

**Project HealthDesign
Full Proposal Narrative**
Proposal Title: Embedded Assessment of Elder Activities (Cognitive Decline and Arthritis) for Augmenting Personal Health Records
Organization: Carnegie Mellon University

Executive Summary

An individual's functional ability to carry out basic activities of daily living (ADLs) is an important indicator for change in the individual's physical or cognitive abilities. These activities include basic activities (BADLs) such as getting out of bed and eating and instrumental activities of daily living (IADLs) such as meal preparation and taking medications. A decline in functional ability can ultimately result in institutionalization if the individual is no longer able to function adequately for living independently. We propose to use a human-centered approach to develop and evaluate new sensing technology that can accurately monitor the routine and observable activities of daily living (ODLs) of 50 older, community-dwelling adults at the low-income senior residences managed by Presbyterian SeniorCare in Pittsburgh, PA, and through recruiting activities of the Area Agency on Aging for Allegheny County, PA. These residents are at risk for cognitive decline and have osteoarthritis, and provide trustworthy longitudinal data for long-term functional assessment.

Previous work has focused on whether ADLs can be completed successfully or not. Our work is transformative in focusing both on *how frequently* and *how well* the participants perform ODLs. This focus will allow for more timely and responsive support for these individuals, both for physical and cognitive impairments, and will support increased awareness and understanding of any impairments for the individuals, caregivers and clinicians, including supporting pre-clinical diagnosis of cognitive decline such as Alzheimer's disease. Studies have shown that early pharmacological (e.g., Nordberg 2003) or psychosocial (e.g., Mittelman *et al.*, 1996) intervention during the pre-clinical period of cognitive decline is effective in delaying the onset of the clinical phases [Dekosky 2003; Cummings *et al.*, 2007]. Earlier diagnosis and treatment can help individuals maintain their abilities longer, delaying the effects of cognitive [Chang and Silverman, 2004] and arthritic [Pelletier and Martel-Pelletier 2007] impairments.

Unobtrusive sensing technology will be added into the living environments of

participants that record observations of daily living, and other data streams that are related to and impact these instrumental tasks: for example, how weather affects adults with arthritis and how participation in social activities changes in those experiencing cognitive decline. The data collected by the sensing technology, along with the individual's self-report, caregiver's proxy-report, and performance-based testing in the home by a trained occupational therapist will be uploaded to Microsoft HealthVault for secure storage, to allow our subjects to manage and control their data, and to support easy access by our team. Based on our past and proposed fieldwork with clinicians, caregivers and at-risk individuals, we will create novel algorithms that will analyze this data and identify correlations between the data to create salient summaries that will be of "meaningful use" to these stakeholders. These summaries will take the form of novel visualizations (displays and reports, also based on our fieldwork), targeted specifically to the information needs of the different stakeholders. In addition to automated summaries, interfaces will be provided to support self-exploration of the captured ODL data, to allow stakeholders to apply their own reasoning and knowledge of the situation.

With the salient summaries and self-exploration support, individuals will be able to be more aware of their arthritis and the impact it is having on their lives, along with being more aware of any evidence of cognitive decline, and understanding of the situations in which these impairments are occurring. This will allow them to manage these impairments, improve their overall health by adjusting their behaviors to match their changing abilities, and avoid situations where potential accidents might occur as a result of their decline. In addition, they will be empowered to share their data (raw and summarized) with caregivers and clinicians to increase their understanding of how individuals actually perform in their home environments. Clinicians will be able to combine this data with other clinical data about individuals to make better-informed decisions about treatments, (e.g., increased monitoring or potential interventions). The development of customized ODL reports should foster increased dialogue among patients and caregivers, thereby addressing the challenges inherent in accurately assessing changes in ODLs and how these changes vary with disease progression.

We are proposing a sensor-based objective and automated collection of ODLs, automated data analysis, and support for self-exploration – all activities which currently

take considerable time and resources. These changes promise to transform ODL assessments and clinical practice. Our proposed system that objectively collects and analyzes data, and can identify correlations in a greater amount of captured data to more effectively identify early disease progression, will be a vital part of self-managing health, managing patient care and will free caregivers and clinicians to spend more time on early treatment. Sensor-based ODL data collection also necessitates social acceptance of non-human monitoring of activities and this will inevitably alter practices and policy guidelines for patient care. For instance, guidelines will need to be considered as patients choose to share their ODL data with caregivers and clinicians or if they wish to compare changes in their ODLs with other patients.

Our major contribution is the *objective*, longitudinal collection and integration of data about the performance of ODLs to augment personal records, and the less frequent clinical assessments of decline, in order to support more rapid intervention, as necessary. The proposed technology and the resulting data and measures of well-being will support earlier (pre-clinical) diagnosis of cognitive impairments and treatment of arthritic conditions. It will also increase awareness and understanding of impairments by the individuals with the impairments, their caregivers, and their clinicians.

To ensure that our work engages individuals with low incomes and limited access to computers, we have partnered with Presbyterian SeniorCare (www.srcare.org - see attached letters of support), an award-winning, not-for-profit network of senior living centers, including residences for assisted living, community living and Alzheimer's care. In addition, our clinical partner, occupational therapist, Linda Kent from Presbyterian SeniorCare, has many years of experience in working with individuals with cognitive impairment, working at Presbyterian SeniorCare's Woodside Experience, a residence for individuals with Alzheimer's Disease and other related dementias. We have also partnered with the Rehabilitation Science and Technology department at the University of Pittsburgh. In particular, we are working with Dr. Diane Collins, an expert in assessing the functional abilities of individuals with disabilities, and a trained and licensed occupational therapist with over 20 years of clinical experience. We are also collaborating with the Allegheny County Area Agency on Aging, as part of the Federal Administration on Aging and working with over 100 service organizations in the

Pittsburgh area, which serves about 60,000 individuals over the age of 60 each year to help maintain their independence and safe, healthy lifestyles.

Vision and Health Impact

An individual's functional ability to carry out activities of daily living (ADLs) and instrumental activities of daily living (IADLs) is an important indicator for change in the individual's physical or cognitive abilities. However, it is difficult for older adults, their relatives/caregivers, and their clinicians to be aware of both *how often* and *how well* the individual carries out these routine and observable activities of daily living (ODLs). In this proposal, we have chosen to automatically monitor the ODLs of older adults. These adults have either been diagnosed with Mild Cognitive Impairment (MCI) or are at risk for MCI or dementia, and have documented osteoarthritis, two common impairments of older individuals. Prior research shows that individuals with MCI (often considered the pre-clinical phase leading to Alzheimer's disease) do exhibit a decline in functional abilities and may not be aware of these declines [Tabert *et al.*, 2002]. Moreover, arthritis is one of the leading causes for institutionalization accounting for approximately 31% among those with dementia entering nursing care. Those with arthritis are likely to require assistance in functional tasks [Guccione *et al.*, 1989].

Older adults who are not aware of the subtle changes in their cognitive or functional abilities over time due to some cognitive condition such as dementia or those who simply do not want to leave their homes to go into institutionalized care, may (purposely) overestimate their own abilities, which can result in further decline and risk to their personal safety [Kiyak *et al.*, 1994]. Because an individual's self-report of his or her own abilities can be inaccurate, clinicians often rely on proxies such as a spouse or relative for information about the functional abilities of the individual. However, proxy reports, while generally more reliable than the individual's self-report, can still be inaccurate [Kemp *et al.*, 2002]. Doctors can also rely on directly collected information about the functional abilities of their patients using performance testing with instruments such as the Performance Assessment of Self-Care Skills (PASS) [Holm *et al.*, 1999] which involves observing the patient carry out particular tasks either in the clinic or in his/her own home. However, these assessments are infrequent and expensive to conduct because they require a trained clinician.

Using the PASS instrument, we have identified a number of observable tasks that will provide insights into the health of our target population, particularly by collecting information about the quality of the performance of the tasks and their sub-tasks. These tasks include (among others) meal preparation, phone use, taking medicine, getting in and out of bed and chairs and walking up and down stairs. Each of these normally difficult-to-monitor tasks is critical for maintaining independence, and emotional, physical and cognitive health. From our interviews with older adults, we found that recorded observations of these tasks and automatically produced analyses can provide meaningful information to stakeholders about changes in functional abilities. This information is valuable for an occupational therapist to implement interventions, for other clinicians to suggest changes in medication and therapies, for caregivers to provide appropriate support, and for individuals to maintain self-awareness of their abilities and the knowledge of when to expend more cognitive or physical effort to avoid mistakes. Collecting automatically-sensed ODLs will allow these stakeholders to generate additional insights about the conditions and types of tasks where cognitive and physical impairments manifest themselves most clearly. For example, a caregiver with the help of our technology might notice that her mother makes fewer mistakes when relatives come to visit, which is a sign that her mother is trying to hide a deficit. Or, a doctor might notice that an individual seems to have more difficulty recognizing family voices after a building-wide social event, which might indicate a temporary period of cognitive confusion, due to overload. These stakeholders can rely on automated analyses of ODL data, explore the integrated data on their own, or use the data as a trigger for further follow up with the patient. The goal of this support is to allow individuals to better manage their healthcare and to live independently for as long as possible, directly addressing the needs of our target population.

Our extended experience with this population [Lee and Dey, 2007; 2008; 2009] reveals that these individuals also commonly suffer from arthritis, a second chronic affliction. As with their cognitive impairments, individuals are limited to anecdotal self-report information when speaking with their caregivers and trained clinicians about their condition. Our recruited subjects have often told us that they get out of bed in the morning only when their arthritis allows them to. Better tracking of the impacts of

arthritis (e.g., in getting in and out of bed, and in and out of chairs) along with self-reports of mood and physical abilities would enable better conversations with caregivers and clinicians. This, in turn, would provide valuable insights into how to provide appropriate support for these individuals and allow them to better maintain their abilities. For example, a doctor might notice that after switching to a new medication, the individual gets out of bed earlier in the morning, which may indicate that the individual's morning arthritic pain has improved. Supporting both self-exploration of the captured data and automatic analysis/summary creation will allow stakeholders to better manage the arthritis. With information to improve communication, all stakeholders can take necessary actions to improve patient health before conditions worsen. The data can also serve as a trigger for further follow up with patients. Recent research on osteoarthritis drugs points to opportunities to alter the course of the disease in the early stages before it becomes too severe [Pelletier and Martel-Pelletier 2007].

Our approach is novel because it examines not just whether individuals *can complete* activities of daily living, as many other projects have already established [Hayes *et al.*, 2006; Huynh *et al.*, 2007; Philipose *et al.*, 2004; Yonghong *et al.*, 2008], but also *how well* they perform these tasks. The frequency of performing an ODL is one measure of interest; a reduction in frequency of, for example, using the telephone, may indicate that functional capacity has already declined significantly enough to impact everyday independence. By measuring how well a given task is performed, caregivers can provide pre-clinical indicators of disability [Fried *et al.*, 1991]. In a pre-clinical stage of disability, individuals use compensatory strategies to maintain their functioning at a level where there is no apparent change to their ability to complete the task. In this stage, neither the individual nor members of their care network may realize, or acknowledge, that an underlying impairment exists or that the individual may be on a trajectory towards disability. For example, individuals who may be experiencing decline in executive functioning may have more difficulty preparing a meal that involves multiple concurrent steps. To compensate, they can slow down, pay more deliberate attention to their actions, and tolerate a few more mistakes. From a purely task completion view, the outcome is the same (the meal is prepared) but the underlying impairment impacts how much effort the person expends to perform the task. Thus, information about *how well*

an individual performs a task is important for earlier prediction [Barberger-Gateau *et al.*, 1999], treatment of decline and delaying the onset of the disability as long as possible.

Information about performance includes whether individuals struggle with a particular sub-task (e.g., opening a medicine bottle, or determining which medicine they should be taking), insert extra sub-tasks, forget particular sub-tasks and/or interchange sub-tasks (based on the PASS instrument). Most individuals are not able to track subtle declines in their physical or cognitive abilities. At best, they can tell anecdotes when communicating issues with caregivers, occupational therapists, and medical clinicians (e.g., geriatricians, primary care physicians). Thus, it is important to augment these anecdotes with *objectively*-sensed data about their abilities. Sensed data can augment the less-frequent assessments conducted by clinicians and can help focus future assessments and interventions. It will empower individuals to understand changes in their own abilities and everyday task performance. In our envisioned approach, clinical practice will be impacted through the use of novel algorithms for analyzing ODL data to create meaningful summaries and to identify correlations between observations of mood and behaviors, sensed data and changes in abilities. Individuals and clinicians will be able to explore novel visualizations of these summaries and correlations to improve awareness. Individuals and caregivers can detect patterns of interest and become more aware of how personal decisions impact their health. This will allow them to engage in more substantive dialogs with their clinicians, and make changes to their own activities to manage their own health. Clinicians can integrate the tools into their existing clinical workflow to detect cognitive/physical impairments and integrate the captured data with their clinical observations, to obtain a fuller picture of a patient's health. By proactively diagnosing and addressing these impairments before they cause irreversible changes to their patients' lives, clinicians can avoid reacting only to big changes or accidents.

To summarize, we envision a sensing technology that will enable older adults at risk for MCI and osteoarthritis, as well as their caregivers, to feel more secure and achieve better health through increased awareness of changes in their functional abilities. Our technology will empower individuals and clinicians to use early objectively-collected information about how frequently and how well patients carry out tasks critical for independence. All stakeholders will be able to make more informed decisions about

whether to collect additional information and how to proactively treat the underlying causes of the declines and ultimately help individuals maintain their quality of life.

Technical Approach, Feasibility and Viability

Pervasive sensing technology embedded in home environments offers the potential to both detect and keep track of changes in functional abilities and to provide this information automatically to various stakeholders. This concept of *embedded assessment* introduced in 2005 [Morris *et al.* 2005] includes three aspects: *monitoring* of the performance of everyday activities, identifying *compensation* for deficits in performance, and achieving early *prevention* of disability. The goal of our work is to support all three aspects: using novel technology to objectively monitor performance of tasks related to cognitive decline and arthritis, developing novel summaries of the performance information, placing both the raw and the summarized data into a health data repository, Microsoft HealthVault, and making this information available to stakeholders (people with or at-risk for cognitive decline and arthritis, caregivers, occupational therapists and geriatricians/primary care physicians) through integration with clinical health records. This will improve understanding and awareness of decline in functional abilities critical for maintaining independence, to provide interventions to compensate for decline, and to detect and prevent decline in its early stages.

Monitoring: Our proposed work will evaluate the effectiveness of sensing technology for monitoring the routine activities (ODLs) of community-dwelling older individuals in their daily lives. These activities may include walking up/down stairs, getting in and out of bed, taking medication, managing finances, using the telephone, keeping appointments, preparing a meal, operating household appliances, and doing particular types of housework. For each participant who has arthritis and who has been assessed as being at risk for cognitive decline, we will work with our clinical partners to identify an appropriate set of tasks to monitor using our sensing technology (see next section on Clinician Engagement). We will then design sensing technology for these tasks. We will observe participants demonstrating their ODLs in their home to help us select the best tasks for each participant and to identify which objects require sensing. This observation and engineering phase of the project is expected to last 3 months.

In the data collection phase, we will add unobtrusive wireless sensors to the

environment and various objects (e.g., pillboxes, chairs, telephone) the participants already use to carry out these activities (see architecture diagram in Figure 1, Appendix). The participants will be able to use the objects in exactly the same manner as they did prior to participation in the study because the technology will be personalized according to the way each individual carries out their activities. This specific design decision allows us to leverage the personalized system of reminders and objects that work for the individual. The sensing technology will include sensors that can track the location of objects in the home or the location of participant him/herself, whether individual parts of an artifact have been operated, and the physical proximity of one object to another, along with touch, contact, and grasp sensors. In particular, the sensors will sense the individual sub-tasks of the tasks of interest. The captured task performance data will be transmitted wirelessly to a laptop located in a participant's home, where it will be encrypted for security. The participants will be able to easily turn off the wireless sensing system, if desired, at anytime, if they feel uncomfortable.

To take an example from our earlier fieldwork [Lee and Dey, 2009], we observed an 85 year-old retired secretary who lives alone in her own home, taking her morning pills. After waking up, she walks into the kitchen, opens the pillbox door for the current day and pours all the pills into her palm because she cannot reach her fingers into the small slot. We can augment her "smart pillbox" with contact, accelerometer, and proximity sensors. The smart pillbox will know its location in the kitchen, when she is grasping it, which door is opened, and how much time she takes to decide which door to open. She places all the pills on the kitchen table and selects out a small round yellow pill, to be taken on an empty stomach. With our augmented approach, a "vision-enabled kitchen table" uses a ceiling-mounted camera to identify which pills are on the table and to monitor her pill-sorting subtask. She takes this pill to the kitchen counter where she has a dedicated glass and a bottle of water for taking the pills. We envision using an "intelligent water glass" that senses its position on the counter, when she fills it and grasps it, and when she tilts it to drink. We can sense when each step starts/finishes, how long she spends in each step, and whether steps were repeated or skipped. New home monitoring systems for older adults are constantly adding new wireless sensors, so it is very likely this level of sensor coverage will soon become a reality.

Once sensing technology for all the selected ODLs has been deployed, we will have participants demonstrate their ODLs again to ensure that there are no differences in the way these activities are being carried out (as a result of having the sensor system). We will then monitor 15-20 participants (at a rate of \$X/month) for 3 months, during which time participants will carry out their normal routine. Our co-investigators, Linda Kent and Diane Collins, will assess each participant's functional and physical abilities, by looking at self-reports (from participants) and proxy reports (from caregivers) about mood, pain and discomfort, and cognitive state, and selected video of participants carrying out tasks during a team visit. These expert assessments will serve as our ground truth for the functional abilities of our participants, against which we can compare our sensor data.

Data Interpretation and Analysis: With the participants and the other stakeholders, we will hold participatory workshops in which we will use the knowledge of stakeholders to determine how to interpret collected data and produce appropriate summaries of the data. Here, our goal is to assess how accurately our sensing system can detect the functional and physical abilities of an individual, and to create software that produces meaningful summaries of this data. Early feedback on our design concepts from stakeholders confirms that stakeholder cannot comprehend or do not have time to view the vast amount of data that could be available. Thus, the summaries are necessary to support comprehension and meaningful use of the data.

With knowledge of what summaries are valuable, we will create software that can automatically produce these summaries (expected to be different for different stakeholders) and deploy it on the laptop in the participant's home. We have experience in creating useful summaries from large amounts of sensor data [Lee & Dey 2008]; in particular, we collected experiential data, including audio, visual and movement data for subjects with Alzheimer's disease, and produced summaries that helped subjects remember experiences better, weeks after the original experience.

In addition to the performance data, we will also collect and integrate other observations that are related to the performance of daily activities. This includes weather information, social interactions, clinical programs that participants partake in, periodically requested self-reports of mood, pain, sense of self, health, and daily caregiver proxy reports of the participant's well-being. We will apply supervised machine

learning algorithms (e.g., decision trees, Bayesian Networks) to better automatically correlate these observations with the collected performance data, including medication type and dosage, to incorporate into the generated summaries. We will also administer periodic standardized assessments of cognitive and physical functioning such as the Craig Handicap Assessment Report Technique (CHART) [Hall *et al.*, 1998] and apply machine learning techniques to find correlations between our sensor data and currently-used, well-validated assessment instruments. If successful, the sensor data and observations can be used as highly sensitive measures of early cognitive or physical decline. These measures will change clinical practice, as they are collected frequently from people's lived environments, not only within the clinical setting.

Data Storage: All of the collected data, summarized data, and integrated data will be encrypted on the laptop for security. The collected data will be kept confidential and will only be accessible by members of the research and clinical team, with the written consent of the participants. In addition, the data will be uploaded automatically to a Microsoft HealthVault account that we will create for each of the participants. We chose to use HealthVault for several reasons. First, the privacy principles of the system are well-aligned with the goals of Project HealthPlan, and, in particular, keeping the individual in control of his/her own health data. Microsoft has a long history of producing reliable and scalable solutions, with easy-to-use interfaces. This will make it easier for us and our clinical partners to integrate with HealthVault for accessing data and building and using health applications that use the stored data, exporting data to electronic health record systems (see below) and creating a plan for scaling our system up to cover thousands, and even millions, of subjects. Finally, we chose HealthVault because of an existing relationship. We developed a novel data logging format (graffiter.org), intended for use with Web 2.0 social applications like Twitter and Delicious. HealthVault contacted us and has incorporated this format into its system. We now have not only do we know have a relationship with the HealthVault team, which will be valuable should we run into any challenges in using this system.

We will work closely with the information technology team from our clinical partners at Presbyterian SeniorCare to fully integrate the sensed and analyzed data that will be stored in Microsoft HealthVault, into the electronics health records system they use:

AOD Software's AnswerElite. AnswerElite consists of a number of relevant components including SmartChart, a system that provides a full view of a patient's electronic health record, modules specifically for working with patients living in their own home and those in an assisted living situation, and the User Defined Electronic Medical Record module, which supports the creation of custom assessments. We will also work with our clinical partners to make this integrated information available to our subjects, caregivers and clinicians (subject to permission being granted by the subjects), through AnswerElite and Microsoft HealthVault. While this extra level of storage will create some computational overhead, having this integrated information will make it possible to analyze data simultaneously for multiple ODLs from raw, summarized, self-reported, and manually explored data sources, and in concert with the EHR information from AnswerElite, an important goal for Project HealthDesign.

Visualizations and Data Exploration Interface: During our initial three-month data collection, we will work to provide feedback on participants' performance to the participants themselves on flat-screen displays located in their homes, and caregivers, occupational therapists and physicians on more traditional computer interfaces. As part of our user-centered design process, we have already studied our target user population, and have identified a number of novel design concepts that show various stakeholders how well the individuals being studied have performed their activities of daily living. These concepts include variations across three important dimensions: task completion vs. task performance, long-term vs. short-term view, and whether details about individual sub-tasks were included or not (see Figures 2, 3 & 4 in Appendix). We tested our design concepts with four older adults, three geriatricians, three occupational therapists and five caregivers. Overall, all stakeholders were excited by the concept of embedded assessment, particularly the ability to capture more frequent ODLs from sensors and self-reports about the performance of activities. They particularly liked the medication taking, meal preparation, phone use tasks for cognitive assessment and getting into and out of chairs and beds for the arthritis assessment – at a minimum, we will include these five activities in our embedded assessment approach. While geriatricians said that they had little time to look at the results of such data collection (due to difficulties in billing for this time), they liked that such information could be made

available in an easy-to-synthesize and understandable form. Surprisingly, none of our stakeholders were concerned about the impact of our proposed system on their privacy.

Another interesting finding from our initial study of stakeholders was that a number of our older adults initially questioned the value of capturing and being made more aware of some ODLs. They did not feel that their skills were diminishing, but all had older friends whose skills were. They were interested in being made more aware of what they could expect in the near future, by being more aware of their friends' conditions. While this knowledge sharing, or "crowd-sourcing", appears to be useful for younger adults [Arnquist, 2009; CureTogether, 2009; PatientsLikeMe, 2009], it is still an open design question on how to make this information available and sharable in a way that it is accessible to older adults, while preserving their privacy and dignity.

A final finding to note is that the captured performance information does not provide explanations as to why a particular performance was better or worse than normal. Instead, analysis of a particular atypical performance (or more likely, repeated atypical performances) will serve as a point to investigate further. This investigation can occur manually by any of the stakeholders (e.g., a caregiver watches how medicine is taken to try and determine why it is taking twice as long as usual), or data exploration can be supported via novel interfaces. To support data exploration, we will provide an interface to support question asking and hypothesis testing on the capture self-reported and automatically collected observations related to the performances of interest (e.g., such as pain and humidity when getting in and out of bed to address arthritis, as well as general feeling of health, mood and participation in community programs when taking medicine to address possible cognitive decline). The interface will support question asking and hypothesis testing, allowing stakeholders to identify their own causations and correlations in their performance of daily activities. Providing such support for has been shown to increase awareness of opportunities for change in overweight people looking to be more physically active [Li *et al.*, 2008], and to, more generally, to improve performance in learning tasks [Lim *et al.*, 2008]. This interface is not intended to replace manual or *in situ* discovery of problems, but is intended to augment it. The data analysis sub-system, integration with HealthVault and AnswerElite, and this visualization feedback and data exploration sub-system will take 6 months to complete.

Feasibility Testing: As we will discuss in the section on Evaluation, we will conduct a number of feasibility tests throughout the design process and continually iterate and improve our proposed technical solution. However, there are a number of risks that we would like to draw attention to. First, and foremost, there is the issue of privacy. We will work with our clinicians and the technology team at our clinical partners to ensure that all of our data sharing and integration is HIPAA-compliant. In addition, we will give our subjects a kill switch, allowing them to completely shut down the sensing system. We will encrypt all captured and created data, and will leverage the HealthVault privacy tools. A second concern is how our technical approach will work in sub-optimal conditions: lack of subject compliance, and loss of power or networking. We are engaging with a large number of subjects to minimize the possibility of complete non-compliance. However, even in the case of non-compliance in terms of providing self-report data, our system can be considered a success based solely on its ability to analyze and visualize automatically collected information to help clinicians. We will be using backup batteries and uninterruptible power supplies to minimize data loss due to loss of power, and we will cache data locally when remote servers (*i.e.*, HealthVault) cannot be reached. In addition, we will use cell phones and text messaging services to alert us when there is either a loss of power or network, so we can manually intervene as appropriate. Third, we guard against our system impacting participant behavior, and the creation of summaries and exploration interfaces that are difficult to use by incorporating participatory and user-centered design of these into our overall design plan. Finally, there are practice/policy challenges that need to be considered. One issue is privacy, discussed above. Another is convincing clinicians to use the system so we can understand the impact on their practice. Our clinicians at Presbyterian SeniorCare and the University of Pittsburgh are wholly supportive of our approach, so for our study, this issue has been mitigated. In the long-term, however, it is our user-centered design approach that engages all stakeholders, that will result in a valuable and usable system for monitoring ODLs and positive impacts on clinical practice and policy.

Summary: Based on our initial concept generation and study of older adults and clinical stakeholders, we believe that our technical approach to sense ODLs and the quality of the performance of those activities (and the sub-steps) will be of great value to

all of the stakeholders. We envision a system that senses data locally within the living environment of the individual with arthritis and at risk for cognitive decline, and that displays interpretations of the sensed data (*i.e.*, quality of task performance) to the individual and caregiver, and that supports data exploration and sharing of data with others. We will not design and build new sensors, but will integrate existing sensing technologies and apply them in novel ways to sense these ODLs. This sensed data will be stored locally within an individual's home, and will be automatically uploaded to a remote secure server operated by Microsoft HealthVault using a cell phone or Internet connection. The data on the remote server can then be accessed via applications custom built for caregivers, for subjects at-risk for cognitive decline and arthritis, and for clinicians such as occupational therapists (OTs) and primary care physicians. These applications can be integrated into existing electronic medical records already used by the OTs and clinicians to augment the evaluations and assessments that they conduct on a less frequent basis. The resulting personal health records can help to provide appropriate levels of detail and to support hypothesis testing and improved understanding of an individual's abilities and changes in those abilities. For both the individual and the stakeholders, a range of analysis, trending and summarization tools (including novel machine learning techniques) will be used to determine what to present to the different stakeholders and how to present it. In the Evaluation Design section, we will discuss how we will deploy and evaluate our entire system and its ability to integrate into current clinical practice and support self-management of participants' health.

We fully expect that our solution for monitoring ODLs related to cognitive decline and arthritis will lead to positive clinical practice change. It will accelerate the collection of data and creation of meaningful observations and correlations for use in detecting and monitoring disease progression. It will eliminate a lot of manual, subjective work and will allow for earlier interventions. Finally, this work will transform patient monitoring and has the potential to greatly improve patient care and extend patient independence. Thus, we expect that there will be great of interest in commercializing our approach.

Patient and Clinician Engagement

Our research approach for developing effective sensing systems to monitor ODLs is influenced by the human-centered methodologies found in the field of Human-Computer

Interaction. Our process involves close engagement with stakeholders, including members of our target population, their caregivers, and the medical professionals (primary care physicians, geriatricians, occupational therapists) they interact with to help manage their health. We engage with the stakeholders at every stage of the project: to help select ODLs, before, during, and after design of the sensing systems through concept validation sessions, and in a formal evaluation of the engineered solution.

As we are not looking to engage with subjects that are already experiencing significant cognitive deficits (in fact, this will be an exclusion criteria for our recruiting), we do not believe that our (potential) subjects will have difficulty in understanding our study descriptions and consent forms, or in participating in our study. We will convey to both Presbyterian SeniorCare and the Allegheny County Area Agency on Aging that we only want them to suggest subjects that are able to give an informed consent to participate in our study.

Stakeholder Engagement for Selection of ODLs: The selection of ODLs will first begin with identifying the existing ways of assessing the everyday cognitive, physical, and functional abilities of individuals from our target population. We start with a literature review on instruments used to assess everyday abilities of our target population. By identifying the instrument limitations, we can identify opportunities for embedded sensing systems to play a role in reliably collecting more useful data. Further, we will observe and interview clinicians (geriatricians, social workers, occupational therapists, and care coordinators at our clinical testbed) who use these instruments to do assessments. We will discuss the strengths and weaknesses of these instruments and how they fit into their practice. We will also identify what information the clinicians feel is valuable for their practice, but difficult to collect currently. This will occur through a repeated set of interviews and contextual inquiries (or guided observations of typical work practice), in which we will ask the above questions, and probe as to how they make their diagnoses and decisions about treatment and when to treat. We will work with the occupational therapists who are already partners on our project, Linda Kent and Diane Collins. As well, we have recruited 3 geriatricians from the Pittsburgh area who gave us feedback on our initial feedback, that we will continue to use throughout the proposed work. Finally, we will engage with the social workers that assist

at Presbyterian SeniorCare's apartment facilities for independent living.

In addition to clinicians, we will also engage with members of our target population and their caregivers. Caregivers and family members are usually the first to notice signs of decline in the everyday functioning of our target population. We will interview family members (adult children) who keep an eye on their elderly relative's health. We will identify the strategies adult children use to inquire and track their parent's health conditions. We will inquire about what "early signs" they did not notice initially but later became an obvious indicator of a large problem. By focusing on different stages of wellness, we will be able to identify opportunities for monitoring ODLs that are critical for maintaining wellness and preventing accidents that may lead to disabilities and further declines. We will also engage our target population by observing the different activities they perform that are critical for maintaining their independence, enabling us to discuss what tasks or abilities are the most important for maintaining independence. Caregivers and members of our target population will be recruited through our clinical partner and will receive \$X (our standard rate, unless otherwise specified) for participating.

Concept Validation: Based on our initial interactions with clinicians, caregivers, and members of our target population, we will identify a range of ODLs that would be helpful if monitored. From this selection, we will identify about five ODLs to be developed into a real sensing system based on factors such as the current state of sensing technology and possibilities for tech transfer and consumer adoption. Based on our initial fieldwork, these should include medication taking, meal preparation, telephone usage, getting in and out of bed/chairs and walking up and down stairs. Note that the intent is to monitor all of these ODLs on a continuous, longitudinal basis, and the concepts presented will make that clear to subjects.

Prior to expending resources to build, engineer, and deploy the sensing system(s) necessary to monitor our selected ODLs, we will employ a user-centered design formative evaluation technique called concept validation [Davidoff *et al.*, 2006]. Through this concept validation, we will be able to place stakeholders mentally into a world in which the proposed sensing systems have been built, used for a length of time, and have produced data for the stakeholder to review. Using low-fidelity prototypes and sketches, a concept validation session with particular stakeholders can identify which

sensing systems are actually useful and usable. Working with validated concepts helps increase the likelihood that our sensing system will be accepted by the stakeholders and integrated into their clinical (and personal) workflow. To this end, we will use sketches and scenarios to depict our potential sensing systems, show how the systems would be embedded in the home environment, how the user is expected to interact with it (that is, little to no interaction with the technology is necessary), and what types of data can be collected by these sensing systems. An additional incentive to payment for our participants in all phases of our design is the opportunity to increase their awareness of their abilities and prolong their independence, as well as to use the sensing system and tools that we develop as a result of their involvement.

The concept validation sessions will also allow us to explore different interpretation strategies for various stakeholders. The concepts shown in the sessions will include mock data designed to mimic the data that would have been collected from a year-long deployment of the sensing system (e.g., Figures 2-4). From these data, we can explore how much pre-processing is necessary and how much of each of the stakeholders want to employ their own sensemaking skills to analyze and explore the data. We will use both a top-down and a bottom-up approach to find the right balance between computer assistance and user expertise. With a top-down approach, we will first show high-level summaries of the mock data for the five ODLs where the system interprets the data and shows a high-level “status” of the individual, hiding the low-level details of the data used to make the interpretation. We will elicit feedback on the quality of the automated interpretation, and what additional low-level information the user needs for their own interpretation or trust the system better. We will show them new scenarios with the system providing more low-level details, which leaves more of the interpretation to the user. With another set of stakeholders, we will use a bottom-up approach where we will begin the session by showing low-level sensor data and then ask about what types of summarization and exploration techniques would be helpful to make sense of the data. Using both top-down and bottom-up approaches, we will be able to identify the “sweet spot” where computer-automated analysis can assist the abilities and intuitions of the user to interpret the ODL data appropriately. From our concept validation, we will narrow our focus to ODLs that were validated by stakeholders and also generate further

design guidelines to refine our sensing and interpretation systems. The next phases of the research involve the engineering and implementation phase followed by a field evaluation (details are in the Technical Description and Evaluation Design sections).

Once again, we will work with our partner occupational therapists, our recruited geriatricians, and social workers, in showing them our concepts and gaining their feedback.

Recruitment and Partner Commitment: Our clinical partner, Presbyterian SeniorCare (PSC), is committed to the success in recruitment of members of our target population. Presbyterian SeniorCare is a non-profit regional network of living and care options for older adults located in southwestern Pennsylvania. PSC provides a continuum of care services ranging from fully independent community-based living to institutional assisted living to specialized dementia care. PSC has over 6,000 older adults in its care system, which includes 54 apartment communities in which 99% of the residents live alone independently but rely on community assistance such as meals, housekeeping, or laundry. PSC also manages low-income rental housing for older adults and person with disabilities and keeps track of how residents perform IADLs by eliciting self-reports during time-intensive visits. Our sensing system has the potential to help produce objective data and thereby help the staff save time and make better assessments so they can provide a resident with appropriate support. The residents in PSC's low-income rental housing communities make good participants for our field evaluation, because they often live alone and are widows or widowers who value their independence and usually plan to live in their apartments for the rest of their lives, or until they lose their ability to remain independent. The PSC staff site care coordinator will be our liaison to them, and will help with recruitment and handling on-site issues.

In addition, we are also collaborating with the Allegheny County Area Agency on Aging, which serves over 60,000 seniors each year to help them remain independent and maintain healthy lifestyles. They are specifically interested in our approach and are working with us to identify a large number of potential subjects, which will then be screened and filtered down to a smaller number of viable candidates, based on cognitive function, living status (single or with others), among other factors. It is telling that the AAA was concerned that only going for a total of 50 subjects did not seem like

enough. We are very confident that we will be able to recruit significant numbers of subjects through this agency.

Our clinical partners, Presbyterian SeniorCare and the University of Pittsburgh, will be able to share in the benefits of our research, in particular, the data collected about the ODLs. We will share anonymized collected data and engage their care workers in discussions about how ODL data can be used to monitoring the functional abilities of PSC residents. Our partners are eager to work with us to reduce the consequence of late detection of changes in cognitive or physical function – in other words, the increased risk of accidental injury or, even worse, disability. PSC also values long-term evaluations of residents as they stay or move among different levels of care and is excited to enhance the richness of their residents' long-term health profile.

The sensing systems themselves and the periodic assessments will be minimally intrusive and should not pose any new risk for study participants. Moreover, study participants will be selected from existing PSC communities in which PSC already has the means to deal with liability issues that might arise. In summary, we will interact with clinicians, members of our target population, and their caregivers throughout all phases of our research process for selecting ODLs and designing and evaluating the sensing systems for ODLs. Our clinical partners are committed to providing us with the expertise to inform system design as well as to recruit participants for our research.

Evaluation Design

As part of our human-centered process, we will work with our target population, caregivers, and clinicians throughout this project. As described in the previous two sections, we have a solid plan for the iterative design of our system. Here, we discuss the summative evaluation of the system we propose to build.

We will build a sensing system to collect data on the ODLs we identified in conversations with our stakeholders. First, we will conduct a feasibility test on each of the sensing sub-systems (one for each ODL), and on the sensing and communication aspects separately including support for power and network loss, in our lab. Then, we will conduct a pilot test in a participant's home for three weeks to work out any significant issues with the system. We will then deploy this sensing system for three months in the homes of 5 to 10 target participants (at an incentive rate of \$X/month).

During this time period, we will collect qualitative information about the intrusiveness of the sensing system, and the impact it had on the participants' behavior, if any. In addition, we will evaluate the sensing system's ability to provide details on the quality of performance of all subtasks of the ODLs, for example, opening the correct slot on a pillbox while taking medicine. This will serve as an additional feasibility test, only in the field. We will validate the accuracy of our sensing systems with occupational therapists using the PASS instrument observing the participants directly or via a recorded video feed. We will iterate on the design of the sensing system to minimize the intrusiveness, to obtain as natural behavior as possible, and to increase the accuracy of the assessment and data collection of ODLs.

The next technical step is to support automated data interpretation and analysis. We will hold a series of three participatory workshops with our stakeholders (in groups of 10 to 15, including potential subjects, caregivers, our OTs, geriatricians and social workers), to determine how to interpret the collected data and produce meaningful summaries. We will translate our results into a system that can automatically produce human consumable summaries of the sensed data. We will test the summarization process in a final workshop with a subset of our earlier workshop participants and with the individuals whose data we collected in the first phase, looking at usefulness and accuracy of the summaries in representing the actual ODL performance data. We will use the workshop to validate that the summarization process produces an accurate result and an understandable result. We will obtain feedback through open discussion and one-on-one interviews with participants.

As part of this technical component, we will also integrate other observations (self-reports, proxy reports, and automated collection) relevant to our chosen five ODLs. The exact set of these other observations will be chosen based on our workshops with stakeholders, and the hypotheses they have about what correlates well with this data. We will again validate the usefulness of this for each of the integrated observations with 3-5 members of each stakeholder group. In addition, we will produce synthetic data (both performance and other observations) in the form of scenarios and ask users to come up with hypotheses about causation and correlation of the integrated data.

Once we have the collected data, summarized data and integrated data, we will

work with the technical leadership team at Presbyterian SeniorCare to integrate these with Microsoft HealthVault, and then HealthVault with PSC's electronic health record system, AOD Software AnswerElite. Assuming HIPAA compliance and participant agreements, we will also integrate these additional data from the electronic health record system with Microsoft HealthVault. We will validate that the interaction among the sensing, data storage and electronic health record systems is sound.

The next step in our development is to design and implement the visualizations of the data in the Microsoft HealthVault and the exploratory interfaces for working with this data. We will use concept validation to determine the appropriate visualizations and interfaces to build. After building these, we will work with 3-5 members from each of our stakeholder groups, to evaluate the effectiveness of this support. We will present different scenarios to different stakeholders and have them work through the process of understanding and working with data. We will apply metrics of time/effort to complete representative tasks, perceived (self-reports) and actual usefulness (number of valid assessments or conclusions made) of the visualizations and exploration interface, and ease of use. We will use the group that we originally collected data from, to help assess the quality of these interfaces, based on the participants' actual data. We will iterate on these interfaces until they provide appropriate support for the various stakeholders.

We will also assess the benefits of a sharing interface for caregivers and patients. This qualitative evaluation will determine the value in sharing information with others and whether it offsets privacy concerns. We will evaluate the sharing functionality for 1 month (in parallel with other activities) with 3 groups of 3 patients that know each other and their caregivers and 3 groups of 3 patients who do not know each other and their caregivers, to assess the impact of familiarity on perceived value. We will then determine whether to keep the sharing interface in the final version of our system.

Finally, we will deploy the following in our target participants' apartments: sensing system, analysis system, integration with electronic health records, and interfaces for viewing and exploring. First, we will conduct a short feasibility and integration test in our lab, before rolling out a small pilot test in the field with 2-3 participants for a period of 3 weeks. Then, after addressing any issues with the pilot test, we will deploy our system for 12 months to 40-50 participants (at an incentive rate of \$X/month). We will leverage

our clinical partners to recruit appropriate subjects with arthritis (as assessed by a physical exam and the Short Arthritis Scale (SAS) assessment) and with or at risk for cognitive impairments (as assessed by the Mini-Mental Status Exam (MMSE) used by our partner OTs). Here, our goal is to study how useful all of our stakeholders perceive the system to be, both as a whole and for individual components, and the impact of the system on the stakeholders. For elders and caregivers, we will study whether the system was successful at increasing awareness of abilities, how they change over time as a result of decline, and areas where they need external assistance. We will also study whether increases in awareness led to specific visits with clinicians, to changes in behavior, and to diagnoses of cognitive impairment or arthritis. With our clinicians, we will study how the tools impact their practice and interactions with patients, whether they are willing to use such tools vs. looking at the results of their patients using the tools, how to modify the tools and visualizations to maximize the useful information throughput in the shortest amount of time, the clinicians' ability to provide useful solutions and diagnoses for discovered problems, and whether they perceive the system to be useful.

We are confident that our complete plan is operationally feasible. During this 12 month long deployment, we will have our partners, Linda Kent and Diane Collins, perform an expert functional assessment (MMSE, PASS and SAS) of the patients every two months. With additional standardized questionnaires (CHART) commonly used in nursing and occupational therapy, we will have individuals self-report their own functional abilities on a variety of tasks that they perform. Caregivers and site care coordinators will also be asked to assess how well individuals perform their tasks, to provide an informant-report. We will also interview all stakeholders on a routine basis, every 2 months, to understand how people are using the system and to have a more continuous assessment of the system. We will identify how well the ODLs captured by our sensing system correlate with standard measures of cognitive and physical abilities. These new measures can augment the infrequent measures used in clinical practice.

One potential issue with our system and evaluation plan is that we may recruit a group of subjects who exhibit no change in their cognitive and physical abilities over the course of the project. This is highly unlikely to occur, given the size of the target population and our access to them provided by Presbyterian SeniorCare and their

assessment of individuals. However, even if it does, our project can still be considered a success. Even without observing and providing feedback about changes in abilities, correlating our sensor data to standard measures of cognitive, functional and physical decline will be very valuable to clinicians. Our automatically collected sensor data can be collected more frequently, avoids the bias of “testing anxiety”, and is cheaper (both financially and in terms of time) than having an occupational therapist collect data on quality of performance of daily activities. If the sensor system is also more accurate, either because it avoids testing bias or because it can detect more subtle and fine-grained performance issues than an occupational therapist, it provides even greater benefit. So, in the worst case where we see no change in cognitive, functional or physical abilities, our project can still be considered a great success.

Partner Commitment and Qualifications of the Team

The three partners on this project include the Human-Computer Interaction Institute (HCII) at Carnegie Mellon University (CMU), Presbyterian SeniorCare and the School of Health & Rehabilitation Sciences at the University of Pittsburgh. The HCII was founded on the principles of interdisciplinary research to design useful and usable computing systems with a human-centered philosophy, and will take the technical lead on this research, focusing on the design and engineering of the sensing systems for monitoring ODLs. Taking a human-computer interaction approach to engineering intelligent systems will ensure not only the technical challenges will be addressed but also the important challenges of designing for the many information stakeholders (*e.g.*, caregivers, doctors, and the individuals themselves).

Presbyterian SeniorCare (PSC) is dedicated to seeking out innovative approaches for improving care for its residents. As our committed clinical partner, PSC will work with us to recruit members of our target population and their caregivers. PSC is also a rich source of clinical expertise and it will play an important role in designing the evaluation of the sensing system. We will work directly with the technical leadership of PSC to integrate our ODL performance data into its electronic health records system.

The School of Health & Rehabilitation Sciences (SHRS) at the University of Pittsburgh is also another committed partner with world-renown expertise in rehabilitation science, functional assessment, and health information management.

SHRS will play a critical role in helping to choosing appropriate ODLs to focus on and ensuring the functional abilities of users will be accurately assessed in our work.

All three institutions are linked together under the Quality of Life Technology Center (www.qolt.org), a joint National Science Foundation center dedicated to creating intelligent systems to give greater independence to older adults. The working relationships among these institutions have been developed over many years of cooperation. It is this cooperation, the strengths of the individual institutions and the combined strengths that allow us to say that we will be able to work together to address any technical, clinical or social challenge that may arise during the project.

Our team consists of five individuals with a broad range of skills, appropriate for this proposal, mixing technical, behavioral and clinical backgrounds. Dr. Dey, an Associate Professor in the HCII at CMU, is an expert in human-computer interaction, and is the world's leading expert in context-awareness, the use of sensors for addressing everyday human needs. He has considerable experience in designing, implementing, deploying and evaluating innovative technical systems. This includes MemExerciser, a sensor-based tool for individuals with episodic memory impairment that captures an important event, filters the captured stream for the most salient details which are used as memory cues. An evaluation shows improved confidence in memory and improved memory about past events [Lee & Dey, 2007; 2008]. It also includes a personal navigation system that learns the preferences of elder drivers by observing them drive and produces routes that match these preferences [Ziebart *et al.*, 2008a; 2008b]; and, a system to explore privacy in such sensor-based applications [Lederer *et al.*, 2004].

Matthew Lee is a senior PhD student in the HCII, specializing in behavioral and cognitive science. Dey and Lee have worked together for 4 years, and have worked with clinicians and residents of PSC for most of that time. They studied individuals with mild Alzheimer's Disease and episodic memory impairment for one year, to understand their needs and the role that technology can play in addressing them [Lee & Dey, 2007]. Based on this, they built MemExerciser (described above) [Lee & Dey, 2008]. An evaluation showed that it improved individuals' confidence in their memory, helped them to remember more details of past experiences, and made those details more vivid. Dr. Yang is a postdoctoral fellow in the HCII, who specializes in pervasive sensing and

machine learning of human activities. Dey and Yang have worked together for two years, on this topic. Yang is an expert in machine learning, and his skills will complement the sensing and clinical expertise of the rest of the team.

On the clinical side, Dr. Collins, an Assistant Professor in the Rehabilitation Science and Technology department at the University of Pittsburgh, is an expert in assessing the functional abilities of individuals with disabilities. As a trained and licensed OT, she has over 20 years of extensive clinical experience. Her recent research has focused on assessing changes in functional and physical characteristics in nursing homes to prevent falls and related injuries. She played an instrumental role in designing a nursing home sensor kiosk that collects frequent, consistent data about many physical and emotional factors that may lead to increased risks of falls. She has also worked extensively with people with cognitive and physical disabilities and is responsible for teaching disability sensitivity training for the nearly 7,000 employees of the University of Pittsburgh Medical Center. Ms. Kent is also a licensed OT, with the PSC, and is an expert in the assessment of functional abilities within the geriatric population. She has worked in long term care for 16 years in assisted living, independent living and skilled nursing environments. Kent has vast expertise in working with a range of cognitive (including Alzheimer's Disease and dementia) and physical disabilities.

To account for the lack of prior collaboration between the clinical and technical team members, we will meet weekly to discuss the project and will hold introductory workshops to ensure we share the same vocabulary and to refine the project goals.

Commitment to the Program

All of the partners on this proposal are extremely committed to the Project HealthDesign program and its goals. We are following a user-centered design process, using existing sensing and machine learning technology to capture different ODLs to extract clinically useful information, integrating this information into clinical practice, and using the information to support patients in self-management of their impairments and to support increased dialog between patients and caregivers and clinicians.

We are also excited about the prospect of working with the other grantee teams through the workshops and also independently. We are already aware of and have worked with 2 of the other short-listed teams before: Dr. Deborah Estrin from UCLA and

Dr. Gillian Hayes from UC-Irvine. We will work with all of the grantee teams to identify areas of overlap where we can contribute to other projects and to shared solutions.

Finally, we have included budget and time in our plan to participate in the 6 workshops and other progress reports as needed, and to prepare the necessary written and financial reports. As our team has a strong academic background, we are also well prepared to provide a written report on our work that can be made available to a large audience with varying backgrounds. We also have weekly time set aside to communicate with other grantee teams that we can form connections with, and to provide content for our project website and the Project HealthDesign blog and website.