

**A Program Plan and Evaluation Plan for the
Carolina Alzheimer's Network:
A Focus on the State-of-the-Art Workshop**

By

Joseph David Hoyle

A Master's Paper submitted to the faculty of
the University of North Carolina at Chapel Hill
in partial fulfillment of the requirements for
the degree of Master of Public Health in
the Public Health Leadership Program.

Chapel Hill

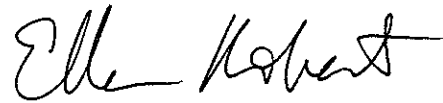
2009



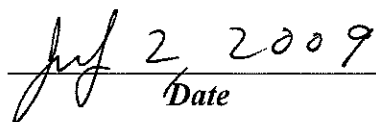
Diane Calleson



Date



Ellen Roberts



Date



Abstract

In July of 2008, two professors from the University of North Carolina at Chapel Hill School of Medicine began the Carolina Alzheimer's Network, a program for expanding resources for specialized dementia care throughout the state of North Carolina. The Duke Endowment provided initial funds for equipping and networking primary care practitioners. In April of 2009, demonstration grant funding from the Administration on Aging became available to further the goal of the program by linking the network to aging services providers through the Area Agencies on Aging. Together, these two grants provide an opportunity for developing activities and infrastructure for sustainable improvements in dementia care throughout the state. As a graduate student in the Public Health Leadership Program, I became involved as a volunteer with several program activities in November of 2008. Based on my involvement, I have tried to provide, in this paper, an update on the program plan and evaluation plan for the Carolina Alzheimer's Network.

The program plan seeks to meet the growing public health issue of dementia care in North Carolina, with a focus on poor, minority, and rural counties. For the purpose of initially networking primary care practitioners and equipping them with state-of-the-art tools for dementia assessment and management, the program plan includes providing continuing medical education workshops throughout the state. These workshops are also serving as an initial linking opportunity to aging services providers, the objective of the Administration on Aging demonstration grant. Other activities in the program plan include direct health services, enabling services, population-based services, and infrastructure services.

The evaluation plan provides a framework for the entire program evaluation, but with a focus on the workshop evaluation. The role of the evaluation is broad and includes improving

program activities, writing progress reports and disseminating program findings, and even planning new program activities. Using the RE-AIM (Reach, Effectiveness, Adoption, Implementation, Maintenance) method², this evaluation plan seeks to fulfill the demonstration Administration on Aging grant purpose of developing knowledge which can be disseminated throughout the nation, while, at the same time, providing for program improvement and the development of a sustainable program for the citizens of North Carolina.

Table of Contents

Abstract	p. 2
Table of Contents	p. 4
Supplemental Material Listing.....	p. 5
Introduction	p. 6
Literature Review	p. 9
I. Introduction to this Public Health Issue	
II. Dementia in Individuals, Families, and Primary Care (p. 10)	
III. Review of Primary Care Practitioner Programs (p. 15)	
IV. Conclusion in Context of Administration on Aging Recommendations (p. 25)	
Program Plan	p. 26
I. Introduction	
II. Program Context (p. 27)	
<i>Program Goal and Grant Proposals, Background, Consistency with National and State Priorities, Alliances, Program Acceptability and Model, Initial Challenges and Feasibility, The Long-Term Challenge of Sustainability</i>	
III. Program Activities and Priority Setting (p. 40)	
<i>Proposed Activities and Theory, Program Logic Model, Program Implementation, Summary of Priorities</i>	
Evaluation Plan	p. 53
I. Introduction	
II. Program Evaluation Context and Role (p. 54)	
<i>Evaluation Roles and Reasons, Evaluators, Key Stakeholders, Potential Challenges</i>	
III. Design for the Workshop Evaluation (p. 59)	
IV. Methods for the Workshop Evaluation (p. 60)	
V. Dissemination Plan (p. 65)	
Discussion	p. 67
References	p. 68
Appendices	p. 71

Supplemental Material Listing

Box 1. Definition of Dementia (p. 8)

Table 1. Estimated number of dementia patients in targeted counties (p. 13)

Table 2. Summary of 17 programs reviewed (p. 16)

Map 1. Area Agency on Aging Regions in North Carolina (p. 34)

Table 3. Primary Care Practitioners in Target Regions and Counties in North Carolina (p. 36)

Figure 1. Program Model Demonstrating Positive Feedback to PCPs (p. 37)

Figure 2. The Public Health Pyramid (p. 41)

Table 4. CAN Logic Model (p. 43)

Table 5. Carolina Alzheimer's Network Activities and Evaluation Timeline (p. 44)

Table 6. Workshop Planning Table (p. 61)

Table 7. Question 1 from Part II of the Practice Needs Assessment in Appendix F (p. 62)

Table 8. Question 1 from Part III of the Post-Workshop Evaluation in Appendix D (p. 63)

Introduction

Alzheimer's disease (AD) affects approximately 5.3 million Americans, including one out of every eight persons age 65 and over.¹ AD is the most common cause of dementia, a loss or decline in memory and other cognitive abilities which is severe enough to interfere with daily life (see Box 1 for formal definition).¹ Alzheimer's disease and related disorders (ADRDs) have a "potentially devastating effect on the functional status" of individuals, and can also adversely affect the quality of life for family members and friends.³ Current models suggest at least a threefold rise in the total number of persons with AD between 2000 and 2050, suggesting that providing quality Alzheimer's care is to remain a major public health issue.⁴

ADRDs increase health care costs for both individuals and for society. The 2009 report of the Alzheimer's Association, the leading voluntary health organization in Alzheimer care, support, and research, highlighted the tripled health care costs associated for Americans age 65 and older with ADRDs, as well as the 148 billion dollars in annual costs nationally and the 9.9 million unpaid caregivers.¹ A 2004 report by the Lewin Group, commissioned by the Alzheimer's Association, suggested that "the future" of both Medicaid and Medicare "depends on getting Alzheimer's disease under control."⁵ The Lewin Group hypothesized that, by 2050, forty percent of Medicare costs will be for beneficiaries with ADRDs.

According to a 1997 consensus statement by the Alzheimer's Association, the American Geriatrics Society, and the American Association for Geriatric Psychiatry, most cases of AD can be diagnosed and managed by primary care practitioners (PCPs), although there are atypical presentations which benefit from specialist referral.⁶ However, dementia has been widely under-recognized and under-treated by PCPs.^{7,8} Certainly, there are barriers to providing quality care for ADRDs, barriers which are not typical for other diseases.⁹ For example, PCPs must develop a "complex alliance with the patient, caregivers, community agencies, and other health

professionals to provide effective treatment.”⁸ In recognition of some of these barriers, the 1997 consensus statement continued, “new approaches are needed to ensure patients' access to essential resources, and future research should aim to improve diagnostic and therapeutic effectiveness.”⁶

Starting in July of 2008, the Duke Endowment, a private foundation for supporting programs in the states of North Carolina and South Carolina, began funding a grant to develop the Carolina Alzheimer’s Network (CAN). The goal of CAN was to “expand resources for specialized dementia care for individuals with ADRDs and their families throughout North Carolina, including poor, rural, and underserved areas,” by “providing training and support to a statewide sample of primary care physicians through outreach efforts by the University of North Carolina (UNC) Memory Disorders Clinic.”¹⁰ CAN has since received a demonstration grant, from the Alzheimer’s Disease Supportive Services Program (ADSSP) administered through the U.S. Administration on Aging, to strengthen linkages with the state’s aging services network. In partnering with the state’s aging services providers, the program will select and develop “methods and materials for developing stronger linkages between medical and aging services providers” and “early ADRD support models that are tailored for rural and minority populations.”^{11,12}

This paper will explain the context and provide the program plan and evaluation plan for CAN’s funded activities, with a focus on the “State-of-the-Art Workshop,” the first intervention. As CAN is being developed to serve the needs of community PCPs, the program plan and evaluation plan continue to evolve.

Box 1. Definition of Dementia¹

Dementia is characterized by loss of or decline in memory and other cognitive abilities. It is caused by various diseases and conditions that result in damaged brain cells. To be classified as dementia, the following criteria must be met:

- It must include decline in memory and in at least one of the following cognitive abilities:

- 1) Ability to generate coherent speech or understand spoken or written language;
- 2) Ability to recognize or identify objects, assuming intact sensory function;
- 3) Ability to execute motor activities, assuming intact motor abilities, sensory function and comprehension of the required task; and
- 4) Ability to think abstractly, make sound judgments and plan and carry out complex tasks.

- The decline in cognitive abilities must be severe enough to interfere with daily life.

Literature Review

I. Introduction to this Public Health Issue

Alzheimer's disease and related disorders (ADRDs) are growing public health issues, whose magnitude can be understood from prevalence data about Alzheimer's disease. In March, the Alzheimer's Association released their 2009 report, which estimated that 5.3 million Americans have Alzheimer's disease.¹ Among adults over the age of 65, approximately one in eight adults is effected. Among this group, Alzheimer's disease is the 5th leading cause of death.¹ As the U.S. population continues to age, disease models suggest a threefold rise in cases between 2000 and 2050, despite potential research breakthroughs.⁴ North Carolina has the 8th highest age-adjusted Alzheimer's disease death rate among all the states, although it is the 10th largest state.^{1, 13}

ADRDs adversely affect individuals and families. These individuals are high users of health care and long-term care services.¹ Primary care practitioners (PCPs), including physicians (MDs), nurse practitioners (NPs), and physician assistants (PAs) and their practices are on the front lines of the health care system and, therefore, are essential to improving detection and treatment for ADRDs. As will be reviewed, many public health programs have targeted PCPs to lessen the public health burden by improving assessment and management of dementia.

II. Dementia in Individuals, Families and Primary Care

ADRDs include a wide variety of dementias whose unifying features are an acquired and persistent compromise in multiple cognitive domains that are severe enough to interfere with everyday functioning. The most common types of dementia include Alzheimer's disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementias, and mixed types. Other memory impairment disorders which must be excluded are delirium, depression, and mild cognitive impairment.¹⁴

Alzheimer's disease, like many of the other ADRDs, is very heterogeneous in presentation and differs greatly among individuals.¹⁵ Studies have shown incidence differences among ethnic and racial groups, and further research into these differences may lead to a more complete understanding of the pathogenesis of Alzheimer's disease.¹⁵ However, mortality is probably similar for most races and, therefore, assessment and management options should be similar.¹⁶

Medical treatment response is also individually heterogeneous, both in the type of symptoms that improve and in the duration of improvement.¹⁷ However, treatment is often not equal between races, despite controlling for demographic, economic, health status, and health utilization factors.¹⁸ Perhaps treatment differences are the result of unexamined cultural factors, although disparities in access to specialty care have also been hypothesized.¹⁸ Certainly PCP's recognition of cognitive impairment is influenced by important patient characteristics, such as race.¹⁹

Because ADRDs interfere with everyday functioning and often result in mood and behavior changes, they can be potentially devastating to the quality of life for individuals and their families. In part due to the slow progression of many dementias, timely assessment is often not done. However, there are many documented advantages of timely assessment, as early

recognition of dementia is important to reducing the burden of suffering, both for individuals and for our society.^{3,20}

Dementia is under-evaluated and under-treated by PCPs. A recent editorial in the *Journal of General Internal Medicine* estimated that primary care physicians will recognize only eight of the twenty-four persons with dementia who are in an average practice load of about 2,000 patients. The editorial attributed this lack of disease identification to limitations of primary care practice, especially in relationship to the biopsychosocial model of health and disease.²¹ In a 2007 cohort study of over 500 patients in three managed care systems in Oregon, only 34.8% of patients classified as moderately to severely cognitively impaired had documentation of cognitive evaluation. In addition, only 4.3% of these patients had been offered one of the first line treatment options, a cholinesterase inhibitor.⁷ However, clinical researchers may bear some of the responsibility for biomedical under-treatment by PCPs, as there has not been sufficient reporting on medication effect.²²

ADRDs alter the long-standing relationship between the practitioner and the individual, requiring the addition of third parties to provide optimal care.³ The third parties, who become involved in medical decision making and care coordination, also act as informal caregivers.²³ Informal caregivers, often family members, can also suffer a decrease in quality of life and have high health care utilization rates – placing additional demands on PCPs to ensure the health of both the individual and the caregiver.²¹ These unpaid caregivers are estimated to include almost 10 million Americans, who in 2008 provided 8.5 billion hours of unpaid care, at a value of approximately 95 billion dollars. Data from the 2004 Behavioral Risk Factor Surveillance System Survey suggests that approximately 12 percent of all North Carolina residents are caregivers for persons with “memory loss, confusion, or a disorder like Alzheimer’s disease.”²⁴ However, according to aging service coordinators in North Carolina, despite the burdens placed on individuals and family caregivers, available services are not well utilized. Persons with early

stage dementia are less likely to be connected to aging services agencies than those persons with moderate or late stages of the disease.¹¹

Although dementia care can be rewarding for practitioners because of the intellectual demand of making a diagnosis, clinical variety, and personal enrichment and significance, there are practice barriers to care, many of which are unique to dementia.^{9,25} For example, barriers include the patient's failure to adopt a "sick role," the difficulty in "relating bad news," "interacting with both patient and caregivers," and "diagnostic uncertainty."⁹ Adams et al. 2005 identified the patient's "impaired ability to provide an accurate history and to participate in self-care" as often resulting in "greater medical uncertainty" and "feelings of inadequacy and frustration for the physician."²⁵ In addition, a recent series of interviews with 40 primary care physicians in northern California found the following real and perceived barriers to be relatively common (in more than 25% of interviews): "insufficient time, difficulty in accessing and communicating with specialists, low reimbursement, poor connections with community social service agencies, and lack of interdisciplinary teams."²⁶

A 2003 Wisconsin needs assessment found that, in addition to practice barriers, knowledge deficits also led to uncertainties for physicians in diagnosing, managing, and providing support to individuals and families.²⁷ The knowledge deficiencies identified included an "inability to identify persons needing evaluation" in the absence of routine screening, an "absence of readily available and easily interpretable diagnostic tools," an "inability to monitor the effectiveness of current therapies," a "lack of information about the benefits of current treatments," and a "lack of knowledge about available resources for patients and families." Perhaps one reason for these knowledge deficiencies is that PCPs do not have much experience managing dementia patients: Although projections for the number of dementia cases are high, the current and past burden of management upon individual PCPs has been relatively low.²⁸ As evident in Table 1, most PCPs (in the counties targeted by this program) may only have, at most,

six diagnosed cases of dementia in their practice, although there may be more than 20 more patients who are candidates for diagnosis.

Table 1. Estimated number of dementia patients in targeted counties.

County	Estimated County Population with ADRDs in 2006 ¹¹ [Diagnosed-(upper estimate of prevalence)]	Number of PCPs in 2007 ²⁹	Pts*/PCP [Column 2 / column 3]
Buncombe	885-(4,807)	488	2-(10)
Henderson	400-(3,037)	147	3-(21)
Madison	82-(470)	17	5-(28)
Transylvania	121-(955)	34	4-(28)
Beaufort	185-(1,005)	47	4-(21)
Bertie	77-(459)	17	5-(27)
Hertford	96-(530)	27	4-(20)
Martin	98-(542)	16	6-(34)
Pitt	586-(1,908)	370	2-(5)

*Pts = Patients with ADRDs

Even if these practice barriers and knowledge deficits are overcome, the increased complexity of dementia care may require an expanded model of care to better address prominent psychosocial and ethical aspects of care.²⁵ Such a model should include multiple disciplines, as the Institute of Medicine called for in 1999, but reimbursement policies do not support this paradigm.²⁵ Although caregiver burden has long been recognized as a predictor of institutionalization in late stages of dementia, linking caregivers to in-home support with personal care and/or chore help during early stages of dementia is also associated with delayed institutionalization.^{30, 31} This early linkage effect on institutionalization delay has been

hypothesized to occur because caregivers are given individualized opportunities to “adapt to the challenges of dementia care earlier.”³¹

Although new models of care may be the future, PCPs have been aware of their knowledge deficiencies and want to learn more about dementia. A 1998 survey of learning interests among PCPs at national conferences found that “Recognize, evaluate, and treat dementia” was the leading topic of 18 choices.³² A 1990 survey of PCPs in North Carolina reported that dementia was the “most challenging” of their “geriatric medicine concerns.”³³ A 2009 systematic review of surveys of primary care showed that physicians have less confidence in treatment matters than in diagnostic stages.²³

As programs, such as the Carolina Alzheimer’s Network, work to reduce the public health burden of dementia, the “fundamental humanity and individuality of each patient” should be remembered – this disease presents differently in each individual. Nevertheless, a broad understanding of challenges for individuals, families, and PCPs is important to improving dementia care for the state of North Carolina. That ADRDs alter an individual’s interaction with the health care system may be best understood by looking at cost: Total per-person payments for individuals with Alzheimer’s disease and other dementias were three times higher for Medicare and more than nine times higher for Medicaid.¹ Reducing the public health burden of ADRDs will involve interventions with PCPs to improve the diagnosing, treating, and health care utilizing practices.

III. Review of Primary Care Practitioner Programs

My literature review for educational programs to primary care practitioners, started with 73 articles from a PubMed search using the terms "education, medical, continuing" and "dementia." I expanded the search using similar terms, such as "training" and "mini-residency," through PubMed, Google Scholar, the *Cumulative Index to Nursing and Allied Health Literature*, and the ISI citations databases. I also searched the references of relevant articles and requested information on a few unpublished programs. In all, seventeen programs were identified to provide a background for the Carolina Alzheimer's Network and its "State-of-the-Art Workshop." Table 2 provides an overview of these programs, including their audience, methods, and the authors' perspective on the success of their education program.

In 1994, researchers in Australia (Pond et al. 1994)³⁴ provided thirteen primary care physicians with fifteen minutes of "academic detailing," during which the detailer, a general practitioner (GP, the term used in other countries to mean primary care physician) with training in geriatric depression and dementia, interacted with the receiving GP(s). The intervention was designed to improve the diagnosis of both depression and dementia among GPs using techniques proven successful by the pharmaceutical industry. During an intervention, advice on overcoming difficulties in diagnosis was provided with written material about the different types of dementia and with specific questions useful to clinically diagnose depression and dementia.

The GPs' ability to diagnosis depression and dementia was compared before and after the intervention using standard screening tools administered independently. The authors concluded that the intervention was successful for depression but not for dementia. The authors learned that several GPs had recently been made aware of their deficiencies in diagnosing dementia and so this may have diluted the intervention effect. Therefore, the authors suggested that future dementia detailing could be targeted to GPs with less knowledge about dementia.

Table 2. Summary of 17 Primary Care Practitioner Programs.

Citation	Audience	Methods	Notes	Success
Pond et al. 1994 ³⁴	13 primary care MDs	One-on-one, 15 minute "academic detailing"	Depression findings	No
Sizemore et al. 1998 ³⁵	28 primary care MDs	8 hour intensive workshop with lecture, discussion	Had referral and community resource training	Mixed
Harvey et al. 2005 ³⁶	10 MDs, RNs, PAs	Train-the-Trainer, 2 hour "Memory Loss Tool Kit"	Only 1 of 8 OLs* conducted sessions	Mixed
	Interdisciplinary, at least 70 people	Three-part case-based videoconferencing	Best practices and clinical judgment	Yes
Byszewski, et al. 2003 ³⁷	145 primary care MDs	Booklet to be read by Ontario physicians	"Driving and Dementia Toolkit"	Yes
Media Release 2004 ³⁸	MDs, educators, medical students	Website with information and web conferencing	up-to-date	NE**
Cherry et al. 2005 ³⁹	345(?) primary care MDs	In-service trainings, "tool kit"	Community referral findings	Mixed
Downs et al. 2006 ⁴⁰	multidisciplinary	Practice based case discussion in small groups	Improved dementia detection	Yes
Chodosh et al. 2006 ⁴¹	8 intervention clinics, 129 MDs	5 x 20 minute modules, small group discussion	Optional and poorly attended	No
Kovacich et al. 2006 ⁴²	multidisciplinary	Interactive powerpoint presentations	Meharry: 3 x 20h CME^ programs	NE^^
		Online self-study module	Harvard	NE^^
		1 hour computer module with case study, communication program	South Carolina: Driving with Dementia	NE
		12 hours of lecture, role-play, discussion, and videotaped vignettes	South Carolina: Train-the-Trainer	NE^^
Dalsgaard et al. 2007 ⁴³	19 MDs	1 hour open discussion with leaflet	Similar to Train-the-Trainer	Yes
Wenger et al. 2009 ⁴⁴	20 MDs (1 NP?)	3hr program, fliers	ACOVE, findings for falls and urinary incontinence	No
Vollmar et al. 2007 ⁴⁵	174 MDs	Internet-learning vs. lecture vs. control	Studying knowledge gain	NE
Meuser (Unpub.) ⁴⁶	multidisciplinary	3 day mini-residency, with didactic, observational, and skill-based learning	Targets rural health providers	NE

* OLs = opinion leaders (8 total: 6 primary care MDs, 1 geriatrician, 1 geriatric nurse practitioner)
 ** NE = no evidence
 ^ CME = continuing medical education
 ^^ no evidence among primary care practitioners

In 1998, faculty from the University of Texas Southwestern Medical Center at Dallas (Sizemore et al. 1998)³⁵ designed and evaluated an intensive workshop for twenty-eight primary care physicians in the diagnosis and long-term care management of Alzheimer's disease.³⁵ They also had a secondary objective of creating a "cadre of primary care physicians who could train health care providers in their communities and maximize dissemination of the information in the community." The seminar content included: current scientific research, diagnosis, behavioral management, current and developmental medications, concurrent medical illnesses, caregiver burden and coping abilities, and community resources.

The findings of their evaluation were mixed, in part due to high baseline measurements of physician knowledge and to a low posttest response rate. Although the intervention did not improve physician knowledge of dementia, it did slightly improve physician knowledge about available community resources. However, the authors concluded that modification of the evaluation approach was indicated to directly measure community referrals. In regards to the secondary objective, the trained PCPs did not end up training significant numbers of community physicians, but they did disperse resources to other professionals, such as nursing home staff.

In 2005, Veterans Health Administration directors of physician education for Alzheimer's disease and dementia (Harvey et al. 2005)^{36, 47} published methods and evaluations for two programs developed in a network of eight facilities. The first program, "Train the Trainer," used six primary care physicians, a geriatrician, and a geriatric nurse practitioner as opinion leaders (OLs) for disseminating continuing medical education.⁴⁷ These eight OLs were trained in a weekend lecture and discussion workshop to present a two hour program discussing cases and the use of resources provided in a tool kit, called the "Memory Loss Tool Kit." The tool kit included professional resources and patient education materials. Although the program intended for each of the OLs to make at least two presentations to other practitioners, including physicians, nurses, and physician assistants, only one of the eight OLs actually made

presentations (three). Another paper studying the process of OL selection, training, and follow-up, identified a need for improved follow-up with OLs and evaluation of their activities.⁴⁷ The most important barriers, expressed as reasons for lack of follow-through by the OLs, included “lack of time and local support.”³⁶ Nevertheless, the participants, trained by the OLs, indicated that about 40% of the material was new, and that the presentations increased their knowledge and skill related to memory loss.

The second program, “Case Studies in Dementia,” used videoconference technology to present a three-part Grand Rounds, attempting to provide an interactive dialogue about best practices and to build clinical judgment.³⁶ The series occurred in the same region as the first program and used a case to illustrate best practices in screening and cognitive testing, administration and scoring of the CLOX⁴⁸ (an executive clock drawing task), discussion of concomitant depression, and both pharmacologic and nonpharmacologic treatment for cognitive decline. Although, originally, there were difficulties with the videoconferencing technology, the series was conducted four times to mixed audiences of physicians, nurses, social workers, psychologists, occupational therapists, and pharmacists. The evaluation is formative, but early findings were that 85% of attendees said they would use the information to “enhance their clinical practice.” The study authors concluded that this was a feasible and successful way to create an ongoing dialog about dementia patient care with providers who are motivated.

In many ways, Canadian physicians have pioneered programs for dementia care in primary settings. In 2003, academicians in Ottawa (Byszewski et al. 2003)³⁷ published findings from their dissemination of a “Driving and Dementia Toolkit” to 145 primary care physicians through the Dementia Network of Ottawa. The original toolkit was printed as a booklet, containing “background information,” “an algorithm of local resources,” forms for accessing the local resources, “screening questions about older drivers’ safety,” “patient-related information,” and a “list of frequently asked questions.” Eighty-six physicians completed the evaluation which

indicated that this intervention increased knowledge and confidence in dealing with driving in persons with memory loss. The authors eventually put the toolkit online and concluded that this type of intervention could be developed for other targeted issues, such as disclosure of dementia diagnosis, capacity assessments, and end-of-life issues.

In 2004, the Ontario College of Family Physicians and the Physician Education Initiative of the Ontario Strategy for Alzheimer Disease and Related Dementias (Media Release 2004)³⁸ launched a website for physicians, educators, and medical students, based on their review of 22 existing dementia education websites. Their website, www.dementiaeducation.ca, offers “up-to-date information on dementia and features web conferencing, e-mail, surveys, boardroom capabilities, and more.” The website technology is the result of a shift towards on-line learning that is “flexible” and “interactive.” The developing committee included representatives from the Alzheimer Society of Ontario, as well as from family medicine, geriatric medicine, and geriatric psychiatry physicians. I was not able to find an evaluation of this online resource.

In 2005, the Kaiser Permanente-Alzheimer’s Association Dementia Care Project (Cherry et al. 2005)³⁹ published results from their multi-intervention program to improve implementation of practice guidelines. The program staff originally developed their own guidelines, but later endorsed 2002 guidelines from the journal *American Family Physician*.⁴⁹ The educational interventions included broad dissemination to physicians of a pocket version of the guideline, a “tool kit,” and annual in-service training, which included a presentation by a theater troupe to increase physician empathy for presenting families. Evaluation by medical record abstraction and a three-year follow-up survey of physicians (126 of 345 physicians returned the surveys) found improved adherence to these guidelines. In addition, structured interviews (conducted with 83 caregivers pre- and post- intervention) showed improvements in satisfaction and in several quality measures, including community services referral. However, the contributions of

the education program to improving adherence was not clear, while the contributions of the social work care managers was clearly linked to improving adherence.

In 2006, researchers in the United Kingdom (Downs et al. 2006)⁴⁰ published the results of a cluster randomized design of 36 primary care practices to either placebo control (10) or one of three educational arms (26) for improved dementia detection. Eight practices were assigned to electronic tutorial, 10 to practice based workshops (consisted of case discussions in small, multidisciplinary groups of general practitioners and practice nurses), and 8 to decision support software built into the electronic medical record. Both the workshops and the decision support software arms showed significantly better detection of dementia based on reviews of medical records. However, neither arm showed significant improvement in adherence to guidelines for diagnosis or management. The results are encouraging in the development of multiple approaches to dementia detection, although this was done without improving adherence to guidelines.

In the same year, Veterans Health Administration physicians in California (Chodosh et al. 2006)⁴¹ published a study of a controlled, pilot-tested, comprehensive care management program in eight of sixteen primary care clinics in San Diego. The program included care managers, software support for communication between care managers and medical providers and for referrals to community agencies, collaborative care planning with caregivers, caregiver self-management support, and ongoing follow-up. In addition to the care management program, there was an optional provider education intervention. This education intervention had five, 20 minute modules of small group presentation and discussion at each intervention clinic (129 MDs at the 8 intervention clinics). Topics included information on the care management program, recognition and treatment of concurrent depression and also concurrent delirium, and assessment of capacity for medical decision-making. However, on average, physicians only completed 40% of the material (median of one module). The authors concluded that, although the care

management program resulted in better quality of care, the success was not mediated by the primary care physicians (the education intervention).

Also in 2006, three directors of Geriatric Education Centers (GECs) reviewed (Kovacich et al. 2006)⁴² current efforts to provide multidisciplinary education and materials to medical students, physicians, and other health providers. Their paper focused on describing the work at three GECs: the Meharry Consortium GEC (in Tennessee), the Harvard Upper New England GEC, and the South Carolina GEC. None of the program evaluations have information specific to the utility of the trainings for PCPs.

The Meharry Consortium GEC offers three 20-hour CME-certified Medical Gerontology certificate programs related to the differences between dementia and normal aging. The titles of the certificate programs are “The Biopsychosocial Model of Aging,” “Clinical Aspects and Disease,” and “Cognitive Vitality.” The programs are targeted to health professionals and students, although open to “any employed individual who works with older adults.” The sessions are interactive powerpoint presentations, also offered at distance learning locations. Qualitative analysis of surveys by the more than 300 participants has shown knowledge gain and improved ability to provide higher quality patient care. Over 50% of participants plan to share parts of the training with their staff or to encourage their staff to attend the training. However, the evaluation did not evaluate primary care practitioners, as a subgroup, of all participants.

The Harvard Upper New England GEC seeks to provide “anytime, anywhere evidence-based clinical practice information” through a series of online self-study modules. The first and only module so far, “Alzheimer’s Disease and Related Dementias” module is for health care professionals, regardless of occupation, and includes a segment on the collaborative roles of social work, occupational therapy, physical therapy, nutrition, and nursing. The topics covered in this module include diagnostic criteria for Alzheimer’s dementia, cognitive assessment tools and their limitations, clinical presentation of various stages of the disease, neuropathological

changes, new discoveries in genetics, contemporary treatment options, and support systems for caregivers and families. There are links to patient-appropriate materials and an additional case study on shared-decision making. Of the 113 end users from various professions and levels of education, 93 percent would recommend the module to others.

The South Carolina GEC offers two training programs for multiple disciplines: “Driving with Dementia: Framing the Discussion” and “The FOCUSED Program: A Communication Guide for Alzheimer’s Disease.” The program about driving has not yet been evaluated but is a one hour module, suitable for self-study, with three objectives: to identify risk factors for unsafe driving, build basic skills of driving assessment, and learn different approaches to assist drivers and their families with driving reduction. The module includes PowerPoint slides with notes, a case study, and resources.

The FOCUSED program for improving the quality of health-related decisions through effective communication includes 12 hours of lecture, role-play, discussion, and videotaped vignettes that can be used for train-the-trainer and in-service education for health care providers, long-term care staff, and family caregivers. The content areas include communication techniques (Face the person, Orient to the topic, Continue the topic, Unstick communication blocks, Structure with questions, Exchange conversation, use Direct statements) and implementation, Alzheimer’s disease related language decline, the value of interpersonal skills, and cultural aspects of communication. One hundred sixty-five professionals and caregivers have given the program an average rating of four on a scale from one to five. Six trainees in the train-the-trainer workshop have already trained over 100 persons. As with all of the GEC programs, no subgroup analysis was done of PCPs.

In 2007, the Quality Improvement Committee for General Practice in the former Vejle County in Denmark (Dalsgaard et al. 2007)⁴³ used qualitative methods to explore the perception of 19 general practitioners (GPs) towards a “facilitator” program of one hour “outreach visits” to

their practices. These visits were for all GPs at a practice and lasted one hour. A total of 162 GPs received the visits by facilitators, who were also GPs trained at a two-day workshop. The hour “outreach visit,” supplemented by a leaflet, involved an open period of questions and discussion focused on three topics: the good referral, the collective agreement, and practical problems (including acute medical treatment). In their evaluation of the visits, the authors found four themes reported by the receiving GPs: increased knowledge about dementia, motivation for self-learning and improvement, implementation of a structured assessment and management, and reflection on dementia care. They suggested that these themes point to the success of the program towards integration of factual knowledge in clinical practice. The authors attributed these successes to the interactive nature of the program that allowed for contextual application.

In 2009, researchers in Southern California (Wenger et al. 2009)⁴⁴ reported on results of a multi-component, practice-based intervention to help practices achieve processes of care consistent with the Assessing Care of Vulnerable Elders (ACOVE) quality indicators⁵¹ for falls, urinary incontinence, and dementia.^{44, 50} The intervention, largely described in another paper⁵¹, included a three hour education program introducing a time-efficient approach, one which did not add length to the patient’s visit. In addition, the physicians were provided with brief, decision-support fliers, based on the American Geriatric Society’s *Geriatrics at Your Fingertips*.⁵² Twenty of the 40 practitioners (39 MDs, 1 NP) participated in the intervention, which also involved medical record prompts, patient education materials, and clinical data collection by nonphysicians. The intervention improved care for falls and urinary incontinence, but not for dementia. The authors did not offer any hypotheses about why this occurred.

As studies have continued to find dementia programs for physicians to have mixed success, programs with different approaches are still being developed. Vollmar et al. 2007 described plans in the United Kingdom to study knowledge gain for 174 general practitioners (GPs), as well as other effects on the GPs’ practice behaviors.⁴⁵ There are three study arms, of

which one is a control. The first intervention involves a “blended-learning approach,” with an internet-based learning module and a structured case discussion. The second study arm relies on a more “classical” approach, with a slide presentation and follow-up discussion. The third arm, the control, will receive some written material on dementia care guidelines.

Another program, yet to be published (Meuser)⁴⁶, is being offered by the Alzheimer’s Disease Research Center at Washington University in Missouri and was developed in response to a state-wide survey of clinician beliefs and practices in dementia care which showed a preference for group lecture and group case presentation formats.^{46, 53} This three day mini-residency program is multidisciplinary and has already trained physicians, nurses, physician’s assistant, psychologists, social workers, dementia educators, and pharmacists.⁴⁶ The training is targeted to rural health providers and covers a wide-range of topics with didactic, observational, and skill-based learning. Topics have included neuropathology, genetics, clinical interviewing for early detection, use of screening measures, differential diagnosis, assessment of driving skills, and grief and coping processes in family caregivers. So far, the clinicians have viewed the training as valuable and preliminary findings have shown “modest gains” in knowledge and confidence.

IV. Conclusion in Context of Recommendations from the Administration on Aging

As my literature review highlighted, there have been many interventions in PCP dementia education that have had minimal to mixed success, even when similar education initiatives for other geriatric conditions have had good success. As a result of continued uncertainty, novel programs continue to be developed throughout the world, although traditional in-person, group lecture and case presentation continuing medical education, continue to be acceptable and even preferred by primary care physicians.⁵³ As several of the more recent studies demonstrated, PCP education may become more regularly incorporated with that of other disciplines, potentially necessary to meet the needs of the increasing population of persons with ADRDs.⁵⁴

However, for now, in seeking to guide the development of demonstration programs, the Alzheimer Association provides three “general principles for establishing and sustaining physician outreach programs.”⁵⁵ The first principle is that the programs must be designed with, for, and by physicians. Successful implementation of this principle involves four accomplishments: identifying a physician champion to articulate the specific benefits of physician education to peers, utilizing acceptable adult teaching methods, addressing identified physician issues, and providing accredited Continuing Medical Education. The second principle is to use state and local partnerships and existing networks to develop and publicize programs. The third principle is to identify essential education components.

I think these principles are useful because they acknowledge the significant uncertainty in dementia education but focus on creating efficient, contextual interventions to network physicians. Improving dementia care through education is obviously difficult and it appears that “multifaceted interventions,” instead of “simple educational initiatives,” are probably the key.⁵⁶ However, as reviewed here, there are useful models for us to use as building blocks in the development of the Carolina Alzheimer’s Network and its “State-of-the-Art Workshop.”

Program Plan

I. Introduction

The Duke Endowment has funded activities to develop a primary care practitioner (PCP) network, known as the Carolina Alzheimer's Network (CAN), to meet the growing public health issue of dementia care in North Carolina. In addition, the Administration on Aging has funded demonstration activities to strengthen linkages with aging services providers. This program plan for CAN approaches the activities funded by both the Duke Endowment and the Administration on Aging as complimentary and explains CAN's approach to providing proven context-appropriate interventions, as well as several novel, demonstration activities. Together, the activities funded by both grants provide "specialized dementia care," the overall program goal cited in the Duke Endowment grant application.¹⁰

With any long-term program, but especially one such as CAN that is seeking to meet such a large public health issue, sustainability is a serious concern that requires an in-depth examination of the program context, at the national, state, and local levels. Sustainability needs to be regularly re-evaluated, as time and resource limits can threaten the replication and/or sustainability "of programs in a manner that maintains fidelity to the interventions."⁵⁷ Through my involvement as a volunteer with this program, I have begun to recognize the ways in which CAN is well-prepared to provide an ecological approach for such "specialized dementia care," care that is "comprehensive" and "accounts for the many dimensions of patient and caregiver needs."⁵⁸ By networking primary care practitioners (PCPs) and linking them with aging services providers, this plan seeks to demonstrate effective, as well as sustainable practices for dementia care activities throughout the state.

II. Program Context

Program Goal and Grant Proposals

Carolina Alzheimer's Network (CAN) Program Goal: To expand resources for specialized dementia care for individuals with ADRDs and their families throughout North Carolina, including poor, rural, and underserved areas.

Grant Objectives and Strategies: *(developed during the grant writing process)*

Duke Endowment grant¹⁰ objective: Provide training and support to a statewide sample of primary care practitioners through outreach efforts by the University of North Carolina (UNC) Memory Disorders Clinic. (September 1, 2008 through June 30, 2011)

- Strategy 1a. Expand the clinical space and training/consultative capacity of the UNC Memory Disorders Clinic, so as to enhance the Clinic's ability to serve as the clinical care and training hub of the proposed program.
- Strategy 1b. Provide of four education outreach programs per year: two for consumers and non-medical professions and two for community medical care providers.
- Strategy 1c. Establish a two-day preceptorship/training program for community physicians in Alzheimer's care, and training of 36 practicing physicians.*
- Strategy 1d. Develop and maintain web-based educational and training materials for primary care physicians (MDs), nurse practitioners (NPs), and physician assistants (PAs).
- Strategy 1e. Establish a statewide Carolina Alzheimer's Network (CAN) registry.

Project Directors:

Daniel Kaufer, MD: Director of the UNC Memory Disorders Clinic; Associate Professor of Neurology

Philip Sloane, MD, MPH: Co-Director of the Program on Aging, Disability, and Long-Term Care, Professor of Family Medicine

Administration on Aging grant¹¹ objective: Establish a partnership between CAN and the state's aging services network in North Carolina. (April 1, 2009 through September 30, 2010)

- Strategy 2a. Develop and implement mechanisms to strengthen the linkages between primary care medical providers and aging service network providers in two service regions of the state.*
- Strategy 2b. Provide counseling for all new clients, a minimum of 112 hours of group support and education services, and ongoing respite services for 26 new clients as a result of the project
- Strategy 2c. Evaluate the effectiveness of the project using the RE-AIM model, and disseminate results.

Project Director:

Philip Sloane, MD, MPH: Co-Director of the Program on Aging, Disability, and Long-Term Care, Professor of Family Medicine

Project Co-Director:

Karisa Derence, MA: Division of Aging and Adults Services Alzheimer's Support Specialist

** As this paper's evaluation plan focuses on the "State-of-the-Art Workshop," I have developed an objective for this workshop, using both strategies 1c and 2a. This objective: By June 2011, provide state-of-the-art workshops in dementia care and service referral for at least 6 PCPs in all 17 Area Agency on Aging regions.*

Background

The Carolina Alzheimer Network (CAN) is funded by two grants, one from a private, regional organization, the Duke Endowment, and one from a federal organization, the United States Administration on Aging. These two grant sources symbolize the growing regional and national interests in dementia care research and support which have made the CAN program possible. Recognizing these growing interests and developing program priorities in line with those of both stakeholders and policy-makers, CAN could become sustainable in North Carolina and, at least in part, reproducible in other states. Directed by two faculty members of the School of Medicine, this program continues to develop alliances with leaders from other disciplines and agencies.

Consistency with National and State Priorities

The goal of CAN, “to expand resources for specialized dementia care for individuals with ADRDs and their families throughout North Carolina, including poor, rural, and underserved area,”¹⁰ seems consistent with the goals of *Healthy People 2010*, to “increase quality and years of healthy life” and to “eliminate health disparities.”⁵⁹ Indeed, Dementia, and specifically Alzheimer’s disease, is recognized in the *Healthy People 2010* “Issues” statement about mental health, one of the ten leading health indicators.⁶⁰ However, there are no objectives directly related to dementia within the goal of “[improving] mental health and [ensuring] access to appropriate, quality mental health services.”⁶⁰ Nevertheless, improving dementia care does seem to be a national priority and is highlighted by the US Senate’s Special Committee on Aging, a committee whose foci include the issues of “health care for seniors” and “long-term care.”⁶¹

However, the Special Committee on Aging is not the only group considering improvements to dementia care at a national level. In June of 1999, the bipartisan, bicameral Congressional Task Force on Alzheimer’s Disease was established to bring national attention to

“Alzheimer's and the grave public health threat it presents” and to advocate for increased funding for research and improved care.⁶² In 2007, the task force established the Alzheimer's Study Group to create a plan to “overcome America's mounting Alzheimer's crisis.”⁶³ This plan, “A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group,” was released at a hearing of the US Senate's Special Committee on Aging on March 25, 2009.⁶⁴ The report recommendations focus on the creation of a national project and on rallying the President of the United States to support such a project.⁶³ However, regardless of future federal priorities, dementia care will likely remain on the agenda of future congresses and administrations because of the growing role dementia will play in Medicare spending.⁵

Federal funding for dementia is another indicator that improving care is a national priority. Since 1992, with the passage of the Public Health Services Act, the Alzheimer's Disease Supportive Services Program (ADSSP), formerly known as the Alzheimer's Disease Demonstration Grants to the States, has provided grants to “expand the availability of community-level support services for persons with Alzheimer's Disease and related disorders.”¹² Currently there are two categories of grants, the first category is for evidence-based interventions and the second category, the type awarded to the State of North Carolina for CAN, is for exploring “innovative approaches to improving the delivery of supportive services at the community-level to people with ADRD and/or their caregivers.”¹² This category, entitled “Innovation Grants to Better Serve People with Alzheimer's Disease and Related Disorders,” provides finances for CAN from April 1, 2009 through September 30, 2010.⁶⁵

The ADSSP is one of at least five federal funding sources for Alzheimer's disease research, most of which is biomedical research through the National Institutes of Health's National Institute on Aging (NIA).⁶⁶ Since 1999, the National Alzheimer's Coordinating Center has facilitated collaborative research among the 29 NIA-funded Alzheimer's Disease Centers nationwide.^{67, 68} The center in North Carolina, at Duke University, was founded in 1985, one

year after the NIA began funding such centers.^{69,70} In addition, other nationwide nonprofit organizations, such as the Alzheimer's Association and the Alzheimer's Drug Discovery Foundation, fund research into Alzheimer's disease.⁴

Improving dementia care is also important to the state of North Carolina. In the primary sign of state support for the CAN program, Ms. Derence, an Alzheimer's Support Specialist with the North Carolina Division of Aging and Adult Services, of the Department of Health and Human services of the State of North Carolina, is co-directing the ADSSP grant, with Dr. Sloane of the University of North Carolina-Chapel Hill (UNC-CH) School of Medicine. Ms. Derence is also the project director for an "evidence-based intervention" through ADSSP, making North Carolina one of only six states to have received a federal grant in both categories.¹²

Just as Medicare spending will keep dementia care an important consideration at the federal level, so will Medicaid spending keep dementia care on the agenda at the state level⁵, as North Carolina is projected to be among the top eight states in the total number of persons with Alzheimer's disease by the year 2025.¹ Certainly the Duke Endowment, in their goal of expanding "preventive and early intervention programs, improve the quality and safety of medical services and increase access to care," have recognized the importance of programs such as CAN to the state of North Carolina.¹⁰ This grant provides finances for CAN from September 1, 2008 through June 30, 2011.

In developing the ADSSP grant and trying to understand statewide priorities, Dr. Sloane and Ms. Derence consulted with four aging service coordinators in the state to identify "areas of need for dementia care."¹¹ The five areas of identified need in North Carolina were:

- a) "Agencies have difficulty identifying and linking with family caregivers, especially in rural counties.
- b) "Physicians and other primary medical care providers are uncommon sources of referral to agencies, and agency attempts to partner with physicians have had limited success.

- c) “Physicians often are not familiar with available community resources or how to refer patients and families to them.
- d) “Families often are reluctant to accept resources; barriers include pride/stigma, financial concerns, and not considering service agency linkages as part of care (because physicians do not recommend them).
- e) “Persons with early dementia are especially difficult to reach.”¹¹

Together, these identified areas of need are useful for understanding the priorities of the state’s aging service coordinators and providers.

Alliances

Although CAN is a state-wide initiative, local and regional alliances, with persons and organizations who have similar goals, are crucial to sustaining the program and providing “specialized dementia care” long-term. The two strongest alliances are with the UNC Memory Disorders Clinic and the Program on Aging, Disability, and Long-Term Care at the Cecil G. Sheps Center for Health Services Research. Both of these organizations have broad influences throughout the state. As co-directors of the Duke Endowment grant, Dr. Kaufer, founder and director of the UNC Memory Disorders Clinic, and Dr. Sloane, co-director of the Program on Aging, Disability, and Long-Term Care and Professor of Family Medicine, demonstrate their respective programs’ interest.

The UNC Memory Disorders Clinic, within the Memory and Cognitive Disorders Division of the Department of Neurology, has two overarching goals.⁷¹ The first, to “improve the assessment, diagnosis, and treatment of dementia” means that clinic personnel will be knowledgeable about and participating in the latest research in dementia care. The second goal, to “better characterize disorders of individual higher cognitive functions, their clinical inter-relationships, and their genetic and neuroimaging correlates” means that the clinic is pursuing an

integrative, multidisciplinary approach. The Memory and Cognitive disorders Division, which Dr. Kaufer chairs, has alliances with the Schools of Public Health and Social Work, the UNC Aphasia Center, the Cecil Sheps Center for Health Services Research, and several other basic research and clinical care programs within the School of Medicine.⁷¹

The Program on Aging, Disability, and Long-Term Care operates within the mission of the Cecil G. Sheps Center for Health Services Research, which “seeks to improve the health of individuals, families, and populations by understanding the problems, issues and alternatives in the design and delivery of health care services.” The center seeks to accomplish this mission through an “interdisciplinary program of research, consultation, technical assistance and training that focuses on timely and policy-relevant questions concerning the accessibility, adequacy, organization, cost and effectiveness of health care services and the dissemination of this information to policy makers and the general public.”⁷² Within this mission, the Program on Aging, Disability, and Long-Term Care recognizes that “the rapid growth of the nation's older population has brought about an increasing awareness of the special health service needs of older adults” and that “there are significant demands on the families, lay persons and professionals who deliver health services to this population.”⁷³ In addition to Dr. Sloane, Dr. Zimmerman, the other co-director of the Program on Aging, Disability, and Long-Term Care is involved in the program as the project evaluator for the Duke Endowment grant.

By signing-on as the Administration on Aging project evaluator, Dr. Altpeter, a senior research scientist with the Institute of Aging, has demonstrated the interest that the Institute on Aging has in the CAN program. The Institute on Aging, based at UNC-CH but representing the entire 16-campus University of North Carolina System, has a state-wide mandate to “promote collaborative applied and basic gerontological research, develop innovative programs of interdisciplinary gerontological education and practice, and provide state-of-the-art information to policy makers, program managers, service providers, clinicians, and the general public” – a

mandate consistent with the goal of CAN to expand resources for providing specialized dementia care.⁷⁴

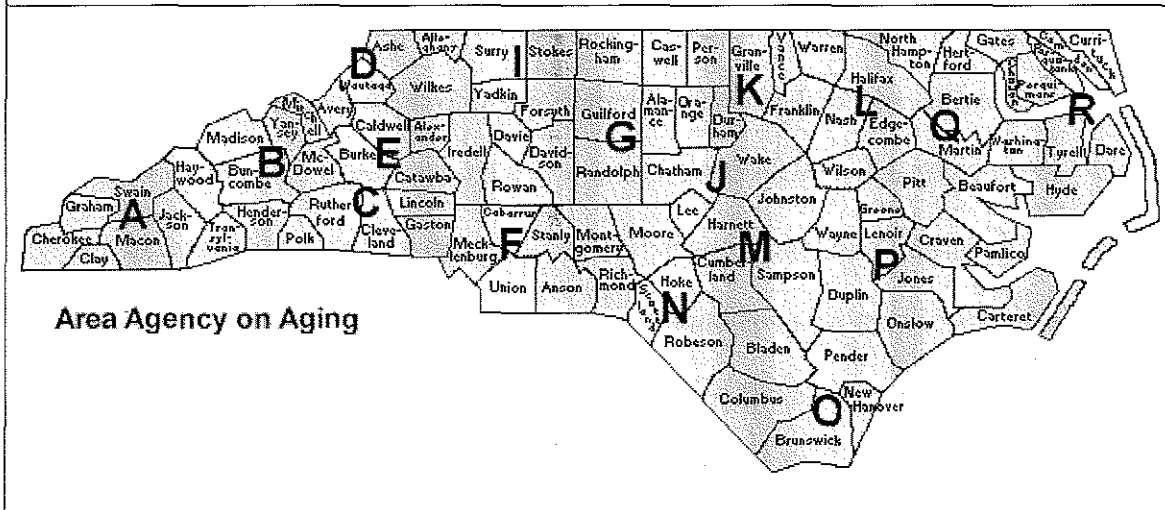
In addition, another local program which has state-wide influence, the Duke Family Support Program, has demonstrated commitment to CAN, with the director, Ms. Gwyther, signing-on as a project consultant. The Duke Family Support Program is funded by the North Carolina Division of Aging as “NC’s one-stop clearinghouse, crisis hotline and technical assistance center for families and professionals caring for people with memory disorders.” Their newsletter, The Caregiver, links families and professionals caring for persons with memory disorders and is the “oldest continuously publishing family caregiver newsletter in the US.”⁷⁵

In seeking to establish partnerships between PCPs and aging services providers, CAN already has the support of several regional agencies, such as the Area Agency on Aging (AAA) in regions B and Q (Map 1) and the two North Carolina Alzheimer’s Association chapters. AAA coordinators, Carol McLimans and Cynthia Davis, in regions B and Q, respectively, have already agreed to serve as regional project coordinators with the Administration on Aging grant. Establishing alliances with these state-wide agencies, in their respective missions of responding “to the needs of Americans 60 and over in every local community” and eliminating “Alzheimer’s disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health,” will be key to the regional sustainability and program success of CAN.^{76, 77} Although there are only two Alzheimer’s Association chapters in the state, there are a total of 17 AAAs which could be connected and linked to CAN.

The next most obvious alliance is with the University of North Carolina at Chapel Hill, mandated in its charter to serve as a resource for the state,¹¹ and its School of Medicine, with its mission of “achieving excellence and providing leadership in the interrelated areas of patient care, education, and research... to meet the needs of our local, state, national, and global

communities.”⁷⁸ Although Drs. Sloane and Kaufer are professors within the School of Medicine, they will need to develop other allies within the school and university to take full advantage of the available resources, such as public health student volunteers and satellite locations throughout the state.

Map 1. Area Agency on Aging Regions.⁷⁹



State-wide with regional agencies, the North Carolina Area Health Education Centers (AHECs) program, is also an important alliance to develop. One regional agency, Mountain AHEC, provided meeting space for the first CAN workshop. Their example of logistical support could be a model supporting state-wide sustainability, especially in rural regions where AHEC may be the only program present. Certainly the state-wide program’s mission, “to meet the state’s health and health workforce needs by providing educational programs in partnership with academic institutions, health care agencies, and other organizations committed to improving the health of the people of North Carolina” could lend itself to support CAN activities.⁸⁰ It seems likely that other AHECs would also be willing to provide CAN with resources, including meeting space, long-term.

Program Acceptability and Model

CAN and the workshop must be acceptable to both target populations: the direct recipients of the workshop, the PCPs, and the indirect recipients, but primary target population, the persons with ADRDs and their families. Table 3 provides 2007 licensure information on the number of PCPs in the targeted regions, as well as projected population figures and the number of neurologists.

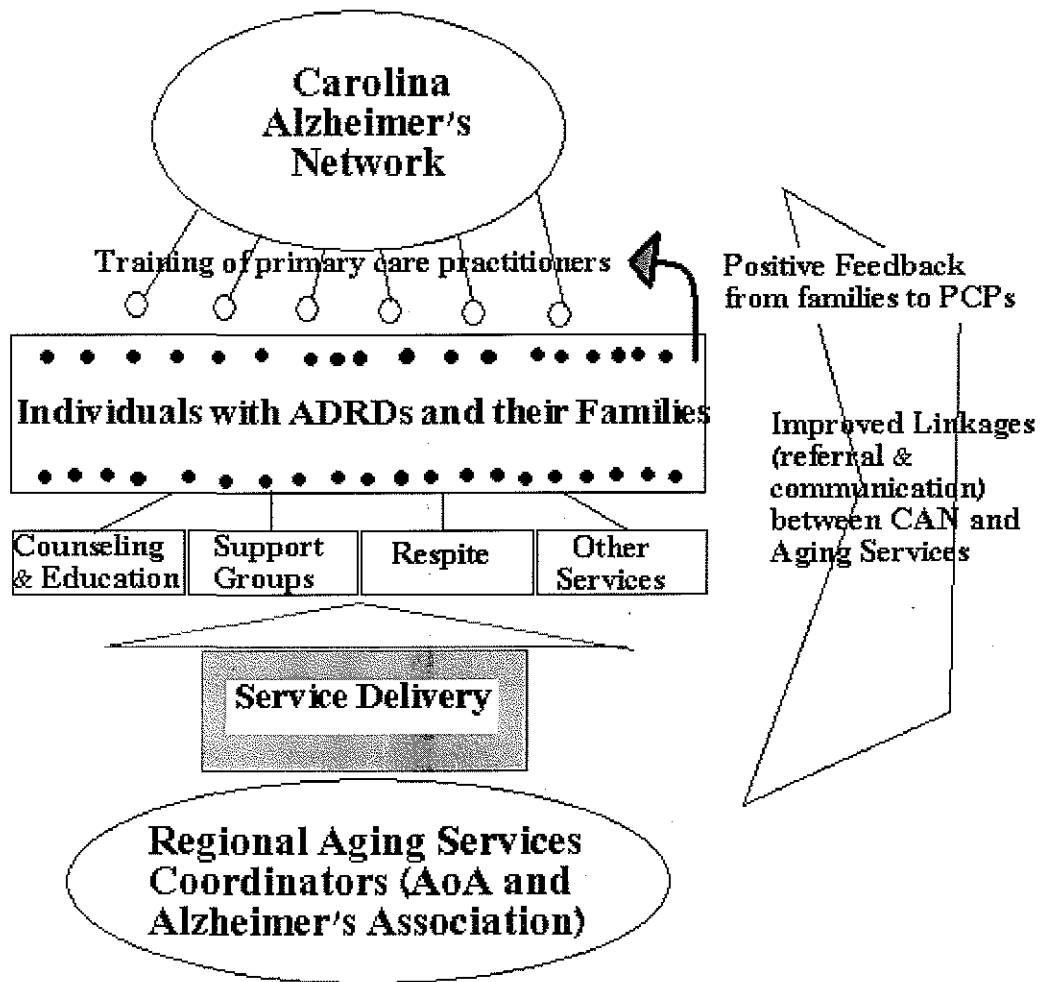
As previously reviewed, dementia care presents many unique challenges to PCPs.^{3, 9, 21} Therefore, if PCPs are approached with adequate reimbursement for their time and given administrative support to be involved with CAN, it seems that they would be very amenable to the program. As will be discussed, CAN personnel will provide pre-workshop visits designed to collect data for a needs assessment of attending PCPs and their practices. There are many reasons for this assessment, including an assessment of their interest and learning about the incentives and programming resources necessary to maintain program acceptability to PCPs and their practices.

As also previously reviewed, persons with ADRDs and their families need support and want resources.^{20, 21, 23} Therefore, if the PCPs and/or CAN provides individualized and family support and resources, these stakeholders would also be amenable and hopefully would provide positive feedback to providers about the training and services offered through CAN, as demonstrated in Figure 1: *Program Model Demonstrating Positive Feedback to PCPs*. In addition, surveys and feedback will be provided by the aging service agencies, to further assess program acceptability and effectiveness in serving individuals with ADRDs and their families.

Table 3: Primary Care Practitioners in Target Regions and Counties in North Carolina²⁹

County	Projected Population		# Primary Care Practitioners			65+/PCP	Neurologists
	Total	65+	MD	NP	PA		
AAA Region B							
Buncombe	225,609	34,100	234	121	133	70	12
Henderson	102,142	21,793	80	37	30	148	2
Madison +	20,495	3,334	11	4	2	196	0
Transylvania +	30,758	7,249	25	6	3	213	0
AAA Region Q							
Beaufort	46,070	7,751	26	13	8	165	0
Bertie + #	19,971	3,276	5	4	8	193	0
Hertford + #	23,730	3,800	14	5	8	141	0
Martin + #	23,906	3,811	12	1	3	238	0
Pitt #	151,970	14,563	168	111	91	39	12
<p>MD = Physicians in family practice, general practice, and general internal medicine; NP = nurse practitioners; PA = physician assistants; 65+/PCP = Number of persons 65+ per Primary Care Practitioner; + = rural counties; # = counties whose population is more than 33% non-white;</p> <p>Source: North Carolina Health Professions Data System (2007)</p>							

Figure 1: Program Model Demonstrating Positive Feedback to PCPs ^{adapted from 11}



Initial Challenges and Feasibility

The first challenge to CAN is recruiting PCPs to the workshop to invite them into the network. By offering Continuing Medical Education (CME) credits through the workshop, as well as financial reimbursement, CAN hopes to accomplish this goal. In addition to CAN mailers (Appendix 1), recruitment and support for these physicians will be provided through the Area Agencies on Aging and CAN personnel pre-workshop visits. To make sure that physicians can attend, the workshop schedule has been limited to one full day, a Saturday, in the AAA region, making the workshop accessible to PCPs traveling by car.

The second challenge is strengthening, or even establishing, linkages with aging services providers. According to a series of telephone interviews with aging services providers in North Carolina, PCPs are not currently “familiar with available community resources or how to refer patients and families to them.”¹¹ Although aging services are important to providing dementia care, as previously reviewed, many families may be reluctant to pursue or even accept such resources because they do not view them as part of care, perhaps because physicians do not recommend them.¹¹

The Long-Term Challenge of Sustainability

A third challenge is to establish a sustainable foundation of finances, logistics, and administration. For finances, CAN should begin to look soon for funding other than the current sources. Especially in light of the 14.9% midyear budget gap being experienced by the state of North Carolina, with projected shortfalls into 2010 and beyond, state funding will be very limited and perhaps other federal grants should be explored.⁸¹ However, once the network, linkages, and activities are established, costs should be greatly reduced if strong alliances are developed which allow for resource sharing. Nevertheless, early demonstration of program effectiveness and a comparison of the costs and benefits of the program will be important to obtaining further financial support. This demonstration is also required under grant guidelines.

Finding logistical support throughout the state will be a challenge, especially in rural areas. The types of logistical support needed include space, materials, and staff for training PCPs. Obtaining logistical sustainability will require pursuing regional groups and organizations, as well as individuals. Examples of regional groups, other than those mentioned in the Alliances section of this paper, include local churches and medical societies. In addition, the Duke Alzheimer's Disease Center and other programs within the Division of Health Affairs at UNC-CH, such as the Division of Geriatric Medicine within the Department of Internal

Medicine, the Department of Psychiatry, and the Schools of Public Health and Social Work could provide valuable resources. Other resources could be identified and/or provided by state-wide professional societies, such as the North Carolina Association of Family Physicians, and nation-wide patient advocacy organizations such as the National Alliance for Caregiving or the Lewy Body Dementia Association. Even pharmaceutical companies and their unrestricted education grants could be useful allies in this process.¹⁰

Administration, made up of dedicated professionals and volunteers for long term sustainability, also needs to be identified. Ideally the current administration of the UNC Memory Clinic and the Program on Aging, Disability, and Long-Term Care can expand to include partnerships with leaders from organizations such as the AHECs, AAAs, and the School of Medicine.

III. Program Activities and Priority Setting

Proposed Activities and Theory

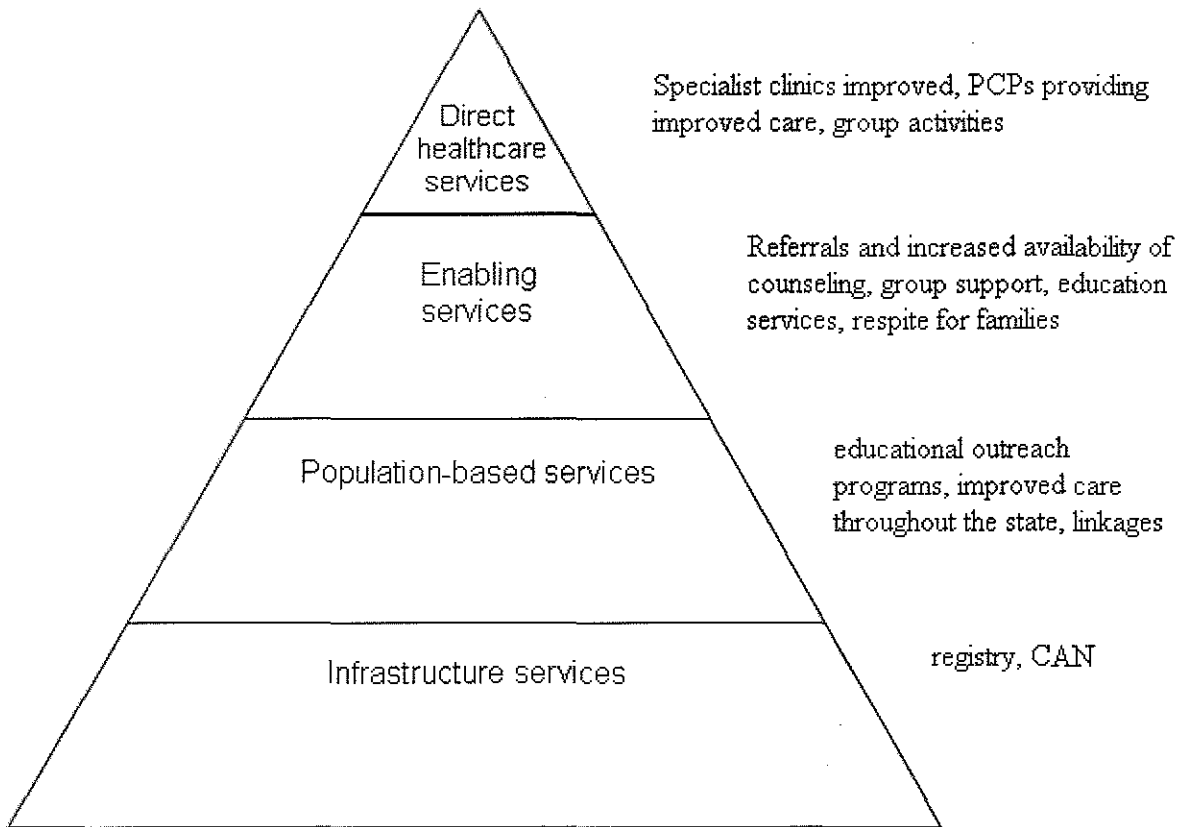
In developing the program activities, some of which are interventions, CAN demonstrates an ecological approach to dementia care. This approach views individuals with ADRDs as members of an intimate social network (family) that is part of ever expanding social networks (community, aging services region, state of North Carolina). Rather than being isolated medical cases, people with ADRDs are considered part of the “broader society,” a society which itself needs to change to provide better care for the people and their families.⁸² This approach is consistent with the “Public Health Pyramid” used by the U.S. Public Health Service to explain the “tiered” nature of healthcare (Figure 2).⁵⁷

The first step in the pyramid, “direct healthcare services,” involves strategies 1a and 1c from the Duke Endowment grant and strategies 2a and 2b from the Administration on Aging grant. Strategies 1a and 1c, expanding the clinical space of the Memory Disorders Clinic and establishing the training program (now the “State-of-the-Art Workshop”), should improve the services that PCPs give directly to persons with ADRDs. These strategies should improve the quality of dementia care that PCPs can provide both because of the opportunity to refer more patients to neurologists and, more importantly, their improved knowledge and behaviors developed at the workshop. 2a should improve referral to aging service agencies, and although 2b is more focused on providing “enabling services” for families and caregivers of individuals with ADRDs, it also will include some direct services to the individuals.

“Enabling services” through the CAN program include counseling, group support and education services, and respite, as described in strategy 2b and shown in Figure 1. These services support the families and/or caregivers of individuals with ADRDs. Although these

services are already being provided, CAN provides finances and personnel to increase the number and reorganization of these services, especially for early stage dementia.

Figure 2: The Public Health Pyramid ^{adapted from 57}



“Population-based services” are described in strategies 1b, 1d, and 2a. Strategy 1b describes educational outreach programs which could be disseminated to the population through aging services providers and through the media. Strategies 1d and 2a describe the development of a new approach to dementia care for the entire state population through “educational and training materials for” PCPs and “linkages between primary care medical providers and aging service network providers.”

Finally, “infrastructure services” are mentioned in strategies 1e and 2a. The registry would be a new state-wide infrastructure, as would the CAN program itself as it strengthens linkages among PCPs and with aging services providers.

By addressing dementia care at every step along the “Public Health Pyramid,” the CAN program recognizes and addresses the social networks of individuals with ADRDs. However, as will be described in this paper, and is alluded to in several of the program strategies (1d, 2a), there may be other interventions which the program will pursue in the future, especially as aging services providers and PCPs give their feedback about how the CAN infrastructure can best serve individuals with ADRDs and their families.

Program Logic Model

The CAN logic model (Table 4) I developed for this paper is a synthesis of both the proposed activities, as described in each of the original grant applications, and my observations as a volunteer with the program. Although all program interventions are briefly listed in the “Activities” column, this paper will not explain the logic behind all of the activities.

Program Implementation

To achieve the outcomes listed in the logic model, CAN is pursuing a systematic, sustainable approach to conducting the program activities, as demonstrated in the timeline I created in Table 5. This timeline differs significantly from the grant proposal timeline because funding from the Administration on Aging did not become available until March of 2009, seven months after funding from the Duke Endowment. The following pages describe plans for implementation of each activity listed in the logic model I developed.

Table 4. CAN Logic Model

ADRDs = Alzheimer's Disease and Related Disorders; PCPs = Primary Care Practitioners, CME = Continuing Medical Education in dementia care, AAA = Area Agency on Aging

Inputs	Activities	Outputs	Outcomes
<p>Money</p> <p>CAN Staff/Volunteers and their expertise with state-of-the-art dementia care</p> <p>Alliances</p> <p>Data (including evidence about state-of-the-art dementia care and education, and a needs assessment of community aging services, conducted among aging services providers)</p>	<ol style="list-style-type: none"> 1. Develop and pilot a "State-of-the-Art Workshop" (workshop) on dementia care, including referral to aging services providers. 2. Conduct a needs assessment of PCPs to plan the workshops, as well as consider other activities 3. Provide the workshop in each of the 17 AAA regions (regions) 4. Develop a CAN website with clinical and community resources for PCPs 5. Create a Clinical Dementia Registry based on PCPs' interest and registry feasibility 6. Create 1 new support group (per region), especially for individuals with early state ADRDs and their families 7. Establish regional workgroups to plan future program activities 8. Determine a single-point of entry for referral to aging services within each region 9. Develop 4 educational outreach presentations in dementia care: 2 for PCPs and 2 for non-medical professionals (social workers, aging services providers) 	<p>6-10 PCPs (per region) trained through the "State-of-the-Art Workshop" (within 3 years)</p> <p>Improved self-efficacy about clinical dementia care among PCPs</p> <p>Improved ability of PCPs and their practices to provide education, counseling, and referrals to individuals with ADRDs and their families</p> <p>50 new referrals by PCPs of persons with ADRDs to aging services providers (within 3 years)</p> <p>150 patients enrolled in the Clinical Dementia Registry (within 3 years)</p> <p>Region-specific plans developed for improving dementia care (within 3 years)</p> <p>30 PCPs and 80 non-medical professionals made aware of dementia care needs</p> <p>CAN program and workshop plans and results disseminated</p>	<p>Sustainable network of PCPs receiving CME and implementing state-of-the-art dementia care</p> <p>Improved, seamless dementia care provided by networked PCPs</p> <p>Improved health and support for individuals with ADRDs and their families in each region</p> <p>New evidence on state-of-the-art dementia care</p>

Table 5. Carolina Alzheimer's Network Activities and Evaluation Timeline

Task	Lead Staff Involved	Start/End Dates*
1. Develop and pilot a "State-of-the-Art Workshop" (workshop) on dementia care, including referral to aging services providers.	Sloane, Kaufer, Riedel-Leo	9/08-3/09
2. Conduct a needs assessment of PCPs to plan the workshops, as well as consider other activities.	Altpeter	4/09-11/10
3. Provide the workshop in each of the 17 AAA regions (regions).	Sloane, Kaufer	4/09-12/10
4. Develop a CAN website with clinical and community resources for PCPs.	Sloane, Kaufer	9/08-6/11
5. Create a Clinical Dementia Registry based on PCPs' interest and registry feasibility.	Sloane, Kaufer	9/08-6/11
6. Create 1 new support group (per region), especially for individuals with early state ADRDs and their families.	Sloane, Riedel-Leo, McLimans, Davis	4/09-9/10
7. Establish regional workgroups to plan future program activities.	Sloane, Riedel-Leo, McLimans, Davis	4/09-9/10
8. Determine a single-point of entry for referral to aging services within each region.	Sloane, McLimans, Davis	4/09-9/10
9. Develop 4 educational outreach presentations in dementia care: 2 for PCPs and 2 for non-medical professionals. (social workers, aging services providers)	Kaufer, Riedel-Leo	4/09-9/10
Refine evaluation plan	Sloane, Altpeter, Zimmerman	9/08-6/09
Prepare semi-annual performance reports for AoA	Sloane, Altpeter	10/09, 4/10, 10/10
Prepare evaluation report, disseminate results	Sloane, Kaufer, Altpeter, Zimmerman	8/10-6/11
* September 1, 2008 through June 30, 2011 – Duke Endowment grant; April 1, 2009 through September 30, 2010. – AoA grant		

1. *Develop and pilot a “State-of-the Art Workshop” on dementia care, including referral to aging services providers.*

The CAN curriculum team began recruiting PCPs (registration brochure available as appendix A) and developing the workshop on dementia care soon after grant funding from the Duke Endowment became available in September of 2008. Members of the curriculum team included Drs. Kaufer and Sloane, as well as several other staff and volunteers, such as a geriatric fellow (Dr. Khandewals), a dementia care social worker (Charlene Riedel-Leo), and two medical students (Chloe Hill and Joseph Hoyle). Our systematic approach to curriculum development included eight meetings, over a seven-month time span, and a workshop pilot.

The team meetings resulted in developing a list of topics for the workshop, which were then delegated to different subgroups, each under the leadership of either Dr. Kaufer or Dr. Sloane, responsible for producing curriculum that was up-to-date and evidence-based. Therefore, the workshop was entitled “State-of-the-Art Workshop.” (The subgroup which I joined also developed an algorithm, the “Recommended Primary Care Approach to Dementia Screening and Diagnostic Assessment,” available as appendix B.) Each subgroup had to submit continuing medical education objectives which were approved by the UNC School of Medicine. Because continuing medical education certification requires participant evaluation of these objectives, they were included on pages 1-3 of the “Post-Workshop Evaluation for Participant Practitioners,” available as appendix C.

The workshop pilot took place on March 20th, 2009 and involved five medical students and two geriatric fellows who volunteered approximately five hours of their time to attend. They were provided lunch and received didactic lectures from Dr. Kaufer, as well as some case discussions led by Dr. Khandewal. The entire curriculum team attended the pilot, as well as the Duke Endowment evaluator, Dr. Zimmerman. The pilot allowed the curriculum team to practice much of the material and to obtain feedback from the volunteers about suggested improvements.

As discussed in the literature review section of this paper, novel approaches to dementia care education are still being developed, although certain principles have been found to be helpful.⁵⁵ Some of the approaches that the curriculum team developed included the workshop location – to be within each of the area agency on aging regions, duration – to be one full-day, and format – to include an open networking session with aging services providers to discuss local challenges to dementia care. The agenda for the first workshop is available as appendix D.

2. Conduct a needs assessment of PCPs to plan the workshops, collect baseline data, and refine activities.

As a program volunteer, I conducted interviews with each of the enrolled PCP workshop participants to plan the workshops, collect baseline data, and refine program interventions. This “Physician Participant Pre-Training Interview,” is available as appendix E. (Also, a subset of the questions, questions used to generate self-efficacy scores, are available in table 7.) Interviews were conducted in region B, April 28-29, and in region Q, May 11-12. Certain characteristics of these regions are listed in table 3, “Primary Care Practitioners in Target Regions and Counties in North Carolina.”

Ideally, each workshop curriculum would be tailored to the needs of each region. However, at this point, most of the material has been standardized. The notable exception would be the networking sessions, each of which were developed with the regional aging services providers. Assuming that future community needs assessments show relatively consistent education needs, it may be appropriate for the curriculum to remain consistent, so that the training remains standardized and able to be better evaluated over time.

Baseline data was collected about the number of dementia patients seen by the participating physicians, in the office, in nursing homes, and in other non-nursing home long-term care settings, such as assisted living facilities. In addition, a question was asked about the

use of formal evaluation instruments. As other baseline data concerning community linkages was desired, this information was included in the post-workshop evaluation (appendix D), as described in the evaluation section of this paper.

In refining program interventions, PCP responses to questions about their “interests and goals in the dementia care training program” and “interest in dementia research” were and will be used. Already, their responses were disseminated to the workshop presenters to prepare for the open networking session. Certainly these comments were helpful to further the discussion about the purpose and practicality of a dementia registry. Their comments, when paired with follow-up data and aging services providers’ ideas will be used to consider other activities.

These practice visits were also useful to orient PCPs to the purpose of CAN and to confirm their dedication to the program. In addition, I distributed “requests for billing and reimbursement information for persons with dementia” to the billing manager at each practice to study reimbursement, an assumed concern for PCPs. (appendix F)

3. Provide the workshop in each of the 17 Area Agency on Aging regions.

By providing the workshops in each of the Area Agency on Aging (AAA) regions, CAN staff hope to enable the local aging services providers and practitioners to network. In addition, holding the workshops in these locations respects the community context of care and the time limitations of the community practitioners.

The first two workshops were conducted in Asheville (region B) on May 9th, 2009 and in Ahoskie (region Q) on May 16th, 2009. The workshops included PCPs from the following counties: Henderson, Madison, Transylvania, Bertie, Hertford, and Martin. Future workshops will be planned after the mid-year report has been completed and future funding received. In the long-term, CAN hopes to implement a systematic, reproducible three-year cycle of providing

these workshops in each of the AAA regions, with a goal of presenting in each of the 17 regions by July of 2011.

Of note, holding the workshops locally may also enable other community partnerships to develop. For example, in Asheville, representatives from the local Area Health Education Center and from the “Memory Care” clinic in Asheville⁸³ attended, demonstrating their interest in providing specialized dementia care to the state. In Ahsoskie, the regional hospital provided space and could be considered as a future partner for network development.

4. Develop a CAN website with clinical and community resources for PCPs.

The proposed website would include educational and training materials for practitioners, including an expanded toolkit (appendix E), continuing medical education case studies, and links to patient, community, and provider resources.¹⁰ The links would be to both state-wide and nation-wide resources, as well as region- and even county-specific information. In addition, the website could provide a portal to the proposed Clinical Dementia Registry.

Further purposes and usefulness of such a website have been discussed during the networking session of the workshop. As proposed, the sustainability of the website would achieve regular management and updates of the continuing medical education modules by Dr. Kaufer or other dementia specialists at the UNC Memory Disorders Clinic. In addition, Charlene Riedel-Leo, the head social worker for the UNC Memory Disorders Clinic, would also be involved with website maintenance, as would staff members from the Program on Aging, Disability, and Long-Term Care.

Additionally, CAN program staff have discussed the creation of a website especially for patient resources. From a sustainability viewpoint, it may be better to simplify the current website of the North Carolina Department of Health and Human Services (DHHS). Their website, nccarelink.org, could be made more patient and caregiver friendly.

5. Create a Clinical Dementia Registry based on PCPs' interest and registry feasibility.

The first major task in completing this activity is to determine the outreach and research purposes of such a clinical dementia registry (CDR). The outreach purposes could include patient education, tracking, and follow-up, as well as PCP education. The research potential can be understood in the context of the proposed registry being more representative of the general dementia population and including more cases of early stage dementia than included by existing, specialist and tertiary-care registries.¹⁰

The needs assessment of PCPs will be used to determine baseline interest in such a registry and to gather feedback about suggestions for improving feasibility and enrollment. At the first workshop, seven of the eight practitioners said they would be willing to initiate a version of the registry. To reinforce and reward interest, as well as increase interest, CAN is considering yearly recognition at state-wide professional conferences to participating PCPs. This could be in the form of a ceremony, a dinner, or an announcement.

The CDR would be established and maintained by the Program on Aging, Disability, and Long-Term Care in the Cecil G. Sheps Center for Health Services Research and enrollment would take place either online or through fax. It would be confidential and secure and include standardized demographics, cognitive function data from the toolkit instruments, and overall health status information.¹⁰

Once the CDR is established, the next step will be to publicize opportunities for PCP involvement throughout the state. Possible methods of publicizing the CDR would be officially through the North Carolina Department of Health and Human Services publications and practitioner professional organizations, as well as more informal publicity through patient advocacy groups and the news.

6. Create one new support group (per region), especially for individuals with early state ADRDs and their families.

Although many of the Area Agency on Aging and Alzheimer's Association chapters may have similar support groups going, CAN will be able to temporarily fund other groups while helping the aging service coordinators reorganize their groups and resources. The proposed support groups would have both educational and activity components.¹¹ The education component would be six sessions appropriate to the needs of individuals and families with early stage dementia.¹¹ The activity component would focus on group outings to dementia-friendly activities in each region, such as Kiwanis club pancake breakfasts and craft festivals. In addition, the groups would be opportunities for individualized counseling and for raising awareness about regionally-available respite services.

7. Establish regional workgroups to plan future program activities.

Regional workgroups would be developed among aging service coordinators, interested practitioners or their representatives, and other interested regional organizations. The groups would meet every other month to develop regionally-appropriate short- and long-term goals to achieve the four outcomes listed in the logic model. They will plan activities to accomplish these goals, stay in contact with participating PCPs, and give feedback to CAN staff about challenges, needs, and opportunities in each region. In addition, the groups would be opportunities for raising awareness about regionally-available respite services.

8. Establish single-point entry for PCPs' referral to aging services within each region.

One proposed idea for improving linkages between PCPs and aging services providers is to develop a "single-point entry" for referral to these services. This "single-point entry" could be region, county, or practice-specific. For example, at the first workshop, aging services providers

recommended that PCPs throughout the region contact the Alzheimer's Association. It would be the task of the regional workgroups to establish this point of entry to services and to disseminate information about it to PCPs.

9. Develop 4 educational outreach presentations in dementia care.

Although the CAN program seeks to systematically deliver workshops throughout the state, most PCPs will not be reached directly by the program. However, in coordination with the two North Carolina chapters of the Alzheimer's Association, CAN staff plan to provide large, educational outreach presentations, some to PCPs and some to non-medical professionals and consumers.

Each presentation for medical professionals would provide a few hours of continuing medical education with the goal of reaching approximately 30 PCPs. There would be two such presentations each year, one coordinated with each of the Alzheimer's Association chapters. These presentations would also be coordinated with the North Carolina Academy of Family Physicians and with the AHECs. The material presented would include a condensed version of the curriculum developed for the workshop, the toolkit and website resources, and information about the single-point(s) of entry, as developed by the regional workgroups. In addition, these presentations would be a venue for recruiting PCPs to the workshops and informing PCPs about the registry.

There would also be two presentations yearly to non-medical professionals and consumers, with the goal of reaching approximately 80 people. Most of the professionals would be social workers, and Charlene Riedel-Leo, the head social worker for the UNC Memory Disorders Clinic, will coordinate and help develop the topics for these presentations. The presentations would be made by the UNC Memory Disorders Clinic staff, including Charlene Riedel-Leo and Dr. Kaufer.

Summary of Priorities

The two funding sources from the Administration on Aging and Duke Endowment present a great opportunity for providing specialized dementia care for the citizens of North Carolina. Drs. Kaufer and Sloane will need to balance out the two grants' activities and work together to ensure that the comprehensive approach of the full project is maintained. Although the project is comprehensive in its conception, the development of the PCP network is the first priority, as this infrastructure is required for sustainability of the program and evaluation of successful interventions. The first major step in networking PCPs is through the "State-of-the-Art Workshop," which is discussed in more detail in the evaluation plan section of this paper.

In addition to these program activities, the public health pyramid (Figure 2) can be useful for considering and planning future interventions. Empowering individuals responsible for each step in the pyramid to work together both for the good of their community and in step with their own roles and reimbursement strategies will support this ecological approach to dementia care in North Carolina and, hopefully, make it sustainable.

Evaluation Plan

I. Introduction

This paper provides a framework for the full program evaluation with a focus on the “State-of-the-Art Workshop,” also called the “Dementia Care Preceptorship” in the initial recruitment brochure (appendix A). There are many roles for the evaluation, but the most important ones are improving existing program activities, planning other activities and strategies, and demonstrating the results of resource investments.⁸⁴ As required, the evaluation plan is designed to meet reporting and updating guidelines of both funding sources.

Evaluation has the ongoing role in monitoring the outputs of activities listed in the logic model (Table 4). This ongoing role means that the details of the evaluation are regularly changing and developing. However, the design and methods of the evaluation for the “State-of-the-Art Workshop” can now be explained, based on my experiences and the updated plans of the CAN curriculum committee to use this activity to fulfill the grant objectives specified in the program plan.

Similar to program planning, program evaluation should take place at all steps along the public health pyramid. Ideally, this evaluation process will involve a wide range of stakeholders to contribute to quality improvement and to prepare for knowledge transfer or dissemination. Although not described in this evaluation plan, CAN evaluation staff plan to use the RE-AIM method² for most activities (strategy 2c). For practice, I wrote RE-AIM method questions applied at each level of the public health pyramid, available in appendix I. This method is designed for evaluating the adoption, implementation, and sustainability of programs.⁸⁵ Therefore, the RE-AIM method can also be ideal for the purposes of developing and improving a program with broad implications for state-wide infrastructure and health policy.

II. Role and Context for the Evaluation

Evaluation Role and Reasons

Throughout the duration of the evaluation plan (Table 5), the role of the evaluators will change. However, the three-fold role or reasons for evaluation will remain as described by the Centers for Disease Control and Prevention in their publication “Framework for Program Evaluation in Public Health.”⁸⁴ These reasons are “improving existing programs,” “planning effective public health strategies,” and “demonstrating the results of resource investments.”

The initial reason for evaluating this project will be to provide quality improvement for the “State-of-the-Art Workshop,” as this activity is the first program intervention. Especially since there are aspects to the workshop which are relatively novel, the evaluation of the curriculum and format will be instrumental in developing a workshop curriculum that is both effective and reproducible. Based on my experiences with the CAN curriculum and evaluation committees, I have written the following outcome to be evaluated: *By June 2011, provide state-of-the-art workshops in dementia care and service referral for at least 6 PCPs in all 17 Area Agency on Aging regions.* Of note, this evaluation should include data on disadvantaged populations, such as those living in areas that are poor, rural, or underserved.¹⁰

The workshop evaluation process is also an opportunity to plan and develop new program activities. Along with the needs assessment, the workshop provides an opportunity to hear from primary care practitioners about their perceived needs to improve dementia care for their patients. Making adjustments to plans for linkages, the proposed clinical dementia registry, and regional workgroups will be important early on in the program, to ensure program effectiveness and adoption by the PCPs.

The RE-AIM format will be used to demonstrate the results of resource investments for both the workshop and for other program activities. In the short-term, evaluation will be used to

determine if the program activities are realizing the anticipated outputs, particularly in regards to the number of individuals involved in each activity. Short-term evaluation will also be important to ensure effective use of resources so that the program can continue throughout the length of the grant. In both the short and long-term, the evaluation process will measure the progression through goals towards outcomes and impact.

Later steps in the evaluation process include justifying further funding support and disseminating research findings. These steps should begin within the next several months, if the initial workshops are considered effective and reproducible in the other 15 AAAs. If high efficiency of resource investment is demonstrated, future funding and policy development opportunities may follow. These could be opportunities for results dissemination, from presentations at conferences to perhaps testimony for legislators and other potential funders.

Evaluators

There are two grants; thus there are two separate performance reporting policies. Drs. Sloane and Kaufer, the program directors, have selected two separate, but experienced, evaluators to fulfill the role of principle evaluator for each grant. For the Duke Endowment, the lead evaluator is Sheryl Zimmerman, the Co-Director of the Cecil G. Sheps Center for Health Services Research Program on Aging, Disability, and Long-Term Care. For the U.S. Administration on Aging grant, the lead evaluator is Mary Altpeter, the Associate Director of UNC's Institute on Aging. Both of these evaluators are internal, in that they are familiar with program goals and staff, and yet external, in that they are separate from the development of activities, particularly the workshop curriculum.

In addition to these two lead evaluators, program director Dr. Sloane, research assistant Amanda Bowers, and I make up the current evaluation committee. Dr. Sloane and I will continue to give an internal perspective from the curriculum committee to the evaluation

committee. Amanda Bowers is responsible for maintaining data and coordinating the team. All of us will have data collection responsibilities.

So far, my responsibilities have been to collect needs assessment data from the practitioners before the two workshops and to collect workshop evaluations afterwards. Along with Amanda Bowers, I have been responsible for double data entry. However, some of these responsibilities will be given to new staff members or contracted out, as our roles on the evaluation team are temporary.

Key Stakeholders

The activities of different sets of stakeholders will be important as the program develops through different activities to the four impacts discussed in the program plan (Table 4). Initially, we will evaluate the activities, such as the workshop, of the program staff and the effect of the activities on the PCPs and their staffs. Over time, the focus will shift to evaluating the outcomes and impact in the community. For example, community stakeholders such as caregivers could be surveyed to evaluate the reach and effectiveness of the direct services referred by the PCPs. Finally, the evaluation development will focus on the four primary outcomes, namely the sustainability of the PCP network, the seamless nature of dementia care, the health of and support for individuals with ADRDs and their families, and the development of new evidence on state-of-the-art dementia care.

Current and potential stakeholders need to be involved in regular performance reporting so that the program can secure future monies. These stakeholders include the Duke Endowment and the U.S. Administration on Aging, and also interested groups, with resources, such as the Division of Aging and Adults Services (DAAS) of the Department of Health and Human Services of the State of North Carolina and the North Carolina Area Health Education Centers (AHECs) program.

DAAS could be interested in how CAN would complement the North Carolina Alzheimer's Support Program (NC-ASP), a "primary statewide initiative" to "provide basic public support by delivering critical core services to individuals with Alzheimer's disease and related disorders, their families and caregivers." The NC-ASP works to provide information, referral, training, education, and emotional support to individuals dealing with ADRDs, as well as support to aging services providers. Therefore, CAN's contribution to direct services seems to be a key interest for the DAAS. The DAAS could be instrumental in and knowledgeable about securing long-term state funds, because the DAAS has received appropriations from the state budget for over 20 years.

North Carolina Area Health Education Centers program (AHEC), in its mission "to meet the state's health and health workforce needs by providing educational programs," would be interested more in the educational components of the CAN program and in how the program will meet the health workforce needs. With CAN's plan to reach those patients who are poor, minority, and underserved, and especially with CAN's plan to reach PCPs, AHEC could be interested in providing the CAN training to their efforts, which include emphasizing primary care and targeting the improvement of "diversity and cultural competence of the health care workforce."⁸⁰

Before approaching them for future funding, CAN staff could approach them for their input and interest in program results. One way in which this could be done is through discussing the possibility of disseminating results through these groups and then determining if the group considers these results to be important enough, and in line with their organization goals, to support CAN.

Potential Challenges

I envision four potential challenges to this evaluation plan. The most significant challenge seems to be the rural and disconnected nature of the PCPs and aging services providers. Regular, efficient, and useful communication from CAN staff to the PCPs and aging services providers will be important for maintaining connections. In addition, regularly analyzing the evaluation results, especially the response rate, will be important to anticipating needs for increased incentives or new evaluation approaches.

Another significant challenge is that evaluation results may be region-specific: PCPs from different regions may face different challenges or barriers to providing specialized dementia care. Therefore, the curriculum committee will need to take this possibility into consideration when trying to improve and reproduce programs, such as the workshop, in other Area Agency on Aging (AAA) regions. Promptly evaluating and communicating these region-specific needs to the curriculum committee will be essential.

The third challenge will be applying the RE-AIM framework to the entire program. By my literature search, this has not yet been done with dementia programs. However, Dr. Altpeter is an expert at program evaluation and is very familiar with the RE-AIM model being applied.⁸⁶

Finally, a fourth challenge will be planning ahead with the evaluation to anticipate the somewhat transitory nature of evaluation team. Some members, such as medical student volunteers and employees of the university, will have to leave the team. Other members, such as Dr. Altpeter, have traveling and teaching commitments.

III. Design for the Workshop Evaluation

The design for this evaluation is quasi-experimental, a one group, pre-test/post-test design at the individual PCP level. This design will involve a series of qualitative and quantitative questions which are collected at baseline and used for following PCPs' self-efficacy and self-reported behavior. Although there will be series of groups of PCPs, there are no control groups and the assignment to these groups is not random.

In addition, follow-up interviews with aging service coordinators are planned to evaluate linkage outputs and outcomes, such as increased referrals and improved support for individuals with ADRDs and their families. This would also be considered a pre-test/post-test design, because the pre-test results would be no linkages, as aging service coordinators indicated before the program began. Program staff plan to use these follow-up interviews for longitudinal assessment of the program's impact.

IV. Methods for the Workshop Evaluation

The CAN “State-of-the-Art Workshop” has three different methods to meet the evaluation role of improving the existing workshop curriculum, planning future workshops, and demonstrating the effectiveness of resource investments. These methods are evaluations from a workshop pilot, prepost evaluations of practitioners, and prepost evaluations of the aging services coordinators. This section will describe each method and its purpose.

The evaluation planning table, table 6, provides one approach to evaluating the overall workshop output goal I synthesized from grant strategies 1c and 2a. Planning tables can be developed from logic models with detailed outputs, short-term outcomes, and long-term outcomes. However, a workshop logic model was not constructed because the RE-AIM model is being used for this program. Nevertheless, the three methods, mentioned above and described below, are ongoing evaluation plans to answer planning table questions 2, 3, 4, and 5.

First, CAN staff used evaluations from a pilot of the practitioner program materials to evaluate and improve the workshop curriculum. A member of the evaluation committee, Sheryl Zimmerman, developed an open-ended post-pilot evaluation. Because the pilot attendees (five graduating medical students and two geriatric fellows) were persons who regularly evaluate curriculum their input was thought especially helpful for meeting planning table question #4.

A list of their hand-written comments and recommendations were transcribed (typed) and emailed to all of the members of the CAN curriculum committee, for each member to consider improvements to the section for which they were responsible. Additionally, two members of the CAN curriculum committee, Joseph Hoyle and Amanda Bowers, developed a summary of the the recommendations and feedback. This summary was presented to the CAN curriculum committee in order to discuss potential changes to the schedule and content of the curriculum.

Table 6: Workshop Planning Table for an Outcome Goal

Output Goal: By June 2011, provide state-of-the-art workshops in dementia care and service referral for at least 6 PCPs in all 17 Area Agency on Aging regions.		
Evaluation Questions	Participant	Evaluation method
1. By June 2011, were state-of-the-art workshops in dementia care and service referral provided for at least 6 PCPs in all 17 Area Agency on Aging regions?	Primary care practitioners (MD, NP, PA); Family Caregiver Resource Specialists for Area Agency on Aging regions B and Q (Carol McLimans and Cynthia Davis); Project Manager	Workshop attendance roles; Workshop publicity materials; Workshop curriculum materials
2. Were the workshops state-of-the-art in relation to dementia care? (Was self-efficacy improved?)	Primary care practitioners	PrePost survey
3. Were the workshops state-of-the-art in relation to dementia service referral? (Were PCPs behaviors and planned behaviors improved?)	Primary care practitioners; Family Caregiver Resource Specialists for Area Agency on Aging regions B and Q	PrePost survey
4. How could the workshop be improved?	Primary care practitioners (MD, NP, PA); Family Caregiver Resource Specialists for Area Agency on Aging regions B and Q	Workshop Pilot; Post-Workshop Evaluation; open-ended interviews
5. Did the workshop meet the needs of all PCPs, including those who work in poor, minority, or underserved areas?	Primary care practitioners (MD, NP, PA); Family Caregiver Resource Specialists for Area Agency on Aging regions B and Q	PrePost survey; open-ended interviews
6. Were there unexpected attendees?	Family Caregiver Resource Specialists for Area Agency on Aging regions B and Q; Project Manager	Workshop attendance roles
7. Why did the unexpected attendees come and what needs do they have?	Family Caregiver Resource Specialists for Area Agency on Aging regions B and Q; Project Manager	Completed curriculum evaluations; Open-ended interviews

Second, the CAN evaluation committee is conducting pre- and post- workshop practice evaluations with the primary care practitioners (PCPs). The pre-workshop practice evaluation has been embedded in the practice needs assessment (Appendix F) and as pre-program outcome measures (e.g. diagnostic coding data and referral statistics in appendix G) from practice

managers. The sections in the practice needs assessment will be used to include questions for the PCPs about self-efficacy data (Table 7) and the self-perceived learning needs. These evaluations will be done several days to weeks before the workshop (For example, they were administered 10-11 days before the first workshop and 4-5 days before the second workshop). The self-efficacy data and the self-perceived learning needs will be used to recognize the region-specific learning needs and to plan for the discussion time and resource needs of PCPs. These data will also serve as practice baseline data for the duration of the entire program.

Table 7. Question 1 from Part II of the Practice Needs Assessment in Appendix F

1. How confident are you with:	Not at All Confident	A Little Confident	Moderately Confident	Mostly Confident	Extremely Confident
a. Your ability to screen patients for dementia?	1	2	3	4	5
b. Your ability to make a diagnosis of dementia?	1	2	3	4	5
c. Your ability to distinguish Alzheimer's Disease from other forms of dementia?	1	2	3	4	5
d. Your understanding of the value and use of assessment instruments for cognition?	1	2	3	4	5
e. Your understanding of the role of MRI scans in the diagnosis of dementia?	1	2	3	4	5
f. Your ability to provide initial treatment to patients with memory loss?	1	2	3	4	5
g. Your ability to use medications for memory loss [e.g., donepezil (Aricept), Rivastigmine (Exelon), and memantine (Namenda)]?	1	2	3	4	5
h. Your ability to approach behavioral symptoms in patients with dementia?	1	2	3	4	5
i. Your office's ability to deliver patient and caregiver education about dementia care?	1	2	3	4	5
j. Your knowledge of community resources for persons with dementia and how to refer patients to them?	1	2	3	4	5
k. Your ability to disclose and explain a diagnosis of dementia to the patient?	1	2	3	4	5
l. Your ability to provide information to, assist, and respond to family caregivers of patients with dementia?	1	2	3	4	5

The post-workshop evaluation was administered immediately after the workshop and will continue to be administered as 3, 6, and 12 month follow-up questions through a website

(Appendices C, G, and H, respectively). The immediate post-workshop questions included seven items written in the Currently/Before format (Table 8, similar to the Evaluation Questionnaire used by Harvey et al. 2005^{36, 87}), of which the first six can be used to validate some of the pre-workshop questions in Table 7. Other sections of the post-workshop evaluation included open-ended questions to assess baseline physician behavior and intent for disseminating the knowledge and resources they gained.

The evaluation was also meant to help PCPs plan changes in their individual practices. This information will be useful for giving immediate feedback on the degree to which the curriculum met community-specific, self-perceived learning needs, as well as the continuing medical education objectives.

Table 8. Question 1, from Part III of the Post-Workshop Evaluation in Appendix

	CURRENTLY					BEFORE				
	Low				High	Low				High
1. Please rate yourself on the following items (1) as you are CURRENTLY and, (2) retrospectively, as you were BEFORE participating in the workshop.										
A. your ability to screen patients for dementia	1	2	3	4	5	1	2	3	4	5
B. your ability to distinguish Alzheimer's Disease from other forms of dementia	1	2	3	4	5	1	2	3	4	5
C. your ability to provide initial treatment to patients with memory loss	1	2	3	4	5	1	2	3	4	5
D. your understanding of the value of assessment instruments in the evaluation of memory loss	1	2	3	4	5	1	2	3	4	5
E. your office's ability to deliver patient and caregiver education about dementia care	1	2	3	4	5	1	2	3	4	5
F. your knowledge of community resources for persons w/dementia and how to refer patients to them	1	2	3	4	5	1	2	3	4	5
G. your ability to promote Quality of Life	1	2	3	4	5	1	2	3	4	5

Third, follow-up, open-ended interviews will be conducted with aging service coordinators who attend the workshop, such as the Family Caregiver Resource Specialists for Area Agency on Aging regions B and Q, currently Carol McLimans and Cynthia Davis. These interviews will be based on the “areas of need for dementia care”¹¹ that were developed with aging service coordinators and described in the program context section, “Consistency with

National and State Priorities.” The exact questions have not yet been developed, but will include open-ended questions about the perceived usefulness of the curriculum. The number and quality of linkages developed with PCPs will be compared to the baseline linkage statistics reported by coordinators to be nonexistent in the two AAA regions surveyed so far.

VI. Dissemination Plan

This dissemination plan focuses on the workshop, as an example of program dissemination. The post-workshop evaluation has three purposes: to improve the workshop, to evaluate its effectiveness in meeting the needs of attending practitioners, and to determine how and why the workshop was successful. To meet these purposes, qualitative and quantitative analyses of the evaluation methods and strategies for the workshop could be conducted and used to develop a power-point presentation to help project staff, especially the curriculum committee, to decide on the feasibility of future workshops and to analyze quality improvement opportunities. This information could be reformatted into a poster for presentation at annual practitioner meetings (such as the gatherings of the North Carolina Medical Society and the North Carolina Academy of Family Physicians) to fulfill grant proposal commitments to describe program progress at these annual gatherings.

Also, the following written reports could be useful to fulfill commitments and meet the aforementioned three purposes:

- Evaluation summary to the Institute on Aging
- Practitioner Executive Summary (for practitioners who attended the workshops and who might attend future workshops) to be published on the CAN website
- At least one report for an academic journal (for disseminating the development of new knowledge, strategy 2c)

In addition, further reports about results will be developed as semi-annual and annual progress reports to funders. These reports could be reformatted toward the following audiences, making other local, state, and national agencies aware of program results:

- Press release to UNC News
- Press release to the School of Medicine
- Press Release to “At a Glance: Aging and Adult Services in North Carolina,” the web-based newsletter of the Division of Aging and Adults Services

Discussion

The grants supporting the creation of the Carolina Alzheimer's Network provide an exciting opportunity for improving dementia care throughout the state of North Carolina. By partnering with primary care practitioners and aging services providers, the program gives academic hospitals and departments, such as those at UNC, an opportunity to serve the growing need for community dementia care in novel and far-reaching ways.

The public health burden of dementia is great and, as reviewed, previous programs have met with mixed results. However, there are ways to reduce this burden if cases are detected earlier and individuals and families are linked to existing resources.²⁰ This program plan is presented in the hope of empowering practitioners to provide state-of-the-art care which recognizes the multiple dimensions of patient and caregiver needs. With rising advocacy for increasing funding for dementia research and for program planning, CAN could be useful for quickly disseminating new treatment methods and research findings to communities.⁶³ I hope that the ecological approach of CAN will prove to be a sustainable method for expanding resources for "specialized" dementia care throughout North Carolina.

Although the grant applications call for program evaluation using the RE-AIM framework, this evaluation plan of the "State-of-the-Art Workshop" describes evaluation methods related to an evaluation planning table. Nevertheless, this program's ability to reach families dealing with ADRDs, to effect improvements in care, to be adopted by communities, to be implemented correctly, and to be maintained over the time will describe the program's utility to both program stakeholders and future collaborators. Additionally, the RE-AIM framework should equip this program to transfer results and new knowledge of dementia care to other program planners and policy makers, especially those making North Carolina health policy plans.

References

1. 2009 Alzheimer's Disease Facts and Figures: Alzheimer's Association.
2. RE-AIM.org. 2006; <http://re-aim.org>. Accessed 7/17/09.
3. Lawhorne L, Ogle KS. Approaches to the office care of the older adult and the specter of dementia. *Prim Care*. Sep 2005;32(3):599-618.
4. Sloane PD, Zimmerman S, Suchindran C, et al. The public health impact of Alzheimer's disease, 2000-2050: potential implication of treatment advances. *Annu Rev Public Health*. 2002;23:213-231.
5. *Saving Lives. Saving Money: Dividends for Americans Investing in Alzheimer Research*: The Lewin Group;2004.
6. Small GW, Rabins PV, Barry PP, et al. Diagnosis and treatment of Alzheimer disease and related disorders. Consensus statement of the American Association for Geriatric Psychiatry, the Alzheimer's Association, and the American Geriatrics Society. *JAMA*. Oct 22-29 1997;278(16):1363-1371.
7. Boise L, Neal MB, Kaye J. Dementia assessment in primary care: results from a study in three managed care systems. *J Gerontol A Biol Sci Med Sci*. Jun 2004;59(6):M621-626.
8. Callahan CM, Hendrie HC, Tierney WM. Documentation and evaluation of cognitive impairment in elderly primary care patients. *Ann Intern Med*. Mar 15 1995;122(6):422-429.
9. Foster NL. Barriers to treatment: the unique challenges for physicians providing dementia care. *J Geriatr Psychiatry Neurol*. Winter 2001;14(4):188-198.
10. Sloane P, Kaufer D. Carolina Alzheimer's Network: A Grant Proposal Funded by the Duke Endowment.
11. Sloane P, Derence K. Strengthening the Linkages between Primary Care Medical Providers and Aging Service Programs in the Support of Persons with Alzheimer's Disease: US Administration on Aging.
12. Alzheimer's Disease Supportive Services Program. 2009; http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/index.aspx#current. Accessed 6/30/09.
13. Annual Estimates of the Resident Population for the United States, Regions, States, and Puerto Rico: April 1, 2000 to July 1, 2008. U.S. Census Bureau, Population Division; 2008. <http://www.census.gov/popest/states/NST-ann-est.html>.
14. Bradley WG, Daroff RB, Fenichel GM, Jankovic J, eds. *Neurology in Clinical Practice*. 5 ed 2008. DeKosky ST, Kaufer DI, Hamilton R, Wolk DL, Lopez OL, eds. Chapter 70: The Dementias.
15. Weiner MF. Perspective on race and ethnicity in Alzheimer's disease research. *Alzheimers Dement*. Jul 2008;4(4):233-238.
16. Wilson RS, Aggarwal NT, Barnes LL, Bienias JL, Mendes de Leon CF, Evans DA. Biracial population study of mortality in mild cognitive impairment and Alzheimer disease. *Arch Neurol*. Jun 2009;66(6):767-772.
17. Kaufer DI. Dementia Treatment: The Hare and Tortoise Revisited. 2008; http://www.alznc.org/index.php?option=com_content&view=article&id=141:dementia-treatment&catid=51:medications&Itemid=88. Accessed 7/6/09.
18. Zuckerman IH, Ryder PT, Simoni-Wastila L, et al. Racial and ethnic disparities in the treatment of dementia among Medicare beneficiaries. *J Gerontol B Psychol Sci Soc Sci*. Sep 2008;63(5):S328-333.
19. Borson S, Scanlan JM, Watanabe J, Tu SP, Lessig M. Improving identification of cognitive impairment in primary care. *Int J Geriatr Psychiatry*. Apr 2006;21(4):349-355.
20. Holsinger T, Deveau J, Boustani M, Williams JW, Jr. Does this patient have dementia? *JAMA*. Jun 6 2007;297(21):2391-2404.
21. Boustani M, Sachs G, Callahan CM. Can primary care meet the biopsychosocial needs of older adults with dementia? *J Gen Intern Med*. Nov 2007;22(11):1625-1627.
22. Molnar FJ, Man-Son-Hing M, Fergusson D. Systematic review of measures of clinical significance employed in randomized controlled trials of drugs for dementia. *J Am Geriatr Soc*. Mar 2009;57(3):536-546.
23. Schoenmakers B, Buntinx F, Delepeleire J. What is the role of the general practitioner towards the family caregiver of a community-dwelling demented relative? A systematic literature review. *Scand J Prim Health Care*. 2009;27(1):31-40.
24. Alzheimer's Disease and Dementia. *North Carolina Division of Aging and Adult Services* [2008; <http://www.dhhs.state.nc.us/aging/ad.htm>. Accessed 6/30/09.
25. Adams WL, McIlvain HE, Geske JA, Porter JL. Physicians' perspectives on caring for cognitively impaired elders. *Gerontologist*. Apr 2005;45(2):231-239.
26. Hinton L, Franz CE, Reddy G, Flores Y, Kravitz RL, Barker JC. Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives. *J Gen Intern Med*. Nov 2007;22(11):1487-1492.
27. Continuing Professional Education. *Wisconsin Alzheimer's Institute* [<http://www.medsch.wisc.edu/wai/profeduc/profeduc.html>. Accessed 6/30/09.

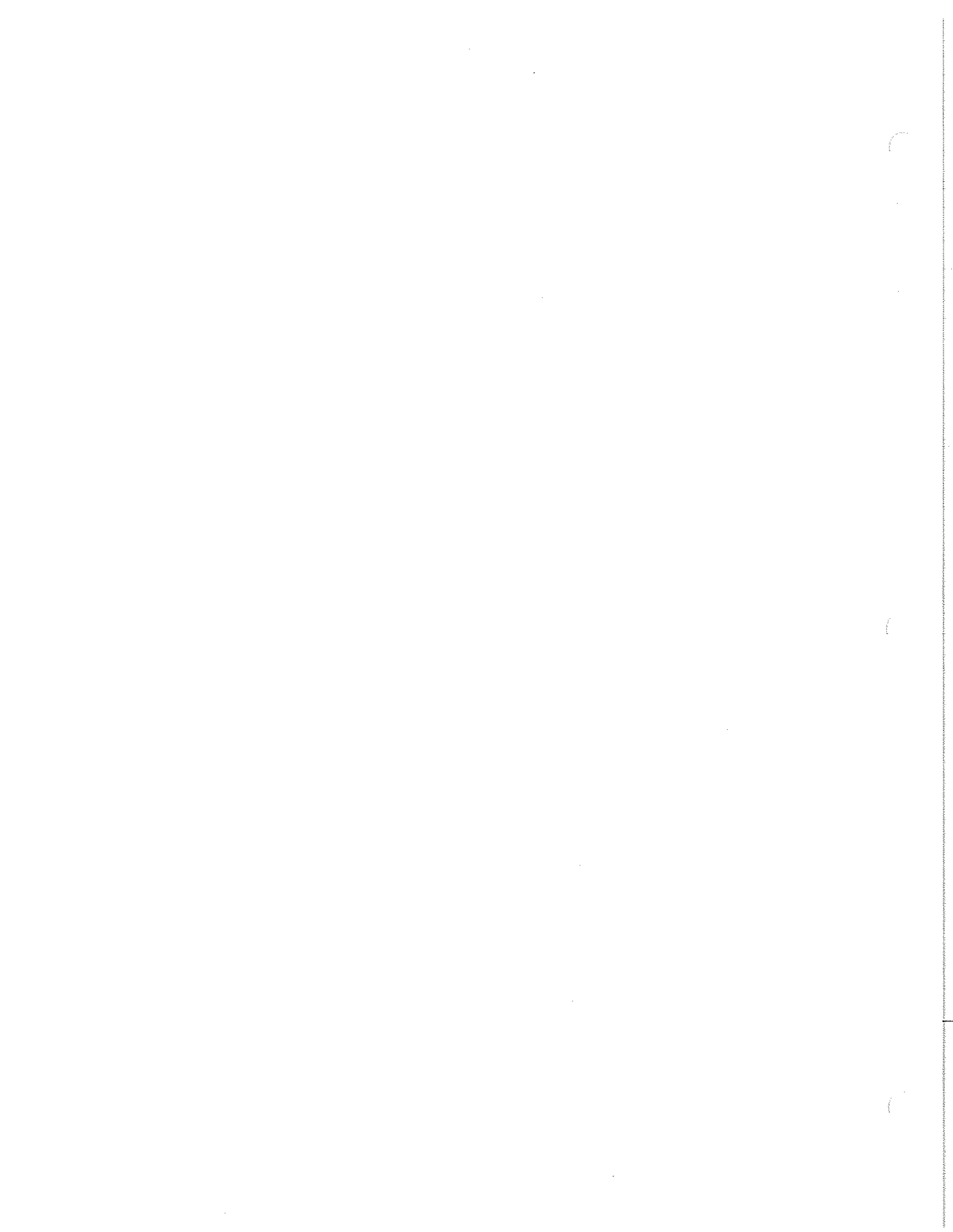
28. Sloane P. Evaluation Meeting. In: Hoyle J, ed.
29. North Carolina Health Professions Data System. Cecil G. Sheps Center for Health Services Research; 2007. www.shepscenter.unc.edu/hp/index.html.
30. Gaugler JE, Duval S, Anderson KA, Kane RL. Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatr*. 2007;7:13.
31. Gaugler JE, Kane RL, Kane RA, Newcomer R. Early community-based service utilization and its effects on institutionalization in dementia caregiving. *Gerontologist*. Apr 2005;45(2):177-185.
32. Robinson BE, Barry PP, Renick N, Bergen MR, Stratos GA. Physician confidence and interest in learning more about common geriatric topics: a needs assessment. *J Am Geriatr Soc*. Jul 2001;49(7):963-967.
33. Williams ME, Connolly NK. What practicing physicians in North Carolina rate as their most challenging geriatric medicine concerns. *J Am Geriatr Soc*. Nov 1990;38(11):1230-1234.
34. Pond CD, Mant A, Kehoe L, Hewitt H, Brodaty H. General practitioner diagnosis of depression and dementia in the elderly: can academic detailing make a difference? *Fam Pract*. Jun 1994;11(2):141-147.
35. Sizemore MT, Vicioso B, Lothrop JL, Rubin CD. Outcome of a pilot dementia training program for primary care physicians. *Educational Gerontology*. Jan-Feb 1998;24(1):27-34.
36. Harvey RM, Horvath KJ, Levine SA, Volicer L. Models of physician education for Alzheimer's disease and dementia: Practical application in an integrated network. *Clinical Gerontologist*. 2005;29(2):11-23.
37. Byszewski AM, Graham ID, Amos S, et al. A continuing medical education initiative for canadian primary care physicians: the driving and dementia toolkit: a pre- and postevaluation of knowledge, confidence gained, and satisfaction. *J Am Geriatr Soc*. Oct 2003;51(10):1484-1489.
38. New Website Provides Dementia Education for Medical Professionals. *Media Release* [2004; <http://www.ocfp.on.ca/local/files/Communications/Current%20Issues/MEDIA%20RELEASE-March2004.pdf>. Accessed 7/1/09.
39. Cherry DL, Vickrey BG, Schwankovsky L, Heck E, Plauche M, Yep R. Interventions to improve quality of care: The Kaiser Permanente - Alzheimer's Association Dementia Care Project. *American Journal of Managed Care*. Aug 2004;10(8):553-560.
40. Downs M, Turner S, Bryans M, et al. Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study. *BMJ*. Mar 25 2006;332(7543):692-696.
41. Chodosh J, Berry E, Lee M, et al. Effect of a dementia care management intervention on primary care provider knowledge, attitudes, and perceptions of quality of care. *Journal of the American Geriatrics Society*. Feb 2006;54(2):311-317.
42. Kovacich J, Garrett R, Forti EM. New learning programs in cognitive vitality, Alzheimer's disease, and related dementias. *Gerontol Geriatr Educ*. 2006;26(4):47-61.
43. Dalsgaard T, Kallerup H, Rosendal M. Outreach visits to improve dementia care in general practice: a qualitative study. *Int J Qual Health Care*. Oct 2007;19(5):267-273.
44. Wenger NS, Roth CP, Shekelle PG, et al. A practice-based intervention to improve primary care for falls, urinary incontinence, and dementia. *J Am Geriatr Soc*. Mar 2009;57(3):547-555.
45. Vollmar HC, Butzlaff ME, Lefering R, Rieger MA. Knowledge translation on dementia: a cluster randomized trial to compare a blended learning approach with a "classical" advanced training in GP quality circles. *Bmc Health Services Research*. Jun 2007;7:15.
46. Meuser TM. Multidisciplinary Geriatric Education: A 3-Day Mini-Residency in Dementia Diagnosis, Treatment & Care (Unpublished Powerpoint): University of Missouri - St. Louis; 2009.
47. Pereles L, Lockyer J, Ryan D, Davis D, Spivak B, Robinson B. The use of the opinion leader in continuing medical education. *Med Teach*. Jul 2003;25(4):438-441.
48. Royall DR, Cordes JA, Polk M. CLOX: an executive clock drawing task. *J Neurol Neurosurg Psychiatry*. May 1998;64(5):588-594.
49. Cummings JL, Frank JC, Cherry D, et al. Guidelines for managing Alzheimer's disease: part I. Assessment. *Am Fam Physician*. Jun 1 2002;65(11):2263-2272.
50. ACOVE-2 Quality Indicators. http://www.rand.org/health/projects/acove/docs/acove_qi.pdf. Accessed 7/8/09.
51. Reuben DB, Roth C, Kamberg C, Wenger NS. Restructuring primary care practices to manage geriatric syndromes: the ACOVE-2 intervention. *J Am Geriatr Soc*. Dec 2003;51(12):1787-1793.
52. Reuben DB, Herr KA, Pacala JT, Pollock B, Semla TP. *Geriatrics at Your Fingertips*. 4th ed. New York, NY 2002.
53. Meuser TM, Boise L, Morris JC. Clinician Beliefs and Practices in Dementia Care: Implications for Health Educators. *Educational Gerontology*. 2004;30(6):491-516.
54. Murray LM, Boyd S. Protecting personhood and achieving quality of life for older adults with dementia in the U.S. health care system. *J Aging Health*. Mar 2009;21(2):350-373.

55. *Physician Outreach Tips and Tools: Alzheimer's Disease Demonstration Grants to States National Resource Center.*
56. England E. Improving the management of dementia. *BMJ.* Mar 25 2006;332(7543):681-682.
57. Issel LM. *Health Program Planning and Evaluation: A Practical, Systematic Approach for Community Health.* 2 ed: Jones & Bartlett Publishers; 2008.
58. Kaufer D. Personal Email. In: Hoyle J, ed2009.
59. What Are Its Goals? *Healthy People* [<http://www.healthypeople.gov/About/goals.htm>. Accessed 6/30/09.
60. 18: Mental Health and Mental Disorders. *Healthy People 2010* [<http://www.healthypeople.gov/Document/HTML/Volume2/18Mental.htm>. Accessed 6/30/09.
61. Issues. *Special Committee on Aging* [<http://aging.senate.gov/issues/index.cfm>. Accessed 6/30/09.
62. Sen. Warner joins Alzheimer task force as co-chair. *Alzheimer News* 3/11/09 [http://www.alz.org/news_and_events/sen_warner_joins_alz_task_force.asp. Accessed 6/30/09.
63. *A National Alzheimer's Strategic Plan: The Report of the Alzheimer's Study Group.*
64. The Way Forward: An Update from the Alzheimer's Study Group. *Special Committee on Aging.* Vol 3/25/09.
65. Alzheimer's Disease Supportive Services Program Innovation Grantee Project Summaries: Innovation Grantee Project Summaries: Administration on Aging.
66. Hodes RJ. Public funding for Alzheimer disease research in the United States. *Nat Med.* Jul 2006;12(7):770-773.
67. National Alzheimer's Coordinating Center. <http://www.alz.washington.edu/>. Accessed 6/30/09.
68. AD Research Centers. <http://www.nia.nih.gov/Alzheimers/ResearchInformation/ResearchCenters/>. Accessed 7/9/09.
69. Bryan ADRC Introduction. <http://adrc.mc.duke.edu/adrc.HTM>. Accessed 7/9/09.
70. National Institute on Aging: Important Events in NIA History. *The NIH Almanac* [<http://www.nih.gov/about/almanac/organization/NIA.htm>. Accessed 7/9/09.
71. Memory and Cognitive Disorders. *Department of Neurology* [<http://www.med.unc.edu/neurology/divisions/memory-and-cognitive-disorders>. Accessed 6/30/09.
72. *Cecil G. Sheps Center for Health Services Research* [<http://www.shepscenter.unc.edu/index.html>]. Accessed 6/30/09.
73. Aging, Disability, and Long-Term Care. *Cecil G. Sheps Center for Health Services Research* [2007; http://www.shepscenter.unc.edu/research_programs/aging/]. Accessed 6/30/09.
74. Mission. *Institute on Aging* [<http://www.aging.unc.edu/about/mission.html>]. Accessed 6/30/09.
75. About Us. *Duke Family Support Program* [<http://www.geri.duke.edu/service/dfsp/about.htm>]. Accessed 6/30/09.
76. About Us. *Alzheimer's Association* [http://www.alz.org/about_us_about_us.asp]. Accessed 6/30/09.
77. About n4a. *National Association of Area Agencies on Aging* [<http://www.n4a.org/about-n4a/>]. Accessed 6/30/09.
78. Mission. *UNC School of Medicine* [2005; <http://www.med.unc.edu/www/about/mission>]. Accessed 6/30/09.
79. Area Agencies on Aging. *North Carolina Division of Aging and Adult Services* [<http://www.ncdhhs.gov/aging/aaa.htm>]. Accessed 6/30/09.
80. Mission. *North Carolina Area Health Education Centers Program* [<http://www.med.unc.edu/ahec/about/mission.htm>]. Accessed 6/30/09.
81. Lav IJ, McNichol E. *State Budget Troubles Worsen* Center on Budget and Policy Priorities;2009.
82. Harris N, Grootjans J, Wenham K. Ecological aging: the settings approach in aged living and care accommodation. *Ecohealth.* Jun 2008;5(2):196-204.
83. *MemoryCare of Asheville NC* [<http://www.memorycare.org/>]. Accessed 6/30/09.
84. Framework for Program Evaluation in Public Health: Centers for Disease Control and Prevention; 1999.
85. Glasgow RE. The RE-AIM Model for Planning, Evaluation and Reporting on Implementation and Dissemination Research 2007.
86. Altpeter M. Frameworks and Tools for Translating Research *Institute on Aging Seminar.* Vol 2009.
87. Enhancing Geriatric Care through Practicing Physician Education: Evaluation Questionnaire. *Memory Loss: Evaluation in Primary Practice.* Vol: The John A. Hartford Foundation and The American Geriatric Society.



Appendices

- A. “State-of-the-Art Workshop” Recruitment Brochure
- B. Recommended Primary Care Approach to Dementia Screening and Diagnostic Assessment
- C. Post-Workshop Evaluation for Participant Practitioners
- D. “State-of-the-Art Workshop” Agenda
- E. Pre-Training Interview (Needs Assessment)
- F. Billing and Reimbursement Assessment
- G. 3 Month Follow-Up questionnaire
- H. 12 Month Follow-Up questionnaire
- I. Example of RE-AIM questions at each level of the public health pyramid.



Each participant will:

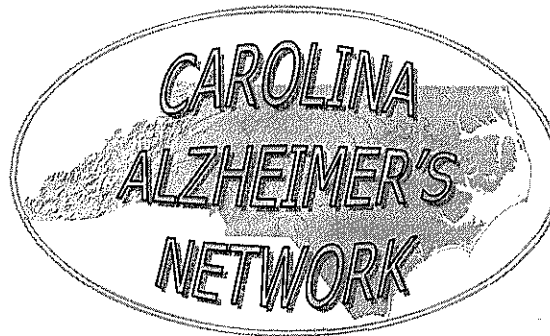
- Review cases, learn management guidelines, attend the memory disorders clinic (optional) and develop skills that are applicable to primary care practice.
- Earn CME credits (8 hours).
- Receive reimbursement for travel and lodging expenses.

Carolina Alzheimer's Network

- Created to improve access to quality dementia care throughout North Carolina by training and supporting primary care providers and conducting outreach to non-medical professionals.
- Co-directed by Dan Kaufer, MD (Associate Professor of Neurology and Director of the UNC Memory Clinic) and Philip Sloane, MD, MPH (Professor of Family Medicine).

Preceptorship Goal:

To train motivated physicians to be dementia care leaders in their practice and community.



Funding for this preceptorship is provided by

The Duke Endowment



UNC
DEPARTMENT
OF NEUROLOGY

Dementia Care Preceptorship

Sponsored by:
UNC Memory Disorders Program
and the
Carolina Alzheimer's Network



For inquiries and registration, contact:

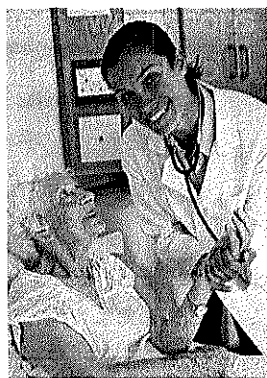
Phone: 919.966.5039
919.966.8172

Fax: 919.966.2922

A Program Designed for Primary Care Physicians

Participation will involve an intensive one-day preceptorship that will employ seminars, workshops and a case-based approach to teach state-of-the-art, practical approaches to the diagnosis and management of Alzheimer's disease and other dementias.

Training will also include on-site visits to clinical practices in order to help implement and optimize dementia care practices. Those who attend can schedule a one-on-one shadowing experience with Dr. Kaufer at the UNC Memory Disorders Clinic to review skills.



Learning Objectives:

- Develop an efficient approach to: a) screening for dementia, and b) conducting a diagnostic assessment of persons with suspected dementia
- Acquire practical knowledge of managing persons with Alzheimer's disease and related disorders, including management of behavioral symptoms and use of community resources
- Serve as a resource within your practice and community on dementia care

Course Content:

[Readings and a CD-ROM with study materials will be provided before the course]

- Practical screening for dementia
- Diagnostic assessment in primary care
- Role and interpretation of brain imaging and laboratory studies
- Lunch with case presentations from practice
- Comprehensive management of dementia
- Video cases / skill practice
- Clinical "shadowing" (optional)

For More Information....

If interested in attending or learning more about the program, please contact either Dr. Kaufer:
(kauferd@neurology.unc.edu) or
Dr. Sloane (psloane@med.unc.edu)

OR

Complete the information below and mail or fax it to:

Dementia Care Preceptorship
c/o Dan Kaufer, MD
170 Manning Drive
University of North Carolina
Chapel Hill, NC 27599

fax: 919 966-2922

Name: _____

Address: _____

City: _____

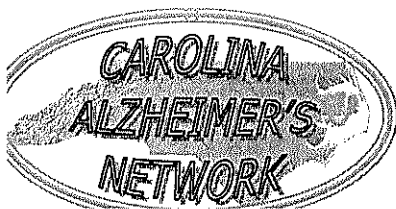
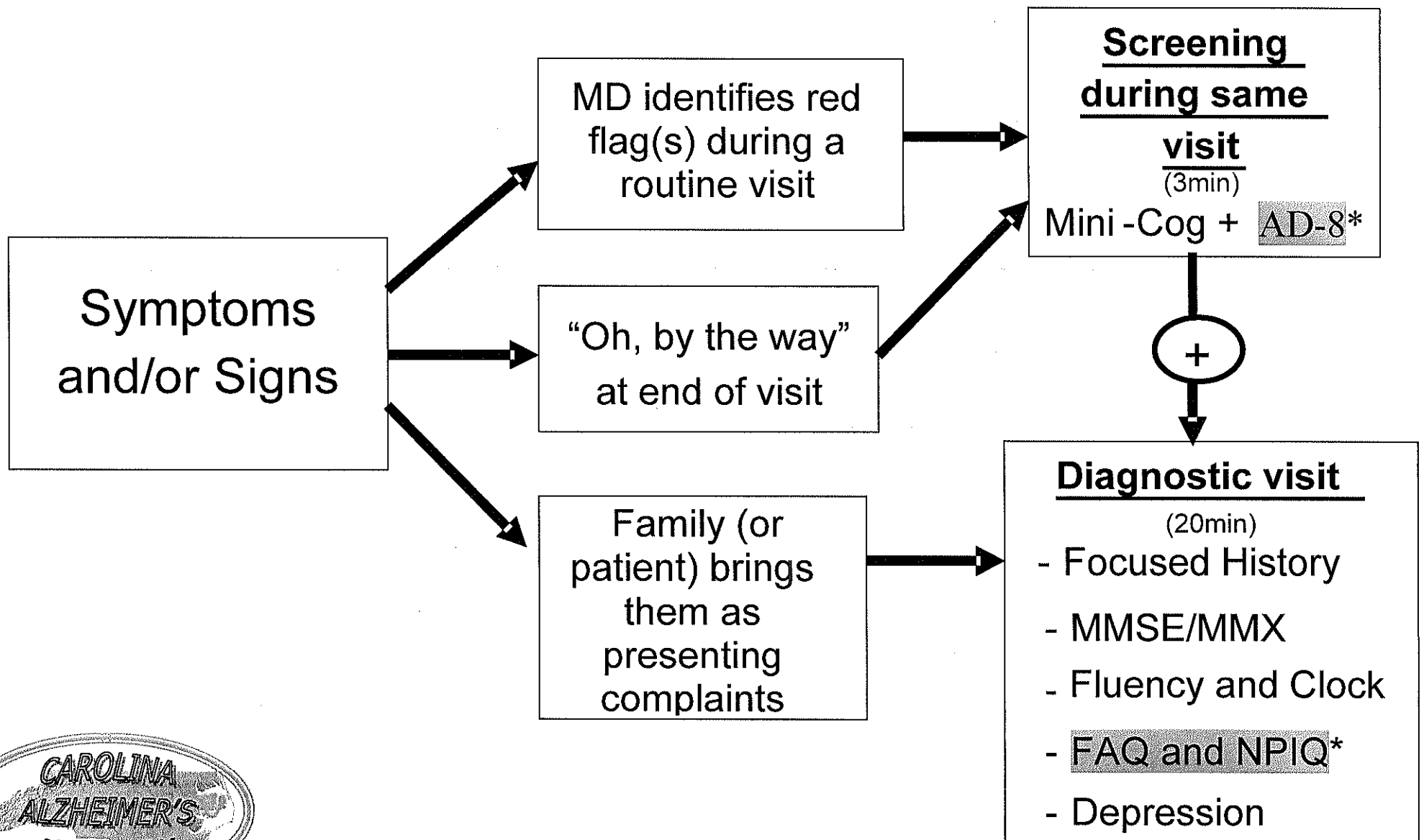
State: _____ Zip: _____

Phone: (____) _____

County: _____

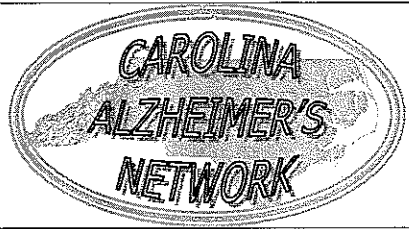
E-mail: _____

Recommended Primary Care Approach to Dementia Screening and Diagnostic Assessment



* = to be completed by the caregiver





Carolina Alzheimer's Network

Post-Workshop Evaluation for Participant Practitioners

Practitioner Name: _____ Workshop Date: _____ (ID: _____)

Your degree: (please circle) M.D. N.P. P.A. Year Degree Received: _____

The goals of this evaluation include improving the workshop, evaluating its effectiveness in meeting your needs as a dementia care provider, and determining how and why the workshop was successful.

I: Education Objectives and Workshop Content

1. A. What did you **most** want to learn from this workshop?
- B. Explain whether you did or did not learn that.

2. Where, **1 = Not at all**, **2 = A little**, **3 = Moderately**, **4 = Mostly**, and **5 = Completely**, please rate your your satisfaction with this workshop on a scale from 1 to 5? _____

How well were the following objectives met for each session?	Did not attend (NA)	Not at all	A little	Moderately	Mostly	Completely
3. Dementia: State-of-the-Art Update for Primary Care						
A. Understand the current status of scientific knowledge related to Alzheimer's disease	NA	1	2	3	4	5
B. Recognize the role of the primary care practitioner in dementia care and the barriers to optimal care	NA	1	2	3	4	5
C. Learn the aim of C.A.N. to overcome barriers	NA	1	2	3	4	5
4. Cognitive Screening in Primary Care: "Yes You Can"						
A. Determine who to screen for cognitive impairment	NA	1	2	3	4	5
B. Review key clinical features that are early warning signs of Alzheimer's disease	NA	1	2	3	4	5
C. Develop knowledge base and skill in performing a brief and efficient cognitive screen	NA	1	2	3	4	5

How well were the following objectives met for each session?	Did not Attend (NA)	Not at all	A little	Moderately	Mostly	Completely
5. Clinical Assessment and Differential Diagnosis						
A. Develop knowledge and skill in performing a comprehensive dementia evaluation	NA	1	2	3	4	5
B. Learn how to use cognitive, behavioral, and functional testing and laboratory studies in formulating differential diagnosis	NA	1	2	3	4	5
C. Recognize core features of non-Alzheimer's dementias	NA	1	2	3	4	5
6. Cases						
A. Cases were used to illustrate assessment	NA	1	2	3	4	5
B. Cases were used to illustrate differential diagnosis	NA	1	2	3	4	5
C. Practitioners were able to discuss their own cases	NA	1	2	3	4	5
7. Dementia Treatment: Pharmacological Treatment of Cognitive and Behavioral Symptoms						
A. Understand the characteristics, uses, and adverse side effects of the available drug treatments for cognitive symptoms in dementia	NA	1	2	3	4	5
B. Describe a systematic approach for managing behavioral symptoms in dementia, including planning and monitoring of nonpharmacological and pharmacological therapies	NA	1	2	3	4	5
C. Understand the evidence base for and be able to implement minimizing the use of anticholinergic medications	NA	1	2	3	4	5
8. Caregivers, Communication, and Community Resources						
A. Able to identify common behavioral challenges that present to caregivers of persons with dementia	NA	1	2	3	4	5
B. Able to identify education and support resources in your area	NA	1	2	3	4	5
9. Networking						
A. Explain the purposes and function of the Clinical Dementia Registry	NA	1	2	3	4	5

How well were the following objectives met for each session?	Did not Attend (NA)	Not at all	A little	Moderately	Mostly	Completely
10. Case Presentations (session)						
A. Cases were used to illustrate comprehensive treatment approaches and longitudinal management	NA	1	2	3	4	5
B. Cases were used to discuss clinical therapeutic decision-making	NA	1	2	3	4	5

11. Where, **1 = Not at all, 2 = A little, 3 = Moderately, 4 = Mostly, and 5 = Completely**, how likely are you to enroll patients in the Clinical Dementia Registry on a scale from 1 to 5? _____

12. Was conflict of interest information made available? Yes / No

13. Do you think this program was balanced and objective? Yes / No

II: Linkages

1. A. Do you feel better linked to resources in your community? Yes / No

B. Why or why not?

2. A. What types of connections would you like to have with UNC-Chapel Hill?

III. Your Practice

1. Please rate yourself on the following items (1) as you are CURRENTLY and, (2) retrospectively, as you were BEFORE participating in the workshop.

	CURRENTLY					BEFORE				
	Low			High		Low			High	
A. your ability to screen patients for dementia	1	2	3	4	5	1	2	3	4	5
B. your ability to distinguish Alzheimer's Disease from other forms of dementia	1	2	3	4	5	1	2	3	4	5
C. your ability to provide initial treatment to patients with memory loss	1	2	3	4	5	1	2	3	4	5
D. your understanding of the value of assessment instruments in the evaluation of memory loss	1	2	3	4	5	1	2	3	4	5
E. your office's ability to deliver patient and caregiver education about dementia care	1	2	3	4	5	1	2	3	4	5
F. your knowledge of community resources for persons w/dementia and how to refer patients to them	1	2	3	4	5	1	2	3	4	5
G. your ability to promote Quality of Life	1	2	3	4	5	1	2	3	4	5

Please rate your interest or confidence .	Not at all	A little	Moderately	Mostly	Completely
2. Please rate your interest in a “referral prescription pad” for dementia care resources in your community.	1	2	3	4	5
3. Please rate your interest in using the flow-diagram called the “Recommended Primary Care Approach to Dementia Screening and Diagnostic Evaluation.”	1	2	3	4	5
4. Please rate your confidence in using the flow-diagram called the “Recommended Primary Care Approach to Dementia Screening and Diagnostic Evaluation.”	1	2	3	4	5

5. A. Will you use the information gained to enhance your clinical practice? Yes / No

B. Do you feel better equipped to be a resource in dementia care for your practice? Yes / No

C. Will you use the information gained to train or teach others? Yes / No

D. What specific goals and plans do you have for changing office practice with respect to dementia?

6. What topics would you like to have discussed in more depth at this workshop?

7. Was anything presented not useful, in your opinion, or how could the training be improved?

8. Please suggest future workshop topics of interest to you and your practice:

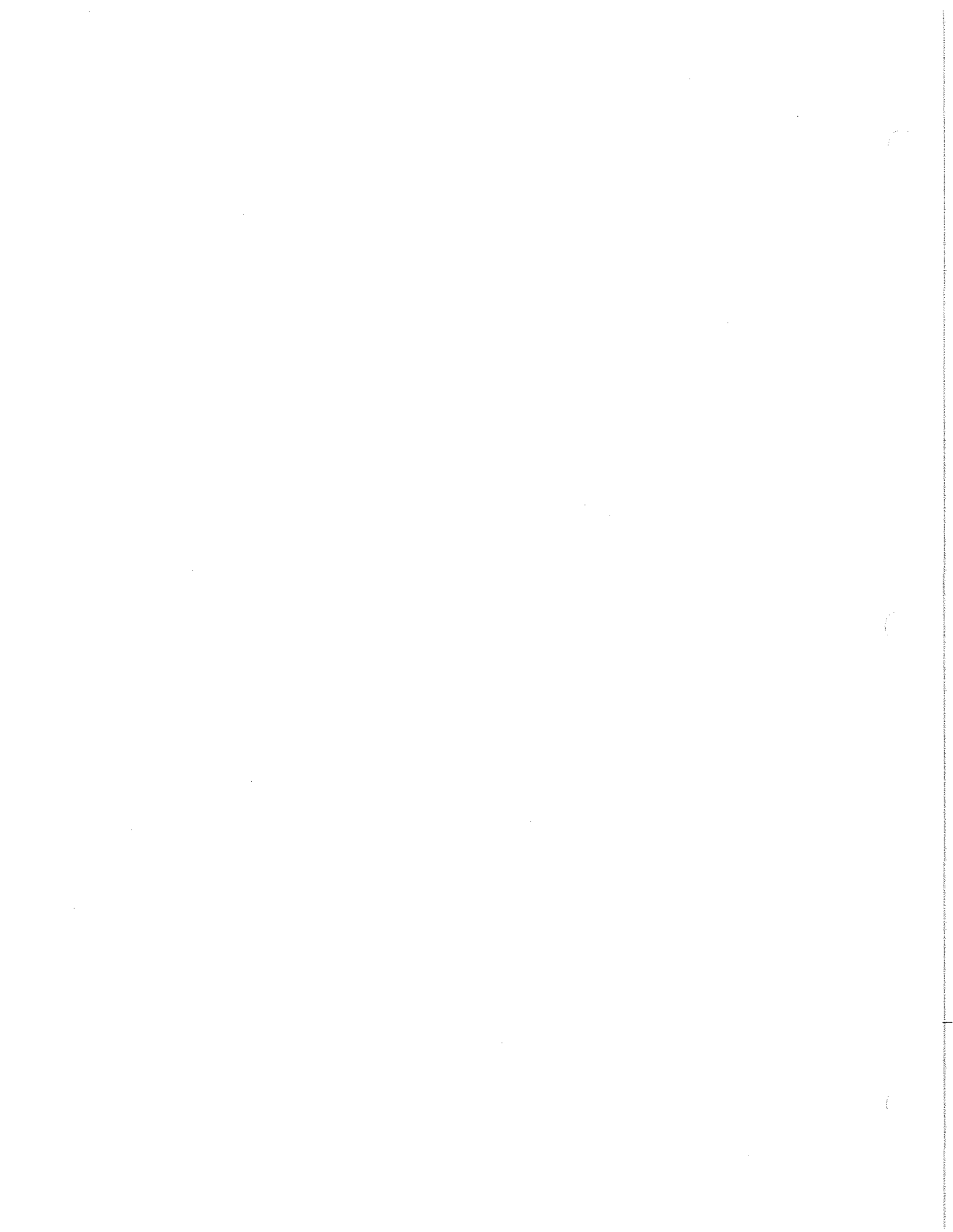
Thank you for your completion of this evaluation



DEMENTIA CARE PRECEPTORSHIP
 Presented by the UNC Memory Disorders Program and
 Carolina Alzheimer's Network

AGENDA

TIME	TITLE	COMMENT
9:00 - 9:15 am	Objectives & Introduction	Present goals, overview, and introduce participants
9:15 – 9:45 am	Dementia: State-of-the-Art Update for Primary Care	Overview of Alzheimer's disease and other dementias, emphasizing relevant aspects to primary care
9:45 – 10:45 am	Cognitive Screening in Primary Care: "Yes You Can"	Review rationale for screening, different tools (AD8, Mini-Cog, etc), and practice administration / interpretation (focused case examples)
10:45 – 11:00 am	Break	
11:00 – 12:00 pm	Clinical Assessment & Differential Diagnosis	Review diagnostic and longitudinal assessment of dementia: history (cognition, behavior, and functional abilities), cognitive assessment; highlight key clinical, laboratory, and structural/functional imaging findings (focused case examples)
12:00 – 1:00 pm	Lunch	Case Presentations: Assessment and Diff Dx (2-3 Cases)
1:00 – 2:00 pm	Dementia Treatment: Pharmacological Treatment of Cognitive and Behavioral Symptoms	Review evidence-based treatments, discuss indications, expectations, practical issues, behavioral symptom management (case-based examples)
2:00 – 3:00 pm	Caregivers, Communication, and Community Resources	Discuss caregiver role in dementia; communication re: diagnosis, driving, durable POA, financial capacity, institutionalization, living will, etc.; review community and educational resources
3:00 – 3:15 pm	Break	
3:15 – 3:45 pm	Networking	Discuss how UNC can provide ongoing support and brainstorm the registry concept.
3:45 – 4:45 pm	Q&A / Follow-up	Use case-approach to illustrate comprehensive treatment approaches and longitudinal management; provide opportunities for clinical therapeutic decision-making
4:45 – 5:00 pm	Summary & Conclusion	Feedback



APR 20 2009



Carolina Alzheimer's Network

Physician Participant Pre-Training Interview

Version 4-1-09

Date: _____ Physician Name: _____ ID: _____

Instructions: Please read each question carefully and answer by placing an "X" in the appropriate box. If you are unsure of an answer, please make your best guess. You may also leave an item blank if you are unsure. Your responses will be used for program evaluation purposes and may be reported in summary form in reports; however no report will ever identify you specifically by name without your express consent.

Brief follow-up questionnaires will be mailed to you in 3, 6, and 12 months to assess the program's impact over time. Please make every effort to complete and return these later surveys, as this data is critical for validating the program and securing future funding.

Part I: A. Information about Your Practice

1. How many years have you practiced medicine? _____

2. How many days per week do you provide clinical care to patients in your office? _____

3. Hours per week that you see patients in your office: _____

4. a. Do you attend patients in the hospital? ₁ Yes ₀ No

If yes → b. What would you estimate to be your average daily hospital census? _____

5. Approximately what % of your patients are age 65+? _____

6. a. Do you see patients who reside in nursing homes? ₁ Yes ₀ No

If yes → b. Approximately how many patients do you have in nursing homes? _____

c. On average, how many hours/week are you present in a nursing home? _____

7. a. Do you see patients who reside in adult care homes, assisted living facilities, family care homes, or similar non-nursing home long-term care settings? ₁ Yes ₀ No

If yes → b. Approximately how many patients do you have in these facilities? _____

c. On average, how many hours per week are you present in one or more of these facilities? _____

8. a. Do you use any formal evaluation instruments to evaluate patients with memory loss and possible dementia?
 Examples include: MMSE, clock drawing, orientation x 3, geriatric depression scale. ₁ Yes ₀ No

If yes → b. Which instruments do you use?

Part I: B. Information about Your Practice

1. Gender: ₁ Male ₂ Female

2. Age: _____

Part II: Information about how Your Knowledge and Experience in Dementia Care

1. How confident are you with:	Not at All Confident	A Little Confident	Moderately Confident	Mostly Confident	Extremely Confident
a. Your ability to screen patients for dementia?	1	2	3	4	5
b. Your ability to make a diagnosis of dementia?	1	2	3	4	5
c. Your ability to distinguish Alzheimer's Disease from other forms of dementia?	1	2	3	4	5
d. Your understanding of the value and use of assessment instruments for cognition?	1	2	3	4	5
e. Your understanding of the role of MRI scans in the diagnosis of dementia?	1	2	3	4	5
f. Your ability to provide initial treatment to patients with memory loss?	1	2	3	4	5
g. Your ability to use medications for memory loss [e.g., donepezil (Aricept), Rivastigmine (Exelon), and memantine (Namenda)]?	1	2	3	4	5
h. Your ability to approach behavioral symptoms in patients with dementia?	1	2	3	4	5
i. Your office's ability to deliver patient and caregiver education about dementia care?	1	2	3	4	5
j. Your knowledge of community resources for persons with dementia and how to refer patients to them?	1	2	3	4	5
k. Your ability to disclose and explain a diagnosis of dementia to the patient?	1	2	3	4	5
l. Your ability to provide information to, assist, and respond to family caregivers of patients with dementia?	1	2	3	4	5

2. What do you see as your specific strengths and weaknesses in your clinical work with older adults with cognitive impairment?

a. Strengths: _____

b. Weaknesses: _____

Part III. Your Interests and Goals in the Dementia Care Training Program

1. What do you hope to learn or otherwise gain by participating in the UNC dementia care training program?
Please give examples.

- a. _____
- b. _____
- c. _____
- d. _____
- e. _____
- f. _____

2. Please describe one patient with memory loss and/or dementia that you have personally managed, where you wished you had more information, skill or experience.

Part IV. Your Experience and Interest in Dementia Research

1. a. Have you ever referred a patient with dementia to participate in a clinical research study or drug trial?

₁ Yes ₀ No

If yes → b. How many patients have you referred in the past 12 months? _____

c. To whom were they referred? _____

2. Because little research has been done on persons with dementia seen in community settings (as opposed to referral centers), we are interested in developing a primary care-based dementia registry. This would be a way for primary care providers such as yourself to enroll patients who may be interested in participating in research – either drug studies or other research on cognitive impairment and dementia. This would involve having you obtain consent from the patient and provide some basic information using a brief web-based information sheet

a. What is your initial reaction to this idea in terms of your possible participation?

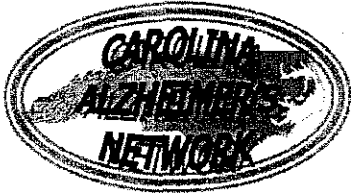
b. What features of such a system might make it more feasible for you and/or providers like you to participate?

This completes the questionnaire. Thank you for your time and participation.

Some items were adapted from:

- Levine SA, Brett B, Robinson BE, Stratos GA, Lascher SM, Granville L, Goodwin C, Dunn K, Parry PP. Practicing physician education in geriatrics: Lessons learned from the train-the-trainer model. *J Am Geriatr Soc* 55:1281-1286, 2007.
- Meuser T. Multidisciplinary Geriatric Education: A 3-day mini-residency in dementia diagnosis, treatment, and care. Clinician Partners Program, Alzheimer's Disease Research Center, Washington University, St. Louis MO. Unpublished.

APR 20 2009



**Supporting Statewide
Education, Research, and
Community Outreach to
Improve Care of Persons with
Alzheimer's Disease and
Related Dementias**

Co-Directors:

Daniel I. Kaufer, MD
Director, Memory Disorders Program
Department of Neurology
University of North Carolina
at Chapel Hill
kauferd@neurology.unc.edu

Philip D. Sloane, MD, MPH
Elizabeth and Oscar Goodwin
Distinguished Professor of Family
Medicine and co-director,
Program on Aging, Disability and Long-
Term Care, Cecil G. Sheps Center for
Health Services Research
University of North Carolina
at Chapel Hill
psloane@med.unc.edu

Administration and Contact Information:

**Cecil G. Sheps Center for Health
Services Research, University of
North Carolina at Chapel Hill**

Julia Thorp (project assistant)
919-966-7173

Amanda Bowers (project assistant)
919-843-3085

UNC Memory Disorders Clinic
Charlene Riedel-Leo, MSW (Clinical
Research and Outreach Coordinator)
919-966-5039

Karen Curtis (clinic appointments)
919-966-8168

Supported by grants from the Duke
Endowment and the US Administration
on Aging

[Name of Provider Participant]
[Name of Practice Administrator]
[Address]
[Fax Number (if sent by fax)]

RE: Request for billing and reimbursement information for persons with dementia

Dear _____:

One of the goals of the dementia care training being conducted by the Carolina Alzheimer's Network is to help participating primary care providers be able to receive appropriate reimbursement for dementia care services they provide.

For this reason, we are asking you to help us by providing pre-participation data on the patients you have seen during the past 6 months and coded with dementia diagnoses.

The attached worksheets are for providing these data for us. To obtain these data for us, you will need to have electronic billing records that can be searched by ICD-9 code. We are requesting that you:

- tell us how many patient visits you billed under each of a series of ICD-9 codes during the most recent 6 months for which you have available data. This information should be entered in attached worksheet #1.
- for 10 consecutive office visits in which one of the ICD-9 codes in Worksheet #1 was the primary diagnosis, and (if you do nursing home and/or assisted living visits) 5 consecutive visits to each of these sites, please provide information about the level of service you billed and the reimbursement you received. For this information start 6 months ago and provide information on consecutive visits that were billed. This information should be entered in attached worksheet #2.

We will collate and analyze data from multiple practices and provide you later with a summary of the data, with recommendations based on what we have learned.

In about 9 months we will come back to you and request similar data, to see if anything has changed as a result of our training and technical assistance.

In advance, we thank you for your assistance in this work.

Sincerely,

Philip Sloane, MD, MPH

ID: _____

**WORKSHEET #1:
SUMMARY OF ICD-9 CODES USED IN BILLING FOR PROVIDER SERVICES**

Instructions: For the most recent 6 months for which billing data are available, please provide a summary of how many patient visits this provider billed under each of following ICD-9 codes (as primary diagnosis), by site of service.

Provider name: _____

Months summarized (we are requesting a summary of 6 months of data): _____

Beginning date: ____/____/____

Ending Date: ____/____/____

ICD-9 Codes [note: include any diagnoses that have additional digits after the decimal point]	Number of Encounters with This Code During Those 6 Months		
	Office Visits	Nursing Home Visits	Assisted Living Visits
290.0 Senile dementia, uncomplicated	_____	_____	_____
290.1 Presenile dementia(s)	_____	_____	_____
290.20 Senile dementia with delusional features	_____	_____	_____
290.21 Senile dementia with depressive features	_____	_____	_____
290.3 Senile dementia with delirium	_____	_____	_____
290.4 Atherosclerotic dementia	_____	_____	_____
294.1 Dementia, not otherwise specified	_____	_____	_____
294.10 Dementia... without behavior disturbance	_____	_____	_____
294.11 Dementia... with behavior disturbance	_____	_____	_____
331.0 Alzheimer's disease	_____	_____	_____
331.19 Frontotemporal dementia	_____	_____	_____
331.2 Senile degeneration of the brain (Organic Brain Syndrome)	_____	_____	_____
331.82 Dementia with Lewy bodies (including dementia with Parkinsonism)	_____	_____	_____
331.83 Mild cognitive impairment	_____	_____	_____
331.9 Cerebral degeneration, unspecified	_____	_____	_____
438.0 Late Effects of CVD	_____	_____	_____
780.93 Memory loss (also can be used for those diagnosed with MCI)	_____	_____	_____
997.01 Central nervous system complication-anoxic brain damage or cerebral hypoxia	_____	_____	_____

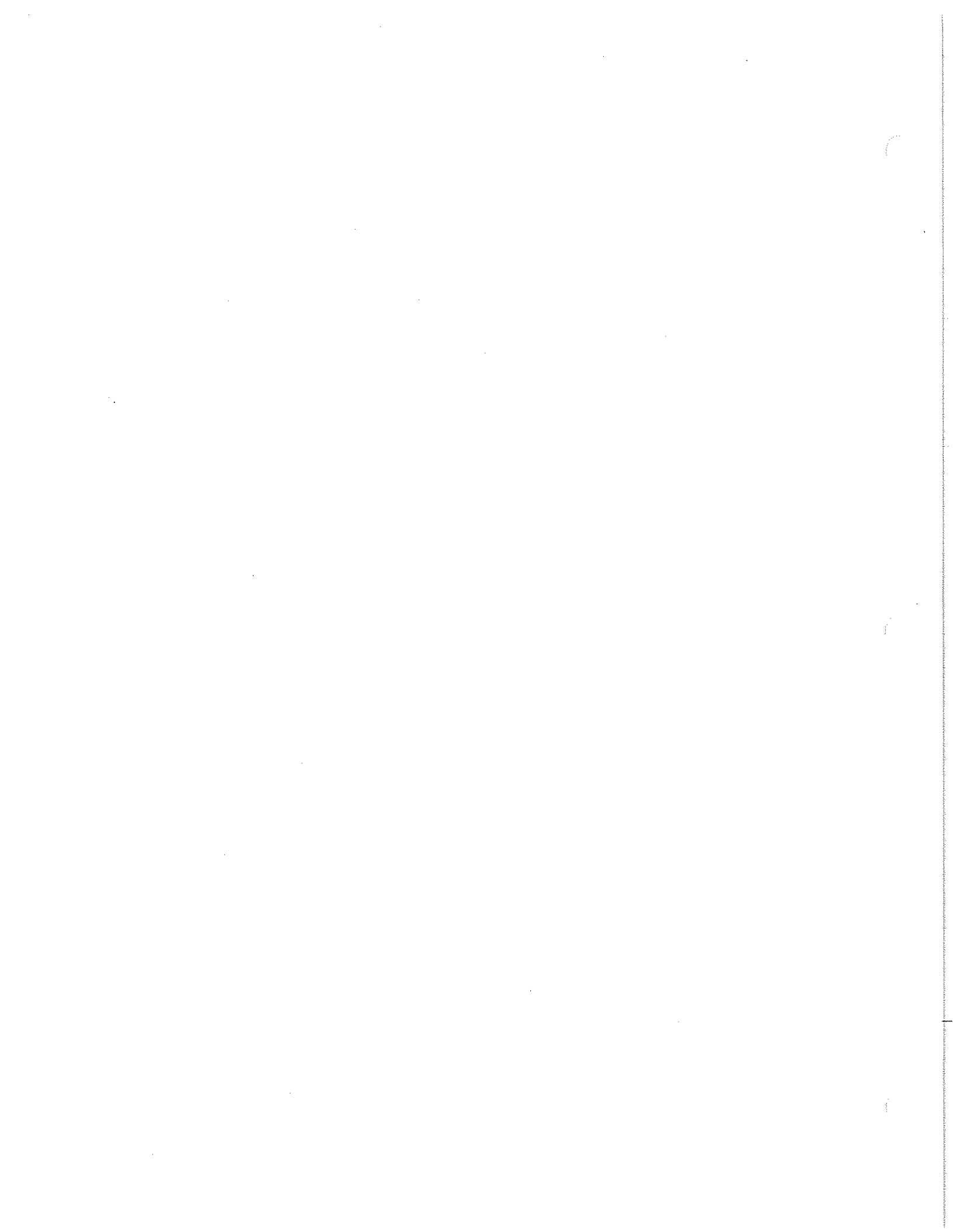
**WORKSHEET #1:
SUMMARY OF ICD-9 CODES USED IN BILLING FOR PROVIDER SERVICES**

- Instructions: for 10 consecutive office visits, 5 consecutive nursing home visits (if applicable), and 5 consecutive assisted living visits (if applicable) for which one of the ICD-9 codes listed in Worksheet 1 was billed as the primary diagnosis, please provide information about the level of service you billed and the amount of reimbursement you received. For this information start 6 months ago and provide information on consecutive visits that were billed under any of the ICD-9 codes listed in Worksheet 1.

Provider name: _____

	Date of Service	Site of Service	ICD-9 Code billed (for eligible codes, see Worksheet #1)	E&M Code(s) Billed	Amount Billed	Amount Received (mark "P" if still pending)	Who Paid (MR, MD, PI, and/or PT; see below for definitions) *	Comments
1.		Office						
2.		Office						
3.		Office						
4.		Office						
5.		Office						
6.		Office						
7.		Office						
8.		Office						
9.		Office						
10.		Office						
11.		Nursing home						
12.		Nursing home						
13.		Nursing home						
14.		Nursing home						
15.		Nursing home						
16.		Assisted living						
17.		Assisted living						
18.		Assisted living						
19.		Assisted living						
20.		Assisted living						

* Codes to use for payment source: MR = Medicare, MD = Medicaid, PI = private insurance; PT = patient out-of-pocket





Carolina Alzheimer's Network

Workshop Participant 3 Month Follow-Up Questionnaire

Version 7-29-09

Date: _____ Practitioner Name: _____ (ID: _____ to be assigned)

Instructions: This survey should about 5 minutes of your time. Please read each question carefully. If you are unsure of an answer, please make your best guess. You may also leave an item blank if you are unsure. Your responses will be used for program evaluation purposes and may be reported in summary form in reports; however no report will ever identify you specifically by name without your expressed consent.

Part I: Information about Your Knowledge and Experience in Dementia Care

1. How confident are you: (circle your answer)	Not at All Confident	A Little Confident	Moderately Confident	Mostly Confident	Extremely Confident
a. Your ability to screen patients for dementia?	1	2	3	4	5
b. Your ability to make a diagnosis of dementia?	1	2	3	4	5
c. Your ability to distinguish Alzheimer's Disease from other forms of dementia?	1	2	3	4	5
d. Your understanding of the value and use of assessment instruments for cognition?	1	2	3	4	5
e. Your understanding of the role of MRI scans in the diagnosis of dementia?	1	2	3	4	5
f. Your ability to provide initial treatment to patients with memory loss?	1	2	3	4	5
g. Your ability to use medications for memory loss [e.g., donepezil (Aricept), Rivastigmine (Exelon), and memantine (Namenda)]?	1	2	3	4	5
h. Your ability to approach behavioral symptoms in patients with dementia?	1	2	3	4	5
i. Your office's ability to deliver patient and caregiver education about dementia care?	1	2	3	4	5
j. Your knowledge of community resources for persons with dementia and how to refer patients to them?	1	2	3	4	5
k. Your ability to disclose and explain a diagnosis of dementia to the patient?	1	2	3	4	5
l. Your ability to provide information to, assist, and respond to family caregivers of patients with dementia?	1	2	3	4	5

2. A. Since you became involved with the Carolina Alzheimer's Network, have you adopted the use of any of the materials provided at the workshop? Yes / No

B. If no, go to question 3A. If yes, which materials?

3. A. Have you used the information gained to train, teach, or consult with others? Yes / No

B. If no, go to the next section. If yes, who?

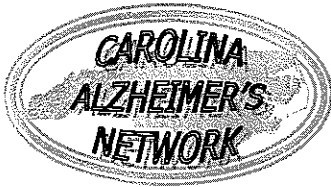
Part II. Linkages

4. Since you became involved with the Carolina Alzheimer's Network, would you say you're using linkages to dementia care services: (Circle your answer) More / Less / About the same.

5. What other types of services or resources linkages would you like to have?

6. Are there any other comments you would like to make about the Carolina Alzheimer's Network? _____

This completes the questionnaire. Thank you for your time and participation.



Carolina Alzheimer's Network

Workshop Participant 12 Month Follow-Up Questionnaire

Version 7-29-09

Date: _____ Practitioner Name: _____ (ID: _____ to be assigned)

Instructions: This survey should about 10 minutes of your time. Please read each question carefully. If you are unsure of an answer, please make your best guess. You may also leave an item blank if you are unsure. Your responses will be used for program evaluation purposes and may be reported in summary form in reports; however no report will ever identify you specifically by name without your expressed consent.

Part I: Information about You and Your Practice

1. Approximately what % of your patients are age 65+? _____
2. a. Hours per week that you see patients in your office: _____
 - b. Average number of patients you see in your office per month: _____
 - c. Number of patients you see in your office with dementia: _____
 - d. Number of patients you see in your office with mild cognitive impairment: _____
 - e. Number of patients who you see in your office who live in adult care homes, assisted living facilities, family care homes, or similar non-nursing home long-term care settings: _____
3. a. Do you see patients who reside in nursing homes? ₁ Yes ₀ No
 - If yes → b. Approximately how many patients do you have in nursing homes? _____
 - c. On average, how many hours/week are you present in a nursing home? _____
4. a. Do you see patients in adult care homes, assisted living facilities, family care homes, or similar non-nursing home long-term care settings? ₁ Yes ₀ No
 - If yes → b. Approximately how many patients do you see in these facilities? _____
 - c. On average, how many hours per week are you present in one or more of these facilities? _____

5. a. Do you use any formal evaluation instruments to evaluate patients for memory loss and possible dementia?

Examples include: MMSE, clock drawing, orientation x 3.

₁ Yes ₀ No

If yes → b. Which instruments do you use?

Part II: Information about Your Knowledge and Experience in Dementia Care

1. How confident are you: (circle your answer)	Not at All Confident	A Little Confident	Moderately Confident	Mostly Confident	Extremely Confident
a. Your ability to screen patients for dementia?	1	2	3	4	5
b. Your ability to make a diagnosis of dementia?	1	2	3	4	5
c. Your ability to distinguish Alzheimer's Disease from other forms of dementia?	1	2	3	4	5
d. Your understanding of the value and use of assessment instruments for cognition?	1	2	3	4	5
e. Your understanding of the role of MRI scans in the diagnosis of dementia?	1	2	3	4	5
f. Your ability to provide initial treatment to patients with memory loss?	1	2	3	4	5
g. Your ability to use medications for memory loss [e.g., donepezil (Aricept), Rivastigmine (Exelon), and memantine (Namenda)]?	1	2	3	4	5
h. Your ability to approach behavioral symptoms in patients with dementia?	1	2	3	4	5
i. Your office's ability to deliver patient and caregiver education about dementia care?	1	2	3	4	5
j. Your knowledge of community resources for persons with dementia and how to refer patients to them?	1	2	3	4	5
k. Your ability to disclose and explain a diagnosis of dementia to the patient?	1	2	3	4	5
l. Your ability to provide information to, assist, and respond to family caregivers of patients with dementia?	1	2	3	4	5

2. A. Since you became involved with the Carolina Alzheimer's Network, have you adopted the use of any of the materials provided at the workshop? Yes / No

B. If no, go to question 3A. If yes, which materials?

3. A. Have you used the information gained to train, teach, or consult with others? Yes / No

B. If no, go to the next section. If yes, who?

Part II. Linkages

4. Since you became involved with the Carolina Alzheimer's Network, would you say you're using linkages to dementia care services: (Circle your answer) More / Less / About the same.

5. What other types of services or resources linkages would you like to have?

6. Are there any other comments you would like to make about the Carolina Alzheimer's Network? _____

This completes the questionnaire. Thank you for your time and participation.

[unreadable]

[unreadable]

Appendix I. Examples of RE-AIM questions at each level of the public health pyramid.

Direct Health Services Level	Reach -- How many individuals with ADRDs and their families are being reached by PCPs in CAN?
	Effect -- Are these individuals and families satisfied with their dementia care, especially compared to individuals and families whose PCPs are not aware of the CAN program?
	Adoption – Why are these individuals and families satisfied/What is different about their dementia care (from CAN PCPs)?
	Implementation – Are these care differences consistent throughout CAN regions? (Even in rural, poor, and underserved areas?)
	Maintenance – How can these care differences be sustained?
Enabling the Community	Reach – Are the web-based resources, such as the dementia assessment toolkit being taught to PCPs?
	Effect – Are these resources useful to PCPs for improving care to individuals, both clinical care and referral to resources?
	Adoption – Are these resources/tools being used by CAN PCPs?
	Implementation – Are the resources/tools being used appropriately? (Is the algorithm being used?)
	Maintenance – Are PCPs continuing to use these resources/tools after trying them? Are they teaching office staff to administer them?
Population-Based Health Services	Reach – Are support groups being offered in each of the AAA regions?
	Effect – Are individuals with ADRDs and their families satisfied with these support groups?
	Adoption – How do they work? (Which aging services providers are staffing these groups?)
	Implementation – Are these support groups similar among the regions and how many resources are required for each one?
	Maintenance – Are individuals with ADRDs and their families showing long-term interest in these support groups and are they sustainable?
Infrastructure	Reach – How many PCPs are enrolling patients in the registry?
	Effect – How is the registry being used? (What type of research proposals? Are individuals with ADRDs and their families satisfied with their involvement in the registry?)
	Adoption – Are PCPs using the registry regularly? (For most of their patients?)
	Implementation – Is the registry working correctly, without any technical difficulties?
	Maintenance – Are PCPs showing long-term interest in this registry?

