Project Summary

**EAGER: In-Home Monitoring in Support of Caregivers for Patients with Dementia**

This project develops, integrates, and tests advanced video and networking technologies to support family caregivers in managing behavioral symptoms of individuals with dementia, a growing public health problem that adds to caregiver stress, increases morbidity and mortality, and accelerates nursing home placement. The project builds upon a recent University of Kansas Medical Center (KUMC) clinical pilot study that tested the application of video monitoring in the home to support family caregivers of persons with Alzheimer’s disease who exhibited disruptive behaviors. The proposed project focuses on expanding the in-home technological tools available to strengthen the linkage between patients and caregivers with their healthcare team via multi-camera full-motion/high definition video monitoring. Google’s deployment this year of a 1 Gbps fiber network throughout Kansas City provides the ideal environment for measuring the impact that ultra-high speed networking will have on health care.

Captured video will be streamed and stored on secure cloud-based servers. Upon notification and authorization by caregivers, the videos can be made accessible for viewing by clinical experts from web-enabled devices for the purpose of providing feedback to the caregivers in the home. To further enhance patient-caregiver support, the project will seek to incorporate technology developed through another National Science Foundation/EAGER – US Ignite initiative. This initiative, *Enhanced care through multipoint HD Video Conferencing* from Case Western Reserve University, provides low-latency, high-quality videoconferencing capability that would be particularly valuable over existing technology by supporting direct video communication between the patient and their multidisciplinary care team.

**INTELLECTUAL MERIT.** The proposed research application provides the laboratory to model how patient-controlled personal digital records (video) might interleave with health care professionals who traditionally interact with electronic medical record systems controlled by a healthcare provider organization. The project will evaluate the applicability of GENI software defined networking and OpenFlow/Openstack technologies to support the secure transmission and storage of personal health information with the Google Fiber network. Further, within the project, metrics and measurement techniques will be developed for Google’s network to create an understanding of the scalability of home monitoring in conjunction with the expansion of video communications to support healthcare professionals working at home and in distributed teams.

**BROADER IMPACT.** The technology platform will be applicable to a broad range of both physical and behavioral illnesses/conditions and caregiver/parental situations with the subsequent result being: 1) improvement in care/treatment within home-based settings; 2) avoidance or reduction of nursing home placements, hospital admissions/readmissions or other institutionalizations; 3) improvement in the quality of life of caregivers; and 4) overall reduced costs for the health care system. Potential applications for this monitoring platform may also be extendable to care settings outside the home. The project will also catalyze multidisciplinary research and education between electrical engineering/computer science, medical informatics, nursing, and other health professions and support the training of graduate students.

**Key Words:** Video Monitoring; 1 Gbps Fiber Network; Dementia; Remote Care Coordination; Home-based Care; Multipoint HD Video Conferencing, Cloud-Based Servers; GENI
# Project Description

1. **Introduction and Motivation**

   Family caregivers currently provide $375 billion in care (National Alliance for Caregiving, 2009) for 35.6 million persons with dementia, a population is forecasted to grow to 115.4 million by 2050 (Wimo & Prince, 2010). Yet, the physical and psychological stress of caregiving results in depression, insomnia, and psychotropic drug use, and increases caregiver morbidity and mortality (Hooker et al., 2002). The stress and negative health outcomes experienced by family caregivers of PWD have recently been recognized as a growing public health problem (Talley & Crews, 2007). Disruptive behaviors such as physical aggression and vocal outbursts that occur in 90% of PWD are particularly stressful for caregivers and frequently accelerate nursing home (NH) placement (Kunik et al., 2010).

   Identifying antecedents, consequences, and the function of behavior is the most effective way to prevent and manage disruptive behaviors in PWD (Moniz-Cook et al., 2008). Dementia care professionals can observe behavior, identify precipitating factors, select targeted interventions, and can guide caregivers in effective behavior management interventions (Moniz Cook et al., 2008). Linking caregivers to health care professionals is critical for successful dementia care in the home (Talley & Crews, 2007).

   The proposed study will fortify these linkages using home monitoring to provide observational data, interpreted by experts who can guide family caregivers in strategies to continue to care for their loved one at home. Caregivers that use technology overwhelmingly report that it reduces time and stress, increases ease and efficacy of providing care, and improves safety of the care recipient (National Alliance for Caregiving, 2011). The project builds on a 2011 pilot study that established feasibility for home video capture of disruptive behaviors as these occur using a remote-controlled web cam to capture the preceding 15 minutes of video footage, thus recording triggers to disruptive behavior. The home monitoring technology used in that pilot study had previously improved parent and teacher success in managing behavior problems of autistic children in home and school settings (Oberleitner et al., 2007; Reischl & Oberleitner, 2009).

   The US Ignite program aims to foster the development of applications enabled by high-bandwidth access that benefit a significant portion of the US population, including healthcare delivery. The NSF GENI program is constructing programmable network infrastructure to enable network researchers to experiment with Future Internet architectures and will provide the flexibility needed to meet the goals of the US Ignite program. The proposed work will exploit the capabilities of GENI, in general, and the KU GpENI and KanREN–GENI projects in particular to help meet the goals of the US Ignite program, and explore the benefits of flexible networking to exploit high-bandwidth access to support family caregivers.

   In March 2011, Kansas City, Kansas “won” a nationwide Request for Information (RFI) solicitation for construction of a next generation broadband network by Google achieving upload and download speeds of 1 gigabit per second (Google 2011). Google subsequently announced the expansion of service to Kansas City, Missouri for a potential deployment of 500,000 individuals. The University of Kansas Medical Center’s (KUMC) early support led to a collaborative working relationship between KUMC Medical Informatics and the Google Fiber team to explore leveraging the technology to further health care delivery, education, and research. On July 26, 2012, Google unveiled their services and began preregistration throughout the Kansas City metropolitan area. KUMC is actively participating by providing nutritional consults via telepresence as part of the Google Fiber Space located a few blocks from the medical center.
campus.

The combination of prior NSF GENI funded network investigators, clinical pilots seeking to support caregivers with video capture technology, medical informatics software development expertise, and early engagement with the Google Fiber deployment provides a unique opportunity to improve healthcare by cultivating next generation gigabit applications in a market likely to have the largest 1 GBps fiber deployment in the nation. Furthermore, while this project seeks to use evolving GENI infrastructure, there is no current NSF program directly supporting research for healthcare applications on GENI. We are also unaware of any NIH funding opportunities to conduct research in the areas of next generation networking and gigabit applications. These factors support this project as an EAGER.

2 Proposed Research

The proposed project will have three phases. Phase one develops use cases and requirements, identifies appropriate emerging technologies for the project, and defines modifications required to support the health care delivery process. The second phase will include technology integration, application development, and the development of metrics around network requirements for delivering new transformative healthcare processes. Finally, upon identification of the research subjects (anticipated to be healthy elderly volunteers), we will evaluate the usability of the technology as well as metrics and measurement techniques to project bandwidth utilization and scalability.

2.1 Requirements Analysis and Technology Evaluation

Phase 1 will include requirements definition, the development of use cases, and the creation of the solution platform for the primary and secondary applications:

1. Marking, transmitting, reviewing/monitoring, and providing feedback of personally recorded video. While not within the scope for demonstration we will anticipate expansion to incorporate technologies developed through NSF EAGER initiative In-Home Health Alert System with Remote Care Coordination from the University of Missouri, which uses passive, high bandwidth in-home sensors (Skubic et al., 2009)

2. Leverage recently funded NSF/US Ignite technology (NSF News, 2012) to initiate real-time video based coaching between the caregiver in the home and provider with extension to the multidisciplinary care team.

We hypothesize future systems will have the personal digital record at the control of the family, typically provisioned by commercial off-the-shelf (COTS) infrastructure such as the 1 TB of Google Drive (Google, 2012) storage included for Google Fiber customers or cloud based video monitoring services such as Dropcam (Dropcam, 2012). Such personally controlled systems will serve a variety of functions and not be dedicated to providing information for healthcare alone. Instead, methods need to dynamically provision information to the provider. Healthcare providers’ infrastructure is typically aligned with their provider organization. Provider effectiveness increases when information integrated into their clinical workflow which increasingly revolves around electronic health record (EHR) systems (Poissant et al., 2005). While we will not be fully integrate personal digital records within an operational EHR in this project, we will design protocols and prototypes with that goal in mind. We will also consider the role of personal digital data with respect to provider-centric EHR patient portals and personal health records (Tang et al., 2006, Halamka et al., 2008, Tsai & Rosenheck 2012) and emerging national standards for direct exchange (ONC, 2010). We will evaluate the clinical pilot’s Behavior Imaging Solutions technology with COTS.
technologies for video-monitoring and storage compatible with Google’s home network (video acquisition and display devices, wireless routers, consumer cloud storage options) and the appropriate role for GENI technology for transmission and provisioning functionality for the healthcare provider organization. A very brief overview of the various technologies that will be evaluated follow.

2.1.a Requirements and Use Case

Figure 1 provides a high level diagram of the technology deployed in the current clinical pilot study.

![Diagram](Image)

**Figure 1: Current clinical pilot for video capture and review**

The Laptop/webcam is treated a resource of the trial investigator (healthcare provider) by the KUMC institutional review board and is dedicated to acquiring data for monitoring behavior/dementia and not a general resource in the home. Data is transmitted to Behavioral Imaging Solutions “Behavior Connect” portal where providers/investigators can login and view the videos. Review and feedback is asynchronous: delayed up to a week and provided via in person meetings and phone calls. Piloting of this current method has been well received however by the patients and caregivers though it has revealed opportunities for enhancement.

An outline of our initial use cases for the two applications is shown below:

- **Caregiver activities for primary use case:**
  - Establishing provider relationship authorizing review by provider(s)
  - Mark event
  - Transmit event
  - Review feedback
  - End relationship

- **Provider activities for primary use case:**
  - Establish patient relationship
  - Receive and review event
  - Consult event to multidisciplinary team
  - Send feedback.
Additional multipoint real time video consultation and monitoring:

- Caregiver: initiate request for real-time coaching.
- Caregiver: establish a real-time continual monitoring
- Caregiver: accept request for real-time session/appointment from provider.
- Provider: accept request for real-time session
  - Consult/extend multipoint session to the multidisciplinary care team
- Provider: initiate request for real-time session based on monitoring

### 2.1.b Home based technologies

We will select from COTS video technology for the proposed research depending on the ability to integrate such technology into the Google Fiber environment and a provider infrastructure that ideally leverages previously funded NSF GENI research (e.g. Case Western Reserve EAGER and GENI Rack). Google Fiber deployment was launched on July 26, 2012 and while it outlined the components of their offerings, the technical specifications are not yet provided (Google Fiber, 2012, Greenbaum, 2012). We will work with Behavioral Imaging solutions to determine if it’s feasible to extend their current technology platform and also evaluate emerging technologies such as Dropcam high-definition cameras and services. For example, DropcamHD devices have 2.4GHz 802.11b/g/n Wi-Fi radios that support WEP/WPA/WPA2 security, LEDs for night vision, plus a microphone and rear speaker for two-way audio. The service sends video over the Internet to secure cloud-based servers using AES 256-bit encryption and SSL connections.

For the second application real-time video based coaching, we will evaluate the current Case Western Reserve University technology (Schwartz 2012) and whether opportunities exist to integrate with the Google Fiber Google TV offerings. We anticipate elderly individuals would have less difficulty adopting real-time video coaching if it was offered via a television instead of a computer. Dr. Kristi Williams has planned two focus groups for this Fall between health care providers and a public group which meets at a nursing home to discuss the current pilot grant technology. If funded, we will expand those focus groups to obtain feedback regarding the proposed research technology.

### 2.1.c Provider technology GENI Technology

There are many tradeoffs to be evaluated in the technologies needed to enable the proposed healthcare monitoring application. These tradeoffs include local storage in the home vs. instantaneous high-bandwidth in the access network, latency of video delivery vs. access bandwidth, privacy and authorization of continuously streamed video vs. the latency and bandwidth of video streamed as the result of an event needing analysis. We expect programmable network technology leveraged from the GENI, KU-led GpENI, InstaGENI rack (GENI 2012), and OpenFlow-based GENI-KanREN projects to help us evaluate these tradeoffs. We will use and monitor these flexible infrastructures over which our proposed remote healthcare monitoring application and trials. Due to the importance of privacy and HIPAA requirements in this application, we will also investigate the application of the GENI-funded ABAC (Attributed-Based Access Control) project, as well as monitoring and auditing in this context (Faber et al., 2007).

### 2.2 Infrastructure Deployment, Application Development, and Subject Recruitment

Phase 2 will include deploying infrastructure, developing the application(s), recruiting subjects, and defining metrics and measurement strategies for the evaluation phase.

#### 2.2.a Acquire and deploy infrastructure
Our budget currently reflects an assumption that we will be able to leverage the planned NSF investment in GENI Racks to be installed at University of Kansas-Lawrence Information and Telecommunication Technology Center (ITTC). We will work with ITTC staff and leadership to establish HIPAA business associate agreements so that that infrastructure could be used to prototype infrastructure required at the provider organization (HSS, 2012). If that is not possible, we will evaluate options for HIPAA compliant cloud based storage options aligned with GENI Openflow/OpenStack, or as a last resort, depend on servers managed directly by KUMC Information Resources and medical informatics in the KUMC data center.

2.2.b Establish development environment and develop software

The division of medical informatics will establish development environment, lead the design, but partner with ITTC faculty to identify graduate students to join the development team. Since much of the current work of the division of medical informatics is either directly funded or in-kind support of National Institutes of Health research, we utilize our existing open source development environment (Edgewall, 2012) as much as possible: source code, documentation, and issue/ticket tracking are visible at the medical informatics research and development website. After discussion with Will Barkis at the Mozilla Foundation regarding the open innovation challenge between US Ignite, the NSF, and Mozilla (Mozilla, 2012), we will evaluate our ability to solicit open source software development from interested participants. Generally Agile software development processes will be tracked with milestones and can be monitored from http://informatics.kumc.edu/work/roadmap

2.2.c. Recruiting Human Subjects

Due to uncertainty in the deployment of Google Fiber through “fiberhoods” cite, their alignment with current research subjects in the clinical pilot, and ethical concerns deploying untested technology in patient care settings, upon funding we will amend the current protocol to expand the piloting of the proposed research to three healthy elderly volunteers using simulation of typical case scenarios based on the clinical pilot study. We have included the approval letter for the current clinical pilot study from the KUMC Institutional Review Board. Simulation scenarios will include scripts related to communication and behavior issues and will also test enhanced technology (such as selected capture of video when moving between rooms in the home or extended periods of recording such as night time sleep observations). KUMC is a leader in clinical simulation and we will integrate health professional students as part of a simulated team for review of submitted videos and to interact with participants in the home to provide simulated feedback. Depending on technology maturation and funding we will seek to expand the technology into the clinical pilot when appropriate.

We will facilitate recruiting through two partners: 1) the Landon Center on Aging and 2) Frontiers: the Heartland Institute for Clinical and Translational Research. Through the Landon Center on Aging, Dr. Williams maintains the Grayhawk Volunteer database (Landon, 2012). The older adults who participate in the research projects of the Grayhawk Laboratory are community members from both Kansas and Missouri who volunteer their time to our efforts. Many of our volunteers are alumni of the University of Kansas and of the University of Kansas Medical Center. We have also recruited older adults through local health fairs and by word of mouth. To date, we have recruited over 700 Grayhawk volunteers. Frontiers maintains a participant registry of over 11,000 individuals who have received care at the University of Kansas
Physicians’ outpatient clinics that is fully integrated with medical informatics’ HERON data repository (Frontiers, 2012). A current search of HERON indicates there are over 2,000 living individuals over the age of 65 in the participant registry.

2.2.d. Developing metrics and measurement plan.

There has been much work done on measuring internet access networks; including web-based, client-based and router-based approaches. The router-based approach was used in the FCC sponsored effort with SamKnows (SamKnows, 2012) that deployed gateways to several thousand homes, and the project BISMark (Sundaresan et al. 2011) where more extensive capabilities were deployed to ~16 homes. Extensive tools for performing and archiving internet measurements have been developed; the Measurement Lab (M-Lab, 2012) provides such an open platform.

We will apply the basic monitoring tools deployed in GpENI (Nagios and Cacti) and the GpENI OESS OpenFlow controller to the GpENI clusters in KUMC and KU (including the InstaGENI rack). We will tailor profiles to monitor and measure this healthcare delivery application over different flexible network scenarios to help determine the best points in the space of tradeoffs mentioned previously (storage vs. bandwidth, local vs. network processing, etc.). Furthermore, we will determine the applicability of the current GENI measurement and monitoring projects to this application, including Purdue/HPLabs S3MONITOR, UKentucky InstrumentationTools, and the capabilities of the Indiana University GMOC (GENI Meta-Operations Center). The set of initial measurements will include applications in use and their resource utilization; upload rates; download rates; latency and jitter. Understanding evolving user behavior as it related to the network will inform the design of home monitoring systems that will follow the deployment of the proposed prototype.

2.3 Application Deployment, Use, and Evaluation

In phase 3 we will deploy the solution, conduct qualitative evaluation of the enhanced technology upon typical case scenarios, and provide quantitative measurement of network performance and scalability. Figure 2 provides a high level overview of the final state incorporating the proposed research applications and areas for future expansion to home sensors and integration into operational clinical workflows. Under the direction of Dr. Ryan Spaulding, we will use the services of the University of Kansas Medical Center’s Center for Telemedicine and Telehealth to provide installation and support for the subjects in the home and the providers. A goal of the effort is to document the user behavior of the network. The measurements collected as part of this effort will inform the design and deployments of future home monitoring systems. The effort will measure the performance of the network from the user’s perspective. What network service is the user actually receiving? How is the network performing between customer nodes and external servers or hosts? Finally, while our gigabit application seeks to take advantage of advanced network infrastructure, it will also function as a laboratory which can inform expansion into other healthcare scenarios and information exchange efforts led by the Office of the National Coordinator for Health Information Technology.
Figure 2: Proposed research system for personal digital record integration with healthcare provider systems and supporting real-time video based coaching.

3 Principal Investigator/Co-Investigator Experience

Dr. Lemuel Waitman, Principal Investigator, is an Associate Professor in the Department of Biostatistics and arrived at KU Medical Center in 2010 to lead the Division of Medical Informatics (currently 10 FTE). Dr. Waitman is Director of Biomedical Informatics for Frontiers: the Heartland Institute for Clinical and Translational Research (an NIH funded Clinical and Translational Science Award), Assistant Director of Informatics for the Biostatistics and Informatics shared resource for the recently awarded National Cancer Institute designated Cancer Center Support Grant at KUMC, a co-investigator with the NIH funded Alzheimer’s Disease Core Center at KUMC, and chairs the NIH CTSA Integrated Data Repositories Affinity Group. The cornerstone initiative of the division has been the development of HERON: a data repository containing over 750 million facts from 1.9 million patients. Dr. Waitman was previously responsible for directing the development, implementation, commercialization, and operation of the inpatient clinical systems used at Vanderbilt University Medical Center—both internally developed applications by the Computerized Provider Order Entry team (the WizOrder project, medication reconciliation) and commercial nursing documentation and barcode medication administration systems. Waitman conducted research to extend education and decision support into clinical systems as well as NIH funded research to discover medication-laboratory result relationships, measure the utility of preadmission medication data for post-marketing surveillance of
adverse drug events, and build surveillance systems for acute kidney injury.

Dr. Kristine Williams, Co-Investigator, is Associate Professor of Nursing and Associate Scientist of Gerontology at the University of Kansas. She is the Principal Investigator for the clinical pilot study using the FamTechCare intervention to test home video monitoring and professional feedback. In addition, she is currently engaged in two NIH-funded studies testing interventions including cognitive training to improve self-care in assisted living residents and communication training for nursing home staff to reduce resistiveness to care in care recipients with dementia. Her research builds on her clinical expertise as a home care nurse and has been highlighted by the Alzheimer’s Association and reported on Good Morning America and in other national news programs and in the New York Times, stimulating professional and lay stakeholder awareness of the importance of nursing communication to Alzheimer’s care. Dr. Williams is a Fellow in the Gerontological Society of America.

Dr. James Sterbenz, Co-Investigator, is the lead PI of a currently funded NSF GENI project: The Great Plains Environment for Network Innovation (GpENI, $462,000 from 09/2008 – 08/2011). The Great Plains Environment for Network Innovation (http://www.GpENI.net) is a regional network between The University of Kansas, Kansas State University (KUS), University of Missouri – Kansas City, and the University of Nebraska – Lincoln (UNL) with the Great Plains Network. GpENI is funded in part by the National Science Foundation GENI Program as part of Cluster B in Spiral 1, and is one of only two research test beds funded in the first round of GENI funding. An additional second solicitation grant was received that is supporting international expansion of GpENI: GpENI-MMO: Great Plains Environment for Network Innovation – Measurement, Monitoring and Outreach ($30,000 from 01/2009 – 10/2010), and the KanREN-GENI project ($300,000 from 09/2011 – 08/2014) which is OpenFlow-enabling the KanREN (Kansas Research and Education Network) on which KU and KUMC reside, as well as interoperating with the GpENI and the installation of InstaGENI racks. In addition, Dr. Sterbenz is currently funded under NSF NeTS-Find: Collaborative Research: Postmodern Internetwork Architecture, CNS-0626949 for $200,355 from 09/2006 – 08/2012. This research is collaboration with the Universities of Kentucky and Maryland.

4 Additional Partners and Other Professional Staff

Additional partners for the project include:

- The University of Kansas Medical Center’s Center for Telemedicine and Telehealth
- The University of Kansas Medical Center’s Alzheimer’s Disease Center and the Landon Center on Aging
- Frontiers: the Heartland Institute for Clinical and Translational Research
- Case Western Reserve University – Information Technology Services
- US Ignite (Sue Spradley, William Wallace) and the Mozilla Foundation (Will Barkis)
- Behavior Imaging Solutions, Boise, ID
- Google, Mountain View, CA

Other professional participants are listed below.

Steve Fennel, MHSA, KU Medical Center’s Director of Telecommunications Outreach will serve as Project Manager. In addition to experience within the health care sector, Mr. Fennel has over twenty years
of telecommunications industry experience in various operational, strategy development and project management roles. He is currently managing KU Medical Center’s partnership with Google Fiber for their launch of the 1 Gbps fiber network in the Kansas City area.

Ryan Spaulding, Ph.D., leads the KU Center for Telemedicine and Telehealth. In conjunction with the department’s Medical Director, Dr. Spaulding establishes the Center’s clinical, educational and technologies priorities for the provision of telehealth services to communities in Kansas City and across Kansas. Dr. Spaulding has authored and co-authored multiple published articles and book chapters on the use of health information technologies, particularly to medically underserved areas.

Victor Frost, Ph.D. will work in conjunction with James Sterbenz in the network evaluation component and the applicability of GENI technologies for personal health information security. Dr. Frost is the Dan F. Survey Distinguished Professor, Electrical Engineering & Computer Science at the University of Kansas, Lawrence, Kansas.

Daniel Connolly is the biomedical informatics lead software engineer responsible for establishing the development environment and integration for medical informatics. For over 15 years, Mr. Connolly chaired the working groups defining technical standards for web and prototyped semantic web technologies at the Massachusetts Institute of Technology and the World Wide Web Consortium (W3C).

In addition to the medical informatics software development team, we will engage graduate level students from the KU Medical Center School of Nursing, KU Medical Center School of Health Professions, and the KU School of Engineering/KU Information and Telecommunications Technology Center.

5 Broader Impact

Ultimately the results of this effort are applicable to a broad range of physical and behavioral illnesses/conditions and caregiver/parental situations with the subsequent result being: 1) improvement in care/treatment within home-based settings; 2) avoidance or reduction of nursing home placements, hospital admissions/readmissions or other institutionalizations; 3) improvement in the quality of life of caregivers; and 4) overall reduced costs for the health care system. Potential applications for this monitoring platform may also be extendable to care settings outside the home and also to monitoring by health care professionals operating outside a traditional health care facility.
References Cited


Dropcam (2012). Dropcam HD Wi-Fi Video Monitoring Camera Features: 720p, 2-way audio, view


Data Management Plan

This project will generate:
   a) Software and software development artifacts
   b) Workshop, conference, and journal publications
   c) Simulation data of behavioral situations with healthy, elderly volunteers
   d) Potentially pilot data of personal health information from dementia patients and their caregivers.

We will take the utmost care to ensure there are no unauthorized releases of protected healthcare information. Specific aims of the proposed research are to determine the appropriate secure and auditable methods for transmission and storage of personal health information. Because of re-identification risks\(^1\), we do not anticipate providing public access to any patient video data. If granted by consented healthy volunteers we will seek to make videos of scripted disrupted behaviors available for researchers.

Our initial assumption is that we will be able to use NSF investments in GENI Racks at KU-Lawrence for data storage and hosting applications. If that is not possible, evaluation of third party cloud-based storage vendors will require the ability comply with the requirements of the Healthcare Insurance Portability and Accountability Act requirements for business associates\(^2\). We will evaluate the storage of personal digital records on commercial available options (Ex: Google Drive, Dropcam.com, etc). If we are unable to secure appropriate third party storage, our fallback position will be storing data transmitted to the healthcare provider on physical servers within the KUMC data center similar to how medical informatics and KUMC Information Resources to manage our clinical data repository. Physical access to the data center is controlled by locked doors and the servers are accessible only to those who a) are logged on to the KUMC internal network and b) have been explicitly granted access to the servers. Data at rest will reside behind campus firewalls and the environment is monitored by KUMC Information Resources Network Security.

Policies for access and sharing
Right to the products of the research will be owned by The University of Kansas Medical. The University of Kansas Medical Center will grant a non-exclusive royalty-free license for generated products to the U.S. Government for governmental purposes.

Policies, provisions for re-use, and re-distribution.

We will make our software developed as part of this project available under the MIT license\(^3\). Additionally, such software and non-sensitive software development artifacts (design documents, documentation, milestones tracking) will be available on our TRAC wiki and website: http://informatics.kumc.edu

Plans for archiving data

Non sensitive research results will be published in archival journals with responsibility for long-term preservation of access. Subject video data will be archived for four years to support analysis and publication of results.

3. http://opensource.org/comment/935

**Post doctoral Researcher Mentoring Plan**

No postdoctoral research will be supported by this effort.

**Facilities, Equipment, and Other Resources**

The University of Kansas Center Medical Division of Medical Informatics is located within the Department of Biostatistics on the 5th floor of the Robinson Building. The department has over 3000 square feet of office, cubicle, storage, and conference room space. Medical Informatics has several servers to support our research and production environments. Our development environment consists of a two VMWare virtualized SUSE Linux servers managed by KUMC Information Resources. Most development is LINUX based. Tools and languages include Python, Java, PHP, SQL, Javascript, JBoss, Apache, Oracle, and MySQL. Our production environment consists of two HP DL180 servers managed by Information Resources. The server which stores identified data has a two 6 core 2.66 GHz Xeon processors with 96 GB RAM, two FusionIO IoDrive Duo 1.28 TB ultra high speed memory cards, and 4.8 (2.193 after RAID10) TB of fast storage (15,000 rpm 600 GB SAS drives) in a RAID10 configuration and one 600 GB SAS hot spare drive and 4 (1.838 after RAID5) TB of backup and file storage (7,200 rpm 2TB SATA drives) for obtaining source data from our clinical partners. The server which stores de-identified data has a two 6 core 2.66 GHz Xeon processors with 72 GB RAM, two FusionIO IoDrive Duo 1.28 TB ultra high speed memory cards, and 2.4 (1.116 after RAID 10) TB of fast storage (600 GB SAS drives) in a RAID10 configuration and 4 (1.838 after RAID 5) TB of backup and file storage (2 SATA drives) for obtaining source data from our clinical partners. Servers also have an additional 4 TB of dedicated high speed storage on the campus XiOTek Storage Area Network. Two virtualized SUSE Linux servers for hosting i2b2 and REDCap applications managed by Information Resources. These virtualized server’s storage, processors and RAM can be dynamically assigned by Information Resources in response to utilization.

The network is managed by KUMC’s Information Resources who provides installation, training, and maintenance on all information systems. The Department of Biostatistics local area network is connected to a switched, 1 Gigabit Ethernet backbone that provides high speed Internet access through the KUMC Internet-2 communication network. Currently KUMC’s Internet2 access is via the Kansas Research and Education Network (KanREN). KanREN supports Internet2 connectivity for all of its members via a 10Gbps link to the Great Plains Network (GPN) and KUMC is connected to KanREN via a 1 Gigabit per second connection.

The University of Kansas Information and Telecommunication Technology Center (ITTC) provides researchers have full access to Linux and MS Windows desktop machines and a high-performance computing cluster. Numerous simulation and development tools are provided, including C++, Perl, Python, MATLAB, Mathematica, ns-3, Eclipse, svn, LaTeX, and Acrobat. KU is the lead institution for the GpENI (Great Plains Environment for Network Innovation) international programmable network testbed, with facilities located in ITTC, and access to Internet2 through KanREN (Kansas Research and Education Network) and GPN (Great Plains Network). This project will benefit from the existing GpENI node cluster and KanREN-GENI OpenFlow switches and planned InstaGENI rack at ITTC, and the KanREN-GENI interconnection and planned OpenFlow switch at KUMC.

Equipment at KU ITTC: No new equipment is required for this project other than the development environment provided by ITTC and infrastructure deployed as part of the GENI-funded GpENI and KanREN-GENI projects described above, including KanREN connectivity between KU ITTC and KUMC. KUMC will procure the equipment for a GpENI cluster, consisting of a managed Ethernet switch.
interconnecting several PCs running GpENI PlanetLab, VINI, Quagga, and XORP software, which will be attached to the planned KanREN-GENI OpenFlow switch in the KanREN rack at KUMC.

**Theo and Alfred M. Landon Center on Aging** KUMC’s Theo and Alfred M. Landon Center on Aging opened in 2001 in a new 52,000 square-foot complex adjacent to the KUMC campus. Construction of the Center was financed through a $3.9 million U.S. Department of Health and Human Services grant to KUMC. The facility supports clinical research related to aging. Research resources include cognitive testing laboratories and a human performance laboratory dedicated to advancing the understanding of motor function through interdisciplinary research and education. The primary focus of the human performance laboratory is the study of age related changes in mobility, which includes the study of healthy elderly as well as those with age related pathologies. Center activities are carried out in partnership with other academic units of KUMC, including the schools of Medicine, Allied Health, and Nursing and with affiliated institutions, such as the University of Kansas Alzheimer’s Disease Center, VA Medical Centers, the Wichita branch of the School of Medicine, the University of Kansas in Lawrence, state agencies, and service organizations. Research protocols undertaken at the Center by KUMC faculty address a variety of problems related to aging, ranging from social concerns to cellular biology.

**The University of Kansas Alzheimer’s Disease Center (KU ADC)** [http://www.kualzheimer.org/](http://www.kualzheimer.org/) and its clinical core’s Alzheimer and Memory Program is housed within the new Clinical Research Center 82,400 square foot Clinical Research Center [http://www.kumc.edu/crc/clinical-research-center.html](http://www.kumc.edu/crc/clinical-research-center.html). The AMP is under the direction of Jeffrey Burns, MD, and Russell Swerdlow, MD serves as its co-director. The mission of the KU-AMP is to promote healthy brain aging and strategies for the prevention of Alzheimer’s disease. All clinical-based AD research projects at KU are either run directly through or directly supported by the AMP. The AMP has been an active and rapidly expanding research group at the University of Kansas (KU). The AMP plays a major role in numerous investigator-initiated trials with both extramural and intramural funding and a major focus for several of these investigator-initiated studies includes the impact of fitness and exercise on AD risk and progression. The Clinical Trial Unit of the AMP (see below and Clinical Core) also participates in several multicenter research efforts and is a full member of the Alzheimer’s Disease Cooperative Study. Currently there are 12 team members in the AMP including an administrative nurse coordinator, psychometrician, research assistants, research coordinators, administrative assistant, post-doctoral fellows and graduate students.
Lemuel Russell Waitman  
3901 Rainbow Blvd., MS 1026  
Kansas City, Kansas 66160

Associate Professor, Department of Biostatistics, Kansas University Medical Center (KUMC)  
Director, Division of Medical Informatics  
Assistant Vice Chancellor for Enterprise Analytics

a) Professional Preparation:

Washington University  Electrical Engineering  BS, 1990  
Vanderbilt University  Biomedical Engineering  MS 1998  
Vanderbilt University  Biomedical Engineering  PhD, 2001

Appointments:

3/2012-present  Assistant Vice Chancellor for Enterprise Analytics, KUMC  
2/2010-present  Director Medical Informatics, KUMC  
2/2010-present  Associate Professor, Biostatistics, KUMC  
2005-2009  Director, Horizon Clinicals, Vanderbilt University Medical Center, Nashville, TN  
2002-1/2010  Assistant Professor, Vanderbilt University, Biomedical Informatics, Nashville, TN  
2002  Health Systems Software Engineer III, Vanderbilt University, Biomedical Informatics, Nashville, TN  
1995-2001  Research Assistant, Vanderbilt University, Biomedical Engineering and Anesthesiology, Nashville, TN  
1995  Teaching Assistant, Vanderbilt University, Biomedical Engineering, Nashville, TN  
1994  Teaching Assistant, Vanderbilt University, Electrical Engineering, Nashville, TN  
1991-1993  Medical Service Corps Officer, United States Air Force, Dayton, Ohio

c) Publications:

i) Five Selected Publications Closely Related to the Proposed Project:

Fennel SH, Atkinson BF, Gebar S, Waitman LR. Identification and Evaluation of Initiatives to Improve Health Care and Health Education Utilizing Google Fiber. Accepted as a poster presentation to the American Medical Informatics Association Annual Fall Symposium.


ii) Other Significant Publications:


d) Synergistic Activities:

- Chair, Integrated Data Repositories Affinity Group, NIH Clinical and Translational Science Award Consortium (2012-)
- Co-Investigator NIH Grant Number: UL1 RR033179-0 title: Heartland Institute for Clinical and Translational Research Clinical and Translational Science Award, Director of the Biomedical Informatics Section. Principal Investigators: Lauren Aaronson and Richard Barohn
- Co-investigator NIH Grant Number: 1 P30 AG035982 Title: University of Kansas Alzheimer's Disease Core Center. Principal Investigator: Russell Swerdlow
- National Science Foundation, Division of Information and Intelligent Systems, MERIT and Computing and Communications Foundations Division Smart Health and Wellbeing, study sections

e) Collaborators and Other Affiliations:

Adagarla B (KUMC), Adam TJ (Minnesota), Aronsky D (Vanderbilt), Atkinson BF (KUMC), Bhave G (Vanderbilt), Brown SH (VA), Campion TR (Cornell), Choma DP (University Medical Center, TN), Choudhary A (SCIOfirst Corp), Connolly DW (KUMC), Cox ZL (Lipscomb), Danciu I (Vanderbilt), Denny JC (Vanderbilt), Dittus RS (Vanderbilt), Doan S (Vanderbilt), Doran JB (Vanderbilt), Ellis B (State of Kansas), Fennel SH (KUMC), Fitzhenry F (Vanderbilt), Gadd CS (Vanderbilt), Gebar S (KUMC), Go AS (Kaiser Permanentente), Grande JF (Vanderbilt), Halpenny RM (IJK Controls), Hanase S (Vanderbilt), Ikizler TA (Vanderbilt), Johnson DC (Vanderbilt), Johnson KB (Vanderbilt), Jones I (Vanderbilt), Keighley J (KUMC), Lewis JB (Vanderbilt), Lorenzi NM (Vanderbilt), Mahnkne JD (KUMC), Manos EL (KUMC), Matheny ME (Vanderbilt), May AK (Vanderbilt), Mayo MS (KUMC), McCoy AB (UTexas-Houston), McCoy JA (UTexas Houston), McElgunn L (KUMC), Miller RA (Vanderbilt), Neel EB (Vanderbilt), Nelsen CL (Vanderbilt), Ong FR (Vanderbilt), Ozdas A (Vanderbilt), Parikh CR (Yale), Peterson JF (Vanderbilt), Peterson NB (Vanderbilt), Phillips IE (Vanderbilt), Porcelli PJ (Wake-Forest), Rudge NK (Vanderbilt), Schildcrout JS (Vanderbilt), Shi Y (Vanderbilt), Siew ED (Vanderbilt), Shireman T (KUMC), Smith JP (FDA), Starmer JM (Vanderbilt), Stenner SP (Vanderbilt), Strom S (Flagler Hospital), Sullivan M (Vanderbilt), Walz R (KUMC), Warren JJ (KUMC), Weinberg ST (Vanderbilt), Wright JA (Vanderbilt), Xu H (Vanderbilt)

Graduate and Postdoctoral Advisors: P.H. King (Vanderbilt); D.H. Fisher (Vanderbilt); M. Higgins (Vanderbilt); R.A. Miller (Vanderbilt)

Thesis Advisor and Postgraduate-Scholar Sponsor: T.R. Campion (Cornell); A.K. Beck (UT-Houston); T.W. Berutti (Vanderbilt)
Kristine Nordlie Williams
3901 Rainbow Blvd., MS 4043
Kansas City, Kansas 66160

Associate Professor, Kansas University Medical Center (KUMC) School of Nursing
Associate Scientist, Gerontology Center & Scientist, Center for Biobehavioral Neurosciences in
Communication Disorders, University of Kansas, Lawrence, KS

b) Professional Preparation:

Kent State University       Nursing       BS, 1978
The University of Connecticut Nursing, Primary Care MS, 1983
The University of Kansas     Gerontology   PhD, Honors, 2001

Fellowships: National Academies of Practice (Nursing), Gerontological Society of America, American
Academy of Nursing (induction October 2012), Board Certified Family Nurse Practitioner (ANCC)

Appointments:

7/07-present  Associate Professor KUMC School of Nursing (Tenured), Affiliated
             faculty, University of Kansas Gerontology Center, Lawrence, KS
             Associate, Landon Center on Aging, KUMC, Kansas City, KS
7/01-7/07    Assistant Professor KUMC School of Nursing, Kansas City, KS, Associate faculty,
             University of Kansas Gerontology Center and Landon Center on Aging, KUMC, Kansas City
1/99-5/01    National Institute on Aging Predoctoral Fellow in Communication and Aging, KU
             Gerontology Center, Lawrence, KS (T32 AG000226)
3/99-8/00    Teaching Associate & Clinical Assistant Professor, KUMC School of
             Nursing, Kansas City, KS
8/98-12/99   Graduate Research Assistant, KU Gerontology Center, Lawrence
6/96-7/98    Nurse Practitioner, Health Care Access, Lawrence, KS
8/89-6/96    Clinical Assistant Professor, KUMC School of Nursing, Kansas City, KS
8/93-6/96    Nurse Practitioner, Occupational Health and Environmental Medicine, University
             of Kansas Medical Center (KUMC), Kansas City, KS
5/88-6/89    Quality Assurance Specialist, Kimberly Quality Care, Richmond, CA
10/83-1/88   Clinical Consultant, Community Health & Counseling, Bangor, ME
9/81-5/83    Graduate Assistant, Univ. of Connecticut School of Nursing, Storrs, CT
9/82-6/83    Visiting Nurse, Glastonbury Visiting Nurse Association, Glastonbury, CT
3/82-9/82    Visiting Nurse, Visiting Nurse Services of Central Conn., New Britain, CT
12/79-3/82   Visiting Nurse, Summit County Visiting Nurse Service, Inc., Akron, OH
12/78-7/79   Staff Nurse/Team Leader, Akron City Hospital, Akron, OH

c) Publications:
i) Five Selected Publications Closely Related to the Proposed Project:

Montgomery, R. & Williams, K., (2001). Future directions for research on family and Alzheimer
care; Role relationships and differential impacts of caregiving. Aging & Mental Health, 5
(supplement), 23-34.
and Health, 29, 121-133. PMID: 16532478.


ii) Other Significant Publications:


d) Synergistic Activities:

2012 NIH Special Emphasis Panel/Scientific Review Group, Institute for Dental and Craniofacial Disorders.

2012-14 Editorial Board, Geriatric Nursing.

2011-13 Gerontological Society of America, Research, Education, and Practice Committee, Health Sciences Section Executive Committee.

2011-14 Midwest Nursing Research Society, Grants Review Committee.

2010-13 Board of Directors, Kansas State Nurses Association, District 17.

e) Collaborators and Other Affiliations:

Collaborators: University of Kansas Ruth Herman, Mary Lee Hummert, Susan Kemper, Byron Gajewski, Diane Boyle, Carissa Coleman, Wichita State University Lou Medvene

Graduate and Postdoctoral Advisors: Susan Kemper, Mary Lee Hummert, University of Kansas; Rhonda Montgomery, University of Wisconsin, Milwaukee; Veronica Rempusheski, University of Delaware.

Total undergraduate honors students advised: 4 (Marchant, Cooper, Wassmer, Sims).

Total masters student committees (Chair): 16. Total PhD student’s dissertation advisor: 5 (Hooks, Rattanavilai, Hober, Barrett, Schiefelbein), PhD committee member: 6 (Schmalzreid, Wolcott, Davis, Klaus, Nolan, Mitzner). Total postdoctoral scholars sponsored: 1 (Coleman).
James Sterbenz  
EECS and ITTC  
The University of Kansas  
Nichols 154  
2335 Irving Hill Rd.  
http://www.ittc.ku.edu/~jpgs

1. PROFESSIONAL PREPERATION:  
Washington University in St. Louis  
Economics  
A.B. 1980  
Washington University in St. Louis  
Electrical Engineering  
BSEE. 1980  
Washington University in St. Louis  
Computer Science  
BSCS. 1980  
Washington University in St. Louis  
Computer Science  
MSCS. 1986  
Washington University in St. Louis  
Computer Science  
D.Sc. 1991

2. APPOINTMENTS:  
2005 – present  
Associate Professor, EECS University of Kansas (tenured 2011).  
Research and teaching in resilient and survivable mobile wireless, high-speed networks, and Future Internet architecture.  
2004 – 2011  
Visiting Professor, Comp. Dept. Lancaster University.  
Research and teaching in resilient and autonomic networks.  
2004 – 2005  
Part-time Lecturer, Northeastern University  
2003 – 2005  
Visiting Research Scientist, University of Mass. Amherst  
1999 – 2003  
Sr. Network Scientist, BBN Technologies.  
Research and research management in mobile, wireless, and active networking.  
1994 – 1999  
Sr. MTS, GTE Laboratories  
1991 – 1994  
Advisory Engr./Scientist, IBM HPCC and Research

3. SELECTED PUBLICATIONS:  
Closely related  
Other publications


4. SYNERGISTIC ACTIVITIES:

   1. Lead PI, NSF GENI Great Plains Environment for Network Innovation (GpENI) project
   2. PI, DoD Highly-Dynamic Airborne Ad Hoc Networking project
   3. PI, NSF FIND Postmodern Internet Architecture Project
   4. PI DARPA Active Nets, SUMOWIN, WiaB, NASA PACE (completed)

5. COLLABORATORS and OTHER AFFILIATIONS

   a. Collaborators and co-editors:
      Tricha Anjali, IIT; Samrat Bhattacharjee, UMd; Cort Buffington, KanREN; Ken Calvert, UKy; Georg Carle, TU München, Victor Frost, NSF; Michael Fry, U. Sydney; Jim Griffoen, UKy; Don Gruenbacher, KSU; David Hutchison, Lancaster U.; Rui Lopes, ISCTE; Deep Medhi, UMKC; Bernhard Plattner, ETH Zürich; Byrav Ramamurthy, UNL; Marcus Schöller, NEC; Caterina Scoglio, KSU; Andrew Scott, Lancaster U.; Paul Smith, Austrian Institute of Tech.; Neil Spring, UMd; Linlin Xie, Siemens.

   b. Graduate advisors and postdoctoral sponsors: Gurudatta Parulkar, Stanford, D.Sc. advisor; Jonathan Turner, MS advisor

   c. Thesis advisor: Mohammed Alenazi, KU; Dan Broyles MS, Sprint; Radovan Bruncak, Lancaster; Yufei Cheng, KU; Egemen Çetinkaya, KU; Santosh Gogi, KU; Siddharth Gangadhar, KU; Abdul Jabbar PhD, KU; Ralph Keller PhD, Google; Junyan Li, KU; Rabat Mahmood MS, unknown; Philip Mein, JCCC; Vinay Muralidharan MS, unknown; Hemanth Narra MS, KU; Anh Nguyen, KU; Kamakshi Pathapati MS, KU; Kevin Peters MS, unknown, Roman Pletka, PhD, IBM; Bharat Raman MS, Sprint; Justin Rohrer PhD, KU; Sripriya Srinivasan MS, IBM; Tyson Thedinger MS, Gilmore & Bell; Greeshma Umpathi, KU; Piyush Upadhyay MS, Sprint; Christoph Wirz, Dipl.Ing., unknown; Linlin Xie Ph.D.Siemens; Dongsheng Zhang, KU.

   d. Total number graduate students advised: 11 PhD, 19 MS

   e. Postdocs: none