

# Do We Have All of the Public Health Information We Need in North Carolina?

William D. Kalsbeek, PhD

Much of the progress in public health at the national, state, and local levels has depended on information about the populations that are served. Indeed, successes in dealing with susceptibility to infectious disease, injury, tobacco use, dental disease, and other major health issues of the past century have occurred because of the availability of objective scientific evidence to inform the development and affirmation of steps in the right direction. This evidence has also served as a signal to halt misguided steps and thus winnow out ideas that have proven to be ineffective. But science has only played a partial role in advancing the health of the population. Some decisions have been made based on anecdotal evidence, political expediency, and organizational inflexibility to change. A 1988 Institute of Medicine of the National Academies panel further noted that in reality, many program and policy decisions in public health are made as a reaction to the pressure of hot-button issues and organized interest groups.<sup>1</sup>

This article first examines the role of information in public health decision-making and then touches on some steps to assure that future decisions affecting the health of North Carolina's citizens will be made with the best information available. By implication, I suggest that continued progress towards improving the health of North Carolinians will be made most expeditiously by having the best population-based data systems available.

## Data and Information in Decision Making

Within the past 10 years several practitioners and academic researchers have proposed more formal frameworks for integrating the use of objective evidence in public health decision making.<sup>2-5</sup> The adoption of this notion in practice has come to be called evidence-based public health (EBPH), which Ross Brownson and colleagues have defined as “the development,

implementation, and evaluation of effective programs and policies in public health through application of principles of scientific reasoning including systematic uses of data and information systems and appropriate use of program planning models.”<sup>2</sup>

Three “tools and processes” recommended for EBPH involve using data gathered from those who are affected by decisions. *Risk assessment* requires data on public exposure to

*“...continued progress towards improving the health of North Carolinians will be made most expeditiously by having the best population-based data systems available.”*

harmful physical and chemical agents, *economic evaluation* weighs the cost of a population-directed intervention against the impact on those to whom the intervention is directed, and *public health surveillance* involves a continuing effort to profile relevant health-related behaviors, exposures, and outcomes in the general population.

Surveys and administrative records are 2 common sources of data for EBPH. A survey involves systematic data collection by having respondents complete a specifically designed questionnaire. These respondents are usually selected from a carefully chosen sample to reflect a broad cross-section of the studied population. Administrative records contain data that are recorded as an inherent part of a health-related process that affects a selective part of the population (eg, those who have visited a hospital, are Medicare beneficiaries, are members of a managed health

---

William D. Kalsbeek, PhD, is director of the Survey Research Unit and a professor in the Department of Biostatistics in the School of Public Health at the University of North Carolina at Chapel Hill. He can be reached at bill\_kalsbeek (at) unc.edu or 730 Martin Luther King, Jr. Blvd, Suite 104, Chapel Hill, NC 27599-2400.

care organization, or have a particular disease). Administrative data are less expensive to use when they are available as a data source, but surveys are more adaptable to specific needs since the questionnaire and sample designs are based solely on the information needs the survey is intended to meet. Sometimes administrative data are used to improve the quality or reduce the cost of surveys.

However having appropriate data is not sufficient for EBPH to work since “data” and “information” are related but not equivalent concepts. There are two types of data: *micro data* and *macro data*. *Micro data* are bits of information about individual members of a population such as what a survey respondent reports as the status of his or her private health insurance coverage (ie, covered or not covered). These member-specific data may be used to form *macro data* for the population as a whole or for important geographic or demographic subgroups—for example, the percentage of persons in Bertie County who are covered by private health insurance. Data become *information* when findings from macro data provide answers to questions that are raised in making decisions. For instance, to deal with access to health insurance we may need to know which counties in North Carolina have the lowest private insurance coverage rates or if private insurance coverage is statistically associated with personal employment status. Answering questions that arise during decision making requires the technical ability to work with micro data as well as the ability to interpret macro data findings. Thus the mere existence of micro or macro data does not imply that we have the information we need.

Information must also be scientifically valid to be useful in decision making. The right kind of data and the resources to produce information are needed to create credible information about the general public. For example, estimating the rate of private health insurance coverage from a sample of those who have visited doctors’ offices would produce invalid findings if those seen by a doctor are more likely to be insured than those who are not seen by a doctor. In this context resources are ultimately the financial wherewithal to assure that those using the data will be familiar with the statistical methods needed to transform micro data into the kinds of macro data that will inform decision making.

Gathering useful micro data, particularly in public health surveillance, must therefore follow well-established principles of survey practice.<sup>6</sup> The wording of questions used to produce micro data items must be appropriate for the type of macro data that are needed, samples must be representative and large enough to meet established standards, and the statistical estimation approach used to produce macro data findings from micro data items must properly take into account how the sample was chosen.

## Data and Public Health Information in North Carolina

The capacity to create data and produce public health information from them is well-established in North Carolina. The State Center for Health Statistics (SCHS) in the Division

of Public Health has a long history of effectively compiling and reporting data from all births and deaths as part of the state’s vital registration system. The State Center for Health Statistics also compiles data from other targeted sources of health data including case registries, hospital and emergency room visits, and reported pregnancies. The SCHS collects and disseminates data from the following 3 sample surveys of all North Carolinians in specific age ranges:<sup>7</sup>

- *The Pregnancy Risk Assessment Monitoring System (PRAMS)*. An annual mail-plus-telephone survey of about 2400 recent births on childbirth, maternal behavior, and morbidity. PRAMS is conducted in collaboration with the national Centers for Disease Control and Prevention (CDC).
- *The Behavioral Risk Factor Surveillance System (BRFSS)*. An annual telephone survey of 15 000 to 17 000 persons 18 years and older that covers various topics on health promotion and disease prevention. BRFSS is also conducted jointly with CDC.
- *The Child Health Assessment and Monitoring Program (CHAMP)*. An annual telephone follow-up survey of 3000 BRFSS households with children under age 18 years covering topics on child health and development.

The paper by Paul Buescher in this issue of the *Journal* more fully describes each of the SCHS data sources. The Survey Research Unit (SRU) at the University of North Carolina (UNC) at Chapel Hill School of Public Health has also conducted many important health-related telephone surveys of North Carolina citizens in recent years. These studies have covered a broad range of topics including back and neck pain, health care utilization, domestic violence, youth labor injury, and oral cancer.<sup>8</sup> Staff from the SRU have also assisted the SCHS and the CDC to develop and refine the designs for many of the surveys they conduct.

## Are There Unmet Information Needs?

Clearly the statewide surveys conducted by the SCHS and the SRU have addressed a wide range of health topics and population groups—to the point that one might suspect that the state has all the public health data it needs. I am skeptical of this notion, however, since a closer look at the designs of these surveys reveals the potential for gaps affecting important parts of public health practice. For example, while the BRFSS sample is sufficiently large to produce a wide variety of acceptably precise estimates at the state, regional, and county levels, it does not currently include topics like health insurance coverage, food insecurity, and cancer prevalence. Moreover, sample sizes in the PRAMS, CHAMP, and SRU surveys are too small to provide estimates for most local areas like counties and municipalities. Even the largest national health surveys conducted by the National Center for Health Statistics and the Agency for Healthcare Research and Quality are of little help to North Carolina’s health professionals since they generally do not have

samples of sufficient size or design to produce statistically useful findings at either the state or local levels. Local area macro health data findings in North Carolina are therefore currently limited to topical estimates that can be produced with acceptable precision from BRFSS, and to county-level findings that are generated from the vital registration system and other sources of health-related micro data aimed at specific population subgroups in the state.

Efforts are now underway to determine if information needs are being met by those working in various sectors of the public health system in North Carolina.<sup>a</sup> The specific goal of a detailed assessment being conducted by the UNC Chapel Hill Department of Biostatistics, in conjunction with the North Carolina Division of Public Health, is to identify gaps in public health information by asking the state's users of public health data what their unmet information needs are and by determining which of these needs are being met, or could be met, by currently available data and resources. During this assessment, health professionals in the state's public and private sectors will be asked to report the kinds of public health information they have needed for their practice and research activities but have not had available. The discovered information needs will then be compared against the data available from existing sources, and each information need that cannot be met by existing data and/or resources will be considered an "unmet" need.

## What If There Are Unmet Information Needs?

Several possible findings could emerge from this assessment of the need for public health information. One is that we have all the information we need and that no action is required. This would be the ideal outcome of course, but perhaps it is not the most realistic one to expect. Indeed, the assessment may conclude that we lack the data we need, that we lack the resources to turn data into the information we need, or both.

Finding that North Carolina lacks important public health information will hopefully prompt a search for new ways to expand or enhance the state's existing data systems. Concluding that the data exist but that we need to boost the state's capacity to create information will mean that creative new ways must be found to make better use of existing data. Fortunately, some effort in this direction is already underway. Faculty from the UNC Charlotte Department of Health Behavior and Administration are currently creating an online, user-friendly data warehouse that will offer visitors the ability to more fully use data from existing SCHS surveys and other sources.

In the event that more health data are needed, recent experiences in California may be useful to North Carolina. California's assessment of its health information needs in the late 1990s concluded that it lacked both data and resources and that a significant expansion in its information production capacity was necessary. This expansion led to the creation of a new statewide survey of all Californians called the California Health Interview

Survey (CHIS) to supplement the state's relatively small BRFSS.<sup>9</sup>

One remarkable feature of the CHIS is its strong commitment to data dissemination, an activity for which roughly 25% of its budget is earmarked, according to Dr. E. Richard Brown, director of the University of California at Los Angeles (UCLA) Center for Health Policy Research and principal investigator of the CHIS. The CHIS not only makes its micro data files and macro data findings readily available to its many user constituencies, but it also actively promotes the widest possible use of CHIS data through a user-friendly online query system and a series of data user workshops that have been developed especially for nontechnical health professionals at the local level.<sup>10</sup>

Data from the CHIS come from a periodic telephone survey of all major age and race-ethnicity groups, with total sample sizes in its first three 2-year cycles ranging from about 42 000 to 56 000 households.<sup>10</sup> Its design was developed following a "community-based participatory research" model in which key features are made to directly accommodate the information needs of the diverse set of geographic and demographic constituencies that the CHIS serves.<sup>11</sup> The result was a survey design of sufficient size, breadth, and dexterity to make its data both easily accessible and sufficient to produce high-quality statistical estimates down to the local level and for each of California's major demographic subgroups. While some of the survey topics in the CHIS overlap with the BRFSS, many are unique to the CHIS, especially in the areas of health insurance coverage, employment, income, and public program participation. Support is likely to continue beyond the current (fourth) cycle of the CHIS since the impact of its data in the state and beyond has been considerable.

The CHIS has become the main source of state and local public health information in California. Its users have included policymakers, advocacy groups, philanthropic foundations, hospitals, health care organizations, and state and county public health agencies. One illustration is typical of the dozens of documented ways that the CHIS has made a difference in the health of Californians.<sup>12</sup> A research and consulting firm used CHIS data to estimate the number of uninsured children in San Luis Obispo County including those who could have enrolled in existing health insurance programs but did not. Data from CHIS were also used to estimate the cost of covering all children in the county, thus paving the way for a program initiative to cover more children.

To assure that high quality health information is there to guide the future of public health in North Carolina two questions should be considered in the near term: Is the state poised to produce all of the health information it will need and, if not, what remedial steps should be taken? Findings from the needs assessment study in progress will help to answer the first of these questions, but if the second must be addressed as well, finding a meaningful answer will require the state's information users to agree on a solution that could require major enhancements in the state's health data infrastructure to get us where we need to be.

---

a Besides North Carolina and California, continuing work groups have been formed in Illinois, New York, New Mexico, and Texas to examine and/or expand their health data and information infrastructures. Several other states are in the process of establishing efforts to do this.

## REFERENCES:

- 1 Institute of Medicine, Committee for the Study of the Future of Public Health. *The Future of Public Health*. Washington DC: National Academies Press; 1988.
- 2 Brownson RC, Gurney JG, Land GH. Evidence-based decision making in public health. *J Public Health Manag Pract*. 1999;5(5):86-97.
- 3 Fielding JE, Briss PA. Promoting evidence-based public health policy: can we have better evidence and more action. *Health Aff*. 2006;25(4):969-977
- 4 Ibrahim MA, Savitz LA, Carey TS, Wagner EH. Population-based health principles in medical and public health practice. *J Public Health Manag Pract*. 2001;7(3):75-81.
- 5 Kohatsu ND, Robinson JG, Torner JC. Evidence-based public health: an evolving concept. *Am J Prev Med*. 2004;27(5):417-421.
- 6 Scheuren F. *What Is a Survey?* Chicago, IL: National Opinion Research Center; 2004. <http://www.whatisasurvey.info/>. Accessed January 2, 2008.
- 7 Statistical services. North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/about/statserv.html>. Updated June 28, 2005. Accessed January 2, 2008.
- 8 Survey Research Unit. University of North Carolina at Chapel Hill, School of Public Health Web site. <http://www2.sph.unc.edu/sru/home.html>. Accessed January 2, 2008.
- 9 California Health Interview Survey. University of California at Los Angeles, UCLA Center for Health Policy Research Web site. <http://www.chis.ucla.edu/>. Accessed January 2, 2008.
- 10 Brown ER, Holtby S, Zahnd E, Abbott GB. Community-based participatory research in the California Health Interview Survey. *Prev Chronic Dis*. 2005;2(4):A03. [http://www.cdc.gov/pcd/issues/2005/oct/05\\_0046.htm](http://www.cdc.gov/pcd/issues/2005/oct/05_0046.htm). Accessed January 2, 2008.
- 11 Israel BA, Schultz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health*. 1998;19(1):173-202.
- 12 Brown ER. *The California Health Interview Survey: a qualitative study on the access, use, application and impact of CHIS data*. Los Angeles, CA: UCLA Center for Health Policy Research; 2007.

Coming in the May/June  
2008 issue of the

**North Carolina  
Medical Journal**

a look at:

**Chronic Kidney  
Disease**