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January 15, 2010

Marlene H. Dortch, Secretary
Office of the Secretary
Federal Communications Commission
445 12th Street, S.W.
Washington, D.C. 20554

FILED/ACCEPTED

JAN 15 2010

Federal Communications Commission
Office of the Secretary

RE: NBP Public Notice #17
GN Docket Nos. 09-47, 09-51, 09-137
WC Docket No. 02-60

Dear Ms. Dortch:

Intel respectfully submits two copies reflecting ex parte comments in response to the FCC's request for comments on health care delivery elements of the National Broadband Plan. The two documents describe the University of Virginia's NIH grant applications to conduct telehealth and remote patient monitoring studies in Central and Southwest Virginia.

If I can answer any questions regarding these documents or other matters, please do not hesitate to contact me.

Sincerely,

Alice Borrelli

Alice Borrelli
Director
Global Healthcare and Workforce Policy
Intel Corporation
202-626-4393

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COMMONWEALTH of VIRGINIA

Department for the Aging

Linda L. Nablo, Commissioner

November 24, 2009

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JAN 15 2010

Federal Communications Commission
Office of the Secretary

Dr. Carol Manning
Associate Professor of Neurology and Nursing
Department of Neurology
University of Virginia
PO Box 800394
Charlottesville, VA 22908-0394.

Dear Dr. Manning:

As Commissioner of the Department for the Aging for the Commonwealth of Virginia, I fully support the University of Virginia's (UVA) and JABA's proposal to expand the use of telemedicine in rural communities and low income public housing sites in Charlottesville. The funding requested will be a wonderful addition to the work JABA is beginning with home tele-monitoring in Nelson County, in collaboration with UVA, as part of the Administration on Aging's 2009 Community Living Program. This funding request will allow such services to be expanded to serve seniors who are more able to participate in community activities at JABA's Community Center and at the Ryan School Apartments. With this funding, services will also be more readily available to residents of Mountainside Senior Living, an assisted living facility managed by JABA and multiple community housing sites in Charlottesville.

In spite of having a renowned tertiary medical center in Charlottesville, seniors in rural and urban communities are often reluctant to venture into the large and confusing maze of teaching hospitals. As a result, those with chronic medical conditions often do not seek or receive the ongoing, regular care they need to better manage their health. Failure to do so can result in rapidly deteriorating conditions that often require emergency room visits or hospitalizations to restore stability to the seniors' health. This is a costly use of precious resources.

Providing health monitoring in the community, where seniors gather and live can alleviate the delays in quick attention to readily manageable situations.

I look forward to seeing the results of this project, as it will serve as a model for so many Virginia communities.

Sincerely,

Linda Nablo

Linda Nablo
Commissioner, Virginia Department for the Aging

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Virginia department for the Aging

I. BACKGROUND & PRELIMINARY STUDIES

A. Broad Goals: The Coalfields region of far Southwest Virginia (SWVA) is a uniformly rural area in the heart of Central Appalachia. It is a region of well-documented, longstanding geographic health disparities with significantly higher disease morbidity and mortality rates when compared to Virginia and the United States. (VDH, 2006; Behringer et al., 2007; McGarvey et al., 2009) To address these disparities, we propose the development and dissemination of a community-based participatory research (CBPR) infrastructure -- **the Healthy Appalachia Community-University Research Network** (Healthy Appalachia CURN) -- to facilitate health sciences research supported by the region's extensive telehealth network. This network will provide a venue through which community-academic health center partnerships can support interdisciplinary research designed to reduce the burden of disease by improving access to care, health promotion, professional education and clinical studies. The proposed project will create an organizational structure (see Approach) that provides for an innovative community-academic health center interface that collaboratively develops research standards and questions that target specific regional health issues. Using these standards and questions, translational research opportunities, grounded in community relationships, will be advanced using the region's extensive distributed health networks and telehealth capabilities. **This culturally sensitive, community-based model will be applicable to other regions and widely disseminated throughout the 13 states served by the Appalachian Regional Commission.**

SOUTH WEST PLANNING DISTRICTS I AND II

B. Proposed Improvements & Innovations in Research, Public Health and Health Care Delivery: The proposed Healthy Appalachia CURN builds upon the extensive research and clinical resources of the University of Virginia Health System (UVA) and the knowledge and experience of key regional partners: the Southwest Virginia Health Authority (SWVA Health Authority), the Healthy Appalachia Institute (HAI-Wise), a member of the National Network of Public Health Institutes, Mountain Empire Older Citizens (MEOC), the Area Agency for the Aging, and The Southwest Community Healthcare System (SVHS), a large network of Federally Qualified Community Health Centers.

This partnership is grounded in the region's strategic health plan: *The Blueprint for Health Improvement and Health-Enabled Prosperity* (hereafter called the *Blueprint*). The *Blueprint,* created and adopted by the region's government-sanctioned Health Authority, has broad objectives designed to reduce the burden of disease in SWVA with a defined goal of enhancing academic engagement to improve regional health. This goal includes specific objectives to: 1) establish community-based participatory research standards; 2) create a mechanism for operational collaboration among regional academic institutions to advance translational research including using telehealth capabilities; and, 3) advance the skills of the local healthcare workforce. Importantly, this *Blueprint* carries with it the weight of a regional entity sanctioned by the Virginia legislature to generate resources, develop policies and procedures toward the advancement of these goals.

As detailed below, Appalachian SWVA is a region of low educational attainment, high rates of poverty and significant health risks leading to high rates of premature mortality despite a long history of community-university engagement. The development of a well-coordinated system of care that incorporates a research infrastructure supported by telehealth technologies will help address such system failures by: creating unique community-based research standards calibrated to Appalachian culture, improving bi-directional partnerships focused on specific, community-defined, public health research questions and expanding the use of telehealth capabilities to improve access to specialty care, health promotion and clinical studies. This work will be set in a process that addresses both cultural and socioeconomic barriers and the systemic failures that impact the health of the citizens of Central Appalachia.

Improvement in the area's health disparities will be documented over time using epidemiologic studies and outcome assessments in partnership with the Virginia Department of Health. In addition, community

assessments will provide process and outcome evaluations of both the operations of the Healthy Appalachia CURN as well as research infrastructure building programs (Orians, et al, 2009). Although many successes have been realized by UVA and its SWVA partners in providing clinical care and establishing telemedicine sites, the need for a well-defined research infrastructure supported by telehealth technologies is critical. This is demonstrated by the relatively few pilot research projects initiated in the region to date and the absence of research designed to determine "best practices" for the provision of medical care in the SWVA region. Barriers to participation in clinical trials have been associated with low socioeconomic status; compounding those barriers, SWVA Appalachian cultural norms (e.g, excessive self-reliance, fatalism) add another layer to the challenge of engaging the people in preventive care as well as treatment (Ford et al., 2007).

The heart of this innovative approach is the partnership with the Southwest Virginia Health Authority (SWVA Health Authority), one of the nation's first government sanctioned regional health authorities. The Authority covers the planning districts of Cumberland Plateau (PD1) and LENOWISCO (PD2). UVA, HAI-Wise located in SWVA and the SWVA Health Authority have formed an equal, strategic partnership – the Healthy Appalachia CURN - to build and sustain a needed research infrastructure in SWVA (Figure 1). This collaboration between key leadership in health care, government, economic development and academic health is already well-established; however, we propose the development of an infrastructure to expand upon service delivery and workforce development to the systematic and measured application of translational science supported by telehealth technologies.

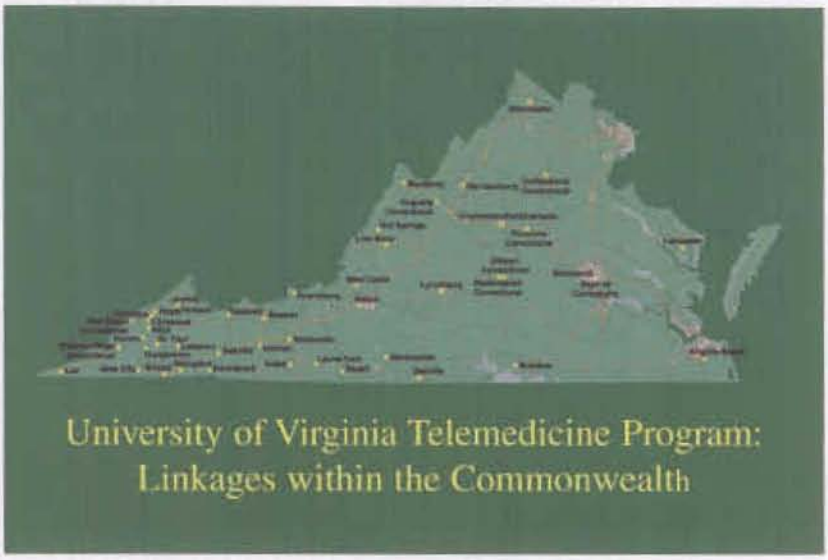
Figure: 1. Strategic Partners

This shift signifies an awareness that the application of external resources to the health crises of the region is, by itself, not a sufficient solution. Innovation must come from plans generated within the region and be adopted by a broad-based partnership with support from critical surrounding research institutions such as UVA, ETSU and Virginia Tech. The implementation of the CURN and the strategic health plan through regional collaboration has the potential to dramatically improve the quality of life in SWVA by enhancing, fostering and creating opportunities that improve health status.

C. The History among Partners

1) The University of Virginia: UVA is an academic health center adjacent to the 25 county Appalachian region of Virginia but geographically distant from the Coalfields region identified in this proposal. UVA has a longstanding and important historical relationship with the communities of Southwest Virginia, with a 40 year history of providing onsite clinics. Equally important is our commitment to the University of Virginia's College at Wise. Essential to advancing community and University efforts to reduce the burden of health disparities and improve health outcomes has been the development of a comprehensive network of collaborative partnerships within the region. This network includes partners from the Health Authority, correctional facilities, critical access and small rural hospitals, health systems, free clinics, school systems, federally qualified community health centers (FQHCs), the local area agency on aging (AAA), health departments, regional cancer centers, educational institutions, regional, state and national government, community agencies and mental health facilities.

One foundational element of this capability is the regional UVA telemedicine network grounded in the extensive contractual partnerships with FQHCs and the AAA within Southwest Virginia. Currently the UVA telemedicine network has over 60 sites statewide with 30 sites located within the Appalachian region including contracts with more than 20 FQHCs that define the scope of services, clinical and technical protocols, HIPAA and patient consent. These centers serve as the backbone for a network that ensures access to screening and prevention initiatives, specialty clinical care, patient and workforce education as well as a potential mechanism to expand community-based research and clinical studies. Since its founding in 1994, the UVA Office of Telemedicine, under the direction of Karen Rheuban, MD (Co-PI), has conducted more than 16,000 clinical encounters in 36 specialties and subspecialties providing care in such specialties as endocrinology, gynecology, psychiatry, dermatology and nephrology to patients in the coalfields where these critical resources are not locally available. In addition, over the past two years, UVA has worked to further enhance an infrastructure of community engagement and research through its integral involvement in the creation of the SWVA Health Authority, the Healthy Appalachia Institute (described below) and the region's Strategic Blueprint. UVA has engaged Virginia Medicaid, Medicare and through the Wampler-Phillips bills, the private payer community in the reimbursement of telemedicine services.



2) The SWVA Health Authority: Spurred by the leadership of the SWVA legislators, the Virginia General Assembly created this special state governmental authority in Health Planning Districts I and II with the primary goal of improving health and health related economic conditions in the region. This 22-member authority includes individuals from SWVA who represent each of the seven counties and one city within the districts including the regional health systems, local legislators, the medical directors over each district *(Cantrell, Dreyzehner, Grant - Community Co-Investigators)*, the Southwest Virginia Community Health System (FQHC) *(Community Research Associate, Howard Chapman)*, economic development representatives and academic health centers including UVA (Rheuban & Prior, Grant Co-PIs), East Tennessee State University and Virginia Commonwealth University. The SWVA Health Authority has broad powers to conduct its affairs in Virginia (e.g., receiving appropriations; the issuance and sale of bonds) and is charged to implement the region's Strategic Blueprint including a model to improve access to specialty care including clinical studies.

3) Healthy Appalachia Institute at Wise: Simultaneous with the development of the SWVA Health Authority was the formation of the HAI-Wise, which was officially adopted as a strategic, academic partner. HAI supports the goals of: developing a common understanding of the health status of the region, implementing the region's integrated strategic health plan and operating an institute to conceive and implement initiatives that ensure a healthier future for Central Appalachia. The HAI is designated as a Robert Wood Johnson Emerging Public Health Institute and is unique among university-based Appalachian programs in that it seeks *to transform Central Appalachia by developing a sustainable, effective model for health that would be applicable for rural, relatively isolated communities with similar barriers to health wherever they may be located.* This shared vision is moved forward through the mission of HAI to improve the health, education and prosperity for the residents of the region.

One example of the strength of this tripartite partnership was the effort to examine the feasibility of what could be accomplished by collaboration targeting key community health issues linked to premature mortality from cancer, particularly by advancing education, screening and access to advanced oncology care, especially for the region's workforce. In 2009, the UVA Emily Couric Cancer Center, was awarded a $1 million grant from the Virginia Tobacco Commission, to launch **Healthy Appalachia Works** to provide: increased cancer screening services including innovative programs in digital mammography and tele-colposcopy; expanded cancer expertise through shared tumor boards with regional cancer centers; expanded telemedicine capability;

improved patient outcomes through patient navigation services; advanced oncology education for patients and professionals.

Within these programs and partnerships within the region, UVA has developed, implemented and advanced an organized community engagement infrastructure for: 1) improved access to specialty care; 2) collaborative community-based health planning efforts; 3) enhanced community and workforce educational programs; and, 4) small pilot studies in community-based participatory research linked to identified health needs. The programs and projects below are designed to increase access to care and improve health outcomes:

UVA Programs	Regional Partners	Outputs 2009
Goal: Improved Access to Specialty Care Access		
UVA Telemedicine	Health Departments, Regional Hospitals, FQHCs, AAA, Free Clinics	1,563 patient encounters through 30 regional sites
UVA Southwest Specialty Care Clinics	Health Departments, Regional Hospitals	1,901 patient encounters in 14 clinical specialties
Remote Area Medical Expedition	RAM, National & State Community & Health Agencies, Regional Health Systems	6,153 patient encounters
Healthy Appalachia Works Cancer Control Projects	Healthy Appalachia, Health Depts., Free Clinics, FQHCs, AAA, Regional Cancer Centers	Regional programs launched (patient encounters included above)
Goal: Improved Regional Health Planning		
Participation in the development of the regional strategic health plan	SWVA Health Authority HAI-Wise	Publication of *The Blueprint for Health Improvement and Health Enabled Prosperity*
Facilitation of the formation of a regional substance abuse consortium	HAI-Wise, Community Service Boards, Health Departments, Community Agencies	Consortium formed and funded
Health Resources and Economic Impact Analysis	SWVA Health Authority, Healthy Appalachia	Data collection and analysis completed
Leadership in advancing the State Cancer Control Plan	In SWVA: Virginia Tech, Community Agencies, Health Departments, Regional Cancer Centers	Regional cancer forums, prevention and screening programs
Goal: Expanded Opportunities for Educational Engagement		
Regional Nursing Education Efforts	Health Departments, Free Clinics, Regional Health Systems	6 new preceptor sites, NP training programs conducted
Outreach Health Librarian at UVA Wise	Residents, and Regional Agencies	1, 013 health education encounters
Diabetes Prevention and Education Initiatives	Health Departments Free Clinics	393 patients reached
Healthy Appalachia Student Fellowships	UVA Wise, UVA, Health Departments, Free Clinics, Community Agencies	Four student fellows named and active for 09-10
Continuing Medical and Professional Education	Health Systems, Health Professionals	SW: 1,502 hours

Preliminary Studies: Although SWVA community-UVA relationships are well developed, particularly in clinical services (i.e., Telemedicine, Pediatrics, Neurology, Oncology), there has been very limited research-related community engagement in SWVA, in part because there has been no formalized infrastructure to facilitate these endeavors. Some initial success has been realized through small community-based pilot projects with various partner organizations. However, the inclusion of feedback from community residents and members of the SWVA patient population has been limited. Active inclusion of the resident population will be addressed as a key component of this proposal, by involving members in: a) identifying critical health problems from their perspective; b) contributing to the development of research questions; c) providing input on methods to be used in their community; and, d) helping develop implementation and/or evaluation of these projects. The following pilot research studies - in alignment with the *Strategic Blueprint* and designed to advance translational science - have recently been initiated:

Diabetes Education, Prevention and Treatment

- *Interactive Tele-education Program to Reduce Obesity & Prevent Diabetes in Rural Areas of Virginia,*
  - PI: Terry Saunders, PhD UVA Virginia Center for Diabetes Education
  - Funding: The Virginia Department of Health
  - Partners: Health Planning District I, The Health Wagon Free Clinic, UVA

Cancer Prevention, Screening, Education and Treatment

- *Preventing Cervical Cancer in Rural Impoverished Women through Nurse Practitioner Colposcopy Service: Ensuring Patient Safety and Effectiveness*
  - PI: Beth Merwin, PhD School of Nursing
  - Funding: CTSA Pilot Award - The UVA Cancer Center
  - Partners: Wise County Health Department, Scott County Health Department, UVA
- *Southwest Virginia Alliance for Telemedicine Cancer Outreach Project*
  - PI: Karen Rheuban, MD UVA School of Medicine
  - Funding: US Department of Agriculture
  - Partners: Regional FQHCs, Health Systems

Pain Management

- *Appalachian Community Partnership for Pain Management Study: An Analysis of Nursing Pain Management Training and Skills*

  PIs: Cathy Campbell, PhD and Diane Boyer, DNP PMHNP-BC, UVA School of Nursing
  Funding: UVA Academic Community Engagement Award
  Partners: Nurses in far Southwest Virginia

Public Health

- *Feasibility of a Public Health Course "Healthy Appalachia: A Community-based Participatory Research Partnership" to train students to conduct projects in SWVA*

  Elizabeth McGarvey, EdD, David Cattell-Gordon, Gary Crum, PhD, Tanya Wancek, PhD), School of Medicine Public Health Sciences
  Funding: Academic Community Engagement Faculty Fellowship
  Partners: UVA Wise, SWVA Health Wagon.

Mental Health

- *Enhanced Mental Health Services Using Telemedicine*

  PI: Larry Merkel, MD UVA School of Medicine
  Partners: Dungannon Community Health Center (FQHC), UVA

Smoking Cessation and Obesity

- *Tobacco Use Prevention Project*

  PI: Pam Kulbok, RN, DNSc, UVA School of Nursing
  Funding: NIH funded UVA Rural Health Care Research Center
  Partners: Dickenson County School System, UVA
- *Reducing Obesity and High Risk Behavior through the Use of Telehealth*

  PIs: Karen Rheuban, MD, Susan Cluett, NP
  Funding: Wachovia and Westwind Foundations
  Partners: Craig County School System, UVA

Broadband Infrastructure Development

- *Establishing Rural Broadband Infrastructure to Advance Health Care*

  PI: Karen Rheuban, MD, Eugene Sullivan, MS
  Funding FCC Pilot
  Partners: FCC, Rural Health Care providers, VDH, VTN, UVA

Access to Clinical Studies

- *An Evaluation of Attitudes towards Clinical Trials in Southwest Virginia,*

  PI: Anneke Schroen, MD
  Funding: UVA Office of Economic Development Award
  Partners: Regional Cancer Centers

II Opportunity and Potential Impact

A. Addressing a Gap in Infrastructure to Advance Research and Reduce Health Disparities: The proposed Healthy Appalachia CURN provides a mechanism by which patients in far SWVA can work in partnership with academic investigators to better inform relevant research, health service delivery and health policy issues. This opportunity does not presently exist. The goal of reducing health disparities by the improvement in health and health related prosperity requires a systematic approach to public health by its many stakeholders guided by a CBPR approach. This can be facilitated by telehealth technologies in a distributive network that ensures access to both specialty health care, education and the benefits of research.

Successful implementation will bring attention to health problems in the region and advances in state-of-the-art treatment through translational research, professional education and expanded use of telehealth opportunities (Rheuban, 2006; Rheuban, 2004).

The Healthy Appalachia CURN will result in the development of a model research infrastructure for collaborative community-academic health centers that will be relevant to other Appalachian regions. Appalachia extends across 13 states from New York to Mississippi in the United States (USA) including 410 counties, and is characterized by mountains, hollows and rivers that wind through areas of low-population density (Appalachian Regional Commission, 2009). Common themes across Appalachian communities include high rates of uninsured citizens, greater geographic isolation, lower educational attainment, less public transportation, and shortages of healthcare professionals (Behringer et al., 2007).

B. The Communities of Far Southwest Virginia and their Health Care Needs: The seven coalfield counties and one city that make up Health Planning Districts I and II in Appalachian Southwestern Virginia are a uniformly rural area with miles of mountainous landscape and a population of nearly 207,000 persons. The region is a relatively homogenous white population (<5% race/ethnic minorities) and suffers from declining population, low educational attainment, high rates of poverty and approximately 50% of the per capita income of the rest of the state. These persistent social problems are intertwined with significant disease risk factors that contribute to disproportionately high rates of heart disease, cancer, respiratory disease, diabetes, and depression. To complicate these social and health issues, the sharp mountain ridges and deep valleys that divide the region adversely impact access to healthcare and to employment opportunities. There are serious healthcare workforce shortages in the area and no large-scale population centers capable of financing a full spectrum of specialty medical practice.

Demographic Data	PD I & II	Virginia
Population Growth	-4.9%	+14.4%
H.S. Graduation Rate	61.0%	81.0%
College Graduation Rate	9.0%	29.5%
Percent of Pop. Working	41.8%	62%
Below Fed Poverty Level	19.5%	9.6%
Uninsured	19.3%	12.5%

Heath Risk Factors	PD I & II	Virginia
Obesity	33.5%	25.1%
Hypertension	38.2%	26.7%
High Cholesterol	39.5%	36.2%
Not in Wellness Activity	33.75%	22.6%
Smoking (Adults)	29.1%	20.6%
Smokeless Tobacco Use	16.8%	3.4%

The consequence of these adverse socio-economic and health risk factors is that the residents of the region are more likely to die prematurely than residents of other regions in the Commonwealth. In addition, the Coalfields region of Virginia continues to experience a full-scale public health crisis in rates of addiction to prescriptive narcotics, leading to astronomically high rates of fatal, unintentional overdose. According to the state medical examiner, the adjusted mortality rate from unintentional overdose is **40 deaths per 100,000** in the region compared to **8.3 per 100,000** for the state as a whole. Taken together, the health status of the region represents a significant geographically-based health disparity and efforts to reduce this by developing a robust research infrastructure will have a major impact.

Premature Mortality by Disease (adjusted rate per 100,000)	PD I & II	Virginia
Heart	341*	203
Solid Tumor Cancer	253*	185
Chronic Lower Respiratory	79*	38
Stroke	64	54
Diabetes	80	22
Unintentional Injury	145*	82

**All data is from the Virginia Department of Health (VDH) through health records of mortality and incidence rates between 1999 and 2005 as well as the Office of the State Medical Examiner. Socioeconomic and demographic information was extracted from census data from 1990 and 2000 at the Census tract level.3*

III Approach

Successful and innovative community-university partnerships incorporate a number of critical elements including: bi-directional communication leading to trust; synergy among partners with a shared vision; equitable process and procedures; diverse membership; tangible benefits to all partners; balance between the parts; significant community involvement; supportive organizational policies and reward structure, leadership at multiple levels, culturally competent, skilled staff and researchers, collaborative dissemination, ongoing partnership assessment, improvement, celebration; and sustainable impact based on measurable outcomes. (Rubin, 2000; Baker, 2001; Seifer, 2006). A number of community-academic partnerships have also

incorporated these elements to create collaborative research infrastructures with some success, as reported by collaborators targeting health disparities in urban areas (Satcher, et al, 2006; Fox et al. 2004; Plumb et al, 2004; Edwards, 2003). While a number of lessons can be learned from their successes, no community-university research infrastructure efforts have yet been initiated within the region of SWVA targeted in this proposal. As such, the approach must take into account the defined elements of successful partnerships (above) and the regional culture shaped by its history and the geography of the mountains.

The following section outlines our approach to accomplish each of the specific aims of the grant.

Approach to Aim 1: Develop within the context of Appalachian culture a community-academic research infrastructure that addresses the identified health needs of SWVA, and undertake joint CBPR studies across scientific disciplines, diseases and conditions related to these needs.

A. Goals: The SWVA Health Authority will facilitate the governance of the Healthy Appalachia-CURN with UVA and will work collaboratively, with the community and with researchers from UVA, to establish the Steering Committee, the Advisory Committee, with two Subcommittees to accomplish the following goals in order to:

1. **Define policy:** a) develop a mission statement, b) establish rules and objectives to guide operations, c) ensure that CBPR principles are followed, d) create locally crafted research standards for clinical and public health CBPR in SWVA, e) field test pilot UVA-funded telehealth projects, f) develop a descriptive document of Healthy Appalachia CURN as part of a process of evaluation, and, g) outline terms of agreement to become a participating member.
2. **Determine regulation**: a) ensure leadership roles for culturally competent, skilled staff and researchers, b) finalize how policies will be implemented, c) establish meeting procedures, d) clarify all operational issues (openness, mutual respect of members, transparency and decision-making by consensus).
3. **Sustain a functional organization:** a) coordinate all the parts of an effective whole toward the accomplishment of specific objectives according to organizational standards for excellence (Green & Kreuter, 1999, IOM, 2004), b) conduct monthly meetings of the members to develop the basic organization structure, c) develop and implement a plan for bi-directional communication and exchange of knowledge between UVA, other research institutions and community partners, d) review the needs assessment and *Strategic Blueprint* and prioritize the top 10 issues of local relevance to the community, d) ensure ongoing community organization and participation in the Healthy Appalachia CURN, e) ensure the representation of all race/ethnic groups and a range of age groups, e) conduct ongoing partnership assessments, make adjustments as needed for improvement and celebrate successes, f) develop a formal regional sustainability plan.
4. **Prepare and plan CBPR studies**: a) conduct a current inventory of all translational and other research occurring in SWVA, b) conduct a current inventory of public health education, health promotion, health interventions in SWVA by location and venue (e.g. schools, health department), c) Use information obtained from the research and public health inventories and create GIS maps to use for discussion and planning, d) Survey area physicians and other health care professionals to determine level of interest and barriers to engage in clinical studies, including clinical trials (Beebee et al., 2007), e) Conduct community dialogue groups and focus groups of community residents to determine knowledge, interest, barriers and obtain recommendations for their active involvement and participation in research in SWVA, and develop case studies (Yin, 2002; Bakken et al., 2009), f) prepare reports of data from items a though c, g) HAI-Wise will use their www.HealthyApplachia.org website to make information available to partners, other organizations and the public, and, h) prepare a dissemination plan for research results.

Figure 3 illustrates the organizational model through which Health Appalachia-CURN will accomplish aims.

Figure 3: Model

B. Governance: The Healthy Appalachia-CURN Infrastructure Governance will be established through the SWVA Health Authority. Two of the UVA CO-PIs (*Rheuban, Prior*) serve on the SWVA Health Authority as do the Community Co-Investigators (*Dreyzehner, Cantrell*) along with other community leaders. Academic research resources will be provided by UVA faculty with expertise in CBPR methodology and evaluation (*Schroen, McGarvey, and Chen*). Principles of community-based research to be followed will include: recognition of the community as a unit of identity, building on the assets (resources) and strengths within the community, facilitating collaborative partnerships in all phases of the research, ensuring that knowledge and action are integrated for the mutual benefit of all partners, support a co-learning and empowering process that is sensitive to both inequalities due to socio-economic conditions as well as Appalachian cultural norms (Blumenthal & DiClemente, 2004).

1) The CURN Steering Committee is the leadership structure that will reinforce an ongoing, collaborative partnership of equals who bring their respective unique knowledge and perspective to the project. This Committee will oversee the approach, process and outcomes through two Co-Directors, one from the University (*Rheuban)* and one from the community (*Dreyzehner*), the Community Research Associates (CRAs) (*Maxwell and Chapman*) and the CURN coordinator (*to be named*). Marilyn Maxwell is well-qualified and eager to represent the region of SWVA for this project. She has held the position of Executive Director of the Mountain Empire Older Citizens organization for 35 years. This organization is the Area Agency on Aging and also includes the Children's Advocacy Center, Cancer Resource and Support Center, and Public and Specialized Transportation Provider under its umbrella. She is a well-respected leader in the community. Howard Chapman, Jr. is the Executive Director of SWVA Community Health Systems, which operates nine FQHCs in far Southwest Virginia. He is also very well-respected and is able to represent the community. Institutional agreements to ensure compliance with all pertinent federal regulations and policies have been signed by both CRAs.

2) The Healthy Appalachia CURN Advisory Committee: This committee will be established by the SWVA Health Authority. The CURN Advisory Committee will be comprised of two subcommittees: a Community Advisory Committee (CAC) and a Research Advisory Committee (RAC) (described below):

a) The Community Advisory Committee (CAC) will include a set number (to be determined) of members of the resident population and community organizations who are representative of the region, and will include ethnic/racial minorities. It is recognized that if the problems are found within the community then innovations and solutions must come from plans generated within the region and adopted by a broad-based partnership from government, education, the business communities and other community organizations, including the area churches. The primary function of the CAC will be to provide practical guidance on maintaining the existing partnerships and direction on expanding partnerships across disciplines to ensure community expertise for priority health issues in alignment with the strategic health plan for the region.

b) The Research Advisory Committee (RAC) will consist of the academic researchers (above) and community partners identified by HAI-Wise, UVA and the SWVA Health Authority. The first priority of the RSC will be to develop and draft, in collaboration with the CAC, a document that outlines community-based participatory research standards that are *crafted locally* and calibrated to the needs of SWVA Appalachia. The Standards will outline the ethics and decision-making process for the development, implementation and evaluation of research supported by Healthy Appalachia-CURN. UVA faculty with expertise in CBPR ethics (Chen) will review the ethnical framework and will coordinate involvement of the UVA School of Medicine Center for Biomedical Ethics & Humanities' Research Advisory Group in the review. Once this is refined and adopted by the Health Authority, it will be communicated to all surrounding Academic Health Centers with researchers who wish to engage in studies and interventions in the region.

C. The Communication Plan: The Community Research Associates *(Maxwell, Chapman)*, who are critical to the administrative core, represent two of the region's largest partners--the region's federally funded distributed networks—the Southwest Community Health System (FQHC) and the Mountain Empire Older Citizens (AAA). The Community Research Associates will facilitate the development and implementation of a bi-directional plan for communication among existing partners within Healthy Appalachia-CURN, those organizations that become partners in research and within the broader community. They are both seen in the region as well respected leaders. This communication plan will be developed within the leadership group, reviewed by the advisory board and adopted as a regional policy by the SWVA Health Authority.

Approach to Aim 2: Develop the needed telehealth infrastructure to serve as a distributive network to advance: a) health care delivery, b) professional education, and c) health science research, with an emphasis on a CBPR approach.

A critical part of ensuring access to health care delivery, professional education, and health science research, such as clinical studies within this rural, underserved region is to develop research opportunities within the already established telehealth networks, as well as an expansion to other sites. As outlined earlier, these telehealth networks are established and currently provide access to clinical care and educational services to many residents of the region. The existence of telemedicine equipment and expertise in a variety of locations (e.g. local schools, health departments, hospitals) provides an excellent opportunity to overcome the problems of isolation of communities separated by mountains and distance. Healthy Appalachia-CURN will use this robust telehealth infrastructure as an avenue for needs assessment and to translate advances in science into medical practice in SWVA by working with the community

UVA telemedicine partners have already signed letters of agreement to facilitate the exchange of patient information, and developed protocols for patient consent, HIPAA, and for clinical and educational exchange. All such letters of agreement will be modified to facilitate the distributed research network in the region, aligned with the goals of the SWVA Health Authority and the Healthy Appalachia CURN proposed herein. Working in collaboration with our existing telemedicine partner sites, in particular the regional network of federally qualified health centers, the following objectives will be accomplished: (see timeline for more details)

1. Identify "best practices" in community based participatory research utilizing telemedicine.
2. Designate a research nurse coordinator to be located in the region.
3. Organize meetings with telehealth stakeholders in SWVA.
4. Develop acceptable strategies for needs assessment and communication with stakeholders.
5. Develop a methodology for identification of partner research opportunities.
6. Create standard operating procedures related to remote access to clinical trials.
7. Create needed addendum to telemedicine partner agreements.
8. Engage UVA-Wise Department of Nursing to involve nursing students in telemedicine and clinical trials.
9. Identify additional partner sites to add to expand the telemedicine network.
10. Secure funding through federal, state and philanthropic sources to expand the regional footprint.
11. Identify potential pilot research projects.

Approach to Aim 3: Develop and disseminate the model of a sustainable infrastructure by offering training in research, with an emphasis on CBPR approaches, to community health care professionals, researchers, faculty and stakeholders to promote ongoing collaborative research.

- **Establish academic certificates in health (e.g. Public Health) geared toward "in career" adult learners with or without bachelor's degrees through an education/training website to:**
  - Support and deliver professional education and training.
  - Create an Introduction to Public Health course in the regional colleges to enhance awareness and understanding of health among ancillary health care workers and others.
  - Provide UVA undergraduate and graduate public health education, health promotion and evaluation courses using current health behavior models (e.g. Precede-Proceed) for staff in local health departments, staff in other health-related venues, and interested others (Green & Kreuter, 1999).
- **Develop a communication website to:**
  - Disseminate research and evaluation results to all parties using appropriate health literacy versions for the lay public and researchers.
  - Provide, research assessment instruments and tools created for use in SWVA to interested community health care professionals, researchers, faculty and stakeholders.
- **Develop CBPR education modules:**
  - Develop for physicians, nurses and allied health professionals related to clinical trials and other clinical research.
  - Notify potentially interested parties via professional organizations
  - Train health care professionals in the region and the university on CBPR, emphasizing the Standard for CBPR in SWVA.
  - Provide training in the process for participation as an equal partner in clinical studies using telemedicine sites
  - Incorporate professional education modules to include clinical studies into practice and CBPR standards for nursing.

III Project Timeline, Milestones and Deliverables

Months	Activities and Actions	Milestones and Deliverables
1 - 2	• HA-CURN planning meetings are convened • HA-CURN coordinator through HAI-Wise is hired • SWVA Health Authority establishes HA CURN Advisory Committee and Community and Research Subcommittees • Steering Team, Committee Members, and staff participate in CBPR training (use telehealth resource) • Inventory of existing research initiatives with the region through HAI-Wise is initiated • Broad Axe Technology meeting to finalize technology decisions; initiate website development	Committees formed CURN Coordinator hired CBPR training completed Regional inventory initiated Contract signed to expand telehealth capabilities
2 - 8	• Define HA-CURN policy and finalize mission statement • Determine regulation, develop policies and procedures • Develop draft HA CBPR standards for SWVA through an iterative process with HA-CURN members • Review best-practice CBPR standards and practice sites • Begin development of Training/Education and Communication websites • Complete distributed research network (Broad Axe)	Documents: ***HA CURN Mission, Policies and Procedures*** ***Proposed CBPR Standards for SWVA***
3-4	• CRAs organize meeting with telehealth stakeholders re CBPR opportunities • Identify "best practices"" in clinical studies using telehealth (UC-Davis model) • Begin steps to establish academic certificates in public health • Initial review of standards by ethics workgroup at UVA	Telehealth Stakeholder Meeting held Documents: ***Literature Review*** ***Report to SWVA Health Authority***

	• Report progress to SWVA Health Authority • Secure review of initial standards by health center in the region and select researchers • Measures and outcomes for network established	
4-8	• Accomplish key steps to establish a functional organization and explore sustainability issues • Review Strategic Blueprint and align CURN efforts to health issues • Develop initial communication plan (CRAs) • Develop strategies for needs assessment/ communication with telehealth stakeholders using CBPR methods • Determine methodology for identification of partner telehealth research opportunities using AAA and FQHC sites with CRAs • Finalize survey for region on barriers to clinical trials	Documents: ***CURN Communication Strategy for Community-University Research Partnerships*** ***Check list of Telehealth Strategies*** ***Regional Inventory of Community-based Research***
6-12	• Conduct ongoing assessments of CURN members for satisfaction, concerns • Complete development of websites for Educational/Professional Training and Communication website • Develop CBPR Education Modules for physicians, nurses and allied health professionals • Have standards adopted by SWVA Health Authority • Develop plan to address barriers to clinical trials • Collaborative evaluation meeting with NIH evaluators • Begin Authority process to evaluate the specialty medical center training model	Survey completed of members at 6 months & 12 months Training/Education and Communication/Education link established on HAI site Documents: ***Inventory Tables*** **Adopted standards** Established training site on www.healthyappalachia.org
End Year 1	• **Prepare Annual NIH Progress report**	***NIH Annual Report Year 1***
8-18	• Conduct inventory of all public health education, promotion, and/or interventions in place in SWVA through HAI-Wise • Finalize standard procedures and processes for Telehealth studies for clinical trials • Through the CURN identify a process to match need to researchers. • Regional meeting held by HAI at UVA-Wise for regional researchers and interested parties (UVA, VT, ETSU, UK, LMU, Holston Medical Group, etc.); explore shared research opportunities • Implement plan to address barriers to clinical trials • Complete white paper including feasibility and implementation plan on specialty medical center including translational science elements	Research opportunities and standards site on web Central Appalachia Research Roundtable Documents: **Guide to Health Education & Promotion** **Specialty Medical Education White Paper**
18-19	• Using both inventory results, create GIS maps illustrating distribution of research across SWVA	Power Point: ***GIS maps in presentation***
6- 21	• Survey SWVA physicians and other health care professions to determine interest/barriers to engaging in CBPR including clinical trials • Prepare interview guides, goals and objectives for conducting Community Dialogues Groups and Focus Groups with residents • Report on progress to SWVA Health Authority • Using process to date, begin development of sustainability plan	Survey data: ***collected and entered into SPSS software*** Document: ***Written Guidelines***
21-24	• Conduct Community Dialogues Groups (focus groups), transcribe qualitative data using UVA MPH students at	Documents: ***Report Summaries of Results***

	no cost to project • Finalize development of CBPR Educational Modules for physicians, nurses and allied health professionals • Pilot initial studies using telehealth sites	***Educational Modules***
End Year 2	• **Prepare Annual NIH Progress report**	***NIH Annual Report Year 2***
18-27	• UVA Wise/regional nursing students learn telehealth and clinical study skills • Prepare publications for peer-review and other journal using data collected in focus groups, dialogue groups, health professional surveys • Present outcomes at American Telemedicine Association Meeting, APHA	Documents: ***Plan to provide nursing students exposure to telehealth & trials*** ***National presentations*** **CURN Sustainability Plan**
28-33	• Identify additional partners site to add to the telemedicine network • Continue work to connect research opportunities with community organizations	***Articles published***
24-28	• Provide additional training in the process for participation as an equal partners in clinical studies at existing and new telehealth sites	
28-36	• Launch pilot CBPR research projects	
End Year 3	• **Prepare Annual NIH Progress report** • **Launch dissemination plan**	***NIH Annual Report Year 3***

IV. Long Term Sustainability and Dissemination Plan: Key elements that will ensure the long-term sustainability of the HA-CURN include:

A. Sustainability Plan:

- The SWVA Health Authority and its power to bring the weight of a regional governmental entity, sanctioned by the Commonwealth, to generate resources, develop policies and procedures;
- The Wampler-Phillips Bills before the Virginia General Assembly that will mandate coverage of telehealth services thereby sustaining network partners
- The direct link of the Healthy Appalachia-CURN to the Authority's Strategic Blueprint, which calls for the establishment of community-based participatory research standards and a mechanism for operational collaboration (HAI) among regional academic institutions that advances translational research;
- The commitment to the HA-CURN of the federally funded networks in the region including the Southwest Community Health Systems, Inc network of FQHCs and Mountain Empire Older Citizens, both of whom provide broad reach, access to residents, credibility based on experience, and wisdom around the region's culture;
- The utilization of the region's extensive telehealth network, which includes the FQHCs, the AAA, health departments and other regional facilities and provides comprehensive telemedicine services, access to distance learning and specialty medical care to remote, underserved regions;
- The strength of the community and academic PIs who provide access to regional needs, telehealth expertise, knowledge in CBPR and biomedical ethics, research in access to trials, education, and a tie to the clinical trials program and leadership at UVA;
- The availability within the region of diverse funding sources including the Appalachian Regional Commission and the Virginia Tobacco Indemnification Commission;
- The mentorship opportunities through these programs for community professionals and UVA new investigators to participate in obtaining extramural funding for local studies.

B. Dissemination plan:

- Adoption of the model by the Health Authority and communication to the Virginia General Assembly;
- Distribution of the model through the CURN Communication plan;
- Incorporation of the model into the Virginia Rural Health Plan;
- Presentations to the state and federal Appalachian Regional Commission;
- Communication of the model with Appalachian Community Cancer Network
- Facilitation of a regional research roundtable
- Presentations at national conferences including the American Telemedicine Association, APHA, Health equity conferences

Community Partnerships and Mobile Telehealth to Transform Research in Elder Care

Short Summary

The University of Virginia and the Jefferson Area Board on Aging will advance community-based research on vulnerable elderly populations through an innovative infrastructure that facilitates community engagement and employs cutting-edge technologies in telehealth and telemonitoring. Our goal is to generate research on early detection and prevention of chronic illness, so older Americans may age in place and avoid premature institutionalizations, unnecessary hospitalizations and emergency room visits.

Abstract

This project, led by the University of Virginia (UVA) and the Jefferson Area Board for Aging (JABA), seeks to advance community-based research with and to the benefit of vulnerable elderly populations. For the past twenty-six years, UVA and JABA have jointly studied and developed solutions for the aging population in the Thomas Jefferson Planning District of Central Virginia. Building on this foundation, we seek to expand infrastructure to facilitate participation of low-income residents in both rural and urban settings. While most susceptible to chronic illness due to poverty and scarcity of resources, these groups are less likely to participate in academic research for reasons including apprehension and inaccessibility to health science centers. Our overall goal is to enable research that focuses on the early detection and prevention of chronic illness, so these populations may age in place and avoid premature institutionalizations and unnecessary hospitalizations and emergency room visits. We also seek to develop a state and national model for university-community partnerships that can be employed by other academic health centers and area agencies on aging. The proposed infrastructure will develop research capacity at the sites where low-income older adults live or receive health care, including public housing, assisted living facilities, community health clinics, and individual homes. The rural county selected is a federally-designated medically underserved area. The specific aims for this 2-year award are to: (1) Develop a bi-directional administrative structure to: (a) support the successful implementation of collaborative health sciences research studies between UVA and JABA; (b) expand and sustain the collaborations of community leaders and experts in funded health sciences research related to aging at UVA; and (c) support the subsequent development of sustained research programs and collaborations for health sciences researchers at UVA in partnership with JABA; (2) Systematically include potential research participants as partners in research to reduce barriers to and increase meaningfulness of participation. Gather and disseminate data to the scientific community, consumers, and policy-makers regarding this knowledge gained to facilitate the use of telehealth and personal telemonitoring, with translation of findings to care and research in urban and rural older adults.; and (3) Develop and deploy telehealth and personal telemonitoring capacity in rural and urban community living sites for older adults to: (a) identify research questions and to support collaborative research projects; (b) enable objective measurement of personal health parameters to optimize data collection and scientific discovery. This novel infrastructure will serve to increase access to vulnerable outpatient populations for development of and participation in health sciences research, and it allows researchers and community organizations to collect and pool data at the both the individual and aggregate level. Our infrastructure plan provides mechanisms for dissemination of our research findings and for long-term sustainability of this transformative infrastructure.

2. Specific Aims

By 2030, the numbers of Virginians 65 years and older are expected to double, from 900,000 to 1.8 million, an increase from 12% to 19% of the Commonwealth population (Cai, 2009). In the Charlottesville and surrounding counties areas of Virginia, the number of people 65 and over is expected to increase by 109 percent by 2024, far outpacing the 41 percent increase in the total population.

The Commonwealth of Virginia encompasses both urban and rural localities, making a "one size fits all" approach to providing state-wide models of care and to developing sustainable approaches to health sciences research illogical and unlikely to succeed. Older adults, regardless of geographic location, share many attributes—from their desire to "age in place" and avoid premature institutionalization to their desire to maintain a high quality of life. However, a recent study showed that rural and urban Virginian older adults differ in significant ways: rural Virginian elders are more likely to be widowed and to live alone; are slightly older (74 years vs. 73.5 years of age); have received less formal education; and depend more heavily on Social Security income than their urban counterparts. Rural Virginia elders are also more likely to be in poorer health as compared to urban older adults who reside in Virginia (Cai, 2009). In response to these figures, a plan was developed by the community that recommends telehealth as a strategy to enable older adults to age in place. Proponents of this plan also envision that through the use of innovative, home-based technology, scientific discoveries could be made that would positively impact senior citizens' quality of life and abilities to age in place. The challenge remains to engage older adults in the processes to support the use of telehealth applications and in their participation in health sciences research.

Older adults often do not choose to engage in health sciences research for a number of reasons, including apprehension, inconvenience, misunderstanding or lack of knowledge about research value, and the possibility of randomization to control group conditions. Expectations of older adults regarding participation in research include privacy, professionalism by research staff, and respectful treatment (Schlenk et al., 2009). Thus, building a structure and process for bi-directional, collaborative health sciences research using community engagement models and telehealth applications will serve to empower older adults to have a strong voice in the problems that are addressed through research, the manner in which the studies are undertaken, and will expand the numbers of those who choose to participate in health sciences research. Similarly, it will enable their health care providers to engage and have meaningful participation in the program.

The University of Virginia (U.Va.) and the Jefferson Area Board of Aging (JABA), are uniquely positioned to address the needs of *both* rural and urban older Virginians, as the service areas for these entities encompass both rural and urban localities. Building upon more than 20 years of ongoing collaborations in health sciences research, including numerous projects focused on the unique needs of older Virginians, these partners propose to strengthen their research infrastructure by leveraging existing and cutting-edge telehealth and telemonitoring capabilities in rural and in urban community locations to enable older Virginians to age in place.

The specific aims for this 2-year award are to:

1. Develop a bi-directional administrative structure to: (a) support the successful implementation of collaborative health sciences research studies between UVA and JABA; (b) expand and sustain the collaborations of community leaders and experts in funded health sciences research related to aging at UVA; and (c) support the subsequent development of sustained research programs and collaborations for health sciences researchers at UVA in partnership with JABA.

2. Systematically include potential research participants as partners in research to reduce barriers to and increase meaningfulness of participation. Gather and disseminate data to the scientific community, consumers, and policy-makers regarding this knowledge gained to facilitate the use of telehealth and personal telemonitoring, with translation of findings to care and research in urban and rural older adults.

3. Develop and deploy telehealth and personal telemonitoring capacity in rural and urban community living sites for older adults to: (a) identify research questions and to support collaborative research projects; (b) enable objective measurement of personal health parameters to optimize data collection and scientific discovery.

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RESEARCH DESIGN AND METHODS

BACKGROUND/PRELIMINARY STUDIES

Goals and Innovations: This project, led by the University of Virginia (UVA) and the Jefferson Area Board for Aging (JABA), seeks to advance community-based research with and to the benefit of vulnerable elderly populations. For the past twenty-six years, UVA and JABA have jointly studied and developed solutions for the aging population in the Thomas Jefferson Planning District of Central Virginia. Building on this foundation, we seek to expand infrastructure to facilitate participation of low-income residents in both rural and urban settings. While most susceptible to chronic illness due to poverty and scarcity of resources, these groups are less likely to participate in academic research for reasons including apprehension and inaccessibility to health science centers. Our overall goal is to enable research that focuses on the early detection and prevention of chronic illness, so these populations may age in place and avoid premature institutionalizations and unnecessary hospitalizations and emergency room visits. We also seek to develop a state and national model for university-community partnerships that can be employed by other academic health centers and area agencies on aging.

Comment [A2]: Find and replace all "U.Va." with "UVA" for consistency.

The proposed infrastructure will develop research capacity at the sites where low-income older adults live or receive health care, including public housing, assisted living facilities, community health clinics, and individual homes. The rural county selected is a federally-designated medically underserved area. The two components of the infrastructure are:

- A bi-directional administrative structure, employing a community engagement model developed by the Pew Partnership for Civic Change This initiative serves as the basis for a national academic-community research program, but has never been used in a health research context. Dr. Suzanne Morse, who played a lead role in design of the model, has recently joined the UVA faculty, and will direct its application for this project. The engagement plan will enable both aging individuals and their health care providers to be active partners, not just participants, in the research process.

- Use of mobile telehealth and telemonitoring technologies that will enable ongoing, objective measures of personal health parameters. We will employ new technological innovations in wearable, wireless body sensor developed at the University of Virginia by Dr. John Lach. His TEMPO system monitors individuals on a daily, continuous basis. These non-invasive remote systems allow "real time" data collection in naturalistic settings, a valuable tool for studies in early detection and prevention of problems such as falls and cognitive impairment.

This infrastructure will serve to increase access to outpatient populations for measurement and assessment. It will allow researchers and community organizations to collect and pool data at the aggregate level, so they may tailor studies and interventions for the special needs of the urban and rural elderly.

Background and preliminary work: This project builds on a successful track record between UVA and JABA in collaborative, community-based research. We have engaged in major health initiatives in areas such as long-term care, rural mental health, and dietary nutrition based on locally-sourced foods that have been supported by the National Institutes on Health, the US Department of Agriculture, the Robert Wood Johnson Foundation, the W.C. Kellogg Foundation, and the Older American Act Fund. For the past four years, UVA and JABA have sponsored a competitive grant program designed to bring faculty investigators together with community service agencies to conduct joint research (Appendix 1). This initiative advances the priorities of the 2020 Plan: Aging in Community, nationally recognized by the Administration on Aging as a guide for integrated approaches in response to the dramatic growth in the population 65 and older. UVA and JABA have developed a community infrastructure that includes government agencies, service associations, health care professionals, long-term care providers, consumers and community leaders that will allow us to quickly and successfully launch this project.

The lead investigators represent an interdisciplinary collaboration among community partners, the Schools of Medicine, Nursing, Engineering, Arts and Sciences and Architecture. The team members are:

- **Carol Manning**, Associate Professor of Clinical Neurology, will serve as overall Project Director. Dr. Manning serves as Director of the Memory and Aging Care Clinic in the UVA Health System and Vice

Chair for Faculty Development in the Department of Neurology. Dr. Manning has expertise in cognitive aging and neurodegenerative disease, having published multiple papers and given talks at national and international meetings. Her research involves cognitive control in Alzheimer's and Parkinson's diseases. She has significant administrative experience managing the Memory and Aging Care Clinic and the Behavioral Neuropsychology Laboratory. She has significant ongoing ties with the Alzheimer's Association as Director of the Medical Scientific Committee and a board member and the Jefferson Area Board for Aging. She received a grant from the Commonwealth of Virginia Department of Aging to provide telemedicine consultations to rural health care providers. She has established relationships with providers of health care to the elderly across disciplines at the University of Virginia and throughout Virginia.

- **Gordon Walker**, Chief Executive Officer, JABA, an area agency on aging, will serve as the Community Research Associate. In his position at JABA, Walker has responsibility for the overall administration, planning, and program inadequate coordination of timely services. management of more than 20 services Individuals in medically underserved areas rural areas face special challenges including insufficient supply of family caregivers, home care aides, transportation deficiencies, and across the continuum of preventative care, long-term health care and housing. JABA operates adult day care centers, an assisted living facility and 270 apartments. JABA is the designated Aging and Disability Resource Center for central Virginia. Over the last three years JABA has administered several grants from the Centers for Medicare and Medicaid Services (CMS) to improve the capacity of persons to age at home. The most recent, the Community Living Program, includes a telehealth component. JABA continues to be the lead organization for the development and implementation of the regional 2020 Plan: Aging in Community. Collaboration with UVA has included participation and consultation on fifteen community-university research projects from 2006 to 2009.

- **Suzanne Morse,** Research Associate Professor, Department of Urban and Environmental Planning, School of Architecture. Morse is a nationally known leader in the research and developmental of successful community development research models. As president of the Pew Partnership for Civic Change from 1991-2007, she was responsible for the Partnership's research, grantmaking, and technical assistance components. Her book, Smart Communities: How Citizens and Local Leaders Build a Brighter Future (Jossey Bass 2004) is used across the country as a blueprint for improving the practice and results of collaborative problem-solving. Morse has worked across the country in large urban area, small towns, and regions to help citizens create collaborative practices that can lead to improved economic and civic outcomes for all. With research support from the Kettering Foundation, she is currently examining the engagement of the public by non-profit organizations, higher education, and funding agencies specifically the National Institutes of Health. Her ongoing academic work centers on community development and housing in particular the redevelopment of public housing and the services needed to move residents to self-sufficiency.

- **John Lach**, Associate Professor of Electrical and Computer Engineering, School of Engineering and Applied Science. Lach has been researching and developing wearable, wireless body sensors for the past five years. His Lab has developed the TEMPO (Technology-Enabled Medical Precision Observation) motion capture technology, a wristwatch-like device that allows for continuous data collection and analysis of gait, motion and posture. TEMPO has been deployed in a number of medical research studies, including exploring tremor in Parkinson's disease and Essential Tremor patients and agitation and akathisia in dementia patients. These studies have been enabled by this technology, as they all depend on continuous and precise motion data capture and analysis. In addition, and specifically related to the proposed project, TEMPO has been used to study the relationship between gait disorders and fall risk.

- **Karen Rose**, Assistant Professor of Nursing. Dr. Rose will serve in the role of Co-investigator for this proposal. Dr. Rose's expertise is in improving the quality of life for community-dwelling persons with dementia and their family caregivers. To this end, she has current funding to develop and pilot-test an instrument to measure family quality of life in dementia. Additionally, she has experience in conducting clinical trials using non-pharmacologic interventions to relieve distressing symptoms (sleep disturbances, depressive symptoms) in older adults who are family caregivers of persons with dementia and is completing post-doctoral training in sleep in dementia. Dr. Rose has experience in the development and implementation of academic-community partnerships as she served as the Project Director for "Caregivers

Community Network," a project that received funding through the Administration on Aging's Alzheimer's disease Demonstration Project Award. For this proposal, Dr. Rose will serve as a member of the Leadership team and she will conduct the pilot test of caregiver education, exercise, and consolidated rest/nap for persons with cognitive impairment. In this study, the TEMPO telemonitoring unit will be used as a screening tool to assess gait safety to participate in the study and as an outcome measure of gait and sleep/wake cycle in study participants.

- **Elizabeth Friberg**, Assistant Professor of Nursing. Friberg's focus of interest is in community and population level practice and health services research. Her academic and scholarly endeavors target the independently living elder population, community-based long-term care service infrastructure and issues related to elder functional independence and assessment. She currently serves on the Virginia Department for the Aging, No Wrong Door Resource Team, and the Jefferson Elder Care, Inc. Board of Directors for Mountainside Senior Living, Crozet, VA. She has a working knowledge of the project's pilot sites, working relationships with the agency's staff and the populations served at these sites.

- **John Nesselroade**, Hugh Scott Hamilton Professor of Psychology and Director, Institute on Aging (IoA). Nesselroade is an international leader in lifespan development studies and leads a major NIA-funded training program in quantitative modeling methods. Graduate students and postdoctoral fellows in the training program will team with current investigators, as well as supporting their own investigations employing this data. He will also bring the resources of the Institute on Aging to provide program coordination. The Institute is a pan-university initiative that reports to the Vice President for Research. It acts as a catalyst and coordinator for interdisciplinary research between the Schools of the University, bridging the basic, medical and applied sciences together with clinicians to facilitate translational research. The Institute has bridged research teams and resources from Medicine, Engineering, Nursing and Arts and Sciences to conduct integrated research in key topics including fall prevention, behavioral health, and cognitive impairment, key topics to be addressed through this infrastructure.

- **Karen Rheuban,** Senior Associate Dean for External Affairs and Continuing Medical Education and Medical Director, Office of Telemedicine, School of Medicine. Dr. Rheuban, leads a longstanding and successful program that connects clinicians, educations, and researchers with patients and health professionals located in more than 60 sites in Virginia. The Office has supported more than 16,000 encounters in more than 35 subspecialities. She is the current President of the American Telemedicine Association. She has overseen an innovative collaboration between the University, Habitat for Humanity, the Intel Digital Health Group, and Comcast to fund and construct the Health House. Remote monitoring tools are integrated into a community-based, affordable housing initiative to enhance access to care and to monitor residents in their home setting. Intel equipment will be employed in the project infrastructure for individual home settings.

OPPORTUNITY AND POTENTIAL IMPACT

Research: The project will employ novel mechanisms to advance translational research. The partnership will pool the knowledge, people and resources from the University, JABA, community partners, and the aging population. It will allow a continuous feedback loop to research, informing the next generation of topics. It offers academic investigators a contextual learning environment in which to conduct research and test solutions. It also provides a central place for investigators to introduce new studies to the community.

Another objective of this infrastructure is to facilitate interdisciplinary research. It will be designed to support studies that examine the relationships between physical, psychological, behavioral and social health, and integrated approaches to enable intergenerational, independent living environments. Cross-disciplinary areas of study that will immediately benefit from the infrastructure include fall detection and prevention, cognitive impairment, sleep disturbances, diabetes, and Alzheimer's disease (with pilot studies including these domains already proposed). The IoA will serve to identify and coordinate working groups across the Schools of Medicine, Nursing, Engineering, Arts and Sciences comprised of faculty from the basic, medical and applied sciences, and network them into the infrastructure. IoA and JABA also co-sponsor a community-based research grant program that will be able to support pilot studies.

The infrastructure will also generate research by building on other HHS-funded initiatives at UVA and JABA. At the University, these include: the major NIA training program in quantitative modeling directed by co-investigator John Nesselroade; the Rural Health Care Research Center at the School of Nursing, which examines and tests new methods of extending health care to rural areas; and the Southeastern Rural Mental Health Research Center in the School of Nursing, dedicated to improving health care for impoverished rural minority persons, the elderly, women and children. JABA, as part of the Administration on Aging (AoA) Services Network, is working with Virginia's Department for the Aging in the 2009 Community Living Program, which supports development of telemonitoring in Nelson County, a medically underserved rural community.

The academic-community partnership that is proposed in this application is in alignment with the goals of *Healthy People 2010* (U.S. Department of Health and Human Services, 2006), as we are focusing on all of the 6 determinants of health that are listed in this national agenda: biology, behaviors, social environment, physical environment, policies and interventions, and access to quality health care. Additionally, our academic-community partnership illustrates what *Healthy People 2010* iterates: that there should be increases in the proportion of federal, tribal, state, and public health agencies that conduct or collaborate on population-based prevention research, and that opportunities should be provided to attract new researchers and to encourage collaboration among federal agencies, states, local communities, and academic institutions.

Community: JABA is the designated area agency for aging for the Thomas Jefferson Planning District in Central Virginia, which includes the city of Charlottesville and the counties of Albemarle, Nelson, Fluvanna, Greene, and Louisa. According to the 2000 census, the total population age 65 and over is nearly 200,000, and is projected to grow to 263,820 by 2010, a thirty-two percent increase. Thirty-six percent of people 75 and older live in households with annual incomes under $20,000. Thirty-seven percent have a chronic illness or disability. Barriers in the community to health care include insufficient supply of family caregivers, home care aides, transportation deficiencies, and inadequate coordination of timely services.

Our infrastructure will extend to both urban and rural communities. It will be based at six residential facilities and clinics operated by JABA and government agencies. At each location, the common characteristics of study participants are low income and limitations in independent activities of daily living. The locations include:

- Two public housing facilities (Westhaven Housing Complex and Crescent Halls) owned by the Charlottesville Housing and Redevelopment Authority where JABA operates nurse wellness clinics for residents. Westhaven Housing Complex has 126 units with approximately 25 seniors. Crescent Halls has 105 units with approximately 50 seniors.
- Mountainside Senior Living, a rural licensed 108 bed JABA assisted living facility that operates a nurse wellness clinic for residents. Sixty percent of residents have incomes below $1,200 per month.
- Two *JABA Communities* operated as congregate living sites (Woods Edge Apartments and Ryan School Apartments) with nurse wellness clinics for residents. Woods Edge, located in Charlottesville, has 97 units and approximately 115 residents age 55 and older. Ryan School Apartments, located in rural Nelson County, a federally designated medically underserved area, has 31 units and approximately 32 senior residents whose average income is at or below poverty level.
- The Nelson County Community Center co-owned by JABA and located in a federally designated medically underserved area, serves approximately 60 seniors two-days per week and operates a nurse wellness clinic on those days.

It will also include participation of the home health care agencies of UVA and JABA to collect data and employ telehealth systems in individual home settings.

The infrastructure will facilitate understanding of chronic diseases and their management. It will give the community tools to avoid repeated hospitalizations and enable residents to age safely and independently in the home environment. The data collected will promote effective planning for service delivery targeted to the specific problems within each community.

The data collected and research investigations will also have impact for other AoA networks in Virginia. The Commonwealth of Virginia is currently engaged in a state-wide long-term care system transformation initiative

to improve access to long-term support services; increase consumer choice and control; and transform information technology to support system change. The Virginia Department for the Aging (VDA) in partnership with Senior Navigator is the lead agency for developing a one-stop system for improving access to long-term support services by leveraging information technology. This initiative is No Wrong Door (NWD) and being rolled out by planning district with the local area agencies on aging as regional leads. JABA is one of the current implementation sites for the NWD initiative. The NWD consumer website (Virginia *EasyAccess*) and secure provider portal has the potential to support the provision and transmittal of information and dissemination of findings utilizing the information technology infrastructure thereby advancing academic research that enhances elder choice and control, aging-in-place and home-community-based long-term care services.

APPROACH

We propose to invest in building our infrastructure in two areas: people and technology. Because the literature suggests that building trust and good communication processes are foundational for building long-term, sustainable academic - community partnerships, we have chosen to invest 2/3 of the financial resources in this application to "people" and the remaining 1/3 of financial resources to "technology." The project timeline, milestones, expected measurabe outcomes and deliverables, and possible alternative paths to be taken as needed are depicted in Table 2.

Plan for Community Partnerships: Community-academic partnerships around health research have historically been too unilateral and invasive to allow for the discoveries and sustainability required for the transfer of protocols and technologies necessary to change the health outcomes for aging patients. The community engagement model proposed builds on the synergy of a trilateral approach to health research that encourages a different level of conversation and interaction with the community and a deliberate intent to make stakeholders—partners not participants. Dr. Suzanne Morse, a renowned expert in civic engagement across the U.S. and a faculty member in the Architecture School at the University of Virginia, will lead the community engagement model ("people") that serves as the foundation for the development of bi-directional communication across all partner entities. The partners, roles and responsibilities are shown in the following table:

Partner	Roles	Responsibilities
Jefferson Area Board on Aging	CRA Health Care Coordination	• Engage with JABA sites, clients, service provider partners and staff in ongoing manner to ensure active participation by all. • Recruit study participants • Educate clients and JABA staff re: telehealth applications. • Plan for integration of existing projects with this project (e.g., USDA food initiative, the CMS Community Living Project, ADRC development). • Cultivate resources, funds for sustainability. • Assist with leadership development design and presentation.
University of Virginia	PI and Co-investigators	• Execute leadership development plan. • Engage and communicate with all partners. • Develop and disseminate infrastructure opportunities to UVA researchers. • Deploy telehealth technology throughout 6

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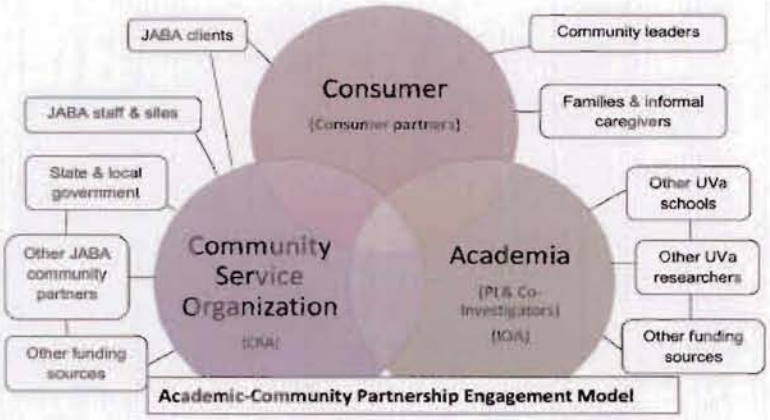
		JABA sites. • Cultivate resources, funds for sustainability. • Develop and submit end-of-year reports to NIA. • Pilot test telehealth technology through pilot research study. • Cultivate additional community partnerships.
Stakeholders (resident associations and site councils)	Stakeholder Board members	• Partner in development of on-going communications structure and processes. • Participate in needs assessment . • Engage in ongoing communication and pilot-testing of telehealth monitoring.

Using a "hub and spoke" design, the University of Virginia and its Community Research Associate (CRA), the Jefferson Area Board of Aging, propose to create an avenue to research and practice for older adults in the Planning District 10 that gives them access to the latest mobile telehealth technologies while providing needed "real-time" data related to intervention research that encourages older people to stay in their homes and be vital throughout their lives.



Academic-Community Partnership Engagement Model

The "hub" of the community engagement model will be UVA, the CRA, and an advisory group representing the stakeholders from all the potential sites. It is important to build an initial foundation and relationship with multiple sites for long-term partnership not just with those that will participate in the initial research phase. The "spokes" of the community engagement model are a range of organizations and individuals that have a stake in improving the outcomes for older adults. This would include but not be limited to the city, county, and state governments, other health service providers including medical centers and clinics, caregivers, local and state funding agencies, and resident associations of senior center and housing developments. The combination of these constituents gives this model the elements so often lacking: 1) ways to communicate broadly through

and -with trusted partners; and 2) avenues to reach stakeholders who may not know or be afraid of participating in research studies.

This model of engagement requires frequent interaction between the hub institutions and organizations and the spoke entities. This will require a range of engagement techniques, information and dissemination, and leadership development that expands the circle and allows all parties to build trust, develop communication patterns that are appropriate and comfortable for the stakeholders, and to find regular outlets both formal and informal to highlight findings from the work. These will include but not be limited to the following:

ENGAGEMENT TECHNIQUES. Focus groups, large group meetings, and one-on-one conversations will be used throughout the two-year process but particularly at the start-up phase. The hub organizations—Health Center, CRA, and advisory group—will organize a range of ongoing interactions on-site(s) with the health professionals who lead the study and the stakeholders who will participate in the research to provide information about the proposed research but most important ask and listen to the answers to the following questions:

- What are the kinds of health conditions that concern you most and what does the research suggest about their prevention?;
- What are the anticipated and the expected results from initiating and participating in a research study?;
- How will the research study work and who will be my primary contact person?;
- How will the lessons learned from the researchers and the stakeholder participants be shared where I live and with the larger audience?;
- How will research findings better enable local community policy makers and service providers to design improved care delivery processes and products?.

These questions set up a community dynamic that encourages a two-way, synergistic conversation about the process, the outcomes, and the results from the very beginning. It translates this approach to research to a critical but simple question: How will participating in this kind of research study help me and help my neighbors? All research on community engagement, particularly with seniors, suggests that ultimately people want to make a difference for themselves and others.

- INFORMATION AND DISSEMINATION is a critical component of the infrastructure. It encourages trust in the early stages of the research but as important is that this is the key strategy for long-term sustainability. This effort requires a clear understanding of how the range of partners who will participate in the research either as stakeholders or supporting organizations, get and receive information, and the avenues most trusted. National surveys have shown that the most favored information source among all ages and income levels are people you know. This requires going beyond a press release or an editorial board meeting in the information and dissemination process. This model will be built on getting accurate information to and from stakeholders first but also their caregivers and others in the process who can answer questions on the ground and dispel misleading information. Most important, the communication vehicles must assure all the partners of the importance and the impact of community-based research on people's lives. The "hub" organizations will work together to develop strategies and opportunities to improve access to research results, and recommendations.

- LEADERSHIP DEVELOPMENT will be an ongoing part of the model in order to build sustainability for the infrastructure by fostering new collaborative skills so that the partners can plan together the transition from research to community practice with full community ownership. There will be five leadership retreat sessions during the duration of the grant. In July 2010, representatives from all six project sites and well as the "hub" partners will participate in a train-the-trainer session and be licensed to offer the nationally known community leadership program, LeadershipPlenty® in each site. This training will build the capacity of all the stakeholders by creating an asset-based community-driven program housed at each of the six sites. Using the focus of aging in place as the foundation, participants will develop their skills through these site-based leadership programs to build and work more effectively in partnership with others, implement action plans for change, and manage conflict. This project has a proven track record of community change. An independent evaluation on the application of LeadershipPlenty® in the Northwest Area Foundations Horizons program conducted by QED Consulting showed that participants who completed the training had highly significant gains in leadership capacity (greater than a 99% probability that this gain was a result of

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the program and not a chance occurrence). This type of skill-based training will add to the effectiveness of the community infrastructure and strengthen the aims of this project in several key ways: 1) increased knowledge of community change projects; 2) better understanding of how partnerships influence community problem solving; and 3) improved methods for understanding the value of group problem solving efforts. (QED:LeadershipPlenty® Update, October 1, 2007).

The facilitator training will be held in July, 2010. Subsequent daylong sessions will occur in October 2010; and February 2011. These meetings will provide opportunities for the trainers from each site to report back on the discussion and input of community participants and others from the site who are receiving the leadership training. The concluding session in July 2011 will allow the facilitators to evaluate the research design used and how it will be sustained going forward.

Telehealth and Telemonitoring Systems: New technologies have shown success in chronic disease management. For example, the Department of Veterans Affairs has reduced hospital readmissions by nearly 20 percent through its telehealth programs. Our project will employ these systems as tools to facilitate data collection in remote settings.

The Office of Telemedicine will draw on its work in the Health House project, which uses a remote monitoring and videoconferencing technology that transmits vital signs and other medical readings. It will adapt these systems to test a diverse number of research initiatives in areas including congestive heart failure, chronic obstructive pulmonary disease, and diabetes. The Office will also develop a secure platform for remote monitoring that will be accessible by all the partners and allow for integration of research investigations.

Body-worn sensors are emerging that have the potential for tremendous impact in healthcare and medical research, both for improving the quality of care and for reducing healthcare costs. Instead of relying solely on expensive and invasive in-patient monitoring, infrequent and inconvenient clinical visits, and qualitative and imprecise patient self-reports, inexpensive body-worn sensors enable continuous, non-invasive collection of key physiological and biokinetic parameters over an extended period of time and in any location. This data can greatly enhance healthcare professionals' abilities to diagnose, monitor, and care for their patients, all while enabling patients to maintain their independence. The data can also be provided to family members and even to the patients themselves, empowering them to participate in their own care.

The continuous and remote monitoring capabilities of body-worn sensors provide a natural extension to telehealth technology, which has been developed to address many of these same issues. The telehealth technology also provides a conduit and infrastructure for the downloading and relaying of the data to the relevant stakeholders.

The TEMPO system – providing high-precision motion capture and analysis to aid in a variety of medical research and healthcare applications – is only one example of this emerging family of body-worn technologies. Sensors for nearly any physiological parameter are emerging, including a number of sensors that are being incorporated into healthcare and medical research applications. For example, the Sensium™ from Toumaz Technology (http://www.toumaz.com/public/news.php?id=91) provides heart rate, body temperature, respiration, and a number of other parameters via a patch that adheres to the skin like a small adhesive bandage. The Sensium™ is currently undergoing an extensive clinical trial to demonstrate the relevance of the collected data in healthcare practices and ultimately the impact on patient outcomes. The proposed project includes interfacing TEMPO and a sampling of other body-worn sensors like Sensium™ (to be selected based on the needs of research projects and as requested by patients and community partners) with telehealth technology, enabling a wide range of medical research studies and enhancing the current capabilities of telehealth-based medicine.

The TEMPO system can be immediately deployed to study the relationship between gait disorders, cognitive impairment, and fall risk. The TEMPO body area sensor system was designed to provide precise human motion and orientation data continuously and non-invasively in any location over an extended period of time [Bar09]. TEMPO supports up to seven wireless sensors nodes that can be placed at arbitrary points of interest on the human body. Sensors capture three axes of both linear acceleration and angular rate, providing six degrees of freedom motion capture in the form factor of a wristwatch.

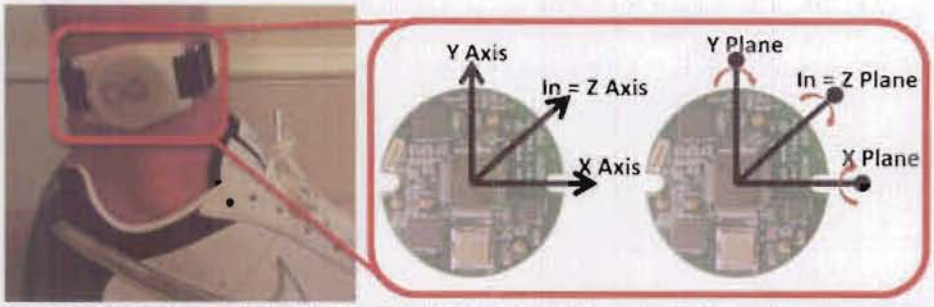

Figure 1. TEMPO node providing six degrees of freedom motion capture in a wristwatch form factor

Pilot Studies: The infrastructure will be tested and evaluated during the project period through two pilot studies.

Pilot #1 – The purpose of this pilot is simply to validate the capacity of the telehealth system (data collection, storage, retrieval), and to test the infrastructure processes for gathering information regarding the barriers and facilitators to participation in health sciences research from the study participants perspectives. For pilot-testing purposes only, study participants will be asked to wear the TEMPO device for 1 week for collection of gait and sleep/wake cycle data and will be monitored for other parameters ables, such as blood pressure, heart rate, and others, asare identified as important parameters of health from the resident stakeholders. As the pilot-testing will be used for descriptive purposes only, all residents of the 6 JABA sites will be invited to participate in this pilot project. There is no proposed intervention for this pilot-testing study.

Pilot#2 - Beyond cognitive impairment, impaired behavioral responses to stress, sleep disturbances, and declining physical health are central clinical features in persons with Alzheimer's disease (PwAD). A *combined, tailored caregiver education program on ways to lower **a**ccumulated **s**tress, increase **e**xercise, and consolidate daytime rest/nap in persons with **A**lzheimer's **d**isease (**LASER-AD**)* holds promise for improving cognitive function, impaired behavioral responses to stress, sleep disturbances, and physical function in PwAD. Data on gait in PwAD will be obtained by telehealth technologies (TEMPO) as a measure of safety to participate in the study and as an outcome measure of sleep and physical function.

The sample for the pilot study will consist of 10 caregiver/care-recipient dyads of PwAD. Participants will walk 5 times each week with their caregivers for up to 30 minutes during each morning walk; will rest/nap each afternoon for a maximum of 90 minutes; and caregivers will receive 3 standardized education sessions regarding recognition and response to behavioral responses to stress in PwAD, followed by 2 therapeutic telephone calls to problem-solve any difficulties that the caregiver may be encountering in implementing LASER-AD interventions over 8 weeks. Cognitive testing will occur at study entry and study completion. Study findings will be used as a foundation for the development of a subsequent large-scale research proposal (R01) by the Project Director, Dr. Karen Rose, who is an early-stage investigator.

TIMELINE, MILESTONES, EXPECTED MEASURABLE OUTCOMES AND DELIVERABLES

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The project timeline, milestones, expected measurabe outcomes and deliverables, and possible alternative paths to be taken as needed are depicted in the table below:

Timepoint	Milestones	Expected Measurable Outcomes and Deliverables	Possible Alternative Paths to be Taken
3 months	Training of all parties; Leadership teams assembled and first	• Process for making decisions at team levels and at project level is established.	Additional meeting times/communication per Suzanne Morse if

	meetings have occurred.	• Telemedicine Project Coordinator hired and oriented to role & responsibilities. • First "Leadership retreat" is held. • 1st draft of plans for sustainability are developed.	deliverables not met.
6 months	Leadership teams meeting on regular basis; specifics of telehealth/telemonitoring installation being addressed.	• First draft of plan for preparing, deployment and evaluation of remote monitoring and home telehealth systems completed. Draft of proposed secure platform, home telehealth technology, and broadband communications services for 6 facilities presented to leadership team for review. • Second "Leadership retreat" held. Leadership meeting minutes with long-term goals established; meeting minutes reflect discussion of infrastructure desires of 6 sites and infrastructure capacity of telemonitoring disoussed.	Additional meeting times with Suzanne Morse if deliverables not met.
9 months	Leadership teams meeting on regular basis; specifics of telehealth/telemonitoring installation being addressed.	• Revised draft of plan (as above) completed. • Leadership meeting minutes with long-term goals established; meeting minutes reflect discussion re: infrastructure desires of community partners, JABA, and UVA discussed.	For work groups that have not made satisfactory progress, we will have "Project level" leadership team intervene.
12 months	Initiation of telemonitoring broadband cable, etc. Leadership teams have developed "success" criteria	• 3rd "Leadership retreat" is held. Final plans for sustainability are prioritized and plan of action is executed. • Installation of telemonitoring equipment to all 6 sites is occurring per schedule; Training for health care providers in telehealth and telemonitoring occurs at remote facilities; 1st year report submitted to NIA	Telemedicine Project Coordinator will address any unforeseen challenges with installation of telemonitoring.
15 months	Pilot-testing of telemonitoring capacity. Additional researchers throughout UVA propose projects that use the infrastructure processes.	• Guidelines & criteria for researchers to present research proposal to Community-Academic Partnership • Results of pilot testing of equipment are compiled; decisions made by teams re: adjustments that are needed	Telemedicine Project Coordinator and John Lach will address any unforeseen challenges with installation of telemonitoring.
18 months	Pilot projects are launched to evaluate both "people" and "technology"	• Volunteer participants from all six sites are enrolled in Pilot Study #1	Engage Continuum Home Health services for identification of additional

	infrastructures. Additional researchers throughout UVA propose projects that use the infrastructure processes.	• 10 participants enrolled in Pilot Study #2.	potential study participants in their service areas.
21 months	Leadership teams continue to meeting on regular basis;	• Pilot studies evaluated. • 4th Leadership Retreat is held. Ongoing evaluation of telehealth applications through focus groups. • Ongoing evaluation of telehealth applications through focus groups.	Engage Continuum Home Health services for identification of additional potential study participants in their service areas.
24 months	Development of potential research projects continues.	• 5th Leadership Retreat is held. Recommendations are made for next steps in collaboration processes. Final Report submitted to NIA.	

LONG TERM SUSTAINABILITY PLAN

The sustainability plan is multi-faceted. The IoA, a pan-University initiative which stimulates interdisciplinary engagement and ongoing research, has a functional structure which involves the formation of working groups to foster the formulation of mature research questions and potential mechanisms to address those questions. The Institute has historically provided small pilot grants (Appendix 1) for the purpose of gathering preliminary data. In addition, the Institute collaborates with JABA to foster and fund community-based research performed by University/community teams. These seed mechanisms have generated substantial funding success. There are a number of burgeoning areas of research that could be immediately deployed upon establishment and preliminary testing of the proposed infrastructure. These include projects that involve interdisciplinary teams in social and emotional wellbeing, geriatric medicine, renal function and wound care. It is clear from the letters of support provided by cognizant deans and the Vice President for Research that generating and maintaining a systematic mechanism for community-based research is highly valued at the University of Virginia (Appendix 2)

The Institute also works closely with the Office of University Community Partnerships. Reporting to the Provost, this Office advances a university priority to connect academic research and education to public service. It helps support over 450 public service programs that serve over one million people each year. It administers the Community Engage Network, comprised of central public service and community engagement administrators that meets monthly to facilitate partnerships, and will be another resource to support the infrastructure.

Through an ongoing dialog with the Virginia Department for the Aging, reflected in the letter of support provided by the Commissioner, our goal of establishing an accelerated feedback loop for to inform best practices and improve patient care consistent with the goals of the Commonwealth of Virginia and the federal Administration on Aging. Our infrastructure plan would provide a mechanism for dissemination of our research findings. We have already begun discussions regarding the potential for expansion of our plan to other area agencies on aging, which are contiguous to the Jefferson Area Board for Aging. Expansion of our model, which includes both urban and rural populations, could readily become a model for the Commonwealth.

The University of Virginia is home to a number of mechanisms which train the next generation of researchers in aging. Our international training programs and collaborations with the Max Planck Institute as well as the National Institute on Aging training grant, 2 T32 AG020500-06, Quantitative Training in Aging, are mechanisms which provide opportunities for collaboration within and education of future cohorts in aging research. John Nesselroade serves as director of the training grant and the Max Planck LIFE program. As such, Nesselroade is uniquely positioned to formalize dissemination of research findings to both the U.S. and international cohorts through an ongoing series of classes via AccessGrid.

The IoA is already engaged in ongoing collaborative efforts with the JABA that includes joint fundraising. This effort has raised federal and foundation grants to support major programs, such as building community infrastructure for food systems that bring locally-sourced foods to low-income older adults for dietary health. The NIH infrastructure award is expected to leverage support from regional foundations, as well as grants for specific research projects from NIH and other federal agencies.

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RESOURCES

The project will draw on the following resources to develop and sustain the infrastructure:

The Institute on Aging

The Institute on Aging (IoA) is a pan-university initiative sponsored by the Office of the Vice President for Research and Graduate Studies. It promotes basic and applied research on topics related to aging, serves as an information and education resource about aging issues, and seeks to influence the development and implementation of public policy that addresses the needs of older adults. To that end, the Institute offers seed money grants to stimulate new research and educational programs, and sponsors lectures and conferences for scholars, service providers, and the community at large. The Institute is directed by John R. Nesselroade, a leading authority on quantitive research methods in the field of lifespan development and the aging process. Its Advisory Board is comprised of faculty from the UVA schools of Arts and Sciences, Architecture, Education, Engineering, Law, Medicine and Nursing. The IoA also engages in partnerships at both the international and community levels, to stimulate cross-cultural and translational approaches to the study of aging.

The School of Medicine

Principal Investigator Carol Manning is faculty in the **Department of Neurology**, Virginia's foremost research and treatment center for disorders affecting the nervous system. The Neurology Department at The University of Virginia Health System is among the nation's top 20 centers ranked by U.S. News & World Report. The Department of Neurology is Virginia's foremost research and treatment center for disorders affecting the nervous system and it offers the most advanced diagnosis and treatment for strokes, headaches, epilepsy, dementias, movement disorders, brain tumors, multiple sclerosis, and all other neurological disorders and diseases.

Dr. Manning also directs **The Memory and Aging Clinic** in the Department of Neurology, which is dedicated to helping people cope with challenges brought on by impaired memory and related complications. The Program was established in 1990 to provide comprehensive treatment of memory disorders through a multidisciplinary team of neurologists, neuropsychologists and neuroradiologists. It offers diagnostic services,treatment, support and education for patients and their families. Patients and families of patients faced with a memory disorder are often under a great deal of stress. The program offers a broad range of special services to make a visit as comfortable as possible in a private and non-threatening atmosphere.

Office of Telemedicine. Co-investigator Karen Rheuban leads a longstanding and successful telemedicine program that connects clinicians, educators, and researchers with patients and health professionals located in more than 60 sites in the Commonwealth. It has supported more than 16,000 clinical encounters in more than 35 subspecialties in healthcare. The Office of Telemedicine has secured more than $5 million in federal, state, corporate and foundation grants to enhance access to care for patients located throughout Virginia.

The University, the Office of Telemedicine and Continuum Home Health have partnered to fund, construct and launch an innovative collaboration with Habitat for Humanity, the Intel Digital Health Group and Comcast Cable, "Health House", in which remote monitoring tools will be integrated into a community based affordable housing initiative. Telemedicine, home telehealth and remote monitoring tools provide a unique opportunity to enhance access to care, and to monitor patients in their home setting. Congestive heart failure, chronic obstructive pulmonary disease, hypertension, and diabetes have been targets for many home telehealth proposals. It will use the above model in partnership with the Jefferson Area Board on Aging and our regional home health agencies to develop the infrastructure in both rural and urban settings to establish the infrastructure required to test a diverse number of research initiatives addressing chronic disease, fall prevention, and other conditions of the aging population.

The School of Nursing

The **Rural Health Care Research Center (RHCRC)**, an interdisciplinary research center located in the School of Nursing is funded by the National Institute of Nursing Research for the time period of 9/30/04-6/30/09. The goals of this center aim to promote the development of infrastructure to strengthen the research environment in

the School of Nursing as well as to conduct and advance rural health care research. The RHCRC seeks to increase the research capacity of the SON and the research capability of nursing faculty while promoting interdisciplinary collaborations and research. This center provides the infrastructure to conduct and disseminate research responsive to the clinical and information needs of rural populations in the United States. The RHCRC tests innovative clinical and system interventions for the rural health care system and adapts existing interventions for use in rural areas. This center promotes the development of researchers through the provision of ongoing development activities such as monthly Think Tank Sessions, consultant visits, workshops and conferences. It provides ongoing availability of methodological experts including statistician support and the inclusion of an expert on the development of culturally relevant research designs.

The **Southeastern Rural Mental Health Research Center is** dedicated to improving health care for impoverished rural minority persons, the elderly, seriously mentally ill adults, and women and children. Center faculty are working to develop the capacity of the rural mental health service delivery system and rural mental health researchers through development of partnerships with consumers and rural health care providers, engaging in community-based research, development of interdisciplinary research teams, and investigator development all facilitated by "state of the art" communications technology. The center began in 1992 with funding from NIMH as a public-academic liaison (PAL) mental health service research center focused on the rural Southeast, with this funding ending in 2000. Center faculty developed a strong portfolio of research documenting unmet need for mental health care, the poorly resourced mental health system in the rural Southeast, and individual and community level factors that contributed to under treatment of rural dwellers. One outcome of this research is the defacto model of Rural Mental Health Services Research which depicts the fragmentation of the mental health service delivery system, the influence of population and rural environmental characteristics on the care system, portals of entry and outcomes treatment. A particular emphasis of its research is impoverished rural minority populations and the development of culturally acceptable mental health care services. Center faculty have a commitment to a strong consumer perspective that guides our evaluation of existing practice environments, the development of interventions, as well as a commitment to recognizing and supporting informal care. Studies used state of the science qualitative and quantitative methods, and included primary data collection studies as well as the use of large nationally representative secondary data sets.

The **Center for the Study of Complementary and Alternative Therapies (CSCAT)**, a collaborative center committed to evaluating and disseminating information about integrative health care practices and products for reduction of pain and other pain-related symptoms, was established in 1995 at the University of Virginia as one of the original NIH-funded centers to stimulate research in complementary and alternative medicine (CAM). The research theme in the CSCAT has focused on pain and pain-related symptoms as well as the study of basic physiological mechanisms underlying the beneficial effects of selected CAM modalities. A range of research opportunities exists in the five CAM program areas. The CSCAT promotes information exchange through seminars, generates new research ideas, and fosters interdisciplinary collaboration among students, trainees and faculty in four major schools within the University of Virginia (Schools of Nursing, Medicine, Engineering and Applied Science's Department of Biomedical Engineering, and the Curry School of Education). The CSCAT provides superb facilities at the University of Virginia where CAM research is carried out and research training provided for both pre- and postdoctoral trainees.

The School of Nursing's **Center for Nursing Research (CNR)** provides support to faculty and graduate students in all aspects of grant proposal preparation, including budget formulation, biosketches, resources and environment information, preparation and copying appendix material, assurance of proposal compliance with sponsor requirements, and routing of proposals through the institutional approval process. To further support the research enterprise of faculty and students, the School of Nursing and the CNR began in the fall of 2001 the "Virginia Nursing Research Enhancement Initiative". This initiative involves several components to increase research and scholarly activities in the School of Nursing. The SON has contracted with Dr. Ada Jacox, an expert consultant with a distinguished research career, to work closely with faculty and graduate students to help them develop research trajectory plans with yearly goals and evaluations. Dr. Jacox provides monthly consultation to support faculty research.

The School of Engineering and Applied Science

Co-investigator John Lach is a member of **The Inertia Team**, a lab that researches and develops body area sensor networks for medical applications. It is involved in major studies in aging and gait, neurosurgery and neurology, physiology, and psychology. It seeks to develop tools for data collection through objective motion measures, in order to enhance medical research and develop technologies for independent living.

University of Virginia Health System

Continuum Home Health has been in business since February 1995 and is the largest home health agency in Central Virginia. Structured as a department of the University of Virginia Medical Center, Continuum provides two integrated product lines: home health and home infusion. Through its home health service, Continuum provides all the traditional direct home health services (ie Registered Nurses, Physicial and Occupational Therapists, Speech-Language Pathologists, Social Work and certified Home Health Aides) to patients requiring skilled home health care under the supervision of a physician, and who reside in one of the ten counties of Central Virginia which include the counties of Albemarle, Greene, Madison, Orange, Fluvanna, Louisa, Buckingham, Nelson, Augusta and Rockingham. Additionally Continuum also provides a number of specialty programs such as its Psychiatric Service, Pediatric Service, specialized Wound Care Program and a Nutritional Support Team. Through its home infusion product line, Continuum provides an array of enteral, parenteral and IV therapies (some examples being IV antibiotics, pain management and chemotherapy) from its own on site home infusion pharmacy and supports patients with these needs who reside anywhere in the State of Virginia or in the surrounding states of West Virginia, North Carolina or Maryland. If a Continuum home infusion patient resides outside of its direct service area, then Continuum will work with another identified certified home health agency to provide the necessary skilled nursing support.

Continuum Home Health cares for patients referred from a number of area and out of area hospitals, insurers and physician practices or through patient self referral. With its focus on maximizing patient/family capabilities to manage care at home, Continuum routinely exceeds both State and Nationally publicly reported patient outcomes benchmarks

Jefferson Area Board for Aging

JABA Health Services are provided regularly for seniors. Clinics are scheduled at JABA Community Centers and Adult Care Centers, as well as other locations in the community (JABA communities and public housing sites). Homebound clients may also request a visit at home. Emphasizing health promotion and disease prevention, the **JABA health model** provides a geriatric assessment and intervention team consisting of a nurse practitioner, a registered nurse case manager and a geriatric case manager. Working closely with clients, their caregivers and primary physicians, the nursing staff provides screenings for blood pressure, height, weight, vision, hearing and diabetes. They also provide treatment for minor illnesses and injuries, infections, foot care, hygiene, diagnostic test, and prescription assistance and counseling. JABA's Health Services are made possible through the generosity of the University of Virginia-School of Nursing, United Way, the Charlottesville Housing and Redevelopment Authority, and local jurisdictions.

JABA operates two (2) **Adult Care Centers** (Hillsdale location and Louisa County), serving individuals (18 years and older) who need assistance with daily health or personal care activities. These centers provide social and recreational programs; hot, freshly prepared lunch incorporating local foods when available; two healthy snacks and special diet supplements when required. These sites specialize in dementia care. Guided by the specific needs of a personalized care plan, JABA nurses monitor health, administer medication, and oversee specialized Alzheimer's and dementia care.

JABA operates eight (8) **Community Centers**, serving independent adults (age 60 and older). These centers provide a broad range of health-related and therapeutic programming; hot, freshly prepared lunch incorporating local foods when available; and opportunities for intergenerational activities. Many Community Center sites offer home delivered meals (*). Cooking classes for preparing tasty, healthy meals to stretch a food budget are conducted at the Hillsdale location.

JABA operates residents-only, nurse-managed wellness clinics at four (4) **JABA Communities (**three independent living retirement communities and one assisted living facility). In partnership with the

Charlottesville Redevelopment & Housing Authority (CRHA), JABA operates two (2) residents-only, nurse-managed wellness clinics in **public housing complexes**.