Enhance Data to Support Prevention Efforts

Throughout its deliberations, the Task Force focused on identifying evidence-based practices that would address North Carolina's most pressing health needs most effectively. Data plays a critical role in this process both by helping to identifying North Carolina's most immediate health concerns and the health risks contributing to these problems, as well as by measuring the progress—or lack thereof—in improving the health of the state's population. North Carolina needs information both about the prevalence of certain types of diseases or health conditions (e.g. data on specific types of cancer), as well as the number of people engaging in certain risky health behaviors. While North Carolina has many different data systems that collect specific health data, these data systems are not well-integrated. They often operate in silos, making it difficult to capture a complete understanding of the health problems facing the state. Additionally, there are significant gaps in the data that are collected.

Data plays a critical role in this process both by helping to identifying North Carolina's most immediate health concerns and the health risks contributing to these problems, as well as by measuring the progress—or lack thereof—in improving the health of the state's population.

The state and community groups also need information about evidence-based interventions which have been shown to be effective in addressing certain health problems. However, evidence-based interventions do not exist for every health problem. In these instances, community groups need access to best or promising practices which they can employ or modify to address their specific health concern. More needs to be done to disseminate both evidence-based strategies as well as those best or promising practices that have been identified in North Carolina. Development of a clearinghouse of options well-suited to North Carolina communities would make this information-gathering more efficient.

Health Data

Currently, there are many different state agencies that collect or have access to data that can help monitor one or more aspects of the health of the state's population. For example, the State Center for Health Statistics within the North Carolina Division of Public Health (DPH) collects information on pregnancies, births, and deaths; health risks for adults and pregnant women; and some child health data. It also receives hospital discharge data, emergency department data, poison center data, and ambulatory surgery data. The Epidemiology Section of DPH collects information on HIV and other communicable diseases (e.g. sexually transmitted diseases (STDs)). The North Carolina Department of Public Instruction collects information on youth risk behaviors and broader school health data. The North Carolina Division of Medical Assistance has the claims data for Medicaid recipients, including utilization and diagnoses information. There are also various registries, including the cancer and birth defects registries, which collect data on the number of people affected by cancer or birth defects and the type of cancer or birth defect. The State Center for Health Statistics has primary responsibility for either collecting the data or for linking different health data systems across the state. However, the State Center for Health Statistics does not currently have access to all the different health-related data in the state. Further, there are gaps in the data that are currently collected.

A strong data infrastructure system is vital to ensuring that policymakers have access to the most current information on the state of the population's health.[a] During the Task Force's deliberations, specific data gaps were identified in the data collected to identify youth risk behaviors, school health, environmental health hazards, and the prevalence of certain types of cancers.

Youth Risk Behavior Survey and School Health Profiles

Health data on adolescents in school and the school environment typically come from two major data sources: the Youth Risk Behavior Survey (YRBS) collects data on student risk behavior and the School Health Profiles Survey collects data on the school environment from surveys of school administrators and health educators. Both surveys were designed by the Centers for Disease Control and Prevention (CDC) in order to help schools plan and implement effective health strategies, policies, and programs that meet the needs of their community in order to improve health outcomes.[1]

A strong data infrastructure system is vital to ensuring that policymakers have access to the most current information on the state of the population's health.

YRBS is a biannual survey of middle and high school students sponsored by the CDC to collect data on health risk behaviors for adolescents. The priority health behaviors monitored include tobacco use, unhealthy dietary behaviors, physical inactivity, alcohol and other drug use, mental health behaviors, sexual behaviors that can lead to unintended pregnancy and sexually transmitted diseases, and risk behaviors for unintentional injury and violence. These behaviors often begin in early adolescence and can have immediate health-impairing effects, as well as effects that impact health into adulthood. The YRBS also tracks the prevalence of asthma, obesity, and the general health status of adolescents; therefore, the results have widespread applications.[1] The YRBS is the only data source for most of this information at the state level.

To obtain meaningful data for the state, students are selected randomly within schools that have been identified by the CDC to participate in the survey.[b,2] Local Education Agencies (LEAs) and schools have historically had the option of refusing to participate if selected. If many schools refuse to participate, the validity of statewide estimates is threatened. Reasons for declining to participate include the loss of instructional time and an increasing number of survey requests.[c]

The School Health Profiles Survey collects data from principals and lead health teachers. The survey covers a wide range of school-level health policies, including the health education curriculum, tobacco policies, and violence prevention programs. Again, schools often refuse to participate. As a result, the statewide estimates are being based on a more selective sample of LEAs from across the state.

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[a] The March/April 2008 issue of the *North Carolina Medical Journal* outlines the importance of various data systems in shaping health policy. Available online at http://ncmedicaljournal.org

[b] The survey design involves stratification of schools, randomly selecting schools within each stratum, and then random selection of students within the selected schools.

[c] Langer S. Physical Activity and Nutrition Branch, Division of Public Health, North Carolina Department of Health and Human Services. Written (email) communication. July 30, 2009.

The results from this more limited sample of schools may, or may not, reflect the experience of the state as a whole. A critical connection between these two data systems is the ability to link school-level policies with student risk behavior. In order to best inform state-level policy, the North Carolina State Board of Education needs to have comprehensive and complete information on the linkages between local policy and local behavior and outcomes.

Environmental Risks

As noted in Chapter 7, environmental hazards can cause significant health risks. Yet data on some specific environmental hazards—particularly interior environmental hazards in buildings including schools and homes—are limited. Without such data, it is difficult to ascertain the risks of certain diseases and conditions resulting from these factors. For example, the prevalence of lead paint in homes is usually estimated based on the age of the home. County-level data on the risk for radon are based on the geology of the county; however, risk will vary depending on the particulars of home construction. Collecting data on environmental risk more systematically—from households via the Behavioral Risk Factors Surveillance System (BRFSS) and from schools via the Profiles survey—will allow better prevalence estimates and more targeted interventions aimed at mitigating these risks. The CDC has already developed environmental risk questions for both surveys; North Carolina has never chosen to use the BRFSS optional questions on environmental risks and the Profiles survey part II (which has the questions on environmental risks) is not always used. By periodically collecting these data, policymakers would have more complete information on the environmental hazards faced by North Carolinians.

Central Cancer Registry

The North Carolina Central Cancer Registry (CCR), housed in the State Center for Health Statistics, is charged with collecting and analyzing data on all North Carolina cancer diagnoses. All providers licensed in North Carolina are legally required to report all new cancer diagnoses to the CCR;[d] reported data include information on the tumor itself, treatment, and patient demographics. Registry data are combined with other data sources (such as geographic data on environmental hazards and death certificates) for various purposes including identifying emerging "cancer clusters," reporting burden of disease, and informing health planning. Despite the legal requirement to report data on cancer diagnoses, there are some barriers to timely, complete reporting by providers. For example, there are some challenges with collecting data from urologist offices and laboratories, which often provide the information necessary to diagnose prostate cancer.[3] Incomplete data can diminish the utility of the CCR to inform the cancer prevention and treatment strategies of the state.

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[d] NCGS §130A-209.

Based on these gaps in current data collection, the Task Force recommends:

Recommendation 13.1: Enhance Existing Data Systems

a) North Carolina agencies should enhance specific existing data collection systems to ensure that the state has adequate data for health and risk assessment including:

  1) The North Carolina State Board of Education (SBE) should support and promote the participation of Local Education Agencies (LEAs) in the Youth Risk Behavior Survey (YRBS) and the School Health Profiles Survey (Profiles). As part of this effort, the SBE should:

    i) Identify strategies to improve participation in the YRBS and the Profiles survey. Options should include, but not be limited to, training for superintendents and local school boards, changing the time of year the survey is administered, financial incentives, giving priority for grant funds to schools that participate, a legislative mandate, and convening a clearinghouse to reduce duplicative surveys of youth risk behaviors and other school health surveys.

    ii) Expect any LEA selected by the Centers for Disease Control and Prevention to participate in the YRBS and/or the Profiles survey to implement both surveys in their entirety unless a waiver to not participate is requested by the LEA and granted by the SBE.

    iii) Develop policies addressing the ability of schools, parents, and students to opt out of the YRBS and Profiles surveys, over-sampling for district-level data, and any additional data that needs to be added to the surveys.

  2) The North Carolina Department of Health and Human Services and the North Carolina Department of Public Instruction should periodically collect environmental risk data using the Behavioral Risk Factor Surveillance System and Profiles survey, respectively.

b) The North Carolina General Assembly should appropriate $165,000 in recurring funds beginning in SFY 2011 to the North Carolina Cancer Registry to improve data collection and compliance with required reporting.

Clearinghouse of Evidence-Based Programs and Practices

When possible, the Task Force identified evidence-based programs, policies, practices, and clinical interventions that have been shown to be effective in preventing or reducing certain health risks. Furthermore, the Task Force recommends that all public and private funders place a priority on funding evidence-based strategies (See Recommendation 10.1.).

There are numerous organizations that have been charged with, or have taken on, the responsibility of reviewing and evaluating interventions to determine whether the interventions have been shown to be effective. (See Appendix B.)[f] Generally, these organizations focus on specific health risks (e.g. violence or substance abuse prevention) or on different settings (e.g. in primary care offices or schools). For example, the US Preventive Services Task Force is charged by Congress with reviewing the effectiveness of screening, counseling, and preventive medications that should be routinely offered to large groups of the population in the primary care setting. The CDC's US Task Force on Community Preventive Services is charged with identifying evidence-based, community-based prevention initiatives that cover a variety of health risks. In addition, the Center for the Study of Prevention of Violence at the University of Colorado at Boulder examines programs aimed at decreasing violence, and the Center for Excellence in Training and Research Translation, managed by the University of North Carolina Center for Health Promotion and Disease Prevention, includes information, toolkits, and case studies on interventions targeting obesity.

As noted throughout this Prevention Action Plan, priority should be given to funding evidence-based strategies, including clinical interventions, school-based curricula, programs, and policies which have been shown to be effective in reducing health risks and improving population health. Further, organizations that are implementing these interventions should be provided the technical assistance and oversight to ensure that evidence-based programs are implemented with fidelity. To the extent possible, the programs implemented should be those which produce positive outcomes across a variety of measures, rather than focusing on one particular outcome or health behavior.

Community-based programs funded by the state or local foundations on a pilot basis that have not been subject to evaluation should be evaluated and the results disseminated.

While many evidence-based interventions exist, there are not evidence-based strategies to address every type of health risk or health problem for every demographic. Additionally, implementing evidence-based strategies with fidelity is generally more difficult and more costly than other interventions. Although the use of evidence-based strategies should be a priority, in cases where this is not possible—due to lack of evidence-based strategies, funding limitations, or other restraints—community-based interventions are often used. North Carolina's state and private philanthropic organizations have funded many community-based interventions. Some of these community-based interventions show promising results.

There are numerous web-based resources for identifying evidence-based programs (See Appendix B.), however, there are no efforts to review and evaluate these North Carolina specific community-based interventions. Community-based programs funded by the state or local foundations on a pilot basis that have not been subject to evaluation should be evaluated and the results disseminated. This would help to incubate further innovation, identify barriers to effective implementation, and disseminate lessons learned so that subsequent efforts can be improved. When programs are shown to be ineffective, sharing such

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[f] Appendix B includes a list of organizations that have compiled data evaluating the strength of the evidence for different interventions aimed at reducing certain health risks or problems.

information will help ensure they are not duplicated in other communities. Community-based interventions that are shown to be effective should be submitted to national repositories for evidence-based practices so that they can be disseminated nationally. Community-based programs that are not evidence-based are being implemented across the state for a variety of reasons, having a system for evaluating these programs and disseminating the results will help improve the quality of programs and services in North Carolina communities.

The UNC Center for Health Promotion and Disease Prevention, using funding from the CDC, manages a website that contains information on evidence-based and best intervention strategies to prevent obesity, heart disease, stroke, and other chronic diseases. With the existing infrastructure, expansion to reviews of North Carolina community-based programs could be accomplished with modest additional investment. This would leverage the infrastructure developed by national investment to create a compendium of programs well-suited to North Carolina efforts. If the Center were to partner with the North Carolina Division of Public Health to ensure technical assistance is available to community partners, the information contained in the compendium could be customized and adapted to North Carolina communities. Furthermore, foundations could include on their websites lists of funded projects as well as technical assistance in implementing these projects. Therefore, the Task Force recommends:

Recommendation 13.2: Identify and Disseminate Effective Nutrition, Physical Activity, Obesity, and Chronic Disease Prevention Practices in North Carolina

The UNC Center for Health Promotion and Disease Prevention should work with North Carolina foundations to identify effective practice-level nutrition, physical activity, obesity, and chronic disease prevention interventions within the state.

- **a) North Carolina foundations should provide $50,000 annually beginning in SFY 2011 to the UNC Center for Health Promotion and Disease Prevention to use an existing systematic process to review five foundation-funded prevention interventions within North Carolina that have not been formally evaluated and disseminate these interventions through a web-based interface designed for, and accessible to, all public health practitioners and community partners.**
- **b) The website should be used:**
  - **1) To provide toolkits for users to replicate interventions at the community practice level.**
  - **2) As a resource for potential grantees.**
  - **3) As a mechanism for sharing the results of funded and reviewed projects with other grantees.**

References

1 Center for Disease Control and Prevention, US Department of Health and Human Services. Youth Risk Behavior and Surveillance System, 2007. http://www.cdc.gov/HealthyYouth/yrbs/pdf/yrbss07_overview.pdf. Published 2008. Accessed June 14, 2009.

2 Eaton DK, Kann L, Kinchen S, et al. Methodology of the youth risk behavior surveillance survey. *MMWR Surveill Summ.* 2004;53:RR-12.

3 Knight K. Cancer and the environment in North Carolina. Presented to: the North Carolina Institute of Medicine Task Force on Prevention; January 14, 2009; Morrisville, NC.