Outcome measurement is an essential part of the rehabilitation process. Rehabilitation professionals need standardized means to document the effectiveness of their treatment and to monitor the results of their efforts through patient-reported outcomes, such as quality of life or community participation.

To that end, we feel it is crucial to share the knowledge we’ve gained to advance the use of outcome measurement in clinical practice and research. In this issue, we describe two upcoming events that will support rehabilitation professionals in this endeavor.

In addition, we encourage you to visit our website to access over 20 PowerPoint presentations and lectures that are free to the public. Finally, the Rehabilitation Measures Database continues to grow, providing a wealth of information about available measurement tools.

For more information about our projects and educational opportunities, please visit our page at www.ric.org/cror. And don’t forget to “like” us on Facebook!

Allen Heinemann, Director

Richard Gershon: A Pioneer in Patient-reported Outcomes

Back in the 1980s, the exam to become a registered nurse took 12 hours to complete and was only offered twice a year to cut down on cheating. But these days, the exam takes about 90 minutes, it can be given almost any day of the year and the opportunity to cheat is virtually nil.

How can a shorter, simpler test also be more secure? Richard Gershon, Ph.D., a Clinical Psychologist and Vice Chair for Research in the Department of Medical Social Sciences at Northwestern University’s Feinberg School of Medicine, has made that subject the centerpiece of his life’s work.

Gershon found the answer in the intersection of two areas of primary interest for which his expertise is well known - Item Response Theory (IRT) and Computerized Adaptive Testing (CAT).

“Item Response Theory is a relatively new branch of statistics that is used to evaluate items and questions used in tests and surveys. It looks at everything from the quality of the items to the quality of tests,” Gershon says. “A computer adaptive test based upon IRT zeroes in on the person’s ability level. We go beyond branching. We actually evaluate your pattern of responding and then identify the next item from a large “bank” of items that will tell us the most about you.”

Summer Institutes for Researchers and Clinicians

It has only been two years since the Center for Rehabilitation Outcomes Research (CROR) offered its first ever Summer Institute on Measuring Rehabilitation Outcomes, but much has improved since then for clinicians and researchers seeking better ways to help patients.

“There are a number of new measures available since we last did this,” says Nan Rothrock, Ph.D., Assistant Professor in the Department of Medical Social Sciences at Northwestern University’s Feinberg School of Medicine, who is a co-instructor.

“The scope of patient-reported outcome measures has increased.”

Several large, federally-funded research initiatives including the National Institutes of Health Toolbox (www.nihtoolbox.org), Quality of Life in Neurological Disorders (Neuro-QOL; www.neuroqol.org) and the Patient Reported Outcomes Measurement Information System (PROMIS; www.nihpromis.org) are coming to the end of their grant cycles and the instruments constructed by these initiatives are now available to clinicians and researchers.

Each measurement effort has a different focus, Rothrock explains. PROMIS is a set of patient-reported measures evaluating physical, mental and social health across chronic conditions. The NIH Toolbox is a set of self-report and proctor...
Nicholas Formanski’s life changed in an instant. In 2001, the Chicago native was on vacation in Cancun, Mexico, relaxing by the pool in the hot September sun. His wife urged him to get a drink of water. He stood up, passed out, and cracked his head on the bottom of the shallow pool, breaking his neck.

The next thing Formanski remembers is waking up in Northwestern Memorial Hospital a month later unable to breathe on his own and paralyzed from the neck down. “I was deathly afraid,” he recalls. “I didn’t know what was going to become of me. When you’re laying there and you can’t feel your feet or the touch of your wife, it’s scary.”

Despite the devastating spinal cord injury he suffered, Formanski’s story has an inspiring ending. He is no longer paralyzed and now works part-time as a research assistant at the Center for Rehabilitation Outcomes Research (CROR). The focus of the research is close to his heart—working on projects that can help determine the best rehabilitation practices for patients with spinal cord injuries.

Formanski knows he was lucky. His spinal cord wasn’t severed and as the swelling went down, he was able to get off a ventilator, which allowed him to be admitted to the Rehabilitation Institute of Chicago (RIC). He had heard that rehabilitation there was “boot camp,” but that’s what he wanted— to work as hard and fast as possible to get back on his feet.

After three months of intensive therapy, he did. It took another seven months of home-based and outpatient therapy before Formanski was able to go back to work part-time at his previous employer. But he missed his doctors and therapists at RIC.

“Every time I came here for a doctor’s visit, I felt RIC was my home away from home. It was a comfortable place to be. I told my wife, ‘This is the place to work.’ I started watching the openings there and applying and then one day, I got a call.”

He was offered a job as a research assistant at CROR, working on a database study of people with spinal cord injuries. Formanski took the job and was sent to Craig Hospital in Colorado to be trained to read patient charts and abstract detailed information about treatment. While there, he got another job offer—this one from RIC offering him a position in the accounting department. Although he worked in accounts receivable before his injury, he turned the position down, choosing a new career in healthcare research instead.

“This was like a dream come true. It was learning something new but everything I was doing, I could relate to,” he says.

In addition to recruiting patients to be part of research studies, he also volunteers as a peer counselor at RIC, talking with new patients who have experienced injuries similar to his own. “It’s not so much fear,” he says. “They want to know if what they’re experiencing is what I’ve experienced. They ask questions about driving, pain, numbness and tingling. I’ve talked with musicians about playing the guitar.”

“*This was like a dream come true. It was learning something new but everything I was doing I could relate to.*

- Nicholas Formanski

These days, Formanski drives to work from the Northwest side of Chicago and shares a small office with three other researchers. “It’s a busy environment, but there’s always a lot of friendly chatter in the research office. We have a bulletin board dedicated to office pets; Nick loves to talk about his three shepherd mixes,” says Holly Neumann, Formanski’s supervisor for the past four years. “He is such a team player. He is willing to take on any new challenge. He’s committed to these projects in a way that nobody else quite is.”

And Formanski, who still experiences some pain and uses a cane to steady himself if he has to walk far, says his job comes with intangible fringe benefits. “I can still see the therapists from 12 years ago—they became good friends who helped me in my time of need. They hold a special place.”
Many physical and occupational therapists are familiar with administering basic tests to patients to measure cognitive functioning and motor skills. But far fewer of them know how to assess a patient’s level of community participation, a measure that a growing number of accreditation organizations are looking for before handing out their seals of approval.

“Rehabilitation measurement is being elevated to a level where it fosters greater understanding of the environment and participation issues faced by people with disabling conditions,” explains Carolyn Baum, Ph.D., Professor of Occupational Therapy and Neurology at Washington University in St. Louis. “It’s really important that people get socialized to this new knowledge and information because it’s taking a higher priority these days.”

To help do that, Baum and Joy Hammel, Ph.D., Professor of Occupational Therapy and Disability Studies at the University of Illinois at Chicago (UIC), have worked with research staff at the Center for Rehabilitation Outcomes Research (CROR) to develop a package of four educational modules targeted toward entry and advanced level rehabilitation professionals. The modules are being pilot tested at UIC as part of an intervention course on motor and cognitive functioning. The National Institute on Disability and Rehabilitation Research is funding the work under a five-year grant to CROR to improve the measurement of rehabilitation outcomes.

The content is delivered through PowerPoint slide presentations that include case videos, teaching notes, and learning activities for instructors. The first module is an introduction to rehabilitation measurement and includes information about how changes in the U.S. healthcare system require the ability to measure outcomes across services.

The second module gets to the heart of the issue—an overview of how to apply measurement in clinical practice. What should be measured? What are the diagnostic purposes behind measurement? How should results be evaluated? The module explains that a key to a successful measurement practice is being able to monitor change over time.

The third module contains detailed information about the technical aspects of measurement and explores the concepts of validity and reliability. The fourth focuses on issues related to implementing practice changes. “Clinicians are people working in complex organizations that may or may not facilitate that kind of change,” explains Al Kozlowski, Ph.D., a former post-doctoral fellow at CROR who worked on the modules. “The last module gives clinicians ways to identify barriers and look for opportunities to get other staff members onboard.”

There’s no question that more education about measurement is needed, Hammel and Baum agree. “Students currently get a very minimal amount of instruction,” says Hammel.

Although the class isn’t quite over, the feedback Hammel is getting about the content from students in the intervention class is positive. They were particularly engaged with a video of a stroke survivor participating in a variety of outcome assessments, from body structure and function, to activities, to community participation in context. “People really like the case studies and it increases their active learning substantially,” Hammel says.

Eventually, Hammel and Baum plan to create a version of the content that can be used to fulfill clinical continuing education requirements needed to renew state licenses to practice. Baum’s overall goal: “I would like to see therapists with the know-how to apply measures in practice that will give them the information they need to be as efficient and efficacious as they can be in their practice role.”

For more information about these modules, please contact Jillian Bateman at jbateman@ric.org.
Put simply, CAT eliminates questions that are too easy for individual applicants and follows up with increasingly difficult ones that assess the upper range of their knowledge. That dynamic process is faster and it creates a multitude of possible tests so “your friend won’t see the same items, and even though the test is short we can get a highly reliable assessment of your true ability,” Gershon explains.

Computers are critical to the process as sophisticated software is used to rate a person’s responses and to select the next query.

“Because I know the difficulty of each question I ask you, and I continuously track your ability level, I can predict your answer on the next question,” says Gershon. “For example, when I give ability CATs, I can make certain that even the lowest able test takers get exactly 70% correct.”

Gershon had never heard of IRT when he attended Northwestern University as an undergraduate in the late 1970s with the goal of joining the clergy and working with youth. He did however spend most of his undergraduate years in the computer lab where the then cutting age computer took up an entire floor. After graduating, Gershon spent two years at a private psychiatric hospital for children and adolescents creating educational plans for their stays and coordinating their reentry to school.

Gershon returned to Northwestern to pursue his Masters and Ph.D. work in both Clinical and Personality psychology. To support his studies he took a part-time job at a research foundation where he worked with Benjamin Wright Ph.D., a University of Chicago faculty member and internationally recognized expert in IRT. Gershon was hooked. Gershon took the insight of Wright’s use of IRT and meshed it with his intuitive sense of what computers could and would be capable of doing. Over time he became recognized as a leader in a new field - Computer Adaptive Testing. The science and application of CAT is now the platform for many computer-based certification, licensure and academic assessments.

In 1987, Gershon met Allen Heinemann, Ph.D. then-assistant director of the Rehabilitation Services Evaluation Unit at the Rehabilitation Institute of Chicago (RIC). Heinemann quickly realized the potential of Gershon’s work and engaged him to write software that would enable spinal cord injury patients to answer survey questions about their quality of life on the primitive (and expensive) laptop computers that were available at the time.

It was an early example of what has become widely known as “patient-reported outcomes” research.

“It was clear he was ‘going places,’” recalls Heinemann, who now heads the Center for Rehabilitation Outcomes Research (CROR) at RIC. “I learned much from him about data management and security as well as technology that promote effective and secure...Continued on Page 7

Acknowledgements

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Articles written by Susan Chandler.

Note: The contents of this newsletter do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government.

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administered tests that assess cognitive, emotional, motor and sensory function. And Neuro-QOL measures quality of life issues for those with neurologic conditions.

“All these initiatives have produced patient-reported outcome measures,” Rothrock says. “The quality of measures is better and the metric they are scored on is compatible. So you can now compare between measures using the same metric.”

The Institute will kick off with a two-day conference for researchers in Chicago on June 17-18. This course is for both professional (MDs, PhDs, OTDs, DPTs) and student-level rehabilitation researchers who desire to develop skills in applied and theoretical measurement. A second Institute geared for practicing clinicians will be held July 29-30 in St. Louis, Missouri.

The two-part schedule incorporates feedback received from the 2011 Summer Institute. At that time, some clinicians in attendance said they felt the instruction was too focused on research and not enough on the challenges of their daily practice.

“They wanted it more clinically focused,” says Jillian Bateman, a clinical research coordinator at CROR who is coordinating the project. “Clinicians wanted to know more about using outcomes measures in day-to-day practice. They didn’t want to know how to use it in a research project.”

The St. Louis conference, which will be held at Washington University, will provide an in-depth look at integrating measurement into clinical practice. Among the topics covered will be how to evaluate, interpret and document client goals and outcomes in clinical practice.

Seminar leaders will discuss facilitators and barriers that clinicians face when trying to introduce outcome measures into their practice. “There are barriers,” says Bateman. “It’s difficult as a practicing clinician when you’re expected to do so much on a daily basis and in addition have to know how to identify, use, and interpret these outcomes measures.” Attendees will also be introduced to the many resources that exist to help clinicians use outcome measures in practice.

Speakers will include Carolyn Baum, Ph.D., Professor of Occupational Therapy and Neurology at Washington University; Allen Heinemann, Ph.D., Director of CROR; and Joy Hammel, Ph.D., Professor of Occupational Therapy and Disability Studies at the University of Illinois at Chicago.

The program should be especially interesting to veteran clinicians who trained years ago before outcome measurement was emphasized. “There’s a need to update the knowledge and skills for clinicians who are already practicing,” says Al Kozlowski, Ph.D., a former post-doctoral fellow at CROR who helped develop content for the clinician course.

“Many of them haven’t had the benefit of a career path that has allowed them to learn more about measurement. That’s true even for those who have entered practice in the last five to 10 years.”

The program also will be geared toward educators and current students in the field of occupational therapy and physical therapy. Online registration is now open. Back in Chicago, Rothrock and Richard Gershon, Ph.D., Associate Professor in the Department of Medical Social Sciences at Northwestern University, will be leading the seminar focusing on researchers and clinicians who also do research.

Gershon will introduce participants to various measures used to assess outcomes for patients receiving rehabilitation services. And he will draw on his extensive experience in Item Response Theory (IRT) and Computerized Adaptive Testing (CAT) as well as his work on large federally-funded projects, including PROMIS and the NIH Toolbox.

IRT is a modern test theory that focuses on evaluating questions and responses so that tests can be both shorter and more accurate. CAT software tailors each patient’s test to that person in real time based upon his or her previous answers. This creates customized and shortened tests (see related profile of Richard Gershon). “Five years ago, a typical fatigue instrument was 30 to 70 questions. Now we can get a clinical level in about five items with comparable reliability,” Gershon says.

In the 15 minutes it took patients to fill out the longer survey, they can now answer 10 questionnaires covering a much broader range of topics including depression and social support, for example.

“It helps us in research as well as clinical practice,” Gershon says.

Summer Institute for the Clinician

**Monday, July 29, 2013**

8:00 - 8:30 Registration and Continental Breakfast
8:30 - 8:45 Welcome and Course Objectives
8:45 - 9:30 Introduction to Outcome Measurement
9:30 - 10:30 Selection of Rehabilitation Measures for Clinical Planning and Assessment; Policies and Rights Requiring a Focus on Participation
10:30 - 10:45 Break
10:45 - 12:00 Case Study: Using a Client-Centered Approach and Assessments to Set Goals
12:00 - 1:00 Lunch
1:00 - 2:00 Making Tests Accessible to Clients w/ Impairments
2:00 - 2:15 Break
2:15 - 5:00 Understanding Measurement Principles

**Tuesday, July 30, 2013**

8:00 - 9:30 Continental Breakfast
8:30 - 9:30 Recap of Measurement Properties and Clinical Applications
9:30 - 10:45 Introduction to and Exploration of Outcome Measurement Resources
10:45 - 11:00 Break
11:00 - 12:30 Using Outcome Measures in Clinical Practice: Facilitators & Barriers to Using Outcome Measurement
12:30 - 1:00 Discussion and Wrap-up
Congratulations are in order...

Dr. Dennis Moore
NARRTC Distinguished Service Award Winner

Please join us in congratulating Dr. Dennis Moore, Professor Emeritus at Wright State University, on his recent Distinguished Service Award from NARRTC (formerly known as the National Association of Rehabilitation Research and Training Centers). He is lauded for his invaluable contributions to the field of rehabilitation research, particularly on the topic of substance abuse and disability issues. He embodies the mission of NARRTC, which is to “promote the full inclusion of persons with disabilities in American society through applied research and training” and we are proud to have worked with him on several projects. Dr. Moore was profiled in our Fall 2011 issue of CROR Outcomes. We invite you to read about his accomplishments and learn about the development of the Substance Abuse Vocational Rehabilitation Screener (SAVR-S), a joint collaboration project between CROR and Wright State University.

Dr. Alex Wong
ARCA Research Award Winner

Dr. Alex Wong, a postdoctoral fellow who joined CROR last year, recently received the Third Place 2013 ARCA Research Award, presented by the American Rehabilitation Counseling Association. His article, “Five-Factor Model of Personality, Work Behavior Self-Efficacy, and Length of Prior Employment for Individuals with Disabilities: An Exploratory Analysis” has been published in the Rehabilitation Counseling Bulletin. You can read more about Dr. Wong in the 2013 Winter issue of CROR Outcomes.

Summer Institutes (Continued from page 5)

Rothrock, a health psychologist with an interest in quality of life issues, will describe how to select and use patient-reported measures in research and outline what software tools are available to collect data and interpret it. The second day will be spent in a computer lab learning about various data collection platforms and featuring access to the Assessment Center, a free, online, dynamic application that allows researchers to centralize research activities.

While the short-term goal of the Summer Institute is to help researchers and clinicians better utilize patient-reported outcomes, the long-term goal is to expand use of patient-reported outcomes in research and clinical practice.

“The goal of patient-reported outcomes measures is to ensure the patients’ voices are being heard in their medical care,” Rothrock says. “There are a number of issues - pain, emotional distress, fatigue - where the only way to understand them is to ask patients. With highly precise measures of those constructs, we can get clinicians the information so they can act on it clinically.”
By 1996 when Gershon’s dissertation on “The Effect of Individual Differences Variables on the Assessment of Ability for Computerized Adaptive Testing” was accepted, he and his wife had built a consulting firm, bridging his interests in computer based technologies and testing, with over 45 employees internationally doing psychometric consulting for organizations as diverse as IBM and a national security organization.

Venture capitalists heard about Gershon’s work and funded him in 1997. The company doubled in sales and the following year educational publisher Houghton Mifflin Co. made Gershon an offer he couldn’t refuse. He sold the company but stayed on until 2001 when Houghton Mifflin itself was sold.

Gershon, who was 41 at the time, took early retirement and went to work as a consultant. One of his clients was David Cella, Ph.D., then director of the Center on Outcomes, Research and Education (CORE) at Evanston Northwestern Healthcare. Cella was working on patient-reported outcome measures and Gershon’s work on IRT and CAT was a good fit. So too was their partnership and Gershon eventually joined Cella full time.

In 2009, Cella became chairman of the new Department of Medical Social Sciences at Northwestern, and Gershon moved with him as Vice Chair. The timing was ideal - the healthcare field was ready for the improved testing that IRT made possible and Northwestern University was ready to open its first new department in a decade - dedicated to enhance the quality of patient care through the application of outcome science.

During the last decade, Gershon has been involved in dozens of major research projects involving IRT. He worked with Cella to develop the Patient Reported Outcomes Measurement Information System (PROMIS) for the National Institutes of Health (NIH), a system of highly reliable assessment tools that measure patient-reported health status. Gershon also oversaw the creation of the NIH Assessment Center, a free online resource that allows investigators to administer CAT’s and other assessments and manage their data collection at one site.

Gershon also worked as the principal investigator on the NIH Toolbox for the Assessment of Neurological Function and Behavior, overseeing a team of 250 scientists at 80 institutions.

“For over 50 sub-domains of neurological functioning, we identified existing measures or constructed new instruments to create a royalty free battery, with most individual measures requiring less than five minutes to administer.” Gershon says. “For example, we validated a two minute version of a walking test for endurance which had previously been validated as taking six minutes. In turn, we saved four minutes! Multiplied across the Toolbox battery those savings result in the creation of four – 30 minute assessment batteries of cognitive, motor, emotional and sensory health and function which accurately measure what had once taken multiple administrators several days to complete.”

His largest current project is his role with the National Children’s Study, a government-mandated health assessment of 100,000 children (pre-natal to age 21) along with their parents. The goal of the study is to assess all aspects of child health and also to explore the effect of environmental toxins on human development. Gershon is working with other scientists to develop the shortest valid measures possible “because we have limited access to a child at any given age.”

Married for 33 years and a father of four, Gershon tries to maximize his time by scheduling conference calls in his car during his daily commute from his home in Lincolnwood. He enjoys foreign travel and makes several international trips a year, one of them a family trip. Alas, he says, “many conferences abroad that I am invited to often don’t lend themselves for time to tour.”

“I am privileged to be invited to wonderful places but more often than not I don’t have time to spend there. I recently spent 18 hours from arrival to departure in Amsterdam and am about to do that again. That said,” Gershon says “while I have helped to develop numerous innovative measures and assessments, they will only be of value to researchers and in clinics if people know about them in the first place. Speaking nationally and abroad insures that they are recognized and shared with the broadest audience possible.”

Recent CROR Dissemination Activities

**Manuscripts**


**Presentations**


Development and Evaluation of Environmental Factor Items for Persons with SCI. Paper presented by **Allen Heinemann** with contributions from Jin-Shei Lai, Noelle Carlozzi, Joy Hammel, Sophia Garcia, David Gray, Elizabeth Hahn, Susan Magasi, David Tulsky, Allan Kozlowski, and **Sara Jerousek** at the annual meeting of the American Spinal Injury Association, Chicago, IL, May 6, 2013.