

National MS Society  
Current Health Care Delivery and Policy Research Projects  
2008

**Robert J. Buchanan, PhD**  
Mississippi State University  
Mississippi State, MS  
Area: Mississippi Division, All America Chapter  
Award: Health Care Delivery & Policy Research Contract  
Term: 8/16/05 -6/30/08  
Funding: \$117,259

**“The long-term care needs of people with multiple sclerosis”** Exploring the long-term care needs of people with MS and the services they receive in care facilities.

Approximately one quarter of people with MS will need long-term care at some point during their illness. Robert Buchanan, PhD, is examining long-term care provided for people with MS, focusing particularly on how care needs change as disability levels increase.

Several long-term care options are available, including nursing homes and an array of home- and community-based support services. Dr. Buchanan is profiling nursing home residents with MS and analyzing the care they receive to determine the impact of specific services, such as physical therapy, counseling, drug therapies and group therapies, on their physical and mental health. He is also surveying informal caregivers who provide in-home and community-based care to learn about the services they offer and the barriers that exist to providing this care.

Identifying nursing home characteristics that are associated with improved quality of life and learning about the impact of formal and informal long-term care will give a clearer picture of the long-term care needs of people with MS.

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**Barbara J. Gage, PhD**

RTI International

Waltham, MA

NMSS Area: Central New England Chapter

Award: Health Care Delivery & Policy Research Contract

Term/Amount: 7/1/06-6/30/08; \$220,840

**“Comprehensive evaluation of rehabilitation services in multiple sclerosis”** Exploring the use of rehabilitation among people with MS, and the barriers that may prevent this need from being met.

Rehabilitation can help people with multiple sclerosis achieve maximal physical, psychological, social and vocational potential. Although such interventions have gained increasing acceptance, research in this area has been limited.

Barbara J. Gage, PhD, is examining the costs and use of rehabilitation services for people with MS. Dr. Gage’s team is using Medicare administrative data to profile the types and levels of inpatient and outpatient rehabilitation services used by Medicare beneficiaries with MS during 2004. The team is also hosting a technical advisory panel to gain insight from consumers, providers, advocates, and other experts involved in helping this population access appropriate rehabilitation services.

This study which resulted from a request for proposals from the Society’s Health Care Delivery and Policy Research Program is crucial to improving rehabilitation interventions for people with MS. Dr. Gage is implementing a strategy for disseminating the results that will maximize their impact on policymakers, providers, and patients.

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**Lisa I. Iezzoni, MD, MSc**  
Beth Israel Deaconess Medical Center  
Boston, MA  
NMSS Area: Central New England Chapter  
Award: Health Care Delivery & Policy Research Contract  
Term/Amount: 7/1/06-6/30/08; \$315,004

**“Mobility aids for persons with multiple sclerosis”** Exploring why more people with MS do not use mobility aids, for clues to fulfilling this unmet need.

Many mobility aids are now available, but for complicated reasons, persons with MS may not use these devices. Without such aids, their lives may be needlessly restricted.

Learning more about the use of mobility aids might suggest where to focus efforts to improve the situation. Lisa Iezzoni, MD, is exploring the extent, nature, and consequences of unmet needs for the full range of mobility aids from canes and crutches to wheelchairs and scooters among people with MS. Her team is doing a telephone survey of about 850 people nationwide to learn about their use of mobility aids and about any barriers they have faced in obtaining and using this equipment. They are doing more in-depth interviews with a subset of people, along with detailed evaluations of their mobility aid needs by skilled rehabilitation therapists. They also are evaluating Medicare and Medicaid policies on paying for mobility aids.

This study which resulted from a request for proposals from the Society’s Health Care Delivery and Policy Research Program – will provide vital information that can help improve the use of mobility aids among people with MS a critical step toward improving quality of life.

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**Katia Noyes, PhD, MPH**

University of Rochester

Rochester, NY

NMSS Area: Upstate New York Chapter

Award: Health Care Delivery & Policy Research Contract

Term/Amount: 7/1/05-6/30/08; \$484,543

**“Cost-effectiveness of treatments in multiple sclerosis (COSTRIMS)”**

The annual cost of taking a disease-modifying drug for MS, such as one of the interferons or Copaxone, can exceed \$16,000. Cost-effectiveness analysis is a special kind of clinical research that deals with both costs and health consequences of medical interventions. Katia Noyes, PhD, MPH, is seeking to identify the most appropriate methodology for assessing the cost-effectiveness of MS treatments.

In the first phase of this project, Dr. Noyes and an international study team are conducting a systematic literature review of cost-effectiveness research, particularly in progressive illnesses with periodic relapses such as MS, asthma, and lupus. An advisory panel of experts will critically evaluate the findings of this review, and help formulate guidelines which will be used during the second phase of the study to analyze the cost-effectiveness of disease-modifying agents in MS. If new drugs enter the market, the analyses will be adjusted accordingly.

As the results become available, Dr. Noyes will collaborate with the National MS Society to disseminate them to people with MS, healthcare professionals, healthcare policy makers, federal and state governments, and service providers. This study will be crucial in the treatment, insurance, and advocacy efforts on behalf of people with MS.

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**Carol Simon, PhD**

Abt Associates Inc.

Cambridge, MA

NMSS Area: Central New England Chapter

Award: Health Care Delivery & Policy contract

Term/Amount: 7/1/07-6/30/09; \$384,233

**“Financial modeling of multiple sclerosis medical care”** Analyzing how the costs and financing of MS health care influences the quality of that care and the ability of people to access care.

This project is designed to better understand the organization and financing of MS care. Carol Simon, PhD and colleagues will attempt to identify misalignment between costs and reimbursements, and ascertain its impact on access to and quality of care.

Using information from sources such as care private providers, MS clinics and Medicare payments, the investigators will identify principal diagnostic and therapeutic procedures required by people with MS. They will then ascertain costs incurred by care providers and the sources and amounts of payment for their services, and determine any gaps between costs for services rendered and payments received.

This study will provide data to guide improvements in the structure and processes of MS care, and suggest strategies to help care providers negotiate appropriate reimbursement of medically necessary services. It should also provide the National MS Society with important data with which to advocate for improvements to improve the quality of care available for people with MS.

**Michael G. Trisolini, MBA, PhD**

RTI International

Waltham, MA

NMSS Area: Central New England Chapter

Award: Health Care Delivery & Policy Contract

Term/Amount: 7/1/04-6/30/07; \$466,148

**“Comprehensive evaluation of multiple sclerosis adult day programs”** Defining the impact of MS adult day programs in terms of quality of life, costs, health and functional status, and identifying optimal practices and funding sources.

Some individuals with MS have progressive disease that eventually increases their need for assistance and support. Adult day programs are one long-term care option that may allow individuals to maintain independence and gain access to rehabilitation and activities that can improve quality of life. However, these programs are expensive and very little research has addressed their possible benefits and costs. As a result more information is needed to guide future program development and advocacy efforts.

Michael G. Trisolini, MBA, PhD, is leading a study of established adult day programs for persons with MS to evaluate the impact of these programs in terms of quality of life, costs, impact on health and functional status and other measures. In collaboration with MS adult day programs, the team is also investigating costs for establishing and running the programs, funding sources for the programs and optimal ways of setting up and running the programs so that they best meet the needs of persons with MS.

This study should provide clear information about the impact of adult day programs on quality of life, and offer guidelines for implementing these programs more widely.

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**Barbara Vickrey, MD, MPH**

VA Greater Los Angeles Healthcare System  
Los Angeles, CA

NMSS Area: Southern California Chapter

Award: Health Care Delivery & Policy contract

Term/Amount: 7/1/07-6/30/10; \$487,570

**“Development of indicators for multiple sclerosis”** Defining what constitutes quality MS health care and how to measure it to establish better standards of medical care for people with MS.

Multiple sclerosis (MS) is a complex neurological disorder that can cause a wide spectrum of symptoms. There is currently no set of tools for measuring whether persons who have MS are receiving high-quality health care. Barbara Vickrey, MD, MPH, is leading a team of MS specialists and social scientists to analyze the medical evidence and to gather input from key stakeholders, including patients, clinicians, insurers, and administrators, as to what constitutes high quality MS care.

The researchers will then draft a set of quality indicator measures and obtain ratings from a stakeholder group on each measure’s importance and impact. The final set of MS quality indicators will be field-tested in a wide range of practice settings, so that the indicators can be ready for widespread use.

Future applications include use of the indicators in studies to test new ways of delivering high-quality MS care, and to help clinicians and healthcare systems in evaluating the quality of the MS care they are providing.