



**Priority Statement Title:** Collaborative Longitudinal Study Centers

**Priority Statement Code:** LF2F

**Domain:** Cell; Joint; Whole Body; Outcomes

### **Priority Statement**

#### **Background and Relevance**

The majority of funding frameworks available through federal agencies have maximum temporal limits of 5 years. These limits hamper the ability of investigators to longitudinally study chronic diseases or pathologies which manifest over a longer period of time (e.g. osteoarthritis, cerebral palsy). The Framingham Heart Study provides an example of the benefits of such longitudinal data collection. The long timespan of the data collected has resulted in findings far beyond the initial study mandate that would not have been possible via any single current funding mechanism.

Establishing research centers for longitudinal studies would provide a means to enhance this type of research, and could facilitate productive collaborations between multiple research groups and institutions. Specifically, creation of central testing sites for longitudinal studies could enable the correlation of multiple biomechanical, anatomical, and physiological attributes with the development and progression of chronic diseases and pathologies. A group of central sites could take responsibility for recruiting and testing a large pool of subjects using a wide battery of tests that are independently and *a priori* proposed by secondary research groups. Multiple collaborating research groups and institutions would analyze the results to provide unique and valuable insight into chronic diseases and pathologies. The results could also be made publicly accessible on a secure internet-based database system for data mining by tertiary research groups. NASA has employed a mechanism similar to this in their studies on astronaut biology research due to the need to maximize the scientific impact of research on a small subject pool being exposed to extended microgravity.

#### **Objectives**

1. To develop complex multidisciplinary longitudinal data sets of environmental, biomechanical, anatomical, and physiological parameters in a large number of subjects at risk or experiencing chronic diseases and pathologies
2. To identify statistical relationships between environmental, biomechanical, anatomical, and physiological parameters and symptoms or incidence of chronic diseases and pathologies.

#### **Recommended Actions**

1. Create collaborative research centers (e.g. modeled after the NIH National Centers for Biomedical Computing) that function as clinical treatment consortia. These centers would focus on longitudinal studies of a specific chronic disease or pathology (e.g. osteoarthritis) over a time frame of 10 or more years. The centers would be comprised of central recruitment/testing sites and secondary data analysis sites.
2. Define a series of benchmarks to assess the progress toward project goals.
3. Define a means of analyzing care efficacy and cost-effectiveness over the timespan of data collection, and consider sustainability of the study center beyond the bounds of the initial funding (e.g. institutional-level support, industry sponsorship, etc.)
4. Define criteria for an information infrastructure capable of dynamic data management which incorporates necessary levels of information security.