Selecting Health Indicators for Public Health Surveillance in a Changing Health Care Environment

Family Health Outcomes Project Staff

Geraldine Oliva, MD, MPH
Director
Teddy Milder, PHN, PNP
Associate Director
Peter Michael Miller, MD, MPH
Physician Consultant
John Greene, MA
Research Assistant
Isabel Sobozinsky
Research Assistant
Nicole L. Cosand
Project Assistant

with Guidance from the Family Health Outcomes Project's
Cooperative Agreement Advisory Committee

Maternal and Child Health Bureau Staff

Russ Scarato
Chief Economist
Maternal and Child Health Bureau
and
Division of Science, Education and Analysis
Woody Kessel, MD, MPH
Director, Division of Science, Education and Analysis

EXECUTIVE SUMMARY

Selecting Health Indicators for Public Health Surveillance in a Changing Health Care Environment was developed to serve as a reference for public health agencies to utilize in assessing the impact of programs and services and systems and policy changes on the health and well being of women, infants, children and youth. Individual measures can be used by states as performance or outcome measures in their Title V block grant applications.

In 1993, the Family Health Outcomes Project (FHOP) at the University of California, San Francisco was funded through a cooperative agreement with the Federal Maternal Child Health Bureau (MCU-06D501). A primary objective was to develop a set of health indicators to assess the public health impact of recent changes in the delivery of health care services on women and children — specifically the transition of Aid to Families with Dependent Children (AFDC) recipients from a fee-for-service Medicaid reimbursement system to a prepaid managed care system.[1] To oversee this task, FHOP convened an advisory group that included: program directors from state Maternal and Child Health and representatives for Children with Special Health Care Needs agencies in HRSA Regions IX and X, representatives from a state Medicaid managed care program, private and non-profit managed care organizations and the American Academy of Pediatrics.

The advisory group decided that the scope of the effort would be broadened to include other changes occurring in the health care system impacting women, infants, children and youth including:

- Decisions by private businesses to raise insurance premiums for both the employee and his or her dependents, to limit benefits to employee dependents, to eliminate coverage through private indemnity insurance, to replace full time employees with benefits with part time employees without benefits

- Decisions by businesses to downsize or relocate to increase profits, thereby leaving many employees to find lower paying or part-time jobs without benefits

- The passage of the 1996 Welfare Reform bill which separated Medicaid eligibility form AFDC eligibility and gave states the option of eliminating legal immigrants from eligibility for Medicaid coverage

- Decisions by government agencies to limit or eliminate public benefits for legal or illegal immigrants

The advisory group established the following goal and objectives to guide the process:

Goal: To assure the health and well-being of the Maternal, Child and Adolescent Health (MCAH) population by the developing of an approach to monitor changes in the health care delivery and finance systems.

Objective 1: To develop a set of recommended public health indicators with which to monitor the impact of changes in the health care delivery system

Objective 2: To identify the risk/protective factors associated with the recommended indicators

Objective 3: To identify the methods for collection and analysis of the data necessary to calculate the indicators at the state and federal level

Objective 4: To identify the system barriers which impact the measurement of these health outcomes

Initially, the group reviewed the following literature: staff summaries of the managed care evaluation literature, Government Accounting Office (GAO) reports[2] and a core set of recommended maternal/child health indicators most frequently used by Maternal and Child Health programs.[3] In order to provide a framework for consideration of the large number of potential indicators, the group reached consensus on a set of indicator selection criteria. The following criteria were used to assess the utility of each indicator:

- The indicator is quantifiable

- It can be uniformly defined across programs

- Data on the indicator are available or could be available for a reasonable cost

- The condition to be measured is preventable

- The indicator definitions are consistent with documented authoritative standards where possible

- Interventions are available which have been shown to be cost/effective or cost beneficial

- The information would be relevant and informative to public health policy makers

- There are significant costs associated with a negative outcome

- The condition impacts a large number of individuals or is severe

These criteria were used by each member of the group to evaluate and rank the indicators. The group then reviewed the most highly ranked indicators and established a subset to be recommended for use.

Staff facilitated a group process with the advisory committee to determine the following: precise indicator definitions, definitions of the numerator and denominator for calculations of percents and rates and data sources for locating the necessary information. Staff then assessed each data source for adequacy along with advantages and disadvantages of each data source. (See Appendix E: Inventory of National Data Sources and Appendix F: National Data Sources: Advantages and Disadvantages.)

Staff then reviewed available literature on the risk and protective factors for many of the indicators. Due to the extensive and often conflicting nature of the literature on many of these indicators, a decision was made to rely primarily on those risk factors documented in the Healthy People 2000 (HP2000): Objectives for the Nation[4] and on protective factors as documented in the U.S. Preventive Services Task Force: Guide to Preventive Services.[5] (See Appendix G: Risk and Protective Factors for Selected Public Health Indicators summarizes these findings.)

The public health indicator table is organized by the following four age groups: less than 12 months, 12 months through 9 years, 10 through 19 years and adult women. Within each age group, indicators have been included to measure the following domains:

- Health risks/status/outcomes

- Health service utilization

- Prevention activities

Also included in this document is: a background section on the current changes that are occurring in the health care system and their potential impact, a section on how to use the indicator table, the appendices and a discussion of the potential barriers to implementing an effective public health surveillance system.

BACKGROUND

The current rapid expansion of managed care is having an impact on the way health services are delivered in the United States. As of July 1996, 48 states, the District of Columbia and Puerto Rico were operating one or more managed care programs for Medicaid recipients.[6] Between 1987 and 1996, states' total enrollment of Medicaid beneficiaries in managed care increased more than 600%, from 1.8 to 13.3 million, or 40.1% of all Medicaid recipients.[7] By 1997, California, the most populous state in the United States, had implemented a managed care program that covered more than three quarters of its Medicaid recipients and did so in a period of two years.

The decision to dramatically restructure the way services are delivered to our highest risk population was based primarily on the perceived need to rapidly curtail escalating program costs. Surprisingly, there were and still are very few data available upon which to base conclusions about the effectiveness of managed care for the Maternal and Child Health population. For example, there are a number of evaluation studies of the Medicaid Managed Care Demonstration projects from the early 1980s, but the methodologies utilized were not rigorous[8]. Frequently, they did not contain comparisons with matched controls, did not contain sampling plans that avoided bias, nor did they in any way assess the particular risk factors of the enrolled populations. Effects on use of specialty services, costs, hospitalization and prescriptions were inconsistent. The only consistent finding in the evaluation studies conducted on

Medicaid Managed Care Demonstration projects was a decrease in Emergency Room use.

The few studies that have looked at quality of care for women and children have not shown any significant differences in outcomes between patients with fee-for-service insurance vs. patients covered under a managed care program[9]. A study by Adolph and Falterman in 1996 showed a lower incidence of severe appendicitis and in post-appendectomy complications in children receiving care through a managed care plan compared to those covered by traditional indemnity insurance.[10]

However, In recent years, there has been a tremendous interest from purchasers, consumers and the managed care community in measuring quality through the use of performance measures. In 1993, The National Committee for Quality Assurance, with input from these sectors, developed the Health Plan Employer Data and Information Set (HEDIS).[11] This contains a set of precisely defined measures for quality of care, member access and satisfaction, membership, utilization, finance, health plan management and activities. The latest HEDIS, version 3.0, incorporates measures appropriate for Medicaid managed care.

However, HEDIS contains very few measures specifically related to women, infants, children and youth. In addition, the definitions used by HEDIS assume that the population being measured has had significantly long periods of continuous enrollment. The continuous enrollment requirement overlooks those members who elect to frequently change plans (as is allowed by most state Medicaid agencies) or those families in which the adults have intermittent or seasonal employment and thus go on or off Medicaid a number of times during a year. A number of studies have shown that only 50% of Medicaid families continuously remain in a plan for a year. Thus, HEDIS performance measurement, although shedding some light on the quality of clinical services provided by a health plan, does not assess the health status of many children who either come under a plan's care for more limited periods of time or those families who are assigned to a plan, but never enroll. For example, using the HEDIS measure on immunization adequacy, it could be found that 90% of those two year olds continuously enrolled for 10 months are up to date on their immunizations. However, it could be quite possible that the immunization levels of the Medicaid population as a whole has gone down to 50%.

In addition to the changes in the Medicaid program, there is an increasing percentage of children who have lost insurance coverage due to the loss of parental benefits. This is a result of the downsizing and benefit containment policies of private businesses and corporations. A 1997 GAO study states that between 1989 and 1995, the percent of children with private insurance decreased from 74% to 66%.[12] During this same time period the population of children in the U.S. increased by 7 million while the number covered by private insurance remained the same. Expansion of Medicaid coverage mitigated the negative effects of these changes. Despite the increase in Medicaid coverage, by 1995 there were 1 million more children who were uninsured, bringing the number to 10 million.

Welfare reform can also be expected to impact the health of children. The 1996 Welfare Reform Bill separated Temporary Assistance to Needy Families (TANF - formerly AFDC) eligibility from the eligibility processes for Medicaid and food stamps.[13] Historically, 60% of Medicaid enrolled children have come through the AFDC eligibility process. Past studies of the Medicaid population have shown that automatic enrollment in Medicaid for people receiving AFDC has led to higher Medicaid coverage levels compared to people who had to apply separately for Medicaid.

The welfare reform bill legislation also tightened the eligibility requirements under SSI for children with disabilities. These tighter eligibility requirements could limit Medicaid enrollment for this population and possibly have an adverse effect on the health status of children.

Lastly, there is a national trend to limit or eliminate public benefits for legal and/or illegal immigrants. The welfare reform legislation allows states to determine whether and to what extent they will continue to provide Medicaid coverage to legal immigrants.[13] For example, California has been providing state funded Medicaid services to undocumented immigrants, and has now begun to limit those benefits.

Some of these adverse changes may be offset by the new health insurance coverage plan for children called the States Children's Health Insurance Program (SCHIP), a program which is included in the provisions of the Balanced Budget Act of 1997.[14] However, it will take some time before this program will be fully implemented by the states.

Although public health departments have traditionally focused on low income people and/or those populations at the highest risk, many of the current changes in the health care delivery system impact people living in the United States of all incomes. For example, in their effort to contain costs, many businesses have changed the premium structure for employees. The GAO reports that between 1989 and 1996 employee premiums have risen 36%, while those for family coverage increased 59%.[13] In addition, the majority of employers now offer managed care plans as the options with the lowest premiums or offer only managed care plans. Therefore, most privately insured individuals are also moving into the managed care system. A Peat Marwick survey done for the GAO showed that the percent of employees who had the option to choose private indemnity insurance decreased from 89% in 1989 to 57% in 1996.[13] From 1984 to 1993 the number of employees in large firms who were enrolled in managed care plans (such as HMOs), increased from 5 percent to 50 percent.

Thus, there remains a very critical role for public health agencies in monitoring the health of the entire population during this period of turmoil and the implementation of untested strategies for cost containment. Given the escalating shift of the majority of the United States population into the managed care system, it is important to explore the possible ramifications of this shift and the role of public health agencies in moving

from service provisions to core public health functions, specifically needs assessment, monitoring and assurance.

THE INTERFACE BETWEEN PUBLIC HEALTH AND MANAGED CARE

Considering the confusion regarding the value of public health monitoring vs. managed care performance measurement, it is useful to compare the goals of these sectors and the way that indicators and performance measures are selected and utilized.

The stated goal of most public health agencies is: To ensure the health and well-being of the population of an entire community through the monitoring of health status and the assurance of access to prevention and intervention services. This goal reflects the value placed on public sector accountability to governmental bodies elected by the total population and supported by tax dollars to provide services over the lifetime of an individual, regardless of ability to pay. Thus, public health agencies base the selection of specific services on the observed or expressed needs of the public and conduct prevention efforts with both short and long term effects, recognizing that their responsibility for an individual is not time-limited.

In contrast, managed care organizations (MCOs) contract to deliver a specific set of services for a dollar amount to a specific member population with the goal to provide cost-effective, quality health care to plan members with an awareness that preventive services may reduce cost.

This goal is based on the values placed on accountability to a board of directors that demands contract compliance and fiscal responsibility to generate a profit. In the case of a nonprofit, the goal is to operate within a capped budget and to meet fiduciary and ethical responsibility to effectively prevent and/or appropriately treat disease and illness in members. The plan's focus is on the well-being of an individual while he/she remains under the coverage of the plan.

Although these goals are quite different, they both result in a number of shared concerns:

- The need for readily available, accurate and consistent data for planning and resource allocation
- The need to assess the costs and benefits of various approaches to service delivery
- The need to monitor access to and utilization of services
- The primary prevention of (costly) negative outcomes
- The need to ensure high quality services
- A desire to optimize client satisfaction

It is important to understand the difference between health indicators as utilized by public health agencies and performance measures as utilized by managed care organizations. Public health agencies use indicators to identify unmet needs, to evaluate the impact of changes in the health care delivery system (particularly as they impact low income or disabled people), to measure the impact of access to preventive or primary care, to set appropriate benchmarks against which to measure change and to provide data to inform policy makers at all levels of government in their allocation of diminishing resources. These measures are not intended to be used to judge the clinical competence of individual health care providers or plans (although some could serve this function), but to look at all negative outcomes and to develop strategies, clinical and otherwise, to address them. Health departments can use indicators to monitor outcomes by payor source or model of care. In addition, there is a growing pressure to monitor positive outcomes as well as negative. Looking at positive outcomes could serve to demonstrate the improvement of health status of a population with better access to primary care services.

Managed care organizations use performance measures to look at how adequately they are meeting the needs of a particular population of enrolled clients. Specifically, performance measures are used to document and measure the adequacy of their administrative processes, to monitor clinical outcomes using evidence-based care guidelines and treatment protocols, to measure cost-effectiveness, to monitor provider performance, to assess client satisfaction and to produce report cards for review by potential purchasers that document the quality of their services (i.e., for marketing purposes).

It is important to acknowledge that there is an inherent tension between the public sector and MCOs around the conclusions that can be drawn from the results of outcome studies.

This tension is a result of the MCOs' concerns that documentation of poor outcomes, for conditions only partially under their control, will be used to judge or rate them. As a result, they may be reluctant to provide data or to agree to specific outcome measures. However, the definition of some of the public health indicators as health monitoring measures and the inclusion of some "positive" indicators may be more acceptable to many plans.

Despite the differences in goals and values, the outcome indicators included in the Title V guidance for state Maternal and Child Health programs and the performance measures recommended by HEDIS both meet the following criteria:

- They are quantifiable

- They are expected to be uniformly defined across programs or plans

- Data are available or will be in a reasonable period of time

- Measured conditions are severe or affect large numbers of people

- Access to care can be expected to affect outcomes

- There is broad consensus among involved constituencies on their utility

- They are expected to be consistent with the Healthy People 2000 Objectives wherever possible

Public health agencies can learn much from the recent HEDIS process about the values and practices of the health plans vis-à-vis their concern with quality and their willingness to participate in cooperative efforts to measure the impact of their models of care on health status and outcomes. All indications are that the plans have accepted the inevitability of having to collect and report on performance measures and that there are more commonalties than there are differences between these measures and those utilized by public health. In addition, the willingness of many plans to collect encounter data will give public health agencies data on primary care utilization patterns and clinical health status measures that have not been previously accessible without costly special studies frequently involving medical chart reviews. Careful review of the managed care literature will also inform public health agencies with oversight responsibilities about techniques to better categorize models of care for comparative evaluations.

Managed care plans stand to benefit as well from exposure to the public health perspective. Through a better understanding of the risk factors and current health status of the Medicaid and other vulnerable populations as they compare to the total population, they can better estimate the cost of providing care to this group and thus bid competitively and realistically. Through exposure to the public health literature on barriers to care and approaches to overcoming them, the plans can better design models of care that would encourage these high risk, culturally diverse populations to access preventive services rather than use the more costly secondary or tertiary services.

Once this common ground is discovered, groups can then turn to the practical and technical issues of selecting and defining health status and outcome indicators and the collection of necessary data. In a climate of mutual respect and recognized interdependency, both can take advantage of the tremendous potential for achieving a far more in depth appreciation of the health status of target groups as well as the impact of service delivery on them.

Today's challenge is to use both the public health indicators and the managed care performance measures to develop or adapt indicators that reflect the shared concerns. These indicators will not necessarily reflect the "performance" of the plan or the "quality" of services, but the impact on the population as a whole of the totality of changes in the financing of health care and of the variety of new service delivery models.

[1] Note that AFDC has been superseded by the Temporary Assistance to Needs Families Program (TANF) as of July 1, 1997.

[2] **Medicaid. States Turn to Managed Care to Improve Access and Control Costs.** United States General Accounting Office (GAO). Report to the Chairman, Subcommittee on Oversight and Investigations, Committee on Energy and Commerce, House of Representatives, March 1993.

[3] **Health Status/Outcome Indicators for Maternal, Child and Adolescent Health.** Family Health Outcomes Project/University of California, San Francisco, January 1995.

[4] Public Health Service. **Healthy People 2000: National Health Promotion and Disease Prevention Objectives.** Washington, DC. U.S. Department of Health and Human Services/Public Health Service, 1990.

[5] **Barriers to the Measurement of Public Health Indicators.** Family Health Outcomes Project/University of California, San Francisco. August, 1997.

[6] **Managed Care State Enrollment.** Health Care Financing Administration. Baltimore, MD. June 30, 1996. http://www.hcfa.gov/medicaid/pntrtn3.htm

[7] **Medicaid at the Crossroads: A Report of the Kaiser Commission on the Future of Medicaid.** Prepared by the Commission Staff, Rowland, D. et al. Baltimore, MD: The Commission, c1992.

[8] **Managed Care in Medicaid: Lessons for Policy and Program Design.** Hurley, RE; Freund, DA; Paul, JE. Ann Arbor: Health Administration Press 1993; 37-95.

[9] Fox HB; McManus MA. **Medicaid Managed Care Arrangements and Their Impact on Children and Adolescents: A Briefing Report.** Washington, DC: The Child and Adolescent Health Policy Center, November 1992.

[10] Adolph VR; Falterman KW. **Appendicitis in Children in the Managed Care Era.** Journal of Pediatric Surgery, 1996 Aug, 31(8):1035-6; discussion 1036-7.

[11] **Health Plan Employer Data and Information Set (Version 3.0).** National Committee for Quality Assurance, July 1996.

[12] **Health Insurance for Children. Declines in Employment-Based Coverage Leave Millions Uninsured; State and Private Programs Offer New Approaches.** Testimony before the Subcommittee on Health, Committee on Ways and Means, House of Representatives. United States General Accounting Office. GAO/T-HEHS-97-105.

[13] **Employment-Based Health Insurance. Costs Increase and Family Coverage Decreases.** Report to the Ranking Minority Member, Subcommittee on Children and Families, Committee on Labor and Human Resources, U.S. Senate. United States General Accounting Office. GAO/HEHS-97-35.

[14] **H.R. 2015** Balanced Budget Act of 1997 (Enrolled Bill (Sent to President)). Title IV - Medicare, Medicaid and Children's Health Provisions. http://Thomas.loc.gov/cgi-bin/query/z?c105:H.R.2015.ENR:

GUIDELINES FOR THE USE OF THE INDICATOR TABLE

The indicators presented in the table which follows are intended to be a reference set which public health agencies can use to guide them in their development of effective assurance activities. It is hoped that since they are not provider performance measures, they will be acceptable to the medical service community as a whole. This should result in a cooperative effort from all providers to collect and analyze these data.

INDICATOR TABLE CONTENT AND ORGANIZATION

The indicators are grouped into the following age categories: infants up to 12 months, children 12 months through 9 years, youth 10 through 19 years and women. Many indicators are repeated for each age group with age-appropriate additions or changes.

Within each age group, indicators have been included to measure the following domains:

- Health risks/status/outcomes
- Health service utilization
- Prevention activities

We have not included indicators for risk and protective factors. However, a summary of risk and protective factors is included in Appendix G.

Each indicator includes a reference to an appropriate Healthy People 2000 Objective, where one exists. The table references the Healthy People 2000 objectives in three ways:

1. Where the Healthy People 2000 objective appears as a bullet and precedes an indicator definition, the Healthy People 2000 definition is used verbatim.
2. Where the phrase "Adapted from Healthy People 2000" appears at the end of an indicator definition, the definition has been altered slightly and one can refer to Appendix A for the exact HP2000 wording.
3. Where the phrase "Reference objective" appears in the notes following a definition, a new definition has been developed; the related Healthy People 2000 objective is noted for comparison.

Column I   Indicator name

Column II   Indicator definition for public health surveillance -- includes the FHOP definition and the Healthy People 2000 reference, if available

Column III   Numerator definition for standardized measurement

Column IV   Denominator definition for standardized measurement

Column V   National data sources for numerator and denominator information

LIST OF INDICATORS

The indicators in each age group category are as follows:

INFANT INDICATORS — Up to 12 Months of Age

INFANT MORTALITY*
    a. NEONATAL MORTALITY
    b. POST NEONATAL MORTALITY
    c. INFANT MORTALITY

FETAL DEATH*

NEWBORN SCREENING

CONGENITAL/BIRTH-RELATED INFECTION

IMMUNIZATION:
    a. VACCINE STATUS
    b. VACCINE PREVENTABLE CONDITIONS

INFANT GROWTH

ACCESS TO PRIMARY CARE

ADEQUACY OF PRIMARY CARE

ADEQUACY OF WIC UTILIZATION

INFANT SUBSTANCE/ALCOHOL/TOBACCO EXPOSURE

INJURIES:
    a. INTENTIONAL INJURIES*
    b. UNINTENTIONAL INJURIES*
    c. PREVENTION

HOSPITAL DISCHARGES FOR AMBULATORY CARE SENSITIVE (ACS) DIAGNOSIS

*Indicates FHOP data templates in Excel spreadsheet format available

CHILD INDICATORS — 12 MONTHS THROUGH 9 YEARS OF AGE

IMMUNIZATION:
- a. VACCINE STATUS
- b. VACCINE-PREVENTABLE CONDITIONS

CHILDREN GROWTH

ACCESS TO PRIMARY CARE

ADEQUACY OF PRIMARY CARE

CHILD SUBSTANCE, ALCOHOL AND TOBACCO EXPOSURE PREVENTION:
- a. EXPOSURE
- b. PREVENTION

ORAL HEALTH:
- a. CHILDREN WITH A DENTAL EXAMINATION
- b. CHILDREN WITH EARLY CHILDHOOD CARIES, INCLUDING BABY BOTTLE TOOTH DECAY (BBTD)
- c. CHILDREN WITH UNTREATED DENTAL CARIES
- d. CHILDREN WITH PROTECTIVE SEALANTS ON PERMANENT MOLAR TEETH

INJURIES:
- a. INTENTIONAL INJURIES*
- b. UNINTENTIONAL INJURIES*
- c. INJURY-PREVENTION ACTIVITIES

LOW HGB/HCT

HOSPITAL DISCHARGES FOR AMBULATORY CARE SENSITIVE (ACS) DIAGNOSIS

*Indicates FHOP data templates in Excel spreadsheet format available

YOUTH INDICATORS — 10 THROUGH 19 YEARS OF AGE

IMMUNIZATION:
- a. VACCINE STATUS
- b. VACCINE-PREVENTABLE CONDITIONS

ACCESS TO PRIMARY CARE

ADEQUACY OF PRIMARY CARE

YOUTH SUBSTANCE, ALCOHOL AND TOBACCO USE/ABUSE/EXPOSURE:
- a. USE/ABUSE ILLICIT:
  - 1. SUBSTANCES
  - 2. ALCOHOL
  - 3. TOBACCO
- b. EXPOSURE
- c. PREVENTION

ORAL HEALTH:
- a. YOUTH WITH A DENTAL EXAMINATION
- b. YOUTH WITH UNTREATED DENTAL CARIES
- c. YOUTH WITH PROTECTIVE SEALANTS ON PERMANENT MOLAR TEETH

INJURIES:
- a. INTENTIONAL INJURIES*
- b. UNINTENTIONAL INJURIES*
- c. PREVENTION

LOW HGB/HCT

HOSPITAL DISCHARGES FOR AMBULATORY CARE SENSITIVE (ACS) DIAGNOSIS

SEXUALLY TRANSMITTED DISEASES

TEEN BIRTHS:
- a. TEEN BIRTHS*
- b. TEEN FATHERS
- c. TEEN BIRTHS TO ADULT FATHERS

TEEN PREGNANCY

REPEAT TEEN PREGNANCY

*Indicates FHOP data templates in Excel spreadsheet format available

WOMEN'S INDICATORS

FIRST TRIMESTER ONSET OF PRENATAL CARE*

INADEQUATE PRENATAL CARE*

PRENATAL SCREENING

MATERNAL ALCOHOL AND SUBSTANCE USE/ABUSE

CIGARETTE SMOKING BY PREGNANT WOMEN*

MATERNAL WEIGHT GAIN DURING PREGNANCY

PRETERM DELIVERY

LOW BIRTH WEIGHT*

WOMEN WHO BREASTFEED THEIR INFANTS

ADEQUACY OF WIC UTILIZATION

SEXUALLY TRANSMITTED DISEASES

MATERNAL HIV INFECTION*

LOW HGB/HCT

    a. PREGNANT WOMEN

    b. WOMEN NOT CURRENTLY PREGNANT

INTENDED BIRTHS

CERVICAL CANCER

    a. SCREENING

    b. OCCURRENCE

BREAST CANCER SCREENING

HOSPITAL DISCHARGES FOR AMBULATORY CARE SENSITIVE (ACS) DIAGNOSIS

*Indicates FHOP data templates in Excel spreadsheet format available

RECOMMENDATIONS FOR ANALYSIS AND PRESENTATION OF INDICATOR DATA

Indicators should be reported in census-defined age categories, less than 1, 1 - 4, 5 - 9, 10 - 14 or 15 - 19 years of age unless otherwise specified. Women's indicators should also be measured in census-defined categories, 15 to 44, 44 to 65 years unless otherwise specified. We recommend that all of the indicators be analyzed by geographic area (e.g., ZIP, census on county), gender and by race/ethnicity. In order to fully grasp the rapid changes in the health care delivery, we suggest that indicators be analyzed by payor source, by health plan and by provider where the numbers allow. Indicators should be measured for a calendar year to ensure consistency and at least five years of data should be presented to allow analysis of trends. Maternal education (where available) may be useful as a proxy for socioeconomic status. Normative comparisons should also be performed for comparison with state trends and for benchmarking with national rates and standards such as Healthy People 2000.

Since it will require significant financial, personnel and technical resources to measure these indicators, it may not be possible for all of the indicators to be measured at any one point in time. Rather, it may be more feasible for states to select a core group of the indicators to monitor each year and, depending on both state resources and needs, to monitor an additional subset of indicators each year, perhaps on a rotating basis.

ORIENTATION TO APPENDICES

Appendix A, is a summary of the specific Healthy People 2000 objectives referenced within the Indicator Table. It also gives the Healthy People 2000 baseline performance estimate, and baseline year.

Appendix B, *HEDIS 3.0 Performance Measures for Comparison with Maternal and Child Health Surveillance Indicators* defines specific HEDIS 3.0 Reporting Set managed care performance measures that address topics included in the Public Health Indicator Table. For example, you might find it useful to compare HEDIS 3.0 performance measures for childhood immunization with the public health indicator for childhood immunization as it appears in the Public Health Indicator Table (page 11).

Appendix C, *ACS Conditions with ICD9 Codes* is a reference to the indicator, Hospital Discharges for Ambulatory Care Sensitive (ACS) Diagnoses, which appears in the Infant, Child, Adolescent and Women's tables. Ambulatory care sensitive (ACS) diagnoses are those which are preventable, acute but controllable or chronic manageable conditions for which hospitalization may have been avoided if timely, effective outpatient treatment had been provided. ACS discharges are particularly useful as a proxy for lack of access to primary care. Appendix C lists each identified ambulatory care sensitive condition with related ICD9 codes.

Appendix D, *Recommended Childhood Immunization Schedule, United States, January - December 1997*, is included as the most recent immunization recommendations for the Immunization indicator, which appears in the Infant, Child and Youth tables.

Appendix E, *National Indicator Data Source Inventory***,** is a glossary of data sources referenced in the Public Health Indicator Table, by type (e.g., survey data, population-based data, program data).

Appendix F, *Data Source Advantages and Disadvantages*, addresses the strengths and limitations of selected state and federal data sources, including hospital discharge data, vital statistics, and national surveys conducted by the Centers for Disease Control and Prevention (CDC), the Department of Commerce and the National Institutes of Health. Identification and evaluation of appropriate Maternal and Child Health indicators for use in needs assessment requires a comprehensive review of each indicator's data source, validity, content, periodicity and measurement methodology. At a minimum, knowledge of indicator data sources, their strengths and limitations, as well as systems barriers to obtaining and using these data, will enhance the accuracy of the interpretation of public health needs assessment data.

Appendix G, *Public Health Indicator Table Risk and Protective Factors*, is designed to assist states and counties in problem analysis and development of intervention strategies. It includes a comprehensive list of risk factors (as referenced in Healthy People 2000) for most indicators included in the Public Health Indicator Table. Appendix H also includes a summary of protective factors and suggested public health interventions for each indicator (based on the Centers for Disease Control and Prevention's Guidelines for Intervention). The CDC suggested interventions summary is provided to assist public health professionals in designing appropriately targeted, effective interventions once public health indicators have been measured and needs assessed.

Appendix H, *Sample Data Template* is an example of an automated approach to the recording of data on a particular indicator. The templates have been developed in Excel software. The templates allow the display of state data over time with comparisons to national data and with Healthy People 2000 objectives. Rates or percentages are automatically calculated to ensure consistency with state and national standards. To aid in determining the significance of observed differences between state an national rates or between rates over time, confidence intervals are automatically generated. The data templates are intended to assist state and local health jurisdictions in displaying data on selected indicators. Throughout the Indicator Table, indicators for which FHOP data templates exist are noted.

BARRIERS TO THE MEASUREMENT OF PUBLIC HEALTH INDICATORS

The indicators recommended for consideration in this monograph are meant to serve as a reference set for states or other entities wishing to document the impact of health policy and financing changes on the Maternal Child and Adolescent population. It is expected that not all of the indicators will be selected by any one jurisdiction and that a jurisdiction will select those indicators that are most relevant to the specific demographic, socioeconomic and environmental conditions within that jurisdiction. The availability and accessibility of data and the methodological and systems barriers that may be encountered in attempting to analyze these data also have a significant impact on which indicators are selected.

BARRIERS TO THE USE OF SPECIFIC DATA SOURCES

Appendix G, Data Source Advantages and Disadvantages, addresses the particular issues related to the utility of each data source recommended in the table. It is critical to evaluate each data source prior to the selection of an indicator to ensure that these data will be available and relevant to the task of monitoring health systems changes for a specific jurisdiction. Although each data source has very distinct characteristics, there are some criteria that apply to evaluating any data set. The following factors should be considered when assessing the feasibility of utilizing a particular data set.

TIMELINESS

Many population-based data sets are extremely useful when comparing state data against other state and national findings. However, due to the complexity of collecting, cleaning and preparing large data sets, there is frequently a 2 to 3 year delay in the availability of these data for use by local health agencies. Thus, in order to monitor the impact on health status or outcomes of the rapid transition of Medicaid enrollees into managed care plans, states may need to collect and/or analyze more timely data. For example, rather than use the NCHS Natality Data to monitor perinatal health, the state would choose to analyze state birth certificate data.

GEOGRAPHIC SPECIFICITY

Data sets differ in their level of geographic specificity. Some data sets, such as the Federal Census of Population and Housing, contain ZIP code and census tract level information. However, population-based data are frequently collected through surveys of only a sample population, e.g., the National Hospital Discharge Survey or the National Health Interview Survey (NHIS). Sample representativeness and generalizability may limit the utility of such data sets for evaluating local conditions. For example, national data set samples such as NHIS may be relevant to a region and not be reflective of a local or state population. States often address these barriers by using the standardized instrument from a national survey and sampling a much larger local population. However, additional local sampling requires additional financial resources.

SPECIFICITY OF DEMOGRAPHIC DATA

As in the section on geographic specificity, national population samples are often limited in the number of race/ethnic groups for which data are collected in large enough numbers to analyze with any degree of statistical validity. For example, the size and content of the samples in the Youth Risk Behavior Survey or the High School Senior Survey on drug use do not allow results to be calculated for Asian/Pacific Islander populations.

In addition, age is often reported as a categorical age group rather than a continuous variable (e.g., data on age group categories are gathered - rather than data on actual years of age). At the national level, for example, mortality reports frequently aggregate age into broad ranges such as 0 to 24 years for injuries, or 15 to 24 years for motor vehicle related indicators. This makes the age specific analysis necessary for program planning and evaluation more challenging, if not impossible.

As with geographic sampling, states often attempt to correct this limitation by using a standardized instrument and oversampling the groups of particular interest.

DATA CONSISTENCY AND STANDARDIZATION

In order to adequately compare health outcome measures from one jurisdiction to another, or to monitor changes in health outcome measures over time, it is necessary to compare similar groups using standardized variables. Standardization requires that state data collection efforts use identical definitions and standard instruments where possible. This may be a challenge since the existing data available from multiple sources frequently measures the same construct in different ways. For example, race/ethnicity may be collected and/or coded using different categories: Asians may be reported as an aggregate or by specific categories such as Japanese, Chinese, Southeast Asians, etc.

Whether a measure is recorded by self-report or "assigned" by the data collector may also lead to discrepancies across data sources.

Differences in methodologies for combining variables (or codes) into groups, may also lead to inconsistent comparisons across data sets. This frequently occurs with grouping of diagnostic codes in hospital discharge data where, for example, different researchers measure heart disease using different diagnostic ICD-9 code groupings. Similarly, age groupings are frequently not comparable across datasets.

In some cases, the data may be collected in a more detailed fashion and reported in categories that are not useful or consistent with other data being utilized. In this case, obtaining the raw data and recoding the variables may solve the problem. In other cases, the data set may simply not be helpful and a primary data collection effort will be necessary.

A most useful project would be to initiate a data standardization effort for any future data collection at the state level, e.g. deciding on a uniform way to collect race/ethnicity data that will be used by all programs.

ABILITY TO PRODUCE UNDUPLICATED COUNTS AND CLIENT SPECIFIC DATA

Many service utilization data sources were developed for billing purposes. They contain records for encounters, admissions, or visits, as opposed to records for unique individuals and are therefore subject to duplication of information. For example, three types of duplication can be found in hospital discharge data:

1. More than one record for the same admission to a hospital.

2. Two or more records associated with one episode of care. For instance, if a person is admitted to a hospital and then transferred shortly to a second hospital, this may be considered one episode of care, rather than two distinct episodes.

3. More than one episode of care for one individual. Depending on the unit of analysis under consideration (e.g., billed claims, episode of care, or individual case), records may need to be considered separately as distinct episodes of care, or be linked to represent utilization for one individual.

Deterministic and probabilistic record linkage strategies would have to be developed and utilized to obtain client-specific data within and across data sets. A more long term strategy would include developing a unique personal identifier by utilizing, for example, client identification numbers or a set of standardized variables.

WEIGHTING OBSERVATIONS

National surveys that contain data for a sample of the population may need to be weighted to produce state or national estimates. For example, most national surveys produced by the National Center for Health Statistics require special software to weight records to produce national estimates. The cost of acquiring this software and the technical skill needed to use it represent barriers to the proper utilization of data sources for which weighting is required.

AVAILABILITY OVER TIME

Some data collection efforts occur at specific intervals and are not available every year. Most notable is the US Census, which is only collected every ten years. In order to supplement this, states collect intercensal samples and make projections for each year. However, these samples may not be detailed enough to provide data at the ZIP code or census tract level for all ages or race/ethnic groups. This limits the ability to generate rates for these groups between census years.

National survey data are also collected for specific time periods. Other surveys may be done only once due to the one-time availability of resources or the political climate. An example of this might be toxicology screening of newborns for in utero substance

exposure to drugs or alcohol. In order to use a particular data set for ongoing monitoring, resources would have to be identified to repeat the data collection effort on an ongoing or periodic basis.

SAMPLE VALIDITY

Some national survey data are collected on convenience samples. For example, the High School Senior Survey collects self-reported data on students who are enrolled and in attendance at a school on a particular day. This methodology excludes those students who have dropped out of school or who attend school sporadically from participating in this survey. Thus, it would be inaccurate, for example, to use this sample to estimate overall teen drug use since it excludes those teens who are more likely to have frequent, chronic or severe drug use.

SYSTEMS BARRIERS

Often the most serious obstacles to the completion of a monitoring effort are those that result from a health department's lack of adequate internal resources and systems for data collection, storage and analysis.

COMPUTING FACILITIES

Lack of adequate computing facilities may hinder surveillance and needs assessment activities. Storage space, processor speed, and memory are vital aspects of computing facilities. In addition, as more and more data files and information become available on the Internet, hardware and software that allow fast and efficient access to this medium are becoming essential. Many states rely on outdated mainframe technology, which is inadequate to meet the demand for readily accessible data.

TRAINED PERSONNEL

Different tasks involved in data management and analysis require different levels of technical competence. As activities and methods become more complex, additional staff, including computer programmers, statisticians and epidemiologists, may be needed to manage and analyze data used in needs assessment and surveillance. In order to adequately measure the recommended indicators, a number of important skills and resources are required. For the analysis of large state data bases, for example, familiarity with statistical analysis software, data linkage and translation software and software that will interface between legacy systems and GIS packages are required.

STORAGE MEDIA

Capacity to read and write to various storage media must be considered. Many data sets are extremely large and require expensive storage and retrieval methods. Data

sets may be disseminated in various forms such as 9-track tape, 18-track tape, CD-ROM disk, Zip drive or Jaz drive. Access to the appropriate storage media read/write equipment is important to consider before obtaining a data set.

STORAGE FORMAT

In addition to storage media, storage format is another important consideration. Data may be stored in ASCII or text format, in a binary form or in a software-specific format. Software packages that can translate software-specific files to other formats are especially useful. In addition, operating system characteristics may hinder the transmittal of data from one storage medium to another. Many data sources provide hard copy reports of analyses that may be converted into electronic format. More and more agencies and organizations are placing data files, in various storage formats, on the Internet. To access data from the Internet, file transfer capability and appropriate software to open such files are needed. In addition, confidentiality and security of the data must be assured.

DATA SECURITY

Many government agencies will not release data unless data security requirements are met. Protection methods for computer accounts, files and storage media are necessary, especially when data sets contain confidential information. These methods include passwords, encryption, fingerprint or smart card "keys." In addition, physical storage media (computers, disks, tapes, hard copies) should be kept in secured and locked locations.

CONFIDENTIALITY

Data sets and reports may include confidential information that could be used to identify individuals. Confidentiality standards and protocols for protecting the confidentiality of subjects must be implemented when these data are used. These confidential data are especially useful when analyzing data collected by more than one agency. The need for access to confidential data must be balanced against requirements for maintaining and protecting confidentiality and privacy.

DATA OWNERSHIP

Adequate acknowledgment of data collection agencies and adherence to protocols for claiming ownership and allowing dissemination of data must be practiced. Many government agencies will not release data to "outside" analysts. Private agencies often charge prohibitive fees for obtaining their data.

POLITICAL PRIORITIES AND LIMITED FINANCIAL RESOURCES

Health agencies have lagged behind other professional and business organizations in the utilization of information technology. Many legislatures have considered investing in information technology as a luxury and have redirected resources to the delivery of services. In order to change this mentality, state program staff must be able to provide compelling evidence of the cost effectiveness of a needs assessment and monitoring system for directing a more effective use of limited resources.