Patients Accessing Technology at Home (PATH) Project

A PATH for engaging, training and supporting older adults and their family caregivers to use computers with internet access to enhance their health and well-being

MAIMONIDES MEDICAL CENTER AND
OLDER ADULTS TECHNOLOGY SERVICES

Maimonides Medical Center

OATS Older Adults Technology Services

PATH Project Pilot Phase Report

Acknowledgments

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INTRODUCTION

While patient access to health information technology is a core component of current health system reform and its promise for increased quality, cost control and satisfaction, most adults over the age of 65 are stranded on the other side of the "digital divide." The PATH Project's overarching goal is to develop an effective model for engaging, training and supporting older adults and their family caregivers to access internet-based information and technology in their homes to improve their health outcomes, support coordination of their care, and control their healthcare costs, as well as enhance the quality of their lives.

The story of one PATH patient and her family caregiver...

Mrs. A is an 84 year-old woman whose husband of 58 years recently died after she had spent several years as his caregiver because of his dementia. Mrs. A herself has hypertension, anemia, severe degenerative joint disease, and osteoporosis, and she currently takes four prescription and three over-the-counter medications, as well as five types of vitamins. Prior to the PATH Project, she reported being "very depressed" because she had been through "a very hard time." She said that the PATH Project was "exactly what I wanted at a time that was very apropos" because the project made her feel "excited," "connected" and "up on things."

Learning how to use the computer with internet access made Mrs. A feel "a very close connection with [her physician]." "We email each other at any time. I don't need to go through a secretary and she responds immediately. My fear of physician distance is gone. It's great." As her physician confirmed, "I love the emails. [Mrs. A] used to call me every single day, but now I can respond quickly by email and she feels more secure."

Using the technology increased Mrs. A's knowledge about her health conditions. Now she conducts research on her diagnoses and any new medication prescribed about side effects. "I am becoming very knowledgeable. Questions slip my mind during the [medical] visit and I can find out [answers] on the computer."

Mrs. A found the personal health record (PHR) "very interesting and having all medications on the computer is very helpful to me and [my physician] who I gave access to [my PHR]". She also reported that, "Now, I check my medications which my daughter used to do for me," and Mrs. A accesses her PHR to add any new medications.

As for improving the quality of her life, Mrs. A said, "Now, I'm magnificent! I have the world at my fingertips. It's the first thing I do every morning – check my email and read the New York Times – any time, even 7am. It's great for my mental health. I do not feel so separated from the world. I contact my children and grandchildren." She generalized that "especially for senior citizens, [computers with internet access] take the loneliness out of living alone. You're not alone. You keep in touch with the world."

Mrs. A's daughter, who is her family caregiver and lives at a distance, reported similar benefits from her mother's participation in the PATH Project. "It opened up a whole new world to my mother." She observed that her mother's communication "has definitely increased with my husband and children." The daughter, who is "not very computer literate," was quick to offer that "now I'm motivated to learn since my mother has." In the meantime, the daughter is "happy" that her mother has put all her medications online in the PHR and indicated that her mother now also carries a hard copy of her medication list. The PHR "gives [the daughter] peace of mind" knowing that her mother's medication can be accessed online and that her mother's physicians "can access this, too."

OVERVIEW

Maimonides Medical Center, in close collaboration with Older Adults Technology Services (OATS), developed the PATH Project's six-month pilot phase during which:

❖ A range of 19 chronically ill older adults living at home, [i] ten with family caregivers, [ii] were recruited by their medical providers from the Maimonides Geriatrics Division.

❖ Techniques, tools and curriculum were created and used by OATS to provide services in the homes of participating older adult patients, including home technology assessments, provision and installation of appropriate computers and printers with internet access, ten weeks of both in-person and remote training sessions, a printed PATH Participant Guide, a special PATH Project page on the OATS *Senior Planet*™ website, and ongoing trainer support during and for a few months after the training period.

❖ A variety of caregivers, with the permission of their patient participants, were encouraged to attend the training sessions and support the patient participants' use of computers between sessions, and these caregivers were provided with their own copies of the PATH Participant Guide as well as the United Hospital Fund's *Next Step in Care*™.

❖ Selected health information technology tools and resources were incorporated into the training, including the ActiveHealth™ personal health record (PHR) being adapted for the Brooklyn Health Information Exchange and the United Hospital Fund's *Next Step in Care*™ resources for family caregivers.

❖ The participating geriatric medical providers used encrypted email to communicate with their patients and their family caregivers when they had these skills.

❖ On-going qualitative formative assessments (including participant pre-intervention assessment interviews with patients and caregivers, pre- and post-training Patient Activation Measure (PAM) 13™ surveys, weekly skills and attitude trainer assessments and self-assessments, weekly trainer meetings, and trainer and provider team meetings approximately every three weeks) were conducted for project problem-solving, development and improvement.

❖ Post-training qualitative assessments (including extensive individual interviews four-to-six weeks after the end of the training program with 15 older adult participants, six caregivers, three geriatric healthcare providers, and the three trainers) were conducted to obtain multiple perspectives on the project experience, the integrated resources, and the future of the PATH Project.[iii]

OVERALL ASSESSMENT

The PATH Project pilot phase demonstrated that access to a computer with internet technology in the home can improve the lives of many chronically ill older adults. The diverse sample of Maimonides Geriatrics Division patients and their caregivers revealed a wide variety of ways that, with individualized training in their homes, many older adults can appreciate and benefit from using computers and internet technology to enhance their health and well-being.

> *[The computer with internet access] gives me all the sources I need, plus some information I was not aware of. It's like a joyous feast of information! (Patient)*
>
> *This is what the world is coming to. Everything is changing. I saw how it would benefit people – you keep connected. (Patient)*
>
> *[Maimonides and OATS are] pioneers in the vanguard of something very important. (Caregiver)*
>
> *These patients were empowered by the project. They saw the benefit for themselves. (Provider)*
>
> *Definitely, [my patient's] quality of life improved. She is much more involved in her own healthcare issues and socially communicates more. (Provider)*
>
> *I don't get bored but when I get the feeling I want to do something, I get my computer and just start writing to this one and that one. (Patient)*

Most patient participants reported that they had positive experiences in the project, regardless of the levels of their prior familiarity with computers and the levels of skills they achieved during the project. Most expressed interest in having additional home training sessions after the ten weeks of the project's training concluded and many recommended the project's expansion to include a broader range and larger number of older adults.

All family caregivers and all medical providers involved in this project described their patient participants' experiences consistently with the patients' reports. Thay shared the patients' positive assessments of the project's potential for both patients and family caregivers. In addition to the benefits of email correspondence and internet research, most were impressed by the promise of health information technology for communications among patients, caregivers and medical providers, especially when the technology and tools become better adapted and more widely adopted for use by patients, family caregivers, and the many medical providers involved in each patient's care.

While the limited scope of this project made it impossible to measure the model's potential for improving health outcomes, coordination of care, and cost control, all the participants appreciated the potential for achieving these outcomes through the use of computers with internet technology by chronically ill older adults, their caregivers and their healthcare providers. Patient participants used the technology for diverse applications, including health research, communicating with providers and caregivers, and "quality of life" activities such as playing games and reading the news. While health benefits might be inferred from these observations, more extensive research is needed to identify whether some populations of older adults might benefit more than others, and which kinds of health and cost benefits, if any, might be significantly associated with technology use.

USE OF COMPUTER AND INTERNET TECHNOLOGY

The PATH Project pilot phase demonstrated that many chronically ill older adults can be trained to use computer and internet technology for a range of purposes, and most of them can and want to continue this use. Patient participants who had some prior familiarity with

computers reported increased and expanded use, especially related to health research and PHR integration into their health self-management and their communications with their providers. Those without prior computer familiarity varied in their levels of skills development during the project, from just learning to use the mouse for games, to engaging in regular email correspondence, to conducting frequent on-line research for personal pleasure and health issues, as well as utilizing the PHR. Despite being provided with computer and internet technology in their homes, however, episodes of illness and other unanticipated life events among patients and caregivers sometimes interfered with both initial training and ongoing computer use, requiring unusual flexibility in the scheduling and pacing of training sessions and creating difficulties in predicting who would be most likely to benefit from this project.

Many patient participants expressed pride in their new skills while many also wanted to advance their skills further, often expressing some frustration with their own diminished learning capacities at the same time as admiration for the trainers' patience with them. Most reported that they use the computer daily or at least several times a week in the four-to-six weeks following the training sessions' conclusion. Approximately half described using their computer for emailing family members, having fun playing games or listening to music, and/or researching information about their health conditions and medications. Several also said they use the computer to access resources through the OATS Senior Planet website and/or to read newspapers, primarily foreign press. Although a few refrained from using the internet for medical matters due to privacy concerns, many said they had emailed their Maimonides providers about a range of issues and/or accessed and shared resources on their ActiveHealth™ PHR, primarily to keep updated medications lists and research their health conditions and medications.

> *Initially I came to the computer with a degree of angst and questioned, 'What do I need this for? Is it able to give me something I would need?' Now – it fascinates me. You Google a name and bang – you can get an address, a phone number. It gives you access to certain things you want. (Patient)*

> *In the old days, the doctor's word was law, he was a god. Now I can look it up on the computer. If [doctors] feel you are more knowledgeable, they have more confidence in you, too. It works both ways. (Patient)*

> *The reliability of the health sites in PATH was a big help. I don't have to wonder anymore about health information I find on the internet. (Patient)*

Participating caregivers described their patients' ongoing use of computer and internet technology consistently with patients' reports. They shared the patients' enthusiasm about the benefits to patients' self-esteem, social connections, and health self-management. While the medical providers who participated in this project were less aware of the patient participants' increased use of computer and internet technology after the training sessions ended, none of the providers were concerned that their patients were emailing them too often or inappropriately, and all were enthusiastic about their patients' various benefits from their use of computers and internet technology.

> *[The PATH program] got an 87 year old man who was never on [a computer] in his business life and was not interested in computers [before], to send emails, web surf and put medications into a database. (Caregiver-son)*

> *This is a great program, gives people more control, empowers them to make better health care decisions, and is helpful to doctors, too. It helps them make better decisions if they have current medical information and history available to them. (Caregiver–wife)*

> *I love the emails. They save a lot of time on the phone. (Provider)*

The ongoing development of the technology integrated into the project influenced the participants' experiences. During the time of this project, the ActiveHealth™ PHR system, like others on the market, was improving its user interface, upgrading its information base, creating additional functionality, and obtaining consents to access data from patients' electronic health records being maintained by various providers. Encrypted email communication systems were also being modified for easier and broader use. Patient participants who attempted to use these technologies sometimes found them difficult or confusing, but they were generally enthusiastic about their promise for providing useful platforms to communicate with their providers and caregivers, obtain health information, and help manage their medical care.

IMPACT OF INTERNET COMMUNICATIONS

Few participants reported any change in the amount of communication with the participating providers or with families and friends based on this project, although participants who used email reported high levels of satisfaction with it.

For communications with healthcare providers, patient participants differed about whether and when they preferred to use the telephone or email, but neither they nor their caregivers reported confusion about when it would be appropriate to use email. Most participants thought they would email the providers in the future, to the extent that their skill and internet access permitted. The medical providers were similarly interested in maintaining email communications with the patients and their caregivers, varied in the ways they integrated telephone communications, and did not experience or generally anticipate overuse or misuse of email communications.

> *Things happen during the day and you can ask without interrupting. It's better than waiting for an appointment. (Patient)*

> *With email, you would have something else in your arsenal to communicate with. When you call your doctor and he is not there, you have to leave a message with a secretary or answering service. Your message is filtered. With email, it is not filtered and the doctor can answer any time. (Patient)*

> *[There were] fewer visits because things were resolved over email, such as questions about medications based on information they sent. (Provider)*

> *It is easier to deal with certain things on email than by phone tag. It is more efficient, streamlined and less time-consuming. No one misused it. I never came in Monday morning and read someone had been having a heart attack over the weekend. (Provider)*

For communications with family and friends, participants who used email were particularly pleased with this option to maintain long-distance communication for less cost and easier coordination across time zones. While these participants also differed about whether and when they preferred telephone or email communication, most of them thought they would continue to use email in the future, especially with children and grandchildren who seemed very supportive of the patient participants' new internet accessibility and skills development.

> *My granddaughter who just got her PhD, I got her to be with me on the computer all afternoon. (Patient)*

> *I feel more wanted, desired by others now that I use email. (Patient)*

> *I sent email to Europe and wrote in Polish and German to friends there. I saved money on phone calls. (Patient)*

The project gave him the opportunity to work with family and bring him closer to our world. He is very sociable and liked the challenge and stimulation. (Caregiver–daughter)

FEEDBACK ABOUT THE PATH MODEL

Almost all of the participating patients and caregivers expressed general enthusiasm about the PATH model, were grateful to have been included in the pilot phase, and seemed reluctant to criticize anything about it.

[The PATH model] was very well designed. They thought of everything. (Patient)

When probed about the specific components, they provided the following feedback:

❖ All but one of the participants were extremely positive about their individual trainers, commenting admiringly on their technical expertise, pedagogical techniques, and respectful, encouraging and patient attitudes.

[My trainer] was great – prompt, patient and did whatever she could do to help me understand the computer and what it was all about. She answered questions and was responsive, not robotic. (Patient)

[My trainer] was exceptionally punctual, well-prepared, knowledgeable, and professional. (Patient)

❖ The participants were particularly pleased with the in-person training sessions at patients' homes, especially when impaired mobility not only interfered with their ability to attend courses outside their homes but also limited their opportunities generally for face-to-face interpersonal contacts.

Doing the training at home removes the anxiety about getting to training sites. (Patient)

❖ The participants were also pleasantly surprised by the remote sessions, during which their regular trainers could see what they were doing on the computer while talking with them over the telephone.

[The remote sessions were] almost as helpful as in-person sessions. (Patient)

❖ When asked about the helpfulness and uses of the Participant Guide, the patient participants' responses varied widely, primarily at either extreme; however, the caregivers were almost all very positive.

[The PATH Guide was] simple and simple to follow, well-written and to the point. (Patient)

❖ The *Senior Planet*™ PATH page got a more moderate range of reviews from the several patient participants who used the website for very different purposes; however, caregivers did not consider this website as a resource.

I use the PATH icon [on the Senior Planet website] and I have already found out about aspirin, news, videos, and Trump Village, and I did exercises with the mouse. (Patient)

❖ The hard copies of the UHF's *Next Step in Care*™ resources given to participating caregivers were only briefly reviewed by some, all of whom thought these resources might be useful to them or other caregivers in the future.

> *I realized [Next Step in Care] would be important at some later date. (Caregiver)*

❖ Among the several patient participants who learned to use the ActiveHealth PHR, most overcame the initial frustrations with the technical difficulties and were eager to have it integrated into their healthcare providers' communications with them and treatment of them; however, few caregivers had any exposure to the PHR although they all thought PHRs would be important care management and communications tools in the future.

> *The PHR organizes your thoughts and has you tabulate your medical history, summarize your thoughts about your own health, and be more directive and concerned on a preventive basis. (Patient)*

> *There are so many medications that I rely on, so I list and update them after every change. Also I use [the PHR] to calendar appointments. Before I go to a doctor's appointment, I make a copy of the medication list and they are very grateful. (Patient)*

Most participants thought the ten-week training period was too short, even with the follow-up session and ongoing access to the trainers, and most wanted to have the home training period extended since they were confident that further skill development would be possible and useful over time.

IMPLICATIONS OF THE PATH PROJECT PILOT PHASE

The PATH Project pilot phase demonstrated that many chronically ill older adults can benefit from using a computer with internet technology when they are provided with access, training and support in their homes. However, due to the small sample, the short timeframe and healthcare technology issues, the PATH Project pilot was unable to provide quantitative data to generalize for whom and to what extent the PATH Project can improve health outcomes, support coordination of care, and control healthcare costs. Therefore, while it would be relatively easy to make minor but important revisions in the PATH model based on the feedback above, there are more challenging implications about project design that future phases should consider:

Expand and diversify the sample: A larger sample would allow comparisons among diverse groups of chronically ill older adults to identify those who would realize the greatest improvements in health and well-being from computers with internet access in their homes. For example, patient participants could be classified according to number and types of chronic illnesses, self-management behaviors, social isolation factors, cognitive and motor skills, familiarity with computers, and current healthcare utilization, among other variables.

Increase the duration of the project: To measure the impact of computers with internet technology on the health and well-being of chronically ill older adults, patient participants would need to be followed for an extensive period of time. Increasing the project duration would provide longitudinal data on a variety of health and well-being measures as well as utilization of healthcare services, including office and emergency room visits, hospitalizations, and nursing home placements.

Work with healthcare networks with more extensive health-IT: To assess the potential for improving healthcare coordination for chronically ill older adults through their use of computers with internet technology, it would be important to partner with healthcare providers in health-IT environments that have electronic health records (EHRs) integrated with personal health record (PHRs), access across providers and care settings, and support for email communications among patients, caregivers and providers. These systems would also make it easier to obtain data on healthcare utilization and health status changes that could be used to evaluate impact on health outcomes and healthcare costs.

Focus directly on training and supporting family caregivers to use computers with internet technology: Based on the difficulty of engaging caregivers, despite their best intentions, to participate regularly with their patient participants in the PATH Project pilot phase, it would be useful to design and test models that would target the family caregivers directly, in ways that are more convenient and supportive for them. Interventions to provide family caregivers with the internet access and skills would enable them not only to reinforce the computer use of the chronically ill older adults whom they care for, but also to obtain the benefits of the available online information and support resources for family caregivers, including UHF's *Next Step in Care*™.

Reach chronically ill older adults in locations other than their homes: In addition to working with chronically ill older adults in their homes, many can be reached in other locations, such as community and senior centers, meeting places in senior housing complexes and naturally occurring retirement communities (NORCs), and adult day programs and sub-acute rehabilitation facilities. Opportunities for partnering with these types of programs and facilities would permit modifying and testing models to analyze the effectiveness of working with this population in various settings.

Explore options for reducing costs to bring the model to scale: There are numerous options for reducing the costs of the PATH Project's pilot model that included the provision of computer equipment, internet access and training in the homes of chronically ill older adults. Trainer costs could be reduced by using group sessions for all or part of the training, using trained volunteers rather than paid professional trainers for all or part of the training, and reducing the number of in-home training sessions by increasing the use of remote training sessions. Of course, participants could also be required to offset costs by providing their own computers, paying for their own internet access, or paying fees for training and support services.

CONCLUSION

The PATH Project pilot phase indicates that chronically ill older adults can realize benefits to their health and well-being by providing them with access, training and support to use computers with internet technology in their homes. This qualitative assessment supports other research on aging and technology that indicates positive trends on a variety of measures, including reduced social isolation, improved self-esteem, and increased skills to retrieve online health and other information. Given the projected growth in the number of older adults, the age-based digital divide, and the increasing development of technology for use by patients and their caregivers, this project provided important insights on which to build so that chronically ill older adults are better able to age in place and live healthier lives at home.

END NOTES

[i] After the Maimonides geriatric providers described the PATH Project to approximately 40 patients, 25 patients consented to participate, of whom six withdrew before the training began due to their health conditions, hospitalization or "changing their minds." During the project, two more patient participants withdrew from the project due to their health conditions and one seemed functionally unable to participate in training sessions although her regular home health aide continued to participate enthusiastically. The participating patients ranged from 69 to 95 years old, with an average age of 86, and all had chronic illnesses and multiple medications. Nine patient participants reported having at least some familiarity with computers at the start of the project and various accommodations were made for patient participants' physical disabilities, ranging from visual impairments requiring customized screen resolutions to hand tremors requiring that a caregiver perform all keyboard functions at the patient participants' direction. Fifteen patient participants were able and willing to engage in post-training telephone interviews.

[ii] Among the 19 patient participants, ten identified caregivers whom they believed might participate. Of these, eight eventually engaged with the project. Four caregivers were spouses living with the patients. Three of these caregivers were at least somewhat familiar with computers and were closely involved in the project, often participating in the in-person and remote training sessions and actively supporting the patient participants. The remaining four caregivers did not live with the participating patients but were very supportive of their participation in the project. Three of these caregivers were patients' children and one was an aide, and two of them were at least somewhat familiar with computers before the project. Six caregivers were able and willing to engage in post-training telephone interviews.

[iii] Given the small, non-random sample of the PATH Project's participating patients and their caregivers, this qualitative assessment is only directional and should not be generalized to the population as a whole without further research based on statistically valid quantitative techniques. Note that for these patient participants, rating scales used in the assessment tools did not produce reliable responses because many patient participants found the scales confusing, resisted using them or provided inconsistent responses.

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