Healthcare Data Forum Discussion Paper

Findings and Recommendations: A Collaborative Effort of Stakeholder Groups Involved with Healthcare Data in Maine

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Executive Summary

A group of healthcare professionals has been meeting for several months to discuss the current status and future of healthcare data in Maine. This discussion paper summarizes the discussions at the meetings, input from professionals in the field, and feedback from interested parties such as employers, groups representing consumers, etc.

This paper is not intended to be all inclusive. Many more months could have been spent conducting in-depth inventories of all the data sources and potential uses. This paper is simply a start. It has brought representatives of very different organizations together to collectively discuss the issues and to collaboratively identify a list of next steps for data activity in Maine.

The following next steps identified by the group have not been endorsed by their respective organizations. It is hoped that each of the organizations will use this discussion paper for input to their strategic planning for healthcare data initiatives. The group has decided to continue to meet to discuss the identified next steps and potential action plans for different parties to adopt.

The following next steps have been categorized by the major data topics identified in the discussions by the group.

GENERAL RECOMMENDATION

Principal organizations involved with health data should collaborate in making data available and useful. Efforts should be made to allow flexible access to data and provide technical support and analytical assistance.

CONFIDENTIALITY

1. As patient privacy regulations go forward, legitimate data users will need to collaborate on reviewing legislation to protect against the elimination of current data sources for appropriate third party use.

HEALTH STATUS AND BEHAVIOR

- 2. Efforts need to be made to collect data on indicators of health status for the population of Maine that can be used for surveillance, planning, and evaluation at all geographical levels including but not limited to communities.
- 3. The Behavioral Risk Factor Surveillance System (BRFSS) survey statistical sampling of the Maine population should be modified to allow users to obtain meaningful and reliable data for specific geographical areas and demographic groups in Maine.

4. A central listing should be developed to assist employers in selecting wellestablished and certified health promotion programs and materials for their work sites and communities.

DATABASES AND INFORMATION SUPPORT

- 5. Environmental data that relates to health outcomes should be housed in a data warehouse environment for easy access by users focussing on linking environmental indicators with health care utilization and outcomes.
- 6. All licensed, certified, or registered health professionals should answer a survey about their practice activity whenever they obtain a renewal. The State should collect and report on trends in the supply of specific professionals by geographical area in Maine.
- 7. An inventory of the infrastructure of the Maine healthcare delivery system should be conducted to provide an accurate account of the services and provider supply by area to assist in planning for shortages and/or a more efficient delivery system.
- 8. Although provider utilization databases have been mandated for many years in Maine, the timeliness of the data reporting and availability is of concern. Efforts should be made to guarantee the timely compliance of data reporting by providers according to required mandates.
- 9. More efforts should be made to educate users about the statewide long-term care database and its applications.
- 10. The feasibility of collecting claims encounter data from health plans, insurers, third party administrators, and governmental programs on a statewide basis to create an all setting and all payer database should be pursued.
- 11. Efforts should be made to obtain data on all providers delivering outpatient type services to provide a more comprehensive market share and planning database.
- 12. It would be worthwhile to adopt an approach for standardizing the composition of Maine geographical analysis areas with an annual review process including an "official" endorsement of the standard areas for use in analyzing data for specific geographical areas.

CONSUMER

13. Collaborative efforts should be made to work with Maine professional associations, clinical groups, and health plans to identify the best and most widely used clinical quality and outcomes measures. Once identified, there should be an effort to provide this information to consumers in a user-friendly manner that is fair and respectful of providers of care.

- 14. In addition, there is a need to identify highly reliable web sites for access by consumers and others to identify best practice outcomes and quality indicators so consumers and providers are accessing the same information when they discuss experience and expectations. These efforts should result in linkage with Maine web sites directing the user to the statewide, regional, and national data.
- 15. Efforts should be made to establish a meaningful source of patient satisfaction data that can be shared with consumers. Efforts should be made to identify common measures across all providers that can be utilized by providers for continuous quality improvement and for purchasers and consumers to use when choosing health plans and providers.
- 16. Criteria for evaluating best practice by providers and health plans should be reviewed and agreed upon as a statewide initiative.
- 17. The Maine healthcare community should keep informed of federal funding opportunities to develop demonstration projects focussing on patient safety.

COST

- 18. Efforts should be made to generate an annual health expenditure report including categories such as hospitals, physicians, dentists, other professionals, drugs, nursing home care, and other health services. The report should include per capita estimates using annual population estimates generated by the state. In addition, a system for capturing the cost of the components of the delivery should be developed using standard definitions and comparable categories.
- **19.** Efforts should be made through the Bureau of Insurance to identify Maine-only costs by insurance companies including administrative costs.

Introduction

The Maine Health Information Center (MHIC) is a non-profit healthcare data organization with a mission to promote informed decision making by designing, managing, and analyzing timely, high quality, integrated healthcare databases. The following organizations are represented on the MHIC Board.

| Maine Hospital Association | Maine Osteopathic Association |
|-------------------------------------|-----------------------------------|
| Maine Medical Association | The Bingham Program |
| Medical Care Development | CIGNA HealthCare of Maine |
| Maine EMS | MaineHealth |
| UNUM Provident | Department of Human Services |
| Anthem Blue Cross | Maine Health Management Coalition |
| Maine Medical Assessment Foundation | C |

Each year the MHIC reviews the healthcare data environment in Maine to develop a strategic plan for the following year. With the Y2K activities, the rapid development of Internet applications, and the increased demand for data, the MHIC determined the need for this type of planning was even more important this year.

In February 2000, the MHIC senior staff presented to the MHIC Board of Directors the following list of external factors they had identified as potentially influencing the future of healthcare data collection and use in Maine.

• Technology

With the introduction of the Internet, advanced systems for connectivity among different groups, and new federal regulations for data formats, the following factors were identified.

- Electronic/web based reporting of data.
- HIPAA regulations mandating uniform formats and definitions for administrative data including claims, UR certification, eligibility queries, etc.
- Office-based patient centered care (knowledge couplers, computerized medical records, etc.) providing a computerized patient specific integrated database for office care.
- Internet products and systems allowing for telemedicine, on-line consultations, e-mail communication, etc.
- Enhanced technology that provides large capacity for database storage and linkage across multiple databases.
- More timely, quickly retrievable data will be available as a result of the technology thereby enhancing the usefulness of data output.
- Consumers will have more access to a wide range of healthcare information.

• New/Enhanced Types of Data

Various parties are identifying new data needs. These new data interests will influence the focus of data collection systems as modifications are made to existing systems or new systems are established.

- Increased demand for consumer information that is easily understood and relevant.
- Increased pressure to measure quality of care and efficiency of providers.
- Need to use quality measures to make purchasing decisions.
- Increased need for community based data.
- Health status measurement to be used for planning and evaluating populations.
- Expanded data reporting clinical indicators, etc. to provide more robust data related to the complete spectrum of care.

• Confidentiality/Access

As new privacy rules and regulations are adopted, access to detailed data by appropriate parties may be jeopardized. Data users, researchers, and others will need to educate the public and policy makers on appropriate use, confidentiality agreements, and standard restrictions on third party use.

- HIPAA regulations on patient privacy and confidentiality.
- Maine patient rights and privacy legislation.
- Insurance code legislation for health plans.
- Increased affiliations among delivery systems: integrated and linked databases that will be considered proprietary.

• Resources

New resources are being developed by parties collaborating to share costs related to data collection and use. At the same time, other resources are being decreased or eliminated to support data.

- Purchasing alliances are being discussed in Maine that will create a collaborative initiative with specific data needs.
- Collaboration of parties to use and disseminate information such as MHMC contributing data to support the Healthy Lung Indicators adopted by the American Lung Association of Maine.
- Decreased opportunities to conduct outcome studies that require the participation of primary care offices given their financial restrictions and demanding administrative functions for managed care purposes.
- Decreased Maine based employers reduces the participation of these employers in Maine specific healthcare and healthcare data issues.

• Lack of funding to support data activities is an on-going issue but becomes more of an issue as data needs are publicly identified by key policy makers in Maine.

In response to these issues, the MHIC Board discussed the need to develop a vision for the future of healthcare data in Maine over the next three to five years. Several members of the MHIC Board thought other groups in Maine might be addressing the same issues. The MHIC Board asked the staff to sponsor and coordinate a forum of interested parties and experts to jointly address the different categories of data needed, identify the current status of data collection, and develop objectives for the future of healthcare data in Maine. The Board intended that the results of the forum activity contribute to discussions regarding health data in any statewide plan, provide direction for individual organizations and initiatives developing strategic plans for data activity, and promote collaboration among parties.

Healthcare Forum Process

Starting in the spring 2000, the MHIC staff scheduled five meetings of stakeholders to come together to discuss healthcare data in Maine. Ted Rooney was hired as facilitator to conduct the meetings and the following individuals participated in at least one of the meetings.

Warren Bartlett - Department of Human Services, Bureau of Health Paul Campbell – Center for Public Health Devore Culver – Eastern Maine Healthcare Julie Fralich - Muskie School Terry Garrett - Anthem Blue Cross* Frank Johnson – State Employee Group John LaCasse - Medical Care Development, Inc.* Doug Libby - Maine Health Management Coalition* Catherine Longley - Bureau of Insurance Mary Mahew - Maine Hospital Association* Greg Michaud – Anthem Blue Cross* Ed Miller – American Lung Association of Maine Kellie Miller - Maine Osteopathic Association* Susan Payne – Muskie School Bill Perry - CIGNA HealthCare of Maine* Rod Prior – Franklin Memorial Hospital Alan Prysunka – Maine Health Data Organization Linda Riddell - Public Health Resource Group Jeff Sanford – Eastern Maine Healthcare Gordon Smith - Maine Medical Association* Kathy Stuchiner - Maine Hospital Association* David Wennberg - Maine Medical Assessment Foundation* Diana Friou - City of Portland, Public Health Department Brian Pearson – Maine Health Information Center Suanne Singer – Maine Health Information Center Alice Chapin – Maine Health Information Center *Member of the MHIC Board of Directors.

Scope of the Forum

The forum members discussed and developed the following language to describe the intent of the forum activity and the goals for healthcare data currently and in the future.

• Intent of the Healthcare Data Forum

The group reviewed the general intent for the forum as stated by the MHIC Board and identified the following statements as the intent they thought was meaningful and collaborative.

- To invite interested parties and experts to jointly address the different types of data wanted by healthcare stakeholders.
- To begin to identify the current status of data collection.
- To develop principles for the future of healthcare data in Maine.
- To provide the findings of the forum as a contribution to discussions regarding plans for the collection and use of healthcare data.
- To assist in providing direction for individual organizations and initiatives developing strategic plans for data activity.
- To support data systems that serve clinical, administrative, and public health purposes.
- To promote collaboration.

The forum members also explicitly stated that they were not recommending specific policies, legislative action, nor speaking for the organizations whose members participated in the forum.

• Healthcare Data Principles

The forum members discussed and agreed upon the following principles for healthcare data.

- Data systems should take advantage of new technology.
- Disclaimers on what data can not do should be attached to data sources.
- Data should be affordable to collect and use.
- Efforts should be made to standardize data.
- Data systems should meet user needs.
- Data should be timely and of high quality.
- Data should allow for measurement, evaluation, and accountability.

Data Users and Questions They Have

At the first meeting of the forum, the facilitator asked the members to identify who the customers/users of the data were in Maine, what type of information do these customers want, how do they want to receive it, and what data currently exists to create that information. A member of the group provided an interesting picture of the overlapping and separate users of data. (Attachment I). The overlapping circles clearly demonstrate how inter-connected some of the data needs are among the various groups.

The forum members identified the following groups and some of the questions they thought these groups were trying to answer.

Consumers

The forum members thought this group was becoming increasingly assertive about wanting data and information that could be easily understood by the average lay person trying to deal with the healthcare system. Even though no direct consumers participated in the forum, the group was able to access some excellent work by the Foundation for Accountability and the California Healthcare Foundation. They each conducted an extensive series of focus groups with consumers over the last year addressing what type of health information they wanted and would use. Some of the questions consumers want to answer are:

- What will increase my quality of life the most?
- If I need medical treatment:
 - What is the best treatment?
 - Who is the best doctor?
 - Which is the best hospital?
- What is the most cost-effective plan/provider to use?

• Purchasers

The forum members defined purchasers as employers, associations (e.g. MEA), and governmental purchasers (e.g. Medicaid, HCFA). They recognized that through the Maine Health Management Coalition and other initiatives, employers have become more active in recent years in wanting and using data to evaluate the value of healthcare services and benefit designs. Employers are also addressing outcomes, quality of care, and return on investment for preventive services. The group thought the employers were asking:

- What is the best value for our company/employees?
 - patient safety
 - clinical quality
 - functional outcome
 - consumer satisfaction with providers
 - provider satisfaction with health plans
 - cost
 - health plan performance

- efficiency of delivery system regarding return to work and ability of employer to compete in the marketplace.
- How does benefit design impact access to care and outcomes?

• Providers

Several hospital and physician representatives participated in the forum. They thought providers were asking the following questions most often:

- What is the health status of the population served?
- What are the medical/health services needed by the populations in my service area(s): regional and local?
- What facilities/programs can I provide that will be more cost effective?
- What can I do to maintain and increase my market share?
- What are the quality, outcome, and satisfaction indicators for services provided?
- How can I provide cost efficient, high quality care?

• Government/Private Organizations

This group was comprised of regulatory state agencies, community coalitions, healthcare advocates, voluntary health agencies, educational institutions, public health groups, and non-profit programs. The forum members thought they were trying to answer the following questions:

- What is the health status and behavior of population served?
- What are the health data needs of the area population?
 - state
 - regional
 - local
- What policies/programs are needed to serve and protect the public?
- What programs are needed to improve the health of the population?
- What facilities/manpower are needed?
- What programs/policies are most effective/efficient?

• Insurers/Fiscal Intermediaries

Different insurers have different questions. However, most agreed that the following questions represent the major types of questions asked:

- Who are the most efficient providers in Maine who render high quality care at efficient prices?
- What are the healthcare needs of the people in Maine?
- How do Maine healthcare costs compare to other states, regions and nationally?
- What support services assist in providing more comprehensive services and care in Maine?
- Do the people of Maine have adequate and appropriate access to care?

• Researchers

This group is responsible for developing valid and reliable research projects to address the questions identified by each group.

Although some of the questions are different, many of the groups identified above are looking for the same types of data (e.g. cost, quality, satisfaction, etc.) It is thought that all of the groups are interested in obtaining reliable information to promote improvements in many of the same areas.

Framework for Data Collection in Maine

The forum members developed a one page graphic (Attachment II) to identify the framework for data collection in Maine. They identified three categories for the framework: users, information, and data. The intent was to develop a one-page overview recognizing that more circles could be added for each category but this graphic represented the majority.

Users represent the spectrum of groups that are asking for information as they go forward with managing programs, developing policy, measuring effectiveness, evaluating impact, and planning for future policy and system changes.

The information section identifies the different types of data needed by the users. The information categories encompass the needs of the different users listed above in the graphic

The bottom section starts to identify what data are available or should be available to address the information needs. The forum members agreed early on in their meetings that just building new or expanded databases would not meet the needs of the users. Data needs to be converted to information to be useful in the decision making process.

It was not always clear as to how various categories should be labeled (e.g. patient satisfaction may mean something different to different groups). Also, it was not always evident what data elements would be needed to provide the identified information to the groups (e.g. patient safety is probably more dependent on identifying safe systems of care rather than just a count of the number of medical errors).

DATA ASSESSMENT

The MHIC staff met with several healthcare data professionals to develop a format for a data inventory. The format adopted was to use the categories of data as identified by the group, identify some of the informational needs in that category, and then comment on the available data to provide that information. Some information needs are stated as specific data elements/indicators while others are identified as questions. Several forum members thought a more formal data inventory might be the next phase of work.

This format lends itself to more of an assessment rather than a single dimension inventory. The next section of this report provides the results of the assessment. The assessment focuses on the following categories developed by the MHIC staff with input from the forum members.

> Demographics Health Status Health Behaviors Public Health Environmental Resources Health Personnel Utilization & Access Market Share Outcomes & Quality Patient Safety Patient Satisfaction Best Practice Cost

It is the intent of this assessment to only highlight indicators. It is recognized that each discussion could be significantly expanded given additional time and resources.

There are some common themes across many of the different categories. Much of the information needs to be population based for easy comparison within Maine and to other parts of the country. There are data that can be obtained at the level of census tract, hospital service area, county, regional, and state levels. It is important that data be obtained at the demographic detail level consistent with planning needs. Data also needs to be obtained over time to allow for trends analysis. The Maine data needs to be comparable to best practice benchmark data available from various national and regional groups.

The data collected and used must be compliant with confidentiality rules and patient identification must be respected at all times.

DEMOGRAPHICS

Information Needs

- Percentage of the population that live in rural vs. urban areas
- Percentage of males and females by age categories
 - working population
 - elderly population
 - children
- Per capita income by
 - town/comparative towns, aggregate areas
 - age categories by town, aggregate area
 - median household income by town, aggregate areas
 - low income households (federal poverty thresholds) by town, aggregate area, state
- Dependent ratios (% of dependent age population young & old to working-age population) by
 - town/comparative towns, state
- Households
 - by type (single, married couple, etc.) by town, aggregate area
 - with children
- Education attainment
 - by town, aggregate area, state
- School enrollment
 - by school type by town, comparative towns, aggregate areas, state
- Employment status
 - unemployed, employed, not in labor force by town, comparative town, aggregate area, state
 - female labor force with children, with no children
- Households by persons per unit
 - by town, comparative towns, aggregate areas, state
- Population by standard racial categories by town, state, U.S.
 - percent of foreign born
 - percent by year of entry into the U.S.
- Insured/Uninsured population
 - Medicaid recipients
 - Medicare (age 65+)
 - commercially insured
 - uninsured
- Transient populations
 - seasonal migrants
 - part-time retiree residents

Data Sources

The Office of Data, Research and Vital Statistics develops population estimates on an annual basis. 1990 U.S. Census data are available from the State Planning Office and the U.S. Census Bureau. Data are available in a variety of formats and for selected data elements. However, resources are limited at the state agencies and data requests are not easily fit into the already large workload for these agencies.

The 2000 U.S. Census is being processed and should be available for public use in early 2001. The State Planning Office will also have preliminary data available. Data needs to be available at the level of minor town subdivisions to be meaningful for community assessment and planning.

The Maine Department of Education maintains school enrollment statistics by town on an annual basis. The statistics are available by the first of the calendar year for the current school year. The Office of Data, Research and Vital Statistics maintains some statistics on private religious school enrollment.

Local schools often maintain statistics on language minority students and special tutorial classes for foreign born students.

Local shelters for homeless can also provide statistics on local beds available and utilization numbers to provide another poverty indicator for towns.

Comments

There seems to be a fairly robust amount of data available on the demographics of towns. It is important that the data be collected and made available on the full range of demographic categories (i.e. lowest education level to highest). The data sources should allow for cross tabulation of information such as asthma death rates by income level. Since most of the data are zip code based, it can be aggregated into groups of towns and by the state total. However, zip codes may not provide the meaningful local population estimates needed for minor subdivisions. The 2000 Census data will provide timely information and the new data can be compared to the 1990 census to identify trends that may not have been available through updated estimates. Data needs to be housed in a data warehouse environment with flexible access by appropriate users. This approach to data use would also lessen the burden on state agencies that now deal with data requests in an ad hoc manner.

HEALTH STATUS

Information Needs

- Birth rate
 - percent of live births/ low birthweight
 - infant mortality rate per 1000 live births
 - percent of women with live births who obtained prenatal care in the 1st trimester
 - teen pregnancy rate, women 15 17 years (per 1000 pregnancies regardless of outcome)
- Communicable Diseases
 - AIDS mortality rate
 - AIDS/HIV prevalence and/or incidence by age, gender, and mode of transmission
 - chlamydia incidence rate
 - gonorrhea incidence rate
 - primary and secondary syphilis incidence rate
 - hepatitis
- Chronic Disease (Population-based utilization, prevalence, survival, and mortality rates)
 - cancer
 - heart disease
 - cerebrovascular disease
 - chronic obstructive pulmonary disease
 - diabetes
 - cirrhosis
 - asthma
 - percent of adults who currently smoke cigarettes
 - percent of high school students who currently smoke
 - percent of adults at risk of health problems related to being overweight(using BMI)
- Immunization of kids
 - percent of kids receiving the full 4:3:1 series
 - immunization rates for children of 24 months
 - high rate areas vs. low rates
- ♦ Injury
 - unintentional injury mortality and hospitalization rates
 - motor vehicle-related mortality and hospitalization rates
 - alcohol or motor vehicle related mortality and hospitalization rates
 - state police crash data on motor vehicles accidents
 - firearms-related mortality and injury rates
 - fall-related mortality rate
 - number of ambulance transports by type of injury, location, and destination
- Mental Health
 - suicide mortality rate by age and sex
 - percent of adolescents committing injurious suicide attempts

- percent of adults reporting their mental health was not good for 3+ days in the past month
- claims data for utilization including Rx and episodes of care
- Employer Disability Data
 - workers compensation claims
 - short and long-term disability claims
 - sick time and other health-related absenteeism
- Social Security Disability Data
- Occupational Data
 - Injuries
 - Diseases
 - Deaths

Data Sources

Office of Data, Research and Vital Statistics maintains the vital statistics data files that provide all birth and mortality specific data. Some statistical work needs to be done to develop accurate town or area rates for selected indicators. Reports can be generated or copies of data files may be obtained with certain confidentiality restrictions on identifiers for individuals.

The HARS (HIV/AIDS reporting system) maintained by the Maine Bureau of Health maintains statistics by town. Although the individual identification is protected, statistics can be obtained on incidence.

The Bureau of Health maintains other communicable disease databases for reporting to CDC. Statistics may be obtained from these databases. The CDC website is also a resource for conditions by state.

The Office of Data, Research and Vital Statistics maintains the mortality data for chronic disease. Utilization rates for hospitalizations can be obtained from the Maine Health Data Organization or the Maine Health Information Center.

The Office of Data, Research and Vital Statistics maintains a CODES file that provides information on motor vehicle related injuries and use of seatbelts/helmets.

The Office of Emergency Medical Services (EMS) provides data on ambulance transports by type of injury and type of transport. The hospital discharge database is also a source of data related to hospitalization for injuries.

The Maine Department of Labor collects and reports on occupational disease and deaths on an annual basis.

The Youth Risk Behavioral Surveillance System (YRBSS) also maintains statistics on youth behavior that can be aggregated to the state.

The Bureau of Health maintains the cancer and immunization registries that report on incidence. Data is available from these registries for research and policy planning purposes.

Comments

The Office of Data, Research and Vital Statistics and the Bureau of Health provide the best data available on health status, but the data are still fairly limited for community based use. *Efforts need to be made to collect better data on the health status of the population of Maine regarding indicators of health status, i.e. prevalence of chronic disease, etc.*

With the new patient privacy rules, it may become more difficult to obtain electronic copies of cancer registries even with identifiers excluded. *As patient privacy regulations go forward, legitimate data users will want to collaborate on reviewing legislation to protect against the elimination of current data sources for appropriate third party use.*

HEALTH BEHAVIORS

Information Needs

- percent and rates per capita of people, 18 yrs. + who have had their cholesterol checked within the past 5 years
- percent and rates per capita of people, 18 yrs. +, who have had their blood pressure checked within the past 2 years
- percent and rates per capita of 19–35 month olds who are fully immunized
- percent and rates per capita of women, 50+, who have had breast exam & mammogram within the past year
- percent and rates per capita of adults, age 65+, who were immunized for influenza within the past year
- percent and rates per capita of adults, age 65+, who have ever been immunized for pneumococcal
- percent and rates per capita of adult smoking
- percent and rates per capita of youth smoking
- percent and rates per capita of perinatal smoking
- percent who used substance in the past 30 days
 - -Adolescents Alcohol Marijuana Binge drinking - Young adults Alcohol Marijuana Binge drinking
- HEDIS indicators for screening services, e.g. colon cancer, etc.
- Sexual Risk Behaviors (SRBs)
- Percent of population
 - Exercising
 - Using seat belts
 - Overweight
 - Meeting recommended dietary guidelines

Data Source

Sources for the utilization of preventive services are the Behavioral Risk Factor Surveillance System (BRFSS) and CDC. Other proprietary sources are claims data maintained by the health plans and the Maine Health Management Coalition. Collaborating researchers may request aggregate data from MHMC.

The Maine Pregnancy Risk Assessment Monitoring System (PRAMS) is a populationbased risk factor surveillance system designed to identify and monitor selected maternal behaviors. PRAMS captures data on prenatal and postpartum behaviors, e.g. cigarette smoking, alcohol use, nutrition, use of prenatal care, etc. The Office of Substance Abuse survey results are reported in Substance Abuse Prevention: Maine's 1997 Data Report.

The HEDIS indicators are reported by the health plans. National health plans do not identify the individual states when reporting their indicator rates. The plans in Maine may maintain the statistics for Maine, but it is unclear if the statistics would be available for public use.

The Youth Risk Behavior Surveillance System (YRBSS) data for Maine is not statistically adjusted for the age and sex demographics of the Maine youth and therefore not comparable to the national data. More efforts need to be made on a state level to process this data for comparability.

Comments

The BRFSS survey is based on a limited sample according to some users. *The BRFSS* survey should be expanded to provide a larger sample and more reliable data for projection for specific geographical areas in Maine.

Indicators related to smoking, substance use, and utilization of preventive services do provide some indication of the health status of Maine's population. The data become less useful for projections to specific communities or clusters of towns. The Healthy People 2010 goals will also provide new indicators that should be reviewed and adopted with performance data for Maine.

ENVIRONMENTAL

Information Needs

- ♦ Blood lead levels exceeding 10µg/dl among children 6 mos 6 years
- Proportion of homes tested for radon
- Water quality
 - drinking water
 - percent of lake areas suitable for swimming
 - miles of river unsuitable for fish consumption
 - numbers of acres of estuarine areas not suitable for shellfish harvesting
- Air quality in Maine
 - annual number of days with unhealthy air quality
 - use of toxic materials in manufacturing in Maine

Data Sources

The National Health and Nutrition Examination Survey is a source for statewide data on lead testing. Using a statistical methodology, estimates can be calculated based on the U.S. census data for children populations.

The Bureau of Health maintains statistics on radon testing of households in Maine.

The Maine Geological Survey, DEP, and the Bureau of Health all maintain various databases related to water supply contamination. Linking of water supply contaminant data to health status/demographic data for a population provides an excellent source of health related environmental data.

The Maine Department of Environmental Protection and the State of Maine Water Quality Assessment 1998 provide statistics on the quality of lake water. The Maine Department of Marine Resources collects and maintains statistics on fish and shellfish health as it relates to water quality.

The Maine Department of Environmental Protection, Bureau of Air Quality Control and the Office of Innovation and Assistance maintain data on air quality related to groundlevel ozone. Toxic substances are defined by the federal government and include phenol, chlorine, propylene oxide, and hydrogen chloride. Reporting on the use of these toxics is maintained on approximately 128 Maine companies.

In 1998 the Maine Indoor Air Quality Council was established to promote a better quality of life and increased productivity through improved indoor environments. Indoor air issues are crosscutting through many settings (work, school, and home). The Council is working towards maintaining meaningful data on air quality in different settings.

Comments

Obviously, there are many more indicators that could be listed for environmental health and factors. For example, there are ambient air pollutant data collected and analyzed throughout the state as well as environmental release data. There are also fish data (e.g. mercury, dioxin), hazardous waste/petroleum contamination site data, etc. It is important that healthcare encounter data be connected to environmental data for potential correlation. For example, outbreaks of food poisoning, specific cancer rates, etc. need to be environmentally evaluated and possibly connected. This type of data will support the focus on prevention such as cancer screening and control initiatives. A more complete inventory type report would include many more categories of environmental data due to the importance of cross linking environmental data with health encounter data.

HEALTH PERSONNEL

Information Needs

- How many doctors (M.D.s and D.O.s) and nurses actually practice in Maine?
 - by town, aggregate area, statewide
 - full-time vs. part-time
 - in what setting
- What is the number of active providers in the following professions?
 - Dentists
 - Optometrists
 - LPNs
 - Medical Assistants
 - Chiropractors
 - Psychologists
 - Physical Therapists, Occupational Therapists
 - Physician Assistants
- Have there been any complaints about my doctor or has there been any disciplinary action against my doctor?

Data Sources

The physician, dentist, and dental hygienist licensing boards require applicants to complete a survey on their current level of practice and their educational background, specialty, etc. The licensing data alone are not a source for how many professionals are actually practicing in their profession. Often retirees and individuals not working in their licensed profession still maintain a license. For example, the M.D. licensing file contains a large number of physicians who do not practice in Maine. Without the additional survey data, there would be no way of determining the accurate number.

The National Practitioner Data Bank maintains a list of physicians who have made payments due to malpractice claims. This information can be accessed by eligible entities such as hospitals or health plans.

The licensing boards do maintain data on individual physicians who have been disciplined. They are providing that information to the public and some of the data are available on their web sites.

Comments

A critical component of information in addressing access to care and quality of care is to know how many providers are practicing in a specific area. Maine is unable to compile accurate numbers beyond the M.D. and D.O. survey data. All of the licensing boards maintain accurate mailing lists for all licensed individuals. *All licensed, certified, or registered health professionals should answer a survey about their practice activity whenever they obtain a renewal. The State should collect and report these data, including projections on where there is and will be unmet needs.*

ACCESS TO HEALTHCARE SERVICES

Information Needs

- percent of adults with no medical coverage
- percent of children <18 years old with no medical coverage
- percent of adults, without health care coverage, who have been without coverage for 5+ years
- Inpatient beds, out-patient services, LTC beds by community for Maine compared to national and regional benchmarks
- Average # of patients managed by PCPs and ER use
- Evaluation of EMS system coverage by geographical areas
- Disease prevention and health promotion services, i.e. nutritional programs, smoking cessation programs, etc.

Data Sources

The BRFSS data provides information on the uninsured that can be projected to community areas by using statistical methodologies. Bed supply can be obtained from the DHS facility licensing divisions. There is some discrepancy between licensed beds and used beds. The Maine Hospital Association can provide some data on staffed beds. However, the best source of information is the facility itself for specific time periods. For example with the low unemployment and labor shortage this past summer, many LTC beds were not staffed and therefore not available.

Health plans have a wealth of information on services that are covered by health insurance programs. Each insurer uses its own coding system to identify providers. The Maine Health Information Center in collaboration with the Maine Health Management Coalition has developed a master provider file linking the insurer specific provider identifications to a statewide master file. This file contains all providers who are reimbursed for a service in Maine. The health plans also maintain membership files that record the PCP for all members enrolled in managed care plans. These statistics can provide the average number of commercially insured patients managed by PCPs that can be compared by area and correlated with ER use to determine adequate primary care coverage of a given population.

DHS does license facilities, clinics and programs. The data maintained by DHS could provide the preliminary information for an infrastructure inventory.

Maine EMS maintains an excellent database on all ambulance transports (emergency and routine) in Maine. The data on each transport includes response time, injury type, limited clinical data, and destination and transport time.

Comments

The BRFSS data has been addressed in other sections. The data from this survey has multiple uses and with its expansion, more reliable analysis could be conducted on the status of community populations.

An inventory of the infrastructure currently in place in Maine could be helpful for planning purposes. The area by area comparison could identify areas with shortages. The inventory could also be compared to national and regional benchmarks to determine if certain areas in Maine are under-served. *An inventory of the infrastructure of the Maine healthcare delivery system should be conducted to provide an accurate account of the services and provider supply by area to assist in planning for shortages and/or a more efficient delivery system*.

MHMC employers have asked for assistance in selecting best practice programs for promoting health at their work sites. It would be helpful to have a central source of information on these services including contact persons, price, etc. *A central listing should be developed to assist employers in selecting well-established health promotion programs and materials for their work sites and communities.*

Maine Emergency Medical Services maintains licensure data on the level of EMS certified personnel by services and area. This data could be combined with other provider data in the infrastructure inventory.

UTILIZATION

Information Needs

- Hospital inpatient and outpatient utilization rates and trends for selected conditions by area and compared to regional and national benchmarks
- Out-patient ambulatory services by area
- Physician utilization trends
- Prescription drug utilization and trends for total utilization and for specific drugs
- ER utilization by area
- LTC utilization by level of care, by geographical area
- EMS utilization and evaluation of system performance

Data Source

The statewide hospital discharge data, ambulatory surgery data, and hospital-based outpatient data provide statewide information on utilization rates and trends. A unit record electronic copy of the database with restrictions on patient and physician identification is available from the Maine Health Data Organization to users on a quarterly basis. Outpatient data for hospital services is also available from the Maine Health Data Organization. The same confidentiality restrictions apply to the patient and physician identifiers. This data are the source for information on ER use, diagnostic testing and other outpatient services.

The national long-term care minimum data set is collected from LTC facilities. DHS and the Muskie School maintain these data. The database is available to researchers through DHS but the process is not well established and requests are handled on an individual basis.

Health plans have a wealth of information on utilization via their administrative claims databases. Internally they analyze the utilization experience for selected conditions compared to regional and national health plan data. The claims databases are for all settings and providers. The health plans also maintain membership files that identify the primary care physician for all members and their families enrolled in managed care plans.

The business coalition in Maine (MHMC) maintains a database of member data and claims for employers who belong to the coalition. The current claims files cover approximately 150,000 lives and include all members of the State of Maine group. The Medicaid claims database also has data on enrollees as well as claims activity. These data are housed at DHS, at the Muskie School, and at the MHIC where it is being used for output reporting to DHS and comparative analysis with the MHMC commercially insured population. Together these files cover approximately 300,000 lives.

Maine Emergency Medical Services maintains an excellent database on all ambulance transports (emergency and routine) in Maine. The data on each transport includes response time, injury type, limited clinical data, destination and transport time.

BRFSS collects utilization data on selected procedures such as mammography, Pap smear, hysterectomy, colon and prostate cancer screening, and skin cancer screening.

Comments

The hospital-based reporting systems have been long standing in Maine. The timeliness of the reporting has been of concern over the past two years. These data are very valuable in assessing utilization trends in a timely manner. *Efforts should be made to guarantee the timely compliance of data reporting by providers according to required mandates.*

The MDS+ long term care database is a very large patient specific database that is not widely used beyond DHS and the Muskie School. The database contains demographic data elements as well as functional data based on activities of daily living (ADL). The lack of use of this data may be the result of lack of understanding of the availability of the data and its applications. *Effort should be made to educate users about the LTC MDS*+ *database and its applications*.

Although health plans have a wealth of data, most of it is considered proprietary and therefore not available to external users. The Maine Health Management Coalition receives claims data from a wide variety of insurers and processors. The release of that data to other parties is governed by the MHMC Confidentiality Policy and by individual agreements with some of the health plans. *Potential users of the data may want to meet with the largest health plans in the state to identify information needs and determine if the health plans can release non-proprietary information for appropriate use.*

MARKET SHARE

Information Needs

- What populations are being served by which providers including hospitals, mental health providers, dentists, and others for what conditions?
- Are tertiary hospitals receiving primary care cases from the local community areas?
- Where are communities going for care beyond hospital care?
- Where are hospitals and other providers providing outpatient services?
- Where are the specialists and what is the market share for these services?
- How is market share changing given mergers and affiliations by providers?
- What areas are used to assign market share on a statewide basis?

Data Sources

The statewide databases collected by MHDO are all zip code based for individuals. These data allow groups such as the MHIC, MCD, PHRG, and others to aggregate the data into service areas and identify the number of people from the area using the local hospital for services vs. other hospitals in the state. Hospital specific data are available to the public with notification requirements to the hospitals prior to releasing identifying data.

Outpatient data will also provide the same type of population-based analysis for all services provided by hospitals.

There are several systems for aggregating individual towns into service areas. The hospital service areas are used by most hospitals for statewide analysis. The Bureau of Health recently released 30 community service areas. There are also primary care service areas and school districts. The tables for building these areas can be obtained form MHDO, MHIC, DHS/ Office of Primary Health Care, and others.

Comments

Except for the timeliness issue and non-compliance of a few hospitals, the statewide hospital-based databases are excellent. The problem is with outpatient services. Non-hospital facilities performing ambulatory type procedures identified by a list are required to report on those cases. It has been a difficult job to identify these facilities and to motivate them to comply with the data reporting requirements. The other problem is many of the services provided by hospitals in the outpatient setting are now also provided by freestanding facilities that have no data reporting requirements. This lack of data on other facilities limits the value of the market share analysis for certain outpatient services. *Efforts should be made to obtain data on all providers delivering outpatient type services*.

There are multiple aggregation approaches for the service areas in Maine. Some are more standard and widely used. *It would be worthwhile to adopt an approach for standardizing the composition of Maine geographical areas with an annual review process including an "official" endorsement of the standard areas.*

OUTCOMES & QUALITY

Information Needs

- How well do people do when they have a particular treatment?
- Are people receiving good quality care?
- How do the outcomes compare by treatment and by provider?
- What percentage of admissions to Maine hospitals are deemed avoidable based on published methodologies?
- What percentage of Maine hospital admissions is preventable given timely ambulatory care?
- Is Maine experiencing the best outcomes and quality of care compared to others?

Data Sources

Nationally there have been many studies published by the Agency for Healthcare Research and Quality (AHRQ – formerly AHCPR). The Maine Medical Assessment Foundation has conducted several outcome studies in areas such as prostatectomy, hysterectomy, carpal tunnel, low back pain, etc. The results of these studies have been published in professional journals. The prostatectomy data have been incorporated into a computerized interactive patient decision making system.

Other groups in Maine have been or are involved in conducting project specific outcome studies. MCD has been involved with cardiovascular outcomes, the MHIC is conducting a depression Nurse TeleCare project, and the Bureau of Health is conducting a comparative study on diabetes care.

In addition, a private employer working with the New England Medical Center conducted functional health status and productivity studies in recent years, documenting the effect of medical treatment on functional health status and productivity.

There are conditions that have been identified as avoidable hospitalizations in the literature. These conditions are coded as ICD-9 that can be identified in the Maine hospital discharge data. Some work has been done by the MHIC, MMAF, Muskie, and others to review variations in Maine by hospital service area.

Hospitals and many other healthcare organizations undergo inspection by either the Joint Commission for Accreditation of Hospitals (JCAHO) or the American Osteopathic Association for accreditation. JCAHO accreditation information is publicly available through the JCAHO website (www.jcaho.org) and the AOA accreditation information is publicly available through the AOA website (www.aoa_net.org). As part of the JCAHO and AOA accreditation process, organizations are required to engage in performance measurement activities which will provide measures of quality including process and outcome measures. This initiative, called ORYX by JCAHO, also requires that these organizations subscribe to one or more of approximately 200 JCAHO-approved sources of comparative quality data. One such project, the Maryland Quality Indicator Project, is endorsed through the Maine Hospital Association and has several Maine hospitals as participating institutions. The program is designed to be an internal tool to assist in identifying potential areas for improvement. The comparative quality information is not publicly provided either by JCAHO or by the Maryland Hospital Indicator Project.

The Healthcare Financing Administration (HCFA), the federal agency responsible for the administration of the Medicare and Medicaid programs, has mandated quality improvement activities through contracted agencies called Peer Review Organizations (PROs). The PRO for Maine is the Northeast Health Care Quality Foundation. It has a number of comparative quality improvement activities underway to improve the quality of care in diabetes, congestive heart failure, atrial fibrillation, and other topics. (http://www.medicarequality.org/providers/projects.htm). Comparative information about their performance in these activities is regularly provided to all hospitals in Maine and may be available from these hospitals. The PRO does not publish these comparative statistics.

Health plans have the data for monitoring some outcomes that involve covered services. They also have access to Rx data to enhance the value of their analysis. The health plans review quality via their administrative databases and site specific audits. Most of these data are proprietary. In addition, various provider groups (PHO's, large practices, etc.) are measuring outcomes and quality, the PRO has some data, and there are other sources of some data from patient surveys, medical record transactions, etc.

There are standard data calculations used for quality indicators such as mortality rates, readmission rates by hospital, complication rates using nationally studied methodologies, etc. Although these indicators are used widely, they also have arguments against their reliability. The MHIC and others generate these indicators for multiple users on a regular basis.

Comments

There does not appear to be agreement on the specific quality or outcome measures that are the most important for providers, health plans, and purchasers. Even when people use those terms there are different interpretations of what they mean.

There does not appear to be a central repository for clinical quality or patient outcome data in Maine, nor does there seem to be any endorsed linkage with national data sources. The Internet provides a wealth of information but a road map may be needed to guide people to where the best web sites are located for the most reliable benchmark clinical outcome and quality data. Most of these data are on a national or regional basis. Some data are available on a statewide basis but the small numbers involved are of concern. Without Maine specific data, consumers and others will not be able to compare their own experience with the demonstrated benchmarks.

Whereas some efforts are focused on collecting quality and outcomes for a specific project, there is recognition that there needs to be an ongoing effort to collect and monitor outcomes and quality information on a routine basis.

Collaborative efforts should be made to work with Maine professional associations, clinical groups, and health plans to identify the best and most widely used clinical quality and outcome measures. In addition, there is a need to identify highly reliable web sites for access by consumers and others to identify best practice outcomes and quality indicators so consumers and providers are accessing the same information when they discuss experience and expectations. These efforts should result in linkage with Maine web sites directing the user to the statewide, regional, and national data.

PATIENT SAFETY

Information Needs

- Are there best practice medical safety systems?
- How does Maine's patient safety experience compare to the national situation?
- Where are the systems that have demonstrated success in leading to patient safety across Maine and compared to national trends?

Data Sources

Individual hospitals are collecting some data on adverse events within their hospital. Some hospitals are implementing fairly sophisticated and costly systems for tracking adverse events and medical errors.

Complication rates calculated from the hospital discharge data do not necessarily correlate with medical errors. Variations among facilities may often be the result of coding practices rather than actual occurrences.

Discussions are underway in Maine to create a statewide adverse event reporting system. Access to the data, however, will be limited.

Comments

A concern in this area is how should information be collected and to whom should it be disseminated. The needs of providers might be to use these data quietly in quality improvement efforts, while purchasers and consumers might want more access to these data to use in making decisions of where to seek care. A similar concern is what data are confidential versus non-confidential.

A concern among many is that the focus might be on individual providers rather than systems of care. Focus on the former might discourage and distract efforts at making system wide improvements that will have more significant and lasting improvements. There is also a concern that focusing on individuals aggravates the problem by creating an atmosphere where people are afraid to admit quality concerns.

Some wonder if the effort on patient safety should learn from the efforts of the National Highway Transportation Administration, the Federal Aviation Association, and other private industry efforts to disseminate information to the public.

A great deal of national money has been earmarked for studies to be conducted starting in 2001 on systems for capturing adverse events and medical errors. *The Maine healthcare community should keep informed of federal funding opportunities to develop demonstration projects focussing on patient safety.*

PATIENT SATISFACTION

Information Needs

How well are patients satisfied with their health care system?

- providers
- health plans

Data Sources

Satisfaction with health plans is readily available through the National Committee on Quality Assurance HEDIS results, as well as in several magazines (US News and World Report, Newsweek), and from the Federal Employee Health Plan Survey. Standard survey measures are used and comparative data can be obtained.

A new measure called Consumers Assessment of Health Plans (CAHPS) is being disseminated for the plans to use, and a pilot survey is being tested at the physician provider group level.

In 1998 and 1999, the MHMC and the Maine HMO Council collaborated in a best practice survey for physician satisfaction and preventive health. Ten best practice physicians were identified in 1998 and 72 in 1999. Results were shared with the MHMC member employees as well as some media dissemination.

Most hospitals conduct patient satisfaction surveys after the patient is discharged from the hospital. The questions range from addressing amenities such as the decor of the room and the food, to the level of communication by the doctor and the discharge instructions by the staff. Most of the hospitals use the results of the surveys for internal purposes.

The Maine Health Management Coalition recently engaged the Picker Institute to conduct patient satisfaction surveys for some of the MHMC hospitals for selected conditions. The hospital specific data was kept confidential and fed back to the hospitals.

Comments

There is recognized difficulty in obtaining consistently reliable patient survey data due to differing survey and validation techniques.

There doesn't appear to be any central source of patient satisfaction data available in Maine. *Efforts should be made to establish a meaningful source of patient satisfaction data that can be shared with consumers. In addition, efforts should be made to identify common measures across all providers that can be utilized by providers for continuous quality improvement and for purchasers and consumers to choose health plans and providers.*

BEST PRACTICE

Information Needs

- How do providers in Maine compare to best practice?
- Is a particular doctor a good physician?
- How can a consumer select a best practice physician?
- How can providers that are doing a good job be recognized?
- Which health plan is the best?

Data Sources

The Maine Health Management Coalition collaborated with several health plans for the past two years to award practice excellence awards to recognize physicians that ranked the highest regarding health plan patient satisfaction surveys and preventive services. The satisfaction data are collected on a regular basis by health plans.

Health plans do maintain preferred physician status and network participation for all physicians. It is not clear what criteria are used to make the determination of status and whether the information is proprietary.

The Bureau of Insurance does maintain information on health plan and provider complaints and action in their consumer advocacy division. The Bureau intends to make that data available to the public.

There are national best practice criteria that could be used to evaluate practices but access to the necessary data is limited. Health plans and others use practice guidelines to influence care in Maine and to establish a common baseline for outcome comparisons. The guidelines are nationally developed and recognized. Claims data provide an excellent source for evaluating compliance with guidelines as long as the service identified in the guideline is a covered service generating a bill to a payer. HEDIS provides comparable best practice guidelines for selected diagnoses and/or conditions, and health plan performance on HEDIS indicators is ranked and published nationally on an annual basis.

Comments

There are increasing requests for this type of information but most of the databases that hold relevant data are proprietary within health plans or hospitals. There are some criteria nationally that could be used to evaluate best practice as a starting point. Before we search for the data, it would be helpful to have agreement on the criteria that will be used. *Criteria for evaluating best practice of providers and health plans should be reviewed and agreed upon as a statewide initiative.*

COST

Information Needs

- What are the healthcare expenditures including prescription drugs in Maine?
- What are the cost factors causing the increase in health care costs?
- What are the comparative costs across hospitals, nursing homes, physicians, and other providers?
- How much does it cost for a selected procedure across hospitals and other providers?
- How do Maine's hospital, nursing home, physician, and other provider costs compare to other states and to the nation?
- How do Maine's total health care costs on a per capita basis compare to the rest of the nation?
- What are the indirect costs of the inefficiencies of the system?
- What are the costs of treatment options for selected conditions?
- How do we measure our investment in preventive cost and the return on investment?

Data Sources

The Blue Ribbon Commission recently compiled a cost profile on healthcare expenditures in Maine. That data are available on how much is being spent on a per capita basis and how it compares to other selected states and the nation.

The MHDO is starting to collect hard copy cost reports from hospitals and intends to computerize selected data elements for comparative purposes.

The MHIC has recently acquired a national cost report database containing computerized cost reports for all hospitals in the country for six years. The data are audited and there are approximately 1,200 data elements per hospital. The data allow for case mix adjusted cost and utilization data by hospital. They also allow for peer grouping of hospitals by region, size, and type.

The Maine Health Management Coalition has convened a study group of financial representatives from several hospitals to study case mix adjusted costs across hospitals.

The health plans are analyzing their costs by type of provider to determine the percent of premium spent for hospital care vs. other providers.

Comments

There is a lot of activity right now around the issue of cost. The Blue Ribbon Commission has spent months trying to address this whole issue. The issue of cost is complex and the need to compare costs is difficult given the differences in accounting systems and definitions. It appears that the national computerized cost report database at the MHIC may provide the best comparative data available for hospitals but hospital costs is only one component. *Efforts should be made to generate an annual health* expenditure report including categories such as hospitals, physicians, dentists, other professionals, drugs, nursing home care, and other health services. The report should include per capita estimates using annual population estimates generated by the state.

The issue of health plan administrative costs is another area that is discussed often. The confounding factor in identifying health plan administrative expense is the presence of national plans in Maine. Most plans are now bundling their costs into their national performance and not reporting those costs by state. *Efforts should be made through the Bureau of Insurance to identify Maine-only costs by insurance companies including administrative costs*.

ATTACHMENTS

ATTACHMENT I.

Users of Data

ATTACHMENT II.

Framework for Data Collection

ATTACHMENT III.

List of Web Sites for Data Access