

G.2.7. Community Engagement: Moving the Community from Subject to Collaborative Partner

Numerous Duke entities have ongoing relationships with community groups, practitioners, public health organizations, social service agencies, community advocacy groups and faith-based communities at the local, regional, and national level in order to implement outreach activities, clinical services, and research endeavors. While many of the outreach and clinical services include the community in design and implementation, the majority of the research projects follow the standard academic model in which generation of research questions and the determination of methodologies is the responsibility of the researcher. Community members are recruited as “subjects” and of course, are the ultimate beneficiaries of the outcome, but the CTSA calls for a more innovative model - research that “effectively involves the community, both the public and practitioners, in clinical and translational research priority setting, participation, and follow-up.”

Through this application, Duke will create the Duke Center for Community Research (DCCR). One aspect of the DCCR will be to work with the Bioinformatics Group within the CTSI to establish an electronic health record (EHR) that can be used throughout Durham. The EHR component of the DCCR is described in the Introduction (Section G.1.3) and in this section of the application (Section 2.7.3). As another element of the DCCR, Section 2.7.2 will describe how the Center will leverage the talent of the academic research community to create a training and research system that will effectively and systematically involve the community in clinical and translational research training, priority setting, participation, and follow-up.

The DCCR will take advantage of existing programs that have established a symbiotic Duke-community research relationship, building capacity within the community to frame and undertake research, and at the same time building capacity within Duke to work cooperatively in effective, community-centered projects. This paradigm is based on the shared goal of improving the health of the community, and starts with the premise that working with and within communities is a more ambitious and difficult undertaking than securing “research subjects” from community settings. To make community-based research work, ideas must be vetted and tested in the context of proven relationships that have been built between the academic medical center and community members, organizations, and practitioners.

The members of DCCR understand that like most communities, Durham is complex, and approaches to working with community organizations, practitioners, and residents will vary with the setting and population. It is incumbent upon the academic medical center to not only have a full range of skills in community engagement, but also to have skills to help understand the bases, structures, relationships and history on which communities operate. Although Duke expects community-engaged research to be undertaken in Durham, we also anticipate that there will be community-engaged research occurring through the CTSI across the region, state, nation, and internationally.

But Duke’s work begins in Durham. The city of Durham is majority African-American, the County 40%, and Durham has a long tradition of African-American political and commercial power. At the same time, Durham is home to large concentrations of low-income African-Americans who face problematic disparities in morbidity and mortality from both communicable and chronic disease. Into this mix have come thousands of new Latino immigrants, making Durham one of the fastest growing Latino populations in the US, with an increase in the census of 729% between 1990 and 2000, and a projected increase in Latinos by the state of North Carolina by 44% from 2005 to 2009. Tensions between African-Americans and Latinos in Durham have improved in the last several years, but competition for housing and jobs remains high, and crime, including a high rate of both African-American and Latino gang violence, continues to be a problem. New immigrants from Africa, Asia, the Caribbean, and Eastern Europe are making their way into Durham, intensifying the demand for services and the need for better understanding of their health needs and beliefs. Clearly, sending well-intentioned researchers into the Durham community armed only with a course in cultural sensitivity will assure that they are met with suspicion and mistrust.

Fortunately, Duke has established solid and sustaining relationships with people and organizations throughout Durham and neighboring counties. These relationships can be built upon to assure that both the community and Duke are successful in improving the health of community residents.

G.2.7.1. Core Community-linked Research Programs

Duke is fortunate to have a number of programs that engage in community-oriented research, service, and education. The entities are all interdisciplinary and demonstrate Duke's excellence in a wide-range of areas that extend beyond the Medical Center. Duke believes that these entities, a sampling of which is listed below, represent the base, and their endeavors represent the initial framing necessary to build true community engagement into every aspect of a leading research enterprise. Using these resources, centers, and already functioning projects as a foundation, an enhanced program (the DCCR) focused on community engagement will be built.

G.2.7.1.1 Duke University School of Nursing

The mission of the Duke University School of Nursing (SON) is to create a center of excellence for the advancement of nursing science and scholarship, the education of advanced practitioners, and the development of systems for rapid entry of best practice and innovation into practices that serve community populations. DUSON's students, graduates, and faculty seek to enhance nursing care and influence the health care delivery system to be increasingly responsive to the health care needs of people of all cultures, economic levels, and geographic locations. In fulfilling this mission, the DUSON trains leaders at undergraduate, masters, and doctoral levels to care for, manage, and study individuals, families, and communities in ways that advance nursing science and ultimately improve care for individuals and groups across a variety of institutional and community-based settings. Examples of community initiatives include:

- Work to improving Latino access to health care in *El Centro Hispano* in Durham through studies of access issues for low income, newly immigrated Latinos and on issues related to timely use of infant immunizations.
- Examination of maternal-infant interaction and infant development in low income mothers from minority populations and among families with high risk preterm infants.
- Work with the *North Carolina Coalition against Domestic Violence* to improve outcomes among women who are suffering from symptoms of posttraumatic stress disorder resulting from intimate partner violence.
- Establishment of the *DUSON Long-Term Care Consortium*, a group of approximately 12 nursing homes across North Carolina that have agreed to partner with DUSON in quality improvement activities and research. The Consortium provides faculty strong sites for educating graduate students and developing interventions that address vexing gerontological nursing problems such as premature loss of function among older adults with cognitive impairment.
- Efforts to understand how family belief systems mediate decisions about health care-seeking behaviors through community-based research that aims to increase sustained participation by African Americans in free mass prostate cancer screening clinics in Durham.
- Work to test community-based interventions for a) informal caregivers of elderly individuals with progressive dementia, including Alzheimer's or Parkinson's disease and b) symptom management among persons with HIV-related fatigue.
- Efforts to link Information Systems (in- and out-patient) for larger multidisciplinary team follow-up that will allow nurses to examine nurse-sensitive indicators of outcomes, improve care quality and patient safety, and examine care transitions from the health system to the community.
- DUSON and Duke Hospital Nursing Services committed in 2005 to the development of a jointly governed Center (Center for Nursing Innovation, Care Excellence and Translation Science) to accelerate the cycle of knowledge development and translation that will improve health outcomes for patients along the hospital-clinic-home continuum.
- The initiation (in 2006) of a DUSON Center for the Development of Community Partnerships and Global Health Initiatives, led by the former dean of Howard University who was instrumental in the District of Columbia for care improvement activities in homeless shelters and prison communities.

G.2.7.1.2 The TRAC Center, School of Nursing

The School of Nursing's TRAC Center (Trajectories of Aging and Care) includes a cadre of nurse scientists who are collaborating with leading investigators from a variety of disciplines to conduct nurse-directed interdisciplinary studies. These research efforts examine longitudinal patterns of health, illness, function, and care in later life across diverse care contexts, including at home and within institutions. The Center has an NIH P20 Nursing Research Award (5P20NR007795-05) that supports investigations regarding aging and care.

G.2.7.1.3 Duke Comprehensive Cancer Center

The NIH-funded Duke Comprehensive Cancer Center conducts outreach, education and information dissemination activities at a local, state, and national level, with particular emphasis on inclusion of underserved populations.

- Maintains Tumor Registry database of more than 100,000 cancer patients and follows more than 26,000 active cancer patients worldwide who have been evaluated and treated at Duke since 1990. This allows the Center to identify specific audiences, including high risk populations, in order to provide targeted outreach.
- Serves 25 affiliate sites in six states, where almost 15,000 new cancer patients are seen and have access to the services offered by the Duke Oncology Network. The Cancer Center partners with hospitals and private practices throughout North Carolina and the Southeast by providing:
 - state-of-the-art research programs and education and training programs for community physicians, nurses, and other healthcare professionals.
 - new cancer education initiatives directed at patients in the communities.
 - patient access to clinical trials for a variety of new cancer treatments resulting in hundreds of patients in these communities enrolling each year in clinical trials.

G.2.7.1.4 Center for Clinical Health Policy Research

This center, lead by Dr. David Matchar, MD, evaluates scientific evidence in order to determine best clinical practice. A national leader in this domain, the Center has funding from the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention, and the NIH. The achievements of the Center for Clinical Health Policy Research (CCHPR) faculty are organized by three focus areas:

- Evidence synthesis,
- Clinical policy development, and
- Clinical practice improvement initiatives.

a. Evidence Synthesis: Evidence synthesis includes the comprehensive evaluation of scientific evidence, development of reports for clinical policy entities (e.g., practice organizations, professional societies), decision modeling and cost-effectiveness analysis (the latter two activities denoted as “disease modeling”). The core of Center activities in evidence synthesis is organized under the Evidence-based Practice Center (EPC), an official designation extended by the Agency for Healthcare Research and Quality (AHRQ), and includes projects commissioned by federal and non-federal agencies in support of clinical and public policy decision making. In addition to traditional EPC responsibilities, the Duke EPC has been charged with working with the Centers for Medicare and Medicaid Services (CMS) Technology Assessment Group in efforts related to coverage and reimbursement decisions.

The Center was recently designated as a DEClIDE Network Team (\$1.5 million for the first two years). Through funding from CMS and administered by AHRQ, the DEClIDE initiative supports CMS in responding to the Modernization Act, especially the mandate to optimize the Part D pharmacy benefit.

Disease modeling efforts, in support of informed policy and clinical decision-making, have proceeded apace, including models of stroke, multiple sclerosis, Alzheimer's Disease, migraine, chronic kidney disease,

and replacement/retention of devices under recall. We have had planning meetings of individuals on campus with interest and experience in model development.

b. Clinical Policy Development: Clinical policies are typically developed by entities such as professional societies, clinical practice organizations, and insurers. These policies are intended to apply to groups of providers and classes of patients, and represent a vehicle for translating best evidence into actionable recommendations. In addition to our work with CMS, we have collaborated with the American College of Chest Physicians, the Renal Physicians Association, the Carotid Stent Consortium (consisting of eight professional societies), the Institute of Medicine, the National Center for Quality Assurance, and the American College of Physicians.

c. Practice Improvement Initiatives: Implementation of evidence-based recommendations is where the “rubber meets the road” for clinical health policy. The Center has major ongoing efforts in stroke, anticoagulation management, migraine, hypertension, diabetic eye disease, and chronic kidney disease. Notable expansion of this work by Center faculty relates to two areas. The first area is international health care quality improvement including the MANAGE project, an initiative designed by Center researchers to evaluate and improve the care of individuals with coronary artery disease in Central India, and the WHO Blood Pressure Measurement Project, to develop, distribute, and evaluate a practical and accurate device to measure and manage hypertension in low resource settings. The second area is an initiative to link clinical practice improvement research by Duke faculty to Duke clinical practices. This involves a collaboration between clinical administrators and clinical researchers. A proposed flagship project is in the domain of improving the care of individuals with advanced chronic kidney disease.

G.2.7.1.5 Center for Clinical and Genetic Economics

This center, a component of DCRI, was established in 1999 to evaluate issues at the interface of economics and medicine. The Center is led by Kevin Schulman, MD, who is a professor of Medicine and Business Administration, and works at both DCRI and at Duke’s Fuqua School of Business. Issues recently addressed by the center include:

- Studies of the economic implications of medical practice and reimbursement policies.
- Collection and analysis of cost and quality-of-life data in clinical trials.
- Studies regarding physician and patient decision making, including conducting health services research in such areas as access to care, physician payment, and the ethics of managed care.
- Studies of the economic and policy implications of recent advances in genetics, genomics, and gene therapy.

G.2.7.1.6 Terry Sanford Institute of Public Policy: Center for Health Policy, Law, and Management

The Sanford Institute for Public Policy is an inter-disciplinary Duke University initiative that brings together faculty from many academic traditions in order to understand and transform public policies. It’s director, Frank Sloan, is an internationally known scholar in mental health care economics. The Center for Health Policy has as its mission to:

- stimulate and facilitate collaborative interdisciplinary research by faculty and students at Duke in Health Policy, drawing in particular on expertise in the social sciences, law and management,
- disseminate research findings on health policy to persons who make health policy decisions, and
- provide a rich array of educational opportunities for undergraduate and graduate students seeking careers in health policymaking, research and analysis.

Issues regarding health inequalities are a particular research focus of the Center.

The Institute offers undergraduate and graduate certificates in Health Policy.

G.2.7.1.7 The Duke Primary Care Research Consortium

The Duke Primary Care Research Consortium (Duke PCRC) is a network of primary care providers who work together to enroll patients in clinical research studies. The Consortium involves 25 practices with 29 sites located in 8 counties of the Piedmont area of North Carolina (urban and rural). The clinics are made up of Duke University Health System primary care practices, the Ambulatory Care Service of the Durham VA Medical Center, and independent community practices with a total of 192 providers (69 Family Medicine, 61 Internal Medicine, 28 Pediatrics, 5 Medicine-Pediatrics, and 29 physician extenders, not including residents in training) who care for an estimated 211,000 patients. Since its inception in 1997, the Consortium has enrolled more than 3000 subjects and conducted greater than 50 trials. The goals of the PCRC are:

- To perform clinical studies that will improve health care delivery and patient outcomes.
- To provides educational opportunities for clinicians to maintain their clinical skills and develop new research skills
- To offers clinicians support through a central administrative office and trained study coordinators enabling them to participate in primary care research.
- To generate research to support the practice of evidence-based medicine.

The Primary Care Consortium began as a component of the DCRI in order to improve its ability to enroll patients in the regional community, but while it began within DCRI, it has developed an independent life. Its operating model consists of a group of dedicated research nurses trained by the network office. PCRC project managers ensure that study milestones are completed according to timelines, and the PCRC coordinates research-related contracts and financial services for the network practices. Use of this model ensures quality data collection, enhances the allocation of site personnel, and protects sites from fiscal responsibility for a full-time study coordinator position.

In the new Duke CTSI, the PCRC will continue to be administratively housed in the DCRI, but there will be training of staff and attempts to integrate into the community coordinated through the DCCR. In addition, the Primary Care Consortium will work closely with the Duke CRU to move studies that can be moved outside the walls of the on-campus CRU.

G.2.7.1.8 The Great Smokey Mountain Study

The Great Smoky Mountains Study (GSMS) is a longitudinal, population-based community survey of children and adolescents in North Carolina. The study is part of a collaborative effort between Duke University and the North Carolina State Division of Developmental Disabilities, Mental Health, and Substance Abuse Services. It began in 1992 and will continue until 2010 with funding provided by NIDA (2R01DA011301-06A1). Some of the goals of the study are to estimate the number of youth with emotional and behavioral disorders, the persistence of those disorders over time, the need for and use of services for emotional and behavioral disorders, and the possible risk factors for developing emotional and behavioral disorders. The participants in GSMS include 1,420 children aged 9 through 13 when first assessed in 1993, and their parents, from 11 counties in western North Carolina. These counties include both urban and rural areas, and every agency in the area that provides child mental health services are included in the study. This area is also home to a fairly large American Indian population, and 25% of the youth in the study are enrolled members of the Eastern Band of the Cherokee Nation. These youth represent a population that has been under-represented in mental health research across the country.

The GSMS has provided policy-relevant information in the areas of: 1) need for mental health services, 2) risks for emotional and behavioral disorders, 3) outcomes of serious emotional disorders, 4) use of mental health services across sectors, and 5) effectiveness of mental health services among cohorts.

G.2.7.1.9 Epidemiology of Dementia in Cache County, Utah

Established in 1994, the Cache County Study is a population-based longitudinal investigation of dementia in relation to genetic and environmental antecedents that has been funded by the National Institute on Aging (5R01AG011380-12). Kathleen Welsh-Bohmer is the PI. As of 2005, there are four major specific aims of the project, which are as follows: 1. Conduct two more triennial waves of screening (Waves 3 and 4) among Cache County residents not demented at prior screenings. Use the nine years of observation to

examine the trajectory of cognitive change to dementia and to obtain more precise estimates of the incidence of Alzheimer's disease, especially after age 85. 2. Use an expanded cognitive screening battery for proposed Waves 3 and 4. Examine the efficiency of the new battery as a screen for dementia. Also, use the resulting expanded information base to extend existing data on trajectory of cognitive functioning to a nine-year time interval. With this new information, examine: a) Individual (cross sectional) features of cognitive dysfunction, or clusters of such features, that most strongly predict subsequent development of dementia; b) Nature and extent of change in such features or their clusters over time, including specifically a search for changes that most strongly predict the development of dementia; c) Various operationally defined categories of cognitive impairment (e.g., "Mild Cognitive Impairment" [MCI], etc.) and compare their abilities to predict subsequent dementia. 3. Extend prior studies of the influence of genetic and environmental factors on risk of AD, noting whether these same factors predict trajectory of cognitive decline as a prodrome of AD. 4. Continue and extend the study's existing autopsy program, expanding its aims to clinically diagnosed dementia subtypes and to unaffected participants, particularly those with risk factors for dementia (age 85+, MCI).

G.2.7.1.10 The Department of Community and Family Medicine

The Department of Community and Family Medicine has taken a leadership role in developing programs to improve the health of communities and is a diverse collection of educational, research, and clinical programs which are united in seeking ways to improve the health of the members of our communities. The Divisions of the Department include:

Community Health: The Division was created in 1998 to build a bridge between Duke and the communities it serves by addressing health disparities in Durham and in communities across North and South Carolina. The Division operates more than 20 programs, ranging from school-based clinics in schools where more than 90% of students qualify for free lunch; to a multi-agency, multi-disciplinary team providing in-home primary care, nutrition, occupational therapy and case management for elderly residents of Durham public housing projects; to distance learning programs for informal family caregivers of patients with chronic disease and/or disability. While the programs of DCH, (summarized below) are service and educational programs they demonstrate the core concepts of collaboration that will be required of clinical and translational research that engages community members, practitioners, and organizations and builds trust in the research enterprise.

The Programs of DCH include:

- Two neighborhood clinics designed and implemented in partnership with Durham's Lincoln Community Health Center and local faith-based communities providing an anticipated 10,000 patient visits with a payer mix of 80% uninsured and 15-20% Medicaid, serving largely African-American and Latino patients.
- Four School-Based Health Clinics (1 Durham high school and 3 Durham elementary schools) serving more than 3,000 students, more than 70% of whom are African-American and 8% to 20% Latino. A high proportion of the students are economically disadvantaged.
- In-home clinical services designed and implemented in partnership with Durham's Federally Qualified Health Center (Lincoln Community Health Center), the Durham County Department of Social Services, the Durham County Mental Health Agency, and the Durham City Housing Authority, that employs an interdisciplinary, inter-agency team to deliver primary care, nutritional counseling, occupational therapy, and case management services in 10 low-income senior housing sites in Durham. All of these services are provided in patients' apartments. The client population consists of almost 400 indigent, medically fragile, medically complex patients, 84% of whom are African-American.
- Two care management programs serving 36,000 Medicaid beneficiaries, over two-thirds African American, with a fast-growing Latino sub-population, across five counties (Durham, which is urban, and 4 rural counties north of Durham) in partnership with 33 physician practices, 3 hospitals, county health departments, social service departments, and Durham's Federally Qualified Health Center. In Durham, services are delivered in patient homes, where a Duke-led multi-agency team offers health education, service support, disease management coaching, translation, and advocacy in English or in Spanish. In the rural northern counties, where driving distance is a factor, a multi-disciplinary team operates out of local practices and health departments and conducts home visits. The Network operates through a

web-based patient information system (COACH: Community-Oriented Approach to Community Health Care, described below in Section G.2.7.4)

- A Care Management Program for the uninsured in Durham County in partnership with the local Latino self-help organization, Durham's FQHC, the county Health Department and Department of Social Services and local health, social service, and faith-based organizations. The program provides patient navigation, patient education, advocacy, and chronic disease education to 7,161 patients, 98% of whom are Latino.
- Technical Assistance and operational management for three chronic disease health promotion/disease prevention intervention programs supporting multi-agency, community inclusive coalitions in 56 counties in North Carolina and 3 counties in South Carolina. Coalitions include health agencies, hospitals, private practices, faith groups, school systems, and local programs like United Way and Cooperative Extension. These coalitions serve 300,000 people across the two states.
- Graduate level, fellowship, external and internal faculty development, and service-learning programs that focus on the principles and practice of community health and health care leadership development.

All of the DCH programs share key characteristics:

- Community needs and stakeholders determine the services to be developed.
- Programs are overseen by steering committees composed of community stakeholders/partner organizations and DCH faculty and staff.
- Programs focus on populations plagued by health disparities.
- Programs are designed to be financial sustainable; grant funds are used to finance research, development, and evaluation, but not to sustain the services provided.
- Programs are rigorously evaluated, but are not posited as traditional research.
- Innovative models of care delivery, not experimental medical care, are offered, again a key element in gaining community trust.

By 2004, the Division of Community Health believed that this history of collaboration and community service had built a foundation of trust that would support an integrative model for community-based participatory research and is currently administering a three-year community-based participatory research planning grant, funded by the National Center for Minority Health and Health Disparities. The R24 grant (1 R24 MD001655-01,) "The African- American Health Improvement Project", is led by a senior faculty member in Duke's Terry Sanford Institute for Public Policy, supported by a research team from Community Health, and is developing a pilot to be expanded to improve the of working and middle class diabetic African-American residents of Durham. This community-based participatory research initiative is another key step in building a solid platform for enhancing the community's trust in participating in research.

Whether emanating from strong traditional academic research principles or addressing clinical service needs, all of the aforementioned community-focused activities demonstrate the tremendous potential Duke has to build collaborative clinical and translational community-based research, and to educate a new generation of researchers of community-based researchers. Through DCCR, Duke will harness this power, marrying rigorous research with relationship-building and collaborative processes that are inclusive and respectful of the community, both the public and practitioners, to enhance public trust and participation in clinical and translational research.

G.2.7.1.11 Occupational and Environmental Medicine (OEM)

- Conducts multidisciplinary clinical and epidemiological research involving occupational medicine, mental health, occupational injuries, occupational diseases, toxicology, indoor air quality, and biohazard sciences.
- Provides toxicological assessments of consumer and commercial products necessary to comply with labeling and worker hazard communication laws.

G.2.7.1.12 Division of Clinical Informatics

- Draws from the disciplines of clinical medicine, computer science, and information science.
- Develops and evaluates computer applications to collect, process, and represent medical data including a cross-institutional core health information and communication system, known as the Community-Oriented Approach to Coordinated Health Care (COACH) (described in Section G.2.7.4).
- Creates computer-based tools to improve the quality and cost-effectiveness of health care delivery through electronic health record systems, decision support systems, hospital information systems, community-based information networks, standards development, security, confidentiality and privacy practices, and medical data mining.
- Facilitates collaboration in medical informatics across Duke Medical Center.

Prevention Research (*A joint program of CFM and Duke's Comprehensive Cancer Center*)

- Conducts epidemiologic studies of disease risk, with a particular focus on cancer research.
- Designs and implements interventions to prevent disease.
- Develops communication strategies for educating high-risk patients and their families about genetics and disease risk.
- Researches issues of obesity, diabetes, heart disease, and menopause – conditions that may have overlapping risk factors with cancer.
- Utilizes multi-disciplinary research teams consisting of epidemiologists, psychologists, statisticians, clinicians, and nutritionists to address the heterogeneous and multi-factorial aspects of disease and prevention.

Chronic Disease Epidemiology

- Integrates research programs in chronic disease epidemiology, family medicine research, and public health research.
- Conducts research on the epidemiology of obesity and aging-related illnesses with projects based on national data as well as observational and intervention studies in Durham and elsewhere in North Carolina.
- Facilitates extensive international research collaborations.
- Supports research in the family medicine clinics involving interventions to improve health-related quality of life, severity of illness, patient satisfaction, and utilization of health services.

G.2.7.2 The Community as a Collaborative Partner: DCCR in Durham

The purpose of the DCCR is to assure effective, well-formulated, timely research into the health issues confronting patients and their communities through the creation of a two-way highway that trains, translates, and, most importantly, builds confidence, trust, and participation in the research enterprise.

G.2.7.2.1 DCCR: Community Participation in Governance

As the interactive arm between Duke and the communities it serves, DCCR is designed to be accountable to both. DCCR's Director and Associate Director will be members of the faculty with longstanding and successful involvement in community engagement, reporting to the director of the Duke CTSI. Duke will also establish a DCCR Community Research Advisory Board with representation from community members, community service programs, both non-profit and governmental, as well as local business, civic, and advocacy organizations to provide a community voice for researchers to consider in formulating ideas for research, as well as serving as a sounding board for appropriate approaches to communities and populations. The DCCR Community Advisory Board will be limited to 15 members with three year, staggered appointments, to assure continuity. The Board will have a President, Vice President, and Secretary, and will meet monthly. The Board will also serve as an advisory arm to the Duke Institutional Review Board to offer advice on research proposals

to be conducted in and for the community. The Community Advisory Board will be staffed by the Director and Associate Director of DCCR and their staff.

G.2.7.2.2 DCCR Programs

Two major units will report to the Director and Associate Director of DCCR: the **Community Health Research Training Center** and the **Community Research Liaison Center**.

- The **Community Health Research Training Center** will be the education and training resource, as well as the community-related compliance entity, for Duke faculty and trainees contemplating research in community settings or population-based research.
- The **Community Research Liaison Center** will be the Community's resource, where agencies, organizations and residents can avail themselves of formal training so as to better understand research, receive research coaching, better define their concerns, and seek researchers with whom they can work. The Community Research Liaison Center will include a virtual library available to both researchers and members of the community, helping both to better understand the nature of the populations and communities to be studied, and relevant community-centered research and best practices at Duke and elsewhere.

a. DCCR Community Health Research Training Center: Under the oversight of a faculty Director, this Center will have two major functions: it will serve as the training and compliance center for any faculty or trainees interested in undertaking research in community settings or population-based research, and it will serve as the educational arm of the DCCR to educate faculty and trainees to work effectively and appropriately in community settings.

Training/Compliance/Community Service: Since 2002, Duke University Medical Center has required formal privileges in Community Health as a clinical domain for faculty who wish to design community-based programs. For faculty not eligible for privileges, Community Health has developed on-line modules with a graded post-test that teach faculty and trainees the fundamentals of developing collaborative working relationships with community organizations and residents, essential elements of medical screenings, and a specific module on working with the Durham community. Since 2002, 567 faculty, staff, and trainees have completed and passed the basic training module. The Medical Center formally tied successful completion of the module, as well as formal community health event approval, to institutional approval and event malpractice coverage.

To train and provide community benefit service opportunities for trainees, Duke Community Health created **Learning Together**. Since 2005, Learning Together has taught community engagement skills and principles to 522 trainees from multiple Medical Center and University disciplines. Trainees come through a unified web portal to select community programs operated by Duke or its multiple Durham partner organizations, and choose those that mesh with their interests and schedules. All trainees must complete and pass online module(s), and attend a workshop on community engagement, as delineated above. The existing staff work collaboratively with local partners and Duke programs requesting health trainees, supervise project work, connect with supervising faculty from the trainee's program, and offer volunteer internships. This service program has been operating with 1.5 FTE professional staff and part-time faculty oversight, serving a population comprised largely of medical students and nursing students.

With CTSI we will greatly increase the number of researchers and trainees wishing to undertake community-based research, and therefore, will add a full-time Program Manager for Compliance Training and Regulatory Issues to assure that faculty and trainees receive:

- Formal credentialing review for submission to the Duke University Hospital Credentialing Committee;
- Technical assistance to support those taking the on-line modules;
- Formal community health event approval;
- Workshops on community engagement in Durham, as well as in surrounding counties;
- Cultural competency training, in coordination with the University's Office of Institutional Equity;

Principal Investigator/Program Director (Last, First, Middle): Califf, Robert

- Community service and service-learning opportunities to enrich the trainees' understanding of community dynamics.

While the Program Manager will be housed in the DCCR Community Health Research Training Center and will possess specialized knowledge of community engagement practices, they will interface with CTSI Regulatory Affairs, Duke's IRB, and all of Duke's Compliance Groups.

Education/Training: Since 2000, Duke Community Health has trained clinicians in successful community program development and community engagement through coursework within its **Master of Health Sciences in Clinical Leadership**, granted through the School of Medicine. This two-year program for practicing clinicians from multiple disciplines provides coursework and academic oversight through 4 Duke Schools and the Sanford Public Policy Institute. Along with courses that include health law, management operations, strategy, informatics, and finance, are courses and seminars that train clinicians to understand community dynamics and community change, and to work effectively within communities.

In 2004, Duke Community Health launched its **Health Leadership Program**, a certificate training program in community health for academic medical center faculty and their local partners from across the US. The program offers practical, didactic and experiential learning for health professionals on how to approach community partners, form viable community coalitions, work with public data sets, conduct community-based participatory research, prepare community health program evaluations, plan and conduct sustainable disease prevention/reduction programs, recognize and engage the community in health disparities reduction/elimination strategies, provide community-responsive service learning, and develop partner resources to contribute to the enterprise. These educational programs have operated with one faculty FTE, using contributed faculty time to make the programs viable.

Creating a formal learning laboratory with multiple, ongoing training programs for the projected volume of CTSI faculty and trainees will require a faculty director to oversee and teach in the Community Health Research Training Center, and a faculty member to train researchers, and a faculty member to teach the burgeoning number of trainees, through classes, seminars, workshops, and community experiences. These faculty and staff will also oversee the fourth year medical student elective in Community Health, as well as third year medical student year-long mentoring of research projects. [The Duke University School of Medicine has an atypical curriculum in which students do one year of basic science, one year of clinical rotations, one year of research, and one year of electives.]

b. Community Research Liaison Center: Part of the core mission of DCCR is to make community residents and their local non-profits and governmental organizations full partners in the research enterprise. This means much more than simply connecting researchers and community members, organizations, and practitioners. True engagement will require that the DCCR reaches out to the community, provides training for the community, and serves as an effective advocate for the community when working with researchers.

The Community Research Liaison Center will be overseen by a faculty Director and will employ three Masters' prepared project leaders to reach deeply into NC's communities to develop the crucial relationships necessary to engage, and to help local organizations frame their research questions. These Translational Project Facilitators will serve as advisors and guides between an interested community group or organization and the CTSI at Duke. They will deliver both print and on-line materials to share with community groups, outlining the resources available and providing practical guidance on what community members can expect when engaging with CTSI. Their interaction with local agencies and organizations will follow best practices in community engagement, providing the kind of training the community requests, in the community, at times that convenient to the groups seeking to engage. We anticipate this will include coaching for community groups and coaching for local practitioners as well as training sessions, lunch and learn sessions and workshops in such areas as identifying their research issues, forming a research agenda, and in developing working relationships with researchers.

The Community Research Liaison Center will therefore provide a series of services not currently available in any formal context through Duke, including but not limited to:

- Seminars developed for community members by the faculty Director and staff of the Community Research Liaison Center, describing the elements of research, its language and ethical boundaries,

research funding and its priorities, the role of the researcher and issues that affect researchers' interest in particular subjects, and critical tips for working successfully with researchers and trainees. These seminars will be delivered at community sites on a regular basis, and as requested. Accommodation will be made to offer the seminars when community members are available. Seminars can be delivered in English and in Spanish and will include education on:

- The language of research, to enable community groups to interpret researchers' requests and to enable them to critically examine and support the research;
- The ethics under which researchers are bound, and how that affects their capacity to structure their work;
- The rights of research subjects;
- The limitations of research, to help community members deal with difficult questions such as why research subjects from the same community may be divided into intervention and control groups, or why an intervention may not be able to continue following completion of the research;
- The IRB process and its associated accountabilities;
- Academic freedom and issues concerning publication and authoring;
- Web-based modules for community members, on engagement with researchers and connections to the Community Research Liaison Center, in English and in Spanish.
- Assistance locating potential researchers with whom to discuss their interests and needs.

In addition, the Center will provide access to a virtual library, available to both researchers and members of the community, helping both to better understand the nature of the populations and communities to be studied, and relevant community-centered research and best practices at Duke and throughout the US and the world. The Virtual Library will maintain listings that include:

- best community-engaged practices and research, culled from national and state agencies and reputable awardees;
- a compendium of available national, state and local resource organizations that can offer guidance and effective practice of community-engaged research to assist community members and researchers.
- a local agency database on Durham service organizations, including their service listings and limitations, and contact information;
- a regularly updated listing of validated population research methods.

An out stationed Community Research Librarian will assist community groups to seek data, published studies and best practices, and to work with researchers to use the CTSI virtual library effectively. We anticipate a high level of interest in the library, but also a need for assistance to locate appropriate resources and to deal with large public databases so important to community health planning to improve health.

The Community Resource Liaison Center will also inform communities, both the public and providers, about the DCCR, invite those communities to participate and will present relevant research findings. In addition to using existing print materials such as DukeMed Magazine (cir. 56,000 health professionals, referring physicians, and members of the general public), DukeHealthLine (cir. 97,000 health professionals and members of the general community in Durham and surrounding areas), the Community Research Liaison Center will utilize local and regional news media sources, and, with CTSI and DCCR Community Advisory Board leadership, create a website available to the public that offers a broad range of information on all aspects of DCCR and that serves as a portal to the DCCR.

The Community Research Liaison Center will be housed in a community setting, and the Project Facilitators and Librarian will be expected to travel to interested communities and practices for most engagements.

G.2.7.3 DCCR and the Electronic Health Record

As described in Section G.2.3 (Biomedical Informatics), the Duke University Health System will be implementing an electronic health record system. The design and roll-out of this system will take several years, although the design process is currently underway as a partnership with McKesson. If appropriate waivers can be obtained (to avoid Stark anti-kickback rules), the Health System intends to offer the ambulatory health record system to local health care practices at a minimal cost. The primary reason for this arrangement is to allow Duke to obtain county-wide healthcare information, to better monitor and understand the impact of health-related strategies on status of Durham's citizens.

In order for the system to be accepted in the community, several objectives will need to be clear. First, Duke will not use the data for marketing purposes. Practices will be able to strip practice-specific identifiers from what Duke staff are allowed to see, while retaining those identifiers so the practice can use the information to monitor their own patients. Second, a committee of community physicians and practice managers will be created to establish rules regarding access to data and to monitor adherence to those rules. Third, outreach to the Community will be critical so that this broadly based system is not misunderstood.

For the practitioners, this system should be very powerful. The Community Liaison Research Center staff will help interested physicians and community members query information in the Decision Support Repository. For example, if a physician thought he was seeing an outbreak of fever with shaking chills, he or she could query the Repository regarding the current incidence of influenza or other febrile syndromes. As another example, they could scan their own practice to see how many patients had been diagnosed with tuberculosis, or lung cancer, or any other disease with an ICD9 designation, over a fixed period of time.

The more powerful the tools are that Duke can offer, the more likely practices will be to contribute their data to the county-wide data set. Community practitioner input will be sought in the design process. Another benefit will be expedited access to clinical information and recommendations for those patients seen in the Duke Health System. Referral patients' Duke records should be visible to the practices in real time. In addition the patient experience will also be improved by having routine data entered once and shared across sites. Problem lists will be held in common, and disease registries auto-updated.

Durham County, like most of the US, and all of the Southeast is plagued by morbidity and mortality rates that are higher than many other economically advanced countries and dominated by vascular disease (coronary disease, stroke and heart failure), depression, drug abuse and respiratory illness (chronic obstructive lung disease and asthma) and diabetes and obesity. In this electronic health record system providers from nurses in schools and Medicaid funded home visiting nurses to nurse practitioners in primary care clinics to specialists in clinics and hospitals will have common access to records of quality measures identified by the US Public Health Service guidelines and key specialty societies. Reminders about scheduled preventive and treatment activities will be shared and medications and procedures will be kept in a commonly accessible format to reduce errors and unnecessary redundancy. For patients with interest and ability, self management will be encouraged. On this substrate, hard wired into the fabric of the health care system, we plan to systematically overlay informatics that will integrate predictive information from our evolving clinical and molecular models to enable improved personal and system decision making.

G.2.7.4 Community-Oriented Approach to Coordinated Health Care (COACH)

Dr. Lobach and colleagues are currently conducting a three-year project that uses health information technology (HIT) to promote the translation of evidence-based practice standards in an established community-wide network of facilities. A clinical network of service providers was created in 1998 as a jointly funded federal and state demonstration project (HCFA Section 1915B) to support community-based care management for Medicaid beneficiaries in Durham County known as the Durham Community Health Network (DCHN). This network is composed of eight primary care clinics, including a federally qualified health center; two government agencies; two hospitals; and three urgent care sites. It encompasses all of the major healthcare organizations providing services to the majority of non-institutionalized Medicaid enrollees in Durham County (G.2.7 Table 1) and has a total active program enrollment of 16,673 Medicaid patients.

G.2.7 Table 1: Community Partner Organizations Participating in the Clinical Network			
Organization Type	Partner Organization	Clinical Site	# CAII Patients
Hospitals	Duke University Hospital (DUH)	Inpatient Wards Emergency Department	n/a
	Durham Regional Hospital (DRH)	Inpatient Wards Emergency Department	n/a
Clinics	Duke Primary Care Clinics	Family Medicine	2,339
		Pediatrics	4,307
		Adult Outpatient Clinic	1,287
		Ob-Gyn	446
	Duke Affiliated Primary Care Practices	Durham Pediatrics	733
	Private Primary Care Clinics	Regional Pediatrics	733
		Central Family Practice	278
	Lincoln Community Health Center (LCHC)	Lincoln Health Center	6,550
Duke Specialty Care Clinics	Duke Clinic	n/a	
Urgent Care Facilities	Duke Urgent Care	Duke North	n/a
		Duke South	n/a
	Lincoln Community Health Center (LCHC)	Lincoln Health Center	n/a
Government Agencies	Durham County Health Department (DCHD)	Health Department	n/a
	Durham County Department of Social Services (DSS)	n/a	n/a
	NC Medicaid	n/a	n/a
Community Organizations	Durham Community Health Network (DCHN)	n/a	n/a

This project is based on a cross-institutional core health information and communication system, known as the Community-Oriented Approach to Coordinated Health Care (COACH), to share information electronically among care providers for Medicaid beneficiaries that bridges institutional boundaries.[Proceedings: AMIA Annual Fall Symposium 2001; 398-402] COACH provides a shared data repository for all the partner organizations participating in the care management of CAII enrollees. Basic demographic and eligibility data for CAII enrollees are uploaded to the system from the North Carolina Office of Rural Health, and data transfer protocols are in place to import clinical data from partner sites. The types of data collected by the system are listed in G.2.7 Table 2. These data are displayed in nine record sections as shown in Figure aa. In addition, data on health risks and barriers to care are being collected directly from Medicaid patients through data collection kiosks developed by Dr. Lobach and colleagues that adapt the human-computer interface to accommodate the native language, reading literacy and computer skills of the user.[Proceedings: AMIA Annual Fall Symposium 2003; 391-395, Medinfo 2004; 1142-1146]

G.2.7 Table 2: Information Collected in COACH

Administrative	Care Management	Clinical	Communication
Demographic Services used Encounter tracking Provider associations Audit trails Billing data	Health risk assessment Utilization risk assessment Services required Environmental factors Socio-economic data Home assessment Special needs (e.g. transport) Care management plans	Problems/procedures Medications Allergies Laboratory results	Messages Referrals Notices of new information Health triggers

This project also relies upon a flexible, system-independent decision support tool created by Dr. Lobach and his colleagues known as SEBASTIAN (an acronym for System for Evidence-Based Advice through Simultaneous Transaction or an Intelligent Agent across a Network) (R01 HS10472) to encourage the use of evidence- [Proceedings: AMIA annual Fall Symposium In Press]

G.2.7.5 Use of Clinical Decision Support to Promote Translation of Research into Community Practice

Over the next five years Duke, will build upon its initial efforts using clinical decision support tools (see Section G.2.1013) to promote further translation of evidence-based practices into Durham County, NC. This approach will entail the creation of a computer-based knowledge resource that facilitates general access to “actionable” evidence-based care standards using the existing SEBASTIAN decision support infrastructure. Additionally, SEBASTIAN functions as a “black box” for decision support in that the knowledge representation and decision processing functions are hidden from the end users. One of the “services” SEBASTIAN offers is a detailed description of decision rules contained in its knowledge base Through this design, SEBASTIAN can function as a centralized, shared decision support resource that is independent of any one specific application.

In order to support the translation of research from clinical trials to routine clinical use in Durham County, validated research findings will be encoded into the SEBASTIAN knowledge base. The availability of new knowledge will be advertised to the community-based practitioners who are participating in the Durham County Healthcare Collaborative that was created to promote the diffusion of research into practice. The practitioner’s receiving system can then use the recommendation content as appropriate for the context of that clinical record system.