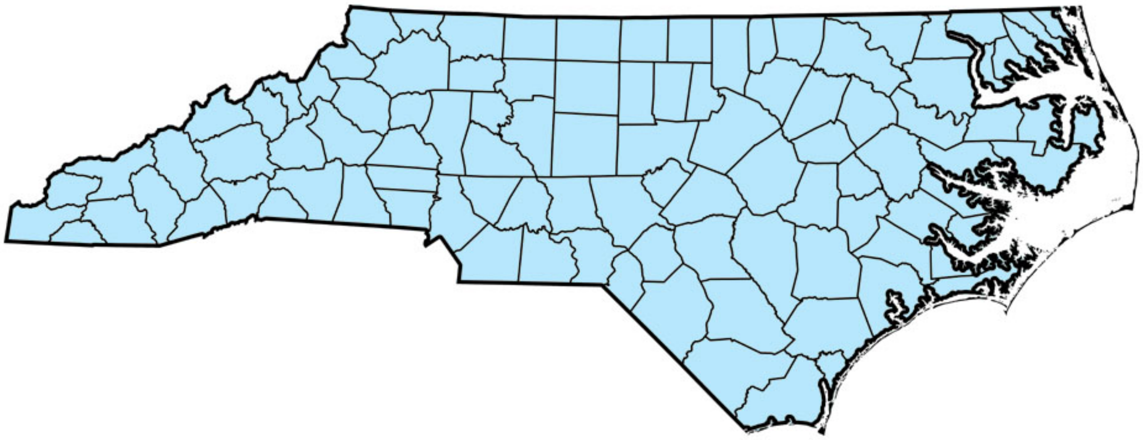
UNC
THE CECIL G. SHEPS CENTER
FOR HEALTH SERVICES RESEARCH

ANNUAL REPORT

July 1, 2014 – June 30, 2015



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

725 Martin Luther King Jr. Blvd.
Chapel Hill, NC 27599-7590
http://www.shepscenter.unc.edu

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As in the past, this year's annual report is organized into several sections. Initially, the mission of the Center is discussed, followed by a narrative review of its research, technical assistance, and training activities. The research and technical assistance activities are described by program area, followed by a description of the Center's graduate and postgraduate education activities and the library and informational services available. The Appendices summarize the Center's organizational structure, organizational chart and Policy Board members, the contract and grant proposal success and sources of funds supporting Center activities, the seminars sponsored by the Center during the year. A list of publications produced by Center investigators during the fiscal year is the final appendix.

MISSION STATEMENT AND ORGANIZATION

The Cecil G. Sheps Center for Health Services Research, one of the nation's oldest and largest academic health services research centers, opened its doors over forty-seven years ago. It 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. This is accomplished 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 policymakers and the general public.

The Center is a separate organizational unit under the Vice Chancellor for Research at UNC Chapel Hill. Oversight responsibility for the Center is vested in a Policy Board whose members include senior faculty and administrators from the five health science schools, as well as representatives of the health services community at large. The director receives assistance in planning and leading the Center's activities from the four deputy directors, one associate director, and from the program directors responsible for areas of health related research/policy analysis. A copy of the organizational chart for the Center can be found in Appendix A and a listing of the Policy Board members in Appendix B. Center principal investigators have faculty appointments in the following UNC-Chapel Hill schools and departments:

- School of Medicine (Departments of Family Medicine, Medicine, Pediatrics, Obstetrics and Gynecology, Radiation Oncology, Psychiatry, Social Medicine, and Surgery),
- School of Pharmacy,
- School of Dentistry,
- School of Public Health (Departments of Epidemiology, Health Policy and Management, Health Behavior, Nutrition, and Maternal and Child Health),
- School of Nursing, and
- School of Social Work.

NARRATIVE REVIEW OF SHEPS CENTER RESEARCH, TECHNICAL ASSISTANCE, AND TRAINING ACTIVITIES

The Sheps Center currently focuses the majority of its research, technical assistance, information dissemination, and educational activities in 11 areas (*Aging, Disability, and Long-term Care; Child and Adolescent Health Services; Health Care Economics and Finance; Health Care Organization; Health Disparities; Primary Care; Medical Practice and Prevention; Mental Health and Substance Abuse Services and Systems; Rural Health; Health Workforce;* and *Women's Health Services*), however the Center remains responsive to new issues.

The value of conducting studies in each of these areas is assessed continuously, and other areas of potential concentration are explored periodically to ensure that the Center applies its resources as productively as possible to questions of particular importance. In addition, since 1994 the *North Carolina Institute of Medicine* (NC•IOM) has been administratively linked with the Sheps Center.

Dr. Tom Ricketts retired in 2015, after decades of dedicated service as a researcher and as the **Deputy Director for Policy Analysis** at the Sheps Center. In the upcoming year, the current Director of the Sheps Center, **Dr. Tim Carey**, will step down after 16 years of growth for the Center and hand the reins to a new Director. There is currently an active national search to fill this leadership position.

For the purposes of this report, we discuss the organization and leadership that was present for most of the 2014-15 year.

The Center continues active engagement with the Patient Centered Outcomes Research Institute (PCORI) and the Centers for Medicare and Medicaid Services (CMS) Master Task Order Contracts. These federal contracts are competitive and have increased our partnerships with other agencies such as *RTI International* and *American Institutes for Research* (AIR). Over the past few years, we have had early success with both organizations, adding to the portfolio of funders of health services research at UNC. Center affiliated faculty are also continuing their relationships with NIH, HRSA, AHRQ, foundations and other traditional funders of health services research. As the structure of the US health system changes, UNC will modify its approach in evaluating and advising it.

Sheps Center leadership is working with the program directors and investigators to strategically focus on care quality improvement, workforce, implementation research and other areas of rapid development in health services research. The deputy and associate directors meet weekly with the director to discuss Center administration, upcoming grant proposals, and center external relations. Seminar series are open to all staff and University collaborators. A *Staff Liaison Committee* includes staff from each of the programs and support areas. This committee meets monthly and plans activities to improve Center cohesion and mission. A recently designed external website and internal-only "intranet" provide features that promote Center **services,** events, idea sharing, and security awareness. Each of these forums has greatly facilitated the sharing of knowledge and expertise among projects and with campus and research partners.

The Center's IT infrastructure available to the 11 research program areas and to research partners include: primary and secondary data management and analysis; web and database systems design and development; and, technical support and systems administration for our secure computing environment.

In data management and analytic programming, we have had continued expansion of our health care utilization secondary data services. We have also enhanced our data exploration and reporting techniques using SAS and other tools. In web and database systems, we are supporting more than 40 research projects with customized web/database systems in production for project management, participant tracking, and primary data collection. We are also developing groundbreaking data visualization techniques via the web for real-time exploration of primary data. At the infrastructure level, we are migrating to a next generation flexible server infrastructure for all computing services, partnering with other UNC units for shared services, and implementing additional security controls. We have continued SANS GSEC security training certification for our lead systems administrator since 2009 and require security awareness training and rules of behavior attestation for ***all*** users of the Center's systems.

Heart Health NOW! Combines Expertise and Training to Fight Heart Disease Through Primary Care

A cooperative team of researchers led by Dr. Sam Cykert was awarded a $15M federal grant from the Agency for Healthcare Research and Quality (AHRQ) to help primary care practices use the latest evidence to improve the heart health of millions of Americans.

UNC's Heart Health Now! Advancing Heart Health in NC Primary Care project is based at the Sheps Center and one of seven grantees awarded as part of the AHRQ initiative, EvidenceNOW – Advancing Heart Health in Primary Care, which supports the broad U.S. Department of Health and Human Services (HHS) effort for Better Care, Smarter Spending, and Healthier People, and is aligned with the Departments' Million Hearts® national initiative to prevent heart attacks and strokes.

As part of the EvidenceNOW- Advancing Heart Health in Primary Care, Heart Health Now! is composed of public and private partnerships and multidisciplinary teams of experts that will recruit and engage 250-300 small, independent primary care practices and provide quality improvement services typically not available to them because of their size. These services include onsite practice facilitation and coaching, expert consultation, shared learning collaboratives, and electronic health record support.

"I've cared for many people throughout my career who suffered the debilitating effects of a heart attack or stroke way too early," said Cykert. "Because of the lack of sophisticated information systems and processes that could quickly identify risk and prioritize new evidence for care, many of these folks missed opportunities that could have prevented the paralysis, shortness of breath and death that often resulted from premature disease. By partnering with North Carolina practices to build in the needed supports, we have the potential to prevent thousands of heart attacks, strokes, and deaths within a few short years."

Heart Health **NOW!**

Each Sheps Center program is briefly described below, with component projects listed. Some of the completion dates occurred during the duration of this report, however, some of the projects may be in a no-cost extension. Additional detailed materials for Fiscal Year 14-15 at the Sheps Center may be found in the **Appendices** of this Report on the website http://www.shepscenter.unc.edu/.

Program on Aging, Disability, and Long-term Care

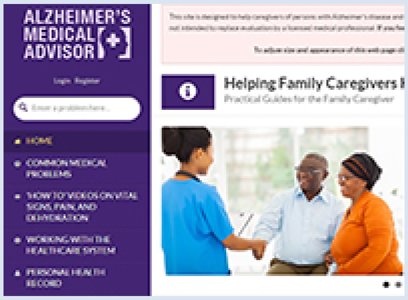
Phillip D. Sloane, M.D., M.P.H. and Sheryl Zimmerman, Ph.D., Co-Directors

The rapid growth of the nation's older population has increased awareness of the health service needs of older adults, and also made clear the significant demands on families and professionals who deliver health services to this population. Consequently, the primary aim of the **Program on Aging, Disability, and Long-term Care** is to improve the well-being of older persons with chronic and acute illness, as well as that of their caregivers. The program emphasizes factors that affect functional status and promote self-care, independent living, and quality of life among older adults. In addition, the program embraces a concern for the extent, quality, and availability of long-term care services for persons of any age, and for programs that address the special needs of people who have impairments. Dementia care, end-of-life care and hospice, person-centered care and practices, medication administration, caregiver training and education, falls prevention, mouth care, lighting, health care screening, nursing services, and a host of other topics are special areas of research focus.

The following research projects were active during the year:

Accelerating Change and Transformation in Organizations and Networks (ACTION II) – Note: This is a Master Task submission; there are no specific tasks for this master contract proposal. The goal of ACTION II is to promote and accelerate the development, implementation, dissemination and sustainability of evidence-based innovation in health care delivery and organization to measurably improve health care in the U.S. In support of this goal, ACTION II will focus on practice-based research to achieve the following four objectives: (1) implementation of a proof of concept, through which a previously untested innovation is tested on a small scale to demonstrate its feasibility for addressing an identified problem; (2) implementation of an innovation or improvement approach to provide information for decision-makers about structural, contextual and process factors that play a critical role in increasing (or reducing) the chances that a proven, evidence-based innovation will actually work in a given setting; (3) spread, or the taking to scale, of one or more proven innovations or delivery system improvements, including the active, wide dissemination of information about what works, accompanied by concrete guidance on how to maximize the likelihood of successful implementation and sustainability; and (4) sustainability, to increase knowledge about the factors that contribute to, or impede, the long term sustainability of innovation.
Principal Investigator: Sheryl Zimmerman, PhD
Funding Source: AHRQ via Abt Associates, Inc
Project Period: 07/01/10 – 06/30/15
Total Funding: $0

Program Highlight: Alzheimer's Medical Advisor



Program on Aging, Disability, and Long-term Care co-directors Philip Sloane, MD, MPH and Sheryl Zimmerman, PhD have led the development of Alzheimer's Medical Advisor,© a website that aims to help family caregivers of persons with dementia deal with new and worsening medical symptoms in their relatives. When people with Alzheimer's disease or related dementias develop symptoms, such as cough, fever, or agitation, their family caregivers have to decide whether the problem is minor enough to try treating at home, or whether to go to a physician's office or the emergency department. This can be challenging when the person with dementia has difficulty communicating accurately how they feel, or resists going to medical providers. As a result, family caregivers need tools to help them assess, make decisions, communicate with medical providers about, and potentially manage symptoms that could represent new or evolving medical illness. Learn more at http://alzmed.unc.edu.

Evaluation of the Use of iN2L Technology in North Carolina Nursing Homes – Through an application to The Duke Endowment (Charlotte, NC), FutureCare of North Carolina, Inc., the non-profit educational and research foundation of the North Carolina nursing home industry (the North Carolina Health Care Facilities Association), is proposing to conduct an 18-month evaluation of the implementation and use of a touch-screen computer-based technology for use in nursing homes that has the intention of enriching the lives of long-term care facility residents through recreational/activities enabled through the use of this technology, and to extend the impact of specific therapies offered to residents of

these facilities in occupational, physical and speech therapy. Under a subcontract from FutureCare of North Carolina, Inc., the Sheps Center will provide essential services in evaluation study design, in resident, staff and family survey methodology, in primary and secondary data analysis, report preparation and presentation to relevant audiences in the long-term care field.
Principal Investigator: Kristie Thompson, PhD
Funding Source: Duke Endowment via FutureCare of NC
Project Period: 01/01/14 - 06/30/15
Total Funding: $196,454

Goals of Care: A Nursing Home Trial of Decision Support for Advanced Dementia – Dementia is a progressive syndrome of decline in cognitive function. For 5 million Americans with dementia, therapies slow progression but do not reverse or cure the disease. Nursing home care is common; 67% of people dying from dementia die in this setting and families act as surrogates in major health care decisions. Shared decision-making about goals of care is the ethical standard for serious illness, yet families report poor quality communication, decision-making and palliative care. Compared with decisions about using or withholding a treatment, the goals of care approach encourages discussion and agreement on the primary goals of medical care, followed by treatment decisions designed to meet agreed upon goals. The study is a cluster randomized, controlled trial to test a decision support intervention for surrogates considering goals of care in advanced dementia. The intervention has two components: an audiovisual decision aid followed by a structured interdisciplinary care plan meeting. Study subjects are 300 nursing home residents with advanced dementia and their surrogates, recruited from 20 sites, to meet these Aims: Aim 1. To test the effect of the Goals of Care intervention compared to usual care, on the quality of communication and decision-making, defined as: a) quality of communication; b) family - health care provider concordance on goals of care; and c) family report of treatment consistent with wishes. Aim 2. To test the effect of the Goals of Care intervention on quality of palliative care, defined as: a) number of palliative care domains addressed in the care plan; b) symptom management; and c) family satisfaction with care for advanced dementia. Aim 3. To test the effect of the Goals of Care intervention on quality of dying, measured as: a) family - health care provider concordance on goals of care, and b) comfort in dying. This research will provide the first empiric test of decision support for the goals of care framework in dementia care. It extends decision support research to surrogates, who make most decisions on behalf of patients with serious and incurable illness. To permit future dissemination, the intervention design is pragmatic and well integrated with nursing home interdisciplinary care.
Principal Investigator: Laura Hanson, MD, MPH
Funding Source: National Institute on Aging
Project Period: 04/15/11 - 03/31/16
Total Funding: $2,452,398

Individually Tailored Lighting System to Improve Sleep in Older Adults – Exposure of the retina to light in the short-wavelength (blue) portion of the spectrum is the primary stimulus causing the human brain to synchronize circadian rhythms to the 24-hour light/dark cycle, resulting in daytime wakefulness and night-time sleep. Depending on its timing, spectrum, and intensity, a light stimulus can phase advance, phase delay, or have little effect on underlying circadian rhythms. Mediators and measures of this system include serum melatonin levels and the core body temperature (CBT), as well as activity/sleep. This proposed study will help translate recent research findings related to this physiological system to practical application in the treatment of persons with primary insomnia and other sleep disorders. In collaboration with scientists at the Lighting Research Center of Rensselaer Polytechnic Institute (Troy, NY), we will develop and evaluate a low-cost, minimally obtrusive device that delivers individualized light therapy to adults with early-awakening insomnia – the most common type of insomnia in older adults, and a significant problem because of its relationship to daytime sleepiness, use of potentially hazardous sleep medication, and reduced quality of life.
Principal Investigator: Philip Sloane, MD, MPH
Funding Source: NIH via Rensselaer Polytechnic Institute
Project Period: 07/01/12 – 06/30/17
Total Funding: $1,440,330

Alzheimer's Medical Advisor A Symptom and Sign Management Toolkit for Caregivers - Most persons with Alzheimer's disease (AD) live at home with informal (usually family) caregivers who must evaluate, manage, and communicate with health care providers about medical symptoms (e.g., pain and shortness of breath) and signs (e.g., fever and agitation). As dementia progresses, susceptibility to comorbid illness increases, communication and decision-making capacity are reduced, and transport to medical facilities becomes increasingly difficult. As a result, informal caregivers need tools that will help them evaluate, make decisions about, and manage symptoms and signs that could represent new or evolving medical illness. The proposed project will develop, field test, refine, evaluate, finalize, and disseminate the Alzheimer's Medical Advisor (AlzMA), a multi-component website that will assist informal caregivers of persons with AD to identify, evaluate, and manage new or increasing symptoms and signs of illness and then, if necessary, clearly and effectively communicate the information to health care providers. This project represents a collaboration of teams from the University of North Carolina at Chapel Hill; the Duke Family Support Program; and Horizon Productions.
Principal Investigator: Philip Sloane, MD, MPH
Funding Source: National Institute of Nursing Research
Project Period: 09/27/12 – 06/30/17
Total Funding: $3,022,814

Geriatric Symptom Protocols for Medical Practice Office Staff – This project will: (1) advise on the structure of the message management platform; (2) develop a general problem management protocol and five specific problem management protocols; (3) work with the practice (DMH) and two AL communities to integrate the platform into daily symptom management; and (4) participate in reviewing evaluation data and drafting reports.
Principal Investigator: Philip Sloane, MD, MPH
Funding Source: NIH via Keona Health
Project Period: 07/01/14-06/30/15
Total Funding: $74,767

An RCT of an Educational Video to Improve Nursing Home Care in End/Stage Dementia – Alzheimer's disease afflicts over 5 million Americans and is the 6th leading cause of death in the U.S. To date, advanced dementia research has largely focused on describing the end-of-life experience of patients with this disease. Designing and testing interventions targeting those opportunities is the current research priority for this field. Advance care planning (ACP) is the most consistent modifiable factor associated with better palliative care outcomes in advanced dementia. The opportunity for ACP is exceptional in advanced dementia but often inadequate. Thus, advanced dementia patients often get aggressive interventions that may be inconsistent with preferences and of little clinical benefit. Recent work has particularly underscored the need to avoid unwanted and unnecessary hospitalizations among these patients. Traditional ACP primarily relies on ad hoc verbal descriptions of hypothetical health states and treatments. This approach is limited because complex scenarios are difficult to envision, information from providers is inconsistent, and verbal explanations are hindered by literacy and language barriers. To address these shortcomings, the co-PIs have developed video decision support tools for ACP and shown their efficacy in several randomized controlled trials (RCTs) in out-patient settings. The over-riding goal of the EVINCE (Educational Video to Improve Nursing home Care in End-stage dementia) study is to conduct a cluster RCT of an ACP intervention vs. control among 360 nursing home (NH) residents with advanced dementia (N=180/arm) in 20 matched NHs (10 intervention/10 control). At baseline, proxies in the intervention NHs will view a video ACP decision support tool. Their preferred level of care (comfort care, limited care, life prolonging care, or uncertain) ascertained ~ 10 minutes after the video will be communicated to the primary care team. Proxies in the control NHs will experience usual ACP practices. The Aims are: Aim 1: To compare proxies' preferences for the residents' level of care in the intervention vs. control NHs at baseline (10-minutes post video in intervention NHs), 3, 6, 9 and 12 months. Aim 2: To compare the % of residents with ACP in the intervention vs. control NHs at 3, 6, 9, and 12 months as measured by documented: 1. Decisions to forego hospitalization; 2. Decisions to forego other treatments (tube-feeding, parenteral therapy), and 3. Goal of care discussions; and Aim 3: To compare the % of residents with hospital transfers and other burdensome treatments over 12 months in intervention vs. control NHs. A documented decision to forego hospital transfers by 6 months will be the primary outcome of this RCT. Impact: Better ACP is a key opportunity to improve advance dementia care. Video decision support is a practical, evidence-based, and innovative approach to ACP. If this RCT is successful, this will be one of the first rigorously tested interventions shown to improve outcomes for NH residents with advanced dementia. This work could have significant clinical and policy implications for the millions of Americans dying with this disease by promoting care that is more consistent with their preferences and that is less burdensome and costly.
Principal Investigator: Laura Hanson, PhD
Funding Source: Hebrew Rehabilitation Center
Project Period: 09/30/12 - 08/31/17
Total Funding: $150,048

Daily Mouth Care to Prevent Pneumonia in Nursing Homes: A Systems-Level Approach – Every year, almost two million episodes of pneumonia are suffered by nursing home (NH) residents across the United States, resulting in more deaths than from any other infection. Further, NH residents acquire pneumonia at a rate 6-10 times higher than older adults in the community, indicating that characteristics of these individuals and/or the NH setting put them at increased pneumonia risk. Pneumonia is an inflammatory condition usually initiated by the introduction of bacteria into the lung, such as through aspiration. In aspiration, contents from the mouth, throat, or stomach that are colonized with pathogenic bacteria are inhaled into the lungs. Poor oral hygiene is therefore a critical risk factor for pneumonia because it increases the volume and infectious nature of secretions from the mouth and throat. The objective of this project is to determine whether and to what extent pneumonia incidence in NH residents can be reduced by training nursing assistants and supervisory nursing staff to provide a pragmatic, system-level, comprehensive mouth care program to all NH residents, including use of a dedicated oral care aide.
Principal Investigator: Sheryl Zimmerman, MSW, PhD
Funding Source: AHRQ
Project Period: 09/01/13 - 06/30/18
Total Funding: $2,971,601

2013 ASPIRE US Vaccines_Streptococcus Pneumonia in Older Adults in Retirement Community (SOAR) – We proposed to work with one of the nation's most experienced long-term care research groups to study S. pneumoniae carriage, serotypes, and antibiotic susceptibility among the growing population of older adults living in retirement communities and extended care. 1.To measure the prevalence of pneumococcal carriage, circulating pneumococcal serotypes, and antibiotic susceptibility of pneumococcal isolates from older adults living in retirement communities and extended care. 2.To examine the above endpoints among individuals with increased risk of pneumococcal infection, such as diabetes mellitus, chronic pulmonary

disorders, or other immunocompromising conditions. 3.To identify potential target populations for PCV-13 immunization, by finding independent risk factors for pneumococcal carriage. Setting. 3 retirement communities in central North Carolina, and the extended care facility of the Durham Veterans Affairs Medical Center. Participants. 400 adults > 65years of age, recruited with equal distributions from skilled nursing facilities (SNF), assisted living (AL), and independent retirement community settings. A nasopharyngeal swab will be collected from each participant. Specimens will be cultured for S. pneumoniae, and analyzed for serotype and antibiotic susceptibility using methods developed by the CDC. In addition, a survey will be administered to all participants to assess chronic diseases, potential risk factors for pneumococcal carriage, and prior pneumococcal and influenza immunization status. A chart review will be performed to confirm immunization history, and record chronic conditions difficult to capture by self-report (e.g., chronic renal failure). Finally, we will examine independent risk factors for carriage using multivariate logistic regression. Our study will: 1) Measure circulating serotypes and antibiotic resistance of S. pneumoniae in this population, and the potential benefit of PCV-13; 2) Generate information on the possibility for herd protection in this population; and 3) Identify individuals at higher risk of carriage, which would enable prioritization of immunization to protect the community.
Principal Investigator: Sylvia Becker-Dreps, MD, MPH
Funding Source: Pfizer, Inc.
Project Period: 10/01/13 – 10/01/14
Total Funding: $99,999

Infection Management and Antibiotic Stewardship in Nursing Homes – Antibiotic stewardship (i.e., promotion of appropriate antibiotics to improve outcomes, reduce antibiotic resistance, and decrease the spread of multidrug-resistant organisms) is an innovation increasingly viewed as urgent for the care of nursing home (NH) residents. Reasons underlying the call for antibiotic stewardship in NHs include an increasing prevalence of healthcare-associated infections with multidrug resistant organisms, high rates of use, and estimates suggesting that some prescriptions may not be needed. Challenges to reducing "potentially inappropriate" antibiotic use are many, however, and relate to the NH structure, prescribing processes, and patient characteristics. The proposed implementation and dissemination project, conducted by a multidisciplinary team with extensive experience in the field, seeks to identify and field test the best methods for promoting antibiotic stewardship in nursing homes. Approximately 33 nursing homes in North Carolina will be involved in the study.
Principal Investigator: Phillip Sloane, MD
Funding Source: AHRQ
Project Period: 05/01/14 - 04/30/17
Total Funding: $498,698

Updating Bathing without a Battle and Providing Three Year's Free Internet-Based Training –
Since its development over 10 years ago, the *Bathing Without a Battle* educational program has become a cornerstone of the person-centered care and culture change movements in nursing homes, and an ongoing source of important staff education around person-centered dementia care. The program has been recognized by advocates, regulators, and researchers alike as essential training for nursing home staff. Despite the quality, importance, and ongoing relevance of the *Bathing Without a Battle* content, its technical specifications have become outdated, making the program difficult to use and inaccessible on the internet, an increasingly preferred source of nursing home training programs. Further, the demographics of nursing home staff have changed in the past decade, and an increasing minority of long-term care staff members speak Spanish as their native language, and therefore learn better in that language. This project will address these challenges by creating an updated version of the three-hour interactive *Bathing Without a Battle* training program that is suitable for presentation as an internet-based training program; this program will be placed on the internet and access provided free-of-charge for three years. This project will additionally create a Spanish version of the one-hour key concepts training video, which will also be placed on the internet and distributed to a sample of 300 nursing homes on hard-copy DVD. The evaluation will address dissemination, use, and end-user learning.
Principal Investigator: Philip Sloane, MD, MPH
Funding Source: Retirement Research Foundation
Project Period: 10/01/15- 09/30/18
Total Funding: $200,930

Program on Child and Adolescent Health Services Research

Betsy Sleath, Ph.D., R.PH., Director

Barriers to quality health care services for children and adolescents, as well as racial and regional disparities in child and adolescent health status, persist throughout the United States. To address the challenges these realities present, the **Program on Child and Adolescent Health Services** focuses on ways to ensure the development, implementation, and evaluation of high quality, evidence-based services for children and adolescents. Researchers strive to find innovative ways to empower children, adolescents, and their families to become more active participants in their care, and conduct research to evaluate interventions and programs that address health status and disparities. The program also provides technical assistance to policymakers, advocates, and health care providers. Investigators work with national, regional, state, and local organizations and agencies to improve child and adolescent health through research that assures that health care services will be accessible, affordable, comprehensive, coordinated, community-based, child and family-centered, and culturally competent. Current areas of investigation include: mental health and well-being, children with complex health care needs, Latino health, provider-patient communication, community-based participatory research, and interventions to promote positive parenting skills.

The following research projects were active during the year:

Padres Efectivos (Parent Activation) – Skills Latina Mothers use to get Healthcare for Their Children - Latinos are the largest and fastest growing minority population in the US; by 2050, 2 in 5 children will be Latino. Latino children are disproportionately affected by poverty and other factors associated with increased risk of psychiatric disorder. However, Latino children with mental health needs are half as likely to use services as children in white non-Latino families. Latino families are more likely to report problems getting services, lack of a usual source of care and a medical home, and dissatisfaction with the care they receive. Unmet mental health needs, in turn, are associated with poor outcomes over the lifespan, both economic and social. Assessing the comparative effectiveness of interventions to overcome these disparities is a major national health priority central to PCORI’s mission and mandate. Activation is a promising focus of research to eliminate disparities because it reflects a set of attitudes and skills that people can use to reduce disparities. Our work provides evidence that activation in Latino adults is associated with better quality health care and outcomes; and in African American parents with greater child mental health service use. There is need for further research on parent-focused interventions founded on culturally meaningful concepts to address these needs and disparities.
The long-term goal of this research is to improve the mental health care and outcomes of Latino children with mental health needs. The proposed study will examine the comparative effectiveness of an activation intervention for Latino families raising children. The study will provides evidence of the comparative effectiveness of an enhanced, culturally sensitive, advocacy skills intervention to build activation among Latino families and improve service use of their children with mental health needs compared to a preliminary adaptation of an existing intervention and to a usual care discussion group. Activation skills are a promising strategy to improve child mental health service use and to bridge cultural differences and disparities with wide-ranging impacts consistent with PCORI’s research agenda.
Principal Investigator: Kathleen Thomas, PhD
Funding Source: Patient Centered Outcomes Research Institute (PCORI)
Project Period: 08/01/13 - 07/31/16
Total Funding: $1,249,005
Secondary Program Area: Mental Health and Substance Abuse Services and Systems

Improving Care Coordination for Children with Disabilities Through an Accountable Care Organization – Children with disabilities have complex healthcare needs requiring multiple providers in multiple locations. The lack of coordinated care for this vulnerable population leads to poorer outcomes, higher costs, and increased stress and time demands for patients and their caregivers. Traditionally, under arrangements known as fee-for-service, there have been no financial incentives for providers to coordinate care; however, the Affordable Care Act is changing that. Accountable care organizations (ACOs) are groups of healthcare providers that organize in new ways to take responsibility for the care of a defined population. ACOs share in any savings associated with improved quality and efficiency of the care they provide. Although most ACOs currently do not cover children with disabilities, many are considering adding these to the populations they serve. Yet we know little about effectiveness of the care coordination strategies they employ on children with disabilities.
Principal Investigator: Paula Song, PhD
Funding Source: Patient Centered Outcomes Research Institute (PCORI)
Project Period: 08/01/14 - 07/31/17
Total Funding: $1,915,494

Since its inception, the Child and Adolescent Health Services Program has included projects which were primarily technical assistance in nature, several aimed at improving the planning and evaluation skills of maternal and child health (MCH) leaders at the state and local levels primarily in the Southeast. The following technical assistance projects were active this year:

Evaluation of the NC Healthy Start *Baby Love Plus* Program to Address Racial Disparities in the Eastern, Northeastern, and Triad Regions of North Carolina – This project is a partnership between the Sheps Center’s Program on Child Health Services and the NC DHHS Division of Public Health. Since 1996, the Sheps Center team has worked closely with colleagues at the Division of Public Health in the continued development of the enhanced maternity care coordination and outreach program, as well as identifying special areas of concern to improve perinatal health outcomes in some of the poorest counties of our State. The goal of the program is to reduce disparities in infant mortality through strengthening community capacity and enhanced individual perinatal services in Bertie, Edgecombe, Greene, Martin, Pitt, Tyrrell, and Washington counties (East); Gates, Halifax, Hertford, Nash, and Northampton counties (Northeast); and Forsyth and Guilford counties (Triad). We provide information on birth outcomes, use of perinatal health services, associated costs, and consumer satisfaction using primary and secondary data, including vital records, Medicaid claim data, Health Department administrative records, and a series of community surveys. The combined effort of the Sheps Center and NC Division of Public Health's *Baby Love Plus* Program has resulted in over $14 million in federal awards from the Maternal and Child Bureau, HRSA, DHHS.

Principal Investigators: Milton Kotelchuck, PhD (97-01) and Julia L. DeClerque, DrPH (since 2001)
Funding Source: Maternal and Child Health Bureau, U.S. Department of Health and Human Services via subcontract with N.C. Department of Health and Human Services
Project Period #1: 12/97 – 06/01 Funding: $1,021,031
Project Period #2: 07/01 – 06/05 Funding: $947,324
Project Period #3: 07/05 – 05/13 Funding: $610,050
Project Period #4: 07/13 – 05/14 Funding: $123,777
Project Period #5: 08/14 - 08/15 Funding: $11,669
Secondary Program Area: Women's Health Services Research

Young Parents Connect – The purpose of this research is to evaluate of the North Carolina Support for Expectant and Parenting Teens, Women, Fathers and Their Families project (Young Parents Connect), serving five counties – Bladen Nash, Onslow, Rockingham and Wayne. This adolescent health initiative of the North Carolina Department of Health and Human Services Division of Public Health / Women's and Children's Health Section, funded by the federal Office of Adolescent Health, Office of the Assistant Secretary for Health, US Department of Health and Human Services, enhances the previous North Carolina Young Mothers Connect offered in counties with demonstrated need for (1) self-sufficiency (high drop-out rates in grades 7 – 12, high poverty races); (2) parenting skills (high rates of substantiated child abuse and neglect case), utilization for preventive care services for children, late entry into prenatal care, unmet need for family planning services, maternal tobacco use and poor pregnancy and birth outcomes (short birth interval, repeat teen pregnancy.. This initiative was initially designed to reduce infant mortality through enhanced community capacity, responsibility, and ownership of infant mortality reduction efforts and enhanced individual perinatal services. Since 1997, federal funding for this project has centered on reducing racial disparities in infant mortality and most recently includes components for screening and treatment of perinatal depression as well as targeted case management for high-risk families in the interconceptional period who are enrolled in the Medicaid program. Using primary and secondary data (including: vital records, Medicaid files, health department administrative records, and community surveys), information on birth outcomes, use of perinatal health services, associated costs, and consumer satisfaction is being provided to program staff to use for on-going evaluation and program planning. The community surveys are conducted using a combination of in-person interviews, telephone interviews, public "intercept" interviews, and group interviews. This Initiative involves four component intervention models, which are purposefully overlapping and integrative: 1) Community-based Consortium, 2) Care Coordination/Case Management, 3) Outreach and Client Recruitment, and 4) Education and Training Services. Community-based Consortia have been formed as joint efforts between the project counties in each Region, and serve in an advisory capacity for the program. They assist with program planning, operations, monitoring, and evaluation. The Care Coordination and Case Management portion of the program enhances the current Pregnancy Medical Home, Care Coordination services provided by the State. The Outreach and Client Recruitment effort involves Community Health Advocates who function as case-finders in the community and provide population-based education and assist families with accessing and using local perinatal health services. And the Education and Training efforts are intended to improve knowledge and skills of consumers, public health service workers, and community leaders with respect to infant mortality issues and risk factors. The North Carolina Healthy Start Initiative is in its fifth cycle of federal funding. The upcoming contract year will be the fifth of a five-year cycle for the Triad Region, the fourth of a five-year cycle for the East Region and the final year of a two-year cycle for the Northeastern Region.
Principal Investigator: Julie DeClerque, DrPH
Funding Source: NCDHHS Division of Public Health
Project Period: 01/17/14 - 07/31/15
Total Funding: $446,901

Program on Health Care Economics and Finance

Sandra B. Greene, Dr.P.H. and George "Mark" Holmes, Ph.D., Co-Program Directors

A central concern in the health care system is the rising cost of services and the growing realization that resources are limited. The Sheps Center's **Program on Health Care Economics and Finance** continues to focus on both the general economics of personal health services as well as the specifics of program and organizational finance. In the former category, the Center's emphasis is on issues of fair and effective distribution of resources, both public and private. In the financial sector, issues of efficiency and productivity in delivery units and targeted programs are examined.

The following research projects were active during the year:

Cardiovascular Outcomes Research Center for Atherosclerosis Risk in Communities (ARIC) – The Atherosclerosis Risk in Communities Study (ARIC), sponsored by the National Heart, Lung, and Blood Institute (NHLBI) is a prospective epidemiologic study being conducted in four U.S. communities (Forsyth County, NC, Jackson, MS, suburban Minneapolis, MN, and Washington County, MD). ARIC is designed to investigate the causes of atherosclerosis, clinical outcomes, and variation in cardiovascular risk factors, medical care, and disease by race, gender, and location over time. To date, the ARIC project has published over 800 articles in peer-reviewed journals. Starting in November 2010, NHLBI provided funding for an ARIC Cardiovascular Outcomes Research Center (CORC) based

at the Sheps Center. The multi-disciplinary research team, led by Sally Stearns, is composed of health economists, cardiologists, internal medicine clinicians, epidemiologists, and faculty in cardiovascular pharmacy practice. ARIC includes two components: a Cohort Component, which has tracked a sample of approximately 16,000 people who were age 45-65 in 1987 through five clinic visits and annual telephone follow-up; and a Community Surveillance Component. Detailed hospital record abstractions (for heart failure, stroke, and coronary heart disease) and Medicare claims data are available for both components. The CORC is currently conducting five studies using the Cohort Component: (1) an overview of the potential for outcomes research in an ongoing epidemiologic study; (2) the association of anger-proneness with increased risk of onset of heart failure; (3) the association between Medicare claims for antihypertensive medications among persons self-reporting hypertension and subsequent cardiovascular outcomes; (4) socio-demographic and health-status factors associated with self-reported medication adherence; and (5) the effects of medication adherence following hospital discharge and subsequent readmission for persons with heart failure.
Principal Investigator: Sally Stearns, PhD
Funding Source: National Heart, Lung, and Blood Institute (NHLBI)
Project Period: 11/01/10 - 10/01/14
(extended through 11/14/16)
Total Funding: $2,929,978

Master Task Order-Advisory and Assistance Services in the Areas of Health Care Financing and Medicare – Note: This is a Master Task submission; there are no specific tasks for this master contract proposal. This master task, MedPAC, order allows UNC and the Sheps Center to compete for an indefinite number of specific tasks for the Medicare Payment Advisory Commission.
Principal Investigator: Mark Holmes, PhD / Marisa Domino, PhD
Funding Source: Medicare Payment Advisory Commission
Project Period: 10/01/11 - 09/30/16
Total Funding: $0

HRSA Evaluation Studies IDIQ Master Task Order: Domain 1 – Assessment of Effectiveness and Efficiency of HRSA-Supported Programs-Operations, Outcomes and Performance and Analysis of Contextual/Policy Issues which may Impact HRSA-Supported Activities – This application from the Cecil G. Sheps Center for Health Services Research (the Sheps Center) at The University of North Carolina at Chapel Hill (UNC-CH) responds to RFP 13-250-SOL-0005, Domain One. We propose to provide focused, high-priority, short-term evaluation activities in support of various Bureaus and Offices within the Health Resources and Services Administration (HRSA). Specifically we will conduct assessments of the effectiveness and efficiency of HRSA supported programs and their operations, outcomes, and performance as well as analysis of contextual and/or policy issues which may impact HRSA supported activities. The core investigative team is drawn from senior research fellows at the Sheps Center who also have faculty appointments at the Department of Health Policy and Management within the School of Public Health. Additional investigators affiliated with the Sheps Center or School of Public Health will be available according to specific project needs, including faculty from the School of Medicine.
Principal Investigator: G Mark Holmes, PhD
Funding Source: HRSA/ Office of Acquisition Management and Policy
Project Period: 09/27/13 – 09/26/18
Funding Period: 09/27/13 – 09/26/14
Total Funding: $2,500

Program on Healthcare Engineering Research

Stephen D. Roberts, Ph.D., Program Director

The **Healthcare Engineering Research Program** is an affiliation with the North Carolina State University Edward P. Fitts Department of Industrial and Systems Engineering and with the Personalized Medicine Faculty Cluster (consisting also of faculty from Statistics and Mathematics) at NC State through the Chancellor's Faculty Excellence Program. The purpose of Healthcare Engineering is to develop "analytics" that support the optimal allocation of scare health resources in the delivery of health care and the optimal treatment decisions for individual patients based on diverse information. Quantitative methods provide a complement to experimental methods for the evaluation and design of new health e delivery programs and health policy. The relationship within Sheps provides a cross-university collaboration whose shared interest is in improving the access, quality, and cost of health care.

Program on Health Care Organization Research

Bryan J. Weiner, Ph.D., Program Director

The organization of health services and practice arrangements for health care providers is changing continually. Emphasis in the **Program on Health Care Organization Research** is given to understanding the fundamental changes confronting providers and the way in which the organization of medical services at the community level influences the dissemination of prevention, treatments and early detection services.

The following research project was active during the year:

ACTION III – This is an IDIQ Task Order Contract to conduct field-based research to develop, test, adapt, implement, and spread interventions that improve health care quality, safety, and efficiency. Likely topics of

interest may include Patient safety and Patient engagement in targeted settings, such as Primary care and Nursing homes. This master task order allows UNC and the Sheps Center to compete for an indefinite number of specific tasks with our partner, RTI.
Principal Investigator: Bryan J. Weiner, PhD
Funding Source: AHRQ via RTI
Project Period: 10/01/14 - 09/30/19
Total Funding: $0

Developing, Testing, and Reviewing Measures in Implementation Science – Poor quality and impractical measurement has impeded the study of implementation barriers, facilitators and strategies necessary for promoting widespread delivery of evidence-based care and improving mental health.

Our long-term goal is to develop a comprehensive battery of reliable, valid, and pragmatic measures that researchers and stakeholders could use to advance the science and practice of implementation. The overarching objective of this project is to put forth a measurement-focused research agenda for implementation science (i.e., which constructs possess psychometrically strong and pragmatic measures, which require further development) as well as measures and methods to accomplish this work. Three aims guide this proposal. One, establish a stakeholder-driven operationalization of pragmatic measures and develop reliable, valid rating criteria for assessing the construct. Two, develop reliable, valid, and pragmatic measures of acceptability, appropriateness, and feasibility. Three, identify CFIR and IOF-linked measures that demonstrate both psychometric and pragmatic strength. We predict that few existing measures are psychometrically sound and pragmatic, but that rigorous, replicable development and testing procedures will generate measures that possess these qualities. Once pragmatic, psychometrically strong measures are identified, the field can generate robust scientific knowledge about which implementation strategies work best, when, and for whom so that stakeholders can use evidence-based approaches for implementing evidence-based practices.

UNC will develop reliable, valid, and pragmatic measures of three implementation outcomes: acceptability, appropriateness, and feasibility. Our approach involves a series of laboratory studies that allow us to assess psychometric properties under controlled conditions (e.g., standardized materials containing known variation) and a field study that allows us to gauge psychometric performance under "real life" conditions (i.e., health professionals facing immediate, salient implementation situations). The rationale for this aim is that implementation scientists and health professionals need reliable, valid, and pragmatic measures to advance scientific knowledge and achieve implementation success; yet, existing measures fall short in meeting their needs. By involving implementation scientists and multiple types of health professionals in the measurement development process, we expect the outcomes of our work to be psychometrically sound measures that could be used in research and practice in a range of implementation contexts.
Principal Investigator: Bryan J. Weiner, PhD
Funding Source: NIH via Indiana University
Project Period: 04/01/15 - 03/31/18
Total Funding: $548,394

Program Highlight: The Importance of Measurement

Measurement forms the foundation of any scientific field, yet gaps related to measurement issues are among the most critical barriers to advancing implementation science. Dr. Bryan Weiner is the Sheps Center leader for a collaboration with Indiana University on a R0-1 research project with the long-term goal of developing a comprehensive battery of reliable, valid, and pragmatic measures that researchers and stakeholders can use to advance implementation science and practice. Weiner and his team are developing reliable, valid, and pragmatic measures of three critical implementation outcomes: *acceptability, appropriateness, and feasibility*. Their work will yield three high-quality (psychometrically validated and pragmatic) broadly applicable measures of implementation outcomes and a replicable measure development process.

The Health Care Organization Research Program had the following technical assistance project active this year:

Division of Health Services Regulation Support of Databases – This project supports the Division of Health Services Regulation in the development and use of the hospital discharge database and the ambulatory surgery database. The Sheps Center receives data from the State data processor on a quarterly basis, reviews and edits the data, and builds an annual database. These databases are used to support the Division in health planning and related activities.
Principal Investigator: Sandra B. Greene, DrPH
Funding Source: NC Department of Health and Human Services, Division of Health Services Regulation (formerly Division of Facility Services)
Project Period: 11/01/02 – 06/30/12
(extended through 06/30/15)
Total Funding: $144,768

Impact of Parity Legislation on Use and Costs of Oral Cancer Medications – In this proposal, we aim to quantify the impact of state-level cancer parity legislation for oral drugs on medication use and health care spending. Such information will inform the development of rational health insurance coverage policies that increase clinically-appropriate use of life-extending therapies.

Specific Aims are to assess the effect of state cancer parity legislation on: (1) the use of cancer medications; (2) patient and health plan spending; and (3) adherence to oral cancer medications. The study will provide actionable data to states and the Congress as they consider

parity legislation and to health plans, who will benefit from a better understanding of the cost implications of this legislation. We believe that this information could be used as a basis for advancing federal legislative efforts to increase access to oral cancer medications, ensuring equal access for patients across states and for the 60% of privately insured patients in plans that are currently exempt from state laws.
Principal Investigator: Stacie Dusetzina, PhD
Funding Source: American Cancer Society
Project Period: 07/01/14-06/30/16
Total Funding: $480,000

Clinical Trials Matrix Support to the NCI Community Cancer Centers Program – This project has 3 Tasks: 1. Develop Expert Consensus on weighting of attributes using Delphi method 2. Compare ASCO Quality Tool with CT AIM Tool for potential harmonization and 3. Identify program characteristic data to be collected as part of web-based CT AIM survey.
Principal Investigator: Bryan J. Weiner, PhD
Funding Source: Leidos Biomedical Research, Inc.
Project Period: 05/01/14 - 09/26/14
Total Funding: $24,527

Program on Health Disparities Research

Giselle Corbie-Smith, M.D., M.Sc. and Paul A. Godley, M.D., Ph.D., Program Co-Directors

The **Program on Health Disparities Research** seeks to foster multidisciplinary, policy-relevant research to improve the health and healthcare of underserved communities through community and academic partnerships in research, teaching, and dissemination of knowledge. Central to its mission is the development and training of new investigators in health disparities research, strengthening and empowering communities of color to address health disparities, and enhancing the national visibility of health disparities research at the University of North Carolina at Chapel Hill. The Program brings together a diverse and multidisciplinary group of investigators with expertise in quantitative and qualitative research methods to address complex social, environmental and organizational issues affecting underserved populations.

The following research projects were active during the year:

Mentoring in community influences on CVD risk – The specific aims for the new research to be supported through this K24 Midcareer Investigator award include: 1) Determine the feasibility of training a current cohort of community health advisors as navigators to link residents with multiple cardiovascular risk factors to local healthcare systems; 2) Determine the impact of health navigators on cardiovascular risk factor control (HgbA1C, physical activity, BP control, smoking) and access to care for community members at increased risk for cardiovascular disease; 3) Identify community and social factors that influence cardiovascular risk factor control and outcomes. This two-arm trial will investigate the role of navigators on cardiovascular outcomes in community based outreach programs to improve access and utilization of medical services. Two to three navigators at each of the four sites will be utilized. Patients will be randomized to either a navigator intervention or to usual patient management practices, with measurement at baseline and six months. This study targets a disease condition and population of significant importance — CVD risk factor prevention in rural African Americans — and extends an existing effective model in several important ways. This study situates the navigator and patient within the community (rather than the healthcare system) thus increasing the cultural relevance of the intervention. Rather than a focus on one condition, navigators will support access and management of several chronic conditions, thus addressing the reality of multiple co-morbidities in underserved patients. Lastly, augmenting patient data with community variables allows a comprehensive analysis of external influence on cardiovascular disease prevention and healthcare utilization.
Principal Investigator: Giselle Corbie-Smith, MD, MSc
Funding Source: National Heart Lung and Blood Institute
Project Period: 12/01/10 – 03/31/16
Total Funding: $1,217,443

Lung Cancer Surgery: Decisions Against Life Saving Care - The Intervention Center – This American Cancer Society sponsored study is designed to use a health literacy and culturally appropriate communication intervention for patients and electronic data tools for providers to optimize surgical treatment for early stage lung cancer for all patients and to reduce the surgical gap between African-American and white lung cancer patients. Currently, more minority patients fail to undergo potentially life-saving surgery for lung cancer. The reasons appear to be largely related to poor communication between patients and health care providers. This multi-site study will attempt to determine whether a brief intervention will reduce that disparity.
Principal Investigator: Samuel Cykert, MD
Funding Source: American Cancer Society
Project Period: 07/01/11 – 06/30/16
Total Funding: $600,000

Reducing Cardiovascular Disease Risk Factors in Rural Communities in NC – Cardiovascular disease (CVD) is the leading cause of death in the U.S., however African American residents of rural areas in the south and southeast regions have the highest prevalence of CVD of any group. African Americans carry a significant burden of CVD risk factors that often co-occur; this burden is amplified in rural communities. CVD disparities at the intersection of race and geography are driven by individual risk behaviors and complicated by factors such as limited access to quality healthcare, socio-economic inequities, limited health care infrastructure and environmental barriers to behavior change. Interventions

to ameliorate CVD burden in rural African American communities will require placing the individual in the context of the larger community and taking advantage of new technologies to support behavior change. However, how best to integrate mobile technology into existing evidenced based interventions (EBIs) is still an emerging field and social and physical environmental factors important in rural communities are rarely considered in existing EBIs. The proposed study will address this gap in the literature by determining the feasibility and efficacy of adapting EBIs to consider the social and physical environment in important in rural African American communities and determining the acceptability of mobile technology in these communities to support behavior change. The proposed study is built on the strong foundation of Project GRACE's 8-year history of designing and testing interventions using a community-based participatory research (CBPR) approach, and individual and collaborative expertise in community-based CVD outreach, service and research. We have developed a phased CBPR study with a long-term goal to reduce rates of CVD in Eastern NC. The overall objective of this proposal is to assess feasibility of implementing an EBI, adapted to the needs and interests of a rural community in order to plan a large scale study. To that end our specific aims are to 1) expand and sustain. Project GRACE CVD coalition of community and academic stakeholders to develop successful CVD risk prevention strategies in rural communities; 2) conduct a mixed-method community needs and assets assessment based on: a) assemble, review and assess existing sources of CVD data; b) identification of community strengths and resources using a web-based survey of community, faith based, social service and health care organizations; c) determine the acceptability of components of CVD risk reduction EBIs and community members' perceptions of possible targets for intervention using focus group interviews; d) determine specific family influences (barriers and facilitators) on acceptability of EBI acceptability; 3) adapt PREMIER, a multi-component EBI using intervention mapping; and 4) conduct a small-scale randomized control trial to assess a) efficacy; and, b) feasibility and adaption of implementing adapted PREMIER in rural settings.
Principal Investigator: Giselle Corbie-Smith, MD, MSc
Funding Source: NHLBI
Project Period: 03/15/14 - 03/31/16
Total Funding: $381,962

Program on Primary Care Research

Donald E. Pathman, M.D., M.P.H. Program Director

An ample supply of primary care services is a fundamental building block of any health care system. Historically, much of the Sheps Center's **Primary Care Research** has addressed the access, personnel, organization, quality, and cost issues that pertain to health services delivery, especially in rural areas. The focus of much of this research is on access, personnel, organization, quality, and cost issues that pertain to health services delivery, especially in rural areas. Current research efforts in this program include addressing issues of recruitment and retention of health care practitioners.

Current research efforts in this program include addressing issues of recruitment and retention of health care practitioners in rural practice and the projection of need and demand for health professional personnel and helping primary care practices in their goals to improve quality patient care and reduce costs.

The following research projects were active during the year:

Effect of Glucose Monitoring on Patient and Provider Outcomes in Non-insulin Treated Diabetes – For the nearly 75% of patients living with type 2 diabetes (T2DM) that do not use insulin, decisions regarding self-monitoring of blood glucose (SMBG) is unclear. The overarching goal of this proposal is to assess the impact of three different SMBG testing approaches on patient-centered outcomes in patients with non-insulin treated T2DM within the real-world, clinic setting. In this

Program Highlight: PCORI at Sheps
The Patient-Centered Outcomes Research Institute (PCORI) is an independent non-profit authorized by Congress to improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions. The Sheps Center has been successful at obtaining PCORI funding to help achieve these goals, with XX current projects funded through the institute.

One project is **Effect of Glucose Monitoring on Patient and Provider Outcomes in Non-insulin Treated Diabetes,** which studies the real-world outcomes of three self-monitoring blood glucose testing approaches in patients with non-insulin treated Type 2 diabetes. Drs. Katrina Donahue and Laura Young are leading a pragmatic clinical trial in 15 primary care offices on the effectiveness of home blood glucose monitoring (SMBG) in 450 patients with non-insulin treated type 2 diabetes on clinical and patient oriented outcomes. Patients are randomized to one of the following three SMBG testing regimens: 1) no SMBG testing, 2) once daily SMBG testing with standard patient feedback consisting of glucose values being immediately reported to the patient through the glucose meter, and 3) once daily SMBG testing with enhanced patient feedback consisting of glucose values being immediately reported to the patient PLUS automated, tailored feedback messaging following each SMBG testing event delivered to the patient through the glucose meter. They are currently in the one year follow up phase of the study.

pragmatic trial, 450 patients randomized to one of the following three SMBG testing regimens: 1) no SMBG testing, 2) once daily SMBG testing with standard patient feedback consisting of glucose values being immediately reported to the patient through the glucose meter, and 3) once daily SMBG testing with enhanced patient feedback consisting of glucose values being immediately reported to the patient PLUS automated, tailored feedback messaging following each SMBG testing event delivered to the patient through the glucose meter. Using qualitative methods, we will assess health care providers attitudes and experiences with using the automated system to deliver SMBG results within the real-world, busy clinic setting. Given the time and resource intensive nature of SMBG and the rapidly growing prevalence of T2DM, the practice of medicine is overdue for a pragmatic assessment of the utility of SMBG in every day, routine clinical practice that evaluates outcomes of central importance to patients living with the disease.
Principal Investigator: Katrina Donahue, MD, MPH, and Laura Young, MD, PhD
Funding Source: PCORI
Project Period: 08/01/13 - 07/31/16
Total Funding: $2,090,699

Multi-State Retention Collaborative & Practice Sights Continuation Project – This project is to: Incorporate North Carolina Office of Rural Health’s State Loan Repayment data from the Practice Sights legacy retention module to the web-based Practice Sights Retention Management System; Incorporate North Carolina Medical Society Foundation’s Community Practitioner Program data from the Practice Sights legacy retention module to the web-based Practice Sights Retention Management System; Incorporate Year 1 of the Multi-State/NHSC Retention Collaborative NHSC survey data into the Practice Sights Retention Management System; and Have data included in summary reports, available for ad hoc analyses and show in an individualized report for each clinician.
Principal Investigator: Donald Pathman, MD, MPH
Funding Source: NC Foundation for Advanced Health Programs, Inc
Project Period: 03/01/2014 - 09/30/14
(extended through 03/31/16)
Total Funding: $280,827

Understanding the Direct and Indirect Costs of Transformation to Medical Homes – The Patient-Centered Medical Home (PCMH) model involves complete primary care practice redesign with the ultimate goal of improving the quality of patient care and at reduced cost. Detailed information regarding the practice level costs of performing transformative activities is needed to help the growing number of practices and practice organizations as they navigate this process. The overall objective of this study is to examine the direct and indirect practice level costs of supporting care transformation by evaluating costs within five small to medium sized primary care practices that have demonstrated improved clinical outcomes in diabetes or asthma measures within the North Carolina AHEC Practice Support Program and have also received PCMH recognition status by the National Committee for Quality Assurance. The aims of the study are to 1) analyze the overall costs of transformative activities that are supported by the NC AHEC practice support program that include the original and ongoing quality improvement activities defined by the NC IPIP program as well as the activities performed to qualify these practices as Medical homes by NCQA and 2) to disseminate our costs analysis results to stakeholders in health care and care transformation. This project will enhance understanding of the practice level costs of transformation which will be of value to policy makers, quality improvement organizations and primary care physicians. It is expected that products of this work could help practices streamline and anticipate costs when embarking on work related to practice transformation.
Principal Investigator: Jacqueline Halladay, MD, MPH
Funding Source: AHRQ
Project Period: 09/31/13 – 03/31/15
Total Funding: $99,998

Mid Southern Primary Care Networks Node of the NIDA Clinical Trials Network – The goal of this project is to support and establish a Southern Primary Care Node within the NIDA CTN. We seek to expand collaborations to include additional primacy care locations, investigators and clinicians to develop and execute clinically meaningful and feasible research projects that will help improve behavioral health care in primary care and impact practices. The funding mechanism of the RFA will provide infrastructure support for a research node (center). Separate funding sources will be available to support protocol-specific projects developed by the research node and approved by NIDA, including funding support for site investigators, clinicians, consultants, and research staff as well site payment and patient compensation. The application does not need to propose a specific plan for one research project. A research agenda for the CTN is required to be included in the application. The proposed research agenda will build on our existing CTN studies. Specifically, we seek to conduct need assessments and evaluate barriers/ facilitators of substance use care in primary care; develop brief, quick, and valid substance use screening tools for adolescents and adults in primary care; develop effective risk-based Screening and Brief Interventions; design and test EHR-based clinical decision support algorithms for targeted substance use screening and brief interventions; develop care models to increase office-based treatments for substance use disorders (prescription opioid use disorder); and explore coordinated care models for substance users with common medical comorbidity (diabetes).
Principal Investigator: Jacquie Halladay, MD, MPH
Funding Source: NIDA via Duke
Project Period: 09/01/15-08/31/20
Total Funding: $$283,399

Program on Medical Practice and Prevention

Daniel Jonas, MD, MPH, Program Director

Variations in the practice of medicine have received national scrutiny because of their considerable social, economic and quality of care implications. The Center's **Program on Medical Practice and Prevention** collaborates with practicing physicians in North Carolina and across the United States to explore these variations and their implications for health care outcomes. Work with the Agency for Healthcare Research and Quality (AHRQ) has continued and expanded over the past decade, with continuing investigator initiated awards but, most prominently, rapid growth in contract work.

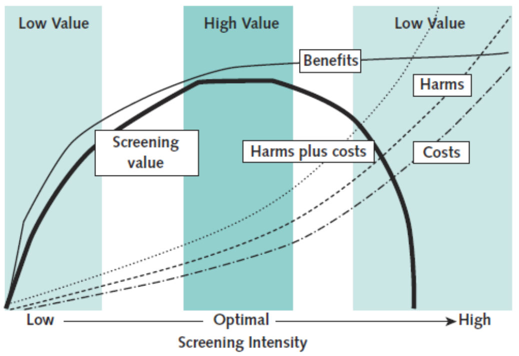
Initiated in October 1997, AHRQ funded the Research Triangle Institute (RTI) and the University of North Carolina at Chapel Hill to become one of 12 Evidence-Based Practice Centers (EPCs) nationally. In September 2012, AHRQ awarded the 4th AHRQ master task order contract to provide a variety of services and products to support the development of new scientific knowledge through research on the outcomes of healthcare items and services. The activities below reflect many EPC-related projects, including the recently funded EPC V.

The following research projects were active during the year:

Evidence-based Practice Centers (EPCs) IV – Note: This is a Master Task Order; there are no specific tasks for this master contract proposal; there will be multiple tasks undertaken. **Research Triangle Institute and UNC-CH, as the RTI-UNC EPC,** have been awarded a *fifth consecutive* 5-year master task order by the Agency for Healthcare Research and Quality (AHRQ).UNC-CH will be a subcontract to RTI for this Indefinite Delivery/Indefinite Quantity (IDIQ) award. The goal of EPC work is to present the 'state of the science' on a given topic in a manner that can be directly applied to decisions made by users of health care information. These users include clinicians, patients, policy-makers, and payers, and may be individuals or their related organizations. Topics cover all health care clinical and therapeutic areas of focus, from preventative services to implementation of medical devices. EPCs conduct rigorous systematic reviews, synthesize results of systematic reviews and report the findings, advance the methodology of systematic review, collaborate with partners and perform other related EPC activities. Successful execution of each of these essential activities requires an effective and efficient team of multidisciplinary individuals with a high level of consistent functioning at both the individual and collective levels.
Principal Investigator: Daniel E. Jonas, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 09/01/12 – 08/31/17

Program Highlight: High Value Care screening advice
Dr. Russ Harris, investigator at the Sheps Center and UNC School of Medicine, co-authored two papers published in *Annals of Internal Medicine* in May 2015 which developed a value framework and gave advice for screening for average-risk adults for the five most common types of cancer. The authors suggested clinicians and patients consider the benefits and harms of screening, and that less frequent or no screening can be a viable option for some patients. High intensity screening strategies (screening broader populations, more frequently, and/or with more sensitive screening tests) are not necessarily high value care. ACP defines high value care as the delivery of services providing benefits that make their harms and costs worthwhile. ACP encourages physicians to implement a health care strategy that focuses on tests or treatments that improve health, avoid harms, and eliminate wasteful practices.

Figure 1. The value framework.



Total Funding: Varies. Master Task Order Contract with Multiple Task Order Contracts listed below.

Associate Editor Duties for the EPC – Timothy Carey, MD, MPH, will serve as an 'associate editor' for the EPC, conducting edits and providing comments of EPC reports by other Centers for AHRQ.
Principal Investigator: Timothy S. Carey, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 12/31/11-08/31/12
(extended through 08/31/17)
Total Funding: $31,113

Comprehensive EPC Comparative Effectiveness Reviews for Effective Health Care – The RTI-UNC Evidence-based Practice Center (EPC) will build on existing work of the EPC program within the context of the Agency for Healthcare Research and Quality's Effective Health Care (EHC) program to expand the scope and delineation of a comprehensive approach to systematic review for evidence synthesis. The ultimate goal of EPC work is to present the "state of the science" on a given topic in a manner that can be directly applied to decisions made by users of health care information.

These users include clinicians, patients and caregivers, policy-makers, funders and payers, and may be individuals or their related organizations.

This work focuses on a comprehensive approach to comparative effectiveness review (CER) and evidence synthesis through an expanded scope of work with three major work components: 1.) Develop and refine topics for CERs that are informative to stakeholder decisional needs; 2.) Conduct CERs with systematic and transparent methods; 3.) Identify and explicate future research needs that are important to answering real-world healthcare decisions. The RTI-UNC EPC will focus on mental health and substance abuse topics for this work.

DERP

DERP IV

Drug Effectiveness Review Project (DERP) – Utilizing the infrastructure of the RTI-UNC EPC, this research aims to summarize the available evidence comparing the efficacy, effectiveness, and harms of drugs in many widely used drug classes. DERP is a collaboration of public entities (including the OHSU Center for Evidence-based Policy and the Oregon Evidence-based Practice Center) who have joined together to produce systematic, evidence-based reviews, and to apply the findings to inform public policy and related activities in local settings. UNC-CH investigators will search online databases for scientific literature on two selected topics. The investigative team will review titles and abstracts and identify eligible articles. The team will produce one report and slide presentation describing the eligible literature for each topic. The RTI-UNC EPC has produced reviews on antidepressants, asthma medications, targeted immune modulators, inhaled corticosteroids, and constipation medications.
Principal Investigator: Daniel Jonas, MD, MPH
(Carey, PI 2005-2007)
Funding Source: Oregon Health & Science University
Project Period: 01/01/04 – 06/30/13
(extended through 06/30/18)
Total Funding: $1,874,903

EPC IV

EPC IV Task Order #1
Methods Workgroup
UNC personnel will serve as an associate editor (AE) to ensure consistent quality of EPC program products, including systematic reviews and technology assessments. AE responsibilities include reviewing draft and revised reports, reviewing peer and public comments, and preparing decision letters addressed to the authors.
PI: Daniel Jonas, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 01/01/15-12/31/15
Total Funding: $50,052

EPC IV, RFTO #4: Systematic Evidence Reviews to Support the U.S. Preventive Services Task Force – The Research Triangle Institute – University of North Carolina Evidence-based Practice Center (RTI-UNC EPC) will complete systematic evidence reviews of scientific literature for the U.S. Preventive Services Task Force (USPSTF). Over the course of 3 years, the EPC will complete up to 15 work plan developments and systematic evidence reviews on various topics selected by the USPSTF. The timeline and length of each review will vary. Some topics may require meta-analyses. Each effort will include the identification of eligible literature, data extraction, qualitative and/or quantitative synthesis of data, assessment of quality for each included study and the strength of the available evidence for a given question, production of draft and final reports, an in-person presentation of the draft report to the USPSTF, responses to peer and public reviewers' comments, and production of a peer-reviewed manuscript.

Systematic Evidence Reviews to Support the U.S. Preventive Services Task Force (2012 – 2015)

- Screening for Carotid Artery Stenosis
- Screening for Depression in Children and Adolescents
- Screening for Speech and Language Delay

Principal Investigator: Daniel E. Jonas, MD, MPH
Funding Source: AHRQ via RTI via Kaiser
Project Period: 10/01/12-03/31/17
Total Funding: $563,911

EPC IV RFTO #21
Systematic Evidence Reviews to Support the U.S. Preventive Services Task Force (USPSTF) RFTO #21 – UNC-CH will be supporting and/or leading the development of systematic reviews for the US Preventive Services Task Force by providing leadership, clinical, methodological, and content expertise, and/or support for project tasks such as work plan and research plan development, literature searches, development of data abstraction forms, abstract and full text review, data abstraction, writing and preparing the draft and final reports, collating and responding to peer and public comments, and disseminating findings.

Systematic Evidence Reviews to Support the U.S. Preventive Services Task Force (2013 – 2016)

- Obstructive Sleep Apnea
- Tuberculosis
- Folic Acid Supplementation to Prevent Neural Tube Defects

Principal Investigator: Daniel E. Jonas, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 09/17/13 - 09/16/16
(extended through 08/17/17)
Total Funding: $1,813,971

Supplemental Work for Screening for Preeclampsia: Add-on Systematic Evidence Reviews to Support the U.S. Preventive Services Task Force (USPSTF)

UNC-CH will be supporting the development of a systematic review for the US Preventive Services Task Force by providing content expertise to the topic team on clinical issues related to preeclampsia screening and review drafts of project deliverables. The Kaiser Permanente Center for Health Research will provide adequate project management, scientific expertise, and administrative assistance to support the review activities.
PI: Daniel Jonas, MD, MPH
Funding Source: AHRQ via Kaiser via RTI
Project Period: 08/01/14-05/31/15
Total Funding: $15,179

EPC IV RFTO #33
Systematic Evidence Reviews to Support the U.S. Preventive Services Task Force (USPSTF)
On the following topics:

a. Screening for Herpes
b. Osteoporosis
c. Menopausal Hormonal Therapy for the Primary Prevention of Chronic Conditions
d. Vision Screening in Children
e. Behavioral Interventions for Stress Management (Topic Refinement only)

UNC-CH will be supporting and/or leading the development of one topic refinement and 4 systematic reviews for the US Preventive Services Task Force by providing leadership, clinical, methodological, and content expertise, and/or support for project tasks such as work plan and research plan development, literature searches, development of data abstraction forms, abstract and full text review, data abstraction and synthesis, writing and preparing the draft and final reports, collating and responding to peer and public comments, and disseminating findings.
PI: Daniel Jonas, MD, MPH
Funding Source: AHRQ via Kaiser via RTI
Project Period: 02/01/15-08/19/17
Total Funding: $921,957

EPC IV RFTO #41
Evidence Synthesis and Translation under MMA Section 1013: Total Worker Health (Systematic Review)
UNC personnel at the RTI-UNC Evidence-based Practice Center (EPC) will collaborate with investigators at RTI to (a) conduct a small systematic review of available literature on integrated approaches to worker health relevant to the National Institute for Occupational Safety and Health's (NIOSH's) Total Worker Health™ program, (b) produce an organized report of the findings of the small systematic review that presents available evidence for the identified key questions, and (c) present findings of the report via a Webinar, and also in person during a two-day Conference in Washington DC.

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PI: Daniel Jonas, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 02/09/15-12/18/15
Total Funding: $102,066

Ongoing Projects from EPC IV

EPC IV
Evidence-based Practice Centers (EPCs) IV – Note: This is a Master Task Order; there are no specific tasks for this master contract proposal; there will be multiple tasks undertaken. Research Triangle Institute and UNC-CH, as the RTI-UNC EPC, have been awarded a *fourth consecutive* 5-year master task order by the Agency for Healthcare Research and Quality (AHRQ).UNC-CH will be a subcontract to RTI for this Indefinite Delivery/Indefinite Quantity (IDIQ) award. The goal of EPC work is to present the 'state of the science' on a given topic in a manner that can be directly applied to decisions made by users of health care information. These users include clinicians, patients, policy-makers, and payers, and may be individuals or their related organizations. Topics cover all health care clinical and therapeutic areas of focus, from preventative services to implementation of medical devices. EPCs conduct rigorous systematic reviews, synthesize results of systematic reviews and report the findings, advance the methodology of systematic review, collaborate with partners and perform other related EPC activities. Successful execution of each of these essential activities requires an effective and efficient team of multidisciplinary individuals with a high level of consistent functioning at both the individual and collective levels.
Principal Investigator: Daniel E. Jonas, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 09/01/12 – 08/31/17
Total Funding: Varies. Master Task Order Contract with Multiple Task Order Contracts listed below.

EPC IV RFTO #12
Evidence Synthesis and Translation under MMA Section 1013: Binge Eating Disorder
Topic Refinement and Systematic Review for Management and Outcomes of Binge Eating Disorder – UNC-CH personnel at the RTI-UNC Evidence-based Practice Center (EPC) will collaborate with investigators at RTI to: Conduct a literature scan and review published and unpublished literature to develop key questions, background information, and PICOTS (population(s), intervention(s), comparator(s), outcomes, timing, settings) and to define terms in preparation for a systematic review of the Management and Outcomes of Binge Eating Disorder; Conduct a large systematic review of available literature for evidence for the Management and Outcomes of Binge Eating Disorder; and, Produce an organized report of the findings of the large systematic review that presents available evidence for the identified key questions.
Daniel Jonas, MD, MPH, and Kim Brownley, PhD
Funding Source: AHRQ via RTI
Project Period: 11/06/13 - 05/25/15
Total Funding: $200,000

EPC IV RFTO #15
Evidence Synthesis and Translation under MMA Section 1013: Major Depressive Disorder
Topic Refinement and Systematic Review for Treatment of Major Depressive Disorder – UNC-CH personnel at the RTI-UNC Evidence-based Practice Center (EPC) will collaborate with investigators at RTI to: Conduct a literature scan and review published and unpublished literature to develop key questions, background information, and PICOTS (population(s), intervention(s), comparator(s), outcomes, timing, settings) and to define terms in preparation for a systematic review of the treatment of Major Depressive Disorder; Conduct a large systematic review of available literature for evidence for the treatment of Major Depressive Disorder; and, Produce an organized report of the findings of the large systematic review that presents available evidence for the identified key questions.
Principal Investigator: Daniel E. Jonas, MD, MPH, and Bradley Gaynes, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 10/31/13 – 09/16/15
Total Funding: $239,250

EPC IV RFTO #23
Evidence Synthesis and Translation under MMA Section 1013: Management Strategies to Reduce Psychiatric Readmissions
Technical Brief on Management Strategies to Reduce Psychiatric Readmissions – The goals of this project are to describe and compare three core management strategies to reduce psychiatric readmissions—length of stay for inpatient care, transition support services (i.e., care provided as the individual moves to outpatient care), and alternatives to hospitalization (i.e., outpatient care provided in place of psychiatric hospitalization)—for patients at high risk of psychiatric readmission. We will search published and unpublished sources for information about the effectiveness of these strategies. We will also interview key informants, representing mental health providers, health services researchers, policymakers, payers, and patient advocacy groups, to confirm and augment our findings. The technical brief produced will describe the current status of the evidence base addressing these strategies.
Principal Investigator: Daniel E. Jonas, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 05/29/14 - 01/02/15
Total Funding: $90,000

EPC IV RFTO #32
Evidence Synthesis and Translation under MMA Section 1013: Strategies to Improve Mental Health Care for Children and Adolescents
Topic Refinement and Systematic Review on Strategies to Improve Mental Health Care for Children and Adolescent
UNC personnel at the RTI-UNC Evidence-based Practice Center will collaborate with investigators at RTI to (a) conduct a Topic Refinement involving the design and conduct of a literature scan and review of published and unpublished literature to guide the development of key questions, analytic framework, and background information in preparation for a systematic review of Strategies to Improve Mental Health Care, (b) conduct a large systematic review of available literature for evidence for Strategies to Improve Mental Health Care, and (c) produce an organized report of the findings of the large systematic review that presents available evidence for the identified key questions.
PI: Daniel Jonas, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 06/02/14-09/16/15
Total Funding: $223,844

EPC V

EPC V
Evidence-based Practice Centers (EPCs) V
This is a Master Task Order; there are no specific tasks for this master contract proposal; there will be multiple tasks undertaken. Research Triangle Institute and UNC-CH, as the RTI-UNC EPC, have been awarded a *fifth consecutive* 5-year master task order by the Agency for Healthcare Research and Quality (AHRQ). UNC-CH will be a subcontract to RTI for this Indefinite Delivery/Indefinite Quantity (IDIQ) award. The goal of EPC work is to present the 'state of the science' on a given topic in a manner that can be directly applied to decisions made by users of health care information. These users include clinicians, patients, policy-makers, and payers, and may be individuals or their related organizations. Topics cover all health care clinical and therapeutic areas of focus, from preventative services to implementation of medical devices. EPCs conduct rigorous systematic reviews, synthesize results of systematic reviews and report the findings, advance the methodology of systematic review, collaborate with partners and perform other related EPC activities. Successful execution of each of these essential activities requires an effective and efficient team of multidisciplinary individuals with a high level of consistent functioning at both the individual and collective levels.
PI: Daniel Jonas, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 11/12/14-11/11/19
Total Funding: Up to $4,330,356; Master Task Order contract with multiple Task Order contracts described separately.

EPC V RFTO #1
Technical Brief for Disparities and Serious Mental Illness
UNC-CH personnel at the RTI-UNC Evidence-based Practice Center will collaborate with investigators at RTI to produce a technical brief based on a systematic and comprehensive review of published and unpublished literature to identify the types of evidence available

regarding Disparities and Serious Mental Illness. Research activities include developing a protocol for data collection, organization, and presentation; gathering input from key informants; forming guiding questions for the topic; developing a search strategy to scan for relevant published and unpublished literature; reviewing available resources; and producing a final peer-reviewed technical brief that provides an overview of key issues related to the topic.
PI: Daniel Jonas, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 02/23/15-09/22/15
Total Funding: $90,000

EPC V RFTO #4
Topic Refinement and Systematic Review for Strategies to De-escalate Aggressive Behavior in Psychiatric Patients
UNC-CH personnel at the RTI-UNC Evidence-based Practice Center will collaborate with investigators at RTI to (a) conduct a literature scan and review published and unpublished literature to develop key questions, background information, and PICOTS (population(s), intervention(s), comparator(s), outcomes, timing, settings) and to define terms in preparation for a systematic review on strategies to de-escalate aggressive behavior, (b) conduct a systematic review of available literature for evidence on strategies to de-escalate aggressive behavior, and (c) produce an organized report of the findings of the systematic review that presents available evidence for the identified key questions.
PI: Daniel Jonas, MD, MPH
Funding Source: AHRQ via RTI
Project Period: 03/02/15-05/12/16
Total Funding: $220,800

EPC V RFTO #12
Topic Refinement and Systematic Review for Management and Outcomes of Binge Eating Disorder – UNC-CH personnel at the RTI-UNC Evidence-based Practice Center (EPC) will collaborate with investigators at RTI to: Conduct a literature scan and review published and unpublished literature to develop key questions, background information, and PICOTS (population(s), intervention(s), comparator(s), outcomes, timing, settings) and to define terms in preparation for a systematic review of the Management and Outcomes of Binge Eating Disorder; Conduct a large systematic review of available literature for evidence for the Management and Outcomes of Binge Eating Disorder; and, Produce an organized report of the findings of the large systematic review that presents available evidence for the identified key questions.
Principal Investigator: Daniel E. Jonas, MD, MPH, and Kim Brownley, PhD
Funding Source: AHRQ via RTI
Project Period: 11/06/13 - 05/25/15
Total Funding: $200,000

Communication about Glaucoma and Patient Outcomes – Between 9 and 12% of all blindness in the United States is attributed to glaucoma. The absence of symptoms in glaucoma patients increases the risk of regimen non-adherence among these patients. Approximately 50% of individuals who start on glaucoma medications discontinue them within 6 months. Provider-patient communication about glaucoma and its treatment can be a critical factor that impacts initial treatment adherence and persistence. Little is known about provider-glaucoma patient communication. This project will examine how the provider-patient communication that occurs when patients are initially started on glaucoma medication treatment impacts medication adherence, medication persistence, and intraocular pressure (IOP) during the 8 month period after the drops are started. The findings from this study can be used to educate providers and patients about how to optimize communication during glaucoma visits to assure improved patient outcomes.
Principal Investigator: Betsy Sleath, PhD
Funding Source: National Eye Institute
Project Period: 05/01/09 – 04/30/13
(extended through 04/30/15)
Total Funding: $3,134,760

Decision Support Lab - Medical Editor – Dr. Pignone will serve as a Medical Editor and as UNC-CH Principal Investigator for the grant. His duties include: 1) Participating in evaluations of new and existing decision aids developed by the Foundation, through administrative support, oversight, and participation in data analysis and reporting. 2) Serve as the Medical Editor for the following decision aids: colon cancer screening, "Living with Coronary Artery Disease", and heart failure. 3) Participate in further development and evaluation of decision making tools for the primary prevention of heart disease as determined by the Foundation. 4) Prepare Health News Reviews. 5) Participate in the IPDASi process as co-chair, including subsequent validation of the items included in the IPDAS instrument. 6) Facilitating the expansion of decision support and decision aid use in Australia for the Foundation.
Principal Investigator: Michael Pignone, MD, MPH
Funding Source: Foundation for Informed Medical Decision Making
Project Period: 07/01/09 – 06/30/15
Total Funding: $104,639

Validation of a Mortality Prediction Model for Prolonged Mechanical Ventilation – Many patients who survive the first few days of critical illness do so with multiple residual organ failures. These patients become dependent on mechanical ventilation and other organ support systems initiated in the ICU. Patients requiring prolonged mechanical ventilation (PMV) account for up to 20% of mechanically ventilated patients and consume up to 40% of all ICU resources. The patients have survived the initial severe stages of their illness, yet they remain dependent on life support systems, progress is slow, and complications are frequent. Physicians are often

confused and uncertain about prognosis for PMV patients, therefore they usually do not share prognostic information with patients' families. In order to clarify prognosis for these complicated patients, a prognostic model that identifies PMV patients who are at high risk of death at 3 months and 1 year was developed and validated at a single tertiary care medical center. This model is based upon 4 easily measured variables and converts to a clinical prediction rule called the ProVent Score. External validation of the model is required before general clinical application can be considered. This study proposes to validate the PMV prognostic model in two external cohorts with the following Aims: 1.) To validate the PMV prognostic model and ProVent Score in a heterogeneous group of patients from multiple medical centers. 2.) To evaluate the performance of the ProVent Score and develop new models in patients who are earlier in the course of PMV. 3.) To validate the ProVent Score in patients with Acute Lung Injury and the Acute Respiratory Distress Syndrome. The cohort for the first two Aims will consist of 600 consecutive PMV patients identified at 5 diverse tertiary care hospitals. Data will be obtained by review of medical records, and one-year survival will be confirmed by the National Death Index. The second cohort will consist of all patients in the NHLBI ARDS Clinical Trials Network FACTT trial who received PMV. A valid PMV prognostic model will allow investigators to standardize illness severity in future studies of interventions for PMV patients, and a clinically useful prognostic score will enhance the confidence of clinicians in communicating prognosis to patients and families.
Principal Investigator: Shannon Carson, MD
Funding Source: NIH
Project Period: 09/01/09 – 06/30/14
(extended through 06/30/15)
Total Funding: $584,876

PROMIS Pediatrics: Longitudinal Validation and Linking Pediatric and Adult Items Banks – The overall objectives of this project are to validate the PROMIS pediatric item banks in 4 pediatric chronic illnesses, and to link pediatric and adult item banks. We developed 9 pediatric item banks during the first PROMIS grant cycle and have performed cross-sectional testing in children with several chronic illnesses. The proposed work is the natural next step toward integration of PROMIS scales into clinical research. We propose longitudinal studies in children with asthma, cancer, nephrotic syndrome, and sickle cell disease. Each study follows children through a clinical transition known to affect health-related quality of life, and each study will examine the responsiveness of the PROMIS instruments and estimate the minimum important difference (MID) for children. As part of these studies, we have proposed to test a new method for establishing MID and to compare that method with traditional distributional and anchor-based methods. The second overall objective is to link PROMIS pediatric item banks with PROMIS adult item banks. We designed most of the pediatric banks to measure the same underlying trait as their counterpart adult banks (e.g., fatigue), but used the concepts and language of children. We will administer pediatric and adult short forms to adolescents with chronic illnesses with a cross-sectional data collection. For this objective, we will use factor analysis and structural equation modeling to establish the empirical relationships between the pediatric and adult item banks and domains, and, to the extent supported by those relationships, use item response theory to link the pediatric and adult item banks. This study will enable researchers to have comparable scores between children and adults participating in the same study and enable longitudinal studies that follow children into adulthood.
Principal Investigator: Darren A. DeWalt, MD
Funding Source: National Institute of Arthritis Musculoskeletal and Skin Diseases
Project Period: 09/30/09 – 07/31/13
(extended through 07/31/14)
Total Funding: $3,609,406

Demonstration of Health Literacy Universal Precautions Toolkit Task Order #10 – Dr. DeWalt is an internationally recognized expert in health literacy and first author of the Health Literacy Universal Precautions Toolkit. He will direct the scientific content of the Maintenance of Certification (MOC) Part II module and also chair the committee of content experts who will review, select, and revise the content to be included in the module. The deliverables for this project include: an environmental scan report of existing health literacy education activities; a health literacy MOC training outline; a health literacy MOC training module (English and Spanish); a list of organizations giving CME credit, and a report on the dissemination activities for the training module.
Principal Investigator: Darren DeWalt, MD, MPH
Funding Source: AHRQ via University of Colorado
Project Period: 08/01/11 - 09/21/14
Total Funding: $129,646

An Economic Framework for Evaluating Biomarkers Used to Target CVD Prevention – Dr. Pignone will help update the UNC-CH/RTICHD Prevention Model for use with novel cardiovascular risk markers. He will then work in collaboration with colleagues at RTI and UCSF to test, through modeling, the cost-effectiveness of using coronary artery calcium in addition to the standard Framingham risk assessment to guide cardiovascular prevention decisions. In doing so, the team will test a variety of different clinical and policy scenarios and systematically examine the effects of key individual variables on the results. Dr. Pignone will also participate in manuscript preparation and revision.
Principal Investigator: Michael Pignone, MD, MPH
Funding Source: AHRQ via University of California at San Francisco
Project Period: 07/01/11 - 7/31/13
(extended through 07/31/14)
Total Funding: $82,243

Merck Program for Assistance with Transitions from Hospital to Home (PATHH) – The purpose of the study

is to determine impact of the Hospital Transition in Care (HTiC) Service on the following patient outcomes: 1) 30-day hospital readmission rate 2) Emergency room visits within 30-days after discharge 3) Patient satisfaction 4) Patient knowledge of discharge
Instructions 5) Patient adherence with discharge plans, In addition, the project seeks to test the technology and integration required to successfully execute, operate, and scale the HTiC Service and to identify opportunities to improve its design.
Principal Investigator: Carlton Moore, MD
Funding Source: Merck Sharp & Dohme
Project Period: 12/01/11 - 12/31/13
(extended through 08/31/14)
Total Funding: $1,250,759

Evaluation of Stage 3 Meaningful Use Objectives – The purpose of this work is to gain an understanding of the proposed stage 3 meaningful use (MU) objectives in the areas of care coordination (CC) and patient and family engagement (PFE). To accomplish this, RTI International is partnering with the University of North Carolina Health Centers (UNCHC in Chapel Hill, NC) for a 12-month project. The project objective is to obtain important practical feedback from hospital and ambulatory clinic sites about the draft Stage 3 MU objectives, the EHR innovations to support the objectives, and the anticipated value provided to organizations pursuing the objectives in the areas of CC and PFE. The specific objective of this project is to answer three questions: (1) How can the evaluated Stage 3 MU objectives be improved at the policy level? (2) What EHR innovations would support meeting the evaluated Stage 3 MU objectives? (3) What will increase the value for hospitals and/or ambulatory practices of implementing the proposed Stage 3 MU objectives? In order to explore proposed PFE and CC MU objectives, hospital-based and ambulatory care sites in North Carolina were selected for their early implementation experience in these areas will be recruited and evaluated using direct observation and staff interviews. A total of 10 sites, 5 with a focus on patient and family engagement and 5 with a focus on care coordination, along with focus groups conducted at two regional extension centers (RECs) will be included to gain a broad range of experiences. Following data collection activities and qualitative data analysis, findings will be synthesized into a final report.
Principal Investigator: Carlton Moore, MD, MS
Funding Source: AHRQ via RTI
Project Period: 09/26/13 - 09/25/14
Total Funding: $99,823

Comparative Effectiveness of CyberKnife Robotic Radiosurgery for Prostate Cancer now called: Comparative Effectiveness of Management Options for Localized Prostate Cancer – The Agency for Healthcare Research and Quality (AHRQ) has funded a large, 3-year study at the University of North Carolina (UNC) to examine the comparative effectiveness of prostate cancer treatments. This is a prospective cohort study of about 1,500 patients in North Carolina who will complete surveys at baseline (pre-treatment) and then prospectively during follow-up. There are few patients treated with Cyberknife radiation therapy in the state of North Carolina, so this treatment modality will not be fully examined in the cohort study. The Cyberknife Robotic Radiosurgery "parallel study" is a collaboration with other institutions across the United States to enroll 100 patients onto a prospective cohort, who will be followed using identical methods as the North Carolina cohort. This will allow comparisons of quality of life, disease control and survival of patients treated with this newer treatment modality against those of other treatments.
Principal Investigator: Ronald Chen, MD, MPH
Funding Source: Accuray Incorporated
Project Period: 06/01/12 - 05/31/15
Total Funding: $100,000

UNC Research Center of Excellence in Clinical Preventive Services – The Agency for Healthcare Research and Quality (AHRQ) awarded a 3-year study at the University of North Carolina (UNC) to examine the comparative effectiveness of prostate cancer treatments. This was in response to the important problem of overuse of some screening services, which can expose patients to avoidable harms and contribute to high health care costs. The Center seeks to understand and encourage appropriate use of screening through an integrated research agenda and the activities of the Core Office. Three primary research projects are currently in the field. In Project 1, qualitative interviews have been conducted to determine patients conceptualize the potential harms of preventive screening, and a randomized trial will test the effect of different presentations of potential harms on patient intent to undergo prostate cancer screening, colorectal cancer screening, or osteoporosis screening. Project 2 aims to understand physicians' knowledge, attitudes, and decision making about potentially harmful screening clinical preventive services, through qualitative interviews and a quantitative survey. Project 3 is investigating, in a randomized trial, the effect of a patient decision support intervention on colorectal cancer screening decision in older patients.
The Center's Core Office administers the research efforts, and is charged with promoting research innovation in appropriate use and potential harms of screening, fostering collaboration with a variety of partners, advancing awareness of the topic among practitioners, other researchers, and policy makers, and providing a theoretical and practical foundation for the education of future clinicians.
Principal Investigator: Russell Harris, MD, MPH
Project Lead Investigators: Christine Kistler, MD,
Stacey Sheridan, MD, MPH,
Maihan Vu, DrPH
Funding Source: AHRQ
Project Period: 09/30/11 – 09/29/15
Total Funding: $4,500,000

Developing Evidence to Inform Decisions About Effectiveness Research Network: Developing and Evaluating Methods for Record Linkage and Reducing Bias in Patient Registries – Non-experimental comparative effectiveness research (CER) and patient-centered outcomes research (PCOR) provide important information about "real world" combinations of interventions for heterogeneous patient populations. To overcome the limitations of single databases, data from sources such as administrative claims can be linked securely and confidentially with data from patient registries. Registry linkage can facilitate exposure and control group identification, improve measurement of risk factors and outcomes, or allow researchers to monitor events without contacting participants directly. However, at least four major challenges persist. First, unique personal identifiers for linkage are not always available. Second, non-experimental studies are subject to validity threats such as confounding by indication, selection bias, and misclassification of exposures or outcomes. Third, linkage errors can systematically bias estimates of treatment effectiveness. Fourth, although researchers have continued to develop new methods for deterministic and probabilistic linkage, these methods have not been tested thoroughly, and comprehensive guidelines are lacking. This project addresses these challenges by pursuing three major objectives: (1) Develop a framework and guidance for researchers on record linkage of registries to other data sources; (2) Develop and test new methods to improve confounding control and generalizability in CER/PCOR using linked data; and (3) Develop a method to improve instrumental variables analysis using linked registry data.
Principal Investigator: Til Stürmer, MD, MPH, Task PI
Alan Brookhart, PhD, Task Order PI
Funding Source: AHRQ
Project Period: 09/27/12 - 07/24/14
Total Funding: $1,112,042

Using Health Outcomes in Establishing the Effectiveness of Clinical Preventive Services – UNC-CH personnel will work with American Institutes for Research (AIR) and other organizations subcontracting with AIR to develop a protocol; engage technical experts and stakeholders; review US Preventive Services Task Force (USPSTF) recommendations and methods used by other groups; synthesize, catalog, and analyze findings to develop options for the USPSTF; write a draft and final report, and present results to the USPSTF. The aim of the project is to inform the methods that the USPSTF uses to evaluate the effectiveness of clinical preventive services through the conduct of an in-depth study of how the USPSTF considers intermediate outcomes and final health outcomes in determining the effectiveness of a clinical preventive service. The final stage of the award focuses on articles and publications.
Principal Investigator: Russ Harris, MD, MPH
Funding Source: AHRQ via AIR
Project Period: 09/30/12 - 09/29/13
(extended to 06/30/16)
Total Funding: $292,651

Implementing Best Practice in Palliative Care – Palliative care and hospice focus on the relief of suffering and achieving the best possible quality of life, including ameliorating symptoms, relieving psychological distress, and promoting spiritual well-being for patients their caregivers. The new National Institute of Nursing Research funded national research network, the Palliative Care Research Cooperative Group (PCRC), is an efficient mechanism for evidence development including comparative effectiveness research. Quality monitoring and performance improvement initiatives are an important approach to reinforce evidence implementation. Over the past 5 years, a regional electronic point-of-care quality monitoring program called QDACT-PC has been developed and piloted in North Carolina; it has been demonstrated to be well-liked by clinicians, usable, feasible, and able to generate reliable information that can be used to benchmark conformance with palliative care quality metrics and reinforce best practice. Specific aims of the project include: AIM 1: To develop and nationally implement a uniform approach to palliative care quality monitoring using a PCRC specific version of QDACT-PC (QDACT-PCRC). Upgrades include the addition of new data elements and question modules about caregivers, clinical sites characteristics, hospital-based palliative care, and assessment of the 5 items newly endorsed by the American Academy of Hospice & Palliative Medicine through the American Board of Internal Medicine (ABIM's) Choosing Wisely campaign. AIM 2: To define benchmarks for key quality measures in palliative care using network-wide data from the QDACT-PCRC as a mechanism for delivering clinical decision support. Using descriptive baseline data collection from all network sites, investigators will generate the first multi-site data on NQF endorsed and other quality measures for palliative care. AIM 3: To test the use QDACT-PCRC as a mechanism for delivering clinical decision support that reinforces agreed best clinical practice. Using an overarching PDSA approach, we will use a collaborative process to define areas for quality improvement based upon measures with greatest practice variation identified in Aim 2. For each area we will develop an improvement program including clinical decision support to be delivered via QDACT-PCRC, implement the intervention, monitor impact and update the intervention and process until goals are achieved. This project will generate a national system of real-time point-of-care quality monitoring for palliative care, with demonstrated capabilities to support quality improvement and implementation of best evidence.
Principal Investigator: Laura Hanson, MD, MPH
Funding Source: AHRQ via Duke
Project Period: 09/30/13 - 09/29/18
Total Funding: $284,136

Refinement and expansion of the Palliative Care Research Cooperative Group – The overarching objective of this U24 grant application is to amplify the role of the national Palliative Care Research Cooperative (PCRC) as a resource for efficient conduct of high-quality, collaborative, and multisite PCEOL research. Our

intention is to advance the PCRC to its next phase of development by leveraging and building upon the prior NINR investment and all accomplishments of the PCRC to date. The requested funds will allow us to advance the PCRC such that it will be recognized as a hub of expertise, interest, and activity in PCEOL research and key player in the development of the PCEOL research workforce. It will serve as an access point for: (a) critical PCEOL research infrastructure, including research cores, statistical support, data systems and procedures, measures and methodological guidance and technical support; and, (b) diverse PCEOL-relevant populations including patient, caregiver, and the historically underserved. We intend for the PCRC to set the gold standard for multisite PCEOL research. **Specific Aim #1:** To develop national ***research capacity*** for collaborative, multisite, PCEOL research in a way that maximizes the quality and efficiency of research, and the effectiveness of cooperative groups. **Specific Aim #2:** To provide integrated ***support for PCEOL research***, specifically, for the conduct, analysis, and dissemination of clinically meaningful, high-quality, efficient, patient-centered, multisite studies.
Principal Investigator: Laura Hanson, MD, MPH
Funding Source: National Institute of Nursing Research via Duke
Project Period: 07/01/13 - 06/30/18
Total Funding: $702,200

Integration of Patient Reported Outcomes Measures Into Pain Management Practices for Patients With Hemophilia – More than 100 million people in the United States suffer from pain each year, at an estimated cost of $600 billion for pain treatments and lost productivity.1) Deaths due to opioid pain medications are rising at an alarming rate.2) Patients with hemophilia are particularly afflicted by pain, with more than half of adults and nearly 10% of children experiencing chronic pain, either constant, episodic, or both.3,4) Despite pain’s negative and often disabling impact, our current system for providing care to these patients is failing: up to half of hemophilia patients with pain report their pain is not well controlled.5,6) In addition, pain remains an essential clinical marker for bleeding episodes in both pediatric and adult patients with hemophilia, often serving as a direct proxy measure of bleeding episodes. Although pain is often used as a primary measure of the efficacy of therapeutic interventions, we do an inadequate job of assessing, documenting, and following pain and its impact on patients’ well-being. 7) This shortcoming is largely due to lack of practical, well-validated, self-report measurement tools for pain in patients with hemophilia. It is not known whether incorporating patient-reported measures of pain into the clinical care of patients with hemophilia will affect health-related outcomes that matter to our patients.
Principal Investigator: Tyler Buckner, PhD
Funding Source: National Hemophilia Foundation (Clinical Fellowship Program)
Project Period: 07/01/13 - 06/30/15
Total Funding: $188,333

Comparing Traditional and Participatory Dissemination of a Shared Decision Making Intervention – Despite rapid advances in medical knowledge, significant gaps remain in our ability to rapidly translate new evidence into everyday practice. Indeed, the most common dissemination technique is passive diffusion that includes journal publications, didactic presentations at conferences, and educational material distribution. This process often fails to produce timely or sustainable practice level changes. The Asthma Shared Decision Making Tool Kit was adapted and implemented by investigators from the Carolinas Medical Center across a regional network of 6 Pediatric, Family Medicine, and Internal Medicine ambulatory practices in Mecklenburg County North Carolina. During this study, key principles of community based participatory research were used to engage providers and patients to develop a facilitator-led participatory approach to dissemination that provided an ideal framework for rapid dissemination of the toolkit across 6 practices. Use of the tool kit revealed improved patient outcomes including improved medication adherence, decreased asthma exacerbations and increased patient involvement in the creation of an asthma care plan. To translate these findings more rapidly into clinical care, methods to disseminate the tool need to be tested for effectiveness. Methods: For this study, we will leverage a partnership between the statewide Medicaid network and the NCNC, a state-wide meta-network of practice based research networks centered around Duke University, UNC Chapel Hill, East Carolina University and the Carolinas Medical Center (see www.ncnc.unc.edu) to identify best practices for dissemination of the shared decision making toolkit. We will test this novel method for dissemination on a larger scale by randomizing 30 primary care practices from these 4 NCNC PBRNsto one of three arms representing different levels of exposure to the tool kit and facilitation methods: (1) Control with no dissemination; (2) Traditional dissemination with one didactic session an introduction to the educational materials; and (3) Facilitator-Led Participant Owned” (FLOW) approach to dissemination The FLOW approach includes on site project meetings for up to 12 weeks to assist with the adoption and implementation of the shared decision making tools and processes to enhance shared decision making with patients. Results/Outcome measures: The primary outcome measures will be: number of emergency room visits and hospitalizations for asthma related symptoms at the practice level and aggregate patients’ perceptions of involvement in their asthma care decisions. Secondary outcome measures will include: beta agonist overuse, controller medication use, oral steroid use and practice level use of shared decision making. We will compare the results within each of the exposure arms. Conclusions/Impact: This study will provide crucial data to support the effectiveness of a novel method for dissemination of an evidence-based toolkit into a primary care practices.

Principal Investigator: Jacquie Halladay, MD, MPH
Funding Source: PCORI via Carolinas Medical Center
Project Period: 09/01/13 - 08/31/16
Total Funding: $318,201

PCRC: Colorectal Chemoprevention with Calcium and Vitamin D – The Palliative Care Research Cooperative Group (PCRC) addresses national research priorities in palliative care and end-of-life (PCEOL) through enhancing efficient conduct and dissemination of high-quality, collaborative, multisite, PCEOL research. These studies will ultimately enhance and improve care for people with serious and life limiting illnesses.
Principal Investigator: Laura Hanson, MD, MPH
Funding Source: National Institute of Nursing Research via Duke
Project Period: 09/01/14-08/31/18
Total Funding: $123,243

Hospice Quality Reporting Program Measure Development, Maintenance, and Support – The goal of this research is to assess care coordination for and patient-centered outcomes of children with disabilities under an ACO as compared with traditional fee-for-service plans. We will use a recent policy change in Ohio that mandates children with disabilities move from traditional fee-for-service Medicaid plans into managed care arrangements such as ACOs. This mandate resulted in 8,000 disabled children automatically becoming part of the nation’s largest pediatric ACO.
Principal Investigator: Laura Hanson, MD, MPH
Funding Source: CMS via RTI
Project Period: 9/14/14- 08/31/18
Total Funding: $375,700

High Value Care Issues: Deciding to Stop Screening and Dealing with Insufficient Evidence – Our proposal consists of 2 linked parts to help physicians and patients make better decisions about stopping screening, which offers little or no benefit to patients with limited life expectancy. In the first part, we will use critical appraisal of published data from the CISNET modeling consortium of the National Cancer Institute, with additional model outputs as needed, in order to formulate incremental estimates of benefits and harms of screening for 3 types of cancers (breast, cervical, and colorectal) at different ages. We will then develop outcomes tables giving absolute numbers of cancer deaths prevented (CDP) and absolute numbers of false positive screening tests (FP) and over-diagnosed cases (ODC) per 1,000 people screened. In the second part, we will review the literature on presentation of quantitative information to patients, to inform our development of graphics illustrating the trade-offs between CDP and FP/ODC at various ages. Finally, we will incorporate these materials into “screening plans” intended to facilitate discussions with patients about stopping screening.
Guideline panels frequently conclude that existing evidence does not permit a clear assessment of the balance of benefits and harms for a given intervention. We aim to develop a method for enhancing the utility of this I statements and weak recommendations with low evidence. We will analyze a total of 8 selected recommendations (4 each from ACP and USPSTF), and assign ratings of the type/quality of evidence in the domains of potential benefits, potential harms, ad costs, as well as an overall rating. Based on this assessment we will develop a decision rule that the guideline panels could publish alongside I statements or weak recommendations, to shift the default away from action and help clinicians avoid implementing low-value care.
Principal Investigator: Russell Harris / Colleen Barclay
Funding Source: Department of Veterans Affairs Health Services Research and Development, Minneapolis
Project Period: 06/01/15-09/30/15
Total Funding: $14,998

Heart Health Now! – The objective of HEART HEALTH NOW! is to determine if primary care practice support accelerates the dissemination and implementation of PCOR findings to improve heart health and increases primary care practices' capacity to incorporate other PCOR findings in the future. HEART HEALTH NOW! is a stepped wedge, stratified, cluster randomized trial to evaluate the effect of primary care support on evidence-based CVD prevention and organizational change process measures. Each practice will start the trial as a control, receive the intervention at a randomized time point, and then enter a maintenance period 12 months after starting the intervention. 150 high readiness then 150 low Readiness practices will receive facilitation in a staggered manner beginning at project month 7 with the last practices starting at month 16. All practices will receive 12 months of the intense intervention including onsite QI facilitation, academic detailing, EHR support, and, through the North Carolina Health Information Exchange, a shared statewide utility providing whole population analytics, care gap identification, benchmarking, and an external reporting mechanism which otherwise would not be available to independent practices. A successful intervention would prove that practice facilitation supported by effective informatics tools is an effective method of translating PCOR findings into practice. Discernible reductions in cardiovascular risk in 300 practices covering over an estimated 900,000 adult patients would likely lead to prevention of thousands of cardiovascular events within 10 years.
Principal Investigator: Samuel Cykert, MD, MPH
Funding Source: AHRQ
Project Period: 02/01/15-01/31/18
Total Funding: $14,967,568

White Paper on Behavioral Health in High Point, NC – The goal of this work was to conduct a focus group with key informants from the High Point area about priorities in behavioral health and write a brief white paper.
Principal Investigator: Marisa Domino,
Funding Source: High Point Community Health Fund
Project Period: 03/15/15-05/15/15
Total Funding: $10,000

Mentoring Junior Investigators: Comprehensive HIV Prevention – This career development award gave Dr. Golin the dedicated time to expand and build her patient-oriented research in HIV/AIDS prevention by mentoring several promising, bright, young investigators at UNC in HIV prevention research. Dr. Golin's objective is to create a formal UNC Program on Prevention of HIV in the Southern US by achieving four immediate goals are to: 1) enhance her capacity to evaluate structural determinants of health and cost effectiveness of HIV prevention intervention programs through formal and informal training and collaboration; 2) extend her patient-oriented investigations (exploring the interface between motivation, self-efficacy, and risky sexual behavior) by examining the role that interpersonal and structural determinants of the HIV epidemic play in influencing the effectiveness of HIV prevention programs; 3) evaluate the cost-effectiveness of the SafeTalk HIV prevention program; and 4) enhance her capacity to provide effective and outstanding mentoring to junior investigators. The patient-oriented research proposed in this application: 1) Examines interpersonal and community factors that moderate the effects of risk reduction programs among heterosexual HIV-infected individuals; 2) Explores perceptions of 32 imPACT participants and their social network members regarding contextual and dyadic factors that may have helped or hindered their response to imPACT; 3) Evaluates the cost-effectiveness of the imPACT program; 4) Explores views of HIV-negative women and their male partners living in high poverty, high HIV prevalence census tracts in Durham and Wake Counties in NC.
Principal Investigator: Carol Golin, PhD
Funding Source: NIH/Eunice Kennedy Shriver National Institute of Child Health & Human Development
Project Period: 09/17/13 - 05/31/18
Total Funding: $947,286

Community Engagement to Enhance EBI Implementation in a Public Housing Community – The plan for this project is to use CBPR techniques to engage a broad range of community stakeholders in the design and implementation of study methods. Specifically, we will use an innovative community engagement consulting model (Charrettes) to convene and build structure to sustain a Community-Academic Coalition (CAC) decision making entity that will provide input throughout the study and the design of the next grant. We will assess perceived community resources, needs, priorities, and obstacles to the implementation of HIV prevention programs, particularly RAPP, among DHA residents and DHA and CAARE program staff. Informed by Andersen's Care Access Model32-34,we will complete 2a) Use qualitative methods (Photovoice, focus groups and interviews) to explore barriers and facilitators to and needs for HIV prevention implementation in the DHA; and 2b) Conduct a door-to-door needs assessment survey of 200 randomly selected DHA residents.
Informed by data from Aims 1 and 2, and in collaboration with CAARE, we will create and test for feasibility and acceptability a program plan for implementing RAPP within DHA housing developments.
Principal Investigator: Carol Golin, PhD
Funding Source: NIH
Project Period: 08/01/15-05/31/18
Total Funding: $680,200

Using CHART to deliver a smoking cessation and lung cancer screening intervention – This program proposed to 1) build a CHART-based prototype interface for delivering lung cancer screening decision aid and smoking cessation messaging; and 2) determine the feasibility of using CHART to deliver a web-based LCa screening decision aid and smoking cessation information in the target patient population at one primary care site.
Principal Investigator: Daniel Reuland, MD, MPH
Funding Source: Lineberger, Health e-NC
Project Period: 01/01/15 - 12/31/15
Total Funding: $75,000

North Carolina Prostate Cancer Comparative Effectiveness and Survivorship Study (NC ProCESS): A Stakeholder-Driven, Population-Based Prospective Cohort Study – This research is to examine comparative outcomes after four to five years among different prostate cancer treatment options.NC ProCESS is a cohort of 1,700 patients from diverse backgrounds diagnosed with early prostate cancer and who were enrolled from January 2011 to June 2013. This observational study collects information on quality of life, cancer control, and health care received, inclusive of treatment and management of subsequent effects including complications and recurrence. We will use several statistical techniques to minimize the chance that differences between patients receiving different treatments will lead to misleading results about the effect of the treatments on quality of life, disease-free survival, and use of healthcare resources.
Principal Investigator: Ronald Chen, MD, MPH
Funding Source: PCORI
Project Period: 08/01/14 - 07/31/17
Total Funding: $$2,099,671

The National Person-Centered Assessment Resource (PCAR) – With its five subcontract sites, Northwestern University will refine and sustain a research resource infrastructure that will educate and enable researchers and other interested health professionals on the use and interpretation of person-centered health outcomes. Person-centered health outcomes are those that are reported or performed by an individual research participant or patient, and that have importance to the quality of life of that participant. We refer to this resource as The National Person-Centered Assessment Resource, or PCAR. Specifically, PCAR will support the use and enhancement of four measurement information systems, currently funded as separate NIH programs: The Patient Reported Outcomes Measurement Information System® (PROMIS®); The NIH Toolbox for Assessment of Neurological and Behavioral Function (NIH Toolbox);

The Neurology Quality of Life Measurement System (Neuro-QOL); and The Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me). PCAR will provide an integrated platform for automated use of these four measurement information systems. The PCAR platform is already compatible with various modes of information collection (including web/mobile-based entry, non-digital paper source data, and others). During the funded period, we will move to sustain this platform and the educational and statistical services around them, under a fee-for-service model that will support free and open distribution of static, downloadable measures as well as administration, scoring, and interpretation tools. PCAR will also be designed to allow resource users (i.e., external researchers and clinicians unaffiliated with the resource) to access and use any of the four systems together or in isolation and tailor use to meet the specific study needs, while capturing and transmitting participant data securely.
Principal Investigator: Bryce Reeve, PhD
Funding Source: NIH via Northwestern University
Project Period: 0 9/01/14 - 08/31/18
Total Funding: $458,692

Program on Mental Health & Substance Abuse Services & Systems Research

Marisa Domino, Ph.D., Program Director

There is growing recognition of the importance of mental health and substance abuse treatments, due to the high prevalence of disease and disability burden, as well as interactions with other chronic conditions. Providers in both the private and public sectors are searching for effective models of short- and long-term care for people with acute and chronic mental illness and substance abuse disorders. Many of the issues confronting policy makers and service providers at the global, national, state, and local levels require new knowledge and research about:

- the effectiveness and cost-effectiveness of a large number of potential interventions in use by service providers;
- clinical and social outcomes for service recipients;
- the structures, processes, and effects of managed behavioral healthcare programs; and
- the integration of mental health services with other substance abuse, primary care, criminal justice, and social welfare systems.

The Sheps Center's work in this area involves studies taking place in North Carolina and throughout the world.

The following research projects were active during the year:

Research Training in Mental Health Services & Systems – Program for social/behavioral scientists and clinicians seeking pre- and post-doctoral advanced training in mental health services research has two components: core activities and individualized study. The core component involves a weekly research seminar, participation in departmental seminars and grand rounds at the collaborating institutions, and other research seminars/workshops at UNC-CH or Duke. The individualized study component is tailored to the special interests and needs of each fellow and their prior experience. It is based on an apprentice-type model whereby each fellow is linked to one or more mentor(s) who works with the fellow to develop his/her own research and skill development program. The program is jointly sponsored by the Department of Psychiatry and Behavioral Sciences, Duke University Medical Center.
Program Director: Marisa Domino, PhD
Funding Source: National Institute of Mental Health
Project Period: 07/01/90 – 06/30/16
Total Funding: $5,913,098
Type: Training

Future research needs for autism: Disseminating findings from a PCORI pilot project –
Stakeholder involvement in identifying and prioritizing future research needs is a core principle of PCORI's mission and mandate. Yet, the evidence base for how to capture stakeholder inputs in the knowledge development process is surprisingly underdeveloped. Attributes can be measured by discrete choice experiments administered as a survey as done to model community preferences for health services. Using discrete choice experiments to model preferences for future research needs as proposed in this application is novel. Autism is an instructive context for methods development because of a wide diversity of stakeholder opinion, but the methods developed here can be readily applied to other disease conditions. The proposed study will be carried out in relation to three aims: Aim 1: To compare attributes and utilities for future research from small and large panels of stakeholders. Aim 2: To compare priorities for future research generated by the small and large panel utility models estimated in Aim 1. Aim 3: To explore stakeholder satisfaction with the small and large panel approaches.
Principal Investigator: Kathleen Thomas, PhD
Funding Source: PCORI
Project Period: 06/01/15 - 09/28/15
Total Funding: $50,000

Robeson County Bridges for Families – For this evaluation, the investigator will interpret data for the perinatal programs and other evidence-based programs that have been approved by the NC Practice Improvement Collaborative for statewide rollout. This project is a part of a larger scope (annual $500k). Dr. Greene leads a management team made up of representatives from three state agencies and non-profit partner agencies, as well as a local management team with leaders from service agencies, the court, and the county government. There are over 60 local partners involved in implementation and numerous additional state and local partners for which Dr. Green provides project leadership.

Principal Investigator: Sherri L. Green, PhD, LCSW
Funding Source: Governor's Institute on Alcohol and Substance Abuse Inc.
Project Period: 08/01/08 – 06/20/12
(extended through 09/30/14)
Total Funding: $97,993

Perinatal and Maternal SA Initiative – Dr. Sherri Green, and her research team, will provide evaluation support, technical assistance, and policy research for the North Carolina Perinatal and Maternal Substance Abuse Initiative. Associated research activities will result in information that helps the state improve the quality of substance abuse services in North Carolina ($108,775). The contract also covers activities associated with the position of principal investigator and collection and management of evaluation data for the Robeson County Bridges for Families (RCBF) Program. Funding for activities associated with the RCBF program come from the US Department of Health and Human Services, Administration for Children and Families.
Principal Investigator: Sherri L. Green, PhD, LCSW
Funding Source: Governor's Institute on Alcohol and Substance Abuse, Inc.
Project Period: 7/1/11 - 06/30/14
(extended through 06/30/16)
Total Funding: $445,340

Expansion of Research Capability to Study Comparative Effectiveness in Complex Patients (CMS MAPCP Project) – The project will do the following: 1. Collaborate with NCCNC staff to create an integrated database linking three data sets maintained by the NC Department of Health and Human Services: HEARTS (state psychiatric hospital admissions), IPRS (outpatient mental health services), and Medicaid claims.
Sheps Center staff will provide technical assistance in identifying relevant mental health data elements in each data system, composite measures of service use, the development of codebooks for the integrated database, and the creation of an oversight structure for managing the integrated database and making it available to the research community in NC and elsewhere. 2. Conduct a small proof of concept study to confirm the accessibility and usability of the integrated data base. This study will focus on medical homes for patients with mental illness and explore variations in primary care visits, services received and outcomes for patients with varying levels of psychiatric illness as contained in the integrated database.
Principal Investigator: Marisa Domino, PhD
Funding Source: AHRQ via North Carolina Community Care Networks, Inc (NCCCN)
Project Period: 9/30/10 - 03/31/14
(extended through 12/31/14)
Total Funding: $488,593

An Approach to Capture Divergent Stakeholder Views on Future Research Needs – Involvement of a wide range of stakeholders in identifying future research needs in a clinical area is a relatively new concept, and best practices for doing so are untested and evolving. One approach has been to rely on a small group of thought-leaders, the underlying assumption being that they can represent the disparate views in their community. It is possible on the one hand that a small group of stakeholders is likely to miss important variation in opinion; on the other hand, there may be a point at which too many stakeholders creates redundancy. Given the wide range of disease and disorders characterized by divergent stakeholder opinion, developing methods that capture variation in stakeholder opinion, as a foundation for prioritizing future research needs, is critical for PCORI's mission. The proposed study seeks to develop an evidence base for determining priorities among stakeholders with divergent opinions using the treatment of autism in childhood as an example. This will be accomplished by means of three aims: 1. Conduct an assessment of future research needs using point allocation and conjoint analysis among a small group of stakeholder thought-leaders, 2. Conduct an assessment of future research needs using point allocation and conjoint analysis based on a large web-based survey of stakeholder constituents across the US, and 3. Assess the concordance of the two approaches and their relative advantages with respect to stakeholder buy-in with the protocol and satisfaction with the outcomes. Using conjoint analysis to discover stakeholder priorities for future research needs will identify what aspects of research are valued and their relative importance, providing a metric with which to assess new research opportunities. Conjoint analysis also provides a way to identify constituencies with divergent views, providing a structure for hosting cross-constituency dialogue. Comparison of conjoint analysis with a point allocation approach will elucidate whether attention to underlying values refines priority rankings. Comparison of the approaches in small and large groups will assess the net value of the large group approach. The proposed study addresses PCORI's interests in developing methods for bringing together stakeholders to prioritize research questions, identifying stakeholder-identified gaps in comparative effectiveness knowledge and elucidating national stakeholder priorities for patient-centered outcomes research
Principal Investigator: Kathleen Thomas, PhD
Funding Source: PCORI
Project Period: 07/01/12 - 12/31/14
Total Funding: $692,734

An Evaluation of the Effectiveness of Mobile Health Diabetes Technologies for Adults with Co-occurring Severe Mental Illness – The goal of this project was to evaluate the available mobile health applications for individuals with diabetes in order to identify interventions which are most likely to be successful for subpopulations with severe mental illness; to pilot one or more interventions identified in a population of individuals with schizophrenia and diabetes; and to develop recommendations for redesign of the existing diabetes technologies for the population of individuals with co-morbid severe mental illness.

Principal Investigator: Marisa Domino, PhD
Funding Source: UNC- CH TraCS
Project Period: 08/15/14-08/14/15
Total Funding: $49,672

UNC-CH/ Duke Training Program in Mental Health Services & Systems Research – The goal of the UNC-CH / Duke Training Program in Mental Health Services & Systems Research is to expand the pool of investigators capable of undertaking policy-relevant mental health services and systems research.
Principal Investigator: Marisa Domino, PhD
Funding Source: NIMH
Project Period: 07/01/14-06/30/15
Total Funding: $250,366

Tough choices: Autism, private health insurance and family out-of-pocket – The goal of this study is to develop firmer evidence about the relationships between private health insurance plan features and family needs. We can advance this agenda in a one-year HRSA grant by examining secondary data already available through the Medical Expenditure Panel Survey (MEPS) as a stepping-stone to future intervention studies focused on improving family insurance choices. For the proposed one-year study, two hypotheses will be examined following from our prior work: that families will value low deductibles, but that low deductibles expose families to unanticipated expenditures. Three aims will guide the proposed study: Aim 1: To determine the private health insurance plan features and child service use experiences associated with family ratings of insurance plan adequacy, aim 2: To develop objective measures of plan quality for selected health insurance plans offered through state health insurance exchanges by generating family expenditures for premiums, copayments, and uncovered services, Aim 3: To develop subjective measures of plan quality for selected health insurance plans by simulating family ratings based on the model from Aim 1 and the expenditures from Aim 2 to highlight family choice strategies needing improvement.
Principal Investigator: Kathleen Thomas, PhD
Funding Source: Maternal & Child Health Bureau/HRSA
Project Period: 09/01/14-08/31/15
Total Funding: $99,999

The Cultural Authority of Science in the Public Sphere: Creating Data Streams for Further Advances – Intellectual Merit – The rationale for this project is that it will create the foundation for a vibrant research community that can examine how social groups vary in their trust/distrust of organized science. The proposed research will accomplish the overall objective of this application by pursuing the following specific aims: Aim #1: Bring together scholars from multiple backgrounds to discuss the core issues related to the cultural authority of science, provide new perspectives on existing data, and suggest measures for future surveys. This aim will be completed by organizing an expert panel that will bring together scholars who possess specialized knowledge related to the overlap of social theory and public opinion, social studies of science, survey research on public understanding of science, current data archives, and the development of public opinion questionnaires. Aim #2: Develop new measures and collect new data to examine the social and cultural factors that shape the cultural authority of science in the public sphere. The outcomes of this project will have wide-ranging benefits. The benefits to students learning and training will be twofold. Understanding the mechanisms that the divide the public sphere will help the NSF and other scientific organizations engage the public and improve public participation in science, both among adults and children.
Principal Investigator: Joseph Morrissey, PhD, and Gordon Gauchat, PhD
Funding Source: National Science Foundation
Project Period: 08/01/12 – 07/31/14
Total Funding: $113,999

Program Highlight: Marisa Domino new director of Mental Health Program

Marisa Domino, PhD, is the new Director of the Program on Mental Health and Substance Abuse Services and Systems at the Cecil G. Sheps Center for Health Services Research.

Domino was selected for this new role by Joe Morrissey, PhD, who has served as director of the program for many years. Morrissey will retire from UNC later this year.

Domino is a professor in the department of health policy and management at the UNC Gillings School of Global Public Health. She has conducted many studies on the costs and outcomes of various systems of care for patients with mental health problems, especially focused on care through state Medicaid programs.

“Mental health and substance abuse is an essential area of research in health policy, both domestically and globally, because of its high prevalence and great costs to society,” said Domino. “My goals for the program are to continue the excellent track record of collaboration and high-impact research built by Dr. Morrissey in order to improve the quality of life of all those touched by mental illness and substance abuse, while looking for greater efficiencies in service provision and insurance

Adequate Health Insurance for Children with Autism: Evidence and Implications for Defining Essential Benefits – There is evidence from national data that children with special health care needs who have both private insurance and Medicaid are less likely to experience barriers to care than those with private insurance alone, but there is a major research gap about the extent to which combined coverage provides adequate insurance for children with autism, how it improves access to care, and its impact on the mix and level of mental and other health care services they use.

The long-term goal of this research is to improve access to care and outcomes for children with autism. The objective of the proposed study is to inform state deliberations about new definitions of essential benefits for mental health and other health care services by identifying the segment of children with autism who have the most adequate health insurance and examining their health service use. We hypothesize that having combined coverage will be associated with greater insurance adequacy and increase the breadth and amount of service use particularly for mental health services.

Principal Investigator: Joseph Morrissey, PhD, and Kathleen Thomas, PhD
Funding Source: Maternal & Child Health Bureau/HRSA
Project Period: 09/01/13 - 08/31/14
Total Funding: $99,496

Program on Rural Health Research

George 'Mark' Holmes, Ph.D., Program Director

The **Rural Health Research Program** (RHRP) is built on the forty-four year history of rural health services research at the University of North Carolina's Cecil G. Sheps Center for Health Services Research. The program draws on the experience of a wide variety of scholars and researchers, analysts, managers, and health service providers associated with the Center. The Program also has an ongoing partnership with the NC Foundation for Advanced Health Programs, Inc. and the Office of Rural Health and Community Care in the NC Department of Human Resources.

The RHRP is working to address problems in rural health care delivery through basic research, policy-relevant analyses, the geographic and graphical presentation of data, and the dissemination of information to organizations and individuals in the health care field who can use this information for policy or administrative purposes. The Program's research involves primary data collection, analysis of large secondary data sets, and in-depth policy analysis. The Program brings together a diverse, multidisciplinary team including clinicians in medicine, nursing, pharmacy, allied health, mental health, and other professions and disciplines along with experts in biostatistics, geography, epidemiology, sociology, anthropology, and political science to address complex social issues affecting rural populations.

The North Carolina Rural Health Research Program's project portfolio currently includes the *NC Rural Health Research and Policy Analysis Center* and the *Medicare Rural Hospital Flexibility Program*. There is also an active dissemination component and emphasis on the use of geographic methods in research.

The following research projects were active during the year:

Medicare Rural Hospital Flexibility Program Evaluation – The Sheps Center's current role in this evaluation focuses on three areas. 1) *Development of a Financial Performance Measurement System:* This project uses research and expert opinion to select dimensions and indicators of financial performance, develop appropriate bases or methods of peer comparison, investigate the relationship between quality of care and financial performance, and identify characteristics of high performing Critical Access Hospitals (CAHs). 2) *CAH Conversion Tracking:* The Sheps Center continues its work tracking CAH conversions. 3) *Quality Financial Relationships:* This joint project with the University of Minnesota will investigate the relationship between CAH financial performance and quality of care.

Principal Investigator: Mark Holmes, PhD
Funding Source: Office of Rural Health Policy, HRSA via University of Minnesota
Project Period: 09/01/03 – 08/31/13
(extended through 06/30/15)
Total Funding: $1,863,332
Secondary Program Area: Health Care Economics and Finance

North Carolina Rural Health Research and Policy Analysis Center (NC RHR & PAC) – Extending and expanding the work of the North Carolina Rural Health Research Program at UNC-CH, this project primarily focuses on Federal insurance programs (Medicare and Medicaid) and their effect on rural populations and providers. In addition, faculty and professionals working with the NC RHR & PAC respond to short-term queries using the unique availability of multiple national and special datasets to investigate key rural health policy issues. The following six projects are under investigation: 1) rural health clinics: Medicare & Medicaid profile, 2) the 21st century rural hospital: outpatient services and access to care, 3) hospital readmission following care in a swing bed, 4) swing beds versus skilled nursing facilities: Medicare expenditures for episodes of care, 5) early rural experiences of changes to Medicaid, 6) identifying limitations of prospective payment system (PPS) reimbursement for rural hospitals. The NC RHR & PAC has also been designed to have staff, data, and resources to address other issues as they become salient.

Principal Investigator: Mark Holmes, PhD
Funding Source: Office of Rural Health Policy, HRSA
Project Period: 08/15/04 – 08/31/16
Total Funding: $5,940,000
Secondary Program Areas: Aging, Disability, & Long-Term Care & Health Care Economics & Finance

Program Highlight: Rural Hospital Closures

The Program on Rural Health Research has been an important resource for communities affected by rural hospital closures this year. Dr. Mark Holmes has been interviewed by multiple media outlets about the impact of rural hospital closures. One interview was for WUNC Radio's State of Things Program on July 23rd. Dr. Adam Zolotor, director of the North Carolina Institute of Medicine, was also part of the hour-long discussion about rural health care across the state.

Rapid Response to Requests for Rural Data Analysis and Issue Specific Rural Research Studies – The North Carolina Rural Health Research & Policy Analysis Center (NC RHR & PAC) of the Cecil G. Sheps Center at the University of North Carolina proposes to provide rapid response for rural-focused data analysis and to conduct issue-specific rural research studies in response to emerging policy issues. The NC RHR & PAC is uniquely qualified to provide this service, as it builds on previous and current work conducted during twenty-one years as a Federal Office of Rural Health Policy (ORHP) Rural Health Research and Policy Analytic Center. The NC RHR & PAC has created a national identity as a rural center that can quickly respond to requests for data analysis, and one that produces rapid turn-around policy-relevant research and analysis to inform the rural health policy community. The NC RHR & PAC will partner in this effort with the Rural Policy Research Institute Center for Rural Health Policy Analysis. In order to ensure that rural policy is designed to protect and improve the health of rural residents, data on the unique characteristics of rural people, health care providers, and the health care infrastructure, and the potential impact of policy and challenges rural areas face in health care delivery must be made available to policy makers, rural organizations and ORHP. The maintenance of data archives that are sufficiently broad to be able to address whatever issues surface requires many data sets, programmer experience using them, statistical knowledge, understanding the geographic issues surrounding different definitions of rural and levels of geography, how to merge data and use GIS, and substantial computing capacity. Organizations and agencies whose task is to focus on rural health policy do not have this capacity, and must rely on organizations that do. The NC RHR & PAC and other members of the project team have been serving this role for the rural policy community for a number of years, and propose to continue to do so. The development and evolution of rural health policy occurs in a rapidly changing context, and the support of rural health policy can also require issue-specific studies involving greater time and resources and more complex study design than rapid response data analysis. Under this cooperative agreement, the NC RHR & PAC, with its collaborator, will also provide these vital services to individuals and organizations involved with rural health policy.
Principal Investigator: George Pink, PhD
Funding Source: HRSA
Project Period: 09/01/10 – 08/31/16
(extended through 06/30/18)
Total Funding: $1,350,000

Technical Assistance to the ORHCC – The purpose of this contract is to provide financial support for technical assistance and consultation which will assist in fulfilling the ORHCC mission. The Office of Rural Health and Community Care (ORHCC) assists underserved communities and populations to develop innovative strategies for improving access, quality, and cost effectiveness of health care. The mission of the ORHCC is to provide access for underserved populations who would otherwise be unable to receive the needed health care services due to geographic, economic, or other barriers. Distribution of primary care providers in North Carolina has historically been skewed toward the cities and larger towns. Rural residents, who often suffer from transportation issues, find accessing affordable primary care services difficult. Safety net clinics and Critical Access Hospital networks have provided a local solution to this problem by providing rural residents with access to quality primary care services that are both cost effective and easily accessible. The purpose of this contract is to provide financial support to the UNC CH – The Cecil G. Sheps Center for Health Services Research for technical assistance and consultation which will assist in fulfilling the ORHCC mission.
Principal Investigator: Kristin Reiter, PhD
Funding Source: NC Office of Rural Health and Community Care
Project Period: 07/01/12 - 08/31/13
(extended through 8/31/15)
Total Funding: $104,179

Program on Health Workforce Research and Policy

Erin Fraher, Ph.D., M.P.P., Program Director

The **Program on Health Workforce Research and Policy** is dedicated to producing timely, objective and policy-relevant research that informs local, state, national and international health workforce policy debates. Through our reports, manuscripts, presentations and service to the state and nation, we provide the information needed to redesign the workforce to meet the rapidly changing needs of the health care system. The Program's work is interdisciplinary, spanning medicine, nursing, pharmacy, dentistry, allied health and the direct care workforce. Our research is cutting edge both in the questions we seek to answer and in the methods we use to answer those questions.

The Program focuses on "engaged scholarship." We seek opportunities to work with an extensive network of stakeholders who are on the front lines of practice, education, regulation and government. These stakeholders reach out to us with health workforce problems to solve and questions they want answered. Because our work emerges from the front lines, our research is constantly refreshed with new research questions that, once answered, have immediate and "real world" impact. An important component of our work is providing a training ground for the next generation of health workforce researchers.

The following research projects were active during the year:

North Carolina Health Professions Data System (HPDS) – The HPDS is often held up nationally as the gold standard in state-level data systems that track the supply and distribution of health professionals. The HPDS contains data from 1979 to the present on 19 licensed health professions. These data are shared with the HPDS by 12 regulatory bodies that license the health professions. HPDS data are used to plan and evaluate the supply, characteristics and distribution of NC health professionals. Each year, HPDS staff produce an annual North Carolina Health Professions Data Book, as well as data, presentations, fact sheets, reports and manuscripts that inform state policy. HPDS publications and materials are widely used by the legislature, state policymakers, researchers, media, and professionals in the health care industry as the official source of health professions statistics in North Carolina. The HPDS website can be accessed at http://www.shepscenter.unc.edu/hp.
Project Director: Erin P. Fraher, PhD, MPP
Funding Source: NC Area Health Education Centers Program and UNC-CH Office of the Provost (Health Affairs)
Project Period: 10/74 – ongoing
FY14-15 Funding: $107,062

Tracking Physician Careers – Following legislation passed by the NC General Assembly in 1994, the Program on Health Workforce Research and Policy has collaborated with the North Carolina Area Health Education Center (AHEC) Program to produce an annual report that tracks where NC medical school graduates are practicing and in which specialties they practice five years after graduation from medical school. These reports are shared with the UNC Board of Governors each November and are forwarded to the Fiscal Research Division of the General Assembly. In addition to tracking primary care specialties, the Program tracks graduates practicing in general surgery and psychiatry, as well as graduates who practice in rural areas. Because medical residency in subspecialty disciplines may take longer than 5 years to complete, the Program also analyzes data at 10 years after graduation from medical school.
Project Director: Julie Spero, MSPH
Funding Source: NC Area Health Education Centers Program and UNC School of Medicine

Program on Health Workforce Research and Policy: Service to North Carolina and the Nation

In 2011, the Institute of Medicine and the Robert Wood Johnson Foundation published *The Future of Nursing*, a landmark report that called for an increase in the education levels of nurses and an expansion of nurses trained at the baccalaureate level from 50% to 80% by 2020. In an effort to meet this goal, states have been identifying ways to train more Bachelor of Science in Nursing (BSNs) by opening new programs, expanding existing programs and creating additional pathways to allow Associate Degree Nurses (ADNs) to obtain their BSN degrees.

Researchers from the Program on Health Workforce Research and Policy have provided data and analyses to policy makers leading academic progression efforts in North Carolina and nationally. Our work has been used by the Foundation for Nursing Excellence, the Regionally Increasing Baccalaureate Nursing (RIBN) Initiative and a North Carolina Community College System task force on the Future of Community College Nursing Education. Data have also been used by regional AHECs, who work with local employers to ensure that they have a sufficient pool of skilled nurses to meet patient demands.

Additionally, the Robert Wood Johnson Foundation invited the Program team to share North Carolina's data with other states involved in rural health and academic progression because we have some of the only data in the country that reveal the geographic distribution, specialty areas and practice settings of ADN nurses who have advanced their careers by earning a BSN or higher degree.

Key questions that Program researchers helped to answer are

1. What percentage of ADNs in the state have gone on to earn a BSN or higher? Is the trend increasing?
2. What is the distribution of ADNs vs BSNs by location, specialty and practice setting?
3. Do nurses who earn higher degrees stay in rural and economically distressed areas, and practice in needed specialty areas and settings such as long term care, geriatrics, home health and hospice?

Our data indicate that ADNs are more likely than BSNs to practice in rural areas and even after ADN nurses go onto pursue a BSN, they are twice as likely to practice in rural communities and three times more likely to practice in economically distressed communities than nurses who entered the workforce with a BSN or higher degree . However, ADNs nurses who advance to a BSN are less likely to remain in higher-need specialty areas such as geriatrics, home health and hospice. They also vacate staff-nursing jobs for nursing positions that do not involve direct clinical care (e.g. teaching, administrative and supervisory roles).

These data imply that creating pathways for the current ADN workforce to advance their education, such as online RN to BSN programs and other educational opportunities, will help meet the *Future of Nursing* report's recommendation while maintaining a stable supply of RNs in rural locations. Understanding how to support nurses in specialties and practice settings where they are most needed is a challenge North Carolina will need to address.

Project Period: 1994 – ongoing

An Open Source Model for Projecting Physician Shortages in the United States – The question of whether the United States is facing a physician shortage is hotly contested. Some projections estimate a shortfall of between 85,000-200,000 physicians by 2020. Other analysts suggest that supply is not the issue, rather it is the distribution of physicians both geographically and between specialties that is most problematic. In this project, staff developed an open source projection model that can be used by medical and policy leaders to assess whether current and future physician workforce will meet population health care needs. The model is intuitive, easy to use, and incorporates numerous parameters that can be adjusted under a variety of scenarios to forecast the supply and demand for physician services at the county, state and national levels. Scenarios allow the user to change assumptions about the expansion of Medicaid under the *Affordable Care Act*, physician retirement rates, FTE rates, increased use of NPs and PAs, and redistribution of Graduate Medical Education slots. Data can be visualized as maps, line graphs and/or population pyramids, and can be downloaded in graphic and tabular formats.

The model has benefitted from the input of an expert advisory board comprised of clinician leaders from a variety of disciplines and specialties. The model is transparent and dynamic so it can be used by practicing physicians in leadership roles in their states and communities, the Physicians Foundation, state medical societies, national and state specialty society groups, public health officials, policy makers and health workforce experts to better understand and debate the effect that different data sources, workforce assumptions and policies will have on physician workforce estimates. The model, released in July 2014, can be accessed at https://www2.shepscenter.unc.edu/workforce.

The team is now **Developing Version 2 of the FutureDocs Forcasting Tool.** Version 2 will have updated data and training materials to assist users in better understanding and acting upon the model's results.
Principal Investigator: Erin Fraher, PhD, MPP
Funding Source: The Physicians Foundation
Project Period: 07/01/11 - 09/30/17
Total Funding: $1,596,634

Health Workforce Research Center Program – The mission of the Carolina Health Workforce Research Center (Center) is to conduct and disseminate policy-relevant research for the National Center for Health Workforce Analysis, other federal agencies, health care consumers, practitioners, employers, educators, states and communities. The goal of the Center is to provide the research needed to guide programs and policies to support the flexible deployment of the workforce in a reformed health care system. The Center's work focuses on numerous aspects of worker flexibility: existing workers taking on new roles within new models of care; existing workers shifting employment settings; existing workers moving between needed specialties; existing workers altering the types of health services they offer; the emergence of new types of health professionals taking on new roles within new models of care; and the broad implementation of team-based models of education and practice.
Principal Investigator: Erin Fraher, PhD, MPP
Funding Source: Bureau of Health Workforce/HRSA
Project Period: 09/01/13-08/31/17
Total Funding: $2,123,482

Health Workforce Research Center Program – Technical Assistance Center – Since 2003, Program staff have provided technical assistance to states wishing to develop health workforce data systems. These systems, once implemented, provide data to policy makers, educators, employers and other stakeholders to make data-driven decisions and engage in more deliberate health workforce planning. In 2013, The Sheps Center partnered with the Center for Health Workforce Studies at SUNY-Albany to create the Health Workforce Technical Assistance Center (HWTAC). HWTAC activities include providing information, guidance and feedback on data collection, analysis and dissemination efforts; participating in webinars and conference calls; facilitating stakeholder meetings; developing reports and other informational materials; and providing more comprehensive assistance to individual states as needed. The HWTAC website can be accessed at http://www.healthworkforceta.org.
Principal Investigator: Katie Gaul Frizzelle, MA
Funding Source: Bureau of Health Workforce/HRSA via Health Research, Inc.
Project Period: 09/01/13-08/31/17
Total Funding: $385,014

The Future of Nursing: Campaign for Action Research Manager – The goal of this project is to develop local, state and national capacity to "improve health workforce data collection to better assess and project workforce requirements." Projects have included a three-part series of briefs on developing state-level nursing workforce data systems, a sensitivity analysis of the number of NPs practicing in primary care, and a systematic literature review and brief on nurses' role in care coordination. Work will continue to focus on producing policy-relevant research to advance the Future of Nursing initiative.
Principal Investigator: Erin Fraher, PhD, MPP
Funding Source: Robert Wood Johnson Foundation
Project Period: 04/15/12-1/31/17
Total Funding: $225,000

Study of the North Carolina Optometrist Workforce – In response to legislation passed in the 2014 state budget, the University of North Carolina General Administration (UNC GA) funded the Program on Health Workforce Research and Policy to conduct a study on NC's optometry workforce. This study was intended to inform decisions about the potential creation of a state-funded school of optometry. The HPDS served as the key source

of data for the study, supplemented by various national data and proceedings from an expert advisory group convened by Program staff. Study results indicated that North Carolina has a sufficient supply of optometrists to meet demand in the state, and there is a strong pipeline of students enrolling in other states to meet our needs in the future. Two new optometry schools are under development in nearby states (KY and VA) and will begin enrolling students in Fall 2016. Given the data on the strong NC optometrist supply and the costs to build and maintain a state-funded school of optometry, the UNC GA recommended that the NC General Assembly refrain from planning a new, state-funded school of optometry in the NC. The final report was published in March 2015 and can be accessed at http://www.shepscenter.unc.edu/wp-content/uploads/2015/04/NC-OptometryRpt-March2015.pdf.
Principal Investigator: Erin Fraher, PhD, MPP
Funding Source: UNC General Administration
Project Period: 08/1/14-02/28/15
Total Funding: $24,244

Evaluation of Workforce Needs in Pediatric Surgery – The goal of this project is to investigate the workforce needs in pediatric surgery. This study will refine and update the FutureDocs Forecasting Tool to specifically include pediatric populations and the range of pediatric surgical procedures to generate predictions of a) the numbers of pediatric surgeons and pediatric surgery subspecialties likely to be in practice through the year 2030; b) the estimated need for these surgeons; c) comparisons to other surgical specialties whose operative work overlaps that of pediatric surgeons (e.g., general surgery); and d) the pathways of surgeons into and out of pediatric specialty training.
Principal Investigator: Erin Fraher, PhD, MPP
Funding Source: American College of Surgeons and American Pediatric Surgical Association
Project Period: 11/15/14-11/14/15 $52,000

Program on Women's Health Services Research

Wendy R. Brewster, M.D., Ph.D., Director

The **Program for Women's Health Services Research**, which emphasizes research related to improving the delivery of health services to women, is part of the *UNC-Chapel Hill Center for Women's Health Research*. The Center provides research services for women's health investigators to optimize research quality and improve the health of women. Together, they are working to serve the women of North Carolina and the nation by:

- documenting the health status of women,
- studying models for improving care,
- evaluating promising new treatments, and
- developing effective prevention programs.

The Center, founded in March 2000, is a joint effort of the *School of Medicine* and the *Cecil G. Sheps Center for Health Services Research*. Experienced staff and start-to-finish resources are available to assist UNC investigators plan, launch, and conduct women's health research. The Center's operating principle is to provide connections among research peers, foster career development and infrastructure, and assure the visibility of women's health research.
No specific research program was within Women's Health Services Research this year, although many of the perinatal programs designated in the Child and Adolescent Health Program overlap substantially.

Program on General Health Services Research

Although not directly related to one of the Center's program focus areas, the following research projects were active in the **Program on General Health Services Research** during the past year:

A Systematic Review of Empathy Development in Medical Education – Understanding how empathy can be developed in medical education is an important component of advancing humanistic medicine. Two recent reviews of changes in empathy among medical students and residents reached disparate conclusions. In a systematic review, Neumann and colleagues (2011) determined that empathy declines during medical training as students engage more with patients. Colliver et al (2010) conducted a meta-analysis drawing on much of the same research and concluded that declines in empathy during medical training are minimal—perhaps even nonexistent. Colliver and colleagues argued that the instruments used to study "empathy" may not be measuring anything meaningful to clinical practice or to patient satisfaction. (For example, most past research has utilized student self-assessments, which may be an ineffective way to measure empathy). The discrepancy between these two reviews poses serious concerns for researchers and educators seeking to maximize empathy in medicine. We propose a systematic review of how empathy is operationalized in medical education research, complemented by a critical analysis that considers how it might be. What are we measuring when we measure empathy? What could we measure?
Program Director: Timothy S. Carey, MD, MPH, and Sandra Sulzer, PhD
Funding Source: The Arnold P. Gold Foundation
Program Period: 08/31/13 - 02/27/15
Total Funding: $6,000
Type: Training

UNC-CH Training Program in Health Services Research – The program offers academic training and directed research experience in the application of the concepts and research methods of a number of disciplines to the study of the organization, financing, utilization, provision, and effectiveness of personal health services. Predoctoral training is offered in collaboration with the Departments of Epidemiology, Health Policy and Administration, Health Behavior, and Maternal and Child

Health at the UNC-CH School of Public Health. Upon completion of this program, both pre-doctoral and post-doctoral fellows have a generalized background in contemporary health policy issues, the historical significance of these issues, a solid understanding of the most common statistical and study design methods applicable to health services research and policy analysis, a set of materials to use as supporting references in their own work, experience in the design and conduct of health services research under supervision of at least one mentor with expertise in relation to the subject and methods being used, and a set of data ready to be published. This training program, recently refunded, has been continuously supported since 1989.
Program Director: Timothy S. Carey, MD, MPH
Funding Source: AHRQ,
National Research Service Award
Program Period: 09/01/89 – 06/30/16
Total Funding: $2,968,103
Type: Training

Sheps Center Research at Academic Conferences

Sheps researchers create knowledge to improve health services in many different ways, and they disseminate their findings each year through journal articles, books, white papers, conference presentations and seminars, and a variety of outlets for lay audiences. Two of the largest events our researchers attend are AcademyHealth and the American Public Health Association Annual Meeting. This year, Sheps was well represented at both events:

AcademyHealth 2015 Annual Research Meeting
June 14-16, 2015
Minneapolis, MN
***21 presentations from Sheps-affiliated researchers**

APHA 142nd Annual Meeting and Expo
November 15-19, 2014
New Orleans, LA
***8 presentations from Sheps-affiliated researchers**

Primary Care Research Fellowship – The goal of this fellowship is to train primary care physicians for research-focused academic careers. This two to three year fellowship provides participants with the knowledge, skills, and experience to plan, fund, complete and disseminate quality research. The curriculum includes course work in the UNC School of Public Health, seminars in the campus' K-30 sponsored research curriculum, weekly works-in-progress seminars, in-depth hands-on involvement and leadership in research projects, and mentoring by clinical and research faculty. Housed within the Sheps Center, the program also receives support from the primary care clinical departments of the UNC School of Medicine. The program was recently funded for another 5 years.
Principal Investigator: Donald E. Pathman, MD, MPH
Funding Source: AHRQ,
National Research Service Award through the Bureau of Health Professions
Program Period: 07/01/98 – 06/30/14
(extended through 06/30/16)
Total Funding: $3,889,472
Type: Training

National Information System on Health Services Research (HSRProj) – HSRProj is a health services research information system that collects available information on ongoing research projects funded by both public and private sector agencies for the National Library of Medicine. Through HSRProj, individuals can access information about ongoing health services research projects before results are available in published form. This project has been expanded to support and enhance the information infrastructure for health services research represented by the HSRProj (Health Services Research in Progress) database: 1) to solicit, select, collect, review and edit descriptions of new and additional research projects from publicly available resources and from the wide variety of funders and producers of ongoing health services research projects already represented in HSRProj; 2) to maintain and enhance the quality of information in the HSRProj database, adding to the records links to publications that result from the funded research; and 3) to identify and implement changes and improvements to the database record structure and functionality.
Principal Investigator: Christiane Voisin, M.S.L.S.
Funding Source: National Library of Medicine, NIH via Academy Health and The Foundation for Health Services Research
Project Period: 05/01/04 – 09/14/17
(extended to 09/14/19)
Total Funding: $2,867,428
Type: Technical Assistance

Prevention/Care Management Technical Assistance Center (Master Task) – Note: This is a Master Task submission; there are no specific tasks for this master contract proposal. UNC Sheps shall furnish personnel, information and materials as reasonably necessary, and shall devote reasonable business efforts to assist AIR in developing and preparing sections of the PCM TAC RFTO Proposal(s) and any modifications thereto related to NCQA's relevant Scope of Work. • UNC Sheps shall work with AIR to determine whether or not to submit proposals to future RFTO bids. • UNC Sheps will work with AIR on any future work that warrants their area of expertise.
Principal Investigator: Russell Harris, MD, MPH
Funding Source: AHRQ via AIR
Project Period: 08/01/10 – 09/29/14
Total Funding: $0

Support of Transparency Efforts by the USPSTF –

The overall purpose of this task order is to support AHRQ's Prevention/Care Management (PCM) Portfolio by expanding transparency efforts of AHRQ in its role as supporter and convener of the USPSTF. Specific tasks supported by UNC Chapel Hill key and other personnel: Task 1. Administration, Task 2. Process Development, Task 3. Reviewing and Synthesizing Public Comments, Task 4. Communication, Task 5. Product Dissemination.
Principal Investigator: Russell Harris, MD, MPH
Funding Source: AHRQ via AIR
Project Period: 09/30/10 – 03/22/14
(extended through 06/30/16)
Total Funding: $829,316

Agency for Healthcare Research and Quality Measure Development Contract (QMDC) – Note: This is a Master Task submission; there are no specific tasks for this master contract proposal. This Scope of Work states that UNC shall furnish personnel, information and materials as reasonably necessary to successfully accomplish assigned RFTO tasks through contribution of analytic data capacity, measurement expertise, content expertise (e.g., in areas of needed clinical specialties, health services research, health economics, and other areas central to assigned RFTOs), and/or tool development. UNC will assist AIR and our other teamed subcontractors in building infrastructure for AHRQ to support work that connects research and data for purposes of developing and facilitating the use of evidence-based health care quality and efficiency measures. UNC shall work with AIR to determine whether or not to submit proposals to future RFTO bids and will work with AIR on any future work that warrants their areas of expertise. UNC's areas of expertise potentially utilized in RFTO bids include, but may not be limited to: improving the science of quality measurement through the application of rigorous methods of development, psychometric testing, and other analyses; innovating, expanding and integrating the range of data considered in quality measurement development, including capacity for data collection, storage, security, manipulation, and integration; and fostering and facilitating the use and adoption of quality measures developed under the AHRQ QM.D.C's RFTOs, including dissemination and knowledge transfer, communication strategies and materials development, trainings and/or webinars, stakeholder engagement and needs analysis, usability testing, and development of tools and products to meet the needs of end users.
Principal Investigator: Janet Freburger, PhD
Funding Source: AHRQ via AIR
Project Period: 08/15/11 -08/01/16
Total Funding: $0

Carolina Advance Health Evaluation – The purpose of these activities will be to provide technical assistance to TPN and the establishment and monitoring of CAH. 1) Planning and evaluation of patient satisfaction data. 2) Qualitative evaluation of organization and modification of CAH. 3) Assistance in quality of care evaluation.
Principal Investigator: Timothy S. Carey, MD, MPH
Funding Source: Triangle Physician Network, LLC
Project Period: 09/01/11 - 08/31/14
Total Funding: $141,709

Research, Measurement, Assessment, Design and Analysis (RMADA), Umbrella IDIQ – The Sheps Center investigators have teamed up with the American Institutes for Research and have won one of a limited number of spots to be a bidder for evaluation, implementation or technical support to the Centers for Medicare and Medicaid Services (CMS). The purpose of this MIDS Task Order (TO) is to support the CMS quality and payment programs/initiatives. The Master Task submission contains no specific tasks at this point, but future projects are anticipated.
Principal Investigator: Marisa Domino, PhD
Funding Source: CMS via AIR
Project Period: 04/01/14-03/31/19
Total Funding: $0

Measure & Instrument Development and Support (MIDS), Umbrella IDIQ – Note: This is a Master Task submission; there are no specific tasks for this master contract proposal. The purpose of this MIDS Task Order (TO) is to obtain services for the development, re-evaluation, and implementation of the Centers for Medicare and Medicaid Services (CMS) and support the CMS quality and payment programs/initiatives. The Sheps Center will contract with AIR in building infrastructure for CMS to support work to develop outcome, process, structural cost and composite quality measures suitable for endorsement by a consensus endorsement entity and reflective of quality care for healthcare settings. This contract also includes the identification or development of the data elements and items necessary to implement data collection for the proposed measures across the health care continuum, as well as the data collection vehicles. UNC-CH will work with AIR to determine whether or not to submit proposals to future RFTO bids, on any future work that warrants our area of expertise. UNC-CH's areas of expertise potentially utilized in RFTO bids include, but may not be limited to: environmental scan and empirical review to describe existing measures, uses and gaps; instrument/item Quality Measure development; and, data testing and validation.
Principal Investigator: Timothy S. Carey, MD, MPH
Funding Source: CMS via AIR
Project Period: 10/01/13 -09/30/18
Total Funding: $0

Dr. Tom Ricketts gives Defriese Lecture

Dr. Tom Ricketts delivered the Gordon H. DeFriese Lecture on April 1, 2015. His lecture, “So make me! Translating research into action,” covered the challenges and successes of research translation. The event was also a celebration of Dr. Ricketts’ career, as he retired from the University in the spring. More than 100 people attended the event, and the entire lecture can be seen on the Sheps YouTube Channel: