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Tarheel Footprints in Health Care

Recognizing unusual and often unsung contributions of individual citizens who have made health care for North Carolinians more accessible and of higher quality

Paul A. Buescher, PhD **Director, State Center for Health Statistics**



North Carolina has a deserved reputation for excellence in collecting and reporting vital and health statistics. This is due in large part to the early development of a State Center for Health Statistics (SCHS) and the quality of individuals who have led that Center. The current director, Paul Buescher, is keeping alive the tradition of objectivity, responsiveness, and accuracy that has marked the SCHS since its beginning. Paul, in a sense, is one of our own at the *North Carolina Medical Journal* since he has edited a regular feature, *Running the Numbers*, for the past 7 years. We wish to recognize him, however, for his work at the Center. Paul has steadily and constructively made the State Center for Health Statistics a trusted and relevant participant in the health policy making process in North Carolina, and his willingness to bring the data of the Center into public forums sets him apart.

Paul became director of the State Center for Health Statistics in 2005 after serving in progressively responsible roles. He began work at the SCHS in 1980 as a statistician and gained a reputation as a productive contributor to its work. In 1993 he became head of the Statistical Services Unit. Having spent most of his career at the SCHS, Paul is intimately familiar with its programs and is highly committed to its ongoing success and improvement. Leah Devlin, state health director, notes that Paul "...is a master of turning data into meaningful information that is routinely used across North Carolina to identify health problems, define effective strategies, and evaluate outcomes. He is incredibly knowledgeable and dedicated—we all stand on his recommendations with absolute confidence."

Paul's role as a communicator is an important asset for both state and community leaders. Paul has been tasked to publicly explain positions that are often hard to grasp by a layperson, such as how an unusual number of cancer cases occurring in a community is unlikely to be due to a specific environmental cause but has a much greater probability of happening due to chance. These kinds of public discussions can become stressful and contentious, but Paul is able, through his calm demeanor and clear language, to make convincing arguments that rely on statistical facts and understanding—a skill that he has mastered.

An Eagle Scout who received his undergraduate degree in Sociology from Louisiana State University, Paul went on to receive a MA in Sociology and a PhD in Sociology/Demography from the University of North Carolina (UNC) at Chapel Hill. He has been an adjunct professor in the Department of Maternal and Child Health in the UNC Chapel Hill School of Public Health since 1991 and is a ready and willing mentor to students and faculty at the university.

Paul is an accomplished scholar and has published extensively in the medical and public health literature. He was the recipient of the national 2004 Maternal and Child Health (MCH) Epidemiology Effective Practice at the State Level Award from the Coalition for Excellence in MCH Epidemiology. The Effective Practice Award recognizes individuals who make significant contributions to MCH public health practice through the effective use of data and epidemiology. North Carolina is fortunate that Paul Buescher brings his knowledge and skills to the work of the State Center for Health Statistics.

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The Economic Impacts of Medicaid in North Carolina

Christopher Dumas, PhD; William Hall, PhD; Patricia Garrett, PhD

Abstract

Objective: The purpose of this study is to provide estimates of the economic impacts of Medicaid program expenditures in North Carolina in state fiscal year (SFY) 2003.

Study Design: The study uses input-output analysis to estimate the economic impacts of Medicaid expenditures.

Data Sources /Study Setting: The study uses North Carolina Medicaid program expenditure data for SFY 2003 as submitted by the North Carolina Division of Medical Assistance to the federal Centers for Medicare and Medicaid Services (CMS). Industry structure data from 2002 that are part of the IMPLAN input-output modeling software database are also used in the analysis.

Principal Findings: In SFY 2003 \$6.307 billion in Medicaid program expenditures occurred within the state of North Carolina—\$3.941 billion federal dollars, \$2.014 billion state dollars, and \$351 million in local government funds. Each dollar of state and local government expenditures brought \$1.67 in federal Medicaid cost-share to the state. The economic impacts within North Carolina of the 2003 Medicaid expenditures included the following: 182 000 jobs supported (including both full-time and some part-time jobs); \$6.1 billion in labor income (wages, salaries, sole proprietorship/partnership profits); and \$1.9 billion in capital income (rents, interest payments, corporate dividend payments). If the Medicaid program were shut down and the funds returned to taxpayers who saved/spent the funds according to typical consumer expenditure patterns, employment in North Carolina would fall by an estimated 67 400 jobs, and labor income would fall by \$2.83 billion, due to the labor-intensive nature of Medicaid expenditures.

Limitations: Medicaid expenditure and economic impact results do not capture the economic value of the improved health and well-being of Medicaid recipients. Furthermore, the results do not capture the savings to society from increased preventive care and reduced uncompensated care resulting from Medicaid.

Conclusions: State and local government expenditures do not fully capture the economic consequences of Medicaid in North Carolina. This study finds that Medicaid makes a large contribution to state and local economic activity by creating jobs, income, and profit in North Carolina. Any changes to the Medicaid program should be made with caution.

Relevance: The rising costs of health care and the appropriate role of government health insurance programs are the object of current policy debates. Informed discussion of these issues requires good information on the economic and health consequences of alternative policy choices. This is the first systematic study of the broader economic impacts of Medicaid expenditures in North Carolina.

Medicaid is a health insurance program for certain low-income individuals and families. The program covers children in low-income households; the aged, blind, and/or disabled; and people who are eligible to receive federally-assisted income maintenance payments.^a In North Carolina,

Medicaid is jointly funded by federal, state, and county governments. (In October 2007 the state began a 3-year phaseout of county funding with this share being assumed by the state.) The North Carolina Division of Medical Assistance manages the Medicaid program.¹ Approximately 1 out of 6 North

a For additional information on Medicaid, see <http://www.cms.hhs.gov/>.

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William Hall, PhD, is a professor in the Department of Economics and Finance and director of the Center for Business and Economic Services at the University of North Carolina Wilmington.

Patricia Garrett, PhD, is a former project director at NC Covering Kids & Families for the North Carolina Pediatric Society Foundation in Raleigh, North Carolina.

Carolinkians (1.4 million people) was eligible for Medicaid coverage at some time during state fiscal year (SFY) 2003. Although considerable information is available on Medicaid program services, recipients, and costs, relatively little information is available on the economic impacts of Medicaid expenditures, especially at the state or regional level. The purpose of this study is to estimate the economic impacts of Medicaid program expenditures in North Carolina in SFY 2003.

It is well-known that Medicaid program costs are large and growing.² In 2001 Medicaid financed \$5.32 billion of the \$31.6 billion spent on health care in North Carolina, or 17% of total health care spending in the state.³ From 1978 to 2003, Medicaid expenditures in North Carolina increased from \$307 million to \$6.3 billion.^{4,5} By 2003, average nationwide Medicaid costs (22.3% of state government expenditure) had displaced elementary and secondary education (21.4% of state government expenditure) as the largest state expenditure.⁶ In North Carolina Medicaid is a large and growing proportion of the state budget—currently about 16%.⁷ Moreover, because Medicaid is an entitlement program, state expenditures cannot be capped. This introduces unpredictability into the budgetary process, which is one factor that makes Medicaid a challenging program for states to administer.^{6,8}

The individual and public health benefits of Medicaid are also well-known. Figure 1 provides a schematic summary of the health and economic benefits of Medicaid for individuals and communities. Health care professionals appropriately emphasize both the clinical benefits (see Figure 1.A) and public health benefits (see Figure 1.B) of the Medicaid program. By promoting access to timely and appropriate medical care, and with an emphasis on preventive care and best practice protocols, Medicaid improves health status and mitigates the possibility that chronic conditions will become disabilities. For example, a recent study finds that enrolling children in Medicaid before

they get sick promotes the use of preventive care, reduces the need for hospitalization, and improves health.⁹ In a recent review study of health insurance and access to prescription medicines, insurance coverage was found to be essential for access to prescription drugs with increased access consistently observed for insured compared to uninsured children.¹⁰ In another recent study of automobile accident victims receiving hospital care, victims without health insurance were found to receive less care and suffer a substantially higher mortality rate compared to victims with health insurance.¹¹ In terms of public health effects, Medicaid expenditures support health care infrastructure used by the general public (eg, community hospitals), contain communicable diseases, and promote general public health through health awareness and wellness campaigns.

In addition to health benefits, Medicaid indirectly confers economic benefits to recipients (see Figure 1.C.1-2) and to other patients in the health care system (see Figure 1.C.2-3). By improving health, Medicaid improves labor participation—an individual's capacity to stay employed and work productively. By facilitating timely and preventive care, Medicaid reduces costly emergency care,⁹ thus reducing the overall cost of health care to the individual and to the economy. Additionally, by reducing unpaid medical costs, Medicaid reduces cost-shifting. Cost-shifting occurs when unpaid medical costs are absorbed by hospitals, county health departments, or other safety net providers and/or passed on in the form of higher premiums to consumers with private health insurance. For example, a recent study by Families USA¹² finds that the uninsured cannot pay two-thirds of their health costs, and of this amount, two-thirds is passed on to those with private health insurance in the form of higher premiums. The Families USA study found that in 2005 the annual premium cost for a family health insurance policy provided by private employers was an average \$922 higher due to the cost of care for the uninsured.

Figure 1.
Major Health and Economic Benefits of Medicaid Expenditures for Individuals and Communities

Benefits	Beneficiaries	
	Individual	Community
Health	A. Clinical effects. By promoting access to timely and appropriate medical care, and with an emphasis on preventive care and best practice protocols, Medicaid improves health status and mitigates the possibility that chronic conditions will become disabilities.	B. Public health effects. Medicaid expenditures support health care infrastructure used by the general public (eg, community hospitals), contain communicable diseases, and promote general public health through health awareness and wellness campaigns.
Economic	<p>C. 1. Improved labor participation. By improving health Medicaid improves an individual's capacity to stay employed and work productively.</p> <p>2. Reduced cost of care. By facilitating timely and preventive care Medicaid reduces costly emergency care, reducing the overall cost of health care to the individual and the economy.</p> <p>3. Reduced cost shifting. By reducing unpaid medical costs Medicaid reduces health care provider write-offs that are passed on to the insured in the form of higher insurance premiums.</p>	D. Direct and multiplier effects. Medicaid expenditures stimulate the local economy through supporting jobs, labor income (wages, salaries, and sole proprietorship/partnership income), capital income (rents, interest payments, and corporate dividend payments), and taxes.

What is less well-known is that Medicaid has substantial, positive impacts on state business activity (see Figure 1.D). Medicaid expenditures stimulate the local economy, supporting jobs, labor income, business income, and taxes. Recent studies nationwide have begun to assess these impacts at the state level.¹³⁻³¹ For example, studies conducted in both Alaska¹⁴ and Texas¹⁵ found that Medicaid has substantial economic impacts in those states. The Alaska study found that Medicaid program expenditures supported over 9 000 jobs in the state and generated more than \$346 million in personal income (wages, salaries, and business income). Each dollar of Alaska state funds invested in Medicaid resulted in \$2.31 dollars of personal income to state residents due to the infusion of Medicaid cost share dollars from the federal government (ie, Alaska made money on Medicaid). As would be expected, the Medicaid program has larger impacts in states with larger economies and populations such as Texas. In Texas Medicaid supported 474 420 jobs and \$20 billion in personal income. Unlike Alaska, Texas didn't make money on Medicaid—each dollar of Texas state funds invested in Medicaid returned 91 cents of personal income to Texans due to the vagaries of the federal cost sharing formula. However, it is critical to remember that these figures do not include the economic value of the improved health and well-being of Medicaid recipients or the medical cost savings resulting from preventive care funded by Medicaid.

This study provides estimates of the economic impacts of Medicaid program expenditures in North Carolina in SFY 2003 including estimates of economic impacts on employment; labor income (wages and salaries); capital income (rents, interest payments, and corporate dividends); and government tax revenues at the federal, state, and local levels. These estimates do not include the economic value of the improved health and well-being of Medicaid recipients or the medical cost savings resulting from preventive care funded by Medicaid. Hence, the goal of this study is to provide results for the direct and multiplier effects in the community (see Figure 1.D). In addition, our data set allows us to investigate Medicaid expenditures at the county level and to determine whether urban or more affluent counties receive disproportionately larger expenditures relative to rural or less affluent counties. We also report the results of a policy simulation experiment in which we determine the economic impacts of shutting down the Medicaid program, returning the money (federal, state, and local) to taxpayers, and allowing the taxpayers to spend the funds according to typical consumer expenditure patterns.

Data

The study relies on North Carolina Medicaid program expenditure data for SFY 2003 as submitted by the North Carolina Division of Medical Assistance to the federal Centers for Medicare and Medicaid Services (CMS). The data included all SFY 2003 North Carolina Medicaid program expenditures including the following associated programs: Baby Love; Community Alternatives; Dental Program; Health Check; Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Services; Managed Care; Piedmont Behavioral Healthcare and Piedmont Innovations; and Transportation Program administration.^b The analysis does not include NC Health Choice for Children (SCHIP) program expenditures.^c The data used in this study are unique in that they provide Medicaid expenditures by county of health care provider location rather than by county of patient residency.

Methodology

This study uses input-output analysis to estimate the economic impacts of Medicaid.³² Input-output analysis is commonly used by economists to estimate the full economic impacts of an initial change in spending in a regional economy. Input-output models are not perfect; they are approximations of spending patterns in regional economies. Nonetheless, they are widely used as good, first-order approximations of regional economies, and their use by economists to estimate economic impacts is standard operating procedure. IMPLAN Professional[®] Input-Output Analysis computer software was used in this study to conduct input-output analysis.³³ IMPLAN is a leading input-output modeling software package used by university researchers, government agencies, and consultants nationwide. In a review of the literature, we identified 19 studies¹³⁻³¹ of the economic impacts of Medicaid at the state level, all of which used some form of input-output analysis to estimate economic impacts. Ten of the 19 studies used IMPLAN input-output modeling software. (Five studies used the RIMS II input-output model, which is fundamentally similar to IMPLAN, and the remaining studies used custom-built input-output models or did not report the type of input-output model used.) Carbaugh et al³⁴ reviewed 17 studies of the role of Medicaid in state economies. Of these, 11 used IMPLAN; 3 studies, including those of Families USA,^{35,36} used RIMS II. IMPLAN has also been used to estimate the economic impacts of hospital closures.^{37,38} Rickman and Schwer³⁹ compared benchmarked versions of IMPLAN, RIMS II, and a third leading input-output software package called REMI, and found that

b For additional information on the distribution of Medicaid expenditures across program areas in North Carolina, see: <http://www.dhhs.state.nc.us/dma/prog.htm>.

c Unfortunately, this study is limited to the economic impacts of Medicaid because comparable information was not available for SCHIP dollars. Substantively, this has limited consequences because the Medicaid budget is much larger than the SCHIP budget. Nevertheless, because SCHIP dollars are targeted exclusively at children, their absence limits a nuanced appreciation of how public spending on children's health impacts the economy.

the economic impact multipliers of the benchmarked models do not differ significantly. Duncombe and Wong⁴⁰ provide a good introduction to the differences between input-output models and other methods of regional economic analysis.

Input-output models are interconnected systems of linear equations that track the flow of dollars between and among households, businesses, and government in a specified geographic region as small as a county or as large as the United States. The IMPLAN input-output modeling system consists of 2 parts: a mathematical computer model and a database. The IMPLAN modeling system contains equations for over 500 industry categories plus additional equations that model household and government spending. In essence, there is one equation for each *industry* in a regional economy. (The equation for a given industry can be different in different geographic areas.) Each industry equation specifies the dollar amounts of *input* goods and services required to produce the dollar amount of industry *output* in the region. The equations are linked together such that the output dollar amount produced by one industry is the total of all the input dollar amounts required by all of the other industries in the system. For example, the dollar value of electricity output produced by the electricity industry feeds into all of the other industry equations as the (dollar-valued) electricity inputs to those industries. (The electricity industry also uses some of its own electricity, which feeds back into its own equation.) In addition, some of the outputs leave the system as *exports* from the region, and some inputs enter the system as *imports* into the region. Furthermore, households (workers) and taxes are treated as inputs in the industry equations in the sense that industries pay for (send money to) workers and taxes. Households are treated as separate industries that receive their own inputs (eg, wages, salaries, rental income, dividend payments, government program payments) and produce their own outputs (eg, household expenditures for food, clothing, electricity, rent, mortgage payments, taxes). (In fact, there are multiple household industries, each corresponding to a different household income level, because households of different income levels have different patterns of inputs and outputs.) Each level of government (federal, state, and local) is treated as a separate industry in that it receives input tax receipts from households, businesses, and other levels of government, and it produces outputs (eg, expenditures on the military, highway construction, public schools, health care programs, payments to other levels of government).

The IMPLAN database is derived from federal and state employment and income data and government survey data of businesses and households.³³ The data are cleaned, organized, and transformed into consistent units. The industry equations, household receipts and expenditures, and government receipts and expenditures are all based on the employment, income, and survey data. The IMPLAN database is updated every few years as the government surveys are updated. The equations, receipts, and expenditures can be calculated at the national, state, or county level (or a collection of counties smaller than a state). When data are scarce for a particular industry in a particular geographic area, average results for that industry at the next level of aggregation are used (for example, if data are scarce for

the widget production industry in a particular state, the average results for the nationwide widget industry might be used for that state). In addition, the database contains information on imports and exports for each geographic region.

When conducting economic impact analysis, IMPLAN is used to calculate changes in the economy relative to the baseline condition of the economy when local and system wide data were collected. The present study of Medicaid expenditures in 2003 relied on the 2002 IMPLAN database (ie, the 2002 IMPLAN structural matrix was used in the analysis). The initial change to the economy must be specified by the user. This initial change is called the *direct impact*. For example, if the state of North Carolina is the region of analysis then Medicaid dollars initially spent in the state constitute the *direct impact*. These initial expenditures purchase output from various health care industries. For example, in this study Medicaid dollars purchase output from the following list of IMPLAN health care industry sectors in North Carolina in 2003:

- Pharmaceutical and medicine manufacturing
- Surgical and medical instrument manufacturing
- Surgical appliance and supplies manufacturing
- Ophthalmic goods manufacturing (eg, eyeglasses)
- Home health care services
- Doctors, dentists, and other health care professionals
- Other ambulatory health care services
- Hospitals
- Nursing and residential care facilities
- Office administrative services (eg, program administration, tracking patient records)

In order to produce the purchased health care products and services, health care industries must, in turn, pay workers and purchase various goods and services from other industries. Next, the industries producing these goods and services must, in turn, purchase other goods and services, and so on. However, the process does not go on forever. At each round of purchasing, the dollar amount of purchases becomes smaller, eventually becoming negligible. The second and subsequent rounds of purchases constitute the *indirect impacts* of the initial Medicaid expenditures. At each round of purchasing, some of the dollars received by the producing industries go toward paying workers and owners of the firms. The workers and owners pay taxes on this income, save some of the income, and spend the rest. This spending by workers and owners initiates additional, attenuating rounds of purchasing called the *induced impacts* of the initial Medicaid expenditures. The indirect and induced impacts are collectively known as *multiplier effects*. The sum of the direct, indirect, and induced impacts is called the *total impact*.

The direct, indirect, and induced impacts of the Medicaid expenditures lead to changes in business sales (also known as business activity or business output), employment, labor income (eg, wages and salaries), capital income (eg, rents, interest and dividend income), and taxes paid to various levels of government. IMPLAN tracks the changes in business sales, employment,

and other areas separately for the direct, indirect, and induced impacts and also cumulates them into total impacts.

Results

The Economic Impacts of Medicaid

In SFY 2003 \$6.307 billion in initial Medicaid program expenditures occurred within the state of North Carolina—\$3.941 billion federal dollars, \$2.014 billion state dollars, and \$351 million in local government funds. Each dollar of state and local government expenditures brought \$1.67 federal cost-share Medicaid dollars to the state. Of the \$6.307 billion in Medicaid expenditures, \$1.63 billion or 25.8% was spent on children ages 0-18. The economic impacts of these Medicaid expenditures are both deep and broad. The estimated statewide total economic impacts (including economic multiplier effects) of the \$6.307 billion in Medicaid expenditures within North Carolina in SFY 2003 are summarized in Table 1.

Table 1 provides impact estimates for 3 economic indicators

of interest: employment (including full- and part-time jobs), labor income (including wages and salaries plus income from sole proprietorships or partnerships including many physicians' practices), and capital income (including rental income, interest income, and corporate dividend income). The economic impacts within North Carolina of the 2003 Medicaid expenditures in the state included 182 000 jobs supported (including both full-time and some part-time jobs), \$6.1 billion in labor income (wages, salaries, and sole proprietorship/partnership profits), and \$1.9 billion in capital income (rents, interest payments, and corporate dividend payments).

We find that Medicaid expenditures directly support 92 489 jobs (including both full- and part-time jobs) in North Carolina. An additional 89 634 jobs are supported by the indirect and induced multiplier effects of Medicaid spending for a total of 182 124 jobs statewide supported by Medicaid. Of these jobs, Medicaid directly supports the equivalent of approximately 85 000 health care industry jobs with multiplier effects supporting an additional 6 000 health care jobs for a

Table 1.
Economic Impacts of Medicaid Expenditures on Employment, Labor Income, and Capital Income:
North Carolina State Fiscal Year 2003

	Economic Impacts of Federal Expenditures	Economic Impacts of State & Local Expenditures	Economic Impacts of Total Expenditures
Employment¹			
Direct Impacts	57 738	34 751	92 489
Indirect Impacts	12 066	7 243	19 309
Induced Impacts	43 940	26 385	70 325
Total Impacts	113 744 jobs	68 380 jobs	182 124 jobs
Labor Income²			
Direct Impacts	\$1 857 157 998	\$1 115 689 427	\$2 972 847 425
Indirect Impacts	\$436 380 583	\$262 417 396	\$698 797 979
Induced Impacts	\$1 524 323 030	\$915 342 114	\$2 439 665 144
Total Impacts	\$3 817 861 699	\$2 292 842 764	\$6 110 704 463
Capital Income³			
Direct Impacts	\$310 423 367	\$186 369 112	\$496 792 479
Indirect Impacts	\$252 410 077	\$151 467 201	\$403 877 278
Induced Impacts	\$619 650 077	\$372 115 364	\$991 765 441
Total Impacts	\$1 182 483 521	\$709 951 650	\$1 892 435 171

SOURCE: Unless otherwise indicated all data reported in this article reflect the IMPLAN® analysis of data provided by the North Carolina Division of Medical Assistance for North Carolina State Fiscal Year 2003 as reported to the US Centers for Medicare and Medicaid Assistance.

NOTES:

1. Employment includes all jobs both full- and part-time.
2. Labor Income includes wages, salaries, sole proprietorship income, and partnership income. Values are 2003-year dollars.
3. Capital Income includes rental income, interest income, and corporate dividend income. Values are 2003-year dollars.

total of about 91 000 health care jobs supported. Estes³ estimated that 395 000 individuals were employed in the North Carolina health care sector in 2001. Allowing for moderate growth (8% per year) in the total number of health care jobs in North Carolina between 2001 and 2003, Medicare conservatively supports at least 20% of all health care jobs in the state.

The direct impact of Medicaid spending on capital income is \$497 million. The indirect and induced impacts of Medicaid spending on capital income are nearly 3 times larger than the direct effects. This means that the multiplier effects of Medicaid expenditures on capital income are very strong. It is not just the corporations in the health care industry that benefit from Medicaid; business quite broadly benefits as well.

The aggregate impact of Medicaid expenditures on labor income (\$6.1 billion) is much larger than the impact on capital income (\$1.9 billion). This is consistent with the fact that health care is a labor-intensive sector characterized at the service delivery level by many small firms with relatively high employment. While direct impacts occur predominantly in health care industries, Medicaid also produces substantial multiplier effects in nonhealth industries through business-to-business transactions (indirect impacts) and consumer purchasing (induced impacts). Industry-by-industry results produced by the IMPLAN model (not reported here for the sake of brevity) indicate that the construction, transportation, wholesale and warehousing, retail trade, finance and insurance, and hotel and restaurant industries in North Carolina each received over \$100 million in wages and salaries due to the indirect and induced impacts of Medicaid expenditures in 2003.

How does Medicaid job creation compare to economic development efforts that offer firms incentives to open or expand activities in North Carolina? In a November 9, 2004 press release,⁴¹ Governor Mike Easley announced that North Carolina offered Dell Computer an incentive package of \$242.5 million over 20 years to create, directly and indirectly, 8 000 jobs within the state or \$30 313 spending per job. By comparison North Carolina state and local governments invested \$2.371 billion in Medicaid in 2003, which when leveraged with federal cost share dollars, supported 182 000 jobs or \$13 000 in state/local spending per job. Although some Medicaid-supported health care jobs such as physician may pay higher salaries than the average Dell job, and other Medicaid-supported jobs such as hospital custodian may pay less, the average wage/salary of North Carolina health care workers in 2003 was \$39 660—similar to the state-average median household income in 2004 of \$40 863.⁴² Furthermore, Medicaid-supported jobs are widely distributed geographically across the state, whereas the jobs

created by specific industrial projects are typically concentrated in a relatively small geographic region.

Much of the labor income and capital income supported by Medicaid is taxable by federal, state, and local governments. The federal government collects personal income, corporate profit, and payroll taxes. There is a comparable set of taxes at the state level. In addition, households pay local property taxes plus state and local sales taxes.^d Table 2 summarizes tax receipts by governmental entity.

Panel 1 of Table 2 shows that the federal government collected approximately \$1.6 billion in taxes as a result of all Medicaid expenditures (by all levels of government) in North Carolina in 2003—most in the form of personal income taxes (53.6%) with another substantial proportion in payroll taxes (41%). Consequently, the federal government recouped approximately 42% of its \$3.9 billion in North Carolina Medicaid expenditures. State and county governments contributed \$2.365 billion in Medicaid expenditures and collected taxes of \$567 million. Consequently, state and local governments recouped approximately 24% of their Medicaid expenditures in the form of tax collections supported by Medicaid expenditures. The larger share of taxes (60.5%) went to the state, principally in the form of personal income (44.6%) and sales taxes (38.6%). State and federal Medicaid funds flowing into each county do not appear directly as line items on the budgets of county governments; they appear only indirectly in the sales tax and property tax revenue lines. Counties and localities realized \$224 million in sales and property tax receipts from Medicaid expenditures in 2003, which offset more than half (56%) of their \$400 million in Medicaid contributions.

A Policy Experiment: “What if We Gave the Medicaid Money Back to Taxpayers?”

Although the economic impacts of Medicaid spending are large, the economic impacts of spending on this scale would likely be significant if the money were spent on something other than Medicaid. The opportunity cost to society of spending money on Medicaid is that society gives up the economic impacts of spending money in other ways. To investigate the opportunity cost of Medicaid spending, we conduct a policy simulation experiment in which we assume the Medicaid program is shut down, and the federal, state, and local taxes paid by North Carolina taxpayers to support Medicaid are returned to the taxpayers. The taxpayers save and spend the returned funds based on observed patterns in federal consumer expenditure survey data. The expenditure patterns vary by household income level (eg, higher income households save a larger proportion

d In North Carolina separate sales taxes are levied by the state and local governments.⁴³ In SFY 2003 the North Carolina state sales tax rate was 4.5% on retail sales (or rental) of tangible personal property, room/lodging/hotel rentals, and laundering services with some exceptions. The North Carolina state sales tax does not apply to unprepared food (eg, groceries) but does apply to prepared food and other items (eg, restaurant meals, food purchased in the deli sections of grocery stores, alcohol, tobacco products). Nor does the North Carolina state tax apply to drugs or medical equipment sold with a prescription. The tax does not apply to insulin or prosthetic devices sold with or without a prescription. Every county may charge an additional 2.5% sales tax on all items subject to the North Carolina state 4.5% tax rate. In addition to general sales taxes, some counties levy additional sales taxes on particular items or activities, such as hotel occupancy taxes. Specific policies vary by county. Hence, the allocation of sales taxes in this table is a rough but realistic estimate.

Table 2.
Economic Impacts of Medicaid Expenditures on Federal, State, and County/Local Tax Receipts:
North Carolina State Fiscal Year 2003

Government Entity	Tax Receipts Supported By		
	Federal Medicaid Expenditures	State & Local Medicaid Expenditures	Total Medicaid Expenditures
Federal Tax Receipts			
Personal Income	\$547 681 505	\$328 918 317	\$876 599 822
Corporate Profit	\$54 857 270	\$32 931 277	\$87 788 547
Payroll	\$418 640 859	\$251 423 317	\$670 064 176
Total Receipts	\$1 021 179 634	\$613 274 911	\$1 634 452 545
State Tax Receipts			
Personal Income	\$95 705 675	\$57 477 472	\$153 183 147
Corporate Profits	\$28 857 605	\$17 323 462	\$46 181 067
Payroll	\$7 285 231	\$4 375 321	\$11 660 552
Estimated Sales ¹	\$82 773 004	\$49 694 615	\$132 467 619
Total Receipts	\$214 621 515	\$128 870 870	\$343 492 385
County/Local Tax Receipts			
Property	\$93 337 918	\$56 037 732	\$149 375 650
Estimated Sales ¹	\$46 559 814	\$27 953 221	\$74 513 035
Total Receipts	\$139 897 732	\$83 990 953	\$223 888 685
All Entities	\$1 375 698 880	\$826 134 734	\$2 201 833 615

SOURCE: IMPLAN model calculations.

NOTES: Because of the way data are reported estimates are necessary to apportion sales taxes between state and county governments. For the purposes of this exercise, we assume a state sales tax rate of 4.5% and a local sales tax rate of 2.5%. Under these assumptions the state receives 64% ($4.5\% / [4.5\% + 2.5\%] = 64\%$) of combined state and local sales tax revenues with counties/localities receiving the remaining 36%.

of each dollar returned). Because most Medicaid dollars are spent on labor-intensive, in-state health care services rather than goods imported into the state, Medicaid spending has a relatively large in-state economic multiplier effect. By contrast, a large proportion of the typical consumer's spending pays for goods imported into the state (eg, gasoline, food, clothing, entertainment, electronics). If the Medicaid program was shut down, funds returned to taxpayers, and taxpayers allowed to spend these monies according to typical consumer spending patterns, the in-state economic impacts of these expenditures would be smaller than the in-state economic impacts of Medicaid. In fact, our simulation indicated that employment in North Carolina would fall by an estimated 67 400 jobs and labor income would fall by \$2.83 billion if Medicaid funds were returned to taxpayers. The reason for this perhaps surprising result is that most Medicaid dollars are spent on labor-intensive, in-state health care services rather than goods imported into the state.

In contrast, a far larger proportion of typical consumer spending buys goods and services imported into the state. In comparison to typical consumer spending, Medicaid dollars stay in the state, supporting employment and businesses within North Carolina.

The County Cost Share Issue

The rapid growth in Medicaid payments in recent years has put pressure on county government budgets in North Carolina, causing counties to lobby the state to assume the county portion of Medicaid payments. One issue of concern has been that some rural or less affluent counties may be more reliant on Medicaid and may be paying a disproportionate share of Medicaid costs. Another issue has been that Medicaid funds allocated to residents of a given county may not support businesses and tax collections in that county since residents travel across county lines to access health care services not available in the

county of residence. As a temporary measure, the state government agreed in 2006 to cap county Medicaid expenditures.⁴⁴ On July 31, 2007, the governor of North Carolina signed into law a measure requiring the state to assume the county portion of Medicaid expenditures.⁴⁵ The transfer would be phased in over 3 years beginning October 1, 2007. In partial compensation, counties would be required to give up a portion of their sales tax revenues to the state.

To address the issue of whether some counties may be more reliant on Medicaid, we consider two measures of Medicaid reliance: county Medicaid expenditures⁵ as a percentage of county budget⁴⁶ in 2003 and Medicaid eligibles⁵ as a percentage of county population⁴⁶ in 2004. We regressed each of these measures on (1) per capita county income⁴⁶ (\$1 000s) in 2003; (2) county population⁴⁶ (10 000s) in 2003; and (3) the United States Department of Agriculture Economic Research Service (USDA-ERS) Rural-Urban Continuum Codes,⁴⁷ 2003, an index of county rural character (larger code numbers indicate a more rural character). County Medicaid expenditures as a percentage of county budget in 2003 are negatively related to per capita county income at the 0.05 level of significance, indicating that wealthier counties spend a smaller percentage of the county budget on Medicaid. County population and USDA-ERS Rural-Urban Continuum Codes are not statistically significant determinants of county Medicaid expenditures as a percentage of county budget in 2003, indicating that rural/urban status does not appear to be a significant determinant of county Medicaid expenditures as a percentage of county budgets. Medicaid eligibles as a percentage of county population, 2004, is negatively related to per capita county income (\$1 000s) in 2003 at the 0.05 level of significance. It is also positively related to both county population in 2003 and USDA-ERS Rural-Urban Continuum Codes at the 0.05 level of significance. Hence, wealthier counties tend to have fewer Medicaid eligibles as a percentage of county population while more populous counties and more rural counties have more Medicaid eligibles as a percentage of county population. We conclude that reliance on Medicaid does vary by county type with more affluent counties spending a smaller percentage of the county budget on Medicaid and having a smaller percentage of the population eligible for Medicaid, while more populous and more rural counties have a larger percentage of the population eligible for Medicaid.

To investigate the issue of whether Medicaid funds allocated to residents of a given county actually support businesses and tax collections in the county, we analyze the Medicaid expenditure data by county of health care provider location. The analysis shows that for every North Carolina county, the state and federal government cost share expenditures paid to health care providers located in the county were far greater than the county contribution to Medicaid. For example, relatively populous, urban, and affluent Wake County spent approximately \$20 million in local government funds on Medicaid in SFY 2003, but the federal government paid over \$200 million in Medicaid expenditures to health care providers located in Wake County. Similar results hold for rural, less populous, or less affluent counties. Even small Yancey County, which spent only \$500 000

in local funds on Medicaid in 2003, received over \$5 million in federal Medicaid expenditures paid to health care providers located in the county. (Results for all North Carolina counties are available on request from the authors.) One reason that Medicaid expenditures are significant even in rural locations is that a relatively large share of Medicaid expenditures in rural counties goes to nursing and residential care services that are provided in the rural counties themselves. We conclude that even after accounting for Medicaid expenditures that cross county lines, every county in North Carolina has far more state and federal Medicaid money spent in the county than the county itself collects and spends on Medicaid.

Discussion And Conclusions

The rising costs of health care and the appropriate role of government health insurance programs in the health care system are the source of current policy debates. Informed discussion of these issues requires good information on the economic as well as the health consequences of alternative policy choices. The purpose of this study is to estimate the economic impacts of Medicaid program expenditures in North Carolina in SFY 2003 (see Figure 1.D.). In SFY 2003 \$6.307 billion in Medicaid program expenditures occurred within the state of North Carolina—\$3.941 billion federal dollars, \$2.014 billion state dollars, and \$351 million in local government funds. Each dollar of state and local government expenditures brought \$1.67 federal Medicaid cost-share dollars to the state. The total economic impacts (including direct, indirect, and induced impacts) in North Carolina of Medicaid expenditures in 2003 included (see Table 1):

- 182 000 jobs supported (including both full-time and some part-time jobs)
- \$6.1 billion in wages, salaries, and sole proprietorship/partnership income
- \$1.9 billion in rents, interest payments, and corporate dividend payments

State and local governments recouped approximately 24% of their Medicaid expenditures in the form of various tax collections on Medicaid expenditures and the economic ripple effects of Medicaid expenditures.

Our unique data set allows us to estimate Medicaid expenditures and economic impacts by health care provider location at the county level. Although we find that reliance on Medicaid does vary by rural/urban and rich/poor county type, the data also show that every North Carolina county received far more in state and federal government cost share expenditures paid to health care providers located in the county than they paid in county-share Medicaid expenditures.

Although Medicaid spending generates large economic impacts, it should be recognized that the Medicaid program diverts spending away from other potential uses that would have generated other economic impacts. In a policy simulation experiment we answer the question, “What would be the net

economic impacts of giving the Medicaid money back to taxpayers?” In the experiment we assume that the Medicaid program is shut down, that federal, state and local taxes paid by North Carolina taxpayers to support Medicaid are returned to the taxpayers, and that the taxpayers save and spend the returned funds based on typical consumer expenditure patterns. We find that the in-state economic impacts of these expenditures are substantially smaller than the in-state economic impacts of Medicaid. In fact, our simulation indicates that employment in North Carolina would fall by an estimated 67 400 jobs and labor income would fall by \$2.83 billion. The reason for this perhaps surprising result is that most Medicaid dollars are spent on labor-intensive, in-state health care services rather than on goods imported into the state. In contrast, a far larger proportion of typical consumer spending buys goods and services imported into the state. In comparison to typical consumer spending, Medicaid dollars stay in the state, supporting employment and businesses within North Carolina.

It is important to keep in mind that the Medicaid expenditure and economic impact results do not capture the economic value of the improved health and well-being of Medicaid recipients. Furthermore, the results do not capture the savings to society in general of emphasizing preventive care and reducing uncompensated care nor the long-term benefits of promoting wellness. Health insurance like Medicaid provides access to routine medical care, thereby promoting preventive care and timely and appropriate medical interventions and minimizing the necessity of relying on costly emergency services. Medicaid also reduces uncompensated care, which in turn reduces health care providers’ need to shift costs to patients with private insurance. Additionally, comprehensive Medicaid services may allow covered adults to obtain or return to employment more quickly. Medicaid services for children— especially Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) services—support both the typical child as well as children with special health care needs. This investment in human capital should improve the capacity of young Medicaid beneficiaries to become productive members of society in the future.

Another caveat is that Medicaid plays a role in supporting the health care infrastructure available to the general population.

Medicaid cuts could threaten the financial health of key facilities such as hospitals, or at least shift a larger share of the infrastructure support costs to those with private insurance. Further, to the extent that health care facilities provide amenity effects—such as those associated with living near an ocean—that boost community property values, facility closures could reduce property values. Similarly, a factory may choose to relocate elsewhere if the only hospital in a community closes. These effects are not captured by standard economic impact analysis.

This article poses a basic question: “What are the economic impacts of Medicaid on the North Carolina economy?” Medicaid is a large program with complex implications for its beneficiaries and the communities in which they live. The program is important for the health of many North Carolina citizens. In addition, the economic impacts of the program are substantial and felt statewide from urban research hospitals to rural nursing home facilities. Budgetary costs do not fully capture the economic consequences of Medicaid in North Carolina. This study finds that Medicaid makes a large contribution to state and local economic activity by creating jobs, income, and profit in North Carolina. Any substantial changes to the Medicaid program should be made with caution. **NCMJ**

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REFERENCES

- 1 North Carolina Division of Medical Assistance (NCDMA). How the NC Medicaid program works. Addendum A to Medicaid North Carolina Annual Report 2003. North Carolina Department of Health and Human Services. http://www.dhhs.state.nc.us/dma/2003report/03annrpt_adda.pdf. Published March 2004. Accessed June 27, 2005.
- 2 Holahan J, Ghosh A. Understanding the recent growth in Medicaid spending, 2000-2003. *Health Aff.* 2005;W5:52-62.
- 3 Estes J. *Health Care and North Carolina's Economy*. Raleigh, NC: Office of Research, Demonstrations, and Rural Health Development, North Carolina Department of Health and Human Services; 2005.
- 4 Kaiser Commission on Medicaid and the Uninsured. *Medicaid Financing Issues: Intergovernmental Transfers and Fiscal Integrity, Key Facts # 7282*. Washington, DC: Kaiser Family Foundation; 2005.
- 5 North Carolina Division of Medical Assistance. *Medicaid in North Carolina. Annual Report, State Fiscal Year 2003*. Raleigh, NC: North Carolina Dept of Health and Human Services; 2004. <http://www.dhhs.state.nc.us/dma/annreport.htm>. Accessed June 27, 2005.
- 6 Wachino V, Schneider A, Rousseau D. *Financing the Medicaid Program: The Many Roles of Federal and State Matching Funds*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured; 2004.
- 7 National Association of State Budget Officers. *2004 State Expenditure Report*. Washington, DC: National Association of State Budget Officers; 2006. <http://www.nasbo.org/publications/Report.php>. Accessed March 13, 2006.
- 8 The Medicaid Program at a Glance - Key Facts #7235. Kaiser Commission on Medicaid and the Uninsured Web site.

- <http://www.kff.org/kcmu>. Published January 2005. Accessed January 7, 2005.
- 9 Aizer A. Public health insurance, program take-up, and child health. *Rev Econ Stat*. 2007;89(3):400-415.
 - 10 Ungar WJ, Rinat A. Health insurance, access to prescription medicines and health outcomes in children. *Expert Review of Pharmacoeconomics and Outcomes Research*. 2005;5(2):215-225.
 - 11 Doyle JJ. Health insurance, treatment and outcomes: using auto accidents as health shocks. *Rev Econ Stat*. 2005;87(2):256-270.
 - 12 Paying a premium: the increased cost of care for the uninsured. Families USA Web site. <http://www.familiesusa.org/resources/publications/reports/paying-a-premium.html>. Published July 13, 2005. Accessed October 22, 2007.
 - 13 Hogan T. *The Economic Impact of Proposed Budget Cuts to Arizona's Health Care Safety Net*. Tempe, AZ: Arizona Hospital and Health Care Association, Center for Business Research, L. William Seidman Research Institute, Arizona State University; 2003.
 - 14 Doeksen GA, St.Clair C. *Economic Impact of Medicaid Program on Alaska's Economy*. Stillwater, OK: Oklahoma State University; 2002.
 - 15 Perryman Group. *Medicaid and the Children's Health Insurance Program (CHIP): An Assessment of Their Impacts on Business Activity and the Consequences of Potential Funding Reductions*. Waco, TX: Perryman Group; 2003.
 - 16 Miller W, Pickett J. *Economic & Fiscal Impact of Additional \$100 Million in State Funding for Medicaid Programs*. Little Rock, AR: University of Arkansas, Cooperative Extension Service; 2003.
 - 17 Sampath P. *Penny Wise & Pound Foolish: Why Cuts to Medicaid Hurt Florida's Economy*. Human Services Coalition of Dade County, Inc.; 2003.
 - 18 Essig A. *Governor's FY 2004 and FY 2005 Medicaid Budget Proposals*. Atlanta, GA: Fiscal Research Center, Andrew Young School of Policy Studies, Georgia State University; 2004. Georgia budget notes no. 16.
 - 19 Warn D, Peterson S. *Medicaid Supports Idaho's County Economies*. Seattle, WA: Northwest Federation of Community Organizations; 2004.
 - 20 Stoll K, Sullivan J, Babaeva L. *Good for Kids, Good for the Economy: Health Coverage for All Kids in Illinois*. Washington, DC: Families USA; 2005. Publication no. 05-106.
 - 21 Blair B, Millea M. *Economic Impacts of Federal Medicaid Expenditures on Mississippi, 2002*. Mississippi State, MS: Mississippi Health Policy Research Center, Mississippi State University; 2003.
 - 22 Missouri Foundation for Health. *Economic and Health Benefits of Missouri Medicaid*. St. Louis, MO: Missouri Foundation for Health; 2004. Show Me Series report 5.
 - 23 Seninger S. *Economic Impact of Medicaid on Montana and on the Billings, Butte, and Miles City Health Care Market Areas*. Missoula, MT: Bureau of Business and Economic Research, University of Montana-Missoula; 2003.
 - 24 Greenbaum R, Desai A. *Uneven Burden: Economic Analysis of Medicaid Expenditure Changes in Ohio*. Columbus, OH: School of Public Policy and Management, Ohio State University; 2003.
 - 25 Desai A, Kim Y, Greenbaum R. *Estimating Local Effects of Medicaid Expenditure Changes*. Columbus, OH: Health Policy Institute of Ohio; 2005.
 - 26 Miller M. *RtIe Care: Right for Rhode Island—A Briefing Paper on RtIe Care's Positive Economic Impact on Rhode Island*. Boston, MA: Community Catalyst; 2002.
 - 27 South Carolina Department of Health and Human Services. *Economic Impact of Medicaid on South Carolina*. Columbia, SC: Division of Research, Moore School of Business, University of South Carolina; 2002.
 - 28 Crispin-Little J. The economic impact and importance of Medicaid and CHIP on Utah's economy. *Utah Economic and Business Review*. 2003;63(3-4):1-10.
 - 29 Fiscal Analytics, Ltd. *The Impact of Additional Medicaid Spending in Virginia*. Richmond, VA: Commonwealth Care Coalition; 2003.
 - 30 Christiadi, A, Witt TS. *Economic Impact of Medicaid Federal-Match on the West Virginia Economy FY2002*. Morgantown, WV: Bureau of Business and Economic Research, College of Business and Economics, West Virginia University; 2003.
 - 31 Deller SC, Hall LA, Peacock J. *Economic Impact of Reducing Medicaid and BadgerCare Expenditures*. Madison, WI: Wisconsin Council on Children & Families; 2003.
 - 32 Miller RE, Blair PD. *Input-Output Analysis: Foundations and Extensions*. Upper Saddle River, NJ: Prentice Hall; 1985.
 - 33 *IMPLAN System* [computer program]. Version 2.0.1025. Stillwater, MN: Minnesota IMPLAN Group, Inc.; 2005.
 - 34 Carbaugh A, Lyons B, Hudman J, Wachino V. *The Role of Medicaid in State Economies: A Look at the Research, Policy Brief #7075*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured; 2004.
 - 35 Families USA. *Medicaid: Good Medicine for State Economies*. Washington, DC: Families USA; 2003. Publication no. 03-101. <http://www.familiesusa.org/assets/pdfs/GoodMedicineReport5a53.pdf>. Published January 2003. Accessed October 20, 2004.
 - 36 Families USA. *Medicaid: Good Medicine for State Economies: 2004 Update*. Washington, DC: Families; 2004. Publication no. 04.-102. http://www.familiesusa.org/assets/pdfs/goodmedicine_2004_update93b7.pdf. Published May 2004. Accessed May 17, 2004.
 - 37 Cordes S, Van der Sluis E, Lamphear C, Hoffman J. Rural hospitals and the local economy: a needed extension and refinement of existing empirical research. *J Rural Health*. 1999;15(2):189-201
 - 38 Doeksen GA, Loewen RA, Strawn DA. A rural hospital's impact on a community's economic health. *J Rural Health*. 1990;6(1):53-64.
 - 39 Rickman DS, Schwer RK. A comparison of the multipliers of IMPLAN, REMI, and RIMS II: benchmarking ready-made models for comparison. *Ann Reg Sci*. 1995;29:363-374.
 - 40 Duncombe W, Wong W. Building state and local government analytic capacity: using regional economic models for analysis of public policy. *State and Local Government Review*. 1997;30(3):165-180.
 - 41 "Easley Announces Dell to Locate in Piedmont Triad." Press release, November 9, 2004. State of North Carolina, Office of the Governor. Web site. http://www.governor.state.nc.us/News_FullStory.asp. Accessed October 22, 2007.
 - 42 North Carolina State & County QuickFacts. US Census Bureau Web site. <http://quickfacts.census.gov/qfd/states/37000.html>. Updated January 2, 2008. Accessed October 22, 2007.
 - 43 Sales and use tax. North Carolina Department of Revenue Web site. www.dor.state.nc.us/taxes/sales/salesanduse.html. Updated October 31, 2007. Accessed October 21, 2006.
 - 44 Counties want relief from cost of NC's Medicaid setup. *News & Observer*. February 27, 2007.
 - 45 McGee T. Medicaid relief made simple. North Carolina Association of County Commissioners Web site. http://www.ncacc.org/medicaid_1007.html. Accessed October 22, 2007.
 - 46 Budget and tax survey. North Carolina Association of County Commissioners Web site. <http://www.ncacc.org/>. Accessed October 22, 2007.
 - 47 Rural-Urban Continuum Codes, 2003. United States Department of Agriculture, Economic Research Service (USDA-ERS) Web site. <http://www.ers.usda.gov/Data/RuralUrbanContinuumCodes/>. Accessed October 22, 2007.

Accuracy of Self- and Parental Perception of Overweight Among Latino Preadolescents

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Abstract

Background: This investigation examines self-perception and parental perception of child body size and factors associated with accurate parental perception of child body size.

Methods: Latino at-risk for overweight (AROW) and/or overweight preadolescent children (ages 8-11 years) along with their parents were recruited (N=123 dyads). Children's body mass index (BMI) was measured but not discussed before participants were shown pictures of body sizes and asked to select the image that represented the child's body.

Results: The correlation between the child's body size selection and the child's actual BMI was 0.117 ($p=0.20$) whereas the correlation between the parent's assessment of the child's body size and the child's actual BMI was 0.470 ($p<0.001$). Logistic regression revealed that only parental education level (\geq college) was associated with a more accurate parental perception of their child's body size (OR: 0.11/95% CI: 0.01, 0.89) while child's sex, parental BMI, and parental health status were not associated with a perception that corresponded to the child's BMI.

Limitations: The sample was drawn from a single community clinic in Forsyth County which serves a large population of newer Latino immigrants in the county.

Conclusions: The results indicate that (1) Latino AROW/overweight preadolescent children do not have an accurate perception of their own body size; (2) Latino parents have a more accurate perception of their child's body size with a moderately sized correlation suggesting that their perception of their child's body size is frequently inaccurate; and (3) Latino parents with higher education perceive their child's body size more accurately than less educated parents.

Keywords: Weight perception; body mass index; ideal body size; Hispanic Americans; body image

Accuracy of Self- and Parental Perception of Overweight Among Latino Preadolescents

Interventions for childhood obesity have, at times, been shown to be successful if they include parents.^{1,2} But for parents to choose to actively participate in obesity prevention efforts with their children, they must first be aware of overweight in their children and must be concerned about the possible consequences. Erroneous perception of body size may have important health and behavioral implications.

Latino adults have been found to be inaccurate in their perceptions of their own overweight.³ In a study of low-income

Latinas and their children aged 5-7 years, all of the women selected a relatively thin body image as the most desirable and healthy for themselves but preferred a plumper figure for their children.⁴ Several studies using multiethnic samples but not breaking results out by ethnicity have shown that parents often fail to identify their children as overweight.^{5,6} These findings indicate that Latina mothers may have a more favorable view of childhood obesity and may fail to perceive overweight in their children as problematic. We examined the research question, "Do Latino preadolescents and their parents have similar interpretations of overweight as do medical providers who utilize Body Mass Index (BMI) to make this determination?"

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PATIENTS AND METHODS

Participants

Hispanic-American at-risk for overweight (AROW) (BMI $\geq 85\%$ and $\geq 95\%$) and overweight (BMI $> 95\%$) preadolescent children (ages 8-11 years) along with one of their parents were recruited from a clinic that serves the greatest number of Latino families in Forsyth County, North Carolina. All patients who met the eligibility criteria (child's BMI $\geq 85\%$, child's age 8-11 years, self-identified as Latino, and parent willing to participate with child in the study) were invited to participate. Of the 210 families contacted, 159 families agreed to participate on the telephone, and 123 families provided data.

Measures

We obtained approval for this study from the Institutional Review Board of Wake Forest University Health Sciences. We present baseline data collected at the community-based health center in Winston-Salem, North Carolina prior to any discussion between the patient family and the health care provider. Children's and parents' BMI were measured⁷ but not discussed before participants (both adults and children, separate from one another) were shown pictures of child body sizes and asked to select the image that most looked like the child's body. Body size perception was gathered from a picture scale ranging from 1-7 for children where 1-2 was considered by health care providers to be underweight, 3-4 was considered by health care providers to be the ideal body size, 5 was considered to be AROW, and 6-7 was considered to be overweight.⁸ This scale is significantly and highly correlated with measured percentage overweight ($r=0.79$).⁸ Additional variables that were collected include the following: (1) educational level of parent (using Census 2000 format);⁹ (2) health status of parent (using questions from the Service Utilization Assessment);¹⁰ and (3) parental acculturation (using questions from Marin's short acculturation scale for Hispanics).¹¹

Statistical Methods

To assess how accurately Latino preadolescents perceive their body image compared to their parents, we calculated two correlations using Pearson's correlation coefficient: (1) between the child's assessment of his or her body size and the child's BMI, and (2) between the parent's assessment of the child's body size and the child's BMI.

To assess which factors are associated with a more accurate parental perception of body size, we created the variable AGREE. This was calculated by applying a cutoff point of 95% to the measured BMI percentile and classifying those above as overweight. We grouped the parental evaluation scores of 6 and 7 and defined this category as parents perceiving their child as overweight. When the parent's perception matched with the measured classification, the variable AGREE was coded 1; otherwise, it was coded 0. In a logistic regression, AGREE was used as the dependent variable with the sex of the child, education level of the parent (college degree versus no college degree), and self-reported health status of the parent included as independent variables.

RESULTS

In our sample of participating parents, 88% were mothers and 73% were from Mexico (other participants came from Guatemala, El Salvador, Dominican Republic, Columbia, Venezuela, and Nicaragua). Ninety-nine percent of our sample of parents reported that Spanish was spoken at home and with their friends. Moreover, 99% of these adults chose to complete surveys in Spanish. Forty-five percent (45%) of the adults had an education of 8th grade or less; 16% had education up to the 12th grade but not including graduation; 22% graduated from high school; 5% reported some college; 4% reported an associates degree/technical school; and 8% reported a college degree or higher. Average adult age was 35 years (SD 7.4) and average adult BMI was 33.4 (SD 7.8). Only 17% of adults rated their health as "very good" or "excellent;" 38% reported "good" health; and 45% reported "fair" or "poor" health. Average child age was 9.3 years (SD 1.3). The distribution of female and male children was approximately equal. Average study child's BMI was 25.9 (SD 5.5) indicating that 30% were AROW and more than 60% were overweight.

The correlation between the child's body size selection and the child's actual BMI was 0.117 ($p=0.20$) whereas the correlation between the parent's assessment of the child's body size and the child's actual BMI was 0.470 ($p<0.001$). The two correlations were statistically different ($p=0.001$), suggesting that parents had a more accurate assessment of the child's body size than did the child. While the correlation between parental perception and child's true BMI is statistically significant, we note it is only moderate in magnitude and thus conclude that parental perception of body size is frequently inaccurate.

Table 1 shows the results of the logistic regression. Parent's education was significantly associated with a more accurate perception of the identified obese child (OR: 0.11, 95% CI: 0.01, 0.89, comparing parents with less than a college education to parents with a college education or higher).

Table 1.
Factors Associated with Accurate Perceptions of Child Obesity (N=123 Parent-Child Dyads)

	Odds ratio estimate	95% CI
Child's Sex ¹	0.68	0.30, 1.52
Parent's Education ²	0.11	0.01, 0.89
Parent's BMI	0.97	0.92, 1.02
Parent's Health Status	1.04	0.67, 1.61

An estimate of higher than 1.0 in the odds ratio indicates an increased odds of agreement between perceived and actual overweight.

1 Reference category: Female

2 Reference category: With college degree

DISCUSSION

In this study, we found that Latino preadolescent overweight children perceived their body size inaccurately while their parents perceived their child's body size more accurately (but still with only a moderately sized correlation, suggesting frequent inaccuracy). Accuracy of parental perception was associated with higher parental educational levels, greater than or equal to a college level education.

Prior work from Killion et al demonstrated that African-American and Hispanic mothers' perceptions of their children's body sizes are often inaccurate for children with BMI > 95%.¹² However, that study only focused on young children aged 3-5 years. Likewise, Olvera et al demonstrated that less acculturated children and mothers identified thinner body sizes than the BMI would indicate.¹³ A third of their sample of children were overweight or at-risk for overweight as indicated by the BMI. In our sample of only at-risk for overweight and overweight preadolescents, children were inaccurate in their body size identification, but parents were more accurate in identifying the correct body size for their child. Accuracy of perception was not affected by child's sex as it was in the study by Olvera et al.

The potential factors that create only a moderately-sized correlation between parental perception of their child's body size and actual BMI could be due to many reasons. Among low-income mothers in general, it has been shown that Latino parents do not believe growth charts are useful in defining a child's weight but that physical activity and good appetite are more important markers of health status.¹⁴ Studies of Latino families in particular indicate that these individuals may have different standards for what constitutes a healthy child when compared to the standards of physicians or other ethnic groups.¹⁵ One analysis demonstrated that Mexican-American mothers of obese children selected a "chubby baby" as ideal significantly more often than Mexican-American mothers of non-obese children.¹⁶ From this report, one can infer that Latina mothers may strive to have overweight babies since it is perceived as an ideal body size. Mendoza et al proposes that the discrepancies in perception of a child's health between mother and physician, as revealed in the Hispanic Health and Nutrition Examination Survey (HHANES), may be due to an alternate view of what constitutes good health status in children, "one that is not fully appreciated by traditional measures."¹⁵ In Mendoza's family-community health promotion model, he suggests that Latinos understand good health as the absence of problems that limit functional ability to perform everyday activities.¹⁵

Health professionals should not assume that defining overweight according to BMI has meaning for all parents. Furthermore, even if a group of people is able to assess body size accurately enough to appropriately apply the term "overweight," there still remains the issue of engendering an understanding that overweight/obesity is an unhealthy state.

Where should we focus future interventions? Jain et al believes that although a discrepancy exists between the views of parents and health professionals regarding the definition of overweight in children, both parties share a general belief that children should be physically active and eat healthy diets.¹⁴ Future interventions should consider that it may be more valuable to focus on these common goals in our efforts towards decreasing the epidemic of childhood obesity.¹⁴

Limitations

The study was limited due to a sample that was drawn from a single clinic in Forsyth County; therefore, generalizability may be limited. However, this clinic is one of the predominant clinics providing health care to Latino immigrant families in the county and might offer a glimpse into the less acculturated Latino family. The study involved mostly Latina mothers; it would be interesting to determine whether Latino fathers share similar degrees of body image perceptions for their children. Lastly, future research on Latino families should investigate other factors that enable parents to more accurately perceive their child's body size such as acculturation of the parent and child.

Relevance

Erroneous perception of body size may have important health and behavioral implications. Understanding the mutable factors that reinforce parental ability to see their child's body size accurately is a necessary first step to developing effective pediatric obesity interventions. Consistent with the Health Belief Model,¹⁷ perceived severity of a problem impacts the likelihood that individuals are willing to change their behaviors. In this case, connecting an accurate perception of an overweight child to poor health would be an important first step for Latino parents to promote behavior change to address obesity in their overweight children. **NCMJ**

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REFERENCES

- 1 Epstein LH. Methodological issues and ten-year outcomes for obese children. *Ann N Y Acad Sci.* 1993(699):237-249.
- 2 Golan M, Kaufman V, Shahar DR. Childhood obesity treatment: targeting parents exclusively v. parents and children. *Br J Nutr.* 2006;95(5):1008-1015.
- 3 Yancey AK, Simon PA, McCarthy WJ, Lightstone AS, Fielding JE. Ethnic and sex variations in overweight self-perception: relationship to sedentariness. *Obesity.* 2006;14(6):980-988.
- 4 Contento IR, Basch C, Zybert P. Body image, weight, and food choices of Latina women and their young children. *J Nutr Educ Behav.* 2003;35(5):236-248.

- 5 Eckstein KC, Mikhail LM, Ariza AJ, Thomson JS, Millard SC, Binns HJ. Parents' perceptions of their child's weight and health. *Pediatrics*. 2006;117(3):681-690.
- 6 Baughcum AE, Chamberlin LA, Deeks CM, Powers SW, Whitaker RC. Maternal perceptions of overweight preschool children. *Pediatrics*. 2000;106(6):1380-1386.
- 7 World Health Organization. *Obesity: Preventing and Managing the Global Epidemic—Report of a WHO Consultation on Obesity*. Geneva, Switzerland: World Health Organization; 1989.
- 8 Bulik CM, Wade TD, Heath AC, Martin NG, Stunkard AJ, Eaves LJ. Relating body mass index to figural stimuli: population-based normative data for Caucasians. *Int J Obes Relat Metab Disord*. 2001;25(10):1517-1524.
- 9 Bauman KJ, Graf NL. *Census 2000 Brief C2KBR-24: Educational Attainment: 2000*. Washington, DC: US Census Bureau; 2003.
- 10 Hunter WM, Cox CE, Teagle S, et al. 2003. Measures for Assessment of Functioning and Outcomes in Longitudinal Research on Child Abuse. Volume 1: Early Childhood. LONGSCAN Web site. <http://www.iprc.unc.edu/longscan/pages/measures/>. Accessed April, 1 2008.
- 11 Marín G, Sabogal F, Marín BV, Otero-Sabogal R, Perez-Stable E.J. Development of a short acculturation scale for Hispanics. *Hispanic J Behav Sci*. 1987;9(2):183-205.
- 12 Killion L, Hughes SO, Wendt JC, Pease D, Nicklas TA. Minority mothers' perceptions of children's body size. *Int J Pediatr Obes*. 2006;1(2):96-102.
- 13 Olvera N, Suminski R, Power TG. Intergenerational perceptions of body image in Hispanics: role of BMI, gender, and acculturation. *Obes Res*. 2005;13(11):1970-1979.
- 14 Jain A, Sherman SN, Chamberlin LA, Carter Y, Powers SW, Whitaker RC. Why don't low-income mothers worry about their preschoolers being overweight? *Pediatrics*. 2001;107(5):1138-1146.
- 15 Mendoza FS, Fuentes-Afflick E. Latino children's health and the family-community health promotion model. *West J Med*. 1999;170(2):85-92.
- 16 Alexander MA, Sherman JB, Clark L. Obesity in Mexican-American preschool children – a population group at risk. *Public Health Nurs*. 1991;8(1):53-58.
- 17 Rimer BK, Glanz K. *Theory at a Glance: Application to Health Promotion Practice*. National Cancer Institute, US Dept of Health and Human Services; 2005.

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Newborn Screening in North Carolina: The Evolution of Policy and Practice

H. Neil Kirkman, MD

Abstract

Newborn screening policies in North Carolina are due to the efforts of skilled and knowledgeable state officials, clinicians, and scientists who are able to develop effective newborn screening procedures. A newborn screening that was developed in North Carolina is the first automated method for diagnosing phenylketonuria. This process was later adopted in many other states. The use of tandem mass spectrometry in newborn screening was also pioneered in North Carolina, and it is being used in an increasing number of states. Newborn screening is more than testing, however; follow-up and specialized care are essential. State-level policies should recognize the multiple links necessary to make newborn screening effective and efficient.

In 1934 Norwegian physician Asbjørn Fölling reported a pair of siblings with a disease we now call phenylketonuria or PKU. Left untreated, PKU usually affects brain development and leads to mental retardation.¹ The disease was soon recognized as an autosomal recessive disorder in which each sibling of an affected child has a 25% chance of being born with the condition. By the early 1960s an infant formula low in phenylalanine was marketed and showed promise, when begun early, of preventing mental retardation. In 1963 Robert Guthrie, a microbiologist at the State University of New York at Buffalo, published a blood test for detecting the disorder in infants soon after birth.² The test utilized blood spotted onto filter paper. A punch of the blood-spotted filter paper was placed on agar containing the bacterium *Bacillus subtilis* and a substance that made the bacteria dependent on phenylalanine for growth. Affected infants had a greater zone of bacterial growth around their paper disk than did unaffected infants.

Early Days

Along with concerned parents, Dr Guthrie lobbied the legislatures of various states to mandate the testing of all newborn infants for phenylketonuria. Many states passed the mandate in the 1960s and subsequent events justified the early detection of PKU through newborn screening. At that time, North Carolina was fortunate to have Dr Theodore D. Scurletis as chief of the Maternal and Child Health Section of the State

Board of Health. With input from Dr James B. Sidbury, Jr of Duke University; Drs George Summer, John Hill, and Harrie Chamberlin of the University of North Carolina at Chapel Hill; and others, Dr Scurletis urged the governor and legislators to go beyond a mandate and authorize adequate funds for a state newborn screening laboratory in Raleigh. Governor Terry Sanford appropriated \$52 000 toward the laboratory in 1964, and the legislature approved continued funding. The laboratory became what is now the Newborn Screening Laboratory in the North Carolina State Laboratory of Public Health. Before testing was mandated in North Carolina, Dr Scurletis recognized the value of informing medical personnel about the importance of screening, and in 1965 he undertook an educational campaign for physicians, nurses, and health department staff. As a result, North Carolina's compliance rate reached 97%, exceeding rates in some states with compulsory testing.

Legislative action benefited North Carolina's newborn screening initiative by providing additional funds that were seriously needed at the time. Funding in North Carolina is influenced by the fact that the Newborn Screening Laboratory has an all-volunteer advisory committee made up of physicians and scientists who are experts in the various disorders being screened and who are from the different North Carolina medical teaching centers. The committee, which includes the parents of affected children and a representative of the North Carolina Pediatric Society, meets several times a year. The practicing physician representative can relay concerns about problems

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with newborn screening as well as practice-related details about newborn screening.

North Carolina as a Leader in Newborn Screening Methods

In addition to proposing funding, Dr Scurletis encouraged the use of an automated test³ for detecting elevated concentrations of phenylalanine rather than Guthrie's bacterial method. The automated test was developed in the early years of automated analysis—an approach now commonly used in laboratory medicine—and seemed more advanced and accurate than the Guthrie test. North Carolina physician-scientists Drs John Hill and George Summer of the University of North Carolina at Chapel Hill created the test. In the early years North Carolina was the only state using this test. It was later adopted by many other states as well as by regions of Canada.

The second major breakthrough in newborn screening also had its origin in North Carolina. In the late 1980s investigators at Duke University, principally Dr David S. Millington and Dr Steve Kahler, began using powerful tandem mass spectrometry (MS/MS) to study blood spots of newborns and to screen for amino acid disorders. Dr Mohamed Rashed of Saudi Arabia developed an electrospray method⁴ that allowed samples to be processed more rapidly with MS/MS. After the feasibility of newborn screening with MS/MS was reported,⁵ the procedure began to gain general use.⁶⁻⁸ The International Society of Neonatal Screening awarded their 2006 Guthrie prize to Drs Millington and Rashed. The MS/MS method superseded the automated fluorometric method and is now being used in an increasing number of other states. Since MS/MS screening is a major component of so-called "expanded" newborn screening,⁹ North Carolina was once again at the forefront. The MS/MS method can detect a wide variety of inborn errors of metabolism, some of which are so rare they are found in North Carolina infants only once every few years. (See Table 1.) Of the disorders detected by MS/MS in North Carolina, only those having an incidence of 0.5 in 100 000 or higher are individually listed in Table 1. While some disorders are too rare to justify screening for them individually, MS/MS detects them with little additional effort, raising ethical and legal questions about omitting them from screening.¹⁰

The Issue of Priority

In many states parents vigorously lobby state legislators to authorize screening for a disorder affecting their own child. Such action, while understandable, can result in testing with insufficient regard to cost or benefit. Hypothyroid screening in North Carolina came about in part because a distinguished pediatric endocrinologist, the late Dr Judson Van Wyk, explained the need for hypothyroid screening to his local state representative

in 1978. The origin of state funding for galactosemia screening is not clear. But one story is that a bill was introduced by a state legislator after he read an article on the subject while waiting for a haircut. Congenital adrenal hyperplasia can take the potentially lethal salt-wasting form or the less severe virilizing form. Screening for the disorder in North Carolina was initiated by a laboratory manager who had successfully established a screening protocol in a previous position.

The 2006 Newborn Screening Fact Sheets^{11,a} from the American Academy of Pediatrics briefly describe the disorders listed in Table 1 (and certain others) and include information on incidence and screening. In North Carolina, as in other states, the introduction of a test has not necessarily correlated with the prevalence of the disorder. Congenital hypothyroidism is over 10 times as common as PKU, also causes preventable mental retardation, and is easier to treat than PKU; however, testing for it was introduced after the PKU test. (See Table 1.) Screening for hemoglobinopathies was limited to infants of African American descent when introduced in 1987, although hemoglobinopathies can be present in other infants. Universal screening did not begin until 1994. Detection and treatment of galactosemia soon after birth can prevent cataracts, liver damage, and death but does little to prevent the moderate developmental disorders that occur. Screening for hearing impairment, which appears to be the most prevalent disorder, is on the basis that early intervention allows the affected infant to develop nearly normal speech, but this claim needs to be confirmed.¹¹ Figures for North Carolina are not yet known, but national surveys for this test indicate that the false positive rate is high and the follow-up rate is low.¹¹ For tracking of tests results to occur, a very serious need exists nationally¹¹ as well as in North Carolina for funding and policies that allow integration of hearing screening with ongoing programs of newborn screening and follow-up.

Prioritizing can be more complex than might be appreciated. As shown in Table I, biotinidase deficiency is rare, yet the extremely low cost of treating this potentially debilitating condition offsets its rarity. Congenital hypothyroidism and PKU have two features in common: both produce mental retardation if untreated in childhood, and both require management through adulthood. Considerations of the vulnerability of the developing brain led to the possibility that the costly phenylalanine-restricted diet of the child with PKU might be discontinued at age 4.¹² Subsequent experience revealed that discontinuing the diet caused the patient with PKU to have irritability, mood disorders, and a risk for seizures. Moreover, it is important for the woman with PKU to have her diet closely regulated during each pregnancy. Since high blood phenylalanine concentrations interfere with development of the brain in children with PKU, it is easy to understand why the same will occur with the brain of a fetus of a woman who has a high blood phenylalanine concentrations (even though the infant of a woman with PKU usually will not actually have PKU). Without treatment of pregnant women

a Fact sheets are available with updates, at <http://www.pediatrics.org/cgi/content/full/118/e934>.

Table 1.
Disorders for Which Newborn Screening is Provided in North Carolina in 2007

Disorder	Date testing started in NC	Confirmed cases per 100 000 newborns*
PKU	1966	See MS/MS
Congenital hypothyroidism	1979	49.7 ^a
Hemoglobinopathies	1987 & 1994	83.4 ^a
Galactosemia, classical	1988	1.6 ^a
Galactosemia, variant	1988	3.4 ^a
Congenital adrenal hyperplasia	1989	4.3 ^a
Hearing impairment	2001	146 ^b
Biotinidase deficiency	2004	0.5 ^c
Detected by MS-MS	1999	25.6 ^d
<i>Amino acidopathies</i>		
PKU		3.7
Hyperphenylalaninemia, not classical PKU		2.3
Citrullinemia		0.6
<i>Organic acidemias</i>		
3-methylcrotonyl-CoA carboxylase deficiency (3-MCC def)		2.9
Glutaric academia type 1		1.1
Methyl malonic acidemia		1.0
Isovaleric acidemia		0.6
<i>Fatty acid oxidation defects</i>		
Medium chain acyl-CoA dehydrogenase deficiency (MCADD)		7.6
Very long-chain acyl-CoA dehydrogenase deficiency (VLCADD)		1.4
Short-chain acyl-CoA dehydrogenase deficiency (SCADD)		1.0
Disorders (12 such) with incidence less than 0.5 per 100,000		3.4

*The following numbers of newborns screened and inclusive dates are from the North Carolina Newborn Screening Laboratory.

a 609,101 and 2002-2006.

b 363,974 and 2004-2006.

c 371,148 and 2004-2006.

d 930,321 and May 1999-December 2006. Of the infants in these MS/MS results, 81% are in the recent report⁸ of Frazier, et al

with PKU, the frequency of mental retardation (from maternal PKU) would equal the frequency of mental retardation in people with PKU before newborn screening and treatment was initiated.¹³ Thus, the total cost of managing PKU would seem to make it prohibitively expensive, yet the lifetime expense of the diet is less than the high cost of lifetime management of mental retardation or the costs associated with becoming unemployable.

Finally, early detection will not stop the ultimate progression of certain diseases but will provide opportunity to intervene and delay the onset of complications. Early detection also means the expense of unnecessary hospitalization and studies can be avoided. Examples of such diseases include sickle cell

disease and cystic fibrosis. Newborn screening for the latter occurs in some states and is under consideration in North Carolina.

State or Commercial Laboratory?

The campaign of Dr Guthrie and concerned parents for mandated PKU testing probably encouraged the screening of newborns to be conducted in state laboratories rather than private laboratories since the bacterial methods required by the original test are used there. In most states this served to prevent the privatization of newborn screening. Private laboratories made an effort in the late 1990s to introduce bills in various state

legislatures that would close state newborn screening laboratories and turn the activity over to commercial labs. At the same time the slowness with which many states adopt new screening methods prompted a discussion of the need for a national policy.¹⁴ Directors of state laboratories cannot act independently to regularly update methods and equipment but are often dependent on legislative appropriation and are slowed by bureaucratic red tape. The breakup of communist governments in Europe in the 1990s revealed the inefficiency of government operated services and made a case for privatization. In North Carolina some physicians and parents, unaware of the 1999 incorporation of MS/MS into the state program, sent samples to a private laboratory in another state.

The director of one private laboratory based in another state lobbied the North Carolina Pediatric Society to recommend closing the state laboratory and allowing his lab to do testing (including MS/MS screening) on a broader range of disorders. Members of the Society were unaware that this director had earlier visited Duke University to learn that MS/MS could be used in newborn screening. More critically, his suggested tests included detection of glucose-6-phosphate dehydrogenase deficiency, a disorder for which testing on newborn infants had been found inadvisable 35 years earlier, as was recognized by a member of the Newborn Screening Advisory Committee (appointed by the Newborn Screening Lab directors) who had authored over 20 articles on this subject. It must be conceded, however, that this private laboratory provided 20 months of MS/MS screening under contract during development and confirmation of the MS/MS method in the state laboratory.

Remaining to be proven is whether privatizing newborn screening would result in lower costs. Many states now charge fees to support their state laboratories. In 1991 the North Carolina General Assembly authorized the North Carolina Department of Environment and Natural Resources to charge hospitals for testing. The charge was \$10 per initial test in 2002 and \$14 in 2005. The funds remain in the department to be used to support the Newborn Screening Program.

Screening and Follow-Up

Since the early days of newborn screening, the Newborn Screening Quality Assurance Program of the Centers for Disease Control and Prevention has been responsible for checking the accuracy of newborn screening laboratories in the United States. In North Carolina the extremely low rate of cases missed through laboratory error is due to the high quality of leadership within the Newborn Screening Laboratory. During many of the earlier years, the laboratory was under the capable direction of Maxine Matheson. As newborn screening became more technically complex, it was apparent the laboratory should be directed by someone board-certified in clinical chemistry, as has been the case for over 20 years.

The importance of an aggressive follow-up program became apparent in the early years of screening when 33 of 37 North Carolina infants detected as having PKU were promptly started on the low-phenylalanine diet. The 4 infants who were not placed

on a phenylalanine-restricted diet developed retardation,¹⁵ and several lawsuits were filed against physicians. None of these cases was the result of a laboratory error; all resulted from a breakdown in follow-up. This is in contrast to a national survey that revealed missed cases of PKU and hypothyroidism were more often the result of laboratory error than of failure to follow up.¹⁶

A system had evolved by 1974 for tracking abnormal results in North Carolina infants and seeing that each infant was either retested or referred for confirmation and treatment. That system was monitored by Elizabeth Moore, Genetic Program Manager of the Division of Maternal and Child Health. In the 1980s, during the period when MS/MS screening was contracted to a private laboratory, it became apparent that difficulty in coordinating follow-up was a potential problem. Another factor contributing to failed follow-up is a change in the physician of record when an infant is discharged from the hospital. A policy was finally established in North Carolina for laboratory staff to directly contact parents if repeat testing had not been obtained. This caused initial and understandable resentment among physicians until missed cases were documented. Despite the great importance of an effective follow-up program, the follow-up component is easily overlooked in funding of newborn screening programs.

The Issue of Who Will Manage Each Disorder

After an abnormal result from newborn screening, the confirmation and management of congenital hypothyroidism and the hemoglobinopathies (eg, sickle cell disease) may occur in many North Carolina medical teaching centers. In sharp contrast, the management of inborn errors of metabolism often requires specialized expertise. The dietary management of pregnant women with PKU, for example, is complicated by the nausea of early pregnancy and the changing metabolism of the pregnant woman. This situation is even more complex than that of the growing infant or child with PKU. Dietary management of many inborn errors of metabolism requires the expertise of a dietitian who has specific training and experience in managing such cases. Underrestriction can result in mental retardation or brain damage; overrestriction can result in death. Moreover, management of maple syrup urine disease, for example, requires regulating blood levels of three amino acids simultaneously.

In North Carolina, all PKU cases, approximately 90% of disorders detected by MS/MS, and certain inborn errors of metabolism are managed at the University of North Carolina at Chapel Hill by a dietitian who has a doctorate degree in biochemistry. This model of centralization also includes Duke University where confirmation and management of certain other inborn errors of metabolism occurs. This centralization is due to the difficulty of obtaining specialized skills in many locations. The disadvantage of centralization is the travel required of patients living elsewhere in the state. To offset this disadvantage, maximum use is made of mailed samples and telephone consultations. Although the Guthrie bacterial test is now seldom used, the method of collecting blood on filter paper (the Guthrie card) is ingenious and is widely used.

Guthrie cards have made newborn screening practical and have allowed North Carolina parents of infants and children with certain inborn errors of metabolism such as PKU to obtain samples for dietary monitoring and to inexpensively mail them to a laboratory. However, the cost of making available to needy families the expensive dietary formula and specialized care they require is a second area that is easily overlooked in funding newborn screening programs. The Guthrie card, incidentally, should not be called a "PKU card;" it is used to test for many more disorders than PKU. Until Dr W. Harry Hannon of the Centers for Disease Control and Prevention intervened in 1996, postal policies to prevent the transmission of HIV could have essentially put an end to newborn screening and subsequent dietary monitoring.

Current and Future Policies

Numerous considerations must be examined in developing policy on newborn screening. Little justification exists for screening for conditions that require no treatment until much later in life. It may be argued that the condition might be later missed, but such failure in later detection is a problem that must be addressed separately. The detection of some disorders must await technical advances that make screening reliable and relatively inexpensive. As newborn screening is extended to detecting more rare or less treatable conditions, testing becomes difficult to defend financially. Perhaps a standard should be applied that is unknown to newborn screening but familiar to other areas of public health. Will the dollars expended for the new screening prevent more grief and suffering than the same amount spent in other ways? Would funds be better directed to immunizations and accident prevention?

About 20% of current test samples need to be repeated because of an inadequate sample or borderline result. The introduction of screening for each new disorder inevitably leads to an increase in the total proportion of false positives, some of which can cause harm. A false positive for hypothyroidism or PKU is not as disturbing as one for galactosemia, which requires an immediate appraisal of whether the infant has septicemia, an early feature of untreated galactosemia. False

negatives are still worse. Thyroid deficiency is not necessarily excluded by results soon after birth. Some infants have enough thyroid function to carry them through early infancy but then later become thyroid deficient (especially infants with birth weights under 1 500 g). With extensive transfusions, a condition can be missed when the test is dependent on a blood protein (eg, biotinidase deficiency and the hemoglobinopathies). Physicians can decrease the number of false negatives by considering how the tests are done. High levels of metabolites in the affected infant occur largely after birth. With mothers and babies being discharged very early, a blood sample should always be obtained at discharge with an additional sample obtained by 1 week of age if discharge was before 24 hours. Infants on soy formula or total intravenous feedings cannot be diagnosed as having galactosemia from an elevated blood galactose and therefore require an additional assay.

Present techniques in DNA analysis are unlikely to simplify newborn screening since each disorder often results from any of many mutations. Moreover, the most common type of congenital hypothyroidism does not have a genetic basis. Of very great importance in newborn screening is the changing effectiveness of treatment particularly when early treatment is essential. It is possible that future bone marrow or stem cell replacements, for example, will make additional disorders appropriate for newborn screening. Krabbe disease¹⁷ and severe combined immunodeficiency¹⁸ are two disorders presently approaching this point.

Future policy should reserve decisions about future tests within the staff of the Newborn Screening Laboratory and their consultants. Printed policies for newborn screening can be obtained by calling the Newborn Screening Clinical Chemistry Unit at (919) 733-3937. **NCMJ**

Dedication and Acknowledgements:

This article is dedicated to the memory of Dr Theodore Scurletis. Appreciation is expressed to the following individuals for information used in writing this article: Drs John Hill, George Summer, David Millington, William McLendon, Dianne Frazier, Shu Chaing, and Marcia Fort. Appreciation is also expressed to Joan Crissey and Ann Grush.

REFERENCES

- 1 Centerwall SA, Centerwall WR. The discovery of phenylketonuria: the story of a young couple, two retarded children, and a scientist. *Pediatrics*. 2000(1 Pt 1);105:89-103.
- 2 Guthrie R, Susi A. A simple phenylalanine method for detecting phenylketonuria in large populations of newborn infants. *Pediatrics*. 1963;32:338-343.
- 3 Hill JB, Summer GK, Pender MW, Roszel NO. An automated procedure for blood phenylalanine. *Clin Chem*. 1965;11:541-546.
- 4 Rashed MS, Ozand PT, Bucknall MP, Little D. Diagnosis of inborn errors of metabolism from blood spots by acylcarnitines and amino acids profiling using automated electrospray tandem mass spectrometry. *Pediatr Res*. 1995;38(3):324-331.
- 5 Millington DS, Kodo N, Norwood DL, Roe CR. Tandem mass spectrometry: a new method for acylcarnitine profiling with potential for neonatal screening for inborn errors of metabolism. *J Inher Metab Dis*. 1990;13(3):321-324.
- 6 Wiley V, Carpenter K, Wilcken B. Newborn screening with tandem mass spectrometry: 12 months' experience in NSW Australia. *Acta Paediatr Suppl*. 1999;88(432):48-51.
- 7 Chace DH, DiPerna JC, Naylor EW. Laboratory integration and utilization of tandem mass spectrometry in neonatal screening: a model for clinical mass spectrometry in the next millennium. *Acta Paediatr Suppl*. 1999;88(432):45-47.

- 8 Frazier DM, Millington DS, McCandless SE, et al. The tandem mass spectrometry newborn screening experience in North Carolina: 1997-2005. *J Inherit Metab Dis*. 2006;29(1):76-85.
- 9 Hampton T. Expanded newborn genetic testing urged. *JAMA*. 2004;292(19):2325-2326.
- 10 Sweetman L, Millington DS, Therrell BL, et al. Naming and counting disorders (conditions) included in newborn screening panels. *Pediatrics*. 2006;117(5 Pt 2):S308-S314.
- 11 Kaye CI. Newborn screening fact sheets. *Pediatrics*. 2006;118(3):e934-e963.
- 12 Holtzman NA, Welcher DW, Mellits ED. Termination of restricted diet in children with phenylketonuria: a randomized controlled study. *N Engl J Med*. 1975; 293(22):1121-1124.
- 13 Kirkman HN. Projections of a rebound in frequency of mental retardation from phenylketonuria. *Appl Res Ment Retard*. 1982;3(3):319-328.
- 14 Mitka M. Neonatal screening varies by state of birth. *JAMA*. 2000;284(16):2044-2046.
- 15 Kirkman HN, Carroll CL, Moore EG, Matheson MS. Fifteen-year experience with screening for phenylketonuria with an automated fluorometric method. *Am J Hum Genet*. 1982;34(5):743-752.
- 16 Holtzman C, Slazyk WE, Cordero JF, Hannon WH. Descriptive epidemiology of missed cases of phenylketonuria and congenital hypothyroidism. *Pediatrics*. 1986;78(4):553-558.
- 17 Escolar ML, Poe MD, Provenzale JM, et al. Transplantation of umbilical-cord blood in babies with infantile Krabbe's disease. *N Engl J Med*. 2005;352(20):2069-2081.
- 18 Borghans JA, Bredius RG, Hazenberg MD, et al. Early determinants of long-term T-cell reconstitution after hematopoietic stem cell transplantation for severe combined immunodeficiency. *Blood*. 2006;108(2):763-769.

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North Carolina
MEDICAL JOURNAL

The Governor's Initiative to Improve Health Care: Taking Measure of Medical Care in North Carolina

Charles Willson, MD

Most physicians I know are working longer hours and seeing more patients each day in order to meet the increasing demand for services and to make financial ends meet. We are practicing, as we were trained, to evaluate and treat each patient as an individual with unique complexities and needs. Much of the time, we deliver care that is timely, effective, and highly valued by our patients.

After the last patient of the day has been seen and the billing and paperwork is complete, we often put our feet up on the desk and read our journals and newspapers. Then we hear the drum beats of critics who say that medical care in America is not accessible to all Americans, often falls short of best practice, and sometimes is unsafe. Certainly, with our citizens' health status measuring below many third world countries and our per capita health care spending almost double that of the next most costly country (Switzerland), the question of value is most appropriate.

Payers for medical services, employers, insurers, and government are talking about mandating physician reporting of quality measures and outcomes of their care. There is talk of practice profiles, community ratings, and "pay for performance." Implementing best guidelines and generating these reports will require new office resources. Having practiced in a busy pediatric office for 19 years, often seeing more than 40 patients a day, I know how difficult it is to change how we care for patients. My analogy is that changing office processes while seeing your patients is like trying to change your pants while riding a bicycle.

As a leader of the North Carolina Medical Society, I have been privileged to participate in discussions at many venues of how we can improve and document the quality of care we physicians in North Carolina are delivering every day. I am

totally committed to the proposition that it is no longer enough to say that our quality is good because we are well-trained, dedicated, and hardworking. However, I see a bicycle wreck coming down the road if physicians are required to report their compliance with best practices to each payer, in different formats and measuring different parameters.

Why not build on the data reporting primary care physicians

"...I believe that the act of measuring our processes and outcomes will be seen as the pivotal change that led to a safer, higher quality, and more affordable health care system."

already do for Community Care of North Carolina, our unique and highly successful case management program for NC Medicaid? Let's develop a system where one report on a care initiative meets the requirements of all insurers in North Carolina (and hopefully the federal Centers for Medicaid and Medicare Services)? Let's give our physicians the knowledge and resources necessary to measure the care they deliver to certain populations of patients within their practices. To meet this vision, a group of stakeholders, led by Governor Mike Easley, has developed a new initiative aimed at improving the quality of health care delivered to all North Carolinians.

For nearly two years, leaders from North Carolina government (the Governor's office), health care providers (the NC Medical Society, the NC Hospital Association), organizations helping practices document and improve their quality (NC Area Health Educations Centers Program, Community Care of North Carolina, the Improving Performance in Practice program), and

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insurers (Blue Cross and Blue Shield of North Carolina, the NC State Health Plan, Medicaid) have been meeting to see if we could agree on an approach that would support practice-based physicians in the implementation and measurement of best practices and produce data reports that would be accepted by the payers' *quality* programs. Generous funding from a variety of organizations, including Blue Cross and Blue Shield of North Carolina, NC Medicaid, the NC Health and Wellness Trust Fund, the Center for Health Care Strategies, and the National Governors Associations, has enabled this group to develop the plan and infrastructure necessary for this ambitious objective.

Fortunately, through a grant from the Robert Wood Johnson Foundation, the Improving Performance in Practice (IPIP) program in the Department of Family Medicine at the University of North Carolina at Chapel Hill School of Medicine has been rolled out to selected practices in eastern and western North Carolina. Using agreed upon best practices and hands-on office system analysis by field agents, IPIP provides a model for how this initiative might be implemented throughout our state without disruption of patient care or financial hardship to the practices.

In October 2006, the North Carolina Medical Society House of Delegates adopted a series of recommendations on quality reporting that parallels the American Medical

Association policy on pay for performance. These programs must be voluntary, evidence-based, nonpunitive, and transparent and must provide the financial and technological resources needed to support them. A group of physicians in the state of Washington has sued an insurer for using quality data to unfairly channel patients to certain practices. We need safeguards that ensure the data generated by the initiative will not be used by insurers to direct patients to practices based on lower cost rather than higher quality.

As medical historians write about the crisis we face today in American health care, I believe that the act of measuring our processes and outcomes will be seen as the pivotal change that led to a safer, higher quality, and more affordable health care system. Every physician I know wants to practice the highest quality of care, but time and financial resources are limiting barriers. The first step is to measure what we do today. With that knowledge, we can integrate a continuous quality improvement culture within our practices.

In North Carolina, I believe that we are uniquely positioned to develop an honest statewide quality of care reporting program that will be the model for our country. By participating, North Carolina physicians will not only be measuring our care, we will be taking measure of our profession. The result will support my opinion that our physicians truly are the best in the world. **NCMJ**

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North Carolina
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POLICY FORUM

Data and Health Policy

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*Karen L. Knight, MS; Paul A. Buescher, PhD;
Walter L. Shepherd, MA*

*“Wherever health
policy is determined
and by whomever it
is made, the goal is
to strive for policy
decisions that are
based on sound
North Carolina
data because these
policies will have
greater credence
and acceptability.”*

INTRODUCTION

Policy Forum: *Data and Health Policy*

North Carolina is fortunate to have many rich sources of data that provide a solid foundation for making good policy and practice decisions to improve health and health care. Relevant, timely data and high quality analyses and interpretations provide justification for the development of evidence-based medicine, public health practice, and health policy to improve health in North Carolina.

Recently the role of evidence-based health care has been expanded with the announcement of a new, data-driven initiative from Governor Mike Easley. In April, Governor Easley announced a groundbreaking health care initiative in which insurers, organizations working to improve physician practices, providers, and others will collaborate to ensure North Carolinians receive optimal health care. Clinical as well as claims data are at the very core of the initiative. The goal is to extract information from these data, and the information will be used in innovative ways to promote optimal care through performance feedback and encouragement of best practices.

Despite the wealth of health data in the state, significant health information needs remain. For example, due to small samples, some data characterizing ethnic and racial groups yield imprecise estimates, and data pertaining to patient-practitioner interactions are also needed. Likewise, data representative of small geographic areas and subsets of the population—especially those at risk—are needed so that interventions and limited resources can be best targeted. Relatively new technologies such as electronic health records and geographic information systems are filling these gaps and providing researchers with access to much-needed data.

The issue brief by Sandra Greene, DrPH, discusses the relationship between health policy and data and provides an excellent backdrop for the commentaries. The commentary on the North Carolina Health Professions Data System (HPDS) highlights a prime example of data providing useful information to spur policy action and guide state health planning. Thanks to HPDS data, areas with health professional shortages have been identified and a possible future decline in the ratio of health providers to residents has been detected. As a result, medical schools in the state are expanding their programs, incentives are being offered to increase the number of medical school graduates, and physician retention is being encouraged.

In the run up to the fall 2008 elections, data and information systems are also at the heart of several proposals to improve health care quality and reduce the rapid growth of health care costs. North Carolina has explored the development of coordinated electronic data systems for over 15 years starting with data and information committees that were part of the Health Planning Commission and its successor, the Health Reform Commission. The Planning Commission issued a report in 1996 that formed the basis for a strategic plan for the adoption of statewide standards and systems for electronic medical records and information exchanges. The North Carolina Health Information and Communications Alliance (NCHICA) was subsequently formed to help move that plan forward. The time is now right for taking specific tactical steps toward implementation of a comprehensive health information strategy.

This issue of the *Journal* highlights the work of many organizations and individuals committed to collecting, analyzing, interpreting, and using data to improve health within the state. We hope this issue provides readers a broad understanding of the existing data resources in our state and provokes thoughtful discussion about how to enhance existing data resources, recognize possible synergy among datasets, and identify needs and potential solutions.

Thomas C. Ricketts III, PhD, MPH
Editor-in-Chief

Jennifer Hastings, MS, MPH
Interim Managing Editor

Data and Health Policy: Do We Do Our Best?

Sandra B. Greene, DrPH

Health care policy has emerged among the general public as a priority issue for the November 2008 presidential election. Second only to the war in Iraq, health care and the economy are the domestic issues foremost on the minds of Republicans, Democrats, and Independents polled by the Kaiser Family Foundation.¹ Specific issues of greatest concern are the intertwined problems of cost and the availability of health insurance to provide financial access to care. While some candidates propose sweeping change to address the nation's health care ills,² historically the health care system has evolved incrementally through moderate policy reform.

Health care policy positions are formulated at the national, state, and local levels. In the state of North Carolina there are many stakeholders responsible for decision making, ranging from departments and divisions of state and local governments to public and private institutions. Collectively, health care policies impact who is eligible to receive health care, what types of care are available and provided, where facilities and services are located, and who pays the bill. In sum, health policy provides the direction, specifications, and building blocks that define our health care system.

Sources of Data for Health Policy

Data useful for health policy decision making in North Carolina originate from numerous sources. This issue of the *North Carolina Medical Journal* describes what these data are and where they come from and explains how they are or can be used. While some data are collected in a one-time study or survey, the most commonly used sources are collected on an ongoing basis, either mandated by state or federal law or by voluntary submission. The range of data sources includes population-based surveys, patient registries focused on specific diseases or conditions, vital records of births

and deaths, workforce databases, electronic medical records, and insurance billing records.

The Behavioral Risk Factor Surveillance System (BRFSS), an example of a population-based survey, was originally developed by the Centers for Disease Control and Prevention to measure health behaviors and use of health care services.³ It is now in use in all states and the District of Columbia and in this state is conducted by the North Carolina State Center for Health Statistics (SCHS). Paul Buescher discusses this survey and other data collection projects in an accompanying commentary. A sample of North Carolina households is randomly contacted by telephone, and adults in the household are interviewed. Questions cover topics including perceived health status, self-reported health care conditions, availability of health insurance, and respondent's use of health care services including screening.

“Assuring that health policy decisions made for the citizens of our state are the best they can be calls for nothing less than data-driven decisions.”

Results are reported on a statewide basis and for individual counties with large populations. Core questions are repeated each year, allowing analysis of trends. Additionally, selected questions are added annually as new policy interests emerge. While the BRFSS focuses on North Carolina adults, a companion survey was recently implemented to gather health characteristics of children. Data collection for the Child Health Assessment and Monitoring Program (CHAMP) began in January 2005.⁴

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The North Carolina State Center for Health Statistics also administers patient registries which focus on specific at-risk populations. The Birth Defects Monitoring Program (BDMP) collects and analyzes information on infants born with serious congenital anomalies.⁵ These data are aggregated from multiple sources including hospital medical records, hospital billing data, and vital records. A second registry, described in a commentary by Karen Knight, Paul Buescher, and Walter Shepherd, tracks cancer cases in the state, reporting that is required by law. These data are gleaned from hospital records, death certificates, and in cases where the patient is not hospitalized, by physician report.⁶ Another source of health care data collected by the National Center for Health Statistics (NCHS) is vital records. Also mandated by law, these databases include registrations of all births and deaths occurring in the state.⁷

The North Carolina Trauma Registry (NCTR) has collected data since 1987 from state EMS agencies, acute care hospitals, and other providers in an effort to provide quality care for injured patients throughout North Carolina. Michael Thomason writes about NCTR and its coordinated data system in his commentary.

Data on the state's healthcare workforce can be found in the North Carolina Health Professions Data System (HPDS), housed at the Cecil G. Sheps Center for Health Services Research.⁸ This system is a collaborative effort with the Area Health Education Centers Program and the independent licensing boards of each participating health profession. Included in the database are over 2 decades of demographic and employment history on physicians, nurses, dentists, chiropractors, and other types of health care professionals. Jennifer King and Mark Holmes speak to the importance of these databases and their uses.

Insurance billing records, also referred to as administrative records, provide a rich source of data for use in health policy decisions. These data originate from 2 primary billing forms: the Uniform Billing-92 (UB-04 after June 1, 2007) used for billing institutional charges and the Health Care Financing Administration (HCFA) 1500 used for billing professional charges.^{9,10} Information from these records contain patient-level detail on health care services provided to a covered population including physician and clinic visits, emergency room care, hospitalizations, outpatient prescription drugs, and the charges and payments for those services. These databases also contain information on patients' diagnoses, tests, and procedures. Grouping an individual's claims into episodes illuminates patterns of care that when aggregated across population groups provides a picture of how illnesses are treated and how health care services are utilized.

Insurance billing records are maintained by insurance companies or, in the case of publicly funded programs such as Medicaid and Health Choice, a system administrator. The largest database of this type in North Carolina is maintained by Blue Cross and Blue Shield of North Carolina. The Division of Medical Assistance maintains the second largest insurance billing database which contains claims on all Medicaid eligible recipients. Databases such as these housed by private and

public insurers are proprietary, and data from them are generally only available for analysis and use in health policy considerations on an ad hoc basis.

The most detailed information documenting patient care is contained in medical records. These are patient-specific files kept in every health care facility. They contain information on all care provided to the patient including patient symptoms and presenting complaints, information that is not contained on billing records. Medical records also contain results from laboratory tests, screening, and outcomes of treatments and procedures. While medical records have traditionally been handwritten, limiting their usefulness for analysis across population groups, the electronic medical record affords significant opportunities for data aggregation and population-based study. Xiaoming Zeng addresses this potential in his commentary.

The articles in this issue of the *Journal* focus on some specific data sets and their policy context. One data set in particular, the hospital discharge and ambulatory surgery data set, has a history that illustrates how policy can be shaped both by the information extracted from the data and by the data themselves, and how the data used can be shaped by the policy process.

History of the Medical Database Commission

As medical costs rose rapidly in the early 1980s, many legislators, employers, and health policy analysts recognized a need for public information on cost and utilization of health care services. Insurance billing records were viewed as a valuable potential data source. In 1985 the General Assembly created the North Carolina Medical Database Commission with the charge "to establish an information base to be used to improve the appropriate and efficient usage of medical care services, while at the same time maintaining an acceptable quality of health care services in this State. This is to be accomplished by compiling a uniform set of data and disseminating aggregate data, including but not limited to price and utilization data."¹¹ The Commission began its work in 1986, and 3 years later the first data reports, based on electronic copies of UB-92 records, were released. The reports contained summary information on all discharges from North Carolina acute care hospitals. For the first time, North Carolina had information on hospital discharge diagnoses, procedures, and associated facility charges for the entire population.

Through the early 1990s the North Carolina Medical Database Commission continued to expand its efforts to make health care data available to the public. In addition to enhanced hospital discharge data reports with comparisons of charges among providers and analyses of where patients travel to receive care, it also expanded into ambulatory surgery reporting. All licensed free standing ambulatory surgery centers submitted copies of UB-92 billing forms to the Commission's data processor. Annual reports were developed and released. By 1995 both hospital and ambulatory surgery utilization and charge information were available and widely disseminated.

Not all stakeholders were comfortable with the public availability of the Commission's data. In the 1995 session of the

General Assembly, the North Carolina Medical Database Commission was abruptly eliminated. In its place, the Medical Care Data Act was passed establishing the authority of a state data processor, with oversight of the Division of Facility Services [now the Division of Health Service Regulation (DHSR)], to assume responsibility for the collection and reporting of data.¹² The state data processor chosen for this role was Solucient (now Thomson Solucient). Under the direction of DHSR, a copy of the state databases is housed at SCHS for use by the state medical director, and a second copy is maintained at the Cecil G. Sheps Center for Health Services Research for use in state health planning. During the transition from the Medical Database Commission to the state data processor, 1995 data were not collected. Data collection resumed in 1996 and continues today with ongoing reporting by hospitals and freestanding ambulatory surgery centers. However, the public reporting function that existed under the Medical Database Commission no longer exists.

In 2004 statewide collection of health care data expanded with the collection of data from hospital emergency departments. Mandated by law, all emergency departments are required to report an electronic record of each visit.¹³ Reporting is to occur daily. The purpose of this data collection effort is to provide data for public health surveillance and to enable an early warning system of bioterrorism or other public health crisis resulting in patients presenting for emergency care. The North Carolina Hospital Surveillance System, a collaborative project between the North Carolina Division of Public Health, the North Carolina Hospital Association, and the University of North Carolina at Chapel Hill School of Medicine, collects and processes the data from all North Carolina hospitals.¹⁴

How Do We Use Data for Health Policy?

The policy relevant data sources available in this state are used in a multitude of ways to identify new policy directions, support or change existing policy, or to illuminate health problems that if addressed would improve the public's health. Dianne Enright writes about how data provided by geographic information systems help determine allocation of limited public health resources. David Murday and Elizabeth Corley discuss how philanthropic foundations use health data to identify communities whose needs are aligned with a philanthropy's priorities. Christopher Manfield and James Wilson explore how data are used at the local level by citizens, providers, organizations, and policy makers to improve community health. Mark Massing and Anna Schenck discuss how data are used at The Carolinas Center for Medical Excellence to inform consumers, assist providers, and develop information to improve health policy at the federal and state levels.

BRFSS survey results provide relevant examples of how data sources are used to develop and direct policy. General population prevalence estimates of chronic conditions such as arthritis, asthma, and diabetes are calculated from the survey results. The North Carolina Division of Public Health develops programs to provide technical assistance, resources, and care management

tips to reduce illness burden for these conditions.¹⁵⁻¹⁷ Behavioral Risk Factor Surveillance System estimates also are used to measure levels of personal behavior that negatively impact health including smoking, alcohol use, and seatbelt use. Programs are then developed to address these behaviors.^{18,19} The continuous data gathering of the BRFSS allows program administrators to evaluate their success in reducing negative behaviors by reviewing subsequent survey results.

In a similar fashion to the population estimates from the BRFSS survey, data from the state's vital records and condition-specific registries are used to develop and monitor health care programs. Infant death rates, for example, are closely monitored as a key indicator of the quality of our health care system. North Carolina's high rate of 8.5 infant deaths per 1000 live births in 2004,²⁰ compared to 6.8 in the US,²¹ directs attention to programs that improve access to and use of prenatal care. Overall population death rates also provide rich opportunities to identify and address health care challenges. County and regional death rates, along with disease specific rates, illuminate program opportunities to reduce disease risk and improve the provision of care for those impacted by disease. An advantage of the ongoing availability of these data sources is that it allows continued monitoring and evaluation of program effectiveness.

Information from the state's workforce database, the Health Professions Data System, is used in a wide array of program and policy development activities. These data show where health professionals are employed and the relative availability of the workforce by county and region. It helps track trends in workforce use and identifies shortages in supply. It also enables determination of the age distribution of those working, allowing estimates of how retirements will impact future workforce availability. All of this information is essential for understanding employment needs and drives policy decisions on training programs required to assure a continued supply of the right discipline and number of health care professionals.²²

The health planning process in this state is largely data driven as reflected in the annual state medical facilities plan developed by the Division of Health Service Regulation (DHSR) under the direction of the North Carolina State Health Coordinating Council.²³ This plan provides need projections for health care facilities and services as specified in GS § 131E-177 including hospital beds, rehabilitation beds, skilled nursing beds, operating rooms, technology, and medical equipment. Much of the data used in health planning are derived from the annual license renewal application form. These forms are required by DHSR for a facility to renew its operating license. Facilities currently complete a handwritten copy and submit it by mail to DHSR. Plans for electronic submission are underway. The form asks for counts of services provided at the institution with instruction on how services should be defined and counted. It is a lengthy form requiring considerable time and effort to complete. Facilities are generally diligent and conscientious in completing these forms. However, there is no audit function to determine the accuracy of the data submitted, and reporting categories are subject to individual interpretation by the facility completing the form.

Other sources of data used to support health planning are the hospital and ambulatory surgery databases collected by Thomson Solucient under the Medical Care Data Act. The State Health Coordinating Council committees that oversee the development and refinement of methodologies for determining needed facilities and services use these databases to understand how services are currently utilized and to project future use. As an illustration, to determine when additional acute care hospital beds are needed, 4 years of historical hospital discharge data are analyzed. An average annual historical rate of change is calculated for those 4 years. Using this rate of change, coupled with a projection of population growth or decline, a calculation is made to determine how many beds will be needed in a service area 6 years into the future. A comparison of the number of existing beds to the number projected to be needed determines if additional beds should be built. Starting with data on current utilization rates and reflecting recent changes in those rates provides a sound basis for future planning. The advantage of using the Thomson Solucient databases to determine utilization rates, rather than a self-reported number of cases from the provider, is more assurance that each facility is treated fairly by counting past utilization consistently.

Emergency room data collected by the North Carolina Hospital Surveillance System are used by the public health community for surveillance and planning. These data are submitted to the North Carolina Disease Event Tracking and Epidemiologic Collection Tool (NC DETECT) which is a tool for categorizing, analyzing, and reporting the data.²⁴ These data on nearly 3.5 million emergency department visits annually are available to approved users for population-based studies.²⁵

What Additional Data Do We Need?

While there is always the desire for more and better data for policy and decision making, collecting additional data has significant ramifications, particularly if it is new information that would place administrative burden on providers to report. While expanding data collection is a worthy goal, we should carefully choose areas of expansion where the expense and effort can be justified. William Kalsbeek's commentary describes an effort underway at the University of North Carolina to identify gaps in public health information. We should also seek opportunities to make optimal use of the data we have. In this spirit the State Health Coordinating Council recently acted to transition to the use of the Thomson Solucient databases for determining operating room need in North Carolina. The current methodology utilizes self-reported aggregated data on the license renewal application form. Using administrative data will enable counts of individual procedures that are consistent for each provider. This change in methodology will take a number of years to accomplish but will improve the accuracy of the need projections and advance the credibility of the process.

Another initiative designed to make better use of the data we have is the North Carolina Comprehensive Assessment for Tracking Community Health (NC-CATCH). James

Studnicki, John Fisher, and Christopher Eichelberger describe the development of this Web-based portal for community surveillance in their commentary.

The Thomson Solucient hospital discharge databases provide comprehensive data for care provided in the state's inpatient facilities. However, the Thomson Solucient ambulatory surgery database contains some gaps, with not all freestanding ambulatory surgery centers reporting as required. There has also been a void in data and information on services provided in hospital emergency departments. The new North Carolina Hospital Surveillance System data may serve to fill this gap if the data are made available to planners and policy analysts.

The biggest gap in available data, however, is in records for care provided in physician offices, clinics, and hospital outpatient departments. While approximately 12 in every 100 persons experience a hospitalization during the year and discharge records are available for these events, each person averages between 3 and 4 outpatient visits per year, and we have no database chronicling these events.²⁶ Outpatient settings are where most contacts with the health care system occur. If we are to adequately understand what care is provided, where it is provided, to whom it is provided, and for what conditions, there is a need to have data on these visits contained in publicly available databases that can be used for a wide range of planning and policy functions.

Another significant gap in publicly available data is information contained in medical records. To fully understand the care process, it is important to know more than diagnoses and procedures. It is necessary to understand patients' presenting complaints, signs, symptoms, and test results. These data are critical for determining the quality and appropriateness of provided care, for assessing patient outcomes, and for measuring and reducing racial and ethnic disparities in treatment patterns. As more medical records are converted to an electronic status, access to these data will become feasible. However, the challenges to the use of electronic medical records are significant. First, there is no standard acceptable format for a medical record like the standard UB-04 and CMS 1500 forms. Combining multiple formats can be difficult and costly. The second major challenge is finding a vehicle for pulling together medical records from multiple sites including physician offices, clinics, and hospitals. Yet this is necessary to aggregate data for population groups. Overcoming these obstacles would provide rich data for surveillance, research, and health policy.

What prevents us from collecting more expansive data and making it available for use in health planning and policy? Cost is perhaps the most significant deterrent, though there must also be the political will. It is costly to collect large amounts of new data. Extracting data that has already been collected for another purpose is less costly, as electronic processing and data storage costs have declined. Expansion of data collection is not viable, however, on a voluntary basis. Mandated reporting by providers, achieved through legislation, is critical to assure complete reporting.

Where Do We Go From Here?

To improve our ability to make data driven decisions in health policy, we should continually look for additional data sources and make publicly accessible those data sources that already exist for other purposes. In this spirit, the Carolina Cost and Quality Initiative (CCQI) was created. The Carolina Cost and Quality Initiative is a collaborative partnership between the University of North Carolina School of Public Health and the Sheps Center to build, maintain, and oversee the use of administrative databases on health care services provided to North Carolina population groups.²⁷ The purpose of this project is to promote population-based research on the incidence and prevalence of disease in insured populations, to study patterns of health care utilization and cost of care, and to provide information for informed policy decisions on issues impacting our population's health.

Owners of administrative databases in North Carolina have been invited to partner with the University of North Carolina in this project and to share their data. Two are currently participating, and we expect more to join. The Carolina Cost and Quality Initiative project now houses databases contributed by the North Carolina State Employees Health Plan (SEHP) and the North Carolina Division of Medical Assistance (DMA). As the data owners, SEHP and DMA share data through contractual agreements with the university. Each database contains 5 years of historical claims data, and the data owners have agreed to provide periodic updates to keep the databases as current as possible. University faculty and research staffs are invited to submit project proposals for use of the data. Each project request is reviewed by an oversight committee consisting of representatives of the data owner and of the university; upon approval, data are prepared by CCQI staff for the researcher's use.

The Carolina Cost and Quality Initiative databases include insurance claims for hospitalizations, doctor visits, outpatient surgery and treatments, emergency room use, and outpatient prescription drugs. Patient identifiers are encrypted to protect patient confidentiality and to allow the researcher to track all treatments provided to the same individual. The 2 databases combined represent all health care services provided to approximately 1.5 million persons who are geographically

dispersed throughout the state. Such a rich set of data for this large population group provides a significant opportunity for research that can favorably impact health policy decisions in the state. We invite project requests and encourage these databases to be used in this way.

Administrative databases, as useful as they are, do not contain information on the results of tests and procedures. To add this additional level of detail, we must also strive to find ways to use electronic medical records for large population groups. Such an undertaking will require combining files of medical records across providers and facilities and encrypting identifying information to protect confidentiality in the process. Holt Anderson and Gary Bowers discuss health care information exchange across provider groups in their commentary. The resulting databases will be extremely large for a population group, but the advantages from this type of data aggregation in informing policy makers and researchers would be significant.

The potential rewards from increasing data collection and availability will be diminished if we do not simultaneously prepare researchers, planners, and policy makers to use available data sources. Elizabeth Layman, and Debbie Travers and Lawrence Mandelkehr, address these issues in their respective commentaries. We must put a greater focus on data and analytics in university curriculum in the courses and programs that are training our next generation of health care leaders. Health care researchers should be trained in the use of claims data analysis and electronic medical records. Those who are preparing for leadership roles should be trained in data literacy to ask for and expect quantitative assessment of health policy issues in their workplace.

All of us in the health care field must look for ways to work collaboratively towards increased availability and use of appropriate data. Assuring that health policy decisions made for the citizens of our state are the best they can be calls for nothing less than data-driven decisions. And as Marcus Pleścia and Jeffrey Engel point out in their commentary, future public health data needs must reflect the foreseen and unforeseen changes in our state. Wherever health policy is determined and by whomever it is made, the goal is to strive for policy decisions that are based on sound North Carolina data because these policies will have greater credence and acceptability. **NCMJ**

REFERENCES

- 1 Kaiser Health Tracking Poll: Election 2008. The Henry J. Kaiser Family Foundation Web site. <http://www.kff.org/kaiserpolls/elections2008.cfm>. Published August 30, 2007. Accessed December 17, 2007.
- 2 New Leadership on Health Care: A Presidential Forum. Center for American Progress Action Fund Web site. <http://www.americanprogressaction.org/events/healthforum/>. Accessed December 19, 2007.
- 3 NC Behavioral Risk Factor Surveillance System (BRFSS). North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/brfss/>. Updated December 16, 2007. Accessed December 10, 2007.
- 4 NC Child Health Assessment and Monitoring Program (CHAMP). North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/champ/>. Updated July 19, 2007. Accessed December 10, 2007.
- 5 North Carolina Birth Defects Monitoring Program (BMP). North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/bdmp/>. Updated May 11, 2007. Accessed December 10, 2007.
- 6 North Carolina Central Cancer Registry (CCR). North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/CCR/>. Updated August 9, 2007. Accessed December 10, 2007.

- 7 North Carolina Vital Records. North Carolina Department of Health and Human Services Web site. <http://vitalrecords.dhhs.state.nc.us/vr/index.html>. Updated August 22, 2006. Accessed December 12, 2007.
- 8 North Carolina Health Professions Data System. The Cecil G. Sheps Center for Health Services Research Web site. Published 2007. <http://www.shepscenter.unc.edu/hp/about.htm>. Accessed December 11, 2007.
- 9 UB92 Claim Form. <http://www.valueoptions.com/newmexico/provider/forms/UB92ClaimForm.pdf>. Accessed December 14, 2007.
- 10 Outpatient Hospital Services – HCFA 1500 Claim Form. Rhode Island Department of Human Services. <http://www.dhs.state.ri.us/dhs/heacre/provsvcs/manuals/hospital/ouhc1500.htm>. Accessed December 14, 2007.
- 11 NC Gen Stat § 131E-210.
- 12 NC Gen Stat § 58-2-131(f).
- 13 NC Gen Stat. § 130A-480.
- 14 State health department unveils new public health surveillance system: North Carolina is first state in nation with new system to save lives [press release]. November 16, 2005. North Carolina Department of Health and Human Services Web site. <http://www.ncdhhs.gov/pressrel/11-16-05.htm>. Accessed December 14, 2007.
- 15 NC Arthritis Program. <http://www.ncarthritis.com>. Accessed December 14, 2007.
- 16 North Carolina Asthma Program. <http://www.asthma.ncdhhs.gov/>. North Carolina Department of Health and Human Services Web site. Accessed December 14, 2007.
- 17 North Carolina Diabetes Prevention and Control Branch. <http://www.ncdiabetes.org/>. Accessed December 14, 2007.
- 18 North Carolina Tobacco Prevention and Control Branch. North Carolina Department of Health and Human Services Web site. <http://www.tobaccopreventionandcontrol.ncdhhs.gov/data/index.htm>. Updated December 14, 2007. Accessed December 14, 2007.
- 19 *North Carolina 2010 Health Objectives: Healthy Carolinians 2005 Midcourse Review*. http://www.healthycarolinians.org/pdfs/114_Amend_Eo91_Healthy_Carolinians.pdf. Accessed December 14, 2007.
- 20 Selected Vital Statistics for 2004 and 2000-2004: North Carolina. North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/vitalstats/volume1/2004/nc.html>. Updated October 19, 2005. Accessed December 12, 2007.
- 21 Overall infant mortality rate in US largely unchanged: Rates among black women more than twice that of white women [news release]. May 2, 2007. National Center for Health Statistics Web site. <http://www.cdc.gov/nchs/pressroom/07newsreleases/infantmortality.htm>. Updated May 21, 2007. Accessed December 12, 2007.
- 22 Fraher, EP. Shaping health workforce policy through data-driven analyses: The Sheps/NC AHEC Collaboration. Presented at: The National AHEC Organization Program Directors; April 26, 2007; Washington, DC.
- 23 North Carolina Department of Health and Human Services, Division of Facility Services. *2007 State Medical Facilities Plan*.
- 24 NC Detect: North Carolina Disease Event Tracking and Epidemiologic Collection Tool. University of North Carolina at Chapel Hill Web site. <http://www.ncdetect.org/>. Accessed December 14, 2007.
- 25 Waller AE, Ising AI, Deyneka L. Running the Numbers: North Carolina emergency department visit data available for public health surveillance. *NC Med J*. 2007; 68(4):289-291.
- 26 National Center for Health Statistics. US Department of Health and Human Services. *Health, United States, 2006 With Chartbook on Trends in the Health of Americans*. Hyattsville, MD: 2006.
- 27 Carolina Cost and Quality Initiative. The Cecil G. Sheps Center for Health Services Research Web site. <http://www.shepscenter.unc.edu/ccqi/>. Updated October 8, 2007. Accessed December 14, 2007.

Electronic Records in Health Care

Xiaoming Zeng, MD, PhD

Health care can be studied from many viewpoints. Using information as the primary way to examine our health care system has lately been on the agenda of national health care policy. Physicians need to process large amounts of data into information to make clinical decisions. Public health practitioners need to aggregate heterogeneous data at population levels to prevent and detect epidemics. Health care policy makers need to use a variety of secondary databases as evidence for policy making. How can we ensure the right health care information is accessible to the right person at the right point in a timely manner? At this moment, the only solution to the question is to digitalize the information and share it on a secure, networked information system. Electronic health records (EHRs) offer one such solution by providing a platform for acquisition, storage, access, analysis, and presentation of health data. Electronic health records systems are touted as one of the keys to a new health care system that provides quality and cost-effective care.¹⁻⁶ President George W. Bush set a goal of making the use of electronic health records universal by 2014.⁷ Various initiatives have been implemented across the health care spectrum from federal to community-level programs.^{8,9} Studies demonstrate the promising effects of EHRs on controlling cost, enhancing quality, and reducing medical errors.^{5,10-13}

We are currently in a transition period in that many health care facilities are upgrading their paper-based record systems to electronic health records systems. Among the many functions of health records, documenting patient care over time is the most essential. To deliver quality care, providers need timely and accurate data on a patient's current and past medical history which may include findings from physical examinations, laboratory results,

insurance, and other sources. This situation is made more complex due to increased life expectancy and the shift of the disease delivery model from acute care to chronic care. More data and information are created in the process of caring for a patient with complex, often multiple, diagnoses. Patients with chronic diseases often visit multiple providers and take multiple medications. It is cumbersome for doctors to go through the process of acquiring data from various sources in order to make the right diagnosis, perform the right procedures, and prevent

medical errors. Even if practitioners obtain all of the data, they need enormous logistical and technical assistance in order to link it together.

Data in health care, especially patient-based clinical data, have long been entered and stored on paper. Paper records usually allow practitioners to record information in

a semi-structured, free-text format. One weakness of paper records is that the information recorded there can be accessed by only one person at a time at one location. Sharing paper records is cumbersome and cost-inefficient. More importantly, it presents a challenge to aggregate all the data from different sources in order to find patterns which are often used in health policy analysis.

A consensus national priority is to establish a networked EHR system that shares the integrated information of each individual at the point of care. To achieve this goal, a totally automated EHR system is needed at each health care institution. More importantly, these institutions should have the capacity to share information with others. This commentary offers more detailed information about EHRs and their value as a data source for health policy, as depicted by Greene in the issue brief of this journal.

“Electronic health records systems are touted as one of the keys to a new health care system that provides quality and cost-effective care.”

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Definitions

Historically, many terms have been used for the concept of an EHR system.¹⁴ The electronic medical record (EMR) is a term often used interchangeably with EHR. The key conceptual difference between EMR and EHR is the owner and location of the record. Electronic medical records are usually included in a local clinical data repository used to support clinical operations. They are usually owned by an individual health care provider and are often accessible to the patients who are the customers of the health care provider. Electronic health records refer more to an overarching system based on information shared by individual care practitioners regardless of practitioner specialty, type of care (eg, inpatient, ambulatory), or location of care. Electronic medical records are often practitioner-oriented while the EHR is patient-centric and supports coordinated care. More importantly, the concept of EHR goes beyond episodic care in health care facilities by providing not only a comprehensive medical history (when patients interact with practitioners) but including patients' own records of their health status (when patients don't interact with practitioners). So, even an EMR system in an integrated delivery system is not equivalent to an EHR system because it does not contain the entire picture of a patient's health status.

Electronic medical records and EHRs are interrelated. Successful EHRs rely on EMRs as the data providers to construct different segments of the individual's health history. The key for the success of patient-centric EHR systems is for each EMR system to have the capability to share data in an automated and error proof way. Because a patient may have different records located in different EMRs, accurately and efficiently linking all the records together is a challenge because there is no existing centralized patient index. Such sharing is called health information exchange.¹⁵

To undertake the task of health information exchange, two solutions are being implemented by the Office of the National Coordinator of Health Information Technology. One is to build a national health information network which enables providers to access needed patient-related information. The US government is currently promoting a bottom-up, market-oriented approach by advocating regional health information organizations (RHIOs) as the foundation of a national health information network. Stakeholders within each RHIO will share data with their own selection of network and information architecture. The North Carolina Healthcare Information and Communications Alliance (NCHICA) is coordinating an effort to create a regional health information organization in North Carolina. Sharing data among regional health information organizations will complete the national health information network.

Fully functional regional health information organizations and national health information networks rely on information interoperability, which has a long way to go.¹⁶ The other solution to health information exchange is to let patients manage their own personal health information using tools like personal health records. The American Health Information Management Association defines personal health records as "a collection of

important information about your health or the health of someone you are caring for (such as a parent or child) that you actively maintain and update. The information comes from your healthcare provider and from you."¹⁷ It is not necessary to have only the encounter data stored in the personal health record. Ideally, patients also would record data related to their health status such as weight, diet, and exercise routines. A successful personal health record system should have interfaces to all the EMR systems in which patients have data footprints.^{18,19} Microsoft recently started a Web-based personal health record that allows consumers to store their health records online and share them with their designated providers.²⁰

Electronic Health Records and Health Policy

The advocates of EHRs believe they are integral to controlling the cost, improving the quality, and increasing the efficiency of health care. These benefits are largely at the direct patient care level. There also are important benefits to health policy makers at a system level. As Sandra Greene defined in her issue brief, "health policy provides the direction, specifications, and building blocks that define our health care system." As such, EHRs could systematically be used for quick data collection and policy dissemination in health care.

Electronic Health Records As a Data Source for Health Policy

The EHR has primary and secondary usages. Examples of primary usage of EHRs include informing and supporting direct patient care, management support, financial and administrative processes, and patient self-management. Secondary usages of EHRs include education, regulation, research, public health policy, homeland security, and policy support.

The medical or clinical encounter record, whether in paper or electronic format, is the primary data source in health care because it contains specific data pertaining to a specific patient. Primary data sources, after de-identification and aggregation, are the raw inputs to the secondary data sources that are used in health care policy making. For example, a cancer registry is a secondary data source that collects data related to cancer diagnosis and uses it for monitoring patterns of cancer cases in the US. After a patient is diagnosed with cancer, demographic data, occupational history, and administrative and pathological data will be recorded into a facility's cancer registry. The information is then sent to state and national registries. The process of data collection historically relied on manual chart review and reporting due to the paper-based record environment. In an EHR system, data collection is simplified by querying a well-structured database. Moreover, it accelerates the data transmission from an individual facility to a state or national registry. The National Program of Cancer Registries' Modeling Electronic Reporting Project (NPCR-MERP) is an effort at the Centers for Disease Control and Prevention to enable cancer registries to obtain most cancer data electronically and to produce more complete, timely, and accurate cancer surveillance data.²²

Electronic health records may not necessarily reduce the burden of data entry; however, they will largely facilitate data retrieval and analysis. For example, drug recalls in the past required nurses to manually review patient charts at one facility to find all patients who had the drug on their medication list. In the electronic health record environment, it would take a fraction of the time to query a database in order to identify these same patients.²³ Because EHR and personal health records systems are patient-centric and health-oriented, they make it easy to collect data that would be hard to collect from paper records. For example, the Behavioral Risk Factor Surveillance System (BRFSS) collects data from telephone surveys. If the BRFSS survey is implemented as data elements in an EHR or personal health records system, the data can be easily collected electronically. Ball and Gold²⁴ proposed a Health Record Bank model that provided patients the power to share their health data with researchers. This would expand the scope of health policy data collection from clinical care to health status.

Electronic Health Records as a Distribution Vehicle of Health Policy

The other implication of EHR for health policy is that health care providers can be informed of important policy by integrating health policy with EHR systems. The Institute of Medicine of the National Academies defined 8 core functions of EHRs in *Key Capabilities of An Electronic Health Record System: Letter Report*: (1) health information and data; (2) results management; (3) order entry/management; (4) decision support; (5) electronic communication and connectivity; (6) patient support; (7) administrative process; and (8) reporting and managing population health.²⁵ The functions of administrative process and reporting and of managing population health could be used as the leverage points for implementing health policy at the practitioner's level.

Improvements in health care, once verified, need to be disseminated quickly to individual practitioners to be effective, especially at the point of care. This could consist of reminders generated from guidelines related to preventive public health interventions. Many studies have demonstrated that relevant,

integrated reminders in EHR could increase the level of compliance with accepted health care guidelines or policies. Alerts could include important information about disease outbreaks or important medication updates. When available, information could be extended to providers on applicable public health interventions, preventive medicine, or disease management.

In the event of a health event affecting a large population, a key activity of health policy is to notify practitioners and patients about available actions to prevent a disease or reduce its impact at the individual and the community levels. Electronic health records can facilitate such intervention in several ways. First, they can provide decision support that enables the implementation of a public health intervention directed to the patient at the point of care. Additionally, they can be a means to inform clinicians of health policy updates. Ultimately, they can provide necessary education to both practitioners and patients.

As mentioned above, EHRs also offer the opportunity to improve policy compliance by incorporating policies, or rules, into the EHR system. Because each EHR system should have decision support capability, transforming health policies—particularly those for disease prevention and management—to unambiguous knowledge representation modules will systematically standardize treatment of consumers at the point of care. For example, the use of reminders in an EHR system increased the number of mammograms, glycosylated hemoglobin tests, and varicella and influenza immunizations for persons with diabetes.²⁶

Many barriers remain on the way to having a universal electronic health records system by year 2014—notably lack of initial financial support, misaligned incentives, and missing business models for sustainable health information exchange.^{17,27} The US Department of Health and Human Services has recently started a 5-year project to encourage small and medium-size medical practices to adopt EHR systems by providing bonuses to participating practices that adopt certified electronic health records.²⁸ There is still a long way to go to before there is an EHR system that can store the entire health history of a patient and provide instant access to those who need the information. Until then, the benefit of electronic health records to health policy will not be fully realized. **NCMJ**

REFERENCES

- Dick RS, Steen EB, eds, Committee on Improving the Patient Record, Institute of Medicine of the National Academies. *The Computer-Based Patient Record: An Essential Technology for Health Care*. Washington, DC: National Academies Press; 1991.
- Dick RS, Steen EB, Detmer DE, eds, Committee on Improving the Patient Record, Institute of Medicine of the National Academies. *The Computer-Based Patient Record: An Essential Technology for Health Care*. Revised ed. Washington, DC: National Academies Press; 1997.
- Committee on Quality of Health Care in America, Institute of Medicine of the National Academies. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press; 2001.
- Aspden P, Corrigan JM, Wolcott J, Erikson SM, eds, Committee on Data Standards for Patient Safety, Institute of Medicine. *Patient Safety: Achieving a New Standard for Care*. Washington, DC: National Academies Press; 2004.
- Walker JM. Electronic medical records and health care transformation. *Health Aff*. 2005;24(5):1118-1120.
- Martin JC, Avant RE, Bowman MA, et al. The Future of Family Medicine: a collaborative project of the family medicine community. *Ann Fam Med*. 2004;2 (suppl 1):S3-S32.
- Transforming health care: the president's health information technology plan. The White House Web site. http://www.whitehouse.gov/infocus/technology/economic_policy200404/chap3.html. Accessed January 8, 2008.

- 8 Bolster C. National health IT initiative moves into action: an interview with David Brailer. *Healthc Financ Manage.* 2005;59(7):92-93.
- 9 Halamka J, Overhage JM, Ricciardi L, et al. Exchanging health information: local distribution, national coordination. *Health Aff.* 2005;24(5):1170-1179.
- 10 Hillestad R, Bigelow J, Bower A, et al. Can electronic medical record systems transform health care? Potential health benefits, savings, and costs. *Health Aff.* 2005;24(5):1103-1117.
- 11 Einbinder JS, Bates DW. Leveraging information technology to improve quality and safety. *Methods Inf Med.* 2007;46(suppl 1):22-29.
- 12 Chaudhry B. Computerized clinical decision support: will it transform healthcare? *J Gen Intern Med.* 2008;23(suppl 1):85-87.
- 13 Chaudhry B, Wang J, Wu S, et al. Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. *Ann Intern Med.* 2006;144(10):742-752.
- 14 Mon DT. Defining the differences between the CPR, EMR, and EHR. *J AHIMA.* 2004;75(9):74-75, 77.
- 15 Walker J, Pan E, Johnston D, et al. The value of healthcare information exchange and interoperability. *Health Aff.* 2005;(suppl):5-10, 5-18.
- 16 Adler-Milstein J, McAfee AP, Bates DW, Jha AK. The state of regional health information organizations: current activities and financing. *Health Aff.* 2008;27(1):w60-69.
- 17 My PHR.com - My personal health record. American Health Information Management Association (AHIMA) Web site. <http://www.myphr.com>. Updated 2008. Accessed January 8, 2008.
- 18 Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc.* 2006;13(2):121-126.
- 19 Halamka JD, Mandl KD, Tang PC. Early experiences with personal health records. *J Am Med Inform Assoc.* 2008;15(1):1-7.
- 20 HealthVault. Microsoft Web site. <http://www.healthvault.com>. Updated 2008. Accessed January 8, 2008.
- 22 CDC. Modeling Electronic Reporting Project (NPCR-MERP). Available at <http://www.cdc.gov/CANCER/npcr/informatics/merp/>. Accessed January 8, 2008.
- 23 Fitzgerald M. Doctors in small and midsize business should have electronic health records (EHR). CIO Web site. http://www.cio.com/article/19677/Doctors_in_Small_and_Mid_size_Business_Should_Have_Electronic_Health_Records_EHR_Published_April_1_2006. Accessed January 8, 2008.
- 24 Ball MJ, Gold J. Banking on health: personal records and information exchange. *J Healthc Inf Manag.* 2006;20(2):71-83.
- 25 Committee on Data Standards for Patient Safety, Institute of Medicine. Key capabilities of an electronic health record system; Letter report. http://www.providersedge.com/ehdocs/ehr_articles/Key_Capabilities_of_an_EHR_System.pdf. Accessed January 8, 2008.
- 26 Gill JM, Ewen E, Nsereko M. Impact of an electronic medical record on quality of care in a primary care office. *Del Med J.* 2001;73(5):187-194.
- 27 Ford EW, Menachemi N, Phillips MT. Predicting the adoption of electronic health records by physicians: when will health care be paperless? *J Am Med Inform Assoc.* 2006;13(1):106-112.
- 28 Tanne JH. US government announces electronic health records project. *BMJ.* 2007;335(7627):959.

Public Health Surveillance Data in North Carolina

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Data from a variety of sources comprise the public health surveillance system for North Carolina today. The purposes of public health surveillance go far beyond collecting data. Effective public health surveillance ensures that the data are used by health policy makers, state and local public health agencies, and health program managers for effective public health planning, resource allocation, and program evaluation. Surveillance is a core public health function. A number of the 10 national essential public health services involve using data and include the following: monitor health status to identify community health problems; diagnose health problems and health hazards in the community; inform and educate people about health issues; evaluate the effectiveness, accessibility, and quality of personal and population-based health services; and conduct research for new insights and innovative solutions to health problems.

The purpose of this article is to describe the major public health surveillance databases available in North Carolina and present some examples of how these data have been used for education, policy, planning, and evaluation. A number of these databases are housed in the State Center for Health Statistics (SCHS), which is located organizationally in the Chronic Disease and Injury Section of the North Carolina Division of Public Health. Until 1980, the SCHS was named the Public Health Statistics Branch and dealt mainly with vital records data such as births and deaths. It was renamed the State Center for Health Statistics, and its mandate was broadened to include responsibility for a wider range of databases. Even when the SCHS does not produce and house the data, it is responsible for accessing health data from a variety of sources and making

it available for health policy and program planning. A number of these “outside” data sets are included in this inventory.

The State Center for Health Statistics consists of about 65 employees organized into the following 5 major work units: Statistical Services, Birth Defects Monitoring Program, Central

Cancer Registry, Health and Spatial Analysis, and Operations/Quality Management. The State Center for Health Statistics serves the entire Division of Public Health and also some agencies in other areas of the North Carolina Department of Health and Human Services. In addition to providing data and technical support to health and human services programs, the SCHS produces a comprehensive set of health-related publications and answers thousands of requests for data from a variety of individuals from across the

state and the nation. More information about the SCHS and its data products, publications, and services can be found at its Web site at <http://www.schs.state.nc.us/SCHS>.

The State Center for Health Statistics has a Health Data Query System (<http://www.schs.state.nc.us/SCHS/data/query.html>) that allows the user to generate custom designed, detailed data reports for deaths, births, birth defects, pregnancies, and population data. In addition, public use data files with individual birth, death, fetal death, and matched birth/infant records for the years 1968-2006 (with complete data file documentation) can be downloaded from the Odum Institute for Research in Social Science Web site (http://www.irss.unc.edu/odum/jsp/content_node.jsp?nodeid=10).

This article is not intended to provide a comprehensive inventory of health data available in North Carolina. We include databases that are (1) used extensively by public health programs for surveillance purposes; (2) statewide in coverage;

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and (3) regularly produced or updated as opposed to special or one-time data collection efforts. In general, we do not include health program databases that contain mainly patient and medical encounter information.

Some of the databases described here can be used only for statewide estimates (this includes most of the sample-based surveys) while many will support production of data at the county level. County-level data are used extensively for community health assessment and other local planning and evaluation efforts. (For information about the North Carolina Community Health Assessment Initiative, go to <http://www.schs.state.nc.us/SCHS/about/chai.html>.) Usually, data are tabulated by county of residence (regardless of the location of the event) so population-based rates can be produced. Even where the data represent a complete count of events (such as deaths), there may be substantial random error in rates based on small numbers of events. (See "Problems with Rates Based on Small Numbers" at <http://www.schs.state.nc.us/SCHS/pdf/primer12.pdf>.) Combining several years of data before producing rates or aggregating counties will stabilize the rates by reducing random variability due to small numbers.

MORTALITY DATA

Death Certificate Data

Vital records have been core data for public health surveillance since complete registration began for North Carolina in about 1918. North Carolina law requires that a death certificate be filed for each death that occurs in North Carolina. In addition, there is an interstate vital records exchange agreement where we receive death certificates for all North Carolina residents who died in other states. We combine these data to produce complete mortality data by county of residence. For most chronic diseases and for injuries, we do not have comprehensive morbidity data so death rates are often used to portray rates of chronic disease and injury in the state. *The Leading Causes of Death* publication of the SCHS shows numbers of deaths, unadjusted death rates, and age-adjusted death rates for 20 causes of death by county of residence.¹ For details about the rationale for and calculation of age-adjusted death rates, visit <http://www.schs.state.nc.us/SCHS/pdf/primer13.pdf>.

Medical Examiner Data

The Office of the Chief Medical Examiner (OCME) investigates all deaths due to injury and violence, those from suspicious or undetermined causes, and deaths not attended by a physician. The OCME collects additional information that is not available from the death certificate data system including alcohol and other toxicology test results and more detailed information on gun type for deaths involving firearms. Approximately 9000 of the 75 000 deaths in North Carolina each year are investigated by medical examiners. Limited medical examiner data can be found on the SCHS web site at <http://www.schs.state.nc.us/SCHS/data/medexam>. For additional information or further data, contact the OCME at (919) 966-2253.

North Carolina Violent Death Reporting System

The North Carolina Violent Death Reporting System (NC-VDRS) began collecting data in January 2004. The NC-VDRS provides detailed statistics about victims and suspects involved in incidents where intentional violence resulted in death (ie, homicide, suicide, legal intervention). Data also are collected for unintentional firearm deaths and deaths with undetermined manner/intent. The NC-VDRS uses information from multiple data sources (eg, death certificates, law enforcement records, medical examiner reports) to provide a description of circumstances, demographics, relationships between victims and suspects, and weapons. Provisional counts and selected data from the NC-VDRS are typically available within 8 months of the calendar year in which the deaths occurred, and complete data are available within 18 months.

The National Violent Death Reporting System (NVDRS) Web site at <http://www.cdc.gov/ncipc/profiles/nvdrs/default.htm> provides information about the system, its goals, the data it collects, the states that are funded, and how to access NVDRS data. Requests for North Carolina data can be made to the North Carolina Injury and Violence Prevention Branch at (919) 707-5432.

BIRTH-RELATED DATA

Birth Certificate Data

North Carolina law requires that a certificate be filed for each live birth that occurs in North Carolina. In addition, there is an interstate vital records exchange agreement where we receive birth certificates for North Carolina residents who deliver in other states. We combine these data to produce complete natality data by county of residence. In addition to live births, data are collected for each fetal death (stillbirth) of 20 or more week's gestation. *The Basic Automated Birth Yearbook (BABY Book)*,¹ an annual publication of the SCHS, shows live birth numbers for the state and each county tabulated by a number of characteristics captured on the birth certificate: mother's age, mother's race, mother's education, smoking during pregnancy, month prenatal care began, number of prenatal care visits, birth weight, birth order, and medical conditions of the mother. The State Center for Health Statistics also annually publishes *North Carolina Vital Statistics, Volume 1*,¹ which contains selected live birth and fetal death measures for the state and each county. North Carolina live birth and fetal death data are submitted to the National Center for Health Statistics as part of the national vital statistics system.

Reported Pregnancies

The State Center for Health Statistics combines data on live births, spontaneous fetal deaths, and induced abortions to produce statistics on reported pregnancies in North Carolina.¹ In 2006 there were 127 646 live births, 868 fetal deaths, and 29 430 induced abortions reported for North Carolina residents. Fetal deaths in North Carolina are reportable to the state only if they are 20 weeks or more in gestation, so our pregnancy

statistics do not include spontaneous fetal deaths of less than 20 weeks gestation (ie, early stillbirths or miscarriages).

Birth Defects Data

The North Carolina Birth Defects Monitoring Program (BDMP)² was formally established by the North Carolina General Assembly in 1995. The BDMP gathers data on infants who are born with serious congenital anomalies (birth defects) diagnosed within the first year of life (approximately 4000-5000 infants per year). Data are collected by trained field staff who systematically review and abstract hospital medical records, supplemented by information from administrative health databases such as hospital discharge data, vital records, and other sources. This intensive method of case ascertainment provides the most complete, accurate, and timely data on the incidence of birth defects thereby enhancing its usefulness to public health programs. The program maintains a central registry with patient-identifying information which is considered confidential under state law.

HOSPITAL-RELATED DATA

Inpatient Hospital Discharge Data

Selected data are collected for each of the more than 1 million inpatient hospital discharges occurring each year in North Carolina. This database is owned by Thomson Healthcare, Inc, and the data are made available to the North Carolina Division of Public Health through a special legislative provision. The State Center for Health Statistics can provide these data to agencies in state government and county public health departments for purposes of improving public health. The State Center for Health Statistics has North Carolina hospital discharge data files for calendar years 1995-2005. Data items collected include age and gender of patient, dates of service, expected source of payment, county of residence, admission source, discharge status, principal and additional diagnoses, E codes, principal and additional procedures, and total billed charges. The Healthcare Cost and Utilization Project (HCUP)³ of the federal Agency for Healthcare Research and Quality provides national and state-specific data and reports including hospital discharge data for North Carolina. The HCUPnet section provides free or low-cost national, regional, and state-level inpatient hospital statistics.⁴

Ambulatory Surgery Data

The North Carolina Hospital Based and Freestanding Ambulatory Surgery Facilities database contains more than 1.5 million records per year for surgeries performed in an outpatient setting. Approximately 155 facilities in North Carolina are reporting information into this database. The State Center for Health Statistics has recently started receiving quarterly updates of the North Carolina ambulatory surgery data from Thomson Healthcare, Inc, under the same arrangements as for the hospital discharge data. The State Center for Health Statistics can provide these ambulatory surgery data to agencies in state government and county public health departments for purposes of improving public health. Data items received by the SCHS include age

and gender of patient, dates of service, expected source of payment, county of residence, principal diagnosis, principal and additional procedures, total billed charges, and detailed charges.

Emergency Room Data

North Carolina is the first state in the nation to establish a comprehensive system for electronic reporting of data by hospital emergency departments. Nearly all hospitals in the state with 24 hours a day 7 days a week emergency departments are reporting into the system and the goal is to have all hospitals reporting in the near future. One use of these data is for the North Carolina Disease Event Tracking and Epidemiologic Collection Tool (NC DETECT) system.⁵ NC DETECT currently monitors real-time emergency department data and categorizes visits into syndromes in order to detect unexpected cases and outbreaks earlier in their course than traditional disease-based surveillance would allow.

Since data are collected for all types of visits, emergency department use for chronic disease, injury, or any other health condition can also be monitored. Selected North Carolina emergency department data may be accessed at the North Carolina Emergency Department Database Web site at <http://www.ncedd.org>.

The State Center for Health Statistics has recently started receiving quarterly updates of the North Carolina emergency department data from Thomson Healthcare, Inc, under the same arrangements as for the hospital discharge data. These data files are comprised of records for more than 3 million emergency room visits per year. Emergency room visits that result in an inpatient hospital admission are not included in the data files received by the SCHS since these visits can be counted from the inpatient hospital discharge data. The State Center for Health Statistics can provide these ER data to agencies in state government and county public health departments for purposes of improving public health. Data items received by the SCHS include age and gender of patient, dates of service, expected source of payment, county of residence, admission source, discharge status, principal diagnosis, principal procedure, and total billed charges.

POPULATION SURVEY DATA

Behavioral Risk Factor Surveillance System

The Behavioral Risk Factor Surveillance System (BRFSS) is a random telephone health survey of adults conducted in every state. It is sponsored by the Centers for Disease Control and Prevention (CDC).⁶ In North Carolina, survey estimates are available for the state, major regions, and about 25 single counties. The annual sample size is more than 15 000 adult respondents. The BRFSS⁷ collects data on many topics including perceived health status, health insurance coverage, physical activity, asthma, arthritis, smoking, disability, diabetes, overweight/obesity, and cancer screening. The BRFSS survey is revised each year and it includes so-called "core" questions from the CDC which are uniform across all states plus questions specific for North Carolina.

Child Health Assessment and Monitoring Program

The Child Health Assessment and Monitoring Program (CHAMP)⁸ is a North Carolina health survey of children ages 0 to 17 years. Data collection for CHAMP began in January 2005. Adult respondents to the BRFSS survey with children living in their households are invited to participate in the CHAMP survey. One child is randomly selected from the household, and the adult most knowledgeable about the health of the selected child is interviewed in a follow-up survey. The CHAMP survey is revised each year to meet the child health surveillance needs of North Carolina. It is a state-level survey with more than 3000 annual respondents and does not provide county-specific information. Data topics include health care access, asthma, mental health, disability, nutrition, physical activity, overweight, tobacco, child safety, and injury.

Pregnancy Risk Assessment Monitoring System

The North Carolina Pregnancy Risk Assessment Monitoring System (PRAMS)⁹ is a survey of women who have recently had a baby. The survey is sponsored by the CDC¹⁰ and is currently conducted in 35 states. Birth certificates are selected at random and then a health survey is mailed to the mother; for those who do not respond by mail, attempts are made to complete the survey via telephone. Approximately 1500 PRAMS surveys are completed each year in North Carolina usually between 3 and 5 months after birth. Statewide data for 1997-2005 are available as well as some multiyear regional data. The PRAMS sample size is not large enough to produce county-level estimates. While the major purpose of PRAMS is to collect information about risk factors for poor birth outcomes (information not available on the birth certificate), there also are some topics pertaining to women's health and chronic disease before, during, and after pregnancy.

Youth Risk Behavior Survey

In the spring of every odd numbered year, the North Carolina Healthy Schools project conducts a statewide Youth Risk Behavior Survey (YRBS)¹¹ among middle school and high school students in North Carolina. The North Carolina YRBS helps assess behaviors in youth that impact their health now and in the future. Topics include violence, personal safety, physical activity, nutrition, mental health, tobacco, drugs and alcohol, and sexual behavior (for high school students only). Estimates are produced for the state as a whole and for major regions of the state. There is also a separate YRBS for the Charlotte area. The YRBS is funded by the CDC and North Carolina data are included as part of a national surveillance system.¹²

Youth Tobacco Survey

The North Carolina Youth Tobacco Survey (YTS)¹³ provides an important source of public health data for understanding the scope of the tobacco problem and measuring progress toward overall goals among youth. The 2005 North Carolina YTS is a comprehensive statewide representative sample of more than

6000 middle and high school students. Every other year a core set of CDC¹⁴ tobacco-related questions are asked. In addition, North Carolina adds state-specific questions. In 2005 the North Carolina Tobacco Prevention and Control Branch together with the NC Health and Wellness Trust Fund added questions regarding media, community participation, and secondhand smoke attitudes. The sampling design now generates large enough numbers to produce reliable regional estimates (Mountains, Piedmont, and Coast). North Carolina submits data to the CDC as part of the national YTS sample.

OTHER STATEWIDE SURVEILLANCE SYSTEMS

Newborn Hearing Screening Surveillance System

A Web-based tracking and surveillance database called WCSWeb was developed collaboratively by the Early Hearing Detection and Intervention Program,¹⁵ the Sickle Cell Program, and the State Laboratory of Public Health. It contains data on all infants born in North Carolina since January 1, 2004 and on all infants born in North Carolina with suspected hearing loss since newborn hearing screening was mandated in 2000. Patient information is obtained by either direct data entry by hospital, clinical, or public health staff or transfer of newborn screening data from the State Laboratory of Public Health Laboratory Information Management System (LIMS). With the implementation of WCSWeb, the Early Hearing Detection and Intervention Program is able to provide statistical information on the effectiveness of birthing facility newborn hearing screening programs. In 2006 97% of nearly 130 000 babies in North Carolina who were eligible for newborn screening services received a screening which was reported into WCSWeb. Of these babies screened at birth, 4099 or 3.2% needed further follow-up. Of these 4099 babies, 430 had diagnostic evaluation results reported into WCSWeb and 202 were confirmed with a hearing loss. Regional consultants of the Division of Public Health are making a concerted effort to educate hospitals and physicians on the importance of providing prompt rescreening for infants who do not pass the newborn hearing screening and on the use of WCSWeb to report follow-up results.

Cancer Incidence Data

The North Carolina Central Cancer Registry (CCR)¹⁶ collects data on all new cases of cancer in North Carolina. The data are collected primarily from tumor registries in the larger facilities that submit data electronically and by CCR field staff who abstract cancer case data in smaller facilities. In addition to demographic and diagnostic information, data are collected about the first course of cancer treatment. This is one of the few complete morbidity reporting systems for chronic disease in North Carolina. North Carolina participates in the National Program of Cancer Registries¹⁷ and submits data regularly to the CDC as part of the national cancer incidence database. For more information about the CCR, see the article in this issue by Karen Knight.

North Carolina Nutrition and Physical Activity Surveillance System

The North Carolina Nutrition and Physical Activity Surveillance System (NC-NPASS)¹⁸ provides indicators of body mass index status among children such as overweight, underweight, and healthy weight for each county in North Carolina and for the state as a whole. In the future NC-NPASS will monitor trends in key nutrition and physical activity behaviors such as soft drink consumption, fruit and vegetable consumption, levels of physical activity, and television viewing. The NC Nutrition and Physical Activity Surveillance System may not be representative of the population as a whole since it is comprised primarily of data about low-income children seen in the North Carolina public health-sponsored Women, Infants, and Children (WIC) program, child health clinics, and some school-based health centers. The information on older children (who are not eligible for WIC) is especially underrepresented since it comes from a very select population who receive health care from public health clinics. Information on weight status is available only for children ages 2-18 whose height and weight were measured during a health care visit.

Pregnancy Nutrition Surveillance System

The North Carolina Pregnancy Nutrition Surveillance System (PNSS)¹⁹ monitors the prevalence of nutrition problems and behavioral risk factors among women who are enrolled in public health programs. The NC Pregnancy Nutrition Surveillance System links data from the WIC program and public maternity clinics with birth certificates and fetal death records. The system collects prenatal and postpartum information about these women and outcome information about their infants. The majority of the women in the North Carolina PNSS participate in WIC during either the prenatal or postpartum period. The Centers for Disease Control and Prevention collects and analyzes data from the states for the national PNSS.²⁰

Pediatric Nutrition Surveillance System

The Pediatric Nutrition Surveillance System (PedNSS)¹⁹ is a child-based public health surveillance system that monitors the nutritional status of low-income children in WIC and other federally funded maternal and child health programs. Data on birth weight, short stature, underweight, overweight, anemia, and breastfeeding are collected for children ages 0-18 who visit public health clinics for routine care and nutrition services including education and supplemental food. Data are collected at the clinic level and then aggregated at the county and state levels. North Carolina data are sent to the CDC for incorporation into the national PedNSS data.²⁰

Communicable Disease Data

HIV and other communicable sexually transmitted diseases (STDs) pose public health risks and thus are made reportable to public health authorities in North Carolina. Most often the cases are reported by physicians to local health departments (as required by law) which then forward the reports to the

Epidemiology Section of the North Carolina Division of Public Health. Medical facilities may also report cases, usually through the infection control staff. Persons making these reports are immune from liability for doing so. Laboratory reports are sent to the Epidemiology Section and act as a trigger for investigation and reporting of cases not already in the system. The data on reported cases are used to identify risks and vulnerable populations and to design control measures to limit the spread of these diseases through the HIV/STD Prevention and Care Branch.²¹ State- and county-level data are available through the General Communicable Disease Control Branch.²² De-identified North Carolina data are submitted to the CDC as part of the national communicable disease and HIV/STD surveillance systems. North Carolina is developing a comprehensive electronic disease reporting system called the North Carolina Electronic Disease Surveillance System (NC EDSS) that will replace paper-based reporting of communicable and other diseases between local health departments and the Division of Public Health. Initial deployment of the NC EDSS started in 2007 for tuberculosis, and other diseases are being added.

OTHER HEALTH-RELATED DATA

Medicaid Data

Medicaid is a medical insurance program for low-income North Carolinians. Since the 1980s the State Center for Health Statistics has had a cooperative relationship with the Division of Medical Assistance^{23,24} (the state Medicaid agency) that involves sharing data for planning and evaluating public health programs. The North Carolina Medicaid Management Information System captures data on all payments for medical services for adults and children enrolled in Medicaid. This is one of the few data systems available to the North Carolina Division of Public Health that contains information on the complete range of medical services provided to a defined population: inpatient, outpatient, emergency room, physician, dental, home health, nursing home, prescription drug, and hospice services. There is also an enrollment file with information on the characteristics of the Medicaid enrollees. The State Center for Health Statistics strictly protects the confidentiality of these data and produces only aggregate data reports unless specifically authorized in writing by the Division of Medical Assistance to release individual-level data. The State Center for Health Statistics has a limited capacity to meet special Medicaid data needs of programs outside the North Carolina Division of Public Health.

Health Workforce Data

The North Carolina Health Professions Data System²⁵ of the Cecil G. Sheps Center for Health Services Research has detailed county-level health workforce data including physicians by specialty, dentists, nurses, and many other health provider types. The data system also presents state and county health manpower profiles and will accept special data requests. (See <http://www.shepscenter.unc.edu/hp>.)

Population Data

Population data²⁶ are not strictly health data, but population counts are important for assessing caseloads or persons at risk when planning for provision of health services. And population data are used extensively as denominators of health-related rates. The NC State Demographics unit produces population estimates and projections with age, race (White and minority), and gender detail for North Carolina and its 100 counties. In addition, the SCHS publishes reports showing annual state demographer population estimates by county, age, race, and gender.²⁷ Population estimates from the State Demographics unit also are provided through the SCHS Health Data Query System, which also includes more detailed race and ethnicity breakouts.

LINKING DATA

Linking the records in different data sets can increase the utility of the separate components. After linking, the variables of both data sets become available for joint analysis and cross tabulation. For example, each year the SCHS creates a composite linked birth file²⁸ which consists of the birth certificate records linked to several health program data files: Medicaid babies, Medicaid mothers, maternity care coordination, Medicaid costs, prenatal WIC, health department prenatal care, and child service coordination. This allows for the tabulation of birth certificate measures by participation in these health service programs.

The State Center for Health Statistics annually links all infant death certificates to the corresponding birth records. This matched file²⁹ allows analysis of infant mortality by characteristics that are available only on the birth certificate such as birth weight, mother's age, mother's education, mother's self-reported race, smoking during pregnancy, and prenatal care participation.

The State Center for Health Statistics has recently linked the

NC-NPASS data described above for adolescents ages 12-18 to the Medicaid paid claims and enrollment data to analyze health care utilization and expenditures by body mass index categories.³⁰ The Medicaid data alone do not capture any information on body mass index. It was found that adolescents who are overweight and at risk for overweight have higher Medicaid expenditures and that overweight adolescents had a significantly higher incidence of diabetes, asthma, and other respiratory conditions.

USING DATA FOR EDUCATION, POLICY, PLANNING, AND EVALUATION

These public health surveillance data are used extensively for education, policy, planning, and evaluation. A few selected examples include the use of PRAMS data to develop a statewide public education and awareness campaign to reduce the risk of Sudden Infant Death Syndrome (SIDS); the use of Medicaid data, live birth data, and PRAMS data as part of a North Carolina Medicaid Program and Division of Public Health application to the federal Centers for Medicare and Medicaid Services (CMS) to obtain a family planning waiver to extend Medicaid eligibility for family planning and sexually transmitted disease services for men and women up to 185% of the federal poverty level; use of birth defects data to help target and evaluate programs to reduce certain birth defects through the intake of folic acid; and the use of BRFSS survey data by several community-based organizations and health departments to apply for grants, guide intervention strategies, and support policy changes for their initiatives. Data are of little value unless they are used, and use of data in turn provides incentives to increase the quality of the databases. North Carolina is fortunate to have such a wealth of state and local data sources. Additional and ongoing data collection will continue to provide the state with valuable measures for determining appropriate policy interventions for improving the health of individuals and communities. **NCMJ**

REFERENCES

- 1 Vital statistics data available from SCHS. North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/data/vitalstats.cfm>. Updated February 9, 2006. Accessed February 27, 2008.
- 2 North Carolina Birth Defects Monitoring Program. North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/bdmp>. Accessed February 27, 2008.
- 3 Healthcare Cost and Utilization Project (HCUP). Agency for Healthcare Research and Quality Web site. <http://www.hcup-us.ahrq.gov>. Accessed February 27, 2008.
- 4 Welcome to HCUPnet. Agency for Healthcare Research and Quality Web site. <http://hcupnet.ahrq.gov/>. Accessed February 27, 2008.
- 5 North Carolina Disease Event Tracking and Epidemiologic Collection Tool (NC DETECT) Web site. <http://www.ncdetect.org>. Accessed February 27, 2008.
- 6 Behavioral Risk Factor Surveillance System (BRFSS). National Center for Chronic Disease Prevention and Health Promotion. Centers for Disease Control and Prevention Web site. <http://www.cdc.gov/brfss>. Updated January 31, 2008. Accessed February 27, 2008.
- 7 Behavioral Risk Factor Surveillance System (BRFSS). North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/brfss>. Updated December 13, 2007. Accessed February 27, 2008.
- 8 Child Health Assessment and Monitoring Program (CHAMP). North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/champ>. Updated July 19, 2007. Accessed February 27, 2008.
- 9 North Carolina Pregnancy Risk Assessment Monitoring System (PRAMS). North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/prams>. Updated January 30, 2008. Accessed February 27, 2008.

- 10 Pregnancy Risk Assessment Monitoring System (PRAMS): Home. Centers for Disease Control and Prevention Web site. <http://www.cdc.gov/prams>. Updated June 22, 2007. Accessed February 27, 2008.
- 11 NC Youth Risk Behavior Survey (YRBS). NC Healthy Schools Web site. <http://www.nchealthyschools.org/data/yrbs/>. Accessed February 27, 2008.
- 12 Healthy Youth! Data & Statistics. YRBSS: Youth Risk Behavior Surveillance System. National Center for Chronic Disease Prevention and Health Promotion. Centers for Disease Control and Prevention Web site. <http://www.cdc.gov/HealthyYouth/yrbs/index.htm>. Updated June 6, 2007. Accessed February 27, 2008.
- 13 2005 NC Youth Tobacco Survey. Tobacco Prevention and Control Branch. NC Division of Public Health, Chronic Disease and Injury Section. <http://www.tobaccopreventionandcontrol.ncdhhs.gov/data/yts.htm>. Updated December 14, 2007. Accessed February 27, 2008.
- 14 Smoking & tobacco use. National Youth Tobacco Survey (NYTS). Centers for Disease Control and Prevention Web site. http://www.cdc.gov/tobacco/data_statistics/surveys/NYTS/index.htm. Updated February 28, 2007. Accessed February 27, 2008.
- 15 North Carolina Early Hearing Detection and Intervention Program. North Carolina Department of Health and Human Services Web site. <http://www.ncnewbornhearing.org>. Updated February 27, 2008. Accessed February 27, 2008.
- 16 Central Cancer Registry. North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/CCR>. Updated August 9, 2007. Accessed February 27, 2008.
- 17 National Program of Cancer Registries (NPCR). Centers for Disease Control and Prevention Web site. <http://apps.nccd.cdc.gov/uscs/>. Accessed February 27, 2008.
- 18 Data. Eat Smart Move More North Carolina Web site. <http://www.eatsmartmovemorenc.com/data/index.html>. Accessed February 27, 2008.
- 19 Surveillance data and statistics. North Carolina Nutrition Services Branch Web site. <http://www.nutritionnc.com/nutrsurv.htm>. Accessed February 27, 2008.
- 20 Pediatric and Pregnancy Nutrition Surveillance Systems. Centers for Disease Control and Prevention Web site. <http://www.cdc.gov/pednss>. Updated June 12, 2006. Accessed February 27, 2008.
- 21 HIV/STD prevention & care. NC Division of Public Health Web site. <http://www.epi.state.nc.us/epi/hiv/>. Updated January 17, 2008. Accessed February 27, 2008.
- 22 Communicable disease control. NC Division of Public Health Web site. <http://www.epi.state.nc.us/epi/gcdc.html>. Updated February 8, 2008. Accessed February 27, 2008.
- 23 North Carolina Medicaid. Division of Medical Assistance. NC Department of Health and Human Services Web site. <http://www.dhhs.state.nc.us/dma>. Updated February 26, 2008. Accessed February 27, 2008.
- 24 County specific snapshots for NC Medicaid services. Division of Medical Assistance. NC Department of Health and Human Services Web site. <http://www.dhhs.state.nc.us/dma/countyreports/countyreports.html>. Updated May 10, 2007. Accessed February 27, 2008.
- 25 North Carolina Health Professions Data System Web site. <http://www.shepscenter.unc.edu/hp/index.html>. Updated September 18, 2007. Accessed February 27, 2008.
- 26 State demographics. North Carolina State Demographics Web site. <http://demog.state.nc.us>. Accessed February 27, 2008.
- 27 2008 County Health Data Book. North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/data/databook>. Updated January 2, 2008. Accessed February 27, 2008.
- 28 Vital statistics data available from SCHS. North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/births/matched/2006>. Updated February 9, 2006. Accessed February 27, 2008.
- 29 Buescher PA. Statistical primer no. 14. Matched live birth/infant death files. April 2000. <http://www.schs.state.nc.us/SCHS/pdf/Primer14.pdf>. Accessed February 27, 2008.
- 30 Buescher PA, Whitmire JT, Plescia M. Relationship between body mass index and medical care expenditures for North Carolina adolescents enrolled in Medicaid in 2004. *Prev Chronic Dis*. 2008;5(1). http://www.cdc.gov/pcd/issues/2008/jan/06_0131.htm. Accessed February 27, 2008.

Geographic Information Systems and Health in North Carolina

Dianne Enright

A geographic information system (GIS) is a powerful tool in shaping North Carolina health policy and research. A geographic information system is more than a mapping tool; it is defined as a database that is tied to locations in space. However, the true power of a GIS comes from the ability to view many types of data together and to query or ask questions of the data.

There are some challenges in using health data with GIS. First, you must be able to geocode the data or assign a location to it in some fashion. Sometimes this could be simply presenting data that are already aggregated at the city or county level such as rates for a particular cause of death. (See Figure 1.) However, patient- or provider-level data must become geo-enabled. This type of point-level data could be geocoded by either gathering data in the field with a global positioning system (GPS) or through address matching.

A global positioning system captures location coordinates that are easily imported into a GIS to display locations. A global positioning system provides very accurate data; however, time must be spent in the field traveling to each location to ascertain specific coordinates. Geocoding at the address level involves matching an address against source data such as a road network that is attributed with existing address ranges. The geographic information system interpolates the position along the road where the address falls and captures the coordinates to display location. Numerous problems can occur with address matching. Mistakes can be made when the address is entered into a data system. In addition, problems can occur with the interpolation, or the source data that the address is compared to could have mistakes. Sometimes a person's current address is newer than the source data's creation date, or the address given simply does not exist and therefore cannot be

located. Also, collection of patient data is often done for billing purposes. Many patients report a post office box for mailing purposes, thus the patient's physical residence is not locatable.

The State Center for Health Statistics (SCHS) has been using GIS since 1989 to assist health programs with evaluations, to establish or modify health policy, and to facilitate research. A simple choropleth (shaded) map can provide valuable information obtained by visualizing where in space a health event or problem is occurring. A choropleth, or thematic map, is based on statistical data that have been aggregated to an areal unit. The maps are

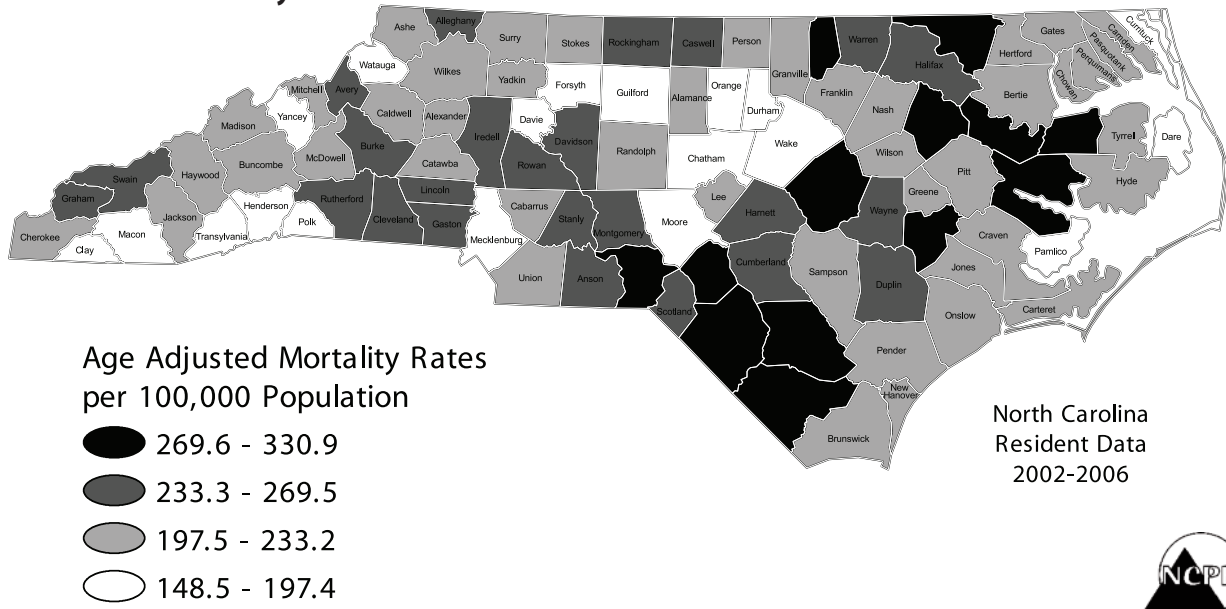
“...a valuable tool for emergency response, program evaluation, and health research. The geographic information system has proved to be an essential tool to help allocate limited public health resources.”

then shaded using different degrees of the same color, traditionally displaying the highest values as the darkest shade. (See Figure 1.)

Geographic information system techniques are also used for more sophisticated public health analyses. For example, the SCHS uses the power of GIS to assist in making decisions for nutrition services programs. The Health & Spatial Analysis Unit of the SCHS has been working with the Women's & Children's Health Section (Nutrition Services Branch, North Carolina Division of Public Health) to support decisions about the Child and Adult Care Food Program. The program funds meal reimbursements to family day care homes. The reimbursement for meals served in day care homes is based upon eligibility for tier I

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**Figure 1.
Heart Disease Mortality**

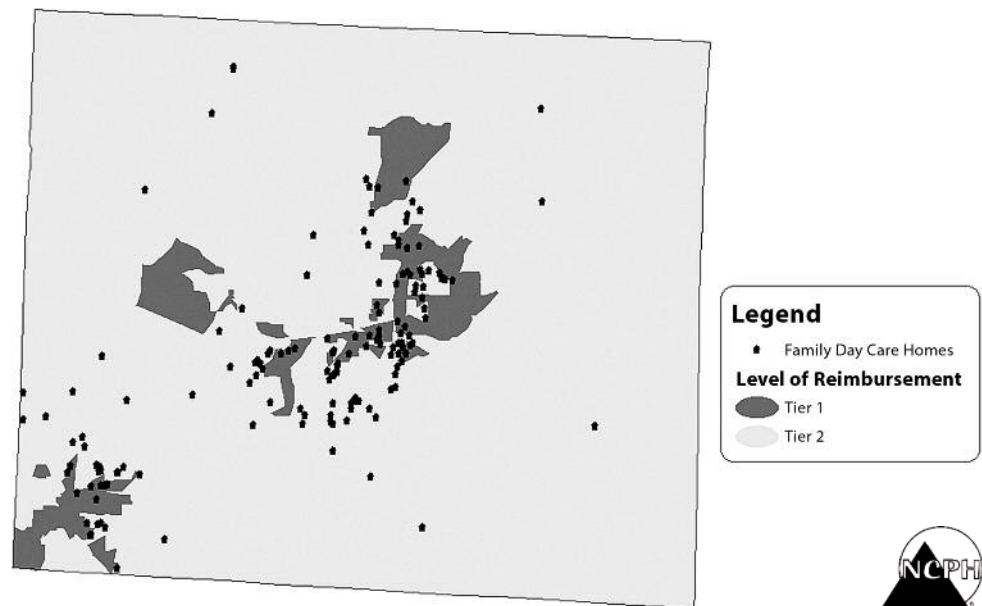


SOURCE: NC State Center for Health Statistics



rates (which targets higher levels of reimbursement to low-income areas, providers, or children) or lower tier II rates.^a After the Nutrition Services Branch approves an application, the family day care homes are located using GIS and then overlaid on a special run of census data. The census data show the percentage of children in poverty to determine the amount of reimbursement the family day care home may receive. (See Figure 2.) Using a different population age, the same type of analysis is applied to the Summer Adult Food Program. These analyses help target where limited funding dollars are truly needed.

**Figure 2.
Family Daycare Home Reimbursements**



SOURCE: NC State Center for Health Statistics



Another ongoing project the North Carolina Division of Public Health has been working on for several years is syphilis elimination. New syphilis cases are geocoded and mapped on a quarterly basis in the 6 counties

with the highest rates in the state. Each quarter is assigned a different color so the new cases identified throughout the year are easily traced. The staff of the HIV/STD Prevention & Care

a Child & Adult Care Food Program. Food and Nutrition Service. United States Department of Agriculture Web site. <http://www.fns.usda.gov/cnd/Care/CACFP/aboutcacfp.htm> Accessed January 3, 2008.

Branch (Epidemiology Section, North Carolina Division of Public Health) and local health departments use these maps to help reduce outbreaks. Again, by using a GIS to pinpoint where new syphilis cases occur, testing, education, and prevention methods are targeted directly to the neighborhoods where they are needed the most.

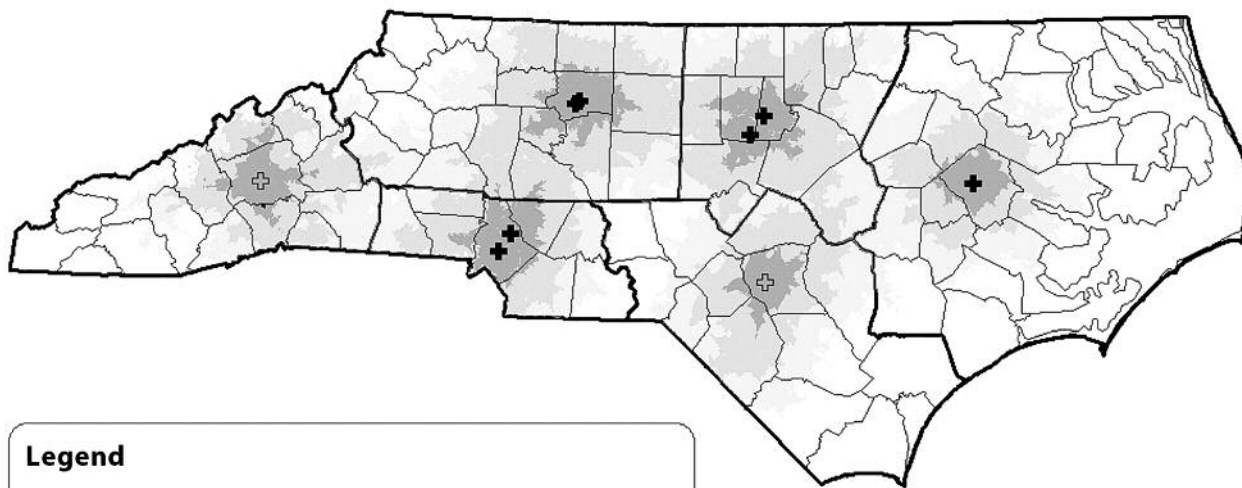
Geographic information systems are also becoming a widely used tool in emergency responses throughout the state. Many law officers and paramedics are equipped with GIS and GPS, which allows for real time vehicle routing for personnel to find locations quickly and for dispatchers to manage personnel and equipment. The North Carolina Office of Public Health Preparedness and Response (Epidemiology Section, North Carolina Division of Public Health) is also using this technology to better serve North Carolina residents. The North Carolina Office of Public Health Preparedness and Response is charged with responding to public health emergencies and has developed methods for gathering information from the field using GIS. It is vital to gather information very quickly in a public health emergency or following a natural disaster. Interviewers in the field are equipped with handheld computers that include a GPS. This equipment allows the staff in the field to navigate to interview locales as well as capture the coordinate location of where the interview occurs. Interviewers can use questionnaire forms on the handheld devices to gather required information from the population affected by the emergency or event. The information gathered is associated with the collected location coordinates. All of this information is then uploaded to a central database where it can be analyzed. Reports are shared with

multiple authorities to assist in determining needs and allocating resources.

A geographic information system also was used in a recent study of the time spent traveling to health care providers for families with a child having an orofacial cleft. It is important for infants born with an orofacial cleft to receive coordinated treatment from craniofacial centers or teams in the first 2 years of life. For the study, residential addresses of children with orofacial clefts were mapped, and the craniofacial centers were located. Using “closest facility methodology” the most efficient route from the residence to the closest care provider was calculated. By using this analysis method the actual distance and time spent traveling to the closest craniofacial center was estimated (although patients may not always travel to the closest facility or care provider) which is more accurate than using a straight line distance. This analysis was performed again after 2 new proposed locations for craniofacial centers were included where there were previously none. The analysis demonstrated that the addition of 2 new centers would result in an average decrease in orofacial cleft patient travel time of 16 minutes. (See Figure 3.) A geographic information system is a useful tool for evaluating the role that travel distance may play as a potential barrier to accessing health care among children with orofacial cleft and/or other types of birth defects.

The North Carolina Division of Public Health uses GIS for a variety of projects and purposes. It is a valuable tool for emergency response, program evaluation, and health research. The geographic information system has proved to be an essential tool to help allocate limited public health resources. **NCMJ**

Figure 3.
Orofacial Clefts and Drive Time to Current and Proposed
North Carolina Craniofacial Centers, 1995 - 2002



Legend

Craniofacial Centers (CFC)	Drive Time
Type	0-30 Minutes
+	31-60 Minutes
+	61-90 Minutes
+	Perinatal Care Regions (PCR)
~	
~	



SOURCE: NC State Center for Health Statistics

NC-CATCH:

North Carolina Comprehensive Assessment for Tracking Community Health

James Studnicki, ScD; John W. Fisher, PhD; Christopher N. Eichelberger, MS

Although the United States invests more resources than any other nation in the world for health, we are far from the healthiest country. In fact, the US languishes in the lower half of industrialized nations for a range of indicators used to measure health status and even trails nations considered to be economically underdeveloped for selected health indicators.¹ Accompanying this disappointing level of overall health status are the enormous disparities in the health of groups defined by race, ethnicity, socioeconomic status, and geography.² Despite decades of scrutiny by researchers and health policy analysts and numerous reports and white papers on the subject by prestigious and influential organizations such as the Institute of Medicine (IOM) of the National Academies, these vast differences are pervasive and seemingly intractable.^{3,4}

For example, poor White females in Mississippi and in Appalachia experienced declines in life expectancy between 1982 and 2001.⁵ Similarly, in North Carolina between 1975 and 2005, despite reductions in absolute rates, Black infant mortality steadily increased from 1.8 to 2.3 times the White rate.

The Measurement Mandate

While the problem of variation in community health status is complicated and has many underlying causes (known and unknown), there is nearly universal agreement that if we are to have any hope of improving it there must be a monitoring system to measure and benchmark community health status in a systematic way. There have been frequent attempts to provide a framework for community health status monitoring systems. The Planned Approach to Community Health (PATCH) developed in 1985 by the Centers for Disease Control and Prevention (CDC) sought to determine root causes and key intervention points for a few selected health issues.⁶ In 1991 the American Public

Health Association developed the Healthy People 2000 (and later 2010) protocol for addressing a series of defined national objectives.⁷ At about this time, the IOM of the National Academies proposed a model for community health improvement that involved an iterative process that cycled through assessment, evaluation, and action phases. The IOM of the National

“Access to a wide range of data sources is a prerequisite to effective community health status assessment.”

Academies proposed a set of 25 indicators which expanded on the 18 recommended by the original Healthy People 2000 objectives.⁸ The National Association of County and City Health Officials and the CDC developed the Assessment Protocol for Excellence in Public Health (APEXPH) which focused on process indicators to determine the internal capacity of public health organizations, and this protocol was later expanded to include other community health organizations.⁹ There have been other community health assessment models developed by the hospital industry,¹⁰ state and local government agencies, university research groups, and collaborations of multiple partners. Although these methods vary in their approach to assessment, they all share a common requirement: data. The data required to populate these various methodologies typically include existing secondary sources such as vital statistics (birth and death registration) and the extensive menu of secondary data from the surveys maintained by the National Center for Health Statistics (NCHS). Some of the methods also require

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primary data collection efforts to provide a perspective on local populations or providers not available in existing secondary data sources.

From Data to Knowledge: The Challenge of Analytics

Access to a wide range of data sources is a prerequisite to effective community health status assessment. Bringing together data from multiple sources, linking and integrating them, and continually updating and maintaining them for useful analysis can be a daunting challenge to even the most capable and resourceful organization. For the typical local community organization, such a task is often beyond their financial and technical capabilities.

The potential of the Internet as a means to disseminate data for health assessment has been recognized, and there has been a rapid increase in the number of states which maintain at least some form of access to health data through the World Wide Web. Although only 10 states reported a Web-based query tool in 2000, by 2006 the number had grown to 27 states.¹¹ In most cases, the state systems are limited to a static interface which provides prestructured statistics such as death counts or rates organized into preformatted reports. In a few instances, the query menu itself is dynamic and enables the user to make a selection of data sets, statistics, tables, and maps. These systems, however, do not have the kind of multidimensional navigation and analytical capabilities that can be made available with modern online analytical processing software. Therefore, when viewed from the perspective of what is really state-of-the-art given the rapid advances in computational software and Web-enabled applications, currently existing systems demonstrate major limitations. These include unidimensional filtering queries; single grain data without real time “roll up” or “drill down” capability; data set “silos” which are unlinked and nonintegrated; inconsistent definitions across data sets; lack of metadata (ie, data about the data necessary to facilitate the understanding, use, and management of the system); and lack of an imbedded, organized framework for extracting decision support knowledge from the underlying data.

The Community Health Assessment Portal

North Carolina has been one of the most active states nationally in promoting community health status assessment, and counties are required to produce a formal report at least every 4 years. The State Center for Health Statistics maintains a number of databases useful to this process and works closely with Healthy Carolinians in performing assessments and mobilizing multisector community action. With assistance from a health services research and technical development team from the University of North Carolina at Charlotte, the Division of Public Health (with additional funding from the Kate B. Reynolds Charitable Trust) initiated the development and deployment of a system that will address many of the weaknesses of current systems, thus bringing modern Web-enabled software technology

to public health. To this end, the Division of Public Health decided to move beyond merely producing data to actually enhancing the capability to analyze the data more effectively.

The North Carolina Community Health Assessment Portal (NC CHAP) can best be understood as a means to bring the capabilities of business intelligence to public health surveillance, particularly community health assessment. The original innovators in this field used the word “business” in a broad sense as a collection of activities carried on for some purpose such as commerce, science, government, or public health. “Intelligence” is also defined in a general sense as the ability to “apprehend the interrelationships of presented facts in such a way as to guide actions toward a desired goal.”¹² Modern business intelligence systems use data that has been gathered into a data warehouse or data mart and also occasionally use transactional or operating data. Using various types of software to support reporting, interactive pivot-table analyses, visualization, statistical data mining, and other technologies and applications, business intelligence systems provide historical, current, and predictive fact-level views of the enterprise in order to support better decision making.

NC-CATCH

As a business intelligence system, the Comprehensive Assessment for Tracking Community Health (NC-CATCH) has the following components:

Data Warehousing. Extant data organized into the data warehouse will include demographic/population data at the census tract level (updated annually by a commercial firm); mortality data; birth data; pregnancy data; hospital discharge data; emergency department visit data; behavioral risk factor survey data (regional and county level only); cancer incidence and treatment data; and other miscellaneous social, economic, and health-related data available at least at the county level. The data will be geocoded to the census tract where possible. Access to the various levels of warehouse capability will be through a portal on the Web site of the State Center for Health Statistics.

Methodology. Health is a multidimensional concept, and there is no single perfect measure for summarizing the health status of a defined population. CATCH is a comparative framework that provides a consistent, objective, multidimensional method for organizing and interpreting community health data. Key elements of CATCH include multiple indicators organized into categories (eg, infectious disease, maternal and child); comparisons with peer counties; state values; Healthy People 2010 values and other benchmarking standards; trend analysis for the most recent 3-5 year time period; an objectively derived rank ordered list of community health challenges; and a concise assessment of racial/ethnic health status disparities.¹³ The CATCH report, uniformly aggregated for each North Carolina county, will provide a comprehensive starting point from which the relative health challenges and achievements can be understood, and areas requiring further analyses can be identified. The CATCH

report includes embedded hyperlinks into the appropriate queries that allow full investigation of the underlying data.

Prestructured Queries. Prestructured queries allow the user more flexibility to choose the variables and dimensions of interest, but the choices are necessarily limited. A user, for example, may want to view infant mortality by race or by county, or hospitalization rates for diabetes by county. Some of these views are precalculated and made available through the portal, but they too are static like the CATCH report. These types of queries are the typical method for supplying information in most states. Another type of query is more active in that the user can select from a few number of dimensions to provide a limited form of query customization. These systems are interactive only to the extent that the user is given a menu of queries to select from. Since the number of possible queries is limited only by available data, the challenge is to provide a menu of queries that satisfy the needs of most users or provide information about the most important problems. Structured queries, however, can never maximize the use of information since they cannot anticipate nor perform all the multidimensional data navigation and analysis necessary to model a complex system such as population health.

Online Analytical Processing. Online analytical processing is a category of software technology that enables users to gain insight into data through fast interactive access to a wide variety of possible views of information transformed from raw data. The NC CATCH user utilizing online analytical processing functionality will be able to calculate and model across dimensions, through hierarchies, and across members; slice subsets for onscreen viewing (eg, organize hospital discharge data by pay source); drill down to deeper levels of consolidation (eg, identify all census tracts with a certain percentage of population in poverty); reach through to underlying detail data (eg, compare infant mortality in different counties by the specific causes of infant death); or rotate to new dimensional comparisons in the viewing area (eg, move from Black/White comparisons to Hispanic/non-Hispanic comparisons of age-banded chronic disease mortality). Online analytical processing truly brings the power of the data warehouse to the user's desktop. Multidimensional analysis makes it easier to navigate the database, and because the data are physically stored in a multidimensional structure, the speed of these operations is faster and more consistent than is possible in other database structures.

A Brief Explanation of the Technical Approach

The principal challenge to presenting consolidated health data consists of identifying the appropriate levels at which to enforce data standards. Raw health data exist in many different forms and formats: plain text documents, images, printed tables, spreadsheets, and databases. Each of these forms is well suited for its particular audience.

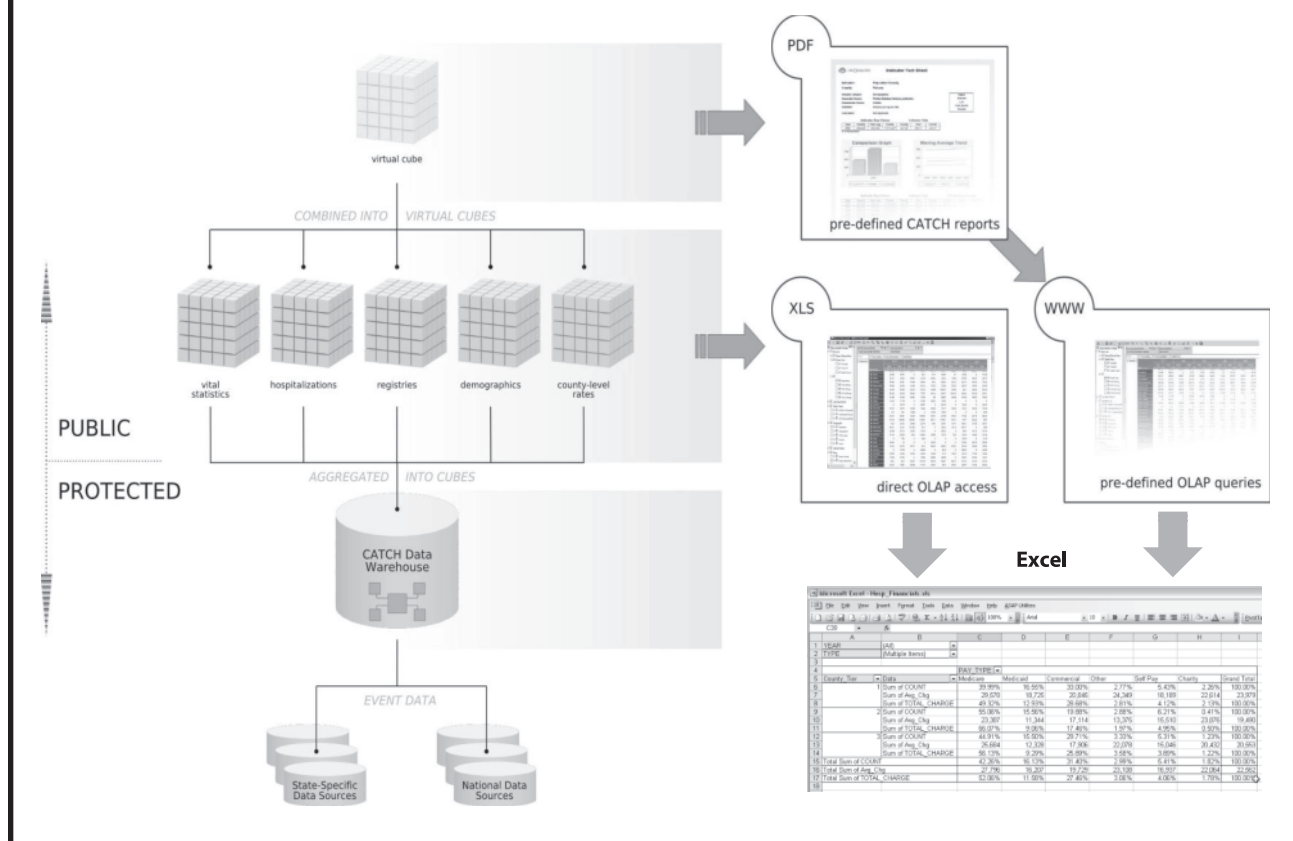
Each of these levels is treated separately within the following sections and related to the left-hand side of Figure 1:

- (1) The raw health data sources (the small cylinders at the bottom of the figure) were identified at the beginning of the project. Each was defined in terms of format, layout, and meaning. Staff used this information to build small software routines that load a given raw data source into a central database (the large cylinder in the figure). This transaction-level database is the first level of standardization in the project.
- (2) Once the raw data have been loaded into the transaction-level database, a second set of standards is applied to bridge separate sources and construct a series of unified multidimensional data cubes. A data cube is merely a collection of data that has been preaggregated along a given set of dimensions so that every possible combination of dimension values can provide a set of output measures efficiently. In the figure, the data cubes are depicted as gridded boxes in which each small component corresponds to one intersection of dimensions. Typically, we interpret dimensions as X, Y, and Z, but in data cubes the dimensions are more likely to be time, age band, race, sex, cause of death, etc. Identifying the standards that allow for the bridges among data sets, as well as defining the common dimensions and measures that typify the logical cubes, is the second level of standardization in the project.
- (3) The logical data cubes themselves can be recombined into virtual cubes (illustrated as translucent, gridded boxes at the top of the figure) providing glimpses into the data that were not previously available. For example, one logical cube is dedicated to the detailed demographics of North Carolina; another cube is dedicated to the deaths that have occurred over time. Combining these 2 cubes into a virtual cube allows us to explore not only the base demographics and the deaths, but rates and age-adjustments across all geographies, years, demographic splits, and causes of death. Identifying the meaningful combinations of logical cubes into virtual cubes is the third level of standardization in the project.

This project seeks to provide 3 levels of access targeted to meet the needs of 3 distinct user communities, differentiated by the trade-off between ease-of-use and analytical flexibility/complexity. These users are served with different views as shown in the right-hand side of Figure 1:

- (1) The general public and many senior policy staff are likely interested in the predefined county profiles that are part of the CATCH report (available as a Web page). This use of the commonly used report format provides rapid access to the highest level of aggregation and comparative benchmarks. However, since the report is not a static document but actually contains active hyperlinks, it also

Figure 1.
North Carolina Health Assessment Portal Construction and Interface



provides immediate access to the more detailed underlying data.

(2) These data, of significant concern for county health departments, are accessed through a large set of predefined online analytical processing queries or exploratory reports using both the logical and virtual cubes. Once again, a report-style interface is employed to minimize the technical expertise required to quickly access the desired information. This simplified drill-down capability provides a powerful tool for investigating multidimensional relationships.

(3) At the high end of complexity and flexibility, researchers have access to the lowest level data in the free-form online analytical processing queries. The full range of dimensions is available in a drag-and-drop visual interface for creating ad hoc queries across the entire data warehouse.

Each of these levels serves a specific role in the reporting of health data, and each has an independently maintained set of standards for how data are allowed to participate. These metadata themselves constitute one of the most significant new capabilities of the project. **NCMJ**

REFERENCES

- World Health Organization. *The World Health Report 2000. Health Systems: Improving Performance*. Geneva, Switzerland: World Health Organization; 2000: 143-145.
- Bloche MG. Health care disparities: science, politics and race. *N Engl J Med*. 2004;350(15):1568-1570.
- Committee for the Study of the Future of Public Health, Division of Health Care Services, Institute of Medicine of the National Academies. *The Future of Public Health*. Washington, DC: National Academies Press; 1988.
- Durch JS, Bailey LA, Stoto MA, eds, Committee on Using Performance Monitoring to Improve Community Health, Division of Health Promotion and Disease Prevention. *Improving Health in the Community: A Role for Performance Monitoring*. Washington, DC: National Academies Press; 1997.
- Murry CJL, Kulkarni SC, Michaud C, et al. Eight Americas: investigating mortality disparities across races, counties, and race-counties in the United States. *PloS Med*. 2006 September;3(9):e260. doi:10.1371/journal.pmed.0030260.
- Green LW. PATCH: CDC's planned approach to community health, an application of PRECEED and an inspiration for PROCEED. *J Health Educ*. 1992;23(3):140-147.
- US Department of Health and Human Services. *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*. Washington, DC: US Government Printing Office; 1991.

- 8 Perrin EB, Koshel JJ, eds, Panel on Performance Measures and Data for Public Health Performance Partnership Grants, National Research Council. *Assessment of Performance Measures for Public Health, Substance Abuse, and Mental Health*. Washington, DC: National Academies Press; 1997.
- 9 National Association of County and City Health Officials. *Assessment Protocol for Excellence in Public Health*. Washington, DC: National Association of County and City Health Officials; 1991.
- 10 Gordon RL, Baker EL, Roper WL, Omenn GS. Prevention and the reforming US health care system: changing roles and responsibilities for public health. *Annu Rev Public Health*. 1996;17:489-509.
- 11 Friedman DJ, Gibson Parish R. Characteristics, desired functionalities, and datasets of state web-based data query systems. *J Public Health Manag Pract*. 2006;12(2):119-129.
- 12 Luhn HP. A business intelligence system. *IBM Journal*. 1958;October:314-319.
- 13 Studnicki J, Steverson B, Meyers B, Hevner AR, Berndt DJ. A community health report card: Comprehensive Assessment for Tracking Community Health (CATCH). *Best Pract Benchmarking Healthc*. 1997;2(5):196-207.

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The Emerging Field of Informatics

Debbie Travers, PhD, RN; Larry Mandelkehr, MBA, CPHQ

The field of health care informatics brings together the various health sciences (eg, medicine, nursing, public health) and other relevant fields including information science, computer science, and cognitive science. The focus of this emerging field is to promote the effective organization, analysis, management, and use of information in health care in order to facilitate optimal health care delivery.^{1,2} An important mission of the informatics field is to prepare practitioners to utilize health data for direct care as well as in support of optimal health services organization and delivery, public health surveillance and practice, and clinical research. In this article we describe how the field has developed and how clinicians and health care managers are being prepared to make the best use of data.

Early applications of information technology in health care began in the 1960s with a focus on financial (eg, generating a bill) and clerical (eg, admission, discharge, and transfer transactions) systems. These systems typically ran on large mainframe computers and produced basic management reports but often lacked the flexibility to produce customized reports. They were organized around generating a bill for a health care encounter as opposed to providing a longitudinal view of patients' health. With the introduction of powerful personal computers and networking technologies in the 1980s came the development of more clinically-oriented computer systems for health care. These systems were also more robust in supporting administrative functions.³ Early clinical applications included laboratory results reporting and order entry systems; administrative applications included human resources, materials management, and project management systems.

As the field of health care informatics continued to develop, more vendors entered the health care information technology (IT) environment. The health care IT companies offered an

expanded array of products including computerized provider order entry, clinical documentation (eg, physician and nurse notes), and specialized systems for areas such as the emergency department, the pharmacy, and the operating room. More recently, the field has grown to include bioinformatics applications which have been developed to manage the large quantity of genomic and other basic scientific data.

During this time researchers began to study the impact of clinical IT systems on the health care delivery system and eventually on patient outcomes.³ These studies identified best

“As the health care informatics field has developed, there has been recognition of the need to prepare informatics experts in both the clinical and managerial ranks.”

practices and systems for health care IT design, integration with clinical workflow, and implementation.⁴ Outcome studies showed the greatest impact on patient outcomes from computerized provider order entry and clinical decision support tools embedded in the IT systems.⁵⁻⁷ Currently there are many large health care IT initiatives aimed at improving patient outcomes and reducing errors through well-designed decision support applications. Examples of such applications include drug-drug incompatibility alerts to providers during electronic prescribing and the use of standardized order sets.

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How We Teach People How To Use Data

Formal Informatics Education

Many of the early pioneers in health care informatics came from various clinical and technical fields and learned informatics on the job. Formal degree-granting educational programs in health care informatics began in the 1970s with a variety of foci such as health administration, clinical sciences (eg, medicine, nursing, pharmacy), computer science, bioinformatics, and public health.

National organizations have begun to develop recommendations for health care informatics content in the curricula for various professions. This emphasis on preparing practitioners to address informatics is an outgrowth of recommendations by the Institute of Medicine of the National Academies' 2003 report *Health Professions Education: A Bridge to Quality*.⁸ This report was issued partly in response to the Institute of Medicine's 2001 report, *Crossing the Quality Chasm*, which focused on safety and quality of care.⁹ In the 2003 report, the IOM recommended 5 core competencies that all clinicians should possess in order to meet the needs of the 21st century health system. One of those 5 is to utilize informatics to "communicate, manage knowledge, mitigate error, and support decision making using information technology."¹⁰ These recommendations have spawned many educational initiatives directed at health professionals including the American Medical Informatics Association (AMIA) 10x10 Program, the goal of which is to train 10 000 health professionals in basic informatics content by the year 2010.¹¹ Though AMIA is just beginning to delineate core informatics content for physicians, it has partnered with leading academic informatics programs to deliver the 10x10 continuing education programs and short courses in both clinical and bioinformatics. This initiative is using curricular content from existing informatics training programs, distance learning, and other innovative educational strategies to deliver quality education to busy working professionals. A sample of key content from some of the clinically-oriented 10x10 programs is shown in Table 1.

Several of the content areas address preparation of practitioners for utilizing health data effectively including evidence-based medicine, data mining of databases/data warehouses, information integration and knowledge management, and data standards.

The National Library of Medicine (NLM) of the National Institutes of Health began funding medical informatics research training programs in the 1990s and currently funds 20 university-based programs.¹² Their goal is to advance the scientific basis underpinning the informatics field by training researchers. Some of these programs provide tuition and even

stipends to health professionals wishing to gain expertise in informatics research. North Carolina participated in a joint Duke University and University of North Carolina at Chapel Hill medical informatics training program in the 1990s, but the formal NLM-sponsored program was discontinued in the early 2000s. Both universities continue to offer various types of education in health care informatics.

Informatics Competencies and Certifications

There are national recommendations for informatics competencies and certifications for many professions including nursing and health management. There is currently an effort to develop similar structures for physicians. The American Medical Informatics Association has received a grant from the Robert Wood Johnson Foundation to establish a subspecialty of applied clinical informatics in medicine which will include a certification process for physicians.¹³

The National Center for Healthcare Leadership has established a set of competencies for graduates of health care management programs.¹⁴ Competencies that are relevant to informatics include data analysis, manipulation, understanding, and ability to explain data.

Specific informatics competencies for nurses are also being developed based on recommendations from the Institute of Medicine of the National Academies.¹⁵ The competencies include skills, knowledge, and attitudes that are clinically-oriented as well as some that emphasize use of data for supporting safe processes of care and metrics for monitoring health outcomes. Nurses can achieve certification in the specialty of Nursing Informatics through successful completion of an examination.¹⁶ Table 2 includes the key content included in this Informatics Nurse certification offered by the American Nurses Credentialing Center.

Table 1.
Informatics Content From Various American Medical Informatics Association 10x10 Programs¹¹

Discipline overview, history
Evidence-based medicine
Role of information and technology in improving health care efficiency and quality
Databases, data warehouses, and data mining
Data standards
Decision support
Privacy, confidentiality, and data security
Information integration and knowledge management
Networking and telemedicine
Information system planning and project management
Clinical and administrative information systems
Electronic health records
Computerized provider order entry
Consumer health informatics

Table 2.
Informatics Content For Nursing Informatics Certification

Systems life cycle
Systems planning, analysis, and selection
Systems design
Systems implementation and testing
Systems evaluation, maintenance, and support
Human factors (eg, usability)
Hardware, software, and networks
Data standards
Security
Data aggregation, warehousing, and mining
Knowledge generation (outcome probabilities, expert and rule-based systems)
Professional practice, trends, and issues
Models and theories (eg, change theory)

Content areas such as data standards, data aggregation/warehousing/mining, and knowledge generation address preparation of practitioners for utilizing health data effectively.

Examples of How Data Usage Can Be Taught in Clinical Settings

Increasing the use of data in decision making and driving improvement in busy health care organizations is a challenge on many fronts. Patients are sicker, staff shortages exist in key markets such as nursing and pharmacy, and new regulatory requirements and technology seem to appear at every turn. Incorporating data in applications such as statistical process control via the use of control charts to identify outlier events is a useful strategy but needs to be easily incorporated into the busy clinical environment. Educating clinical leaders, including nursing managers and physicians, to create statistically correct control charts with a spreadsheet is not feasible due to the complexity of the analysis and the different computer skill levels of the managers. Purchasing specialized computer software is expensive and the software often has a long learning curve.

The preferred alternative approach is to simplify the process such that each manager only needs to enter data into a spreadsheet and click a few buttons to create the control chart. The primary educational focus is the use of customized spreadsheet menus which create the charts as well as interpret graphs and develop action plans to improve patient care and operations. The education process focuses on the mechanics of chart creation and then shifts to problem solving and root cause analysis techniques to address the identified issues.

Key elements of the informatics curriculum for public health and health care professions include data definitions, data management tools, data quality, and system selection. The following sections describe these topics in detail.

How Data Are Collected and Managed

Identification of Common Data Definitions Is Essential

It is very common for different individuals or departments to have different definitions of the same data element. Unless everyone is using the same set of data definitions from the beginning, there will likely be errors in data collection, analysis, and conclusions. For example, does the hospital admission date and time occur when the patient arrives at the emergency department or when they are admitted to an inpatient bed? Is the infection rate based on all patient days or only the days on which the patient has a catheter placed? Are children's ages stored in the database in months or years? Are names entered as "John Doe" or "Doe, John?" A lack of planning and agreement on basic information in any of these examples will result in confusion, rework, and lack of useful data.

In addition to agreement on the definition of each data element, the following aspects should be considered and documented:

- *Data elements.* Sufficient data are needed to avoid ambiguity in names. Admission date and inpatient admission date should be distinguished.
- *Description.* Brief but clear descriptions of complaint/treatment should be understandable by the nonexpert.
- *Numerator and denominator definitions for rates.*
- *Data storage format.* For example, options may include text, number, yes/no.
- *Units of measure.* For example, body temperature may be recorded in Celsius or Fahrenheit.
- *Default value.* To speed data entry time the most common value for a data element might automatically appear.
- *Is the data element required?*

Tools for Managing Clinical Data

Desktop computers contain a variety of powerful desk tools for data management and analysis. Selecting the best tool or tools for each situation is a key element of the education program. Three common data management and analysis tools available to public health and health care students and professionals are spreadsheets (eg, Microsoft Excel), databases (eg, Microsoft Access), and statistical applications (eg, STATA, SAS).

Spreadsheets are the analytical computer programs with which most people are familiar. They are the easiest to learn and provide both data management and statistical tools and typically have a wide range of capabilities that enable them to be used in lieu of more complicated computer programs. Spreadsheets are relatively intuitive to use and learn, excel in graphically displaying data, provide a variety of statistical functions,

and can support up to millions of data values. On the downside, spreadsheets lack strong data validation tools which can lead to data quality issues when entering large amounts of data. The standard spreadsheet data format (2-dimensional table) is easy to create but is inefficient for complex data sets and often results in data redundancy. This redundancy wastes data entry time, increases file size unnecessarily, and creates more opportunities for data entry errors. Finally, spreadsheets can only be updated by one person at a time.

Database programs are less intuitive to learn and use. When properly designed, however, databases can provide very efficient data storage for complex data sets and eliminate the data redundancy inherent in spreadsheets. Databases also provide strong validation and entry tools that facilitate data entry and improve data quality. Database programs allow multiple users to add and update data simultaneously—a key feature for large scale data collection and sharing via a central data repository. Reports can be designed to quickly generate weekly or monthly reports without needing to cut and paste data as when using a spreadsheet. On the downside, databases tend to have fewer tools for statistical analysis or graphing capability as compared to spreadsheets.

Specialized statistical programs provide for extensive analyses of large data sets using a wide range of statistical functions. They provide graphing capability but typically not to the extent of spreadsheets. These statistical programs are the tools of choice when performing analyses for publication which are beyond the basic regression and t-test functions available in spreadsheets. However, these programs do not support the strong data validation, management, and reporting functions common to databases.

A key educational focus emphasizes the strengths and weaknesses of each tool and how to quickly move data between them in order to utilize the benefits of each application without being limited by a program's weaknesses. A typical example of using the programs together might be to use the database for data entry and validation, the statistical program for detailed statistical analysis, and the spreadsheet for graphing the results.

The Importance of Data Quality

No matter how well a spreadsheet or database is designed, it will not be able to serve its purpose if the data it contains are inaccurate or incomplete. Maintaining the quality of data in a spreadsheet or a database requires diligence, planning, and constant monitoring. Clinical managers must be taught to evaluate the quality of data prior to using the data to make decisions.

It is always faster and more efficient to prevent inaccuracies or incomplete data during the data entry process than it is to find and fix problems after the damage is done. Several strategies can improve the quality of data in a database. Proper design is the first step to preventing data quality problems. Most computer programs contain standard features to prevent data entry errors such as selecting the type of data that can be stored in a particular location. For example, if the database requires entry of a date in a certain location then the entry of an invalid date would be

prevented. Assigning range limits prevents entry of invalid data while requiring the entry of a value prevents incomplete data. Required fields should be used carefully, however, as requiring the entry of too many values may introduce bad data if users become frustrated with a lengthy data entry process. Involving data entry personnel early in the development of a database improves the data entry process and tools and reduces the potential for errors.

Data users should understand how the data they are using are defined. This is particularly important if the data are being used secondarily, and it is not possible to influence how the data are entered. For example, there are two federal data standards for information regarding race (eg, American Indian or Alaskan, Asian or Pacific Islander, Black or White) and ethnicity (eg, Hispanic or Non-Hispanic).¹⁷ However, many health care organizations collect only one combined field, and it is not possible to accurately determine the race or ethnicity of their patients.

If a spreadsheet or database contains bad data, auditing the data may be an option to identify or correct errors.¹⁸ Range checks can identify values that are too large or too small, and sample calculations can identify invalid or missing entries. Although auditing will often find a majority of bad data present in a program, it is always better to prevent the bad data from being entered in the first place.

System Selection Issues

Clinicians and managers should participate in the selection of clinical information systems whenever possible, and they should be prepared to consider data needs during the selection process. This issue should be included in the curricula of health informatics programs; however, the focus of systems selection is often weighted heavily toward clinical issues. While issues such as user friendliness and integration with the clinical workflow are important considerations in the selection of clinical information systems, data management issues should also be kept in mind. The quality and availability of data for use on the back end is important in order to facilitate other uses of routinely collected health data such as benchmarking, quality improvement, research, and surveillance. Vendors should be questioned about the types of reports that are available from these systems as well as the option to customize reports, export data for use with other computer applications, or run ad hoc reports locally rather than having to request the data from the vendor.

As the health care informatics field has developed, there has been recognition of the need to prepare informatics experts in both the clinical and managerial ranks. There also is a need to educate nonmanagers in basic informatics content. Professional and educational organizations are working to address these needs through formal educational programs as well as the development of competencies and certifications. While the various educational programs, competencies, and certificates continue to be developed, it remains to be seen how widely adopted these initiatives are at present. Clinicians and managers

would be wise to take a proactive approach to acquiring health care informatics knowledge and skills in order to make the best use of data for direct care as well as in support of optimal health

services organization and delivery, public health surveillance and practice, and clinical research. **NCMJ**

REFERENCES

- 1 Englehardt SP, Nelson R. *Health Care Informatics: An Interdisciplinary Approach*. St. Louis, MO: Mosby; 2002.
- 2 About informatics. American Medical Informatics Association Web site. <http://www.amia.org/informatics>. Updated June 15, 2007. Accessed January 4, 2008.
- 3 Austin C, Boxerman S. *Information Systems for Health Services Administration*. 6th ed. Chicago, IL: Health Administration Press; 2003.
- 4 International Medical Informatics Association (1992-2003). *Yearbook of medical informatics*. New York: Schattauer.
- 5 Kaushal R, Jha AK, Franz C, et al. Return on investment for a computerized physician order entry system. *J Am Med Inform Assoc*. 2006;13(3):261-266.
- 6 Osheroff JA, Teich JM, Middleton B, et al. A roadmap for national action on clinical decision support. *J Am Med Inform Assoc*. 2007;14(2):141-145.
- 7 Teich JM, Osheroff JA, Pifer EA, et al. Clinical decision support in electronic prescribing: recommendations and an action plan: report of the joint clinical decision support workgroup. *J Am Med Inform Assoc*. 2005;12(4):365-376.
- 8 Greiner AC, Knebel E. *Health Professions Education: A Bridge to Quality*. Washington DC: National Academies Press; 2003.
- 9 Committee on Quality of Health Care in America, Institute of Medicine of the National Academies. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington DC: National Academies Press; 2001.
- 10 Greiner, AC, Knebel, E, eds. *Health Professions Education: A Bridge to Quality*. Washington DC: National Academies Press; 2003: 4. <http://www.nap.edu/catalog/10681.html>. Accessed January 14, 2008.
- 11 AMIA 10x10 prospective students. American Medical Informatics Association Web site. <http://www.amia.org/10x10/students.asp>. Updated July 25, 2007. Accessed January 8, 2008.
- 12 NLM's university-based biomedical informatics research training programs. National Library of Medicine Web site. <http://www.nlm.nih.gov/ep/GrantTrainInstitute.html>. Updated January 8, 2008. Accessed January 15, 2008.
- 13 American Medical Informatics Association. AMIA receives grant from Robert Wood Johnson Foundation to foster the development of applied clinical informatics as a medical specialty. <http://www.amia.org/inside/releases/2007/rwjf2007grantannouncement.pdf>. Published March 8, 2007. Accessed January 22, 2008.
- 14 National Center for Healthcare Leadership. *Health Leadership Competency Model*. Chicago, IL: National Center for Healthcare Leadership; 2005.
- 15 Cronenwett L, Sherwood G, Barnsteiner J, et al. Quality and safety education for nurses. *Nurs Outlook*. 2007;55(3):122-131.
- 16 Informatics nurse certification examination content outline. American Nurses Credentialing Center Web site. http://www.nursecredentialing.org/cert/TCOs/Informatics_TC O.html. Updated December 14, 2007. Accessed January 22, 2008.
- 17 Standards for the classification of federal data on race and ethnicity. Office of Management and Budget Web site. from <http://www.whitehouse.gov/omb/fedreg/race-ethnicity.html>. Published August 1995. Accessed January 22, 2008.
- 18 Wright D. Developer forum: seven enemies of good data. *Filemaker Magazine*. Published February 28, 2001. <http://www.filemaker.com/articles/developer-forum.html-3>. Retrieved January 23, 2008.

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The Role of Data at The Carolinas Center for Medical Excellence

Mark W. Massing, MD, PhD, MPH; Anna P. Schenck, PhD, MSPH

Few organizations rely more heavily on data than The Carolinas Center for Medical Excellence (CCME). CCME is not a health care provider but rather a developer of data-driven services that enable providers to deliver the best possible care to their patients. CCME's existence depends on its ability to make complex data meaningful and relevant to the health care concerns of its customers. The CCME offices in Cary, North Carolina, and Columbia, South Carolina, house a diverse staff of more than 100 skilled health care and information technology professionals. Many of the physicians, nurses, health services researchers, epidemiologists, statistical analysts, quality improvement specialists, medical record abstractors, coding specialists, and information technology specialists employed at CCME were trained at and are affiliated with the major academic and medical centers of the Carolinas.

CCME uses data to influence health policy and health care delivery in hospitals, skilled nursing facilities, outpatient practices, home health agencies, and other medical settings. Data that are meaningfully summarized and reported can influence policy through their effects on clinical decision makers responsible for health care quality and costs. The internal organization of CCME is oriented around 4 major market areas: federal programs and services; state programs and services; physician and community services; and research. Below we describe the data assembled at CCME and how they have been used in these market areas to influence clinical decision makers and to improve care.

Federal Programs and Services

The primary activity of CCME's Federal Programs and Services Division is the Quality Improvement Organization (QIO) contract with the Centers for Medicare & Medicaid Services (CMS). As the QIO for both North and South

Carolina, CCME is responsible for assuring quality of care for nearly 2 million Medicare enrollees. The QIO program is the product of the federal government's evolving need to contain costs and provide appropriate care in the Medicare program. It developed from antecedent programs formed shortly after the creation of Medicare in 1965. These earlier programs focused on hospital-based utilization control and physician peer review. Data from administrative claims and medical records were used to identify physicians providing substandard or unnecessary care. The focus was on outliers with little emphasis on improvements in the general population of providers. In response to

“CCME’s existence depends on its ability to make complex data meaningful and relevant to the health care concerns of its customers.”

recommendations of the Institute of Medicine of the National Academies in 1990,¹ the emphasis of Medicare quality assurance changed from case-specific punitive and regulatory action toward a population-based approach focusing on clinical decision making, outcomes, and professional capacity building to improve care. Now the QIO works collaboratively with health care providers in virtually all settings to collect and use data describing health outcomes and overall patterns and processes of care. QIOs analyze and review complex data from many sources to create meaningful information that guides clinical decision makers.

The collection of data and the dissemination of information

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derived from data to health care consumers and clinical decision makers is a major activity of CMS and QIOs. In 2000 Jencks and colleagues² described national- and state-level rates on a series of clinical performance indicators for care provided to Medicare enrollees in the hospital and outlined the intended expansion of a system to monitor care provided in nursing homes and home health agencies. In the 2 Carolinas, CCME has worked with 173 hospitals, 479 nursing homes, and 235 home health agencies to improve quality as measured though data collected and made publicly available on government websites. The data are publicly reported in an effort to produce incentives for increased quality and reduced costs by creating market pressure from informed consumers and increased competition among providers.

The publicly reported quality measures for Medicare patients in hospitals include 24 care processes and 2 outcome measures.³ (See Table 1.) Data sources for the hospital measures include clinical and administrative records. Nineteen quality measures are used to monitor nursing home care⁴ and 12 indicators are used to monitor home health care.⁵ (See Table 1.) Both the nursing home and home health quality measures are created from standardized patient level assessments.

The DOQ-IT (Doctor's Office Quality-Information Technology) program supports the adoption and effective use of information technology in the outpatient setting.⁶ Participating outpatient medical practices may voluntarily report patient-level health care data captured from electronic health records to a clinical data warehouse administered by CMS. The DOQ-IT program has assisted 104 medical practices in

North Carolina and 61 practices in South Carolina with selection, implementation, and use of electronic health systems. CMS is currently redirecting QIO physician support activities from implementation of electronic systems to effective use and central reporting of electronic data.

As a Quality Improvement Organization, CCME uses a data-driven approach to assist with Medicare-related activities, making use of enrollment databases, Medicare service claims, selected clinical information from medical record abstractions, and setting-specific quality measure data. With the capacity to link data for patients across settings and across files, CCME can create population-based maps showing variation in care by geographic location and can assess quality of care by demographic characteristics. Data can be aggregated to the county, facility, or single provider to assess quality of care. CCME uses Medicare data to identify the need for policy or clinical interventions at the local or state level.

This approach is illustrated by the trend reports CCME sends to nursing homes in the Carolinas every quarter. (See Figure 1.) The example shows almost 3 years of trended data and provides the facility the ability to compare its progress in improving care (in this case, reducing the number of residents in restraints) with that of the state and the nation. CCME creates thousands of facility level data reports every year to share with North and South Carolina health care providers.

Clinical data will grow in importance and volume as medical practices implement electronic systems. These systems will provide the raw data needed to support public reporting and pay-for-performance initiatives. Considering that as many as

Table 1.
Measures Assessing Quality of Care for Medicare Enrollees

Patient Population	Beneficiaries	Source(s) of Data
Hospitalized Heart Attack Patients	<ul style="list-style-type: none"> ■ Percentage of patients with aspirin within 24 hours of arrival ■ Percentage of patients with aspirin prescribed on discharge ■ Percentage of patients with beta blockers prescribed on discharge ■ Percentage of eligible patients with ACE inhibitor prescribed at discharge ■ Percentage of smokers offered cessation counseling at discharge ■ Percentage of patients with fibrinolytic medication within 30 minutes of arrival ■ Percentage of patients with percutaneous coronary intervention (PCI) within 90 minutes of arrival ■ 30-day risk adjusted mortality rates among enrollees hospitalized for heart attack 	<p>Hospitals submit specific data elements to clinical data warehouse about care provided to heart attack patients using the patient record as the data source</p> <p>Medicare claims and enrollment informations</p>
Hospitalized Heart Failure Patients	<ul style="list-style-type: none"> ■ Percentage of patients with evaluation of left ventricular systolic function ■ Percentage of patients with left ventricular systolic dysfunction who are prescribed ACE inhibitor or ARB ■ Percentage of patients provided with discharge instructions ■ Percentage of smokers offered cessation counseling at discharge ■ 30-day risk adjusted mortality rates among enrollees hospitalized for heart failure 	<p>Hospitals submit specific data elements to clinical data warehouse about care provided to heart failure patients using the patient record as the data source</p> <p>Medicare claims and enrollment information</p>

Patient Population	Beneficiaries	Source(s) of Data
Hospitalized Pneumonia Patients	<ul style="list-style-type: none"> ■ Oxygenation assessment ■ Initial antibiotic timing ■ Pneumococcal vaccination ■ Influenza vaccination ■ Blood culture performed in the emergency department prior to initial antibiotic received in hospital ■ Appropriate initial antibiotic selection ■ Smoking cessation advice/counseling 	Hospitals submit specific data elements to clinical data warehouse about care provided to patients with pneumonia using the patient record as the data source
Hospitalized patients receiving selected surgical procedures	<ul style="list-style-type: none"> ■ Percentage of patients who receive prophylactic antibiotic within 1 hour prior to surgical incision ■ Percentage of patients who have prophylactic antibiotics discontinued within 24 hours after surgery ends ■ Percentage of patients who receive a prophylactic antibiotic that is recommended ■ Percentage of patients who have an order for recommended venous thromboembolism prophylaxis ■ Percentage of patients who receive appropriate treatment to prevent blood clots within 24 hours prior to or 24 hours after surgery 	Hospitals submit specific data elements to clinical data warehouse about care provided to patients undergoing selected surgical procedures using the patient record as the data source
Nursing home residents in home for extended stay	<ul style="list-style-type: none"> ■ Percentage of residents given influenza vaccination during the flu season ■ Percentage of residents who were assessed and given pneumococcal vaccination ■ Percentage of residents whose need for help with daily activities has increased ■ Percentage of residents who have moderate to severe pain in past week ■ Percentage of high-risk residents who have pressure sores in the past week ■ Percentage of low-risk residents who have pressure sores in the past week ■ Percentage of residents who were physically restrained in the past week ■ Percentage of residents who are more depressed or anxious in the past month ■ Percentage of low-risk residents who lost control of their bowels or bladder in the past 2 weeks ■ Percentage of residents who had a catheter inserted and left in their bladder in the past 2 weeks ■ Percentage of residents who spent most of their time in bed or in a chair in the past week ■ Percentage of residents whose ability to move about in and around their room got worse in the past week ■ Percentage of residents with a urinary tract infection in the past month ■ Percentage of residents who lost too much weight in the past month 	Minimum Data Set (MDS) Repository The MDS is a patient level assessment conducted by nursing homes on residents at regular, specified intervals.
Nursing home residents in home for short period of time	<ul style="list-style-type: none"> ■ Percentage of residents given influenza vaccination during the flu season ■ Percentage of residents who were assessed and given pneumococcal vaccination ■ Percentage of residents with delirium in the past week ■ Percentage of residents who had moderate to severe pain in the past week ■ Percentage of residents with pressure sores in the past week 	Minimum Data Set (MDS) Repository The MDS is a patient level assessment conducted by nursing homes on residents at regular, specified intervals.

Patient Population	Beneficiaries	Source(s) of Data
Medicare enrollees receiving home health care	<ul style="list-style-type: none"> ■ Percentage of patients who get better at walking or moving around ■ Percentage of patients who get better at getting in and out of bed ■ Percentage of patients who have less pain when moving around ■ Percentage of patients whose bladder control improves ■ Percentage of patients who get better at bathing ■ Percentage of patients who get better at taking their medicines correctly (by mouth) ■ Percentage of patients who are short of breath less often ■ Percentage of patients who stay at home after an episode of home health care ends ■ Percentage of patients whose wounds improved or healed after an operation ■ Percentage of patients who had to be admitted to the hospital ■ Percentage of patients who need urgent, unplanned medical care ■ Percentage of patients who need unplanned medical care related to a wound that is new, is worse, or has become infected 	<p>Outcome and Assessment Information Set (OASIS)</p> <p>The data come from comprehensive patient assessments conducted by home health agencies at regular, specified intervals</p>

75% of physician practices do not use electronic medical records,⁷ it is clear that most clinical data currently reside on paper where they are difficult to access and use. A major policy challenge involves the removal of barriers and the creation of incentives for physicians to adopt electronic systems, to undertake the expensive migration of data to these systems, and to fully integrate electronic systems into practice and care management.

State Programs and Services

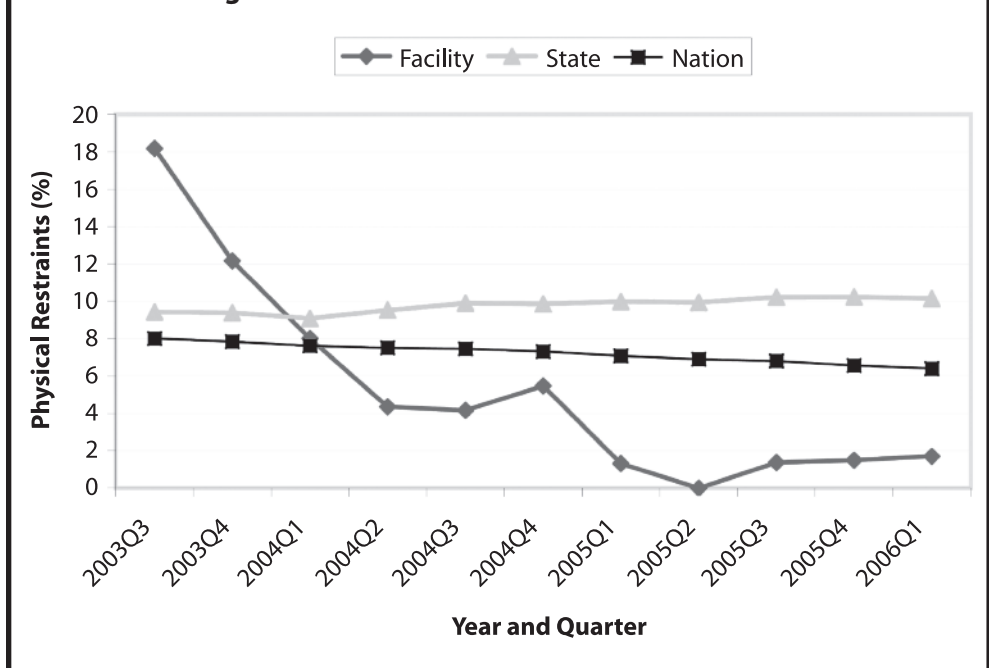
Programs conducted by states are another important source of health data used by policy makers to reduce costs and improve health outcomes. The Medicaid program administered in North Carolina by the Division of Medical Assistance (DMA) of the state Department of Health and Human Services rivals the federal Medicare program in terms of population and costs. About 1 out of every 5 North Carolina residents were served by the Medicaid Program in 2006 (1.7 million persons in total) at costs exceeding \$11 billion.⁸

Data available through state programs include sociodemographic information for eligibility and enrollment, administrative claims for reimbursement of services, and limited, but growing, clinical information used for

quality improvement and disease management. State health data are typically collected and maintained by a variety of agencies and contractors. Identifying, linking, and fully utilizing these fragmented data sources constitute a major challenge. But the rewards are great because these data are a rich and often underutilized source of information.

CCME has extensive experience in the use of state health data through its contracts and collaborations with a number of state agencies. A good example of how CCME has worked with DMA to expand the use of state health data relates to the Community Alternatives Program for Disabled Adults

Figure 1.
Example of Trend Report for Residents in Restraints Sent to a North Carolina Nursing Home



(CAP/DA).⁹ This program reimburses eligible disabled adults for home-based care as an alternative to more expensive nursing facility care. CCME collaborated with CAP/DA consultants to create its Automated Quality and Utilization Improvement Program (AQUIP) that allows the state to assess the health status of its home-based clients in a manner similar to the way they would be assessed at nursing facilities. AQUIP captures client information and assessment data from the state and from county case managers and uses their data to assess the need for services and to examine variations in quality and costs. It also allows for the comparison of this population with institutionalized patients. AQUIP offers an example of how existing state health data can be used for multiple purposes.

About 1 in 5 North Carolina Medicare beneficiaries is enrolled in Medicaid. These dually eligible persons qualify for Medicaid due to disability or extreme medical or financial need. As a group, they are more likely to have complex health conditions that are difficult and expensive to treat.¹⁰ Improving health outcomes and reducing costs is challenging in this population. Contributing to the challenge is the fragmentation of their health data between the federal Medicare system and the state Medicaid administrative agencies.

Evaluating the cost and quality of pharmacologic therapy in the treatment of chronic diseases such as diabetes and heart failure is especially problematic in the dually eligible population. Prior to the implementation of the Medicare Part D pharmacy benefit in 2006, state Medicaid agencies administered pharmacy benefits for dually eligible clients. Thereafter, the pharmacy benefit for the dually eligible was federalized and rolled into the Medicare Part D program.^{11,12} Due to limitations imposed by the Medicare Modernization Act, Part D administrative claims data have been generally unavailable to Medicare contractors, state agencies, and health services researchers. Efforts to contain costs, reduce errors, and improve outcomes associated with pharmacotherapy have been limited by restricted access to these data.

Despite these data challenges, CCME has collaborated with DMA in projects that combine Medicare and Medicaid data to better understand and improve health care outcomes in their client populations. Medicaid data were used to evaluate the effectiveness of a CCME quality improvement project to reduce the use of antibiotics for nonbacterial respiratory tract infections.^{13,14} CCME data abstractors collected clinical care information from outpatient medical records in a statewide heart failure quality improvement project involving Medicaid and private managed care.¹⁵ In this project, clinical data from the medical records were linked to administrative claims data. In an ongoing project, CCME has linked Medicare and Medicaid administrative claims data for the dually-eligible population with heart failure in North Carolina and South Carolina to better understand and improve heart failure care in this high-risk population.

Billings and Mijanovich in a recent Medicaid study¹⁶ demonstrated that given sufficient data it is possible to identify populations at high risk for future adverse health outcomes.

The same data can be used to focus prevention efforts on persons most likely to benefit and to enable administrators to predict costs and make the business case for prevention. Medicare and Medicaid offer 2 of the few comprehensive data sources to capture the complete health experiences of large populations as they transition through the medical system. Combining and linking these data offers even greater opportunities to understand and improve health care effectiveness while containing costs.

Physician and Community Services

CCME provides a number of data-intensive services to support physicians and other health care providers in clinical decision making and quality improvement. Each addresses a fundamental need to get the right data, understand what the data mean, and act appropriately on the data.

Community Health Care Coordination

The impact of fragmentation of the health care system and its data on patient care, costs, and quality is substantial. Patients with complex medical conditions frequently obtain care from multiple settings and from different providers within settings. The task of identifying and linking patient data in different formats across diverse settings and providers can be daunting. Legislation designed to protect patient privacy creates further barriers to data sharing. This makes cross-setting data use difficult if not impossible. The failure of data to travel with patients as they transition through health care settings contributes to inefficient and uncoordinated health care. This can lead to increased costs, lower quality, and poorer health. CCME recognizes that effective health care requires a community approach to care coordination. To that end, it is developing community-based projects to promote cross-setting care coordination through information exchange and patient-centered care.

Care Management Support

Although the widespread adoption and implementation of electronic systems is an issue of central concern, there is a growing realization that the next major challenge will be the use of electronic health data to support effective care management and public health. CCME has found that the full capabilities of electronic health information systems and the data they generate are greatly underutilized. The availability of electronic data is the prerequisite to transformational system change, but it does not guarantee it. The lack of expertise and resources to understand and act on electronic data are a major barrier to achieving the substantial improvements in health outcomes and efficiencies that they promise. CCME is addressing this need through support services that enable providers to translate data into actions that measurably improve patient outcomes, enhance satisfaction, and demonstrate savings and revenues consistent with a business case for quality.

Physician Leadership and Education

The volume of data is growing much faster than the ability of physicians to understand and act on it. Recent advances in information technology provide data at levels not conceived of when most physicians were receiving medical training. Health care providers now have additional requirements to understand and use these data in routine patient care. There is a great need to enhance the skills of health care providers in the use and interpretation of data. There is also a need to develop data-driven physician leaders who are comfortable with a rapidly evolving data environment that guides clinical decision making and informs health policy. A major objective of CCME's Physician Leadership Institute is to enhance skills in the use of data to inform and support physician leadership.¹⁷

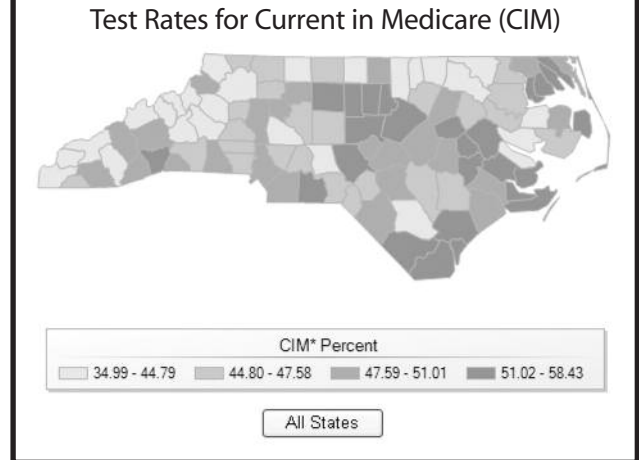
Research

The Research Division of CCME has 3 areas of focus: developing improved ways to measure quality and effectiveness of care, monitoring quality of care, and evaluating approaches to improve quality of care. The development of improved measures is crucial to the improvement in quality. Quality measures not only need to be scientifically sound (eg, valid and reliable), they must also be feasible and responsive to changes in care. CCME research focuses on the development of measures that meet these criteria. It has become an accepted tenet of quality improvement professionals that "if you don't measure something, you can't improve it!" Thus, monitoring care is a vital function of any quality organization. CCME routinely monitors the quality of care for Medicare enrollees as part of the QIO contract. It extends the power of quality monitoring to state and local organizations by hosting a Web-based surveillance report on Medicare which includes enrollment information, utilization statistics, and quality of care measures.¹⁸ Monitoring care undoubtedly leads to identification of opportunities to improve care. CCME research in this area focuses on assessing the effects of policy or system changes and evaluating interventions to change provider or consumer behaviors.

The Palliative Care Quality Measurement Project provides an example of measurement development research conducted by CCME. Under contract from CMS, CCME was asked to identify and develop new quality measures for hospice and palliative care. CCME researched existing quality measures and identified a subset of measures for further consideration. We gathered data on 140 potential measures from other organizations and directly from care providers for measures that had not previously been tested. The project resulted in a set of 34 quality measures that technical experts agreed were appropriate for hospices to use in internal quality improvement. The results of this project were shared with CMS and made available to providers on the MedQIC website.¹⁹

Our Web-based report on colorectal cancer screening in the Medicare population illustrates the type of research CCME conducts to monitor care.²⁰ Figure 2 displays geographic

Figure 2.
Colorectal Cancer Testing in the Medicare Population in 2005 (Rates per 100 Medicare Enrollees)



variation in the proportion of Medicare enrollees in North Carolina who have had the recommended colorectal cancer testing. Lighter areas of the map represent the areas of the state with lower levels of adequate colorectal cancer testing—areas where interventions to increase screening are needed. Since 2000 CCME has, under contract with CMS, monitored test use rates for the national Medicare population. The data in the Web-based report have been instrumental in the inclusion of colorectal cancer screening in the next QIO contract, which will require QIOs in all states to work towards improving colorectal cancer testing.

Conclusion

It is only when data are turned into information that the full power of data-driven solutions can be leveraged. At CCME we are working to develop the information that will help improve health policy at the federal and state levels; inform consumers so they can take a more active role in both selecting their own care and improving the care in their communities; assist providers in improving their care delivery systems; and educate physicians and providers on the patterns, problems, and opportunities to improve the health and health care of the population as a whole. We invite readers to join us in these efforts. **NCMJ**

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REFERENCES

- 1 Lohr KN. Medicare: a strategy for quality assurance. *J Qual Assur.* 1991;13(1):10-13.
- 2 Jencks SF, Cuerdon T, Burwen DR, et al. Quality of medical care delivered to Medicare beneficiaries: a profile at state and national levels. *JAMA.* 2000;284(13):1670-1676.
- 3 Hospital compare. Centers for Medicare and Medicaid Services Web site. <http://www.hospitalcompare.hhs.gov>. Updated March 27, 2008. Accessed April 30, 2008.
- 4 Nursing home compare. Centers for Medicare & Medicaid Services Web site. <http://www.medicare.gov/NHCompare/Include/DataSection/Questions/SearchCriteria.asp?version=default&browser=IE%7C6%7CWinXP&language=English&defaultstatus=0&pagelist=Home&CookiesEnabledStatus=True>. Updated January 16, 2008. Accessed January 18, 2008.
- 5 Home health compare. Centers for Medicare & Medicaid Services Web site. <http://www.medicare.gov/HHCompare/Home.asp?version=default&browser=IE%7C6%7CWinXP&language=English&defaultstatus=0&pagelist=Home&CookiesEnabledStatus=True>. Updated April 10, 2007. Accessed January 19, 2008.
- 6 CCME DOQ-IT program overview. The Carolinas Center for Medical Excellence Web site. <http://www.mrnc.org/doqit/default.aspx?ID=overview>. Accessed January 25, 2008.
- 7 Jha AK, Ferris TG, Donelan K, et al. How common are electronic health records in the United States? A summary of the evidence. *Health Aff.* 2006;25(6):w496-w507.
- 8 Division of Medical Assistance. North Carolina Department of Health and Human Services Web site. <http://www.dhhs.state.nc.us/dma/>. Updated April 18, 2008. Accessed January 24, 2008.
- 9 Community Alternatives Program. NC Division of Medical Assistance Web site. <http://www.dhhs.state.nc.us/dma/commaltprog.htm>. Updated January 11, 2007. Accessed January 24, 2008.
- 10 Lied TR, Haffer SC. Health status of dually eligible beneficiaries in managed care plans. *Health Care Financ Rev.* 2004;25(4):59-74.
- 11 Hall JP, Kurth NK, Moore JM. Transition to Medicare Part D: an early snapshot of barriers experienced by younger dual eligibles with disabilities. *Am J Manag Care.* 2007;13(1):14-18.
- 12 Deshpande M. The implications of the Medicare Modernization Act for dual eligibles. *Am J Geriatr Cardiol.* 2005;14(6):298-300.
- 13 Brown DW, Taylor R, Rogers A, Weiser R, Kelley M. Antibiotic prescriptions associated with outpatient visits for acute upper respiratory tract infections among adult Medicaid recipients in North Carolina. *N C Med J.* 2003;64(4):148-156.
- 14 Kelley M, Massing MW, Young J, et al. Feasibility of a primary care intervention to decrease oral antibiotics for acute upper respiratory tract infections: a pilot study. *N C Med J.* 2006;67(4):249-254.
- 15 Goff DC, Jr., Massing MW, Bertoni AG, et al. Enhancing quality of heart failure care in managed Medicare and Medicaid in North Carolina: results of the North Carolina Achieving Cardiac Excellence (NC ACE) Project. *Am Heart J.* 2005;150(4):717-724.
- 16 Billings J, Mijanovich T. Improving the management of care for high-cost Medicaid patients. *Health Aff.* 2007;26(6):1643-1654.
- 17 Physician Leadership Institute. The Carolinas Center for Medical Excellence Web site. <http://www.physicianleaders.org/>. Accessed January 24, 2008.
- 18 CMED: Carolina Medicare Epidemiological Data. The Carolinas Center for Medical Excellence Web site. www.mrnc.org/cmmed. Accessed January 24, 2008.
- 19 Medicare Quality Improvement Community. Centers for Medicare & Medicaid Services Web site. www.medqic.org/. Accessed January 24, 2008.
- 20 Colorectal cancer testing in the Medicare population for 1998-2005. The Carolinas Center for Medical Excellence Web site. www.thecarolinascenter.org/crcreport. Updated November 11, 2007. Accessed January 24, 2008.

Shaping Health Workforce Policy Through Data-Driven Analyses: The North Carolina Health Professions Data System

Jennifer King; Mark Holmes, PhD

There is growing concern among North Carolina's policymakers that the state's supply of health professionals may not be adequate to meet future demands. Decisions about whether to enact or change policies directed at training, recruiting, and retaining health professionals affect a wide range of stakeholders and can be the source of contentious debate. For example, an important proposal considered by the North Carolina General Assembly in the 2007 legislative session was the development of a new dental school. The House Select Committee on Health Care Subcommittee on Healthcare Workforce reviewed extensive data analyses describing the supply of dentists.

The ability of legislators, legislative staff, and policy makers to understand, consider, and debate pressing issues and potential policy solutions depends on their access to ready sources of rich data and researchers who can work with the data to objectively present the analyses. One such resource in North Carolina is the North Carolina Health Professions Data System.

In partnership with the North Carolina Area Health Educations Centers (AHEC) Program and 12 state licensing bodies, the North Carolina Health Professions Data System (HPDS) maintains licensure files for 20 health professions and has continuous data for most of these professions dating back to 1979. Through consistent annual reports, analysts are able to monitor the supply of health professionals and detect new trends as they emerge. Further, interested stakeholders frequently use the HPDS data when debates about workforce issues surface. Finally, workforce policy experience has enabled HPDS analysts to identify emerging issues in the supply of unlicensed health professionals that are important to health care delivery as well as to the health of the state's economy.

The North Carolina Health Professions Data System

The NC Health Professions Data System contains a broad array of information on a variety of licensed health professionals. In 2006 the HPDS included data on 20 different licensed professions. (See Table 1.) The inventories include physicians and nurses as well as professions with fewer members such as podiatrists and occupational therapy assistants. The NC Health Professions Data System annually produces the "Orange Book,"

"...state policy makers have recognized that the objective analysis available from the HPDS uniquely informs North Carolina policy makers and helps ensure that public policy on health workforce issues is based on the best available evidence."

an annual report of the state of North Carolina's health professions as well as maps depicting the supply of professionals across the state. Administratively located within the Cecil G. Sheps Center

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Table 1.
Professions Included in the 2006 NC Health Professions Data System Data Files

Physicians	Chiropractors
Primary Care Physicians	Occupational Therapists
Physician Assistants	Occupational Therapy Assistants
Nurse Practitioners	Optometrists
Certified Nurse Midwives	Podiatrists
Registered Nurses	Practicing Psychologists
Licensed Practical Nurses	Psychological Associates
Dentists	Physical Therapists
Dental Hygienists	Physical Therapist Assistants
Pharmacists	Respiratory Therapists

for Health Services Research, the HPDS is supported by the North Carolina Area Health Education Centers (AHEC) and the University of North Carolina at Chapel Hill Office of the Provost. Consistent with the university system's increasing commitment to community engagement, the HPDS routinely provides communities with local health professional data; these data are used for multiple purposes such as grant applications and local government priority setting. North Carolina residents highly value the HPDS as a resource; in 2007 the HPDS responded to over 200 data requests from the public.

The data available in the HPDS legally remain the property of the licensing boards that provide the data to the HPDS under a joint agreement allowing HPDS analysts to use the data for research and public policy purposes but restricting use of the data to very specific applications. This agreement maintains the security and privacy of the data. Available data in the system vary widely depending on the specific profession and the license renewal form. Although other data sources provide data on North Carolina's supply of some health professions, these sources typically contain less information, are updated in a less timely manner, or contain only a sample of professionals.

Monitoring Trends

By monitoring annual changes in the supply of health professionals in the state and in comparison to national trends, HPDS analysts are able to identify trends that merit special attention. For example,

based on data from 2000 to 2004, researchers became concerned that North Carolina's past experience of robust growth in physician supply relative to population was slowing. This realization prompted the North Carolina Institute of Medicine (NC IOM) to convene a year-long task force to examine the state's physician supply and recommend options to address the projected shortage.

Using the HPDS data to examine the supply and practice characteristics of physicians, physician assistants, nurse practitioners, and certified nurse midwives, researchers developed a model that projected the future supply of providers relative to the projected growth in North Carolina's population. Figure 1 shows this projection from 2004 to 2030.

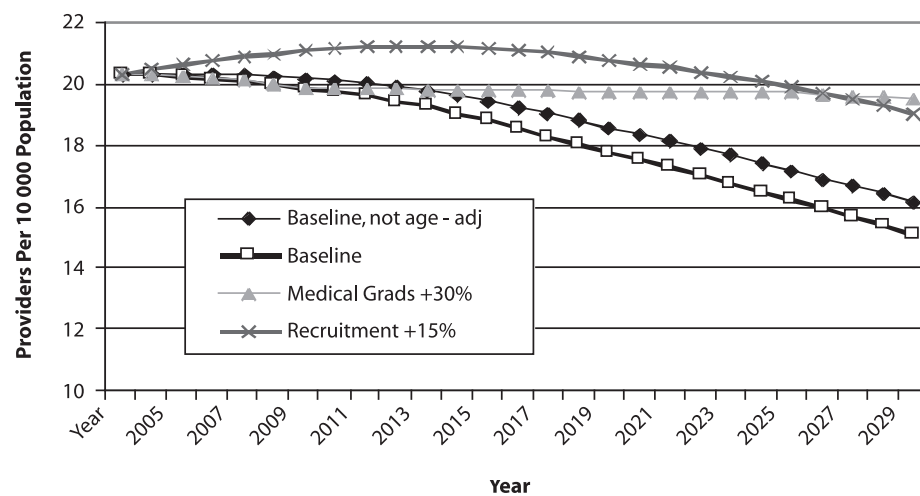
The model incorporated historical migration and retirement patterns available from the HPDS data and projected the effect of different policy options (eg, increasing the number of medical graduates, recruiting more physicians from out of state, increasing productivity through new models of care). The model allowed the NC IOM to test the impact of a variety of policy scenarios on provider supply. The model revealed that, if nothing changes, the state will face a decreased supply of providers in the near future.

Without the long, uninterrupted, historical time series of physician data, the model's ability to project supply would have been more limited. Tom Bacon, DrPH, director of the North Carolina AHEC Program, and a member of the NC IOM task force, described the importance of regular monitoring of supply (February 2008), "With so much attention to workforce policy, it is critical to develop comprehensive data on the location and practice patterns of all types of health care practitioners if we aim to resolve our pressing needs. More fundamentally, without a rich data source on health care practitioner supply, we might not even be aware of the problems."

Informing Workforce Policy Debates

The HPDS is also frequently called upon by institutions or groups when they wish to make the case for a new policy or

Figure 1.
Projected Provider Supply, North Carolina: 2004-2030



Source: North Carolina Health Professions Data System and the North Carolina Institute of Medicine.

educational program, or when an issue related to health professionals surfaces in public debate. Data from the HPDS are readily available and equally accessible to stakeholders on all sides of issues; thus, there is no need to undertake expensive one-time studies.

For example, in recent years analyses based on the HPDS have been used to inform debates and proposals regarding:

- New schools of pharmacy, dentistry, and optometry
- The supply of psychiatrists in the context of state mental health reform
- The retention of medical students and residents trained in North Carolina
- Changes in health professionals' scopes of practice
- The effect of malpractice rates on the supply and distribution of obstetric care providers
- The designation of health professional shortage areas
- The supply of health professionals from underrepresented minority groups

Data are also frequently used by researchers and the press to investigate issues related to the distribution, cost, and quality of health care services in the state.

Highlighting New Areas of Workforce Research

In recent years, the HPDS has expanded its workforce analysis capacity to focus more on allied health—a sector of the health care industry that currently faces labor shortages and is likely to grow in the future. The HPDS contains licensure data on dental hygienists, physical therapists, physical therapy assistants, occupational therapists, occupational therapy assistants, and respiratory therapists. However the majority of the allied health workforce is not licensed and assessing the supply of these unlicensed workers can be especially challenging.

To address this challenge, the HPDS has begun an Allied Health Job Vacancy Tracking Project that tracks vacancies through newspaper and online advertisements. While not a definitive measure of demand, the project has proven useful in identifying professions facing acute shortages as well as important differences in the demand for allied health professionals among the state's 9 AHEC regions.

The HPDS allied health workforce research has drawn the attention of state policymakers who are looking for ways to address manufacturing, textile, and furniture job losses in North Carolina. Allied health jobs represent not only a large and increasingly important employment sector in the state but an engine for economic growth as well. Between 1999 and 2005 allied health employment in North Carolina grew much faster than total health care employment and total employment. (See Table 2.) Over 69% of the total job growth in the health care sector between 1999 and 2005 was due to growth of allied health jobs.

Recognizing the growth potential of allied health employment, state policy makers in the Office of the Governor, the legislature, and the Departments of Health and Human Services and Commerce are collaborating with HPDS staff, the state's community college and university systems, health care employers,

Table 2.
Total, Health Care and Allied Health Employment, North Carolina

	1999	2005	% Growth (1999-2005)
Total NC Employment	3 801 670	3 809 690	0.2%
Health Care Jobs	251 550	302 270	20.2%
Allied Health Jobs	76 590	111 630	45.8%

Source: Occupational employment statistics. State cross-industry estimates: 1999-2005. U.S. Department of Labor, Bureau of Labor Statistics Web site. <http://www.bls.gov/oes/>. Accessed June 28, 2006.

Note: Allied Health Jobs are also included in the Health Care Jobs category.

and industry to develop innovative ways to transition unemployed individuals into allied health jobs. The hope is that these efforts will reduce workforce shortages, increase access to health care services, and improve the economic outlook in the state's neediest counties.

Hawley Truax of Governor Easley's Policy Office called the data "crucial" in developing the allied health sector strategy (February 2008). Again, the discovery was somewhat serendipitous, once HPDS staff initially identified the rapidly increasing number of allied health professionals in the data. When this was brought to the attention of the Office of the Governor the strategy quickly developed.

The North Carolina Health Professions Data Systems as a "Neutral" Data Source

Researchers and policy makers in other states have watched what North Carolina has accomplished with its HPDS and have sought out advice and guidance on building their own systems. For example, HPDS staff have assisted North Dakota, Florida, and Missouri in developing similar systems and have offered advice to researchers in at least 6 other states. Other state policy makers have recognized that the objective analysis available from the HPDS uniquely informs North Carolina policy makers and helps ensure that public policy on health workforce issues is based on the best available evidence. Advocates representing opposing sides of an issue will often cite the same HPDS data and interpret it slightly differently. This is a subtle, yet profoundly complimentary statement on HPDS's reputation in the public policy community—opposing sides may disagree on what the data mean, but few disagree with the quality of the data. In public policy debates, access to a neutral, unbiased data source is the most important tool for building solutions. Without it, public policy may be based on the volume of the argument rather than the quality of the data, and the outcomes may be far less useful than hoped for. **NCMJ**

Community-Level Data

Christopher J. Mansfield, PhD; James L. Wilson, PhD

Health-related data are used at many geographic and political levels by individuals and groups for a multitude of purposes. The focus of this paper is on what and how data are used at the local level, for what purposes and by whom, as well as some of the unique challenges and methodological manipulations involved. Examples of common and unique uses of data and the analytic challenges involved are included.

Health-related data are typically used at the local level to describe populations in terms of demographics, economics, social and environmental conditions, disease prevalence, births, causes of deaths, health behaviors, and available health care resources. They may also be used to characterize access to health services and the use and cost of such services. The data are generally secondary, ie, obtained from another agency that specified form and content without local user input. The data may come from the US Census (eg, income, housing, education), the state and federal vital statistics system (eg, births, deaths, communicable disease incidence), disease registries (eg, cancer incidence, prevalence), or national or state surveys (eg, Behavioral Risk Factor Surveillance System). Other sources may be agencies responsible for Medicaid, Medicare, licensing and regulation, environmental protection, education, commerce, agriculture, transportation, highway safety, or law enforcement. With increasing technology and governmental investments in data collection, there is a wealth of data available, but they may not be readily useful to or easily analyzed by the local user.

Local Users and Uses

The users of health-related data at the community level in North Carolina might be local chapters of voluntary health organizations (eg, American Heart Association, American Lung Association), Healthy Carolinians groups, hospitals, health departments, health care providers, professional associations, academic institutions, news media, governmental agencies,

elected officials, and individual citizens interested in their own health or the health of their family and community. Typical purposes for data use include community diagnosis, program planning, policymaking, advocacy, justification of requests for resources, and program evaluation. The purposes may be categorized within the 3 core functions of public health (ie, assessment, policy development, and assurance)¹ and within the 10 Essential Public Health Services.^{2,3} The core functions and essential services are related and provide a useful typology of the various uses. (See Table 1.)

“The fundamental purpose of using data at the local level is to inform and empower citizens, health providers, and policy makers to take actions to improve community health.”

These core functions and resource allocation decisions should be guided by empiricism and rational analysis, ideally leading to the greatest good for the greatest number. Good decisions depend on good information. Data, however, are not the information. They are the raw material of information. Data must be refined to become information, and information must then be turned into knowledge that is then diffused and understood before it can lead to action. Data are useful only if transformed into information about problems that can and should be solved and put in the hands of people able and willing to solve them. Because problems identified and prioritized at

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Table 1.
Uses of Data at the Local Level in Relation to 3
Core Functions of Public Health and the 10
Essential Public Health Services

Assessment
1. Monitor health status to identify community health problems
2. Diagnose and investigate health problems and health hazards in the community
Policy Development
3. Inform, educate, and empower people about health issues
4. Mobilize community partnerships to identify and solve health problems
5. Develop policies and plans that support individual and community health efforts
Assurance
6. Enforce laws and regulations that protect health and ensure safety
7. Link people to needed personal health services and assure the provision of health care when otherwise unavailable
8. Assure a competent public health and personal health care workforce
9. Evaluate effectiveness, accessibility, and quality of personal and population-based health services
10. Conduct research for new insights and innovative solutions to health problems

the community level are often the ones most likely to be solved, data may be most useful when applied at the local level.

There is a history of community action for health improvement in North Carolina from the Comprehensive Health Planning Councils of the late 1960s, through the Health Systems Agencies from the mid-1970s to mid-1980s, to a public health community diagnosis and planning process that began in the mid-1970s and continues today. In the mid-1990s, the North Carolina Department of Health and Human Services began to require local health departments to submit legislative priorities for funding requests and encouraged the local departments to base their priorities on a community diagnosis process to be conducted every 4 years. Local planning was bolstered in the late 1990s by the establishment of the Governor's Task Force for Healthy Carolinians and the Office of Healthy Carolinians which developed the state's health plan called *Healthy Carolinians 2010*.⁴ It was aligned with the federal *Healthy People 2010*⁵ blueprint and contained goals and objectives with quantified benchmarks and targets. The Healthy Carolinians initiative embodied the first 5 of the 10 Essential Services under the functions of *Assessment* and *Policy Development* listed in Table 1 above. It encourages local health planning with small grants and "certification to communities who have broad-based community partnerships which represent the needs of the

disadvantaged and whose mission is prevention based."⁶ As certification requires a community assessment, the communities and staffs of the local public health departments, who are principal partners, are some of the most active users of health-related data. They are guided by a Community Health Assessment Guide Book⁷ and an online County Health Data Book,⁸ the contents of which are described in the commentary by Paul Buescher. As local communities *monitor health status to identify community health problems*, they typically examine data on mortality, communicable disease prevalence, pregnancy rates, and birth weight. However, the Healthy Carolinians approach goes beyond typical health statistics. They may also look at population demographics, education and socioeconomic conditions, and behaviors that contribute to health. The Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System (BRFSS), a statewide telephone survey conducted annually in North Carolina, is an excellent source of data on risk factors, but there are only 22 counties with samples large enough for statistical generalization, and the complex sampling strategies require special statistical procedures for valid description.⁹ Local groups frequently conduct their own behavior and opinion surveys but often do so with small convenience samples from which valid generalizations cannot be made. The community assessment and planning process also includes an evaluation of community resources (ie, asset mapping). Healthy Carolinians partnerships are now certified in 78 of the state's 100 counties.¹⁰

Health workforce data are particularly useful. Historically, inventories of physicians and other providers have been used in requests for designation of Health Professional Shortage Areas (HPSAs) which may bring federal and state resources to build and staff community health centers. These data, combined with information on local and regional health disparities, are constantly used to *inform, educate, and empower* policy makers, *mobilize partnerships to identify and solve health problems*, and *develop policies and plans*. They have been effectively employed to justify the need for medical and dental schools at East Carolina University, the Area Health Education Centers Program, and expansion of curricula and enrollments in the state's medical, nursing, and allied health schools. Other frequent users of health workforce data at the local level are hospitals, community health centers, Area Agencies on Aging, and voluntary health organizations. They *develop policies and plans that support individual and community health efforts* and use data on health resources for *linking people to personal health services*. Physician directories and community service inventories are very valuable data assets. Local public health departments, hospitals, and academic institutions are interested in local data for their roles in *assuring a competent workforce* and in *evaluating the effectiveness, accessibility, and quality of personal and population-based health services*. Academic institutions use local data to *conduct research for new insights and innovative solutions to health problems*. While there is a rich array of secondary data, they may not be appropriately defined or available in a form for valid and ready application at the local level.

Focusing the Data on Specific Regions and Communities

Professional policy analysts and knowledgeable policy makers at the state or federal level may be able to refine or transform data easily into information and to act on it. Users at the local level may be challenged. Technical expertise notwithstanding, a number of problems may exist at the local level. The variables in data collected by a state or state-level agency may not have been chosen or measured to answer local questions. The geographic level of observation and measurement may not be appropriate. The county is a common level of aggregation for most health and health resource data but health problems and community planning efforts do not always follow county boundaries. Local users may need to lump or split the data for multi-county or partial-county analyses. Census data are obtainable down to the census block but analysis may require that they be lumped together. When data are from statewide samples, sample sizes at the county level may not be large enough to draw statistically significant conclusions, particularly when describing smaller population subgroups (eg, Hispanics or American Indians) by gender and age group. When county level data are large enough to split, more specific locations within a county may not have been collected or available. Another problem is that the time frames of data in standard reports may not be useful. Single-year data may not have enough observations; multiple-year data (particularly rates) may occlude trends. The needs of community-level data users, contexts, and relevant issues vary widely, as do their analytic capacities. The challenge for local users is to get simple patterns to emerge without torturing the data, the analysts, or the end users. The data must be clean, of sufficient size, and amenable to simple analysis for information to emerge and be seen, not through statistical smoke, but in clear graphic displays and then stated in simple sentences. A few examples of unique uses and challenges are useful.

Variable Must Be Redefined

A planner at a local health department wants to look at leading causes of death for people under age 75 in her county, but available reports do not provide mortality rates for that specific age group. She suspects that for those under age 75 cancer rather than heart disease is the leading cause of death. She asks colleagues at the local university to analyze recent death file data. They aggregate death certificate data (available from the Odum Institute¹¹) into a 0 through 74 age group and recalculate mortality rates by race and gender. Her hypothesis is confirmed and community attention will be focused on cancer prevention and treatment.

Longer Exposure in Taking the Data Snapshot

A Healthy Carolinians group wants to develop programs to address obesity in the county. BRFSS data are available, but sample sizes in single years are too small to show any statistically significant differences between the county and the state. A custom analysis reassembling the raw data into a 5-year period to provide a larger sample shows there is in fact a higher body-mass index

for the county population than the rest of the state. They will use the information in a grant application.

Produce a Moving Picture Instead of a Snapshot

Elimination of health disparities is a goal of *Healthy Carolinians 2010*. Halfway through the decade, how are individual counties doing in relation to this goal? By analysis of single-year data as a 25-year time series, trends may become apparent at the county level.

Gerrymandered Health Statistics

Data geocoded at the county level are not adequate to define phenomena that do not respect county boundaries. Local communities would certainly be interested in the health impacts of a flood, tornado, or toxic discharge—events likely to cross governmental boundaries. So also might we be interested in the relative health of one political jurisdiction to another. How, for instance, does North Carolina's Third Congressional District differ from the First Congressional District in terms of mortality? By political design, the First Congressional District contains 17 whole counties and 6 partial ones. The Third District contains 9 whole counties in addition to 6 partials, split from the First District. Demographically, the First District is 54% nonwhite versus 22% nonwhite for the Third. Mortality data are coded in public files only at the county level so important health statistics are not available at the congressional district level, which is an unfortunate disconnect between democracy and public health. Mortality rates for congressional districts can be estimated, however, by applying race- and/or age-specific rates to populations in census blocks weighted by race and age proportions and then aggregated up to the district.¹² The race and age proportions are known accurately at the census-block level. Indeed, that information was used to create the politically gerrymandered districts. For example, the estimated mortality rate (2000-2004, age-adjusted) for the total population of the First District is 1039 deaths per 100 000 population versus 966 for the Third District. The estimated rates could have considerable political significance and lead to advocacy for resources to address health disparities. This kind of analysis is not difficult, but it does require powerful computing. The same methods can be used to calculate mortality rates for state legislative districts. Similarly, we can lump together data about populations affected by natural and manmade disasters. This could be very useful in disaster planning, management, and recovery.

The fundamental purpose of using data at the local level is to inform and empower citizens, health providers, and policy makers to take actions to improve community health. There are methodological challenges in refining, redefining, repackaging, and analyzing the data, but with available technology, programs to train local users, and community-campus partnerships for technical assistance, these challenges can be overcome. State agencies and academic institutions can provide training and expertise in survey design and sampling, statistical analysis, interpretation of data, and cartographic presentation of information. We can and should improve how we collect and disseminate data for local users. Death and health-related data

should be geocoded and available for analysis—with privacy safeguards—at the smallest community level whenever possible. One of the objectives of *Healthy People 2010* (23.3) is the “development of data systems that use geocoding to promote use of geographic information systems (GIS) at all levels.”⁵ Realization of this objective would allow local users flexibility to define neighborhoods and communities in more appropriate

ways and to show their elected representatives the problems, needs, and resources of their “designer districts.” We should develop dynamic, electronic public health data systems that allow users to define queries in terms of units of analysis, levels of aggregation, and combinations of variables of interest at the community level. The systems should be customizable, current, convenient, and collaborative. **NCMJ**

REFERENCES

- 1 Committee for the Study of the Future of Public Health, Division of Health Care Services. *The Future of Public Health*. Washington, DC: National Academies Press; 1988.
- 2 Public health in America. US Dept of Health and Human Services Web site. <http://www.health.gov/phfunctions/public.htm>. Updated December 14, 1999. Accessed March 25, 2008.
- 3 National public health performance standards program; ten essential public health services. Centers for Disease Control and Prevention Web site. <http://www.cdc.gov/od/ocphp/nphpsp/EssentialPHServices.htm>. Accessed March 25, 2008.
- 4 North Carolina 2010 health objectives. Healthy Carolinians Web site. <http://www.healthycarolinians.org/healthobj2010.htm>. Accessed March 25, 2008.
- 5 US Department of Health and Human Services. *Healthy People 2010*. Washington, DC: US Dept of Health and Human Services; 2000.
- 6 Certification process. Healthy Carolinians Web site. <http://www.healthycarolinians.org/certific.htm>. Accessed March 25, 2008.
- 7 Rosenberg DC, Britnell M. *Community Assessment Guide Book*. Office of Healthy Carolinians/Health Education and State Center for Health Statistics. North Carolina Dept of Health and Human Services; 2002.
- 8 2008 County Health Data Book. North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/data/databook>. Updated January 2, 2008. Accessed March 25, 2008.
- 9 Behavioral Risk Factor Surveillance System (BRFSS). North Carolina State Center for Health Statistics Web site. <http://www.schs.state.nc.us/SCHS/brfss>. Updated December 13, 2007.
- 10 Healthy Carolinians certified partnerships 2007. Healthy Carolinians Web site. <http://www.healthycarolinians.org/countyprof.htm>. Accessed March 25, 2008.
- 11 NC vital statistics. The Odum Institute for Research in Social Science Web site. http://www.irss.unc.edu/odum/jsp/content_node.jsp?nodeid=10. Accessed March 25, 2008.
- 12 Hao Y, Ward EM, Jemal A, Pickle LW, Thun MJ. US congressional district cancer rates. *Int J Health Geographics*. 2006;5(8). <http://www.ij-healthgeographics.com/content/5/1/28>. Accessed March 25, 2008.

Using Health Data to Focus Philanthropy on Critical Needs

David E. Murday, PhD; Elizabeth A. Corley, MA

In early 2003 The Duke Endowment began planning for a special grant program for early childhood health issues with an emphasis on preventive care and services. During the first phase of the proposed program, grant projects in North and South Carolina were expected to target critical primary health care access issues that affect specific child health outcomes in those states.

The Duke Endowment was concerned that a competitive request for proposals would place communities with high needs but fewer resources at a disadvantage. To avoid this, the Cecil G. Sheps Center for Health Services Research at the University of North Carolina Chapel Hill and the Center for Health Services and Policy Research at the University of South Carolina were asked to assist the Endowment in determining the specific areas in their respective states with access-related health problems for children. The centers were asked to provide data-based answers to the following questions:

- Where are the documented areas of unmet need for children's primary care services?
- What do key people in those areas see as the most important barriers to accessing services and the most important activities needed to improve access to child health care services?
- What improvements in the health status of children can be expected if access to child health care services improves?

This article describes the efforts in South Carolina to answer these questions and support the Endowment's efforts to target the program in communities with the highest needs.

Background

Access to health care is not equal for all children who need it. Prior research in South Carolina examined hospitalization for ambulatory care sensitive conditions as an indicator for access to primary care and found regional disparities.¹ Ambulatory care sensitive conditions are medical conditions for which children who receive appropriate and timely primary care are less likely to need emergency or inpatient care.² Examining 1995 data from the statewide inpatient hospital discharge database maintained by the Office of Research and Statistics of the South Carolina Budget and Control Board, the 10 highest ambulatory care sensitive conditions for pediatric

“...health data can be used to help a foundation identify communities whose needs are aligned with the philanthropy's priorities.”

admissions were bacterial pneumonia; asthma; dehydration; gastroenteritis; severe ear, nose, and throat infections; convulsions; kidney/urinary infections; cellulitis; diabetes; and immunization-preventable conditions. Access to primary care was the strongest factor affecting these admissions—children without a primary care physician were 9.5 times more likely to be hospitalized for a preventable problem than children with a primary care physician. Other demographic factors such as race, income, and insurance coverage were also significantly associated with ambulatory care sensitive conditions hospitalizations.¹ These results were consistent with findings from other research on the topic.

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There are 3 types of barriers to access of primary care services:

- Structural barriers are related to the number, type, concentration, location, or organizational configuration of primary care providers.
- Financial barriers restrict access. After reviewing evidence about financial and nonfinancial barriers to health care access, the Institute of Medicine of the National Academies determined that health insurance coverage is the major determinant of whether children have access to health care.
- Personal and cultural barriers such as language, attitudes and beliefs, social support, and education may inhibit people who need medical attention from seeking it, or once they obtain care, from following recommended treatment guidelines.

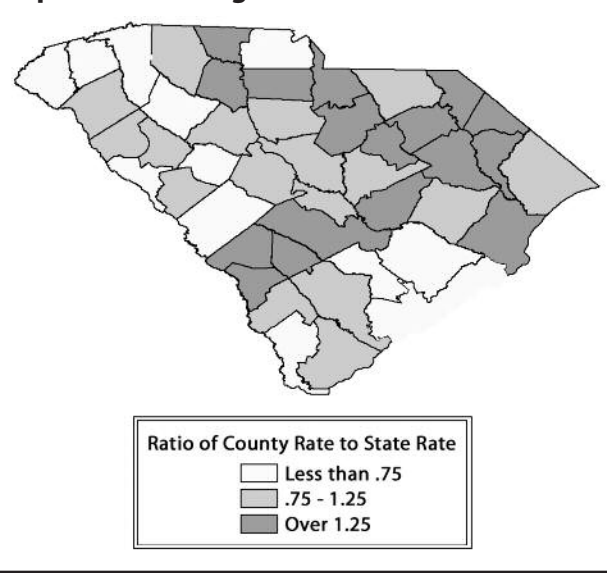
Geographic Information System Maps

Building on the prior work in South Carolina, researchers at the South Carolina Center for Health Services and Policy Research collaborated with the SC Office of Research and Statistics staff to examine several factors that could be used to identify specific areas of the state with access-related health problems for children. Within 2 months, geographic information system maps were generated (counties were grouped into those within 25% greater than or less than the statewide average and those lower or higher than this range) and counties were compared on a number of characteristics:

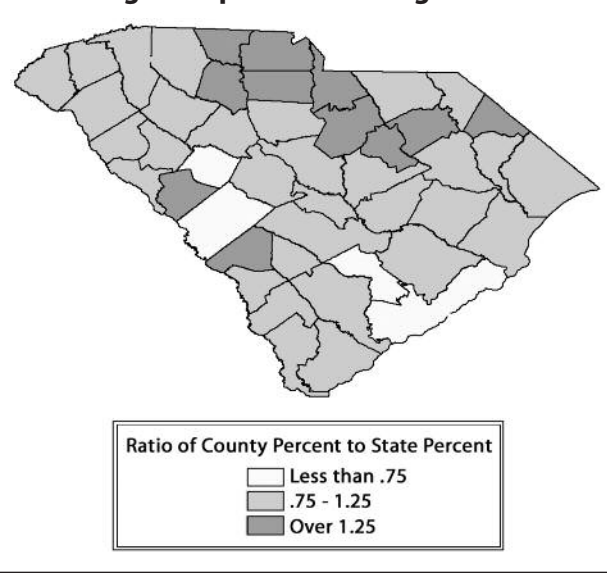
- All ambulatory care sensitive conditions and most common ambulatory care sensitive condition hospitalizations for persons under age 18 by
 - o Rate of ambulatory care sensitive condition hospitalizations per population.
 - o Percentage of ambulatory care sensitive condition hospitalizations as a percentage of all hospitalizations. (This adjusts for differences in overall utilization among counties.)
 - o Differences by payer.
- All ambulatory care sensitive conditions and most common ambulatory care sensitive condition emergency room visits for persons under age 18. (The same comparisons were used as above.)
- Rate of pediatric primary care health professionals per population under age 18 for each primary care service area.
- Percent of population with less than a high school education. (Used as a proxy for socioeconomic status.)

Maps for ambulatory care sensitive condition hospitalizations and emergency department visits used FY 2002 data; the darker counties were more than 25% above the statewide average and the lighter counties were more than 25% below the statewide average. The map for primary care physicians used 2001 data; the darker counties were more than 25% below the statewide average and the lighter counties were more than 25% above the average. So darker counties were likely to be areas with access-related problems for children. (See Maps 1-6.)

**Map 1.
Rate of Ambulatory Care Sensitive Condition Inpatient Discharges**



**Map 2.
Ambulatory Care Sensitive Conditions as a Percentage of Inpatient Discharges**

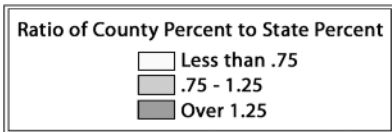
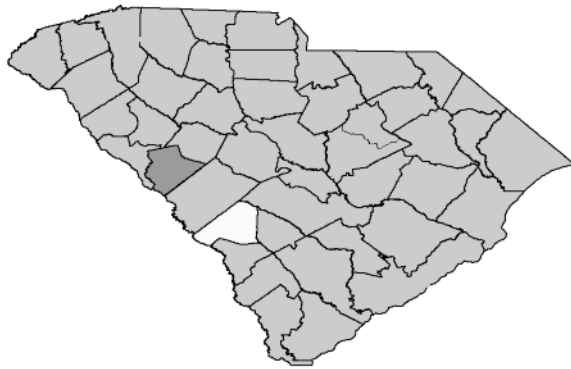


Potential Intervention Sites

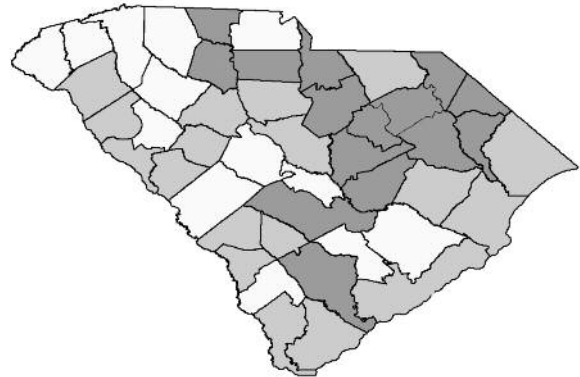
Using the geographic information system maps, 9 potential target counties were identified. Based on past involvement by The Duke Endowment and the availability of hospitals eligible for Endowment grants, 4 potential intervention sites were chosen. Table 1 presents some comparative data for these sites and for a county with similar demographics but a much lower ambulatory care sensitive conditions hospitalization rate.

Over the next 2 months, Center for Health Services and Policy Research staff conducted a series of key informant interviews with 6 to 8 key people in each of those communities

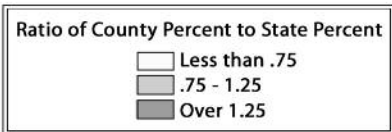
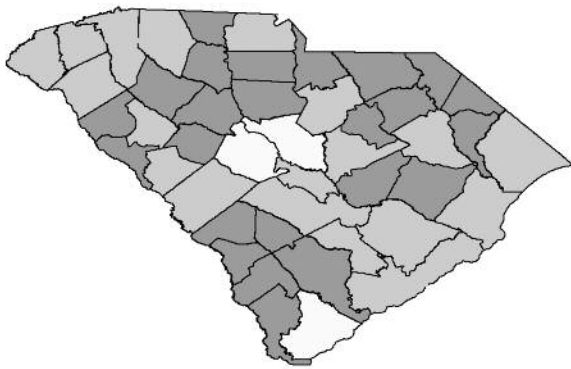
Map 3.
Ambulatory Care Sensitive Conditions as Percentage of Emergency Department Visits



Map 4.
Rate of Asthma Inpatient Discharges



Map 5.
Percentage of the Population with Less than a High School Education



Map 6.
Primary Care Physicians per 10 000

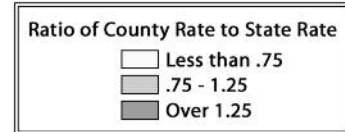
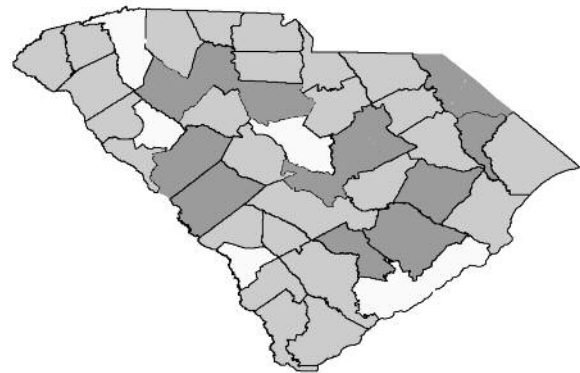


Table 1.
Actual Versus Expected Ambulatory Care Sensitive Condition Discharges, FY 2002

County	Actual	Expected, if at rate of:	
		Statewide Average	Laurens County
Dillon	309	90	65
Kershaw	425	145	106
Lee	120	56	41
Union	174	77	56

to identify the probable reasons for the higher rates. Key informants included hospitals administrators, health department staff, school nurses, community health centers staff, pediatricians, and other stakeholders. Individual reports were created for each community. Tables 2-5 summarize the common findings.

Forum for Potential Grantees

Similar geographic information system analyses and qualitative research were occurring in North

Table 2.
Major Child Health Problems

Asthma, allergy, upper respiratory infections
Obesity, nutrition
Diabetes
Mental health problems
Developmental delay
Teen pregnancy
Children presenting much sicker
Dental problems
Child abuse/neglect
Urinary tract infections/sexually transmitted diseases
Otitis media
Premature births

Table 3.
Barriers to Primary Care for Children

Transportation
Parental perception of importance of care
Lack of providers (especially Medicaid)
Lack of coordination, long waits, lack of follow-up
Family constraints: finances, job, child care, health coverage
Illiteracy
Poverty/working poor
Lack of care, translators, advocates for Latinos
Lack of awareness, outreach, advocacy

Carolina. Staff from both states then assisted The Duke Endowment staff in developing a forum for potential grantees held in early summer 2003. Teams from each potential target county attended with the goal being for the attendees to consider the data for their areas, then consider interventions to improve access to primary care that The Duke Endowment would be willing to fund. The forum provided an opportunity for Endowment officials to explain in detail the concept of this funding initiative and for prospective target grantees to understand the proposal process. A key agenda item included data presentations by researchers from both state organizations that highlighted the specific data analyses and informant survey results for each of the target areas. Ample time was allotted for target area representatives to brainstorm with their respective research organizations regarding some of their ideas for improving access in response to the data presented and to suggest additional data that might enlighten their proposal processes.

The Duke Endowment Funded Projects

As a result of the forum and further technical assistance, 3 of the 4 target counties in South Carolina developed proposals that were subsequently funded by The Duke Endowment and

Table 4.
Common Needs

Transportation, including resources for non-Medicaid
Early periodic screening, diagnosis, and treatment resources, perhaps provided by school nurses
Spanish interpreters, outreach coordinators, advocates
Fund for non-Medicaid clients for prescriptions
Outreach, screening, education, coordination, advocacy, public awareness
Primary care centers
Physicians, nurse practitioners, nurses
More family support services/school nurses
Psychiatrists, therapists

Table 5.
Common Strengths

Caring, committed, and creative individuals working with and on behalf of children
Organized networks, interagency groups
Belief in collaboration to meet the critical needs of children in their communities
Strong "finger-on-the-pulse" awareness of needs of children in the communities
History of successful grant partnerships

implemented in early 2004. The proposals varied widely in their approach to addressing access to primary care.

- The Union County proposal emphasized postnatal home visits by public health nurses to link new parents to a variety of services. Some services were directly related to access (eg, linking infants to medical homes, education about recognition of health problems, and appropriate use of ER) while others were not related to access (eg, family planning, education on caregiving and injury prevention).
- In Dillon County, the proposal focused exclusively on children with asthma with the goal of reducing the burden of asthma in the county. Improving access to primary care for these children was just one of several different strategies to address asthma related problems.
- The Lee County proposal's stated purpose was "to reduce identified barriers to health care access" with strategies directly related to improving access such as referral, case management, establishment of medical homes, education regarding appropriate and timely use of the health care system, and resource development.

Follow-Up Data

Since, with expected implementation delays, the projects did not begin until 2004, the earliest expected effects of the programs would be visible in state fiscal year 2004-2005.

Discussion

This case example illustrates how health data can be used to help a foundation identify communities whose needs are aligned with the philanthropy's priorities. The relationship between access to primary care and hospitalizations for ambulatory care sensitive conditions is clearly established, and qualitative data can be used to identify specific needs, barriers, and strengths. The combination of these data can help communities consider the comprehensive nature of a problem and suggest strategies that reflect the community's resources and priorities.

This case example also illustrates the limitations of health data. Health data is but one factor a community will consider in determining its most important needs and the strategies to address them. The postnatal nurse home visiting program in Union County had been reduced due to budget cuts; restoring the program was a community priority even if it was only indirectly

related to access to primary care. In Dillon County, data on high hospitalization rates for children with asthma (an ambulatory care sensitive condition) reinforced ongoing community concerns about children with asthma. As a result, strategies for improving access to primary care were focused on this limited population and other strategies were not related to access at all.

Tables 6-8 present data on pediatric admissions for ambulatory care sensitive conditions for each county during the 3 years before and 3 years after implementation. In terms of actual admissions, each county shows a substantial decrease from the 3-year average before implementation to the 3-year average after implementation—from 152 to 97 admissions per year in Union, from 264 to 156 in Dillon, and from 126 to 84 in Lee. However, since the statewide average was also decreasing over the same period, not all of those reductions can be attributed to the grant initiatives. **NCMJ**

Table 6.
Union County Ambulatory Care Sensitive Condition Discharges

	SFY02	SFY03	SFY04	SFY05	SFY06	SFY07*
Actual	174	144	138	112	103	75
Expected (at rate of state)	77	118	103	82	81	58
Ratio of Actual/Expected	2.26	1.22	1.34	1.37	1.27	1.29

*Quarters 3 and 4 of SFY 2007 are not finalized. The data is approximately 97% complete.

Table 7.
Dillon County Ambulatory Care Sensitive Condition Discharges

	SFY02	SFY03	SFY04	SFY05	SFY06	SFY07*
Actual	309	340	143	180	169	120
Expected (at rate of state)	90	203	136	128	111	112
Ratio of Actual/Expected	3.43	1.67	1.05	1.41	1.52	1.07

*Quarters 3 and 4 of SFY 2007 are not finalized. The data is approximately 97% complete.

Table 8.
Lee County Ambulatory Care Sensitive Condition Discharges

	SFY02	SFY03	SFY04	SFY05	SFY06	SFY07*
Actual	120	130	127	84	94	74
Expected (at rate of state)	56	90	85	67	65	54
Ratio of Actual/Expected	2.14	1.44	1.49	1.25	1.45	1.37

*Quarters 3 and 4 of SFY 2007 are not finalized. The data is approximately 97% complete.

REFERENCES

- Shi L, Samuels ME, Pease M, Bailey WP, Corley EH. Patient characteristics associated with hospitalizations for ambulatory care sensitive conditions in South Carolina. *South Med J*. 1999;92(10):989-998.
- Bindman AB, Grumbach O, Osmond M, et al. Preventable hospitalizations and access to health care. *JAMA* 1995;274(4):305-311.

The North Carolina Trauma Registry

Michael H. Thomason, MD, FACS

Unintentional injuries are the leading cause of death in North Carolina and throughout the United States for ages 1 to 44, with medical expenditures of \$117 billion each year.^{1,2} Optimal care of seriously injured patients requires an organized and coordinated approach by emergency medical services (EMS), hospitals, and other health systems. The Office of Emergency Medical Services (OEMS) is the lead agency for coordinating trauma care in North Carolina and began designating individual trauma centers in the 1980s.³ The Trauma System Act of 1993 enabled development of an inclusive statewide trauma system with every acute care hospital required to affiliate with 1 of the 7 newly created Regional Advisory Committees (RACs). Each RAC is led by a regional Level I or Level II trauma center^a and is expected to develop regional treatment protocols, transfer guidelines, and programs for education, training, and performance improvement.⁴ Unfortunately, the legislation which created the trauma system and RACs was an unfunded mandate, so efforts to build and support it to date have been voluntary and the establishment of an integrated, inclusive trauma care system has been incomplete.

The North Carolina Trauma Registry (NCTR) was created in 1987 as a cooperative effort between the state's trauma centers and OEMS to facilitate the collection of consistent data on all injured patients admitted to the trauma centers. Each of the 11 trauma centers in North Carolina (6 Level I, 3 Level II, and 2 Level III) are required to collect and submit data using NTRACS (National Trauma Registry of the American College of Surgeons) software. Over 250 data points are collected on each trauma patient, with standard data

definitions provided in a data dictionary which is regularly revised and updated. Since 1994 the registry has collected data on more than 200 000 patients treated at North Carolina's trauma centers.⁴

Data from the registry has been a resource for many scientific publications over the past 20 years, including those focusing on the evaluation of care and outcomes of specific injuries, causes of injury, impact of injury prevention equipment such as seat belts and motorcycle helmets, and in other benchmarking and

“The goal of the coordinated data system is inclusion of all state EMS agencies, acute care hospitals, and other providers in an organized, multidisciplinary, data-driven structure to provide optimal quality care for all injured patients throughout North Carolina.”

outcomes studies. The NCTR Research Review Committee and Publications Committee oversee access to registry data and assure that resulting publications are accurate and maintain confidentiality of the patients and hospitals. However, since state law only mandates data submission by designated trauma

a Level I and II trauma centers provide comprehensive care for trauma patients, and serve as regional resource centers. Level III centers provide initial stabilization of injured patients, with transfer to Level I or II centers for those patients with more complex or critical injuries.

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centers, the registry does not currently provide a population-based profile of injured patients cared for in more than 100 acute care hospitals throughout the state.

The impact of the NCTR on health policy decisions has thus been somewhat limited. Several databases currently contain information on injured patients throughout the state, including the NCTR, PreMIS (the EMS prehospital database), and NC DETECT (the North Carolina Division of Public Health database which is updated daily with information from all emergency department visits to hospitals in North Carolina). These various databases must be linked to provide a comprehensive

profile of injury in North Carolina, and efforts are currently underway to do so. If successful, this will create a registry, maintained and administered by OEMS, with accurate and accessible data to support ongoing evaluation of the evolving trauma system with benchmarking for performance improvement and outcomes research, injury prevention, and public health planning. The goal of the coordinated data system is inclusion of all state EMS agencies, acute care hospitals, and other providers in an organized, multidisciplinary, data-driven structure to provide optimal quality care for all injured patients throughout North Carolina. **NCMJ**

REFERENCES

- 1 National Center for Injury Prevention and Control. CDC Injury Fact Book. Atlanta, GA: Centers for Disease Control and Prevention, US Dept of Health and Human Services; 2006.
- 2 WISQARS. National Center for Injury Prevention and Control. Centers for Disease Control and Prevention Web site. <http://www.cdc.gov/ncipc/wisqars/>. Accessed April 7, 2008.
- 3 The North Carolina Office of EMS (NC OEMS) Web site. www.ncems.org. Updated January 10, 2008. Accessed January 28, 2008.
- 4 Trauma. The North Carolina Office of EMS (NC OEMS) Web site. <http://www.ncems.org/trauma.htm>. Updated February 20, 2008. Accessed January 28, 2008.

Transforming Care in the Physician Workplace Through Electronic Data Exchange

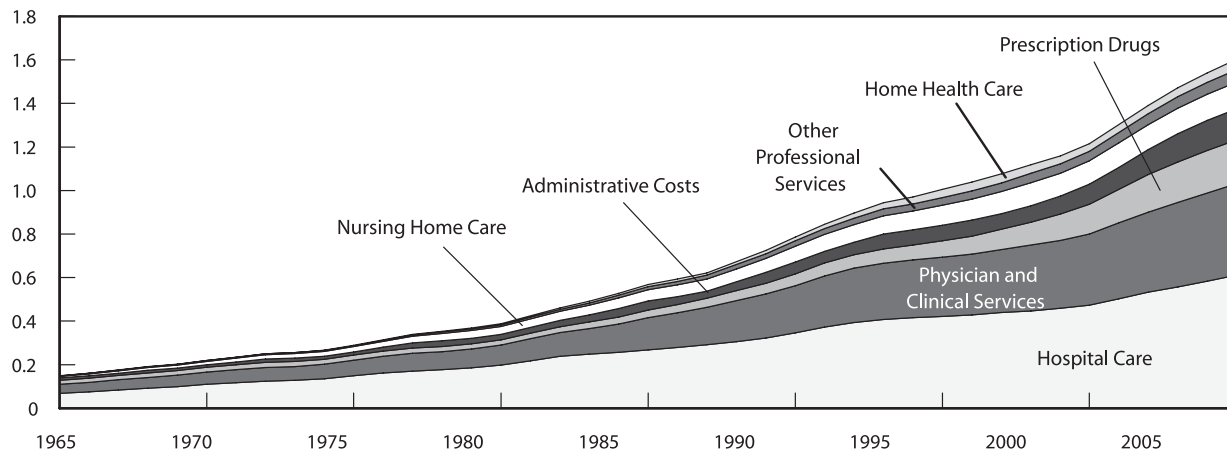
Holt Anderson; Gary Bowers

In 2007 total national health expenditures were expected to rise 6.9%—2 times the rate of inflation. Total spending was \$2.3 trillion in 2007 or \$7600 per person. Total health care spending represented 16% of the gross domestic product (GDP).¹ Health care spending in the US is expected to increase at similar levels for the next decade reaching \$4.2 trillion in 2016 or 20% of GDP.¹ (See Figure 1.)

A study by the Congressional Budget Office, *Technological Change and the Growth of Health Care Spending*, published in January 2008 estimates that the percentage of GDP spent on health care will grow from 16% in 2006 to over 20% within a few years due to the aging population and growth in chronic care expenditures, and if left unchecked, will approach 49% of GDP by 2082.² (See Figure 2.)

“The danger of missing information is increased with the dispersal of care among multiple specialists serving patients with a variety of chronic conditions.”

Figure 1.
Real Spending on Health Care in Selected Categories, 1965 to 2005 (Trillions of 2005 dollars)



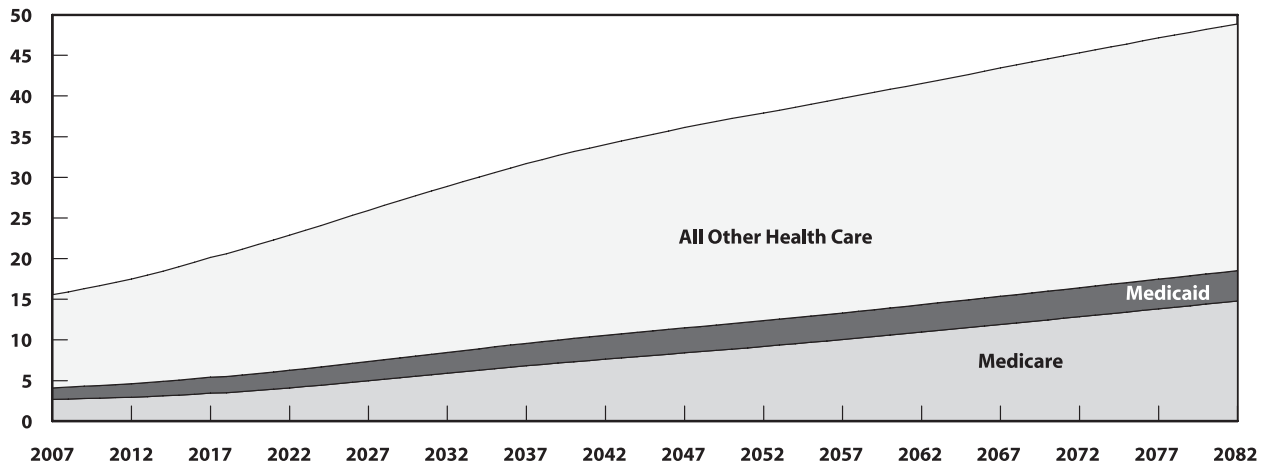
Source: Congressional Budget Office based on data on spending on health services and supplies, as defined in the national health expenditure accounts, maintained by the Centers for Medicare and Medicaid Services.

Note: Spending amounts are adjusted for inflation using the gross domestic product implicit price deflator from the Bureau of Economic Analysis.

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Gary Bowers is executive director of the Western North Carolina Health Network.

Figure 2.
Projected Spending on Health Care as a Percentage of Gross Domestic Product, 2007 to 2082
(Percent)



Source: Congressional Budget Office.

Note: Amounts for Medicare are net of beneficiaries' premiums. Amounts for Medicaid are federal spending only.

The fiscal impact of these increases in overall spending for health care in relationship to limited growth in tax revenues or corporate profits will force choices that may accelerate the number of uninsured and underinsured individuals and increase pressure on reimbursements to practitioners, hospitals, and other related services. Often cited reports including those from the Institute of Medicine of the National Academies such as *To Err is Human* and *Crossing the Quality Chasm* highlight the human and economic costs of inefficient and paper-based care and encourage a swift movement to electronic health records and secure electronic health record exchange.^{3,4} Work is being done by the North Carolina Healthcare Information and Communications Alliance (NCHICA) and others to build an economic business case that will support the transition to electronic health records in the practice setting where the cost and change in work flow have deterred adoption up to this point.

The Role of Quality in Improving Health Care Safety and Outcomes

The North Carolina Medical Society established the Quality of Care and Performance Improvement Committee to examine the relationship between better information management and practitioner job satisfaction and improvements in the quality of care provided. Evidence is emerging that practitioners who use electronic health records keep their patients healthier through built-in structured reminders and avoid mishaps by using electronic prescribing with automatic drug-to-drug interaction checking.⁵ The current system of prescribing and dispensing medications in the United States has widespread problems with safety and efficiency. Experts predict that a shift to electronic prescribing (e-prescribing) systems could avoid more than 2 million adverse drug events annually, of which 130 000 are life-threatening.⁶

E-prescribing also has enormous potential to create savings in health care costs through reduction of adverse drug events and in improved workflows. One recent study estimated the potential savings at \$27 billion per year in the United States.⁷

By design, practitioners also are in a better position to take advantage of incentive programs such as Bridges to Excellence and increased reimbursements from Medicare. The Bridges to Excellence North Carolina initiative is one that encourages the use of electronic health records in practitioner offices to improve health care for partner health plan members. In North Carolina the Bridges to Excellence program provides funds to practices that are certified by the National Committee for Quality Assurance as having certain electronic and process capabilities and that serve members of health plans whose employers have subscribed to the Bridges to Excellence program. This program is showing participating employers that employees served by physicians who have electronic health records are healthier, have chronic conditions better under control, and have fewer trips to emergency departments. In turn, the health plan saves money, providing the business justification for paying incentives to physicians using electronic health records.⁸

Better and More Timely Information at the Point of Care Drives Quality

Lack of timely and reliable information about a patient has the effect of slowing accurate diagnosis and treatment. Such a delay can be frustrating for physicians and dangerous for patients, especially if knowledge about allergies and medications is not available when prescription orders are being entered. The danger of missing information is increased with the dispersal of care among multiple specialists serving patients with a variety of chronic conditions.

In a recent request for proposals, the Agency for Healthcare Research and Quality stated that the burden of providing treatment and supportive services for individuals with complex health care needs continues to increase.⁹ In 2000, 60 million Americans had multiple chronic conditions, and it is projected that this will rise to over 81 million by 2020.¹⁰ Yet care for these patients is often fragmented across multiple settings and across providers—with limited or no communication or coordination and no sense of overarching responsibility. Patients often do not seek services until there is some crisis in their condition, a crisis that may have been avoided had they sought care earlier or if their care had been better coordinated. Also, these transitions in care are often accompanied by changes in a patient's functional status which may further complicate future care needs.⁹

Information management is key to addressing these issues because it provides physicians with better and more organized information which saves them time and achieves better diagnoses and treatments (and healthier patients). Furthermore, the time saved can translate into more patients served. While there is a steady increase in the numbers of practitioners and practices adopting electronic health records, the cost and required workflow changes present barriers to many practitioners. However, a business case is being made for overcoming these barriers as peer practitioners show evidence of the benefits of electronic health records and payers begin to offer incentives for their use.

Health Information Exchange Networks

As more practitioners adopt electronic health records, additional issues arise. Of primary concern is the ability to share information collected across provider groups as needed to serve patients. As such, hospitals and health systems are building referral networks in their communities to connect radiology, labs, and pharmacies through community health information exchange (HIE) networks. In order for these networks to succeed, they must address a number of issues including data compatibility and privacy. Following a 2004 Presidential Executive Order, the US Department of Health and Human Services established the Office of the National Coordinator of Health Information Technology (ONC). The Office of the National Coordinator was tasked with facilitating privacy and security, developing and recommending standards for certification of applications, harmonizing codes, and building a "network of [community] networks, that will enable most Americans to have an electronic health record by 2014."¹¹

Sixteen hospitals in western North Carolina have been recognized as leaders for their early implementation of a community HIE network which is called WNC Data Link. Their vision was to create a network to connect all of the regional hospitals to enable the sharing of electronic longitudinal records for patient care. Through WNC Data Link authorized physicians can quickly access patient lab results, medications, radiology reports, discharge summaries, histories and physical examinations, and other information from any hospital in the region via the Internet. WNC Data Link has become particularly

valuable as patients transfer between hospitals and also in emergency departments where immediate access to patient information is vital. The next phase of this initiative will link physician practices and other providers to this network.

North Carolina has a number of unique capabilities and organizations that can lead the transformation from an inefficient, paper-based system of care to a high-quality environment that enhances the practice of medicine, improves efficiencies and outcomes, and makes our state even more attractive for business. NCHICA is being recognized nationally for its past and current activities as described below.

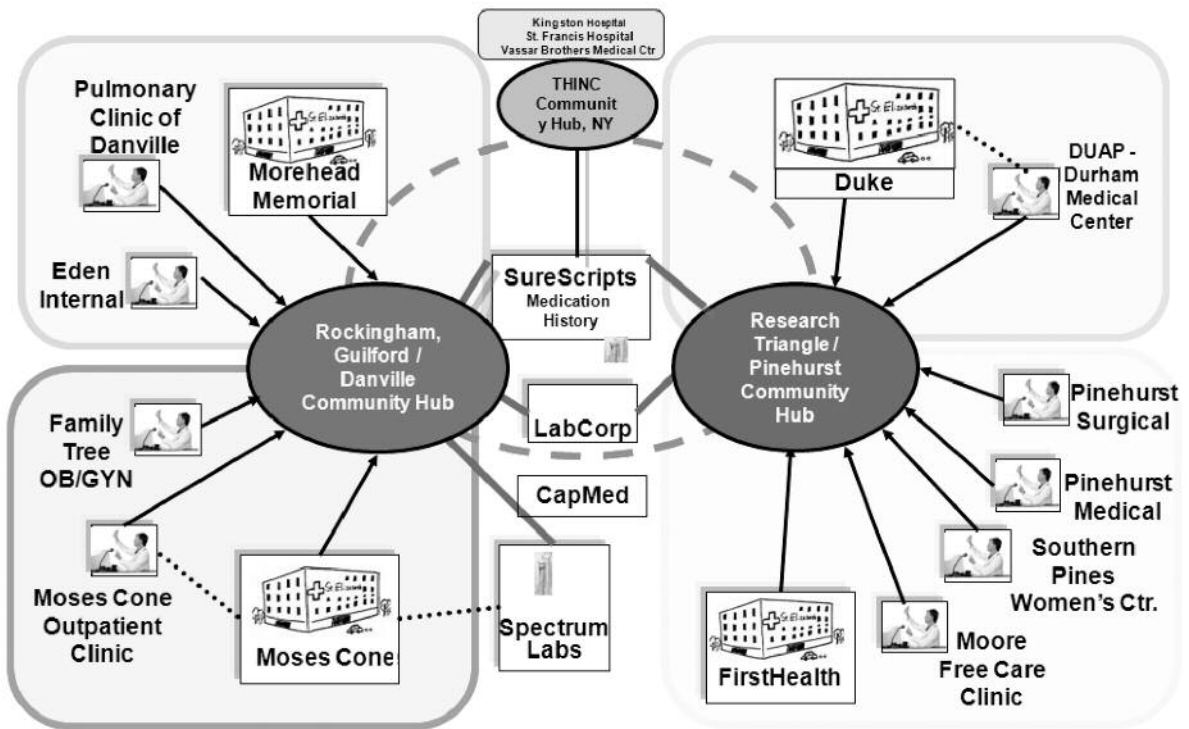
1. North Carolina is involved in national efforts to transform health and care through the North Carolina Healthcare Information and Communications Alliance (NCHICA).

NCHICA was formed in 1994 by Executive Order of the Governor of North Carolina as a nonprofit organization with a mission of "improving health and care in North Carolina by accelerating the adoption of information technology and associated policies."¹² NCHICA fosters collaboration among all sectors of health and care and works on policy and technology solutions that enable secure health information exchange.

North Carolina has received significant funding for 2005-2008 to participate in national efforts to develop better laws and regulations that enable exchange for treatment purposes. At the request of the Office of the Governor, NCHICA applied for and received a contract from the Agency for Healthcare Research and Quality (AHRQ) and the Office of the National Coordinator for Health Information Technology (ONC) to study business practices, laws, and regulations that have the effect of impeding the exchange of electronic health information that is required for treatment purposes.¹³ Among the barriers revealed by the study, the most prominent was confusion over the Health Insurance Portability and Accountability Act (HIPAA) and the labyrinth of state and federal laws and regulations governing consents and privacy. After a legal analysis was completed, a legal work group developed recommendations for solutions and how changes might be implemented. North Carolina and 33 other states collaborated on this phase of the work that concluded at the end of 2007. In the next phase, underway in 2008, North Carolina will collaborate with other states in the development of intrastate and interstate consents and interorganizational agreements that will enable the secure exchange of information in a consistent manner that takes into consideration concerns over liability and standards.

Another major project involves North Carolina and a select group of states in the development of policies and technologies to support 2 phases of the Nationwide Health Information Network (NHIN): Architecture Prototypes and Trial Implementations. North Carolina participated in the development of the Architectural Prototype of the NHIN in 2006 and early 2007. This development was led by IBM with a subcontract to NCHICA. This phase included participation by the organizations shown in Figure 3.

**Figure 3.
Nationwide Health Information Network, Phase 1**



Source: North Carolina Healthcare Information and Communications Alliance, Inc.

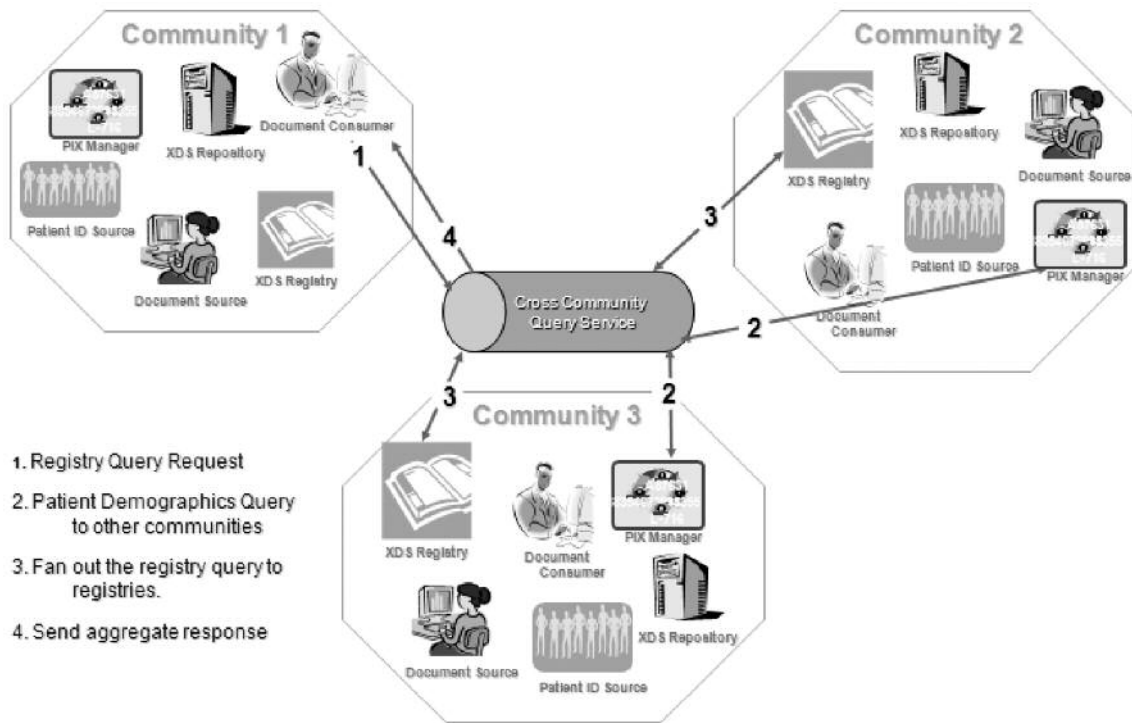
As communities continue to build their own HIE capabilities, the challenge will be to connect neighboring communities, regions, and states. The vision is for this network to eventually become nationwide and possibly worldwide. It is clear that the best business case for greatest value can be made for the community HIE network where over 90% of all traffic will occur. Less justifiable is the cost to construct and maintain a cross-continental capability that would be rarely used. However, if the “network of networks” is constructed for clinical exchange on the local level, the connections and security capabilities would be useful for national and regional activities such as public health and claims/payments that cross community boundaries. Figure 4 graphically displays how a locator and switching service might be established to serve multiple communities in a region. The connections in a nationwide “Network of Networks” are represented in Figure 5.

2. The North Carolina Health Information Exchange (NC HIE) Council was formed to develop consensus strategies and actions that will keep North Carolina on the forefront of health information exchange efforts.

The NC HIE Council was formed in 2007 as a consensus-building body of knowledgeable individuals representing the leading sectors of health and care in North Carolina. The Council includes representatives from the following:

- North Carolina State Health Director or designee
- North Carolina State Chief Information Officer or designee
- North Carolina Consumer Advisory Council on Health Information
- North Carolina Medical Society
- North Carolina Hospital Association
- North Carolina Nurses Association
- North Carolina Health Information Management Association
- North Carolina Association of Pharmacists
- North Carolina Health Departments
- North Carolina Office of Emergency Medical Services
- North Carolina Association of Free Clinics
- North Carolina Division of Medical Assistance
- North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services
- North Carolina Association of Health Plans
- Health Information Exchange
- Private-sector behavioral health organizations
- Long-term care/nursing homes
- Laboratory service providers
- Radiology service providers
- NCHICA CIO Roundtable
- At-large members appointed by NCHICA Board of Directors

Figure 4.
Nationwide Health Information Network, Architecture



Source: North Carolina Healthcare Information and Communications Alliance, Inc.

Figure 5
Nationwide Health Information Network, Architecture

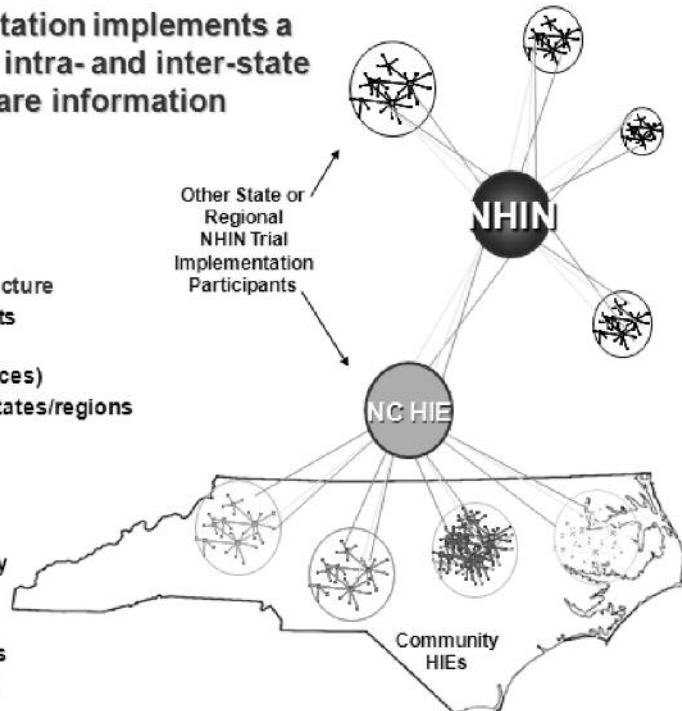
The NHIN Trial Implementation implements a “network of networks” for intra- and inter-state exchange of healthcare information

NC HIE

- Convener, Educator, Facilitator
 - Privacy/security framework
 - Standards/reference architecture
- Incubator for piloting new concepts
- Utility for Foundational Services (e.g., EMPI, Record Locator Services)
- NHIN compliant linkage to other states/regions

Community HIEs

- Encourage EHR adoption and “last mile” connectivity
- Develop real-time patient summary and data aggregation capabilities
- Provide training and education
- Engage non-provider stakeholders (payers, employers, public health)



Source: North Carolina Healthcare Information and Communications Alliance, Inc.

It is the mission of the NC HIE to enable the timely and secure exchange of electronic health information among its authorized members for the purposes of:

- Improving the quality of health and care provided to individuals in North Carolina.
- Improving the efficiency of the health care system in North Carolina.
- Enhancing patient safety in North Carolina.
- Improving the overall health of North Carolina's residents.

The NC HIE Council will develop policies and procedures that facilitate these objectives and may contract with one or more health care information service providers to operate a health information exchange network to fulfill this mission.

3. The North Carolina Consumer Advisory Council on Health Information was formed in response to privacy concerns.

In 2006 NCHICA established the North Carolina Consumer Advisory Council on Health Information in response to consumer concerns regarding privacy and the move to electronic health records with the attendant ability to share personal information across networks. These concerns connect broadly with the vision of a national and international capability to move information to any point on the globe. The Council is expected to become

informed about both North Carolina and national initiatives and to advise NCHICA on policy and technology matters.

4. A series of regional town meetings will be held in the spring and summer of 2008 to inform North Carolina residents of NCHICA efforts and how they can become engaged in the process.

At the urging of its members, NCHICA will undertake a series of educational town meetings in various regions of North Carolina in the spring and summer of 2008. NCHICA representatives will share information about state and national initiatives and solicit feedback regarding local priorities that will help shape future efforts. Expected attendees are physicians and nurses, hospital administrators and chief information officers, business and political leaders, and other individuals interested in increasing health information exchange to improve quality of care and to positively impact the cost-effectiveness of the health system in North Carolina. This is particularly important as we balance the increasing demand for services with the limited resources to pay for those services.

The future looks bright for transforming health and health care practices in North Carolina from the inefficient, paper-based environment of today to the advanced electronic systems of tomorrow. Such a transformation will support health professionals in their delivery of high-quality care to their communities and will elevate North Carolina into a position of national leadership. **NCMJ**

REFERENCES

- 1 Paisal JA, Truffer C, Smith S, et al. Health spending projections through 2016: modest changes obscure part D's impact. *Health Aff.* 2007;26(2):w242-253.
- 2 Congress of the United States Congressional Budget Office. *Technological Change and the Growth of Health Care Spending*. Washington, DC: Congressional Budget Office; 2008. Publication no. 2764.
- 3 Committee on Quality of Health Care in America, Institute of Medicine of the National Academies. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press; 2001.
- 4 Committee on Quality of Health Care in America, Institute of Medicine of the National Academies. *To Err Is Human: Building a Safer Health System*. Washington, DC: National Academy Press; 1999.
- 5 Binns, P. The Impact of the Electronic Health Record on Patient Safety: An Alberta Perspective. *Healthcare Papers*. 2004;5(3):47-51.
- 6 Johnston D, Pan E, Middleton B, Walker J, Bates DW. *The Value of Computerized Order Entry in Ambulatory Settings*. Boston, MA: Center for Information Technology Leadership; 2004.
- 7 Electronic Prescribing Initiative Team. *Electronic Prescribing: Toward Maximum Value and Rapid Adoption*. Washington, DC: eHealth Initiative; 2004.
- 8 BTE research and analysis. Bridges to Excellence Web site. <http://www.bridgestoexcellence.org/Content/ContentDisplay.aspx?ContentID=81>. Accessed April 6, 2008.
- 9 RFA-HS-08-002: Ambulatory Safety and Quality Program: Improving Management of Individuals with Complex Healthcare Needs through Health IT (R18). US Department of Health and Human Services Web site. <http://grants.nih.gov/grants/guide/rfa-files/RFA-HS-08-002.html>. Posted November 16, 2007. Accessed April 9, 2008.
- 10 Mollica RL, Gillespie J. Partnership for solutions: better lives for people with chronic conditions. http://www.partnershipforsolutions.org/DMS/files/Care_coordination.pdf. Published January 2003. Accessed April 6, 2008.
- 11 Executive order: incentives for the use of health information technology and establishing the position of the National Health Information Technology Coordinator. The White House Web site. <http://www.whitehouse.gov/news/releases/2004/04/20040427-4.html>. Published April 27, 2004. Accessed April 6, 2008.
- 12 Governor James B. Hunt, Jr. Executive order 54: to create the North Carolina Health Care Information and Communications Alliance. North Carolina Healthcare Information and Communications Alliance Web site. <http://www.nchica.org/AboutNCHICA/CorpInfo/ExecOrder.htm>. Published July 1, 1994. Accessed April 8, 2008.
- 13 North Carolina Health Information Security and Privacy Collaboration (HISPC) Project. North Carolina Healthcare Information and Communications Alliance Web site. <http://www.nchica.org/NCHISPC/intro.htm>. Updated February 15, 2008. Accessed April 6, 2008.

Training Health Care Personnel to Work with Health Care Data

Elizabeth Layman, PhD, RHIA, CCS, FAHIMA

The Institute of Medicine of the National Academies (IOM) has recognized since the early 1990s that the United States needs an electronic health record system.¹⁻³ An electronic health record system is the keystone of the US Department of Health and Human Services' overarching initiative to increase the use of health information technologies in the health care sector. Two IOM reports, *To Err Is Human: Building a Safer Health System* and *Crossing the Quality Chasm: The IOM Health Care Quality Initiative*, particularly encouraged the migration to electronic health record systems.^{4,5}

Underpinning the requirements for health care data are the recommended 8 core functionalities and 6 key capabilities of electronic health record systems.³ A brief review of selected core functionalities and key capabilities suggests the extensive scope of health care data that is needed. For example, health information and data is a core functionality. Data associated with health information are patient or client demographics, facility and provider identification, encounter dates, admission and discharge dates, disease and service codes, clinical notes, problem lists, and medication lists. Decision support is another core functionality. Limited examples of health care data needed for decision support are warnings and contraindications for medications, out-of-range values for laboratory tests, and reminders for interventions and screenings. Reporting and population health management is another core functionality. A few examples of health care data needed for this management include specimens, procedures, results, laboratory identification, patient's temperature, outbreak data, adverse event reports, and registry data.

The 6 key capabilities describe what electronic health record systems should be able to do. The first key capability is longitudinal collection of data for and about individuals. Thus, electronic health record systems should be able to assemble the health care

data about an individual across the span of that individual's life from all the sites of health care delivery. Examples of these sites include hospitals, physician offices, health departments, pharmacies, fitness centers, student health services, radiologic centers, dental offices, ophthalmologic practices, mental and behavioral health centers, rehabilitation units, and skilled nursing facilities. Related to longitudinal collection is interoperability, another key capability. Interoperability allows linkages among providers. Through these linkages, providers are able to exchange data. For example, dental offices can check insurance eligibility and benefits. Another important capability is that electronic health record systems allow authorized users to access individual

“Effective use of health care data means that health care personnel, health care organizations, and health care systems have real-time information about the health of individuals and of populations...”

and aggregate data. Thus, in addition to supporting clinical decision making at the point of care, electronic health record systems allow policy makers to analyze aggregate data. The key capabilities, therefore, support the delivery of integrated health care to individuals and to populations.

The variety, sources, and uses of health care data indicate the complexity of the training effort that is needed. After training, health care personnel should be able to transform individual health care data elements into information and information into knowledge. With knowledge, the health care sector can

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promote high standards, interoperability, and effective use of health care data.

High standards of care are represented by evidence-based practice. Evidence-based practice can be the use of medical and health knowledge in external referent systems or the use of standards promulgated by the professional associations and oversight entities. One key capability of electronic health record systems is the ability to connect to external knowledge such as drug references, clinical laboratory tests manuals, and anatomical references. For health care organizations, an example of a high standard of care is assuring that providers have complete health records upon which to base diagnosis and treatment. Evidence-based practice may also be supported by clinical guidelines and quality measures. For example, the National Quality Measures Clearinghouse sponsored by the Agency for Healthcare Research and Quality lists quality measures by professional association/developer, disease/condition, treatment/intervention, and measure.⁶ These measures are data driven. The mortality rate for acute myocardial infarction per 100 discharges requires data on diagnostic codes, discharge status, and numbers of discharges. In addition, to put the rate in context, data on numbers of transfers, on length of stay, and on risk factors are also needed. In another example, the Centers for Medicare and Medicaid Services has process measures that require data to calculate median time from arrival at a hospital to the administration of fibrinolytic agents in patients with ST segment elevation and to calculate the percent of patients with acute myocardial infarction who have a history of smoking cigarettes and who receive smoking cessation counseling during the hospital stay. Thus, health care data can support quality improvement when the data are available in real time at the point of clinical decision making as well as retrospectively when they are available for analysis.

Interoperability is based on messaging standards or data exchange standards for information systems. These standards enable health care data to be exchanged and used among information systems across multiple sites of care. Many organizations have been involved with the development of these standards, and a lack of coordination has impeded interoperability. Examples of standards include Health Level 7 (HL7); clinical medical vocabularies such as the Systemized Nomenclature of Medicine, Clinical Terms (SNOMED-CT), Logical Observation Identifiers Names and Codes (LOINC), and the Unified Medical Language System (UMLS); and Digital Imaging and Communications in Medicine (DICOM). E-prescribing has been made possible by the National Council for Prescription Drug Programs (NCPDP) standards. The American National Standards Institute (ANSI) has developed messaging standards for the exchange of financial and administrative transactions. The ASTM (formerly American Society for Testing and Materials) has created many standards for electronic health record systems in the areas of health data security, record content, and the continuity of care record. Recently, a working group of the American Health Information Community has been very active in recommending and testing interoperability specifications

(IS).⁷ Functional electronic health record systems are dependent upon the coordination of these many standards.

Effective use of health care data means that health care personnel, health care organizations, and health care systems have real-time information about the health of individuals and of populations and that they have this information when they need it and in formats they can easily understand. For example, when opening the record of a patient with diabetes, the endocrinologist has immediate access to HbA1c values both as raw data and as a line graph. Moreover, if the patient was hospitalized in another state, the HbA1c values from the out-of-state hospital stay have automatically flowed into the physician's record. In terms of effective use of health care data at the organizational level, the medical group to which the endocrinologist belongs can aggregate the data for its patients with diabetes. In another example, health care data will flow—when authorized—from the hospital to the home health agency or from the rehabilitation center to the durable medical equipment vendor. At the system level, effective use of health care data would allow policy makers, administrators, and analysts to project demand, supply, and distribution of health care personnel. Generally, effective use of health care data also requires that health care personnel, health care organizations, and health care systems can manipulate the data to create knowledge about individuals' and populations' health at any point in time as well as over time.

Within health care organizations, the key health care personnel needing initial training are physicians, nurses, information service technicians, and clerical personnel. Physicians and nurses generate the volume of health care data. Information service technicians could anticipate report structures if they understood secondary uses of health care data in accreditation, regulation, and reimbursement. Training clerical personnel would enhance the accuracy of data entry. This training could be received in many formats including continuing education at conferences, on-site sessions in education departments of health care organizations, online continuing education from universities, and formal classes at community colleges and universities.

According to a recent report, 1000 public health informaticians and 1000 public health executives with informatics leadership training are needed in the health care system by 2010.⁸ A public health informatics officer would be placed in each state health department. The authors of the report recommend both continuing education and formal education.

Nationally, several training and educational opportunities exist, many of which are online. The American Medical Informatics Association (AMIA) is developing a certification for physician clinical informaticians.⁹ Under a grant from the Robert Wood Johnson Foundation, the AMIA is also developing a core content document and a draft set of training requirements for a physician subspecialty in applied clinical informatics.⁹ Additionally, in order to generate sheer numbers, the AMIA has the "10x10" initiative or 10 000 clinical informaticians by the year 2010.¹⁰ Under this initiative, universities, professional medical associations, and the AMIA itself are offering single and multiple courses to

expand the knowledge of electronic health records, health care quality, exchange standards, public health informatics, and bioinformatics. Examples of initiatives include the Centers for Disease Control and Prevention two-year fellowship in public health informatics¹¹ and the Technology Informatics Guiding Education Reform (TIGER) Initiative which aims to make informatics a nursing competence.¹² The establishment of these initiatives represent current efforts to prepare health care personnel to use health care data.

In North Carolina, several options exist to train people to work with health care data. First, North Carolina has a well organized and robust system of Area Health Education Centers (AHECs). A search of the statewide calendar identified an offering entitled "health information on the Internet."¹³ The AHECs also offer online courses. Second, North Carolina has an extensive community college system. This system offers individual courses on health care data or one-year certificates and associate degrees in fields that use and manage health care data. Community college offerings are both face-to-face and online. Finally, campuses of the University of North Carolina system offer individual courses and baccalaureate, masters, and doctoral degrees in health or medical informatics. Some of these offerings are also online.¹⁴ While these examples focus on systems in North Carolina, other states have similar systems.

A 2006 joint report of the American Health Information Management Association and the AMIA identified 2 levels of competence for health personnel, as both health information users and health information specialists.¹⁵ Physicians and nurses are the prime health information users, while other users include health administrators, policy makers, and regulators who make decisions based on the data. Reimbursement specialists at a health insurance company are also health information users and use the data to determine whether to pay a claim. Health information specialists comprise health information managers, applied clinical informaticians, and information technology resource managers. These personnel work to assure the integrity of the technological infrastructure and the quality of the health care data. For example, they work to ensure the security of off-site storage and the accuracy of coded data. The competence required of these health information specialists and health information users depends upon the support available to them

and the independence of their use of the health information.

Competence involves both breadth and depth of knowledge within domains. General domains include biomedical sciences; health care delivery system; information and communication technologies; information management planning; electronic health information systems; data standards; data privacy, security, and confidentiality; data analysis and outcomes (decision support, accreditation, regulation, accountability); and leadership. Minimal educational foundations needed to work with health care data include biomedical sciences, health care delivery systems, information and communication technologies, and regulations and accreditation standards. Health informaticians such as public health informaticians or nurse executive-informaticians would need knowledge across the 4 general domains. Dependent upon the discipline of the health personnel member, additional content areas could include classifications, nomenclatures, terminologies, and taxonomies; epidemiology; health law; organizational behavior and management; and research and statistics.

Within all the domains, the extent of expertise depends upon the role of the health personnel member. For example, a telehealth communications specialist setting up the connection between a local physician at an assisted living center and a tertiary care center needs to know the definitions of the sites in the continuum of care so he or she will know what assisted living centers and tertiary care centers are. On the other hand, an inspector from the North Carolina Division of Health Service Regulation not only needs to know all the sites of care but also all the regulatory requirements for each of those sites. Determining how wide and how deep people need to be trained will require ongoing study and review by professional associations and academic disciplines as electronic health records develop and spread throughout the continuum of care.

Promoting high standards for quality through interoperability and effective use of health care data are compelling reasons to train health care personnel to understand how to use health care data. Current health personnel need training through continuing education, and future health personnel need training in their basic and academic preparation. A sustained effort is needed to achieve the long-term goal of a data-prepared workforce. **NCMJ**

REFERENCES

- 1 Dick RS, Steen EB, eds. *The Computer-Based Patient Record: An Essential Technology for Health Care*. Washington, DC: National Academies Press; 1991.
- 2 Dick RS, Steen EB, Detmer DE, eds. *The Computer-Based Patient Record: An Essential Technology for Health Care*. Revised ed. Washington, DC: National Academies Press; 1997.
- 3 Committee on Data Standards for Patient Safety, Institute of Medicine of the National Academies. *Key Capabilities of an Electronic Health Record System*. Washington, DC: National Academies Press; 2003.
- 4 Committee on Quality of Health Care in America, Institute of Medicine of the National Academies. *To Err is Human: Building a Safer Health System*. Washington, DC: National Academies Press; 2001.
- 5 Committee on Quality of Health Care in America, Institute of Medicine of the National Academies. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academies Press; 2001.
- 6 National Quality Measures Clearinghouse. Agency for Healthcare Research and Quality Web site. <http://www.qualitymeasures.ahrq.gov/about/about.aspx>. Updated March 24, 2008. Accessed March 22, 2008.

- 7 American Health Information Community: Meetings, January 22, 2008. Department of Health and Human Services Web site. <http://www.hhs.gov/healthit/community/meetings/m20080115.html>. Accessed March 22, 2008.
- 8 American Health Information Community: Meetings, January 22, 2008. Population Health and Clinical Care Connections Workgroup of the American Health Information Community. Department of Health and Human Services Web site. <http://www.hhs.gov/healthit/community/meetings/m20080115.html>. Accessed March 22, 2008.
- 9 Frequently asked questions – draft core content document for applied clinical informatics. American Medical Informatics Association Web site. <http://www.amia.org/inside/initiatives/rwj/faq.asp>. Updated January 2, 2008. Accessed January 10, 2008.
- 10 AMIA 10x10: 10,000 trained by 2010. American Medical Informatics Association Web site. <http://www.amia.org/10x10/>. Updated July 25, 2007. Accessed January 8, 2008.
- 11 Public health informatics fellowship program (PHIFP) at CDC. Centers for Disease Control and Prevention Web site. <http://www.cdc.gov/EPO/PHIFP>. Updated November 26, 2007. Accessed March 31, 2008.
- 12 The TIGER initiative: evidence and informatics transforming nursing: 3-year action steps toward a 10-year vision. T.I.G.E.R. Technology Informatics Guiding Education Reform Web site. https://www.tigersummit.com/uploads/TIGERInitiative_Report2007_bw.pdf. Accessed January 8, 2008.
- 13 State-wide calendar of continuing education. North Carolina Area Health Education Centers Web site. <http://db.ncahec.net/ncahec/cecal/calendar.cfm>. Accessed January 11, 2008.
- 14 The University of North Carolina Online. University of North Carolina system Web site. <http://www.online.northcarolina.edu/>. Accessed March 31, 2008.
- 15 Steering Committee of the American Health Information Management Association and the American Medical Informatics Association. *Building the Work Force for Health Information Transformation*. Chicago, IL: American Health Information Management Association; 2006. http://www.ahima.org/emerging_issues/Workforce_web.pdf. Published January 8, 2008. Accessed March 31, 2008.

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.¹

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.²⁻⁵ 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.”²

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

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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.⁶ 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:⁷

- *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.⁸ 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.^a 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.⁹

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.¹⁰

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.¹⁰ 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.¹¹ 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.¹² 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. 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
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a look at:

**Chronic Kidney
Disease**

Into the Future: Public Health Data Needs in a Changing State

Marcus Plescia, MD, MPH; Jeffrey Engel, MD

Population-based health data are the driving forces of good public health. Health surveillance, program evaluation, and research data provide the scientific basis for public health decision making at every level of the public health system, and each of the 3 core functions and 10 essential services of public health rely on these data systems to meet their objectives.¹ Recent information technology advances have improved the scope and quality of public health data sources, many of which are described in this issue of the *North Carolina Medical Journal*. As we move forward, our state faces a number of challenges and opportunities in assuring a continued strong public health data system.

Communities determine much of the North Carolina public health agenda. Community health assessments guide local health departments and community coalitions in identifying emerging health problems and in prioritizing needs. Communities want local data that can be easily understood both by public health professionals and community leaders. A web-based system is currently being developed to provide these data to communities in a highly accessible format that includes comparisons to peer counties.

One of the biggest problems facing smaller communities in developing their priorities is the lack of sufficient numbers from which we can draw conclusions. County-specific data in rural areas can present methodological challenges for certain conditions that are uncommon but highly visible (ie, infant mortality). Rates and indicators developed from statistical analyses can become unstable if the case counts are small. Where there are small denominators, one or two cases can change rates dramatically. One approach that would help with this situation is to allow specific data for small counties to be

aggregated across years or geographic areas that are more meaningful to local citizens and state policymakers. For example, North Carolina's Behavioral Risk Factor Surveillance System (BRFSS) currently provides county-specific data annually by oversampling the state's 20 most populous counties. The survey could be expanded to oversample every county annually, but the

“Public health plays a leadership role in health information exchange initiatives with the private health care sector and could serve as a neutral party in the oversight and governance of North Carolina’s emerging electronic health data systems.”

expense would be considerable. Less expensive solutions include oversampling a few large counties annually and oversampling all others in staggered 4-year cycles. Alternatively, the surveillance system could oversample a larger geographic unit such as a region or legislative district.

Our traditional definition of the local county as the population denominator for rates in public health is outdated. In a state with growing urban populations, generalized county data are often applied to disparate groups; socioeconomic and demographic characteristics vary considerably across urban counties with individual urban neighborhood populations as large as the total

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population of many rural counties. There are often demands for data relevant to different areas; for example planning occurs at the municipal level but also for hospitals and health facilities that serve urban and suburban neighborhoods or target only the medically underserved across multiple boundaries. Data are often available by ZIP codes or other small geographic units. Analyses within and across these arbitrary boundaries are often necessary. Geographic information systems technology presents the opportunity for focused assessments of data using multiple levels of geography to define communities and has been used increasingly to understand the needs of urban and rural areas. Geographic information systems can analyze geographic data that use addresses of locations that are frequently not included in public health datasets. In order for community health assessments to document and meet the needs of underserved and special populations, future data systems must collect address data and define protocols that allow small area analyses while protecting individual privacy. Urban health departments should include such analyses in their assessment and planning efforts.

Just as infectious diseases threatened the health and well-being of communities in the early 20th century, chronic diseases and injuries are now the greatest threat of the 21st.³ With rapid increases in rates of childhood obesity, chronic illness also has become an urgent reality for our children and youth. The majority of chronic diseases are caused by modifiable behavioral risk factors. The North Carolina Behavioral Risk Factor Surveillance System has one of the largest sample sizes in the nation and provides the majority of information on adult health behaviors and local data for the state's most populous counties. Comparable data are needed for children and youth. North Carolina's recent implementation of a Child Health Assessment and Monitoring Program demonstration project provides surveillance data for a wide range of child health and health behavior areas and should be fully funded and expanded. Given the significance of emerging child health issues, more aggressive surveillance systems are warranted. An anonymous school-based system to measure body mass index in randomly-sampled children would provide useful information to better quantify and monitor childhood obesity patterns, guide interventions, and support research in the school-based setting. A child maltreatment surveillance system should be expanded beyond surveillance of only the most severe cases documented by the state medical examiner's office. This would provide better indicators of at-risk children and provide opportunities to track and evaluate preventive interventions.

Racial and ethnic health disparities have emerged as a public health and civil rights priority issue at the national and state level.⁴ African Americans comprise more than 20% of North Carolina's population,⁵ and in the last census decade, the Latino population in North Carolina grew 394%, from 76 726 in 1990 to 378 963 in 2000.⁶ State surveillance of health disparities is primarily limited to birth, death, and behavior survey data. The North Carolina Minority Health Report Card depends solely on these limited datasets. It is well-established that quality of health care services plays a significant role in health disparities.⁴ Self-reported race and ethnicity data are accurate and reproducible,

and a number of states have mandated hospital reporting of these data. Medicaid, Medicare, and the State Children's Health Insurance Program collect race and ethnicity data from enrollees. North Carolina data on health care utilization among racial and ethnic minorities are limited. Only 55% of North Carolina hospital discharge data currently have complete race and ethnicity fields. With the exception of Medicaid and Medicare, North Carolina insurers do not routinely collect data on enrollees' race and ethnicity. Race and ethnicity reporting must be improved among all North Carolina health care providers and the Minority Health Report Card should be expanded to include utilization and quality of care indicators.

Individual medical records are rapidly moving from being paper-based to electronic and are an important emerging source of public health surveillance data. Electronic health records (EHRs) represent an interconnected system of electronic health care information encompassing medical records of care from multiple provider networks. EHRs contain data essential for public health practice such as notifiable diseases and conditions, chronic disease management, and preventive measures such as immunizations. Exchange of health information between the electronic health record and public health systems such as cancer registries, immunization registries, and reportable disease surveillance systems offers the potential for rapid and synchronized reporting of public health events. This has obvious implications for emergency preparedness and response as well as for improving mandated reporting of routine conditions such as sexually transmitted diseases and lead poisoning.

Robust health information exchange between public health entities and electronic health records requires some unified set of policies to guide information managing organizations; currently the federal government is promoting this coordination through regional health information organizations (RHIOs). Confidentiality, use of a limited data set with patient identifiers, and sharing of health data among entities that are normally in competition are the main reasons regional health information organizations need authority granted to them by elected officials. Many states have enacted or are considering legislation to establish separate authority for public-private collaboration and regional health information organization formation.⁷ Public health plays a leadership role in health information exchange initiatives with the private health care sector and could serve as a neutral party in the oversight and governance of North Carolina's emerging electronic health data systems.⁸

In addition to the challenges of governance over health information exchange, an unprecedented need exists to enhance the skills of the public health workforce in the area of informatics and emerging public health data systems. It is estimated that the immediate (2008) demand for skilled public health informaticians is 1000 positions nationwide.⁹ Unique skills are needed to manage public health information systems, to turn complex data into useful information, and to develop the business plans and systems needed to assure financial sustainability. New systems such as the applications of a Public Health Information Network (including disease and laboratory reporting systems, immunization registries, and

health alert systems) will require sophisticated expertise to manage the systems, and those who use these systems at the local level will require informatics training to facilitate usage. Undergraduate, graduate, and certificate training programs in the new science of public health informatics should be established at North Carolina educational institutions.

North Carolina is fortunate to have a strong system for

health surveillance and health assessment at the state and local level. The last decade has brought significant increases in public health data, technology, and emerging public health issues. Federal resources have helped meet a number of these demands, but the state must implement new policies and expand data systems to remain a public health leader as we move into the future. **NCMJ**

REFERENCES

- 1 National public health performance standards program. Centers for Disease Control and Prevention Web site. <http://www.cdc.gov/od/ocphp/nphpsp/EssentialPHServices.htm>. Accessed March 12, 2008.
- 2 Ricketts TC, Savitz LA, Gesler WM, Osborne DN. *Geographic Methods for Health Services Research: A Focus on the Rural-Urban Continuum*. Lanham, MD: University Press of America; 1994.
- 3 Mokdad AH, Marbo JS, Stroup DF, Gerberding JL. Actual causes of death in the United States, 2000. *JAMA*. 2004;291(10):1238-1246.
- 4 Smedley BD, Stith AY, Nelson AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. Washington, DC: National Academies Press; 2003.
- 5 US Census Bureau. *Statistical Abstract of the United States: 2000*. Washington, DC: US Census Bureau; 2000.
- 6 Mapping census 2000: The geography of US diversity. Hispanic or Latino origin: all races. US Census Bureau Web site. http://www.census.gov/population/www/cen2000/dt_atlas.html. Updated December 7, 2001. Accessed March 12, 2008.
- 7 A Vision of health care from and framework for the state alliance for e-health. National Governor's Association Web site. www.nga.org. Updated January 25, 2007. Accessed November 20, 2007.
- 8 Hill M, Hodgkin R, Turner S, et al. Local public health departments: enablers of health information exchange. *JHIM*. 2007;21(3):25-30.
- 9 Friedman CP. Building the workforce: An imperative for public health informatics. Keynote address at: 5th Annual Public Health Information Network Conference; August 27, 2007; Atlanta, GA.

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Cancer Surveillance and Its Use to Reduce Cancer Burden in North Carolina

Karen L. Knight, MS; Paul A. Buescher, PhD; and Walter L. Shepherd, MA

The North Carolina Central Cancer Registry (CCR) is the state agency that collects data and produces statistics on the burden of cancer among North Carolinians. The CCR works closely with the North Carolina Comprehensive Cancer Control Program to plan and evaluate programs that address prevention, early detection, treatment, and survival. This article describes the history and purpose of the CCR, mechanisms of cancer reporting and processing, and uses of cancer data in cancer surveillance, program planning and evaluation, and research.

History and Operation of the North Carolina Central Cancer Registry

The North Carolina General Assembly established cancer as a reportable disease in 1945 for the purpose of population-based cancer surveillance. The North Carolina Central Cancer Registry was formed after the General Assembly provided funding in 1985 to collect information on the incidence of cancer among North Carolina residents to compile relevant statistics and to support “public health work.”¹

Funding is also provided through a cooperative agreement with the Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries (NPCR) which funds central cancer registries in 45 states, the District of Columbia, and 3 United States territories.

The CCR is a unit of the State Center for Health Statistics (SCHS) in the Chronic Disease and Injury Section of the North Carolina Division of Public Health. (Paul Buescher, PhD, director of the SCHS, reports in this issue on other public health surveillance databases.) The CCR works closely with other units in the SCHS such as the Vital Statistics Unit to monitor mortality trends and the Survey Unit to monitor

screening and prevention behaviors. The addition of prevention, screening, and mortality data to incidence information (which includes stage at diagnosis and treatment) provides a more complete assessment of cancer burden. For instance, a shift to an earlier stage at diagnosis for a highly treatable cancer, such as colon cancer, should correspond with a declining mortality rate in the following years.

“The Central Cancer Registry is structured to ensure complete, timely, and high quality production of cancer incidence data for use in cancer control and research.”

The CCR is structured to ensure complete, timely, and high quality production of cancer incidence data for use in cancer control and research. Standards for reporting are set by the North American Association of Central Cancer Registries (NAACCR), of which the CCR is a member. The CCR also collaborates with other standard-setting organizations including the NPCR, the National Cancer Institute’s Surveillance Epidemiology and End Results (SEER) program, the American College of Surgeons Commission on Cancer, and the American Cancer Society.

Consistent standards across central cancer registries make meaningful national statistics and comparisons possible across

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states and regions. Cancer control and research programs can trust the sources of these data when measuring outcomes in different populations. To that end, NAACCR provides evaluation for certification of central cancer registries, and the CCR submits data each December for this purpose. The CCR has achieved NAACCR certification for every diagnosis year since 1997. The cooperative agreement with CDC through the NPCR also sets additional guidance and goals for the CCR, with the CCR submitting data for evaluation and incorporation into United States statistics each January.

Completeness of Reporting

Complete ascertainment of cancer is the first priority of the CCR. This ensures accurate detection of disparities in incidence. The legislation that established the registry requires that all health care facilities that diagnose or treat cancer report to the CCR within 6 months of diagnosis. Reporting sources include hospitals, freestanding surgery and radiation centers, physicians' offices, pathology laboratories, nursing homes, and hospice agencies. Reportable conditions include all malignancies except *in situ* cancers of the cervix, and includes benign brain and central nervous system tumors. Because the CCR is a public health entity, reporting to the CCR is exempt from the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

Information collected about each case includes demographics of the patient at time of diagnosis including name, Social Security Number, race, ethnicity,^a date of birth, and address, as well as information about the diagnosis including cancer site, histology, stage and grade, and first course of treatment. Over 90% of the data are reported via the CCR's secure Web-based database. CCR staff members assist small facilities and physicians' offices with reporting.

Changes in Cancer Reporting

Ten years ago almost all cancers were diagnosed and treated in hospitals, the primary source of cancer reporting. As more, large physician practices and freestanding chemotherapy and radiology centers have opened, cancers are being diagnosed and treated more frequently outside the hospital setting. Cancers such as prostate, melanoma, leukemias, and lymphomas are most often diagnosed at physicians' offices. Cancers of other sites such as breast and colon are often treated at small facilities with chemotherapy or radiation, without the patient being admitted to a hospital. To ensure that diagnosis and first course of treatment data are completely ascertained, CCR resources have been devoted to recruiting physicians to report cases although many of these small facilities do not have the trained staff or resources to adequately report the needed information.

Electronic reporting of cancer is necessary in order to make use of the electronic medical record and to promote efficient

use of scarce resources. For example, electronic pathology reports are linked with the current database to identify cases not previously reported. CCR staff then use the information provided in the pathology report to partially abstract the case and contact the ordering physician to complete the case information. This process not only increases immediate reporting and identifies facilities that may be underreporting, but also identifies physicians' offices for recruitment and reduces the information needed from those offices.

In 2007 the General Assembly passed legislation to fund a Cancer Research Fund to be administered at the University of North Carolina (UNC) at Chapel Hill.² The administrators of the fund have been consulting with the CCR and Comprehensive Cancer Control Program for ways to support these programs as they relate to cancer research. Identified areas for partnership with the registry include enhancing cancer treatment data and enhancing geographic information systems to study patterns of care.

Accuracy of CCR Data

Data quality standards include accuracy and consistency of case abstraction and occurrence of few missing data items. This ensures that the data are appropriate for analysis and reporting. When a case is reported to the CCR, the data fields must pass a standard set of data requirements, and 90% are reviewed by certified tumor registrars (CTRs).³ If a case for the same person has been reported previously by other facilities, CTRs determine if the case is a subsequent "primary" diagnosis or a "multiple primary." If the case has been reported previously by other facilities, the best information is selected from each report and a consolidated record is maintained for analytic use. The rules for consolidating records are standardized by NAACCR. Staff conduct routine quality control audits to identify common errors and follow up to provide training for reporting facilities.

Professional certification is provided by the National Cancer Registrars Association, and reporting facilities are strongly encouraged to hire CTRs for data collection and reporting. There is a nationwide shortage of CTRs, making recruiting difficult for both reporting facilities and for the CCR.⁴ Recruiting new people to the rewarding work of cancer registration is necessary to ensure high quality cancer data.

Cancer Prevention and Control Activities and Data Use in North Carolina

The first major steps taken to address cancer prevention and control in North Carolina began in the mid-1940s through the joint efforts of the North Carolina Medical Society and the American Cancer Society, and resulted in the passage in 1945 of House Bill 786 which authorized the establishment of the Division of Cancer Control as part of the State Board of Health.⁵ In 1957 the first Governor's Cancer Commission was

a The only ethnicity captured is Hispanic.

created and continued to exist in some form for the next 2 decades. Several ad hoc study committees followed. Finally in 1992, former Senator George Daniel and the late Representative Nick Jeralds helped to create a study commission that resulted in 1993 legislation creating the North Carolina Advisory Committee on Cancer Coordination and Control.⁶ The Advisory Committee has continued its work since then. Two 5-year State Cancer Control Plans have been developed and disseminated (1996-2001, 2001-2006). A third 5-year plan was put on hold while transitioning to a new, continually evolving “living cancer plan,” which began to be distributed for public review and comment in the fall of 2007. The current plan can be found on the cancer control Web site at <http://www.nccanceradvisory.com/cancerplan.shtml>.

The purpose of the State Cancer Control Plan is to examine the burden of cancer in North Carolina and develop a set of goals and objectives. The goals and objectives are associated with strategies for adoption and implementation by public and private organizations, thus creating a blueprint for action.

In addition to mortality and Behavioral Risk Factor Surveillance System (BRFSS) data compiled by the State Center for Health Statistics, the Advisory Committee relies heavily on the work of the CCR to determine the extent of cancer risk and burden, to provide baseline measures for establishment of targets, and to provide the basis for measurement of progress towards meeting the goals. The following describe some of the ways cancer data have been used along the continuum of cancer control:

Prevalence Estimates. The CCR has partnered with UNC to statistically model the state’s cancer prevalence. This will be the first time cancer prevalence statistics will be available for North Carolina.

Prevention. Cancer incidence data can be used to target prevention educational messages to subpopulations. Several years ago, the CCR was involved in strategic planning for tobacco control by helping to target populations. In 2007 the CCR worked with the Advisory Committee’s Melanoma Task Force to identify areas in the state with high melanoma incidence at younger ages to support efforts at addressing tanning bed use.

Early Detection. Each year the CCR links the incidence data with data from the state’s Breast and Cervical Cancer Control Program to identify missed cases and to determine the stage at diagnosis for cases detected through the program.

Treatment. The CCR has worked with researchers from Wake Forest University to link both breast and colorectal cancer data with Medicaid paid claims data to evaluate access and quality of care across the state. Currently, the CDC’s Breast and Prostate Patterns of Care study is being conducted by 8 states, including North Carolina, to better understand disparities in cancer treatment and potential barriers to treatment.

Survivorship. Several research studies using CCR data have examined quality of life issues among cancer survivors. Contacting patients can be difficult for these studies since physician notification is required and often physician information is not reported or the physician at time of diagnosis is no longer relevant. New standards in reporting physician information will be in effect for 2008 diagnoses, remedying the first issue.

This year, the CDC negotiated an agreement with the Social Security Death Index and the National Death Index to make these data available to central cancer registries for follow-up and calculation of survival statistics. Survival statistics currently in widespread use are produced by the National Cancer Institute’s SEER program which follows all patients until death. Although the CCR links incidence data with North Carolina death records each year, many deaths are missed because patients move and die out of state. By linking incidence data with these additional data resources, the CCR will be able to produce its own survival statistics for the first time, which will be a helpful tool for physicians, patients, and researchers.

Other Uses of Cancer Data in North Carolina

More broadly, data use activities include investigating patterns in cancer incidence and mortality across subgroups of the population, responding to citizens’ concerns regarding cancer in their communities, supporting research addressing the causes and outcomes of cancer, and supporting the planning and evaluation of prevention, early detection, and survivorship studies in cancer control. Examples of recent projects are provided to illustrate the variety of ways cancer incidence data are used to address the cancer burden in North Carolina.

Routine Surveillance. Each year the CCR examines the data across the state, evaluating trends over time, racial and geographic disparities, and patterns in stage at diagnosis. The CCR also produces annual reports of cancer incidence statistics and provides more detailed statistics upon request. The latest cancer incidence statistics by race, gender, and county are available on the State Center for Health Statistics Web site at <http://www.schs.state.nc.us/SCHS/CCR/>. Refer to the section “Availability of Data” in this article for information on how to obtain additional data.

Response to the Public. The CCR responds to citizens’ concerns about cancer in their communities by providing opportunities for education about the causes of cancer, how to reduce risk factors, and cancer screening. The CCR also works with the Occupational and Environmental Epidemiology Branch in the Division of Public Health to investigate possible links between exposures in the community and incidence of cancer. However, because there is often a long latency period between a carcinogenic exposure and a cancer diagnosis, it can be difficult to find such associations.

Support of Cancer Research. The CCR works with researchers across the state and the nation to study the causes and outcomes of cancer. There are currently 32 studies in which the CCR is directly involved or releases data for epidemiologic research. Many studies ask the CCR to link incidence data to external data sources. Examples include linkages with Medicaid data in order to look at differences in treatment, as well as linkages with cohorts of employees to study links between occupational exposures and cancer. The Agricultural Health Study, funded by the National Cancer Institute, the National Institute of Environmental Health Sciences, and the US Environmental Protection Agency, has linked information with the registry data in North Carolina and Iowa for the past 15 years to study the effects of a farmer's diet, physical activity, and exposure to pesticides on the incidence of cancer.

Researchers studying the causes of cancer and treatment choices of cancer patients often need to contact patients soon after diagnosis in order to enroll them into studies. Through a partnership with the University of North Carolina's Lineberger Cancer Center's Rapid Case Ascertainment (RCA) Core, the CCR is one of a few state central registries that offer this service for epidemiologic research to research institutions across the state. These university staff members represent the CCR and obtain pathology reports from hospitals within a few weeks of diagnosis. Current and recent studies using RCA include the role of diet and genetics in racial disparities in prostate cancer, risk factors and access to care for colorectal cancer, level of screening mammography in communities, risk factors for ovarian cancer, and risk factors and quality of care for meningioma, a common brain tumor.

Availability of Data

Cancer incidence data by gender, race, and county are provided in reports on the State Center for Health Statistics Web site at <http://www.schs.state.nc.us/SCHS/CCR/>. Additional aggregate statistics are available by request. A version of cancer incidence statistics that can be queried online is expected in 2008. CCR staff members consult with requestors to assure the best information is

provided to address the research or program questions. Some aggregate statistics, in combination with information from other sources, may provide enough information to identify a patient. To mitigate the potential identification of individuals, aggregate counts are released only when there are 5 or more cases per cell of a table. If the number of cases is fewer than 5, the director of the State Center for Health Statistics must approve the data release. If patients are to be contacted for epidemiologic research, the Advisory Committee for Cancer Coordination and Control is consulted for review of the request.

Requests for aggregate statistics not available on the Web site can be obtained by contacting the statistical staff at the CCR at 919-715-7289.

Future of Cancer Surveillance in North Carolina

High quality population-based cancer surveillance data are important for understanding the causes of cancer, detecting demographic and geographic differentials in cancer incidence, and tracking changes in cancer treatment and health care utilization. Projects slated for the next few years to improve our cancer surveillance data include an increase in electronic reporting from pathology laboratories and physician offices, survival analysis, and increased analytic capacity for linkages with external data sources for research. In 2007 the CCR migrated its database management system to California's system, which has a greater capacity to support these projects. Increased electronic reporting in the future will allow the CCR to more efficiently provide data for studies that require patient contact soon after diagnosis and will also increase the ascertainment of cancer cases for cancer control. **NCMJ**

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REFERENCES

- 1 NC Legislation, Chapter 130A-208. North Carolina General Assembly Web site. <http://www.ncleg.net>. Accessed October 31, 2007.
- 2 NC Legislation, Chapter 116-291. North Carolina General Assembly Web site www.ncleg.net. Accessed March 31, 2008.
- 3 National Cancer Registrars Association (NCRA). NCRA Web site. <http://www.ncra-usa.org>. Accessed March 31, 2008.
- 4 UCSF Center for the Health Professions; 2006. Chapman SA, Lindler V, McClory V, Nielsen C, Dyer W. Frontline workers in cancer data management: workforce analysis study of the cancer registry field, executive summary. San Francisco, CA. NCRA Web site. <http://www.ncra-usa.org/members>. Accessed March 31, 2008.
- 5 McPherson H. *Second North Carolina History of the American Cancer Society*. Raleigh, NC: The North Carolina Division, American Cancer Society, Inc.; 1976.
- 6 Wright JC, Greene LP, Aldrich TE. Cancer control legislation and policy milestones in North Carolina. *NC Med J*. 2001; 62(5):252-255.

Comment from The Duke Endowment: The Importance of Data for Grant Making

M. Tina Markanda, FACHE, MBA, MSPH

The mission of The Duke Endowment is to improve lives and communities in the Carolinas. It seeks to achieve this through efforts dedicated to supporting higher education, health care, rural Methodist churches, and children's services. In support of this mission, the Endowment seeks to make an impact that can be demonstrated by quantitative, measurable outcomes for funded projects.

In 2002 The Duke Endowment began a unique collaboration to identify and target "high risk, high need" communities with regard to access to primary care for children with key child health problems. The goal in identifying these communities was to target them for project funding for increasing access to primary care services for children. It is well-documented that primary care services for children are critical to child development. Further, research indicates that children who are poor, minority, and uninsured often do not receive appropriate primary care services.

The Duke Endowment partnered with the Cecil G. Sheps Center for Health Services Research at the University of North Carolina (Sheps Center) and the Center for Health Services and Policy Research (CHSPR) at the University of South Carolina in conjunction with the South Carolina Office of Research and Statistics (ORS). The Sheps Center and CHSPR dedicated significant effort to a multifaceted analytical evaluation to identify high risk, high need communities in each state. The process required accessing and evaluating data from various existing databases and data systems (eg, hospital discharge data, Medicaid claims data, census data, State Health Plan data, North Carolina State Center for Health Statistics data, North Carolina Child Advocacy Institute data, Geographic Information Systems data) to identify communities where ambulatory care sensitive condition rates indicated the highest health risks for children. Ambulatory care sensitive conditions are medical conditions such as asthma and pneumonia that can be managed in an outpatient setting, thus avoiding the need for emergent care in the emergency department or inpatient hospital. Unnecessary emergent or inpatient care can adversely impact

both short-term and long-term child well-being. Therefore, managing these conditions can lead to improved child well-being and reduce health care costs. In addition to monitoring variance of rates at this macro level, individual grant recipients also monitored data related to hospital utilization, emergency department services, and other appropriate project-centric indicators at a local level.

This identification of high risk, high need communities allowed the Endowment to focus grant funds on specific communities where it would be possible to apply collaborative interventions and monitor their impacts. Those identified communities were invited to apply for grants to improve access to primary care for children. Of the 8 communities identified, 6 were selected to participate in the program.

Throughout the course of the grant, project leaders have continuously monitored project-specific indicators related to program implementation. Simultaneously, they have monitored variance in county and state ambulatory care sensitive condition rates reported by the Sheps Center, CHSPR, and ORS. As a result, the grantees have been able to proactively test implementation strategies and monitor impacts using ambulatory care sensitive condition data as a gauge. If implementation does not impact outcomes, then grantees can modify strategies as needed. Without this data, monitoring impact would be difficult.

Using this approach of demonstrable impact has been very effective and will serve as a model for future initiatives. As The Duke Endowment continues to focus even more strongly on impact-related grants, partnerships with organizations that can analyze local- and state-level data such as the Sheps Center and CHSPR will continue to be essential from two perspectives. First, grant funds can be targeted to specific communities facing particular health-related challenges and those communities with the greatest needs. Second, both grantees and The Duke Endowment will be able to continuously monitor progress and thus evaluate the impact of interventions to improve the health of citizens and communities in North Carolina and South Carolina.

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Readers' Forum

To the Editor:

As published in the journal *Annals of Internal Medicine*, the American College of Physicians (ACP) and the American Pain Society (APS) convened a multidisciplinary panel of experts to perform a systematic evidence review and develop guidelines in the evaluation and management of low back pain. Spinal manipulation was recommended as the only proven non-pharmacologic, non-invasive means of treatment for acute low back pain. Additionally, spinal manipulation was recommended in the care of sub-acute and chronic low back pain.¹

In the United States, it has been estimated that direct health care costs attributable to low back pain are in excess of \$26 billion per year.² Indirect costs including associated disability, administrative activities, and lost productivity have been found to generate a societal financial burden of 7 to 8 times greater than direct costs.^{3,4} Stewart et al⁵ reported \$61.2 billion in losses due to lost productivity related to spinal complaints during a one-year period.

The goal of evidence-based protocols is to provide clinicians with practice guidelines based on the best evidence available; to make recommendations based on that evidence; to inform clinicians of when there is no evidence; and, finally, to help them deliver the best health care possible.⁶ The ACP/APS spinal manipulation guideline reflects an opportunity to improve health care outcomes through medical and chiropractic inter-professional patient comanagement. The implementation of this guideline may necessitate a paradigm shift in decision making that will cause physicians to insert chiropractic referrals into their algorithms of care.

Medical practitioners should consider the training necessary

to attain a chiropractic doctorate. In North Carolina, chiropractors must achieve a baccalaureate degree, complete chiropractic school, and pass national board and licensing examinations. In the United States, 16 accredited chiropractic university programs require a minimum of 4200-5500 hours of combined core science and clinical coursework. Some chiropractic schools are affiliated with medical hospitals, providing chiropractic interns clinical rotations and invaluable clinical experience.^{7,8}

Some chiropractors undergo additional postgraduate training to attain advanced subspecialty board certification. Chiropractic colleges provide postdoctoral training in orthopedics, neurology, sports injuries, nutrition, rehabilitation, radiology, industrial consulting, family practice, forensics, pediatrics, and applied chiropractic sciences.⁹

It is important to recognize that medical schools now provide chiropractic course electives and clinical rotations in chiropractic offices. Major medical universities such as the Duke University School of Medicine, the University of North Carolina at Chapel Hill School of Medicine, and the Albert Einstein College of Medicine actively participate in these programs.¹⁰

In light of the economic impact and morbidity associated with low back pain, it is imperative for physicians to consider the evidence-based guidelines put forth by the American College of Physicians and the American Pain Society. As substantiated by available data, medical and chiropractic interdisciplinary collegiality is now reasonable, appropriate, and in the best interest of patients and our society.

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REFERENCES

- 1 Chou R, Qaseem A, Snow V, et al. Diagnosis and treatment of low back pain: a joint clinical practice guideline from the American College of Physicians and the American Pain Society. *Ann Intern Med.* 2007;147(7):478-491.
- 2 Luo X, Pietrobon R, Sun SX, Liu GG, Hey L. Estimates and patterns of direct health care expenditures among individuals with back pain in the United States. *Spine.* 2004;29(1):79-86.
- 3 Walker BF, Muller R, Grant WD. Low back in Australian adults: the economic burden. *Asia Pac J Public Health.* 2003;15(2):79-87.
- 4 Maniadakis N, Gray A. The economic burden of back pain in the UK. *Pain.* 2000;84(1):95-103.
- 5 Stewart W, Ricci J, Chee E, Morganstein D, Lipton R. Lost productive time and cost due to common pain conditions in the US workforce. *JAMA.* 2003;290(18):2443-2454.
- 6 Clinical Efficacy Assessment Project. American College of Physicians Web site. http://www.acponline.org/clinical_information/guidelines/process/ceap/. Accessed January 10, 2008.
- 7 Dunn AS. A chiropractic internship program in the Department of Veterans Affairs Health Care System. *The Journal of Chiropractic Education.* 2005;19(2):92-96.
- 8 Hospital rotation program. Texas Chiropractic College Web site. <http://www.txchiro.edu/students/rotation.asp>. Accessed January 10, 2008.
- 9 US Department of Labor, Bureau of Labor Statistics. *Occupational Outlook Handbook.* 2006-2007 ed. Washington, DC: US Dept of Labor; 2007.
- 10 Clinically-oriented training opportunities. Consortium of Academic Health Centers for Integrative Medicine Web site. <http://www.imconsortium.org/cahcm/opportunities/trainingopportunities.html#duke>. Accessed January 10, 2008.

Spotlight on the Safety Net

*A Community Collaboration
Kimberly M. Alexander-Bratcher, MPH*

Safety Net Survey and Web Site www.nhealthcarehelp.org

A new and essential safety net resource for North Carolina will be launched this spring. The Web site, www.nhealthcarehelp.org, will provide a unified resource for locating safety net services throughout the state. As such, it will be an invaluable tool for improving access to health care services for the millions of uninsured and underserved people in North Carolina. Health care providers, patient advocates, and consumers will be able to search the database-driven website by service type, county, insurance status, and patient eligibility criteria.

Evolution of the Safety Net Web site

In 2004 with funding from the Kate B. Reynolds Charitable Trust, the North Carolina Institute of Medicine (NC IOM) convened the Healthcare Safety Net Task Force to examine safety net services in North Carolina. The Task Force developed recommendations to expand and strengthen the service capacity of safety net providers. A group known as the Safety Net Advisory Council (SNAC) grew out of the Task Force. With support from the Blue Cross and Blue Shield of North Carolina Foundation, the SNAC developed a web-based survey to collect and house information from the state's safety net organizations.

Through the survey, safety net organizations provided contact information, physical location, services offered, hours of operation, eligibility criteria (if any), forms of payment (eg insurance, sliding fee scale), and whether they were accepting new patients. Additional data were collected on the number of patients, patient visits, and the percentage of uninsured patients. To date more than 200 health care safety net organizations have participated in the survey. Safety net organizations can enter or edit their information at any time on the Web site (www.nhealthcarehelp.org). This spring, information gathered through the survey will be made available to the public at www.nhealthcarehelp.org. Another benefit of having access to these data is that they will provide an estimate of the number of uninsured individuals in North Carolina who are accessing health care through safety net organizations and help identify areas within the state with the most unmet need.

The Safety Net Web site is the result of the combined dedication of health care safety net organizations, foundations, and many other groups to improve the health of North Carolinians. To learn more about the Web site, visit www.nhealthcarehelp.org.

Examples of Safety Net Organizations in North Carolina

Community Care of North Carolina practices	Hospital outpatient clinics and centers
Federally certified rural health clinics	Project Access programs
Federally qualified community health centers	Public health departments
Federally qualified migrant health centers	Free clinics
School-based and school-linked health centers	State funded rural health centers

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