

**INSTITUTE FOR PUBLIC
HEALTH AND MEDICINE AT
NORTHWESTERN MEDICINE
CENTER FOR PATIENT-
CENTERED OUTCOMES**

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When a person develops a medical condition, it sets in motion a range of options for testing and treatment. Sorting through these options can be distressing, confusing, and overwhelming. Yet, healthcare is usually delivered best when patients and family members are engaged actively in understanding their options and in making informed decisions. Often, patients will have symptoms and even functional limitations caused by their condition. These symptoms and limitations, as well as the side effects caused by the treatments they receive, must be considered carefully when deciding on and receiving that treatment. The range of treatment options for most medical conditions is broad, and very often there is little or no clear evidence as to which of the available options is best. In fact, what might be best for one patient is often not what is best for another with the same disease.

Increasingly, we are defining which treatments work by asking patients to help identify optimal outcomes from their own perspectives. This shift is at the heart of the concept of patient-centered outcomes, which are health outcomes ranging from traditional clinical outcomes to those measuring symptoms, function, and other aspects of health-related quality of life. Patient-centered outcomes take into account, among other things, the voices of patients and their families to improve healthcare and treatment decision-making.

Program in Developmental Mechanisms of Health & Disease

The goal of the Program in Developmental Mechanisms of Health and Disease is to characterize clinically relevant behavioral and psychological phenotypes across the human lifespan. A particularly novel aspect of our program is the generation of developmentally sensitive tools for identifying and characterizing disease vulnerability and early symptoms as they are expressed in very young children. We have developed the first early identification tools specifically designed to distinguish the normal misbehavior of early childhood from clinical problems in order to provide scientific parameters that indicate “when to worry” about young children’s development. We also have done leading-edge work in pinpointing how adverse prenatal environments contribute to these early disease pathways. The Developmental Mechanisms Program is a translational program that promotes the integration of neurobiology, including genetics, neurocognitive processes, and neuroimaging into studies of behavioral and psychosocial aspects of disease as it emerges in early life. Research in this program provides an integrated model of how diseases develop and affect quality of life from their earliest origins, as well as the implications of these processes for early identification and prevention.



“Our work often seeks to understand human behavior and its interface with pressing health issues. We focus on the human experience of disease and treatment, interaction of the healthcare system, and understanding health in the context of social science methodologies in an effort to better understand and improve health and healthcare delivery.”

David Cella, PhD, Director, Center for Patient-Centered Outcomes



Center for Patient-Centered Outcomes

The Center for Patient-Centered Outcomes within the Institute for Public Health and Medicine provides a bridge and an incubator for investigators and clinician-scientists across Northwestern Medicine whose research focuses on the centrality and perspective of the patient.

Faculty and staff within the Center are intensely focused on the following patient-centered research initiatives that:

- Place the patient at the center of care;
- Promote innovative and diverse approaches that improve healthcare decision-making and our understanding of biobehavioral mechanisms of disease;
- Build scientific capacity and strategic alignment toward federal resources for patient-centered outcomes research support;
- Utilize well-developed research infrastructure to enable engaged investigators;
- Foster scientific exchanges that enable cross-fertilization and critical feedback;
- Create opportunities for engagement with patients, caregivers, and other key stakeholders; and
- Provide mentorship and apprenticeship opportunities for postdocs, graduate students, medical students, and residents.

Through our Center for Patient-Centered Outcomes, we can expand the use of clinical/health measures and deepen our societal understanding of treatment-related and disease-related outcomes. We believe that through collaboration with clinicians, we can enhance their work and refine our tools for more meaningful results in future study. We are experts in questionnaire and survey development, technical design, software programming, and statistical (psychometric) analysis of data collected in outcomes research and outcomes management.

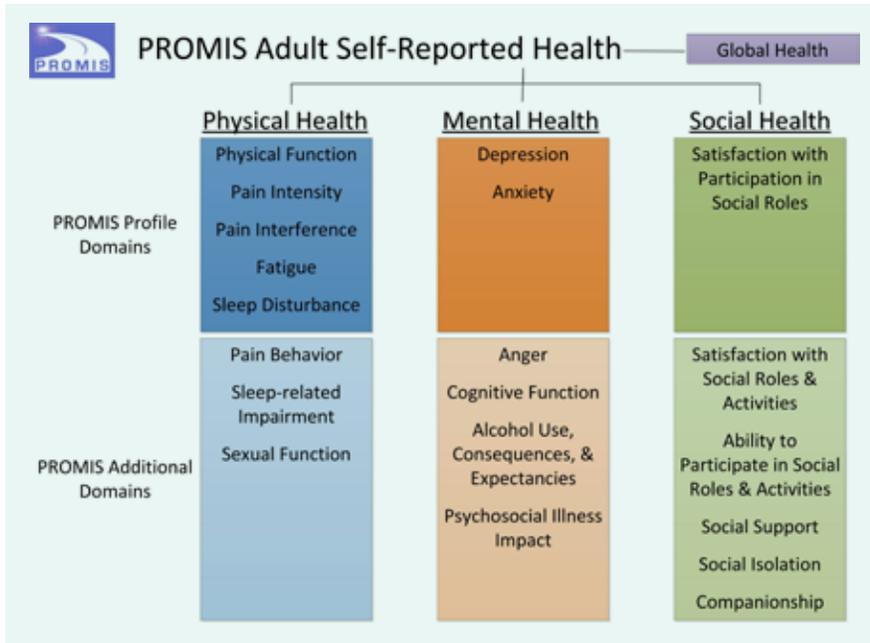
CENTER FOR PATIENT-CENTERED OUTCOMES PROGRAMS

Program in Health Measurement

Our Program in Health Measurement has a depth of internationally recognized expertise in the area of patient-reported outcomes measure development and application. In fact, the Program in Health Measurement has been at the forefront of state-of-the-science initiatives to develop brief, flexible, and reliable measurements of patient-reported outcomes and other health outcomes measures. This includes leadership in the Patient-Reported Outcomes Measurement Information System (www.nihpromis.org), Neurological Quality of Life in Neurological Disorders (www.neuroqol.org), NIH Toolbox for the Assessment of Neurological and Behavioral Function (www.nihtoolbox.org), as well as efforts to create linkages between these federally-funded projects (www.prosettastone.org). In sum, the focus of our Program in Health Measurement is to develop instruments and surveys to measure patient-reported outcomes and measures of neurocognitive and behavioral health across the lifespan. The goal is to help evaluate healthcare delivery and policy.

Program in Patient-Centered Informatics

Our Program in Patient-Centered Informatics showcases our expertise in developing hardware and software tools for electronic data warehousing and monitoring and patient assessment, education, and training. Assessment CenterSM is an online research management tool developed by the Program in Patient-Centered Informatics. It enables researchers to create customized websites for secure collection of patient-reported data. While the Assessment Center tool was developed to support the collection of measures developed in our Program in Health Measurement (e.g., NIH PROMIS, NIH NeuroQOL, NIH Toolbox), it also allows for customized set-up to include other measures. Not only do such tools facilitate patient-centered research, they can also be used to improve patient-physician communication, shared decision-making, and to optimize health outcomes via clinical interventions.



THROUGH NORTHWESTERN MEDICINE, WE ARE CREATING A NATIONAL EPICENTER FOR HEALTHCARE, EDUCATION, RESEARCH, COMMUNITY SERVICE, AND ADVOCACY.

Northwestern Medicine

Northwestern Memorial Hospital and Northwestern University Feinberg School of Medicine are seeking to impact the health of humankind through Northwestern Medicine. We aspire to be the destinations of choice for people seeking quality healthcare; for those who provide, support, and advance that care through leading-edge treatments and breakthrough discoveries; and for people who share our passion for educating future physicians and scientists. Our commitment to transform healthcare and to be among the nation’s top academic medical centers will be accomplished through innovation and excellence.

Our new Institute for Public Health and Medicine is comprised of world-class centers that serve as a nexus for innovation, collaboration, and growth in research.

The Center for Patient-Centered Outcomes is an integral part of the Institute. Through both the Center and the Institute, we are working to innovate and introduce public health solutions to address the biggest health challenges of our time. At Northwestern, we recognize that without dramatic changes in our approach to public health and healthcare delivery, we will confront surging, unsustainable costs and an inability to meet the healthcare needs of our citizens. We see this urgent need as a tremendous opportunity to provide leadership and a new direction to improve the health of our nation and world.