCFA Case-Mix Index File ICD-9-CM Version 15.0 File PPS—Payment Impact PPS—Standardizing File Provider Specific File After Outlier Removed/Before Outlier Removed (AOR/BOR) Tables DRGs Relative Weight File
Payment rates—nonin- stitutional providers	Durable Medical Equipment, Prosthetics/Orthotics, and Supplies (DMEPOS) Fee Schedule Ambulatory Surgical Center (ASC) Base Eligibility File Physician Fee Schedule Payment Amount File National/Carrier Carrier/Locality State and County File National Physician Fee Schedule Relative Value File Clinical Diagnostic Laboratory Fee Schedule
Utilities/miscellaneous	Alpha-Numeric HCPCS File HCFA Capital-related Tax Adjustment File Berenson-Eggers Type of Service (BETOS) File

From ref. 7.

include more than 500 public use data files) and publications (which include published reports, journal articles, and working papers). Table V provides a summary of the subjects and surveys for which NCHS provides electronic data files. Data from NCHS also are presented in a variety of publications. The most comprehensive of these is *Health, United States*,¹¹ an annual compendium of about 500 pages on health status, health care resource use, and vital statistics. The Vital and Health Statistics series¹² includes descriptions of NCHS data collection programs and methods and presents data analyses for each data collection program or family of related programs. Other NCHS publications include *Advance Data*, *Monthly Vital Statistics Reports*, *Vital Statistics of the United States*, *Healthy People 2000*, and *Life Tables*.¹³

While not technically a source of data like HCFA or NCHS, since its formation in the 1950s the National Committee on Vital and Health Statistics (NCVHS)*

*Additional information on NCVHS activities may be accessed at <http://aspe.os.dhhs.gov/ncvhs>.

TABLE V Summary of National Center for Health Statistics Data Sets, by Subject and Survey

Subject	Survey
Aging	Longitudinal Study of Aging
Births	Nativity Data
Deaths	Compressed Mortality File
	Fetal Death Data
	Linked Birth and Infant Death Data
	Mortality Data, Underlying Cause-of-death
	Mortality Data, Multiple Cause-of-death
	National Health Interview Survey, Multiple Cause-of-death
Health care and health services utilization	Inventory of Long-Term Care Places
	National Ambulatory Medical Care Survey
	National Health Provider Inventory
	National Home and Hospice Care Survey
	National Hospital Ambulatory Medical Care Survey
	National Hospital Discharge Survey
	National Master Facility Inventory
	National Nursing Home Survey
	National Nursing Home Survey; Next-of-kin Component and Followup
	National Survey of Ambulatory Surgery
Health care utilization and expenditures	National Medical Care Utilization and Expenditure Survey
Health and nutrition	National Health and Nutrition Examination Survey (NHANES) I-III
	NHANES I—Epidemiologic Followup Study
	NHANES I—Radiographic Absorptiometry Bone Density Data
	Hispanic Health and Nutrition Examination Survey
	National Health Examination Survey, Cycles I-III
Health promotion	National Survey of Personal Health Practices and Consequences
Health status	National Health Interview Survey
	National Health Interview Survey, Current Health Topics
	National Health Interview Survey on Disability, Phase I
	National Health Interview Survey, Multiple Cause of Death
	National Health Interview Survey, State Data
Marriage and divorce	Marriage Data
	Divorce Data
Maternal and child health	National Maternal and Infant Health Survey (NMIHS)
	Longitudinal Followup to the 1988 NMIHS
	National Natality and Mortality Surveys
Reproductive health and behavior	National Survey of Family Growth
Risk factors	Linked Birth and Infant Death Data
	National Mortality Followback Survey
	National Natality and Mortality Surveys

From ref. 10.

has stimulated a host of improvements in national and international health data and statistics. These include such areas as disease classification, health surveys, and health data sets and standards, as well as privacy protection for health information. The long-term goal of the NCVHS is to improve the compatibility of private sector, state, and federal health information systems while ensuring the confidentiality of the information collected. It informs the Department of Health and Human Services (DHHS), state, and private sector about data policy decision making.¹⁴

Of particular importance to the field of health policy are NCVHS activities in the areas of Core Health Data Elements and implementation of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 (Pub L 104-191).¹⁵ In its 1996 report on Core Health Data Elements, the NCVHS identified a small set of data elements that almost always are included in data-collection efforts. The committee then developed a set of agreed-upon standardized definitions for these data elements that can be used to collect and produce standardized data.¹⁶ Under HIPAA, DHHS and the NCVHS are required to advise the Congress on any legislative or regulatory actions needed to promote full electronic medical records. The DHHS Data Council has been given the assignment to implement the provisions of the law, acting through its Health Data Standards Committee and Interagency Health Privacy Working Group. NLM serves on both these committees and cochairs the implementation team focused on codes, classifications, and vocabulary.

LEGAL AND LEGISLATIVE MATERIAL

As noted in Table II, there is a wealth of jurisprudence and legislative material already in the NLM databases. However, this is an area of currently increased emphasis in HealthSTAR as previous testing of the database¹⁷ indicated a gap in this area, particularly related to technology assessment issues.

On the federal level, the Library of Congress' THOMAS Web site* has been the definitive source for this area of health policy information since its debut in January 1995. Among the databases THOMAS currently offers, those shown in Table VI are of particular interest to the policy audience.

On the state level, the National Association of State Information Resource Executives (NASIRE),† maintains a topical clearinghouse to state government information available on the Web. NASIRE's StateSearch currently contains over

*Additional information on THOMAS may be accessed at <http://thomas.loc.gov>.

†Additional information on NASIRE may be accessed at <http://www.nasire.org>.

TABLE VI Selected Thomas Databases

Type	Coverage	Description
Congress this week: floor activities	105th Congress, current and previous work	All bills that are receiving or are expected to receive floor action
Major legislation	105th and 104th Congresses	Selected bills/amendments deemed significant by legislative analysts in the Congressional Research Service at the Library of Congress
Bill summary and status	93rd through 105th Congresses (1973–1997)	Information about bills and amendments: sponsor(s); cosponsor(s); official, short, and popular titles; floor actions; detailed legislative history; <i>Congressional Record</i> page references; bill digest; committees of referral, reporting, and origin; subcommittees of referral; links to other committee information; amendment descriptions (and text, when available); subjects (indexing terms assigned to each bill); and a link to the full text of the bill/law
Bill text	105th, 104th, 103rd, 102nd, 101st Congresses	Full text of all Government Printing Office (GPO)–supplied versions of bills
<i>Congressional Record</i> text	105th, 104th, 103rd, 102nd, 101st Congresses	Full text of daily <i>Congressional Record</i>
<i>Congressional Record</i> index	105th, 104th, and 103rd Congresses	Index to the daily <i>Congressional Record</i>
Committee reports	105th and 104th Congresses	The full text of House and Senate committees
Committee home pages	105th Congress	Links to House and Senate committee home pages, typically including committee jurisdiction, chair, full committee and subcommittee membership, committee schedules, press releases, witness lists, hearing transcripts, committee publications

From ref. 18.

2,000 entries in more than 20 categories, including health, human services, and welfare (including links to health departments and data centers); judicial (including links to court decisions, bills, codes); regulation and licensing (including links to state boards); and state legislatures (including links to statutes, bills, legislators).¹⁹

EXAMPLES OF SPECIFIC HEALTH POLICY INFORMATION RESOURCES

In closing, three specific recent examples of health policy information available on the Web are discussed below: a literature-based bibliography, a data-based surveillance report, and documentation of efforts under way to implement 1996 health legislation.

BIBLIOGRAPHY ON CONFIDENTIALITY OF HEALTH DATA

Each publication in NLM's Current Bibliographies in Medicine (CBM) series* covers a distinct subject area in health of current policy interest. Most are prepared in support of a specific NIH Consensus Development Conference, for which full text of a Consensus Development statement† also is available electronically in HSTAT (see above). The CBM entries are prime examples of how literature may be selected and organized to provide information to inform both health policy formulation and implementation. One CBM entry, completed in 1996 by a team led by NLM staff, covers *Confidentiality of Electronic Health Data: Methods for Protecting Personally Identifiable Information*. As stated in its opening section, electronic health data can improve the quality and efficiency of health care, research, and public health surveillance and interventions. From a policy perspective, the authors make it clear that, to achieve these benefits without unacceptable risk to patient confidentiality, electronic health data must be created, used, transmitted, aggregated, and abstracted in ways and in environments that maintain data security and accuracy; prevent inadvertent or accidental release; prevent or deter access by unauthorized users; and discourage, detect, and punish inappropriate use of health data by unauthorized users. This selective bibliography includes 448 references to publications, organizations, and electronic sources dating from January 1990 to March 1996 that address methods for preserving the confidentiality and security of electronic health data. The methods covered include technical approaches, institutional policies and procedures, staff and patient education, and legal and regulatory requirements. In addition to substantive discussions of measures for preserving confidentiality and security of health data, the bibliography also has references to some recent standards and guidelines that apply to electronic data in general.²⁰

In conjunction with, but not in time for inclusion in, this bibliography, NLM commissioned and was the principal funder (in collaboration with the Warren Grant Magnuson Clinical Center of the National Institutes of Health and the Massachusetts Health Data Consortium) of the National Research Council study, *For the Record: Protecting Electronic Health Information*.²¹ In addition to a review of the literature, the study involved site visits to organizations that had demon-

*Additional information on NLM's Current Bibliographies in Medicine series may be accessed at <http://www.nlm.nih.gov/pubs/resources.html>.

†These guidelines or policy statements and technology assessments address controversial issues in health important to providers, patients, policymakers, payers, and the general public. Additional information on NIH's Consensus Development Program may be accessed at <http://odp.od.nih.gov/consensus>.

strated leadership in developing health care applications of information technology to gather data on best practices for safeguarding electronic health data. The study's recommendations should assist those implementing the HIPAA security requirements, as well as any organization responsible for electronic health information.

EPIDEMIOLOGIC SURVEILLANCE OF MEDICARE QUALITY OF CARE

Peer Review Organizations (PROs) are for-profit or nonprofit organizations of practicing physicians, osteopaths, and dentists under contract to the federal government to monitor the care given to Medicare patients. In every state, PROs decide whether care given to Medicare patients is reasonable, necessary, and provided in the most appropriate setting.²² In 1996, HCFA contracts with PROs included an agreement that "HCFA will provide epidemiologic surveillance reports and data to PROs on a regular basis. (Epidemiologic surveillance is the ongoing, systematic collection, analysis, interpretation and timely dissemination of health data to help guide *policy* [emphasis added], intervention, and evaluation.)"²³ Subsequently, in 1997, HCFA announced its Medicare Quality of Care Surveillance System, which is designed to provide information about inpatient and outpatient Medicare health care utilization. Using this information, HCFA's PROs are able to identify sentinel events of possibly deficient care and target health care quality improvement activities based on patterns and trends revealed in regular epidemiologic surveillance reports. These publicly available reports,* entitled *Quality Resume*, include quality-of-care measures based on HCFA data analyzed at the national and state-specific level.²⁴

IMPLEMENTATION OF HIPAA LEGISLATION

Among the purposes of the Health Insurance Portability and Accountability Act of 1996 (Pub L 104-191)† is "to improve portability and continuity of health insurance coverage in the group and individual markets . . . [and] to simplify the administration of health insurance." Perhaps because it is one of the most important portions of the law, DHHS has established a Web site‡ to provide continuous updates on implementation of the administrative simplification provision (Title II, Subtitle F, Sec. 262, Part C). This site includes links to the full range of related

*To date, only one of these has been released. To access *Quality Resume*, Number 1 (October 1997), go to <http://www.hcfa.gov/quality/qlty%2D3g.htm>.

†The text of Pub L 104-191 may be accessed at <http://thomas.loc.gov/bss/d104/d104laws.html>.

‡See <http://aspe.os.dhhs.gov/admsimp/index.htm>.

HIPAA legislative health policy information, such as the DHHS Implementation Plan, milestones in the process, hearings and other calendar events scheduled by the NCVHS on this topic, work in progress on which site visitors may comment, and frequently asked questions. It also provides a listserv* to which anyone may subscribe to receive e-mail notifications when any document (like a Notice of Proposed Rule-Making) is published and/or posted regarding the administrative simplification provision of HIPAA.

Perhaps one of the most controversial portions of the administrative simplification provision has to do with Unique Health Identifiers [Sec. 1173 (b)], in which it states that "the Secretary shall adopt standards providing for a standard unique health identifier for each individual, employer, health plan, and health care provider for use in the health care system."^{15,(p104)} The reasons for the controversy over possible policies on unique patient identifiers and a description of the importance of this provision are contained in a report,²⁵ *Analysis of Unique Patient Identifier Options*, prepared for the NCVHS.†

DISCUSSION

A recent Institute of Medicine report, *Information Trading: How Information Influences the Health Policy Process*, includes a number of common themes the authors identified as they developed case studies on the information driving major national and state health care initiatives.²⁶ Many of these are discussed in other presentations in this special forum section of the *Journal of Urban Health*. Of greatest importance to this presentation are (1) the explosion in the amount and sources of health policy information; (2) the increasing demand for speed in identifying and retrieving information; (3) the tendency of policymakers to rely on consultants, lobbyists, or information brokers; and (4) the idea that often what turns out to be important to the policy process is not the quality of the information, but rather the timing of when that information is obtained and used.²⁶ Therefore, this look at knowledge bases and search engines for health policy information has focused first on Web-based resources, so that the need for immediacy of information is more easily addressed, and second at Web resources from reputable purveyors of information, so that quality is at least implied. The challenge to users and producers of health policy information is to find the best ways to ensure speed of information availability without compromising information quality.

*See <http://aspe.os.dhhs.gov/admnsimp/lnotify.htm>.

†The text of this report may be accessed at <http://aspe.os.dhhs.gov/ncvhs/app0.htm>.

REFERENCES

1. Health policy; identifier: UI-D006291. MESH VOCABULARY FILE [database online]. Bethesda, Md: National Library of Medicine; 1998. Updated June 20, 1997. Accessed February 23, 1998.
2. Arenales D, et al. *Collection Development Manual of the National Library of Medicine*. 3rd ed. Bethesda, Md: National Library of Medicine; 1993:26-27.
3. National Information Center on Health Services Research, Related Health Services Research Web sites page. National Library of Medicine Web site. Available at: <http://www.nlm.nih.gov/nichsr/hrsites.html>.
4. Newman ML. Health statistics sources [monograph on line]. 3rd ed. Bethesda, Md: National Library of Medicine; updated July 12, 1997. Available at: <http://www.nlm.nih.gov/nichsr/stats/contents.html>. Accessed February 23, 1998. Paper copy available from: Michael L. Newman, Falconer Biology Library, Stanford University, Stanford, CA 94305; michael@krypton.stanford.edu.
5. Health Care Financing Administration. *Health Care Financing Review*. Washington, DC: US Government Printing Office; Summer 1979-. Health Care Financing Review: Annual Supplement, 1984-1992; Health Care Financing Review: Statistical Supplement, 1995-.
6. Health care financing review. Health Care Financing Administration Web site. Updated March 18, 1996. Available at: <http://www.hcfa.gov/pubforms/hcfrdesc.htm>. Accessed February 23, 1998.
7. Public Use Data Files. Health Care Financing Administration Web site. Updated February 23, 1997. Available at: <http://www.hcfa.gov/stats/pufiles.htm>. Accessed February 23, 1998.
8. Stats and data. Health Care Financing Administration Web site. Updated February 6, 1998. Available at: <http://www.hcfa.gov/stats/stats.htm>. Accessed February 23, 1998.
9. NCHS mission statement. National Center for Health Statistics Web site. Updated October 22, 1996. Available at: <http://www.cdc.gov/nchswww/about/mission/mission.htm>. Accessed February 23, 1998.
10. Directory by subject and survey. National Center for Health Statistics Web site. Updated August 28, 1997. Available at: <http://www.cdc.gov/nchswww/products/catalogs/subject/subject.htm>.
11. National Center for Health Statistics. *Health, United States, 1995*. Hyattsville, Md: Public Health Service; 1996. 328 pp.
12. National Center for Health Statistics. *Vital and Health Statistics*. (Series 1-24). Hyattsville, Md: Centers for Disease Control and Prevention, Public Health Service; 1963.
13. Published reports. National Center for Health Statistics Web site. Updated August 27, 1997. Available at: <http://www.cdc.gov/nchswww/products/pubs/pubd/netpubs.htm>. Accessed February 23, 1998.
14. Introduction to the NCVHS. National Committee on Vital and Health Statistics Web site. Updated May 5, 1997. Available at: <http://aspe.os.dhhs.gov/ncvhs/intro.htm>. Accessed February 23, 1998.
15. Health Insurance Portability and Accountability Act of 1996 (HIPAA), Pub L 104-191, 110 Stat 1936 (August 21, 1996).
16. Core health data elements: report of the National Committee on Vital and Health Statistics [monograph on line]. Executive summary, introduction. August 1996. National Committee on Vital and Health Statistics Web site. Available at: <http://aspe.os.dhhs.gov/ncvhs/NCVHSR1.HTM#Summary>. Accessed February 23, 1998.
17. Cahn M, et al. (National Information Center on Health Services Research and Health Care Technology). *Report on NLM Test of Access to Citations of HSR Literature in MEDLARS*. Bethesda, Md: National Institutes of Health, National Library of Medicine; November 1993. 54 pp.
18. About Thomas. Thomas—US Congress on the Internet Web site. February 20, 1998. Available at: http://thomas.loc.gov/home/abt_thom.html. Accessed February 23, 1998.

19. NASIRE Statesearch. National Association of State Information Resource Executives Web site. Updated July 20, 1997. Available at: <http://www.nasire.org/ss/index.html>. Accessed February 23, 1998.
20. Auston I, et al., compilers. *Confidentiality of Electronic Health Data: Methods for Protecting Personally Identifiable Information*. (Current bibliographies in medicine; CBM 95-10). Bethesda, Md: National Library of Medicine; 1996:1. Electronic version available at: <http://www.nlm.nih.gov/pubs/cbm/confiden.html>.
21. National Research Council. For the record: protecting electronic health information [monograph on line]. Washington, DC: National Academy of Sciences; 1997. Available at: <http://www.nap.edu/readingroom/books/for/>. Accessed February 23, 1998.
22. Peer Review Organizations Directory. Health Care Financing Administration Web site. Updated September 9, 1998. Available at: <http://www.hcfa.gov/quality/docs/prodir.htm>. Accessed October 15, 1998.
23. Dicker RC, Ordian DL, Han LF, Campbell MK. Introducing the Medicare quality of care surveillance system. Quality Resume, no. 1. Baltimore, Md: Health Care Financing Administration; 1997:1.
24. Medicare Quality of Care Surveillance System. Health Care Financing Administration Web site. Updated February 3, 1998. Available at: <http://www.hcfa.gov/quality/qity%2D3g.htm>. Accessed October 15, 1998.
25. Appavu SI. Analysis of unique patient identifier options: final report prepared for the Department of Health and Human Services [monograph on line]. National Committee on Vital and Health Statistics Web site. November 24, 1997. Available at: <http://aspe.os.dhhs.gov/ncvhs/app0.htm>. Accessed February 23, 1998.
26. Lewin ME, Lipoff E. *Information Trading: How Information Influences the Health Policy Process*. Washington, DC: National Academy Press; 1997:3-4. Also available at: <http://www.nap.edu/readingroom/records/0309057930.html>. Accessed February 23, 1998.