Just *What* Did the Doctor Order?

Addressing Low Health Literacy in North Carolina

2010 Update

North Carolina Institute of Medicine
In collaboration with the North Carolina Department of Health and Human Services and the North Carolina Area Health Education Centers Program

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NORTH CAROLINA INSTITUTE OF MEDICINE
2007 TASK FORCE ON HEALTH LITERACY
UPDATES TO RECOMMENDATION IMPLEMENTATION: 2010

Much of the current health reform discussions focus on the need to improve health outcomes and reduce health care expenditures. One way to reach these goals is to help people engage in healthy lifestyle choices, manage their chronic illnesses, and become better stewards of their own care. Another is to improve health care quality. As part of this effort, people will be given information to compare the quality of health providers and insurers. In short, many efforts to improve health and our health care system depend on having informed consumers. These goals will be hard to achieve if people cannot understand the information they receive.

Health literacy is the ability to obtain and understand basic health information and services needed to make appropriate health decisions. Literacy—or the ability to read—is not the same as health literacy. Many people who can read without difficulty have problems understanding complex medical terminology or insurance terms. Some groups of people, including older adults, people with less education or cognitive impairments, racial and ethnic minorities, and low-income people are more likely to have health literacy problems. However, the issue of health literacy affects us all.

In 2007, the North Carolina Institute of Medicine (NCIOM) released a report entitled **"Just *What* Did the Doctor Order? Addressing Low Health Literacy in North Carolina."**[a] The report was the culmination of almost a year of work by the NCIOM Task Force on Health Literacy. The Task Force consisted of more than 50 health professionals, educators, consumers, insurers, and state and local agency staff who met to study the problem of health literacy in our state. This work was a collaborative effort between the NCIOM, the North Carolina Department of Health and Human Services, and the North Carolina Area Health Education Centers program. The initial work of the NCIOM Task Force on Health Literacy was funded by the Chronic Disease and Injury Section, Division of Public Health, North Carolina Department of Health and Human Services (DHHS), through a Centers for Disease Control and Prevention grant (cooperative agreement U50/CCU421315-05), and the Division of Medical Assistance, DHHS.

The Task Force made 14 recommendations to improve health literacy for all North Carolinians. This 2010 update includes information about the progress, or lack thereof, in implementing the 2007 Task Force recommendations. In total, progress has been made in implementing 11 (79%) of all the Task Force recommendations. No action has been taken to implement 3 of the 14 recommendations.

[a] A copy of the full report and fact sheet is available at: http://www.nciom.org/publications/?just-what-did-the-doctor-order-addressing-low-health-literacy-in-north-carolina-7796

TOTAL RECOMMENDATIONS: 14

- ***FULLY IMPLEMENTED:* 0**
- ***PARTIALLY IMPLEMENTED:* 11 (79%)**
- ***NOT IMPLEMENTED:* 3 (21%)**

EFFECTIVE COMMUNICATION PRACTICES

Recommendation 3.1: Partially Implemented

Foundations at state and national levels should develop a competitive process to create a North Carolina Health Literacy Center of Excellence. The Center would work collaboratively with other organizations to educate health professionals, identify evidence-based guidelines or best practices of health communication, collect and disseminate appropriate health education materials, and otherwise work to address problems of low health literacy throughout the state.

(a) The Center should help increase the capacity of health care professionals to communicate more effectively and otherwise address the problems faced by people with low health literacy. Specifically, the Center should work in conjunction with other appropriate organizations to:
  - **i) review existing and emerging research to identify evidence-based methods of communicating health information and serving people with low health literacy;**
  - **ii) disseminate evidence-based models of health care communication and services for people with low health literacy;**
  - **iii) develop undergraduate, graduate , and continuing education curricula that teach health professionals about the problems of health literacy and evidence-based guidelines or best practices for people with low health literacy; and**
  - **iv) develop expertise in designing health education materials appropriate for people with low health literacy and work with other organizations on "train the trainer" events to help disseminate these skills to state and local agencies, health care providers, and other organizations.**

(b) The Center should help increase the capacity of adult literacy professionals to address problems of low health literacy. Specifically, the Center should work with adult literacy experts to:
  - **i) identify best practices in improving health literacy skills and**
  - **ii) develop a health literacy toolkit designed to build literacy and self advocacy skills for use in adult education settings.**

(c) The Center should identify, collect, and disseminate examples of effective written and nonwritten health information designed to educate consumers with low health literacy about different health conditions and about how to manage health problems. The Center should identify, collect, and disseminate practical tools for providers to evaluate current materials and should provide links to examples of effective health information. These materials and tools should be made available throughout the state to public

and private agencies, organizations, and providers through the Area Health Education Centers (AHEC) Program Digital Library and NC Health Info. The Center should develop a process to evaluate or obtain feedback on the usefulness of the materials and tools in providing and evaluating health information.

(d) The Center should evaluate the effectiveness of its dissemination and educational efforts to ensure the Center's collaborative activities are helping improve communication and health services provided to people with low health literacy.

(e) The Center shall have an Advisory Committee that includes, but is not limited to, representatives of adult literacy programs and local literacy councils, academic medical schools and other health professions schools, AHEC, North Carolina Department of Health and Human Services divisions and agencies, North Carolina Community College System, health professional associations, health care providers, safety net providers, Community Care of North Carolina, North Carolina State Health Plan, private insurers, and consumers with low health literacy.

Several of the specific components of this recommendation have been implemented by various agencies and organizations. However, funding constraints have been a barrier to the establishment of a formal North Carolina Health Literacy Center of Excellence. Though a Center of Excellence has not yet been created, two North Carolina programs independently fulfill many of its recommended functions: the North Carolina Program on Health Literacy and the North Carolina Health Literacy Council.

North Carolina Program on Health Literacy

The North Carolina Program on Health Literacy was founded in 2007 by the Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill.[b] Numerous UNC professional and graduate schools, UNC-Greensboro, Duke University, and other university, community, and state agencies work together as part of this program. The Program fosters collaboration throughout the academic community to advance health literacy research and improve practice. The ultimate goal of these efforts is to positively impact health outcomes. The Director of the North Carolina Program on Health Literacy is Darren DeWalt, MD, MPH. Dr. DeWalt serves as an Assistant Professor at the University of North Carolina-Chapel Hill School of Medicine. He is a nationally recognized researcher and health literacy expert who has educated health professionals within North Carolina and throughout the country about the various aspects of health literacy.

The NC Program on Health Literacy is a central resource for information on the relevant research conducted by its members. These researchers have published a number of works addressing such topics as the impacts of health literacy, health literacy assessment, and

[b] Information about the North Carolina Program on Health Literacy included in this report is available at their website.[1]

the practical application of health literacy concepts and interventions. The Program also assists faculty at UNC with grant-writing to support continued contributions to this field.

The NC Program on Health Literacy disseminates a variety of resources designed to improve clinical practice. Continuing education opportunities and teaching materials are available for health professionals who wish to increase their health literacy knowledge and learn more effective communication skills. The Program offers tools for practical use with patients such as literacy assessment instruments and health education materials. Program consultants will also work with providers and organizations to help them develop or assess their own patient education materials. In general, the scope of this work has been limited and conducted as part of larger research projects supported by funding from government agencies or foundations.

Among its services, the NC Program on Health Literacy offers consultations for health care organizations interested in conducting quality improvement projects that aim to improve health literacy. In addition, a recently added practice improvement resource is the comprehensive Health Literacy Universal Precautions Toolkit. Commissioned by the Agency for Healthcare Research and Quality (AHRQ), this toolkit was designed by Dr. DeWalt and his colleagues to help clinical practices systematically improve health literacy for all of their patients. Eight medical practices throughout North Carolina served as pilot sites for toolkit implementation and evaluation.[2]

North Carolina Health Literacy Council

The North Carolina Health Literacy Council (NCHLC) is sponsored by the University of North Carolina at Greensboro and its Center for Youth, Family, and Community Partnerships.[c] The Director of the Council is Jen Kimbrough, PhD. Dr. Kimbrough is a Research Assistant Professor at UNCG and serves as the Community Health Section Chair for the Center for Youth, Family, and Community Partnerships.

The NCHLC advances health literacy throughout the state by increasing awareness and fostering collaboration within communities. The cornerstone of this organization is its focus on building community capacity through the organization of community coalitions. These coalitions determine and prioritize local health literacy needs and coordinate improvement efforts. The Guilford County Health Literacy Forum was the first coalition and was established in 2005. There are currently four active coalitions in the state with several additional communities in various stages of coalition development. Established coalitions include those in Wake, New Hanover, and Guilford Counties. A fourth group has been formed in northeastern North Carolina and is comprised of stakeholders from multiple counties. Additional coalitions are developing in Scotland, Rockingham, Richmond, Carteret, Moore and Catawba counties. Support for coalition development has been provided by the Blue Cross and Blue Shield of North Carolina Foundation and the Centers for Disease Control and Prevention. The NCHLC provides instruction and technical support throughout all phases of coalition development and has created toolkits

[c] Information about the North Carolina Health Literacy Council included in this report is available at their website.[3]

to help groups define and achieve their objectives. In addition to assisting communities in their implementation of health literacy initiatives, the Council also conducts participatory research to identify the most effective strategies for improving health literacy at the local level.

The NCHLC strives to support health professionals in their efforts to communicate more effectively with patients. The Council offers a variety of seminars addressing such topics as the scope and impact of health literacy, health literacy assessment, and evidence-based practices to improve health literacy. The NCHLC provides resources for appropriate patient education materials and tools to help assess their readability and improve design. The Council has also become involved in quality improvement initiatives within health care settings and has conducted assessments at several North Carolina hospitals and community pharmacies. Results of these assessments are used to improve provider-patient communication in clinical practice.

The NCHLC helps educators and adult literacy professionals learn about health literacy and better understand the educational needs of their students. The Council offers resources that educators can use to integrate health literacy content into adult education curricula.

IMPROVING COMMUNICATIONS IN CURRENT SYSTEMS OF CARE

Recommendation 4.1: Partially Implemented

- **(a) Institutions and organizations that train health professionals should incorporate health literacy training into their undergraduate, graduate, and continuing education curricula. Health literacy training should be integrated into existing provider-patient communication classes, condition-specific educational curricula, interpreter or cultural sensitivity courses, clinical rotations, and ongoing continuing education courses. The curricula should provide information about the number of people with low health literacy and how low health literacy affects patient understanding, adherence to medical instructions, and health outcomes. Trainings should emphasize communication skills that enhance consumer understanding of health care information. In addition, training should give providers an opportunity to test and model new communication skills.**
  - **(i) Medical and other health professions schools should incorporate health literacy information into their undergraduate and graduate curricula, clinical rotations, and residency programs.**
  - **(ii) North Carolina community colleges should incorporate health literacy information into their allied health, interpreter training, practice management, and other health-related curricula.**
  - **(iii) The North Carolina Area Health Education Centers (AHEC) program should incorporate health literacy information into their continuing education courses, residency programs, and clinical training in community settings.**

(iv) Professional associations should include information on health literacy in their annual meetings and continuing education curricula.

(b) AHEC, Carolinas Center for Medical Excellence, Community Care of North Carolina, Division of Public Health, North Carolina Center for Hospital Quality and Patient Safety, North Carolina Community Practitioner Program, safety net organizations, and health professional associations should work collaboratively to help practices and health care professionals effectively implement successful health literacy strategies into their practices.

Institutions highlighted for this recommendation include health professions schools, community colleges, the North Carolina Area Health Education Centers (AHEC) program and professional associations. Health literacy training has been incorporated into the education of health professionals via these routes in varying degrees as discussed below.

Health Professions Education

Recognizing the important role nurses play in educating patients, health literacy has been incorporated into nursing curricula. The NC Community College System has supported a statewide Associate Degree Nursing Curriculum Improvement Project (CIP) that has incorporated material on consumer education into the Associate Degree in Nursing programs. Health literacy is addressed within each course of this curriculum which was scheduled to be implemented throughout the state by Fall 2010. Furthermore, all pre-licensure Registered Nursing (RN) education programs have included a focus on patient education.

In addition, material on health literacy has been introduced using individual didactic sessions and lectures in other health professional training programs. For example, the North Carolina Health Literacy Council has conducted health literacy workshops for the internal medicine and family practice residency programs at Moses Cone Health System. These workshops educate physicians about the issue of health literacy and allow physicians in training to learn and demonstrate more effective communication skills. Both the North Carolina Program on Health Literacy and the North Carolina Health Literacy Council offer continuing education sessions on health literacy for professionals within the medical community.[1,3] In addition to targeting medical professionals and trainees, several initiatives have focused on educating professionals from a variety of health professions as highlighted below.

Faculty Development Program in Health Literacy and Aging: This program is offered by the UNC Center for Aging and Health and the Carolina Geriatric Education Center.[d] Participants include health care leaders who represent diverse disciplines and work in a variety of settings throughout North Carolina. These health professionals are educated about the scope and consequences of inadequate health literacy. They also receive training in effective communication strategies and means to improve health care delivery

[d] Information about the Faculty Development Program in Health Literacy and Aging included in this section is available at the program's website.[4]

for patients with lower literacy levels. The program aims to equip participants with the knowledge and skills needed to implement practice and organizational improvements and educate others about health literacy. The curriculum is conducted over six months and includes 30 hours of instruction using a combination of on-site and distance-based curricula. The program is supported by funding from the Health Resources and Services Administration (HRSA).

UNC Eshelman School of Pharmacy: Several faculty members from the UNC Eshelman School of Pharmacy have played an active role in integrating health literacy into the current Doctor of Pharmacy (PharmD) curriculum. Health literacy content has been incorporated into both core and elective courses. Covered topics include the definition, scope, and impact of low health literacy, effective means of communication and counseling, and selection of appropriate consumer information materials. Students develop and apply skills in assessing readability of patient education materials and create materials appropriate for those with low literacy. They also gain experience in adapting counseling techniques to best address the needs of individual patients. Faculty members have presented continuing education sessions on health literacy and have shared their approach to integrating health literacy into the School of Pharmacy curriculum as speakers at professional meetings.

UNC-Greensboro: The North Carolina Health Literacy Council has developed a graduate course in health literacy to be offered at UNC-Greensboro. The course will provide an opportunity for students in public health, social work, psychology, and nursing to learn about health literacy.

2010 North Carolina Health Literacy Conference: The North Carolina Health Literacy Council has conducted its first annual state conference on health literacy. This conference was held in Greensboro, North Carolina on September 21-22, 2010 and was entitled "The Keys to Unlocking Health Literacy." This conference is designed to educate health professionals, community college professionals, and members of community agencies about the issue of health literacy and to help them develop skills to improve communication with patients. The conference includes presentations by a selection of speakers with expertise in health literacy. The NCHLC has worked with the North Carolina Community College Association to include a track entitled Community College Family Literacy dedicated to the needs of community college professionals.

North Carolina Area Health Education Centers (AHEC) Program

The North Carolina Area Health Education Centers (AHEC) program has widely incorporated health literacy into its continuing education curricula. Throughout the state, AHEC has offered a variety of health literacy continuing education opportunities ranging from local presentations to Internet-based sessions.[5] Since January 2007, North Carolina AHEC has provided over 45 hours of instruction with health literacy content to more than 500 participants. AHEC has also collaborated with other agencies to provide health literacy education to many more North Carolina health professionals. In addition, both the Southern Regional AHEC in Fayetteville and the Greensboro AHEC are

incorporating health literacy training into their family medicine residency programs using newly developed models. Health professionals are more likely to attend health literacy related workshops if the content is embedded in other related topics, such as patient safety, patient engagement or chronic disease management.

Professional Associations

Several professional associations have incorporated health literacy into larger educational programs. Specific examples of these initiatives are those undertaken by the North Carolina Academy of Family Physicians and the North Carolina Community Health Center Association.

North Carolina Academy of Family Physicians (NCAFP): The NCAFP has incorporated health literacy into its ongoing initiative addressing health disparities and cultural competency: The NC Health Disparities Project.[e] This six-year project is supported by a grant from the North Carolina Health and Wellness Trust Fund Commission. It is designed to improve physician understanding and practice with regard to cultural competency using a combination of didactic sessions, online curriculum, and practice-based interventions. As part of the larger context of cultural competency, information about health literacy is contained within this curriculum. The NCAFP has collaborated with other agencies to help broaden the reach of this program. During the first phase of the project, NCAFP worked with the Carolinas Center for Medical Excellence to provide an Internet-based portion of the curriculum. Since 2009, NCAFP has expanded access to education, training and resources by collaborating with other professional organizations in the state. These organizations include Old North State Medical Society, North Carolina Pediatric Society, North Carolina Academy of Physician Assistants, Mecklenburg County Medical Society, and Buncombe County Medical Society. In addition to these initiatives, an NCAFP staff member is involved in the Wake County Health Literacy Coalition and several members are undertaking health literacy efforts in other parts of the state.

North Carolina Community Health Center Association (NCCHCA): Since 1988, the NCCHCA has organized the East Coast Migrant Stream Forum.[f] This annual conference is supported in part by the Centers for Disease Control and Prevention and the Health Resources and Services Administration (HRSA), Bureau of Primary Health Care. Forum participants develop knowledge, skills and relationships to improve health care delivery for seasonal and migrant farm workers and their family members in the eastern United States. A core focus of the Forum is cultural competency. Instruction on health literacy has been included within this larger content area. In addition to this formal conference, the NCCHCA website provides visitors with information about a Web-based CME activity offered by HRSA. This program is entitled "Unified Health Communication: Addressing Health Literacy, Cultural Competency, and Limited English Proficiency."[8]

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[e] Information about the NC Health Disparities Project contained in this section is available at the NCAFP website.[6]

[f] Information about the East Coast Migrant Stream Forum included in this section is available at the NCCHCA website.[7]

The *North Carolina Medical Society* has also included health literacy content in its educational activities. In 2008 a webinar addressing this topic was offered for health care providers and their practice staff. A section on health literacy was also included in a practice management seminar presented to participants of the Community Practitioner Program. It is anticipated that health literacy will be incorporated into future trainings as well.

Recommendation 4.2: Not implemented

The North Carolina Board of Pharmacy should develop requirements for oral and written consumer medication information and standard prescription bottle labeling that incorporate evidence-based guidelines or best practices for effective communication of prescription information to consumers. The North Carolina Board of Pharmacy should consult with stakeholders, consumers, and content experts in developing these materials.

Though specific requirements for medication information and prescription bottle labeling have not yet been developed, the North Carolina Board of Pharmacy remains interested in addressing these issues.

Recommendation 4.3: Partially Implemented

(a) North Carolina foundations should fund demonstration projects to test new models of care that enhance the role of pharmacists as medication counselors to ensure patients understand how to appropriately take their medicine. New models should be evaluated to determine whether they enhance patient understanding of medication, improve medication adherence, and improve health outcomes.
(b) If successful, public and private insurers and payers should modify reimbursement policies to support the long-term viability of these successful models of care.

North Carolina foundations have supported projects designed to enhance the role of pharmacists as medication counselors. Two such projects are ChecKmeds NC and Senior PharmAssist.

ChecKmeds NC: This program is funded by the North Carolina Health and Wellness Trust Fund and is available at no cost to seniors throughout North Carolina who participate in a Medicare Prescription Drug Plan.[g] ChecKmeds NC enlists the expertise of pharmacists to optimize medication utilization and minimize the risk of adverse events. Participating pharmacists counsel patients about their medications and help them understand such things as their indications, proper use, and side effects. Pharmacists also identify potential drug interactions and offer recommendations for more simplified and/or

[g] Information about ChecKmeds NC included in this report is available at their website.[9]

cost effective medication options when appropriate. Pharmacists share their evaluations with patients' physicians to facilitate the most effective plan of care.

ChecKmeds NC was established in October 2007 with more than 31,600 individuals receiving assistance to date. The NC Health and Wellness Trust Fund Commission allocated funding for program evaluation to be conducted by The Carolinas Center for Medical Excellence.[10]

Senior PharmAssist: This local program has been serving Durham County residents since 1994.[h] Its founder and executive director is Gina Upchurch, RPh, MPH. Senior PharmAssist is a multi-faceted program that has helped thousands of participants receive their medications and use them more safely and effectively. The program provides seniors with medication counseling to improve understanding, adherence, and cost-effectiveness and to lessen the risk of adverse effects. Senior PharmAssist also assists eligible participants of all ages with choosing Medicare Prescription Drug Plans, obtaining available Medicare Part D subsidies, and accessing additional resources.

Program processes and outcomes are monitored using both internal and external evaluations. The results of these assessments are used to guide program planning. Previous studies have shown a reduction in participant emergency department utilization and hospitalization rates. Additionally, clients have reported stable functional status and better perceived health.[11-13]

Foundations are among the various sources of funding for Senior PharmAssist. For example, the program has received $10,000 from The Kate B. Reynolds Charitable Trust. These funds have supported the development of a replication/implementation guide which is publicly available to those interested in implementing similar programs in their communities. Senior PharmAssist is also a participating agency in the ChecKmeds NC program which is funded by the North Carolina Health and Wellness Trust Fund.

The Blue Cross and Blue Shield of North Carolina (BCBSNC) Foundation has also been involved in funding projects designed to enhance the counseling role of pharmacists. For example, the BCBSNC Foundation has awarded funds to Alliance Medical Ministry to increase the capacity of their pharmacy services and allow resources for patient counseling.[14] Alliance Medical Ministry is a Wake County nonprofit organization that provides comprehensive health care for uninsured patients.[15]

<u>Recommendation 4.4: Partially Implemented</u>

(a) The North Carolina Department of Health and Human Services (NC DHHS) should develop standardized criteria to guide the development of all written consumer information materials used by state and locally funded programs. The criteria should be based on adult education principles aimed at ensuring

[h] Information about Senior PharmAssist included in this report is available at their website.[11]

the readability of written materials for people with lower literacy levels. To the extent possible, written materials should:
(i) be written at an appropriate level for the targeted audience;
(ii) be easy to read with a lot of white space;
(iii) include visual materials that motivate the reader or explain the text;
(iv) be linguistically and culturally appropriate;
(v) engage and inspire the reader towards targeted health behaviors; and
(vi) be reviewed by consumers and families prior to use.

(b) NC DHHS also should incorporate best practices for website development that include, but are not limited to, the factors listed above.

(c) NC DHHS should review other visual or audio patient or community education materials to ensure the materials are linguistically and culturally appropriate and should incorporate best practices for communication in these media. To the extent possible, materials should be reviewed by consumers and families prior to use.

(d) NC DHHS should refine the existing review process in each division to ensure materials are understandable for the targeted audience prior to use.

(e) NC DHHS and all appropriate divisions and agencies should review their paperwork and procedures to ensure materials and signage do not discourage individuals with low health literacy from obtaining needed assistance.

The North Carolina Department of Health and Human Services (NC DHHS) follows a set of procedures to ensure materials generated by each of its divisions meet accepted standards and are suitable for their intended audience and purpose.[i] This approval process first involves a multilevel divisional review of each proposed item to make certain content is accurate and consistent with existing guidelines. Next, the NC DHHS Office of Public Affairs conducts a final review and grants approval when indicated. Examples of reviewed materials include printed items such as posters, pamphlets, and newsletters as well as audiovisual presentations. A review process is in place for materials requiring language translation to ensure they are appropriate for their target audience. Furthermore, the Office of Public Affairs has a Latino Public Information Officer who is available to help staff produce materials for the Latino population.

Website materials undergo an approval process with guidelines provided by the *Website Style Guide* produced by the Office of Public Affairs. According to this guide, content directed to the general public should conform to a seventh grade reading level.[17] Currently NC DHHS is in the midst of a website redesign project in which division and office websites are being improved to facilitate their use by website visitors.[18]

[i] Information about the review process as outlined in this section is available at the NC DHHS Public Affairs website.[16]

Recommendation 4.5: Partial Implementation

The North Carolina Department of Health and Human Services (NC DHHS) should ensure there are trained and competent staff in each Division who can disseminate health literacy skills and strategies more broadly to health care professionals and others who work with people with low health literacy.

- **(a) Community Care of North Carolina (CCNC) should ensure there is at least one case manager (eg, nurse, social worker, or health educator) in each CCNC network that is competent to teach health literacy skills and strategies and is responsible for disseminating this information to other health professionals and care coordinators in his or her network.**
- **(b) The Division of Public Health should ensure there is at least one health educator in each health department who is competent to teach health literacy skills and strategies and is responsible for disseminating this information to other health department staff and local providers of care.**
- **(c) The Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MHDDSAS) and local management entities should ensure there is at least one health educator at the state and local management entities who is competent to teach health literacy skills and strategies and is responsible for disseminating this information to providers of MHDDSAS services.**
- **(d) The Division of Aging should ensure there is at least one health educator at the state level who is competent to teach health literacy skills and strategies and is responsible for disseminating this information to Area Agencies on Aging, senior centers, and other organizations serving older adults.**
- **(e) Other NC DHHS divisions and agencies that work with health care professionals should ensure there is at least one trained and competent staff person who can disseminate health literacy skills and strategies to other staff and to providers of care at the state and local communities.**

Community Care of North Carolina (CCNC) currently facilitates health literacy through its efforts to promote cultural competency. Each CCNC provider network has at least one bilingual care manager with Spanish proficiency. Furthermore, network providers are required to offer interpreter services. All CCNC care managers receive training in motivational interviewing, a technique that includes a focus on cultural competency.

While CCNC does not have staff specifically trained in health literacy, they have established a patient education workgroup whose membership includes representatives from each CCNC network. Members of this group collaborate to implement strategies that improve communication with patients with low literacy. CCNC has also evaluated and compiled health education materials for use with CCNC clients. Details are provided under Recommendation 4.6.

Division of Public Health: The Division of Public Health, Children and Youth Branch, has institutionalized the training of its staff about the various aspects of health literacy.

This process began in 2006-2007 with several trainings and lectures designed to build knowledge, skills, and support for the value of addressing this issue. Since 2007, the Branch has also provided health literacy training to local health department staff in child preventive health and primary care clinics, child service coordination and newborn home visiting. Webinar training sessions for local health departments continued in 2009-2010. In addition, since 2009 the Division of Public Health has required local health departments providing a number of child health services to ensure their child health staff receives health literacy training. These policies apply to staff that work in child health clinics and perform newborn home visits. These measures are designed to help ensure that patients and clients can effectively act on health information to improve and support health.

Ideally *all* materials at local health departments should be evaluated for readability prior to public use and/or distribution. Aside from the child health services offered through local health departments, we have no data on the extent to which local health department staff have been trained in health literacy skills, or the extent to which materials have been evaluated for readability.

Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMHDDSAS): This division combines its efforts with those of the Office of Minority Health and Health Disparities to address the issues of cultural competency and health literacy. A key subgroup comprised of representatives of both divisions has focused on the issue of health literacy at the community level for the past several years. Specific initiatives have included staff training and provision of appropriate native language materials. It is uncertain to what degree local management entities possess staff specifically trained in health literacy. However, there are at least two staff members at the state level with an interest in health literacy who work on cultural competency issues and disseminate information and resources to staff at the community level.

The Division of Aging does not currently have a formally trained staff member responsible for disseminating health literacy information. However, there is a staff member within the division who is a point person for health literacy and addresses this topic as needs arise.

<u>Recommendation 4.6: Partially Implemented</u>

In order to ensure written health care materials are understandable to people with low literacy levels:

- **(a) Public and private insurers and payers, health care systems, health care providers, academic institutions and researchers, and other health-related businesses should develop criteria to guide the development of all written consumer information materials. The criteria should be based on adult education principles aimed at ensuring the readability of written materials for people with low literacy levels. To the extent possible, materials should:**
  - **(i) be written at an appropriate level for the targeted audience;**

(ii) be easy to read with a lot of white space;
(iii) include visual materials that motivate the reader or explain the text;
(iv) be linguistically and culturally appropriate;
(v) engage and inspire the reader towards targeted health behaviors; and
(vi) be reviewed by consumers, families, and other members of the target population prior to use.

(b) Public and private insurers and payers, health care systems, health care providers, academic institutions and researchers, and other health-related businesses should incorporate best practices for website development that include, but are not limited to, the factors listed above.

(c) Public and private insurers and payers, health care systems, health care providers, academic institutions and researchers, and other health-related businesses should establish a review process to ensure all materials are reviewed for understandability prior to use.

(d) Public and private insurers and payers, health care systems, and health care providers should review other visual or audio patient or community education materials to ensure the materials are linguistically and culturally appropriate and should incorporate best practices for communication in these media. Materials should be reviewed by consumers and families prior to use.

(e) The Department of Insurance should seek changes in existing insurance laws, N.C. Gen. Stat. §§ 58-38-1 et seq., 58-66-1 et seq., to ensure the readability of written insurance materials for people with low literacy levels using the criteria listed in (a) above.

(f) North Carolina foundations and other health care funders should give priority to organizational grantees that produce health materials for use by consumers that meet the criteria listed in (a) above.

Public and Private Insurers and Payers

This recommendation highlights the potential role for public and private payers to play in improving care for those with low literacy. Examples of two agencies that have incorporated health literacy considerations into their communication strategies are the North Carolina State Health Plan and Blue Cross and Blue Shield of North Carolina.

The *North Carolina State Health Plan* follows procedures to ensure that its written patient education materials are composed at a 6th-9th grade readability level. This same standard applies to written outreach materials used by its NC Health*Smart* wellness program. Materials are reviewed internally by communications professionals and then approved by management staff prior to distribution. Literacy criteria are also considered in the use of enrollment and benefits information.

The NC State Health Plan strives to improve communication with consumers through use of its website. Clients who visit the NC Health*Smart* website can participate in a personal health assessment that has been redesigned and simplified to ease completion.

Information about various medical conditions and lifestyle modification is also available. Clients may enlist the services of a health coach who can help them access and understand educational materials.[19] Health information may also be provided in a variety of alternative forms, such as video and audio CDs.

Blue Cross and Blue Shield of North Carolina (BCBSNC) ensures that the readability of its written consumer materials is in compliance with Department of Insurance guidelines. These currently require materials to be written at no higher than an 8th grade reading level. Similar standards apply to the company's prevention and wellness consumer information. Consideration is given to improving readability using literacy criteria similar to those suggested in this recommendation. In general, consumer materials are reviewed internally by the company prior to distribution.

On its website, BCBSNC offers clients health information and an opportunity to complete a personal health risk assessment tool. The results of this assessment guide consumers to online materials that may be of interest. BCBSNC also provides educational materials to address specific chronic conditions. These may be presented in written, audio or video formats and have been developed with the assistance of literacy experts. Clients may seek the help of health coaches to clarify information and obtain referrals to appropriate resources. A selection of resources and materials are available in Spanish and bilingual staff members facilitate service for Spanish-speaking consumers.

Health Care Systems and Providers

In general, some health care systems and providers are taking steps to improve health literacy within their institutions and practices. In some instances these efforts are linked with broad quality improvement initiatives. For example, *Carolinas HealthCare System* is addressing health literacy as the content focus of a collaborative structure that includes the teaching and implementation of quality improvement strategies. Furthermore, their Myers Park Pediatrics Clinic has served as a pilot site for the Health Literacy Universal Precautions Toolkit described under Recommendation 3.1.[2]

Also described under Recommendation 3.1 is the hospital assessment program offered by the North Carolina Health Literacy Council. The Council has assembled a team to conduct assessments at hospitals throughout the state. The team provides these institutions with feedback and assists them in developing plans to improve health literacy within their organizations. Thus far the program has been conducted with ten North Carolina hospitals. A similar program assessing nine community pharmacies was completed by the Council last fall. These assessments informed participants' health literacy improvement efforts and connected them with appropriate resources to facilitate more effective patient communication. Both of these projects included conducting readability assessments of frequently used patient forms and education documents. In addition, the Council redesigned sample documents for each organization to encourage use of materials below the 9th grade reading level. Council staff have conducted readability workshops for staff of a number of hospitals to build organizational capacity to improve document readability.

Other organizations have focused on optimizing health education tools. *Community Care of North Carolina* has established a collection of patient education materials that are appropriate for those with lower health literacy.[j] A large number of online resources were reviewed by CCNC physician Dr. Holly Biola with help from UNC medical student Anna Rose Poole. Dr. Darren DeWalt provided additional guidance with this process. Available health education materials were evaluated using a formal assessment instrument. Materials already in use by CCNC networks were assessed in a similar manner. The final product is a library of patient management tools that are available for use by CCNC network providers and staff.[k]

The North Carolina Community Health Center Association (NCCHCA) has also collaborated with other agencies to obtain and disseminate appropriate educational materials. Resources addressing such topics as cancer and smoking cessation are available to community health center providers and patients.

Academic Institutions and Researchers

Within the academic community, both the *North Carolina Program on Health Literacy* (UNC-Chapel Hill) and the *North Carolina Health Literacy Council* (UNC-Greensboro), described under recommendation 3.1, focus on supporting collaborative health literacy work. Among their initiatives are efforts directed toward the provision of effective patient education tools. Program consultants are available to assist with assessment and development of effective materials. Examples of tools for the care of asthma, diabetes and heart failure are available via program websites.[1,3]

Department of Insurance

No changes have occurred in existing insurance laws to incorporate the specific literacy criteria suggested in this recommendation.

Foundations

With regard to some of the larger North Carolina foundations, no specific provisions give funding priority to programs that produce low-literacy health materials. However, the Blue Cross and Blue Shield of North Carolina Foundation addresses the issue of health literacy in their information for potential grantees. They advise programs providing care to vulnerable populations to incorporate cultural competency and health literacy considerations into the delivery of their services.[21] Some grantees have utilized low-literacy materials in implementing their projects. Though the North Carolina Health and Wellness Trust Fund does not use health literacy to prioritize funding, it does consider literacy criteria in program implementation. All consumer materials used by grantees

[j]Information about this process included in this report is available at the CCNC website.[20]
[k] These health education materials are also available for public access on the CCNC website under the heading of Patient Management Tools.[20]

must be approved by NCHWTF staff, and readability and health literacy are considered at this time.

Recommendation 4.7: Partially Implemented

The North Carolina Department of Health and Human Services, Community Care of North Carolina, Division of Public Health, public and private insurers and payers should:

- **(a) Incorporate health literacy strategies in their disease management and case management initiatives so that people with all levels of health literacy can benefit and become active managers of their own health conditions;**
- **(b) Use and reimburse case managers, health educators, community health workers, and lay health workers who have been trained in health literacy strategies to help educate people about their health problems and how to manage their conditions; and**
- **(c) Explore the appropriate use of CDs, videos, and other non-print information as a means of better educating people with low health literacy.**

NC DHHS

The Office of Minority Health and Health Disparities established the Community Health Ambassador Program (CHAP) in 2006. This program focuses on the training and use of lay health advisors within ethnic minority communities. These volunteer Community Health Ambassadors inform fellow members of their communities about the prevention and care of chronic diseases such as cancer and diabetes.[22]

Community Care of North Carolina (CCNC) has incorporated health literacy into programs designed to empower patients to care for their health. They have focused on implementing effective patient education materials that address chronic disease management. As described under Recommendation 4.6, materials have been evaluated to ensure they are appropriate for target audiences. These tools are made available to participating networks for use with their patients.[20] Furthermore, approximately half of the CCNC networks have implemented group education sessions for patients with chronic disease. Most commonly, groups are led by lay health advisors. Overall, CCNC makes ready use of lay health advisors, care managers, and community health workers/educators. Though not all of these individuals possess formal training in health literacy strategies, care managers are trained in how to more effectively communicate with patients with low literacy.

Division of Public Health (DPH*)*

Within the Division of Public Health**,** the Diabetes Prevention and Control Program (DPCP) includes lay health leaders as a key component of community-based interventions. As an example, the DPCP trains educators in two disease self management programs developed by Stanford University researchers: the Chronic Disease Self Management Program and the Diabetes Self Management Program.[23] The DPCP conducts workshops to train health professionals and lay health leaders in the curriculum

for both of these programs so that they may in turn educate persons with chronic illnesses within their communities. Key collaborators in this initiative are Community Care of Wake and Johnston Counties, the NC Division of Aging and Adult Services, local health departments, community-based organizations, and faith-based organizations.[24] The DPCP also utilizes health education videos in its outreach efforts with both health professionals and persons with diabetes and other related cardiovascular diseases in settings such as training workshops and health fairs.

The Division of Public Health, Children and Youth Branch, has worked to support youth with special health needs and their families as they transition from pediatric to adult health systems of care. The Branch has contracted and partnered with several agencies to assemble a toolkit, fact sheets, CME and additional training for youth, families and health care providers to help address self management of disease for children 14 years of age and older. The information incorporates several health literacy principles. Case managers and providers can use these principles to help families and youth develop the skills and knowledge that will help them manage their disease and preventive health needs in partnership with their medical homes.

Insurers

As discussed under Recommendation 4.6, insurers such as Blue Cross and Blue Shield of North Carolina and the North Carolina State Health Plan have incorporated initiatives to facilitate patient self-management. Both utilize multiple forms of communication to optimize patient understanding and self-care. These insurers offer patient education materials which have been developed taking health literacy into consideration. Educational materials may take a variety of forms such as written, audio and video. Health coaches and case managers are also used to help patients better manage their health.

Recommendation 4.8: Not Implemented

(a) The Division of Medical Assistance should pilot new reimbursement systems to encourage individual and group education sessions that teach patient self-management using appropriate health literacy techniques. In developing this pilot project, the Division should explore tying reimbursement to health care professionals, case managers, health educators, lay health advisors, or other trained health communicators who have received health literacy training.

(b) Public and private insurers and payers should consider reimbursing for existing CPT codes or other payment methodologies that pay for individual or group education self-management sessions by health professionals, care coordinators, health educators, and lay health providers who have received health literacy training.

As discussed under Recommendation 4.7, some CCNC networks provide group education sessions for Medicaid clients. CCNC is provided a Per Member Per Month payment for care and disease management services. Some of the networks can use these

funds to support group patient education sessions. Over the past three years, no specific progress has been made toward implementation of this recommendation within the Division of Medical Assistance.

Recommendation 4.9: Partially Implemented

Malpractice carriers should incorporate health literacy education and effective provider-patient communication skills into their risk management training and should develop systems to reward more effective provider-patient communication.

Implementation of this recommendation is exemplified by initiatives undertaken by Medical Mutual. This company has incorporated health literacy education into their risk management training and has developed tools to improve provider-patient communication.

Medical Mutual focused their initial efforts in an area likely to have a direct patient care impact—the informed consent process. They started by implementing literacy software to create informed consent documents with a 7th-8th grade readability level. This was followed by a series of community board meetings to educate insured health professionals and practice managers about the importance of health literacy and the methods used to improve the informed consent process. These meetings were conducted throughout the majority of the company's coverage region.

In 2009 Medical Mutual built on their initial efforts creating and publishing the Informed Consent Toolkit. This toolkit contains a collection of over 50 procedure, medication, and treatment specific forms along with customizable templates. Medical Mutual continually develops new forms based on identified needs and makes them available to all members on the company's website. The toolkit also contains a section focusing specifically on health literacy. Medical Mutual offered their members two educational audio conferences that provided a review of the informed consent process as well as an overview of the components of the toolkit and its health literacy aspects. Insured providers may receive this toolkit free of charge. Furthermore, the company has initiated an incentive program that grants a 3% annual premium discount to insured North Carolina providers who utilize and comply with the Informed Consent Toolkit guidelines.

Medical Mutual continues to extend their health literacy education efforts. The company is currently delivering workshops on health literacy and training participants to create appropriate informed consent documents. These workshops are offered for insured providers throughout North Carolina, Virginia and Georgia. They are conducted by the company's risk management staff and a physician consultant conversant in health literacy.

Recommendation 4.10: Partial Implementation

(a) North Carolina foundations should fund demonstration projects using promising new models of care in both inpatient and outpatient settings that increase the effectiveness of communication provided to patients with low health literacy. New models should be evaluated to determine if they improve health outcomes.

(b) Public and private insurers and payers should modify reimbursement policies to support the long-term viability of successful models.

North Carolina foundations play an important role in improving patient care, particularly for those with low health literacy. Foundations have contributed funds for projects that increase the effectiveness of patient communication. Programs have the potential to advance health literacy by providing health education and more culturally competent care.

A number of funded projects involve the delivery of health education. The Kate B. Reynolds Charitable Trust has supported organizations that utilize or train lay health advisors. They also have provided grants to numerous organizations and agencies throughout the state for implementation of diabetes self-management programs.[25] The Blue Cross and Blue Shield of North Carolina Foundation has awarded funds to Diabetes Management Solutions in support of their Reaching Communities Project and the Diabetes Bus, a mobile diabetes education program that delivers services to rural communities.[26] The Duke Endowment has worked with faith communities in the development of parish nurse programs.[27]

Foundations have also funded several projects designed to foster culturally competent care and education. Both the Blue Cross and Blue Shield of North Carolina Foundation and The Duke Endowment have supported projects that improve access to language interpreter services for those with limited English proficiency.[14, 27] The Kate B. Reynolds Charitable Trust has granted funds to a number of organizations whose projects aim to deliver culturally competent interventions to Latino and African American communities.[25]

The North Carolina Health and Wellness Trust Fund developed and funds the Health Disparities Initiative.[l] This multimillion dollar initiative supports programs throughout North Carolina that address health disparities and strives to improve health outcomes by fostering culturally competent care. Grantees conduct projects employing such methods as the use of community and lay health advisors, peer health educators, self-management educational programs and group medical visits. An evaluation of The Health Disparities Initiative is being conducted by researchers from East Carolina University who will study both processes and outcomes.

[l] Information about the Health Disparities Initiative included in this report is available on the Care to Act NC website.[28]

Recommendation 4.11: Partially Implemented

In addition to disease management, the North Carolina Department of Health and Human Services, health care systems and providers, and insurers should explore other ways of educating patients. For example, these organizations and providers should consider:

(a) expanding the use of trained lay health advisors, case managers, and patient navigators to disseminate health information and to prepare patients and their families for provider-patient interactions;
(b) using group education settings when appropriate;
(c) disseminating materials through other forums, such as religious institutions, community fairs, senior games, barber shops, or beauty salons; and
(d) identifying and implementing outreach efforts to encourage consumers to more actively engage in dialogue with their health care providers.

NC Department of Health and Human Services

The *Division of Public Health* has historically implemented community outreach interventions within a number of settings. An example of one such initiative was the work conducted by the Diabetes Prevention and Control Branch and its collaborators as part of Project DIRECT (Diabetes Interventions Reaching and Educating Communities Together).[29] This program was a community-based research demonstration program which aimed to prevent diabetes and its complications by promoting community walking programs, church and community nutrition education programs, and diabetes education programs. A key component of Project DIRECT was leadership from a committed Executive Committee consisting mostly of community volunteers. Project DIRECT worked with Community Ambassadors (lay health leaders) who reached out to community members in a number of settings such as barber shops, beauty salons, fraternal organizations, and faith communities.

Also within the Division of Public Health, the Children and Youth Branch has supported the implementation and funding of 15 new evidence-based parenting programs. These programs use the Incredible Years or Strengthening Families Program materials.[30-31] These programs have sections that disseminate health information to families and help prepare patients for provider, child, and family interactions.

Health Care Systems and Providers

North Carolina Community Health Centers have made use of group diabetes classes as a means of improving patient education. This program is a collaborative effort between the North Carolina Community Health Center Association (NCCHCA) and the North Carolina Division of Public Health, Diabetes Prevention and Control Program (DPCP), with funding provided by the Kate B. Reynolds Charitable Trust. The DPCP provides training in diabetes self management curricula to staff from various North Carolina community health centers. These trained providers may in turn conduct group diabetes education classes for patients in their community practices. Patient education materials of

an appropriate readability level are obtained from both the American Diabetes Association and the NC DPH.

Community Care of North Carolina: As mentioned under Recommendation 4.7, CCNC has implemented group education sessions and/or visits in approximately half of its provider networks. Groups are commonly led by trained community volunteers who function as lay heath advisors. Overall, CCNC utilizes lay health advisors and community health workers/educators who can help with community outreach activities.

Health education programs have been implemented in other community forums such as religious institutions. One such example is the Congregational Nurse Program in Guilford County which has been offered by the *Moses Cone Health System* since 1998. Initial funding for this program was provided by The Duke Endowment and The Moses Cone-Wesley Long Community Health Foundation. Nurses work within a number of local congregations to provide a variety of services, one of which is health education. These nurses organize educational activities addressing health topics of interest to church members.[32] Sessions addressing health literacy have been conducted for several congregations as part of this program. These sessions have focused on how to effectively communicate with physicians. Nurses also work individually with clients to interpret and incorporate physician instructions into their daily lives. In addition to these activities, the Congregational Nurse Program collaborated with the Guilford County Department of Public Health to create and establish a Lay Health Coach Program in 2008. Volunteers attend 16 hours of basic health education to become a Lay Health Coach for their faith communities. These coaches then relay approved health messages to members of their congregations. They also arrange educational programs and promote policy and environmental changes within the faith communities to promote health. Both the congregational nurses and the lay health coaches were prominent in educating the public about the recent H1N1 general health precautions and in promoting vaccination in Guilford County.

Recommendation 4.12: Not Implemented

The North Carolina General Assembly should provide funding for the Division of Public Health to undertake a broad-based social marketing campaign to activate consumers to engage in dialogue with their health care providers to help mitigate the effects of low health literacy. The Division of Public Health should work with the faith community, safety net providers, and other community leaders and organizations to disseminate this information and to engage these groups as partners in other support activities.

No progress has been made toward implementation of this recommendation.

INCORPORATING HEALTH LITERACY INTO ADULT EDUCATION

Recommendation 5.1: Partially Implemented

Adult Basic Education and English as a Second Language programs within the North Carolina Community College System, local literacy councils, and other community-based organizations that provide literacy education should disseminate and incorporate health literacy curricula. The curricula should incorporate evidence-based guidelines or best practices for enhancing health literacy.

- **(a) The curricula should include, but not be limited to:**
  - **(i) basic information about the US health system and where to go for care;**
  - **(ii) information about health insurance programs and billing;**
  - **(iii) information on nutrition and health-related topics; and**
  - **(iv) tools designed to encourage consumers to more actively engage in dialogue with their health care providers.**
- **(b) Teaching resources should include access to best practices through on-line resources.**

Health literacy education has been advanced by efforts to incorporate health content into the existing curricula used by Adult Basic Education and English as a Second Language (ESL) programs, local literacy councils and community-based literacy organizations.

Expecting the Best: This is a program created to serve the health literacy needs of those with limited English proficiency.[m] The program was funded through the North Carolina March of Dimes and was developed with other key collaborators including the Coastal Area Health Education Center, UNC School of Medicine, UNC School of Public Health, NC Department of Health and Human Services, Division of Public Health, and the NC Community College System. Designed by Sandy Diehl, MPH, the Expecting the Best curriculum is intended to equip ESL students with knowledge and skills to more successfully access and interact with the health care system and engage in effective self-care. The curriculum is comprised of a number of lessons addressing such important topics as obtaining and navigating appropriate emergency and routine medical services, completing forms, and communicating with health care professionals. Additional lessons incorporate material on preventive self-care with an emphasis on nutrition. Lessons can be introduced individually or as a block and can be integrated into existing literacy curricula. Each lesson consists of a variety of adaptable teaching techniques. The Expecting the Best curriculum is available for statewide implementation in a range of settings including community college ESL classes, literacy council services, and programs offered by community or volunteer organizations.

Community-based literacy organizations have also incorporated and disseminated health literacy information. For example, The Guilford Health Literacy Forum, spearheaded by Reading Connections, Inc., has incorporated a number of projects aimed at literacy professionals. With funding from the United Way of Greater Greensboro, Reading

[m] Information about Expecting the Best included in this report is available at their website.[33]

Connections has offered Health Literacy Study Circles to Guilford County literacy faculty and tutors. They have also provided health literacy skills training to adult ESOL teachers with Guilford County Schools. Reading Connections includes a health literacy curriculum among the services provided to its students and conducts health literacy classes for new immigrants and refugees. In addition to providing health literacy programming, this agency has played an integral role in distributing low-literacy health education material to community members.[34]

Training and assistance are available to educators who are interested in implementing health literacy curricula. The North Carolina Health Literacy Council offers resources for delivering health literacy instruction in adult education settings.[3] As described earlier, the North Carolina Health Literacy Council included specific programming for community college professionals within its statewide health literacy conference in September 2010.

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Chris Collins, MSW, Office of Rural Health and Community Care, Division of Medical Assistance, NC Department of Health and Human Services
Darren DeWalt, MD, MPH, North Carolina Program on Health Literacy, School of Medicine, University of North Carolina at Chapel Hill (UNC-CH)
Sandy Diehl, MPH, Project Director, Expecting the Best, Coastal Area Health Education Center
Lisa Dinkins, PharmD, Eshelman School of Pharmacy, UNC-CH
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Steven Hairston, Division of Mental Health, Developmental Disabilities and Substance Abuse Services, NC Department of Health and Human Services
Denis Levis Hewson, RN, BSN, MSPH, NC Community Care Network, Inc.
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A. Dale Jenkins, NC Medical Mutual
Jen Kimbrough, PhD, North Carolina Health Literacy Council, University of North Carolina at Greensboro
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Barbara Moeykens, MS, NC Health and Wellness Trust Fund
Benjamin Money, MPH, NC Community Health Center Association
Debi Nelson, MAEd, RHEd, Division of Public Health, NC Department of Health and Human Services
Mike Newton-Ward, MSW, MPH, Division of Public Health, NC Department of Health and Human Services
Laura Noonan, MD, Carolinas Healthcare System
Lois Nilsen, Public Affairs, NC Department of Health and Human Services
Joyce Page, Division of Public Health, NC Department of Health and Human Services
Ruth Peterson, MD, MPH, Division of Public Health, NC Department of Health and Human Services
Anne Rogers, RN, BSN, MPH, NC State Health Plan
Meka Sales, MS, CHES, The Duke Endowment
Maggie Sauer, NC Medical Society Foundation
Alice Schenall, MPH, CHES, RHEd, Area L AHEC
Kelly Scolaro, PharmD, Eshelman School of Pharmacy, UNC-CH
Betsy Bryant Shilliday, PharmD, Eschelman School of Pharmacy, UNC-CH
Steve Shore, MSW, NC Pediatric Society
Betsy Sleath, PhD, RPh, Eshelman School of Pharmacy, UNC-CH
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Karen Stallings, RN, Med, NC AHEC
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K.T. Vaughan, MSLS, Eshelman School of Pharmacy, UNC-CH
George Wolff, MD

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