Multiple Sclerosis & Telehealth
New Models of Care

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www.va.gov/ms
Faculty Affiliation and Disclosure

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Merit Review Grant System
MS & Telehealth
Topical Outline

• Telehealth Overview
• Neurology and Telehealth
• MS Telehealth Studies
  – MS Home Automated Telemanagement (MS HAT)
  – Remote neurological exam in MS
  – Physical telerehabilitation in MS
We’ve Come a Long Way
Taking Charge of Your Health Care
When and Where you Need it

• Telehealth: a means of utilizing technology so that patients and providers can communicate remotely, enabling patients to receive health care through telecommunications
  • Clinical Video Telehealth
  • Home Telehealth
  • Store & Forward
My HealtheVet

https://www.myhealth.va.gov
Health Care Reform
The Affordable Care Act

• Patient-Centered Medical Home
  – Health homes would be composed of a team of health professionals and would provide a comprehensive set of medical services, including care coordination.

• Honoring America’s Veterans Act of 2011
  – Optimization of health IT capabilities to improve the healthcare delivery system for Veterans.
Patient-Centered Medical Home
Joint Principles (Kirschner, 2010)

• Personal physician
• Whole-person orientation
• Integrated care
• Quality and Safety
• Enhanced Access
Patient-Centered Medical Home Joint Principles

• An approach to primary care that ensures care is integrated:
  • Comprehensive care
  • Patient-centered care
  • Coordinated care
  • Accessible services
  • Committed to quality and safety

http://pcmh.ahrq.gov/portal/server.pt/community/pcmh_home/1483/PCMH_Defining%20the%20PCMH_v2
Patient-Centered Medical Home
Joint Principle Endorsement


• Promise of improved coordination, quality & efficiency

• Concerns:
  – Unrealistic expectations
  – How will new services be reimbursed
  – Implementation challenges for small practices
Telehealth Implementation Challenges

- Variability and unpredictability of symptoms
- Patient confidentiality & data security
- Limited computer skills
- Reimbursement of telehealth care
- Standards for telemedicine equipment and competencies of health care professionals using telehealth
Telehealth & Neurology
(Agarwal S. J Neurol 2011)

Telestroke: initiated in 1990s for acute stroke thrombolysis consultation, AHA Class I evidence for reliability of remote NIH Stroke Scale exam

Teleneurology Pilots:
• Parkinson’s Disease
• Epilepsy
• Neurorehabilitation
• Multiple Sclerosis
Teleneurology & Cost Effectiveness

- Epilepsy: savings of ~10% based on travel & related expenses (Ahmed S. Epilepsia 2008)
- Neurocritical Care: robotic monitoring of ICU patients produced an annual cost savings of $1.1 million (Vespa P. Surg Neurol 2007)
- Parkinson’s Disease: outpatient follow-up costs reduced in a community cohort of patients (Samii A. J Telemed Telecare 2006)
Telemedicine in Leading US Neurology Departments
(George B. Neurohospitalist 2012)

• 60% of respondents provide limited telemedicine services
  – Stroke
  – Movement disorders
  – Neurology critical care
• Most programs started 2008-2010
• External funding sources
Integrated MS Care

- Comprehensive & coordinated care between health and social sectors
  - Many unmet needs found in review of MS care delivery in part due to fragmentation and discontinuity of the health care system
  - Multidisciplinary community team worked with MS specialists
  - Home-based care interdisciplinary team intervention
Existing approaches of care using telehealth

- do not utilize constructs from evidence-based models for chronic care which were shown to successfully improve quality of care;
- current technology is not cost-effective;
- existing IT tools are not fully integrated into the health information systems
Telehealth Projects at MSCoE
(www.va.gov/ms)

—Home Telehealth:
  • MS Viterion® Symptom Survey  (Turner A. et al *IJMSC* in press)
  • Telehealth Pilot 2: USB Cameras-Clinic to Home EDSS
  • VA Central Office IT Project: MS HAT Demo Project
  • MS Physical Telerehabilitation Randomized Trial
  • MS Adherence Pilot (INF beta and Vitamin D)
  • MS Cognitive Rehabilitation Pilot Project

—Clinical Video Telehealth:
  • Telehealth Pilot 1: Polycom ® VAMC-DC to VAMC- Baltimore
  • Telehealth consultation between MS Regional Centers & other specialty centers

—Store & Forward Telehealth:
  • Remote cognitive assessment project
Home Telehealth
Beyond the Basics: Your MS Care

• Home-based teleneurology is just-in-time care
• When transportation is a challenge
• What our research has shown:
  – The remote neurological exam is similar to the live exam
  – Patient satisfaction is high
  – Cost of care is less
  – Multidisciplinary care is enhanced
Home Automated Telemanagement (HAT) System

- HAT was developed by J. Finkelstein/JHU Chronic Disease Informatics Dept and has been designed to:
  - Help patients in following their self-care plans
  - Help health care practitioners to follow their patients’ self-management process
  - Facilitate multi-component chronic disease management according to the current clinical guidelines
Technical Design of HAT

Patient Unit
- Data Collection Module
- Presentation Module
- Computing Module
- Communication Module

HAT Server
- HAT Database
- Decision Support Module
- HAT Web Server
- EMR Link

Clinician Unit
- Presentation Module
- Communication Module
MS HAT: Information Infrastructure

Web browser (IE + .NET)

Smart Phone (WML + .NET)

Desktop / Laptop (VB + Win 9x/2k)

PDA (eVB + WinCE)

Wireless network

WAP Proxy

Central Database

Offline Synchronization via serial port/USB
MS HAT
VA Demonstration Project
MSCoE and Johns Hopkins U
2011-2013

Home Unit

HAT Server
(Austin Automation Center)

CPRS-VISTA

Home Unit

Home Unit
MS Telemanagement Evaluation

- Interactive patient education and counseling
- Telerehabilitation
- Remote Neurological Examination
- Telemanagement


Computer-Assisted Education in MS Patients

Multiple Sclerosis is a disease that affects the Central Nervous System.

What is Multiple Sclerosis?

1 - A disease that affects the Central Nervous System
2 - A disease that affects the eyes
3 - A disease that affects the muscles

Select your answer using the keyboard

Sorry, the correct answer is:

Multiple Sclerosis is a disease that affects the Central Nervous System.

Congratulations! Your answer is correct.

Press '0' to Return to Main Menu
Feasibility of Computer-Assisted Education (CO-ED) in MS Patients

- Convenience sample of 23 consecutive patients was enrolled into the study
- Patient age was in the range of 31 to 59 years
- 40% did not have any computer experience
- 91% stated that they prefer using CO-ED as an education tool rather than a brochure
- 100% claimed that they would advice other patients to use CO-ED for disease-specific education
- 92% felt that using CO-ED was not complicated at all
- More than 50% stated that they learned new information about their disease using CO-ED
- 98% felt that immediate feedback was very helpful
- 22.5% improvement in knowledge score

Home Physical Telerehabilitation in MS

• Life-long rehabilitation measures, together with medication treatment, are the major components of MS patient management.

• Physical exercise has a positive impact on patients’ quality of life and their functional capacities.

• Interactive, web-based telemanagement systems may facilitate patient adherence to rehabilitation plans.
Primary Objective

• To assess the feasibility and acceptance of the Home Automated Telemanagement (HAT) system for MS patients participating in a structured exercise program.
Use the table below to create a new exercise plan:

<table>
<thead>
<tr>
<th>Exercise</th>
<th>Sequence Num</th>
<th>Seconds</th>
<th>Times</th>
<th>Sets</th>
<th>Sessions</th>
<th>Weights</th>
<th>Add new</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOW BACK STRETCHING</td>
<td></td>
<td></td>
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<tr>
<td>Knee to Chest</td>
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</tr>
<tr>
<td>Trunk Rotation</td>
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</tr>
<tr>
<td>Face-Lying over Pillow</td>
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<tr>
<td>Seated</td>
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<tr>
<td>MID BACK STRETCHING</td>
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<td></td>
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<tr>
<td>Hands and Knees</td>
<td></td>
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<tr>
<td>HIP FLEXOR STRETCHING</td>
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<tr>
<td>One Joint (Iliopsoas)</td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Two Joint (Rectus Femoris)</td>
<td></td>
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<tr>
<td>HAMSTRING STRETCHING</td>
<td></td>
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</tr>
<tr>
<td>Active - Seated</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
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</tr>
<tr>
<td>Active - Lying down with Towel</td>
<td></td>
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</tr>
<tr>
<td>Assist</td>
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</tr>
<tr>
<td>HAMSTRING &amp; CALF STRETCHING</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Passive - Seated with Towel</td>
<td></td>
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<td></td>
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<tr>
<td>Assist</td>
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<td></td>
</tr>
<tr>
<td>CALF MUSCLE STRETCHING</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Calf Muscles: Gastroc</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Stretching-Standing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Calf Muscle: Soleus Stretch-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Alert History

Patient Name: 
Phone:  

Home Monitoring (Details)

Exercise Date: 8/25/2006

Exercise Name: Trunk Rotation

<table>
<thead>
<tr>
<th>StartTime</th>
<th>EndTime</th>
<th>Question_Num</th>
<th>Diary_Question</th>
<th>Patient_Answer</th>
</tr>
</thead>
</table>
MS HAT Home Station: Menu

1 - Start Exercises
2 - View Exercise Safety Tips
3 - Update My Current Exercises
4 - Review My Exercise Program
5 - Shut Down My Computer

Your Exercises for this Session...
1. Knee to Chest
   Sets Completed: 1
2. Trunk Rotation
   Sets Completed: 0
3. Face-Lying over Pillow
   Sets Completed: 0
4. Seated
   Sets Completed: 0

Press ENTER to start an exercise | Press EXIT to end this session
Home Station: Exercise Directions

**Stretching Exercises**

**Knee to Chest**

1. Lie on back with knees bent
2. Slowly pull both knees toward the chest, gently stretching the low back muscles just enough to flatten the low back on floor.
3. Hold for three breaths.
4. Return to starting position.

Press <Replay> to Start/Stop Video

**Do 4 times**

Press Enter to continue
How many seated stretching sessions did you do?

Use arrow keys and then press ENTER
The side effects of interferons include:

- Injection-site reactions
- Possible depression
- Flu-like symptoms
- All answers are correct

Sorry, the correct answer is:

All interferons have side effects. The main side effects are flu-like symptoms and possible depression. There may also be a skin reaction where the medicine is injected.
Congratulations! Your answer is correct.

Here is your next tip:

Blood tests must be done every 6 months when you take interferons. They should not be taken during pregnancy.
Home Physical Telerehabilitation in MS Pilot Study

- N=12 patients with MS
- Mean Age: 52 years
- Mean number of years with MS: 13
- 83% females
- Mean Education: 15 years

Berg Balance Scale

Baseline: 38
12 weeks: 43

Series1
MS HAT: Remote Neuro Exam

Background

• Physician care is routinely carried out in doctor’s offices and hospitals.

• Patients with MS are often separated from specialty care due to disability or distance.

• The value of low-cost webcams as a tool for remote neurological exam has not been systematically evaluated.
MS HAT: Remote Neuro Exam

Objective

• A videoconferencing application utilizing low-cost webcam was developed to assist patients in remote neurological evaluation.

• This study evaluated the feasibility of using regular webcam and microphone as a tool to aid in the management of multiple sclerosis (MS).
MS HAT Webcam System Design
MS HAT: Remote Neuro Exam
Study Design

• A total of 20 patients with MS were recruited
• Trained study asst. played role of patient’s caregiver
• Two MS clinicians examined each patient at the clinic using the Kurtzke Expanded Disability Scale (EDSS).
• On a single visit, each patient underwent two identical sets of neurological assessment:
  – Traditional in-person evaluation
  – Remote assessment using portable webcams
MS HAT: Remote Neuro Exam
Kurtzke Expanded Disability Scale Scores (EDSS)
Overall, the remote assessment system received positive ratings from both patients and providers.

- 100% - Patients felt comfortable with the equipment used.
- 85% - Patients were satisfied with the telemedicine parts of this examination.
- 90% - Providers were able to obtain adequate information interviewing the patients via video chat.
- 95% - Providers felt confident in the final assessment.

Successful User Interface

- Large font
- Color markers
- One task per screen
- Prompts in each screen
- Adaptation to various disabilities
- Persistence and respect in training
- Clear statement of individual advantages
- Tailored content and functionality
- Multiple health communication channels
- Ability to increase user self-efficacy
MS HAT: Home Unit

my Diary
my Exercise
my Education
my Messages

1. Loss of co-ordination or dexterity (37 questions left)

- Yes
- No

Back  Next
### Attitudinal Survey (N=40)

<table>
<thead>
<tr>
<th>Attitudinal Survey</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>How complicated was it to use the self-testing procedures</td>
<td>92.5</td>
</tr>
<tr>
<td>Not Complicated at all/ Slightly Complicated</td>
<td></td>
</tr>
<tr>
<td>Did you have any difficulty in moving from one screen to another</td>
<td>87.5</td>
</tr>
<tr>
<td>Not at all/ Very Rarely</td>
<td></td>
</tr>
<tr>
<td>How difficult was it to use the keypad</td>
<td>75.0</td>
</tr>
<tr>
<td>Not difficult at all/ Slightly difficult</td>
<td></td>
</tr>
<tr>
<td>Did you have any difficulties in reading text from the telecare device</td>
<td>92.5</td>
</tr>
<tr>
<td>Not at all/ Very Rarely</td>
<td></td>
</tr>
<tr>
<td>Was the size of the text presented on the screen sufficient</td>
<td>75.0</td>
</tr>
<tr>
<td>Fully sufficient/ Sufficient most of the time</td>
<td></td>
</tr>
<tr>
<td>Did you like the colors used on the screen</td>
<td>67.5</td>
</tr>
<tr>
<td>Certainly yes/ To a large extent</td>
<td></td>
</tr>
<tr>
<td>Did you like the audiovisual content provided by the telecare device</td>
<td>70.0</td>
</tr>
<tr>
<td>Certainly yes/ To a large extent</td>
<td></td>
</tr>
<tr>
<td>Did you come across any unknown words which were not explained by the telecare device</td>
<td>97.5</td>
</tr>
<tr>
<td>None/ A few</td>
<td></td>
</tr>
<tr>
<td>How difficult was working with the computer</td>
<td>100</td>
</tr>
<tr>
<td>Not difficult at all/ Slightly difficult</td>
<td></td>
</tr>
<tr>
<td>How difficult was answering the symptom diary and medication side effect questions</td>
<td>92.5</td>
</tr>
<tr>
<td>Not difficult at all/ Slightly difficult</td>
<td></td>
</tr>
<tr>
<td>Did you get all the necessary information about self-testing during the first introductory meeting</td>
<td>92.5</td>
</tr>
<tr>
<td>All information/ Almost all information</td>
<td></td>
</tr>
<tr>
<td>How much of your time did the self-testing take</td>
<td>90.0</td>
</tr>
<tr>
<td>Very little/ little</td>
<td></td>
</tr>
<tr>
<td>Attitudinal Survey</td>
<td>%</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------------</td>
<td>-----</td>
</tr>
<tr>
<td>Would the self-testing interfere with your usual activities</td>
<td></td>
</tr>
<tr>
<td>No/Very Little</td>
<td>82.5</td>
</tr>
<tr>
<td>What is the maximum frequency of self-testing you think you can tolerate</td>
<td></td>
</tr>
<tr>
<td>Four times a week/Three times a week</td>
<td>57.5</td>
</tr>
<tr>
<td>Would you feel safer while monitored by the system</td>
<td></td>
</tr>
<tr>
<td>Significantly safer/Moderately safer</td>
<td>50.0</td>
</tr>
<tr>
<td>How important for you is it to know that the results of your self-testing can be</td>
<td></td>
</tr>
<tr>
<td>reviewed in the medical center immediately after the test</td>
<td></td>
</tr>
<tr>
<td>Extremely important/Very important</td>
<td>87.5</td>
</tr>
<tr>
<td>How often will you review the test results</td>
<td></td>
</tr>
<tr>
<td>Once a week. Once a month</td>
<td>85.0</td>
</tr>
<tr>
<td>Would you like to use this self-testing program in the future</td>
<td></td>
</tr>
<tr>
<td>Certainly yes/Maybe</td>
<td>95.0</td>
</tr>
<tr>
<td>Would you like to receive personalized education via this device</td>
<td></td>
</tr>
<tr>
<td>Certainly yes/Maybe</td>
<td>92.5</td>
</tr>
<tr>
<td>Would you like to communicate with your doctor via this device</td>
<td></td>
</tr>
<tr>
<td>Certainly yes/Maybe</td>
<td>97.5</td>
</tr>
<tr>
<td>Would you like to use this telecare device in the future</td>
<td></td>
</tr>
<tr>
<td>Certainly yes/Maybe</td>
<td>97.5</td>
</tr>
<tr>
<td>Would you advise other patients to use this telecare device</td>
<td></td>
</tr>
<tr>
<td>Certainly yes/Maybe</td>
<td>97.5</td>
</tr>
<tr>
<td>Overall how would you grade this telecare device</td>
<td></td>
</tr>
<tr>
<td>Excellent/Good</td>
<td>80.0</td>
</tr>
</tbody>
</table>
Adherence to Self-Testing Regimen (N=20)

Finkelstein J, Cha E, Wood J, Wallin MT. Predictors of Successful Acceptance of Home Telemanagement in Veterans with Multiple Sclerosis, 2013, in press
## Predictors of Successful Acceptance

<table>
<thead>
<tr>
<th>Attitudinal survey score</th>
<th>Parameter estimates</th>
<th>T value</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How long have you had MS? (years)</strong></td>
<td>-0.9</td>
<td>-2.9</td>
<td>0.02*</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>0.2</td>
<td>0.5</td>
<td>0.6</td>
</tr>
<tr>
<td><strong>Computer use at home</strong></td>
<td>-20.1</td>
<td>-3.5</td>
<td>0.007*</td>
</tr>
<tr>
<td><em>Never/Once a month or less/Once a week (0)</em></td>
<td><strong>Once a day (1)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>English proficiency</strong></td>
<td>16.3</td>
<td>4.0</td>
<td>0.003*</td>
</tr>
<tr>
<td><em>Excellent (1)</em></td>
<td><strong>Good/Poor/None (0)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Education (years)</strong></td>
<td>-0.7</td>
<td>-0.9</td>
<td>0.4</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td>-5.1</td>
<td>-0.9</td>
<td>0.4</td>
</tr>
<tr>
<td><em>White (0)</em></td>
<td><strong>African American (1)</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Patient Feedback about MS HAT

• “Using the computer was easier than using the remote control.”
• “I liked the whole concept of self-testing.”
• “My symptom may disappear by the time I meet my doctor. MS patients have memory problem, too. If I don’t record it, I will forget to tell my doctor. It keeps you mindful and aware of your condition.”
• “I thought it would give a better sense how patients are feeling on daily basis.”
• “It is very important to me that my doctors can review my results from the diary. I would only review them occasionally.”
Patient Feedback about MS HAT

• “I could go through the diary as many times as needed, but I would prefer to go through it three times a week at the most.”
• “I also want to document side effects from medication. I may get flu-like symptoms from medication.”
• “Education was good. It’s a good part of the program. It helps to reinforce the knowledge.”
• “I like how there was a question after each message and the quiz is a good way to help with memory, and get you to remember the information that you read.”
Patient Feedback about MS HAT

• “The webcam would be good for me to talk with my doctor if I have any problems. The doctor would be able to see what is wrong and I would not have to try to remember any problems that I had in between doctor visits.”

• “I can access it anytime according to my schedule and it makes me more confident to report how I feel.”

• “I think computer is the best way to digitize the symptoms and see the trend. It has a positive impact on the ability to manage the disease.”

• “I feel more confident with managing MS while being monitored via computer. It was very convenient that I can do it at home, no driving involved.”
Home Automated Telemedicine (HAT):
Comprehensive Support for MS Care
MSCoE & JHU Collaboration

• Evaluation & tracking of individualized treatment plans
• Secure messaging services to exchange information with health care provider
• Medication monitoring & adherence enhancement
• Physical and Occupational Therapy with evaluation of efficacy and safety
• Neurologic symptom monitoring
• MS Disease modifying therapy (initiation, monitoring & support)
• Integration & data transfers with national CPRS
• Social support (virtual patient groups, message boards)
• Home televisits
• Telecognitive assessments and cognitive rehabilitation
MS Therapy Adherence Trial Utilizing HAT

• Randomized study to improve adherence to MS therapy for up to 1 year
• Quarterly follow-up visits in the home
• Sponsors: Biogen-Idec, Inc & MSCoE

• Study candidates:
  – Diagnosis of MS
  – Taking interferon-beta 1a weekly & Vitamin D supplement
  – 18-65 years
MS Physical Telerehabilitation Trial

• Randomized study of MS HAT vs. optimal with a primary aim to improve walking speed and balance in patients with MS
• 6 month trial with follow-up visits at 3 and 6 months (DC/Baltimore region)
• Sponsors: VA Merit Review & MSCoE
• Study candidates:
  – Diagnosis of MS
  – Able to walk with or without gait aids
  – 18-65 years
Conclusions: Telehealth & MS Care

• Telehealth can improve access and integration of care for patients with MS

• MS HAT can be an efficient platform for the management of MS patients when and where they need it:
  – Telerehabilitation and MS RCT (VA Merit Review)
  – MS Therapy Adherence Study (Biogen-Idec)
  – Home telecognitive assessment Pilot (Vista Partners)

• Telehealth tools must be tested in the clinical setting to evaluate their value for patients & providers
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