

1. Project Purpose

The purpose of the proposed project is to provide access to cutting edge technology, in an innovative manner, to help 100 low-income workers who have caregiving responsibility for frail elderly family members with cognitive or physical disabilities. WIN (Worker Interactive Networking) gives all participating nonprofessional employees access to and employer permission to participate in a worksite based Intranet E-mail caregiver (CG) support group, and to interact with memory loss and caregiving experts via Internet linkages. A randomly selected subset will also have wireless sensor technology (Virtucare) installed in their homes, and customized to quickly inform them at work about their family members' performance or non-performance of usual activities of daily living through an Internet linked array of wireless delivery devices. We seek to answer the following key questions – Who and to what extent will caregivers use these services? To what extent can system usage reduce the need to leave or miss work to oversee family members? What is the cost-benefit analysis of the program considering findings from both the quantitative and qualitative data?

Target Problems

Underserved communities. According to the NITA executive summary (FTTN'00) in spite of the growth of computer ownership, use and increased Internet access in the U.S., the “digital divide” still exists among certain groups. Minorities, low-income persons, those less educated, and families living in central cities and persons with a disability are among those people who still lack access to information resources. The rate of non-Caucasians over the age of 85 in the U.S. is expected to increase from 16% to 34% by 2050¹. The term “racial ravine” has been used to describe the significantly low rates of computer ownership and Internet access among Blacks and Hispanics, controlling for income and education. It is reported that the difference between the numbers of high and low income households that have access to the Internet between 1997 and 1998 increased by 29% and that the difference between Internet users according to high and low educational levels increased by 25%. We expect to enroll a diverse population (Whites, Blacks, and Hispanics) of low-income workers, with disabled caregivers thereby promoting ‘digital inclusion’ by making Internet based information resources available to those least likely to have access. (See Appendix E for our project area demographics).

Juggling work and Elder Caregiving. Contrary to public perception, the majority (80%) of frail older adults needing assistance with their activities of daily living are not institutionalized, but are cared for at home by primarily female family members². Research indicates that 23% of all employees are caring for an impaired or frail elder³ and that 44% of female, and 55% of male caregivers, are employed.⁴ Working caregivers are unable to monitor and supervise the activities of an impaired loved one, leaving the family member vulnerable to mishap while alone at home with the caregiver at work worried about their well being. The burdens and health risks inherent in the role of caregiver are well documented.⁵ Prior research indicates that persons experiencing strain in the caregiver role had a 63% higher mortality rate than non-caregivers. The MetLife worker caregiver study documented many problematic work related outcomes, such as absenteeism, tardiness, work interruptions, missed advancement opportunities, and employee termination.^{6,7} Reports indicate that 30% of all employed caregivers either made accommodation to their work schedules or terminated employment due to caregiving,⁸ while others found that 40% of working CGs have conflicts between work and caregiving and use vacation, sick time and arrive late due to caring activities.⁹

We are targeting non-professional low-income workers because they are most acutely caught between the need to work to financially sustain the family, and the demands of family caregiving. When these workers punch out to go home to see if their parents ate lunch and took their morning pills, they do not get paid for their missed work time. Higher income professional workers are more likely to be on salary and have some choice of benefit time available as well as more income to pay for caregiving help when they are at work. Professionals

are more likely to have a computer and access to the Internet for information at home besides work. While the plight of working caregivers is becoming more appreciated, business solutions are lacking. Notably we approached over 15 companies to partner with us in this proposal. While many were interested, common refusal reasons were lost productivity from workers surfing the web, damage to the computers from unskilled workers using them, interference with normal business operations, demands on their tech support services, and potential breach of company security and trade secrets. Knowing these barriers, we will assess whether they are realistic or unfounded fears as part of our project evaluation. Interestingly, the majority of these companies wanted someone else to take the research risk, but they want our results. We will partner with local companies who have a national stature, and multiple sites across our state with large numbers of potentially eligible employees. Although they also have trade secret security concerns, we are experienced in developing trusting relationships with key managers in administration, human resources, information support (IS) and corporate communications. We all are excited to develop an innovative model program that could easily translate into the business world. The national stature of the business community will help us to readily disseminate findings in both the local and national business worlds.

Solution

The technology intervention entails a comparison of two approaches – a low tech (lower cost) and a high tech (higher cost) intervention. We made this division knowing that cost will factor into adoption by business. Thus we designed two components to allow us first to answer whether or not providing access to technology in the workplace is used and makes a difference. Second, whether adding a more expensive high tech computational sensor technology monitoring results in significantly better outcomes that managers believe are worthwhile. We need to enroll 100 caregiving employees into the study to be able to make these determinations^{14,15}. We do not anticipate this to be a problem, given the large number of Massachusetts employees employed by the targeted business and the common occurrence of employee caregiving described earlier. Employees will be eligible if they provide oversight for an elderly person who lives alone during working hours and has cognitive and or health disabilities that put him or her at risk for harm. Harm, for example, could result from missed medications, forgotten /omitted meals, falling, not moving or forgetting to turn off the stove. Consenting employees will be randomized to one of 2 groups. The low technology group A (n=70) will receive access, to the Employer Intranet E-mail support group for caregivers that we will establish to reduce caregiving workers sense of isolation and to facilitate problem solving. Members will also have linkages to our web based liaisons at the Alzheimer' s association for memory issues or to HRCA's geriatrician, Muriel Gillick M.D. for personal responses to geriatric physical disability issues. The enhanced high technology group B (n=30) in addition to the previous opportunities, will also have access to the remote home monitoring component known as Virtucare. The system will be customized to the participant's particular areas of concern and potential harm such as monitoring medications, meals, and activities through wireless sensor communication. Due to space limitations, the reader is referred to Section 4 for the detailed explanation and technical specifications.

In summary, all 100 participants (group A and B) will have access to a caregiver E-mail workplace Intranet support group, either at their usual computerized workstation, a project specific computer station convenient to their work location, or wireless connections via pagers, cell phones. The variation depends on the workers role, i.e. drivers already use pagers / cell phones and this project will enhance their capabilities vs. secretaries who have no need for wireless technology since they have desktop network linkage. Participants in the high technology group B will be able to periodically monitor, in real time, their family member during the workday using Virtucare sensor technology. The program will stagger enrollment of participants over a 17-month field period but individual participation will only be for a period of six months.

Outcomes:

We hypothesize that workers who use the enhanced remote technology will have increased sense of control and fewer work disruptions due to caregiving demands in comparison to pre-project levels and the comparison group B. We will also evaluate employee use and satisfaction with the various technological components, and managers' impressions of the program's costs and benefits. (Evaluation plan is in Appendix F)

2. Innovation

This proposal offers an innovative application of technology to a new area, worker caregiving for elderly family members. The project is important because it challenges the traditional barriers between workplace and home responsibilities and can act as a model for partnering between community based organizations and local business. The project extends the notion of corporate social investing by creating a partnership between large employers and smaller community based organizations for the purpose of implementing and evaluating a program that supports the caregiving activities of employees from the workplace. Typically, community based organizations remain non-participants or ineffective in their efforts to create new and innovative alliances with corporations that result in model programs.¹⁰ This proposal is designed to ameliorate what are often conflicting and competing agenda in the workplace between employee caregiving responsibilities and work demands. The proposed project provides the mechanism for much needed continuity of care, across the day, of memory / physically impaired in-home family members by employees using readily available technology at their workplace. It uniquely offers a mutually beneficial outcome for the problems associated with working caregivers by putting in place a technologically simple and reliable method to monitor impaired family member with little interruption to their workday demands.

An on-line review of grant information and the National Telecommunications and Information Administration (NTIA) report: Project Descriptions, 1999 -2000 revealed that recent Health Section grant awards, in the area of health and aging, frequently provided telemedicine networking between frail seniors and their professional health providers in order to facilitate medical, nursing and social service (Lubec, ME and Springfield, PA, 1998 and Wichita, KS and Tupelo, MS, 2000). No project to date targets employed caregivers of impaired elders or delivers an intervention in the workplace using wireless computational sensor technology. A review of the caregiving and business literature finds a similar void, attesting to the unique and innovative nature of this proposal.

3. Very High Diffusion Potential

Increasing problem. Looking exclusively at Alzheimer's disease (AD), the most common source of serious memory loss, the number of people with AD in the United States doubles every five years after age 65, with 360,000 new cases reported annually. High incidence rates of AD among elders combined with a growing aged population forecasts an increasing need for working family members to manage family members with AD, and or frailty concerns. The need for workplace intervention programs will only increase.

Addresses lack of established approaches and generalizability. Model replication is fostered since this project uses readily available technology, namely 'off the shelf' equipment and the Internet specifically to allow ease of replication and adaptation. The Intranet support group could easily be replicated on another company system. Sharing technology in the workplaces provides access and opportunity for low-income workers in particular to utilize computer and wireless technologies. Firms with computer support staff could train employees and offer enduser support to users of the home monitoring system. Our partnering with a major nationwide employer with visibility and influence in the business community further enhances the likelihood of program replication. Furthermore, the Massachusetts Alzheimer's Chapter is a subsidiary of the national

association, which promotes sharing of successful caregiving interventions through their publications and annual conference. Lessons learned from this project's e-mail /web linkages to the HRCA's geriatrician and the Alzheimer's Association counselors will probably encourage expansion of these services. Successful project delivery and evaluation will be disseminated to an influential audience of supporters. (See Appendix D for support letters.) Furthermore, the applicants are well experienced in project information dissemination with an exceptionally strong track record of numerous publications, professional and community presentations. (See Appendix A for bio -sketches). We anticipate sharing the study findings as presentations to a variety of national professional audiences, publishing in related major journals, and we have budgeted and planned our timeline to complete these activities.

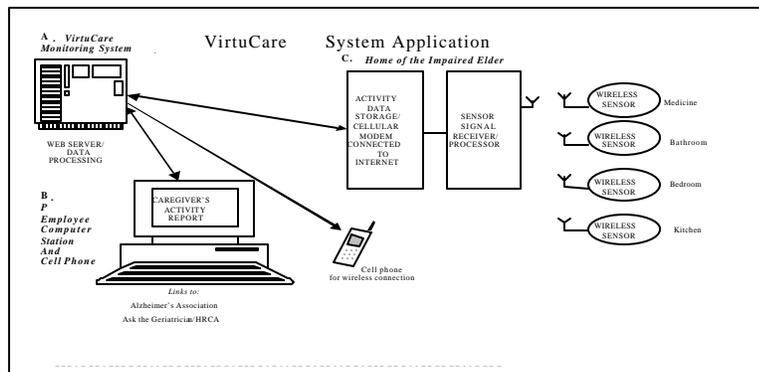
Expected Presentations- Greater Boston metropolitan businesses. Community Support Agencies: Alzheimer's Association, Multicultural Coalition on Aging. Medical, Educational and Research Institutes: Harvard School of Medicine, Division on Aging, Alzheimer's Disease Research Center, Gerontological Society of America and American Society on Aging Tech subgroups and Medical Informatics.

Publications and Web postings- Journals: The Gerontologist, Journal of Gerontology, Journal of the American Medical Informatics Assoc, Alzheimer's Disease and Related Disorders and the Journal of Occupational and Environmental Medicine. Project report and findings will be posted on the HRCA, BII, AD and Employer Corporation's Websites to encourage replication.

4. Project Feasibility.

Technical approach and procedures. The project is designed to support caregiving employees at the workplace by means of a two pronged technology intervention that strategically takes advantage of existing infrastructure and commercially available telecommunication services. (1) An Intranet E-mail support group will be established at the worksite for participating employees, and facilitated by the project field manager who will train endusers to use the system, provide technical help to endusers in need, and problem solve any technical issues. The project director will facilitate the support group and remind users about the dedicated Alzheimer's and Geriatric care linkages for unresolved content issues or users questions. The corporate IS department will adapt their pre-existing Intranet mail service at the worksite for this purpose and ensure that all participants have password access. Participants will be able to use this technology from several points according to convenience. For secretaries it may be their own desk computers, for the manufacturing or janitorial staff it may be a computer workstation available exclusively to WIN participants, for drivers it may be the company supplied wireless pagers or cell phones. Participants randomized into High technology group B, will use their same source of technology access to link to the computational sensor computer located in their home.

NB: Enlarged diagram in Appendix B



Point A: The secured Web server is located at Behavioral Informatics Inc and links to Employer based interfaces (Personal computers, hand held devices, cell phones) and the caregivers home. All monitoring

data and contacts are logged in and maintained here as part of the utilization database that will be available for the analyses.

Point B: The working caregiver logs onto the Care page at work and receives an update about their family members activities – eating, dressing, pill taking etc. If a designated monitoring function does not occur, such as eating or pill taking, the system automatically sends this information to the caregiver via a page alert or direct notice to the worker's pc depending on his or her preference and access options.

Point C: A small unit about the size of a laptop computer is placed anywhere in the monitored individual's home that has access to an electrical receptacle. The half dollar size sensors are mounted via adhesive to the inside of drawers, refrigerator, cabinets, and or the back of the bedroom /bathroom doors according to the needs of the person. For those requiring medication reminding, a special pill bottle holder is used that has a built in sensor plate. Signals are sent from the home via wireless cellular modem. Following the grant guidelines, the support for endusers is described in Section 5.

Technological alternatives considered included video surveillance equipment products but they were found unacceptable because of high costs associated with the need for multiple camera stations around each home. Additionally, potential users found the cameras intrusive as well as objectionable in the bedroom and bathroom due to privacy concerns. Geriatric research indicates that the most serious accidents occur in the bathroom, and many elders dress and take naps in the bedroom; so eliminating these two areas markedly reduces the usefulness of video home monitoring and favors sensor monitoring. (See Appendix B for fully explicated technical system architecture, and specifications.)

Applicant Qualifications. Diane Mahoney, Ph.D. has considerable experience in management of telecommunications based research projects and publication productivity, beginning with a telecommunications project designed to facilitate the monitoring of homebound disabled elders by professional case managers.¹¹ Currently, she heads the Reach for TLC project, which is a four, pronged computerized telecommunications intervention designed to monitor AD caregivers' stress and provide advice and counseling, funded by the National Institute on Aging (NIA)¹². The WIN project emanates from knowledge gained through Reach focus groups and outreach sessions, which identified workplace struggles¹³. We will also use several of the caregiving measures from the Reach project that are tailored to family caregivers. Brandeis Professor Phyllis Mutschler, Ph.D, a nationally known expert on the economic impact of caregiving on workers and the workplace, will serve as our external evaluator. As director of the National Center on Women & Aging, she is well known to business and the geriatric caregiving research communities^{6,7} and her findings will be well respected by both fields. She and her team will be vitally involved in the project from the development stage to the manuscript production phase. (See Appendix F for her memorandum of understanding and evaluation plan.) Behavioral Informatics Inc. is considered to be the leader in the field of sensor monitoring caregiving applications and brings the technical expertise to successfully implement their Virtucare product. Behavioral Informatics, Inc. (BII) was founded in April 1999, by Anthony P. Glascock, Ph.D. and David M. Kutzik, Ph.D. both of whom since have been actively researching appropriate technological solutions for expanding the effectiveness of care giving and case management for at-risk elderly populations since 1993. The VirtuCare System resulted from five years of laboratory and field-testing, and the version to be used in this project offers the latest state of the art development in computational sensor monitoring technology. We chose BII because they are the leaders in developing wireless sensor applications. Other firms we investigated (i.e. Vigilcare) require hardwire installations and less robust technology at a greater price. Appendix B offers the technical specifications and description of the system; BII memorandum of understanding p36. (See Appendix B).

Budget. We request \$527,433 in federal funding over a three-year period. In turn, we are providing \$528,677 in matching funding. The budget was constructed carefully to provide adequate manpower and resources to meet our objectives based upon Mahoney's consistent track record of bringing projects in on time and within budget. See Budget section for specific costs and the budget justification. Participant's contributions are found in Appendices B, D, and F and summarized in the Statement of Matching Funds section.

Timeline of three years: 10/01/01 to 9/30/04 (See Appendix C for three year Timeline tasks.)
Phase 1: Refine evaluation pre and post data collection tools. Configure technology, recruit 100 participants, and conduct enduser training. Phase 2: Implement intervention and collect formative and summative evaluation data. Phase 3: Evaluate and disseminate results.

Privacy. The nature of home monitoring and workplace interventions demands close attention to issues to privacy and confidentiality. BII brings their expertise in the area of computer and Internet security to ensure participant privacy for this project with the use of log-in and password codes, encryption and other security mechanisms designed to ensure only authorized users access the system. In making the physical arrangements for participants to monitor their impaired family member from the worksite, privacy issues drove the choice of motion sensor technology over video surveillance. All participants in the home monitoring group will have choice over the type of information to be monitored and control over the placement of the sensors in their homes for monitoring. (See Appendix B for technical security specifications). Employee data will only be reported in the aggregate and all personal identifiers are removed in the analytic files.

Sustainability. The Intranet E-mail employee support group will remain available to participating employees. Internet access to the HRCA's ask-the Geriatrician and the Massachusetts Chapter, Alzheimer's Association e-mail programs will remain available, enabling workers to continue to access the multiple on-line resources of both agencies. Home sensor equipment will continue to be used by workers with documented expressed need to monitor their family member. If improved worker outcomes result, the system will be proposed to corporate administrators for adoption as a new employee benefit.

5. Community Involvement

Widespread community involvement has led to the development of this proposal. Foremost at HRCA we have strong linkages to the minority community to help us better understand the needs of the underserved. We host the Community Education and Training core component of a National Institute on Aging sponsored Alzheimer's Disease Research Center (ADRC) in Massachusetts. Under this aegis, we financially support two minority outreach workers to work with the Hispanic and African American Alzheimer's caregiving communities. From them we heard about the problems working caregivers have and the difficulty for them to gain access to geriatric specialists to have their medical questions answered.

Community Partnerships and Evidence of Demand

We also participate in the Multicultural Coalition on Aging, a group of 60 Massachusetts' agencies that meet monthly to exchange ways of supporting health and caregiving needs of ethnically diverse older adults. Our proposal idea received wide support from the membership and input. (See Appendix D Coalition Support letter) Dr. Mahoney has a long term collaborative relationship with the national Alzheimer's Association, having received grants from them, serving as a grant reviewer, and sharing her research about Internet outreach and on-line caregiver support groups both nationally and locally. Due to consumer demand, AD chapters are developing websites and seeking ways to introduce new services and support. The Ma AD chapter is one of these and is offering their staff services for information, referrals and linkage to their Internet based help line (See Appendix D for the Alzheimer's Association support letter). Corporate partners are aware that workers face competing demands and hardships due to work and caregiving. They are providing tangible support and

substantial staff time and work accommodations to facilitate this project (See worker's support letter Cobbett, Appendix D). Behavioral Informatics joined our team because of their unique sensor technology expertise and our mutually collaborative interest in geriatric interventions. Finally, the investigators have conducted qualitative/quantitative studies that ascertained consumer demand and the need for workplace programs. Specifically, Mahoney conducted a yearlong analysis of an Internet based Alzheimer's caregiver support group¹² and Mutschler conducted a national survey of working caregivers. Findings from both surveys, as well as the public press, attest to the critical need to help working caregivers.^{6,7}(See Appendix E for Herald Press synopsis).

Support for endusers.

Low status occupational workers will be targeted for enrollment, as it is known that this group generally has lower income and educational levels associated with more limited access to both computers and the Internet. It is anticipated that some portion of these participants will not be computer literate, while others may have computer experience but not have Internet access at home. We therefore have designed resources into the proposal and budget for the training and continued technology usage support for the employee participants. In addition, hardware and software components used by the participants have been selected for ease of use. Computational Sensor monitoring equipment has been evaluated for its simplicity of installation use and non-intrusiveness in the home environment. HRCA project staff will conduct formal training sessions at each of the employee participant worksites, providing ongoing educational materials on-line and telephone support for both intervention groups throughout the field period. The corporate IS department will also be available for ongoing support to employees in both groups, as necessary, during work time. For group B, HRCA staff will make home visits during evenings and weekends to help the end user decide on the customization approach and then install the sensors according to endusers determination of need and preferences. They will also personally instruct endusers both at home and in the workplace until they gain proficiency in the use of the wireless technology for remote monitoring and / or Intranet usage.

In her article "Factors affecting the use of a telecommunication system for Alzheimer's caregivers" (Journal of Telecommunications and Telemedicine, 2001;7:139-148) Mahoney and team found that the proficiency ratings given by the field manager and research assistants after the enduser training were most predictive of technology adoption and usage. She will develop a similar training approach and proficiency-rating checklist for this project. We have the added benefit of having the same project director and field manager participating in this project both of whom realize the critical importance of training and the need for enduser comfort as well as knowledge about the technology and competence in using it.

Example enduser scenario

Ms. Stressed will turn on her unit at home as she leaves the house for work. At 10 am she will check home to determine if Dad is up and finished his breakfast. On the first screen she is assured by seeing the green light indicating everything she requested to be monitored is showing that those activities have occurred. She decides to pursue further and double clicks on the screen and proceeds to the next level where she can view the activities individually. She sees that the sensor feedback reports that dad arose at 8:30, dressed by 9, and ate his breakfast by 9:30. He is due to take 10 am medications and she watches while that turns green and is checked off. If he had not taken them by 11 she would have been notified via an email notice. She exits this system and decides to get some help on how to manage Dad by sending a message to others on the Intranet email support group as well as from the triage staff member at the Alzheimer's Association who is linked via her desktop system. At noon she will remotely check that he ate the sandwich she left for him. He has, and she is greatly relieved. At 2 pm she receives a call from the homemaker saying her father is not answering the door to let her in and something may be wrong. Ms. Stressed remotely checks in and sees indications of normal activity. She tells the aide she should go to the rear door and knock loudly. Ms. Stressed then checks the home

sensor screen to see Dad's movements indicating that he has opened the door. One last check before she leaves work lets her know that Dad is settled and can comfortably wait until she does some errands on the way home. She comes home knowing that all is well in marked contrast to Ms. Cobbett's caregiving experience who had to leave work several times each week to check on her mother's activities and safety (See Appendix D, Cobbett support letter).

6. Evaluation We have a two group (high and low tech endusers) experimental evaluation design.

Evaluation Questions We will conduct both a formative and summative evaluation. The formative evaluation will answer the questions - Are the low and high technology systems working as intended? Do they need any changes? Are the employees using them? This analysis will allow us to identify and rectify problems in a timely manner to ensure that the summative evaluation will be able to answer – Do the systems make a difference in outcomes? Are the observed effects those envisioned by the developers or are they different? Were there any breaches in company security due to the intervention systems? Does the employer realize fewer work disruptions and lost productivity? (Cost-benefit analysis)

Evaluation Strategy- A randomized efficacy study. Two stakeholder groups are included in the evaluation, the caregiving employees (n=100) and the employer managerial staff, who will be interviewed at baseline, 3months and at the end of the 6month field period. Outcomes have been specified and the instruments to measure their indicator attainment have been identified. (See Appendix F for evaluation plan.)

Data Collection-data collection methods will include baseline, 3 and 6 month surveys, semi-structured worker and managerial focus groups, worksite observation of technology proficiency, interviews, monitoring of enduser information and help line requests, technology usage, and pre-post intervention testing using measures associated with caregiving role management and workplace disruptions.

Data Analysis. Both quantitative and qualitative research methods will be implemented as a means to triangulate the data to foster better understanding of the results. Win-Max, a computer-assisted qualitative software program will be used for the content analysis of the interviews to gain a subjectivist understanding. SPSSx, a quantitative software program will be used to perform enduser univariate descriptive statistics and the bivariate and multivariable comparisons between the low and high tech groups for objectivist findings¹⁶.

Evaluators-. Dr. Mutschler, who is a national expert in identifying personal and financial costs associated with work disruptions, has been contracted to be the external evaluator. (See Appendix A for Dr. Mutschler's Bio-sketch and Appendix D for commitment letter to serve as the Evaluation Consultant and the Evaluation plan.) Dr. Mahoney is an experienced researcher in the area of Gerontology, Caregiving and Health Care Informatics and familiar with standardized practices for evaluating experimental research activities. However, given the specifications of this grant she has subcontracted the major study outcome responsibilities (summative evaluation) to Dr. Mutschler to ensure an arms length distance between the intervention designer and the evaluator who determines whether or not predicted worker outcomes were attained. At HRCA, Dr. Mahoney will oversee the project implementation and formative evaluation to readily discern and rectify any technical, organizational or enduser problems. Dr Jones, HRCA statistician, will establish the randomization schema and maintain its' confidentiality. He will also be responsible for confirming the data supplied by Behavioral Informatics on Virtucare technology usage statistics. Dr. Jones is a member of the Research and Training Institute but is not administratively accountable to the PI of this study. Dr. Tarlow also is from HRCA where she is a research sociologist who conducts qualitative studies¹³. She will be responsible for conducting the focus groups to gain better understanding about the issues surrounding enduser and workplace adoption and implementation of the remote technologies. Having multiple analysts provides quality oversight for the data, strengthens the evaluation, and promotes numerous project publications.